

PHI Membership MEMO

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Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through Education, Advocacy, Research and Networking.

Remember to check post-polio.org, polioplace.org and ventusers.org often!

Post-Polio Health International *including International Ventilator Users Network*

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Greetings, PHI Members

PHI's seventh annual awareness week: We're Still Here! What Having a Disability Taught Me

PHI invites you to participate in its 2013 WERE STILL HERE! campaign during the week of October 6-12 by speaking to students in your local elementary, middle and high schools sharing with them *What Having a Disability Taught Me*.



What has disability taught us? In 2006, Sunny Roller, MA, with funds from the National Institute on Disability and Rehabilitation Research (NIDRR), conducted a study called "Adaptation Into Late Life for Persons with Long-Term Neuromuscular Disabilities: Lessons Learned from Polio Survivors." Her goal was to describe late life success strategies, this investigation concentrated on the perceptions of a small and elite set of polio survivors--those who were designated the most highly regarded by their peer group as senior role models (or polio mentors), who were over 65 years of age and more than 50 years past disability onset. She interviewed 15 post-polio leaders.

Here are her key findings:

- *Major issues throughout life included: achieving and maintaining independence which required diligent effort; fighting shame and creating a positive self-image with a disability; and reconciling social and functional losses*
- *Over time, perception of life with a disability from polio changed for this group. Before encountering the late effects of polio at mid-life, individuals operated and*



worked hard using their “lens of difference,” a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial. Later in life they became more willing to look at their lives through the “lens of disability,” more fully embracing their disability as part of their overall personal identity. In so doing, they found a new freedom to be more content with this new self-perception and life in their retirement years.

- *Key coping strategies included* having a strong social support system, enjoying life, being optimistic, self-acceptance, assertiveness, education and spirituality.
- *Successful late life adaptation* was defined as self-acceptance and adaptation, having the right resources, and being surrounded by loved ones.

Can you identify? Have your perceptions changed? What wisdom have you acquired? Be a part of WE'RE STILL HERE! 2013 and tell a short story from your life's “book” to the younger generation in your community. [READ MORE](#)

Remember to send us photos!

Another idea: Use Sunny's key findings as a starting point for a discussion at your next support group meeting.

Promoting Healthy Ideas

A stylized graphic of the Gateway Arch and a city skyline, rendered in a dark red color, positioned to the right of the text "Promoting Healthy Ideas".

PHI's 11th International Conference

May 31 – June 3, 2014 are the dates for our next international conference. Speakers have been invited to share their expertise about **Promoting Healthy Ideas**. Using our Members' ideas and requests, we have created a program with six sub-themes. For a preview of them and just a small sampling of some sessions

being planned, [click here](#). This link, along with information about reserving your hotel room, is available at www.post-polio.org. Watch the site for the latest program information. We will add more sessions and speakers' names as they are confirmed. The committee decided that it would be good to hear a variety of opinions on the topics, so each session will be 1 ¼ hours long (or longer) and will feature panels. We will be asking polio survivors to moderate sessions and to relate their personal experiences on specific topics. Watch for the invitation and consider volunteering! See you in St. Louis!

Looking Ahead to 2014

August 17-21

Rocky Mountain Post-Polio Wellness Retreat (Coordinator: Marny Eulberg, MD)

[Rocky Mountain Village, Easter Seals Colorado](#)

Details to follow.

September 8-12

Polio Wellness Retreat (Coordinator: March of Dimes Canada)

[Easter Seals Camp Horizon, Bragg Creek, Alberta](#)

Details to follow.

Have you seen this medical information?

- [Polio provocation: The health debate that refused to go away](#)
- [The Hidden Threat That Could Prevent Polio's Global Eradication](#)
- [Polio Virus: Cure for Brain Cancer?](#)
- [Transcranial direct current stimulation improves sleep in patients with post-polio syndrome; Definition of Transcranial Direct Current Stimulation from Johns Hopkins](#)
- From Selma Calmes, MD, anesthesiologist (retired): [Questions Baby Boomers \(and their parents\) should ask about anesthesia \(25th August, 2013\)](#) by Karen Sullivan Sibert, MD, a Los Angeles anesthesiologist, was written at the request of the American Society of Anesthesiologists as a public service for patients and families. It is an excellent

article for the post-polio community. I have received a few questions lately about excessive sleepiness after an endoscopy. Often a patient receives a “cocktail” of meds and it takes some digging to find the cause of any problems. To start, request a copy of your anesthesia record and then discuss it with your GI MD. If problems continue, visit your primary care physician and get basic lab work and a physical exam, to rule out other problems. In a recent case, the person who had a similar experience turned out to have an electrolyte problem from medicine taken for high blood pressure. Again, post-polio people should ask the questions described in the above link.

PHI Resources

PHI has funding available for bracing or special shoes for survivors in need in its Joyce and Arthur Siegfried Memorial Fund. Survivors living in Missouri can apply for funds from the Gilbert Goldenhersh Memorial Tribute Fund. Email us at info@post-polio.org for an application. The maximum amount given per applicant is \$800.

New on Polio Place

From 2004-2012, Post-Polio Health International collaborated with the Post-Polio Specialty Clinic at the John P. Murtha Neuroscience and Pain Institute in Johnstown, Pennsylvania, to provide conference calls for post-polio clinic directors and staff. The presentations and discussion points of selected calls have been posted on Polio Place to benefit health professionals and polio survivors. The 29 topics are listed at [PHI's Post-Polio Clinic Directors Network](#).

Post-Polio Health International's Websites: www.post-polio.org



Health Care Considerations for Families and Friends (click on image)



Polio Place (www.polioplace.org)



International Ventilator Users Network's website...

www.ventusers.org



Joan L. Headley, Executive Director