



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - January 2008

Current Research in Post-Polio Syndrome – May 2007

What's New in Post-Polio Research? Part 1

**With Susan L. Perlman, M.D.
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This report focuses on some of the post-polio research reported this past year and Dr. Perlman's comments. It is divided into two parts.

Part 1 includes:

Medical Literature
World Health Organization Report
Current NIH Research Studies since 2003
Completed Studies from Other Centers
Respiratory and Sleep Issues
Disability, Aging, and Rehabilitation Research
Resources

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The information presented at our meetings and/or contained in this newsletter is solely for information. It is not an endorsement of any product, medication, or individual.

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Part 2 includes:

Inflammatory Markers of Post-Polio Syndrome

Current Research Studies

Update on Immune Treatments

Fatigue

Proposed Research Studies in 2006

What We Already Know

Resources

Medical Literature

There is a continuing groundswell of research and published articles about polio and post-polio, including 333 publications dealing with acute polio and vaccination. In the past 12 months there have been 20 new publications in the medical literature dealing with polio and post-polio:

- 3 review articles of post-polio syndrome
- 2 dealing with better diagnostic techniques
- 4 dealing with respiratory or sleep issues
- 5 dealing with fatigue
- 1 dealing with immune treatment
- 4 dealing with disability and aging related factors
- 1 dealing with bracing

Two abstracts were presented at the Neurology meetings in early May 2007 and are reviewed in Part 2 of this report.

For this presentation, Dr. Perlman chose to look at some of the highlights of this literature and focus on things that might see some action during the next twelve months. Her resources are listed at the end of each part.

World Health Organization Report

In 2003 there were only six countries that still reported cases of acute polio, compared to 125 countries twenty years ago. But by the end of 2005 the World Health Organization's goal of eradicating polio worldwide had not been met.

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The number of polio cases and countries are continuing to increase. There were 315 outbreaks of polio during 2006; by May 15, 2007 the World Health Organization had already reported 155 cases of acute polio in 18 countries, three times as many countries as four years ago. That means that post-polio syndrome will be a medical concern for another fifty years. Vaccination programs need to continue even if active polio infection is not apparent.

Current NIH Research Studies since 2003

Although no polio related studies were completed this year, the National Institutes of Health have completed these research studies since 2003:

- **Ultrasound & Videofluoroscopy for Diagnosing Swallowing Disorders**
- **Electromyography to Diagnose Neuromuscular Disorders**
- **Brain Physiology in Polio Survivors**

Dr. Perlman:

This is the area that involves brain fatigue, or more central factors such as memory problems, control of blood pressure, things that were mentioned in a previous report, "Polio Above the Neck". In the brain as well as in the spinal cord there are old polio changes and there may be symptoms that relate to post-polio. They did MRIs (magnetic resonance imaging), MEPs (magnetic evoked potentials) which involve a strong magnetic stimulation to see what kind of motor function they can trigger, SSEP (sensory evoked potentials) to stimulate a hand or foot with a vibrating sensation and measure from the brain how the signals get through and if there is a difference in polio survivors.

They are working on mapping not just spinal cord pathways but central brain pathways that may be affected by post-polio. "The brain itself is probably involved more often than not in post-polio symptomatology."

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- **Study of Post-Polio Syndrome**

Dr. Perlman:

Dr. Marinos Dalakas was involved in this study using single fiber EMG, blood, spinal fluid, and muscle biopsy looking at inflammatory factors. "From this study, here and also in Europe, has come this new very large area of research dealing with the immune system and post-polio. Ten years ago the immune system was one of five factors felt to contribute to post-polio. Now it seems to be the one that people are focusing on the most in their research."

- **Modafinil to Treat Fatigue in Post-Polio Syndrome**

Modafinil for treatment of fatigue in post-polio syndrome: a randomized controlled trial.

Vasconcelos OM, Prokhorenko OA, Salajegheh MK, Kelley KF, Livornese K, Olsen CH, Vo AH, Dalakas MC, Halstead LS, Jabbari B, Campbell WW.

Neurology. 2007 May 15;68(20):1680-6. (Also reported at the May 2007 Neurology meeting)

OBJECTIVE: To determine if modafinil [Provigil] can improve fatigue in patients with post-polio.

METHODS: A randomized, placebo-controlled crossover trial. Intervention with modafinil (400 mg/day) [2 times the average dose] and placebo occurred over 6-week periods. Primary endpoint (fatigue) was assessed using the Fatigue Severity Scale as the main outcome measure. Other measures included the Visual Analog Scale for Fatigue and the Fatigue Impact Scale. Secondary endpoint (health-related quality of life) was assessed using the 36-Item Short-Form. Analysis of variance for repeated measures was applied to assess treatment, period, and carry-over effects.

RESULTS: Thirty-six patients were randomized, 33 of whom (mean age: 61 years) completed required interventions. Treatment with modafinil was safe and well-tolerated. After adjusting for periods and order effects, no difference was observed between treatments.

CONCLUSION: Based on the utilized measures of outcome modafinil was not superior to placebo in alleviating fatigue or improving quality of life in the

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studied post-polio syndrome population. Better results may have been seen in younger patients.

Dr. Perlman:

No machine can adequately measure the experience of fatigue, but strength and muscle fatigability can be measured. No difference in quality of life or fatigue was observed between treatments. There is a small group of patients, possibly younger than 60 years old, who may benefit from modafinil.

Modafinil has been FDA-approved for the treatment of:

- narcolepsy*
- excessive daytime sleepiness due to sleep disordered breathing (sleep apnea)*
- idiopathic excessive daytime sleepiness*
- shift work sleep disorder*

As with pyridostigmine (Mestinon), it seems reasonable to try modafinil for excessive daytime sleepiness and generalized fatigue associated with post-polio syndrome. Start with 100 mg. and slowly increase up to 400 mg. daily, taken in the morning.

Completed Studies from Other Centers:

- Post-Polio Syndrome Treated With Intravenous Immunoglobulin (IvIg)**
[Reviewed in Part 2 of this report]
- Efficacy and Safety of Xepol (Human Immunoglobulin) in Subjects With Post-Polio Syndrome (PPS)**

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Respiratory and Sleep Issues

- **Menopause and post-polio symptoms as predictors of subjective sleep disturbance in poliomyelitis survivors.**

Kalpajian CZ, Quint EH, Toussaint LL.
Climacteric. 2007 Feb;10(1):51-62.

Participants were 465 women aged 50-65 years who had physical disabilities due to poliomyelitis and trouble sleeping. Psychological symptoms exerted the most influence on sleep, followed by post-polio symptoms, vasomotor symptoms, an interaction of vasomotor and post-polio symptoms, and estrogen use.

- **Bi-level positive airway pressure ventilation maintains adequate ventilation in post-polio patients with respiratory failure.**

Gillis-Haegerstrand C, Markstrom A, Barle H.
Acta Anaesthesiol Scand. 2006 May;50(5):580-5.

Eight post-polio patients on nocturnal volume-controlled ventilation were investigated. Three of them used a nasal mask and each of the remaining five had a tracheostomy. It was shown that bi-level pressure support ventilation (PSV) reduces the oxygen cost of breathing and gave a significant decrease in PaCO₂ in PPS patients. These data suggest that bi-level PSV ventilation maintains adequate ventilation in patients who suffer from post-polio syndrome with respiratory failure.

Dr. Perlman:

This group studied BiPAP use in a group of 8 individuals with respiratory failure who were on some kind of pulmonary rehab program and were doing reasonably well. It specifically looks at their nighttime breathing performance where more likely, because of their being asleep, the voluntary muscles don't have the same muscle tone. Certainly low oxygen levels and high carbon dioxide might be more apparent when sleeping. These individuals might require pressure support ventilation at night.

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Five of these people had tracheostomies and three used a nasal mask at night. They did find that by using a BiPAP (ventilatory support that gives a certain pressure when breathing in and reduced pressure when breathing out) the person does not have to work so hard to breathe out. They found that the work of breathing was reduced. It did improve oxygen levels as well as carbon dioxide levels.

For people in general, it is known that when using a BiPAP with sleep apnea, there is much less work of breathing at night because they are not breathing out against a huge pressure.

This article supports arguments for using a BiPAP rather than a CPAP because BiPAP is less fatiguing and probably safer overall for the polio survivor who needs to use positive pressure ventilation at night.

Many polio survivors, certainly survivors of bulbar polio, do have decreased pulmonary function either because of weakness of the breathing muscles, weakness of diaphragm, or scoliosis - which may impair how much the chest can expand. They may actually get to the point where they are short of breath, where they can't get enough oxygen in, and may be at risk of having a simple upper respiratory infection result in respiratory failure, where they can't breathe at all.

"Others have milder symptoms that may only be apparent at night and may contribute to fatigue. If you are not getting enough oxygen in, if you are not getting the carbon dioxide out, it is going to cause fatigue, it is going to cause mental clouding, and impair your performance."

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Disability, Aging, and Rehabilitation Research

- **Disability in a 4-year follow-up study of people with post-polio syndrome.**
Willen C, Thoren-Jonsson AL, Grimby G, Sunnerhagen KS.
J Rehabil Med. 2007 Mar;39(2):175-80.

A total of 106 individuals with poliomyelitis sequelae were included in the study. Minor changes in disability during a 4-year period were shown. A significant reduction in muscle strength was only seen for 60 degrees flexion in the left leg and for right and left dorsal flexion. The minor changes in disability found in this study are an indication that we still do not know which subjects are at risk for deterioration. It is possible that participation in the polio clinic contributed to a lesser degree of decline.

Dr. Perlman:

This Swedish group looked at 106 individual from their post-polio clinic and monitored them over four years regarding muscle strength or progressive muscle weakness. Similar studies have been done in the United States also. The average decline in strength is about one percent per year.

Over four years they only found reductions in muscle strength that were measurable and significant in hamstrings (in the left leg in this group) and in dorsiflexion in either foot. Other muscles that were measured didn't really decline very much.

They commented that these seemed to be relatively minor changes in disability over a four year period. They would expect to see at least a four or five percent decline in these individuals who theoretically were not getting drugs or being treated.

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One of the problems in doing a study like this is measuring decline, a problem which also compromised the results in the Mestimon and Provigil studies. They are measuring a placebo group that theoretically declines and a treatment group that hopefully improves. Based on an exam, the problem in measuring is that all polio survivors are different. Some people have only arm involvement, some have only leg involvement, others have problems only on one side of the body, etc.

In the group of polio survivors as a whole, the Mayo Clinic's ongoing study has shown that 40-60% of polio survivors are likely to have problems later in life; 40-50% will probably not have problems or have not yet been shown with problems. Not everybody who is a polio survivor has post-polio related symptoms.

There are unknown factors that separate those two groups. Even polio survivors who do have symptoms now are different from each other. When trying to average these people together in a study that measures disability, improvement, or decline, the statistics are going to suffer.

In this Swedish study they did comment that these people were attending the polio clinic and heard all the lectures about energy conservation. Certainly they were on some kind of rehab treatment program and perhaps it was having some benefit by protecting many, many muscles that could have been involved.

The minor changes in disability found in this study are an indication that we still do not know which subjects are at risk for deterioration. It is possible that participation in the polio clinic contributed to a lesser degree of decline.

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- **Effective intervention strategies for management of impaired posture and fatigue with post-polio syndrome: a case report.**

Wise HH.

Physiother Theory Pract. 2006 Nov;22(5):279-87.

This is a case report on a 49 year old polio survivor with a right ankle-foot orthosis (AFO) and addition of a forearm crutch.

Six-month and 18-month re-examinations found that the patient was compliant with the assistive device, reported a 30% reduction in fatigue, and walked with a more upright posture for longer distances in a shorter period of time. Patient education, health promotion, and energy conservation strategies that included walking with a properly fitting assistive device reduced perceived fatigue and improved posture and function in an individual with post-polio syndrome.

Dr. Perlman:

This 49 year old polio survivor had a right short leg brace for many years but was listing more to the right and having more trouble staying erect, probably because of progressive hip and trunk weakness. This physiotherapist used patient education, health promotion, energy conservation strategies, and one forearm crutch to help restore upright posture.

At the 6 month and 18 month re-evaluations, the patient using the crutch appropriately, had a 30% reduction in fatigue, walked more upright so she was using less energy to walk, and could go longer distances in a shorter period of time. That is a significant benefit.

Although this was just one person, it shows that the result of rehab is measurable, it is real. Sometimes it involves equipment, sometimes it involves energy conservation. Assistive devices like mobility devices to avoid fatigue over long distances, or even simple things like a differ-

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ent kind of brace, can make measurable changes in fatigue, which is one of the key measures in post-polio, and daily performance. So you cannot minimize rehab.

- **Clinical application of carbon fibre reinforced plastic leg orthosis for polio survivors and its advantages and disadvantages.**

Hachisuka K, Makino K, Wada F, Saeki S, Yoshimoto N, Arai M.
Prosthet Orthot Int. 2006 Aug;30(2):129-35

This new brace technology improved the scores in the functional ambulation categories, but there was no difference between walking with an ordinary brace and with a carbon knee-ankle-foot orthosis (KAFO). The self-evaluation of walking with a carbon KAFO revealed that the subjects using a carbon KAFO were satisfied with their carbon KAFO. The carbon KAFO is lightweight, durable, slim and smart, and is positively indicated for polio survivors.

Dr. Perlman:

This is a report from a Japanese group who were looking at the black carbon fiber reinforced plastic KAFO (long leg brace) for polio survivors.

They found that the carbon KAFO seemed to work as well as the ordinary plastic ones. The patients walked equally well when walking with one type brace and then switching to the other type. The carbon KAFO was lightweight, durable, slim, and smart looking.

These orthotists seemed to think that the old traditional braces (the metal and leather braces, the plastic braces with ankle joints and without ankle joints that may also use metal) and these new carbon polymer ones can be designed more creatively to benefit a polio survivor.

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Obviously a polio survivor's bracing needs are very individual; one muscle may be working while another one is not. Brace design for polio survivors is very, very tricky because you want a brace that will support the muscle that is not working while not inhibiting the working muscle(s). Newer materials can be utilized in the hands of a skilled orthotist who knows how to assess a polio survivor's muscles and communicate with the physician about which muscles they want to support and which muscles to protect.

Part 2 of this report will appear in next month's newsletter.

Additional information on these studies can be found in the resources below.

Resources

www.post-polio.org (PHI)

www.ncbi.nlm.nih.gov/entrez (PubMed articles)

www.clinicaltrials.gov (NIH source)

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Late Breaking News: The Rancho Los Amigos Post-Polio Support Group has a new meeting room. It is the 1150 Conference Room of the Support Services Annex. We have used this room for special presentations and we now have this as our regular meeting location. You will receive a detailed map and directions in a separate mailing. Hope to see you there throughout 2008.

Happy New Year