



San Gabriel & Pomona Valley Polio Support Group Newsletter

MISSION STATEMENT: We with PPS will provide and maintain current Southern California resource information to help others improve their lifestyle and sustain supportive relationships.

Publisher/Editor: Mary Ellen Stan Volume No. 2 Issue No. 10 Date: October 2, 2009

Next Meeting – Saturday, October 17, 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
www.post-poliopartners.org

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

During the last meeting the group discussed a variety of “We’re Still Here” activities that we might adopt for this year’s campaign. It was decided that we each send a letter to our city to find out what is its policy for enforcing Handicap Parking violations. A template letter was sent to you (via email or mail) for you to edit and send. The group will discuss your cities’ responses at the October Meeting and/or the November luncheon.



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

“We’re Still Here” Stickers have been ordered for group members to display proudly.

And thank you, Kathie, for leading an informative discussion about nutritional issues that apply to polio survivors.

October Program:

Members Pattie Jebbia and Joyce Rowland will present this month’s program.

Also during this meeting, group members will be given the opportunity to discuss possible Programs for next year.

Casa Colina Community Seminar:

Who: Dr. Richard Shubin and PT Kathy San Martino

What: “Managing Symptoms of Post-Polio Syndrome”

Where: Casa Colina Centers for Rehabilitation, Tamkin Education Center (Bldg 1D, Rooms A,B,C). 255 E Bonita Ave, Pomona

When: October 20, 2009 6:00 – 8:00 PM

RSVP: Call (866) 724-4132

Be there to support not only Dr. Shubin and Kathy San Martino but our other polio survivor colleagues!!!

183731
CITY OF VISTA
PARKING VIOLATION NOTICE

DATE: 9-29-09 TIME: 11:15 DAY: Tues
VIN: A 7A9A75 STATE: CAL
EXP: 1-30-11 MAKE: Toyota
MODEL: RAV4 COLOR: Red
LOCATION: Vista, CA

OFFICER: Cecelia Bunch # 123

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TOTAL FEE IF PAID WITHIN 30 DAYS: \$ 42.00
SEE REVERSE FOR IMPORTANT INFORMATION.

Note: Mary Ellen does not recommend that you use this method of verifying a city’s code enforcement No one needs to contact the City of Vista because she found out the hard way what that city’s policy is when she forgot to display her Handicap Placard at the Vista Library! A \$424.00 Parking Fine!!! When she paid her \$25 “Undo Fee” she thanked the city worker for diligently enforcing the parking code and then apologized for being an idiot! It was bound to happen sooner or later ☺

Polio Survivors Ask...

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

Q: I am disillusioned by the US healthcare reform discussion, partly because I don't know who or what to believe. It occurred to me that it is the same problem I have sometimes when reading about post-polio issues. Do you have some advice on how to be sure I am getting the correct information?

A: This is a question many of us have pondered through the years. We have an essential responsibility to seek the truth and not allow ourselves to be hoodwinked. It's easy to become confused if we don't take charge, ourselves.

LOOK IT UP—DON'T MAKE IT UP

Remember when the move was on to get people to use the word "disabled" rather than "handicapped"? A few proponents invented a sensationalized version of the origin of the soon-to-be-discarded "handicapped," insisting it suggested pitiful beggars standing on street corners, *cap in hand*, pleading for alms. (Thus hatching, as etymologies go, the nonsense word *capihand*.)

A quick glimpse in the *Oxford English Dictionary*, a prime source, always straightens things out. Checking here would have revealed that the word handicapped derives from *hand in cap*, a phrase referring to a complicated game of chance involving, among other things, reaching into a cap with the hand—thereby creating the word *handicap*. Its definition, befitting the game, points to a burden of some sort that makes it more difficult to have an equal opportunity. HUGE difference.

I want to be aware of that difference. I can't afford to let myself be bamboozled, misled, unfairly influenced. Do I allow others to play on my fears and emotions? Do I listen for solid truth? Have I trained myself to recognize outlandish statements, manipulations of my thinking?

THE REAL DEAL

Question number one: Does what I'm being told make good sense?

True experts exist. Good solutions are available. Survivors returning from PHI's 2009 Conference expressed high praise for the excellent practical information they gleaned from their sessions. New stuff. Unusual and innovative stuff. All delivered to them by experienced pros in their field.

Often I get a clue that I'm working with experts when I'm dealing with individuals who launch ideas or document facts. These kinds of people have no vested interest in steering me wrong or leading me to an outrageous conclusion. I'll place my trust here.

There's a great difference between information found on a website featuring well-researched medical articles—and one that merely relies on the chatter of casually-cognizant polio survivors. Which should I believe? Truth only exists in the truth.

I've gotten excellent help at medical libraries, where trained librarians can guide me right where I hope to go. Sources like CNN.com's regular "Empowered Patient" feature can be enlightening. Networking works—PTs, OTs, doctors, other professionals can give us exceptional leads. PHI's website offers an enormous number of resources in a wide variety of directions. Websites of institutions of known quality, like the Mayo Clinic's mayoclinic.com and the National Institutes of Health's nih.gov. can be most beneficial.

IN THE END

But no matter where I look, I know I'm the one who must make sense of it, the one to decide the worth of the information I'm considering, whether it refers to health care reform, polio issues, or frankly, anything else.

Emerson says that every mind is given the choice between truth and repose. Sounds about right to me. If I'm dedicated to the search—exercising my curiosity, making the effort, refusing to stop short, declining to accept someone else's easy (and often incorrect) answer—I'll know when I get to the truth.

I hear ya, Ralph! I'm crawlin' off my couch.

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. 37



Announcements

Meeting Dates:

Mark your calendars:

- **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 November 5, 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.

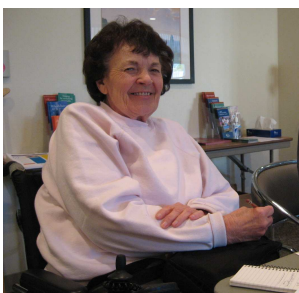
Breathing & Sleep – a free symposium:

Solutions for people with Neuromuscular disorders such as post-polio syndrome, ALS, MS, and muscular dystrophy. Sunday, November 1, 2009, Noon to 5:00 PM at the Salk Institute for Biological Studies Auditorium, 10010 North Torrey Pines Road, La Jolla, CA 92037. To register, contact Gladys Swensrud at 858-271-9288 or email her at swensrud@pacbell.net or register online at this address: www.salk.edu/breathingandsleep

October Birthdays



Jenny – 10/15



Hilda – 10/24



Education

This Month’s Web Link:

In September, Mary Ellen was contacted about including our support group information on the Salk Institute website. A review of the site shows an extensive collection of information and personal stories.

This is their description of their website:

“PolioToday.org is published by the Salk Institute for Biological Studies. This website is designed to raise awareness of post-polio syndrome and to be a resource for polio survivors. Dr. Jonas Salk, who developed the first safe and effective polio vaccine, founded the Salk Institute in 1960.”
www.Poliotoday.org



Alive, Well in Spirit . . . by marie oden

Conceptions without experience are void.

Experience without conceptions is blind.

Albert Einstein

I love the breezy days of autumn when the wind fills the mountain air with its music, sometimes sounding like waves breaking on the seashore, other times like a soprano practicing her high notes. I love that I can hear the sounds of nature and see the leaves fluttering on the oaks, and the branches of the cedars waving as though they are in a mood to socialize. What I also love is the ability to read, research and contemplate the way nature works, how it grows, blooms and bears fruit.

One of the advantages of having Infantile Paralysis rather than some of the other ravaging afflictions that plague the human body on earth happens to be the extent to which the mind and a capacity to form or understand ideas or abstractions or their symbols and acquisition of knowledge have not been tampered with. I find this amazing, especially when I read what Dr. Richard L. Bruno has written in his book, *THE POLIO PARADOX: David Bodian found the main event of poliovirus infection was an inflammation of the brain, a polioencephalitis, whether or not the virus got into the spinal cord. Bodian saw a consistent pattern of damage to neurons in the brain stem, especially in the reticular formation that sends signals upward through your brain to activate the cortex, which keeps you awake and focuses your attention.*

Isn't it incredible that we *polio* survivors can not only think clearly, but as a population we tend to be mentally astute? Just look around at your fellow *polio* survivors and you will see in them a decided predilection, a polarity toward mental acuity, fine tuned discernment, keen evaluation, sharp perception, quick intelligence all infused with the wisdom that long-term suffering imparts; and heightened by experience, rather than diminished by it. Our perceptions and conceptions are entwined with our experience in ways that add depth and dimension and impart crucial data to outlook and point of view.

The inclination of our mind, thoughts, and ideas tends to be innovative. We've had to figure out how to best maneuver within our limitations in a world that is slow to accommodate or relieve hardship. This tendency to be innovative has far-reaching consequences. It works its way into relationships. We end up advising and counseling the able-bodied whose conceptions are very often lacking the vital experiences requisite for a well-developed sense of savvy. And we have garnered strong, grounded, ample cadres, a battalion of defenses that not only surprise, but activated tend to win friends and fellowship; relatives delight in the shelter extended by our careful mindfulness. Expressed another way, we are good to have around. We think through and discern what is hurtful and what is wholesome, what is harmful and what is restorative. We become a sheltering stronghold for loved ones because our conceptions have been informed by grueling experiences. We long to spare and protect, defend and ward off abuse and treachery.

That there are times when our brains become fatigued, that we have to direct our focus aright during bouts with stress or undue usage of resources only increases our awareness over time; we garner appreciation of managing and mastering our brain capacity. That there are times when I simply cannot think and must rest causes me to so greatly value all of the wonderful and delightful times when I can think so clearly, perceive so accurately, research, read and study so diligently! This is a gift, to be sure!

The owl's large eyes face forward and allow them to navigate through their habitat in the dark. They have a mechanism that serves to turn night into day. Just so, we've been given an added boost: our conceptions have assuredly been quickened, fueled and fostered by life experience. Our life experience is a light of sorts in the dark informing and instructing us in a multiplicity of ways. We perceive and think with a built-in informant (experience) regarding the trauma and tragedies lurking in this unpredictable world; and we are privileged to extend wisdom and advice regarding coping skills while seeking further knowledge, truth and prudence. (Do I sound like I'm tooting-*hooting* my own horn? Hey I'm definitely tooting yours, my dear fellow survivors. Bravo to our PPS population! Your mindfulness and spunk invigorate and inspire.)