

30 Years Later ... We're Still Here!

Thirty years ago, in October 1981, some 250 health care providers and polio survivors held an international symposium in Chicago to consider this question: **What ever happened to the polio patient?**

Hosted by the Rehabilitation Institute of Chicago and the *Rehabilitation Gazette* (which later became St. Louis-based Post-Polio Health International), sponsors included the March of Dimes, National Easter Seals Society, the Anesthesia Departments of Children's Memorial and Northwest University Hospitals in Chicago, and LIFECARE Services, Inc.

Rehabilitation Gazette founder Gini Laurie had an encyclopedic mind and networked – before it became a buzz word – with a vast community of polio survivors and health care professionals. This she did with no computers, email or Internet connection. For more than 20 years, she and her husband, Joe, had produced publications that chronicled the stories of polio survivors from the 1940s and 1950s.

In the late 1970s, Gini and others involved in health care for polio survivors became aware of new problems that seemed to be related to earlier polio diagnoses. In 1979, the *Rehabilitation Gazette* published a letter from a reader who said, “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.”

Letters poured in, and the first international post-polio conference was organized. In a summary of the proceedings of that conference, the editors note “What ever happened to the polio patient? Those survivors – the former generation that pioneered the advances – seem to be ‘prematurely aging,’ and no one really understands why.”

Writing in the August 2011 *Archives of Physical Medicine and Rehabilitation*, Lauro S. Halstead, MD, himself a polio survivor, presents “A Brief History of Post-polio Syndrome in the United States,” that tracks the increased interest in post-polio issues growing out of that first conference and others that were organized almost simultaneously in Oakland, California, and Ontario, Canada.

“At about this time, the term ‘postpolio syndrome’ was introduced, which quickly became the unofficial designation for these new health problems, although many other terms have been used as well including ‘postpoliomyelitis muscular atrophy,’ ‘the late effects of polio,’ and ‘postpolio sequelae.’”

Dr. Halstead notes that in the three decades since that first conference, “many thousands of survivors organized themselves into self-help groups, attended specialized clinics and helped energize a vigorous enterprise of basic and clinical research. More recently, as the population continued to age and the energy and enthusiasm of the early years waned, there has been a decline in published research and the number of clinics and support. Regardless of these trends, there are still thousands of survivors who, more than ever, require expert rehabilitation assistance as they cope with advancing age and declining function.”

For the last 30 years, Post-Polio Health International has focused on its mission to enhance the lives and independence of polio survivors and home ventilator users worldwide through education, advocacy, research and networking.

Many post-polio groups around the world can trace their beginnings to attendance at a PHI international conference and attribute their success to the work of PHI. Building on the network Gini Laurie nurtured since 1958 that connected polio survivors around the world, the solutions and achievements PHI has documented inform and motivate others to explore options to also live independently. ▲