



Bruno “Bytes” – December, 2015

(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 Coenzyme Q-10 (12/22/2015)

Dr. Bruno’s Post: CO-ENZYME Q10 DOES NOT HELP FATIGUE IN PPS PATIENTS

A randomized controlled trial of coenzyme Q10 for fatigue in the late-onset sequelae of poliomyelitis.

Peel MM, Cooke M, Lewis-Peel HJ, Lea RA, Moyle W

Complement Ther Med. 2015 Dec; 23(6):789-93

OBJECTIVE:

To determine if coenzyme Q10 alleviates fatigue in the late-onset sequelae of poliomyelitis.

DESIGN:

Parallel-group, randomized, placebo-controlled trial.

BACKGROUND SETTING:

Coenzyme Q10 has been shown to boost muscle energy metabolism in post-polio subjects but it does not promote muscle strength, endurance or function in polio survivors with post-poliomyelitis syndrome. However, the collective increased energy metabolism might contribute to a reduction in post-polio fatigue.

PARTICIPANTS:

Polio survivors from the Australian post-polio networks in Queensland and New South Wales who attribute a moderate to high level of fatigue to their diagnosed late-onset sequelae of poliomyelitis. Those with fatigue-associated comorbidities of diabetes, anemia, hypothyroidism and fibromyalgia were excluded.

METHOD:

Participants were assigned (1:1), with stratification of those who use energy-saving mobility aids, to receive 100mg coenzyme Q10 or matching placebo daily for 60 days. Participants and investigators were blinded to group allocation. Fatigue was assessed by the Multidimensional Assessment of Fatigue as the primary outcome and the Fatigue Severity Scale as secondary outcome.

RESULTS:

Of 103 participants, 54 were assigned to receive coenzyme Q10 and 49 to receive the placebo. The difference in the mean score reductions between the two groups was not statistically significant for either fatigue measure. Oral supplementation with coenzyme Q10 was safe and well-tolerated.

CONCLUSION:

A daily dose of 100mg coenzyme Q10 for 60 days does not alleviate the fatigue of the late-onset sequelae of poliomyelitis.

On the topic of Chiropractic Care (12/18/2015)

Original Post: You talk about back muscle spasm pain and various ways to treat it. Can't polio survivors just go to a chiropractor and get their backs “cracked?”

Dr. Bruno’s Response: The answer is a very cautious “sometimes.” Before you see a chiropractor you need to know what chiropractic is. Chiropractic is an American creation that was developed in 1895. Chiropractic treatment is based on the theory that there is a “strain or sprain” between spinal vertebrae that causes a misalignment, called a “subluxation.” Subluxation is thought to trigger muscle spasm and back or neck pain by

reducing the movement of the vertebrae. Chiropractors "adjust" or "manipulate" the spine with their hands, or with a device called an "activator," which "pops" the vertebra back into proper position, restores spinal movement and decreases pain. However, chiropractor Howard Vernon, writing in *Chiropractic in the United States: Training, Practice, and Research* said that this theory remains "largely speculative" and that "all of the theories of the effects and mechanisms of action of spinal manipulation still lack adequate research."

There isn't just a lack of research documenting how chiropractic treatment for back pain works. It is more than a little disturbing that, in spite of admitting there is no good research to support its claims, the American Chiropractic Association (ACA) says that chiropractors treat not only back pain, but also allergies, asthma, digestive disorders, childhood ear infections, and even attention deficit disorder in children. The conclusion of chiropractic studies of autonomic nervous system "abnormalities" (*The Morgan Autopsies*) on which chiropractors base such wild claims is just plain wrong, both anatomically and physiologically.

There are some studies showing that manipulation can be effective in treating back pain. But with such broad claims about chiropractic and so little research documenting its mechanism of action and effectiveness, should polio survivors ever see a chiropractor?

There are two situations where spinal manipulation could help: when back pain is caused either by the sacroiliac (SI) joints in the pelvis or mid and lower back spinal vertebrae going out of alignment after a fall, an auto accident or just by turning, bending or lifting improperly. After the initial muscle spasm is calmed down, the SI joints or vertebrae can often be moved back into place and pain reduced. Although some chiropractors recommend adjusting the entire spine to treat back pain, there is no evidence that this is more helpful than adjusting only the low back or SI joints. What's more, spine adjustments that include neck vertebrae are risky. Neck manipulation has been reported to cause spinal cord injury, damage to blood vessels supplying the brain and stroke. Even low back spinal adjustment is not recommended if you have a history of spinal surgery or a spinal fusion, osteoporosis or have neurological symptoms -- numbness, tingling or recent loss of muscle strength in an arm or leg -- that may indicate a pinched nerve or a severely herniated disc.

As with all symptoms in polio survivors, the cause of pain must be identified, or potential causes ruled out, before spinal manipulation is attempted. And you should also know that it's not just chiropractors who can adjust the spine. Medical doctors of osteopathy and specially trained physical therapists can also perform spinal manipulation. But regardless of who's doing the "back cracking," polio survivors should talk to their physicians before being adjusted by anyone.

Unfortunately, even when spinal manipulation does help to relieve back pain, chiropractors don't usually teach "painless posture," which is vital to maintain the alignment of the spine and SI joints (see *THE POLIO SURVIVORS HANDBOOK* at www.postpolioinfo.com.) This leads some patients with chronically poor posture to depend on frequent adjustments to "realign" their spines. The Mayo Clinic concluded that four to eight chiropractic sessions are reasonable to treat new back pain, but that there is no evidence additional treatments are helpful. Repeated adjustment can cause irritation, inflammation and continued or additional pain. So, once the SI joints or vertebrae have been moved back into proper position, patients should see a physical therapist with experience treating both PPS and chronic pain for help in learning proper posture in sitting, standing and walking. PTs can also suggest braces, forearm crutches and lumbar and seat cushions to help keep your pelvis and spine straight.

Note: My goal with this response/article was to provide information by a chiropractor who reviewed the literature on the efficacy of treatment and dangers so that polio survivors would be able to make an informed decision. Knowledge is power; you have to make your own decisions about treating your body.

On the topic of Being Cold (12/13/2015)

Original Post: Go figure...it is a warm 70 degrees today and my feet and legs are still so very cold. If this was spring or summer I would not have the terrible coldness. Do my feet and legs know that it is December? I am a great fan of the heating pad - sitting with my feet in the heating pad bag day and night! They get so cold it is such a distraction. I REALLY don't like this. Anyone else?

Dr. Bruno's Response: The problem is that it's already been chilly and your body told your blood vessels that it's winter. As a result, your arteries stay constricted and prevent the blood from flowing back to your heart, allowing it to dump your core body heat and make your legs cold. This has probably been the worst fall in years for polio survivors. The temperature is 32 when you get up and 62 by 4 o'clock!

Hey, global warming! Please make up your mind!

PPS IS A DIAGNOSIS OF EXCLUSION. PPS - even cold "polio feet" - are always a Diagnoses of Exclusion.

If you are feeling unusually cold it's a good idea to have general bloodwork that includes thyroid tests (TSH, T4). In addition, if you have new or increased cold or pain in your legs or feet, see a vascular specialist for a Doppler venous study and an arterial ABI to make sure your arteries and veins are "open for business."

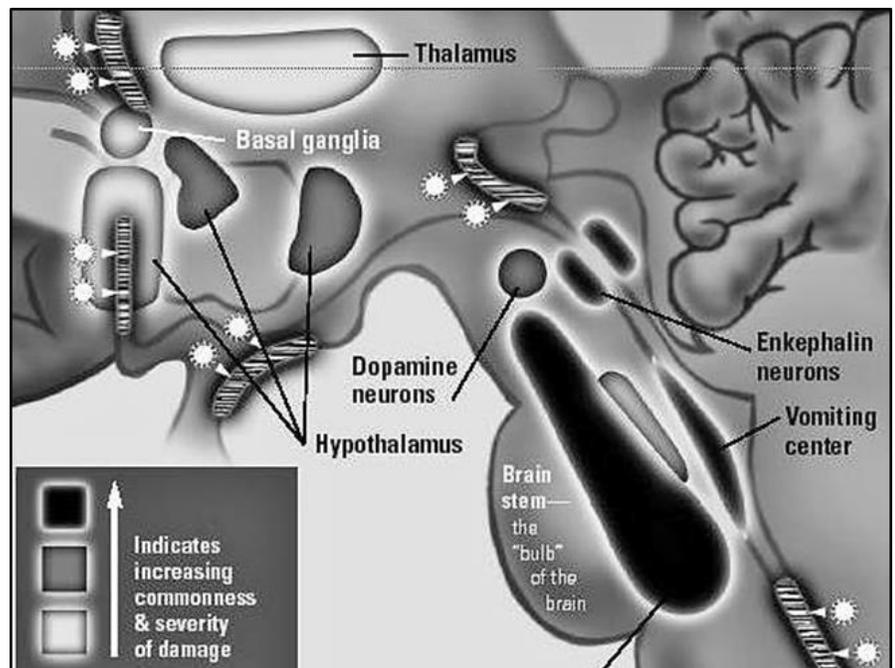
Additional Post: Both of my legs are driving me batty with feeling cold. It's worse if I've been on my feet a bit more than I should. Once I've started dressing for winter, I keep dressing for winter, even if it gets a little warmer. I think it takes at least 2 days for our brains to figure out and adjust to temp change.

Dr. Bruno's 2nd Response: I never actually measured the time, but I'd say that it takes at least five days of a consistent temperature for the body of a polio survivor to adjust. You know, any extreme in temperature isn't good for polio survivors. From our 1985 National Survey, 33% of polio survivors report fatigue with heat! And I'm not sure 133 degrees for 20 minutes is good for anyone. The brain's thermostat (the hypothalamus) is broken by the poliovirus on the up side as well as the down. You have two quick ways to dump body heat (vasodilation then sweating) and to conserve body heat (vasoconstriction then shivering). Dumping heat is much more effective than trying to stop becoming frozen.

So, consider a desert dry 80 degrees F outside as a "normal" temperature. Polio survivors will be much more comfortable without sweating (and maybe without much vasodilatation) at 100 dry degrees than at 60 (the temperature of most restaurants all year long, it seems.)

So 20 degrees colder is more difficult for polio survivors to deal with than 20 degrees warmer.

Still, as a treatment, a 133 degree sauna isn't going to help your shoulder especially when you get out, your blood pressure drops, so do you and break a hip. Ultrasound, LOCAL heat and deep tissue massage for shoulder muscle spasm -- and a little valium --are better than sitting in a convection oven.



On the topic of Muscle Tone Loss (12/12/2015)

Original Post: I saw a post which suggested that we have 7% loss (referring to muscle tone) per year. I have gone back and tried to find what book /publication printed this and by whom. Can you help?

Dr. Bruno's Response: A Canadian doctor Alan McComas, who studies polio survivors and ALS, found that UNTREATED polio survivors who reported muscle weakness, lost 7% of their motor neurons each year (when studied in a two-year follow up).

People who didn't have polio lose 1% of their motor neurons each year after the age of 60.

With polio survivors having lost an average of 50% of the motor neurons that run each muscle as a result of the polio virus, polio survivors don't have any motor neurons to lose!

On the topic of Fasting and Neuron Function (12/12/2015)

Original Post: If fasting can increase neuron function in the brain, what effect would it have on muscle?

<http://www.collective-evolution.com/2015/12/11/neuroscientist-shows-what-fasting-does-to-your-brain-why-big-pharma-wont-study-it/>

Dr. Bruno's Response: Asking about the effects of fasting on brain neurons versus muscle fibers is like comparing apples and oranges. Polio survivors should never fast. Even religions where fasting is required exempt those who have medical illnesses from fasting. Polio survivors need protein for their remaining, poliovirus-damaged neurons to function.

On the topic of Leg Numbness (12/11/2015)

Original Post: If I sit for any length of time my leg dies. It's not numb or asleep per say, it just won't hold me. I have to get up and walk around, but I can't walk because my legs won't hold me! It's a vicious circle. I use a walker and I used to be able to walk around the house without it, but no more. My arms are giving out now. It's scary.

Dr. Bruno's Response: I think you need a thorough evaluation by a rehabilitation specialist, including bloodwork and an MRI of your spine, to rule out other causes for your numbness and weakness. Remember, PPS is a diagnosis of EXCLUSION!

Additional Post: When that happened to me? We ruled out other issues first. That is when my doctor said to use a power chair to save my arms. My "good leg", also affected by polio, used to go to sleep like that. I could not drive for more than an hour before it would start to go to sleep and be useless. I never connected it with polio at the time.

On the topic of becoming Wheelchair Bound (12/8/2015)

Original Post: I'm new to the group, and had a sharp decline this year. I'm barely able to walk at night with my walker, without my braces on. I have a wheelchair. I'm afraid of the future. I'm getting a commode chair and a shower chair with a bench. I'm getting a nurse's aide to help me with the shower and dressing. I just got a bi-pap machine. It's all overwhelming me. I want to stay in my home, but plan for the future. I know I'll be wheelchair bound some day and the reality terrifies me.

Additional Post: Use a wheelchair now when you can get in and out of it as you need to. Don't wait until you have to be in one most of the time. I have had an electric scooter for 18 years now. I don't like sitting on it but it sure gets me loads and loads of places that I could not without it and it saves me wasting energy. Without it my life would have been so limited. Aids are there to help us manage our energy levels so we can do more of what we want. I know the changes are hard to take.

Another Post: I love my scooter and it takes me everywhere. Nothing slows me down. I've been places I didn't think I'd ever be able to go again.

Another Post: Start using your wheelchair now. I fought using mine for the longest time, but looking back I wasted a lot of strength doing that. Once I adjusted to seated life? I had tons more energy to DO things and enjoy life rather than struggle with pain.

Dr. Bruno's Response: All I can say is to walk is human, to roll divine! You may be wheelchair-bound, you may be Alabama-bound. But no one need ever be "confined" to a wheelchair. A wheelchair does exactly the opposite of confinement: it opens up your entire World! Get a head start and get a power wheelchair for distance before you need it so that you can conserve and never be "confined."

Wheel Chair "Bound"



The Freedom to Roll? "Divine"



On the topic of an Autopsy Performed on a Polio Survivor with Muscle Weakness (12/11/2015)

Original Post by Dr. Bruno: AUTOPSY OF A POLIO SURVIVOR WITH MUSCLE WEAKNESS

This isn't the first autopsy of a polio survivor with PPS. But it does remind us that:

- 1) Progressive muscle weakness means motor neurons are dying;
- 2) The original poliovirus attack killed motor neurons not only in the spinal cord area that controlled this man's the left leg but also caused "silent damage" THROUGHOUT THE SPINAL CORD, silent in that the patient had no muscle weakness in the right leg or his arms after polio but did have arm and leg muscle weakness beginning at age 58;
- 3) Neuron death caused glial scars in the spinal cord, the same type of scar our MRI studies found in fatigued polio survivors' brain activating systems;
- 4) NONE of the markers for ALS was found.

Conserve to Preserve. The neurons you save will be your own!

**An Autopsy Case of Progressive Generalized Muscle Atrophy over 14 years,
due to Post-Polio Syndrome.**

By Oki R, et al. Rinsho Shinkeigaku.

November, 2015

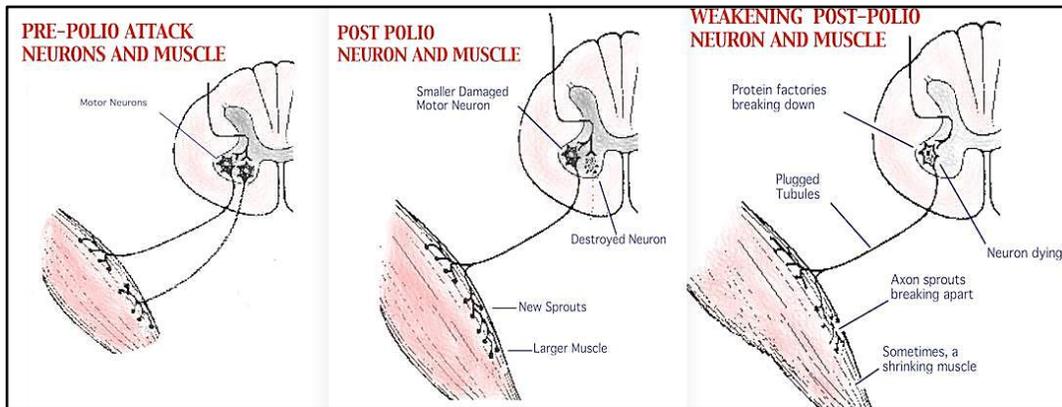
We report the case of a 72-year-old man who had contracted acute paralytic poliomyelitis in his childhood. Thereafter, he had suffered from paresis involving the left lower limb with no relapse or progression of the disease.

In his 60s he began noticing slowly progressive muscle weakness and atrophy in the upper and lower extremities. At the age of 72, muscle weakness developed rapidly, and he demonstrated shortness of breath on exertion and difficulty swallowing. He died after about 14 years from the onset of muscle weakness symptoms.

Autopsy findings demonstrated MOTOR NEURON LOSS and GLIAL SCARS not only in the motor neurons in the anterior horns, which were result of his old poliomyelitis, BUT ALSO THROUGHOUT THE SPINE. NO Bunina bodies, TDP-43 or ubiquitin inclusions, which are seen in ALS, were found.

The pathological findings in the patient are considered to be related to the development of muscle weakness.

Dr. Bruno's Additional Post: Once again, I refer to this graphic Conserve to preserve. The neurons you save will be your own!



On the topic of “Pushing” Yourself too Far (12/9/2015)

Original Post: I've noticed for a few years now, that when I pushed myself either because I just want to, or because I need to. At the end of the day, maybe even 1 to 2 days later, I experience shivers or fever like symptoms. I've always concluded it was due to me pushing myself beyond my limits. Could that be true?

Dr. Bruno's Response: At the Post-Polio Institute we call it the "48 hour lag." You beat yourself up on Monday, are surprised you feel good on Tuesday and then crash on Wednesday. Back in the early 80s people talked about PPS symptoms and described flu – like symptoms similar to those survivors had with polio originally. In the thousands of patients we've studied and treated, very few talk about shivers and fever – like symptoms. That being said, especially as the weather gets colder, the more fatigued you are the harder it is to control your body temperature and the more likely it is you are to feel cold inside when you overexert yourself.

It's always good to remember that PPS IS A DIAGNOSIS OF EXCLUSION. If you're feeling cold, general blood work, thyroid blood tests (TSH,T4) and for new or increased cold legs & feeds get Doppler and ABI to make sure arteries and veins are open for business.

On the topic of Finally Feeling Better when we “Conserve to Preserve” (12/4/2015)

Original Post: How long did it take you to start getting more energy after you started the “conserve to preserve” philosophy? It's been about three months for me and I still feel tired and have no energy.

Dr. Bruno's Response: The Post-Polio Institute patients are told to take the 6 weeks of treatment off, do only what HAS to be done -- going to work, maybe shopping for groceries -- but no painting your kid's kitchen or running the church tag sale. So, as a holiday gift, I hereby give you the rest of the month off!

As far as feeling better? If you follow all the guidelines, the Post-Polio Institute's rule of thumb is six months.

(I'm glad Polio Paradox has helped. It can be a disturbing read). The Post-Polio Institute patients are told to take the 6 weeks of treatment off, do only what HAS to be done -- going to work, maybe shopping for groceries -- but no painting your kid's kitchen or running the church tag sale.

One item that we have found to be invaluable in identifying triggers for post-polio symptoms and to help polio survivors "conserve to preserve" is the daily activity and symptom log (below). Is the log a pain to keep? Absolutely.

Is the log the best way for you to find out how you are throwing away your energy and when you should stop and be resting? Absolutely!

Name: _____ Day: _____ Date: _____

Time	Activities & Steps	Perceived Exertion	Specific Muscle Weakness	Overall Fatigue	Pain Mood Breathing	Activities that produced Symptoms & Modifications
Up	Food?: _____ Sleep Quality?: _____		Rate as mild-moderate-severe			Activity: Symptom: How did you do the activity & how were you positioned?
BREAK						
Noon	Food?: _____				How could you modify?	
BREAK						Activity: Symptom: How did you do the activity & how were you positioned?
6 pm	Food?: _____					How could you modify?
Bed	Total Steps: _____					

Perceived Exertion Scale: 6 Very, Very Light; 7 Very Light; 8-9 Fairly Light; 10-13 Somewhat Hard; 14-15 Hard; 16-17 Very Hard; 18-20 Very, Very Hard

On the topic of the difference between Gullian-Barre and Polio (12/7/2015)

Original Post: Last night I heard a speaker tell us about her experience with Guillian-Barre Syndrome. I've heard it called French Polio.

Dr. Bruno's Response: Gullian-Barre Syndrome is an autoimmune disease where the body attacks the COVERING of both motor and sensory nerves, not the neurons themselves as poliovirus does to motor neurons. Symptoms usually begin in both feet and travel up both legs, sometimes to the chest. 70% of those with GBS have a full recovery.

For there to be a neurological post-GBS Syndrome like PPS, the "recovered" nerves would have to fail in some way. Only about 3 percent have a relapse of muscle weakness and tingling sensations many years after the initial attack.

Additional Post: Isn't that kind of like MS? I think I read that MS attacks the myelin coating of the nerves.

Dr. Bruno's Response: Yes, it's kind of like MS except only peripheral nerves are damaged, not brain neurons.

On the topic of PPS and Bladder Control "Issues" (12/6/2015)

Original Post: Dr. Bruno--my bladder control problems have worsened over the years. My primary care physician (PCP) recently put me on Trosipium, but I'm not sure it is helping. Are there any reasons why a post-polio patient should not take these antispasmodic types of meds? I am thinking of going off this med, because it causes my mouth and throat to become very dry, and I am afraid of choking. My physiatrist says that polio/PPS does not affect bladder muscles.

Dr. Bruno's Response: The Polio virus affected smooth muscle nerves (like those around blood vessels and in the intestines) by damaging the autonomic nervous system in the brain stem and spinal cord. Right after polio inability to pee was most common, but leaking was also seen. These problems were usually short lived, but the damage remains.

Today, polio survivors' bladder problems are most likely due to aging but can be made worse by polio virus-damage. There is no question that polio affected the vagus nerve, which should automatically control urination. Right after polio, the inability to void was most common, but the inability to retain urine could also occur. These were usually short-lived problems, but the damage remains. So, just as with bowel issues, bladder problems can be caused by poliovirus-damage but are usually age-related and made worse by having had polio.

Regardless, bladder issues should be treated as in non-polio survivors, but with doctors keeping in mind that the drugs they use may be more or less effective due to underlying poliovirus damage.

On the topic of Inflammation and Post-Polio Sequelae (12/4/2015)

Dr. Bruno's Post: INFLAMMATION IS NOT A POST-POLIO SEQUELAE

A member's daughter, a nurse, asked a fascinating question: Do polio survivors have more inflammatory diseases (like rheumatoid arthritis), lupus and an elevated sedimentation rate, which is an indicator of inflammation. The answer to all three is no. What's more, inflammation does NOT cause PPS. Here is a summary about studies of markers of inflammation and muscle breakdown:

A BLOOD TEST FOR POST-POLIO MUSCLE PAIN?

By Dr. Richard L. Bruno

Q: I recently had arm and chest pain. I went to the ER. The only abnormal blood tests showed high C-reactive protein and high creatine kinase. My blood pressure and cholesterol are normal, I have never smoked and I'm thin. My EKG showed that I hadn't had a heart attack. Could high CRP and high CK be related to PPS?

A. C-reactive protein is a blood marker for inflammation somewhere in the body. High CRP can be seen with type 2 diabetes, autoimmune diseases and cancers. Could inflammation somewhere in your body, as indicated by an elevated CRP, be related to PPS? Fifty consecutive patients evaluated at The Post-Polio Institute had CRP measured. The patients were on average 59 years old and 55% were women. Thirteen percent had an elevated CRP, 66% of whom were men. CRP was on average nearly three times the normal value. However, there was NO significant difference between those with high and normal CRP on self-ratings of daily fatigue,

difficulty with self-care or ability to perform activities inside or outside of the home. So, there is no evidence that elevated CRP or inflammation is related to post-polio fatigue or difficulty in functioning.

Elevated CRP has been related to having a heart attack or stroke. The theory is that a bacterial or viral infection (although definitely not a poliovirus infection) somehow inflames plaque in arteries, causing it to break off and clog arteries. Our 1985 National Survey found no more heart disease or high blood pressure in polio survivors than in the general population. However, two studies found that 5% more male post-polio patients had abnormally elevated cholesterol as compared to the general population. In one of the studies, only 33% of those with high cholesterol had been given a cholesterol screening test by their own doctor and not even 25% were on cholesterol-lowering medications, like the statin drugs such as Lipitor and Pravachol. This is not good, since reducing “bad” cholesterol reduces heart attack risk and may increase survival even after having a first heart attack. But, as you know, statins can and do cause muscle pain and can cause muscle breakdown. So several may have to be tried before finding one that helps and doesn't literally hurt (see CHOLESTEROL DRUG article in the POSTPOLIO LIBRARY <http://www.PostPoliInfo.com>).

CK AND STATINS

CK is an enzyme released when muscle is damaged. One half of one percent of anyone taking a statin develops muscle breakdown, which causes muscle pain (especially in the calves), muscle weakness and an increase in CK. Even without muscle breakdown or an elevated CK, many polio survivors report muscle pain or weakness when taking a statin, usually one of the older statins, like Lipitor.

But polio survivors can have an elevated CK without taking a statin. Two studies found that 40% of polio survivors had abnormally elevated CK, with men having significantly higher CK than did women. In one study, CK increased with the number of steps polio survivors walked in a day. In our fifty Post-Polio Institute patients, 21% had abnormally elevated CK levels (on average about 33% higher than normal) with men having higher CK than did women. But, as with CRP, there was NO significant difference between those with high and normal CK on self-ratings of daily fatigue, difficulty with self-care or the ability to perform activities inside or outside of the home.

However, an elevated CK may mean that polio survivors are making their muscles work too hard and are causing them to break down. So, neither CRP nor CK is related to fatigue or loss of functional abilities in polio survivors, but an elevated CK may be a warning of muscle overuse abuse.

Polio survivors need to have their cholesterol and CRP measured to assess heart disease risk. And, since an elevated CK indicates muscle breakdown -- either from taking a statin or from muscle overuse -- polio survivors should have CK measured before taking a statin. If you are worried about possible muscle weakness or breakdown with statins, ask your doctor about using newer cholesterol-lowering drugs, like Zetia and Zocor that seem less likely to cause pain, or older medications like slow-acting niacin or bile acid sequestrants. Besides medication, polio survivors need to eat high fiber foods, reduce saturated fat, treat high blood pressure and stop smoking to keep their tickers ticking.

Additional Bruno “Bytes” are available for you to share by going to:

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

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

Previous months are located there, and are available by “clicking” on them, in easily printable PDF format.