



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - May 2017

Post-Polio Pain

A Multi-Discipline Approach

Earlier this year there was an exchange of questions and replies on one of the original post-polio internet lists (post-polio-med@listserv.icors.org). That discussion began with a question about relief from leg pain.

The first post was from a gentleman who was trying to find a substitute for Bengay ointment. He had been using it for leg pain, but felt it was no longer strong enough. One of the first responses came in the form of another question, “Before anyone can suggest something for pain relief, we should know a little bit about your pain. For example, when does it hurt, why do you think it hurts, what are you doing when it hurts, etc.”

Several posts followed with suggestions about other ointments and salves. One person recommended massage. The person who asked the original question about leg pain and a substitute for Bengay responded, “No, I have never tried a massage, primarily because my pain is every day and I can’t afford getting a massage every day. My pain is the result of exhaustion. As the day wears on it gets worse. My legs have gotten weaker caused by post-polio. I have very little muscle left. I cannot bend down without extreme pain, then once I am down I cannot get back up without the aid of my canes. I suppose I could get a mobile device, but I refuse to allow myself to ride around the Walmart in one of those electric devices.”

A member of our support group replied, “My doctor, mentor, and friend, Jacquelin Perry, MD,

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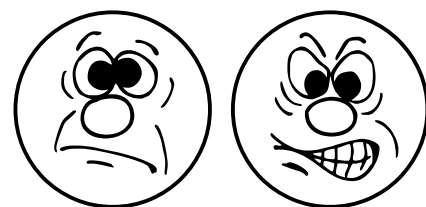
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The information presented at our meetings and/or contained in this newsletter is solely for information. It is not an endorsement of any product, medication, or individual.

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was one of the most respected polio experts. She would often tell her patients to be ‘intelligent hypochondriacs’ and listen to our body. She also described pain as our friend. She reasoned that pain is telling us that something is wrong, or we are doing something that we shouldn’t do. Our support group member reminded the gentleman about his refusal to use an “electric device” while shopping, and added that using one might lessen his pain level.

Within a short time another person posted, “I agree. Dr. Perry also said that their approach was to have people try ‘exercise’ (for pain or weakness, which can be overuse weakness, disuse weakness and weakness due to misuse of muscles, tendons, ligaments around the joints). If the pain goes away, continue it. If it gets worse, cut back. If it still causes pain, cut back even more. The mobility devices are for your convenience and for your safety and many, many people like seeing older people out and about. The honest ones know aging happens to all.”



Another person agreed, and added, “Dr. Perry is spot on. At Warm Springs, in GA, we were constantly reminded to listen to our bodies. As I aged, I chose to ignore this. My pain started getting so bad at night it was hard to sleep. When the physiatrist recommended I start wearing a brace at age 61, after 50 years of being brace free, I balked. A few years later at a post-polio clinic, the doctor again suggested bracing as well as using a motorized chair. I did get a brace and my pain levels went way down. I am now 77, and the weakness on my good side is really bad **if** I don't use the motorized chair when I go to grocery stores as well as big box stores. My point is, my quality of life is improved when I listen to my body and my doctors.”



A Physician’s Perspective

This discussion was brought to the attention of Sofia Chun, MD, the Chief of the Post-Polio Clinic at Rancho Los Amigos National Rehabilitation Center. Dr. Chun began, “The first step is, you need to figure out where the pain is coming from and get a diagnosis. Depending on the source of the pain, the treatment could be quite different.”

She added, “If it is tendinitis or bursitis of the joints: shoulder, wrists, fingers, etc., it might be treated with anti-inflammatory medications, injections, or even some topical creams. If the pain is determined to be from fatigue and is muscle related, which is probably the most common after joint pain, the treatment begins by identifying the reason for the pain.

“If it is coming from overuse and pushing yourself too much, then the treatment is obviously to

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give your muscles and nerves* a rest. There are certain circumstances where rest might not be fully possible. Sometimes you have to use your arms to do things. For instance, people who do not have good leg muscles must use their arms to transfer. In those cases, obviously, rest is good. You want to break it down into lifestyle changes, and break it into smaller tasks so you do less at a time and take breaks in between.

** Remember, polio is not really a muscle disease. The polio virus damaged our motor nerves. We have muscle weakness because the nerves that transmit signals, telling our muscles to move, were damaged.*

“If, despite all of those efforts, you are still having pain originating from the muscles, the treatment is somewhat similar to some anti-inflammatory type medications you take by mouth, or muscle creams like Bengay. But, you must understand that they are only symptomatic. If you take a lot of pain medications, even stronger pain medications than anti-inflammatory medications, and you block out the pain, that is actually doing yourself harm. Now you don't feel the pain, so you are doing more and you end up damaging your nerves and muscles permanently.

“For example, if leg pain is from overuse and fatigue, elevating the legs for periods might help the pain. Using pain medications, rubs and other things like that, is not really going to help the situation.”

Dr. Chun suggested that one way to reduce your pain is to ask yourself these questions:

- What am I doing?
- Can I do this less, or do it a different way?
- Is there anything that can be done to modify the way I am sitting or doing necessary daily activities?

She continued, “This is where a post-polio clinic comes in. The clinicians can help bounce off ideas – things that you might not have thought about. There are specialists at the Rancho Los Amigos Post-Polio Clinic, like occupational therapist Honor Galloway, who can assess the situation and make recommendations.

“You need to be knowledgeable and understand your own body. Couple that with experts who know what needs to be done. That is how you get to the root of the problem.”

I can't help it. It hurts!



**But, you see,
maybe you can help it.**

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Research and Studies

Studies that have been reported by the National Institutes of Health (NIH) show that fatigue, muscle weakness, and joint and muscle pain are the most common symptoms of PPS.

In a sampling of nearly one thousand polio survivors, about 80% of those surveyed complained of pain. When surveying pain intensity, people with PPS have reported levels of pain severity significantly higher than those without PPS.

Pain is not only common in PPS, but the pain tends to be rated as moderate to severe and is related to disruptions in daily living. Some researchers have documented that women with PPS are more likely to experience pain, and may experience more severe pain than men with PPS.

Joint pain in persons with PPS tends to be caused by overuse and postural changes due to unbalanced muscle strength. This often includes long term use of crutches. The shoulders are not designed to be the principal support for the human body.

Muscle pain is most often caused by overuse. Overuse, when thinking of PPS, usually refers to repetitive movements. Repetitive movements are things we do all of the time without even thinking about it, e.g. household chores, arts and crafts, going up and down stairs, and of course walking.

Each muscle in the body includes many *motor units*. A *motor unit* consists of a group of individual muscle fibers that are activated by a single motor neuron. Since polio attacked motor neurons, polio survivors often have fewer “motor units”.

When a muscle does not have a full supply of “motor units” it may still be able to function for a limited number of repetitions, but it fatigues sooner. The goal is to find a way to do the things we “must” do or “want” to do in a way that will reduce overuse.

Treatment and Preventing Overuse

Excerpts from a 2009 presentation by Vance Eberly, MD

You need to be smart about your activity level and you need to know your personal limitations. Remember, we are not saying don't do anything, just don't do too much. You have to learn from your body, and that is going to change over time.

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You may get a little weaker as you age, so you can't do what you used to do. If there is some activity you must do, you may have to break it up into three parts.

Many people need to break up their day; they lie down for 15 or 20 minutes, two or three times a day. That helps especially with back pain. Post-polio syndrome frequently affects your spinal muscles and your antigravity muscles. So sitting down doesn't help because you are using those muscles when you sit upright. If you didn't use them you would flop over, so you have to lie down. Polio survivors need to get out off their feet out of the chair and lie down to rest those muscles. When you get to this point where you've overdone it and you are having these problems, the best treatment is rest. Taking an anti-inflammatory medication might help and you can use ice packs, but it is best if you don't overdo in the first place.

If you have been going along fine and are now beginning to have these muscle spasms and achiness, it may be a sign that you are getting weaker and no longer have the strength and endurance. Maybe you need a brace which would help substitute for that muscle weakness. If you already have a brace, maybe you need a different one. These are signs that perhaps it is time to be re-evaluated by a polio specialist to learn your current muscle strength, and what recommendations will be made for your condition.

Lifestyle Modification

from the Physical Therapists' perspective
Maureen Jennings, PT and Eirik Blydt-Hansen, PT

The key for people with PPS is to understand that "pushing through" pain and fatigue is no longer acceptable. Rather, it is important to realize that pain and fatigue are signs that an activity is too stressful for the muscles and may lead to permanent damage and weakness. Prolonged or repetitive high demand activities, which result in pain and fatigue, must be moderated or discontinued.

One way to monitor muscle overuse is by keeping a log of daily activities. This will help pinpoint activities causing excessive fatigue and which may need to be moderated or avoided.

A survivor may be able to continue performing some activities but with frequent rest periods and monitoring. Studies have shown that resting for twice as long as the activity time may result in improved endurance and avoidance of fatigue. If these changes are made early, strength may be recovered enough to bring the muscles up to a more useful level but not for excessive strain. Dr. Jacquelin Perry's activity guideline is that a polio survivor can do anything as long as it causes (1) No pain and (2) No fatigue that last longer than ten minutes.

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Another important way to prevent overuse, especially with antigravity muscles and walking, is with a wheelchair or scooter. They are great, especially for long distances. Many patients, especially younger ones, are resistant to wheelchairs. They have to get to the point where it is a little too late and they have caused that damage and have gotten weaker because they have been overdoing it; then they will begin using a wheelchair or scooter, and say to themselves, “Why didn’t I do this sooner?” They will find that a wheelchair or scooter is actually very liberating.

We thank Drs. Chun and Eberly, and PTs. Jennings and Blydt-Hansen for their advice.

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Please submit your request to:

RanchoPPSG@hotmail.com - or send it to 12720 La Reina Ave., Downey CA 90242

Please Note! Important Meeting Date Changes!

Post-Polio Support Group of Orange County

On Saturday May 13, 2017, 2:00 to 4:00 p.m., Lorri Morris will talk with us about current Physical Therapy strategies for the treatment of the symptoms of Post-Polio Syndrome.

Ms. Morris is a highly experienced Physical Therapist who has helped many members of Post-Polio Support Group of Orange County. She is a valuable member of the team of therapists at the St. Jude Medical Center Rehabilitation Center.

This will be a joint meeting with the Rancho Los Amigos Post-Polio Support Group. **There will be no Rancho meeting in May.** We encourage all polio survivors in the area to attend this special meeting of the Post-Polio Support Group of Orange County.

Dr. Perlman’s presentation has been rescheduled for Sunday, July 16, 2017

Please see the following page for details.

Rancho Los Amigos Post-Polio Support Group Meeting Notices

No meeting in May. Please attend the Post-Polio Support Group of Orange County meeting on Saturday, May 13.

Saturday, June 24, 2017 - Annual Picnic. Our group will furnish all the food and beverages. You bring an appetite and a friendly smile (please see map on page 8).

Sunday, July 16, 2017 - Dr. Perlman. Joint meeting at the Post-Polio Support Group of Orange County (see announcement below).

A Presentation by Susan Perlman, MD

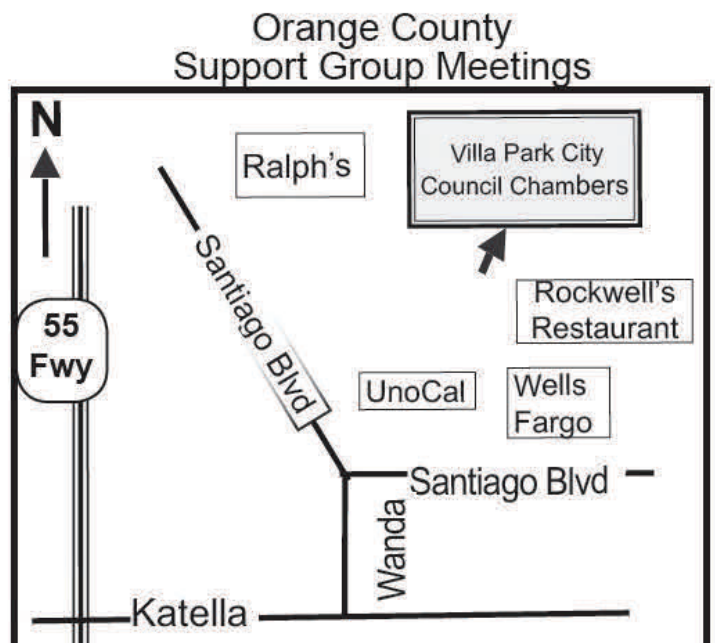
For many years Dr. Susan Perlman has met with Southern California polio survivors to talk about the latest polio research, and the most current treatment strategies. Dr. Perlman heads the Post-Polio Clinic at UCLA and consults with Post-Polio International, as well as with many of the physicians we rely on for our ongoing care.

These meetings are coordinated by the Post-Polio Support Group of Orange County and are scheduled as a joint meeting with the Rancho Los Amigos Post-Polio Support Group.

For Dr. Perlman's scheduling convenience, her presentations are always on a Sunday afternoon. This year's presentation will be on **Sunday, July 16**, from 2 p.m. to 4 p.m.

We always look forward to these annual presentations, when Dr. Perlman generously shares her time, energy, and knowledge with local polio survivors.

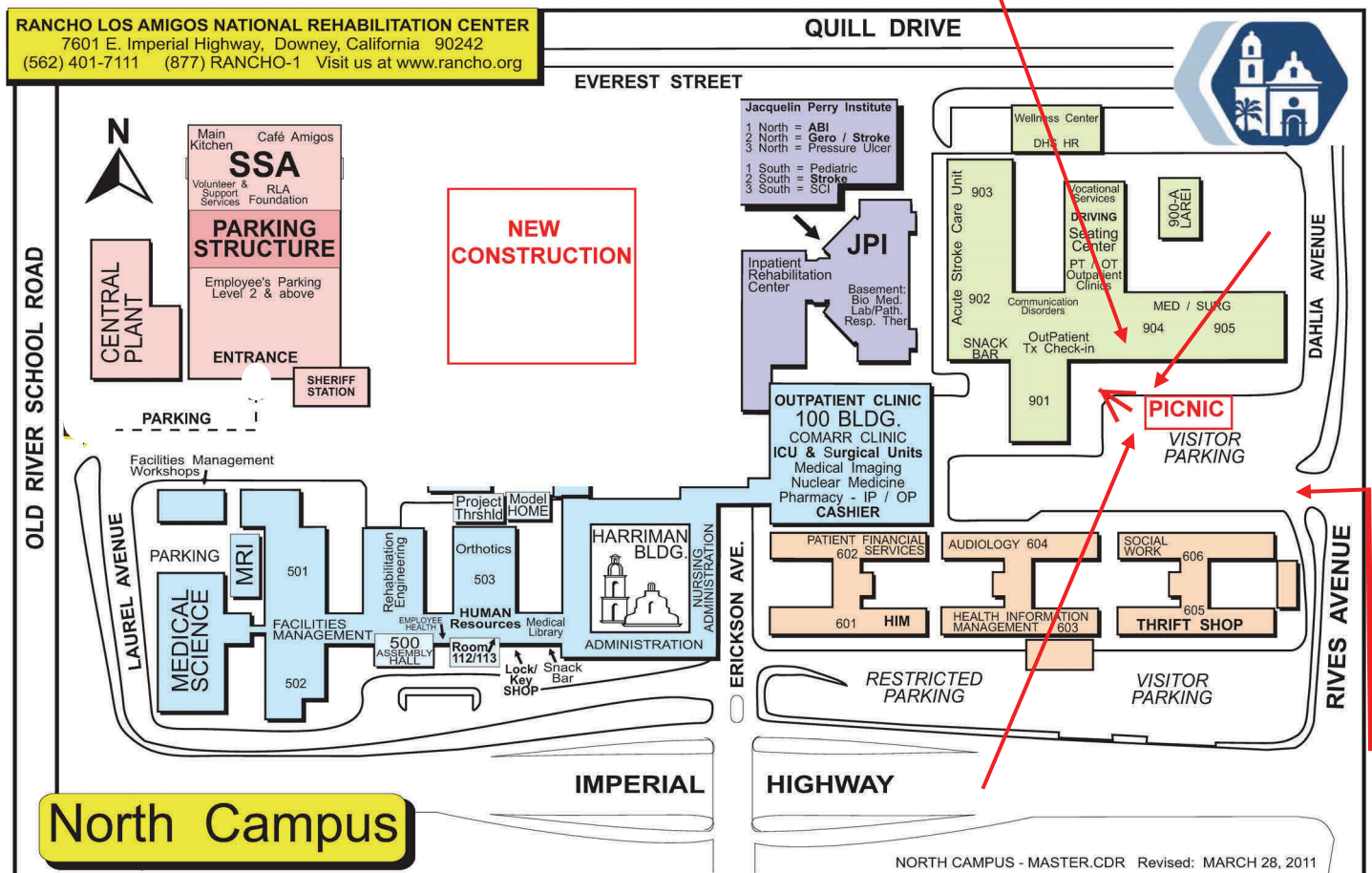
The meeting will be in the Villa Park City Council Chambers. Follow the map at right, and join us for this informative presentation.



Rancho Los Amigos Post-Polio Support Group - Annual Picnic

Saturday, June 24, 2017 2:00 p.m. to 4:00 p.m.

At Rancho Los Amigos National Rehabilitation Center, in front of the 900 Building
Enter Rancho from Rives Avenue - Please see map below. If you need additional directions
or more information, please send an email to: polio1953@gmail.com



Please join us for this fun time.

You will enjoy yourself, and we will enjoy seeing you.

Bring a family member or friend.

FOR SALE

2005 Dodge Grand Caravan with VMI Conversion

Very good condition. Please telephone Diane at 562-861-8128