



Bruno “Bytes” – August, 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 Neurons in a Polio Survivor Regenerating (8/11/2016)

Original Post: I have a physical therapist that believes that the neurons in my legs can grow back again. Does anyone know if it could be true?

Dr. Bruno’s Response: Sadly the neurons do not grow back. I would recommend finding a new physical therapist. Quickly.

On the topic of Medical Marijuana (8/12/2016)

Dr. Bruno’s Original Post: The Missing Case for Medical Marijuana

Research is still needed to find out how therapeutic, or dangerous, marijuana might be.

From Bloomberg.com

<http://www.bloomberg.com/view/articles/2016-08-12/the-missing-case-for-medical-marijuana>

Dr. Bruno’s Additional Post: Bottom Line:

Everyone needs to get information, weigh the pros and con of every self-care issue and make their own decisions.

On the topic of Injections for Muscle Pain/Spasms (8/15/2016)

Original Post: I have PPS with all the signs of muscle weakness and fatigue. My doctor sent me to therapy and it's a chiropractor who suggested having shots once a week in the different places in my back which would be something like an ibuprofen and a small amount of Lidocaine to numb it. My back is very stiff I'm very tight and I have a lot of knots in my upper back, shoulders neck area. I have scoliosis that is very bad he doesn't believe he can do much with the scoliosis but he wants to help the spaces in between the spine to be able to continue to move and not fused together. My question is does that sound like a good plan along with stretching and traction?

Dr. Bruno’s Response: I would be concerned about a chiropractor doing a manual adjustment of your back. Will the chiropractor inject you? Massage for deep tissue spasms is good, although painful during the treatment. The best thing you can do though to prevent the spasms is to find out what's causing them and get rid of the cause. You have to look at how you sit, whether you have appropriate support for your lower and upper back and if not get support. I would think a physical therapist that specialized in back pain would be more helpful.

It would be best to see a Rehabilitation physician (physiatrist) who knows something about PPS.

In the hands of a good rehab doc, injection of a local anesthetic into painful areas or actual dense and painful muscle spasms in the back and neck, combined with deep tissue massage and eliminating the spasm/pain triggers, can be really helpful to break the spasm/pain cycle.

Plus, the injections can be done in the office and they hurt way less than a bee sting.

On the Topic of Portable – Light Weight Wheelchairs (8/22/2016)

Dr. Bruno's Original Post: Lots of survivors have been asking about the lightweight, foldable power wheelchair (that was first produced in China). Two friends of the Coffee House have the chairs and love them . . . especially for travel. Here is the latest version that's made closer to home: <http://kdsmartchair.com/>



Dr. Bruno's Additional Post: The bad thing about scooters for polio survivors is that YOU have to steer with the tiller, and that's not good for the arms and shoulders. They often don't have appropriate back support which can be bad for the back. As always, you have to weigh the pluses and minuses of any purchase this significant.

On the topic of IVIG to "Treat" PPS (8/21/2016)

Original Post: What do we know about IVIG (intravenous immunoglobulin) treatment for post-polio syndrome? My friend has been referred to a neurologist who recommends that she join a trial. She wants to know more before she says yes or no.

Dr. Bruno's Response: There have been several studies of IVIG in polio survivors and not one of them has shown any benefit.

The company that did the studies sent out press releases instead of publishing the data in a journal. The press releases made all kinds of fantastic claims about the benefits of the drug. Then they sold the drug to a Japanese pharmaceutical company & no more press releases in the west.

Dr. Bruno's Additional Post: The use of IVIG to "treat" PPS is being discussed in another thread. Here's a summary of IVIG and PPS "treatment."

IVIG and PPS

YOU HAVE TO BE CAREFUL ABOUT MEDIA-REPORTED RESEARCH BECAUSE MUCH OF IT Can be FALSE

There is a significant problem with the new world of 24-hour TV news. Drug companies, universities, hospitals and national medical associations distribute press releases about unpublished research to reporters instead of publishing research findings in peer-reviewed medical journals.

One example is a Swedish drug, Xepol, touted as the first medical PPS treatment, which we discussed in February 2008. Xepol actually first surfaced in 2004. A Karolinska Institute press release, headlined "Promising anti-inflammatory treatment for post-polio syndrome," reported on 16 polio survivors with progressive symptoms of muscle weakness treated with intravenous immunoglobulin (IVIG), a standard treatment for inflammatory diseases: "Most patients...reported improvements in their physical status. However, the value of this is unclear, since this first study did not include a placebo group.

"Most patients" improving doesn't tell us how many improved or by how much. A Xepol study was finally published in a 2006 medical journal. IVIG was given to 73 polio survivors and placebo to 69, and then given again in three months. Of 10 measures -- including muscle strength, questions about physical symptoms and activity, the distance subjects could walk in six minutes and time it took to stand up -- not one was statistically different between Xepol and placebo.

What's more, there was no before-drug comparison of the Xepol and placebo subjects. Subjects in the placebo group were worse than the drug group to begin with, having 17% percent more pain and walking 17% more slowly, making it harder for them to get any benefit from the drug. The authors concluded that "further studies on responding subgroups, long-term effects, and dosing schedules are needed."

...THEN IN 2008 WE'RE BACK TO A DRUG COMPANY PRESS RELEASE...

"PHARMALINK REPORTS POSITIVE RESULTS FOR XEPOL." Xepol was "effective and well tolerated" in the same subjects reported in the 2006 journal article, but now they were one year post IVIG treatment. Pain, walking ability and self-report of health "all showed significant and clinically meaningful results," the release reported.

Said Pharmalink's managing director, "We are very excited about this data as patients in the treated group have experienced a reduction in disease symptoms after just 12 months."

Whoa!

First, the published six-month study showed no "significant" benefits of Xepol.

Second, the new 12-month data hasn't yet been published in a peer-reviewed journal, so how can we really know if any of the new results are significant or clinically meaningful in reducing "disease symptoms"?

Third, even without Xepol, the placebo group reported a decrease in pain and increase in walking speed after 12 months. However, their greater pain and walking limitation at the beginning of the study made it unlikely that they could catch up to the drug group.

Finally, the company is "very excited" because polio survivors had a reduction in symptoms "just 12 months" after taking Xepol? "Just 12 months"? Can you imagine a drug company press release excitedly proclaiming, "NEW HEADACHE MEDICATION WORKS JUST 12 MONTHS AFTER TAKING THE FIRST PILL"?

I've been in this PPS business long enough to remember that one boat sailed long ago: that inflammation causes PPS. A 1995 study found that high doses of prednisone, the king of anti-inflammatory drugs, didn't decrease PPS symptoms but did cause subjects to have horrible side effects. Even a 2007 study from Norway, in which polio survivors also were given IVIG, found no change in "fatigue and muscle strength three months after treatment."

I don't know why Scandinavian researchers are hot on the trail of a treatment for PPS that's gone cold. But, regardless, you have to be careful about media-reported research because much of it turns out to be crap. Medical "facts" presented by the media change from week to week. Chocolate causes obesity, then fights cancer; a daily glass of red wine is a symptom of alcoholism, then it prevents heart disease. In this age of voracious 24-hour cable news, it's vital that we are extremely cautious when medical research is "published" via press release. Be it PPS or any medical condition, we need to read the actual published research studies, not just listen to stories on TV, to understand what's happening to our bodies and really know how to take care of ourselves.

...AND THEN THIS HAPPENED...

Thursday, May 20, 2010 - Grifols SA announced that it has reached an agreement with the Swedish company Pharmalink AB to acquire various forms of intellectual property (IP) associated with the treatment of post-polio syndrome (PPS). The acquisition is expected to be finalized in the next few weeks and will include documentation, know-how, and Swedish regulatory approvals under the trade name Xepol. Furthermore, Grifols also acquires U.S., European and Japanese patents for a specific PPS treatment method utilizing human immunoglobulin and unrestricted use of existing Pharmalink clinical trial data supporting the treatment method.

Acquisition of the PPS drug development project creates new clinical research and therapeutic treatment areas for Grifols. "Exploring the treatment of PPS consistent with our mission of developing therapies for chronically ill and underserved patient populations," said Ramon Riera, Director of Global Sales and Marketing for Grifols. Currently there are no therapies approved for the treatment of PPS.

PPS is widely recognized as a rare disease and the U.S. FDA has granted orphan drug designation for the use of human immunoglobulin in the treatment of PPS. "The promise of research on potential treatments for post-polio syndrome is welcomed by the thousands who experience its debilitating symptoms, and we hope that it is fulfilled," said Joan L. Headley, Executive Director of St. Louis, Missouri based Post-Polio Health International (PHI), the leading organization working to enhance the lives and independence of polio survivors. "It has been challenging to find treatments for this condition. We are pleased that Grifols is investing in the PPS community," Headley added.

Previous clinical trials on the use of human immunoglobulin for the treatment of PPS have been sponsored by Pharmalink using Grifols' proprietary intravenous immunoglobulin. Grifols' acquisition of the Pharmalink PPS

project will give Grifols unrestricted use of those data and set the stage for Grifols to investigate clinically relevant research questions growing out of prior studies.

The acquisition also includes U.S., European and Japanese patents which will effectively give Grifols exclusive rights to the treatment method.

...AND XEPOL HASN'T BEEN HEARD FROM SINCE.

On the topic of Difficulty Standing (8/27/2016)

Original Post: I am gradually losing the ability to stand up. What should I be doing? Prevention? How do I learn to use the toilet and transfer to a shower seat when I can't get up?

2nd Post: You should probably ask your doctor about rehab services in your area. They can tell you the equipment you'll need and teach you how to use it. Also ask about Occupational Therapy referral--they do the "practical" therapy items for ADLs (aides for daily living)--they can be a great in-home help!

Dr. Bruno's Response: I agree with the information in the 2nd post. You need some time with an occupational therapist. For now raised toilet seat and limiting the amount you get up and down would be the best thing to do.

Always Conserve to Preserve.