

POLIO NETWORK NEWS

International Polio Network

Winter 1990 ■ Vol. 6, No. 1

National Polio Awareness Week

International Polio Network has initiated the proclamation of National Polio Awareness Week through Congressman Richard A. Gephardt's office.

PROCLAMATION for JUNE 1-7 1990

Whereas there are an estimated 650,000 paralytic polio survivors in the United States today, a significant number of whom may experience polio's late effects;

Whereas it is essential to locate polio survivors and educate them as to the late effects of polio;

Whereas it is still important to inform the health care community and the general public about the impact of polio and its late effects on survivors;

Whereas the International Polio Network continues to reach and inform those experiencing the late effects of polio and to provide accurate information to the medical community and the public;

Whereas it is necessary to create an atmosphere of recognition and acceptance of all individuals with a disability: Now, therefore, be it

Resolved by the Senate and House of Representatives of the United States of America in Congress assembled, that the week of June 1 through June 7, 1990, is designated as "National Polio Awareness Week," and that the President is authorized and requested to issue a proclamation saluting the work of the International Polio Network and calling upon the people of the United States to observe the week with appropriate ceremonies and activities.

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Leaders' Workshop

Date: June 8-10, 1990

Time: From 6:00 p.m. on June 8 to 10:30 a.m. on June 10

Place: Sheraton St. Louis Hotel

Tentative Schedule:

Friday evening--Demystifying Under-ventilation and Ventilatory Equipment (physician explanation, survivor discussion, equipment demonstration).

Saturday morning--Sharpening Support Group Leader Skills (asking good questions and listening actively, providing support, handling difficult situations, recruiting new members).

Saturday afternoon--Dealing with the Consequences of Disability (personal acceptance, family acceptance, dealing with depression).

Saturday evening--Organizational Issues (setting priorities for the 90s, screening post-polio information, coordinating our independent efforts, sharing survivor names, etc.). Please send additional topics for discussion to IPN.

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National Polio Awareness Week

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We have requested that the proclamation be introduced much earlier this year. You can help by writing to your legislators and asking them to co-sponsor "Congressman Gephardt's joint resolution proclaiming National Polio Awareness Week." IPN also urges groups within a state to coordinate their efforts and request a similar proclamation from their governors.

A poster will be included in every Spring Polio Network News and we ask you to display it in your area. Extra posters may be ordered for \$0.35 each (postage) from IPN, 4502 Maryland Avenue, Saint Louis, MO 63108 (314/361-0475).

* * *

Polio Survivors Interviewed for National Public Radio (NPR)

Maeve McGoran, Philadelphia, PA has interviewed several individuals for a half-hour documentary on polio survivors. The segment, a part of the regular show "Horizons," will be distributed to over 300 local stations by March 13th. Call your local NPR station to find out air time or NPR in Washington (202/822-2300).

Leaders' Workshop

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Sunday morning--Ad-Hoc Presentations (How to Disagree with the Medical Profession; Is it Possible to Agree on Terminology?; Ideas for Fund Raising; Status of the Surgeon General's Commitment to Self-Help Groups; G.I.N.I.'s 1991 Polio & Independent Living Conference; etc.) This session is set aside for brief, factual presentations that will benefit leaders. Contact IPN with ideas for presentations or requests to present.

Cost:

Registration--\$10; Meals--\$78; Hotel--\$70 single & double, \$90 triple and \$110 quadruple; Transportation--Airport/hotel roundtrip by airport van--\$12, Airport/hotel roundtrip by van with wheelchair lift--\$25. To help cut costs, IPN will coordinate roommates for attendees. Also, if additional funding is secured, the savings will be passed on to the attendees.

Registration Forms will be sent by bulk mail to all individuals listed in the support group section of the Post-Polio Directory 1990. Other individuals may contact IPN at 4502 Maryland Avenue, Saint Louis, MO 63108 or 314/361-0475 for a form.


International Polio Network

4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

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

ISSUED QUARTERLY

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Joan Headley

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Joan Headley, *Executive Director*

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Post-Polio Directory

The Post-Polio Directory 1990 was mailed earlier this month. Additions, deletions, or corrections are welcome.

A listing does not imply endorsement by IPN or Gazette International Networking Institute (G.I.N.I.). If you have questions, call IPN at 314/361-0475.

Post-Polio Bibliography

"Polio and Postpolio Sequelae: The Lived Experience" by Dorothy Woods Smith. Orthopaedic Nursing, September/October 1989, Vol. 8, No. 5. Pages 24-28.

New Post-Polio Clinics

Atlanta, GA: Brigitta Jann, M.D. & Gerald Bilsky, M.D., Rehabilitation Center, Emory University, 1441 Clifton Road NE, Atlanta, GA 30322. (404/727-5486).

Bronx, NY: Alan Berger, M.D. & Herbert H. Schaumburg, M.D., Montefiore Medical Center, NYC Post-Polio Center, 111 East 210th Street, Bronx, NY 10467. (212/920-4930).

Toledo, OH: Greg Nemunaitis, M.D., Medical College of Ohio, 3000 Arlington/PO Box 10008, Toledo, OH 43699-0008. (419/381-4022).

Leaders Write...

Readers Write ...

UPDATE FROM FRANCE

By Henry Charcosset, "Club de Loisirs et d'Entraide," Garches

In France there is estimated to be about 25,000 polio survivors. Over the years polio survivors have had the opportunity to receive follow-up treatment in the great treatment centers that have survived from the

days when polio was widespread. These centers are located in Garches (near Paris), Rennes, and Lyon. Polio survivors needing help with breathing have, of course, been given priority treatment.

The long-term effects of polio in general have not been given the same degree of attention as in the USA or Canada, even though the percentage of survivors with problems is likely to be the same. There is one article dealing with this topic, by O. Dizien and J. P. Held, published in Readaptation, 1984, No. 813, p. 7. These authors suggest that survivors with the late effects of polio should be carefully monitored, with particular attention given to any changes in body weight.

New polio associations have not been started in the eighties, but associations that date from the time when polio was epidemic are serving polio survivors (and other people with physical disabilities) and are listed in the IPN Post-Polio Directory-1990.

The magazine "Le Point Carre" has now included a column about the late effects of polio. Professionals and survivors are invited to contribute to this column. Number 92, published in December 1989, included an article by Dr. G. T. Spencer, London, England.

It is important that the work carried out on the long-term effects of polio be given worldwide distribution. The International Symposium held in Munich, FRG (7-10 April, 1988) was an excellent step for Europe.

Our association is trying to increase the circulation of IPN publications in France. A useful complement would be the publication of general surveys written in French for our medical, paramedical, and association journals.

UPDATE FROM CZECHOSLOVAKIA

By Alois Wokoun, Chabarovicka 133,
Prague 8 - 182 00, Czechoslovakia

I enclose my contribution to the Fifth International Polio and Independent Living Conference the results of my survey of 12 Czech polio survivors as to the late effects of their polio.

Twelve polio survivors (five women and seven men) from Bohemia, the western part of Czechoslovakia, born in the years 1924-1939 and affected by polio in 1932-1949, have been questioned about their late effects of polio. The survivors range in age from 49-64.

Ten of them have begun to feel new weakness of muscles which were originally affected by polio. (Six of these are not yet 60 years old.)

Seven of them have begun to feel increased weakness of muscles which were originally not affected by polio. (Four of these are not yet 60 years old.)

Eleven of them have begun to suffer from joint pains 35-50 years after polio. (Six of these are not yet 60 years old.)

Other problems include "flu-like" aching in muscles, shortness of breath, partial muscle cramps and fasciculations, muscle tingling, and sleep disturbances. Age differences, as well as sex differences of the respondents, have not influenced the late effects of polio in this examined group of polio survivors.

Fifty-eight percent of the questioned polio survivors had 3-4 limbs affected by polio in the acute stage, but 1-2 limbs remained paralyzed after subacute treatment. In forty-two percent of the respondents, the originally affected limbs have remained paralyzed.

I share information about your organization and the conference with polio survivors and therapists during my treatment at Czechoslovak Janske Lazne Spa.

Research--Is It for You?

By Roberta Simon, RN, Darien Park, IL

Research is an important aspect for the medical community in dealing with any health difficulty which has no previous history of known causes or treatments. Unfortunately, as we are all aware, post-polio syndrome falls into this category. Since many of us have been or will in the future be asked to participate in research, I think it is wise for us to consider a few questions and options.

Of course, the first consideration is what the physician conducting the research hopes to learn. You would also want to know if there is a risk to you by participating in the research and if there would be any charges to you or your insurance company. Most research is funded totally by either a grant or the institution conducting the research. All research plans must be reviewed by that institution's review board for the use of human subjects so that they can evaluate the ethical use and the amount of risk to the prospective participant. These results should be available to you if you inquire.

You will also want to know how many visits the research will require and evaluate your personal situation to see if this is a possibility for you. Some research programs require only yearly evaluations. Others may require weekly or even more frequent visits. If this is the case, are you willing and able to cooperate? This follow-up is extremely important to the physician or institution, so try to be fair in evaluating this aspect.

Would the results of this research benefit your treatment in any way? Would it improve your function and slow the progression of post-polio syndrome? Or would it give clinical information that would be of benefit only to other clinicians trying to determine the cause of the problem? I don't mean to imply that this is not important, because answers often come from the knowledge gained by understanding the cause.

Last, but certainly not least, is the consideration, "Is this procedure invasive?" Muscle biopsies or spinal fluid studies are invasive and increase the risk to the subject. If you participate in such a study, you might want to be informed not only of the risks, but also who will finance the treatment and costs if complications occur. Exposure to radiation is also an important consideration. If this type of study is proposed, be certain to discuss it with your family physician or primary caregiver. If you are having numerous x-ray studies for other health problems, this may not be the study for you.

Research holds the key to understanding and treating post-polio syndrome, and we should all try to contribute in some small way to finding these answers. If you feel uncomfortable with participation in one research study, don't feel guilty or embarrassed to say no. There will be other possibilities, and perhaps another would be better for you. Remember: you are in control, and the decision is yours.

From New Mexico

"Controlling Pain and Fatigue" is being published in many group newsletters without mention that it is an outline of a video I made last spring. The outline was intended to be used with the tape which is available on loan or can be purchased for \$6.10 which covers the cost of the blank tape and mailing.

I am honored by the response to the outline, but in the tape I make it quite clear that I am not a medical professional and urge everyone to check with a physician before trying one of the "tips." Also, I wonder how well newsletter editors are checking the sources of their information to avoid misinformation.

Since my diagnosis of post-polio sequelae, my husband Frank and I have been dedicated to helping polio survivors. We have noticed a lack of information in the following areas: When did you first notice a symptom that led you to seek medical care? Have you had bladder problems? Have you had digestive problems? I am interested in collecting information in all areas that cause you distress.

Caroleanne Green, New Mexico Polio Survivors Organization, 1008 Ivydale Drive, Las Cruces, NM 88005.

From British Columbia

An order form for audio tapes of MANAGING POST POLIO PROBLEMS, the November 1989 polio conference in British Columbia, is available from PPASS Office, 813 Darwin Avenue, Victoria, BC V8X 2X7, Canada.

During the recent First Pacific Northwest Regional Polio Conference, in Richmond, BC, I met with polio survivors who had had paralysis of the throat and/or face.... We had several concerns. How do we maintain the function we have? How do we keep from deteriorating? We also had several things in common. We all have swallowing problems, choke easily, grind our teeth, and have varying degrees of hassles with other people's attitudes. I would appreciate receiving comments.

Sieglinde Stieda, 2790 West 21st Street, Vancouver, BC V6L 1K4, Canada.

From California

The Lake Tahoe Polio Network will produce 1/25 scale die-cast metal banks for National Polio Awareness Week. Any organization wishing to use them for their own local fund raising should contact David Kelly, PO Box 10005, South Lake Tahoe, CA 95731. (916/544-1126).

Because of David's efforts, Nintendo of America has included a category for individuals who use the "no hands unit" in its Nintendo World Championships. The championships will start in March and will run for 30 weeks in various U.S. cities.

From Florida

Individuals living in the Jacksonville area interested in connecting with other polio survivors may contact Wally Cornwell, 2600 Art Museum Drive, Apt. 68, Jacksonville, FL 32207.

From Washington State

LaVonne Schoneman, author of "LaVonne's Coping Column" published in the Polio Survivors Newsletter of the Pacific Northwest, invites polio survivors to send their coping tips. LaVonne is compiling a new booklet, "HOW TO COPE: Practical Tips for Polio Survivors" and will offer a price break to individuals who send in a tip. Contact LaVonne Schoneman, 16734 - 8th NE, Seattle, WA 98155 U.S.A.

From Michigan

COPING SUCCESSFULLY WITH POLIO'S LATE EFFECTS, a videotape prepared by Sunny Roller, M.A., Educational Director, and Frederick Maynard, M.D., Medical Director of the University of Michigan Post-Polio Research and Training Program, is available on 1/2" video cassette for \$50 and 3/4" for \$75. Contact The Post-Polio Research & Training Program, N11A0491 300 N. Ingalls Building, Ann Arbor, MI 48109-0491.

Americans with Disabilities Act (ADA)

The Americans with Disabilities Act was overwhelmingly passed by the Senate in September 1989.

During the months of January and February, the Act is being considered by four House committees (Education & Labor; Public Works & Transportation; Judiciary; Energy & Commerce). It is still necessary to contact your representatives and ask that they support the ADA without any further weakening amendments. Mail your personal letter (they do not receive many personal letters) of support to Hon. (Name), U.S. House of Representatives, Washington, D.C. 20515.

Over 1 million ADA postcards have been printed. Quantities of 200 or more are available by contacting ADA Regional Contact Persons. Call IPN at 314/361-0475 for the names and phone numbers of these contact people.

Information on...

SIX POINT PLAN

The Six Point Plan is a section of the Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203). The law which became effective January 1, 1989, outlines the new payment system for the purchase or rental of DME (durable medical equipment).

Equipment is classified into six categories and the "capped rental items" category has caused major problems for individuals with a disability covered by Medicare.

Before the passage of the Six Point Plan, lump sum purchase of DMF was allowed, and the user retained ownership of the equipment.

Under the present law, in most cases, expensive DME (in excess of \$150, which includes power wheelchairs, chest cuirass with pump, commodes, and walkers) is

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Reports from Fifth International Polio & Independent Living Conference

"Bridging the Gap between Research & Clinical Applications" by Frederick Maynard, M.D., "The Body AND the Mind" by Jack Genskow, Ph.D., and "Being an Active Participant in Your Health Care" by Dorothy Woods Smith, R.N., were presented at the Fifth International Polio & Independent Living Conference. Their remarks provided a transition from the research reports (Polio Network News, Vol. 5, Nos. 3 & 4) to the panels discussing "prescriptions" for the late effects of polio which will be printed in future issues of Polio Network News. These articles are followed by a revision of the remarks made by Raymond Roos, M.D., during the research panel. This article is clearer than the original version published in Vol. 5, No. 4.

THANK YOU

International Polio Network would like to thank the Delaware Chapter of March of Dimes, Wayne, PA for their assistance in transcribing the tapes from the Fifth International Polio & Independent Living Conference. A special thank you to Mr. Larry Morgan and Mrs. Marge Torre for coordinating this very beneficial contribution.

Bridging the Gap between Research & Clinical Applications

By Frederick M. Maynard, M.D., University of Michigan, Ann Arbor, MI

We the collective people from around the world who are interested in the late effects of polio have always been the unique aspect of G.I.N.I. (Gazette International Networking Institute) conferences. Attendees include an unusual mixture of professionals working in the field of medicine and rehabilitation and people who are experiencing the problems.

The major theme of the 1981 international G.I.N.I. post-polio conference in Chicago was one of trying to validate a problem. At that point in time, no one really knew whether there was such a thing as late effects of polio. But the survivors knew. They were experiencing many new symptoms, they weren't getting any answers, and professionals didn't understand. So a major part of the first meeting had to be defining the problem.

There have been three subsequent G.I.N.I. conferences. Also two research symposiums held at Warm Springs, Georgia, brought together researchers from around the world to share ideas and the results of studying the late effects of polio.

Once the problem was defined in '81 and '83, we have spent the last three to five years both describing it and determining who has it. Some studies have been population-based, and some have been based on questionnaires and surveys. We've gone through a stage of focusing our research energies to break down the difficult problem of late effects of polio into pieces that can actually be studied.

One of the problems that we face is semantics. We need to reach some common understanding of the terminology we use. The definitions that I would like to propose are these.

Late Effects of Polio or Polio Sequelae

--specific new health problems which result from chronic polio-caused impairments.

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Post-Polio Syndrome (PPS)

--the symptom cluster of muscle weakness, fatigue, and pain resulting in new disabilities.

Post-Polio Progressive Muscular Atrophy (PPMA)

--new weakness and/or atrophy in muscles with clinical or subclinical signs of chronic partial denervation/reinnervation compatible with previous acute polio.

First of all, there are problems that are unrelated to the person's past history of polio. With some new health problems there is no reason to believe a causality or a relationship between the history of polio and the new health problems exists.

Secondly, there are late effects of polio or sequelae of old polio which are probably synonyms. Late effects of polio or polio sequelae refer to any number of conditions that are occurring when there is some causal relationship as well as a time relationship between the new health problem and a history of polio. The new problem is more likely if not certain to occur as a result of a previous history of polio and its residual effects--the nerve damage and the resulting muscle weakness.

I'd like to explain the difference between post-polio syndrome and post-polio progressive muscular atrophy (PPMA). The latter is a term that Dr. Marinos Dalakas, National Institutes of Health, Bethesda, MD, first used in one of his classic articles in The New England Journal of Medicine. In my experience PPMA is unique to a small number of polio survivors. In the chronic partially denervated muscles of people

with PPMA, the nerve function is progressively deteriorating, and the muscle is shrinking. One of the problems is that atrophy implies a smaller size of the muscle. Many times you can't see the shrinkage, and it's hard to know what the size was before. Certainly we, as professionals, cannot tell if it's smaller than it used to be unless we've done some serial measurements or known you awfully well for a long period of time.

Some people with a history of polio have lost some function as a result of a cluster of classic symptoms--pain, weakness, and fatigue. But pain, weakness, and fatigue can be symptoms of so many different problems. If the diagnosis is clearly known, this is a late effect of polio. The classic example is degenerative arthritis of the knee joint. The diagnosis is known, and the condition is treatable.

If that degenerative arthritis causes enough pain so that the person can't walk and the muscle gets weaker, the person then has to revert to a wheelchair, cane, or make major life-style adaptations. Because of weakness, loss of endurance, and loss of energy, they have a new disability (as defined by the World Health Organization--"any restriction or lack of ability to perform an activity in a manner or within a range which is considered normal...") and they fit the definition of post-polio syndrome. To me, post-polio syndrome is really a new disability.

This morning you learned about current research results, and I would highlight a couple. By most population studies, only a quarter to a third of polio survivors are likely to experience the post-polio syndrome or some new significant loss in function. It certainly is not an inevitable sequelae from having a past history of polio. Exactly what percentage will experience problems over the course of 40, 50, 60 years or an entire lifetime will

depend on what you define as a new problem and meets the definition of post-polio syndrome.

Certainly, one of the things we've learned in the last five years is that true progressive post-polio atrophy (PPMA), where there is rapid deterioration of nerve and muscle function, is very unusual. Exactly what percentage, again we don't know because population-based studies on that specific question have not been done. Neither has a definition been agreed upon.

Next, I would say that most of the new symptoms that people are experiencing have a specific known diagnosis. We have found in our clinic that you can specifically label the problems of the majority of people (bursitis, tendinitis, a tight muscle, other illness that caused deconditioning). Most of these conditions can be treated, but the causes are very complex. People come in, not as isolated pure subjects for research studies, but with all of their other health problems. They come to the clinic with all of their late effects, and then they may come with the classic (but not specific) symptoms of post-polio syndrome.

Another point that I would like to make is one concerning the issue of aging. Obviously, the polio population is not getting any younger. The more we study the questions of the late effects of polio, the more we have to acknowledge that much of what we're seeing is related to aging. It may be related to accelerated aging particularly of the muscles, joints, and nerves. But as the non-polio population gets older, they also have many more new health problems and a greater number of disabilities.

Another statement we can make is that exercise is in fact neither good nor bad. Exercise can achieve many positive results when it is done carefully and correctly. On the other hand, there is still the

issue of how much exercise is damaging for certain parts of the body.

Where is the post-polio movement now on this issue? I would say that the research efforts are beginning to mature. We have reached the stage where we have a recognized field of study. At the medical meetings of rehabilitation professionals, new scientific information about post-polio matters is regularly presented. Articles are being published in a variety of medical journals. Professionals in the field of rehabilitation, at least, are no longer saying, "What is this post-polio problem?" They realize that this is an area to be studied.

Admittedly, post-polio problems are not being studied to the degree that many of us would like, but it has reached a stage of respect. Unfortunately, there are still people in medicine who have not yet heard about it, and as we heard this morning, there are parts of the world where people have not heard.

I think we have to acknowledge our accomplishments but we have a lot of work ahead of us. I think we are still federally under-funded. We need to come together to focus on what are the priority areas for further research. Where do we really want to go with this area of post-polio study?

Besides the obvious need to continue spreading the knowledge of what we have already learned, we need to begin focusing on prevention. We need to investigate what can be done to prevent the problems occurring among a population who is growing older with a chronic disability.

I think what we are going to learn in our studies will not only benefit people with a history of polio but will benefit people with motor disabilities from other causes.

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We are going to learn more about aging. We have already discovered that we can't cure aging! What we can learn to do is to manage aging.

We are going to learn more about the impact of the environment and life-style choices on our health. Also, we will be able to relate the effect of psychological and social adaptations to physical disability to health in general.

My own intuition is that many of the problems we are seeing in some people with a history of past polio are health issues related to life-style--whether it is over-exertion, poor diet, smoking, or exposure to environmental toxins.

Problems are also related to attitude. When people get depressed, they perhaps overreact. How does that affect their health and physical decline? These are some of the things that I think we must learn and will want to apply as we now go into the next stage of the post-polio movement.

* The International Classification of Impairments, Disabilities and Handicaps was published by the World Health Organization in 1980. Available for Swiss Fr. 15 from WHO Sales Service, 1211 Geneva 22, Switzerland or from local WHO bookstores.

The Body And the Mind

By Jack Genskow, Ph.D., Sangamon State University, Springfield, IL

My role today is to aid in the transition from the medically, physiologically "Body" oriented morning to the more psychological "Mind" focus of this afternoon. There are different ways to approach this transition from physical to psychological.

First, the cognitive psychologists would point out that in adjusting to disability or any problem, it's

not the problem itself, but rather how one interprets the problem, or what you tell yourself about the problem, that causes the response. It's not the disability that causes adjustments or maladjustments; rather it's the way the person interprets that disability.

For example, you might have two people in the same room with the same disability. One person might be very depressed, very sad, and giving in, while the other person might be upbeat, optimistic, working hard on their rehabilitation. What's the difference? The first person might be telling himself or herself, "Oh I'm so sad, I'm so unfortunate, look at everything I've lost. My life's essentially over." The other person might be saying, "Hey, I nearly died; am I lucky to be alive! I'm going to work hard and try to make the most of things."

The cognitive psychologists say, "You don't have control over your disability itself, but you do have control over what you tell yourself about your disabilities. You can work on that and aid in your adjustment."

Another approach comes from the grief therapists. A therapist named Worden says that in dealing with any loss it's important to fully grieve your loss in order to fully adjust to it whether it be loss through death, loss of a relationship, or loss of physical abilities. Worden suggests four tasks that you need to work through for healthy resolution of your grief. These are tasks you can work on and that you have psychological control over.

The first task is to accept the reality of the loss. This may take time. The second, as you accept the reality, is to experience fully your emotional response to the loss, whether it be sadness, depression, or anger. These tasks go together.

The third task is getting used to living your life without that which you've lost. In other words, get used to living with your disability instead of with your loss. Fourth is to let go emotionally of what you've lost and reinvest that emotion and the available energy into new relationships, new activities, or in the case of a disability, in what you still can do. Until you complete all those tasks you may still be grieving.

Perhaps some of us have never fully completed the tasks of grieving our loss. How many of us really fully experienced the anger we may have felt or the depression? What might be happening now is as we begin to face these new losses related to polio, there may be some of those old, delayed grief responses coming to the fore. In that sense the past is re-lived again and again in the present.

A third approach to make this transition might be the way Beatrice Wright describes when she writes about indicators for identifying whether a person is succumbing or coping with their disability. She has quite a list of indicators for succumbing versus coping.

For example, do you focus on the abilities that you have (a coping response) or do you focus on the abilities you lost (a succumbing response)? Second, in looking at yourself do you compare yourself with yourself and what you have as assets (a coping response) or do you compare yourself with others, with non-disabled people, and find yourself to be lacking (a succumbing response)? There are a number of others that she has cited and you may recognize people you know who represent either coping or succumbing adjustments.

Fourth, a natural transition thought is that many people are now looking at things from holistic viewpoints. There's really no difference between mind and body and

spirit; they are so interconnected that they greatly influence one another. People point to bio-feed-back techniques, through which a person can be trained to increase or decrease their body temperature, to reduce anxiety, to slow their heartbeat. People point to hypnotism whereby a person can learn pain control and similar mind/body control and to yoga masters who can greatly reduce their metabolism through mental processes.

There are techniques used for mentally treating a physical process such as cancer. For example, using visual imagery people are trained to visualize small armies of soldiers in their body attacking the wicked looking enemies or the cancer cells.

One last comment about the body as matter and the mind as energy. There's a thought now in modern physics that if we could take a photograph of the smallest particle of matter, the smallest bit of matter undergirding our physical systems, we would not get a clearly focused photograph; rather we'd get a blur, because at that level everything's in transition: matter and energy are co-existent. Things are constantly in flux; there is no solid product or base, there's only process. Mind and body and matter and energy are essentially the same. A physicist recently speculated that when the universe began, it wasn't a big bang, an explosion of matter, rather it was a great burst of thought, of energy, which became matter.

The transition from medical body-oriented morning to psychological mind-oriented afternoon may actually be a continuation of the same topic but from a different point of view, merely a shifting of our attention.

Being an Active Participant in Your Health Care

By Dorothy Woods Smith, R.N., University of Southern Maine School of Nursing, Portland, ME

At this point in the conference, I would suggest that we pause, and ask ourselves the question, "What does all this information mean to me?" For the health professionals in the audience, that is probably fairly straightforward--to integrate the new insights and information into an existing practice. I suspect it is less clear-cut for the people who came as polio survivors, and it is especially to this group that I would like to speak.

We who have had polio are part of a unique group. We are a population whose health care needs were once fully met regardless of income and insurance. From the mid-'40s on, the diagnosis of poliomyelitis meant that all medical and rehabilitation expenses would be paid for by the National Foundation, popularly known as the March of Dimes. The health care assured was so comprehensive that some infants with neurological problems were knowingly "misdiagnosed" as having polio in order to enable them to receive the needed services.

The National Foundation has moved on to other causes, and now we need to learn about health care in the '80s, how to access the system, and who and what may be available to help meet our needs. Many of us also have to make attitudinal changes: giving up the false comfort of magical thinking; no longer empowering the doctor, nurse, and therapist to make our choices for us; learning instead to join with health care professionals as partners in our care.

I would like to share a personal experience that led me to exchange wishful thinking--that I would be taken care of--for the realization

that I needed to participate actively in my own health care. I had been in a back brace for seven years, since the birth of our fourth child, and was experiencing increasing pain and spasms. Despite (or because of) increasingly high doses of valium for the spasms and codeine for the pain, I grew less and less able to function, until I was admitted to a hospital under the care of a rehabilitation physician I had never met--a gruff, dictatorial man who gave orders and expected compliance.

I remember telling him one morning that my pain had intensified and asking whether I should go to physical therapy as scheduled. His reply was a brusque pat on the shoulder and the comment, "Raise your pain threshold." I had had it. I rallied energy I didn't know I still had! I went to the physician's office and engaged in a "sit-in," refusing PT, stating that I would wait as long as necessary to see him.

I can still picture the startled secretary as she reported this mutiny over the phone and remember how she followed his orders to make me comfortable in his office. I ate lunch seated in his big leather chair as I waited! This act of rebellion, refusing to go along with my treatment until I knew what was going on, proved to be the beginning of a warm and supportive relationship with a physician I had formerly viewed as unapproachable. It also marked the beginning of my feeling like I was treated as an individual, having my sense of self worth restored, and taking an active role in my own health care.

As a nurse, I am attracted to the work of Dr. Elizabeth Barrett of N.Y.U., who believes that nurses should work with people to help them participate knowingly in change...to make them aware of the power they have in terms of influencing the nature and direction that changes take in their lives.

Barrett's concept, which she calls power-as-knowing-participation, has four components, each of which has meaning for us: awareness, choices, involvement in creating changes, and freedom to act intentionally.

AWARENESS: By attending this conference, by listening to the speakers, and by networking with one another, we are increasing our awareness not only of change, but of some ways in which we can respond to it.

CHOICES: We are certainly faced with choices and are involved in making choices regarding our therapy, our life-styles, and our priorities. We can choose to seek help or not, to listen or not, to conserve our strength and ration our muscle function...or to go on a major energy-spending spree, flaunting and enjoying what we can do while we can do it. We can also choose whether or not our experiences will lead to personal growth.

INVOLVEMENT IN CREATING CHANGES: One of the important changes we can be involved with is how we respond to what happens in our lives. Maslow described self-actualization as the process of selecting the "growth choice" over the "fear choice" many times. He also noted that the most holistic levels of human consciousness seemed most frequently found in "heroic" people who had been strengthened, rather than weakened, by adversity.

FREEDOM TO ACT INTENTIONALLY: According to psychologist Al Siebert, people who take an active role in responding to personal trauma are among "life's best survivors." We are free to act intentionally, selecting health professionals to work with us as we make choices about our rest and exercise, eating habits, use of orthotic aids, ways to minimize our pain, and maximize our energy, and our physical abilities. And it seems to me that many of us are indeed among the group called "life's best survivors."

As knowing participants in change, each of us is empowered to participate in changes in the manner and direction we value. I urge my friends who have also had polio to take an active role in your health care. Be aware. Become knowledgeable. And make the choices that work for you, reflecting your own values and priorities.

I would like to close with a plea to my fellow health professionals to hear us. We are trying to learn to swallow our pride and ask for help. We are working to overcome years of conditioning that we are "the lucky ones," that others need help more than we do, and that to ask for help is to admit failure. When we do realize that we need help and finally reach out to you, please hear us, believe us, and work with us. Together we can find a way for us to continue to enjoy meaningful, productive lives with our sense of self-esteem intact.

NEUROLOGICAL RESEARCH *

By Raymond Roos, M.D., University of Chicago, Chicago, IL

I want to discuss three research directions we are involved in at the University of Chicago. I'll very briefly describe: analyses of the neuromuscular junction (the nerve and muscle junction) in post-polio individuals; studies looking for immunological or virological abnormalities in post-polio individuals; and molecular studies of the poliovirus and related viruses to learn more about why motor nerve cells die.

But first, let's review a previous study that tried to answer questions still very much on our minds. What laboratory studies differentiate post-polio syndrome individuals from post-polio individuals who have no new weakness or functional disturbance? How can we make the diagnosis of post-polio syndrome from a laboratory point of view?

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What's the cause of post-polio syndrome?

While still at the University of Chicago, Dr. Neil Cashman led a group of investigators, including the moderator Roberta Simon and me, in studying post-polio syndrome. We performed muscle biopsies and electrical studies on post-polio individuals with and without post-polio syndrome. As a result of the studies, we can report these findings.

First, no laboratory study presently available differentiates post-polio individuals from non-weakening post-polio individuals. In other words, we could not detect a statistical difference between these two groups with respect to findings with conventional electrical studies and muscle biopsy--because there is ongoing nerve damage in members of both groups (non-weakening as well as weakening post-polio individuals). We also found that the ongoing denervation was associated with very large motor units. Let me explain the origin of these large units. In acute poliomyelitis some motor nerve cells that innervate muscle fibers die. The remaining living motor nerve cells have to take over a larger number of motor fibers, and consequently these motor nerve cells have to do more work. The large units seem to be associated with progressive nerve problems. One question is whether terminal sprouts of the motor nerve cells die or malfunction causing the denervation.

We decided to try to examine the sprouts using a biopsy of the anconeus muscle (small muscle in the forearm), since it can be used for sophisticated neurophysiological research. Dr. Ricardo Masselli of the University of Chicago and I are very much involved in this study now. In fact, we are interested in recruiting post-polio patients for the biopsy study.

Dr. Robert Wollman is looking at the actual terminal sprouts of the motor nerve itself to investigate whether they show anatomical abnormalities. We are able to do electron microscopy to look at the actual terminal nerve sprouts as well as the muscle itself and the neuromuscular junction. The neuromuscular junction is abnormal in the case of another neuromuscular disease that shows fatigue (like the post-polio syndrome) as a prime clinical symptom--myasthenia gravis. Our preliminary studies show that the neuromuscular junction of the anconeus muscle of a post-polio individual appears very different from normal. We are midway in these studies and currently analyzing this data. We are looking very carefully in an effort to determine whether the terminal sprouts or neuromuscular junction is a critical site in the development of post-polio syndrome.

Now let's talk about the relationship of the post-polio syndrome to a viral or immune abnormality. It's interesting to note that viruses similar to poliovirus can persist for a long time in the central nervous system. However, there is no evidence that poliovirus can persist. Although I do not believe that a virus is present in post-polio syndrome individuals, it is important to look carefully and scientifically at poliovirus persistence, especially since at least one investigator reported abnormalities of the immune system in post-polio syndrome individuals. He found bands of immunoglobulin in the spinal fluid after electrophoresis, a very common finding in multiple sclerosis spinal fluid. Dr. Edgar Salazar and I just completed a study looking at the spinal fluid in post-polio individuals. Out of the twenty spinal fluids that we looked at, none of the individuals had bands except for a patient who also had multiple sclerosis. In other words, we found no evidence of any immune abnormality in this study of

post-polio syndrome, and we were unable to confirm the findings of the previous study.

Lastly, we might ask the question, "What can the study of poliovirus infections teach us in a very broad sense about post-polio syndrome?" One of my interests is to learn about factors key to the survival and death of the motor neuron itself. Remember the poliovirus is very selective. The virus only infects and kills motor nerve cells. We should remember that the living vaccine that is presently given to prevent polio is also a live poliovirus. It replicates in the human body, but it does not paralyze.

Other investigators have cloned and sequenced the parental paralytic strain and the Sabin vaccine strain of poliovirus as well as paralytic revertant mutants that rarely arise after vaccination and may cause poliomyelitis. We now know that the vaccine strain that Sabin developed has mutations that occurred during passage of the parental paralytic strain. Investigators can now "mix" the Sabin vaccine strain with the parental strain and make recombinants of the genes. Each of these recombinant genes can be made into a virus which can be tested to determine how paralytic it is. As a result of these experiments, we now know exactly what the key mutation is that makes the paralytic parental strain a non-virulent vaccine strain. In other words, the part of the genes of this virus, as well as viruses related to poliovirus, that causes paralysis or death of motor neurons has been identified. This knowledge is important in our understanding of which genes and gene products kill motor nerve cells and the mechanisms involved. In addition, these studies will be important in making the "perfect" poliovirus vaccine. We have very good vaccines, but as a result of this kind of work, we will be able to make changes in the genes so that the vaccine will

"never" generate a revertant that can cause poliomyelitis.

* This article is a revised version of the transcribed and edited remarks published in Polio Network News (Vol. 5, No. 4).

FOR YOU TO CONSIDER

A HYDROTHERAPY PROGRAM FOR PATIENTS WITH POST-POLIO SYNDROME

By Lynette Jenkins, M.C.S.P.,
M.C.P.A., O.N.C., Toronto Rehabilitation Centre, Toronto, Ontario, Canada

Post-polio survivors referred to the Toronto Rehabilitation Centre from Dr. William Franks and other physicians in Toronto are assessed by the Centre's own physician, an occupational therapist, a social worker, and a physiotherapist.

THE POOL

The pool is approximately 30' by 18', with a "stepped" floor providing four depths, 2'6", 2'11", 3'5", 4'5". Access is either by shallow steps or by a mechanical hoist. The temperature of the water is kept at approximately 96 degrees Fahrenheit. The pool is equipped with "furniture," consisting of aluminum chairs and parallel bars.

The Hydrotherapy Program

Polio-affected muscles are weak and in some cases paralyzed. This can lead to a tightening or even a contracture of the affected tissue. Slow, gentle stretches, always within a pain-free range, help to alleviate this tension, reduce contractures, and relieve cramping. While it may be impossible to strengthen muscles affected by polio, it is possible to strengthen the unaffected muscle groups. Very often extra strain is exerted on them, and so strengthening routines can help prevent damage because of the overload.

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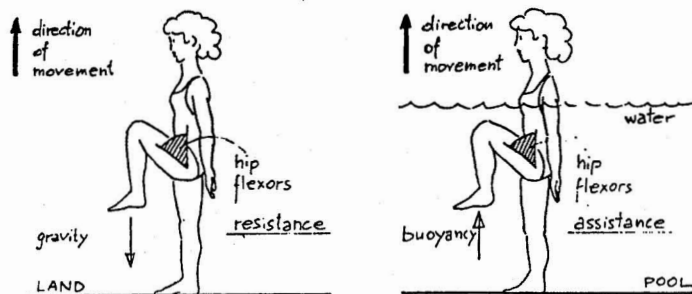
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It is easy to work in the security and warmth of the water, and it may be possible to overwork. Survivors are constantly reminded to work within their own exercise tolerance level and to take frequent rest periods to ensure that muscles do not get overtired. Exercising the individual part at the expense of the whole body is constantly guarded against.

Postural corrections are taught, as inefficient posture can aggravate joint aches and pains. Body mechanics and activities of daily living are also discussed because an increase in body awareness leads to a decrease in body use.

On land people with polio often cannot raise their level of physical activity to bring about a rise in the heart and respiratory rate. It is possible to do this in the water, so quick repetitive, small-range movements are taught to help improve cardio-pulmonary efficiency. Pool sessions last for approximately half an hour, with two-thirds of the time being given to formal exercising and the remainder to "free" time.

It may be impossible for the person with polio-affected hip flexor muscle to stand on one leg and bend the other knee up to the chest on land. The muscle has to have a certain strength to produce movement to resist the downward pull of gravity. The effects of gravity are eliminated when that person is in a pool. The buoyancy of the water acts as an upthrust that actively assists the movement, making the action possible.



When the bent leg is brought down next to the standing leg, buoyancy may also be used as a resistance for exercising (Figure 2a). The hip extensors work against the buoyancy of the water making the exercise more difficult to perform.

Buoyancy, either as an assistance or resistance, determines the starting position. Available muscle strength also determines the starting position for every exercise. Sometimes buoyancy is just too efficient and webbing straps are used as seat belts to stop people from floating away when they are doing sitting exercises.

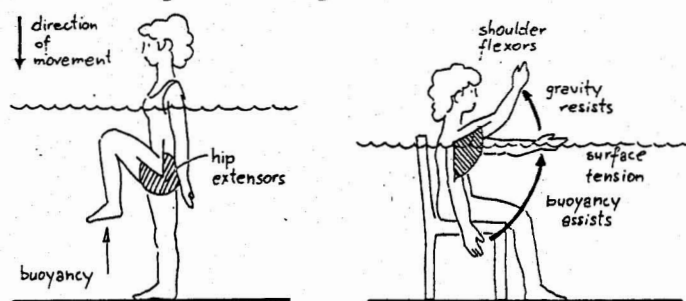
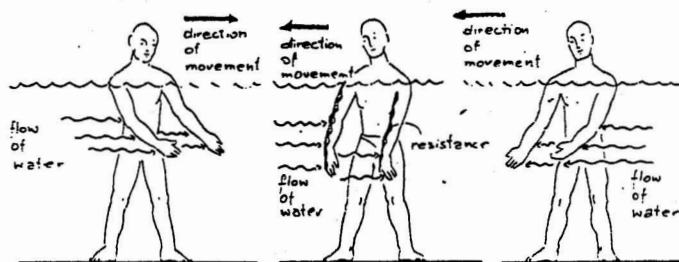


Figure 2a & 2b

Exercising under the water is easier than exercising out of it, but the water itself can also act as a resistance. At the point of change from water to air or air to water (Figure 2b), the surface tension of the water acts as an extra resistance to the movement. The speed of the exercises may be increased or decreased depending on the available muscle strength. The faster the exercise, the harder it becomes because the mass of the water now acts as a resistance. When performing an exercise that involves a change of direction, the turbulence of the water created by the initial movement acts as a resistance at the changeover position.



The various depths of water are needed not only because of the various heights of people, but also the deeper water exerts greater hydrostatic pressure on the limbs. This pressure, combined with the warmth of the water, aids the return of venous blood to the heart and helps prevent edema in the extremities.

THE PHYSICAL EFFECTS OF HYDROTHERAPY

The stretching routines help to increase flexibility, prevent contractures, and relieve cramping in all muscles. Strengthening exercises improve muscle tone, strength, and endurance. The duration and pace of the program helps raise the cardio-respiratory efficiency. An increase in body awareness, joint conservation, and postural control encourages a greater level of responsibility on the swimmer's part.

THE PSYCHOLOGICAL EFFECTS OF HYDROTHERAPY

The warmth and buoyancy of the water promotes a general reassuring environment. There is a freedom from restrictive braces, canes, crutches, and wheelchairs.

LONG-TERM MANAGEMENT

Follow-up exercises to be done in a bathtub are taught, but the lack of space is rather limiting. As we received more and more referrals from West Park, the original group of patients had to make way for the newcomers. The graduates formed the Post-Polio Penguins, with the motto "wobbling on land...waltzing in the water," and since discharge from the Centre have continued to meet as a group, using community pools for their exercise sessions.

Hydrotherapy is, of course, pleasurable for the patient. We can all attest to that. However, I should stress that I am speaking from my own experience. There are doubtless other centers which can claim equally good results from specially designed dry-land

regimes. For those areas where therapeutic pools are not available, therapist and institutions must devise and apply other forms of assistive exercise programs to help control the potentially progressive problems of post-polio.

THE POST-POLIO PENGUINS

By Dorothy Gowen, Scarborough, Ontario, Canada

The Post-Polio Penguins is a self-help group which evolved from a handful of people meeting twice a week for water therapy at the Toronto Rehabilitation Centre. We were given an hour each week following our pool time to assemble, together with our physiotherapist, to discuss mutual experiences, problems, and possible solutions for them. During these sessions we would often discover that one or more members of our group had coped with a similar situation to the one being discussed. Many times these problems were resolved. When they were not, the person facing them had the positive support and caring of a concerned group. We also gained a more healthy approach to admitting that we had weaknesses. Some of us had been loath to share our problems with family members, thinking it unfair to burden the family; but through this group we learned to share the knowledge we had gained.

The group has given many of us the determination and the courage to say to others that we are no longer able to do certain things. We no longer place ourselves in the harmful position of having to say "Yes" to every request. In fact, if our group hears of a member attempting to do something rash or too tiring, we do not hesitate to butt in and advise that person against it.

We are learning to take charge of our own lives. We make decisions that are good for us. We have gained enough confidence in our

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worth to recognize that it is not selfish to do this.

When we had to leave Rehab to allow room for other post-polio clients to use the pool, we felt the need to function as a group, so we organized ourselves into the Post-Polio Penguins. Our express goals are to support each other and to find suitable therapy pools to continue our beneficial exercise and recreation program as a group. Post-polio people do not necessarily feel the benefit of hot water therapy, nor are they interested in locating suitable pools. The Penguins belong to the larger group of Toronto/Peel Post-Polio Chapter under the March of Dimes, and we applaud and support its efforts; nevertheless, we feel the need to retain a separate identity. We are a much smaller group and have the opportunity to become closer to one another. This results in closer communication, better knowledge of each other, and a very caring colony of Penguins.

We have made an observation we should like to pass on to others--the happiest Penguins are the ones who are ready to accept change and adopt a new life-style. We are all trying to learn to "go with the 'floe.'"

FOR YOU TO CONSIDER

Sandra Hughes Grinnell, B.A., graduated from the University of California, Santa Barbara, with a major in Sociology and a minor in psychology with emphasis on behavior modification. She and her husband, an environmental specialist, have lived in Southern California for the past 15 years. The following article is available in its entirety from IPN for \$2.50 (photocopying and postage). The first part was printed in the Fall Polio Network News (Vol. 5, No. 4).

A Post-Polio "Normal's" Reconciliation with the Ghost of Polio Past - Part II

By Sandra Hughes Grinnell, Independent Medical Researcher, Pasadena, CA

I had muscle strength tests done in areas never evaluated since the onset of polio in 1953. There was a large variation in muscle strength in the trapezius muscles (located in the upper back) as follows: upper trapezius muscles left and right, good; middle trapezius left and right, fair plus; and lower trapezius left and right, poor. I asked the therapist if that major drop from good to poor could account for the incapacitating attacks of pain and fatigue I had experienced for many years in that area and represent a residual loss of muscle strength directly related to "old polio." He answered with an emphatic "Yes, absolutely" to both questions. It was the first "yes" I had heard from the medical profession with regard to questions making a connection to my polio experience since a doctor said to my parents in 1953, "Yes, your daughter has polio." Now, in 1984, the "yes" was actually comforting to hear, because it put some logical perspective on my present situation.

Also, I learned during the trapezius muscle tests that I was not lifting myself up from a lying position with any significant upper body assistance. I was going through the motions with the arms and hands and it appeared as though I was lifting myself up, but I learned that in reality I was substituting muscles and lurching into a sitting position using my low back and abdominal muscles. In hindsight, I realize that since I had graduated from college I had gained 25 pounds, and my abdominal muscles were not as strong as they used to be. It is true that with the exception of shortened hamstrings, my lower extremities were

not initially affected by polio. However, it makes sense to me that the uneven levels of muscle strength in my upper back combined with increased stress on my low back muscles (as my abdominal muscles weakened) to pull me up with this lurching motion could have been the cause of all those low back spasm episodes that had always occurred after repetitious physical exertion since 1962 (and with increasing frequency each year since 1975).

Now in early September of 1984, while looking through some medical journals, I noticed a letter written by a physician complaining of the sorry state of affairs in medical records departments across the country. Doctors were often being told records were not available when in fact they were. I began to wonder if my own polio records had really been destroyed in a fire. I decided that without further delay I must write a letter to Dr. Frederick Robbins at the National Academy of Sciences. Even if he did not remember my case, he might take an interest simply because doctors that he had some acquaintance with during the polio epidemics were directly involved at present. On September 30, 1984, I received a two-page letter from him. He said in part, "...it was most interesting to hear from someone I treated 30 years ago. I do not remember your specific case after 30 long years, but the records should be available at the hospital." He then suggested that I get in touch with a doctor who was, he wrote, "the only doctor from those days who is still there." That night I sat down and wrote to the physician he had specified. I enclosed a copy of Dr. Robbins' letter. In December 1984, a copy of the original transcript of my polio care in 1953 arrived in the mail along with a note from the doctor expressing his dismay that I had been given erroneous information regarding the status of my records. He had personally gone into the

medical archives to locate them. (The arrived with narry a "char" mark on them!) What I learned from those records is a good illustration of why they are worth the extra effort to obtain!

First of all, because I did not require respiratory care during my two-week stay in isolation at the hospital, the records indicate a change of status from an initial diagnosis of "bulbar" polio upon admission to a diagnosis at the time of discharge of "non-paralytic poliomyelitis." The records showed "bulbar symptoms" which involved "difficulty swallowing" two days prior to admission. An interesting fact regarding my diagnosed "bulbar symptoms" (for which I was put in isolation) is that upon discharge from the hospital after the customary two-week stay, "my gag reflexes were present, but weak." I must note that on many occasions from my college days on, when I was involved in theatre productions or jobs involving daily speaking engagements, I would lose my voice, but there was no throat infection on any of those occasions! It would be extreme muscle fatigue in my throat and the only thing that helped was resting my voice for a couple of days or more. I got to the point in the late 1970s that I would not schedule activities of that nature on a daily basis because if I did, I would have to give the activity up altogether. At the time of my release from the hospital my records show that I still had a stiff neck and tight hamstring muscles with some stiffness in the lower back, but a muscle evaluation at that time did not indicate muscle weakness. The discharge recommendations were that my parents have a physical therapist come to our home twice a day for six weeks to help me regain flexibility in my hamstring muscles. My legs gradually began working well again, but the hamstrings remain shortened, and I need to stretch them every day so as not to injure them. Upon leaving the hospital,

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the record states that I was "referred to private physicians." Now in 1989, Dr. Jacquelin Perry, upon reading a rough draft of this article, advised me by letter that "a more appropriate diagnosis would have been 'bulbar-spinal' to identify scattered involvement here and there."

Interestingly, my parents would tell me two very revealing things in September of 1984, in light of my sharing the news that I had received my polio records. First, upon my release from the hospital one of the doctors on staff said to them, "Your daughter will make a complete recovery except for the fact that she will not have a normal level of stamina during her life." My parents decided that to tell me would set limits on me at the outset; so they just kept an eye on me and gave me gentle reminders to "pace myself." Because I was at my peak recovery in my high school and early college years, I am glad they chose not to tell me at that time.

The second thing my parents told me in 1984 was that before I had polio, I had a very flexible spine. After I returned home from the hospital and started to resume normal activities, they noticed that I was still very well coordinated but my spine had lost a lot of its original flexibility. It just seemed that afterwards I had to work a lot harder at athletic activities I had accomplished with ease before I had polio. I think this may be a good example of the ability to substitute muscles instinctively that many of us had at the onset. Enter the "swiss cheese analogy." As the years passed I began to minimize any connection between having to give up some activity I enjoyed and poor stamina.

Because I continued to be in excellent health as far as routine annual physicals go and because I had been repeatedly told by the medical profession that my muscle weakness

and spasms had absolutely nothing to do with polio, I virtually stopped talking about it. I continued to get totally absorbed in many different jobs, community activities, and hobbies for as long as I could. If I eventually began to get into trouble with major muscle spasms, I would quit that activity, get some physical therapy, and rest before charging into a whole new area. I was always hoping I would use my muscles differently in a new endeavor. (I would later learn that it was the extended repetitious use of weakened muscles that was the problem.)

In October of 1984 I started thinking about that day back in June when I crossed paths with the young intern in the local hospital library who had directed me to the article he had read by Dr. Richard Bruno at Columbia University on post-polio problems. I decided to send Dr. Bruno a note along with the documentation of my medical history that I had gathered so far. I received a handwritten note from him in which he said in part, "As you suggest, it is vital that we know that 'normal' post-polios who don't have residuals are reporting weakness and fatigue; you are not alone!" He concluded the letter by writing, "Best wishes and best of luck both personally and in educating the physicians in your area."

In November of 1984 I received a letter from Dr. Tom Gucker whom I mentioned earlier. He wrote that "It is vitally important not to confuse similar neuro-muscular diseases." He went on to say, "I admire your zeal about research but suggest that it is a very complex and demanding endeavor." Needless to say, he was pleased upon his return from several back-to-back speaking engagements to review the recently acquired copy of my original polio records! I told him that in keeping with a determined "polio personality" (which obviously included his own), I viewed the comments in his letter on the demands

of ongoing research as a challenge, which with my new understanding of how to conserve my energy would be one activity I would not have to give up. He, and he alone, had created a climate in which the logically oriented side of my brain was to thrive and get me to where I am now. My only regret is that he did not live long enough to witness it.

Dr. Gucker's untimely death brought on by a sudden and unexpected stroke in August of 1986 would have left a tremendous void in my research efforts if it were not for my personal physicians taking a renewed interest in my case after reviewing my original polio records and the medical summaries from the polio clinic in August of 1984, along with highlights of some of the post-polio research in general.

I realize that everyone does not have the time to get as involved in the research process as I have done or the desire to write in this format, but people who have really chronic problems are probably spending more time focusing on those problems than they realize and could spend the time far better focusing on solutions through their own research efforts. Often doctors will evaluate a person as being obsessed with their problems. Obsession in and of itself is not a problem. After all, getting through medical school is an obsession! When a patient becomes obsessed with solutions to problems, it changes the whole nature of the doctor-patient relationship. It becomes a partnership. The important thing is that you communicate results in writing to as many people in the medical profession as you can--not necessarily an effort such as mine, but a simple one-page case study which can be used for reference and further evaluation within the medical community later on.

I sincerely hope in taking you through my research journey during

the past five years that I have shown you that it is possible to experience renewed vitality by reconciling with the "ghost of polio past" I referred to at the outset. I have personally found that it is only by losing fear through knowledge, understanding, and finally acceptance that we gain control over our problems and see the "ghost" as no longer a threat but rather a source of knowledge. In my own case, because of what I learned at the polio clinic regarding my areas of muscle weakness in 1984, combined with the exercise routine that I have developed during the past few years, I have not had another incapacitating episode of upper or lower back spasms.

If I start to experience pain from occasional overuse of weakened muscles, I have found that cold packs applied to the problem area for five to ten minutes give very quick relief and often eliminate the necessity for bed rest in order to resume normal activities. Dr. Jacquelin Perry has often referred to post-polio problems being not unlike the "overuse syndrome" seen in athletes. In sports medicine cold packs are routinely used for tired, swollen muscles, so I decided to try them, with excellent results. Dr. Perry recently explained to me that in the acute state of polio the pathology is a neuritis (or inflammation of involved nerves) which responds well to heat, whereas the late effects of polio represent various stages of tissue damage with the first reaction being an inflammation of the involved tissue--which responds well to cold. It has occurred to me that if cold packs help enough post-polios perhaps the formal guidelines for post-polio care could be expanded to say that just as in the initial stages of the disease process our muscles responded to heat, in the latter stages our muscles need to be "cooled down" so to speak, to make the process of "slowing down" less painful.

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At my request, in the spring of 1989 my orthopedist gave me an open-ended prescription for some routine physical therapy to eliminate some lingering deep muscle spasms that were not causing pain but were limiting my range of motion and general flexibility. During the course of these treatments (twice a week for six weeks) my physical therapist applied a "medical establishment version" of acupuncture to my thoracic spine (upper back). This procedure, which in my case consisted of four treatments in a two-week period of time, is referred to as "thoracic mobilizations--spinous processes." The result has been a dramatic return of strength and function to my arms and hands as long as I do not push myself beyond my limits. By doing slow stretching and deep breathing exercises combined with riding an exercise bicycle for 5-10 minutes daily with zero to low resistance, I have gradually lost 25 pounds and have kept it off for almost two years. My muscle tone is actually better than it was when I was in college. By exercising with minimal resistance (as recommended in formal post-polio guidelines) and avoiding prolonged repetitious activities which require heavy use of the trapezius muscles, I have gradually built up acceptable energy reserves to protect the lower trapezius muscle group which I know is almost non-functional. I can now consciously protect the same muscles that for years I had instinctively overused.

The quality of my home life has always come first during my 20-year marriage, and when I have worked outside the home, it has always been part-time by choice--aside from the issue of stamina. I am very fortunate to continue to have a choice because in all honesty the pursuit of a full-time career at this point in my life would be totally "beyond my limits" physically. I feel it is important to include this information because it could well be that my ability to

turn things around rather dramatically is due in part to a life-style that affords me a better opportunity to pace myself and to get the rest I need when I really need it. This may not be the case for a post-polio person who works full-time to make ends meet and may even live alone. I am optimistic that what I have accomplished can be of great value to many others like myself, but at the same time I do not want to over-simplify the solutions because life-styles vary tremendously.

A final thought: perhaps the more severely disabled members of the polio community have unintentionally contributed to the dilemma that many post-polio normals find themselves in when trying to get appropriate medical care. Based on those "first impressions" I spoke of at the outset of this article, they often view the possibility of our symptoms stemming from old polio with as much skepticism as our doctors often have! Possibly, just as we "normals" fear them as reminders of the things that could have happened, they may look upon the rest of us with resentment because we symbolize the many people who fared so much better than they did at the outset. Since both emotions are negative and unhealthy, if we cast them aside, we can learn from each other because, in reality, any level of disability that keeps each of us as individuals from doing something we really love is equally traumatic to all of us.

A poignant example was published in an article in The Saturday Evening Post, September 19, 1936 issue, about a young boy named "Larry." The title of the article was "My Son--Handicapped?" The following is a passage from a conversation Larry has with his mother regarding his attempts to understand why he has polio.

"Why did this have to happen to me? Why to me instead of some other boy? To Joe? Or to Tom? What did

I do? Then, Mother, I got an idea. I said to myself that this had been done to me rather than to some other boy, because I was better able to overcome the handicap than some other boy. That made me feel pretty proud, in a way."

That boy named "Larry" was in fact, Dr. Thomas Gucker III. During our visit in his office back in July of 1984, he told me of an article he thought I would enjoy reading. Before his death in 1986, he had revealed publicly that the story about Larry was in fact written by his mother about him. He had such a long and difficult recovery, requiring several surgeries to reach the level of recovery he would enjoy from his medical school days right up until his death. But he didn't want people to feel any pity for what he had gone through. For many years in speaking engagements all over the world, he would often cite the case study of Larry when the topic was polio. Reading "Larry's" words in the article had as much impact on my thinking about my own situation as an adult in 1984 as it did on him (who was far more disabled than I!) when he actually said those words to his mother years ago as a child. I'd like to think his words speak for all of us in the post-polio population.

Renewal Notices

Individuals who need to renew their subscription to Polio Network News have received the new Gazette International Networking Institute (G.I.N.I.) order form. This new form includes all G.I.N.I. publications. If you subscribe to more than one, we will gladly work with you so you can renew all of them at the same time each year.

(continued from page 6)

SIX POINT PLAN

classified as "capped rental items." The rental agreement is for a maximum of 15 months with Medicare paying the vendor a monthly rent calculated as "10% of the average submitted purchase prices on assigned claims for new equipment between July 1 and December 31, 1986, updated to account for inflation."

The total rental payments cannot exceed 150% of the original DME cost. After the 15th month, the vendor retains ownership and the client continues to use the equipment. The vendor may only bill for maintenance six months after the initial 15 months.

The above regulations have had a definite financial impact on vendors. Consequently, vendors are refusing services to Medicare recipients. Medicare consumers are left with no means of access to repairs or new DME.

Dianna Poggetto at the Center for Independent Living (CIL) in Berkeley, CA, chairs the CIL Medicare Committee which has proposed an amendment to the Six Point Plan.

"Our solution to this problem is to retain the option of either lump sum payment or rental. The option to rent is acceptable for consumers who only need equipment for a short time."

For long-term DME users (i.e., individuals with a disability), the lump sum payment is the only sensible procedure. The lump sum payment will financially allow vendors to provide the services that keep DME functional. In addition, the user will own the equipment which is very important to an individual with a disability when traveling or relocating.

For more information contact Dianna Poggetto, CIL, 2539 Telegraph Avenue, Berkeley, CA 94704 (415/841-4776).

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Calendar

May 23-25, 1990. Post-Polio International Conference: Poliomyelitis-A Forgotten Disease and its Late Effects. Topics include: fatigue, weakness, pain, exercise, energy conservation, swallowing, breathing, & psychological adjustment. Approved for CME credits for physicians and CEUs for RNs, RTs, & PTs. Galt House East, Louisville, KY. Contact: Frances Brown, Polio Survivors Organization, 6203 Fegenbush Lane, Louisville, KY 40228. 502/239-9792. Or Lee King, Heart & Lung Jewish Hospital, Louisville, KY. 502/587-4044.

June 8-10, 1990. Support Group Leaders' Workshop. Sheraton St. Louis Hotel, St. Louis, MO. Contact: Joan Headley, International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63018. 314/361-0475. (See page 1.)

September 28, 1990. The Late Effects of Polio. Allis Plaza Hotel, Kansas City, MO. Contact: Sheryl Max, R.N., M.N., Research College of Nursing, 2316 East Meyer Boulevard, Kansas City, MO 64132. 816/276-9340.

October 13, 1990. N.J. Conference on the Late Effects of Polio. Somerset Marriott Hotel, Somerset, NJ. Contact: Post-Polio Conference of New Jersey, Box 537, Martinsville, NJ 08836. Attention: Jean Brogdon.

Your Help Is Needed!!

WE EXPERIENCED A MAJOR COMPUTER CRASH IN SEPTEMBER 1989.

Individuals who renewed in August or September did not receive the Fall Polio Network News (Vol. 5, No. 4) in the bulk mailing. We believe the error has been corrected. Those individuals were mailed the fall issue in February and will receive Polio Network News (Vol. 6, No. 1) and the Post-Polio Directory-1990 via bulk mail in early March.

INDIVIDUALS WHO WERE FIRST-TIME SUBSCRIBERS TO THE POLIO NETWORK NEWS IN AUGUST OR SEPTEMBER HAVE BEEN LOST. IF YOU KNOW SOMEONE WHO DID NOT RECEIVE THEIR FALL OR WINTER NEWSLETTER, PLEASE ASK THEM TO WRITE OR CALL US.