Founded in 1989

The Post-Polio Support Group of Orange County

Newsletter

November 2009

15231 Marne Circle
Irvine CA 92604

Website: **ppsupportoc.org**

Polio Survivors Ask...

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

Q: I have a significant pain problem in my shoulder and I've heard about a special taping technique used by athletes. What's the deal? Could it help me?

A: Kinesio® Taping is a method of using therapeutic taping to alleviate pain arising from muscular-skeletal problems. This interview with polio survivor Marlene Orton sheds light on her experiences with this process:

Nancy: What led you to try Kinesio® Taping, Marlene?

Marlene: At the PHI Conference in Warm Springs, the pain in my shoulder suddenly became almost unbearable. By pure luck, Michelle Guevin, PT, MHSc, MTC, a Conference presenter, described Kinesio® Taping, and I asked if she would tape my shoulder.

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Inside this Issue

What I took from Warm Springs last April

by BALDWIN KEENAN

At our September meeting I gave a slide presentation of summaries of the talks I attended at the Post-Polio Health 10th International Conference held for the first time at Warm Springs Georgia, April 23-25, 2009. I am not going to attempt to give that presentation here. You can find the slides as a page on our website: **ppsupportoc.org.** Participation this conference marks a clear turning point in my life as a polio survivor with PPS and a new direction in how I think I can live within its limitations.

I was diagnosed with PPS nine years ago. Since then I have gone from being angry and in denial to taking some leadership in our group and co-editing our newsletter. On paper the onset of PPS for me was 2000 – 50 years after my polio. Dr. Perlman, who diagnosed me with PPS, has helped me to understand that I had been undergoing PPS for probably ten years prior. I had just plowed through pain and fatigue until a knee injury sent me into a rapid downward spiral. Our support group was wonderful to me. With time my strength and vitality improved. I used crutches and got a powerchair which I used extensively for several years – especially for long distance events and activities which required a lot of standing. I also worked consistently

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with water therapy. In 2007 I started feeling much stronger and felt that I could go back to doing things like home remolding and sailing. I discussed this with Dr. Shanfielld, my "polio" orthopedist and my PT Julie Simpson and OT Kathleen Shanfield at St. Jude Medical Center. My manual muscle test scores had significantly improved over the previous five years. My "team" gave me the go ahead with the caution that I should <u>not</u> <u>add</u> my normal exercises to new physical activity, and that I needed to be very careful about stopping before fatigue set in. Julie explained to me that total relaxation periods in the middle of a high activity period might extend the amount of activity I could safely accomplish. I have increased physically activity – some requiring considerable exertion. I do fine. And I rarely feel the need to use crutches or the powerchair.

A medical, maybe philosophical, dilemma had nagged me ever since I had started with our PPS group. With probably good reason, most in the group my age and older had been urged, if not pushed, to retire once diagnosed with PPS. That was seen as the only way we, with our Type A personalities, would slow down enough to get on an even keel and learn to live with our disability. Retiring also conformed with the mantra: "Conserve to Preserve'' which was often proclaimed by group members, emphasizing that we only had a finite number of steps left. We could take them now or spread them out over many years by conserving. Yet, I couldn't help but see contradictions. Young polio survivors from Asia, with increasing weakness, were not being told by doctors to retire but rather to seek ADA workplace accommodations. More confusing was that I met four physicians with PPS who had not retired. That seemed like a double standard. *Let me inject right now that I am of the opinion that retiring at the onset of PPS is probably a good move, in general. At the same time, I sympathize with older survivors who feel it best to "hide" PPS from their employers for the sake of getting better "full retirement pay", rather than risk being forced into lower paying disability retirement.* What bugged me was that I did not see doctors telling younger survivors with PPS <u>and themselves</u> to retire. Why didn't younger survivors and physicians need to Conserve to Preserve?

I went to Warm Springs last April much recovered from my early PPS years — ready to listen to doctors and researchers who were dedicated to helping us live with polio in the 21st Century. I could go on at some length about how special it was to be in Warm Springs. I urge any of you that can to go there and take the tours of the facility, the Little White House, and the museums.

Observing participants, it was obvious that much of the work of Post-Polio Health and all of us who want to help will be to assist post-polio support groups in Latin America, Asia, India, and Africa. Polio is still endemic in some regions and the campaign goes on to get the best vaccine disseminated. 10% of the US goes un-vaccinated, a risk Americans should not take. Our support groups are essential -- often the main source of information for PPS patients. We need to encourage our folks to use the internet both for entertainment and for information. Despite that many of have assertive personalities, we also can have a tendency to "learn helplessness" and to "take obstacles personally". Instead we should uphold the rich legacy of polio survivors who refused to accept "how things are" and have made life for all disabled much more worth living by continuing their struggle. Yoga for post-polio patients is getting a lot of play. A DVD was distributed at the conference by the John P Murtha Neuroscience and Pain Institute. We need to get the OK from our polio doctor and our polio physical therapist and the Yoga instructor needs to understand polio. Sessions can be done seated and can be cardio exercise and improve mood and lung capacity and much more.

Pain and, even more often, fatigue are the symptoms we complain of most often and much research was presented. Besides traditional scans and testing other factors were observed:

- Disordered sleep. PPS patients with daytime fatigue need sleep study. Might be caused by obstructed breathing or another treatable problem
- Cardio respiratory problems are due to lack of exercise not polio impairment. Need to identify PPS patients at risk early. Prevention is same as for reducing stress
- Polio patients do not reduce walking until pain is severe which supports concept that overuse is the cause of PPS complaints
- Osteoporosis is common with PPS and all of us should be evaluated at hips and lumbar spine
- Essential to correctly diagnose source of pain by consulting orthopedist, physiatrist, neurologist or all three
- Not using prescribed devices such as braces or body corsets can cause pain
- It can be deadly to consider all our symptoms to be part of PPS
- Polio patients with PPS have more difficulty than stable survivors utilizing "good" muscles
- Fatigue usually related to physical factors such as poor quality and decreasing capacity of recovered muscles (Overwork) Endurance is a big problem even if some strength remains
- Fatigue can also be caused by under using viable muscles, damaging them, which leads to fatigue, which leads to inactivity and de-conditioning and more fatigue
- Energy conservation can be combined with non fatiguing exercise
- Physical therapy helps physically and mentally
- Adaptations: work/home, transportation, assistive devices. Carbon composite braces improve walking
- Best practice is multidisciplinary: Psychologist, physical therapist, occupational therapist, orthotist, etc ...
- Study in Sweden found that PPS quality of life improved with age

Other research:

- Five proteins have been found to be predictors of PPS
- No biomarker has been identified yet to predict PPS in polio survivors
- Yet there are viral particles in our spinal fluid at the same level as patients with Multiple Sclerosis a neuro-inflamatory disorder
- Ivig reduces pain. Not FDA approved
- Dr. Selma Calmes noted that she will be making changes to her recommendations in regards anesthesia with PPS

Living with PPS in the 21st Century

- Pacing which might include reducing work hours, retiring, using a scooter or powerchair. Usually comes with a boost in energy. Finances, self image and personality can may pacing difficult
- Social and psychological factors determine how well we cope
- It is **NOT INEVITABLE** that we will undergo rapid progression of pain, fatigue and loss of function

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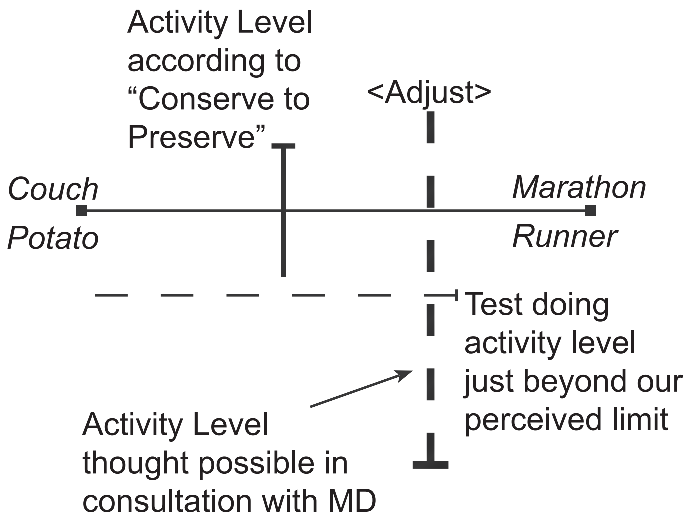
- Very long periods of stability are possible with PPS
- Early intervention is crucial
- UNDER USE can be as much of a problem as overuse
  - Cause new weakness and pain
  - Circulatory and heart problems
  - Mood problems
  - Function problems

One of my favorite speakers was Dr. DeMayo who put forward the following **diagram** about how we can determine our proper activity level with our doctors and physical therapists:



As a result of the information communicated at the conference I feel confident that I am on the right track by testing my physical limits, now that I have stabilized with PPS. I am not fearful about "using up my allotted steps". In fact, my carbon fiber brace has me walking with virtually no limp. My powerchair is wrapped in plastic and stored, but I am getting a lightweight scooter for travel and long distance events. I don't pretend that what is working for me will work for all. One thing the conference made clear is that each of us has to set the direction we want our lives to take within the limits PPS places upon us.

End

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Nancy: I've read that Kinesio® Tex Tape is 100% cotton, and stretches to 30-40% of its resting length, so the muscle has complete range of movement at the same time it's upheld by the tape. The tape supposedly lifts the skin, reducing edema and inflammation by allowing a freer flow of body fluids. What did you notice about it?

Marlene: I felt it gave me more support and left me more relaxed, feeling comfortable. When my shoulder was in so much pain, I had tried to control the pain by moving more. Directly after the taping, the shoulder had a certain stability that felt good—I knew this was how it belonged. I still had some shoulder pain, but this seemed to be easing up.

Nancy: I know how desperate I become when nothing I do seems to help a situation. How did the taping make you feel?

Marlene: I had been in such awful pain that I actually cried. I was ready to head for home. The first glimmer of hope came when Dr. Maynard and Joan Headley said, "We will find something that will help you." This allowed me to believe that perhaps there was a way to lessen the pain. I thought, "OK, we're going to get this worked out." Icing and other remedies all helped, and after the taping, the pain was so much better that I didn't want to take the tape off when the three-to-five day wearing period was up. I determined by then that I wanted to have more experience with the taping.

Nancy: I notice that there is no certification required for Kinesio® Taping, nor is there any regulation. How did you find a capable PT to do the job when you got home?

Marlene: It wasn't easy. I called all over town to find someone with experience to do this. I did a lot of networking, called PTs at numerous sites, investigated sports medicine options, contacted physical therapy colleges, searched online, all with no luck. Finally someone called me back who had found a PT in private practice. She taped my shoulder differently from the way it was done in Warm Springs, but it feels just as effective.

Nancy: What qualifications do you think one should look for?

Marlene: I'd ask how the person was trained in Kinesio® Taping—if he learned from a successful practitioner, or took a continuing education course in the technique, or what. Since so much of this taping is done in sports medicine, I'd want to know if my therapist had experience with people with post-polio or other neuromuscular conditions. Also how long she'd been doing this, and if her goals for me seemed realistic.

Nancy: Is it true that Medicare and other insurance don't pay for this procedure?

Marlene: Depends. There's a pretty good chance of getting it paid for if the therapist bills for her skilled services rather than billing for "taping," which Medicare won't pay for and neither will most insurance companies. However, considering the part this process played in relieving my pain—well, I'd think twice before saying I wouldn't shell out for it.

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)

End

Ventilator users need to be very careful during H1N1 outbreaks

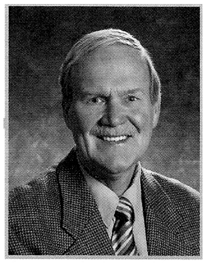
While the over 65 population is at greatest risk for seasonal flu, the high risk groups for H1N1 (swine flu) are under the age of 25. This said, if you have chronic health problems, especially respiratory disabilities, you should follow all directions given by public health officials to avoid contacting he H1N1 virus because **pre-existing conditions put you at the greatest risk of having complications from the flu.**

- Be prepared to stay at home long periods during an outbreak
- Stock up on non perishable food
- Have prescriptions filled in advance
- Question health care workers to see if they have had ***H1N1 vaccination***
- Have health, home care workers, and family members use latex gloves and proper masks
- You should consult physician to determine if your using a mask will be helpful or harmfully impair your breathing
- See your physician if you feel you have been exposed to H1N1.
- Consult your physician about advisability of ***H1N1 vaccination*** for you

From information compiled by Dr. Lex Fieden (retrospectively) with contributions by Kim Funn MD and Gerard Francisco MD (The University of Texas Health Science Center) Material is intended to be advisory and used only for informational and educational purposes. Individuals in need of personal medical advice or treatment should consult a licensed physician or health care provider.

Up to date info:
www.cdc.gov/h1n1flu/#stay_healthy

Ask Dr. Maynard



Question: People in my post-polio support group say I need to see a "polio doctor." What is a polio doctor? Do you agree that polio survivors must see a physician with such a designation? Do I need my old medical records?

A. There is no official certification for a "polio doctor." I believe the most common use of this informal designation is for a physician with knowledge, experience and interest in evaluation and treatment of polio survivors.

Given the most common new disabling medical problems of polio survivors, physicians with expertise in neuromuscular disease management that includes the ability to recognize and treat chronic musculoskeletal pain and respiratory problems are ideal. The specialty background of these physicians is most commonly neurology, physical medicine & rehabilitation (physiatrist); orthopedics; pulmonary and family practice.

I am not of the opinion that every polio survivor must see a polio doctor. If a survivor is experiencing a series of new unexplainable and disabling symptoms and is unable to obtain satisfactory help, then I would encourage him/her to seek evaluation by a polio doctor/post-polio clinic. These physicians most commonly will provide consultation services to your primary care physician and may also provide continuing comprehensive follow-up of post-polio related problems.

The late Gini Laurie, PHI's founder, liked to add the honorary degree "RD" (Real Doctor) to recognize physicians who have genuine empathy for and effective communication skills with polio survivors. The best way to find a knowledgeable polio doctor is networking with other polio survivors and through the Post Polio Directory 2009 in the "Networking" section of www.post-pollio.org

Many survivors need a network of medical providers (orthopedist, pulmonologist, orthotist, physiatrist, neurologist, etc.) and may need help with coordination and communication among them. A primary care physician can fill this role, although many polio survivors do this function themselves, because they are sufficiently sophisticated with medical and rehabilitative issues.

There is no "one size fits all" answer to your question. The question is better asked, "Are polio survivors' medical and rehabilitative needs being met by their current providers?" If not, then specialist consultations are appropriate. If survivors need a comprehensive evaluation of medical concerns and functional changes, then I think seeing a "polio doctor" is invaluable.

A. Regarding the question about tracking down your medical records, they might be of interest, but of little real value to your physicians in making treatment decisions. To find an explanation for your muscle pain, seek an evaluation by a physician who is familiar with post-polio syndrome, such as a local neurologist or physical medicine & rehabilitation specialist.

He/she should perform an EMG (electromyography) for two good reasons. First, it is the best test to establish that the muscles now having pain do show a pattern of electrical activity compatible with having remote (old) polio involvement; that is, they appear to have lost the typical number of motor nerve cells.

Second, the test will show if the nerve/ muscle cell status is stable or unstable. This fact can guide your physicians and therapists in treating your muscle pain with exercise, including how much exercise and how concerned you or they need to be about over-exercising/ overusing these painful muscles.

Check the following reference in the medical literature to become familiar with the use of EMG information for guiding management. Halstead, L., Carrington, G., & Pham, B. (1995). National Rehabilitation Hospital Limb Classification for Exercise, Research, and Clinical Trials in Post-Polio Patients. In M.C. Dalakas, H. Bartfeld & L.T. Kurland, (Eds.), The post-polio syndrome: Advances in the pathogenesis and treatment (pp. 343-353). New York, NY: New York Academy of Sciences.

POST-POLIO HEALTH
Summer 2009 Vol. 25, No.3

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Help our physicians and researchers!
REGISTER AS A POLIO SURVIVOR:
www.conemaugh.org/apps/post polio

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

Website: **ppsupportoc.org**

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 December 5th

Joint meeting of OC & Rancho PPSGs

Vance Eberly MD

an othopedist who is part of the Rancho Post-Polio Clinic team.

SEE MAP BELOW

Pre-submit your polio questions:
RanchoPPSG @hotmail.com or
Rancho PPSG
1270 La Reina Ave
Downey CA 90242

Future Rancho PPSG Meetings

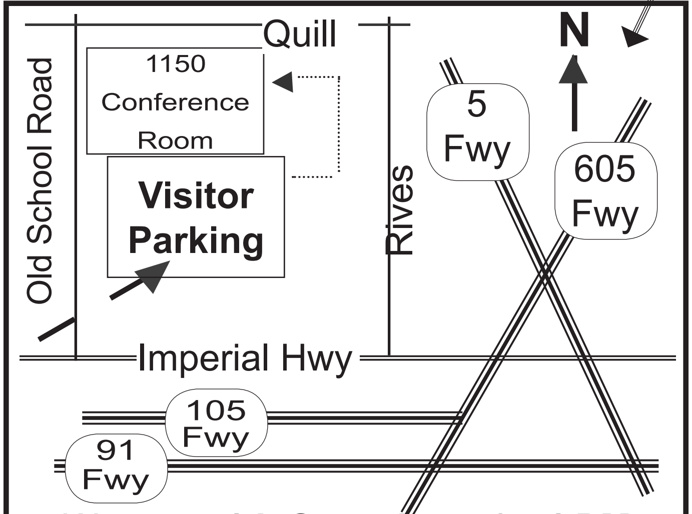
Saturday January 23

10th Post-Polio Health International Conference – Warm Springs GA

Summary and photos by Baldwin Keenan

Saturday February 27th

ANNUAL POTLUCK



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

Orange County Meeting

SATURDAY NOVEMBER 14TH

2 TO 4 PM

MEDICARE 2010

BY HEALTH INSURANCE COUNSELING AND ADVOCACY PROGRAM

THE MOST TIMELY INFO AVAILABLE

Future PPSG of OC Meetings

Saturday December 5th

Vance Eberly MD

Joint meeting of OC & Rancho PPSGs
—pre-submit polio questions—
SEE INFO AND MAP AT LEFT

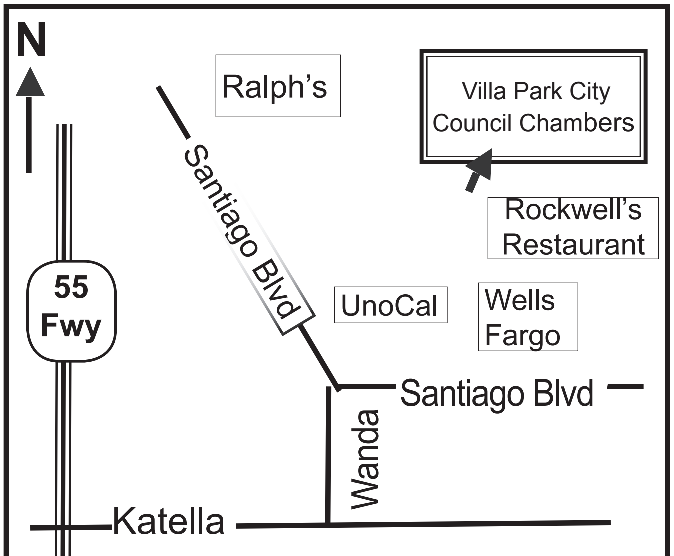
Saturday January 10th

Finger Food Potluck

Saturday February 14th

Yoga for Post-Polio Patients

(tentative)



We meet **2nd Saturdays** 2 - 4 PM
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park
May meeting usually 3rd SUNDAY
December at Rancho in Downey