

POLIO NETWORK NEWS

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INDEPENDENT
LIVING
CONFERENCE
ST. LOUIS, MISSOURI, USA

LESSONS LEARNED — FUTURE CHALLENGES

JOAN L. HEADLEY, EXECUTIVE DIRECTOR, GAZETTE INTERNATIONAL NETWORKING INSTITUTE,
SAINT LOUIS, MISSOURI

In 1987, when I was about to turn forty, when I had accepted the fact that I would not have children, and when I found I could diagram and discuss the functions of all the body systems of a frog while planning dinner, I sent resumes to several schools including doctoral programs, hoping for a change and a challenge. The day I dropped them in the mail, I received my *Polio Network News*, so I wrote one more cover letter inserting a paragraph about having had polio, knowingly playing the “polio card” for the first time in my life, and sent the letter to a Gini Laurie and Judith Raymond at Gazette International Networking Institute, publisher of *Polio Network News*.

By August, I had quit my teaching job of 18 years, put my house on the market, and moved to Saint Louis to work with Gini Laurie and for G.I.N.I. She had explained to me that the organization supported the independent living philosophy — the philosophy that people with disabilities should be integrated into society, not isolated: that they should have an opportunity to receive an education, be employed, have a family, have access to appropriate health care and personal assistance; in short, have an opportunity to do all the things that others can do, including failing classes while getting the education, being fired, and getting divorced. She also explained that through her 30-some years of work for polio survivors and people with disabilities, she was most frustrated by two things — “UBI” (universal bureaucratic idiocy) and the “edifice complex” exhibited by people who felt they could not act or help until they had all the hierarchy in place and a large building built.

People with disabilities, she felt, no matter what issue they are facing, immediately need two things: accurate information and the connection to others, specifically people who have knowledge based upon a similar experience and the willingness to share it. “We network by sharing vital information,” she said, “through our publications, our conferences, and

through all the mail and phone calls we receive, changing one life at a time, hoping and knowing that those who are affected go on to change the lives of others.”

It all made sense to me. I had polio at the age of 15 months and was not hospitalized. Having had polio was part of who I was — a girl from a small town in Ohio with parents who made me feel loved for the person I was and encouraged me “to do my best.” I had a sister who was four years older and a brother

13 months younger — born immediately after me because my father, back from the War, wanted a son. My version of the story that I heard and re-told many times was that Father wanted a son “too,” not “instead.”

Having attended college during the ‘60s, the whole concept of the “wrongness” of excluding people who were different resonated in me. Because of the level of my disability, I personally had never been excluded for architectural reasons and had never felt excluded based on attitude. However, because of my permanent limp, I instinctively did know what it was like to be and feel different. Being a veteran biology teacher, I was committed to education and knew the power of knowledge. G.I.N.I. was in need of an employee, and I accepted the challenge.

“There are survivors who have received information about the late effects of polio, taken action, ‘found the balance,’ and have moved on with their lives.”

What lessons have I learned?

I have learned that many polio survivors remember their acute polio experience — some with very traumatic stories to tell, and some with hilarious stories to tell about hospitalization; some who played football before polio but could never play again due to the extent of the paralysis, and some who due to rehabilitation and desire did play again.

Some spent their childhood in special schools, isolated from other children. Some were educated with children without disabilities, at times being ridiculed.

There are polio survivors who sleep in iron lungs or on rocking beds or who use portable volume ventilators at night, and run their own businesses, teach in universities, preside from the bench by day. But there are also polio survivors who have a limited education. There are polio survivors who are blue-collar workers doing hard physical labor so they, too, can put their children through college and pay the mortgage.

Some polio survivors with significant disabilities use personal assistance services and are living on their own — not institutionalized; there are polio survivors in their 50s and 60s with rather significant disabilities — not institutionalized, but living with their parents who are in their 70s and 80s.

There are parents of polio survivors who did the very best they knew how in the medical, social, and psychological context of the '40s and '50s, when most of us had polio, who are now confused and a little "hurt" when we discuss the late effects of polio. They interpret our discussions to mean that we are blaming them for their actions years ago. There are polio survivors who are protective of their parents and are reluctant to openly discuss some of these sensitive past experiences.

I learned that polio survivors refer to themselves in different ways: some call themselves "polios," a term dating back to acute polio rehabilitation. Some are offended by the term "polios," saying that people who have had cancer do not call themselves "cancers."

JOAN L. HEADLEY, born and raised in northwest Ohio, received her BS in biology from Huntington College (Indiana) in 1965 and her MS in education from Indiana University in 1973. All 18 years of teaching was with the Lakeland School Corporation in LaGrange, Indiana. This August marks her tenth year of work with G.I.N.I.

Some refer to polio survivors as dinosaurs, minimizing us as people and our current needs, not acknowledging that some of us have, based on average life expectancy, another 25 years to live, or that the World Health Organization estimates that 12 million polio survivors live in the world today.

We must think about what we call ourselves because it reflects how we think about ourselves. As Al Siebert, PhD, one of our 1994 speakers, and author of *The Survivor Personality* says, "People who adopt the victim style are thinking, 'If only other people would change, my life would be better.'" And as he further explains, "Of course, it is true, our lives would be better if everyone else changed to our liking, but the reality is that that is unlikely." According to Siebert's study of life's most successful survivors, they recognize that the world constantly changes and that constant learning is required; that being flexible is an absolute necessity. Successful survivors are good troubleshooters, having empathy and the edge when it comes to intuition, creativity, and imagination.

I have met loving spouses and families who are supportive of their family member with the disability. I know some spouses who are tired, ill, aging, and in need of support themselves.

I have spoken with physicians who do not understand post-polio problems; however, I am privileged to know many who give of their time, expertise, and talents to help us, to tell us the truth, not just what we may want to hear, and to educate their fellow health professionals.

From listening at conferences and to other polio survivors, I know that some of the best polio doctors are not the greatest conference speakers. I have learned that good polio doctors are good listeners. I also have learned that polio survivors need to listen as well.

Some polio survivors are well-educated about their own polio, but many others have not had the occasion to give much thought to polio until now.

I hear from polio survivors who feel the message about post-polio needs to more prominently broadcast. Simultaneously, I hear from polio survivors in the work force who fear every media message about the potential fatigue and weakness of polio survivors because it might jeopardize their job status.

There are polio survivors who attend support groups; some who have dedicated hours to coordinating support groups, finding energy in this association. There are polio survivors who receive support from their families, synagogues, or churches and do not choose to associate with other people with disabilities.

I learned that the late effects of polio and post-polio syndrome have many faces and varying definitions;

that the major symptoms of pain, fatigue, and weakness can be caused by many other things. I learned that treatments have many faces as well, that we must be careful when touting specific ones. The treatment for fatigue, the major cause of which is respiratory muscle weakness, may be night-time ventilation. Fatigue due to failure at the neuromuscular junction has potentially another treatment, or fatigue related to depression, which may or may not be related to polio, has yet another potential treatment.

I learned that having had polio can explain some of our problems. I also realize that polio may be getting some unwarranted blame. It has been suggested to me that polio is the reason I did not marry and have children. After some introspection, I have concluded that I have enough faults to account for the fact.

There are survivors who have received information about the late effects of polio, taken action, "found the balance," and have moved on with their lives. I also know that some of these same people who made an adjustment five or six years ago are now calling again, sensing a need for another readjustment.

I learned that there are polio survivors all over the world who are experiencing the consequences of having had polio; that polio is not completely eradicated in some countries; and that therapy for the acute polio is not always available. In some countries, polio survivors and other children with disabilities do not have access to an education or hope for future employment. Some people with disabilities live in countries where they are shunned. There are also countries in which survivors have developed their own outstanding networks regarding post-polio and disability issues to meet the need within their own culture, their own medical establishment, and their countries' social policies.

This list is just a small part of what I have learned. Within the list are many challenges. The question is: how will we meet those challenges?

We who are involved in the Network need to recognize that polio survivors and health professionals are not all alike. For many of the questions, there are no cookie-cutter answers. We need to listen to each other — health professional to health professional, polio survivor to health professional, health professional to polio survivor, polio survivor to polio survivor. We must stay up-to-date on post-polio and disability issues, continually re-evaluating what we have to offer. We need to be open-minded but also to think for ourselves. To find solutions for ourselves as polio survivors or as health professionals, each of us will need to invest something — our time, our talents, perhaps our resources. Then we must pass our solutions along. In doing so, we must think carefully

about what we say and how we say it, knowing that there are consequences of misinformation, too little information, or information out of context.

I am not saying here that all information must be AMA approved. I am well aware of the fact that when Gini Laurie approached the medical community in 1981 with post-polio issues, many did not receive her. I am also not saying that there is no room for differing opinions because there are unresolved issues. The G.I.N.I. tradition is relating experiential stories which expose problems and offer what works, opinions if you will. But those stories and opinions can and should include facts and resources. As someone once said, "Everyone has a right to be wrong about their opinions, but no one has the right to be wrong about their facts."

The reason the *Polio Network News* was in my mailbox that April day in 1987 was the result of my first exposure to the late effects of polio being misinformation. While shoe shopping with a friend, she said, "Joan, I do not want to scare you, but have you read that polio survivors are getting polio again?" I reacted as a biology teacher, immediately thinking about the poliovirus and acute polio, and I had an immediate and physical reaction to the statement: a reaction in that part of me somewhere between my heart and stomach. My next reaction was to try to find accurate information, a search that led me to G.I.N.I., an organization which believes in the power of information, the independent living philosophy, and the resourcefulness and generosity of man- and womankind.

We are pleased to welcome you to our Seventh International Post-Polio and Independent Living Conference — offering you an opportunity to learn from each other, to be energized by each other, to find solutions, and then in turn, to become part of the solution. ←

This issue of *Polio Network News* initiates our publication of the presentations from G.I.N.I.'s Seventh International Post-Polio and Independent Living Conference, May 1997.

Most speeches were captured in realtime by Kimberly A. Pfeinger, CRS, CRT, Saint Louis, Missouri, and displayed immediately on a screen in the conference room. These edited transcripts are submitted to each speaker to check for accuracy, to add thoughts and resources, and to modify a speech with or without slides into the readable, written word. Presentations from the Home Mechanical Ventilation Forum will be published in *I.V.U.N. News*.

TARGET 2000: REACHING THE GOAL OF POLIO ERADICATION

ROBERT A. KEEGAN, PUBLIC HEALTH ADVISOR,
CENTERS FOR DISEASE CONTROL AND PREVENTION, ATLANTA, GEORGIA

Three years ago you invited me to review progress towards global polio eradication. I am pleased to be back to give you an update. The executive summary is: progress has been extraordinary worldwide, yet the challenges continue to be daunting.

Let's begin with a few words about the global polio eradication initiative. The community of nations represented by the World Health Assembly in 1988 resolved to eradicate polio by the year 2000. The goal is to eliminate polio in every country in the world and to eradicate the virus that causes it.

A global partnership has formed to achieve this objective and includes the World Health Organization; the United Nations Children's Fund; Rotary International; the governments of Australia, Canada, Denmark, Finland, Germany, Japan, Norway, Sweden, and United Kingdom; the Task Force for Child Survival and Development; Centers for Disease Control and Prevention (CDC) and U.S. Agency for International Development (USAID). Other partners are joining by the year.

Rotary International is a particularly unique partner. They have raised more than 250 million dollars from the pockets of their members and expect to contribute a total of 400 million dollars by the end of the program.

When I last spoke to you in 1994, I pleaded for more dollars. I am pleased to report to you, although we still need more dollars, funding from the international partnership has increased to more than 100 million dollars annually. No longer do we have a serious problem with obtaining the funds to buy polio vaccine for every child in the world.

The basic strategies to eradicate polio are the same as they were three years ago. We must have strong routine immunization programs. We must have effective surveillance for acute poliomyelitis, including surveillance for every child under the age of 15 with acute flaccid paralysis. (Polio is difficult to diagnose in many countries, so we look for every child with newly developed muscular weakness or complete paralysis of the legs or arms.) We must examine suspected cases and have stools collected for laboratory analysis. And the final strategy, when every child under the age of five is vaccinated even if they been vaccinated previously in national immunization days (NIDs).

The results of these strategies continue to be remarkable. Since 1988 there has been nearly a 90 percent decline in reported polio cases globally. In 1996 less than 4,000 cases of paralytic polio were reported in the entire world representing fewer cases than occurred in the United States alone during the epidemics of the 1950s. These positive results have occurred in the face of an improved ability to find paralytic polio. However, our surveillance is not at all perfect. WHO estimates that 40,000 cases actually occur each year, acknowledging a substantial under-reporting of cases. This is truly a remarkable achievement and reflects literally hundreds of thousands of children who are not paralyzed who otherwise would have been.

The entire Western Hemisphere has been free of naturally occurring polio since 1991. Western Europe is free from polio, although we experienced a scare last year when a large outbreak of paralytic polio occurred in Albania and spread to Greece and other surrounding countries. Thanks to immediate action, Western Europe is polio free again. The lesson from the Albania outbreak is that no country is free from polio until all countries are free of polio.

The major problem areas continue to be in Pakistan, India, Bangladesh, and many countries in sub-Saharan Africa. More than 80 percent of the cases of polio in the world occur in these countries.

Approximately 100 countries on four continents have conducted one or more NIDs to eradicate polio during the last ten years. China is now considered a polio free country having no reported cases of endemic polio for two years. This is a tremendous achievement and is the result of massive immunization efforts since 1991.

Operation MECACAR (Middle East Caucasus and Central Asian Republics) was a special initiative to conduct synchronized immunization days in large blocks of countries in the former Soviet Union and nearby Asian countries. Ultimately, 22 countries agreed to conduct NIDs at the same time, including the Russian Federation. As a result of these extensive efforts, only a handful of cases of polio have been reported in the European region excluding Albania.

The results in India and surrounding countries has been dramatic as well. For example, India conducted NIDs in each of the last two years and vaccinated

more than 100 million children each year resulting in a 90% reduction of reported polio cases since 1988.

People have always said, "Africa is different. You will never be able to eradicate polio there." So, the African region has always been a great worry to us ever since the global polio eradication initiative was launched. For three years extensive polio eradication activities have occurred in the African continent and last year more than 25 countries conducted NIDs, many achieving polio vaccination coverage of greater than 80 percent of the targeted children. However, the Democratic Republic of Congo, Nigeria, and Ethiopia are heavily populated countries which continue to report many cases of polio and give us great cause for concern.

The accomplishments of 1996 can be summarized as follows:

- a 90% reduction in reported polio cases since 1988 despite improving surveillance;
- NIDs or SNIDs (SubNational Immunization Days) conducted in 28 sub-Saharan African countries;
- No laboratory confirmed indigenous cases in China for more than 2 years;
- 250 million children received OPV (oral polio vaccine) in NIDs in China, India, and South Asian countries in December 1996;
- 60 million children received OPV in NIDs in 22 countries during Operation MECACAR.

Despite this progress, the challenges remain. During a recent meeting in Geneva, it became clear that additional surveillance activities are needed and that the funds needed to implement this have been seriously underestimated in Africa and some South Asian countries.

In addition to funds, greater political commitment is needed both to strengthen routine immunization programs and implement polio eradication strategies in the numerous countries with civil unrest such as Sierra Leone and the Democratic Republic of Congo.

I was in Cambodia recently to help conduct village-to-village and house-to-house vaccinations in a mopping up campaign. On the last day we visited a two-year-old baby who was suspected of having paralytic polio. Laboratory results confirmed the diagnosis. I was disappointed that despite all of our efforts, transmission has continued in Cambodia. Eight children have been paralyzed this year.

Despite these cases I was particularly encouraged by one thing. My Cambodian counterpart was upset and angry when she saw this child with polio. She clearly understood that polio doesn't have to happen any more in any country in the world.

When the world community reacts the same way my Cambodian colleague did, I know polio eradication will be achieved. I thank you for your encouragement and continued support so that we can be sure that the children in the next century will not have to, as you at this conference must, face the many possible consequences of having polio. ✦

APPAREL RESEARCH COMPANY NEEDS INPUT

Joanne Gillease, President, Gillease and Associates, a textile and apparel research and consulting firm, is conducting a survey of adults with disabilities and seniors to define their apparel needs. Without documented research on the needs of these two specific populations, it is unlikely that manufacturers will develop or market adaptive apparel lines.

Gillease and Associates is consulting with occupational therapists and other health care professionals, but needs input from individuals who have difficulties with personal dressing on questions such as: Are there special closure concerns, e.g., are buttons, zippers, or snaps difficult to use? Are there garment design and construction needs necessitated by specific physical or medical conditions? Are there special sizing needs? Is there a need to construct garments with new lightweight fabrics that permit added warmth or cool, dry comfort?

If you want to share your opinions and knowledge about the apparel needs of adults with disabilities and seniors, please contact Gillease and Associates at 800/510-7170. You can request that a survey be sent to you, or you can participate in an interview over the phone. Research will be conducted and the results compiled and validated through October 1997. ✦

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The goal of a self-help group is to empower its members with the tools necessary to make adjustments needed to continue a life of dignity and independence.

Self-help group(s) ...

- ... share a common health concern.
- ... govern themselves and their agenda with success dependent on each member's feelings of ownership.
- ... may use professionals as resource persons but not as leaders.
- ... provide non-judgmental emotional support.
- ... gather and share accurate and specialized information.
- ... have membership which is fluid; newcomers are helped by veterans and become veterans who may outgrow the need for the group.
- ... have a cause and actively promote that cause.
- ... increase public awareness and knowledge by sharing their unique and relevant information.
- ... charge small or no dues for involvement and typically struggle to survive.

*International Polio Network, 4207 Lindell Blvd., #110, Saint Louis, Missouri 63108-2915

SUPPORT GROUP SUCCESS

“Many support groups are extremely empowering and valuable; unfortunately, others promote victimization. When considering a support group, be sure to evaluate what the support group is supporting.”

Excerpted from *Five Steps to Selecting the Best Alternative Medicine: A Guide to Complementary and Integrative Health Care* by Mary and Michael Morton. First published in December 1996, this book is divided into two parts, Part I: The Steps — How to Make Alternative Medicine Work for You, and Part II: The Five Licensed Systems of Alternative Medicine — the Terrain of Alternative Medicine, is a very readable, logical, and balanced treatment of the subject. (ISBN-10880032-94-5; New World Library, Novato, California; \$16.95 at your local bookstore.)

The secret to our success is ...

Planning a meeting that is worthwhile to come to with both a time for sharing and a time for education.

Over the years we have learned ...

To quit fighting the late effects of polio and to concentrate on helping ourselves adjust to the changes.

MID-WILLAMETTE SUPPORT CHAPTER, OREGON

The secret to our success is ...

Offering a variety of activities; drawing each person present into the meeting, making him or her feel that they have contributed; having lots of laughter.

Over the years we have learned ...

That knowledge is our power; sharing is caring; and our success is 80% our attitude.

THE WEST VIRGINIA CHAPTER OF POLIO SURVIVORS

The secret to our success is ...

The fact that we have a very faithful core group who likes to keep in touch with each other, even when we do not get together for meetings. We meet four times a year, so we call just to check on each other in between.

Over the years we have learned ...

That there are always new people who do not know about post-polio and our support group. We have found that meetings with speakers draw more of a crowd, so we plan two meetings with speakers and the other two are luncheon meetings just for us.

TOPEKA POST-POLIO SUPPORT GROUP, KANSAS

The secret to our success is ...

Combining structure and flexibility. We decided early to have elected board members who, in turn, elect officers and committee chairs (these elections yearly); we put together and mail a monthly newsletter to members and their physicians; and we have informative and relevant monthly programs, as well as two luncheon meetings a year. This structure has allowed us to obtain local grants for state-wide forums, for buying books and videos, and for sending interested members to out-of-state meetings. We have been functioning now for over six years, which indicates that we're meeting somebody's needs!

Over the years we have learned ...

That different polio survivors need different things from a support group. Some are searching for information and once they find it, they remove themselves from the group, sometimes returning with new needs. Others are looking for social interaction or a need to rehearse their polio history. Others need a place to



Some board members of the Birmingham Post-Polio Support Group starting work on the group's 1998 Forum: (l to r) James Jarrell (president), Danny Junkins, Faye Perkins, and Dave White.

vent their fear or anger. Occasionally, a family member needs help in coping, and always the community needs education about polio issues. Our support group organized with the purpose to educate, but we provide a little of everything for those who want to learn.

BIRMINGHAM POST-POLIO SUPPORT GROUP,
ALABAMA

The secret to our success is ...

Listening ... because many polio survivors have not talked about their polio in decades. We put more emphasis on our mailings than meetings and try to network information so a person with any level of education finds it understandable. Our meetings are informative, informal, and friendly with time to answer questions. We maintain a file of knowledgeable resources — social security, teacher disability, etc., in each county so our resources are close to home. We take advantage of the community resources already in place.

Over the years we have learned ...

That polio survivors must become the experts in their own condition and be active, assertive managers of their own healthcare, keeping a file of polio materials. Polio survivors should find a good quarterback physician who will take care of the whole person and coordinate information from specialists. Polio survivors need to know that it is okay to say "I hurt;" to get angry, depressed, frustrated, and grieve; to know that they are not imagining their symptoms; and to realize that they are not alone. Polio survivors should view canes, braces, scooters, wheelchairs, etc. as friends and realize that there is no magic pill or shot.

POLIO HEROES OF TENNESSEE

The secret to our success is ...

Our cumulative assessing of the needs and wants of our membership and addressing them accordingly. Our key word is support, and we work hard to ensure that we provide any and all aspects of our needs which make post-polios unique unto themselves. Good organization, a viable leader, volunteerism, all contribute to making our support group thrive. To help meet needs, we call upon our members with special professional skills — psychology, geriatric social services, nursing, financial advising, legal advice, etc. The establishment of a post-polio clinic formed three years ago at the University of Miami School of Medicine, staffed with a physiatrist from the Department of Orthopedics and Rehabilitation, a physical therapist from the graduate School of Physical Therapy and an orthotist — has benefited our group. Other specialties to enhance total well-being are easily assessed and utilized. Brochures were developed, printed, and are being distributed. Flyers are being developed in English and Spanish.

Over the years we have learned ...

That we must make ourselves available to those in need of our support and that we still have much to learn and are open to any and all information provided to us. Even though we feel we are unique, we know that we are just a part of the whole and we are not alone. Like most such groups, we have no paid staff. It is important that the officers have time to devote to fulfilling their responsibilities, be enthusiastic, and have their hearts in what they are doing. Since everyone is a volunteer, it is sometimes easy for one to leave the completion of important tasks and the meeting of deadlines to the president. The location and time of meetings are important. We now meet at the Metro-Dade Center for Disability Services and Independent Living, centrally located with gener-



Annual picnic of the Post-Polio Association of South Florida — Social events are essential to a support group.

CONTINUED ON PAGE 8

ous parking in a lot adjacent to an all-ramped building. The facility provides a large meeting room with kitchen and space for our library. Audio-visual equipment is also available for our use. We meet every third Saturday of the month at 10:30 a.m., a day best suited to our members' schedules since many are still gainfully employed.

Communication is vital and accomplished by a monthly newsletter and a telephone committee which has not only increased meeting attendance, but has served to enhance support. Close friendships have developed between members with pleasurable socialization. Our members are becoming increasingly involved in community activities. Following intensive training, they are certified as handicapped parking enforcement specialists. Committees, standing and ad hoc, do not lack volunteers. Members join eagerly and participate actively.

POST-POLIO ASSOCIATION OF SOUTH FLORIDA

New Groups Meet **SACRAMENTO** The Sacramento Post-Polio Group meets at 11:00 am on the first Saturday of each month January-April and September-November at the Fairvale Baptist Church on Madison Avenue in Fair Oaks. The group plans social events for the months of May and December. For more information, contact Alice Basco, 3510 Cheri Court, Rocklin, California 95677 (916/624-0448).

SAVANNAH The first official meeting of the Coastal Empire Polio Survivors in April had 25 people in attendance. Future meetings will be held the fourth Tuesday of each month at 7:00 pm at Candler Hospital in the GI waiting room, just off the lobby of the Candler Professional Building. Shirley Carnell, a retired RN, began the group with the assistance of Cheryl Brackin and Lorraine Poling. For further information about the group, call 912/927-8332 or 912/355-7341.

Videos on Loan Michigan Polio Collection Library is located at 4291 Squires Road, Quincy, Michigan 49082 (near Coldwater and Hillsdale) and has a collection of books, periodicals, audio tapes, video tapes, etc. Contact Nancy Miller, Librarian at 517/869-2996 or 517/869-2611 FAX, for a listing of materials and borrowing information which usually just requires return postage. International Polio Network has donated the video *My Body Is Not Who I Am*, in which polio survivor Jeanne Putnam interviews individuals with disabilities who share their thoughts and feelings. The video would instigate discussion in any support group meeting. If you have new polio-related materials you wish to donate to the library, send them to Miller for review. ↵

THE POST-POLIO TASK FORCE

WHAT AND WHO

In early 1997, the Post-Polio Task Force was formed to help promote awareness and advance medical knowledge of post-polio syndrome. The task force is chaired by Neil R. Cashman, MD, associate professor of Neurology at the Montreal Neurological Institute and Hospital at McGill University in Montreal, Canada. It includes two groups: clinicians and researchers who specialize in diagnosing and treating polio survivors with symptoms of post-polio syndrome, and advocates for survivors of polio.

Other members include: Lauro Halstead, MD, director of the Post-Polio Program at National Rehabilitation Hospital in Washington, DC; Joan L. Headley, executive director of the International Polio Network, headquartered in St. Louis, Missouri; Burk Jubelt, MD, a neurologist at the SUNY Health Sciences Center in Syracuse, New York; Frederick M. Maynard, MD, medical director of the MetroHealth Center for Rehabilitation in Cleveland, Ohio; Robert Miller, MD, chairman of the Department of Neurology at California Pacific Medical Center in San Francisco, California; Dorothy Woods Smith, RN, PhD, associate professor at the University of Southern Maine College of Nursing in Portland, Maine; and Daria A. Trojan, MD, MSc, assistant professor at the Montreal Neurological Institute and Hospital at McGill University in Montreal, Canada.

WHY AND HOW

Mission Statement

The Post-Polio Task Force is dedicated to improving the care and quality of life for people with post-polio syndrome.

Objectives

- ◆ To raise awareness of issues surrounding the diagnosis and management of post-polio syndrome through education and the promotion of research;
- ◆ To develop educational tools and events that raise awareness of post-polio syndrome and its clinical significance;
- ◆ To facilitate the definition of standards of care for people with post-polio syndrome.

ACCOMPLISHMENTS TO DATE

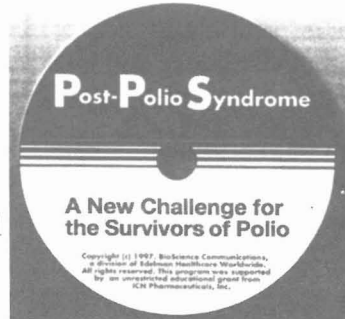
Prior to the opening of the April, 1997 American Academy of Neurology (AAN) meeting in Boston, the task force conducted a roundtable discussion during which members gave presentations aimed

at reaching a consensus on issues relating to the diagnosis and treatment of post-polio syndrome. The proceedings of the all-day discussion will be used to produce the following:

- ◆ A bulletin for physicians, which will be distributed in November, 1997;
- ◆ A slide kit for use in academic settings;
- ◆ A consensus statement for publication in medical literature.

EDUCATIONAL MATERIALS CURRENTLY AVAILABLE

CD-ROM: At the April AAN meeting, a CD-ROM entitled "Post-Polio Syndrome: A New Challenge for the Survivors of Polio," was introduced. It is designed to provide physicians and survivors information on this condition, including its history, prevalence, pathophysiology, diagnosis, and management. Over 150 neurologists visited the booth of International Polio Network to pick up literature on post-polio syndrome and to receive a copy of the CD-ROM. While the supply lasts, readers of *Polio Network News* can also receive a free copy by contacting International Polio Network, 4207 Lindell Boulevard, #110, Saint Louis, Missouri 63108-2915 U.S.A. The CD-ROM runs on Macintosh; Windows 3.X or NT 3.5X; and Windows 95 or NT4.X.



Pamphlet — "Questions and Answers about Post-Polio Syndrome" was completed for the May, 1997 Seventh International Post-Polio and Independent Living Conference in Saint Louis, Missouri. The 4" x 10," 12-page pamphlet is also available by contacting International Polio Network.

Post-Polio Task Force materials are developed by BioScience Communications, a division of Edelman Healthcare Worldwide, with the guidance of the members of the task force.

FUNDING

The Post-Polio Task Force is funded by an unrestricted educational grant from ICN Pharmaceuticals, Inc., a company based in Costa Mesa, California, that manufactures Mestinon® (pyridostigmine bromide). The company has also supported the North American Post-Poliomyelitis Pyridostigmine Study (NAPPS), a double-blind, randomized, placebo-controlled trial that is following 126 individuals given either 60 mg. of pyridostigmine three times daily or a placebo for six months.

Why pyridostigmine? In the late '80s, several researchers, knowing that pyridostigmine was used for the neuromuscular disorder myasthenia gravis, treated polio survivors who were experiencing muscle fatigue. The interface of nerves and muscle cells is called the neuromuscular junction, and the message across this space is transmitted by acetylcholine. Over decades, nerve cells appear to reduce their release of acetylcholine and researchers hypothesize that pyridostigmine, an anticholinesterase, decreases the natural breakdown of acetylcholine, thus improving the message from nerve to muscle and decreasing muscle fatigue.

Researchers and clinicians recognize that there are many causes of fatigue and that pyridostigmine may only be helpful for some individuals. The NAPPS study will provide further insight into its potential use and the relationship between the level of pyridostigmine in post-polio individuals and of IGF-1 (Insulin-like Growth Factor 1), which is believed to support the sprouting of motor neurons.

All data has been collected and analysis of the NAPPS Trial will be announced at the meeting of the American Academy of Physical Medicine and Rehabilitation in Atlanta, Georgia, on November 13-16, 1997. International Polio Network will be distributing materials. ←

Questions and comments regarding the Post-Polio Task Force may be directed to Joan L. Headley.

POST-POLIO BIBLIOGRAPHY

Ring, D., Vaccaro, A.R., Scuderi, G., Klein, G., Green, D. & Garfin, S. (1997). An association between the flat back and postpolio syndromes: a report of three cases. *Archives of Physical Medicine and Rehabilitation*, 78, 324-326.

LEAD AUTHOR DAVID RING, MD COMMENTS:

"Our purpose in reporting these three cases in which a stooped posture either resulted from or was not improved by spinal surgery was to increase awareness that postural difficulties may be in some way associated with the abnormalities of the muscle units of polio survivors. Rather than viewing our report as a condemnation of spinal surgery for polio survivors, the possibility of postural problems should simply be taken into consideration along with the other risks and benefits of spinal surgery. Our report gives no indication of how often postural problems will occur in polio survivors or which surgeries place such patients at particular risk."

PRELIMINARY RESULTS

A two-year research project, supported by a grant from the Department of the Army, is currently underway at the Albert Einstein Medical Center and Moss Rehabilitation Research Institute in Philadelphia, Pennsylvania.

One of the goals of the project is to enroll 300 individuals with a history of polio. Each participant will undergo a strength and symptom evaluation four times over a one-year period. So far 173 polio survivors, made up of 88 men and 85 women, have been seen in the research clinic for at least one visit.

Early results indicate that overuse symptoms are present in 57% of the polio survivors, compared to 27% of the people without a history of polio. This confirms that polio survivors are at higher risk for overuse symptoms. Many of the polio survivors have significant weakness in several of their leg muscles and also in one of the muscles responsible for shoulder rotation. In terms of overuse symptoms, the data analysis shows that the individuals with the most shoulder symptoms have moderate or midrange levels of hip and knee extensor strength. These individuals also have the highest ratings for symptom severity. This supports the prediction that individuals with moderate weakness in their hip and knee extensors would tend to use their arms to compensate for this weakness (i.e., an individual with moderately weak leg muscles will tend to lean heavily on his/her arms when rising from a chair). Conversely, if an individual has severely weak leg muscles, they will restrict their walking and limit their standing and are therefore less likely to use their arms to compensate for their weak legs.

Several treatment intervention studies have begun. One focuses on individuals with heel pain or plantar fasciitis and has received a great deal of positive feedback from the participants. Also, data is being analyzed to determine which patterns of muscle weakness are most common and what muscles are used to compensate for this weakness.

Polio survivors who are interested in participating or would like additional information may contact: The Post-Polio Project, Moss Rehabilitation Research Institute, Korman Building, Suite 213, 1200 West Tabor Road, Philadelphia, Pennsylvania 19141 (215/456-4993 or 215/456-9514 FAX). ↵

The principal investigators on the project are Drs. Mary Ann Keenan (orthopaedics), Alberto Esquenazi (physiatry), and John Whyte (physiatry). Drs. Keenan and Esquenazi head the Post-Polio Clinic at Albert Einstein Medical Center (215/456-7900).

BUSINESS INCENTIVES FOR MAKING ACCOMMODATIONS

Consider Your Needs

As a polio survivor who may be experiencing the effects of aging or post-polio syndrome, you may benefit from requesting an accommodation or the removal of an architectural or transportation barrier. The potential benefits of requesting these changes include improving access to your place of employment, making it easier for you to perform your job more efficiently, and increasing access to services and stores available to the general public.

Examples of modifications and accommodations you may want to consider requesting are:

- ◆ installing an automatic door opener; changing door handles making them easier to grasp;
- ◆ lowering locks on doors, phones, towel dispensers, mail boxes, trays, utensils and products in cafeteria lines, service counters, etc.;
- ◆ adding handrails to stairs; improving surfaces on ramps, stairs, and walkways; improving lighting;
- ◆ widening doorways, hallways, and aisles in retail stores, community buildings, physicians' offices, hospitals, churches, synagogues, etc.;
- ◆ building ramps or adding lifts to entrances which are more convenient to your needs;
- ◆ adding places for disabled parking including van access;
- ◆ purchasing ergonomic furniture for the office and software programs for easier computer usage (e.g., voice transmission);
- ◆ purchasing equipment to allow you to work at home (e.g., computer equipment, phone and FAX lines, etc.);
- ◆ purchasing ramps for accessibility to conference rooms, stages, and speakers' tables;
- ◆ modifying or adding an accessible restroom located near your work station.

In requesting these changes, remind the managers and owners that tax incentives are available to assist in paying for these accommodations and modifications.

See the next page for details prepared by the President's Committee on Employment of People with Disabilities.

Tax Incentives for Business

For additional information, contact Mark Pitzer, Attorney, Office of Chief Counsel, IRS, 1111 Constitution Avenue NW, Washington, DC 20224 (202/622-3110).

■ SMALL BUSINESS TAX CREDIT: IRS CODE SECTION 44, DISABLED ACCESS CREDIT

What is it?

Small businesses may take an annual tax credit for making their businesses accessible to persons with disabilities.

Who is eligible?

Small businesses that in the previous year earned a maximum of \$1 million in revenue or had 30 or fewer full-time employees are eligible.

What is the amount?

The credit is 50 percent of expenditures over \$250, not to exceed \$10,250, for a maximum benefit of \$5,000. The credit amount is subtracted from the total tax liability after calculating taxes.

What expenses are covered?

The credit is available every year and can be used for a variety of costs such as:

- sign language interpreters for employees or customers who have hearing impairments;
- readers for employees or customers who have visual impairments;
- the purchase of adaptive equipment or the modification of equipment;
- the production of print materials in alternate formats (e.g., braille, audio tape, large print);
- the removal of architectural barriers in buildings or vehicles.

What expenses are not covered?

The tax credit does not apply to the costs of new construction, and a building being modified must have been placed in service before November 5, 1990.

How can this credit be claimed?

Businesses can claim the Disabled Access Credit on IRS Form 8826.

■ ARCHITECTURAL/TRANSPORTATION TAX DEDUCTION: IRS CODE SECTION 190, BARRIER REMOVAL

What is it?

Businesses may take an annual deduction for expenses incurred to remove physical, structural, and trans-

portation barriers for persons with disabilities at the workplace.

Who is eligible?

All businesses are eligible.

What is the amount?

Businesses may take a tax deduction of up to \$15,000 a year for expenses incurred to remove barriers for persons with disabilities. Amounts in excess of the \$15,000 maximum annual deduction may be depreciated.

What expenses are covered?

The deduction is available every year. It can be used for a variety of costs to make a facility or public transportation vehicle, owned or leased for use in the business, more accessible to and usable by persons with disabilities. Examples include the cost of:

- providing accessible parking spaces, ramps, and curb cuts;
- providing telephones, water fountains, and restrooms accessible to persons using wheelchairs;
- making walkways at least 48 inches wide.

What expenses are not covered?

The deduction may not be used for expenses incurred for new construction, or for a complete renovation of a facility or public transportation vehicle, or for the normal replacement of depreciable property.

May I use the tax credit and tax deduction together?

Small businesses may use the credit and deduction together, if the expenses incurred qualify under both Sections 44 and 190. For example, if a business spent \$12,000 for access adaptations, it would qualify for a \$5,000 tax credit and a \$7,000 tax deduction.

Are there limits on annual usage?

Although both the tax credit and deduction may be used annually, if a business spends more than may be claimed in one year, it cannot carry over those expenses and claim a tax benefit in the next year.

How can this credit be deducted?

The amount spent is subtracted from the total income of a business to establish its taxable income. In order for expenses to be deductible, accessibility standards established under the Section 190 regulations must be met.

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e-mail: gini_intl@msn.com

Also publisher of
Rehabilitation Gazette and *I.V.U.N. News*

Readers Write

"Has anyone experienced or had help in solving the problems related to post-polio swallowing plus G peg feeding, and renal failure, thus dialysis? We are confident in our doctors in each category, but the combined problem is new to them. Bill, who had polio 60 years ago, is 77 years old and has an 'unsinkable Molly Brown' attitude, but we both feel the need of someone who sees his whole problem."

Etta and Bill, New Jersey

"Does anyone know of a source for 'designer' crutches, i.e., crutches which are made of attractive wood or a variety of colors?"

Gary, California

For "designer" canes and walking sticks, call or write House of Canes and Walking Sticks, 767 Old Onion Mountain Rd., P.O. Box 574, Wilderville, Oregon 97543 (800/458-5920) for a catalog with extensive collection of shafts made of walnut, oak, ebony, birch, lucite; covered with fabric; handles and knobs made of sterling silver, silver-plated, brass, etc.

"Can anyone offer suggestions as to which is the best car to purchase for putting a wheelchair in the back seat?"

Ed, Missouri

CALENDAR

Post-Polio Symposium '97, SEPTEMBER 27,
Mackay Center, Montreal, Quebec, Canada.
Contact: Sally Aitken (514/932-6092).



Fourth Post-Polio Management Update,
OCTOBER 4, Sioux Falls, South Dakota. Contact:
Nancy Olson, Tri-State Polio, Inc., 321 Meyer
Lane, Sioux Falls, South Dakota 57103
(605/322-5065).



Ohio Polio Network Annual Meeting,
OCTOBER 11, Ohio University, College of
Osteopathic Medicine, Athens, Ohio. Contact:
David Livingston, 33001 Fern Tree Lane, North
Ridgeville, Ohio 44039 (216/641-6000, ext. 504).



**Post-Polio Syndrome: Past, Present, and
Future — The Role of Rehabilitation,**
OCTOBER 18, Royal Sonesta Hotel, Cambridge,
Massachusetts. Contact: Harvard Continuing
Education (617/432-1525 or
<http://www.med.harvard.edu/conted/>).



**Fourth Forum Luncheon, NOVEMBER 2, Holiday
Inn, Bethlehem, Pennsylvania. Contact: Beverly
Solomon, 924 N. 33rd Street, Allentown,
Pennsylvania 18104 (610/398-3958).**