Surgery: Another Point of View

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

few years ago an orthopedic surgeon suggested rotator cuff surgery for me. "You could raise your arms," he said. He saw the inactivity in my shoulders and wanted to help.

"But I have no serratus," I replied, remembering how my first polio doctor flattened his hand wide and moved it from my ribs around to and beneath my shoulder blade area to demonstrate the location of this broad muscle. Only when he pushed hard on my scapula, no longer served by the serratus, could I even begin to raise my arm. I understood why I need that muscle.

The orthopedic surgeon looked puzzled for a moment and finally said, "Oh. Then the surgery won't help you raise your arms."

He had been thinking of his experience with rotator cuffs, not my experience with muscles.

Herein lies a **RED LIGHT!** when it comes to polio survivors and certain types of surgery. Let's say I have a problem I can see is getting worse. I don't want to lose function. I want desperately to be put back together again, maybe even to become "the way I used to be." I know that surgeons want equally as much to help their patients, to bring a missing quality back to their lives. Here's the important part: I cannot allow my thought process to stop here, or I might find myself in deep trouble.

Function cannot always be restored. This is hard for some to swallow. How can we be sure we are not allowing our desire to be made whole again to lead us to believe an uninformed surgeon can make our dreams come true? What risks are involved? Sometimes we simply need to put our

common sense to work and make sure we're dealing with reality.

A Surgery Story

A 40-year polio survivor in her fifties wore a full leg brace on her left leg. Her right leg had a slight recurvation (bowing back from the knee down) problem, but did not require a brace. That leg worked well when she walked, climbed stairs, got up from the floor.

The head of orthopedic surgery in a teaching hospital examined her and proposed surgery in the right leg. He said he could correct the bent-leg condition and also wanted to transplant a hamstring in that leg to the quad, which he said would result in strengthening the quad to give more mobility. He saw this as a bonus to the recurvatum surgery and said, "I can make that leg stronger and prevent recurvatum from happening again."

RED LIGHT! "I didn't know if the recurvatum would be a problem later on as the doc said it would be," says the woman. "The doc said he could

continued, page 6

The Winter 2008 issue of PHI's newsletter gave us an excellent guide in "To Have Surgery or Not to Have Surgery — That Is the Question!" Now we take a look at further concerns, this time from a different point of view.



POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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 2009, Vol. 25, No. 1

ISSN 1066-5331

Editor: Joan L. Headley, MS editor@post-polio.org Designer: Sheryl R. Rudy webmaster@post-polio.org

Special thanks ...
Judith R. Fischer, MSLS
Michael Shadix

©2009 Post-Polio Health International (PHI).

Permission to reprint must be obtained from

Post-Polio Health International (PHI).

How to contact PHI Post-Polio Health International (PHI)

Including International Ventilator Users Network

4207 Lindell Blvd., #110 Saint Louis, MO 63108-2930 USA 314-534-0475, 314-534-5070 fax info@post-polio.org www.post-polio.org

To be sure you receive email updates from PHI, set your spam filters to allow messages from info@post-polio.org.

Worthy of Note

Did you know that Welcome Home is a bed and breakfast in a house of wheelchair-friendly modifications located in Newburg, Wisconsin? Visit and try out possible modifications. (www.welcomehouseof.org; 262-675-2525) *** If aging in place is not an option, Medicare.gov, the official website for people in the US on Medicare, has a section with information relating to Medicaid and Medicare-certified nursing homes throughout the United States. (www.medicare.gov/Nursing/Overview.asp) *** www.NewLifeStyles.com houses a database of all statelicensed senior housing facilities, and home health and hospice agencies nationwide, plus other non-licensed housing, and senior products and services. *** An 80+-year-old polio survivor sold her condominium several years ago and moved into a Residence Inn by Marriott, paying by the week. She is fortunate enough to have funds to live until she is 120! *** Mary Esther Boyd, Cambridge Harbor Development, LLC, (maryestherboyd@comcast.net) writes, "We have an approved project in Cambridge, Maryland for eight elevator townhouse projects and two cottages across the street from Cambridge Creek. A rough estimate of the cost of each of the eight units is \$500,000. Details can be found at www.post-polio.org. "This week at PHI" April 29, 2008. *** Many of you will remember polio survivor Jane Dummer, who was instrumental in securing disability for the late effects of polio through Social Security in 1987. In her holiday letter she wrote, "I co-chair the ABLE committee at my retirement center and have learned that the term 'disability' completely turns off the residents, so I go about 'enhancing our environment.' "

Polio survivor Reji Mathew, PhD, New York University, Student Health Center Counseling and Behavioral Health Division, writes for Advance for Occupational Therapy Practitioners. To view her helpful and practical columns, search for "Reji Mathew Advance for Occupational."

Update on Global Polio Eradication: Total cases as of January 13, 2008: 1625; January 13, 2007: 1083. *** India: The next National Immunization Day (NID) round will be launched on February 1, following NIDs held on December 21. Monovalent oral polio vaccine type 1 (mOPV1) will again be used in Bihar, Uttar Pradesh and key re-infected areas, and trivalent OPV in the rest of the country. *** Pakistan kicks off its 2009 eradication effort with NIDs on January 19-21 (parts of Punjab and Sindh held their campaigns on January 12-14). In total, more than 33 million children under the age of five years will be immunized across the country.

From the US Food and Drug Administration: Daily vitamin D needs in International Units (IU): 200 IU, until age 50; 400 IU, age 51-70; 600 IU, over age 70. Multivitamins typically provide 400 IU of vitamin D. One cup of vitamin D-fortified milk or juice provides 50 IU of vitamin D.

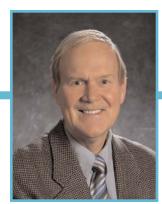
Joan L. Headley, Executive Director, PHI

Networking



elcome to Ask Dr. Maynard, a new feature of Post-Polio Health. Frederick M. Maynard, MD, a longtime member of PHI's Board of Directors, is a recently retired physiatrist, a specialist in physical medicine and rehabilitation. He dedicated a significant portion of his academic and clinical practice over the last 25 of his 40-year medical career to the unique problems of polio survivors.

If you have a question for Dr Maynard, please send it to info@postpolio.org, with "Ask Dr. Maynard" in the memo line. Select questions will be published in future issues, while others will be posted on www.post-polio.org.



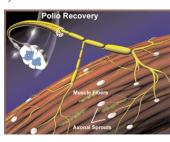
Frederick M. Maynard, MD

Question: I am aware that as polio survivors recovered from the initial bout with polio, we went through a process called denervation. Does this process of losing anterior horn cells (AHCs) and establishing new nerve pathways continue with post-polio syndrome? Gary Fredericks

A: Denervation is actually not a process but a condition of muscle that has lost its connection to a motor nerve cell body (AHC). Death of an AHC results in a process of Wallerian degeneration of nerve axons (fibers), and results in atrophied denervated muscle fibers. Partially denervated muscles are weak, whereas completely denervated muscles are paralyzed.

When nerve fibers from AHCs that survived the poliovirus infection grow new sprouts, which reconnect to mus-

cle fibers without a nerve supply, reinnervation is said to have occurred.



In most polio-weakened muscles there is a lifetime process of continuing new muscle fiber denervation and new re-innervation. In post-polio syndrome, the rate of denervation exceeds the rate of reinnervation, and new weakening is experienced.

Both normal aging and any ill health can slow down the process of reinnervation, which results in more denervated weakened muscle fibers. Postpolio syndrome may also result from something triggering a sudden speeding up of denervation, including new dying of AHCs.

Question: As my leg muscles become weaker, I notice that now I use my toes more than my whole foot when I walk. A polio friend of mine has made the same observation about his method of walking. Is this coincidence or is there a connection between weak leg muscles and using toes more to walk? GARY FREDERICKS

A: The anterior tibialis muscle is the primary contracting muscle that normally picks up the foot at the ankle joint to help your toes clear the floor as you pick up your leg. To compensate for weakness in the anterior tibialis muscle, adjacent muscles (toe extensors) that act to move the toes upward also contribute to picking up the foot when they contract and shorten because their tendons go across the ankle. In fact, you are not walking more on your toes, but with the over-activity, the toe extensor muscles and the big toe in particular, are in an abnormal "cocked-up" position during the swing phase of walking. **\(\rightarrow\)**



Feldenkrais®: An Exploration in Possibility

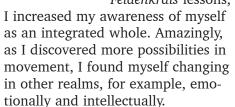
Rosanna L. Mattingly, Portland, Oregon, rosannamattingly@gmail.com

oshe Feldenkrais, the physicist and martial artist who developed the *Feldenkrais Method*® of Somatic Education, said, "If you know what you are doing, you can do what you want." Is it possible for persons experiencing the late effects of polio to do more of what they want? Of course it is!

The "Method"

In my view, *Feldenkrais* is far more a process of exploration than a method. *Feldenkrais* is a means through which

we can discover what is possible, much as a child does in exploring his or her movement in the world. The child, as we know, learns to roll over, creep and crawl, stand, walk, skip and run. By participating in Feldenkrais lessons.



The Lessons

Feldenkrais lessons take place with a Feldenkrais practitioner either on an individual basis (Functional Integration®) or in a group setting (Awareness Through Movement®). Participants are invited to remain open rather than have expectations, to be gentle with themselves, to do less than what may be possible at a given time, to adjust to their own capabilities, and to attend to the means rather than the outcome. I remember laughing at the not-having-expectations part during my own first lessons. Of course, I was there for a reason!

Along with the initial improvements that occurred in my balance in standing, I quickly learned that *Feldenkrais* is not about "fixing," but rather about developing and maturing. I was not confined by my previous experience and ways of learning, but was engaged in a spirit of exploration, playfulness and being present to what happens. I became open to other possibilities, foreseen and unforeseen.

The Background

Moshe Feldenkrais considered our capacities for moving, sensing, feeling and thinking in developing his "method." Although each of these capacities is present to various degrees in every action, he focused on movement as perhaps the easiest means for initiating change.

Change occurs in part as we begin to recognize and re-evaluate habits. Although many habits are useful, some are based on misperceptions and some, though necessary for survival early on, may no longer serve us. The pathways of our habits are so well worn that we often travel them without conscious awareness. As an example, most of us remember being rattled by all that needed our attention when first learning to drive, but now, years later, we drive 65 miles per hour down a freeway, and at some point realize that our attention was focused elsewhere.

Feldenkrais lessons focus on movement, yet awareness, the act of consciously



Rosanna Mattingly with her great nephew, Logan Arnold.

Rosanna Mattingly is a *Guild Certified*Feldenkrais Practitioner^{CM} who teaches and writes in Portland, Oregon.

What Happens in a Feldenkrais Session?

Feldenkrais is done in two formats.

In group classes, called *Awareness Through Movement*, the *Feldenkrais* teacher verbally leads you through a sequence of movements in basic positions: sitting or lying on the floor, standing or sitting in a chair.

Private *Feldenkrais* lessons, called *Functional Integration*, are tailored to each student's individual learning needs; the teacher guides your movements through touch.

People participating in *Feldenkrais* lessons are usually referred to as "students" rather than as clients or patients. This reinforces the view of the work as primarily an educational process.

paying attention during the lessons, is fundamental to the process. The lessons provide opportunities to discover alternative pathways, consciously or not – pathways that are easier, more efficient, more to our liking. They help us recognize our choices.

The Relevance

There is no way to deny my limitations, but my experience as a *Feldenkrais* student and practitioner suggests that we tend to limit ourselves more by our thinking than by our actual physical limitations. What we believe, whether true or false, can have enormous power over what we are able to do. More than once I've been surprised to find myself moving in a way that differed from what I thought I was doing, and I was delighted to find that something I did not think possible actually was.

Those who participate in Feldenkrais lessons, myself included, generally experience improvement in balance, coordination, flexibility and quality of life. We learn to move in ways that are more appropriate for our situations and ourselves. We begin to recognize stress and strain, and find alternative movements for following through. We take time to spread the effort and thereby reduce the tendency toward overuse. We find ways to support ourselves more through our bones, experience less pain, and manage uncertainty. We recognize our first attempts for what they are: first approximations. As we expand our sense of self, we expand our options. We become more grounded, self-reliant, and able to remain open and in the moment.

Because there is limited research in the late effects of polio and few experts in the field, we are finding our own ways, learning more and more to trust ourselves. *Feldenkrais* can contribute to our lives as we continue to find what is possible. It begins with awareness of what we do, acceptance of what is, and openness to what might be.

This, in the end, is what Feldenkrais said that he wanted: "to restore each person to their human dignity." His approach enables us to both acknowledge and experience the self as ever-creative, whole and rich in possibility.

For additional information, visit: www.feldenkrais.com

Resources

Alon, Ruthy. 1996. *Mindful Spontaneity: Lessons in the Feldenkrais Method*. North Atlantic Books. Berkeley, California.

Feldenkrais, Moshe. 1977. Awareness Through Movement. HarperCollins Publishers. New York.

Feldenkrais, Moshe. 1981. *The Elusive Obvious*. Meta Publications. Capitola, California. Feldenkrais, Moshe. 2002. *The Potent Self: A Study of Spontaneity and Compulsion*. Frog, Ltd. and Somatic Resources. Berkeley, California.

Plonka, Lavinia. 2004. What Are You Afraid Of? A Body/Mind Guide to Courageous Living. Jeremy P. Tarcher/Penguin. New York.

Related Resources

Claxton, Guy. 1999. Wise Up: The Challenge of Lifelong Learning. Bloomsbury Publishing. New York.

Damasio, Antonio. 1999. The Feeling of What Happens: Body and Emotion in the Making of Consciousness. A Harvest Book/Harcourt, Inc. New York.

Langer, Ellen J. 1997. *The Power of Mindful Learning*. Addison-Wesley Publishing Company, Inc. New York.

LeDoux. Joseph. 2002. Synaptic Self: How Our Brains Become Who We Are. Penguin Books. New York.

Schwartz, Jeffrey M. and Sharon Begley. 2002. *The Mind and the Brain: Neuroplasticity and the Power of Mental Force*. HarperCollins. New York.

continued from page 1

keep the condition from becoming worse, and I believed him. He had studied with a Warm Springs doctor, and this helped convince me that he knew what he proposed would work. He did not warn me of any consequences – everything was positive. I simply trusted him."

Results

After a much longer recovery time than anticipated, the transplant didn't work. Nobody had checked the strength of the hamstring, which got worse, not better, and thus did not provide mobility to the quad. The woman can no longer bend that right knee back, requiring a locked full-leg brace for walking. She can't use steps as she did before, or get up if she falls down. She can't drive a car without hand controls, and balance problems make it difficult to get into a car on the passenger side.

RED LIGHT! "Today I know a good physical therapist should have checked the muscle strength before the surgery," says the woman. "I wasn't aware enough to realize this was something I could have taken care of myself."

The recurvatum surgery left her with a pin improperly placed below the knee. Nerves to the right ankle were cut accidentally so she can no longer move her right foot to the right or lift it up, essentially giving her a drop foot. The necessity for using two full-leg braces put a bigger burden on her shoulders and arms, causing them to deteriorate more quickly."

Emotional Implications

"This surgery essentially left me with a second disability," she says. "It prevented me from doing activities that I had done before. "I am more angry now than I was at the time of the surgery, because I realize the gravity of what actually happened to me. It has to do with independence – the fear of becoming dependent.

"When I had one good leg, I had much better balance. Now I use a powerchair because doctors have determined I should not add to my shoulders' task by using crutches."

RED LIGHT! "The surgery presented a lot more of a risk than I imagined. I'm disgusted with myself for not investigating more thoroughly. I guess the idea of having a 'normal' leg again swept away my reasoning powers," the woman concluded.

Using Common Sense

Avoiding **RED LIGHTS** becomes an important step in any surgery decision. Here are some tips to consider.

REHABILITATION

- Be sure surgery is necessary, that it's the best answer. Therapists with post-polio training, among others, can frequently devise ways of dealing with situations that preclude surgery. Pain can often be alleviated by physical therapy, exercise, learning not to overdo, or bracing. These methods can be much less complicated, expensive and chancy. Even accepted alternative medicine approaches (such as acupuncture, massage, Yoga) may be encouraged by doctors, allowing both disciplines to work successfully together. Try the easy route first.
- Get rehab people lined up before the surgery. Have them determine your muscle strength/capability. Discuss the working of involved muscles with them and get their professional judgment of how the proposed surgery will affect those muscles.

Share their findings with your surgeon as you plan for the surgery.

■ Discuss future needs with rehab experts. Can you count on certain muscles to behave the way you anticipate during recovery? Will your arm be able to aid in transferring the way you expect? Should you have additional equipment on hand for moving around, for bathroom activities, for other daily tasks and desires?

DOCTORS

- Find the right doctor. Ask lots of questions. How many surgeries has he done that are similar to the one proposed? Is she qualified to work with the vagaries of polio muscles/bodies? Are you convinced this surgery involves doing something that can be done? Are you listening with an inquisitive mind, looking for downto-earth solutions?
- Get a second opinion from an expert not affiliated with your doctor. A little more caution can put minds at ease when making important decisions.

ANESTHESIA

- Talk to your anesthesiologist well ahead of the surgery about your specific postpolio anesthesia issues what to watch for, what to avoid, what to do. A detailed respiratory evaluation is very important. Consider, for example, that polio survivors may have an altered sensitivity to induction drugs, maintenance agents, muscle relaxants and opioids. Doctors should consider carefully the dosage of whatever they're using initially to prevent intraoperative overdosing.
- Discuss post-operative pain with the anesthesiologists. Bring up that using local anesthesia at the incision plus patient controlled analgesia may be one way to prevent pain. Increased vigilance during the post-operative period is appropriate and "fast-tracking" a transfer from the operating room to a ward should be avoided.

■ Realize it's possible for anesthetics to cause such temporary problems as gastroesophageal reflux, tachyarrhythmias, and even maintaining blood pressure. Anesthesiologists should be made aware of upper airway and swallowing difficulties, and risk of aspiration. Special care must be taken so that affected limbs are carefully positioned and not fractured. Blankets and warming devices are needed due to cold intolerance. Talk about these issues. Have your doctor arrange for you to have the same anesthesiologist you consulted.

IN ADDITION

- If possible choose a hospital that uses a team approach. Doctors, therapists, technicians and counselors planning together, coordinating their efforts, are more likely to make your experience smooth and successful.
- Do your research. Use the Internet and other reliable resources for sound suggestions and explanations.

Unfortunately we have no definitive list of surgical procedures that always work well for polio survivors – nor do we have one for dreamers to avoid. But we can learn to take precautions that leave us glad we spent the time to check things out.

I got lucky 19 years ago when I needed truly challenging spine surgery. Fate stepped into my life and sent a brilliant doctor to watch over me. I felt totally safe. I knew this was right for me.

It isn't always this way. Sometimes I find myself stuck with a doctor who simply is not interested in looking into unfamiliar polio territory. That's when it's time to move on, find another doctor, search for better answers. Maybe I need the surgery, maybe not. Mainly what I need is to play it smart.

My Experience Using a SureFoot® Cane

Karen Street, kstreet@core.com



wo years ago, while on vacation aboard a cruise ship, I noticed an individual who walked with a unique cane design, always walking with a swift pace. I asked her about the concept, and she explained it was a spring cane that she used for balance and took while rock climbing.

After a nasty fall earlier that year and an injury to my unaffected polio leg, I was struggling to get back on my feet. After 50 years of not using assistive devices and being very active, I had returned to a wheelchair and crutches. I wanted something that would aid my balance. This cane might be the answer.

My physical therapist had never heard of anything like this nor had several medical supply stores in our area. But, I was able to purchase one on the Internet (www.icanwalk.com).

The cane is constructed with an "ankle" and a "foot" articulated (move backward and forward) for increased traction and security. The "foot" is a flat surface pad, about the size of a brick, and allows the cane to stand on its own. The spring action of the cane allows the cane to walk with me.

I have used it from the locker room into the pool area. The "foot" maintained constant contact with the surface for better grip and support.

Last fall, I was nervous about how I would handle the uneven, cobblestone walking I would encounter on a trip to the British Isles. My SureFoot® allowed me to do excursions, and as I tired, I would change the angle of the cane allowing the springs to aid in my gait and balance. I never felt unsure of my balance, and I came home tired but rewarded that I was able to enjoy my trip.

I, like many other polio survivors, find I have to evaluate what tasks I am going to do each day. The SureFoot® allows me to stay active in a smarter way.

Polio-Related Programs on PBS and HBO

The Polio Crusade on American Experience

The Polio Crusade aired on American Experience on most PBS stations on February 2, 2009. Check your local listings for possible future broadcasts and the website – www.pbs.org/wgbh/amex/polio/ to purchase the DVD.

The Polio Crusade, a one-hour documentary from filmmaker Sarah Colt (Geronimo, RFK), interweaves the personal accounts of polio survivors with the story of New York lawyer Basil O'Connor who tirelessly fought on their behalf while scientists raced to eradicate this dreaded disease. His innovative public relations campaign transformed polio into a nationwide cause, as he took an unlikely new approach and turned to the public for donations.

Based in part on the Pulitzer Prize-winning book *Polio: An American Story* by David Oshinsky, *The Polio Crusade* features interviews with historians, scientists, polio survivors, and the only surviving scientist from the core research team that developed the Salk vaccine, namely Julius Youngner.

Polio survivors interviewed include PHI's Board President Lawrence C. Becker and several individuals from Wytheville, Virginia.

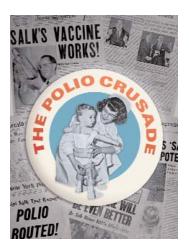


Photo Credit: March of Dimes Foundation

Research

Aging Well with Post-Polio Syndrome

Mark P. Jensen, PhD, Department of Rehabilitation Medicine, Hughes M. and Katherine G. Blake Endowed Professor in Health Psychology, University of Washington, Seattle, Washington

rowing older comes with a number of benefits, including increased wisdom and experience. But growing older also can pose challenges that can limit participation in many valued life activities. This can be particularly true in people who have a history of polio, who not only have to face the residual effects of polio, but who as they age develop the symptoms, such as muscle weakness, pain and fatigue, associated with post-polio syndrome (PPS). Other problems associated with aging can also include increased sleep and mood disturbance. At the same time, researchers have not given adequate attention to identifying, developing and testing effective treatments for problems in people with a history of polio.

To address this gap, the National Institute on Disability and Rehabilitation Research has recently funded a Rehabilitation Research and Training Center (RRTC) at the University of Washington's Department of Rehabilitation Medicine, with the purpose of better understanding the challenges faced by those aging with PPS and other physical disabilities. The target objectives of the RRTC are to better understand the natural course of aging with a disability, to test the effectiveness of interventions for combating depression in people with disabilities as they age, to enhance the employment experience of those with a physical disability, and to disseminate the findings to people with disabilities, their family members and their healthcare providers.

To aid in the goal of disseminating the findings, we plan to publish a quarterly informational column called "Aging Well with Post-Polio Syndrome" in *Post-Polio Health*. The column will be based on the best science available, including a summary of important new findings from the research literature and the findings from our RRTC as they become available. \triangle

For more information, please send an e-mail to agerrtc@u.washington.edu.

The contents of this column were developed under a grant from the Department of Education, NIDRR grant number H133B080024. However, these contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

>

The Final Inch to be on HBO; Receives Oscar Nomination

The Final Inch by Irene Taylor Brodsky of Vermilion Films in collaboration with google.org, follows the massive – and yet highly personalized mission – to eradicate polio from the planet. Polio is described as "one of history's most feared diseases. Now largely forgotten, polio has become a disease of the world's poor."

The film includes footage of "a quiet army" of individuals who go door-to-door to reach the last unvaccinated children. In the most marginalized Muslim enclaves, children are hidden from vaccinators because American-made medicines are not to be trusted.

The Final Inch includes film of polio survivors Martha Mason, North Carolina, who has been living in an iron lung for 60 years and Mikail Davenport, who rode his hand-cycle 950 miles across his native Texas to raise awareness about polio.

To learn more about the film and watch a trailer, check out the website www.thefinalinch.org.



The Final Inch received an Oscar nomination in the short documentary category.

Advocacy

It wasn't a typo! Some reader's of "The Amendments Act of 2008" by Jacquie Brennan of Southwest ADA Center in the fall issue of *Post-Polio Health* (Vol. 24, No. 4) questioned the "not" in this sentence.

People who are regarded as being disabled are <u>not</u> entitled to reasonable accommodations or modifications. Previously, courts had debated whether the ADA required having to accommodate a disability that didn't actually exist.

Ms. Brennan explains, "It goes back to the definition. Remember that the ADA covers people who meet the definition (physical or mental impairment that substantially limits one or more major life activities), who have a record of an impairment, or who are 'regarded as' having an impairment. For people who are regarded as having an impairment, but do not actually have a disability, there is no 'reasonable accommodation' available because they don't actually have a disability. This comes up most often with facial disfigurements or burns. The person doesn't have a disability, is not limited in a major life activity, but may be 'regarded as' having a disability by, say, a potential employer. Because the person does not have a disability, there is no need for a 'reasonable accommodation.' "



WE'RE STILL HERE! Activity in India

Dr. Ujagar Singh from G.S. Memorial Hospital, Rampura Phul, reports, "A recent *Post-Polio Health* motivated me to sensitize society about the need of rehabilitation and other related issues of polio survivors. I organized a press conference and invited local journalists, and they in turn wrote articles that polio survivors don't need sympathy or pity but rehabilitation, attention and care.

"Since I have been doing polio surgeries for the last 30 years, I gave a talk on the role of surgery and emphasized that crawling children can regain their human dignity and take a place in society.

"I have put up a board on the entrance of my hospital depicting the plight of polio survivors who need attention and rehabilitation."

Dr. Singh (center) with members of the press in front of the hospital.

Living with Polio in the 21st Century
April 23-25, 2009

REMINDER: Post-Polio Health International and Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) are finalizing plans for "Living with Polio in the 21st Century" to be held on the campus of RWSIR in Warm Springs, Georgia. Sessions start Thursday, April 23, 2009, and end Saturday, April 25, 2009. The comprehensive three-day program, registration form and options for lodging and transportation are online at www.post-polio.org.



Attendees will be able to tour the RWSIR campus, the Little White House Historic Site and the Historic Pools Museum. The main number at RWSIR is 706-655-5000.

There is no longer space available at the pre-conference Post-Polio Wellness Retreat.

Donations in Recognition of Others

Post-Polio Health International extends a heartfelt thank you to its many Members and friends who financially support its mission by recognizing loved ones.

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

In memory of

Susan Bello Iver J. Boreen Samuel S. Brooker Dale Brown

Mary Ellen Buckley Nat Chrisler Harvey Copper Margaret Cowgill Regina Cuomo

Carl Danielson, Jr. Justin Dart, Jr.

Charles & Bernice Detriek Sue Douglas Marcella Edgington Merle Eyestone Alan Fischer Cleo Fowler Hugh Gallagher Jack K. Genskow

Dr. John Griffin Mary Ann & Ed Hamilton Michael Neubelt Hankin

Werner & Ilse Heumann Betty Hills

Edna Hudson D. Rose Huffaker

Dr. Anne Gawne

George Jarvis Jean Jasperse Virginia Kawamura Gini Laurie Dr. Jack Leven

Jan Little

In honor of

James Agre, MD Augusta Alba, MD Linda L. Bieniek Richard Bruno, PhD

Elizabeth A. Cavalieri Richard L. Daggett Judith R. Fischer

Morton Freilicher Nancy Frick, MDiv, LhD Sandy Guarino Barber

Clifford P. Mackin

George Drummond Mansfield

Louise K. Mathews Donald Mock Stan Natowitz Gladys Neff Mike Nelson

Michelle Nelson's mother

Louise Olmer Bernie Page Margaret Pfrommer Beverly Pokojni Barbara Joyce Price Thomas S. Reed II Ethel H. Reese Bonnie Brady Reynolds Gladys Richards

Bertie Rutledge Helen Sieker Jeanette Slobodin Tom St. John Vergene Timm Marlin Trafton Rose M. Varga Ida Wagner

Mr. & Mrs. Tony Wensman

Alice J. Weseen DeValca White Helen Wichern Sally Williamson Sandy Wipula Corley H. Wright

Jim & Judy Headley Joan L. Headley Frances Lesser

Viola G. Malmgren Roosevelt Warm Springs Institute

for Rehabilitation Stephen Shurick Ellen Tahtinen Joan Wick Joan Zeller

Contributions to The Research Fund ...

In memory of

Cindy Farrell Marilyn Horseman Alice J. Weseen

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

In memory of

Ralph Hartmann Ethel H. Reese

Setting and reaching goals: At year's end, Post-Polio Health International asked its Members to increase their Membership level or to give an extra \$10 to reach a fundraising goal of \$30,000. Many of you responded immediately and generously, helping to raise 93%. We publically thank you for your contributions and invite others to help us reach 100%.

PHI Thanks its Members for their support. If you are not yet a Member,

Join PHII

□ \$30 Subscriber

Quarterly newsletter of your choice:

Support Post-Polio Health International's educational, research, advocacy and networking mission.

Rates Effective July 2007

PHI membership levels make it easy to start taking advantage of timely and important news and activities relating to the late effects of polio. Select your level below and return it with your check or credit card information. Memberships are 100 percent tax-deductible.

Post-Polio Health OR Ventilator-Assisted Living
■ \$55 Subscriber Plus Both quarterly newsletters: Post-Polio Health AND Ventilator-Assisted Living
■ \$100 Contributor ALL the benefits of Subscriber Plus AND Post-Polio Directory AND Resource Directory for Ventilator-Assisted Living; discounts on special publications and meetings sponsored by PHI ■ \$150 Sustainer ALL the benefits of Contributor AND One additional complimentary gift membership to: ■ Person of your choice (include name and address) or ■ Person who has expressed financial need to PHI
Membership at the following levels includes ALL benefits PLUS special recognition in PHI publications: □ \$250
Name
Affiliation
Address
CityState/Province
Country Zip/Postal Code
email
Phone (include area/country code)
Fax (include area/country code)
am enclosing a check for \$ made payable to 'Post-Polio Health International." (USD only)
Please charge \$ to this credit card: ☐ VISA ☐ MasterCard ☐ Discover
Card No.
Exp. Date Card Verification # (3 digits on back of card)
Name on Card
Signature
Send this form to: Post-Polio Health International 4207 Lindell Blvd, #110

PPH25/1

Saint Louis, MO 63108-2930 USA 314-534-0475 314-534-5070 fax Winter 2009 Vol. 25, No. 1

Polio Hall of Fame Monument Expanded

Four organizations, known as the Global Partners, were permanently enshrined on bronze plaques in front of the original monument on Founders Hall in the historic Quadrangle at Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.

Rotary International, the World Health Organization, the Centers for Disease Control and UNICEF were added to the original monument that was unveiled by Eleanor Roosevelt, wife of Franklin D. Roosevelt, in 1958.



In attendance on November 14, 2008, were representatives of the honored organizations and other dignitaries, including Heloisa Sabin, the 90-year-old widow of oral vaccine developer Albert Sabin, and Dr. Peter Salk, the eldest son of inactivated vaccine developer Jonas Salk.



Heloisa Sabin and Dr. Peter Salk

Inside Post-Polio Health (Vol. 25, No. 1, Winter 2009)

Surgery: Another Point of View ... pp. 1, 6-7 ■ Worthy of Note ... p. 2 ■ Ask Dr. Maynard ... p. 3 ■ Feldenkrais®: An Exploration in Possibility ... pp. 4-5 ■ and more.

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" and address and the dates you will be at which address, we will do our best to send the newsletter.



POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 LINDELL BOULEVARD, #110 SAINT LOUIS, MO 63108-2930 USA Non-Profit Org. U.S. Postage PAID Jefferson City, MO Permit No. 210