



# PA Polio Survivors Network

Information and Inspiration  
for All Polio Survivors and Their Families

*Serving the Keystone State and Beyond*

[www.polionetwork.org](http://www.polionetwork.org)

July, 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:

**Post-Polio Syndrome.** WHY is it so hard to diagnose? This is one of the most frequently asked questions that come our way. PPS is always a diagnosis of exclusion. What does that mean?

“I was in the hospital for months – isn’t that enough?”

“I still remember the sound of the iron lung. This weakness in my body *must* be PPS.”

“My brother had polio. Could my fatigue be related to that?”

In her clear and remarkable writing style, Primary Care Physician Marny K. Eulberg, MD explains the importance of the lengthy process that goes into this diagnosis.

**Neuropathy.** If the word “neuropathy” means neuron damage, and I have it, doesn’t that mean that polio (and now PPS) caused it? It’s not that easy. Richard L. Bruno, HD, PhD explains what “neuropathy” is and the causes.

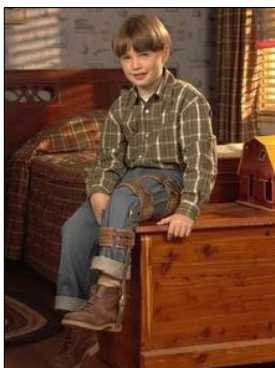
**We love hearing from you.** Survivor Laura Vittorioso surprised us with her marvelous review of a book that many polio survivors have read - *The Polio Paradox* by Richard L. Bruno, HD, PhD. Her ability to apply what she read to her life – both as a young child and now as an adult is honest and thoughtful.

**Wild Polio Virus vs Circulating Vaccine-Derived Poliovirus – What’s The Difference?** How is it that in 2022, polio was found in the sewage in a country that hasn’t seen a case of the wild poliovirus since the early 1980’s? It’s complicated and sad all at the same time. We’ve gone to our most trusted resource – the Global Polio Eradication Initiative (GPEI) for information on this discovery in the UK.

What IS the difference between these two? We’ve brought you an article published in Rotary Magazine from Great Britain and Ireland that explains. In today’s world, we must acknowledge that Polio, COVID-19, Flu, Measles (and the list goes on . . . .) are ONLY a plane ride away.

**Polio is being featured in prime time dramas.** We have found four dramas that included the realities of this terrible disease in their story lines. With the ease of streaming devices and “On Demand” TV many of us can enjoy these episodes.

American Dreams  
Season 2



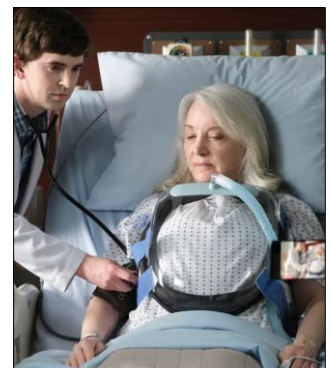
Call the Midwife  
Season 3, Episode 1



Chicago Med  
Season 7, Episode 14



The Good Doctor  
Season 5, Episode 15





## One Doctor's Visit Does Not A Comprehensive PPS Evaluation Make.

Marny K. Eulberg, MD

[Primary Care Perspective](#)

I frequently get questions via email or phone from polio survivors about a particular problem that they are experiencing. I appreciate a short summary of their history and of the "chief complaint". Often, they will indicate that they have seen a doctor who did some tests, but did not answer their question(s) in a way they could understand. Without question, I will want more information about the extent of paralysis from the polio, other medical conditions that have developed over their lifetime, and/or exactly what tests were done by other physicians, and the results of those tests.

Wouldn't it be wonderful if all doctors could make a diagnosis and develop a treatment plan in only one visit? Sometimes that is possible - for example when the person has the typical rash of shingles, classic gout involving the big toe or the classic symptoms of uncontrolled diabetes. But other times the symptoms may be vague or they could be caused by one or more than a hundred different diagnoses.

Let me share with you the thought process that I go through when a patient presents with a common but non-specific symptom such as a headache. In that first visit, my goals are to determine if the headache is caused by something needing urgent/emergent evaluation and management such as a stroke or a brain tumor. At the same time, I start deciding if a much more common cause is at play such as a sinus infection or a tension (muscle contraction) headache. It is rare that I know exactly what is causing that person's headache when they leave the office, but I have begun making a list in my head and/or on the chart prioritizing the most likely causes and what I will be looking for if they return for a follow-up visit. It's important to note that many of the symptoms that affect people go away on their own, so many patients may get better and not need any further evaluation.

If the patient comes back because they are not better, then I can ask more questions and start ruling in or ruling out various diagnoses that are on my differential diagnosis of causes of headaches. It is a bit like trying to determine why those strings of Christmas lights won't light - testing each light bulb set, then one by one each light within that string, and sometimes the final step that should have been the first, is it plugged into a working outlet? Just like those Christmas lights, sometimes the answer comes quickly and simply and sometimes it takes lots of time and testing.

A similar thought process happens when you consult a doctor about your post-polio concerns - *especially* some of the non-specific ones such as fatigue, or a sense that you are weaker than you used to be.

When seeing a doctor for the very first time they cannot know what you used to be able to do, the degree a deformity has changed, or how much strength in a particular muscle you had 5 years ago or even last year. In fact, the criterion for making a diagnosis of PPS is showing worsening from your baseline over time. I cannot, nor can any physician, make a diagnosis of PPS when seeing a person for the first time! We can suspect PPS if it is known that the patient has a history of polio and then put it on our list of "differential diagnoses" to consider as we go forward. Also remember one of the most important criteria for a diagnosis of PPS, is that other likely causes of the symptoms need to be ruled out. That will take at least three or more visits and some testing possibly by other medical professionals - neurologist, rehabilitative physician (physiatrists) and physical/occupational/speech therapists.

When I am seeing a person with concerns about late effects of polio or post-polio syndrome, I generally schedule 2 hours of time to interview them, do an examination, provide some education, and make some recommendations. Sometimes this is more time than I need and sometimes it is not enough. But if your healthcare provider routinely allows 15 to 20 minutes per patient, it will require four or more visits to equal one of my evaluations.

If you were never formally diagnosed with having *had* polio, then the process to make a diagnosis of late effects of polio or post-polio syndrome is likely going to take longer and require more doctor visits

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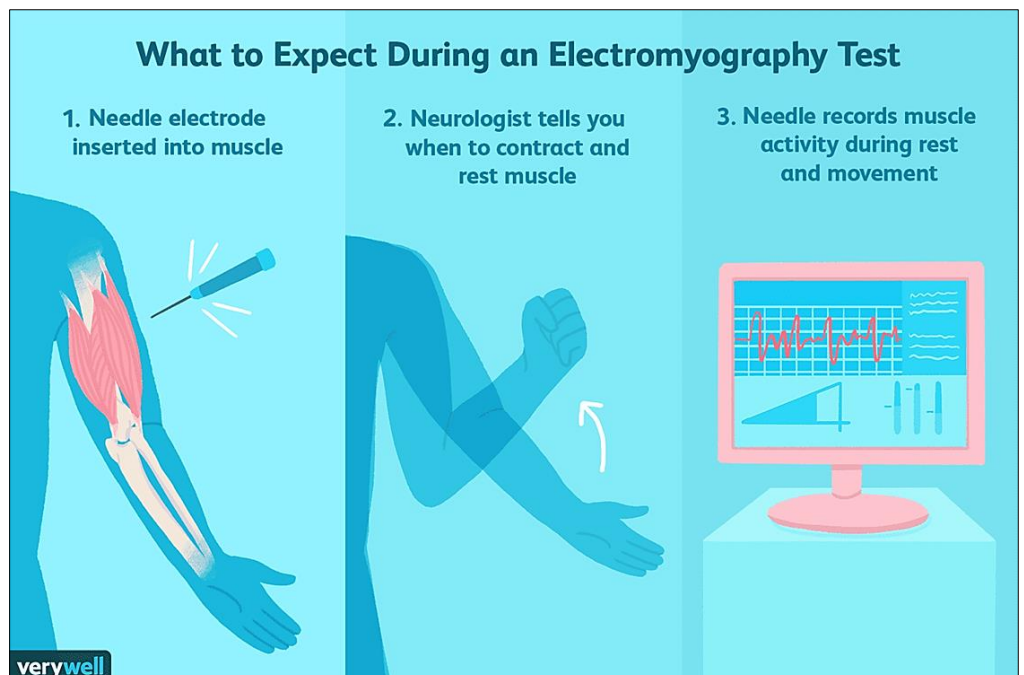
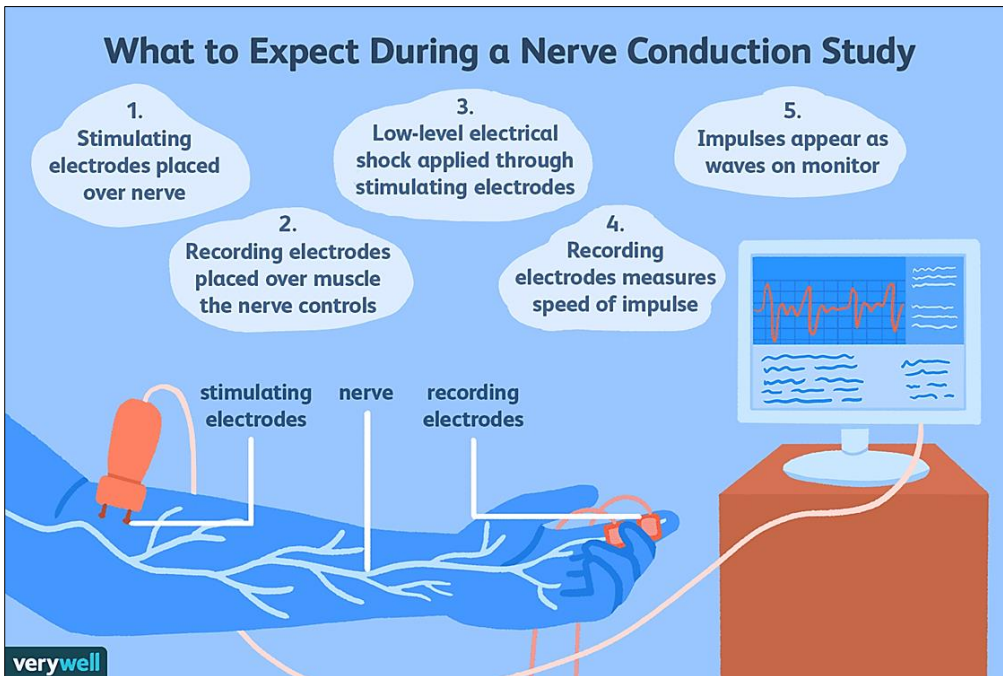
late effects of polio or post-polio syndrome is likely going to take longer and require more doctor visits than if you clearly have evidence of previous polio. It probably, at minimum will require at least one electromyogram (EMG) with a Nerve Conduction Study.

An [EMG](#) is a test in which the neurologist or physiatrist places small needles into the muscle and around nerves in your arm(s) and/or leg(s) to determine how the nerve and muscle “talk” to each other. There is a classic pattern seen in the nerves and muscles affected by prior polio which shows evidence of chronic denervation (loss of nerve supply to the muscle) and chronic innervation (creation of new nerve connections to the muscle).

Please note:

- the EMG can establish/prove that a person had polio affecting certain parts of their body;
- it does *not* confirm that the person has PPS!
- However, many physicians now in practice have never seen this pattern and thus may not recognize it when they see it.
  - If the written conclusion on the EMG report says something like results are “bizarre” or “unusual” or “unexplainable” it would be wise to get another neurologist or physiatrist to look at the tracings obtained and render their opinion.

[Marny K. Eulberg, MD](#)





# Neuropathy – What is it?

A Bruno Byte

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

International Centre for Polio Education

What is a Neuropathy? The definition seems obvious:

neuro = neuron.

pathy = damage.

So neuropathy just means damage to a neuron. Unfortunately, it's not that simple.

A neuron (nerve cell) communicates with other cells, the brain or activates muscle fibers by sending a signal from the nerve cell body down an insulated extension called the axon (see below). (1)

When you hear about a “peripheral neuropathy” it is almost always caused by damage to the insulation around the axon of **sensory** neurons that receive touch, heat and pain signals and transmit them to the brain. This damage to axons’ insulation can cause numbness, pain, burning, tingling (and sometimes muscle weakness) in the arms, hands, legs and feet. (2)

But since the polioviruses’ target was not the axons but the motor neuron cell bodies inside the brain and spinal cord, Polio/PPS does not cause damage to sensory neurons or axons.

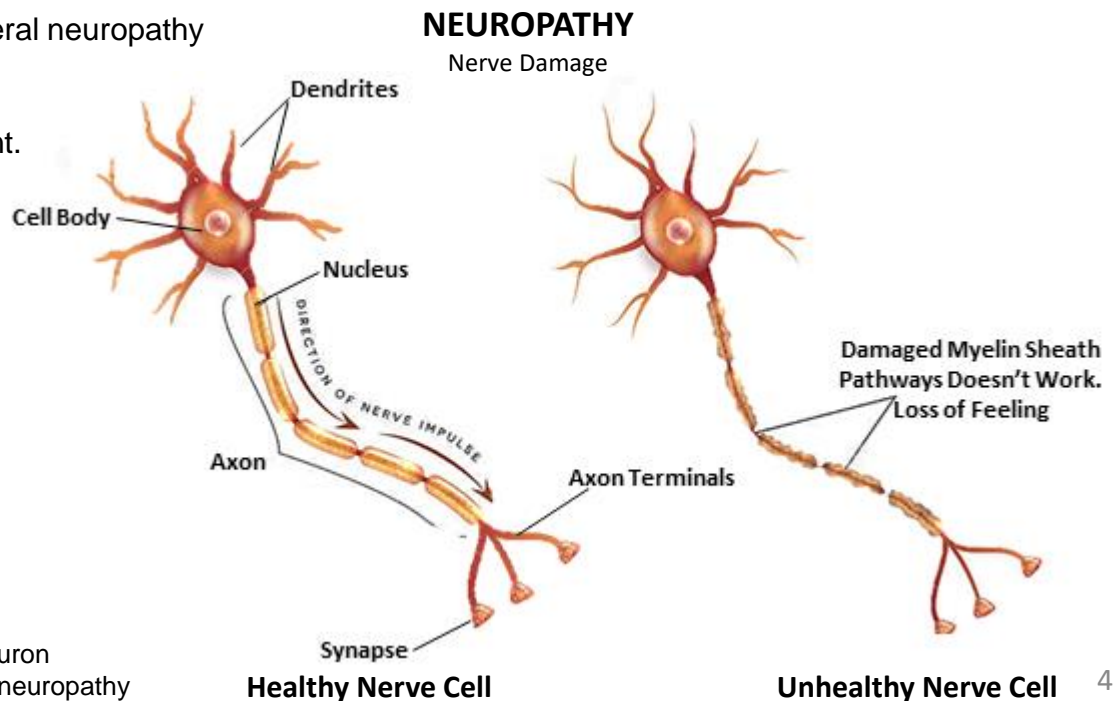
So Polio/PPS is *not* a neuropathy.

However, polio survivors can develop neuropathies, like carpal tunnel syndrome, damaging sensory axons by significantly overusing wrists and elbows across decades to compensate for arm or leg muscle weakness (e.g., by walking with crutches).

Other common causes of peripheral neuropathy are:

- Diabetes
- Pressure on or damage to nerves, commonly from typing (e.g., carpal tunnel syndrome)
- Nutritional issues and vitamin deficiency
- Alcoholism
- Autoimmune disorders (rheumatoid arthritis, lupus)
- Infections and diseases (liver, kidney and thyroid dysfunction, Lyme disease)
- Inherited disorders
- Exposure to toxins, certain drugs and cancer treatment

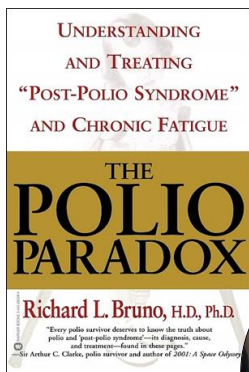
If you have any of the peripheral neuropathy symptoms described above, please talk to your doctor about diagnosis and treatment.



Sources:

(1): [www.en.wikipedia.org/wiki/Neuron](http://www.en.wikipedia.org/wiki/Neuron)

(2): [www.epainassist.com/nerves/neuropathy](http://www.epainassist.com/nerves/neuropathy)



## The Polio Paradox

A Book Review by Laura Vittorioso

I just finished reading Dr. Richard Bruno's book, *The Polio Paradox*. I learned so much about polio that I never knew. Did the medical professionals fully understand this disease back in the 50's when I contracted polio? I was told that the motor neurons that control muscle movement were damaged or destroyed and that was all. I contracted polio at twenty months which left me a paraplegic. I have since walked with braces and crutches.

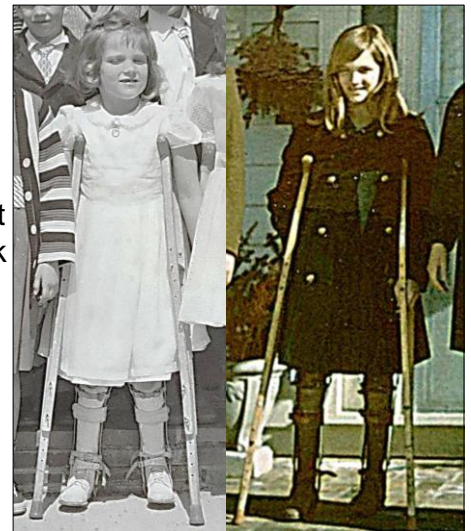
I didn't realize that polio is a disease of the brain and spinal cord. Many of the "ailments" I've been dealing with for the past twenty years, I attributed to "getting older with polio." My primary care doctors didn't seem to understand my symptoms either, often sending me for repeat sessions of physical therapy for the purpose of muscle "strengthening" to build up my weakening muscles. PT always left me feeling more fatigued and "spent." Instinctively I've realized over the years that I can no longer do what I used to do; that I need to slow down because of the muscle pain and fatigue. But this is difficult for us who have built our lives on over doing to compensate for our disability. In fact I was told as a young child by the physical therapists that I would have to work harder and be better, than those who were not disabled. "The world doesn't owe you a living" I was told. It was an either/or situation. You either worked hard to achieve some type of normalcy or you were left behind to stay at home and not participate in society.

I never wanted to *be* my disability; I wanted to be like everyone else. I went about my life as if I wasn't disabled; however, it would trip me up every so often as a reminder. Now in my 70s it is a constant reminder. I have to make decisions every day about what I can and cannot take on. For example, Sunday has always been my cleaning and laundry day as I have always worked full time. I can no longer vacuum, do the laundry, change the bed and cook food for the week in one day. I may be able to get the laundry done and change the bed, but that is about it. It's hard for me to see the things I want and need to get done (being the Type A that I guess we all are) and not do it. I'm trying to listen to my body, but it's difficult as I've always pushed through pain and fatigue.

I got involved with adaptive sports in my early 50's. I wish we had adaptive sports when we were growing up. I purchased a used handcycle. It's a three wheel bike that you motorize with your arms. It's been an activity that I have so enjoyed. I've been able to get out in nature, on wooded paths and ocean boulevards. I would go out with organized groups so there was help in getting the bike out of my car and assembled. We would ride for 5-10 miles. Once I did a 20-mile ride. Now I take short rides around my development. If I want to do a bike ride I have to give up something else, like doing laundry or changing the bed. It's trying to figure out how to hang on to the activities I enjoy without totally tiring myself (or as I've learned causes further damage) that is so hard.

As polio survivors we've had to figure things out. When I had my first child that wasn't easy to do. How would I carry the baby? How would I get him into the car for a doctor's visit when my husband was at work? Somehow I figured it out and raised two sons.

The late effects of polio can be difficult to understand – not just for me but for my family and friends who have never considered me disabled. This book is well-written and easily read. Dr. Bruno's detailed diagrams enable one to understand what is going on in the brain and spinal column. The case studies were very interesting and some were a sad reminder of the abandonment and loneliness we experienced as young children. As a result, I understand not only what happened to me when I was a child but perhaps of greater importance, I understand what is happening to me now. Since reading the book I am trying to make conscious decisions about: reducing my work load, taking more rest breaks and transitioning to more wheelchair time. It's yet another challenge to be figured out. I now have a better understanding of Dr. Bruno's primary advice, "conserve to preserve."



# Wild Polio Virus Vs Circulating Vaccine-Derived Poliovirus – What’s The Difference?

By **Dave King**

Published: October 8, 2021

**Here is everything you need to know about cVDPV – a form of polio that has been spreading in recent years due to low immunisation rates within community.**

“While cVDPVs are rare, they have been increasing in recent years due to low immunisation rates within communities. cVDPV type 2 (cVDPV2) are the most prevalent, with 959 cases occurring globally in 2020. Notably, since the African Region was declared to have interrupted transmission of the wild poliovirus in August 2020, cVDPV are now the only form of the poliovirus that affects the African Region.

## How do cVDPVs occur?

“The oral polio vaccine (OPV) that has brought the wild poliovirus to the brink of eradication has many benefits: the live attenuated (weakened) vaccine virus provides better immunity in the gut, which is where polio replicates.

The vaccine virus is also excreted in the stool, and in communities with low-quality sanitation, this means that it can be spread from person to person and actually help protect the community.

However, in communities with low immunisation rates, as the virus is spread from one unvaccinated child to another over a long period of time (often over the course of about 12-18 months), it can mutate and take on a form that can cause paralysis just like the wild poliovirus.

This mutated poliovirus can then spread in communities, leading to cVDPVs.”

*“While cVDPVs are rare, they have been increasing in recent years due to low immunisation rates within communities. cVDPV type 2 (cVDPV2) are the most prevalent, with 959 cases occurring globally in 2020.”*

## How is the Global Polio Eradication Initiative (GPEI) working to stop cVDPVs?

“The cause of cVDPV is low immunisation rates. So, the best way to prevent them and stop them when there is an outbreak is to vaccinate children. 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 two to three rounds of high-quality immunisation campaigns.

In addition to high-quality immunisation campaigns, the GPEI is working to deploy an improved outbreak response tool: the novel oral polio vaccine type 2, or nOPV2.

This vaccine is similar to mOPV2 (the monovalent oral polio vaccine type 2), the current outbreak response vaccine that is used when cVDPV type 2 outbreaks occur.

However, it contains improvements that help make the vaccine virus less likely to mutate and cause disease in communities with low immunisation rates – meaning that it can help reduce the risk of cVDPV2 outbreaks.”

## What are the other vaccine-derived polio viruses?

“While cVDPVs affect communities and warrant public health action 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.”

“Notably, since the African Region was declared to have interrupted transmission of the wild poliovirus in August 2020, cVDPV are now the only form of the poliovirus that affects the African Region.”

### **Tell me about 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.”

### **What about ambiguous vaccine-derived polio viruses (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.”



## **Vaccine-Derived Poliovirus Type 2 (VDPV2) Detected In Environmental Samples In London, UK**

22 June 2022

“The Global Polio Laboratory Network (GPLN) has confirmed the isolation of type 2 vaccine-derived poliovirus (VDPV2) from environmental samples in London, United Kingdom (UK), which were detected as part of ongoing disease surveillance. It is important to note that the virus has been isolated from environmental samples only – no associated cases of paralysis have been detected. Recent coverage for the primary course of DTaP/IPV/Hib/HepB vaccination, which protects against several diseases including polio, in London suggests immunization coverage of 86.6%.

“Initially, vaccine-like type 2 poliovirus (SL2) had been isolated from samples taken from the same site between February and May 2022. Genetic analysis suggests that the new VDPV2 and previous SL2 isolates have a common origin, still to be identified, but the technical definition and criteria for ‘circulation’ of VDPV2 are not met at this time. Additional sewage samples collected upstream from the main waste-water treatment plant’s inlet are being analysed.”

“Investigations and response by the UK Health Security Agency are ongoing to:

- assess both origin and risk of circulation associated with these isolates;
- strengthen poliovirus surveillance including enterovirus and environmental;
- explore routine immunization catch-up of children who are under-immunized, including of families that have recently arrived in the UK from countries with recent use of type 2-containing oral polio vaccine; and,
- enhance communications about this incident to health professionals and caregivers.”

“It is important 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.”

[Source:](#) Global Polio Eradication Initiative

## Our Monthly Newsletter is Available for Home Delivery by US Mail

With gratitude to a local printer (whose father was a polio survivor); we are still able to offer our newsletter, in full color for a very reasonable price.



Mumps  
Measles  
Flu  
Polio  
COVID-19  
....  
and the list goes  
on

**THE GLOBAL AVIATION NETWORK  
DISEASE CAN SPREAD NEARLY  
ANYWHERE WITHIN 24 HOURS**

Image from openflights.org



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



Understanding is  
much deeper than  
knowledge. There are  
many people who know  
us, but very few who  
understand us.



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