



Pa. Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.papolionetwork.org

October 2019

Our Mission:

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

Bruno Bytes Cover Three Different Topics this Month.

[Dr. Bruno](#) talks about PPS as it relates to:

Immunity, Kidney Disease and Post-Polio Sequelae.

Note: We will now be updating Bruno Bytes on a quarterly basis.

Look in your inbox for 4th Quarter 2019 tidbits from the Post-Polio Coffee House in early January.

As we look at our medical insurance for the new year, we are continuing our series on Primary Care Physicians (PCP).

Our September issue talked about “why” they do what they do. This month, we found some great information on strategies to search for one that is right for us.

[Dr. William DeMayo, MD](#) has shared his very experienced advice on expectations regarding our PCP and their in depth knowledge of the late effects of polio and PPS.

Thank you to our friends in Australia.

They have multiple organizations providing care and information for polio survivors.

Spinal Life Australia is hosting a conference featuring Dr. William DeMayo, MD, at 8pm EST, on World Polio Day (October 24th). Although he will actually be in Abu Dhabi, through the beauty of technology, he will be part of a live Q&A, available to ALL polio survivors and our caregivers worldwide.

They have extended the registration for subscribers to be able to watch the live stream event. Please email: jkretschmann@spinal.com.au BY October 23. They will send you all viewing instructions. **Note: The video will be available for 24 hours.**

Polio Australia published an outstanding description of the Late Effects of Polio (LEOP). We are happy to be sharing it this month.

And speaking of our friends in Australia . . .

What are the Late Effects of Polio/Post-Polio Syndrome?

Post-Polio Sequelae

Years after contracting the initial polio infection, increasing numbers of polio survivors in Australia have developed a range of symptoms, now recognized as post-polio sequelae.

The time lag from the initial infection to this second phase varies but is commonly approximately 30 years. The onset is usually slow and steady. It may occasionally develop suddenly and progress at an irregular pace. Symptoms sometimes emerge after a period of physical or emotional strain, or after a period of immobility (for example, disease or surgery).

The post-polio sequelae cause a range of debilitating health effects, and manifest primarily as biomechanical and neurological symptoms. The condition is referred to broadly as the Late Effects of Polio (LEoP) or, in circumstance where specific clinical diagnostic criteria are satisfied, as post-polio syndrome (PPS).[1]

Post-Polio Syndrome

PPS is a diagnosed neurological condition which will affect up to 40% (depending on the study) of people who had “paralytic” polio. The main symptom of PPS is new muscle weakness that gradually worsens. It is often accompanied by decreased muscle endurance during activities, muscle and joint pain, muscle wasting, muscle spasms/twitching, and severe fatigue. These problems usually come on gradually, but may start suddenly following surgery, hospitalization or being confined to bed. Even muscles that were believed to be unaffected by the previous bout with polio may be affected. The March of Dimes International Conference on Post-Polio Syndrome identified the Criteria for Post-Polio Syndrome [2] as:

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.
- Symptoms persist for at least a year.
- Exclusion of other neurologic, medical and orthopedic problems as causes of symptoms.

The Late Effects of Polio (continued . . .)

Paralytic Polio vs Non-Paralytic Polio – What is the Distinction?

The diagnostic distinction between “paralytic” and “non-paralytic” polio was entirely arbitrary during the epidemics of the last century. In fact, the category of non-paralytic polio contained many patients with mild or temporary paralysis and with encephalitis, which occurs in people reaching the later stages of this illness. Modern studies indicate that overt paralysis in these people depends entirely on the percentage of spinal nerve cells destroyed. For damage to be visible as weakness or paralysis at least 50% to 60% of the nerves controlling muscular action must be damaged or destroyed.

It should be absolutely understood that patients who were told that they had ‘non-paralytic’ polio did, in reality, have polio, which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affect other persons with postpolio syndrome.

A Clarification of “Nonparalytic” Polio, Johnson, Ernest W MD
American Journal of Physical Medicine, Vol. 79(1), Jan/Feb 2000

Asserting that a history of paralytic polio is required for a history of PPS effectively, and incorrectly, says that no neurologic damage was done during acute nonparalytic polio.

Late Functional Loss in Nonparalytic Polio
Falconer, Marcia PhD; Bollenbach, Edward MA
American Journal of Physical Medicine, Vol. 79(1), Jan/Feb 2000

PPS must be considered in the differential diagnosis of individuals with unexplained fatigue and weakness ... regardless of whether they report a prior history of paralytic polio.

Late Functional Loss in Nonparalytic Polio
Halstead, Lauro S MD; Silver, Julie K
American Journal of Physical Medicine, Vol. 79(1), Jan/Feb 2000

Late Effects of Polio (LEOP)

The broader condition known as the Late Effects of Polio takes in both PPS and a host of additional ‘bio-mechanical’ symptoms including: scoliosis; kyphosis; respiratory problems; dysphagia (swallowing difficulties); muscle contraction; head, neck and joint aches; chronic tendonitis; bursitis; nerve compression; osteoporosis; arthritis; and fatigue; many of which will impact on virtually every survivor of polio. These symptoms vary considerably in the polio community, both in range and severity.

As both paralytic and non-paralytic polio survivors age, the neuronal ‘sprouts’ that supported muscle activity post-infection are degenerating as part of the ageing process, causing increased muscle weakness and atrophy, joint pain, and physical disability – even for those who appeared to have no residual disability at all.

Many of these symptoms may be confused with premature ageing, especially if the person was unaware of – or is unable to acknowledge – having been infected with polio.

Although there is currently no definitive data on the prevalence of LEOp/PPS in Australia, it is estimated that hundreds of thousands of individuals are either affected or at risk of developing the condition [3]. Many of those affected by LEOp/PPS are over 50 years of age, reflecting the fact that polio was an uncommon infection in Australia by the early 1960s. However, migrants to Australia from countries where polio was eradicated later, or where polio continues to be endemic, means that there is cohort of younger polio survivors who contracted their infection outside of Australia more recently.[4] LEOp/PPS is a condition that needs to be addressed now for Australia's aging polio population, with diagnosis and management required for at least the next 20 years. Younger polio survivors will require services for many more years to come.

Managing the Late Effects of Polio

A report Identifying Best Practices in Diagnosis & Care was another outcome of the 2001 March of Dimes Conference.[5] Polio-experienced health professionals recommend an interdisciplinary evaluation leading to a management plan that is designed specifically for the individual polio survivor.[5,6] The plan may include a variety of recommendations including:

- bracing to support weak muscles and/or over-used and stretched joints;
- use of walking sticks and crutches to relieve weight on weak limbs and to prevent falls;
- customized shoes to address unequal leg lengths, which can be the cause of back pain and requires extra energy to walk;
- use of wheelchairs or motorized scooters for long-distance;
- recommendation of weight loss;
- recommendation of specific select exercises to avoid disuse weakness and overuse weakness;
- management of pain through lifestyle changes, reduction of activity, pacing, stretching, and use of assistive devices;
- use of a breathing machine at night to treat under ventilation.

Many survivors report feeling better after adopting assistive devices and interspersing activities with brief rest periods.

Finally ... Be Careful When Attributing Symptoms to LEOp/PPS

Polio conditions exist along with other diseases. Therefore, it is important not to get hung up on a diagnosis of the late effects of polio and/or post-polio syndrome. Polio survivors and their medical professionals are encouraged to work together to find the causes of any symptom and provide appropriate treatment (for example, medication for hypothyroidism, hypertension, diabetes, irritable

The Late Effects of Polio (continued) . . .

bowel syndrome, and so on). An evaluation that too quickly determines that prior polio is the sole cause deprives survivors of potential treatments.[7] 4

References / Downloads

[1] House of Representatives Standing Committee on Health and Ageing, Discussion paper on the late effects of polio/post-polio syndrome, June 2012. (66 pages, 691.2 KB)

[2] March of Dimes International Conference on Post-Polio Syndrome, Criteria for Post-Polio Syndrome, 2001. (2 pages, 50.8 KB)

[3] Polio Australia Position Paper, Numbers of polio survivors living in Australia, April 2014. (2 pages, 170.8 KB)

[4] Polio Australia (Ms Gillian Thomas), Official Committee Hansard, Melbourne, 30 March 2012, p 5. (42 pages, 612.7 KB)

[5] March of Dimes International Conference on Post-Polio Syndrome, Identifying Best Practices in Diagnosis & Care, 2001. (28 pages, 218.0 KB)

[6] Polio Australia, Managing Muscles and Mobility, 2014.

[7] Post-Polio Health International Education Resource.

<https://www.poliohealth.org.au/late-effects-of-polio/>



The Role of the Primary Care Physician in the Life of a Polio Survivor

Dr. William DeMayo, MD.

On each of my several trips to Post-Polio Health International conferences, as well as on my recent three-week lecture circuit in Australia, I have been amazed at the number of individuals who see my specific expertise as “the missing piece” in their future health, yet their local therapists and primary care physicians (PCP) seem to be relegated to some distant and less important role. While I appreciate the importance of specific expertise in this sub-specialty area, I often find myself trying to bring folks back to their local resources. In my opinion, regardless of expertise, it is local therapists and PCPs that can have a much bigger role in long term health. The most obvious reason to conclude this is that a polio survivor’s health is not solely dictated by their history of polio. They are just as susceptible to the same medical conditions as everyone else. In fact, for some, a relatively sedentary life will make them more susceptible.

The following conditions each have an incidence of at least 10% in those over 65 and ALL ARE ON THE RISE in this age group:

- High Blood Pressure (55%)
- High Cholesterol (45%)
- Diabetes (20%)
- Cancer (>10)
- Mental Illness (>10%)
- Back Problems (>10%)

Multiple other conditions pose a significant threat of disability as we get older:

- Obesity
- Coronary Disease/ Congestive Heart Failure
- TIA/Stroke
- Arthritis
- Bladder and Bowel difficulties
- Infection
- Lung disease
- Kidney disease

Most individuals develop MULTIPLE chronic conditions as they age:

- For 65-75 year olds
 - >20% had a chronic condition
 - >50 % had two to four chronic conditions
- This trend increases after 75 years of age with
 - >20% having more than five chronic conditions.



Primary care physicians are the “go-to person” for nearly all the above conditions yet, somehow, their role seems to be minimized by many polio survivors. It has been my sense that this is, at least in part, due to a frequent “disconnect” that occurs when the issue of polio or post-polio related issues come up. Most PCPs willingly admit to a lack of expertise in this area and, sometimes, this creates a dynamic that their opinion on other matters is also downgraded. In fact, from my standpoint, it is unreasonable to expect that a PCP have extensive post-polio knowledge.

Rather than downgrading the PCP opinion on other matters, it is my opinion that polio survivors are better off being unusually grateful for the PCP. Since the vast majority of physicians went into medicine for good reasons, a statement like:

“I really need your help with ...” goes a long way.

Consider comments like:

“I really appreciate your keeping such a close eye on my blood pressure” (or)
“My polio slows me down enough, I’m really glad that you help me tightly control my diabetes, so I won’t have complications that worsen my disability.”

These comments will increase the connection rather than allow a disconnection that may result when a PCP is not familiar with concerns that relate to adaptation to slow progress of weakness and chronic disability (aka PPS).

Having said all of the above, most of us have noticed that medicine has been changing. There may be PCPs out there that just won’t engage. In this case: find another PCP. One physician’s lack of interest should not dictate a polio survivor to poor future health.

Polio survivors, as a group, have a long history of focusing on goals and making things happen despite adversity. It is surprising that in dealing with the healthcare system, some can become passive or even fatalistic.

In my opinion, the same “Can Do” attitude can be applied to assuring optimal

health care by working with the healthcare system to insure that it meets their needs. The stakes are too great not to address the issue. If developing polio is seen as a strike, and post-polio is a second strike, one more unmanaged (yet preventable) chronic condition could be the last strike leading to severe disability and loss of independent living.

In this light, one can say that the role of the PCP becomes even greater, not less, for aging polio survivors.

William DeMayo, MD
DeMayo's Q&A Clinic

Rev from original, by Post-Polio Health Vol. 33, No. 1 Winter 2017



Finding a Primary Doctor in the Digital Age

Reviewed by [Arefa Cassoobhoy, MD, MPH](#), September 20, 2019

Looking for a good primary doctor? Your best bet is usually word of mouth. But that's not so easy if you're new in town or your health plan limits the doctors you can see. What's more, you'll probably want to do some research after you get recommendations. Enter the internet. You read about restaurants and smart phones online. You can read all about doctors, too.

What to Search For:

The right fit for your insurance. First, ask your insurance provider for an up-to-date list of doctors in your network. Then look for primary docs in your area and start your search. Don't give up if you don't find everything in one place. Some websites list only the basics, like specialty and office location. To get a complete picture, you may need to check a few sources.

Hospital affiliation. If you need to go to the hospital, you usually end up wherever your doctor can admit people (called admitting privileges). But some hospitals are better than others and have better outcomes. Medicare's website has a feature called "Hospital Compare" that rates most hospitals, including VA and military medical centers.

Board certification. Choose doctors who are board certified. This means they have at least 3 years of advanced training (called residency) after medical school. They also have a license from a state medical board and they've passed certain tests. Most primary docs are board certified in family medicine or internal medicine. Kids' doctors are certified in pediatrics.

Make sure your doctor is board certified, not board eligible. The American Board of Medical Specialties has a website (certificationmatters.org) that can help you find out.

Black marks. Has a doctor harmed someone in their care? Have they been in trouble for other reasons? You might have to dig deep to find out. Start with the website of the Federation of State Medical Boards. It lists education, certification,



and license info, and you can find any actions against the doctor. You can also check with the medical board in your state. Or try a Google search.

Dollars for docs. Some doctors invest in companies that make drugs or medical devices like stents. Others get research money or other benefits from drug makers. All of this can influence how a doctor selects your treatment options. Medicare has a website (openpaymentsdata.cms.gov) that can tell you what you need to know.

Online Reviews?

You probably don't care much about where your doctor went to medical school. You probably do care if a doctor has a good bedside manner and can help you get well. But how do you know ahead of time? Websites where people review doctors try to answer that question. They usually rate how well the doctor: Listens, keeps on time, (and) explains medical problems.

They may even rate the office staff and how long you have to wait to get in. These reviews are fun to read, but they can have problems.

First, they're opinions, not facts. What one person thinks is a good doctor might be different from what you think. Worse, some reviews are phony or paid ads, but there's no way to find that out.

Get to Know Your Doc

After you do your homework online, go to one of the doctors you picked for your next appointment. See if you click. You should trust and feel relaxed with them. Did the doctor listen to you? Was the information you got from the doctor clear and easy to understand? Do you and your doctor see eye-to-eye on the goals of treatment?

If the answer to any of these is no, you might want to move on to your next choice.

Check Out the Office

If the staff isn't helpful and friendly, it might not be the right place.

You'll also want to know: How electronic medical records are kept, How things like follow up for labs and pharmacy requests work, What kind of online presence does the office have? Does the office have a place where you can see your records whenever you want? Can you make appointments, get lab results, or ask for prescription refills online? Can you email the doctor or nurse with questions or concerns?

Don't be afraid to "sample" a few doctors. This is one of the most important health care decisions you make. It's worth the time to get it right.

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Bruno Bytes

By: [Dr. Richard Bruno, HD, PhD](#)

Director, International Centre for Polio Education

www.postpolioinfo.com

On the topic of Post-Polio Syndrome, Kidney Disease and Liver Enzymes

Question: My Doctor has diagnosed me with chronic kidney disease from a blood test without a urinalysis. At one point he diagnosed me with a high homocysteine level. I read that certain renal problems can cause a false homocysteine level. I am concerned and confused that I might be possibly misdiagnosed because of the possible effects PPS can have on the kidneys. I am not sure what to do or believe. Can PPS have caused these findings in my blood work? I have looked at "kidney friendly" diets and they recommend cutting down on protein and other stuff that could help polio survivors with fatigue and bone issues.

Answer: Polio and PPS have no effect on kidney function. Kidney disease should be diagnosed by blood tests for [BUN](#), creatinine (NOT creatine) and [GFR](#), not homocysteine alone. A second opinion with a kidney specialist is in order. Talking to a dietician/nutritionist about diets that are "kidney friendly" is a good idea.

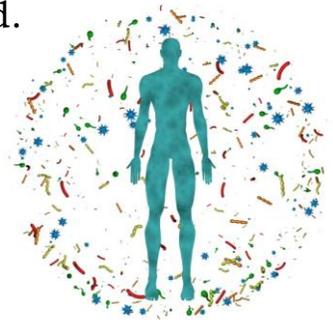
Additional Question: Is creatinine a liver enzyme? The last time I went to the doctor he said my liver enzymes were high and didn't understand why. Would this be caused from PPS?

Answer: Neither kidney function issues nor elevated liver enzymes are polio or PPS issues. And Creatinine is not a liver enzyme but a muscle breakdown product removed by the kidneys. Abnormally high levels of creatinine warn of possible malfunction or failure of the kidneys. It is for this reason that standard blood tests routinely check the amount of creatinine in the blood.

On the topic of Polio Survivors having Lower Immunity.

Question: A friend of mine insists that post-polio patients have a lowered immunity. I have never heard of this.

Answer: Polio does not cause lowered immunity. This is only an anecdotal finding, but I was always surprised that Post-Polio Institute patients didn't catch bugs floating around while non-polio survivors got sick.



On the topic of PPS vs Post-Polio Sequelae

Question: What is the Difference Between Post-Polio Sequelae and Post-Polio Syndrome?

Answer: "Post-Polio Sequelae" was coined by the always insightful Dr. David Bodian, at the First Warm Springs Conference on PPS in 1984. It means "the

sequel" to having had polio and refers to all of the things that could possibly happen to a person as a result of their having had polio (not just fatigue, muscle weakness and pain) but also brain stem damage causing slowing of their guts, heightened sensitivity to pain and to anesthesia.

“Post-Polio Syndrome” has many definitions but only refers to muscle weakness and, depending on who's suggesting the definition it could also cause fatigue and pain. Post-Polio Syndrome is a subset of Post-Polio Sequelae.

It is important to note that Post-Polio Sequelae is the diagnosis used by the US Social Security Administration to determine sedentary work disability.

Check out [The Encyclopedia of Polio and Post-Polio Sequelae](#) on our website.

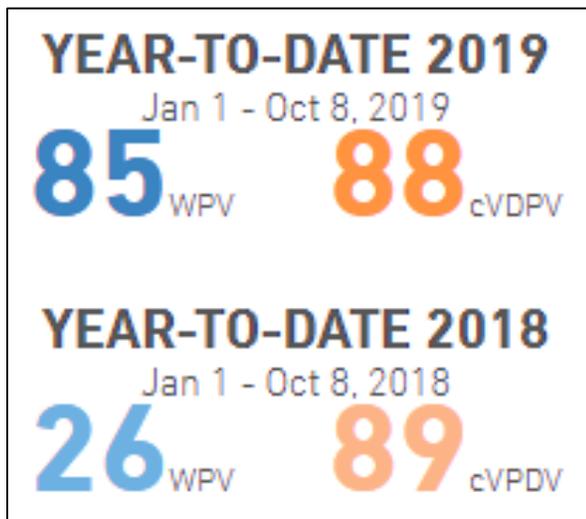
It contains all of Dr. Richard Bruno’s newly published and updated: articles, monographs, commentaries, videos and “Bruno Bytes” (Q & A articles). You can easily access it from Dr. Bruno’s website as well: www.postpolioinfo.com

We Always Like To End Our Newsletters On A Positive Note.

Thank you polio survivor Bill Peacock for providing this month’s message. There couldn’t have been a better way to describe your generosity as we celebrated working together as [Team Survivor](#) once again. When it comes to eradicating Polio, NO ONE is quitting and we won’t either. Our goal has been to bring our donations past the 40,000 vaccines mark this year. If you want to donate, please do so up until World Polio Day, October 24th.

We are survivors who are thriving as we join together to be part of the solution. Whether you donate \$5 or \$50, the Gates Foundation will match it 2 for 1. Together, we *are* making a difference.

We all understand that no child should suffer from a vaccine preventable disease. The pain and disability can last a lifetime.



WPV - Wild Poliovirus
cVPDV – Circulating
Vaccine- Derived Poliovirus

We are truly grateful for your kind words of support.



**Check out our “[What’s New](#)” page for the latest information.
We have two newly published Polio Survivor Stories**

Together, we *can* and *ARE* making a difference.



Always feel free to contact us.

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Contact us: Email: papolionetwork@gmail.com Phone: 215-858-4643
PO Box 557, Doylestown, Pa. 18901
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