



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 Vol. No. 5 Issue No. 01 Date: January 14, 2012

Next Meeting – Saturday, January 28, 2012

Meetings are usually held once a month on the 4th 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

Meeting Agenda

- 01:30** ARRIVE & SET UP
- 01:45** GREETINGS
- 01:55** TREASURER’S REPORT
- 02:00** PROGRAM/DISCUSSION TOPIC
- 02:45** “Found on the Internet”
- 03:00** ANNOUNCEMENTS & GROUP BUSINESS
- 03:15** SHARING & SUPPORTING

January Program:

Vern & Marilyn Grimshaw will present information regarding “Palliative Care” (i.e., care that addresses the desire for quality of life during a serious illness and end of life choices) obtained from a seminar that they attended in December.

December Mini-Minutes & Highlights:

THERE WAS NO DECEMBER MEETING.

2012 Meeting Schedule

January 28	At Casa Colina
February 25	At Casa Colina
March 24	No Host Lunch
April 28	At Casa Colina
May 26	At Casa Colina
June 23	No Host Lunch
July 28	At Casa Colina

August	No meeting
September 22	At Casa Colina
October 27	At Casa Colina
November 17	No Host Holiday Lunch
December	No Meeting

2012 Program Presenters

January	– Vern & Marilyn Grimshaw
February	– Don & Lydia McIntosh
March	– Lunch
April	– Mary Ellen Stan
May	– Pattie Jebbia & Joyce Rowland
June	– Lunch
July	-
August	– No Meeting
September	–
October	– Dick & Kathy Stoney
November	– Lunch
December	– No Meeting

Note: We still need Presenters for July and September. Your presentation can be about any topic of interest to the group. You can simply lead a group discussion about an article or book you’ve read, or news story you saw or heard about. It doesn’t have to be an elaborate presentation. Remember, we are about SUPPORT ! Any other content provided is “icing on the cake.”

Post-Polio Thoughts

On Getting Older

Audrey King, Toronto, Canada

king.aj@rogers.com

"Aging ain't for sissies" Wade Hampton, one of Toronto's "pioneering polios," used to say. I thought him funny as he sagged his skinny frame from too tall crutches and spoke down to me from a pedestal of years.

Many years later I understood. My own adjustment to aging was not easy. My head had always overruled my body, made the decisions, dragged my limbs around as it were, but now it wouldn't listen – no matter what I did. My body was in charge it seemed, constantly allowing serious illnesses and overwhelming fatigue to interfere with the goals and plans still in my head.

Over the years I had accomplished much, surviving many times beyond anyone's wildest predictions, achieving postgraduate studies and a professional career even though I had not been able to walk, feed or dress myself following an encounter with polio at age 9.

For decades I passionately believed I could accomplish just as much as any able-bodied person. I knew it might take longer, might mean doing things in a different way and would probably involve other people – but getting there in the end – was something I could do. I believed in myself and my abilities – in spite of a society that constantly reminded me otherwise.

"Denial ain't just a river in Egypt" somebody once said. If my tenacious belief was denial then denial worked marvelously for me – until I reached that period of life when an already compromised, overworked body had no reserves left.

The tenacity of my belief surprises me now. After all, if a lame horse plows a field for many years would we expect that horse to plow for as long and as efficiently as a horse who's never been lamed?

I have always believed "post-polio syndrome" is aging. It is nothing more than motor neurons aging and dying off unnaturally early due to their compensatory overwork. (Normally expected natural motor neuron reserve was long ago used just to re-innervate muscle fibers orphaned from initial polio damage). Compounding this is the long-term impact of muscles and joints being used abnormally to keep the body optimally functioning over the years.

We live in a society that honors the Olympic motto – "Citius, Altius, Fortius" (Fastest, Highest, Strongest). Our culture worships achievement and abhors disability, decline and death. This sets us on a path, a growth chart that is forever aiming upwards. We recognize and accept the cyclical nature of life in all living things, e.g. plants and trees and animals, but we cannot easily see ourselves as similar biological creatures living in the same world and subject to the same laws of nature.

Unlike aboriginal peoples who see all life as cyclical and circular in its pattern, we spend millions searching for ways to stay young, active and productive and to live forever – from the most basic marketplace to the highest levels of scientific research.

"What is aging actually?" one of my students asked this summer. "What causes it?" I googled far and wide to get answers, plowing through epidemics of anti-aging elixirs, creams, exercises, meditations, therapies, retreats, clothing and every other possible age denying resources you might imagine. The answers were hard to find and, ultimately, there is no cure.

Everything biological at the most basic and primitive cellular level has a built in pre-determined finite lifespan. We might be able to modify and extend the cellular life of body structures and organs by taking care of ourselves, but ultimately, there is no cure. Every living thing inevitably declines and eventually no longer exists.

This is tough to think about, especially for many polio survivors who have lived their everyday lives as Olympians – faster, higher, stronger. For many, the days of "trying to be normal again" following acute polio happened during an era when disablement carried a stigma much greater than exists in today's more accepting world. Losing what many of us fought so hard to conquer, losing stamina, function and independence at a stage of life often earlier than our able-bodied peers carries with it a sense of loss and grief that is perhaps more difficult to bear.

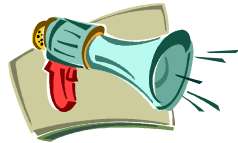
But, "Aging Ain't for Sissies." Giving up and giving in is not in our nature. As Margaret Somerville, a famous North American bioethicist once wrote, "Hope is oxygen for the soul." We cannot live without it. It is as essential as food. It may be impossible to regain our physical abilities, but we can reset the barometer by which we live, value and measure the satisfaction of our everyday lives.

There is much wisdom about coping with aging from both polio survivors and able-bodied peers. There are many fine examples of living life well amongst the older people we admire in our everyday communities. There is much to learn. Aging is aging, regardless of the cause or pattern it will take in each of us. Polio survivors reinvented themselves following polio and got on with life. We can do it again.

Audrey King, MA (Psychology) is a Toronto artist, author and advocate who worked with children and youth with disabilities for 30 years. She is currently involved in teaching, research and consultation, living and enjoying the Olympic motto at a level her body agrees with.

Source: Post-Polio Health International (www.post-polio.org) Communiqué No. 65

Announcements



Meeting Dates:

Mark your calendars:

- **January:** 01/28/2012
- **February:** 02/25/2012
- **March:** 03/24/2012

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 February 10, 2012. 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 in the “Chapter Information” section.

Post-Polio Information on the Internet:

To learn more about Post-Polio information on the Internet, visit our web page for a current list of web sites. Or, see group member **Vern Grimshaw** during one of our meetings for a

printed list.

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.



December Birthdays

Dick – 01/14
Cynthia – 01/17

CONGRATULATIONS!



Education

This Month’s Web Link:

This link for the Pass It On Center is featured in the current edition of Post-Polio Health International.

passitoncenter.org/locations/search.aspx

From their web site: *The Pass It On Center is creating national and state resources to foster the appropriate reuse of AT so that people with disabilities can get the affordable AT they need in order to live, learn, work and play more independently.*

(Note: “AT” means “assistive technology.”)

This Month’s Book/Newsletter Review:

Group Member Don McIntosh brings us information this month about “Wings” - A non-official quarterly newsletter for United Methodists with disabling conditions and all others interested in the issues of disability, accessibility, and the church. The newsletter contains a variety of pertinent articles.

If you are interested in seeing a copy of a sample newsletter or in receiving it, please see Don during one of our meetings.



ALIVE, Well in spirit...by marie oden

β Wouldn't I just love to start 2012 by giving each of you—my fellow sufferers and comrades, shipmates and cronies, precious lambs and good chaps, you heroines and heroes in difficulties; you, with pluck and courage; you, with hardihood and mettle; you, with fortitude and spunk, you with insight and humor, determination and wisdom; and dash and vigor and a song—a big, huge, warm, heartfelt hug and a Happy New Year!

It has been my personal experience that the disadvantages in life can, in mysterious ways, open the door for unexpected opportunities or spur new interests... When I take the time (however frustrating it may be) to consider all of the strain, pain, difficulty, the liabilities polio foisted upon my

little three year old body, with its damaging influence, its paralyzing and robbery—the horror and tragedy of it, grieve the soul. Of course, I well know if it were, say, like a sore throat, something one recovers from, then, I do believe I'm the type of person who would holler a hearty farewell to the symptoms and not spend a minute wallowing in past ordeal or bemoaning my fate. But, let's face it, polio just keeps on giving and giving; it never goes away. The aftereffects demand attention, and therefore, we give it thought and consideration, this experience: polio and post polio syndrome!

Have you ever been tempted to ask, "Who would I be, and what would I, or could I, have done had I not had Infantile Paralysis?" That question stirs within me a world of unknowns. I have no idea what I'd be like if I hadn't been rushed to Los Angeles County Hospital on Thanksgiving Day, 1947. And what if I had not lost my walking legs and could run, skip, jump, sprint? Who would I have been without all that suffering? All the hospitalizations, surgeries, physical therapy; braces, crutches, casts; limping, falling, feeling inferior!

Don't get me wrong, I believe it is emotionally and spiritually healthy to take honest inventory, face the facts about oneself, and go forward realistically with a true sense of what has been and what is possible, all the while adding a sprinkling (or dousing) of hope, faith and cheer! And this, I have done over the years; I've counted the costs, evaluated the disadvantages, while keeping my eye alert to what may *not* have transpired, had I never had polio. So, here's a major insight about me: when I was foisted into the polio experience, I was also hurled into a world where words became rich and crucial beyond all imagining. Polio, I believe, heightened my listening ear, somehow. As a three year old I mastered the language that I heard within my new setting. My three year old vocabulary suddenly increased by leaps and bounds; and way back then, a fascination for words took hold of my soul like a dog's jaw on a tasty bone! I began to speak in the technical language of doctors and nurses and adopted the brogue and perception of Scottish patient's families. After a year in the hospital, I went home touting a new fascination for words, words, words; and full of questions and curiosity and wanting to know, research, read and discover. In some strange way, being confined as I was, enlivened me to, perhaps (who knows?), what I would not have otherwise been astute to espy! (Smile) And, all these many years later, give me a day or a week or a month or a year or many years to pour over words, dictionaries, books of all sorts; or give me a life-time to write my heart out, and I'm a very *happy camper!* I do my hiking in spirit. I hike through the forests of meaning and up the mountainsides of literature. In spirit, I skip, jump, hop and sprint! Maybe I'd be crazy about words even if I had not had polio. Yet it is possible that the wonder of unlimited excursion into the world of books and the love of writing may not have gotten such a grip if it weren't for my feeling completely stifled in other areas of functioning. (I might add, also, this fun task of contributing to our P.P.S. Support Group Newsletter would probably not have happened!)

So, may all of the above add weightiness to my New Year wishes for you, 2012, which are: May all of the hardships, hindrances, difficulties and wounding of soul that polio has over time bestowed again and again fade in comparison; so mysteriously, wonderfully, fabulously, joyously, amazingly fade into the background, as your gifts (everyone has unique qualities) come to the forefront, and not only arrest your attention anew, and bring you delight, and dispense glorious personal satisfaction, but also, bless and enrich the people with whom you interact and love.

A Happy New Year, my dear Polio Support Group!