The Vagus Nerve

The Body’s “Life” Nerve

- Tongue
- Pharynx
- Vocal chord
- Vagus nerve
- Lung
- Heart
- Liver
- Spleen
- Stomach
- Pancreas
- Kidney
- Large intestine
- Small intestine
Red arrows indicate Brain Activating System

Lighter Yellow & Black cross hatching areas of mild to moderate poliovirus damage.

Darker Yellow & Black cross hatching areas of most severe poliovirus damage.

(Source: Dr. David Bodian)
Directory of Resources for Polio Survivors and their Caregivers

Sharing and Caring . . . we’re not alone.

International Centre for Polio Education (Dr. Richard L. Bruno, PhD.) –
Website: www.postpolioinfo.com Email: postpolioinfo@aol.com

Polio Survivor’s Network of the U.K. –
Website: www.poliosurvivorsnetwork.org.uk

Post-Polio Health International –
Website: www.post-polio.org Email: info@post-polio.org Phone: 314-534-0475

State Networking and Information Sites
(Information sharing and newsletters are available to all survivors)

Pennsylvania Polio Survivor’s Network –
Website: www.papolionetwork.org Email: papolionetwork@gmail.com
Phone: 215-858-4643

Polio Network of Michigan - www.michiganpolionetwork.com Phone: 989-739-4065

Polio Network of New Jersey - www.pnnj.org Email: info@pnnj.org Phone: 201-845-6860

Polio Network of Ohio - www.ohiopolionetwork.org Phone: 740-374-0538

Post-Polio Branson Goers (Branson, Mo www.postpoliobransongoers.org/newsletter

Reputable Post-Polio Facebook Pages.

What does “reputable” mean? These sites are “closed”. No one can just “join” without the Administrator knowing. For these sites, the Admin’s talk to each other. When someone has a member concern, the information is shared with the others and can be monitored.

The Post-Polio "Coffee House"
Post Polio
Post-Polio Health International
Pennsylvania Polio Survivor’s Network

From Medicare and Social Security

Benefits Check Up from the National Council on Aging:
www.youtube.com/watch?v=FO96XjS6ZpM


Medicare Coverage for Durable Medical Equipment:
www.medicare.gov/coverage/durable-medical-equipment-coverage.html

Social Security Disability Process for those who have Post-Polio Syndrome:
www.postpolioinfo.com/ssdisability2.php

The IRS and Disability. What can I deduct?
www.papolionetwork.org/uploads/2/7/7/2/27726699/the_irs_and_disability.pdf
This page is filled with information to take to your Health Care Providers.
Give them this “link” – http://www.papolionetwork.org/information-for-our-caregivers-and-providers.html

Information to give our Families and Health Care Professionals:

(Combine this information with articles on the page "How Do We Live With It" and Research Articles in our Reference Library)

**Acute Polio and Post-Polio Theories**
From Post-Polio Health International

**Components of a Post Polio Evaluation**
Dr. Frederick Maynard, PHI

**Medications and Post-Polio Syndrome**
From Post-Polio Health International

**Parallels between Post-Polio Fatigue and Chronic Fatigue**
International Centre for Post Polio Research

**Polio Patients Take a Second Hit (for Nurses)**
The Modern Medicine Network

**Polio Survivor 101**
From Post-Polio Health International

**Polio Survivor 101**
From our friends in the United Kingdom

**Post-Polio Health Care Considerations for Survivors and their Families**
From Post-Polio Health International

**Post Polio Syndrome - for our families and physicians**
From Survivor Miss Farrow

**Physical Therapy Exam and Treatment of the Polio Survivor**
For Physical Therapists & Occupational Therapists, from Post-Polio Health International

**Complications from Undergoing Surgery (or) Having Procedures Requiring Anesthesia**
International Centre for Post Polio Research

**Summary of Anesthesia Issues for the Post-Polio Patient**
Selena H. Callins, MD, for Post-Polio Health International

**Ten Commandments of Living with Post Polio Syndrome**
A Video from Dr. Richard Bruno (published by our friends in Australia)

**10 Commandments of Living with Post Polio Syndrome**
International Centre for Post-Polio Research

**Video Series from the Salk Institute**
Susan L. Perlman, MD

**What Having Had Polio Causes, Might Cause and Does Not Cause**
Dr. Manny Eulberg, for Post-Polio Health International

**What Polio Survivors want their Health Care Providers to Know**
A video from Rotary International
Footwear – Why it is the Foundation of Balance

By Bartholomew H. Faherty, C.Ped,O.S.T

One of the consequences of Polio is diminished muscle bands in the legs and feet. Some of these bands control the ability to balance. Whether you have managed to avoid braces or are currently wearing braces, shoes are the foundation in stability.

Shoes that have soft soles on them are like standing on your bed mattress. The sponginess allows rotation of the shoe, causing the body to shift, making it harder to keep ones balance. In the old days, footwear had leather soling on the bottom. This didn’t have cushioning, but was a stable platform. Modern footwear has basically blown rubber outsoles. Rubber is an oil product. In order to make manufacturing more profitable, increased amounts of air are being used in outsole materials. This economic change has resulted in a significant decrease in the stability of the product.

The fitting of footwear is important. All shoes are custom sized to the manufacturing specifications. This makes buying footwear a challenge – no size 8 is like another size 8. Shoes come in pairs. Your feet are not a pair; you get a right and a left. Use, gravity and injury change the shape of your feet. You can’t even accurately check your shoe length on yourself because when you bend over, your toes contract (to help you keep balance) and this shortens your foot. Having a professional do your fitting is always a better way of getting the correct size. We recommend that anyone needing orthotics; (Polio survivors in particular) always seek out a reputable company who has a Board Certified Pedorthist (C.Ped.) available – who is supervising and training those who will be fitting you.

Properly made and installed custom alterations, wedges, flares, braces and orthotics help keep the foot more perpendicular to the ground, making it easier to keep the body in centerline. This can help your balance.

About Our Business

Since we opened in 1959 as a children's shoe store we've specialized in structured shoes that fit properly. Over the years we've added to our normal service expertise with the addition of orthopedics, children and adults, and many different Orthotic devices.

Our staff has had the privilege of being part of the front runners of pedorthics, orthotic manufacturing, and the culmination of knowledge from 3 generations in shoe alteration, design, and fitting

461 – 463 Second Street Pike
Southampton, Pa. 18966
(215) 357-3621

http://fahertyshoes.com/services.html

August 2015
1. **Take deep breaths.** The average adult takes 8 to 16 breaths a minute. Slowing that down to 5 or 6 deep breaths that really fill your lungs will help you relax, which can lessen your discomfort.

2. **Get a good night’s sleep.** Without enough rest, pain triggers may worsen. So how much sleep is enough? It varies by person, but most adults need 7 to 8 hours a night. The simple answer: however much you need to wake up rested and rejuvenated.

3. **Exercise regularly.** Get the big 3 - stretching, strengthening and aerobic activity - into your routine 3 to 5 days a week for at least 30 minutes. Stretching keeps muscles limber and tendons elongated. Strengthening core muscles in your back, pelvis, hips and abdomen aids balance and stability. Aerobic activity works the most important muscle, your heart, and stimulates circulation.*

4. **Tackle your tobacco habit.** Smoking cigarettes or cigars decreases circulation, aggravates medical conditions, increases sensitivity to pain and may interfere with pain medication. Same goes for chewing tobacco.

5. **Practice “mindfulness meditation.”** This involves observing your pain rather than suppressing it. It sounds crazy, but by relaxing and accepting discomfort, you may better tolerate it. So for 20 minutes a day, sit or lie in a comfortable position in a quiet spot and just be aware, moment by moment, of your breathing, the unfolding of sensations (including pain), and your thoughts and feelings.

6. **Eat a whole-food, plant-based diet.** A healthy diet promotes circulation, curbs inflammation and may soothe aching muscles and joints. Base meals on whole or minimally processed foods like vegetables, 100% whole grains, legumes and fruits. Start by ditching the worst offenders: processed meats, red meats and refined carbohydrates like sugar, white bread and pasta.

7. **Try yoga.** Yoga can quiet your breathing, reduce muscle tension and energize your body and mind, all of which can ease pain. And you don’t have to be a yoga master to reap rewards: See “Yoga for Polio Survivors” below.*

8. **Indulge your hobbies.** Take part in activities that bring you pleasure, whether gardening, fishing, cruising garage sales or carving wood. There’s a hobby for everyone that can reduce stress and take one’s mind off the pain.

9. **Be social.** People who interact with others tend to reduce anxiety and better manage chronic pain. So have lunch with co-workers, take on a special group project, cheer on your grandson at a soccer game or go to an arts festival.

*NOTE: These are simply guidelines, that can be adapted for our individual needs as polio survivors. Numbers 3 and 7? Work with a qualified Physical Therapist to determine your capabilities.

See the article below: “Exercise – Use it and Lose it”

There are 2 Yoga articles here – listed alphabetically under “Wheelchair Yoga” and “Yoga for Polio Survivors”

Question: I read that you don't recommend exercise for polio survivors who are getting weaker. But if I stop exercising and do nothing, won't I lose muscle tone, get flabby and become deconditioned and even weaker?

Answer: You're asking a good question but are using buzzwords that Americans hear on infomercials. It's vital that polio survivors understand what the research really says about exercise for newly weakened muscles and know the definitions of "muscle tone" and "deconditioned." We never tell polio survivors to "do nothing." Both The Post-Polio Institute and Warm Springs long-term follow-up studies find the same thing. All PPS symptoms, fatigue, pain and muscle weakness, decrease when polio survivors stop exercising and follow The Golden Rule:

If anything causes fatigue, weakness or pain, DON'T DO IT! (Or do much less of it.) Unfortunately, those who recommend strengthening exercise to polio survivors quote from the conclusions of half a dozen small studies of leg muscle strengthening, apparently without having read them critically. The studies' conclusions say that exercise programs "lead to significant gains in strength." However, when you look at the responses of individual subjects the "significant gains in strength" are hard to find. Just over half of the studies' subjects had an increase in upper leg muscle strength of about 26%. One quarter had no change in strength while 21% actually had a decrease in strength of about 10%. So almost as often as not exercise either had no effect or actually decreased muscle strength.

What's more, only two studies asked whether exercise affected polio survivors' fatigue and their ability to function in their daily lives. In one study, strength increased by 36% but muscle fatigue also increased by 21%. In the other study, although muscle strength increased by 30%, there was no improvement in polio survivors' ability to do daily activities, and muscle fatigue increased as much as 300%! You have to ask what good comes from any small percentage increase in muscle strength that is not related to improved functional ability and that actually increases muscle fatigue more than strength.

And what of "muscle tone"? Most people think that muscle tone means muscles that are firm and have a nice shape. Muscle tone actually means that muscle fibers are ready to contract. Muscle tone is lost when motor neurons are damaged and can't turn on muscle fibers. Loss of tone can happen when polio survivors exercise too much and muscles become weaker when poliovirus-damaged motor neurons fail. Remember, PPS researcher Alan McComas found that polio survivors who have muscle weakness lose at least 7% of their motor neurons each year. This is why he concluded that "polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking."

Polio survivors' muscles get smaller lose tone if they're overused and the motor neurons that turn on the muscle fibers die. Arms and legs get flabby because of increased fat deposits, not a loss of muscle tone. Exercise does burn fat and at first causes muscles to increase in size. But polio survivors don't want bigger muscle fibers because they "further stress metabolically damaged neurons that are already overworking." The best way to prevent flabby arms and legs is to stop overusing and abusing your motor neurons and to follow the higher protein, low fat and lower carb Post-Polio Diet.

And what does "deconditioned" mean? Many polio survivors believe that there are only two ways to live: overusing and abusing or being a couch potato and becoming "deconditioned." Deconditioning is something that happens when astronauts live in space or you put someone to bed for weeks, removing the pull of gravity and causing a decrease in blood volume and blood pressure. Deconditioning can only happen if polio survivors never leave the couch, not if they take two daily rest breaks on the couch, take a ninety minute nap, stop strengthening exercising or use a power wheelchair.

However, polio survivors may need to "condition" their hearts, especially if they have had a heart attack. "Cardiopulmonary conditioning" uses exercise to strengthen the heart muscle (which was not affected by polio) and make it work more efficiently. However, there is no benefit to running on a treadmill or riding a bicycle to exercise the heart if you thereby stress and kill off poliovirus-damaged motor neurons. Some polio survivors can do heart conditioning by using their less affected limbs, usually their arms, in a carefully monitored program of paced and non-fatiguing exercise. But for many this type of exercise doesn't increase heart rate enough to get a conditioning effect and leads to fatigue and muscle weakness so it can't be continued for more than a few sessions.
For almost ten years, I had the opportunity to work in a clinic that took a multi-disciplinary approach towards working with patients who have PPS. Although the clinic is no longer in existence, I wanted to share with you what physical therapy aimed to do in the clinic, what information was important for us to know about the patients we worked with, what PT’s evaluated, and what our treatment interventions were.

**GENERAL GOALS OF PPS PHYSICAL THERAPY**

Our aims as PT’s working with the PPS population were to:

1) Decrease symptoms of pain and weakness;
2) Teach activity modification and energy conservation techniques; and
3) Promote safety and efficiency with mobility and daily function.

**GETTING TO KNOW YOU**

Information from a patient with PPS that is helpful to have prior to a physical therapy evaluation would be the following:

The areas of your body or the physical functions that were originally impaired by Polio

- If you had OR currently use a leg brace
- If you use any adaptive equipment or assistive devices
- If you have any new pain or muscle weakness
- If you have frequent falls or balance issues
- If you have difficulty walking or difficulty with stair negotiation
- If you have difficulty with bed mobility and transfers
- If you have difficulty performing self-care tasks such as dressing or bathing
- If you have difficulty performing tasks inside or outside of the home
- If you have decreased energy, endurance or have poor sleep quality
- Your social history (i.e. work, retired, living situation)

Past and current medical/surgical history, test results and medications

**PPS PHYSICAL THERAPY EVALUATION**

After reviewing the “GETTING TO KNOW YOU” information with the patient, the PT would direct their evaluation towards what the patient’s areas of limitation were.

Many times the PT Evaluation was a combination of both an orthopedic/neuromuscular evaluation and a functional evaluation because the patient would have joint or muscle pain along with a limitation in their ability to function or mobilize. The PT would assess the ability to stand and sit, the technique of getting in and out of bed, the ability to perform stairs safely, measure leg muscle circumference and leg length, test balance and upper and lower extremity muscle strength, and observe gait and posture.
Based on the physical therapy evaluation and consideration of the patient’s goals, the treatment plan could include (but not limited to) the areas of focus below:

**Safety with Mobility.** It’s important to assess whether a patient needs an assistive device for mobilizing in the community or at home. This can be a wheelchair, chair lift, walker, or a forearm crutch amongst many other mobility devices. It can also come in the form of a lower extremity brace (orthosis). It’s important for the therapist to assess muscle strength, fatigue levels, balance, fall history, pain, home environment, and the patient’s support system when recommending the proper device or orthosis, to make mobilizing safe and efficient. With regards to leg braces, finding a licensed orthotist whom you can easily access and has experience in working with patients with neuromuscular conditions, is desirable.

**Energy Conservation:** A common issue amongst patients with PPS is fatigue. Some Polio survivors also have respiratory impairments that cause shortness of breath with activity and even with rest. Doing activity logs where you can correlate possible relationships of shortness of breath, pain and fatigue with your everyday activity is an effective method of determining whether you need to eliminate or modify the performance of your daily tasks, use adaptive equipment, OR take more rest breaks throughout your day.

**Pain Management:** In addition to pain medications that your physician may prescribe, they may also refer you to a physical therapist to assist with pain that they suspect is from a musculoskeletal/neuromuscular source. If your pain stems from postural dysfunction, overuse or compensatory strategies secondary to longstanding weakness, PT’s will educate you on proper posture and positioning with your static and dynamic activities. This can include (but not limited to) the use of lumbar cushions for sitting, cervical pillows for sleeping, or making your workstation more ergonomic. If your pain is of an orthopedic nature, PT’s can teach you non-fatiguing flexibility and stabilization exercises to help restore or maintain function. Modalities such as ultrasound or heat can provide temporary relief and are primarily utilized as an adjunct to manual therapy or exercise. PT’s may also choose to use manual therapy techniques such as joint and soft tissue mobilization, myofascial release, or gentle muscle energy techniques which can be helpful to address restricted mobility.

**Functional Activity Training:** Patients with PPS can have difficulty with getting in/ out of bed, or standing up from lower surfaces or standing to cook amongst other limitations not mentioned here. Physical therapy treatment may focus on safe techniques to perform those everyday tasks. Additionally PT’s may also recommend durable medical equipment and adaptive devices to make those tasks less painful, less effortful and most importantly SAFE for patients.

**EXERCISE AND THE PPS POPULATION**

Many of you may be wondering about aerobic or strengthening exercise in the PPS population. Since many of our patients came to the clinic being very symptomatic with increased fatigue, newer pain and weakness, as well as having difficulty performing their daily activities, our recommendation was that they suspend aerobic or strengthening exercises during their time in our program. Our goal was to reduce the pain and overuse of weakened muscles and focus on conservation.
LOOKING FOR A PHYSICAL THERAPIST?

I would recommend that you work with a therapist that has experience with orthopedic and neuromuscular conditions who can work with you 1:1. Obviously it would be a PLUS if they have experience with the PPS population OR can do the research to understand the pathophysiology of the polio virus, late onset problems, and treatment of the polio survivor. It would also be helpful if the PT has working relationships with the following:

1) a licensed orthotist if you are a candidate for a leg brace; and
2) an occupational therapist if you need to address limitations in activities of daily living performance or wheel chair management.

In Summary -
It would be my recommendation to review the latest research related to exercise prescription recommendations for the PPS population.
However, if you feel more fatigue, more pain, or more weakness with exercise or any activity –

LISTEN TO YOUR BODY and stop doing it!
The “Best” of Bruno Bytes
Questions from the “Post-Polio Coffee House”

Questions and Answers from Dr. Bruno are available in their entirety (by date) through a “link” on www.postpolioinfo.com
And directly on the Pennsylvania Polio Survivor’s Network Website.
http://www.papolionetwork.org/bruno-bytes.html

On the topic of Bowel and Swallowing Issues  (3/28/2015)
Question: Dr. Bruno, I keep on trying to block out anything to do with the Polio . . . as I truly think this is not healthy. That being said, if I had any medical training, I’d look into the neuro-pathways of the very few times that I felt the throat muscles give out when I was taking a sip of water; causing me to really choke. In addition, I’d research the very few instances that for about 2 to 3 days, my bowels just seem to get into a ‘funk’ and decide not to push what they should (like in a rhythmic sequence); but yet I’ll be in cramps with nothing moving until I gather up the courage to buy over the counter, what I seem to need.
As a kid, I remember something called Neocultol that at times my Mom had to give me (it was a chocolate flavored, thick gelatin like laxative). But, it’s only recently that I’ve been having these excruciatingly painful episodes.
I’m uncomfortable bringing up issues like this at our Support Group. Deep down, I know it has something to do with the Polio. Can you help me with this?

On the topic of Fatigue  (3/16/2015)
Question: I am tired all the time but sometimes I forget just how bad it gets. I swear I could sleep away the rest of my life! The doctor ordered 2 pages worth of blood tests but my follow-up appointment isn't for 3 weeks yet. I am so anxious to see if they find anything other than PPS that is causing this! They have already ruled out thyroid & all the 'normal' things like vitamin deficiencies. Feeling tired.

On the topic of Post-Polio Fatigue  (6/26/2015)
Original Post: I watched "Awakenings" with Robin Williams. Does that movie affect any of you as much as me? I see some similarities with we who were affected by polio. We were so sick at first and went through many days of learning to walk, therapy for our legs and arms, and multiple surgeries in the hospital. Then we lived a life of somewhat "normalcy" taking on many varied forms and functions for each one of us. Now some of us find ourselves back to square one with braces, wheelchairs, scooters, crutches, and canes and it almost seems like a dirty trick! It can tend to get us down if we let it. However, at the end of the movie the point is made, that life is more...it is the love of family and friends, it is the touch of another human being, it is knowing that there are others facing the same things you are facing and you realize you are not alone! We'll get through this together!

On the topic of having to take Social Security when we turn 65  (9/20/2015)
Question: I will turn 65 next year. Right now I am on disability. Do I have to go on Social Security or can I wait another year until I am 66? Is it true that Social Security Payments are less than Disability??

Dr. Bruno’s Response: If you are receiving Social Security disability you must continue to receive it. You'll get the same amount of SSDI. A recent suggestion from financial advisors is to postpone receiving Social Security benefits until you're 70 when the amount will be higher than at 65. You can't postpone payment from Social Security if you're getting SSDI.
On the topic of Intravenous Immunoglobulin (IVIG) treating PPS (3/23/15)
Dr. Bruno’s Post: I’ve been writing since 2004 about the failure of intravenous immunoglobulin (IVIG) as a treatment for PPS in spite of glowing “press releases” from the IVIG manufacturers (please see below). Independent researchers have reviewed the published studies on IVIG in 508 polio survivors and have just come to the same conclusion:

**Intravenous Immunoglobulin for Post-Polio Syndrome:**
**A Systematic Review and Meta-Analysis**

**Summary**
Background: Post-Polio syndrome (PPS) is characterized by progressive disabilities that develop decades after prior paralytic poliomyelitis. Because chronic inflammation has been suggested as causing the development of PPS, immunomodulatory management, such as intravenous immunoglobulin (IVIg) administration, may be beneficial.

Methods: We performed a systematic review and combined analysis of 3 published randomized, placebo-controlled trials of 241 patients and 5 prospective studies of 267 patients that evaluated the effect of IVIg in managing PPS. Pain severity, fatigue, muscle strength, physical performance and, quality of life were measured before and after IVIg infusion.

Conclusion: The present review indicated that IVIg is unlikely to produce significant improvements in pain, fatigue, or muscle strength. Thus, routinely administering IVIg to patients with PPS is not recommended.

On the topic of the Side Effects of Beta Blockers (3/2/15)
Question: I have been taking a beta blocker for blood pressure. I was curious as to the side effects, so I stopped taking it. I slept well, and actually woke up in a good mood. I did not experience, what was always a problem of shortness of breath, until late in the evening. As I read the side effects to my wife, she confirmed many of them. Interesting for sure.

"The Golden Rule of PPS:" If anything causes fatigue, weakness or pain - **Don’t Do It** (or) Do less of it.

On Exercise and Blood Sugar issues (1/17/2015)
“Today my glucose level was low and my legs gave out and I went down twice, I hate the fact everyone says more exercise ... the whole world doesn't understand. It’s so defeating... I don't know what to do.”
Dr. Bruno’s Response – “No exercise and you need a specialist in diabetes to deal with your blood sugar.”

Blood Sugar Can Be Too Low in Post-Polio Diabetics (1/13/2015)
In 2000, we measured polio survivors’ blood sugar and gave them the same tests of attention and memory that we’d been using to study polio survivors with fatigue. We found that the lower polio survivors’ blood sugar the worse they did on the most difficult attention tests. Attention was about 20% BELOW normal for those whose blood sugars were around 80, which is the bottom of the normal range for blood sugar. In fact, polio survivors’ ability to pay attention with a blood sugar of 80 was actually WORSE THAN IN DIABETICS with a blood sugar of 65! In terms of focusing attention polio survivors’ brains act as if they are hypoglycemic, with blood sugar levels in their brains about 15 points LOWER than the measurement from their doctors' lab.

An Interesting Study on Restless Legs and PPS (1/5/2015)
The authors studied one of two different conditions that are always confused by doctors: restless legs syndrome vs. periodic leg movements in sleep. RLS is a need to move the extremities because of discomfort or disagreeable sensations to relieve the discomfort. PLMS is where your legs and other muscles twitch and jump on their own, which our study found in 50% of polio survivors. We don’t know the criteria for the diagnosis of PPS in this study. But, the findings about RLS show the importance for all polio survivors of having a sleep study to diagnose MORE than just breathing problems!
On the topic of Leg “Twitching” (8/21/2015)
Original Post: For the last two nights, my polio leg has uncontrollable jerks and twitches. They wake me up from a sound sleep and so needless to say I am up until 4 in the morning! I've had them before, but they seem to be getting worse. Is this just part of PPS? Or is it something I need to go to the Post-Polio Clinic about?
2nd Post: Mine are generally connected to over use. That and the cramping (two different things). Also I don't have restless leg but I notice at times my feet jerk and twitch by themselves.
3rd Post: Twitching and jerking were my first identifiable symptoms of PPS. I had full body jerks that woke me up.
4th Post: It hits my left leg really badly if I have done too much and then lay down. I put a hot water bottle under my knee and it sure helps calm the leg down.
Dr. Bruno’s Response: Twitching happening all of a sudden is a sign of overuse. Of course, polio survivors have mastered the art of all muscles twitching all night long, which is knocked out by a low dose of alprazolam right before bed. Alprazolam is the generic for Xanax. It's not addictive taken before bed because you’re asleep when it works. (We’ve never had a polio survivor addicted to alprazolam even up to 2 mg before bed.)

On the topic of “Summer Grippe” (5/13/2015)
Question: The more I learn about Polio and PPS? The more interested I get. Here’s the question: How many of us were not diagnosed (initially) with polio, but The Summer Grippe. The history tells us (p. 277 Polio Paradox) that Albert Sabin started to really look at this in 1946. I was sick in 1954 with the Summer Grippe (PA); recovered on my own, no doctors. Drop foot appeared immediately.
2nd Post (5/13): My whole family came down with “Summer Grippe” in 1948. Seven kids, I was the youngest at 1 year. No doctor was called till I started walking again and dragging one foot. We were some of the lucky ones, no iron lungs or long hospital stays. Dealing with the PPS now is tough, having all sorts of problems with pain in the back and legs. My siblings have also had PPS problems.
3rd Post (5/13): Had flu like symptoms at 2 1/2 and in my baby book it says..."came down with virus X"....I guess they figured it out when I didn't run and fell alot...also had a slight limp when fatigued...later had therapy in Jr High for spine and strengthening.........wore saddle shoes, but no braces and was never hospitalized and we lived in Southern California outside LA.....now I am totally disabled and cannot stand, plus rotators, arms and hands are gone from over-use. Parents and family always used the word polio.....was always encouraged to do what I could but to stop when I felt tired. Parents motto was, "if you can't do it one way, find another" and that's how my life has been.
Dr. Bruno’s Response: All three types of poliovirus caused paralysis. The type I poliovirus is the epidemic virus that paralyzed(es) most people. Albert Sabin discovered that it was the type II poliovirus that apparently caused "THE SUMMER GRIP" and it was also the cause of the polio epidemic in Iceland the next year. I think the article in the post-polio library about "non-paralytic" polio describes the summer grip.
4th Post (5/14): Initially the doctor told my mom that I had the flu. So she took me home and I weathered it at home. No hospitalization, no hot packs during the acute stage, no isolation. This has always made me wonder how contagious polio really was, since no one else in my family got it from me. I've heard of very few people where more than one person in the family had polio. Maybe my family had some natural immunity.
5th Post: Dr. Bruno? I'll always wonder how many Summer Grippe children, have muscle weakness issues that have never been attributed to Type 2 Polio, especially the MS thing. I was told 4 times that I had it (even though they didn't see the lesions in my brain). If that rehab doc hadn't spotted my "foot" when I was 12?
I'd have never heard the word polio and would be living in a scary world of mis-diagnosis. My father couldn't ever say the word. Finally, in the last 5 years of my mother's life (when she could walk farther and faster than I could) did my mother talk about how in their gut they thought that might be what was happening when I was 2, with that awful flu. I'm grateful beyond words that I've learned the truth and am finding this "history" fascinating, for sure.
Dr. Bruno’s Response: We will never know how many Summer Grippe children there were nor how many children went undiagnosed with "non-paralytic" polio. Take a look at the article in the post-polio library about non-paralytic polio. The grippe was apparently caused by the type II poliovirus.
6th Post: My dad was a doctor and suspected polio. The first doctor he took me to said it was not polio, but that my dad was just overly concerned; it was just a summer flu. The second doctor he took me to told me later, that one of the
hardest thing he ever had to do was tell my father he was correct in his diagnosis. I was rushed to St. Louis and quarantined. It was polio. 1952

7th Post: I was one of the summer gripe polios in 1944. Big epidemic in Trenton, NJ and the only hospital taking polios had patients lining the hallways. Since I wasn't paralyzed Dr. came to the house. I had all the symptoms, stiff neck, pain, fever, etc. After a week I got out of bed to go to bathroom and collapsed on the floor. My legs just wouldn't hold me up. The Dr. said he thought it was polio but my parents didn't want to admit it. Took me about six months to get my strength back and be able to get up off the floor myself and climb stairs to bedroom. All the effects I had afterwards was a skinny right calf and not good coordination. But for the last 40 plus years there has been no question that I had polio. All my muscles are so weak I am in a power chair and can do little for myself. I am just grateful that I had about 30 years of "normalcy" before I began to have symptoms that something was really wrong. Diagnosed in 1984 but by then I knew it was due to the childhood polio. My heart goes out to all of you who had a full blown case and spent so much of your childhood paying the awful price that polio demanded. I was very fortunate.

Dr. Bruno's Response: And, that's the Summer Grippe!

On the topic of Unaccustomed Muscle Pain (5/8/2015)
Question: Lately I've had muscle pain on front of the thighs. Not the pain of spasm, with which I am only too familiar. I might attribute it to getting up from my chair or couch more frequently than usual, to deal with tradesmen, for about half a week (so far). I'm hoping this attribution is correct, because if so, it will pass. Above normal walking about doesn't do it. 600mg Paracetamol doesn't touch it. However, 400mg Ibuprofen on top does. For 'deep' pain I prefer a little codeine, though I *shouldn't* combine it with my other meds. Celebrex seemed to work well enough in one case.
A little history: My legs were paralyzed during the acute stage, but recovered (abnormally) well. At age of 6 or 7 I wasn't allowed upright - until reporting I did it when nobody was watching - because of neck weakness. Instead, I had a mini stretcher on castors and pushed myself around using my legs. When I reported the burning/pain on front of the thighs, 'nurse' said "it's a sign of healing". Of course, we all know better than that now. Thanks to Dr. Bruno.

Dr. Bruno’s Response: The thigh muscles turn on when you sit and lock your knees when you stand. The up and down for the tradesmen may be the cause (hope they're doing a good job for your trouble). Could it be your couch and "throne" in the loo are too low? Please let us know how your thighs are when the workers have gone. Avoid overuse in the first place is the key: "conserve to preserve."

An interesting Conversation about the “Truth” to the existence of PPS (1/3/2015)
No polio survivor experiencing overwhelming fatigue, new weakness, pain, sensitivity to anesthesia, difficulty sleeping, breathing and swallowing is being "forced into thinking that they are ill." It is absolutely true that PPS is not a disease or syndrome, nor a "flare-up" due to the poliovirus becoming active again. It is absolutely unquestionable, after 30+ years of published research, that PPS is real and does not have symptoms that would be experienced by a person aging with any disability. If you don't accept that PPS is a real condition caused by the failure and death of poliovirus-damaged neurons that have been overworked for decades? Perhaps it is because you have not read the enormous amount of research available.
PPS is a real process that has a cause and can be treated!
Conversation Continued: As Senator Daniel Patrick Moynihan said, everyone is entitled to their own opinion but not their own facts. The reality of PPS is a scientific fact, not an opinion or a "belief," as in doctors "not believing that PPS is real." Having the opinion or belief that PPS doesn't exist is like having the opinion that gravity doesn't exist. You're entitled to your opinion about gravity. But when a weak leg gives out, you fall and break a hip, scientific fact -- and your orthopedist -- trump opinion and belief by those who are uninformed.

On Getting Polio from the Vaccine in 1955 (2/22/15)
Question/Comment: I'm asking a question for a friend - He was in the hospital for 15 months in an iron lung from 1943-1944. He got polio for the 2nd time after getting the vaccine in 1955. He was back in the hospital, that time for 9
months. He remembers being told that he got the virus the second time from the vaccine in the sugar cube. Wasn't the sugar cube the Sabin Vaccine in 1960?

Dr. Bruno’s Response: The Sabin vaccine was released in 1962 so that was not the cause. But you have to remember that the vaccine was not 100% effective and that individuals did not develop the same degree of immunity to all three types of polio virus. It’s also possible that the individual who got polio twice was inadequately immunized to all three types of poliovirus. Finally, he could have been a victim of the “Cutter Incident”. Talk about bad luck!

Additional Question: Was the Salk vaccine always injected (or) was it also given on sugar cubes?

Dr. Bruno’s Response: The Salk vaccine was always injected, never given by sugar cube. The Sabin vaccine came out in 1962 and people should've received three sugar cubes. By the way the injectable vaccine was killed, or should have been, and the oral vaccine was live and could cause polio if it mutated. The Cutter Incident was only caused by the Salk vaccine, in which the virus wasn’t completely killed, it did not involve the sugar cube. It involved a company thought to be not following the protocol in the manufacturing of the Salk vaccine. The Salk vaccine was likely more than 80% effective.

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

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

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

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

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

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

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

**On the topic of “Neither Exercise nor Psychotherapy Reduces Fatigue in Polio Survivors” (8/25/2015)**

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

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


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

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

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

Dr. Bruno’s Response: One thing remains true for post-polio fatigue: Want to feel better? Conserve to preserve!
As "TRUE" Survivors we accept the truth that we had Polio, that we have Post-Polio Sequelae, and that we have made the commitment to listen to our bodies, take care of ourselves and support each other.