

POST-POLIO HEALTH

FORMERLY POLIO NETWORK NEWS

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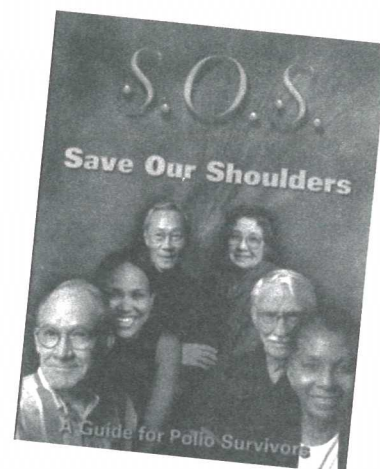
EXCERPTS FROM

S.O.S. Save Our Shoulders: A Guide for Polio Survivors

Jennifer Kuehl, MPT; Roberta Costello, MSN, RN; and Janet Wechsler, PT; Moss Rehabilitation Research Institute, Philadelphia, Pennsylvania

Many polio survivors report new symptoms as they age. Some of the more common symptoms include loss of strength, fatigue, muscle twitching, cramping, and muscle or joint pain. These symptoms, combined with muscle weakness caused by the poliovirus, often lead to problems with activities like climbing stairs or getting up from a chair or sofa.

When muscle weakness and/or pain is present in one area of the body, people often compensate by putting more stress on another area of the body. For example, polio survivors who have weak leg muscles often rely on their arms to assist with mobility-related tasks such as pushing off of the armrests of a chair when getting up or pulling upon the railing when going up a flight of stairs. This behavior can increase the risk for symptoms of shoulder overuse. These symptoms can include pain, swelling, weakness, and loss of motion or function in one or both shoulders.



Facts about Shoulder Problems

- Shoulder problems are one of the most frequent complaints in the post-polio population.
- Shoulder issues are also common among older adults without a history of polio, occurring in about 30% of people who are 60 years and older.
- Shoulder problems can increase with age and changing levels of physical activity.
- People who are involved in sports are not the only ones to suffer from shoulder problems.
- Shoulder problems are common in those with long-standing medical conditions such as post-polio syndrome, arthritis, spinal cord injury, stroke (CVA) or multiple sclerosis.

Our research has shown that polio survivors who have weakness in their legs or who are overweight are at high risk for developing shoulder problems.

Shoulder Problem Treatment Options

1. Rest
2. Cold Pack or Hot Pack
3. Massage
4. Ultrasound
5. Aquatic Therapy
6. Electric Stimulation
7. Anti-inflammatory medicines or cortisone injections
8. Pain Management at a pain clinic
9. Modifications (home/work; adaptive devices or equipment; lifestyle changes)
10. Surgery

And, education and exercise ...

The comprehensive, colorful 32-page booklet is based on research at Moss Rehabilitation Research Institute. The investigators were Mary Klein, PhD, Mary Ann Keenan, MD (now at the University of Pennsylvania) and Alberto Esquenazi, MD.

Want a copy?

S.O.S. Save Our Shoulders can be downloaded from www.einstein.edu/polioandmobility.

Internet not available?

Call Roberta Costello, MSN, RN, at 215-456-4993.

Diabetes and Post-Polio Syndrome: Conditions Which Are Chronic but Manageable

Jann Hartman, Baltimore, Maryland (jann@comcast.net)

It is estimated that 5.2 million Americans have diabetes and don't know it. Diabetes is more treatable when caught early.

If you have any of these symptoms — frequent urination, excessive thirst, extreme hunger, unusual weight loss, increased fatigue, irritability or blurry vision — see your health care professional.

I was diagnosed with post-polio syndrome in 1989, and I assumed that my extreme exhaustion was due to overusing my muscles. It should have dawned on me that it isn't wise to dismiss all symptoms as due to having post-polio syndrome. Last spring, during a routine visit to my physician, a simple blood test revealed an elevated blood glucose level over twice the normal amount. I, unfortunately, became one of the 18.2 million Americans who have diabetes.

Looking back, I now see I had several of the common symptoms of diabetes, including a family history. I was over my ideal weight, and since I come from a long line of short, heavyset women, I tended to think my weight was inherited. What I had inherited was a body type, not my weight. (Being overweight makes it more difficult for the body's insulin to change food into energy.)

My immediate response to finding out I had type 2 diabetes was to eliminate all sugars from my diet. My blood glucose numbers declined to under 200 mg/dl very quickly and to 110 mg/dl in a couple of months. The next step was to devise a low-calorie meal plan that I could live with and adjust as needed. Even though I was familiar with the American Diabetes Association's exchange lists for meal planning, my meeting with a Certified Diabetes Educator (or Registered Dietitian) was a great benefit as she helped adapt meal plans for my individual needs.

My family started reading labels to find the amount of sugars in products, and we were disturbed to find that

"high fructose corn syrup" was in more and more of the foods. We changed to low-fat dairy products and started to choose healthier fats, like extra virgin olive oil. Maintaining glycemic control is also very important for those of us with diabetes. I use the glycemic index (GI).^{*} My goal as a diabetic is to use this "tool" to keep my blood glucose levels as normal as possible.

Complex carbohydrates (whole grains, fruits and vegetables), proteins (lean meats, fish, poultry and soybeans) and fiber are very important in our diet. I found that, like most people, I needed more fiber. (The average person only eats about half of the 20 to 35 grams of fiber they should eat each day.) I began to substitute whole grains, brown rice, wild rice, various beans, legumes and nuts for less nutritious alternatives. It was a pleasant surprise to find I could add small amounts of sweets back into my dietary plan and still keep my blood glucose numbers at the desired levels. Some fresh fruit on whole grain cereal, low-sugar jam on whole grain bread, and a little bittersweet (dark) chocolate on occasion, were welcome additions to my new nutritional plan.

I had been eating low-calorie meals for years, but I was unable to lose any weight. My physician told me that it was due to the high blood glucose levels. As my glucose levels fell, I slowly lost weight. I now eat six small meals a day (3 meals and 3 planned snacks).

^{*}The Glycemic Index (GI) is a listing of carbohydrate foods ranking them according to how quickly they are changed to glucose and thus increase the glucose level in the blood. (More about this in future issues.)

Telling Stories

Joan L. Headley, MS, Executive Director, Post-Polio Health International, Saint Louis, Missouri
(editor@post-polio.org)

Telling your story, as a polio survivor, has several benefits. Remembering and making peace with the past is healing. Telling your story allows you to acknowledge the many people who assisted you through the years. And telling your story can help others.

When the worldwide coalition of the UN, WHO, CDC, USAID and Rotary International succeeds in eradicating the poliovirus, your story will be an important contribution to the record of the polio epidemics.

READING STORIES

By reading the stories of others, you can easily explore your past and “write” your own story. Each description of a rehabilitation unit, a classmate’s reaction and an overheard comment by a parent registers an internal, “Yes, that’s how it was,” or “No way.” There is as much value in finding the differences in your experience (your individuality) as in finding the commonalities, those connections that make you feel part of a special group.

READY TO READ?

Walking Fingers: The Story of Polio and Those Who Lived It, edited by Sally Aitken, Helen D’Orazio and Stewart Valin, was launched in Westmount, a suburb of Montréal, Canada, in late March. The 225-page paperback was published by Véhicule Press (www.vehiculepress.com). Liberally sprinkled with well-identified historic photographs, the book contains end-

continued on page 4

Diabetes and Post-Polio Syndrome

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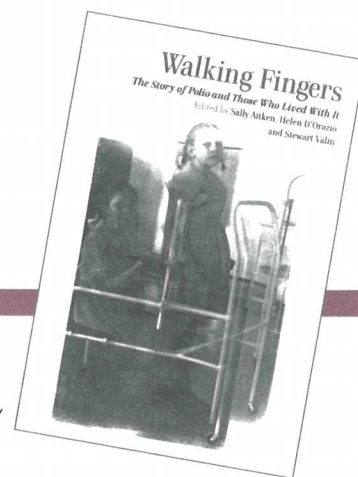
I use smaller luncheon plates since they make the portions appear larger. At a restaurant, I will share an entrée, or bring half of it home with me.

So far, I haven’t switched to artificial sweeteners. My decision is a personal preference to nourish my body with natural foods. I’d rather use a small amount of pure maple syrup in my muffins than use something artificial. I don’t drink soft drinks or juice anymore and prefer filtered water or unsweetened teas (sometimes flavored with lemon).

I am taking an oral diabetes medication, not insulin shots, and am using my glucose meter daily to monitor my

progress. My health care professionals are pleased with my progress and, I’m very thankful that my choices seem to be working for me.

How has my new lifestyle affected my post-polio symptoms? I am pleased that I have much less fatigue. While I still take a nap when I am tired, I am no longer taking a two-hour nap every afternoon. I have not driven for the past couple of years since I was unsure of my reactions. Fortunately, I have not needed to drive, and I am less fatigued now when riding in a car, when previously it was very stressful. I now feel in control of my emotions and in better health than I have in years. ●



Telling Stories

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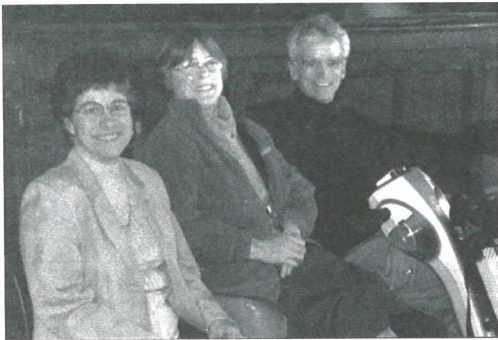
Polio Stories Featured on PBS ...

KERA Dallas/Fort Worth is presenting a co-production of Texas Scottish Rite Hospital for Children and Ken Mandel Productions, "A Fight to the Finish: Stories of Polio."

Check your local listing or schedule at www.kera.org/tv/productions/fight.

notes, bibliography, index and post-polio resources in Canada.

The personal stories are arranged chronologically based on the year of onset (1924-1984). Doing so gives a small glimpse of the succession of limited treatments used to treat acute poliomyelitis. The stories, as edited, feel honest, conveying the sense that this *is* their story and their analysis (although limited) and not the story they *think* is the typical polio story.



Editors of *Walking Fingers*: (left to right) Helen D'Orazio, Sally Aitken and Stewart Valin, members of Polio Québec (www.polioquebec.org/fr), a group founded in 1984.

Story after story lauds the contributions of Neil Cashman, MD, and Daria A. Trojan, MD, physicians at the Montréal Neurological Institute and Hospital. (Cashman is now in Toronto and Diane Diorio, MD, a neurologist, is working with Dr. Trojan.) Many of the survivors have accepted the wisdom of respecting and working with a knowledgeable physician, while educating and proactively helping themselves.

Dr. Trojan contributed the concise chapter about post-polio syndrome. Other chapters include a history of polio in Canada and the Canadian vaccine story which involves Paul Martin, Sr., the father of the current prime minister. Both father and son had polio, and the book contains an interview by the editors with Paul, Jr., although it is attributed erroneously to another.

Parts Three and Four provide the points of view of health professionals and family members. "Maybe My Dad

Didn't Go to War, but He Fought One of the Great Battles of the Century" is editor Stewart Valin's heartfelt tribute to his father and the story from which the book title was extracted. The post-polio literature is lacking in stories written by others involved in our polio history and these small sections attempt to correct this.

Editor Helen D'Orazio contributed the chapter about Sister Kenny and her story — "I Am More Than My Polio" — as a polio survivor whose arm was affected and who lived in a family where polio was never discussed.

The impetus for *Walking Fingers* was *Histoire vécu de la Polio Québec* published in 2000 by Carte Blanche and sold by Polio Québec (www.polioquebec.org/fr/livre.html). Polio survivor Sally Aitken, whose story is not included, was the force behind both books as she served as visionary, interviewer and editor. Aitken's personal polio experience, '60s individualist spirit, years of involvement in post-polio advocacy, willingness to allow others to have a voice, and her recent battles with benign brain tumors uniquely qualified her to initiate and complete the project. ●

Walking Fingers: The Story of Polio and Those Who Lived It (ISBN-1-55065-180-3) is an excellent addition to the literature documenting Canada's polio past. Copies may be ordered by your local bookstore for US \$18.95/CAN \$24.95 or at www.vehiculepress.com.

Post-Polio Breathing and Sleep Problems Revisited

Judith R. Fischer, MSLS, Editor, *Ventilator-Assisted Living*, and Joan L. Headley, MS, Editor, *Post-Polio Health*

"Post-Polio Breathing and Sleep Problems" was published in the fall of 1995 (Polio Network News, Vol. 11, No. 4). As a result of the continual flow of phone calls and emails from polio survivors and family members about this life and death topic, Judith Fischer, editor of Ventilator-Assisted Living (our other quarterly newsletter), and I decided to revisit and revise the original article. Our goal is to educate and to clarify misinformation about breathing problems of polio survivors. —Joan L. Headley, Editor, Post-Polio Health (ventinfo@post-polio.org)

New breathing and sleep problems in aging polio survivors can be insidious and often go unrecognized by either polio survivors, their family members or their health care providers. Polio survivors may have weakened breathing muscles as a result of the initial damage by the poliovirus; the lungs themselves were not affected. Those who were in an iron lung during the acute phase should be aware of the potential for developing problems later in life and educate themselves in order to recognize important signs and symptoms which may indicate underventilation which may lead to respiratory failure. Even those who did not need ventilatory assistance during the acute phase may also be at risk for underventilation and should be aware of problems with breathing and sleep.

Underventilation (hypoventilation is the medical term) means that not enough air reaches the lungs to fully inflate them. The result may be too little oxygen and too much carbon dioxide (CO₂) in the blood. Underventilation can be caused by one or more of the following: weakness of the inspiratory muscles (mainly the diaphragm and rib muscles) for breathing in, weakness of the expiratory muscles (the abdomen) for breathing out and producing an effective cough

to clear secretions, scoliosis (curvature of the spine), and sleep apnea.

Other factors contributing to a polio survivor's breathing problems are a history of smoking, obesity, undernutrition, and other lung diseases such as asthma, bronchitis and emphysema.

Vital capacity (VC) is the volume of air that can be expelled after taking a big breath and is a measure of how well the lungs inflate. VC normally decreases with age, but this decrease in VC is more serious in an aging polio survivor with weakened breathing muscles. Many polio survivors had impairment of their inspiratory muscles, and the normal changes due to aging may cause them to lose VC at a greater rate. Polio survivors may not experience symptoms of underventilation until their VC falls to 50% or less of predicted (normal).

Signs and symptoms of underventilation during sleep include:

- ♦ inability to breathe when lying flat — the need to sleep sitting up (orthopnea)
- ♦ inability to fall asleep and/or to stay asleep (insomnia)
- ♦ anxiety about going to sleep
- ♦ restless fragmented sleep with frequent awakenings

Thanks to
Lisa Krivickas, MD,
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Hospital, Boston,
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E.A. Oppenheimer, MD
(retired), Los Angeles,
California; and
Mark H. Sanders, MD,
University of Pittsburgh
Medical Center,
Montefiore University
Hospital, Pittsburgh,
Pennsylvania, for their
reviews of this article.

continued on page 6

- ◆ shallow breathing or pauses in breathing
- ◆ awakening from sleep with choking sensation
- ◆ nightmares, night sweats, bedwetting or need to urinate frequently
- ◆ excessive daytime sleepiness
- ◆ morning headaches
- ◆ worsening mental status and impaired memory, concentration and cognition

Other symptoms may include:

- ◆ shortness of breath on exertion
- ◆ fatigue or exhaustion from normal activities
- ◆ claustrophobia and/or feeling that the air in the room is somehow bad
- ◆ general anxiety
- ◆ difficulty in speaking for more than a short time
- ◆ low voice/volume speech with fewer words per breath
- ◆ use of accessory muscles, such as neck muscles, to breathe
- ◆ weak cough with increased respiratory infections and pneumonias.

Polio survivors experiencing one or more of the above signs and symptoms should seek a respiratory evaluation (simple and noninvasive pulmonary function tests) by a pulmonologist, preferably one experienced in neuromuscular disorders. Physicians are listed in the *Resource Directory for Ventilator-Assisted Living* (www.post-polio.org/ivun/d.html).

Pulmonary function tests should include the following measurements. The values that indicate a warning sign for respiratory problems are in parentheses.

- ◆ VC — upright (<50%)
- ◆ VC — supine (a drop of >25% from upright to lying down)
- ◆ MIP — maximum inspiratory pressure (<60 cm H₂O)
- ◆ MEP — maximum expiratory pressure (<60 cm H₂O)
- ◆ peak expiratory cough flow (<300 L/min)
- ◆ end-tidal CO₂ (>45 mm Hg)
- ◆ overnight oximetry may be prescribed to detect episodes of oxygen desaturation (<88% during sleep).

Management of breathing and sleep problems can be achieved largely through the use of nocturnal noninvasive ventilation, commonly in the form of small, lightweight bilevel positive pressure units. The units have a long tube/circuit that attaches to a mask (nasal, facial or oral), nasal pillows or mouthpiece worn during sleep. Polio survivors may find themselves gradually extending periods of ventilator use, perhaps during a daytime nap. Some polio survivors may need to use a volume ventilator to guarantee delivery of a larger volume of air than a bilevel unit can provide. Noninvasive ventilation may eventually fail, and invasive tracheostomy positive pressure may be necessary.

Treating underventilation with oxygen therapy instead of assisted ventilation can lead to respiratory failure and death because supplemental oxygen

Question: *Why would my physician add oxygen to bilevel positive pressure ventilation, such as BiPAP®, if there is no underlying lung problem?*

Answer: It would be extremely worthwhile to request that PHI members who use a ventilator due to post-polio breathing problems ask that their physicians explain their oxygen advice so we can all benefit, or at the very least develop a list of justifications that can be reviewed. The question is simple and can be stated, "The use of oxygen for people with neuromuscular disease without any lung disease or pneumonia is a subject of considerable interest, and some controversy. Please explain why oxygen is advised as part of my post-polio treatment plan." Send your physician's comments to PHI (editor@post-polio.org).

A physician might advise adding oxygen to BiPAP® when there is no underlying lung problem, if the person is traveling by air, where the air has a lesser concentration of oxygen. Another possibility is that the bilevel device is not satisfactorily set up and not adjusted from time to time. If that is the case, the oximetry or ABG oxygen saturation might be below 95% and the physician might prescribe oxygen. The advised response to this, of course, would be to increase the IPAP (inspiratory positive airway pressure) to improve ventilation, and then to re-check the oxygen level until it stayed at 95% or better while using ventilation.

Reliable small portable oximeters, such as the Nonin Onyx® 9500, can now be purchased on the Internet without a doctor's prescription. Having one at home to monitor assisted ventilation would allow minor adjustments of the IPAP as needed — if the treating physician agrees. Prices vary considerably on the Internet so search carefully. Most often an oximeter is not covered by health insurance.

Edward Anthony Oppenheimer, MD, FCCP, Member of PHI's Medical Advisory Committee
Pulmonary Medicine (Retired, consultation only), Los Angeles, California (eaopp@ucla.edu)

Question: *I am a polio survivor who uses a ventilator during the night. My physician wants me to undergo a colonoscopy, but I am worried about anesthesia for this procedure. Should I proceed?*

Answer: A colonoscopy is an important test that can be performed safely on polio survivors who use assisted ventilation. In your case, I suggest a pulmonary evaluation before the procedure to document your respiratory reserve and a candid discussion with whomever is performing the colonoscopy. Sedation is needed because this procedure is uncomfortable. Usually a gastroenterologist does the colonoscopy with a nurse giving the sedation and supposedly monitoring the patient.

The colonoscopy should be done in a hospital (not an outpatient surgery center) with an anesthesiologist in attendance and administering the sedation. The procedure can be in the hospital's GI lab or in an operating room. The GI lab has adequate monitors; someone (the anesthesiologist) needs to watch you closely and to be careful with sedation. Afterward, you can be observed for respiratory problems in the regular recovery room and, if necessary, go to a "monitored" bed for an overnight stay — one night should be enough. You can bring and use your own home ventilator, just be sure this is discussed with the hospital staff ahead of time. I have received this question several times and after dispensing the above advice, I have not heard of any problems.

Selma Harrison Calmes, MD, Member of PHI's Medical Advisory Committee
Chair, Department of Anesthesiology, Olive View/UCLA Medical Center (shcmd@ucla.edu)

can blunt the function of the brain's respiratory control center. However, polio survivors who use assisted ventilation and have additional medical problems such as COPD, pneumonia or heart problems, or who are undertaking long airplane flights, may benefit from oxygen therapy under careful supervision.

Polio survivors may also have sleep apnea contributing to underventilation. Sleep apnea, an interruption of breathing during sleep, can be obstructive,

central or mixed. Obstructive sleep apnea (OSA) is the most common form and is prevalent in the general population. The standard test for OSA is a sleep study; the standard treatment is the use of a continuous positive airway pressure (CPAP) unit with a nasal mask or nasal pillows during sleep. However, polio survivors with both weakened breathing muscles *and* sleep apnea should use bilevel positive pressure or volume ventilation, not CPAP. ●

Options for Long-term Care for US Polio Survivors

Matt McCann, Lombard, Illinois (800-959-7055)

We face many involuntary risks, so we buy homeowner and auto insurance, although the chance of something happening is very low. If we reach the age of 50, half of us will require some type of long-term care in our lifetime — making this the biggest involuntary risk we will face in life.

Long-term care is care required in our own homes, in adult daycare facilities, assisted living facilities and skilled nursing facilities (nursing homes). The cost of long-term care is a financial burden for many because traditional health insurance or Medicare does not pay for it. (Most health insurance plans and Medicare will only pay up to 100 days of skilled care in a facility and only if you are improving.)

Long-term care insurance is available and will pay for all areas of care, either at home or in a facility. But, the problem with most long-term care insurance plans is that you must “health qualify” to get a policy. Many of the limitations caused by prior polio can disqualify you from long-term care insurance plans.

For some people who had polio, an insurance company called Penn Treaty Network America (www.penntreaty.com/ProdpenntreatyV2) will consider some limited benefits pending a home interview done by a RN. Based on your medical records and the home interview, the company will determine if you are eligible.

This option from Penn Treaty would provide \$100 per day for up to two years of care with 5% compound inflation. In 15 years, you would have \$200 per day with the inflation protection.

(Because of pricing, this is better for people under 65 years of age.) A rider, at extra cost, for some limited home-care is also available pending health approval. A 59-year-old in Illinois, for example, could get this plan with the limited homecare rider for \$1,097 per year.

For people who may not health qualify for the above policy, a company called Homeward Bound (TLC Services, Inc., www.tlcservicesinc.com) has a program that provides homecare services for cooking, cleaning, bathing, dressing, shopping, laundry, housekeeping, toileting, taking a person to and from the doctor, medication management and other “non-skilled” needs. This program, available in most states, is not an insurance contract nor is it an insurance policy. It as a maintenance agreement, such as the one you have on your refrigerator. But, this “fee for service” contract is for you.

Any person can qualify for this program from Homeward Bound as long as they are not in a nursing home or other facility or suffering from a terminal illness.

For a yearly fee (paid annually, semi-annually, quarterly or monthly), you can buy a certain number of “home-care hours” for each “event.” An event is any reason you need help due to illness, age or injury. You could have many events in one year or you could have no events in a year.

A person who had polio may purchase up to 720 hours of care per event. (There is a maximum number of hours for each diagnosis.) Remember, this is not per year but for each need. If you run

McCann is a national long-term care insurance consultant and sells long-term care insurance plans from all the top insurance companies including plans from Penn Treaty Network America and Homeward Bound.

out of hours for one event, your hours will restore in one year (e.g., one year after the hours expire.)

While you are waiting for the hours to restore, you can keep the same caregiver at a discounted rate, but you will pay the fee. In the meantime, whether you recover or not, if you have another "event," you have a new set of hours to use.

If you do not recover and have an ongoing need, every other year you will get another set of hours for that need, as stated in the agreement.

An example: As a 56-year-old person who has post-polio syndrome, you purchase 360 hours per event at a cost of \$1,172.49/ year or \$97.71/month.

You fall and break a leg. You have 360 hours available (usually scheduled in four-hour shifts) for home care, so you or a family member contacts Homeward Bound and an RN case manager assists in developing a "plan of care." Homeward Bound contracts with health care agencies in advance and uses those companies to select the caregiver. However, if you don't like a person who is hired, you can request a new person.

You recover and after 53 days (212 hours when using 4 hours per day) you no longer need care. Five months later, you require heart surgery and are recovering at home. Since this is a new event, you have another 360 hours available.

To continue the example, next year you have a stroke and it is decided that you will always need care. For this event, you will use up all of your

hours and then go on private pay at a discounted rate. But, another 360 hours becomes available in one year. If you fall and break a hip and need care, this is considered a new event and a new set of hours is available.

Homeward Bound also can maintain full review and coordination of other services (i.e., physical therapy, respiratory therapy, infusion therapy, etc.) under your "Plan of Service."

Should you need an RN/LPN or other specialist, Homeward Bound's service coordinator can make the arrangements for you on an individual fee basis.

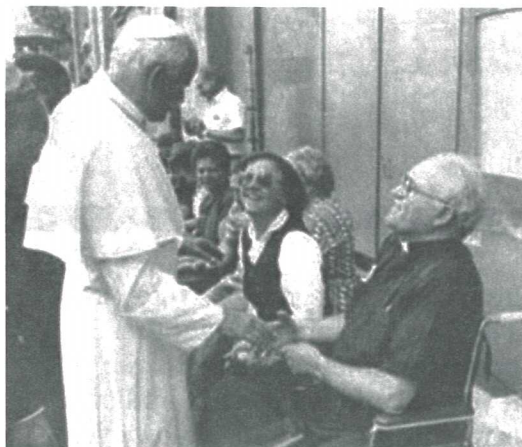
This program is guaranteed renewable and may not be cancelled except for nonpayment or for reporting false information on the application. ●

PRINTER APOLOGY: The last sentence of "Report from the 2003 recipient of The Research Fund Award: Participants, Their Health Status and Data about Menopause" in the last issue of *Post-Polio Health* (Volume 20, Number 1) was incomplete.

The sentence should read: "In addition to professional dissemination, a final report to Post-Polio Health International will be available by the end of February 2004 along with a new website dedicated to this project and its findings. Claire Z. Kalpakjian, PhD, Project Manager, Model Spinal Cord Injury Care System, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, Michigan, reports that the website is not yet ready."

If you would like a corrected copy of the article, compliments of our printer, please contact Justine Craig-Meyer (314-534-0475, info@post-polio.org)

Fr. Bob Ronald, SJ, Retires



Father Ronald with the Pope in 1984 at St. Peter's Square, Rome.

2003 was a memorable year for Fr. Bob Ronald. He celebrated the 30th anniversary of Operation De-Handicap (ODH), published an anniversary book highlighting the work of ODH, and received a Medical Service Award from Taiwan President Chen Shui-Bien, and he retired from ODH (<http://odh.oceantaiwan.com>).

Fr. Ronald recalls, "When I got polio in Taiwan in 1958 there were no rehabilitation facilities. Thirteen years later, when I first began work as a vocational

rehabilitation consultant in Taipei, there were several good rehabilitation facilities offering therapy, but few, if any, follow-up services. Rehabilitation patients often went home to vegetate, not knowing where to go or what to do. They were in need of guidance, information and referral. So I began to dream of starting such a service myself, if only I could find someone motivated and qualified enough to help me." That someone was an old friend, Ignatius Huang.

After 31 years as a consultant for vocational evaluation at the Veterans General Hospital, Fr. Ronald is now an English consultant at the Jesuit-run Kuangchi Program Service. ●

Read the complete story at www.post-polio.org/netwkg-ronald.html.

Fr. Ronald's new address: Kuangchi Program Service, PO Box 108-108, Taipei (106) Taiwan, ROC (+886 2 2771 2244, ext 215,

Gertrud Weiss Receives the German Award of Merit



Gertrud Weiss in her summer home near Rosenheim (1997).

In March, Gertrud Weiss, Honorary Board member of Post-Polio Health International, received the German Award of Merit (Bundesverdienstkreuz) from Federal President Johannes Rau for her service to polio survivors.

The Bundesverdienstkreuz is the sole state award of merit given by the Federal Republic of Germany.

Gertrud was very active in the Bundesverband Polio e.V

in its early development and wrote two book and numerous articles about the late effects of polio to help spread the word in Germany. Regrettably, Gertrud died in April, just prior to her 84th birthday. ●

Post-Polio Directory 2004 has been mailed to those who pre-purchased a copy and to all Contributor and Sustainer members. The *Directory*, listing clinics, health professionals, and support groups and individuals with knowledge about the late effects of polio, is also online at PHH's site: www.post-polio.org/ipn/locate.html.

Special Thanks

We thank our supporters for their contributions to our work ...

In memory of ...

Lorna Eby	Margene Elaine Kohn
Mary Ann Farrington	Gini Laurie
Arlo Felland	Michael Lowen
Violet L. Gormly	Corley H. Martin
Annie Hartman	Eleanor E. Orlop
Clela Headley	Dale Pahl
Ira Holland	Douglas Schultz
Mary R. Houde	Armand Savaria
Marie Vienneau Iliff	Peggy Wathen

and to The Research Fund ...

In memory of ...

Helen Estus Cason	Bernice A. Rice
Herbert Martin	Armand Savaria
Gabriel Nava	

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Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors
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DEADLINE JULY 1, 2004

CALL FOR PRESENTATIONS

for the

Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: STRATEGIES FOR LIVING WELL

to be held June 2-4, 2005, Saint Louis, Missouri.

Submit your presentation for review online at
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Or, contact Justine Craig-Meyer (314-534-0475;
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Need a scooter? Need orthotics?

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