

## Bruno Bytes – May, 2015

### On the topic of Polio Survivors and being “Type A” 5/28/2015

Member Post: <http://www.cnn.com/2015/05/27/health/type-a-personality/index.html>

Dr. Bruno’s Response: Do you remember that Type A was originally called the "heart attack-prone personality"? We found in 1985 that #1 - Polio survivors were even more Type A than non-polio survivors who already had had heart attacks and #2 - Type A behavior was the #2 cause of PPS “

(The #1 cause of PPS is physical overexertion and exercise)

The result? Being Type A is like living while holding a gun to your OWN head.

Life's too short. Drop the gun.

### On the topic of “CPAP” – a Red Flag 5/28/2015

Dr. Bruno’s Post: **\*\*RED FLAG\*\***: For polio survivors with moderate to severe CENTRAL SLEEP APNEA and HEART FAILURE using the ResMed Adaptive Servo Ventilation (ASV) “CPAP”

ResMed, maker of the Adaptive Servo Ventilation (ASV) “CPAP” machine has just announced that a study of patients treated with ASV for moderate to severe CENTRAL SLEEP APNEA and who ALSO had symptomatic, chronic HEART FAILURE (with a heart blood ejection fraction of 45% or lower) had a 34% greater risk of sudden cardiac death.

DON'T BE FRIGHTENED BY THIS ANNOUNCEMENT. Very few polio survivors being treated for central or obstructive sleep apnea or hypopneas, even if they have heart failure, are likely to be affected.

But, out of an abundance of caution, if you do use ANY machine (CPAP, Bi-Pap, or volume ventilator) and have a history of ANY heart disease – even if not heart failure -- please see your lung doctor and cardiologist, have an echocardiogram to measure your heart blood ejection fraction and discuss what nighttime device is best to treat sleep-disordered breathing and is safest to use for your heart.

<http://www.resmed.com/us/en/consumer/newsandinformation/news-releases/2015/resmed-provides-update-on-phase-iv-serve-hf-study-of-adaptive-servo-ventilation-therapy.html>

PLEASE SHARE!

FYI: Adaptive Servo Ventilation

ASV is similar to the continuous positive airway pressure (CPAP) therapy that is used in the treatment of obstructive sleep apnea but there are significant differences. ASV is a device that can be placed in your home to treat central and complex sleep apnea. The ASV device works during sleep by gently blowing air from a machine into a mask applied over the person's nose. When the ASV unit detects significant reductions or pauses in breathing, it intervenes with just enough support to maintain the patient's breathing at 90% of what had been normal for that individual just prior to the decrease in breathing. When the breathing is stable, ASV provides just enough pressure support to help keep the airway open, providing an approximately 50% reduction in the work of breathing.

### On the topic of Cellulitis 5/18/2015

I’m having repeated problems with cellulitis in my Polo leg. Anyone else have this problem ?

Dr. Bruno’s Response: Cellulitis, an infection under the surface of the skin, and skin breakdown on your bottom are not common in polio survivors because circulation is good (except during winters like the one we just had). But your skin certainly needs to be watched if you have rubbing braces or sit in a wheelchair all day.

And, ALWAYS dry between each toe.

<http://www.nlm.nih.gov/medlineplus/ency/article/000855.htm>

## 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.

2<sup>nd</sup> 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.

3<sup>rd</sup> 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.

<http://www.postpolioinfo.com/library/npp.pdf>

4<sup>th</sup> Post (5/14): Initially the dr. 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.

5<sup>th</sup> 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 smile emoticon ) 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.

6<sup>th</sup> 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

7<sup>th</sup> Post: I was one of the summer grippe 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! Since so many folks are interested in the Summer Grippe, here's an article from USA TODAY.



## Polio-Chronic Fatigue Link Explored

Randy Dotinga for USA Today – April 27, 2001

"The bottom line is that half of the people being diagnosed with chronic fatigue syndrome could have had polio as kids and didn't even know it."

-- Dr. Richard Bruno, PhD. International Centre for Post-Polio Education.

During the middle decades of the last century, thousands of American kids came down with "summer grippe," an illness that caused high fevers, flu symptoms and sore necks. They recovered and went on with their lives -- and few realized they had survived a mild form of polio.

Now, an expert in brain disorders is launching an international study to determine whether the grippe -- also known as non-paralytic polio -- may have left those children vulnerable to chronic fatigue syndrome, one of the modern era's most mysterious and controversial diseases.

Baby boomers as young as 40 could have been affected; says Dr. Richard L. Bruno, the Director of the International Centre for Polio Education, who will be conducting the study. "The bottom line is that half of the people being diagnosed with chronic fatigue syndrome could have had polio as kids and didn't even know it," he says. Chronic fatigue syndrome tends to come on suddenly and afflict its sufferers, mostly women, with weakness, tiredness, muscle aches, sore throat and fever. Some complain of memory loss and confusion.

Researchers at DePaul University estimate that 800,000 people nationwide suffer from chronic fatigue syndrome. A study found that most people with the syndrome knew they were sick but had no idea what was wrong, says DePaul psychology professor Leonard Jason. The causes of chronic fatigue are anything but clear. Some researchers speculate it is closely related to mental illnesses like depression, while others suspect viruses and sleep disorders. "We know a lot about anxiety and depression, but we know much less about fatigue," Jason says. "It's a very difficult entity for people to study and take seriously."

In fact, skeptics claim chronic fatigue is imaginary, a symptom of mental illness. A decline in dopamine.

Bruno, also Director of the International Post-Polio Task Force, says the key to chronic fatigue may indeed be in people's heads. But he suspects the culprit is in the brain itself, not the mind. Before it was wiped out by vaccine, severe polio targeted the brain and spinal cord and caused paralysis.

Mild polio -- the Sumer Grippe, which Dr. Albert Sabin found was caused by the Type II poliovirus -- may have spared the spinal cord but left a time bomb behind in the brain, Bruno says. The virus could have killed off neurons that produce dopamine, a chemical that activates the brain, keeping you alert and awake. Humans naturally lose dopamine-producing neurons as they age and Bruno thinks the dopamine neuron loss caused by aging and mild polio could combine to cause a "brownout" of alertness -- or never-ending fatigue.

(<http://postpolioinfo.com/library/bromo.pdf>)

Bruno treats and studies polio survivors having Post-Polio Sequelae, an energy-sapping condition that causes chronic fatigue. He speculated in a published study about a link between polio and chronic fatigue syndrome, that link being damage in both conditions to dopamine-producing neurons in the brain stem's "fatigue generator." (<http://postpolioinfo.com/library/parallels.pdf>). Dr. Oliver Sachs, author of Awakenings, supports Bruno's theory, saying that he "has made a very powerful case for the role of dopamine" in causing chronic fatigue.

Support Groups Polled

A woman in San Diego who read about Bruno's work asked members of her chronic fatigue support group whether any of them suffered from the grippe as children. "A bunch of hands went up," Bruno was told. "She said, 'My God, even I had something like that when I was a kid. I think you're on to something.' "

Other support groups had similar results, inspiring Bruno to draft a questionnaire that will soon be sent to every known chronic fatigue support group in the United States, Canada and Great Britain. It will also be distributed to support groups for people who suffer from fibromyalgia (FM) and myalgic encephalomyelitis (ME), disorders considered by some experts to be related to chronic fatigue or, possibly be even the same illness. Administering the survey to chronic fatigue sufferers won't be easy, Bruno notes, because some people won't remember being ill as children, even if they were.

Some chronic fatigue experts are intrigued by Bruno's work. "He's a very competent individual and very respected," says Fred Friedberg, a clinical assistant professor of psychiatry at the State University of New York at Stony Brook. Another expert, San Diego neurologist Dr. James Grisolia, says existing research supports the idea that the causes of chronic fatigue lie in the nervous system.

#### Skeptics Question the Link

Not all experts, however, support Bruno's theories.

Dr. Jay Goldstein, director of a California chronic fatigue clinic and author of several books on the subject, doubts that Bruno's research will be helpful to patients. "If chronic fatigue is a result of having polio when (patients) were children, and they don't have it any more, what difference does that make? And how would that explain the onset of new cases?" he says.

Bruno responded saying, "The finding will help not only polio survivors and baby boomers with CFS to understand that their symptoms are 'real' but also will, in the same way, help young CFS patients." As to the onset of new cases of CFS in younger people Bruno says, "I don't know why doctors forget that, although polio isn't an issue in the western hemisphere, there are still 100 polio-like viruses in the US that could damage the "brain fatigue generator" and brain dopamine-producing neurons -- just as the polioviruses did -- and could cause chronic fatigue. For his part, Bruno doesn't support medication in cases of post-polio syndrome or chronic fatigue. He supports something much cheaper: Common sense. Sufferers should pace their activities, take breaks and stop before they get tired, he says, a treatment that reduces fatigue in his Post-Polio Sequelae patients. "The idea is that if something happened to your brain, you need to listen to your brain and body, stop before you get fatigued and you'll feel better," he adds. "This should at least be tried before people take drugs and herbs and God-knows-what-else."

What To Do ? If you are always tired, consult your doctor. A variety of medical problems, from thyroid trouble to sleep disorders, could be responsible. Be prepared to be treated with skepticism by some people if you do think you have chronic fatigue syndrome. There is much information (<http://www.postpolioinfo.com>) and many support groups for polio survivors (<https://www.facebook.com/groups/148377278537482>) and those with CFS that can help you deal with your feelings, physical and emotional

#### On the topic of Clonazepam (Klonopin) and Flexeril 5/10/2015

Question: Are these used for any PPS symptom relief?

Dr. Bruno's Response: Clonazepam is effective for relaxing the esophagus when people get food stuck behind their breastbone. The better drug for muscles twitching and jumping at night is alprazolam. Flexeril is VERY sedating, slows the gut, makes it hard to pee and is not a good muscle relaxant.

#### 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: #1 question: How many steps are you walking and stairs are you climbing each day?

Response to Dr. Bruno's Question: From computer or tv to toilet and back, and repeat as necessary, is the usual routine, Dr. Bruno. Good question about the stairs (we don't have any). That would do it, I imagine, as does stepping up onto a stool/step ladder too many times. I have done some extra walking around shops lately. While exhausting and kind of stressful, that didn't cause any pain as far as I'm aware. Anyway, iirc, level walking would cause pain in my calves first.

The way it works for me is any pain doesn't manifest until after the damage is done, so I have think back (and sometimes it takes a while) to figure out what I was doing to cause it. There was also some weakness/unsteadiness in the same area for a couple of days, but it passed. I'm still pretty sure it's getting up from my seat working those muscles. I'll get some rest over the weekend, and see how that turns out. Then, it's only a day or two before we're back to 'normal'.

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."