

Bruno Bytes

First Quarter 2021

From Dr. Richard L. Bruno, HD, PhD Bits and Tidbits from the Post-Polio Coffee House

1st Quarter 2021 Topics Include:

Anesthesia, Catching Polio without knowing it, CoQ10, Diagnosis and Management of PPS, EMGs, Is Everything PPS?, Polio Survivor's "good" limbs, Muscle Weakness, Sprouting Neurons, "Types" of Polio.

On the topic of Anesthesia and Polio Survivors

ANESTHESIA and the CAUSE and TREATMENT of PPS.

This is not only a detailed article that will help anesthesiologists care for polio survivors, but also a review of the cause and treatment of PPS. https://pubs.asahq.org/.../Postpolio-Syndrome-and-Anesthesia

There are four links to Anesthesia Articles (under "Anesthesia") in the Encyclopedia of Polio and PPS.

On the topic of CoQ10

EFFICACY AND SAFETY OF CoQ10 FOR STATIN-RELATED MUSCLE PAIN.

Polio survivors often ask about muscle pain that can occur with statins and if there is a treatment. "A 2019 randomized controlled trial investigated the effect of CoQ10 on statin-related muscle pain. The study involved 60 participants who had previously reported muscle pain while



taking statins. Over 3 months, each participant received daily doses of either 100mg of CoQ10 supplement or a placebo. The participants who took the CoQ10 supplements had significantly reduced statin-related muscle pain. Those who received the placebo reported no change in muscle pain.

However, the authors of a 2015 meta-analysis evaluated the efficacy of CoQ10 supplementation for treating statin-related muscle pain. The meta-analysis included six studies with a combined total of 302 patients. The authors found no evidence that CoQ10 significantly improves statin-related muscle pain." https://www.medicalnewstoday.com/articles/327209#benefits

"Coenzyme Q10 is LIKELY SAFE for most adults. While most people tolerate coenzyme Q10 well, it can cause some mild side effects including stomach upset, loss of appetite, nausea, vomiting, and diarrhea. It can cause allergic skin rashes in some people. People with chronic diseases such as *heart failure, kidney or liver problems, or diabetes* should be wary of using this supplement. *CoQ10 may lower blood sugar levels and blood pressure*. Doses of more than 300 milligrams may affect liver enzyme levels." https://www.webmd.com/vitamins/ai/ingredientmono-938/coenzyme-q10

Always have blood drawn for creatine kinase (CK) **before** starting a statin and if you have muscle pain. And always talk to your doctor before starting anything you buy over the counter.

On the topic of Esophagus Spasms and Not Everything Being PPS

A REMINDER THAT NOT EVERYTHING IS PPS . . .

Esophagus spasms are not uncommon in polio survivors. At the Post-Polio Institute, we found that low dose Klonopin (clonazepam), taken 30 minutes before eating, is effective in treating spasms of the esophagus muscles that prevent food from going down. But, as always, you have to rule out causes other than PPS that may trigger muscle spasms or swallowing difficulty:

"I had spasms and choking where food would get stuck in my esophagus, very painful until food went down. Foods that would especially cause the choking were bread and spaghetti. I would even choke on my saliva at times. I also had a lot of coughing. This had been going on for many years. In the last year, I was embarrassed to go out in public because I would get strange looks when I started coughing because of COVID. I thought it was due to a sinus drip.

I mentioned choking, spasms and coughing to my doctor four months ago. He said symptoms were caused by acid reflux and not a sinus drip. He prescribed pantoprazole (Protonix). I went in for a checkup recently. He asked how were the pills working. I said they appear to be helping out a lot. Since I have been taking that medication I haven't been choking or coughing."

On the topic of Family Members/Friend Catching Polio Without Knowing it

From The Polio Paradox:

In 5% to 20% of households where poliovirus attacked one family member, another was also stricken. From 1909 to 1955 more than 2,000 family members in over 1,000 households were surveyed in which at least one person had polio. On average if one child in a household became ill he "shared" polio with one other sibling of similar age. Just over half of those who became ill were paralyzed. But others had flu-like symptoms ranging from a fever, sore throat and nausea to a stiff neck and muscle pain. This "minor illness" was caused by the poliovirus but may never have been diagnosed as polio at all, or may have been called "abortive" or "non-paralytic" polio. In three-quarters of the households the first case of polio was paralytic and the second was "non-paralytic."

BOTTOM LINE: there's about a 1-in-5 chance that if you had paralytic polio one of your brothers or sisters had non-paralytic polio and may not have known it.

On the topic of Polio Survivors and their "Good" Limbs

Now, About Your "Good" Leg

It's well-known that "good" limbs (those thought to be unaffected by polio) commonly show electromyographic (EMG) evidence of prior poliovirus damage to motor nerves. A large study from India brings home this point. (1) EMGs were performed on all four limbs (not something we recommend) in 116 polio survivors. In 42% of the limbs that survivors said were "unaffected by polio," EMG revealed evidence of poliovirus damage. On manual muscle testing, 26% of the "unaffected" muscles with poliovirus damage had decreased strength.

This study is a reminder that "non-paralytic" polio (NPP) wasn't necessarily "damage free" polio. For example, it was reported in 1953 that 39% of those diagnosed with NPP had measurable weakness on manual muscle testing in at least one muscle group. A 1954 paper - "The Infrequent Incidence of Nonparalytic Poliomyelitis" - documented that 89% of polio survivors who were acutely "persuasively nonparalytic" had "very definite muscle weakness" as long as three years after the diagnosis of NPP.

So, it should be no surprise that more recent studies have documented late-onset weakness and fatigue in NPP survivors. A study of 828 polio survivors found new muscle weakness and fatigue, respectively, in 38% and 34% of those who had been paralyzed and in 14% and 21% of those diagnosed with NPP. (2)

What's more, a study of 34 sets of twins found PPS symptoms in 71% of the twins who had had paralytic polio but also found "PPS-like symptoms" in 42% who had had no symptoms of paralysis. (2) I wasn't surprised when Post-Polio Institute patients would report that their "good" ("unaffected") muscles were becoming weaker while their obviously polio-affected muscles were not. Taken together, the studies above are reminders that overworking your "unaffected good muscles" could make a good limb turn "bad".

References:

- 1) Ann Indian Acad Neurol. 2016; 19(1): 44-47
- 2) <u>Bruno, RL. Paralytic Versus "Non-Paralytic" Polio: A Distinction without a Difference? Am J Physical Med</u> Rehabil, 2000; 79: 1-9.

On the topic of "Normal" EMGs in Paralytic Polio Survivors

Question: I have a friend who at age 79 is now developing weakness in the hips. She was around me when I got polio and her cousin was the carrier. The question is can she have a normal EMG and have had polio? The doctor told her that she could *not* have had polio because her nerves are fine.

Dr. Bruno's Responses: Studies show that a substantial percentage of polio survivors with a clear history of muscle weakness or paralysis have *normal* in-office EMGs, meaning that there was no EMG evidence that they ever had had polio (see above). One study using regular EMG found that almost 25% of paralytic polio survivors' limbs had no evidence of motor neurons having been killed.

What's more, using a special "macro" EMG found over-sprouted motor neurons in 85% of muscle that were thought to have had "no clinical polio." And research by David Bodian and Alan McComas showed that seemingly unaffected muscles had lost 40% of their motor neurons. So, a "normal" EMG is not evidence of the absence of poliovirus-damaged neurons.

Search "**EMG**" in the "Complete Index" and "Articles" sections of the ENCYCLOPEDIA of POLIO & PPS by Richard L. Bruno, HD, PhD

On the topic of Muscle Weakness

Question: Is the weakness associated with PPS generalized or can it be muscle specific?

Dr. Bruno's Response: Both, sort of. Weakness is caused by failure of individual motor neurons, not all of your motor neurons at once. And not all motor neurons were damaged to the same extent by the poliovirus. When you do manual testing of a given muscle, weakness is "specific". When you're doing your life, muscle weakness can feel "general," or maybe "generally" in the legs or the arms. Also, it's hard to separate "general" muscle weakness from fatigue, which is caused by brain neurons browning out.

BOTTOM LINE: Don't work until you feel "specific" or "general" muscle weakness. Muscle weakness and fatigue are your body's way of saying, "You've done too much!"

On the topic of Local Anesthetics

BUPIVICAINE: A long-acting local anesthetic for post-surgical analgesia.

Since we found in 1984 that polio survivors are TWICE as sensitive to pain as compared to non-polio survivors, you should talk to your surgeon about using BUPIVICAINE *before* you have surgery.

Local anesthetic injected into the surgical site is an important part of postoperative pain relief. A single dose of BUPIVICAINE injected into the surgical site has been associated with both pain relief for 72 hours and a 45% reduction in total opioid consumption at 72 hours.

www.formularywatch.com/view/liposomal-bupivacaine-long-acting-local-anesthetic-postsurgical-analgesia

On the topic of Neurons "Sprouting"

A new study found in fruit flies what's been known for 70 years to happen in polio survivors...

"What happens when a neuron dies? Can other neurons around it pick up the slack to maintain the same level of function? In the fruit fly, each muscle is activated by two motor neurons. Researchers wondered what would happen if one neuron were removed. Would the other neuron compensate for this loss? They found that the remaining neuron expanded its synaptic arbor ("sprouted") and compensated for its missing neighbor."

FROM The Polio Paradox: Axons Sprouts and Fat Fibers. Remaining, poliovirus-damaged motor neurons did something amazing after the poliovirus infection had run its course. The axons grew, sending out sprouts -- like extra telephone lines -- to turn on the muscles that were orphaned when their motor neurons were killed. Those sprouts took from nine months to 2 years to grow and ultimately activated about 16 times more muscle fibers than were connected to the motor neuron originally.

Yet another important process took place that allowed polio survivors to regain strength. Muscle strengthening exercise and physical therapy caused muscle fibers to grow larger, a process called hypertrophy, enabling the fibers to do more work. Polio survivors' individual muscles fibers have been found to be twice the size of fibers in those who didn't have polio. So, motor neuron recovery, sprouting and muscle fiber hypertrophy allowed polio survivors to get stronger after the poliovirus attack. A 1955 study by British polio pioneer W.J.W. Sharrard found that polio survivors regained nearly 95% of the strength they would ever recover during the first 11 months after the polio attack as a result of sprouting, muscle fiber hypertrophy and learning to use functioning muscles to substitute for those that were permanently paralyzed.

So, where do you stand (or sit) today with regard to your post-polio motor neurons? If you had any paralysis, muscles that you know were affected during the poliovirus attack have on average only 40% of the motor neurons you were born with, neurons that were damaged, are smaller than normal, whose internal "pipes" are clogged, but have sprouted to turn on 16 times more muscle fibers, fibers that are twice the size they were before you had polio. If you have muscles that were not paralyzed or had so-called "non-paralytic" polio, you lost 40% of the motor neurons you were born with, neurons that were damaged and are also smaller, clogged, over sprouted and overworked.

BOTTOM LINE: "Save Your Sprouts!"

https://www.newswise.com/articles/study-shows-how-some-neurons-compensate-for-death-of-their-neighbors?sc=mwhn

On the topic of the Diagnosis of "Post-Polio Syndrome"

Question: Is post-polio syndrome an accepted medical diagnosis or does every polio survivor of a certain age just automatically develop muscle weakness, fatigue and pain?

Dr. Bruno's Response: Polio survivors can develop new symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold intolerance, and difficulty swallowing and breathing – at any age. Not all polio survivors develop all of these symptoms and they don't automatically appear. But the presence of one or any number of symptoms in polio survivors, when other causes are ruled out, meet the criteria for accepted medical diagnoses:

"Post-Polio Sequelae" is the US federal designation since 2003 for late onset symptoms related to having had polio, which the Social Security Administration uses for disability determination. (www.ssa.gov/OP_Home/rulings/di/01/SSR2003-01-di-01.html)

"Post-Polio Syndrome" is the International Classification of Diseases (ICD-10) name (Code G14) for late onset symptoms related to having had polio. (B91 is the ICD code for the signs and symptoms of ACUTE polio and shouldn't be used for an adult with late onset symptoms.)

The name for the diagnosis and your age don't matter. The symptoms and treatment do!

Search "**Social Security**" in the "Complete Index" and "Articles" sections of the ENCYCLOPEDIA of POLIO & PPS by Richard L. Bruno, HD, PhD

On the topic of the "Types" of Post-Polio Sequelae

Question: After reading the PA Post Polio Newsletter I can't help but wonder if, since polio entered our bodies and affected our spinal cords, if spinal arthritis causing lower back pain another late effect of polio? I have a follow-up visit after my last epidural with my orthopedic doctor and he wants to talk to me about a possible Radio Frequency Ablation. Is that a good idea?

Dr. Bruno's Response: Arthritis isn't caused by the poliovirus but it is related to polio's effects.

I separate PPS symptoms into two groups:

DIRECT: symptoms caused by the poliovirus (e.g., muscle weakness)

INDIRECT: symptoms caused by problems *due to* poliovirus damage (e.g., arthritis)

For example, muscle weakness (see below) is obviously a DIRECT PPS symptom, directly related to overworked, poliovirus-damaged neurons. But, muscle weakness can cause INDIRECT symptoms, among them arthritis (in joints and the back), joint pain, deformities and pinched nerves (spine, wrists and elbows) and muscle pain.

While DIRECT PPS symptoms are often unique to polio survivors, INDIRECT symptoms (like spinal arthritis) can occur in anyone and often can be treated by doctors knowing nothing about PPS. In picking a treatment for back pain, you need to find out if the pain is due to the pinching of nerves as they exit the spine (radiculopathy) or central stenosis (pressure on the spinal cord).

Facet joint injections often help treat radiculopathy and epidurals help central stenosis. Radio Frequency Ablation should only be considered if injections fail and on the basis of what nerves are being pinched and where. A second opinion from another physician is always in order.

On the topic of Managing PPS

STRATEGIES TO SUCCESSFULLY MANAGE PPS

A far too long and turgid <u>article</u> reports the result of questionnaires being used to measure resilience and depressive symptoms in 630 polio survivors over age 65 who were diagnosed with PPS. Forty percent (40%) of the polio survivors scored as moderately to severely depressed, but 53% of the sample rated their health as good or excellent.

"These findings reveal a paradox," the authors admit. "How could depressive symptoms be quite pervasive, yet more than half the sample report good or excellent self-rated health?" the authors ask. And then they answer: the questionnaire that measures depression "may not fully control for the influence of fatigue and pain, known mediators of depression in disabled populations."

If a questionnaire uses the presence of fatigue and pain to measure depression in polio survivors, it's more surprising that *all* subjects weren't identified as "depressed." So bang goes their conclusion about polio survivors being moderately to severely depressed.

But, regardless of the shortcomings of the study, it did identify strategies to help successfully manage PPS that are worth a look (see next page). See if you already are using any of these and if some others could be helpful.

STRATEGIES TO SUCCESSFULLY MANAGE PPS

1. Psychological traits, values, social support and behaviors.

Read more about polio and PPS, have strong desire to learn, use cognitive skills, intelligence and feel a sense of mastery.

Feel you are growing and changing in positive directions.

2. Become more involved in interests you can still pursue.

Acceptance, self-confidence, belief in your own abilities, have multiple interests/hobbies.

Find each day interesting and pleasantly challenging.

3. Talk with family/friends about PPS.

Good communications skills, positive interpersonal interactions and commitment to satisfying relationships.

Be aware of what is important to you in relationships.

4. Develop new interests and leisure pursuits.

Wide-ranging interests, seek out new things, be creative, set goals, be achievement oriented, curious, recognize your internal control, adapt to changing circumstances, resourcefulness.

Expose yourself to new experiences and challenges.

5. Develop your philosophy of life.

Committed to reflecting on life over time, belief that self-knowledge is valuable.

· Feel content and at peace with yourself.

6. Develop your inner life.

Realize that life has a purpose, faith in a positive vision of your world, belief in self-help.

Believe your life has purpose and is worthwhile.

7. Choose to be optimistic.

Have a positive outlook, find positive meanings in experiences.

Feel you are growing and changing in positive directions.

8. Constructive problem solving.

Resourcefulness, take action, realistic appraisal of situations and capacities, repertoire of problem solving approaches.

Work toward short- and long-term goals in your life.

The Encyclopedia of Polio and Post-Polio Seguelae

contains all of <u>Dr. Richard Bruno's</u> articles, monographs, commentaries, "Bruno Bytes" (Questions & Answer articles) and his Video Library.

The Encyclopedia of Polio and PPS is also available by a direct link from: www.postpolioinfo.com

Are you looking for a specific topic?

The Encyclopedia Index (By Subject) is available by clicking HERE