



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - June 2012

Ask a Post-Polio Specialist #4

With Vance C. Eberly, M.D.

Rancho Los Amigos National Rehabilitation Center
Downey, California

Reported by Mary Clarke Atwood

Editorial assistance by Richard Daggett

At the December 3, 2011 meeting with Vance Eberly M.D., orthopedist in the Rancho Los Amigos Post-Polio Clinic, spoke to our support group and very willingly answered questions from the audience.

During recent months, Dr. Eberly was temporarily away from the clinic while establishing his private orthopedic practice. He expects to resume seeing patients at the Rancho Post-Polio clinic in September 2012. For polio patients, he recommends seeing him in the clinic because a wider range of specialists and services are available there.

Dr. Eberly recommended that all polio survivors be evaluated at a post-polio clinic for a baseline assessment. Even if there seem to be no major problems, a polio survivor may be helped to function at a higher level.

During the acute phase of polio, nerve cells going to the muscles were damaged or killed. Some of those damaged nerve cells were re-inervated during recovery but were still not normal. Dr. Eberly stressed the importance of not overworking those neuromuscular units, because when nerve cells are damaged or killed they no longer function properly.

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The following are a sample of comments and questions from his talk:

Muscle – Three muscles are needed for standing and walking:

gluteus maximas (butt),
quadriceps (thigh),
calf muscles

Knees – those people considering knee replacement surgery should seek quadriceps tendon sparing style of surgery. If a person cannot walk after recovery from knee replacement surgery, they will need a Knee-Ankle-Foot Orthosis (KAFO)

Braces – are prescribed by a knowledgeable doctor and fabricated by an orthotist. They need to be adjusted until they fit well and feel good. Sports type braces are only good for weak ligaments.

Arthritis – is usually inherited but polio can cause a predisposition to arthritis

Neck pain – gentle traction can give some relief of neck pain due to a pinched nerve in the neck or spine

Acupuncture – may provide some relief for myofascial nerve pain

Exercise – How do you know if your exercise was too much? The answer is in your recovery after exercise. If you are not out of breath after 15 or 20 minutes of rest, and are not exhausted the next day, that exercise was not too much for you.

Medical Records – Following your diagnosis and recommendations at the Rancho clinic, go to Medical Records and make arrangements to get a copy of those reports for your personal use. Keeping a copy of your medical records, test results, etc., is always a good idea.

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More Answers to Questions

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

Editorial assistance by R. Daggett

Are GI problems an aspect of post-polio syndrome?

Simple GI problems in PPS are reflux and constipation. If you are sitting a lot or are using a wheelchair most of the day, that tends to put pressure on the stomach, and then reflux is very common. Constipation in people who are less mobile is also very common. Dr. Perlman has not seen other G.I. problems although several patients had completely sluggish bowel that may be from post-polio. In Dr. Perlman's neuromuscular groups in general, there are a few people who have total bowel relaxation that could well be from the original polio and post-polio changes.

What is bulbar polio?

Bulbar polio is where the motor nerves in the brain stem were affected, causing loss of breathing, often using a ventilator (an iron lung), perhaps affecting swallowing and speech. The sleep center is also in the brain stem and could easily have been damaged. The three areas that are most affected are muscles that depend on the brain stem: muscles of speech, muscles of swallowing, and muscles of breathing.

Problems with swallowing - should I go to an ENT doctor and what kind of tests should be done?

For problems with swallowing, usually you are sent for a modified barium swallow study. They take fluoroscopic pictures as you swallow barium in liquid form, barium in pudding form, and barium frosting on a cookie. The images of the liquid, the soft, and the crumbly textures are analyzed to see what happens in your throat while swallowing.

However, this person is not choking, but at night is constantly swallowing while sleeping. So that needs to be made very clear. Things that could cause that sense of needing to swallow are post-nasal drip, acid reflux, stuff getting in your throat. It would be helpful to

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see an ENT but also consider a sleep study.

Donating Blood – and still dizzy five days after giving blood. It is not bad for post-polio people to give blood, but Dr. Perlman would wonder about this person's blood pressure and nutritional status. She suggests this person have blood pressure checked at the pharmacy or primary care doctor to be sure it's not something else.

Can overworked muscles cause high liver enzymes or large or too many red blood cells?

Regarding high liver enzymes, there are enzymes in the liver that are similar to the enzymes in muscles. So if you have a general blood screening for enzymes, and one of the liver enzymes seems to be elevated, and you had muscle overuse, it could be from the muscles because the enzymes are the same. There are some that are more specific for liver and there are some that are more specific for muscles, but there are several in the middle that show up in both of them.

So if someone has high liver enzymes it would be appropriate to have your doctor check the muscle specific enzymes to make sure it's not really a muscle problem.

High Blood Protein - I have been diagnosed with high blood protein and my MD does not know why. I saw on my patient chart that it may have something to do with my post-polio syndrome.

No, that's odd. Regarding high blood protein, was it a general elevation of protein? Was it a specific component of protein? There are certain proteins that are intimately involved with the immune system. Typically, the levels are not high enough to show up on a blood scan of protein. Dr. Perlman would want to know more about the type of protein. Elevated blood protein is not something that is seen in post-polio syndrome. She recommends this person try to get a better explanation of the elevated blood protein condition.

What do you know about external body braces as seen on TV?

There are probably three or four companies that are now developing these exo-skeletons. They are like extensions of some of the personal mobility devices we have seen. This is interesting technology, and obviously is going to get a lot of funding from the military which will push ahead the development. The availability outside the armed forces is not known, but it is very creative and does seem to work.

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How quick is fast recovery from acute polio?

If you have a partially damaged nerve cell from the acute polio infection, the odds are good that it could heal itself in one and a half to three months. If you have a dropout of nerve cells that have been permanently damaged you need the other nerve cells to grow back in to take over. That takes six to twelve months. Somebody who had excellent recovery in six to twelve months after their acute polio probably had a lot of remodeling, especially if their original polio was severe. So that person will be susceptible to post-polio related changes down the road.

Are just as many post-polio people showing up for help? More? Fewer?

Dr. Perlman thinks she is seeing fewer polio survivors, partly because it is harder to get an appointment. However, more polio survivors are probably seeking help because there is more knowledge about post-polio syndrome. Polio survivors are not just going to write it off to not exercising enough, etc., they are actually going to think about it. There are now more community resources, so many of the people who only went to Rancho or went only to see her at UCLA, have actually found reasonable advice in the community - usually from physical medicine and rehabilitation doctors.

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The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association. For additional information please call Diane at **562-862-8128**, or Richard at **562-862-4508**. Or email us at: **Rancho PPSG@hotmail.com**

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Support Group Meeting Information

NOTE: There will be NO June meeting for the Post-Polio Support Group of Orange County. We invite everyone to attend the Rancho Los Amigos Post-Polio Support Group on Saturday, June 23, 2012. The meeting will be at 2:00 p.m. in the regular meeting room - Room 1150 of the Support Services Annex (SSA Bldg.)

Post-Polio Support Group of Orange County will have their annual **Indoor Picnic and Barbecue** on Saturday, July 14, 2012, at 2:00 p.m. Meeting is in the Villa Park City Council Chambers. Marte Fuller **562-697-0507** or Marilyn Andrews **714-839-3121** for information.

Rancho Los Amigos Post-Polio Support Group will meet on Saturday, June 23, 2012. The meeting will be at 2:00 p.m. in the regular meeting room - Room 1150 of the Support Services Annex (SSA Bldg.). We will have an open discussion and review of post-polio information.

Rancho Los Amigos Post-Polio Support Group will have their **Annual Picnic** on Saturday, July 28, 2012, at 2:00 p.m. The picnic will be at Rancho Los Amigos National Rehabilitation Center, in the ATM Courtyard. A map is printed below. Please call Diane at **562-862-8128**, or Richard at **562-862-4508** for information.

