



The Pa. Polio Survivor's Network. How We Began Our Mission of Service

www.papolionetwork.org



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. I am a Summer Grippe kid (often referred to as “non-paralytic”) polio survivor with PPS. 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 the International Conference soon to 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 PA. 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 at the Post-Polio Institute in Englewood, NJ. 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 had been and 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 leaders in the area of post-polio support 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. Information for them to share was cumbersome to accumulate and had to be gathered from numerous places. Everyone was struggling with interesting and credible programing to bring survivors to 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 2, 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 PHI 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.

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 rag tag 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 are funded solely on and grateful for *all* [donations](#).

- Our [newsletter](#) is published each month, all over the US and abroad, for no charge (by email). We publish in both regular and large print formats.
- Our [website](#) is updated regularly. The biographies of our regular contributors are clearly visible with a simple “click” on their name (when highlighted in red).
- With the help and support of our amazing professional contributors, we launched an updated [Anesthesia Warning /PPS Symptom](#) Card. At the advice of Dr. William DeMayo, MD the information is easily maintained and accessed through a “scan code” on the card.
- At the request of survivors, we have published a [PPS Symptom Checklist](#) to share with our families and health care professionals.
- We have hosted/sponsored two conferences and a worldwide webcast. We have published the videos ([HERE](#) and [HERE](#)), thus allowing the information to be shared with all Polio survivors.
- 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 have actively engaged with [Rotary International](#), whose mission of “Service Above Self” has made it their goal (in partnership with the GPEI) to eradicate Polio. We personally visited their headquarters in Evanston, Illinois and presented a gift of gratitude from Polio survivors all over the world.
- “[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.
- In 2018, we partnered with Dr. Richard Bruno, HD, PhD, the Director of the International Center for Polio Education to edit and publish the [Encyclopedia of Polio and PPS](#). This publication contains all of Dr. Bruno’s newly updated articles (including Research articles), Bruno Bytes and videos. In addition, we have created an Index (by Subject) with more than 1,000 entries. The entries are updated regularly in a joint effort with Dr. Bruno and our volunteer team.
- 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.

- Everything we publish is applicable to ALL Polio survivors and caregivers, not just those in Pennsylvania.
- We are grateful beyond words for the regular contribution(s) of our professional contributors (listed alphabetically) Dr. Richard L. Bruno, HD, PhD, Dr. William DeMayo, MD, Post-Polio Health International, Rotary International and Professor Daniel J. Wilson, PhD. The full list of our professional contributors (including their biographies) is on our [website](#).

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 “main stream” 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](#) Director Brian Tiburzi when he 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 (both mental and physical) of the Polio virus. 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. Ideas such as “non-paralytic” Polio being able to result in PPS, the reality of there being survivors seeking care who are not “aged” and “Yes”, PPS does exist. We talk about how credentialed our professional contributors are – referring to the easy access through our website to *their* biographies/websites.

The “hits” on our website continually grow when we distribute the Polio Awareness image that encourages Polio vaccination. This image has a direct “scan” link to the Rotary International video: [Why Zero Matters](#), which is a film that explains just how easily the virus could return to all countries who are now Polio “Free”.

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.

Carol Ferguson and the entire [Pa. Polio Network Team](#)

Polio

**It's only a plane ride away.
Please Have Your Children Vaccinated.**



**The Pain and Disability from
Polio Lasts a Lifetime.**



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Polio Awareness

There is an outstanding video on our website that clearly explains WHY Zero Matters with Polio, and the truth to it only being a plane ride away.

<https://www.papolionetwork.org/end-polio-now-rotary-international.htm>



Polio Awareness Message



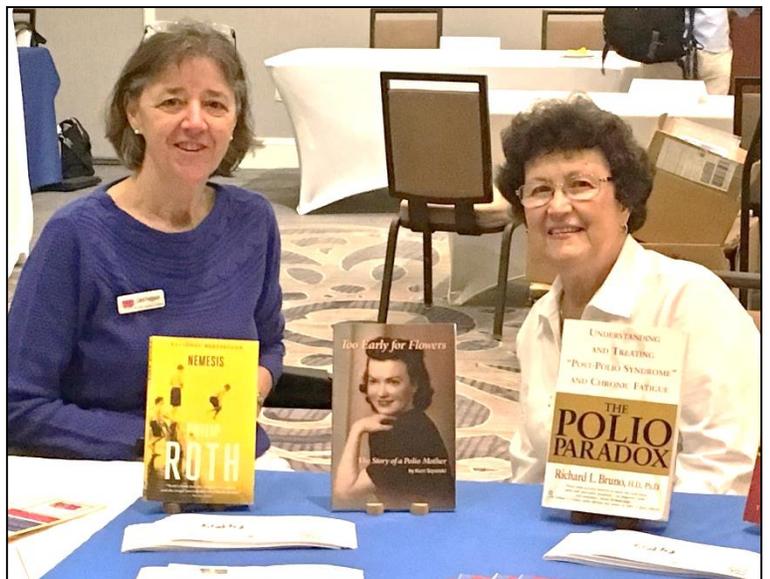
Jim Smith speaking at a group meeting.



Joe Randig in a photograph from the Pittsburgh Post Gazette.



Joe Randig – all ready for the Western PA. “Live” Post-Polio Care event. [Conference Photos](#) below presentation videos.



Carol Ferguson and Deb Stambaugh exhibiting at the Pa. State Immunization Conference.



Jim Smith and Carol Ferguson at the “Race to Zero” (Purple Pinkie) to raise funds for Polio Eradication. [\(Slide Show of photos\)](#).



Deb Stambaugh exhibiting at a Senior Health Fair in Central PA