



# San Gabriel & Pomona Valley Polio Support Group Newsletter

www.post-poliopartners.org

Editor: Mary Ellen Stan      Volume No. 2 Issue No. 2      Date: February 7, 2009

## Next Meeting – Saturday, February 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**

### 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 – January Highlights

We welcomed back to the group a former member, Josie Howard. What a treat to have her experiences and valuable input!

The group welcomed two Azusa Pacific students, Karina Cole & Sarah Ann Medlen, who are interested in observing the group dynamics and in learning more about polio. For their benefit, everyone shared their name and the place and year they got polio. It was amazing to learn the various years and places.



After substantive group discussion it was decided that we try rotating the Program Host position. Each meeting, two members will volunteer to present a speaker, a discussion topic, a movie, etc. It was unanimously agreed that the primary group function is to provide

SUPPORT for each other. While it is valuable to provide informational content, it is even more important that we get to know each other and share our life experiences. An example of that is Kathy Blackett sharing information about her visits to Rancho Los Amigos. Other members who might be interested in going there are benefitting from her meeting reports.

Dick Stoney will continue to act as treasurer, serve as the Casa Colina liaison, and distribute the Newsletter. Mary Ellen Stan will continue to be the Newsletter publisher/editor and the Polio Health Institute liaison. They will share conducting the meeting.

Don McIntosh had requested we send away for PHI's brochure for polio survivors, their families, and their doctors. He is going to share the brochures with his UCLA doctors. We have additional copies for members who didn't receive one during this meeting.

### 2009 Meeting Sign Up Schedule

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

- April 18\*\*      Vern/Marilyn Grimshaw & \_\_\_\_\_
- May 16 \*\*      Josie Howard & \_\_\_\_\_
- July 18\*\*      Dick/Kathy Stoney & \_\_\_\_\_
- September 19\*\*      Kathy Blackett & \_\_\_\_\_
- October 17      Patti Jebbie & Joyce Rowland

Suggested Meeting Topics are listed on the last page.

### February Program:

At the time the Newsletter was being printed, there was no confirmation of a February meeting speaker. So, the meeting topic will be a surprise!

## Polio Survivors Ask...

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

**Q:** *We have known about the late effects of polio for almost 30 years. I've gotten a lot of advice during that time and wonder about other polio survivors. What's the best post-polio advice you ever received?*

**A:** I've always felt I got wonderful advice from Dr. Ann Bailey at Warm Springs. My body had hit a patch of frightening paralysis, and I called her to cry on her shoulder. After listening to my weeping and wailing for quite a while, she finally said, "Accept it, Nancy." These simple words gave me the serenity I needed to go on. No amount of teeth gnashing could help me in the way that accepting the reality of the situation did. This is lasting help—I use her words of wisdom often.

But this is a question with a million answers. I wondered what others would say. Curiosity caused me to contact a number of polio friends around the country to get their responses.

From Illinois, Jan says, "Rest. Schedule it into your day. It's as important as anything else you may do and will possibly give you the oomph! to do what you must."

"The best advice I've ever gotten is 'walk the knife edge: too much exercise can hurt you and too little exercise can debilitate you,'" says Larry in Minnesota. "Just in case you're interested, the second best advice was 'take charge of your own health care.' Certainly that does not mean ignore the advice of your health care professionals but it does mean make sure you understand their recommendations and that those recommendations fit with everything else you know. If they don't, it is your responsibility to question the provider until you do understand."

What popped into Becky's mind in Texas is "PACE YOURSELF. Conserve energy—stop along the way when we need a rest from walking; stop to admire a rose halfway up the staircase. This reminds me of a favorite quote from Georgia

O'Keeffe: 'Nobody sees a flower really; it is so small. We haven't time, and to see takes time—like to have a friend takes time.' I am encouraged to enjoy the precious things in life, and that doesn't require physical energy."

Richard, in California, tells us "You must acknowledge to yourself that you have a disabling condition. Don't be consumed by that reality, but be honest with yourself. Ignoring or denying this reality leads to anger and frustration. It can also lead to counterproductive behaviors. When you make peace with your body you can begin to make appropriate adjustments. And, don't be afraid of all the things available to assist you in life. These assistive devices can be your friends, not your enemies."

"In looking back, the best advice I received was that when judging my activities and exercise, I should be aware that there is weakness from disuse as well as from overuse," says Missouri's Joan.

"Pace myself," Peggy, another Missourian, replies. "I must be a hard learner, because on the good days, I find myself trying to do more to sort of catch up with things I was unable to do on the bad days. I call it 'Hallelujah I'm healed' syndrome, on the good days, and it drives my husband nuts! I try to be good, I really do. But there is a little voice inside that says 'Go for it Peggy. You'll be able to do all of it, and then rest.' I can tell you with certainty that life at our house is not boring."

Aren't these terrific! Now I'm thinking many of you have gotten excellent post-polio advice, as well. Why not share these gems with us—send them to [info@post-polio.org](mailto:info@post-polio.org) and we will post them on [www.post-polio.org](http://www.post-polio.org).

*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. 29

## Announcements



### Meeting Dates:

Mark your calendars:

- **February: 02-21-09**
- **March: 03-21-09 (No Host Lunch)**

### 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 March 7, 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.

### Post-Polio Health 10<sup>th</sup> International Conference:

The Roosevelt Warm Springs Institute for Rehabilitation in Warm Springs, Georgia is hosting a 3 day conference April 23-24, 2009. The conference will conduct a variety of educational sessions and campus tours that include the Little White House Historic Site and the Historic Pools Museum. If you are interested in attending, details about registration, lodging and transportation are available at [www.post-polio.org](http://www.post-polio.org) or by calling 314-534-0475.

### Member News:

Everyone hold positive thoughts for our writer, Marie Oden, who fell off a tall stool and is recuperating from a fractured right knee. In the true polio survivor spirit, she is persevering.



## February Birthdays

Per the Roster – No Birthdays This Month



## Education

### This Month’s Web Link:

In last month’s meeting the group requested that information about Rancho Los Amigos National Rehabilitation Center be published in this month’s Newsletter. To learn all about the center you can access this web address:

[www.rancho.org/ser\\_postpolio.htm](http://www.rancho.org/ser_postpolio.htm)

### This Month’s Book Review:

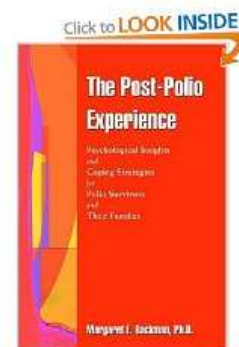
The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families by Ph.D., Margaret E. Backman

### **Product Description from Amazon.com**

Today many polio survivors are finding themselves with new symptoms reminiscent of the earlier days when they first had polio—new symptoms that trigger frightening memories, along with anxieties that had long been repressed. Dr. Backman, a Clinical Psychologist, examines polio survivors’ psychological reactions to their earlier experiences and to their current struggles with the late effects of polio. *The Post-Polio Experience* includes guidelines for polio survivors on:

- Coping with the emotional and interpersonal aspects of Post-Polio Syndrome
- Managing stress and depression
- Negotiating relationships with family and friends
- Developing a positive self-concept
- Improving doctor-patient communication

Family and friends learn how to deal with the changing roles that they and the survivor now face, and gain insight into their own needs, as they interact and sometimes conflict with the polio survivor’s needs.



## SUGGESTED MEETING TOPICS OR ACTIVITIES

(from [www.polionet.org/MeetingIdeas.htm](http://www.polionet.org/MeetingIdeas.htm))

- \* Watch a video or movie relating to polio
- \* A discussion about different ways we have found to cope with pain
- \* A dietitian presents suggestions on how we can better control our weight by eating properly; lower body weight greatly reduces the work load on weakened muscles. The presentation can also address how to eat to maximize muscle function, decrease brain fatigue, and enhance general energy.
- \* A pulmonary specialist presents information about possible respiratory problems of persons who have had polio. Discusses what types of tests we might need
- \* A representative from CORD (Coalition of Responsible Disabled) discusses the Americans with Disabilities Act (This could also be any expert qualified to discuss this topic).
- \* A qualified massage therapist discusses the benefits of massage therapy
- \* A medical supply company representative shares information about scooters, wheelchairs, and lifts, etc.
- \* An orthotics practitioner discusses various products that are available and how we can work with them to meet our needs.
- \* A physical therapist (qualified to discuss post-polio syndrome) discusses proper body positioning for efficient movement.
- \* The owner of a van adaptation company speaks about van lifts, stairway chairs, etc.
- \* A gardening expert discusses techniques on how to garden even with reduced muscle strength
- \* A "Sit and Be Fit" aerobics teacher can demonstrate a program of exercise that can be adapted to persons with various disabilities.
- \* Members can share information that they read in articles or books or that they saw on TV.
- \* Members can share information about experiences they've had with medical practitioners or facilities.
- \* Members can share their experiences or invite someone to talk about community services available to the physically challenged.

