



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

November, 2022

Our Mission:

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

Inside this Issue:

Polio and COVID – Living with the Effects of a Virus. Over the last two years, your questions regarding all aspects of the effects of COVID have been sincere and concerning. Then, it happened. In June, polio reared it's ugly head in both the UK and the US and your questions regarding the need for a polio vaccine have been considerable. Recognizing our lack of professional background to answer your questions regarding vaccines, we were guided by our thoughtful and very caring professional contributors. As part of that, we had the opportunity to talk with a renowned virologist, asking him YOUR questions. Paul A. Offit, MD is the Director of the Vaccine Education Center at the Children's Hospital of Philadelphia (CHOP). During the interview (on page 7), we were introduced to his very personal connection with polio survivors.

PPS – WHY is it so hard to diagnose? PPS is *always* a diagnosis of exclusion. What does that mean? We've been featuring a discussion on this topic – which is of concern for polio survivors all over the world.

- In July, we began our series with an article from [Marny K. Eulberg, MD](#) - *One Doctor's Visit Does Not A Comprehensive PPS Evaluation Make.*
- In [August](#), we brought you the article *Diagnosing Post-Polio Syndrome* - from Post-Polio Health International.
- [Mark A. Lopatin, MD](#) often sees patients with the symptoms that can come from PPS . . . but realizes it may be numerous other issues. In October, we brought you [Muscle Pain, Post-Polio, and The Importance of Being a Medical Detective](#) as he explained this complex issue.
- This month, we are rounding up our series with the article *Post-Polio Syndrome: A Diagnosis of Exclusion* by [Richard L. Bruno, HD, PhD](#). Originally published in *The Polio Paradox* in 2002, Dr. Bruno has updated this important article.

November is a Special Month of Thanks.

- A very special THANK you goes out to our professional contributors. We appreciate your kindness, generosity and for having the "heart of a teacher".
- [Veterans Day](#). In the US, this is a holiday honoring all men and women who have served in the US armed forces. It is celebrated annually on November 11th - the anniversary of the end of World War I. We asked veterans to tell us their stories. Donald P. Abrams and Wayne Nichols, Jr. both served with honor. Both survivors, they have very different stories to share. We give thanks for ALL military veterans.
- [Thanksgiving](#). The US isn't the only country that celebrates this special day.
 - Australia. In the Australian external territory of Norfolk Island, Thanksgiving is celebrated on the last Wednesday of November.
 - Canada. The Canadian Thanksgiving, is celebrated on the 2nd Monday in October. It is an annual celebration meant to honor life's blessings while spending quality time with close family and friends.
 - Grenada. Celebrated on October 25th, Thanksgiving is a public holiday. It is a day off for the general population. Schools and most businesses are closed.
 - Liberia. Thanksgiving in Liberia is an annual observance on the first Thursday of November to thank God for His blessings and mercy. This year, it fell on November 3.
 - Netherlands. Thanksgiving celebration in Leiden (the Netherlands) has everything to do with the US celebration. Every year, on the day of American Thanksgiving, people gather in a 900-year old church (known as Pieterskerk) to celebrate the perseverance and good fortunes of the early American settlers. Before heading to North America, the Pilgrims landed in Leiden in the Netherlands (where they stayed for 11 years).





Post-Polio Syndrome: A Diagnosis of Exclusion

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

Updated from the original, published in *The Polio Paradox*

Before treating new symptoms, you have to make sure that the symptoms are in fact Post-Polio Sequelae. Thus this essential Post-Polio Precept:

‘All PPS are diagnosed by exclusion.’

Post-Polio Sequelae (PPS) encompasses many symptoms. All are ‘diagnosed by exclusion’ meaning that your doctor has to perform tests to exclude all other possible causes for muscle weakness -- for all new symptoms that you think might be PPS -- before concluding by a process of elimination that your symptoms indeed *are* PPS. A process of elimination is needed because, in spite of more than 40 years of research, there still is not one test that can prove new muscle weakness or any new symptom is PPS. Even polio related problems, e.g., sleep disorders, must be ruled out before a diagnosis of post-polio fatigue can be made.

It had been hoped in the 1980s that the EMG would become the one tool for diagnosing PPS. There have been dozens of studies using EMG to test polio survivors with and without new muscle weakness. Not one has found that the regular EMG your doctor can do in the office diagnoses PPS. So watch out for a detrimental Post-Polio Fiction:

‘You can’t have PPS because your EMG doesn’t prove it.’

There are studies using special EMG techniques performed at university medical centers, but not at your local doctor’s office, showing that polio survivors’ motor neurons are dying and breaking up. Your local doctor doesn’t do these special EMGs. What’s more, the special EMG studies showing the death and disintegration of motor neurons were conducted in subjects over the course of years. Even if you went to a medical center today where a special EMG could be done, you wouldn’t know for a year whether your neurons were dying or sprouts shrinking. However, your doctor may legitimately want a regular EMG to rule out another cause for your muscle weakness, such as a herniated disc pressing on the spinal cord or a neurological disease like ALS. EMGs are both expensive and painful. So before you agree to one, ask what the doctor is looking for and make sure that he isn’t doing an EMG to “prove” you have PPS. What’s more, you shouldn’t be denied long-term disability or Social Security Disability because an EMG didn’t “prove” you have PPS.

If you have new weakness is there a chance that you have something other than PPS? Yes, but the chance is very small. In our 30 plus years of treating polio survivors, we never saw a patient that had a herniated disc or a rare muscle disease that caused weakness. We did see six patients who had PPS plus another neurological disease (four with Parkinson’s, one with Alzheimer’s and one with ALS). But the additional diagnosis was apparent as the patient came through the door. Again, you must be fully evaluated to exclude all other conditions, neurological and medical, before the diagnosis of PPS is accepted. But there’s an old medical adage: “If you hear hoof beats expect horses, not zebras.” The good news is, if you hear the “hoof beats” of new muscle weakness, expect PPS.

‘EMG and Exercise’

If an EMG can’t diagnose PPS, is it of any use in guiding treatment for muscle weakness? A regular EMG can identify muscles that have lost motor neurons to the poliovirus. But, physiatrist [Mark Bromberg](#) found that almost 10% of patients who had a clear history of muscle weakness with their acute polio, and who were reporting new pain, fatigue or weakness, had *normal* regular EMGs, meaning that there was no EMG evidence that they’d ever had polio!

But, in spite of the finding that an EMG can actually miss damage done by the poliovirus, it has been suggested that every polio survivor get a regular EMG to identify muscles that were not affected by the poliovirus and identify which limbs can be exercised without worrying that they will become weaker. One study using regular EMG found that almost a quarter of paralytic polio survivors’ limbs had no evidence of motor neurons having been killed. Those limbs were classified as having “no clinical polio” and therefore continued

could be exercised like anyone else's muscles. However, neurologist [Carlos Luciano](#) used that special EMG and found over-sprouted motor neurons in 85% of muscles that were thought to have had "no clinical polio." This finding highlights research by Dr. [David Bodian](#) in the 1940s and Dr. [Alan McComas](#) in the 1990s showing that seemingly unaffected muscles had lost an average of 40% of their motor neurons to polio. Dr. McComas' study of polio survivors was clinical confirmation of David Bodian's findings from autopsies of more than 100 polio-infected individuals, plus hundreds of monkeys infected with polio, that polio survivors had to lose more than 60% of motor neurons for weakness to be apparent with the acute polio.

The danger of using a regular EMG to diagnose polio or identify "unaffected" muscles comes through loud and clear in the experience of one of our patients, whose legs had been severely weakened by polio and were getting weaker, causing him to walk with crutches. He believed that polio had not affected his arms and he wanted to go on a "walking tour" of Europe. He asked for a regular EMG of all of the muscles of his arms, which showed no evidence of polio. Off he went on his crutches to Europe, where his arms started to become weak. He returned to the Post-Polio Institute a month later, barely able to lift his arms.

The moral is that an expensive and painful EMG is neither reliable nor desirable if you're trying to decide how you should preserve your remaining overworked, poliovirus-damaged motor neurons and your muscle strength. The safest thing to do is assume that every muscle was affected by polio, and follow **this** Post-Polio Precept, the fundamental tenet that underlies all PPS treatment. We call it "The Golden Rule".

"If anything causes fatigue, weakness or pain DON'T DO IT! (Or do much less of it.)"

Text originally published in The Polio Paradox.

Updated from the original by Richard L. Bruno, HD, PhD., 2022



A Little Fall Fun

Try This . . .

From Survivor Janet Whitworth

How Smart is your right foot? You have to try it.
It's absolutely true.

I guess there are some things that the brain cannot handle.

1. While sitting in a chair, lift your right foot off the floor and make clockwise circles.
2. Now, while doing this, draw the number '6' in the air with your right hand.
3. Your foot will change direction !



What's fun is that there is absolutely nothing you can do about it ! You and I both know how crazy this is, but before the day is done, you are going to try it again . . . If you haven't already done so !

We are Thankful
for YOU.



Thank you for your kind words and generous [donations](#).
We genuinely appreciate it.

Serving my country . . . and paying it forward.

By Donald P. Abrams



Photo Source: Donald Abrams

In August, 1954, when I was 8 years old, I contracted Polio. My Polio was bilateral and affected my right leg from the hip all the way down to my “drop” foot. My left arm was affected as well - especially my triceps and thumb. I was never fitted with braces, but used crutches for about a year.

For the first year, I was treated at Herman Kiefer Hospital in Detroit, Michigan, and had continuing therapy (including Sister Kenny treatments) at the Rehabilitation Institute of Detroit. We purchased orthopedic shoes from the Hack shoe Company in Detroit that had straight laces and had what were referred to as “Thomas” heels. The

heel extended below the arch for additional support. It was never easy wearing brown orthopedic oxfords to school when all the other kids had ‘cool’ shoes! Until I was 18, my progress was reviewed annually by an orthopedic surgeon. He was an advocate of my swimming as therapy and I was enrolled in classes at the YMCA. As a boy, I was not strong enough for organized sports, but played pick up sports including baseball, basketball and football with my other “not so athletic” friends.

I had an Armed Forces physical in 1967 and took my medical records with me. I presented all of these documents to the examining physician at the Fort Wayne facility in Detroit. I remember him observing that my right leg was smaller than my left and that I had a dropped foot as well. He also observed that my left arm was smaller than my right. I felt this should have disqualified me from service but the doctor felt differently and I was drafted into the US Army.

I reported to basic training at Fort Knox, Kentucky, in January 1968. I really struggled with physical training known as PT, but my inability to complete exercises went unnoticed. When the final PT test was given, I finished very low in every event, but somehow moved on to graduation. I was then sent to Fort Belvoir, Virginia, for training as a depot level generator repair and rebuild. Upon completion, I was assigned to go to Vietnam. My journey began in the 101st Airborne Screaming Eagle Replacement Training School where I spent the first two weeks. Ultimately, I was assigned to Camp Eagle near Hue in I Corps. For a year, I served with the 801st Maintenance Battalion, Company A. We were driven tirelessly to repair broken gear for 10-14-hours per day, seven days a week in temperatures that could reach 110 degrees in the shade – except for monsoon season, when it cooled off but brought 12 or so inches of mud.

Physically exhausting? You bet! The only break from this was a three-day R&R at China Beach and a seven-day R&R with my spouse in Hawaii. The 801st received a Meritorious Unit Citation in 1969. I was awarded a Bronze Star (meritorious), an ARCOM (meritorious), a National Defense medal, a Vietnam Service Medal and a Vietnam Campaign Medal.

I retired in 2009 due to the physical demands of my work. At that point, I didn’t know it was PPS. It would be another five years before I would finally get a diagnosis. Constant issues with muscle pain and exhaustion led my primary care physician to refer me to a neurologist who made the PPS diagnosis based on my history, an EMG and high levels of the CPK enzyme in my blood work. He prescribed Xanax and Tramadol. A second neurologist reached the same conclusion and course of treatment.

After a few years, I felt that this wasn’t working out for me. A web search turned up a local rehabilitative physician (physiatrist) and a Post-Polio clinic! I was examined there by the doctor, an internist, a physical therapist, and a prosthetist. At the time, I was fitted with an AFO (for my foot drop) and received physical therapy, replacing the Tramadol for my elevated pain levels. I now am on a course of Lyrica and Cymbalta which is working well for me. I can walk without a cane about one half mile or so before my muscles tell me - enough! I can rest and recover so that a museum or zoo visit isn’t out of the question. I’m still able to share the chores with my wife and do some repairs around the house. Some days I just rest.

Based upon the likelihood that the physicality of my service resulted in my current polio-related health conditions, in early 2022, I made the decision to file a Veterans Administration (VA) disability claim for my post-polio syndrome (PPS). My physiatrist (rehabilitative physician), was most helpful writing a nexus letter with his diagnosis along with the opinion that my military service caused the onset of PPS. (A nexus letter is a letter from your physician detailing the connection between your current conditions and your military service. The connection could be directly to a military event or circumstance, or to another medical condition

continued . . .

that occurred in service).

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As a veteran, I was able to search the archives of the VA for PPS claims. Searching back several years, I found that most were denied or remanded. Only two awards for PPS showed up. What I don't know is how many PPS vets were awarded disability without having to appeal. Though my disability claim was awarded without having to appeal, I'm pretty sure that PPS hasn't been recognized by the VA very often. Perhaps the groundwork was set earlier by others.

I am grateful that I was successful in my claim and would like to pay it forward by reaching out to as wide an audience as possible. Since the VA has recognized my PPS as service related, all my care is now received there, which also includes CPAP therapy (which is considered secondary to the PPS). I'm finally on a good path.

Polio affected each of us differently, and I realize that no two experiences are the same. Even so, I would like to encourage other veterans with PPS, who believe they qualify, to work with their physicians and initiate a claim with the VA.



Serving with Honor – A Family Tradition.

By Wayne Nichols, Jr.



Photo Source: Wayne Nichols

I contracted Polio in 1953 when I was 3 years old. I was paralyzed from my left knee down and wore a hard brace from my hip to ankle. This allowed me to walk until my first surgery in 1956 – where they transplanted a tendon from the left side of my leg to the front. Afterwards, I was able to walk without the use of the brace. Three years later, a pin was inserted into my “great” toe (more commonly known as my “big” toe). This allowed me to walk without throwing my left leg out.

In 1962, they “tweaked” a tendon which gave me further stability in my gait. Six years later, I was determined to join the Navy. When I completed the physical exam, they deemed me 4F. In other words, I was identified as a person who was “unfit for military service”. It was a “nice” way for the military to tell me I was physically unqualified for any of the Armed Services.

Just like so many polio survivors, I have been gifted with a “Type A” personality, meaning being rejected was not an option. I visited an Orthopedic surgeon who examined me and drafted a three-page medical report letter stating that I was physically fit. I sent this report to Washington, DC where it was reviewed by the Department of Defense. After a review that spanned three months, they approved me for a 2-year enlistment. This was unheard of in the Navy because normally enlistments were between 4-6 years.

I served through 1969 where I was stationed in Coronado, CA. I was attached to the Sea Bees, preparing for action in Viet Nam. I never went to war, but our entire company was ready to mobilize at a moment's notice. I was proud to carry on my family's tradition of service. My 2 brothers and father (WWII) all served with honor.

Twelve years ago, I was diagnosed with Post-Polio Sequelae. As a result of these late effects of polio, I live with fatigue, poor sleep and a decline in respiratory function. I have had some life changing symptoms, including significant walking and gait issues that have resulted in three back surgeries. I have had both hips replaced.

As time marches on, muscle weakness and stamina are my number one concerns. Wearing a AFO (ankle/foot/orthotic) and the use of a cane helps me navigate through my daily life. As T.S. Eliot wrote “Only those who will risk going too far can possibly find out how far one can go.” This speaks not only to me, but to the millions of polio survivors who are continuing on, today and every day.



Polio and the Military . . . A Little History

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

Director, International Centre for Polio Education

Question: Has anything been written about the effects of military service on polio survivors? I had polio at age 8. Navy service at age 21 - 25 aboard aircraft carrier (lots of ladder climbing). After I left the Navy, I went on to college. I was an electrical engineer (office work) until retirement at age 68. The strength in my legs degenerated until age 51, when I could no longer walk without assistive devices. Now I have to use power mobility equipment. Didn't my time in the Navy trigger PPS?

Dr. Bruno's Response: It is amazing that childhood polio survivors who regained normal muscle strength were inducted into the military despite their history of polio and even obvious muscle atrophy seen during their induction physicals. In 2005, I negotiated with the U.S. Veterans Administration and wrote the VA regulation on PPS treatment but also on receiving benefits. The benefits negotiations were a hard slog. We finally agreed that PPS symptoms (e.g., leg muscle weakness) would have to have been reported before discharge or within one year of discharge to be considered service related. If your record shows leg muscle weakness during that time frame you have a good argument that PPS symptoms are service connected and should be able to collect benefits. For those who contracted polio while serving in the military there is no question that polio and its sequelae are service connected.

G.I.s having polio brings up an interesting point about who gets polio. In 1946, although there was an outbreak of polio among American Marines stationed in northern China, not one case was reported among the Chinese. Albert Sabin was told by a British physician in the region that he frequently saw paralytic polio in the foreigners but rarely saw the disease among natives.

Polio also occurred with unexpected frequency in American servicemen stationed in the Philippines and Korea despite the fact that there had been no prior polio epidemics and that even individual cases of polio among the local populations were rare. In Hawaii, there was no segregation of racial groups at all in terms of work, play or housing. Between 1938 and 1947, whites had almost 3 times more polio than did Japanese residents, at least 4 times more polio than Chinese residents, and nearly 6 times more polio than Hawaii's Filipino residents.

These findings suggest that one factor that predisposes to getting polio is a gene associated with your racial or ethnic background. Apparently, the poliovirus has a peculiar affection for white Germanic folk and southern Europeans.

For more information:

Please read: [Benefits and Treatment for US Military Veterans with PPS](#) and the [Veterans Association Medical Letter](#) under the topic: Muscle Pain and Weakness in the Encyclopedia of Polio and PPS



A Webinar of Interest:

Topic: Is Polio Coming Back?

Supported by the Thomas F. McNair Scott Endowed Research and Lectureship Fund

Presenter: [Paul Offit, MD](#)

Director, Vaccine Education Center

Attending Physician, Division of Infectious Diseases, Children's Hospital of Philadelphia

Professor of Pediatrics and Maurice Hilleman Professor of Vaccinology,

University of Pennsylvania School of Medicine

Date and Time: Wednesday, Dec. 7, 2022, noon - 1 p.m. ET

You can find it on the CHOP website ([Winter, 2022](#)): www.chop.edu/pages/vaccine-webinar-archive

Polio and COVID. Living with their effects in 2022.

Over the last two years, we have had an enormous number of phone calls and emails regarding vaccines (both COVID and Polio). You told us stories of your concern regarding reactions to the COVID vaccine and your fears of the virus itself. Since polio has reared its ugly head in Israel, the UK and New York, you have contacted us regarding the need for polio vaccination and whether you needed “anti-body” testing to determine just what type of polio you had years ago.

Recognizing our lack of professional background to answer your questions regarding vaccines, we were guided by our thoughtful and very caring professional contributors.

- Early on, we published PHI’s “COVID Vaccine Information” by their Medical Advisory Committee.
- In January, 2022 Primary Care Physician (and polio survivor) [Marny K. Eulberg, MD](#) talked about Allergies, Colds, COVID, Flu and what differentiates them.
- In February, 2022 we published Part 2 of this article from [Dr. Eulberg](#) as she focused on COVID and addressed the questions we heard asked so often.
- In May, 2022 Richard L. Bruno, HD, PhD wrote about a repeating theme with COVID - “[Breakthrough](#)” Infections. He explained that this frequently used term wasn’t new and that there were breakthrough infections with the polio vaccine as well. He reminded us that no vaccine is 100% effective in preventing infection in every person who receives it.
- In June, 2022 we featured the last interview of [Daniel J. Wilson, PhD](#). In that interview he explains the differences between the COVID and Poliovirus(es) and yet the similarity in why he believed vaccination for both is so very necessary. Richard L. Bruno, HD, PhD wrote about our immune systems and viruses.
- In July, 2022, with the help of the Global Polio Eradication Initiative, we began our four month series explaining the poliovirus and differentiating between WPV and cVDPV. Sadly, we had to report the discovery of the cVDPV in London and New York during that time.
- Our [advocacy](#) regarding the importance of vaccination was clear throughout. Six polio survivors from our network supported the video series “[Perspectives on COVID-19 Vaccine for Kids](#)” from the Children’s Hospital of Philadelphia. Three polio survivors were featured by the PA Immunization Coalition and the PA Chapter of the American Academy of Pediatrics in their article “[Polio and COVID19 – Then and Now](#)”.
- This summer, polio came back to the US. In August, Richard L. Bruno, HD, PhD worked with us to write an article that has circulated all over the US and abroad: [Polio – It’s Happened Again in the US](#).
- In [October](#), Marny Eulberg, MD published an outstanding account of what and why this has happened.

And still, your questions kept coming.

- We had the opportunity to speak with a renowned virologist, [Dr. Paul Offit, MD](#). He is the Director of the Vaccine Education Center and professor of pediatrics in the Division of Infectious Diseases at the Children’s Hospital of Philadelphia. Along with many other credentials, he is a member of the FDA Advisory Committee on Vaccines. Dr. Offit has a personal connection with polio and true compassion for survivors of this terrible disease. We asked him YOUR questions on multiple topics.

Regarding COVID:

- What happens when we get this virus?
- What to do with weakness after the vaccine, paralyzed limbs and whether the second booster is necessary.

Regarding Polio:

- He tells his story of hospitalization with polio survivors, and how that began his journey into the world of vaccines.
- How has it returned to countries that saw its eradication many, many years ago?
- Whether we should be tested for polio antibodies and the importance of a “titer” test to determine what type of polio we had.

We must thank [Richard L. Bruno, HD, PhD](#), [Marny K. Eulberg, MD](#), [Rotary International](#) (and the [Global Polio Eradication Initiative](#)), the [Vaccine Education Center at CHOP](#) and in memoriam, [Daniel J. Wilson, PhD](#). They are true advocates for serving our mission of support - to survivors, to the eradication of polio and for being a resource for credible information about vaccines.





www.youtube.com/watch?v=L7PFKaHxamY

Program Video from the Post-Polio Syndrome Advocacy Group:

This International Group meets on the 2nd Thursday of each month at 10am (Eastern) Join us.

Meeting ID: 878 0943 9212

Passcode: PPS

Hosted By The Post-Polio Syndrome Group

The Philadelphia Inquirer

'WE ARE STILL HERE'

THANK you for the kind words that have come our way since this article (and the video within) was published in the [Philadelphia Inquirer](#).

It was an amazing experience working with such amazing professionals who took the time to cover six survivors and truly cared about the reality of the late effects of polio.

We were happy to see it picked up and shared by the Children's Hospital of Philadelphia, Post-Polio Health International and Rotary International

www.polionetwork.org/news



Thank you Survivor Martha Guthrie for this moving graphic.



November

A decorative border for the word 'November' featuring various autumn leaves in shades of red, orange, yellow, and brown.

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