

Founded in 1989
Post-Polio Support Group of Orange County
15231 Marne Circle Irvine CA 92604

WEBSITE: ppsupportoc.org

March 2018 Newsletter

Saturday March 10th 2-4 pm

Are you prepared for:

Earthquakes?

Fires?

Flooding?

We have had all 3 recently! The 5000 homes that burnt to the ground in Santa Rosa were in terrain similar to most of suburban Southern California. One change in wind direction could have brought the Anaheim Hills fires racing into Tustin. A fire in one neighborhood would have generated internal wind and a rolling fire storm that could have leaped into Irvine and Santa Ana. And we all know that it is only a matter of time before a large quake hits. All it will take is a huge downpour in a short period of time and our drainage system will be overrun, even in "flat" terrain. Fire, flood, or earthquake could knock out electricity, clean water, and natural gas supply. Come and get the latest information on disaster preparation March 10th from Jerry

Inside this issue

Pg 2: Disasters Continued

Pg. 2: New meeting place starting July 2018

Pgs.3 - 4: Ask Dr. Maynard

Pg 5: Reasons to subscribe to Post-Polio Health International

Pg 7: Meetings and info

Pg 8: Maps

**Dr. Perlman
Presents!
Sunday May 6th**



Dr. Perlman is the director of the PPS Clinic at UCLA. She spreads her knowledge of the late effects of polio to neurologists, orthopedists, primary care and physical medicine and rehabilitation doctors to whom we go for ongoing care.

On Sunday May 6th we will hear about the latest PPS research and care. Last year she gave us the latest understanding of the cause of PPS and why some of us may be affected more than others. She also listed the things known for certain about PPS. Notably, new or increase "polio" symptoms are actually PPS only about 1/3 of the time. New or increased symptoms may be due to another medical or neurological illness or orthopedic problem which must be identified and treated. She emphasized 5 key guidelines that many studies have shown to be successful in halting the progression of PPS symptoms and promoting improvement of 1 to 2% per year. You or a friend or family member could go to ppsupportoc.org and click on Newsletters, and then select our 2017 October-November issue to read a summary of Dr. Perlman's 2017 presentation. **Prepare for May 6th!**

Couchman. He is a volunteer educator for the Red Cross. He also volunteers for fire watch in Orange County. As a career carpenter he is very knowledgeable about road, building and housing construction. Also, he has first hand experience of the needs of the disabled through work on volunteer projects for clients of the Dayle McIntosh Center, and being the son of a very "independent" woman now in her late 90s.

- Are you registered with your city/county for special assistance with first responders?
- Do you have a list of your medications and physicians in your wallet/purse and in a prominent place in your home?
- Do you have proper disaster supplies?

Do you have plans for an extended blackout, no clean water, or no natural gas?

- Do you have a disaster communication network to neighbors, friends, and family?

Most of us cannot say "yes" to all of these questions. Jerry will motivate us and give us the information to do the necessary preparation to be able to answer **YES** to

each. **See you Saturday March 10th at 2pm!** ■



Jerry Couchman

Excellent communicator with lots of handouts!

Living Independently and safely with PPS is a goal we all share.



Some of us have used the services of the Dayle McIntosh Center for Independent Living. We are very fortunate to have this outstanding organization located in Anaheim.

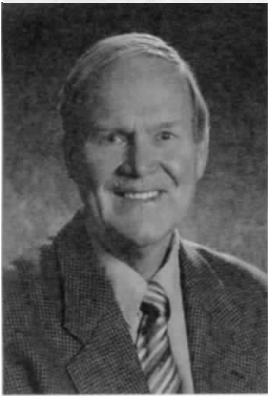
They take safety seriously!

DMC supervisor, Bruce Morgan is responsible for **safety and emergency planning**, and serving on specific task forces and advisory bodies related to disaster coverage.

Call DMC at: **(714) 621-3300**

Starting July 14 we will meet in the community room of the Newland Street Church of Christ in Garden Grove. No charge! Easy to get there. Good parking and wheel chair access. A detailed map will be on the first page of our July newsletter. Our March and May meetings will be in Villa Park. The move will save us at least \$270 per year.

Ask
Dr. Maynard



Frederick M. Maynard, MD

Dr Maynard:

- Great analytical ability
- Vast knowledge of medical literature
- Many years of clinical experience
- Responds to each individual
- Respects patients intelligence
- Encourages patients to take charge of their health care
- His approach is appreciated by many polio survivors
- His approach is emulated by health professionals

These are Joan Headley's (retired PHI director) phrases. She started his column in 2009. It is a gift PHI readers look forward to each issue.

Question: *My sister who had polio in 1953 at age 17 was affected from the waist down. She also struggles with bipolar disorder. Last winter she was hospitalized on a behavioral health floor for 44 days. Her crutches were taken away because they were considered weapons. She spent the days in a wheelchair and did not receive any physical therapy. Upon her release, we found she has lost what strength she had and now uses the wheelchair all of the time and is in a nursing facility. It is difficult to convince hospitals to allow the use of the usual assistive devices or equipment, and even more so, when it is a mental health facility. Do you have any advice for the family members who are advocates?*

Answer: It is very important for family members or friends to become effective advocates for polio survivors when they are hospitalized for serious medical problems, including mental health problems. One of the best ways that they can do this is to read PHI's monograph titled "Post-Polio Health Care Considerations for Guidelines for Families & Friends" available at www.post-polio.org/edu/healthcare/.

They will learn that it is an important issue for a polio survivor to minimize any major decrease in their usual daily activities, especially walking and self-care related mobility. This is because a polio survivor's strength and/or flexibility can rapidly decrease with inactivity. Most health care professionals cannot be expected to know this.

One of the basic problems your sister's unfortunate experience illustrates is the difficulty our current health care system has in treating people with "double diagnoses," such as an acute mental health condition necessitating hospitalization AND a chronic medical disability condition. Significant post-polio leg weakness requires continued physical exercise to not worsen, even if a person's usual daily walking provides sufficient exercise.

Your sister should have received physical therapy services in order to ensure that her walking would continue in a manner safe in her unfamiliar environment of a psychiatric facility. An advocate might need to explain to physicians and nurses of the psychiatric facility that continued walking with crutches and performance of other self-care activi-

ties in her usual fashion are essential for her continued capability for doing them in the future. It is important for them to understand that her daily walking is as necessary as continued insulin or chemotherapy treatments for a person with diabetes or cancer who is hospitalized in a psychiatric facility.

One of the challenges for family members or other advocates who may try to ensure that a polio survivor's need for usual activity-related exercise are met is that they must "play by the rules" of confidentiality and get written permission from the patient to speak with providers, especially when a hospitalization is for mental health problems.

This can present a formidable challenge. In addition to addressing necessary assistive device use and usual activity, one of the best things for an advocate to insist on is a consultation by a physician who is familiar with the polio survivor's usual needs for maintenance mobility and independence. This could be a primary care physician or a physical medicine and rehabilitation or neurology specialist who knows them and who is willing and able to get involved.

In summary, my best advice is to "get involved" and to not rely on or trust the "system" to do the right thing relative to addressing important special needs arising from a person's polio-related impairments and adaptations. ■

Question: *I would like your take on using drugs such as gabapentin for use in treating PPS pain.*

With the new drug laws, my doctor has prescribed this drug for pain instead of the hydrocodone I was taking. (Editor's Note: Under a final rule issued by the U.S. Drug Enforcement Administration, hydrocodone combination products are now in a more restrictive category of controlled substances, along with other opioid drugs for pain like morphine and oxycodone. (See more at: <http://blogs.fda.gov/fdavoices/?s=oxycodone&submit=Search#sthash.e7bJpWM6.dpuf>) I can usually manage the pain during the day but have problems sleeping. Some nights it feels like someone is trying to peel my muscles from my bones.

I am asking because gabapentin is used to treat seizures, but I do not have seizures. When I looked up the usage, it is also given for treatment of pain for the shingles for a period of three to four months. Whatever I decide to take for pain, I will possibly use for the rest of my life. Has anyone done a study of the long-term usage of gabapentin for post-polio pain? I do not want to take this medication and find out it was not good for managing post-polio syndrome.

Answer: Gabapentin and pregabalin are only approved for control of seizures and fibromyalgia (in the case of pregabalin). There are no studies supporting their effectiveness for leg cramps in the survivors of polio. Gabapentin is the most widely prescribed drug and used "off-label" for chronic pain syndromes of all sort. If these drugs are used for leg cramps, they should be evaluated carefully on an individual basis relative to their effectiveness and the optimal minimally effective dose.

For survivors with leg cramps, a thorough history and exam should be done regarding the most likely cause(s) of the cramps. Tight muscles are the most common contributing factor, but they can be treated with stretching. The next most common cause is overuse/misuse of the leg muscles. Metabolic imbalances of calcium and magnesium are also common. None of these common causes are likely to respond to treatment with gabapentin/pregabalin.

In regard to your specific concerns about trying it: gabapentin appears to be safe from the standpoint of serious side effects from long-term use. There are many non-serious side-effects in the short-term for many people who take it, particularly sleepiness, fatigue, mental slowness, nausea. They stop when the drug is not taken.

In your question, you mention problematic pain, particularly at night, and for this problem I would encourage you to try gabapentin at a small dose (100 mg) taken about one hour before going to bed. If it is helpful and your night-time problem is not every night, you can take it “as needed” at night, but it may take an hour or more to be helpful.

Don't be too concerned about it being listed as an anti-seizure medicine or a helpful treatment for shingles-related pain. It does help these conditions and because they have been studied sufficiently, it is legal and appropriate to say that it helps some with these conditions.

I know from my own practice and from speaking with other physicians that it can be prescribed safely and is sometimes helpful as an adjunct to effective pain management for polio survivors. It is probably a better choice for chronic pain than regular use of hydrocodone. Nevertheless, it should be considered as a “pain modulator” for chronic musculoskeletal pain and certainly not a true analgesic or a primary treatment for PPS pain. ■

The preceding article has been granted the Permission to Reprint

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A Cautionary Tale about Post-Polio Shoulder Surgery: One Story, Three Perspectives

Sunny Roller, MA, Ann Arbor, Michigan, and Frederick M. Maynard, MD, Marquette, Michigan

One must be very careful about choosing to have orthopedic shoulder surgery, especially if one is a polio survivor with a complicated disability. This is the story of Liina Paasuke, our friend with polio who recently had shoulder surgery. It is our hope that by presenting it and our individual perspectives on it, readers—both consumers and professionals—will more fully understand the issues and benefits of the choice to have, or to prescribe, shoulder replacement surgery (also known as Total Shoulder Arthroplasty or TSA).

Liina contracted polio at age 17 months. As a preschooler, she underwent several surgical procedures on her severely paralyzed legs. When she began mainstream schooling at age 6, she was able to walk using bilateral long leg braces, a corset and forearm crutches. After high school graduation, Liina earned an MA in Guidance and Counseling at the University of Michigan (U-M) which commenced her 30-year career with the Michigan Department of Vocational Rehabilitation at U-M, counseling people who had physical disabilities. During her young adulthood, Liina was entirely independent in all personal and advanced activities of daily living (ADLs). She walked as far as she needed to go using her devices with minimal difficulty. She drove a car with hand controls. In 1979, she purchased a three-bedroom home that she still lives in today.

Although Liina's general health remained excellent, by the early 1980s she found it increasingly difficult to walk long distances and experienced symptoms of Carpal Tunnel Syndrome. Adapting to these issues in 1984, she obtained her first electric scooter.

Over the next 20 years, she slowly gained 25 pounds and gradually decreased the amount of time and distance that she walked due to increased effort and greater fatigue. By 2006, she was essentially ambulatory inside her home only. She began dragging her right foot during sitting and could not negotiate a single step. By 2010, due to slowly declining strength and endurance, she could no longer complete bathing and toileting in a regular bathroom. With assistance from her church, she was able to remain independent in her home with a remodeler scooter-friendly bathroom, bedroom and kitchen.

Beginning in 2012, she developed increasing right shoulder pain. After her physiatrist diagnosed her with rotator

Liina Paasuke (left) connects over coffee with Frederick M. Maynard, MD.

continued on page 3

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Welcome to Polio Place

EXPLORE THE PAST, THE PRESENT AND HELP BUILD A PROMISING FUTURE FOR THE WORLD'S POLIO SURVIVORS

You are invited to learn by searching the major sections and sub-sections and to add your knowledge by Submitting an Artifact or Contacting Us.

WHAT'S NEW?

Home

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Medical Articles

There may come a day when there will not be a volunteer to be the editor for the Post Polio Support Group of Orange County. There is more and better information In Post Polio Health. We could use postcards to announce meetings and hope that readers will take the personal responsibility to keep informed about PPS through Post-Polio Health.



Rancho Los Amigos Meetings

Saturday, March 24, 2018

2:00 p.m. to 4:00 p.m.

Preparing for Disasters

Saturday, April 28, 2018

2:00 p.m. to 4:00 pm

Improving our lives with gadgets, home improvements, and helpful ideas.

Sunday May 6th

Dr. Perlman will give her annual presentation in Villa Park

Orange County Meetings

- Saturday March 10th 2-4 PM
Disaster Preparedness for the disabled
by Jerry Couchman, Red Cross Volunteer
- **Sunday** May 6th 2-4 PM
Latest PPS research and care
Dr Perlman from UCLA PPS Clinic
- Saturday July 14 2-4 PM (tentative)
Travel designed for the disabled
- Saturday September 8th 2-4 PM
Sharing ideas for home modifications and "gadgets" to live better with PPS.
- Saturday November 10th 2-4 PM
HICAP on Changes in Medicare

A thank you to these donors since our January newsletter: Roberta Rak, Kenneth Baragar, Audrey Hoodkiss, Nancy Powers, John Tully, Jack Delman, Marilyn Andrews, Eileen Keeler, Bob Robinson. Lillie Jones and Emma Eivers.

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@hotmail.com

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Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102

or email Priscilla at prisofoc@aol.com

WEBSITE: ppsupportoc.org

Please mail your donation to **Polio Survivors 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 section.

The OC Group usually meets 2nd Saturdays of odd numbered months. Its newsletter is published more or less quarterly. The Rancho Los Amigos PPS Support Group meets most months and publishes on even months. We share the same mailing list. All donations are shared equally.

Disclaimer: Information provided in ours newsletters and at our meetings is provided by the PPSG of OC and the Rancho Los Amigos Support Group solely as information. It is not to be taken as an endorsement of any product, individual, medication, or treatment. If you have personal medical problems, please consult a physician knowledgeable in the late effects of Polio. Unless otherwise stated, the articles in this newsletter may be reprinted, provided that they are reproduced in their entirety and that the author, the original source, and the PPSG of OC and/or the Rancho Los Amigos Support Group are acknowledged in full. Copyrighted articles require prior approval before re-printing. No article may be edited.

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