

# NEWSLETTER

Post-Polio Support Group of Orange County

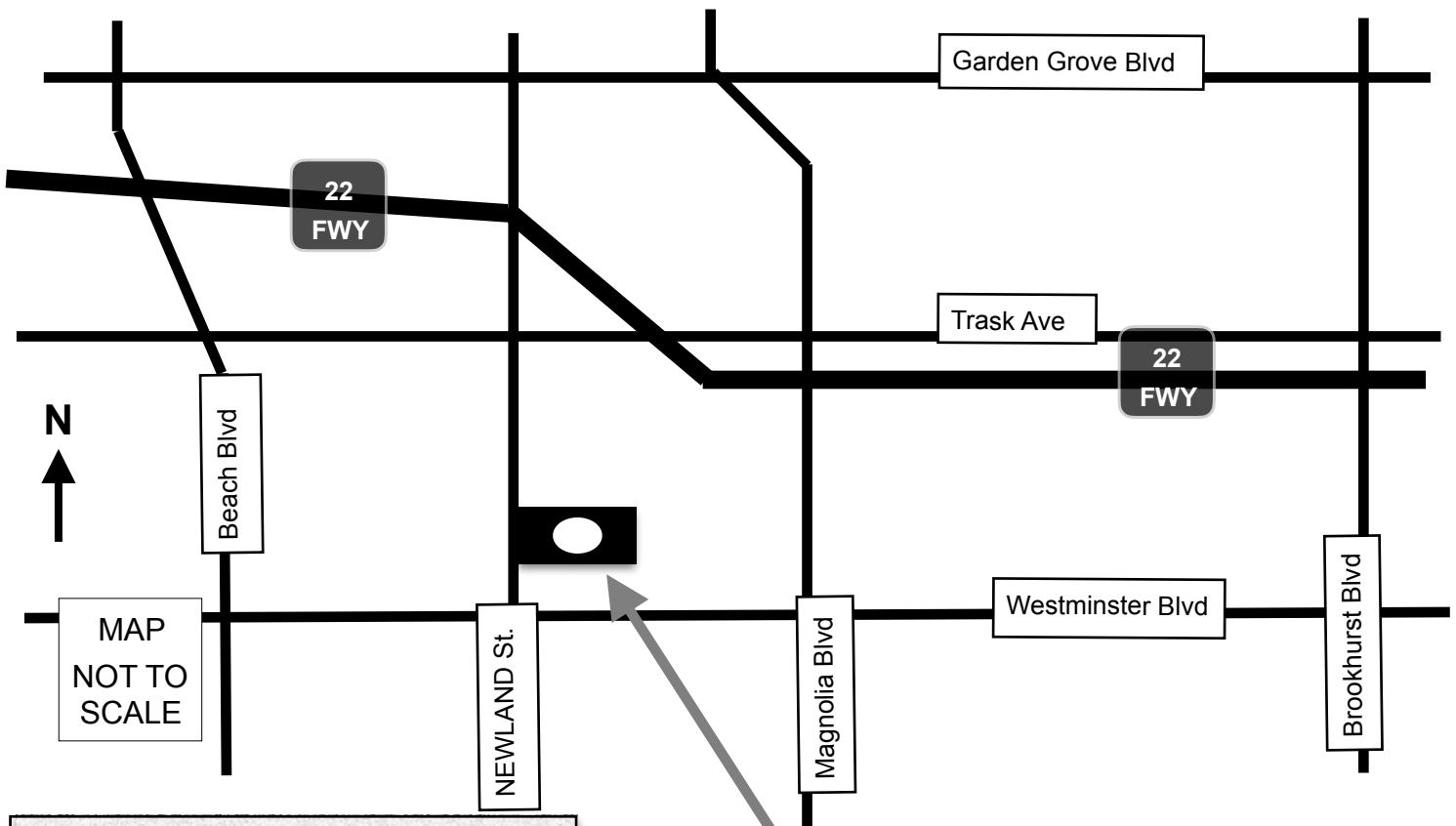
Founded 1989

WEBSITE: [ppsupportoc.org](http://ppsupportoc.org)

15231 Marne Circle Irvine CA 92604

July - Sept 2018

## New Meeting Location !



Going WEST on 22 FWY  
EXIT Magnolia/Trask  
Turn LEFT onto Trask  
Turn LEFT onto Newland  
Church is on **left** in one mile

Going EAST on 22 FWY  
EXIT Beach Blvd  
Turn RIGHT onto Beach  
Turn LEFT onto Trask  
Turn RIGHT onto Newland  
Church on **left** in one mile

Newland Street  
Church of Christ  
13852 Newland Street  
Garden Grove CA 92844

**JULY 14th** 2pm - 4pm

**What are our travel opportunities?**

**What can we do to work around unforeseen barriers?**



### SEEING MANY PLACES

- Tours of USA by train, bus, or riverboat
- Tours of Europe, Latin America, Asia by ocean liner
- Riverboat tours of Europe

### KICKING BACK IN ONE OR TWO PLACES

- In a lodge in one of our **majestic** National Parks or Monuments
- In an **auberge** in rural Europe

### John Mowbray

has years of experience helping people with disabilities achieve what we want when we choose to use our savings to travel.



☀ We have a **right to experience** the joys of seeing the historic and beautiful places we read about in books or see on our television screens.

- ☀ We also have a right to **bathrooms** with toilets we can use!
- ☀ Pitfalls we can avoid
- ☀ Best and worst countries for those with our needs to visit
- ☀ **Questions** we MUST ASK our travel planner.

**SEPTEMBER 8th** 2pm - 4pm

### Old School New School and Beyond

**Which of the following has been used to open a jar of pickles?**

- Butcher knife
- Floor
- Table or counter
- Rubber band
- Gripper-pad
- Rubber gloves
- Cap gripper
- Church key or replica
- Six foot tall can opener
- Black and Decker Jar opener
- Twister fits on lid



Bring this list with you to September 8th meeting and find out some answers to the question. You may have better answers.

**We will discuss more than pickle jars, of course**

— Orva Sodman: Someone who has had years of experience living with the aftermath of polio. **And** Aleta Connolly

### MUST "TO GO" ITEMS TO SURVIVE DISASTER



Join the **challenge to show and tell your TO GO KIT** when the alert is issued for you to vacate your home immediately. This is the **kit** you have **PREPARED BEFORE THE ALERT**.

- ★ Before the fire is on your block
- ★ Before the quake splits your street

# Post Polio Update 2018

from a neurological perspective

Susan L. Perlman M.D.

Clinical Professor of Neurology

David Geffen School of Medicine at UCLA

Excerpts, Summaries and  
Redactions from Dr. Perlman's  
Powerpoint and oral  
presentation

May 6th. 2018

Part 1 (Part 2 in November)

Polio is nearing being declared eradicated. In 2018, 8 WPV1 cases were reported as of April (7 in Afghanistan, 1 in Pakistan). But wild-type polio is still out there — in the environment and in labs.

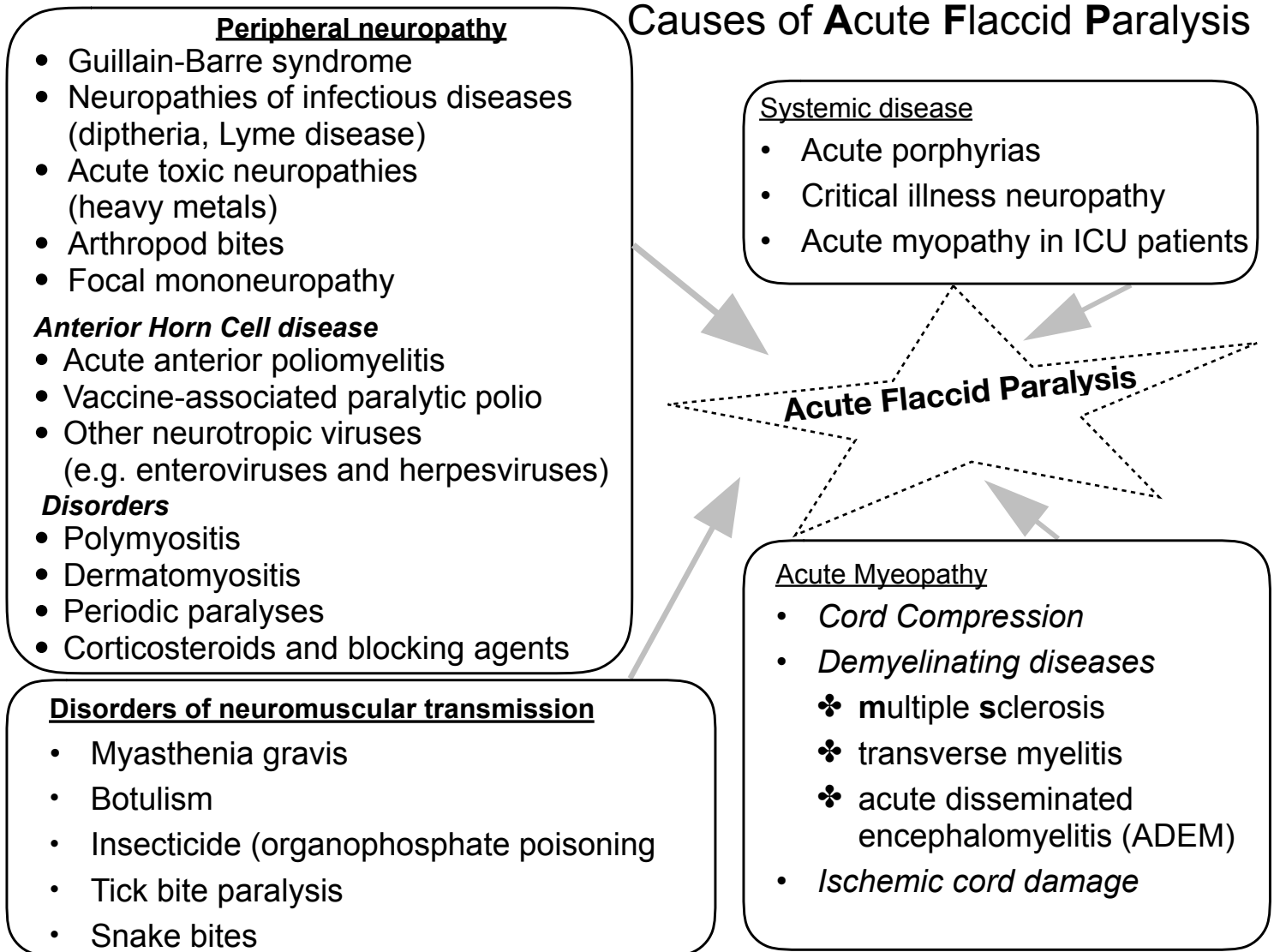
Once polio is eradicated, polio experts hope funding will be redirected to supporting PPS patients. Joan Headley (PHI) expressed concern that once polio was eradicated, the money spent on tackling it would be redirected to other diseases that have more visible and devastating consequences. Nora Groce, director of the Leonard Cheshire Disability and Inclusive Development Centre at the University College London, agrees. “I would like the **Global Polio Eradication Initiative** to review its budget devoted to polio eradication and move that funding over to ensure that people who’ve had polio are better served in terms of resources, medical services, and education. I also hope some of that money goes towards training health-care workers in low and middle income countries about the coming of PPS”, but right now, **I’m certain it will shut down.**”

**Polio-like syndrome** is a general description of a group of symptoms **which mimic polio**, including rarely permanent paralysis.

- “Acute flaccid paralysis”--Most common in children ages 7-12 years old.
- Various causes have been found including some viruses from the same virus group as polio--the enteroviruses: **enterovirus 68** and 71, coxsackie virus A7.
- A study of some of the cases in 2014 (CA, CO, PA) found that when **enterovirus 68** was detected, it was from a strain that only emerged in 2010.
- Further studies and discussion are needed on this front, and the development of a vaccine is prudent before this becomes a pandemic as was Polio.
- Over 50 cases were reported in the U.S. in 2014.
- West **Nile Virus** and now **Zika Virus** are known to cause paralytic syndromes.
- [In endemic infected countries, acute polio must always be considered.]
- **But will these polio mimics also lead to post-polio syndrome?**

**Polio is in one of several disease subsets** that lead to **Acute Flaccid Paralysis**. Ours is an **Anterior Horn Cell Disease** in the spinal column. Multiple sclerosis is **Acute Myelopathy** (severe muscle disfunction). **See diagram on next page.**

## Causes of Acute Flaccid Paralysis



## Things We Know For Certain about Post-Polio Syndrome

- New or increased symptoms in a polio survivor are **PPS only about 1/3 of the time.**
- New or increased symptoms may be due to another medical or neurological illness or to orthopedic problems, **which must be identified and treated.**
- Treatment of other illnesses in a polio survivor must be monitored relative to the sensitivities of PPS

(eg. anesthesia, surgery, chemotherapy, use of cholesterol lowering medication).

## If You Need Surgery Requiring Anesthesia

1. **Prior to surgery**, have **Pulmonary Function Studies** performed. Eg. Residual phrenic (not consciously controlled) nerve problems may not be detected beforehand.
2. **Only have surgery preformed at a major hospital.** Do not use out-patient surgery centers for surgery with **general anesthesia unless they are physically connected to a major hospital.** Evidence mixed on polio survivors' reaction to *conscious sedation* used. For example it is used in most of Colonoscopies. *Testimonials* from our



PPS group indicate that procedures like colonoscopies should be done with same cautions as major surgeries. *See links to excellent articles.* Read!

3. Be fully aware of anesthesia and pain medication to be used — doses might need to be reduced, certain drugs might need to be avoided, and recovery time might be prolonged and there are very helpful recover procedures. (*Links to excellent articles*)

4. **Prepare for surgery.** Eat a proper diet and be in as good physical health as possible. Be doing whatever exercises are proper for you. **Discuss anesthesia with the anesthesiologist.** You *may only be able to contact* the anesthesiologist's group prior to surgery. Give them Dr. Calmes's recommendations and any other articles you think will help. You *may only be able to talk* with your actual anesthesiologist *right before surgery*. Probably best to give him or her only Dr. Calmes's article: <http://www.post-polio.org/edu/anesthesia-specifics.html>

**More excellent articles  
about surgery and anesthesia  
for polio survivors:**

[gbppa.org/anesthes2.htm](http://gbppa.org/anesthes2.htm)

<http://www.post-polio.org/edu/pphnews/PPH27-2sp11p1-3.pdf>

<http://anesthesiology.pubs.asahq.org/article.aspx?articleid=2026110>

**Dr. Perlman reviewed our personal responsibility in care for PPS:**

It is of utmost importance that we have a Primary Care physician **that listens to us** and **whom we trust**. If we are on Original Medicare, we have the full range of doctors **to interview** in the area we live. And all Medicare Advantage Plans provide a panel of doctors from which **to interview**.

We may have to educate our Primary Care doctor on Post Polio Syndrome. But it isn't like it was in the 1980s. **The mystery** of the late effects of polio **has been solved**. Dr. Perlman is the director of the post-polio clinic at UCLA. She communicates her knowledge with Primary Care physicians and Specialists when requested and feasible. Also some survivors have come to the clinic for an initial diagnosis or for help with a particular issue later in life.

There is a **wealth of concise material** for any physician or patient at :

- [post-polio.health.org](http://post-polio.health.org)
- Medical Board of CA <http://mbc.ca.gov/> January 2002
- Excellent easy-to-read reviews on PHI, MayoClinic, NIH websites
- And the latest review:

*The Role of the Primary Care Physician in the Life of a Polio Survivor*

William DeMayo, MD, Summit Medical Rehabilitation, PC, Johnstown, PA

*Post-Polio Health* Vol. 33, No. 1 Winter 2017 [www.post-polio.org](http://www.post-polio.org)

The **bottom line** is that we must sort out with our Primary Care doctor *what are polio problems* and *what are problems we share* with the rest of aging patients.

# Important Things to Discuss with your Doctors

## General Guidelines:

**New muscle atrophy and fatigue are essential to the PPS diagnosis.** Some time **after** you are diagnosed with PPS — *you have new pain . . .*

- **When is it not Post Polio Muscle Atrophy? (PPMA)**

- When it is anything **other than new** muscle, atrophy, weakness, pain, or fatigue. And *if it is new pain and fatigue* you have to double check that it's not something else.
- PPMA may increase symptoms of **other conditions**.
- Why are you reporting new pain or related problems now? Your doctor will want to know **why** you are seeking evaluation **now**.

It is **our responsibility** to *discuss and define* with our doctors **what we do going forward** to live well with PPS.

1. Modify lifestyle to the degree necessary to **manage pain and fatigue**.
2. Avoid overuse: Be aware of **messages** our bodies send us.
3. Use *assistive devices* and *bracing*. Possibly prevent muscular/neurological damage, increase safety, and extend duration and distance of mobility.
4. Control : (Good articles on all the below in Post Polio International newsletters)

weight gain

sleep problems

stress

5. Engage in non-fatiguing exercise for strength and conditioning.

Many studies have shown that **success in these areas** can halt progression of PPS symptoms and promote **improvement of 1-2% per year**.

**Part 2 of Dr. Perlman's May 2018 Presentation in November 2018 PPSG of OC News**

Dear Co-Survivors,

First, I know that I may offer condolences from all of us to Orva Sodman on the loss of her husband-lifelong companion, Marvin.

Second, it makes me sad to inform you that I will no longer be editing the newsletter after our November 2018 issue. It has been a labor of love. I hope that someone volunteers to take my place. Our grandchildren live away, and Roni and I have made it a priority to be part of their lives.

For the foreseeable future I will still be able to prepare Post Card and Email Meeting Notices. I plan to maintain our database and to coordinate with the Rancho group. Hopefully, I will keep updating the WEBSITE, which has steadily drawn new readers. I want to remind you that **Post Polio International** provides a **top notch mailed quarterly newsletter**, with up-to-date information and advice for only \$30 per year. Past issues are free at [post-polio.org](http://post-polio.org). Call 314-534-0475 to subscribe. (M-F 8:00 am - 4:30 pm Central Time) or subscribe at [post-polio.org](http://post-polio.org).

Forever bonded,

Baldwin Keenan



## Rancho Los Amigos

**Saturday July 28** to be determined.

### **Future Rancho SG Meetings**

**Saturday August 25** 2-4pm TBD

**Saturday September 22** 2-4pm TBD

**Saturday October 27** 2-4pm TBD

### **Orange County Meeting**

**JULY 14th** 2pm - 4pm

What are our travel **opportunities?**

**See a lot or kick back?**

What can we do to **work around**  
unforeseen **barriers?**

### **Future PPSG of OC Meetings**

**Saturday September 8th** 2-4 pm

Sharing ideas and "gadgets" to live  
well with PPS

Including **evacuation** TO GO KITS

**Saturday November 10th** 2- 4 pm  
HICAP on Changes in Medicare

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 memo area of the check.

### **Please read BELOW**

The Rancho Support Group publishes on even numbered months and probably Orange County's last newsletter will be November 2018. We share the same mailing list, and all donations are shared equally. We list all donors but not the donation amount. Please subscribe to **Post Polio International Newsletter** (\$30) and **donate enough to sustain** the Rancho Newsletter and at least post card meeting notices from Orange County. Of course we hope that someone volunteers to be the new editor in Orange County.

### **How to contact support groups**

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 us:

**Rancho PPSG@hotmail.com**

Contact PPSG of OC for information:

**Newsletter Editor through November 2018**

*Baldwin Keenan* 949-981-2605

[abaldwinkeena@gmail.com](mailto:abaldwinkeena@gmail.com)

**Agenda ideas for PPSG of OC?**

Please call Aleta at 949-559-7102

or email Priscilla at [prisofoc@aol.com](mailto:prisofoc@aol.com)

WEBSITE: [ppsupportoc.org](http://ppsupportoc.org)

**Disclaimer:** Information provided in our 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.

**Orange County  
Post-Polio Support Group**

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Irvine CA 92604**

**FREE POSTAGE FOR  
THE BLIND AND  
PHYSICALLY DISABLED**

