

**POLIO PERSPECTIVE**  
**AUGUST 2016**

*Millie Malone Lill, Editor*

*Wilma J. Hood, Publisher*

**IN THIS ISSUE**

**Abnormal movements in sleep as a Post-Polio Sequelae (CME article)**

*By Dr. Richard L. Bruno*

**I Go The Distance**

*a poem by Glenda Crawford*

**Of Frozen Fingers and Polio Feet**

*by Dr. Richard L. Bruno*

**Don't Say That!**

*By Millie Malone Lill*

**Web Corner**

**Other Polio Newsletters**

**A Little Bit of Humor**

**Abnormal movements in sleep as a Post-Polio Sequelae (CME article).**

*FROM*

*The Post-Polio Institute*

*and*

*The International Centre for Post-Polio Education and Research*

*postpolioinfo@aol.com*

*American Journal of Physical Medicine and Rehabilitation ,*

*1998; 77: 1-6.*

***Dr. Richard L. Bruno***

## ABSTRACT

Nearly two-thirds of polio survivors report abnormal movements in sleep (AMS), with 52% reporting that their sleep is disturbed by AMS. Sleep studies were performed in seven polio survivors to objectively document AMS. Two patients demonstrated Generalized Random Myoclonus (GRM), brief contractions and even ballistic movements of the arms and legs, slow repeated grasping movements of the hands, slow flexion of the arms and contraction of the shoulder and pectoral muscles. Two other patients demonstrated Periodic Movements in Sleep (PMS) with muscle contractions and ballistic movements of the legs, two had PMS plus Restless Leg Syndrome (RLS) and one had sleep starts involving only contraction of the arm muscles. AMS occurred in Stage II sleep in all patients, in Stage I in some, and could significantly disturb sleep architecture even though patients were totally unaware of muscle contractions. Poliovirus-induced damage to the spinal cord and brain is presented as a possible cause of AMS. The diagnosis of post-polio fatigue, evaluation AMS and management of AMS using benzodiazepines or dopaminergic agents is described.

## INTRODUCTION

Despite numerous late-onset symptoms reported by polio survivors --fatigue, muscle weakness, pain, cold intolerance, swallowing and breathing difficulties -- one symptom was totally unexpected: abnormal movements in sleep (AMS). As early as 1984 our post-polio patients were reporting muscle contractions as they fell asleep. The 1985 National Post Polio Survey included two questions about AMS: "Do your muscles twitch or jump as you fall asleep" and "Is your sleep disturbed by muscle twitching?" It was surprising that 63% of the 676 respondents reported that their muscles did twitch and jump during sleep and that 52% -- a third of the entire sample --said that their sleep was disturbed by twitching.

These percentages are markedly elevated as compared to the incidence of AMS in the general population. In one survey only 29% of those without neurological disease who were at least 50 years old reported AMS, versus 63% of surveyed polio survivors who were 52 years old on average. In another survey only 34% of those older than 64 reported AMS, slightly more than half the incidence of AMS in the younger post-polio sample. Given the apparent increased prevalence of AMS in polio survivors, and with daytime fatigue the most commonly reported Post-Polio Sequelae (PPS), we were interested in objectively documenting AMS, relating them to possible disturbances in sleep architecture and identifying an effective treatment for AMS.

## METHODS

**Subjects.** Seven polio survivors were referred for sleep studies to a sleep disorders center. This was a sample of convenience, in that the subjects were patients presenting with PPS who themselves knew (three patients) or whose bed mates knew (four patients) that AMS were occurring. Patients were on average 54 years old and 44 years post acute polio which occurred at age 10. The patients had had AMS for a mean of eight years which was on average 35 years post acute polio. Patients reported moderate-to-severe difficulty sleeping at night and moderate-to-severe daytime fatigue that did not respond to the treatments of choice for post-polio fatigue (i.e., pacing of activities, daytime rest periods, energy conservation and use of appropriate assistive devices). In addition to fatigue, patients reported an average of two limbs having late-onset muscle weakness.

### Procedure.

Patients underwent a standard polysomnographic evaluation with EEG and facial EMG recorded for sleep staging. Blood oxygen saturation, measured using a finger pulse oxymeter, chest and abdominal wall excursion and nasal air temperature were also recorded; video monitoring of sleep was also performed. Surface EMG was recorded from patients' legs as well as from limbs in which AMS were reported.

## RESULTS

Four types of AMS were seen: Two patients presented with what has been called Generalized Random Myoclonus (GRM) (1,6), two patients had Periodic Movements in Sleep (PMS), two had PMS plus Restless Leg Syndrome (RLS) and one had Sleep Starts (also called "hypnagogic massive myoclonic jerks"). Generalized Random Myoclonus. GRM was seen in two patients. One had had bulbar polio with little or no arm or leg involvement acutely, while the other has been diplegic since polio but had no bulbar or respiratory symptoms acutely. These patients had random contractions of muscles throughout their bodies. One had such violent

contractions of the trunk muscles that she was pulled into the fetal position during the night. This patient had been very aware of GRM for about 10 years.

However, the other patient had been completely unaware of GRM until they were noticed by her husband. Random, rapid muscle contractions were noted in all four limbs, jaw and pectoral muscles, in addition to slow repeated grasping movements of the hands, slow flexion of the arms and movement of the shoulders. The presence of bilateral toe flexion was notable since the patient's right leg has always been totally paralyzed except for a minimal ability to flex her toes; the toes of her right foot contracted numerous times during the night.

In both patients, GRM occurred during Stage II sleep; the latter patient also had GRM in Stage I. The patient with violent trunk flexion had muscle contractions, causing a severe disturbance of sleep architecture, only during the first third of the night. She also had a few episodes of obstructive apnea that were not related to the muscle contractions but did disturb her sleep. She was prescribed clonazepam, 0.5 mg B.I.D., which eliminated her GRM.

The other patient had GRM throughout the night but had no disturbance of sleep architecture and was not treated pharmacologically. Periodic Movements in Sleep. Two patients demonstrated PMS with contractions only of the leg muscles of which neither patient was aware. Both had limb and respiratory involvement with the acute polio and had PMS during Stage II sleep with one patient also having muscle contractions during Stage I. The former patient had nearly continuous EMG activity in his legs throughout the night and had a severe disturbance of sleep architecture. He also had some central episodes of apnea early in the night as he was falling asleep that did not disturb his sleep. The latter patient had PMS occurring only during the first half of the night which caused no disturbance of sleep architecture. However, he had frequent hypopneas which did severely disturb his sleep. Both patients were prescribed lorazepam, 1.0 mg H.S., which eliminated the PMS.

#### PMS plus Restless Leg Syndrome.

Two patients had PMS plus Restless Legs Syndrome. RLS is characterized by the subjective feeling that the legs must be moved. This feeling increases during the evening, often preventing sleep onset because patients feel as if they must get up and walk. The patients with PMS plus RLS had been very little affected by the acute polio, one having no polio residual and the other having one leg weakened. PMS were seen in both legs and occurred during Stage II in both patients and during Stage I in one patient. One patient's leg muscle contractions were so violent that she was propelled one to two inches off the surface of the bed. Although her PMS occurred only during the first half of the night, her sleep was severely disturbed and she was very aware that she had had PMS for about 5 years. She was prescribed L-dopa/carbidopa (Sinemet) 200/50 mg, 1/2 tablet B.I.D., and clonazepam, 0.5 mg H.S. and at 3 A.M., which reduced the RLS and PMS by about 80% and allowed her to have a restful night's sleep.

The other patient did not know he had PMS which were continuous throughout the night and did moderately disturb his sleep architecture. He was prescribed L-dopa/carbidopa, 200/50 mg H.S., which eliminated his RLS and PMS.

#### Sleep Start.

One patient was diagnosed as having a Sleep Start, her arms ballistically abducting as she began to fall asleep. She was very mildly affected by the acute polio and had no AMS in the legs, even in the leg in which she reported new muscle weakness. The patient's sleep was markedly disturbed since her arms would move as she started to fall asleep and prevent sleep onset. She was prescribed alprazolam, 0.125

mg H.S., which eliminated her AMS.

## DISCUSSION

Sleep studies in this sampling of post-polio patients objectively documented three different types of AMS. Whether other types or combinations of AMS occur in polio survivors cannot be determined from this study, nor can this study or the 1985 National Post-Polio Survey state the actual incidence of AMS in polio survivors, since neither sample was random or population-based. However, the objective documentation of AMS in these post-polio patients, and the Post-Polio Survey finding that 63% of polio survivors reported muscle "twitching or jumping" as they fell asleep, suggest that AMS may in some way be related to the pathophysiology of the original poliovirus infection.

In 1964, Loeb coined the phrase "hypnic myoclonus" to describe muscle contractions during sleep onset in healthy individuals without neurological disease. (7) Loeb described the contractions as rapid (less 0.5 seconds long), arrhythmic (occurring without a pattern) and causing a variety of movements - finger flexion, thumb adduction, forearm and foot flexion and extension, shoulder elevation and facial twitching during Stages I and II sleep - identical to those seen in the post-polio patients. However, in contrast to the post-polio patients, none of Loeb's subjects demonstrated contractions in more than one muscle group and in none was sleep disturbed by hypnic myoclonus.

Loeb thought that hypnic myoclonus resulted from an abnormality at the level of the brain stem reticular formation causing decreased descending inhibition of anterior horn motor neurons during sleep. Martinelli thought PMS also resulted from an increase in anterior horn cell excitability, with Walters (9) finding that PMS decreased with the administration of an opiate receptor agonist.

Loeb and Askenasy suggested that AMS were also related to abnormal discharges from the thalamus, cerebellum and basal ganglia. The implication of the basal ganglia in the generation of AMS is interesting since PMS are common in patients with Parkinson's disease, whose decreased dopamine production impairs basal ganglia functioning, in patients with narcolepsy, who have an increased number and sensitivity of dopamine receptors in the basal ganglia, and have been found to decrease with the administration of dopamine receptor agonists.

AMS, Polioencephalitis and Poliomyelitis.

All of the CNS regions implicated in the pathogenesis of AMS are known to have been lesioned by the poliovirus. The anterior horn motor neurons, cerebellar nuclei and reticular formation were frequently and severely damaged by the poliovirus. The periaquiductal gray, paraventricular hypothalamus and lamina II dorsal horn neurons were all lesioned by the poliovirus (cf. 9;13); damage to these opioid peptide-secreting neurons may be evidenced not only by AMS but also by polio survivor's doubled sensitivity to pain. Finally, the thalamus and basal ganglia (the substantia nigra, putamen and globus pallidus) were also damaged by the poliovirus, damage that has been implicated in the pathogenesis of post-polio fatigue. Given the distribution and extent of poliovirus lesions in all of the CNS areas implicated in the pathogenesis of AMS, we should not have been surprised in 1985 that a majority of polio survivors reported muscles that twitch and jump during sleep.

Clinical Implications.

PPS remains a diagnosis of exclusion. All possible causes for new symptoms in polio survivors, especially causes for late-onset fatigue, must be ruled out before the diagnosis of PPS is made. Therefore, it is important to rule out a sleep disorder as a cause of late-onset fatigue. Clinicians need to take a thorough sleep history from their post-polio patients, asking not only about symptoms of sleep

apnea, which occurs frequently in polio survivors, but also about AMS. The patient's bed partner must also be asked about AMS since the majority of polio survivors will not know that they have AMS.

Patients are referred for a sleep study if sleep apnea or AMS is suspected. The lowest dose of a short acting benzodiazepine will be prescribed before sleep by the Post-Polio Institute physiatrist if a patient has AMS, since these medications seem to virtually eliminate GRM and PMS in our post-polio patients. Treatment of sleep apnea is deferred to the sleep disorders center as is treatment for RLS, since a dopamimetic agent in combination with a benzodiazepine may be required. However, there is a caveat to prescribing dopamimetics for polio survivors. One of our PPS patients developed vasovagal syncope with cardiac asystole during the administration of a dopamine receptor agonist. We consider a history of vasovagal syncope or unexplained faints a contraindication to prescribing dopamimetics for polio survivors with AMS or RLS.

## **I GO THE DISTANCE**

**Written by Glenda Crawford**

*I want to run so fast I feel the wind tug against my face.  
I want to go the distance, I want to keep the pace.  
Like a marathon runner I am driven to win,  
I push and I try with all my strength and then.  
Suddenly limp and weak I hit that wall.  
Barely able to move; not able to finish at all.  
I yell and I scream why does my body do me this way?  
Why does it refuse to cooperate and obey.  
My body responds and I am shocked at what I hear.  
I go the distance you abuse me, my dear.  
You push me beyond what I am able to do.  
You refuse to listen when I talk to you.  
Polio attacked us and left us weak and paralyzed.  
When do you accept. When do you realize.  
A block for me is another's mile.  
I go the distance. I go my mile.*

## **“Of Frozen Fingers and Polio Feet”**

*A warming winter tale for everyone who hates the cold.*

*By Dr. Richard L. Bruno*

*Chairperson International Post*

*Polio Task Force*

*And*

*International Centre for Polio Education*

*Postpolioinfo.com*

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, polio

survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report intolerance to cold and that their limbs have become more sensitive to pain as the temperature decreases. Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%.

When polio survivors were cooled in our laboratory from 86° F to 68° F, motor nerves functioned as if they were at 5° F and polio survivors lost 75% of their hand muscle strength. Although polio survivors were twice as sensitive to pain as those without polio at room temperature, no increase in pain sensitivity was found at lower temperatures.

The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the automatic computer that controls the inner bodily environment) was damaged by the poliovirus, including the body's thermostat and the brain area that tells your blood vessels to constrict. In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it's cold were also by the poliovirus. Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow passively as they get cold; trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult. As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength.

However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop (see Bruno, 1996). The pooling of blood in the feet also explains why polio survivors' feet swell, swelling that increases as they get older. And polio survivors' easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change. Polio survivors need to dress as if it were 20° F colder than the outside temperature. The trick is to stay warm from the get-go. You need to dress in layers and wear heat-retaining socks or undergarments made of a woven, thin, breathable plastic fiber called polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm in the morning. Then put on warm socks, even electric socks with battery-powered heaters. Also, try to keep your feet elevated during the day.

For your hands, Valu-tek ([www.cleanroomconsumables.com](http://www.cleanroomconsumables.com)) makes lightweight gloves that are designed for dexterity indoors. We tested three gloves in polio survivors whose hands are cold inside the home. The nylon "Glove Liner" (VTGNLR-1/1) and the "Conductive Glove" (VTGCONKT), which is made of polyester knit, have full-length fingers. Of the two, the polyester knit is warmer, but somewhat thicker. There is also a nylon glove liner" (VTGNLR-1/2) that has half-fingers that allow more dexterity, but isn't as warm. Polio survivors found that the gloves keep hands warm and allowed them to use their fingers, to read, to eat and even to knit, but they liked the nylon "Glove Liner" with full fingers best. The gloves come by the dozen, so you can launder them and have some to wear. The gloves liners and conductive gloves are rather expensive, but worth it. Since these are disability-related products, they should be tax deductible. If you still can't stay warm, you can talk to your doctor about taking the anti-hypertension drug Minipress that open your arteries and get more hot blood to your feet.

However, these drugs can open arteries too much and cause you to lose heat from your uncovered skin and drop your blood pressure when you stand. These are drugs of last resort to be used very carefully!

Polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75° F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery

## **Don't Say That!** *By Millie Malone Lill*

Not that I'm the sensitive type, not really. I realize that people don't intend to be rude, as a rule, it's just hard to know what to say when they meet someone who is disabled. I believe they actually mean to be kind, supportive, or maybe funny. It's not their fault that they fail so miserably in the attempt. Still...my friends and I get very tired of hearing things like

1. "Oh, you look so good! You surely don't need that wheelchair!" (Ummm, yes, I do need my wheelchair and I need it even when I am dressed up for a special occasion and "look good.")"
2. (When I can't get my chair into a store or there are no electric scooters available) "It's so wonderful to see you walking! I'm so glad you don't need that awful chair anymore." (Yeah, I'll be paying for this big time tomorrow, but you won't be there to see it.)
3. "Once you get into a wheelchair, you won't want to ever get out because everything is so much easier from a chair." (Really? Have you tried to cook a meal, do the laundry, pick up after your dog from a wheelchair? Didn't think so. Going from point A to point B is easier with the chair, but that's pretty much it.)
4. "Why would you want to use a wheelchair when you can still walk?" (Because, weird as it sounds, the more I use my chair, the less I *have* to use it.)
5. "I've seen you walk. You do not need that chair!" (Hey, you are not my doctor, you don't know what my diagnosis is. I have actually used a device to measure how many steps I can take without pain...1000...and anything over that number means I may not be able to walk at all the next day.)
6. "And what will she have?" by a waitress, speaking to my non disabled friend . (I am unable to walk, but my hearing and speech are just fine thankyouverymuch. I will do my own ordering.)
7. "Will she pee on the floor?" Also spoken by a wait person, to a friend who accompanied a disabled woman in a wheelchair to the restaurant. (I do not randomly pee on things. I am an adult, and if I did have an incontinent problem which I do not, I would wear Depends in order to prevent such .)
8. "What did you do to yourself?" (Well, I was four years old and I thought, You know, I'm kinda bored. I know, I'll go get polio!")
9. "If you'd just lose X number of pounds, you wouldn't need that wheelchair!" (Loss of weight does not cure PPS. I know people who have lost huge amounts of weight and they still have PPS. )
10. "You should exercise more, that would get you out of that chair." (Yes, it actually might. If I exercised till I burned out the rest of my pitifully small store of motor neurons, I could go right into a bed at a nursing home, but tempting as that sounds, no.)

As I said before, it can be awkward talking to a disabled friend, but it really doesn't have to be. Just talk to him/her the way you would talk to any of your other friends. And if the disabled person is a

stranger, well, I'm pretty sure your Momma did not raise you to be rude to strangers. Mine sure didn't.

## Web Corner

Five things to do at Capilano Suspension Bridge Park, besides cross the bridge

<http://www.insidevancouver.ca/2016/08/18/5-things-to-do-at-capilano-suspension-bridge-park-besides-cross-the-bridg>

Centers for Independent Living

<http://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

A New Drug for Osteoporosis.

<http://www.nytimes.com/2016/08/17/health/osteoporosis-a-disease-with-few-treatment-options-may-soon-have-one-more.html?ref=todayspaper>

Order groceries online for same day pickup. Put in your zip code to see if it's available in your area

<http://grocery.walmart.com/usd-estore/m/home/anonymouslanding.jsp?adid=1500000000000039633760&veh=soc>

Another interesting radio interview

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

Bathroom remodeling tips for Aging in Place.

<http://www.stretcher.com/stories/16/16aug08a.cfm>

Pain in persons with PPS.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2651567/>

Respect Ability

<http://respectabilityusa.com/take-action/>

Polio Revisited, a 50 minute video on one man's experience

<https://vimeo.com/66577988>

Dutch Pragmatism at it's best

<https://www.facebook.com/lovetheNetherlandsforever/videos/1124188397640491/>

## Other Polio Newsletters

<http://www.papolionetwork.org/post-polio-health-international-monthly-posts.html>

[www.post-polio.org](http://www.post-polio.org)

[www.polio-place.org](http://www.polio-place.org)

## A Little Bit of Humor

A mechanic was removing a cylinder head from the motor of a Harley motorcycle when he spotted a well-known heart surgeon in his shop.

The surgeon was there, waiting for the service manager to come and take a look at his bike.

The mechanic shouted across the garage, "Hey, Doc, can I ask you a question?"

The surgeon a bit surprised, walked over to the mechanic working on the motorcycle.

The mechanic straightened up, wiped his hands on a rag and asked, "So Doc, look at this engine. I open its heart, take the valves out, fix 'em, put 'em back in, and when I finish, it works just like new. So how come I get such a small salary and you get the really big bucks, when you and I are doing basically the same work?"

The surgeon paused, smiled and leaned over, and whispered to the mechanic, "Try doing it with the engine running."