

Founded in 1989

The Post-Polio Support Group of Orange County Newsletter

15231 Marne Circle Irvine CA 92604

November 2008

We all need to be able to ask for help

BY BALDWIN KEENAN

As newsletter co-editor and as a facilitator at many of our meetings I have the opportunity to discuss the late effects of polio with many of you reading this newsletter. 90% of you do not attend our meetings and for you this newsletter is a primary source of polio information. Janet Renison and I, with the input and support of the PPS of OC board, are attempting to provide articles that cover the full scope of what it takes for a polio survivor to live well. Your donations and letters of support indicate that we are achieving some of that goal. In September we emphasized financial matters. In this issue we focus on how post-polio syndrome requires that one change from being a mainly self reliant person in the years after we "recovered from polio" to a person who accepts the fact that to continue to live a quality life, she or he must find inside herself or himself the ability to ask for and receive assistance.

I have the extraordinary fortune to be much healthier and stronger than I was when I was first hit with PPS in 2000. With the care of many doctors, therapists, my wife, and my children, I have returned to doing considerable household repair and modification work, as well as some strenuous boating -- with the approval of my PPS physical therapist and PPS doctor. I need the help of medication to calm periodic limb movement, and be able to get a full night's sleep refreshing, both my good and weak muscles. My crutches are my assistants for walking moderate distances and my wheelchair is my friend who takes me on long trips into a sports stadium on down a beach boardwalk. At the other end of the spectrum there are members of our group who endure severe back pain while struggling with deciding about surgery. We have "single" survivors who make modification after modification to be able to stay in their homes. We have couples in which the non-polio spouse's health is declining as fast or faster than that of the polio survivor. Questions arise: Are more and better assistive devices needed? Is it time to hire in-home care? Or is it time to move to a assistive living residence? Given all the resources in Southern California, we have no excuse not to ask for the help we need. That's hard enough on our pride. But harder yet is finding the courage to accept help. **Please read on.**

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Key Findings from the FINAL REPORT
*Adaptation Into Late Life for Persons with
Long-Term Neuromuscular Disabilities:*

Lessons Learned from Polio Survivors

BY ALLISON (SUNNY) ROLLER, M.A.

- Major issues throughout life included: achieving and maintaining independence which required diligent effort; fighting shame and creating a positive self-image with a disability; and reconciling social and functional losses.

- Over time, perception of life with a disability from polio changed for this group. Before encountering the late effects of polio at mid-life, individuals operated and worked hard using their “lens of difference,” a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial. Later in life they



became more willing to look at their lives through the “lens of Disability,” more fully embracing their disability as part of their overall personal identity.

In so doing, they found a new freedom to be more content with this new self-perception and life in their retirement years.

- Key coping strategies included having a strong social support system, enjoying life, being optimistic, self acceptance, assertiveness, education and spirituality.

- Successful late life adaptation was defined as self-acceptance and adaptation, having the right resources, and being surrounded by loved ones.

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION
RESEARCH FELLOWSHIP PROGRAM AWARD
H133FO50039 12/1/2005-8/31/2007

A. CATE MILLER, PH.D. PROJECT OFFICER

DECEMBER 2007



Funds Available for Bracing and Modified Shoes

Post-Polio Health International has again received a grant from SPIN, a charitable organization in Chicago Illinois. The funds totalling \$3000 were awarded to assist polio survivors in purchasing braces or modified shoes. To assist the greatest number of survivors, the maximum funds available per individual is \$500.

To receive an application call Brian Tiburzi at 314-534-0475 or email him at info@post-polio.org.

Applicants from any country may apply.

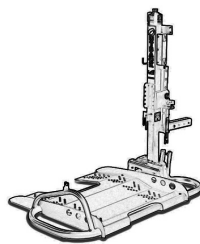
There is no deadline and payments will be disbursed as eligible applicants are reviewed.

Correction!

In our September issue we printed Grace Young's blog incorrectly. We apologize to you and to Grace. This is correct:

www.graceryoung.com

Grace R. Young, MA,OTR/L is a polio survivor and retired occupational therapist. For many years she was the polio resource person for all of the Kaiser-Permanente medical centers in Southern California and taught classes in how to conserve one's energy. Check out her **blog** which covers various topics related to living well with a disability.



Chair/Scooter hoist for sale

VMI Outback external, rear-mounted lift. \$2,500 new. Used very little. Stored inside. It has a No.2 trailer hitch slide-in mounting apparatus that must be bolted to the car chassis (underneath the trunk area) Runs off the car battery to lift and lower. \$1,500 or best offer. Contact: Janet Renison: renison@cox.net or (949/951-9613).



A few notes from our last two meetings

Assisted Living Residences

There are three types of care when we can no longer live in our homes:

Assisted Living Communities

- These are usually large “apartment type” buildings which usually offer many activities but have a low caregiver to resident ratio
- You are charged for the amount of services you require such as a nurse to administer injections
- The reputable local communities will cost at least \$3000/month

Board and Care Domestic Units

- These are residential homes located in standard neighborhoods run by a live-in staff of two which have been modified to take in a maximum of six residents -- a ration of one caregiver to three residents
- Usually less expensive than assisted living communities



Skilled Nursing Facilities

- The most intense level of care and resemble hospitals

We do not endorse any business, however we do feel that the Patrick Van Slyke of *Assisted Living Placements*, who made this presentation could be included in the list of people you should talk to before making a move to assisted living. His phone number is **888-854-7750** and the website is **[www.assisted living placements .com](http://www.assistedlivingplacements.com)**

In-Home Care



- In home care workers are companions who can do meal preparation, bathing and hygiene, toileting/incontinent care, dressing, assistance in exercises, transportation to medical and social appointments, grocery shopping, limited medical assistance , light housekeeping
- In home care workers are not home health workers. They are not nurses and they are not permitted to give injections.
- Protect yourself. Only hire through an agency. If you hire someone directly you expose yourself to liability and workers compensation claims, payroll taxes and social security taxes. All of this should be responsibility of an agency who is the employer, not you! TA good bonded agency runs a criminal and financial screen on its employees, tests for TB, pays them a competitive wage, and trains them well.

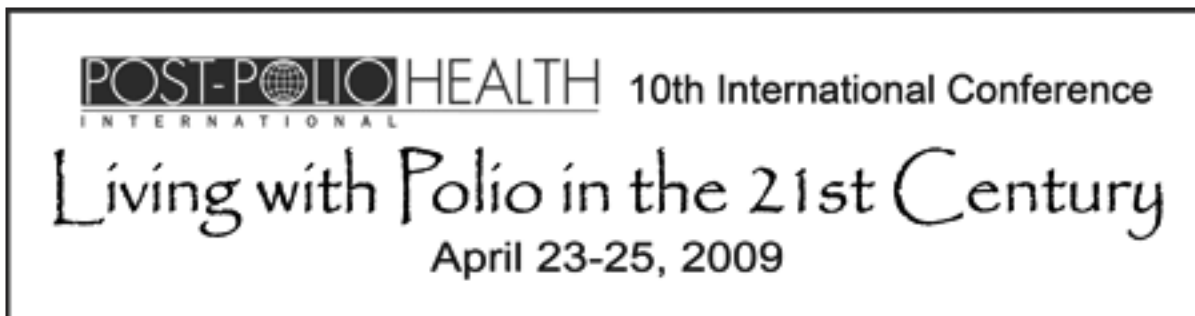
- Miguel Ortin of *Evergreen Care Providers* made the In-Home Care presentation to us. You could include them in your research: **714-701-1182** or **949-206-0646** Their website is **www.**

Reverse Mortgages

Co-editor Janet Renison gave a very full explanation of Reverse Mortgages in our **Sept. 08 Newsletter**. Each of us have very different needs and goals. If you want, a reverse mortgage could get you a monthly

check for life even if disbursements end up exceeding the value of your home and yet not make your estate liable for one penny. **Bob McLatcher** of *Wells Fargo Bank* made this presentation to us. He could be a good resource for you: **310-821-2532.** We do not endorse any business.





**Join us in
Roosevelt Warm Springs, Georgia
for the 10th gathering of the post-polio community
coordinated by Post-Polio Health International.**



The extensive program will provide polio survivors tools to live well with the late effects of polio; offer a forum for the exchange of ideas among survivors, families and health care professionals; and explore the history and legacy of the polio epidemics and its survivors. (The conference is scheduled to begin at 1:00 pm on Thursday, April 23, 2009. The final educational session will

end at 4:00 pm on Saturday, April 25, 2009, but there will be a social event on Saturday evening.)

Hotel accommodations will vary in cost and luxury.

See www.post-polio.org for details.

Interested in a pre-conference retreat that will go one-step beyond re-rehabilitation and focus on health and wellness?

A Post-Polio Wellness Retreat is being planned for Sunday, April 18, 2009 – Thursday, April 23, 2009. It



will be modeled after the popular retreats held at Bay Cliff Health Camp in Big Bay, Michigan. Want to know more? Watch the 10-minute DVD "Holistic Health and Wellness Retreat for Polio Survivors."



For the complete schedule and registration information please go to post-polio.org or call 314-534-0475

Dr. David Oshinsky, who won the Pulitzer Prize for *Polio: An American Story*, will address the closing session.



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

How to contact OC Support Group:

Call us for information:

Marte Fuller	562-697-0507
Marilyn Andrews	714-839-3121

Newsletter co-editors:

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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 _____. 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 PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708.

Disclaimer: Information provided in ours 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.



Rancho Los Amigos Meeting

Future Rancho SG Meetings

Orange County Meeting

Workshop on Polio Short Stories

Polio survivor Patricia Folkerth will help us put pen to paper and write about an episode of our polio experience which we would like to share with readers.

Saturday OCTOBER 11th 2-4 PM

Future PPSG of OC Meetings

Saturday NOVEMBER 8th 2-4 PM
Positive Outcomes in post-polio occupational therapy
 and her PPSG of OC Oral History Project
 presented by Kathleen Shanfield OT

Saturday DECEMBER 6th 2-4 PM
 Joint meeting with Ranch Group at Rancho los Amigos in Downey

Rancho Doctors Report

Saturday JANUARY 10th
Finger Food Potluck 2-4 PM

