

PHI's mission is supported by its Membership.

## PHI's Historic First Post-Polio Conference, 40 Years Later



Forty years ago, in October 1981, Gazette International Networking Institute, or GINI (which later became Post-Polio Health International), along with the Rehabilitation Institute of Chicago, brought over 200 polio survivors and health care professionals together in a ballroom at the Americana-Congress Hotel in Chicago to explore the question, “What Ever Happened to the Polio Patient?”

The spark of an idea for a conference came from a 1979 letter from polio survivor Larry Schneider, which appeared in the *Rehabilitation Gazette*. Schneider remarked, “I find myself being able to do less and less and tire far too easily.” He suggested that the *Gazette*, “which seems to be the last polio link,” solicit names of “simpatico” doctors and publish a national directory for polio survivors to turn to for “genuine and honest advice.”

Soon letters from other polio survivors poured in and a planning committee was formed consisting of Gini and Joe Laurie, Dr. Allen Goldberg and his wife, Dr. Evi Faure, Don Olson, PhD and Margaret Pfrommer. They decided on Chicago as the location, as Dr. Goldberg was treating hospitalized children on ventilators there. He brought on Dr. Henry Betts, Medical Director of the Rehabilitation Institute of Chicago, as a cosponsor, and the rest, as they say, is history.

continued on page 2

PHI asked some of the organizers and attendees from that first conference to share their recollections. Below are some of the responses.

**Allen I. Goldberg, MD,  
Chicago, Illinois**

Dr. C. Everett Koop and his wife Betty met with me in 1980 to start a new approach to communication of health care: CARE FOR LIFE. The purpose was to find ways to educate, demonstrate and document information that people would understand, use and trust about health-related issues. CFL was thus born, and we needed to develop a Board of Expert

Advisors. It was Marca Bristo (Access Living) who led me to Gini and Joe Laurie and my visit to St. Louis. There I learned about the *Rehabilitation Gazette*.

Gini, Joe, Evi and I discussed the need to demonstrate the concept of communication in health care. We planned a meeting to celebrate the International Year of Disabled Persons 1981. Thus, “What Ever Happened to the Polio Patient?” was born. This interdisciplinary meeting was to bring together all experienced parties to present the whole picture and to highlight the issues facing persons with post-polio health issues. It served as a template for how to do it by involving experts and a diversity of perspectives from all essential viewpoints: professional, community, organizational and the most important experts: the person with a disability and their families.

The question “What Ever Happened to the Polio Patient?” came to me during an international flight when I was on a quest to learn how to help long-term ventilator-assisted children who were saved by critical care medicine but had to remain in institutions with nowhere to go. I decided to find answers to that question from people who experienced the polio era and found solutions. What I learned was applicable to my life’s work in home mechanical ventilation and improving the lives of disabled persons. Now, as a



Dr. C. Everett Koop addressing the group.

**POST-POLIO HEALTH**

Summer 2021

Vol. 37, No. 3

ISSN 1066-5331

Editor: Brian Tiburzi, MA  
info@post-polio.org

Designer: Sheryl Prater

©2021 Post-Polio Health International (PHI).  
Permission to reprint must be  
obtained from Post-Polio Health  
International (PHI).

*Post-Polio Health International's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.*

**How to contact PHI**

50 Crestwood Executive Center #440  
Saint Louis, MO 63126 USA  
Phone: 314-534-0475  
Fax: 314-534-5070  
info@post-polio.org  
www.post-polio.org  
www.polioplace.org

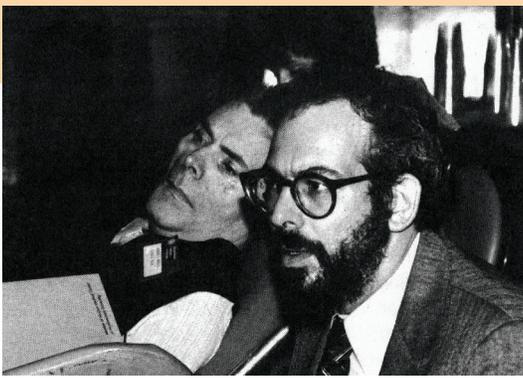
**PHI sends PHI Membership Memos via email.  
Be sure to set your spam filter to receive emails  
from info@post-polio.org.**

**Moving? Change of address?**

Notify PHI before you move by calling 314-534-0475 or email info@post-polio.org, and tell us your old and new addresses.

**Away temporarily?**

Send us your second address and dates you will be there and we'll do our best to send your newsletter.



Allen Goldberg, MD (right)

20+ year veteran caregiver, my education has been made more complete on my understanding that, “Working Together, We Can Make a Difference.”

This was the significance of the meeting:

- ◆ Demonstrated the importance of process: who was involved, how they interacted, how they learned from each other’s perspectives that when all considered would promote people working together.
- ◆ Set the tradition of such meetings at PHI and other organizations (e.g., JIVD, CHEST) on a regular basis to continue the process of communication and actions working together for the broadest impact of education.
- ◆ Developed PHI into what it is today: a documentation center communicating information that people can use, trust and understand involving experienced, credible people.

### Gayla Hoffman, St. Louis, Missouri

As next-door neighbors of Gini and Joe Laurie, my husband, Art, and I had been happily sucked into the vortex of energy that was Gini Laurie. She put our writing/editing skills to work composing grant proposals, folding and stuffing envelopes and sending out the “Brown Bag” appeals for funds.

Keeping in touch with her world-wide network of polio survivors and medical professionals, Gini’s idea of an international conference gradually took shape, and with her characteristic enthusiasm and optimism, she proceeded to make it happen.

Undaunted by the task of bringing people in wheelchairs (some using respirators or iron lungs) from all over the world

together with the foremost medical experts (including the U.S. Surgeon General), Gini and her many, many volunteers made the conference a reality.

Remarkably, she did this without employing special events or meeting planners, using only landline telephones and snail mail in an era before the internet, email or cell phone service even existed!

At the conference held in the hotel’s huge ballroom, there was an atmosphere of warmth and joy as participants met one another and shared their life stories. A number of the attendees had contracted polio in the early 20th century long before Salk or Sabin vaccines came along in the 1950s.

Comments from those attending were overwhelmingly positive:

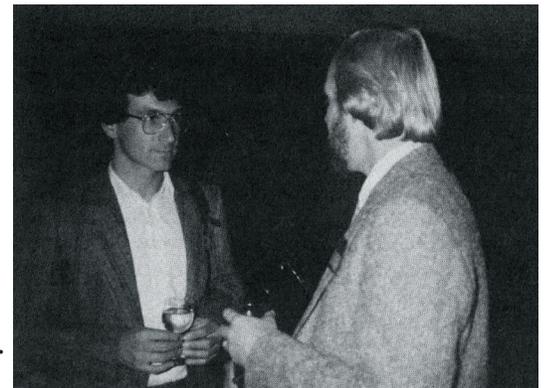
*“I felt I met 200 strangers and went away with 200 friends.”*

*“I’ll never be the same. This conference will change my whole life.”*

Echoing Gini Laurie’s philosophy, Dr. Fred Maynard summed it up best: “I believe the most powerful message generated by the conference is that the human spirit is not only capable of surviving but can truly flourish and grow to tremendous power in spite of severe restrictions to the physical human body.”

### Frederick M. Maynard, MD, Marquette, Michigan

As the first large gathering of professional people to address issues resulting from the large polio epidemics of the 1940s and 1950s, it was a truly exciting and memorable convocation, and it launched what became known as the Post-Polio Movement. It was organized for the purpose of



Frederick Maynard, MD (right)

continued on page 4



Front, L-R: Gill Whitworth, England; Dr. Alba; Adolf Ratzka, Sweden; Stewart Anderson, Scotland; Susan Ambrecht, Ohio; Marion Greene. Back, L-R: Dr. D. Armin Fischer, California; Judy Raymond, Ohio; and Mickie Martin, Missouri, in the Gazette's Suite 700.

dealing with a perceived crisis in meeting the care needs of ventilator users and technology-dependent disabled persons. New medical problems of polio survivors were considered due to premature aging, and there were concerns about the lack of knowledge and experience among health professionals with post-polio patients. Topical sessions began with prepared talks, then progressed to small group discussions for brain-storming ideas and concluded with a large group summary that included plans to address the topic of concern.

On a personal level, I have always thought myself fortunate for the opportunities that came to me as a result of my participation in that symposium. As one of the youngest non-polio medical professionals on the faculty, I did not have the confidence of an expert on the subject. On the one hand, I was frightened and intimidated by the stern-faced large audience in a high-ceilinged hotel ballroom that echoed with the sounds of over 20 operating ventilators. On the other hand, I was energized and encouraged by the audience's keen attentiveness to my message about early onset age-related muscle weakening among many polio survivors. I explained how this was a result of polio-affected motor nerve cell deterioration and

outlined the most likely theories to explain changes in muscular strength and endurance. I also spoke about some of the other new health concerns developing among aging polio survivors.

The symposium's discussions validated the concerns of individual polio survivors that stimulated many supportive attendees to begin talking about their new health problems and to formulate plans for finding solutions to them. It left participants hopeful that by working together across disciplines and through professional-consumer partnerships, new knowledge and innovative methods for providing specialized services could be found.

What we've learned since the first conference is that collaboration between professionals (both physicians and many other health care providers) and patients as consumers of health care services is essential to creating effective and enduring solutions to the complex and challenging problems of aging with residual effects of a disabling illness like poliomyelitis. We would do well to reflect on those lessons while we as a society begin to face the long-term residual disabilities that can follow another life-threatening viral illness, COVID-19. Physicians, researchers, care providers, counselors, political and religious leaders, disability rights activists, people with the disabling condition—all stakeholders must be included in discussions about the range of problems and about how to begin ameliorating and/or curing them.

**Adolph Ratzka, PhD, Independent Living Institute, Stockholm, Sweden**

The 1981 GINI conference was to impact my life in many decisive respects. Looking back on the meeting, I see several developments in my life as a result that might not have taken place without my participation in this most memorable event.

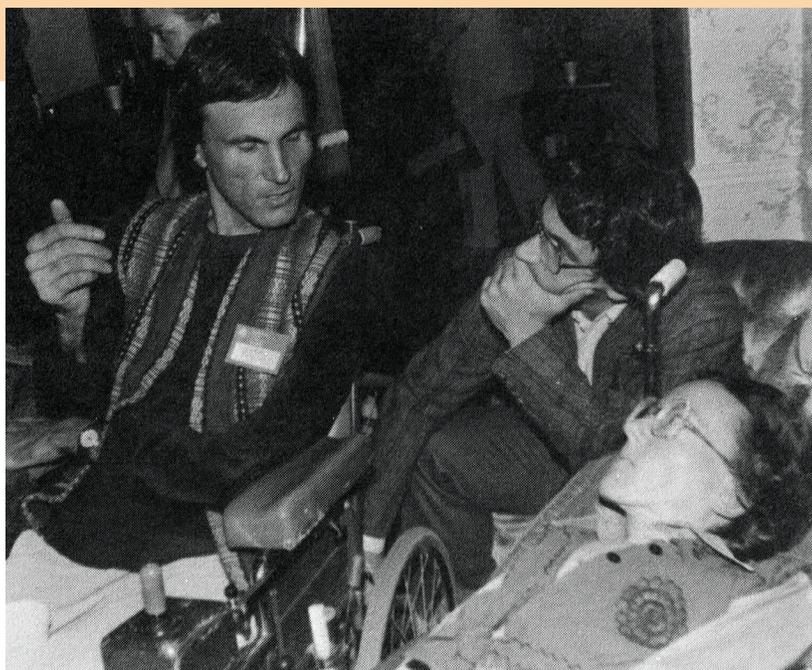
Gini Laurie had managed to spread the word about the conference, its themes and aims among her newsletter subscribers in all parts of the world, many

of whom she knew personally, like myself. Never before had I seen so many people with extensive disabilities in one place as in that Chicago hotel—hundreds of people, many of whom needed different types of mechanical ventilation. I saw people wheeling and even walking with chest shells (cuirass), on rocking beds, in an Iron Lung and holding a vacuum cleaner hose in their mouth that filled their lungs with air. We assembled in a huge meeting hall and milled around in the hallways during breaks. I still remember the excitement and euphoria I felt over being together with all these people.

The majority were from North America, though many had also come from Australia, Japan and Europe. These were not “moaners and groaners” (Audrey King’s words) but individuals who had accomplished something in their lives, worked in professions, raised families, traveled, had wide interests. With them I could identify—it was not only the disability we shared, it was the attitude. As a teenager, I had been forced to spend five years in an institution. This experience had led me to avoid other disabled people for a long time. It had taken me years to accept my disability. In Chicago, I felt completely at ease, proud to belong to this group of people who had come to learn and share how to make the best of their situation.

The conference was perfect for networking. I reconnected with dear old friends from my years at UCLA, such as Doug Martin and Bob Gorski, and I made new friends—Judy Heumann, Audrey King, Max and Colleen Starkloff, Marca Bristo and others—people I would stay in contact with long afterward. Judy invited me to stay at her house while in Berkeley. I had not met her before. For us, Chicago was to become the beginning of a life-long close friendship and work relationship.

I first heard about the late effects of polio at the Chicago conference. In the twenty years after I contracted polio, I had only experienced improvements, such as gaining more in terms of muscular strength and learning a few tricks for



L-R: Adolf Ratzka, Sweden; Otto Bong, Germany; Susan Armbrrecht, Ohio

doing things more by myself. Yet, I had the first bout of pneumonia in my life in 1979. Friends of mine with the same compromised diaphragm had died, and my chest shell did not ventilate me sufficiently anymore. I first made the connection in Chicago, learned what signs to look out for, and became one of those who try to find solutions for themselves and others to stave off underventilation.

A couple of years earlier, I had started experimenting with masks for nose, mouth and face to replace my cuirass, which had compressed my chest over the years and affected my ventilation. The Chicago conference showed me that I was far from being the only one who’d benefit from a comfortable nose mask. At the following conference that Gini organized in St. Louis, in 1983, I came with one of my first working prototypes.

One of the messages I took home from Chicago was that people with underventilation and their organizations do wise to make sure their medical contacts are updated about underventilation management and to collaborate with them. We need to listen to their expertise; they need to respect us as experts on our lives. The more we ourselves or our relatives and friends know about our condition, its treatment, and the assistive technology involved, the better we can

continued on page 4



Sunny Weingarten and Jason Sloan

make the best of our lives.

We need to be at least one step ahead of the development of the late effects of polio on our body. That was another powerful lesson of the Chicago conference for me. With regard to getting older with a disability, we need to be proactive. I know, my breathing will not get better, so I try to maintain my vital capacity as much as I can by practicing with the CoughAssist and by frog breathing. I have been gradually

losing strength in my fingers. Soon, the time will come when I can't type anymore. What can I do? Learn to use the voice control features of my phone and computer.

What I had seen and heard in Chicago about underventilation impressed me and upon returning to Sweden I joined the Swedish organization RTP (Riksförbundet för polio och trafikskadade or national organization for persons impaired by polio or traffic accidents) to spread the important facts. In 1984, we organized the first Scandinavian conference on underventilation and the late effects of polio in Stockholm with international presenters—people I'd met in Chicago—Audrey King, Toronto; Dr. Geoffrey Spencer, St. Thomas Hospital, London. The organization also translated, reprinted and distributed the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* that the GINI had published a few months earlier.

Gini Laurie's work has truly made an impact.

### Audrey King, MA, Toronto, Canada

In the late 1970s many of us “post-polios” in Ontario were experiencing new

difficulties related to having had polio so many years before. I, for one, was having respiratory challenges and couldn't get the outdated equipment I needed.

I searched far and wide, honestly believing I must be the very last “respiratory” polio in the world! Finally, I discovered a copy of the *Rehabilitation Gazette* and the announcement of a proposed conference in 1981 called “What Ever Happened to the Polio Patient?” I telephoned, reaching Gini Laurie herself, to find out more about the conference and if she thought I might find some answers to my problems. She assured me I would!

A few months later I received the program brochure with details. I was utterly shocked to discover I was listed as one of the panel speakers, my topic being the post-polio situation in Ontario. She had never ASKED me, and I had never agreed. Then I was angry. “What nerve!” I thought. “How could she be so presumptuous?” My next reaction was, “I'll darn well show her!”

So, I set about researching the topic at all levels, contacting individuals such as polio survivors, retired public health nurses, government persons. I came to that meeting prepared. I delivered the Ontario perspective, as Gini expected. People came from all over the world. We were fellow polios, physicians, families, other health care providers, all of us collaborating and sharing, bringing different perspectives to the picture and welding them together. It felt like a meeting of war veterans. Lifelong friendships happened.

For me, it was indeed a watershed moment. I learned so much that was personally helpful as well as the powerful realization that real problem solving happens when all levels and sectors collaborate in genuinely interested “lateral” partnerships.

I came back to Toronto, approached the Ontario March of Dimes (now March of Dimes Canada) and the “Post-Polio Program” was born. ■

# A Guide to Using Zoom for Support Group Meetings

Elaine Allen, Nebraska Polio Survivors Association

A pivot means making an abrupt or quick change in direction. That's exactly what happened in March 2020 when the Nebraska Polio Survivors Association (NPSA) had to make a decision on how to continue monthly meetings during the coronavirus pandemic. Our normal meeting place, an independent senior living community, had closed its doors to visitors like us.

Fortunately, our NPSA Foundation Board of Directors met in mid-March and voted to begin meeting via Zoom, an online video meeting platform that also allows for dialing in via telephone. Zoom does not require people to have an account to join a meeting.

Our first Zoom meeting was held Sunday, April 11, 2020. Many of our regular, local members attended. Our guest speaker "Zoomed" in from his office at the University of Nebraska Medical Center to discuss the medical research of viruses and what it would take to develop a vaccine. Of course, vaccines were a hot topic at the time, since none had yet been developed.

As each month passed and word traveled about our Zoom meetings among polio survivor groups, more people joined our meetings from outside our local area. Since April 2020, we've had polio survivors join us from as far away as Germany and Quebec, and from other states, including Florida, Montana, Missouri and Minnesota.

The way we've reached out to our members is by publishing the meeting information in our quarterly publication, *Gleanings*. The information includes the Zoom link (for online subscribers), the Meeting ID and the password. We also include the phone numbers so that people can call to get into the audio portion of our meetings, especially if they don't have internet access. The other way we have communicated how to join our meetings is to send out the meeting invitation with the steps to get signed in.

On occasion, we've had to coach people who had trouble connecting through

Zoom. A member usually calls them off-line and guides them through the sign-in process. Most of the time, the issues have been resolved by updating the Zoom software on their computers. If all else fails, we've encouraged those folks to call in on their mobile phones or landlines so they can listen in and participate.

## Requirements for Online or Call-in Meetings

The only three things a person needs to have for an online meeting when using a computer:

- ◆ The downloaded program or app
- ◆ The meeting ID and password
- ◆ An Internet connection

Or, if calling into a meeting via phone:

- ◆ Dial the phone number provided with the invitation.
- ◆ Use your phone keypad to enter the meeting ID and meeting password.

## Best Practices

Here are some points we've recommended as "Best Practices" for attending online meetings, regardless of the program that is used:

Download the app onto your mobile phone. We've found the app on a smartphone is easy to download and use, though the downside is that a small screen can make it hard to see everyone at the same time or read any materials in the presentation.

If you are connecting to the online meeting program on your computer (laptop, desktop or tablet), make sure to log on early enough so that any updates to the program are downloaded to your computer before the meeting begins.

When joining an online meeting, it's advisable to turn on your microphone and video only until the program begins if a topic is being presented. When the program begins, mute your mic and stop your video to avoid distracting the speaker or others.

When you have questions or want to participate in the discussions, use the "Raise Hand" icon to let the meeting moderator know you'd like to speak. Or, better yet, turn on your video and raise your real hand!

NPSA will continue to meet on Zoom for the foreseeable future. One of the positive outcomes from the pandemic is the awareness and efforts to provide accessibility to everyone. We welcome all who are interested in our group. We meet the first Sunday afternoon of every month from 2:00 to 4:00 pm, except for Sundays that fall on a holiday weekend. Those meetings are postponed until the following Sunday.

*Elaine Allen is the executive director of Nebraska Polio Survivors Association (NPSA). More information can be found at [www.ne-polio.org](http://www.ne-polio.org).*

**PHI:** *I usually call myself a 'polio-survivor.' I've heard some people say 'polios' and others say 'living with the after effects of polio.' Some say 'I'm handicapped' and others say 'I'm disabled.' Are these all acceptable, or am I accidentally insulting someone if I use the wrong language?*

**Response from Rhoda Olkin, PhD:**

Such a great question because words convey concepts. They also may convey a political stance or a value judgment. For example, think of these words: girls, ladies, broads, females, women—these all mean essentially the same thing but would be received very differently. Words related to disabilities, including polio, likewise carry meanings beyond the words themselves.

Let's go through some language. First up is 'polios.' I personally dislike this term as it reduces us to a single factor and feels not that much different than saying 'cripples' (a once regularly-used term that is now considered highly derogatory). 'Polio survivors' is better as it conveys resilience and life after polio, but it still is a single demographic devoid of context. 'A person living with the after-effects of polio' is a wordier version of polio survivor. 'A person who had polio' starts to suggest that the person has other things about them besides polio. I don't think any of these are wrong and within polio circles would be well received.

Another language issue is whether we 'polio survivors' consider ourselves part of a larger group of people with other types of disabilities. For about 20 years, 'people first' language was encouraged: 'a person with polio' or 'a person with a disability.' In this language, the person was central, and the polio or disability was one thing the person 'had' (not 'is'). Recently within the disability community, there has been a move towards 'identity first' language: a disabled person. This connotes disability as an essential part of identity, disability pride, and affiliation with the disability community.

What are the differences among these terms: handicap, impairment and

disability? The World Health Organization distinguishes these terms as follows:

**Impairment:** This term is used by professionals to identify some disruption at the system level of an organ in the body, like the brain or the left leg, that leads to loss of use or some variation from a norm. Impairments are not defects and they can be psychological, physiological or anatomical; some are permanent, others are temporary. Impairments can lead to disruptions in thinking, emotion or behavior.

**Handicap:** A handicap is an obstacle that affects people because, once present in their environment, it blocks them from completing some role. Thus, a disabled person can be *handicapped*—that is, disadvantaged—by a missing ramp, but the handicap does not reside within the person.

**Disability:** "Disability results from the interaction between individuals with a health condition such as cerebral palsy, down syndrome and depression as well as personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support." As such, disability is not a feature of the person but of the interaction of the person and the contextual variables (e.g., attitudes, built environments, economic policies).

Whichever language you use, it needs to feel right to you and nobody else but you. The way in which polio played a part in your life may lead you to feel more comfortable with one phrase over another, and that is okay. (Rhoda Olkin describes herself as a polio survivor, a disabled person and a disability rights activist.)



**Dr. Rhoda Olkin** is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

**PHI:** *I just recently moved and joined the post-polio support group in my area. Because of the pandemic, they aren't holding any in-person meetings. The group has a private Facebook page and gets together on Zoom each month. I've only been on a few calls, but I'm finding it hard to fit in. I'm not overly shy, but I feel a bit like an outsider and am reluctant to speak up. Any advice?*

**Response from Stephanie T. Machell, PsyD:**

It might be Zoom. While it may be easy for you to enter a physical room full of strangers and quickly feel comfortable speaking with them, entering a Zoom room full of unfamiliar people is a different experience. Information you would automatically gather and rely on to guide your interactions may be more limited and/or difficult to read.

Interactions will be limited as well. There may be little or no informal chatting before the meeting starts, and any that does will include all present, with no opportunities to speak one-on-one or in smaller groups. It can be challenging to know when it's your turn to speak or whether others are paying attention when you do. And no matter how hard you try, it's difficult not to watch yourself, which can increase your self-consciousness.

Or it might be the group. Groups vary in how welcoming they are to newcomers, especially if the members have been together for a long time and are more interested in catching up with each other than getting to know a newbie. Ongoing discussions about the experiences of longtime members may be difficult for a newcomer to join in meaningful ways. Or the group may have done a good job of welcoming new members in person but failed to consider how to do this on Zoom.

When you attend the next meeting, take the pressure off yourself about participating. Instead, observe the group and its interactions. See how much you can discern about each member and about group norms around participation. In the absence of eye contact, can you identify

signs that members are listening to each other? What cues do they use to know it's their turn to speak?

As you observe, think about how you feel about the group as well as how the group makes you feel. Are the issues they're addressing relevant to you? Is there too much (or not enough?) negativity, either about living with PPS or towards other members? Do certain members dominate or is there an equitable division of time? Are they welcoming to you as a newcomer and respectful of each other?

*Getting to know a few people will help you feel more like part of the group.*

Consider whether there are one or more members you'd like to get to know better and use Zoom's messaging function to send them a private message asking if you could speak with them later (make sure you are sending only to them and not to the group!) or reach out via a private message on Facebook or by email. Getting to know a few people will help you feel more like a part of the group.

After observing the group, you may decide it's not right for you. Not all groups are a good fit for everyone. Even if you do decide to stay with the new group, if your former group meets on Zoom, why not continue to attend their meetings and benefit from the extra support and camaraderie? ■

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.



## Remembering Daniel J. Wilson (1949-2021)



Daniel J. Wilson, PhD

Post-Polio Health International recently lost a valued member of its family, Daniel J. Wilson. Dan passed away peacefully at his home in Bethlehem, Pennsylvania, on June 11, 2021. Dan joined PHI's board in 2006 and served in various roles, most recently as Board President from November 2020 until his death. He was a scholar of the history of medicine and history of disability, chronicling the polio epidemics and the lives of polio survivors in his books, *Polio*, *Living with Polio: The Epidemics and Its Survivors* and *Polio Voices*, along with numerous articles and interviews.

"He not only had an extensive list of achievements, honors and recognition for his work, but he was also generous with his time and energy to benefit others," remarked fellow board member Dr. Carol Vandenakker-Albanese. "The loss of his leadership, well-informed perspective and wisdom will be greatly missed."

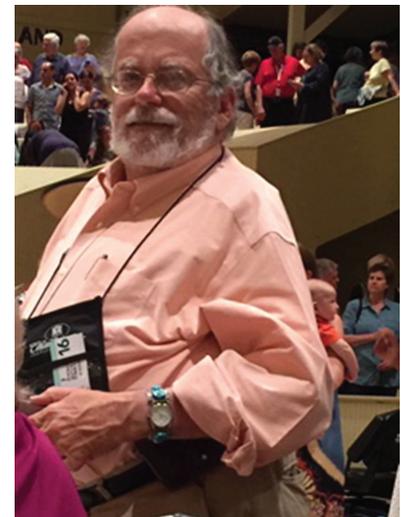
Dan was Professor of History Emeritus at Muhlenberg College in Allentown, Pennsylvania, where he taught from 1978 to 2018. He was the recipient of the National Endowment of the Humanities and American Council of Learned Societies fellowships. Dan served on both the board of the Lehigh Valley Center for Independent Living, including two terms as president, and on the board of the Good Shepherd Rehabilitation Hospital. He was also a longtime member and newsletter editor for the Lehigh Valley Post Polio Support Group before it disbanded about ten years ago.

In his personal life, Dan enjoyed classical music and jazz, traveling (France and Shelburne Farms, Vermont, were favorites), fine dining with his wife, Carol, reading and walking their dogs Abbey and Jasper. He particularly cherished time spent with his family and friends from Johns Hopkins, Muhlenberg and Allentown.

PHI board member Fred Maynard, who served alongside Dan throughout his long tenure on the board remarked, "I'll remember Dan as being the strong and calm leader with never-failing equanimity during all moments of tension and uncertainty as PHI faced tough decisions about how to get our message out to the public about the post-polio experience and what was needed to continue to support polio survivors in pursuing life to its fullest."

"Dan's insightful comments along with his warmth and humor were his trademark. It was a pleasure to be in his company," recalled Mark Mallinger, who will take over as PHI board president. "He was one of my valued mentors since I joined PHI. He made an impression on all those he came in contact with."

Members can find a listing of Dan's publications regarding polio along with links at <https://post-polio.org/2021/08/15/wilson/>. ■



# WE'RE STILL HERE! WEEK: October 10-16, 2021

## PHI's 15th annual awareness campaign will run October 10-16, 2021.

Over the past year and a half, the pandemic has upended many of our normal routines. For many, the result has been a more sedentary lifestyle. Over the past year, we've heard from many of you seeking advice on exercise and nutrition.

Daniel Ryan, MD, Center for Physical Medicine and Rehabilitation, Warren, Michigan, attests:

"Since the outbreak of the COVID-19 pandemic, there have been a number of issues that the post-polio patient has experienced. Many of these issues are similar to the population in general, including weight gain, lack of exercise and psychological stress due to reduced social interaction and not being able to follow the usual life pattern. Oftentimes post-polio patients have dealt with additional stress because it brings back the experiences of their own personal history of poliomyelitis and dealing with that illness. The information brought out in the social media brings back memories within the polio patient to the forefront creating more anxiety and depression."

This "We're Still Here!" campaign, PHI wants to hear from those of you who've found ways to break out of your pandemic ruts and stay active and healthy. We're asking you to submit a photograph and a descriptive paragraph or two about changes you've made to your routine or diet in order to lead healthier, more balanced lives.

Post-Polio Health International will select a grand prize winner (\$100 USD) and four runners-up (free PHI Membership for one year). The winning entries will be published in the fall issue of *Post-Polio Health*.

The runners-up will be announced October 11-14 with the announcement for grand prize to follow on October 15th.

### Contest Rules

- ◆ Email your submission to [info@post-polio.org](mailto:info@post-polio.org) (Subject: WSH 2021 Contest) or mail it to our office at 50 Crestwood Executive Ctr, Suite 440, St. Louis, MO 63126.
- ◆ Include your name, mailing address, phone and/or email.
- ◆ Each person is limited to submitting one entry.
- ◆ Deadline to submit an entry to [info@post-polio.org](mailto:info@post-polio.org) is Friday, October 1, 2021.



### Bay Cliff's 2021 Post-Polio Wellness Retreat

Bay Cliff Health Camp in Big Bay, Michigan will hold its final annual Post-Polio Wellness Retreat on September 12-16, 2021. The program will include customized mind, body and spirit wellness activities led by post-polio specialists and set on the shores of Lake Superior. Activities will include medical updates, handicrafts, massage, physical therapy options, campfire sing-alongs, yoga, fishing sauna, accessible hikes, discussions on healthy aging strategies and more.

Companions are welcome to register and participate. To learn more and sign up, call Bay Cliff Health Camp at 906-345-9314. ■

50 Crestwood Executive Center #440  
Saint Louis, MO 63126 USA

**Not a Member?** Join PHI for just \$30 a year (Subscriber Membership) and receive your own copy of *Post-Polio Health* four times a year (February, May, August, November), plus *PHI Membership Memos* in January, March, April, June, July, September, October via email. For \$55 (Subscriber Plus Membership), join PHI and IVUN and also receive *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October, December).

You can join online at <https://post-polio.org/support-us/membership/> or send (or fax 314-534-5070) this form to: Post-Polio Health International, 50 Crestwood Executive Ctr #440, Saint Louis, MO 63126 USA. Questions? 314-534-0475.

## Inside *Post-Polio Health*

Vol. 37, No. 3, Summer 2021

PHI's Historic First Post-Polio Conference,  
40 Years Later ... 1

A Guide to Using Zoom for  
Support Group Meetings ... 7

Promoting Positive Solutions ... 8

Remembering Daniel J. Wilson ... 10

- \$30 Subscriber  
*Post-Polio Health* (quarterly)
- \$55 Subscriber Plus  
Both *Post-Polio Health* (quarterly) AND  
*Ventilator-Assisted Living* (bi-monthly)

Name \_\_\_\_\_

Affiliation \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State/Province \_\_\_\_\_

Country \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_

email \_\_\_\_\_

Phone (include area/country code) \_\_\_\_\_

I am enclosing a check for \$\_\_\_\_\_ made payable to "Post-Polio Health International." (USD only)

Please charge \$\_\_\_\_\_ to this credit card:

VISA  MasterCard  Discover

Card No. \_\_\_\_\_ Exp. Date \_\_\_\_\_

Name on Card \_\_\_\_\_

Signature \_\_\_\_\_