



San Gabriel & Pomona Valley Polio Support Group Newsletter

www.post-poliopartners.org

Publisher/Editor: Mary Ellen Stan Volume No. 2 Issue No. 6 Date: June 5, 2009

Next Meeting – Saturday, June 20, 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 – May Highlights

It was reported to your Editor, compliments of Dick Stoney, that the group had a very productive luncheon. Several ideas were formulated about how we can observe this year's national "We Still Here" campaign. All of the ideas were submitted to Joan Headley, the Executive Director of Post-Polio Health International during a conference call I participated on 5/22/09. I will give an update report about this during the June meeting.

2009 Meeting Sign Up Schedule

Note: We still need Co-Hosts for the dates marked with an asterisk *

July 18** Dick/Kathy Stoney & _____
September 19** Kathy Blackett & _____

June Program:

Josie Howard and Elizabeth Lamar will present an informational program.



Meeting Dates:

Mark your calendars:

- **July: 07-18-09**
- **August: 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 July 3, 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.

June Birthdays



Josie – 6/3

No Photo Available

Mary Ellen – 6/23

Need New Photo ☺

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) PHI Communiqué No. 33



Education

This Month's Web Link:

Healthline Networks offers its original health content, the HealthExpert Health Forums, as well as physician-reviewed content, health tools and videos from more than 20 leading medical reference publishers and media partners, visit <http://www.healthline.com>. Type in "polio" in the Search box to view doctor reviewed articles. You can also refer to this website for other medical information.



Alive, Well in Spirit. . .
by marie oden



I am in the process of developing my own philosophy/theology regarding disability. I want to own and also reflect my personal understanding of how polio particularly affected me and how best to grapple with its disruptive annoying troubling difficult presence and affects for sixty years and counting. Of course this can and will spill over into ways of perceiving all types of physical illness and loss of functioning. I yearn to generate words that inspire a lofty noble outlook and suggest ways to daily triumph within the grip of physical ordeal. This might take several years because it requires a lot of reading and research, and investigation into my own deep feelings, attitudes and conclusions. I am acquainted with up-to-date literature pertaining to polio, yet I want to embrace a more personal perspective and own it, not simply adopt someone else's view.

But, for now, suffice it to say, those of us who had polio suffered immensely, far beyond what anyone understood in the 1930's, 40's or 50's, because it wasn't simply a matter of affected limbs, paralysis or limitation. It was a nightmare experience, literally. Just as in a nightmare when one has zero control over frightening images, when one is hurled into swirling darkness, the brain generating wretched terror and horrifying scenario, just so, polio hurled each one of us into a place where brain functioning, specifically the brain stem and neurological capacity were subverted. In aggravatingly clandestine, hidden, undisclosed ways, polio catapulted us into perplexing unknown territory for various lengths of time. In my case, polio symptoms have always included sleep disorders, attention deficit and brain fatigue; this is not a phenomenon solely associated with PPS!

However, as polio played havoc with my brain and body in various ways at 3 years of age, polio also informed and enlivened me to a vast array of personality types. Polio quite literally enlisted me into the ranks of *People Watchers*! As I grappled with this mysterious thing that happened to me, as I found myself in a strange world of hospital procedures and regulations, bedfast; as I became the object of care and curiosity, my little brain switched itself on to watching a very damaged world full of interesting humanity care or contort, manage or mangle, help or terrorize. Early on I discovered that healthy people, who can effortlessly walk, run, climb stairs and mountains, swim 100 laps, hike with ease and think unhindered, often do not possess one of the most vital qualities: heartfelt compassion. Compassion is such an underrated commodity. The world is starved for compassion. And, it turns out, as I contemplate my experience, what I loved about every person I've ever met who had polio: they possess a depth of savvy, vast understanding, a fellow feeling, a soft heart, a willingness to commiserate, a compassionateness extended like a gift wrapped up with a satin bow! What a gift it is when one is in the throes of agony to be given a *word in season* fitting and appropriate, a word infused with consolation and genuine empathy. In my estimation the entire polio population (I've yet to meet the rare exception to this rule) due to having been foisted into such crazy mind-boggling misery and suffering, forever learned that life can be harsh; people NEED words and effectual help saturated with warmth, affection, gentleness, tenderness and affinity! Kind words bestowed with grace and good humor, like a beautiful present, cheer the soul!

So, thank you my dear fellow sufferers for your depth of compassion; the world needs it and YOU!!