

## Every Body Benefits from Massage

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Leslie Drawdy

Massage is known to have many general health benefits, including decreased stress and anxiety, increased blood flow, decreased blood pressure, decreased pain and stiffness. Certain techniques can also result in decreased edema and hypersensitivity. Many people with post-polio syndrome (PPS) suffer from pain, cold intolerance and hypersensitivity. Most research and books on PPS management simply state that massage may be helpful in managing these symptoms; however the medical literature lacks more specific information.

### Clinical Approaches to Massage:

Traditionally, deep tissue massage or Swedish massage are the methods of choice for improving blood flow, decreasing muscle spasm and promoting muscle relaxation. However these techniques can produce pain for several days afterward. This can cause decreased function for certain individuals with PPS while the muscles are recovering. Other techniques can be just as effective.

For example, the strain counterstrain (SCS) method of manual therapy is often very effective, and easily taught to a patient and/or spouse/partner. Although it sounds painful and aggressive, it is actually quite the opposite. The therapist places the limb in the most relaxed position to mechanically reduce the stress on the muscles in question, and then uses light manual pressure specifically at the sites of spasm or palpable soft tissue abnormality to get the muscle to relax. This type of therapy actually retrains the muscle and can have a long-lasting effect.

Physical therapists, occupational therapists and massage therapists all use massage for different purposes in their practice. Massage therapists are certainly the experts in different massage techniques and are able to devote their time to relaxing the whole body. They can concentrate more of their efforts on the body part you request them to, but they are also able to address all the muscle groups and improve the whole body fluid flow.

Physical and occupational therapists use specific soft tissue mobilization techniques to promote pain relief and improved muscle function as it relates to specific mobility issues and edema management. If you have significant amounts of ongoing pain and muscle tightness, one recommendation might be to have massage therapy to address the pain and muscle tightness, and also have physical or occupational therapy to correct the underlying mechanical problems that are causing your continued symptoms.

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

## **Post-Polio Health** Winter 2011, Vol. 27, No. 1

ISSN 1066-5331

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### **For Families and Friends**

As she placed the receiver back on the phone, Gini Laurie, founder of our organization, said, "That will be a waste of postage. The lady asked us to mail information to her sister who had polio." She pragmatically explained, "People will only pay attention when they make up their minds themselves."

That was 1988. Human nature hasn't changed. Post-Polio Health International (PHI), then Gazette International Networking Institute, continues to empower polio survivors by providing accurate information and a connection to knowledgeable professionals. Polio survivors have always been and will remain the focus of our work.

However, several years ago, we noticed that more and more of the calls and emails were from family members and friends asking for help. Often the polio person was in the hospital, many times not able to speak for themselves. Caring family members were asking for information about polio and post-polio and were frustrated at how little they knew and fearful for their loved one.

### **PHI Responds**

"Post-Polio Health Care Considerations for Families & Friends" is PHI's latest contribution to its Members. Funded by The Phyllis and Max Reynolds Foundation, Inc., with assistance from The Chervenak-Nunnallé Foundation, PHI surveyed polio survivors and their families and gathered a team of experts to review their concerns and to determine what would be the most useful information.

"Post-Polio Health Care Considerations for Families & Friends" is available on PHI's website [www.post-polio.org](http://www.post-polio.org). It can be downloaded as a booklet or can be viewed in sections choosing the most relevant topic by clicking "Let's Begin" on the helpful and colorful flowchart.

PHI has been a trusted resource for polio survivors for five decades. Please tell your families and friends how PHI can help them too.

*Joan L. Headley, Executive Director, PHI*



# PHI Launches Polio Place - [www.polioplace.org](http://www.polioplace.org)

**P**olio Place, a dynamic internet repository for medical and practical information, historical records and artifacts is now available to the post-polio community around the world. Polio Place ([www.polioplace.org](http://www.polioplace.org)) looks at the past – not only the history of the disease, but also the stories of its survivors. It examines the present from the perspective of people around the world who are living with polio and post-polio syndrome today.

“We see Polio Place as an extension of our mission to enhance the lives and independence of polio survivors through education, advocacy, research and networking,” said PHI Executive Director Joan L. Headley.

PHI developed the Polio Place website, which is sponsored through the generous support of the Roosevelt Warm Springs Foundation. The website went live on January 30, the 129th anniversary of Franklin D. Roosevelt’s birth.

“Right now, survivors are living with the effects of poliomyelitis in such diverse places as Cuba, Democratic Republic of Congo, Ireland and the United States, and they are creating their individual narratives every day,” Headley said.



## HERE’S HOW TO PARTICIPATE:

**Polio survivors** – Have you devised a unique way of doing something to increase your independence? Have you created a simple device to assist you? Can you write an essay on *Living with Polio*? *Contact* us. Do you have a photograph, letter, newspaper article, etc., that tells your polio story? Please visit the *Artifacts* area of the website, and submit it.

**Health Professionals and Researchers** – Are there *Medical Articles* you would recommend or articles you judge to be classic, seminal, excellent overviews or longitudinal studies? Click on *Contact* and let us know.

**Historians and Authors** – Do you have suggestions for additional *Collections* of historical material or recommendations for additions to the *People* section? Have you written a book that should be included? *Contact* us.

“We are committed to reaching out to polio survivors and their families, health professionals and policymakers, particularly in countries where living independently and successfully as a polio survivor is not a priority.”

Headley said PHI invites survivors and health professionals worldwide to explore this storehouse of information. “We want to hear about your needs, your concerns and your successes.

“We are thrilled to be able to add this unique resource to our other trusted sources of online information – [www.post-polio.org](http://www.post-polio.org), Post-Polio Health International’s website, and [www.ventusers.org](http://www.ventusers.org), International Ventilator Users Network, the gateway for ventilator users, health professionals and equipment manufacturers to access comprehensive information and knowledgeable people,” Headley said. ▲





Florence Anrud

## Thoughts from a Seminar on Aging with a Physical Disability

Florence Anrud, Alexandria, Virginia, floanrud@gmail.com

**P**olio survivors are aging! In the Washington DC area, six of us with varying mobility and post-polio syndrome problems, plus the supportive spouses of two, shared our fifty-plus years of experience in a seminar for persons aging with a physical disability. The sessions were led by Lauro Halstead, MD, director of the Post-Polio Clinic at the National Rehabilitation Hospital, and Kris Halstead, a licensed clinical social worker.

Basic ground rules for each of the ninety-minute sessions over the six-week period established the core values of confidentiality and respect. We all recalled displays of respect, and/or disrespect, not only from family and friends, but also from strangers and members of the medical profession. Does the stoicism of many individuals who have had polio foster empathy?

How much recognition does the disabled person want? In social situations, many adults feel uncomfortable referring to a disability and therefore often ignore the disability. How well do our families and close associates know us? At the end of the session we were offered questions for an assigned reflection: “Who in my life should know more about me and my experience with polio?” and “What should a person say to me about my disability?”

Our next discussions grew from these questions, questions that also apply to the aging population as a whole. Many polio survivors date the aging process from the onset of polio rather than from a biologic year and many believe they have benefited from a head start on aging! The advantage the polio survivors have is that they have lived in comparatively good health through the demanding challenges of paralysis, and since they were not provided with a “how-to” manual, they have found methods

of adjustment, adaptation and compensation.

“How Resilient Are You?” a recent *AARP Magazine* article, provided insight to many positive coping skills, and as a group we scored well on a “resiliency” scale. We have been able to set a course for the future in direct proportion to the confidence we have felt in ourselves and in our bodies. We have become expert at taking one step at a time, at living one day at a time, and we have avoided looking too far ahead. We have put up a good fight against indulgence.

One vital key to healthy living, we decided, is to find and follow an activity that provides meaningful purpose to our lives. By setting goals and by not allowing our lives to be defined by a disease, we are able to nourish a sense of accomplishment. We can find joy in stepping out of ourselves and in embracing a different perspective.

Still, as our bodies become less dependable, a creative approach to living with purpose can become more of a challenge. If a pursuit has been a conscious goal through the years, the depth of that decision will continue to bear fruit. One satisfying and enriching activity we endorsed is the gathering of stories and photos of family history for an organized presentation, either in a journal, a scrapbook or on a CD. Of course, we need to continue

### For more information, visit these websites:

“How Resilient Are You?” *AARP Magazine*, Nov/Dec, 2009.  
[www.aarp.org](http://www.aarp.org)

*Aging With Dignity's Five Wishes* helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. [www.agingwithdignity.org](http://www.agingwithdignity.org)

Surveys on rehabilitation questions for the aged are available from the University of Washington Rehabilitation Department (<http://agerrtc.washington.edu>) and The Center of Aging, Studies Without Walls, The University of Missouri-Kansas City (<http://cas.umkc.edu/casww/>)



to pay attention to diet and exercise, knowledgeable direction in physical therapy and the proper fitting of braces.

A big question: how can lessons and techniques for dealing with polio (or other chronic conditions) prepare one for a terminal condition? As seasoned veterans, what confidence might we muster in the final battle? Are we emotionally and legally prepared for death and dying? To facilitate putting our affairs in order we were urged to follow the “Five Wishes” guidelines, the first living will that talks of personal, emotional and spiritual needs besides medical wishes.

What strengths do we derive from a spiritual commitment? Are we hesitant to articulate our needs on this subject? One participant admitted that attendance at a healing service produced an anxiety attack. This person did not want to think that God was responsible for the onset of disease nor for withholding healing or ignoring prayers for renewed physical strength. Nor should the presence of physical disease symbolize evil or punishment for a moral sin as it did in the Dark Ages. We are not Bruegel’s cripples begging outside the gate. Though all might wish for a dramatic vision or clear-cut answers, many agreed that active participation within a community of worshippers offers a milieu to build strength.

Another major question: should psychological counseling become a required step in addressing the impact of a major disease? Few in the group had undergone formal counseling, nor had the subject ever been initiated as a pivotal ingredient to understanding and accepting the disease. Most had to find their own way through the

**Florence Anrud** contracted polio her first week in college in 1954. Paralyzed from the waist down plus the face and throat, she returned to classes after three months of physical therapy dependent on full leg braces and crutches. By the time she graduated, she required only the aid of a cane, which she still uses. Throughout a 25-year career as a secondary teacher and librarian, she published articles in regional and national periodicals. After retirement, she became active in a post-polio support group, served on the board and as co-chairman of the Tacoma (Washington) Area Coalition for Individuals with Disabilities and was a member of the speakers’ circuit for Tacoma area Rotary clubs. In 2007, she moved to Alexandria, Virginia, to be closer to her daughter and grandchildren.

labyrinth. Support groups offer emotional support on a social level but usually do not offer professionally trained personnel for exploration in any depth. Isolation can become a primary concern when a person is disabled. How can guidance and treatment for depression and grief be positively administered?

Can polio survivors offer leadership to an aging population? A growing number of universities now pursue rehabilitation questions specifically for the aged. Some of the questions might remind one of sipping at the proverbial “fountain of youth,” but exploring solid information and analyzing experience are traditional paths to building a foundation for growth and can offer an arsenal and protective shield against adversity. In particular, the polio survivor has learned that all types of knowledge contribute not only to achieving some control over a disability but also to realizing a profoundly rich and purposeful life.

Though initially strangers, the six polio survivors, benefiting from professional leadership, had covered a great deal of territory in depth. We felt like comrades in arms. As we approach the future, we feel assured that the accent mark will not shift: the meaning of invalid will not change from IN-val-id to in-VAL-id. ▲

#### **Upcoming conferences:**

Growing Older with a Disability is one of six concurrent conferences at **FICCDAT (Festival of International Conferences on Caregiving, Disability, Aging and Technology)**, June 5–8, 2011, Toronto, Canada. [www.ficcdat.ca](http://www.ficcdat.ca)

**European Conference on Post-Polio Syndrome** sponsored by the European Polio Union and The Danish Society of Polio and Accident Victims, August 31 – September 2, 2011, Copenhagen, Denmark. [www.poliocconference.com](http://www.poliocconference.com)



Rhoda Olkin, PhD

## Promoting Positive Solutions

**QUESTION:** *I am worried about my father (and my mother). He is in his 70s, and for the past few years, we have had trouble getting him out of bed each day. He doesn't use any assistive devices, but he has one weaker leg, and he was in an iron lung when he had polio. His medication for depression is being adjusted, but he has refused to see a psychologist or psychiatrist. He tells us, "You just don't understand how I feel." Our problem as a family is this: How much should we "encourage" him to stay active?*

### Response from Rhoda Olkin, PhD:

I'm sorry, I know this must be difficult for your whole family. I have several thoughts. First is something I notice about your question that has been true for previous questions we've received: often people ask about someone in their family rather than about themselves. Therefore, I am usually answering a question from a person who does not have polio about a family member or friend who does have polio.

\*It strikes me that there is so little information available about interactions between people with physical disabilities and their family and friends, that there is a real void about how to handle day-to-day interactions, much less the deeper situations like the one you describe.

Alas, it is harder for me to answer questions about another person without hearing directly from that person. I can't tell whether your father is significantly clinically depressed, in physical pain, fed up with disability difficulties or in early stages of dementia or Parkinson's. Thus, I can only answer more generally.

Of course my first response has to be that he needs an evaluation. Anyone who refuses to get out of bed and needs encouragement to engage in life should be evaluated for medical complications, depression and suicidality. If he won't see a mental health

\*See Page 2. "Post-Polio Health Care Considerations for Families & Friends" was developed by PHI specifically as a resource for families and friends of polio survivors.

provider, his general practitioner can do an initial screening. Unfortunately, medication alone for depression is not always effective, and relapse rates are very high.

Second, I may understand a bit of what he feels. Disability is very hard work. So is depression. The two together are quite a barrier to engagement and enjoyment of life. What helps? All those things he's refusing to use: assistive devices, distraction, good evaluation of any secondary conditions and therapy. Has the full family system been mobilized to help him make a change? For example, is everyone on board with the idea of his using assistive technology? What if a scooter just showed up in his bedroom one day? What if you announced that he had an appointment with his physician on Thursday and that you would be arriving at 11:00 AM to drive him there? In other words, are you taking him at his word, or are you taking actions?

Third, he's not so old. My parents are in their upper 80s, and I want them to still enjoy life fully, living as if they have more time ahead of them. The 70s are too young to be giving up. He may have twenty more years in him; how does he want to live them?

Okay, suppose he wants to die. Is that an option? What would the family do differently today if they knew he might die tomorrow? Has everyone said what they needed to say? Is there a will? What would happen to your mother?

**Dr. Rhoda 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. She is a polio survivor and single mother of two grown children.

I am really giving you two options: let him stay in bed, and stop trying to change him, or move heaven and earth to get him actively engaged in his own life. Whichever you choose, do it as a family. I wish the best for all of you!

**Response from  
Stephanie T. Machell, PsyD:**

As the child of a polio survivor, I know that family members walk a fine line in situations like this. Your father wants to have his independence, and that may mean rejecting (or seeming to reject) help from his wife and children. He may be fearful of becoming a burden – or of burdening you with his fears for the future. He wants to solve the problem his way, even though his way may no longer be working.

The simple answer to your question is, yes, of course you should encourage him to stay active. Being active would help your father's depression. The problem is that a person who is depressed doesn't feel like being active. And a person who is having more difficulty doing what he previously could do with little effort may avoid activities that are now more problematic. If your father feels that he can't do what he once did, being "encouraged" may feel more like being told he is inadequate – and misunderstood.

Your father might be feeling that he is losing control of himself and his life right now.

The best way to help is by helping him find ways to feel in control again. Ask your father what help he would like from you, and encourage your mother and other family members to do the same. Offer him choices and encourage him to make them. Give him information that would help him; for example, letting him know that

being active would help his depression. When he says you don't understand, say, "You're right, I don't understand how you feel, but I really want to. Would you tell me about it?"

It would definitely be helpful if your father would see a psychologist or psychiatrist who understands the issues he is dealing with. If he is determined not to go, you may not be able to persuade him, and pressuring him to go would just make him feel more out of control. Is there anyone else he might trust to talk to about his concerns – a member of the clergy or his health care professional? Would he be willing to try a post-polio support group? It might also be helpful for him to see a polio doctor, if he hasn't already. He might benefit from assistive devices and/or physical or occupational therapy if he is having more difficulty getting around and/or increased pain or weakness. Again, provide him with the information, and offer to help if he wants it.

It would be beneficial for you and your mother to get support for yourselves. Caregiving is stressful and difficult, as is living with someone who is depressed. There are support groups for caregivers, and, of course, psychotherapy is an option as well. One or both of you getting help (and sharing your experiences of doing so) might even encourage your father to do the same. Good luck to all of you! ▲

***Please send questions for Drs. Olkin and Machell to [info@post-polio.org](mailto:info@post-polio.org).***



Stephanie T. Machell, PsyD

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

### Guidelines for home massage

Massage doesn't have to be performed by a professional in order to be helpful. Generally speaking, if it feels good, it is okay. If your spouse is massaging your legs, for instance, give him/her specific feedback about what feels good and what doesn't. It's always a good idea to start with lighter pressure, and then ask them to increase the pressure as you feel it is necessary. Massage does not have to hurt to be beneficial. For increased blood flow and muscle relaxation, moderate pressure is often very effective without producing painful side effects.

Using a heat pack prior to massage may help to relax the muscle, making the massage a little easier. The more fully the hand is in contact with the area to be massaged, the more relaxing the massage will be. Digging in with fingertips can cause stress and hand pain for the person performing the massage and can be irritating to the recipient. Applying pressure through the heel of the hand is better.

If you have a muscle spasm or trigger point, holding constant pressure to the area is the best way to relax it. This is referred to as trigger point therapy. The mis-

take most people make is to dig their fingers into the area of spasm and rub back and forth. This can be very irritating and cause more pain as well as actually aggravate the spasm and cause the surrounding muscles to tense. Start lightly, and gradually increase the pressure until the trigger point relaxes. Take intermittent breaks, or alternate between areas of spasm. Once the spasm is relaxed, perform gentle, even strokes to the general area with the heel of the hand.

Although typically not as relaxing or easy to do, self-massage can still be helpful. It is important to listen to your body's feedback. Don't be too aggressive. Try to find the most relaxed position you can. You don't want to increase your pain or muscle tension in your arms and neck while massaging your foot! The same principles and techniques of massage with a partner apply here.

Self massage can be performed whenever you feel you need it. Many of my clients initially perform home massage daily, and then decrease the frequency as their pain improves. The best parameter is to listen to your body.

### Concerns/issues and modifications

There are some circumstances in which massage must be performed more carefully. Limbs with chronic edema, hypersensitivity, fragile skin, open wounds, or diabetic neuropathy must be approached a little differently. Aggressive massage may be intolerable and could cause more problems. In these

### Choosing a physical therapist

*It can be difficult to find the right physical therapist. If you cannot find a therapist who has knowledge and experience in treating PPS, look for a therapist who is familiar with neurological/neuromuscular disorders, preferably with experience treating multiple sclerosis patients.*

Start by asking others you know with PPS who have had successful physical therapy.

If a therapist has a good understanding of multiple sclerosis, they already know the basic treatment principles for post-polio syndrome, whether they are aware of it or not! You're most likely to find a qualified therapist in a hospital-based outpatient therapy clinic.

If your function has declined to the point that leaving your home for an appointment completely wears you out and you are avoiding activities outside your home, you may qualify for home health therapy services. Most home health therapists are qualified to treat patients with PPS, since they see a wide variety of complicated diagnoses and situations. This would be an excellent place to start if you are finding that you need increased help with your activities of daily living and general mobility in your home.

PHI's online *Post-Polio Directory* ([www.post-polio.org/net/PDIR.pdf](http://www.post-polio.org/net/PDIR.pdf)) includes the names of physical therapists. If you are a therapist and wish to be listed, or if you know a therapist who should be listed, please contact [info@post-polio.org](mailto:info@post-polio.org).



## PHI Announces Research Grants for 2011

Joan L. Headley, Executive Director, Post-Polio Health International (PHI),  
director@post-polio.org

Teams from the Departments of Physical Medicine and Rehabilitation at the Hadassah Medical Center, Jerusalem, Israel, and at the University of Michigan, Ann Arbor, Michigan, were awarded \$25,000 each from The Research Fund of Post-Polio Health International for research to be conducted in 2011.

Zeev Meiner, MD, will lead the study, "Characteristics of poliomyelitis and post-polio patients among Jews and Arabs in Jerusalem." Demographic, medical, socioeconomic, occupational and functional data will be collected on 250 polio survivors (Jews and Arabs) and will be compared to the age and gender-matched "non-polio" population to determine the extent of post-polio problems and to develop programs to prevent further problems. Dr. Meiner will be assisted by Isabella Schwartz, MD, head of the post-polio clinic established in 1997 at the Hadassah Medical Center.

Survivors in the study will be evaluated according to the March of Dimes criteria, and post-polio syndrome severity will be evaluated according to the IPPS (Index of Post-Polio Sequelae). Fifty survivors will receive group or individual therapy twice a week for six weeks to evaluate the effectiveness of specific rehabilitative therapies. Dr. Meiner's team also includes Irina Gartsmn, MD, (Physical Medicine and Rehabilitation), Yechiel Friedlander, PhD, and Orly Manor, PhD, in the Hebrew University Braun School of Public Health Biostatistics and Epidemiology Department.

Claire Z. Kalpakjian, PhD, MS, is the principal investigator for "The Role of Oral Glutathione in Improvement of Health Outcomes among Persons with Late Effects of Poliomyelitis." The critical role in a number of cellular processes of glutathione, a powerful antioxidant, is suggested, but there is little published data about its effectiveness.

The study conducted at the University of Michigan will examine the effect of oral glutathione supplementation on subjective measures, such as fatigue, physical function, sleep and emotional distress, and on objective measures of physical activity, sleep efficiency and functional mobility. Twenty individuals between the ages of 50 and 65 will have blood drawn on the first and last of four data collection visits to measure glutathione levels. Participants will be recruited from the University of Michigan outpatient clinics and the Michigan Polio Network. Mark J. Ziadeh, MD, Assistant Clinical Professor in the Department of Physical Medicine and Rehabilitation is co-investigator. ▲

cases, a very light technique is helpful. It can be relaxing and pain relieving and may even be helpful with edema management.

The best technique in these situations is one similar to the Manual Lymph Drainage technique used for lymphedema patients. Starting at the top of the affected limb, using full contact with the palm and fingers of the hand, apply enough pressure only to stretch the skin. Gently pull the skin toward the top of the limb. Then move your hand down a bit on the limb and repeat, working your way down to the end of the limb. This technique is helpful with multiple types of swelling, and has been very successful in

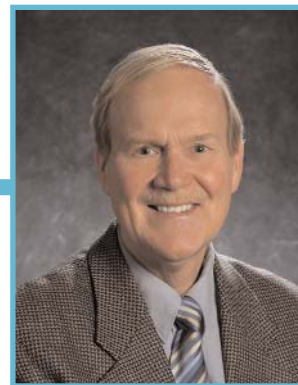
reducing hypersensitivity. If you struggle with either of these issues, I would recommend getting a referral to a lymphedema therapist or seeing a massage therapist who is trained in lymphedema management. They can teach you and your partner exactly what to do. It is very easy to learn, but it is a little different for each person.

If the skin is very fragile or there is an open wound on the limb in question, use caution. Keep the skin well moisturized, and never apply direct pressure over the site of a wound. However very light massage over areas of intact skin can still be performed. Simple, light stroking of the skin without any application of pressure, or the

lymphedema technique described above can be used safely.

If you have diabetic neuropathy, you must keep in mind that your sensation is altered. You may not be able to accurately assess whether the amount of pressure during a massage is okay. Light to moderate pressure is best to avoid any soft tissue damage.

Don't be afraid to seek professional advice! If you have any concerns or struggle with any of the specific issues listed above, one or two visits with a professional for instruction on the correct massage method for you may be well worth it. ▲



Frederick M. Maynard, MD

**Question:** *I am a polio survivor who has had untoward and paradoxical responses to muscle relaxants and meds in particular, but also possibly to lidocaine pain patches used for the first time this year. I was hospitalized, through the emergency room, with cellulitis of my stronger leg while on vacation. I don't remember the first few days in the hospital, and suspect this was treatment-related. I found it scary to think that my medical history information was not treated as important! I would like to know if this reaction relates to being a polio survivor. I'm open to new information and suggestions of how to avoid this in the future.*

**A:** There are only a small number of drugs that have unique side effect problems among people with a history of paralytic polio, and the issues are greatest among people with the most extensive and severe residual nerve damage/weakness. Among the problematic drugs is one class of anesthetic agents, known as neuromuscular blockers (succinylcholine family). These drugs are used very rarely.

Other problems relate to medications, including some anesthetics, that are diffused throughout the body's tissues when given and are particularly concentrated in muscles. If a polio survivor has a significantly decreased proportion of total body tissue as muscle, then the usual doses of medications may have a greater than expected effect, because blood levels of the medications become higher than expected. Therefore it is wise for polio survivors with extensive chronic paralysis and/or a personal history of poor tolerance to medications to always begin new medications at a smaller than usual dose and increase doses slowly to the desired goal/benefit to minimize the risks of undesirable side effects or individual sensitivities.

Having said all of that, I do believe that individual differences in "medication tolerance" among the general population is very large and is probably more of a factor in explaining your problems of medication tolerance than is your history of polio

per se, especially if you experience "idiosyncratic" (unusual/unexpected/unique) reactions.

The most likely reason for some people to be "more sensitive to" or "have exaggerated responses to" some medications is the extent of individual differences in enzyme systems and effectiveness in metabolizing (processing) different drugs in the body. Recent scientific studies have shown these differences to be genetically based and some people now advocate testing for these differences before using certain drugs. I think there will likely be a lot more differences than current medical knowledge understands, and we will hear more about this subject in the future.

Relative to your distress about people not listening to your history, all you can do is keep a list of all drugs that have caused you problems. Call them "allergies," even if they are really "sensitivities," because all U.S. medical providers do ask about and consider a new patient's "List of Drug Allergies" before initiating treatment. Include "History of Polio" on the same list, and at least it will probably be seen! However, there are not many medical procedures or drug contraindications that result inherently from the fact that a person has had polio. The history of specific, or generalized, difficulty with medication tolerance/sensitivity would be the more important issue to emphasize. ▲

SEND YOUR QUESTIONS  
FOR DR. MAYNARD TO  
INFO@POST-POLIO.ORG.

## Thank you

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

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

#### In Memory of

|                      |                         |
|----------------------|-------------------------|
| Julia Beard          | Mildred Maxine Mitchell |
| Jennie Bieniek       | Robert Leon Norris      |
| Leonard Blumberg     | François Nunnallé       |
| Nat Chrisler         | V.G. & Ganga Patel      |
| Martin F. Fagan      | Helen Sieker            |
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| Robert J. Kerby      | Ruthe Vanderwart        |
| Darwin C. Larson     |                         |

#### In Honor of

|                                   |  |
|-----------------------------------|--|
| Jim & Judy Headley                | Ed Roberts and all polio survivors who fought for the ADA, on its 25th anniversary |
| Joan L. Headley                   |  |
| Joanne Kelly, PsyD                |  |
| Laura Saelinger-Shafer, MD        |  |
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### PHI acknowledges the following special contributors ... January 8, 2010 - January 11, 2011

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## Inside *Post-Polio Health* (Vol. 27, No. 1, Winter 2011)

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**Moving? Change of address?** Notify PHI before you move by calling 314-534-0475 or email [info@post-polio.org](mailto:info@post-polio.org), and tell us your old and new addresses. **Away Temporarily?** Send us your "second" address and dates you will be there, and we'll do our best to send your newsletter.

## Updating *Post-Polio Directory*

Health Professionals and groups assisting polio survivors are asked to check their information in PHI's *Post-Polio Directory*.

To access the *Directory* and to review your entry, go to [www.post-polio.org/net/pdirhm.html](http://www.post-polio.org/net/pdirhm.html). Email changes to [info@post-polio.org](mailto:info@post-polio.org) or call 314-534-0475.

*Post-Polio Directory* is PHI's major networking tool. The online version is downloaded more than **1,200 times per month**. (Print copies are available for \$12 USA; \$14 Canada/Mexico; \$16 Overseas air.)

The *Post-Polio Directory* is divided into three sections, listing international contacts in alphabetical order by country followed by groups in the United States in alphabetical order by state.

**Clinics** lists medical facilities with a special interest in the late effects of polio. The *Directory* provides the name of the physician who leads the team of health care professionals involved in the clinic's treatment options.

The **Health Professionals** section lists individual health professionals, along with their medical specialties, who are knowledgeable about the late effects of polio.

**Support Groups** are listed in the third section with the groups' usual meeting schedules. It also includes organizations that provide information and support to polio survivors throughout the world.

Additions are welcome: To be added to *Post-Polio Directory 2011*, email or fax details to [info@post-polio.org](mailto:info@post-polio.org) or 314-534-5070 (fax). ▲



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