

Founded in 1989
The Post-Polio Support Group of Orange County
NEWSletter
 January 2016

18552 Cork St
 Fountain Valley CA

Website: ppsupportoc.org

Roni and I back from retirement RV Travels



Our trip was a big success. We visited a majority of the National Parks in the USA and Canada. National treasures of both countries, which draw millions from around the world to marvel at plunging canyons, surreal

volcanic activity, glaciers, multitudes of lakes, towering mountains, vibrant swamps and old growth forests, etc... Somehow the world got on with us being "disconnected" from newspapers and TV. We read books and played board games when we didn't have electric hook-ups. When we did, we could watch DVDs which were fun and relaxing after a day of driving (tow car) or walking to see the views. We are working on a list of power chair accessible trails we encountered.



I am happy to rejoin Janet as co-editor of our newsletter. She is having eye surgery and I may be doing the lion share for several months. It is a labor of love for me.

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Finger Food Potluck
Saturday January 9th

Villa Park City Council Chambers
17855 Santiago Blvd Villa Park
2pm - 4pm



You probably would not be surprised that this informal setting is very good to get to know others in our group better. However, you might be surprised that

this yearly event is somehow the best way for many of our members to ask questions, and for others to have a chance to reply. We, as a whole, have many hundred years of practical know-how in living with Post Polio Syndrome. More than that, we truly care about how each of our members is coping with what has turned out to be a life long illness. Most of us have raised children and now care for family members who are in worse shape than we are. Conversation and some good laughs with people who understand does wonders.

Please bring a dish to share, if you are able. If not, please come anyway. There is always enough!



We will get together rain or shine. Call **949-981-2605** from the parking lot if you need assistance making your way into the meeting hall. ■

Question: *I am a 61-year-old female who has recently been diagnosed with post-polio syndrome. I am looking for the latest research on improving muscle function in the affected limb. Are there new medicines that can improve muscle functioning?*



Answer: Research studies have demonstrated that muscle strength and endurance can be improved among polio survivors, even those diagnosed with PPS, through individually designed exercise programs that are monitored and advanced slowly over three to six months. The major challenge is to find a personally optimal intensity of resistance and of duration to achieve desired results (a goal) without any negative consequences (side effects such as pain or activity-limiting fatigue).

There are no medicines that research has clearly shown to be effective for specifically improving muscle functioning of post-polio survivors. Clinical experience suggests that medicines to control pain that interfere with activity or exercise may help restore or improve lost muscle function. Taking medicines to control or cure other general health problems can also be important for permitting improvements in muscle function by promoting participation in exercise and/or activity. However, all medicines must be monitored for possible negative side effects.

It is also important to remember that a healthy diet with sufficient protein, optimal fat and calories and generous vitamins and minerals is critical for optimal muscle functioning. Limiting high stress, having optimal sleep and achieving good emotional health are also all important for obtaining and maintaining limb muscle function through optimal activity and exercise. ■

Question: *Why does no one ever address the problems that polio caused to the digestive system? I had polio when I was 6 years old and have had problems with my digestive system ever since. Has there been any research on the effects polio had on the digestive system?*

Answer: While there are many polio survivors who complain of heartburn and GERD symptoms, there is no evidence to support the idea that these problems are more common than among people of the same age without a history of polio. You are the first polio survivor that I know of that has experienced "stomach digestive problems" ever since their original polio. You don't indicate how severely affected by polio you were or if your breathing muscles were affected greatly or if you have scoliosis.

Some of the secondary complications of more severe polio paralysis can contribute to digestive problems because of inactivity/immobility and/or weakness of abdominal wall vs. diaphragm muscles. There is no evidence that the poliovirus had a direct damaging effect on the digestive system organs, and symptoms or problems would need to be managed in the same way that they would in anyone, with the exception of any need to modify treatments because of significant disability.

Research on the subject isn't being done because of the absence of plausible hypotheses for why polio would have directly affected the GI system. ■

Question: / had polio at age 5 in 1968 apparently contracted from the oral polio vaccine. The acute illness lasted about a month, then a slow recovery ensued (upper and lower right limb involvement) that took about a year. Is there any difference between PPS symptoms in patients who have contracted the disease through vaccine and those who contracted it naturally?

After many years with mysterious health problems, I have been diagnosed with PPS by my family doctor, but neurologists who we have consulted are confused by some of my most prominent symptoms. They say that they are not familiar with PPS causing anything more than difficulty swallowing (which I have). However, I also have severe reflux, intermittent gastroparesis, slow GI motility, constipation and right upper quadrant pain after fat-containing meals. Are these added GI problems in line with what could be caused by PPS?

Answer: In answer to your first question, there are no known differences between the late effects of polio that develop in people with a history of vaccine-related polio vs. wild polio. The way you describe your recovery after polio also sounds typical for recovery from wild polio illness/paralysis, and there is a wide variation in the speed of recoveries that is primarily due to the severity and extent of nerve damage/nerve loss, not immunological issues.

Regarding your second question about gastrointestinal problems beyond swallowing difficulties related to throat muscle weakness, I would have to say that there is no convincing scientific evidence or study that shows they are directly related to having had polio. There are reports that suggest aging polio survivors MAY have a higher incidence of gastrointestinal motility disorders, as you describe them, but the evidence is weak and not widely accepted as "real" compared to chance occurrence because these problems are common in many older populations. The treatment would also be the same in any case. ■

Question: *What are the symptoms in patients with post-polio syndrome with facial involvement? I am a PT with facial nerve involvement due to polio.*

Answer: Regarding facial nerve involvement after poliomyelitis: It is not common but also not rare. I have seen well over a dozen patients with significant one-sided facial weakness secondary to polio. I have not seen anyone who reported facial weakness early on after acute polio who then had complete resolution of facial weakness and who then found the facial weakness returned during the typical post-polio syndrome years (20-40 years later).

Among the post-polio survivors with chronic facial weakness whom I have known for more than 20 years as a doctor, none have had appreciable or significant worsening of the facial weakness or any new complications from it. Some minor concerns that have occurred include increased drooping of the face and appearance change, some tendency to slur words more and/or work harder on clear articulation, and some increase of minor drooling from the mouth, particularly if there are also new swallowing difficulties at the throat.

If any of these problems were to become significant, I would suggest a consultation and evaluation by a PhD speech and language pathologist who sees patients with dysphagia (swallowing problems) and/or an Ear, Nose, Throat (ENT) surgeon. ■

Send Dr. Maynard your questions to info@post-polio.org
See other Q &A s at www.post-polio.org/edu?askmay.html

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

Question: *I worked so hard to walk again after acute polio. I have extreme pain in my hip in my weaker leg and since I had a knee replaced, my back pain when standing is also extreme. I use a cane sometimes and I know I should use a scooter or wheelchair, but I just can't overcome that horrible feeling of being a failure if I do. Besides that I have gained weight and if I don't move some I will gain even more. Help!*

Response from Rhoda Olkin, PhD:

Ohhhh, been there! I have pain in my knee area, my back hurts, I can't stand or more than a minute, and I spent my formative years doing everything possible to remain ambulatory. Now I use a wheelchair or scooter 90% of the time, crutches the remaining 10%, starting about 10 years ago. My weight gain has been alarming, and I no longer see in the mirror the person I think I am from the inside (who seems to be much younger, cuter, thinner and with great hair!). But I do not see a failure, only flaws that I can address. The flaws do not include the fact that I use a wheelchair, because doing so got me my life back. Pain and limited ambulation were forcing a reduction in activities that narrowed my world.

We get so many messages from everywhere about how walking is good and how the need for any sort of assistive devices is bad. Consider the language often used: "Wheelchair bound" (with the emphasis on the inability to get out of the wheelchair), "non-ambulatory" (not able to walk), "suffers from polio" (as if that's all you are). What if we said "uses a wheelchair" and "fully mobile" (by whatever means!) instead? A wheelchair is not a failure, but a window into a wider world of options. Imagine you lived in a poor country with no access to wheelchairs. In such circumstances people devise their own sets of wheels, and getting a real wheelchair would not represent failure, but wings to fly. Try an experiment. Go to a big store that has a scooter for customers to use. Do not use it. Go up and down each aisle. Note your level of fatigue and pain. Now go on another day and use the scooter, again going up and down each aisle, and again noting your level of fatigue and pain. What do the results tell you?

Okay, I'm not going to gloss over the significance of using a wheelchair. First, using a wheelchair often means less overall body movement, which can lead to secondary conditions (weight gain, decubitus ulcers, lassitude of some muscles). You have to be careful to avoid these. Since you can walk, do so a bit, or get on the floor and move/exercise, or do chair exercises. (Once a day I walk with crutches from my office to the bathroom and back, a total of 100 steps. I notice I feel better when I do this.) Second, it's a change in body image. People everywhere start reacting to you differently, and that feedback forces some recalibration of the self. Third, it can be harder to maintain or lose weight. Make sure you don't have another condition (hypothyroid, sleep apnea) and then find a balance in intake and output that you can live with. And when you do, write me, so I can use it as well!

Do not let anyone - family, friends, doctors, rehabilitation specialists, physical therapists - lead you to believe using a wheelchair represents failure. It is an alternate means of mobility and does not change the fundamental you. ■



Rhoda Olkin, PhD

Ankle Braces for Post-Polio Leg Pains

Frederick M. Maynard, MD, Chair, PHI Medical Advisory Committee, Marquette, Michigan

Greg Ramme is 52 with a history of mild weakness in his legs since developing vaccine-related paralytic polio in 1964 at age 3. He learned to walk with bilateral long-leg braces and crutches and used them until age 8 when his legs had become strong enough to walk well. After high school he studied mechanics and worked for more than 25 years as a diesel mechanic. He enjoyed many active hobbies, including fishing and hunting, around his home in the Upper Peninsula of Michigan.

At age 43, he still enjoyed frequent Nordic skiing for 10 to 12 kilometers. When he was 45, Greg developed numbness in his legs over a short period of time and began to notice gradual weakening and pain after exercise of his leg muscles.

At 49, he was diagnosed with lumbar spinal stenosis and received decompressive laminectomy surgery. After post-operative physical therapy, he was able to walk without a limp, but his leg muscle strength was only a grade of 4 to 4+ on the right and 4 to 4- on the left, which represents mild weakness.

Greg retired at age 50 on disability. In spite of further physical therapy, stretching exercises and massage therapy, he had to take pain medication and was frustrated by not being able to walk very far without more leg pains and by being unable to enjoy hobbies or sleep well because of leg muscle pains.

After evaluation by doctors and therapists at a Post-Polio and Wellness Retreat in Big Bay, Michigan, bilateral lightweight "partial ground-reaction force" ankle foot orthoses¹ were recommended. Their purpose was to assist his functional, but weakening, leg muscles that had chronic overuse pains.



Greg Ramme holding one of his braces. "Without PHI's help I would not have been able to get my braces. The braces were the extra assistance I needed, and I am very grateful to have them."

Because he had lost his health insurance and was not yet eligible for Medicare, he applied for financial assistance from PHI's Joyce and Arthur Siegfried Memorial Fund. He received the maximum amount of \$800, which covered about half of the cost for his two braces, and he was able to obtain them a few months after they were recommended.

After using them for two months, he reports that he is mostly pain free at last and off regular pain medication. He wears the braces all day, not walking more than a quarter mile without resting, does stretching exercises, takes frequent hot baths and receives weekly leg-muscle massages from a friend who is a massage therapist. ■

Reference

1. Ottobock WalkOn® model of AFO

PHI administers the Joyce and Arthur Siegfried Memorial Fund. Polio survivors living in Missouri can apply for funds from the Gilbert Goldenhersh Memorial Tribute Fund for bracing and modified shoes. Email Brian Tiburzi at info@post-polio.org for an application for either Fund. The maximum amount given per applicant is \$800.

Challenges ahead for our group!

- Too few are attending meetings, despite the fact that we provide excellent presentations. Do we need to meet in such a large meeting space every meeting? Would a restaurant side room be better for a small group? What topics would get you to attend a meeting?
- Are you getting what you want from the newsletter. What topics would you like to read about?

Please call Aleta at **949-559-7102** with your thoughts. Or email Priscilla at prisofoc@aol.com or Baldwin at abaldwinkeen@gmail.com

Discussion suggestion:

This issue provides a variety of topics using Post-Polio Health International as the information source. I highly recommend subscribing to those who can: \$30 a year gets you their info packed quarterly newsletter. Reading the newsletters and attending two PHI conferences made a huge impact on the way I have personally come to live with PPS. I started using forearm crutches and got a power chair early after I was diagnosed in 2000. PHI started me to question decisions. I absolutely see the need for many, if not most, survivors to use power chairs and other mobility devices. For myself, I have gradually reduced my use of them and expect to not use any device other a brace for the time being. Due to motivation in dealing with non PPS health problems my personal mobility has markedly improved. I have lost and kept off weight, get daily exercise, including lots

of walking using a **custom full leg brace**. I would like to discuss with newsletter readers my experiences without boasting or appearing to have answers. I don't know why I am able to do as much physical activity as I do, but it might be useful to some for me to describe what I have done over the last 15 years to regain mobility. I would be very interested if anyone else has had a similar experience. Write in via "snail mail" or email. Let's share with other readers. ■

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Author: Rhoda Olkin, PhD and Stephanie T. Machell, PsyD
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Author: Frederick M. Maynard, MD
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Rancho Los Amigos Meeting

Movie Time

**Saturday January 23rd
2 pm - 4 pm**

Future Rancho SG Meetings

Topics to be determined

Saturday February 27th

Saturday March 26th

Orange County Meeting

Finger food potluck

**Saturday January 9th
2pm - 4pm**

Future PPSG of OC Meeting

Custom Bracing with live model
Rod Cuervo

Certified Orthotist
Mission Prosthetics, Inc.
Orange, CA

Saturday March 12 2-4 PM

We survive on year round donations from our readers. Small donations from all readers will ensure that our newsletters and meetings will continue to provide accurate information for polio survivors.

Please mail your donation to **Polio Survivor Association Support Groups' Newsletters** at 12720 La Reina Avenue, Downey, CA 90242. Make your check out to **PSA—Support Groups**, and write "Newsletters" in the memo area of the check.

The Rancho Los Amigos Post-Polio Support Group publishes on even numbered months and the Post-Polio Support Group of Orange County publishes on the odd numbered months. We share the same mailing list, and all donations are shared equally.

Special thanks to Wes Chapin, Betty Thompson, and Orva Sodman. We mention **donations** but not the amount, as all donations make our support groups possible.

How to contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association.

For additional information please call Richard at **562-862-4508**

Or email:

Rancho PPSG@hotmail.com

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Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102

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