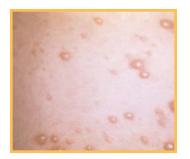
Post-Polio Health

## www.post-polio.org

## Shingles Vaccination: Should Polio Survivors Receive One?

hen polio survivors began asking about the shingles vaccination, PHI polled 19 doctors (experienced in treating polio survivors) for their recommendations. No conclusion could be drawn from their varied responses. Also, currently there is no experimental data regarding whether or not polio survivors should get this vaccine. Therefore, the most prudent thing to do is to study available information, talk with your physician about your individual circumstances, and then make your own decision.



Herpes zoster (shingles). Courtesy of Centers for Disease Control and Prevention

Consult your personal physician about receiving a shingles immunization and to be sure that you have received all of your adult shots. **The Vaccine:** In 2006, a vaccine called ZOSTAVAX<sup>®</sup> was licensed to prevent shingles in people over age 60. In the clinical trial, the vaccine was successful in 51% of the participants 60 and older, and was most effective in those aged 60 to 69. Shingles-related pain was also reduced in many of those receiving the vaccine.

**Precautions:** The Centers for Disease Control and Prevention (CDC) says those who should not get this vaccine are people who have had a life-threatening allergic reaction to gelatin, the antibiotic neomycin, or any other component of the shingles vaccine. The CDC advises those who have severe allergies to inform their doctor when considering the vaccine.

Because the shingles vaccine contains the live though weakened chickenpox virus, the CDC does not recommend the vaccine for individuals with the following: a weakened immune system due to HIV/AIDS or another disease that affects the immune system; a history of cancer affecting the bone marrow or lymphatic system, such as leukemia or lymphoma; treatment that affects the immune system, such as steroids for organ transplants, or radiation/chemotherapy for cancer; and active untreated tuberculosis.

Individuals who are moderately or severely ill (including those with a temperature of 101.3° or higher) should wait to get their vaccine until they are well.

The Disease: Approximately one million cases of shingles (also known as herpes zoster) occur in the United States each year, generally in people over age 50. Varicella-zoster virus (VZV), the same virus that causes chickenpox, causes shingles. Anyone who had chickenpox is at risk for shingles because the chickenpox virus remains in the nervous system for the rest of one's life. Certain circumstances, such as stress or immune deficiency, can cause the virus to reactivate and move back down the nerve fibers to the skin, causing the rash of blisters that is the hallmark of shingles.

Shingles may begin as a sensitive or burning feeling in the skin that turns to a rash, usually down a certain continued, page 3



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**

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

> Special thanks ... Nancy Baldwin Carter Judith R. Fischer, MSLS Sunny Roller, MA

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## 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.

Inside this Issue ...

#### Pages 1 and 3

#### Shingles Vaccine: Should Polio Survivors Receive One?

Although difficult to view, the cover photo is intended to be educational, so you will speak with your physician. My internist's office does not keep the vaccine on hand, but after observing the excruciating pain my Uncle John endured, I had them place an order for me.

Pages 4 and 5

#### **Study Tour of United States and Canada**

It is interesting to see ourselves as others see us. Among her observations of the tour sites, Community Officer Mary-ann Liethof, Australia, points out the need for outreach to younger polio survivors who have emigrated to the US. However, it has become more difficult for anyone to enter the US, and preference is given to nondisabled people. Typically, people with disabilities who enter the US now were disabled in a refugee camp.

#### Pages 6 and 7

**My Story about Polio** is an article by a younger survivor, **Dai-Ming Tang**, who describes his treatment by others as he grew up in Shenyang, China. Page 7 also contains information about a new book and a new blog, both by polio survivors.

#### Pages 8 and 9

Plan now to attend PHI's 10th International Conference, Living with Polio in the 21st Century, and the pre-conference Post-Post Wellness Retreat.

#### Pages 10-12

Learn how you can participate in the 2008 **WE'RE STILL HERE!** campaign and promote awareness of post-polio issues. Need braces or modified shoes? PHI receives a grant to assist. PHI's (then Rehabilitation Gazette) first conference was held in 1981 in Chicago, Illinois. The "Proceedings" from the 1981, 1983 and 1985 conferences are now online.



**Brian Tiburzi**, joined the staff of PHI in late April as the new Executive Assistant. He and his wife, Jai, are the proud parents of a new daughter, Issaline Sophia, born on July 18th.

> Joan L. Headley, Executive Director of PHI

nerve on one area and one side of the body. Shingles blisters then form for a number of days before they pop and finally crust over and heal. The entire process can take several weeks.

## **Symptoms and Complications:**

Fever, chills, upset stomach and headache can indicate shingles. Very rarely, shingles can result in pneumonia, hearing difficulties, blindness, encephalitis or death. A common complication of shingles is nerve pain. When this pain continues for more than a month, it's known as postherpetic neuralgia, which occurs in more than 40% of those over 60 who have had shingles. This can be devastating. In some cases, certain medications may be used to alleviate the situation.

**Interesting Facts:** People who have had shingles can get it again. Only people who had chickenpox or chickenpox vaccine can get shingles; the chickenpox virus stays in the body forever. Shingles is not contagious. However, a person who never had chickenpox or the chickenpox vaccine can get chickenpox from someone with shingles.

**Cost:** The cost of the vaccine ranges between \$195 and \$220, and it is covered by most private insurers. In one area of the US, the vaccine is administered in pharmacies for a cash fee of \$220. Plan D picks up from \$25 to the full amount, depending on the coverage one has chosen. Medicare itself won't pay for the vaccine, though it will pay a \$20 administration fee. Getting the best price may take a few phone calls in each separate locality. ▲

ZOSTAVAX® (Zoster Vaccine Live) is a registered trademark of Merck & Co., Inc.

## Wise Choices Feeling Better with Shingles

See your doctor at the first sign of shingles. It often begins as burning or shooting pain and tingling or itching on one side of the body, followed by a blistering rash. Early treatment can help shorten the length of infection and reduce the risk of other problems.

#### Your doctor may prescribe:

- Antiviral drugs to help kill the varicella-zoster virus.
- Steroids to lessen pain and shorten the time you're sick.
- Antidepressants, anticonvulsants or analgesics to reduce pain.

### Things you can do:

- Get enough rest and eat well-balanced meals.
- Try to relax. Stress can make the pain worse.
- Dip a washcloth in cool water and apply it to your blisters to ease the pain.
- Do things that take your mind off your pain. Watch TV, read books, talk with friends, or work on a hobby.

Source: NIH News in Health

## Resources

NINDS Shingles Information Page www.ninds.nih.gov/disorders/shingles/shingles.htm

Centers for Disease Control and Prevention (CDC) 1600 Clifton Rd Atlanta, GA 30333 USA Public Inquiries: 404-498-1515 / 800-311-3435

Shingles Vaccine; What You Need to Know www.cdc.gov/vaccines/pubs/vis/downloads/vis-shingles.pdf

## Message to newsletter editors:

The above article is just one in a series of monthly columns that PHI continues to develop and make available to its Association Members to "cut and paste" for their newsletters.

For details on how your group can become an Association Member and receive the *PHI* Association Member Communiqué, contact director@post-polio.org.

## **Study Tour of United States and Canada Identifies Techniques to Better Manage the Late Effects of Polio**

**P**ost-Polio Health International, St. Louis, Missouri, was the second stop on a five-week tour of post-polio facilities in ten cities. The force behind the tour, Mary-ann Liethof, is the Community Officer of PolioNetwork, a service of ParaQuad, a non-profit organization in Collingwood, Victoria, Australia. Liethof secured funding through The Winston Churchill Memorial Trust of Australia to identify techniques to better manage the late effects of polio, with the ultimate goal of improving the services of PolioNetwork.

Liethof faithfully chronicled her visits in words and in photographs at www.polionetworkvic.asn.au/studytour. The site also features a PDF file of the final report and *Jill's Jottings*, the impressions of polio survivor and retired occupational therapist Jill Pickering, who accompanied Liethof on the tour.

# The final report lists the following as highlights of the tour:

The incredible dedication of Jacquelin Perry, MD, and range of facilities available at Rancho Los Amigos, Downey, California.



Liethof, at right, discussing post-polio issues with Martin B. Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, Saint Louis, Missouri, and polio survivor Jill Pickering.

- The historical significance of Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.
- The holistic approach to wellness being practiced at John P. Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania.
- The youthful team at Spaulding Rehabilitation Hospital's long-term commitment to provide ongoing services for polio survivors, Framingham, Massachusetts.
- The valuable clinical research being conducted by Daria Trojan, MD, at Montreal Neurological Institute and Hospital in Canada.

# The following are listed as the major lessons and conclusions:

- The most effective way of managing the late effects of polio and ensuring polio survivors remain as active and independent as possible is through self-management techniques, coupled with regular specialist clinic assessments and intervention strategies.
- Services for polio survivors will be required for at least another 20-30 years.
- Services are merging post-polio syndrome with other neurological disorders in order to attract funding to continue service provision.

Networking

- The apparent lack of active community outreach to younger polio survivors who may be unaware of post-polio syndrome is reflected in the decline of support groups in the USA/Canada.
- There are very few clinics, institutions or individuals doing postpolio research.

### **DVD to Come**

While traveling to the aforementioned places, Liethof interviewed many individuals. Their opinions will be compiled on a DVD by the PolioNetwork of Victoria.

Other stops on the tour included Washington, DC; New York City; Englewood, New Jersey; and Toronto and Ottawa, Canada.

### For more information:

Mary-ann Liethof, Polio Community Officer 208 Wellington St Collingwood 3066, Australia (03) 9418 0411 polio@paraquad.asn.au www.polionetworkvic.asn.au

## **Development of a Polio Antiviral Drug Begins**

Joan L. Headley, St. Louis, Missouri, director@post-polio.org

The Global Polio Eradication Initiative, launched by the World Health Organization (WHO) in 1988, with the help of Rotary International's PolioPlus Program, sizable contributions from the Gates Foundation, and the commitment of UNICEF and the CDC, has stepped up its activities to finish the job of eradicating poliovirus worldwide.

In 2005, the powers-that-be initiated a discussion of the role of a polio antiviral drug in the efforts to eradicate poliovirus and to explore its added benefits of maintaining a polio-free world.

Compounds belonging to the antiviral mechanistic class termed "capsid inhibitors" inhibit the function of the poliovirus capsid, the outer protein coat of the virus. The inhibitors, by integrating into the capsid at a specific site, prevent the poliovirus from releasing its RNA and block the infection that leads to acute poliomyelitis.

One anti-poliovirus compound, V-073, has promise. Consequently, investigational new drug (IND) studies will begin with V-073 and be conducted by ViroDefense, Inc., Rockville, Maryland.

Schering-Plough, Kenilworth, New Jersey, recently licensed the exclusive rights for development of a specific compound series for polio to ViroDefense. The license was provided in exchange for the purchase of compound testing supplies and potential future royalties on sales.

# Disaster Planning Help for People with Disabilities at www.disability911.com

The website features televised interviews with disaster preparedness and emergency response officials, with people who were displaced by Hurricane Katrina, and with experts on issues pertaining to disaster preparedness and response. Links are provided to webcasts, books and newsletters, training materials, and other resources, which have been prepared to assist centers for independent living, public officials, emergency preparedness officials, and people with disabilities and their families. The site was developed by Lex Frieden, University of Texas Health Science Center professor and long-time disability rights advocate, and the Independent Living Research Utilization (ILRU) program at Memorial Hermann/TIRR in Houston, Texas.

# **My Story about Polio**

Dai-Ming Tang, Shenyang, Liaoning Province, China, dmtang@imr.ac.cn

had polio when I was about two years old, which was 24 years ago. It seemed to me that I was born with this disease. My parents sent me to hospital at the capital of Hunan province as soon as they could when they found that I was not able to stand. I was confirmed to have polio. At the hospital, I was treated with acupuncture to stimulate my nervous system. After one month, my right leg responded. Half a year later, the treatments were ended. Thus I had to face the fact that my right leg is two centimeters shorter and that my ground and my life would not be flat anymore.



Networking

Dai-Ming Tang is a PhD candidate in Materials Sciences at the Chinese Academy of Sciences, Shenyang, China. He stands before a bridge located at Bird Island in the Shenhe River and near a natural preservation zone of wetlands, which he photographs often. View his online photo album: http://picasaweb.google.com/dmtangimr However, physical disability is the least thing that polio gave me. I grew up with few friends. Many of the boys enjoyed calling disabled people all kinds of nicknames, without being aware of the hurt. To be honest, I hated those guys. I even hated my parents and God, blaming them for my bad fate. For a long time, I had to talk with myself and play by myself. After growing up, I had problems

speaking to people, especially girls. It seemed to me that I would end my life in solitude, if not for the appearance of some important people who made all the difference.

Mr. Gan, a righteous and humorous man, and a successful businessman, spent half a year in my home. It was he who told me that I was very talented and that he was very glad to make friends with me. He led me into a different world, where friendship dominated instead of hatred and revenge. He told me the importance of health and knowledge as well. I thought that it would be great to be like him. With his encouragement, my studies improved, and I later got the chance for higher education after junior high school.

Mr. Gan taught me the right thing to do. While at Xiong, a pretty girl who edited a popular magazine in our high school, told me the beauty of the world. Isn't it magical that such a girl told me that she thought I was thoughtful and a nice person as a friend? No matter what mistakes I made, I knew there was still a place to go.

Many more people helped me and treated me nicely. It is not only the things that they did for me that made me grateful, but also, more importantly, the kind hearts and the thoughts that I am accepted as a person helped me to stand up.

Polio also gave me some good things. For example, I was alone for most of my childhood. Therefore, I am more used to thinking independently which is important for study and scientific research. Another important gift from polio is that I am more concerned about the poor people. Sometimes I was laughed at for giving some money to the beggars at the roadside. Looking back, my experience is like a movie in which all the elements such as hatred, love, friendship and disaster are included. And now here comes the happy section, of course not the ending at all. I am happy to accept the fate and the disease as facts that are impossible to change. As long as I am doing the right thing, I am happy regardless of the weird looks from anyone.

I want to take more part in activities associated with helping people with difficulties caused by polio and other diseases.  $\blacktriangle$ 

## **Snapshot of Polio in China**

- In 1980, 7,442 cases of acute polio were reported in China.
- In 2000, China was certified free of wild poliovirus.
- In 2004, six non-immunized children in Guizhou were reported to have acute and residual polio-like paralysis. The vaccine-derived poliovirus (type 1) was isolated from them. Guizhou had the lowest immunization rate of China's provinces – 72%.
- China's immunization rate for polio was 94% in 2006 and 2007.
- China holds a special position in regional and global efforts in polio eradication because its population accounts for 80% of the population of the Western Pacific Region and 20% of the world's total.

Source: World Health Organization

## New Blog at www.graceryoung.com

**Grace R. Young, MA**, **OTR/L** is a polio survivor and retired occupational therapist. For many years she was the post-polio resource person for all the Kaiser-Permanente medical centers

in Southern California and taught classes in how to conserve one's energy.

Check out her blog that covers various topics related to living well with a disability.

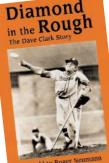


Live in the United States? Are you registered to vote? Do you have trouble getting to the polls?

# Remember you may be eligible to vote with an absentee ballot.

Where to start:

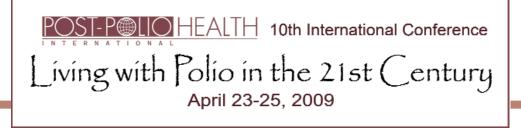
- www.usa.gov/Citizen/Topics/Voting/Register.shtml
- Call your local election office.
- Check the National Association of State Election Directors website at www.nased.org/membership.htm



## Diamond in the Rough: The Dave Clark Story

by Roger Neumann, with contributions by Dave Clark, is a selfpublished book (iUniverse) and available at www.iuniverse.com and at other online booksellers.

Clark, from Horseheads, New York, now living in Florida, works parttime as a scout for the Baltimore Orioles, the team that gave him a chance to fulfill his dream to play professional baseball. Born in 1952, Clark had polio in June of 1953, and spent time at Corning Hospital and Ithaca Recontruction Home, Ithaca, New York.











Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia; (Top to bottom) Quadrangle, Roosevelt Hall, Columbus Colonnade, Inside Georgia Hall

**Living with Polio in the 21st Century** is the theme guiding the program of Post-Polio Health International's 10th International Conference.

The conference will open officially on Thursday, April 23, 2009, at 1:00 pm in historic Roosevelt Hall on the campus of Roosevelt Warm Springs Institute for Rehabilitation (RWSIR), Warm Springs, Georgia.

The closing lecture, "Polio: A Look Back at the Public Health Crusade that Mobilized a Nation" will be presented by David M. Oshinsky, author of *Polio: An American Story,* a book for which he received the 2006 Pulitzer Prize in History. The session will conclude at 4:00 pm, Saturday, April 25, 2009. A social event will be held that evening at Camp Dream on the RWSIR campus.

The core program takes advantage of RWSIR's current facilities by offering sessions such as "Your Mobility Device and Your Posture"; "Demonstration and Discussion of a Post-Polio Examination: Sorting out Secondary Conditions"; "Demonstration and Discussion of a Post-Polio Examination: Don't Forget Breathing"; "Benefits and Techniques of Aquatic Therapy"; and "Demonstration and Discussion of a Seating Evaluation: Cushions and Pressure Sores."

RWSIR is the perfect setting for sessions such as "Warm Springs during the Epidemic Years: Not the Usual Story" and a "Memoir Writing Workshop."

The program committee recognizes that the basics of the late effects of polio are readily available and chooses to offer targeted and in-depth sessions, as well as sessions that offer "tools" to live with polio in the 21st century. Other examples of the 40 sessions include: "Tools to Use in Evaluating Treatment Choices"; "Making the Tough Decisions: Palliative Care and David M. Oshinsky, Jack S. Blanton Chair in History, University of Texas, and Distinguished Scholar in Residence, New York University.



Photo by Don Rogers (www.drogersphoto.com)

End-of-Life Decisions"; "Complementary and Alternative Medicine: What You Don't Know Can Hurt You"; "Anesthesia Update: Separating Fact from Fear"; "Housing Options: What's Out There"; and "Poly Pharmacy: Making It All Work."

The program schedule, with the session titles and names of presenters for the 40 sessions, will be available on the PHI (www.post-polio.org) and RWSIR (www.rooseveltrehab.org) websites in the fall. Registration materials will include information about lodging, ranging from historic and/or rustic rooms on campus to area chain motels to Callaway Gardens, Pine Mountain, Georgia. Rates range from \$60 to \$109 per night for double occupancy, less for single. There are also campgrounds in the area.

The regional airport is Hartsfield-Jackson International on the southwest side of Atlanta. The drive to Warm Springs is about 1½ hours. A list of rental car agencies, including their disability services, will be provided.

Roosevelt's Little White House Historic Site, operated by Georgia State Parks, is adjacent to RWSIR, and tours will be available. The site also includes the FDR Memorial Museum & Video and the Historic Pools Museum. Tours will also be available of RWSIR, a National Historic Landmark, which is home to the Smithsonian Exhibit "Whatever Happened to Polio?" and the Polio Hall of Fame.

Watch www.post-polio.org and www.rooseveltrehab.org for details. Lodging information will be posted in early September. If you do not have access to the Internet and want to receive the registration materials, send your name and address to PHI or call 314-534-0475.

## Post-Polio Wellness Retreat Promises Personal Attention, Renewal

Would you like an opportunity to renew your mind, body and spirit under the whispering Georgia pines? Would you like to have every one of your post-polio questions answered by unhurried medical experts and spend four custom-designed days sharing your stories and ideas, enjoying recreational activities, and learning more about how to stay strong and healthy in the years ahead? If "yes" is your answer, then you may want to attend the Post-Polio Wellness Retreat to be held at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) prior to PHI's 10th International Conference (See page 8).

Based on two well-received post-polio retreats in Upper Michigan held in 2006 and 2007, this one is being planned by an experienced faculty led by Frederick M. Maynard, MD. Moving several steps beyond rerehabilitation, the program will offer ongoing wellness approaches that promise to improve your overall health and quality of life. The group is designing a varied and flexible program that will appeal both to polio survivors and their retreat companions (spouse, significant other, caregiver, friend).

Participants will be asked to set retreat goals based on individual needs and preferences. At least 25 different topics will be offered as options for full group and breakout sessions, which will include both traditional and complementary approaches to staying healthy and well.

The retreat will take place at Camp Dream on the RWSIR campus starting at 2:00 pm, on Sunday, April 19, 2009, and ending about 10:00 am, Thursday, April 23, 2009. Enrollment will be limited to 55 participants, including companions. The fee, including food and lodging, is \$350.00 per person.

Camp Dream is a 74-acre recreational area in a natural but fully accessible

setting. Callaway and Lanier Lodges provide comfortable sleeping quarters with wheelchair access to private attached bathrooms featuring roll-in showers. Rooms have either three or four beds in them, which may necessitate sharing the space and getting to know your roommates.

Both lodges have great rooms and wrap-around decks that feature views of Lake Dream. The dining hall offers meals served family-style. Camp Dream has a woodland nature trail, a covered pavilion, and lake activities such as canoeing, fishing and kayaking. It is conveniently located near the Center for Therapeutic Recreation, a building which houses exercise, game and meeting rooms, and a mineral spring-fed pool.

# Watch www.post-polio.org and the next issue of *Post-Polio Health* (November)

for details. A short video describing the Upper Michigan retreats can be viewed at www.baycliff.org (click on "post-polio"). If you don't have access to the Internet, contact PHI and/or call Reenae White, Camp Dream Director, at 706-655-5715 weekdays from 9:00 am-5:00 pm EDT.

First-come, first-served enrollment will open soon with a cut-off deadline in early March 2009. Hope to see you there!





# **2008 Campaign Focus Announced**

Post-Polio Health International (PHI) challenges individuals and groups from around the world to make the October 12-18, 2008, **WE'RE STILL HERE!** campaign even more visible than the successful 2007 campaign. The goal is to alert health professionals, policy-makers, and the general public to the fact that polio survivors are active individuals within their communities with successes to tell, and for many, unmet needs.



## Focus for 2008

PHI is collaborating with Polio Survivors and Associates (PSA), a Rotarian Action Group, in asking polio survivors and post-polio support organizations to contact the local Rotary Club with an offer to speak during WE'RE STILL HERE! week.

"Speaking to Rotary Clubs is a natural," says Joan L. Headley, Executive Director of PHI. "Rotary International's commitment to eradicating the poliovirus from the world is unyielding. PHI and the extensive post-polio network carry on from there, assisting those for whom the vaccine was too late."

Because of the success of the eradication effort, the total number of survivors worldwide has dropped

considerably. The exact number is unknown, but polio survivors throughout the world are in need of programs that will provide rehabilitation and re-rehabilitation, which is the key to participating in society.

Ann Lee Hussey, Chairperson of PSA, notes, "As Rotarians, who are also polio survivors, we know personally the significant difference rehabilitation made in our lives and how it contributed to our success in life. Our specific goal is to ensure younger polio survivors have the same opportunity." (www.rotarypoliosurvivors.com)

Focusing on PHI's mission, Headley advises, "We want to encourage Rotary's eradication effort and at the same time encourage them to remember on behalf of those among the world's survivors who are in need of rehabilitation – WE'RE STILL HERE!"

## **Activities Announced**

PHI challenged groups to be creative in designing activities for this year's campaign; the following groups have responded to date.

**Manuscript for Post-Polio Players** – The brainchild of Vera Moore, Mobile Area Post-Polio Support Group, this fast-moving script of polio survivors chatting before their support group meeting raises post-polio issues in a personal way. The short script, which can be modified to fit any area's history, is easy and fun for groups to produce. Book the production for Rotary meetings, church and community action groups, school assemblies, social interest groups. Schedule a Q&A session after the skit. The script, needing minimal props, set and characters, can be downloaded from the WE'RE STILL HERE! section of www.post-polio.org.

**Virtual Workshop** – The Polio Society, Washington, DC, is developing a virtual seminar/support group to be offered during the week of October 12-18, 2008. Polio survivors and their loved ones and caregivers will be able to register for this free program by mail or through the Polio Society website. The only cost will be a long-distance phone call to the telephone bridge line. Contact the Polio Society online (www.poliosociety.org) or by phone (301-897-8180) for additional details.

Locating local polio survivors – The John P. Murtha Neuroscience and Pain Institute (JPMNPI) and the Rotary Clubs of District 7330 in Johnstown, Pennsylvania, are collaborating to locate and assist area polio survivors. Ideas include a public service announcement highlighting polio history, Rotary's involvement in polio eradication and rehabilitation, and the services at JPMNPI; developing a grant to fund continuing education for Emergency Medical Services Personnel; and a "Post-Polio Walk."

WE'RE STILL HERE! Home Base – Post-Polio Health International's website (www.post-polio.org) is home base for facts, ideas and latest updates on the WE'RE STILL HERE! campaign and will have links to all participating groups.

As plans develop, send them to director@post-polio.org to be added to the WE'RE STILL HERE! section of www.post-polio.org.

## **Funds Available for Bracing** and Modified Shoes

Post-Polio Health International has again received a grant from SPIN, a charitable organization in Chicago, Illinois. The funds, totaling \$3,000, were awarded to assist polio survivors in purchasing braces or modified shoes. To assist the greatest number of survivors, the maximum funds available per individual is \$500.

To receive an application, call Brian Tiburzi at 314-534-0475 or email him at info@ post-polio.org.

Applicants from any country may apply. There is no deadline for applying and payments will be disbursed as eligible applicants are reviewed.

## Donations in Recognition of Others

Post-Polio Health International thanks the many friends and family members who contributed in support of its mission.

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

#### In Memory of

Joseph Richard Brown Preston Covey, Jr. Margaret Cowgill Charles L. Crook Billie Jean Dille (Jeanne) Harry B. Guarino D. Rose Huffaker

Virginia Love Delores Mansfeldt Jenny & Jerry Moher Barbara Joyce Price Clifford E. Rowan Suzanne C. Seariac Lucy Weaver

In Honor of Susan Douglass

Beverly Pokojni

#### Contributions to The Research Fund ...

#### In Memory of

Cheryl Koger Aragon Harry B. Guarino Virginia Love

Bernard Pershin Suzanne C. Seariac

In Honor of Sridevi Mukkamala, MD

**Contributions to the Gilbert Goldenhersh** Memorial Tribute Fund ...

In Memory of Jerome Brody

In Honor of Edward Goldenhersh



## 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.

#### □ \$30 Subscriber

Quarterly newsletter of your choice: 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

. 0	tion in PHI publications:	
	Bronze Level Sustainer	
	Silver Level Sustainer	
	Gold Level Sustainer	
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Address		
City	State/Province	
Country	Zip/Postal Code	
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Phone (include area	/country code)	
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# When and where will the tenth conference be held?



See pages 8 and 9 for more details.



## When and where was the first conference coordinated by Post-Polio Health International (then called Rehabilitation Gazette) held?

October 14-16, 1981, Chicago, Illinois

Post-Polio Health International has posted the "Proceedings" from this historic meeting, "What Ever Happened to the Polio Patient?" on the Internet. Follow this path from www.post-polio.org:

click on About PHI:

History of PHI; scroll

to 1981 and click on "Proceedings."

The "Proceedings" from the 1983 and 1985 meetings are also available online in PDF format, and are accessed from the same page. Need ideas to increase post-polio awareness?

See page 10.





Post-Polio Health International Including International Ventilator Users Network

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