

Promoting Positive Solutions

Post-Polio Health International introduces a new column dedicated to questions about relationships and other aspects of living with the late effects of polio.

Question: *I am getting weaker and my friends and family encourage me to find “the answer” and get irritated with me when I say there isn’t one answer. I think they just want me to be like I was.*

Response from Stephanie T. Machell, PsyD: Yes, that’s exactly what they want! It’s hard for them to see you getting weaker. Because there’s nothing they can do to change things, they feel helpless. And because the model most of us have for being sick is one of a “disease” that has a “cure,” a condition like post-polio syndrome is hard to understand.

Their irritation won’t change your condition or improve your relationships, and certainly won’t help them (or you) to feel any better. Tell them this in a nondefensive manner. If you normally use humor, you can say this in a funny way.

Depending on your relationship with them and their coping style, there may be simple things you can do to help them to feel less helpless. You don’t want or need to become the “educator” for your friends and family about post-polio syndrome or disability, but it may help them to have some information.

Talk to them about your own frustrations about what is happening, and empathize with their frustrations. Finding ways of enlisting their sup-

port may help them to feel less helpless, as well as provide you with increased support, and, possibly, assistance that will help you to conserve energy and deal with weakness.

Finding ways to have fun together that don’t further weaken or fatigue you will help you all feel better.

Question: *I recently attended PHI’s 10th Conference in Warm Springs, Georgia, with my spouse. I loved every minute of it. However, since we were in unusual surroundings, he had to assist me more, and I could see how tired he was. He didn’t complain; I felt guilty. We haven’t talked about this, yet. Should we? Do you have any suggestions as to how to approach the topic?*

Response from Rhoda Olkin, PhD: This is a great question, because it incorporates so many aspects of disability into the question. I hear in this question issues about gender, traveling outside one’s own accessible environment, the way disability gets incorporated into the partner relationship, asking for and receiving help, and deciding how to expend one’s precious energy. So let’s tackle these as best we can.

First, women have trouble asking for and accepting help. Studies on gender differences when a spouse incurs a disability indicate that when the male

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Stephanie T. Machell, PsyD and Rhoda Olkin, PhD will answer your questions in future issues of *Post-Polio Health*. Please send them to info@post-polio.org. See page 10 to find out more about Drs. Machell and Olkin.

PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

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Special thanks ...
Brian Tiburzi

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PHI is sending PHI Membership Memos via email. Be sure to set your spam filter to receive emails from info@post-polio.org.

Worthy of Note

We publish the last in a series of articles about surgery. The series was precipitated by rumors that “no polio person should have surgery.” I think we have sufficiently examined the pros and cons and, more importantly, have given you tools to use in making the best decision for you. Comments about anesthesia are not included to cause fear, but to provide information to alleviate fear.

Call for Proposals

PHI is seeking proposals from researchers affiliated with an institution who are interested in studying an aspect of the cause(s), treatment and management of problems of the late effects of poliomyelitis.

The Research Fund will award \$25,000 in the fall of 2010 to a recipient selected by a panel of experts that includes representation of people with disabilities.

The grant's funds can be used to initiate new research, to continue notable projects, or to combine with other resources to complete relevant research.

The criteria for applying are online (www.post-polio.org/res/rfcall.html). The process is conducted in two phases. Applicants from Phase I will be screened and select grants will be asked to complete Phase II.

Deadlines

Receipt of Phase I	Friday, March 5, 2010
Invitation for Phase II	Friday, May 21, 2010
Receipt of Phase II	Friday, September 24, 2010
Award Announcement	Friday December 17, 2010

Report Coming Soon

The Italian team from University of Insubria Medical School (Microbiology and Virology), Varese, and University of Verona Medical School (Neurological Sciences), Verona, led by Antonio Toniolo, MD, continue their studies into developing extremely sensitive tests for detecting polioviruses (and other enteroviruses). The method is used to detect fragments in individuals, such as polio survivors, their family members, and healthy adults. A report is pending.

Joan L. Headley, Executive Director, PHI

The Mohs and Me

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

“If you have to have cancer,” the nurse said, “this is the one to get.” I had just been diagnosed with basal cell carcinoma (BCC), a form of skin cancer occurring more than any other cancer — over a million new cases in the USA annually.

The nurse is right; compared with others, this is an “easy” cancer. It’s normally slow growing, and its cure rate using Mohs is 99%.

Cancer had not occurred to me. One day as I was seeing my internal medicine physician on another matter, his eagle eye spotted what I considered a small, sort of doughnut-shaped red blemish about three-fourths an inch under my right eye. “Looks like cancer,” he said and had someone make an appointment for me to see a dermatology surgeon.

🌀 GETTING STARTED

The surgeon was ready to do my biopsy when I got there. I asked what local anesthetic he would be using and explained it was important to reduce the dose for me to avoid the polio-related weakness and serious side effects I encountered in the past. He measured the lesion — 6 mm, about the diameter of a pencil eraser. As I sat in my power chair, he deadened the area with 1 cc of lidocaine, took the required slice for the biopsy, and the entire procedure was over in minutes. The nurse scheduled me for surgery in ten days, in case the biopsy proved I had cancer.

I had left some excellent anesthesiology material from PHI with the surgeon. When his nurse called to confirm my BCC, I told her I was concerned about using lidocaine, knowing it affects nerves. I explained that the right side of my throat is paralyzed and I cannot swallow solids (among other swallowing difficulties). I added that my neck and upper body are considerably paralyzed, and my breathing is compromised by weak muscles. I wanted to be sure we got this anesthesia thing right. She replied that the doctor had read the articles and

deemed the information “irrelevant.” I said a silent “goodbye” to this doctor.

🌀 GETTING HELP

Immediately I wrote Selma Calmes, MD, retired anesthesiology expert, explained my situation, and asked for advice.

I called the office of the dermatologist who had removed my husband’s skin cancers, David Watts, MD, described my physical limitations to his nurse, and asked for an appointment to talk with him. She said she’d get back to me.

Four things happened that told me I had hit pay dirt:

- Dr. Watts called me back, himself.
- He had already searched for and read available articles pertaining to the anesthesia problem his nurse relayed to him.
- When I told him I had written Dr. Calmes for advice, he asked me to have her send a copy of the answer to him, as well.*
- Before he hung up he said, “I’m really glad you called me, Nancy.”

Dr. Watts’s response almost made me weep. It made one very important truth clear to me: It is possible to find doctors who possess “that special quality.” A day later I called for an appointment to see Dr. Watts. The nurse asked me to have the biopsy slides sent to their office and said she’d get back to me.

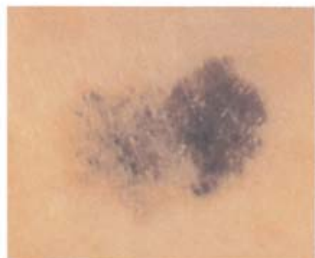
Again, Dr. Watts returned my call. I told him it frightened me to think of losing more of my ability to swallow

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Basal cell carcinoma
Used with permission of the
American Academy of Dermatology

*Carter’s question and Dr. Calmes’s advice is at www.post-polio.org/net/help12.html



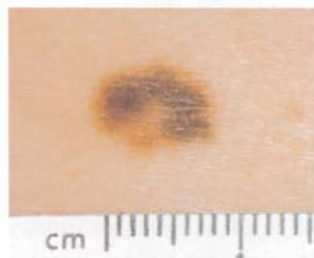
Asymmetry



Border irregularity



Color



Diameter

Melanoma

Most moles are harmless, but watch for a change in appearance using the ABCD rule.

or speak or breathe by not making judicious decisions regarding the local anesthetic to be used. I had experienced problems before from anesthetics administered in “nothing” procedures, and I wanted to be sure what he used didn’t present more of a risk than the cancer did. I mentioned I’d been having spasms in my throat since the biopsy.

MOHS

Dr. Watts is a board-certified dermatologist who is fellowship-trained in Mohs surgery through an accredited program at the American College of Mohs Surgery. He completed two years of Mohs training in addition to his three-year dermatology residency. Dr. Watts performs over 50 Mohs surgeries a month.

Mohs micrographic surgery is a technique devised in the 1930s by a University of Wisconsin medical student named Frederic Mohs and refined by others over the years. Here’s what happens: A surgeon injects a local anesthetic, removes the tumor and a thin layer of surrounding tissue, constructs a schematic map, and carefully checks the tissue while the patient waits for results. In a process that can take over an hour, the tissue is frozen and then examined under a microscope. If cancer cells remain in the undersurface or edges, the surgeon takes another thin layer, pinpointing those malignant sites for examination, and repeats this process until no cancerous tissue remains.

In two-thirds of the cases, surgery on small-to-medium-sized cancers can be completed in only one pass. But since there is no way to predict exactly how extensive the cancer is, it could be necessary to repeat the procedure

numerous times, thus requiring multiple injections of anesthetic. Mohs is usually done in the surgeon’s office, where he has the required surgical and laboratory facilities.

GETTING INFORMATION

By the time we met, Dr. Watts and I had both read Dr. Calmes’s thoughtful reply to my plea for help. She offered a number of observations and suggestions that Dr. Watts helped me understand:

- Since we have no data regarding the effects of local anesthetics in polio-damaged peripheral nerves, the surgeon needs to consider the concentration of local anesthetic used to deaden the area (with lidocaine being the best option at this time) and what to do about adding epinephrine, used to decrease bleeding during surgery and to prolong the numbness.
- Because it is remotely possible for some of the local anesthetic injected at the site to travel down through the infraorbital foramen (a tiny canal in the front surface of the upper jaw bone), this could block some motor fibers to the tongue and throat area. Such an event might be avoided by injecting a smaller-than-usual amount of the local anesthetic and keeping the patient in a head-up position.
- Using the least possible amount of anesthetic and epinephrine while proceeding as quickly as possible would be best. Having the patient remain in a position as upright as practical would mean less bleeding and would assure better function from polio-damaged breathing muscles. Dr. Calmes then emphasized the necessity for doing all of this in a way that fulfills the surgeon’s need to work within his comfort zone, as well.

For more information:

American College of Mohs Surgery
— www.mohscollege.org

American Academy of Dermatology
For explanations, demonstration video and list of surgeons
worldwide — www.aad.org

GETTING READY

Dr. Watts began by discussing my specific polio needs with me, one by one. Up to this point, everything had been done with me sitting in my power chair. I didn't realize this surgery is usually performed with the patient lying on an operating table. I had not been supine in twenty years. When I mentioned this to Dr. Watts, he said this was "no time to start," and determined he'd do the surgery with me in an examination chair.



"Crutch" for chin

We rehearsed. As Dr. Watts slowly reclined the chairback to about 15 or 20 degrees off of vertical, we kept my air passage open by elevating my chin with my "chin crutch." We supported my shoulders (which have a tendency to dislocate) with pillows and a sash wrapped behind them so I could pull them forward if they started slipping out of socket.

The doctor marked my face as if for surgery and explained exactly what he intended to do. First, he would partially anesthetize the skin by icing the area to make injecting the anesthetic a more pleasant experience. Instead of the normal 3 to 4 cc's of lidocaine, he would use about 1 cc. Since he believed the long-lingering numbness of my biopsy was due more to epinephrine than to lidocaine, he used a concentration of only 1 part epinephrine to 200,000 parts lidocaine, rather than the usual 1 part to 100,000. So that he would have to numb the area only once, he planned

to take more aggressive margins (2 to 3 mm rather than the usual 1 to 2) as he removed the tissue surrounding the cancer. He would then suture the wound closed immediately after the first pass, betting that the microscopic examination would confirm the cancer was gone and no more surgery was needed, thus escaping the necessity for additional lidocaine. I felt secure. I knew I was in the right hands.

At the same time, I continued to prepare myself for the coming experience. Each day I drank a high-protein Ensure to boost my energy level. And I continued my daily meditations, focusing on bringing healing energy and relaxation into my mind and body.

S-DAY AND BEYOND

On the day of the surgery, I felt serene and fully prepared. Dr. Watts strode into the room humming and ready to go. We followed our plan. All of the cancer was removed in the first pass. Everything came off perfectly. I don't mean to suggest that my full body was not affected by this surgical invasion; it was, as it always is. I felt weaker and more vulnerable for a time. But I did avoid the throat spasms I underwent after the biopsy and had none of the extreme repercussions I had feared.

What made it so easy is that Dr. Watts is an extraordinary man. What motivates a doctor like this? He says what he does is fun, that he gets to help people of all ages. His work encompasses everything in medicine, from surgery to psychology, a neat little package all tied up somehow with the way he relates to people. He enjoys the magic his coordination and skills produce.

Whatever it is, I got lucky. ▲

As for Dr. Watts, he leaves us with a message: As skin cancer becomes more common, individuals need to focus on these considerations:

Prevention: Avoid direct sun on the skin, particularly middle-of-the-day sun, which is more carcinogenic. Avoid sunburn. Avoid tanning beds.

Early detection: Have an appreciation for what skin cancers look like. Melanoma, for example, can be easy to cure if caught early – and can be deadly if not.

Reaching for Wellness: Skill by Skill

Reji Mathew, PhD, New York University, New York, rm@rejimatthewwriter.com



Reji Mathew and
Dr. Angela Ryan

Photo Credit: Susan Marell

Wellness is a growing movement in health care centers around the country, aiming to guide persons seeking medical care to go beyond the demands of managing their illness and work towards achieving as much health as possible.

The post-polio community is a diverse one, as polio has affected each person differently, and the subsequent challenges each person faces are unique. My story is that I contracted bulbar polio at 9 months and spent the majority of my early childhood overcoming my original paralysis. Despite haphazard outpatient care, I recovered and achieved a high level of functioning. Three years ago, at 38, I started exhibiting symptoms of post-polio syndrome (PPS). To adapt to the mobility changes, I transitioned into walking with leg braces and forearm crutches, driving with hand controls and typing with my voice.

The unexpected changes in my functioning were stressful and anxiety provoking. I was catapulted into a new emotional journey, requiring me to re-evaluate my coping skills. As a working university professional and writer in New York City, I took this turning point in my life as an opportunity to refocus my academic interests and writing efforts to the study of hope and resilience. Through my own learning and countless interviews of others, I have come to understand wellness in terms of the themes I describe below.

Attitude of Curiosity and Learning

Anytime there is a change in a person's ability to function, it is a new experience. It is common to feel loss or anxiety. Learning how to re-negotiate my mobility using assistive devices was a challenge, but the real jolt was the shift to living my daily life in slow motion. I move slower, tasks take longer and fatigue can be inhibiting.

Managing fatigue is the first skill I have had to master. An attitude of curiosity and learning has helped me rethink how I reestablish daily activities. Whenever I want to achieve a

goal, I conduct experiments – calculating time frames, setting smaller goals, consulting with experts – until I find the right formula to achieve it. This mindset is helpful to me when I am working on writing assignments, as my projects require a mix of travel, interviews in different time zones and multiple deadlines all at the same time.

Each day I calculate my muscle exertion for the day, just as a diabetic person would do with diet and exercise. The main insight I learned from managing fatigue is that I don't take one day at a time any more, because New York City life can be unpredictable: traffic jams, navigating crowded city streets and commuter delays.

I have a general idea of what I want to accomplish each week. I then plan each day in units, early/late morning, for example. When I am on the road for a writing assignment, I may not be able to rest as I need to, so then I will break down my day further into moments. I will say to myself, "Let me just take a deep breath, relax and focus on getting through the next 15 minutes."

Dr. Mathew is writer and advocate ... See her website at www.rejimatthewwriter.com showcasing her articles on health, wellness, living well with disability and links to various resources.

Positive Cycles versus Vicious Cycles

I have built the majority of my new skills around relapses and setbacks. In the first year of living with PPS, my mobility challenges slowly started to narrow my life. Determined to improve my daily functioning, I learned that I need to start positive cycles of wellness instead of recovering from vicious cycles of relapse. For example, I relapsed two weeks after my first discharge from outpatient rehabilitation. My entire left side shut down, and I was unable to walk.

I used my behavioral analysis skills to understand how I was using my muscle strength. I realized that I was opening and closing doors in my office complex about 15-20 times a day. I started asking for help so that I could reduce this daily strain. Planning for or avoiding unnecessary drains is a central way I maintain a steady pace of life.

Intermittent Rehabilitation

The other side of managing a medical condition well is keeping the body as healthy as possible. My physiatrist advocated for me to receive intermittent rehabilitation treatment, and we problem-solve every step of the way to build skills for every mobility quandary: gait training, driving, transferring safely and managing my activities to keep me as injury free as possible.

My physical and occupational therapists taught me that there are a variety of ways to modify each standard exercise, and this helps me to find the right amount of movement my body can tolerate. Now, in addition to my daily exercise, I stretch throughout my workday to keep my contractures as flexible as possible.

I recently was also referred back to a brace clinic to update my ankle foot orthosis for a new design to aid in my walking. Being able to go back to rehabilitative care every few months to learn new techniques and ask questions has enabled me to preserve and maintain a high quality of life.

I also commit to staying updated on the latest technology. Once a month, I scope the latest websites or rehabilitation magazines to learn of any tool that could help me function better. I recently discovered iGoogle, an interactive web page where I can download tracking tools to help chart medical appointments. I also use a wide range of hand tools, such as grip gloves for walking with crutches, as both of my hands have atrophied and I don't have grip strength.

Vital Absorbing Interest¹

Managing a chronic medical condition can easily feel like a fulltime job. Finding a vital absorbing interest, activity or hobby that can help in taking a mental break is critical.

I have always considered the expressive arts a path to hope. A central theme in my writing is how the arts can aid in coping with the stressors of illness. To expand my life, I took a painting class. After the first few weeks, I was unable to sustain the muscle energy to paint and then drive home independently. I stayed in the class regardless and observed. It awakened me to the world of visual arts, now a constant source of uplift. I also studied with a music teacher who guided me to connect to music without playing an instrument.

I started a guided imagery project two years ago, which has been most

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The Fifth Brazilian Symposium on Post-Polio Syndrome (PPS) was held in September 2009 in São Paulo, Brazil.



Tatiana Mesquita E Silva, PT

The Brazilians involved with organizing this seminar are very determined to add to the world's knowledge of PPS and improve the health status of Brazilian polio survivors. Groups and health professionals from Portuguese speaking countries who would like materials from the conference presentations should contact Tatiana Mesquita E Silva, PT (TATIMSILVA@GMAIL.COM).

Dr. Acary Oliveira, Chief of the Neurology Department at Federal University of Sao Paulo's Medical School and head of its PPS Clinic, was the conference manager who also gave informative and entertaining talks on the "Neurologic Aspects of PPS," and its history and management in Brazil.

Frederick Maynard, MD, Marquette, Michigan, presented "PPS – Where Are We Now?," Daria Trojan, MD, Montreal, Canada spoke on "PPS Fatigue" and Olavo Vasconcelos, MD, Bethesda, Maryland, reviewed "Clinical Trials on PPS Treatment."

Local faculty member Tatiana Mesquita E Silva, PT, reported research results on "Sleep Dysfunction and Its Treatment in PPS Patients" and "Hydrotherapy for PPS." Micra Ocanhas, PT, talked about "Bowel and Bladder Incontinence in PPS Patients."

Fernanda Maggi, PT, gave an excellent summary of PHI's 10th Conference in Warm Springs, Georgia, April 2009, which was attended by five representatives from Brazil.

Polio survivor Luiz Baggio, Secretary for the Rights of Disabled People's Office and founder of the Brazilian Post-Polio Association (www.abraspp.org.br), also a conference organizer, convened and ended the seminar with thoughtful remarks on the role of polio survivors in society and the current needs of those with PPS. ▲

Reaching for Wellness: Skill by Skill

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gratifying. Friends donate cinematic photos of natural landscapes from around the world, which I then share in guided imagery stress management sessions with patients.

Repeatedly, I've learned the importance of staying open to new ideas to manage stress and lift my spirits. Ongoing learning has led me to adaptive yoga, Reiki, laughter therapy and relaxation techniques to refuel both emotionally and physically.

Restoring Flow

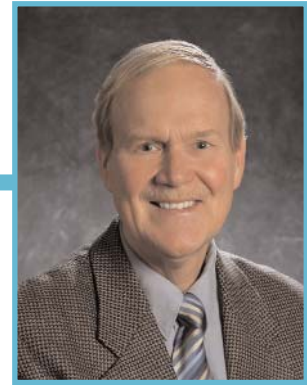
Good days and bad days occur equally, but with my skills, I manage my condition as well as I can, and I have

restored a state of flow to my life.

Wellness is an integration of a holistic set of strategies. It can be accessible to everyone, but it is an acquired skill set that takes time, practice, experimentation and effort.

The main focus of my writing is seeking out the details of coping, which is how I understand hope. I am always in search of stories to share with my readers, so they will be encouraged to keep reaching for wellness, skill by skill. ▲

1. Ellis, Albert. (2007). *Overcoming Resistance: A Rational-Emotive Behavior Therapy Integrated Approach*. Springer Publishing.



Frederick M. Maynard, MD

Question: *Is there a definitive medical position if polio survivors should take the flu vaccine each year? Last year when I went to get the vaccine, the staff notified me that Guillain-Barré syndrome is one of the risk factors of the vaccine. Should one not take the vaccine if you have a history of paralysis?*

A: My opinion is that there is no evidence to say that having a history of paralysis (residual muscle weakness) after poliovirus infection would raise your risk of new paralysis or other complications after flu vaccinations. Recently the question of risks to polio survivors from taking the new ‘shingles virus’ vaccine was raised among the PHI Medical Advisory committee members. The unanimous consensus was there was no known reason to anticipate increased risk for polio survivors.

Question: *I have concerns regarding the H1N1 vaccine. Are polio survivors considered an at-risk group?*

A: Based on my reading of current public health updates, people who had polio earlier in life are NOT considered ‘high-risk’ for developing H1N1 flu. I suggest that you consider receiving the vaccine when it is available to the general public, if you are a polio survivor with significant respiratory compromise (reduced pulmonary function), or if your general health is poor from heart or kidney problems, or if you will be around many young children as a child care worker or health care professional.

I recommend that you consult your family physician who knows your complete health history, and after doing a little homework of your own, make the decision in consultation with him/her.

PHI recommends the following sites.

This list was sent via email to all PHI Members who have an email in our records. If you are a Member and did not receive it, please send your email address to info@post-polio.org and set your computer to receive emails from info@post-polio.org, so they don't end up in spam.

- One-stop access to US Government H1N1, avian and pandemic flu information (www.flu.gov)
- 2009-2010 Seasonal Influenza Vaccines from the US Food & Drug Administration (www.fda.gov/ForConsumers/ConsumerUpdates/ucm100139.htm)
- CDC: Influenza (Flu) from the Centers for Disease Control and Prevention (CDC) (www.cdc.gov/flu)
- The Lancet's H1N1 Resource Centre from collaborative effort by the editors of over 40 Elsevier-published journals (www.thelancet.com/H1N1-flu)
- Pandemic (H1N1) 2009 from the World Health Organization (www.who.int/csr/disease/swineflu/en/)
- Stopping the Spread of Germs at Home, Work & School from the CDC (www.cdc.gov/flu/protect/stopgerms.htm)
- INFORMATION FOR PEOPLE WITH DISABILITIES ABOUT H1N1 VIRUS from long-time disability activist and educator Lex Frieden with contributions by Kim Dunn, MD, and Gerard Francisco, MD (The University of Texas Health Science Center at Houston, USA). (www.post-polio.org/H1N1BulletinLF0809.pdf)
- *It's Flu Season* by Judith R. Fischer, published in *Ventilator-Assisted Living* (Vol. 23, No. 3) is online at www.ventusers.org ▲



has the disability, women will try to pick up the tasks that he vacates, but when the female has the disability, the male will hire help. Perhaps males have the right idea? There is a reason why depression in females is twice as common as in males.

Consider the tasks your spouse did for you. How would you feel if you were doing those tasks for him? Would you whine and complain? No, because doing these things – *that's what love is*.

Second, traveling often is a hassle for people with some types of disabilities. All of our issues of weakness, fatigue and pain get brought to the forefront as we're faced with more tasks in inaccessible venues. Then there are the annoyances of other people who don't understand, crowded places with little room to maneuver, lack of places to sit or rest, etc. PHI conferences aim to be hospitable to people with disabilities. And still you needed assistance. Because that's the bottom line – as people with the late effects of polio/post-polio syndrome, we need assistance more than other people might, so we'd better get used to it.

Third, your assistance was from your uncomplaining spouse. You felt guilty. You two didn't talk about it. Should

you? Yes. The best time? Before the trip. The next best time? Anytime. Having trouble starting? *"Hon, you do lots of things for me and for us. When we travel, I notice you have to do even more, and sometimes it tires you. I can't help but wonder if you would tell me if it was too much?"*

There's your opening; after that you're on your own. Just try to believe him when he says he doesn't mind, and remember that your guilt is yours to deal with, not his to make it go away.

Would we ourselves choose to be people with disabilities? Probably not. Would our partners choose for us to experience pain, fatigue and weakness? I would guess not. But this is the hand you (the collective you, i.e., both you and your partner) got dealt. Trust him to make decisions that are wise.

Let me relate a personal experience to illustrate. Recently my two siblings decided to visit Australia without me. I was hurt, but as I thought about it, I realized that a trip to Australia *with me* is a whole different experience for them. Let's face it, I can be a pain – from the whole airport extravaganza of going through security in a wheelchair to finding accessible transportation to hotels with accessible rooms to accessible restaurants, and all that is before we even talk about my reduced energy level. So, although there are things they would never do without me, every once in a while they choose not to include me.

My task is to (a) accept that this is wise for us overall in our relationships and to try not to be hurt, and (b) accept that when they do include me they know the drill and are willing to help me for the privilege of the three of us being together. Your partner also wants the privilege of being with you. ▲

Who is Stephanie T. Machell, PsyD? Dr. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio (IRCP), Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. She specializes in working with medical trauma, physical disability and chronic illness. Her father is a polio survivor.

Who is Rhoda Olkin, PhD? Dr. Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. Her book on "What Psychotherapists Should Know about Disability," along with her video "Disability-Affirmative Therapy," are well respected and widely cited. She is a polio survivor and single mother of two grown children.

Thank you for recognizing your friends and loved ones with donations to support the unique mission of PHI and IVUN.

Contributions to PHI's educational, advocacy and networking activities ...

In Memory of

Susan Armbrecht	Marvin Neben
Robert J. Carson	Françoise Nunnallé
Edie Elterich	William H. Stewart
William Lewis Mosier, Jr.	Lynn L. Teal

In Honor of

Allen Goldberg, MD

Contributions to The Research Fund ...

In Memory of

Dr. Margaret Bates	Patricia Campbell LiBassi
Robert J. Carson	William H. Stewart

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

In Honor of

The birth of Joseph Edward Lawson

Sue Suter, now residing in the Champaign-Urbana area of Illinois, recently joined the PHI Board of Directors. Suter has more than 30 years of experience working in disability-related agencies and organizations. Most recently, she was the Associate Commissioner, Office of Employment Support Programs, Social Security Administration. PHI welcomes her expertise in education and training and policy development, as well as her personal perspective on polio. ▲

Polio (Biographies of Disease) by Daniel J. Wilson is available in hardcover (172 pages) online. This is a new title in the Biographies of Disease series by Greenwood Press (www.greenwood.com). The series is written for a general audience including high school students.

Polio is a thorough examination of medical and scientific efforts to battle polio, from the 19th-century identification of the virus to the great 20th-century epidemics, from the unprecedented campaign to find a vaccine to recent efforts to confront polio in West Africa and South Asia and eliminate it entirely. Beyond the science, *Polio* looks at the effects of the disease on individuals and the United States as a whole. The book gives readers a sense of what it was like to have polio and to recover from it. ▲

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4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
314-534-0475 314-534-5070 fax

Update and Thank you

We at the Aging Rehabilitation Research and Training Center at the University of Washington would like to thank PHI Members for the response to our request for participation in our survey. To date, we have received 311 surveys of the 420 mailed. Our goal is 500 people. If you're interested in receiving the survey, please email agerrtc@u.washington.edu or call toll free 866-928-2114.

In the coming years, as we analyze the findings from this survey we will report them in *Post-Polio Health*.

The survey covered pain, fatigue, depression, quality of life, mood and outlook, and exercise. Our team is interested in what you think would be good topics for future surveys.

More importantly, as a person with prior polio, send us your ideas about topics for research on aging that would be most useful to you personally. Send them to the email above. ▲

Mark P. Jensen, PhD, Professor and Vice Chair of Research, Department of Rehabilitation Medicine, University of Washington School of Medicine, Seattle, Washington

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Moving? Change of address? Please notify PHI before you move by calling 314-534-0475 or email info@post-polio.org. It is helpful if you tell us your old and new addresses. Will you be temporarily away? If you send us your "second" address and the dates you will be at each address, we will do our best to send the newsletter.