

**The Polio Perspective**  
**December, 2012**  
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# **P O S T – P O L I O 1 0 1**

## **WHAT YOU NEED TO KNOW**

### **1. DID YOU HAVE POLIO?**

- Spinal tap?
- Unexplained fever?
- Flu like symptoms?
- Paralysis?
- Severe neck pain and/or headache?
- A disease that severely affected the nervous and muscular systems?

### **2. WHAT IS POST-POLIO SYNDROME?**

#### **(PPS) (late effects of polio)**

##### **TRUTHS:**

- A secondary condition to having had polio
- New symptoms approximately 10-40 years after recovery from polio
- Not everyone who had polio develops PPS
- Other conditions have been ruled out including normal aging

##### **MYTHS:**

- It doesn't exist
- The virus has returned
- You can't do anything about it
- Everyone gets the same symptoms
- PPS is life threatening
- All polio survivors have atrophied limbs

### **3. WHAT CAUSES POST-POLIO SYNDROME? (PPS)**

- Decades of "overuse and abuse" of the body
- Polio damaged the nervous system, including the brain

- Motor neurons, that move muscles, weakened by polio are beginning to fail
- Triggered by a trauma (surgery, accident, immobilization, death of a loved one, etc.)

#### **4. WHAT ARE SOME OF THE SYMPTOMS/SIGNS OF PPS?**

- Unaccustomed fatigue – either rapid muscle tiring or feeling of total body exhaustion
- New weakness in muscles – both those originally affected and those unaffected by the virus
- Pain/burning sensations in muscle and/or joints
- Breathing difficulties and/or sleep problems
- Swallowing problems
- Functional decline
- Depression and/or anxiety
- Weakness and muscle atrophy
- Muscle spasms, twitching and tingling
- Nerve compression problems, (carpal tunnel, tendonitis, etc.)

#### **5. WHAT CAN BE DONE?**

To **PREVENT** new symptoms from occurring

- Awareness of type “A” behavior
- Plan frequent rest periods
- Pace daily activities
- Limit exposure to cold
- Increase protein and decrease added sugars in diet.
- Gentle exercise program as prescribed by a professional familiar with PPS

To **PRESERVE** remaining strength

- Conserve energy, “Conserve to Preserve”
- Stop overusing and abusing
- Be active, but STOP short of fatigue and pain
- Use assistive devices (braces, canes, wheelchairs etc.)
- Use quality nutritional supplements as advised by a nutritionist
- Control your weight
- Maintain a positive attitude
- Join a post-polio support group

#### **6. WHAT ABOUT BREATHING PROBLEMS?**

Polio survivors may experience new breathing problems; the acute polio affected breathing muscles, such as the diaphragm and rib muscles, not the lungs.

##### **SYMPTOMS:**

- The need to sleep sitting up
- Insomnia
- Morning headaches
- Excessive daytime fatigue/sleepiness
- Night sweats, interrupted sleep and/or bad dreams
- Unproductive cough and increase in respiratory infections

##### **APPROPRIATE ACTIONS:**

- See your Healthcare provider and/or a pulmonologist

for pulmonary function test.

- Appropriate treatment may be assisted ventilation;
- Be wary of oxygen therapy if your lungs are not damaged
- A Tracheostomy may be appropriate in a limited number of cases.
- Possible need for sleep study

## **7. WHAT TO DO WHEN SURGERY IS REQUIRED.**

- Talk to your healthcare provider about the planned procedure and post-polio concerns
- Set up a consultation with the anesthesiologist during the pre-admission process about concerns with postpolio and curare types of anesthesia
- Review your previous medication reactions with surgeon
- Assess with Healthcare provider your need for inpatient vs. out-patient surgery:
- Body positioning during procedure

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- Cold intolerance
- Additional post-operative recovery time may be required
- Additional anesthesia and/or pain medicine may be required
- Assess level of fatigue to determine your ability to tolerate out-patient or in-patient procedures

## **8. WHAT TO DO ABOUT PAIN?**

### **Tips that have worked**

- Use moist heat and/or ice packs to the painful area
- Get light massages
- Try warm water therapy
- Get tested for sleeping and/or breathing problems

Use assistive and adaptive aids, as necessary to reduce stress to muscles and joints

- Check into need for anti-depressant prescription drugs
- Use pain medication as prescribed by your Healthcare provider (ibuprofen, Celebrex, Vicodin, Percocet, Oxycontin, etc.)
- Try alternative type treatments (acupuncture, yoga, myofascial release, Reiki, Watsu, etc.)

## **9. WHAT ABOUT MEDICATION?**

It is your responsibility to know all your prescriptions, over-the-counter (OTC) drugs, and supplements. Inform your health care provider with:

- Name
- Purpose
- Dosage
- Interaction with other medications
- Side effects and risks
- Previous medication reactions
- Change your lifestyle before turning to pain medications

- Avoid stimulants that cause increased fatigue

## **10. HOW IS PPS DIAGNOSED?**

Having a Healthcare provider exclude all other possible causes for new symptoms, (normal aging, ALS, MS, MD, Guillain-Barre, etc.)

## **11. HOW TO COMMUNICATE WITH YOUR HEALTHCARE PROVIDER?**

**BEFORE** you visit your Healthcare provider

- Keep a journal of progression of symptoms, making simple entries concerning:

- Daily living
- Physical
- Emotional
- Time of day most affected
- Positive and negative changes
- Note current symptoms, (tiredness, fatigue, exhaustion, etc.)

- From journal, make a list of questions and concerns to present to your Healthcare provider

**DURING** the visit with your Healthcare Provider

- Describe all current symptoms and when/how they have changed over time
- Be specific about what you need
- Avoid giving “Yes” and “No” answers
- Describe HOW: (i.e. much, long, in what way). (“I can climb 3 steps in 5 minutes with assistance.”)
- Clarify what you hear by asking, “Did you say...?”
- Bring written post-polio information
- Build a relationship with your Healthcare provider
- REMEMBER, some symptoms are not PPS related, (normal aging, heart disease, diabetes, etc.)

**AFTER** your Health care provider’s visit

- Request copies of all reports and test results
- Call if you have further questions

## **12. DID YOU KNOW?**

- People still get polio
- There are Post-polio Clinics and support groups all over the world: many resources are available
- Rotary International goals are to:
  1. Eradicate polio worldwide
  2. Develop programs to assist polio survivors
- Polio survivors are likely to develop post-polio symptoms
- “No Pain – No Gain” DOES NOT apply to postpolio syndrome

## **13. WHERE DO YOU FIND MORE INFORMATION?**

- Polio Epic, Inc.

P.O. Box 17556

Tucson, AZ 85731-7556

(520) 750-8608 (message)

[www.polioepic.org](http://www.polioepic.org)

- Polio Echo, Inc.

P.O. BOX 61024

Phoenix, AZ 85082-1024

(480) 545-1147 [w](http://www.polioecho.org)

[www.polioecho.org](http://www.polioecho.org)

**Post-polio Health International** (PHI) including

International Ventilator Users Network

St. Louis, MO

(314) 534-0475

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

**TAKE CHARGE OF YOUR MEDICAL CARE. YOU KNOW YOUR OWN BODY  
BEST!**

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

**By 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), 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 (Figure 1). 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 nights 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. 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; 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.

**From:**

**The Post-Polio Institute  
and**

**The International Centre for Post-Polio Education and Research  
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**American Journal of Physical Medicine and Rehabilitation, 1998; 77: 1-6.**

## The Web Corner

If you're of a certain vintage, you might remember a certain TV show called 'That's Incredible'. It was a hit in the early 80's, featuring people doing - you guessed it - incredible things.

Arguably, the most incredible thing was John Davidson's hair, which is equally remarkable these days, but we digress.

A British woman named Sue Austin has come up with something that's incredible - an underwater wheelchair. Austin has been in a wheelchair for more than 15 years. About 7 years ago, she decided she'd like to try scuba diving.

Well, with the help of diving experts and academics, she's developed a wheelchair that she can operate underwater.

<http://www.cbc.ca/strombo/technology-1/into-the-deep-british-woman-explores-the-oceans-depths-in-her-underwater-wheelchair.html>

A good article on physical therapy is within this website for this newsletter. <http://postpolio.wordpress.com/> Click on Newsletter. "How to Have A Successful Physical Therapy Experience" by Leslie Drawdy, PT & Polio Epic Medical Advisory Board. From Second Time Around Newsletter, October, 2012. Boca Area Post-Polio Group, Boca Raton, FL.

Do you really know how to exercise your body now, years after having had polio? Don't just do it on your own. Check out what Kat Wollam, physical therapist specializing in PPS has to say about it Monday 10/29 8PM ET. [www.wq4d.com](http://www.wq4d.com) Don't worry if you miss it. Just listen when you wish anytime after the show airs. All you need is an internet connection and click on the episode.

**Got Ramps? The Architectural Barriers Game:**

<http://postpolioproblemadediscapacidad.blogspot.mx/2012/10/this-activity-illustrates-changes-in.html>

**First Randomised Controlled Trial to show spinal cord regeneration in dogs**

<http://www.mrc.ac.uk/Newspublications/News/MRC008928>

Sharlene Taylor has started an online support group for people going through ailments, conditions and diseases which cause them daily pain. She has started a Facebook page (see below) and is interested in having anyone who may be in the same situation to help share their stories in a book. Check it out....

<https://www.facebook.com/YouAreNotAloneInThis>

**An article about Hand Controls:**

<http://mobilityexpress.com/handcontrols.htm>

Please take the time to read Christine Miserandino's personal story and analogy of what it is like to live with sickness or disability. The Spoon Theory:

[www.butyou dontlooksick.com](http://www.butyou dontlooksick.com)

## AN ATTITUDE OF GRATITUDE

*By Millie Malone Lill*

At this time of year, we are all counting our blessings. I thought it would be appropriate to list some of mine. So here they are, my Top Ten list of things for which I am grateful.

10. I'm grateful that I had polio. Well, think about it...I wouldn't have had a 20+ year run writing for a polio newsletter otherwise, would I?
9. I'm grateful for alcohol and the lack of penicillin. If my grandfather hadn't stopped for a couple of brewskis on his way to the ship with my grandmother, my favorite aunt and a bunch of other family members, they would not have missed the ship they'd bought passage to America on. That ship sank. And had there been penicillin, my dad's first wife would not have succumbed to pneumonia and Dad would never have married Mom and I would not exist!
8. I'm grateful that I lived too far from medical services to have been a lab rat for some of the experimental surgeries that many of my polio pals had.
7. I'm grateful that none of my family and very few of my friends are 'normal.' How boring that would be!
6. I'm grateful my 11 lb. dog Fiona is not the Giant Great Dane she thinks she is. That would be so wrong on so many levels, not the least of which would be the fact she likes to share my recliner with me. Or, rather, she insists I share with her.
5. I'm grateful that I married too young, had my kids too close together and became a young grandmother and great grandmother. I enjoyed my kids, had energy to play with my grandkids before PPS smacked me upside my head, and now I have grown up grandkids that can carry on adult conversations. Plus I can spoil an entire new generation.
4. I'm grateful that old age is not what it used to be. At 71, I'm still active socially, am not in a nursing home, and have realized the two big benefits of old age: If I don't want to, no one can make me. And, if I do want to, no one can stop me.
3. I'm grateful that spiders can't fly. I can't emphasize this enough. It's bad enough that they exist.
2. I'm grateful that wrinkles don't hurt. Not only would I be in lots more pain, but I'd be headed inevitably for more every year! FYI, Aleve has no effect on wrinkles.
1. I'm grateful most of all for being a part of the Wonderful World of Polio Survivors. It's quite a ride, thrills and chills galore, but the company can't be beat.

## **A Little Bit of Humor**

### **No Panhandlers!**

A panhandler was caught trying to sneak aboard a Princess liner about to embark on a three-day trip to the Bahamas. He was caught by the Purser who threw him off the ship telling him..."Beggars can't be cruisers."

#### Thinking Quickly

One evening, a college professor had some idle time on his hands. All the papers had been graded, the next week's lectures prepared, and it was still 3 hours until bedtime. As he was a computing instructor, the professor was also well-versed in locations of game rooms online. That is where he went to help pass time.

Now this professor happened to be a very good chess player. He had not been beaten by any of his friends in several years, so he felt confident as he entered an online chess room. Since there were an odd number of people there, he had to wait a few minutes until the next person to come into the room.

Within very few minutes, a new player, whose screen name was "still\_learning", showed up. He introduced himself only as "John" and so the professor reciprocated and said he was Brad.

Well, "still\_learning" may have been still learning, but he was well along that path. He defeated the professor in six straight games, even achieving checkmate in less than 10 moves one game!

Fascinated, the professor asked John how old he was.

"I turned thirteen last month. How old are you?" replied John.

Feeling totally humiliated, and thinking quickly, the professor typed in, "I'll be eleven next Tuesday!"