



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - February 2012

Basic Principles of Managing Post-Polio Syndrome With Susan L. Perlman, M.D.

Clinical Professor of Neurology
David Geffen School of Medicine
University of California, Los Angeles

Presented at the Orange County, CA. PPSG meeting, May 15, 2011
Reported by Mary Clarke Atwood with editorial assistance by R. Daggett

Once again Dr. Perlman generously shared her time and energy with local polio survivors to discuss post-polio research and answer our questions. The two articles based upon this presentation are printed separately. This report is based on a study in Norway looking at Treatment Options for PPS, plus Dr. Perlman's answers to questions from the audience; our April 2012 newsletter will feature a summary of the results from Pain research in Sweden and answers to more questions. Although the post-polio news in 2010 was limited, many post-polio researchers around the world continue to enlarge our knowledge.

Update on Current and Emerging Treatment Options For Post-Polio Syndrome By Elizabeth Farbu

Neurocenter and National Competence Center for Movement Disorders
Stavanger University Hospital, Stavanger, Norway

Therapeutics and Clinical Risk Management. 2010 Jul 21;6:307-13

Post-polio syndrome (PPS) refers to the clinical deterioration experienced by many polio

(Continued on page 2)

No article in this newsletter may be reprinted without written approval. **No** article may be edited. The full text of an article, including most graphics, can be obtained by request. Please send requests to: RanchoPPSG, 12720 La Reina Avenue, Downey, CA 90242 or **RanchoPPSG@hotmail.com**

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.

(Continued from page 1)

survivors several decades after their acute illness. The symptoms are new muscle weakness, decreased muscle endurance, fatigue, muscle pain, joint pain, cold intolerance, and this typical clinical entity is reported from different parts of the world. The pathophysiology behind PPS is not fully understood, but a combination of distal degeneration of enlarged motor units caused by increased metabolic demands and the normal aging process, in addition to inflammatory mechanisms, are thought to be involved. There is no diagnostic test for PPS, and the diagnosis is based on a proper clinical workup where all other possible explanations for the new symptoms are ruled out.

The basic principle of management of PPS lies in physical activity, individually tailored training programs, and lifestyle modification.

- Muscle weakness and muscle pain may be helped with specific training programs, in which training in warm water seems to be particularly helpful.
- Properly fitted orthoses can improve the biomechanical movement pattern and be energy-saving.
- Fatigue can be relieved with lifestyle changes, assistive devices, and training programs.
- Respiratory insufficiency can be controlled with noninvasive respiratory aids including bi-phasic positive pressure ventilators.
- Pharmacologic agents like prednisone, amantadine, pyridostigmine, and coenzyme Q10 are of no benefit in PPS.
- Intravenous immunoglobulin (IVIG) has been tried in three studies, all having positive results. IVIG could probably be a therapeutic alternative, but the potential benefit is modest, and some important questions are still unanswered, in particular to which patients this treatment is useful, the dose, and the therapeutic interval.

“All polio survivors are not the same and will not necessarily respond to the same treatment,” said Dr. Perlman. ***“It is important to control pain and fatigue in people with any type of illness. Once your pain is under control and your energy levels are coming back, you can do almost anything.”***

(Continued on page 3)

(Continued from page 2)

Answers to Questions from the Audience

How do I find out which specialist my primary physician should refer me to for fatigue, exercise, incontinence, etc. in post-polio?

This primary physician is clearly feeling overwhelmed by a lot of symptoms. The best type of physician to see is one who can actually deal with rehabilitation of all these areas and that is a physiatrist, a physical medicine and rehabilitation physician (PM&R) specialist.

Brain fatigue – what is it?

Brain fatigue, as described in surveys of polio survivors, is a sense of not being able to think clearly, having trouble with multi-tasking, thinking, and following things through without getting distracted. If you have ever had the flu, that's brain fatigue. Polio survivors can get that exact feeling. It is felt to be related to the immune system chemicals that have been found to be elevated in the spinal fluid of polio survivors. Some of them are the same immune system chemicals that are elevated in multiple sclerosis (MS) and cause fatigue in MS. For people with brain fatigue, the immune system needs to be an area of research.

Does brain fatigue contribute to physical fatigue?

Yes, if your brain is fatigued you don't feel like doing anything.

Is it possible to strengthen my breathing muscles, as I have to sleep with oxygen? My oxygen level while sleeping is between 85 to 90%.

I think the only way to strengthen breathing muscles is to work with a pulmonary rehab person who will actually target some of the muscles that are involved in expanding the chest, especially when you are asleep and it is involuntary. During the day when you are awake, you can breathe deeply, but at night it is really out of your control. For somebody clearly with oxygen problems and breathing muscle problems, Dr. Perlman would strongly recommend a round of pulmonary rehab.

Is a surgery such as removal of parathyroid gland contraindicated? (This is someone who uses a BiPAP at night, suggesting there is some respiratory or neck involvement.)

Whenever you have a surgery in a region, whether it is a shoulder or neck, where there are muscles involved, you are going to lose a grade of muscle strength. It might come back, but

(Continued on page 4)

(Continued from page 3)

post-operatively you may find that the neck is weaker just because they had to manipulate the muscles to get to the parathyroid gland.

What is resistive exercise?

Resistive exercise is when you add some resistance, such as a weight or something you are pushing against. You can get the same mileage in half as many repetitions, with less fatigue. That includes ankle weights, wrist weights, using an exercise machine that has a resistive plate that you push, elastic rubber bands, etc.

Antigravity exercise does help strengthen bones. It is one of the things they recommend to people with osteoporosis. Polio survivors can have thinner bones in their polio limbs. So strengthening exercises in those limbs, even two or three repetitions, not only will help the muscles, but will also help the bones – any place where the force of the exercise is felt.

When exercising, do you recommend a day in between exercises?

Most exercise for strengthening and conditioning can be done every other day. A rest day in between is good protection from overdoing.

Exercise for pain, which is usually stretching, or exercise for balance does need to be done every day. It is hoped that stretching and balance exercises will not be fatiguing.

Would Pilates be an appropriate type of exercise for strength and conditioning?

Pilates works on the core so in that way it does strengthen and condition core muscles. If you have a more specific problem with shoulders, upper arms, or quads you may have to ask for something special with the Pilates therapist. One thing about Pilates is that it tends to be non-fatiguing so it seems to be well tolerated by neuromuscular patients.

Is there exercise for torn rotator cuffs?

What you need is advice from your orthopedist about what is safe exercise to do for the amount of rotator cuff tear you have, in order to not make the tear bigger and to promote healing.

(Continued on page 5)

(Continued from page 4)

Are there any hopeful studies showing stem cell treatment for post-polio? Is post-polio not a good candidate for stem cell treatment?

If we want to replace nerve cells in a shoulder that has no deltoid muscle, no posterior shoulder muscles (they come from the same part of the cervical cord), potentially this could be treated like a spinal cord injury. You have a specific place to go, and you can target it regionally.

Does post-polio research relate to other diseases or disabilities?

Absolutely. Post-polio research relates to any disease of the spinal cord and any disease of motor nerves, for sure. If there is an immune component, then it connects itself with all the immune mediated neurological diseases such as Guillain-Barre, multiple sclerosis, and there are many others. Dr. Perlman knows people who have done studies on ALS, and have added a small parallel group with post-polio. Discoveries in post-polio can help research in other diseases and vice versa. That needs to be emphasized when talking with research groups.

Is there a need for funding of post-polio research?

Yes. The National Institutes of Health (NIH) have funded a lot of prior post-polio research. Many of the studies on www.clinicaltrials.gov are funded by the NIH but their budget has gone down and there is less money for research.

In order to get money from the NIH you have to demonstrate that you have an ironclad, rock solid research project that is going to hit the basic clients of post-polio and combine it with something that has some treatment related potential. They are not interested in general reviews. They want to see things that get to the heart of post-polio and similar diseases and will also open a door to treatment. Certainly there are excellent researchers working.

Those \$25,000 grants by Post-Polio Health International fund extremely important research. That is enough money to hire a technician to do research in your lab on a particular project. Even those small amounts of money, as opposed to the mega grants, can be helpful.

Why are polio and post-polio syndrome not addressed in medical school?

Changes in curriculum are very slow; polio was never part of the original curriculum. Post-polio is still not well enough defined as an immune problem so that it could be presented in the same unit as Guillain-Barre. That is one reason it is not in the main curriculum.

On the other hand, if a school has a neuro-rehab unit and students hear a lecture on it, polio and

(Continued on page 6)

(Continued from page 5)

post-polio syndrome absolutely should be mentioned. If the medical students hear a lecture by a physiatrist about rehab, which hopefully they are hearing about, that lecturer could include post-polio.

Remember, “*All polio survivors are not the same and will not necessarily respond to the same treatment,*” said Dr. Perlman.

Conclusion

As PPS research in many areas continues worldwide, we look forward to learning more from Dr. Perlman in the future.

© Copyright 2011 by Mary Clarke Atwood

All rights reserved. To protect the integrity of this report, no parts may be used in other newsletters, posted online, reproduced or transmitted in any form without prior written permission from us. Please submit your request to RanchoPPSG@hotmail.com - or send it to 12720 La Reina Ave., Downey CA 90242

This report can also be viewed at www.RanchoPPSG.com

IMPORTANT—Please Read—Meeting Changes—IMPORTANT

The **Post-Polio Support Group of Orange County** has decided to schedule meetings every other month. You will find the meeting schedule on the next page.

The **Rancho Los Amigos Post-Polio Support Group** has changed the location of the **February** meeting only. You will receive a separate notice of this soon.



A very special *Thank You* to everyone who sent donations and/or returned the questionnaire. This has been very, very helpful. If you have not responded it is not too late. We need you to complete the attached survey in order to know what your interests are. A donation is welcome but not required. You may use the enclosed, postage free envelope.

Post-Polio Support Group of Orange County has changed to meeting every other month

ALSO DUE TO RENOVATION WORK AT VILLA PARK OUR **MARCH AND MAY** MEETINGS WILL BE HELD AT THE **CARPENTERS HALL AT 1916 W CHAPMAN IN ORANGE**. East of 57 Fwy. West of Main Street. Across the street from McDonalds. Park at rear of building. ADA accessible.

February - No Orange County Meeting

Saturday, March 10, 2012 2pm - 4pm - *Double Presentations:* First one by **Mobility Center** on scooters, wheelchairs, ramps. lifts and vans. Second one by **Evergreen Care** on "Assisted Living at Home" on how to use in-home caregivers. *See Map Below!*

April - No Orange County Meeting

SUNDAY May 20th, 2012 2pm - 4pm **Dr. Perlman from UCLA on current PPS research and care.** *See Map Below!*

June - No Orange County Meeting

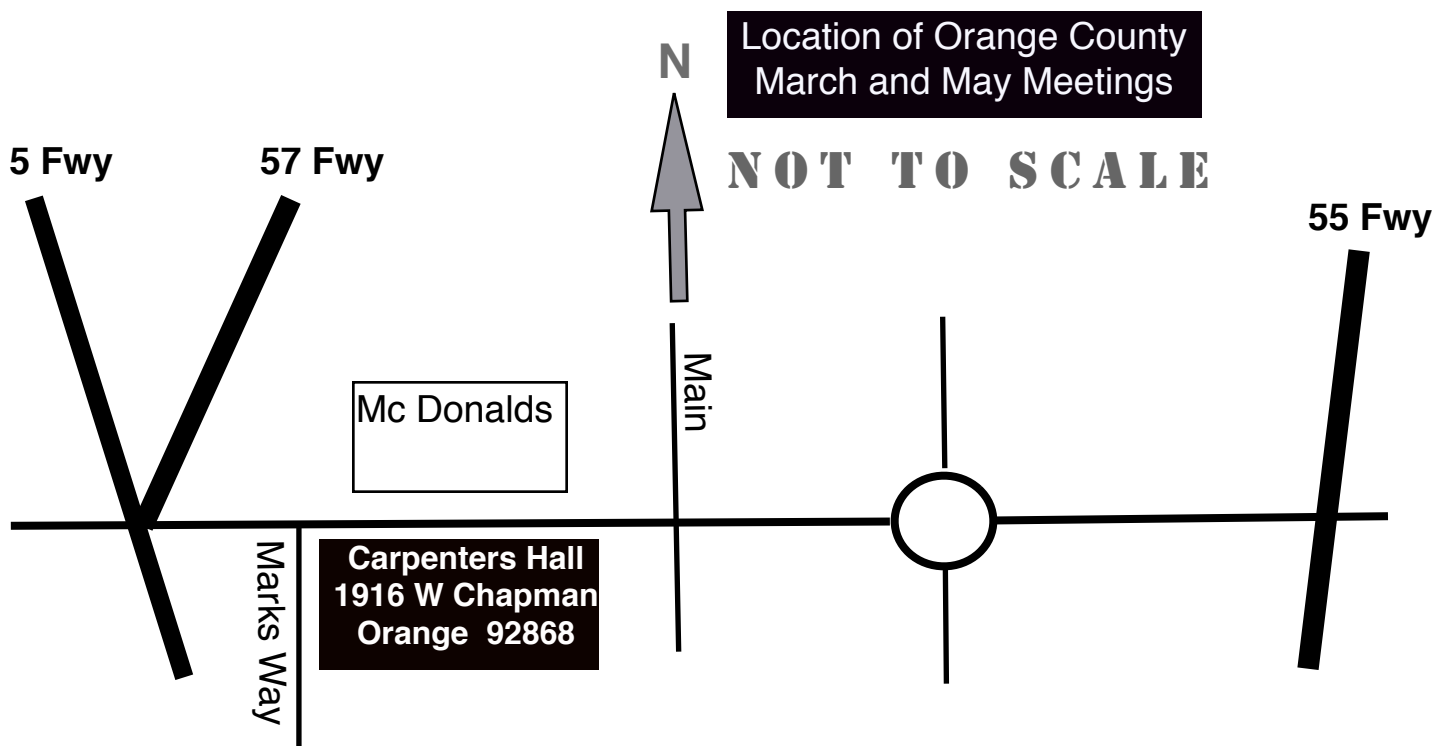
Saturday, July 14, 2012 2pm - 4pm **Indoor Picnic and Sharing**

August - No Orange County Meeting

Saturday, September 8th, 2012 2pm - 4pm **2013 changes in Medicare presented by HICAP.**

October - No Orange County Meeting

Saturday, November 10, 2012 2pm -4pm -- We are inviting Dr. Christine Phan, a leading doctor of Physical Medicine and Rehabilitation (Physiatrist) at Kaiser Permanente and is a supporter of Post-Polio Health International. Her presentation has NOT been confirmed.



Please remove this page and save it, or make a copy of the other side and save it. This will help remind you of the new meeting schedule for the Post-Polio Support Group of Orange County.

NOTE: Those of you who have elected to receive the e-mail addition of the newsletter will also receive a hard copy in the mail this month. This will make it easier for you to fill out the questionnaire and return it in the postage free envelope.

Topics that would get you to attend our meetings: (write in)

- 1. _____
- 2. _____
- 3. _____

Subjects you would like to see covered in our newsletters: Please check

How to diagnosis PPS <input type="checkbox"/>	Assisted Living with PPS <input type="checkbox"/>
PPS Research <input type="checkbox"/>	Finding Medical caregivers for PPS <input type="checkbox"/>
Treatments and Exercise for PPS <input type="checkbox"/>	Which HMOs have best records in caring for PPS <input type="checkbox"/>
Physical Therapy for PPS <input type="checkbox"/>	Medicare changes <input type="checkbox"/>
Traveling with PPS	Making your home accessible <input type="checkbox"/>
Nutrition and weight control <input type="checkbox"/>	History of Polio <input type="checkbox"/>
Non PPS symptoms that polio survivors often have <input type="checkbox"/>	Polio Eradication <input type="checkbox"/>
Effect of PPS on our families <input type="checkbox"/>	Advance Medical Directives <input type="checkbox"/>
Depression and PPS <input type="checkbox"/>	Living Wills <input type="checkbox"/>
Alcoholism <input type="checkbox"/>	Reverse Mortgages <input type="checkbox"/>
Pain Killers and PPS <input type="checkbox"/>	Sleep and PPS <input type="checkbox"/>
Braces <input type="checkbox"/>	Sleep Apnea <input type="checkbox"/>
Crutches & Walkers <input type="checkbox"/>	Ventilators and PPS <input type="checkbox"/>
Scooters, and Wheelchairs <input type="checkbox"/>	Other topics: _____
Van Conversions <input type="checkbox"/>	_____
Digital Audio Books for Disabled <input type="checkbox"/>	_____
Independent Living with PPS <input type="checkbox"/>	_____

General comments: _____

Post-Polio Support Group 2012 Questionnaire & Appeal for Funds

It has been four years since we have needed to have a fund drive. The Rancho and Orange County support groups operate on shoestrings. However, we do have substantial newsletter publication costs and fees for meeting space use. We hope that many of our readers will respond with donations. Yet, we want to **EMPHASIZE** that the **newsletter is sent to you free of charge**. We do ask that you let us know if you want to keep receiving the newsletters. Precious volunteer hours are consumed to produce them and we want to make certain that we use donated time and energy effectively. We also ask that you take a few minutes to respond to the questions that appear below so that our support groups can function in the best way possible for the polio survivors we serve. **Return envelop enclosed.**

**Enclosed is my donation of \$ _____ to Polio Survivors Association
(No donation is required to receive newsletter)**

I want to continue to receive the newsletter by: standard mail email (✓ one)
My email address is _____ @ _____

Topics that would get you to attend our meetings: (write in)

1. _____
2. _____

Subjects you would like to see covered in our newsletters: Please check ✓

- | | | |
|--|---|---|
| How to diagnosis PPS <input type="checkbox"/> | PPS Research <input type="checkbox"/> | Independent Living with PPS <input type="checkbox"/> |
| Treatments and Exercise for PPS <input type="checkbox"/> | | Assisted Living with PPS <input type="checkbox"/> |
| Physical Therapy for PPS <input type="checkbox"/> | | Finding Medical caregivers for PPS <input type="checkbox"/> |
| Traveling with PPS | | Which HMOs have best records in caring for PPS <input type="checkbox"/> |
| Nutrition and weight control <input type="checkbox"/> | | Medicare changes <input type="checkbox"/> |
| <u>Non</u> PPS symptoms that polio survivors often have <input type="checkbox"/> | | Making your home accessible <input type="checkbox"/> |
| Effect of PPS on our families <input type="checkbox"/> | | History of Polio <input type="checkbox"/> |
| Depression and PPS <input type="checkbox"/> | Alcoholism <input type="checkbox"/> | Polio Eradication <input type="checkbox"/> |
| Pain Killers and PPS <input type="checkbox"/> | | Advance Medical Directives <input type="checkbox"/> |
| Braces <input type="checkbox"/> | Crutches & Walkers <input type="checkbox"/> | Living Wills <input type="checkbox"/> |
| Scooters, and Wheelchairs <input type="checkbox"/> | | Reverse Mortgages <input type="checkbox"/> |
| Van Conversions <input type="checkbox"/> | | Sleep and PPS <input type="checkbox"/> |
| Digital Audio Books for Disabled <input type="checkbox"/> | | Ventilators and PPS <input type="checkbox"/> |
| | | Other topics: _____ |
| | | _____ |
| | | _____ |

I willing to volunteer: Please fill in the circle

- Co-edit the Newsletter Help assemble the newsletter mailings
Work with local newspapers and community centers to promote our meetings
Take phone calls from polio survivors new to PPS and our groups
Help get speakers and presenters for our meetings

General comment: _____