



Bruno “Bytes” – November, 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 the “Polio Like” mysterious disease (11/4/2016)

Dr. Bruno’s Original Post: Although the headline is completely misleading and this is not about “polio drugs” it does describe possible treatment of children with enterovirus paralysis.

Additional Post: I didn’t think there WERE any Polio Drugs.

Dr. Bruno’s Response: Vaccination against the three polioviruses did not prevent being affected by any of the other enteroviruses - EV68, EV71 -- that MAY be causing AFM. The new drugs described in the article are similar to the anti-HIV medications and interfere with the action of enteroviruses.

There is the possibility that anti-enteroviral medications could interfere with poliovirus activity in individuals already infected. These drugs could be of use if there were an outbreak of polio and exposed, unvaccinated individuals could be identified. But vaccination BEFORE infection is still the silver bullet to prevent polioviruses from causing paralysis.

These children COULD have EV 68 but it is certainly is NOT a poliovirus. There is not any polio in the US!

<http://www.chicagotribune.com/lifestyles/health/ct-polio-drugs-treatment-mysterious-paralyzing-disease-20161104-story.html>

Could polio drugs treat children with a mysterious paralyzing disease?



A Pakistani health worker administers polio vaccine drops to a child during a door-to-door polio campaign in Karachi on October 24, 2016. (Rizwan Tabassum / AFP/Getty Images)

On the topic of a Polio Survivor having Surgery (11/7/2016)

Original Post: Is there anything special I should know before having general anesthetic? I am to have the right side of my thyroid taken out.

Dr. Bruno’s Response: Print out the entire PREVENTING SURGICAL COMPLICATIONS article in the post polio library.

Editor’s Note: These articles, the original NJ Anesthesia Warning Card and the updated Anesthesia Warning Card (with scan-code for your doctor to read with his/her cell phone) are all HERE

<http://www.papolionetwork.org/-anesthesia-warning.html>

On the topic of Osteoporosis Medications (11/10/2016)

Dr. Bruno's Original Post: We all have to research the research and not just take the TV "pill of the week." So often, people will put more time into research before buying a car than they will study medications they're offered.

"A new study suggests probable scientific misconduct in at least some of 33 bone health trials published in various medical journals."

<http://www.newswise.com/articles/view/664512/?sc=mwhn>

Study Suggests Probable Scientific Misconduct
In Bone Health Studies



On the topic of Polio Survivors having PTSD (11/13/2016)

Original Post: At a recent visit, my Polio doctor asked me three questions that I could not answer. His response was "you are a perfect candidate for PTSD". He had just been to a conference, where PTSD in relation to polio patients was discussed. My doctor has now referred me to a counsellor.

Dr. Bruno's Response: Dr. Bruno's Response: Fortunately, after studying and treating more than 6,000 polio survivors, I can say that PTSD in polio survivors is very rare. To have PTSD a person needs to understand the concept of life and death and that a situation can cause physical harm. Most children in hospital with polio were too young to understand this.

That being said, it doesn't mean that PTSD doesn't happen in polio survivors. It's just not common for polio survivors to meet the DSM-V criteria for PTSD. However, Adjustment Disorder with Anxious/Depressed Mood is virtually universal in polio survivors with PPS and often prevents them from doing what's necessary (slowing down, saying "No," using a brace, crutches or wheelchair) to treat PPS. This is why psychotherapy was included as part of every Post-Polio Institute patient's treatment protocol.

On the topic of needing a "Physiatrist" (11/15/2016)

Original Post: I am so discouraged. My doctor (a physiatrist) questions whether I have PPS.

Additional Post: My PPS was diagnosed by a Physiatrist. He encouraged me not to overdue, he spoke to PT explained PPS and what should be done and what *not* to do. He suggested what assistive aids would help me and explained it was my decision to decide when I was ready. I got my cane, my brace, then KFO, walker and finally my scooter. When I found I could no longer work, he filled out all my papers for disability. I am thankful to him because I learned "early" not to overdue and the need to preserve.

Dr. Bruno's Response: Physiatrists (rehabilitation medicine physicians) are not new. Physical medicine and rehabilitation (PM&R) dates back to the second world war and was really expanded, in terms of numbers of doctors and knowledge, by the polio epidemics. Polio survivors actually promoted an entire medical specialty!

Physiatrists don't want to "fix" everything by cutting, like orthopedists do, or "cover" problems over, like pain management docs do by using narcotics. What physiatrists do is treat the *cause* of a problem to reduce symptoms and to make you as functional as you can be by using therapy and assistive devices, from a cane to a power wheelchair.

On the topic of Weight Gain when we're less active (11/21/2016)

Original Post: I am 68 years old and have been diagnosed with PPS. Over the last year I can't seem to get my weigh. What I should try now that I'm so inactive?

Dr. Bruno's Response: Go to the Post Polio library at www.postpolioinfo.com and take a look at the POST POLIO DIET. It's intended to give polio survivors the protein they need and not for weight loss. But if you have two carbohydrate free dinners a week and follow the diet polio survivors typically lose about a pound a week. Additional Post: If you have a Smartphone, check out the App, "Fat Secret". You can track not just calories but also you get a graphic of Carbs, Fats & Proteins. It's easy to use and I lost 85 lbs on it in 7 months. Additional Post: I use a wheelchair too. I'm a Weight Watcher and with the new program I lost 25 pounds and am back at my lifetime goal weight.

On the topic of "Frozen Fingers" and being COLD (11/22/2016)

Dr. Bruno's Original Post: "Of Frozen Fingers and Polio Feet" A warming winter tale for everyone who hates the colddddd!

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, polio survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report intolerance to cold and that their limbs have become more sensitive to pain as the temperature decreases. Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. (Bruno & Frick, 1987).

When polio survivors were cooled in our laboratory from 86° F to 68° F, motor nerves functioned as if they were at 5° F and polio survivors lost 75% of their hand muscle strength. (Bruno, et al., 1985a) And, although polio survivors were twice as sensitive to pain as those without polio at room temperature, no increase in pain sensitivity was found at lower temperatures. (Bruno, et al., 1985b)

The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the automatic computer that controls the inner bodily environment) was damaged by the poliovirus, including the body's thermostat and the brain area that tells your blood vessels to constrict. (Bodian, 1949) In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it's cold were also by the poliovirus. (Bodian, 1949) Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow passively as they get cold; trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult. As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength.

However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop (see Bruno, 1996). The pooling of blood in the feet also explains why polio survivors' feet swell, swelling that increases as they get older. And polio survivors' easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change.

Polio survivors need to dress as if it were 20° F colder than the outside temperature. The trick is to stay warm from the get-go. You need to dress in layers and wear heat-retaining socks or undergarments made of a woven, thin, breathable plastic fiber called polypropylene (marketed as Gortex or Thinsulate) that

should be put on immediately after showering when the skin is warm in the morning. Then put on warm socks, even electric socks with battery-powered heaters. Also, try to keep your feet elevated during the day.

For your hands, Valu-tek (www.cleanroomconsumables.com) makes lightweight gloves that are designed for dexterity indoors. We tested three gloves in polio survivors whose hands are cold inside the home. The nylon "Glove Liner" (VTGNLR-1/1) and the "Conductive Glove" (VTGCONKT), which is made of polyester knit, have full-length fingers. Of the two, the polyester knit is warmer, but somewhat thicker. There is also a nylon glove liner" (VTGNLR-1/2) that has half-fingers that allow more dexterity, but isn't as warm. Polio survivors found that the gloves keep hands warm and allowed them to use their fingers, to read, to eat and even to knit, but they liked the nylon "Glove Liner" with full fingers best. The gloves come by the dozen, so you can launder them and have some to wear. The gloves liners and conductive gloves are rather expensive, but worth it. Since these are disability-related products, they should be tax deductible.

If you still can't stay warm, you can talk to your doctor about taking the anti-hypertension drug Minipress that open your arteries and get more hot blood to your feet. However, these drugs can open arteries too much and cause you to lose heat from your uncovered skin and drop your blood pressure when you stand. These are drugs of last resort to be used very carefully!

Polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75° F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery (Bruno, 1996).

[On the topic of Polio Survivors being Type "A"](#) (11/28/2016)

Dr. Bruno's Original Post: Since there is so much discussion here about being "Type A", here's the background on polio survivors and Type "A" behavior...

When polio survivors first came to us 35 years ago, we discovered that polio had had a profound effect on learning and earning. The subjects in our first post-polio research study made clear that polio survivors were very unusual. The subjects used power wheelchairs and had, not just bachelors, but also graduate degrees. It became apparent that polio survivors were unique, not only among individuals who had disabilities of equal severity, but also among non-disabled peers. Polio survivors had risen to high levels in their professions. More than the expected percentages of polio survivors are corporate executives, members of both houses of Congress and professionals of all types -- teachers, lawyers, doctors and nurses. This level of achievement points out a startling fact: Polio survivors, who were told that they would never go to college or even get a job, became America's "best and brightest."

Polio survivors apparently shared a personality type that first had been described in those who developed heart disease: The hard-driving, time-conscious, competitive, self-denying, perfectionist, overachieving "Type A" personality. We weren't surprised when our 1985 National Post-Polio Survey found that polio survivors reported 50% more Type A behavior than people without disabilities, even more than in those who'd had heart attacks. We also discovered that the more Type A behavior polio survivors reported, the more new fatigue and muscle pain they had.

The polio experience provided the ideal environment for becoming Type A. Lack of social support, low self-esteem, loss of control and fear of punishment have been found to teach Type A behavior. Our 1995 International Post-Polio Survey found that polio survivors reported 34% more physical abuse and 94% more emotional abuse than in those without disabilities.

The Survey included a questionnaire measuring sensitivity to criticism and failure that found polio survivors were 15% more sensitive to the criticism of others and thinking of themselves as failures than were non-

disabled respondents. Not surprisingly, the more abuse polio survivors experienced the more sensitive they were to criticism and failure and the more Type A they had become. So, polio survivors became Type A to prevent criticism and abuse by others and to protect against feelings of failure. That's why so many survivors discarded in childhood any evidence of polio – crutches, canes, braces, wheelchairs – and refuse to accept them now when they develop PPS. Polio survivors want to both act and appear “normal.”

Our 1995 Survey also found that protecting against criticism and failure was more important than polio survivors own emotional or physical well-being. Nearly three-quarters answered "yes" to the question "I often do what others expect, regardless of how I feel emotionally or physically." Said one of our Post-Polio Institute patients, "Polio survivors aren't just Type A, we're Type 'E: We do everything for everybody every minute of every day!" For most polio survivors, it is more important appear "normal" and take care of others than it is to physically or emotionally care for themselves. Unfortunately, the ultimate price polio survivors have paid for being Type A -- and “Type E” -- is Post-Polio Sequelae.

The sad paradox is that, in spite of survivors cheating death by polio, conquering disability and dealing with years of severe physical and emotional abuse and pain to become “the best and the brightest,” many polio survivors believe that they have no ability to survive PPS. This paradox is why psychotherapy for polio survivors is so important: To help them deal with the terrible things that have happened in the past, to stop them from expecting more abuse and to help them accept that they are competent adults whose emotional and physical future is in their own hands.

It is exactly because of everything polio survivors have already experienced that they will survive in spite of PPS. To do this, polio survivors need to read these two words again and again and take in the full depth and breadth of their meaning: I am a polio SURVIVOR!

If polio survivors can acknowledge the abuse they have survived,
there is no question that they can cope with the past and make the physical and emotional changes necessary
to survive and *thrive* with PPS.

On the topic of PPS and “Motor Neuron Disease” (11/28/2016)

Original Post: Can PPS be confused with Motor Neuron Disease?

Dr. Bruno's Response: Sure. This is why *all* other diseases and conditions have to be ruled out before Post Polio Sequelae is accepted as the diagnosis. That's the definition of "diagnosis by exclusion."

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).

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