



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

August, 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:

Muscle Spams in the Neck Can Be Terribly Painful. Neck pain is not uncommon for polio survivors. Many are diagnosed with something called “Torticollis”. [Richard L. Bruno, HD, PhD](#) has written a Bruno Byte that explains the most common symptoms of this painful condition. Neck muscle spasm and pain, pain down the spine, headache, inability to turn the head or it being twisted to one side. As he talks about why this happens and what can be done, his humor comes through.

“Polio survivors have enough ‘pains in the neck’ without having neck pain, too”.

Post-Polio Syndrome. In our July, 2022 newsletter, we published Dr. Marny Eulberg’s article: [One Doctor’s Visit Does Not A Comprehensive PPS Evaluation Make](#). The feedback from you has been significant and fascinating. As a follow-up to that, this month we have another article on this topic - *Diagnosing Post-Polio Syndrome* from Post-Polio Health International. The article discusses the process, the reality of PPS fatigue and EMG. EMG is painful and is often required (to find concrete evidence of someone having had Polio).

There’s One Topic Everyone Is Talking About. A young, 20 year old man was paralyzed from the poliovirus – in the US! Those words are deeply personal and difficult for everyone reading this to hear. The discovery of the VDPV poliovirus being in the sewage in NY, the UK and Israel is completely unnecessary. The CDC, one of Rotary’s partners in the Global Polio Eradication Initiative ([GPEI](#)) has been called in to all 3 countries. What IS vaccine derived poliovirus? How can this happen? Does the vaccine protect for this kind of polio? We have gone to our most trusted resource (the GPEI) for information that helps explain this complicated issue.

This topic is painful and difficult for any of us in the post-polio community. We have partnered with Richard L. Bruno, HD, PhD to verbalize our concern.

It’s National Immunization Awareness Month in the US. The importance of vaccination is certainly front and center in the news not just in the US but all over the world. Published prior to the discoveries in the UK, US and Israel, [Rotary International](#) verbalized the risk to under vaccinated communities.

“Vaccines are one of the safest and most effective ways to protect people from life-threatening and preventable diseases. The COVID-19 pandemic has interrupted life-saving vaccine campaigns.

As a result, there is a growing risk of resurgence of vaccine preventable infections including polio, measles, and tuberculosis.”

Rotary has led the way by immunizing more than 2.5 *billion* children in 122 countries.

Rotarians have invested \$2.4 *billion* to fight polio around the world.

On a lighter Note: Our topics are often of a serious nature, but we always strive to end this newsletter on a positive note. We had an unexpected surprise when we received a review of a children’s book by children! Both lovers of science, sisters Avery and Ariana gave us the perfect way to celebrate National Immunization Awareness Month with their “two thumbs up” review of *Ava Antibody Explains Your Body and Vaccines*.

[The Children’s Hospital of Philadelphia](#) agrees.

Kids Say
The *Darndest*
Things

The VDPV and WPV spreading throughout the world is proof that polio and many other vaccine preventable diseases are only a plane ride away.

There has never been a better time to support [Team Survivor](#).



Torticollis...or Just Plain Muscle Spasm?

A Bruno Byte

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

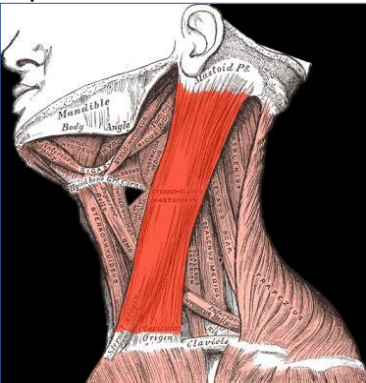
Director, International Centre for Polio Education

Recently, several members of the [Post-Polio Coffee House](#) have described severe pain on one side of the neck and have been diagnosed with torticollis. Torticollis is as much a description as a diagnosis and defined as a “twisting of the neck that causes the head to rotate and tilt at an odd angle” (*tortus*, twisted; *collum*, neck).

The most common torticollis symptoms are neck muscle spasm and pain, pain down the spine, headache, inability to turn the head or it being twisted to one side. The neck muscles that are most likely to go into spasm to cause torticollis symptoms are the sternocleidomastoids (that turn your head left and right) and the scalines (that pull your head sideways, ear to shoulder).



Spasmodic torticollis is a rare condition that originates in the brain. But common chronic or intermittent torticollis in adults is most often caused by injury or infection of neck muscles or the nerves that run them, a herniated disc, spinal arthritis or simply sleeping in an awkward position. In polio survivors there are two additional causes.

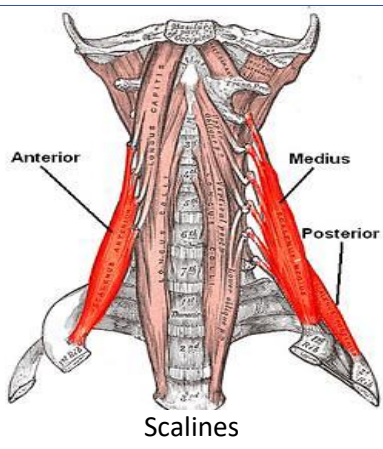


Sternocleidomastoid

Let's return to 1985 for a moment to our first National Post-Polio Survey, which found headaches reported by one third of polio survivors while neck and back pain occurred in nearly three-quarters. Evaluating patients at The Post-Polio Institute, we found that these three types of muscle pain are most often the result of spasms in the neck, upper back and shoulder muscles.

Why are polio survivors spasm-prone? Many have muscle imbalances where stronger muscles on one side of the neck or back go into spasm as they try to compensate for weaker muscles. And weak muscles spasm when they are being forced to do too much work. Poor posture forces weak upper back muscles to hold you up so that you don't topple forward or to one side. Muscle imbalances, compensation and poor posture in your neck, arms, shoulders, upper back - - even in your low back, hips and legs -- can lead to neck muscle spasms and headaches.

I am always dismayed when a polio survivor with severe neck pain or headache goes to a doctor who doesn't even examine their neck muscles, is diagnosed with "torticollis" and sent on their way with the suggestion of taking Tylenol. Or, on the opposite end of the spectrum, others are given a recommendation for Botox injections to paralyze the muscles in spasm, a dicey situation given that Botox will paralyze muscles that have already been paralyzed, or whose nerves have been damaged, by polio.



Scalines

Polio survivors with neck pain or headaches should not just accept a diagnosis of "torticollis". They should have their neck and back muscles examined and posture evaluated by a rehab doctor and physical therapist to find and treat the cause of the painful spasms.

While the evaluation process is going on, there are a number of anti-spasm medications (diazepam, tizanidine, cyclobenzaprine) that you can discuss with your doctor. In skilled hands, an injection of 2% lidocaine into the spasm can both decrease pain and "breakup" a spasm.

Polio survivors have enough "pains in the neck" without having neck pain, too.

Diagnosis

“The criteria for diagnosing post-polio syndrome include:

- a prior episode of paralytic polio confirmed by medical history, neurologic examination, and, if needed, an electrodiagnostic exam to show changes consistent with prior anterior horn cell disease (exam is not required for limbs with obvious polio paralysis);
- a period of neurologic recovery followed by an extended interval of neurologic and functional stability, usually 15 years or more, preceding the onset of new weakness;
- the gradual or abrupt onset of new weakness and/or abnormal muscle fatiguability (decreased endurance), with or without generalized fatigue, muscle atrophy, and/or pain; and
- exclusion of medical, orthopedic, and neurologic conditions that may be causing the health problems listed above. New weakness (usually accompanied by diminished function) is the cardinal symptom of post-polio syndrome.

Without a clear history of new weakness, the diagnosis cannot be made. In addition, the diagnosis cannot be made without excluding other likely causes of new weakness and other new health problems. For this reason, post-polio syndrome is called a diagnosis by exclusion.”

Fatigue

“Unaccustomed or disabling fatigue is one of the most common symptoms expressed by polio survivors and occurs for multiple reasons. Some polio survivors describe fatigue as a decrease in stamina, in endurance, and in the ability to perform repetitive actions (rapid muscle fatiguability), either measured in ambulatory distance or in the performance of upper extremity tasks. Others report a more global sense of tiredness, describing sleepiness, decreased attentiveness, and forgetfulness. Many require more than normally expected amounts of sleep, and frequently feel refreshed by a nap. Many polio survivors also describe a major decrease in stamina following illness, surgery, or trauma (Yarnell, 1988).

“While electrodiagnostic studies have shown that polio-involved muscles commonly show signs of chronic denervation/reinnervation and defective neuromuscular junction transmission, not all polio survivors experience fatigue.” “It is clear that fatigue may result from poor pacing or pushing past the point of ‘tiredness’.” (abbrev)

Electromyography

“Electromyography records the changes in electric potential of muscles by means of surface or needle electrodes. An electromyogram (EMG), the record of electromyography, characterizes the electrical activity of motor units and, in polio survivors, will typically show evidence of chronic neuropathy (a disease of the nerves) which reflects the paralysis of many years ago. During recovery from the acute disease, the terminal ends of the motor nerves sent out ‘sprouts’ (Wohlfart, 1958) to the orphaned muscles resulting in larger than normal motor units, detectable by EMG.”

“EMG findings from polio survivors appropriately diagnosed with post-polio syndrome, and those not experiencing symptoms, are not significantly different (Cashman et al., 1987). Consequently, an EMG is not a test to diagnose post-polio syndrome. The diagnosis is a clinical one and a diagnosis of exclusion. Clinicians do use an EMG to confirm a history of prior polio if there is doubt, and to eliminate other diseases that may be causing the symptoms and/or co-existing with post-polio syndrome (Peach, 1997).”

“Research using EMG suggests that the enlarged motor units are not stable and that the disintegration of the reinnervated motor unit occurs over time (Wiechers & Hubbell, 1981). One study demonstrated an increased motor unit size with time after acute paralytic poliomyelitis (Stålberg & Grimby, 1995). Using motor-unit number estimation (MUNE), a study reported that 87% of previously affected limbs exhibited denervation as did 65% of supposedly unaffected limbs, and that the progression cannot be attributed to normal aging (McComas et al., 1997).”

29 July 2022

“The Global Polio Eradication Initiative (GPEI) has been informed of a case of paralytic polio in an unvaccinated individual in Rockland County, New York, United States.

The US Centers for Disease Control and Prevention (CDC) are coordinating with New York State health authorities on their investigation. Initial sequencing confirmed by CDC indicates that the case is [type 2 VDPV](#). Following the detection, the Global Polio Laboratory Network (GPLN) has confirmed that the VDPV2 isolated from the case is [genetically linked](#) to two Sabin-like type 2 (SL2) isolates, collected from environmental samples in early June in both New York and greater Jerusalem, Israel, as well as to the [recently-detected VDPV2](#) from environmental samples in London, UK. Further investigations – both genetic and epidemiological – are ongoing to determine possible spread of the virus and potential risk associated with these various isolates detected from different locations around the world.

It is vital that all countries, in particular those with a high volume of travel and contact with polio-affected countries and areas, strengthen surveillance in order to rapidly detect any new virus importation and to facilitate a rapid response. Countries, territories, and areas should also maintain uniformly high routine immunization coverage at the district level and at the lowest administrative level to protect children from polio and to minimize the consequences of any new virus being introduced.

Any form of poliovirus anywhere is a threat to children everywhere. It is critical that the [GPEI Polio Eradication Strategy 2022-2026](#) is fully resourced and fully implemented everywhere, to ensure a world free of all forms of poliovirus can be achieved. ”

[Source](http://www.polioeradication.org/news-post/report-of-polio-detection-in-united-states): www.polioeradication.org/news-post/report-of-polio-detection-in-united-states



Why Vaccinations Matter

Vaccines are life-changing scientific breakthroughs and play a critical role in fighting preventable diseases.

Thanks to vaccines:

Measles deaths have dropped by 73% worldwide from 2000-2018

73%



We're closer than ever to polio eradication, with cases down 99% worldwide

99%



The world has been smallpox-free since 1980



Vaccine-derived Polioviruses: Managing the risks

What are vaccine-derived polioviruses and vaccine-associated paralytic poliomyelitis?

“The oral poliovirus vaccine (OPV) contains a live, attenuated (weakened) vaccine-virus. When this vaccine is administered, the weakened vaccine-virus replicates in the intestine and enters into the bloodstream, triggering a protective immune response. However, during this replication process, some of the vaccine-virus may genetically mutate from the original attenuated strain and become neurovirulent (able to cause paralysis and circulate in communities). The neurovirulent virus is referred to as vaccine-derived poliovirus (VDPV). This is a very rare event. In the 10 years leading up to 2015 there were around 750 cases of paralysis caused by VDPVs reported worldwide.”

There are three recognised categories of VDPV (Vaccine Derived Polio Virus):

- Circulating VDPVs (cVDPVs)
- Immunodeficiency-associated VDPVs (iVDPVs)
- Ambiguous VDPVs (aVDPVs)

“Vaccine-associated paralytic poliomyelitis (VAPP) is a rare event associated with OPV, which is caused by a strain of poliovirus that has genetically changed in the intestine from the original attenuated vaccine strain contained in OPV. It is a one-time case, with no risk of spread to others and occurs at a rate of approximately 2 to 4 events per 1 million births.” (1) (2)

“The polio vaccine protects children whether the kind of polio is wild poliovirus or vaccine-derived poliovirus. Outbreaks (whether WPV or cVDPV) are usually rapidly stopped with 2 - 3 rounds of high-quality supplementary immunization activities (immunization campaigns).”

Additional Information on Vaccine-Derived Polioviruses

“ ‘While cVDPVs affect communities and warrant public health action (i.e., outbreak response) given the public health threat that they pose, there are other kinds of vaccine-derived polioviruses (VDPV) that are found in individuals and the environment. This section provides more information on those types of VDPVs.’

Immunodeficiency-related vaccine-derived poliovirus (iVDPV)

‘Prolonged replication of VDPVs has been observed in a small number of people with rare immune deficiency disorders. Because they are not able to mount an immune response, these people are not able to clear the intestinal vaccine virus infection, which is usually cleared within six to eight weeks. They therefore excrete iVDPVs for prolonged periods.

The occurrence of iVDPVs is very rare. Only 111 cases have been documented worldwide since 1962. Of these, most stopped excretion within six months or died.’

Ambiguous Vaccine-Derived Polioviruses (aVDPV)

‘When a vaccine-derived poliovirus is found in an individual that is not immunocompromised (i.e., it is not an iVDPV) *and* it is confirmed that this VDPV is not circulating within a community (i.e., it is not a cVDPV), then this case is referred to as an aVDPV.’” (3)

Resources:

- (1) It is anticipated that this rate will significantly decline, following the removal of the type 2 component in trivalent OPV in April 2016, which was responsible for approximately 40% of all VAPP cases.
- (2) www.polioeradication.org/tools-and-library/current-research-areas/vaccine-derived-polioviruses
- (3) www.polioeradication.org/polio-today/polio-prevention/the-virus/vaccine-derived-polio-viruses



Polio. It's happened again, right here in the US.

The July, 2022 announcement of a 20 year-old man from Rockland County, NY, paralyzed by the poliovirus, brings back memories of the fear, disability and death that came each summer with the polio epidemics. *How* can polio be happening here? We have had an injectable polio vaccine (IPV) that is 99% effective available to *all* children in the US since 2000. Vaccines can't do their job if people don't take them, and the young man from New York was not vaccinated. That's why polio is happening again.

Initial reports indicate that his paralysis was caused by a mutation of the oral Type 2 poliovirus vaccine (OPV), a mutation that occasionally causes the vaccine to result in paralysis. The oral polio vaccines have not been given in the US since 2000, suggesting that the chain of transmission of this contagious disease began abroad. The CDC and WHO have reported the virus that infected him is genetically related to the vaccine-derived poliovirus recently found in London and Israeli sewage (like the US, they are countries that have seen the eradication of polio). The paralyzed man must have come in close contact with someone who had received the oral Type 2 polio vaccine outside the US.

For polio survivors, this case in NY is horribly sad and deeply personal. Sad because the injectable polio vaccine, the *only* vaccine given in the US, is 99% effective in its protection against all three types of polio. If *only* he had been vaccinated, the man who was paralyzed never would have become ill at all. Even sadder is that he will have to live with a disability and chances are high that he will experience and become even more disabled as a result of Polio Syndrome (PPS) - the late effects of polio - as he ages.

Why is one case of polio deeply personal? Because lack of vaccination has added one more *preventable* case of polio paralysis to the WHO estimated 20 *million* polio survivors, 75%+ of whom will develop PPS. Survivors of this disease will always remember:

- Those who died.
- The terror that came with being so sick.
- Lonely months and years of hospitalization, surgeries and painful rehabilitation all while separated from parents and siblings.
- The frightening reality of an iron lung.
- The sorrow that came with discovering wheelchairs, leg braces and crutches were ours for life.
- The loneliness that came as we returned home, and were forced to accept that everyone around us knew that it was the home of a "cripple", and parents kept their children away.
- The shock that has come with the reality of the long-haul effects of polio (PPS), when those of us who thought we escaped or recovered from paralysis find ourselves with new weakness, fatigue and pain as we age.

(["In Our Own Words"](#) is in the Survivor Story section of our website that features stories and videos of the realities of this terrible disease.)

Yes, the story of this young man's suffering is sad and deeply personal. Even *one* unvaccinated person with polio is one too many. His pain is completely unnecessary. The miracle of the polio vaccines came too late for us and for the millions of others who are living with polio's effects.

We celebrate [Rotary International's focus on disease prevention](#) and the [Global Polio Eradication Initiative](#) for their determined efforts to rid the world of polio and educate parents about the gift of modern vaccines. In spite of these determined eradication efforts overseas, polio *is* happening in the US.

Please choose to vaccinate. No one needs to suffer from the effects of polio, ever again.

The foreign origin of the poliovirus that paralyzed the unvaccinated man in New York is a painful reminder that polio (and many vaccine preventable diseases) are only a plane ride away.

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

and

[Carol Ferguson](#)

Director, International Centre for Polio Education

Representing the PA Polio Survivors Network 6



“Meet Ava the Antibody !”

“She’s here to give you an inside look at your amazing body. Have you ever had the flu?

Maybe you’ve heard of chickenpox, the measles or the mumps?

All of these are viruses that can make you sick.

But, vaccines can help keep us safe and healthy and Ava is here to show you how !”

Ava Antibody Explains by Andrea Cudd Alemanni

Ava The Antibody

A Book Review by Avery and Ariana

Hi! I’m Avery, age 10, along with my sister Ariana, who is 7. Together, we read the book *Ava Antibody Explains Your Body and Vaccines* by Andrea Cudd Alemanni.

The book explains how shots/vaccines show your immune system what different germs and viruses look like. It also explains how your immune system can get rid of the germs before they make you sick. The book tries to help you feel better about having to get these vaccines. Shots are never fun and can be scary!

We wish they would have told us about other viruses than just Charlie Chickenpox. We ask a lot of questions when we’re at the doctors. We want to know why we are getting a shot and what it’s for. Then we can go home and look it up and learn more about the virus. We are now curious on how the immune system fights back and helps us in other ways.



“We give this book two thumbs up!”

Avery & Ariana



We have three outstanding videos that can help explain vaccines.

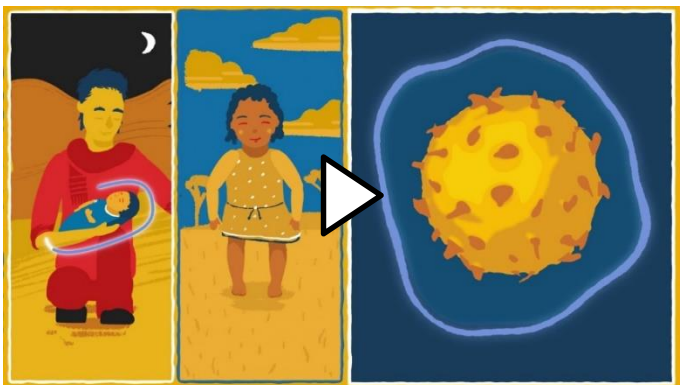
All three are available in the Vaccine and Polio Vaccine Video Libraries on our website.

Why Should I Get Vaccinated?



www.youtube.com/watch?v=9nadrnOxvE74

Vaccine Derived Polioviruses



www.youtube.com/watch?v=mg_XFQ2zib4&t=77s

Sticking to Zero – Polio Surveillance



www.youtube.com/watch?v=jY4AaZq9sSY



Team Survivor

We ARE a part of the solution.

With the heartbreaking news around us, we are grateful for the reminder that the Rotary Foundation has been a key player in the [Global Polio Eradication Initiative](#) (GPEI), since 1988 when it began. They have had an enormously difficult 3 years . . . yet, *no one* is letting up.

The wild poliovirus is endemic in 2 countries. While COVID-19 safety measures were being followed by vaccinators, 33 *million* children in Afghanistan and 270 *million* children in Pakistan were vaccinated in 2021. Why does this matter to those of us outside those two countries?

Because the virus (VDPV and WPV) spread throughout the world is proof that polio and many other vaccine preventable diseases are only a plane ride away. There has never been a better time to support this enormous effort.

What is Team Survivor?

It is a means for Polio Survivors, our friends and families to come together in a thriving, spirited way to help rid the world of this terrible disease. What Can YOU Do?

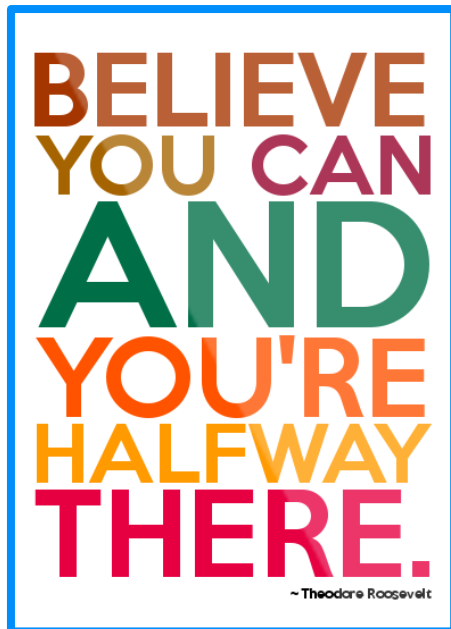
- Call your local Rotary Club.

Tell them you are a polio survivor and are grateful for their ongoing participation in Polio Plus.

- Are you a Rotarian? We know you've donated ! Email your photo to info@papolionetwork.org
- Make a [Donation](#) to the Rotary Foundation for Polio Eradication.
 - In just five years, survivors and family members in our network have sent donations providing more than 87,000 Polio vaccinations to children in the most difficult to reach corners of the world.
 - Because of the Gates Foundation 2 for 1 Match - Your \$25 Donation will become \$75
 - NO donation is too small. That's what makes it so special.



August



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