



# Polio Survivors Serving Others

Information & Inspiration  
For All Polio Survivors and their Families

The PA Polio Network

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

June, 2023

## Our Mission:

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

## Inside this Issue:

**Frontiers in History: People, Places, and Ideas.** During the 2022–2023 school year, National History Day® (NHD) invited students to research topics related to this theme. The contest culminates in mid-June. We were contacted by high school juniors who “chose to investigate how the Polio Vaccine has shaped the modern landscape of public health, including how it has changed polio from one of the world’s most feared diseases to one that could be put under control and prevented.” Sisters Angel and Rachel did an outstanding job on their project – placing in the California State Finals. We were happy to support their work and to be publishing their documentary.

**Introducing the "Post-Polio Article Review":** Dr. [Richard Bruno, HD, PhD](#) gets requests from polio survivors around the world to explain and assess the accuracy and applicability of often complicated studies published in scientific journals. First in a new series he has entitled "Post-Polio Article Review" is the article “The Risk of Post-Polio Syndrome Among Immigrant Groups In Sweden”. Fortunately, the conclusion of this study serves us all: “It is of importance to be aware of PPS in the whole health care system in Western countries . . . PPS patients need treatment and follow-up for their lifetimes. PPS will only disappear decades after the worldwide eradication of polio.”

**Post-Polio Syndrome – What is it? What are the Symptoms? How is it diagnosed?** The Christopher Reeve Foundation has done an outstanding job explaining these issues. We are happy to bring you their outstanding article.



## Polio Network

Polio Survivors Serving Others

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

**PPSN News:** With gratitude to the PA Chapter of the American Academy of Pediatrics, PAIC (The PA Immunization Coalition) the generosity of the outstanding professionals who have donated their time and outstanding contributions, and our dedicated working team of survivors, family members and friends; we have launched a new and updated website.

Continue . . .

At the suggestion of survivors all across the globe, we are now: [www.polionetwork.org](http://www.polionetwork.org)

“Our Polio Network, managed by polio survivors and friends, is in service to bring support and information to polio survivors, their families, caregivers and healthcare providers. Known as the PA Polio Network (PPSN), we work with many professionals providing valuable information to help educate and spread awareness about the late effects of the poliovirus, and the importance of being vaccinated against this terrible disease. We serve others all across the globe.”

Across the top on the [Home](#) Page on our website, you will easily find these headers. Hover over that title to see what’s inside.

**Post-Polio Syndrome   Professionals   Polio   Our Advocacy   Articles/Resources**

Over the next few months, we will cover each of these Heading Sections in this newsletter.



## **The Polio Vaccine: A Medical and Personal Frontier** A National History Day Documentary

In November, 2022 we received an email from Rachel – a high school Junior from California. She told us that she was creating a paper and project to be entered for [National History Day](#). This historical investigation, which culminates in a national competition in June, asks students to explore a topic aligned with the 2023 year theme *Frontiers in History: People, Places, and Ideas*. “I chose to investigate how the Polio Vaccine has shaped the modern landscape of public health, including how it has changed polio from one of the world’s most feared diseases to one that could be put under control and prevented.” She was optimistic that we could answer questions that surfaced as she researched the personal stories on our website. What were our experiences like? “How do you feel the polio vaccine has changed your life and the lives of the people around you for the better?”

We have helped students in the past and were especially intrigued by Rachel’s questions and enthusiasm towards learning more – not just about the vaccine but about the reality of this terrible virus. We sent her links to multiple articles re:

- The [Late Effects of Polio](#) (PPS)
- The [Polio Vaccine](#).
- [Historical information](#) and
- encouraged her to research stories of interest about the less known "[Unsung heroes](#)" of the polio vaccine.

We also noted how easily she could find the sources for ALL of our articles.

Prior to our first video conference, we sent her the written stories and videos of the three survivors who would be participating: [Carol Ferguson](#), [Joe Randig](#) and [Shirley Smith](#). We “met” with Rachel and her sister Angel in December and again in January. Both calls found us fascinated by how thorough and interested they were. In mid February, they told us they had submitted their final documentary for judging on March 4.

We were humbled by the trust they had in the three of us, to confidentiality share their film.

Five days later, we got the news from Rachel: “Angel and I made it to the state competition! Our documentary was one of the three winning documentaries, so we were able to advance to the California National History Day, which will be on April 15-16 in Sacramento! Thank you so much for your help!”

The image shows a certificate from the 2023 San Diego County Winners Report. It features the NHDSO logo (National History Day San Diego) and the title "Senior Group Documentary". The winning entry is "The Polio Vaccine: A Medical Frontier" by The Cambridge School, Independent, with ID number 31107. The teachers are Cherie Redelings. The students are Angel and Rachel.

After the State competition, we heard the wonderful news from Rachel - “Angel and I were able to make it to the final round, which was the top 15 documentaries in our state! From there, the top two documentaries were selected to go to the national competition, and although we didn’t make nationals, we still had a great experience in Sacramento.”

Working with these two amazing high school juniors intrigued us from the very beginning. Could it be that today’s students WANT to learn about the poliovirus and the miracle of modern vaccines? When we watched the video and saw the level of detail they went to in their research, we were grateful for the opportunity to support them in their effort.

“What a fantastic job they did. Although now retired, as an educator I am always interested in the education of young people. We know now that the general public needs to be informed on the need for vaccines to prevent or minimize the spread of communicable diseases. Vaccines are developed after much research and testing before they are approved for use in the general public.” Shirley Smith

When we saw how their documentary began, we knew these young women were focused on their message.

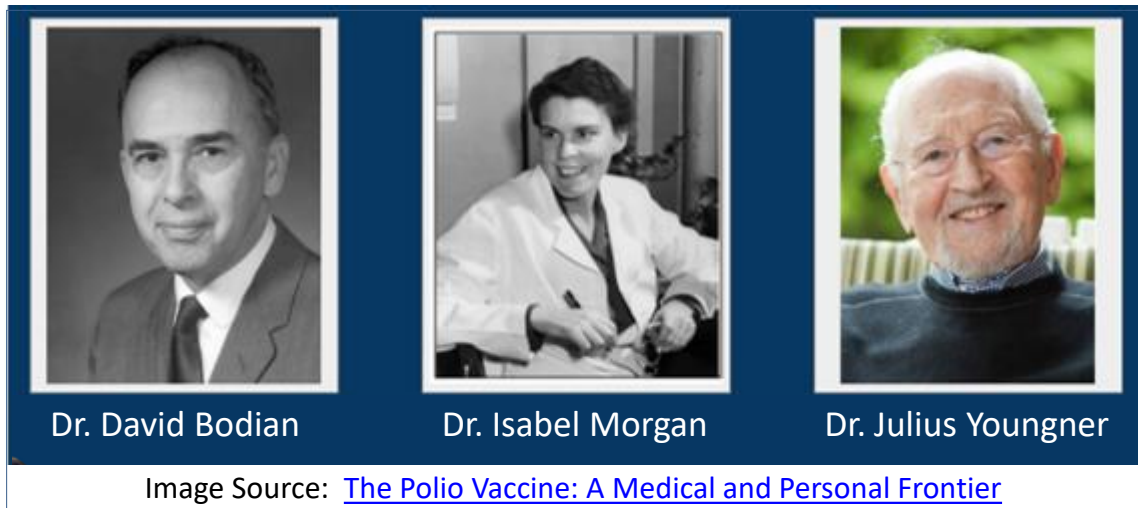
The polio vaccine WAS, without question, a medical and personal frontier.

“Remember them. Remember them all. They can and are being helped. But for them, polio may never be over, and polio is not over for you. It will not be over until the Salk polio vaccine is available to all. Then, and then only, can we begin to see clear skies and an end to all scenes like this.”

-Remember Me, 1955 Polio Outbreak Awareness Film



Image Source: [The Polio Vaccine: A Medical and Personal Frontier](#)



So often, when people speak about the polio vaccine, they speak only of Jonas Salk and Albert Sabin. Angel and Rachel could see and clearly understand, that those two amazing men didn't do it alone. They highlighted three of the amazing heroes that had a part in this miraculous discovery.

### THE FINAL PRODUCT

Congratulations Angel and Rachel on a job well done. We celebrate your work and appreciate your asking us to be a part of it. We know you understand -

No child should suffer from a vaccine preventable disease.  
The pain and disability CAN last a lifetime.

**The Polio Vaccine:**  
**A Medical and Personal Frontier**

A 2023 National History Day  
Documentary

“Click” on the arrow to play the video.  
You can watch the documentary: [www.vimeo.com/832360433/b3b071bf44?](http://www.vimeo.com/832360433/b3b071bf44?)





## POST-POLIO ARTICLE REVIEW:

"The Risk of Post-Polio Syndrome Among Immigrant Groups In Sweden."

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

Director, International Centre for Polio Education

I was excited when I saw a paper published in 2023 about the incidence of polio and PPS. The authors used the Swedish National Patient Register (NPR) as the data source, a database that is incredibly complete, capturing 99% of inpatient and 97% of outpatient diagnoses and associated information, and providing just over 1 million polio survivor subjects for the study.

The authors performed multiple complex, graduate-level statistical analyses. But I found that the more statistical analyses performed, the less I was learning about polio and PPS. I've converted the fancy statistics to percentages and I'm interested in your take.

### The Risk of Post-Polio Syndrome Among Immigrant Groups in Sweden.

#### INTRODUCTION

The percentages of immigrant polio survivors and those diagnosed with post-polio syndrome were compared to Swedish-born polio survivors using the Swedish National Patient Register (NPR). The NPR records data on medical diagnoses in inpatient and outpatient specialist care. The NPR also records demographic information e.g., age, gender, marital status, years of education, socioeconomic status and place of residence. These data from 1998 through the end of 2018 were collected for native-born Swedes and immigrants to Sweden 18 and older who were polio survivors.

The goal of this study was to examine the incidence of polio and PPS in foreign-born immigrants as compared to native-born Swedes.

#### RESULTS

Compared to a total Swedish population of 6.18 million, there were 5,300 polio survivors (.086% of the population) with 4,307 Swedish-born (81%) and 993 foreign-born (19%). The incidence of polio among immigrants as compared to the Swedish-born was higher in men by 77% and by 38% in women. The incidence of PPS in immigrants as compared to the Swedish-born was higher in men by 77% and by 46% in women.

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POLIO	%	PPS	%
<b>MALE</b>		<b>MALE</b>	
<b>All Immigrants</b>	<b>178</b>	<b>All Immigrants</b>	<b>202</b>
Africa	655	Africa	430
Asia	511	Asia	624
S. America	300	S. America	50
Baltic	21	Baltic	---
N. America	71	N. America	---
Europe	-34	Europe	-16
Nordic	-3	Nordic	-67
Russia	-62	Russia	193
<b>FEMALE</b>		<b>FEMALE</b>	
<b>All Immigrants</b>	<b>133</b>	<b>All Immigrants</b>	<b>212</b>
Africa	749	Africa	474
Asia	327	Asia	495
S. America	89	S. America	---
N. America	14	N. America	86
Nordic	-7	Nordic	-34
Europe	-17	Europe	40
Baltic	-41	Baltic	---
Russia	-52	Russia	---
<b>Percentage of Polio Survivors and PPS in Immigrants to Sweden Compared to Native-Born Swedes.</b>			

Not surprisingly, 90% of native–born Swedish polio survivors were aged 50 or older, while 50% of immigrants were younger than 40. Also not surprising, and as we found in our 1985 U.S. National Post Polio Survey, a larger percentage of polio survivors were married (68%) versus the general population (57%) and had more than a high school education (25%) versus the Swedish population (23%).

Other diagnoses. Swedish-born male polio survivors were at higher risk of hypertension, stroke, depression and cancer, while immigrant men only had a higher risk of stroke. Swedish-born female polio survivors were at higher risk for hypertension and cancer, while immigrant female polio survivors were at no higher risk for any condition.

#### The Geography of Polio and PPS.

Statistical analyses removed the effects of age, education, other medical diagnoses, marital and socioeconomic status from the data to calculate the incidence of polio and PPS in immigrants as compared to native–born Swedes.

Consulting the Table on page 1, and combining males and females, polio was 156% and PPS 207% higher in immigrants as compared to the Swedish-born population. Combining Asian and African immigrants, it was no surprise that polio was 560% higher and PPS 506% higher as compared to the Swedes.

Among Europeans, the incidence of polio was 43% *lower* and PPS 12% higher. Among Russian immigrants the incidence of polio was 57% lower than among Swedes. However, the incidence of PPS in Russian males was 193% *higher*.

#### DISCUSSION

The data collection and statistical analyses in this study were a Herculean undertaking. Unfortunately, the paper tells us about the incidence of polio and PPS in Swedish immigrants but little we don't already know about the incidence of polio and PPS throughout the world.

Also unfortunate, the paper seems more about applying complex data analysis than using the data to help identify factors that may cause, exacerbate or potentially reduce PPS symptoms. Instead of using statistics to remove the effects of diabetes, hypertension, heart disease, stroke, depression and osteoporotic fractures, these conditions could have been analyzed to describe their effects in polio survivors and potentially their relationship to PPS.

Even more unfortunate - and confusing - is the way in which the authors organized the paper and their inconsistency with naming, referring to subjects who had had polio as “post–polio” in most instances, but as “polio”, “sequelae of poliomyelitis”, “polio patients” and “polio survivors” in others. Subjects having PPS are most often identified as such, but also are referred to as having “post-polio myelitic syndrome” and “post-polio syndrome.”

The inconsistency with naming reminds us of the flaws in using large population databases: you can't know with consistency the criteria doctors are using to make their diagnoses - here of polio and especially PPS - that they then input to the database. How many polio

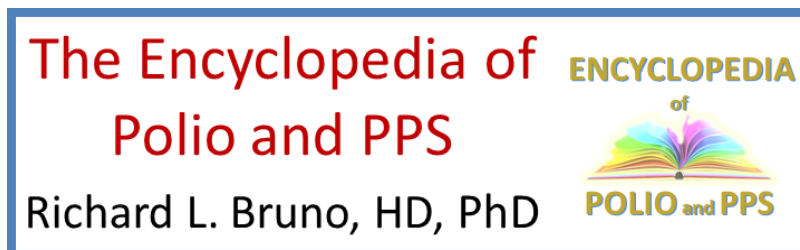
“The Risk Of Post-polio Syndrome . . .” (continued)

survivors in any country have had the experience of going undiagnosed or being given an incorrect diagnosis?

Fortunately, the authors come to a conclusion we all can support:

“It is of importance to be aware of PPS in the whole health care system in Western countries . . . PPS patients need treatment and follow-up for their lifetimes. PPS will only disappear decades after the worldwide eradication of polio.”

Source: [www.nature.com/articles/s41598-023-33240-w.pdf](http://www.nature.com/articles/s41598-023-33240-w.pdf)



You can find the [Encyclopedia of Polio and PPS](#) on our website.

Dr. Bruno’s name with links to his work, is easily found under the Heading: Professionals

You can access both Bruno Bytes and the Encyclopedia of Polio and PPS under the

Heading: Articles/Resources

Look for the Index/Category button to search Dr. Bruno’s entire inventory of articles by topic.



## Post-polio syndrome (PPS)

### What is post-polio syndrome?

“Polio was an epidemic in the United States in the 1940s and 1950s. People in the United States do not often contract polio because of the development of a polio vaccine which was developed in 1955 by Jonas Salk and an oral vaccine in 1962 by Albert Sabin. Vaccinated individuals cannot host a virus which makes it unable to replicate and spread. The polio virus is still active in some areas of the world. Improved sanitation measures have also helped to control it.

Poliomyelitis or polio is a contagious virus that enters the body. It is spread in respiratory droplets and through solid body waste. Most individuals who have polio will have flu-like symptoms. Rarely, polio affects the motor nerves (nerves that control movement) of the body especially in the spinal cord. This can be a sensation of tingling (paresthesia), an infection in the covering of brain and spinal cord (meningitis), or weakness in the muscles of the body (paralysis). Motor nerves are affected by polio which can lead to paralysis anywhere in the body with decreased movement seen in the arms and legs and most notably in the muscles that control breathing.

Some individuals survived the polio epidemic. Those with motor nerve damage may have

Continue . .

some residual movement deficits. To accommodate the loss of movement, affected nerve fibers develop new nerve-end terminals (dendrites) that will connect with other nearby muscle fibers. The result is functional movement recovery. This process is a representation of neuroplasticity or the ability of the nervous system to recover by developing nerve buds to improve the strength of the polio affected nerve fibers and muscles. After the initial polio episode, the individual can have partial to what appears to be a full recovery.”

“Over time, some individuals with a history of polio which affected the motor nerves may develop new muscle pain, weakness, or paralysis 10 to 40 years after the original polio episode. This is post-polio syndrome (PPS). Years later, the overused motor nerves become unable to keep up with movement demands which results in their slow deterioration. There may be some improvement a second time, but eventually, the nerve terminals slowly malfunction without further recovery. Progressive weakness and paralysis can occur.”

“Post-polio syndrome is not contagious. It is not a re-activation of the virus but rather an effect of deterioration of the replacement or supplemental nerves.”

### **Symptoms and Risk Factors of Post-Polio Syndrome**

“Post-polio syndrome tends to develop slowly with alternating periods of stability followed by increasing symptoms. The development of PPS occurs over time.

PPS occurs in individuals with a history of polio that included motor nerve involvement. It is typically not life-threatening unless breathing is affected and untreated. Individuals differ in the amount of affected function. Some will have mild cases of PPS with minor adaptations while others will have more significant issues requiring changes in lifestyle.”

Symptoms include some or all of these factors:

- progressive weakness in muscles and joints
- pain in muscles and joints
- body/mind fatigue and exhaustion with minimal activity
- loss of appetite
- Fever
- muscle atrophy (wasting)
- bone distortions such as scoliosis (curving of the spine)
- breathing issues
- sleep disorders, insomnia, sleep apnea
- swallowing issues
- cold temperature intolerance, occasionally intolerance to heat

### **Risk Factors for Post-Polio Syndrome**

Risk factors for PPS include a higher incidence in those individuals who had a severe initial course of polio with motor nerve involvement. If recovery of function was good or excellent from the initial polio event, more stress is placed on the supplementing nerves which can lead to post-polio syndrome motor nerve failure.

Continue . . .



Development of polio later in life as a teen or adult can relate to a higher risk of PPS because the sprouting nerve terminals are slower to develop as individuals age. Over exercising to the point of muscle fatigue can be a trigger for PPS if you have a history of polio with motor nerve involvement.

### **Complications of Post-Polio Syndrome**

Issues that result from PPS depend on location of injury to the nerve such as in the spinal cord, in the body or both. Complications arise as weakness progresses. These are some of the key issues.

1. Falls: muscle weakness can lead to balance problems, slipping or getting your toe caught under a rug or stair step. Falls can have profound consequences such as pulled muscles, bruising, and broken bones.
2. Difficulty swallowing: individuals with PPS that affects oral motor activity such as chewing and swallowing can lead to nutritional issues and dehydration. Poor oral motor control can lead to pneumonia if food is misdirected into the lungs.
3. Breathing: issues arise due to weak chest and abdominal muscles. This can reduce the ability to produce a strong cough to clear airway passages which can lead to pneumonia. Muscular changes can lead to breathing issues such as sleep apnea or chronic respiratory failure.
4. Muscle and skeletal structure: changes from strong muscles pulling the body against weaker muscles can result in structural bone changes leading difficulty in body positioning, discomfort, pain, contractures, difficulty in hygiene. Muscular changes can lead to breathing issues such as sleep apnea or chronic respiratory failure as well as pressure injury. Scoliosis, a change in the structural positioning of the spine affects the body's ability to inhale deeply and effectively.
5. Neurogenic bowel and bladder: nerve miscommunications change your ability to toilet. Bowel and bladder programs can be established to keep your body healthy. These programs reduce complications and maintain continence if elimination is challenged.
6. Bone mineral density: reductions from skeletal changes or inactivity can create osteopenia (low bone mass) or osteoporosis (extremely low bone mass).
7. Assistive device: issues such as braces and splints rubbing on the skin or use of crutches can lead to pressure injury and joint pain.

### **Diagnosing Post-Polio Syndrome**

Your healthcare provider will perform a complete physical examination and health history. They will be differentiating your symptoms from other neurological issues. Clues to PPS include a history of polio specifically affecting the motor nerves followed by partial or complete recovery for a period of 10 years or more.

The history of PPS includes a new onset of slowly progressive muscle weakness, decreased endurance, muscle atrophy, muscle and/or joint pain and fatigue. Typically, later developing symptoms include breathing or swallowing issues. Onset of PPS is gradual but inactivity from trauma or surgery can make the symptoms appear suddenly. Even though you see your healthcare provider early, a diagnosis of PPS is typically not made until symptoms have been in process for a minimum of a year.

Questions about other health concerns that could be similar to PPS symptoms will be asked. These include issues with depression which affect activity levels or functional issues such as joint pain from use of braces or crutches. Some of the symptoms of PPS are stand-alone medical conditions, such as breathing dysfunction or scoliosis, and are therefore not conclusive symptoms for PPS.

Included in your healthcare professional's physical examination is manual muscle testing (MMT) where the strength of each of your major muscle groups is assessed and rated. This is done by the provider in their office at a usual visit. You are asked to push or pull muscle groups against the resistance of the examiner.

Some instruments may be used for more precise measurements.

- An electromyography (EMG) test is done to establish motor neuron loss. This is performed on any muscle of the body by using a sensor or needle to assess electrical conduction to the muscle by the nerve. Nerve conduction studies (NCS) may or may not be done depending on individual circumstances.
- Imaging such as magnetic resonance imaging (MRI) and computed tomography (CT) of the spine can follow progression of PPS.
- A muscle biopsy might be done to exclude other diagnoses.
- There are no laboratory blood tests used to diagnose PPS.
- There is no test that predicts which survivor of polio with affected motor nerves is at risk for PPS.”

Note: Article Abbreviated for space. Image (Page #11) has been enlarged for clarity.

Complete article: [www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis](http://www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis).

# POLIO

## Contagious Viral Illness

**Poliovirus Destroys Nerve Cells in the Spinal Cord** → **Causing Muscle Wasting and Paralysis**

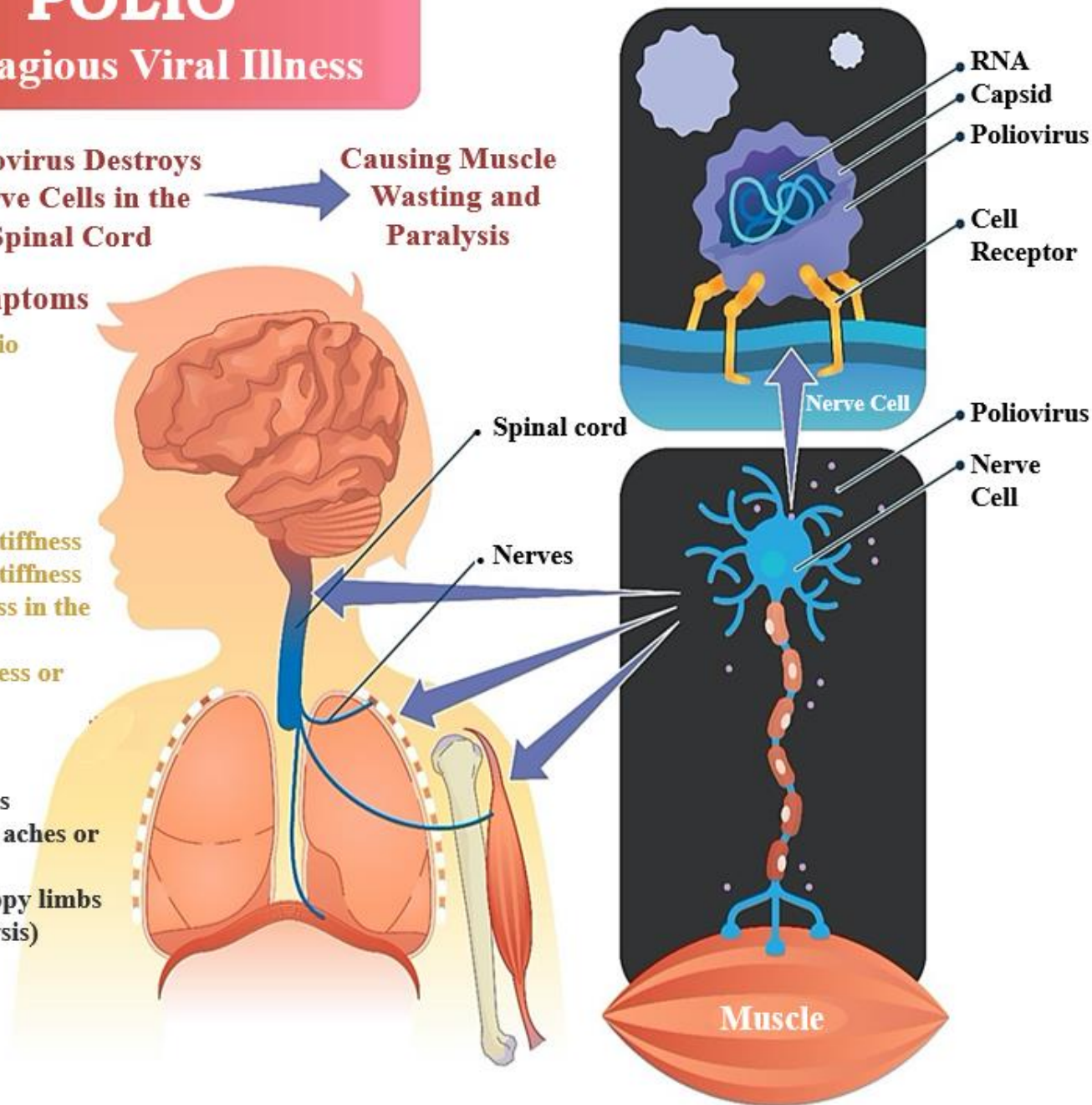
### Signs and symptoms

#### Nonparalytic polio

- Fever
- Sore throat
- Headache
- Vomiting
- Fatigue
- Back pain or stiffness
- Neck pain or stiffness
- Pain or stiffness in the arms or legs
- Muscle weakness or tenderness

#### Paralytic polio

- Loss of reflexes
- Severe muscle aches or weakness
- Loose and floppy limbs (flaccid paralysis)



### Sources:

- [www.christopherreeve.org/todays-care/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis/](http://www.christopherreeve.org/todays-care/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis/)
- [www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis](http://www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis)

## Transitioning from [www.papolionetwork.org](http://www.papolionetwork.org) to [www.polionetwork.org](http://www.polionetwork.org)



In the summer of 2014, we began our journey creating and maintaining this network of support for *all* polio survivors and our caregivers. We did so with the investment of \$90 for our domain name, a free website and the best group of professional and non-professional volunteers possible.

Nine years later, we are the home of [Bruno Bytes](#), [DeMayo's Q&A Clinic](#), the [Encyclopedia of Polio and PPS](#), [Living with Post-Polio Syndrome](#), [Primary Care Perspective](#), [Polio: Putting the pieces of Polio History Together](#) and more than 100 [Polio Survivor Stories](#).

We are advocates (both through our [written](#) work and personal [attendance](#)) regarding the reality of the Late Effects of Polio and the gift of the Polio Vaccine.

The mission of our Polio Survivors Network is to serve ALL polio survivors, both in the US and abroad by providing information for them, post-polio support groups, survivors' families, and their caregivers.

We draw attention to the importance of being immunized against polio and all the crippling childhood diseases.

We are survivors of a vaccine preventable disease who share a passion with Rotarians all over the US and abroad as we support Rotary International's focus on disease prevention and immunization. Together, those who are not affiliated with their local Rotary Clubs have joined us with the gift of more than 100,000 polio vaccines through [Team Survivor](#).

With this amount of information, our website needed significant search options that we did not have. In addition, we learned from you that with the "PA" in front of our name, survivors believed that they could not "Join" our network unless they were from the Keystone State. We are polio survivors who are serving others – regardless of where you may live.

We are grateful for the trust and funding from the PA Chapter of the American Academy of Pediatrics and the PA Immunization Coalition. In addition, we must thank the owner and website designers at [Stay Calm Industries](#). They spent more hours with us than we can count learning about the realities of this terrible disease and the importance of being able to communicate the gift that comes with the work from outstanding, generous professionals – work that can help us help ourselves once again.



The polio vaccine was a significant frontier in history because it not only brought a once terrifying disease under control for the first time and revolutionized public health, but also personally changed the lives of millions of people around the world who experienced it firsthand.

Angel and Rachel

 June



THANK YOU for your kind words and generous [donations](#).  
You inspire us to keep moving forward.

Unless noted with the article, feel free to copy and share what you see. Always give credit to the original source, include a visible, working link to our website: [www.polionetwork.org](http://www.polionetwork.org) and email us a copy of what you “share”. THANKS.



Email: [info@papolionetwork.org](mailto:info@papolionetwork.org)  
US Mail: PO Box 557, Doylestown, PA 18901  
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