



# 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 & Distributor: Dick Stoney Volume No. 3 Issue No. 6 Date: June 11, 2010

## Next Meeting – Saturday, June 19, 2010

Meetings are usually held once a month on the 3<sup>rd</sup> 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](http://www.post-poliopartners.org)**

### Meeting Agenda

Although there is no formal Agenda this month, Don will lead a topic of conversation – “What factors guide our decision to dine at particular restaurants? And, how is the definition of “accessibility” determined by each of us?”

See Luncheon Details in the “June Meeting Details” section below.

### From the Editor – May Highlights

The program was a presentation by Kathy & Dick Stoney regarding some of the implications of the recently passed healthcare legislation. We all agreed to try to stay informed about those issues that will affect us most and share what we learn with the group.



The group was visited by two Western University Doctor of Physical Therapy students, Vu Nguyen and Ricky Kwock. In answer to their question about what value do we find in a support group we heard “being able to talk with someone who already knows,” “sharing

like-type experiences,” “providing and learning information,” and “validation of our situation and friendship.” In answer to another question about what do we want from our doctor(s), we heard “listen to the patient,” and “spend more time on a visit.” The group expressed its sincere appreciation of their taking the time to learn about our issues. (Editor's Note: Vu and Ricky sent a lovely “thank you” note – their mommies raised them right ☺.



Vu & Ricky leading the group in discussion

### June Meeting Details:

The meeting will be a No Host Lunch at:

**Marie Callenders**  
**1175 E Alosta Avenue**  
**Azusa, CA 91702**  
**(626) 963-9475**

**Located on the northwest corner of Alosta and BARRANCA AVENUES approximately one half mile north of the 210 freeway.**

**LUNCH STARTS AT 1:30 PM**

## Editor's Note: Two Articles This Month – Now, We're Caught Up.

### Post-Polio Thoughts

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

#### Building Bridges

At first she irritated me. A relative newcomer to a literature study group I attend was heading my way, and I didn't want to deal with her. The previous week she had given me a condescending pat on the head as she threw a bit of baby-talk at me, a common reaction of some folks when they first encounter a person with a disability, and I didn't want any more of that.

But she was rushing toward me full-tilt, and I couldn't see a way to escape her this time, either, so I gritted my teeth and smiled.

"Oh, it's like a miracle!" she gushed. "I can't believe it! I didn't know you can walk."

Of course she didn't know I can walk; she didn't know me at all. Clearly she knew nothing about polio, either. From the very beginning, she had been making a lot of unwarranted assumptions about my capabilities.

That day she had seen me rise from my power chair during the meeting to hand out some pamphlets, not realizing I use the chair mainly for going distances and, since I cannot sit in regular chairs, for sitting. The last thing I need, I thought, is some irritating ratchet-mouth trying to engage me in a conversation about faith healers or wheelchairs.

I was building quite a case for being unpleasant to the woman when it struck me: Wait a minute! I didn't know her, either. I had no idea who she is, and already I'd decided she's some addleheaded airhead without a clue. To be honest, I had no hint what she wanted—or even if she wanted anything at all.

Immediately I thought of a little plaque my grandmother used to have hanging in her kitchen: Presume Goodwill. A fine place to start. Quickly it became essential for me to see how the woman and I are alike. My philosopher husband calls this "Immersing yourself in the 'what is'—joining the cosmos."

And so we chatted. She was a kind woman with lovely eyes. Her family came from Italy, and she had learned their secret to making the best biscotti in the world, she said—and offered to bring me some. The recent death of a loved one weighed heavily on her. She was reaching out the only way she knew how.

Over time, searching for the inner value of the woman led me to realize something else: When my focus was on finding her, I was no longer touchy about me or how she viewed my disability. I made an effort to see her positively and to see things from her vantage point. This was not simply a lesson on tolerance; we were becoming friends.

Amazingly, the more I found to appreciate in her, the more I saw to appreciate in me, too. In spite of my initial opposition, the more I knew of her, the more alike we seemed—and that's what I was looking for. My willingness to view her in a new light changed me for the better.

The experience made me realize, once again, how easy it is to be wrong about people. And how ill-served I am by not being open-minded enough to give the other guy a chance, not taking the time to build relationships. It doesn't matter whether it's a stranger on a park bench or Aunt Suzie. The smallest effort can make a huge difference.

It's a clear path to serenity and happiness. Puts a smile on my face, just remembering.

*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](http://www.post-polio.org)) Communique No. 45

#### Whose Life Is It, Anyway?

My friend Mary called with what she termed a dilemma: She has a friend whose mother won't take a bath. "It's been three months," she said. "The woman refuses to bathe. Her daughter promises her a night out at her favorite restaurant if she'll clean up, but she won't do it." "So?"

"What do you mean, 'so'? She *stinks*. She's a health hazard."

"A health hazard? To whom? Is putrid stench catching?"

"She's dirty. Maybe she could die from her own filth, I don't know."

"Good for her! I love it when people have creative ideas about their own death, don't you? How many folks do you know who have died from personal malodorousness? Here's an inventive mother with spunk!"

"Stop joking around. This is serious. She shouldn't be allowed to go without bathing. I'm telling you—she *reeks!*"

"What you mean is her gaminess repulses her daughter."

"Well, it certainly does."

"Is she incompetent? Under guardianship?"

"No."

"Does she live with others where there are covenants about bathing?"

"No. She lives alone."

"Does she have a job that has 'offensiveness' rules?"

"She's retired."

"Then leave the poor soul alone. If she wants to stink, let her stink."

"She's not going to have a friend left."

"If that's true, then she has a choice to make, doesn't she. Either she hops into the tub before getting together with pals—or she doesn't. But this is for sure: I ain't makin' that decision for her."

When did this country turn into such a nation of do-gooders? Outright busybodies? When did it become O.K. to make other people's personal business *our* business? What is wrong with us!

Of course we want to offer a hand to those who ask for assistance. We want to be there for the disabled woman who's seeking an affordable power chair so she can get to her doctor's office or to the mall. We want to be on call for the elderly man who's looking for someone to change the sheets on his bed and vacuum his carpet. We even want to give aid to a mother who requests help taking a bath.

I'm talking about people who are mentally alert and quite capable of making up their minds. They know what they need—and what they want. Some may simply require a little outside help. What they do NOT need are wildly opinionated, totally uninvited pushy "supporters" who believe they have the right to determine how others should live. If individuals happen to choose a path detrimental to themselves, fully cognizant of the consequences, why should it be up to any of us to force them onto a different route?

What's next? How big a leap is it for some self-appointed saint to decide the solution for a guy requesting help changing his sheets is to pack him up and trot him off to a nursing facility? Do we have a prayer of convincing such meddlers that health care changes now encourage our having the freedom to get the help we want and need, even in our own homes?

Let's be sure independent living involves independence.

Oh, by the way—Mary called back. Things changed with her stubborn friend's stubborn mom. Once everyone got off her back, she grabbed a bar of soap, filled the tub for a steamy, bubbly bath, and started soaking. Hmm...

*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](http://www.post-polio.org)) Communique No. 46



## Announcements

### Meeting Dates:

Mark your calendars:

- **June:** 06/19/10 – No Host Lunch
- **July:** 07/17/10
- **August:** NO MEETING

### 2010 Program Presenters Schedule

July – Don & Lydia McIntosh

September 18 - Kathy Blackett & Phyllis Phelps

October 17 - Patti Jebbia & Joyce Rowland

### 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 9, 2010. Contact Mary Ellen Stan (by phone or email).

### Previous Newsletter Issues:

You can view all newsletter issues on our web site [www.post-poliopartners.org](http://www.post-poliopartners.org) in the "Chapter Information" section.

### Equipment Needs:

If you have problems with your assistive equipment, need help in getting such equipment, or have donations of equipment, you can contact our group member Raul Esparza at (626) 355-1851.

### "You Have Our Support":

Earlier this month, Dick Stoney's sister, Diane, lost her valiant struggle with cancer. As always,

Dick and his family have our prayers and support.

**“SAVE THE DATE”:** November 21 2010, “Breathing & Sleep Symposium II” at the Salk Institute; additional details to follow.

## June Birthdays



Josephine – 6/3 (No Photo Available ☹ )



Mary Ellen – 6/23

BIRTHDAY NOTE FROM THE EDITOR:

In April, “we” missed Vern’s birthday (4/5).  
Better late than never ....



Vern & Marilyn – aren’t they a cute couple?



## Education

### This Month’s Web Link:

Although the March of Dime’s main focus is not polio, their web site offers many articles and brochures. Visit, [www.marchofdimes.com](http://www.marchofdimes.com) to see what **info they offer**. **Also, your editor** recently watched an interesting television show called “The Polio Crusade” on the PBS series “American Experience. Check out their web site and your TV listings to learn more about the

creation of **The March of Dimes in 1939 and about the battle against time to develop a vaccine. There is some great historical photos and films in this one hour show.**

<http://www.pbs.org/wgbh/americanexperience/films/polio/>

## **Mary Ellen’s Field Trip**

North County PPS Group Members, John & Glenda Hagee, attended the October Casa Colina seminar, at which I had the pleasure of chatting with them. They inquired if I would address their group sometime. You know I said “yes.” Their leader, Marilyn Loba, contacted me, so, on 6/8 I attended their meeting in Escondido. What an honor to share information with a sister group about our group and about Casa Colina. And, because there were two new attendees, the exchange of ideas was extensive and meaningful. Another attendee was Gladys Swensrud, co-facilitator of the San Diego Polio Survivors group. What an amazing lady she is! (Note: “google” her name, and you’ll see what I mean). She is a driving force behind the effort to create a California community and resource center on [www.PolioToday.org](http://www.PolioToday.org). I came away with some new contacts, meeting ideas, and most importantly, new friends. And, for better or worse, they all know now what you have to put up with. ☺



Gladys & Marilyn



John, Glenda, Marilyn, and Mary Ellen



## *Alive, Well in Spirit . . . by marie oden*

*So this is what I will do. I will gather together my past and look.*

*I will see a thing that has already happened.*

*The Joy Luck Club by Amy Tan*

I returned to the scene of numerous childhood experiences this week, a place that evokes pleasant memories. As I approached the beautiful renovated facility of Casa Colina, flashbacks, like airy good ghosts rose up and dispensed a minds-eye full of sights and old feelings: when I was four years old, after my initial bout with polio and a year-long stint at Childrens Hospital, going to Casa Colina from West Covina to Pomona was a full day's outing for my mother and me. It felt as though we were venturing hundreds of miles away from civilization. In the back seat of our 1950 Chevrolet Woody Wagon, we had hampers full of food, jugs of lemonade, changes of clothes and money for unforeseen difficulties. Southern California in the early 1950's was not what it is today! The scenic route included orange trees, brambles, walnut groves, vineyards, blowing tumbleweeds, vast tracks of farmland; bumpy narrow roads with dust flying; and strawberry stands, rows of tractors, braceros bent down tending to the crops, and flatbed trucks. Nothing resembling modern convenience stores, malls, gas stations or fast food places to be found along the way. Our jaunt seemed daring; my mother invincible; I summoned courage from my her independent nature.

Entering the main lobby, like finding civilization once more, boosted morale. Immediately although I could not have expressed the sensation, I felt this was a kind place, full of heart. Nurses and physical therapists welcomed our arrival, imparting a good-natured, leisurely and soothing approach to disease and disability. Here, walking with braces was not a tragedy, it was a badge of honor. Here, grown-ups dispensed respect and welcomed interaction. Here, they asked questions. How did I feel about various modes of treatment? How did I view my recovery? Things I secretly thought *I should* be consulted about! I can still see the indoor pool, vast, enormous; as big as a lake, it seemed; its size alone made me shiver; made me feel like a speck of sand floating to the ocean floor. Clamminess and musty odors combined with the scent of chlorine and disinfectants reminded me of dreaded things, things I didn't want to revisit, like examination rooms, blood transfusions; hospital wards, scrubbed shiny by men with furtive eyes; and steel tables where legs are marked with black ink and arrows, and measured for braces. The indoor pool made me shiver: Looking up, I see a dreadfully skinny man on a wooden plank being lowered down from the rafters. Nearly naked, his skinny arms and legs are paralyzed. I say a little prayer. I don't want to be lowered into the pool from the rafters like him. In a few years I will discover a Life Magazine filled with pictures of the Holocaust, and forever after, associate the man on the wooden plank, a victim of polio, with the ravaged prisoners at Auschwitz. The connection between the two forever imprinted on my soul. Identification with suffering rooted in my spirit. Yet, I think the kind nurse senses my fear, she steers me forward out of the pool area into a large physical therapy room while chatting about what we are going to do together on this hot California day. "We are going to learn to fall! It'll be fun, you'll see," she says. And, yes, I like falling lessons. For me, Casa Colina is not like the hospital. It is a place where I learn to walk better with braces; fall without harming myself; I am consulted about my case and joyfully commended for my accomplishments.

In my sixties now, I find Casa Colina updated and beautified on the outside, flowers grace the grounds, but within, has it changed? Ah, it imparts heart, empathy flows, a soothing ambiance fosters bravery and my present experience devoid of shame aligns itself with childhood memories.