

Bruno Bytes – August, 2015

On the topic of Voice Issues and PPS (8/28/2015)

Original Post: Is there any connection between voice issues and PPS?

2nd Post: Unfortunately, I had to give up choir. The mechanics of voice are driven by muscles. The diaphragm itself is a big muscle that pulls air in and pushes it out. The vocal cords change to produce tones, kind of like strings on a violin. The intercostal muscles lie between the ribs and cause the rib-cage to expand. It sounds complicated, but it's amazingly effective. I knew it was causing me trouble when I could no longer project my voice to the rear of the church.

Dr. Bruno's Response: Adding to the description (above), polio survivors could have one paralyzed vocal cord as well. Regardless, any change in your voice should be evaluated by an ear nose and throat specialist.

On the topic of Unvaccinated Children (8/27/2015)

Dr. Bruno's Post: "Unvaccinated Children Called a Threat"

http://www.nytimes.com/2015/08/28/us/unvaccinated-children-called-a-threat.html?_r=0

1st Response: This is a hot topic in today's culture. If they lived with everything we have lived with, they would be quick to change their mind. I speak out on it every chance I get. If we don't learn from history, we are doomed to repeat it!

2nd Response: As a polio survivor I know the high cost of not having the vaccine which had not been developed when I had polio.

3rd Response: How I wish I could have been protected against polio, and "the childhood" diseases. There is so much fear and misinformation being told, and re-told that a lot of people don't realize they have been duped.

On the topic of Muscle Cramping (after an EMG) and the importance of fluids (8/25/2015)

Original Post: Has anyone had an EMG and had problems with the muscles knotting up and cramping for about two weeks afterward? My neurologist said he had never heard of that happening. In 1950 I was diagnosed with polio and unable to walk or hold my arms over my head. I have had to deal with aches and weakness all my life but it is getting worse. My neurologist stated there was nothing wrong with my EMG and I should not have had any problems post procedure.

Dr. Bruno's Response: To do an EMG, as you painfully know, you have to stick a large needle into many places in a muscle and *that* causes damage. If the muscle fibers that are being pierced are not functioning properly due to polio damaged neurons I can make a case for you having pain and cramping. If it's hot where you are make sure your electrolytes are OK and maybe drink some Gatorade.

2nd Post: I did drink a lot of fluids, especially Gatorade. It was hot but I had to use a blanket to keep warm in the house. I have had to drink a lot this summer due to dehydration.

Dr. Bruno's Response: The fluids help the cramping at all?

3rd Post: Yes they did somewhat but made me go to the bathroom more and when I am really fatigued I don't make it to the bathroom in time.

On the topic of Increasing Fatigue (8/25/2015)

Original Post: Dr. Bruno, how far does one regress or lose strength? For the last 8 years I've been going downhill. I just keep losing stamina and getting weaker. Will it ever stop??

Dr. Bruno's Response: Because I don't know you, all I can say is that our research finds that polio survivors either plateau or actually get better when they listen to their bodies and, I hate to say it again, "conserve to preserve." Certainly a sleep study for increased fatigue would be a first step as would blood work to rule out

any other problem. If you're walking, what about going to RadioShack and buying a pedometer to measure your steps and see if you're over 1500 per day?

On the topic of having PPS without Previous Paralysis (8/24/2015)

Original Post: Can people who had "non-paralytic polio" have Post-Polio syndrome?

Dr. Bruno's Response: There is no such thing as "non-paralytic polio."

There is a good paper for you in the Post-Polio Library at postpolioinfo.com

"Non-Paralytic Polio" as a Prelude to PPS -

<http://www.postpolioinfo.com/library/npp.pdf>

Another Post: In 2003 my wife was having symptoms that to me sounded like PPS and she said that she didn't have Polio. After talking to her mother we found out that she was very sick in the fall of 1955 in Kansas City, MO. After talking with her local doctor (who had seen polio at its "prime" said that maybe she did. We found out there is a test for the wild strain which showed that she had actually experienced both bulbar and paralytic polio. She never had any paralysis that she knew of but definitely suffers the symptoms of PPS today. So our experience is yes.

On the topic of "Neither Exercise nor Psychotherapy reduce fatigue in Polio Survivors"

(8/25/2015)

Dr. Bruno's Post: A recently published article describes the authors' surprise that they found NO REDUCTION OF SEVERE FATIGUE IN PATIENTS WITH POSTPOLIO SYNDROME AFTER EXERCISE OR COGNITIVE BEHAVIORAL PSYCHOTHERAPY and that "further research" is needed to investigate why neither exercise nor psychotherapy reduced severe fatigue. "Further research" as to why exercise and psychotherapy didn't reduce severe fatigue? These people must be kidding, right? But they're not. Read for yourself:

NO REDUCTION OF SEVERE FATIGUE IN PATIENTS WITH POSTPOLIO SYNDROME BY EXERCISE THERAPY OR COGNITIVE BEHAVIORAL THERAPY.

Koopman F, et al. *Neurorehabilitation and Neural Repair*. 2015 August

<http://nnr.sagepub.com/content/early/2015/08/12/1545968315600271.abstract>

One Polio Survivor's Response: Actually, I beg to differ. My psychotherapy with you, Dr. Bruno, reduced my fatigue enormously. Of course, that is because you convinced me to cut back my activities and not feel guilty about it. I will always feel guilty but....the therapy worked.

Dr. Bruno's Response: That's good to hear. The Post-Polio Institute's psychotherapy goal is to help polio survivors to do less and feel better physically while they deal with the guilt and the "vampires" in their heads. But the cognitive/behavioral psychotherapy these "researchers" used is to convince polio survivors that they will "Feel less fatigue if only they do more." The implication is that polio survivors have a "phobia" to exercise and feeling rested.

Another Polio Survivor's Response: Expecting PPS fatigue to improve with psychotherapy and cognitive therapy is starting with the assumption that it's caused by mental and cognitive issues. This sounds like a master's thesis proposal looking for a design. But one cannot design a study for a poor idea.

Dr. Bruno's Response: One thing remains true for post-polio fatigue: Want to feel better?

Conserve to preserve!

On the topic of Polio Survivors and Anesthesia Issues (8/21/2015)

Dr. Bruno's Post: Since several recent posts discuss surgery and anesthesia. I thought this graphic was timely:

(Continued)

POLIO SURVIVORS AND ANESTHESIA COMPLICATIONS:
NEED FOR CLINICIAN EDUCATION.

Presentation to the American Association of Nurse Anesthetists.

 Polio Survivors and Anesthesia Complications: Implications for the Clinician Laura L. Ardizzone ¹ , CRNA, DNP & Dr. Richard Bruno ² <small>1. Columbia University School of Nursing, NY, NY 2. The Post-Polio Institute and International Centre for Polio Education, NJ</small>	
Key Points Providers Should Know About Polio Survivors and Anesthesia	2010 SURVEY & RESULTS
Fatigue/Weakness <ul style="list-style-type: none"> Note pre-op functional level Epidural may cause prolonged paralysis Careful administration of lower doses of anesthesia. 	<ul style="list-style-type: none"> Survey of anesthesia providers' and students' knowledge about PPS. Response rate was 86% (n=113) 92% practice in the Northeastern United States 68% were female 73% were CRNAs 65% had five or greater years of experience 14% had previously cared for a patient with PPS > 85% of respondents were "not familiar" or "vaguely familiar" with PPS or its anesthetic implications <p>CONCLUSIONS</p> <ul style="list-style-type: none"> A majority of polio survivors receiving anesthesia report complications, however a minority of anesthesia providers are familiar with PPS. Most US polio survivors are > 50 and many will present for surgical procedures that require anesthesia. Providers should be educated about polio survivors' experiences of prolonged sedation, vomiting, respiratory impairment, inadequate pain management and cold intolerance so that safe and effective care can be provided. <p>REFERENCES</p> <p>Bruno R. Preventing Complications in Polio Survivors Undergoing Anesthesia and Surgery. Post-Polio Sequelae Monograph Series. Vol 7(2). NY: random harvest, 2011.</p> <p>Bruno R. The Polio Paradox: Understanding and Treating "Post-Polio Syndrome" and Chronic Fatigue. New York: Warner Books; 2002.</p> <p>Lambert DA, Giannouli E, Schmidt BJ. Postpolio syndrome and anesthesia.</p>
Cold Intolerance <ul style="list-style-type: none"> Ask patients' if they're cold Multiple warming measures (Bear Hugger) 	
Respiratory Dysfunction <ul style="list-style-type: none"> Ask patient about post-op breathing and monitor CO2 Awake extubation Encourage post-op clearing of secretions Vigilant post-op monitoring 	
Dysphagia <ul style="list-style-type: none"> Higher risk for aspiration Succinylcholine can cause prolonged paralysis 	
Sensitivity to Pain <ul style="list-style-type: none"> Multi-modal approach to post-op pain Increased need for pain medications Careful positioning in OR 	

On the topic of Leg "Twitching" (8/21/2015)

Original Post: For the last two nights, my polio leg has uncontrollable jerks and twitches. They wake me up from a sound sleep and so needless to say I am up until 4 in the morning! I've had them before, but they seem to be getting worse. Is this just part of PPS? Or is it something I need to go to the Post-Polio Clinic about?

2nd Post: Mine are generally connected to over use. That and the cramping (two different things). Also I don't have restless leg but I notice at times my feet jerk and twitch by themselves.

3rd Post: Twitching and jerking were my first identifiable symptoms of PPS. I had full body jerks that woke me up.

4th Post: It hits my left leg really badly if I have done too much and then lay down . I put a hot water bottle under my knee and it sure helps calm the leg down.

Dr. Bruno's Response: Twitching happening all of a sudden is a sign of overuse. Of course, polio survivors have mastered the art of all muscles twitching all night long, which is knocked out by a low dose of alprazolam right before bed. Alprazolam is the generic for Xanax. It's not addictive taken before bed because you're asleep when it works. (We've never had a polio survivor addicted to alprazolam even up to 2 mg before bed.)

5th Post: I have switched from Ambien to Alprazolam and have found that I only need to take half of a 1mg tablet to help me relax enough to fall asleep. If I take the full tablet I wake up groggy in the morning. I have found that I am very susceptible to narcotics even in very small doses. I had a stronger than normal episode the other evening with my leg twitching but after taking Alprazolam it calmed it right down enough for me to fall back to sleep.

On the topic of a "local" Anesthetic for a Spinal Fusion (8/18/2015)

Original Post: I had Polio in 1950 and in 1956 I had a complete spinal fusion using bone from me and from my
(Continued . . .)

mother. In Sept I am having my right hip replaced and the anesthesia provider wants to use local anesthetic not general. I have always had general but was told that local would be better for my recovery. I'm trying to determine if the local is wise with my fused back.

Dr. Bruno's Response: You need to have a complete pulmonary evaluation and have the lung doctor determine whether general anesthesia would be detrimental. If they follow the surgery rules for polio survivors you can find on our website (below) and you have no special breathing issues they should use intravenous and gaseous anesthesia for a hip replacement. I don't know how they're going to do an adequate local block for anesthesia when there's no way that they can do an epidural with your spinal fusion. The pulmonary doctor must consult with your surgeon and the anesthesiologist long before you go to the hospital.
http://www.postpolioinfo.com/lib_surgical.php

On the topic of Antibiotics and Fatigue in Polio Survivors (8/13/2015)

Original Post: I got polio when I was 5 years old in 1944. I've lived a Type A life for over 50 years. 2 months ago I was diagnosed with C-Diff. I have had 2 rounds of antibiotics. I somehow blame my new weakness to this disease and its treatment. I'm getting PT and OT. Has anyone in your group experienced C-Diff? Can it cause this kind of weakness and fatigue? Could it be the anti-biotics?

Dr. Bruno's Response: Any serious infection, bowel problems and some antibiotics cause fatigue and weakness. Don't let the physical therapist make you do muscle strengthening! Stay hydrated and rest.

On the topic of "What your Pharmacist isn't telling you" (8/12/2015)

Dr. Bruno's Post: Seven Things Your Pharmacist Isn't Telling You
<http://www.goodrx.com/blog/7-things-your-pharmacist-isnt-telling-you/>

On the topic of FDA Approval of Extended Release Drugs (8/10/2015)

Dr. Bruno's Post: DANGER: THE F.D.A. ALLOWS SALE OF EXTENDED RELEASE GENERIC DRUGS THAT ARE NOT EQUIVALENT IN DOSE TO BRAND NAME DRUGS.

(The substitution of generic for brand name EXTENDED RELEASE drugs has caused near fatal consequences in some Post-Polio Institute patients. Polio survivors should never take Concerta or Ritalin. BEWARE and talk to your doctor and pharmacist before accepting or filling an Rx!)

<http://www.nytimes.com/2015/06/17/business/generic-ritalin-drug-not-equivalent-to-the-brand-is-in-use-anyway.html>

On the topic of Insomnia Medications (8/6/2015)

Dr. Bruno's Post: For all Post-Polio "Insomnia sufferers" (Especially those on Bi-Pap)
http://www.uphs.upenn.edu/news/News_Releases/2015/08/perlis/