

Bits of Wisdom from Living with Polio in the 21st Century

Living with Polio in the 21st Century was the title of Post-Polio Health International's 10th International Conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) in Warm Springs, Georgia, April 23-25, 2009.

"The Spirit of Warm Springs" was evident as the staff at RWSIR welcomed 436 registrants. In attendance were survivors, family members and health professionals from 11 countries (46 individuals) and 39 US states and the District of Columbia.

Below are bits of wisdom submitted by participants at the conference.



Distributing scooters

Dr. Dale Strasser, Emory University School of Medicine, Center for Rehabilitation Medicine, Atlanta, Georgia, said, "Those with post-polio syndrome who are best able to cope are the ones who are able to articulate their needs, such as what is going on and what they need to be done." In other words, I think that the more we learn about post-polio problems and our own bodies, the better we will be able to handle life going forward.

-ANN CROCKER, MAINE

I don't think I ever felt so comfortable and unconditionally accepted by a group of strangers. The conference was a life-changing experience.

-ROXANN O'BRIEN, INDIANA

Writers Jacqueline Foertsch and Joyce Tepley, both from Texas, held a session on writing a "polio narrative." I was there to hear about how the tone and message of these narratives have changed and evolved over the past 50 years. I hadn't thought of writing a narrative myself, because acute polio hit me when I was 3 and I was hospitalized only three months, so I have

hardly any memory of the experience. Also, the aftereffects, compared to most of those I saw at the conference, were mild and not dramatic. Many stories have been told already and I wondered what I could add.

I commented that my encounter with polio is more about the experience I'm having now with post-polio, not with the initial polio attack. Joyce answered, "That's your story." And she steered me to Kathryn Black's superb memoir, *In the Shadow of Polio*, for an example of how exploring my family's memories can reconstruct not only my "lost" story of having polio, but their stories of how the family was affected, as well. I have saved the list of exemplary narratives and guides to writing one's life story, hoping I will be inspired to start down that path.

-TOM HANOLD, PENNSYLVANIA

It was good to be with people who were going through the same thing that I am, and to not feel guilty if I got tired or was not feeling well.

-MARY LYNN YOUNG, NORTH CAROLINA

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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.

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Joan Miller

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How to contact PHI

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Worthy of Note

Who will advocate for you? What should they know?

Post-Polio Health International, with the continued support of its Members, still answers the phone and provides information person-to-person each day. In addition, our websites – www.post-polio.org; www.ventusers.org – are visited hundreds of time a day. Over the last two years, I have observed a substantial increase in the number of conversations with children, nieces and nephews of polio survivors, and staff in assisted living and skilled nursing facilities. The frantic questions focus on the crisis of the moment. It appears that many families do not know about poliomyelitis and its late effects. They are not prepared to be our advocates when we need to interact with the medical community. PHI will address this problem, and you can help by answering these questions. Send your thoughts to PHI. (See contact information at left.)

- What is the most important information your advocate should know?
- Have you talked about polio/post-polio with your adult children or other family members? If not, why?
- Have you been through a medical crisis? What lessons did you learn?
- Are you in an assisted living facility? What should the staff know?

PHI would like to interview several adult children of polio survivors who may serve as medical advocates in the future. If you would like to “volunteer” your child, ask them to contact me at director@post-polio.org.

ICD-10-CM

The International Classification of Diseases, Clinical Modifications, is used to code and classify morbidity data from the inpatient and outpatient records and physician offices. Many countries use the 10th revision (ICD-10-CM). Relevant codes are polio vaccine and vaccination – Z24 and Z27; acute poliomyelitis – A80; sequelae of polio – B91; post-polio syndrome – G96.8.

The United States still uses ICD-9-CM (9th revision) in which acute poliomyelitis and the late effects of polio are 138. A proposal before Congress to mandate use of ICD-10-CM by 2011 is meeting resistance from many medical organizations, including the American Academy of Family Physicians, because the increase in the number of codes makes the manual too huge and the cost of converting computer software expensive.

Joan L. Headley, Executive Director, PHI

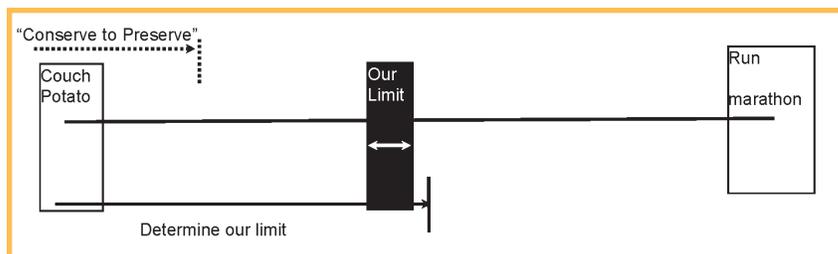
I had two insights. I knew that polio survivors were affected in different ways by the poliovirus, but the magnitude of the differences was very eye-opening. Even the effects of the post-polio syndrome is affecting us in different ways. I wish the world could see what I saw those few days of the conference – a great number of polio survivors – most of them strong, determined, unique and all very special, and each dealing with their lives in very different ways.

The second insight I had was in the session concerning the family. I had a chance to talk to a wife of a polio survivor, and she expressed that she was fearful. I have been the strong one in the family for all of these years but, with the decline in my strength and abilities, I hadn't thought about what they must feel. When I returned home, I asked them to think about what they would like to say to me on this subject, and we had family time in which they spoke and I listened. It was very enlightening. –SHEILA KILGORE, FLORIDA

I observed that I didn't hear "Conserve to Preserve" once during the conference. Nor did any speaker allude to living with post-polio syndrome in reference to having finite use of remaining muscles or neurons. There was no mention of my atrophied leg having finite number of steps left which, once taken, are gone forever. No one advocated overworking my remaining muscles either.

Instead, I heard consensus that I need to pay much more attention to underuse and disuse of my viable muscles. Having post-polio syndrome does not excuse me from taking care of my health in general.

Dr. William DeMayo, John P. Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania, gave the following illustration. He recommended that we be active to our limit.



Each polio survivor is distinct. I have distinct limits. I need to test and establish my limits by doing exercise and activities *slightly* beyond what I perceive to be my limit. To me, this is a significant modification to the "Conserve to Preserve" maxim. Using it, I don't really know my limits, because, according to it, the goal is to not use up remaining strength.

My experience is that I don't have difficulty in knowing when I overwork – my body rebels big time. But, do I know when I am underusing a viable muscle group? This is where I need the assistance of a trained physical therapist.

A clear message that I took away from the sessions is that we become much better at taking care of the challenges of post-polio syndrome if we take care of our health in general by weight control, maybe low-impact seated yoga, good sleep hygiene, relaxation techniques, improved assistive devices, and, of course, by having an uncompromising primary care physician.

–BALDWIN KEENAN, CALIFORNIA



Taking a break

Bits of Wisdom from Living with Polio in the 21st Century

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Education session

It was the first time my husband and I were able to gather not only with such gifted

leaders, but also with other polio survivors. How I like that term, *polio survivor*. How much better than a *polio victim*, which is all I ever heard before the conference. It is much more positive. –EDNA LOVE, FLORIDA

Dr. DeMayo stated that the various muscle weaknesses showing up immediately after the initial viral illness does not necessarily represent all the motor nerves that were damaged by the virus. Other damaged nerves become apparent in post-polio syndrome. Because of the great number of possible damaged nerves, each polio survivor has a unique set of problems, but any one of those problems overlaps with others.

–PAUL SEIB, KANSAS

The sessions not only taught us what symptoms to look for, but gave us needed information as to what could be done. I was especially interested in the Yoga and Tai Chi sessions. I had tried Tai Chi several years ago in the standing position and was not able to do it. Since coming home, I have tried

seated Yoga and Tai Chi. Constant movements of Tai Chi are tiring to me, but I have solved that by “pausing” when the instructor changes positions!

–MONA PHILLIPS, RPT, ARKANSAS

I had not been back to Warm Springs since I was there for treatment at age 5 and that was quite a few years ago. It was a very emotional trip for everyone. The first day was full of tears and bits and pieces of memories. The last day I left with pleasant memories of loving and caring doctors and nurses. Prior to this conference I had no knowledge of post-polio problems. One thing I learned was to be my own advocate and to research thoroughly any surgeries and procedures. The most important thing I gained from the conference was to feel part of a group. For years I felt like a lone ranger, but now I’m part of a new family. –MELVIN COLLEY, GEORGIA

Fernando Torres-Gil, PhD, University California Los Angeles, Public Policy & Social Research, gave me great insight into what I should do with my next ten years. All my life I have been working with older adults and persons with disabilities. Now the task at hand is to develop coalitions between the two groups. At the age of 77, this seems to be a good idea. I am grateful for his wisdom. –MARY ESSERT, ARKANSAS

Once there, the presenters codified a lot of what I already knew or felt – even more valuable were the huddles after times for questions. Being an articulate and assertive person, question times were feisty and when answers did not satisfy, the spontaneous gatherings produced validations, suggestions, comfort. Also in those huddles were practitioners offering their expertise. For me the most important realisation, was that we are relatively well off compared with children in developing countries with polio. –FRAN HENKE, HASTINGS, VICTORIA, AUSTRALIA



Tour stop at the Polio Hall of Fame



I am not a polio survivor myself, but I have been working with the post-polio community in Victoria, Australia, for the last five years. A highlight for me was “Demonstration and Discussion of a Post-Polio Examination: Sorting Out Secondary Conditions,” which provided an overview of a clinical assessment by Drs. Fred Maynard, Retired, Marquette, Michigan; William DeMayo; and Brenda Butka, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee, ably assisted by two polio survivors who were happy to strip down to their shorts (male) and swimsuit (female) in order to demonstrate key physical considerations.

This impressive demonstration and discussion really brought home the importance of being thorough if a physician is serious about assisting their patients: history and current health; physical examination (identify functional ability – with and without the usual aids, range of motion, strength assessment, gait assessment, pain evaluation, etc.); other testing, such as orthopaedic or neurological exams; and the determination of goals and treatment plan mutually agreed upon.

Although general health professionals may not be as experienced as these presenters, I don’t believe they lack the ability or skills to do this type of assessment for polio survivors – it’s more likely to be a lack of time and even a lack confidence.

–MARY-ANN LIETHOF, POLIO NETWORK
VICTORIA, AUSTRALIA ▲

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The Post-Polio Wellness Retreat, facilitated by nine faculty members, was attended by 46 polio survivors, 15 caregivers/spouses from three countries and 21 states.

Total Hip Replacement: My Procedure of Choice

Robert A. McLain, Assistant Professor of Computer Science,
Tidewater Community College, Virginia Beach, Virginia, tomclar@tcc.edu

After contracting polio at the age of 3, I was treated at the Shriner's Hospital for Crippled Children in Philadelphia, Pennsylvania, until the age of 16. The many months I spent in the hospital and years devoted to rehabilitation helped me reach a condition where I could lead a fairly independent life. I have a wonderful wife of 34 years and three great children. I accomplished a 33-year career as a software engineer in the Department of Defense.

My abnormal gait and significant scoliosis, combined with years of coaching baseball and basketball, caused severe damage in my right hip. Several orthopedic surgeons recommended hip replacement surgery.

While doing extensive research, I discovered that there are essentially two very different surgical approaches that can be used for performing hip replacement, and I wanted to be able to choose appropriately between them. My research is summarized in this article. With it, I hope to provide helpful information to my polio associates who may be facing this type of surgery themselves.

Conventional Posterior Approach

Most hip replacement patients undergo surgery using the conventional/standard posterior or anterolateral approach. In a posterior approach hip replacement, the patient lies on his side and the body is held in place with vertical posts or supports. An 8- to 10-inch curved skin cut is made behind the hip joint in the butt. The large muscle close to the skin (gluteus maximus) is split. The deep muscles are then reached and detached. The small muscles that control hip rotation are also detached. The joint capsule that wraps the ball and socket hip joint is then exposed. The joint capsule is cut open, and the hip joint is reached.

Anterior Approach

The anterior approach, first described in 1947 by Dr. Henri Judet, requires that no muscles be cut to get to the hip joint. This technique uses a very special operating room table, a "hana™ table," which is not generally available in most hospitals. The patient lies on it facing up and is supported only at the small of the back and the feet. Replacing the joint is fully seen by the surgeon on an X-ray screen.



Finding a Surgeon

When I decided on the anterior hip replacement, I had to find a hospital that had the special table and a doctor with experience in this approach. This search was not as easy as I thought it would be. Many orthopedic surgeons have not been trained in the anterior surgical approach, and thus do not have any experience. After an extensive search for a doctor, I found Anthony T. Carter, MD, FAAOS, of Hampton Roads Orthopaedics & Sports Medicine in Newport News, Virginia. Dr. Carter is also currently pioneering the technique for hip resurfacing using the same minimally-invasive muscle-sparing anterior approach. In early May 2009, Dr. Carter replaced my right hip.

Comparison of the Posterior and Anterior Approaches to Hip Replacement Surgery

	Conventional (Posterior) Approach	Anterior Approach
<i>Approach to hip joint</i>	Very invasive	Minimally invasive
<i>Skin cut</i>	8-10 inches	4-5 inches
<i>Muscles cut</i>	Many	None
<i>Length of surgery</i>	More than two hours	One and a half hours
<i>Blood transfusion</i>	Usually	Rarely
<i>Post-op movement</i>	Severely restricted	Early mobilization
<i>Post-op inpatient rehab</i>	One to two weeks	Days
<i>Post-op meds</i>	Blood thinner (Coumadin)	Aspirin
<i>Post-op pain</i>	Significant due to severed muscles	Minimal
<i>Recuperation time</i>	Lengthy, with extensive physical therapy	Short (depending upon the patient)

Recuperation

Many post-surgery patients age 62 and with numerous challenges require in-patient rehabilitation for one to two weeks, but I did not. The first day after surgery, a physical therapist had me up walking with a walker, and I had absolutely no hip pain. After a year and a half, it was a wonderful feeling!

In order to be released from the hospital, I had only one more requirement to satisfy. I had to step up on a 6-inch step. All my life, I have ascended stairs by pushing up with my right leg, and then bringing my weak, polio-affected left leg up to the new step. After several unsuccessful attempts, I resigned myself to take one more day of hospital recuperation. The second day was a charm. I transitioned right up the step and was released from the hospital.

For the next three weeks, I had home physical therapy (PT). I walked with the aid of a walker for week one, transitioned to a cane during week two, and used no assistive device by week three. After the formal PT, I continue strengthening my right leg by riding a three-wheel bicycle and aquatic exercise.

The anterior approach in total hip replacement certainly has many advantages over the standard posterior surgical technique. Not only are the medical, financial and aesthetic aspects of the approach easier, but the psychological aspects are predominant because the person's well-being is rapidly restored. The anterior approach to hip replacement worked for me. As with any decision of this magnitude, each individual must do his/her own research, evaluate the advantages and disadvantages, and do what they think is best. ▲

McLain reports to PHI that his insurance paid for his surgery. His plan has a \$30 co-pay for each physical therapy session.

Aging Well with Post-Polio Syndrome: Addressing Habits that Cause Sleep Problems

Researchers at the University of Washington's Aging Rehabilitation Research and Training Center, Seattle, Washington, mcmulk@u.washington.edu

Getting a better night's sleep may not always happen, but if your sleep problems are due to medical issues, there are ways you can manage them. Many medical problems can disrupt sleep in people with post-polio syndrome, such as breathing problems, so treating them is a first step in addressing sleep concerns. Sleep apnea, or episodes where people stop breathing during sleep, is a very important problem to discuss with your doctor if you have this symptom. Pain, which can also disrupt sleep, is a major topic that will be addressed in a future column.

Here are some physical factors that can disrupt sleep and tips on eliminating them.

Caffeine ... Caffeine often plays a role in sleep problems, because it is a stimulant that affects the central nervous system. It temporarily increases alertness and wards off drowsiness, which are also the reasons it can cause sleep problems. People who drink caffeine are less likely to sleep well than those who do not. If you have sleep difficulties, it is a good idea to avoid caffeine or limit it only to the morning. Caffeine is present not only in coffee and black tea, but also in many sodas. Check labels. Decaffeinated coffee and tea are good substitutes.

Alcohol ... Alcohol is a sedative. Although it may seem like it helps with sleep problems, it can actually cause them. For example, alcohol can help you to fall asleep, but it also disrupts the sleep cycle and the quality of sleep. The sleep you get after drinking alcohol is not restful, because it interferes with the ability to achieve and stay in the deep (so-called "Stage 3" and "Stage 4") sleep cycles. It is a good idea to avoid alcohol altogether if you have sleep problems; at a minimum, you should limit drinking it to earlier in the evening rather than right before going to bed.

Sleeping pills ... Even though they are often prescribed to help people fall asleep, sleeping pills can actually worsen sleep problems over time. They also can depress breathing. However, like alcohol, most sleeping medications disrupt the sleeping cycle by interfering with our ability to achieve deep and restful sleep. Almost all sleeping medications, if they are sedatives, are recommended to be prescribed for a very short time (two weeks at most) to help someone sleep during a stressful time. Many sleep medications are addictive, and your body builds a tolerance to them. This is especially true of the benzodiazepines such as Xanax®, Librium®, Valium® and Ativan®. If you are taking a strong sedative for sleep, you should talk to your doctor about tapering off. Getting off these drugs must be done gradually and with medical supervision. Stopping abruptly can be dangerous.

Nicotine ... Nicotine, whether smoked or chewed, is a stimulant like caffeine. It causes temporary alertness or jitteriness, and raises your metabolism. These physical changes can in turn keep you from falling asleep or disturb your sleep once you've fallen asleep.

Aging with a Physical Disability Survey Study

Aging Rehabilitation Research and Training Center, Department of Rehabilitation Medicine, University of Washington, Seattle, Washington

Announcing a new study on aging with a disability (muscular dystrophy, multiple sclerosis, post-polio syndrome and spinal cord injury)

PURPOSE It may be surprising to you, but rehabilitation professionals don't know much about the *natural course of aging* with physical disabilities such as muscular dystrophy, multiple sclerosis, post-polio syndrome and spinal cord injury. It is important to understand how aging impacts your life with a disability, and what to expect long-term as a person with a physical disability ages. The most fundamental requirement for increasing our knowledge and developing effective treatments is the availability of reliable, sensitive and meaningful ways of measuring things like pain, fatigue, mobility and communication, and their effects on day-to-day functioning.

RESEARCH ACTIVITIES If you decide to participate in this study, we will ask you to fill out two to four surveys over the course of four years, depending on your age. As long as you are over 18, you are eligible to participate. These surveys will ask you about your experience with pain, fatigue, sleep, participation in daily activities; your social support; and general mood and outlook. The survey will also ask for some basic demographic information, such as your age, gender and education. The survey will take about 60 minutes to complete. We will mail you the survey and include a postage-paid envelope that you can use to return it to us. Each time we have received your completed survey, you will receive a check for \$25 for your time and effort.

Participating in this research is completely voluntary. You may decide not to participate in this study, and you may withdraw from the study at any time. Your decision to withdraw will not affect your healthcare in any way. There are no penalties or loss of benefits if you choose not to take part in the study or if you decide to withdraw early.

PARTICIPATE If you would like to participate, please contact project staff at: University of Washington, Aging Rehabilitation Research and Training Center, Department of Rehabilitation Medicine, 206-221-5641 or 1-866-928-2114, agerrtc@u.washington.edu* ▲

**Please remember that we cannot guarantee the confidentiality of any information sent by email.*

For these reasons and more, nicotine can contribute to sleep problems (another reason to quit smoking).

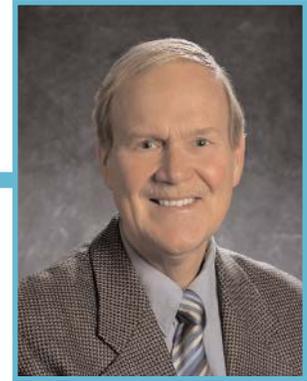
To help you sleep better, you can try:

Exercise ... Getting regular exercise and being aerobically fit can contribute to good sleep. Fitness helps the body naturally create healthy sleep cycles. However, people with sleep problems may want to limit exercise to the morning, since vigorous exercise late in the day may make it difficult for your body to start winding down for sleep. If you have

sleeping problems and you aren't already exercising, explore an exercise program.

Other medications ... Unlike sedatives (discussed above), medications for depression *can* improve sleep and help you get back into a more normal sleep cycle. Talk to your doctor about this to see if a prescription would be right for you. Some anti-depressants that can help with sleep are trazodone, amitriptyline, Paxil® and Zoloft®. ▲

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



Frederick M. Maynard, MD

Question: *People in my post-polio support group say I need to see a “polio doctor.” What is a polio doctor? Do you agree that polio survivors must see a physician with such a designation? Do I need my old medical records?*

A: There is no official certification for a “polio doctor.” I believe the most common use of this informal designation is for a physician with knowledge, experience and interest in evaluation and treatment of polio survivors.

Given the most common new disabling medical problems of polio survivors, physicians with expertise in neuromuscular disease management that includes the ability to recognize and treat chronic musculoskeletal pain and respiratory problems are ideal. The specialty background of these physicians is most commonly neurology, physical medicine & rehabilitation (physiatrist), orthopedics, pulmonary and family practice.

I am not of the opinion that every polio survivor must see a polio doctor. If a survivor is experiencing a series of new unexplainable and disabling symptoms and is unable to obtain satisfactory help, then I would encourage him/her to seek evaluation by a polio doctor/post-polio clinic. These physicians most commonly will provide consultation services to your primary care physician and may also provide continuing comprehensive follow-up of post-polio related problems.

Many survivors need a network of medical providers (orthopedist, pulmonologist, orthotist, physiatrist, neurologist, etc.) and may need help with coordination and communication among them. A primary care physician can fill this role, although many polio survivors do this function themselves, because they are sufficiently

sophisticated with medical and rehabilitative issues.

There is no “one size fits all” answer to your question. The question is better asked, “Are polio survivors’ medical and rehabilitative needs being met by their current providers?” If not, then specialist consultations are appropriate. If survivors need a comprehensive evaluation of medical concerns and functional changes, then I think seeing a “polio doctor” is invaluable.

A: Regarding the question about tracking down your medical records, they might be of interest, but of little real value to your physicians in making treatment decisions. To find an explanation for your muscle pain, seek an evaluation by a physician who familiar with post-polio syndrome, such as a local neurologist or physical medicine & rehabilitation specialist.

He/she should perform an EMG (electromyography) for two good reasons. First, it is the best test to establish that the muscles now having pain do show a pattern of electrical activity compatible with having remote (old) polio involvement; that is, they appear to have lost the typical number of motor nerve cells.

Second, the test will show if the nerve/muscle cell status is stable or unstable. This fact can guide your physicians and therapists in treating your muscle pain with exercise, including how much exercise and how concerned you or they need to be about over-exercising/overusing these painful muscles. ▶

The late Gini Laurie, PHI’s founder, liked to add the honorary degree “RD” (Real Doctor) to recognize physicians who have genuine empathy for and effective communication skills with polio survivors. The best way to find a knowledgeable polio doctor is networking with other polio survivors and through the *Post-Polio Directory 2009* in the “Networking” section of www.post-polio.org.

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- Check the following reference in the medical literature to become familiar with the use of EMG information for guiding management. Halstead, L., Carrington, G., & Pham, B. (1995). National Rehabilitation Hospital Limb Classification for Exercise, Research, and Clinical Trials in Post-Polio Patients. In M.C. Dalakas, H. Bartfeld & L.T. Kurland, (Eds.), *The post-polio syndrome: Advances in the pathogenesis and treatment* (pp. 343-353). New York, NY: New York Academy of Sciences. ▲

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is the 2009 focus of WE'RE STILL HERE!**



PHI members: TRY THIS! Pick one accessibility problem in your community – maybe it is the steps at the closest dry cleaner or your physician's office; the lack of curb cuts near your favorite coffee shop; the impossible placement of disabled parking stalls at the far end of a parking lot – and tackle it.

Experience tells us that people in charge want to make changes that will benefit their customers, all the citizens in their community – not only polio survivors but others with disabilities, the elderly, and mothers with strollers. They may simply be unaware. We can help them understand.

Work with the establishment to solve the problem. Take pictures to explain, get positive publicity by calling your favorite local TV newsperson or newspaper features writer. Arrange coverage for October 11-17, 2009.

Remember to report your activities to PHI at info@post-polio.org. ▲

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Aging Well with PPS ... Sleep Problems ... pp. 8-9 ■ Ask Dr. Maynard ... p. 10 ■ 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" address and the dates you will be at each address, we will do our best to send the newsletter.

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