

Founded in 1989  
The Post-Polio Support Group of Orange County

# Newsletter

January 2012

15231 Marne Circle  
Irvine CA 92604

Website: [ppsupportoc.org](http://ppsupportoc.org)

## Joint Rancho & Orange County fund drive

The last fund drive to benefit the Rancho Los Amigos and Orange County Post-Polio Support Groups was four year ago. Our treasuries are dangerously low. We run our groups on shoestrings. Our major expenditures are for producing our newsletters and for meeting room rentals. Minor expenses include website maintenance supplies for "food" meetings. **We need your support!**

### RETURN ENVELOP & QUESTIONNAIRE ENCLOSED

We want to emphasize that no one is required to make a donation to receive our newsletters. However, we do ask that all readers confirm that they want to continue to receive our newsletters. We regret that readers who do not submit a confirmation will be removed from the mailing list.

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## Come to our Finger Food Potluck January 14th 2-4pm

We have had relatively low turnout at meetings for which we do not have speakers. Those of us who do come to our potluck who like to convince others to join us.

- **Companionship.** It is a relaxed atmosphere in which we get to know each other as not just another person with PPS.
- **Easy Conversation:** In the past couple of years survivors have found it very comfortable to bring wide variety of concerns, sitting around a table enjoying Swedish meatballs, creole shrimp, St. Louis spare ribs, crispy coleslaw, fresh vegetable dips, and down home macaroni and cheese.
- **Unique Information:** In the past several years survivors have talked about swallowing problems, which primary care doctors they like best for PPS, which HMO has help polio survivors the most, and the pros and cons of reverse mortgages to make it financially possible to keep living independently.
- **Time to get it all out to good listeners!** None of us are medical experts but we all share years of experience dealing with the twists and turns of PPS.
- If you want to bring some dish to share that would be great. **You do not have to. There is always plenty to go around!**

# POST POLIO SYNDROME

-- a challenge of today

EUROPEAN CONFERENCE ON POLIO

## Summary

- by Dr. Frans Nollet, chairman of the scientific committee

## Conference Post Polio Syndrome – A Challenge of Today

Copenhagen, Denmark,

31 August – 2 September 2011

### Scope of the Conference

The primary aim of the conference was to bring patients, health care providers from different professions, and researchers together to find ways to improve care for polio survivors in Europe and to stimulate research in this area.

The conference was initiated by the European Polio Union, the umbrella organisation of 19 polio patient unions in 13 EU countries, and organized by the Danish Polio Society PTU. The program was decided by a joint committee of European researchers and EPU representatives.

The conference was attended by 330 participants from 25 countries from all continents. Half of them were patients, spouses and carers, and half health care providers and researchers. The program consisted of 21 sessions and included almost 70 lectures.

The conference atmosphere was excellent with high attendance of sessions. The opportunity to meet, exchange ideas and discuss between patients and professionals was highly appreciated and fruitful.

### Main conclusions

#### Research

• The most promising research area to the cause of post polio syndrome focuses on the role of inflammatory factors that may be related to persistence of poliovirus fragments in the genome. Based on this,

intravenous immunoglobulines may be beneficial to arrest or reduce the loss in strength and functional decline due to post polio syndrome.

• A recent Cochrane review concluded that the evidence for both pharmacological and rehabilitation interventions are insufficient and guidelines are based on limited levels of evidence.

• Therefore, high quality research to the effectiveness of pharmacological and rehabilitation interventions are needed, including cost-effectiveness evaluations to facilitate implementation in health care systems.

• Research interest needs to increase. Although research is being conducted in this area, the number of intervention studies in progress is scarce. Trial registries mention only one randomized study of rehabilitation interventions including health-cost evaluation.

• Research is hampered by little research interest, based on the false notion that post-polio syndrome is irrelevant because polio is a disease of the past, and, as for many orphan diseases, by funding barriers to execute pharmacological studies.

• The following specific priority topics for intervention studies were indentified:

1. Effectiveness of immunoglobulines needs to be confirmed. An international multicenter study is in preparation.

2. Effectiveness of multidisciplinary rehabilitation and its components such as exercise and psychological interventions.

3. Symptom management, especially to reduce fatigue and pain.

4. Interventions to reduce the high rate of falls and subsequent injuries; studies should include the prevention of osteoporosis in underdeveloped limbs.

5. Prevention of secondary damage to the locomotory system in aging polio survivors due to long term abnormal overloading of limbs.

6. To warrant healthy aging and to reduce the negative influence of multi morbidity and life style factors such as overweight and inactivity.

7. The effectiveness of orthotic innovations.

## Care

- Care should aim at societal participation at the highest functional level, and should be provided by interdisciplinary rehabilitation teams including the individual with post polio syndrome as full team member.
- An inventory among 19 polio unions in 13 European countries revealed a lack of interest and knowledge in many countries and few specialized clinics and poor access to help. Yet, it is estimated that around 700.000 EU inhabitants will suffer from post polio syndrome.
- To improve care provision in the EU, standards of care should be formulated and published.
- Each EU country should have an expertise centre for post polio syndrome to improve care at the national level.

## Networking

- Post polio syndrome must be kept on the political agenda, as major health care issue in the EU, and is a major aim of the European Polio Union. EPU will be strengthened by establishing a medical advisory board.
- More national polio patient unions need to join the EPU and EPU may be instrumental in setting up patient union's in European countries so far lacking such unions.
- A professional European network of health care professionals and researchers with interest and expertise on post polio syndrome to improve care and facilitate research will be established and facilitated by EPU.
- Priorities of the professional network are to establish diagnostic and therapeutic guidelines and to define a standard set of outcome measures for clinical research purposes.

## Endemic countries

- The WHO considers initiatives to improve rehabilitation care, especially in developing countries for the millions of people growing up and living with the lasting impairments of polio, to ensure that they can live full lives.

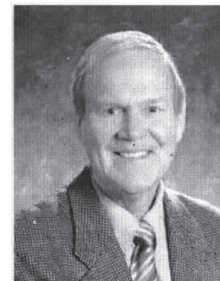
- The knowledge on post polio syndrome in developed countries should be transferred to developing countries to seek ways to prevent post polio syndrome and the secondary damage due to physical overloading and to set up care for post polio syndrome that will also become a future issue in these countries.

## Next Conference

- The next conference will be held in 2 years, likely in Amsterdam.

*Ask*  
**Dr. Maynard**

POST-POLIO HEALTH  
Fall 2011 Vol 27 No 4



**Question: Do you know of any polio survivors who are experiencing numbness in their affected areas? I did some physical therapy recently for about six weeks using both sides of my body to improve the strength in my unaffected leg, and noticed that my left arm (the affected side) was becoming numb and then later in the day, my left leg would also become numb (just the top part of my arm and leg). My family doctor is sending me to a neurologist to see if I have a pinched nerve but he and I both think it is polio related. Since I have stopped physical therapy it has quieted down, especially if I use Aleve®, a heating pad or warm water at the pool. I'd appreciate your advice.**

**A:** There are many causes of numbness, but post-polio syndrome is never the DIRECT cause. Polio affected motor nerves only and, therefore, does not lead to numbness or true loss of feeling. Numbness and tingling are, however, common complaints among polio survivors because of the many musculo-skeletal problems that they develop as they become older and because of other medical and neurologic conditions they may concurrently develop. A burning feeling in post-polio muscles fatigued by exercise/activity is

also a common report.

Based on your description of symptoms (coming and going; located on the top of the arm and/or leg; relieved by Aleve and local heat), it is very likely your symptoms are a referred pain from a more central spinal problem, but they could be due to a “pinched or irritated nerve,” nerve entrapments, circulatory diseases or other causes. A neurologist’s consultation is a good idea in order to rule out serious conditions. If nothing specific is found and symptoms do relate to activity/movement/exercise, then a referred pain from a musculoskeletal problem remains most likely as the cause. Working with your PT to alter your exercise program may also be successful in eliminating/controlling the symptoms.

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“Promoting Positive Solutions”

Author: Rhoda Olkin, PhD

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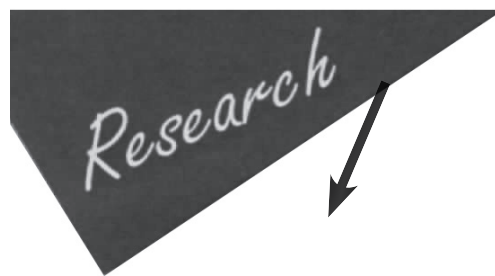
“Aging Well with Post-Polio Syndrome: Don’t Take Fatigue Lying Down”

Rehabilitation Research and Training Center (RRTC) on Aging with a Physical Disability

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Summary of EUROPEAN CONFERENCE ON POLIO 2011

by Frans Nollet, Head of Dept. of Rehabilitation,  
University of Amsterdam, The Netherlands  
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Fatigue is a major problem for many people with post-polio syndrome (PPS), one that is frustrating and hard to measure. It’s a symptom that can affect your ability to work, your mobility and your quality of life. People with PPS report fatigue as their most persistent and debilitating symptom.

Although most people (with or without PPS) report increases in fatigue as they grow into middle age, interestingly, they report decreases in fatigue as they transition from middle age to retirement. Middle age is a time of great stress - work responsibility, saving for retirement and preparing children for independence.

After retirement, the decrease in daily stress helps to reduce fatigue. Unfortunately, analyses from a recently completed survey study that many of the people reading this article participated in shows that people with disabilities (including PPS) do not reap the “retirement benefit” on fatigue. Instead, for people with disabilities, fatigue stays the same or gets worse as people age into the retirement years (Cook, 2011).

In our study surveying 441 people with PPS, we found individuals with disabilities are not only at greater risk to experience fatigue than people without disabilities, but this risk increases with age. Moreover, we found that fatigue in people with PPS was the highest of those surveyed, which also included people with multiple sclerosis, muscular dystrophy and spinal cord injury. A 5-year longitudinal survey of people with the late-onset of sequelae of poliomyelitis



# Aging Well with Post-Polio Syndrome: Don't Take Fatigue Lying Down

Rehabilitation Research and Training Center

(RRTC) on Aging with a Physical Disability, agerrtc@uw.edu

done in the Netherlands showed that fatigue was associated with perceived restrictions in physical functioning, higher levels of pain and sleep problems. A task-oriented (problem-focused) coping style correlated with higher levels of fatigue. This type of coping style may be pushing survivors beyond their physical abilities and increasing levels of fatigue (Tersteeg, 2011).

There are several non-medication ways to manage fatigue:

**Assistive Device/Equipment/ Technology -** Protect your weakened muscles - talk with your doctor or physical therapist about the best assistive devices for you, such as braces, canes, walkers or power chairs.

**Self Management** is defined as methods, skills and strategies that can effectively direct activities toward the achievement of a goal or objective. For people living with a chronic condition, this translates to “overcoming the physical and emotional problems caused by the disease. The goal is to achieve the greatest possible physical capability and pleasure from life” (Lorig et al, 2006). This idea can be applied to fatigue. You can manage your activity level by planning and scheduling, prioritizing, delegating or asking for help and pacing yourself. (Ghahari, 2010)

**Exercise/physical activity** -Historically, people with PPS were often told to minimize exercise as a way to conserve energy. Current research has shown the benefits of a carefully tailored and gentle exercise program designed specifically for each person

depending on how PPS is affecting the body (Davidson et al, 2009). Be sure to talk with your doctor or physical therapist about starting any new exercise program.

## References:

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- Davidson AC, Auyeung V, Luff R, Holland M, Hodgkiss A, & Weinman J. (2009). Prolonged benefit in post-polio syndrome from comprehensive rehabilitation: A pilot study. Disability & Rehabilitation, 31(4),309-317.
- The National Center on Physical Activity and Disability (NCPAD) To Reap the Rewards of Post-Polio Exercise -[www.ncpad.org/disability/fact\\_sheet.php?sheet=136](http://www.ncpad.org/disability/fact_sheet.php?sheet=136)



Rhoda Olkin, PhD

## Promoting Positive Solutions

Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor

**QUESTION:** I am not bitter because of my love of life, my family and my God, but it just gets tougher and tougher to survive and tougher on those who help me. I have children who help me and a wife who loves me but hates PPS and what it has done to her husband. How do I deal with a wife/support person who loves me but hates my PPS?

### **Response from Rhoda Olkin, PhD:**

I want to respond first to the fact that it gets tougher and tougher. I presume you mean as you age - the symptoms get more pronounced, weakness from polio combines with weakness from aging and new symptoms appear. Where maybe you could walk a city block, now it seems like a big effort to go from the bedroom to the kitchen. Perhaps you have started to use assistive technology such as a scooter or wheelchair, or now you have to use crutches all the time instead of just some of the time. Yes, these are big adjustments, not only for you but for your family.

I am going on the assumption that they love you, and would rather have you around, polio and all, than not. So, if you will forgive my bluntness, everyone needs to get over it. That is, I suspect you had polio all during your marriage, and hence all during your children's lives. This is not a new issue for the family. But I hope the family is able to talk about it openly and honestly, perhaps with the help of a professional counselor or a church elder.

Hold a family meeting, ask everyone to be

honest in how they feel. Problem-solve the areas that are emotionally and/or physically difficult. For example, does your wife feel held back because you cannot do something? Would you be okay with her going some places without you? Does she feel able to do so? Is she worried that as she ages she can no longer help you in the same ways? Do some tasks need to be doled out (to children, neighbors, church members, hired help) or even not done at all?

I want to emphasize that we polio survivors need to be careful about ascribing any new or worsening symptoms to polio when in fact they could be due to a treatable cause. For example, I went for several years thinking I had just reached a new stage of disability. In fact my thyroid hormone levels were low, and taking thyroid medication returned me to my previous levels of energy (which, admittedly, were still low and still decline with age, but are no longer debilitating)

Second, I have to wonder about your idea that it is possible to love you but hate the polio. Imagine substituting another descriptor for "polio" and see how it sounds. For example, you could never say "my wife loves me but not my gender." They are one and the same. You are who you are as a polio survivor. There is no you, and then on the side the polio. There is only you with polio. It's a package deal. I suspect it may be that your wife doesn't hate what it is doing to you, but rather what it is doing to her (e.g., preventing the two of you from taking trips, or putting more responsibility on her for household tasks).

So re-read what I've said above, and find out what the issues really are. And remember, those vows say "for better or worse," even if the worse sucks.

# Southern California Kaiser Permanente will commence 18 months of lunch hour Webinar Meetings for their physicians in February 2012 on:

## POST-POLIO SYNDROME – A MISSED DIAGNOSIS

The current plan is to include a few polio survivors in some of the presentations

Too fatigued or weak to read?

Contact the Braille Institute for its new digital player. Call Nancy Stanton 721-821-5000



### 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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### Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102 or email Priscilla at [prisofoc@aol.com](mailto:prisofoc@aol.com)

### Website: [ppsupportoc.org](http://ppsupportoc.org)

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: During our fund drive we will not be feasible to list donors. Please know how much we :  
: appreciate your support. Please write checks to **Polio Survivors Association**. :  
: Please mail checks to **Polio Survivors Association 12720 La Reina, Downey, CA** :  
: **90242**. THE FUNDS WILL BE DIVIDED BETWEEN THE RANCHO LOS AMIGOS :  
: AND THE ORANGE COUNTY POST POLIO SUPPORT GROUPS. :  
: .....

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## Rancho Los Amigos Meeting

**Continuation of  
discussion of Dr.  
Eberly's report**

**Saturday January 24th  
2pm -4pm**

***Future Rancho SG Meetings***

## Orange County Meeting

**FINGER FOOD**

**POTLUCK &  
GREAT CONVERSATION**

**Saturday January 14th  
2pm - 4pm**

***Future PPSG of OC Meetings***

**PLEASE FILL OUT THE  
QUESTIONNAIRE INCLUDED WITH  
THIS ISSUE AND LET US KNOW  
TOPICS THAT WOULD GET YOU  
TO OUR MEETINGS**

The board of the Post-Polio Support Group of Orange county is meeting in early January to begin setting a program of presentations for 2012. So far we have Dr. Perlman speaking to us Sunday May 20th.

**PLEASE FILL OUT THE  
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