



# San Gabriel & Pomona Valley Polio Support Group Newsletter

[www.post-poliopartners.org](http://www.post-poliopartners.org)

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## Next Meeting – Saturday, April 18, 2009

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**

### 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 – March Highlights

In March the group met at the Home Kitchen restaurant, and as you can see from the photos we had a very nice turnout. The young man pictured below is Brian Marsh, a physical therapy student from Azusa Pacific University. He was an avid listener, and the group thanked him profusely for his interest in our stories.



### 2009 Meeting Sign Up Schedule

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

June 20 **	Josie Howard & _____
July 18**	Dick/Kathy Stoney & _____
September 19**	Kathy Blackett & _____

### April Program:

Don/Lydia & Vern/Marilyn will present **“Our Respiratory System and Post Polio.”**

Why am I more sensitive to cold than my family members? Should I be more concerned about weight loss than others? I really don't have the energy that I used to have. What might my breathing have to do with all this? We'll take a quick tour of our respiratory system, do an onset survey, look at some danger signs, and provide some reference information and a game plan to proceed.

## Polio Survivors Ask...

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

**Q:** An important topic families tend to ignore is a discussion of those all worthwhile decisions we may have to make at the end of our lives. Knowing that we should discuss it and actually doing so are two different things. Do you have any ideas on this topic?

**A:** More often than not, we can't be certain when an "end-of-life" discussion is due. If we have serious thoughts about certain issues dealing with life and death—or even how we want to be treated as age or disability or illness comes upon us at any point in our lives—the time for that talk is today.

It doesn't matter how resistant our loved ones may be to listening to such talk or how frighteningly ghoulish it may seem to us, we must not put it off. Tough as it may be to reveal how we feel, doing so not only removes from others the burden of decision-making, it ensures that we're going to have a better chance of being treated the way we want in times of change.

We need to be in charge of our lives. We have rights. While we are still able, we need to be the decision makers. To do this, we have to become aware of our options and take the action that puts us where we want to be.

For some of us, the day may come when we can no longer voice our desires because we have become incompetent. This doesn't mean, however, that we cannot have a say in what becomes of us. We can speak through a Living Will as well as through a person we have appointed to spell-out our health care wishes, known as a Durable Power of Attorney for Health Care.

A Living Will is nothing like a will that distributes our assets. A Living Will expresses directives we have made—such as whether or not we want our lives prolonged artificially if attending physicians have determined our condition is incurable or irreversible or terminal. It may address whether we want nutrition and hydration to be withdrawn. It may

direct that we not be resuscitated; or that we be kept as pain-free and as comfortable as possible. We decide.

An attorney can draw up such a Living Will for us—or we can find one on the Internet to adapt to our needs. To be valid, this must be properly witnessed and notarized, everything according to the laws in our state.

For a Durable Power of Attorney for Health Care, we choose a trusted friend or relative we know we can count on to speak up for us to see that others follow our wishes when we are unable to do so ourselves. The appointment is made through the same route as the Living Will.

We then have the task of spreading the word. We must tell our doctors what we want and give them copies of the Living Will for our files. Tell our children, our cousins, our friends and neighbors, the butcher at our favorite grocery. Tape a copy of the instructions inside the closet door where it can be found easily. The more people who know about our intentions, the better chance we have of getting them carried out. Talking is the key here.

And while we're at it, we'll discover an even greater reward than dealing with end-of-life issues. The moments spent with loved ones, remembering our lives together, laughing, touching, letting each other know how much we care—these are the words that really count.

Better start talking.

*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)) PHI Communiqué No. 31

## Announcements



### Meeting Dates:

Mark your calendars:

- **May: 05-16-09 (No Host Lunch) This is a CHANGE.**
- **June: 06-20-09**

### 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 May 1, 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](http://www.post-poliopartners.org) in the “Chapter Information” section.

### New “Member”:

Mary Ellen reports that earlier this month she received a call from Beverly Favian who lives in Newport, Oregon. A friend of hers from CA had sent her a notice from the local newspaper about our support group. She explained that she is visiting southern CA during April and would like to attend our April meeting. Alas, she already has the 18<sup>th</sup> booked. But then she and ME had a wonderful chat about her life experiences and about our group. Although she cannot attend in person, she very much wants to participate from afar. So, each month she will receive the emailed version of our Newsletter so she can “play along.” And if ever she is back down this way, she will try to meet with us.

Interesting Beverly Facts: she got polio in October 1949 while in her second year of College at Pasadena City College. She was one of eighteen students from the school who got polio. So they really grilled them on habits, food, entertainment etc. She didn't know any of the other students. She spent one month at the county hospital in L.A. and then transferred to Rancho los Amigos for three months. Her left leg and left arm were the worst, but she also had trouble swallowing; her lungs are very weak now. She acknowledges it is “tough to get old,” but she keeps going. For the last 18 years or so she has participated in a polio study group at Rancho where her abilities are measured against a

“normal” group of folks. Her next door neighbor in Whittier works in the Rancho brace department, and she reports that he is after her periodically “when are we going to see you?” She’s a workin’ on it ☺.

Welcome, Beverly (and husband Frank) to our support group.

## April Birthdays



Pin Ming Liang – 04/28



## Education

### This Month’s Book Review:

Editor’s Note: this book relates to this month’s topic. “Through A Looking Glass” by Doris Nelson

### Product Description from Amazon.com:

In 1930, Wesleyan University cancelled its football season. Health officials closed schools in Topeka, Kansas, and banned public meetings in Los Angeles, California. Why? Because of the threat and fear of polio. Through A Looking Glass is a powerful and moving story of Doris Nelson and her spirit that would not, could not, be contained...even though her body was paralyzed from the neck down from polio and imprisoned in an Iron Lung for thirty seven years. Doris contracted polio in 1946 during a state-wide polio epidemic, in the prime of her life and at the height of her dreams. Doris' incredible journal of courage and inspiration will touch you deeply. This is her story, her struggle and her small victories living with a life-threatening disease. This is the original manuscript as Doris typed it herself one letter, one word, one sentence at a time using a typing rod held in her mouth.





*Alive, Well In Spirit . . .*  
by marie oden  
(P.P.S: Perseverance-Perspective-Spirit)

(My son Patrick and Amy Oden)  
3 January 2009  
And I was there! Yay!  
Hurrah for P.P.S!

Is it just me, or do we all vacillate? One minute I'm feeling grateful that I didn't grow up with a sense of entitlement, and the next I'm wondering what advantages would be forthcoming were I to demand the rights and privileges of the ill-fated? That is to say, I wasn't taught to adopt the outlook of a *victim*. I only rarely perceived myself as such. In our rural California community in 1947 and in my household in particular, it was just a fact of life, polio. I was expected to overcome and triumph within my set of difficulties as much if not more than my folks who not long after I had polio lost a huge thriving farm due to an unexpected hail storm, the crops ruined in a matter of hours. My daddy, a seasoned, successful, lucrative farmer for Hunt's Foods one day, and the next he was bankrupt due to wild, destructive weather. He took inventory of his losses, embraced a completely new lifestyle, pursued what he considered a *call* to things more vital and never bemoaned his lot; instead, he relished a new beginning, a new kind of investment.

Land, possessions, relationships, the physical body, can sustain enormous assault even as the spirit prods the mind and heart to proceed forward in pursuit of requisite wisdom and noble endeavors. Advancing, progressing in times of adversity requires enormous focus and energy. Only in retrospect do we marvel at the strength necessitated, the perseverance required, how vital a proper perspective, how needful a lively inner life! And, is it ever possible to measure the influence of faith in a loving God? Happily, there are stellar experiences in this life that quell self criticism and doubts because the outcome is joyous!

This last winter as we were preparing for a wonderful trip to Oregon, where my youngest son was to be married in a grand Corinthian pillared-ported church setting, to a beautiful woman we adore, the weather turned brutal. On the day we were to embark from Lake Arrowhead, we found ourselves snowbound; 2 ½ feet of snow had accumulated overnight on top of prior snowfall. Our deck disappeared; our Jeep, buried. A white-wonderland gorgeous beyond telling, but we needed to be off and away. Incapable of walking out the front door, or tackling thigh-high snow banks, the only recourse was bundling up like Eskimos, climbing into a toboggan with all of our stuff, and sliding down the snow banks to the excavated Jeep.

Ah, a winter full of dramatics, 2008! We encountered blizzards, damaged roads, freeways similar to ice skating rinks, cars sliding from one side of the highway to the other; accidents; people panicked, even sheep and cows looked stunned battered by gale force winds. Gigantic snow plows and emergency vehicles upended, skidding and crashing into snow berms. Then, add to weather-gone-berserk, me falling off a high counter stool, fracturing my poor right knee; this indeed seemed too horrendous. Yet, it is at times like this that intent becomes clarified: what matters and what doesn't! What mattered to me was getting to my son's wedding; giving up, not an option; tackling the obstacles, imperative. This is one memorable time I shall not forget feeling exceedingly glad that I had an upbringing which inspired me NOT to cave in easily, my family ever prodding spunk, faith, pluck, and insights such as: dependency escalated can be so humiliating or it can strengthen ties as mutuality within rueful circumstances cultivates true heroics. Pain instigates compassion. Limitation engenders inventiveness. Good isn't cancelled out by calamity. Help along the way, kind, intelligent doctors and hospital personnel; compassionate hotel staff and also strangers along the route who say funny wise thoughtful things all seem heaven sent, all fortifying spirit, enabling a forward mode; everything rather dream-like, yet possible. Oh! I will always be deeply grateful that we persevered! We were present, participating, me in my pretty Mother-of-the-Groom clothes; my husband and I holding hands with a sense of pure gratitude! The Wedding was joyous! On January 3<sup>rd</sup> as though honoring the occasion, nature became still, hushed. Sunbeams honeycombed huge white billowy clouds and gilded the Oregon countryside as heaven bestowed its blessing on our son and his new Bride!