



Bruno "Bytes" – June, 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 having had Undiagnosed Polio (6/8/2016)

Original Post: Maybe you could give me some feedback on my situation. Seems as though I am alone with what I believe to be PPS. I have a weak left leg that often times also feels like a dull tooth ache or very painful. My chiropractor feels as if I had a mild case of polio that was never noticed by my parents. I was born in 1950. My closest friend had polio in 1955. I've never forgotten those awful braces on his legs. I now have a C-pap machine for sleep apnea and fatigue. I have had severe IBS constipation all my life. In my heart, I kind of feel he is right about that diagnosis. Thank you for your concern and commitment to this cause.

Additional Post: I believe my parents were aware and chose to keep it a secret. My neurologist said many parents did that if it was possible. My mother told my wife that my legs were paralyzed for a short time (I have no memory except being carried). My year was also 1955.

Additional Post: I thought I was alone on that one. I had the summer "grippe" in 1954 - recovered on my own, only a drop foot remained. 10 years later my parents were told it was a "polio" foot. It was never mentioned again. I was diagnosed with PPS in my early 50's. At age 90 (10 years after my diagnosis), Mom told me that she and my Dad knew in their gut that it was polio at the time, but I recovered so they just put it aside and never mentioned it again.

Dr. Bruno's Response: Your experiences are exactly why we will never know how many people in North America actually had polio! The 1987 national health interview survey estimated that there were 1.63 million American polio survivors. But you would've had to know that you had polio to answer "yes" to the survey. What's more, reporting cases of was not required until 1955 and was only required to verify that the vaccine was working. Nobody cared how many people had polio before the vaccine. The federal government just wanted to make sure that the vaccine was actually preventing new cases.

Additional Question: My sister had paralytic polio and I had what the doctor said was the flu at the same time. Could my "flu" have been a mild case of polio?

Dr. Bruno's Response: If the poliovirus entered the nervous system there was no mild "case." The poliovirus killed brain stem (bulbar) neurons even if it didn't affect the spinal cord. And you had to have 60% of your spinal cord motor neurons killed to have any lasting paralysis!

As it applies to having had a "mild case," here's another stat. We went through the Mayo Clinic's Olmsted county data base. We found data that indicates there are 150,000 Americans who had polio (usually siblings of paralytic polio survivors) who were never diagnosed, not even as having "non-paralytic" polio or the "summer grippe."

Bottom lines:

- 1) Poliovirus did lots of damage whether or not you had muscle weakness or paralysis.
- 2) We have no idea how many people had polio.

This is exactly what's happening in India right now. It is estimated that there are 8 million Indian polio survivors whom aren't being cared for. But new cases of polio must be reported to make sure that India remains "polio free." The Indian reporting system has found that the country has traded 200,000 cases of

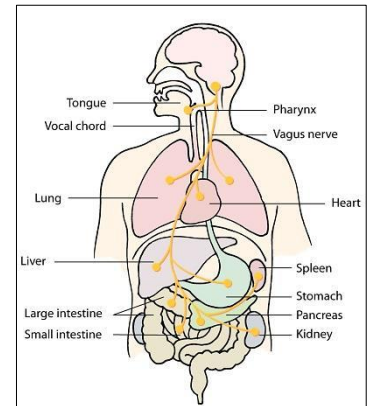
polio per year for 60,000 cases of non-polio paralysis caused by other viruses that live in your intestines and are passed from person to person just as the polioviruses were.

On the topic of Viruses Damaging the Intestines (6/11/2016)

Dr. Bruno's Original Post: This new study finds that viruses damage intestine's nerves and is a "surprising cause" of constipation. Surprising? Polio survivors knew this 60 years ago! Polioviruses can enter the brain and spinal cord via the vagus nerve that controls the gut and damages the vagus and it's brain stem control centers --> slow polio gut = constipation.

<http://neurosciencenews.com/constipation-herpes-spinal-cord-4412/>

Vagus Nerve – The Body's "Life" Nerve



On the topic of needing a new brace (6/11/2016)

Original Post: Since I have stopped wearing a full leg brace when I walk, my paralyzed leg has been rotating outward and my foot has been rotating outward. Has anyone else had this happen? Would it warrant getting another brace to stop the rotating problem? My old brace is over 30 some years old and doesn't fit anymore.

Dr. Bruno's Response: Simple answer. You need a new brace.

On the topic of high blood pressure and PPS (6/12/2016)

Original Post: I just got out of the hospital. My blood pressure spiked to 202/189. Ambulance took me to hospital. After lying there 2/12 hours of being monitored the doc came in and ignored that I have had polio. When the doc left my BP was 206/189. I told the nurse how upset the doctor's lack of concern made me feel.

Dr. Bruno's Response: A spike in blood pressure like this is not a Post-Polio issue. If your blood pressure is this high you need to be seen by both a cardiologist and a kidney specialist to figure out the cause. First of all you need to let your local doctor take some blood and do an exam.

The diastolic pressure is the pressure in your arteries between heartbeats. So if anything your diastolic pressure should drop when your arteries become more open in the heat. Your body's first line of defense against overheating is opening up arteries and veins to get blood from the hot core of your body to the surface for cooling. If that doesn't work, then you also sweat for evaporative cooling.

On the topic of Non-Opioid pain relief (6/13/2016)

Original Post: What kind of non-opioid pain relievers are there? I've been surprised at the lack of choices in that regard. I use Lyrica at times, and ansaids (nonsteroidal, anti-inflammatory drug). What else??

Dr. Bruno's Response: Gabapentin and Lyrica, but they are for nerve pain. Toradol and Diclofenac are nonsteroidal anti-inflammatory drugs, and they are stronger than ibuprofens.

Additional Post: I generally take 1-2 pain meds before bed & get maybe 4 hours sleep before taking another, usually just aspirin at that point. Last night I took a Baclofen with a Lyrica and had a ragingly weird dream after 2 hours. This stuff is hard to get sorted out.

Dr. Bruno's Response: For those of you from Europe and the UK, Paracetamol is Tylenol in the US.

Baclofen and Lyrica very sedating, cause weird dreams and are not of help for post-polio muscle pain.

Additional Post: Most of my pain is from overuse. This may have happened two or three days before the pain. The only way to get rid of that is to rest; really and *truly* rest. Heating pads help. I have found that much of my pain is from muscle spasms. I deal with that at night by taking a half dose of Flexeril. I can't take that in the daytime. If my pain is localized, like my back or shoulder, I use a lidocaine patch.

Dr. Bruno's Response: For muscle spasms, Valium is much less sedating than Flexeril.

On the topic of Homeopathic Remedies and PPS (6/13/2016)

Original Post: I found this report very interesting. Could it have worked? It sounds a little too good to be true; especially the mention of a "cure".

<http://thehomeopathiccollege.org/acute-treatment/post-polio-syndrome-aggravation/>

Dr. Bruno's Response: There are NO published, double-blind peer reviewed studies of homeopathic treatment for PPS, let alone a cure. Patient reports aren't sufficient as evidence of effectiveness. Therefore, I cannot recommend homeopathic treatment for PPS and they are *not* reported in the Post-Polio Coffee House. NO medication, homeopathic or otherwise, is a treatment or cure for PPS.

Remember, the placebo effect is a powerful thing; 33% of subjects in any study of treatment for pain, fatigue and depression respond to placebo. Unfortunately, there is no hope for a drug treatment. As the years go by our standard prescription for the treatment of PPS still stands to protect your remaining, polio damaged and overworked neurons. Conserve to Preserve.

CONSERVE TO PRESERVE

On the topic of Polio Survivors and Osteoporosis (6/16/2016)

Dr. Bruno's Original Post: Here is one of the many emails I've received about Osteoporosis

Q: I have both osteoporosis and acid reflux. I just read that the anti-reflux drug I'm taking may cause my bones to get thinner. I already am taking Fosamax, which I also read can cause my jawbone to die! Should I stop both these pills?

A. Polio survivors are finding themselves between drugs and a soft place, that soft place being their bones. Osteonecrosis -- bone death -- was reported in the jaws of 63 patients taking bisphosphonates, drugs that are given to increase bone density. Fifty-seven patients received intravenous bisphosphonates as treatment for cancer. But, six took Fosamax, the well-known oral anti-osteoporosis medication. Dentists across the country have reported about fifty cases of jaw osteonecrosis. Given that about three million women take Fosamax, fifty is a small number of cases. Even if you assume that only about one percent of problems caused by a given medication are reported, jaw osteonecrosis would occur in only two-tenths of one percent of women taking Fosamax. Still, if it's your jaw that's dying, who cares about percentages? So, the FDA now wants labels on all bisphosphonates to warn about the possibility of osteonecrosis.

If drugs to treat osteoporosis aren't causing enough worry, in late 2006 a study of nearly 150,000 people over 50 year-old found that taking proton pump inhibitors (anti-acid reflux drugs like Nexium) for more than a year increased their risk of a hip fracture by 44 percent. The higher the dose and the longer the drugs were taken, the risk of a hip fracture, especially among men, rose nearly 200 percent. The increased risk of fracture may be caused by proton pump inhibitors interfering with your body's ability to deposit calcium inside your bones to increase their strength. This unfortunate side effect of proton pump inhibitors is a two-headed dragon for polio survivors.

The first head is that polio survivors with paralysis, both female and male, have osteoporosis more frequently because they either haven't been "pushing" on their bones by standing on their legs (the result of using a weight-bearing brace, crutches or a wheelchair) or because their weak or paralyzed muscles haven't been "pulling" on bones. It's the pushing and pulling that makes calcium bind inside bones so they won't become brittle.

The second dragon's head is that our 1985 Post-Polio Survey found that gut problems, including ulcers and acid reflux, are between six and fifteen times more common in polio survivors than in the general population.

To make things worse, sleep apnea, which we have found in 25% of Post-Polio Institute patients, may increase reflux.

Oh, and another "head" has just reared its ugly self. A 2007 study of 5,000 adults 50 year-old and older found that daily use of the newer antidepressant medications (selective serotonin reuptake inhibitors -- SSRIs -- like Prozac) decreased bone density by as much as four percent and doubled the chance of breaking a bone.

What's more, the higher the dose of an SSRI, the risk of falling increased by fifty percent.

So, what's to be done about your belly, your brain and your bones? All female polio survivors, and males who have muscle weakness or paralysis, should have a DEXA bone density scan to determine if they have osteoporosis or osteopenia, a lesser decrease in bone density that still increases your risk of fracture. If you have decreased bone density, ask your doctor if you could try to increase calcium, vitamin D and protein before starting a bisphosphonate. If you need medication, ask about using calcitonin, a hormone that also increases calcium inside your bones, or the non-bisphosphonate drug Evista.

If you are taking a proton pump inhibitor or an SSRI, ask your doctor if increasing calcium would be helpful in combating these drugs' unwanted effects on bone density and falling. And, Postmenopausal women should talk to their gynecologist about whether hormone replacement is an appropriate treatment.

Unfortunately, fatiguing exercise or walking to "push and pull" on bones is not a treatment for osteoporosis or osteopenia in polio survivors, since exercise can cause muscle weakness and exactly what you're trying to prevent: a fall and a fracture.

[On the topic of the Children of Polio Survivors needing to have the Polio Vaccine](#) (6/17/2016)

Original Post: Dr. Richard Bruno isn't it true that all of our children are automatically immune from polio, even if they are not vaccinated? I got Polio at the age of one in 1937. At that time I was advised my children are automatically immune from contacting polio. Now I'm hearing all children (even children of survivors) need the vaccine. When was this changed?

Dr. Bruno's Response: It NEVER was changed because it's not true. Sadly, whoever told you that children of polio survivors did not need the vaccine was grievously uninformed. Just because you developed antibodies after having polio or by receiving the vaccine does not mean that your children received antibodies from you during your pregnancy. Poliovirus antibodies (immunoglobulin A and others) are found in breast milk and do protect the infant, but only during breast feeding. After that, the antibodies disappear and polio vaccination is vital.



What's more, if you're traveling to a country where the poliovirus — the wild virus or mutated oral vaccine strains -- are still around (the Middle East, India, Ukraine, Pakistan, all the other "stans" and even Europe, where Syrian refugees are flocking) it would be prudent to have a booster shot of the polio vaccine.

John McFarlane, President of the European Polio Union, agrees: "All children require vaccination, even those of polio survivors, as immunity against the virus has been shown not to cross the placental barrier. In addition protection needs to be ensured for all three types of poliovirus. It is important to note that polio survivors can contract polio again, from a different type of the virus from the one they originally contracted (Usually Type I). For this reason it is imperative that polio survivors, like everyone else have up to date vaccinations, especially when travelling to "high risk" regions. Double infections in polio survivors have been allegedly reported on the Indian sub-continent."

Here's the bottom line:

EVERYONE, EVERY CHILD, NEEDS TO BE VACCINATED AGAINST POLIO.

On the topic of Stem Cells Curing PPS (6/23/2016)

Dr. Bruno's Original Post: "CAN STEM-CELLS CURE PPS?" I get this question once a month. Here is a frightening story from the NY Times, and a reminder that if something sounds too good to be true, IT IS.

A Cautionary Tale of 'Stem Cell Tourism'

By GINA KOLATA

NY TIMES JUNE 22, 2016

The surgeon gasped when he opened up his patient and saw what was in his spine. It was a huge mass, filling the entire part of the man's lower spinal column.

"The entire thing was filled with bloody tissue, and as I started to take pieces, it started to bleed," said Dr. John Chi, the director of Neurosurgical Spine Cancer at Brigham and Women's Hospital in Boston. "It was stuck to everything around it. I had never seen anything like it."

Tests showed that the mass was made up of abnormal, primitive cells and that it was growing very aggressively. Then came the real shocker: The cells did not come from Jim Gass. They were someone else's cells.

Mr. Gass, it turned out, had had stem cell therapy at clinics in Mexico, China and Argentina, paying tens of thousands of dollars each time for injections in a desperate attempt to recover from a stroke he had in 2009. The total cost with travel was close to \$300,000.

A growing number of clinics, often in places like Russia or China, but also in Europe and elsewhere, say on websites that they can treat, even cure, diseases like muscular dystrophy, Alzheimer's, Parkinson's, and spinal cord injury as well as strokes, by injecting patients with stem cells that, in theory, could develop into a missing nerve, a muscle or other cells and repair damage from an illness or an injury.

Reports by injured athletes of seemingly miraculous results have contributed to a growing interest among desperate patients. Estimates are that tens of thousands of patients around the world have had such treatments and that the industry is worth hundreds of millions of dollars.

The clinics, which are unregulated, have websites with glowing testimonials from patients, some of which, Mr. Gass's sister-in-law discovered, have financial interests in the clinics. The clinics often claim to be doing clinical trials, giving a veneer of legitimacy to their work.

Academic researchers say stem cells hold enormous promise, but they are proceeding cautiously with clinical trials because stem cells divide rapidly and can form tumors in laboratory animals. In lab studies, stem cells also can quickly accumulate mutations like those in cancer cells.

While there have been reports in medical literature of patients who developed tumors after stem cell injections, few patients have been as open about their quest for a cure, the money they paid and the tragic consequences as Mr. Gass, a 66-year-old former chief legal counsel for Sylvania who lives in San Diego, has been.

After the stroke, Mr. Gass lived independently although his left arm was useless and his left leg weak. Now, however, with the foreign body in his spine, he is paralyzed from the neck down, except for his right arm. He needs a hoist to move from his bed to a wheelchair, and his doctors do not know how to stop the tumor from growing.

The doctors wrote about his case in a letter published on Wednesday in The New England Journal of Medicine. Experts who have written articles in medical and scientific journals bemoaning "stem cell tourism" said this case could make a difference.

"We scientists and clinicians say, 'Don't do this,'" said Dr. Jaime Imitola, a neurologist and stem cell researcher at Ohio State University Wexner Medical Center who has written about the dangers of stem cell tourism. But, he said, their warnings often do not resonate.

Dr. Imitola said that Mr. Gass “puts a human face to a tragedy.” Patients might see what happened to Mr. Gass “and say, ‘Oh my God, that could be me.’”

“This is a really cautionary tale,” said Timothy Caulfield, research director of the Health Law Institute at the University of Alberta, who wrote a recent commentary on stem cell clinics.

Mr. Gass’s problems began on May 10, 2009, when he woke with a terrible headache. He tried to get out of bed and fell to the floor, unable to move. He’d had a stroke. Two years later, he was able to walk only with a leg brace and a cane.

“I began doing research on the internet,” Mr. Gass said. He was particularly struck by the tale of the former football star and professional golfer John Brodie who had a stroke, received stem cell therapy in Russia and returned to playing golf again.

So Mr. Gass contacted a company, Stemedica, that had been involved with the clinic, and learned about a program in Kazakhstan. When Mr. Gass balked at going there, the Russian clinic referred him to a clinic in Mexico. That was the start of his odyssey.

Mr. Gass’s doctors and his sister-in-law, Ruth Gass, tried to dissuade him. Ms. Gass called the clinics and demanded evidence that their treatments worked.

Some of the clinics hung up, saying they would not talk to a terrified relative, she said. Websites often had data but it did not hold up to basic analysis, Ms. Gass said, and when the data was published, it appeared in vanity journals. Other clinics simply told her, “People get dramatically better.”

She raged against the clinics, telling them: “You ought to be ashamed for charging \$40,000 a shot. You prey on people like my brother-in-law who is desperate for help.”

Then came her kicker: “I said, If what you are saying is true, you should get the Nobel Prize. If not, you ought to go to hell. Shame on you.”

But Mr. Gass was undeterred. He was willing to spend his money and go anywhere. What did he have to lose? The worst that could happen, he thought, is that he would have no improvement.

He went from clinic to clinic, ending up back in Mexico for an injection of fetal cells shipped from Russia. Six months later, his walking improved. But the improvement did not last long, so he had another injection. Then something disturbing happened.

“I felt pain when I would lie down, like I was lying on a tumor,” Mr. Gass said. “I started to lose my ability to walk and I fell down a lot.” He was in Thailand at the time, a place he likes to visit. Doctors at a hospital there tried to do a spinal tap but told Mr. Gass that something was wrong. There seemed to be no spinal fluid.

He returned to the United States, to Boston, where he had spent most of his life and where his brother and sister-in-law lived and asked the doctors at Brigham and Women’s Hospital for help.

They did a magnetic resonance imaging scan of his spine and were aghast when they saw the image. “The entire lower portion of his spinal column was filled with a mass,” said Dr. Aaron Berkowitz, director of the hospital’s global neurology program.

The only option was to operate.

But now that the doctors knew what the mass was, they were left with another problem: How could they stop it from growing? If it had been an infection, they could have used antibiotics. If it had been cancer, they could have used drugs to target it. This mass, though, was unique.

They decided to try radiation. It seemed to slow the mass’s growth a bit, maybe even shrink it. But recently, Mr. Gass has had another scan in San Diego, and doctors told him that the mass was growing again.

Asked what he would like others to learn from his experience, Mr. Gass said, “Don’t trust anecdotes.”

His sister-in-law had a different reply: “If something sounds too good to be true, it is.

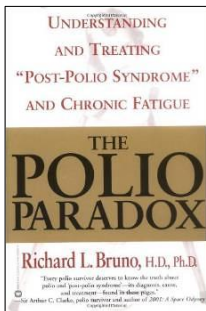
<http://www.nytimes.com/2016/06/23/health/a-cautionary-tale-of-stem-cell-tourism.html? r=0>

On the topic of PPS and Bladder Muscle Weakness (6/24/2016)

Original Post: Would PPS affect the bladder muscles? I take Vesicare but I still have accidents.

Dr. Bruno's Response: Vesicare is typically not a good drug for polio survivors. Bladder problems may be worse in polio survivors but are treated the same as in non-polio survivors. Vesicare blocks receptors in the brain stem that are required for breathing and has the potential to slow or even stop it! One polio survivor went into respiratory failure as a result of taking Vesicare. What's worse, there were articles in the medical literature documenting the effects of this chemical on the brainstem and, when I called the medical director of the pharmaceutical company that produces Vesicare, he admitted that they knew about this problem. You may have noticed that it is no longer advertised like it was.

On the topic of the Polio Paradox and Correct Diagnosis (6/24/2016)



Original Post: Dr. Bruno, your book "*The Polio Paradox*" was a turning point for my husband. Every system in the body is covered. We showed the book to all his specialist, his care has turned around after previous doctors misdiagnosed him and ordered strenuous PT, which he did faithfully. The beginning of his correct diagnosis came from his hand surgeon who was treating him for carpal tunnel and noticed extreme muscle atrophy in the thumb. After the correct doctor of Neuro-muscular diseases diagnosed him with PPS, your book became our game plan. His doctors are very willing to listen to all your info and especially were interested in the anesthesia guidelines. Thank you from the bottom of our hearts.

Dr. Bruno's Response: This is so good to hear! I wish you two all the best.

On the topic of Joint Pain and PPS (6/24/2016)

Original Post: My knee is painful and weak. What is the best kind of doctor that is knowledgeable about PPS problems?

Dr. Bruno's Response: Typically, unless they've done internships with PPS trained physical medicine docs, neurologists are not going to be helpful. You need to see a Physical Medicine (Rehab doctor), called a Physiatrist.

On the topic of New Pain and Fatigue in the Upper Arms (6/28/2016)

Original Post: I got polio in late 1948 or early 1949. I was about 3 years old. At one point I was near death and completely paralyzed. When I recovered I walked for many years with a very pronounced limp. The weakest part of me was in my right foot and ankle. My foot rolled outward. In 1993 while wearing a small leg brace I broke the fibula in my right leg and tore both anterior and posterior cruciate ligaments. I used a long leg brace a manual wheelchair until 2008. A steep infection entered my blood stream and paralyzed me once again. While I recovered well enough to stand and transfer I no longer could walk without fear of falling.

Now I am beginning to experience pain and fatigue in my upper arms. Has anyone else discovered weakness where they had never had weakness before?

1st Response: I think as Dr. Richard Bruno states in his book and on his recent interview, *all* parts of our body were affected when we contracted polio. However, not everything that goes on with us is polio related. It is a process of elimination to rule out what it isn't.

2nd Response: We were affected all over. Years of using canes, crutches or manual wheelchairs will wear on your shoulders and arms. Besides a multitude of other problems, I have spent 62 yrs. using my arms to get up from a seated position. Now, they are a mess with tears in the rotator cuffs, achiness and hands that no longer function well. I don't like taking pain medications, so now I take one day at a time and do what I can.

3rd Response: Polio is like a wildfire that sweeps the whole body. Some damage is immediately obvious; some damage shows up years later when functioning parts wear out!

Dr. Bruno's Response: Wearing out of the poliovirus-damaged, remaining neurons causes weakness of muscles. Even if you *weren't* paralyzed, 90% of your motor neurons were affected if not killed. Then put decades of physical stress and, wham, PPS!



[On the topic of Butter Consumption and Chronic Disease](#) (6/30/2016)

Dr. Bruno's Original Post: RED WINE, CHOCOLATE AND NOW BUTTER ARE HEALTHY AND EVEN HELPFUL!

Little to No Association Between Butter Consumption and Chronic Disease or Total Mortality.

An epidemiological study analyzing the association of butter consumption with chronic disease and mortality finds that butter was only weakly associated with total mortality, not associated with heart disease and slightly protective with diabetes.

<http://www.newswise.com/articles/view/656178/?sc=mwhn>

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<http://www.papolionetwork.org/bruno-bytes.html>

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