



# Branson Goers Gazette

November, 2006

Volume 1, Number 3

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## IN THIS ISSUE:

*Back-to-Basics (page 1)*

*Puffs from the Frozen North (page 6)*

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We're on the Web!

[www.postpoliobransongoers.com](http://www.postpoliobransongoers.com)

Apologies to Roma Wing...I forgot to give her credit for her article "Confessions of a Former Pusher," which was published in the October issue.

Signed,  
Your very embarrassed editor

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In this issue, we are going to get back to basics. There are, surprisingly, many people who are not entirely sure of just what PPS is. This article is provided by NINDS (National Institute of Neurological Disorders and Stroke). NINDS health-related material is provided for information purposes only and does not necessarily represent endorsement by or an official position of the NINDS or any other Federal agency. Advice on the treatment or care of an individual patient should be obtained through consultation with a physician who has examined that patient or is familiar with that patient's medical history.

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*(You might want to print this article out and take it to your doctor, especially if you are 'breaking in' a new physician.)*

## What is post-polio syndrome?

Post-polio syndrome (PPS) is a condition that affects polio survivors years after recovery from an initial acute attack of the poliomyelitis virus. PPS is mainly characterized by new weakening in muscles that were previously affected by the polio infection and in muscles that seemingly were unaffected. Symptoms include slowly progressive muscle weakness, unaccustomed fatigue (both generalized and muscular), and at times, muscle atrophy. Pain from joint degeneration and increasing skeletal deformities such as scoliosis are common. Some patients experience only minor symptoms. While less common, others may develop visible muscle atrophy, or wasting.

PPS is rarely life-threatening. However, untreated respiratory muscle weakness can result in under ventilation, and weakness in swallowing muscles can result in aspiration pneumonia.

The severity of residual weakness and disability after acute poliomyelitis tends to predict the development of PPS. Patients who had minimal symptoms from the original illness will most likely experience only mild PPS symptoms. People originally hit hard by the polio virus and who attained a greater recovery may develop a more severe case of PPS with a greater loss of muscle function and more severe fatigue. It should be noted that many polio survivors were too young to remember the severity of their original illness and that accurate memory fades



over time.

According to estimates by the National Center for Health Statistics, more than 440,000 polio survivors in the United States may be at risk for PPS. Researchers are unable to establish a firm prevalence rate, but they estimate that the condition affects 25 percent to 50 percent of these survivors, or possibly as many as 60 percent, depending on how the disorder is defined and which study is quoted.

Patients diagnosed with PPS sometimes are concerned that they are having polio again and are contagious to others. Studies have shown that this does not happen.

**What causes PPS?**

The cause is unknown. However, the new weakness of PPS appears to be related to the degeneration of individual nerve terminals in the motor units that remain after the initial illness. A motor unit is a nerve cell (or neuron) and the muscle fibers it activates. The polio virus attacks specific neurons in the brain stem and the anterior horn cells of the spinal cord. In an effort to compensate for the loss of these neurons, ones that survive sprout new nerve terminals to the orphaned muscle fibers. The result is some recovery of movement and enlarged motor units.

Years of high use of these enlarged motor units adds stress to the neuronal cell body, which then may not be able to maintain the metabolic demands of all the new sprouts, resulting in the slow deterioration of motor units. Restoration of nerve function may occur in some fibers a second time, but eventually nerve terminals malfunction and permanent weakness occurs. This hypothesis is consistent with PPS's slow, stepwise, unpredictable course.

Through years of studies, scientists at the National Institute of Neurological Disorders and Stroke and at other institutions have shown that the weakness of PPS is a very slowly progressing condition marked by periods of stability followed by new declines in the ability to carry out usual daily activities.

**How is PPS diagnosed?**

Physicians arrive at a diagnosis of PPS by completing a comprehensive medical history and neuromuscular examination and by excluding other disorders that could explain the symptoms. Researchers and physicians typically use the following criteria to establish a diagnosis:

*Criteria for diagnosis of post-polio syndrome*

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neuromuscular examination, and signs of nerve damage on electromyography (EMG). Rarely, persons have sub clinical paralytic polio, described as a loss of motor neurons during acute polio but with no obvious deficit. That prior polio now needs to be confirmed with an EMG. Also, a reported history of non paralytic polio may be inaccurate.
- A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neuromuscular function.
- Gradual onset of progressive and persistent new muscle weakness or abnormal

muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. Onset may at times follow trauma, surgery, or a period of inactivity, and can appear to be sudden. Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.

- Symptoms that persist for at least a year.
- Exclusion of other neuromuscular, medical, and orthopedic problems as causes of symptoms.

*Modified from: Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care. March of Dimes, 2001.*

PPS may be difficult to diagnose in some people because other medical conditions can complicate the evaluation. Depression, for example, also is associated with fatigue and can be misinterpreted as PPS or vice versa. For this reason, some clinicians use less restrictive diagnostic criteria, while others prefer to categorize new problems as the late effects of polio — for example, shoulder osteoarthritis from walking with crutches, a chronic rotator cuff tear leading to pain and disuse weakness, or breathing insufficiency due to progressive scoliosis.

Polio survivors with PPS symptoms need to visit a physician trained in neuromuscular disorders to clearly establish potential causes for declining strength and to assess progression of weakness not explained by other health problems.

Physicians may use magnetic resonance imaging (MRI), computed tomography (CT), neuro-imaging, and electro physiological studies as tools to investigate the course of decline in muscle strength. Less commonly, they will conduct a muscle biopsy or a spinal fluid analysis. These tests are also important to exclude other, possibly treatable, conditions that mimic PPS, but the tests do not identify survivors at greatest risk for new progression of muscle weakness.

It is important to remember that polio survivors may acquire other illnesses and should always have regular check-ups and preventive diagnostic tests, such as mammograms, pap smears, and colorectal exams.

### **How is PPS treated?**

There are currently no effective pharmaceutical or specific treatments for the syndrome itself. However, a number of controlled studies have demonstrated that non fatiguing exercises can improve muscle strength.

Researchers at the National Institutes of Health (NIH) have tried treating PPS patients with alpha-2 recombinant interferon, but the treatment proved ineffective. Another study in which PPS patients received high doses of prednisone demonstrated a mild improvement in their drug's side effects, led researchers to recommend that prednisone not be used to treat PPS.

In an effort to reduce fatigue, increase strength, and improve quality of life in PPS patients, scientists conducted two controlled studies using low doses of the drug pyridostigmine (Mestinon). These studies showed that pyridostigmine is not helpful for PPS patients.

In another controlled study scientists concluded that the drug amantadine is not helpful in reducing fatigue. And other researchers recently evaluated the

effectiveness of modifinil (Provigil) on reducing fatigue and found no benefit. Preliminary studies indicate that intravenous immunoglobulin may reduce pain, increase quality of life and improve strength. Research into its use is ongoing.

The future of PPS treatment may center on nerve growth factors. Since PPS may result from the degeneration of nerve sprouts, growth factors can target these and help to regenerate new ones. Unfortunately, one small study that NINDS scientists participated in showed that insulin-like growth factor (IGF-1), which can enhance the ability of motor neurons to sprout new branches and maintain existing branches, was not helpful.

Although there is no cure, there are recommended management strategies. Seek medical advice from a physician experienced in treating neuromuscular disorders. Do not attribute all signs and symptoms to prior polio. Use judicious exercise, preferably under the supervision of an experienced professional. Use recommended mobility aids, ventilator equipment and revised activities of daily living. Avoid activities that cause pain or fatigue that lasts more than 10 minutes. Pace daily activities to avoid rapid muscle tiring and total body exhaustion.

Learning about PPS is important for polio survivors and their families. Management of PPS can involve lifestyle changes. Support groups that encourage self-help, group participation, and positive action can be helpful. For some, individual or family counseling may be needed to adjust to the late effects of poliomyelitis, because experiencing new symptoms and using assistive devices may bring back distressing memories of the original illness.

### **What is the role of exercise in the treatment of PPS?**

The symptoms of pain, weakness, and fatigue can result from the overuse and misuse of muscles and joints. These same symptoms can also result from disuse of muscles and joints. This fact has caused a misunderstanding about whether to encourage or discourage exercise for polio survivors or individuals who already have PPS.

Exercise is safe and effective when carefully prescribed and monitored by experienced health professionals. Exercise is more likely to benefit those muscle groups that were least affected by polio. Cardiopulmonary endurance training is usually more effective than strengthening exercises. Heavy or intense resistive exercise and weight-lifting using polio-affected muscles may be counter-productive because they can further weaken rather than strengthen these muscles.

- Exercise prescriptions should include the specific muscle groups to be included,
- the specific muscle groups to be excluded, and
- the type of exercise, together with frequency and duration.

Exercise should be reduced or discontinued if additional weakness, excessive fatigue, or unduly prolonged recovery time is noted by either the individual with PPS or the professional monitoring the exercise.

### **Can PPS be prevented?**

Polio survivors often ask if there is a way to prevent PPS. Presently, no

intervention has been found to stop the deterioration of surviving neurons. But, physicians recommend that polio survivors get the proper amount of sleep, maintain a well-balanced diet, avoid unhealthy habits such as smoking and overeating, and follow an exercise program as discussed above. Proper lifestyle changes, the use of assistive devices, and taking certain anti-inflammatory medications may help some of the symptoms of PPS.

### **What research is being conducted?**

Scientists are working on a variety of investigations that may one day help individuals with PPS. Some basic researchers are studying the behavior of motor neurons many years after a polio attack. Others are looking at the mechanisms of fatigue and are trying to discover the role played by the brain, spinal cord, peripheral nerves, the neuromuscular junction (the site where a nerve cell meets the muscle cell it helps activate), and the muscles.

Determining if there is an immunological link in PPS is also an area of intense interest. Researchers who discovered inflammation around motor neurons or muscles are trying to find out if this is due to an immunological response.

Other investigators have discovered that fragments of the polio virus, or mutated versions of it, are in the spinal fluid of some survivors. The significance of this finding is not known and more research is being done.

### **Where can I get more information?**

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

#### **BRAIN**

P.O. Box 5801  
Bethesda, MD 20824  
(800) 352-9424  
<http://www.ninds.nih.gov>

Information also is available from the following organizations:

#### **Post-Polio Health International**

4207 Lindell Blvd., Suite #110  
St. Louis, MO 63108-2915  
[info@post-polio.org](mailto:info@post-polio.org)  
<http://www.post-polio.org>  
Phone: 314-534-0475  
Fax: 314-534-5070

#### **March of Dimes Birth Defects Foundation**

1275 Mamaroneck Avenue  
White Plains, NY 10605  
[askus@marchofdimes.com](mailto:askus@marchofdimes.com)  
<http://www.marchofdimes.com>  
Phone: 914-428-7100

914-MODIMES (663-4637)  
Fax: 914-428-8203

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### **Puffs from the Frozen North**

According to their papers, I am the owner of two dogs. It's not true, of course. Anyone involved with dogs knows that we don't own them. They own us. You don't see them following us around with a plastic bag, worrying about what we'll eat and if we have plenty of water and treats. Nope, they own us, alright.

The two canines who own me and who graciously allow me to pay for their every comfort are small dogs. I used to be owned by large, farm dogs. I have also been owned by the odd cat or two. Some of them very odd, indeed.

Pets are important for people who, like me, are disabled and who, like me, live basically alone. I'm married to a wonderful man, but he's a long-haul trucker, so I'm alone most of the time. My little 'girls' keep me company, take my mind off my problems and give me more love and companionship than anyone could imagine.

I have heard that petting an animal lowers your blood pressure. Since blood pressure meds make me groggy and sick feeling, I vastly prefer having one of my little friends sit on my lap and let me stroke her.

Are they service dogs, you might ask? Well, yes and no. They do think I'm here to perform any service they might need. But, do they perform services for me? Well, in a way, they do. They help me to keep my sense of humor, do their best to teach me patience, and offer unconditional love.

Fiona, the 8lb. Papillon, sees to it that I don't spend long periods of time at the computer without taking a 'let's play fetch' break. She also protects me from falling leaves and rabid squirrels by keeping a constant watch out the window and yapping her head off if any such thing should hove into view.

Daisy, 25 pounds of Bichon/Lhasa cross, has taken on the job of keeping my back warm in bed by curling up almost on top of me. Both of them help me take a nap by curling up at my feet or on top of me.

I think everyone should try to be owned by a pet of some kind. They really do make life infinitely better.

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### **October's Contest Winner**

The winner of the October contest, which was a picture of you or your pet in Halloween costume, was Roma Wing, dressed as a witch. Jerri Dillon and her son dressed as Little Red Riding Hood and the wolf, were second, with Isabelle, Sharon Hansche's Pomeranian, dressed as a witch was third.