POST-POLIO HEALTH INTERNATIONAL 10th International Conference

Living with Polio in the 21st Century

April 23-25, 2009

Thursday, April 23, 2009

Session T1, 1:00–2:00 pm
through
Session T4, 6:15–8:30 pm

This book belongs to

POST-POLIO HEALTH INTERNATIONAL

Post-Polio Health International
Including International Ventilator Users Network

ROOSEVELT WARM SPRINGS

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110
Saint Louis, Missouri 63108-2930 USA
314-534-0475
314-534-5070 fax

www.post-polio.org
info@post-polio.org

director@post-polio.org

www.ventusers.org
info@ventusers.org

QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International (PHI) thanks the presenters for providing the excellent information contained in the daily program books.

If you share this information, we respectfully ask that you acknowledge the presenter and that the information was disseminated at PHI's 10th International Conference: Living with Polio in the 21st Century (April 2009). PHI will incorporate additional information presented at the conference and make it available to attendees and others at a later date. Details will be published in *Post-Polio Health* and on www.post-polio.org.

In case of emergency, call 911.

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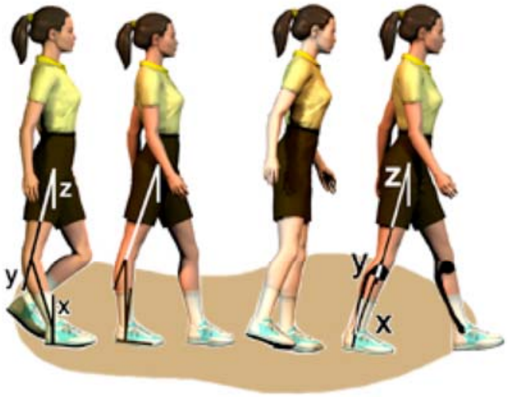

Marmaduke Loke
DynamicBracingSolutions
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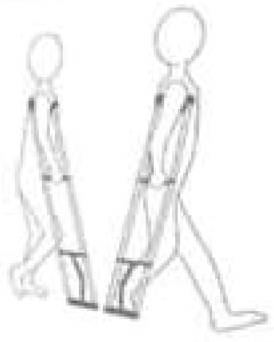

EXHIBITORS

Visit the following companies in Georgia Hall during these hours:

Friday, April 24 from 11:30 am–7:00 pm

Saturday, April 25 from 8:30 am–1:30 pm

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Washington, DC 20008
202-363-4046
888- 667-4046
www.icanwalk.com

Welcome to the Roosevelt Warm Springs Institute for Rehabilitation.

Whether you have been here before or this is your very first time on our campus, we are thrilled to have you here as our guests. As you may know, we are the “living legacy” of FDR’s vision for healing, so as you enjoy your symposium you will notice patients and students coming and going, and that we are very much a living and breathing rehabilitation center. We have been providing rehabilitation for 81 years, and you will also note that parts of our campus show our age.

We are not a modern conference center like you may find in downtown Atlanta, but we have something that they don’t. My hope for you during your visit is that you experience what we call the “Spirit of Warm Springs,” which refers to our caring and compassion. We are very proud of our historic legacy, and I encourage you to reflect on that as you travel around and across our campus. Franklin D. Roosevelt never learned to walk by coming here, but I believe it made him a better man and a much better President. So on behalf of all of us who come to work here every day in pursuit of the same mission “to empower individuals with disabilities to achieve personal independence” as FDR did, welcome to this place of healing. May you enjoy your conference and fully enjoy your stay with us.

Greg Schmieg
Executive Director, RWSIR

From Post-Polio Health International (PHI):

Welcome to the tenth in our series of international conferences.

PHI's goal for these conferences has always been threefold: First, we aim to promote the face-to-face exchange of authoritative, up-to-date information about the late effects of polio and independent living with its consequences. Second, we aim to sustain a productive network of active polio survivors and healthcare professionals with relevant expertise – by providing a forum in which these two groups can inform each other and interact. Third, we aim to disseminate the results of our conferences to all those interested polio survivors and medical professionals who are unable to attend.

We are honored to have this conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). RWSIR's place in the history of physical medicine and rehabilitation is a prominent one indeed. It began with Franklin Delano Roosevelt, and with the idea of rehabilitation as a cooperative venture between medical professionals and polio survivors. From its beginnings, like PHI, it has also been dedicated to helping people develop and sustain the functional abilities necessary for independent living with a physical disability.

This event was made possible by the dedicated labors of many staff members at RWSIR. To all of them, we owe our thanks. We also thank Carolyn Raville, founder of the North Central Florida Post-Polio Support Group, for suggesting a post-polio conference at RWSIR.

Thank you for joining us to learn about "Living with Polio in the 21st Century."

Lawrence C. Becker
Chair, Board of Directors, Post-Polio Health International

Acknowledgements

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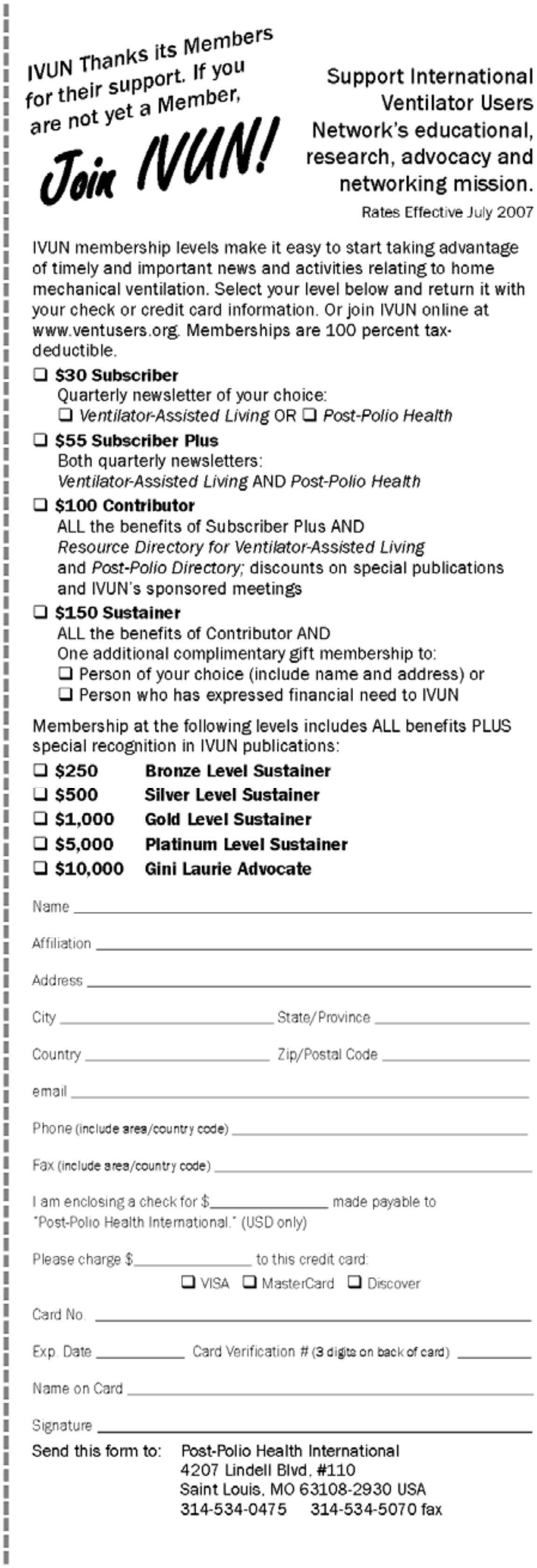

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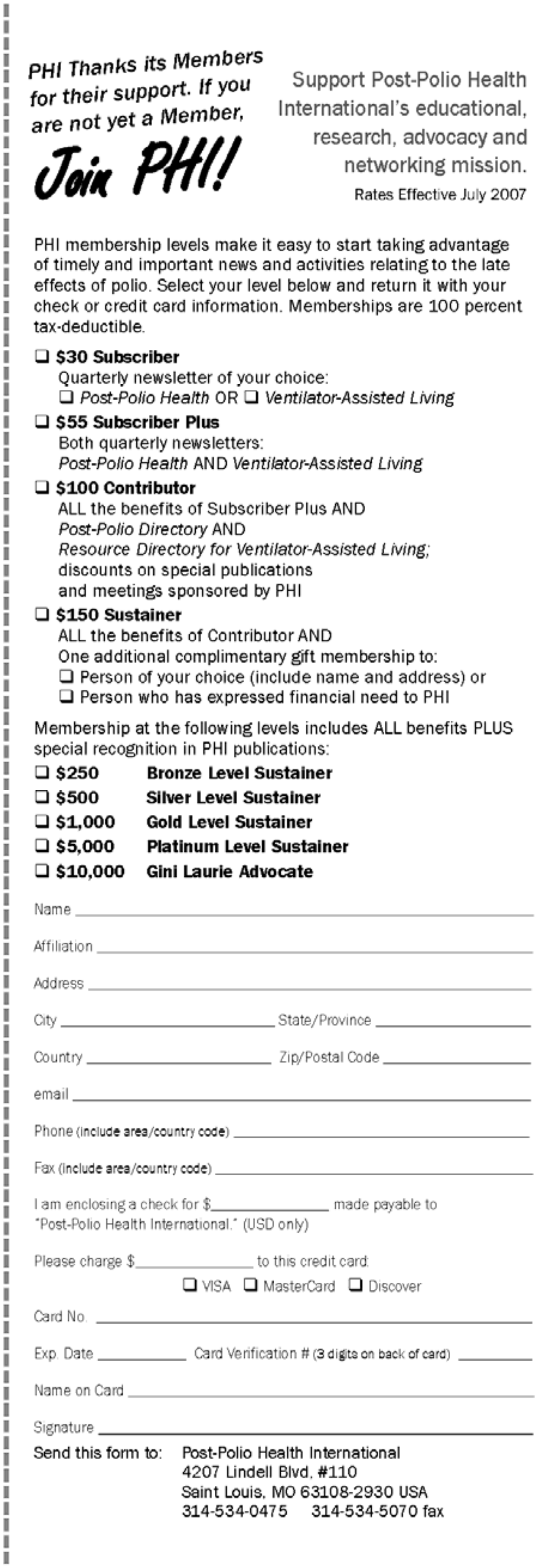

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☐ **$30 Subscriber**
Quarterly newsletter of your choice:
☐ *Post-Polio Health* OR ☐ *Ventilator-Assisted Living*

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ALL the benefits of Contributor AND
One additional complimentary gift membership to:
☐ Person of your choice (include name and address) or
☐ Person who has expressed financial need to PHI

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Program / Thursday, April 23, 2009

9:00 am – 6:15 pm

Registration in GEORGIA HALL

1:00–2:00 pm

SESSION T1 – OPENING PLENARY

Location & Legacy – Purpose & Possibilities

ROOSEVELT HALL AUDITORIUM

Representatives of Roosevelt Warm Springs Institute for Rehabilitation and Post-Polio Health International

2:30–3:45 pm

SESSION T2 OPTIONS

First Things First: Understanding Poliomyelitis

SCHOOLHOUSE 105

John Fitzsimmons, Centers for Disease Control and Prevention, Atlanta, Georgia

Tools to Use in Evaluating Treatment Choices

VRU AUDITORIUM

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Polio: The Legacy of Warm Springs

ROOSEVELT HALL AUDITORIUM

Edith Powell, Ed.D, MT(ASCP)SBB, Tuskegee University, Tuskegee, Alabama

Naomi Rogers, PhD, Yale University, New Haven, Connecticut

Daniel J. Wilson, PhD, Muhlenberg College, Allentown, Pennsylvania

Modifying ADL Techniques to Accommodate New Weakness

MEADOWS CLASSROOM

Carolyn Podolski, OT,
Peachtree City, Georgia

4:15–5:30 pm

SESSION T3 OPTIONS

Demonstration and Discussion of a Post-Polio Examination: Sorting Out Secondary Conditions, Part 1

ROOSEVELT HALL AUDITORIUM

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Martin Wice, MD, Medical Director,
St. John's Mercy Rehabilitation Hospital,
St. Louis, Missouri

Feel Good Food: Boosting Energy, Maintaining Weight

SCHOOLHOUSE 105

Kathryn Bussey, RD, LD,
St. Francis Hospital/Sodexho,
Columbus, Georgia

Meeting Other Users of Home Mechanical Ventilation

MEADOWS CLASSROOM

Moderator and Attendees

Finding and Disseminating Information through Support Groups

SCHOOLHOUSE 111

Moderator: Margaret Hinman, editor, *Colorado Post-Polio Connections,* Westminster, Colorado

Using the Internet

Barbara Gratzke, International Post-Polio Support Group, Miami, Florida

Developing Special Projects

David Holland, Post-Polio Awareness and Support Society of British Columbia (PPASS BC), Langley, British Columbia, Canada

Suggestions for Increasing Advocacy

Linda Priest, CTRS/L, Atlanta Post-Polio Association, Decatur, Georgia

Sharing Newsletters

Attendees

DINNER AND SESSION T4 OPTIONS

5:30–7:30 pm *Dinner*
6:15–8:30 pm *Sessions*

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

Improving Your Mobility Device: *Move Forward*

CTR GYMNASIUM

Michelle Guevin, PT, MTC, Bay Area Physical Therapy, Bradenton, Florida

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

Water Can Still Benefit Survivors

CTR POOL

Mary Essert, BA, ATRIC, Conway, Arkansas

Cynthia Henley, PT, Miami, Florida

Kathryn Wollam, PT, Coral Springs, Florida

(6:00–8:15 pm; Stop in anytime.)

Yes, You Can Bowl

CTR BOWLING

Rosanna Borders, CTRS, RWSIR, Warm Springs, Georgia

(6:45–8:15 pm)

Polio Narratives: Readings and Discussion of the Writing Process

CTR 201

Jacqueline Foertsch, PhD, University of North Texas, Denton, Texas

Joyce Tepley, LMSW, Dallas, Texas

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

Learn About Acupuncture

CTR GAME ROOM

Susan Harris, Lic Ac, Kingman, KS

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

Yes, You Can Practice Yoga

CTR 202

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

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SESSION T1

Opening Plenary
Location & Legacy – Purpose & Possibilities

Representatives of Roosevelt Warm Springs Institute for Rehabilitation
and Post-Polio Health International

SESSION T2

First Things First: Understanding Poliomyelitis

John Fitzsimmons,
Centers for Disease Control and Prevention, Atlanta, Georgia

Tools to Use in Evaluating Treatment Choices

Barbara Duryea, MSN, RN, CPHQ,
John P. Murtha Neuroscience and Pain Institute (JPMNPI),
Johnstown, Pennsylvania

Five Basic Steps

Following are five basic steps to help you cope with your diagnosis, make decisions, and get on with your life.

Step 1: Take the time you need.

Do not rush important decisions about your health. In most cases, you will have time to carefully examine your options and decide what is best for you.

Step 2: Get the support you need.

Look for support from family and friends, people who are going through the same thing you are, and those who have "been there." They can help you cope with your situation and make informed decisions.

Step 3: Talk with your doctor.

Good communication with your doctor can help you feel more satisfied with the care you receive. Research shows it can even have a positive effect on things such as symptoms and pain. Getting a "second opinion" may help you feel more confident about your care.

Step 4: Seek out information.

When learning about your health problem and its treatment, look for information that is based on a careful review of the latest scientific findings published in medical journals.

Step 5: Decide on a treatment plan.

Work with your doctor to decide on a treatment plan that best meets your needs.

As you take each step, remember this: Research shows that patients who are more involved in their health care tend to get better results and be more satisfied.

Ten Important Questions to Ask Your Doctor After a Diagnosis

These 10 basic questions can help you understand your disease or condition, how it might be treated, and what you need to know and do before making treatment decisions.

1. What is the technical name of my disease or condition, and what does it mean in plain English?
2. What is my prognosis (outlook for the future)?
3. How soon do I need to make a decision about treatment?
4. Will I need any additional tests, and if so what kind and when?
5. What are my treatment options?
6. What are the pros and cons of my treatment options?
7. Is there a clinical trial (research study) that is right for me?
8. Now that I have this diagnosis, what changes will I need to make in my daily life?
9. What organizations do you recommend for support and information?
10. What resources (booklets, Web sites, audiotapes, videos, DVDs, etc.) do you recommend for further information?

Now that you know your treatment options, you can learn which ones are backed up by the best scientific evidence. "Evidence-based" information– that is, information that is based on a careful review of the latest scientific findings in medical journals–can help you make decisions about the best possible treatments for you.

Evidence-based information comes from research on people like you.

Evidence-based information about treatments generally comes from two major types of scientific studies:

- **Clinical trials** are research studies on human volunteers to test new drugs or other treatments. Participants are randomly assigned to different treatment groups. Some get the research treatment, and others get a standard treatment or may be given a placebo (a medicine that has no effect), or no treatment. The results are compared to learn whether the new treatment is safe and effective.
- **Outcomes research** looks at the impact of treatments and other health care on health outcomes (end results) for patients and populations. End results include effects that people care about, such as changes in their quality of life.

Take advantage of the evidence-based information that is available.

Health information is everywhere–in books, newspapers, and magazines, and on the Internet, television, and radio. However, not all information is good information. Your best bets for sources of evidence-based information include the Federal Government, national nonprofit organizations, medical specialty groups, medical schools, and university medical centers.

Some resources are listed below, grouped by type of information. The on-line version of ***Next Steps After Your Diagnosis*** lists many more, and includes links to Internet sites.

Information.

Information about your disease or condition and its treatment is available from many sources. Here are some of the most reliable:

- **Post-Polio Health International:** www.post-polio.org/index.html
  Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.
- **healthfinder®:** www.healthfinder.gov/organizations/OrgListing.asp
  The healthfinder® site – sponsored by the U.S. Department of Health and Human Services-offers carefully selected health information Web sites from government agencies, clearinghouses, nonprofit groups, and universities.
- **Health Information Resource Database:** www.health.gov/nhic/#Referrals
  Sponsored by the National Health Information Center, this database includes 1,400 organizations and government offices that provide health information upon request. Information is also available over the telephone at 800-336-4797.
- **MEDLINEplus®:** www.nlm.nih.gov/medlineplus
  MedlinePlus® has extensive information from the National Institutes of Health and other trusted sources on over 650 diseases and conditions. The site includes many additional features.
- **National nonprofit groups** such as the American Heart Association, American Cancer Society, and American Diabetes Association can be valuable sources of reliable information. Many have chapters nationwide. Check your phone book for a local chapter in your community. The Health Information Resource Database (www.health.gov/nhic/#Referrals) can help you find national offices of nonprofit groups.

- **Health or medical libraries** run by government, hospitals, professional groups, and other reliable organizations often welcome consumers. For a list of libraries in your area, go to the MedlinePlus® "Find a Library" page at http://www.nlm.nih.gov/medlineplus/libraries.html.

Current medical research.

You can find the latest medical research in medical journals at your local health or medical library, and in some cases, on the Internet. Here are two major online sources of medical articles:

- **MEDLINE/PubMed®:** http://www.ncbi.nlm.nih.gov/entrez/query.fcgi PubMed® is the National Library of Medicine's database of references to more than 14 million articles published in 4,800 medical and scientific journals. All of the listings have information to help you find the articles at a health or medical library. Many listings also have short summaries of the article (abstracts), and some have links to the full article. The article might be free, or it might require a fee charged by the publisher.
- **PubMed Central:** http://www.pubmedcentral.nih.gov/
  PubMed Central is the National Library of Medicine's database of journal articles that are available free of charge to users.

Clinical Trials.

Perhaps you wonder whether there is a clinical trial that is right for you. Or you may want to learn about results from previous clinical trials that might be relevant to your situation. Here are two reliable resources:

- **ClinicalTrials.gov:** http://clinicaltrials.gov/ct/g
  ClinicalTrials.gov provides regularly updated information about federally and privately supported clinical research on people who volunteer to participate. The site has information about a trial's purpose, who may participate, locations, and phone numbers for more details. The site also describes the clinical trial process and includes news about recent clinical trial results.
- **Cochrane Collaboration:** www.cochrane.org
  The Cochrane Collaboration writes summaries ("reviews") about evidence from clinical trials to help people make informed decisions. You can search and read the review abstracts free of charge at http://www.cochrane.org/reviews/index.htm. Or you can read plain-English consumer summaries of the reviews at www.informedhealthonline.org.

The full Cochrane reviews are available only by subscription. Check with your local medical or health library to see whether you can access the full reviews there.

Outcomes research:

Outcomes research provides research about benefits, risks, and outcomes (end results) of treatments so that patients and their doctors can make better informed decisions. The U.S. Agency for Healthcare Research and Quality (AHRQ) supports improvements in health outcomes through research, and sponsors products that result from research such as:

- **National Guideline Clearinghouse™:** www.guideline.gov
  The National Guideline Clearinghouse™ is a database of evidence-based clinical practice guidelines and related documents. Clinical practice guidelines are documents designed to help doctors and patients make decisions about appropriate health care for specific diseases or conditions. The clearinghouse was originally created by AHRQ in partnership with the American Medical Association and America's Health Insurance Plans.

Steer clear of deceptive ads and information.

While searching for information either on or off the Internet, beware of "miracle" treatments and cures. They can cost you money and your health, especially if you delay or refuse proper treatment. Here are some tip-offs that a product truly is too good to be true:

- Phrases such as "scientific breakthrough," "miraculous cure," "exclusive product," "secret formula," or "ancient ingredient."
- Claims that the product treats a wide range of ailments.
- Use of impressive-sounding medical terms. These often cover up a lack of good science behind the product.
- Case histories from consumers claiming "amazing" results.
- Claims that the product is available from only one source, and for a limited time only.
- Claims of a "money-back guarantee."
- Claims that others are trying to keep the product off the market.
- Ads that fail to list the company's name, address, or other contact information.

Where to Find More Information

Get the support you need.

American Self-Help Group Clearinghouse
http://mentalhelp.net/selfhelp/

National Board for Certified Counselors (NBCC) 3 Terrace Way, Suite D
Greensboro, NC 27403-3660 336-547-0607. www.nbcc.org

National Institute of Mental Health
Public Information and Communications Branch 6001 Executive Boulevard, Room 8184, MSC 9663
Bethesda, MD 20892-9663
Phone: 866-615-6464 (toll-free) TTY: 301-443-8431
http://www.nimh.nih.gov/HealthInformation/GettingHelp.cfm

Talk to your doctor.

Be an Active Member of Your Health Care Team. Food and Drug Administration. 2004. http://www.fda.gov/cder/consumerinfo/ active_member.htm. Phone: 888-INFO-FDA (888-463-6332).

Be Informed: Questions to Ask Your Doctor Before You Have Surgery. Agency for Healthcare Quality and Research. 1995. http://www.ahrq.gov/consumer/surgery.htm. Phone: 800-358-9295.

Five Steps to Safer Health Care. Agency for Healthcare Research and Quality. 2003. http://www.ahrq.gov/consumer/5steps.htm. Phone: 800-358-9295.

Getting a Second Opinion Before Surgery. Centers for Medicare & Medicaid Services. 2004. www.medicare.gov/Publications/Pubs/pdf/02173.pdf. Phone: 800-MEDICARE (800-633-4227).

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Polio: The Legacy of Warm Springs

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A Black Oasis: Tuskegee Institute's Fight Against Infantile Paralysis, 1941-1965

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Note: This presentation is based on original research funded by a Basic Research Grant #1-1046 with the same title, co-authored with John F. Hume M.D.

Purpose: To share the knowledge about the Infantile Paralysis Centre at Tuskegee Institute, it's mission, work and relationship to the National

Introduction

At a time in our history when the country was in a great depression, in the rural South there was much ignorance, poverty and desolation. The land was not productive anymore, having been used up by many years of growing cotton. Segregation still required separate water fountains, eating places and entrances to health care facilities. Blacks had no money, clothes and little food. They were living in dilapidated houses with no electricity, outdoor toilets, appalling morbidity, and high mortality.

Yet, in the midst of this rural Alabama bleakness of the 1930's, lay a beautiful little town known as Tuskegee. It occupied the site of the Indian village known as Tuskigi, and on its outskirts was the most noted institution in the United States for the education of blacks—Tuskegee Institute. Within the tree-lined, immaculately groomed grounds of this famous educational facility, were streams of happy, laughing black students whose education was carefully tended by many of the outstanding black educators of this decade---truly a black oasis ---where the thirst for learning, described by Dr. Washington in 1881, was satisfied by those who carried on the philosophy of excellence and quality of the education put forth by the Institute's founder, the same Booker T. Washington.

Because of the commitment and dedication of the people who made up the Institute and due to their mission to teach, to guide, to encourage and to serve the blacks of the rural South, a program began at Tuskegee which became one of the most outstanding health care services available for blacks anywhere in the country---the Tuskegee Infantile Paralysis Centre.

(*A Black Oasis: Tuskegee Institute's Fight Against Infantile Paralysis*, 1941-1975, pp.xiv-xv.)

This Center was made possible by the first grant from the National Foundation for Infantile Paralysis (1938) newly established by President Franklin D. Roosevelt; and, was announced at Commencement Exercises at Tuskegee Institute by Foundation President, Basil O'Connor in May, 1939.

In Tuskegee, there were two hospitals: one for whites and one for blacks. Macon County Hospital , a small 30-bed, ill-equipped facility admitted only whites. The John A. Andrew Memorial Hospital, located on the campus of Tuskegee Institute and provided quality health care for Negroes plus all the other amenities that insured a wholesome and pleasant environment for the sick. While John A. Andrew Memorial Hospital was an excellent health care facility for blacks, a poliomyelitis epidemic which swept through the South in 1936, crippling black children and adults, was beyond its scope. Those institutions capable of treating poliomyelitis effectively were either too far away to permit travel for poor rural blacks or w ere open to whites only. Therefore, blacks really had nowhere to turn for the critically needed specialized care.

Also, at Tuskegee Institute, there was a nurses' training program begun in 1921, graduates were working all over the country as public health nurses, private practice, and at smaller institutions. This expanded to include an additional 4-month intensive course in midwifery. This further expanded in 1941 to a graduate nurse training course in midwifery culminating in a certificate.

Additionally, at Tuskegee Institute, there was the world-famous scientist, Dr. George Washington Carver, who had training as a mass-use for the Ames, Iowa football team. He continued his "research" using his peanut oil, in conjunction with rubbing sore muscles, on people who came to him daily, seeking relief. Although not a medical doctor, he did report positive results. In 1933, an article published by an AP writer was carried by papers all over the country, describing the tremendous improvement of two polio patients. This generated much publicity, letters, and future patients. Dr. Carver, personally, never claimed a cure: that was the spin put by the reporter in the press release. Dr. Carver later sent a sample of his peanut oil and directions for use to President Roosevelt, saying that it might offer him some relief. The President responded with a letter of thanks.

In 1936, Dr. John Watson Chenault, a young black man who was a junior attending orthopedic surgeon from Provident Hospital in Chicago, attended the 25th Annual John A. Andrew Clinic. He presented a paper on "The Crippled Child." While making rounds during the Clinic in the crippled children's wing, he noted that many of the little patients had infantile paralysis, an observation which was directly contradictory to the generally accepted statistics showing that Negro children did not contract this disease. Further, they required a much different type of medical care than those children routinely admitted to the pediatric ward. To this end, Dr. Chenault began a crusade for specialized treatment facilities for all children suffering from polio, and especially those at Tuskegee. Dr Chenault returned to Tuskegee in 1937 as Director of Orthopedic Surgery at the John A. Andrew Memorial Hospital.

There was also a shoe and brace making curriculum at Tuskegee Institute whereby a student could study orthopedic shoe and brace making, either as a two-year vocational diploma or a 4-year B.S. degree. Interns of Dr. Chenault, and later, Dr.John F. Hume, could also rotate through this program.

This then describes the environment of health care that met the criteria for the establishment of the Infantile Paralysis Center at Tuskegee Institute in 1941.

The National Foundation for Infantile Paralysis was founded in 1938, as you know, by President Franklin D. Roosevelt to raise money for finding a cure and treatment of polio. One of the fund raisers was the Presidential Ball held all over the country in January on the President’s birthday. Separate balls were held for blacks and whites, with each of the groups’ contributions added to the total. The Warm Springs Foundation had already been established, however, blacks were not admitted, and their care was confined to inadequately equipped and staffed facilities in various local hospitals. The onus to “do something for blacks” thus fell upon the National Foundation and its President, Mr. Basil O’Connor.

My comments today will be divided into five topic and related sub-topic areas, and will be very brief due to time constraints : 1) Poliomyelitis Among Blacks:1936-1941, President Roosevelt’s trip to Tuskegee, Role of Basil O’Connor; 2) The Infantile Paralysis Center at Tuskegee Institute, Warm Springs Contribution;
3) Educational Activities, Nursing Education, Liaison with National Foundation for Infantile Paralysis;
4) New Missions, Tuskegee Rehabilitation Center, Carver Research Foundation and HeLa Cell Cultures.

The Polio Crusaders: Disability Activism at Warm Springs in the 1930s

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During the 1930s, disabled adults at Warm Springs initiated a public disability rights campaign. So effective was this campaign that President Franklin Roosevelt's able-bodied advisors considered it a political threat, and sought to displace the articulate adult polio survivor in the public mind with the image of the poster child, vulnerable, silent and grateful. At the core of this disability rights movement were polio patients who wanted more than a healing refuge. They saw the Warm Springs' high profile as a potent weapon in a cultural war to challenge discrimination against the disabled. Their eight-page newsletter, the *Polio Chronicle*, its slogan "Every Patient, a Polio Crusader," boldly protested the narrow, medicalized definition of rehabilitation and provocatively suggested "rehabilitating" prejudiced, able-bodied employers and health professionals. And they consciously redesigned Warm Springs to function as an exemplar of the way polio survivors and other disabled people deserved to live. To make what seemed like a special interest demand into a public right, these Polio Crusaders built a feisty and hedonist community filled with poker games, vaudeville shows and romance.

The community of activists at Warm Springs was part of a broader, nascent disability rights movement. In 1935 the League of the Physically Handicapped protested discriminatory government policies and marched with signs that that read "We Don't Want Tin Cups We Want Jobs," mocking the piteous images of the disabled typically promoted by charities and New Deal agencies. But the class allegiances of most Warm Springs patients were worlds away from the League, an organization never discussed in the Polio Chronicle. In the 1930s this community was made of up of wealthy adults, and from the beginning Warm Springs patients, administrators and medical staff were all white, with, as was typical of other Southern institutions, African Americans working as maids, waiters, body servants, gardeners and janitors.

By the end of the 1930s, with the founding of the March of Dimes, the Polio Chronicle had ceased publication, the League for the Physically Handicapped had dissolved, and disabled activism was in retreat. The March of Dimes developed no policies for employing the disabled or battling discrimination. Despite increasing numbers of adolescents and adults disabled by polio, March of Dimes publicity campaigns remade the polio survivor into a hopeful, young child, attractive and eager to walk again, silent and smiling. Now, rehabilitation meant an adjustment to physical limitations and not integration into society, a striving for normality and not an open realism about physical difference. Children were good for fund-raising, but they also signaled the shift back to the treatment of the disabled as the objects of sentimental publicity, and a renewed disregard for the disabled as agents of policy and change. Polio survivors continued to fight social and economic discrimination at their homes, schools and workplaces. The emergence of the Independent Living Movement in the 1960s was spearheaded by a new generation of adult polio survivors, who were children just as Warm Springs oriented its rehabilitative efforts around child patients. Perhaps the legacy of activism can be traced to the inspiring example of Warm Springs as a "Polio's Paradise.

Polio: The Legacy of Warm Springs

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Seventy years ago the Georgia Warm Springs Foundation was the most famous rehabilitation facility in the nation. Part of that fame, of course, derived from its founder and frequent visitor, President Franklin D. Roosevelt. But by the late 1930s Warm Springs had also garnered national attention for the rehabilitating survivors for the annual polio epidemics. Beginning in 1934, millions of Americans contributed to the President's Birthday Balls to help support the work at Warm Springs. But now, some eighty years after Roosevelt established Warm Springs as a polio rehabilitation facility, much of that fame has faded. Most of my history students have no sense of what Warm Springs was or what it accomplished. It good to recall why Warm Springs was so important to people with polio, and to explore its legacy for polio survivors, for rehabilitation, and for the history of disabilities in the United States.

- I want to explore briefly this afternoon several important legacies of Warm Springs and I hope that at the end of the presentations we can have a good conversation about this place that meant so much to so many polio survivors. Let me just note the legacies I want to discuss:
- Perhaps more than any other rehabilitation facility at the time, Warm Springs never forgot that patients in rehabilitation are people first. The doctors and the staff seemed to recognize the individuality of the boys and girls, men and women, they treated even as they pushed them to achieve maximum possibly recovery.

- Warm Springs was one of the first, perhaps the first, rehabilitation facility to emphasize the psycho-social element of rehabilitation. For individuals who had experienced a devastating disease and the paralysis of their body rebuilding their self esteem and social skills was no less important than rebuilding their bodies.
- Warm Springs demonstrated the importance of a powerful role model-FDR.
- Warm Springs created a temporary haven for people with serious disabilities, in which disability was the norm-in which polio survivors were the normals.
- Warm Springs and the need to put it on a solid financial footing gave rise not only to the President's Birthday Balls, but also to the National Foundation for Infantile Paralysis, the March of Dimes, and the development of the polio vaccines of Salk and Sabin.

Modifying ADL Techniques to Accommodate New Weakness

Carolyn Podolski, OT, Peachtree City, Georgia

SESSION T3

Demonstration and Discussion of a Post-Polio Examination: Sorting Out Secondary Conditions, Part 1

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNI), Johnstown, Pennsylvania

Martin Wice, MD, Medical Director, St. John’s Mercy Rehabilitation Hospital, St. Louis, Missouri

Post-Polio Patient Assessment

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

I. History

- **A. Chief Concerns: eg. Pain, fatigue, new weakness, change in function**
- **B. Polio History**
  1. Age and severity during first month; historical year
  2. Early rehabilitation highlights and timeframes of recovery
  3. Residual disability at maximum recovery or after 2 years
  4. Any rehabilitative surgeries and/or History of device/brace use
  5. More recent or later(>15 years) changes in strength or function
  6. Current motor functional capacity
- **C. Past General Medical History**
  1. Chronic conditions
  2. Injuries
  3. Surgeries
  4. Timing of above in relation to PPS symptoms
- **D. Current Health**
  1. Review of Systems: pain, fatigue, new weakness, breathing or swallowing problems, sleep, weight change
  2. Current medications
- **E. Family & Social History**
  1. Lifestyle Assessment relative to health & wellness
  2. Psychologial & social stressers
- **F. Review Relevant Medical, Laboratory & Imaging Reports**

II. Examination

- **A. Observe Function: seating/standing/walking postures and capacities—do fully clothed and with usual devices/methods**
- **B. Formal Range of Motion assessment of joints & muscles**
- **C. Strength assessment of key functional muscle groups(modified MMT)**
- **D. General and/or focused Orthopedic Exam**
  1. Structural deformities of neck, back, chest, limbs
  2. Joint Instability
  3. Leg Length Discrepancy
- **E. General and/or focused Neurologic Exam**
  1. Muscle tone and bulk(?atrophy)
  2. Reflexes
  3. Sensation
  4. Co-ordination
  5. Mental status & affect
- **F. Provocative Pain Examination**
  1. Can pain be reproduced during the exam?
  2. Does pain occur with active and/or passive movements, or with pressure?
- **G. Focused Evaluation of Gait or other Functions**
  1. With and without devices
  2. Challenged

III. Planning

- **A. Is More Information Needed?**
  1. Lab Studies: eg. CBC, thyroid, blood sugar, etc.
  2. Further X-Rays or Imaging Studies
  3. Electrodiagnostics: EMG, Conduction studies
  4. Pulmonary Function Studies and Arterial Blood Gases
  5. Sleep Studies
  6. Rehab.Team Evaluations: PT, OT, CR, Psych/social work, orthotics, dietician
  7. Medical evaluations: Orthopedist, Neurologist, Internist (pulmonologist, cardiologist), ENT, Psychiatrist, Surgeon
  8. Medical Records/Reports: eg. Primary Care Physician, original polio care, reconstructive surgery operative reports, etc.
- **B. Preliminary Goals Presented and Discussed with Patient (and family)**
- **C. Short-term and Long-term Goals Agreed to by Patient & Physician**
- **D. Treatment Plan Outlined and Agreed To**

  For Example:
  1. Weight Loss Plan
  2. Use Bi-PAP at night
  3. Obtain orthosis (brace) and follow with PT to learn correct use & adjust
  4. PT for Individualized Exercise Program
  5. Pain Management Plan
  6. Counseling & anti-depressent use
  7. OT for energy conservation plan

How does one assess an individual for the post-polio syndrome?

Martin Wice, MD, Medical Director
St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

The first thing I do when I examine polio survivors is to get a very detailed medical history from the time they had polio through their entire recovery process and then their new decline. I conduct a detailed physical examination, including a neuromuscular and functional evaluation. Tests are performed not so much to prove one has the post-polio syndrome (no test can do this), but to rule out other problems which can masquerade for it. Tests include blood work (including a CBC, chemistry profile, thyroid screen, CPK, and ANA), and a vital capacity (a breathing screen).

If I have cause for concern about breathing, I request a blood gas, which checks for oxygenation and for CO_2 retention. I may request a sleep study I may also do a special barium "cookie" swallowing study if swallowing is a problem. I may do electrodiagnostic testing of the arms and legs, not to prove that someone has the post-polio syndrome, but to look for other problems -- carpal tunnel syndrome, radiculopathy -- which may explain someone's symptoms. I also may request appropriate radiological testing such as x-rays of joints that are hurting to look for arthritis or for fractures. I may request an MRI scan of the spine to make sure nothing else is masquerading for the post-polio syndrome.

Other tests can be requested depending on what is found during the physical examination. Depending on the results of the above-mentioned tests, I will arrange appropriate referrals.

It is important that the patient and his/her family get the most out of the evaluation. It is to bring in all relevant information including a completed patient profile, if sent, records of past evaluations, test results, treatments and treatment results and to have their questions in writing with someone to help record the answers.

Feel Good Food: Boosting Energy, Maintaining Weight

Kathryn Bussey, RD, RWSIR, Warm Springs, Georgia

Meeting Other Users of Home Mechanical Ventilation

What is currently known as Post-Polio Health International (PHI) was incorporated in 1960 as the International Iron Lung Polio Assistance, Inc. The organization's original focus was to provide information to polio survivors and their families who had spent time in an iron lung. In 1987, International Ventilator Users Network (IVUN) was formed to enhance the lives and independence of home ventilator users through education, advocacy, research and networking. Its work mirrors that of PHI in that it has a unique newsletter (*Ventilator-Assisted Living*), directory (*Resource Directory for Ventilator-Assisted Living*), and website (www.ventusers.org).

Problems and solutions for users of home mechanical ventilation are also unique. Ventilator users and their families and attendants will gather at this early session to discuss issues and to meet each other to instigate networking throughout the conference. Health professionals, representatives of ventilatory manufacturers and those who have post-polio related breathing problems are encouraged to attend.

Finding and Disseminating Information through Support Groups

Moderator: Margaret Hinman, editor, *Colorado Post-Polio Connections*, Westminster, Colorado

Using the Internet

Barbara Gratzke, International Post-Polio Support Group, Miami, Florida

Developing Special Projects

David Holland, Post-Polio Awareness and Support Society of British Columbia (PPASS BC)
Langley, British Columbia, Canada

Suggestions for Increasing Advocacy

Linda Priest, CTRS/L, Atlanta Post-Polio Association, Decatur, Georgia

Sharing Newsletters

Attendees

Use the Internet to Expand Your Knowledge, Meet Friends, Join PPS Groups, Play Your Favorite Games, Read Articles, Shop, Take Classes and More.

Barbara Gratzke
President, International Post Polio Support Organization (IPPSO)
www.ippso-world.org
President, Post Polio Assn. of South Florida
2660 SE 7th Place, Homestead, FL 33033
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The International Post Polio Support Organization (IPPSO) is an Internet-based nonprofit organization.

IPPSO's mission is to provide Internet forums for communication so polio survivors can support each other and share information. IPPSO also strives to advocate for polio survivors to have the best quality of life possible.

IPPSO currently:

- Hosts a Yahoo group bulletin board and supports real-time voice and type chat for its members. We plan to solicit prominent people to be guests to answer questions on various topics of interest to polio survivors. To join go to: http://groups.yahoo.com/group/ippsobulletinboardchat

- Hosts a Yahoo group "Polio World" with a bulletin board and chat forum which is restricted to PPS support group leaders and PPS advocates so they can share creative ideas, successes, failures and strive to gain creditability by joining forces to speak as "one loud voice." The goal is to organize the PPS community to be a powerful force for change – politically, economically, medically and socially. To join go to: http://groups.yahoo.com/group/polio-world

- Maintains a website with a list of recommended PPS medical professionals, PPS groups, articles related to PPS, and links to other pertinent web sites. If you would like your web site linked via our web site, please contact us.

- Emails medical updates, a monthly IPPSO Magazine, and other PPS-related articles to its members that have completed an application for membership at www.ippso-world.org.

- Responds to questions and offers support via individual emails.

For the Computer Novice

Be sure to start out very slowly so you are not over-whelmed. A good way to begin is to play a game like Solitaire which teaches you mouse operations and selecting icons on the screen. Next, you should obtain an email box and email address (many go to www.yahoo.com or www.msn.com to do this). Then, you can learn to type key words into the search field in your Internet browser in order to navigate to what you want to find.

Check with a senior citizen center, library, school or Center for Independent Living near you for free computer lessons. Best Buy stores in the US now offer computer services (called their "Geek Squad") and will come to your home to assist you with set up, installing programs, or instructions on how to use your computer.

Due to mobility impairments, many seniors and persons with disabilities, spend the majority of their time at home, isolated from social interaction and the Internet can reduce feelings of loneliness and depression.

Reasons to Utilize the Internet:

Keep in touch with family and friends easily

- Emails can take the place of postal mail to send greetings quickly without the cost of stamps.
- Pictures and short movies can be shared easily.
- Type or voice chat real-time. *(Especially the youngsters love to communicate this way.)*
- Use a webcam for live viewing. It's a great way to watch the little one's grow up.

Make new friends all over the world without leaving your home

- Internet chat rooms are the source of new friendships and possible new relationships.
- Listservs, blogs and newsgroups can be sources for interesting group conversations.

Enjoy online games – solitary games or play with other people real-time

- Get on the Internet and play online mind games when you're bored. An active mind is especially vital as age catches up with us.
- Play word, card or board games with real people or against the computer. (www.yahoo.com has free games)
- Can't sleep – go to the Internet. (www.pogo.com has many games at a cost of about $30 a year)

Gain knowledge and perform tasks required in your everyday activities such as:

- Banking and paying bills
- New recipes for meals
- Maps and directions for travel
- Yellow pages and white pages (*You no longer have to use heavy telephone books.)*
- Local TV and Movie Listings
- Order products and services including:
  * Compare prices * Look up product ratings & best buys for your money. * Discounts and coupons * Newspapers available online from many locations * Fix things around the house by learning how to at web sites such as www.fixya.com * Encyclopedia-type information at such web sites as www.en.wikipedia.org. * Online seminars are available from colleges, museums and libraries. * Take travel tours, learn about sculpture, or discuss poetry or history without ever having to leave your home.

Research to get articles to improve your medical health and well-being

* Review drug information and interaction of drugs, herbs, and vitamins. * Search for assistive devices. (*pictures, specifications, prices and testimonials)* * Look up medical symptoms and information. * Check ratings of doctors, hospitals, and nursing homes. * Get tips and products to make your home more accessible. * Find various online government services and often you can fill out questionnaires to find out what benefits are available to you. * Contact organizations that support your conditions or interests.

Internet web sites that many find useful

- *Note that the list below is not all inclusive.*
- *Please contact us to share more websites that you find helpful to add to this list.*
- *This list will soon be posted on our web site (www.ippso-world.org) with hyperlinks to click on which will take you directly to the sites. Please contact us to have our web site linked to yours.*

Government Information in US

Nat'l Institute of Neurological Disorders & Stroke (NINDS) - www.ninds.nih.gov.
Post Polio Information Page is http://www.ninds.nih.gov/disorders/post_polio/post_polio.htm

Social Security Regulation for PPS used to determine eligibility for disability income (SSDI) and also Supplemental Security Income (SSI) which provides payments for individuals who are disabled and qualify. In most states, individuals who qualify for SSI also receive Medicaid health care benefits right away. - http://www.post-polio.org/edu/di245801.html

Navigate the world of disability benefits - www.disabilitybenefits101.org

Disability-related government resources - www.disabilityinfo.gov

Magazines & Newsletters Geared to People with Disabilities

- **World of Possibilities** is a magazine that offers disability-related information about equipment, products and goods. It features articles on health, employment, technology, education, sports, travel, universal design, mental health and much more. - www.caringcommunities.org

- **DisabilityWorld** is the online international periodical of news and views by World Disability Resources. - www.disabilityworld.org

- **Disabled On Line** provides a newsletter, web directories, forums, chat rooms, shopping and classifieds. - www.disabledonline.com

- **New Mobility Magazine** is a monthly magazine with all types of disability information. They distribute an annual guide to use to review and purchase assistive devices. - www.newmobility.com

- **Disabled Dealer** is a US Magazine online or by postal mail of new and used accessible vans, power chairs, and RV's - www.disableddealer.com

Medical Professionals Familiar with PPS & Post Polio Support Group Directories by Locale

- www.ippso-world.org
- www.post-polio.org
- www.ott.zynet.co.uk/polio/lincolnshire/directory/org.html

Organizations for People with Disabilities

Global:

Centers for Independent Living –location closest to you - www.ilru.org/html/publications/directory/index.html

Rotary International Polio Survivors & Associates (PSA) Action Group - www.rotarypoliosurvivors.com

US:

- **The Alliance of Technology Access for people with disabilities** - www.ataccess.org
- **Families USA** (“the voice for Health Care consumers”) provides advocacy tools, resources, information, and easy to understand explanations of current healthcare coverage issues. – www.familiesusa.org
- **The National Council on Disability** (NCD) examines employment, housing, education, transportation and other federal policies that affect people with disabilities. - www.ncd.gov
- **The American Association for People with Disabilities** (AAPD) is the largest nonprofit cross-disability member organization in the US, dedicated to ensuring economic self-sufficiency and political empowerment for the more than 56 million Americans with disabilities. - www.aapd.com
- **The Medicare Rights Center** works to ensure access to affordable health care for older adults and people with disabilities through counseling, educational programs and public policy initiatives – www.medicarerights.org
- **The US Clearing house for home and community based services** - www.hcbs.org

PPS-related Chats, Bulletin Boards & Email Listservs

- **IPPSO Yahoo group bulletin board and chat availability for members** to support each other by discussing meeting the challenges of everyday life and making friends. To join go to: http://groups.yahoo.com/group/ippsobulletinboardchat
- **IPPSO Yahoo group bulletin board and chat availability for the major PPS support group leaders and advocates.** To join go to: http://groups.yahoo.com/group/polio-world
- **POST-POLIO-MED** is a forum for PPS researchers & medical professionals, polio survivors and others interested in PPS. Posts are limited to the topics of PPS research, clinical issues, clinical trials, current treatment practices, and support group newsletters. Get Information at: www.skally.net/ppsc/ppsc-l.htm. Subscribe via e-mail to: Post-Polio-Med-subscribe-request@listserv.icors.org.
- **Justice For All (JFA) Email** is a free service of the American Association of People with Disabilities (AAPD) that shares disability news (legislation and policy, popular culture, etc.) and issues calls to action to advocates across the country. To join go to - http://www.aapd.com/Advocacy/JFA.html
- **Dear Marci** is a weekly e-newsletter that features Medicare coverage advice, health tips and links to health care resources. Tel# is (800) 333-4114 or sign up to receive emails at - www.medicarerights.org
- **The Boulevard** is a disability resource directory of products and services for the physically challenged and healthcare professionals. It has a message board and a newsletter to subscribe too. – www.blvd.com

Products for Independent Living

- **Apparel for those in wheel chairs** - www.agapparel.com/shop.php
- **Daily living aides, personal care, orthopedic and fitness supplies** - www.goallegro.com
- **Disability resource directory of products and services** - The Boulevard - www.blvd.com
- **Exhibits of Assistive Devices in the US**
    - Abilities Expo - independent and assisted living products and services from retailers and.seminars on topics of interest to people with disabilities - www.abilitiesexpo.com
    - Medtrade Show –the largest exhibition of assistive devices from the leading manufacturers of home medical equipment. Also seminars offered for retailers of HME. - www.medtrade.com
- **Mobility challenges** - The Institute for Rehab Research and Development gives you basic guides on choosing ambulatory devices, basic principles of wheel chair seating, etc. - http://www.irrd.ca/education/default.asp
- **Seating International Symposium** - the University of Pittsburg sponsors a conference each year that covers topics for people with disabilities that have seating and mobility issues. - www.iss.pitt.edu
- **Wheelchairs, scooters and other home care needs** – www.Spinlife.com
- **Wheel chairs, scooters, lifts, ramps, bathroom products.** They are starting a free classified ad section where you can list free and purchase used power chairs, accessible vehicles etc. – www.planetmobility.com
- **Wheelchairs & scooters**- assists in determining what will work for you - www.wheelchairjunkie.com

PPS Support Group Newsletters on the Internet

International PPS Organization Newsletters

Post-Polio Health International (PPHI) - www.post-polio.org
International Post Polio Support Organization (IPPSO) - www.ippso-world.org
European Polio Union (EPU) - www.postpolio.eu

Global PPS Support Groups (excluding the US - see below):

Africa	Post-Polio Network RSA - www.postpolio.co.za
Australia	Post-Polio Network NSW, Inc. - www.post-polionetwork.org.au
	Australia PP NETWORK OF WA INC) - www.upnaway.com/~poliowa/
Brazil	www.abraspp.org.br
Britain	Lincolnshire Post-Polio Network (Cornwall United Kingdom) www.zynet.co.uk/ott/polio/lincolnshire or www.lincolnshirepostpolio.org.uk
	British Polio Fellowship - www.britishpolio.org.uk
Canada	Victoria - PPASS of BC - www.ppass.bc.ca
	Canadian March of Dimes - PPS group - www.poliocanada.com
	Saskatchewan Polio Regina Inc - http://nonprofits.accesscomm.ca/polio/
Ireland	PPS Group - www.ppsg.ie/index.htm
Italy	Erba - www.postpolio.it/convegno_post_polio
Mexico	Asociación Post Polio Litaff - www.postpoliolitaff.org
New Zealand	The Post Polio Support Society of NZ – www.nzordgroups.org.nz/postpolio

US PPS Support Group Newsletters

Arizona	Tucson - www.aztecfreenet.org/polioecho/org06.htm
California	Los Angeles area - Los Ranchos Amigos – http://www.polioassociation.org/Rancho.html
	Los Angeles area - The Southern California PPS Manager Newsletter

	www.ppsmanager.com
	Sacramento & Auburn - www.poliosurvivors.com
	San Diego - http://polio.home.mindspring.com/
Colorado	Colorado Post Polio Connections - www.co.easterseals.com and select “Post-Polio Support Group”
Connecticut	Norwalk - Polio Outreach of Connecticut - www.the-polio-outreach-of-ct.com
Florida	Boca Raton – Boca Area Post Polio Support Group – www.postpolio.wordpress.com
	Ocala - North Central Florida Post-Polio Support Group – www.postpoliosupport.com
	Orlando (eastside) - Post-Polio Resource Group of Central Florida - http://homepage.mac.com/j.annsingleton
	Ormond Beach - Florida East Coast Post-Polio Support Group – http://home.iag.net/~bgold/polio.htm
Massachusetts	Greater Boston Post-Polio Assn. - www.gbppa.org
Michigan	Michigan Polio Network Inc - http://www.geocities.com/mi_polio_net/index.html
Missouri	St. Louis - Post-Polio Health International (PHI) - www.post-polio.org
	Branson - http://www.postpoliobransongoers.com
New Jersey	Northern New Jersey - www.njpolio.org
	Ocean County - http://tomsrivernjpolio.org/
New York	Polio Connection of America - http://www.geocities.com/w1066w/
Pennsylvania	Conemaugh Health Systems - http://postpolio.conemaugh.org
Texas	San Antonio - http://sapsa.mu.nu/
Washington	Spokane - http://polionet.org/
Wisconsin	Milwaukee - www.pprg.org

Recreational Activities for People with Disabilities

Access Anything encourages people living with disabilities around the world to enjoy life to its fullest through the sense of freedom provided by travel and adventure. - www.AccessAnything.net

Access to Recreation - catalog of adaptive equipment for recreation i.e. bowling, cycling, hunting and fishing, swimming, travel, exercise equipment, pool lifts, portable shower, & ramps - www.accesstr.com

Adaptive Adventures is a nonprofit organization dedicated to improving the lives of people with disabilities through outdoor sports & recreation. - www.adaptiveadventures.org

US Air Travelers with Disabilities - Hotline # 800-778-4838 to obtain information about the rights of persons with disabilities during air travel, or report a disability-related air travel service problems. File a complaint to airconsumer@ost.dot.gov or mail to: US Department of Transportation, 400 7th St SW, Washington, DC 20590.

Disaboom is a community forum where people with disabilities can share lifestyle articles, blogs, forums, and health information and a special interest in exploring adaptive sports. - www.Disaboom.com

US National Sports Center for the Disabled - www.nscd.org

US Northeast Passage provides therapeutic recreation services. They deliver disability-related health promotion and adapted sports programs throughout New England. - http://www.nepassage.org/

RV rallies and travel club – RV Tips and newsletter, plus used accessible RVs for sale by owners – www.handicappedtravelclub.com

The Society for Accessible Travel & Hospitality (SATH) raises awareness of the needs of travelers in order to remove physical and attitudinal barriers and expand travel opportunities globally. Members include travel professionals, consumers with disabilities and other individuals and corporations that support this mission. Conferences are hosted and are a great place to exchange travel tips to make travel less stressful. - www.sath.org

Research References for Post Polio Syndrome (PPS)

National Library of Medicine & the National Institute for Health – see research and clinical trials as well as all types of information on polio and PPS - www.nlm.nih.gov/medlineplus/polioandpostpoliosyndrome.html

Post-Polio Central archives web site for research and clinical trials - http://i-sites.net/ppsrl/reslarc.html

Post-Polio Central - PPS recently published medical articles – http://i-sites.net/ppsma/medindx.html

Online Health Forum – (put "Post Polio" in the search field) - www.medicalnewstoday.com

PubMed is the world's largest medical library and is a service of the U.S. National Library of Medicine and the National Institutes of Health (put "Post Polio" in the search field) - http://www.ncbi.nlm.nih.gov/pubmed/

Vent-User & Respiratory Resources

Vent Users Mailing List provides a forum for people who require a ventilator (respirator) to breathe to communicate with others with like issues. Send questions to vent-users@eskimo.com. To subscribe send an email to: vent-users-request@eskimo.com - in the Subject line type: "subscribe"

International Ventilator Users Network, an affiliate of (PHI) - www.ventusers.org

The Institute for Rehabilitation Research and Development's web site section on "Respiratory Protocols for SCI and neuromuscular diseases" teaches you about frog breathing, assisted cough using an ambu bag and abdominal trust to expand your lungs and many other issues - http://www.irrd.ca/education/default.asp

Progressive Medical in Carlsbad, California USA has an organization that specializes in sleep apnea and respiratory function tests geared to people with neurological conditions- www.progressivemed.org

Developing Special Projects

A presentation by:
David Holland, Vice-President Mainland, (PPASS BC) Post Polio Awareness and Support Society of British Columbia, Canada

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Introduction:

PPASS came into being in 1986, as a result of a number of Polio Survivors who live in Victoria, the capital of British Columbia, finding out about Post Polio Syndrome. The society has 30 Area Support Groups throughout the Province – some of which are very active, having monthly or bi-monthly coffee / lunch meetings with speakers.

Our mandate is to provide resource information for our members, increase awareness of the existence of PPS to the general public, the medical profession and most importantly, Polio Survivors.

While we don't solicit members outside of our own Province, we welcome anyone who wishes to join PPASS BC, resulting in our membership stretching from as far a-field as Scotland to New Zealand, and of course many states within the USA, with of course the vast majority of our members being located in our own Province of British Columbia.

British Columbia is situated between the Rockies and the Pacific Ocean, the 49th parallel (U.S. / Canada border) to the south and the Yukon Territory, located over 1,000 miles to the north. With a population of only 4.1 million scattered over this vast area of 365,000 square miles, our population density is low, resulting in large distances between towns and cities. This has necessitated us bringing events to the population centres, rather than expecting our members to travel to these events under their own steam, when in many instances their "steam" is diminishing and their energy levels are falling fast.

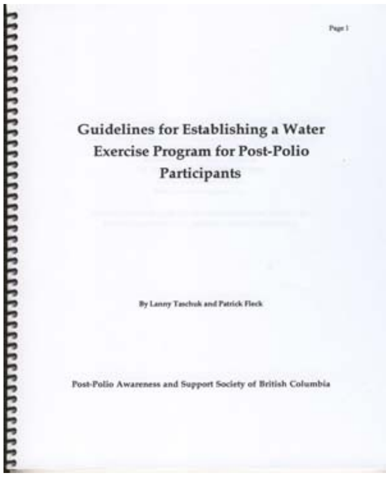
The PPASS Water Exercise Programme:

PPASS established its water exercise programme for polio survivors in the Greater Victoria area in 1995 under the supervision and guidance of a Dr. Alan Bass, a physiatrist working at the Gorge Road Hospital in Victoria. Dr. Bass was associated with a rehabilitation aquatics programme at the Esquimalt Recreation Centre and although several polio survivors had participated in this programme, both they and Dr. Bass realized that it did not meet the needs of polio survivors, resulting in the development of a specific programme together with an exercise regime that would suit the needs of polio survivors.

Qualified kinesiologists were trained as instructors for the programme by Dr. Bass and funding to support the programme was secured from the British Columbia Provincial Employees Community Services Fund. This funding continues to this day for which we are very grateful. The 1 ½ hour sessions are held every Monday and Friday now on a year round basis apart from the time when the pool is shut down for annual maintenance. Attendance ranges from 6 to 12 participants at every session. Generally there is a ratio of 10 participants to one kinesiologist, resulting in a high level of personal supervision and instruction. Participants have their own specialized exercise programmes, dependent upon their individual level of motor skills. These exercises may range from simply walking back and forth along the bottom of the pool with the water level at chest height to stretching and rotating arms and / or legs in specified patterns and for a predetermined number of cycles.

PPASS BC Members at George Pearson Rehabilitation Centre.

Of the six pools in the Victoria and Vancouver areas that have suitable facilities and sufficient instruction to undertake exercise programmes for Polio Survivors, it has been found that the water temperatures range should be from 30 Celsius (86 Fahrenheit) to 34 Celsius (93.2 Fahrenheit). This temperature range is higher than the usual public pool temperatures of 28 Celsius (82.4 Fahrenheit) due to Polio Survivors' intolerance to the cold, coupled with their limited exercise regime that Polio Survivors are capable of undertaking.



Page 1

Guidelines for Establishing a Water
Exercise Program for Post-Polio
Participants

By Lanny Taschuk and Patrick Fleck

Post-Polio Awareness and Support Society of British Columbia

It is interesting to note that the Esquimalt pool in Victoria is a salt water pool with a limited amount of chlorine which provides greater buoyancy for the participants – a helpful feature.

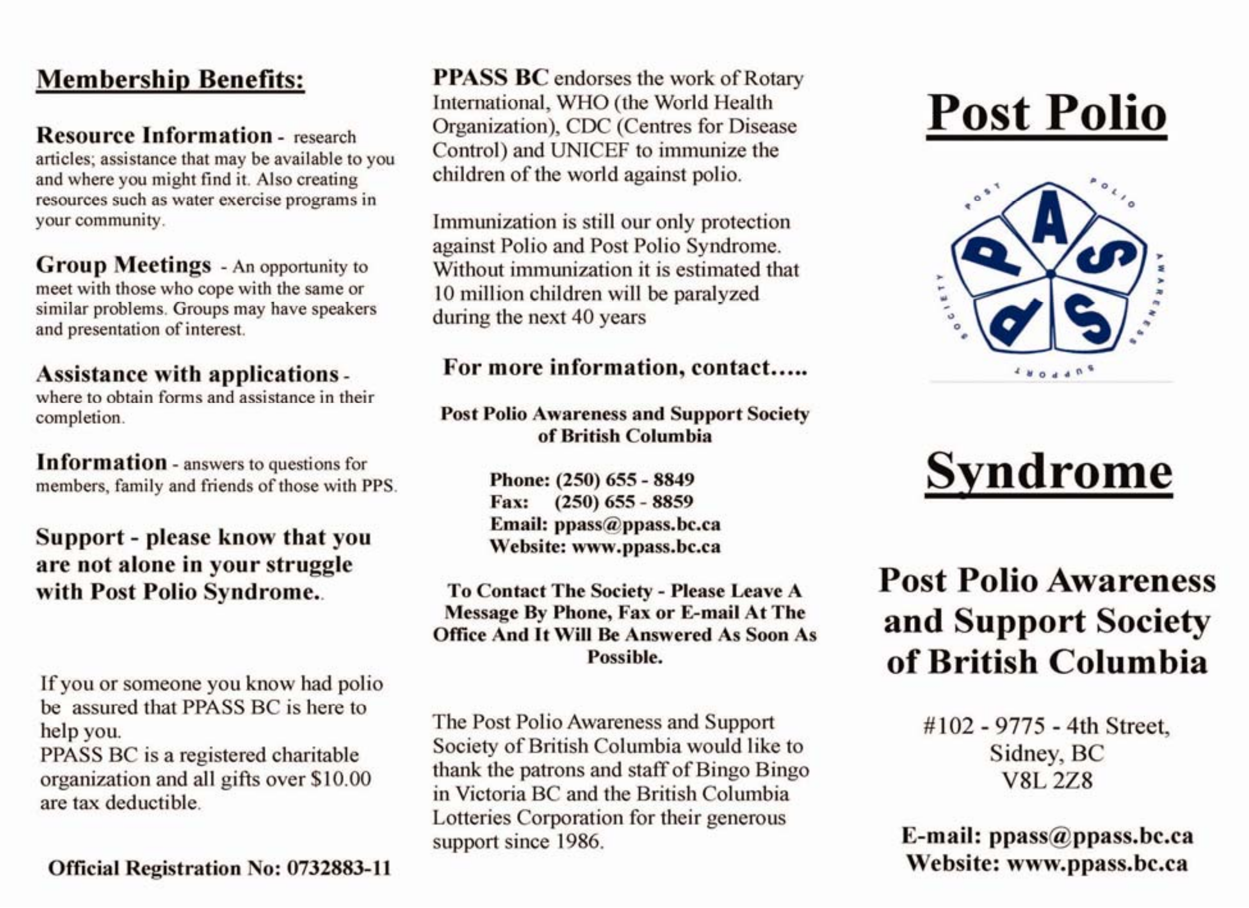
Even though the PPASS WEP programme is partially funded by the B.C. Provincial Employees Community Services Fund our members still have to pay a nominal monthly fee for the sessions. These fees help to cover the pool lane rental (see photo showing sign) and the exclusive use of the kinesiologists.

The other pool of note that has specialized facilities and supervisors is located at the George Pearson Rehabilitation Centre in Vancouver, which is part of the Vancouver General Hospital. This pool's water temperature is at the high end of the range, possibly on account of the fact that the facility deals with many stroke and trauma cases. As a result of this facility being part of a hospital both kinesiologists and physiotherapists are available for advice.

At Pearson participants pay $3.00 for each session. This fee also covers equipment and assistance from the kinesiologist and physiotherapist. At the West Vancouver Aquatic Centre the fee is $6.00 per person per session, again covering equipment use and supervision from medically trained staff. It must be noted that none of the pool facilities or the Water Exercise Programmes that take place, other than the Victoria (Esquimalt) pool are supported by outside funding. These facilities have WEP programmes that follow some of the guidelines as set out in the WEP programme but are not necessarily endorsed by PPASS BC.

The PPASS BC Brochure:

Our tri-fold brochure has been developed by various members of PPASS during the past few years, resulting in the version as you see here. We have attempted to provide a publication that is both helpful to potential members as well as the medical profession. These brochures are distributed by PPASS members to Health Centres, doctors and other medical professional’s offices, together with medical laboratories throughout the Province. Distribution is specifically concentrated during Polio Awareness month, but when recipients request copies of the brochure of course we are pleased to make sure that an inventory of brochures is always available for distribution.



Membership Benefits:

Resource Information - research articles; assistance that may be available to you and where you might find it. Also creating resources such as water exercise programs in your community.

Group Meetings - An opportunity to meet with those who cope with the same or similar problems. Groups may have speakers and presentation of interest.

Assistance with applications - where to obtain forms and assistance in their completion.

Information - answers to questions for members, family and friends of those with PPS.

Support - please know that you are not alone in your struggle with Post Polio Syndrome.

If you or someone you know had polio be assured that PPASS BC is here to help you.
PPASS BC is a registered charitable organization and all gifts over $10.00 are tax deductible.

Official Registration No: 0732883-11

PPASS BC endorses the work of Rotary International, WHO (the World Health Organization), CDC (Centres for Disease Control) and UNICEF to immunize the children of the world against polio.

Immunization is still our only protection against Polio and Post Polio Syndrome. Without immunization it is estimated that 10 million children will be paralyzed during the next 40 years

For more information, contact…..

Post Polio Awareness and Support Society of British Columbia

Phone: (250) 655 - 8849
Fax: (250) 655 - 8859
Email: ppass@ppass.bc.ca
Website: www.ppass.bc.ca

To Contact The Society - Please Leave A Message By Phone, Fax or E-mail At The Office And It Will Be Answered As Soon As Possible.

The Post Polio Awareness and Support Society of British Columbia would like to thank the patrons and staff of Bingo Bingo in Victoria BC and the British Columbia Lotteries Corporation for their generous support since 1986.

Post Polio

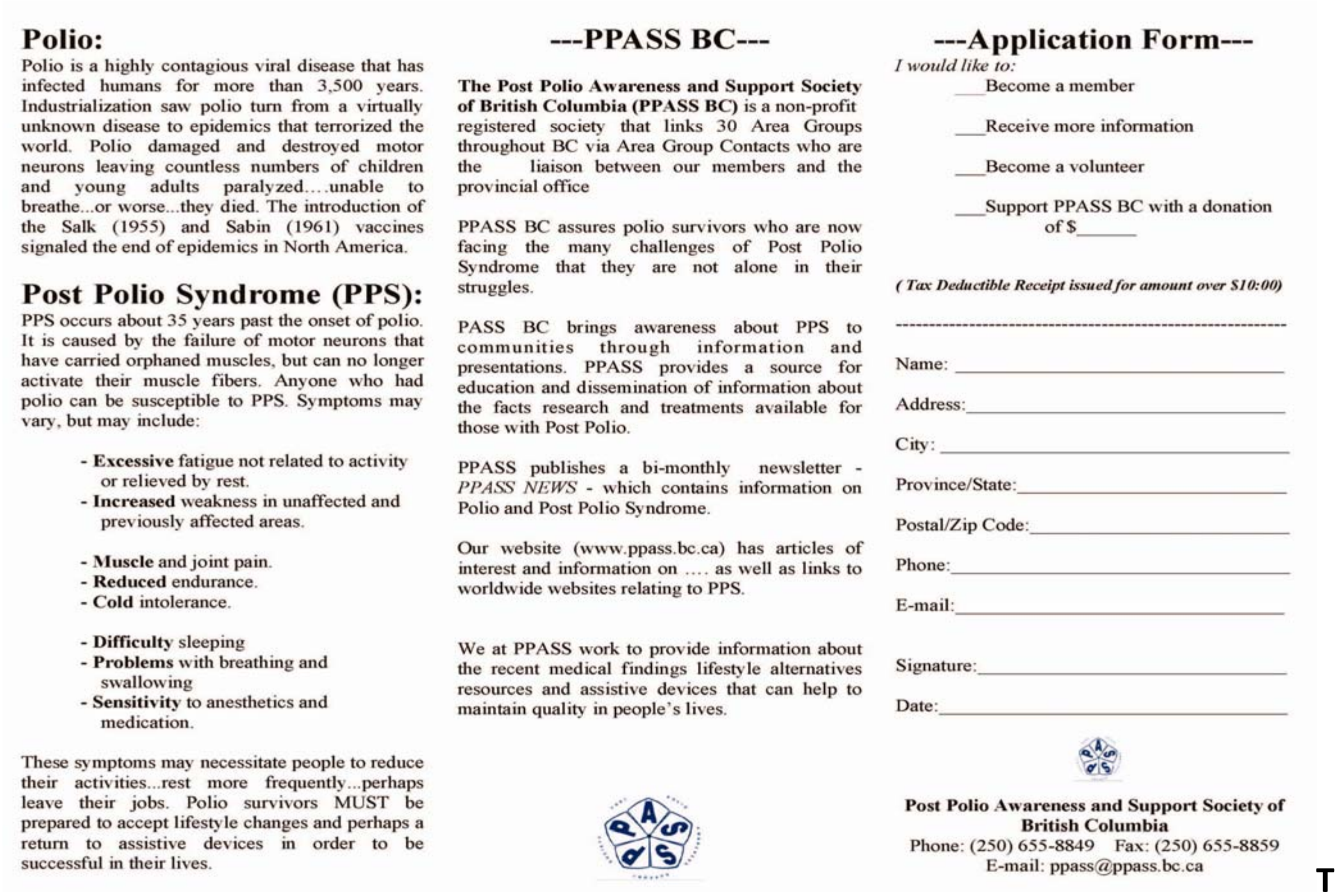
Syndrome

Post Polio Awareness and Support Society of British Columbia

#102 - 9775 - 4th Street,
Sidney, BC
V8L 2Z8

E-mail: ppass@ppass.bc.ca
Website: www.ppass.bc.ca

The PPASS BC Website Home Page – go to www.ppass.bc.ca for more information.



Polio:

Polio is a highly contagious viral disease that has infected humans for more than 3,500 years. Industrialization saw polio turn from a virtually unknown disease to epidemics that terrorized the world. Polio damaged and destroyed motor neurons leaving countless numbers of children and young adults paralyzed….unable to breathe...or worse...they died. The introduction of the Salk (1955) and Sabin (1961) vaccines signaled the end of epidemics in North America.

Post Polio Syndrome (PPS):

PPS occurs about 35 years past the onset of polio. It is caused by the failure of motor neurons that have carried orphaned muscles, but can no longer activate their muscle fibers. Anyone who had polio can be susceptible to PPS. Symptoms may vary, but may include:

- **Excessive** fatigue not related to activity or relieved by rest.
- **Increased** weakness in unaffected and previously affected areas.

- **Muscle** and joint pain.
- **Reduced** endurance.
- **Cold** intolerance.

- **Difficulty** sleeping
- **Problems** with breathing and swallowing
- **Sensitivity** to anesthetics and medication.

These symptoms may necessitate people to reduce their activities...rest more frequently...perhaps leave their jobs. Polio survivors MUST be prepared to accept lifestyle changes and perhaps a return to assistive devices in order to be successful in their lives.

---PPASS BC---

The Post Polio Awareness and Support Society of British Columbia (PPASS BC) is a non-profit registered society that links 30 Area Groups throughout BC via Area Group Contacts who are the liaison between our members and the provincial office

PPASS BC assures polio survivors who are now facing the many challenges of Post Polio Syndrome that they are not alone in their struggles.

PASS BC brings awareness about PPS to communities through information and presentations. PPASS provides a source for education and dissemination of information about the facts research and treatments available for those with Post Polio.

PPASS publishes a bi-monthly newsletter - *PPASS NEWS* - which contains information on Polio and Post Polio Syndrome.

Our website (www.ppass.bc.ca) has articles of interest and information on …. as well as links to worldwide websites relating to PPS.

We at PPASS work to provide information about the recent medical findings lifestyle alternatives resources and assistive devices that can help to maintain quality in people's lives.

---Application Form---

I would like to:

___Become a member

___Receive more information

___Become a volunteer

___Support PPASS BC with a donation of $______

(Tax Deductible Receipt issued for amount over $10:00)

Name: ______________________________

Address:______________________________

City: ______________________________

Province/State:______________________________

Postal/Zip Code:______________________________

Phone:______________________________

E-mail:______________________________

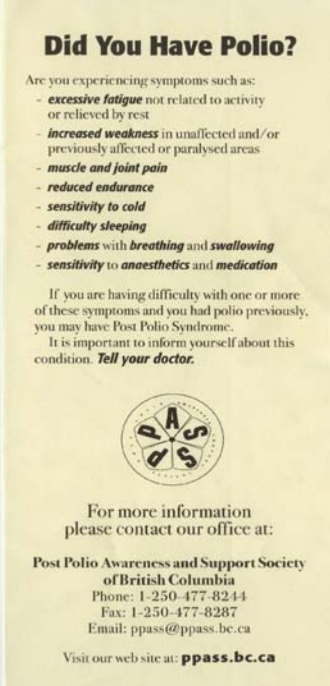
Signature:______________________________

Date:______________________________

Post Polio Awareness and Support Society of British Columbia
Phone: (250) 655-8849 Fax: (250) 655-8859
E-mail: ppass@ppass.bc.ca

T

The PPASS BC Flyer:



Did You Have Polio?

Are you experiencing symptoms such as:

- ***excessive fatigue*** not related to activity or relieved by rest
- ***increased weakness*** in unaffected and/or previously affected or paralysed areas
- ***muscle and joint pain***
- ***reduced endurance***
- ***sensitivity to cold***
- ***difficulty sleeping***
- ***problems*** with ***breathing*** and ***swallowing***
- ***sensitivity*** to ***anaesthetics*** and ***medication***

If you are having difficulty with one or more of these symptoms and you had polio previously, you may have Post Polio Syndrome.

It is important to inform yourself about this condition. ***Tell your doctor.***

For more information
please contact our office at:

Post Polio Awareness and Support Society of British Columbia
Phone: 1-250-477-8244
Fax: 1-250-477-8287
Email: ppass@ppass.bc.ca

Visit our web site at: **ppass.bc.ca**

An inexpensive and easily produced flyer meant to bring people's attention to "Polio" and in turn make people aware of the possible future problems associated with Post Polio Syndrome.

This flyer was developed by the PPASS BC office and is distributed to our members, who in turn arrange to leave the materials in various health and doctor's offices. You will note that very little technical and medical wording is used – the reason being is that we intend for this document to be used to prompt people to visit their doctor if they suspect that they have suffered with Polio in the passed.

We are in the throws of translating this document into Mandarin and Punjabi – they being two of the languages spoken by many members of the immigrant population in British Columbia. The various ministries within the Provincial Government, associated with multiculturalism are delighted to learn of our initiative and in turn propose to assist us with the printing costs.

The *PPASS News:*

Our bi-monthly newsletter is mailed out to all members along with a considerable number of medical professionals. We also make sure that copies of the newsletter are exchanged with other PPS groups throughout the world.

Mini Conferences and Trade Shows:

We have found that for the amount of man-hours spent in setting up a one day mini conference and trade show generates a greater return than organizing a multi-day event. Generally, the plan is for the Trade Show (with say 6 to 10 exhibitors) takes place up until lunchtime, by so doing the attendees are able to speak one on one with equipment suppliers and have their questions answered. This has resulted in many orders for the suppliers, coupled with our members feeling at ease when trying to get help with either a medical or equipment problem. Lunch is served following the Trade Show, with the exhibitors joining the attendees and the speakers – again promoting a relaxed atmosphere. Exhibitors are more than willing to pay a nominal fee for a 10' x 10' booth space, with this fee also covering up to two lunches for the company representatives. The registration fee for attendees is normally $25, which covers their lunch, coffee breaks and facility rental. We have managed to run these events at a profit, with all net profits being used to financially help those members wishing to attend but are living on a restricted budget – a win-win situation.

A Big "Thank You"
Goes to Our Supporters

We wish to extend our thanks to the following organizations, companies, and individuals who have helped make this event possible:

PPASS BC

Langley Central Rotary Club

The Langley Times

Dundee Securities - The Timms Investment Team

5 Star Catering

Our Volunteers

Our Exhibitors:

A-1 Wheelchairs Unlimited (Chilliwack),

CMHC

Motion Specialties BC Limited

Regional Disabled Persons Association.

Sam Sullivan Disabilities Foundation.

Shoppers Home Health Care,

Tetra Society of North America

Travel Only

Our Registrants:

Without you , an event such as this would not be possible - thank you for attending. We hope you find it enjoyable and beneficial.

And finally, our Guest Speakers:

Ramesh Ferris - Cycle to Walk Society

Dr. Simon Mai

Dr. Saul Pressman

The Post-Polio Awareness Support Society of BC

PPASS is a non-profit support organization designed specifically for people who have survived the onslaught of the Polio virus many years ago, and are now suffering from its after-effects - commonly known as Post-Polio Syndrome (PPS).

PPASS BC

Langley AG-37

Coordinators & Contacts:

David-(604)530-5739
Zosia-(604)530-9342

PPASS BC
#214—10114 McDonald Park Road,
Sidney, BC
V8L 5X8

Phone: (250) 655-8849
Fax: (250) 655-8859

Email: ppass@ppass.bc.ca

Post Polio Awareness
&Support Society
of BC

Langley(AG-37)

March 6, 2008
Symposium & Trade Show
At
5 Star Catering at the
Sunrise Golf Centre
5640 - 188th St.
Surrey, BC V3S 4N5

PPASS BC

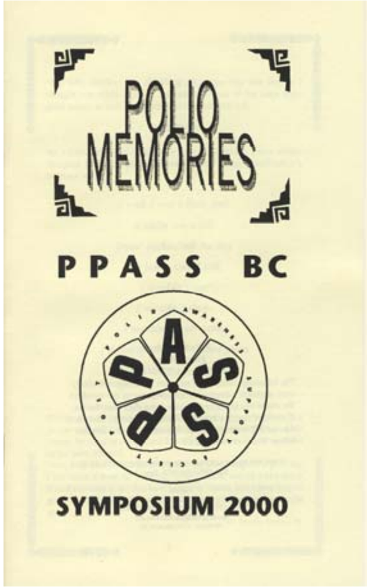
Langley AG-37

Coordinators & Contacts:

David-(604)530-5739
Zosia-(604)530-9342

The success of the Mini Conferences has resulted in the trade show / speaker meeting structure being used for the PPASS BC Annual General Meetings, which has ended up with the media and general public being made more aware of the scourges of Polio, and its lifelong effects in the form of Post Polio Syndrome. The difference between the mini trade shows and the AGM being that exhibitors are not expected to pay any fees at the AGM, nor are they allowed to sell products, however we encourage them to make appointments to meet potential clients at a later date.

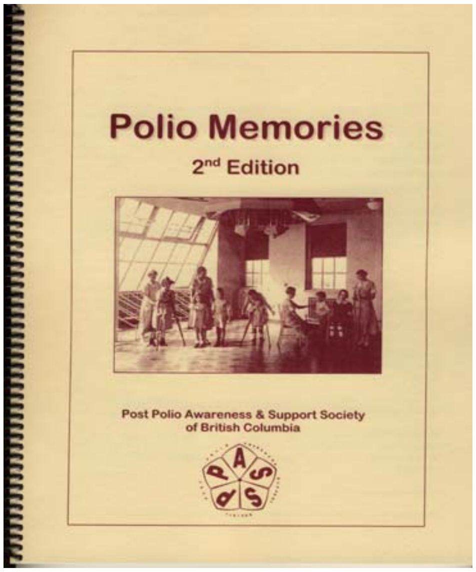
Polio Memories:


POLIO MEMORIES

PPASS BC

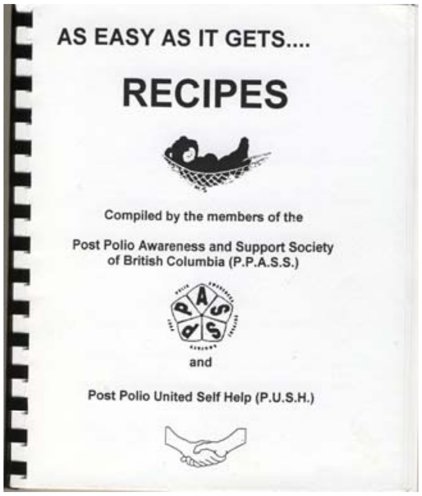
SYMPOSIUM 2000

Two editions of “Polio Memories” have been published – these consisting of articles written by our members about their own experiences both during their fight with Polio and the years that followed, with in many cases the Polio Survivor ending up with Post Polio Syndrome. There are many examples of courage, funny situations and some sad instances. The popularity of this publication first resulted in a second edition being published and this edition has had two printings to date. There is a possibility of a third edition being created in the future.


Polio Memories

2^{nd} Edition

Post Polio Awareness & Support Society
of British Columbia


AS EASY AS IT GETS....

RECIPES

Compiled by the members of the

Post Polio Awareness and Support Society
of British Columbia (P.P.A.S.S.)

and

Post Polio United Self Help (P.U.S.H.)

PPASS Recipe Book:

“As Easy as it Gets” A recipe book specifically designed for people with disabilities in mind, using recipes with only a few ingredients.

PPASS Poster:

A group of members located in the Metro Vancouver area are currently working on designing a new poster for PPASS BC that is intended for display during Polio Awareness Month in October. We understand that the poster has illustrations of assistive devices along with children and adults.

Polio Scrapbook:

The most recent PPASS project is one that has been assembled by our President, Joan Toone as an aid to help her illustrate the importance of immunization against Polio whilst speaking to Rotary International Clubs in British Columbia and the United States. If we are able to encourage Rotary International to keep their PolioPlus programme going, more immunization will occur worldwide thus reducing the likelihood of Polio infections and in turn one day eliminate **Post Polio Syndrome.**

All PPASS publications are available for sale, either through our website www.ppass.bc.ca or by contacting the office at 1-250-655-8849. All monies generated are used to promote awareness and education about PPS both to the general public, members of the medical profession, polio survivors their family members and friends.

Advocating for Yourself and Others

Presenter, Linda L. Priest, CTRS/L
Atlanta Post-Polio Association, Decatur, Georgia

Many people who had polio find advocacy uncomfortable and difficult. My struggle to become an advocate will sound familiar to most of you. By its very nature, being an advocate for ones civil rights brings unwanted attention to our disability. After a lifetime of ignoring our disability and discounting its impact in our lives, how can we turn our attitude around? Learning how to advocate is a personal right and privilege. We will discuss effective advocacy strategies that can change “How Things Work” in order to change “How Things Are.”

This presentation will provide a brief overview of disability rights law in the United States, how to find resources and how to put it to good use. It is time to “take it personally.” Many of the disability rights movers and shakers in the early days were polio survivors themselves. We will discuss their accomplishments and how we can use them as role models.

In order to survive the larger society, members of oppressed groups are forced to come to terms with a potent force that constantly, and in many ways, says they are no good. This is truly an impossible dilemma, and it is not surprising that people react with rage and fear, turning inward against themselves or outward against others. One of the less constructive ways people may use to cope with their situation is Learned Helplessness, which may consciously or unconsciously be adopted as a mechanism of defense.
N.I. Brill, 1990

Disability Rights Laws

Americans with Disabilities Act - prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

Telecommunications Act - require manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible to and usable by persons with disabilities, if readily achievable. These amendments ensure that people with disabilities will have access to a broad range of products and services such as telephones, cell phones, pagers, call-waiting, and operator services, that were often inaccessible to many users with disabilities.

Fair Housing Act - prohibits housing discrimination and covers private housing, housing that receives Federal financial assistance, and State and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the disability of that individual, an individual associated with the buyer or renter, or an individual who intends to live in the residence. Other covered activities include, for example, financing, zoning practices, new construction design, and advertising.

Air Carriers Access Act - The Air Carrier Access Act prohibits discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements address a wide range of issues including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities.

Voting Accessibility for the Elderly and Handicapped Act - he Voting Accessibility for the Elderly and Handicapped Act of 1984 generally requires polling places across the United States to be physically accessible to people with disabilities for federal elections. Where no accessible location is available to serve as a polling place, a political subdivision must provide an alternate means of casting a ballot on the day of the election. This law also requires states to make available registration and voting aids for disabled and elderly voters, including information by telecommunications devices for the deaf (TDDs) which are also known as teletypewriters (TTYs).

National Voter Registration Act - The National Voter Registration Act of 1993, also known as the "Motor Voter Act," makes it easier for all Americans to exercise their fundamental right to vote. One of the basic purposes of the Act is to increase the historically low registration rates of minorities and persons with disabilities that have resulted from discrimination. The Motor Voter Act requires all offices of State-funded programs that are primarily engaged in providing services to persons with disabilities to provide all program applicants with voter registration forms, to assist them in completing the forms, and to transmit completed forms to the appropriate State official.

Civil Rights of Institutionalized Persons Act - The Civil Rights of Institutionalized Persons Act (CRIPA) authorizes the U.S. Attorney General to investigate conditions of confinement at State and local government institutions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, publicly operated nursing homes, and institutions for people with psychiatric or developmental disabilities. Its purpose is to allow the Attorney General to uncover and correct widespread deficiencies that seriously jeopardize the health and safety of residents of institutions.

Individuals with Disabilities Education Act - The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student.

Rehabilitation Act - The Rehabilitation Act prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in title I of the Americans with Disabilities Act. **Section 501** requires affirmative action and nondiscrimination in employment by Federal agencies of the executive branch. **Section 503** requires affirmative action and prohibits employment discrimination by Federal government contractors and subcontractors with contracts of more than $10,000. **Section 504** states that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under" any program or activity that either receives Federal financial assistance or is conducted by any Executive agency or the United States Postal Service. **Section 508** establishes requirements for electronic and information technology developed, maintained, procured, or used by the Federal government. Section 508 requires Federal electronic and information technology to be accessible to people with disabilities, including employees and members of the public

Architectural Barriers Act - The Architectural Barriers Act (ABA) requires that buildings and facilities that are designed, constructed, or altered with Federal funds, or leased by a Federal agency, comply with Federal standards for physical accessibility. ABA requirements are limited to architectural standards in new and altered buildings and in newly leased facilities. They do not address the activities conducted in those buildings and facilities. Facilities of the U.S. Postal Service are covered by the ABA.

Resources for Disability Rights Information

US Department of Justice

Civil Rights Division
950 Pennsylvania Avenue, NW
Disability Rights Section – NYAV
Washington, DC 20530
www.ada.gov
Toll-free ADA Information Line 1-800-514-0301

Equal Employment Opportunity Commission offers technical assistance to the public concerning the employment provisions of title I of the ADA.
ADA publications
800-669-3362 (voice)
800-800-3302 (TTY)
ADA questions
800-669-4000 (voice)
800-669-6820 (TTY)
www.eeoc.gov

Federal Communications Commission offers technical assistance to the public concerning the communication provisions of title IV of the ADA.
ADA publications and questions
888-225-5322 (voice)
888-835-5322 (TTY)
www.fcc.gov/cgb/dro

U.S. Department of Transportation, Federal Transit Administration provides information about the transportation provisions of title II of the ADA.
ADA Assistance Line for regulations and complaints
888-446-4511 (voice/relay)
www.fta.dot.gov/ad

U.S. Architectural and Transportation Barriers Compliance Board, or Access Board, offers technical assistance to the public on the ADA Accessibility Guidelines.
ADA publications and questions
800-872-2253 (voice)
800-993-2822 (TTY)
www.access-board.gov

DBTAC: ADA Centers are funded by the US Department of Education through the National Institute on Disability and Rehabilitation Research (NIDRR) in ten regions of the country to provide resources and technical assistance on the ADA.
800-949-4232 (voice & TTY)
www.adata.org

Project ACTION is funded by the U.S. Department of Transportation to provide ADA information and publications on making transportation accessible.
Information on accessible transportation
800-659-6428 (voice/relay)
http://projectaction.easterseals.com

The **Job Accommodation Network (JAN)** is a free telephone consulting service funded by the U.S. Department of Labor. It provides information and advice to employers and people with disabilities on reasonable accommodation in the workplace.
Information on workplace accommodation
800-526-7234 (voice)
877-781-9403 (TTY)
www.jan.wvu.edu

Americans with Disabilities Act: Assistance at Self-Serve Gas Stations

People with disabilities may find it difficult or impossible to use the controls, hose, or nozzle of a self-serve gas pump. As a result, at stations that offer both self and full service, people with disabilities might have no choice but to purchase the more expensive gas from a full-serve pump. At locations with only self-serve pumps, they might be unable to purchase gas at all.

The Americans with Disabilities Act (ADA) requires self-serve gas stations to provide equal access to their customers with disabilities. If necessary to provide access, gas stations must -

- Provide refueling assistance upon the request of an individual with a disability. A service station or convenience store is not required to provide such service at any time that it is operating on a remote control basis with a single employee**,** but is encouraged to do so, if feasible.
- Let patrons know (e.g., through appropriate signs) that customers with disabilities can obtain refueling assistance by either honking or otherwise signaling an employee.
- Provide the refueling assistance without any charge beyond the self-serve price.

Fair Housing Law

The Fair Housing Act covers most housing. In some circumstances, the Act exempts owner-occupied buildings with no more than four units, single-family housing sold or rented without the use of a broker, and housing operated by organizations and private clubs that limit occupancy to members.
What Is Prohibited?
In the Sale and Rental of Housing: No one may take any of the following actions based on race, color, national origin, religion, sex, familial status or handicap:
Refuse to rent or sell housing
Refuse to negotiate for housing
Make housing unavailable
Deny a dwelling
Set different terms, conditions or privileges for sale or rental of a dwelling
Provide different housing services or facilities
Falsely deny that housing is available for inspection, sale, or rental
For profit, persuade owners to sell or rent (blockbusting) or
Deny anyone access to or membership in a facility or service (such as a multiple listing service) related to the sale or rental of housing.
In Mortgage Lending: No one may take any of the following actions based on race, color, national origin, religion, sex, familial status or handicap (disability):
Refuse to make a mortgage loan
Refuse to provide information regarding loans
Impose different terms or conditions on a loan, such as different interest rates, points, or fees
Discriminate in appraising property
Refuse to purchase a loan or
Set different terms or conditions for purchasing a loan

Air Carrier Access Act

* Carriers may not refuse transportation to people on the basis of disability. Airlines may exclude anyone from a flight if carrying the person would be inimical to the safety of the flight. If a carrier excludes a handicapped person on safety grounds, the carrier must provide the person a written explanation of the decision.

* Airlines may not require advance notice that a person with a disability is traveling. Carriers may require up to 48 hours' advance notice for certain accommodations that require preparation time (e.g., respirator hook-up, transportation of an electric wheelchair on an aircraft with less than 60 seats).

* Carriers may not limit the number of handicapped persons on a flight.

* Carriers may not require a person with a disability to travel with an attendant, except in certain limited circumstances specified in the rule. If the person with the disability and the carrier disagree about the need for an attendant, the airline can require the attendant, but cannot charge for the transportation of the attendant.

Airlines are required to provide assistance with boarding, deplaning and making connections. (They need not hand-carry a person on board a plane with less than 30 seats whose physical limitations preclude the use of existing lifts, boarding chairs, or other devices. DOT is continuing to seek additional data about lifts for small aircraft.) Assistance within the cabin is also required, but not extensive personal services.

* Disabled passengers' items stored in the cabin must conform to FAA rules on the stowage of carry-on baggage. Assistive devices do not count against any limit on the number of pieces of carry-on baggage. Wheelchairs and other assistive devices have priority for in-cabin storage space over other passengers' items brought on board at the same airport, if the disabled passenger chooses to preboard.

* Wheelchairs and other assistive devices have priority over other items for storage in the baggage compartment. * Carriers must accept battery-powered wheelchairs, including the batteries, packaging the batteries in hazardous materials packages when necessary. The carrier provides the packaging.

* Carriers may not charge for providing accommodations required by the rule, such as hazardous materials packaging for batteries. However, they may charge for optional services such as oxygen.

* Other provisions concerning services and accommodations address treatment of mobility aids and assistive devices, passenger information, accommodations for persons with hearing impairments, security screening, communicable diseases and medical certificates, and service animals.

How to File ADA Complaints

Title I
Complaints about violations of title I (employment) by units of State and local government or by private employers should be filed with the Equal Employment Opportunity Commission.
Call 800-669-4000 (voice) or 800-669-6820 (TTY) to reach the field office in your area.

Titles II and III
Complaints about violations of title II by units of State and local government or violations of title III by public accommodations and commercial facilities should be filed with --
U.S. Department of Justice
Civil Rights Division

950 Pennsylvania Avenue, N.W.
Disability Rights Section - NYAV
Washington, D.C. 20530
If you wish your complaint to be considered for referral to the Department's ADA Mediation Program, please mark “Attention: Mediation” on the outside of the envelope.

If you have additional questions concerning the ADA, you may call the Department of Justice's ADA Information Line at (800) 514-0301 (voice) or (800) 514-0383 (TDD) or access the ADA Home Page at: (www.usdoj.gov/crt/ada/adahom1.htm).

Newsletters

Margaret C. Hinman, editor
Colorado Post-Polio Connections, **Westminster, Colorado**

Often times, dedicated newsletters for polio survivors, their families and their support system are the only means of remaining connected and keeping informed about current information related to polio and post-polio syndrome. This is particularly the case when people are spread over a large geographical area and are not concentrated in an urban area where they can potentially access support groups. Also, as polio survivors age and their mobility becomes more restricted this medium can be one of the windows to the larger world of other polio survivors.

The continued production of newsletters becomes more difficult as the polio/post-polio population ages, becomes less mobile and they find it harder to meet and put out a newsletter. An added factor is that, in some cases, staff members burn out after many years of putting out newsletters and there is no one to take up the task.

Some of the issues and considerations for the production of a newsletter are:

1. Content

    a. The content of the newsletter depends its purpose and on the audience for which the newsletter is produced. This is a decision that needs to be made and communicated at the onset, and can and will be modified over time. Having a clearly stated vision helps determine what to include and what not to include in the newsletter. It also is a safety net for the editor in that limits can be set, thus allowing for the rationale needed when requests for inclusion of articles must be denied.

    b. Information gleaned from samples of post-polio newsletters across the country show that many newsletters include at least some of the following: articles on health related issues, personal stories, book reviews, announcements of upcoming events, news about members of support groups, helpful hints, inspirational sayings, photos, artwork, contact persons and other information that is tailored to the specific audience that the newsletter serves.

    c. Finding sources of information can be an issue. Again, by using other newsletters as examples, one can uncover a variety of resources, including articles from magazines, the Internet, books, other newsletters, and especially the Post-Polio Health International publications. Also, original articles written by members of the newsletter staff or by the editor of the specific newsletter are great resources and add a personal touch to the newsletter.

2. Copyright laws and acknowledgements

    a. Copyright laws protect the writer, the organization and/or the original publication. Therefore, it is important to get permission from the information source and to cite sources and references, both when copying an article and when copying part of an article. It is also important to cite the variety of sources if an original article is based on research from several sources. In the long run, this protects the newsletter and its writers from legal problems.

    b. It appears that many newsletters borrow information and articles from each other. This seems to be an acceptable practice among those of us who are in the post-polio newsletter business. However, it is a courtesy to ask permission and/or to at least cite the post-polio newsletter source when articles and features are shared. This courtesy also makes those of us who volunteer to put out the newsletter feel a sense of pride because something we produced was good enough to be copied and reprinted.

3. Staffing

    a. Again, looking at samples of post-polio newsletters, the production staff of the newsletters covers a spectrum from one person working alone to having any combination of volunteers, including having a full staff to help with the task. The workload on individuals is lightened if there is more than one person involved, helping with everything from researching information, to writing articles, to proofreading, to distribution. If the staff is large enough, then the same people are not called upon each time and burnout is reduced.

       Because the staff members of most newsletters are volunteers, the opportunity to have professionally trained journalists is limited. This need not be a problem because anyone with reasonable writing skills and a desire to contribute can be of help to a newsletter. On the other hand, those contributing must be assured that any editing of their work is not a personal slight but is needed to make the newsletter work. At the same time, as in any group endeavor, leadership is needed to coordinate every step of the production and distribution in order to insure that the content is consistent with the purpose of the newsletter and that the issues get out regularly.

    b. Communication among staff is vital. Face-to-face planning meetings offer an opportunity to interact with each other, allow people to bounce ideas off each other and provide inspiration and motivation that can help keep a newsletter vital. On the other hand, in this day of the Internet and easy phone communication, editors can call upon the remote resources of the readership to help produce a newsletter. Even as people become less mobile, they can do research, write, interview and communicate without leaving home and can submit their work over the Internet to the editor. Also, the editor can e-mail finished documents to be checked over for errors and to be proofread.

4. Finances and costs

    a. A newsletter cannot be produced without some financial resources. These can come from subscriptions, donations, fundraisers and grants when and where available. Sometimes, if working through non-profit organizations such as Easter Seals, printing companies may be willing to cover part of the cost of printing. To cover mailing costs, some newsletters use the “Free Matter for the Blind and Handicapped” stamp from the U.S. Postal Service. Others use bulk mailing, or cover the cost of stamps through donations. If funding is unavailable at startup, then the support group will need to put forth effort and energy to find funding resources. If funding dwindles or dries up, then the newsletter is no longer viable and ceases to exist.

b. Included in production costs, however the revenue is generated, is the issue of who receives the newsletter. If the purpose of the newsletter is to be all-inclusive, that is, to provide information for anyone in the post-polio community who wants the newsletter, regardless of the ability to help pay for it, then the cost factors are different than if it is limited to paying subscribers/donors only.

c. The re-printing articles from magazines can be a potential added expense as some charge for the right to re-print. It is wise to check the re-print and/or copy policies of the specific magazine when considering copying an article.

Producing and printing a newsletter takes time, effort, leadership and money but the result of such efforts is that polio survivors, those with post-polio syndrome, their families and those in the survivor's community can keep in touch with current information, and can connect with others who are having similar experiences in their lives.

SESSION T4

Improving Your Mobility
Move Forward

Michelle Guevin, PT, MTC, Bay Area Physical Therapy, Bradenton, Florida

Presenter: Michelle Guevin PT, MHSc, MTC is a physical therapist and owner of Bay Area Physical Therapy & Wellness in Bradenton and Palmetto, Florida. She has been treating patients with the late effects of polio since 1997. Michelle has been in practicing therapy for 25 years. She received her Associates of Arts degree in 1982 and Associates of Science in 1984 from St. Petersburg College, her Bachelor of Science degree in Physical Therapy from Florida A&M University in 1991, Manual Therapy certification in 1995, and her Masters of Health Science specializing in orthopedics in 1997 from The university of St. Augustine. Michelle is currently seeking certification in Pelvic health from The American Physical Therapy Association.

The 2 hour presentation will present options for your mobility needs.

The course will contain both didactic lecture and audience participation for problem solving and/or trying new skills. Volunteers will be called on from the audience to participate. Be prepared with questions to seek answers for your mobility needs.

Water Can Still Benefit Survivors

Mary Essert, BA, ATRIC, Conway, Arkansas
Cynthia Henley, PT, Miami, Florida
Kathryn Wollam, PT, Coral Springs, Florida

Post Polio WaterWork Management & Techniques

Mary Essert B.A., ATRIC
www.maryessert.com

HISTORY: Post Polio Syndrome

- PPS is a condition which may develop several decades after a person has polio
- Affects muscles & nerves
- Causes weakness, fatigue, pain etc.
- Polio vaccine: 51 yr.
- 1,630,000 Americans had polio in middle of 20th century
- 70% develop PPS

Criteria for Diagnosing PPS

- Confirmed case history of bulbar, spinal or bulbar-spinal polio
- Changes on EMS compatible with prior polio
- Onset of weakness in affected or seemingly unaffected muscles
- May experience fatigue, muscle or joint pain, decreased endurance & function
- Atrophy
- Exclusion of other conditions with similar symptoms

Common Symptoms

- Unaccustomed fatigue
- New weakness in muscles
- Pain in muscles & joints
- Sleeping problems
- Breathing problems
- Decreased ability to tolerate cold
- Functional decline in ADL's
- Voice difficulties
- Depression or anxiety

Benefits of an Aquatic Exercise Program as Related To PPS

- Increased cardiovascular & respiratory effect
- Weight management, reduced energy expenditure
- Socialization & support group
- Sleep enhancement, reduced spasticity
- Increased function & independence through strength & conditioning
- Development of lifetime wellness principles

Post Polio Exercise

Why Water?

- Non fatiguing
- Conserve to preserve"

Water Provides:

- PREPARATION FOR LAND
- CROSS TRAINING
- SAFETY & COMFORT

Preparation for Living

- **Water is kind**
- **Conditioning can occur during simple waterwork such as walking**
- **Adherence to any exercise program is vital**
- **Comfort makes this possible**

Temperature

- Warmer temperature decreases postural tone
- Encourages relaxation
- Decreases fear
- Cooler stimulates tone & alertness
- Avoid hot water with edema

More Benefits of Water

- Buoyancy reduces weight bearing
- Pain reduction (warm water)
- Viscosity utilized in resistance Work for strengthening & endurance
- Range of motion easily attained with water's assistance/support
- Balance improved w/o danger of falls - decrease fear & guarding

Hydrodynamic Principles

- Effects of immersion:
- Research shows increased venous return due to hydrostatic pressure
- More effective cardiac output
- Heart rate lowered

Effects of Immersion

Walking/running in water requires 1/2 to 1/3 speed of land to reach same metabolic intensity
Because heart works more efficiently in water, we use target H-R 10-17 BPM below land targets
Dr Borg perceived exertion scale

Renal Effects

- Immersion affects renal system mechanically & hormonally
- Increases central blood volume, Increases renal BP, results in more urine output
- Increases with depth
- Faster/greater for elders

Respiratory Effects

- Makes breathing more difficult: hydrostatic pressure on chest & abdomen
- Total work of breathing for a tidal volume of 1 liter increases by 60% with immersion to neck

Skeletal System

- Tsukahara et al. in 1994 found bone density of veteran water exercisers (35 Mo.) was greater than that of beg. exercisers or controls
- Prevents bone loss
- Can comfortably provide strength and conditioning to participate in land work
- Other studies: Becker, Bravo, Goldstein, Sinaki, Rostein, Harush and Vaisman corroborate above result
- NOF suggests resistive excercise

Muscular System

- Hydrostatic pressure promotes return of venous blood and lymph
- Soft tissue compression promotes fluid transport and reduces edema
- Increased blood supply to muscles
- Muscles relax in warm water

Other Effects

- Reduced spasticity
- Reduction of joint compression
- Energy expenditure: aerobic energy expenditure may be less than, greater than or same as land depending on buoyant forces, effect of water's viscosity & thermal conduction - body size, shape, position, angle of movement, speed, water depth & temp. all affect total energy expenditure (Becker, Cole, Kinnaird)

Exercise:

- What is right for you?
- Energy conservation: motto:" conserve to preserve."
- Recognize fatigue
- Assess amt. of muscle damage
- Other contributing conditions?
- Pay attention
- Consider doing half of that you think you can do for each limb, ask?
- What is the most severely involved muscle in this limb? Is it weak? Do I notice increasing weakness?
- Other reasons?

A Limb with No Weakness

- Classified non clinical polio; use like any other
- Cardio vascular workout 3-4 x week for 20 min. hr-80% Mild/moderately weak
- No sign of increasing weakness

Clinically Stable Polio

- Exercise with care; do not fatigue
- 3 x week 10-20 min. with rests
- Progressive resistance work
- Monitor for increased weakness

Severely Weak

- Severely atrophic polio
- Active exercise likely impossible
- Passive ROM will maintain Flexibility, weak & increasing
- Ask "Am I Doing Too Much Or Too Little?"
- Do not fatigue
- Do stretch
- Try carefully graduated program of non fatiguing exercises
- Monitor yourself carefully, make change to conserve energy
- Pay attention to fatigue & rest before exhaustion
- If overweight, lose weight
- Listen to your body, you know it best…..

Cross Training

- Pool/aquatic exercise
- Gym
- Considerations Re: Chair Ex
- Walking
- Use of assistive devices
- Other?
- Adherence?

Safety

- Safety… pool, gym, locker rooms, entry, exit, supervision
- Guidelines Re: Posture…
- Promote strength & conditioning and avoid falls
- Promote education/understanding
- If in doubt, think twice or don't

Program Hints

- Walking : choose depth, waist to mid chest - all directions
- Gentle stretches
- Attention to postural alignment & breathing
- Range of motion
- Strengthening (Model AFYAP)
- Replicate ADL & functional skills
- Trunk stability work
- Gait training
- Balance & agility
- Build confidence
- Provide challenges with position and direction changes
- Teach fall prevention pool, deck/locker
- Discuss safety issues
- Improve trunk, shoulder, lower extremity strength
- Avoid overuse of affected muscles
- Avoid exercises which
- Compromise your posture or cause discomfort
- Strengthen trunk muscles and back extensors
- Practice trunk stability and balance work - at wall, with a buddy
- Independent
- Using board or noodle
- Conclude with extension, deep breathing, postural awareness
- May introduce recreational Exercise or ADL replication in water
- Transition to gravity based environment when possible
- Include general conditioning
- Always stretch warm muscles

Awareness of Polio's Late Effects

- Polio survivors need a complete general medical evaluation by a primary care physician & a specialized neuromuscular evaluation by a knowledgeable polio specialist such as a physiatrist or rehabilitation specialist.

Post Polio WaterWork

- Consider water work as one tool in the tool chest of coping techniques
- Remember …"conserve to preserve."
- Enjoy your adventures in the water!

References:

- Arthritis Foundation Publications: www.arthritis.org
- *Becker, Bruce M.D. "Healing Waters", Aquatics International, June 2007 http://www.aquaticsintl.com/2007.jun/0706_healing.html
- *Post Polio WaterWork DVD*: Essert & Ramsey 2005 www.maryessert.com
- Central Arkansas Polio Survivors: pdsphd@suddenlink.net.
- San Francisco Bay Area Polio Survivors: **www.hometown.aol.com/sfbaps**
- Post Polio Health Newsletter: **www.post-polio.org**
- Jubelt B., *Post Polio Syndrome* Current Treatment Options of Neurology, Dept. of Neurology, SUNY Upstate Medical University, Mar. 2004 jubeltb@upstate.edu

- Wise, Holly H., PT, PHD; *Effective intervention strategies for management of impaired posture and fatigue with post-polio syndrome: a case report;* Physiotherapy Theory and Practice; Sept.9, 2005
- Aquatic Resources Network: www.aquaticnet.com
- Aquatic Therapy and Rehab Institute: atri@atri.org
- www.fmpartenership.com (Fibromyalgia Partnership)

Books

- *Post Polio Syndrome: A guide for Polio Survivors*/Julie Silver/Yale University, 2002/ISBN 0300088086
- *The Polio Paradox* /Richard L. Bruno/Warner Books 2003/ISBN 0446690694
- *Managing Post Polio*/Lauro S. Halstead/ABI Prof. Pub, 1998 /ISBN 1886276178
- *Comprehensive Aquatic Therapy*/A. Cole & B. Becker/Butterworth Heinemann (2nd ed.)
- Vargas. L, *Aquatic Therapy, Interventions & Applications,* Idyll Arbor.

Email: messert@mindspring.com

SAMPLE POOL SESSION

Mary Essert B.A., ATRIC
www.maryessert.com

Posture; breathing
Know your own comfort level, never work thru new pain
Understand safety issues; entry, exit, sculling, recovery

WALKING WARM UP: fwd, backwd, sideways

CIRCLE, GROUP FORMATION:

BREATHING, POSTURE -AI CHI

UE-UPPER EXTREMITY: NECK; LOOK OVER SHOULDERS,RETRACTION, RIB CAGE, SHOULDER LIFT, ROLL BACK & FORWARD, SHRUGS, HOLD, CIRCLES, DOORKNOBS,FOLLOW SHARK, TRUNK ROTATION,SIDE STRETCH,TRICEP STRETCH,
CROSSOVER SHOULDER STRETCH

STANDING AT WALL; RUNNERS
STRETCH
ACHILLES TENDON
HAMSTRING QUAD, WALL CURL

FACING WALL: PEDAL
TIPTOES. HEELS, OUTSIDE, INSIDE

BALANCING BY WALL ONE SIDE & THEN OTHER
OUTSIDE LEG, KNEE LIFT & EXTENSION
CIRCLE FROM HIP

HIP ROM

SWEEP

ENDURANCE ACTIVITIES: USE BORG PERCEIVED EXERTION SCALE

INTERVALS : COMBO JOG, SCULL, MARCH, HALF JACKS, CROSS CO., ROCKING HORSE, SKI, ELBOW KNEE, ETC…TO TOLERANCE
(UTILIZE HYDRODYNAMIC PRINC. OF WATER, BEGIN PROXIMAL, SMALL MOVES, SHORT LEVER, SLOW, PROGRESS TO MORE DISTAL, LARGE ROM, SPEED, TURBULANCE, LONG LEVER
(May walk instead of intervals)

ADD EQUIPT. ONLY WELL CONDIT. 6 WK. OR MORE (may never use additional equipment if not comfortable)

REPEAT STRETCHES AS ABOVE

CORE EXERCISES FOR TRUNK STABILITY

STANDING PELVIC WORK
BALANCE SELF, THREATEN STABILITY WITH SCULLING, DIAGONALS,
DIF. STANCE, SUDDEN CHANGE OF DIRECTION
SIT ON NOODLE OR KICKBOARD, CONT.
ALTER SHAPE, TRAVEL, W & W/O HANDS

BALANCE & AGILITY
DUI WALK ON LINE, W & W/0 HANDS
PINK FLAMINGO
DOWNHILL SKI-USE LINE
SUDDEN DIRECTION SHIFTS
CHANGE ANGLE OF MOVEMT.
WITH AND W/O HANDS
USE CLOCK IMAGE FOR CHALLENGE
RE-VISIT COORD….CROSS COUNTRY. ETC.

GAIT TRAINING:
USE ASSISTANCE, WALL, HANDS, LONG BAR, KICKBOARD, AND NOODLE.ETC.

REVIEW SCULLING & RECOVERY
REVISIT WALKING, POSTURE, BREATH
3 PT. LANDING
CHANGE BODY SHAPE, SURFACE
AVOID FWD. FLEXION

ABDOMINAL WORK/TONING

NOODLE, FRONT, STRETCH, ABS, CRUNCHES, OBLIQUES
NOODLE BEHIND SHOULDERS, EXTEND LEGS, ABDUCTION, ADDUCTION, CHANGE FOOT POSITION
ROTATION
ANKLE, WRIST CIRCLE,
FLEXION, EXTENSION

REPEAT STRETCHES END WITH HUGS & AFFIRMATION….

AI-CHI

CONSIDER WARM WATER BODYWORK (WATSU®) WITH PRACTITIONER OR PARTNERS FOR FURTHER PAIN REDUCTION.

***~Remember:** "Conserve to preserve!"~*

Yes, You Can Bowl

Rosanne Borders, CTRS, RWSIR, Warm Springs, Georgia

Polio Narratives: Readings and Discussion of the Writing Process

Jacqueline Foertsch, PhD, University of North Texas, Denton, Texas

Joyce Tepley, LMSW, Dallas, Texas

In this session, moderators Joyce Tepley (retired social worker and author of her own in-progress polio memoir) and Jacqueline Foertsch (University of North Texas English professor and author of *Bracing Accounts: The Literature and Culture of Polio in Postwar America*) will provide a forum for aspiring polio memoirists to share their ideas regarding the whys and hows of polio narrative-making.

There are many reasons why one might wish to write a memoir of the polio experience – to help oneself better understand the experience, to leave a legacy to family and friends, to reach out to others who had polio in electronic and print venues, to inform or inspire a general audience through publication in the literary marketplace, and to add one's voice to the history of an era.

The moderators will provide some brief opening remarks then lead a discussion with the audience, guided by key questions and favorite passages from early and recent polio memoirs. The goals of the session are to encourage participants in the telling of their unique stories and to offer suggestions regarding the writing process for publication.

Contact the moderators at thrival@ix.netcom.com for Joyce Tepley and foertsch@unt.edu for Jacqueline Foertsch.

Suggested reading:

- Writing Life Stories: How to Make Memories Into Memoirs, Ideas Into Essays, And Life Into Literature (1998) by Bill Roorbach (The author covers all the elements of good narrative and offers practice exercises with a list of creative non-fiction readings in the appendix.)
- Writing For Story: Craft Secrets Of Dramatic Nonfiction By A Two-Time Pulitzer Prize Winner (1994) by Jon Franklin (The author gives in-depth analysis of the structure of good story telling.)
- Warm Springs: Traces Of A Childhood At FDR's Polio Haven (2007) by Susan Richards Shreve (Detailed account of the author's two years at Warm Springs Rehabilitation Hospital from 1950, when she was eleven, to 1952 showing the relationships that shaped her life and encouraged her undaunted spirit.)
- Polio: A Dose of the Refiner's Fire: Surviving Polio (2005) by Jeane L. Curey Dille (The self-published memoir covering the years from 1952, when at twenty-eight and mother of two young children, she was diagnosed with bulbar polio. She leads the reader through her remarkable journey to reestablish her life after rehabilitation, divorce, remarriage, creating a career, and earning her doctorate in education.)
- In The Shadow Of Polio: A Personal And Social History (1996) by Kathryn Black (When the author was four years old her mother got polio, was in an iron lung, and sent out of state for care and treatment. She

did not see her mother again and her father withdrew from the family. This memoir is the authors search to recover the story of her mother and the era that profoundly impacted her family.

- As I Live And Breathe (1996) by Kenneth Kingery (The narrator of this memoir of survival in and out of a respirator effectively focuses on the issue of a marriage challenged – and in many ways ruined – by intensive polio involvement. A “vintage” story from many decades ago, it is available in public libraries and for sale used on-line.)
- View from the Seesaw (1986) by Louis and Dorothy Sternberg (Another memoir from an iron-lung using polio survivor honestly told. Sternberg bravely describes his own moments of weakness and his less-than-admirable behavior as a demanding, frustrated husband.)

Suggested websites:

- www.post-polio.org (The premier website for all things polio including a comprehensive list of polio memoirs.)
- www.iowacenterforthebook.org/ips-home (This is the All Iowa Reads 2007 website for the Iowa Polio History Project. On it are links to Iowan polio survivors telling their stories. A good example of what can be done to encourage polio memoir literature and preserve polio history.)

Learn About Acupuncture

Susan Harris, Lic Ac, Kingman, Kansas

Yes, You Can Practice Yoga

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

The John P. Murtha Neuroscience and Pain Institute has completed a preliminary outcome study evaluating the benefits of Hatha yoga and meditation in patients with post-polio syndrome (PPS). This research integrates clinical trials investigating the application of Hatha yoga with ongoing patient care and education. The results showed significant improvements in a patient population where a lack of deterioration is often viewed as success. These patients improved and at the end of 12 weeks they were actively involved in self-care.

Yoga is a mind-body practice in complementary and alternative medicine (CAM) with origins in ancient Indian philosophy. The various styles of yoga that people use for health purposes typically combine physical postures, breathing techniques, and meditation or relaxation. This Backgrounder provides a general overview of yoga and suggests sources for more information.

Key Points

People use yoga for a variety of health conditions and to achieve fitness and relaxation.

It is not fully known what changes occur in the body during yoga; whether they influence health; and if so, how. There is, however, growing evidence to suggest that yoga works to enhance stress-coping mechanisms and mind-body awareness. Research is under way to find out more about yoga's effects, and the diseases and conditions for which it may be most helpful.

Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care.

Overview

Yoga in its full form combines physical postures, breathing exercises, meditation, and a distinct philosophy. Yoga is intended to increase relaxation and balance the mind, body, and the spirit.

Early written descriptions of yoga are in Sanskrit, the classical language of India. The word "yoga" comes from the Sanskrit word *yuj*, which means "yoke or union." It is believed that this describes the union between the mind and the body. The first known text, *The Yoga Sutras*, was written more than 2,000 years ago, although yoga may have been practiced as early as 5,000 years ago. Yoga was originally developed as a method of discipline and attitudes to help people reach spiritual enlightenment. The *Sutras* outline eight limbs or foundations of yoga practice that serve as spiritual guidelines:

1. *yama* (moral behavior)
2. *niyama* (healthy habits)
3. *asana* (physical postures)
4. *pranayama* (breathing exercises)
5. *pratyahara* (sense withdrawal)
6. *dharana* (concentration)
7. *dhyana* (contemplation)
8. *samadhi* (higher consciousness)

The numerous schools of yoga incorporate these eight limbs in varying proportions. Hatha yoga, the most commonly practiced in the United States and Europe, emphasizes two of the eight limbs: postures *(asanas)* and breathing exercises *(pranayama)*. Some of the major styles of hatha yoga include Ananda, Anusara, Ashtanga, Bikram, Iyengar, Kripalu, Kundalini, and Viniyoga.

Use of Yoga for Health in the United States

A 2002 survey by the National Center for Health Statistics and the National Center for Complementary and Alternative Medicine (NCCAM) on adult Americans' use of CAM found that yoga is one of the top 10 CAM modalities used. Nearly 8 percent of the more than 31,000 survey participants had ever used yoga for health; adjusted to nationally representative numbers, this means more than 15.2 million adults.

People use yoga for a variety of health conditions including anxiety disorders or stress, asthma, high blood pressure, and depression. People also use yoga as part of a general health regimen—to achieve physical fitness and to relax.

The Status of Yoga Research

Research suggests that yoga might:

- Improve mood and sense of well-being
- Counteract stress
- Reduce heart rate and blood pressure
- Increase lung capacity
- Improve muscle relaxation and body composition
- Help with conditions such as anxiety, depression, and insomnia
- Improve overall physical fitness, strength, and flexibility
- Positively affect levels of certain brain or blood chemicals.

More well-designed studies are needed before definitive conclusions can be drawn about yoga's use for specific health conditions.

Side Effects and Risks

Yoga is generally considered to be safe in healthy people when practiced appropriately. Studies have found it to be well tolerated, with few side effects.

People with certain medical conditions should not use some yoga practices. For example, people with disc disease of the spine, extremely high or low blood pressure, glaucoma, retinal detachment, fragile or atherosclerotic arteries, a risk of blood clots, ear problems, severe osteoporosis, or cervical spondylitis should avoid some inverted poses.

Although yoga during pregnancy is safe if practiced under expert guidance, pregnant women should avoid certain poses that may be problematic.

Training, Licensing, and Certification

There are many training programs for yoga teachers throughout the country. These programs range from a few days to more than 2 years. Standards for teacher training and certification differ depending on the style of yoga.

There are organizations that register yoga teachers and training programs that have complied with minimum educational standards. For example, one nonprofit group requires at least 200 hours of training, with a specified number of hours in areas including techniques, teaching methodology, anatomy, physiology, and philosophy. However, there are currently no official or well-accepted licensing requirements for yoga teachers in the United States.

If You Are Thinking About Yoga

Do not use yoga as a replacement for conventional care or to postpone seeing a doctor about a medical problem.

If you have a medical condition, consult with your health care provider before starting yoga.

Ask about the physical demands of the type of yoga in which you are interested, as well as the training and experience of the yoga teacher you are considering.

Look for published research studies on yoga for the health condition you are interested in.

Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care.

NCCAM-Funded Research

Recent studies supported by NCCAM have been investigating yoga's effects on:

- Blood pressure
- Chronic low-back pain
- Chronic obstructive pulmonary disease
- Depression
- Diabetes risk
- HIV
- Immune function
- Inflammatory arthritis and knee osteoarthritis
- Insomnia
- Multiple sclerosis
- Smoking cessation.

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For More Information

NCCAM Clearinghouse

The NCCAM Clearinghouse provides information on CAM and NCCAM, including publications and searches of Federal databases of scientific and medical literature. The Clearinghouse does not provide medical advice, treatment recommendations, or referrals to practitioners.

Toll-free in the U.S.: 1-888-644-6226
TTY (for deaf and hard-of-hearing callers): 1-866-464-3615
Web site: nccam.nih.gov E-mail: info@nccam.nih.gov

PubMed®

A service of the National Library of Medicine (NLM), PubMed contains publication information and (in most cases) brief summaries of articles from scientific and medical journals. CAM on PubMed, developed jointly by NCCAM and NLM, is a subset of the PubMed system and focuses on the topic of CAM.

Web site: www.ncbi.nlm.nih.gov/sites/entrez
CAM on PubMed: nccam.nih.gov/camonpubmed/

ClinicalTrials.gov

ClinicalTrials.gov is a database of information on federally and privately supported clinical trials (research studies in people) for a wide range of diseases and conditions. It is sponsored by the National Institutes of Health and the U.S. Food and Drug Administration.

Web site: www.clinicaltrials.gov

NIH National Library of Medicine's MedlinePlus

To provide resources that help answer health questions, MedlinePlus brings together authoritative information from the National Institutes of Health as well as other Government agencies and health-related organizations.

Web site: www.medlineplus.gov

Acknowledgments

NCCAM thanks the following people for their technical expertise and review of this publication: Sat Bir S. Khalsa, Ph.D., Harvard Medical School; Barry Oken, M.D., Oregon Health & Science University; Karen Sherman, Ph.D., M.P.H, Center for Health Studies, Group Health Cooperative; and Catherine Stoney, Ph.D., NCCAM.

POST-POLIO HEALTH INTERNATIONAL 10th International Conference

Living with Polio in the 21st Century

April 23-25, 2009

Friday, April 24, 2009

Session F1, 9:30–10:45 am
through
Session F4, 2:45–4:00 pm

This book belongs to

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QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International (PHI) thanks the presenters for providing the excellent information contained in the daily program books.

If you share this information, we respectfully ask that you acknowledge the presenter and that the information was disseminated at PHI's 10th International Conference: Living with Polio in the 21st Century (April 2009). PHI will incorporate additional information presented at the conference and make it available to attendees and others at a later date. Details will be published in *Post-Polio Health* and on www.post-polio.org.

In case of emergency, call 911.

To go directly to the Warm Springs Medical Center Emergency Room, exit the main gate, turn right and the entrance will be on your right.

The RWSIR Campus general number to report problems is 5555 and is posted on all Campus phones.


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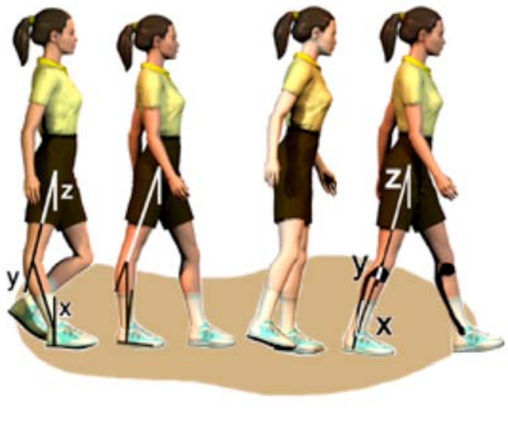
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Welcome to the Roosevelt Warm Springs Institute for Rehabilitation.

Whether you have been here before or this is your very first time on our campus, we are thrilled to have you here as our guests. As you may know, we are the “living legacy” of FDR’s vision for healing, so as you enjoy your symposium you will notice patients and students coming and going, and that we are very much a living and breathing rehabilitation center. We have been providing rehabilitation for 81 years, and you will also note that parts of our campus show our age.

We are not a modern conference center like you may find in downtown Atlanta, but we have something that they don’t. My hope for you during your visit is that you experience what we call the “Spirit of Warm Springs,” which refers to our caring and compassion. We are very proud of our historic legacy, and I encourage you to reflect on that as you travel around and across our campus. Franklin D. Roosevelt never learned to walk by coming here, but I believe it made him a better man and a much better President. So on behalf of all of us who come to work here every day in pursuit of the same mission “to empower individuals with disabilities to achieve personal independence” as FDR did, welcome to this place of healing. May you enjoy your conference and fully enjoy your stay with us.

Greg Schmieg
Executive Director, RWSIR

From Post-Polio Health International (PHI):

Welcome to the tenth in our series of international conferences.

PHI's goal for these conferences has always been threefold: First, we aim to promote the face-to-face exchange of authoritative, up-to-date information about the late effects of polio and independent living with its consequences. Second, we aim to sustain a productive network of active polio survivors and healthcare professionals with relevant expertise – by providing a forum in which these two groups can inform each other and interact. Third, we aim to disseminate the results of our conferences to all those interested polio survivors and medical professionals who are unable to attend.

We are honored to have this conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). RWSIR's place in the history of physical medicine and rehabilitation is a prominent one indeed. It began with Franklin Delano Roosevelt, and with the idea of rehabilitation as a cooperative venture between medical professionals and polio survivors. From its beginnings, like PHI, it has also been dedicated to helping people develop and sustain the functional abilities necessary for independent living with a physical disability.

This event was made possible by the dedicated labors of many staff members at RWSIR. To all of them, we owe our thanks. We also thank Carolyn Raville, founder of the North Central Florida Post-Polio Support Group, for suggesting a post-polio conference at RWSIR.

Thank you for joining us to learn about "Living with Polio in the 21st Century."

Lawrence C. Becker
Chair, Board of Directors, Post-Polio Health International

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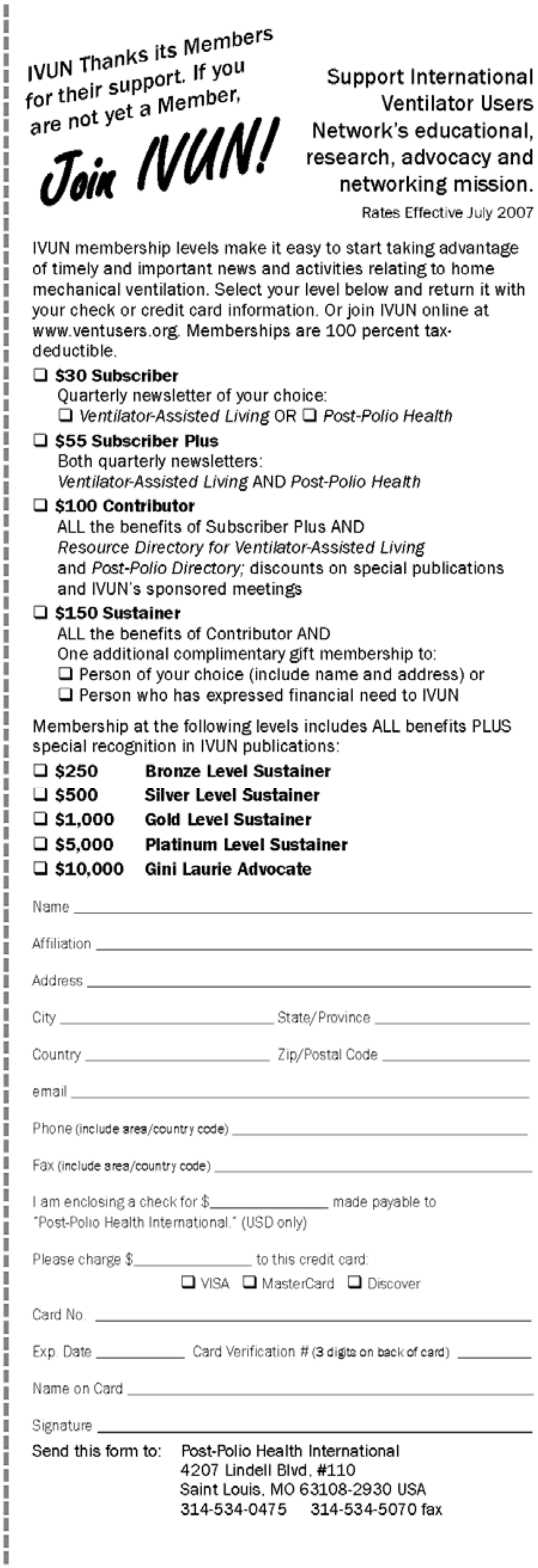

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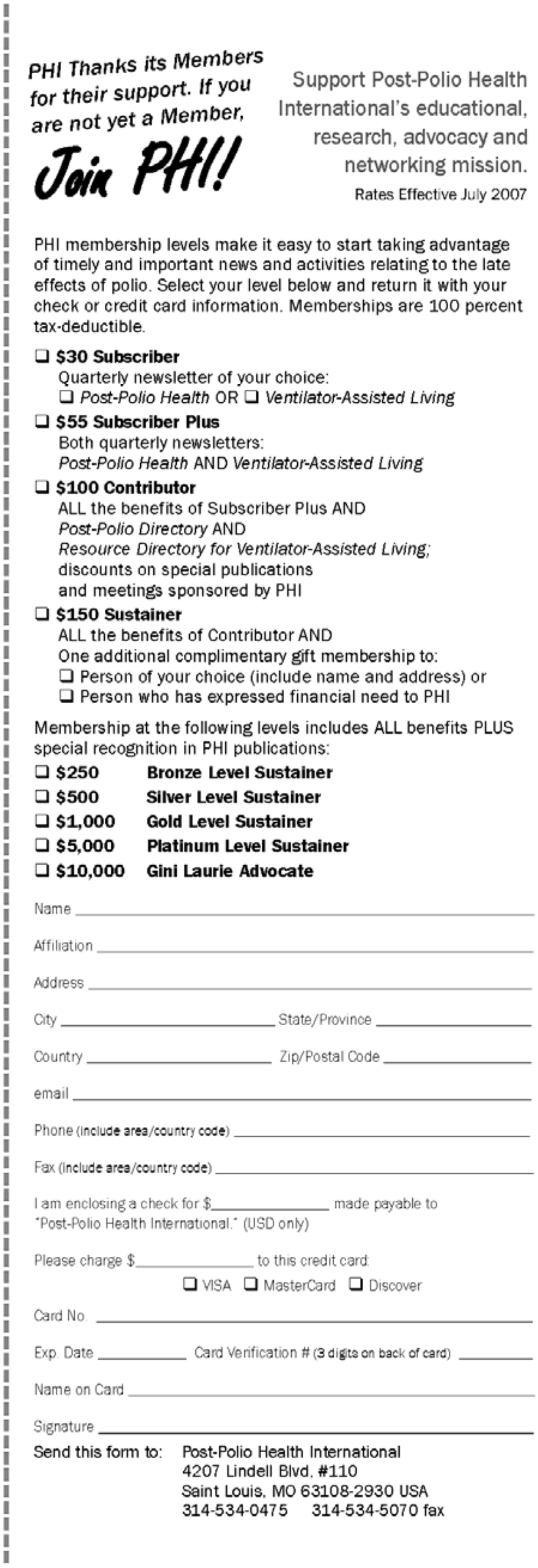

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Program / Friday, April 24, 2009

8:30 am – 1:30 pm
Registration in GEORGIA HALL

8:30 am – 9:30 pm
Continental Breakfast

9:30–10:45 am
SESSION F1 OPTIONS

Demonstration and Discussion of a Post-Polio Examination: Don't Forget Breathing, Part 2

ROOSEVELT HALL AUDITORIUM

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Martin Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

Warm Springs During the Epidemic Years: Not the Usual Story

SCHOOLHOUSE 105

David W. Rose, Archivist, March of Dimes, White Plains, New York

Michael Shadix, Librarian, RWSIR, Warm Springs, Georgia

Daniel J. Wilson, PhD, Muhlenberg College, Allentown, Pennsylvania

Demonstration and Discussion of a Bracing Evaluation

MEADOWS CLASSROOM

David P. Guy, PT, MS, Scottsdale, Arizona

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Mark Taylor, MLS, CPO, FAAOP, University of Michigan, Ann Arbor, Michigan

Research Progress

SCHOOLHOUSE 111

PHI Research Grant: Progress on a Biomarker for PPS

Rahnuma Wahid, PhD, Manager Analytical Immunology, Sanofi Pasteur, Swiftwater, Pennsylvania, formerly University of Arkansas for Medical Sciences, Little Rock, Arkansas

Summary of Post-Polio Research at University of Amsterdam

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Aging with a Disability: Policy Lessons Learned from Polio

VRU AUDITORIUM

Fernando Torres-Gil, Associate Dean for Academic Affairs at the School of Public Policy and Social Research, University of California, Los Angeles

11:30 am – 1:30 pm
Lunch on Your Own at the RWSIR Cafeteria. Vegetarian available. (Attendees will choose from Session F2 or F3 and eat lunch during the other time slot.)

11:15–12:30 pm
SESSION F2 OPTIONS

Finding Causes of and Managing Fatigue, Part 1

VRU AUDITORIUM

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Daria Trojan, MD, Physical Medicine and Rehabilitation, Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada

Martin Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

Making the Tough Decisions: Palliative Care and End-of-Life Decisions

SCHOOLHOUSE 111

Lawrence C. Becker, Fellow, Hollins University, Professor of Philosophy Emeritus, College of William & Mary, Roanoke, Virginia

Fernando Torres-Gil, Associate Dean for Academic Affairs at the School of Public Policy and Social Research, University of California, Los Angeles

Anesthesia Update: Separating Fact from Fear

ROOSEVELT HALL AUDITORIUM

Selma H. Calmes, MD, (Ret),
Olive View/UCLA Medical Center,
Sylmar, California

Demonstration and Discussion of a Seating Evaluation

MEADOWS CLASSROOM

Rene James, PT, RWSIR,
Warm Springs, Georgia

Trina Ouzts, PT, RWSIR,
Warm Springs, Georgia

Benefits and Techniques of Aquatic Therapy

SCHOOLHOUSE 105

Cynthia Henley, PT, Miami, Florida

Kathryn Wollam, PT, Coral Springs, Florida

1:00–2:15 pm

SESSION F3 OPTIONS

Current Epidemics: Status, Lessons and Tasks

SCHOOLHOUSE 111

John Fitzsimmons, Centers for Disease Control and Prevention, Atlanta, Georgia

Ann Lee Hussey, Chair, Polio Survivors
and Associates Rotary Action Group,
South Berwick, Maine

Using Assistive Technology for Personal Independence

SCHOOLHOUSE 105

Samantha Massengale, OTR, RWSIR,
Warm Springs, Georgia

Exercise: The Kinds, the Methods and the Benefits

MEADOWS CLASSROOM

Merete Bertelsen, PT, The Danish Society of Polio and Accident Victims, Rodøvre, Denmark

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Cardiovascular Complications and Prevention Tips

VRU AUDITORIUM

Sunita Dodani, MD, MSc, PhD, FAHA,
Director, Center for Outcome Research
and Education (CORE), Associate Professor,
Department of Internal Medicine,
Kansas University Medical Center,
Kansas City, Kansas

Communicating with Your Physician: Techniques that Work

ROOSEVELT HALL AUDITORIUM

William DeMayo, MD, John P. Murtha

Neuroscience and Pain Institute (JPMNPI),

Johnstown, Pennsylvania

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

William Stothers, The Center for an Accessible Society, San Diego, California

2:45–4:00 pm

SESSION F4 OPTIONS

Finding Causes of and Managing Fatigue, Part 2

VRU AUDITORIUM

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Daria Trojan, MD, Physical Medicine and Rehabilitation, Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada

Martin Wice, MD, Medical Director, St. John’s Mercy Rehabilitation Hospital, St. Louis, Missouri

Effective Family Communication: Do We? How Can We Improve?

ROOSEVELT HALL AUDITORIUM

Annamarie Barber, RN, Polio Survivors & Friends of East Central Illinois, Charleston, Illinois

Linda Bieniek, CEAP, LaGrange, Illinois

Exercise and Activity: How Much and What? Let’s Get Practical

MEADOWS CLASSROOM

Merete Bertelsen, PT, The Danish Society of Polio and Accident Victims, Rodøvre,, Denmark

John G. Fan, MD, Hutchinson Clinic, Hutchinson, Kansas

Complementary and Alternative Medicine: What You Don’t Know Can Hurt You

SCHOOLHOUSE 105

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Assisted Living Communities for Survivors

SCHOOLHOUSE 111

Sue Burgess, Atlanta Regional Commission, Atlanta, Georgia

4:30 – 6:30 pm

Story telling and pizza in GEORGIA HALL

7:00 – 9:00 pm

Film Night in ROOSEVELT HALL AUDITORIUM and VRU AUDITORIUM

SESSION F1

Demonstration and Discussion of a Post-Polio Examination: Don't Forget Breathing, Part 2

**Frederick Maynard, MD, UP Rehabilitation Medical Associates,
Marquette, Michigan**

**Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital,
Nashville, Tennessee**

**William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI),
Johnstown, Pennsylvania**

**Martin Wice, MD, Medical Director,
St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri**

Post-Polio Patient Assessment

**Frederick Maynard, MD, UP Rehabilitation Medical Associates,
Marquette, Michigan**

I. History
- **A. Chief Concerns: eg. Pain, fatigue, new weakness, change in function**
- **B. Polio History**
  1. Age and severity during first month; historical year
  2. Early rehabilitation highlights and timeframes of recovery
  3. Residual disability at maximum recovery or after 2 years
  4. Any rehabilitative surgeries and/or History of device/brace use
  5. More recent or later (>15 years) changes in strength or function
  6. Current motor functional capacity
- **C. Past General Medical History**
  1. Chronic conditions
  2. Injuries
  3. Surgeries
  4. Timing of above in relation to PPS symptoms
- **D. Current Health**
  1. Review of Systems: pain, fatigue, new weakness, breathing or swallowing problems, sleep, weight change
  2. Current medications
- **E. Family & Social History**
  1. Lifestyle Assessment relative to health & wellness
  2. Psychological & social stressors
- **F. Review Relevant Medical, Laboratory & Imaging Reports**

II. Examination

- **A. Observe Function: seating/standing/walking postures and capacities— do fully clothed and with usual devices/methods**
- **B. Formal Range of Motion assessment of joints & muscles**
- **C. Strength assessment of key functional muscle groups (modified MMT)**
- **D. General and/or focused Orthopedic Exam**
  1. Structural deformities of neck, back, chest, limbs
  2. Joint Instability
  3. Leg Length Discrepancy
- **E. General and/or focused Neurologic Exam**
  1. Muscle tone and bulk (?atrophy)
  2. Reflexes
  3. Sensation
  4. Co-ordination
  5. Mental status & affect
- **F. Provocative Pain Examination**
  1. Can pain be reproduced during the exam?
  2. Does pain occur with active and/or passive movements, or with pressure?
- **G. Focused Evaluation of Gait or other Functions**
  1. With and without devices
  2. Challenged

III. Planning

- **A. Is More Information Needed?**
  1. Lab Studies: eg. CBC, thyroid, blood sugar, etc.
  2. Further X-Rays or Imaging Studies
  3. Electrodiagnostics: EMG, Conduction studies
  4. Pulmonary Function Studies and Arterial Blood Gases
  5. Sleep Studies
  6. Rehab.Team Evaluations: PT, OT, CR, Psych/social work, orthotics, dietician
  7. Medical evaluations: Orthopedist, Neurologist, Internist (pulmonologist, cardiologist), ENT, Psychiatrist, Surgeon
  8. Medical Records/Reports: eg. Primary Care Physician, original polio care, reconstructive surgery operative reports, etc.
- **B. Preliminary Goals Presented and Discussed with Patient (and family)**
- **C. Short-term and Long-term Goals Agreed to by Patient & Physician**
- **D. Treatment Plan Outlined and Agreed To**

  For Example:
  1. Weight Loss Plan
  2. Use Bi-PAP at night
  3. Obtain orthosis (brace) and follow with PT to learn correct use & adjust
  4. PT for Individualized Exercise Program
  5. Pain Management Plan
  6. Counseling & anti-depressent use
  7. OT for energy conservation plan

Respiratory Evaluation

Brenda Butka, MD
Division of Allergy, Pulmonary and Critical Care Medicine
Vanderbilt School of Medicine
Vanderbilt Stallworth Rehabilitation Hospital

Symptoms and Examination

Breathing: how do you know you have a problem?
- shortness of breath
- fatigue
- headaches, especially in the morning
- grogginess
- "sleep attack"—need to nap more often
- edema

History
- polio history, including iron lung or respiratory problems
- respiratory symptoms
- recurrent pneumonias
- sleep
- swallowing, especially if associated cough
- cough
- nasal or "sinus" problems
- other elements of complete history

Examination
- oxygen saturation—normal is >95%
- voice: "wet", hoarse, nasal
- chest expansion
- diaphragm excursion
- scoliosis
- auscultation: listen to lungs for abnormal sounds
- heart exam
- edema

Chest X-ray: maybe, especially if smoker

Pulmonary function tests, especially
- vital capacity: "largest breath you can take"
- MIP/NIF: "how hard you can suck"
- MEP: "how hard you can blow"

Arterial blood gases: rarely
- if oxygen saturation is low

Physiology

Breathing
- pulls in oxygen = fuel
- blows off carbon dioxide = waste
- maintains acid-base balance (with kidneys)

Respiratory system
- brain signals
- nerve carries signal
- muscles help keep airway open

- -muscles inhale/exhale gas
- -lungs transmit gas into and out of blood
- -feedback system
    - -oxygen sensors
    - -carbon dioxide sensors
    - -stretch/"work" sensors

Respiratory failure

- -low oxygen
    - -secretions
    - -damaged lungs
    - -high carbon dioxide decreases "room" for oxygen
- -high carbon dioxide
    - -not enough ventilation/air moving through lungs

Shortness of breath is NOT the same as respiratory failure

- -athletes' exertion produces shortness of breath
- -panic attack produces shortness of breath

Polio affects breathing

- -muscle weakness
- -scoliosis
- -obesity
- -sleep disordered breathing
- -bulbar muscle dysfunction
- -aspiration

Muscle Weakness

Muscle weakness

- -diaphragm: inspiration
- -chest wall: some inspiration and cough
- -abdominal muscles: cough

Concerns with muscle weakness:

- -"pulmonary hygiene" = cough = secretion management
- -ventilatory support

Cough

Cough = "queen of pulmonary hygiene": goal is to produce effective cough

Elements of cough

- -inspiratory volume
- -expiratory power
- -close/release vocal cords ("glottis") to build up pressure

Cough: Glottis closure

- -can cap trach
- -otherwise hard to intervene

Cough: Volume

- -main muscle is diaphragm
- -measure vital capacity on pulmonary function tests
- -if less than 50%, may need assist

Cough: Volume assist: goal is to boost inspiratory volume to normal

- -breath stacking
    - -glossopharyngeal breathing
    - -stacked Ambu breaths
        - -have to be able to occlude expiratory port
    - -use volume ventilator to stack breaths

- Cough Assist unit
    - delivers single large breath, pressure-limited
    - goal is pressure of 40 cm water or more
    - be SURE to get an automatic unit!

Interfaces between equipment and human being, depending on oral muscle strength

- mouthpiece
- lip seal
- face mask: less efficient, but much better than nothing
- tracheostomy

Cough: Expiratory power

- muscles are mainly abdominals
- measure peak flow on pulmonary function tests
- some measure cough peak flow
- if less than 5 liters per second, may need assist

Cough: Expiratory assist (after obtaining adequate volume)

- manual assist cough: similar to Heimlich maneuver
- Cough Assist unit
    - switches from breath in to suction/breath out
    - VERY effective in right patients

Vibrating vest

- does not provide volume or expiratory power
- very useful in other conditions
- sometimes used with muscle weakness if patient can’t use Cough Assist

Ventilation

Ventilatory support

- noninvasive (NIV)
- invasive/trach

What can ventilatory support do for you?

- prolong life
- increase energy
- decrease respiratory infections/hospitalizations

Noninvasive Ventilation

Noninvasive ventilation criteria

- sleep-disordered breathing/sleep lab
- dx neuromuscular disease +
    - vital capacity less than 50% OR
    - NIF less than -60 cm H20
- do NOT need sleep study if you fit these criteria

NIV equipment

- mostly Bipap WITH backup rate
- sometimes volume ventilator with mouthpiece during the day

NIV interfaces

- mouthpiece
- nasal mask
- full face mask
- oral interface

Negative pressure ventilation

- cuirass or “iron lung” variations
- less efficient than current positive pressure modalities

Invasive Ventilation/Tracheostomy

Invasive ventilation/tracheostomy
- -respiratory failure in spite of noninvasive ventilation
  - -bulbar muscle involvement
  - -scoliosis
- -acute failure/pneumonia
- -secretion management

Demythologizing trachs:
- -can usually talk, often while being actively ventilated
- -may not be on ventilator all the time anyway
- -can eat

Advantages of tracheostomy ventilation
- -secure airway
- -access for secretion management
- -no mask/mouthpiece in the way for eating and perhaps talking
- -volume ventilators have batteries and alarms = VERY portable

Volume ventilators
- -small
- -batteries for 6-8 hours
- -we use Newport HT50, sometimes Pulmonetic
- -no longer need to rebuild wheelchairs to accommodate vents!

Mobility
- -skydiving
- -horseback riding
- -sledding
- -travel

Sleep Disorders

Sleep disorders
- -obstructive
  - -bulbar muscle dysfunction
  - -obesity
  - -small jaw
- -central
  - -disordered brain signals
- -other sleep disorders

Sleep disorders: evaluate in sleep lab by sleep specialists
- -home sleep study inadequate

Swallowing

Swallowing
- -aspiration risks
  - -concerns if coughing with eating or drinking
  - -recurrent pneumonias
- -swallow evaluation by speech therapy

How does one assess an individual for the post-polio syndrome?

Martin Wice, MD, Medical Director
St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

The first thing I do when I examine polio survivors is to get a very detailed medical history from the time they had polio through their entire recovery process and then their new decline. I conduct a detailed physical examination, including a neuromuscular and functional evaluation. Tests are performed not so much to prove one has the post-polio syndrome (no test can do this), but to rule out other problems which can masquerade for it. Tests include blood work (including a CBC, chemistry profile, thyroid screen, CPK, and ANA), and a vital capacity (a breathing screen).

If I have cause for concern about breathing, I request a blood gas, which checks for oxygenation and for CO_2 retention. I may request a sleep study I may also do a special barium "cookie" swallowing study if swallowing is a problem. I may do electrodiagnostic testing of the arms and legs, not to prove that someone has the post-polio syndrome, but to look for other problems – carpal tunnel syndrome, radiculopathy – which may explain someone's symptoms. I also may request appropriate radiological testing such as x-rays of joints that are hurting to look for arthritis or for fractures. I may request an MRI scan of the spine to make sure nothing else is masquerading for the post-polio syndrome.

Other tests can be requested depending on what is found during the physical examination. Depending on the results of the above-mentioned tests, I will arrange appropriate referrals.

It is important that the patient and his/her family get the most out of the evaluation. It is to bring in all relevant information including a completed patient profile, if sent, records of past evaluations, test results, treatments and treatment results and to have their questions in writing with someone to help record the answers.

Warm Springs During the Epidemic Years: Not the Usual Story

David W. Rose, Archivist, March of Dimes, White Plains, New York

Michael Shadix, Librarian, RWSIR, Warm Springs, Georgia

Daniel J. Wilson, PhD, Muhlenberg College, Allentown, Pennsylvania

Friends and Partners: The Legacy of Franklin Roosevelt and Basil O'Connor in the History of Polio

David W. Rose, March of Dimes Archivist

David Rose has been Archivist of the March of Dimes since 2001. He is a Certified Archivist of the Academy of Certified Archivists, and he oversees the preservation and organization of the documents, photographs, and films of the March of Dimes Archives in its national office in White Plains, New York. He is author of the first photographic history of the March of Dimes in the Arcadia Images of America series published in 2003. David is a writer, amateur mycologist (the study of mushrooms), and contributing editor to Fungi Magazine for which he writes a regular column. He has been Consulting Archivist to the New York State Museum and the North American Mycological Association. He is also an advisor to the Jonas Salk Legacy Foundation. David holds a Masters degree in Anthropology from the New School for Social Research (New York, NY) and a Bachelor's degree in Anthropology and Philosophy from Case Western Reserve University (Cleveland, Ohio).

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Among the multitude of Franklin Delano Roosevelt's enduring accomplishments is his creation of the March of Dimes, founded as the National Foundation for Infantile Paralysis (NFIP) in 1938. FDR created the NFIP by presidential proclamation on September 23, 1937 to "lead, direct, and unify" the fight against polio. The new foundation quickly became a beloved institution through its popular March of Dimes fund-raising campaigns and through which it claimed the conquest of polio with the Salk vaccine licensed on the tenth anniversary of FDR's death, April 12, 1955. In 1958, with polio on the wane, the foundation re-invented itself by launching an adventurous program directed at birth defects. As the birth defects programs developed through the 1960s, the foundation's mission expanded through the burgeoning fields of genetics and perinatology, evolving into its present mission, strongly characterized by a campaign against premature birth launched in 2003. These later developments, which FDR could not have foreseen, continue and thrive as part of his permanent legacy.

While the story of FDR's creation of the NFIP and the first March of Dimes radio campaign in 1938 that deluged the White House in dime donations has often been told, the person who orchestrated these campaigns that revolutionized volunteerism and fund-raising in the United States has been nearly lost to history. Basil O'Connor (1892-1972), FDR's former law partner, who also played key roles in the Georgia Warm Springs Foundation and the President's "Brains Trust" in the 1930s, led the NFIP as president for over three decades, from 1938 to 1972. During that period he served, simultaneously, as head of the American National Red Cross (1944-1949) and was instrumental in creating the Salk Institute for Biological Studies in 1960. Roosevelt and O'Connor are the only two non-medical honorees in the Polio Hall of Fame at Warm Springs, Georgia; and yet there is no complete biographical treatment of Mr. O'Connor's life that can validate his historical importance as "the architect in the fight against polio."

In actuality, Roosevelt and O'Connor together set the groundwork for the massive campaign to end the polio epidemics in the United States through the Georgia Warm Springs Foundation and the NFIP. Well-known is O'Connor's initial reluctance to spearhead the efforts to create the Georgia Warm Springs Foundation, but his loyalty to FDR superseded any initial hesitation he may have had. O'Connor eventually supported FDR's interest in Warm Springs whole-heartedly, and he became a passionate spokesman for the polio cause. Their relationship matured not only through the mutual interest in Warm Springs, but through myriad channels of advice that O'Connor provided for FDR after he became President in 1933. Though FDR served as president of the foundation until his death in 1945, often spending time at his home there, the "Little White House," it was O'Connor who directed the foundation during the Roosevelt years, serving as treasurer and chairman of its Executive Committee and ultimately succeeding FDR as president.

The NFIP was founded in 1938 in part to establish a non-partisan basis for polio fund-raising and research beyond the confines of Warm Springs. Realizing that the problem of polio could not be effectively addressed by a local institution like the Georgia Warm Springs Foundation, FDR issued a proclamation on September 23, 1937 to create the NFIP. In his proclamation, FDR focused on the need to create a national organization to approach the problem of polio in a holistic fashion. He stated that the Georgia Warm Springs Foundation had devoted its efforts "almost entirely to the study of improved treatment of the after effects of the illness" whereas the new foundation would attack "every phase of this sickness." Of course, O'Connor assumed responsibility for leading the NFIP even though he continued to manage the program at Warm Springs.

The formative years of the NFIP coincided with a period of global war, and raising funds for polio in a wartime economy found stiff competition from war bond drives. Yet, in the patriotic climate of support for the President and American armed forces, Hollywood favored the March of Dimes. MGM mogul Nicholas Schenk chaired the Motion Pictures National Committee March of Dimes Drive, ensuring industry support from the highest level. As a result, the March of Dimes had a monopoly on movie theater fund-raising during the war as thousands of theaters were authorized to permit collections that preceded a film. Popular movie stars like Judy Garland, Mickey Rooney, and Greer Garson appeared in March of Dimes trailers and films. Patriotism, the global war, the fight against polio, and the dominance of the film medium at the time all converged to make the March of Dimes extremely popular and successful despite the war. As an ending to the war began to emerge as a real possibility, FDR appointed O'Connor as President of the American Red Cross in 1944. O'Connor's visits to the Pacific and European theatres of the war for the Red Cross provided critical experience to him for the logistical complexities of the Salk polio vaccine field trial to come.

After President Roosevelt's death on April 12, 1945, Basil O'Connor succeeded Roosevelt as president of the Georgia Warm Springs Foundation, headed the Roosevelt Memorial Commission, and continued to lead both the NFIP and the American Red Cross (until 1949). O'Connor led the Roosevelt Memorial Postage Stamp ceremonies at Warm Springs in August 1945 with a speech, "Nothing Could Conquer Him," a title which summarized O'Connor's admiration of FDR as president, commander-in-chief, and fighter against polio. O'Connor promoted FDR's legacy at every opportunity. FDR's influence on the history of disability, polio, and the independent living movement has been repeatedly demonstrated. Through O'Connor, the March of Dimes willingly accepted FDR's legacy and actively promoted its mission in the aura of FDR's colossal reputation as the first and only disabled president. The foundation steadfastly and symbolically honored the memory of FDR in traditions such as the annual visit to FDR's gravesite in Hyde Park by each new national March of Dimes poster child. This practice endured at least until Eleanor Roosevelt's death.

Historian Saul Benison has commented on the historical significance of the NFIP which illustrates the role of ordinary Americans in the fight against polio. Benison said: "In 1937 . . . President Roosevelt became convinced that polio could only be conquered through a broad and sustained program of scientific education and research. The organization of the NFIP was in essence the first step toward the realization of that goal. It was also something more. At a time when deadly assaults had already been launched against the human spirit and life itself in Europe, the new Foundation … stood as an affirmation of the value of conserving human life and dignity. Ordinary people everywhere recognized this quality and quietly and emphatically made its cause their own." However, behind this realization lay the spirit of Warm Springs and the March of Dimes, and the two men – friends and partners – who were most responsible for formulating their vision and realizing their success.

March 23, 2009 / David Rose / March of Dimes Archives

Warm Springs During the Epidemic Years: Not the Usual Story

Mike Shadix – Librarian, Roosevelt Warm Springs
Warm Springs, Georgia

Wild and Wonderful Warm Springs – FDR loved fun. The patients and staff of the Georgia Warm Springs Foundation did not let him down. A visit from FDR always included a special evening of entertainment. This segment will give an overview of patient and staff hi-jinks over the years that were really part of the Warm Springs philosophy of rehabilitation. This segment will also provide an introduction to people who loved Warm Springs and established homes here. Despite all the fun, Warm Springs did have a bit of a dark side in that it was a racially segregated facility during the polio era. This segment will conclude with a look at how that segregation and racism played out at a facility devoted to the rehabilitation and inclusion of all people with disabilities.

Georgia Warm Springs: The Untold Story

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Almost every biography of Franklin D. Roosevelt and every history of polio celebrates Warm Springs as the ideal place in which to be rehabilitated from the crippling disease. Numerous accounts depict an almost resort like atmosphere infused with Roosevelt's sense of fun. Some narratives make it sound as though those who avoided polio during the epidemic years and thus had no need of Warm Springs' services were missing out. There is no doubt that the atmosphere at Warm Springs was different, and better, than at most of the rehabilitation facilities where polio patients went to learn to breathe, and sit, and walk again. While it is worth celebrating Roosevelt's gift to polio survivors some eighty years after its founding, I also want this afternoon to suggest that not every polio patient who passed through Warm Springs found it to be Oz or paradise.

The Warm Springs experience in the period from the late 1920s through the 1950s could be complex and sometimes difficult. Part of one's experience in the Georgia woods was shaped by what came before. How old you were when you went to Warm Springs made a difference, as did the severity of one's paralysis. Family relations and one's contact, or, more likely, lack of contact with family during one's stay made a difference as well. In our well connected and well traveled world it is sometimes hard to remember just how hard it was to get to Warm Springs fifty or sixty years ago and how hard for patients to stay in regular touch with their families. Without dwelling unduly on the negative, I would like to sketch a more complicated picture of polio rehabilitation at Warm Springs during the epidemic years.

This presentation will look briefly at individuals who found it difficult to adjust to the program and culture of Warm Springs, at the difficulties faced by younger children, at the painful work of rehabilitation, at the racial segregation practiced at the Foundation and at other problems that surface in the memoirs of polio survivors who were treated at Warm Springs.

Demonstration and Discussion of a Bracing Evaluation

David P. Guy, PT, MS, Scottsdale, Arizona

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Mark Taylor, MLS, CPO, FAAOP, University of Michigan, Ann Arbor, Michigan

Bracing Evaluation (A Thorough Preparation)

David P. Guy, PT, MS, CPT USA (ret), Physical Therapist

In1968 I was injured in Vietnam. The injury was several compression fractures of my lumbar spine. As a result of the injury I sustained considerable weakness and decreased sensation in both of my legs. After 4 spine surgeries my problems decreased but I still was unable to pick up my toes when walking – what we call a foot drop. My surgeon called together a team of people that included himself, an orthotist and a physical therapist. I was also asked to attend the meeting. At this meeting I was assessed, from what seemed to me, to be every angle. Then each of the professionals offered their suggestions as to what was the best treatment for me. Surgery to fuse my ankle was discussed; strengthening exercises for my legs was discussed; and, bracing was discussed. The decision was made that a brace was the best answer for my problems. The surgeon, however, stated that there was some preliminary treatment that needed to be provided as I was being evaluated for the brace. First, he stated that the focus should be on me as a person and not just my legs and problems walking. Since I still had spine related problems and was wearing a brace that went from my hips to my shoulders, he wanted to see a comprehensive assessment of many factors. Those factors included my motion, strength, balance, stability, endurance, joint alignment, cardio-pulmonary status and psychological preparation for more treatment and the use of another device in addition to the spine brace I already had. I had to admit that this was not what I was taught in my physical therapy training. In my training, I was told the orthotist would do an assessment of the “joint” problem and, then, provide a device to “fix” that problem. Nowhere was it discussed that there might be other data that needed to be collected and assessed by a team of professionals. I was indeed fortunate in the caring I received. I now am able to walk and run with good strength and without the need of a device.

My point in relating this story is that anyone who is being considered as a candidate for bracing should also be provided with a thorough assessment prior to the time a brace is prescribed. It is only after thorough assessment is completed that the alternatives can be listed and examined. There are alternatives to bracing and those alternatives need to be discussed with feedback provided by the patient. As in my case, there were and are several alternatives. Surgery, sometimes, is the appropriate answer. At other times, doing nothing is the right response. The only way to lessen errors is to first complete a full assessment. Unfortunately, we professionals all too frequently look only at the presenting problem and not the person who has the problem. We also need to do a whole person assessment and relate that assessment to the unique environment in which that the person lives.

In the same vein, there is a need to complete some preparation treatment prior to bracing if that is the choice made by the assessment team. Often, a patient is provided a brace and expected to be able to do a whole host of things that they couldn’t do before. It might be more appropriate if the treatment team first assured that other simultaneously existing problems are eliminated or minimized before the brace is provided. For example, many polio patients may benefit from bracing because of problems with their feet and ankles. These same people may also have been sitting most of the time and have really decreased endurance and fatigue quickly in any walking activity. These same people may have limited motion in their chest and decreased breathing capability. They may have a scoliosis and have great difficulty standing straight. If they are older, they may have arthritis that causes pretty severe pain in many other joints. They may have skin problems with either hyper or hypo sensitivity of their skin or they may have some skin wounds caused by decreased circulation. The list could be endless. What is important is that everyone is unique and each patient deserves the opportunity to reduce these associated problems before the brace is applied. Doing so will assure a better result from the bracing and with that, improved function.

In this presentation I will focus on the pre-brace treatment that could and should be provided. The first and most important component to thorough care is communication. The patient, physicians, therapists and orthotists need to discuss the patient's problems and response to treatment on a regular basis. The primary physician should get feedback from other treating physicians to present to the team. A plan for care needs to be developed with everyone's input. The plan should specify goals that need to be achieved prior to brace application. Examples of those goals are as follows:

1. Reduce hip flexion contracture
2. Increase chest expansion to more than 2 inches
3. Increase endurance to tolerance of 15 minutes of activity
4. Increase trunk stability
5. Decrease weight by 10 pounds
6. Increase ability to shift center of mass side to side and front to back

The goals are very patient specific and should be based not only on the patient's particular problems but also on the specific bracing system that will be used. At a minimum, the program should include the following:

1. Flexibility exercises for all joints
2. Strengthening exercises
3. Breathing exercises
4. Conditioning cardiovascular exercises
5. Balance training if able
6. Relaxation training

The majority of these exercises can be taught by a physical therapist in one to three treatment sessions and then the patient can continue the program at home. If done at home, there is a need to call the therapist to report problems and success.

Preliminary treatment should also include what should and should not be expected to result from brace use. What specific improvements in function will result from brace use? What might the patient experience from brace use that needs to be reported to the orthotist? What is the "break in" period and what must the patient tolerate initially that will resolve later? Are there specific activities that need to be completed with the brace on to assure maximum benefit? How long should the brace be worn per day? Does the patient need to continue the exercises now with the brace and, if so, what exercises?

As you can see from these questions, the patient has a critical role. It is only with frequent and complete patient communication that the best brace fitting can be achieved. The patient also needs to know that the initial brace may need to be modified as a result of feedback provided by the patient or other team members.

Once the brace is provided, it is extremely important for the patient to follow up with the physical therapist for gait training. The patient should not expect that the brace without training will meet established goals. The gait training also includes several factors and might require several weeks of therapist treatment.

As a result of this comprehensive assessment and treatment the patient should expect to achieve the maximum benefit from the brace without any severe side effects. A little work at the beginning of new brace use can result in many happy years of increased function.

Assessment for Polio Bracing is part of an Individualized Walking Solution
(Orthotic Evaluation)

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Introduction: Efficiency in standing and walking from point A to point B is the underlying issue for most polio survivors. To gain efficiency one must solve many issues to enable the polio survivor the ability of standing hands-free to accomplish a daily task and/or reduce upper extremity involvement for locomotion. A more detailed assessment and individualized solution development process is required to help the client to overcome fatigue, address balance issues, and provide the stability for improve efficiency.

Assessment starts the process, and it is a process! The Assessment is key in developing a solution. One cannot fix what one does not recognize. The solution must be developed from A-Z to provide optimal potential gains for each person. The future of polio bracing will be the development of comprehensive walking solutions, not just braces. The assessment process is much more involved than traditional methods. Solving human pathomechanics is a true 3D problem and the “Complex Puzzle” must be solved in each of the three dimensions. Besides lower extremity issues, many polio survivors also have upper extremity, spinal, and pelvic weaknesses that can affect sitting, standing and their locomotion. The assessment must include all issues in order to develop a meaningful solution.

Content:

Each polio survivor is unique. There may be similarities, but more often differences or specific attributes, set each polio survivor apart from the next. The old adage, walk a mile in my shoes (if this were possible) would clearly describe this uniqueness.

The first step of the process for the orthotist is collecting all the critical data from the physician(s), physical therapists, gait labs, and most importantly from the polio survivor. Video of a survivor’s gait from different angles must be secured and then analyzed frame-by-frame to properly assess the obvious and finite details of all the gait deviations in each of the three dimensions. A walking solution is developed to plan for success and enable a better quality of life. The solution should improve the potential of an individual.

Collection and reviewing of the documentation from all involved healthcare professionals with open communication, encourages good insight and valuable data.

Biomechanics is the study of normal and efficient gait. Pathomechanics is the study of biomechanics gone wrong. Each polio survivor has his or her unique pathomechanics that culminate into their signature gait pattern. Solutions to the signature pathomechanics are in the minute details. The causes of each pathologic detail must be recognized and followed with a series of decisions to reestablish them to as normal a biomechanical profile as possible.

The solution must address each bone in three dimensions. The medical field knows these dimensions as the sagittal, coronal (frontal), and transverse planes; we will categorize them as Triplanar.

Assessment Components:

Documentation:
Physician(s), Physical Therapists, Gait labs, X-rays, etc.
Video Filming & Evaluation:
Triplanar evaluation of pathomechanics
Manual Evaluation (Orthotist):
Confirm data collected
Assess alignment (realignment) possibilities
Formulate final solution development
Psychological Assessment:
Motivation
Ability to understand, agree and follow the treatment plan
Security Issues:
Recognizing the underlying Security Issues
Mechanical Profile:
Determine and define the mechanical profile
Goal:
Develop a solution-based standing and walking plan to improve efficiency.

Video analysis of each person's gait by the orthotist will provide a greater understanding of the individual's pathomechanical gait deviations. Video is a critical tool used to recognize and assess the small details that must be solved to enable better alignment, balance and efficiency. Video provides more data that can be gathered by normal observation. It also serves as documentation in evaluating before and after outcomes.

The orthotic manual evaluation is important to confirm data collected from other professionals and from the individual, i.e.; "my foot is fused". We often find a once fused foot will have more range of motion than thought. The manual assessment offers more information for the orthotist to utilize in their solution development.

Assessment of motivation and the ability to understand, agree, and follow the treatment plan are key factors in improving the success rate. Checking the expectations of an individual is important to determine whether they are realistic.

To improve an individual's success, the underlying security issues of the polio survivor must be addressed. The security issues are those that elicit fear, instability, and energy consuming compensations. Solutions must include finding a balance to overcome the security issue and allow for efficient mobility.

The mechanical profile is understanding the patterns of structural deviations. The orthotist then needs to devise a counter to the deviations, with corrective forces, to improve alignment and balance. The mechanical profiles vary in complexity, and solutions must vary as well.

The solution development must take into consideration all of the data, the polio survivor's goals, and the structural deficits and functional deficits to be solved. It must incorporate true Triplanar control, under full weight bearing, while employing a better understanding of polio survivors and the progressive nature of Post-Polio Syndrome. The orthotic solutions of the future will do a better job of preventing deformities and surgeries, reducing or preventing painful joints, offer better alignment and balance, free up upper extremities for useful tasks, and allow a better quality of life than can be found from traditional bracing systems.

Conclusion: DynamicBracingSolutions™ obviously has a very different and involved assessment process. A wealth of information is available on our web site: www.DynamicBracingSolutions.net. Also review the "What's New in Orthotics" in this publication.

Bracing Evaluation
(Orthotic Evaluation)

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Evaluation for orthotic management involves several areas of assessments. These areas include but are not limited to: patient's cognitive status, physical environment, health status (including cardiovascular condition) muscular – skeletal condition, age, education and etc. Gathering information from these assessments require adequate time and commitment from health care professionals who have responsibility for and the opportunity to work with polio patients.

Practitioners must understand they need obtain a clear picture of the muscular-skeletal conditions of polio patients. This includes not only observing their gait patterns but getting hands on evaluation knowledge of joint range of motion, skin conditions, muscle strengths and if any discomfort is present. From this information, practitioners can make decisions on how to best gather data for the provision of a custom made orthotic device. Sometimes a combination of casting and tracing techniques along with gait evaluations are appropriate clinical activities for gathering such knowledge.

Proprioception is usually present with the polio population unless there is some underlying pathological condition that limits it. Practitioner need to understand that there probably is hypersensitivity with the affected extremity thus requiring a gentle approach when handling these extremities. Communicating with the patient at this time is helpful in obtaining their feedback concerning their level of sensitivity and location of discomfort.

Gait observation can be extremely helpful in determining where discrepancies are and what type of compensations are required to provide stability and strength for ambulation. Gait observation can be done pre and post hands on evaluation to have a deeper appreciation for the forces involved for upright stability. A competent practitioners will evaluate a patient's gait from two positions, lateral (saggital) and front to back (frontal/coronal) views. From the gait evaluation, a practitioner can better comprehend the motions being used for stability and ambulation. Observance of the activities happening at the foot/ankle complex, knee, hip, low back and trunk is valuable in determining and designing for orthotic management.

Documentation of what is observed and what a practitioners hears also becomes a valuable tool is assessing and planning for orthotic management. Document what the patient says and their response to any questions you may have concerning their ability to ambulate and perform their necessary tasks for daily living and providing. What a practitioner hears and sees during the evaluation process can be extremely helpful as these correlate to the actions taking place. For example, if you hear a foot slap type of noise, it cues the practitioner to look for weakness about the anterior part of the ankle.

History also becomes a valuable tool in orthotic management. Has there been previous orthotic intervention? How successful has this intervention been? If orthotic intervention was not successful , try to find out the reasons why. What caused the patient to discontinue the use of their orthotic device? Was is pain, weight, peer pressure or something else? How long has this intervention been used? During post orthotic intervention it is good to know the patient's likes and dislikes of orthotic use and do they have any ideas of thoughts concerning present and future orthotic use such as, changing orthotic design and or materials.

Obtaining patients' views, goals and suggestions concerning orthotic management can be very valuable in helping design a future course for orthotic use. With the knowledge obtained from a complete and through evaluation, a well trained practitioner should be able to offer an appropriate orthotic design and discuss this with the patient. It is always important to provide options so the patient has the opportunity to decide for themselves which orthotic route to take. Allowing the patient to participate in the decision process will also create a higher rate of acceptance with the proposed orthotic management. Describing this intervention in detail including the advantages and disadvantages/consequences of using such intervention will assist in a greater understanding and success of the care to be provided.

Devise a plan that will address the orthotic needs and allow the patient to approve the plan. Let them know that there is no law that commits them to 24 hour use of the device. Share your orthotic plans with others, listen to the ideas of your peers, research what has been done in the past. Take time to do your homework to help you prepare for all possible options. Communicate your plans/goals to referral sources, physical therapists, occupational therapists, family members and if necessary, third party pay. Through this communication, take advantage of suggestions, ideas and limitations pertaining to your orthotic plan. Then, proceed with your orthotic intervention as a team remembering the patient is the most important part of the team and will be the team member along with their families members who will be affected by the outcome of this investment.

Research Progress

Regulatory T cells as a Biomarker of Post-Polio Syndrome

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There are large numbers of polio survivors today who contracted acute paralytic poliomyelitis prior to the advent of widespread vaccination programs against poliovirus (PV). What is under appreciated is the fact that polio survivors are many years later at risk of developing new neurological deterioration, a condition recognized in the late 80's as post-poliomyelitis syndrome (PPS). PPS is a slowly progressive disease in individuals previously affected by paralytic poliomyelitis that is characterized primarily by new muscle weakness and atrophy. Diagnosis of PPS is time-consuming and complicated by the need to rule out other diseases that could explain the new symptoms. The ability of a physician to diagnose a specific disease can be significantly aided by the availability of one or several disease biological markers (termed biomarkers). No biomarker(s) has been identified for PPS as yet that could assist in providing a definitive, easy and rapid diagnosis.

Disease biomarkers are measures of biological parameters indicative of a disease process. They are useful because they can assist in diagnosis or provide a means of monitoring the disease as it progresses and the effectiveness of different therapies. The study conducted at the University of Arkansas for Medical Sciences (UAMS) was, therefore, designed to answer a simple question: Are there signs or changes in the immune system (that is an immunological signature) that can be linked to Post-polio Syndrome (PPS)? If so, these changes in the immune system could be potentially used as a biomarker to diagnose PPS quickly and efficiently and to possibly provide clues as to the causes of PPS.

In this study there were 3 groups of individuals – (1) healthy individuals who never had disease associated with poliovirus and were vaccinated with the polio vaccine, (2) stable polio survivors, who suffered from poliomyelitis and may have had the vaccine but currently do not have symptoms associated with PPS, and (3) individuals with PPS. The goal was to determine whether the types of immune cells and their functions observed in individuals with PPS were different from those from healthy individuals or individuals with stable polio.

The data from the study show that PPS individuals have higher levels of antibodies and regulatory T cells circulating in their blood than healthy age-matched individuals, while stable polio individuals have variable levels of these immune components, which overlap with both the PPS and the healthy individuals.

The data from this study suggest that there is possible immune dysregulation occurring within polio survivors (both stable and PPS individuals). Importantly, however, there was a lack of sufficient data from stable polio subjects. This lack of sufficient data from stable survivors makes it difficult to make definitive conclusions regarding the role of regulatory T cells (and/or antibodies) as an easily available diagnostic marker for PPS. The cause for the increased levels of the immune components (antibodies and regulatory T cells) is currently unknown.

The observations from this study do, however, suggest that there is a problem with the immune responses in polio survivors, which could contribute to PPS. Whether immune components have a direct role in the initiation and progression of PPS or merely indicate the presence of a problem with the immune system in these individuals is unclear at this time.

Research Progress

Summary of Post-Polio Research at University of Amsterdam

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The research on post-polio syndrome in Amsterdam started in 1989 and was initiated by professor Marianne de Visser, neurologist. From that time on increasing numbers of Dutch patients with post-polio syndrome came to Amsterdam and were also seen in the Department of Rehabilitation. In 1993 funding was obtained for a PhD research project of Frans Nollet. Since then post-polio research has continued in Amsterdam, led by Marianne de Visser, Anita Beelen and Frans Nollet, resulting in 27 peer reviewed scientific papers up till now. PhD theses were written by Barbara Ivanyi in 1999, Frans Nollet in 2002, Herwin Horemans in 2005 and Merel Brehm in 2007. At present 3 PhD students are doing research Janneke Stolwijk-Swüste, Fieke Koopman and Irene Tersteeg and a fourth one will start soon. What has been studied so far and what is presently being studied?

Research has been focused on clinical studies. Some results are summarized according to the topics that have been studied over the past years and can be categorized as:
I - epidemiological and longitudinal studies
II - diagnostic studies
III – physiological studies
IV- intervention studies
V - methodological studies

Epidemiological and longitudinal studies
Polio victims from the last large epidemic in The Netherlands in 1956 with almost 1800 cases were studied 39 years later. In this population-based study among 260 respondents almost 60% experienced signs of new

weakness, increased disabilities and handicaps and diminished health-related quality of life. The use of devices and adaptations had increased.(8,12)

A cohort of 103 polio patients was followed for six years. 27 of them had stable polio and 76 post-polio syndrome.(7,14) It appeared that health-related quality of life of the patients with PPS was lower compared to the stable functioning polio individuals. Over the years physical functioning did not change much. However, it appeared that the severity of paresis at baseline was a prognostic factor for decline in physical functioning in six years. These results supported the concept of overuse, that a (slow) decline in muscle mass, as a late effect of polio, may lead to a decline in physical functioning as the reduced muscle capacity becomes less able to meet the demands of daily physical activities.

In a systematic review of the literature we concluded that so far no conclusions can be drawn from the literature with regard to the functional course or prognostic factors in late-onset polio sequelae.(23) The rate of decline in muscle strength is slow, and prognostic factors have not yet been identified. Long-term follow-up studies with unselected study populations and age-matched controls are needed, with specific focus on prognostic factors. Therefore we are presently conducting a longitudinal study involving 168 polio individuals.(26) This study focuses on the effects of aging and co-morbidity on functioning over time. Individuals ranging in age between 45 and 85 have been included and in contrast with many other studies, co-morbidities are not excluded but its influence on the time course is studied as this reflects what happens in reality with aging. At the moment the participants in the study have been followed for 5 years. Some results have been published. Age and co-morbidities were found to be negatively associated with physical functioning and physical independence. The influence of these factors on the changes over time are being analyzed at present. More publications from this cohort-study will follow in the next years.

Diagnostic studies

The value of muscle computed tomography (CT) was studied. It was shown that muscles of post-polio patients experiencing new muscle weakness showed significantly more CT scan abnormalities compared with stable post-polio patients.(5) Muscle CT scan evaluation was considered a useful adjunct to muscle strength assessment and is now routine procedure in clinical practice. Furthermore, sleep complaints were inventoried. It appeared that up to half of post-polio patients reported complaints of disordered sleep, which was likely to influence daytime functioning. This was not further analyzed.(4) At present we are doing research on this in the aging study in collaboration with pulmonologists form the Center for Home Ventilation in Utrecht.

Physiological studies

Aspects of muscle function and exercise capacity were studied. It appeared that exercise capacity of polio individuals was mainly determined by the available muscle mass. No convincing evidence as found for a poor cardio respiratory condition. Results were comparable to normally active healthy controls.(11) We confirmed reports from others that polio individuals, especially those with post-polio syndrome may have difficulty with activating their muscles and are thus not fully able to recruit the available capacity.(13, 19) A clinical relevant finding is that the energy cost of walking is directly related to the severity of polio residuals.(24) This implicates that in case of two severely affected legs walking may cost twice (or even more) energy as compared to healthy people. Together with a reduced muscle mass this implies that ‘one has to do more with less’ substantiating the concept of overuse as a major cause of post-polio complaints. However, it appeared that only those individuals with severely reduced walking ability, reduced their walking activity in daily life.(22)

Intervention studies

In 2003 we reported a study on the effects of pyridostigmine (a drug that improves neuromuscular transmission) on fatigue, muscle strength and functioning in post-polio syndrome.(15) Unfortunately, we found no effect, which was in line with the results published earlier by Trojan et al. Our hope was that an effect could be found with different outcomes in polio individuals with proven neuromuscular disturbances.(10) However, this was not the case. Since, some limited effects were found, a potential benefit of pyridostigmine can not entirely be ruled out. However, that would require another study, accounting for individual differences in drug uptake. At present no such study is undertaken.

Another area of interventions is innovation and biomechanical optimization of custom-made leg braces. We demonstrated that the energy cost of walking can be reduced substantially by improving braces.(27) A chapter on state-of-the-art carbon composite orthoses for post-polio syndrome was written for the latest edition of the Atlas of Orthoses and Assistive Devices by the American Association of Orthopedic Surgery issued in 2008. At the moment, a grant has been obtained to write a clinical prescription guideline. Research on the innovation of braces is ongoing in collaboration with orthopedic technicians and industry.

Methodological studies

In scientific research it is important to investigate the measurement properties of the instruments that are applied: questionnaires, time scored tests, strength tests, (electro)physiological measurements and so on. A number of papers have been published in this area. It appears that strength measurements with a hand-dynamometer, but also in a fixed chair-dynamometer show large variations and are not very sensitive to detect small changes over time in individuals.(9,19) This implies that it is not easily possible to conclude that strength has really declined in evaluating a person with post-polio syndrome over time. It appears that walking tests and measurements of energy consumption are better able to detect individual changes, although the sensitivity to detect change is less in polio individuals than in healthy controls.(21,24) In a recent paper, we recommended the Medical Outcomes Study Short Form 36 scale Physical Functioning and a 2-min walk test at self-selected speed to be used as core qualifiers for physical functioning, the major increasing disability in late-onset sequelae of poliomyelitis, to assess perceived physical performance and walking capacity in research and clinical practice.(29)

Research in progress

At present we are following up the cohort that is focusing on aging and co-morbidity. These studies are being done by Janneke Stolwijk-Swüste and Irene Tersteeg and supervised by Anita Beelen.

Another study is an intervention study to reduce fatigue and improve functioning. Two different strategies are being investigated physical exercise and a cognitive behavioral approach. This study is part of a larger project involving also other neuromuscular disorders, coordinated by senior-researchers Anita Beelen and Kimi Uegaki. This study is being done by Fieke Koopman and a second PhD student will be involved.

Finally, studies are ongoing regarding orthotic devices and clinical guidelines involving senior-researchers Merel Brehm and Carine van Schie.

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Aging with a Disability: Policy Lessons Learned from Polio

Fernando Torres-Gil MSW, Ph.D.

The concerns of older people and people with disabilities have risen on the nation's political agenda. This political elevation reflects decades of advocacy, lobbying, and public awareness of people with social, economic, health, and physical vulnerabilities. Debates about entitlement programs such as Medicare and Medicaid illustrate the growing public awareness of those important issues. But the real test of how this county responds to the needs of people with disabilities will occur as two important demographic trends come to fruition: the aging of the Baby Boom population and the aging of people with long-term disabilities such as cerebral palsy, spinal cord injury, polio, and multiple sclerosis. Public policy actions, especially in the health area, will have major repercussions for both of these populations. Thus it becomes important for aging interest groups, disability organizations, and people of all ages with disabilities to pay close attention to political decisions and public policy actions over the next several years. Such actions will largely determine the extent of public benefits and services and possibly quality of life for people aging with disabilities.

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SESSION F2

Finding Causes of and Managing Fatigue, Part 1

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Summary

Fatigue is the most frequently mentioned complaint of people with post-polio syndrome (PPS). And fatigue is often severe. However fatigue is not very specific and a prominent complaint in many neuromuscular disorders, in many chronic diseases such as multiple sclerosis, in oncology and even on itself in chronic fatigue syndrome. How to understand fatigue in PPS and how to deal with it is the aim of the two fatigue sessions.

In Session I the focus will be on the magnitude of the problem of fatigue in PPS, the different forms of fatigue and the factors playing a role in fatigue in PPS. In Session II the focus will be on the assessment and treatment of fatigue in clinical practice and what people with PPS can do to reduce fatigue.

Contents

Session I on Friday 11.15 - 12.30 AM covers the following topics:
- the problem of fatigue in PPS; prevalence and severity
- types and definitions of fatigue in PPS
- the mechanisms and factors contributing to fatigue in PPS

Session II on Friday 2.45 - 4.00 PM covers the following topics:
- how to assess fatigue in PPS
- how to treat fatigue in PPS
- energy conservation techniques

Causes of fatigue

Fatigue is mentioned by up to 80% of people with post-polio syndrome and the scores on fatigue questionnaires are often high, indicating severe fatigue. But, what is fatigue? Fatigue can be defined as 'a persistent, subjective sense of tiredness that interferes with usual functioning'. This refers to the general feeling of fatigue, however local muscle fatigue is also often present and is among the symptoms to define post-polio syndrome: 'new muscle weakness or abnormal muscle fatigability'.
In post-polio syndrome fatigue is most frequently related to physical factors.

Local muscle fatigue

Local muscle fatigue is the decline in the ability of the muscle to generate force. Several factors have been identified that may play a role in this:

I - Failure to drive muscles from the central nervous system due to alterations in the central nervous system to activate the nerve cells due to polio - the precise mechanism is not understood;
II - Transmission failure from the nerves to the muscle fibers due to the fact that nerve connections with muscle fibers that were formed in the recovery phase after the acute polio are of less quality and therefore less able to sustain the transfer of the signal from the nerve to the muscle;
III - Decreasing capacity of the muscles due to post-polio syndrome to meet the physical requirements needed to execute daily life activities. The muscles that slowly decline in strength have to work at an increasing level of their maximal capacity and this will be inversely related to the duration physical activities can be maintained.
IV - A decrease in endurance properties of muscles. Muscles that are chronically used at a certain load, especially leg muscles, change their properties towards endurance, however not fully. Shortages of relevant enzymes have been reported.
V - Especially less and not affected muscles may be chronically under loaded in daily life and suffer from disuse. As a consequence they are less loadable.

General fatigue
General fatigue, the feeling of being tired, may have several causes.
I - People with post-polio syndrome may feel fatigued due to the fact that they are constantly acting above or in the upper range of their physical capacities. This may result in a chronic state of exhaustion. It is important to realize that movement efficiency is often reduced. This implies that walking may cost twice (or even more) the energy of normal walking in case of two affected legs.
II - Brain alterations due to polio virus damage have been suggested as a possible cause of general fatigue.
III - Recent studies have demonstrated signs of chronic inflammation in the cerebrospinal fluid in PPS. This may also play a role in fatigue.
IV - Deconditioning of the cardio respiratory system. Persons with post-polio syndrome have been found to be deconditioned, or to have a condition comparable to a sedentary life style.
V - Psychological factors, such as ‘giving up the fight’, social factors related to the persons life situation, and sleep problems may all contribute to fatigue. However, these are not the main causes of fatigue in post-polio syndrome.

Other causes of fatigue
It is very important to rule out other causes of fatigue. Of course the list of potential causes is very long, but a few common causes such as anemia, hypothyroidism, depression need to be mentioned.

Factors associated with fatigue in PPS
In a recent study, so far unpublished data, several of the above mentioned factors were found to be associated with fatigue. Lower physical functioning, more pain, sleep problems, lower well being and an active coping style were found to be associated with fatigue. Of course, in this study not all potential factors were included.

Pharmacological treatment
No pharmaceuticals have been proven effective in reducing fatigue. Randomized controlled trials (RCT’s) in which drugs are tested against a placebo and both investigators and patients are blinded for the intervention are the gold standard to prove effectiveness of interventions. Results from such studies have so far been disappointing in that no drug was found to be effective.
Modafinil, a drug used in narcolepsy, was recently demonstrated as not effective in reducing fatigue in a study by Vasconcelos OM, Neurology 2008 confirming the negative results reported earlier by Chan KM in Muslce and Nerve in 2006.

Intravenous Immunoglobulines (IvIg) have been studied in two trails by Borg K, in Lancet Neurology in 2006 and by Farbu E, European Journal of Neurology in 2007. The study by Borg found effect for muscle strength and for ‘vitality’. The study by Farbu found an effect for pain. Both studies however found no effect for fatigue.

Pyridostigmine, a drug that improves neuromuscular transmission was demonstrated not effective in two studies, one by Trojan DA in Neurology in 1999 and one study by Horemans HL in Journal of Neurology Neurosurgery and Psychiatry in 2003.

Other drugs were investigated in only one study involving limited numbers of patients. Negative results were found by Dinsmore S for high-dose *prednisone*, and by Stein DP, for *amantadine*, an anti-inflammatory drug, both published in Annals of New York Academy of Sciences in 1995. A study in 2005 by On AY, demonstrated a significant effect of *lamotrigine*, an antiepileptic drug, supposed to have neuroprotective properties, on fatigue. So far confirmative studies have not been published. Finally, a recent pilot study by Skough K, in 2008, found no effects for coenzyme Q10.

Assessment of and Managing fatigue in individuals with PPS

Assessment

I Medical evaluation
It is very important to start with a thorough medical evaluation to exclude other pathologies as mentioned earlier.
II What is meant by fatigue?
The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest.
III Are other contributing factors present?
Consideration has to be given to sleep quality, mood disorders and coping styles.
IV What is the activity pattern?
The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking, mobility in and outdoors and so on.
V What is the social system?
How is the person‘s social environment, does he or she have sufficient support and understanding at home and work.
VI What are the own perceptions?
How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on).
VII What are the physical capacities?
What is somebody able to do given the polio residuals and co-morbidities. What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individuals various activities.
VIII Conclusion
Finally a conclusion can be made on which factors cause or sustain fatigue. These are to be targeted in interventions.

Assessment tools

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning.
Diaries to inventory daily life activity are extremely useful to gain insight in what someone life looks like, in what a person actually does over the days. A common finding is that people with PPS appear to be much more active than they spontaneously report.
Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

Management

The first important thing is that the person obtains insight in the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cognitions. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well known that many polio survivors are so-called ‘over achievers’ who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals may avoid physical activity, for instance if they think that this may damage muscles, and they may very well be mainly fatigued due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue energy conservation skills are often to be learned. This may be done individual or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercise program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all be needed tailored to the individual's needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians.

Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during follow-up.

Making the Tough Decisions: Palliative Care and End-of-Life Decisions

**Lawrence C. Becker, Fellow, Hollins University, Professor of Philosophy Emeritus,
College of William & Mary, Roanoke, Virginia**

**Fernando Torres-Gil, Associate Dean for Academic Affairs at the School of Public Policy
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Palliative Care and End-of-Life Decision-making

**Lawrence C. Becker, Fellow, Hollins University, Professor of Philosophy Emeritus,
College of William & Mary, Roanoke, Virginia**

Agenda

There are three elements to this session.
One is about tools -- important resources that are in print or online.
Another is about making sure we have acted effectively and proactively on these issues.
And the third will be a freeform exchange of ideas on this subject.

A framework for making decisions

Don't postpone these matters:
Make contingency plans for a variety of possibilities
Name a health-care proxy /durable power of attorney for healthcare
Make an advance directive
Refine all of this in consultation with your physician(s) and make changes as necessary

Things to consider in doing all this planning
End-of-life trajectories
Types of treatment to consider insisting upon or refusing
What you can, and can't, expect to control about your treatment

Contingency planning

Make contingency plans for a variety of ***possible*** living arrangements
Independent living with ***decreasing independence*** over time
Assisted living at home; respite care options
Assisted living in a private apartment
Skilled care
Hospice care
Insofar as possible, make these specific plans, about specific facilities

Healthcare proxy

Name a health-care proxy /durable power of attorney for healthcare
Choose someone who will be available when needed
Make sure this person is willing and able to be your advocate
Discuss your contingency plans and the plan for your advance directive
Make sure your physician and local hospitals know who your proxy is
Make this information publicly, and prominently available for healthcare workers
Update this as necessary

Advance directive

Make an advance directive
Use the legally defined form for your state
Make sure it includes the name of your health care proxy
Make sure it contains (or that you add) specific information about when you want, and do not want, various kinds of treatment or palliative care
Make sure you have signed off on the appropriate "no transfer" policy

Make sure you have discussed this thoroughly with your physician and healthcare proxy, and have made it accessible to healthcare professionals

Refine this with your physician

Refine all of this in consultation with your physician(s) and make changes as necessary
Review it all in advance of routine physicals
Review it during receipt of new prognoses about life altering changes
Do not count on being able to make changes during emergencies

Things to consider in doing all this

End-of-life trajectories
Types of treatment
Things you can, and cannot, control about your treatment

End-of-life trajectories

Medical textbooks and discussions of these matters assume
that the process of dying is likely be some variation on one of three patterns:
A steep decline from stable functioning to death
A series of stairstep declines and partial recoveries to eventual death
A very gradual decline, or dwindling, from stable functioning to death

Pay particular attention to the level of function starting point.

What does functioning mean at this point? Major organ functioning? Activities of daily living?

CAUTION: medical textbooks on palliative care and discussions of end-of-life matters do not typically focus on how to assess these matters for people who have been living with serious, long-term disabilities.

Types of treatment

Restorative or rehabilitative treatment. Medical treatment is sometimes aimed at full or partial recovery -- that is, at restoring our health or the ability to function ; restoring it from the effects of disease, injury, impairment, developmental interruption…

to achieve that aim, you also need ultimately to sustain life. It is perverse to say that "the surgery was a success, but the patient died.") Nonetheless, merely sustaining life is not the ultimate goal of this form of treatment, and in fact this form of treatment may involve serious *risks* to life. (Think about bone marrow transplants.)

Life-sustaining treatment. Medical treatment is sometimes not aimed at recovery, however, but rather is aimed first and foremost at sustaining life.

Emergency and critical care medicine typically operates with an overriding mandate to stabilize the patient first and ask questions later.

If you have been brought to the hospital in extremis, your advance directive may well be overridden until you are stabilized.

To achieve the aims of stabilization and life-sustaining treatment, risks may have to be taken.

But it would be perverse to take ***life***-threatening risks (say, on some longshot hope of recovery) if your aim is really first and foremost sustaining your life.

Palliative Care. Good medical treatment always involves caring about, and ameliorating the patient's needs:

minimizing anxiety, fear, pain;

keeping the person clean, comfortable, well nourished;

providing a spiritually nourishing environment;

helping the person carry out his own projects;

and so forth.

[To palliate comes from the late Latin verb palliare, palliat-, meaning to cloak; which in turn comes from the Latin noun pallium, meaning a cloak. The idea is, I suppose, that one can palliate, mask, or cloak pain and suffering -- by making people "comfortable" -- even though the source of the pain and suffering remains.]

When this kind of care takes place in the context of medical treatment -- either restorative or life-sustaining treatment -- we don't typically speak of it as palliative care. Though strictly, of course, it is palliative.

But typically what we mean by palliative care is what goes on (or should go on) when for one reason or another the patient, or others, have decided against "treatment" of either the restorative or life-sustaining forms.

Non-beneficial treatment. Treatment which will be, to a reasonable medical certainty, futile in achieving the treatment goal for which it is sought.

Nonbeneficial treatment becomes a problem in palliative care situations when there is sharp disagreement between the patient (or the patient's advocate) and the treating physicians, or disagreement between physicians, or between insurance companies and the patient, physician, or both.

Some of these disagreements are inevitable, but many of them can be resolved by paying careful attention to the following:

What is the good of the treatment sought?

The patient's tolerance for risk, pain, suffering, and death at a given time, or in a given way can vary enormously depending on which conception of the good life is at issue:

the container conception,

the integrity conception,

or the project conception.

When is it reasonable to expect healthcare professionals to defer to the patient's conception of the good in calculating whether a given treatment will be beneficial or not?

That leaves disputes with insurers.

Whose rights are at stake, and what kind of rights are they?

All three stakeholders in these disputes (patient, healthcare provider, insurer) have rights.

But those rights may be claim rights, liberty rights, powers, or immunities.

For example, a patient may have a claim right against the insurance company for coverage of a standard form of treatment if ordered by a physician, but only a liberty right against physicians that they order such treatment. So in that case, when a physician refuses to order the treatment on the grounds that it is "nonbeneficial" -- even deferring to the patient's conception of the good being sought -- then continued demand for that treatment by the patient is on shaky ground, and probably will not succeed unless it can be shown that the physician is flatly wrong, or unless the patient can find a physician who disagrees with the first one and will order the treatment.

Principles of biomedical ethics

Autonomy (to be respected for all involved, but mostly of concern in preserving the agency of the patient)

Beneficence (applicable to all involved, but mostly of concern in defining the physician's duty to provide genuinely beneficial treatment, and the patient's family/agent's duty to seek genuinely beneficial treatment)

Prohibition of harm (applicable to all involved, but pointedly involved in the physician's duty to do no harm unless it is required by genuinely beneficial treatment, and the patient's duty to consider the consequences for others [including the public health consequences -- including costs], and the family/agent's duty to act in the interest of the patient)

Justice (fairness or equity to all involved, and of special concern when there is reason to believe that one or more of the other three principles principle might not be followed, but also commonly of concern in conflicts between public health goals [including cost] and individual treatment goals)

Palliative Care: some resources
Online resources
International Association for Hospice and Palliative Care
http://www.hospicecare.com/

Standards from the US, UK, Switzerland, Spain, Scotland, Romania, Poland, Norway, Moldova, Japan, Italy, Hungary, Canada, Australia:
http://www.hospicecare.com/standards/
For the US, in particular, see the standards from 2004 from
JCACHO (Joint Commission on Accreditation of Healthcare Organizations)
National Consensus Project

National Hospice and Palliative Care Organization (US)
http://www.nhpco.org/   (home page)
Oriented toward healthcare professionals and organizations
Links to their affiliate organizations, including one directly oriented to consumers and their families:
The Caring Connection http://www.caringinfo.org/Home.htm
This is an excellent “consumer service” page

American Academy of Hospice and Palliative Medicine
http://www.aahpm (for physicians, but with some "patient education information")
Hospice and Palliative Nurses Association
http://www.hpna.org/ (for nurses, but with some general standards information)

Medical handbooks

Kuebler, Kim, Debra Heidrich, and Peg Esper (authors). *Palliative and End-Of-Life Care: Clinical Practice Guidelines, 2nd ed* Mosby: 2006. $48.55

Watson, Max, Caroline Lucas, Andrew Hoy, Joe Wells. *Oxford Handbook of Palliative Care*

(Oxford University Press, 2009, $49.95)

Reflections by (and mostly for) physicians & nurses

Fins, Joseph. M.D. *A Palliative Ethic of Care.* Jones & Bartlett, 2005.$46.95

Lynn, Joanne et al. *The Commonsense Guide to Improving Palliative Care*. Oxford University Press, 2007. $27.42

From the patient's side of things

Kiernan, Stephen P. *Last Rights: Rescuing the End of Life from the Medical System*. St. Martin's Press, 2006. $18.94

Well-written investigative journalism with philosophical ambitions.

Legally speaking

Cebuhar, Jo Cline. J. D. *Last Things First, Just in Case… The Practical Guide to Living Wills and Durable Powers of Attorney for Healthcare*. Murphy Publishing, 2006. $24.95

Doukas, John David, M.D. and William Reichel, M.D. *Planning for Uncertainty: Living Wills and Other Advance Directives for You and Your Family*. 2nd ed. Johns Hopkins University Press, 2007.

Mirarchi, Fernando. D. O. *Understanding Your Living Will*. Addicus Books, 2006. $11.96

Emergency room physician describes the "codes" to use to make sure your instructions are not misunderstood by medical staff.

Anesthesia Update: Separating Fact from Fear

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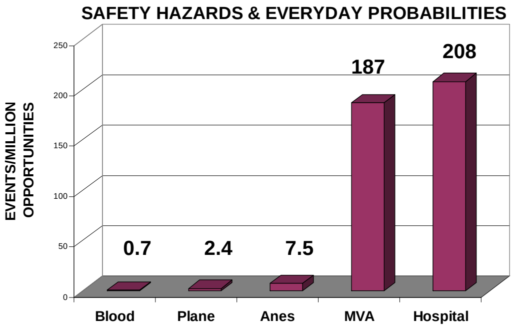
INTRODUCTION:

This talk will briefly review the process of anesthesia care, current anesthesia practice, and how these might relate to post-polio syndrome (PPS) patients having surgery. The goal is to make clear that proper preop planning allows post-polio patients to have surgery and anesthesia with a minimum of risk. Indeed, the risk of anesthesia is much, much less than the risk of death from an error while hospitalized. It also emphasizes that it is not necessary for post-polio patients to keep up with drugs and practices in anesthesia. Anesthesia, like every medical specialty, is rapidly changing, as legions of dedicated researchers and clinicians work to make what we do more effective and safer. It is extremely difficult for anesthesiologists to keep up with all the new drugs and practices; patients can not possibly keep up.

This talk will NOT address pain management, except pain immediately postop. Research has—and is still—finding numerous, complex mechanisms that cause pain, and pain treatment is becoming more and more complicated. Continuing research on pain mechanisms will probably lead to better therapies for PPS patients with pain problems.

THE RISK OF ANESTHESIA:

What is the risk for anyone having anesthesia, and how does this compare it to other risks in our daily lives? The government's Agency for Healthcare Research and Quality looked at this in 2002.



AHRQ data, 2002

DEFINITIONS:

- BLOOD: Getting HIV from transfusion of a single unit of blood
- PLANE: Annual number of passenger deaths/ number US commercial flights, 1992-2002
- ANES: 2002 estimate of mortality from anesthesia
- MVA: Deaths/number registered drivers
- HOSPITAL: Estimate preventable deaths hospitalized patients/number of hospitalizations

(Source: www.webmm.ahrq.gov/dykarchivecase.aspx?dykID=1)

It should be clear where the real risk is: just being in the hospital! The risk of dying from anesthesia is much, much smaller. The focus for worry should move from anesthesia to being hospitalized. Fortunately, a nation-wide effort to improve hospital safety is developing, but safety still varies markedly by individual hospital.

ANESTHESIA RISKS FOR PPS PATIENTS:

What do we know about how PPS patients do during anesthesia? Very little! Medical knowledge like this can be measured by looking at the number and type of medical journal publications over time, something easily done on the National Library of Medicine's PubMed data base. (This lists all articles in standard medical journals over time.) Searching for "post-polio syndrome AND anesthesia," 11 articles were found. The first was in 1990. Ten more articles were published in the next 12 years,. Not all were significant/focused only on PPS. There were 3 case reports, 3 letters-to-the-editor on the cases, 1 was a theoretical article with no cases, 1 article was on dental issues, 1 mentioned PPS as part of a larger study of a new drug and 1 was on indications for modafinil (Provigil), not about anesthesia. This is a very small amount of information, really only 8 articles.

Contrast this meager number of articles with those on PPS itself: 946 articles were published since 1990, when the first article on anesthesia was published! So researchers were focused on the bigger problem of what is PPS and what should therapy be. Additionally, few hospitals have many PPS patients coming for surgery, so a significant study of anesthesia complications would be very difficult.

Fortunately, we _will_ get some real data in the next few years. The Mayo Clinic has had an electronic medical record since 1980, and it is often used to study anesthesia complications. So, I convinced my anesthesia friends there to study this. The question is, "*How many and what type of anesthesia complications occur in PPS patients having anesthesia and how does that compare to other patients with a neuromuscular disease and also how do they compare to normal patients?*"

Data gathering is finished and they are half-way thorough data analysis. They gave me permission to give you some early, preliminary results, as of March 6, 2009. The study covers 1986-2008 and includes all PPS patients having surgery (excludes sedation cases and patients less than 18 yo) . There are 779 patients, a very generous sample size, which will make their results very powerful. Data analysis is complete on the first 300/779 patients. No anesthesia complications occurred. It will take other 6-plus months to finish the data analysis, write this up and get it published, so we won't get the final results for awhile. But, I think this is a most hopeful study, and it supports my clinical impression that if a good preop evaluation is done and if surgical, anesthesia and hospital care are competent, PPS patients can have surgery without problems.

PPS patients have asked numerous questions about anesthesia since 1996, when I gave the first talk on this. Many questions have been about normal things that can happen, for example a drop in blood pressure after a spinal anesthetic was placed. This is due to the effect of the spinal anesthetic on nerves controlling blood vessels and is actually not a complication. Well-trained anesthesiologists look for these "complications" and treat them appropriately and promptly. And, some of the most significant "anesthesia complication" questions were actually about complications from surgery and had nothing to do with anesthesia. We have to use great care about what we call "anesthesia complications."

THE PROCESS OF ANESTHESIA CARE:

Because each patient's anesthesia needs differ, and differ over time as new problems show up, this talk will focus less on specific anesthesia techniques and drugs and discuss how you can hopefully communicate with anesthesiologists about your problems. This is an area of confusion, so the usual process is reviewed here.

Most PPS patients will have surgery in a hospital or an out-patient surgery facility attached to a hospital. (PPS patients should not have anesthesia in physicians' offices, for safety reasons, and that situation will not be discussed.) The anesthesia process is essentially the same, but varies by elective and emergency surgery.

A. FOR ELECTIVE SURGERY:

(1) The surgeon and you decide on surgery. You should state your special problems for anesthesia (sleep apnea or whatever). If you have a request for a particular anesthesiologist, tell the surgeon.

(2) Surgeon's office calls the hospital's scheduling office and schedules time, date and the operation. The special medical problems related to anesthesia should be stated to the scheduling secretary. If there is an anesthesia request, the office secretary should give the information to the scheduling office. (Many hospitals do this process on the web now.)

(3) Anesthesia preop evaluation varies in different institutions. Many hospitals now run a daily clinic for upcoming surgery patients. This is at the hospital; blood work, EKG and chest X-ray can be done at the same time. You receive an appointment, usually from the preop clinic's scheduling office. These clinics are often staffed by specially trained nurses, who follow protocols. Anesthesia residents are also used. An anesthesiologist is always available to the nurse/resident, who would call him/her for complicated patients. The anesthesiologist might suggest special tests or even come to the clinic to examine you. The data on each patient is recorded and reviewed at the end of the day to see if anything is missing. These forms are passed along to the scheduled anesthesiologist, usually the night before. If there is no preop clinic, trained nurses will usually call before surgery to check on your medical history and medications. The answers to those questions are given to an anesthesiologist.

Often, you don't physically see the anesthesiologist until the day of surgery. If your problems are very difficult, for example you need assisted ventilation, appointments can be made well ahead of time for the

Anesthesia Preop Clinic or to see an anesthesiologist. The surgeon's office would facilitate that. Patients with these difficult problems should get evaluations by your pulmonary and post-polio physicians before that preop clinic visit, and you should come with all those records (a pulmonary function test, at least!), so the anesthesiologist has maximum information about you. Be sure you are well-organized and precise when you speak with them ("I've had polio and need or have ---whatever."); they are usually extremely busy and pressed for time.

(4) Hospital operating rooms are chaotic and always in flux, due to emergencies incoming at all hours and also problems possibly occurring in the scheduled operations. As a result, anesthesia staffing is always in flux. The department should do their best to get you your desired staff, but there are times when it just isn't possible. In that case, all the preop information is passed along to the new physician, who should have all the needed information on you.

(5) After surgery, you should get a visit from an anesthesia person, usually a specially-trained nurse or an anesthesia resident. They should ask about your anesthesia experience and if you note any possible complications on this first postop day. Be frank in your responses. They need to know what YOU experienced. This information is typically put into a data base so the department can see how they are doing and compare themselves to national figures.

B. FOR EMERGENCY SURGERY: In a true emergency such as a car accident, there is little choice of hospital or anesthesiologist. The Emergency Room physician will assess you and decide how urgent surgery is. There may be time for your own physician to get involved. The anesthesiologist will talk with you, often in the OR.

You can help by having a MedicAlert bracelet or some other way to identify your health problems and needs. Because of the wide recognition of the MedicAlert program, that is probably the best to use. Also, your companions/spouse should be aware of your needs. Simple wallet cards can provide them with the needed information. This could save your life! It's also helpful to know which are the best hospitals in your geographic area and discuss this with your companions/spouse.

TYPES OF ANESTHESIA:

"What kind of anesthesia is best?" is the question I'm asked most often. The answer is it depends: It depends on your own health problems, including the ones from age-related diseases as well as from polio. It also depends on your wishes and your past experience with anesthesia. It depends on the operation that's planned: Some operations require certain types of anesthesia. It also depends on your surgeon: Some surgeons, for example, just can't operate under local anesthesia. Your anesthesiologist may be particularly skilled in a certain technique, so it can also depend on them.

This calls for discussion as each individual patient comes for each particular operation and at that point in time. After evaluating all these "depends" we can come up with an "Anesthesia Plan." All anesthesia plans should include something for pain relief in the postop period.

There are 3 types of anesthesia:

<u>General anesthesia</u>: You are completely asleep. You receive intravenous drugs and also gases to breathe, by way of a mask or breathing tube.

<u>Regional anesthesia</u>: Only the part of the body being operated on is anesthetized, using local anesthesia injected at the site of surgery, near a major nerve(s) to that area or around or near the spinal cord. The most common types are spinal anesthesia (local anesthesia is given into the fluid around the spinal cord) and epidural anesthesia (local anesthesia is given in the space just before the spinal cord's covering, usually through a small catheter). Regional anesthesia is increasingly popular because pain is actually prevented.

<u>Monitored Anesthesia Care</u> (MAC) The surgeon injects local anesthesia at the surgical site; an anesthesiologist sedates, monitors and makes sure you are comfortable and safe.

Many operations need a certain kind of anesthesia. Common operations and the usual anesthetics are as follow:

Cholecystectomy (removal of the gall bladder, usually done laparoscopically, using a telescope-like instrument inserted into the abdomen through small incisions): Needs general anesthesia because the abdomen is very distended during the operation.

Cataract removal: MAC. The ophthalmologist/anesthesiologist does a nerve block behind the eyeball, anesthesiologist gives sedation so you hold still and are comfortable.

Carpal tunnel release: MAC, usually. Usually done with local injection by the surgeon at the wrist, with sedation added. Can be done with various nerve blocks of arm or general anesthesia.

Orthopedic operations: General/regional, depending on the operation and the surgeon.

Rectal surgery (hemorrhoidectomy, anal fistula): Regional anesthesia has many benefits and is indicated. Sedation can be added.

Urologic surgery (resect the prostate, kidney stone): Simple trans-urethral resection of prostate (TURP) is best done with regional for numerous reasons. Radical prostatectomy calls for general anesthesia because the operation is more extensive and longer. Kidney stone removals are usually done with general anesthesia due to the severe pain.

It is not unusual to combine types of anesthesia: to add sedation to regional cases (to improve patient comfort while lying on the hard OR table), or to do a regional technique and then put the patient to sleep; the regional will be in place at the end of the case to give long-term postop pain relief. Mixed techniques gets the benefits of each.

These recommendations may change in the future. Surgical techniques are changing very rapidly and will lead to less invasive surgery. You may have read about robotic surgery, currently used in prostatic, neurosurgerical, cardiac and gynecology operations. You might also have learned about endoscopic surgery. There are some simple ones already, such as laparoscopic cholecystectomy. Soon, we’ll have major operations on the GI tract done via an endoscope passed through the mouth—and they’ll remove your stomach! Or, they will go through the rectum and remove your colon!

We can also note how anesthesia is advancing. People have very different responses to many drugs, and this can be predicted now, for some drugs, based on genetic studies. In the near future, we will be able to predict ahead of surgery, how you would respond to certain anesthesia drugs, based on your genetic profile. So, we could tailor an anesthetic to each individual patient. I hope you get the sense of how dynamic the practice of medicine is and how rapidly it’s changing.

ANESTHESIA SPECIFICS FOR PPS:

In the absence of any significant published information, the following is based on my clinical experience and ideas developed after extensive study of polio and PPS. As more information becomes available, these will change. These are the recommendations on the PPHI web site (www.post-polio.org/ipn/anes.html). I reviewed them and added an additional one, #9, and a comment.

ANESTHESIA ISSUES FOR POST-POLIO PATIENTS:

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.

2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater

sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible.

4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.

5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilatory support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

*COMMENT: Postop respiratory failure in these patients can be difficult to manage. The patient's pulmonary physician could help by doing a preop evaluation and being involved in postop ventilatory management. This situation might call for the resources of an ICU in a major medical center.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.

8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

*9. NEW IDEAS/THOUGHTS:
Spinals: Recent studies demonstrating the presence of cytokines in the CNS of PPS patients lead me to be less enthusiastic about using spinal/epidural anesthesia. There is no data on this situation, and there are so many benefits to this regional anesthesia, and they might be suitable in some situations. Lidocaine would not be a suitable drug choice for PPS patients.

Regional anesthesia: Should the peripheral nerves of PPS patients be exposed to local anesthetics, especially for long periods postop? There is no data, but many PPS patients have atrophied peripheral nerves. Perhaps smaller doses of local anesthetics and avoiding continuous postop infusions would be safer.

Above-the-clavicle blocks(supraclavicular and interscalene): These have a high risk for diaphragmatic paralysis and should probably not be used in PPS patients, unless the patient can tolerate a 30% decrease in pulmonary function.

SUMMARY:

PPS patients can have anesthesia and surgery safely, with careful preparation. Anesthesia and surgery is a process that involves anesthesia, surgery and hospital care. For an optimal outcome, ALL must be at high levels of performance and achievement! You, the patient, must work to be sure you get these. Remember, few surgeries are truly urgent and you usually have time to get data from the web, the state's hospital licensing department, the state's medical board and other resources. You should also research the operation and its consequences, to be sure you can deal with them. Don't rush into anything until you're satisfied you'll get the best. You deserve it.

HELPFUL RESOURCES:

ON ANESTHESIA:
1. Post-Polio Health International: www.post-polio.org/ipn/anes.html
2. "Post polio Syndrome and Anesthesia" by David A. Lambert, MD; Elenis Giannouli, MD; & Brian J. Schmidt, MD, The University of Manitoba, Winnipeg, Canada, in the September 2005 issue of *Anesthesiology* (Vol. 103, No. 3, pp 638-644). This article reviews polio, post polio syndrome and anesthetic considerations for this patient population.
3. To learn more about anesthesia: The American Society of Anesthesiologists' (ASA) patient education web site: www.asahq.org/patientEducation.htm. Covers many topics.

ON HOSPITALS:
1. To check out a hospital, start with the Joint Commissions (JCAHO) web site: www.jointcommission.org and click on the Quality Check mark.
2. Check the hospital's web site; many show their surgical results.

ON PHYSICIANS:
1. Check your surgeon and anesthesiologist in the state's medical licensing board web site.

Demonstration and Discussion of a Seating Evaluation

Rene James, PT and Trina Ouzts, PT, ATP,
Warm Springs, Georgia

I. Introduction
    A. Goals of seating and wheeled mobility:
        1. **Ultimate goal**: To provide maximum function with minimum pathology
        2. Decrease and prevent deformity
        3. Decrease the incidence of overuse syndromes
        4. Manage pressure
        5. Improve natural functions of internal organs (digestion, respiration, swallowing)
        6. Enhance mobility
        7. Increase comfort
        8. Decrease pain
        9. Conserve energy
        10. Increase sitting tolerance and tolerance to activity
        11. Assist in facilitating a positive self image
        12. Increase ability to perform self care

B. Consequences of poor seating
    1. Pressure sores
    2. Contractures
    3. Spasticity
    4. Poor function of internal organs
    5. Impaired mobility
    6. Increased dependency

C. Seating and wheeled mobility team members:
    1. Client
    2. Family members and caretakers
    3. Rehab specialists (PT, OT, SLP, audiologist, nurse, rehab engineer, recreation therapist, Physician)
    4. Educators
    5. Vocational counselor
    6. Case manager or social service worker
    7. Third party payer

II. Seating evaluation

A. Client's goals
    1. What does the client want? - A person can be provided with the most perfect wheelchair, made to meet their needs, but if it is not what they want, they will never be satisfied.
    2. When and for what purpose will the mobility device be used?
    3. User's abilities and plans:
        a. Activity level
        b. Prognosis - Is the client likely to get better, worse, or stay the same?
        c. Functional abilities
        d. Vocational goals
        e. Lifestyle

B. Medical / surgical history and plans:
    1. Past and present medical problems
    2. Potential for motor return or decline
    3. Height and weight
    4. Bowel and bladder function

    5. Skin condition past and present
        a. Condition
            1) Intact
            2) Current breakdown
            3) History of breakdown - areas of past breakdown are more susceptible to future breakdown
            4) Condition of skin
        b. Sensation
        c. Risk for breakdown - Braden Scale used for predicting pressure sore risk by grading sensory perception, moisture, activity level, mobility, nutrition, and friction & shear
    6. Muscle spasms or spasticity
    7. Contractures/ ROM
    8. Pain

C. Cognitive and behavioral status:
    1. Acceptance of need to using mobility devices
    2. Safety awareness
    3. Motor planning problems
    4. Level of alertness
    5. Problem solving abilities
    6. Motivation

D. Communication / Language
    1. Ability to communicate
    2. Use of augmentative communication

E. Sensory function
  1. Vision
  2. Hearing
  3. Sensory perception

F. Environmental factors – Home, work, school and recreation:
  1. Home environment
    a. GEM Assessment - A comprehensive home assessment tool used to identify problems and possible solutions for each room of a home and the immediate outdoor area (www.cornellEG.org)
    b. Width of doorways
    c. Ramps or curb cuts
    d. Necessary turning radius
    e. Bathroom set-up
    f. Clearance under tables, desks, workstations
    g. Assistive devices, communication devices used
    h. Others using the environment
    i. Distances and surface types required to cover on a regular basis (i.e. college campus v. home bound)
  2. School / Vocation
  3. Leisure activities

G. Transportation:
  1. Does the client drive?
    a. Considerations if drives from the vehicle's seat
    b. Considerations if drives from wheelchair
  2. Type of vehicle (2 or 4-door car, truck, van or van with lift)
  3. Method of transportation for power wheelchair
    a. Lock down/tie down used
    b. Size and style of lift / ramp
    c. Consider the needed external clearance for the lift or ramp to work
    d. Consider the needed internal clearance (head clearance, seat to floor height)
    e. If transported in the back of a pickup or on an exterior lift, the wheelchair is exposed to the environment, which can cause serious damage to the wheelchair
    f. Some power wheelchairs can be broken down and folded into components, but the components are heavy (50-60 pounds) and unwieldy
    g. Community transportation

H. Current and past equipment:
  1. Problems and positives about current equipment
  2. Appearance in current equipment
  3. Past equipment – the good and the bad
  4. Tolerance to technology

I. Functional activities of daily living (Bathing, dressing, toileting, feeding, and grooming)
  1. Level of assistance required
  2. Tasks that are performed in the wheelchair

J. Physical assessment
  1. Transfers
  2. Balance
    a. Sitting balance
    b. Standing balance
  3. Mobility
    a. Bed mobility
    b. Gait
    c. Wheelchair mobility and management

4. Posture
    a. Limitations in extremities
    b. Spinal alignment (scoliosis/ kyphosis)
    c. Pelvic alignment (obliquity / rotation / lordosis)
    d. Symmetry v. asymmetry
    e. Fixed v. flexible deformity
    f. Note differences in range of motion, and pelvic/spinal alignments when in different positions
5. Range of motion
6. Strength
7. Alignment of trunk to extremities
8. Spasticity – When is it present? What breaks it up?
9. Effect of gravity in different positions

K. Measurements (Take these in short sitting position)
1. Seat depth - Measurement from the most posterior aspect of buttocks to behind the knee
2. Seat width - Measurement of widest aspect of hips or thighs.
3. Back height - Varies according to person's trunk control
4. Seat to floor height - The distance from the top of the cushion to the floor
5. Footrest to seat distance (Lower leg length) - The distance from the back of the knee to the bottom of the shoe
6. Armrest height - The height at which the person can be seated in the wheelchair on their cushion with their elbows flexed to 90°, and be comfortably supported with an aligned posture
7. Maximum wheelchair weight to enter home - Power wheelchairs are heavy. If a person lives in an older mobile home or house, the floors may no be able to support the weight of the wheelchair and endanger the patient.

III. Choosing wheelchair and components

A. Problem list
1. Risk for breakdown
2. Postural deformity
3. Risk for future deformity
4. Dependent for mobility
5. Inability to perform effective weight shift
6. High risk for falls
7. Unsafe gait

B. Goals and desired outcomes
1. Independence
2. Mobility
3. Access to community
4. Safety
5. Comfort and tolerance
6. Accommodate needs

C. When possible, create a simulation of potential wheelchair
1. Place client in appropriate wheelchair base, cushion, backrest, etc.
2. Transfer client into the wheelchair and adjust as necessary
3. Allow client time to try it out and to ask questions
4. Assess client's ability to maneuver
5. Make changes, as appropriate
6. Realize that compromises may need to be made

D. Things to consider:
1. Provide symmetry and midline of the head whenever possible
2. Do NOT take away function for appearance
3. Do NOT imprison
4. There is no such things as "use it or lose it" and "no pain, no gain"
5. Define desirable features before selecting equipment

E. Power versus manual bases
  1. Power may be necessary when:
    a. Unable to propel a manual wheelchair
    b. Orthopedic injury, overuse syndrome or medical condition which is aggravated when propelling a manual wheelchair
    c. Vocational or educational needs in hilly areas or in areas requiring being able to go over great distances
    d. Energy conservation needs – a power wheelchair will conserve energy for activities, not use energy for mobility
  2. Environmental considerations
  3. Safety considerations
    a. Safety awareness
    b. Level of distraction or agitation
    c. Adequate visual and motor skills

F. Types of manual wheelchairs
  1. Heights of wheelchairs
  2. Weights of wheelchairs
      1) Transport wheelchair (19-29 pounds)
      2) Standard wheelchair (>36 pounds)
      3) Lightweight wheelchair (28-36 pounds)
      4) Ultralightweight wheelchair (14-28 pounds)
  3. Rigid v. folding frame

G. Types of power wheelchairs
  1. Power Operated Vehicle (POV) = Scooter
    a. Has a larger turning radius than a power wheelchair
    b. Does not provide positioning
    c. Cannot have controls programmed
    d. Not very portable
    e. Client should have good balance, good arm control and function, and ability to safely transfer
  2. Power assist - Added to manual wheelchair (may void warranty on the wheelchair); Increased the effect of each push so that it is easier to propel a manual wheelchair; Must be able to self propel the wheelchair in a symmetrical manner
  3. Power w/c
    a. Drive wheels
      1) Front
        a) Small turning radius
        b) Difficult to learn to drive (configuration backward from rear wheel drive)
        c) Can fish tail when making turns
        d) Good over uneven surfaces and over obstacles
        e) Can get close to objects
      2) Mid
        a) Smallest turning radius
        b) More intuitive to drive
        c) May rock slightly on casters
        d) Not very good on rough terrain (i.e. gravel, sand, off road)
        e) May have problems with steep ramps
      3) Rear
        a) Larger turning radius
        b) Tends to have more power over uneven surfaces
        c) Typically have higher speeds
    b. Power wheelchair controllers

        a) Proportional (i.e. joystick, head drive, chin drive) - Directional movements of the controller produce identical directional movements of the wheelchair; Speed increased in proportion to distance the controller is moved
        b) Microswitch (i.e. sip & puff, single switch) - Activating the switch causes the wheelchair to move in a pre-programmed direction at a pre-programmed acceleration and speed; Course correction requires either accessing a second switch or 2 switches together; It is difficult to use and requires training

  H. Reclining and tilt systems
    1. If a person is unable to adequately perform a weight shift and to reposition themselves, they will require some system to prevent skin breakdown and discomfort
    2. Recliners and tilt in space systems are available for manual and power wheelchairs
  I. Seating systems
    1. Considerations
      a. Pressure reducing properties
      b. Maintenance requirement
      c. Ability to accommodate postural deformities
      d. Comfort
      e. Ease of transfers
      f. Balance and stability
      g. Moisture and heat resistance
      h. Cushion weight
      i. Cost, durability, trial and return policy, warrantee
    2. Types of cushions
    3. Types of backs
    4. Custom systems - Used when positioning needs cannot be met by standard available systems (i.e. significant postural asymmetries)

IV. Funding
  A. All funding sources have their own rules and regulations
  B. Medicare is one of the strictest in their regulations and set the bar for many other funding sources
  C. Medicare requirements for mobility equipment
    1. Manual wheelchairs
      a. Has a mobility limitation that significantly impairs mobility related activities of daily living activities:
        1) Prevents ability to accomplish
        2) Cannot accomplish safely
        3) Cannot accomplish in a reasonable time
        4) Limitation not resolved with a cane or walker (Client unable to functionally walk)
    2. Funding sources coverage of power mobility
      a. Has a mobility limitation that significantly impairs mobility related activities of daily living activities:
        1) Prevents ability to accomplish
        2) Cannot accomplish safely
        3) Cannot accomplish in a reasonable time
        4) Limitation not resolved with a cane or walker (Client unable to functionally walk)
        5) Limitation not resolved by an optimally configured manual wheelchair (Client unable to functionally propel a manual wheelchair)
      b. Coverage criteria for POV
        1) Home is accessible to POV
        2) Can safely work the controls of a POV
        3) Client's weight is within limit
        4) Client is willing to use equipment
        5) Can safely get in and out of a POV
        6) Can safely sit in a POV without additional support.

c. Coverage criteria for power wheelchair
    1) Cannot meet coverage criteria for POV
    2) Home accessible to power wheelchair
    3) Has willingness and ability to use
    4) Pt's weight is within limit of the device
    5) Power wheelchair coverage significantly improves mobility related activities of daily living participation
    6) Client's weight is within limit
    7) Client is willing to use equipment

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Benefits and Techniques of Aquatic Therapy

Cynthia Henley, PT, Miami, Florida, and Kathryn Wollam, PT, Coral Springs, Florida

Almost any person regardless of age or physical condition can benefit from exercise and improve their fitness level. Fitness is defined as adapting to the environment so as to be capable of surviving. A state of physical fitness offers enough energy to perform daily duties with energy left at the end of the day to enjoy leisure time. Fitness exercises are designed to improve endurance. This increased stamina is achieved by making the heart and lungs stronger and more efficient. Additionally, exercise can help decrease blood glucose levels, decrease the risk of cardiovascular disease, control weight, improve quality of sleep and develop a sense of well being.

Challenges of Exercise: Exercise can be a challenge for individuals with a history of polio. The appropriate balance between overuse and disuse must be achieved. It is essential to have an exercise program that is tailored to the individual's specific muscle test in order to be safe and effective. Extremities used in strengthening exercise must be able to move through complete range of motion against gravity. It is important to adhere to the following general exercise guidelines for polio survivors and avoid excessive fatigue.

General Exercise Guidelines for Polio Survivors:

- Check with your doctor before beginning any exercise program.
- Do not use muscles with strength of 3/5 or less for conditioning or strengthening exercise. These muscles must work all day to fight gravity in basic activities of daily living. Attempting to strengthen these muscles may cause overuse and increased weakness.

- Start a conditioning program slowly. Often 3-5 minutes of conditioning is all that can be initially tolerated. If needed, start with one-minute intervals with rest periods and SLOWLY build up endurance. Watch for signs of overuse.
- Strengthening exercise can be done with muscles of strength greater than 3/5. In other words, that muscle must be able to move the joint through full range of motion against gravity. However, remember to start with minimal number of repetitions (5-7) within tolerance. Increase resistance and number of repetitions cautiously. Watch for signs of overuse. As a general rule, muscles that have a grade of 3/5 or less should be protected and not exercised. Grade 3+/5 muscles can be exercised with caution; grade 4 –4+/5 can be exercised moderately; and grade 5/5 muscles can be exercised more vigorously.

Aquatic exercise is very beneficial, as the buoyancy of the water will help to support weak muscles and decrease joint stress while it can also provide resistance to strong muscles. Remember to start slowly (15-20 minutes) and avoid the tendency to overdo in the pool, because it is easier to move in the water.

Signs of Overuse: Although you may feel mild fatigue after exercise, you should not experience the signs of overuse. These signs of overuse can occur within 24-48 hours after too strenuous exercise or a very active day. Pacing activities and modification of the exercise routine is necessary if these occur.

- Muscle cramps or spasm
- Muscle twitching
- Muscle pain
- Extreme fatigue

Aquatic therapy was often utilized during the recovery phase from the original polio. Water is the great equalizer. It allows people to move in ways that they cannot move on land. The buoyancy of water greatly enhances the ability to move and provides resistance based on speed of movement in the water. Further, water exercise offers the ability to improve flexibility, strength, muscle tone and aerobic condition. Water can facilitate a workout that can be tailored to each person's strength.

Physical Properties of Aquatic Therapy:

There are physical properties of water that make exercise less difficult and painful, while increasing its effectiveness. These properties are buoyancy, hydrostatic pressure, relative density, fluid resistance and turbulence.

Buoyancy is the upward pressure exerted by a fluid in which a body is immersed. Archimedes' Principle states that when a body at rest is fully or partially immersed in a fluid, it experiences an upward thrust equal to the weight of the fluid displaced. Buoyancy and gravity constantly oppose each other and reach equilibrium when you float partially immersed. The vertical body is typically at equilibrium when immersed to neck level. Buoyancy can provide support or resistance. As an assist, buoyancy is used to decrease gravitational forces placed on weak limbs that are less able to bear weight. There is less strain on the muscles and joints, requiring less effort to move underwater. Buoyancy adds a challenge to stronger muscles and offers resistance when a floatation device is pushed or held submerged underwater.

Pascal's Law defines ***hydrostatic pressure*** as fluid pressure exerted equally on all surface areas of an immersed body at rest at a given depth. Hydrostatic pressure helps return the blood to the heart, causing it to work more efficiently under less pressure. The water surrounding the body helps circulate blood from the legs to the heart, often reducing any swelling in the ankles and feet. Once swelling is reduced, joint tenderness may decrease and range of motion can improve. Additionally, hydrostatic pressure offers mild resistance around the ribcage. Breathing with the trunk immersed in the water is a form of exercise. Although this can help strengthen people with respiratory involvement, it should be approached with caution. Simply being immersed in water has a positive therapeutic effect on our bodies.

Relative density is the relation of the mass of an object to the mass of an equal volume of liquid at standard temperature and pressure. It determines whether or not an object sinks in the water. Simply stated, if an object is denser than water, it will sink. Muscle tissue is denser than fat. People who are lean and muscular will tend to sink; those with more adipose tissue tend to float. Swollen extremities retain fluid and that fluid is lighter than muscle tissue; giving those body parts a lower relative density and tendency to float. Therefore, it takes less effort to raise weak or swollen extremities than it does to lower them in the water. Muscles that are paralyzed or have atrophied due to polio will have lower relative density and will tend to float.

Fluid resistance is the force that opposes the motion of an object through a fluid. Basically you have to push your way through the water and it slows you down. Fluid resistance is beneficial in aquatic therapy as it supports and helps to hold you in position while also offering resistance to movement. The fluid resistance of water makes it a perfect environment to perform balance exercise. On land, resistance is felt in only one direction, which leads to an over development of some muscles and under utilization of others. Fluid resistance also increases sensory awareness and allows time to react and learn how to maintain proper balance in a gentle environment.

Turbulence is the random motion of the water as it responds to a disturbance. A person or limb moving through the water creates changing pressures and turbulence. This swirling effect in the water can provide therapeutic benefits of massage and resistance. The gentle massage can increase circulation and reduce pain. The sensation of water on the skin overloads the peripheral nerves. This causes the brain to ignore other signals, such as pain, that your body is sending. Changing the speed and direction of motion can alter turbulent forces. The use of equipment, such as aquatic gloves or paddles, is another way to increase turbulence.

Benefits of Aquatic Therapy:

In addition to the benefits of general exercise, aquatic exercise offers unique physical and physiological benefits. The buoyancy of water decreases the weight and stress on the joints, encouraging freedom of movement. Movement and functional activity are more comfortable in water because the pull of gravity on the body is not as strong as on land. Water supports the body, reduces joint stress, and provides resistance and assistance to movement, allowing improved mobility, strength, and function.

Water provides a number of unique properties making it an excellent environment for rehabilitation.

Benefits:

- Increased cardiovascular function - resistance of the water aids in controlled conditioning.
- Reduced stress on joints - buoyancy reduces the stressful effects of gravity on the body.
- Improved muscle strength and tone - resistance of the water aids in gentle muscle strengthening.
- Increased range of motion and flexibility - the support of the water allows effective stretching.
- Increased balance and coordination - balance can be challenged in a safe environment.
- Pain modulation - turbulence and the support of the water decrease pain.
- Decreased edema - the hydrostatic pressure of water decreases swelling.
- Improved posture and trunk stability.
- Promotes relaxation.
- Improved metabolism and calorie burn for weight control.
- Increased circulation - hydrostatic pressure increases venous blood return to the heart.
- Respiratory benefit - hydrostatic pressure offers resistance around ribcage during respiration.
- Improved kidney function - increases blood flow to kidneys, renal clearance and diuretic effect.

Precautions:

- Medical clearance is required prior to initiating any exercise program.
- Cardiac precautions should be taken into account.
- Pool temperature can affect exercise tolerance. The temperature of the water is a personal preference. Recommended temperatures range from 85-94 degrees. Cool water is often not well tolerated and will tap your energy quickly. Warm water temperature helps relax the muscles, however be cautious with excessively warm pools to avoid becoming overheated.
- The exercise guidelines specific to post polio hold true for aquatic exercise.
- Medications that cause drowsiness should be avoided.
- Aquatic exercise is contraindicated with skin infections, rashes, open wounds, sores, stitches or contagious diseases.
- Allergies or reactions to pool chemicals should be considered.
- Avoid aquatic exercise during illness. (fever or cold).
- Urinary tract infection or incontinence (lack of bowel or bladder control) prohibits aquatics.
- Get out of pool immediately with any signs of distress, shortness of breath, or dizziness.
- Supervision during aquatic exercise is a must. Never go in alone. Keep a cell phone nearby.
- Safe access to the pool (parking, lifts, rails, ramps, wheelchair accessibility).
- Surfaces around pools tend to be slippery and dangerous for anyone with a tendency to fall.
- Sun exposure, climate changes and lightning are considerations (indoor vs. outdoor pool).
- Don’t overdo, aquatic exercise can be deceptive. Fifteen minutes is enough initially.

It may take some time for you to determine the correct amount of exercise for your individual needs. Schedule a specific time to exercise. Try different times to see what works best. Do not exercise when tired. Pace your activities on busy days. Don’t exercise right before bed; it can stimulate and interfere with sleep. Breathe normally during exercise: count out loud; exhale with effort. Complete the exercise with correct form and proper posture to prevent injury. Better to do fewer repetitions with good technique and control, than to exercise with sloppy form. It is important to replenish fluids.

Aquatic Therapy Techniques:

Techniques of aquatic therapy will be discussed and demonstrated in the actual session. A booklet of aquatic exercise (“Ready, Wet, Go” by K.Wollam, PT and C. Henley, PT) will be given to participants in attendance at the session. Their philosophy of aquatic exercise for polio survivors, which includes the need for a formal assessment and manual muscle test (MMT) to appropriately plan an individualized program, will be emphasized. The volunteer participants have been evaluated by the presenting physical therapists prior to the aquatic therapy demonstration. These therapists use the water to work towards an individual’s goals as listed in the benefits of aquatic exercise based on the evaluation.

Additional aquatic therapy techniques may prove beneficial to polio survivors depending on the evaluation, MMT, assessment and goals. These techniques, however, will not be discussed in depth and are beyond the scope of this presentation. Techniques such as Ai Chi (deep breathing with concepts of TaiChi, Shiatsu and Qigong in shoulder depth water), Feldenkrais (gentle movement and directed attention to improve movement and enhance human function), Lyu Ki Dou (“ Floating Life Energy Pathways”) and Pool Massage focus on the relaxation benefits of aquatic therapy. BackHab (an aquatic walking program), Proprioceptive Neuromuscular Facilitation (therapeutic exercise that includes three components of motion) and Water Pilates (core strength and spinal alignment) emphasize active exercise and resistive properties of water. Other techniques in the literature include Ai Chi Ne, Bad Ragaz, UCT, Watsu, Water Yoga, Wassertanzen and Yogalates. Additionally, the Burdenko Method and Halliwick Concept include methods of swim training for people with disabilities.

Types of Exercise:

Warm up exercises gently increase the heart rate and respiratory rate. They also prepare the body for exercise by gently loosening the major muscle groups and joints. An adequate warm up can decrease the risk of injury.

Stretching and range of motion exercise help lubricate the joints and prepare the nervous system. Stretching is an important part of any fitness program. Shortened muscles can lead to muscle imbalance. For example, spending a lot of time in a seated position can cause tightness in the legs making it difficult to stand straight. Weak shoulders and tight chest muscles can cause forward flexed posture yielding neck pain or making it difficult to breathe. Aquatic stretching can assist in proper positioning for stretching. Hold stretch position ~15-20 seconds and don't bounce into the stretch.

Resistance exercise helps increase muscle strength. Resistance can be achieved during aquatic exercise by increasing the speed that the limb moves through the water or by adding equipment. This causes increased turbulence and greater resistance. Slowly progress the exercise program by gradually increasing speed and repetitions over time.

Aerobic exercise challenges the cardiovascular system. Aquatic exercises can be performed in deep water (using a floatation belt or Styrofoam noodle for support) including bicycle or jogging movements to increase heart rate. Upper extremity exercises can be performed in the shallow water to increase heart rate as well. Over time, this type of exercise improves endurance and stamina helping to offset fatigue.

Cool down is much like the warm up phase and returns the body to the resting state. The cool down helps prevent post-exercise soreness and reduces the risk of injury.

Progressing Your Program:

Once an appropriate level of exercise is established, fitness is maintained with a consistent program. To advance the program, it is important to progress cautiously and remember the signs of overuse. Some ideas to progress the program are listed. Choose only one variation at a time to advance the program.

- Add repetitions to the current exercise routine, beginning with 1-2 per week.
- Add new exercises to the routine, no more than 1 new exercise per week.
- Work in more shallow water for balance and gait activities to decrease buoyancy. Shallow water is more challenging to balance and trunk control.
- Increase the speed of exercise under water to increase the resistance. Deeper water provides more support at slow speeds and more resistance at fast speeds.
- Exaggerate arm swing, step height or step length during gait activities.
- Increase the time of conditioning exercise (i.e. pool walking, arm cycling or bicycling) 2-3 minutes per week. When swimming laps, find a comfortable stroke, use your strong extremities and swim the width of the pool. Progress to swim the length of the pool, add laps to tolerance.
- Add equipment to increase the resistance in the water.

Equipment:

Equipment can be utilized to provide flotation or resistance, assist or challenge balance or offer protection from the elements. Aquatic equipment can purchased online or at pool, sports and toy stores.

- Flotation devices provide flotation while allowing freedom of movement of limbs:
    - noodles, kickboards, water belt, arm rings, flotation vest, flotation ring
- Balance can be assisted or challenged in the water:
    - water walker, noodles
- Resistance can be increased by the addition of simple equipment:
    - aquatic gloves, foam dumbbells, hand paddles, fins, kickboard
- Protect your body from the elements:
    - wetsuit for cold intolerance
    - solar protection clothing, hat/visors and sunscreen in outdoor pools
    - water shoes protect skin from abrasion, particularly important for diabetics

Enjoy the relaxing and invigorating qualities of aquatic exercise. Keep it fun. Vary the exercises to prevent boredom or exercise with a partner. Approach the exercise program with patience and consistency to reap the benefits of an improved condition with less fatigue, better endurance and functional gains. Avoid excuses and do something special for yourself!!!

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SESSION F3

Current Epidemics: Status, Lessons and Tasks

John Fitzsimmons, Centers for Disease Control and Prevention, Atlanta, Georgia

Ann Lee Hussey, Chair, Polio Survivors and Associates Rotary Action Group,
South Berwick, Maine

Using Assistive Technology for Personal Independence

Samantha Massengale, OTR, RWSIR, Warm Springs, Georgia

A. ASSISTIVE TECHNOLOGY RESOURCE GUIDE

1. Catalogue Company

a) Physical Challenges

- **Sammons Preston. www.sammonspreston.com**
  Voice: 1800 323 5547
- *Parsons* A.D.L Website*: www. parsonsadl.com*

  Voice: 1800 263 1281
- Portable rolling shower: http://www.shower-anywhere.com/Roll-in-Shower-Stall.aspx
- Step in tub: http://walkintubdepot.com/index.php?cPath=2
- Incline platform wheelchair lifts:

http://www.universalaccessibility.com/products/AmeriGlideaipl.html.
(800) 470-893

- Electric leg bag emptier. http://www.rdequipment.com/. Phone/Fax: 508-362-7498

b) Low vision

- LS&S: products for the visually impaired and hard of hearing**;**

www.LSSPRODUCTS.com

- Voice: 1800 468 4789
- MaxiAides: www.maxiaides.com
- Voice: 1-800-522-6294
  TTY: 1-800-281-3555

c) Hearing Devices

- Beyond Hearing Aides: www.beyondhearingaides.com
- Voice\TTY**: 8**00-838-1649
- Sound Bytes: *www.soundbytes.com.*
- Toll Free: (888) 816-8191 | TTY: (516) 937-3546
- Harris Communications: www. harriscomm.com.
  Voice (800) 825-6758
  TTY :(800) 825-9187

d) *Computer and Ergonomic Related Technology*

- Options of Info Grip: computer access technology only
- Enable Mart: computer and telephone tech
- Website: EnableMart.com Tel # 1888 640 1999
- Goldtouch www.goldtouch.com
- Contour designs www.goldtouch.com
- Ergonomic concepts www.ergoconcepts.com

- Kinesis Computer Ergonomics www.kinesis-ergo.com
- Work rite ergonomic www.wrea.com
- Dragon Naturally Speaking. Voice activated computer access www.nuance.com, office Depot

e) Home Automation Devices:
www.smarthome.com
www.exponenta.com

2. Vehicle Modification

- National mobility Dealers Association www.nmeda.org
- National Highway Traffic Safety Administration www.nhtsa.dot.gov

3. Websites:

- Abledata.com, (listing for all types of AT product information and vendor information)
- Techable.org (gives you products available, vendor info)
- iltech.org/catalogue.htm (list of catalogue companies and telephone number)
- www.headsets.com

4. Local Durable Medical Stores: sell durable medical equipment like tub benches, shoe horns etc.

5. Technology Shows: Exposure the latest technology

- Touch the Future
- Medtrade

6. Rehabilitation and independent Living Centers: provide assistive technology products and services.

7. Stores: Home Depot, Office supplies stores, Sears and Wal-Mart**:** sells bathroom equipment, ergonomic office equipment, automation devices.

8. Charity Organization

- Friends of Disabled Adults: free new or refurbished adapted devices, wheelchairs, ambulation, and bathroom equipment. Ramps and home modification
  4900 Lewis Road, Stone Mountain, GA 30083
  (770) 491-9014.
- Reboot computer program: free or discounted rates on refurbished computers.
  Tel # 770-934-8432

9. Non- profit Organizations

- Tools for Life, www.gatfl.org. It is GA technology program: Has 4 Assistive Technology centers in the state of GA.

The Tools for Life Assistive Technology Resource Centers (ATRCs) are "hands-on" learning centers for demonstration, education and evaluation of products available on the market today. They are also a resource for Georgians with disabilities, families, friends, health care professionals and other professionals who are interested in seeing, learning and experimenting with new and existing assistive technology devices and equipment. ATRCS). AT services include: evaluation, demonstrations, training, loan library, acquisition.

- Job accommodation network: **http://janweb.icdi.wvu.edu/.** Tel# 800-526-7234
- State independent Living Centers in your state. Provide Assistive technology services

B. FUNDING SOURCES FOR ASSISTIVE TECHNOLOGY

Refer to the Tools for Life website for comprehensive list. www.gatfl.org

Home Modification:

- Friends of Disabled Adults and Children (FODAC): Ramps and home modification for people in Metro Atlanta area. Ramps for Champs
- FODAC: 4900 Lewis Road, Stone Mountain, GA 30083
(770) 491-9014.
- Brain Injury and Spinal Cord Trust Fund: Awards up $15000. Tel # 1888 233 5760
- State Alternative Financing Programs. A low interest credit union loan. Including rental home Modification. See Attached Handout.
- State Independent Living Centers.
- GA Department of Community Affairs: Disability Housing Coordinator. Office of Special Housing Initiatives. Contact information: 404 327 6864
- Social Security: Plan to Achieve Self Support(PASS), Impaired Related Work Expense((IRWEP)
- First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more. http://www.cerner.com/firsthand/default.aspx

Computer Related

- GA Reboot computer program: free or discounted rates on refurbished computers.
Tel # 770-934-8432
- GiveTech.org: Gives away computer input devices that allow individuals with quadriplegia to use computers. www.givetech.org
- Travis Roy Foundation: Grants for specific modifications or AT awarded to paraplegic and quadriplegics due to *injury*. Grants typically range from $4,000- $7,000 http://www.travisroyfoundation.org/pages/grants.html
- First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more http://www.cerner.com/firsthand/default.aspx
- State Alternative Financing programs. A low interest credit union loan. See Attached Handout

- Brain Injury and Spinal Cord Trust Fund: Awards up $15000. Tel # 1888 233 5760

Vehicle Modification

- Vocational rehabilitation
- Social Security (Work related technology): PASS, IRWEP programs
- Brain Injury and Spinal Cord Trust Fund: Awards up $15000. Tel # 1888 233 5760
- State Alternative Financing programs. A low interest credit union loan. See Attached Handout
- Joni and Friends, Christian Fund for the Disabled: Funds for AT, rehabilitation, special treatment, educational opportunities. CFD up to $2,500 http://www.joniandfriends.org/outreach/fund.shtml

Personal Care Devices

- FODAC. Contact information; 770- 491-9014
- State Independent living centers
- Joni and Friends, Christian Fund for the Disabled: Funds for AT, rehabilitation, special treatment, educational opportunities. CFD up to $2,500 http://www.joniandfriends.org/outreach/fund.shtml
- First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more http://www.cerner.com/firsthand/default.aspx

Low vision

- The Association of Blind Citizens: ATF will provide funds to cover 50% of the retail price of adaptive devices or software. Deadlines: June 30th and Dec 31st http://www.blindcitizens.org/assistive_tech.htm
- Joni and Friends, Christian Fund for the Disabled: Funds for AT, rehabilitation, special treatment, educational opportunities. CFD up to $2,500 http://www.joniandfriends.org/outreach/fund.shtml
- First Hand Foundation: Grants for Children 18 yrs and younger (sometimes up to age 21) for DME, AT, vehicle modifications and more. **http://www.cerner.com/firsthand/default.aspx**
- State Alternative Financing programs. A low interest credit union loan. See Attached Handout
- Brain Injury and Spinal Cord Trust Fund: Awards up $15000. Tel # 1888 233 5760
- Newline: Newsline®, a nationwide newspaper service for the blind, will utilize telephone lines and digitized voice synthesizer systems to provide blind and severely visually impaired people daily access to a variety of newspapers. National Federation of the Blind at 410-659-9314.
- Georgia’s Project Independence for the Older Blind or Visually Impaired: 55 and older. Provides services throughout the state of GA to senior adults experiencing vision loss. Rehabilitation specialists provide instruction in your home environment and in group settings. Peer support groups are available to discuss mutual problems and concerns of vision loss in a supportive setting. A low vision evaluation in designated clinics around Georgia will provide assessment and training to help you remain independent in your own home. Other services may include orientation and mobility training, as well as daily living skills training. Services are

available to eligible seniors regardless of income for little or no cost. (770) 432-7280 or (800) 726-7406.

Hearing Devices

States with **telecommunication distribution** programs:

Telecommunications Equipment Distribution provides a variety of free specialized telecommunications equipment to qualified applicants who have difficulty using a standard phone. For those who qualify, staff also offers assistance selecting telecommunications equipment and training on how to use it properly.

* States in Blue have a website

- Arkansas :: 501 686-9693 V/TTY
- Connecticut :: Text Telephone Loan Program 860-242-4974 (V/TTY)
- Georgia : 404-292-5312 voice/TTY, 800-541-0710 voice/TTY, 404- 299-3642 FAX
- Hawaii :: TRS 808-546-4611 (V)
- Indiana :: TTY Program 317-469-0803 (V/TTY) Telecommunications
- Relay Service 808-546-4611 (V)
- Kansas :: (785) 234-0200 (Voice) (785) 234-0207 (TTY)
- Mississippi :: Project S.T.A.R.T. 601-987-4872 (V/TTY)
- Nebraska :: 402-471-0225 (V) 402-471-0213 (TTY)
- North Carolina :: 919-773-2994 (TTY) 800-999-5737 (V/TTY)
- North Dakota :: 701-328-8950 (V) 701-328-8968 (TTY)
- Ohio :: No Distribution Program
- Oklahoma :: 1-800-833-8973 VTTY 405-522-7930 VTTY
- Rhode Island :: 401-276-0875 (voice/relay) 401-861-6677 (TDD)
- South Dakota :: 605-773-4547 (TTY) 605-773-3195 (V)

Other

- Kate Kimberly Foundation: Grants for individuals with SCI for the purchase of adaptive sports, recreation and exercise equipment
- Grants typically range from $1,000 to $4,000 http://katekimberlyfoundation.org/
- Modest Needs: Grant for individuals who need just a bit of assistance with monthly bills and other things. www.modestneeds.com

Exercise: The Kinds, the Methods and the Benefits

Merete Bertelsen, Physical therapist
Rehabilitation Center at The Danish Society of Polio- and Accident Victims
Fjeldhammervej 8, 2610 Rodøvre
Denmark

Presentation
I work at a Rehabilitation Center for polio and accident victims in Copenhagen, Denmark.
The Rehabilitation Center is owned and run by the patient organization called The Danish Society of Polio- and Accident Victims. The Society employs all staff members, but the counties pay for the treatment, so all assessment and treatment is free of charge for the patient.

I am going to tell you about a study we did from 2002 to 2005, comprising 50 polio survivors who were referred to us for the first time. Dr. Maynard has now told you a lot about how to exercise, and we work according to the same principles in Denmark, so the results of this study will give you an impression of the benefits of exercising. But bear in mind that the intervention in this study was not only exercising. It was a multidisciplinary intervention with social and psychological counseling, technical aids etc.
The study was published in the Journal of Rehabilitation Medicine, January 2009.

The 2 aims of the study were:
To describe the problems of patients with late effects of polio who where referred to the clinic for the first time

To describe the intervention and the results of the treatment after 3 months and at one year follow up

We tested the patients 3 times. First time was before they started any treatment, the second time was 3 months after the start of treatment and the third time was 15 months after start of treatment.

Tests
There were 3 kinds of questionnaires.
The Short Form 36 (SF-36) is a questionnaire which measures 8 different dimensions of quality of life. We also used the Multidimensional Fatigue Inventory-20 questionnaire, which measures 5 different dimensions of fatigue. We developed a third questionnaire with questions about polio related issues and how big an impact the polio problems had on their daily activities.
Functional capacity was tested in functional tests. The 6 minute Walk test which measures how far you can walk in 6 minutes, when you walk as fast as possible, The Timed Stands Test which measures how fast you can get in and out of a chair 10 times without using your arms. The Functional Reach Test, where the polio survivor has to reach as far forward as he can without moving his feet. At last we made the polio survivors climb the staircase at the center, and we measured timed used to reach the top and return.

The physiotherapists were asked to register which kinds of treatment they gave to each participating patient.

Population
The study population consisted of 30 women and 20 men; the mean age was 58; 10 of the persons came from other countries; 23 were still working and 27 were retired; They contracted polio between 1930-1985, 20 of them in 1952/53 in the big epidemic; Their average BMI was 28 (20-60). The borderline of being over weight is 25 in Denmark.
18 persons – normal weight,
20 persons – overweight,
11 persons – obese.

Polio related problems in the study group
The major problems of the patients were not surprisingly: Outdoor walking, climbing stairs, fatigue; pain, anxiety for the future and acceptance of the new situation.

The 6 min Walk Test showed that the polio survivors in this study walked significantly slower than the reference values of the Danish population.

The Timed Stands Test showed that the polio survivors in this study used almost twice the time for performing the test than the reference values.

Approximately half of the polio survivors had problems with their balance and 7 had risk of falling.

Intervention
The treatment was based on each person's individual needs and expectations. Not two patients received the same treatment, because polio survivors are all unique with different problems.

The most frequently used treatments in the individual physiotherapy in this study was:

Individual exercise	37 patients
Massage	36 patients
Stretching	33 patients
Home exercise:	33 patients
Exercising in fitness center:	43 patients
Fitness class:	2 patients
Warm water exercising:	17 patients
Polio education:	35 patients

35 polio survivors joined the polio education program where polio survivors and their relatives are educated in polio issues, principles of exercising, technical aids – what kind of technical aids that are available for their needs, social matters and psychological reactions to the need of changing lifestyle as polio problems arise. But the greatest thing about this "polio education" is that the polio survivors get to meet other polio survivors and to get the opportunity to exchange experiences with each other.

In this study the patients received 15 physiotherapy treatments in average. There is a wide span from 3 to 41 treatments, because some patients only needed some advice and others needed many treatments. They had more severe problems that took longer time to deal with. In average they were treated for 14 weeks, and of course there was a wide span here too.
Many of the patients continued exercising after the individual treatment was ended. Even after one year 22 of the 50 patients were still exercising in the fitness center and 22 of them were exercising somewhere outside PTU. It seems that exercising did them good, since so many continued to exercise.

The intervention at our center is multidisciplinary and below is showed how many of the 50 polio survivors who consulted the other professionals.

	Number of polio survivors
Social worker	15
Psychologist	3
Technical aids therapist	20
Doctor – in addition to the first consultation	12
Dietician	8
Orthotist	25

The results of our intervention at the clinic
The quality of life questionnaire SF-36 shows a significant improvement in the dimensions Bodily Pain, General Health and Vitality. In General Health the improvement stays even at the one-year follow up.

The Fatigue questionnaire showed a significant improvement in the dimension called Physical fatigue. None of the improvements remained at the one-year follow up.

The 6 minute Walk Test showed a significant improvement in walking distance and it remained at the one-year follow-up. 12 of the 50 patients received some kind of walking aid i.e. a brace or a cane. Of course this also improves the ability to walk faster.

The Timed Stands Test showed a significant improvement in the time used for performing the test and the improvement remained at the one-year follow up.

The Climbing Stairs Test showed a significant improvement at the 3 months test, but it didn’t maintain at one-year follow-up.

In our polio related questionnaire we asked the patients to consider how their total situation was at the 3 months test and the one-year follow up. 35 polio survivors felt better or a lot better all things considered after 3 months treatment and 27 polio survivors at one-year follow up.

The conclusions of our study are listed here:
The patients with late effects of polio had a lower level of functioning, experienced more fatigue and had more pain compared to values for the Danish population
The patients can benefit from an individually planned multidisciplinary intervention with emphasis on physiotherapy
The patients experience less pain or copes better with the pain after intervention
The improvement remains at one year follow up

Another way of showing the results is to show them in percent:

6-min. Walk test	10,6% improvement
Timed Stands Test	12,9% improvement
“Vitality” from SF-36	7% improvement
”Bodily Pain” from SF-36	20% improvement
“Physical fatigue” MFI-20	10% improvement

These improvements were all statistically significant

The results of this study are based on several different treatments but the main intervention was exercising, so I will dare to say that exercising is a major reason for the improvements experienced by these polio survivors.

The study was performed with my two colleagues Susse Broberg and Ellen Madsen and was published in Journal of Rehabilitation Medicine 2009¸41: 85-87
The benefits of exercising are multiple:
- Improvement/maintaining strength level or diminishing the polio related loss of strength
- Improvement of functional capacity and balance
- Weight control
- Reduces hypertension, risk of heart disease, risk of diabetes, depression
- Improved sense of well being

Other studies on exercising:
I will supplement my own study by telling you shortly about a few other studies made on exercising in polio survivors.

Strength, endurance, and work capacity after muscle strengthening exercise in postpolio subjects. Agre et al Arch Phys Med Rehabil 78: 681 1997
•Mondays and Thursdays subjects performed three sets of four maximal isometric contractions of the quadriceps held for 5 seconds each. On Tuesdays and Fridays subjects performed three sets of 12 dynamic knee extension exercises with ankle weights
•Conclusion: This home exercise program significantly increased strength, endurance, and isometric tension time without apparently adversely affecting the motor units or the muscle, as the EMG and CK variables did not change.

Effects of resistance training in combination with coenzyme Q10 supplementation in patients with post-polio. Skough, K et al. J Rehabil Med 2008, oct; 40 (09) 773
•A total of 14 patients with post-polio syndrome participated in a 12-week muscular resistance training, 3 days/week 2 groups : Q10 and placebo
•Results:There was no significant difference between the coenzyme Q10 and placebo groups regarding muscle strength, muscle endurance and quality of life.
•Muscle strength, muscle endurance and quality of life regarding mental health increased statistically significantly in all 14 patients.

Low- intensity alternate-day exercise improves muscle performance without apparent adverse affect in polio patients, Agre et el. Am J Phys Med Rehabil 75; 50, 1996
•12 patients performed six to ten repetitions of a 5-s duration knee extension exercise with ankle weights – increasing weights according to their strength gain during a period of 12 weeks.
•Conclusion: Performance was significantly improved, as demonstrated by an increase in the amount of weight the patients lifted in the exercise program from 7 to 11 kg in average
No evidence was found to show that this program adversely affected the motor units or the muscle as the EMG and CK did not change.

Short term effects of aerobic exercise on functional capacity, fatigue, and quality of life in patients with post-polio syndrome. Oncu et.al. Clin Rehabil 2009 feb; 23
•Thirty-two patients were divided into two groups for either hospital- or home-based aerobic exercise programme
•Conclusion: Fatigue and quality of life were both improved in the home and hospital exercise groups. An increase was also found in the functional capacity in the hospital exercise group. A regular exercise programme is beneficial to patients with post-polio syndrome.

Cardiorespiratory responses to arobic exercise training in humans with postpoliomyelitis sequelae Jones et al. JAMA 1989
•Cardiorespiratory responses of 16 patients to a 16-week aerobic exercise program at 70% of maximal heart rate
•Exercising on cycle ergometer in average 20 minutes 2-3 times a week
•Conclusion: The aerobic training program employed in this study is a safe, short-term procedure and that patients with postpolio sequelae respond to training in a manner similar to healthy adults.
You can find abstracts and in some cases the full text on the internet.

I hope this has given you some inspiration to either make exercise programs to your polio patients if you are a professional, or if you are a polio survivor, I hope you will give it a try and see for yourself that exercising in most cases do something good for you.

Exercise: The Kinds, the Methods and the Benefits

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Role of Exercise in Post-Polio Health and Wellness

What is Holistic Health & Wellness?

Critical Components of a Healthy Body
- Nutrition
- Exercise/Activity
- Rest/Sleep

Controversies about Exercise for Post-Polios
- Is it GOOD or BAD?
- Type & intensity of exercise
- Methods of exercise
- Which muscles?
- What if you have PPS?

Definitions
- Exercise – planned, structured, repetitive bodily movement.
- Physical Activity – movement occurring during daily activities.
- Therapeutic Exercise – done for a specific health purpose.

"Common Sense" FACTS
- Inactivity rapidly leads to weakness and deconditioning.
- Over-exertion can lead to injury, pain and overuse weakness.

So, is exercise Good or Bad?
- Devil in the detail
- Is apple pie good or bad?
- Anecdotes abound.
  "Sustaining controversy as a means of discrediting findings that cause economic or social discomfort is one of the greatest sins of science." – T. Colin Campbell

Type and Intensity of Exercise
- Flexibility exercises
- Strengthening exercises
- Conditioning/endurance exercises

Flexibility Exercises
- Maintain optimal lengths of muscles.
- Take muscle to point of tightness and hold.
- Important for pain management.
- Avoid over stretch of elongated/weak muscles.
- Maintain full ROM of joints.

Strengthening Exercises

- Isotonic
- Isometric
- Isokinetic

Key Principles of Strengthening Exercise

- Use “low” reps: 5-8 to start
- Use “high” resistance: 60% of 3 rep max
- Advance slowly: 2 reps every 3-4 days
- Dr. J. Perry’s Rule: If pain or fatigue occur, reduce by ½.

Normal Fatigue Thresholds

- 16% max – continuous use possible
- 37% max – 50/50 rest/activity balance
- 70% max – 90/10 rest/activity balance

Which muscles to target?

- Those with therapeutic goal
- 5 Point Classification System (Halstead)
    1. No clinical polio (no sxs, Nl EMG)
    2. Sub-clinical polio (no sxs, benign EMG)
    3. Clinically stable (no sxs, EMG+, chronic weakness)
    4. Clinically unstable (new weakness, EMG+)
    5. Severely atrophic polio

Methods of Exercise – Strengthening

- Free weights
- Theraband
- Machines
- Body weight
- Targeted movement

Conditioning Exercise Principles

- For ↑ endurance of specific muscles, use “high” reps, “low” resistance
- For whole body endurance, aim for Target Health Rate
- Lower the % target heart rate, longer the exercise bout
- Interval training key for post-polios
- If any heart disease, monitoring needed to begin

Methods of Exercise – Endurance

- Walk/Treadmill
- Stationary Bike/Rowing Machine
- Elliptical
- Aerodyne Bike
- Arm Ergometer
- Free Weights/Body Weight
- 3-4-training bouts weekly to reach goals
- 2-3 training bouts weekly to maintain

Exercise and PPS

- No universal definition of PPS
- Diagnosis of Exclusion
- Exercise approach same but more careful and limited (begin 30% max)
- Activity/Exercise habits before new weakness noted must be honestly described
- Stress, General Health and Lifestyle are critical issues

Factors Leading to Perception of Loss of Strength

- Unawareness of strength loss from acute polio
- Aging process
- Weight gain
- Poor nutritional habits
- Underactivity; deconditioning
- Overactivity; over use
- Poor pacing skills

PHI's Task Force Recommendation on Exercise

- Individualized Exercise Program (IEP) can enhance health and functional activity tolerance of polio survivors
- Professionals with knowledge of PPS & exercise should design and supervise IEPs.
- Two-month minimum needed before transition to self-directed program.
- Follow general principles of low/moderate intensity, slow progression and pacing.
- Consider rotation of exercise type:
    - Less frequent bouts
    - Longer duration of time (weeks/months) to achieve goals

Pain and Exercise

- Muscle Pain vs. Joint Pain
- Muscle pain occurring with daily activity may require some modestly painful strengthening exercise to resolve.
- Vicious cycle of: Pain ← Disuse
  ↓ ↖
  Weakness
- Fear avoidant attitude toward pain & activity is major problem in US population.

Acute and Chronic Stress & Strain Syndrome

- Muscle
- Tendon
- Myofarcial
- Joint
- Ligament

Nothing Ventured/Nothing Gained

- Honest & timely communication with professionals involved with training
- Use of Adaptive Equipment
- --Start exploring uses before you have to
- --May solve one problem but create others
- --Goals are essential

Exercise Studies – Conclusions

- Some muscles can improve strength and/or endurance.
- Some post-polios can improve fitness.
- Interval training and pacing are essential to success.
- Goals for exercise should be clear.

Cardiovascular Complications and Prevention Tips

Sunita Dodani, MD, MSc, PhD, FAHA, Director, Center for Outcome Research and Education (CORE), Associate Professor, Department of Internal Medicine, Kansas University Medical Center, Kansas City, Kansas

Communicating with Your Physician: Techniques that Work

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

William Stothers, The Center for an Accessible Society, San Diego, California

The single most important way you can stay healthy is to be an active member of your own health care team. One way to get high-quality health care is to find and use information and take an active role in all of the decisions made about your care.

Research has shown that patients who have good relationships with their doctors tend to be more satisfied with their care—and to have better results. Here are some tips to help you and your doctor become partners in improving your health care.

Give information. Don't wait to be asked!

You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know.

It is important to tell your doctor personal information—even if it makes you feel embarrassed or uncomfortable.

Bring a "health history" list with you, and keep it up to date. You might want to make a copy of the form for each member of your family.

Always bring any medicines you are taking, or a list of those medicines (include when and how often you take them) and what strength. Talk about any allergies or reactions you have had to your medicines.

Tell your doctor about any herbal products you use or alternative medicines or treatments you receive.

Bring other medical information, such as x-ray films, test results, and medical records.

Get information.

Ask questions. If you don't, your doctor may think you understand everything that was said.

Write down your questions before your visit. List the most important ones first to make sure they get asked and answered.

You might want to bring someone along to help you ask questions. This person can also help you understand and/or remember the answers.

Ask your doctor to draw pictures if that might help to explain something.

Take notes.

Some doctors do not mind if you bring a tape recorder to help you remember things. But always ask first.

Let your doctor know if you need more time. If there is not time that day, perhaps you can speak to a nurse or physician assistant on staff. Or, ask if you can call later to speak with someone.

Ask if your doctor has washed his or her hands before starting to examine you. Research shows that handwashing can prevent the spread of infections. If you're uncomfortable asking this question directly, you might ask, "I've noticed that some doctors and nurses wash their hands or wear gloves before touching people. Why is that?"

Take information home.

Ask for written instructions.

Your doctor also may have brochures and audio tapes and videotapes that can help you. If not, ask how you can get such materials.

Once you leave the doctor's office, follow up.

If you have questions, call.

If your symptoms get worse, or if you have problems with your medicine, call.

If you had tests and do not hear from your doctor, call for your test results.

If your doctor said you need to have certain tests, make appointments at the lab or other offices to get them done.

If your doctor said you should see a specialist, make an appointment.

Remember, quality matters, especially when it comes to your health. For more on health care quality and materials to help you make health care decisions, visit http://www.ahrq.gov/consumer/pathqpack.htm

SESSION F4

Finding Causes of and Managing Fatigue, Part 2

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Summary

Fatigue is the most frequently mentioned complaint of people with post-polio syndrome (PPS). And fatigue is often severe. However fatigue is not very specific and a prominent complaint in many neuromuscular disorders, in many chronic diseases such as multiple sclerosis, in oncology and even on itself in chronic fatigue syndrome. How to understand fatigue in PPS and how to deal with it is the aim of the two fatigue sessions.

In Session I the focus will be on the magnitude of the problem of fatigue in PPS, the different forms of fatigue and the factors playing a role in fatigue in PPS. In Session II the focus will be on the assessment and treatment of fatigue in clinical practice and what people with PPS can do to reduce fatigue.

Contents

<u>Session I</u> on Friday 11.15 - 12.30 AM covers the following topics:
- the problem of fatigue in PPS; prevalence and severity
- types and definitions of fatigue in PPS
- the mechanisms and factors contributing to fatigue in PPS

<u>Session II</u> on Friday 2.45 - 4.00 PM covers the following topics:
- how to assess fatigue in PPS
- how to treat fatigue in PPS
- energy conservation techniques

Causes of fatigue

Fatigue is mentioned by up to 80% of people with post-polio syndrome and the scores on fatigue questionnaires are often high, indicating severe fatigue. But, what is fatigue? Fatigue can be defined as 'a persistent, subjective sense of tiredness that interferes with usual functioning'. This refers to the <u>general</u> feeling of fatigue, however <u>local</u> muscle fatigue is also often present and is among the symptoms to define post-polio syndrome: 'new muscle weakness or abnormal muscle fatigability'.
In post-polio syndrome fatigue is most frequently related to physical factors.

Local muscle fatigue

Local muscle fatigue is the decline in the ability of the muscle to generate force. Several factors have been identified that may play a role in this:

I - Failure to drive muscles from the central nervous system due to alterations in the central nervous system to activate the nerve cells due to polio - the precise mechanism is not understood;
II - Transmission failure from the nerves to the muscle fibers due to the fact that nerve connections with muscle fibers that were formed in the recovery phase after the acute polio are of less quality and therefore less able to sustain the transfer of the signal from the nerve to the muscle;
III - Decreasing capacity of the muscles due to post-polio syndrome to meet the physical requirements needed to execute daily life activities. The muscles that slowly decline in strength have to work at an increasing level of their maximal capacity and this will be inversely related to the duration physical activities can be maintained.
IV - A decrease in endurance properties of muscles. Muscles that are chronically used at a certain load, especially leg muscles, change their properties towards endurance, however not fully. Shortages of relevant enzymes have been reported.
V - Especially less and not affected muscles may be chronically under loaded in daily life and suffer from disuse. As a consequence they are less loadable.

General fatigue
General fatigue, the feeling of being tired, may have several causes.
I - People with post-polio syndrome may feel fatigued due to the fact that they are constantly acting above or in the upper range of their physical capacities. This may result in a chronic state of exhaustion. It is important to realize that movement efficiency is often reduced. This implies that walking may cost twice (or even more) the energy of normal walking in case of two affected legs.
II - Brain alterations due to polio virus damage have been suggested as a possible cause of general fatigue.
III - Recent studies have demonstrated signs of chronic inflammation in the cerebrospinal fluid in PPS. This may also play a role in fatigue.
IV - Deconditioning of the cardio respiratory system. Persons with post-polio syndrome have been found to be deconditioned, or to have a condition comparable to a sedentary life style.
V - Psychological factors, such as ‘giving up the fight’, social factors related to the persons life situation, and sleep problems may all contribute to fatigue. However, these are not the main causes of fatigue in post-polio syndrome.

Other causes of fatigue
It is very important to rule out other causes of fatigue. Of course the list of potential causes is very long, but a few common causes such as anemia, hypothyroidism, depression need to be mentioned.

Factors associated with fatigue in PPS
In a recent study, so far unpublished data, several of the above mentioned factors were found to be associated with fatigue. Lower physical functioning, more pain, sleep problems, lower well being and an active coping style were found to be associated with fatigue. Of course, in this study not all potential factors were included.

Pharmacological treatment
No pharmaceuticals have been proven effective in reducing fatigue. Randomized controlled trials (RCT’s) in which drugs are tested against a placebo and both investigators and patients are blinded for the intervention are the gold standard to prove effectiveness of interventions. Results from such studies have so far been disappointing in that no drug was found to be effective.
Modafinil, a drug used in narcolepsy, was recently demonstrated as not effective in reducing fatigue in a study by Vasconcelos OM, Neurology 2008 confirming the negative results reported earlier by Chan KM in Muslce and Nerve in 2006.

Intravenous Immunoglobulines (IvIg) have been studied in two trails by Borg K, in Lancet Neurology in 2006 and by Farbu E, European Journal of Neurology in 2007. The study by Borg found effect for muscle strength and for ‘vitality’. The study by Farbu found an effect for pain. Both studies however found no effect for fatigue.

Pyridostigmine, a drug that improves neuromuscular transmission was demonstrated not effective in two studies, one by Trojan DA in Neurology in 1999 and one study by Horemans HL in Journal of Neurology Neurosurgery and Psychiatry in 2003.

Other drugs were investigated in only one study involving limited numbers of patients. Negative results were found by Dinsmore S for high-dose *prednisone*, and by Stein DP, for *amantadine*, an anti-inflammatory drug, both published in Annals of New York Academy of Sciences in 1995. A study in 2005 by On AY, demonstrated a significant effect of *lamotrigine*, an antiepileptic drug, supposed to have neuroprotective properties, on fatigue. So far confirmative studies have not been published. Finally, a recent pilot study by Skough K, in 2008, found no effects for coenzyme Q10.

Assessment of and Managing fatigue in individuals with PPS

Assessment

I Medical evaluation

It is very important to start with a thorough medical evaluation to exclude other pathologies as mentioned earlier.

II What is meant by fatigue?

The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest.

III Are other contributing factors present?

Consideration has to be given to sleep quality, mood disorders and coping styles.

IV What is the activity pattern?

The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking, mobility in and outdoors and so on.

V What is the social system?

How is the person‘s social environment, does he or she have sufficient support and understanding at home and work.

VI What are the own perceptions?

How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on).

VII What are the physical capacities?

What is somebody able to do given the polio residuals and co-morbidities. What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individuals various activities.

VIII Conclusion

Finally a conclusion can be made on which factors cause or sustain fatigue. These are to be targeted in interventions.

Assessment tools

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning.

Diaries to inventory daily life activity are extremely useful to gain insight in what someone life looks like, in what a person actually does over the days. A common finding is that people with PPS appear to be much more active than they spontaneously report.

Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

Management

The first important thing is that the person obtains insight in the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cognitions. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well known that many polio survivors are so-called ‘over achievers’ who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals may avoid physical activity, for instance if they think that this may damage muscles, and they may very well be mainly fatigued due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue energy conservation skills are often to be learned. This may be done individual or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercise program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all be needed tailored to the individual's needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians.
Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during follow-up.

Effective Family Communications
Do We? How Can We Improve?

Annie Barber, RN, Polio Survivors & Friends of East Central Illinois, Charleston, IL
Linda Bieniek, CEAP (retired) La Grange, IL

Why is **communicating effectively** especially important for polio survivors and family members? Because as human beings, we each need acceptance, respect, love, and support to thrive. Communicating provides us with opportunities to express and accept these invaluable gifts. Most importantly, our connections can support and energize us to enjoy life's beauty during both good and difficult times.

When polio survivors experience losses of physical abilities, lifestyles, careers, connections, and financial resources, these changes often impact family members' lives as well. Each of us needs to communicate honestly, clearly, and sensitively about our needs and desires to make sure that our relationships are supportive and respectful of each other.

As a polio survivor and daughter of a polio survivor, we share examples of our communication challenges and offer strategies for gaining awareness of communication styles and improving our relationships with our natural or chosen family.

Communication Challenges That We Have Faced

"Speaking up about my physical limitations and needs when I developed post-polio syndrome was one of the greatest communication challenges that I have faced. Although in my job, I was assertive at intervening for other employees with disabilities, I was shocked at my own self-consciousness with men and my inability to ask for assistance at work. I grew anxious, depressed, and self-critical about my avoidance and the changes that my physical condition forced me to make in my life. By practicing what I professionally promoted, I invested in very effective psychotherapy! By working through feelings and limiting beliefs from early polio and family experiences, I learned to face myself with compassion and to communicate honestly about my needs. This also enabled me to ask my mother questions about my childhood--in non-accusing ways. Recently, while we watched the documentary on "Polio: An American Experience," she cried throughout the program. Afterwards, when I asked about her sadness, she revealed that she felt guilty about that period. I am grateful that I was able to thank her for all the ways she supported me and to encourage her to forgive herself for her limitations."

Linda Bieniek, Polio Survivor & Ventilator User, Life & Career Coach

"My father had polio when he was 12. I believe polio comprehensively influenced almost every moment of his life afterwards. As I was a nurse, sometimes Dad chose to allow me to partner with him to seek healthcare solutions. We experienced some very challenging times as we changed roles and he became more dependent and needy. He vacillated between appearing as a rigid, demanding, in-control man and a needy, frightened young boy. Neither of these were the strong, loving, devout, passionate, overworking Dad familiar to me. I found that communicating with my Dad had become, now more than ever, extremely important and yet extremely complex. The more Dad revealed to me about his experiences as a boy, the more I understood the reasons for his strong reactions. Then I was able to provide him with comfort and support through his devastating days of being bedfast again. If I had known some of the strategies we share, they might have eased some of the tensions during that period. I know they are helping me with my children." ***Annie Barber, R.N., Daughter of Polio Survivor, Post-Polio Support Group Leader***

"Communication, both verbal and non-verbal, is the' stuff' that initiates, builds, maintains, and destroys relationships,….Effective communicators attend to the nonverbal aspects of space, energy, and time as well as to their choice of words and actions as they move from situation to situation, building and strengthening relationships." ***Connecting with Self and Others, S. Miller et al***

What Are Your Relationship Goals?

The first step to becoming aware of how to improve your communication with a specific person is to clarify your goals: ***What kind of relationship do you WANT with this person? What do you WANT to change in your relationship? What do you WANT to gain from communicating with this person?"*** Respond to these questions using **positive words that apply to you**. Remember, you only have control over what you can realistically do--how you communicate, listen, and respond to the other person. You cannot control how the other person responds. You can, however, use your insights and the approaches described in this article to plan how to deliver your messages and gain the best results possible.

Do You Communicate Honestly and Directly?

In some families, communicating honestly and directly is or was not considered appropriate. In other families, such as when a parent had an addiction, family members may not have felt safe speaking the truth for fear of reprisals. Now, as adults, we have the opportunity to express ourselves honestly with trustworthy individuals and also to recognize when to be discreet with a person. In order to understand your ability to express yourself honestly, take a few moments and note "yes" or "no" to these questions:

1. Do you say "yes" to requests when you want to say '"no?" Do you avoid expressing your opinion when it differs from that of others?
2. Do you request what you need without feeling guilty?
3. When you get frustrated by a person's behavior do you communicate your needs to the person? Do you avoid the person? Criticize the person doing the behavior? Or complain to someone else?
4. When someone offends you, do you tell the person? Or do you get angry and either avoid the person or say nothing, but feel resentful inside?

Using an approach known as HODSA, the acronym for **honest, open, direct, sensitive, and appropriate,** will enable you to decide how, where, and when to communicate to gain the results you want. The following questions are a checklist for ensuring that your messages reflect these qualities:

- **H--Honest**: Is what you want to say the truth about your thoughts feelings, or experiences?
- **O--Open:** Does your message and body language invite dialogue? What level of openness do you want to share with this person? Is he/she trustworthy? What does your intuition say?
- **D--Direct**: Are you stating your message clearly and concisely?
- **S--Sensitive:** Is what and how you plan to communicate sensitive to the person's feelings, circumstances, and limitations? What about your body language?

- **A--Appropriate:** Are you choosing an appropriate moment and place to address this subject? Will the timing or setting of your interactions cause too much distress for the listener and interfere with your goals? Is your message appropriate given your roles?

In addition, nothing can replace the value of seeking feedback. Whenever you want to verify or confirm that you are getting your point across, request feedback from your listener. Ask open-ended questions such as, "Please tell me what you think I am saying;" "Please tell me what you think I mean by that;" or "How is this coming off to you?"

Does Your Body Language Reflect Your Good Intentions?

Most people can tell whether we are sincere about what we say by how we look and sound. Body language offers us another way to communicate our positive intentions. When we reflect honesty, openness, sincerity and sensitivity, we build trust and encourage cooperation. Does your eye contact, body posture, gestures, tone of voice, pace of speaking, and facial expressions invite openness? Seek feedback from a trustworthy friend to learn if your body language matches your verbal messages.

How Intimately Do You Share With Others?

Awareness provides us with insights about ourselves, others, and our interactions. Examining the terms below may help you become aware of the different levels of communication that you engage in. When you share information only on the sensory level that means you are revealing very little personal information. People who engage with each other only on this level are not very intimate with each other. On the other hand, if you are able to consistently express what you want, and then use that information to enact changes that meet your needs and desires, you are achieving a high level of intimacy, and often greater satisfaction in relationships.

Becoming familiar with these levels can help you to become attuned to your own comfort level and also can challenge you to share yourself with more depth, detail, and clarity. The more comfortable you become with expressing thoughts, feelings, and wants, the more courage you can gain for creating positive changes in your life.

Sensory Information: Verbal and non-verbal data based on the five senses of sight, smell, sound, touch, and taste. *I observed, sense, heard, etc "I see you have a red face."*

Thoughts: Thoughts are the meaning that we give to information and experiences. For example: "*I believe, perceive, think, expect, interpret, and see possibilities for…." "I think you look angry."*

Feelings: Emotional reactions, often to the differences between what we expect and what we actually experience. "*I feel sad, mad, afraid, glad, disappointed, etc "I'm worried that I disappointed you."*

Wants: Are what **you want to DO, to BE, or to HAVE. "***I intend, desire, need, value…."* Hidden agendas such as retaliating or gaining control are negative objectives. *"I want to show you my gratitude."*

Actions: What we do are our behaviors---in the past, present, or future. *"I plan, achieved, will solve, resolved, will negotiate, am developing…." "I plan to listen more carefully next time."*

At what level of this awareness spectrum do you find yourself most comfortable? Do you share deeper levels of awareness with anyone? With whom do you communicate intimately and want to?

Do You Take Responsibility For Your Needs By Being Assertive?

Communicating assertively means taking ownership of our thoughts, feelings, and experiences while respecting the feelings of others. Beginning a statement with "I" rather than "you" is a straightforward approach that invites open and direct exchanges. Saying, *"I disagree,"* rather than, *"You're wrong"* is not blaming or accusatory, and as a result, can reduce defensiveness and conflicts. If you have a hard time turning down requests, respond by simply saying, *"No, I can't do that now"* instead of giving a long explanation of the reasons that you can’t fulfill the person’s request before saying “No.”

As humans, we all have needs which may conflict with another person’s behavior. When this happens, asking the person to change a specific behavior is important for protecting the well-being of each individual and integrity of the relationship. If we avoid communicating directly and honestly about our feelings and needs, we risk revealing them indirectly, perhaps even passive-aggressively, impacting both parties negatively.
Use the four-step framework below to compose a clear and direct request for an individual to change a behavior. The above section on awareness offers useful terms that you can use to fill in the blanks:

“I feel ___________ when __________ because ________. I need ___________.”

Step 1: ***I feel.*** Take ownership for how you feel about the person’s behavior by saying: *“I feel frustrated...*

Step 2: ***When.*** Concisely state the person’s specific behavior that interferes with your needs. “*…when you keep talking while I am reading…*”

Step 3: ***Because.*** Describe the effect of the person’s behavior on you. “*…because I feel ignored.”*

Step 4: ***I need***. State what you want the person to do or change. *“I need quiet time to relax and read.”*

Do You Listen With an Open Mind and Heart?

How we listen is also essential to communicating effectively. Paying attention to the other person’s verbal and non-verbal messages with an open mind and heart contributes to understanding, respect, and trust in our relationships. The questions below reveal traits of ***ineffective*** listening. If you answer “yes” to any of these, consider this an opportunity to change that pattern and to learn to listen attentively!

- Do you have definite opinions and need to be “right?”
- Do people say that you talk too much or get defensive?
- Do you interrupt others when they are speaking? Or finish their sentences?
- Do you change the subject when you are uncomfortable with a topic or person?
- Do you fully focus on what a person is saying? Or do you let your mind drift off and think about the subject or to another unrelated subject or person?

How Do You Come Across with Family Members?

Next, we encourage you to be honest and CIRCLE all the words in the table below that describe how you have communicated with different family members. Often, we express ourselves differently depending on the individual, circumstances, topic, and sometimes, how we feel that day! Also, take a minute to place an “**X”** over words that others might use to describe the way you communicate with them. Insights that you gain can equip you to consciously decide how you WANT to interact in the future.

Communication Styles

Direct
Irreverent
Abrupt
Humorous
Honest
Bossy
Clear
Cynical
Cold
Annoyed
Vulgar

With Avoidance
Aggressive
Inquisitive
Respectful
Open
Demanding
Concise
Diplomatic
Dramatic
Angry
Childlike

Expressive
Passive
Passive-Aggressive
Indirect
Humble
Critical
Verbose
Emotional
Apologetic
Gentle
Cocky/Smart

Playful
Kind
Sensitive
Sarcastic
Patronizing
Accusing
Defensive
Sincere
Loving
Haughty
Oppositional

Inconsistent
Sporadic
Minimal
Effusive
Overwhelming
Flooding
Compulsive
Need-To-Know
Patient
Timid/Hesitant
Encouraging

For polio survivors: ***How do you communicate with family members about the following issues?***

- Your needs and feelings related to changes caused by the late effects of polio?
- How your current condition and having had polio has affected your life?
- How your early polio experiences have impacted your life?
- Their (family members') present day needs and feelings and/or their own past experiences?

For family members: ***How do you communicate with the polio survivor about the following issues?***

- Your own needs, feelings, and life experiences?
- The effects on your own life of the person contracting polio and/or developing its late effects?
- Your reactions to what the person has shared about past and present polio-related issues?
- What you want to know about the person's early polio experiences or present condition?

For polio survivors and family members:

- What do you do to become aware of your own feelings, needs, and desires?
- What "hot button" issues trigger intense reactions such as anger, anxiety, hurt, defensiveness, or avoidance? Have you considered seeking professional assistance to resolve them?
- How do you stay calm and focused when another person overreacts?
- Who is/are a trustworthy person(s) that you can turn to for constructive feedback and support during stressful family situations?

How Can You Plan To Express Yourself?

We recommend that you take time to note your answers to the questions below before approaching a family member to gain the results that you WANT. Your answers can assist you in deciding how to best communicate with the person. For complex and sensitive issues, also use the questions in the next exercise to plan your approach. These questions are all worth spending your time on!

1) With whom do you WANT to communicate?

2) What kind of relationship do you WANT with this person? What do you want to change?

3) What do you WANT to communicate? What is your message?

4) What do you WANT to gain from communicating with this person? For example:
    a) What do you want to change or have happen?
    b) What do you want to know?

5) How does this person usually communicate with you? Select descriptions from the ***"Communication Styles"*** box on Page 4.

6) What obstacles may interfere with your ability to gain a successful outcome with this person?

    This question can help you recognize what you can change and what factors are out of your control. Possible obstacles include but are not limited to addictions; depression/ behavioral health condition; cognitive limitations; unresolved fears, traumas and "hot button" issues; and also mean-spirited, manipulative, abusive, or controlling personalities.

7) How, when, and where will you approach this person to gain the results that you WANT after considering his/her communication style, listening skills, biases, and triggers?

How Can You Respond To Challenging Personalities?

Some individuals have personalities that will not only interfere with communicating effectively but also may cause conflicts within the family (See question #6 on "obstacles" above). The reasons for their personality patterns vary. Some behaviors relate to medical conditions such as having a bipolar condition or an addiction. Even with these conditions, individuals can change many of their behavior patterns. However, they must want to make changes and be willing to seek professional assistance. Your role is not to diagnose or fix the person. Instead, you use the strategies in this article along with these suggestions to take care of yourself and your family:

Gain Knowledge

Understanding a person's condition and behaviors along with your own reactions is especially important when interacting with challenging personalities. For example, a person who was abused or lost a parent as a child may have difficulty trusting others. Your understanding of this pattern can help you recognize that when the person criticizes you, this may be his or her way of creating distance and not of attacking you. Learn what triggers you and the other person and the reasons. Identify what contributes to conflicts or unproductive exchanges. The same advice holds for a medical condition such as bipolar condition. Likewise, if a polio survivor has not worked through anger and fears from early polio experiences, the person may use alcohol to numb uncomfortable feelings. Learning about the effects of traumas and chemical dependency can help you understand the person's behaviors and find effective ways to encourage the person to seek therapeutic resources to improve his or her relationships patterns.

Focus On Your Positive Goals and Values

Set positive goals about how you want to interact with this person. Be clear about your priorities. Think of the person in compassionate terms, for example, "ill" versus "crazy" or "self-destructive" versus "cruel." This can help you approach the person with understanding versus anger and defensiveness. Remind yourself of your values and affirm your good intentions. Focus on what you can do and say—what is in your control. Know that you have options of how to respond. Consider imagining yourself sending the person kind wishes or blessings (HeartMath approach). Imagine a protective clear shield between you and the other person to deflect any name-calling or accusations from feeling like a personal assault. Stay objective in absorbing what the person says. Pray for yourself and the person.

Use Good Judgment in What You Say and Do

Communicate clearly and specifically. Choose your battles and your words carefully. State your boundaries: "No, I will not be able to…." "I can do this, but not that." Stay calm and focused so that you do not fall into the trap of criticizing the person or resorting to saying the person is "crazy' or a "burden." Be discreet about what you share with the person and with others about the person. Avoid using generalizations and judgmental words. Affirm the person's good behaviors. Ask the person to be specific about what he or she wants. Limit contact and time to necessities. Be clear about roles, responsibilities, and consequences. Feed back what you understand he or she wants. Take time outs if the conversation becomes too heated or unproductive.

In all situations, gain support from trustworthy individuals. Consider joining a support group on-line if you can't attend in person. Make sure that you eat, sleep, and exercise (as much as you are able) well. Find ways to relieve stress and boost your energy. Use laughter, a good cry, movies, books, music, art, yoga, relaxation techniques, meditation, spending time outside and in Nature, playful games, and simple pleasures to calm and energize you. Be resourceful and seek assistance from volunteers at local churches, organizations, and college programs. Face yourself with kindness and forgiveness. Seek beauty and goodness. Use spirituality and humor to gain perspective of your situation within the big picture of life!

What Else Can You Do?

If after practicing these strategies, you still experience distress and difficulties gaining positive results from communicating with family members, consider exploring the following resources:

- Books, DVDs, websites, workshops on: communication skills, relationships, resolving conflicts, stress management, polio memoirs, and living well with the late effects of polio: www.post-polio.org/edu/aboutpol/books, Interpersonal Communications, Inc., HeartMath.
- Coaching: Obtain referrals from coachfederation.org or The NLP & Coaching Institute: 1-800-767-6756. Interview coaches by phone to find the professional who matches your needs.
- Counseling & Therapy: Assess website profiles and interview therapists over the phone: GoodTherapy.org; PsychologyToday.com; NetworkTherapy.com. Check backgrounds.
- Call Linda Bieniek, Life and Career Coach and retired Certified Employee Assistance Professional, at 708.354.3640 for professional "assessment and referral" services that match your needs with suitable coaches, counselors, therapists, and/or other resources.
- Read *What Psychotherapists Should Know about Disability* by Rhoda Olkin, Ph.D., and ask a coach, counselor, or therapist whom you work with to read it.
- Interfaith (Community or Care) Partnerships in the US provide visitations and assistance to individuals with chronic health conditions and also support for caregivers.

In conclusion, as polio survivors and caring supporters our lives are full of subtle and difficult changes, fears, opportunities for personal growth, disappointments, role reversals, and unexpected triggers. In these relationships, communication is paramount, yet very complex. We hope these suggestions will equip you to tend to your own and each other's needs to maximize the beauty of being people who really listen, love, and care for each other. May your interactions enrich your relationships and lives!

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Exercise and Activity: How Much and What?
Let's Get practical

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I work at a Rehabilitation Center for polio and accident victims in Denmark. The Center is owned and run by a patient organization called: The Danish association of Polio and Accident Victims. All staff members are employed by the organization, but the counties in Denmark pay for the treatment, so all assessments and treatments are free of charge for the patients.

878 polio survivors were treated at our clinic in 2008. Around 300 polio survivors exercise on a regular basis in PTU once or twice a week in our training center or in the warm water pool. 10,5% of the polio survivors are immigrants. Around 50 polio survivors are annually referred to the center for the first time. Most of them are elderly Danes who have managed to live without our help until now, but we also get a lot of immigrants from third world countries who have polio. They are often much younger and have a lot of social and language problems on top of the polio difficulties.

We have 7 wheel chair accessible apartments where polio survivors from other parts of the country can stay while they attend a 1 or 3 week program at the center.

The center has a multidisciplinary team to take care of the polio survivor comprising: Doctor, physical therapists, technical aids therapists, social workers, psychologists, nurse assistants, dietician and a private orthotist, who is coming once a week. It is necessary to have a doctor's referral to our clinic. Before coming to the clinic the polio survivor is asked to fulfill a questionnaire about his or her social conditions (work situation / housing), the acute and stable phase and the actual problems that have made the patient come to the clinic. The doctor makes an examination of the patient, and she considers if there could be other differential diagnoses, which could cause the symptoms of the patient. She can then refer the patient to different professionals at the clinic or to additional tests at a hospital. Almost all the patients are referred to physiotherapy.

When all the relevant professionals have assessed the polio survivor, a conference is held where all assessments from the multidisciplinary team are presented and we agree on which recommendations should be given to the patient. It is important that we all work in the same direction and of course the plan is made in cooperation with the polio survivor. When there are complicated matters, the patient participates in the conference.

Some polio survivors need changes in there home or at the place of work. Our technical aids therapist can visit the polio survivors home together with the therapist from the county in order to find the best adjustments. Some polio survivors need to save their energy, so they need technical aids, bandages or help with housecleaning. If the patient has a seating problem we can measure the pressure of the buttocks in the seat, which makes it easier to find the right cushion for the wheel chair.

We also have a polio education program where polio survivors and their relatives can learn about polio issues, exercising principles, technical aids and psychological reactions to the need of changing lifestyle as polio problems arise. I could tell a lot about what all the professionals do but I will focus on the physiotherapy and especially how we deal with exercising according to the title of this session.

The physiotherapist uses a check scheme to make a thorough anamnesis and examination of the patient. We use this to be sure that we get all necessary information about the patient and his or her condition before we make a treatment plan.

If the main problem is pain we consider the cause of the pain. Is it overuse of the body structures or is it a more diffuse pain in the polio muscles. Depending on which kind of pain the patient has, we use a variety of pain treatments: Exercise, acupuncture, laser therapy, medication, massage, relaxation, energy conservation, bandages, aids, etc.

If the patient experiences a decrease in strength we always make a manual muscle test. We know that the test does not give us the exact truth about the polio affection, but it gives us a good impression of how much polio affection there is. You can see on the slide that the manual muscle test only detects rather big decreases in strength, but we are therefore aware that there can be polio in a muscle, even if it seems strong in the test.

Grade

0	No muscle contraction	0%
1	Palpable contraction	< 5%
2	Gravity eliminated	5 – 10 %
3	Against gravity	10 –20 %
4	Moderate / good	40 %
5	Maximum resistance	> 60 %

We use the manual muscle test as a guideline for how the patient should exercise or which kind of bandages could be useful. During testing we can also see and feel if there are fasciculations during the test, which tell us that the muscle can be overused. Sometimes we can compare a recent test with a test taken some years earlier and in that way we can follow the development of the decrease in muscle strength. I should maybe mention that we do not take EMG measurements regularly in Denmark. We have very good journals of the patients polio history from their initial hospitalization and we find that the muscle test is enough in most cases.

To be able to tell if the treatment makes a difference we also use other tests. Not for everybody, but when it is relevant. I will mention these tests:

- 6 min walk test which is the distance walked in 6 minutes as fast as possible.
- Time used to walk 10 meters,
- Walking distance outdoor where the patient walk until he or she needs a break. We use this when applying for car or a parking sign.
- We also have balance and fitness tests.
- Timed Stands Test which measures the time necessary for getting in and out of a chair 10 times without using the arms.
  After hearing the polio survivor's story and performing the tests we make an evaluation to decide whether the problems are caused by disuse, overuse or maybe something else.

As in the States Denmark also has a rising number of lifestyle related diseases. The Health Department in Denmark recommends that everybody should do at least moderate exercising for 30 minutes each day. The polio population is in high risk of getting life style related diseases, because they often have a lower activity level than the rest of the population. The well-known life-style related diseases are: Hypertension, diabetes, osteoporosis, cardio-vascular diseases and depression. So even though a person has polio, he has to maintain a certain level of activity if possible and he has to keep his weight down in order to avoid further complications to his condition. The two main ways of handling this is healthy diet and exercising.

So what are the exercising recommendations for polio survivors in Denmark?

When we examine the patient we consider what status the muscles have. Is the strength stable or unstable? As you can see our recommendations of exercising the patients depends on the strength level and if the muscles are stable or not. By stable I mean, that there have not been more decrease in strength than could be explained by age. The last line in the slide represent the muscles that are so overused through daily activities, that they should not exercise more. But only very few patients cannot exercise at all. Most patients can benefit from exercising even in a very light way.

Polio status	**Muscle strength**	**Exercise**
Stable	Normal	No restrictions but be careful
Stable	Reduced	Moderate strength exercise
Unstable	Reduced	Non-fatiguing
Unstable	Very reduced	No resistance
Large atrophy	Very reduced	No exercise

Unless the muscles are very weak (below 3+) we normally recommend a training program for the polio survivor. We want to improve strength if possible, improve muscle endurance and cardio respiratory fitness. If the polio survivor is overweight we offer consultations with our dietician, so the exercise can be combined with a change in diet. Many studies show that exercise is beneficial to polio muscles as long as the patient exercises with non-fatiguing exercises.

The following slides are our recommendations to the Danish polio survivors. If you want to improve cardio respiratory fitness you have to do aerobic training such as leg- or arm bicycling, swimming or rowing.

The principles are that you should exercise at 65% of max heart rate or at Borg scale 12 – 14 “Somewhat hard”.

You should exercise at least for 10 to 30 minutes depending on the condition of the exercising muscles. Preferably you should exercise at least twice a week.

The Borg scale rate of perceived exertion:

6 No exertion at all
7 Extremely light
8
9 Very light-(easy walking slowly at a comfortable pace)
10
11 Light
12
13 Somewhat hard (It is quite an effort; you feel tired but can continue)
14
15 Hard (heavy)
16
17 Very hard (very strenuous, and you are very fatigued)
18
19 Extremely hard (You cannot continue for long at this pace)
20 Maximal exertion

If non-disabled people want to improve strength they should exercise at very close to their maximum capacity. This is not recommendable for polio survivors, so we recommend that you exercise at maximum 50% of max. capacity. In some cases strength will improve even though you train at this lower level. Train in intervals, for instance take 10 repetitions, move on to the next machine, take a round in the machines and then return later. If it is too difficult to go from machine to machine, you have to take breaks in stead. For endurance training you should exercise with low resistance and many repetitions.

If you as a polio survivor experience signs of overuse: Excessive fatigue after exercising, excessive pain after training or fasciculations.; You have to exercise with less resistance (maybe even ½ the load) or decrease the number of repetitions. You can also decrease the frequency of exercising or exercise in a different way. But maybe exercising is not the best solution for you. For some polio survivors daily activities are enough training or even overuse, so you have to think of energy management, bandaging and technical aids. Even though the polio survivors in our clinic are not exercising heavy strengthening exercises, many of them feel that they get stronger and are able to cope with the tasks of daily living in a better way. They all say that when they pause with the training in the summer, they feel they become weaker and less rigid.

You can exercise in many different ways. I.e. Fitness center, swimming, gymnastics, fysio Pilates, home exercising, handicap sports, horseback riding etc. The most important thing is to find something that motivates you. Something you enjoy doing otherwise it will be too much hard work and you may fail to exercise enough. Another good advice is to find a training partner. When you have an appointment with somebody you are not so tempted to skip training. Combine the social aspect with exercising. But I will also advise you to have a therapist who is familiar with polio issues to help you find the right level of training.

If you don’t have the possibility of exercising at a polio clinic nearby or if you don’t feel that at a fitness center is right for you, you can exercise at home. I will just show a few ways of exercising at home. First of all you can have a physical therapist make you a home exercising program especially made for you.

Therabands can be very useful in exercising at home. They can be bought in different resistance levels. I will recommend the white or the yellow ones for polio survivors, unless you have every strong muscles some where in your body. Therabands can be bought on www. amazon.com and you can find all kinds of exercises at www.thera-bandacademy.com/exercises.

Remember to use the polio training principles:
Low resistance,
Exercise in intervals,
Take brakes,
Avoid excessive pain and fatigue

Nordic walking or bicycling can be a good alternative to exercising in-door

In our clinic we have a fitness center, swimming pool and offer group gymnastics. We have several kinds of groups: Relaxing, genuine training, weight reduction groups and we even have special groups for muslim women both in the pool and in the gym. Many of our patients continue to exercise at the clinic after the initial treatment, so they can maintain the fitness level they achieved in the beginning.

The benefits of exercising are multiple: Some polio survivors improve their strength; others maintain their strength level and some are diminishing the polio related loss of strength. Some polio survivors improve their functional capacity and balance. Exercising gives you the possibility of getting control over your weight and exercising reduces hypertension, risk of heart disease, risk of diabetes, depression, improved sense of well being.

We have just published a study of 50 polio survivors who received a multidisciplinary intervention with emphasis on physical therapy at our clinic and a few of the results were these:
<u>6-min. Walk test</u> **10,6% improvement** (a test where you walk as far as you can I 6 minutes

<u>Timed Stands Test</u> **12,9% improvement** (a test which measures the time necessary for getting in and out of a chair without using the arms 10 times)
<u>“Vitality” from SF-36</u> **7% improvement** (a dimension in a quality of life questionnaire)
<u>“Physical fatigue” MFI-20</u> **10% improvement** (a dimension in a fatigue questionnaire)
Most of the patients in this study exercised and 12 of them got new devices for walking.
So it does makes good sense to exercise and to accept the right aids for walking and changes in life style.

Thank you for your attention.

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Exercise and Activity: How Much and What? Let’s Get Practical

John G. Fan, MD, Hutchinson Clinic, Hutchinson, Kansas

Complementary and Alternative Medicine (CAM): What You Don't Know Can Hurt You

Barbara Duryea, MSN, RN, CPHQ, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Decisions about your health care are important—including decisions about whether to use complementary and alternative medicine (CAM). The National Center for Complementary and Alternative Medicine (NCCAM) has developed this fact sheet to assist you in your decisionmaking about CAM. It includes frequently asked questions, issues to consider, and a list of sources for further information. To find out more about topics and resources mentioned in this fact sheet, see "For More Information."

Key Points

- Take charge of your health by being an informed consumer. Find out what scientific studies have been done on the safety and effectiveness of the CAM treatment in which you are interested.
- Decisions about medical care and treatment should be made in consultation with a health care provider and based on the condition and needs of each person. Discuss information on CAM with your health care provider before making any decisions about treatment or care.
- Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care.
- If you use a CAM therapy provided by a practitioner, such as acupuncture, choose the practitioner with care. Check with your insurer to see if the services will be covered. (To learn more about selecting a CAM practitioner, see our fact sheet, "Selecting a CAM Practitioner.")

1. What is CAM?

CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Complementary medicine is used together with conventional medicine, and alternative medicine is used in place of conventional medicine. Conventional medicine is medicine as practiced by holders of M.D. (medical doctor) or D.O. (doctor of osteopathy) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Some health care providers practice both CAM and conventional medicine.

The list of what is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge. For more about these terms, see the NCCAM fact sheet "What Is CAM?"

2. How can I get reliable information about a CAM therapy?

It is important to learn what scientific studies have discovered about the therapy in which you are interested. It is not a good idea to use a CAM therapy simply because of something you have seen in an advertisement or on a Web site or because someone has told you that it worked for them. (See sidebar for some tips on evaluating the information you see on a Web site.)

Understanding a treatment's risks, potential benefits, and scientific evidence is critical to your health and safety. Scientific research on many CAM therapies is relatively new, so this kind of information may not be available for every therapy. However, many studies on CAM treatments are under way, including those that NCCAM supports, and our knowledge and understanding of CAM is increasing all the time. Here are some ways to find scientifically based information:

- Talk to your health care practitioner(s). Tell them about the therapy you are considering and ask any questions you may have about safety, effectiveness, or interactions with medications (prescription or non-prescription). They may know about the therapy and be able to advise you on its safety and use. If your practitioner cannot answer your questions, he may be able to refer you to someone who can. Your practitioner may also be able to help you interpret the results of scientific articles you have found.

- Use the Internet to search medical libraries and databases for information. One database called CAM on PubMed, developed by NCCAM and the National Library of Medicine, gives citations or abstracts (brief summaries) of the results of scientific studies on CAM. In some cases, it provides links to publishers' Web sites where you may be able to view or obtain the full articles. The articles cited in CAM on PubMed are peer-reviewed—that is, other scientists in the same field have reviewed the article, the data, and the conclusions, and judged them to be accurate and important to the field. Another database, International Bibliographic Information on Dietary Supplements, is useful for searching the scientific literature on dietary supplements.

- If you do not have access to the Internet, contact the NCCAM Clearinghouse. The staff is available to discuss your needs with you and assist you in searching the peer-reviewed medical and scientific literature.

- Visit your local library or a medical library to see if there are books or publications that contain scientific articles discussing CAM in general or the treatment in which you are interested.
  Thousands of articles on health issues and CAM are published in books and scientific journals every year. A reference librarian can help you search for those on the therapy that interests you.

Questions to ask when evaluating Web site information:

- Who runs the site? Is it Government, a university, or a reputable medical or health-related association? Is it sponsored by a manufacturer of products, drugs, etc.? It should be easy to identify the sponsor.

- What is the purpose of the site? Is it to educate the public or to sell a product? The purpose should be clearly stated.

- What is the basis of the information? Is it based on scientific evidence with clear references? Advice and opinions should be clearly set apart from the science.

- How current is the information? Is it reviewed and updated frequently?

For more tips on evaluating information on the Web, read NCCAM's "10 Things To Know About Evaluating Medical Resources on the Web."

3. Are CAM therapies safe?

Each treatment needs to be considered on its own. However, here are some issues to think about when considering a CAM therapy.

- Many consumers believe that “natural” means the same thing as “safe.” This is not necessarily true. For example, think of mushrooms that grow in the wild: some are safe to eat, while others are poisonous.

- Individuals respond differently to treatments. How a person might respond to a CAM treatment depends on many things, including the person’s state of health, how the treatment is used, or the person’s belief in the treatment.

- For a CAM product that is sold over the counter (without a prescription), such as a dietary supplement,[1] safety can also depend on a number of things:
  - o The components or ingredients that make up the product
  - o Where the components or ingredients come from
  - o The quality of the manufacturing process (for example, how well the manufacturer is able to avoid contamination).

The manufacturer of a dietary supplement is responsible for ensuring the safety and effectiveness of the product before it is sold. The U.S. Food and Drug Administration (FDA) cannot require testing of dietary supplements prior to marketing. However, while manufacturers are prohibited from selling dangerous products, the FDA can remove a product from the marketplace if the product is dangerous to the health of Americans. Furthermore, if in the labeling or marketing of a dietary supplement a claim is made that the product can diagnose, treat, cure, or prevent disease, such as "cures cancer," the product is said to be an unapproved new drug and is, therefore, being sold illegally. Such claims must have scientific proof.

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[1] “Dietary supplements” were defined by Congress in a law passed in 1994. A dietary supplement is a product (other than tobacco) taken by mouth that contains a “dietary ingredient” intended to supplement the diet. Dietary ingredients may include vitamins, minerals, herbs or other botanicals, amino acids, and substances such as enzymes, organ tissues, and metabolites. Under current law, dietary supplements are considered foods, not drugs.

- For CAM therapies that are administered by a practitioner, the training, skill, and experience of the practitioner affect safety. However, in spite of careful and skilled practice, all treatments—whether CAM or conventional—can have risks.

4. How can I determine whether statements made about the effectiveness of a CAM therapy are true?

Statements that manufacturers and providers of CAM therapies may make about the effectiveness of a therapy and its other benefits can sound reasonable and promising. However, they may or may not be backed up by scientific evidence. Before you begin using a CAM treatment, it is a good idea to ask the following questions:

- Is there scientific evidence (not just personal stories) to back up the statements? Ask the manufacturer or the practitioner for scientific articles or the results of studies. They should be willing to share this information, if it exists.

- Does the Federal Government have anything to report about the therapy?

  - Visit the FDA online at www.fda.gov to see if there is any information available about the product or practice. Information specifically about dietary supplements can be found on FDA's Center for Food Safety and Applied Nutrition Web site at www.cfsan.fda.gov. Or visit the FDA's Web page on recalls and safety alerts at www.fda.gov/opacom/7alerts.html.
  - Check with the Federal Trade Commission (FTC) at www.ftc.gov to see if there are any fraudulent claims or consumer alerts regarding the therapy. Visit the Diet, Health, and Fitness Consumer Information Web site at www.ftc.gov/bcp/menu-health.htm.
  - Visit the NCCAM Web site, nccam.nih.gov, or call the NCCAM Clearinghouse to see if NCCAM has any information or scientific findings to report about the therapy.

- How does the provider or manufacturer describe the treatment? The FDA advises that certain types of language may sound impressive but actually disguise a lack of science. Be wary of terminology such as "innovation," "quick cure," "miracle cure," "exclusive product," "new discovery," or "magical discovery." Watch out for claims of a "secret formula." If a therapy were a cure for a disease, it would be widely reported and prescribed or recommended. Legitimate scientists want to share their knowledge so that their peers can review their data. Be suspicious of phrases like "suppressed by Government" or claims that the medical profession or research scientists have conspired to prevent a therapy from reaching the public. Finally, be wary of claims that something cures a wide range of unrelated diseases (for example, cancer, diabetes, and AIDS). No product can treat every disease and condition.

5. Are there any risks to using CAM treatments?

Yes, there can be risks, as with any medical therapy. These risks depend upon the specific CAM treatment. The following are general suggestions to help you learn about or minimize the risks.

- Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care. For example, herbal or botanical products and other dietary supplements may interact with medications (prescription or non-prescription). They may also have negative, even dangerous, effects on their own. Research has shown that the herb St. John's wort, which is used by some people to treat depression, may cause certain drugs to become less effective. And kava, an herb that has been used for insomnia, stress, and anxiety, has been linked to liver damage.

- If you have more than one health care provider, let all of them know about the CAM and conventional therapies you are using. This will help each provider make sure that all aspects of your health care work together.

- Take charge of your health by being an informed consumer. Find out what the scientific evidence is about any treatment's safety and whether it works.

- If you decide to use a CAM treatment that would be given by a practitioner, choose the practitioner carefully to help minimize any possible risks.

6. Are CAM therapies tested to see if they work?

While some scientific evidence exists regarding the effectiveness of some CAM therapies, for most there are key questions that are yet to be answered through well-designed scientific studies—questions such as whether the therapies are safe, how they work, and whether they work for the diseases or medical conditions for which they are used.

NCCAM is the Federal Government's lead agency for scientific research on CAM. NCCAM supports research on CAM therapies to determine if they work, how they work, whether they are effective, and who might benefit most from the use of specific therapies.

7. I am interested in a CAM therapy that involves treatment from a practitioner. How do I go about selecting a practitioner?

Here are a few things to consider when selecting a practitioner. If you need more information, see our fact sheet "Selecting a CAM Practitioner."

- Ask your physician, other health professionals, or someone you believe to be knowledgeable regarding CAM whether they have recommendations.
- Contact a nearby hospital or a medical school and ask if they maintain a list of area CAM practitioners or could make a recommendation. Some regional medical centers may have a CAM center or CAM practitioners on staff.
- Contact a professional organization for the type of practitioner you are seeking. Often, professional organizations have standards of practice, provide referrals to practitioners, have publications explaining the therapy (or therapies) that their members provide, and may offer information on the type of training needed and whether practitioners of a therapy must be licensed or certified in your state. Professional organizations can be located by searching the Internet or directories in libraries (ask the librarian). One directory is the Directory of Information Resources Online (DIRLINE) compiled by the National Library of Medicine (dirline.nlm.nih.gov). It contains locations and descriptive information about a variety of health organizations, including CAM associations and organizations.
- Many states have regulatory agencies or licensing boards for certain types of practitioners. They may be able to provide you with information regarding practitioners in your area. Your state, county, or city health department may be able to refer you to such agencies or boards. Licensing, accreditation, and regulatory laws for CAM practices are becoming more common to help ensure that practitioners are competent and provide quality services.

8. Can I receive treatment or a referral to a practitioner from NCCAM?

NCCAM is the Federal Government's lead agency for scientific research on CAM. NCCAM does not provide CAM therapies or referrals to practitioners.

9. Can I participate in CAM research through a clinical trial?

NCCAM supports clinical trials (research studies in people) on CAM therapies. Clinical trials on CAM are taking place in many locations worldwide, and study participants are needed. To find out more about clinical trials in CAM, see the NCCAM fact sheet "About Clinical Trials and CAM." To find trials that are recruiting participants, go to the Web site nccam.nih.gov/clinicaltrials. You can search this site by the type of therapy being studied or by disease or condition. If you do not have access to the Internet, contact the NCCAM Clearinghouse for information.

For More Information

NCCAM Clearinghouse

The NCCAM Clearinghouse provides information on CAM and NCCAM, including publications and searches of Federal databases of scientific and medical literature. The Clearinghouse does not provide medical advice, treatment recommendations, or referrals to practitioners.

Toll-free in the U.S.: 1-888-644-6226
TTY (for deaf and hard-of-hearing callers): 1-866-464-3615
NCCAM Web site: nccam.nih.gov
E-mail: info@nccam.nih.gov

Assisted Living Communities for Survivors

Sue Burgess, Atlanta Regional Commission, Atlanta, Georgia

POST-POLIO HEALTH INTERNATIONAL 10th International Conference

Living with Polio in the 21st Century

April 23-25, 2009

Saturday, April 25, 2009

Session S1, 9:30–10:45 am
through
Session S4, 2:45–4:00 pm

This book belongs to

POST-POLIO HEALTH INTERNATIONAL

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Including International Ventilator Users Network

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QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International (PHI) thanks the presenters for providing the excellent information contained in the daily program books.

If you share this information, we respectfully ask that you acknowledge the presenter and that the information was disseminated at PHI's 10th International Conference: Living with Polio in the 21st Century (April 2009). PHI will incorporate additional information presented at the conference and make it available to attendees and others at a later date. Details will be published in *Post-Polio Health* and on www.post-polio.org.

In case of emergency, call 911.

To go directly to the Warm Springs Medical Center Emergency Room, exit the main gate, turn right and the entrance will be on your right.

The RWSIR Campus general number to report problems is 5555 and is posted on all Campus phones.


John P. Murtha
Neuroscience
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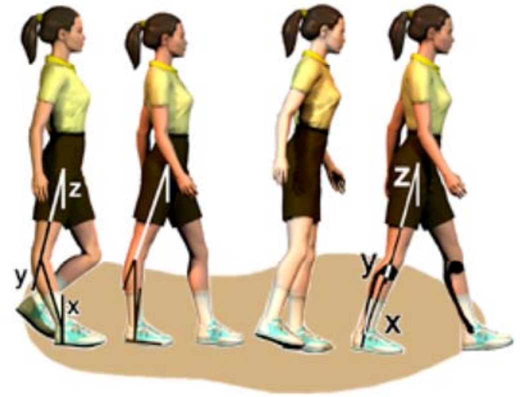

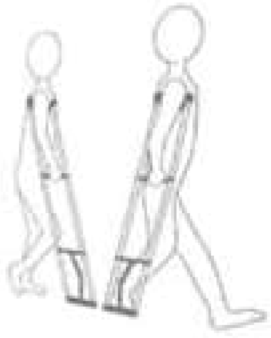

EXHIBITORS

Visit the following companies in Georgia Hall during these hours:

Friday, April 24 from 11:30 am–7:00 pm

Saturday, April 25 from 8:30 am–1:30 pm

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888- 667-4046
www.icanwalk.com

Welcome to the Roosevelt Warm Springs Institute for Rehabilitation.

Whether you have been here before or this is your very first time on our campus, we are thrilled to have you here as our guests. As you may know, we are the "living legacy" of FDR's vision for healing, so as you enjoy your symposium you will notice patients and students coming and going, and that we are very much a living and breathing rehabilitation center. We have been providing rehabilitation for 81 years, and you will also note that parts of our campus show our age.

We are not a modern conference center like you may find in downtown Atlanta, but we have something that they don't. My hope for you during your visit is that you experience what we call the "Spirit of Warm Springs," which refers to our caring and compassion. We are very proud of our historic legacy, and I encourage you to reflect on that as you travel around and across our campus. Franklin D. Roosevelt never learned to walk by coming here, but I believe it made him a better man and a much better President. So on behalf of all of us who come to work here every day in pursuit of the same mission "to empower individuals with disabilities to achieve personal independence" as FDR did, welcome to this place of healing. May you enjoy your conference and fully enjoy your stay with us.

Greg Schmieg
Executive Director, RWSIR

From Post-Polio Health International (PHI):

Welcome to the tenth in our series of international conferences.

PHI's goal for these conferences has always been threefold: First, we aim to promote the face-to-face exchange of authoritative, up-to-date information about the late effects of polio and independent living with its consequences. Second, we aim to sustain a productive network of active polio survivors and healthcare professionals with relevant expertise – by providing a forum in which these two groups can inform each other and interact. Third, we aim to disseminate the results of our conferences to all those interested polio survivors and medical professionals who are unable to attend.

We are honored to have this conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). RWSIR's place in the history of physical medicine and rehabilitation is a prominent one indeed. It began with Franklin Delano Roosevelt, and with the idea of rehabilitation as a cooperative venture between medical professionals and polio survivors. From its beginnings, like PHI, it has also been dedicated to helping people develop and sustain the functional abilities necessary for independent living with a physical disability.

This event was made possible by the dedicated labors of many staff members at RWSIR. To all of them, we owe our thanks. We also thank Carolyn Raville, founder of the North Central Florida Post-Polio Support Group, for suggesting a post-polio conference at RWSIR.

Thank you for joining us to learn about "Living with Polio in the 21st Century."

Lawrence C. Becker
Chair, Board of Directors, Post-Polio Health International

Acknowledgements

Steering Committee

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Program / Saturday, April 25, 2009

8:30 am – 9:30 pm

Registration in GEORGIA HALL

8:30 am – 9:30 pm

Continental Breakfast

9:30–10:45 am

SESSION S1 OPTIONS

First Step in Pain Treatment: Finding the Cause

ROOSEVELT HALL AUDITORIUM

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Paul Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Dale C. Strasser, MD, Emory University School of Medicine, Atlanta, Georgia

Research Progress

VRU AUDITORIUM

Summary of Post-Polio Research at Montreal Neurological Institute & Hospital

Daria A. Trojan, MD, Montreal Neurological Institute & Hospital, McGill University, Montreal, Quebec, Canada

Summary of Post-Polio Research at Karolinska Institutet (1/2 hr)

Prof. Kristian Borg, MD, PhD, Stockholm, Sweden

Bladder Inconveniences

MEADOWS CLASSROOM

Lise Kay, MD, *Urologist,* PTU – Landsforeningen af Polio-, Trafik- og Ulykkesskadede, Rodøvre, Denmark

The Secret to Good Attendant Care

SCHOOLHOUSE 105

Gene Spalding, BSEE, ATP, Warm Springs, Georgia

Report from the Camp Dreamers: Review of the Wellness Retreat

SCHOOLHOUSE 111

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Sunny Roller, MA, Mary E. Switzer Distinguished Research Fellow National Institute on Disability and Rehabilitation Research, Ann Arbor, Michigan

11:15 am – 12:30 pm

SESSION S2 OPTIONS

Second Step in Pain Treatment: Choosing Therapies

ROOSEVELT HALL AUDITORIUM

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Dale C. Strasser, MD, Emory University School of Medicine, Atlanta, Georgia

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Paul Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia

Learning from Wise Elders

SCHOOLHOUSE 111

Sunny Roller, MA, Mary E. Switzer Distinguished Research Fellow National Institute on Disability and Rehabilitation Research, Ann Arbor, Michigan

Poly Pharmacy: Making It All Work

VRU AUDITORIUM

Kathy Wilson, RPH, RWSIR, Warm Springs, Georgia

Too Hot and Too Cold: Causes and Solutions

SCHOOLHOUSE 105

Carol Vandenakker, MD, University of California Davis Health System, Davis, California

When Are Trachs an Option?

MEADOWS CLASSROOM

Linda Bieniek, CEAP, LaGrange, Illinois

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Kristy McClellan, RT, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

11:30 am – 1:30 pm

Lunch on Your Own at the RWSIR Cafeteria. Vegetarian available. (Attendees will choose from Session S2 or S3 and eat lunch during the other time slot.)

1:00 – 2:15 pm

SESSION S3 OPTIONS

Post-Polio Research: Progress, Possibilities and Problems

ROOSEVELT HALL AUDITORIUM

Prof. Kristian Borg, MD, PhD, Karolinska Institutet, Stockholm, Sweden

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Daria A. Trojan, MD, Montreal Neurological Institute & Hospital, McGill University, Montreal, Quebec, Canada

Rahnuma Wahid, PhD, Manager Analytical Immunology, Sanofi Pasteur, Swiftwater, Pennsylvania

Bracing: What's New? Is Old Better?

VRU AUDITORIUM

Moderator: Marny Eulberg, MD, St. Anthony's Family Medical Center West, Denver, Colorado

Curt Kowalczyk, CO, Otto Bock HealthCare, Minneapolis, Minnesota

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Mark Taylor, MLS, CPO, FAAOP, University of Michigan, Ann Arbor, Michigan

Exercise and Activity: How Much and What? Let's Get Practical

SCHOOLHOUSE 111

Merete Bertelsen, PT, The Danish Society of Polio and Accident Victims, Rodøvre, Denmark

John G. Fan, MD, Hutchinson Clinic, Hutchinson, Kansas

Demystifying the Equipment of Assisted Breathing

MEADOWS CLASSROOM

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Kristy McClellan, RT, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Betsy Thomason, BA, RRT, Millennium Respiratory Services, Whippany, New Jersey

2:45 – 4:00 pm

SESSION S4 – CLOSING PLENARY

Polio: A Look Back at the Public Health Crusade that Mobilized a Nation

ROOSEVELT HALL AUDITORIUM

David M. Oshinsky, Jack S. Blanton Chair
in History, and Distinguished Scholar
in Residence, New York University

5:30 pm

DINNER AND ENTERTAINMENT AT CAMP DREAM

SESSION S1

First Step in Pain Treatment: Finding the Cause

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida
Paul Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia
William DeMayo, MD, John P. Murtha
Neuroscience and Pain Institute (JPMNPI),
Johnstown, Pennsylvania
Dale C. Strasser, MD, Emory University School of Medicine, Atlanta, Georgia

The First Step in Treating Pain: Finding the Source

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Dr. Clunn will present the common pain generators in polio patients and help identify ways that the patient can better communicate with his or her physician in regard to symptoms, and outline the process by which the physician should identify the pain generators so that effective treatment can be determined.

Dr. Clunn completed medical school at the University of Cincinnati in 1993, followed by internship at Oakwood hospital and an additional 3 year residency in physical medicine & rehabilitation at the University of Michigan in Ann Arbor, where she also served as chief resident. She now practices with Southeastern Integrated Medical. Pl., a multidisciplinary integrated health system in North Central Florida, (in Ocala) full-time.

Dr. Clunn is board certified in Physical Medicine & Rehabilitation and also in the subspecialty of Pain Medicine. She is a member of the American Academy of Physical Medicine & Rehabilitation, The American Academy of Pain Medicine & the American Academy of Electrodiagnostic Medicine as well as the Florida Medical Association, Florida Society of PM&R and the Marion County Medical Society. Dr. Clunn is the Physician consultant for the North Central Florida Post-Polio Support Group.

Polio survivors have been found to have multiple potential sources of pain as they age. The pain can interfere with function and add further physical decline, lead to depression, poor sleep and fatigue, which are already problems in most post-polio patients. Therefore it is important to be aggressive in treating pain in order to optimize physical and mental function.

The primary findings on physical exam in polio patients are muscle weakness and atrophy (shrinkage) in the affected limbs. Part of the post-polio syndrome includes progressive weakness with or without atrophy in the limbs that were affected originally, and occasionally in limbs that were not affected originally. The atrophy and weakness occurs because the virus affected the anterior horn cell of the peripheral nervous system in a patchy pattern. This then causes the nerve supply to be poor to the receiving muscle, and it can no longer work fully (the nerve supply is the hard wire that gives the muscle its power and its signal to move). Without actively contracting, the muscle atrophies (shrinks) rapidly. What is left is a muscular system that must struggle to maintain posture, activate joints and work with possibly only 10-80% of its usual power. With this understanding of the disease mechanism , it is easy to see the first reason polio patients often have pain: chronic muscle strain. The muscles in the affected limbs are often overused or strained even in everyday activities such as walking or using arms. Muscle strain pain presents with aching soreness and soreness in muscles that become tender to touch. The tenderness can be in the belly of the muscle or at its distal, tendinous insertion near the bone (enthesopathy).

Bones and joints are another source of pain in polio. If a bone is not subjected to regular weight-bearing activity, it becomes osteoporotic (loses its mineral content). This can cause pain and lead to compression or stress fractures that can occur even with normal activity (walking or bending for example). Stress or compression fractures present with acute, focal intense pain, often with swelling, made worse with weight-bearing. It is even more important that post-polio patients undergo bone density studies than the normal population in order to treat osteoporosis if it exists, as it predisposes bones to fractures with falls or even atraumatic activities. Joints can become painful due to arthritis or due to contracture from tightness. Capsulitis (inflammation of the joint capsule) can also occur and presents with very painful and restricted range of motion of a joint. This is particularly common when weakness has made it difficult to move a joint, and the capsule shrinks or tightens because it is not ranged. Subluxation (slippage of a joint out of position) can be commonly found in feet, sacroiliac (pelvic) joints and shoulders when the surrounding musculature is weak. This presents as pain in range of motion or with weight-bearing, deformity, or crepitation with range of motion.

Nerve pain can present as part of an “overuse “ syndrome when certain activities are overdone, often in response to substituting one function for another where weakness exists. An entrapment of the nerve can occur with the repetitive motion. An example of this is carpal tunnel syndrome, particularly common in manual wheelchair or walker users (repetitive gripping with or without direct compression), or a gluteal nerve injury in response to hip weakness and pelvic instability and strain with walking.

Spine pain is also common in polio patients. Spine pain has potential sources such as discs, joints, muscles, ligaments, tendon, bone and nerve roots. Wheelchair users are susceptible to degenerative disc disease (seated position increases intradiscal pressure), atrophy of the paraspinal muscles and scoliosis (curvature). Sitting also creates tightness in tendons of flexor muscles and can lead to pain when in extension, such as lying down. Joints in spines where weakness is present in a lower limb or in the spine itself are subject to premature and more severe arthritic change than usual. Discs are also subject to more strain injuries such as tears and herniations when gait is unbalanced. They present with intense focal back pain and, if pressure on the nerve root ensues, radiating pain to the abdomen, groin or leg & foot (if lumbar). Osteoporosis also affects the spine commonly with compression fractures.

The circulatory system can also be affected by polio, particularly in limbs that are paretic (weak or paralyzed), and in wheelchair users due to sitting. Venous return of the blood is usually impaired in this instance, and blood can pool in the extremity causing swelling, aching and even ulcerations. Patients can get angina (chest pain due to cardiac ischemia (decreased blood flow) due to cardiac disease hastened by lack of cardiovascular exercise.

If polio survivors are facing any pains that are severe or that last more than a few weeks, they should have an evaluation by a musculoskeletal physician, primarily orthopedists and physiatrists. A careful history should be taken, including information regarding the patient’s polio history, other past medical history, functional history and how the pain problem is affecting mobility. The patient should be clear and give an example, such as, “I used to be able to lift a gallon of milk with my right arm and now it is difficult to hold a coffee cup.” This tells the examiner the time frame of the problem as well as the severity. After that, a thorough physical examination should follow including gait evaluation, if the patient is able. Strength, range of motion, sensory testing and inspection/palpation of the affected areas should be evaluated. Subsequent diagnostic testing may be necessary, including x rays, MRIs, bone scans, EMGs and lab work. With this information an appropriate diagnosis can be rendered with treatment to follow.

Beware: One of the worst things a polio survivor can do is feel that all his or her symptoms are part of a post-polio syndrome and think that nothing can be done to help. Hopefully this talk has given polio patients the knowledge to understand some of their unique potential pain generators and what can be done to evaluate them (and formulate a treatment plan).

Pain Symptoms in Polio Survivors

Paul E. Peach, MD
Medical Director, Palmyra Post Polio Clinic

Pain Symptoms are common in many polio survivors. Pain may be related to underlying post-polio syndrome, while in many cases, may also be due to unrelated causes. Therefore, an important first step is in accurately diagnosing the etiology (or, in some cases, etiologies) of the pain. Once the diagnosis is made, appropriate interventions can be undertaken. Common pain symptoms that are polio related include pain due to muscle pain, joint pain, tendonitis and pain due to compressive neuropathies. Most are due to underlying overuse patterns and with appropriate strategies for alleviating these stressors, significant pain reduction often follows.

Research Progress

Summary of Recent Post-Polio Research at the Montreal Neurological Institute and Hospital

Daria A. Trojan, MD, MSc
Physiatrist
Montreal Neurological Institute and Hospital
McGill University
Montreal, Quebec, Canada

We have completed and published several clinical research studies of relevance to post-polio patients over the last few years. Our studies have focused on pathophysiology, on fatigue, and on osteoporosis.

The cause of post-polio syndrome (PPS) is still unclear. Several hypotheses have been proposed including distal degeneration of enlarged post-polio motor units which develop during recovery from paralytic polio, motor neuron loss, normal aging, overuse, disuse, and immunological mechanisms. Gonzalez and co-workers (2002) reported increased mRNA levels of pro-inflammatory cytokines (signaling molecules) in the cerebrospinal fluid (and not the blood) of 13 PPS patients compared to normal controls. We have extended these findings by measuring the actual levels of several pro-inflammatory markers in the blood of 51 PPS patients and comparing them to 26 healthy controls. Another aim of the study was to evaluate the association of elevated inflammatory markers with several clinical parameters including muscle strength, fatigue, and pain. We found that the levels of several inflammatory markers (TNF-α, IL-6, and leptin) were increased in the blood of PPS patients compared to normal controls. Increased levels of TNF-α were associated with pain, specifically muscle pain. The reason for the increased inflammatory markers is unknown, but our findings indicate that inflammation may play a role in the ongoing PPS disease process.

We have also been interested in the area of fatigue in PPS and post-polio patients. Fatigue occurs in most PPS patients and is usually reported as the most disabling symptom. Two studies have been completed. The first was concerned with sleep disordered breathing in fatigued post-polio clinic patients and the second with biopsychosocial correlates of fatigue.

Sleep disordered breathing is the general term used to describe different types of breathing disorders during sleep. Three types of breathing disorders during sleep have been described: obstructive, central, and mixed apnea and hypopnea. Obstructive sleep apnea and hypopnea is characterized by repeated episodes of upper airway collapse during sleep, despite attempts at breathing. This can cause reduced blood oxygen levels during sleep and fragmented, poor sleep. These difficulties can lead to daytime fatigue and somnolence (sleepiness), as well as a number of neurocognitive difficulties (such as problems with attention and concentration) and medical difficulties. In the general population daytime sleepiness and fatigue can improve dramatically with treatment such as nasal continuous positive airway pressure (CPAP). Central apnea is characterized by cessation of airflow without attempt at breathing. Mixed apnea is a combination of the two. The aim of our study was to determine the frequency, predictive factors, and symptoms predictive of sleep disordered breathing in fatigued post-polio clinic patients. The study was a cross-sectional study involving a chart review of 590 post-polio clinic charts. 98 patients were included and all had a complete overnight polysomnogram (sleep study) in a sleep laboratory, 98% in the same laboratory. The gold standard for the diagnosis of sleep disordered breathing is in-laboratory, technician-attended, complete overnight polysomnography. An apnea-hypopnea index (AHI) was calculated. AHI is the total number of sleep related events per hour of sleep, and is used to assess the severity of sleep disordered breathing. The frequency of sleep disordered breathing was 65% (AHI≥5) and 50% (AHI≥10). The most common type was obstructive sleep hypopnea, present in 86% of patients with sleep disordered breathing. Most patients had mild (43%, AHI 5 to 15) or moderate (42%, AHI 15 to 30) sleep disordered breathing. A smaller proportion had severe sleep disordered breathing (16%, AHI > 30). Age, sex, age at acute polio, time since acute polio, weakness and respiratory difficulties at acute polio, speech and swallowing difficulties at acute polio and at evaluation, body mass index, pulmonary function measures, alcohol use, sedative drug use, smoking, fibromyalgia, kyphoscoliosis and scoliosis and ear/nose/throat surgery were not predictive of sleep disordered breathing. Snoring was more common in subjects with sleep disordered breathing. We conclude that sleep disordered breathing is very common in fatigued post-polio clinic patients referred for sleep evaluation. Obstructive hypopnea was the most common type. Snoring was the only clinical symptom that tended to predict sleep disordered breathing. Based on our results, we recommend that all post-polio patients with daytime fatigue and somnolence atypical for PPS undergo evaluation for sleep disordered breathing.

Our second study of relevance to fatigue was concerned with the development of biopsychosocial models for fatigue in PPS. Our aim was to determine the biopsychosocial correlates of general, physical, and mental fatigue in PPS, by measuring the additional contribution of potentially modifiable factors after accounting for important non-modifiable disease-related factors. 52 ambulatory PPS patients were included. Fatigue was assessed with the Multidimensional Fatigue Inventory (MFI) which assesses fatigue on five subscales (General Fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation, and Mental Fatigue) and the Fatigue Severity Scale (FSS) which assesses fatigue in medical and neurological disease. We were concerned with general, physical, and mental fatigue because all three types of fatigue are reported in patients with PPS. Potential correlates for fatigue that we considered were disease-related factors (acute polio weakness, time since acute polio, PPS duration, muscle strength, pain, forced vital capacity, maximum inspiratory pressure, maximum expiratory pressure, body mass index, disability, fibromyalgia), behavioral factors (physical activity, sleep quality), and psychosocial factors (depression, stress, self-efficacy). Multivariate regression models were calculated for MFI General, Physical, and Mental Fatigue and for the FSS. Age-adjusted multivariate models with non-modifiable factors were first calculated. Then, age-adjusted models were calculated by determining the additional contribution of potentially modifiable variables while keeping the previously identified non-modifiable variables in the models. We found a different pattern of variables to be associated with general, physical, and mental fatigue. In multivariate models, correlates of general fatigue included disease-related and psychosocial factors. Correlates of physical fatigue were disease-related and behavioral factors. A correlate of mental fatigue was a psychosocial factor. A portion of fatigue could be explained by potentially modifiable factors. Because we identified several potentially modifiable predictors for both general and physical fatigue, our results suggest that an interdisciplinary rehabilitation team management program that can address several contributors to fatigue would likely be most useful in managing these fatigue types.

We have also been interested in the area of osteoporosis in post-polio clinic patients. Osteoporosis is a progressive skeletal disorder characterized by low bone mineral density that results in bone fragility and an increased tendency to fractures. Weakness is a risk factor for osteoporosis. Osteopenia is a decrease in bone mineral density and can be a precursor of osteoporosis. The aim of our study was to identify the frequency of osteoporosis at the hip and lumbar spine in a post-polio clinic population and to evaluate the association of muscle strength in the legs and other possible contributors contributing factors to osteoporosis with bone density results at the hip. The study was cross-sectional involving a chart review. 379 charts were reviewed and 164 patients were included. Most bone densitometries were performed at the same center with assessments at the hip and lumbar spine. Muscle strength was evaluated by manual muscle testing during a clinic neurological examination. The frequency of osteoporosis at the hip and lumbar spine was 32% and 10% of men, 9% and 6% of pre-menopausal women, and 27% and 11% of post-menopausal women. In a logistic regression multivariate model, the presence of osteoporosis at the hip was significantly associated with strength sumscore in the same leg in which the bone density was performed after adjusting for other important risk factors (age, body mass index, time since polio). We conclude that osteoporosis occurs commonly at the hip in post-polio clinic patients and that hip bone density is related to reduced muscle strength in the same leg. Based on our results, we recommend that all post-polio patients be evaluated for osteoporosis at both hips (or less preferably at the hip of the weaker leg) and at the lumbar spine.

Our studies had several limitations that were discussed in detail in the original publications. All studies summarized above were cross-sectional. Because of this, the temporal relationships and causal effects of the associations observed are unknown. In addition, our study of biopsychosocial models for fatigue in PPS had a relatively small sample size for this statistical technique. A larger sample size could have allowed us to find other contributors to fatigue in multivariate models.

In conclusion, we recommend that all post-polio clinic patients be evaluated for osteoporosis, and that all post-polio patients with fatigue or somnolence atypical for PPS be evaluated for SDB. Both disorders occur commonly in a post-polio clinic population. An interdisciplinary team approach may be best for management of several contributors to general and physical fatigue, but further randomized, controlled studies are necessary. Our finding of raised blood inflammatory markers in PPS, together with results from other research teams, prompt further prospective evaluation of the role of inflammatory mediators in the etiology and symptomatology of PPS.

Acknowledgments:

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Post Polio Research at Karolinska Institutet

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From the beginning of the 1980:s our research group has performed clinical, pathophysiological and interventional studies in the field of post-polio. The group has produced three dissertations and has three planned dissertations in the coming years. The research was in the first phase concentrated on neurophysiological and muscle morphological studies with a focus on consequences of compensatory mechanisms in overused muscles. During the last decade the research has been focused on immunology and intervention with immune modulation with intravenous immunoglobulin (IVIG) and on finding a biomarker in patients with post-polio syndrome (PPS). Furthermore, we have studied different aspects of quality of life in patients with fatigue and pain.

Overuse of muscle and compensatory mechanisms

Data from earlier studies from our group support the hypothesis that PPMD is due to denervation. Neurophysiological studies have shown signs of ongoing denervation which also is supported by findings of atrophic muscle fibres in muscle biopsies (Borg et al 1988, Borg and Henriksson 1991, Borg and Edström 1993). Macro-EMG studies have shown that the motor units in PPS patients are 5-10 times larger than normal indicating reinnervation by means of collateral sprouting (Tollbäck et al 1993). In other studies the largest motor units have been shown to decrease over time suggesting a failing reinnervation in PPS patients. Thus, the new or increasing muscle weakness in post-polio patients may be due to a denervation-reinnervation process that have reached its upper limit, i.e. the insufficiently compensated denervation leads to muscle weakness (Borg 1996).

Reinnervation is probably the most powerful compensatory mechanism. However, there are other compensatory and adaptive mechanisms in muscles of PPS patients leading to an increase of the contractile tissue or changing the contractile properties. Muscle fibre hypertrophy and an increased frequency of type I muscle fibres have been reported in the anterior tibial muscle (Borg et al 1988, Borg et al 1989) and Tollbäck (1995) found that the overused motor units had lost their differentiation and were activated in an all-or-none fashion. The motor unit properties were changed towards a uniform type with intermediate properties favouring strength before endurance and driven into contractile fatigue more easily than normal units (Tollbäck 1995).

In a double-blinded placebo controlled study study muscle training with substitution of enzyme Q-10 was evaluated. The exercise resulted in an increase of muscle power but there was no difference between Q-10 and placebo (Skough et al 2008). A rehabilitation programme based mostly on physiotherapy has been evaluated and found to increase quality of life mostly for mental but also for physical domains (Jung et al 2008a).

Immunological aspects of PPS and outcome of immunmodulatory treatment

Several authors have suggested that an immune response could be one explanation for PPS. In some studies an ongoing inflammatory process in the spinal cord of PPS-patients and oligoclonal bands in CSF have been detected. When evaluating cytokines in cerebrospinal fluid (CSF) of PPS patients we found an increase of cytokines, Il-4, TNFa and IFNg, (Gonzalez et al 2002). The levels were in the same range as those found in Multiple Sclerosis (MS), a well-known neuroinflammatory disorder. In a pilot study a down-regulation of the cytokine levels was seen after intravenous treatment with immunglobulins (IVIG), (Gonzalez et al 2004). This was followed by an increase of muscle strength as well as quality of life, especially for vitality (Kaponides et al 2006). This was confirmed in a randomized, multi-centre and placebo-controlled study (Gonzalez et al 2006) in which an increase of muscle strength as well as quality of life for vitality and general health was found. Decrease of the cytokine levels and the clinical effect lasted for one year (Gonzalez et al 2009a). After 2.5 years the cytokine levels were back to the levels seen before IVIG treatment and the clinical effect had vanished (Gonzalez et al 2009b). In an open clinical study Werhagen et al (2009) found that around 2/3 of 64 PPS patients had a decrease of pain after IVIG treatment.

In order to analyze the occurrence of systemic inflammatory changes muscle biopsies were studied applying more modern immuncytochemical techniques. We were able to find minor signs of inflammation in some of the PPS patients (Melin et al 2009). An increase of serum lipids have been reported in PPS patients. One might speculate that this is due to a systemic inflammatory process. However, we were not able to find a decrease of serum lipids after IVIG treatment (Melin et al, personal communication) and we are now comparing data from PPS patients with normal data in order to evaluate if there is a serum lipid increase in PPS patients.

Biomarkers for PPS

In a recent published study (Gonzalez et al 2009c) proteomics were performed on CSF from PPS patients. A highly predictive and disease-specific differential expression was found in five proteins. The findings provide argument for an ongoing nervous tissue damage in PPS and the proteins are also involved in apoptosis. Further studies are performed in order to correlate these findings to clinical parameters in order to evaluate the clinical significance of the different proteins as biomarkers for PPS. The possibility of a connection with spinal muscular atrophy was disclosed by a normal SMN gene finding (Bartholdi et al 2000). However, other potential genetical factors should be explored.

Pain, fatigue and quality of life in PPS

During the acute polio infection, the patients had signs of meningitis and there has been a discussion of whether or not the increased tiredness and mental fatigue may be due to an affection of higher CNS functions. In a few studies around half of the PPS patients had signs of affection of cognitive functions. We have not been able to reproduce this finding in a Swedish PPS population (Östlund et al 2005).

In contrary to the common belief, PPSpatients perceive less pain and vitality increases with increasing age (Östlund et al 2008). Furthermore, an increase of quality of life with increasing age and with male gender was found when performing SF-36 questionnaire in a large PPS cohort (Jung et al 2009a). It was also found that vitality in PPS patients was mostly of a physiological character in PPS patients and that mental fatigue was not a prominent feature(Östlund et al 2008). We have also been able to identify a subpopulation of PPS patients that were extremely fatigued (Östlund et al 2009). This group of patients were younger than the rest of the PPS patients and a thorough psychological analysis is now being performed. Analysis of pain in PPS patients showed that approximately 10% of the patients had neuropathic pain (Werhagen et al 2008). When neuropathic pain was present there was always a concomitant disorder for example lumbar disc hernia. Neuropathic pain was in most cases relieved by operation or medication.

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Bladder Inconveniences

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Why should polio survivors experience bladder inconveniences?
In order to see how the scene could be set for polio survivors to be at risk of having bladder inconveniencies we have to return to the acute phase of polio – is there evidence it affected the bladder and voiding process? From the epidemics of acute polio voiding disturbances are reported with a prevalence of around 20% (1-4), the prevalence being higher among adults than among children. The problem was by far urinary retention but incontinence also occurred as did serious urinary stasis and urinary stones. Symptoms usually lasted for a week, but permanent damage occurred in 15% of the cases.

Living with polio, however, also increase the risk of having bladder dysfunction. In order to understand that we will have to have a look at bladder anatomy, bladder function, nerve supply and factors affecting the voiding process.

Normal bladder function and voiding process
The bladder is a balloon situated in the pelvis. The detrusor muscle is situated in the bladder wall and by contraction it is able to create pressure and empty the bladder for urine. A successful voiding requires, however, that the sphincter relaxes at the same time. The sphincter is part of the pelvic floor and supported by it. The bladder has two functions: storage of urine controlled by the sympathetic nervous system and voiding controlled by the parasympathetic nervous system. In the baby these two functions automatically follow each other: the bladder fills, when it is full it empties. The first years of life the central nervous system matures and makes it possible for the individual to be conscious of the bladder and to control the voiding process. However, voiding is influenced by several additional factors other than intact nerves and muscles: Urine production, bladder capacity, opportunity, disease, upbringing, culture, habits, and psychological factors contribute as follows:
<u>Urine production</u>: depends on the amount of fluid in the body, consequently on the intake of fluid. The production is in general 1-1.5 litre per 24 hours, and the normal voiding volume 200 cc. Urine production is normally reduced at night under the influence of antidiuretic hormone.

<u>Bladder capacity</u>: normally the first desire to void is felt at about 200 cc, but suppression of voiding can be held to up to half a litre or more. A small capacity gives frequent voiding, and a large capacity – with some exceptions – gives infrequent voiding.

<u>Opportunity</u>: If you do not have nearby toilets with easy access you might come in trouble. Certain occupations as f. ex. bus drivers are at known risk of have problems on this account.

<u>Habits, upbringing, and culture</u>: your decision of when is it appropriate to void is influenced by these factors.

<u>Psychological factors</u>: stress and excitement gives a tendency to void while engagement tends to make you forget to void.

<u>Disease</u>: infection and tumours may give frequent voiding.

How do polio survivors have an increased risk of bladder dysfunction ?
<u>Impaired muscles and nerves</u>: a weak detrusor muscle may result in incomplete voiding, leaving residual urine behind. The bladder is as a consequence soon full again, and voiding becomes frequent. It may become so frequent that incontinence will be the experience. At worst there is no detrusor muscle contraction at all and a total retention of urine develops.

A weak sphincter/pelvic floor results in impaired ability to keep tight and dripping of urine will occur, especially in connection with jumping, laughing and coughing (stress incontinence).

The autonomic (sympathetic and parasympathetic) nervous system, that controls body functions other than striated muscles, may be imbalanced and give rise to difficulties in inhibiting voiding desire (urge-incontinence) (parasympathetic preponderance) or difficulties in initiation of the voiding process (sympathetic preponderance).

Disease: urine is a wonderful media for bacterial growth and sets the scene of frequent infections
Upbringing: in the forties and fifties the attitude in good nursing was to keep things on a fixed schedule, and for voiding this meant that children in hospitals were brought up to suppress their need for voiding until it was scheduled. Bad habits and overstretched detrusor muscle fibres could be the consequences.

Opportunity: weak muscles in arms and legs may make it difficult to get to toilet in time to avoid an accident.

Bladder capacity: weak detrusor muscle, hospital upbringing, bad opportunities and habit result in large bladder capacity, where as sympathetic preponderance may give a small bladder volume.
Urine production: in paralysed legs oedema build up during the day. When the force of gravity is reduced in bed, retained fluid is mobilised and excreted, resulting in a larger urine production at night.

Work-up for bladder dysfunction

Primary work-up: comprises of 3 simple tests and a screening for other diseases. First of all a drinking/voiding chart for three days should be fulfilled by the patient:

Time	Drinking volume	Voiding volume	Leakage/activity
	cc	cc	
	cc	cc	
	cc	cc	
	cc	cc	
	cc	cc	

A measurement of the velocity of the urinary flow is done by having the patient urinate into a flowmeter, and the residual urine (the volume of urine left after voiding) is measured by an ultra sound. Screening for disease is done by urinary stick (blood, infection), vaginal-rectal examination and ultra sound.

This work-up is often enough to get to diagnosis and treatment. If further work-up is needed the patient should be referral to an urologist for a full urodynamic investigation.

Treatment

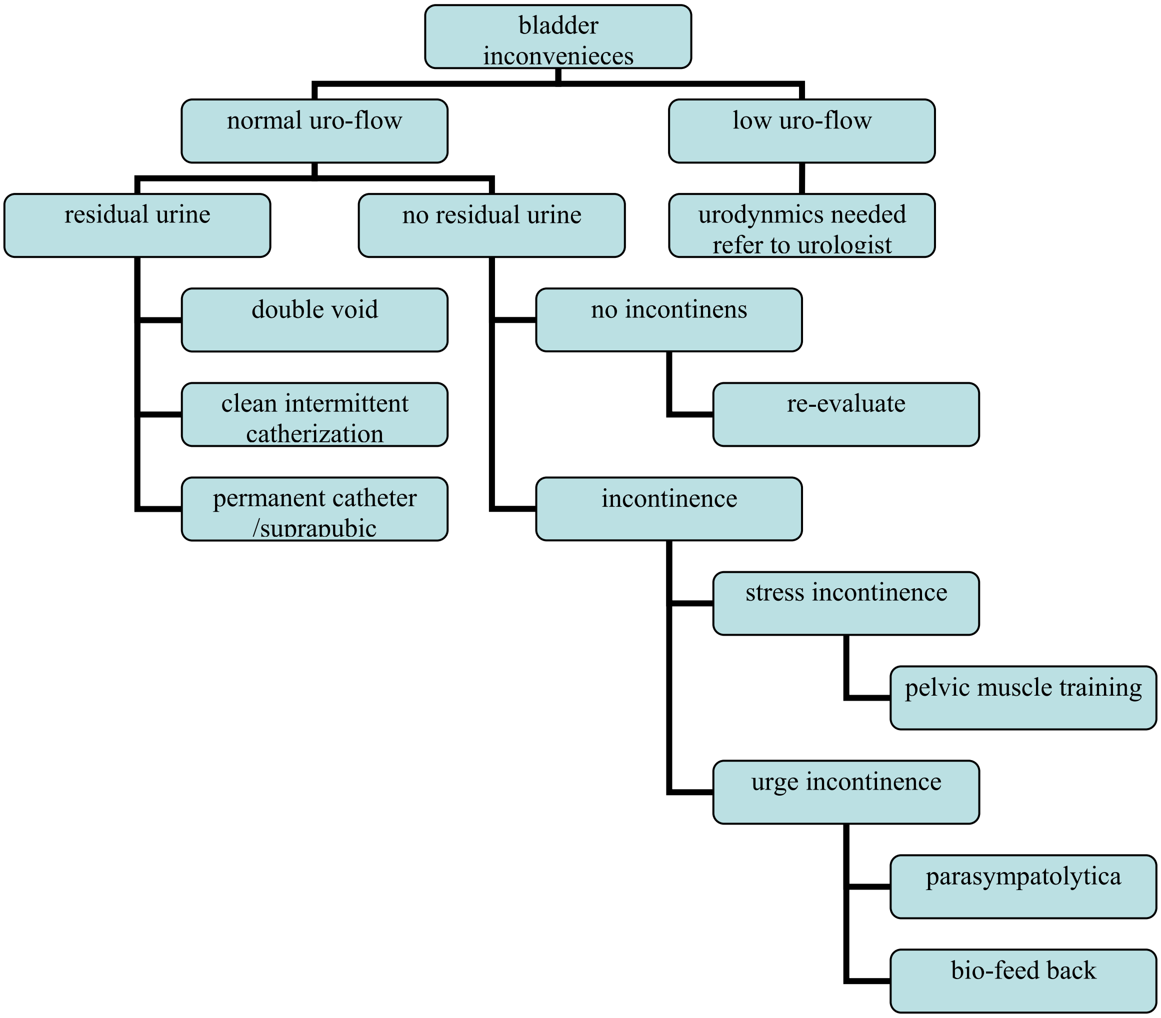
General advice: intake of liquid should be around 2 litres a day, less in the evening or before critical events (as going out). Voiding should also be performed before critical events (as going out or to bed) and with a frequency that gives a voiding volume of 2-300 cc with around 3 hours interval in the day time. Easy access can be important, in order to reach the toilet in time from the first desire to void until voiding is possible. This can implicate adjustments of both house and clothing.

Oedema: If the patient presents with oedema of the legs and the voiding chart shows a large urine production at night, oedema can be prevented in the daytime by elevation of the legs and/or an elastic stocking, and supplemented by a mild diuretic at 5 p.m. when necessary.

Residual urine: first step in the treatment of incomplete emptying (residual urine > 100 cc) is to double void (i.e. void once again at the same visit to the toilet). If this is not sufficient Clean Intermittent Self-catheterisation should be initiated. Most patients are able to do that with the supervision of an experienced urological nurse. The last choice is permanent a catheter, preferably as a suprapubic catheter inserted above the pubic region. This way of insertion gives less discomfort especially in connection with physical activities.

Urinary flow: if the urinary flow is low (< 15 cc/sec) or if it is impossible to obtain volumes > 100 cc the patient should be referred to a full urodynamic investigation.
Incontinence: stress incontinence may be treated by training of the sphincter/pelvic floor, where as urgeincontinence may be treated by bio-feed back and/or parasympatolytica (Darifenacin, Oxybutynin, Solifenacin, Tolterodin).

Summery of work-up and treatment for bladder inconvenience when other disease has been excluded



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The Secret to Good Attendant Care

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Report from the Camp Dreamers: Review of the Wellness Retreat

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The purpose of this presentation is to describe the Post-Polio Wellness Retreat program and provide an evaluation in order to encourage replication of similar retreats in new localities.

The Post-Polio Wellness Retreat at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) was a five-day residential health promotion program customized for polio survivors. Its design was built upon a model program that was successfully conducted in upper Michigan in 2006, 2007, and 2008. For more information, go to http://www.baycliff.org/ and link to Post Polio for a video review. Overall participant feedback from the Michigan program was positive:

> *"It's the best thing I ever did in my life."*
>
> *"The retreat went far better than I had ever dreamed. Everyone was so positive and it met all of their goals and expectations. The sense of group support, acceptance and camaraderie was remarkable!"*
>
> *"I can tell it will be a lifetime turning point for me."*

Developed and led by Frederick M. Maynard, M.D. and a selected planning committee, the 2009 wellness retreat at RWSIR's wheelchair accessible Camp Dream provided an affordable and unique opportunity for 60 participants to take time away from their daily routines to totally focus on their post-polio health and well-being. Retreat attendees set their own learning and health goals for the week. Based on the premise that attention to good health should include all of a person's interlaced parts---mind, body and spirit--participants attended daily educational sessions. Some were didactic with discussion; most were experiential. These were scheduled as a morning lecture and discussion for the entire group, followed by several choices of smaller group programs throughout the day. Morning activities included a choice of exercise sessions. Then following lunch and a one-hour rest period, the afternoons were devoted to two-hour recreational options and then breakout sessions on a variety of topics. Massages, manicures, facials and haircuts were offered throughout two of the days. After supper, the evening programs included full group singing around a campfire, listening to the firsthand stories of a local "historian" about the area, a movie followed by group discussion, and time to visit and play board games.

With a theme of “Discovery,” the basic curriculum more specifically encompassed the following selection of sessions.

- Full Group Instruction with Discussion
    - Post-Polio Wellness: A Holistic Overview Including the Role of Complementary and Alternative Medicine
    - The Post-Polio Body
    - The Mind: Self-Management Strategies for Wellness
    - Inspiration and Wellness: How Spirit Affects Health
    - Bringing It All Together: Reflection and Carry Over

- Morning Exercise
    - Strengthening and Stretching
    - Restorative and Non-Fatiguing Yoga
    - Aquatics
    - Cardiovascular Training
    - Tai Chi
    - Exercise for Shoulder Problems

- Recreational Options
    - Adaptive kayaking
    - Adapted golf, bowling
    - Fishing
    - Adaptive biking and hand cycling
    - Arts for Healing
    - Tour of Historic Sites
    - Warm pool swimming
    - Nature walk and roll
    - Experiencing Massage, a Manicure, a Facial

- Afternoon Breakout Sessions
    - Ask the Doctor: Orthotist and Physical Therapist: Bracing and Walking Aids
    - Ask the Doctor: Pain Management
    - Ask the Doctor: Fatigue Management
    - Ask the Doctor: General Medicine
    - Ask the Dietician: Weight Loss Strategies
    - Healing with Botanicals
    - Ask the Pulmonologist and Respiratory Therapist: Breathing Problems
    - Ask the Physical Therapist: Seating to Alleviate Pain
    - Ask the Nurse: How to Best Access and Use Complementary Medicine
    - Ask the Nurse: Osteoporosis Wellness and Management
    - Ask the Psychologist: Stress Management and Relaxation Techniques for Chronic Pain
    - Caregivers and Spouses: A Time Together
    - Integrating Spirituality
    - The German Health Spa Program: What If You Went to a Spa?
    - Acupuncture
    - Acupressure

This five-day residential wellness retreat, led by post-polio medical specialists and key polio survivors can provide a useful model for post-polio groups internationally and around the U.S. who wish to sponsor similar programs in their areas. Those who would like to initiate plans for a similar retreat may want to consider the following planning steps:

1. Find a Wheelchair Accessible Camp or Overnight Retreat Center
2. Establish a Planning Committee with Core Faculty Including Retreat Co-Directors and an On-Site Program Coordinator
3. Create a Program Budget and Plans for Funding
4. Design a Schedule of Daily Retreat Activities
5. Select and Prepare Additional Session Instructors/Facilitators
6. Publicize the Retreat
7. Select and Prepare Retreat Participants
8. Conduct the Retreat
9. Evaluate the Retreat's Success Level
10. Inform and Help Others Succeed in Conducting a Post-Polio Wellness Retreat

Participant evaluations of the retreat are helpful. The following questions may be asked as part of this process:

For each session they attended,

1. Was the content useful?
2. Which parts in particular?
3. What is one idea or activity you plan to make part of your normal routine within the next few months?
4. Please comment on the facilitator's delivery, pace, ability to relate to the group and ability to individualize material to meet your needs.
5. Overall how would you rate the session:
   5 excellent 4 good 3 average 2 below average 1 poor
6. Did you feel strengthened, refreshed and enlivened at the finish of this session? If yes, why? If no, why not?
7. Overall how would you rate the retreat:

5 excellent 4 good 3 average 2 below average 1 poor

What needs to be changed?

What was especially good?

Faculty and participant comments and evaluations at this Conference presentation of the Camp Dream experience will provide further programming insights and a foundation for the design and delivery of similar post-polio wellness programs.

For more information, contact Retreat Co-Directors, Frederick M. Maynard, M.D. at fmaynard@penmed.com and Sunny Roller, M.A. at elsol@umich.edu

SESSION S2

Second Step in Pain Treatment: Choosing Therapies

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Learning from Wise Elders

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This presentation reports the results of a two-part 2006 study funded by the National Institute of Disability and Rehabilitation Research entitled, *Adaptation Into Late Life for Persons with Long-Term Neuromuscular Disabilities: Lessons Learned from Polio Survivors.* The purpose of the presentation is/was to report the findings of the study and to discuss, with a panel of four study participants (from Arizona, Maine, Connecticut and Michigan), and the presentation audience applications for living successfully into late life with a chronic disability from polio. A summary of the study results follows.

Primary Study: Late Life Lessons Learned from Polio Survivors

Abstract

Even though people with a prolonged disability from causes such as poliomyelitis, spinal cord injury, spina bifida, and cerebral palsy are quickly emerging as a large elder population with accelerating needs, their patterns of adaptation into late life are ill defined. To describe late life success strategies, this investigation concentrated on the perceptions of a small and elite set of polio survivors--those who were designated the most highly regarded by their peer group as senior role models (or polio mentors), who were over 65 years of age and more than 50 years past disability onset.

The goal of this study was to expand knowledge about the late life physical, social and environmental adaptation experience of older individuals who contracted poliomyelitis between 1930 and 1955. To accomplish this purpose, specific physical changes, attitudes, coping techniques and adaptive behaviors facilitating improved quality of life over the life span and into late life were identified. To achieve the study

objectives, the PI, a polio survivor herself,[1] employed qualitative social research methodology, complemented by quantitative measures to describe the sample and document perceptions.

The four research questions guiding the study addressed the following topics: (a) issues polio mentors faced at various stages of the life course; (b) how perceptions of life with a disability changed over time; (c) attitudes viewed as most valuable for coping well with new issues into late life and how these attitudes differed from past ways of thinking; (d) how polio mentors defined "successful adaptation" in late life.

Objective measures of stress and life satisfaction were used to describe the sample. From a national network of post-polio support groups, purposive sampling was used to select 15 study participants with 93 respectively linked support group members in five regions of the U.S. During the study year, in-depth, audio taped semi-structured interviews (in person or by telephone) were conducted with the 15 key participants, who also completed the objective measures noted above. Qualitative analysis was performed using standard qualitative techniques (constant comparative method). Quantitative analyses included descriptive and inferential statistics.

Key Findings:

- Major issues throughout life included: achieving and maintaining independence which required diligent effort; fighting shame and creating a positive self-image with a disability; and reconciling social and functional losses
- Over time, perception of life with a disability from polio changed for this group. Before encountering the late effects of polio at mid-life, individuals operated and worked hard using their "lens of difference," a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial. Later in life they became more willing to look at their lives through the "lens of disability," more fully embracing their disability as part of their overall personal identity. In so doing, they found a new freedom to be more content with this new self-perception and life in their retirement years.
- Key coping strategies included having a strong social support system, enjoying life, being optimistic, self-acceptance, assertiveness, education and spirituality.
- Successful late life adaptation was defined as self-acceptance and adaptation, having the right resources, and being surrounded by loved ones.

Discussion

Successful late life adaptation was commonly defined as an outgrowth of self-acceptance and adaptation, having the right resources, and being surrounded by loved ones. These guidelines were built upon earlier life lessons that were revised for success in later life.

Over the lifespan, this group's perception of living with a disability from polio had changed. The years with polio during childhood, adolescence and as an adult were not comfortable. Before encountering the late effects of polio at mid-life, individuals operated and worked very hard using their "lens of difference," a self-perception that rejected the shame and powerful social stigma of disability. High achievement was crucial. Later in life, due to changing societal attitudes and new public policy, and out of practical necessity, this group became more willing to look at their lives through the "lens of disability," more fully embracing their disability as part of their overall personal identity. Once retired, there was no longer, for example, a need to prove oneself in the mainstream workplace and keep up with non-disabled competitors. These polio mentors seem to have found a new freedom to make further disability-related adaptations and be more content with who they really were becoming, and what they needed to do to live well during retirement years. Ironically, growing older with greater disability has offered this group a fresh sense of not only comfort, but also liberation. In many important ways, life was reported as better in old age than it ever was in youth.

Pilot Sub-Study: Describing Polio Survivors in Terms of Wisdom

Abstract

Some authorities say that wisdom, rather than intellectual knowledge is crucial for aging well, yet understanding and applying the notion of wisdom in the area of personal growth and successful aging among people with disabilities has not been attempted until now. To complement the larger study, a sub-study to explore characteristics of wisdom in this group and their polio support group peers was conducted. The purpose of this concurrent pilot study was to begin to describe polio survivors in terms of their individual perceptions about wisdom as well as Monika Ardelt's concept of wisdom. Ardelt's notion of wisdom is defined in terms of three separate, but interconnected ways of dealing with life: cognitive (intellectual objectivity), reflective (comprehending differing perspectives) and affective (empathy and compassion). The study's objectives were to document how polio mentors personally describe wisdom and its current role in their lives, and to describe the difference between Ardelt's measured wisdom levels in polio mentors and their support group peers. The total N for this sub-study was 108. A mixed-methods approach was utilized: qualitative inquiry complemented with use of the Three-Dimensional Wisdom Scale (3D-WS), Ardelt's quantitative measure. The primary study's sample of 15 key participants was 1) asked several questions about wisdom and 2) to complete the 3D-WS. After being invited by the groups' leaders, 11 of the 15 key participants' support groups volunteered to complete the 3D-WS, resulting in 93 responses. Qualitative analysis was performed using the constant comparative method. Quantitative data were analyzed using one-sample and independent samples t-tests to compare all elders to all support group members.

Key Findings:

- Participants defined wisdom as a combination of education and knowledge, the ability to see situations from another's point of view, and the ability to actively help, listen and share with others. The role of wisdom in their lives was described as being directly related to actively assisting their post-polio peer group.
- As a group, key participants scored significantly higher than support group members on the wisdom scale in the area of reflective wisdom only.

Discussion

Upon reflection, the basic conclusion of this pilot study might be summed up as one wise elder said, "my own wisdom is from things that I've experienced, places I've been, people I've known. Things I've done. That's absolutely the way I see my wisdom." This group's wisdom is real, but unique. This elite group of 15 polio survivors has lived with a chronic disability for more than 50 years, adapting so well they have become elected as "adaptation role models" by their observing peer group. When reviewing this preliminary information, several patterns about their distinctive form of wisdom have emerged.

Key participants defined wisdom as a combination of education and knowledge, the ability to see situations from another's point of view, and the ability to actively help, listen and share with others. The role of wisdom in their lives was described as being directly related to actively assisting their post-polio peer group, which would, of course, be different than that of a cross section of elders in the non-disabled population. These elders did not necessarily see themselves as wise among all men, but they humbly agreed that they did have some type of wisdom based on their unique life experience with polio. Their support groups, by way of this study, had just verified that distinction for them. They could help and advise others from that perspective. It should be noted that one limitation of this study was that there was no direct question asked to further discover how they actually saw themselves more globally in terms of wisdom. Did they feel that the combination of their polio and overall life experience had offered them a wisdom that matched the wisdom levels of society's other wise people?

It is interesting to examine this group's unique form of wisdom based on the results of Ardelt's quantifiable measure. As a cluster, key participants scored significantly higher than support group members on the wisdom scale in the area of reflective wisdom only. In terms of compassion (affective) or thinking/knowledge (cognitive) levels, the 15 did not score any higher that the rest of the support groups as a whole. This may say that the sample of wise elders was selected because they were perceived by their peer group as understanding and able to view life from the perspectives of others, specifically them. They were the individuals who could step outside of themselves and offer an objective point of view to those who needed them. It may be that their ability and willingness to look at phenomena and events from different perspectives may have actually been a key coping tactic that had to be developed over the years to compete and thrive in a non-disabled society. It has been deduced in various writings that any member of a minority group in a diverse society that is led by a privileged majority must study the ways of the majority in order to interact with them well and succeed. For example, although this is changing, black people in the American culture have said they needed to study and understand white people's ways if they were going to do well in a white-dominated society. So this is also likely to be true for those who are disabled in a non-disabled culture. In order to get what one needs to fit in, to become part of the mainstream, the disabled person must take the initiative to understand the dominant majority. (What is valued and important to that person? What does he want to achieve? What emphasis does he place on his and others' physical strength and prowess? How patient is he? How helpful is he? What does he need?) Perhaps it is only seldom that an able bodied person needs to, or chooses to understand the person who is disabled, at least at first meeting. It may be that at least for these selected polio survivors, the responsibility of understanding the other's perspective was well learned throughout life and then easily applied to support group members now in later life.

It is also worthy of note that as a group on the 3D-WS, being a post-polio wise elder is not positively related to the affective dimension of wisdom. Their lowest scores were in this area. Not only that, but the affective dimension of wisdom was correlated negatively (although not significantly due to the small number of cases) with life satisfaction. Hence this group's strong suit was not necessarily sympathetic and compassionate love for others. It may be that for this group, because of their life experience with disability, survival goals often had to trump compassion. Early on they learned that they had to work through the pain they may have felt physically through the years and rise above it. They had no time to feel sorry for themselves if they wanted to make it in society. They had to "use it or lose it" and press forward with persistence when they did not feel like it. At times this may have even seemed a bit self-abusive. Rehabilitation professionals and parents were tough on kids with polio because they were seen as having much weakness to overcome. Hence this study's subjects warned others about not associating with negative people too much. They would drag them down. Because they had to go beyond their own self-pity to overcome disability, they did not approve of self-pity in others and expressed low tolerance for "whiners." As one participant said, life with polio could make a person "damn tough."

Of this Ardelt comments, "I think avoiding "negative" people might be a good strategy for one's own well-being, but truly wise people are not affected by the negativity of others and, hence, are able to spend time with them and even help them to feel better. They can truly love the enemy." But does this reflect the practical real life wisdom of survivors of disabling diseases such as polio? It would be interesting to investigate whether excellent health lends itself better to extending greater compassion toward others than does disability. It may also be that the wisest of the wise elders are the ones who revealed that their experience with disability is now, in later life, making them more compassionate toward others with a disability, because they have grown in greater self-acceptance with their own disability.

…"having good people around me, especially happy, positive people that love to laugh and—that does a lot for me, to help me…"

Polypharmacy: Making it all Work

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Polypharmacy can be defined as the use of multiple medications for the treatment of a patient's medical conditions. The term polypharmacy suggests that more medication is being used than is clinically indicated. The number of meds taken by a patient that constitutes polypharmacy has not been defined. There are several reasons for poly pharmacy:

1) As the population ages, polypharmacy increases. The elderly often require multiple medications to treat multiple health-related conditions.
2) Patients with multiple co-morbid medical conditions also require numerous medications to treat each condition. It is not unreasonable for patients with multiple comorbid medical conditions to be on 6 to 9 medications to reduce his or her long term risk for those conditions, i.e, diabetes complications and coronary events.
3) A recent hospitalization also puts you at risk of polypharmacy. Medicines are started and stopped quite frequently during your hospital stay.
4) Multiple doctors are prescribing medications for the same patient. Once a patient starts a medication, it is never discontinued.
5) Doctor changes from one med to another within the same therapeutic class; but the patient doesn't stop taking the first med. For example: You are taking Protonix 40mg and Dr. gives you a prescription for Prevacid 30mg. Both of these drugs are in the same therapeutic class "Proton Pump Inhibitors" and work the same way. No one should be on both these meds. Prescription drugs switching to over-the-counter (OTC) status is another problem area in this therapeutic class. A patient may take Prilosec (OTC) and get a script for Protonix, Prevacid,, etc. This is why it is so important that you take all the meds you take on a regular basis with you when you go to the doctor.
6) Doctors also may have a patient on a brand name drug and write the next prescription for a generic drug. Example: A patient is taking Coumadin 5mg daily; the Doctor gives patient a prescription for Jantoven 5mg, another tradename for Coumadin. The patient continues to take both not realizing they are the same medication. This could have devastating consequences.
7) In an effort to cut costs, patients fill prescriptions at several pharmacies. Once you choose the most cost-effective pharmacy, stick to one pharmacy. One pharmacy would have a complete list of all your meds to better inform you of duplications, interactions, etc.
8) Lack of patient education is the most common reason. Doctors don't inform patients or patients do not ask questions.

Polypharmacy in of itself is not problematic. Consider, for instance, a patient with type 2 diabetes and existing coronary heart disease who has received a recent coronary stent for myocardial infarctiion. It is not unreasonable or uncommon for this patient to be on 6 to 9 medications to reduce his or her long term risk for diabetes complications and secondary coronary events. In fact, strict adherence to national treatment guidelines for this patient will result in a minimum of 6 concurrent prescription therapies.

Polypharmacy can, however, become problematic when negative outcomes occur. Polypharmacy has been shown to result in:

1) unnecessary and/or inappropriate medication prescribing
2) increased risk for drug interactions and adverse drug reactions
3) nonadherence
4) increased overall drug expenditures.

The prescribing of inappropriate medication often results in polypharmacy. For example, an 85-year old woman is prescribed Elavil® (amitriptyline) 50mg at bedtime for insomnia. Common side effects include constipation, urinary incontinence, dizziness, dry mouth, and dry eyes. To "treat" the side effects, a prescriber may prescribe

Senokot® for constipation, Ditropan® for urinary incontinence, and eye drops for dry eyes. Here, the prescribing of one therapy to treat insomnia results in a total of four medications.

Mark H. Beers, MD, a gerontologist, has been advocating the use of criteria-developed through consensus panels for identifying inappropriate use of medications. He states that "the use of a medication is appropriate if its use has potential benefits that outweigh potential risks". His first list was developed specifically with the frail elderly nursing facility resident in mind. In 1997, Beers updated his criteria to include medication inappropriate in all patients over 65 years old. Pharmacists can use both sets of criteria in prescription processing and drug regimen review to improve the pharmacotherapeutic regimens of their elderly patients.

Treatment of Polypharmacy

1. **Maintain an accurate medication and medical history.** Identify all medications, including any OTC therapies. Having a complete list of medications can deter a provider from adding on an additional therapy. Further, knowledge of a specific medication being used may explain a patient-specific symptom or complaint. For example, knowing a patient is on an opiod analgesic may explain why he or she has constipation. A complete history of the patient's medical condition also is important. Identifying the patient's medical history allows the pharmacist to identify inappropriately prescribed medications. For instance, metformin is not appropriate for patients with end-stage kidney disease.
2. **Link each prescribed medication to a disease state**. Each medication should match a patient's diagnosis. Any medication that does not match a diagnosis is potentially unnecessary, and an attempt to discontinue the medication should be made. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is a not-for-profit (nongovernmental) organization. Its mission is to improve the safety and quality of care provided to the public through the provision of health care accreditation and related services that support performance improvement in health care organizations. JCAHO recognized this problem and instituted Medication Management Standard 3.10 in 2005, which states "*Only medications needed to treat the patient's condition are ordered".* This means that prescribers of accredited facilities (RWSIR is accredited by JCAHO) are required to write indications for all medications prescribed (or at least mention somewhere in the chart why the patient is taking that medication).
3. **Identify medications that are treating side effects.** The use of multiple medications leads to a higher risk of side effects. When side effects occur, additional medications can be initiated to treat the side effect. A common example includes the use of laxatives to treat the medication side effect of constipation. Other examples include:
    - **The use of sleeping meds** to treat insomnia caused by theophylline, prednisone & antidepressants
    - **Aricept® (Donepezil)** to treat cognitive impairment caused by obybutynin,/tolterodine, antihistamines, opiods, and benzodiazepines

    Discontinuing one drug that is causing a side effect can often lead to the discontinuation of several drugs.
4. **Initiate interventions to ensure adherence**. Using combination products (i.e., lisinopril/hydrochlorthiazide combination pill) will reduce overall pill number and potentially improve adherence. Other strategies include using generic options to reduce cost and using adherence aids such as pillboxes.
5. **Reconcile medications upon discharge from hospital or skilled nursing facility**. As mentioned above, a risk factor for polypharmacy includes recent hospitalization. The transfer of a patient from a hospital to his or her home is associated with adverse events and negative outcomes, most of which are related to changes in the patient's drug therapy during treatment in these facilities. Evaluating a patient's medication regimen and educating a patient upon discharge from a facility is likely to reduce duplicate therapy, inappropriate prescribing, and reduce unnecessary medication. JCAHO has recognized this and made medication reconciliation a 2005 National Patient Safety Goal for all accredited hospitals.

6. **Prevention.** The appropriateness of the medication for the patient and the potential for side effects must be considered. As the old adage goes, "an ounce of prevention is worth a pound of cure". Any drug that is unnecessary, inappropriate, or has a high likelihood for causing side effects that would require additional therapy should be avoided.

Role of Pharmacists

The role of the pharmacist in the prevention and treatment of polypharmacy differs depending on the health care setting. Long-term care pharmacists routinely evaluate drug therapy regimens in predominantly elderly patients. They adhere to federal regulations with the goal of reducing negative outcomes associated with polypharmacy. Hospital pharmacists review the complete and accurate list of the patient's medications, evaluate this list for drug therapy problems that arise when medications are discontinued and initiated during hospitalization. Community pharmacists play a vital role in polypharmacy by preventing the dispensing of unnecessary, inappropriate, and side effect-prone medication.

Role of Consumer

By being an informed consumer, you can help prevent polypharmacy. The following is a list of steps to help you get started:

1) The **most important** thing you can do is **get involved** in your healthcare. Studies show that you have better outcomes when you are involved. Don't be afraid to ask questions.
2) **Know the name and strength of the medications you take, their indications, side effects, and drug interactions.**
3) Buy generics whenever possible. When you start on a new medication, ask for samples. You may not be able to tolerate it and can change meds before you get a prescription filled.
4) Brown-bag it: take all your meds including prescriptions, over-the-counter (otc) meds, and dietary/herbal supplements with you when you go to the doctor's office or hospital. You can keep a list, but you have to constantly keep it up-to-date. Remember that otc's are medications and can interact with your prescription meds. The latest news reports have covered the potential interaction where Prilosec® (Omeprazole) decreases the antiplatelet effect of Plavix®(clopidrogel). With the majority of data suggesting this, patients thinking about buying OTC omeprazole might be wise to buy an histamine (H2) antagonist (Pepcid® or Zantac®) at this time.
5) Have someone (spouse, friend) go with you to the doctor. Two ears are always better than one!
6) Ensure dietary/herbal supplements are safe before taking. Long term efficacy has not been determined. The majority of data concerning these products are derived from small trials with poor study design. These so-called natural products are not regulated by FDA, and stronger data supporting their efficacy is needed. For now, look for the USP seal on the label. Only supplements bearing this mark have been verified by US Pharmacopeia that the bottle contains the ingredients listed on label; is free of harmful contaminants; will properly release into body, and was made using good safe manufacturing processes. To become "savvy supplement user", see these Websites:
7) *http://www.cfsan.fda.gov/~dms/ds-savvy.html*
   http://dietary-supplements.info.nih.gov
   http://nccam.nih.gov (1-888-NIH CAM)
   www.ftc.gov
8) Store meds in a cool, dry place; preferably someplace where you can remember to take them (on the kitchen table if you take meds with meals or at the bedside if you take at bedtime). Be sure to keep these meds out of the reach of small children.
9) Ask your pharmacy for flip-top lids if you have a hard time opening the child-resistant lids.
10) If you can't remember if you've taken your meds, try a med dispenser. You can fill them up weekly, and you know at the end of the day if you have taken them or not.

11) Expiration date: The date at which the manufacturer can no longer guarantee the full effect of the medication.

12) Be environmental friendly and avoid flushing and pouring discontinued/expired medications down the sink. Instead, mix meds in cat litter or coffee grounds and place them in the trash.

Different Forms of Therapy

Approximately 4 out of every 10 adults report the use of some type of complementary and alternative medicine (CAM). The most common forms include natural products, deep breathing exercises, meditation, chiropractic or osteopathic manipulation, massage and yoga. CAM use is complementary in nature and is used in conjunction with our conventional medicine. Unfortunately, the forms of CAM that have the best evidence of efficacy, such as acupuncture, have lower rates of use in the survey. The concerns about cost of a conventional therapy could inspire patients to consider CAM over standard treatments, especially given the current economic environment.

Remember, the most important step in preventing negative outcomes regarding polypharmacy is **getting involved** in your own healthcare. Become an informed consumer. All medications (prescriptions and over-the-counter) have risks as well as benefits. As a consumer, you must weigh the benefits vs. the risks carefully before taking. You must appreciate the power of medicine, the value of meds when used properly and the consequences when used improperly.. You have both the responsibility and the duty of learning about how to take each medication safely.

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Too Hot and Too Cold: Causes and Solutions

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Body Temperature Regulation

Body Temperature
- "Core" temperature
  - As warm-blooded creatures, we maintain a consistent internal temperature within 1 degree Fahrenheit in normal circumstances
- Surface temperature
  - The skin and sub-cutaneous tissue temperature is affected by environment

Normal Body Temperature
- Range of normal
  - From approximately 97 F to 99 F (oral measurement)
  - Fluctuates slightly during the day- diurnal variation
  - Temperature variations may be more pronounced in young people
- Minor variations from normal with extreme exercise, and environmental extremes
  - Temperature regulation not 100% effective or instantaneous

Regulation of Body Temperature
- Skin, subcutaneous tissues and fat act as a heat insulator
- Fat conducts heat 1/3 as readily as other tissues
- Insulation maintains internal body temperature, allowing skin to reflect external temperature

Heat Transfer from Core to Surface
- Blood vessels in the subcutaneous tissues transfer heat to the body surface
- Vessels can constrict, reducing blood flow and conserving heat
- Vessels may dilate, allowing a high rate of blood flow to the skin to dissipate internal heat

Heat Production
- Body metabolism produces heat
- The rate of heat production is affected by:
  - Basal metabolic rate
  - Muscle activity
  - Hormones
  - Neurotransmitters

Factors Affecting Basal Metabolic Rate
- Activity/ Exercise
- Digestion (specific dynamic action) of protein
- Age
- Thyroid hormone
- Sympathetic nervous system
- Male hormone
- Growth hormone
- Fever
- Climate
- Sleep
- Malnutrition

Heat Loss

- Radiation: heat radiates to and from the body in the form of infrared heat rays
- Conduction: direct transfer of heat from the body to other objects including air or water
- Convection: removal of heat by convection air currents
- Evaporation: 0.58 Cal of heat is lost for each gram of water that evaporates from the body
- Combination of methods increases efficiency

Heat Balance

- Rate of heat production equals rate of heat loss
- To maintain balance the nervous system can affect either rate of heat production and/ or rate of heat loss by activating various temperature control mechanisms

Role of the Nervous System

- The hypothalamus has heat-sensitive neurons that function as temperature sensors
- Activation of heat-sensitive neurons results in vasodilatation and sweating
- Pathways involved in cold response are found in the hypothalamus, midbrain and medulla
- Multiple feedback- feed forward loops exist

Body Temperature Reduction

- The hyopothalamus may decrease body temperature by:
    - Blood vessel dilatation through inhibition of the sympathetic centers
    - Increased rate of sweating
    - Inhibition of shivering and chemical thermogenesis
- Sweating
    - Sweat glands innervated by sympathetic cholinergic nerves
    - Sweat glands can also be stimulated by adrenergic neurotransmitters circulating in the blood
    - Sweating effectively uses conduction and evaporation to cool the body

Increasing Body Temperature

- The thermostatic mechanism of the hypothalamus can raise temperature by:
    - Skin vasoconstriction by increased sympathetic outflow
    - Pilo-erection
    - Increased heat production through shivering, sympathetic “chemical” excitation (occurs in brown fat) and thyroxine secretion

Detection of Cold

- Cold receptors in the skin, spinal cord, abdomen
- Skin has far more cold receptors than warmth receptors
- Reflex responses include:
    - Shivering to increase body heat production
    - Inhibition of sweating
    - Vasoconstriction in the skin

“Balance Point” Temperature

- Critical value above or below which the temperature control mechanisms are activated to bring temperature back to the balance point
- Original “set-point” term implies a unified control system
- Balance point is affected by temperature receptors in the hypothalamus, midbrain, medulla and peripheral signals

Changes in “Balance Point”

- Pyrogens raise the set-point of the hypothalamus
- Anti-pyretics (aspirin, etc) lower the “set-point”
- Neurotransmitters, hormones and medications may affect thermoregulatory neurons

Dysfunction of Temperature Regulation

What makes us “too hot” or “too cold”?
- Difference between core temperature and “balance point”
- Temperature control mechanisms overwhelmed by external temperature
- Dysfunction of temperature control mechanisms
- Peripheral temperature changes related to core temperature

Too Hot
- Heat Sensitivity
- Heat Intolerance: inability to be comfortable when external temperatures rise
- Hyperthermia: elevation of core body temperature
  - May lead to heat stroke

Causes of Heat Sensitivity
- High basal metabolic rate
- Excess body fat
- Thyroid/ parathyroid disorder
- Hormone changes: pregnancy, menopause
- Myelinopathies (i.e. multiple sclerosis)
- Stimulants: caffeine, amphetamines

Causes of Hyperthermia
- Increased body heat production
  - Overexertion
  - Fever: infection, cancer, auto-immune disease
  - Medications, chemicals and toxins
  - Metabolic disorder: hyperthyroid, parathyroid dysfunction
- Decreased sweating: dehydration, poor circulation, old age
- Decreased conduction: high ambient temperature
- Decreased evaporation: high humidity
- High body mass index- lower surface area in relation to mass

Drugs Associated with Hyperthermia
- MAO inhibitors
- SSRIs
- Amphetamines
- Tricyclic antidepressants
- Dextromethorphan (may be in cough medicine)
- Analgesics: aspirin, tramadol, demerol
- Antihistamines
- Cocaine

Polio-Related Causes of Heat Sensitivity
- Increased energy requirement to perform activities
- Decreased sweating due to sympathetic nerve dysfunction
- Lower peripheral capillary density

Too Cold
- Cold Sensitivity: Feeling cold or sensitivity to the cold
- Cold Intolerance: an abnormal sensitivity to a cold environment or cold temperatures
- Hypothermia: abnormally low core body temperature

Causes of Cold Sensitivity
- Normal genetic variant
- Normal aging
- Stress
- Low body fat
- Low basal metabolic rate
- Raynaud’s phenomenon
- Poor circulation due to cardiovascular disease
- Anemia
  - Iron deficiency
  - Thiamine deficiency
- Thyroid / Hypothyroid disorder
- Metabolic disease
- Malnutrition

Causes of Hypothermia
- Decreased Shivering
  - Normal aging
  - Hypoglycemia
  - Hypothalamic Dysfunction
  - Spinal cord injury
  - Drug effects
- Decreased vasoconstriction
  - Spinal cord injury
  - Hypothalamic dysfunction
  - Drug effects
- Behavioral dysfunction
  - Psychiatric disorders
  - Seasonal affective disorder
  - Drug effects
- Decreased endogenous heat production
  - Sepsis
  - Liver failure
  - Hypoglycemia
  - Hypothyroidism
  - Shock
  - Drug effects

Drugs Associated with Hypothermia
- Alcohols: behavioral, vasodilatation
- Beta-blockers: decreased cardiac output, altered fat and glucose metabolism
- Alpha agonists (Clonidine): hypothalamic depression
- Cholinergic agents (cholinesterase inhibitors): sweating, impaired glucose metabolism
- Neuroleptic drugs (phenothiazines, piperidines, butyrophenones): hypothalamic depression
- Sedative hypnotic drugs (barbituates, meprobamate, chloral hydrate): hypothalamic depression, behavioral

Polio Related Causes of Cold Sensitivity
- Reduced peripheral circulation related to muscle activity
- Immobility of limb
- Lower capillary density
- Decreased basal metabolic rate
- Polio involvement of midbrain and medulla
- Sympathetic nerve dysfunction

Management of Temperature Sensitivity

- Medical evaluation
- Evaluate medications for potential side effects
- Avoid:
  - Smoking- impaired circulation
  - Caffeine- causes vasoconstriction
  - Alcohol- causes vasodilatation (increasing heat loss), slows metabolism
- Optimize body mass index
- Good hydration and nutrition
- Regular exercise program to improve peripheral circulation and efficiency of temperature control mechanisms
- Biofeedback
- Environment Control
  - Climate considerations
    - Temperature, humidity, wind
  - Indoor climate control
    - Drafts/ fans
    - Special programs through gas/ electric companies to ensure ability to heat and cool home adequately
- Proper clothing
  - Do not wear constricting clothing or shoes
  - Wear several layers of loose clothing
  - Insulating fabric/ materials: silk, wool, polypropylene, fleece
  - Cover head, neck, hands, feet
  - Use a blanket or throw when sitting still
  - Camping/ sporting good stores and websites are good resources

Resources

Because heating costs are high, the U.S. Department of Health and Human Services has funds to help low-income families pay their heating bills. For more information, contact the Low Income Home Energy Assistance Program (1-866-674-6327) or the Eldercare Locator (1-800-677-1116).

The NIA has free information about hypothermia. To order the fact sheet, *Hypothermia: A Cold Weather Hazard*, or the brochure, *Stay Safe in Cold Weather*, call toll free 1-800-222-2225. *Hipotermia: El Peligro de las Bajas Temperaturas* is also available. These and other free publications on healthy aging can be downloaded from the NIA Web site at www.nia.nih.gov

Warm Clothing
http://www.wintersilks.com/
http://www.sierratradingpost.com/
http://www.llbean.com/?qs=3009633
http://www.cabelas.com/

When Are Trachs an Option?

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Home Mechanical Ventilation (HMV) has saved the lives of many polio survivors and individuals with other neuromuscular conditions. Its benefits far outweigh its inconveniences and the psychological adjustments of needing a machine to assist with breathing. These include 1) Improving quality of sleep, daytime functioning, and quality of life; 2) Increasing lung functioning, energy, muscle strength, longevity; and 3) Strengthening the immune system and reducing risks of respiratory illnesses.

We believe that non-invasive ventilation (NIV) is the most appropriate form of ventilation for most people with neuromuscular respiratory conditions. However, some vent users have opted to use a tracheostomy (trach). Deciding to use a trach is a complex issue. In the following pages we offer information and assessment tools to explore the option of using a trach when NIV ceases to provide enough of respiratory support to function effectively. While using a trach is not suitable and affordable for every vent user, we consider it a valid option when NIV no longer meets a person's needs. Each vent user needs to decide whether NIV or a trach suits his or her medical conditions and lifestyles best.

"I would definitely prefer to use non-invasive ventilation (NIV) rather than a trach if NIV enabled me to breathe adequately and function effectively. *However, after using NIV for over 22 years, I had increasing breathing problems during the day when I was off of my volume ventilator. Then, in 2006, after an emergency surgery and respiratory failure, I could no longer breathe off my ventilator. I agreed to receive a trach to save my life.*

With the trach, I currently am able to function off the ventilator during the day for extended periods. The airway hole allows me to inhale and exhale room air that I need to breathe easily. Since I still am unable to breathe just through my nose, I would need to be connected to NIV all day if I didn't have a trach. Even then, I am not sure that NIV would adequately ventilate my lungs. When I used NIV, I had difficulties with air leaks and air traveling to my stomach, exacerbating my IBS condition. I used numerous interfaces, including custom made masks. Despite NIV's advantages, I prefer the mobility and freedom that a trach currently affords me. I hope I will grow strong enough to return to using NIV. But if not, I will continue to depend on a trach to keep me alive and able to experience what gives meaning, satisfaction, and joy to my life." ***Linda Bieniek, Polio Survivor & Ventilator User: NIV 22 yrs, Trach 3***

"It is essential that every individual have a knowledgeable ***health advocate*** *who understands their condition, past and recent experiences, personal preferences, and wishes. This advocate must be a person educated in the clinical need…..They should be kept abreast of new developments and usually should accompany the person in person when they access the health system, health facilities, use any health resources."* ***Allen Goldberg, MD, PHI/IVUN Honorary Board Member,*** served as the health advocate for Margaret Pfrommer, a polio survivor friend who was paralyzed from her neck down and used NIV until her final years when she transitioned to using a trach.

Obstacles to Using Home Mechanical Ventilation (HMV) include:

1. **Lack of access** to knowledgeable healthcare professionals: pulmonologists, respiratory therapists, Emergency Room and hospital staff, and home health providers as well as equipped facilities in remote areas and developing countries.
2. **Psychological factors**: such as losses of control, independence, mobility, quality of life, self-esteem; relationship, intimacy, and role changes; fears of institutionalism, isolation; anxiety and PTSD triggers; depression, and dissociation.

Benefits and Disadvantages of Trachs and Non-Invasive Ventilation

Tracheostomy		Non-Invasive	
Benefits	**Disadvantages**	**Benefits**	**Disadvantages**
• Saves lives when person cannot breathe sufficiently on NIV & has dangerous blood gas levels & minimal vital capacity	• **See "Obstacles" above on psychological issues.**	• Significantly lower out-of-pocket costs for assistance & supplies	• **See "Obstacles" above on "access, psychological issues."**.
• Provides more direct and stronger ventilation to the lungs • Reduces problems with interface leaks • Reduces gastrointestinal problems since air is not traveling into the stomach & causing bloating	• Increases out-of-pocket expenses **significantly** for assistance & supplies. • Legislation often limits care to RN & RT professionals with high hourly rates.	• Provides greater mobility if only needed at nighttime & limited daytime hours	• Interface air leaks limit the volume of air into the lungs • Finding an interface (mask, mouthpiece) that fits properly & comfortably
• Provides breathing through inner cannula while off the vent during daytime periods rather than needing to use non-invasive vent continuously	• Increases daily care needs: ➢ Personal assistance ➢ Suctioning ➢ Cleaning equipment	• Reduces risk of infections because airway is not exposed	• No alarms. Risk of tubing disconnections while asleep.
• Aids recovery of pneumonias: ➢ Suctioning access to mucous ➢ Direct pressure via Cough Assist	• May require a speaking valve to talk or may be unable to talk	• Less need for assistance if vent user is able to use arms & hands	• May reduce ability to see well with nasal or full face mask interfaces
• Alarms when equipment disconnects or pressure changes • Internal & external batteries may last 7-8 hrs	• Need for: ➢ Secretion management & humidity ➢ Extra equipment, supplies ➢ Back-up generator	• Provides greater independence & mobility, higher self-esteem	• 24/7 users may experience some difficulties speaking & eating with mouthpiece interface
•	• Possible risks of: ➢ Infections ➢ Bleeding from irritations ➢ Granulated tissue	• Smaller, lighter equipment increases ability to travel	• No back-up battery for emergencies.
•	• Reduces ability to live at home independently	•	• Need for back-up generator during emergencies

"*The cost of care and caregiver legislation and conditions become 'monumentally' more difficult if you have a trach (especially 24/7) and are trying to live in the community…the 'RN only'restrictions in many areas create a huge liability, unless you can take care of your trach yourself- especially the suctioning.*" ***Audrey King, Polio Survivor & Non-Invasive Ventilator User-- Used a Trach for 2 years***

"*When I got home from the hospital I did my own trach care….I had help when doing a complete trach change, once a month at first and now once every other month. ….I need to be suctioned, on average, about once a day. Sometimes I go a week between suctioning and sometimes I'll be suctioned two or three times in one day….*" ***Richard Daggett, Polio Survivor & Ventilator User with a Trach since 1984***

"*Since 2006, the difficulties of living with a trach have been: 1) infections and pneumonias; 2) costs for needing greater assistance; 3) increasing dependencies; and 4) loneliness when I was unable to talk (for months), and when I don't have enough energy to connect with others even by phone or computer. Yet, I have NO REGRETS about getting a trach.*" ***Linda Bieniek, Trach User***

Decide on Whether To Use a Trach Before An Emergency--Factors to Consider The questions in this table can help you identify your needs, available resources, and whether you can afford to live at home with a trach. Each topic is important and relates to the challenges of living with a trach.	**YES**	**NO**	**COMMENTS RESOURCES NEEDED**
Healthcare Resources Do you have access to knowledgeable, responsive healthcare professionals including a pulmonologist, home health care services, and an accessible medical center/hospital equipped to handle your use of HMV?			
Psychological Resilience Do you consider your life worth living? Do you have a purpose in life? Are you creative and resourceful in finding ways to fulfill your personal needs?			
Coordination of Care **Do you have an available, dedicated Health Advocate who understands your clinical conditions, needs, & preferences & will communicate with health professionals & oversee coordination of your care?** Do you have a dedicated supporter who will coordinate a communication network to provide you with information, suggestions, resources, support, greetings, and prayers?			
Daily Assistance: Are you capable of doing your own trach care? How much assistance will you need in addition to what you currently receive? Will you need 24/7 help? Do you have enough reliable assistants (family, friends, volunteers) to provide daily trach care, emergency assistance, & coordination of appointments with health professionals, home health providers, and suppliers?			
Financial Costs What costs will your health care insurance, government assistance, and/or long-term care policy pay for? What will your out-of-pocket costs total after reimbursements from health insurance and other sources? Can you afford the unreimbursed costs for personal assistance, supplies, and equipment? Will you be able to afford to continue living in your current arrangement or will you need to change it?			

Living Arrangement Will you be able to physically manage your current living arrangement--alone or with others? Can you adapt to living in government-funded housing or a nursing home if you cannot afford in-home care?			
Support Network: Do you have a strong network that will visit and assist you? Do you have meaningful relationships that you can depend on for emotional support? Do you stay connected with individuals & organizations through a phone & computer?			

"After experiencing the downsides of receiving a trach in an emergency situation without any prior planning, I highly recommend that vent users consider the following issues to help in making a rational decision about whether to use a trach in the short or long-term." ***Linda Bieniek, Trach User***

Explore Resources and Issues Related to Using a Trach

1. **Obtain information** about using a tracheostomy with HMV from:
    a. International Ventilators Users Network (IVUN). www.ventusers.org articles on NIV and trachs, *Resource Directory for Ventilator Assisted Living,* and *Home Ventilator Guide*.
    b. West Park Health Centre's e-learning modules: www.westpark.org www.ltvcoe.com/training_oelib_home.html.
    c. Ottawa Rehabilitation Institute's e-learning modules: www.irrd.ca/education.
    d. LISTSERVS' participants. See list in the *Resource Directory for Ventilator Assisted Living* on www.ventusers.org. Consider comments from individuals objectively since their attitudes differ for a variety of reasons.
2. **Consult resources** to gain perspectives and determine your sources of support—healthcare, financial and personal**:**
    a. Ventilator users, preferably who have used both non-invasive and invasive ventilation:
        i. Watch CHEST video of Audrey King describing her experiences adjusting to a trach. Contact mlederer@chestnet.org for a copy.
        ii. Obtain referrals from International Ventilator Users Network (IVUN): 314.534.0476. director@ventusers.org.
    b. Your pulmonologist to gain insights about the pros and cons given your conditions.
    c. Other pulmonologists who specialize in HMV. Obtain names from www.ventusers.org: *Resource Directory for Ventilator-Assisted Living* or from IVUN at 314.534.0475.
    d. Insurance carriers about your policy's eligibility and reimbursement provisions.
    e. Government and social service agencies to learn if you qualify for any services.
    f. Your support network to find out the time and assistance they can commit to provide.
3. **Assess the facts and opinions** you have obtained along with the following:
    a. "*Invasive and Non-Invasive HMV: The Benefits and Disadvantages*"
    b. Your answers to questions in "*Decide on Whether To Use a Trach Before an Emergency--Factors To Consider"* section.
4. **Decide** if you are willing and able to afford to live with a trach:
    a. For the short-term, during your recovery from an emergency?
    b. For the long-term, if you use NIV but your breathing worsens and you unable to function.
5. **Inform individuals in writing** of your decisions to accept or decline use of a tracheostomy:
    a. Designated Powers of Attorney for health care. Include instructions in your Living Will.
    b. The person who will serve as your "health advocate."
    c. The person who will serve as your "communication coordinator."
    d. Your health care providers and family/friends who may accompany you in emergencies.
    e. Professionals who can authorize submission of your decisions into a hospital/medical center's electronic records.
6. **Complete** a copy of the "***Take Charge, No Chances***" forms and give a copy to key individuals. Include your ventilator settings and emergency wishes. www.ventusers.org/vume/index.

In Response to Dr. John Bach's Assertion that "*Nobody with polio should have a tracheostomy tube for respiratory management – ever.*" Many of us know of, and admire Dr. Bach's understanding of physiology and work with HMV. While we have great respect for him and his dedication to his patients, we disagree with his assertion. Using NIV 24/7, as he does with individuals who have very low vital capacities, may not suit the lifestyles and preferences of all vent users. Richard Daggett, a Post-Polio Support Group Leader, responded to Dr. Bach's claims. A few of his comments are condensed below:

"Polio survivors differ and need medical care based on each individual's needs and not on a preconceived idea of what is best for "everyone."…Dr. Bach contends that, 'trach tubes are foreign bodies. They contain very bad bacteria that go into the lungs.' Yet instruments such as pacemakers and coronary stents are also 'foreign bodies' that save lives and enable individuals to live actively.

I have had a trach since 1984. It was my decision. I breathe easier and manage colds much better. No doctor told me, "You need a hole in your neck." I asked for the trach. Certainly a trach is not for everyone. Non-invasive respiratory assistance should be tried first. I firmly believe, however, a trach is a viable option for some."

Richard Daggett, Trach User since 1984

A recently published article titled, "*Quality-of-Life Evaluation of Patients with Neuromuscular and Skeletal Diseases Treated With Noninvasive and Invasive Home Mechanical Ventilation*" concluded:

> *"Patients receiving HMV reported a good perceived health, despite severe physical limitations. The patients with post-polio dysfunction and the patients with scoliosis treated with tracheostomy perceived the best health, compared with NIV for this diagnosis."*

Trach? Or Not?

Brenda Butka, MD
Vanderbilt University School of Medicine, Nashville, Tennessee

Why breathe?

"In with the good, out with the bad"
Pull in oxygen: fuel
Push out carbon dioxide: waste product

Breathing: The System

- Lungs: transmit oxygen/carbon dioxide
- Muscles: bellows to push/pull
- Airways: gas transit
- Brain: controller

Muscle weakness

- Lungs usually ok
- Not enough ventilation
- Poor cough

Consider

- Secretion management
- Ventilatory support

Secretion management = Cough

- Deep breath
- Strong exhalation
- Close glottis

Deep breath = volume

- Problem if VC less than 50%
- Supplement by
  - IPPB
  - Stacked ambu
  - Cough assist
  - Breath stacking

Exhalation

- Peak flow < 5 LPS
- Supplement
  - Manual assist cough
  - Cough Assist

Close Glottis for Cough

- Vocal cord problems hard to fix
- Tracheostomy
  - Cap
  - Passy-Muir valve

Secretion Management

- Cough Assist
- Suction
- Vibrating vest
- Flutter valve
- IPV

Consider

- Secretion management
- Ventilatory support

Ventilator support

- Invasive
- Noninvasive

Tracheostomy: WHY?

- Bulbar involvement
- Decreased compliance: “stiff” lungs
- Secretions
- Airway obstruction
- Failure of NIV

Tracheostomy Ventilation

- More secure
- Vents have batteries, alarms
- Usually can eat/talk
- Not necessarily 24/7
- Better interface for secretion management
- Caregiver stress/fatigue
- May not have long-term care options on vent

Ventilator support

- Invasive
- Noninvasive

Noninvasive

- Usually Bipap with backup rate
- Can use volume ventilator
- Negative pressure: cuirass or “lung”
- Belt
- Rocking bed

Noninvasive interfaces

- Fullface mask
- Nasal
- Oral
- Mouthpiece

Noninvasive

- Can be 24/7
- Speech/eating unimpaired
- Airway not as secure
- Doesn’t work if lungs are stiff
- Secretion management more difficult

Explanations and Demonstrations of Equipment

Kristy McClellan, RRT, Vanderbilt Stallworth Rehabilitation Hospital
Nashville, Tennessee

1. Types of Trachs
2. Types of Ventilation used with trachs (Bi-Pap, volume)
3. Types of Suctioning
4. Passy Muir Valve
5. Cough Assist Machine
6. Respiratory Therapist's role in managing ventilation and use of a trach

Trach or not?

You're not like anyone else …

SESSION S3

Post-Polio Research: Progress, Possibilities and Problems

Prof. Kristian Borg, MD, PhD, Karolinska Institutet, Stockholm, Sweden

**Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam,
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**Daria A. Trojan, MD, Montreal Neurological Institute & Hospital,
McGill University, Montreal, Quebec, Canada**

**Rahnuma Wahid, PhD, Manager Analytical Immunology, Sanofi Pasteur,
Swiftwater, Pennsylvania**

Post Polio Research at Karolinska Institutet

**Kristian Borg MD, PhD, Gunilla Östlund PhD, Lars Werhagen MD,PhD, Eva Melin MD,
Katarina Skough reg PT; Tae Du Jung, M.D, Henrik Gonzalez, MD, PhD
Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institutet.
Danderyd Hospital, Stockholm, Sweden**

From the beginning of the 1980:s our research group has performed clinical, pathophysiological and interventional studies in the field of post-polio. The group has produced three dissertations and has three planned dissertations in the coming years. The research was in the first phase concentrated on neurophysiological and muscle morphological studies with a focus on consequences of compensatory mechanisms in overused muscles. During the last decade the research has been focused on immunology and intervention with immune modulation with intravenous immunoglobulin (IVIG) and on finding a biomarker in patients with post-polio syndrome (PPS). Furthermore, we have studied different aspects of quality of life in patients with fatigue and pain.

Overuse of muscle and compensatory mechanisms
Data from earlier studies from our group support the hypothesis that PPMD is due to denervation. Neurophysiological studies have shown signs of ongoing denervation which also is supported by findings of atrophic muscle fibres in muscle biopsies (Borg et al 1988, Borg and Henriksson 1991, Borg and Edström 1993). Macro-EMG studies have shown that the motor units in PPS patients are 5-10 times larger than normal indicating reinnervation by means of collateral sprouting (Tollbäck et al 1993). In other studies the largest motor units have been shown to decrease over time suggesting a failing reinnervation in PPS patients. Thus, the new or increasing muscle weakness in post-polio patients may be due to a denervation-reinnervation process that have reached its upper limit, i.e. the insufficiently compensated denervation leads to muscle weakness (Borg 1996).

Reinnervation is probably the most powerful compensatory mechanism. However, there are other compensatory and adaptive mechanisms in muscles of PPS patients leading to an increase of the contractile tissue or changing the contractile properties. Muscle fibre hypertrophy and an increased frequency of type I muscle fibres have been reported in the anterior tibial muscle (Borg et al 1988, Borg et al 1989) and Tollbäck (1995) found that the overused motor units had lost their differentiation and were activated in an all-or-none fashion. The motor unit properties were changed towards a uniform type with intermediate properties favouring strength before endurance and driven into contractile fatigue more easily than normal units (Tollbäck 1995).

In a double-blinded placebo controlled study study muscle training with substitution of enzyme Q-10 was evaluated. The exercise resulted in an increase of muscle power but there was no difference between Q-10 and placebo (Skough et al 2008). A rehabilitation programme based mostly on physiotherapy has been evaluated and found to increase quality of life mostly for mental but also for physical domains (Jung et al 2008a).

Immunological aspects of PPS and outcome of immunmodulatory treatment

Several authors have suggested that an immune response could be one explanation for PPS. In some studies an ongoing inflammatory process in the spinal cord of PPS-patients and oligoclonal bands in CSF have been detected. When evaluating cytokines in cerebrospinal fluid (CSF) of PPS patients we found an increase of cytokines, Il-4, TNFa and IFNg, (Gonzalez et al 2002). The levels were in the same range as those found in Multiple Sclerosis (MS), a well-known neuroinflammatory disorder. In a pilot study a down-regulation of the cytokine levels was seen after intravenous treatment with immunglobulins (IVIG), (Gonzalez et al 2004). This was followed by an increase of muscle strength as well as quality of life, especially for vitality (Kaponides et al 2006). This was confirmed in a randomized, multi-centre and placebo-controlled study (Gonzalez et al 2006) in which an increase of muscle strength as well as quality of life for vitality and general health was found. Decrease of the cytokine levels and the clinical effect lasted for one year (Gonzalez et al 2009a). After 2.5 years the cytokine levels were back to the levels seen before IVIG treatment and the clinical effect had vanished (Gonzalez et al 2009b). In an open clinical study Werhagen et al (2009) found that around 2/3 of 64 PPS patients had a decrease of pain after IVIG treatment.

In order to analyze the occurrence of systemic inflammatory changes muscle biopsies were studied applying more modern immuncytochemical techniques. We were able to find minor signs of inflammation in some of the PPS patients (Melin et al 2009). An increase of serum lipids have been reported in PPS patients. One might speculate that this is due to a systemic inflammatory process. However, we were not able to find a decrease of serum lipids after IVIG treatment (Melin et al, personal communication) and we are now comparing data from PPS patients with normal data in order to evaluate if there is a serum lipid increase in PPS patients.

Biomarkers for PPS

In a recent published study (Gonzalez et al 2009c) proteomics were performed on CSF from PPS patients. A highly predictive and disease-specific differential expression was found in five proteins. The findings provide argument for an ongoing nervous tissue damage in PPS and the proteins are also involved in apoptosis. Further studies are performed in order to correlate these findings to clinical parameters in order to evaluate the clinical significance of the different proteins as biomarkers for PPS. The possibility of a connection with spinal muscular atrophy was disclosed by a normal SMN gene finding (Bartholdi et al 2000). However, other potential genetical factors should be explored.

Pain, fatigue and quality of life in PPS

During the acute polio infection, the patients had signs of meningitis and there has been a discussion of whether or not the increased tiredness and mental fatigue may be due to an affection of higher CNS functions. In a few studies around half of the PPS patients had signs of affection of cognitive functions. We have not been able to reproduce this finding in a Swedish PPS population (Östlund et al 2005).

In contrary to the common belief, PPSpatients perceive less pain and vitality increases with increasing age (Östlund et al 2008). Furthermore, an increase of quality of life with increasing age and with male gender was found when performing SF-36 questionnaire in a large PPS cohort (Jung et al 2009a). It was also found that vitality in PPS patients was mostly of a physiological character in PPS patients and that mental fatigue was not a prominent feature(Östlund et al 2008). We have also been able to identify a subpopulation of PPS patients that were extremely fatigued (Östlund et al 2009). This group of patients were younger than the rest of the PPS patients and a thorough psychological analysis is now being performed. Analysis of pain in PPS patients showed that approximately 10% of the patients had neuropathic pain (Werhagen et al 2008). When neuropathic pain was present there was always a concomitant disorder for example lumbar disc hernia. Neuropathic pain was in most cases relieved by operation or medication.

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Summary of Post-Polio Research at University of Amsterdam

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The research on post-polio syndrome in Amsterdam started in 1989 and was initiated by professor Marianne de Visser, neurologist. From that time on increasing numbers of Dutch patients with post-polio syndrome came to Amsterdam and were also seen in the Department of Rehabilitation. In 1993 funding was obtained for a PhD research project of Frans Nollet. Since then post-polio research has continued in Amsterdam, led by Marianne de Visser, Anita Beelen and Frans Nollet, resulting in 27 peer reviewed scientific papers up till now. PhD theses were written by Barbara Ivanyi in 1999, Frans Nollet in 2002, Herwin Horemans in 2005 and Merel Brehm in 2007. At present 3 PhD students are doing research Janneke Stolwijk-Swüste, Fieke Koopman and Irene Tersteeg and a fourth one will start soon. What has been studied so far and what is presently being studied?

Research has been focused on clinical studies. Some results are summarized according to the topics that have been studied over the past years and can be categorized as:
I - epidemiological and longitudinal studies
II - diagnostic studies
III – physiological studies
IV- intervention studies
V - methodological studies

Epidemiological and longitudinal studies
Polio victims from the last large epidemic in The Netherlands in 1956 with almost 1800 cases were studied 39 years later. In this population-based study among 260 respondents almost 60% experienced signs of new weakness, increased disabilities and handicaps and diminished health-related quality of life. The use of devices and adaptations had increased.(8,12)
A cohort of 103 polio patients was followed for six years. 27 of them had stable polio and 76 post-polio syndrome.(7,14) It appeared that health-related quality of life of the patients with PPS was lower compared to the stable functioning polio individuals. Over the years physical functioning did not change much. However, it appeared that the severity of paresis at baseline was a prognostic factor for decline in physical functioning in six years. These results supported the concept of overuse, that a (slow) decline in muscle mass, as a late effect of polio, may lead to a decline in physical functioning as the reduced muscle capacity becomes less able to meet the demands of daily physical activities.

In a systematic review of the literature we concluded that so far no conclusions can be drawn from the literature with regard to the functional course or prognostic factors in late-onset polio sequelae.(23) The rate of decline in muscle strength is slow, and prognostic factors have not yet been identified. Long-term follow-up studies with unselected study populations and age-matched controls are needed, with specific focus on prognostic factors. Therefore we are presently conducting a longitudinal study involving 168 polio individuals.(26) This study focuses on the effects of aging and co-morbidity on functioning over time. Individuals ranging in age between 45 and 85 have been included and in contrast with many other studies, co-morbidities are not excluded but its influence on the time course is studied as this reflects what happens in reality with aging. At the moment the participants in the study have been followed for 5 years. Some results have been published. Age and co-morbidities were found to be negatively associated with physical functioning and physical independence. The influence of these factors on the changes over time are being analyzed at present. More publications from this cohort-study will follow in the next years.

Diagnostic studies

The value of muscle computed tomography (CT) was studied. It was shown that muscles of post-polio patients experiencing new muscle weakness showed significantly more CT scan abnormalities compared with stable post-polio patients.(5) Muscle CT scan evaluation was considered a useful adjunct to muscle strength assessment and is now routine procedure in clinical practice. Furthermore, sleep complaints were inventoried. It appeared that up to half of post-polio patients reported complaints of disordered sleep, which was likely to influence daytime functioning. This was not further analyzed.(4) At present we are doing research on this in the aging study in collaboration with pulmonologists form the Center for Home Ventilation in Utrecht.

Physiological studies

Aspects of muscle function and exercise capacity were studied. It appeared that exercise capacity of polio individuals was mainly determined by the available muscle mass. No convincing evidence as found for a poor cardio respiratory condition. Results were comparable to normally active healthy controls.(11) We confirmed reports from others that polio individuals, especially those with post-polio syndrome may have difficulty with activating their muscles and are thus not fully able to recruit the available capacity.(13, 19) A clinical relevant finding is that the energy cost of walking is directly related to the severity of polio residuals.(24) This implicates that in case of two severely affected legs walking may cost twice (or even more) energy as compared to healthy people. Together with a reduced muscle mass this implies that 'one has to do more with less' substantiating the concept of overuse as a major cause of post-polio complaints. However, it appeared that only those individuals with severely reduced walking ability, reduced their walking activity in daily life.(22)

Intervention studies

In 2003 we reported a study on the effects of pyridostigmine (a drug that improves neuromuscular transmission) on fatigue, muscle strength and functioning in post-polio syndrome.(15) Unfortunately, we found no effect, which was in line with the results published earlier by Trojan et al. Our hope was that an effect could be found with different outcomes in polio individuals with proven neuromuscular disturbances.(10) However, this was not the case. Since, some limited effects were found, a potential benefit of pyridostigmine can not entirely be ruled out. However, that would require another study, accounting for individual differences in drug uptake. At present no such study is undertaken.

Another area of interventions is innovation and biomechanical optimization of custom-made leg braces. We demonstrated that the energy cost of walking can be reduced substantially by improving braces.(27) A chapter on state-of-the-art carbon composite orthoses for post-polio syndrome was written for the latest edition of the Atlas of Orthoses and Assistive Devices by the American Association of Orthopedic Surgery issued in 2008. At the moment, a grant has been obtained to write a clinical prescription guideline. Research on the innovation of braces is ongoing in collaboration with orthopedic technicians and industry.

Methodological studies

In scientific research it is important to investigate the measurement properties of the instruments that are applied: questionnaires, time scored tests, strength tests, (electro)physiological measurements and so on. A number of papers have been published in this area. It appears that strength measurements with a hand-dynamometer, but also in a fixed chair-dynamometer show large variations and are not very sensitive to detect small changes over time in individuals.(9,19) This implies that it is not easily possible to conclude that strength has really declined in evaluating a person with post-polio syndrome over time. It appears that walking tests and measurements of energy consumption are better able to detect individual changes, although the sensitivity to detect change is less in polio individuals than in healthy controls.(21,24) In a recent paper, we recommended the Medical Outcomes Study Short Form 36 scale Physical Functioning and a 2-min walk test at self-selected speed to be used as core qualifiers for physical functioning, the major increasing disability in late-onset sequelae of poliomyelitis, to assess perceived physical performance and walking capacity in research and clinical practice.(29)

Research in progress

At present we are following up the cohort that is focusing on aging and co-morbidity. These studies are being done by Janneke Stolwijk-Swüste and Irene Tersteeg and supervised by Anita Beelen.

Another study is an intervention study to reduce fatigue and improve functioning. Two different strategies are being investigated physical exercise and a cognitive behavioral approach. This study is part of a larger project involving also other neuromuscular disorders, coordinated by senior-researchers Anita Beelen and Kimi Uegaki. This study is being done by Fieke Koopman and a second PhD student will be involved.

Finally, studies are ongoing regarding orthotic devices and clinical guidelines involving senior-researchers Merel Brehm and Carine van Schie.

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Summary of Recent Post-Polio Research at the Montreal Neurological Institute and Hospital

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We have completed and published several clinical research studies of relevance to post-polio patients over the last few years. Our studies have focused on pathophysiology, on fatigue, and on osteoporosis.

The cause of post-polio syndrome (PPS) is still unclear. Several hypotheses have been proposed including distal degeneration of enlarged post-polio motor units which develop during recovery from paralytic polio, motor neuron loss, normal aging, overuse, disuse, and immunological mechanisms. Gonzalez and co-workers (2002) reported increased mRNA levels of pro-inflammatory cytokines (signaling molecules) in the cerebrospinal fluid (and not the blood) of 13 PPS patients compared to normal controls. We have extended these findings by measuring the actual levels of several pro-inflammatory markers in the blood of 51 PPS patients and comparing them to 26 healthy controls. Another aim of the study was to evaluate the association of elevated inflammatory markers with several clinical parameters including muscle strength, fatigue, and pain. We found that the levels of several inflammatory markers (TNF-α, IL-6, and leptin) were increased in the blood of PPS patients compared to normal controls. Increased levels of TNF-α were associated with pain, specifically muscle pain. The reason for the increased inflammatory markers is unknown, but our findings indicate that inflammation may play a role in the ongoing PPS disease process.

We have also been interested in the area of fatigue in PPS and post-polio patients. Fatigue occurs in most PPS patients and is usually reported as the most disabling symptom. Two studies have been completed. The first was concerned with sleep disordered breathing in fatigued post-polio clinic patients and the second with biopsychosocial correlates of fatigue.

Sleep disordered breathing is the general term used to describe different types of breathing disorders during sleep. Three types of breathing disorders during sleep have been described: obstructive, central, and mixed apnea and hypopnea. Obstructive sleep apnea and hypopnea is characterized by repeated episodes of upper airway collapse during sleep, despite attempts at breathing. This can cause reduced blood oxygen levels during sleep and fragmented, poor sleep. These difficulties can lead to daytime fatigue and somnolence (sleepiness), as well as a number of neurocognitive difficulties (such as problems with attention and concentration) and medical difficulties. In the general population daytime sleepiness and fatigue can improve dramatically with treatment such as nasal continuous positive airway pressure (CPAP). Central apnea is characterized by cessation of airflow without attempt at breathing. Mixed apnea is a combination of the two. The aim of our study was to determine the frequency, predictive factors, and symptoms predictive of sleep disordered breathing in fatigued post-polio clinic patients. The study was a cross-sectional study involving a chart review of 590 post-polio clinic charts. 98 patients were included and all had a complete overnight polysomnogram (sleep study) in a sleep laboratory, 98% in the same laboratory. The gold standard for the diagnosis of sleep disordered breathing is in-laboratory, technician-attended, complete overnight polysomnography. An apnea-hypopnea index (AHI) was calculated. AHI is the total number of sleep related events per hour of sleep, and is used to assess the severity of sleep disordered breathing. The frequency of sleep disordered breathing was 65% (AHI≥5) and 50% (AHI≥10). The most common type was obstructive sleep hypopnea, present in 86% of patients with sleep disordered breathing. Most patients had mild (43%, AHI 5 to 15) or moderate (42%, AHI 15 to 30) sleep disordered breathing. A smaller proportion had severe sleep disordered breathing (16%, AHI > 30). Age, sex, age at acute polio, time since acute polio, weakness and respiratory difficulties at acute polio, speech and swallowing difficulties at acute polio and at evaluation, body mass index, pulmonary function measures, alcohol use, sedative drug use, smoking, fibromyalgia, kyphoscoliosis and scoliosis and ear/nose/throat surgery were not predictive of sleep disordered breathing. Snoring was more common in subjects with sleep disordered breathing. We conclude that sleep disordered breathing is very common in fatigued post-polio clinic patients referred for sleep evaluation. Obstructive hypopnea was the most common type. Snoring was the only clinical symptom that tended to predict sleep disordered breathing. Based on our results, we recommend that all post-polio patients with daytime fatigue and somnolence atypical for PPS undergo evaluation for sleep disordered breathing.

Our second study of relevance to fatigue was concerned with the development of biopsychosocial models for fatigue in PPS. Our aim was to determine the biopsychosocial correlates of general, physical, and mental fatigue in PPS, by measuring the additional contribution of potentially modifiable factors after accounting for important non-modifiable disease-related factors. 52 ambulatory PPS patients were included. Fatigue was assessed with the Multidimensional Fatigue Inventory (MFI) which assesses fatigue on five subscales (General Fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation, and Mental Fatigue) and the Fatigue Severity Scale (FSS) which assesses fatigue in medical and neurological disease. We were concerned with general, physical, and mental fatigue because all three types of fatigue are reported in patients with PPS. Potential correlates for fatigue that we considered were disease-related factors (acute polio weakness, time since acute polio, PPS duration, muscle strength, pain, forced vital capacity, maximum inspiratory pressure, maximum expiratory pressure, body mass index, disability, fibromyalgia), behavioral factors (physical activity, sleep quality), and psychosocial factors (depression, stress, self-efficacy). Multivariate regression models were calculated for MFI General, Physical, and Mental Fatigue and for the FSS. Age-adjusted multivariate models with non-modifiable factors were first calculated. Then, age-adjusted models were calculated by determining the additional contribution of potentially modifiable variables while keeping the previously identified non-modifiable variables in the models. We found a different pattern of variables to be associated with general, physical, and mental fatigue. In multivariate models, correlates of general fatigue included disease-related and psychosocial factors. Correlates of physical fatigue were disease-related and behavioral factors. A correlate of mental fatigue was a psychosocial factor. A portion of fatigue could be explained by potentially modifiable factors. Because we identified several potentially modifiable predictors for both general and physical fatigue, our results suggest that an interdisciplinary rehabilitation team management program that can address several contributors to fatigue would likely be most useful in managing these fatigue types.

We have also been interested in the area of osteoporosis in post-polio clinic patients. Osteoporosis is a progressive skeletal disorder characterized by low bone mineral density that results in bone fragility and an increased tendency to fractures. Weakness is a risk factor for osteoporosis. Osteopenia is a decrease in bone mineral density and can be a precursor of osteoporosis. The aim of our study was to identify the frequency of osteoporosis at the hip and lumbar spine in a post-polio clinic population and to evaluate the association of muscle strength in the legs and other possible contributors contributing factors to osteoporosis with bone density results at the hip. The study was cross-sectional involving a chart review. 379 charts were reviewed and 164 patients were included. Most bone densitometries were performed at the same center with assessments at the hip and lumbar spine. Muscle strength was evaluated by manual muscle testing during a clinic neurological examination. The frequency of osteoporosis at the hip and lumbar spine was 32% and 10% of men, 9% and 6% of pre-menopausal women, and 27% and 11% of post-menopausal women. In a logistic regression multivariate model, the presence of osteoporosis at the hip was significantly associated with strength sumscore in the same leg in which the bone density was performed after adjusting for other important risk factors (age, body mass index, time since polio). We conclude that osteoporosis occurs commonly at the hip in post-polio clinic patients and that hip bone density is related to reduced muscle strength in the same leg. Based on our results, we recommend that all post-polio patients be evaluated for osteoporosis at both hips (or less preferably at the hip of the weaker leg) and at the lumbar spine.

Our studies had several limitations that were discussed in detail in the original publications. All studies summarized above were cross-sectional. Because of this, the temporal relationships and causal effects of the associations observed are unknown. In addition, our study of biopsychosocial models for fatigue in PPS had a relatively small sample size for this statistical technique. A larger sample size could have allowed us to find other contributors to fatigue in multivariate models.

In conclusion, we recommend that all post-polio clinic patients be evaluated for osteoporosis, and that all post-polio patients with fatigue or somnolence atypical for PPS be evaluated for SDB. Both disorders occur commonly in a post-polio clinic population. An interdisciplinary team approach may be best for management of several contributors to general and physical fatigue, but further randomized, controlled studies are necessary. Our finding of raised blood inflammatory markers in PPS, together with results from other research teams, prompt further prospective evaluation of the role of inflammatory mediators in the etiology and symptomatology of PPS.

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Regulatory T cells as a Biomarker of Post-Polio Syndrome

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There are large numbers of polio survivors today who contracted acute paralytic poliomyelitis prior to the advent of widespread vaccination programs against poliovirus (PV). What is under appreciated is the fact that polio survivors are many years later at risk of developing new neurological deterioration, a condition recognized in the late 80's as post-poliomyelitis syndrome (PPS). PPS is a slowly progressive disease in individuals previously affected by paralytic poliomyelitis that is characterized primarily by new muscle weakness and atrophy. Diagnosis of PPS is time-consuming and complicated by the need to rule out other diseases that could explain the new symptoms. The ability of a physician to diagnose a specific disease can be significantly aided by the availability of one or several disease biological markers (termed biomarkers). No biomarker(s) has been identified for PPS as yet that could assist in providing a definitive, easy and rapid diagnosis.

Disease biomarkers are measures of biological parameters indicative of a disease process. They are useful because they can assist in diagnosis or provide a means of monitoring the disease as it progresses and the effectiveness of different therapies. The study conducted at the University of Arkansas for Medical Sciences (UAMS) was, therefore, designed to answer a simple question: Are there signs or changes in the immune system (that is an immunological signature) that can be linked to Post-polio Syndrome (PPS)? If so, these changes in the immune system could be potentially used as a biomarker to diagnose PPS quickly and efficiently and to possibly provide clues as to the causes of PPS.

In this study there were 3 groups of individuals – (1) healthy individuals who never had disease associated with poliovirus and were vaccinated with the polio vaccine, (2) stable polio survivors, who suffered from poliomyelitis and may have had the vaccine but currently do not have symptoms associated with PPS, and (3) individuals with PPS. The goal was to determine whether the types of immune cells and their functions observed in individuals with PPS were different from those from healthy individuals or individuals with stable polio.

The data from the study show that PPS individuals have higher levels of antibodies and regulatory T cells circulating in their blood than healthy age-matched individuals, while stable polio individuals have variable levels of these immune components, which overlap with both the PPS and the healthy individuals.

The data from this study suggest that there is possible immune dysregulation occurring within polio survivors (both stable and PPS individuals). Importantly, however, there was a lack of sufficient data from stable polio subjects. This lack of sufficient data from stable survivors makes it difficult to make definitive conclusions regarding the role of regulatory T cells (and/or antibodies) as an easily available diagnostic marker for PPS. The cause for the increased levels of the immune components (antibodies and regulatory T cells) is currently unknown.

The observations from this study do, however, suggest that there is a problem with the immune responses in polio survivors, which could contribute to PPS. Whether immune components have a direct role in the initiation and progression of PPS or merely indicate the presence of a problem with the immune system in these individuals is unclear at this time.

Comparison of Manual Muscle Testing and Function pre and post triplanar control dynamic response AFOs in polio survivors

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Background: Patients, including polio survivors, who had been fitted with lower extremity orthoses made by Dynamic Bracing Solutions (DBS) had reported to their orthotists that they felt some of their muscles had gotten stronger after using the DBS brace(s). We decided to conduct a small pilot study to investigate whether there was evidence that muscle strength changed after bracing.

A pilot study was done in 2006 with the first five polio survivors in Colorado who were each fitted with a DBS ankle foot orthosis (AFO). The subjects ranged in age from 59 to 80 years of age, three were women and two were men. The mean time since their original polio diagnosis was 60 years. Each subject had at least one manual muscle test (MMT) done 3 months to 4 ¾ years prior to being fitted with the brace; repeat MMT was done on the braced leg three months to twenty months by the same medical team that had done the original manual muscle testing. Each of the five subjects had improvement in strength in at least two of the seven major muscle actions (ankle dorsiflexion, ankle plantarflexion, knee extension, knee flexion, hip flexion, hip abduction, and hip extension) after wearing the DBS brace; one had improved strength in three muscle actions; one had improvement in five muscle actions and one had improvement in six. One of the subjects did also have decreased muscle strength in two of the major muscle actions.

In 2008-2009, a second study was done on five additional polio survivors who had been fit with DBS orthoses – three had a single AFO, one had bilateral AFOs and one had a KAFO. The subjects ranged in age from 57 to 68 years old and included four women and one man. These subjects had MMT done four to seven months prior to being fitted with the DBS orthoses and then repeated three to nineteen months after receiving the brace(s) by the same physical therapist. The results of this study showed improved muscle strength in only 0-2 of the seven major muscle actions in the ***braced*** leg, but showed improvement in muscle strength in 2-6 major muscle actions in each of the subjects who had a unilateral brace in the ***unbraced*** leg (four of these unbraced legs also had some post-polio weakness and/or deformity)

Five of the six subjects had enough weakness of their quadriceps and gastrocnemius that they would have been normally been prescribed a locked knee KAFO. But each of these people was successfully fit with a DBS AFO.

In the course of interviewing and examining each of the 10 subjects all reported improved function in their personal, professional, and recreational activities. Two had significant decrease in pain in their ankles while wearing the DBS orthoses; one had elimination of long standing back pain.

Summary: Data from this small study suggests that improvement of muscle strength may be possible in some polio-affected muscles after use of orthoses that are constructed utilizing triplanar control and dynamic response. It appears that muscle strength in the unbraced leg may also be improved, possibly as a result of decrease in overuse of that extremity.

Discussion: Further research is needed to determine if bracing results in decreased, increased, or no change in muscle strength (no studies have really investigated this, although the common concerns has been that wearing a brace promotes muscle atrophy and disuse of some muscles; different methodologies of bracing also need to be compared in this regard. In addition, objective research is needed to compare gait efficiency, energy expenditures, and quality of life with different types of orthoses. This would allow “evidence based” decision making when prescribing an orthosis.

Bracing: What’s New? Is Old Better?

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What's New in Orthotics?

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Introduction: "New" can, and is, many things. "New" can be technology, methodology, or a combination of both. New can be in the "eye of the beholder" or universally accepted as something different. My presentation will attempt to touch briefly on some of these issues.

Materials: Thermoplastics have now been used routinely for forty plus years. Traditional double and single upright systems are still provided. Traditional designs often incorporate thermoplastics and even laminates into "hybrid" systems. Today, titanium joints and uprights along with carbon graphite technology, represent the routine materials of the future. Medical grade silicones will augment comfort for limbs with very little protective padding.

Stance Control KAFO's: This type of orthotic joint locks for stance phase and unlocks for swing phase. There are a wide variety of designs and manufacturers that are involved in this technology. A good resource to begin research is the American Academy of Orthotists and Prosthetists web site: www.OandP.org. Another good web site is: www.OandP.com where you can link to some of the manufactures.

Microprocessor controlled joints: Now routinely used in prosthetics, it is, in my opinion, only a matter of time for the crossover to the orthotic field to occur. This crossover should make the concept of stance control more consistently reliable.

Methodologies: I feel at least six main methodologies are emerging.

First, computer aided design and manufacturing is becoming a more routine part of the orthotic and prosthetic industry. Digital imaging has been used prosthetically for some time and is now becoming routine in scanning for cranial helmets in the treatment of plagiocephaly. Again, I think it only a matter of time until the technology is refined enough that it can be applied to lower extremity orthotics. This technology can also store digital shapes of limbs or spine and compared to future scans. Cast molds can also be documented and stored. A replacement mold from one of these scans can be a matter of a few clicks from the computer. Modifications can also be made within the computer.

Secondly, a renewed emphasis on the full weight bearing stance phase control will need to become routine. Outcomes for amputees did not improve to what they are today, until the stance phase control was addressed. Old principles, such as three point pressure systems and ground reaction mechanics, will be advanced to meet the complex demands of the stance phase. Orthoses will be expected to hold a planned Triplanar alignment even when subjected to full loading with a patient's full weight in motion. The triplanar control in full weight-bearing can and will be documented by X-rays and compared.

Thirdly, bracing systems will be expected to provide the orthotic patient with a true dynamic response (energy return with a "push off") just like artificial limbs do today for prosthetic patients.

Fourthly, the concept of designing a unique comprehensive walking solution for each individual will become the treatment model. The development of an elaborate walking solution from A-Z will then dictate the development of each treatment component including the pre-training program, the orthosis itself, and the post-training programs. Each walking solution will consider a very comprehensive set of details. To create a walking solution one must recognize the smallest details that affect the efficiency of gait (the study of Pathomechanics). A greater understanding will be required to not only recognize, but also solve, each and every one of the finite details at every aspect of the gait cycle. Each person will have a unique puzzle and a different set of issues to consider in the solution development. For instance, the skeleton is the most important structure in human locomotion. It is held in an anatomic position throughout the gait cycle by a combination of muscles, tendons, and ligaments. Any compromise to any of these structural components, will alter the skeletal alignment over time. As alignment is compromised, balance, stability, and efficiency will be affected. Unless a multitude of corrective Triplanar forces are applied to counter these deficits, they will continue to progress. The longer these issues go unchecked, the faster the deficits will accelerate and compromise efficiency even further. Increasing deformities, stresses, pain issues, the eroding of joint surfaces, etc. will all lead to a decrease in balance, stability and efficiency.

The fifth, is a concept of Remodeling deformities with more advanced bracing methods. Many fixed deformities normally require surgical procedures to correct. Remodeling techniques and new bracing designs will improve the alignment while walking. Corrective techniques have been utilized in non-weight-bearing applications for a decade or two. For many people who may want to prevent surgery or due to medical reasons that will not be offered surgery, the Remodeling methods will become a viable solution.

Finally, quantifiable outcomes will drive the development of evidence-based care and objective parameters will be better defined and measured. The body of science around lower limb orthotics will expand in the near future. Greater understanding and research will define and build the science needed to improve quality of life in a multitude of ways. Some preliminary studies are showing new bracing methods are offering benefits such as a reversal of disuse atrophy, reduction of pain, reduced incidence of falls, improved efficiency, reduced fatigue, reduction in the use of assistive devices, regained function and improved quality of life.

We at DynamicBracingSolutions™ are using some old principles in new and more complex applications. We are applying new bracing concepts to reduce fatigue and improve efficiency. We are taking advantage of carbon/graphite technology by combining it with new methodologies and applying both to improved patient care. A wealth of information is available on our web site: www.DynamicBracingSolutions.net. On the web site a plethora of topics is covered under "New Bracing Concepts". These topics include balance and security, Triplanar control and alignment, remodeling, and dynamic response. For more information on the complexities of Assessment (the crucial aspect of solution development), please review "Assessment for Polio Bracing is part of an Individualized Walking Solution," in this publication.

Is Older Better?

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True principles/laws always dictate the type of outcomes in which we are all subject. Many times we think that there are simple solutions to everyday challenges that come our way. Meeting these seemingly simple but complex demands become evermore challenging when it comes to providing support/stability to the ambulatory needs of the polio patient.

In the field of orthotics (bracing) technological advances allow us to use newer materials and designs vs. the standard methods and techniques used previously. However, the goals are basically the same and that is to provide assistance to compensate for the discrepancies that have developed from the results and effects the polio virus has left. The development of newer materials allows us to go from biological to technological areas. From animal/mineral (leather and metal) to thermo mold and themo setting plactics (polymers/carbon fibers/acrylic resins).

From the patient perspective, why change? “If it works, I’ll use it.”, “Don’t change it.” Even if the conventional orthosis (brace) is working, is it doing all it can or providing the best support/stability that is available? Regardless of the material or design, it has to provide for the needs of the patient. Example, provides free motion, assisted motion, restricted motion, stopped motion, and or restrained motion. Patients dealing with disabilities are subject to external forces applied upon them. In this day and age, science has provided us with much greater knowledge of these external forces and how these forces affect the ability for functional ambulation. These forces affect the quality of stability and alignment in the areas of toes, mid-foot, hind-foot, ankle, knee, hip, pelvis, low back, trunk, head, neck and the upper extremities.

There are some unique challenges in working with patients who have had polio with its paralyzing effects and now have issues dealing with post polio syndrome. Paralytic motor dysfunction along with sensory input (proprioception) is at times very difficult to work with. This sensory input can at times facilitate and also complicate orthotic management. Both hypersensitive from tissue that has experienced high demands of pressure and joints that have experienced years of overuse syndromes together create very challenging opportunities in orthotic management.

Enhanced knowledge of kinesiology (study of muscles and muscular movement) allows practitioners to take advantage of advances in materials and components. It is essential for the clinician of today to have an acute awareness of the pathology (in this case polio) to be able to answer the questions of: why, what, where and how. Why is the patient here? What instability does the patient have and what devices are being used?

Where are the deformities and where does the path-o-mechanical pathways (pathway of mechanical force) go? How is the body compensating for the loss of normal function? How are current devices being used help in these compensations?

The goal of orthotic management is to take advantage of these ground reaction forces and distribute these forces in orthotic designs that allows the patient to tolerate them within acceptable limits. Proprioception will determine what these limits are and how effective they will be in supporting and providing stability. Patients will always vary in their clinical presentations but usually fall into classifications concerning the foot, ankle, knee, hip and/or a combination of all including spinal and upper extremity involvement. Protection of non-stable joints is essential in order to prevent further path-o-mechanical forces that lead to additional deformities. If at all possible, joint motion needs to be preserved in order to enhance a direction towards a more normal gait pattern. Patients who present with the use of orthotic design and componentry of yesteryear, need to be evaluated as to the effectiveness of design, componentry, durability, adjustability, and bio-mechanical appropriateness. With or without orthotic intervention, the body has a wonderful way of compensating. With this compensation, comes deviations in gait patterns that can lead to further complications in the future. Ground reaction forces in different planes will challenge joints, muscles, ligaments and also orthotic componentry. Orthotic design must be able to specifically resist and direct these forces in a way that will be an advantage and tolerable to the patient. Older orthotic designs and devices that meet these demands will usually continue to be used.

The use of older orthtoics devices usually means, “Status Quo”. However, as physicians, practitioners, therapists have learned, “Status Ouo isn’t always the best route to take as patients age and the demands of ambulation increase. The use of newer devices usually means changes in bio-mechanical forces that will create new forces on the lower extremities. However with new technology and materials, the new forces, unlike the limited pressure areas of the past, will be distributed over broader areas that will be much more tolerable. Older devices usually means heavier with more energy consumption while newer lighter designs reduce energy consumption which is extremely important for continued stability, ambulation and keeping independence.

Finally, change comes much more easily when information about the change is provided. Discussion with education leads to a better informed patient. A well informed patient may be more willing to accept and try change. When the patient makes the decision to try something new, there is a higher level of acceptance and satisfaction with a better understanding of the whys, whats, wheres, and hows regarding newer orthotic design.

Is older better? In my opinion , with over 50 years of experience on the patient side of the exam table and 30 plus years of experience on the practitioner side of the exam table, I would answer: sometimes Yes, but usually No!

Exercise and Activity: How Much and What? Let's get Practical

Merete Bertelsen, Physical therapist
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I work at a Rehabilitation Center for polio and accident victims in Denmark. The Center is owned and run by a patient organization called: The Danish association of Polio and Accident Victims. All staff members are employed by the organization, but the counties in Denmark pay for the treatment, so all assessments and treatments are free of charge for the patients.

878 polio survivors were treated at our clinic in 2008. Around 300 polio survivors exercise on a regular basis in PTU once or twice a week in our training center or in the warm water pool. 10,5% of the polio survivors are immigrants. Around 50 polio survivors are annually referred to the center for the first time. Most of them are elderly Danes who have managed to live without our help until now, but we also get a lot of immigrants from third world countries who have polio. They are often much younger and have a lot of social and language problems on top of the polio difficulties.

We have 7 wheel chair accessible apartments where polio survivors from other parts of the country can stay while they attend a 1 or 3 week program at the center.

The center has a multidisciplinary team to take care of the polio survivor comprising: Doctor, physical therapists, technical aids therapists, social workers, psychologists, nurse assistants, dietician and a private orthotist, who is coming once a week. It is necessary to have a doctor's referral to our clinic. Before coming to the clinic the polio survivor is asked to fulfill a questionnaire about his or her social conditions (work situation / housing), the acute and stable phase and the actual problems that have made the patient come to the clinic. The doctor makes an examination of the patient, and she considers if there could be other differential diagnoses, which could cause the symptoms of the patient. She can then refer the patient to different professionals at the clinic or to additional tests at a hospital. Almost all the patients are referred to physiotherapy.

When all the relevant professionals have assessed the polio survivor, a conference is held where all assessments from the multidisciplinary team are presented and we agree on which recommendations should be given to the patient. It is important that we all work in the same direction and of course the plan is made in cooperation with the polio survivor. When there are complicated matters, the patient participates in the conference.

Some polio survivors need changes in there home or at the place of work. Our technical aids therapist can visit the polio survivors home together with the therapist from the county in order to find the best adjustments. Some polio survivors need to save their energy, so they need technical aids, bandages or help with housecleaning. If the patient has a seating problem we can measure the pressure of the buttocks in the seat, which makes it easier to find the right cushion for the wheel chair.

We also have a polio education program where polio survivors and their relatives can learn about polio issues, exercising principles, technical aids and psychological reactions to the need of changing lifestyle as polio problems arise. I could tell a lot about what all the professionals do but I will focus on the physiotherapy and especially how we deal with exercising according to the title of this session.

The physiotherapist uses a check scheme to make a thorough anamnesis and examination of the patient. We use this to be sure that we get all necessary information about the patient and his or her condition before we make a treatment plan.

If the main problem is pain we consider the cause of the pain. Is it overuse of the body structures or is it a more diffuse pain in the polio muscles. Depending on which kind of pain the patient has, we use a variety of pain treatments: Exercise, acupuncture, laser therapy, medication, massage, relaxation, energy conservation, bandages, aids, etc.

If the patient experiences a decrease in strength we always make a manual muscle test. We know that the test does not give us the exact truth about the polio affection, but it gives us a good impression of how much polio affection there is. You can see on the slide that the manual muscle test only detects rather big decreases in strength, but we are therefore aware that there can be polio in a muscle, even if it seems strong in the test.

Grade

0	No muscle contraction	0%
1	Palpable contraction	< 5%
2	Gravity eliminated	5 – 10 %
3	Against gravity	10 –20 %
4	Moderate / good	40 %
5	Maximum resistance	> 60 %

We use the manual muscle test as a guideline for how the patient should exercise or which kind of bandages could be useful. During testing we can also see and feel if there are fasciculations during the test, which tell us that the muscle can be overused. Sometimes we can compare a recent test with a test taken some years earlier and in that way we can follow the development of the decrease in muscle strength. I should maybe mention that we do not take EMG measurements regularly in Denmark. We have very good journals of the patients polio history from their initial hospitalization and we find that the muscle test is enough in most cases.

To be able to tell if the treatment makes a difference we also use other tests. Not for everybody, but when it is relevant. I will mention these tests:

- 6 min walk test which is the distance walked in 6 minutes as fast as possible.
- Time used to walk 10 meters,
- Walking distance outdoor where the patient walk until he or she needs a break. We use this when applying for car or a parking sign.
- We also have balance and fitness tests.
- Timed Stands Test which measures the time necessary for getting in and out of a chair 10 times without using the arms.

After hearing the polio survivor’s story and performing the tests we make an evaluation to decide whether the problems are caused by disuse, overuse or maybe something else.

As in the States Denmark also has a rising number of lifestyle related diseases. The Health Department in Denmark recommends that everybody should do at least moderate exercising for 30 minutes each day. The polio population is in high risk of getting life style related diseases, because they often have a lower activity level than the rest of the population. The well-known life-style related diseases are: Hypertension, diabetes, osteoporosis, cardio-vascular diseases and depression. So even though a person has polio, he has to maintain a certain level of activity if possible and he has to keep his weight down in order to avoid further complications to his condition. The two main ways of handling this is healthy diet and exercising.

So what are the exercising recommendations for polio survivors in Denmark?

When we examine the patient we consider what status the muscles have. Is the strength stable or unstable? As you can see our recommendations of exercising the patients depends on the strength level and if the muscles are stable or not. By stable I mean, that there have not been more decrease in strength than could be explained by age. The last line in the slide represent the muscles that are so overused through daily activities, that they should not exercise more. But only very few patients cannot exercise at all. Most patients can benefit from exercising even in a very light way

Exercise and Activity: How Much and What? Let's Get Practical

John G. Fan, MD, Hutchinson Clinic,
Hutchinson, Kansas

Demystifying the Equipment of Assisted Breathing

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Kristy McClellan, RT, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Betsy Thomason, BA, RRT, Millennium Respiratory Services, Whippany, New Jersey

Accessible Housing for Aging Polio Survivors: Problems and Solutions

Maria Pellerin Barcus, Housing Partners
of Florida, Miami Beach, Florida

SESSION S4

Polio: A Look Back at the Public Health Crusade that Mobilized a Nation

**David M. Oshinsky, Jack S. Blanton Chair in History, and
Distinguished Scholar in Residence, New York University**

The battle against polio mobilized an entire nation against the mid-20th Century's most feared disease. It came at the height of public confidence in medical research, and it involved tens of millions of ordinary Americans who donated their time and their money to a voluntary effort that produced two successful polio vaccines following the largest public health experiment in world history. Led by the National Foundation for Infantile Paralysis, the polio crusade revolutionized both fundraising and medical research in the United States, as well as the way in which the federal government tested and licensed new drugs and vaccines before allowing them on the market.

In the process, the National Foundation created an enormous research and rehabilitation structure, some of which is still in place today. I call this an "American Story" – although its reach is global – because the largest polio epidemics occurred in the United States, and the battle to contain the disease was planned and carried out within our borders.

Note: A limited number of paperback copies of *Polio: An American Story* by David M. Oshinsky will be sold for $13.00 prior to the presentation, which will be held in Roosevelt Auditorium. Oshinsky, who won the Pulitzer Prize in History in 2006, will be available after the session to autograph copies of his book.