

## Where did we come from?

by Richard Daggett, President, Polio Survivors Association

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No, this is not an article about the birds and the bees. It is a story of how the polio support group movement began. As the Rancho Los Amigos Post-Polio Support Group enters its 12<sup>th</sup> year it seemed a logical time to reflect on where we are and how we got here.

In the beginning there was Gini Laurie. No history of the polio support group movement could begin without mentioning Gini. She is often described as “the glue that held the polios together.” Gini lost two sisters and a brother to polio, and another sister contracted polio but survived. Her early involvement started as a volunteer at the Toomey Respiratory Pavilion in Cleveland, Ohio. In 1958 she began publishing the Toomey J. Gazette, which evolved into the Rehabilitation Gazette\*. Through this publication, and her correspondence with polio survivors, people with other disabilities, medical professionals, and independent living advocates, she began a network that was instrumental in identifying the problems we now face.

\* This evolved into the publications of Post-Polio Health International [www.post-polio.org](http://www.post-polio.org)

Gini Laurie was a vigorous advocate for people with disabilities. She encouraged us to be proactive, seeking solutions to whatever problems we encountered. In 1974 a group of polio outpatients of Rancho Los Amigos Medical Center were discussing some of their common concerns. Among these were how to remain independent in their own homes, and how to obtain and maintain adaptive equipment necessary for their independence. This group of polio outpatients decided to organize as the Polio Survivors Association and, in 1975, formed a nonprofit corporation to promote the well-being and improve the quality of life for severely disabled polio survivors. Few people knew about the late effects of polio, or what we now call post-polio syndrome. The Polio Survivors Association was the first organized polio support group.

In 1981, Gini Laurie planned and coordinated the first large conference dealing with the late effects of polio and living independently with a disability. Among the questions posed at this conference were, “What’s happening to so many of the polio survivors, and why are they experiencing renewed fatigue and weakness?” No definitive answer came out of this conference, but it began to focus our attention. Polio survivors and those health professionals who had been working with them initiated the first preliminary studies.

At the second international conference in 1983, again organized by Gini Laurie, the term “post-polio syndrome” was used by some of the speakers. It was sometimes mentioned in a questioning manner. Was there really something here, or are we overreacting? The CBS Sunday Morning news program with Charles Kuralt taped part of the conference. When this aired on the nation’s television sets it turned a spotlight on the problem. There was no turning back. In 1984, Gini Laurie and Judith Raymond, in collaboration with Drs. D. Armin Fisher and Frederick Maynard, published the *Handbook on the Late Effects of Polio for Physicians and Survivors*.

April 12<sup>th</sup>, 1985, was the 30<sup>th</sup> Anniversary of the Salk polio vaccine. Almost all of the news coverage of this historical event included mention of polio’s late effects. By then several

additional post-polio support groups had begun. These were mostly local or regional groups, but their newsletters helped spread the word beyond their borders. The original Polio Survivors Association started focusing more of its efforts toward educating polio survivors, their physicians, and the general public about this growing problem.

A small, barely two paragraph article titled "*The Polio Scare Returns*" in the July 1986 issue of Family Circle magazine indicated a developing concern. Over 3,000 letters in response to this article were sent to the Polio Survivors Association. Some individuals told of problems they were already experiencing, but didn't understand. Some expressed frustration with the medical community. And others were worried about the future.

The Rancho Los Amigos Post-Polio Support Group was formed in 1987. Rancho was the largest respiratory polio center in the United States and continued to see many polio survivors in its out-patient clinics. Drs. Jacquelin Perry and D. Armin Fischer of Rancho were among the first to recognize the late effects of polio and publish articles in prominent medical journals. Dr. Perry asked permission of the Polio Survivors Association to use their mailing list to contact individuals who might be interested in forming a local support group.

Early estimates of the number of polio survivors were between 250,000 and 300,000, with about 25% of these at risk. As more information became available these numbers increased. Current estimates are that 1.6 million individuals in the United States were diagnosed with polio, and about 600,000 were left with some identifiable residual paralysis ranging from barely noticeable to severe. More than 50% are experiencing problems or may be at risk.

Polio survivors are often categorized as having "Type A personalities." Whether this is true or not, we seem to be very pro-active. No other large disability group has been as passionate about finding the cause or causes of our problems, or as eager to find and educate our health professionals. Probably no other disability has produced more support groups or published more newsletters and informational material.

Where did we come from? We came out of the dedicated efforts of advocates like Gini Laurie, Judy Raymond Fischer, and Joan Headley. We were fortunate to have the vision of polio survivors like Renah Shnaider, Harriet Bell, Nancy Baldwin Carter, and those who founded of the Polio Survivors Association. We were supported by health professionals like Jacquelin Perry, Armin Fischer, Frederick Maynard, Augusta Alba, Stanley Yarnell, and Lauro Halstead. And we've been sustained by those who contributed their time and talents to help others learn to accept change and develop new coping styles. We owe a great deal to so many, and we give each of them our thanks.