

"A remarkable thing happened in Chambersburg, Pennsylvania ..."

Phyllis Bailey, Chambersburg, Pennsylvania

This is a story about the development of a post-polio support group in a small Pennsylvania town.

Composed of well-educated consumers and thus empowered to educate their personal physicians and to become partners in their medical care, the group was recognized as a health advocacy model at a national conference sponsored by the Alliance for Continuing Medical Education headquartered at the University of Alabama, Birmingham, Alabama.

I had polio at age seven and was given the whole gamut of treatments including the iron lung, years of physical therapy, bracing, and orthopedic surgeries. During the early '80s I discovered a post-polio support group in Bethesda, Maryland, where I was then living and working as a special education instructional assistant. There I learned about the late effects of polio, although I was not at that time experiencing symptoms.

In 1990, I retired and moved with my husband, Walt, and our dog, Ginger, to Chambersburg, Pennsylvania. I started to experience some symptoms and began searching for a local support group to have as a resource for future information and treatment options. One was not to be found.

As a result of my search, our local Easter Seal Society asked me to determine if there was sufficient interest in forming a post-polio support group.

After some local publicity, we held our first meeting in May of 1994. There were thirty attendees, some in wheelchairs or scooters, some using walkers or crutches, making

it necessary for us to move from the conference room to the larger entrance hallway.

At our second meeting, the representative from our local hospital education department observed our cramped quarters and volunteered their hospital lecture facility, a recent addition, which is "handicapped accessible." The Easter Seal Society has continued to make available their administrative staff to aid us in the printing and distribution of our monthly newsletter.

At these early meetings I heard amazing stories. One member, who had polio at age five and wore long leg braces with a pelvic band, had to be hospitalized for a fracture. During her rehabilitation, the physician demanded that she try to stand without her braces, a rather ridiculous request since she had needed such support since childhood.

As members talked and shared their experiences, there were tales of being misunderstood, misdiagnosed, patronized by their physicians, and referred to psychiatric facilities.

One morning while I was volunteering, I cornered the hospital CEO and explained that it had become evident that there was a need to educate area physicians about the late effects of polio. He referred me to Robert Pyatt, MD, who was the physician in charge of scheduling weekly staff Continuing Medical Education seminars.

After many attempts, I finally met Dr. Pyatt. His first words to me were, "How many people are we talking about anyway?" I was

armed with a video, printed material, and our membership list of seventy-five-plus people.

Together, we organized a program to educate our physicians on post-polio issues. Invitations were sent from the hospital to our personal physicians. Also, all group members encouraged their physicians to attend. I recommended three speakers and Richard Bruno, PhD, now at Englewood Medical Center in New Jersey, agreed to lecture to the group of over fifty physicians. Also in attendance were retired physicians, physical therapists, occupational therapists, anesthesia specialists, and nurses.

Overall reaction to the seminar was favorable. (The expenses of the seminar were paid by the hospital.) Our health professionals now recognize post-polio problems and the need for pacing and not over-exercising and have a clearer picture of treatment options.

Our support group is not unique and, for our part, we avoid non-productive gripe sessions. We focus on educating ourselves and have become well-educated.

Members of our group are learning how to talk with their physicians and thus be active participants in their own health care. We feel it is up to us to keep abreast of information and often prepare copies of information with highlighted areas applicable to our individual needs for our physicians, who now welcome this information. One member, who has been intimidated by physicians, has now learned that doctors are approachable and is taking initiative and becoming more assertive in working with her physician.

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Halstead, L. (1998). Post-Polio Syndrome. *Scientific American*, 42-47.

Trojan, D. (1997). *NeuroRehabilitation: An Interdisciplinary Journal*, 8(2).

The whole journal, edited by Daria A. Trojan, Montreal Neurological Institute and Hospital, Quebec, Canada, features post-polio syndrome. Major articles include:

Post-polio syndrome: historical perspective, epidemiology, and clinical presentation by A.C. Gawne and L.S. Halstead;

Pathophysiology and diagnosis of post-polio syndrome by D.A. Trojan and N.R. Cashman;

Management of post-polio syndrome by D.A. Trojan and L. Finch;

Muscular function in late polio and the role of exercise in post-polio patients by J.C. Agre and A.A. Rodriquez;

Biomechanical abnormalities of post-polio patients and the implications for orthotic management by J. Perry and D. Clark;

Pulmonary dysfunction and its management in post-polio patients by J.R. Bach and M. Tilton.

Contact: Elsevier Science (USA -- 212/633-3730, 888-4ES-INFO toll free in North America, 212/633-3680 fax, or usinfo-f@elsevier.com; Europe -- +31/20-4853757, +31/20-4853432 fax, or nlinfo-f@elsevier.nl; Asia -- +81/3-5561-5033, +81/3-5561-5047 fax, or kyf04035@niftyserve.or.jp).

We have expanded our educational activities at our local college campus. Two of us speak with a class of physical therapy assistant students each semester, describing when we first were taken ill as well as all the adjustments that we have had to make over the years. This, in effect, becomes our story of living with polio. We have found these classes of 40 to 45 students very interested, attentive, and full of good questions.

Dr. Pyatt, now Medical Director of the Cumberland County Health Network, continues to monitor our group's assessment of their improved medical care. He asked for my participation in the annual Continuing Medical Education Conference in San Diego to highlight our accomplishments, offering it as a model for other groups, i.e., diabetes, arthritis, multiple sclerosis, stroke victims, and to encourage other medical educators to seek input from patient groups.

Our session entitled "Patient-Centered CE: Improving Quality and Outcome," was followed by a workshop with the focus on "Patient-Centered CE." Joan Headley, Executive Director of the International Polio Network in Saint Louis, Missouri, also participated. We emphasized how patients and their advocacy groups can play a critical role in CE.

Self-help philosophy states that people who are part of the problem can also be part of the solution. Our group would add — that an educated patient is their own best resource. ■

"A Paralyzing Fear: The Story of Polio in America,"

a 90-minute film, has been scheduled for national air on PBS on October 5 at 9:00 pm. (Local stations may air at anytime. Check your local listings.)

Following the airing of the film, PBS has scheduled a 30-minute studio show which will feature experts in post-polio syndrome, the worldwide eradication of polio, and the future of vaccination for children.

REMINDER:

The film is being made available to groups wishing to show it prior to its running on PBS. For more information, contact: Nina Gilden Seavey, Center for History in the Media, George Washington University, 801 22nd Street, NW, Washington, DC 20052 (202/994-6787, 202/994-6231 fax, or seavey@gwu.edu). ■

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