



PA Polio Survivors Network

Information and Inspiration for Polio Survivors and Their Families

From the Keystone State and Beyond

www.polionetwork.org

October 2017

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.



Why is having PPS so hard? Why did this happen to me?

In his portion of the presentation at our Conference on August 26th, [Daniel J. Wilson, PhD.](#) discussed why these complex issues have emerged for so many Polio survivors. Some quotes from his presentation:

- "Warm Springs was the first to emphasize the development and recovery of the 'whole' person".
- "During the 40's and the 50's Post-Polio care varied widely. We experienced isolation, hot packs, iron lungs and perhaps PT. Eventually we were sent home. Little thought was given to the psychological aspects of recovery and to the prospect of us living with a disability."
- "We were told we could do anything if we pushed beyond our disability".

With help from [Richard L. Bruno, PhD](#) and [Post-Polio Health International](#), we have some articles that can help you and your family understand why being a Polio survivor can be so difficult . . . and on the other side, how with a little help, we can learn to thrive.

She has taken the advice and her life has been “Bigger than Polio”.

With the help of her family, friends and faith, Sally (Stevens) Luck has learned how to thrive as a Polio Survivor. She told her story to our PPSN Intern, college student Olivia Harrison.



A Note About Anesthesia Warning Cards

Recently, a Polio survivor found herself in an ambulance, on an unexpected trip to the hospital with a serious issue. She emailed us for the “links” to the [Anesthesia Warning](#) and [Post-Polio Care](#) information section of our website. Unfortunately, it was more than an hour before we could respond.

Make sure you put your card in your wallet. It has easy “scan codes” not just to the four articles and biographies of Dr. John Bach, MD., Dr. Richard Bruno, PhD., and Dr. Selma Calmes, MD.; but to the information filled section Post-Polio Care Information for Families and Caregivers. It's easy to provide this information to your spouse or caregiver, by giving one to them as well.

This card is easily [printable](#) (in both English and Spanish).

I am a Polio Survivor with Post-Polio Sequelae

Name: _____

I have these Symptoms (checked):


<input type="checkbox"/> Overwhelming Fatigue	<input type="checkbox"/> Muscle Weakness
<input type="checkbox"/> Muscle and Joint Pain	<input type="checkbox"/> Sleep Disorders
<input type="checkbox"/> Cold Intolerance	<input type="checkbox"/> Difficulty Swallowing
<input type="checkbox"/> Difficulty Breathing	<input type="checkbox"/> Sensitivity to Anesthesia

(Scan Code for Anesthesia Information - Over)
www.polionetwork.org/anesthesia-card

ANESTHESIA WARNING!

I am a Polio Survivor

- Easily Sedated, and can be difficult to wake
- Can have difficulty breathing and swallowing with anesthesia
- Hypersensitive to pain and cold
May need heated blanket and increased pain medication post-op



www.polionetwork.org/anesthesia-card



Type A Behavior and Polio Survivors

[Richard L. Bruno, HD, PhD](#)

Director, International Centre for Polio Education

www.postpolioinfo.com

When polio survivors first came to us more than 35 years ago, we discovered that polio had a profound effect on learning and earning. The subjects in our first post-polio research study made it clear that polio survivors were very unusual. The subjects used power wheelchairs and had, not just bachelors, but also graduate degrees. It became apparent that polio survivors were unique, not only among individuals who had disabilities of equal severity, but also among non-disabled peers. Polio survivors had risen to high levels in their professions. More than the expected percentages of polio survivors are corporate executives, members of both houses of Congress and professionals of all types -- teachers, lawyers, doctors and nurses. This level of achievement points out a startling fact: Polio survivors who were told that they would never go to college or even get a job, became America's "best and brightest."

Polio survivors apparently shared a personality type that first had been described in those who developed heart disease: The hard-driving, time-conscious, competitive, self-denying, perfectionist, overachieving "Type A" personality. We weren't surprised when our 1985 National Post-Polio Survey found that polio survivors reported 50% more Type A behavior than people without disabilities, even more than in those who'd had heart attacks. We also discovered that the more Type A behavior polio survivors reported, the more new fatigue and muscle pain they had.

The polio experience provided the ideal environment for becoming Type A. Lack of social support, low self-esteem, loss of control and fear of punishment have been found to teach Type A behavior. Our 1995 International Post-Polio Survey found that polio survivors reported 34% more physical abuse and 94% more emotional abuse than in those without disabilities.

The survey included a questionnaire measuring sensitivity to criticism and failure that found polio survivors were 15% more sensitive to the criticism of others and thinking of themselves as failures than were non-disabled respondents. Not surprisingly, the more abuse polio survivors experienced the more sensitive they were to criticism and failure and the more Type A they had become. So, polio survivors became Type A to prevent criticism and abuse by others and to protect against feelings of failure. That's why so many survivors discarded in childhood any evidence of polio -- crutches, canes, braces, wheelchairs -- and refuse to accept them now when they develop PPS. Polio survivors want to both act and appear "normal."

Our survey also found that protecting against criticism and failure was more important than polio survivors own emotional or physical well-being. Nearly three-quarters answered "yes" to the question "I often do what others expect, regardless of how I feel emotionally or physically." Said one of our Post-Polio Institute patients, "Polio survivors aren't just Type A, we're Type 'E': We do everything for everybody every minute of every day!" For most polio survivors, it is more important to appear "normal" and take care of others than it is to physically or emotionally care for themselves. Unfortunately, the ultimate price polio survivors have paid for being Type A -- and "Type E" -- is Post-Polio Sequelae (PPS).

The sad paradox is that, in spite of survivors cheating death by polio, conquering disability and dealing with years of severe physical and emotional abuse and pain to become "the best and the brightest," many polio survivors believe that they have no ability to survive PPS. This

continued

paradox is why psychotherapy for polio survivors is so important: To help them deal with the terrible things that have happened in the past, to stop them from expecting more abuse and to help them accept that they are competent adults whose emotional and physical future is in their own hands.

It is exactly because of everything polio survivors have already experienced that they will survive in spite of PPS. To do this, polio survivors need to read these two words again and again and take in the full depth and breadth of their meaning:

I am a Polio SURVIVOR!

If polio survivors can acknowledge that they already have survived tremendous emotional and physical pain, there is no question that they can cope with the past and make the changes necessary to survive and thrive with PPS.

Richard L. Bruno, PhD.
Rev. 2017

Along this same theme . . . This month's Bruno Byte:



Bruno Bytes

From the Post-Polio Coffee House
Richard L. Bruno, HD, PhD.

Dr. Bruno's Original Post: I think this article has a message for us. As the Buddhists say,
"Pain is inevitable; Suffering is optional."

"This newly published study provides New Insight into Patients' Healing Journeys. It found that people on healing journeys created connections with a wide range of helpers, including not only family, friends, and health professionals, but also non-human sources of support, such as pets, spirituality, and personal interests. These relationships proved instrumental in helping participants develop...the ability to reframe suffering in a positive light, the choice to adopt an optimistic attitude, and the capacity to take responsibility for one's recovery."

Source: The Full Article from Newswise.

The Complete Collection of Bruno Bytes as well as a Bruno Byte Index by Subject is available.



Post-Polio Health Care Considerations for Families & Friends

Late Effects of Polio: The Psychosocial

Is your family member struggling with finding out that he or she has PPS? Does he or she appear to be in denial about what seems to you to be obvious changes in his or her functioning? Many polio survivors have difficulties adjusting to new disabilities. Some people with PPS find that they are now reliving their childhood experiences with polio and that can be traumatic and even terrifying. Because of the relatively small number of polio survivors, many physicians see very few, if any, and know very little about PPS. Some still believe that the condition is only in their patients' heads. People with PPS often depend on their own resources to help them cope with this condition, because there is a lack of proper medical and psychological advice. Fortunately, PPS continues to gain attention in the medical community. A growing number of health care professionals understand PPS and can provide appropriate medical and psychological help. In addition, there are PPS support groups, newsletters and educational networks, such as Post-Polio Health International, that provide up-to-date information about PPS while offering individuals the knowledge that they are not alone in their struggle.

Polio: The Experience

Many polio survivors have never shared their experiences with anyone, even their children. You may not have known that your parent even had polio until he or she began to experience the late effects. Why would your family member never have talked about something that seems so important?

The polio experience was a difficult one. Polio carried a stigma similar to HIV/AIDS in that others were afraid to associate with children with polio and their households. It was common for polio survivors discharged from the hospital or rehabilitation to be discouraged from talking about what they had experienced. If they were able to pass as non-disabled, polio soon faded from their awareness. Many didn't feel that polio had really affected them very much at all until they developed PPS.

However, it did affect them. Acute polio was an extremely painful disease. Along with the pain, the patient would have a high fever and become unable to move parts or all of his or her body. He or she may have developed difficulty in breathing, and even been placed in an iron lung. Children and adults who were hospitalized and contagious were kept in isolation from family, and even when rehabilitating allowed few visitors. Professionals thought young children did not need an explanation of what was happening to them. Young polio survivors were confused and afraid, sometimes believing they had done something bad to make their parents leave them. There were few mental health professionals on polio wards to help patients deal with their emotions, and those who did do such work didn't acknowledge the psychological effects of the illness.

The experience, of course, affected children in many ways. For some, especially those who had polio before the age of 4, it became hard to trust and connect with others. Some became mistrustful of doctors and medical treatment. Certain sights, sounds or smells may bring back the polio experience years afterwards. When it was time to go through rehabilitation, polio survivors were encouraged to work as hard as they could, often pushing themselves past the point of exhaustion to regain as much mobility as possible. They learned to do whatever they could to function in a society that would make no accommodations for their disabilities.

Wherever possible they were encouraged to give up braces and crutches as soon as they were able. Essentially, the message was that if they worked hard enough they could be successful at whatever they wanted to accomplish.

Polio survivors, especially the youngest ones, often returned to the hospital for surgeries for many years afterwards. Some children spent every summer in the hospital having "corrective" surgeries that often did little to improve their functioning. Many came to dread summer. Some felt they were in constant need of "correction" and that they were never good enough as they were.

Polio survivors often became stubbornly independent because of these experiences. They learned to be self-reliant. They exercised and exercised out of a belief that doing so would allow them to preserve their abilities. For many, PPS has felt like a betrayal, because what was helpful then has turned out to be harmful now.

Models of Disability/Identity Issues

After polio, survivors learned to cope with their disabilities. Researchers identified three coping styles that polio survivors used during the initial rehabilitation. Men and women with mild disabilities who could give up their braces and crutches could “pass” as nondisabled. Persons who couldn’t do this played down their use of crutches or braces and magnified physical or personal strengths, thereby “minimizing” the more obvious effects of the disease. Persons who used wheelchairs or ventilators faced the architectural and attitudinal barriers of the times. They couldn’t pass nor minimize, and so fully “identified” with their disability. Many identifiers became leaders of the independent living movement that resulted in changes in society, including the passage of the Americans with Disabilities Act (ADA). How your family member deals with PPS depends on how they coped with their original polio. Identifiers don’t question who they are now even though they are distressed by new disability. The changes brought on by PPS distresses mostly minimizers and passers. They may experience a sense of being a different person now, and may have to deal with what it means to be a person with a disability. For some, counseling or psychotherapy can help with these concerns.

Coping with Stress and Physical Changes

Is your family member having trouble coping with PPS? Individuals who are coping well focus on what they can do, rather than on what they cannot do, and play an active role in their lives, rather than respond as passive victims. They participate in areas of life seen as worthwhile and meaningful. They may have problems, but they are not overwhelmed by them.

People who are coping well appreciate their accomplishments and do not deprecate them because they do not meet some “normal” standard. They participate in valued activities and enjoy doing so. When they have problems, they solve them by making changes in their physical and social environments, such as eliminating architectural barriers in their homes and making new friends. They do not wait for a “cure” to fix everything.

To cope well with increased limitations, polio survivors may need to make important realistic value changes. They cannot deny their disability. Persons who successfully cope with their disability enhance their ability to change and to maintain relationships.

The late effects of polio can be complex and distressing as it may arouse painful memories that may interfere with the need to make major lifestyle changes. However, survivors often realize that changes, at their own pace, are manageable. They can use their coping skills to adjust.

Working hard to meet goals and surmount adversity are characteristics of the “polio tradition.” Your family member has coped with many difficult life experiences. With support, he or she can cope with these new challenges.

Relationships: Families and Friends

As family members become more disabled, they may become more isolated from you, other family members and friends. They may be less able to attend functions or engage in activities. Others in your social circles may not know how to deal with a person with a disability. If your parent has cognitive changes, this makes communication harder. Polio survivors’ independence can also pose challenges for those around them.

Everyone needs support from family and friends. If you can help loved ones keep their relationships, and even find new ones, you will help them to have the best possible quality of life. Offer to help them find ways of getting together with friends and family, such as using senior or paratransit services, or provide rides yourself.

Encourage them to have friends or family over. On the other hand, help your family member use other means of connecting, such as the telephone or computer. Aged parents might enjoy getting out to the local senior center. There are many activities available for all interests and usually transportation. Support groups for PPS or other issues might help them feel less isolated. Every relationship is unique, but for any relationship to succeed, both individuals will need to cope with any disability. This requires a realistic acceptance of the disability with an emphasis on what one can do, rather than on what one cannot do.

“Bigger” than Polio

[Sally \(Stevens\) Luck](#)

By Olivia Harrison

polionetwork.org/our-stories

Sally Stevens was born in 1931, in Yardley, Pennsylvania, where she lived right across from the Makefield Elementary School. She grew up with one brother, and had a relatively typical childhood.

She first experienced symptoms of polio at the age of 12, when she visited Lavalette, NJ with her cousins. In order to get away from Trenton, NJ, which was experiencing a terrible epidemic of polio at the time, Sally’s cousins had rented a house there with their children while their husbands were overseas. However, she and two of her younger cousins got sick, and Sally had to be driven home.

After being home for a few days, she had all the symptoms of Polio. The doctor came to the house, and she was told to rest. She stayed in bed for 7-10 days, and at one point got up to use the restroom, and collapsed (another sign of Polio). She would fall onto the floor, and could not get up without assistance, because her legs would not lift her. For the next 4 weeks, she had a hard time getting upstairs.

Sally was still experiencing weakness when she started 8th grade, and remembers vividly how hard she had to struggle to get on the school bus on the first day, and how the bus driver sadly offered no support. She also struggled physically in the school, because it was two levels and she was forced to take the stairs. Eventually, for the most part, Sally did recover. Her right leg remained thinner than her left, and her right ankle had limited motion. She wasn’t skilled in sports, her legs got tired after a lot of walking, and she fatigued easily. Sally had no idea that polio was the reason for all of this.



For high school, she attended The George School in Newtown, Pa., graduating in 1949; and went on to Randolph-Macon Women’s College in Virginia. She was a member of Phi Beta Kappa and Chi Omega sorority, and received a BA in Psychology with a minor in Education. After graduating, she went home to teach for a year so that she could save enough money to attend graduate school. The next year, she went to the University of North Carolina and received a master’s degree in Education.

After receiving her master’s degree, she got a job teaching 1st and 2nd grade in Atlanta, Georgia. At the time, her brother was enrolled at Georgia Tech, and she met friends through him, including her 3 roommates. The four girls rented a 2 bedroom, 1 bath, fully furnished apartment in Atlanta, where they paid just \$125 a month in rent, and \$4 for a cleaning lady once a week!



Sally joined the choir at Grace Methodist Church, which is where she met her soon to be husband, Ed Luck. (After serving in the Navy for 4 years during the Korean War, Ed had come to Atlanta to finish the last two years of his college education at Georgia State University). Sally and Ed were married in 1956. Two years later they welcomed their first daughter, Margaret. They moved to Knoxville, TN for 3 years while Ed worked for Shell Oil, and then moved back to Atlanta, where he became a furniture representative and travelled the state of Georgia. In 1964, they adopted their second daughter, 8 week old Ellen.

(continued)

Sally remembers that after a day of heavy walking while on vacation, she was unable to walk the next day, and had to stay behind while her husband and daughters continued the vacation. Even so, over the years, Sally and Ed did a lot of travelling with her manual wheelchair, making several trips to Europe, and even the Holy Land. They have been to 45 of the 50 states, and have taken several cruises.

1982, she remembers, is when people began “coming out of the woodwork” with Post-Polio symptoms. She was diagnosed in 1986, and joined a support group in Atlanta, which she found particularly helpful. By 1989, the year of her 40th high school reunion, she was in a motorized scooter, because her symptoms had progressed.

After Ed retired at 67, they wanted to move from Atlanta, so they sold their home and moved to Sun City Hilton Head, Bluffton, SC. The next 12 years were like living in paradise for Sally and Ed. The whole community was extremely accessible. They were 20 miles from the beach and 20 miles from downtown Savannah, GA where they joined another very active Post-Polio support group.



Both Sally and Ed were very active in joining lots of clubs and enjoying all the new friends they had made. Sally and a friend started a support group called the Physically Challenged Active Adults and ten years later it is still going strong, serving all the people who moved to Sun City with disabilities. Their support group worked to get more accessibility

in the community, had a medical equipment loan service, and had lots of fun together.

Sadly, Ed was diagnosed with Alzheimer’s disease and Sally needed more physical assistance, so their daughters insisted they move to Chattanooga, Tennessee so that they could be of more help to them. Currently, they live in a one story house, where Sally receives assistance with certain aspects of daily life. They miss their life and friends in South Carolina, but are happy to be closer to their daughters. Sally also continues to have a positive outlook on life, despite dealing with post-polio, as well as back spasms, and two very damaged knees. She is in a wheelchair full time.

In spite of all the challenges, Sally says that her “worst handicap” is that because of a lack of understanding of Polio, she and others affected were often treated like they didn’t matter – as though they were invisible. . . .

Sally’s life is so much bigger than Polio. Together, she and Ed raised a family, traveled extensively, and have found ways to live full and meaningful lives.

Without question, she has lived a life that matters.



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****Editor’s Note:** We researched Sally’s group for Physically Challenged Active Adults. We found a wonderful newspaper article titled:

“There’s no Moaning and Groaning with these Active Adults” Published by Bluffton Today. The article is available [HERE](#) -

Rotary



END
POLIO
NOW

**World Polio Day
October 24, 2017**

One Day. One Focus: Ending Polio

Get ready for our 5th annual World Polio Day event, co-hosted with the Bill & Melinda Gates Foundation. We will stream live from Gates Foundation headquarters in Seattle, Washington to bring together more than 50,000 viewers around the world. Join us as global health experts and celebrities share our progress on the road to polio eradication.

The World Polio Day event will be streamed live at 2:30 (PST) / 5:30 (EST)

Our "[Team Survivor](#)" Donation Deadline is October 20. The Form is on Pg. 9 of this newsletter. Your \$5.00 donation can result in the vaccination of more than 20 children. We CAN make a difference.

We are truly grateful for your kind words of support.

Thank you



OCTOBER



Always feel free to contact us.

[The Polio Network Team](#)

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