

Founded in 1989

The Post-Polio Support Group of Orange County NEWSletter

July 2009

We have a website !

At the **support group session** at the Warm Springs PHI Conference in April it was emphasized that a rapidly increasing number of polio survivors are using the internet. Many PPS Support groups have had websites for several years. In addition some advocated **blogging**. (A blog is a type of website, usually maintained by an individual with regular entries of commentary, descriptions of events, or other material such as graphics or video. Entries are commonly displayed in reverse-chronological order) Well, I would have to be brought kicking and screaming to blogging. I was convinced, however, that we should have a website and, since I work on a Mac, building a website is rather easy. Added to that I have my son in Chicago who is "hosting" or placing the website on the internet for a very small fee. Please check it out and send in comments and suggestions:

ppsupportoc.org

Baldwin Keenan, co-editor

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A few notes from Warm Springs

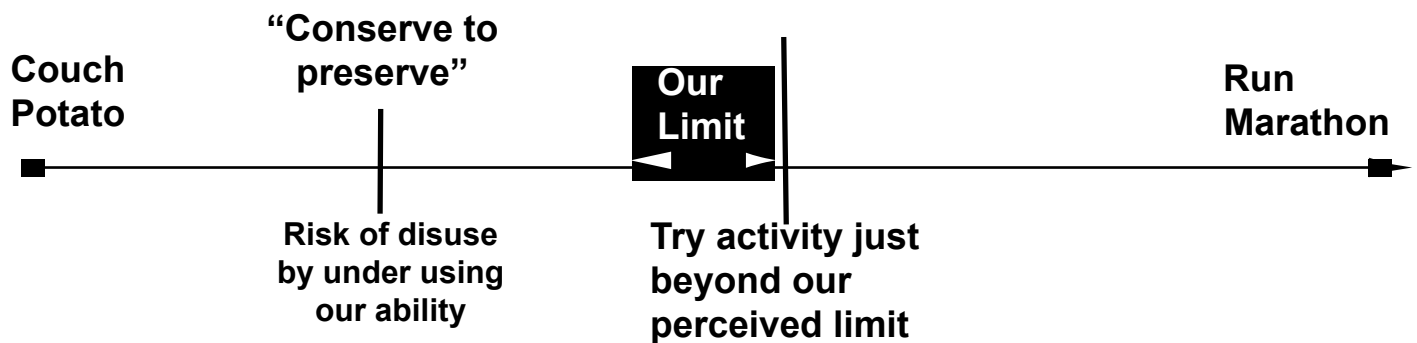
by Baldwin Keenan

At our September meeting I will attempt to give a more comprehensive report on the **10th International Post-Polio Health International Conference** held at Roosevelt Warm Springs, Georgia for the first time.

In this issue I would like to share a few overall impressions. It was truly an "International" meeting. I am a child of the South who was moved into action by Martin Luther King, Jr. As I opened the doors and saw polio survivors from India and Africa I couldn't help but ponder on how even with the care of polio victims one of our greatest presidents was unwilling to dismantle the lie of "separate but equal". Warm Springs remained segregated until the 1960s. I took a deep breath and set those feelings aside and decided to see Warm Springs for what it was and is today. I enjoyed talking with the polio survivors who had come there for surgery and rehabilitation. In the forties they published newsletters, had picnics, and held sporting events such as wheelchair races. I was very moved by see a quite large group of Warm Springs Alumni pose for a photograph in front of the historic colonnades. In the photo page of our new website **pppsupportoc.org** you can see shots I took of the rehabilitation center, some of the cottages, the original warm water swimming

pools, and the Little White House. There is one shot of the original gate to Warm Springs. Selma Calmes (a polio survivor who is a retired anesthesiologist) was taken by the symbolic glow of light at the end of the dirt road when she took the same picture. It was only possible to attend about a third of the sessions offered. There were very practical sessions such as “Wheelchair Seating” and “Home Mechanical Ventilation”. There were forums for alternative medicine and dietary approaches. In my opinion there was a lot for everyone’s interests. I concentrated on the research and medical care presentations which will be a big challenge for me to summarize in September.

At Warm Springs I did not hear “Conserve to Preserve” once during the conference. Nor did any speaker allude to living with PPS in reference to us having finite use of our remaining muscle neurons. There was no mention that those of us with atrophied legs have a set number of steps left which, once taken, are gone from us forever. No one advocated overworking our remaining muscles, rather I did hear a consensus that we need to pay much more attention to underuse and disuse of our viable muscles. Having post-polio syndrome does not excuse us from taking care of our health in general. Each polio survivor is distinct. Each of us have distinct limits. Dr. William DeMayo gave the following illustration. He recommend that we be active to OUR LIMIT. To do that we need to find our limit.



We need to test and establish our limit by doing exercise and activities slightly beyond WHAT WE HAVE PERCEIVED TO BE OUR LIMIT. This is a significant modification to “Conserve to Preserve” mantra or maxim. Using “Conserve to Preserve” we don’t really know our limits because our goal is to not use up our remaining strength, purposely doing less than our limit. Up until this conference I had viewed post-polio exercise as somewhat peripheral, if not controversial, in living with PPS. I don’t think many of us have difficulty in knowing when we overwork. Our bodies rebel big time. But, do we know when we are **underusing** a viable muscle group? This is where we need the assistance from time to time. At this conference speaker after speaker made it abundantly clear that each of us needs to find and utilize a **polio trained physical therapist** to map out an appropriate exercise program and to help us with achieving activities of daily living. Polio trained physical therapists are out there. It might take some looking.

One clear message that I took away from the sessions I attended at Warm Springs is that we become much better at taking care of the challenges of PPS if we take care of our health in general by weight control, maybe low impact seated yoga, sleep hygiene, relaxation techniques, and improved assistive devices, and, of course, having a uncompromising primary care physician.

We need your help to identify PPS care providers!

- **Have you been under the care of any of the following providers?**
- **Do they understand PPS?**
- **Would you recommend other polio survivors to see them?**

Physiatrist (Physical Medicine and Rehab.)

Dr. Sten Kramer - Newport Beach
Dr. Kenneth Lynn - Saddleback Hosp.

Physical Therapist

Jim Harrison - Downey
Steve Ferdig - Huntington Beach
Santa Ana

Chiropractor:

Gary Emerson - Santa Ana Tustin Medical
Michael Ferlita - Huntington Beach
Harold Slack - Fullerton

Pulmonologist .

Dr. Michael Fox - Anaheim
Dr. Glenn Libby - Memorial (Long Beach)

Primary Care

Dr. Douglas Nita - St. Jude
Dr. Donald Smith - Santa Ana

Orthotist

K. Carey or D. Galan Prosthetics - Anaheim
Ortho Kinetics - Downey
David Porter - Downey
Loren Rojek - Fountain Valley

- **Are you or have you been under the care of other doctors, acupuncturists, chiropractors, physical and occupational therapists, *besides those at Rancho Los Amigos Clinic or those who work with Dr. Shanfield (St. Jude), who understand PPS and whom you would recommend to polio survivors?***

Please respond to Baldwin Keenan, keenanwhelan@cox.net,
949-857-8828, or 15231 Marne Circle, Irvine, CA, 92604

Are you a cancer survivor who had limitations in activities of daily living prior to your cancer?

If you have completed active treatment for your cancer, I invite you to participate in a study to help us understand how cancer survivors who had a functional limitation or disability before being diagnosed with cancer take care of their health. We know so little about the cancer experience of people who had a functional limitation prior to their cancer diagnosis and treatment. Your information will help health care providers work more effectively with survivors such as yourself. You can earn \$25 by completing a questionnaire packet. If you are over the age of 21 and have completed active treatment, please call us at 800-687-8010 or email us at maxhealth@mail.nur.utexas.edu for more information.

Heather Becker, PhD, The University of Texas at Austin

From this week at PHI (May 17,2009)

UCI faculty member briefs Congress on stem cell research

Message: Stronger academia-industry relationships necessary

UCIrvine's Hans Keirstead - the neurobiologist behind what will be the world's first human embryonic stem cell clinical trial - presented "Expanding Stem Cell Research: Finding Cures and Changing Lives" to Congress in March.

Keirstead's message in Washington, D.C. was to emphasize the ongoing need for collaboration between academia and industry. "This union is critical to moving new therapies from the laboratory to the clinic," he said.

Keirstead was joined by Robert Klein, a spinal cord-injury research advocate, and Thomas Okarma, *Geron Corp.* president and chief executive officer for the Capitol briefing. *Geron* will conduct the clinical trial for Keirstead's spinal cord-injury therapy developed at UC Irvine, which in testing has allowed paralyzed rats walk again.

"This trial was approved only after rigorous safety testing and consultation of countless experts in the field," says Keirstead, co-director of UCI's *Sue and Bill Gross Stem Cell Research Center* and faculty member at the *Reeve-Irvine Research Center*, which seeks

new treatments for spinal cord injuries. "Any benefit to the patient, even an incremental one, would be a resounding victory."

Earlier in the month, President Obama lifted federal funding restrictions on human embryonic stem cell research, clearing the way for additional money to flow to this fast-growing field, which one day could produce a treatment or cure for people with cancer, diabetes, Alzheimer's or Parkinson's disease, or other life-threatening disorders.



In laboratory tests, Keirstead and his colleague, Gabriel Nistor, developed a technique for prompting human embryonic stem cells to develop into oligodendrocyte cells. These are

the building blocks of myelin, the biological insulation for nerve fibers that is critical for maintaining electrical conduction in the central nervous system. When myelin is stripped away, through injury or disease, paralysis can occur.

Injected into rats with spinal cord injuries, the precursor cells turned into oligodendrocytes and migrated to the injured area of the spinal cord. As the cells wrapped around damaged neurons, new myelin tissue formed, allowing electrical conduction to resume and the rats to walk again.

This success, published in the *Journal of Neuroscience* in 2005, was the subject of dozens of media stories, including a "60 Minutes" segment.

According to *Geron*, patients eligible for the phase-one trial must have a certain type of spinal cord damage and be willing to receive injections 7-14 days after injury. *Geron* has selected up to seven U.S. medical centers that may participate in the study.

UCI has a robust stem cell research program that has received more than \$52 million from the California Institute for Regenerative Medicine. UCI's scientists are pioneers in regeneration, large-scale production of specialized cells with very high purity, and methods for treating damaged tissues.

UCI recently broke ground for a four-story building dedicated to stem cell research. When finished in 2010, the building will house the stem cell center, dozens of laboratory-based and clinical researchers, a stem cell techniques course, a master's program in biotechnology with an emphasis on stem cell research, and programs and activities for patients and public education.

From:
spring '09 alumni magazine
your uci
www.alumni.uci.edu
page 12

Baldwin Keenan
co-editor

repair or replace damaged motor neurons. Gabriel Nistor commented that the research should be beneficial to any disease in which there is motor neuron deterioration: ALS, MS, PPS, etc It is possible that the auto-immune characteristic of these diseases will be an additional challenge not present in working on back injury stem cells. Human trials are still years away for motor neuron stem cells and will more than likely begin on terminally ill ALS patients. As human trials on stem cell therapy develop, some of the work on Hans Kierstead's team will focus on the patients. They will be a valuable database for researchers to examine the efficacy of stem cell therapy and much care and precision must be taken in gleaning the data. Some polio survivors reading this article will conclude, probably correctly, that this research and testing will not be completed in time to be of help to them. Maybe there can be some solace that UCI's efforts will likely benefit the next wave of polio survivors with PPS who were born in countries with late polio eradication dates.

News Flash

Laughter Yoga can reduce your risk of heart disease by 50 percent. Because it's such a good cardio workout it raises your heart rate almost immediately. So at one minute you can get your heart rate at a level it would take ten minutes to get on a bike. See **July Meeting**

EDITOR NOTE:

I have met with Gabriel Nistor, MD, who directs much of the stems cell research for Hans Kierstead, and with some of the members of his staff. They are very excited that working with embryonic stem cell they are able to produce a "pure" stem cell which has wide potential. Now that their work on cells "designed" to treat back injury has moved on to human trials, their next challenge is to develop cells which will be "designed" to

Polio Survivors Ask...

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, (n.carter@cox.net)

Q: *Every now and then I get a feeling of sadness over losses that I associate with my aging with polio. I was never taught to acknowledge my polio emotions, and that left me with a lump in my voiceless throat. Deep down, I think I should not express these feelings that make me feel so vulnerable. If I do, I am concerned I will be judged for expressing my feelings. How can I move through this?*

A: No doubt we all feel hesitant about revealing our innermost selves to others in the beginning. There's that fear. Fear that someone will make fun of us, fear that our feelings will be trivialized, fear that people will think we're complaining, think we're whiners, that we're not tough enough. Whatever. It's a vulnerable spot to be in—must I always take a deep breath when I open myself up honestly, fearful that others will leap in to crush me?

Fears. They can be mighty. Yet, what are the consequences of silence?

Oddly, the more I stifle myself with these fears, the more I believe they are true. Soon I have stuffed myself so full of pent-up emotion that I explode in bitterness or anger or sadness or some other expression of a person I do not want to be. I've decided this isn't the way I want to live.

Much of my fear had to do with being all wrapped up in how I was viewed by others. Then one day I heard a wonderful speaker who brought me down to earth with humor: "We wouldn't worry so much about what others think of us if we realized how seldom they do."

Suddenly I understood this wasn't about them at all—it was totally about me. Thank goodness for that—I can actually do something about me.

First up: take a look. Over time, I had lost track of my identity. I wasn't sure who I was anymore. I started searching. What I discovered was a person who had spent a lifetime rationalizing my physical losses, pretending they meant nothing. I stayed home rather than admit I needed a chair. I even delayed getting SSDI until my time nearly ran out because I couldn't face that my considerable losses were enough to qualify me.

My days had been spent "doing." As my ability to do diminished, I felt myself slowly disappearing, tiny pieces of physical ability falling irretrievably to the wayside until very little was left. It was time to base my perception of my Self on being. I grieved the loss. I loved that other person—the whirlwind of her life, the accomplishment, the fun. I had to learn to appreciate the merits of being. This has to be about who I am, not who I wish I were.

I wasn't sure how I was supposed to act about my disability. My parents never mentioned it and seemed to think it would be better if I didn't. However, I needed to acknowledge it. I learned that while it usually isn't helpful to sally forth with a long catalog of my aches and pains, I do need to talk about what it does to me inside to be the person I am. Post-polio support group discussions can be great for this, as are loved ones and trusted friends. The important thing for me is to express myself. I become stronger each time I speak up. More free.

Not every day is perfect. And of course nobody has everything. But I discovered that what I have is plenty. I take it one day at a time, and I'm still here, still intact, and still purring contentedly.

Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International (www.post-polio.org)

From Dr. Frans Nollet, Academic Medical Center, University of Amsterdam, Netherlands

Radio Netherlands Worldwide recorded two video messages of polio survivors living in the Netherlands – one Dutch and one African – to comment on what it is to live with polio residuals and what they think of the recent acute polio outbreaks.

SEE THE VIDEOS:

<http://www.radionetherlands.nl/currentaffairs/globaldevelopment/090507-polio-disability-health>

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

Missed Warm Springs Conference?

CD of Program Booklets Now Available

Daily program booklets (Thursday–60 pgs; Friday–98 pgs; Saturday–70 pgs) from PHI's 10th International Conference: Living with Polio in the 21st Century are now available. In PDF format on a single CD, the files contain abstracts and handouts.

<http://www.post-polio.org/Membership-BlankCDOrderForm.pdf>

How to contact OC Support Group:

Call us for information:

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

Newsletter co-editors:

Baldwin Keenan 949-857-8828
keenanwhelan@cox.net
Janet Renison 949-951-8613
renison@cox.net

Agenda ideas for PPSG of OC?

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

Our thanks to donors: Shelah Michael, Winifrd Hyson, Helen Li, Charles & Sylvia Agozino. 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.

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Rancho Los Amigos Meeting

Saturday July 25
2pm - 4pm

Tour

Rancho's Model Home

Our guide will be Kathleen Shanfield.

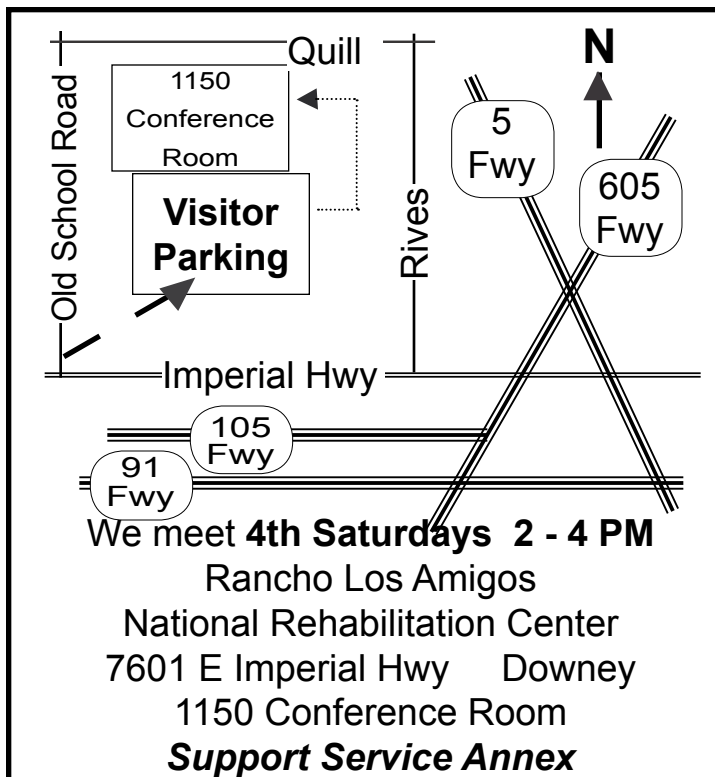
This has been one of our most popular and requested meeting events.

Future Rancho SG Meeting

Saturday August 22

2pm - 4pm

OPEN SHARING



Orange County Meeting

Saturday July 11

2pm - 4pm

Laughter Yoga

lead by **Sue Snyder**

Learn to stretch, breathe, and laugh your way to a healthier body, a clearer mind, an uplifted spirit. Laughter yoga. relieves stress, anxiety, depression, and strengthens your immune system, improves respiratory and circulatory systems, relieves pain, encourages relaxation (after the laughter) and balances blood pressure.

Future PPSG of OC Meetings

Saturday August 8th

2pm- 4pm

OPEN SHARING & INDOOR POTLUCK

Saturday September 12th 2pm- 4pm

REPORT FROM POST-POLIO INT'L CONFERENCE Warm Springs GA by Baldwin Keenan

Saturday October 10

2pm- 4pm

BRACING AND SURGERY FOR POLIO SURVIVORS by Dr. Stewart Shanfield

