



Bruno “Bytes” – April, 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 Medication Gabapentin (Neurontin), Twitching and Restless Legs (4/1/2016)

Original Post: Is anyone on the drug gabapentin? Are you getting results or side effects?

Additional Post: I took it for a while. It never did anything for me, other than caused my eyes to be so bloodshot it looked like I was constantly plastered drunk.

Additional Post: I am about to start taking gabapentin (Neurontin) and hope it helps. My doc gave me a schedule to take starting out with 1 tab. He hopes it will help but no guarantee. I am going to have some PT which I hope will help my back and legs and I do know my limits so they will not push me into something I can or cannot do.

Additional Post: Two a day stopped my foot and leg cramps with no side effects

Additional Post: I had a really bad experience with it - lowest dose (200 maybe?) - it did help the muscle spasms a little, but after a few months? I couldn't connect words & sentences together. It was really scary. I've had to resort to Dr. Richard Bruno's theory of understanding what was causing the muscle spasms in the first place & change the behavior. It was harder, but far better. Those drugs are not good for me at all. (Lyrica was far worse).

Additional Post: I tried taking a third dose (300 mg) midday and it really messed up my mind. I was just not right!! I gave it a few days to see if I would get used to it, but no way. I was adding it (per PPS doctor's orders) to help with insomnia but it was not the way to go. 600 mg/day I don't even notice, but no cramps. We added a half Klonopin for sleep and it helped that problem.

Dr. Bruno's Response: Unless you have a pinched nerve, diabetic nerve pain or similar NERVE pain polio survivors shouldn't take gabapentin or Lyrica.

Additional Post: Aren't restless legs due to nerve pain?

Dr. Bruno's Response: No. Leg pain may make you want to move your legs, but it's not the same thing. Remember - even "sleep doctors" get this wrong:

- Restless Legs Syndrome is when you feel that YOU have to move your legs.
- Nocturnal Myoclonus is when your legs (or any muscles) twitch or jump on their own during sleep.

A low dose of alprazolam 30 minutes before bed treats Nocturnal Myoclonus in polio survivors, who should *not* take drugs that stimulate or block dopamine in the brain (like pramipexole (Mirapex), rotigotine (Neupro), ropinirole (Requip) or Provigil).

Dr. Bruno's Additional Response: Involuntary limb movements, twitching and muscles jumping, is not uncommon in polio survivors and is a sign of overuse. The poliovirus did indeed damage the dopamine producing parts of the brain; you know a dopamine deficit is the cause of Parkinson's and is also what our research has shown to cause postpolio fatigue. So why is there no higher incidence of Parkinson's in polio survivors than the general population?

Back at the 1949 conference on polio, the man who discovered the brain activating system was asked to comment on why polio survivors who had encephalitis, could be in a coma as a result of damage to dopamine brain activating neurons but that polio survivors only incredibly rarely (and by rarely I mean a handful of cases)

had symptoms of Parkinson's. His disturbing conclusion was, "If the poliovirus did that much damage to dopamine producing neurons in the brain individuals had no tremor because they did not survive."

Additional Post: I have this in my legs but not in my arms. Mainly at night in bed.

Dr. Bruno's Response: That's the norm for polio survivors; but any muscle can twitch and jump any time of the day.

Additional Post: I have "tremors" in my hands.

Dr. Bruno's Response: There are many kinds of tremors. Some look like the Parkinson's "pill rolling" tremor in one or both hands where the thumb moved back-and-forth & the wrist turns when the hands are at rest.

Others have the hands shaking only when they are being used. And sometimes the entire arm or both arms shake. What is the tremor like in your hands?

Response Post: There is no way I can thread a needle -ever. I've learned to put less coffee in my cup. The left thumb has crazy movement occasionally. There is more muscle wasting in that hand.

Dr. Bruno's Response: The more affected the muscles and the more muscles involved in "shaking" (whole arm/shoulder vs one thumb) the more likely shaking is due to muscle weakness than a true "tremor."

Twitching is *not* a Parkinson's movement. A rhythmic tremor is.

On the topic of Sedation for a Minor Procedure (4/5/2016)

Original Post: I'm having a gastroscopy this Friday, and I'm not sure what to expect ...they are sedating me. I have no voice and choke so much. They were advised I that I am PPS.

Dr. Bruno's Response: Ask for a low dose of propofol and don't let them add a narcotic and Vistaril. You'll be out for 20 minutes and then wake up and not even know it happened.

On the topic of Anesthesia Warning Cards (4/5/2016)

Original Post: We are happy to be able to highlight an additional ****Anesthesia Warning Card**** This can be used independently or accompany the original, originated by a NJ survivor and done by the State of N.J. This version has a "scan code" for easy access to the anesthesia and breathing information on the website.

We are grateful to John Bach, MD., Richard Bruno, PhD., and William DeMayo, MD. for their support in this endeavor. When the code is scanned (using a smart phone) by your doctor, it will automatically link to these articles on this page), and an enormous number of additional articles that are linked.

The New Card is Available here. <http://www.papolionetwork.org/-anesthesia-warning.html>

Additional Post: How do you get one?

Additional Post: Click on the "link" above. Go down the page (which will show you everything your doctor will see when they scan the code). Underneath the 2 photos, you will see "Anesthesia Warning Cards in PDF format for printing". Just "click" on the red highlighted word "HERE". In one document, you will see 3 versions you can choose from to print, fold and put in your wallet.

On the topic of Dementia and PPS (4/11/2016)

Original Post: I have been diagnosed with Dementia. Is it possible this is a symptom of PPS?

Additional Post: Did you have your Co2 tested? It might be a good thing to do.

Dr. Bruno's Response: On what basis did they diagnose you? All of the trouble with PPS brain fog and attention can skew the test results. In addition? Not sleeping and breathing (as referred to above re: CO2) can also decrease your thinking ability. By the way, the study of Drew University graduates found that polio survivors were 10 times less likely to develop dementia compared to those who didn't have polio. There has to be some benefit from getting polio, no?

Additional Post: I have brain fog, twist words and many "dementia like" things daily....

On the topic of Medicare Coverage for Home Health PT (4/13/2016)

Original Post: My husband has PPS and was recently diagnosed with spinal stenosis. He recently underwent two extensive surgeries within 8 days. (The surgeon was not satisfied with the results shown on the MRI after the first surgery and wanted my husband to have the best results possible which led to the second operation). We are now home after 3 weeks of rehab in the hospital. He is very much in need of PT and OT and is confined to the house. I am having a difficult time convincing the Health Service Agency that PPS are not limited to the amount of PT they are prescribed by their physicians to have. Could you please point me in the right direction? I want my husband to have every chance possible for a good recovery.

Additional Post: PT does not always have to be limited by "showing improvement" but can be paid for to maintain in chronic illnesses ... here is an article on it.

http://newoldage.blogs.nytimes.com/2013/02/04/therapy-plateau-no-longer-ends-coverage/?_r=0

See Pages 5 & 6 –

- No "Improvement Standard" is to be applied in determining Medicare coverage for maintenance claims that require skilled care. Medicare has long recognized that even in situations where no improvement is possible, skilled care may nevertheless be needed for maintenance purposes (i.e., to prevent or slow a decline in condition). For example, the longstanding SNF level of care regulations, specify that the restoration potential of a patient is not the deciding factor in determining whether skilled services are needed. Even if full recovery or medical improvement is not possible, a patient may need skilled services to prevent further deterioration or preserve current capabilities.

<https://www.cms.gov/regulations-and-guidance/guidance/transmittals/downloads/r179bp.pdf>

Dr. Bruno's Response: As you read above, Medicare allows maintenance treatment. But, your husband is getting recovery treatment which is limited by maximum medical benefit. His doctor should ask for more sessions.

On the topic of a "Mild" case of Polio and PPS (4/17/2016)

Original Post: I only had a very mild case of polio and had very few lasting effects. Now, I hurt all the time and have PPS. My doctor said it shouldn't be so.

Response from the European Polio Union: It's common all over the world with PPS. We get calls and messages every day about this. You're not alone & if we could find cause we would.

Dr. Bruno's Response: A "mild case" of polio is like being "a little bit" pregnant.

On the topic of AFO vs KFO (4/18/2016)

Original Post: What do AFO and KAFO mean?

Response: KAFO: Knee, ankle, foot orthotics

AFO: Ankle foot orthotic



On the topic of PPS and Lung Cancer (4/18/2016)

Original Post: I first contracted Polio in Benton Harbor Michigan in 1953 and am now 68 years old. I have recently been diagnosed with a Lung Cancer tumor which was excised on April 5 at the Cleveland clinic in Cleveland, Ohio. My oncologists and surgeon are currently recommending a 9 week course of chemotherapy to begin very soon and I would like to gain more information about the types of chemo that might be "better" for me as a polio survivor. I read Dr. Richard Bruno's book and am wondering if anyone here has any information that could help me.

Dr. Bruno's Response: Dr. Bruno's Response: Chemo can be recommended even if there is no evidence of cancer spread depending on type and size and location of tumor to kill left-over evil cells. Chemo shouldn't

cause more sensory neuropathy in polio survivors than in others. You have to make a decision about side effects with your oncologist.

With anything involving the lungs, I recommend contacting Dr. John Bach: <http://www.doctorbach.com/>

Additional Post: <https://after-cancer.info/2014/08/26/cancer-polio-and-other-conditions/>

On the topic of Polio Survivors and Tracheostomies (4/19/2016)

Dr. Bruno's Original Post: From Dr. John Bach, MD.

EVERYTHING ABOUT POLIO SURVIVORS NOT USING OXYGEN, RETAINING CARBON DIOXIDE AND NOT GETTING THEIR THROATS CUT...

How Polio Survivors Can Avoid Tracheostomies...

By Dr. John Bach, MD.

John R. Bach, MD, Physical Medicine & Rehabilitation, University Hospital, University of Medicine & Dentistry of New Jersey, Newark, New Jersey, is in charge of the Center for Noninvasive Mechanical Ventilation Alternatives and Pulmonary Rehabilitation and has spoken and written extensively. (See "Management of Patients with Neuromuscular Disease" by Hanley & Belfus (2003).

Dr. Bach wrote "Respiratory Muscles Aids to Avert Respiratory Failure and Tracheostomy," which can be found at <http://www.ventusers.org/edu/ConfCall2013Bach.pdf>. His talk supported the premise that "polio survivors can virtually ALWAYS avoid tracheostomies even if continuously (noninvasively) ventilator dependent."

However, If you can't speak or swallow, then you do need a tracheostomy.

Dr. Bach describes his patients. My first patients were those who used ventilators since having had polio.

Then, I started seeing patients who had used iron lungs but had weaned from them but now need to use noninvasive ventilation. There are also some people who never before needed assisted ventilation until recently.

Dr. Bach on the first decision. First, it should be determined if polio survivors are symptomatic for nocturnal under ventilation. It is also possible that there could be a second condition like lung disease (failure of oxygenation) especially if one was a heavy smoker. Most of the time, though, the symptoms are from muscle weakness (failure of ventilation) for which the treatment is nocturnal ventilation. This is most likely for the survivors of polio. The treatments are very different. For lung issues, the solutions include bronchodilators and oxygen. But, for muscle weakness the treatment is the use of respiratory aids which include noninvasive ventilation and mechanical coughing aids. If a patient has both problems, eg, lung problems due to smoking and neuromuscular weakness due to polio, a decision may need to be made as to which is the primary problem and treat it.

Dr. Bach on breathing muscles. Inspiratory muscles assist with inhaling. Shortness of breath when lying flat (orthopnea) is a sign of a weak diaphragm (an inspiratory muscle). Many polio people use pillows to support their backs to prevent shortness of breath when they sleep, but the best solution for weak inspiratory muscles is intermittent positive pressure ventilation (air under pressure when inhaling) from a ventilator and via a nose interface. It takes about 20 ml of water pressure to ventilate someone who has severe muscle weakness.

Expiratory muscles (mostly the abdominals) assist with coughing. If survivors get a cold, they may not complain of shortness of breath but of anxiety and difficulty sleeping due to high blood carbon dioxide levels. It is not helpful to use CPAP and only minimally helpful to use bilevel devices if breathing muscles are weak, because the air blowing in when we exhale is counterproductive.

Bulbar (throat) muscles protect the airways. There isn't anything to be done for bulbar muscle weakness when it results in continuous aspiration of saliva into the lungs but in polio that almost never happens which is why tracheostomy tubes are unnecessary.

Dr. Bach on weak coughing muscles. Weak coughing muscles keep one from getting rid of the bacteria, etc. in the lungs, which results in pneumonia risk. The first thing an ER physician normally would do is to give oxygen, and if the CO2 is already high it will "go through the roof." This is why and how many polio survivors

get intubated and, after the pneumonia clears up, many are trached. It is not necessary. If a person could speak and swallow at least a little before getting intubated he/she certainly does not need a tracheostomy. Do polio people have trouble swallowing? No. But, people with ALS have trouble swallowing and they can need tracheostomy tubes.

Dr. Bach on CoughAssist (Philips Respironics). Some people who have a trach think that it is easier to suction mucus when they have a cold if they have a trach. The only people who think this are those who don't know how to use the CoughAssist through the nose and mouth. For that matter, it is also much better than suctioning the airways to use it via a trach tube too. It is best to use the CoughAssist with an abdominal thrust and at least 35 ml of water pressure in and out. A manually assisted cough will get most polio people a functional cough to help them through most problems, so a cough machine is not as necessary for everybody. Dimi Italia s.r.l., Seoil Pacific Group, B & D Electromedical and Siare Engineering International Group S.r.l. also manufacture cough devices.

Dr. Bach on trach tubes. Four out of five people who get a trach will die because of the trach. Problems include mucus plugs, a fistula between the esophagus and trachea (windpipe), and granulations around the trach that bleed when the trach is changed. The tube itself can puncture the windpipe or trachea, or even an artery. People with trach tubes also carry many bad pathogens, so it is not surprising that people with trachs have a greater number of serious infections than those who use noninvasive ventilation. Trach tubes should be removed in those who can speak and swallow food and can cooperate and communicate.

Dr. Bach on CO₂. Too much CO₂ in the blood causes acidity just like CO₂ causes acid rain. Some CO₂ is needed to trigger the brain to tell muscles to breathe. Most labs do not measure end tidal CO₂ but do painful arterial blood gases which make people hyperventilate from the pain. Painless end-tidal CO₂ is actually much more useful.

Dr. Bach on oxygen use. It's a terrible mistake for polio survivors (without lung diseases) to use oxygen. Oxygen use turns off the drive to breathe, and causes the CO₂ levels to rise. Any polio survivor who has respiratory problems, sees a physician, and is sent home with oxygen will be back for treatment of pneumonia or respiratory failure sooner than if they had not been treated at all. The problems that polio survivors have are weak muscles and extra secretions, and there are solutions for both, ie, the treatment is either assisted ventilation and/or assisted coughing.

Dr. Bach on testing. Pulmonary function testing is for lung disease, not muscle weakness. What polio people need is the measurement of vital capacity, which is the largest breath one can take both while sitting and lying down. The difference between the two should be less than 7%. Other important spirometric tests include measuring air stacking ability. The needed tests are not done in pulmonary function labs and include the measurement of cough flows, both assisted and unassisted. The assisted-cough flow is measured when an Ambu-Bag (manual resuscitator) is used to "air stack," ie, retain consecutive volumes of air and hold it in the throat to attain the highest volume. Then pressure is put on the belly, if the abdominals are weak, to cause a cough, and the flow is measured. If the flow is more than 270 liters per minute a polio survivor has little chance to get pneumonia during a cold, but if less, any respiratory infection is likely to result in pneumonia. Sleep studies (polysomnography) were never meant to test for post-polio muscle weakness, but can be useful to rule out other problems, such as obstructive/central sleep apnea which is NOT the principal problem of polio survivors. If a pulmonologist sends someone for a sleep study and they have weak inspiratory muscles, they will treat the patient incorrectly. CPAP is useless for those with breathing muscle weakness, and BiPAP suboptimal particularly at the usual settings used (Inspiratory pressure of 10; Expiratory pressure of 5).

Dr. Bach on oximeters. All polio survivors should have oximeters to assist with the protocol to prevent pneumonia. When sick, use the oximeter to be sure it never registers below 95%. If it does, it means one of two things. One, your CO₂ is high and ventilation is needed. Two, secretions are high and assistance with coughing is needed. If neither treatment is used, the situation worsens and when taken to the ER, oxygen is

offered which often results in breathing arrest and emergency intubation, then unnecessary tracheostomy. Remember, if this happens, people can have the tube or trach removed and be successfully managed using noninvasive ventilation. (See Extubation of patients with neuromuscular weakness: a new management paradigm, Bach JR, Gonçalves MR, Hamdani I, Winck JC. Chest. 2010 May;137 (5):1033-9.)

Dr. Bach on ventilators. Ventilator use rests a weak diaphragm and weak inspiratory muscles during sleep, and the result is feeling stronger, better during the day and blood gases are better, ie. CO2 is more normal. The way to rest the muscles is to use a ventilator using pressures of 18-20 cm of water, not by using CPAP or BiPAP. Remember: It is not possible to turn off the expiratory pressure on a BiPAP machine and the user cannot air stack using it. Air stacking is important to stretch the lungs to full capacity, because if the vital capacity is 50%, that means that half of your lungs are not being used and they "close down."

Dr. Bach on what breathing device to use. Many polio survivors used negative pressure machines (iron lungs, chest cuirasses, pulmowraps) in the early days, but they caused obstructive apneas and the users experienced desaturations and high blood pressure. I don't recommend negative pressure for anybody any more. I recommend the LTV Series (CareFusion), Trilogy Series (Philips Respironics), and Newport HT50, HT70 (Covidien) here in the United States.

Dr. Bach on nasal masks. There are hundreds of nasal masks on the market, and I recommend that people try several. If someone has trouble with the nasal mask leaking, then try an oral/nasal device such as the Hybrid™ Universal Interface (DeVilbiss Healthcare) or the lip cover Oracle™ 452 (Fisher & Paykel Healthcare), and the oro-nasal Mirage Liberty™ (ResMed Corp).

Dr. Bach on diaphragmatic pacers. A diaphragmatic pacer is completely useless for polio people because to use the device a person need a good phrenic nerve and a good diaphragm and if they had them they would need no help at all.

www.doctorbach.com/

This article is available in an easily shared PDF format "How Polio Survivors Can Avoid Tracheostomies"

<http://www.papolionetwork.org/living-with-post-polio-syndrome.html>

[On the topic of the Shingles Vaccine](#) (4/19/2016)

Dr. Bruno's Post:

Ask Well: Do I Need the Shingles Vaccine if I've Had Shingles?

By Roni Caryn Rabin, April 15, 2016

Does the shingles vaccine prevent recurrence of shingles if you've already had shingles years ago?

I had chickenpox as a child, and a light case of shingles (herpes zoster) when I was 60. I am now 65. Should I still get a zoster vaccination, or do I have some percentage of immunity?

Can you get shingles more than once?

If you've had shingles, do you need a shingles vaccine?



For many years, conventional medical wisdom suggested that shingles, or herpes zoster, was a once-in-a-lifetime occurrence for most adults with a healthy immune system. But a 2011 study that reviewed medical records in Olmsted County, Minn., challenged that assumption, finding the risk of recurrence was comparable to the risk of a first episode, with 6 percent of adults having a second bout of shingles within eight years of the first. The Centers for Disease Control and Prevention recommends all adults age 60 and over be routinely vaccinated "irrespective of whether you've had shingles or not," said Dr. Rafael Harpaz, a medical epidemiologist in the division of viral diseases at the C.D.C. The vaccine is approved starting at age 50.

(NB: Always get vaccines from your DOCTOR who knows your history, not the guy in the pharmacy at WalMart!)

Anyone who has had chickenpox can develop shingles, which occurs when the chickenpox virus, varicella zoster, which lays dormant but never leaves the body, becomes reactivated. But the mechanism is not well understood, Dr. Harpaz said, and having had shingles “may paradoxically be a marker that you’re at increased risk compared to everyone else.”

Whether vaccination reduces the recurrence rate, and to what extent, is less clear, experts say, because carrying out a clinical trial would be prohibitively expensive. But a study of 101 adults age 50 and over with a history of shingles found that vaccination boosted antibodies, and there were no serious side effects aside from soreness at the injection site.

A 2012 study of more than 6,000 Kaiser Permanente members who had had a recent episode of shingles found that those who had been vaccinated were at slightly lower risk of a recurrence of shingles than those who had not been vaccinated, but the difference was not statistically significant, and rates of recurrence were low in both groups.

The vaccine is not designed to treat shingles, but Dr. Barbara Yawn, the researcher who did the Minnesota study, said, “I certainly recommend that my patients who had previous episodes do go ahead and get the vaccine.

<http://well.blogs.nytimes.com/2016/04/15/ask-well-do-i-need-the-shingles-vaccine-if-ive-had-shingles/?ref=todayspaper>

Dr. Bruno’s Additional Post: Like it says in the article - *always* get vaccines from your DOCTOR who knows your history, not the guy in the pharmacy at Wal-Mart!

On the topic of Muscle Spasms vs. Muscle Cramps (4/20/2016)

Original Post: A friend of mine with PPS has gotten several muscle cramps. Magnesium does not help anymore. He is suffering a lot of pain because of them. Now he’s wondering if these are not muscle cramps, but actually muscle spasms? Is this a possible PPS symptom too?

Dr. Bruno’s Response: He should have all electrolytes measured, potassium, magnesium and calcium. A muscle CRAMP is a short-lived, very painful, involuntary contraction of an entire muscle or a relatively large portion of a muscle, usually a leg muscle and sometimes a forearm muscle. Who hasn't had a screamingly painful cramp of the calf muscle that pulls your toes downward and forces you to stand to stretch it out?

A muscle SPASM feels hard, sometimes as hard as bone, and can be as small as an M&M or as big as the entire side of your neck or your low back. No one knows what spasms are or why they can hurt so badly! Spasms seem to be muscle fibers in a small area contracting into a dense knot and usually occur in postural muscles in the neck and back. But, in a 1990 study I did, there was NO relationship between how hard a muscle spasm was, muscle electrical activity and pain. So, a small, not-so-dense spasm in a neck muscle can cause a headache that puts you in bed for hours, in a dark room after driving the porcelain bus. But a large, dense rock of a spasm in your neck or back may not hurt at all even when a physical therapist puts her thumb in it.

Bottom line:

Muscle OVERUSE causes cramps and muscle MISUSE (e.g., poor posture) causes spasms. See the POLIO SURVIVORS HANDBOOK in at postpolioinfo.com for chapters on preventing cramps and spasms.

On the topic of Transverse Myelitis being a "Polio Like" Illness (4/25/2016)

Original Post: Dr. Richard Bruno, can you help us understand the difference? I found this article from the U. of Texas and I'm a tad more confused. This question came up on a support group meeting. Thanks!

<https://myelitis.org/reported-cases-polio-like-illness-relationship-transverse-myelitis/>

Dr. Bruno's Response: This article is 2 years old, written during the EV-68 scare.

Transverse Myelitis (meaning "inflammation across the spinal cord") is like having multiple sclerosis within a narrow band through the spinal cord. TM affects the covering of motor and sensory nerves and can cause paralysis and loss of feeling/nerve pain. Polio damages only the motor nerves themselves and you know the results. TM has nothing to do with the 3 polioviruses.

Additional Post: People are still referring to EV-68 as polio. Is TM the same as Endovirus 68 or 71? The date of the article & locations that the article referred to seems similar to those Endovirus cases I read about a while ago....Polio being an Endovirus is why they first thought the cases I read about were Polio Cases.

Dr. Bruno's Response: TM the NOT the same as Endovirus 68 or 71 or the 3 polioviruses. TM can be triggered by an infection, but these viruses do not do the damage in TM.

It has never been proven that EV-68 cause muscle weakness in the 101 kids affected in 2014. And there was no repeat last summer. EV-71 DOES damage motor neurons and was suggested as "poliovirus Type 4" ...Like we need a 4th poliovirus!

Additional Post: Transverse Myelitis differs from Poliomyelitis in that it can affect more than a specific region of the "grey" part of the spinal cord. The symptom range beyond paralysis or paresis (related to somatic motor neurons), such as the case with polio, and can disrupt sensory and autonomic nerve function as well. Very like MS (Dr. Bruno mentioned). It is an autoimmune disorder, but suggestions are it *may* initially be triggered by an infection.

http://www.ninds.nih.gov/.../detail_transversemyelitis.htm

On the topic of Statin Medications (original post 1/2016 continued 4/26/2016)

Original Post: I'm *NOT* posting this for you to worry about if you're taking a Statin. It's just something to keep in mind and to show your doctor. Polio Survivors need to have their 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.

Additional Post: My husband who also had polio wonders if the Lipitor he's on might be causing him to feel weaker.

Additional Post: What ARE statins?

Dr. Bruno's Response: Statins are a class of cholesterol-lowering drugs that target all aspects of your lipid profile: They lower LDL cholesterol and triglycerides, while raising HDL cholesterol. Although they are very

effective in lowering cholesterol levels, statins may not be for everyone. There are some things you should let your healthcare provider know before you begin statin therapy, such as medical conditions you may have or any medications that have been prescribed to you by another physician.

This is a general list of medical conditions and medications that you should be aware of. For a more complete list, remember to consult the information for the specific statin if you are taking (Crestor (rosuvastatin), Zocor (simvastatin), Mevacor (lovastatin), Lescol (fluvastatin), Lipitor (atorvastatin), or Pravachol (pravastatin)).

Medical Conditions

You should let your healthcare provider know if you have one or more of the following conditions before you begin taking a statin:

Active or chronic liver disease

Pregnancy – Statins may cause birth defects.

Breastfeeding – Statin drugs could cross the breast milk and be ingested by your baby.

Alcohol abuse – Statins could further increase liver enzymes.

Possible Drug Interactions

Some medications may interact with statins, by either decreasing the effectiveness of your statin or increasing the statin level in the blood to the point where it may become harmful to the body. Be sure to notify your healthcare provider if you are already taking any of these medications below. Just because you are on any of these medications, it does not mean that you are not able to take a statin.

However, your healthcare provider may want to monitor you more closely while on these drugs, since taking these medications with a statin may increase your risk of side effects. This list is not inclusive, so if you need a complete list of drug interactions, please read the individual information about your statin (Crestor (rosuvastatin), Zocor (simvastatin), Mevacor (lovastatin), Lescol (fluvastatin), Lipitor (atorvastatin), or Pravachol (pravastatin)) or consult your healthcare provider for further information:

Nicotinic acid, or niacin, in high doses (greater than 1 gram a day) could increase risk of experiencing statin side effects.

Bile acid sequestrants may decrease the effectiveness of some statins. In order to avoid this, your statin dose and bile acid sequestrant dose can be separated by at least four hours.

Fibrates may increase the risk of experiencing statin side effects.

Samdimune or Neoral (cyclosporine) may increase the amount of statins present in the blood and may also increase side effects.

Fluvoxamine may increase the concentration of some statins present in the blood and may also increase statin side effects.

Antifungal drugs ending in "-azole", such as Nizoral (ketoconazole), Diflucan (fluconazole), Mycelex (miconazole), or Sporanox (itraconazole), may increase the amount of some statins present in the blood and may also increase statin side effects.

Antibiotics ending in "-mycin" such as erythromycin or Biaxin (clarithromycin) may increase the amount of statins present in the blood and may also increase side effects.

High blood pressure medications, such as diltiazem and verapamil, may increase the amount of statins present in the blood and may also increase side effects.

Cordarone (Amiodarone) may increase the amount of some statins present in the blood and may also increase the side effects of statins.

HIV Protease Inhibitors, such as Norvir (ritonavir), Agenerase (amprenavir), Crixivan (indinavir), or Viracept (nelfinavir), may increase the amount of some statins present in the blood and may also increase side effects.

Coumadin (warfarin) – Taking a statin with this drug could cause the blood to not clot as well.
Prilosec (omeprazole) may increase the amount of some statins present in the blood and may also increase the side effects of statins.
Tagamet (cimetidine) may increase the amount of some statins present in the blood and may also increase the side effects of statins.
Zantac (rantidine) may increase the amount of some statins present in the blood and may also increase the side effects of statins.
Oral contraceptives – Statins may increase the concentration of these hormones in the body.
Lanoxin (digoxin) – Statins may increase the concentration of some statins in the body.
Antacids containing magnesium or aluminum hydroxide may decrease the concentration of some statins in the body. This can be prevented by separating your statin dose and antacid dose by at least two hours.
St. John's Wort may decrease the effectiveness of some statins.

Statins can cause muscle pain and sometimes muscle weakness in *anyone*. You have to discuss cholesterol control with your doc and not just dismiss statins. Your heart is a muscle you need working 24/7!

<http://postpolioinfo.com/library/Cholesterol.pdf>

On the topic of Post-Polio and Sleep Medications (4/28/2016)

Original Post: I had polio in 1959 I was told that I had the polio vaccine and that's why I didn't have a very serious condition like many that didn't receive the vaccines but I was in the iron lung and wheelchair and then braces and crutches, I now walk with a limp but as I get older I have pains in my legs, fatigue and some short of breath my doctor doesn't know anything about polio and I have shared many things that I get off this site and I thank you for all the information. I told him about not able to sleep well and he said I need to take a sleeping medicine. Well I not sure because I have had bad reactions to some medicine. I was always told as a child that you could have only one kind of polio but now I have heard that you can have different types. Is that true?

Dr. Bruno's Response: I recommend finding another doctor, who will recommend a sleep study.

You didn't have a "very serious condition like many that didn't receive the vaccines" but were "in the iron lung and wheelchair and then braces and crutches?"

What was "serious" polio if not being in an iron lung, wheelchair and having braces and crutches?

Yes, you could have had two types of polio. Type I was the norm. But it sounds like the vaccine you did get did not cause your body to produce antibodies to any strain. The "Salk" vaccine was not 100% effective; probably 80%-85%. There were 10,000 cases of polio in the US in 1959. Something was wrong with that number of cases when everyone had been "100%" vaccinated.

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.