



San Gabriel & Pomona Valley Polio Support Group Newsletter

www.post-poliopartners.org

Publisher/Editor: Mary Ellen Stan Volume No. 2 Issue No. 9 Date: September 4, 2009

Next Meeting – Saturday, September 19, 2009

Meetings are usually held once a month on the 3rd Saturday – 1:30 to 3:30 PM at Casa Colina Centers for Rehabilitation (Tamkin Education Center Room A) – 255 E Bonita Avenue, Pomona, CA 91769
Call (909) 465-0742 for Specific Monthly Meeting Details
Meeting Coordinators: Mary Ellen Stan & Dick Stoney

Agenda

- 01:30 ARRIVE
- 01:45 GREETINGS & ANNOUNCEMENTS
- 01:55 TREASURER'S REPORT
- 02:00 POLIO HEALTH INSTITUTE REPORT
- 02:15 PROGRAM/DISCUSSION TOPIC
- 03:25 CLOSING

From the Editor – Meeting Highlights

Since there was no meeting in August, your Editor is using this space to highlight the October 20 "Managing Symptoms of Post-Polio Syndrome" seminar to be presented at Casa Colina. You all received a flyer explaining the details.

What is significant about this seminar is that Casa Colina was founded many years ago to treat polio patients, but as the number of new polio cases diminished, Casa Colina allocated its resources to other maladies. Our polio support group has been meeting at Casa Colina for many years, and we have been active in trying to motivate Casa Colina to commit some resources to post-polio survivors. Now that they are, it is SO very important that we support their effort so they can support US!

Other folks from polio support groups around the region are also invited, so this will be an opportunity to meet many of our polio survivor colleagues.

Call in your RSVP – ASAP!

September Program:

Member Kathie Blackett, a Master Chef, will present a program on "Nutrition." We'll also be discussing how we can participate in this year's "We're Still Here!" campaign. See the PHI notice that follows.



**Make a difference in your community.
Participate in PHI's awareness campaign.**

***IMPROVING COMMUNITY
ACCESSIBILITY
is the 2009 focus of WE'RE STILL HERE!***

PHI members: TRY THIS!

Pick one accessibility problem in your community – maybe it is the steps at the closest dry cleaners or your physician's office; the lack of curb cuts near your favorite coffee shop; the impossible placement of disabled parking stalls at the far end of a parking lot – and tackle it.

Experience tells us that people in charge want to make changes that will benefit their customers, all the citizens in their community – not only polio survivors but others with disabilities, the elderly, mothers' with strollers. They may simply be unaware. We can help them understand.

Work with the establishment to solve the problem. Take pictures to explain, get positive publicity by calling your favorite local TV newscaster or newspaper features writer. Arrange coverage for October 11-17, 2009.

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, MHS, MTC, a Conference presenter, described Kinesio® Taping, and I asked if she would tape my shoulder.

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)

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Source: Post-Polio Health International (www.post-polio.org) PHI Communiqué No. 36



Announcements

Meeting Dates:

Mark your calendars:

- **September:** September 19, 2009 – Kathie (a Master Chef) will present a topic on “Nutrition”
- **October:** October 17, 2009 (Patti & Joyce)
- **November:** November 21, Holiday Luncheon
- **December:** No Meeting

Meeting Donations:

At each meeting a “hat” is passed to give members an opportunity to contribute whatever amount they wish to help cover the Newsletter costs and our PHI Association Membership. *But Note!* There is no obligation to contribute at any meeting.

Newsletter Submissions: The Deadline for submitting information for next month’s Newsletter is September 30, 2009. Contact Mary Ellen Stan (via phone or email).

Previous Newsletter Issues:

You can view all newsletter issues on our website www.post-poliopartners.org in the “Chapter Information” section.



September Birthdays

Shirley – 09/02 – No Photo

Conrad – 09/15



Education

This Month’s Web Link:

In this month’s “Polio Reporter” there is mention of research done to test the effects of Mestonin for muscle weakness in polio survivors. Here is a link to a Post-Polio Forum article by Dr. Richard L. Bruno in the “New Mobility” web magazine. He states an alternative view.

<http://www.newmobility.com/articleView.cfm?id=778&action=browse>

We have asked Dr. Richard Shubin to address this issue at the October 20 seminar and/or during his patient visits.

The “New Mobility” web magazine

New Mobility encourages the integration of active-lifestyle wheelchair users into mainstream society, while simultaneously reflecting the vibrant world of disability-related arts, media, advocacy and philosophy. Our stories foster a sense of community and empower readers to:

- participate in all areas of life, including education, work, love, sex, home ownership, parenting, sports, recreation, travel and entertainment
- be informed of and take charge of health concerns
- obtain appropriate technology
- assert legal rights.

A search on “polio” in their archives results in numerous articles. And there is a separate PPS Forum.

<http://www.newmobility.com/index.cfm>



Alive, Well in Spirit . . . by marie oden

The daily orientation of the flower to the sun is a direct result of differential growth of the stem. A plant-growth regulator accumulates on the shaded side of the plant when conditions of unequal light prevail. Because of this accumulation, the darker side grows faster than sunlit side. Thus the stem bends toward the sun.

I guess by now you've gathered that I am obsessed with, focused on, crazy about nature. It never-endingly draws me out of myself, my narrow perspective, my finite place in time and space; it opens my eyes and soul to wonders beyond fathoming. I try to get a daily grasp on nature's language, its message, beauty, lessons and wisdom, because it does speak. Its message goes out to all the earth; nature's words go out to the far bounds of the world. So, here I am dealing with a gnarly set of symptoms albeit situated in a glorious setting which daily directs my attention away from pain and restriction to towering trees, splendid sunsets, soaring birds; and today I'm thinking about sunflowers. The above quote by an expert is referring to sunflowers, which by the way, have been blooming in such profusion up and down this mountain that it is impossible to ignore their prolific presence and influence. Their cheery faces all leaning toward the sun seem to say: *We adore summer; we're manufacturing our seeds in amazing amounts, beyond counting!*

Nature is all around me; I'm always trying to discern its particular ways of expressing truth in my little niche of the forest. For me, attached to every wondrous thing I see are words: descriptive, explanatory, words that enlighten, words that soothe or inform; words coming to me, at me, like the splash of a Yosemite waterfall. Nature evokes, it fosters exclamation and expression!

Not a great fan of summer, I have trouble staying cool. Heat plays havoc with my sense of well being due to my having suffered heat stroke several times. Yet I *hear* these sunflowers shouting to the highest heavens loud praise, in unison they vociferously exude thanks for summer's sun coming close, dispensing heat and life-giving energy. Millions of sunflowers (in fact, one mere *sunflower* alone contains 1,000 to 2,000 individual flowers joined by a receptacle base) proclaim that summer is good, summer is rejuvenating. Summer enables their good seed bearing, benefiting an astounding amount of birds like chickadees, song sparrows and wrens; the vast quantity of oil their seeds produce, amaze! Sunflowers exclaim: *we tough it out for good reason!*

Particular words urge consideration during this hot summer weather as I watch and monitor mountain fires and flames all over California. The licking, terrorizing flames devour vegetation, yet the sunflowers sing their songs of summer and lean in toward the sun even as words nudge and cavort in my mind. So, I contemplate the big round yellow hardy flowers that decorate our mountainside; and finally, I jot down the little expression which has attached itself to my sunflower focus: *A pocket of grief; a passel of seed.* (*Passel* is a very large amount!)

Ah! Polio did plant within my soul a never-ending *pocket of grief*. At three years old, I saw and experienced an unforgettable war-like zone of tragedy; babies, children, young adults stricken; the darker side of life, the POLIO experience, created within me an irreparable *pocket of grief*. It burned its message into my consciousness: life is hard, trouble is everywhere, misery abounds, calamity lurks, distress looms unchecked, and death opens its mouth without measure. *A pocket of grief*.

Yet, POLIO, I cannot deny, inexplicably heightened my passion for what is fine, enlightening, beautiful and good. It made me long for happy things and reversal. It fostered hardiness. In that respect, *we* are like sunflowers: known for our determination, full of productivity and pluck. Planted on the slopes of difficult terrain, sunflowers track the sun, utilizing its energy to produce what birds and people need. Similarly, the darker side of life has made us Polio Survivors want to lean toward the sunlit side; and we, too, tend to produce nutritious seeds of *wisdom, curiosity, resourcefulness, perseverance, inventiveness, sensitivity* . . . We, like the sunflowers, *tough it out for good-noble-fine reasons! A pocket of grief; a passel of seeds!*