

POLIO NETWORK NEWS

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International Polio Network

Gini and G.I.N.I. Conferences

Pioneering Independent Living

By Gertrud Weiss
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Erika Bulow, a polio survivor and friend in Berlin, was shocked and, at the same time, relieved when she learned from some of my articles three years ago, that her mysterious new health problems had obviously to do with the late effects of former polio. Her doctors had not found an answer or a reasonable explanation. This was — and often still is — the typical experience of polio survivors when decades after the acute disease and successful recovery, forgotten difficulties turn up again.

Now she wanted to know how I became interested in the subject, and why, as a science writer, took up such an “exotic” theme. The first information and the stimulus to deal with it had come from my doctor more than 10 years ago. The rest was own involvement.

Having had paralytic polio in 1928 and quite a history of nearly full recovery after a muscle transferral, problems came decades later from the damages to the paralyzed leg from an accident. In the ‘70s an odyssey through university hospitals began. Different suggestions for operations were made. But in view of the long-standing and wide-spread muscular-skeletal dysfunctions with severe joint deformities, I regarded them as too risky. Finally, in 1980, I met an orthopedic surgeon who, for the first time, noted the complexity. He suggested bracing; the idea of more surgical “reconstruction” was discarded. Since then, an independent and active, though changed life gradually developed again.

In 1982, my doctor — a famous expert of holistic rehabilitation — showed me papers brought from a medical congress in the U.S. that dealt with a 1981 symposium in Chicago. Under the title “What Ever Happened to the Polio Patient?” progressing functional losses had been discussed. Since they were unexpected and, at that time, somehow incompatible with the accepted philosophy of a stable, physical condition gained after acute poliomyelitis, many doctors as well as family members doubted deteriorations as reported.

However, Gini Laurie, from St. Louis, had strongly pleaded for the conference, attended by nearly 200 persons from five countries. Panel participants included medical as well as research and engineering experts

in various fields, officers from public health and social agencies, and, of course, polio patients. Already for 25 years she had been the person to whom people with severe disabilities from polio, other neuromuscular diseases, and from accidents would talk or write to. Her organization, Rehabilitation Gazette, with a journal of the same title, had developed into a well-known forum. (Since 1984, the name has been Gazette International Networking Institute — G.I.N.I.)

Having lost three siblings herself to polio, Gini visited and cared for paralyzed children, youths, and adults during the time of catastrophic epidemics in the Toomey Pavilion, part of Metropolitan General Hospital in Cleveland, Ohio. It was one of 16 respiratory centers established and supported by the private foundation, March of Dimes. Most of them were closed when the dramatic success of mass vaccinations against poliomyelitis in the early ‘60s became obvious. The foundation set other priorities.

Gini Laurie and friends had already looked to bring ventilator-assisted patients home to live with their families. Physicians and therapists, social workers, teachers, psychologists, as well as engineers and industry managers became interested to cooperate. Special equipment of all kinds was needed — from different beds to lighter ventilators which were not so difficult to maintain. Finally, home care of severely

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Update ...

Several readers have asked about the article “Unintended Casualties in the War on Polio” in the June 6, 1993, *Philadelphia Enquirer*, and the segments on *American Journal* and *Front Page* regarding individuals who contracted polio from the vaccine.

Polio Network News, (Winter 1992, Vol. 8, No. 1), mentioned the vaccine ruling cited in all of the above. “... the essence was that the government is liable for injuries caused over several decades by oral polio vaccine.

“The case asserted that the Federal Division of Biologics Standards (DBS) — now known as the

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physically disabled persons proved to be not only practical when duly organized, but also less expensive than hospital care. And, after all, Gini and her publication — *Rehabilitation Gazette* — had kept polio survivors with experience from respiratory wards in touch with each other, offering advice and solutions for difficulties when living at home.

Letters from polio survivors she had received in the late '70s alerted her to the new health problems. At the time of the Chicago conference, one could only guess for the causes of symptoms such as severe fatigue, exhaustion, muscle and joint pain, new weakness in the affected, as well as formerly not affected, muscles. Chronic overburdening of parts of the body from abnormal motions, abnormal forces on muscle, connective and ligament tissue, and the skeletal system as a result of polio, and the endeavors to compensate for malfunctions, obviously contributed to the new situation.

Based on experiential reports by patients and health professionals, the participants in the Chicago conference advocated for more research in many fields — from epidemiology to biochemistry to rehabilitation. Suggestions for polio patients and their families were discussed. However, questions as to exact diagnostic criteria and special therapies were not answered, neither were questions as to early warning signs.

In her address to a medical congress in 1982, Gini Laurie stressed the pioneering work of the respiratory and polio rehabilitation centers. They had developed the team work concept evident today in all medical institutions, which integrates the patient and his family into the rehabilitation process. The polio patients have become "role models for people who master life with severe disabilities and, with technical devices and personal assistance, do productive work ... Despite the disease and its aftermath many continued school and professional education. Today they are lawyers, physicians, professors, psychologists, therapists, writers, business managers. Nobody needs to speculate any longer whether occupational rehabilitation or university studies are worthwhile for people with severe disabilities."

"A great personality! You should meet her," my doctor said upon his return from said meeting, and handed me, among other papers, an invitation for the next conference (1983) in St. Louis. My reluctance in view of now limited physical abilities was not accepted. "In America you will get help everywhere." Right he was — and Gini Laurie, in a letter, encouraged me. Undemonstrative and self-evident helpfulness in America was experienced in many different situations and regions of the country in years to come.

The 1983 conference in St. Louis turned out as a very important event for my future life — first of all, because I met Gini. Secondly, it was new for me to meet and talk to so many polio survivors from

America and overseas countries with significant disabilities in a non-hospital environment. Thanks to their ventilators, mobile devices, and attendants, they were free human beings living independently.

Upon my return to Germany, I began reading everything available about polio and its late effects, including scientific documentation. An outstanding event of the 1985 conference was the address by Dr. Albert Sabin. In 1987, the "harvest" from medical lectures and interviews with noted physicians was quite extensive. As a result, several articles were published in nationwide daily newspapers and in a medical newspaper. Information to readers from various levels of society had started and has been going on.

Up to now, the last congress about polio late effects, combined with a symposium of independent living, was in 1989. Despite her serious illness, Gini Laurie had prepared every detail. And not only that: she was wheeled into the various conference rooms on a comfortable couch, she appeared for important lectures in forenoon as well as afternoon hours — encouraging, and, if necessary, setting things in perspective. She was deeply irritated by the violent suppression of the student's revolt in China during those days, and much concerned for two participants from Beijing who were to return to their families. Three weeks later, on June 28, 1989, Gini Laurie died, shortly after her 76th birthday — respected, beloved, and mourned by many people in the world. ■

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