Founded in 1989

The Post-Polio Support Group of Orange County

Newsletter

15231 Marne Circle Irvine CA 92604
WEBSITE: ppsupportoc.org

October-November 2017

Latest Confirmed Changes in Medicare 2018

Beatriz Nunez
Health **I**nformation **C**ounseling & **A**dvocacy **P**rogram
Saturday November 11th 2-4 PM
Viila Park City Council Chambers (See map page 8)

HICAP says: **DON'T GO on AUTO PILOT** with MEDICARE. Doing that could cost you big money and quality of healthcare. We have until December 8th to choose new plans. **WAIT** until you hear what HICAP presents and make an INFORMED DECISION.

Partial recap from September:

Sleep & Respiratory Care
Diana Guth, BA, RRT
Home Respiratory Care
2370 Westwood Blvd., Suite D
Los Angeles, CA 90064
310-441-4640 Fax 310-441-4642
diana@hrcsleep.com

→ **Go to Pages 5 & 6**

Full slide presentation on our WEBSITE ppsupportoc.org
Go to: ***Useful Items*** tab.

Inside this issue

This will be our last newsletter, unless sufficent donations are received to fund us through 2018.

Those receiving a mailed paper copy, if at all possible, need to send a check for at least **$10 now**! The work to publish the newsletter, maintain the database and website is donated. The PRINTING and MAILING PREPARATION are not. **And we pay rent for our meeting room.** Email newsletters readers reduce printing and mailing costs. Thank you! However, only half of our readers use email. We need **all readers** to join the ranks of those who have donated much time and effort **for the last 3 decades** to keep polio survivors informed and connected. We need financial donations from email readers too!

PLEASE FIND DONATION INSTRUCTIONS ON PAGE 7.

Partial Summary
of **Dr. Perlman's**
Post Polio Update July 2017
from a neurological perspective

Eradication nears completion.

Wild Polio Virus 2 certified eradicated.

Wild Polio Virus 3 last detected in 2015 in Nigeria.

Only 6 cases of Wild Polio Virus 1 detected as of mid June in three countries. (Afghanistan, Nigeria, and Pakistan)

Wild Polio is still in the environment and in labs.

Post Polio Syndrome will stick around for decades to come.

The countries with later eradication dates will experience survivors with PPS much later than in Europe and the USA. Nevertheless, European countries and the USA will continue to have polio survivors with PPS who immigrate. Post-Polio International is very concerned that funding, now used for eradication, will be completely shifted to fight other diseases. A big effort has to be made to use some of the money towards training health care workers in low and middle income countries about the coming of PPS.

Polio-like symptoms being studied.

Enterovirus 68 (strain emerged recently in 2010), enterovirus 71, and coxsackie virus A7 mimic polio including rarely permanent paralysis. West Nile Virus and now Zika Virus are known to cause paralytic syndromes. **But will these polio mimics also lead to mimics of post-polio syndrome**?

Acute flaccid myelitis epidemic in US.

Most notable in California, Colorado and Philadelphia. Typically pediatric. No cure. More studies and development of vaccine needed before it becomes pandemic.

Duke University is using polio virus to treat brain cancer.

The polio virus is re-engineered by removing a key genetic sequence. The virus can't survive this way so it was repaired with a harmless bit of cold virus. The new modified virus can't cause paralysis or death because it can't reproduce in normal cells. But in cancer cells it does and in the process of replicating, it releases toxins that poison the cancer cell.

Polio Survivors in the US in 2016

315,000 all older than 44 y/o (slightly higher than median age) Multiple Sclerosis gets very much more attention with an estimated 400,000 sufferers.

Current understanding of Causative Factors for PPS

- Survivors with greater motor unit remodeling and greater residual functional deficits at greatest risk of developing PPS.
- <u>Overuse</u> of unstable motor units and mechanisms that relate to aging act as triggers for PPS.
- Mechanisms of <u>inflammation</u> (possibly an anti-inflammatory response) which may contribute to motor unit dysfunction or other PPS symptoms.

Things We Know for Certain about PPS

- New or increased "polio" symptoms are PPS <u>only about 1/3 of the time.</u>
- 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. (e.g. anesthesia, surgery, chemotherapy, use of cholesterol lowering medication).

If You Need Surgery Requiring Anesthesia

1. Have Pulmonary Function Studies done prior to surgery (e.g. Residual phrenic nerve problem. This nerve originates in the neck and passes down between the lung and heart to reach the diaphragm.)
2. Do not use out-patient surgery centers for surgery with general anesthesia.
3. **EDITOR NOTE**: Dr. Selma Calmes, a polio survivor anesthesiologist, urges us to use only major hospitals, preferably connected to a university. Most colonoscopies are done with conscious sedation. Go to **ppsupportoc.org** for link to Dr. Calmes information sheet to be given to your anesthesiologist.
4. Be fully aware of anesthesia and pain medication to be used -- doses might need to be reduced or avoided and recovery time prolonged.

General Guidelines

Polio survivors with PPS symptoms must take care to:

1. Modify lifestyle
2. Avoid overuse
3. Use assistive devices and bracing if appropriate
4. Control weight gain, sleep problems, stress and pain
5. Engage in non-fatiguing exercise for strengthening 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.

Managing Your Polio related Healthcare

You and your primary care physician and other health care givers can go to **www.post-poliohealth.org** and to Mayo Clinic and NIH websites for excellent easy-to-read reviews on current practices in PPS care.

Dr. Perlman refers us to the article by Dr. William DeMayo which appeared in our **July 2017 Newsletter.** It was re-reprinted from *Post Polio Health* Vol. 33, No. 1 Winter 2017. (Also at **ppsupportoc.org**) We are all aging. We cannot ignore the medical disease and threat of disability that the entire population undergoes. For some reason many polio survivors minimize our primary care doc, who is the "go-to-person" for these condition. **There may be PCPs who just won't engage.** In this case, we must **find another PCP.** One physician's lack of interest should not dictate poor future health for a polio survivor.

EDITOR NOTE: There are "polio experts" in Southern California. They may or not be part of your health plan. You might choose to go out-of-pocket and take what you learn from an expert to your Primary Care physician. The best way to find polio experts that will meet your need is to go to at least 2 or 3 support group meetings in OC or at Rancho. Discuss your specific needs with the survivors in attendance. Ask which medical caregivers we have used.

Important Things to Discuss with PCP

- Are you living within the General Guidelines for a polio survivor with PPS?
- *When is a new or chronic condition not Post-Poliomyelitis Muscular Atrophy - part of PPS (PPMA)?* When it is anything other than new muscle atrophy, weakness, pain or fatigue. And, even then, there has to be a **double check** that it is not something else. Also, PPMA may increase symptoms of other conditions.
- Your PCP will want to know why you are seeking an evaluation now. It is VERY DANGEROUS for us to attribute new or, maybe, chronic conditions to PPS, by itself, is not life threatening. But, as Dr. DeMayo makes abundantly clear, the very health factors that affect all persons of our age expose us to big risks.

- If we take care of our general health, we can live long and mostly happy lives, while managing the effects of PPS with the help of our Primary Care doctor.

11 polio related 2017 Publications

- 2 case reports of vaccine related polio
- 1 new drug trial
- 2 on exercise and rehabilitation
- 5 discussed quality of life, including aging and falls
- 1 report on anesthesia risk
- Grifols, a drug manufacturer, has competed Stage 1 of **IVIG** Study for PPS. Stage 2 will be in 2018,which could lead to FDA approval.
- **EDITOR NOTE:** See Summer 2017 Vol. 33 No. 3 Post-Polio Health for information on research supporting Grifols' efforts.

Clinical Trials

Go to ClinicalTrials.gov to view (active, not recruiting, and recruiting) drug trials for Polio survivors.

Exercise

- *Cochrane Database System Review* with 37,143 participants suggests that exercise is an intervention that, with few adverse affects, may improve pain severity, physical function and quality of life.
- *Arq Neuropsiquatr* assessment is that patients with PPS had a higher energy expenditure during life, especially in occupational physical activity at ages 21-30 years, suggesting that this decade is critical for the development of PPS. **VERY INTERESTING !!!**

Quality of Life

- A small Turkish study indicated that PPS had a negative impact on function, pain severity and energy. Early recognition and rehab of PPS patients may improve quality of life.
- A lifelong Danish study of polio victims between 1940 and 1954 compared with 13,762 controls showed that mortality was moderately increased. Hospitalizations were 1.5 times higher for a broad spectrum of diseases. No major differences between paralytic and non paralytic cases.
- A *Rehabilitation Psychology* study concluded/implied that having friends with the same disability resulted in a higher quality of life and satisfied role in society. These friendships buffered the impact of functional disability and can offer unique information. Psychosocial interventions should help the disabled build peer support networks.

Falls

Texas survey of 300 members of a polio support group (both with and without PPS). Participants were asked to document their fall history, medications, and self report depression using Geriatric Depression Scale. 172 usable surveys were returned with 146 completing medication list. Depression was found to be a significant indicator of falls in polio survivors with and without PPS. Medications, including antidepressants or psychoactive medications were not related to fall incidence. Primary Care physicians should screen for depression.

Aging

Growing older with a Physical Disability: A Special Application of the Successful Aging Paradigm

Participants with MS, MD, or PPS ranged in age from 45 to 80 and had lived with their disability an average of 21 years. Analysis revealed 4 primary themes of successful aging: resilience/adaptation, autonomy, social connectiveness, and physical health (including access to general and specialty healthcare).

Registry for Polio Survivors:

https://www.conemaugh.org/apps/postpolio/

The John P. Murtha Neuroscience and Pain

⟶

Institute launched an **online registry** of polio survivors to promote research about the late effects of polio and PPS.

- 5-10 minutes of on-line questions
- Your identity is kept confidential
- Most industrialized countries maintain a registry for polio victims through their health care system. In the US the only way to do widespread, ongoing research is to create our own registry.

Resources

WWW.POST-POLIO.ORG WWW.NCBI.NLM.NIH.GOV/ENTREZ (PUBMED)
WWW.CLINICALTRIALS.GOV

DIANA GUTH on Sleep and Respiratory Care

Why am I having trouble sleeping?

- Do I have a Sleep Disorder?
- Am I Hypoventilating?
- Is pain interrupting my sleep?
- How are the answers to these questions determined?

- **Sleep Disorder Terminology**
- **OSA:** Obstructive Sleep Apnea
- **CSA**: Central Sleep Apnea
- **Mixed Apnea (both OSA & CSA)**
- **Complex Sleep Apnea**
- **Cheyne Stokes Respiration/Periodic Breathing**
- **Hypoventilation:**
  AKA Respiratory Insufficiency
- **PLMD- P**eriodic **L**imb **M**ovement **D**isorder
  (**R**estless **L**eg **M**ovement when awake)

Hypoventilation

The problem with PPS is more likely **Hypoventilation**, not **Sleep Apnea**

Mechanics of Obstructive Sleep Apnea

- Soft tissues in the back of the throat relax, collapse and obstruct the airway

Central Sleep Apnea (CSA)

- Brain doesn't send out the signal to breathe
- Frequently seen in patients with cardiac and neurological disorders
- In PPS or other neuromuscular disorders, weak respiratory effort while asleep can mistakenly be interpreted as CSA

Symptoms of Sleep Apnea

- Snoring with pauses in breathing followed by a gasp for the next breath (witnessed)
- Excessive Daytime Sleepiness (EDS)
- Waking up tired
- Falling asleep at inappropriate & unsafe times
- Waking up with a dry or sore throat
- Insomnia
- Irritability
- Attention problems
- Morning headache (also for hypoventilation)

Causes of Sleep Apnea

- Overweight

–If a person with sleep apnea loses weight, sometimes the sleep apnea disappears.

- Anatomy
- Genetics
- Large neck size
- More common among men

Diagnosing Sleep Disorders

- Go to a pulmonologist (for people with PPS) who is also a sleep medicine specialist. Some neurologists are also board certified in sleep studies.

— ***Sleep Studies***

- Attended split night sleep study in a sleep lab (most data)
- Home Sleep Study (limited data)

Treatment of Sleep Disorders

Different from treating hypoventilation!

- **Sleep apnea** is a serious medical condition

Continued on Pg.6

- Left untreated the person suffering from this disorder is at risk of heart attack, stroke and falling asleep at the wheel.
- Sleep Apnea Disease management requires a team of experienced sleep specialists: physicians, polysomnographic techs, respiratory therapists, dentists, psychologists, ENT and maxillofacial surgeons.
- There are a huge number of devices available. Medicare pays for some of them. Some can depend on how well your management team documents your symptoms and need for particular devices. Most polio survivors do best with a BIPAP as an entry level device.

Editor note: *In my early days of struggling with PPS my orthopedist and primary care doctor were fairly sure I had sleep apnea and ordered a sleep study. It turned out the culprit causing me to not sleep was Periodic Limb Movement Disorder. Once treated by a neurologist, I started to sleep and my pain level began a steady decline. My point is that if we can't sleep well, we MUST get diagnosed and treated by appropriate caregivers.*

Common PP Respiratory Limitations

- Weakened breathing muscles
- Thoracic abnormalities restrict breathing (Restrictive Thoracic Disorder)
- GERD: Gastroesophageal Reflux Disease ("heartburn")
  - – Predisposes one to aspiration pneumonia
  - – Excellent medications available
- COPD (Chronic Obstructive Pulmonary Disease) can be a component: bronchitis, asthma and/or emphysema

Hypoventilation

Definition: A respiratory problem where people intake air at inadequate levels for meeting metabolic needs, *causing the amount of carbon dioxide in the body to rise and oxygen can go down.*

- AKA Respiratory Insufficiency
- Not breathing adequately - each breath is too small

Chemoreceptor Control of Breathing

- Chemoreceptors in the back of our brain respond to (stimulate us to breathe more):
  – Low levels of oxygen
  – High levels of carbon dioxide
- If a person has a chronically high level of CO2, they no longer respond to high levels of CO2.
- If their oxygen level is also low, they are stimulated to breathe by an oxygen want drive.

– If they also need extra some oxygen to breath safely they have to be careful not to get too much oxygen

–If they are given too much oxygen, this will suppress their drive to breathe. They will stop breathing.

- Some people with PPS & respiratory insufficiency need to be careful not to get too much O2

Daytime Symptoms of Hypoventilation

- Shortness of breath on exertion
- Fatigue or exhaustion from normal activities
- Daytime sleepiness
- Poor memory & difficulty concentrating
- Decreased cough effectiveness
- Decreased voice volume, slurred speech
- Pulse Oximeter owners: Drop in oxygen saturation

– We like people to have an O2 saturation above 90%

BUT

– An O2 saturation above 90% doesn't mean you are breathing okay. CO2 still might be too high!

Sleep Associated Symptoms of Hypoventilation

- Orthopnea – Needing to sleep sitting up. Can't breathe well lying down.

– Reason: Gravity helps your diaphragm move down. When you lie down, gravity can't help.

- Morning headaches
- Restlessness with frequent arousals
- Non-restorative sleep
- Snoring with pauses in breathing (could be Obstructive Sleep Apnea)
- Be absolutely clear:
- **Pulmonary Function Tests are required to diagnose Hypoventilation!**

If you donate, we will provide more of Diana Guth's presentation in a January newsletter. Also, you can see her entire slide presentation at **ppsuppotoc.org** and go to Useful Items.

Rancho Los Amigos Meeting

Saturday

October 28th 2-4 PM

OPEN - SHARING

No meeting in November

Saturday December 2nd

PARTY 2-4 PM

- Saturday January 27th 2-4 pm

Topic to be determined

- Saturday Feburary 24th 2-4 pm

Topic to be determined

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**

Orange County Meetings

- Saturday January 13th 2-4 PM

Finger Food Potluck and lively discussion

- Saturday March 10th 2-4 PM

Disaster Preparednes for the disabled
by Jerry Couchman, Red Cross Volunteer

- Sunday May 20th 2-4 PM (tentative)

Dr Perlman on latest in PPS research and care

- 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

OC Newsletter editor :

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abaldwinkeenan@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**

PPSGofOC Newsletters will <u>cease</u> without donations!

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 Amigo PPS Support Group meets most months and publishes on even months. We share the same mailing list. All donations are shared equally. **Recent donors**: Mary Louise Hinshaw, Larry Dornacker, Hal Highborn, Janice Palmer, Anita Cano, Margo Wilson, Helen Gonzalez, Winifred Hyson, Karen Berquist, Mary Armenta, Lois Jackman, Barbara Mackinnon, Orva Sodman, Aleta Connolly, Sandra Godfrey

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Orange County
Post Polio Support Group

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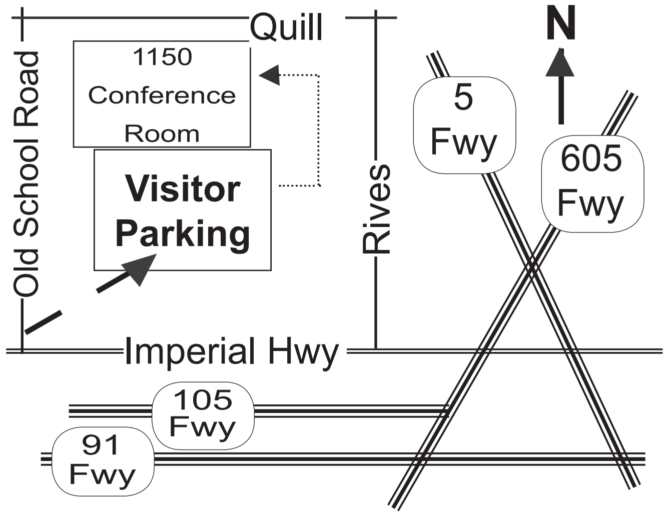
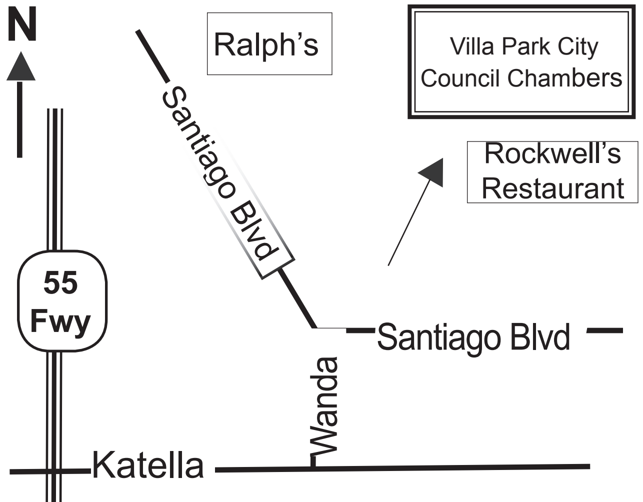


We meet **4th Saturdays 2 - 4 PM**
Rancho Los Amigos
National Rehabilitation Center
7601 E Imperial Hwy Downey
1150 Conference Room
Support Service Annex



We meet **2nd Saturdays** 2 - 4 PM
on odd numbered months.
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park
EXCEPT May meeting is usually
3rd SUNDAY