



# PA. Polio Survivors Network

Information and Inspiration  
for All Polio Survivors and Their Families

*Serving the Keystone State and Beyond*

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

February 2020

## **Our Mission:**

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

## **Health Care Providers . . . Finding The Right One**

This is one of the common threads that surrounds polio survivors.

In our Fall, 2019 and January, 2020 issues we talked about different ways to search for, find and communicate with health care professionals that we can be confident in and comfortable with.

With gratitude to [Post-Polio Health International](#) we have our final article in this series. Dr. [Carol Vandenakker-Albanese](#), MD has shared her comprehensive article on this topic: “Medical Management of Post-Polio Syndrome”.

## **Our Most Frequently Asked Questions . . . Continued**

[Last month](#), we addressed Rehabilitative Physicians (Physiatrists) and why they are so frequently recommended for polio survivors. This month, we’re looking at power mobility equipment and how to purchase it so that it will be right for YOU and covered by Medicare.

From Dr. William DeMayo:

### **[“Power Mobility Equipment – How to Make the Right Choice”](#)**

“I highly encourage individuals interested in power mobility to be educated regarding the guidelines so that they can appropriately advocate for themselves”.

I “work with vendors that routinely bring a demonstration wheelchair to the home and documented this ability as part of the ordering process. They do an awesome job evaluating beforehand and predetermine the likely best wheelchair. It is always a loaner and temporary while the final wheelchair is ordered. Some vendors bring chairs as a pressure tactic. If they bring a piece of equipment to your home that you feel isn’t correct, please don’t hesitate talking to the company who delivered it. If that doesn’t solve the issue – contact your physician. *Don’t* be pressured into something that isn’t right.”

From the Bruno Byte: **[“The Power of Moving to the Right Chair”](#)**

“The [Medicare](#) requirements for a power wheelchair is now upper extremity function, not strength! Therefore, pain and range of motion that limit function (and make pushing a manual wheelchair inappropriate) would qualify you for a power wheelchair. Talk to your Rehabilitation Physicians (Physiatrist) so they can help you get the equipment that is right for you.

All I can say is to walk is human, to roll divine! You may be wheelchair-bound, you may be Alabama-bound, but no one need ever be ‘confined’ to a wheelchair. A wheelchair does exactly the opposite of confinement: it opens up your entire world! Get a head start. Talk to your doctor about getting a power wheelchair for distance before you need it, so that you can conserve and never be ‘confined’. “  
(See the topic [Mobility Issues](#) in the Encyclopedia of Polio and PPS)

## **A Survivor’s Story . . .**

### **One That Takes Her From One Continent To The Other.**

Vera Gottlieb was a young, new college graduate, discovering the beauty of ancient Europe when suddenly one day she fell to the ground. From that moment on, she has followed what has become her “Improbable” Journey.



### **2019 Team Survivor Update**

[Team Survivor](#) recognizes that not all polio survivors are affiliated with their local Rotary Club(s) and are looking for a fun way to become part of the solution to end the world of this terrible disease.

**Team Survivor**

Polio Survivors Joining Together.

We Are Part Of The Solution To  
End Polio . . . Once And For All.



The dust has settled, we’ve caught our breath and “raced” to the finish. On October 12, four Polio Survivors attended the “Race to Zero” Purple-Pinkie Walk/Run on your behalf. It was a beautiful day, we enjoyed every moment and were grateful for the opportunity to be able to talk about the Polio “Truths” to the hundreds of participants.

We are thrilled to report that “Team Survivor 2019” raised \$5,000 in donations. It’s exciting to tell you that with the Gates Foundation participation (2 for 1 match) an additional \$10,000 was added to this amount. This year alone, we raised enough funds to vaccinate an est. 24,000 children (bringing our 3 year total up to an est. 56,000 vaccines) ! This is especially exciting as the WHO announced the eradication of Type 3 polio.

Your Pay Pal donations and checks (in every possible amount) came from all over the United States – from survivors, family members, post-polio support groups and friends. Because of the credibility of the Rotary Foundation, every dollar makes a difference in a child’s life.

There are multiple videos and articles about the eradication of Polio on our [website](#). Take a look and see the work your donation is supporting. Donation contributors are available on our “[Team Survivor](#)” page.

By working together, we *are* becoming part of the solution. No child should suffer from a vaccine preventable disease. The pain and disability can last a lifetime.





As the number of polio survivors gradually decreases in the US, finding medical providers familiar with post-polio syndrome is becoming more difficult. An individual provider is not able to develop expertise when experience is limited to a few patients per year. This necessitates that the polio survivor become an “expert patient.”

The term “expert patient” originated in England and refers to patients who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases. This concept has become part of medical education in the United States. Medical students are trained to provide more patient education and rely on the patient as part of the medical treatment team to contribute to decision making regarding their care. To be an effective “expert patient” it is important to keep expectations realistic. Do not expect a primary physician to know much about post-polio syndrome. Be able to provide concise, scientifically based information for your physician. The Post-Polio Health International website ([www.post-polio.org](http://www.post-polio.org)) has information for medical providers that can provide basic medical information and serve as a resource for specific conditions. Do not bring stacks of unreferenced information from the internet to your provider!

Establishing a good relationship with your primary doctor is key to accessing the medical care you need for the symptoms related to aging with polio sequelae. Medical management of post-polio syndrome includes management of the primary symptoms, treatment of underlying or associated conditions and optimizing health and wellness. Individual treatment plans include a detailed medical history and exam to identify problems, potential problems or health risks and goals. Identifying associated medical, neurological, musculoskeletal and psychological conditions are part of the process. Evaluation may require consultation with a specialist such as a physiatrist, neurologist, orthopedic surgeon, pulmonologist, or otolaryngologist. Interventions may include referral to a physical therapist, occupational therapist, speech language pathologist, orthotist or psychologist.

It is important for providers to recognize the unique physiologic aspects of residual paralysis due to polio. Polio survivors have a number of muscles that have lost some percentage of the normal innervation. These muscles cannot strengthen like normal muscles and lose proportionally more strength with aging. If polio occurred in childhood, bone and joint development were affected in the involved limbs. Muscle imbalances and joint deformities alter body mechanics and put increased stress on the musculoskeletal system, resulting in early degeneration. Body composition, or the ratio of muscle, fat and bone may be

significantly altered and affect metabolism. Many of the symptoms of post-polio syndrome are like those of aging but accelerated and more complicated. Goals of treatment are to minimize symptoms of post-polio syndrome, optimize body mechanics, protect weak muscles and joints, decrease physical demands on the body, treat associated conditions and optimize wellness.

The primary symptoms of post-polio syndrome are excessive fatigue, muscle and/or joint pain, new weakness, cold intolerance and dysphagia or respiratory changes. Each of these symptoms may be exacerbated by other factors that should be addressed as part of the medical management.

Fatigue is a very non-specific symptom with many potential causes and contributing factors. Fatigue is exacerbated by poor sleep, deconditioning, obesity, poorly controlled chronic illness and depression in addition to the fatigue associated with overuse of weak muscles and post-polio syndrome. Managing fatigue involves optimizing body mechanics and cardiovascular health in addition to conserving energy. Pacing activities with intermittent rest periods is key.

Muscle and joint pain associated with post-polio syndrome is often a result of overuse or excess stress on the body. Muscle pain commonly occurs in polio-affected muscles that have functional strength, putting them at risk of overuse. The pain may be associated with cramping, twitching or crawling sensation and is typically worse at the end of the day. Post-polio muscle pain is a warning sign of overuse and muscle tissue damage. Preventing the pain by modifying activity and stress on a muscle is an essential part of treatment. Using pain medication to simply mask symptoms may ultimately lead to further damage and loss of function.

Joint pain may be due to degeneration and inflammation in the joint or stress on the connective tissue surrounding the joint. It may occur in a polio affected limb where there is excess stress on a joint due to joint deformity, altered body mechanics, or poor protection due to weak muscles and ligaments or in a “strong limb” which has been subjected to years of overuse. Treatment of joint and soft-tissue pain must include evaluation and modification of body mechanics. This may require weight loss, physical therapy, bracing, assistive devices or mobility aids. Treatment may also include modalities, medication, injections and, at times, surgical intervention.

New weakness in polio survivors may manifest in muscles known to be affected by polio or in muscles thought to be unaffected. Most likely the “unaffected” muscles had sub-clinical motor neuron loss at the time of the acute polio infection. Loss of motor units and degeneration of the axon sprouts developed when muscles were [reinnervated](#) results in the weakness associated with post-polio syndrome. Medication has not been shown to be effective in preventing loss of strength unless other factors such as low testosterone or neuromuscular

transmission defects are also present. Avoidance of overuse of “at risk” muscles and appropriate exercise to strengthen deconditioned muscles can delay loss of function. Identifying which muscles are weakening due to overuse and which have become deconditioned by changes in mobility requires very careful muscle testing and monitoring.

Cold intolerance, like fatigue, is a non-specific symptom common to polio survivors. Limbs with significant muscle atrophy related to polio have reduced blood flow and microcirculation due to minimal oxygen demand. Individual basal metabolic rate, related to amount and percentage of muscle tissue, is reduced in a polio survivor. Cold intolerance can be managed by improving cardiovascular circulation, insulating with layers of appropriate breathable clothing and ensuring availability of environmental control and external heat sources. Dysphagia and respiratory problems are related to a history of bulbar polio with residual weakness of upper airway, swallowing and respiratory muscles. A history of choking or coughing when eating or difficulty swallowing certain foods may warrant a swallowing evaluation and training in compensatory swallowing techniques. Reduced respiratory function may be a result of upper airway obstruction (weakness of muscles in the throat) or poor ventilation due to chest wall or diaphragm muscle weakness. Pulmonary function tests and sleep studies can identify the etiology of symptoms and indicate appropriate interventions. Assisted ventilation, assisted cough, breathing exercises and pulmonary rehabilitation may be utilized to optimize pulmonary function. Significant illness may be prevented through regular vaccinations and exposure precautions.

Optimizing wellness contributes to overall health and sense of well-being. A good relationship with a primary care provider is essential to monitoring health and managing chronic conditions. Good nutrition, restful sleep and regular exercise help maintain vitality. Preventing injury and illness and modifying lifestyle to minimize risks are key to preserving function. Psychosocial support lends security and purpose to life. Although post-polio syndrome can be a complicated condition to live with, finding the needed medical management and living well is still possible.

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[Dr. Carol Vandenakker-Albanese](#) is a Health Sciences Clinical Professor, the Associate Residency Program Director and Director of Faculty Development in the Department of Physical Medicine and Rehabilitation at the University of California, Davis Medical Center. She is board certified in Physical Medicine and Rehabilitation. Her biography is on our [website](#).



**You can see the informative video  
“Components of Post-Polio Management”**

by Dr. Vandenakker-Albanese and Post-Polio Health International on the [Living with Post-Polio Syndrome](#) page of our website.



Editor’s Note:

**These words in the article “Medical Management of Post-Polio Syndrome” by Dr. Vandenakker-Albanese caught our attention:**

**“Do not bring stacks of unreferenced information from the internet to your provider.”**

We subscribe to that philosophy and provide easily accessed biographical documentation for our professional contributors on our website. Simply “click” on their name when you see it in Bold **Red** letters. When you find something that applies to you, this information is available in multiple places and is easily downloaded for you to share with your health care professional.

- [Anesthesia Warning](#) page. When your physician holds their phone up to the “scan code” on your anesthesia warning card, they will have full access to all articles and biographical information on the page.
  1. The biographical information of every contributor to our Anesthesia Warning Cards is visible (alphabetically) at the bottom of the page.
  2. The biography of the author is accessible with just a “click” on their name with each article as well.
- [Contact](#) page, you can access the biographical information of all our professional contributors in one location.
- [DeMayo’s Q&A Clinic](#) – Dr. William DeMayo’s biographical information is available both through a red “tab” at the top of the pages *and* through links in each of his articles.
- [Encyclopedia of Polio and PPS](#) – Dr. Richard Bruno’s biographical information is available both through a red “tab” at the top of the pages *and* through links in each of his articles.

Editor's Note: continued

- [Living with Post-Polio Syndrome](#) and [Post-Polio Care for our Families and Caregivers](#)

These pages have information from multiple sources – the vast majority are from either Dr. Bruno, Dr. DeMayo or from professionals associated with Post-Polio Health International.

You can find direct link information to PHI both on our “contact” page (above) or on our page – [What's New from Post-Polio Health International](#).

### Anesthesia Warning Card

Front



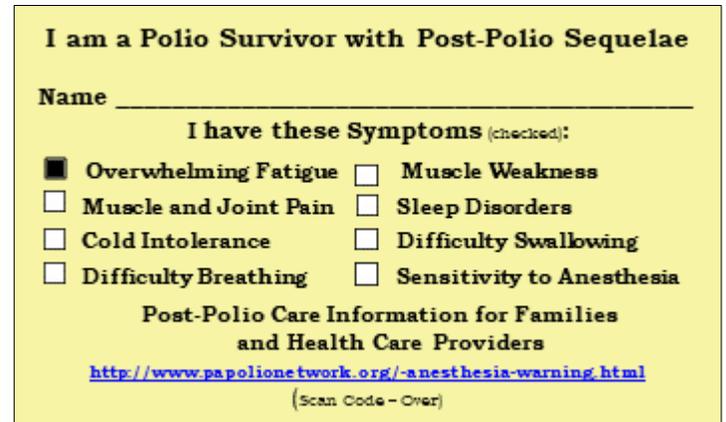
**Anesthesia Warning !**  
**I am a Polio Survivor**

- EASILY SEDATED, and can be difficult to wake
- Can Have Difficulty BREATHING and SWALLOWING with Anesthesia
- HYPERSENSITIVE to PAIN and COLD.  
May Need heated blanket and Increased pain medication post-op.



Information Available (scan code):  
“Preventing Complications in Polio Survivors Undergoing Surgery”  
“Breathing Outcomes: Post-Poliomyelitis Syndrome (PPS)” (Over)

Back



**I am a Polio Survivor with Post-Polio Sequelae**

Name \_\_\_\_\_

**I have these Symptoms (checked):**

<input checked="" type="checkbox"/> Overwhelming Fatigue	<input type="checkbox"/> Muscle Weakness
<input type="checkbox"/> Muscle and Joint Pain	<input type="checkbox"/> Sleep Disorders
<input type="checkbox"/> Cold Intolerance	<input type="checkbox"/> Difficulty Swallowing
<input type="checkbox"/> Difficulty Breathing	<input type="checkbox"/> Sensitivity to Anesthesia

Post-Polio Care Information for Families and Health Care Providers  
<http://www.papolionetwork.org/-anesthesia-warning.html>  
(Scan Code - Over)

Anesthesia Warning Cards (both the original NJ version and the updated version) are easily printed from our [website](#).



### PA. Polio Survivor's Network

Serving *ALL* Polio Survivors . . . in the Keystone State and beyond.

As PPSN enters our sixth year, we are more grateful than ever for your kind words and generous donations. We seek to be a resource for information that can serve *all* polio survivors and their families.

Our 2019 Contributors and In Memoriam celebrants are listed on the [donations](#) page of our website.



## Types Of Medical Equipment Medicare Covers For Home Use



Durable medical equipment (DME) is equipment that helps you complete your daily activities. It includes a variety of items, such as walkers, wheelchairs, and oxygen tanks. Medicare usually covers DME



if the equipment:

- Is durable, meaning it is able to withstand repeated use
- Serves a medical purpose
- Is appropriate for use in the home, although you can also use it outside the home
- And, is likely to last for three years or more

**Durable medical equipment (DME)**

To be covered by Part B, [DME must be prescribed](#) by your primary care provider (PCP). If you are in a [skilled nursing facility \(SNF\)](#) or are a [hospital inpatient](#), DME is covered by Part A.

Whether you have [Original Medicare](#) or a [Medicare Advantage Plan](#), the types of Medicare-covered equipment should be the same. Examples of DME include:

- Wheelchairs
- Walkers
- Hospital beds
- Power scooters
- Portable oxygen equipment

Under the durable medical equipment, prosthetics, orthotics, and supplies (DMEPOS) category, Medicare Part B also covers:

- Prosthetic devices that replace all or part of an internal bodily organ
- Prosthetics, like artificial legs, arms, and eyes
- Orthotics, like rigid or semi-rigid leg, arm, back, and neck braces
- Certain medical supplies

Medicare also covers certain prescription medications and supplies that you use with your DME, even if they are disposable or can only be used once. For example, Medicare covers medications used with nebulizers. Medicare also covers lancets and test strips used with diabetes self-testing equipment.

### Coverage Of Power Wheelchairs And Scooters

If you think you need a power wheelchair or scooter, first speak to your doctor or primary care provider (PCP). If your PCP determines that it is medically necessary that you use a power wheelchair or scooter, they should sign an order, prescription, or certificate after a face-to-face office visit.

Note: Your provider must request prior authorization for Original Medicare to cover certain power wheelchairs and scooters.

The order should say the following:

- Your health makes it very hard to move around in your home, even with the help of a walker or cane
- It is difficult for you to perform activities of daily living (such as bathing and dressing) in your home
- You cannot use a manual wheelchair or scooter but can safely use a power wheelchair or scooter

- The wheelchair will help with a specific medical condition or injury and be used in the home
  - And, you had a face-to-face meeting with the doctor
  - This meeting should take place no more than 45 days before the prescription is written.
- Note: Keep in mind that you can only receive Medicare coverage for one piece of equipment that addresses at-home mobility issues. Your PCP will determine whether or not you need a power wheelchair or scooter or a different device based on your condition.

Once you have your PCP's order or prescription, you must take it to the right supplier to get coverage. Be sure only to use suppliers with approval from Original Medicare or your Medicare Advantage Plan.

Note: There are also certain kinds of [equipment and supplies that Medicare never covers](#). To find out if Medicare covers the equipment or supplies you need, or to find a DME supplier in your area, call 1-800-MEDICARE or visit [www.medicare.gov](http://www.medicare.gov). You can also learn about Medicare coverage of DME by contacting your [State Health Insurance Assistance Program \(SHIP\)](#).

### [Resource material](#)

## **My Improbable Journey**

by Vera Gottlieb

Rome, 1950.

I was twenty-two and had been traveling through Europe for six weeks with Carol, my college roommate. We had another month remaining before returning to the United States.



I attributed my aching neck that morning to our very energetic first day in Rome that had included the Sistine Chapel. I got out of bed and suddenly fell to the floor. Picking myself up, I again fell down. Something was very wrong. I called the American Embassy and asked them to send me an American doctor. A physician arrived and proclaimed I had spinal meningitis. The medication he prescribed would, he assured me, have me well on the road to recovery in twenty-four hours. Twenty-four hours later, I was paralyzed from the waist down.

This time I asked the Embassy to please send me an Italian Neurologist and they sent an impressive Dr. Ruggieri. He spoke no English and I spoke no Italian, but we managed with fractured French. After examining me, he said he was quite sure I had polio. He would have to take me to his Clinic for the definitive spinal tap.

I remember a lot about my experience at the clinic, which turned out to be a mental institution, in post-war Rome. I was placed in isolation. Tests were completed and confirmed the polio diagnosis. I was confined to bed for a month. Once they gave me two canes, stood me up and asked if I could walk. That went

nowhere except back to bed! I could only slightly move my legs (with great distortion of my body). The doctor said they had no experience in Italy with polio in adults because only children got polio or had developed an immunity. Two of the more notable memories are that breakfast was a hard boiled egg, served in an aluminum tin and that toilet paper was simple newsprint.

In the meantime, my parents were expecting to hear about our travels to southern Italy and Sicily, so I had to come up with some excuse. Carol had disappeared, but fortunately a kind bellhop from the hotel where we had been staying supplied me with postcards. I sent one every few days telling my parents I was having such a good time in Rome and had decided to go no further. I was not in the habit of lying to my parents, but I felt I was sparing them.

A month passed, and the day was arriving when I was due in Le Havre, France, to board the ship that would take me home. I had completely ignored the fact that at no time had the subject of money arisen. I was astounded when Dr. Ruggieri told me that he had arranged for a sleeper car in a train that would take me to Le Havre. He rejected my offer to pay him with what little money I had left, but did agree to accept a donation to the clinic. He then gave me two envelopes. One was to be shown at the international border and contained a phony diagnosis. (A polio diagnosis would not have permitted me to continue even though I was no longer contagious). The second envelope contained my complete history and was to be given to my New York doctor.

When our ship docked in New York, the shock to my parents seeing me brought down in a wheelchair made me wonder if I had done the wise thing in not preparing them. A close medical friend of my parents contacted Dr. Frederick Marek, whom he considered to be one of the finest and most experienced polio physicians in New York. The next day, Dr. Marek arrived at our apartment. After examining me, he said it was unlikely I would ever walk again – a prognosis I didn't accept. He said that the previous hospital (in Italy) trying to force me to walk with such distortion was truly harmful and ordered a physical therapist who came five days a week. My physical therapist made no attempts to get me to walk for many months as she worked on me. It took almost a year, but I went from a wheelchair to crutches to two canes and finally, I could walk on my own.



My years in the coop program at Antioch college and the many difficulties I'd faced on various jobs, had prepared me for challenges - and this was just another one. The years that followed were full. I married, raised two children, volunteered at the coop nursery I had co-founded many years earlier, continued my graduate studies and managed my husband Joe's engineering consulting business. There had been a one month hospital stay for a herniated disc, followed by several months in a brace. My

life was busy but I felt something was missing. Finally at the age of 47, I decided I might have the answer.

Continued . . . .

We lived near a small park. I tried walking around it very rapidly. The next day my legs felt so weak I had to remain in bed. I waited three weeks and then started a much slower program, progressing from walking to jogging and finally to running six days a week. I joined the New York Road Runners Club and entered competitive 10k races. In between races I preferred training alone or with my husband Joe. I ran 5 or 6 miles a day in the rain and snow, and I ran whether the temperature was 5 degrees or 95 degrees. I ran the mini marathon. Anyone who has run long distances will probably admit that distance running is addictive. It is! I continued running well into my late 60's. But then something changed.



My left leg which had never fully recovered from polio, would suddenly buckle. I was planning to run another 10k race in Central Park and had always completed every race I took part in. This time I had doubts. Joe and I found a spot at the four mile mark where he would wait for me, instead of at the finish line as usual. Long before I reached four miles, I realized I couldn't finish. Joe knew something had happened when I failed to appear. I had walked the last two miles slowly and after finding Joe and resting, we walked the final two miles together.



Then began the months of testing for everything: multiple sclerosis, brain tumors, spinal tumors, Lou Gehrig's disease and more. Finally, the cause was understood. But, there was less agreement as to what to do about what came to be known as post-polio syndrome.

I went to the National Rehabilitation Hospital in Washington D.C. for a 2-day evaluation at their famous Post-Polio Clinic. They told me that for five months I was to sit for most of the day. I hadn't cried when I got polio, nor when I realized I needed to slow down, nor with the post-polio diagnosis. Now, I burst into tears and said "no." I couldn't do it.

We finally reached an agreement: no more running, not even jogging. Walking was permitted for short distances only. Initially I complied. Five months later, when I returned to the Rehabilitation Hospital, I had increased my walking to four miles a day. This time they were firmer and I gave in. At almost seventy, I was ready to comply.

The experts differ on whether the more than twenty years of running had accelerated my post-polio syndrome or perhaps, had kept it in abeyance. The consensus is that moderation is better. Over the years, many people have asked me if I would have done things differently had I known that the excessive running might have contributed to my current post-polio syndrome. My answer has always been "No!" I have never regretted it for a moment. I have the memories of those many years of joyous running, and an outlook on life that has helped get me through ninety-one years.

This and many other survivor stories are featured on our [website](#).

**Would you like to receive our Monthly Newsletters by US Mail? It's Easy.**

**PA Polio Survivors Network – Newsletter Order Form**



*“Serving the Keystone State and Beyond”*

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Pa. Polio Survivors

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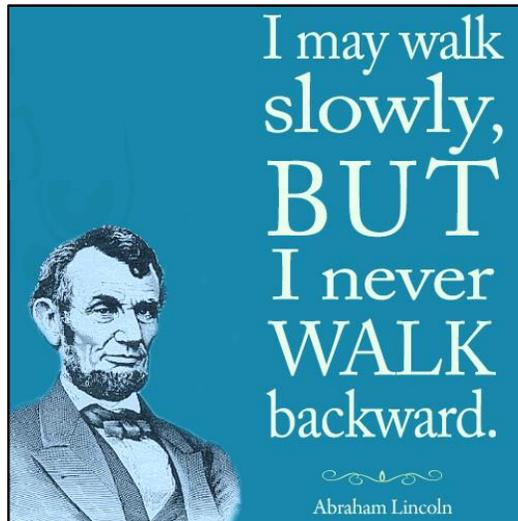
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(Pennsylvania Polio Survivor's Network is a registered 501C3 organization)

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