January 2016

It’s hard to believe we began this journey just one year ago.
We have been very grateful for your feedback.

Since then, we have been striving to follow our mission:
“To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor’s Families and their Caregivers”.

Our website contains articles and information from the most credible sources.

Editor’s Note:
The new year is upon us, with new ideas and some changes. This is the first issue of our “reformatted” newsletter. There will be fewer direct internet “links”, making copying easier.

We are happy to be publishing our first article, from Dr. William DeMayo, MD, “Post-Polio Back Pain”. Dr. DeMayo has nearly 30 years of clinical experience in the field of Physical Medicine & Rehabilitation. He has served as the Medical Director for several comprehensive inpatient rehabilitation units and has also maintained an active outpatient practice. His areas of special interest have included Spinal Cord Injury Medicine, Polio, Charcot Marie Tooth, musculoskeletal/neuropathic pain management and bracing. He will be answering your questions monthly. Do you have a question for Dr. DeMayo? Please email us at papolionetwork@gmail.com

“Bruno Bytes” (Tips and Tidbits from the Post-Polio Coffee House and the International Centre for Polio Education) has more information than ever. Dr. Richard L. Bruno, PhD has been giving us graphics that although don’t appear on our website, have been inserted into the “printable” PDF format. You will find these very informative Q & A’s at the bottom of this page on our website: http://www.papolionetwork.org/bruno-bytes.html. Are you having a difficult time “downloading” and printing them? Please email us. We’re happy to send them to you.

PPSN Thanks Rotary International for Their 30 Years of Dedication and Support to Eradicate Polio.
Their motto "End Polio Now" is an inspiration for us all.

It is one of our goals to publish a new “Survivor Story from the Keystone State” on a regular basis. Would you like to tell your story? Please let us know.
Your story can inspire others to know that we’re not alone.
A member of our team would love to help you through the process.

www.papolionetwork.org
Contact Us: papolionetwork@gmail.com (or) 215-858-4643
Question:
I'm 70 years old. I contacted Polio in 1948 (when I was 3). I had 2 long stays at Warm Springs in Georgia. I went to the Shephard Center in Atlanta for many years and they helped me until the clinic shut down. Currently, I just see a regular medical Doctor.
I'm in constant back pain and my shoulder pain hurts so much I can't sleep at night. All the doctor will supply is Tramadol and it does not help at all. Why is it so hard to get pain medicine that will help me? Please help.

Dr. DeMayo's Reply:
Lack of access to a designated post-polio clinic is obviously a problem of increasing frequency among polio survivors. At the same time, some issues such as low back pain and shoulder pain can often be treated by well-trained rehabilitation physicians or therapists. A good understanding of Biomechanics is the key. Biomechanics includes understanding of how the body moves, the stabilization of the skeleton by muscles, and the normal / abnormal forces transmitted through the body with activity. It is a central part of training for any rehabilitation physician or therapist. I have included a few graphics to provide an idea of how we look at biomechanical forces (my goal with the graphics is to just give you an appreciation of the concepts rather than detailed information on the issue).

A sports medicine physician or therapist will study the biomechanics of the shoulder intensely to help a pitcher improve his throw or rehabilitate from an injury. Similarly, in treating a polio survivor, attention to biomechanics (even without specific polio experience) can be much more effective than any pain medication. This is because most pain medications prevent transmission of pain signals rather than prevent the pain. As an example, Sacroiliac Dysfunction, Facet Arthritis, and Lumbar Spinal Stenosis are common causes of back pain in the general population and the biomechanics will be understood by any quality rehabilitation physician or therapist. These diagnoses are typically some of the most common in polio survivors due to the effects of leg length discrepancy, gait deviations, and asymmetrical muscular stabilization.

A physician or therapist who is not experienced with Polio may not initially recognize these biomechanical issues and so it is helpful for the polio survivor to point out “my left leg is shorter”, “my right hip is weaker than the left”, or “I have more (or less) back pain when I use my leg brace”. Bracing biomechanics can often be important and this is an area that some rehabilitation physicians or therapists get “rusty” if they don’t treat many patients that use braces. Despite this, they should be able to understand the issue IF they engage it.

With regard to shoulder pain, biomechanics is again a key issue. Rotator cuff tears/tendinitis, Impingement Syndrome, and Myofascial pain are all common in polio survivors with shoulder pain as well as in the general population. Because muscles are the key stabilizer of the shoulder, asymmetric weakness or over use of muscles can have significant biomechanical effects. Most rehabilitation physicians or therapists understand the biomechanics and can help polio survivors IF they engage the issue and are aware of the weakness or overuse.

While primary care physicians, orthopedic surgeons, and pain clinics have a role in managing chronic pain; Continued . . . .
polio survivors are likely best served initially by working with a rehabilitation physician or physical therapist because they are more likely to understand the underlying biomechanics. In an ideal situation, one would have a rehabilitation physician and therapist working together. Therapeutic exercise, education on biomechanics/pacing, physical modalities, and medications/procedures can all have a role in an individualized rehabilitation plan. A rehabilitation physician (Physiatrist) can be found at AAPMR.org. Given the broad diversity of populations served by Physiatrists, it would be appropriate to “shop” for a specialist that will meet one’s individualized needs. Local Post-Polio support groups can also be a great place to hear about physicians willing to engage these issues. Most rehabilitation physicians will recommend specific therapists they refer to and regularly communicate with. Conversely, if you find a good therapist, ask what rehabilitation physician they would recommend. Lastly, while shoulder pain is a common cause of lack of sleep, it is also important to understand that lack of deep sleep is an important factor perpetuating chronic pain. A comprehensive rehabilitation plan should also work on sleep as an independent factor.

Perhaps the most important thing for a patient to look for is a physician who takes time with them, listens and “has the heart of the teacher”.

(Note: Graphics from commandfitness.com, eericdalton.com, fixyourrun.com, and pponline.co.uk)

Do You Have a Question for Dr. DeMayo?
The answer to your question could help many other Polio survivors. (Your name will remain confidential)

Email us at: papolionetwork@gmail.com (or) Feel free to Call us – 215-858-4643

For Polio Survivors with Breathing Issues: A Place to “Ask the Experts”
Welcome to The BreatheBB Forum!
From Dr. John Bach, MD

Learn about NVS | Share info with their physicians | Receive optimal care

New for 2016
This forum is for all people who can benefit from noninvasive ventilatory care. This includes people with critical care deconditioning or neuromuscular disease, their families, friends, caregivers, and physicians. BreatheBB is a community forum where you can get critical information that cannot be obtained anywhere else.

First, please visit BreatheNVS.com (NOW LIVE!!) for general information about noninvasive ventilatory support (NVS) and for specific noninvasive outcomes pertaining to the diagnosis of your concern.

Then, if you like, return to BreatheBB.com to ask questions, discuss concerns, uncover insightful advice from people who already benefitted from this, and share experiences. Find your diagnosis-community below and discover how NVS has helped so many people.

Sincerely,
The Breathe BB Team
http://www.breathebb.com/viewforum.php?f=36&sid=206338be02b49f7904d0b47c8be11627
The “End” of Polio?
A Bruno Byte “Tidbit” by Dr. Richard L. Bruno, PhD.
December, 2015

There are significant concerns about “The End of Polio.” For every symptomatic case of polio as many as 200 people carry the poliovirus for months in their intestines with NO symptoms but can spread the virus everywhere they go. We will need to wait 6 more years to see if the new deadly mutation of Type 1 poliovirus that killed 40% of young adult cases the Congo is gone. If not, who will pay for a brand NEW polio vaccine for the mutated Type 1 virus? Probably the US, since Americans are not protected by the current vaccine.

As for eradication of “polio,” only the 3 poliovirus strains are targeted. There are as many as 100 OTHER polioviruses that do identical damage to the brain and spinal cord and have similar if not identical clinical presentations and similar life-long impact. The sad example of this is India where there were 200,000 Type 1, 2 or 3 poliovirus cases each year. Now there are no Type 1, 2 or 3 poliovirus cases. Instead, there are 60,000 cases each year of paralysis and death caused by some of the OTHER "polioviruses" for which there are NO vaccines, cases seen throughout India, documented by the Indian National Polio Surveillance Program and by papers published in Indian medical journals.

"The 60,000" are clearly an embarrassment. A few years ago the Indian Parliament asked me to create post-polio clinics in India. The Indian Medical Association was ready to disseminate Post-Polio Institute treatment information across India, the first hospital clinic was designated and staff ready for training. Then I asked that polio survivors as well as those paralyzed by the "other" polioviruses be treated at the clinics. The Indian government cancelled the post-polio clinics and doctor training; my e-mails were no longer returned.

Crying Wolf AND Closing Our Eyes

In the US we saw EV-68 cause 101 cases of muscle weakness and a few of paralysis during the summer of 2014. Some doctors were screaming about the birth of "new polio epidemics" and the need for a new vaccine. This past summer? We saw no EV-68 epidemic NOR a new vaccine.

EV-71 caused widespread paralysis in Brazil about 10 years ago. And West Nile virus, not a polio enterovirus but one carried by mosquitoes, caused an epidemic of US cases more recently with damage and symptoms identical to polio plus a "post-West Nile" syndrome identical to Post-Polio Sequelae. Is there a West Nile vaccine? Nope.

The Chinese are reportedly working on vaccines for some of "the other" polioviruses. And well they should. Our research and a study published in May 2015 found that the triggers for US polio epidemics beginning in WW II were the movement of large numbers of people from rural areas to the cities and their crowding into apartment buildings, exactly what’s happening in China today. But in India alone, the West is trading at least 200,000 Type 1, 2 and 3 polio cases for 60,000 "other" poliovirus cases each year while hoping the insane radicals in Pakistan and Afghanistan will stop shooting polio vaccinators, allow vaccination and eventually eliminate the "original" poliovirus.

As for the hundreds of thousands of "other" poliovirus cases around the world each year who ultimately go on to develop PPS, they’ll have to fend for themselves with even fewer resources than American polio survivors with Post-Polio Sequelae.

My fear?
“Polio Gone. Polio survivors? Completely forgotten.”

Continued . . . .
“Bruno Bytes” From the Post-Polio Coffee House
2016 has started off with some very interesting Questions from Polio Survivors and Responses from Dr. Richard Bruno

On the topic of “Non-Paralytic” Polio  (January 5, 2016)

Original Post: Why is it when polio is discussed in literature only “paralytic” is mentioned: Bulbar and Bulbar/Spinal. Is “Non-Paralytic” the ugly step child?? When I was talking to a doctor today he said NO SUCH THING AS NON-Paralytic. He acted as though I knew nothing at all.

Dr. Bruno’s Response: ”Non-paralytic” polio can mean that you had:
1) No poliovirus invasion of neurons and no neuron damage;
2) Widespread neuron damage that was not severe enough in any spinal cord or brain area to cause symptoms that could be detected but that now leaves you vulnerable to Post-Polio Sequelae;
3) Neuron damage that was severe enough in a spinal cord or brain area to cause symptoms, symptoms that were not obvious but could be detected had someone tested you.

Two studies during the polio epidemics found that as many as 40% of ”non-paralytic” polio survivors had detectable muscle weakness WHEN THEY WERE TESTED in hospital.

Once again, as with "the 3 types of polio," there is a semantic problem, here the difference between the physiology and clinical findings: "Non-paralytic" polio meaning no neurons damaged and "non-paralytic" polio meaning nobody bothered to see if you HAD muscle weakness caused by neuron damage.

Additional Bruno “Bytes” (in their entirety) are available for you to read and share on our website: http://www.papolionetwork.org/bruno-bytes.html

Scroll down the page (through the current month posts). Previous months are located there, and are available in an easy downloadable PDF format for printing.
The Benefits of Staying Engaged in Life – Despite Chronic Pain
Posted by Post-Polio Health International

What is this research about?
Many people experience chronic pain along with conditions like multiple sclerosis or spinal cord injury. Chronic pain is pain that lasts a long time. It often doesn’t go away with medications. It can also get in the way of doing things like working, socializing and enjoying hobbies. We now know that people’s thoughts and reactions to their pain can have a strong impact on how much the pain affects them. Our researchers looked at one of these factors -- a factor called “pain acceptance”. Pain acceptance involves being OK with experiencing pain and continuing to do things we enjoy and care about in spite of the pain. In our research, we wanted to find out how pain acceptance might affect people’s lives and well-being over time.

What did the researchers do?
We sent two surveys to about 400 people who had either muscular dystrophy (MD), multiple sclerosis (MS), post-polio syndrome (PPS), or spinal cord injury (SCI) and said they had chronic pain. We sent the two surveys about three years apart. On the first survey, we asked questions about pain acceptance, such as “I am getting on with the business of living regardless of my pain”. Then, on both surveys, we asked people how bad their pain was, how much it got in the way of their lives and activities, how well they could do physical tasks, and questions about any problems with mood or sleep. We looked at how the participants’ answers to these questions changed over the three years, and if they were related to how much they accepted their pain in the first survey.

What did the researchers find?
The people who told us that they accepted their pain more at the first survey told us that they felt better over time. Their pain was less likely to get worse, they had more improvements in mood and sleep quality, and they reported more improvements in pain interference.

How can you use this research?
If you have chronic pain, staying involved in activities despite pain may help you feel better over time. Here are some ways to manage your pain and stay active:

1. Focus on doing activities that make you happy such as spending time with family and friends, volunteering in your community, or making art or music. If it’s difficult to do everything that you used to do, focus more on a few activities that you really enjoy and give your life meaning.
2. Exercise regularly. Even gentle exercise or stretching, can help manage pain and improve your physical abilities. If you aren’t currently exercising, talk to your healthcare provider or a physical therapist about starting an exercise program.
3. Relaxation and meditation can help make pain feel more manageable. In particular, mindfulness meditation involves focusing your attention on the present moment and becoming more aware of your thoughts and reactions to pain. Learn more about mindfulness meditation here.

Things you should know:
Staying involved and engaged in life despite pain can improve your well-being over time. Happiness is an important part of living well with chronic pain.

http://agerrtc.washington.edu/node/243

20 Things Wheelchair Users Need to Know
(Continued Next Page)
20 Things Women (and Men) in Wheelchairs Should Know

Posted by ROLAND REZNIK ([http://kdsmartchair.com/blogs](http://kdsmartchair.com/blogs))
November 20, 2015

Daily life for women (and men) who use a wheelchair is filled with unique obstacles. Non-wheelchair users may say odd or rude comments to you, the bathroom mirror is usually located too high for your to see yourself and people seem to pity you for no reason. It’s time to confront these daily naissances and obstacles and present your best self. Below is a list of 20 essential things women (and men) in wheelchairs should know. We have listed 10 of the 20.

1. Ignore Back-Handed Compliments
Almost every girl (woman) in a wheelchair has been on the receiving end of back-handed compliments. The most popular being “You’re so pretty for a girl in a wheelchair,” “It’s so great to see out and about,” “You’re so brave,” and “You’re an inspiration.” People who make these comments are obviously naïve about living life in a wheelchair. You are just like everyone else in the world, human! If they want to put you on a pedestal and label you as brave and inspirational, so be it and just ignore it.

2. You Will Surprise People
Some non-wheelchair users will often be surprised by a lot of things you do, say and experience in life. For some reason these people have a vision in their mind that wheelchair users are limited and this is farthest from the truth. Yes, you do experience more obstacles than others, but your quality life is just as extraordinary as everyone else’s. Get use to seeing surprised looks on people’s faces when they find out you travel to exotic destinations, play sports, have fun and party with the best of them.

3. Invest in a Backpack
Purses are awesome, pretty and depending on the size can fit plenty of essentials. But, they also are bulky, take up space on your lap and are difficult to store on the side of your wheelchair seat. Hanging your purse on the back of your wheelchair is dangerous because it can drag on the floor and fall off easily. Backpacks are all the rage these days. They come in a multitude of colors and styles that will perfectly express your personality and style. They are also easy to put on the back of your chair, often have plenty of pockets to store items and are convenient to use.

4. Accessorize Your Wheelchair
Make your wheelchair as convenient and stylish as possible. Add accessories such as a phone carrying case, flashlight, cup holder and more.

5. Avoid Becoming Your Friend’s Cloakroom
This is easier said than done. Your non-wheelchair using friends may want to load your chair with coats, purses and more while out and about around town. Maybe one or two things is ok, but don’t let them overload your chair. These items can weigh you down and get caught in your wheelchair tires causing damage to your wheelchair and more importantly, your shoulders.

6. High Waist Bottoms and Long Tops Are Your Best Friend
Often shirts naturally rise up when sitting for long periods of time in a wheelchair. High wasted bottoms such as pants, shorts and skirts will eliminate any unsightly bulges and long tops will make your waist look longer. Invest in these types of clothing items to perfect your style and look.

7. Your Wheelchair Will Filter Your Friends
Sometimes all people see is a wheelchair instead of the amazing person sitting in it. If new found friends are always focusing on your wheelchair or making a big deal about it, they may be difficult to deal with on a regular basis. Also, some people are quite cruel and may avoid being your friend because of your wheelchair.

8. Learn to Think Outside the Box
You know you are met with obstacles, but don’t let them hold you back from living your dreams. Learn to think outside the box to achieve your goals. You may have to go about things differently but that’s what makes you unique.

9. Keep a Sense of Humor
You experience a variety of things every day. Some issues and topics that you are confronted with can really make you angry. But keeping a sense of humor and not sweating over the small stuff will make your day go smoother and prevent you from feeling angry on a daily basis.

10. Wear Long Clothing Items With Caution
Scarfs, coats, long skirts and other long clothing items must be worn with caution. These items easily and frequently get caught in wheels or drag on the floor picking up dirt and stains, as well as causing a variety of wardrobe malfunctions. The full Article (and others relating to Living with a Disability), is available on our website: [http://www.papolionetwork.org/about-being-disabled.html](http://www.papolionetwork.org/about-being-disabled.html)
It’s January, and it’s COLD. Going to Florida this winter?
There are active Support Groups all over the Sunshine State, and they LOVE Snowbirds.

All the contact information is on our website:
http://www.papolionetwork.org/support-group-information.html

Not on the Internet? Need help getting the information? We’re happy to help. Email us at: papolionetwork@gmail.com (or) Call us: 215-858-4643

As always, we hope the information we’ve provided in this January News Update has been informative and inspirational.

“
You have permission to rest.
You are not responsible for fixing everything that is broken. You do not have to try and make everyone happy. For now, take time for you. It’s time to replenish.
- UNKNOWN

Stay Warm and Stay Well.
You’re not alone. We’re here to help.

The Pa. Polio Survivor’s Team

www.papolionetwork.org
Contact Us: papolionetwork@gmail.com (or) 215-858-4643