

POLIO NETWORK NEWS

Strategies for Management of Arms and Shoulders

Mary Ellen Brown, PT, Danville, California, and Nancy L. Caverly, OTR/L, Bland, Missouri

STRATEGIES FOR MANAGEMENT OF ARMS AND SHOULDERS was presented at the Eighth International Post-Polio and Independent Living Conference in June. Below is an edited version of some of the strategies suggested by polio survivors, Brown and Caverly. To order the audiotape of this session, send \$5.50 to International Polio Network (IPN). Nine other audiotapes from the conference are for sale. See your most recent issue of *Rehabilitation Gazette* (Vol. 40, No. 2) or www.post-polio.org for ordering information.

POSTURE & ALIGNMENT

- To improve function and to minimize stress and pain, keep your arms in good alignment. To keep your arms in proper alignment, good postural alignment of the entire spine and good stabilization of the shoulder girdle muscles is a requirement. In other words, SIT UP STRAIGHT with chest up and shoulders back and down.
- To have good posture and a stable position of the spine, functional trunk strength is a requirement, so custom seating to support the back while in a seated position, and a custom brace while standing, possibly will be needed.
- Learn RELAXATION techniques for neck, shoulders, arms, wrists, and hands to avoid fatigue from tension and to prevent unnecessary muscle overuse from muscle stress. Explore a variety of relaxation techniques designed for the resting body, to find one suitable for you. Possibilities include meditation, listening to music, creative visualization, and/or taking a class on stress man-

agement. Deep relaxed breathing is essential. (See *Lifestyle*.)

- Do a daily stretching routine to maintain good mobility of joints and muscles. If you cannot do these exercises yourself, have someone do them with you.

FINE MOTOR/HAND TASKS

- Make sure your hands are comfortably warm to facilitate improved function and relaxation. Sometimes gloves with the fingertips cut off are helpful.
- Become more ambidextrous, alternating use of right hand and then left. Do not make the same muscles do everything.
- Make sure your glasses are adjusted to avoid strain on your neck and shoulders. Remember your postural alignment will shift to enable you to see.
- When turning pages of a book, use a rubber eraser on a pencil to decrease use of fingertips, or use a mouth wand to eliminate upper extremity (arms, shoulders) demands altogether.
- Adapt writing implements and other tools, so that your hand is supported and comfortable rather

than held in a tight pinched grip or awkward position.

- When picking up light objects with your hands, mold your hand, using the strength of the palm muscles rather than pinching with the thumb and fingertips.
- Prevent pressure on the thumb side of your fingers. Using hands incorrectly pushes the fingers away from the thumb into a deforming position. For example, hold purses and bags on the forearm instead of with the fingers.
- To reduce hand strain, use scissors to open packaged foods, letters, and tightly sealed packages.
- For drinking, try using a flexible straw with the cup, can, or bottle resting on a tabletop to avoid a sustained grasp.
- Check the activities of daily living (ADL) section of catalogs such as Sammons Preston or Smith & Nephew for self-help devices for kitchen, bathroom, and other needs. (See *Resources on page 8*.) You will find wonderfully helpful things to make life easier from one-handed

CONTINUED ON PAGE 6

INSIDE THIS ISSUE ...

- PTs & OTs Attend Seminar 2
- Traveling with Mobility Aids . . . 4

PTs and OTs Attend Seminar

*Learning About and From Post-Poliomyelitis:
A Seminar for Physical and Occupational Therapists
and Physical and Occupational Therapist Assistants*

was the title of the day-and-a-half seminar offered at the Eighth International Post-Polio and Independent Living Conference in June. Fifteen professionals (listed below) took advantage of this opportunity to learn and to interact with the many polio survivors in attendance.



Frederick M. Maynard, MD, Upper Peninsula Rehabilitation Medicine Associates, Marquette, Michigan, and Sunny Roller, MS, Physical Medicine and Rehabilitation, University of Michigan Health System, Ann Arbor, Michigan, discussed *Coping Styles and Personal Perspectives of Polio Survivors*. Dr. Maynard also presented *Pathophysiology of Acute Polio and Post-Polio Syndrome*.



Seminar coordinator Marianne T. Weiss, MS, PT, presented *Physical Therapy Examination and Treatment of the Polio Survivor* and *The Impact of the Initial Polio*

Experience on PT/OT Management of the Late Effects of Polio.

Weiss is an assistant professor of physical therapy at the University of Findlay in Ohio and practices at Blanchard Valley Regional Health Center, a clinic affiliated with the university. She has been treating polio survivors since 1982 (419-424-6752; weiss@mail.findlay.edu).

Polio survivor Beth Kowall, MS, OTR, presented *Guidelines to Implement Examination and Intervention Options*.

Contact Kowall in Greenfield, Wisconsin (414-329-0601; bkowall@execpc.com).



Physical Therapists

GAYLE BENSON, PT, works with Anne Marie Oberheu, MD at Spain Rehab Center, Birmingham, Alabama (205-934-4940; gbenson@uabmc.edu).

MARY ELLEN BROWN, PT, works part-time at Ygnacio Valley Physical Therapy in Danville, California, a private office with a general orthopedic practice. She has been working with polio survivors since 1958. (925-820-0518; rbrown@ix.netcom.com).

MICHELLE GUEVIN, PT, MTC, Private Practice, Bay Area Physical Therapy, Bradenton, Florida, has treated post-polio survivors since 1997 and has specialized in the treatment of women's issues since 1994. (941-739-7828, BayAreaPT@aol.com).

CYNTHIA HENLEY, PT, Progressive Physical Therapy, Miami, Florida, is in private practice (305-232-4765; henleyr@mindspring.com) and works with Carol Vandenakker, MD, at University of Miami Post-Polio Clinic, Miami, Florida (305-232-9222).

CAROLYN KELLEY, MS, PT, School of Physical Therapy, Texas Woman's University in Houston, Texas, works at the Post-Polio Clinic at The Institute for Rehabilitation Research (TIRR) with Dr. Carlos Vallbona (713-794-2087; hf_kelley@two.edu).

SANDY KREUTNER, PT, works at Avera McKennan Hospital, Sioux Falls, South Dakota (605-322-5000; sdkreutner@aol.com).

ROBBIE B. LEONARD, MS, PT, is Coordinator of the Physical Therapy Department, Medical University of South Carolina, Easley, South Carolina (864-250-8862; leonardr@musc.edu).

JACK MARTIN, PT, works with Jacinth Reid-Artist, MD, MS, at Bacharach Institute for Rehabilitation, Pomona, New Jersey (609-748-5429; oppt@bacharach.org).

ROMMEL VILLAMOR, PT, works with Paul Peach, MD, at Palmyra Regional Rehabilitation Center, Albany, Georgia (912-434-2580).

LINDA WOBESKYA, MS, PT, works at East Meets West PT, Cambridge, Massachusetts (617-465-6679; wobewan@worldnet.att.net).

KATHRYN WOLLAM, PT, works with Carol Vandenakker, MD, at University of Miami Post-Polio Clinic, Miami, Florida (305-232-9222).

Occupational Therapists

MARY BOWMAN, OT, works with Anne Marie Oberheu, MD, at Spain Rehab Center, Birmingham, Alabama (205-934-4966; mbowman@alabama.edu).

NANCY L. CAVERLY, OTR/L, Bland, Missouri, is in private practice (573-646-3732; caverlydn@socket.net).

Physicians

ANNE MARIE OBERHEU, MD, Spain Rehabilitation Center, University of Alabama/Birmingham, Birmingham, Alabama (205-934-3141).

NETE MUNK NIELSEN, MD, Statens Serum Institut, Copenhagen, Denmark (453-268-3962; nmn@ssi.dk). ■

WEB SITE AND NEWSLETTER CONTENT

When I go online, I get very irritated when I cannot find the names of the individuals responsible for the content of the Web sites. We recently added just that information to our site – www.post-polio.org. The same information applies to the content of *Polio Network News*, so I include an abbreviated version here.

—Joan L. Headley, Saint Louis, Missouri

Join me in upcoming months ...

September 29-30 at Indiana's Second Annual Statewide Conference (Indianapolis, Indiana). Contact Rebecca Balsley at 765-759-9094 or ipsaone@aol.com.

October 7 at Northwestern University Post-Polio Clinic's Support Group (Chicago, Illinois). Contact Elizabeth Reeves at 312-664-6071 or Linda Bieniek at LindaLBieniek@compuserve.com.

October 9 at Christ Hospital and Medical Center Post-Polio Support Group (Chicago, Illinois). Contact Mary Ann Buckingham at 708-448-7237 or brhm57@aol.com.

October 10 at Forest City Post-Polio Support Group (Rockford, Illinois). Contact Barbara Ebert at 815-226-9379 or tonguetie@peoplepc.com.

November 9 at The Polio Connection (Cincinnati, Ohio). Contact Sheila Stuckey at 513-321-4094 or sjs45208@yahoo.com.

December 8-10 at Florida East Coast Post-Polio Support Group's Second Conference (Daytona Beach, Florida). Contact Barbara Goldstein at 904-676-2435 or bgold@iag.net.

About Us Gazette International Networking Institute (GINI) was incorporated as a 501(c)3 (a non-profit) in 1960. GINI also “does business as” International Polio Network and International Ventilator Users Network.

GINI is governed by a Board of Directors: (President) Martin B. Wice, MD, Medical Director, St. John's Mercy Rehabilitation Center; Linda L. Bieniek, CEAP, LaGrange, Illinois; Penny Chrisler, Saint Louis, Missouri; Judith Raymond Fischer, MSLS, Cypress, California; Jack Genskow, PhD, Springfield, Illinois; Jack Hannaford, Saint Louis, Missouri; Richard Hokamp, Attorney-at-Law, Saint Louis, Missouri; Frederick M. Maynard, MD, Upper Peninsula Medical Center, Marquette, Michigan; Maurice Sonnenberg, New York, New York; Max J. Starkloff, Paraquad, Saint Louis, Missouri; Gertrud Weiss, Rosenheim, Germany; and Mark Zerman, A.G. Edwards and Sons, Inc., Saint Louis, Missouri.

GINI has a paid staff of three: Joan L. Headley, MS, Executive Director; Sheryl R. Prater; and Carol A. Cox.

Content of www.post-polio.org

Joan L. Headley oversees the content of the site. Please send your comments to gini_intl@msn.com.

The majority of the post-polio information on the site has been published in *Polio Network News*, edited by Joan L. Headley, or was developed by the Post-Polio Task Force (1997). The Task Force information is updated as needed.

The individuals who write articles and stories for *Polio Network News* donate their services. The major medical articles are written

by health professionals and reviewed by another health professional expert in the topic. For example, James C. Agre, MD, PhD, or Gunnar Grimby, MD, PhD, might review an article about exercise for the survivors of polio. Medical questions and concerns about scope and content are resolved with advice from board members with medical and clinical experience.

The articles are edited so that “people first” language is used. For example, “uses a wheelchair” is used; “wheelchair-bound” is not. Other examples include the preferred use of “person with a disability” (not “handicapped”), and “polio survivor” or “survivor of polio” (not “victim”).

The editor screens all materials (including books, videos, CDs, etc.) received and excludes those that are not consistent with GINI's philosophy and those not considered medically sound, of dubious content, or of questionable validity. The content is also nonpartisan and nonsectarian.

Editor Joan L. Headley, a polio survivor, graduated from Huntington College, Huntington, Indiana, in 1969 with a degree in biology. In 1974, she received her MS in Education from Indiana University, Bloomington. Before joining GINI in 1987, she taught junior high science and high school biology in LaGrange County, Indiana. She has edited *Polio Network News* for 13 years and *Rehabilitation Gazette* for 11 years. She has coordinated four of GINI's international conferences and has presented at 40+ meetings. She served as a non-medical member of the Post-Polio Task Force and now serves on the March of Dimes Steering Committee. (See page 9.) ■

Traveling with Mobility Aids

Grace R. Young, MA, OTR, Fresno, California

Experienced traveler and polio survivor, Grace Young, author of *Air Travel with Mobility Aids (Polio Network News, Vol. 16, No. 2)*, offers additional advice excerpted from her forthcoming book, *Help Yourself! Living Well with a Chronic Condition*.

Accommodations

Even if a hotel claims to have accessible rooms and bathrooms, remember that "accessible" means different things to different people, especially outside the USA. When you make reservations, be very specific about your abilities and what you need. Do not use lingo that may be meaningless to hotel personnel. Before my trip to Israel I made hotel arrangements via e-mail with an Israeli travel agent. In frequent e-mails I kept stressing my need for a walk-in shower. Although she assured me that the hotels had walk-in showers, all three hotels she booked had only over-tub showers. When I complained after my return, she said she did not understand what a walk-in shower meant and thought that since I could walk into the bathroom, there would be no problem.

Create a list of what specific accommodations you need, such as a higher bed for easy transferring, a free-standing bed for a lift, wider doorways, a roll-in/walk-in shower, grab bars, lowered sinks, a raised toilet seat, lowered closet bars, wheelchair-height peepholes and light switches, and whether you can exit the room by yourself. Ask about electrical outlets – how many and where they are located. Also ask about emergency situations: if the elevators were shut off due to a fire, who

would assist you if you were not on the ground floor?

Outside the USA the first floor is up one level, so request a room on the ground floor. If you take a room above this level, check that there are no steps to reach the elevator and that the elevator is large enough to accommodate your chair. Also, make sure there is a flat or ramped entrance from the outside into the hotel.

In the USA, do not use 800 numbers when inquiring about accessibility. Phone reservationists are not familiar with the individual hotels. Contact the hotel directly and ask to speak to someone who can provide you with details about the rooms they consider to be accessible. Ask the person to write down the details and call you back. Outside the USA, do your research by fax or e-mail. Send a form and ask them to complete and return it to you, or ask them to hold it and arrange to call them in three days.

Accessibility is not an idea that is understood by most nondisabled people. Even when well-meaning hotel managers truly believe that their accommodations are "state-of-the-art accessible" the reality can be very different and sometimes even humorous.

At one Norwegian hotel advertised as "accessible" the bathroom was up 6 inches and opened into a narrow hallway that led

to the bedroom. The hotel had placed a small platform in front of the bathroom entrance to eliminate the step; however, there was a short, very steep ramp on each side of the platform. My roommate, a wheelchair user, would have had to push herself up to the platform with such force that the chair could not be stopped before it continued down the ramp on the other side, which could have resulted in her being thrown from the chair to the floor. There was also not enough room on the platform to turn the wheelchair to enter the bathroom door.

Another charming, little hotel had a large roll-in shower, but the hand-held showerhead was attached so high that a seated person could not reach it. In a Belgium hotel, the roll-in shower did not have a shower bench to transfer to. Even if you think you have pinned down all the details regarding accessibility, you may be surprised when you get to your hotel.

Charging Your Equipment

Most American hotels have several electrical outlets in each bedroom. Many European hotel rooms have only one electric outlet and it may be located where your wheelchair or scooter cannot fit, so take a long extension cord.

You will need to convert voltage from American 110 to European 220. Also, their wattage is 50 instead of our 60. The standard converter used for hair dryers should not be used for the long slow trickle charge required by wheelchair batteries; it can burn out the charger.

Unfortunately, it can be difficult to get accurate information about

what you need. Before my first overseas trip with my scooter, the service manager at the Electric Mobility factory in New Jersey said that I could charge my Rascal with the small converter used for hair dryers. I felt uncomfortable with this advice and called the Electric Mobility factory in England. They recommended a separate transformer (which weighs about ten pounds) or a dual voltage battery installed inside my scooter. I did the latter, and it just takes a screwdriver to switch the voltage from 110 to 220. On my recent trip to Ireland, one lady in the group was given bad advice by a salesperson at a nationally known electronics store. He sold her a wattage converter instead of a voltage converter and did not advise her to buy an adapter plug. So even advice from trusted sources can be incorrect.

You will need adapter plugs for the foreign outlets. Adapters come as a set of four or five which accommodate the different outlets throughout the world. Even if you plan to visit one country, it would be wise to take the whole set. Some years ago I unexpectedly spent two weeks in Ireland when my husband had a heart attack on the plane coming home from Europe. Electrical outlets are different in Europe and Britain, but fortunately I had taken the complete set of adapters.

Travel with Accessible Tour Companies

Several links to Web sites are listed (see box) for companies specializing in tours for people with disabilities. Many people have chosen this travel option,

Air Carrier Access Act: Common Questions and Answers About Air Travel for Wheelchair Users. Order from Eastern Paralyzed Veterans Association. (800-444-0120; info@epva.org).

General Guide to Accessible Travel: Resources for Travelers with Disabilities. (D15697). Available from AARP Fulfillment, 601 E Street NW, Washington, DC 20049.

Project ACTION Accessible Traveler's Database. A comprehensive database of accessible transportation services in the United States. Includes rural and urban public transit operators; accessible van rental companies; private bus/tour companies with accessible vehicles; accessible taxis; airport transportation services; hotel-motel shuttles; national 800 numbers for domestic airlines, Greyhound, Amtrak, and companies with accessible car rentals; major hotel chains (www.projectaction.org/paweb/index.htm).

Global Access. A comprehensive Internet resource of accessible travel information that links to many other sites (www.geocities.com/Paris/1502/issue.html).

Access-Able Travel Source. A Web site providing free information to disabled travelers. Includes travel agents around the world, cruise lines, accessible attractions, lodgings, access guides, transportation, van rentals, and equipment rental and repairs (www.access-able.com).

Society for the Advancement of Travel for the Handicapped (SATH). Clearinghouse in contact with organizations in many countries. Provides information on air, rail, and bus travel, hotels, and services worldwide for various medical conditions and impairments. (212-447-7284, SATHTRAVEL@aol.com).

Directory of Travel Agencies for the Disabled by Helen Hecker, RN. Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666-0129, USA (800-637-2256). Excellent directory divided by U.S. States, Canadian Provinces, and countries.

Travel for the Disabled: A Handbook of Travel Resources and 500 Worldwide Access Guides by Helen Hecker, RN. Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666-0129, USA (800-637-2256).

Fodor's Great American Vacations for Travelers with Disabilities (2nd Edition). This comprehensive guide covers 39 of America's favorite travel destinations, listing a huge array of facilities and services for the disabled (www.amazon.com).

Wheels Up. Wheelchair travel specialists web site (www.wheelsup.com).

The Boulevard. A comprehensive site linked to products, resources, and publications related to travel for people with disabilities (www.blvd.com/travel.html).

The Oxygen Traveler for those who require oxygen and other durable medical equipment arrangements for domestic, international, or cruise travel (937-848-7100; www.oxygentravel.net).

Breathing Easy: A Guide for Travelers with Pulmonary Disabilities. Articles, tips, and advice about traveling with oxygen, including all the regulations for the safe transport of oxygen (707-252-9333; www.oxygen4travel.com).

including me. You will want to ask the company how long they have been in business and get names and phone numbers of people you can call for references. Ask to be given names of people who travel with the same type of equipment and have the

same level of ability as you. This is especially important if you will be traveling without a companion.

With advance planning, you can enjoy the rewards of new sights, new friends made, and new experiences. Bon Voyage! ■

potato peelers to bookracks to portable toilet seats to graters on suction cups, etc., etc., etc. Regular stores are starting to carry large handled knives, can openers, jar grabbers, etc. JC Penney and Sears have catalogs for "Special Needs."

LIFESTYLE/STRESS MANAGEMENT

- During rest breaks in mid-morning and mid-afternoon, make sure your arms are resting, too. Holding a book to read while relaxing the body doesn't rest the arms.
- DELEGATE chores that are too demanding such as vacuuming, mopping, chopping, and gripping. If you have four things to do today, pace yourself to do one in the morning, one in the afternoon, one in the evening, and delegate the fourth.
- Do deep breathing exercises for relaxation and for increasing the oxygen supply to the tissues. Use ventilatory assistance, if necessary.
- Eat a healthy well-balanced diet low in animal fat and high in vitamins and minerals from fruits, vegetables, and grains. Add extra high-quality protein for neuromuscular maintenance.
- Make sure you get plenty of sleep regularly to allow your body to repair itself from any effects of soft tissue micro-trauma.

MOBILITY

- Avoid stairs! Banisters may help lower extremities (legs), but they only strain upper extremities. Use elevators, or escalators, if your balance is good enough.
- Sit in firm chairs that have sturdy armrests. Avoid "soft" couches, as you will put a great

strain on your arms when getting up and down. The one exception to the rule is – if you are on the floor, maneuver yourself to the nearest couch, put your arms up on the couch, and then roll yourself onto it. This procedure is usually easier and safer than trying to rise from the floor.

- Avoid falls! If you do fall, it does not matter what you hurt, your upper extremities will pay the price. If you hurt a leg, your arms will be stressed by using crutches. If you hurt an arm, you will become more dependent on the other arm, or someone else. Some falls are impossible to avoid, but many can be prevented by using the proper bracing, and by treating medical problems that cause dizziness or balance difficulties. When getting new glasses or trying new medications, be very careful as perceptions and orientation to space may change. Also, avoid falls by keeping your environment safe. Eliminate clutter, stay off slippery floor surfaces, and get rid of all throw rugs. Stay inside on rainy or snowy days. If you have to go out in inclement weather, always carry a small towel to wipe off the bottom of your crutch or cane tips when you go inside.

ENERGY CONSERVATION FOR SHOULDERS

- When using upper extremities for any activity, take a break at the first sign of fatigue. Do not wait for pain. Take frequent stretch and rest breaks – at least every 15 minutes with any activity.
- When lifting anything, use both hands and hold the object close to your body to decrease stress on shoulders.

- When reading a book, support the arms with pillows or with well-positioned armrests. Prop the book on a slanted reading rack or on a stand.
- Use a headset for telephoning to keep neck straight and to eliminate need for using arms and hands. Get comfortable in a recliner chair or by lying down, and enjoy your chat!
- Alternatives for heavy purses or bags are fanny packs, backpacks, and jackets with large pockets. Leave your purse in your vehicle when shopping. Carry cash, checkbook, or plastic in your pocket.
- Large pockets and belt loops are good places to relax arms when standing; rest arms on a fanny pack at your waist or place arms on top of your head for a few minutes. Pillows are essential for arm support when sitting or lying down. Arms are very heavy, so get rid of their weight by supporting them on whatever is available.
- Avoid unnecessary carrying at home by putting duplicate supplies, such as towels, sheets, and cleaning supplies, in each room where they will be needed. Also, try this strategy at work.
- Eliminate ironing by buying permanent press clothing and by hanging garments on hangers when still partially damp from the dryer. If clothes must be ironed, rotate iron on and off of the garment without picking it up each time.
- Use reachers for picking up light objects off floor or other places. Remember the length of the reacher increases the lever arm, so it puts more stress on

the shoulder when lifting. Do not try to lift heavy objects.

❑ If your legs are a little weaker, and it is getting harder to get up and down, don't strain your arms to get into an upright position. Use pillows in chairs to raise the height of the chair a little or get a chair with a hinge mechanism to lift you part way up out of the chair. (Log on to www.abledata.com or write to Carol Cox at IPN for a listing of select brands of lift chairs and bath lift chairs.)

❑ Raised toilet seats make getting up and down easier; now there are even adapters to lift up the height of the toilet itself. (See box below.)

❑ Using a regular toilet in some restrooms is a real challenge; always wait for the handicapped accessible stall. The toilets are higher, there is more space for maneuvering your body, and they have grab bars. These stalls are for "walkers" as well as wheelchair users. Note: Alert the facility to any problems with accessibility in the restroom.

❑ Get a bathtub seat that can be lowered and raised hydraulically. If your legs are weak, don't try to use your arms alone to get in and out of the tub. Using your arms alone is unsafe and places too much stress on your arms and shoulders. Use a sturdy seat in the shower, so you can relax and enjoy the water.

CHOOSING ASSISTIVE DEVICES (ASSISTIVE TECHNOLOGY)

If you are beginning to need assistive devices for walking, think very carefully about which device you choose and seek the advice of an occupational therapist or physical therapist. The use of canes, crutches, walkers, and manual wheelchairs may help your legs but will put more demands on your upper extremities. They already have a full-time job.

❑ If the need for a cane begins to arise because you need extra security with balance, get a cane with an anatomically correct handle. You can get a right-handed or left-handed cane, depending on which side you need support. (The cane usually is in the hand on the stronger side.) Collapsible canes are available for those special occasions when you are feeling a little insecure. A cane with a seat allows you to sit when necessary.

❑ A better choice, if you are beginning to feel weaker, would be very lightweight forearm crutches. These will be less demanding on the upper extremities than trying to take weight off the legs with a cane that is not secure. If you are having increased hip weakness, you definitely need to obtain forearm crutches, as no brace will help the hips. When standing at rest with forearm crutches, rest

forearms on cuffs to relieve stress on hands.

❑ Be sure you use any lower extremity bracing that may increase your stability and security, as this will decrease the need to depend so much on crutches and canes which in turn will decrease stress on the joints and muscles in the arms. Lower extremity bracing will decrease the chance of falling.

❑ Walkers are a good choice for assisting weak legs by using your arms. They are usually stable and you can carry other things in baskets or bags that hang on the walker. Also available are wheeled walkers (four wheels) with a seat, tray, and shelf space. They are useful in your home, the mall, or craft fairs.

❑ For longer distance mobility, you may need wheels. If your arms are really strong, a manual wheelchair may be an option, but again, great demands are placed on your upper extremities. The shoulders, elbows, wrists, and hands are working hard to propel all of you – plus the weight of the wheelchair. If this choice works for you, the wheelchair needs to be very lightweight. The width of the chair needs to be narrow enough to allow your arms to be as close to your body as possible, for better mechanical advantage in propelling the chair.

❑ To make life a little easier and to decrease the demands on the upper extremities, adding a motor to your wheels makes good sense. There are attachments that can be added to manual wheelchairs to convert them into motorized chairs for short distances. Many brands

The TOILEVATOR will add 3.5" of additional height to any standard 14" or 15" toilet. The result is a conventional toilet that now stands up to 19" high (including seat) and supports up to 500 lbs. This easy-to-install, universally designed modification kit will fit a round or elongated bowl. The suggested retail price ranges from \$89-99. Contact LCM Distribution Ltd. (888-726-4646, shawn@lcmdistribution.com, www.lcmdistribution.com).

CONTINUED ON PAGE 8

of motorized scooters are available; choose one according to your needs. Remember, scooters put demands on your upper extremities in that you must be able to steer them. This, in most cases, would be easier than propelling a manual wheelchair. You do need to have fairly good trunk control to stay balanced in the seat of a scooter.

□ If your upper extremities and your trunk and lower extremities are all feeling weaker and fatigued, a motorized wheelchair is certainly the least demanding on the

upper extremities of any mobility device. Custom seating can be developed to support the spine and upper body in a more stable position allowing the upper extremities to be more functional with less fatigue. Sometimes tendinitis can develop in the thumb and fingers from operating the controls of a motorized wheelchair, so the upper extremities always have some demand unless you purchase advanced computer technology.

TECHNOLOGY CHALLENGES

If you have joined the folks in the fast lane and are using a computer, the demands on your upper extremities have multiplied many times. The “normal” population is suffering at epidemic proportions from repetitive strain injury (RSI) from many, many hours at the computer. Over 62% of all workplace injuries are now from upper extremity repetitive strain injuries related to computer work. If the “normal” population is having this much trouble with their arms, you, as a polio survivor, need to take your time at the computer very seriously. The computer can do so much for you, but it is tempting to overuse this great technology. **DON'T SACRIFICE YOUR ARMS** in the process.

- Get an expert in ergonomics (an OT or PT) to set up your workstation.
- Make sure your chair supports your spine in a neutral position, so that your shoulder girdle and upper extremities are in good alignment. Use well-positioned armrests to support the weight of your arms. Your feet should be supported, using a footstool, if necessary. If you are a wheelchair user, have your work-

station designed around your chair.

- Take a five-minute stretch break at least every 15 minutes with micro-breaks more often. Limit the overall time you spend at the computer to four separate hours per day, depending on your strength/weakness.
- Consult your ergonomic specialist frequently about any problem that gives you pain or causes fatigue.

A FINAL REMINDER

If you develop any pain, increased weakness, and/or excessive fatigue in the upper extremities, and reasonable amounts of accommodation and rest do not decrease the symptoms, get a medical evaluation and begin treatment as soon as possible. Many upper extremity problems can be eliminated with proper management, and the sooner the symptoms are addressed, the less risk you face of permanent decrease in upper extremity function. If your doctor does not suggest treatment, such as physical therapy and occupational therapy, **INSIST ON IT**. “Normal” people rarely hesitate to seek medical assistance when pain or weakness occurs in their arms and shoulders. Neither should you, who has much more to lose – your independence. ■

RESOURCES

- Sammons Preston Catalog '00
800-323-5547
- Smith & Nephew Catalog
800-558-8633
- Northcoast Medical Catalog
800-821-9319
- Sportime Abilitations
800-850-8602

INTERNATIONAL POLIO NETWORK

Polio Network News (ISSN 1066-5331)
Summer 2000 ■ Vol. 16, No. 3

Polio Network News is an international newsletter for polio survivors, health professionals, and resource centers to exchange information, encourage research, and promote networking among the post-polio community.

ISSUED QUARTERLY

International Polio Network (IPN)

4207 Lindell Boulevard, #110
Saint Louis, MO (Missouri)
63108-2915 USA
314-534-0475 ■ 314-534-5070 fax
Relay MO: 800-735-2966 TDD, 2466 V
gini_intl@msn.com, www.post-polio.org

COORDINATED AND PUBLISHED BY:
Gazette International Networking
Institute (GINI)

EDITOR: Joan L. Headley, Executive
Director

GRAPHICS/ASSISTANT TO THE EDITOR:
Sheryl R. Prater

SPECIAL THANKS TO: Beth Kowall, MS, OTR

Annual subscription (US dollars only)
USA: \$20
Canada, Mexico, & Overseas surface: \$25
Overseas air: \$30

©Copyright 2000 by Gazette International
Networking Institute (GINI)

**Permission to reprint portions must be
obtained from the publisher.**

May Meeting in Warm Springs

Joan L. Headley, Saint Louis, Missouri

"International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care" was the name of the conference in Warm Springs, Georgia, May 19-20, 2000. "Best practices" is a term used to describe the documented information that is available to guide treatment of a particular disorder. Another term used is "clinical practice guidelines" and is defined by the Institute of Medicine as "...systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances."

Each invited health professional (listed below) was assigned a topic and was asked to review the medical literature and present a summary of the information. The biologic plausibility for each topic, or sub-topic, was judged as theoretical or demonstrated. Case reports, case series, uncontrolled observational studies, controlled observational studies, and controlled clinical trials were reviewed to determine evidence (for, against, indeterminate, or no data) for a causal relationship. The participants also provided a summary of the evidence for the effectiveness of interventions/treatments, when feasible.

Following the formal presentations, the attendees discussed how to proceed to reach consensus on the varied and sometimes inconsistent information. One of the points of discussion was the definition of "post-polio syndrome," and it is apparent that there is not an accepted universal definition. (Another recurring theme was the need

for more dollars for research, with a limited discussion of possible strategies to increase the amount of funds.)

To fulfill the stated goal of the meeting, the evidenced-based recommendations will be incorporated in the final conference report – "Practice Guidelines for the Management of Post-Polio Syndrome." The March of Dimes will facilitate the preparation of this document and will utilize the abilities of the steering committee, the content of the presentations, and the cooperation of the American Academy of Neurology, the American Academy of Physical Medicine and Rehabilitation, as well as several other allied health care professional organizations. The report and other related educational materials will be completed in the fall.

The following panel presented ideas for the dissemination of the committee's findings. Christopher P. Howson, PhD, Moderator, March of Dimes, White Plains, New York; Anne Gawne, MD, Roosevelt Institute for Rehabilitation, Warm Springs, Georgia; Joan Headley,* Gazette International Networking Institute, Saint Louis, Missouri; T. Jacob John, MD,* Christian Medical College, Vellore, India; Pesi Katrak, MD, Prince Henry Hospital, Little Bay, Australia; Andria Spindel, Ontario March of Dimes, Toronto Ontario, Canada.

Leland P. Rowland, MD,* National Institute of Neurological Disorders and Stroke, Bethesda, Maryland, chaired the two-day meeting.

Jennifer L. Howse, PhD, President and Chief Executive Officer, March of Dimes, White Plains, New York, welcomed the participants, and Anna Eleanor Roosevelt, Vice Chair of the March of Dimes National Board of Trustees, opened the meeting by presenting the "Historical Perspective: Role of the March of Dimes and Warm Springs."

Frank Ruzycski, Executive Director, Warm Springs Roosevelt Institute for Rehabilitation, and his staff provided southern hospitality and tours of the historic facility.

PRESENTERS AND THEIR TOPICS

HEALTH IMPACT OF POLIO – Barbara Vickrey, MD, MPH,* University of California, Los Angeles, California

PATHOLOGY – Marinos Dalakas, MD,* National Institute of Neurological Disorders and Stroke, Bethesda, Maryland

ELECTROPHYSIOLOGY – Neil Cashman, MD,* University of Toronto, Ontario, Canada

DIAGNOSIS: INCLUSION AND EXCLUSION CRITERIA – Lauro Halstead, MD,* National Rehabilitation Hospital, Washington, DC

EVALUATION AND TREATMENT – Daria Trojan, MD,* Montreal Neurological Hospital, Quebec, Canada

EXERCISE – James Agre, MD, Howard Young Medical Center, Woodruff, Wisconsin

MUSCULO-SKELETAL SEQUELAE: MUSCLE AND JOINT PAIN – Frederick Maynard, MD, Upper Peninsula Rehabilitation Medical Associates, Marquette, Michigan

DRUG TREATMENT – Susan Perlman, MD,* University of California, Los Angeles, California

CONTINUED ON PAGE 10

PULMONARY DYSFUNCTION – John Bach, MD,* University of Medicine and Dentistry of New Jersey, New Jersey Medical School, Newark, New Jersey

SPEECH AND SWALLOWING – Barbara Sonies, PhD, National Institutes of Health, Bethesda, Maryland

SLEEP DISTURBANCES – Susumo Sato, MD, National Institute of Neurological Disorders and Stroke, Bethesda, Maryland (*unable to attend due to emergency*)

PSYCHO-SOCIAL ISSUES: INCLUDING DEPRESSION – Rhoda Olkin, PhD,* California School of Professional Psychology, Alameda, California

POST-POLIO FATIGUE – Kristian Borg, PhD,* Karolinska Hospital, Stockholm, Sweden

EFFECTIVENESS OF PHYSICAL THERAPY – Elizabeth Dean, PhD, PT,* University of British Columbia, Vancouver, British Columbia, Canada

OCCUPATIONAL THERAPY IN MANAGEMENT – Beth Kowall, MS, OTR, Greenfield, Wisconsin

NURSING INTERVENTIONS – Alexa Stuijbergen, PhD, RN, University of Texas at Austin, Austin, Texas

NUTRITION – Charlotte Gollobin, MS, Bethesda, Maryland

POST-POLIO PROBLEMS OF THE DEVELOPING COUNTRIES – T. Jacob John, MD, Christian Medical College, Vellore, Tamil Nadu, India

**Members of the Executive Steering Committee*

Richard B. Johnston, Jr., MD, National Jewish Medical and Research Center, Denver, Colorado, and William Wendling, Chief Communications Officer of Cleveland Municipal School District, Cleveland, Ohio, are also members. ■

Swiss Community of Interest for the Post-polio Sequelae (SIPS)

SCHWEIZERISCHE INTERESSENGEMEINSCHAFT FÜR POLIOMYELITIS-SPÄTFOLGEN (SIPS)
COMMUNAUTÉ D'INTÉRÊT SUISSE DES SUITES TARDIVES DE LA POLIO (CISP)
COMUNITÀ SVIZZERA DE INTERESSENTI DELLA SEQUENZA TARDIVE DELLA POLIOMIELITE (CSIP)

Thomas Christian LehmannBuri, MD, Berne, Switzerland

Post-polio syndrome is not only an American disease; it is a Swiss disease, too.

After attending an international conference in Munich in 1988, and one year after my visit to the Fifth International Polio and Independent Living Conference in Saint Louis, and after seeing a request by a polio survivor in the Swiss journal *Beobachter (Observer)* for a peer-counseling group, I, too, looked for a group of polio survivors but could not find one.

“Here we go, now!” said a group of Swiss people interested in the medical, psychological, social, and financial aspects of the late effects of polio on an autumn afternoon in 1990. Although Switzerland is a four-language country, we were mainly German-speaking and started the Schweizerische Interessengemeinschaft für Poliomyelitis-Spätfolgen (SIPS).

In the first months after we announced the formation of our group specifically for polio survivors looking for new thoughts on post-polio, we attracted a large number of members, which today has increased to 500. This number represents only 20% of the estimated 2,500 survivors of polio in Switzerland (i.e., 60-70% of the polio survivors from the last epidemics in

1955-1961). The members are from all 26 Swiss cantons and speak their regional language.

The Swiss association for paralysed people (Association Suisse des paralysés (ASPr) I/Schweizerische Gelähmten-Vereinigung (SGV), founded many years ago mainly by polio survivors, was very interested in our new community.

SIPS looked at the major needs of polio survivors: medical information; juridical counseling (general, laws, health-insurance, disability pension); peer-counseling; and assistive devices for mobility, housekeeping, working, and, last but not least, living independently.

But, as known in other countries, the seed that was sown widely and often did not grow very well or very quickly within the medical community.

However, with our first two-day conference in 1992, we united a large number of “not-knowing-it-before post-polios” near Zurich. The first knot of a net of post-polio survivors was made. The net has become larger and larger in the last years. And, with every new conference – mainly in Gwatt (at the lake of Thoune in the Bernese Oberland) – the net has grown tighter, more fine-meshed.



Members of Swiss community of Interest for the Post-polio Sequelae (SIPS)

The major interest of the members has remained medical information. But other themes have been discussed: energy-saving auxiliary devices, special physical therapy, pharmacological treatment, and complementary medical possibilities of treatment. The members discuss coping with special daily problems as a polio survivor, as a woman/man getting older, as a disabled wife/husband and sexual partner, as a disabled mother and father with growing children and grandchildren, as a disabled friend who is losing friends, and as a professional in a business world going (absolutely and relatively) faster, i.e., too fast for our slowing down.

We have learned that the questions of post-polio persons can never be exactly answered for all, because the problems are unique to each individual. It is each one's duty to look for the individual adaptations of lifestyle – physically, psychologically, and emotionally – with the help of a knowing person, physician, or psychiatrist.

The management team of SIPS, now twelve members, is composed of polio survivors elected by the membership. Many members have professional backgrounds as well. Our team includes an editor, several physicians, a social worker, a psychologist, and a lawyer.

We meet three to four times a year at a place that can be reached from Zurich, Berne, and the French-speaking part of Switzerland. If we need to communicate in the meantime, we are in contact by post, phone, or Internet. Sometimes we participate in interdisciplinary conferences that take place in different parts of Switzerland.

A medical and physiotherapeutic rehabilitation center in Leukerbad opened about 50 years ago for polio individuals and, like Warm Springs in the USA, the center has warm water coming from mountain wells.

Berne, the capital of Switzerland, is where the polio center was located (1957-1972) mainly for the respiratory paralysed polio survivors from Switzerland. The polio center moved into the university clinic, got smaller, and was reactivated in 1992 for outpatient diagnostics and treatment in the newly called Polio-Center in the Krankenhaus Wittigkofen. This Center counsels polio survivors with the late effects of polio from every county of Switzerland and the neighbouring countries of Germany, Austria, France, and sometimes of Great Britain, Arabia, and Australia.

Please visit us at our homepage www.polio.ch. It is available in both French and German. ■

POST-POLIO BIBLIOGRAPHY

Final Report Published

Klein, M.G., Whyte, J., Keenan, M.A., Esquenazi, A., & Polansky, M. (2000). The relation between lower extremity strength and shoulder overuse symptoms: a model based on polio survivors. *Archives of Physical Medicine & Rehabilitation* 81(6), 789-795.

New Funding

Drs. Keenan and Esquenazi, along with Mary Klein, PhD (Moss Rehabilitation Research Institute), were recently awarded additional funding from the Department of the Army and the National Institute on Disability and Rehabilitation Research (NIDRR) to continue their work on musculoskeletal problems among polio survivors. These two-year projects, totaling \$1,362,500, will include both polio survivors and elder adults with no history of polio. The objective is to determine how musculoskeletal problems influence quality of life and functional ability in older adults, with and without a history of polio, and the role of exercise in treating these problems. ■

Post-Polio Groups Donate to The GINI Research Fund ...

CENTRAL VIRGINIA POST-POLIO
SUPPORT GROUP

DELAWARE VALLEY POLIO SURVIVORS
ASSOCIATION

ONTARIO MARCH OF DIMES

FDR Statue

Hugh Gregory Gallagher, polio survivor, author, and activist, reports that work has begun on the installation of the statue depicting President Roosevelt seated in his wheelchair at the entrance of the Franklin Delano Roosevelt National Memorial in Washington, DC. The work will be completed by the end of the year and will be dedicated by President Clinton.

The life-sized statue of Roosevelt, sitting in the simple wheelchair he designed, is placed on the pavement without a plinth or pedestal. Nondisabled people may overlook it or bump into it, as they do with people using wheelchairs. Wheelchair users will be able to sit side-by-side with the President; people who are blind will be able to touch his likeness; and children will be able to sit on his lap.

Architect Lawrence Halprin has backed the statue with a granite wall 50 feet long and 12 feet high. Upon this wall will be the following quote from Eleanor Roosevelt. "He had to think out the fundamentals of living and learn the greatest of all lessons – infinite patience and never-ending persistence." The corresponding Braille symbol will be placed underneath each letter. ■

REGISTERED TO VOTE?

If people with disabilities voted at the same rate as the nondisabled, five million more votes would have been cast in the last presidential election. To close this participation gap, the National Organization on Disability's **VOTE! 2000 Campaign** has set the realistic goal of increasing the voter turnout of people with disabilities by three percent.

People with disabilities vote at a rate 20 percent below nondisabled voters. There are approximately 23.5 million people with disabilities who did not vote in the 1996 presidential election and about 9.2 million are not even registered to vote. The United States Census reports a voter registration gap of 16 percent between people with disabilities and the nondisabled.

Most disability service providers are in violation of the National Voter Registration Act (NVRA), which requires them to offer voter registration to their clients. Section 7a of the NVRA requires that "each state shall designate as voter registration agencies ... all offices in the state that provide state-funded programs primarily engaged in providing services to persons with disabilities." Special education offices in public school districts should be offering voter registration opportunities to voting-age students and to all parents. Other service providers that are required to offer voter registration include vocational rehabilitation, commissions for the deaf and the blind, independent living centers, paratransit providers, Multiple Sclerosis Society, Epilepsy Foundation, and the Muscular Dystrophy Association.

The most recent Federal Election Commission (FEC) reports that at least 20,000 of the nation's more than 120,000 polling places are inaccessible to people with disabilities. Most disability advocates believe that the number of inaccessible polling places is considerably higher. Some states have passed laws that will allow people with disabilities to vote by absentee ballot.

If you are not registered to vote – register. If and when you are registered, vote! ■

SOURCE: National Organization on Disability, 910 Sixteenth Street NW, Washington, DC 20006 (202-293-5960; 202-293-5968 TDD; www.nod.org).

GNI Gazette
International
Networking
Institute

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA

Non-profit Org.
U.S. Postage
PAID
Permit No. 210
Jefferson City, MO