



PA Polio Survivors Network

Information and Inspiration for Polio Survivors and
Their Families

From the Keystone State and Beyond

www.polionetwork.org

August 2017

Our Mission:

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

How can we learn to stop worrying and start benefiting from technology?

[Daniel J. Wilson, PhD.](#) has shared a personal story with us once again. He has struggled with the effects of Post-Polio Syndrome for almost thirty years. By accepting the newer advances in assistive technologies he is free to get to his classroom without difficulty, visit the museums that he and his wife love and even “walk” the dog !

Are you worn out from Back Pain? Have you considered Injections?

[William M. DeMayo, MD.](#) had a question from a Polio survivor that he was able to turn into an article that can help us all. She had multiple injections into her lumbar spine and hasn't seen improvement. He explains the process and how we can ask the “right” questions of our health care providers before we choose our course of treatment.

Post-Polio Care: Past, Present and Future

Dr. DeMayo, MD and Professor Daniel Wilson, PhD.

will be the featured speakers at our August 26th Conference

It's not too late to sign up. We will be “live” in three different locations in PA – within easy reach of Delaware, New Jersey, Ohio, Northern Virginia and West Virginia. In addition, we will be webcasting for those who are not within reach of our three locations. Join us for an informative day, highlighted by the camaraderie of being with one another.

Registration forms must be post-marked by Aug. 18, 2017.

Online Registration is available until Aug. 20th. (Contact Details for each location are on Page 8.)

Do your muscles go into “spasms” when you wake up in the morning?

Lots of Polio survivors have this problem.

What IS the difference between a muscle spasm and a muscle cramp?

In this month's “[Bruno Byte](#)” Tidbit, [Richard L. Bruno, HD., PhD.](#) explains the difference between the two. He relates their experiences from the Clinic at the Post-Polio Institute on how they were able to successfully treat patients who have this painful issue.



Attention Medicare Recipients

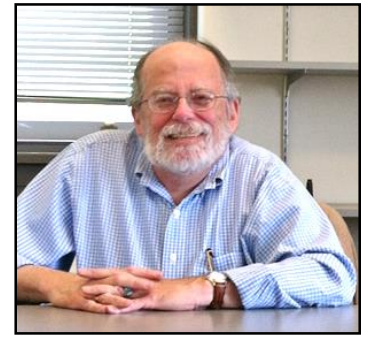
From now through the end of the year, Medicare will mail out new Medicare cards that no longer feature Social Security numbers. The new card identification number will be a random mix of numbers and letters as a way to protect a cardholder's identity.



A cardholder's benefits will remain the same, the cardholder does not have to take any actions and the new cards are free.

How I Learned to Stop Worrying and Love Technology

[Daniel J. Wilson, PhD](#)



I have now been struggling with the effects of post-polio syndrome for nearly thirty years. It first appeared as a weakness in my right leg, the one most affected by polio, in 1987. Over the ensuing two decades, the leg has gotten weaker and I began to have breathing problems at night. These physical problems have led to an increasing reliance on technology to help me breathe at night and to move around during the day. I have used a Bi-Pap machine at night since 2000 and since August 2006 I have used both a scooter outside my home and stair glides in the house.

Like some other polio survivors, I resisted getting the ventilator, the scooter, and the stair glides. I had not used any assistive devices since the early 1960s when I had two surgeries that necessitated using crutches for a couple of months. I was proud of my ability to get around on my own without assistance. I could never walk very far—no Appalachian Trail or marching band for me—but I got around quite easily. I associated assistive devices with disability, and I didn't consider myself disabled. Inconvenienced at times, but not disabled. Using the technology of assistive devices was something I resisted. I wanted to do it my way, even if that was increasingly painful.

My first concession to the encroaching post-polio syndrome was to begin using a Bi-Pap ventilator at night in the fall of 2000. I had spent part of that summer at San Francisco State University studying disability and disability history with 25 other scholars, some of whom had disabilities of various types. I not only studied the way in which disability is constructed by society and the ways in which those with impairments are made to feel inferior, I also observed the ways in which my colleagues used their assistive devices to function effectively and easily. When I returned to Allentown I had a sleep study done, which revealed serious sleep apnea, which explained why I was waking up tired. I wasn't happy about the doctor's recommendation of a Bi-Pap, but decided to try it. Getting used to the mask was not easy. The first couple of nights I did not get through the whole night with the mask on. By the end of the first week, when I could make it through the entire night with the machine on, I began to notice a real difference. I was sleeping through the night, instead of getting up two or three times. And in the morning I was more wide awake and less tired. I have used it every night since, both here and in Europe, except when we have had a power outage. It goes with me when I travel and I rely on it to help me get a restful night's sleep.

In some ways the Bi-Pap was easy, in spite of the challenges of adjusting to the mask. No one had to know except my doctor, my wife, Carol, and our dog, Abbey—who thought it was a vacuum machine when I first turned it on and fled the room. Because I used it only at night, it was a hidden technology unless I revealed the secret. Fortunately, my wife, Carol, and my dog, Abbey, both adjusted to the noise of the machine.

My next device would be more public—using a walking stick when there was snow on the walks. As my leg weakened, it became problematic to walk on uneven pavement such as those covered by snow and ice. So, about fifteen years ago I began using a walking stick in winter. It was a bright red walking stick I had purchased in the early 1990s in Zermat, Switzerland, so I could delude myself that I was getting ready to scale the Alps. At least it didn't look like I had purchased it at a medical supply store. For the last two years I have been using the stick whenever I have any distance to walk. It helped give me stability and prevented several falls. But I could tell from the increasing pain and decreasing distance that I was willing to walk that I needed to think about getting a scooter. In the summer of 2004 I purchased a Volvo station wagon that was capable of hauling a scooter, but I wasn't yet ready to get the scooter. Finally, in the summer of 2006 I decided it was time to get serious about a scooter and stair glides, as I was deciding

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not to do too many things because of the pain it would cause. I checked with friends in the support group about reliable suppliers as well as with colleagues at the Lehigh Valley Center for Independent Living, where I serve on the Board of Directors. I was able to try out three different scooters to see what worked best for me and which fit in my station wagon. My wife and I also decided to put in two stair glides. We had considered moving and had looked at ranch houses, but the prices were high and we liked the house and neighborhood we lived in. In August both stair glides were installed so that I could easily get to the upstairs and to the basement (that way I could help with laundry). I also bought a scooter (a Pride Revo) and had a lift installed in the Volvo so I could get it in and out easily. I began using these new devices immediately.

I think my biggest anxiety about these new technologies was using the scooter. Again, the stair glides were relatively hidden unless you came to the house. But the scooter would be right out there in public—no possibility of hiding if it was going to be useful. I was apprehensive about using at Muhlenberg College where I teach, but I had a few weeks before classes started to get used to using it on campus. I need not have worried. My colleagues and the students, when they arrived on campus, have been very accepting. Some have been interested in the scooter itself, others have asked about the reasons I use it, but most have simply accepted it as part of the scenery. I decided to be very open about why I need it, so I don't really mind the questions. It has made it much easier, and much less painful to get around campus. I no longer have to think "do I really need to go to the library" or "do I really want to go to lunch in the union." I just get on the scooter and go. My only challenge has been the automatic door openers. I have become the unofficial tester of door openers. The maintenance staff is very good at fixing them, but they do seem to stop working all too frequently. Winter and snow pose another challenge, but the crews have traditionally done a good job on clearing the walks, so I am optimistic.

In addition to using the scooter at school, I have used it at Wegmans, Target, and the mall at King of Prussia. I took it to Valley Forge Park and the Allentown Art Museum. I have been walking Abbey with the scooter. For several years our walks had been more of the "stroll and sniff" variety. She adjusted to the scooter very quickly and now enjoys longer and more vigorous walks.

As I got used to the new technologies and discovered that they were liberating in many ways, I began to think about why I, and perhaps others, so often resist using assistive technologies. After all, there are many other technologies I use without a second thought. I have worn glasses since second grade. This essay is written at the computer while listening to the radio. Technologies all. We use technology to heat and cool our homes and to transport us. But we resist when the technologies can help us deal with the impairments of post-polio. In part, that is because so much of society still views scooters or wheelchairs as emblems of disability. But if we buy into those social attitudes about assistive devices, we are the ones who become disabled. We are the ones who choose not to go places because it is too tiring or too painful. We are the ones who miss out on things we enjoy if we don't adopt the available technologies.

So far, people at the college and elsewhere are very accepting of the scooter. I have tried to project a positive approach to using it, treating it as just another piece of technology. Surely, if it is normal for many people to walk around the store talking on their cell phones (another piece of technology), it is normal for me—or you—to scooter through the same store. I know I waited too long to get both the scooter and the stair glides, in large part because I didn't want to admit that I needed them. Polio survivors, and others who need them, will be better off if we can think of assistive technologies as just another modern technology that help us live better and easier lives. Cell phones make for better and easier communication. Scooters and stair glides make for better and easier mobility. I am not sure I really love technology, and that includes computers, cell phones, and scooters, but I know that all three have made my life easier. We don't have to embrace technology, but at least let us use the technologies that improve our lives without fear or trepidation.



Muscle Cramps and Muscle Spasms

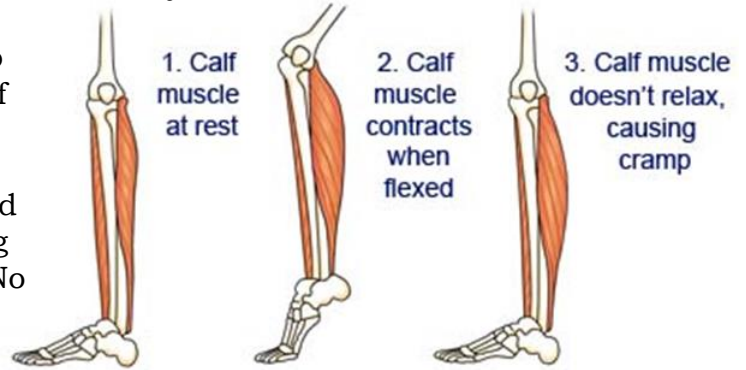
A [Bruno Byte](#) from the Post-Polio Coffee House

From [Richard L. Bruno, HD, PhD](#)

What is the Difference Between a Muscle “Cramp” and a Muscle “Spasm” ?

A muscle CRAMP is a short-lived, very painful, involuntary contraction of an entire muscle or a relatively large portion of a muscle, usually a leg muscle and sometimes a forearm muscle. Who hasn't had a screamingly painful cramp of the calf muscle that pulls your toes downward and forces you to stand to stretch it out?

A muscle SPASM feels hard, sometimes as hard as bone, and can be as small as an M&M or as big as the entire side of your neck or your low back. No one knows what spasms are or why they can hurt so badly! Spasms seem to be muscle fibers in a small area contracting into a dense knot and usually occur in postural muscles in the neck and back. But, in a 1990 study I did, there was NO relationship between how hard a muscle spasm was, muscle electrical activity and pain. So, a small, not-so-dense spasm in a neck muscle can cause a headache that puts you in bed for hours. But a large, dense rock of a spasm in your neck or back may not hurt at all even when a physical therapist puts her thumb in it.



A Question on the topic of Muscle Spasms upon Wakening (7/30/2017)

Original Post: When I wake up in the morning, before I can get out of bed I have to stretch and make my arms and legs go as rigid as I can. I have to do this two or three times before I can function properly.

Dr. Bruno's Response: Painful muscle spasms when you wake from sleep in the morning, which usually happens during REM (dream) sleep when your brain actually paralyzes your muscles, sounds like another polio paradox. But the clue as to why muscles go into spasm after you wake lies in the brain's ability to control your motor neurons and your muscles.

Spinal cord motor neurons are like misbehaving, stubborn children. They want to make muscles contract all the time. It's what motor neurons do! But, to prevent the "kids" from doing what they want their "parent," the brain, sends signals to the spinal cord telling the kids when and how much they should turn muscles on and, just as important, turn muscles off. If something interferes with the signal to turn muscles off -- like a sleeping, poliovirus-damaged brain -- the kids indeed do what they want: They turn muscles on! And when turned on for too long you get rigid muscles and painful spasms come morning.

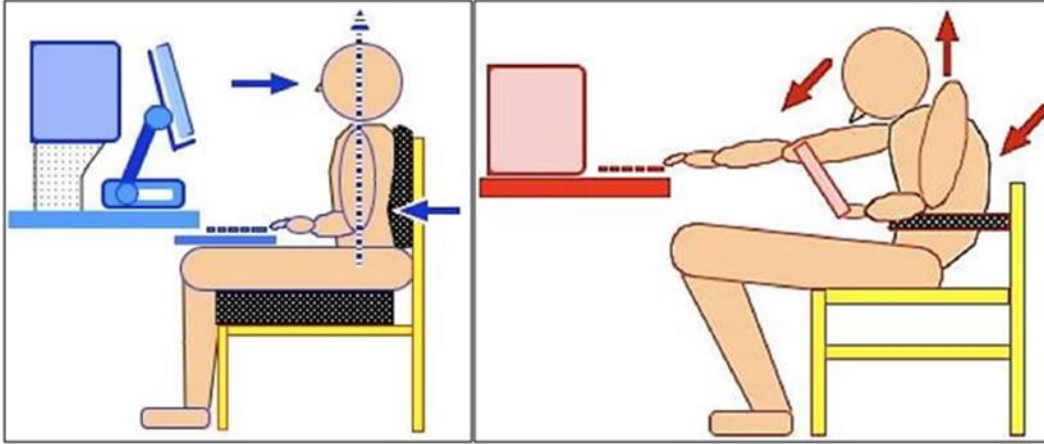
You can see the result of this brain/spinal cord disconnection in a condition that polio survivors know well: leg movements in sleep. Poliovirus-damage to brain muscle control neurons prevents the sleeping brain from automatically sending a "turn off" signal to the spinal cord and allows motor neurons to do what they want: Contract! Our studies of sleep in polio survivors found that these contractions don't just happen in leg muscles but can happen in muscles anywhere -- arms, abdomen, chest and, maybe most painfully, the back and neck.

How do you prevent sleep spasms? Since alcohol turns brain output signals down, you shouldn't drink in the evening. Over using your muscles during the day "irritates" poliovirus-damaged motor neurons and makes them more likely to cause those muscles to contract. Stretching and painless posture during the day, stretching and a hot bath before bed and keeping the muscles that spasm warm while you sleep (using a heating pad with an automatic shut off or a little dab of Capzasin) can help.



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In our experience at the treatment clinic of the Post-Polio Institute, the most effective treatment is 0.5 - 2.0 mg of alprazolam (Xanax) 30 minutes before bed. Alprazolam, like its grandfather diazepam (Valium), directly turns off spinal cord motor neurons during sleep when the post-polio brain can't. We hope your doctor won't say "No" to alprazolam because "it's addictive." The potentially addictive effect of the drug -- relaxation -- occurs when you can't feel it, i.e., during sleep. Alprazolam is a Valium-like drug that directly quiets the spinal cord motor neurons that cause your muscles to twitch at night. In 30+ years, we never have had a Post-Polio Institute patient become addicted to alprazolam or even require higher doses over time. Once the right dose is found, that's the dose the polio survivors' stay on. Sweet spasm-free dreams!



Bottom line:
Typically in Polio survivors,
muscle OVERUSE causes
cramps and muscle MISUSE
(e.g., poor posture)
causes spasms.

See the [POLIO SURVIVORS HANDBOOK](http://postpolioinfo.com) in at postpolioinfo.com for chapters on preventing cramps and spasms.

[Bruno Bytes](#)

As of this date, we have more than 2 ½ years of Dr. Richard Bruno's Q & A's accumulated in one place. Bruno Bytes are available on our website:

polionetwork.org/bruno-bytes

Looking for a specific topic? With Dr. Bruno's help, we have created an "Index" by [Subject](#).



Spinal Injections (and Sciatica vs Sacro Iliac pain)

[William M. DeMayo, MD](#)

DeMayo's Q&A Clinic



Question:

I have terrible pain in my lumbar spine. My medical doctor recommended I see a Spine Doctor. Two MRI's, showed bulging discs and curvature in my spine. He recommended spinal injections. After two, I was still in pain, so he asked me to come back for one more injection. While I was lying face down and supposed to be sedated mildly he injected the needle into my lumbar. I could feel the pain shooting down the back of what has always been my "stronger" leg. I've have been having shooting pain in that leg every day, since last October when I received the injection. I'm diabetic and these shots ran my sugar up. I'm very discouraged.

Reply:

The above letter brings up the common issue of back pain combined with radiating leg pain. In a future article I hope to discuss specific clinical issues including how to differentiate Sciatica (nerve root impingement by a disc) from Sacro Iliac joint – both can cause back pain and leg pain. In this article, I thought it would be helpful to remark on a few key phrases and words in the letter that might be helpful to readers in similar situations. These may reflect some common patient misperceptions and therefore present the opportunity for education.

- "Spine Doctor" In actuality, multiple different specialties can focus on management of spine problems. These can include surgeons such as neurosurgeons or orthopedists. Sports medicine physicians, rheumatologists, rehabilitation physicians, and primary care physicians can

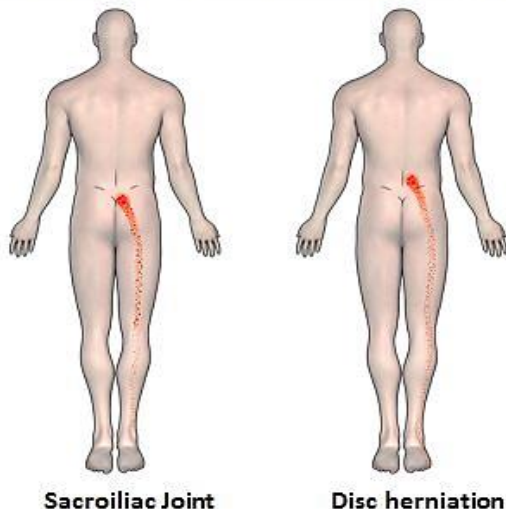
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all develop practices that focus on the spine. Additionally, physicians that perform spine injections can include anesthesiologist, neurologists, and rehabilitation physicians. Any of these physicians may be Board Certified in Pain Medicine but their background training specialty reflects how they approach patient care. In my opinion, it is important to research a physician before a visit to know the background of the person making the recommendations. Of the three specialties, a rehabilitation physician is much more likely to look at the biomechanical issues in polio patients and how this contributes to pain. To find a rehabilitation physician, check out the Physician Finder under the “About Physiatry” tab at aapmr.org. On the other hand, if a spinal injection is *clearly* indicated then anesthesiologists and neurologists are certainly more than competent at providing that service.

- “Bulging Discs” In actuality, bulging discs are extremely common and often are incidental findings that may cause no symptoms. If disc disease progresses and there is actual disc herniation on an MRI scan, the findings MAY be the cause of pain radiating down the leg (*if* the disc is pressing on a nerve with distribution that correlates to the pain). It is very common to see reports with nerve compressions on the opposite side or at a different level than the reported pain – those findings often need to be ignored. In a similar way disc extrusions (when the disc material has disconnected from the disc space) may or may not correlate with the clinical area pain. In my experience, many patients are told the results of an MRI scan and immediately assume findings are the cause of pain while the same findings could be found in a high percentage of people walking the street with no symptoms at all.
- “Spinal injection” There are actually a number of different types of spinal injections and patients should ask enough questions that they understand exactly what procedure is going to be performed. I suggest bringing a friend or family member as well as a notepad to appointments and writing down the exact procedure being proposed. It is rather amazing to me that so many individuals will allow a physician to stick a long needle in the back without clearly understanding where the needle is going.
 - Facet injections address the small joints between spine segments when they become arthritic.
 - “Nerve blocks” or “rhizotomy” procedures can also be performed for facet problems.
 - In the treatment of discs causing nerve impingement, Epidural Steroid Injections (ESI) are often done in a series of three.
 - If there’s no response to the first two, the third injection is usually not provided.
 - ESI can help avoid surgery while dramatically improving pain and function in appropriately selected individuals.
 - The procedure is safe and the epidural injection is the same one typically used during childbirth (with different medicine). This should say something about the overall low risk. I would not hesitate to have one myself, if indicated, since the long-term risks of pain/immobility can exceed the risk of the procedure.
 - Having said that, the question above could reflect transient injury to spinal nerve during the procedure which is a known but rare complication.
 - At the same time, ESI procedures are often recommended without clear indications. If the recommendation is made but the reasoning does not completely “add up” then a second opinion is suggested. As outlined below, the sacroiliac joint is a common source of pain in Polio survivors that can mimic nerve root irritation by a disc.
- Steroids certainly can raise blood sugar in diabetics. This is typically brief and not problematic unless individual has had control blood sugars to begin with. This should be discussed with one’s primary care physician and not presumed to be a problem.
- Lastly, it is important to understand that a good rehabilitation physician can differentiate between back/leg pains due to a disc causing nerve impingement (“Radiculitis” or “Sciatica”) as opposed to pain coming from the Sacro Iliac Joint. The latter is extremely common in polio survivors due to the fact that muscle weakness/imbalance, gait abnormalities, and differences in leg length put enormous stress on that joint. As noted above, this is the subject for another article however some differences are noted on the next page.

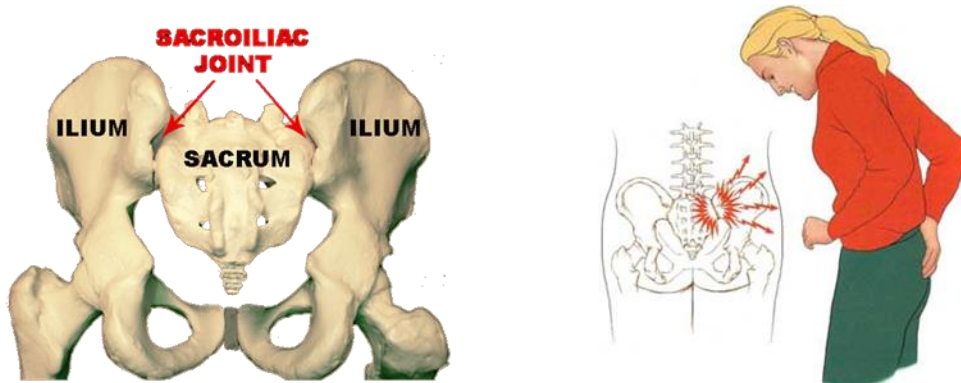
- “Sacro Iliac” pain starts a bit lower than Disc Herniation pain. BOTH cause pain down into the buttocks and leg.

Sacroiliac Joint mimics pain pathways of disc herniation

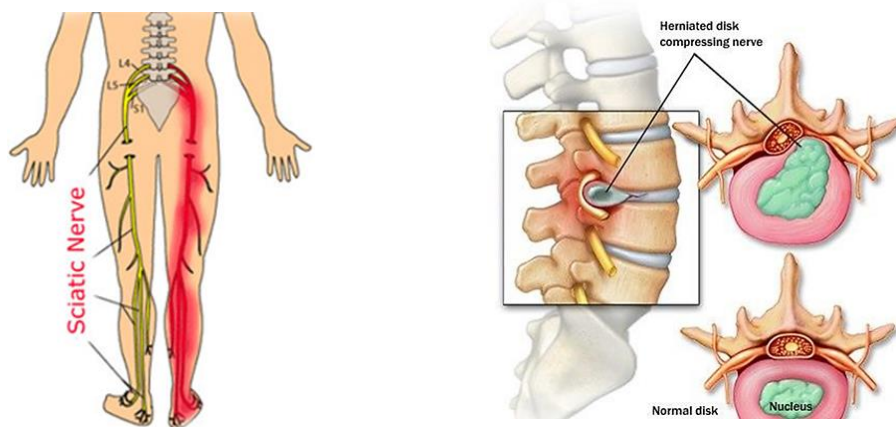


Note: This is pain from Disc Herniation *without* Nerve Compression. See below for Nerve compression pattern.

- Sacro Iliac pain is due to the SI joint. Pain can be constant or it can come and go as the joint is stressed. Sometimes there is “popping” in and out of place.



- When disc herniation causes “Sciatica” (and presses on the L5 or S1 nerve roots that merge into the Sciatic nerve) the pain usually goes all the way to the foot.



Please watch for future articles where we will hope to further discuss the above and address other treatment options. While both Sciatica and Sacro Iliac pain can be appropriately treated with injections, there are many other approaches which should first be considered including exercises and changes to how one sits and walks.

[William M. DeMayo, MD](#)

Conference Location and Registration Information:

Questions? Conference Contact Information:

Cranberry PA -

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Doylestown PA -

Telephone: 267-798-9664 (or) Email: poliojim1945@gmail.com

Hanover PA -

Telephone: 717-969-5049 (or) Email: debs7oaks@gmail.com

Webcast -

Email: info@polionetwork.org

Post-Polio Care
Past, Present and Future
An Interactive Video Conference Presented by:



Featured Speakers:
Dr. William DeMayo, MD and
Dr. Daniel Wilson, PhD.

August 26, 2017

Cranberry, Doylestown and Hanover, PA Locations
Multiple Viewing Opportunities.

Join us.

With gratitude to a local printer here in Doylestown, Pa; we are able to offer this full color newsletter by US Mail, for a very reasonable annual price. Details are [available](#).

From Post-Polio Health International
WE'RE STILL HERE! 2017 Photo Contest
"Aging with Dignity"



Aging is inevitable and well-earned. Aging with the late effects of polio is perplexing and challenges our inner resources. Aging grants wisdom and time for reminiscing.

What photo represents your acquired wisdom?

What photo would best represent your approach to aging?

Send us a photo that illustrates aging from your point of view!

"Even if your body doesn't work the way it used to, the heart and the mind and the spirit are not diminished.

It's as simple as that".

Christopher Reeve

Thank you

We are truly grateful for your kind words of support. Your generous [donations](#) are the key to helping our work continue.

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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