



San Gabriel & Pomona Valley Polio Support Group Newsletter

www.post-poliopartners.org

Publisher/Editor: Mary Ellen Stan Volume No. 2 Issue No. 7 Date: July 4, 2009

Next Meeting – Saturday, July 18, 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 – June Meeting Highlights

Josie and Elizabeth hosted a meeting packed with a variety of informative topics.

First, Elizabeth shared with the group samples of the rubber-like shelf paper that can be used as an excellent gripper. The rest of the group added their ideas for using this product, such as keeping trays from sliding. She then presented printed materials from various sources relating to concerns about anesthesia, statin drugs, various antibiotics, Fosamax, and NSAIDs. We need to be prepared to discuss with our doctors the possible side-effects these medications or treatments may have on our post-polio condition.

Next, Elizabeth, reported on the current prevalence of new cases of polio as researched by Dr. Bruce Aylward, the director of the Global Polio Eradication Initiative at the World Health Organization.

Then, Josie showed two videos. The first was a "Healthline" show about post-polio syndrome featuring several polio experts who discussed topics such as resources, identification, and treatment. Featured in the video were Joan L. Headley, Executive Director of PHI (a polio survivor), Dr. Julie K. Silver, and Dr. Lauro S. Halstead. Finally, we watched the Academy Award nominated HBO documentary, "The Final Inch,"

depicting the tireless work performed by Indian medical professionals and the Rotary to eradicate polio in India. Watching this was truly special as it showed us the enormous efforts being made to educate the population about the necessity for polio vaccinations. See the "Web Links" section below for more information about this month's topics.

Mary Ellen gave a report about the PHI conference call on this year's "We're Still Here" campaign. The call participants discussed several ideas; the final decision will be announced in August. It was agreed that the selected activity should be something that all groups can participate in although groups with bigger memberships are not precluded from pursuing more involved projects. Mary Ellen also displayed a United States map that shows each group member's name and the place & year they contracted polio. As expected, the Los Angeles area is "winning."

Don then shared a variety of written materials divided into 7 categories (he's so organized) that he collected at this year's Abilities Expo. Group members can use these to plan their programs for future meetings.

July Program:

Dick & Kathy Stoney will host the topic "American Disabilities Act & You."

The presentation will be made by Lisa Hayes, Disability Program Manager, of Molina Healthcare of California, and Brenda Primo, Director and Adjunct Associate Professor at Centers for Disabilities in the Health Professions (CDIHP) at Western University of Health Sciences in Pomona.

SPREAD THE WORD!!!! BRING GUESTS!!!!

Polio Survivors Ask...

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

Q: I have been evaluated for a basic power chair. Now my vendor tells me that Medicare will not pay for the chair unless it is intended only for home use. What does Medicare really say?

A: That's pretty much it. In 2003 President Bush "reformed and modernized" Medicare, and in 2005 its revisions for power wheelchair conditions for coverage kicked in. Yet some of us are still not totally aware of its ramifications.

Simply stated, any Medicare beneficiary (B) whose mobility limitations make it difficult to carry out mobility-related activities of daily living (MRADLs) such as toileting, bathing, dressing, grooming, and feeding at home is eligible for power wheelchair coverage. Well, sort of—there's more.

Other points to be considered before making this decision: Are the B's thinking and vision good enough to carry out MRADLs at home? Is a caretaker available to safely help the B needing such assistance, and is the B willing and able to comply? Does the B's home lend itself physically to the safe use of a power chair? Does the B require a power chair for any of these MRADLs or would some other type of equipment work better? Would a cane or walker do just as well? If the B doesn't have enough upper extremity function for safe manual wheelchair use, can a caretaker help with a manual chair? Is the B able to use a scooter safely—and would his home allow for that?

This doesn't mean you can't use your power chair outside the home—it merely means that getting Medicare to **pay** for that chair depends totally on your in-home MRADLs experiences. You may have a legitimate need for a power chair at work, but unless you also meet the "MRADLs at home" standard, Medicare won't pay.

Since Medicare's payment depends on a medical need, proving that need is crucial. Your doctor isn't asked only to conclude that you merit a power chair; he must provide the details that allow Medicare to draw the same conclusion:

- The B's physician, physician assistant, nurse practitioner, or clinical nurse specialist may prescribe the chair following a face-to-face examination.
- Supplier must receive the script within 45 days of the exam. It must be in writing, signed and dated by the practitioner, show B's name, exam date, diagnosis, conditions the chair should modify, description of chair, and length of time it will be needed.
- Supplier must also receive from practitioner supporting information that demonstrates relevance of the chair to solving the B's MRADLs problems. This may mean applicable "medical history, physical exams, diagnostic tests, summary of findings, diagnoses, and treatment plans." Records should also show what led to the need for the chair, what the chair will correct, that nothing else will rule out using the chair, that the chair will work in B's house, and that the B can operate a power chair.

Once all systems are "go," Medicare Part B pays 80%, and 20% of the bill is up to the B.

Finding a certified Assistive Technology Professional (ATP) might be a good move. ATPs are experts at analyzing exactly what the B needs and then helping her choose and learn to use the right equipment. Many equipment providers have ATPs on staff.

OK. So these guidelines don't seem to promote all the independence we hope for in our lives. Still, they are a start. Next step? Develop other funding sources. Medicare may not see the health benefits of having a chair mainly to pursue activities away from home, but these certainly exist. Let's just keep insisting until we get what we need.

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) PHI Communiqué No. 34



Announcements

Meeting Dates:

Mark your calendars:

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

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 August 7, 2009. Contact Mary Ellen Stan (via phone or email).

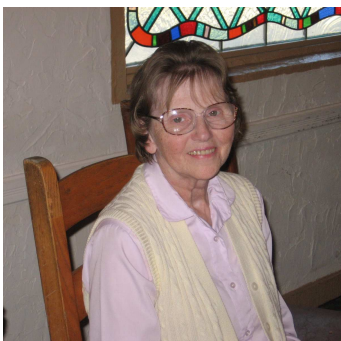
Previous Newsletter Issues:

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



July Birthdays

Marilyn – 7/23



Evelyn – 7/28



Joyce – 7/29



Education

This Month’s Web Link:

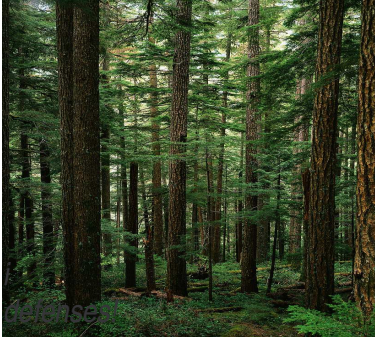
These web links provide you with more information about the topics and/or HBO video presented by Josie and Elizabeth at the June meeting.

At this site you can actually see weekly polio case counts as well as other polio-related reports.

<http://www.polioeradication.org/casecount.asp>

At this site you can read more about the Academy Award nominated short documentary “The Final Inch.” You can even watch this very moving program on your computer.

<http://www.hbo.com/docs/programs/thefinalinch/index.html>



Alive, Well in Spirit . . . by marie oden

Trees normally, not by exception, depend on multiple other organisms of their own and diverse species for sustained health, mutually benefiting from their interdependence. Forest trees, through root fusion, share nutrients and defenses! Rolf Schilling, Horticulturist

Throughout childhood and adulthood, I cannot remember a time or stage of life entirely free of a nagging distaste of dependency, that bitter experience of being subject to another's jurisdiction, often a stranger, someone I feared within the medical community, or at times, people my parents trusted who I did not. It made me bristle, dependency. To this day, an uncomfortable subordinate position devoid of personal choice unnerves and rankles. Growing up, however, there were two wonderful ever trustworthy exceptions which seemed unexplainably magical, transformational and renewing. I was not psychologically sophisticated enough to discern why dread would vanish like dandelion snow in a sea breeze, but, at Grandma McBride's, in the warmth of her love, and also with my childhood friend, Laurie Rubottom, my bruised and broken spirit would take wing and soar on liberating currents and surprising headwinds!

"I want to do it myself", if not adamantly voiced due to timidity, was nevertheless fervently felt, severely. It bubbled out of my pores like sweat on a body builder's brow. It fermented and fomented. "I want to do it myself," a distillation of my incessant frustration of feeling unduly dependent. Unaware of how universal the feeling, not realizing that the drive to *do it myself* actually stemmed from wanting a sense of mutuality, a desire for personal opinion, respect, rumination, reflection and choice. At the forefront of my sensibilities, a desire to be consulted, inquired of, given a chance to grasp and impart perspective regarding what pertained to me ever loomed like a threatening storm cloud. Let it loose and it caused no end of conflict. Yet, when suppressed it would materialize in the form of lengthy bouts of silence and pouting, tears shed and sadness within, loss of appetite and inertia. The number of times I shrunk into a cocoon of guilt and remorse due to bewilderment regarding this confounding pattern of mine cannot be counted. Early on I sadly realized that adults want to specify how and when a service will be rendered and even if it very much concerns you, they will begrudge what they perceive as criticism of their *help* and strongly discourage your opinion even though it dramatically pertains to you. Or so it was in the 1940's and 50's!

What is clear to me now like sunshine in the summer is just how dependent we all are on one another, on the elements, on knowledge and resources outside ourselves. Dependency is not just a phenomena experienced by the disabled or by those with severe limitations. No. Everyone must deal with dependency issues. Every second of our lives we must depend on what is outside of ourselves! We must learn like the forest trees to soak up the sun, breathe fresh air, partake of nourishment, drink untainted water, embrace wisdom and help, benefit, advance, grow, rely on appropriate protection and find equilibrium.

I now know: the magical thing that would lift me out of the Slough of Despond, out of a state of low-spirited dismay, at Grandma's and Laurie's house, was the wonderful experience of active *interdependency* and mutuality. The magical formula at Grandma's was that she needed me as much as I needed her, or so she helped me believe! And my friendship with Laurie, always doused with the fairy dust of mutual give and take, was a consistent exchange of exuberant expression, of lively imagination with gobs of opinions shared and contemplated. We were equally crucial in one another's lives.

Loss, illness, adversity, paralysis, anything that instigates a perverse, lopsided *dependency* will gnarl the human spirit or spur a new passion for choice, character, selfhood and efficacy. Assuming a healthy understanding of just how dependent we all are, coupled with an appropriate, valid sense of one's gifts and spunk foster a wholesome interdependence that benefits and builds spirit. I need you and you need me, ah sweet music to the soul; fresh air to the dispirited; how it is meant to be! The forest trees know, they understand. They are interdependent, each reaching for the sun, with roots entwined, lively, in community.