Final Issue

NEWSLETTER

Post-Polio Support Group of Orange County Founded 1989

WEBSITE: ppsupportoc.org

15231 Marne Circle Irvine CA 92604

November 2018

Changes in Medicare

Please do not finalize your decision on your Medicare plan until after our meeting:

Saturday November 10th

2pm - 4pm

Newland Street Church of Christ

13852 Newland Street Garden Grove

See
Map
Pg 8

Each of us should be very careful <u>not to assume</u> that 2019 plan details will be the same as in 2018. We have until December 7th to make our decision. HICAP (**H**ealth **I**nformation **C**ounseling and **A**dvocacy **P**rogram) will take us through the 2019 changes.

HICAP does not have a crystal ball. However, **political plans to weaken Medicare** are public**.** The decisions we make for our 2019 coverage could make a big difference in weathering the threatened assaults. Of course, it is **essential that each of us write a letter, send an email or make a phone call to our Senators and Congresspersons to demand that they not let the cuts happen!**

Also, if you feel you need personalized attention, you can make an appointment with a HICAP representative. Don't wait! CALL: 714-560-0424

This is my <u>last newsletter</u>. No one has offered to continue. I **plea** with you to ***join*** **P**ost-polio **H**ealth **I**nternational. Its newsletter a **must** for us**.** Maybe family, friends or neighbors could help or make it a gift — $2.50 per month.

Call: 314-534-0475 or go to **post-polio.org**

Part 2

PPS Care and Research May 2018

Dr. Susan Perlman

UCLA Post Polio Clinic

The PPS support groups of Orange County and Rancho deeply appreciate Dr. Perlman's yearly presentation and generous Q&A session. **P**ost-polio **H**ealth **I**nternational—<u>post-polio.org</u> is the most important information resource that Dr. Perlman cites **(only $30** per year). Its newsletter is the **best source** of up-to-date info for us and, sometimes, for our physicians. Support groups around the country are less and less able to produce newsletters with quality primary source (or even timely re-printed) information that polio survivors need to cope with worsening PPS, decreased mobility, depression, multiple illnesses, lack of family support, medications, physical therapy, home accessibility modifications, etc .... These concerns are continually addressed and updated in ***Post-polio Health*** (<u>mailed</u> quarterly), online **M**embership **M**emos, and online **P**olio **P**lace. [*Editor Note*: I don't think that I can get on without PHI. Nor, do I want to try.]

Every year PHI gives a grant to PPS researchers. Some desire to tackle a better understanding of PPS, leading to refining PPS care. A recent grant stimulated research into a drug which shows strong potential for helping alleviate some symptoms of the late effects of polio.

Continued on Page 2

New 2017-18 publications which addressed PPS

Grifols has completed Stage 1 of their IVIG study for PostPolio and in 2018 Grifols will be starting Stage 2 of their IVIG study.

This will be the definitive study that could lead to FDA approval.

Time frame is another 3 years.

Who Might Respond Best to IVIG (from prior studies)

- Age below 65 years
- Paresis (weakness) in the lower extremities
- Lack of concomitant disorders
- Reduced physical function
- Muscle atrophy in the lower extremities
- Higher levels of fatigue and pain
- VAS (0-100) pain score above 20

Limitations to Off-Label IVIG

- **Financial--$$$$$**
- Is FDA approved for certain hematologic immunodeficiencies <u>only</u>.
- Insurance companies may approve for certain immune-medicated neurologic conditions if the literature supports it.
- **Headache, malaise, nausea, low-grade fever, urticaria, arthralgias, and myalgia.** These symptoms typically resolve within a few days after their onset.
- **Rare serious and potentially fatal side effects include:** anaphylactic reactions, aseptic meningitis, acute renal failure, stroke, myocardial infarction, and other thrombotic complications. Many of these side effects have occurred in patients who have significant, underlying risk factors for the development of the event.
- **Treatment** is an infusion, which may be done at home, but usually requires several hours of treatment in an infusion center.

3 studies explored **NON-DRUG SYMPTOMATIC INTERVENTIONS**

Whole body vibration on people with sequelae of polio

Physiother Theory Pract. 2018 Mar 29:1-11. Da Silva CP, Szot CL, deSa N

- The purpose was to explore the feasibility of whole body vibration (WBV) on polio survivors with/without post-polio syndrome (PPS) by studying its effects on walking speed (10-min walk test), endurance (2-min walk test), pain severity/interference, sleep quality, fatigue, leg strength, and muscle cramping.
- Fifteen individuals completed the study, participating in eight sessions in two 4-week blocks. Participants started with ten 1-min vibration bouts/session, increasing to 20 min. Low (amplitude 4.53 mm, g force 2.21) and High (amplitude 8.82 mm, g force 2.76) intensity intervention occurred in random order crossover design. Blinded testing ensued before/after intervention blocks and at follow-up.

- No study-related adverse events occurred. Participants starting first with higher intensity intervention **improved in walking speed** (p = 0.017). BPI **pain severity significantly improved** (p = 0.049) after higher intensity intervention. No significant changes were found after low intensity vibration or in other outcome measures.

Repetitive transcranial magnetic stimulation in treatment of PPS *Neurol Neurochir Pol*. 2018 Mar;52(2):281-284. by Pastuszak Ż, Piusińska-Macoch R, Stępień A, Czernicki Z.

- Patient had rTMS stimulation of left prefrontal cortex twice a week for eight weeks. Patient's health status was evaluated before treatment, after last rTMS session and after three months from the end of the treatment.

RESULTS: Improvement of fatigue score, mood disturbances and motor functions was observed after treatment.

CONCLUSION: rTMS can be an effective method in treatment of post polio syndrome but *further studies with larger group need to be done* to confirm that data

➢ Transcranial magnetic stimulation (TMS) is an *FDA-approved noninvasive procedure that uses magnetic fields* to *stimulate nerve cells in the brain to improve symptoms of depression. TMS is typically used when other depression treatments haven't been effective.*

The treatment of fatigue by non-invasive brain stimulation *Neurophysiol Clin. 2017 Apr;47(2):173-184*Lefaucheur JP, Chalah MA, Mhalla A, Palm U, Ayache SS, Mylius V.

- We found only 15 studies on this subject, including 8 tDCS (Transcranial Direct Current Stimulation) studies and 7 rTMS studies. Of the tDCS studies, 6 concerned patients with multiple sclerosis while **6 rTMS studies concerned fibromyalgia or chronic fatigue syndrome**. **The remaining 3 studies included patients with post-polio syndrome**, Parkinson's disease and amyotrophic lateral sclerosis.
- Three cortical regions were targeted: the primary sensorimotor cortex, the dorsolateral prefrontal cortex and the posterior parietal cortex. In all cases, tDCS protocols were performed according to a bipolar montage with the anode over the cortical target. On the other hand, rTMS protocols consisted of either high-frequency phasic stimulation or low-frequency tonic stimulation.
- The results available to date are still too few, partial and heterogeneous as to the methods applied, the clinical profile of the patients and the variables studied (different fatigue scores) in order to draw any conclusion.
- However, the effects obtained, especially in multiple sclerosis and **fibromyalgia**, are really carriers of therapeutic hope.

■ **40%** of polio survivors with PPS have symptoms consistent with fibromyalgia

Use of medical marijuana

(single subject case report—well tolerated and worked for nausea in this patient).

- **28** FAQ--http://www.canorml.org/faq.html#2 Including: How can I find a lawyer?

3 studies looked at **OTHER SYMPTOMS OF PPS (RESTLESS LEGS, FATIGUE, PAIN)**

Restless legs syndrome is highly prevalent in patients with PPS

Sleep Med. 2017 Sep;37:147- Marin LF, Carvalho LBC, Prado LBF, Oliveira ASB, Prado GF.

The prevalence of RLS was 36% (n = 43; 32 women and 11 men)**.** The ages at onset of RLS (median = 41 years) and PPS (median = 41 years) were concurrent, and the correlation between onset of symptoms of RLS and onset of symptoms of PPS was positive and very strong (Spearman r = 0.93, p = 0.01). The median RLS severity was 23 (range, 20-28). Low educational achievement and depression were predictive of RLS development.

Measuring Physical and Cognitive Fatigue in People With Post-Polio Syndrome: Development of the Neurological Fatigue Index for Post-Polio Syndrome (NFI-PP) *PM R. 2018 Feb;10(2):129-136* Young CA, Wong SM, Quincey AC, Tennant A.A patient-derived Neurological Fatigue Index for PPS, with physical and cognitive subscales and a total score, has demonstrated good reliability, appropriate concurrent validity, and satisfies the Rasch measurement model.

Modeling subjective well-being in individuals with chronic pain and a physical disability: the role of pain control and pain catastrophizing *Disabil Rehabil. 2017 Oct 23:1-10* Furrer A, Michel G, Terrill AL, et al.

The majority of individuals with physical disabilities report having persistent moderate-to-severe pain that may negatively limit daily activities and quality of life. The present cross-sectional study indicates that individuals who reported *greater subjective well-being* showed significantly *lower pain intensity* via the mediating effect of lower pain catastrophizing. Since sample size and respective power are low, these findings should be taken as first indications of potential underlying mechanisms between subjective well-being and pain outcomes that need further confirmation in longitudinal research. However, the findings suggest that treatments which enhance subjective well-being (increasing positive affect and life satisfaction, and decreasing negative affect, e.g., via positive psychology exercises) and reducing pain catastrophizing (via e.g., cognitive-behavioral therapy) may have the highest potential for benefiting individuals with disability-associated chronic pain**.**

6 discussed **PSYCHOLOGICAL AND QUALITY OF LIFE MEASURES**

Cognitive behavioural therapy for reducing fatigue in post-polio syndrome … *J Rehabil Med. 2017 Jul 7;49(7):585-590* Koopman FS, Brehm MA, Beelen A, Voet N, Bleijenberg G, Geurts A, Nollet F.

- Cognitive behavioural therapy does not reduce fatigue in post-polio syndrome

■ **So you can't think yourself out of fatigue like you might be able to do with pain**.

Sense of Coherence in persons with late effects of polio *NeuroRehabilitation 2018;42(1):103-111* Nolvi M, Brogårdh C, Jacobsson L, Lexell J.

- Persons with PPS have a level of **S**ense **o**f **C**oherence, indicating that they generally have the ability to understand, handle and be motivated when dealing with stressful events and problems arising in their lives as a result of their disability. Being married and having a higher education, living many years before onset of PPS, and perceiving a mild to moderate disability contributed to a strong SOC.

■ Pick your battles**.**

Resilience and Function in Adults With Physical Disabilities: An Observational Study *Arch Phys Med Rehabil. 2017 Jun;98(6):1158-1164* Battalio SL, Silverman AM, Ehde DM, et al.

- After controlling for age, sex, diagnosis, psychological health, and symptom severity, resilience was significantly and positively associated with satisfaction with social roles and quality of life, but not physical function.

■ Roll with the punches, but never give up.

Polio survivors perceptions of a multi-disciplinary rehabilitation programme.

Disabil Rehabil. 2017 Oct 3:1-8. Atwal A, Duncan H, Queally C, Cedar SH.

- Our research identified that participants experienced long term positive benefits from attending a rehabilitation programme. If we are to recognise the lived experience and **service user empowerment** within a model of co- production it is essential that patient preferences are evaluated and used as evidence to justify service provision.

Solace in solidarity: Disability friendship networks buffer well-being

Rehabil Psychol. 2017 Nov;62(4):525-533. Silverman AM, Molton IR, Smith AE, Jensen MP, Cohen GL.

- Friends with disabilities can offer uniquely important informational and emotional support resources that buffer the impact of a functional impairment on well-being. Psychosocial interventions should help people with long-term disabilities build their peer support networks.

Perceived consequences of aging with late effects of polio and strategies for managing daily life: a qualitative study *BMC Geriatr. 2017 Aug 9;17(1):179.*

Sjödahl Hammarlund C, Lexell J, Brogårdh C.

- Aging with PPS affected daily life to a great extent. The participants experienced considerable impact of the new and increased impairments on their life situation. Consequently, their ability to participate in various social activities also became restricted. Social comparisons and practical solutions are strategies that facilitate adaptation and acceptance of the new situation due to PPS. This emphasizes the need to design rehabilitation interventions that focus on coping, empowerment and self-management for people aging with PPS.

2 reports on **GAIT RELATED MUSCLE CHANGES**

Predictors of changes in gait performance over four years in persons with late effects of polio *NeuroRehabilitation. 2017;41(2):403-411.* Flansbjer UB, Lexell J, Brogårdh C.

- Gait performance was assessed annually in 51 ambulatory persons (mean age 64 years, SD 6) by the Timed "Up & Go" (**TUG**), Comfortable and Fast Gait Speed (**CGS, FGS**), and 6-Minute Walk Test (**6MWT**). Isokinetic knee extensor and flexor muscle strength was measured with a Biodex dynamometer.
- The small gradual reduction in gait performance over time in persons with late effects of polio is primarily determined by the individual variations in the knee flexor strength.

Gait patterns in association with underlying impairments in polio survivors with calf muscle weakness *Gait Posture 2017 Oct;58:146-153..* Ploeger HE, Bus SA, Nollet F, Brehm MA.

- The objective was to identify gait patterns in polio survivors with calf muscle weakness and associate them to underlying lower extremity impairments, which are expected to help in the search for an optimal orthosis. Unilaterally affected patients underwent barefoot 3D-gait analysis.
- Seven gait patterns in 73 polio survivors were identified, with two dominant patterns: one with a mildly/non-deviant ankle angle, ankle moment and knee angle (n=23), and one with a strongly

deviant ankle angle and a mildly/non-deviant ankle moment and knee angle (n=18). Gait pattern prediction from underlying impairments was 49% accurate with best prediction performance for the second dominant gait pattern (sensitivity 78% and positive predictive value 74%). The underlying impairments explained between 20 and 32% of the variance in individual gait parameters. **Polio survivors with calf muscle weakness who present a similar impairment profile do not necessarily walk the same.** From physical examination alone, the gait pattern nor the individual gait parameters could be accurately predicted. The patient's gait should therefore be measured to help in the prescription and evaluation of orthoses for these patients.

1 report on **RESPIRATORY MUSCLE FUNCTION**

Comparison of activity and fatigue of the respiratory muscles and pulmonary characteristics between post-polio patients and controls: A pilot study

PLoS One. 2017 Jul 27;12(7):e0182036. doi: 10.1371/journal.pone.0182036. eCollection 2017

Shoseyov D, Cohen-Kaufman T, Schwartz I, Portnoy S.

PATIENTS: Patients with PPS (N = 12; age 62.1±11.6 years) able to walk for 6 minutes without human assistance; age-matched controls with no history of polio or pulmonary dysfunction (N = 12; age 62.2±6.5 years)**.**

MEASUREMENTS:A body plethysmograph was used to quantify Residual Volume (RV), Total Lung Capacity (TLC), and Thoracic Gas Volume (TGV) etc. A manometer was used to measure Maximal Inspiratory Pressure (MIP) and Maximal Expiratory Pressure. A spirometer was used to measure Maximal Voluntary Ventilation (MVV). Surface electromyography (sEMG) recorded diaphragmatic muscle activity while performing MVV

RESULTS: The control group had significantly higher TGV and showed improvement in MIP following the effort (difference of 5.5±4.0cmH2O) while the PPS group showed deterioration in MIP (difference of -2.5±5.0cmH2O). Subjects with scoliosis had significantly higher RV/TLC values compared with subjects without scoliosis.

CONCLUSIONS: Maximal respiratory pressure test may identify fatigue of respiratory muscles in patients with PPS. Early diagnosis of respiratory impairment may delay respiratory decline and future need of invasive respiratory aids.

Registry for Polio Survivors:
www.conemaugh.org/apps/postpolio/

Please save this final newsletter for maps and contact information

And join **PHI !** Send $30 check to PHI 4207 Lindell Blvd #110, Saint Louis, MO 63108.

(314) 534-7070 for more info and other ways to pay

www.post-polio.org

It has been a labor of love.

Baldwin Keenan

DR.PERLMAN PLANS TO RETURN IN 2019

New addition to our provider survey:

Dr. Andrei N. Dokukin is a Physiatrist (physician certified in *Physical Medicine and Rehabilitation*) who currently sees polio survivors from the USA and from countries with late eradication dates. His treatments include **pain management** and **bracing**. He is on several major provider plan panels in Orange County and in southern LA County. He offers to see PPS patients in a clinical setting in Orange on Wednesday mornings. Call: (562) 633-1765

Rancho Los Amigos

Next Meeting

December 8th

Holiday Celebration

500 Assembly Hall

See Map on Page 8

Future Rancho SG Meetings

Usually 4th Saturdays

Next Orange County Meeting

Saturday November 10th

2pm - 4pm

Newland Street Church of Christ

13852 Newland Street Garden Grove

WHAT'S NEW FOR MEDICARE IN 2019 by HICAP

Future PPSG of OC Meetings

Finger food potluck

Saturday January 12th

2pm - 4pm

Newland Street Church of Christ

We survive on year round **donations** from our readers. Small donations from all readers will ensure that PPSGofOC post card meeting notices and Rancho newsletters will continue. Please mail your donation to Polio Survivor Association Support Groups at 12720 La Reina Avenue, Downey, CA 90242. Make your check out to **PSA—Support Groups,** and write "Newsletters/postcards" 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. We do our best to mention all donors but not the donation amount. 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

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Irvine CA 92604
abaldwinkeenan@gmail.com

Agenda ideas for PPSG of OC?
Please call Aleta at 949-559-7102 or email Priscilla at prisofoc@aol.com

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FREE POSTAGE FOR
THE BLIND AND
PHYSICALLY DISABLED

500 Assembly Hall
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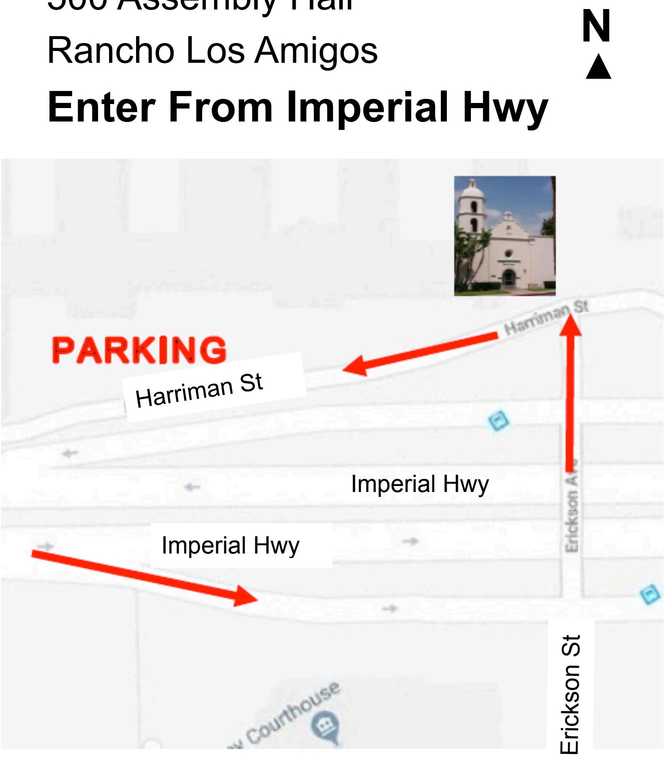
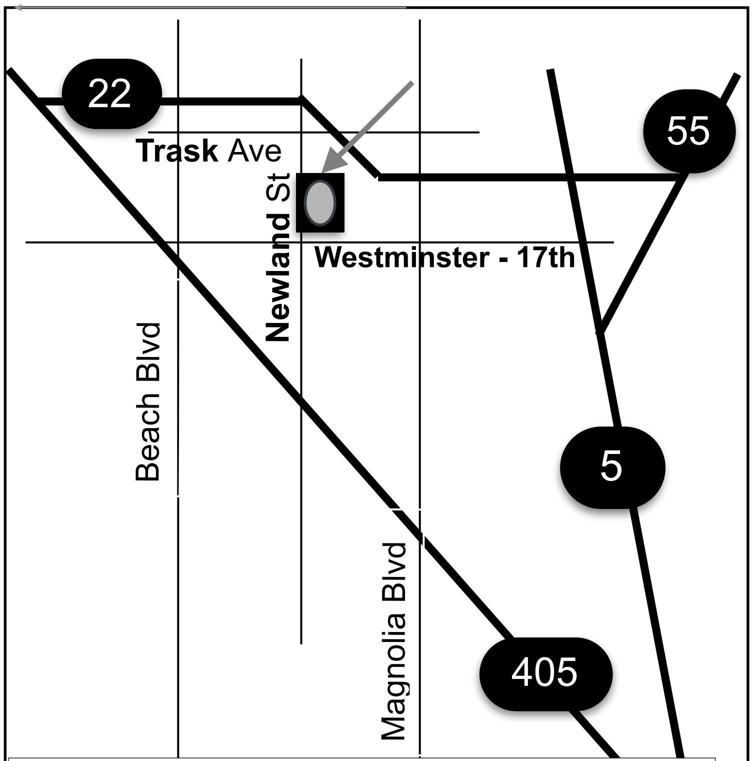
Enter From Imperial Hwy





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