



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - April 2012

Pain in 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. This report summarizes the results of pain research in Sweden and includes answers to questions from the audience. The previous report, which appeared in our February 2012 newsletter, was based on a study in Norway looking at Treatment Options for PPS and also included answers to questions.

Although post-polio news in 2010 was limited, many post-polio researchers around the world continue to enlarge our knowledge.

- There was only one active study of post-polio listed at ClinicalTrials.gov.
- There was no new post-polio research presented at the American Academy of Neurology meeting in Hawaii - April 2011.

“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*

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of illness. Once your pain is under control and your energy levels are coming back, you can do almost anything.”

**Analysis of Long-Standing Nociceptive and Neuropathic Pain
in Patients with Post-Polio Syndrome**

By L.Werhagen, K.Borg

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Journal of Neurology. 2010 Jun;257(6):1027-31. Epub 2010 Mar 30.

The purpose of this study was to analyze pain, both nociceptive (no-see-SEP-tiv) pain [*from joints, muscles and tendons*], and neuropathic [*nerve*] pain, in patients with post-polio syndrome (PPS) and relate the pain to age at the initial polio infection, to age at examination, to gender and disability.

Summary:

- Pain is common in patients with PPS and most patients experienced nociceptive pain.
- Women have pain more often than men.
- Older patients experience pain less frequently than younger patients.
- Age at time of primary polio infection is important for the development of pain.
- When neuropathic pain is present, it is important to proceed with neurological examination to find an adequate diagnosis.

Answers to Questions from the Audience

Is the pain we are feeling coming from damaged muscles or from dying nerves?

It could be either one, or both. Any treatment that would work for diabetic nerve pain could be applied for post-polio nerve pain. This includes drugs that boost serotonin such as Cymbalta or amitriptyline from the old days. However, the drugs gabapentin and Cymbalta may have side-effects, so drugs may not be the way you want to go.

Does pain every day mean you are doing too much?

It could mean you are doing too much. On the other hand, if it is the neuropathic pain you could have it every day even if you were doing nothing. Nociceptive pain from a joint, or a muscle, or a tendon, is more likely to flare up if you are doing too much and is more likely to

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be quiet if you don't do anything.

But nerve pain, which is one of the four types of pain in post-polio, can absolutely be every day; nerve pains from other causes could also be every day. So be sure you are not overdoing and discuss your activities with your therapist. If you are really not overdoing, then you need to see your doctor.

Is there any natural pain control?

The natural pain control would be to manipulate the environment that may be contributing to pain. If you have activities that contribute to pain, the least invasive thing you can do is to modify those activities.

If you have pain because you haven't been exercising and your muscles are deconditioned and ache every time you get up, then starting a gentle conditioning exercise program can help. There are plenty of non-drug strategies for pain. There is enough evidence to suggest that a good conditioning exercise program can help reduce pain.

Regarding natural pain control using herbal supplements, some time ago L-tryptophan was popular as a natural herbal pain control. It stimulates serotonin with an amino acid as opposed to a prescription drug. But the company that was manufacturing most of it had problems with contamination. Some people got very sick on it so it was taken off the market for a number of years; it is now back. But even herbal or amino acid supplements are not 100% free from side effects.

If you want to try an herbal preparation that is touted for pain control, first of all read the label and see what is in it. Then talk it over with your doctor and see if it is something that is safe, try it for a month and then make a decision.

Dr. Perlman has no problem with natural methods. On the other hand, pain every day, severe pain, may need something more than natural strategies. If pain is disabling, it needs to be tackled more directly. Then as pain levels come down, a person can get more involved in rehab and exercise and maybe try out some of the herbal preparations.

How is neuropathic pain treated?

We talked about the drugs and modifying anything that would make it worse.

Some people use heat, other people with use cold. There are creams that you can rub on - hot

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creams, cold creams and numbing creams can also help.

Remember, ***“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.”*** said Dr. Perlman.

Conclusion

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

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Dr. Perlman will again be speaking to a joint meeting of the Post-Polio Support Group of Orange County and the Rancho Los Amigos Post-Polio Support Group. This special joint meeting will be Sunday, May 20, 2012. The meeting will be in Carpenter's Hall, 1916 W Chapman Ave., Orange. We know you will gain valuable and helpful information from Dr. Perlman's presentation. We look forward to seeing you there.

Dr. Susan Perlman

Sunday, May 20, 2012

2pm -- 4pm

Dr. Perlman is asking for our help to prepare her presentation to us on May 20th. What topics you would like her to address? What you would like to ask her?

Email Priscilla at prisofoc@aol.com or call her at 714-968-1675

REMEMBER! This is a joint meeting of the Post-Polio Support Group of Orange County and the Rancho Los Amigos Post-Polio Support Group. There will be no separate Rancho meeting in May!

REMINDER: This meeting with Dr. Perlman will be at the Carpenters' Hall, 1916 W Chapman Ave., Orange. (Across the Street from McDonalds)

How to contact the Rancho Los Amigos Post-Polio Support Group

For additional information about meetings or programs, please call Richard at **562-862-4508**
Diane at **562-861-8128**

Or email us:
RanchoPPSG@hotmail.com

Web address:
www.RanchoPPSG.com

Additional information on polio and post-polio syndrome:
www.polioassociation.org

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