



PA Polio Survivors Network

Information and Inspiration for Polio Survivors and Their Families

From the Keystone State and Beyond

www.polionetwork.org

April 2017

Our Mission:

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

Polio Awareness Month 2017

The beautiful month of April has come around once again.

In 2015, in honor of the 60th Anniversary of the Salk Vaccine, the Pennsylvania House of Representatives voted unanimously to declare April as "Polio Awareness Month".

This year we have focused on the second portion of our "Statement of Purpose" –

Our ongoing goal of Polio Awareness has a dual purpose;

- The first being to draw attention to the estimated 1+ million Polio Survivors in North America, the majority of whom are realizing the disabling effects of Post-Polio Syndrome.
- Second, and equally important is to draw attention to the importance of being immunized against this crippling disease.

In April, 1955 the Salk vaccine enabled children to be protected against the polio virus. Polio virtually disappeared in the US in a very short time and was "officially" declared eradicated in the United States in 1979. We celebrate the efforts of Rotary International's "End Polio Now" campaign that is leading the effort to vaccinate children in every corner of the world.

Even as Rotary International and the Gates Foundation move toward achieving the goal of eradicating the live poliovirus through vaccination, we must not forget that the World Health Organization estimates there are 15+ million Polio survivors throughout the world -- one million plus in the US alone -- living with Post-Polio Sequelae and the disability caused by the polio virus.

We created three images to support our goal to "draw attention" to the importance of being immunized. These images have gone to every Representative in our State, our Board of Health and numerous news organization. We are optimistic that it will help a reluctant parent to change their mind about giving their child the Polio Vaccine.

Thank you Rotary International for supporting our effort. The remaining images are visible throughout this newsletter.

The Pain and Disability from POLIO Lasts a Lifetime.

Please Vaccinate your children.

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“Bruno Bytes”

Tips and Tidbits from the Post-Polio Coffee House

Richard L. Bruno, HD, PhD.

On the topic of Medicare Requirements for Power Wheelchairs (3/18/2017)

Dr. Bruno’s Original Post: There have been questions about power wheelchairs recently.

The [current Medicare requirements](#) are [HERE](#).

Note: The Requirement is now Upper Extremity Function NOT Strength!

Therefore, pain and limited range of motion that limit function (and make pushing a manual wheelchair inappropriate) would qualify you for a power wheelchair. Talk to your Rehabilitation Physician (Physiatrist).



**Power Mobility Devices:
Documentation & Coverage Requirements**

On the topic of “Allergies” to medications (3/18/2017)

Original Post: Have any of you discovered that you are allergic to a lot of pain medications or any kind of other medication that has been prescribed to you? I am allergic to so many.

Dr. Bruno’s Response: Remember: "Allergic" is not the same as "adverse reaction."

- Allergic is when your body responds to a bee sting or peanut allergy and could kill you.
- Adverse reaction is when a medication causes symptoms, like muscle pain (statins), reflux (Celebrex).

Additional Post: When I take any Sulfa Drug – I get itchy all over and my face swells up.

Dr. Bruno’s Response: *That* is an allergic reaction.

Additional Post: Why is it that when we go to the doctor or the pharmacy they ask " Are you allergic to any medications" vs asking the question " Do you have any adverse reactions to any medication"?

Dr. Bruno’s Response: We should be asked both about allergies AND Adverse reactions.

Additional Post: Benadryl makes my legs "restless" for several hours, and makes me want to do anything to stop the sensation. I began listing my allergies to include Benadryl since no one ever asks about "sensitivities". This causes repeated statements about how I cannot possibly be ALLERGIC to Benadryl since it "helps" allergic reactions.

Dr. Bruno’s Response: This is a sensitivity (a bad side effect of the drug), not an allergic reaction. Unfortunately, unless your physician asks you for both, you have to list it as an allergy. Oftentimes, they will ask you “what was your reaction”.

On the topic of Post-Polio Sequelae “What is it ?” (2/5/2017)

Original Post: The medical world seems to use the word “syndrome” when a more definitive term or diagnosis is not available. I remember that early on our problem was often referred to as Post-Polio Syndrome. When I fill out forms at doctors’ offices or speak with physicians I refer to Post-Polio Sequelae.

Dr. Bruno’s Response: Post-Polio Sequelae is the overarching name that covers all of the symptoms that could develop in a polio survivor later in life, including "post-polio syndrome muscle weakness", and is the term that I used in writing the Social Security ruling that allows polio survivors to receive SSDI ([HERE](#)).

“Bruno Bytes”, have been available since November 2014.

These Q&A’s are available on our [website](#).

Looking for a specific topic?

Check out the “Bruno Bytes” Index (by Subject) on the page referenced above. 2



Power Mobility Equipment Medicare and Insurance Coverage

How to go About Making the Right Purchase Decision

[William M. DeMayo, MD.](#)

In a recent post by Dr. Bruno about Power Mobility Equipment (previous page), he suggested individuals interested in this often complex option should consult with a rehabilitation physician. I'm writing this article to accompany his. The subject of payment for Power Mobility has been a volatile issue over the past two decades. Much of our current ordering process has been developed in response to enormous problems with abuse/fraud over the years. A full discussion of that abuse is beyond the scope of this article, but I will refer the reader to following:

- Journal of the American Geriatrics Society: [Epidemiology of Medicare Abuse- The Example of Power Wheelchairs](#) (April 10, 2007).
 - o "Press reports and government investigations have uncovered widespread abuse in power wheelchair prescriptions reimbursed by Medicare, with specific targeting of minority neighborhoods for aggressive marketing."
- The Wall Street Journal: [A Medicare Scam That Just Kept Rolling](#) (August 16, 2014) –
 - o "Since 1999, Medicare has spent \$8.2 billion to procure power wheelchairs and "scooters" for 2.7 million people. Today, the government cannot even guess at how much of that money was paid out to scammers."
- The Scooter Store, LTD. (Wikipedia)
 - o Founded 1990, 2008 revenue \$332 million
 - o On February 20, 2013, Federal agents with search warrants raided the Scooter Store's New Braunfels, Texas headquarters. According to various news sources, the FBI agents were there to investigate the company's billing practices. Company spokespeople declined to comment to the press.
 - The company entered liquidation and terminated remaining employees on September 13, 2013



Unfortunately, companies like The Scooter Store and their widespread commercials have led to a public perception that power mobility is easily funded by insurance. The resultant overutilization and abuse/fraud has led to Medicare having requirements for extensive documentation regarding the functional need for power mobility. Most insurers follow Medicare guidelines. To make things even more complicated, many physicians are not aware of current documentation requirements and, when wheelchairs are denied, they may communicate inaccurate information regarding eligibility criteria. I would highly advise any reader interested in power mobility to seek out a consultation with a Physical Medicine and Rehabilitation specialist (Physiatrist) who regularly prescribes power mobility (the physician finder tool at [AAPMR.org](#) may be helpful). In addition to being sure that documentation guidelines are met, the Physiatrist will be able to provide valuable input regarding specific needs and options.



I also highly encourage individuals interested in power mobility to be educated regarding the guidelines so that they can appropriately advocate for themselves. The September, 2016 Medicare document "[Power Mobility Device Documentation and Coverage Requirements](#)" provides an excellent outline of guidelines (referenced [HERE](#) and on page 2).

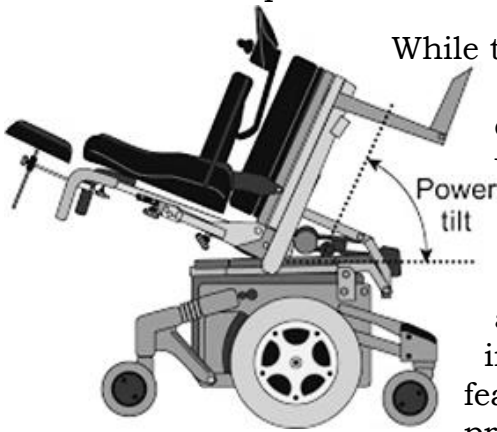
(Please note that Medicare documentation prior to 2016 may not be accurate.)

Significant points in this document include the following (my **Bold** and underlining were added for emphasis with subsequent explanatory note):

- Power Mobility Devices (PMDs) are covered under Medicare part B Durable Medical Equipment (DME) benefits and include:
 - Power Operated Vehicles (POVs)-also known as scooters.
 - Power Wheelchairs (PWCs).
- Power mobility devices are covered for use **in the home**.
 - Note: nothing prohibits using the device outside of the home however, it is the necessity in the home that meets the eligibility criteria. An individual can move about the home functionally without a power mobility device then they are not eligible regardless of opportunities the device might provide outside the home.
- A Mobility-Related Activity of Daily Living (MRADL) limitation must be documented within the home which is not **sufficiently or safely** resolved by using an appropriate fitting cane or walker.
 - Note: it is essential to differentiate potential mobility from reliable/safe mobility. As an example, an individual may be able to walk from the living room to the kitchen or bathroom at times yet other times pain/stiffness/fatigue may preclude this activity or make it unsafe. This individual may meet the criteria.
 - The individual must demonstrate mental capabilities and physical capabilities sufficient for safe operation of the device in the home and using the device must significantly improve ability to participate in MRADLs (Mobility Related Activity to Daily Living such as toileting, feeding, dressing, grooming, and bathing) to a degree that cannot be obtained using other MAE (Mobility Assistive Equipment such as a cane, crutch, walker, or manual wheelchair).
 - Note: 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.
- For scooters, the individual must also show they can maintain postural stability and position while operating the tiller steering system (a power wheelchair typically has a joystick located on or about the armrest rather than the tiller in front).
 - Note: Given the new functional requirements, I find that it is rare for me to order scooters through insurance. In addition to the need for the patient to have good trunk strength, the turning radius of scooters is very poor and require significant space in the home. Also, the captain's chair of the scooter is not customizable and does not lend itself to use throughout the day without resulting in other problems such as back pain. It is particularly poor for individuals with scoliosis. In general, power wheelchairs are the most appropriate for inside the home and scooters are more helpful outside of the home (or for episodic use).
- The physician must conduct a “face-to-face examination” before writing a prescription. Medical necessity for the PMD should be the major reason for the visit and the following questions answered:



- What is the patient's mobility limitation and how does it interfere with the performance of Activities Daily Living?
 - Why can't a cane or walker meet the patient's mobility needs in the home?
 - Why can't a manual wheelchair meet the patient?
 - Does this patient have the physical and mental abilities to operate a PMD safely in the home?
- Documentation must also provide the history of the patient's present conditions including symptoms that limit ambulation, progression of ambulation difficulty over time, pertinent diagnoses, distance the patient can ambulate without stopping, pace of ambulation, assistance provided for ambulation, ability to stand up from a seated position without assistance, and any recent changes that now require a PMD.
 - Examination must include cardiopulmonary examination, musculoskeletal examination, and neurologic examination
 - Wheelchair vendors also have documentation requirements including a home assessment verifying the physical layout of the home, doorway with, doorway threshold, and types of services.
 - Note: a discussion on ramping for the home and a ramp/lift for one's vehicle should also be part of the home valuation.



While the above is not a comprehensive review, the reader can certainly understand that obtaining payment for power mobility can be quite complex. At the same time, a rehabilitation physician who understands this process AND a reputable vendor can still make the process reasonably smooth. I routinely meet with a vendor representative and the patient/family in my office so that we can all collaborate together. The physician can add medical perspective to selection of wheelchair options, including custom seating or options such as "tilt in space" features which elevates the leg/reduces edema while reducing skin problems on the buttocks (very different than a recline feature

which can cause skin problems). When you see a physiatrist for this reason, it is therefore important to ask how frequently the physician orders these devices and establish if he/she has the background you need. Additionally, I would highly advise working with a wheelchair vendor who is certified as an Assistive Technology Professional (ATP) with The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). Most, if not all, vendors have an ATP certified employee in the organization but *you want to be sure the person working on your needs is certified.*

As with most technology, more and more options are becoming available to meet individual needs. This includes options for those that meet Medicare requirements as well as for others who may have other means to fund their device. For those who do not need power mobility within their home but do have difficulty with distance ambulation outside the home, other options do exist. Mobility devices are frequently available second hand via Craigslist or other vendors.

If you are purchasing your new PMD privately, it is important to have a professional review of the device for appropriate fit and function as well as safety.





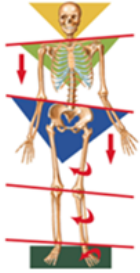
New ultraportable travel scooters are also now available. In addition, many travel locations have rental options available (thus eliminating the need for transportation and damage risk of your device).



Renting something new at a vacation location could bring you new and exciting experiences !

[William M. DeMayo, MD](#)

April, 2017



Do You Have a Question for Dr. DeMayo?

Many of his articles are based on your questions. Feel free to contact us: info@polionetwork.org (or) 215-858-4643



More About Polio Awareness and Anesthesia

It's been a year since we launched our Updated Anesthesia Warning Cards.

Since that time, there have been over 2,500 "hits" on that page of our [website](#) (where cards can be printed) and we have distributed 700+ professionally printed cards.

Doctors have easy access to the information (through the "scan code" on their phones).

We are truly grateful to the International Centre for Polio Education and Survivor Jerry Bajko for having the vision and launching the original cards 10+ years ago.

In addition, thank you Dr. John Bach, MD., [Richard L. Bruno, HD, PhD.](#), Dr. Selma Calmes, MD., and [William M. DeMayo, MD.](#) for making this happen.

Note: The cards do NOT say that *all* Polio Survivors have *all* these issues. They say we "can" and "may" need these things. It's up to us to inform our caregivers what our particular concerns are.

I am a Polio Survivor with Post-Polio Sequelae
 Name: _____

I have these Symptoms (checked):


<input 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

(Scan Code for Anesthesia Information - Over)
www.polionetwork.org/anesthesia-card

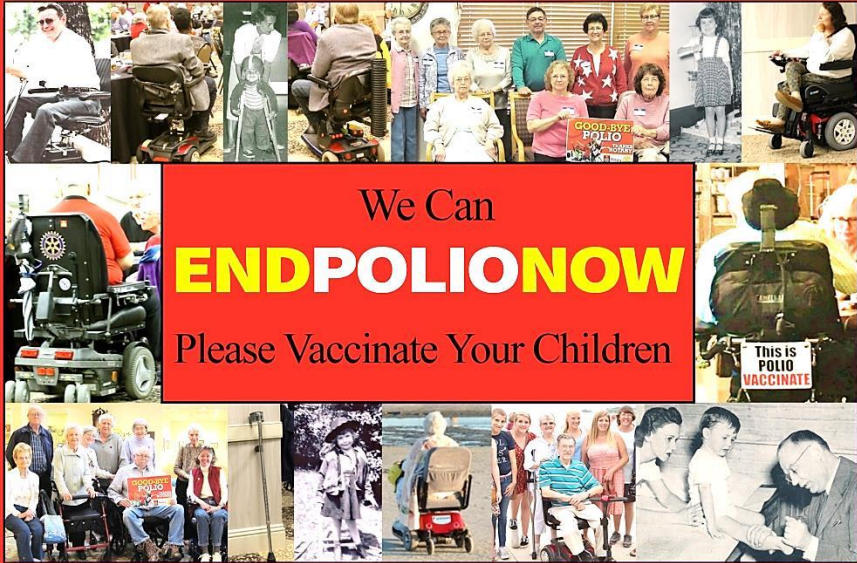
ANESTHESIA WARNING!

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



www.polionetwork.org/anesthesia-card



We Can
ENDPOLIONOW
 Please Vaccinate Your Children

PA Polio Survivors Network

END POLIO NOW

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Wheelchairs Over Time

Disability of any kind can give rise to many challenges that make it difficult for individuals to function efficiently and effectively. Over time, man has used ingenuity to overcome these challenges and has made leaps of progress in the last few decades. A wheelchair is a very basic example of such an ingenious invention, having been innovated over time to make it easier for people to use them regularly.

From Humble Beginnings

The oldest recorded example of a wheelchair can be dated back to 1595. The design has remained somewhat similar over the years, with the main focus on making the wheelchair easier to use through innovation. Wheelchairs first become commercially available to consumers from Bath, England. The three-wheeled wheelchair was invented by an inventor named John Dawson in 1783.

The availability of wheelchairs to the public allowed an uplifting of living conditions for disabled people who could move around short distances with more ease. Further developments also included added comfort and safety features such as sturdier frames, reclining seats, and better seating design to help with the posture. The tubular-style steel wheelchair that is used today was invented by engineer Harry Jennings and his paraplegic friend, Herbert Everest, in 1932.

Towards Ingenious Innovation

As people become more and more aware of the unique needs that people with disabilities have, we are seeing a higher funding in research and development of innovative products to facilitate such people. Newer technologies have been used to make the basic design of a wheelchair better over time, keeping in view individual needs and financial restrictions of the users.

3D Printing is an example of such modern technology where we are breaking ground for the betterment of people with restricted movement. 3D printing allows us to use computers to design all sorts of shapes and then transform them into usable objects with millimeter accuracy. This enables us to develop and design prototypes on a much larger scale with great precision, in a faster time. Creating wheelchairs through 3D printing also reduces the production cost, bringing mobility solutions to a larger number of people globally.



It is true that wheelchairs have evolved into much more complex machines over time, but more improvement is still needed. The coupling of easy usage with modern technology is still not quite there, but we are definitely on the right track.

(Article abbreviated for space).
The original is [HERE](#) from:



Don't let **your** children become
 Polio Survivors.
 Please have them Vaccinated.



The Pain and Disability from
 Polio Lasts a Lifetime.



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Thanks to the generosity of Director Nina Gilden Seavey,
 it's available (advertising free) on our website.

**Both "Polio Revisited" and "A Paralyzing Fear" are available from
 Our Lending Library in DVD format.**

Both of these outstanding documentaries are excellent Support Group programming.


**Would you like to have our Monthly News Updates
 (8 pages in full color) by US Mail?**

Details are [available](#)



We are truly grateful for your kind words of support.

Your generous [donations](#) are the key to helping our work continue.



*Life is not about waiting
 for the storm to pass,
 it's about learning to
 Dance in the Rain*

Whatsapp99.com



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 and include our website: www.info@papolionetwork.org

Do you have a topic you would like us to cover? Please let us know.

Always feel free to contact us.

[The Polio Network Team](#)



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