

NEWSLETTER

Post-Polio Support Group of Orange County

Founded 1989

WEBSITE: ppsupportoc.org

3454 A Bahia Blanca West Laguna Woods CA 92653

May 2016

Thank you for your financial support. Our newsletters will continue !!!

We still need to determine if there are at least 15 who will attend each tentatively scheduled meeting. The March meeting on Bracing was much appreciated by a very good attendance. (see pages 2-3) Please detach this page and snail mail or email your response to Janet Renison 3434 A Bahia Blanca West Laguna Woods CA 92653 or renison@lagunawoodsvillage.net

Sunday May 15th 2- 4pm

Dr. Perlman, director of UCLA's PPS Clinic will do her annual presentation on current **Post-Polio Research and Care**: Please write down your questions in advance. Will you participate? Yes___ No___ **THIS MEETING IS A GO !!!**

Saturday July 9th 2 - 4 pm (Will be held if we have 15 say YES)

Modifying homes with ramps, door widening, grab bars, and other simple changes to make living with PPS easier. Presentation by former builder experienced with ADA. Attend? Yes___ No___

or

Assistive devices: A presentation by MOBILITY CENTER of actual crutches, wheelchairs, powerchairs, lifts, van conversions. (Take a look at some of our member's vans) Attend? Yes ___ No ___

Saturday September 10th 2 - 4 pm (Will be held if we have 15 say YES)

"Becoming a Trustee and/or Executor" We will discuss handling keys as well as documents and funds. Sometimes little things make all the difference.

Attend? Yes ___ No ___

Saturday November 12th 2 - 4 pm (Will be held if we have 15 say YES)

Presentation by the **Health Insurance Counseling & Advocacy Program** on 2017 changes in Original Medicare, Medicare Advantage Plans, and Medicare Prescription Drug coverage, Supplemental policies (Medigap) and The Affordable Care Act. Also into on fighting Medicare fraud and abuse as well as assistance income seniors apply at Benefits Enrollment Center.

Attend? Yes ___ No ___

We will hold a particular meeting, **if and only if**, we have 15 people affirm that they will attend that meeting. Please let us know by regular mail or email to Janet, (See above)

Do you want to receive Newsletter? Printed newsletter___ Newsletter by email***___ None___

*** Your email address: _____@_____

Please **Detach** this page and use regular mail.

Or email your answers.

Notes from *Bracing* presentation at our March 2016 meeting:



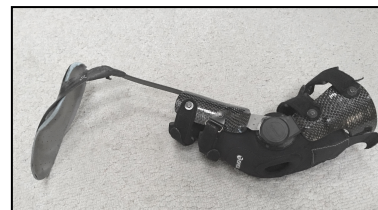
• We were fortunate to have Rod Cuervo, CPO from *Mission Prosthetics* on S. Tustin in Orange speak to us. He started out in

Physical Therapy over 25 years ago, then made the transition to Orthotics. He loves challenges and the satisfaction of improving the lives of his patients. Most of us are challenging.

- He regularly takes discarded braces from the US down to Central America and does what he can to help people who have very little.
- See: <http://www.ocregister.com/articles/cuervo-33635-patients-salvador.html>
- These experiences demonstrate to him that disabled people, (in Central America these are women who do most of the marketing and farming) do manage to walk albeit with pain.
- Many of us are good candidates for some type of bracing. Even if it helps us walk just a little.
- A brace should not hurt! It does us no good sitting in a closet.
- **Communication between patient and orthotist is essential!**
- A lot of new materials are available. For example, using clear plastic molds the orthotist can see where the potential rubbing or pressure problems with the brace may occur. These problems can be corrected before the cast for the brace is made.
- Foot drop can easily be reduced by having the brace hold the foot at 90 degrees. What may be difficult is to get a survivor's **heel** to hit the walking surface first. An inflexible brace may not help a polio survivor achieve his or her gait mobility potential.

- Flexible carbon fiber and fiberglass with stronger resins are now available for stronger more “dynamic” bracing.
- A good orthotist is concerned **first** about not letting the condition get worse and **second** about doing what is reasonable to correct gait and alignment without adding pain.
- A lot has been learned from amputees hit by roadside bombs in the Middle East.
- Physical therapists and orthotists have different roles. Both professions need to work together in helping us maintain maximum strength, flexibility, and mobility.
- Sometimes proper bracing can help a polio survivor regain some strength in “marginal” muscle groups.
- If the survivor has had her or his foot and ankle fused (many of us have), there is no need to mold the brace around the foot. That only adds weight.
- If there is a need to deal with knee issues, usually a full leg brace is required. The mold for the leg brace should be cast over any knee brace the patient wears.

Full Leg carbon fiber and fiberglass brace to address foot drop, propulsion, and knee problems.



March 2016 was one of our largest attendance in recent years. You can find contact information on some local orthotists in our providers link on our website: **ppsupportoc.org**

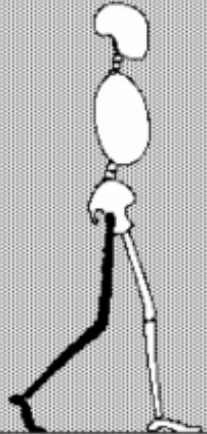
Further inside this issue:

Pas 4 - 7 “Dr. Perlman Presents” including some abstracted studies she may review: *Obesity and Pulmonary Function, Refining the PPS Portrait, and the polio vaccine “Switch”.*

Pg. 8 Maps, Meeting Schedule, and Contacts

Gait

Pre- Swing



Pre-Swing

The final phase of stance, and the second period of double stance. Begins with initial contact of the opposite limb and ends with ipsilateral toe-off. Rapid unloading of the ipsilateral limb occurs as weight is transferred to the contralateral limb.

This phase is sometimes called "weight release" or "weight transfer" (I like "unloading response").

A major objective of this phase is to position the limb for swing.

Interval = 50-60% of gait cycle.

Important to get heel of leading leg to land on the surface first - the position for Initial Swing push off.

Initial Swing

Initial Swing

The first third of the swing period. Begins with lift of the foot from the floor and ends when the swinging foot is opposite the stance foot.

Two important objectives of this phase are advancement of the limb from its trailing position and foot clearance floor. loot.

Interval = 60-73% of gait cycle.

Mid Swing



Mid Swing

The middle third of the swing period. Begins when the swinging foot is opposite the stance foot and ends when the swinging limb is forward and tibia vertical (hip and knee flexion postures are equal).

Two important objectives of this phase are limb advancement and foot clearance. Like mid stance though, this is a phase of relative control.

Interval=73-87% of gait cycle.



A carbon fiber brace can prevent toe drop and propel leg forward

Terminal Swing

Terminal Swing

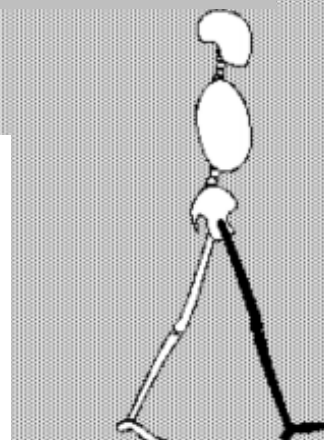
The final third of the swing period. Begins with a vertical tibia and ends when the foot strikes the floor. Limb advancement is completed as the leg (tibia) moves ahead of the thigh. The knee maximally extends.

Two important objectives of this phase are completion of limb advancement (deceleration of the swing limb) and preparation for stance.

Interval=87-100% of gait cycle.

All of us have different degrees of weakness in different muscles. We cannot all expect to get the same mobility from braces that seem very similar.

Low cost carbon fiber brace which could work for a survivor with fused ankle.



Dr. Perlman presents on May 15th!

Dr. Susan Perlman, among many other duties, is the director of the UCLA Post-Polio Clinic. Many polio survivors in both the Rancho and Orange County Groups were first diagnosed with PPS by Dr. Perlman. For the most part she does not do ongoing care, but rather consults with our neurologists, physiatrists (Physical Medicine and Rehabilitation doctors), orthopedists, and/or primary care physicians. In addition she is part of a team of consultants to **Post-Polio International** on a variety of issues, including its recommendations for exercise. For the decades she has cared for polio survivors with PPS, she has been open to trying new medications. She reports very little, if any, benefit from their use. Nevertheless, she keeps abreast with clinical trials and ongoing research. Each May we are extremely privileged to have her report to us what she has learned and answer our questions. This is our most attended meeting of the year. In order for everyone to get the most out of Dr. Perlman's time with us, please write down your questions in advance. She will address similar questions as a group. And also, please understand that the purpose of her presentation is to guide us in having BETTER COMMUNICATION WITH OUR MEDICAL CAREGIVERS, **not to have a one-on-one consultation with her**. Please note that May 15th is a SUNDAY. The parking lot can be quite busy, please park, walk, or roll with care! Below are abstractions of some recent research Dr. Perlman may review with us:

Obesity and Pulmonary Function in Polio Survivors

12-2015

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4720764/>

The **Objective** of the study was to study the correlation between obesity and pulmonary function in polio survivors. The **Methods** of the study were based on questionnaire survey and physical examination. Five university hospitals and one health clinic participated with 73 participants. The **Conclusion** was that decreased pulmonary function correlated with obesity for polio survivors. Therefore, it is necessary to develop specialized exercise programs to help polio survivors reduce their weight and strengthen their respiratory muscles.

Annals of Rehabilitation Medicine. 2015 Dec; 39(6): 888–896.

Published online 2015 Dec 29. doi: 10.5535/arm.2015.39.6.888

Courtesy of Korean Academy of Rehabilitation Medicine



Refining the Portrait of Late Effects of Polio

http://www.oandp.com/articles/2016-02_03.asp

2-2016

by Phil Stevens, Med, CPO, FAAOP

philmstevens@hotmail.com

This is a FASCINATING study that would be very difficult to do in the USA, because our health system has very inadequate tracking of polio survivors and those of us with PPS. Fortunately, there are some centers that still manage large

numbers of patients with PPS. One of these, a rehabilitation clinic based in a university hospital in southern Sweden, maintains a database of over 300 cases. Researchers from this center have published a series of studies to describe a more complete portrait of patients who have mild to moderate PPS. This cohort is defined as individuals between 50 and 80 years of age who are able to walk at least 300 meters with or without assistive devices or lower-limb orthoses, but do not require a wheelchair as their primary means of mobility. This article summarizes some of those findings and refines the portrait of post-polio effects.

- Although it is reasonable that this most survey participants would benefit from their using **Lower Limb Orthotics**, many choose not to.
- The study of **Muscle Strength** shows characteristics which varied widely. There is not a good correlation between Muscle Strength and Gait. And an added difficulty to the study was that a quarter of the participants, as mentioned above, did not use braces.
- A cohort of 122 study participants with PPS were asked about **Limitations**. Running is a big limitation for 78%. Distance walking a factor for 52%. Quality of walk limited for 46%. Stair use affected 45%. Balance affected 31%, and 35% use an assistive device. 34% reported a limitation to their ability to walk. Those patients with fewer limitations generally demonstrate better walking endurance and greater elevated walking speeds, a notable observation, given that ambulatory distances were the second most commonly observed limitation within the cohort.
- The most common **Impairments** of PPS are muscle weakness and fatigue. A cohort of 81 patients self reported in the study. 61% have muscle and/or joint pain during physical activity. An average of 52% have both muscle pain and fatigue, while 47% have general fatigue. 36% report cold intolerance. 26% report muscle and/or joint pain during rest. Not surprisingly, those subjects who identify greater levels of impairment do, in fact, take fewer daily steps.
- While walking is limited for a great majority of the studied polio survivors with PPS, **Activity** with daily walking is not precluded. In their study of 81 random subjects from their database, patients with PPS (average age 67) walked, on average, 6,212 steps per day, well above the normative values cited for adults 60 years old or greater that ranged between about 2,800 to 4,500 daily steps. Physical activity was broken out as household activities (73%), leisure (16%), “targeted” exercise (6%), work related (5%).
- **Fears of Falling** are a common with patients undergoing the late effects of polio. 69% are afraid to walk on a slippery surface. 60% fear an uneven surface. 50% fear walking on slopes. 35% fear falling using stairs. 21% fear they are at risk of falling walking around the neighborhood. The generally high rates of fall concerns appear to be justified as 62 percent of the questioned patients reported having experienced at least one fall in the past year. Of note, higher fall concerns correlated with less physical activity spent in leisure pursuits. A similar correlation was not observed between fall concern and efficacy at household-related physical activity.

Phil Stevens in **Summary** concludes that, when the Swedish data is viewed collectively, a composite portrait of PPS begins to emerge. It is a tremendously variable

patient group frequently presenting with muscle pain, weakness, and fatigue. Despite the obvious potential benefit of lower-limb orthoses, many individuals choose not to pursue these interventions. Mysteriously, muscle weakness is only moderately correlated to gait performance measures, with greater correlations associated with walking endurance and elevated walking speeds. Impairments, limitations, and concerns about falling are frequently reported, yet this patient population generally remains fairly active compared to other populations of older adults.

“The Switch” - - Major Changes to Polio Eradication Strategy

Between April 17 and May 1, 2016, every country in the world currently using the oral poliovirus vaccine (OPV) withdrew the trivalent vaccine (tOPV) and replace it with the bivalent vaccine (bOPV). This will continue to protect infants from poliovirus types 1 and 3 while withdrawing the type 2 component, thereby mitigating the risk of seeding new type 2 circulating vaccine-derived poliovirus (cVDPV2) WATCH:

<https://www.youtube.com/watch?v=4niTkOz03ak&feature=share>

The **preceding** three abstractions have been derived from the **PHI Membership Memo #48**
..... a PHI Membership Benefit

PHI Membership MEMO

www.post-polio.org
www.polioplace.org
info@post-polio.org

Post-Polio Health

PHI's quarterly newsletter contains current information about the late effects of polio, updates about post-polio related and neuromuscular respiratory research, as well as articles that offer practical and useful advice by experienced survivors and health care professionals. *Available with Membership.*



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polio.post-polio.org/

Call: 314-534-0475

Email: info@post-polio.org

Write:

Post-Polio Health International
4207 Lindell Blvd #110
St. Louis MO 63108

www.polioplace.org **It's our place!**

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 to help others. **Visit often!**





Rancho Los Amigos

Sunday MAY 15 2-4 pm
Joint Meeting with Support
Group of OC

Dr. Perlman's annual presentation.

Future Rancho SG Meetings

Saturday June 25
ANNUAL PICNIC

Map in June Newsletter

July 23 and other future meetings
to be determined.

Orange County Meeting

Sunday May 15, 2016 2-4 pm
"Dr. Perlman Presents"

Review of Latest Post-Polio
Research and Care

Future PPSG of OC Meetings

See page 1.

Please **detach it** and **mail** or **email** it to us. If **15** of us answer YES to a tentatively scheduled meeting, it will be held and confirmation made in the newsletter preceding it.

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. There have been too many donations recently to list. Hearty thanks to all who contributed! Please know that **all** donations make our support groups possible.

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 Editors

Janet Renison 949-951-8613

renison@lagunawoodsvillage.net

Baldwin Keenan 949-857-8828

abaldwinkeena@gmail.com

Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102 or email

Priscilla at prisofoc@aol.com

WEBSITE: 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
3454 A Bahia Blanca West
Laguna Woods CA 92653**

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