State of New Jersey
Department of Human Services
Division of Medical Assistance & Health Services
And Division of Disability Services

NEWSLETTER

Volume 12 No. 73 **September 2002**

TO: All Providers - **For Information Only**
Health Maintenance Organizations - **For Information Only**

SUBJECT: Post-Polio Syndrome (PPS)

EFFECTIVE: September 1, 2002

PURPOSE: To promote the awareness of Post-Polio Syndrome (PPS)

BACKGROUND: PPS is a nervous system disorder that is diagnosed in patients with a prior paralytic poliomyelitis infection, usually 15-40 years after the original illness.

ACTION: This newsletter is intended to inform providers about PPS and resources available in New Jersey.

The New Jersey Department of Human Services' (DHS) Division of Medical Assistance and Health Services (DMAHS) and Division of Disability Services (DDS) are acknowledging the special needs of polio survivors.

FREQUENTLY ASKED QUESTIONS ABOUT POST-POLIO SYNDROME (PPS):

What is Post-Polio Syndrome?

Post-polio syndrome (PPS) is a condition that can strike polio survivors anywhere from 15 to 40 years after initial infection with the polio virus. PPS is caused by the death of individual nerve terminals that remained in motor units after the original infection.

What are the symptoms of PPS?

Symptoms include fatigue, progressive muscle weakness, muscle and joint pain, and muscular atrophy. The severity of PPS is dependent upon the seriousness of the original polio infection experienced by a survivor. Less common symptoms may include new muscle atrophy, respiratory insufficiency, dysarthria, dysphagia, muscle cramps, fasciculation, cold intolerance, and joint deformities.

How many people have PPS?

The World Health Organization (WHO) estimates that there are 10 to 20 million polio survivors worldwide. According to the National Institute of Neurological Disorders and Stroke (NINDS), it is estimated that more than 300,000 paralytic polio survivors reside in the United States. Of these, about 25 to 50 percent developed Post-Polio Syndrome (PPS).

What are the causes of PPS?

The exact mechanism is not completely understood. The gradual loss of individual nerve cells may provide some explanation, causing loss of nerve transmissions to muscle fibers.

In the original polio infection, motor neurons are destroyed. There is the loss of muscle function, including weakness or paralysis. To compensate for this loss, surviving nerve cells sprout extra branches, called axonal sprouts, that attached to muscle fibers when their nerve supply was lost from the original polio infection. This process is called re-innervation.

After re-innervation, the muscle fibers work again, sometimes as well as before. Some researchers have suggested that PPS develops because these extra axonal sprouts weaken over time due to "over-exertion." Eventually, the sprouts degenerate, and the muscle fiber again loses its ability to contract.

Research into the causes of PPS is ongoing, as is the development of guidelines on how best to diagnose, treat and rehabilitate people with PPS.

How is PPS diagnosed?

No definitive tests exist for PPS. Standard diagnostic tests of blood and muscle activity often show the same abnormalities in polio survivors with PPS as in those without it; therefore, diagnosing PPS is by exclusion. PPS may be suspected in a polio survivor if:

- The patient is experiencing muscle weakness, generalized or muscular fatigue, or pain involving the muscles or joints.

- The patient has experienced at least 10 years of good health (i.e., muscle function has not deteriorated) since recovery from polio.

If these criteria are met, one must still rule out other causes including pulmonary, cardiac, hematologic, endocrine diseases, cancer, and some chronic infections. In addition, musculoskeletal diseases such as fibromyalgia, rheumatoid arthritis (RA) and osteoarthritis (OS) must also be excluded. Many neurological diseases, including amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), and Parkinson's disease may also cause PPS-like symptoms.

Is there any treatment for PPS?

There is currently no cure for PPS. However, several drugs meant to provide symptomatic relief are being studied. Physicians and other healthcare providers also recommend physical therapy (PT), a healthy diet, exercise in moderation, use of assistive devices such as canes or walkers, appropriate weight loss if needed, and use of over-the-counter (OTC) or prescription (Rx) pain medications.

What research is being done?

Studies of possible treatments for PPS include insulin-like growth factor (IGF-1) and other growth factors. Some researchers, focusing on mechanisms of fatigue, are trying to gain information from the brain, muscles, and neuromuscular junction. Other researchers are trying to determine if there is an immunological link in this disorder.

How does one manage muscular weakness?

Strengthening, stretching, and aerobic exercise may be useful in the management of new weakness. However, exercise regimens must be individualized. In particular, exercises that cause joint pain, muscle pain or fatigue must be avoided. In some patients, exercise should be avoided altogether. Muscle overuse should also be avoided, as this may result in increased weakness. If muscle overuse does occur, rest or supportive devices such as braces may be beneficial. Assistive devices such as canes, crutches, and manual or electric wheelchairs can be helpful for severe muscle weakness. Appropriate weight loss may also be helpful.

How does one manage fatigue?

Energy conservation; relocating household items and supplies to make them more accessible; taking regular breaks during long periods of physical activity; and regular rest periods or naps are beneficial in managing fatigue. Some patients may need to make lifestyle changes, such as working part-time, or switching to a less physically demanding job. A good night's sleep is also important.

How does one manage pain?

Pain associated with PPS may be due to muscle cramps or fibromyalgia. Pains of joint and soft tissue origin, such as osteoarthritis, tendonitis, ligament strains, and joint deformities may also be present. Patients with PPS can manage their pain by modifying the use of their extremities; such as resting a leg periodically that is causing discomfort. Certain "physiotherapeutic" techniques can be used, including ultrasound, transcutaneous electrical nerve stimulation (TENS), and application of ice or heat. Use of supportive devices such as braces, assistive devices, and performance of strengthening exercises can also help to relieve pain. Effective pain relievers include acetaminophen, nonsteroidal anti-inflammatory drugs, such as naproxen sodium, etc. In rare cases, steroid injections or surgery may be necessary to relieve a patient's pain.

NEW JERSEY POST-POLIO RESOURCES:

The Post-Polio Institute at Englewood Hospital and Medical Center
The International Center for Post-Polio Education and Research
Englewood Hospital and Medical Center
Englewood, NJ 07631
Telephone: 877-POSTPOLIO or (201) 894-3724
http://www.postpolioinfo.com

New Jersey Polio Network
P.O. Box 537
Martinsville, NJ 08036
Telephone: (201) 845-6860
Fax: (201) 843-2903
http://www.community.nj.com/cc/njpnpolio

Betty Bacharach Institute for Rehabilitation
61 West Jim Leeds Road
P.O. Box 723
Pomona, NJ 08240
Post-Polio Center
Outpatient Physical Therapy (PT) Department
Telephone: (609) 748-5429
http://www.bacharach.org/services.htm

WEB-BASED INFORMATION AVAILABLE ABOUT PPS:

- The Post-Polio Institute
  http://www.postpolioinfo.com

- National Institute of Neurological Disorders and Stroke (NINDS)
  http://www.ninds.nih.gov

- International Polio Network/Gazette International Networking Institute (GINI)
  http://www.post-polio.org

- Polio Connection of America
  http://www.geocities.com

- New Jersey Polio Network, which links you to the web page for participating Medical Centers, Rehabilitation Centers, Support Groups, and Publications.
  http://community.nj.com/cc/NJPNPolio?display=links

- Ontario March of Dimes
  www.dimes.on.ca

- Easter Seal Society of Oregon
  http://www.easterseal.org

RECOMMENDED PUBLICATIONS:

- Halstead, L. S.; Post-Polio Syndrome, Sci Am Apr, 278(4):42-7.

- Jubelt, B., Agre, J. C.; Characteristics and Management of Postpolio Syndrome, JAMA, 2000 Jul 26, 284(4):412-4.

Division of Disability Services (DDS) INFORMATION AND REFERRAL HOTLINE:

For information and referral resources for NJ Post Polio Survivors, please contact DDS, at the toll-free hotline, 1-888-285-3036.

If you have any questions regarding this newsletter, please contact Fay M. Biernat, M.D., Medical Consultant, Office of Utilization Management at (609) 588-2718.

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