



Bruno “Bytes”

July / August, 2019

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

On the topic of Adjusting to a New Brace 7/9/2019

Original Post: This is my new brace (MAFO, on the left) with shoes alongside my old-fashioned brace. The orthotist has said if this doesn't give my knee more stability then I will need a full length KAFO. It feels very strange and has altered my way of walking, but will it be an improvement? What does this do for my hip/pelvis and back, when I am not used to walking with the altered gait?

Dr. Bruno's Response: Notice that the new MAFO is standing up, not drooping forward like the old brace. The new brace is stiff, will help push your knee back and help a weakened thigh to help lock your knee, hopefully making a long leg brace unnecessary.

What does any brace do to other muscles and joints? Braces help stabilize weakened muscles but also put stresses on muscles and joints, therefore our rules for "bracing assistance:"

- If you use 1 AFO? Use a cane in the opposite hand.
- If you use 1 KAFO? Use 2 Loftstrand (forearm) crutches.
- If you use 2 BRACES? Sit and roll!



On the topic of two Medications and Dopamine 7/10/2019

Dr. Bruno's Original Post: **Rx Warning:** Wellbutrin and Buspirone should NOT be used by polio survivors since they stimulate dopamine receptors and dopamine neurons. The poliovirus damaged and killed dopamine neurons in the brain, making dopamine receptors more sensitive to stimulating drugs.

Rx Rule #1 for Polio Survivors: NEVER mess with dopamine in the brain!

See: [Elevated Plasma Prolactin And EEG Slow Wave Power In Post-Polio Fatigue](#). Implications for a Dopamine Deficiency Underlying Post-Viral Fatigue Syndromes.

You can find this under "Fatigue" in the [Articles](#) section of the Encyclopedia of Polio and PPS.

On the topic of Muscle Atrophy and PPS 7/19/2019

Original Post: Does PPS cause muscle loss or was atrophy caused by the initial polio attack?

Dr. Bruno's Original Post: Killing remaining, poliovirus-damaged motor neurons stops their ability to "feed" muscle fibers, which can then shrink. But I've seen very little muscle atrophy in 37 years of treating polio survivors. Post-polio muscle *weakness* is due to motor neuron brownout, not muscle atrophy.

The overwhelming majority of atrophy was due to the original poliovirus attack and lack of muscle growth due to motor neurons killed. This original muscle atrophy also caused limbs to be shorter because bone growth relies on muscles pulling on bones and bones bearing weight.

Additional Post: It has been hard to explain that I still have tremendous weakness in my body although there is no visible muscle atrophy in my limbs. I am in my 50s and have been wearing a KAFO since age four. Eight months ago I was fitted with a new stainless steel KAFO on my left leg. Perhaps due to the weight of the stainless steel KAFO while walking, I have noticed some new muscle strength on my thigh and lower limb.

Dr. Bruno's Response: Perhaps due to USE of the new KAFO while walking you notice new muscle strength? Bracing can actually INCREASE muscle strength by taking the load off of your remaining, poliovirus-damaged motor neurons. (But see above rules for "bracing assistance.")

[On the topic of a Blood Test or EMG to prove an "old" Polio](#) (7/29/2019)

Original Post: Is there a blood test that can show whether a person had polio? Can an EMG show polio?

Dr. Bruno's Response: Poliovirus antibody titres can show poliovirus infection if person has NOT been vaccinated. It doesn't matter which of the 3 poliovirus types you had. The damage has been done.

An EMG activity documents the denervation, polio-damaged motor neurons barely talking to muscle fibers or no activity at all when the neurons in a given area have all been killed. There is NO relationship between what's seen on a regular EMG and post-polio muscle weakness. Polio survivors should never allow an EMG to be performed because a doctor "wants to diagnose PPS."

[On the topic of Supplements](#) (8/1/2019)

Dr. Bruno's Original Post: SUPPLEMENTS: Don't help, can hurt, cost a lot and you may not even be getting the supplement whose name is on the bottle.

Clearly, you have to be very careful in considering the claims about dietary supplements, be they herbal remedies or vitamins. For example, "PP Tabs" from Europe, "a completely guaranteed and clinically proven herbal treatment for Post Polio Syndrome." (By the way, PP Tabs is out of business.)

The PP Tab site says, "Thousands of patients have been successfully treated with PP Tab over the past few years. Had the effectiveness of PP Tab not been proven beyond any doubt, it would not be possible for us to make such a bold claim.

To download the summary of a clinical research study on the effectiveness of PP Tab, please click the link below." I clicked, and this came up: "Clinical Study soon to be posted." How can companies get away with such claims?"

Unfortunately, manufacturers of herbal "treatments" can get away with saying whatever they want because there is no legal restriction on their claims. The PP Tab site (<http://pp-tab.com>) says that the "Tabs" contain ingredients "blended together in a specific proportion to fight and treat Post Polio Syndrome effectively." What are the ingredients? They're magnesium and zinc, plus eggshell calcium, sulphur, substituted olive oil and turmeric -- an Asian spice and yellow food-coloring agent.

The company claims that their PP Tab treatment is very fast, and obvious results can be seen in 40 days, although "a complete course of treatment lasts three months." So, it will cost you nearly \$240 to get what the company hypes as the "world's most relied upon and clinically proven...safe and effective...natural treatment for Post Polio Syndrome," which has "absolutely no alternative to its unique formula."

But if you search the ingredients in PP Tabs, you'll discover the unique formula for treating post-polio syndrome isn't unique at all. The same company sells a variety of "Tabs," all having the identical formula: Clearotab completely guaranteed and clinically, proven herbal treatment for Dark Circles and Bags Under Eyes; Raynotab, to fight and treat raynauds disease effectively; Syrotab, guaranteed to improve syringomyelia; Guillatab, "clinically proven to treat Guillain-Barre Syndrome successfully." As with PP Tab, the other advertisements say that you can download a summary of a clinical study, but clicking gives the same message: "Clinical study soon to be posted."

For those wanting to spend less than \$240 for PP Tab's "proven beyond any doubt" treatment for PPS, for only \$89.95 polio survivors can "improve all symptoms, prevent and treat later complications, correct imbalance, adjust the immune system and most importantly to boost energy and strong body for better health and quality of life" with Hsin Kuang's Remedy 010-016. This Chinese curative, blended specially for you, contains six herbs plus two dried worms and the dried body of a scorpion. Remedy 010-016 is said to be "without any side effects" and with "Overall Success Rate 100%" (as tested on 19 polio survivors). (And with two dried worms and dried body of a scorpion? Yum!)

Clearly, you have to be very careful considering the claims about dietary supplements, be they herbal remedies or vitamins. The FDA considers herbal remedies as "food additives" (like turmeric) that don't have to go through the lengthy and expensive process that proves they are drugs, i.e., that they are effective in treating disease. That's why the FDA requires a supplement's label to state that it is not intended to "diagnose, treat, cure or prevent any disease."

However, there's a more dangerous problem than unsubstantiated claims. Supplements are required by the FDA to be safe -- and some may not be. Ginko biloba, a common herbal remedy, can decrease the effectiveness of anti-seizure drugs and has blood-thinning properties, so it shouldn't be used if you're taking anticoagulants like coumadin. Conversely, another "remedy," Coenzyme Q10, may decrease the effectiveness of blood-thinning medications. Even vitamins can be dangerous. Too much vitamin A can cause symptoms identical to PPS -- fatigue, muscle and joint pain -- and even can be fatal.

Unfortunately, there's still no "magic pill" to treat, let alone cure, PPS. If you want to take something to reduce PPS symptoms, try a proven dietary "supplement," having protein at each meal. Please see the "[Post-Polio Protein Diet](#)" in the [Articles Section](#) of the Encyclopedia of Polio and PPS (under "Diet"). Protein has been "proven beyond any doubt" to PPS symptoms and is a lot cheaper (and tastier) than herbs, worms and scorpions...or ingredients first found in jellyfish!

[On the topic of Polio Survivors and Reduced Immunity](#) 8/10/2019

Original Post: A friend of mine insists that post-polio patients have a lowered immunity. In your experience is this true?

Dr. Bruno's Response: Polio survivors do NOT have lowered immunity. This is an [anecdotal](#) finding but I was always surprised that Post-Polio Institute patients didn't catch "bugs" that were floating around.

[On the topic of Kidney & Liver Blood Enzymes and PPS](#) 8/10/2019

Original Post: 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. 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.

Dr. Bruno's Response: Polio and PPS have no effect on kidney function. Kidney disease should be diagnosed by blood tests for [BUN and creatinine](#) (NOT creatine) and [GFR](#), not homocysteine alone. I would suggest that a second opinion with a kidney specialist is in order. In addition, you can talk to a dietician about proteins that are "kidney friendly."

Additional Post: Is creatinine considered liver enzymes? 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?

Dr. Bruno's Response: Creatinine is a muscle breakdown product, NOT a liver enzyme, and is removed by the kidneys. Abnormally high levels of creatinine warn of possible malfunction or failure of the kidneys. Elevated liver enzymes are NOT a polio or PPS issue.

[On the topic of Pain Hypersensitivity](#) 8/24/2019

Original Post: I'm wondering if the pain we are experiencing as a PPS symptom could possibly be diagnosed or suggested by our doctor to be reflex sympathetic dystrophy (RSD). My PT says my PPS hypersensitivity to pain is almost like someone experiencing RSD. Since my PPS started after a physical trauma -- just like RSD trauma -- would that make any difference in how a treating physician addresses your post-polio pain?

Dr. Bruno's Response: There is no such thing as "post-polio pain." It is true that our first laboratory study of polio survivors found that they were TWICE as sensitive to pain as individuals who did not have polio. Our studies have never found that polio survivors have some unique pain that could be attributed to the poliovirus infection. Our review of The Post-Polio Institute patients found the trauma of any kind was a leading cause of PPS symptoms.

See: Bruno Bytes, [August 2017](#) (and) [Trauma and Illness as Precipitants for PPS](#) for more information re: Trauma and PPS. (Bruno Bytes can be found in the [Encyclopedia of Polio and PPS](#).)

As for reflex sympathetic dystrophy, the reason I was able to quickly study polio survivors in 1982 was that my laboratory at Columbia was set up to study RSD. Without going into the details of our RSD studies, those with RSD are said to be "hypersensitive" because even the most gentle breeze blowing on the skin can cause excruciating pain. That same breeze would not cause pain in a polio survivor. But unfortunately, once polio survivors experience pain they report twice as much pain as non-disabled controls.

So it would be more correct to call RSD patients "allodynic" (allodynia referring to pain caused by normally non-painful stimulation) and to say polio survivors are hypersensitive to genuinely painful stimulation.

Additional Post: This is so interesting to me as I continue to search for something that doctors can understand when I talk to them about the amount of pain I experience. Although I can definitely tell the difference now that you have explained it, I continue to feel that they don't understand and think our increased pain must be "all in our heads." Why would a doctor think one type of pain is more intense than the other, regardless of the cause of the pain, whether RSD (or any other diagnosis) or PPS? Would pain meds be different in treating the two since both are dealing with neurological factors?

Dr. Bruno's Response: The issue for polio survivors is "sensitivity." If you hit your "funny bone" and rate the pain at 8 out of 10, a non-polio survivor would rate the pain 4 out of 10 since polio survivors are two times as sensitive to pain. Would a doctor think one type of pain is more intense than the other, regardless of the cause of the pain? It doesn't matter what the doctor "thinks." What matters is what the patient FEELS! Would pain meds be different in treating RDS pain in polio survivors? Yes. We found drugs that treated the cause of RDS; none was a pain medication. But these drugs would have no effect on "normal" but heightened pain in polio survivors. As always, the cause of the pain should be addressed in polio survivors, not medicating away the pain.

On the topic of When Fatigue Sets In 8/25/2019

Original Post: The most annoying aspect about PPS fatigue is its variability. There is no empirical measure of how much exertion is too much. Every day is different and my reserves aren't consistent. Some days I achieve a huge amount without any subsequent fatigue. At other times a fraction of that effort will have me crashed out for days.

I've also noticed that today's over exertion doesn't always cause tomorrow's crash. My body's reaction can be several days later or it can be an accumulation of several weeks worth of tiny exertions. I consciously try to listen to my body, limiting my efforts. But every now and then and increasingly, without warning my body says NOT TODAY!!

Dr. Bruno's Response: You're actually defining the predictability of fatigue. "... today's over exertion doesn't always cause tomorrow's crash. The body's reaction can be several days later or it can be an accumulation of several weeks' worth of tiny exertions."

Fatigue does accumulate and you are describing "The 48 Hour Rule:" "Fatigue after exertion often takes 48 hours to reveal itself". This is why measuring steps and keeping a [daily log](#) are the empirical measures that will reveal the triggers of fatigue.

On the topic of More Tests (or) the Right Tests 8/27/2019

Original Post: I went to my new neurologist this morning. He's sending me for brain, cervical spine and lumbar spine MRI's and an EMG. He says he thinks he can help me. I'm so excited to finally, after all these years, to find a doctor that knows what he is doing. He says testing first and then we'll talk about treatment. I think he is talking about medication and assistive devices. He wants to see how much damage shows up on the tests first. I didn't even get home from my office visit before they had called to schedule the tests.

Dr. Bruno's Response: WHOA! Three MRIs and EMG already scheduled? Tests should rule out other conditions, not document "how much damage" polio did. A doctor should be ordering tests based on their findings, not planning a bunch of MRIs and an EMG up front. And what medication is he thinking about?

Doing more tests does not mean doing the *right* tests. You need to ask what he's looking for. MRIs will show pinched nerves and ruptured discs in your back and neck but will not show PPS, nor will MRIs of the brain. EMG's are only effective in showing "proof of old polio damage" and do not diagnose PPS., There is no reason for a polio survivor to have an EMG unless there is a question of whether you had polio or some other disease is suspected.

There's an old saying in medicine that especially applies to diagnosing PPS: If you hear hoof beats, think horses, not zebras.

Additional Bruno "Bytes" are available for you to share in the Encyclopedia of Polio and Post-Polio Sequelae.

Go to: <http://www.papolionetwork.org/bruno-bytes.html>

Scroll down the page (through the Current Month posts).

Previous months are located there, in easily printable PDF format and are available by "clicking" on them,

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