

# Polio Network News

## Eradication of Acute Poliomyelitis in Sight

*Timothy E. Wirth, President, United Nations Foundation*

The international initiative to eradicate polio worldwide, launched as a voluntary effort by Rotary International in 1985 and adopted by the World Health Assembly in 1988, is moving closer to the goal each year. A revised plan for achieving the goal was adopted at the Polio Summit at the United Nations in September 2000. It projects the last case of polio – probably an African child – to occur within the next two to three years, with certification of a polio-free world two years after that in 2005. There is a caveat to the plan: that adequate resources are available to complete the job. The United Nations Foundation has joined the Global Polio Partnership to help ensure that the resources are there.

It is in Africa and Asia that polio continues to attack young children. As with other diseases, the children still threatened by polio live in twenty of the poorest countries in the world. Many of the countries are in conflict, including Afghanistan, Angola, Democratic Republic of the Congo, Sudan, and Somalia. Two large countries of great potential wealth, and great pockets of poverty, Nigeria and India, require large-scale efforts to defeat polio. So the Global Polio Partners and our Foundation are focusing especially on these difficult twenty countries.

The Partners – the World Health Organization, UNICEF, Rotary International, and the

US Centers for Disease Control and Prevention, with private sector support as well as that of governments – have made stunning strides in recent years. Thirteen years ago the number of polio-infected countries was 125. As late as 1988, when the coordinated effort began, polio was paralyzing 250,000 children per year. Since then, by delivering a few drops of the Sabin vaccine to every child under five – in massive immunization campaigns around the world – the eradication initiative has steadily reduced the impact of the disease.

In 1994, the Western Hemisphere was certified to be free of polio. In 2000, the Western Pacific, including China, was certified polio-free. In these 13 years, the concerted effort has succeeded in reducing the annual number of polio cases by 99 percent: there were less than 3500 confirmed cases in 2000.

Indeed, with the virus active anywhere in the world, children everywhere remain under threat. This is why we must redouble our efforts now. Those efforts have sometimes assumed heroic dimensions. In December 2000, with tens of thousands of volunteers (including, once again, many Rotarians) and national and international health workers, 150 million children in India were vaccinated in one day. In African countries in conflict, UN Secretary General Kofi Annan and other leaders have succeeded in securing ceasefires between

warring parties so that children can be vaccinated during “Days of Tranquility.”

All of us involved in the effort are keenly aware that many persons who have survived polio’s greatest threats in childhood, nonetheless experience later effects. We trust that research will soon provide answers to this untimely phenomenon and that health care systems will not back away from providing full care and attention to those who, in mid-life and later, find themselves once again dealing with polio.

Aware and concerned, we must push on with the challenge we do know how to address medically and logistically: to eradicate the threat of polio to the world’s children. As we do this, we are also putting in place a health care delivery infrastructure that can be used to attack other diseases, from malaria to HIV/AIDs.

The cost of reaching the goal of a world that is certified as polio-free by 2005 is estimated to be only \$1 billion US dollars. Half of that amount is already com-

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mitted by national governments and international agencies, and significant amounts are committed by private sector sources. To date, the United Nations Foundation has invested \$78 million, with Ted Turner giving \$28 million and Bill and Melinda Gates, \$50 million; the Rotarians have contributed several hundred million dollars to polio eradication since 1988. To complete the job by 2005, the shortfall now stands at only \$400 million.

The UN Foundation has established a Global Polio Eradication Fund. We are in a special partnership with the Rotary International Foundation to try to

**TABLE 1. Number of confirmed cases of poliomyelitis and wild poliovirus, by type and region — World Health Organization, 1999 and 2000**

Region	1999					2000				
	No. confirmed cases	Wild virus confirmed	Type 1	Type 2	Type 3	No. confirmed cases	Wild virus confirmed	Type 1	Type 2	Type 3
African	2861	246	167	0	79	1763	144	139	0	5
Americas	0	0	0	0	0	0	0	0	0	0
Eastern Mediterranean	914	479 (four were mixed types 1 and 3)	392	0	83	453	259 (six were mixed types 1 and 3)	155	0	98
European	0	0	0	0	0	0	0	0	0	0
South-East Asia	3365	1185 (12 were mixed types 1 and 3)	430	11	732	608	271 (one was mixed types 1 and 3)	140	0	130
Western Pacific	1*	1	0	0	0	0	0	0	0	0
<b>Total</b>	<b>7141</b>	<b>1911</b>	<b>989</b>	<b>11</b>	<b>894</b>	<b>2824</b>	<b>674</b>	<b>434</b>	<b>0</b>	<b>233</b>

\* Imported case.

SOURCE: *Morbidity and Mortality Weekly Report*, March 30, 2001/Vol. 50/No. 12

raise a significant part of that amount from private donors. And we hope many citizens will join us in the effort.

Smallpox was eradicated in the previous century. What a gift it will be to those who come after

us, indeed to the 21st century, to eradicate polio in the next five years. We must do so, and we invite you to join in the cause. ■

United Nations Foundation, 1301 Connecticut Avenue NW, Washington, DC 20036 ([www.endpolionow.org](http://www.endpolionow.org)).

## Editor's Comments

As a faithful reader of *Polio Network News*, you will recall the May 2000 "International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care," sponsored by the March of Dimes, held at Warm Springs, Georgia. Two reports — one for physicians and one for people who had polio — were published and included with your *Rehabilitation Gazette* mailed in July.

The value of "Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care" and "Guidelines for people who had polio" for me is that they represent a peer-reviewed consensus of opinion from researchers and clinicians. They clarified the definition of post-polio syndrome. I think we all should keep this in mind the next time a neurologist tells us we "don't have it." No one is saying there are not consequences to having had polio earlier in life, i.e., the late effects

of polio. The reports are saying that post-polio syndrome is a specific, new neurologic condition.

My satisfaction with assisting in distributing the reports was tempered by some of the press coverage. I reminded one journalist that, "The use of the word 'victim' is outdated, and the image that it presents to non-disabled people, or reinforces in polio people, can be damaging."

Guidelines do exist to assist journalists when writing about disability ([www.accessiblesociety.org](http://www.accessiblesociety.org)). The Research and Training Center on Independent Living ([www.rtcil.org](http://www.rtcil.org)) in Kansas is updating their pamphlet about language. I will let you know when it is available.

However, I was most frustrated at the bleak message the media presented about post-polio syndrome — physicians do not know about the condition and there is nothing that can be done. So where does that leave polio survivors who read these columns? I expressed my

concern with a Letter to the Editor. "To say that the symptoms of post-polio syndrome include weakness, pain, and fatigue, the symptoms of many diseases, and then say there is no cure but rest, or canes and wheelchairs (devices many would rather avoid), might cause polio survivors who read the article to 'treat' themselves and not go to a physician. While 'conserve it to preserve it' is a catchy phrase, it minimizes the seriousness of the problem for some polio survivors, and it ignores the complexity of the problems those survivors present to the medical community." "Conserve it to preserve it" offers some general guidance, but many times the advice is just that — general, and survivors are not offered specific options or encouragement.

I encourage each of you to visit a primary care physician regularly to receive a physical and to have the routine screenings appropriate for your age and sex. Insist that your physician is diligent about finding and treating what can be treated

and insist that you are referred to knowledgeable specialists when symptoms persist. This probably sounds familiar, but one polio survivor with "overwhelming fatigue" was finally and correctly diagnosed with cancer.

Several of you have asked how you can help in distributing the March of Dimes' reports to physicians. One possibility is to contact the medical society in your state or county and ask if we can send copies for an upcoming meeting and/or if we can put a notice in their newsletter or on their website. Be sure to offer a sample copy. The reports will not make a physician an expert, but will alert them as to what to look for and guide them in making referrals.

In July, syndicated columnist Dr. Paul Donohue wrote about post-polio syndrome. Donohue mentioned the importance of maintaining muscle strength, but not exercising to exhaustion. He implied that IPN could send a ready-made set of exercises. We, of course, cannot due to what many refer to as the "exercise controversy." I am not so sure it is controversial as much as it is individual. Exercise for you is different than it is for me. Some of us have overuse weakness; some of us have disuse weakness; some of us have both.

So, what is the exercise solution? Read and review all of the credible information you can. Past issues of *Polio Network News* have contained articles by James Agre, MD, PhD (Vol. 15, No. 2), and Gunnar Grimby, MD (Vol. 16, No. 1), which review the research regarding exercise. Drs. Perry (Vol. 16, No. 4) and Yarnell (Vol. 14, No. 2) have offered general guidelines. These articles are on our website ([www.post-polio.org](http://www.post-polio.org)).

This issue of *Polio Network News* includes a description of four management/wellness programs designed for polio survivors (Post-Polio Resources, pages 6-8) and each program addresses exercise. We have included contact information where you can get specifics.

In addition to educating yourself, find a health professional who will work with you (Selecting a Physician, page 4) and assist you in establishing an individually designed program. If you have an established exercise program that works, I am requesting that you describe it and send it to me for possible publication. Let's help each other to think creatively by sharing what has worked for us. Be sure to include a description of how you were originally affected by polio.

Post-polio has received a lot of press lately, and we generally applaud the publicity. However, a letter from Jack in New Jersey demonstrates the consequences of being diagnosed with post-polio syndrome. "I have been denied long-term medical care insurance because I have post-polio syndrome. Several physicians have said they see no reason that I would be more apt to require extreme or protracted care than anyone else. So I am left worrying if the insurance companies know something we don't, and wondering if there is any reasonable alternative."

More and more survivors are reporting that post-polio syndrome is on the list of conditions that prevents one from obtaining long-term care insurance. I asked FamilyCare America ([www.familycareamerica.com](http://www.familycareamerica.com)) – a group who wrote an article entitled "Who Needs Long-Term Care Insurance?" – about our options. They are researching it. It cannot be just a polio problem; other conditions must also be disqualified. So, I asked the American

Association of Disabled People (AAPD) the same question. I will let you know the answers. I know many polio survivors are relieved at getting a diagnosis of post-polio syndrome, but there are disadvantages to having it. To me, this is why clarifying the definition of post-polio syndrome is important; the ultimate definition has serious ramifications.

– Joan L. Headley, MS,  
Executive Director, GINI

## International Polio Network

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# Selecting a Physician

Sunny Roller, MA, Ann Arbor, Michigan, and Frederick M. Maynard, MD, Marquette, Michigan

*"The good physician treats the disease; The great physician treats the patient who has the disease."*

—SIR WILLIAM OSLER

Osler's words remind us that a doctor must focus his/her skills toward healing of disease and the promotion of health. The effective physician must also possess the knowledge and the skill to educate and motivate patients to achieve higher levels of wellness. In turn, being a wise consumer is a basic foundation for receiving good health care. Selecting an appropriate physician has become an important right and responsibility for people who believe they may be experiencing the late effects of polio. Once a physician has been selected, it is appropriate to take an active role in your diagnosis and treatment plan. You are the one who lives in your body. You are an expert, too.

## Finding Your Physician

Choosing a physician requires great care and thoughtful consideration. Asking the following questions will help.

- ◆ What is the physician's reputation? Talk to friends and acquaintances about their experiences. Try to get a feel for the level of medical care, time spent with the patient, and the physician's willingness to interact with the patient. Has the physician treated many people who had polio?
- ◆ What is the physician's location/availability? Considerations include distance from your home, office hours, on-call hours, after-hours and vacation coverage,

and hospital privileges. Is the physician's practice accessible to people with disabilities (parking, office entrances, examining tables, restrooms)? Are laboratory and x-ray services or rehabilitation team professionals' services located in the same or other convenient facility? How long must you wait for an appointment?

- ◆ What are the physician's qualifications? Check with your local medical society. You can specify what type of doctor you are looking for by sex, specialty, age, or location. Find out if the doctor is "Board Certified" or "Board Eligible." "Board Certified" means that he/she has several years of training in a specialty after graduation from medical school and has passed a national qualifying examination. "Board Eligible" means that the training has been completed, but not the exam. The local medical society can provide this information; however, these credentials do not guarantee competency. Other qualifications may include place of medical school or postgraduate specialty training, professional society memberships, and staff membership at well-recognized hospitals.
- ◆ Are the physician's services covered by your insurance plan and what are the fees? Ask if there is a "fee for service" office policy. This means that you are asked to pay for your visit at the time of the appointment rather than being billed. Determine if the doctor is a member of an HMO or other group health organization.
- ◆ What do you want and/or need from a physician? What is the type of problem you think

you have? Do you need an initial diagnosis or ongoing health care management assistance? Are you looking for a generalist or a specialist?

## Evaluating Your Physician

After your initial visit to the physician, review the following questions to decide if you and the doctor can become "working partners" in your continuing health care management.

- ◆ Is the physician's personality compatible with yours? Can you openly discuss your feelings and talk about personal concerns? Do you believe your doctor will stand by you, no matter how difficult your problems become?
- ◆ Does the physician seem sincerely interested in you and your unique problems as a polio survivor? Are your concerns considered seriously? Has your past history been adequately considered? Is the physician interested in you as a *whole* person — your inner self and your lifestyle, as well as your physical self?
- ◆ Is the physician willing to help you learn about your condition? Do you feel at ease asking your doctor questions that may sound "silly?" Does your doctor clearly explain the nature of your condition? Does he/she listen to you and answer all your questions about the causes and treatment of your physical problems, or is he/she vague, impatient, or unwilling to answer? Does the physician not only diagnose the problem, but take time to discuss specific treatment options such as changes in lifestyle, referrals for adaptive equipment, or choices in therapy, surgery, or medications?

## Medical Specialties

**Cardiologist** ... An internist who specializes in diseases and treatment of the heart

**Internist** ... A specialist in general internal medical diseases and disorders of the adult

**Neurologist** ... A specialist in the diagnosis and treatment of disorders of the nervous system

**Orthopedist** ... A specialist in surgical treatment for skeletal disorders (muscles, bones, and joints)

**Physiatrist** ... A specialist in physical and rehabilitative treatment of nerve, muscle, and bone disorders and their associated disabilities

**Pulmonologist** ... An internist who specializes in treatment of the lungs and respiratory system

**Psychiatrist** ... A specialist in treatment of emotional illness

- ◆ Is the physician familiar with the literature available on the late effects of polio? Has the physician had sufficient experience and/or involvement with post-polio patients for you to have confidence in his/her opinions? Is the physician willing to learn more about the late effects of polio?
- ◆ Is your doctor willing to refer you to others? Does your physician utilize the services of other health care professionals needed to manage polio's late effects – i.e., physical and occupational therapists, nurses, brace makers, and/or social service and counseling personnel? Does the physician use a team approach in his/her practice? Will your physician discuss referral to post-polio specialists?
- ◆ Is the office staff cordial and attentive to you? Does your doctor answer your letters or telephone calls promptly? Are you generally kept waiting for long periods of time when you have an appointment? ■

## Boundary Issues

BASTA! (Boston Associates to Stop Treatment Abuse) has a website ([www.advocateweb.com/basta](http://www.advocateweb.com/basta)) that addresses treatment abuse. The following information is reprinted with BASTA's permission.

*Is There Something Wrong or Questionable in Your Treatment?* contains an extensive list of behaviors that could alert you to boundary issues which frequently result in poor or abusive treatment or health care.

Estelle Disch, PhD, explains, "If you are currently in a treatment that doesn't feel right, and/or if several of the items describe your treatment, I suggest that you find a consultant who does not know your current practitioner in order to assess whether or not the treatment is viable. If you have been in a treatment relationship that didn't feel good to you, this list might help you identify what went wrong.

"The list is not exhaustive. It is intended to offer examples of the kinds of behaviors that very often accompany poor treatment. Although most items apply to psychotherapy, some can apply to other kinds of health care, pastoral counseling, or clergy relationships. There is a section on touch-based health care (including body work) at the end of the checklist.

"Certain items in the list might not always reflect poor treatment. For example, it might make sense to break ties with abusive people in your life, and a practitioner might support this with your best interests in mind. If, however, the practitioner is encouraging you to break ties with all your close relationships with the sole purpose of making you extremely dependent on

him or her, that is very likely to be poor treatment.

"Good, bounded psychotherapy, pastoral counseling, addiction counseling, bodywork, medical practice, etc. should always be oriented to your emotional and medical needs and not to the emotional needs of the practitioner. Practitioners who are lonely, need attention, have deep unresolved problems, and/or who lack good training in boundary issues are apt to do marginal or poor treatment. There are good practitioners, and you have a right to be treated by them."

The site also offers suggestions as to what actions you can take if you suspect abuse in the section called *After Sexual (and Other) Malpractice – What Can You Do?*

*Are You in Trouble with a Client?* contains a series of questions for practitioners/physicians to review to determine if they are crossing any boundaries. ■

These checklists (©1990, 1992) are available at [www.advocateweb.com/basta](http://www.advocateweb.com/basta). If you do not have access to a computer and would like a printout of the questions to assist you in determining questionable treatment, send a self-addressed stamped envelope to International Polio Network or contact Estelle Disch, PhD, BASTA! (Boston Associates to Stop Treatment Abuse), 528 Franklin Street, Cambridge, MA (Massachusetts) 02139 (617-661-4667).

Basta! is part of AdvocateWeb, P.O. Box 202961, Austin, TX (Texas) 78720 ([www.advocate.org](http://www.advocate.org)), a nonprofit organization providing information and resources to promote awareness and understanding of the issues involved in the exploitation of persons by trusted helping professionals.

### Self-Management of Chronic Conditions

*Peter Jay, The British Polio Fellowship*

Presented at the Eighth International Post-Polio & Independent Living Conference, Saint Louis, Missouri, June 2000

#### OVERVIEW OF SELF-MANAGEMENT

Both at home and in the business world managers direct the show. They do not do everything themselves; they work with others, including consultants, to get the job done. What makes them managers is that they are responsible for making the decisions and making sure these decisions are carried out.

As a manager of your condition, your job is much the same. You gather information and hire a consultant, or a team of consultants consisting of your physician/GP and other health professionals. Once they have given you their best advice, it is up to you to follow through. All chronic conditions need day-to-day management. We have all noticed that some people with severe physical problems get on well while others with lesser problems seem to give up on life. The difference is often management style.

Managing a chronic condition, like managing a family or a business, is a complex undertaking. There are many twists, turns, and mid-course corrections. By learning self-management skills you can ease the problems of living with your condition.

The key to success in any undertaking is first deciding what you want to do, second, deciding how you are going to do it, and finally, learning a set of skills and practicing them

until they have been mastered. In fact, mastering such skills is one of the most important tasks of later life.

During the Chronic Disease Self-Management Program (CDSMP), we describe hundreds of skills and strategies to help relieve the problems caused by chronic illness. We do not expect the participants to do all of them. They pick and choose. Experiment. Set their own goals. What they do may not be as important as the sense of confidence and control that comes from successfully doing something they want to do. However, we have learned that knowing skills is not enough. People need ways of incorporating these skills into their daily lives.

The unique self-management course is led by people living with long-term conditions, and utilizes group intervention. The focus is about sharing self-management techniques and not information giving. The course is a generic one working across conditions and is based upon the principle of "can do."

#### MORE ABOUT THE COURSE ...

There are six 2½ hour sessions designed to help people take control of their illness by learning how to effectively manage symptoms – challenging the frustration, pain, and fatigue. Some of the topics covered are relaxation, anger, fear and frustration, fitness and exercise, better breathing, nutrition, medication, and making treatment decisions.

Some traditional self-help groups provide participants with information but not with motivation. Whereas this course empowers people encouraging them to

make small steps towards a long-term goal. Each week every participant sets an action plan to achieve a reasonable goal before the next session. The main goal is to achieve our greatest capability or attain optimum health.

The course also differs from other self-help groups in that the courses are focused and heavily structured. This course has a start point and end point.

As survivors, we should accept a certain amount of responsibility for our own health. After all, we know our own bodies better than anyone. We need to be aware of our bodies without becoming obsessed with them.

For more information, contact Peter Jay, The Nest, Kings Street, Sutton Bridge, Spalding, Lincolnshire PE12 9RB, United Kingdom (+44 1406-365407).

The Chronic Disease Self-Management Program was originally developed at Stanford University. To find courses in the United States, log onto [www.stanford.edu/group/perc/cdsmp.html](http://www.stanford.edu/group/perc/cdsmp.html).

### Wellness for Women with Polio: A Holistic Program Model

#### *A Report of Initial Findings*

*Sunny Roller, MA, Martin Forchheimer, MPP, Denise G. Tate, PhD, Ricardo Rodriguez, MS, University of Michigan Health System, Ann Arbor, Michigan*

Using the framework of a biopsychosocial model of holistic health, this three-year project assessed needs, then developed, implemented, and tested the effectiveness of a cognitive and experiential wellness program for women with polio.

## PARTICIPANTS

Of the 189 who were selected to participate, 159 women completed the study. Eighty-five women were randomly self-selected to become experimental participants, with 74 self-selecting as control group members. All participants visited three assessment clinics: baseline, two weeks post-intervention, and a final assessment six months later.

## DEMOGRAPHICS

The average age of the participants was 56 years. The average number of years the women had lived with polio was 48 with a mean age of polio onset at 7 years.

Their primary source of health care coverage was private insurance (80%). Other sources of health care coverage included Medicare (16%) and Medicaid (2%), with 2% of the total group reporting they had no health insurance coverage.

Thirty-six percent of the women were employed full-time. Sixteen percent reported working part-time and 12% reported working as full-time homemakers. Further, 1% was unemployed and looking for work and 16% were unable to work due to disability. Eight percent had retired from work.

The average body weight of participants was 170 lbs. with the average body mass index score at the obese level of 29.1. The most frequently reported physician-diagnosed secondary conditions at study baseline were: new weakness in previously involved muscles 39%, scoliosis 35%, anemia 33%, depression 33%, circulatory problems related to coldness in extremities 31%, and chronic pain 30%.

## THE PROGRAM

Workshop teachers conducted a total of five wellness interventions. Each wellness workshop was composed of four half-day sessions. For participants, the workshop was followed two weeks later by a 30-minute, one-on-one, coaching/goal setting session conducted at the post-workshop clinical assessment time. At this coaching session, students met with three of their instructors for about ten minutes each to discuss individual issues and to plan for each of the major content areas.

Workshop content always included three topic areas: exercise, nutrition, and stress management. This comprehensive and integrated, or "holistic," approach was developed on the premise that mind and body work together as one unit and that all three of these health promotion areas are interdependent and will contribute to a woman's overall state of wellness.

## RESULTS

*Positive health behaviors* increased as a result of the program. Fifty-nine percent of the program participants increased their physical activity during the six months following the program. From the program's onset until six months after its completion, the percentage of participants eating 2-3 servings of fruit or fruit juice per day increased from 58% to 73%. The percentage of program participants who said that they took time each day to relax increased from 56% to 74%.

*Physical Change* – No significant changes in blood pressure, cholesterol, weight, strength, or

flexibility in workshop group were found.

*Psychological/Perceptual Change* – No significant change or differences (participants vs. controls) in distress levels (which were within normal range) or global perceptions of quality of life were found in the workshop group.

The workshop participants' perception of exercise changed during the course of the study. The percentage of women that reported not getting enough exercise because they believed that *exercise is bad* for post-polio people was 12.5% in the control group's initial visit and 9.5% in their follow-up visit. Ten percent of the workshop participants reported this belief during the initial visit, dropping to 0% during the follow-up visit.

The percentage of women that reported not getting enough exercise because they were *not sure which exercises are good for post-polio people* was 50% in the control group's initial visit and 38% in the follow-up visit. Fifty-three percent of the workshop participants reported this belief during the initial visit, which dropped to 3.5% in their follow-up visit.

Sponsored by the National Center for Medical and Rehabilitation Research, Reference #:1 R01 HD35053 01.

For more information, contact Sunny Roller, MA, Physical Medicine & Rehabilitation, University of Michigan Health System, D4114 Medical Professional Building, Ann Arbor, MI (Michigan) 48109 (734-936-9474, 734-763-0574 fax, [elsol@umich.edu](mailto:elsol@umich.edu)).

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In Queensland last year, a model for the management of Late Effects of Polio was approved – together with funding of \$100,000 – to develop a resource package and undertake training and education of health professionals, and to promote greater awareness about their condition to those who have experienced polio.

**The Late Effects of Polio Training Program** involves prevention and management, and a program to develop strategies which can assist in decreasing the impact of individual symptoms on daily life. It involves working with those affected by post-polio symptoms to improve their quality of life through a prescription of individual care, education, exercise, and lifestyle modification.

In addition to training workshops for rehabilitation health professionals across Queensland, the Late Effects of Polio project included the development of a resource manual for hospital and community health professionals on the assessment and management of late effects of polio; a GP information package; a brochure about “Understanding the Late Effects of Polio” to provide information to the general public regarding this condition; and the development of websites.

The entire education and training package is accessible on [www.health.qld.gov.au/polio/gp/home.htm](http://www.health.qld.gov.au/polio/gp/home.htm).

For more information, contact Penny Beeston, Manager, Community Services, The Paraplegic and Quadriplegic Association of Queensland Inc., PO Box 5651, West End, Brisbane 4101, Australia (+61 7 3391 2044, [pbeeston@pqaq.com.au](mailto:pbeeston@pqaq.com.au), [www.pqaq.com.au](http://www.pqaq.com.au)).

The Queen Elizabeth Hospital ([www.qehospital.co.nz](http://www.qehospital.co.nz)), a private hospital in Rotorua, New Zealand, offers a **Polio Course** three times a year. The three-week course is covered by Public Health if a polio survivor’s physician or specialist refers them. Survivors who are able to pay can make their own arrangements.

The course focuses on education, pain management, fitness, balneotherapy (because of access to geothermal waters), management of daily living activities, and improvement of mobility skills.

Doreen Chandler, Auckland Post-Polio Support Group, Inc., reports that polio survivors live in and the first week is dedicated to assessments. “The second and third weeks include treatment consisting of hydrotherapy, physiotherapy, exercise, orthotics and wheelchair services, and, if required, occupational therapy and counseling. I attended a course four years ago and was given an extra week of treatment.”

For more information, contact Doreen Chandler, Auckland Post-Polio Support Group, Inc., 36 Eastern Beach Road, Bucklands Beach 1704, New Zealand (+64 9 534-6151, +64 9 537-3104 fax, [auckpostpolio@clear.net.nz](mailto:auckpostpolio@clear.net.nz), [www.postpolio.co.nz](http://www.postpolio.co.nz)).

**Post-Polio Syndrome: A Guide for Polio Survivors and Their Families**

(ISBN 0-300-08807-8) by Julie K. Silver, MD, is available from Yale University Press ([www.yale.edu/yup](http://www.yale.edu/yup)) for \$27.50 USD (800-987-7323). Silver, a physiatrist, is an assistant professor at Harvard



Medical School, director of the International Rehabilitation Center for Polio ([www.polioclinic.com](http://www.polioclinic.com)) in Framingham, Massachusetts. Silver draws on her years of professional and familial experience with post-polio syndrome to provide an historical overview of its diagnosis and treatment and to answer many questions regarding the ramifications of the syndrome.

## 小兒麻痺後期症候群

Thanks to Robert Ronald, SJ, **Care of Poliomyelitis** (ISBN 957-744-250-1), a new Chinese language polio manual, is available from Operation De-Handicap, P.O. Box 7-533 (106), Taipei, Taiwan ([odh@oceantaiwan.com](mailto:odh@oceantaiwan.com)). ■

## Selected Bibliography

An article, “Dynamic water exercise in individuals with late poliomyelitis,” by Carin Willén, RPT, MSc, Katharina Stibrant Sunnerhagen, MD, PhD, and Gunnar Grimby, MD, PhD was published in the January 2001 issue of the *Archives of Physical Medicine and Rehabilitation* (Vol. 82, No. 1). Fifteen of twenty-eight individuals with the late effects of polio were assigned to a training group and 13 were assigned to a control group. The training group participated in a 40-minute general fitness training session in warm water twice a week.

After the training period of about five months in heated water, the nonswimming dynamic exercises had a positive impact in that the participants had a decreased peak heart rate at exercise and less pain. There were no reports of adverse effects.

For more information, contact Carin Willén, Dept of Rehabilitation Medicine, Sahlgrenska University Hospital, S-413 45 Göteborg, Sweden ([carin.willen@fhs.guse](mailto:carin.willen@fhs.guse)). ■



## 2001 CALENDAR

SEPTEMBER 7-14th, **National Polio Survivors Reunion**, Geneva Park, Orillia, Ontario, Canada. Conference: Post-Polio in the New Millennium (September 7-9) and Wellness Retreat (September 9-14). Contact Reunion Registration, Ontario March of Dimes (416-425-3463, polio@dimes.on.ca).

SEPTEMBER 15, **Second New Hampshire Conference on Post Polio Syndrome**, Frisbie Memorial Hospital, Rochester, New Hampshire. Contact New Hampshire Network Post-Polio Support Group (603-692-6490, 603-692-4686, or 603-659-7372).

**Joan L. Headley will be speaking at the following meetings this fall:**

SEPTEMBER 22, 2001, **Going Forward**, Elks Lodge, Augusta, Maine. Contact The Post-Polio Support Group of Maine (207-724-3784) or Ann Crocker (bcrocker@ctel.net).

OCTOBER 6, 2001, **T.L.C. – Together – Learning & Coping**, St. Matthews United Methodist Church, Anderson, Indiana. Contact Ellen Crim, Central Indiana Post-Polio Support Group (765-649-3648, Ehope31@cs.com).

OCTOBER 20, **Greater Boston Post-Polio Support Group Quarterly Meeting**, United Parish Church of Auburndale, Newton, Massachusetts. Contact Elaine Burns (781-596-8245, www.gbppa.org).

## For Your Information

The National Odd Shoe Exchange has informed us that they are no longer in business.



Polio survivor Thomas Fetterman of Thomas Fetterman, Inc. now has available **LiteStix®** a titanium forearm crutch made of 7/8-inch tubing and weighing just over a pound and a half. The hand-grips are welded on; the Superlite Zytel Nylon forearm cuffs have leather-covered, neoprene-padded cuff inserts; and the crutches come with Tornado-2 tips. Contact Fetterman, 1680 Hillside Road, Southampton, PA (Pennsylvania) 18966 (215-355-6941, tfetter@voicenet.com, www.fetterman-crutches.com).

The Post-Polio Association of South Florida, Inc. has created a **bumper sticker regarding disabled parking**. To receive one, contact the association at 516 NE 199 Terrace, North Miami Beach, FL (Florida) 33179.



Polio survivor and life-long Catholic **Stephen Mickey** writes poetry and has published several collections of his work. Contact Poetic Expressions, 1500 North Third Street, #137, Manitowoc, WI (Wisconsin) 54220 (920-652-0193).

When Joe Curiale was six years of age, he fell and injured his hip. An orthopedic surgeon determined that he had polio. After rehabilitation, Curiale studied physical therapy and design engineering. In the late eighties, after surgery to remove a brain tumor, he was unable to use traditional crutches, so he designed a crutch to accommodate his disability – **the HESSA Crutch™**.

Contact Mercury Medical Inc., P.O. Box 2744, Sunnyvale, CA (California) 94087 (408-431-3720, 408-730-1924 fax, customerservice&crutchsolutions.com, or visit www.crutchsolutions.com).

The Ontario March of Dimes and Aventis Pasteur awarded its **2000 Jonas Salk Prize** of \$10,000 to Neil Cashman, MD, Director of Neuromuscular Disease Clinic at Sunnybrook Hospital, Toronto, Canada, and professor at the University of Toronto. ■

## **GINI appreciates the donations from the following support groups to The GINI Research Fund.**

Colorado Easter Seals Post-Polio Support Group of Aurora  
Colorado Post-Polio Connection  
Delaware Valley Polio Survivors Association  
Easter Seals Oregon/Roseburg Chapter  
Florida East Coast Post-Polio Support Group  
Greater Utica Area Post-Polio Support Group  
Hemet Area Polio Survivors  
Lake Charles Post-Polio Support Group

Monroe Polio Support Group  
New Jersey Polio Network  
Pasadena Post-Polio Support Group  
Pensacola Post-Polio Support Group  
Polio Heroes of Tennessee/Nashville Area  
Polio Survivors Foundation (California)  
Polio Survivors Plus of Orange County  
Post-Polio Association of South Florida

Post-Polio Awareness & Support Society of Minnesota  
Post-Polio Support Group of Christ Hospital & Medical Center  
Post-Polio Support Group of Delaware  
The Polio Connection (Cincinnati)  
The Tennessee Valley Post-Polio Support Group  
Wichita Post-Polio Support Group, Inc.

## Readers Write

"Your editorial comments regarding breathing problems of polio survivors in the last issue are very on point.

"I had polio in 1944 and in 1990 contracted pneumonia and experienced respiratory arrest. I am now well recovered using a PLV®-100 ventilator at night as well as an LTV by Pulmonetic Systems, Inc. for travel. It has made a world of difference in my daytime energy and capabilities.

"Severe scoliosis has left me with a VC of 1.25 L, yet I play golf, travel, and garden. I use a 'custom-made' silicone system offered by LIFECARE (purchased by Respironics) and, regrettably, since discontinued. Perhaps some other company could offer or otherwise make it available, as its ease of use and comfort are well beyond those provided by standard nasal masks."

—Matt, New Jersey

"I just finished my work for my Doctor of Ministry in Preaching degree. My thesis was on preacher formation and how a disabled working class woman (me) became a pastor. There is not a great deal written about disability and theology, but I hope to change that. One great book, published in 1994, is *The Disabled God: Toward a Liberatory Theology of Disability* by Nancy Eiesland (Abingdon Press). A sermon I wrote was published in the October 2000 *Lectionary Homiletics*."

—Reverend Christine Fontaine,  
Congregational United Church  
of Christ, Armada, Michigan

Contact IPN for a copy of her sermon.

"It is interesting to note, that on the 20th of this month, my sister Florence and I will have survived 85 years of polio. We were among the 27,000 who caught the virus in the first large epidemic in our nation, in the summer of 1916. My sister was 3 and I but 3 months old. I suffered extensive paralysis and my sister was ambulatory with scoliosis.

"As you may know, I was one of the founders of the Arizona Bridge to Independent Living (an independent living center), marking its 20th anniversary this year."

—Abe Jaffe, Arizona

"I have obvious post-polio symptoms and have experienced the ramifications of using the cholesterol lowering 'statin' medications (e.g. Zocor, Lipitor, etc.). I know there was a correlation between taking Zocor and my new decline in capability. It may well be that if I did not have post-polio syndrome, the side effects of muscle weakness would be negligible, but in my case they were not. The information sheet that comes with the medication clearly outlines these side effects. Please remind your readers and the health professionals who treat them of this potential problem."

—Janet, California

"I use Cholestyramine Powder to help control my cholesterol levels along with diet. My physician recommended this older but effective medication. I do not experience the side effects of muscle and joint pains."

—Shirley, Massachusetts

"I want to tell other polio survivors about a recent experience of mine. I fell off of my electric scooter and landed on my hand. As a result, I no longer have use of it. I want to ask polio survivors to write letters, encouraging manufacturers to put seat belts on all models of scooters and chairs, and to request the passage of laws to make seat belts mandatory."

—Arnold Snyder,  
162 Lake Meryl Drive,  
West Palm Beach, Florida 33411

"I experienced extreme and lasting leg pain as a result of my last mammogram. I found out that I could not stand on my toes anymore for the length of time needed. I started asking the center questions about how they did mammograms for woman who could not stand. Evidently, I was the first to ask. If you have any experience or expertise that you can share, please contact me."

—Jacqueline Frost,  
18 Washington Street, #1,  
Ipswich, Massachusetts 01938

"Like many people who had polio in the 1950s, surgery was a part of my life for many years. As far as I was concerned, anesthesia was my friend. In the last decade, however, my 'friend' has turned against me. Every time I have had any kind of anesthesia, my reactions have become more disturbing, feeling as if my body was in 'Park' and my brain was in 'Drive.'

"On two occasions, dentists called 911 when I began shivering uncontrollably and they were unable to wake me following minor dental procedures. Both times, I had requested a reduced dosage of local anesthetic; both

times the dentists administered full adult doses. When I had an endoscopy in June of 1997, I learned that even small doses of sedatives given by IV could wreak havoc on my nervous system.

"My history of adverse reactions to anesthetics has made me extremely cautious about future exposure. I wear a MedicAlert tag stating that I am, 'Hypersensitive to local and general anesthetics – use minimal dose.' My medical and dental charts contain 'alerts' regarding my sensitivity. I carry copies of publications summarizing anesthesia issues for polio survivors.

"I took my first meditation class in February 2000 through my HMO. The Mindfulness Meditation and Relaxation course was designed to help participants cope with the physical and psychological symptoms of chronic illness. At that time, post-polio muscle tension, sleep disorders, and 'buzzsaw brain' were my major concerns. It did not occur to me that I would ever use meditation during surgery.

"After the eight-week class, however, I saw the benefits of a daily meditation practice. Meditation calms me. It recharges my batteries. It helps relax my tense muscles. It nourishes my spirit. Listening to guided meditation tapes every day allows me to completely rest my body and mind. Meditation has become a critical component of my routine.

"In 1999 and 2000, I had become a frequent visitor to the local emergency room when my normal pulse rate of about 80 beats per minute periodically zoomed up to 220 beats per minute. According to my doctors, this condition, supraventricular

tachycardia (SVT), could be eliminated with a relatively simple and safe procedure known as catheter ablation. Special wires would be threaded up into my heart through a vein in my groin. Then, high-powered radio waves would zap – or ablate – the nerve pathway responsible for the rapid heartbeat. In November 2000, I decided to have the procedure and I decided to try meditation instead of sedation.

"I provided extensive documentation regarding my reactions to anesthesia. The medical team was amazingly sensitive to my needs. They made every effort to keep me warm before, during, and after the procedure. They gave me only 20% of the usual dose of local anesthetic used to numb the groin area. They also agreed to let me listen to my meditation tapes rather than use drugs for sedation.

"The three hours I spent on the operating table passed quickly. The guided meditation tape fed a steady stream of positive, relaxing messages into my headset. Meditation allowed me to fully participate in the experience while keeping the discomfort to a minimum. I was able to view the computer monitor tracking the catheter's journey through my body. I was able to ask questions along the way. I was completely at peace. In addition, recovery was rapid, and no pain medication was required following the procedure. For most patients, ablation is an out-patient procedure. In my case, I was hospitalized overnight for observation.

"Although the ablation procedure was successful, an unexpected complication resulted in damage to my heart's 'electrical system.'

For the next three weeks, my pulse rate hovered around 50 beats per minute. The slightest activity left me breathless and weak. I spent a few nights in the hospital cardiac care unit and made some return visits to the emergency room. When my doctors recommended that I have a pacemaker implanted to return my heart rate to normal, I was ready.

"The pacemaker surgery was not nearly as entertaining as the ablation had been. In my case, implanting a pacemaker involved making a three-inch incision below the collarbone and creating a pocket under the skin to hold the pacemaker. Since the medical team was working so close to my head, my face was covered with a surgical drape – eliminating my view of the operating room activities. This time, the doctors injected about 25% of the normal dose of local anesthetic before making the incision.

"During the 90-minute procedure I was able to focus on my meditation tape and avoid additional anesthetic drugs altogether. There was more discomfort with this procedure, but it came in rather short bursts. Meditation has taught me that sensations come and go. I was definitely aware of sensations at each step of the procedure, but I also knew that they were temporary. In my calm, relaxed state, I actually felt somewhat sedated. As with the ablation, recovery was rapid, and I did not require pain medication. Again, I was hospitalized overnight for observation.

"Would I choose meditation again? Definitely. I plan to meditate whenever possible to avoid

CONTINUED ON PAGE 12

or minimize anesthesia for dental or medical procedures. Knowing that anesthesia is available if needed gives me the confidence to try meditation before medication for relatively simple procedures. For more complex surgery, however, I would not hesitate to work with the anesthesiologist to develop a safe and effective sedation plan. I would use my meditation before surgery to maintain a calm, positive attitude and after surgery to enhance healing.

“Obviously, meditation is not for everyone, and it would not be appropriate in every surgical setting. For polio survivors experiencing frightening reactions to anesthesia, however, meditation may be an option.

“Information on meditation is available from a number of sources, including libraries, col-

leges, and/or adult and senior center classes, and the Internet. You may find, however, that information pertinent to your needs may also be found under headings such as stress management, chronic pain management, yoga, or t'ai chi. One book I have found to be useful is *Full Catastrophe Living (Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness)* by Jon Kabat-Zinn, PhD.

“Meditation has been around for thousands of years and has evolved into a variety of forms. My HMO chose to teach mindfulness meditation methods based on a successful stress management program from the University of Massachusetts. Mindfulness meditation involves paying attention to – or being mindful of – each of life's

moments. Basic techniques can be learned easily; the practice of mindfulness can last a lifetime.”

–Becki Gipson, MEd, MBA,  
6182 Vanden Road, Vacaville, CA  
(California) 95687 (925-932-3910,  
925-932-0218 fax,  
beckigipson@earthlink.net)

“Summary of Anesthesia Issues for Post-Polio Patients” by Selma Harrison Calmes, MD, Chairman and Professor, Department of Anesthesiology, Olive View/UCLA Medical Center, was prepared for the Eighth International Post-Polio & Independent Living Conference, June 2000. For a copy, send a self-addressed, stamped envelope to International Polio Network.

The summary contains seven major points and is a complement to her “Anesthesia Concerns for the Survivors of Polio,” published in *Polio Network News* (Vol. 13, No. 2). This article (and the summary), along with many other major articles from past issues of *Polio Network News*, may be found at our website ([www.post-polio.org](http://www.post-polio.org)). ■

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