

POLIO NETWORK NEWS

STANFORD'S PROGRAM: AN OPPORTUNITY FOR SURVIVORS

THE OPPORTUNITY: International Polio Network (IPN) is collaborating with Conemaugh's Regional Neuroscience Center in offering a five-day "train the trainer" workshop August 12-16, 2002 in Johnstown, Pennsylvania, the home of Conemaugh's Health System. The course will train individuals to be leaders of the Chronic Disease Self-Management Program (CDSMP).

WHAT IS THE CDSMP? The program was developed at Stanford University over twenty years ago. The aim of the program is to assist people with chronic conditions to self-manage their health. The program teaches participants the practical skills for making decisions, communicating needs, and taking action to improve their physical, mental, and emotional health. For details about the program, visit www.stanford.edu/group/perc/programs.html.

IPN and Conemaugh are looking for applicants (preferably in pairs) to receive the training to be leaders of the CDSMP.

WHO SHOULD APPLY? Candidates may be a polio survivor, ventilator user, or a health professional; a part of a support group, a post-polio clinic, a pain clinic, an HMO, etc. The course is designed to be taught by two people, so we will offer the training to pairs of individuals who are committed to teaching the course together. Individuals (polio survivors, ventilator users, health professionals) are encour-

aged to apply if they live in area where another person is already qualified to teach the course. To determine if this is so, contact Stanford University's CDSMP at www.stanford.edu/group/perc/cdsites.html.

IS THIS TRAINING FREE? Selected participants will receive the five-day training, training materials, onsite lodging and meals, and material to provide the program free of charge in their own communities. Participants will be responsible for their own transportation costs to Johnstown, Pennsylvania, USA. Pittsburgh is the closest major city.

WHO WILL TRAIN THE SELECTED PARTICIPANTS? Carol Yoder, Barbara Duryea, and Joan Headley, all individuals who have been trained as "master trainers" and individuals who have a chronic condition will teach the August training.

HAVE POLIO SURVIVORS PARTICIPATED IN THIS TRAINING OR TAKEN THE COURSE? Yes, polio survivor Peter Jay of the British Polio Fellowship reported on the United Kingdom's experiences with the CDSMP in the Summer 2001 *Polio Network News* (Vol. 17, No. 3). Jay will present at the May 21, 2002 conference – "Post-Polio Syndrome: Improving Quality of Life with Teamwork" – in Johnstown.

Barbara Duryea, Project Coordinator of the Regional Neuroscience Center, will host the training and reports that Stanford's

research demonstrates that participants have experienced significant improvements in their health behaviors, health status, reductions in hospitalizations, visits to health providers, and days in the hospital.

WILL THIS REPLACE SUPPORT GROUPS? No, the class meets for 2½ hours for six weeks, i.e., it has a beginning and an end. This approach appeals to some survivors. They want to attend a structured class that will assist them in managing their late effects of polio.

COULD OUR SUPPORT GROUP OFFER THE CLASS? Yes. It can be offered as an alternative to the typical support group meeting, but remember it only last six weeks.

WHAT IS MY OBLIGATION ONCE I RECEIVE THE TRAINING? You will be asked to teach the CDSMP at least one time during the next year. You will need to find a place to hold the class and advertise, so polio survivors who want to take advantage of the class can attend and learn ways to self-manage their life as they age with polio. You will also receive the necessary materials to teach a class of twenty.

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HOW DO I APPLY? Contact IPN at 314-534-0475 or at gini_intl@msn.com.

I WOULD LIKE TO TAKE THE COURSE BUT NOT TEACH IT. HOW CAN I FIND OUT IF IT IS OFFERED IN MY AREA? Contact Stanford University's CDSMP at www.stanford.edu/group/perc/cdsites.html or call Carol Cox at IPN (314-534-0475).

If it is not offered in your area, we ask you to encourage your rehabilitation center, post-polio clinic, older citizen centers/organizations/facilities, independent living centers, etc. to send a pair to the training. They will be required to advertise the course for polio survivors, but they can offer the class to anyone with a chronic condition.

GINI will publish the dates of any course that is offered by these newly trained leaders in *Polio Network News* and on our website – www.post-polio.org.

If you have any questions about this opportunity, call Joan Headley at 314-534-0475 or Barbara Duryea at 814-534-5741. ■

International Polio Network

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EDITOR'S COMMENTS

I am told that sometimes my comments hint at my frustration. This time I am not hinting. I am frustrated! For the last 15 years, my job has been to educate polio survivors and health professionals about the late effects of polio – to alert them about the potential problems and to assist in finding solutions. I never anticipated that I would spend so much time clarifying misinformation that results from simplifications or overgeneralizations.

A daughter of a polio survivor called last week and was distressed because her mother had refused surgery that she needed (a 2% chance of living without it) "*because polio survivors should not have anesthesia!*" While we encourage polio survivors to discuss anesthesia issues with their physicians, we never have stated that they cannot tolerate it. We receive calls and questions from polio survivors and health professionals (albeit in a skeptical tone) asking for the "list of medications that all polio survivors should avoid" and for the information that

"supports that all polio survivors should not exercise."

Needless to say, I was pleased when Julie Silver, MD, sent an article about three ideas that are "polio myths," or at best, "half-truths." I have included several "Letters to the Editor" that demonstrate the variety of issues facing polio survivors and their proactive methods of addressing them. We both hope that we can prevent some unnecessary hysteria and guilt.

We must continue to share information and ideas, but also question the soundness of post-polio information, particularly as it relates to each of us as individuals. I challenge you to do your "homework" and determine your own path to optimum health and independence, in conjunction with a caring physician who thinks critically.

Perhaps, you, too, are frustrated by awareness efforts that have gone awry or have resulted in counterproductive responses. I invite you to send your concerns to me.

– Joan L. Headley, MS
Executive Director, GINI

POLIO MYTHS AND HALF-TRUTHS

Julie K. Silver, MD, Medical Director, International Rehabilitation Center for Polio, Spaulding Rehabilitation Hospital, Framingham, Massachusetts

MYTH #1 Some medications are bad for polio survivors and should be avoided at all costs.

Many polio survivors have read that some medication classes are bad for them – the most common I am asked about is probably the “statins” (e.g., fluvastatin, simvastatin, etc.) These are medications that end in *statin* and are used to lower cholesterol levels. The fear is that these drugs will cause muscle pain or weakness (a known side effect) and compound the weakness that a polio survivor is already experiencing.

Heart disease is the leading cause of death in men and women as they age. Stroke is a leading cause of further disability. Both conditions are directly linked with high cholesterol levels and “statin” drugs that reduce cholesterol are critical for many people in order to lower their risk of stroke and heart attack. *But, why give a drug to a polio survivor that may cause him or her to become weaker?* The answer is because it may save a life.

It is important to understand what the actual risk may be of developing musculoskeletal problems if you take a particular medication. For example, the drug Zocor (simvastatin) underwent fairly vigorous testing prior to it being approved by the Federal Drug Administration (FDA). More than 2400 people were tested on the medication.¹ No one in the study knew if they were actually taking the drug (it was blinded), and the results showed that more people

complained of muscular side effects when taking a sugar pill (1.3%) than when taking the actual medication (1.2%). The point here is that even if you do take simvastatin, there is nearly a 99% chance that you *won't* develop muscular side effects.

So, my advice always goes like this: *talk to your doctor* – the one who prescribed the medication in the first place. *Ask him or her whether it would be okay for you to stop the medication for a period of time to see whether it is indeed causing you to feel weaker or more pain or whatever you are concerned about.* A “drug holiday” is a good way to see whether you are actually experiencing side effects from a medication.

When you go off the medication, pay attention to whether you feel any different. If you do not, that medication is probably fine for you. Keep in mind that every drug has a huge list of *potential* side effects. This does not mean that you will experience them – it just means that in studies that were done on the drug, some people had these side effects.

At the same time, ask your doctor whether there are other alternatives that you can try – including medications and lifestyle changes. For example, exercise, smoking cessation, and weight loss have all been associated with reducing cholesterol levels. Although I used the example of the *statin* class of medications, this advice applies to any medication that concerns you.

MYTH #2 Polio survivors should rest, rest, rest!

This is another myth that has some truth to it, but taken to an extreme is dangerous. All bodies become extremely deconditioned without the constant use of the muscles. Even polio-weakened muscles can become weaker from disuse. Not using muscles results in weakness, and diminished endurance and cardiac fitness. If you are at complete bedrest, your muscles will lose 10-15% of their strength per week.² If you stay in bed for a month, you will have lost about half your strength. Muscles need to be contracted regularly in order for them to maintain their size and strength.

On the other hand, it is important to note that the opposite of disuse – overuse – can also cause further weakness in polio survivors. So, the trick is to balance your daily activities with rest and also do an appropriate exercise program.

This sounds easier than it is, and I always recommend that people talk to healthcare professionals who are experienced in prescribing exercise programs for polio survivors. But some simple suggestions are as follows:

- ◆ Nearly everyone, including polio survivors, should exercise regularly.
- ◆ Exercise is not what you do in your daily activities, but rather is a set program that has a time limit and a certain number of exercises with a particular amount of weight or resistance that is used.
- ◆ Doing the same exercises over and over may lead to further weakness. Instead, exercises

CONTINUED ON PAGE 4

should be alternated regularly so all of the muscle groups are used and no one muscle group is overused. The concept of cross-training that is widely accepted in sports medicine is what we promote at our center.

- ◆ Include some strengthening, range-of-motion, and aerobic exercises to be sure you maintain optimal fitness.
- ◆ If you experience pain or undue fatigue, check with your doctor. This generally means that what you are doing needs to be modified or even stopped altogether.

MYTH #3 Swimming is good for you.

If you love to swim, do it regularly, and have easy and safe access to a pool, then swimming probably is good for you and you should continue to do it. However, if you do not swim for exercise and you feel guilty about it, then let me relieve you of your guilt – because swimming can be dangerous for your health.

Famous polio survivor, Franklin Delano Roosevelt, loved the buoyancy of water and the freedom it gave him to move his paralyzed body. The fact that much of his swimming was done in the beautiful Warm Springs, Georgia, only added to the benefits he received from this exercise. But swimming is not for every-

one and there are some good reasons why you might not want to swim.

First, getting ready to go swimming is a lot of work. For most people swimming involves many or all of the following steps:

1. Locate your bathing suit and towel.
2. Go from your house to your car.
3. Drive to the pool.
4. Go from the parking lot to the locker room.
5. Change into your bathing suit.
6. Go from the locker room to the pool.
7. Swim.
8. Go from the pool to the locker room.
9. Change out of your bathing suit.
10. Go from the locker room to your car.
11. Drive your car home.
12. Go from your car to your house.
13. Hang your bathing suit and towel up to dry.

Of the 13 steps I listed, only one of them involves the “exercise” of swimming. But, in order to get that exercise, you must do at least 12 other things that may just serve to wear you out. So, although I am a huge advocate of exercise that promotes cardiovascular fitness for polio survivors (keep in mind that post-polio syndrome is *disabling*, but cardiovascular disease *kills* more middle aged and older people than any other condition), swimming is a lot of work.

Second, you may be at risk to fall as you do these 13 steps. In one study, 46% of polio survivors noted that walking outdoors was difficult.³ In another study,

82% of polio survivors reported increasing difficulty with walking.⁴ Yet another study revealed that 64% of survivors reported falling at least once within the previous year and of this same group, 35% reported they had a history of at least one fracture due to a fall.⁵ Given these statistics, the number of steps it requires to go swimming (often both literally and figuratively) and the likelihood that there may be some slippery surfaces in the locker room or around the pool, it is easy to see how someone might fall and sustain a serious injury while going swimming.

I think it is really important to not discourage anyone from exercising in a safe manner and swimming can be a great exercise for polio survivors. But, it is not a great exercise for ALL polio survivors. If you love to swim and you can do it safely, then definitely continue. But, if you find yourself overly fatigued after swimming, or if you think you are at risk to fall and have a serious injury then consider other exercise options. ■

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JULIE K. SILVER, MD, is the medical director of the International Rehabilitation Center for Polio at Spaulding Rehabilitation Hospital in Massachusetts (www.polioclinic.org). She is also an Assistant Professor at Harvard Medical School and has published several books including the book *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families* (Yale University Press). Dr. Silver's mother, uncle, and grandfather all contracted polio in the summer of 1946. During her medical training, she worked with Lauro Halstead, MD, and they have worked together on polio-related projects throughout her career.

PERU'S POLIO SURVIVORS

Marilú Montero Graña, San Isidro, Lima

Now 63, I contracted polio at the age of 6 months. I did not have a long acute polio phase. After I got over it, my mother noticed that I could not move my legs anymore. Although I started walking around one year, I did not need braces, crutches, or any help, walking normally. I had a slight limp going up the stairs.

At the age of 10, I went to Warm Springs, Georgia, USA, because I was falling often. I had surgery on my left leg and spent two months encased in plaster from my feet to my shoulders. Afterwards, I underwent three months of rehabilitation, including pool exercises, to learn to walk again. When I left Warm Springs, I had a brace on my left leg and used crutches until I was twelve years old. I did not use any aids after that, and one could barely notice anything different in my walking.

In 1952, my mother, Victoria Graña, founded the Clinica San Juan de Dios, the country's first polio center for children from low-income homes. The Clinica was named after a Spanish order of priests, who, by coincidence, had arrived in Peru that same year to start a hospital for poor people. My mother formed a committee with all the other mothers who had children with polio (all between 8 and 12 years). They joined the priests for the same purpose: to provide treatment and support to poor children with no cost to their families.

My mother, who was fortunate enough to belong to a well-known family, looked for a

hospital to buy, but only on one condition: the hospital had to be primarily for polio patients. This hospital became the only polio hospital in South America and provided everything from surgery, rehabilitation, braces, and crutches to school and clothing for all the children. For her humanitarianism, the Peruvian government, as well as the order of San Juan de Dios, three times decorated my mother. The hospital (which just celebrated its 50th anniversary) has not closed, but now any kind of illness is treated.

Over the years, I have lived an active life as a travel agent, singer, nurse, administrator, and mother of three. I wore high heels; I climbed the Pyramids and the Great Wall. But several years ago my bones ached, my muscles felt weak, and I had no energy. I blamed it on age, until Patsy, my childhood friend at Warm Springs who also had polio, revealed that she was having the same symptoms. The weakness of my leg was my first post-polio symptom, and then came fatigue, muscular pain, and difficulty with stairs.

When I began feeling the late effects of polio five years ago, no one in Peru knew anything about it. I had doctors tell me I was depressed, needed to eat more meat, needed to be seen by a cardiologist for fatigue, had menopausal problems, etc. I went to Warm Springs (where I had a KAFO made); Houston; Englewood, New Jersey; and Washington, DC, for three consecutive years. I finally settled on National Rehabilitation Hospital in Washington, DC,



Marilú Montero Graña and Dr. Gaston Barnechea

and Lauro Halstead, MD, for treatment. I later asked him to come to Peru to teach our physicians about post-polio.

I now wear the KAFO on my right leg, which used to be my good leg, and returned to using crutches. I have changed my living habits 90%, lost weight, started pool exercises, and rest for small periods during the day. I have stabilized, and even improved, to the point that I now wear the brace only for a few hours per day and use only one crutch or a cane.

There are still Peruvian physicians who do not take post-polio seriously. They say that polio has been wiped out and that it does not appear in the statistics any more. I explain that it is not polio, but a syndrome that affects people who have had polio, decades later. I explain that we need attention from specialists and that we need to find the thousands of Peruvian survivors of the 1950s and 1960s polio epidemics to make them aware of the symptoms.

After the polio vaccine was discovered and the epidemic was over, all polio survivors who were once patients of the Clinica San Juan de Dios were totally forgotten. The social security hospitals in Peru did not provide

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treatment or orthotics for polio sequelae, and survivors live with significant scoliosis, recurvatum, limps, etc.

In August 2001, Dr. Halstead presented five conferences in Lima to physicians. The physicians who had refused to accept the existence of post-polio syndrome were present. Dr. Halstead also presented a workshop on starting and operating a post-polio clinic. Over 600 people attended the polio survivors' conference.

Sociedad Peruana de Polio, the Peruvian polio society, of which I have been elected president has 380 members and 23 support groups. Our office is in the same Clinica where my mother started working for

polio survivors 50 years ago. We recently received permission from the Peruvian Social Security Institution to mount a campaign to raise awareness among health professionals for better detection and appropriate treatment of the problems of polio survivors. The Society also wants the Ministry of Health to back treatment centers, because post-polio is considered a pre-existing condition not covered by insurance companies.

One of our allies is Dr. Gaston Barnechea, specialist in orthopedics and traumatology at Guillermo Almenara Hospital, who believes it is important to screen for post-polio symptoms in routine physical examinations. In the past two years,

Dr. Barnechea's hospital has treated about 300 polio survivors, and he is the leading doctor in Peru for treatment. Two groups of 25 selected specialists who belong to the social security hospitals have been trained by him in post-polio management and treatment.

Dr. Barnechea estimates that 60,000 Peruvians contracted polio during the epidemics, that about 40,000 of these would still be alive today, and, of those, about 25,000 may experience the late effects of polio. ■

For more information contact, Sociedad Peruana de Polio, Aptdo. Postal 27-0097, Lima, Peru (+511 3260997, speruanadepolio@hotmail.com).

FOR YOUR INFORMATION: MEDICATION ASSISTANCE PROGRAMS

Together Rx™ provides seniors and other eligible Medicare enrollees with savings on medicines from a number of leading pharmaceutical companies, including Abbott Laboratories; AstraZeneca; Aventis Pharmaceuticals, Inc.; Bristol-Myers Squibb Company; GlaxoSmithKline; Janssen Pharmaceutica Products, LP; Novartis; and Ortho-McNeil Pharmaceutical, Inc. You must be a Medicare enrollee. Your annual income must be less than \$28,000 for individuals and \$38,000 for couples. You may not have prescription drug coverage (public or private). Cards become effective in early June. Contact IPN for a copy of the application or apply online at www.togetherrx.com.

Eli Lilly offers a discount card for low-income seniors who have an income of less than \$18,000 a year for individuals or \$24,000 for couples. The card will be honored at CVS, Longs, and Wal-Mart Pharmacies. Call 1-877-RX-LILLY for an application. Eli Lilly has another program that provides medications free of charge; see your physician for the forms.

Pfizer's program is called **Pfizer for Living Share Card™**. You must be 65 years or older or a Medicare enrollee with a gross income below \$18,000 for individuals and below \$24,000 for couples. You cannot have any other prescription coverage. To receive an application, call 800-717-6005.

www.needymeds.com provides information about each company's assistance program, including the company's name, the program's address, telephone and fax numbers, guidelines and notes, the health care provider's role, the patient's role, information needed to initiate enrollment, the amount of medication and how it is dispensed, refill information, estimated response time, and limitations of the program.

Polio survivor Joanna Gaumont and her husband, James, from Salem, Oregon **collect, repair, and distribute used wheelchairs** to people who need them. Please contact Orphaned Wheelchairs at jgaumont@pop.netzero.net or call 503-375-9523. ■

Letters to the Editor

HEALING POLIO MEMORIES

PHYLLIS OSHKOSH, WISCONSIN

"I just had to write and tell you how much the article on 'Healing Polio Memories' meant to me. My bout with polio began when I was a little over three years old. I was hospitalized at Milwaukee Children's Hospital for six months. Visitation was limited to two 90-minute visits each week.

"While I don't believe I suffered from 'attachment disorder,' some of the memories reported by others are identical to mine – of being left unattended in the whirlpool tub and being afraid of drowning – and remembering the smells and tastes. Wet wool and oatmeal bring back unpleasant memories. I continue to experience a needle phobia because of all of the shots I received and being told they 'wouldn't hurt.'

"My most recent anxiety relates to the possible need to use braces or a wheelchair again. I do not think I am embarrassed to use them, but they represent another defeat in my life."

RICHARD VISTA, CALIFORNIA

"I read with interest the latest edition of your *Polio Network News*. I was particularly intrigued with the experiences of the young polio persons and how they managed in later years to overcome the psychological trauma of the disease.

"However, my comments are related to adults who experienced polio in their 20s and beyond. I was a Lieutenant, Junior Grade, USN, when I contracted polio. I was 23 years old, a carrier-

based fighter pilot under orders to Corpus Christi, Texas, as a primary flight instructor.

"The polio was the paralytic type, affecting virtually all of my body. The Navy kept me in the naval hospital in Jacksonville, Florida, from Thanksgiving weekend of 1949 until mid-January of 1950, when they transferred me to Warm Springs, Georgia. This transfer resulted in a prolonged separation from my wife, Mary Margaret, and daughter – 13 months, with a few weekend visits.

"After about five months of comprehensive therapy, I realized that I would never fly again. It appeared that the Navy would release me, as my condition was stabilizing and little progress was being made.

"While at Warm Springs, I met several people who were unable to reconcile their polio with the lives they were to lead. A Navy captain who had been under orders to command an aircraft carrier was bitter and unable to accommodate. A gentleman who had been nominated to a 'chair' at Yale University (a position he had to decline) was another. A lady, who refused to accept the fact that she had polio and then did little or nothing to help with her recovery, is also included in my short 'list' of bitter people.

"My wife and I agreed during a weekend visit that I would have to return to college to get a new career. It wasn't just the new career that was of concern, but the much larger long-term worry of supporting my family. I wrote to 10-15 colleges, but only one offered encouragement – MIT.

"Four years were required for me to obtain the two degrees that I felt I needed to be successful as an aeronautical engineer. Those years included the birth of our second daughter. My family became a fixture, scurrying along the halls of MIT, one daughter riding on the foot pedals of my wheelchair, the other daughter in my arms, and my wife providing the motive power. In those four years I missed only one class – when Mary Margaret forgot to check my schedule – in spite of winter snows, two hurricanes, limitless rains, warm summers, and cold winters.

"I received my Bachelor of Science in June 1953, when the president of the college walked down the steps from the podium to present it to me. My second degree (aeronautical engineering) was received by mail in 1955 while we vacationed in Florida, visiting my in-laws before proceeding to employment in California.

"During the first six years of polio I was primarily on crutches, using the wheelchair to get between classes and buildings. I had to overcome feelings of dismay at my 'disability' and did so with the assistance of Mary Margaret and new-found friends. I realize now that I was given no unusual treatment while in school. Primarily I found that friends and neighbors were of inestimable value when I needed them, giving freely of their time and energies. The same has been true during my entire 53 years of living with the effects of polio.

"Yes, I suffer frustrations. I still dream of flying with my Navy associates. I cannot do many of

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the things I did earlier in my polio life. I am increasingly dependent on Mary Margaret, but I am learning to adjust, accommodate, and accept what I cannot do, and do the best with what I can.

"I know that my history is not necessarily unique, but hope I have conveyed some measure of what it meant to be an adult who contracted polio and the changes that were made and the changes that have been forced on me. Perhaps it will encourage others to carry on."

MARIANNE FINDLAY, OHIO

"The article on 'Healing Polio Memories' is absolutely marvelous. I have been preaching similar things for years, but, of course, I don't have the credentials to make the comments valid! Wonderful suggestions and good references. Thanks."

JUDITH WICHITA, KANSAS

"I am a person who had polio, a social worker by profession, and a retired (due to health) psychotherapist. I was very pleased to see the cover article in the *Polio Network News* regarding 'Healing Polio Memories.' In my experience, there is far too little emphasis placed on the psychological damage that polio caused. My greatest frustration is trying to find people who have actually dealt with the trauma and can talk of their feelings. Would you please ask any of your readers who have dealt with the trauma and who are willing to carry on a discussion via email to contact IPN (gini_intl@msn.com) so their name and email address can be passed on to me?"

ASSISTIVE EQUIPMENT

WINIFRED BETHESDA, MARYLAND

"The lead article in the Summer 2000 issue of the *Polio Network News* (Vol. 16, No. 3), 'Strategies for Management of Arms and Shoulders,' addresses many problems that I have faced as I grow older and as my polio-affected limbs have become progressively more unstable. One of the most daunting problems for me has been to equip my bathrooms so they offer effective assistance to me in using the toilet while maintaining an ordinary bathroom appearance and allowing typical usage by family and visitors.

"My husband was very suspicious of the Canadian-made Toilevator™ suggested in your newsletter, and no local plumber would admit to having experience in its installation. Even the local Access Remodeling firm, while familiar with the product, had no experience either with installation or client satisfaction. Local plumbing supply dealers carry mostly American Standard and Kohler fixtures, and these companies manufacture toilets with a so-called 'comfort' bowl rim height of 16 inches instead of the usual 14 inches. For someone with unsteady knees, 18 inches would be more helpful. After considerable telephone and Internet research, many false leads, and several dead ends, we have found solutions which I would like to share with other *Polio Network News* readers:

"TOTO USA carries several models of toilets having rim heights of 17-19 inches (ADA

compliant). TOTO toilets also have a revolutionary flushing system – quick, effective, and economical of water. TOTO USA, Inc., 1155 Southern Road, Morrow, GA 30260 (770-282-8686, custservice@totousa.com, www.totousa.com).

"Bemis Manufacturing Company carries a line of Medic-Aid toilet seats with a relatively standard appearance which ingeniously raise the seat height 2, 3, or 4 inches above the bowl rim. A listing of wholesale suppliers is available on their website, and the nearest local dealer can be recommended by the closest wholesaler. I found that the dealer did not keep the seats in stock, but my prepaid order was delivered to my home in less than a week. Bemis Manufacturing Company, P.O. Box 901, Sheboygan Falls, WI 53085 (800-558-7651, corp@bemismfg.com, www.bemismfg.com).

"I still need grab bars for stability in sitting and rising, but my life has become much simpler since we have had this equipment installed."

SHELDON CUMMING, GEORGIA

"After eight stitches to close a cut above my right eyebrow following a nasty fall, I visited my optician. I ordered a pair of prescription glasses with frames and lenses identical to those worn by people who participate in contact sports, e.g., racket-ball. The cost was about two-thirds of what I paid for my previous pair of glasses. (The looks I get are worth the price.) I wear them primarily when I'm on my feet, switching to standard (more fragile and expensive) glasses at other times.

"I also called my local fire department and spoke with the head of the rescue unit. I explained that from time to time I may fall and be unable to get myself back on my feet or possibly face other medical emergencies. He responded that I need only call, and they would appear through whatever door I had left unlocked, check me out, get me on my feet, and transport me to an emergency room, if necessary.

"I bought the cheapest, smallest cellphone I could find with the lowest available monthly rate, resolving to keep it in a pocket or on my belt at all times when home alone. I have never needed to use the service, but knowing it is available is of great comfort to me and my dear ones, especially for my wife who is able to leave me home alone without guilt."

SHOES

EDITH MINNEAPOLIS, MINNESOTA

"In the Winter 2001 issue of the *Polio Network News* you printed a comprehensive article on footwear. All the variations followed the basic orthotic principles applying appropriate modifications to the standard shoe design.

"I would like to add to the mix the molded 'space' shoe. Like many other 'molded shoes,' it is prepared on a plaster cast of the foot, so the fit is perfect. Unique because it does not apply any corrective pressures such as wedges, flares, etc., it provides a flat bottom and filler that builds up to fit the natural position of each individual's sole, arch, and toes. The effect

is like walking on your footprint in wet sand.

"I have been wearing molded shoes for 40 years in total comfort and stability. Prior to that, I had the usual pads, wedges, etc. which were designed to push my foot into a 'corrected' position. I never realized the discomfort and diminished stability they caused until I experienced the molded shoe.

"The original shoes were called Murray Space Shoes. In the early days, they looked like ugly clodhoppers. With other manufacturers paying more attention to style, and with the changes in footwear fashion, I now get different comments. It used to be, 'Where did you get those funny shoes?' and now it's, 'Hey, where did you get those neat shoes?'

"These shoes should not be mistaken for the 'molded shoes' listed in *The Yellow Pages*, which are usually based on the common orthotic principles applied to a standard foot design built on a cast of the foot. The philosophy behind these shoes is that the best comfort and stability comes from supporting your foot in its natural position. I have found this to be true.

"I did a quick check on the Internet and found that the Murray shoe is still being manufactured. A few phone calls in a local area should locate the shoe."

WHEELCHAIRS

SOLVEIG PARIS, FRANCE

"Linda Wheeler Donahue told us in *Polio Network News* (Fall 2001, Vol. 17, No. 4) about our fundamental fears of being in a wheelchair.

"Because I am in a wheelchair, I manage much better because my body rests. My former anxieties about falling have disappeared. Some years ago, I met a polio survivor who walks and said that she spends every two days in bed because of fatigue.

"Donahue also referred to our pride. I shall give you one example of being proud. I managed to buy a Motorcycle Honda Vision; these motorcycles have three wheels – one front wheel and two rear ones. I get inside by using a ramp and I ride from my wheelchair. I chose this motorcycle because I have to remain in my chair. I am obviously the only one with such a motorcycle in France, and my fellow motorcyclists and I usually enjoy ourselves at the red traffic lights in Paris."

EXERCISE

NANCY COOPERSBURG, PENNSYLVANIA

"In the Summer 2001 issue of *Polio Network News*, you asked for information from polio survivors about exercise programs that work for them.

"Since being diagnosed with post-polio syndrome in 1990, I have been swimming laps on an average of twice a week. When I began, I could only do one lap (42' pool) at a time, having to rest before going on, and could only swim for about ten minutes with many rest breaks. I now average 30 minutes of almost constant swimming (with occasional short breaks to catch my breath) – 5 minutes of slow warm-up laps, 20 minutes of intense swimming, then another 5 minutes of slow cool-down laps.

CONTINUED ON PAGE 10

"Although my fatigue levels have increased markedly and I now have leg weakness that does not allow me to walk long distances (I use a cane or wheelchair for shopping excursions, etc.), I am still able to walk unaided during routine days. (I am an editor, so most of my work is done seated). However, I believe that swimming has kept my muscles from deteriorating and has given me upper body strength that is helpful in maneuvering in and out of chairs, cars, etc. Also, I find that I usually get an energy lift after swimming, unless I am particularly fatigued before I start.

"I am still employed full-time, but work from home two days a week to save energy.

"I had polio in 1950, with paralysis of both legs. After a year of therapy (Sister Kenny method), I was able to walk unaided and returned to school. I had no discernable weakness nor limitations thereafter until I was in my mid-forties, when I began to experience fatigue, leg weakness, and leg muscle spasms."

PAM MAYWOOD, NEW JERSEY

"I had polio at four years of age and now am 55 years old. I have been teaching middle school for the past 32 years in the field of reading. I work part-time as a receptionist for a local dentist and volunteer at a local hospital one night a week.

"Currently, I am not experiencing post-polio syndrome, other than the aches and pains of middle age. I have exercised for the past 30 years, walking three miles in 45 minutes three times a week at a women's gym.

"However, I found the routine of changing clothes at my school and then hurrying to get to the gym a bit much. So, when they were selling one of their stationary bikes for \$30, I jumped on it (no pun) and began exercising at home.

"I now ride for approximately two hours, spread over four days. On Saturday and Sunday, I ride for 40 minutes, taking short breaks after 15-minute intervals. On Monday and Tuesday, I ride for 15 minutes. Before exercising, I stretch out, and, as I ride, I increase the tension. I always warm up and cool down.

"I exercise my upper body doing various exercises and using 5-pound weights, in addition to doing a range-of-motion regime for my arms since breast cancer surgery in January 2002. I realized, after the diagnosis, that the shape that you are in when something like this hits is very important.

"It is my feeling that the exercise program that I use not only tones me, but, more importantly, builds stamina which allows me to get through my daily activities."

ELEANORA LA MESA, CALIFORNIA

"I have taken an alternative path for managing the effects of polio that primarily affects only one leg. Over the last 55 years, I have learned that every professional in this muscle business recommends something different, so some of my success may be sheer luck.

"I exercise seven days a week. Since 1964, I have done aerobics and stretching exercises geared toward women; I supplement with two sets of 10 reps

of stretching of the muscles in the affected leg. I swim twice a week in an Olympic-size pool and, since 1987, I do 24 laps of the breast stroke and crawl, with a two-minute rest between each set of 8. I also lift free weights (about 8 pounds) and use weight machines twice a week (starting in 1997).

"From these activities, I have created a stronger leg that allows me to continue functioning as a field-based outdoors scientist. And, I continue to follow the recommendation of resting periodically in the field and in the pool.

"I am providing a time line and a narrative of my experience; some aspect of my experience may be useful to others.

"Some of my luck came from very stubborn parents who found a muscle physiologist, Rene Cailliet, MD, who was testing Sister Kenny's techniques at the Kabat Kaiser Institute, Washington, DC, when I emerged from the hospital following polio. Together, they designed hot whirlpool soaks and exercise, which was then followed by six or so years of tap, ballet, and gymnastics lessons. Until I became a teenager, I wore a brace on my skinny polio leg. For a dropped, wobbling foot, I had a tendon transplant and a zig-zag cut into my left Achilles tendon in 1957. Then, I led a normal, active life (including climbing mountains) doing daily aerobic and stretching exercises until post-polio kicked in around 1985.

"Through all the years, it was obvious that the left calf muscle was non-functioning. When I joined a local support organization in 1989, I followed the rec-

ommendation to save muscle function by reducing extraneous physical activity. I did not stop daily exercises because of cardiovascular issues, but I did worry. I got a handicapped placard and used a cane for long distance travel. I also continued to be an active field geologist, using meter-long soil augers as stabilizing crutches.

"I began wearing magnet footpads in my shoes and field boots in 1995. I tested them in the field because there is no scientifically accepted theory as to why magnetism should work. I found that without them, it took four days to recover physically from one full day of field work. With them, recovery took a couple of hours of sitting down. (Dr. Cailliet thinks the benefit of the magnets may be a result of the weight of the pads rather than the magnetism.)

"In 1997, my parents renewed contact with Cailliet. In the intervening years, he was Chairman of the Department of Physical Medicine and Rehabilitation at the University of Southern California and now is a semi-retired clinical professor at University of California Los Angeles (UCLA). He advised that he did not agree with recommendations to cut out exercising and walking so as to save what little function is still present. He told me to "... start exercising and see if you can pull in a nerve from someplace else."

"So, I joined a nearby gym where the trainer put me on a variety of Cybex machines. The soleus (the muscle that extends the foot) muscle started to enlarge, but I was still very unstable on rough surfaces.

"In 1999, I needed physical therapy following rotator-cuff surgery (probably from lifting weights incorrectly or exacerbating a weakened shoulder tendon). The therapist provided the important sentence: strengthen the surrounding muscles because it (missing muscle) is never going to get stronger.

"In 2001, we moved and I found a new gym that had personal trainers and I hired one for six weeks. His analysis of my gait found I was not putting weight on my polio leg, thereby creating the instability. He changed my gait, having me wiggle my hips to shift the weight from side to side ("wiggle like a girl"), added a new exercise for the soleus, started me on calf exercises, and introduced stretching of various muscles. The soleus got stronger and the instability decreased. I decided to add quadriceps exercises to avoid later problems with rising from the seated position associated with aging.

"This year I hired for two weeks a trainer who has a BS in muscle physiology. She added an exercise for the tibialis anterior (flexes the foot) and "core strengthening," a teaching of abdominal physiologist Paul Chek, that involves sucking in at the bellybutton and pulling up at the abdomen while doing stretches.

"Almost all of the instability is gone; when I get wobbly, a function of forgetting to wiggle, I actually feel muscles tightening in both legs to stabilize me. There is still no motion in the calf muscle; that one must be gone for good."

THOMAS J. BIRK, PHD, MPT

ASSOCIATE PROFESSOR, DEPARTMENT OF PHYSICAL THERAPY, PHYSICAL MEDICINE AND REHABILITATION, WAYNE STATE UNIVERSITY, DETROIT, MICHIGAN

"You are perceptive in that you mentioned that disuse may be more prevalent than overuse, particularly in recent years. Unfortunately, I don't comment on that extensively in the chapters I have written, since most data (for the writings) was collected on people who did, in fact, overuse already weakened motor pools. My writings go into what should be done to intervene these overburdened motor units.

"If there has been disuse, unfortunately, it can rapidly turn to overuse with improper quantities of exercise. Thus, the amount of exercise is pertinent to avoiding overuse. Also, the status of the motor units is critical before starting exercise. For example, an EMG/NCV test will entail the 'health' and number of working motor neurons/muscle fibers. This is important in knowing how to start with exercise. Also, past polio history is critical to knowing what levels of exercise to start. In the chapter out this month,¹ there is a section on exercise prescription and programming which addresses these issues. While exercise can be helpful, too much too soon or simply too much after extensive disuse, can be detrimental, especially if there is a history of neuromuscular disease/pathology." ■

¹ACSM's *Resources for Clinical Exercise Physiology: Musculoskeletal, Neuromuscular, Neoplastic, Immunologic and Hematologic Conditions* (ISBN 0-7817-3502-5, softbound, 304 pages, \$46.95) is available from Lippincott Williams & Wilkins (www.lww.com).

GINI appreciates the donations from these support groups ...

... to The GINI Research Fund.

New Jersey Polio Network (Martinsville, New Jersey)
Polio Epic, Inc. - Southern Arizona Post-Polio Support Group
Texas Polio Survivors' Association (Houston, Texas)
Tri-State Polio Survivors, Inc. (Sioux Falls, South Dakota)

... to the Gini Laurie Endowment.

Boca Area Post-Polio Group	Mississippi Polio Survivors Association
Central Indiana Post-Polio Support Group	New Hampshire Post-Polio Support Group
Colorado Post-Polio Connection	Polio Heroes of Tennessee (Nashville area)
Easter Seals Oregon (Roseburg Chapter)	Polio Survivors of Oklahoma
Indiana Polio Survivors Association, Inc.	Post-Polio Association of South Florida
Lansing Area Post-Polio Support Group	Post-Polio Partners (Weslaco, Texas)

2002 Calendar

JUNE 23 (1-4 pm) – **Symposium on Post-Polio Syndrome**, Schaetzel Center, Scripps Memorial Hospital, La Jolla, California. Speakers include Susan Perlman, MD; J. Lindsay Whitton, MD, PhD; and Sam Pfaff, PhD. Contact Mary Clare Schlesinger (760-741-5075, maryclare@cox.net).

SEPTEMBER 21 – **Post-Polio Conference – 2002: We're All in This Together**, Four Points Sheraton, Milwaukee, Wisconsin. Speakers include Frederick M. Maynard, MD and Joan L. Headley. Contact Post-Polio Resource Group of Southeastern Wisconsin (414-454-9093, www.pprg.org).

OCTOBER 19 – **Post-Polio Conference honoring Nancy and Bill Carter** with Joan L. Headley, Nebraska Polio Survivors Association, First United Methodist Church, Omaha, Nebraska. Contact Marian Barnett (402-341-0710, mjbarnett@att.net).

Can You Help?

"I am editing a book for Martha Mason, who will celebrate her 65th birthday in May. She contracted bulbar poliomyelitis in September of 1948, was placed in an iron lung, and was hospitalized for a year. In September 1949, she went home in her iron lung.

"The book is an account of her early years, her struggle with polio, and her life since. I suspect that she has lived longer continuously in an iron lung than anyone else in this country. Can you help me determine whether my suspicion is indeed a valid one?"

Charles L. Cornwell, Lankin Cursley Company, LLC, 56 Broad Street, Suite 2B, Charleston, SC (South Carolina) 29401 (843-853-8326, 843-853-2091 fax, lankincursley@bellsouth.net).

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