

Before 1955, Polio was a health threat to millions around the world. After the discovery of the vaccines by Salk and Sabin the fear of contracting polio became less and less in highly civilized countries. It is a goal of the World Health Organization to completely eradicate the poliovirus in the world during this decade. Once that is accomplished, the fear of polio will be just a memory for the majority of the world. However, there are millions of polio survivors who are now dealing with a new health issue commonly referred to as Post Polio Syndrome. For millions who were stricken with the poliovirus 50 plus years ago this new condition creates the need for major life style changes to adapt to the decline that the syndrome creates.

The poliovirus damaged motor neurons which make our muscles function. With the loss of 59% or more of a motor neuron in a specific muscle, there was paralysis. Most polio patients suffered paralysis during the initial phase of the disease. Nevertheless, with physical therapy and medical care many survivors regained certain muscle strength that seemed to minimize the real damage that had been done to the polio stricken body. There were those of course, that did not survive the dreaded disease. There were others confined to an iron lung for the rest of their lives. Then there were the “lucky” ones who not only survived but also managed to overcome all obstacles and became normal, healthy, productive adults. These polio survivors might wear braces, they might need crutches or even be confined to a wheel chair, but the vast majorities were over achievers and lived life to the fullest. Health care professional worked diligently to help polio patients regain mobility so they could function in a world with many barriers. As patients, we were taught to push through the pain to fight through the weakness and to strengthen both mind and body to overcome the dreaded disease. Millions did just that. Approximately 1.6 million people are alive who are called polio survivors.

We wish this were the end of their story. We wish that Polio left its damage and then never again became a factor for the people unfortunate enough to be a victim of this dreaded disease. However, Polio left a second challenge called Post Polio Syndrome or the late affects of polio. Most Doctors and our members all refer to this condition as PPS. PPS includes many new symptoms that create major life style changes for the polio survivors. Increased pain levels, new muscle weakness, severe fatigue are just a few of the main symptoms that polio survivors began to notice 30 to 50 years after the original onset of the disease. Polio survivors who had conquered the aftermath of the poliovirus are again dealing with the physical limitations that this new condition triggers. Many who had given up bracing or crutches for much of their adult life are returning to use of these devices. Still others are finding it necessary to use electric scooters, or power wheel chairs to provide mobility in due to PPS. There is no cure. The only option is to manage the symptoms and control the loss of additional muscle neurons. Each individual finds their own limits and adapts to the changes as needed. Post polio Syndrome does not cause death, but it does dramatically alter a person’s ability to live life as before.

Our local support group joins thousands of others around the world in sharing our resources and knowledge with other polio victims. We also work to educate a medical community that has little experience with a person who once had polio. Polio survivors are unique in how they react to surgery or anesthesia. The normal regime for physical therapy of another condition must be adapted if a polio survivor is being treated. So our group educates not only other polio victims but also share information with physicians, physical therapist and any medical team that might have an impact on the recovery of a polio patient following a non related event.

Our support group meets monthly for local residents. But we also provide a concise and informative BI-monthly newsletter that goes out to over 450 patients and medical team members in the state of Va. Our local Support group provides Peer Counselors (volunteers from our group)

to new members who are seen at the local Sheltering Arms Post polio clinic. We hold social events, including an annual retreat at Camp Easter Seals in Caroline County. All of these things require funding. The members volunteer their time to act of peer counselors in many different ways. We use the telephone, meet in person, or over the Internet so encourage, help, and provide support for a fellow member struggling through a problem due to PPS complication.

Though we gladly volunteer our limited energy reserves means that the hardest thing for us is finding the energy to gain funding for our various events. If we wish to sponsor a conference, we must solicit funds. If we wish to help a new member with a special need, we must find funding. In addition, few of our members have the energy reserves to canvas for donations.

We make look normal to you, but each one of use has our own way of managing our daily lives. At least two of us MUST take a daily nap to prevent excess fatigue that can become debilitating if not curbed. Two of us have returned to bracing. One uses arm crutches and two of us need canes. All three of us use scooters to walk any distances at all. Life has changed dramatically for us although we are barely into the golden years.