

## Bits of Wisdom from Living with Polio in the 21st Century

**Living with Polio in the 21st Century** was the title of Post-Polio Health International's 10th International Conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) in Warm Springs, Georgia, April 23-25, 2009.

"The Spirit of Warm Springs" was evident as the staff at RWSIR welcomed 436 registrants. In attendance were survivors, family members and health professionals from 11 countries (46 individuals) and 39 US states and the District of Columbia.

Below are bits of wisdom submitted by participants at the conference.



Distributing scooters

Dr. Dale Strasser, Emory University School of Medicine, Center for Rehabilitation Medicine, Atlanta, Georgia, said, "Those with post-polio syndrome who are best able to cope are the ones who are able to articulate their needs, such as what is going on and what they need to be done." In other words, I think that the more we learn about post-polio problems and our own bodies, the better we will be able to handle life going forward.

-ANN CROCKER, MAINE

I don't think I ever felt so comfortable and unconditionally accepted by a group of strangers. The conference was a life-changing experience.

-ROXANN O'BRIEN, INDIANA

Writers Jacqueline Foertsch and Joyce Tepley, both from Texas, held a session on writing a "polio narrative." I was there to hear about how the tone and message of these narratives have changed and evolved over the past 50 years. I hadn't thought of writing a narrative myself, because acute polio hit me when I was 3 and I was hospitalized only three months, so I have

hardly any memory of the experience. Also, the aftereffects, compared to most of those I saw at the conference, were mild and not dramatic. Many stories have been told already and I wondered what I could add.

I commented that my encounter with polio is more about the experience I'm having now with post-polio, not with the initial polio attack. Joyce answered, "That's your story." And she steered me to Kathryn Black's superb memoir, *In the Shadow of Polio*, for an example of how exploring my family's memories can reconstruct not only my "lost" story of having polio, but their stories of how the family was affected, as well. I have saved the list of exemplary narratives and guides to writing one's life story, hoping I will be inspired to start down that path.

-TOM HANOLD, PENNSYLVANIA

It was good to be with people who were going through the same thing that I am, and to not feel guilty if I got tired or was not feeling well.

-MARY LYNN YOUNG, NORTH CAROLINA

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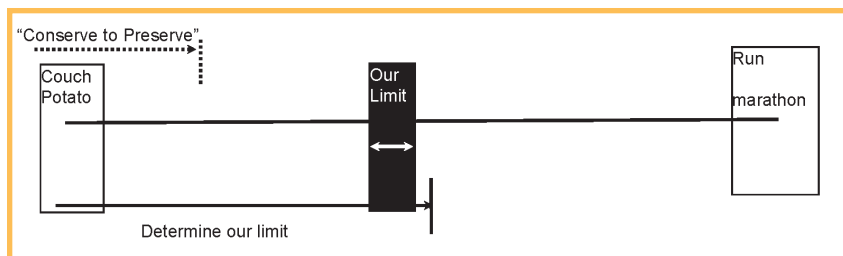
I had two insights. I knew that polio survivors were affected in different ways by the poliovirus, but the magnitude of the differences was very eye-opening. Even the effects of the post-polio syndrome is affecting us in different ways. I wish the world could see what I saw those few days of the conference – a great number of polio survivors – most of them strong, determined, unique and all very special, and each dealing with their lives in very different ways.

The second insight I had was in the session concerning the family. I had a chance to talk to a wife of a polio survivor, and she expressed that she was fearful. I have been the strong one in the family for all of these years but, with the decline in my strength and abilities, I hadn't thought about what they must feel. When I returned home, I asked them to think about what they would like to say to me on this subject, and we had family time in which they spoke and I listened. It was very enlightening. –SHEILA KILGORE, FLORIDA

I observed that I didn't hear "Conserve to Preserve" once during the conference. Nor did any speaker allude to living with post-polio syndrome in reference to having finite use of remaining muscles or neurons. There was no mention of my atrophied leg having finite number of steps left which, once taken, are gone forever. No one advocated overworking my remaining muscles either.

Instead, I heard consensus that I need to pay much more attention to underuse and disuse of my viable muscles. Having post-polio syndrome does not excuse me from taking care of my health in general.

Dr. William DeMayo, John P. Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania, gave the following illustration. He recommended that we be active to our limit.



Each polio survivor is distinct. I have distinct limits. I need to test and establish my limits by doing exercise and activities *slightly* beyond what I perceive to be my limit. To me, this is a significant modification to the "Conserve to Preserve" maxim. Using it, I don't really know my limits, because, according to it, the goal is to not use up remaining strength.

My experience is that I don't have difficulty in knowing when I overwork – my body rebels big time. But, do I know when I am underusing a viable muscle group? This is where I need the assistance of a trained physical therapist.

A clear message that I took away from the sessions is that we become much better at taking care of the challenges of post-polio syndrome if we take care of our health in general by weight control, maybe low-impact seated yoga, good sleep hygiene, relaxation techniques, improved assistive devices, and, of course, by having an uncompromising primary care physician.

–BALDWIN KEENAN, CALIFORNIA



Taking a break



Education session

It was the first time my husband and I were able to gather not only with such gifted

leaders, but also with other polio survivors. How I like that term, *polio survivor*. How much better than a *polio victim*, which is all I ever heard before the conference. It is much more positive. –EDNA LOVE, FLORIDA

Dr. DeMayo stated that the various muscle weaknesses showing up immediately after the initial viral illness does not necessarily represent all the motor nerves that were damaged by the virus. Other damaged nerves become apparent in post-polio syndrome. Because of the great number of possible damaged nerves, each polio survivor has a unique set of problems, but any one of those problems overlaps with others.

–PAUL SEIB, KANSAS

The sessions not only taught us what symptoms to look for, but gave us needed information as to what could be done. I was especially interested in the Yoga and Tai Chi sessions. I had tried Tai Chi several years ago in the standing position and was not able to do it. Since coming home, I have tried

seated Yoga and Tai Chi. Constant movements of Tai Chi are tiring to me, but I have solved that by “pausing” when the instructor changes positions!

–MONA PHILLIPS, RPT, ARKANSAS

I had not been back to Warm Springs since I was there for treatment at age 5 and that was quite a few years ago. It was a very emotional trip for everyone. The first day was full of tears and bits and pieces of memories. The last day I left with pleasant memories of loving and caring doctors and nurses. Prior to this conference I had no knowledge of post-polio problems. One thing I learned was to be my own advocate and to research thoroughly any surgeries and procedures. The most important thing I gained from the conference was to feel part of a group. For years I felt like a lone ranger, but now I’m part of a new family. –MELVIN COLLEY, GEORGIA

Fernando Torres-Gil, PhD, University California Los Angeles, Public Policy & Social Research, gave me great insight into what I should do with my next ten years. All my life I have been working with older adults and persons with disabilities. Now the task at hand is to develop coalitions between the two groups. At the age of 77, this seems to be a good idea. I am grateful for his wisdom. –MARY ESSERT, ARKANSAS

Once there, the presenters codified a lot of what I already knew or felt – even more valuable were the huddles after times for questions. Being an articulate and assertive person, question times were feisty and when answers did not satisfy, the spontaneous gatherings produced validations, suggestions, comfort. Also in those huddles were practitioners offering their expertise. For me the most important realisation, was that we are relatively well off compared with children in developing countries with polio. –FRAN HENKE, HASTINGS, VICTORIA, AUSTRALIA



Tour stop at the Polio Hall of Fame



I am not a polio survivor myself, but I have been working with the post-polio community in Victoria, Australia, for the last five years. A highlight for me was “Demonstration and Discussion of a Post-Polio Examination: Sorting Out Secondary Conditions,” which provided an overview of a clinical assessment by Drs. Fred Maynard, Retired, Marquette, Michigan; William DeMayo; and Brenda Butka, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee, ably assisted by two polio survivors who were happy to strip down to their shorts (male) and swimsuit (female) in order to demonstrate key physical considerations.

This impressive demonstration and discussion really brought home the importance of being thorough if a physician is serious about assisting their patients: history and current health; physical examination (identify functional ability – with and without the usual aids, range of motion, strength assessment, gait assessment, pain evaluation, etc.); other testing, such as orthopaedic or neurological exams; and the determination of goals and treatment plan mutually agreed upon.

Although general health professionals may not be as experienced as these presenters, I don’t believe they lack the ability or skills to do this type of assessment for polio survivors – it’s more likely to be a lack of time and even a lack confidence.

–MARY-ANN LIETHOF, POLIO NETWORK  
VICTORIA, AUSTRALIA ▲

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**The Post-Polio Wellness Retreat**, facilitated by nine faculty members, was attended by 46 polio survivors, 15 caregivers/spouses from three countries and 21 states.