

Bruno Bytes – July, 2015

On the topic of “Adie’s Tonic Pupil” (7/31/2015)

Original Post: Strange question: I've recently been diagnosed with Adie's Tonic Pupil where I have one pupil that dilates differently than the other. There is no treatment. I have read that it's a central nervous system disorder. Does anyone else have this problem? Does anyone know if it could be caused as a result of polio? Dr. Bruno...?

Dr. Bruno’s Response: With the significant damage that Polio did to the vagus nerve, Adie's is very possible.

On the topic of Urinary Urgency and Frequency (7/29/2015)

Original Post: Like many older adults I have urinary tract problems with urgency and frequency. I have taken medication "Flomax" for several years, my urologist tell me it is doing a good job with my prostate but I have had no improvement with the U&F situation. I would like to know if my paralysis could be affecting my bladder function. I am paralyzed on my right side from my hip down. My body is noticeable smaller front and back on my right side from my belt line down. I didn't have and problems when I was young but as I am getting older I wonder if my lack of body/muscle mass in that area could be the cause of my poor bladder function. I trust my urologist but what works for 99% of the population might not be the best solution for aging polio survivors. Thank you so much for your input Dr. Bruno.

Dr. Bruno’s Response: Polio survivors, especially men, could have urinary issues due to poliovirus-damage. This damage was common in acute polio. Even so, these issues would be treated as in anyone else.

On the topic of Pressure Sores (7/29/2015)

Original Post: Anyone having trouble with pressure sores? I never had problems with pressure sores, but I now have one on the bottom heel portion of each foot. I haven't walked since 1955. Have had this wheelchair for 3+ years. No new shoes. I suppose my skin is getting thinner as I age.

Dr. Bruno’s Response: Pressure sores very rare in polio survivors because blood flow is good when limbs (and butt) are warm. Make sure you don't have cellulitis before you treat yourself.

Additional Post: My feet are typically cold and purple. The pressure points are more blue purple, not angry, etc. But, yes, I will keep my MD in the loop.

On the topic of CPAP / BiPap (7/28/2015)

Original Post: I had a sleep study done. Within two hours of falling asleep, the tech was waking me up to tell me it was very evident I had sleep apnea. She tried a couple of different masks on me the rest of the night. I can tell that wearing whichever type my doctor suggests, it's going to take some getting used to. I know though it's a necessity and I'll feel much better after I start using a CPAP.

Additional Post: I thought C-Pap was a no-no with us and Bi-pap the recommended. C stands for continuous and folks with neuro-muscular diseases and possible weakness in the inter-costal (chest) muscles and diaphragm that may make it difficult to breathe out adequately against a continuous pressure system thereby causing the CO2 level to rise, which is very dangerous. Bi stands for bi-level which allows for lower pressure between breaths.

Additional Post: Even with sleep apnea in a polio survivor, a bi-pap is usually recommended not a c-pap. Apparently Medicare will not pay for Bi-Pap unless a sleep study shows that CPAP is not workable for the patient. If I'm not mistaken, one of the most important tests is the vital capacity sitting up but especially lying down. Most doctors don't perform the lying down vital capacity. Takes but a minute but tells a lot about your breathing capacity/weakened respiratory muscles.

Dr. Bruno's Response: Dr. John Bach is Lord of the Lungs. Bi-Pap is usually required for polio survivors but insurance won't pay till you fail with CPAP. Another stupidity in the system . . . In addition, during testing, carbon dioxide must be measured. Polio survivors often retain CO2 even when O2 is normal.

On the topic of EMG's 7/20/2015

Original Post: Today I had my 3-limb EMG. I asked the neurologist performing it if she had ever worked for the CIA. When it was all done she said there were all the signs of post-polio and that I had incredible pain tolerance. I told her all Post-Polioers have incredible pain tolerance or we wouldn't have gotten much done in our lives. It is something we learned through our experience. She seemed genuinely impressed... so to all you PPSers if you didn't know it. You are some tough cookies. She said she needed to do some reading on the subject.

Additional Post: I was supposed to have an EMG today and after several jolts, I said, "ENOUGH!" (I was crying.) Polio or not, I couldn't take it—no way! Who invented this test, Der Fuhrer? I did make it through the muscle test, where they stick a needle into the muscles, no problem. I was told nothing showed up on the needle test. I talked to the neurologist overseeing the test for a while. She was very helpful and basically admitted, that in my case, they weren't expecting to find anything from the EMG "torture test" that could be used to draw any new conclusions—or would change anything. They already have no doubt that I had polio as a child. So, what's the point? I also asked about the muscle test. (Since the neurologists I have seen do not suspect I have anything like ALS, MS, or MG), I asked what things might conceivably show up on the muscle test. She said basically auto-immune type muscle problems. I asked if they were treatable and she said "with Cortisone." I said, "even if I had those, which I highly doubt, I would refuse to take Cortisone." From my experience, when given orally, Cortisone is one of those drugs where the cure is worse than the condition. Forget it. So, I am not going back. Goodbye, neurologists...

Dr. Bruno's Response: There are NO "signs of post-polio" on a clinical EMG. Only signs of an old polio. She'd better do a LOT of reading!

In our 1st study in 1984, we found that polio survivors were TWICE as SENSITIVE to pain as non-polio controls.

So polio survivors had to develop a higher pain tolerance if they were going to do incredibly painful polio rehab. Always Remember: Conserve to Preserve.

On the topic of Extra Light, POWER Folding Wheelchairs (7/19/2015)

Dr. Bruno's Post: Lots of COFFEE HOUSE members are asking about the new, lite, folds-like-a-stroller power wheelchair, originally the PORTASHOPPER, which several members have and love. There is now a website describing and rating these new chairs from different manufacturers.

<http://www.foldablewheelchairs.com/>

On the topic of Polio outbreaks in the US and "Wild" Polio (7/16/2015)

Question: Is it true there haven't been any outbreaks in the US since 1979?

Dr. Bruno's Response: There has been no wild polio since 1979 (from a source within the US). Since the 1980s there was an outbreak among the Amish in Minnesota when the virus was brought in from the Netherlands; one woman who was not vaccinated developed bulbar polio and brought it in from Mexico; and an immuno deficient woman in Minnesota retained the vaccine strain and passed it to her children who were not paralyzed.

Additional Post: I've never understood the "Wild" polio vs the other.

Dr. Bruno's Response: Wild is poliovirus is the real thing, the original, found in nature that's been around at least since the pyramids were built. Vaccine strains are wild poliovirus passed through monkeys until it

becomes non-neuron killing (OPV) or is killed itself with formaldehyde (IPV). "Wild" Polio mutates on its own as it passes from animal to animal and eventually BECOMES the vaccine strain that doesn't cause paralysis.

There are only 5 places on the poliovirus gene that cause it to be paralytic. Since the poliovirus has been sequenced and produced in the lab, a "non-paralytic" poliovirus could be pieced together to create the ultimate vaccine strain. But the virus could always mutate back and cause paralysis.

On the topic of Walking More (7/15/2015)

Question: I am new to this group and mostly have been using it to inform myself on PPS. Polio when I was 8months old, effective my right leg, now I am 48 and have started to feel the effects of PPS, since last August. I have cut out the kickboxing classes I used to do and started water aerobics, worked okay for awhile but wasn't enough cardio. I wear a brace. I have started walking more and using a stationary row machine. I have gained about 10lb since last August. I am sure the weight gain has not helped with the question I am about to ask. My left leg (good leg) has started to get very muscular (calf areas mostly) and is often very stiff and painful. I can hardly stand on it sometimes. I have been using, biofreeze, magnesium, massage therapy, but nothing seems to help. Any thoughts?

Dr. Bruno's Response: Unfortunately, by walking more and using a stationary row machine and you can kiss your remaining poliovirus-damaged neurons goodbye. Once Again: "Conserve to Preserve."

You may want to read my article:

"Exercise – Use It and Lose It" <http://www.papolionetwork.org/how-do-we-live-with-it.html>