



## Bruno “Bytes” – September, 2016

(Bits and Tidbits from the Post-Polio Coffee House)

Available through a “link” from [www.postpolioinfo.com](http://www.postpolioinfo.com)

(or) directly through <http://www.papolionetwork.org/bruno-bytes.html>

### On the topic of Sleep Characteristics and PPS (9/1/2016)

Dr. Bruno’s Original Post: It’s always a relief when another lab confirms your findings.

From Brazil:

#### SLEEP CHARACTERISTICS IN POST-POLIO SYNDROME PATIENTS.

Revista Neurociências 19(1):18-25 December 2010

The objective of this search was examining the clinical features of Post-polio syndrome patients (PPS) through the analysis of polysomnographic recordings. For this we examined 60 polysomnographic exams of patients with PPS, which were carried out at the Sleep Institute during the year of 2008.

RESULTS. in this study, patients with PPS did not show a good sleep quality, which could be evidenced by the decrease in total sleep time, sleep efficiency, increase of the number of micro arousals, DECREASE in slow-wave (“refreshing”) sleep.

In addition, we observed a PERIODIC LEG MOVEMENTS index INCREASE as well as increase in APNEAS and HYPOPNEAS (shallow breathing where oxygen drops).

CONCLUSION. Sleep disorders are frequent in patients with PPS being principally represented by changes in sleep architecture, increase in APNEAS and HYPOPNEAS and PERIODIC LEG MOVEMENTS.

### On the topic of Muscle Loss and Bracing 9/2/2016)

Original Post: I am losing muscle in my “good” leg. I saw a polio doctor and he referred me to a rehab doc for exercise and bracing. Will a brace help anything? It won’t stop the muscle from deteriorating so will it be of any use?

Dr. Bruno’s Response: Bracing (managed by a PPS knowledgeable rehabilitative physician) could stop the muscle from deteriorating. Atrophy and muscle weakness are due to overusing the remaining, poliovirus-damaged, overworked motor neurons. Put them on rest with a brace and they will either get stronger or won’t get weaker. But NO exercises for strengthening or you’re overworking the neurons intentionally!

### On the topic of PPS and Dementia (9/8/2016)

Original Post: This question is for a man in his 80s who is experiencing rapid post-polio changes since his wife died a few months ago. He asked whether there is any evidence of a relationship between having had polio and increased risk of dementia. I know he is frightened. He has a lot of pain, increasing fatigue and weakness and the brain fog that we are all familiar with.

Dr. Bruno’s Response: Since stress is the second leading cause of PPS symptoms after physical overexertion, the stress of losing one’s wife may very likely be the culprit here.

Plus, not only is there no relationship between polio and dementia, one survey of college graduates with and without polio found that polio survivors are significantly less likely to develop dementia. Why? Because the locus on chromosome 19 that produces the poliovirus receptor can alternatively produce one of the proteins

that is thought to be related to Alzheimer's. So you can have a genome that produces the poliovirus receptor or the Alzheimer's protein. You can't have both.

Additional Post: I never put two and two together before this. My wife passed away three years ago. I worked 13 to 15 hours for 10 months afterward; being on my legs most of the time. I then retired and have since developed fatigue and leg weakness in my polio-afflicted leg. I never thought that the event of losing my best friend in the whole world could accelerate PPS. I know that stress is very bad.

Dr. Bruno's Additional Response: Stress isn't just "mental." Another reason to reduce fatigue and stress when we can: Word finding and attention lapses are symptoms of PPS.

### [On the topic of Post-Polio Syndrome and Risk Factors](#) (9/11/2016)

Dr. Bruno's Original Post: Findings in different countries may differ based on the year(s) poliovirus circulating and the type and length of treatment for polio...

#### POST-POLIO SYNDROME AND RISK FACTORS IN KOREAN POLIO SURVIVORS:



Ann Rehabil Med. 2014 October; 38(5): 637-647.

Published online 2014 October 30. doi: [10.5535/arm.2014.38.5.637](https://doi.org/10.5535/arm.2014.38.5.637)

#### A BASELINE SURVEY BY TELEPHONE INTERVIEW.

<http://europepmc.org/articles/PMC4221392>

### [On the topic of Medicare Denials when there is "Failure" to Improve](#) (9/13/2016)

Dr. Bruno's Original Post: Medicare must cover skilled care and therapy when they are "necessary to maintain the patient's current condition or prevent or slow further deterioration."

**"FAILURE TO IMPROVE" STILL WRONGLY USED TO DENY MEDICARE COVERAGE!**

By Paula Span, NY TIMES SEPT. 12, 2016

[http://www.nytimes.com/2016/09/13/health/medicare-coverage-denial-improvement.html?ref=todayspaper&\\_r=0](http://www.nytimes.com/2016/09/13/health/medicare-coverage-denial-improvement.html?ref=todayspaper&_r=0)

Edwina Kirby was having a hard time. She had tripped over a rug in her home in Livonia, Mich., and the fall broke a femur. After she had surgery and rehabilitation, an infection sent her back into the hospital. Her kidneys failed, requiring dialysis; she was also contending with diabetes and heart disease. By the time she entered Glacier Hills Care and Rehabilitation Center, a nursing facility in Ann Arbor, "she couldn't even feed or dress herself," said her daughter Deanna Kirby, 55. "She was basically bedridden."

For months, physical therapists worked with Mrs. Kirby, a retired civil servant who is now 75, trying to help her regain enough mobility to go home. Then her daughter received an email from one of the therapists saying, "Edwina has reached her highest practical level of independence."

Translation: Mrs. Kirby wouldn't receive Medicare coverage for further physical therapy or for the nursing home. If she wanted to stay and continue therapy, she'd have to pay the tab herself.

Medicare beneficiaries often hear such rationales for denying coverage of skilled nursing, home health care or outpatient therapy: They're not improving. They've "reached a plateau." They're "stable and chronic," or have achieved "maximum functional capacity." Deanna Kirby wasn't buying it. "I knew they couldn't refuse you, even if you're not improving," she said.

She's right. A federal judge last month ordered the federal Centers for Medicare and Medicaid Services to do a better job of informing health care providers and Medicare adjudicators that the so-called improvement standard was no longer in effect. What matters, as the 2013 settlement of a class-action lawsuit specified, is maintenance. Medicare must cover skilled care and therapy when they are "necessary to maintain the patient's current condition or prevent or slow further deterioration."

A bit of background: Because the Centers for Medicare and Medicaid Services doesn't publish statistics on why claims were denied, nobody knows how many millions of beneficiaries have been wrongly told that Medicare can't cover continued services because the patients failed to improve. But providers invoked the improvement standard so frequently that "one way or another, most people who had coverage denied were affected," said Gill Deford, litigation director of the Center for Medicare Advocacy, a nonprofit legal organization.

Though never part of Medicare regulations, the improvement standard was written into the C.M.S. manuals that providers and claims administrators relied on. "It was a policy they followed for 30 years," Mr. Deford said.

The lawsuit brought by the Center for Medicare Advocacy and Vermont Legal Aid in 2011 became known as the Jimmo case, after Glenda Jimmo, an elderly Vermont plaintiff. A settlement reached in 2013 required C.M.S. to rewrite its manuals and to begin an educational campaign to publicize the change. Advocates for older adults and people with disabilities cheered; a New York Times editorial praised the settlement as "clearly the humane thing to do."

Patricia Dudek, an elder law and disability law lawyer in suburban Detroit who represented the Kirbys in their appeal, started printing out relevant sections of the settlement agreement to show nursing home and home care administrators that the improvement standard was "an old wives' tale." Older patients with chronic and progressive diseases — dementia, Parkinson's, heart failure — are particularly vulnerable to that now-discredited criterion. They're unlikely to improve over time. Yet therapy might help them stave off decline and hold on to their ability to function a while longer. Edwina Kirby, for instance, used a wheelchair, but hoped to be able to walk the eight steps into her bathroom at home.

By early this year, however, the Center for Medicare Advocacy was hearing from many sources that despite the settlement, providers and the contractors reviewing Medicare claims were still denying coverage when beneficiaries didn't demonstrate improvement. "It's like saying, 'We've been holding you up, but now we're going to let you fall,'" said an exasperated Dr. Michael Wasserman, a California geriatrician and board member of the American Geriatrics Society's Health in Aging Foundation. "For a frail 95-year-old, not continuing therapy and letting her decline only leads to readmission to the hospital, readmission to skilled nursing."

The Centers for Medicare and Medicaid Services showed no inclination to take further steps, so the plaintiffs' lawyers went back to court, seeking enforcement of the agreement. The federal judge in Vermont who oversees the settlement ruled in August that C.M.S. didn't have to further revise its manuals, but did have to mount a better educational campaign.

By early next month, it has to explain how it plans to do that. A C.M.S. spokeswoman said the agency had reviewed the court's order, but would make no other comment.

Of course, patients and families have the same right to appeal coverage denials that they've always had. (A notice to this effect is buried somewhere in the paperwork they sign.) They also have the same odds of

prevailing they've always had: very low, said Judith Stein, the executive director of the Center for Medicare Advocacy.

Patients generally have 72 hours to appeal, a process that involves seeking a "redetermination" and then, if that fails, a "reconsideration." If families go all the way to a hearing before an administrative law judge, Ms. Stein said, they have a good shot.

But most families don't persevere, in part because they can't afford to pay for care while the appeal proceeds. (If they do spend their own money, though, they can appeal for reimbursement.)

"It's so frustrating that families are still going through this," said Ms. Dudek, the lawyer. "They told Deanna the most ridiculous things, all this inaccurate information."

The Kirbys won their appeal, but still didn't get the full number of days of skilled nursing care and therapy Edwina Kirby was entitled to, Ms. Dudek said. As a result, the Kirbys spent about \$100,000 out of pocket on the nursing facility and on at-home care afterward.

And despite her therapist's earlier prediction, Edwina Kirby did improve. She still uses a wheelchair in her ranch-style house, but she can stand and transfer to a chair or use the toilet. She can feed herself and wash the dishes.

She goes to a dialysis center three times a week and spends much of her time crocheting afghans and watching television. She especially cherishes shopping shows on QVC and reruns of "Everybody Loves Raymond."

Deanna Kirby, who lives next door, stays with her mother a few nights a week. But most of the time, Edwina Kirby is on her own, as she wants to be.



Edwina Kirby, right, with her daughter Deanna at home in Livonia, Mich. After a fall that broke Edwina's leg, the Kirbys spent about \$100,000 out of pocket on a nursing facility and on at-home care afterward.  
Laura McDermott for The New York Times

## On the topic of Polio Survivors Experiencing Disabilities long after Treatment for the Disease

<http://www.scidev.net/asia-pacific/disease/news/disabilities-polio-survivors-treatment.html>



9/26/2016 by Neena Bhandari

[SYDNEY] With polio now occurring in just two countries — Afghanistan and Pakistan — investments in medical aid and healthcare are now deemed urgent for polio survivors as they battle the onset of the post-polio syndrome (PPS) decades after first contracting the disease.

The first Australasia-Pacific Post-Polio Conference held in Sydney (20-22 September) discussed the treatment options focusing on neurological and biomechanical decline due to PPS in ageing polio survivors as well as the challenges of preventing and treating severe deformities in young polio survivors mostly in developing countries who will need help for years to come.

“Polio survivors still need support to maintain health and independence.”

Mary-ann Liethof, Polio Australia

PPS is a condition with new muscle weakness or general tiredness in persons with a confirmed history of acute paralytic polio, usually occurring several decades after the acute illness, reinforcing the need for a multi-disciplinary approach and more evidence-based research on alternative and complementary therapies.

“Polio survivors still need support to maintain health and independence,” Polio Australia’s national programme manager, Mary-ann Liethof, tells SciDev.Net.

A 2001 report by The March of Dimes, a non-profit agency founded by US President Franklin Roosevelt, a polio survivor, noted that up to 20 million polio survivors around the world face the threat of new disabilities 15 to 40 years after their original illness, which could leave them using wheelchairs or ventilators for the rest of their lives.

“Basic rehabilitation is very limited especially in developing countries. There is an urgent need for assessing polio survivors to maximize their functionality and prevent deformities from developing through adaptable technologies, bracing, physical therapy and addressing accessibility issues,” says Carol Vandenakker Albanese, physical medicine and rehabilitation professor at the University of California Davis Medical Center in the United States.

Rotary’s End Polio Now zone coordinator for Australia and New Zealand, Bob Aitken, tells SciDev.Net, “We have been conducting a network of workshops for educating young health professionals in long-term treatment of polio survivors. We hope this model can be replicated in developing countries.”

Adds Joan Headley, director of Post-Polio Health International based in St. Louis, Missouri, “The core knowledge about PPS within the medical profession in Australia can be very useful in educating and training people in Asia and South Pacific.”

A study in an Italian cohort of over 100 PPS patients and their family members, together with a number of polio survivors with “stable polio”, found that nearly three-quarters of PPS patients appear to harbour “poliovirus remnants” while survivors with stable polio rarely harbour poliovirus.



However, poliovirus remnants are not transmitted from PPS patients to family members, and do not appear to be dangerous to the population or represent a possible form of poliomyelitis resurrection, explains Antonio Toniolo, microbiology and virology professor at the University of Insubria Medical Centre Varese in Italy.

“The results suggest that chemical antiviral therapy, possibly in addition to immunotherapy, could be of help in clearing the virus from the body and in stopping chronic inflammation and further death of motor neurons and muscle cells,” Toniolo adds.



### Disabilities hound polio survivors long after treatment

Polio survivors contend with emergence of new disabilities decades after being treated for the disease.

SCIDEV.NET | BY PIXL 8

Dr. Bruno’s Response to this article: "Confirmed history of acute paralytic polio" I guess means that there was paralysis and no doubt about the diagnosis of acute polio. Since the number of polio survivors who actually had their spinal fluid or stool cultured for poliovirus is probably less than 1,000, the other 999,000 American polio survivors do not have "a confirmed history of acute paralytic polio" but do have "a confirmed CLINICAL history of acute paralytic polio."

However, not even the US Social Security Administration requires "a confirmed history of acute paralytic polio" to provide SSDI benefits, nor does Medicare require "a confirmed history of acute paralytic polio" to pay for PPS treatment. What is more, those having had "non-paralytic" polio (30%-40% of whom were misdiagnosed and did have acute muscle weakness) can and do have Post-Polio Sequelae and are eligible for SSDI and treatment via Medicare.

### On the topic of “Knee Jerk” Reflex (9/30/2016)

Original Post: Is it possible to have had polio and still have knee-jerk reflex. I have a friend who thinks she had polio as a child but the neurologist said that if she had polio she would not have any knee reflexes. Is this true?

Dr. Bruno’s Response: The less poliovirus-damage you had to motor neurons in the brain and more damage in the spinal cord, the less the "knee jerk" reflex, which is caused by hitting the tendon beneath the knee.

The tendon "hit" stimulates the spinal cord motor neurons that turn on the quadriceps (thigh muscle). If the stimulation is not stopped by brain motor neurons, the thigh muscle contracts. Without brain motor neurons saying "Don't move!" you get a BIG jerk. But without spinal cord motor neurons to turn on the thigh muscle, you will get no kick at all, even if you have NO brain motor neurons.

So the amount of kick is caused by a combination of having fewer poliovirus-damaged brain motor neurons and having more spinal cord thigh muscle motor neurons. That means some polio survivors with lots of brain motor neuron damage and little thigh muscle motor neuron damage have a normal or even too BIG a kick, not no kick at all!  
You polio survivors are complicated!

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

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