



Bruno “Bytes” – July, 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 “New” areas of Muscle Weakness (6/30/2016)

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. I used a long leg brace and a manual wheelchair until 2008. 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?

Additional Post: I believe I’ve learned that 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. Is that correct?

Dr. Bruno’s Response: Yes, that’s correct. 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!

The wearing out of the poliovirus-damaged, remaining neurons causes weakness of muscles.

Additional Post: If I understand it correctly, you need not have been completely paralyzed for your whole body to be affected. Paralysis happened when the number of nerve pathways damaged, for a specific muscle group, exceeded a certain percentage. Complete paralysis occurred when a large number of muscle groups experienced that degree of nerve damage. However, even if your paralysis was quite limited, every nerve pathway experienced some degree of damage. Late effects can show up anywhere, regardless of degree of initial paralysis.

Dr. Bruno’s Response: You are correct. It's the severity of paralysis WITH the amount of recovery that predicts PPS, not the severity of paralysis alone. David Bodian showed with 158 human autopsies of polio non-survivors that, if you had any muscle weakness, 90% of your muscles and their motor neurons were affected, even if not killed, by the poliovirus. "Non-paralytic" polio survivors could have had wide-spread damage but not enough in any one muscle to cause muscle weakness. But those remaining, poliovirus-damaged neurons fail with overuse abuse.

One thing we have to start remembering is that muscles only work when they are stimulated by neurons. Unless you have a disease of your muscles, like muscular dystrophy, you don't have "muscle failure." You have motor neuron failure.

Brain activation difficulty, concentration problems and word finding difficulty are PPS symptoms. Actually the main cause of death in polio survivors was *not* "respiratory failure" but cardiovascular collapse due to poliovirus damaging the brainstem centers responsible for controlling blood vessels, blood pressure and heart rate. "Respiratory failure" was the second leading cause of death followed by aspiration due to failure of the swallowing reflex "Respiratory failure" was the second leading cause of death followed by aspiration due to failure of the swallowing reflex, again due to brainstem damage.

Polio survivors tend to push through pain and muscle weakness. The good thing about conserving your brain function is that fatigue stops you. Once you're fatigued and fall asleep or don't know what you're reading at the computer you have no choice but to stop. (See Article Below) . . .

Additional Post: I never really thought about brain fatigue. In the past 6 months or so memory, reading, loss of words and retention has been working its way in.



POST-POLIO BRAIN FATIGUE
By Dr. Richard L. Bruno
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Director, International Centre for Polio Education
<http://www.PostPolioInfo.com>

LITTLE SPOTS MEAN A LOT.

Fatigue and “brain brownout” -- difficulty focusing attention and word finding associated with fatigue are the most commonly reported, most disabling and, unfortunately, the least believed of all Post-Polio Sequelae (PPS). The biggest problem is that there is no medical test to prove that you have fatigue. Research that we began in 1993 on the post-polio brain has documented damage done by the original poliovirus infection that prevents survivors from activating their brains and thereby causes fatigue and brain brownout. There are three new studies that support our findings.

A summary of the first study begins with a sentence that warms my heart: “While individuals with post-polio syndrome do not have diminished mental function when they are well rested, their mental function declines considerably after even moderate mental fatigue.” Researchers at the US Uniformed Services University of the Health Sciences asked 65-year-old polio survivors to complete computerized neuropsychological tests of attention, thinking or memory once, and then again one hour later. The so-called “practice effect” typically improves scores the second time anyone takes neuropsychological tests. However, more than 40 percent of polio survivors had a *decrease* in performance on the second administration of seven of the eight computerized tests, while 50 percent did more poorly on at least three tests. Subjects didn’t make more mistakes the second time; they were just much slower performing the tests after being fatigued by taking the first set of tests. Slower performance on neuropsychological tests is exactly what our studies found, that polio survivors reporting severe daily fatigue required 23 percent to 67 percent more time to complete tasks requiring attention than did polio survivors with no or mild fatigue.

Why has our neuropsychological research and this new study found brain brownout to be related to fatigue in polio survivors? In our others studies, we used magnetic resonance imaging (MRI) to look inside the brains of polio survivors. We found small individual or multiple “white spots” (technically called hyper intense signal) in the brain activating system of 55 percent of polio survivors reporting moderate or higher daily fatigue, and no spots in those with mild or no fatigue. The more white spots, the more severe were polio survivors’ fatigue, problems with memory, thinking clearly, staying awake, mind wandering, attention and concentration.

Recently, researchers at Duke University published a study using both regular MRI, which we used, and a new, more sensitive imaging technique (called DTI) to look at white spots in the brains of individuals 60 and older without polio or any neurological disease. The study found that visible white spots on regular MRI may be just the tip of the iceberg, since DTI found that damage to the brain under the white spots was larger than the spots themselves. What’s more, the researchers concluded that those with white spots in one part of the brain may have invisible damage in brain areas where spots have not yet become visible on regular MRI, and that this damage may be preventing brain neurons to talk to each other. This could possibly explain why 45 percent of polio survivors with significant fatigue in our study had no visible spots on regular MRI. When it comes to seeing damage on MRI in polio survivors' brain activating system, apparently little spots mean a lot.

So, there actually is physical evidence that poliovirus damage is related to brain brownout in fatigued survivors. But listen to this: Mayo Clinic researchers studied a virus in the same family as the poliovirus -- the virus that causes the common cold. They infected some mice with cold virus and not others. Both groups had their memory tested by completing a maze. Virus-infected mice made more errors and couldn’t figure out where

they were going. (Sound familiar?) The mice that made the most errors had greater damage to their brains. The study concluded that even the cold virus could cause “at least some degree of neurologic deficit” in humans. If having a cold can cause brain damage, how can so many doctors still say that the poliovirus, a known killer of brain neurons, couldn't possibly cause polio survivors to have brain brownout and fatigue? Time for doctors to read a medical journal or two and start seeing the spots.

Fear of Alzheimer's

Asked one polio survivor, “When I am very fatigued or stressed I will totally forget the word I was going to use. I 'm frightened. Am I getting Alzheimer's disease?”

Nope. You are experiencing word-finding difficulty, a problem for polio survivors that has nothing to do with memory loss or Alzheimer's disease. In our 1990 National Survey, 79 percent of polio survivors reported difficulty "thinking of words I want to say." Thirty-seven percent reported frequent, moderate-to-severe word-finding difficulty. In the *American Journal of Physical Medicine and Rehabilitation*, we describe testing polio survivors and finding that they do indeed have the "tip-of-the-tongue" experience--knowing the word you want to say but not being able to say it. Polio survivors have difficulty with naming objects and sometimes even people they know well. Our results indicated that word-finding difficulty was not associated with memory or thinking difficulty -- symptoms of Alzheimer's disease -- but was related to trouble focusing attention, a characteristic symptom of post-polio fatigue.

We also found that difficulty with word finding and focusing attention were related to polio survivors' brains making less dopamine. Low dopamine is the cause of Parkinson's disease, and we found that word-finding difficulty was identical in both polio survivors and Parkinson's patients, even though polio survivors do not experience the tremor and rigidity of Parkinson's.

In 1996, we published a study in the same journal showing that bromocriptine, a dopamine-replacing drug, reduced word-finding difficulty, attention problems and fatigue in polio survivors. However, medication is not necessary to treat word-finding difficulty or any PPS symptom. Reducing physical and emotional stress decreases *all* PPS symptoms. So don't worry that you have Alzheimer's disease. If you're having trouble thinking of a word that you want to say, try to "talk around" the word by describing what you're trying to name. If you are forgetting your friends' names, try calling everyone "Buddy" or "Honey."

On the topic of being “Hotter” in the Warm Weather (7/1/2016)

Original Post: If we feel the cold 10 degrees colder.....do we feel the heat 10 degrees hotter?

Dr. Bruno's Response: The simple answer is no, your nerves don't function as if they are 10° hotter than the ambient temperature, probably because your body temperature is higher than the outside temperature. And while polio survivors are almost all negatively affected by cold, our 1985 study found that only one third got "too hot."

On the topic of being Prescribed a “Single” Crutch (7/9/2016)

Original Post: I just came from P.T. (because I'm having lower back and hip problems). She is suggesting a crutch with a cuff on the arm.

Dr. Bruno's Response: If you really need one crutch you should have 2. You're beating up your back and hip joints/muscles. Maybe you need to see a physiatrist, a physical medicine doctor.

On the topic of using Medications for PPS (7/13/2016)

Original Post: Could someone give me some feedback on using either provigil (Modafinil) for PPS pain?

Dr. Bruno's Response: Two separate studies have found that the medications have absolutely no effect in reducing post-polio fatigue. Patients feel as if they were drunk 12 cups of coffee and are desperate to sleep but can't because they're high on these medications.

- Provigil (modafinil) is a medication that promotes wakefulness. It is thought to work by altering the natural chemicals (neurotransmitters) in the brain. Provigil is used to treat excessive sleepiness caused by sleep apnea, narcolepsy, or shift work sleep disorder).

2nd Post: If I can't take these meds to help me feel better, what's the best way to help myself during the day?

Dr. Bruno's Response: Follow the post-polio diet; take 2 (15 minute) breaks with your feet up, one in the morning and one in the afternoon; and have a sleep study to make sure that you're sleeping at night.

Of key importance here: When your body tells you you're tired or feeling weaker you should have already stopped what you've been doing.

On the topic of which "Type" of Polio we had (7/13/2016)

Original Post: How can I know what type of polio I had? (Bulbar; Type 1, 2 or 3...)?

Dr. Bruno's Response: If you were vaccinated you probably can't find out the type of polio you had in terms of the viruses. Every polio survivor had some degree of bulbar polio and if your limbs were affected you had so-called spinal polio.

On the topic of Long Term Care (7/14/2016)

Dr. Bruno's Original Post: Talk to family and friends and research resources from local agencies BEFORE you need care...

STUDY SHOWS A RISING, BUT UNEVEN, TIDE OF IN-HOME CARE FOR DISABLED SENIORS

University of Michigan Health System

<http://www.newswise.com/articles/view/656745/?sc=mwhn>



On the topic of Neck pain and Vertigo (7/14/2016)

Original Post: I have been experiencing extreme vertigo, muscle soreness in my neck, ringing in my left ear and sometimes my hearing in the left ear sounds as if my ear is full of water? (It's not an infection although I was still given an antibiotic just in case). My sister is a trained massage therapist and when she goes to do deep muscle massage therapy on my neck it is so painful that I cannot tolerate it.

Dr. Bruno's Response: Some low dose Valium (to reduce the spasms), heat, gentle massage, "Painless posture" and then physical therapy to prevent this from happening again.

On the topic of understanding the limitations of PPS (7/20/2016)

Original Post: Well, I did a lot today. I went to the library for Dr. Bruno's book, pharmacy for an anniversary card, made my puppy a raincoat, made my awesome breakfast muffins, then I prepared 4 batches of the dry ingredients to make more of those muffins. I made supper and I am finally sitting down . . . Mind you I made all of this in stages while sitting down for long periods in between. I'm tired but happy with my day. This means I'll be pooped for the next few days so I'll rest, rest, rest.

Dr. Bruno's Response: You should have read the book first so you wouldn't have done so much. Polio survivors only have so much energy. It's like money. On days when you have cash (energy) you can't spend it all on shopping and cooking and then be poor (pooped) for days! Being totally "pooped" is your body saying "TOO MUCH!!!!" Damn the muffins and full nap ahead!

[On the topic of the daily amount of Protein for Polio Survivors](#) (7/20/2016)

Original Post: Does anyone know the amount of protein recommended for PPS'ers each day?

Dr. Bruno's Response: Go to the Post-Polio Library at postpolioinfo.com and look at the post-polio diet.

The formula for protein grams per day is basically the bodyweight you want to have divided by two.

[On the topic of "Spinal" and "Bulbar" Polio](#) (7/23/2016)

Original Post: I had polio in 1954, was told I had spinal & bulbar. I have had so much trouble with my spine & legs for 18 yrs. I have so much pain. Is this coming from the spinal polio? What does the Bulbar do?

Dr. Bruno's Response: Bulbar polio refers to poliovirus damage to the brain stem that is clinically apparent at the time of the infection, causing difficulty breathing, swallowing and even death due to cardiovascular collapse. (Cardiovascular collapse was the most common cause of death in polio survivors, not difficulty breathing).

In point of fact everybody who had spinal polio had some degree of bulbar damage. That's one of the reasons polio survivors have slow intestines and difficulty swallowing.

[On the topic of a Plant Based Polio Booster](#) (7/23/2016)

Dr. Bruno's Original Post: WOW! Now THIS is science!!!!

The article is full of polio gems and worth the read. Did I say

WOW? Full Article Below

<https://news.upenn.edu/news/penn-led-team-develops-plant-based-polio-booster-vaccine>



Additional Post: Doesn't everyone traveling to a country that has the "active" polio virus need a booster?

Dr. Bruno's Response: To be safe, because of the refugees, anyone leaving the US should have a booster. You can also have your antibodies tested to see if you need a booster. Most labs will do that.



Penn-led Team Develops Plant-based Polio Booster Vaccine

Media Contact: Katherine Unger Baillie | kbaillie@upenn.edu | 215-898-9194
July 20, 2016

Jonas Salk created a vaccine against polio that has been used since 1955; Albert Sabin created another version that has been on the market since 1961. Together, these two vaccines have nearly eliminated polio from the face of the earth.

Emphasis on nearly. Outbreaks have persisted in developing nations in Asia, Africa and the Americas, in part due to limitations of these vaccines. Most recently, in 2013, Israel reported a "silent" outbreak of polio, in which no one got sick but the virus was found in the environment and in vaccinated individuals.

New research led by **University of Pennsylvania** scientists offers hope for an alternative. Collaborating with researchers from the **U.S. Centers for Disease Control and Prevention** and the **U.S. Food and Drug Administration**, the Penn team developed an oral vaccine booster by manipulating plants to express a protein found in the polio virus. Tests with sera from immunized mice show that the booster confers immunity against all three serotypes of polio.

"Our vaccine research has the potential to provide a timely solution to deal with polio outbreaks around the globe," said **Henry Daniell**, professor in the Department of Biochemistry in Penn's School of Dental Medicine and senior author on the work.

Daniell, whose plant-based system was used to create the vaccine, worked with lab members Hui-Ting Chan and Yuhong Xiao on the paper, as well as with William C. Weldon and Steven M. Obserste from the CDC and Konstantin Chumakov from the FDA.

The paper appeared in *Plant Biotechnology Journal*.

Since the 1988 launch of the **Global Polio Eradication Initiative**, a collaboration spearheaded by the **World Health Organization, Rotary International**, the CDC and **UNICEF** that made polio vaccines widely available, the incidence of disease has been reduced by more than 99 percent, from 350,000 cases in 1988 to 74 in 2015. Yet challenges remain to ensure that the world is polio free.

Two vaccines, bivalent oral poliovirus vaccine, or bOPV, and the inactivated poliovirus vaccine, IPV, are currently used throughout the world to protect against polio. Each has distinct advantages; while IPV protects the individual, oral vaccines can help protect a community. Both have been critical in bringing the world closer than ever to eradication.

IPV is extremely safe but is substantially more expensive than bOPV, and, because it is given as a shot, it is not as easy to administer as bOPV, which is administered in oral drops. Also, it does not induce intestinal immunity, which means that vaccinated individuals can still shed the virus. This is what occurred in 2013 in Israel when poliovirus was found in sewage, and a rapid vaccination campaign with oral polio vaccine was instituted to prevent transmission to unvaccinated people.

bOPV induces superior intestinal immunity compared with IPV and, thus, has the potential to better prevent transmission of polioviruses. However, due to the live attenuated virus found in the oral polio vaccine, in rare instances in under-immunized communities the virus can mutate over time and revert into a form of the virus that can cause paralysis. This risk is what led to the global withdrawal of tOPV, the trivalent OPV that targets all three serotypes of the virus, in April. Eventually all forms of the oral polio vaccine will be withdrawn globally. However, the importance of maintaining intestinal immunity against poliovirus remains a concern.

In an effort to address the current vaccines' shortcomings, Daniell and colleagues aimed to design a booster vaccine that would not be based on live attenuated poliovirus and would induce mucosal immunity to all three serotypes of polio. In addition, whereas IPV and bOPV require refrigeration, the researchers wanted to design a vaccine that would be stable without refrigeration for very long periods, making storage, transport and administration at the point of care easier. Daniell's plant-based drug-development platform was suited to the task. In it, plants are coaxed to grow a biomolecule of interest by bombarding the leaves with the gene until it is taken up by chloroplasts. The plant then produces the associated protein in its leaves, which can be grown and then freeze dried and encapsulated for oral administration.

To induce immunity against polio, the researchers decided to target viral protein 1, or VP1, a structural protein present in all three serotypes of polio. They fused it to carrier protein cholera toxin subunit B, which enables the protein to cross mucosal surfaces, then confirmed that they could stably express the fused protein in tobacco and lettuce plants.

Next they fed the freeze-dried plant material expressing the fused protein to mice to see if it could induce an immune response in mice that had already been primed with an IPV vaccination.

"The vaccine, when formulated with adjuvants, induced high levels of mucosal and systemic immunity in the mice," Daniell said, corresponding to IgA and IgG antibody responses, respectively. "And when the CDC performed tests on several hundred samples of sera from immunized mice, they found it could neutralize all three serotypes of polio virus."

The researchers hope to pursue FDA approval to conduct clinical studies in humans with this virus-free vaccine, which could be produced relatively inexpensively and does not require refrigeration or special handling and could therefore eventually contribute to a polio-free world.

"We can ship capsules to every corner of the world and boost that IPV inoculation," he said. "It's time to improve upon the vaccinations we've been using for 75 years."

In addition, Daniell said the concept of a low-cost booster vaccine could be used for many other viral diseases, as immunity can wane in old age, leading to reactivation of a latent virus. Shingles is a prime example.

"This could be avoided with a simple boosting," he said.

The work was supported by the **Bill & Melinda Gates Foundation** and **National Institutes of Health**.

On the topic of using Prozac (7/28/2016)

Original Post: I recently met another woman with PPS who said she takes Prozac once a day and has done for many years and said it helps to "even out the nervous system". She was a graduate of Massachusetts General Chronic Pain Clinic overseen by Jon Cabot Zinn, the man behind Mindfulness.

Dr. Bruno's Response: Prozac doesn't "even out the nervous system." It can reduce symptoms of depression but it can also cause mania and fatigue.

Mindfulness meditation does "even out the nervous system," without side effects and costs nothing.

Antidepressants are not analgesics, no matter what the drugs companies say. The data is terrible on antidepressants for pain, and by terrible I mean concocted by a mob accountant who "backed into" the numbers to make it look like antidepressants reduce pain. But big pharma owns the FDA, so some antidepressants get approved for pain.

Bless the very real placebo effect: 33% of people who take a "sugar pill" will have reduced pain and fatigue.

After 50+ years, no one knows how any antidepressant works. We do know that raising serotonin suppresses dopamine, the brain-stimulating chemical that is in short supply in polio survivors.

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

Scroll down the page (through the Current Month posts).

Previous months are located there, in an easily printable PDF format.