



# Polio Survivors Serving Others

Information & Inspiration  
For All Polio Survivors and their Families

The PA Polio Network

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

February, 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:

**“African-Americans, Polio and Racial Segregation”.** Prior to his death in 2021, historian (and polio survivor) Daniel J. Wilson, PhD, wrote the article with this title and we loved realizing how much the article meant to him. We are grateful to have had the opportunity to work as his photo “assistant” to find sourced images to accompany his work. Always the professor, he explained each and every image he chose for this historical reference.

February is Black History Month in the US and is the perfect time to share his article. Black History Month is an annual celebration of historical achievements by African Americans. Since 1976, every U.S. president has officially designated the month of February as Black History Month. (Other countries around the world, including Canada and the United Kingdom, also devote a month to celebrating Black history.)

**Foot Drop (sometimes referred to as “drop foot”) is something many polio survivors share.**

What IS foot drop? Physical therapist Janet Drake Whalen, PT, DPT explains what it is and why a rehabilitative medicine assessment can be so valuable.

**Your Stories are being shared:** Last summer, we were contacted by the Advocacy & Education Director from [Vaccinate Your Family](#). She wanted to learn more about our Mission of Service and why we are so passionate about our advocacy work, bringing support to polio survivors and speaking out about the importance of pediatric vaccines. The call came shortly after polio had paralyzed a young man in New York and two of us had just returned from visiting a community in our state that has a very low pediatric vaccination rate. We had learned a lot about that community and hoped we had shared with them the reality of the life long effects of polio.

Engaging with such a reputable foundation was a pleasure. They asked for permission to publish stories from our website. With the permission of each of those survivors, the stories have now been shared.

“Vaccinate Your Family (VYF) builds on the important legacy of Former First Lady Rosalynn Carter and Former First Lady of Arkansas Betty Bumpers. Together, these pioneers worked to advance a national focus on protecting all people in the United States from vaccine-preventable diseases.” Their mission is clear.

***“As long as a single person gets sick from a vaccine-preventable disease, our work is not done.”***

Founded in 1991, Vaccinate Your Family (VYF) is a national nonprofit organization that strives to protect people of all ages from vaccine-preventable diseases by:

- Raising awareness of the critical need for timely immunizations
- Increasing the public’s understanding of the benefits of vaccines
- Increasing confidence in the safety of vaccines
- Ensuring that all families have access to lifesaving vaccines
- Advocating for policies that support timely vaccination

We would love to share YOUR story. Feel free to send us a few paragraphs along with some photos. You can easily see the many (long and short) stories we’ve published on our [website](#):

[www.polionetwork.org/our-stories](http://www.polionetwork.org/our-stories).

Telling your story can help others. We’re not alone.



Vera

While traveling abroad at age 22, Vera was diagnosed with polio. Later in life, she developed post-polio syndrome. →



Nancy

Nancy had polio in 1950 when she was six years old. Physical therapy allowed her to walk again. →



John M.

Due to his illness John has used crutches for 65 years and developed post-polio syndrome. →

“In 1950, Vera was 22 and had been traveling through Europe with her college roommate. After her energetic first day in Rome, she got out of bed and fell to the floor, unable to get up. Something was very wrong. She asked the American Embassy for an American doctor. A physician arrived and diagnosed spinal meningitis.

Twenty-four hours later, she was paralyzed from the waist down. This time they sent an Italian neurologist. He spoke no English and she spoke no Italian. It was polio. He took her to his clinic (which turned out to be a mental institution). Placed in isolation, she was confined to bed for a month in a foreign country. The doctor said they had no experience in Italy with polio in adults because they believed only children got polio.

Vera returned home to the U.S. and with physical therapy, she was able to walk again on her own within a year. Later in life, Vera developed post-polio syndrome.

Read her [full story](#) on the Polio Survivor’s Serving Others website.”

“In 1950, 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. She says, “No wonder we polio survivors are so brave and fearless.” Later in life, Nancy developed post-polio syndrome. Read her [full story](#) on the Polio Survivors Serving Others website.”

“One day John was an active 12-year-old riding his bike, playing baseball, and climbing trees. The next day, he remembers feeling bad, missing school, developing a limp, and being in an ambulance on his way to the hospital. He went to the Industrial Home for Crippled Children in Pittsburgh, Pennsylvania for rehabilitation. He was in a ward with five other boys, one with tuberculosis, two with cerebral palsy, and two other polio patients. The first step in the recovery process came from a physical therapist who put John through a very painful process, seven days a week, working to and past the point of pain for every muscle affected. Once a week they went to the pool. There he was put onto a submerged board where a physical therapist would work him over. John was fitted for braces, given a wheelchair, and finally returned home to attend 8th grade. As a result of his illness, he has used crutches for 65 years and was diagnosed with post-polio syndrome at age 79. Read his [full story](#) on the Polio Survivors Serving Others website.”



Deborah

*Deborah remembers being 5 years old when her parents had to leave her at the hospital.*



John N.

*John caught polio as an infant in 1953; he's now a passionate advocate for immunization.*



Richard

*Richard Daggett was 13 years old when he got polio; that day was the beginning of a life-long journey.*



“Deborah was completely paralyzed on her right side at age five. There was no hospital in her town, so her parents were told to take her to a hospital 100 miles away. After a spinal tap confirmed Deb had polio, her parents had to leave 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. Over the course of her life, Deb has become a passionate advocate for polio survivors, even as she experiences post-polio syndrome. Read her [full story](#) on the Polio Survivors Serving Others website.”

“In 1953, at 10 months old, John came down with polio just six months before the Salk vaccine was widely tested. He was paralyzed from the neck down and hospitalized. Over the course of a year, his mother cared for him and with physical therapy, John was able to finally walk. Throughout his childhood, most people didn't realize John had suffered from polio. He went on to play sports in high school, but around age 40 began experiencing muscle weakness and fatigue. After two years, he was eventually diagnosed with post-polio syndrome. He is a proud Rotarian and as a passionate advocate, he continues to raise awareness about the importance of vaccination. You can listen to John's [full story](#) on YouTube, courtesy of the Polio Survivors Serving Others website.”

“Richard was 13 years old when he got polio the summer before eighth grade. After a day of headaches, he woke up with a neck and back so painful and stiff that he couldn't get out of bed despite the beautiful summer weather.

That day was the beginning of a long journey for Richard. Polio meant the teenager underwent a tracheotomy with only a local anesthetic, spent months in an iron lung, and endured years of intensive physical therapy. Through it all, he maintained his positive outlook and determination to return home to live a long, full life.

Richard shared an excerpt of his memoir, [Not Just Polio](#), with Vaccinate Your Family. Please take a moment to read his incredible story of perseverance. [>> Read the excerpt from Not Just Polio](#)”







## African-Americans, Polio and Racial Segregation

By Daniel J. Wilson, PhD

### [Putting Together the Pieces of Polio History](#)

Many physicians in the early twentieth century believed that African-Americans were less susceptible to polio, or infantile paralysis as it was then called. They came to this conclusion because they saw fewer Black patients in their practices. Later work by scientists and historians has determined that Blacks were about equally susceptible to polio as whites, and that the differences noted by physicians at the time had more to do with the impact of Jim Crow segregation rather than some biological difference in susceptibility. Before World War II most African-Americans lived in the Jim Crow South where there were fewer polio epidemics. Most polio epidemics in these years occurred in the Northeast and the Midwest which were overwhelmingly white. In addition, because of segregated medical practices and facilities, Blacks were less likely to be treated and much less likely to be treated by white doctors engaged in polio research. There were relatively few Black physicians in this era and almost none participating in polio research.

The medical historian Naomi Rogers noted that in the 1930s the neglect of Black polio patients became “publicly visible and politically embarrassing.” Few facilities in the segregated nation treated Black patients and few Black physicians and physical therapists were available to provide treatment. The result was that most Black polio patients received no care or substandard care. This situation became politically embarrassing in connection with the polio rehabilitation center Franklin D. Roosevelt had established in Warm Springs, Georgia, in the heart of the Jim Crow South. Although African-Americans contributed substantial funds to the President’s Birthday Ball campaigns that funded Warm Springs, they were not admitted as patients to the facility. During and after Roosevelt’s 1936 campaign for re-election, Black leaders publicly protested this injustice.

According to letters in the Roosevelt Library from Basil O’Connor, the head of the March of Dimes, to President Roosevelt, O’Connor took up the issues of black exclusion from Warm Springs in spring 1937. After soliciting advice from the Warm Springs Board of Trustees and from Henry Hooper, the administrator of Warm Springs, O’Connor informed the President the facility did not and would not admit Blacks as patients. In the mid-1930s all of the patients, medical staff, and administrators at Warm Springs were white. However, 43 of the 93 employees were African-American. The Black employees were restricted to service roles such as maids, waiters, push boys (who moved patients around the facility), laundry workers, janitors, and groundskeepers.

A letter from Henry Hooper to O’Connor put the case against Black patients at Warm Springs. Hooper assumed that to admit Black patients would require Warm Springs to maintain racial segregation. Accordingly, admitting Black patients would require building a separate cottage to house 8-10 patients and a separate pool in which they could receive the hydrotherapy that was key to the Warm Springs treatment. A separate pool alone would cost some \$3,000 (\$53,000 in 2020). They would also require separate African-American staff including a graduate nurse, an attendant, a physical therapist, an automobile driver, a maid, and a cook. Hooper also noted that Black graduate nurses and physical therapists were almost nonexistent. Other factors arguing against Black admissions included the fact that many Black patients had received inadequate care in the early stages of their illness and thus were unlikely to benefit from the kinds of therapy that Warm Springs offered. Hooper also worried that poor Black families would be unable to provide proper care after patients were discharged from Warm Springs. Finally, there was the matter of cost. Warm Springs patients were expected to pay for their care and Hooper argued that most Black families would be unable to pay for their child’s care at Warm Springs. He assumed



Margaret Bourke-White: Unpublished photo from the Warm Springs series, 1938



White guests and black waiters at Warm Springs dining room, c. 1950. Source: March of Dimes Archives, White Plains, NY.

that most would be charity cases and Warm Springs would have to assume the cost. He estimated that caring for 8 patients a year would cost the facility about \$18,000 (\$320,000 in 2020). Such a sum would only add to the annual deficit and detract from the already existing programs for white patients. Hooper suggested that a better solution would be for the March of Dimes to establish a segregated rehabilitation facility for Blacks at a Black institution.



James Clark Allen, March of Dimes poster child, 1955. Courtesy of March of Dimes

In passing Hooper's recommendations to the President, O'Connor commented that it was his understanding that Blacks were less susceptible to the disease than whites, implying that they thus needed less care. He also complained that the objections to the absence of Black patients at Warm Springs came largely from what he called "professional colored promoters" and "sob-sisters connected with institutions such as Teachers College at Columbia University." In another letter to the President, O'Connor endorsed Hooper's suggestion of establishing "relations with an institution already equipped for the care of colored people."

To his credit, O'Connor did move relatively quickly to provide funds for a facility to treat Black polio patients with the most up to date methods. In 1939 he announced that the March of Dimes would provide \$161,350 (\$2,864,000 in 2020) to create a modern rehabilitation facility for Blacks at the nearby Tuskegee Institute in Alabama. This was a college and trade school for African-Americans established by Booker T. Washington following the Civil War and the end of slavery. This facility would provide care for Black patients as well as training in polio treatment for Black physicians, nurses, and physical therapists. The Tuskegee facility opened in January 1941. Once opened, it clearly provided the best polio care available to Black patients in the segregated South, but the overall number of patients treated there was relatively small. For one thing, it was difficult for many Black families to transport their children long distances to Tuskegee and to pay for their care once there.

\*In an interesting side note, O'Connor in the 1940s became president of the Tuskegee Institute Board of Trustees.

An exception to the segregation of polio treatment in the South occurred in Texas. Texas generally practiced racial segregation, but somewhat less rigidly than other states. In 1941 citizens and physicians in Gonzales, Texas, east of San Antonio, established a polio rehabilitation facility modeled on the Georgia Warm Springs facility which they called the Gonzales Warm Springs Foundation. Unlike their Georgia counterpart, the Gonzales facility admitted white, black, and Latino patients equally. According to historian Heather Wooten, the Gonzales institution was the only racially integrated rehabilitation in the nation at its founding. At least two other Texas institutions that treated polio patients in the 1940s were also racially integrated. The Texas Scottish Rite Hospital for Crippled Children in Dallas and the Jefferson Davis Hospital in Houston had integrated polio wards for children. Ironically, the Jefferson Davis Hospital was named for the president of the Confederacy. When the March of Dimes established the Southwestern Poliomyelitis Respiratory Center at Jefferson Davis Hospital in 1950 it admitted Black, White, and Latino polio patients, adults as well as children. These centers were established across the nation to centralize the treatment of polio patients in iron lungs and were the precursors of intensive care units. Wooten speculates that Texas was more accepting of racially integrated polio facilities because of the complex racial mixture of White, Black, and Latino in the state and because the facilities were not tied to the political fortunes of a president who needed the support of racist Southern white Democrats.



In 1939, the National Foundation for Infantile Paralysis supplied funding for a center at Tuskegee Institute in Alabama, where black patients could go for treatment. Courtesy of March of Dimes and National Museum of American History

The rigid racial segregation of polio patients began to break down during the 1940s. During the massive 1944 polio epidemic in Hickory, North Carolina, the March of Dimes established a polio hospital that was racially integrated. By 1945 at least some Black children were being treated at Warm Springs. In the mid-1940s, the March of Dimes hired an African-American, Charles H. Bynum, to coordinate the organization's inter-racial



activities. Bynum pushed the organization to include Blacks not only on the fundraising side, but also to ensure that they had access to the treatments funded by the March of Dimes. When the March of Dimes supported the 1954 trial of the Salk polio vaccine, Black children were included in the trial. However, there were still inequalities. In some Southern cities where the Salk shots were given in school auditoriums, black children



A second grade girl receives a poliomyelitis vaccination during the 1954 field trial in Laurel, Miss.

Source: Winifred Moncrief Photo Collection

were forced to take their shots on the front lawn since they were not allowed into the white school buildings. Blacks were also included in the Sabin vaccine campaigns in the early 1960s.

Although it is clear that polio was no respecter of artificial racial distinctions, it is also clear that African-American children and adults who contracted polio in the first half to the twentieth century received inferior care in both the acute and rehabilitative phases of their disease.

Black hospitals were almost always inferior in both the facility itself and in the physicians and nurses who provided the care. There were simply not enough well-trained Black medical personnel to provide the necessary care. Black polio patients in northern cities were more likely to receive better care, but even here they might be confined to segregated wards in white hospitals. The

situation began to improve only when Black leaders and physicians publicized the inequities and embarrassed the March of Dimes, which provided much of the funding for polio care and treatment from 1940 to 1955, into moving to provide access to up to date care and treatment.



March of Dimes official Charles H. Bynum accepting a check from Mrs. J.A. Jackson, secretary of the Grand Chapter of the Order of the Eastern Star of Virginia, December 3, 1955.

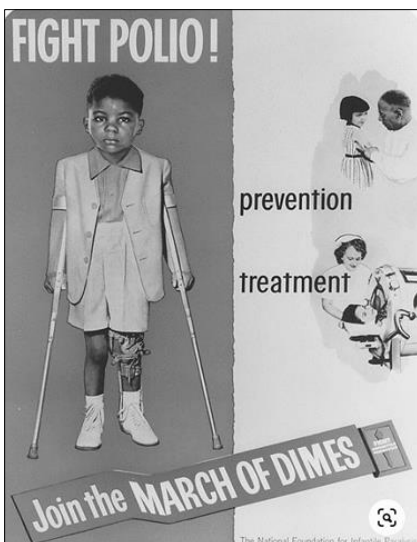
Source. Afro-American Newspaper Archives and Research Center, Baltimore, Md.

Source Notes:

1. The Basil O'Connor letters to President Roosevelt are in the Roosevelt Presidential Library in Hyde Park, New York.
2. On Georgia Warm Springs, see:
  - Naomi Rogers, "Race and the Politics of Polio: Warm Springs, Tuskegee, and the March of Dimes," *American Journal of Public Health*, Vol. 97, No. 5, May 2007 (The article is available through Google at Tuskegee polio.)
3. For polio in Texas see, Heather Green Wooten, *Polio Years in Texas: Battling a Terrifying Unknown*, Texas A & M University Press, 2009.

[Daniel J. Wilson, PhD](#) – 2020

You can see a full collection of Dr. Wilson's articles, videos and interviews on our website:



James Clark Allen, March of Dimes poster child, 1955. Courtesy of March of Dimes



Nurse Grace Kyler working with polio victims at the FAMU Hospital in Tallahassee, 1953. Tallahassee Democrat Collection



Rose Marie Waters and Linda Brown, March of Dimes poster children, 1949. Courtesy of March of Dimes

# Foot Drop

Janet Drake Whalen, PT, DPT

Foot drop, sometimes called "drop foot," is very common in the post-polio community. Before I can explain the value of physical therapy, it was important that I show exactly what it is. These graphics and this article by [Gabriela Pichardo, MD](#) explain it clearly.

Foot drop is the inability to lift the front part of the foot. This causes the toes to drag along the ground while walking. To avoid dragging the toes, people with foot drop may lift their knee higher than normal. Or they may swing their leg in a wide arc. Foot drop can happen to one foot or both feet at the same time. It can strike at any age.

In general, foot drop stems from weakness or paralysis of the muscles that lift the foot. It can have many different causes. Treatments for foot drop vary according to the cause.



## What Causes Foot Drop? (1)

"Foot drop is a symptom of an underlying problem, rather than a disease itself. It can be temporary or permanent. The causes of foot drop include:

### • Nerve Injury

Most commonly, foot drop is caused by an injury to the peroneal nerve. The peroneal nerve is a branch of the sciatic nerve that wraps from the back of the knee to the front of the shin. Because it sits very close to the surface, it may be damaged easily.

An injury to the peroneal nerve may also be associated with pain or numbness along the shin or the top of the foot.

Some common ways the peroneal nerve is damaged or compressed:

- sports injuries
- diabetes
- hip or knee replacement surgery
- spending long hours sitting cross-legged or squatting
- childbirth
- time spent in a leg cast
- Injury to the nerve roots in the spine may also cause foot drop.

### • Brain or Spinal Disorders

Neurological conditions can contribute to foot drop. These include:

- stroke
- multiple sclerosis (MS)
- cerebral palsy
- Charcot-Marie-Tooth disease

### • Muscle Disorders

Conditions that cause the muscles to progressively weaken or deteriorate may cause foot drop.

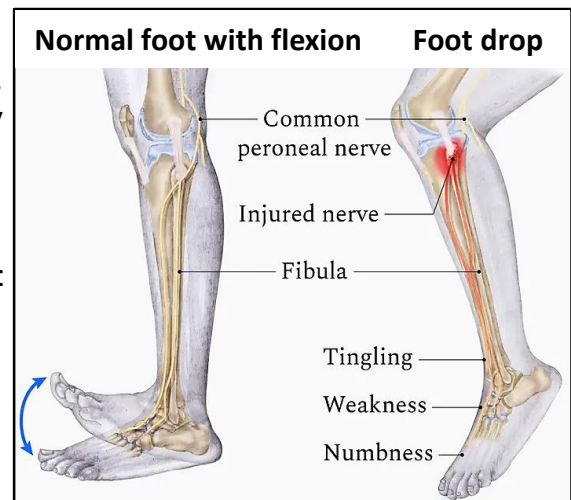
These include:

- muscular dystrophy
- amyotrophic lateral sclerosis (Lou Gehrig's disease)
- Polio

## How Do Doctors Treat Foot Drop?

Treatment for foot drop will depend on the cause. Early treatment may improve chances of recovery. The treatments may include:

- lightweight braces
- shoe inserts (orthotics)
- physical therapy
- Surgery
- Lightweight braces are the most common treatment. They're used to support the leg.



continued . . .

How do doctors treat foot drop (continued . . . )

Physical therapy is used to strengthen foot and leg muscles. It may improve a person's ability to walk. In some cases, electronic devices that stimulate the leg nerves during walking may be appropriate.

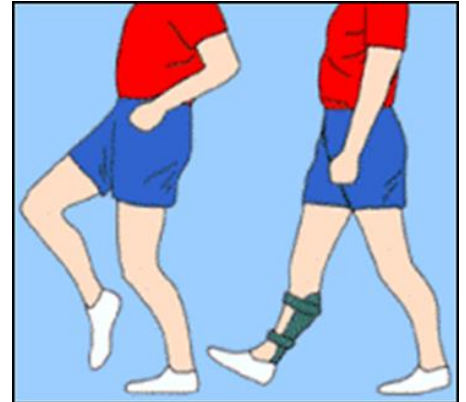
Surgery may be recommended to try to repair or decompress a damaged nerve. In cases where foot drop is permanent, surgery to fuse the foot and ankle joint or to transfer tendons from stronger muscles may help improve gait and stability.” (1)

The term strengthening has a different meaning for polio survivors. Instead, think of maintaining function through body awareness and guided movement.

With a drop foot it is important to have adequate length of the calf muscle that attaches to the Achilles tendon. If the calf muscle is short, it will resist the muscles on the front of the foot and lower leg to lift the ankle.

To determine your ability to lift your toes, foot and ankle -

- Sit straight, with your feet flat on the floor.
- Keeping your heel(s) down, see how much of the front of your foot you can lift. Actively try to tap the front of your foot 2-3 times.
- This will help you be aware of your ability to lift your toes, foot and ankle and give you information to share with your physician and/or PT.
- Your physician may decide to recommend physical therapy.



Due to there being a high risk of falling, wearing an ankle/foot brace is imperative if you have a drop foot. This will allow you to walk more safely, with less effort, and will help keep your posture/gait to be more symmetrical.

- Utilizing a professionally measured cane on the opposite side of the drop foot (or)
- Canes/walker/crutches (if both legs have drop foot) is recommended.

Using a motorized wheelchair or scooter for long distances is often recommended to reduce overuse of your muscles.

A licensed physical therapist can evaluate both your gait and assistive devices. No one wants the issues that come with a drop foot to increase your risk of falling.

Janet Drake Whalen, PT, DPT

Source: [www.webmd.com/a-to-z-guides/foot-drop-causes-symptoms-treatments](http://www.webmd.com/a-to-z-guides/foot-drop-causes-symptoms-treatments)

### **We asked some survivors to have some fun and “check out” the exercise referred to in Janet’s article above.**

We quote both [Richard L. Bruno, HD, PHD](#) and [William M. DeMayo, MD](#):  
“Polio Survivors – You are all the same and you are all different “

Barb: “My big toe and the next one over wiggle. Do I get bonus points for a 2 toe wiggle ? “

Carol: “My right foot is fine. My left foot? I can only wiggle my big toe. The front of my foot doesn't MOVE ! “

Joe: “Nothing happens for either of my feet.”

May: “I can lift both of my feet.”

Shirley: “Both of my feet have the same result – I can only wiggle my toes.”

Win: “I can lift my foot on my ‘good’ leg, but not my polio leg.”



Bracing (Orthotic Care) for Polio Survivors  
Featuring [Marny K. Eulberg, MD](#)

On January 16<sup>th</sup>, [Post-Polio Health International](#) held the first in their series of 2023 Town Hall Meetings.

You can view it here.

This informative presentation is also available on our [website](#) with Dr. Eulberg's collection of articles and additional video presentations.

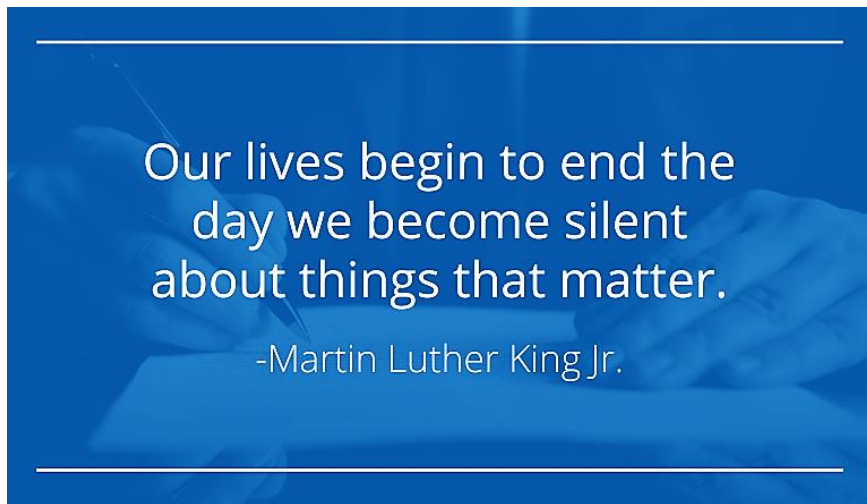
[www.papolionetwork.org/primary-care-perspective](http://www.papolionetwork.org/primary-care-perspective)



THANK you for your kind words, generous donations and active participation.  
Your monetary [contributions](#) help our work continue.  
Your active participation brings forward the questions that many, MANY polio survivors are wanting to ask. Feel free to [contact us](#).



**FEBRUARY**



Always feel free to contact us.

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