



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

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Our Mission:

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

Inside this Issue:

- **HISTORY** - Since the beginning of time, history has played a critical role in the storytelling of life. When it comes to diseases and the vaccines designed to eradicate them, it's no different. We came across an article by the History Channel that tells the story of four of those debilitating diseases and the vaccines that have resulted in them being completely forgotten by many.
- **COMPASSION** - Polio is one of those four diseases mentioned. The publication of this article in the midst of another world wide pandemic stirred a special kind of emotion in us. As we write this, the world has come together to defeat yet another terrible virus. Your stories show that, without question, our hearts go out to those struggling with the pain and isolating realities of COVID-19.
- **ONE SURVIVOR'S STORY** - Flo Black thought she had the "Rheumatic Flu" until her right arm became paralyzed. Doctor after doctor struggled with the diagnosis until one realized it was Polio. Flo spent her life caring for others.
- **A 2,100 MILE HIKE TO ERADICATE POLIO** - Whether in the US or abroad, we can be part of this amazing odyssey. Why is this necessary? Why would a man dedicate a year of his life to training for something this big? We hear all around us - Polio? That's "gone", "eradicated". It's just a word. By using our cell phones and computers, we can help him communicate the truths to this terrible disease. Even in a quarantined, COVID world, we all can come together and be a part of the solution.



**During these difficult times,
many of us will be alone during these winter months.**



We must remember that we are not alone. We ARE all in this together and have been, for many, MANY years – long before COVID19.



Four Diseases You've Probably Forgotten About Because of Vaccines



Vaccines are so effective at fighting disease that sometimes it's easy to forget their impact.

By [Becky Little](#)

Widespread vaccination has helped decrease or virtually eliminate many dangerous and deadly diseases in the United States. Yet because vaccines have been so effective at removing threats, it's sometimes difficult to appreciate just how significant they have been to public health.

"We're very bad at measuring risk," says epidemiologist [René Najera](#), editor of [The History of Vaccines](#), an online resource by [The College of Physicians of Philadelphia](#). "And so when we don't see a lot of people dying from something, we think that it's not a big deal."

Here are four major diseases that you may have forgotten about (or downplayed) thanks to how effective vaccines have been at mitigating or eliminating them.

1. Smallpox



English physician Edward Jenner's first smallpox vaccination, performed on James Phipps in 1796. Bettmann Archive/Getty Images

[Smallpox](#) is the only human disease that has been globally eradicated through vaccines. It's also responsible for the first known vaccine, created by the English physician Edward Jenner in 1796. After observing that milkmaids who caught cowpox (a milder disease) seemed to gain immunity to smallpox, [Jenner inoculated](#) an eight-year-old boy using a milkmaid's cowpox lesion. He then exposed the boy to smallpox, and when the boy didn't develop any symptoms of the deadly disease, Jenner realized he'd developed a way to prevent it.

The experiment, while highly unethical by today's standards, was a big deal. Smallpox could kill up to 30 percent of people who caught it, and had already killed enormous numbers of Native

people in North and South America after European colonists [brought smallpox](#) and other new diseases to the continents. Shortly after Jenner developed the vaccine, Spain began using it to inoculate people across its empire. The British soon followed, and in the 1850s, Massachusetts became the first U.S. state to mandate smallpox vaccination.

"By the mid-1900s, right after World War II, countries all around the world decide... 'Why don't we just get rid of smallpox?'" Najera says. "And so they undertake an effort like no other since or before." This global effort led to the eradication of smallpox by 1979.

2. Rabies



Man standing beside a sign warning about rabies in Chicago, Illinois, 1954. Francis Miller/The LIFE Picture Collection/Getty Images

[Rabies](#) has played a large role in American film and literature—think *Old Yeller*, *To Kill a Mockingbird* and *Their Eyes Were Watching God*. But the deadly disease, which causes erratic behavior, is no longer a major threat in the United States because of vaccines.

In this case, most of the vaccines that have helped save human lives aren't used on humans—they're used on other animals that can carry the disease and infect humans by biting them. State rabies programs have guidelines for vaccinating pets and wildlife and tracking animals that might have rabies.

Continued . . .

Any human who is bitten by an animal, regardless of whether the animal has been vaccinated, must go to a doctor or hospital to receive a rabies vaccine.

Though rabies is still a threat in some parts of the world, many countries have robust vaccination and tracking programs. “Latin America has one of the best anti-rabies programs in the world,” Najera says. “I got bitten by a rabid dog when I was six years old [in Mexico]. They caught the dog and the dog died a couple of days later from rabies, and so if I would have not gotten the vaccine I probably would have been dead.”

3. Polio



Jimmy Nickle gazes at the adornments on his iron lung . 1945. Bettmann /Getty Images

[Polio](#) was once one of the most feared childhood diseases in the U.S. The viral infection can cause temporary or permanent paralysis, as it did with wheelchair-user [Franklin D. Roosevelt](#). This paralysis could stop a person’s body from breathing on its own, which is why so many infected people had to be placed in an “iron lung.” By the late 1940s, it was disabling more than [35,000](#) Americans each year. The number of U.S. polio cases peaked in 1952, when it caused [57,879 infections](#) and 3,145 deaths.

During the 1954 trials for [Jonas Salk](#)’s polio vaccine, parents flocked to sign their children up to get the shot. As a result, [623,972 children](#) received the vaccine or a placebo. The trials showed the vaccine was 80 to 90 percent effective at preventing polio. Thanks to the [continued vaccination](#) of children through today, no polio cases have originated in the United States since 1979. However, polio has not been eradicated, and remains a health threat in [Afghanistan and Pakistan](#).

4. The Flu



[WATCH](#): The 1918 Flu Was Deadlier Than WWI From the History Channel

During the early spread of COVID-19, there was a lot of discussion about whether the infectious disease was serious, or “like the flu” - i.e., not a threat. However, [influenza](#) remains a deadly disease that has caused previous pandemics and has the potential to cause [future ones](#) as well ([Najera](#) speculates the next flu pandemic will happen “sooner rather than later”).

The Centers for Disease Control and Prevention estimates the flu caused between [12,000 and 61,000 U.S. deaths](#) annually between 2010 and 2020. Globally, it kills between [291,000 and 646,000](#) people each year.

The deadliest outbreak ever recorded was in 1918 and 1919.

That [flu pandemic](#) killed roughly 675,000 people in the United States and up to 50 million people worldwide. It also may have infected a third of the world’s population, or about 500 million people. Since then, there have been several other flu pandemics.

READ MORE: [How the 1957 Flu Pandemic Was Stopped Early in Its Path](#)

[Becky Little](#) is a journalist in Washington, D.C. Follow her on Twitter at [@MsBeckyLittle](#).

Ref: https://www.history.com/news/vaccines-diseases-forgotten?fbclid=IwAR1J_i4iKb7jpEp74DmJ9cXWkoTfyZboErzGtMsNpIU9kLHFsHUTDEWnt6g

POLIO: Pain and progress

The Polio History section of our website is quite extensive.

It’s great reading on a cold, wintry day. Check out the following sections:

[Polio History – Articles](#)

[Polio History Video Library](#)

[Daniel J. Wilson, PhD](#)

Putting the Pieces of Polio History Together



Polio, COVID, Compassion and Understanding

We found the need for a response to this excellent article "[Four Diseases You've Probably Forgotten About Because of Vaccines](#)" by the History Channel. As we are actively engaged with Rotarians, we see current photos of struggling polio survivors on a regular basis from the war torn corners of the world. What we rarely see is the reality of what happened here in the US and abroad, not so very long ago.

Our correspondence has more than doubled since this pandemic began. Much of it has been recording and responding to the true compassion and empathy that polio survivors have for those currently experiencing COVID19. Sadly, another piece is the fears that are re-emerging from those who understand first hand what it is to have experienced another insidious virus that has killed or permanently disabled millions of children and young adults all over the world.

As polio "long haulers", the vast majority of us - even those that experienced the most "mild" cases - are living with the lifelong, damaging effects that the virus (long gone from our bodies) left in its wake. We survived. We lived. Polio has no cure and we are truly grateful that it is now a vaccine preventable disease.

We have all seen photos of hospitalized COVID patients looking out of hospital windows. We have heard time and time again that a virus can spread even when the infected person has minimal or no symptoms. We have heard concern that the hospitals could be "overwhelmed". We are now hearing the word "long haulers" being associated with the potential long term effects in those who recover from COVID19. Only history will be able to tell our health care professionals the truth as to what damage this virus is leaving in its path of destruction. We only need to read about the survivors actively engaged in our network to understand the empathy. Pools and schools were closed. Children left with leg braces and crutches were ostracized. Families waited hours in line for the precious vaccine. Fear reigned.

- Jim was completely paralyzed from the neck down at age two. The hospital(s) were "overwhelmed" with polio patients. His parents were told to take him home, live in quarantine and do the best they could. His little brother (an infant) was quarantined on the next floor. The entire neighborhood knew that polio was in that house and once he recovered, no one would befriend the "cripple".
- Deb was completely paralyzed on her right side at age five. The local clinic was full. After a spinal tap, her parents were told to take her to a hospital 100 miles away. They left their frightened, paralyzed little girl with strangers and were told they could only see her on weekends. For the first four weeks (while she was quarantined) they drove 200 miles round trip so they could wave to her through a window from the parking lot. Once she was out of quarantine, they made the same weekly drive for five more months, to visit their permanently paralyzed little girl.
- Joe woke up at age five, partially paralyzed from the waist down. He was in the hospital for two years, and was left alone to learn how to navigate with the double braces and double crutches that would become his new "normal". He did this without his family except for one brief weekly visit (once the quarantine period was over).
- Roger was 12 when he became ill. Because the hospitals were overflowing he was kept at home. After a three-week battle with the virus, much of his right side was paralyzed and he was taken to the hospital. Because there were no open beds, his parents were told to leave their son in the "garage like" building next door.
- Sally had only a "mild", viral like illness. No one knew that she could be inadvertently spreading the poliovirus. No one will ever know if she did. As a "long hauler", the virus caused untold damage and she requires the use of a wheelchair on a daily basis.
- Dan's mother, not permitted to visit, refused to be parted from her five year old son. She got a job working in the hospital kitchen.
- Josephine had a "mild" case of polio at four. She recovered completely and had fond memories of playing in the public rooms and gardens of the Roosevelt Whitehouse. At age 35, her life changed as her gradual muscle weakness changed her life. She became dependent on her wheelchair full time.

- Charlotte, ill at age nine, was diagnosed with Rheumatic fever. Two days later her legs were completely paralyzed. It was polio.
- John was only two when he was confined to an iron lung for 15 months. He went home with a partially paralyzed left arm. At age five, after being hit by a car, the arm was broken. The doctor saw no need to set it as “he’s already crippled anyway”. The arm was now permanently paralyzed. At age 14, he got polio again. He spent nine months in an iron lung. Twice he fell, twice he got up again.
- Arlene was eight when she was taken alone into a dark room where a spinal tap was given to the young, frightened child. It was polio. For fear of exposure to the virus, the ambulance would not take Arlene and another little girl to the hospital. Because the other little girl’s parents owned a funeral home, they were taken to the hospital in a hearse.
- Diane was eight when she had trouble tying her shoes. Later that day, she was sent home from school because of pain. The doctor said she was “seeking attention”. The next day, her grandfather took her to another doctor. Polio. She was taken by ambulance, far from her home, to a hospital for crippled children and placed in an isolation ward. THAT was where she discovered that the pit of fear has no bottom. She was totally alone. The lives of Diane, her brothers and sister and her parents were forever changed with that one word. Immediately, the neighbors withdrew because of “fear”. Her father (active military) was restricted to his base because of “fear”. It was a fear that her entire family carried the disease.
- Nancy was six when she came down with a high fever and a stiff neck. The next thing she knew, she was alone in an ambulance bound for a hospital at the other end of the county. She barely remembers weeks in isolation, where nurses and doctors wearing face masks came and went. There were so many hours with steaming hot packs on her legs that she’ll never forget the smell of wet wool. Sixty years later, she can clearly remember the awful pain of the spinal tap that confirmed the polio diagnosis. “No wonder we polio survivors are so brave and fearless.”

And the stories go on and on. With those stories comes compassion and empathy for what's happening all around us today, at a level very few can understand. With those stories comes gratitude beyond words for the infrastructure that has been created by Rotary International and their partners in the [GPEI](#), not only to end polio, but to embrace the much larger, worldwide focus of Disease Prevention and Treatment.

History . . . It’s something that we will all be a part of years from now.
History will tell the story.

[The Polio Network Team](#) - 2021



PPS and a Glass of Water

A psychologist walked around a room while teaching stress management to an audience. As she raised a glass of water, everyone expected they'd be asked the "half empty or half full" question. Instead, with a smile on her face, she inquired: "How heavy is this glass of water?"

Answers that were called out ranged from 8 oz. to 20 oz.

She replied, "The absolute weight doesn't matter. It depends on how long I hold it. If I hold it for a minute, it's not a problem. If I hold it for an hour, I'll have an ache in my arm. If I hold it for a day, my arm will feel numb and paralyzed. In each case, the weight of the glass doesn't change, but the longer I hold it, the heavier it becomes."

She continued, "The stresses and worries in life are like that glass of water. Think about them for a while and nothing happens. Think about them a bit longer and they begin to hurt. And if you think about them all day long, you will feel paralyzed – incapable of doing anything."

Remember to put the glass down.

“This applies to PPS - Consider using power mobility outside and inside the house. One step at a time. But, don't wait until your legs and/or arms are not stable anymore.” A post from survivor Jann Hartmann



Flo Black

Her life of experiences, travel and caring for others.



I had just returned from a week's vacation at Geneva on the Lake. I was almost eighteen years old and was embarking on a nursing career. While at home, I was preparing to start an "on the floor" study the on the following Monday. Three days prior, I started having a weird sensation on my skin. It continued all day. By evening I was vomiting and had spinal pain. My mother called our doctor who arrived on Saturday morning. He said I had "Rheumatic Flu". I worsened that night and began to have left leg pain. My mother (having read Sister Kenney's polio treatment) wrapped hot towels around my leg all night. By morning I was worse and my right arm was paralyzed.

The doctor returned and tried to get me out of bed. I couldn't move. He had me go to the ER where four doctors checked me out. The doctors thought I had a brain tumor, but one suggested that I get to Pittsburgh to see Dr. Jessie Wright who was a leading orthopedist specializing in rehabilitation.

I was taken to Dr. Wright's office in Oakland where her waiting room was filled with an iron lung, many stretchers and ill patients. She diagnosed me with Polio. This was in 1950 and not many people in Butler, PA had polio. I returned home with my parents. Dr. Wright had me doing daily exercises on my leg and arm but I was not allowed to do stairs for six months. I saw her two more times and by then I was able to walk with a customized shoe.

A year later, I was offered a spot at Butler Memorial Hospital in the School of Radiology Technology. I accepted and began a new life. Although I did not need a leg brace I was left with a limp. I felt very lucky to have gotten through this. Of course, I got the polio vaccine as soon as possible after the onset of my illness, but the damage was already done.

Fast forward about forty years. I had never heard of Post-Polio Syndrome but I had shown some signs of left leg weakness. I decided to cut back and work only two or three days a week. About a month later I tripped at home, twisting my left leg causing me to fall. Looking down I saw my tibia

(shinbone) sticking out of my left leg. That was career-ending for me.

My orthopedic surgeon told me my polio had left my leg without muscle support. My leg was totally shattered. I went through two years of operations and healing.

The forty years prior were as normal as possible, but by this time my parents had passed, and being an only child, I really had to lean on my friends. I returned to Radiology four hours a week as a volunteer. As time progressed, my right leg (my "good" leg) became swollen and painful. My orthopedic surgeon suggested orthoscopic surgery which was not a big deal.

Unfortunately, I but I ended up with a Staph infection. I spent six days in the hospital and left with a port in my arm and two months of infusions with visiting nurses coming twice a week for blood checks.

During my "Post-Polio Life" I had the chance to travel. I was able to visit Hawaii, Alaska and Europe with friends. I have been blessed. Now I live alone with my cat Boots. I read, watch TV (mostly thrillers) and belong to Netflix for movies. (I got my



love of movies from my dad who was a projectionist). I am able to get out for lunch and shopping with the help of a small rollator which I also use at home.

Even with my experiences with Polio and Post-Polio, I have had a good life. I am so grateful to be a member of this organization due to Joe Randig, also a Butler resident and polio survivor.

I hope that the polio vaccine will touch people everywhere and eradicate this disease.

Flo Black, Butler, PA



Owen's Odyssey is A Special Opportunity to Tell YOUR Polio Story

Owen's Odyssey is his Hike to End Polio. It will begin in March of 2021. Rotarian Owen Standley will embark on a hike of the [Appalachian Trail](#) (to be completed in 100 days or less), to raise awareness and funds to eradicate polio through Rotary International.

What does this mean? Within 100 days, Owen will hike from Georgia to Maine (2,190 miles). He has a fundraising goal of \$100,000 for PolioPlus. This is a huge number, as the Gates Foundation, with their two for one match, will turn that into \$300,000.

What can WE do to help?

Owen is asking us, our families and friends to submit personal stories (in video format). He wants to see stories from those who have witnessed polio firsthand. His goal is to show and tell the world, through the personal stories of those affected, why it is so important to eradicate polio. This can be accomplished with a smartphone or simple recording device. He will begin sharing the stories *as soon as possible* as he trains for and builds an audience for his enormous effort.

For social media, short videos are better than long videos (approx. 2 minutes is a good length), but do your best in telling your story. Do not let time hinder your storytelling. Your message is more important. The goal of bringing our stories into this event, is to bring increased awareness for the cause of polio eradication. Owen has a lot of followers on social media, many of whom are not in tune with the realities of this terrible disease. The realities of polio (including the disabling effects of PPS) will help him create a “cause for action” that will increase donations to PolioPlus.

1. Record a video talking about any of the following topics:

- How you contracted polio?
- How polio has changed your life?
- How do you overcome everyday challenges because of polio?
- Describe participating in a National Immunization Day (if you were able).
- Why is it important to eradicate this disease?

2. It's easy to record a video (or) audio:

- Use your phone, recorder or computer.
- Email it to and info@polionetwork.org
 - Save to and send an mp3 or mp4 video file
 - Send a compressed file of your video (if necessary)
- Post it to your own Facebook/Instagram*

Send your video as soon as possible. As Owen goes through training process, we can help him educate people as to WHY this is necessary.

We are going to be featuring your stories on a special new page of our website:

[Survivor Stories – In Our Own Words](#)

Let's join Owen as he embarks on this amazing journey.

We ARE a part of the solution.

“Long Haulers”

“Post-Polio experts also see a resonance between polio and the coronavirus currently affecting the world, particularly in the experience of so-called long-haul COVID-19 patients who have lingering symptoms for many months, or longer.”

[Sarah DeWeerd for Medscape](#)

In our article on Page 4, we refer to this relatively new term. If you're not familiar with it, you may be interested in this outstanding article:

[Warning for COVID Long Haulers from Polio Survivors](#)

This Outstanding Article from Medscape features interviews with many friends of our Network.

Note: Medscape may ask you for an email address and password. It's a one time sign in, there is NO cost involved.



Thank you for your kind words and generous [donations](#).

January



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