



## 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” or “non-apparent” polio survivor with [Post-Polio Syndrome](#) (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 acceptance of my new limitations. I am a polio survivor who is truly thriving. With that, has come a new kind of energy.

Gathering a supportive “team” became a necessity. My 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 friendship and love for her brother who is also a survivor. The third in our initial journey was a kind and generous 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 we worked together, while I learned how to launch a website, use Facebook and call complete strangers for advice.

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 it, we asked every contributor for their permission to publish their work, along with their biographies, as it was/is critical for us to provide only the most credible information. At the same time, we were truly naive as to the power of the internet.

Nine 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 volunteers. Five of us are polio survivors, each of whom has a completely different polio story. One, paralyzed from the waist down, spent two years in the hospital and has spent his entire life using braces & crutches. One realized the complete paralysis of her right arm, spent 6 months in the hospital, and still has that complete paralysis. One, completely paralyzed from the neck down, was cared for at home by his (quarantined) mother because the hospitals were filled. One was an infant in Taiwan when she had polio and except for her “quad” muscles, seemed to have very little polio damage. I had a case of the summer “flu” and was better in a week. The weakness, pain and fatigue of PPS has affected us all differently.

We understand that Post-Polio Syndrome is *always* a diagnosis of exclusion. We accept the words of both Dr. Bruno and Dr. DeMayo when they say “Polio survivors – you are all the same and you are all different”. We realize that diagnosis and treatment can be complex because we are all so very different.

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 by email, for no charge. We publish in both regular and large print formats, all over the US and abroad.
- Our website is updated regularly. The biographies of our regular contributors are clearly visible.
- With the help and support of many professional contributors, we launched an updated [Anesthesia Warning /PPS Symptom](#) Card. The information is easily accessed through a QR code on the card. These cards have had a positive response from polio survivors and health care professionals all over the US.
- 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 on our website, thus allowing the information to be shared with all polio survivors.
- We have become active with the PA Immunization Coalition (PAIC). As a result, we have attended as exhibitors and as speakers at our State Immunization Conference. We work as vaccine advocates.

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- We have actively engaged with Rotary International, whose mission (in partnership with the GPEI) is 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](#)” (a means by which survivors and our families who are not directly affiliated with their local Rotary Clubs can become part of the solution) has raised enough funds to bring more than 100,000 polio vaccines to children in the most war torn areas of the world.
- We happily do presentations (throughout our State and beyond) for support groups, Rotary Clubs, students and health care professionals, about the “Polio Truths”. We actively engage in the Health Fairs (often sponsored by our Representatives). As COVID winds down, we are attending events once again.
- In 2018, we partnered with Dr. Richard Bruno, HD, PhD, Director of the International Center for Polio Education to edit and publish the [Encyclopedia of Polio and PPS](#). This ongoing publication contains all of Dr. Bruno’s newly updated articles (including Research articles), Bruno Bytes and videos.
- We are grateful for the regular contribution(s) of our professional contributors (listed alphabetically) Richard L. Bruno, HD, PhD, William M. DeMayo, MD, [Marny K. Eulberg, MD](#), Post-Polio Health International, Rotary International and Professor Daniel J. Wilson, PhD (now deceased). The full list of our professional contributors (including their biographies) is on our [website](#).
- The last week of April is World Immunization Week. Each year, we publish new initiatives during that month. Over the last nine years, these [advocacy projects](#) have grown to be increasingly more meaningful to us.
- We work closely with the [PAIC](#), the [PA AAP](#) and the [Vaccine Education Center at CHOP](#).

It is our dream that post-polio care will become “main stream” for health care professionals and survivors. We are grateful to be working with generous professionals who are experienced in the care of polio survivors and understand the long-term effects (both mental and physical) of the poliovirus. 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 and students when we talk about the Polio Truths, has been truly inspiring. We are grateful for their wanting to attend and encourage their questions and concerns. We talk about ideas such as “non-paralytic” polio being able to result in PPS, the reality of there being survivors seeking care who are not old enough to be eligible for Medicare 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.

Our ongoing goal of polio awareness has a dual purpose.

- The first being to draw attention to the estimated 1 million Polio Survivors in North America, the vast majority of whom are realizing the disabling effects of Post-Polio Syndrome.
- Second and equally important is to draw attention to the importance of being immunized against polio and all crippling childhood diseases.

Even as Rotary International and the Global Polio Eradication Initiative move toward achieving the goal of eradicating the wild poliovirus through vaccination, we will not forget that the World Health Organization estimates there are 15+ Million polio survivors throughout the world, the majority of whom are living – or will live, with Post-Polio Sequelae and the disability caused by the poliovirus.

For some of us, PPS brings the answer to “I always knew something was wrong” along with dependence on assistive devices for the very first time. For the majority, along with new pain and weakness, PPS brings memories long forgotten – memories of long hospitalizations, isolation, fear and abandonment. COVID brought forward long forgotten and very painful memories, of isolation and hospitalizations. For young survivors, we present the reality of PPS with the hope they can begin the lifestyle changes at an early age, that can perhaps reduce symptoms later. We provide information that can help survivors to help themselves and thus be independent once more.

It is the positive response to our work from polio survivors all over the US and abroad, that has been continued . . .

humbling and truly inspiring. The survivors on our working 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, 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 this disease.

We are survivors of a vaccine preventable disease who have come together to serve others by providing them information, so they too can thrive.

Carol Ferguson and our [PA Polio Network Team](#)

\*Note – this article was originally written in 2019 at the request of (and published by) [Post-Polio Health International](#).  
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