Bruno "Bytes" – January, 2016

(Bits and Tidbits from the Post-Polio Coffee House)

Available through a "link" from www.postpolioinfo.com (or) directly through http://www.papolionetwork.org/bruno-bytes.html

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?? Talking to a doctor today he said NO SUCH THING AS NON-Paralytic. He made me feel small .

Additional Post: It has only been in latter years that asymptomatic polio has been properly recognized and this has only occurred when patients started to present with PPS. And that took a mindset change as PPS is a diagnosis of exclusion (one of the first prerequisite was a history of paralytic poliomyelitis)! It is now recognized, (certainly in Europe through medical centres and the European Polio Union) that asymptomatic can result in PPS. Without question, this should be the case when we realized that under WHO (World Health Organization) definitions: a single paralytic case is counted as an epidemic. Therefore, up to 1000 persons may have had the virus pass through the gut. It is only the few where this "gastro-enteritis virus". Polio virus enters the body through the intestinal route, e.g. most commonly by mouth (although in rare occasions it has been shown to enter the bloodstream directly through an open wound such as a cut). Those who have had asymptomatic polio are just a part of the "polio family" as those affected with paralysis.

Dr. Bruno's Response: "Non-paralytic" polio can mean that you had:

1) No poliovirus invasion of neurons and no neuron damage;

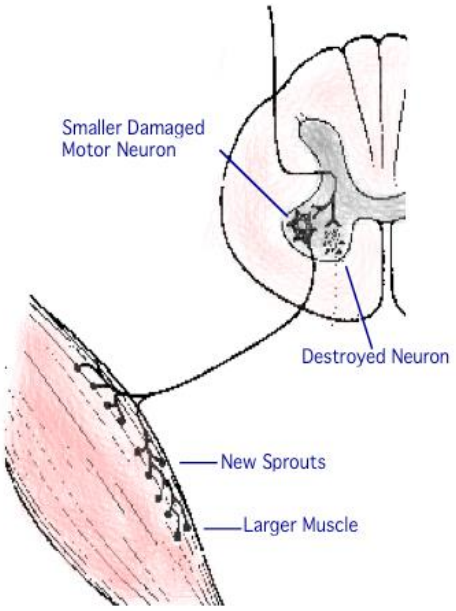
2) Widespread neuron damage that was not severe enough in any spinal cord or brain area to cause symptoms that could be detected but that now leaves you vulnerable to Post-Polio Sequelae;

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 Post (from original): I understand now. You have made so much sense of my insensible youthful experience. No one tested me. The weakness must have shown itself later, and always confused me.



Paralytic or Non-Paralytic – How do you know?

Dr. Bruno's Response: The weakness was probably there at the beginning and nobody took the time to do a manual muscle test. Sadly, some polio survivors weren't "bad enough" to get care at the peak of the

epidemics. And even more sad? Some parents realized there were weakness issues, and didn't want to discuss it.

On the topic of Upper Respiratory Issues and CO2 (January 7, 2016)

Original Post: I have been experiencing upper respiratory issues for a while now. I was just wondering since I did not have them as a child (I had a mild case of polio), could I be experiencing it now later in life?
Additional Post: Please find a pulmonary specialist ASAP. I had issues a year ago and found out that the left hemisphere of my diaphragm was paralyzed, probably since I had polio in 1949.
I always had a hard time running and could never catch my breath.
Additional Post: My dad had no lasting effects of polio following initial diagnosis and treatment. It was only later in life that he developed breathing issues which have now been diagnosed as being from late effects of polio. His siblings didn't even know he had had polio. He's waiting to see if it gets worse.
Dr. Bruno's Response: NO polio survivor should wait for evaluation and treatment of breathing issues, whether they had breathing problems with the polio or not.

In with the good air AND Out with the bad.

On the topic of Statins and Polio Survivors (January 12, 2016)

Dr. Bruno's Original Post: I'm not posting this for you to worry if you are taking a statin. It's just something to keep in mind, and to show your Doctor. You need to have blood drawn to measure CK *before* you take a statin.

Statin-Induced Myopathy in a Patient with Previous Poliomyelitis
AMERICAN JOURNAL OF PHYSICAL MEDICINE & REHABILITATION, 92(11); JANUARY 2013
From the University Hospital, Turku, Finland.

This report describes a patient with a history of poliomyelitis who developed new, progressive symptoms of muscle fatigue and weakness, suggestive of post-poliomyelitis syndrome. However, comprehensive investigations led to the diagnosis of statin-induced myopathy as the cause of the patient's symptoms. This case highlights the possibility of statin-induced myopathy in patients with a history of poliomyelitis and the differential diagnosis between post-poliomyelitis syndrome and statin-induced myopathy in these patients. The possibility of statin-induced myopathy should be considered when patients with previous poliomyelitis who take statin medication develop symptoms suggestive of post-poliomyelitis syndrome.

On the topic of Keeping an Activity Log (January 16, 2016)

Original Post: I am once again going to extoll the value of an activity log…
Some of you may recall that I have encouraged keeping a log of activity and any symptoms. This was recommended to me by Dr. Bruno. It was useful to help me spot the triggers which led to fatigue, so I could avoid them. My log began in 2008, and is still going. And now, it just paid off big time for me.
Since being PPS diagnosed (and educated) in 2008, I have been able to do light hiking. I knew it was a risk. "Conserve to preserve" was always present in my mind, but was balanced by a desire to see and explore the world around me. So, I walked that knife edge, using my legs, but monitoring and logging everything that might relate to PPS in any way, noting the triggers that caused problems and avoiding those triggers, once noted.
This winter I suspected that things were changing. Reviewing my log confirmed it. In the summer of 2014, my average hike was about 4 miles, with my longest being 8.4 miles. Last winter, my hikes with a friend were 3 to 5 miles long. In 2015, my summer hike average dropped to about 3 miles with the longest being 5.5 miles.

Recently this winter, our hikes have been 2 miles, more or less. Clearly my ability to walk was dropping. If I pushed, my log would show fatigue 2 days after the hike. I didn't push, dropping distances as needed to avoid fatigue.

Recently, something new showed up. I was experiencing some leg weakness in the later parts of a hike. As this was usually during descent, it was a little unexpected and almost indistinguishable from my legs being tired, but I noticed it because my log had warned me that things were changing, and I was being hyper-attentive. I logged the weakness. Over the past 2 weeks, my log shows an increase in frequency of leg weakness, and that I needed a longer recovery time.

Hopefully, I will continue to be mobile, because I will not be pushing the issue. I will be conserving to preserve. The lesson for me, and what I hope to share, is once again that keeping a good log is invaluable in managing PPS, in spotting problems, and in avoiding them. Whether you spend your day in a comfy chair reading a book (is any hand strain occurring?), cleaning the house, doing a little walking around the house without your braces, taking a long trip in the car that tires you, or whether you take a walk in the woods, log it, and log any problems that show up. Keep the log, and look back periodically to look for patterns. I looked back 2 years to spot the pattern and to understand what was happening to me. Without my log, I would probably have continued hiking every other day, oblivious to the harm I was doing to my neurons. Instead, I am going to sit in my recliner and read a book that a friend gave me. It is about hiking with a dog.

Dr. Bruno's Response: Our daily log is said to really help polio survivors to understand the triggers and treatment for muscle weakness, fatigue and pain. But the log is a lot of work! Is the log worth it? It's up to you.

Name: **Day:** **Date:**

Time	Activities & Steps	Perceived Exertion	Specific Muscle Weakness	Overall Fatigue	Pain Mood Breathing	Activities that produced Symptoms & Modifications
Up	Food?: Sleep Quality?:		Rate as mild-moderate-severe			
				—		Activity:
BREAK						Symptom:
						How did you do the activity & how were you positioned?
Noon	Food?:					How could you modify?
BREAK						Activity:
						Symptom:
6 pm	Food?:					How did you do the activity & how were you positioned?
						How could you modify?
Bed	Total Steps:					

Perceived Exertion Scale	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
	Very, Very Light			Very Light	Fairly Light			Somewhat Hard		Hard		Very Hard	Very, Very Hard		

Additional Bruno “Bytes” are available for you to share by going to:
http://www.papolionetwork.org/bruno-bytes.html
Scroll down the page (through the Current Month posts).
Previous months are located there, and are available by “clicking” on them, in easily printable PDF format.