

## Remembering *The Polio Crusade*

Reji Mathew, PhD, New York University, rm150@nyu.edu

It is not often that we get to see an intricate behind-the-scenes account of the human drama fueling a medical breakthrough. *The Polio Crusade*, a documentary film written, produced and directed by Sara Colt for PBS's "American Experience," based in part on the Pulitzer prize-winning book *Polio: An American Story* by David Oshinsky tells of the tireless efforts of researchers, advocates and fundraisers to find a vaccine for poliomyelitis.

To further elucidate the enduring lessons of *The Polio Crusade* for our modern times, David Oshinsky, Sara Colt, David Rose (archivist for the March of Dimes) and Larry Becker (board member of PHI) share their insights.

### A Personal Crusade

What first emerges in screening *The Polio Crusade* is that this crusade was a strikingly personal one. "The great challenge was to take people to the place of fear and contagion; that the polio epidemic changed the way people lived their lives at the time," Colt stated.

The sense of the personal became even more dramatic when polio, considered primarily a childhood illness, affected a most unlikely adult, Franklin Delano Roosevelt, at age 39 in the summer of 1921. FDR transformed his personal pain into an unwavering passion to serve the needs of polio patients.

As the film illustrates, the personal nature of the Crusade was deepened by the entrance of Basil O'Connor, FDR's close friend and law partner. Basil O'Connor was not a self-chosen crusader, but his fierce loyalty to FDR fueled him to take the crusade to the next level. In 1938, O'Connor was appointed the first president of the

National Foundation for Infantile Paralysis, founded by FDR, known today as the March of Dimes.

### The Polio Vaccine: Building-Block Science

In the book, Oshinsky documents that the achievement of the polio vaccine, despite focus on its central celebrity figure Jonas Salk, is the result of numerous building-block steps of scientists that came before Salk. These include the research team of Enders, Weller and Robbins (1948); they received the Nobel Prize in 1954. Yet the fierce debate between Salk, who favored the killed-virus vaccine, and Sabin, who advocated for a live-virus vaccine, remains the central narrative thread of the race for a vaccine. Salk, who was favored by Basil O'Connor, was granted the go-ahead for a vaccine field trial, which in 1954 was administered to over two million children in 44 states.

The road to a vaccine for polio was not without its controversies. Previous to the trials of 1954, Salk tested his vaccine on children in institutions for the "crippled" and the "feebleminded." The vaccine was tested at a time when there was no such thing as informed

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Polio survivor Reji Mathew attended the premiere screening of *The Polio Crusade* in New York, resulting in an analysis of the film based on interviews with the principals. Here is an abbreviated version. To savor the longer version with additional insightful comments, go to PHI's website, [www.post-polio.org/edu/pphnews/PPH25-2sp09polcrusex.pdf](http://www.post-polio.org/edu/pphnews/PPH25-2sp09polcrusex.pdf). Members may contact PHI for a copy.

*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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## **Worthy of Note**

**NeedyMeds** ([www.needymeds.org](http://www.needymeds.org)) has the tagline of “find help with the cost of medicine.” Visit the site to find patient assistance programs, drug coupons and extensive listings of brand name and generic drugs. The newest project is a “Discount Drug Card” that is good at approximately 50,000 participating pharmacies, including CVS, Rite Aid and Walgreens. Please note: This card is not a prescription insurance program — it’s a drug discount card. The card is not valid for those who use Medicaid or Medicare to pay for their medications. There may be no savings for certain drugs, including many inexpensive generics. Go to [www.needymeds.org/drugcard](http://www.needymeds.org/drugcard) to download the card. \*\*\* The National Institute on Aging suggests you will want to ask these questions about each new medicine. What is the name of the medicine, and why am I taking it? What medical condition does this medicine treat? How many times a day and how much medicine should I take? For how long? How long will it take to work? What should I do if I miss a dose? Are there any side effects I should know about? When should I call you if I am having side effects? Can I safely mix this medicine with the remedies, vitamins and OTC drugs I am taking? *Each time you visit:* Be sure to ask your doctor if you still need to be on all your medicines. \*\*\* According to the FDA, name confusion is among the most common causes of drug-related errors. For example, errors have occurred in prescribing the arthritis drug Celebrex, the anticonvulsant Cerebyx, and the antidepressant Celexa. \*\*\* While it is not a blanket recommendation for all polio survivors, some survivors who have considerable muscle atrophy, and consequently weigh less, take a lesser dose of some medications than normally prescribed. Only do this in consultation with your physician.

**192** is the total number of reported cases of acute polio worldwide in 2009, as of April 1, 2009, according to [www.polioeradication.org](http://www.polioeradication.org).

**April 8, 2009 from the IFRC:** The International Federation of Red Cross and Red Crescent Societies is launching an emergency appeal for 2.4 million Swiss francs (US \$2.1 million, EUR 1.6 million) to support Red Cross and Red Crescent Societies from 14 countries in Africa to respond to wild poliovirus outbreaks across the continent. There are 15 countries that have been affected by a recent outbreak (Angola, Benin, Burkina Faso, Central African Republic, Chad, Democratic Republic of Congo, Côte d’Ivoire, Ethiopia, Ghana, Kenya, Mali, Niger, Togo, Sudan and Uganda). THE IFRC campaigns will be operated by the Ministries of Health, with support from the Global Polio Eradication Initiative, spearheaded by the World Health Organization (WHO), Rotary International, the US Centers for Disease Control and Prevention (CDC), and UNICEF.

*Joan L. Headley, Executive Director, PHI*

**Reji Mathew, PhD**, is a disability advocate and freelance writer. She is also a psychotherapist and clinical instructor at New York University. See her monthly column in *Advance for Occupational Therapy* (<http://occupational-therapy.advanceweb.com/Article/Mental-Health-Center.aspx>) exploring the psychological aspects of recovery and rehabilitation.

consent as we know it today. Another setback was the haste to reproduce the vaccine. The National Foundation contracted with several drug companies, notably Cutter Pharmaceuticals, to manufacture the vaccine. What resulted was the distribution of a contaminated batch of the polio vaccine that led to several cases of paralysis and death. "It was a time of risk and reward outweighing the risk of getting harmed," Oshinsky stated.

### The Role of the March of Dimes

*The Polio Crusade* also deserves a subtitle, *The March of Dimes Crusade*, as it is also a remarkable case study of how a nonprofit organization stood at the forefront, organizing a multi-level effort to conquer the disease, more specifically, the cultural beginnings of public philanthropy.

Additionally, as portrayed in the film, O'Connor's approach was to seek donations from the public rather than from established philanthropists, asking every American to contribute what small change they could, "even as small as a dime." Hundreds of nameless, faceless Americans contributed to the cause. "The people who contributed felt it was their vaccine; they were invested in the outcome," Colt stated. David Rose also notes the pioneering strategies of the March of Dimes – engaging celebrities, broadcasting public health announcements, and hosting fundraising events – are now commonplace in today's health advocacy culture.

Both the book and the film do fall short in not fully exploring the issue of race, as the polio crusade took place in the context of a segregated America. March of Dimes history reveals forgotten heroes such as Charles Bynum, a civil rights activist who served as the

Director of Interracial Relations for the March of Dimes, worked tirelessly on outreach and fundraising initiatives to offer equal representation in care for African-Americans.

### Polio Pioneers and Polio Survivors

Sarah Colt tells two parallel stories of polio. First, she depicts the polio vaccine pioneers, with endearing footage of children wincing, smiling and braving first doses of the polio vaccine. She then provides an account of the children and adults who contracted polio.

For example, Colt tells the story of Annie Crockett-Stark's brother, who contracted polio in Wytheville, Virginia. Crockett-Stark described in compelling detail, how her parents took everything of her brother's belongings – his entire identity – and "burned it in the front lawn." Colt's efforts to tell these stories raise awareness of the countless American families that were shaped for a lifetime by the lasting effects of polio.

The personal story of Larry Becker is a central one. "Remembering polio history is the first necessary step in re-establishing our social context. Unless people remember, it's not going to be easy to enlist them in the aftermath – post-polio," Becker stated.

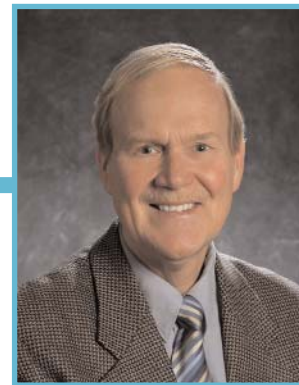
Polio survivors may have a myriad of feelings about this aspect of polio history, but the narrative of *The Polio Crusade* is not simply a story about polio. It is a story of how scientific advances reach people. Millions of people in the United States are waiting for cures, interventions and advances from science. The lingering lesson of *The Polio Crusade* is that for any other disease community to achieve a similar outcome, they will require no less than the same charismatic, integrated effort. ▲

### Resources

*Polio: An American Story*, David M. Oshinsky

*Images of America, March of Dimes*, David W. Rose

*The Polio Crusade*, "The American Experience," PBS



Frederick M. Maynard, MD

**Question:** *I am 69 and had polio in my right foot when I was 20 months old. I have had tendon transplants, heel cord lengthening surgery, and some toes fused. I wore a short leg brace following surgeries when I was eight years old at Warm Springs in Georgia. I had five children and have always been active, e.g., marched in the band, rode horse-back, biked, skated and swam, and usually did it better and faster than the others. (I was still “different” though.)*

*I have had rheumatoid arthritis since age 30 and now have osteoarthritis. I noticed at age 40 that I was getting much weaker and more unstable on my feet. My right calf is much smaller than my left one. All the tricks I used to hide my limp failed me. Since a total hip replacement, I tire much more easily and walk with a cane. (I have a 1-7/16 inch difference in leg length.) I also go to a pain clinic for spinal stenosis. Should I walk as much as possible (30 minutes or so a day) or “save my strength,” and pray tell, save it for what? NAME WITHHELD*

**A:** Thank you for sharing your story. It illustrates the challenges faced by people with moderately severe polio-related residual weakness who have led surprisingly active lives. You, as have many others, faced declining strength already in middle age. You next confronted age-related and, possibly, overuse-related complications, such as hip arthritis. Rheumatoid arthritis and spinal stenosis would be considered unrelated medical conditions (also known as “co-morbid medical conditions”) that complicate and compound your post-polio condition. I would advise you stay as active as you can while not aggravating your pain problems. You may wish to consider water exercise workouts to

maintain fitness and vitality, rather than walk “as much as possible.”

I identify with your rhetorical question of “save my strength, and pray tell, for what?” You should use what strength you still have to fulfill your life’s priorities requiring motor function as best you can. You should not obsess about saving your energy for unknown future needs. Please, just don’t push yourself to such a degree that you hasten the day when you can’t even walk at all or do transfers by yourself. Post-polio life requires constant rebalancing, like walking a tightrope!

**Question:** *I am a male age 60 who contracted polio at age six months and Guillain-Barré syndrome at age 40. I was diagnosed with post-polio syndrome at age 55. Four weeks ago I had testosterone pellets implanted when I found out I had a major testosterone deficiency. What happened four weeks later, as reported to my naturopathic doctor who prescribed it, was simply amazing.*

*My legs, hips, hands, arms, chest and stomach muscles are beginning to look like they did as a younger man when I was body building. My balance is 100% changed. I avoided hugging people because it knocked me off balance. I normally could not step off a curb due to weakness in my good leg. Now I just do it! I am walking upright instead of hunched over for fear of falling. I feel “solid” again.*

*I have zero fatigue. My joint pain, other than the left knee, is gone. My right*

*ankle is a bit sore in the morning, and it takes a step or two to warm it up. Of course, that is because I am walking around now. I've lost weight, and more importantly, lost inches off my waist. I am able to sleep 6-7 hours without medication. My mind is clearing; my enthusiasm is off the charts. I own and run several corporations and had pretty much given up on the future of any normal activity. I don't have to fake optimism.*

*I felt compelled to write to you and describe the results in hope that you may pass them along. I have no logical answer other than the testosterone replacement. I have been confounded, and somewhat discouraged, by the lack of response from my mail to physicians and researchers around the world that explained how my post-polio syndrome symptoms have disappeared since I had the testosterone pellets implanted. While my results may be too good to be true, they are true nonetheless. Can you explain the lack of response?* MR. HALSETH

**A:** Your story nicely illustrates how post-polio symptoms can be confused with other diseases. Given the dramatic reversal of your muscle atrophy, and the complete resolution of other symptoms within one month of treatment with testosterone, I have no doubt the primary diagnosis was low testosterone, not post-polio syndrome.

In answer to your second question about the lack of response from doctors and researchers, it is likely a result of professional skepticism. One person's story of dramatic improvement attributed to a "treatment" does not prove that the "treatment" was the cause of the improvement, as opposed to another unknown coincidental cause, or even a placebo effect. Only a well-designed study can prove this, and all

doctors and researchers are literally trained to be skeptical about claims of improvement. Therefore, they are rarely impressed by or responsive to undocumented miracle stories.

**Question:** *Often we polio survivors have very few options that are helpful in understanding our circumstances and what direction to take. Thank you for being available to provide this important service. Here is my question in three parts. When I read The Polio Paradox by Richard L. Bruno, PhD, he assured us that post-polio syndrome (PPS) is not life threatening. Is this still a valid statement? Is there any evidence to the contrary? Secondly, will the effects intensify and cause weakness to the level that one experienced during acute polio? Also, does PPS affect the brain's ability to function normally in speech, sight or thought processes (through stress or brain lesions)?* MR. MALIGIA

**A:** There is no evidence that PPS is "directly" life threatening. PPS symptoms can become sufficiently disabling to "indirectly" shorten one's life, such as by imposing a fearfully sedentary lifestyle that leads to hypertension, obesity, high cholesterol and heart disease. If severe post-polio breathing and swallowing problems develop and are not treated appropriately, critical life functions can also be put in jeopardy.

A clear answer to your second question is more difficult. Theoretically, at least, one could again become as weak as one was at the time of initial recovery from the acute polio infection. In my clinical experience of 25 years, this never happens. While severe worsening may happen TO a post-polio person, it does not result FROM post-polio syndrome as defined by a consensus

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# THE GARDEN

## Incorporating the Principles of Universal Design

Susan Miller, San Diego, California, susanrsf@sbcglobal.net



Spring is here! Spring is traditionally the season of renewal, inviting us to bear witness to the cycles of nature. Communing with nature is an antidote for depression and anxiety, a break from the boredom of winter's confinement and isolation from the wider world ... that is, for those of us who can access these benefits.

Over our 43 years of marriage and my steadily increasing limitations, we've moved a number of times. With each move, I became increasingly aware of how to bring the world and nature to me, through my personal space in the great outdoors – The Garden.

**We've done so with the help of Universal Design.** Its goal is to create access in the broadest sense, to the greatest number of people – of every age, stage of life, and ability – in a manner that is safe, efficient, convenient and requires minimum physical effort. As it applies to the garden, simply put, it means creating access to the outdoors, directly, or indirectly from the home's interior via the glass openings. It means access through all of our senses, including touch, taste and smell.

We came up with three overarching objectives, giving them easier to remember catchphrases: OUTSIDE IN; 360+ FIVE; and MAKE IT YOURS.

**OUTSIDE IN:** Bringing the outside into the home's inside means making the outside a part of our everyday lives, even when we can't get outside. On the other side of every window and doorway of the house, we can create or encourage some sort of visual interest that connects us with the fauna and flora.

Why else would we plant several butterfly bushes? You can add interest with birdbaths and feeders specific for various birds, like hummingbirds, a true joy

to observe. My father used to put nuts on the window sills of his office so he could observe the squirrels, "nose to nose" he'd say, as they worked on their tasty treats.

Another part of this objective is to make ingress/egress easier, through such things as making existing thresholds level, the use of easy-open or automatic push-button doors, and through use of proper hardware, such as lever-type handles. We increased access by making structural changes to doors, converting one to a Dutch-door and another to a glass door.

We also added new glass doorways, where one had been a window, enhancing visual access. We eliminated the bumpy threshold of a sliding door to the patio by changing it to glass-paned double doors. Flooding the interior with light has the advantage of making it brighter and more cheerful. In sum, to bring the outside in, work from the inside out ... going through the house and planning the view from each window and door.

**360+ FIVE** refers to the 360 degrees around the property, and adding 'plus five' to 360 = 365 days of the year. It is another way of saying that the entire property should be part of The Garden, and it should have year-

For more advice from Susan and photographic examples of universal design in gardening, visit [www.post-polio.org/edu/pphnews/PPH25-2garden.pdf](http://www.post-polio.org/edu/pphnews/PPH25-2garden.pdf). Members may contact PHI for a copy.



“The Principles of Universal Design and their guidelines were developed by a working group of architects, product designers, engineers, and environmental design researchers as part of a project coordinated by the Center for Universal Design at North Carolina State University. The seven principles that describe characteristics that make designs universally usable are: Equitable Use; Flexibility in Use; Simple and Intuitive Use; Perceptible Information; Tolerance for Error; Low Physical Effort; Size and Space for Approach and Use.”

round interest. In selecting plants, it is important to consider their appearance in each season, not just the blooming one. Are there berries or fruit or fall color? After the leaves drop, are there interesting branching structures (curly willow) or are the branches themselves colorful, (red-twig dogwood)?

To utilize the entire property, it's necessary to “visually improve” the less attractive things, such as garbage cans and maintenance equipment and supplies. To enclose the garbage, we installed a three-sided tall picket fence along the garage, and planted bushes and vines along the front and sides to make the fence less conspicuous.

**MAKE IT YOURS:** Simply put, personalize your property. Let your imagination come alive and make it uniquely yours, just as you do inside. As you examine your yard, think of what feelings you want to evoke. Do you want to memorialize someone or something? Is there a piece of sculpture or memento that someone gave you? A special flower or plant that reminds you of a significant person or place? A favorite fragrance – jasmine, lily, gardenia? What about a little vegetable/herb garden – either in pots or in ground?

Container gardens are perhaps the most versatile and convenient for people with disabilities, as they offer endless variety in terms of size, height, grouping and location. They can be easily changed or moved without disturbing anything else in the landscape that's dependent on it to fill some purpose. In fact, they can be used to add “landscaping” to an area that has no soil, such as we did along a long barren wall on our patio that wasn't deep enough for seating. We grouped

a bunch of oversized pots, putting a small tree in one. That wall is now one of the most interesting, indeed, spectacular spots on our patio.

In constructing container gardens, select plants with a variety of textures and complementary colors. Succulents have proven to be real winners, and can be combined with bromeliads, cacti and deciduous plants, including small trees. Kalanchoes are one of my favorites for container arrangements with their waxy, thick leaves and long-lasting blooms.

Remember, these plants all must have the same general requirements for light, water and nutrition!

#### **PLANT SELECTION and PLACEMENT:**

Given our limitations, it's important to avoid plants that are temperamental or require too much maintenance. With thousands to choose from, and so many resources available to help navigate through them, finding the right ones is pretty straightforward. And there are maintenance techniques that can make them easier as well.

One way to start is by choosing plants highly recommended by professionals in your area; these will get you proven winners. However, if you'd like your garden to be unique, try some unusual or rare species. Or be adventurous by trying plants from other countries with similar climates. You can easily find them on the various websites.

Indeed, we have plants from every continent on the globe, except the two polar extremes, including the Mediterranean, South Africa, Australia,



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England, Portugal, Mexico, Brazil, Spain, Indonesia, Japan, Bolivia, etc.

Regardless of the kinds of plants you choose, it makes sense to select plants that have advantages such as low water needs, or are drought tolerant, insect or disease resistant. (For hand watering, as in containers, make sure the water source is handy; if possible, install multiple water spigots around the house perimeter.)



Avoid plants that need lots of attention – trimming or pruning, dead heading, staking – or those that are unruly or messy due to their dropping leaves or sap. Definitely avoid plants labeled as aggressive or invasive, plants that take over the garden, crowding out all the others, and are impossible to kill!

While creating our own gardens requires a good deal of research and

planning up front, we found that making one overall “Grand Plan” allowed us to bite off one piece at a time, as budget and time allowed. Good planning up front will help pay for itself by eliminating costly mistakes, keeping us focused on our goals to avoid impulsive temptations.

Remember this: Our property is our own personal stake in the great outdoors, a worthy investment to plan and create in such a way to bring joy, satisfaction and inspiration throughout the year and years; it will be an enduring contribution to our communities, serving as the legacy we leave for others, even beyond our lifetimes.

### FINAL THOUGHTS

The home that people create today will survive them by many years. There’s no ADA or other federal mandate to require built-in flexibility or visitability. (See box.)

The significance of this is that every year in the US alone, many thousands more of these inaccessible properties become a permanent part of the landscape, adding to the already huge inventory of inaccessible homes, thus perpetuating inaccessibility for future generations. These structures will dictate who may and may not be able to live in them, long after their original owners are gone.

Can you begin to sense the mandate appearing before us? Look at it this way: If we don’t take on this mandate by doing our part to build fully accessible homes and properties, *who on earth will?* ▲

Photos by Bob Wigand

“**Visitability**” has been a growing trend nationwide for the past ten years. The term refers to single-family housing designed in such a way that it can be lived in or visited by people with disabilities. A house is visitable when it meets three basic requirements:

- at least one no-step entrance;
- doors and hallways wide enough to navigate through;
- a bathroom on the first floor big enough to get into in a wheelchair, and close the door.

“When someone builds a home, they’re not just building it for themselves – that home’s going to be around for 100 years,” Concrete Change founder Eleanor Smith told *The New York Times*. “These things hurt nobody – and they help a lot of other people.”

“The visitability movement is based on the conviction that inclusion of basic architectural access features in all new homes is a civil and human right and improves livability for all,” according to *Visitability: an Approach to Universal Design in Housing*, a publication by the Rehabilitation Engineering Research Center on Universal Design at The State University of New York, University at Buffalo.



## Aging Well with Post-Polio Syndrome and Sleep Problems

Researchers at the University of Washington's Aging Rehabilitation Research and Training Center, [mcmulk@u.washington.edu](mailto:mcmulk@u.washington.edu)

One of the first things that people notice as they grow older is a change in their sleeping patterns. The older they get, the less they sleep; or they just feel less rested when they wake up. Most people are not sure why they do not feel rested, nor are they always sure how to improve their sleep. Adding post-polio syndrome into this equation can lead to more confusion about what exactly is causing the sleep problem and, perhaps more importantly, how to deal with it.

People aging with the effects of polio are not alone in dealing with sleep problems. In 1995, Mellinger and colleagues found that 25% of people between the ages of 65 and 79 reported serious insomnia as compared to only 14% of people between the ages of 18 and 34. In addition to asking generally about insomnia, researchers evaluate sleep quality by asking about the number of times a person wakes up after they've fallen asleep, the amount of time someone spends in the lighter stages of the sleep cycle (so called "Stage 1" and "Stage 2" sleep), and the total amount of time a person spends asleep.

All of these factors change as a person gets older. Aging people increasingly wake up during the night, spend more time in lighter sleep stages and spend less time in deeper sleep stages, and spend less total time asleep.

Talk about sleep problems leads to one question: What's the big deal? While sleep problems can be annoying and lead to feeling sluggish and less energized throughout the day, some researchers, such as Al Lawati and colleagues in 2009, Bradley and colleagues in 2009, and King and colleagues in 2008, have found that poor sleep can lead to heart disease, diabetes and stroke. The fact is that

sleep problems are important and should not be ignored.

What can and should people do to improve sleep? The answer depends on the type of sleep problem. In general, there are four reasons why people who had polio may have trouble sleeping. Physical issues can cause breathing problems (such as sleep apnea) that can interrupt sleep or reduce the quality of sleep.

A second cause is anxiety or a "racing mind." Both of these issues can cause trouble falling asleep as well as a shorter amount of total sleep time.

A third reason is due to medications (commonly taken by individuals with post-polio syndrome) that disrupt the sleep cycle and lower the quality or amount of sleep.

And, people with post-polio syndrome report pain problems, and pain can contribute to problems in sleeping.

One reason why the research that we do at the University of Washington is so important is that it can lead to interventions and solutions that actually work. Once the cause of sleep problems is known, each cause has its own set of management solutions. In four future columns, we will discuss each sleep problem category in depth, and we will offer strategies and solutions for dealing with them. ▲

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statement of medical researchers (March of Dimes Birth Defects Foundation, 1999, *Identifying Best Practices in Diagnosis & Care*, Warm Springs, GA: March of Dimes International Conference on Post-Polio Syndrome). Certainly, PPS will not be more debilitating than acute polio, because it develops slowly and does not suddenly challenge all critical life functions like an acute infection does. Additionally, small changes in motor function can and should be treated with appropriate rehabilitative strategies, such as use of compensatory devices and making activity changes.

Last, PPS does not directly affect the brain's capacity to see, talk or think, but it can at times affect those functions temporarily if its symptoms (such as severe fatigue or pain) are so intense that they overwhelm one's concentration and/or alertness. When well rested, all brain functions will return to their normal state.

**Follow-up Question:** In Vol. 25, No. 1 (page 3), Dr. Maynard responded to a question about "using my toes more than my whole foot to walk now." He explained that 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 this muscle, adjacent muscles (toe extensors) that act to move the toes upward also contribute to picking up the foot. In fact, one is not walking more on the 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. Ms. Toher asked, "What can I do about this?"

**A:** If the toes are rubbing on your shoe tops, a "high toe box" shoe design may be helpful. It wouldn't hurt to try taping the toes. If the muscles continue to weaken, a lightweight short brace may become necessary. There are several new designs that may be satisfactory, including ones that merely attach to the back of a shoe's counter and are hardly visible. A high-topped shoe or hiking boot might solve the problems on unlevel ground. Some people also do much better with very lightweight soft moccasin footwear, at least when weather and walking surfaces permit. Seeing a good orthotist and/or working with an experienced post-polio physician to find a feasible individual solution would be your best option. ▲

### *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.

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PHI strives to publish an accurate list. Contact us if we made an error.

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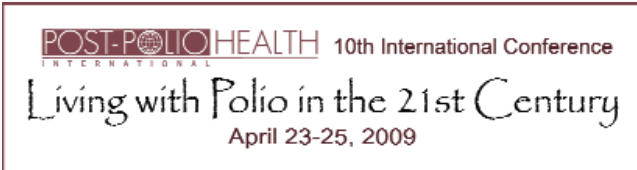
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**Help us decide.** PHI is looking for ideas for the focus of WE'RE STILL HERE, October 11-17, 2009. In 2007, Members wrote "Letters to the Editor." In 2008, Members spoke at Rotary meetings. The purpose of the week is to call attention to the accomplishments and needs of the survivors of polio. Do you have a unique idea for 2009? Send it to [info@post-polio.org](mailto:info@post-polio.org). ▲



**Information to be available.** Due to the outstanding response, registration for the conference to be held at Roosevelt Warm Springs Institute for Rehabilitation in Warm Springs, Georgia, was closed March 21, 2009.

PHI has compiled the abstracts/handouts/summaries in daily program books as is our custom. We will incorporate the additional information presented at the conference and make the books available at a later date for a reasonable fee. Watch [www.post-polio.org](http://www.post-polio.org) and the next issue of *Post-Polio Health* for details.

Co-Directors of the Post-Polio Wellness Retreat, Fred M. Maynard, MD, and Sunny Roller, MA, report that 60 individuals will be attending the pre-conference event. The National Center on Physical Activity and Disability ([www.ncpad.org](http://www.ncpad.org)) will videotape parts of the Wellness Retreat and PHI will summarize the activities. The goal is to encourage others to duplicate the retreat in other parts of the world. ▲

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- **The Garden** ... pp. 6-8 ■ **Aging Well ... and Sleep Problems** ... p. 9 ■ **and more.**
- Moving? Change of address? Please notify PHI before you move by calling 314-534-0475 or email [info@post-polio.org](mailto: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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