



Bruno “Bytes” – October, 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 another “Polio Like” Virus (10/6/2016)

Original Post: What is this "Polio like" disease that has no cure that I heard about on this morning?

Dr. Bruno’s Response: There are more than 100 enteroviruses (viruses that live in your intestines), many having the same or similar neuron damaging capabilities as the 3 polioviruses. "Polio-like virus" is a short-cut way of saying neuron-killing enteroviruses. There are 60,000 cases of AFM in India each year, caused by "polio-like viruses," but no cases of polio.

Enterovirus-68 caused about 100 cases of muscle weakness and some paralysis a few summers ago, if you remember the terrifying headlines: POLIO RETURNS TO AMERICA! Last summer? There were few or no cases.

From CDC.gov: What is enterovirus D68?

Enterovirus D68 (EV-D68) is one of more than 100 non-polio enteroviruses. This virus was first identified in California in 1962.

How common is EV-D68 in the United States?

Small numbers of EV-D68 have been reported regularly to CDC since 1987. However, during 2014 the number of people reported with confirmed EV-D68 infection was much greater than that reported in previous years. We can’t predict whether EV-D68 will be a common type of enterovirus detected this year or in future seasons. That’s because a mix of enteroviruses circulates every year, and different types of enteroviruses can be common in different years.

What time of the year are people most likely to get infected?

In the United States, you are more likely to get infected with enteroviruses in the summer and fall. However, you can get infected year round.

What is happening with EV-D68 in 2016?

CDC is aware of limited sporadic EV-D68 detections in the U.S. in 2016. There is no indication of unusual activity. Enteroviruses are ever-present in the community, and each year we expect to detect cases. As in previous years, CDC will continue to work in 2016 with states by testing specimens to determine virus type, supporting the identification and investigation of outbreaks, and monitoring seasonal activity.

What happened with EV-D68 in 2015?

U.S. laboratories reported zero EV-D68 detections to CDC’s National Enterovirus Surveillance System (NESS) during the 2015 enterovirus season (summer and fall). Also, CDC received about 700 specimens for enterovirus testing during 2015; zero were positive for EV-D68, many were positive for a rhinovirus type.

What happened with EV-D68 in 2014?

In summer and fall 2014, the United States experienced a nationwide outbreak of EV-D68 associated with severe respiratory illness. From mid-August 2014 to January 15, 2015, CDC or state public health laboratories confirmed a total of 1,153 people in 49 states and the District of Columbia with respiratory illness caused by EV-D68. Almost all of the confirmed cases were among children, many whom had asthma or a history of wheezing. Additionally, there were likely many thousands of mild EV-D68 infections for which people did not seek medical treatment and/or get tested.

CDC Works 24/7

As the nation's health protection agency, CDC saves lives and protects people from health.

<http://www.cdc.gov/>

On the topic of Choosing a Drug Plan (10/10/2016)

Dr. Bruno's Original Post: October 15th is almost here and it's time to start thinking about health insurance for 2017. I want to warn you about changes in your drug plan that you may not be aware of (I realize they may not make sense).

All medications in Medicare part D drug plans are assigned a "Tier." Tier 1 is the least expensive, often older generic drugs, Tier 3 is for brand-name drugs while Tier 5 is expensive specialty drugs. What the insurance companies don't tell you that they can change a drug's Tier every year.

For example, one drug plan has listed generic diazepam (brand name Valium, which has been around since 1963) as a Tier 1 drug. But, in 2017, the same generic diazepam will be listed by the drug plan as a Tier 4 drug, a "non-preferred drug." The price for Tier 1 generic diazepam had been \$15 for 3 months. Come 2017, the price for Tier 4 generic diazepam will be \$343 for 3 months!

Why, you ask, would a generic drug that's been around for 53 years be switched from Tier 1 to Tier 4? For that question I have no answer. But imagine how you would feel if you didn't check the Tiers and prices for 2017 and bought generic diazepam through your drug plan. You would go from paying \$60 a year to \$1,372!

So call your prescription drug plan and find out the Tiers and costs for all of your medications. But remember that you don't have to buy all of your medications through your drug plan. You can go to <http://www.goodrx.com/> and find the prices you would pay for your medications at local pharmacies, pharmacies inside big-box stores (Target, Walmart, Stop & Shop) and by mail. Using diazepam as an example, a three-month supply bought through one supermarket's drugstore would be \$19 for 3 months. What's more, some of the big-box stores and pharmacies also have discount cards that can reduce the price even further. If you find that your drug plan charges more for some medications than does a local pharmacy, you can ask your doctor to send prescriptions for reasonably priced medications to your drug plan while you take a handwritten prescription to your local Walmart and pay cash.

On the topic of EMG and "Old" Polio (10/11/2016)

Original Post: I had an EMG done yesterday on my right leg. The doctor that did the EMG told me I had "old polio". I didn't even think much about it till I got home because I was talking about PPS. Has anyone else had PPS referred to as "old polio"?

Dr. Bruno's Response: What should have been said is, "Your EMG shows damage consistent with having had polio". This is a reason polio survivors shouldn't have EMGs unless ANOTHER diagnosis is suspected. EMGs hurt and are very expensive.

On the topic of Post-Polio Neuropathy (?) (10/12/2016)

Original Post: Is there a way of distinguishing between diabetic neuropathy in motor neurons vs. polio / post-polio neuropathy? I've had diabetes for 20 years and PPS for about 2, but yet some specialists just off-handedly dismiss my motor neuropathy in my legs as "probably" diabetes.

Dr. Bruno's Response: A Nerve conduction study should've told the tale. There is no such thing as a post-polio or polio neuropathy. The poliovirus damages the neuron in the spinal cord, not the axon going to the muscle. What's more the polio virus doesn't damage sensory neurons or their axons. So if you have "nerve pain" it's not due to having had polio.

Dr. Bruno's Additional Response: There are conditions that cause motor nerves to lose their myelin. In people who are middle-aged a common cause is an autoimmune process. Slowed conduction along motor nerves can be associated with muscle weakness because not all of the muscle fibers are being stimulated at the same time; think of listening to someone...speaking...very...slowly & you not being able to quickly understand the speaker.

Your doctor should be looking for some cause for the motor demyelination other than polio.

On the topic of Marijuana and Osteoporosis (10/12/2016)

Dr. Bruno's Original Post: The use of Pot creates stirring debates. Here's some new information:

<http://www.independent.co.uk/news/science/cannabis-marijuana-thin-bones-osteoporosis-lower-weight-munchies-a7357056.html>

On the topic of being Unable to Wake up from Surgery (10/17/2016)

Original Post: I had cataract surgery on one eye three weeks ago. The anesthesiologist said he understood PPS. It was supposedly a "twilight" sleep and I would be able to follow commands in the surgical room. The minute I felt that medication, I was OUT. I remember nothing. It took days to feel halfway alert. I'm going back for other eye, and I'm concerned.

Dr. Bruno's Response: Tell them what happened and ask that they revise dose they used.

ANESTHESIA Warning Cards and a Polio Survivor's Symptom Checklist are available and easily printable here

<http://www.papolionetwork.org/-anesthesia-warning.html>

On the topic of the Healing Power of Relationships (10/17/2016)

Dr. Bruno's Original Post: DON'T SCOFF AT THE PLACEBO EFFECT. RELATIONSHIPS ARE HEALING...

Conventional medical wisdom has long held that placebo effects depend on patients' belief they are getting pharmacologically active medication. A paper published today in the journal Pain is the first to demonstrate that patients who knowingly took a placebo in conjunction with traditional treatment for lower back pain saw more improvement than those given traditional treatment alone.

"These findings turn our understanding of the placebo effect on its head," said joint senior author Ted Kaptchuk. "This new research demonstrates that the placebo effect is not necessarily elicited by patients' conscious expectation that they are getting an active medicine, as long thought. Taking a pill in the context of a patient-clinician relationship – even if you know it's a placebo – is a ritual that changes symptoms and probably activates regions of the brain that modulate symptoms."

Newswise — BOSTON — Conventional medical wisdom has long held that placebo effects depend on patients' belief they are getting pharmacologically active

 Beth Israel Deaconess Medical Center

Study Finds Knowingly Taking Placebo Pills Eases Pain
'Fake pills' significantly reduced pain and disability in patients with chronic low back pain



Credit: BIDMC

Ted Kaptchuk, director of the Program for Placebo Studies and the Therapeutic Encounter at Beth Israel Deaconess Medical Center (BIDMC) and an associate professor of medicine at Harvard Medical School.

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“These findings turn our understanding of the placebo effect on its head,” said joint senior author Ted Kaptchuk, director of the Program for Placebo Studies and the Therapeutic Encounter at Beth Israel Deaconess Medical Center and an associate professor of medicine at Harvard Medical School. “This new research demonstrates that the placebo effect is not necessarily elicited by patients’ conscious expectation that they are getting an active medicine, as long thought. Taking a pill in the context of a patient-clinician relationship – even if you know it’s a placebo – is a ritual that changes symptoms and probably activates regions of the brain that modulate symptoms.”

Kaptchuk, with colleagues at Instituto Superior de Psicologia Aplicada (ISPA) in Lisbon, Portugal, studied 97 patients with chronic lower back pain (cLBP), which causes more disability than any other medical condition worldwide. After all participants were screened and examined by a registered nurse practitioner and board certified pain specialist, the researchers gave all patients a 15-minute explanation of the placebo effect. Only then was the group randomized into one of two groups; the treatment-as-usual (TAU) group or the open-label placebo (OLP) group.

The vast majority of participants in both groups (between 85 and 88 percent) were already taking medications – mostly non-steroidal anti-inflammatories (NSAIDs) – for their pain. (Patients taking opioid medications were excluded from the trial.) Participants in both the TAU and OLP groups were allowed to continue taking these drugs, but were required not to change dosages or make any other major lifestyle changes, such as starting an exercise plan or new medication, which could impact their pain.

In addition, patients in the OLP group were given a medicine bottle labeled “placebo pills” with directions to take two capsules containing only microcrystalline cellulose and no active medication twice daily.

At the end of their three-week course of pills, the OLP group overall reported 30 percent reductions in both usual pain and maximum pain, compared to 9 percent and 16 percent reductions, respectively, for the TAU group. The group taking placebo pills also saw a 29 percent drop in pain-related disability. Those receiving treatment as usual saw almost no improvement by that measure.

“It’s the benefit of being immersed in treatment: interacting with a physician or nurse, taking pills, all the rituals and symbols of our healthcare system,” Kaptchuk said. “The body responds to that.”

“Our findings demonstrate the placebo effect can be elicited without deception,” said lead author, Claudia Carvalho, PhD, of ISPA. “Patients were interested in what would happen and enjoyed this novel approach to their pain. They felt empowered.”

Kaptchuk speculates that other conditions with symptoms and complaints that are based on self-observation (like other kinds of pain, fatigue, depression, common digestive or urinary symptoms) may also be modulated by open-label treatment.

“You’re never going to shrink a tumor or unclog an artery with placebo intervention,” he said. “It’s not a cure-all, but it makes people feel better, for sure. Our lab is saying you can’t throw the placebo into the trash can. It has clinical meaning, it’s statically significant, and it relieves patients. It’s essential to what medicine means.”

“Taking placebo pills to relieve symptoms without a warm and empathic relationship with a health-care provider relationship probably would not work,” noted Carvalho.

<http://www.newswise.com/articles/view/662854/?sc=mwhn>

[On the topic of PPS going into “Remission”](#) (10/18/2016)

Original Post: My sister read where PPS can go into remission. Is this true?

Dr. Bruno's Response: PPS is not a disease so there is no process to go into remission. PPS results from the overuse/abuse of the small number of remaining, polio-damaged neurons that have been taking the load for the neurons the poliovirus killed for decades. When polio survivors stop the overuse/abuse and conserve to preserve their neurons, symptoms either plateau or more commonly actually decrease. Please ask your sister to go to the post-polio library at postpolioinfo.com and read about the cause and treatment of PPS.

On the topic of having a "Good" Leg (10/20/2016)

Original Post: I'm feeling that my so-called "good" leg is not coping and might also need a brace. I've read that it takes 35 per cent more extra energy to move around on sticks and with braces. Do others have braced 'good' legs?

Additional Post: I have a knee brace on my "good" leg and it's the best thing ever for me.

Dr. Bruno's Response: Unfortunately there is no "good leg." You may have 80% of normal strength on a manual muscle test in your "good leg" and have it become weaker and more painful because it's:

- 1) Taking the load for your other leg and
- 2) Your "good leg" has only 60% of the neurons running the muscles that you were born with because the neurons were killed off by the poliovirus! At the Post-Polio Institute we found that the use of a light weight, composite brace to hold your "good" foot up and give you some push-off significantly reduces both weakness and pain and normalizes your gait.

On the topic of Posture as it relates to Overwhelming Fatigue (10/21/2016)

Original Post: I was wondering if most polio survivors have weak back muscles. My back muscles have tightened and contracted and become weak after so many years of imbalance. I have not been able to sit up straight for many years because the pain is unbearable in my back. I always need to sit back on a chair. Could these tight muscles and the inability to hold our backs straight be causing some of my overwhelming fatigue?

Dr. Bruno's Response: Tight muscles and the inability to hold backs straight with proper posture is tiring, but not the basic cause of overwhelming fatigue. Still every little bit hurts. Pain alone saps your energy.

There's a chapter on "painless posture" in the POLIO SURVIVORS HANDBOOK at

<http://postpolioinfo.com/handbook.php>

THE POLIO SURVIVORS HANDBOOK, given to all Post-Polio Institute patients, contains the research-based and time-tested protocol that has been found to successfully treat Post-Polio Sequelae. But this "home version" of the HANDBOOK has been rewritten to educate you, your local doctor and therapists so that you can receive the same customized treatment for PPS close to your home that you would receive at The Post-Polio Institute.

The HANDBOOK explains the causes of PPS symptoms: fatigue, muscle weakness, pain, sleep disorders, cold intolerance and heightened sensitivity to pain and anesthesia. Then, the HANDBOOK helps you to identify and avoid PPS symptom "triggers" and describes a combination of energy conservation, diet, assistive devices, stress and pain management -- BUT NOT EXERCISE -- that addresses both the physical and psychological aspects of PPS, helping you to substitute the old "Use it or Lose it" philosophy for a new "Conserve to Preserve" lifestyle that reduces fatigue, muscle weakness, pain and stress

On the topic of "Misinformation" about Vaccines (10/24/2016)

Dr. Bruno's Original Post: An important article ON WORLD POLIO DAY...

"...misinformation about vaccines has been linked to anti-vaccination viewpoints, contributing to reduced vaccination rates and outbreaks of previously controlled diseases. The lower (anxiety about transmissible

diseases) from the anti-vaccination comments may reflect a lack of understanding about the potential risks of the diseases that vaccinations prevent.”



High Profile Facebook Post Provides Insights Into Pro- And Anti-Vaccination Beliefs

Language analysis of responses to Mark Zuckerberg post reveals crucial data, reports the journal Vaccine

Released: 24-Oct-2016 5:05 AM EDT

NewsWise — Amsterdam, October 24, 2016 – One of the challenges to understanding the concerns behind vaccine hesitancy is that very seldom are people with worries about vaccines and vaccine advocates brought together in the same space, especially online. Both groups gravitate towards internet “echo chambers,” only communicating with other likeminded individuals. In January 2016, however, Facebook co-founder Mark Zuckerberg posted a photo of himself holding his baby daughter with the caption “Doctor’s visit – time for vaccines!” With his undeniable reach and the ability of anyone to comment, the post represented a unique opportunity to analyze the language used to express pro- vaccination and anti-vaccination viewpoints and understand how people on both sides of the debate perceive the risks of vaccination.

While the internet has revolutionized the dissemination of information, misinformation about vaccines has been linked to anti-vaccination viewpoints, contributing to reduced vaccination rates and outbreaks of previously controlled diseases. Many public health initiatives aimed at trying to reduce vaccine hesitancy have had poor results. In an attempt to better understand the discussion surrounding vaccines, researchers from the University of New South Wales (UNSW) and La Sierra University looked at the language people used in an open online forum on Facebook discussing vaccines. They found important clues that may help shape more effective pro-vaccination communications.

Researchers analyzed approximately 1,400 comments on the Zuckerberg post using the Linguistic Inquiry and Word Count (LIWC) text analysis program. The software sorts words into psychologically meaningful categories and then outputs a percentage of words belonging to each category. They found that while the anti-vaccine viewpoint is often seen as highly anxious about the issue, it was the pro-vaccination comments that expressed greater anxiety – especially around family and broader social processes (e.g. herd immunity). In contrast, the anti-vaccination comments were more logically structured, and tended to emphasize topics related to health and biology, as well as talking about research and science.

“This concerns us because the scientific evidence is very clear in demonstrating the safety and benefits of vaccines,” noted Kate Faasse, PhD, Lecturer, Health Psychology, UNSW, Sydney, Australia. “Because these skeptical comments appear on the surface to be quite logical and, because they focus on health, biology, and research, they may be particularly compelling for parents who are uncertain about what decision to make about childhood vaccination and are seeking more information.”

Other studies have shown the persuasive power of anti-vaccination websites and according to this new study, the lower use of anxiety words from the anti-vaccination comments may reflect a lack of understanding about the potential risks of the diseases that vaccinations prevent. “The findings from this research suggest that providing better information about how vaccinations work and how they improve health, as well as increasing public understanding of science and the scientific process, may be particularly important when encouraging vaccination,” added Leslie R. Martin, PhD, Department of Psychology, La Sierra University, Riverside, CA.

While vaccines are safe and effective for most of the population, there are people who cannot be vaccinated for legitimate health reasons, including very young children and the immunocompromised. These populations become vulnerable when large numbers of people opt-out of being vaccinated, because it decreases herd immunity. In 2014, the U.S. experienced a record number of measles cases; in developed countries a large proportion of these infections occur among the intentionally unvaccinated.

“Outbreaks of vaccine-preventable infectious diseases related to vaccine refusal are on the increase,” explained Dr. Faasse. “It’s important to find ways to better understand what people’s concerns are and why they make the decisions they do about vaccination – in particular, the decision not to vaccinate. Research using social media can give us a different perspective on the types of concerns that people have – and can help researchers and public health officials understand what sorts of information might be useful for addressing these concerns for people who are making decisions about vaccination.”

These data, gathered from responses to one high profile Facebook post, suggest that pro- and anti-vaccination viewpoints see the risks of vaccination in very different ways, and often seem to communicate at cross-purposes. Pro-vaccination comments expressed a lot of anxiety about the risks to families, and to society as a whole, of choosing not to vaccinate. In contrast, anti-vaccination comments talked much more about vaccination decisions in terms of biology, health, science, and research. Dr. Faasse concluded that this information is particularly useful because “greater insight about the specific worries people have about vaccination and decisions not to vaccinate can help us provide accurate information to better address these concerns.”

<http://www.newswise.com/articles/view/663340/?sc=mwhn>

On the topic of Dopamine being a “Wake up” for our Brain (10/26/2016)

Dr. Bruno’s Original Post: DOPAMINE: The Brain's Wakeup Call!

Researchers have found that turning on dopamine neurons (which are damaged by the poliovirus, damage that our research found underlies post-polio fatigue and the Brain Fatigue Generator) "produces a powerful arousal response" that actually can move an animal from an "unconscious, anesthetized state to an awake state."



Proceedings of the National Academy of Sciences of the United States of America

Optogenetic activation of dopamine neurons in the ventral tegmental area induces reanimation from general anesthesia

Contributed by Emery N. Brown, September 14, 2016

(sent for review February 29, 2016; reviewed by Loren M. Frank, Robert W. Gereau, and Andrew Jenkins)

Significance

Although dopamine is known to promote wakefulness, the specific dopamine circuits in the brain that regulate arousal are not clear. Here we report that selective optogenetic stimulation of ventral tegmental area (VTA) dopamine neurons in mice produces a powerful arousal response sufficient to restore conscious behaviors, including the righting reflex, during continuous, steady-state general anesthesia. Although previous studies found that VTA dopamine neurons do not appear to play a central role in regulating sleep–wake transitions, our findings demonstrate that selective stimulation of these neurons is sufficient to induce the transition from

an unconscious, anesthetized state to an awake state. These results suggest that VTA DA neurons play a critical role in promoting wakefulness.

Abstract

Dopamine (DA) promotes wakefulness, and DA transporter inhibitors such as dextroamphetamine and methylphenidate are effective for increasing arousal and inducing reanimation, or active emergence from general anesthesia. DA neurons in the ventral tegmental area (VTA) are involved in reward processing, motivation, emotion, reinforcement, and cognition, but their role in regulating wakefulness is less clear. The current study was performed to test the hypothesis that selective optogenetic activation of VTA DA neurons is sufficient to induce arousal from an unconscious, anesthetized state. Floxed-inverse (FLEX)-Channelrhodopsin2 (ChR2) expression was targeted to VTA DA neurons in DA transporter (DAT)-cre mice (ChR2+ group; n = 6). Optical VTA stimulation in ChR2+ mice during continuous, steady-state general anesthesia (CSSGA) with isoflurane produced behavioral and EEG evidence of arousal and restored the righting reflex in 6/6 mice. Pretreatment with the D1 receptor antagonist SCH-23390 before optical VTA stimulation inhibited the arousal responses and restoration of righting in 6/6 ChR2+ mice. In control DAT-cre mice, the VTA was targeted with a viral vector lacking the ChR2 gene (ChR2- group; n = 5). VTA optical stimulation in ChR2- mice did not restore righting or produce EEG changes during isoflurane CSSGA in 5/5 mice. These results provide compelling evidence that selective stimulation of VTA DA neurons is sufficient to induce the transition from an anesthetized, unconscious state to an awake state, suggesting critical involvement in behavioral arousal.

<http://www.pnas.org/content/early/2016/10/18/1614340113.abstract>

*This is a research link, and has been posted in our Reference Library:

<http://www.papolionetwork.org/research-articles.html>

On the topic of EMG being able to Diagnose PPS (10/27/2016)

Original Post: I understand an EMG does not diagnose PPS but is a test used to eliminate other potential problems, like ALS. However, according to two physiatrists I've seen, I do not have PPS based on my EMG results. I had "non-paralytic" polio as a child but was told my EMG did show old polio damage. I have suffered with worsening PPS symptoms since the late 90s. No one has an answer for my leg weakness and shrinkage or developing scoliosis and leaning to one side. I know I need a brace on my left ankle but who do I go now? I'm feeling totally cut off from any PPS care.

Dr. Bruno's Response: First, you're right: An EMG CAN NOT diagnose PPS! Many thought in the 1980s that EMG would be THE test for PPS. But not one EMG study could tell the difference between a newly weakened muscle and one that has always been strong.

What's more, at least 10% of EMGs are negative even in polio survivors who had obvious paralytic polio. An EMG finding of polio damage depends on how many motor neurons were killed, where and how many times the EMG needle is inserted in a muscle and the number of muscles tested.

But your EMG was positive for having had polio, meaning that you DID have motor neurons killed and certainly can develop PPS. So you have didn't have "non-paralytic" polio. You had "paralytic polio" (the EMG showing motor neurons indeed were killed) even if you didn't have obvious paralysis or even muscle weakness. As many as 40% of children diagnosed with "non-paralytic" polio had obvious muscle weakness on manual muscle testing.

We should discard the clinical descriptors of “non-paralytic” and “paralytic polio” and replace them with “non-neuropathic” (the poliovirus did NOT get into your brain or spinal cord) and “neuropathic” polio, where the poliovirus DID get into your neurons. (There is a long discussion about this in THE POLIO PARADOX.)
Bottom line: If everything else is ruled out and you have PPS symptoms, you should be treated for PPS. Find some competent doctors and get that brace!

On the topic of Restless Legs (10/30/2016)

Original Post: Does anyone else suffer from Restless legs Syndrome at night or when resting? Is the RLS more severe in polio survivors or are medications for RLS different for those who do not have PPS?

Dr. Bruno’s Response: Let me start with the confusion among polio survivors and doctors. Restless Legs Syndrome is the overwhelming urge to move your legs when you’re trying to sleep. RLS is often confused with Nocturnal Myoclonus (also called periodic leg movements in sleep, PLMS) where your muscles twitch and jump on their own when you're trying to sleep.

We have done three studies of sleep problems in polio survivors. In the 1985 National Post-Polio Survey, 63% of polio survivors reported that their muscles twitch and jump during sleep and half of those said that their sleep was disturbed by twitching.

In 1995 a group of our post-polio patients underwent sleep studies. Forty percent of the patients had periodic leg movements in sleep (PLMS), the common form of twitching where only leg muscles move. Almost 30% had what we dubbed Generalized Random Myoclonus (GRM), where not just the legs but muscles all over the body, including toes, arms, hands -- even face and chest muscles -- contract randomly throughout the body during the night. Almost 30% had PLMS as well as Restless Legs Syndrome (RLS).

But PLMS and GRM are sneaky. Sixty percent of the patients who had sleep studies didn't know that their muscles were twitching and jumping. This is the sneaky part, since patients also didn't know that twitching was responsible for them getting too little deep sleep or dream sleep and that their brains woke up repeatedly during the night, even though they thought they were sleeping “soundly.”

In 2001, we reviewed all the sleep studies ever performed on Post-Polio Institute patients. One-third were found to have abnormal muscle movements that disturbed their sleep. Nearly half had breathing abnormalities: Ten percent had central sleep apnea, where the diaphragm stops moving; fifteen percent had obstructive sleep apnea, where muscles in the back of the throat become relaxed during sleep, closing off the throat and physically preventing air from entering the lungs; and a whopping 60% had hypopneas, where air freely enters and exits the lungs, but oxygen in your blood decreases anyway because the diaphragm is not able to move enough air in and out. Hypopneas are the sneakiest of all sleep disorders because even if someone were looking, they couldn't tell that you weren't moving enough air in and out of your lungs, that your blood oxygen was dropping and that your brain was being awakened hundreds of times a night. Overall, the combination of twitching and breathing problems resulted in our patients losing 60% of their deep sleep and 20% of dream sleep. Is it any wonder that these folk felt fatigued during the day?

We have found that a very low dose of Xanax (alprazolam) taken 30 minutes before sleep stops muscle twitching and jumping. But breathing problems have to be treated before taking Xanax, since any muscle relaxant can impair breathing. Dopamine stimulating drugs should not be used to treat RLS since polio survivors’ brain awakening dopamine neurons were already damaged by the poliovirus.

The most effective treatment for apneas and hypopneas is variable positive airway pressure (PAP), where a bread-box sized machine blows air into the nose, mouth, or both during the night to prevent floppy throat muscles from closing off the air passage and inflates the lungs. A volume ventilator is THE device to treat hypopneas.

Bottom line: Any polio survivor who has muscle twitching while falling asleep or during the night, who snores, wakes in the middle of the night with anxiety, heart racing, choking, or shortness of breath, has headaches, isn't rested in the morning or has daytime fatigue should have a sleep study in a hospital or sleep clinic.

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