

The Pennsylvania Polio Survivor's Network

How We Began Our Mission of Service

Carol Ferguson

My post-polio journey was long, painful and truly confusing. Happily, in the fall of 2013, I was finally “there.” Polio was no longer defining my life. Had I discovered the limitations that came with disability? Yes. Had I discovered new and pain-free abilities? Yes. I had been given the gift of understanding what was happening and complete acceptance of my new limitations. I was a polio survivor who was truly thriving. With that, came a new kind of energy.

For two years I had been writing the fascinating, joyful, painful and truly memorable survivor stories of my friends. Although active in my support group, my new energy was looking for more. I knew without question that in the end, I had been truly blessed in my care. I read every PHI newsletter from cover to cover and in early spring 2014 discovered their international conference would soon be held in St. Louis. I told my husband I wanted to go. He responded, “You can’t travel alone.” Poor guy, I will never forget the look on his face as he dropped me off at Philadelphia airport on my bright red scooter, suitcase under my feet. From that moment, my life changed.

There was kindness everywhere I turned in the form of smiles, patience and people willing to help. Although nervous when I arrived at the conference location, I was excited as well. I was thrilled my daughter-in-law was joining me and that I could engage her in my “new” world. She is curious, loving, funny and kind and was the perfect companion, attending sessions one after another for two days.

The first night, while waiting outside the dining room, I met a kind gentleman, also from Pennsylvania. As I was sitting and he was standing, I could not read the MD next to his name—Bill DeMayo. Little did I know he was a rehabilitative physician, one of the featured professional speakers for the weekend and an incredibly nice man. There at dinner was Daniel Wilson, PhD, who I had met years before and whose advice was significant in my complex diagnosis.

The next day, when I heard Dr. William DeMayo speak, I was fascinated. His integrative treatment program for polio survivors had the same philosophy as the one I had successfully completed in New Jersey. I met, listened to, laughed with and learned so much from so many amazing people that

weekend; my head was spinning. While on the flight home, I focused on how truly blessed I was and how I knew my life had changed forever. I finally found a place for my newly found energy.

While in St. Louis, I had met outstanding professionals from all over the world and fellow survivors who had become post-polio support group leaders in their various states. I knew from my own experience and from the stories I had the opportunity to write, that Pennsylvania seemed to be behind other states regarding information about post-polio diagnosis and care. At that time, there were four active support groups in our state. Gathering information to share with their groups was cumbersome and had to be gathered from numerous places.

Everyone was struggling with interesting and credible programing to bring to survivors at meetings.

Gathering a supportive “team” became a necessity. My ever-supportive husband and two close friends were my sounding board for some great (and not so great) ideas. One, who is filled with wisdom, was interested in the topic because of her love for me and for her brother who is also a survivor. The third in our initial journey was a man I met in the local support group. Paralyzed from the neck down at age two, his journey with polio was one that I could not imagine. His sense of humor and ability to be very “grounding” all at the same time were the perfect combination. Over the next few months, I learned how to launch a website, use Facebook and call complete strangers for advice. Our total financial investment was the \$90 we had spent for the website.

November 2014, we were ready to go. We were devoted to our mission statement: “To Be in Service Providing Information to all Polio Survivors, Post-Polio Support Groups, Survivor’s Families and their Caregivers.” Our website put information from multiple credible sources in one place.

Prior to launching the website, we asked every contributor for their permission to publish their work. I will never forget the response from then PHI Executive Director Joan Headley. As was typical of her work, she not only read every article but found more than one typo! I was truly grateful for her attention to detail. The idea of “Bruno Bytes” was born and our first month’s publication was uploaded. At the same time, we were truly naive as to the power of the internet.

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Eastern Pa. attendees at the “Post-Polio Care,” 2017 Conference. This event was live in Eastern, Central and Western PA, thus connecting over 200 survivors and caregivers at one time. Rotarians from 3 locations were on hand to assist.

More than four years later, our mission of service is more intact than ever. Our team has grown to be what we call a “joyful ragtag bunch” of nine volunteers. (Four of us are survivors who are geographically spread throughout PA). We serve ALL Polio survivors regardless of where they are from and charge no dues. We rely solely on, and are grateful for, *all* donations.

- ❖ Our newsletter (www.papolionetwork.org/newsletter.html) is published each month, all over the US and abroad, for no charge (by email); in both regular and large print formats.

- ❖ Our website (www.papolionetwork.org) is updated regularly. The biographies of our regular contributors are clearly visible with a simple click on their name.

- ❖ We have hosted/sponsored two conferences and a worldwide webcast. We have published the videos from all three, thus allowing the information to be shared. (www.papolionetwork.org/post-polio-care-video.html)

- ❖ We have communicated with and introduced ourselves to every hospital, senior residence community, neurologist, home health care agency and oral surgeon in the State of PA.

- ❖ April is now “Polio Awareness Month,” passed unanimously by our PA State Representatives. Each year, we launch a new “initiative” during that month.

- ❖ We have become active on the Immunization Coalition for our State. (Two of us attended as exhibitors and speakers at the PA State Immunization Conference). We published a Polio Immunization card being sent to new mothers in three counties.

- ❖ “Team Survivor” (quite simply a means by which survivors and our families can become part of the solution) has raised enough funds to vaccinate more than 32,000 children in the most war torn areas of the world.

- ❖ We happily do presentations about the “Polio Truths” throughout the State of PA. In 2018, we did 30+ events.

- ❖ We actively engage in the Senior Health Fairs (sponsored by our Representatives) held throughout PA.

- ❖ We have hosted two events in the Pittsburgh area (home of the Salk vaccine). The positive press in that area resulted in a significant number of survivors and their caregivers being able to gather and renew with one another.

In December of 2014, we made the decision that we would continue to be active as long as it is necessary. It is our dream that post-polio care will become “mainstream” for health care professionals and survivors. Until that happens, and as we venture into a new year, we are focused on answering the question from PHI asked us to write this article: “What motivates your group to continue?”

We are blessed to be able to work with amazing professionals who truly care about polio survivors and the long-term effects of polio. The opportunity to read and publish their work on a regular basis is something we will never take for granted and want to continue. The positive response from health care professionals when we talk about the “Polio Truths” has motivated us as well. When we do presentations, we encourage their questions and concerns. We are grateful for their wanting to attend and be open to ideas.

Most of all, it is the positive response from polio survivors all over the US and abroad to our work that has been humbling and truly inspiring. The four survivors on our team see the effects of polio as something that we “have” but not something that will continue to define us. The non-survivors, truly wonderful family and friends on our volunteer team, are focused on our energy, *not* on our disability. That combination has resulted in what we believe to be a positive and encouraging message when discussing the reality of the *very* painful and difficult effects of polio. ■