

FROM THE EDITOR

Hi Fellow PPS Managers.

In this, the last newsletter of the year 2006, there seems to be a lot to talk about.

Big news: **The San Diego PPSG in La Jolla** has had the same meeting time and location for nearly a decade, but that's about to change. Check your Meeting report for details.

Gladys has followed up on PPS group meetings with some really good research and information. You go, girl.

You may want to take a little (or big) vacation this spring and visit Florida. The PHI conference offers a chance to learn more about PPS and have a nice vacation at the same time.

You may have noticed that once in a while I do a book review. It might be about polio or PPS, or it could be written by a polio survivor. In this issue there's one of each.

Finally, in the Letters department, you may find that Carolyn tells some pretty familiar horror stories.

Have fun....Rick VDL

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Letters and much more...

Making the Rounds of PPS Meetings

By Gladys Swensrud

Most of us experiencing the ill effects of Post-Polio Syndrome stay fairly close to home; occasionally, however, visits to children and/or grandchildren lure us further from the comfort of our easy chairs and find us braving airport security checkpoints with the best of them. My latest trip to Sacramento was a classic example of how it is, indeed, humanly possible to juggle crutches, a bi-level machine and a Starbucks!

Over the last few years, I have tried to double my pleasure while scheduling trips outside of the San Diego area. By contacting post-polio support groups in other cities to see what days and dates they hold their scheduled meetings, I am often able to combine visits to family and friends with the additional excitement of meeting polios in other parts of California.

Establishing friendships with other polio survivors is not only a wonderful way to make new friends, but it is a terrific way to network and share information between groups. My recent Sacramento trip was testimony to that; I was able to attend the Fair Oaks/Sacramento Post-Polio Support Group Meeting, reacquaint myself with friends I had met there the prior year, be present to hear an outstanding guest speaker, and at the same time set up a brainstorming opportunity with good friends I made while attending the San Francisco Bay Area Polio Survivor's 2003, Kaiser/Oakland Conference. I traveled north...my San Francisco friends traveled east...and in the process we set up a statewide triangle of shared post-polio knowledge second to none.

What is so wonderful about polio support groups in California is that there is a direct correlation between our bulging over-population and the number of PPS support groups located in our state. Finally we found a bonus to those packed freeways and long lines in the grocery store! The PPS Manager Newsletter alone covers reports for in excess of nine groups just in the Southern and eastern parts of our state. And there are many other support groups scattered throughout the southern area as well.

If the confusion of airports or train stations deters you, try staying a little closer to home and travel by car to attend nearby PPS support group meetings. You could be pleasantly surprised by the benefits even one trip offers in the way of new friendships and connections/networking within your own geographical area.

So help yourself reduce that feeling of "cabin fever," enjoy the beautiful scenery throughout our state, stretch your comfort zone, and visit support groups near and far. You'll be surprised by the rewards.

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The Fair Oaks/Sacramento, CA Sept. 2, 2006, PPS Meeting Review

By Gladys Swensrud

The Sacramento/Fair Oaks meeting began as scheduled at 11:00am. Leslie Smith, the group president, announced to the audience that this meeting was being taped for future reference. He began by introducing interesting data, such as the fact that there were approximately 175 survivors in the Sacramento area. He also took a moment to introduce out of area visitors in the audience: Stella Cade and Sue Peeters from the San Francisco Bay Area Polio Survivor's group, Gladys Swensrud representing the San Diego Area Polio Survivor's group, and Leslie's brother and sister-in-law, herself a polio survivor, down from Sandy, Oregon. There was a new survivor introduced, Evelyn, attending for the first time.

This group seemed very congenial; Leslie had a way of introducing everyone and making them feel very comfortable and welcome. There were approximately 35 people in attendance. They recognized birthdays and anniversaries (actually singing Happy Birthday to all), and visitors could tell it was a very close and comfortable group.

They took just a minute to carry out an annual vote required for their board to be certified, in which only members participated. And then they moved right into introductions of

their guest speaker, Bill Hollingshead, a member of Rotary International, along his wife Dianne, both from the Sacramento area. Bill, himself a polio survivor, has been involved with his Rotary International District, 5160, in the awesome task of inoculating everyone against polio that they can possibly reach in the world.

Bill explained that as a child, his polio was cared for by Children's Hospital in San Francisco. He received Sister Kenney treatments, and, quite strangely for a doctor of that era, his doctor was aware of future complications from polio and warned him early on that he might have a little trouble in the future from the aftermath of this original attack (quite an understatement).

Mr. Hollingshead briefly told some of his personal memories after contracting polio at the age of fourteen in the epidemic of 1951. There were a host of activities in which he could no longer participate, like his life's joy of marching in his high school's marching band. He greatly disliked the fact that he was ostracized, sighting the time he asked a girl to a dance, and she said yes, but her parents refused to let her go when they learned Bill was a survivor of polio. He likened it to being a leper, which people shied away from in fear. He recalled it was as if polio survivors wore a badge of shame, and many families, whose member(s) had been stricken, never again spoke of polio or how it had affected them.

Bill entertained everyone with not only historical facts, but he also performed magic tricks. He said that as many who had polio, he made lemonade out of the lemons in his life, and he more fully developed his creative talents than he perhaps otherwise might have had his life's course been different.

Bill decided as an adult that he wanted to give back to the world a little of what he was fortunate enough to be given in life. So as part of his career path, he joined Rotary International, which eventually took him to Ghana, Africa, in a quest to inoculate their citizens who might be vulnerable to the virus. It was his calling in a sense to attempt to prevent others in the world from contracting polio as he had.

Bill told what is being done within Rotary to mount a final assault to eliminate polio worldwide, and he also explained through a wonderful slide show what his trip to Ghana entailed.

Via slides he also presented a segment of the history of polio. Along with slides of Iron Lungs he displayed one showing a person receiving the spinal tap, a test everyone who contracted polio had to endure to correctly identify the virus.

When he realized he was suffering from the late effects of polio, Mr. Hollingshead made an appointment with Dr. Carol Vandenakker at U.C. Davis, who had been identified to him as a physician with particular skill in working with survivors of polio. Bill told us of his four and a half hour evaluation with her, and how he was also placed in the combined care of a Physical Therapist to assist in solving some of the back problems. He couldn't speak highly enough about getting into some type of therapy program.

In October 2001, just after 9-11, twenty-seven Rotarians traveled together to Ghana, Africa, in search of helping others in that part of the world in danger of contracting polio. Once they arrived and began settling in for this serious mission, they were delighted to find they would have the help of a native nurse, Olivia, to do most of the inoculations. Bill knew from

the onset this experience would be a life-changing event for him. He felt overwhelmed with emotion when one man approached him requesting that "Mr. Rotary Man" give his child medicine against polio. This particular man's brother had contracted polio; he relayed that this brother was crippled and was not able to work as a result of the virus, and he was very concerned that his son have protection from the poliovirus.

While Rotary International travels abroad to foreign countries to inoculate children (5 and under) against polio, they also do community service projects for the citizens of the communities they enter, such as a school building project in which Bill was involved. His slides showed an overhead-only, covered shelter children had been using as their school. It was quite open to the elements with no sides – only a roof. When it rained, all the children had to pick up their books or tablets and run for cover, so Rotary International's work to provide them with a real school was applauded by the entire community.

Bill, in culmination, then asked the question: "What is left?" and he listed a couple of misconceptions we still must face.

Misconceptions:

- Polio is not dangerous..."just another childhood disease"
- Polio is already eradicated
- Rotary International, Polio Plus (who does the bulk of their work), is already funded

Then he followed a couple of additional facts:

Polio Eradication:

- The primary cost is forty-two cents per 2 drops to inoculate a child.
- The real cost is what it takes to travel to foreign countries to get the job done.

In 1988 there were 350,000 cases of polio still reported in the world within 125 countries. In May of 2006 there were 453 cases in 12 countries. However that number jumped to 1,115 cases in 14 countries as of August 29, 2006. This latest increase indicated how quickly known cases can multiply in just a few months time.

Bill showed us a pie chart of what the financial contributions were from people all over the world, and he drew our attention to some of the people they come from, like Bill Gates.

Rotary says that they need to think globally to eradicate this problem, and "Now...more than ever: Stop polio forever," is the new motto Rotary uses. Mr. Hollingshead feels the plan to eradicate polio is back on track now. The fight needs to continue in an effort to free the world of polio once and for all!

Following the rousing, round of applause and a big thank you to Mr. Hollingshead for his wonderful presentation, the meeting was officially concluded at approximately 12:30pm; we broke for a delicious potluck lunch that was graciously contributed to by everyone.

Bill Hollingshead
Polio Eradication Chairman
2006/2007
Rotary District 5160

and
Davis Rotary - Davis, CA
bhptalent@aol.com
Ph (530) 758-9779

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PRESS RELEASE

Post Polio International Conference Partnering for a Better Tomorrow

April 9 -11, 2007, at the Radisson Hotel Downtown, Miami, Florida. Call hotel (800) 333-3333 - ask for “Post Polio International Conference” block room rate of \$119. Registration forms and fees to be available soon. Watch for more details in the near future at our websites: www.postpolioworld.org and www.ippso-world.org or email postpoliomiami@aol.com with questions.

Post Polio group cruise offered after Post Polio International Conference, April 9-11, 2007 in Miami, Florida. A 7-night cruise to the Eastern Caribbean aboard Royal Caribbean’s ship, Voyager of the Seas, will depart the Port of Miami on Saturday, April 14, 2007. If interested in joining them, contact Faye at:

Toll free # 1-866-447-0750 or email to faye@travegroupint.com. Mention “Post Polio Conference Cruise” to get the group rate. Visit www.postpolioworld.com or www.ippso-world.org in the near future or email BAPPG@aol.com (Maureen of the Boca Raton Post Polio Group) to get more detail on how to accommodate any special needs.

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BOOK REVIEW

Dancing with Katya

A children’s picture book

by Dori Chaconas

illustrated by Constance R. Bergum

Peachtree Publishers

Kathryn Kozak had polio in the early 1900’s and went on to live a long and fruitful life in spite of the obvious mark the disease left on her. Dori, one of her seven children, wrote this wonderful story in which a little girl, fashioned after her mother Kathryn, overcame the stigma of polio’s devastating aftereffects.

In this inspiring tale Katya, helped by her loving older sister, regains her lost love of life.

Constance R. Bergum's illustrations, reminiscent of the period, add color and life. Not by coincidence, I assume, Ms. Bergum's father is also a polio survivor.

Although the book is marketed as a children's picture book, this child of sixty found it quite moving. It does, however, seem a little heavy for the very young.

Rick Van Der Linden

Katya review by Sandy Van Der Linden, wife of polio survivor:

I was very impressed with the story. The love of one sister for another was very heart warming. So many times siblings are embarrassed to have someone in the family that is "different". Anna's love for her little sister and her desire to make Katya's dream come true shows that Anna is a very special young lady. I shall enjoy reading the story to my grandchildren and nieces and nephews.

The illustrations were wonderful. The expressions on the faces are adorable. I can remember wearing dresses just like the ones in the story.

It was helpful to read about the author's and the illustrator's notes at the end. It helped to understand polio a little better. Most of us do not realize how devastating Polio was to the victims and their families.

"I'd venture a guess it would be people our age who will buy the book [Dancing with Katya] to read as a lesson to our grandchildren along with stories of our own about what we experienced."
Gladys Swensrud

BOOK REVIEW

101 Character Profiles:

A Writer's Reference Guide

By Harold F. Burks, Ph.D

AuthorHouse.com

From the book cover:

“*How to craft behavioral traits and internal feelings shown by over a hundred psychological and medical types ranging from addictive gamblers to voyeurs.

*Explains the biological, family, and cultural influences on male and female personality development.

*Explores child and adult trait differences.

*Supplies suggestions how personality types can be integrated into story plots.”

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Dr. Burks, also a fiction writer, provides an excellent guide to help fill in your fictional characters' idiosyncrasies – always a good idea if you want to keep your readers interested. And, he does it in simple, straightforward language as if he's giving personal advice to a fellow writer. He also includes references with each disorder if you would like to do further research.

If you're a fiction writer, this book makes it easy to bring out the worst in your bad guy, or give your good guy that little problem needed to complicate the plot.

If you're not a fiction writer but you've considered getting into it, this may be the inspiration you've been looking for.

[Note: Hal Burks is a million selling author, polio survivor, and member of the Hemet Area Polio Survivors. See him in Hemet on December 9, 11 AM to 2 PM, at his book-signing event at Cameron Books 3077 W. Florida Ave.]

MEETING REPORTS

San Diego Post-Polio Support Group

NOTICE!

New meeting day and location.

We will be meeting on **Saturdays**, starting **November 11** 10 AM at **Kaiser's** main hospital on **Zion Avenue**. The address is: 4647 Zion Avenue San Diego, CA 92120

This first meeting we will be in Classroom 4 in the basement. Take the elevator down, the classrooms are across the hall from the cafeteria, so follow the signs to the cafeteria and you can't miss our room!

Parking will be easily available and handicapped accessible restrooms are nearby. The hospital has also offered us a private portion of their cafeteria for luncheons where we may bring our own food, or purchase food there.

September 14, 2006 Meeting Notes

by Gladys Swensrud.

Our September meeting was well attended; we were delighted to welcome a few new visitors.

Our guest speaker this month was Ryan Baker, representing the Ability Center in San Diego, a van conversion company working to meet the needs of handicapped drivers and passengers. Ryan not only related the history of the Ability Center, but he also shared a bit of

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his personal history as a paraplegic. He related how an automobile accident the day after high school graduation resulted in spinal injury to his T-6 vertebrae, which paralyzed him from slightly above his waist down to his toes. We could immediately tell Ryan had a special understanding and personally unique view of the needs of the disabled community. We found him intelligent, articulate and very personable.

Ryan brought a Toyota, Sienna mini-van to demonstrate the newest technology available in lifts and swing-out seats. He was very well versed in his products and was able to answer all questions we posed to him. We enthusiastically thanked him for his time, and upon his departure, he left brochures and business cards so those who might have questions could easily contact him.

Upon reassembling after the break, Dr. Jim Donovan delivered a short report on new research occurring within almost all neuromuscular/neurological disorders that have strong financial backing. He delved into the secrets genes hold and how it is hoped research will unlock some of the mysteries of genes, enabling solutions to be found for everything from Amyotrophic Lateral Sclerosis to Parkinson's Disease. Dr. Jim noted that funding-wise, Post-Polio Syndrome continues to ride on the coattails of other disorders.

After new business, we next dove into a group discussion of the possibility of changing our meeting day and location. Gladys detailed how she and Rick had been scouting for a modern facility with space available on Saturdays. This change would allow those who are still working to attend meetings. They were also searching for a location with access to AV equipment, including projection screens and television capabilities. Kaiser Permanente's contact graciously opened room availability in a classroom at their main hospital on Zion Avenue; it has all the amenities we would need.

Nov 11 Carlos Valenzuela Progressive Orthopedics "FDR's Warm Springs Trip"

Dec 9 11 AM Holiday party

___The next La Jolla meeting: ___

November 11

December 9, 11 AM

Regular meetings (until further notice) are at 10 AM on the second Saturday of odd numbered months at: Kaiser Permanente 4647 Zion Avenue San Diego, CA 92120.

For more information call **Rick Kneeshaw** 858-566-4016 or piecon@mindspring.com

Or go to <http://polio.home.mindspring.com>

Escondido Post Polio Group

___The next meeting: ___

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December 12

Regular meetings on the second Tuesday of even # months from 1:00 to 3:00 at Joslyn Senior Center, Dorothy Boeger building, 728 N Broadway, Escondido
For more Escondido info. call Mary Clare at 760-741-5075 or postpolio@cox.net

COACHELLA VALLEY POST-POLIO SUPPORT GROUP

We had a few new members and we distributed the new Membership Information books. I understand there are a few errors and would like all of the members to look carefully through the book and let me know if they see anymore. Also the Portola Community Center will be closed on November 10th so our November meeting will not happen. Linda Dempster is setting up a speaker from the Community Access Center to speak at our December 8 meeting. Hoping to see everyone then.
Joe Camaya

Special Meeting Announcement:

The new Director for the COMMUNITY ACCESS CENTER in INDIO, has indicated she will provide a speaker on Dec 8 at 10:15 to explain services available from the Community Access Center. This is our regular meeting at the Portola Community Center in Palm Desert.

They provide home assessment for modifications or special equipment needed and can sometimes provide funding also. Advocacy Services and other Special Programs are available.

This is a great opportunity for us. A question and answer period will follow the presentation. Take-home materials will be provided.

The Community Access Center has offices in Banning, Riverside and Perris as well, and all communities have something similar. Since these services are available throughout California, ALL are invited from other areas.

The Indio Office number is 760-347-4888

Linda Dempster

Note: Because the Center will be closed, there will be no meeting in November.

_____ **The next meeting:** _____

December 8

2nd Fridays at 10 AM at Portola Community Center, 45-480 Portola Ave, Palm Desert CA Park in rear.

For information, contact Joe Camaya stan-n-ollie@msn.com , phone (760) 365-3587

HEMET AREA POLIO SURVIVORS

Hi Everybody.

Our meetings in September and October were fun and informative as usual.

If you've never been to a HAPS meeting, you'd think we were disorganized. Well, I guess we are, but it's fun. At one table Bunny and Glenda and Betty might be planning the Christmas party while at other tables three separate discussions are going on at once. We like to think of it as multitasking.

Every once in a while we all listen to the same story. At the last meeting, Bunny reported on the party plan: (see below) and, Melanie Arledge had the floor long enough to report on the effects of the latest Medicare changes regarding bilevel ventilators and how Progressive Medical hopes to handle the problem. She said that her boss, Helen Kent is going to a big meeting in Chicago to make a plea for better Medicare coverage. She suggested that under the new Medicare rules, companies that provide bilevel S/T vents will lose income and that means reduced service (or increased cost) to users. Details of the existing regulations are in the article at the beginning of this issue.

Melanie also told us about a new device that takes the place of laboratory sleep studies. Sounds like a real winner, unless you own a sleep lab.

Have fun ... Rick

SPECIAL ANNOUNCEMENTS

One of our HAPS members just released his latest book. There will be a book signing in Hemet, and it would be great if we could all show our support by dropping in.

**101 Character Profiles:
A Writer's Reference Guide**
By Harold F. Burks, Ph.D.

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Book signing

Saturday, December 9, 2006

Time 11 AM to 2 PM

Cameron Books

3077 W. Florida

Hemet, CA

Read a review in this issue.

EVERYBODY'S WELCOME

to our HAPS

CHRISTMAS PARTY

December 17 from 1 to 4 PM

At Valley Wide Recreation Banquet room

Esplanade Ave, San Jacinto.

Live entertainment, tea, coffee, and paper plates etc. provided. Ornament exchange if you feel like it (one per family)

Bring a dessert – RSVP contact Bunny 766-7118

____ Our next HAPS meetings are: ____

November 15

Regular meeting

December 17

Christmas Party

Regular Hemet meetings are at 11 AM to 12:30 on the third Wednesday of every month at: Sun West, 1001 N. Lyon, Hemet. For more info call RickVDL (951) 926-5492

Riverside PPS Group

October 21, 2006 Meeting

Eight of us gathered for brunch, plus phone contacts to two others who were unable to join us. We had a lot of good discussion and learned a few things!

Sue had problems all summer with fluid in the pleural cavity around the lung. Many tests, procedures, surgery August 31. Most recently she saw a respiratory doctor, and still needs more testing to see if BiPap can be prescribed. When the therapist found that Sue was post polio, she said post-polios need the BiPap and NOT the C-Pap.

A non-Kaiser pulmonologist who has been very helpful to polio survivors is Dr. Jeffrey Simon (Riverside). He says polios don't recover well from bronchoscopy and should avoid it. Sue volunteered that she was a long time recovering from the tube inserted down her throat during her surgery, and also had hard time breathing immediately after the procedure.

Featured Topic: Bracing presented by Christy Stevenson

A lot of us are guilty of not using our brace – we put it off. It's clumsy, heavy, we have to learn to walk again. But not using it causes other problems. That's how my back got bad – not wearing it. I have only a little over _ inch difference, but it does cause a problem. Originally I wore two full length braces. As an adult, I said, Okay. But then I wouldn't wear it.

Results? Arthritis, bursitis. Hip, back problems. But a doctor drilled into my head the importance of wearing the brace, and I listened. I just had back surgery (arthritis related, which I had even as a child). Because I had listened to the doctor re bracing over the last few years, there was no new damage, and the surgery they did 7 weeks ago was completely successful. All the pain from arthritis is gone. They were amazed – how I'm walking now is so much better, and that's because I'm not in pain. You have to have the right doctor – who knows post polio.

When I finally started wearing the brace, Christy continued, it didn't correct the damage that had built up, so listen to the doctor and wear your bracing now!

You need a doctor who will analyze your gait. Christy recommended a resource in Las Vegas (“Hi-Lo Clinic”?) that will videotape of your gait, analyze it, and fit a brace that's just for you. They are very accommodating. Insurance may cover 80%. My brace \$4,400, my cost \$1,300. It's for the rest of your life. For more info, contact PPSRiverside@aol.com or call Judy (951) 788-9310.

Christy said, “The brace kept me walking – where without the bracing I wouldn't have been walking.” Listen to the doctor (when you find one that knows what's going on with PPS).

Someone asked – But what if I've never worn a brace? How often would I have to wear it, in bed? What if my hip keeps hurting? Do we make adjustments? Sue confessed – Mine's in the closet! My doctor bawled me out, but I don't care. You get tired, it's inconvenient...

Betty W said the weight of her original brace (in the 1930s) was too difficult, worse than the original problem. But the bracing material is light-weight now. And, Christy's Las Vegas resource will accommodate your needs, working out every detail until they get it just right.

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Holiday Party **Saturday, December 16th**

11 am at Bryan & Judy's 3465 Ramona Dr, Riverside CA.

Featuring the music of "Rick n Eddie"

– a perfect blend of guitar and other instruments,
familiar songs and holiday good vibes.

Turkey dinner, potluck. Contact Judy to see what to bring, but you don't have to bring something – just bring yourselves!

Meetings 2007 first half - (tentative schedule)- February 17, April 21, June 16

Judy

_____The next meeting:_____
December 16
Holiday Party

Riverside PPSG Meetings: third Saturday of even # months at 10 AM. - at the home of Bryan & Judy Mahoney, 3465 Ramona Drive, Riverside CA. For more info. contact: Judy PPSRiverside@aol.com (951)788-9310 or Betty McFarland (951)243-6991
bbooplink@aol.com

Big Bear PPS Group

For information contact Marsha at (909) 878-3092

High Desert PPS Group

Our next meeting will at 12:00 on Nov 14, 2006 at Rinconsito Del Mar Restaurant on 7th St., in Victorville. Dina Lambert owner of Comprehensive Therapy Center will be our speaker!

Kay

_____Next meetings:_____

November 14
December 12

Regular meetings: Second Tuesday of every month. Location varies.

For information contact Vi at (760) 949-6775, or e-mail BillHerold@aol.com

Polio Survivors Plus

Of South/West Orange County

At the September meeting, the latest innovations in adaptive equipment and aids for polio survivors and people with physical challenges were unveiled for all meeting attendees to touch, experience and evaluate. From drinking cups to wheelchairs, Adapt-2-It was the focus of this hands-on meeting.

For the holidays, a limited number of seats are still available to view the **98th Newport Beach Holiday Boat Parade of Lights** on Thursday, **December 14, 2006**, from an Upper Newport Bay Ecological Reserve launch that'll leave the docks at 6 p.m. Dress warmly (wearing gloves, scarf and hat), bring a blanket(s), your musical instruments and caroling voices to join over a million viewers and see beautifully decorated yachts, boats, kayaks and canoes as they sail to the theme "Holiday Magic Through the Eyes of a Child."

The boat parade starts off Collins Island and will set the Newport Harbor ablaze. For more information: visit <http://www.christmasboatparade.com/>

If you have a decorating guru who would like to help decorate the boats, let us know that, too, or contact Sue Lau to make a reservation. The Board of Directors of Polio Survivors Plus wishes you a special holiday season and a happy new year!!

Notice There will be no meetings for the rest of 2006.

Sue Lau

Next meeting: _____

January 24, 2007

Regular meeting are held on the fourth Wednesday of each month, 1:30 to 3:30 PM. At Laguna Woods Village's Clubhouse 3

23822 Avenida Sevilla, Laguna Woods, CA

For information and to RSVP, contact:

Sue Lau at (714) 639-7497 or e-mail Maliebchen@aol.com

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Carolyn Writes

Dear Rick,

There was a potentially dangerous mistake in the Polio Survivors Plus column. The writer mentions epinephrine as being beneficial. Anecdotal research is showing (my pulmonologist confirms this) many PPS people are allergic to it. I ended up in the ER in shock after using Primatine Mist before I was diagnosed as allergic. Under doctor's orders I carry a letter at all times (from the allergist) which is to be shown to emergency personnel and new doctors. I also wear a Medic Alert necklace. I believe some of the new material put out by Dr Richard Bruno

also mentions this allergy. I think this is the type of new information that should be brought up at PPS meetings – it could save lives ...

I have an idea for all the support groups nationwide: Can you think of any illness that afflicted more famous people than polio? I can't. Why don't we get some of these people to do public service announcements about PPS? If [we] started writing to our famous fellow sufferers maybe we could spread word of this nasty condition.

An interesting question has come up and I'd like some feedback from your readers. I know a forty-year-old woman who caught polio prior to coming to the U.S. – she was two at the time of her illness. She uses a full-length leg brace, and has since she had polio. She's now starting to feel the initial intrusions of PPS, but knew little about the condition until she met me. Her doctor, of course, is no help at all. (One doctor attributed the beginnings of her increased fatigue, weakness, and pain to aging – when she was 35!) Anyway, today she happened to mention that for the past two years she's experienced a terrible problem with a dry mouth, that insufficient saliva is causing all sorts of difficulties. I really perked up my ears because the same thing is really bedeviling me, though I'd just attributed it to a side effect of my medications. Now I'm wondering, as Rosa takes no medications at all. Have you heard of a dry mouth as a PPS symptom?

As to dry mouth in general, I've been trying for three years for a doctor to take this seriously and provide some help. No luck. I even tore out a column by a doctor in the Press-Enterprise and showed it to him. After a one-second eye scan the column was just handed back without comment, and the subject was changed. I finally got so desperate I called a pharmacist the other day and asked about the product listed in the column and found out they're sold over-the-counter! They're uncommon so they've had to order it. I'll keep you posted on whether or not the stuff works.

One other aspect that bears mentioning – all the kids who had polio but were never diagnosed. In our neighborhood every child but one came down with the same symptoms in a two week period. I was the worst, and the only one hospitalized and given the diagnostic spinal tap. Both of my sisters eventually developed the same PPS symptoms that I have, so it wasn't too hard to figure out. But, what of all those little playmates from years ago? My guess is there are millions of people out there with PPS – and you'd think that might merit some interest from the medical community!

I had another experience that yet again points up how ignorant some of these doctors are about PPS. My primary care doctor put in a request to the insurance company for me to get a motorized wheelchair or one of those carts. They responded by saying I'd have to go to an orthopedist to have "an evaluation of disability". I went for the appointment and it was a disaster. He asked me questions that made no sense, and while I'm answering them with descriptions of my current status – increasingly weakening breathing muscles, worsening pain, etc. – he started getting angry with me, cutting me off and sarcastically repeating the question he's just asked.

For instance, he'd ask something like, "What's wrong with you?" and I'd start answering about how I'm having breathing problems because my chest muscles are weakening. "No, what IS wrong with you?" And then, "The polio did not affect your torso or arms!" (You could have fooled me – what were all those years of exercises on them for?)

The whole picture was suddenly clear when he said, "Yes, I understand that you had polio as a child, but why should that have anything to do with increasing weakness now?" This man had obviously never heard of PPS.

By the end of the appointment, it had become obvious he wasn't going to approve my motorized chair. [He concluded that] "A non-motorized wheelchair would be sufficient." This to a person who's having more and more trouble getting around with crutches – imagine how much harder operating a manual wheelchair would be. I can hear my poor remaining neurons and axons mewling in their death throes just thinking about it.

Seriously, though, the whole experience was very upsetting for reasons beyond the probability of not getting a motorized wheelchair because it showed me once again that the places we should find help (the medical community) contain those who are so ignorant they can actually be dangerous to us.

[A similar incident happened] two years ago when I got something caught in my throat and was blocking all but a small portion of my breathing passage. The ER people absolutely refused to listen to my daughter's explanation that PPS had left me with weak chest muscles and I couldn't cough this up. Frustrated for over an hour, they pumped asthma medication into me. I couldn't have kept up the strength to breath much longer when someone finally called the respiratory therapist. As soon as my daughter said, "She has Post-Polio Syndrome ..." the woman finished the sentence with, "... she's got weak muscles and can't cough out something stuck in her throat. I'll just vacuum it out." Ten minutes later I was ready to walk out on my own steam, very weak but breathing fine. Like I said earlier, we've got to get the medicos educated before they kill us.

Thanks for letting me beat the drum on all this. You're doing a fabulous job – we'd all be so lucky if we could find a doctor who was a fraction as knowledgeable.

Sincerely, Carolyn Moyer

LETTERS

Readers respond to "Attend Support Group Meetings ..." By Gladys Swensrud – The PPS Manager Newsletter 09/06

Dear Gladys,

I'm one of those people who had to say "OUCH!" when I read your article about absenteeism from our support group meetings. In my defense, I have to say that I start with the best of intentions, always planning to go to my local (Palm Desert) PPS Group meeting. For me, though, the problem is the time. The group meets at 10:00 AM, about 30 minutes from my house. Mornings are terrible for me, making it even more of an obstacle to get myself dressed and mentally-organized for a 9:30 or so departure.... and it can take me 2-3 hours to get dressed

and ready! This makes meeting attendance more than just a challenge and almost an impossibility some months! Thus, I rarely attend.

I've been told by others in the group that the meeting time isn't ideal but that it's the only time available at the community center for our meetings. I know that I'm not the only member who can't plan to be ANYWHERE by 10:00 AM on ANY DAY! I don't even schedule physician or clinic appointments before Noon, ever!

I enjoyed your article, though, and thank you for raising the issue!

Rick, Thank you for the incredible job.

Bill Wells

One reader who asked to remain anonymous wrote to tell us that she quit attending meetings because (to put it in general terms) personal beliefs outside the realm of post polio were expressed on a regular basis at meetings. She felt that, even though these personal beliefs were not contrary to her own beliefs, she was uncomfortable with the public display in the wrong place at the wrong time.

If you feel uncomfortable or if you feel like the group is going in the wrong direction, tell your leader. Your leader is a giving, caring person or he/she wouldn't be trying so hard to lead the group.

Dear Rick,

Thank you for the PPS Manager Newsletter. It's #1 on my list of what helps with my PPS.

Take care,

Dolores Masturzo.

Thank you for all the work you do to keep us informed. I read every word twice!

Betty S. Thompson

Rick,

I'm wondering if anyone has some tips on how to beat the PPS and have made themselves stronger by some magical system. I'm searching and would like to hear from others that are tackling the problem.

Kaptain Bill

Bill,

Unfortunately, there's no magic bullet. The only thing that seems to work over the long run is careful management of stress and physical output.

First, control the physical side of daily life with proper assistance. A caregiver or housekeeper, assistive devices such as scooter, bracing, and breathing assistance. Concern yourself with your own comfort. Then, to heck with the little things that don't matter all that much. If you can't fix it, forget it.

Since I had bulbar polio, I made a lot of headway using a bilevel ventilator. Before using it I had no idea how severely my bad breathing effected the rest of my body. It turned back the clock about ten years, but the clock continues to run and the downhill slide continues. That's life, eh?

Some people have found minor relief from things like L-Carnitine, Co-Enzyme Q-10, B-12, and Neurontin. Others use pain medications. I've tried most of these things and found that nothing works as well as careful management.

Careful management in a nutshell:

Stay warm, but not too warm.

Stay active, but not too active.

Use assistive devices that don't shift overuse to other areas of the body.

Avoid drugs if possible.

Find a way to feel good inside.

You'll have good days for no apparent reason. Appreciate them.

You'll have bad days for no apparent reason. Wait it out.

Rick.

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People tend to downplay PPS breathing issues. They think that because they had polio in one leg they don't or won't have a breathing problem. It's an open door to denial.

THANKS

Thank you for reading the PPS Manager Newsletter. And, thanks for your help and your words of encouragement.

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