PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

October, 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 Pain and Post-Polio – PPS is *always* a diagnosis of exclusion. Sorting out the cause of the muscle pain that comes to many polio survivors isn't necessarily easy – for even the most experienced health care professionals. This month, we welcome Mark A. Lopatin, MD, a highly experienced rheumatologist – which is a specialty that often sees patients with muscle pain. Dr. Lopatin understands how difficult these diagnoses can be. In his article, he explains what it's like to be a medical detective and the important steps a physician goes through when a polio survivor seeks their care.

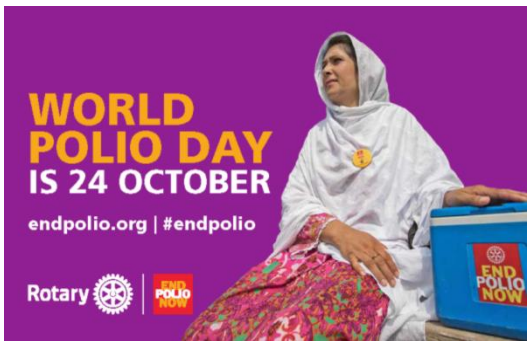
Polio Reported in the United States – By now, we've all heard the news regarding the poliovirus, once again, harming children in Israel, the UK and the United States. Marny K. Eulberg, MD wrote an outstanding article (published by Post-Polio Health International) in July. She has updated that article, and clearly explains the most up to date information.

Serving the New York community – We were contacted by Montebello Media to see if there were survivors from our network who were born in New York and who would help them create a message for vaccine hesitant parents in the Rockland County New York area. Within hours you responded. As of this date of publication, three posters have been distributed throughout the four counties in NY with low vaccination rates and where the poliovirus was discovered in their sewage. That message by Bonnie Kittle, Ann Melone, John Nanni and Norma Sepulved has been published in English, Spanish and Creole – the three languages necessary to serve their community. Creole was a little more difficult, but Rotarians (as always) were there to serve and support that translation effort. Thank you EVERYONE for being so willing to respond to the call so quickly.

World Polio Day – October 24, 2022 : "The solution to stopping all polio outbreaks globally is the same whether they are caused by WPV or VDPV. Vaccinate."

- "Continued support for the successful completion of the Global Polio Eradication Initiative is critical to eliminating the threat of any live poliovirus."
- "The absence of high vaccination coverage anywhere poses a risk everywhere."

The New England Journal of Medicine October 5, 2022



If ever there was a year to join Team Survivor, this is it. There is only one cure for this terrible disease: Vaccination.

As survivors, we know that even one more child experiencing the lifelong realities of the poliovirus is too many. When we support the Rotary Foundation's efforts to eradicate polio, we are donating to one of the most highly rated charitable organizations in the world. Every dollar you give will be turned into three by the Gates Foundation. NO amount is too small.

- Donate to Team Survivor by US Mail: Make your check out to The Rotary Foundation
  - Mail to: PPSN - Team Survivor, PO Box 557, Doylestown, Pa. 18901
- Note: Are you a Rotarian? When you donate to Team Survivor your donation will be credited to you, your Club & District.

Together with our families and friends, we *have* become a part of the solution. Join us.

June, 2022. Polio Reported in the United States

Marny K. Eulberg, MD

By now, the majority of you in our polio survivor community have already heard the news that a case of acute polio has recently been confirmed in Rockland County, New York. More information will likely come forward, but what we currently know is that one of the United States' newest polio survivors is an adult male who was unvaccinated, developed the first symptoms in June, and was infected with an oral polio vaccine-derived type 2 poliovirus.

Reportedly he had not traveled abroad, although some reports now are saying he had traveled to Europe. The type of poliovirus that caused his paralysis is what is called "circulating vaccine-derived poliovirus" (cVDPV). That means it was imported into the U.S. from somewhere in the world where the oral polio vaccine is still used. It has become more common, although still rare, in parts of the world where the oral (Sabin) polio vaccine is used, where there are large numbers of unvaccinated or under vaccinated individuals, and especially where there is inadequate sanitation and access to clean water.

Globally, there were 1,113 children diagnosed with paralysis from polio caused by the cVDPV viruses in 2020, 689 in 2021, and 359 as of 9/28/22. These individuals, mostly children, are just as paralyzed as they would have been had they been infected with the "wild"/occurring-in-nature polioviruses. This NY case demonstrates that we, in the developed world, can still see cases of acute polio anywhere that there is inadequate immunity to polio. A recent report that sewage samples in London had shown presence of circulating vaccine-derived poliovirus type 2 (a similar type to that implicated in the NY case) stimulated concern that polio could show up in parts of the world that have not seen polio for decades.

Organizations dedicated to polio eradication such as Rotary International and the Global Polio Eradication Initiative (GPEI) - of which Rotary is a partner, often quote the sayings, "Any form of poliovirus anywhere is a threat to children everywhere" and "Polio is just an airplane ride away." Most polio survivors do not need to be convinced of the value of polio vaccines because they have seen the devasting effects these nasty viruses can have.

A course of three doses of any form of polio vaccine has been demonstrated to be 99% effective in preventing polio. There are several advantages to using the oral polio vaccine. A novel oral polio vaccine type 2 (nOPV2) has been developed that is much less likely to mutate when out in the environment, and cause vaccine-derived disease as a result.

The United States stopped using all oral polio vaccine in 2000 and switched back to the injectable (killed) (Salk) polio vaccine. There is NO risk of cVDPV when the polio shots are used instead of oral polio vaccine drops (or remember the "sugar cubes" with the polio vaccine drops were placed on top) Some of you who have traveled to developing countries in the past few years may have been surprised to learn that an additional booster dose of polio vaccine was recommended before travel to certain countries even though you had had the disease and had been fully immunized for polio. This is an extra precaution because of the theoretical risk of exposure to wild poliovirus or the circulating vaccine-derived poliovirus.

For the past five years, wild poliovirus cases (Type 1) have been confined to Pakistan and Afghanistan, but in late 2021 and in 2022 there has been one case in Malawi and 6 in Mozambique. As of 7/28/22 there have been 27 individuals paralyzed by wild polio virus. Circulating vaccine-derived polioviruses (mostly Type 2) have been reported in nearly 30 countries including in many parts of Africa, Southeast Asia, Israel, Ukraine, and the Arabian Peninsula.

The bottom line is that this case in New York presents *no* threat to those who have been immunized but is a reminder that polio is not yet "gone". It is unfortunate that this man now is suffering from a

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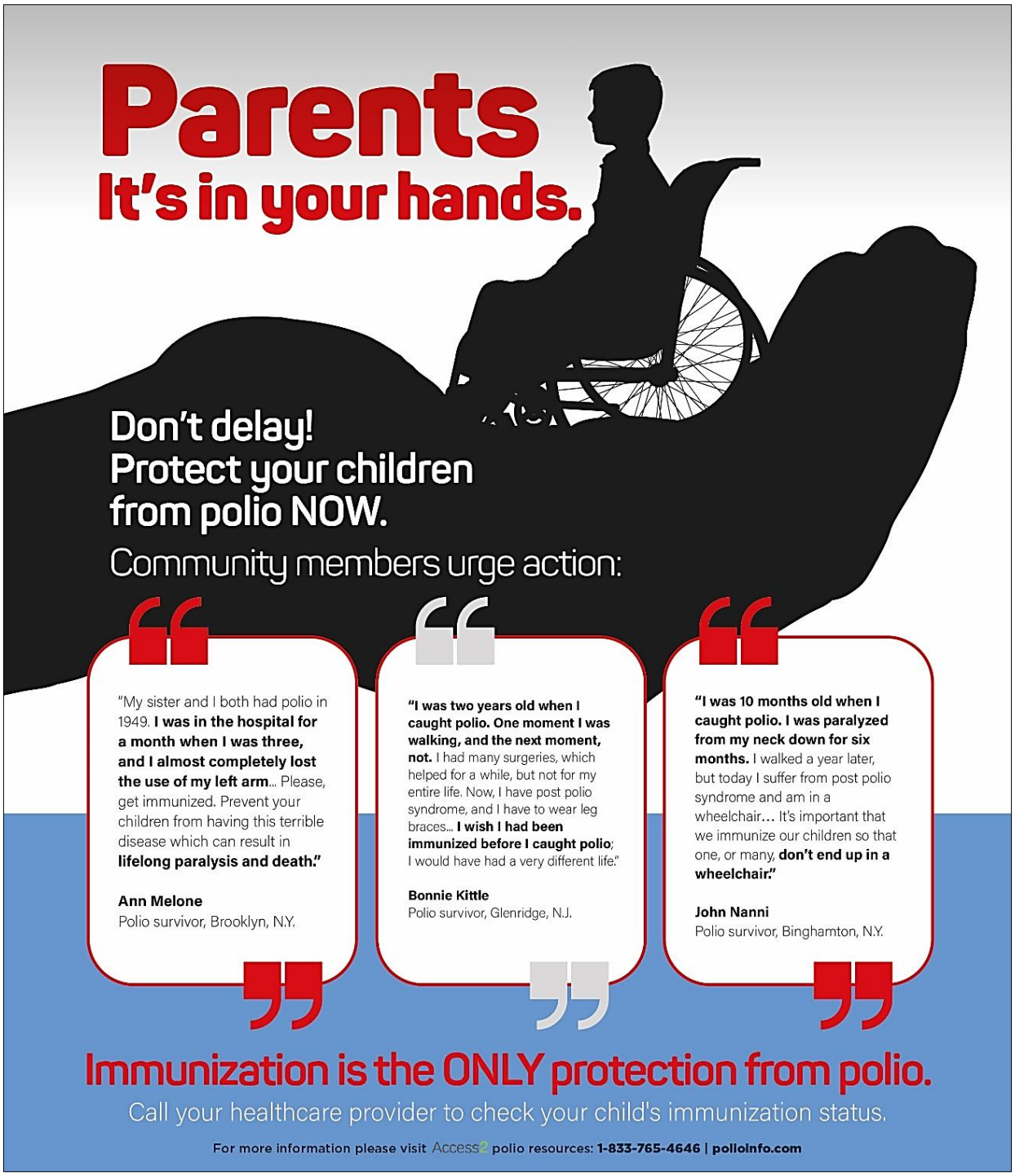
vaccine- preventable illness! Although this will be life-changing for this young man and his family, the good news is that despite poliovirus being detected in the wastewater of several counties around the New York City area to date there have been no more confirmed cases of paralysis caused by polio.

For up-to-date information about polio and the eradication efforts, go to www.polioeradication.org

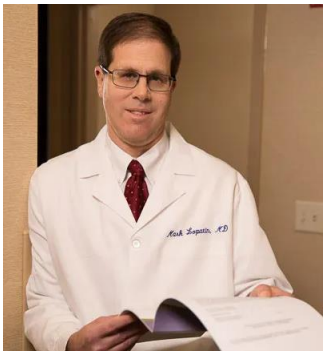
This article was originally published by Post-Polio Health International, July 2022.
Revised and updated from the original by Marny K. Euberg, MD October, 2022

You can see an extensive number of articles and videos by Marny K. Eulberg, MD in the Primary Care Perspective section of our website.



Thank you Montebello Media for asking us to participate in this project. No child should suffer from a vaccine preventable disease. The pain and disability *can* last a lifetime.

Muscle Pain, Post-Polio and The Importance of Being a Medical Detective



Mark A. Lopatin, MD

A 70 year old female patient, whom I will refer to as RA, presented to me with widespread pain, generalized fatigue, and muscle weakness. She had a history of hypothyroidism along with polio as a child which had left her with a residual of right lower extremity weakness. There was also a history of underlying depression. Her only meds were Synthroid, and Zoloft. The pain had started about 3 years prior to her seeing me, but was finally reaching the point where she felt it needed to be investigated. She also noted a decrease in strength which manifested as increased difficulty with walking and getting up from a chair. This was separate from her chronic right leg weakness. The differential diagnosis was extremely broad, but as a rheumatologist, my job is to be a medical detective.

The process starts with a complete history and physical exam, looking for evidence of an underlying etiology.

There are several parts to obtaining a medical history. First, I ask all kinds of questions relevant to the patient's major complaints, in this case, pain and weakness. When and how did RA's symptoms start? Was the onset gradual or sudden? Was her pain muscular or joint related? Had she experienced any joint swelling? Was the illness limited to the musculoskeletal system or was it part of a bigger picture? These were just some of the questions that needed answers as I attempted to narrow down the diagnostic considerations.

The next step is the patient's past medical history. Are there other conditions that might relate to what she is experiencing now? Examples might include a prior diagnosis of cancer, which would raise concerns of recurrence as a cause of her symptoms, or a history of sexual assault which could be a clue to fibromyalgia. Is she taking any other medications such as Lipitor which can cause muscle pain and weakness? Is there an underlying history of any arthritic conditions? Is she up to date with her cancer screenings? All of these questions further help to define the possibilities. RA's history was unremarkable except for the thyroid disease and depression which were already areas ripe for questioning. In doing so, I learned that both were generally stable entities, and were not likely playing a role in her current symptoms.

I also routinely go through a complete review of systems, looking for other symptoms not specifically related to why the patient came to see me, which might provide a clue. Symptoms such as excessive thirst or urination, might steer me towards diabetes. Blood in the stool, a breast lump, or a history of smoking might be a clue to an underlying cancer. And so on.

RA's physical exam revealed normal joints. She had diffuse muscle tenderness and she did indeed have difficulty getting out of a chair. Strength testing revealed some deficits beyond the chronic right leg weakness from the aforementioned polio. Physical exam was otherwise not particularly helpful.
After the history and physical, the physician must determine what blood work, imaging, and other studies are necessary. X-rays are rarely helpful in a case of widespread pain, but labs can provide significant clues towards an underlying etiology. RA's blood count, urine, and chemistries were normal as were her thyroid studies. Markers of inflammation, which if elevated can suggest an underlying systemic disease, were normal. Given her complaints of weakness, I checked muscle enzymes looking for muscle damage. They were also normal. I was left with a patient with various complaints, but no specific evidence of an active disease.

It is very easy to write patients like this off. Patients are often labeled as having either depression, anxiety, or fibromyalgia, or they may be told, "It's all in your head." After all, if I can't find an etiology as a

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physician, it must not be present and the patient must be either imagining it or making it up for attention. Frankly, I find that attitude to be the height of arrogance. Fortunately, it is the exception rather than the rule.

Fibromyalgia (FMS) is a specific diagnosis which is often made as a diagnosis of exclusion in patients with widespread pain and fatigue. Labs are normal, and there are no objective findings on exam other than tender points in a characteristic distribution. There is often a history of depression or anxiety and it is amazing how many times patients report a history of sexual or physical abuse (if the physician asks about it). Patients with FMS do not have objective weakness as RA did. Furthermore, her tenderness did not fit the characteristic distribution. FMS remained a possibility, but RA's presentation was not classic.

Patients with widespread pain often have underlying psychosocial issues. RA was being treated for depression, but my sense was that this was not playing a role in her current symptoms. Again, depression should not cause objective loss of strength. Patients such as RA often get discounted and shuttled off to the psychiatrist with the idea that "there is nothing really wrong with them." I have often maintained that the one thing a physician can do for every patient regardless of what they may or may not find on evaluation is to validate the patient's suffering, even if the physician does not know why it is present.

So now what? Thyroid disease and depression were off the table as were underlying forms of arthritis and systemic diseases like diabetes. Should I treat her for FMS even though it was not a classic presentation? Should I recommend that her meds for depression be changed, which would be beyond the purview of a rheumatologist. Should I get more invasive tests such as a muscle biopsy even though her labs were normal, also keeping in mind that myopathies are usually painless? These are the kinds of decisions physicians must make on a daily basis, as we weigh the risks and benefits of potential actions.

My patient asked me if her polio could be playing a role. As a rheumatologist, I had very little knowledge of post-polio syndrome, so I could not discount it as a possibility. I could not tell her yea or nay, so I decided to follow her to look for other developments. Over time, illnesses that were not present at the initial visit can declare themselves. In the meantime, I did some reading on post-polio syndrome and sent her for physical therapy. As I saw RA at subsequent visits, I got to know her better. It became clear that depression absolutely was not the issue and that she did not have fibromyalgia. Follow up blood work was also unrevealing. In the absence of a firm diagnosis, I opted not to treat her medically for any condition such as FMS that I did not think she had. I certainly was not about to put her on pain killers. I never made a firm diagnosis on RA and it was ultimately presumed that her symptoms were due to post-polio syndrome. I learned from my reading that this can look very much like hypothyroidism, fibromyalgia, or even an underlying cancer. It is critical that entities such as these are excluded. There is no specific test to prove this diagnosis, so it becomes a diagnosis of exclusion in the right circumstances. Patients typically present many years after the diagnosis of polio with the gradual onset of widespread pain, fatigue, and/or progressive weakness. There may be other symptoms such as cold intolerance. They may have difficulties with breathing, walking, or swallowing depending on which muscles are affected. The key factor in this case was objective weakness. I did not have much to offer her medically, but what was important was that I excluded other conditions and did not expose her to the risks of treatment for conditions she did not have.

The most important thing I could offer RA was validation. I listened to her, engaged her, and excluded a multitude of diagnostic possibilities. As it turned out, that in and of itself proved to be of significant benefit to her. I can honestly say that even though I did not treat RA medically, I helped her. As a physician I can't always resolve the issue, but one thing I can always do is care for and about my patients. Sometimes the caring is more important than the curing.

Mark A. Lopatin, MD

Routine Vaccines, Extraordinary Impact: Polio

Polio cases have nose-dived by 99% since the late 1980s after a push to eradicate the disease, but clusters of cases across the world indicate that it could resurge if we don't double down on eradication.

By Priya Joi 25 July 2022

"The discovery in the summer of 2022 that poliovirus had been found in sewers in London as well as in an unvaccinated community in New York startled many who had long forgotten about polio. The outbreak was a perfect demonstration that vaccines are often so successful at stopping deadly diseases, that we can be lulled into a false complacency.

Although the disease is now endemic only in Afghanistan and Pakistan, it was a dangerous childhood disease across the world for much of the late 19th and early 20th centuries. Although polio vaccines were introduced as routine immunisations in the 1970s, which reduced cases substantially, by the late 1980s, polio still was paralysing over 1,000 children a day.

In 1988, the launch of Global Polio Eradication Initiative (GPEI, of which Gavi is a member) had a galvanising effect on efforts to eliminate the disease, bringing together governments, donors, local communities and health workers in a joint effort to raise awareness of the disease and widen access to polio vaccines.

Cases began to drop dramatically and are down 99%, with most countries having zero cases. An estimated 20 million children have been prevented from getting polio since the GPEI was launched. When Nigeria was declared free of wild poliovirus in 2020, it was a major achievement: it had been one of the last few countries where the disease had clung on.

As remarkable as these successes have been, polio experts warn that there is no room for easing off on eradication efforts until the world is polio-free. Infectious diseases that are nearly wiped out can bounce back with alarming ease when the global circumstances change – measles rates have started climbing in the past few years as vaccination rates have fallen in Europe and the US.

Uneven polio vaccine coverage across the world, compounded by the COVID-19 pandemic's toll on routine immunisation worldwide, has meant the disease has popped up in unexpected places. In October 2021, Ukraine saw an outbreak, followed by a case of wild poliovirus in February 2022 in Malawi. In March, vaccine-derived polio was spotted in Israel, and in Pakistan, where the disease is still entrenched, more polio cases were recorded in the first quarter of 2022 than in the whole of 2021.

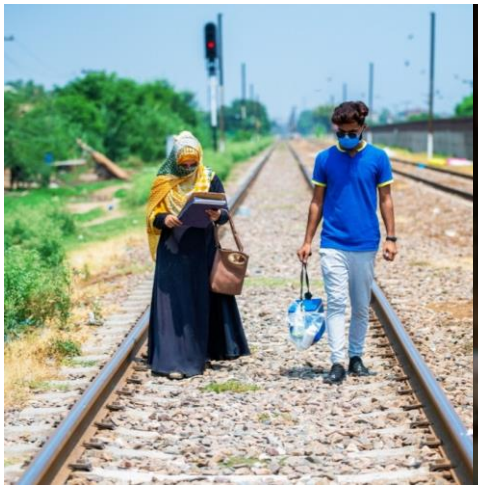
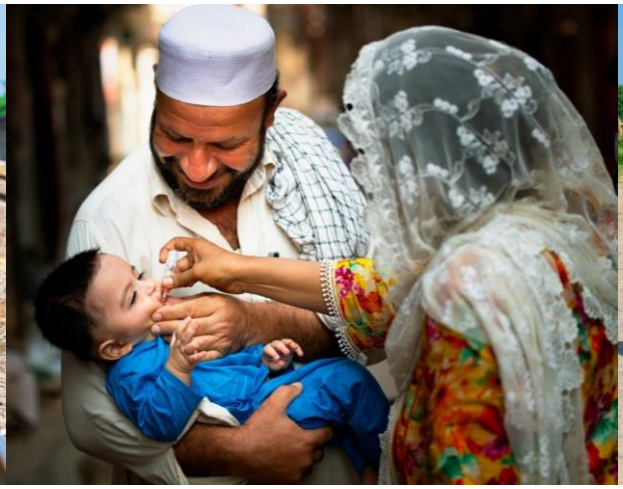
Although polio only affects a handful of countries currently, the potential threat from its continued circulation means that the World Health Organization still classifies it as a Public Health Emergency of International Concern (PHEIC) despite this classification being given back in 2014.

An Ancient Disease

Polio is one the world's oldest diseases – 14th century Egyptian engravings have been found depicting a priest with a withered leg, the trademark of a disease that can paralyse the leg, leading to muscle weakness and shrinking. The British physician Michael Underwood produced the first clinical description of the disease in 1789. In 1840, the German orthopaedic doctor Dr Jacob Von Heine understood that poliomyelitis was a distinct disease from other forms of paralysis and theorised it had an infectious cause. The poliovirus that causes the disease was identified in 1909 by Austrian immunologist Karl Landsteiner. The disease is caused by a highly infectious virus that spreads when people ingest food or water contaminated by human feces, or through poor hygiene. Because of this it is common in areas where there is poor access to clean water and sanitation."

"Although polio only affects a handful of countries currently, the potential threat from its continued circulation means that the World Health Organization still classifies it as a Public Health Emergency of International Concern (PHEIC) despite this classification being given back in 2014."

Source: Gavi


Many Faces, One Mission: Polio Free for Every Child !

Polio workers operate in difficult and challenging conditions, to reach and protect every last child from the crippling virus. The whole nation is indebted to you for your efforts.

Thank you Susanne Rea for sharing this from the Pakistan Polio Eradication Initiative.

A Reason

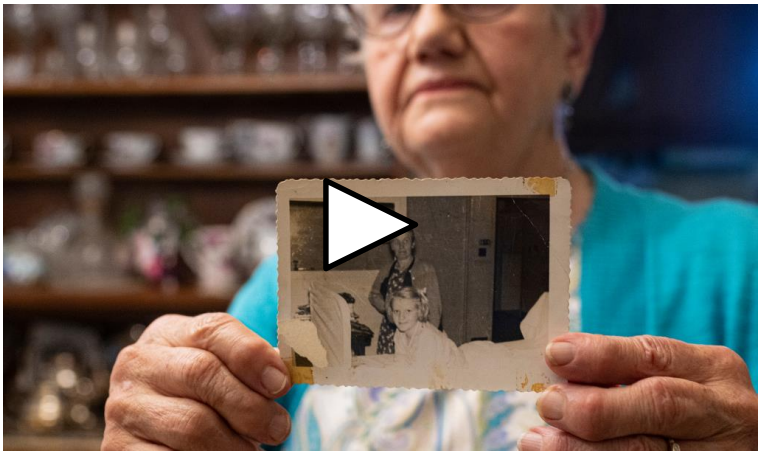
By Donald E. Hunter

Can't change bygone days.
But we can dream of what could have been.
Things happen for a reason.
That's what they seem to say.
Making sense of how things go seems a fruitless task at times.
When things happen
Some we change
With no control of others.
They just happen.
All have struggles some more then others.
Some make us stronger
Others take a toll.
Higher tolls are paid by some
But not by others.
In the end we are free, pain is gone, to walk like others,
Our debts are paid
We pay no more.

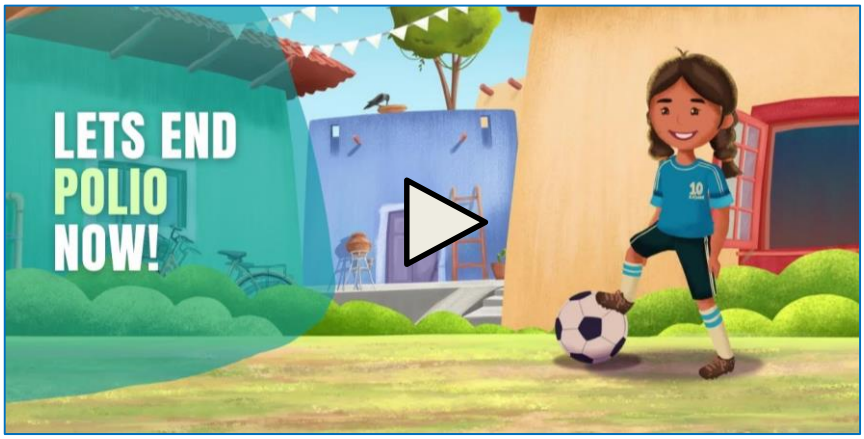
Thank you survivor Donald E. Hunter for your special work.
You can find his poem
Have You Ever Wondered? in the Survivor Story section of our website.

'WE ARE STILL HERE'

“These Philadelphia area polio survivors continue to suffer from a disease thought to be long gone.”



The Philadelphia Inquirer



THANK YOU for your kind words. This is the inspiration that keeps us moving forward.

Always feel free to contact us.

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