

POST-POLIO HEALTH

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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.”

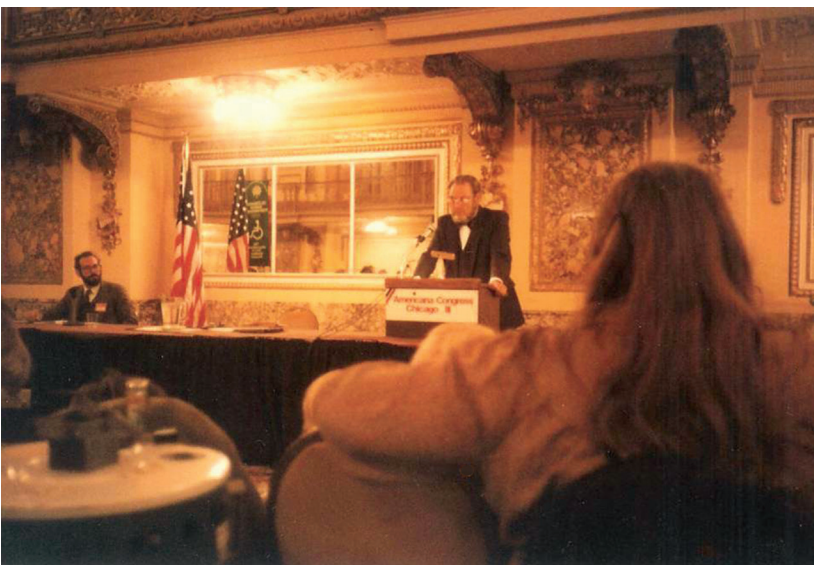
Soon letters from other polio survivors poured in and a planning committee was formed consisting of Gini and Joe Laurie, Dr. Allen Goldberg and his wife, Dr. Evi Faure, Don Olson, PhD and Margaret Pfrommer. They decided on Chicago as the location, as Dr. Goldberg was treating hospitalized children on 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.

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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



Dr. C. Everett Koop addressing the group.

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

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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.

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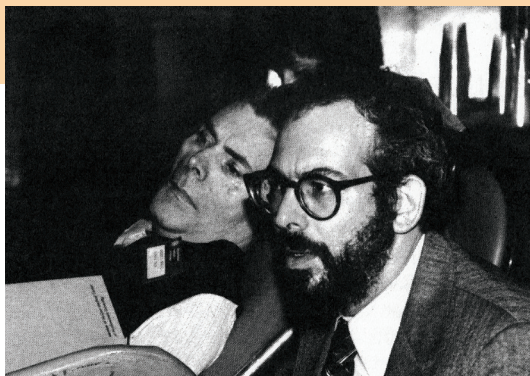
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Allen Goldberg, MD (right)

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:

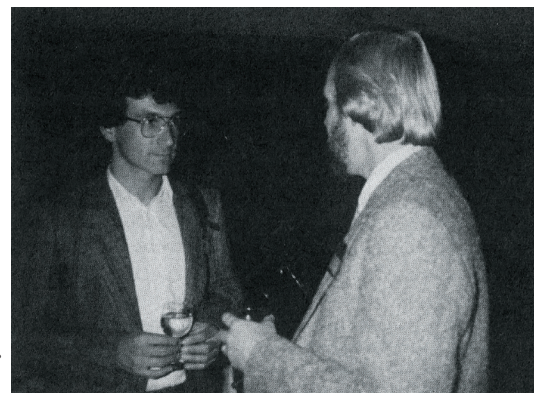
“I felt I met 200 strangers and went away with 200 friends.”

“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)

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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.

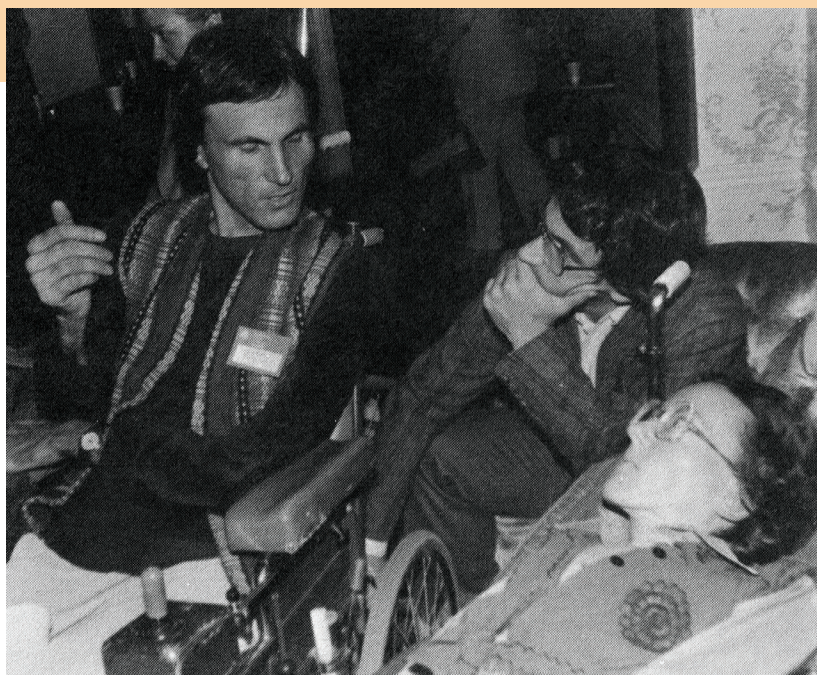
Gini Laurie had managed to spread the word about the conference, its themes and aims among her newsletter subscribers in all parts of the world, many

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

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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. ■