



# 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

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## Next Meeting – Saturday, November 21, 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**

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

### Agenda

There is no formal meeting Agenda in November.  
We are celebrating the Season with a No Host Lunch



### November Program:

Lunch Location: Acapulco Restaurant  
998 E. Alostia Avenue  
Azusa, CA 91702  
(626) 969-8818

**Lunch Time: 1:00** 

This month we are gathering for our annual NO HOST lunch at the Acapulco Mexican Restaurant (see details under “November Program” section). **You must give your RSVP to Dick Stoney no later than Wednesday, November 11.** His number is 626-332-3772 or send an email to him at [dstoney@dslextreme.com](mailto:dstoney@dslextreme.com)

During the lunch, a Program Sign-Up Sheet will be passed around so that we can pick a month for next year to Host a meeting. The group will also discuss any responses they received from their cities in answer to their “We’re Still Here” letters.

### From the Editor – October Meeting & Casa Colina Post-Polio Seminar Highlights

Your Editor was unable to attend the October meeting, however, it was reported that Pattie and Joyce presented several “Helpful Hints” for all of us to use to provide assistance to us in our daily lives.

The Casa Colina sponsored “Managing Symptoms of Post-Polio Syndrome” seminar was well-attended (about 150 people; more than 10 from our group alone) by polio survivors and family members. One couple drove from Escondido. Other area polio support groups were represented as well.

Dr. Richard Shubin



Kathy San Martino



Casa Colina CEO, Dr. Felice L. Loverso, presented opening remarks. Most interesting was his description of Casa Colina’s origins. The center was started by Frances Eleanor Smith (“Mother Smith”) in a farmhouse in Chino 1936. One of our group members, Kathy Stoney, actually was at Casa Colina during this time!

in an able-bodied world most of my life. When I lived in California, I served on the Board of the Post Polio Network of San Diego County. I saw many polio victims with various degrees of difficulty. Some were even afflicted again with post polio syndrome that turned their lives upside down.

Please go to <http://www.sharonlibby.com/> to

learn more about me. As you read my story and take this journey with me, I pray if you are disabled, you will find help in dealing with your disability. On the other hand, if you are not disabled, you might better understand and appreciate what difficulties disabled persons face every day."



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

*CORNUCOPIA: a curved goat's horn overflowing with fruit and ears of grain that is used as a decorative motif emblematic of abundance. An inexhaustible store. . .*

I love well placed, lovely cornucopias. They speak to me of autumn's bounty; full and spilling over with luscious fruit, beautiful shaped pumpkins, ripe tomatoes, golden corn, delectable juicy apples: Red Delicious, Jonathans, Winesaps and Honeycrisps; and pomegranates with their jewel-like seeds; and nuts, almonds, cashews, pecans; caramels and candy corn; and all sorts of squash: Ambercups, Acorns and Sweet Dumplings; autumn leaves in every shade, magenta, saffron, copper and plum, adding eye appeal. Cornucopias impart delight, they invite perusal, so full of nature's colorful harvest, yet it takes talent and an eye for detail to compose a truly lovely cornucopia; it takes finesse. And of course every single item has its own story, how it came to be a thing of admiration.

Our human lives are in many ways a cornucopia with various things spilling out for all to see. We can be a thing of beauty and *good fruit*. Or unfortunately, we can be a rather grim sad wilted presentation for the various critics that show up on the stage of life ever like vultures looking for something ugly.

We've all got a personal *receptacle* loaded with the fruits of our labor, inner life and experience. The challenge always has to do consciousness of what to value here on earth, what to use, what to toss, what to nurture, what to discard. What goes, what stays. What to remove; what to give prominence. Hate isn't useful. Love enables richness of spirit. Kindness reaps lovely things. In the final analysis, our *presentation* will very much reflect the hard work we've done, the things we've treasured, the attention given to what is noble, fine, and excellent. Certain things placed way in back, hidden from view, not denied their place yet purposely not showcased, nevertheless add dimension. What will take the forefront and in effect reflect personal choice, priorities and worthiness in our estimation, will ultimately inspire appreciation, or not.

For years, the culture of disability has prodded personal awareness. We've felt the tug within and without to grapple and wrest from our personal experience of PPS, extract from our physical ordeal, a world of truth; we've been pressed and driven by circumstances to glean that particular and requisite balance between acknowledging the fearsomeness and tragedy of polio while willingly allowing *light to arise*, so to speak, by welcoming the process of growth and maturity. We've incorporated and assimilated the tough acceptance of limitation while becoming wiser, more courageous and insightful, utilizing the very experience that sought to do us in! Evaluating and then maximizing necessary acumen: how to use the resources within reach and how to reach for what is not easily apprehended, this becomes our never-ending challenge. It takes finesse to live this life! It takes a great deal of thought, integrity, faith and understanding to become a thing of beauty in the final presentation. But these are things we think about because we've not breezed through life. On the contrary, it has been hard and full of, *in your face, what's wrong with you, and what are you going to do about this?* Questions and dilemmas abounding!

It was my great pleasure recently to attend a meeting addressing the challenges and treatment of PPS, at Casa Colina in Pomona, California. What pure delight it was to be reunited with my PPS Support Group, to share an evening replete with compassionate and timely medical information and suggestions. But long after the dissemination of valuable advice and the latest knowledge regarding PPS and its symptoms, what remains like the after-taste of something excessively delectable: for instance a bowl of warm, smooth, creamy, velvety butternut squash soup with a touch of nutmeg on a frigid autumn night, as the full moon rises and shines through cathedral windows adding its luminous glow; just so, what remains in my emotional *taste buds* are the warm hugs, the humor, the delightful camaraderie, the wonderfully kind words of encouragement and deeply comforting acceptance of my fellow sufferers within the PPS community, my beloved PPS Support Group. It was as delightful and memorable, as festive and happy, as full and overflowing with story as a gorgeous cornucopia spilling forth its diverse and bountiful harvest sampling!

Next up was Dr. Richard Shubin who provided a general history of polio and the eventual development of post-polio syndrome and how it can impact polio survivors.

Dr. Shubin then introduced Physical Therapist Kathy San Martino who gave a more specific PowerPoint presentation about PPS symptoms and various treatments. Most importantly, she gave details about Casa Colina's new initiative to dedicate resources to a Post-Polio clinic.

Following her, was Lance Clawson of J&K Orthopedics who described his services for orthotics. He emphasized the importance of using and properly maintaining our braces.

Last up was Yours Truly. I gave a "commercial" about Polio Health International and our group and encouraged everyone to participate in a support group – not only for information, but most importantly for the **support** we can give to each other. On my soap box, I tried to rally all of us to be our own best supporters – come to the Casa Colina clinic to identify ways to improve and extend our quality of life and stop worrying about the logistics or cosmetics of wearing a brace or using a power chair or scooter. I described how I am a product of Dr. Shubin's, Kathy SanMartino's, and Lance Clawson's expertise having been their client for the last 4 years. I have more mobility, strength, and enthusiasm about life because of them! So, I thanked Casa Colina for providing a meeting place for our support group and the speakers on behalf of everyone there and urged them to "go forth and do good works" because ..... "*We're Still Here!*"

PS: due to the generosity of Polio Health International, we were able to provide "We're Still Here" stickers to most of the attendees.

## Polio Survivors Ask...

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

**Q:** A friend who had polio told me that since he uses a cane, people give him more room so he has less fear of being bumped by others. He wishes he used it a few years earlier. Me, too! How can we help people "get over" the fear of looking disabled?

**A:** Fear can be so self-destructive, can't it. Early support group organizers ran into the problem of people's not wanting to appear disabled again and again. We'd call polio survivors to interest them in attending meetings and would get this frequent response: "You know, I think I'd be so out of place there—I don't look disabled. People can't actually see that I had polio."

Then, being assured that there would be many others in that same situation, they'd show up at the meeting—with one leg two inches shorter than the other, or a withered hand, or obvious scoliosis. For whatever reason, they told themselves they didn't look disabled. Was this fear? What did "looking disabled" mean to them?

Recently a woman who, at the least, wore a short brace on one leg from the beginning said, "I didn't think I had a disability. Nobody told me I couldn't do things. The issue was whether or not I could perform, not whether or not I wore a brace."

So disability doesn't have to be a stigma. Not everyone is concerned about what others think of their using a cart or walking with a limp.

Perhaps the fear of looking disabled has less to do with how we believe others perceive us than with how we see ourselves. Will "they" think I'm odd? stupid? helpless? worthless? These are *our* fears. Do they truly reflect society's conception of who we are?

Since the advent of the ADA, many of us realize a newfound kinship with the rest of the world. Often we can get *there* now. And where physical obstructions still exist today, tomorrow they may not. Clearly others care more than before about making our surroundings serve us better. Some of them look with refreshing understanding upon disability. Can we say as much about the barriers in our own minds?

As for how we might help people "get over" the fear of looking disabled—maybe we should introduce them to this wonderfully auspicious line from polio survivor Dr. Arnold Beisser's *Flying Without Wings*: "Acceptance with dignity is surrender without a sense of capitulation."

That's what our friend above finally did, isn't it. He accepted his disability—found a way to allow himself to be OK with it. He discovered the good in using a cane, created a positive reason to go for it. That's acceptance with dignity. This is an inside job. Nobody else can do it for us.

It's a choice. Say I roll into the sexy nightie shop and the cashier pretends she doesn't see me—reaches right over my chair to wait on the guy in line behind me. What do I do? Take it personally? Get angry, bemoan my disabled state, feel ashamed, wish I'd never thought of coming into this store?

Or do I say to myself, "Poor baby—she doesn't have a clue," move in closer, read the name tag she's wearing, smile, and say in a cheery voice, "Hey, Gladys, let me help you reach these pajamas so you

can ring them up more easily.” I know which response is going to make me feel better. And feeling better is in my best interest.

Truth is, we all do what we want to do. Me? I think Beisser is right. I choose acceptance.

*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. 38



## Announcements

### Meeting Dates:

Mark your calendars:

- **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 December 4, 2009. Contact Mary Ellen Stan (via phone or email).

### Previous Newsletter Issues:

You can view all newsletter issues on our website [www.post-polio.org](http://www.post-polio.org) in the “Chapter Information” section.

### “You Have Our Support”:

Last month, one of our members – Cynthia Stauffer – lost her husband Brad suddenly due to a heart attack. Brad was a truly loving and supportive helpmate to Cynthia. Now it is our turn to be there for her – because we care!

Another member – Kathie Blackett – reported to us that she was diagnosed with breast cancer and had surgery to remove it. It was found early and she is optimistic about the outcome.

## November Birthdays



Kathie – 11/15



Fenia – 11/23



John – 11/04



## Education

### This Month’s Web Link:

The Link below takes you to the Center for Disease Control’s website which provides numerous additional links to information about the prevention and care of flu. We’ve heard this all before, but given the seriousness of this year’s flu season, it doesn’t hurt to think again about preparedness. <http://www.cdc.gov/flu/about/season/index.htm>

Also, I received this email from Sharon Libby, a polio survivor.

*“First, I would like to introduce myself. My name is Sharon Libby. I currently reside in Richland, Washington. I contracted polio at the age of six and have learned to live as a handicapped woman*