

Newsletter

Post-Polio Support Group of Orange County

Founded 1989

3454 A Bahia Blanca West Laguna Woods CA 92637

Coming Events:

JULY, 2016

MODIFYING YOUR HOME FOR YOUR DISABILITIES

Baldwin Keenan, who does volunteer work other retired carpenters for the disabled and Ed Ripley, who has done considerable ADA work in the past, are putting together a fairly comprehensive presentation on home modification (grab bars, conveniently placed electrical outlets, closet organization, ramps, finding good contractors, free/low cost help. Primary emphasis will be on persons who need to use wheelchairs inside their homes and the difficulties presented by conventional door widths. However, we will cover a wide range of home modifications and safety issues: Grab bars, reconstructing closets, light switch and plug heights, ramps, transfer seats for tubs, and bathroom safety in general. And we will deal with how to hire a legal contractor and what is a legal contract. Ed did extensive work on disabled housing and headed So-West Carpenters Trng. Ctrs. Baldwin led Retired Carpenters Club working extensively with Dayle Macintosh Center to provide help to the needy disabled.

Please invite anyone who is disabled (polio survivor or not), who you think could benefit from the information.

SEPTEMBER, 2016

PLANNING FOR THE FUTURE

Putting your affairs in order to facilitate the disposition of your estate, be it through an Executor/Executrix or your Trustee. Make it easy to find estate information and necessary keys policies and other objects of importance for your heirs. Inform, Organize and Identify, and, foremost, plan ahead.

DR. PERLMAN PRESENTATION – MAY 15, 2016

Once again, Dr. Susan Perlman, Director of the Polio Clinic at UCLA Medical Center, presented a clear, concise and interesting overview of the research, treatment and advances in polio and post polio throughout the world from last May to this year. There is good news in that one additional country, Nigeria, reported no new cases of wild polio in the past 12 months. Unfortunately, that still leaves both Pakistan and Afghanistan as countries which have not yet eradicated this scourge from their populations. Their failure to do so is most likely attributed to the difficulty in administering the vaccine to their remote and suspicious populations. In addition to this, the vaccine is now limited to strains 1 and 3. The initial vaccine was comprised of strain Types 1, 2 and 3 but type 2 is no longer seen in the populations which have experience wild polio cases. This is a significant improvement as Type 2 is the more difficult to treat. Type 1, however, is the most common seen throughout all populations. The only country known to have exported the wild polio virus in the past twelve months has been Pakistan so real inroads have been made in eradicating this disease globally.

However, we cannot become complacent because there are still three countries, Ethiopia, Israel, and Syrian Arab Republic where there are no vaccination programs in place and their populations are at risk for exposure from people from other countries where there are still ongoing infections.

While real advances have been made regarding polio cases, there are several polio-like syndromes that mimic its symptoms including paralysis---which occurs only about 2% of the time.

Some enteroviruses (#68, #71, and coxsackievirus A7) from the same family as polio have been identified. #68 has been identified as only having emerged since 2010. The polio like symptoms have also been identified as having derived from snakebite, spider bite, scorpion sting, ticks or some chemical exposures. The West Nile and Zika viruses are also known to cause similar paralytic syndromes. It is much too soon to predict whether or not these new syndromes will generate conditions like Post Polio. One good bit of news is that Korea has begun to actively look at Post Polio and polio survivors.

Last years report talked about Duke University's research study on using a modified, non contagious form of the polio virus to treat glioblastoma, invasive, inoperable brain tumors. The study was able to identify the most appropriate dosage to inject into those glioblastoma growths that cause the persons own immune system to attack and destroy the tumorous body. The efficacy of the treatment and identification of the proper dosage has encouraged the Federal Drug Administration to "fast track" the process for "breakthrough" treatment nationwide, something that seldom happens in the US and now gives great hope to those who had in the past faced few positive treatment options. The enlarged clinical trials are currently recruiting for a much larger trial population in an effort to get the modified polio treatment available to those in need.

Things we know for certain about Post Polio Syndrome:

1. New or increased symptoms in a post polio survivor are PPS only about 1/3 of the time. These symptoms generally present as new atrophy, new pain, new fatigue or new neuropathy. 2. All other new or increased neurological or orthopedic symptoms must be correctly identified and a treatment regimen put into place at the earliest possible time to minimize additional deterioration of

survivors condition. 3. Treatments of other illnesses or conditions in a polio survivor must be monitored relative to the sensitivities of Post Polio (i.e., surgery and anesthesia, chemotherapy, cholesterol drugs, etc.).

If you need surgery, prior to such you would be well advised to have a Pulmonary Function Study so that anesthesia presents few surprises and your surgical center is properly prepared to treat you. It is further advised that your physician send you to well equipped surgical center, most likely not out patient centers if you will be receiving general anesthesia. A clear understanding of the medications, dosages, to be used should exist and be discussed thoroughly by all members of your medical team.

Guidelines for those with Post Polio.

Nearly 60% of those who survived an acute case of polio exhibit some symptoms of Post Polio and show some decline in capability over time. These survivors must take care to: 1. Modify lifestyle; 2. Avoid overuse; 3. Use assistive devices or bracing as appropriate; 4. Control weight gain, avoid sleep problems, stress and pain; 5. Engage in non-fatiguing exercise for strength and conditioning. Studies have shown that following these lifestyle modifications can both halt progression of PPS Symptoms and promote improvement of 1-2% per year. It is especially important to educate your medical team on PPS and how imperative it is that they all work in conjunction to treat your medical conditions, whatever they may be, in a way that coordinates with all others and with PPS, specifically. Do not allow anyone on your medical team to treat one condition independently of the others. If necessary, find a new team member committed to this unified treatment process.

New Publications of 2015-2016

There were no new presentations at major symposia on PPS this year, but some 16 new publications addressed some aspect of the subject. They were: 3 reviews or case studies; 2 on treatment guidelines; 2 addressed diagnoses or classification; 3 looked at Quality of Life and the effect of falls; 2 addressed pain /fatigue; 3 focused on general Aging With a Disability; 2 looked at IVIG infusion factors.

Falls and the effects on Quality of Life issues in particular, are of some note to the Koreans and in their publications this year provided results of one study of 317 polio survivors. Two findings of consequence were that leg-length discrepancy was particularly perilous when survivors were ambulating and the second indicated that if the survivor wore bracing and suffered a fracture from a fall, the fracture tended to occur just above the braced area. Sweden also studied falls this past year and determined that fear of falls was a huge factor for those being studied. The participants were averaging some 6,000 steps per day, a significant level of ambulation.

The studies on Treatments focused largely on Fatigue and Pain. Inflammatory involvement can cause both. Knowledge of on-going inflammatory involvement in PPS has been known for 20 years or more but has been somewhat ignored in studies until more recently. But both Pain and Fatigue influence the quality of life which has become of great interest to researchers. The Nollet, et al., study from the Netherlands addressed severe Fatigue in PPS survivors Quality of Life. They

looked, specifically at the efficacy of exercise therapy and cognitive behavioral therapy and their ability to reduce or modify fatigue. The 68 study participants did not show any change in their fatigue level as a result of those therapies but felt that further study should address why those therapies were ineffective.

The Treatment of Pain was also a study focus by a group in Germany led by R. Muller, et al. They wanted to determine if positive psychological exercises could influence the treatment for pain.

Their findings indicated that such psychological interventions could, in fact, cause improvement in pain management (intensity, control, interference, depression and life satisfaction) for a period up to the 2.5-month follow-up.

There was an update to the study done in 2011 by Koopman, Nollet, et al, on primarily pharmaceuticals and other factors and their effects on those with PPS. Results indicated that IVIg, lamotrigine, muscle strengthening exercises, as well as static magnetic fields may be beneficial, but further investigation is needed to clarify if the effects are real and meaningful.

Aging With a Disability

Psychological Resilience, the ability to adapt to stress and adversity is hugely important in predicting functional outcomes for people who are aging with a disability. Studies show several factors that impact our development and how we sustain our Resilience levels. They are: The ability to make realistic plans and the capability to follow through with them. Having a positive self concept and confidence in one's strengths and abilities.

Having good communication and problem-solving skills. The ability to adequately manage strong impulses/feelings. These factors are not necessarily inherited but can be developed.

A study by AM Silverman, et al., investigated the link between Resilience and functional outcomes and found that Resilience is a protective factor that supports optimal functioning for people aging with disability.

CURRENT UNDERSTANDING of CAUSATIVE FACTORS of PPS

Polio survivors with greater motor unit remodeling (change in which the orphaned muscles connect with a different live nerve) and greater residual functional deficits (fewer usable functioning motor muscles and nerves) are at greatest risk to develop symptoms of post-polio syndrome per Sorenson, et al, 2002. OVERUSE of unstable motor units and mechanisms that relate to aging act as triggers for PPS. Mechanisms of INFLAMMATION may contribute to motor unit dysfunction or other symptoms of post-polio.

Inflammation Studies

The role of Inflammation was studied in Italy and Sweden with the following results: "Our findings demonstrate a high prevalence of Restless Leg Syndrome (RLS) in PPS and that RLS occurrence may significantly influence the Health Related Quality of Life (HRQoL) and fatigue of PPS patients. A hypothetical link between neuroanatomical and inflammatory mechanisms in RLS and PPS is suggested". Italy

A Swedish study concluded that "...a possible persisting inflammatory process in PPS does not seem to be associated with increased lipids and an increased risk for coronary heart disease events." Sweden

Journal of Neuroimmunology. 2015 (Dec.)

The Netherlands study by Nollet, et al., found specifically:

- Elevated plasma inflammatory mediators in PPS had no association with long term functional decline. This suggests that, while there is evidence for systemic inflammation in PPS, there is no hard evidence that it has anything to do with the clinical deterioration seen in PPS patients.

Grifols SA Study of IVIg Infusions in the US

In prior years updates, Dr. Perlman has given a synopsis of the findings of the Pharmalink sponsored Grifols clinical trial study and other research studies done in Europe which showed the promising aspects of IVIg infusions in PPS patients. UCLA's Post Polio Clinic, under the direction of Dr. Perlman, applied last year to be the main center on the West Coast for an expanded clinical trial which is to take place in the US, Japan and Europe and has been chosen as that study infusion site. In addition, because PPS is recognized worldwide as a rare disease, the US Food and Drug Administration has granted orphan drug designation for the use of IVIg in the treatment of PPS.

Current IVIg Limitations: Off label IVIg cost prohibitive; Side effects are substantial and potentially fatal; Treatment sites/methodology - usually require infusion center administration

Who Might Respond Best to IVIg?:

Those under 65 years of age; Having lower extremity partial or severe motor muscle weakness; No other major physical disorders; Reduced physical function; Muscle atrophy in the lower extremities; Higher levels of fatigue and pain; Visual Analog Score of pain measured above 20

Grifols IVIg (FORCE) Study Protocols

1. International; 2. Infusions given monthly for one year, split dosing over a 2-day period; 3. Target enrollment is 210 PPS patients; 4. 1/3 will receive 2g/kg; 5. 1/3 will receive 1g/kg; 6. 1/3 will receive a placebo

Inclusion Criteria:

Must be: 18-75 years of age; BMI less than 35 kg/m²; Must have March-of-Dimes clinical criteria diagnosis of PPS; Must be ambulatory with or without walking AIDS; Have two PPS weakened muscle groups, one of which is in the lower extremities with an mMRC scale score of 3D or more; Females may not be pregnant and they and their partners must be willing to use reliable and approved contraception while in the study; Must be able to walk 2 minute walking distance of 50 meters or 164 feet (about 1/2 a city block) consistently;

Exclusionary Criteria:

Those having received Immunoglobulin through, IV, subcutaneous, or intramuscular route within the last three years; Those with poor venous access; Those having intractable pain requiring narcotics/psychotropic drugs; Those receiving corticosteroids, except asthmatics; History of recent (1yr) myocardial infarction, stroke or uncontrolled hypertension; Suffer from congestive heart failure, embolism or show signs of unstable angina, a-fib, or electrocardiogram changes; Suffer from depression; Females who are pregnant or nursing infants; Those with known selective IgA deficiency and serum antibodies anti-IgA; Those with Renal, liver impairment or Anemia; Those with Hepatitis C, HIV-1 and/or -2

Outcome Measurements:

Change by week 52 from 2MWD baseline; Change from VAS pain baseline; Change from medical Outcomes Study 36-item health survey Physical Component Summary; Change from baseline in Six Minute Walk Distance; Change in muscle strength, fatigue, pain, QoL, blood markers

For those interested in applying to become a study patient, please contact Dr. Perlman's clinic by phone or e-mail.

Other infusion sites selected for this clinical trial in the US are Washington Univ., St. Louis, MO; SUNY, Syracuse, NY; Thos. Jefferson Univ., Philadelphia, PA; and internationally are: McGill Univ, Montreal, Quebec, Canada; Netherlands; Sweden; Denmark; Germany; Italy; Poland; Romania; Spain

If you have not yet joined the Registry for Clinical Trials here in the US and would be interested in applying for such studies, we would urge you to do so at <https://www.conemaugh.org/apps/post-polio> or contact the John P. Murtha Neuroscience and Pain Institute, Johnstown, PA. This registration process takes 5-10 minutes answering on-line questions and your identity and information is confidential.

RESOURCES: www.post-polio.org
www.Nob.nlm.nih.gov/entrez (pubmed)
www.clinicaltrials.gov



**Rancho Los Amigos
Meeting
Saturday July 23**

Orange County Meeting

Saturday, July 9, 2015

Modifying your home to
accommodate your disabilities

“HOW TO...”

Retired Carpenters Union
Ed Ripley & Baldin Keenan

Future Rancho SG Meetings

Future PPSG of OC Meetings

SATURDAY, Sept. 10

Planning for the disposition of your
estate using an Executor or a Trustee

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. We mention donations but not the amount, as **all** donations make or 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

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Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102 or email

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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.

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PHYSICALLY DISABLED**

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