Founded in 1989

The Post-Polio Support Group of Orange County

Newsletter

15231 Marne Circle
Irivine CA 92604

September 2012

Social Security in Jeopardy

No matter how the vote goes in November very little will change in foreign policy, energy, or even eduction. Social Security and Medicare are different. In the *Business Section of the LA Times 8-15-12* Michael Hiltzik discusses the effect of the proposals of VP hopeful Paul Ryan: **replace Medicare payments with vouchers**, cut top tax rate 39.6% to 25% and eliminate mortgage deductions which mostly benefit the middle class. Replacing original Medicare or Medicare Advantage with vouchers would rapidly eliminate the control Medicare has over what doctors and hospitals charge us in premiums and out-of pocket. The Kaiser Family Foundation *(not Kaiser Permanente)* calculates that by 2022 one half of the typical 65 year old's total out of pocket medical costs will use up ½ of his or her Medicare check. The same people who are proposing vouchers also want to cut national funding of Medicaid, which benefits the very poor. States, if they choose to participate in the program, would have to fund Medicaid by drastically cutting other state programs. Hospitals and doctors will pass off the cost to care for those who are dumped out of programs for the poor onto those who have employer insurance or Medicare. If Ryan's program is enacted, older seniors will eventually pay most of their Social Security money for health care. **Social Security, as we know it, will be destroyed**.

CHANGES TO THE NEWSLETTER TEAM

After many, many years of committed and dedicated service to our Orange County group, including Co-editing the newsletter, Baldwin Keenan and his wife, Roni, will be taking a much deserved hiatus to travel and spend time with their family throughout the United States. Because of his departure, there are a number of changes anticipated in producing and disseminating the newsletter.

The most important is the formulation of an Editorial Board whose focus will be on the development of topics of interest for the coming issues. Anyone who has an interest in serving on this Board or helping to write for the newsletter should contact Janet Renison who will be assuming responsibility for the content and production of the Orange County newsletter. She can be reached via e-mail at renison@cox.net; by phone, 949-951-8613 or writing to 3454-A Bahia Blanca West, Laguna Woods, CA 92637. It is not necessary to have prior experience but good writing skills and an ability to effectively communicate is a major consideration. Those who wish to be on the team but do not wish to write articles, we also welcome your input and your participation.

On the pages inside this Issue

Dr. Susan Perlman Presents Her Annual *State of the Disease* Report

Dr. Susan Perlman spoke to the Orange County group on Sunday, May 20. She gave an overview of the research achievements and studies over the past year.

She began the presentation with a review of what we know about PPS. She continued by sharing how she, personally, soon after joining UCLA's Neurology Dept., became the focus for post-polio patients and, because of her need to acquire additional expertise outside of Neurology, slowly built a team of experts in those disciplines most relevant to the physical presentations of PPS. The initial group also included Trainees in a Physiatry Program, sponsored by the Veterans Administration Hospital who began working with her patients as well. For the past 8 years, her team has grown to include Neurology residents.

NEXT TWO MEETINGS

The next Orange County meeting will be Saturday, **September 8**. Our scheduled speaker is from HICAP and will be discussing the proposed Medicare plans for 2013.

On Saturday **November 10**, we are scheduling Dr. Christine Phan, a leading physiatrist (Physical Medicine & Rehab) from Kaiser Permanente, who will discuss her care for PPS patients in Southern California.

Next, she outlined the efforts being made by Kaiser Permanente Medical Group to develop their training program, a series of Webinars, on treating their PPS patients. They have long had their medical records computerized. And, as the Affordable Care Act is focusing on this as a way to save money and improve care in the implementation of the expanded national health coverage, they are considerably ahead of many other providers in their efforts.

Even with the international efforts to vaccinate against polio, it is still a threat. As of the date on which Dr. Perlman spoke, 55 cases of the "Wild Polio Virus" had been identified this year, globally. In 2011 there were 153 cases through the same period and a total of 650 for the year.

Typically, 30-50 years after the onset of the acute case of polio, those who develop Post Polio Syndrome will begin to present manifestations of the new symptoms. Generally, they are excessive fatigue, muscle and joint pain, new weakness or atrophy, cold intolerance, and breathing and sleep changes. Even patients who had no identifiable bulbar involvement in the acute phase can and do develop breathing problems with PPS.

Her Statistics indicate that most symptoms would be noted in areas previously affected by Polio. However, 10-20% of survivors of non-paralytic polio ALSO noted similar symptoms. These symptoms commonly caused functional declines in mobility, Activities of Daily Living (ADL), and general health which were also impacted by complications of injuries, immobility, weight gain, etc.).

The Diagnostic Criteria for confirmation of the PPS diagnosis requires:

- A prior episode of Acute Polio or the suspicion of one.
- A period of neurological recovery, followed by at least 15 years of functional stability.
- Gradual (or abrupt) onset of new weakness or muscle fatigue, with or without generalized fatigue, muscle atrophy or pain.
- EXCLUSION of other medical, orthopedic or neurological conditions.

Essentially, the diagnosis is one of EXCLUSION.

- One-third of polio survivors with new symptoms will have an unrelated medical, orthopedic or neurological condition that may have led them to seek treatment irrespective of polio or post polio.
- One-third will be experiencing deterioration of previously stable orthopedic problems (old fusions or tendon/muscle transfers, secondary arthritic changes in the spine or joints).
- Only one-third will actually have true NEW progression of motor unit dysfunction.

Risk Factors in Aging With A Disability

— Static Old Neurological deficits are risk factors for Future new Neurological Problems.

- Survivors of acute polio with Neurological deficits have a 40% risk of developing new and progressive muscle weakness.
- Similar delayed progressive decline is seen in survivors of other conditions (myelopathy) that can injure anterior horn cells.
- Possible development of conditions such as Guillan-Barre Syndrome or early stroke.
- Mayo Clinic studies estimate that 40-50% of acute polio survivors will experience new neuromuscular problems.
- Prospective studies of these survivors have not shown increasing percentages, which suggests a specific subpopulation is at enhanced risk of PPS.
- Those risk factors may include: the severity of the acute illness, the time that has elapsed since the acute phase, and OVERUSE (including muscle pain and fatigue.
- Things not deemd to be risk factors are: Age at Acute Onset phase, the severity of the deficits nor is gender deemed to be a factor.
- RESIDUAL DEFICIT, OVERUSE and TIME/AGING ARE PREDICTIVE of PPS.

Causative Factors Related to AGING

- Genetics (longevity, genes that turn OFF due to protein synthesis or growth factors, genes that turn ON, stealing resources needed by other genes, genes that are only good at certain ages and bad at others, gene MUTATIONS and even programmed death cell factors which show up in later life.

- Free Radical Build Up
- Hormone Changes
- The Immune System

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Mechanisms of inflammation may contribute to Motor Unit Dysfunction and other symptoms of PPS. One study, done in Sweden, showed increased amounts of inflammatory Cytokines in the spinal fluid and blood of polio survivors with PPS. Those finding were similar to that found in MS patients. These cytokines are associated with damage to nerves and may cause sleepiness, fatigue and depression. Inflammatory Markers such as these are increased in both MS and PPS

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NEW RESEARCH

Dr. Perlman listed several specific studies and their findings. IVIG treatments studied in the Scandinavian countries have shown some success. But, these treatments are extremely expensive and seldom covered by insurance here in the US. In addition there are a number of side effects of IVIG such as headaches, malaise, nausea, fever, and others. Many of these are short term and subside within a few days. There are also rare and potentially life threatening side effects such as anaphylactic shock, meningitis, renal failure, stroke, heart attack and other clot complications.

Polio Survivors must modify their lifestyle to avoid overuse, using assistive devices when appropriate, control their weight and sleep problems, monitor and avoid stress and pain and engage in non-fatiguing exercise for strength and conditioning. If PPS patients are careful to do these things, there can be an improvement of 1-2% per year.

However, there are cautionary signs. Progressive Post-Polio Muscular Atrophy **(PPMA)** weakens nerve-muscle communication and performance so drugs that affect those areas may be toxic and caution must be employed. Overexercise is to be avoided and makes **PPMA** worse. This is especially true for repetitive motions. It is wise to pace ones daily living activities to make certain that one does not overdo to the point of pain or fatigue. POLIO SURVIVORS ARE NOT IMMUNE TO OTHER DISEASES so make certain that one does not attribute all new symptoms and conditions to PPS.

DRUG FAILURES

While neuromuscular junctions are unstable in all PPS muscles, not all cause symptoms. PPS nerve fiber sprouting is already at its maximum so that growth factors that induce more sprouting may be redundant or even harmful to an overextended nerve.

REHABILITATION IS KEY

There is an extensive body of literature showing that rehab (therapeutic exercise, conditioning, energy conservation, adaptive devices and bracing) is able to stop progression of symptoms and improve function and quality for life in patients with **PPMA**. Even improvement of one small part results in an overall improvement (pain management, pulmonary or sleep interventions, weight and good nutrition, stress reduction and treated depression being a few areas). No specific drug trials have shown efficacy,, statistically. Such therapies are probably years away. Thus there is an EDUCATIONAL imperative for those PPS patients on the best practices and care of post-polio syndrome.

WHY?

* Polio survivors report poorer functional status and health-related quality of life than non-polios.

* Life altering effects of PPMA have not been adequately addressed by health care providers.

* Many publications indicate that polio survivors are best served in multidisciplinary clinics (clinics with a focus on many areas of medicine) and staffed by knowledgeable professionals.

Dr. Perlman then went through the findings and theories behind a variety of studies. These studies and their findings, study subjects and parameters, can be seen in detail at the website for those who wish to view this information in greater depth. SEE: ppsupportoc.org

After Dr. Perlman's presentation, she took questions from those in the audience who had written in advance or during the foregoing presentation. Following is a brief summary of those questions and answers in an abbreviated form:

1. Why should PPS patients use a Physiatrist rather than some other type of specialist?

Because these professional are rehabilitation specialists who view the patient in totality and can treat all of those conditions presented.

2. Are hand tremors associated with PPS?

They can be, brain implants are being used to treat some tremors.

— Would homopathic treatment such as red yeast rice as a cholesterol supplement be detrimental to muscles?

It is suggested that one use an antiinflammatory and antioxidants such as Resvinatrol. Many drugs have side effects which can present additional problems. It is also suggested that survivors also try Occupational and Physical Therapy to treat them.

— What is bulbar polio?

It is a type of polio that effects the lung muscles and used to require an iron lung to breath for those patients, short or long term.

3. Is swimming a good form of exercise for PPS-ers like my dad?

Yes but with some restrictions based on individual circumstances.

4. Is there anywhere I can get a copy of the presentation which contained too much information for the layperson to absorb?

Yes. It will be posted at the website for Orange County: ppsupportoc.org

5. If one sees no relief for symptoms after six months of treatment with their medical gatekeeper, should one go to see a specialist?

Yes. There is a list of specialists, by city on the OC website.

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6. Is palates (seated only version) or stretching and resistive exercise good for all PPS patients?

Work with your physician and Physical Therapist to determine the best program of exercise for each individual.

7. Is massage effective to treat pain?

It can provide short term relief but do not use rolfing techniques.

8. Are computer implants available?

They are in the developmental stage and not currently implantable.

9. Is there a research program that might want my body/brain when I die? I am 88 now, had polio at age 27.

Not to Dr. Perlman's knowledge but you might want to check national databases.

10. What is your opinion on Myofacial release therapy? *Response not noted.* Could having had polio cause atrophy in the psosais muscle?

Yes. If so, is it a residual of the disease itself or caused by motor difficulties in walking? It depends on the patient.

11. There are all of these diets around that are "anti-inflammatory". Will they have any effect on the inflammation caused by the "floating pieces" of the polio virus detected in the research studies?

Doubtful.

12. There were a series of questions specific to implants, type of implants and case law relative to them which were also specific to one individual that were addressed. In addition, there was a discussion of medications such as Ultram, which is a combination of endorphins, anti-inflammatory and serotonin and only minimally habit forming *vis a vis* Aleve and Motrin, and Sleep aids that do not carry-over effects.

13. Is it possible to get IVIG treatment if I were willing to pay for it myself?

Yes, but treatments are about $1,000 each and require a minimum of three treatments. The length of the benefit varies from patient to patient as well as does the efficacy.

14. Dr. Perlman was asked to discuss her experience with the new computerized exoskeletal mechanical framework that allows paraplegics and those with spinal column injuries to walk and even climb stairs.

These devices are worn on the lower body, often in conjunction with crutches which may be used specifically for balance and not necessarily for weight bearing.

There was some additional discussion after the program was officially concluded that the note taker did not hear.

Generally, there was a consensus that the meeting had produced a greater awareness on the history, treatments available and the research currently being done in the field.

END

WHO is HICAP?

HICAP (the **H**ealth **I**nsurance **C**ounseling & **A**dvocacy **P**rogram) offers free, one-on-one Medicare counseling. Trained volunteer counselors can answer your questions and help you understand your Medicare rights and benefits, including how to appeal denials of coverage; Medicare supplemental insurance (Medigap policies); Medicare Advantage plans; employee and retiree coverage; and long-term care insurance. Legal help and representation at Medicare appeals or administrative hearings are also available.

HICAP provides free educational presentations on Medicare and related topics. Call your local HICAP to schedule a presentation or find out about one happening in your area.

HICAP counselors do not sell, recommend, or endorse any insurance product, agent, insurance company, or health plan.

The California Department of Aging administers this volunteer-supported program and CHA supports the HICAPs through trainings, technical assistance and up-to-date consumer materials, including our website and fact sheets.
1-800-434-0222 http://www.coaoc.org/

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 us:
Rancho PPSG@hotmail.com

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Call us for information:

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Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102 or email Priscilla at prisofoc@aol.com

Special thanks to our donors: There were so many, nearly 10% of our readers, who contributed to our fund drive, that they cannot all be named individually. We do, however, appreciate ALL of their contributions. We mention donations but not the amount, as all donations make our support group possible. Please write checks to **Polio Survivors Association** and write "Orange County" in the memo section. Please **mail checks to** Priscilla Hiers, Treasurer, 18552 Cork St., Fountain Valley, CA 92708.

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Rancho Los Amigos Meeting

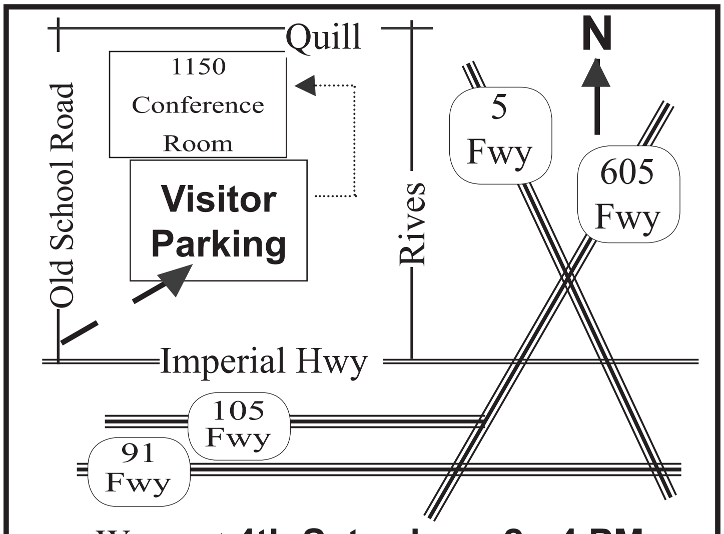
Saturday,
September 22, 2-4 PM

HELP!!! I Can't get Up!

How do we deal
with emergencies?

Future Rancho SG Meetings

Contact Rancho Group for information
on Future Meetings



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

Orange County Meeting

Saturday
Sept. 8, 2012 2-4 PM

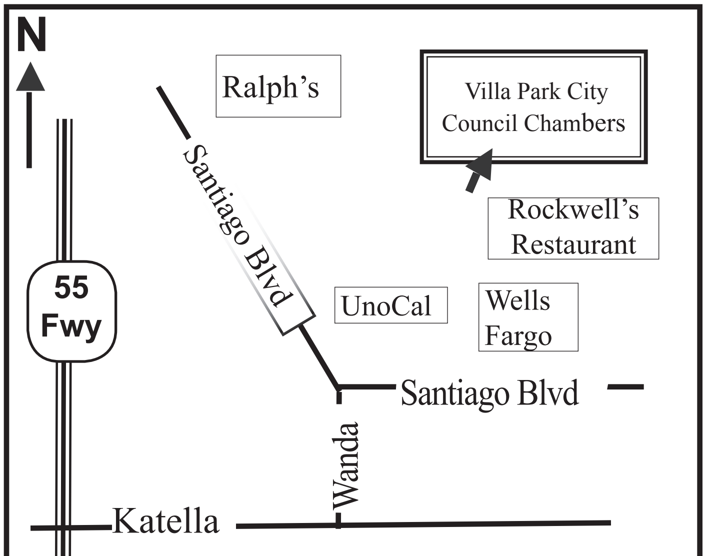
HICAP presents:

MEDICARE changes & impact of Affordable Care Act in 2013

Future PPSG of OC Meetings

Saturday
November 10, 2012 2-4 PM
Christine Phan MD. One of Kaiser Permanente's leading physiatrists (Physical Medicine & Rehab) has been asked to speak on her care of polio survivors.

In **December** we will have a joint meeting with Rancho Los Amigos to hear their "Doctors' Report".
Date to be announced.



We meet **2nd Saturdays** 2 - 4 PM
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park
May meeting usually on a SUNDAY
December at Rancho in Downey