

**FROM THE EDITOR**

Hi Fellow PPS Managers,

The loss of Lee Seitz is a huge moment for all of us. Lee, though profoundly disabled by polio, fought hard to help PPS folks in need. She will always be an inspiration to me.

During the past several weeks I learned a lot about Casa Colina. Their Pomona facility is simply beautiful, and the people are wonderful. Best of all, they seem to be well qualified to diagnose and treat PPS!

Though they have been treating PPS folks for at least 9 years, they just recently decided to think of themselves as a multidisciplinary PPS clinic.

As far as I'm concerned, they have all the bases covered. The only thing I'm unsure of, because the subject was not adequately covered at the October 20 seminar, is their ability to treat neuromuscular breathing issues. I suspect they are up to the task, I just can't say for sure. You can bet I'll look into it.

Also, pay attention to the MDA warning about the type of H1N1 vaccine you receive. It could make a big difference.

Rick VDL

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Meeting Reports, Letters, and much more...

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**PRESS RELEASE**

From The Polio Survivors Foundation

**Remembering  
Lee Seitz**

# PPS MANAGER

It is with deep sorrow that the Polio Survivors Foundation (PSF) announces the passing of our beloved President, Lee Seitz. She died peacefully in her sleep on Saturday, September 26<sup>th</sup>. She was 83 years old.

Lee dedicated her life volunteering as President of PSF since its 1978 inception. The Foundation ran entirely on donations and had a membership of over 800 people. Lee was available around the clock to help other polio survivors. She was an inspiration to each and every person she met. She gave unselfishly of her time and talents to help other polio survivors and will be sorely missed.

There will be a memorial to celebrate Lee's life on Sunday November 15<sup>th</sup> at the Bermuda Mobile Home Park Clubhouse, 15445 Bermuda St., Mission Hills, CA 91345. If you are able to attend, please call Willa Hubert at (818) 920-6540 or Robin Mitz at (818) 772-6554 by November 1.

Lee was the heart and soul of The Foundation. With her passing, the office is now closed.

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## Casa Colina

10/20/09

Casa Colina Centers for Rehabilitation held a free seminar entitled “**Managing Symptoms of Post-Polio Syndrome**” at their beautiful Pomona facility on October 20, 2009. Guest Speakers included neurologist Richard Shubin and physical therapist Kathy San Martino.

Casa Colina CEO Felice Loverso welcomed over 100 PPS folks and family with a brief history, description of services, and outline of the upcoming multidisciplinary program.

Casa Colina (House on the Little Hill) was founded in 1936 by polio survivor Frances Eleanor Smith, aka. Mother Smith. The original purpose of the foundation was treatment and care of polio victims. Due to the success of the Salk (and later Sabin) vaccine, polio patients became so few that they began treating people with brain injuries and neurological trauma.

Throughout their history, Casa Colina, “has been recognized throughout the nation as the first to introduce many of the modalities that are implemented in rehabilitative care today.”

### **Full Circle**

For several years, Dr. Shubin and his team have been seeing more and more PPS cases. Now, according to Mr. Loverso, Casa Colina has come full circle and returned to its roots as they unveil their full service PPS clinic. Included are Dr. Shubin, Kathy San Martino, two neuromuscular disorder qualified pulmonologists, referral to a trusted orthotist, and supporting staff. There are over 200 physicians on staff.

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He then introduced Dr. Shubin.

Dr. Richard Shubin displayed his vast knowledge of the effects of the virus in an outline of the history of polio, and the current understanding of PPS basics.

PPS symptoms and the possible causes of those symptoms were covered in a very easy to understand manner.

Dr. Shubin outlined the clinic's approach to diagnosing and treating the late effects of polio and, interestingly, the aftereffects of surgeries performed following the initial infection.

## Q & A

Susan from Big Bear asked about the medical community's lack of interest in our disease due to our age and dwindling numbers. Dr. Shubin answered that, since West Nile is such a close cousin to polio, there is evidence that there will be an ongoing interest in similar problems in the future. Add to this the shift toward a warmer climate, and you have the potential for new polio-like viruses popping up, so "it's something we're going to see a lot more of in different forms. So, polio will evolve, and will never go away."

One person said that the loss of his eyesight had been attributed to polio, to which Dr. Shubin commented, "Whoever came to that conclusion didn't know what they were talking about. Wrong disease."

Question: Will Casa Colina have a complete diagnostic program? Answer: Yes. The large staff of doctors is on hand to eliminate other possible causes of symptoms and, therefore, narrow it down to a PPS diagnosis.

Dr. Shubin was asked to explain brain fatigue. His first response was a reference to sleep disorders. Secondary reasons could be related to medications and general aging.

Dr. Shubin thinks that Fibromyalgia (FMS) may sometimes accompany PPS. He says that fibromyalgia-like symptoms in PPS folks can often be treated successfully with normal FMS treatment methods.

Drugs for PPS: FMS drugs, Gabapentin (brand name Neurontin), anti-inflammatory meds, and others. He also referred to the work of physical therapist Kathy San Martino as being helpful in identifying and correcting the individual causes of pain.

Several other questions came from folks new to the symptoms of PPS looking for basic information.

After a short break, Physical Therapist Kathy Martino was introduced.

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The Casa Colina PPS rehab program includes: Physical Therapy, Occupational Therapy, Speech Therapy, and a Recreational Therapy.

The Physical Therapist addresses: strength, ability, energy conservation, pain management, home modification, wellness program, edema (swelling) management, gait analysis, balance, and equipment evaluation.

They have a fitness center with pools for aquatic therapy, and gym equipment, and a wheelchair seating clinic.

Occupational Therapy can help deal with Activities of Daily Living (ADL) to help you become more efficient. The Speech Therapist helps with swallowing and breathing issues, and the Recreational Therapist helps with a variety of adaptive activities.

You might think that a Physical Therapist would talk about the exercise and/or activities you should be doing, but Ms. San Martino went on to speak as much about the things we should NOT do as the things we should do. Along with this, she explained in detail how polio damage determines what we should or should not do.

Orthotics, assistive devices, and wheelchairs (both manual and powered) were discussed in detail, including your insurance (Medicare or otherwise) payment strategy. Very good advice.

Kathy seemed to have a firm understanding of the PPS situation.

Next up was Orthotist Lance Clauson of J & K Orthopedics across the street. He pointed out that, even if your insurance won't pay, it's worth it to use whatever funds you have available to improve your life. Your children won't want you to save it for them.

He also said that when you ask your insurance for a device or service, you should be very specific about what you need, use the proper code whenever possible, and note who you spoke to and when you spoke to them.

Another point he made is that if you have braces, a nick or scratch can significantly weaken them. In some cases a scratch can be the beginning of a crack. Your orthotist can polish out a scratch or nick to prevent early breakage.

Mary Ellen Stan, Co-facilitator of the San Gabriel PPS Support Group, spoke next. As a 3 year patient of Dr. Shubin, she was very complimentary of the Casa Colina PPS crew and facility.

The group meets at 1:30 on the 3<sup>rd</sup> Saturday of the month. For information, call (909) 465-0742  
Visit [www.post-poliopartners.org](http://www.post-poliopartners.org)

The Casa Colina PPS Clinic is taking new patients. Their waiting list is only a week or two. The facility is conveniently located between the 10 and 210 freeways off Gary Ave. Payment methods

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include Medicare, Medicaid, private insurance, Kaiser referrals for some services, very limited HMO access, and cash.

Casa Colina  
255 East Bonita Ave.  
Pomona, CA 91769  
(909) 593-0096 x3800  
www.casacolina.org

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From the Muscular Dystrophy Association October 16, 2009

The H1N1 Nasal-Spray Flu Vaccine:  
What Individuals with Neuromuscular Diseases Need to Know

People diagnosed with neuromuscular diseases [PPS is a neuromuscular disease] are among those prioritized to receive the H1N1 vaccination, and the first doses of the H1N1 vaccine are now being distributed to state health departments throughout the country. While the nasal-spray flu vaccine is currently widely available, the injectable H1N1 vaccine has not yet made its way to most states for distribution. **Individuals diagnosed with neuromuscular diseases should not receive the nasal-spray flu vaccine and instead should wait to receive the injectable H1N1 vaccine.**

Who does the CDC recommend receive the H1N1 vaccine?

Anyone diagnosed with a neuromuscular disease and any close family members and caregivers. People who are in contact with others with severely weakened immune systems when they are being cared for in a protective environment should not receive the nasal spray vaccine. Click here [<http://www.mda.org/H1N1/>] for a complete list of those prioritized at higher risk of complications from H1N1.

What form of the vaccine does the CDC recommend that people with neuromuscular diseases receive?

The injectable H1N1 vaccine. The nasal mist of the H1N1 vaccine contains a live virus and, unlike the general public, individuals with neuromuscular disease are at increased risk of complications from the nasal mist vaccine.

If my child's school is administering the H1N1 vaccine, what should I do?

Parents of children with neuromuscular diseases should ensure that their child NOT receive the H1N1 vaccination via nasal mist. According to the CDC, children whose classmates are provided the nasal mist are not at an increased risk of infection due to exposure. Click here [[http://www.cdc.gov/h1n1flu/vaccination/nasalspray\\_qa.htm](http://www.cdc.gov/h1n1flu/vaccination/nasalspray_qa.htm)] for more information about exposure to people who have received the nasal mist.

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For additional questions regarding the nasal-spray flu vaccine, log onto the MDA H1N1 Resource Center. [<http://www.mda.org/H1N1/>]

An ounce of prevention ... will help to protect you and your loved ones this flu season.

Used with permission of the Muscular Dystrophy Association

For more information:

<http://www.mda.org>

Muscular Dystrophy Association - USA

National Headquarters

3300 E. Sunrise Drive

Tucson, AZ 85718

1-800-572-1717

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## **FROM TEN YEARS AGO**

[The following article was published in the October 1999 issue of the PPS Manager Newsletter]

A little understanding works wonders.

### SPREADING THE WORD

The big story for me this issue is the publication of a PPS story in the local countywide newspaper, the Riverside Press Enterprise [August, 1999]. In the article staff health writer Mike Schwartz did an excellent job of describing what polio and post-polio are. He interviewed me, and Dr. Jaquelin Perry, he researched the work of Dr. Halstead, and he included a very good illustration of the motor unit's damage and "recovery".

At the forefront of the article was the fact that many are misdiagnosed and mistreated by physicians who do not understand or accept PPS.

In a follow up story he covered the methods of managing PPS and included my phone number as a referral to those in need of help.

I was on the phone for three weeks solid. It's been two months since the article came out and I still get a call every other day.

Some highlights of the experience:

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## Misdiagnosis:

About two out of three calls were from people who told their doctor that they had had polio and yet were being treated for other things, mostly Fibromyalgia Syndrome (FMS). The usual treatment of FMS is exercise and a diet high in fruits and vegetables. As a result of this treatment most people with PPS (who normally need little or no exercise beyond necessary daily activity and a high protein diet) will have an increase in pain and fatigue for which the doctor prescribes painkillers, antidepressants and then more exercise.

## We have a lot in common:

In the past six years I've talked to hundreds of polio survivors at local meetings and on the Internet and I know that polio survivors have a lot in common but it didn't really sink in until I started hearing the same story over and over again.

The big difference between us is the level of acceptance (or knowledge) of the condition and therefore our learning to calmly manage PPS without severe medications.

## How many Americans have PPS?

In the article Mike Swartz used the lowest estimate of 300,000, or roughly one in four or five polio survivors who have or will get PPS. The highest estimate I've read is 1.6 million had polio and 90% have or will have PPS. That's potentially one and a half million people with PPS!

Out of seventy calls only one was from someone who had polio and had no noticeable symptoms of PPS.

I started HAPS (Hemet Area Polio Survivors) over a year ago. In that time I located about a dozen polio survivors in my local area. After the article that total has increased to over thirty. That's almost triple!

[My 2009 list includes over 100]

## Learning to manage PPS:

A knowledgeable, open-minded doctor will prescribe assistive devices and a minimum of invasive medications or surgeries. They will also suggest that you join a support group and change your lifestyle. Those who trust their doctor to "fix it" with pills and/or supplemental O<sub>2</sub> are suffering the worst pain, fatigue, depression and mental confusion.

Several of the calls were from people who seemed to have a sixth sense about the effects of polio. They intuitively know that pain-causing activity is bad, rest and relaxation is good. One particular man comes to mind, Walter Dwarschak. His advice: Accept and understand the situation. Use relaxation, hot water therapy, assistive devices as needed, and when you feel the stress or pain take a deep breath of fresh air in through your nose and blow it slowly out your mouth.

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The most obvious roadblock to good management is the mindset that only the doctor can help you. You also have to help yourself.

RE Van Der Linden, PPS Manager 10/1999

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## MEETING REPORTS

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### San Diego Post-Polio Support Group

No report filed

\_\_\_The next San Diego meetings:\_\_\_

**November 14**

**December 12**

**Holiday Party**

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Regular meetings are at 10 AM on the second Saturday of odd numbered months at: Kaiser Permanente 4647 Zion Avenue San Diego Classroom #2

For more information call **Rick Kneeshaw** 858-566-4016 or [piecon@mindspring.com](mailto:piecon@mindspring.com)

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

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## COACHELLA VALLEY POST-POLIO SUPPORT GROUP

I received the following email shortly after Bill wrote to say he would be moving to Texas. His letter sounded hopeful.

Dear Friend of Bill Wells,

I am writing to you because you, like myself, received an email from Bill last Thursday describing his planned move from his home in CA back to his hometown of San Antonio, Texas.

On Sunday, October 4, Bill passed away at his home. Cause of death is presently unknown. Funeral / Memorial details are still being worked out. Bill's cousin, Jerry, was due to arrive in California today to help make arrangements. As soon I know what the arrangements are, I will contact you.

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I am so sorry to be the bearer of such terrible news. However, I knew that if you were on Bill's email list, you were an important person in his life and that you needed to be told of his passing.

Over the past few days, I've spoken with many old friends and had some tender and funny moments reminiscing about our dear friend. He was an amazing human being and a wonderful friend and I know he will be sorely missed by all of us.

Sincerely,  
Deborah (Debbie) Rhine

The Low Desert is looking for new leadership. If you would like to get involved, contact me, Rick, at the PPS Manager. (951) 926-5492

\_\_\_\_\_ **The next meetings:** \_\_\_\_\_

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

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## Victorville PPS Group

The High Desert PPS September 9th mtg. was held at the home of Larry & Vi Macias, 15 members had a wonderful potluck and shared an afternoon of fun camaraderie.

El Pescador Restaurant in Victorville held one of our biggest luncheons October 9th.

Info was passed out on the seminar to be held at the Salk Institute along with various pieces of info taken from the PHI Communique. Unfortunately, folks had gone down to the Hemet mtg. and were tested and received their breathing apparatus and no others were inclined to go down.

A lively discussion followed with a rousing approval of ordering the "We Are Still Here" bumper stickers to put on our vehicles to proclaim that WE REALLY are still here, even in Victorville! It was also decided to order business cards with a logo, mtg. date & time listed for all to hand out to friends and strangers alike to those interested in learning more about PPS. We are also trying to establish a list of physicians in the area who are knowledgeable about PPS and not afraid to discuss or treat same!

Our November mtg. will be held at Carrow's in Hesperia on November 11th with our Christmas Party luncheon and gift exchange to be held at Marie Calendar's on December 9th. All are welcome to come join us!

\_\_\_\_\_ **Next meetings:** \_\_\_\_\_

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**November 11**

**December 9**

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

For information contact Vi Macias @ (760) 949-6775 or Kay Mears @ (760) 243-6200 or Im-A@Blessing.com

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## **Escondido North County Post Polio Support Group**

By Marilyn Loba

Our speaker for our October 13<sup>th</sup> meeting was Dr. Pietrek, doctor of chiropractic, of Pietrek Spinal Care. He is currently working with a PPS patient at his practice and has had some success. She is a 40 year-old female who moved to the United States from Korea in her teens. Besides traditional treatment (in which her tibia was lengthened) she has also previously tried herbal remedies and acupuncture. With chiropractic treatment, she has a more balanced body.

The number 1 stressor to the body is gravity. Dr. Pietrek presented The Seven Steps To Wellness:

- 1- Create Peace: Have balance – take better care of yourself – don't do things that you know that you can't or shouldn't. During stress, your auto immune system makes the brain tell a gland to produce a chemical to change your actions.
- 2- Energy Breathing: use good posture – stretch and hold for 30 seconds – do breathing exercise; breathe from diaphragm (use belly muscles instead of chest), breathe in through nose, hold, exhale through mouth. Do three times daily for more energy. It takes 21 days to break a bad habit.
- 3- Vital Waters: the amount of water needed is figured by taking body weight and divide in half – drink that many ounces per day. Water should be at body temperature. It should be pure to increase the oxygen binding ability. Some of the better waters are Arrowhead, PH Miracle, reverse osmosis, Pure system. Use microwave oven as little as possible as it heats by going after the water molecules in the food. Use aluminum or #7 or higher plastics for water bottle.
- 4- High Energy Nutrition: eat food that are more alive than dead – the wrong foods can cause muscle breakdown – consume enough protein. Suggest reading “The PH Miracle” by Dr. Young of Valley Center.
- 5- Dynamic Movement and Rest – exercise enough to be able to sleep.
- 6- Increase Fitness – do as much exercise as possible to keep fit. Find exercise that causes as little stress as possible.
- 7- Keep Your Spine Balanced – the upper cervical is the weakest link, prone to being injured. The atlas bone [between the skull and the first disk of the neck] is the most malformed bone

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in the body – make sure it is adjusted right. When considering upper cervical treatment, adjustment should be very gentle and only after a very careful evaluation. The better the body is aligned, the better the body will feel.

Keep your mind active. You can reduce Alzheimer's by 43%. Keep learning: the mind is a sponge. Life = Movement.

Pietrek Spinal Care is located in Rancho Bernardo at 16939 Bernardo Center Dr., Suite 215, San Diego CA 92128. Phone: (858)676-1218

We would like to thank Dr. Pietrek for his very informative presentation. Our December 8<sup>th</sup> meeting will be a general discussion and holiday party.

\_\_\_The next meeting:\_\_\_  
**December 8**

Regular meetings on the second Tuesday of even # months from 12:30 to 3:00 at Joslyn Senior Center, Dorothy Boeger building, 728 N Broadway, Escondido  
For more info. call Marilyn Loba (760) 745-2787 or email ppsnorthsd@cox.net

## **HEMET AREA POLIO SURVIVORS (HAPS)**

We had a normal meeting in September. In October we looked at a few of Salk's [www.poliotoday.org](http://www.poliotoday.org)'s videos and discussed whatever questions came up as a result. It was a good way to bring up topics.

One particularly interesting discussion came about in reaction to my statement: "PPS is not a problem if you manage it correctly. But you've got to manage it."

Betty responded, "I wish PPS weren't a problem."

My response: We have PPS. If we accept that fact and roll with the punches, it's an inconvenience. If we fight it, it becomes a major problem. That's where proper management comes in. We have to relax and deal with it intelligently -- in a stress free way. Being uptight and angry doubles its affect on us. Sure, we can be a little bit bugged about it now and then, even get a little depressed once in a while, but don't scream and yell and punch the walls. Just relax and say to yourself, "Now, what can I do to get through the next challenge?" and relax while you figure it out. Maybe you'll fall asleep while you're thinking about it :-)

\_\_\_Our next **HAPS** meetings are:\_\_\_

**November 17**  
**December**

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Regular Hemet meetings are at 11 AM to 1 PM on the third TUESDAY of every month at: Sun West, 1001 N. Lyon, Hemet. For more info call RickVDL (951) 926-5492 or Bunny Smith (951) 766-7118

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## Riverside PPS Group

Support Group Meeting – October 17, 2009

Pre-Existing Conditions. Sue said Kaiser informed them her husband's former employer had dropped Kaiser medical coverage, and the new insurer wouldn't be covering retirees. This puts Sue and Wes out of the loop. Here's the problem: to retain Kaiser, Sue has to reapply (22 pages of forms), even though she has been a Kaiser patient for at least 10 years, which now moves her into the category of "pre-existing conditions" – with a huge increase in premium.

If you are 50 years old, let's face it, you have some "pre-existing condition." Is there someone who does *not*? So why is it that American citizens tolerate this abusive loophole?

Scoliosis. Sue's respiratory doctor told her she has scoliosis. In all the years of seeing doctors, no one had ever pointed this out. Regina's doctor told her that her scoliosis has been building up over the years, getting worse. We went online and found that about 30% of polios develop scoliosis, with early age being a contributing factor. See <http://www.scoliosis.org/forum/archive/index.php/t-3009.html>

The Polio Crusade. Thanks to the miracle of DVD, actress Linda Hunt was our guest speaker! During lunch we watched "American Experience: The Polio Crusade," which aired on KCET February 2, 2009, a documentary about the polio epidemics and the rise of the March of Dimes, which FDR and Basil O'Connor created to raise "small contributions from the millions, rather than large contributions from the few" to fund research for a preventive vaccine.

"When the vaccine was pronounced safe for public use, factory whistles blew, schoolchildren cheered, parents wept." Headlines announced, "Polio Is Conquered." "The man saved the world from polio." A sign posted on a building read, "Dear Dr. Salk. Thank you for the polio vaccine. I am six years old."

The public vaccination program began April 12, 1955, but came to a halt for eight days, when a bad batch of the vaccine caused a small outbreak of new polio cases. Thousands of children given the new vaccine became sick, hundreds were permanently paralyzed, and a few even died.

All polio vaccine was taken off the market until the government determined the problem: Cutter Laboratories in Berkeley, California, "after a hasty and poorly staffed screening process," had released a batch of vaccine containing virulent, live polio virus.

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“The Salk vaccine was licensed at a time when we basically didn’t have vaccine regulation in this country. The government learned that having ten people oversee vaccines, and, frankly, doing it on a part-time basis, was not good enough. The Cutter incident was a painful lesson about the fact that we needed much better oversight. ... In the wake of the tragedy, manufacturing standards would be tightened and government regulation increased.” [Thus the Salk vaccine experience benefited Americans beyond polio.]

The program can be viewed online at: <http://www.pbs.org/wgbh/americanexperience/polio/>

Next: Christmas Party Potluck: Saturday, December 19, 11am – 1pm, at 3465 Ramona Dr, Riverside 92506. – RSVP by Dec.16. (951) 788-9310

\_\_\_The next Riverside PPSG meeting:\_\_\_

## December 19 Pot Luck Party

Riverside PPSG Meetings: third Saturday of even # months at 11 AM. - at the home of Bryan & Judy Mahoney, 3465 Ramona Drive, Riverside CA. Lunch provided.  
For more info. contact: Judy [PPSRiverside@aol.com](mailto:PPSRiverside@aol.com) (951)788-9310

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### Big Bear PPS Group

For information contact Marsha Hart at (909) 878-3092 or Email [healthwithhart@charter.net](mailto:healthwithhart@charter.net)

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### Polio Survivors Plus

No report filed

\_\_\_Next meetings:\_\_\_

Call for information

Meetings are held at Laguna Woods Village, 23822 Avenida Sevilla, Laguna Woods, CA  
For information and to RSVP for gate entrance permit, contact: Sue Lau at (714) 639-7497, or email [Maliebchen@aol.com](mailto:Maliebchen@aol.com); or Gene Minder [efminder1@cox.net](mailto:efminder1@cox.net) (949) 830-9347

### Letters

Letters11/09

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## Bag of Toys

[Editor's note: "Dead Flies" written by Judy Neiman-Sander was published in the July 2009 issue of the PPS Manager. The story brought back memories to many of us, but one response was particularly touching.

In her story, Mary Ann Hayes took us back to the hours and days she struggled to recover the strength to do a simple task without help from others. It was the moment that defined her polio personality.

That story was published in the following (September 2009) issue along with Judy's reaction to Mary Ann's story. The only problem was: because of a "copy and paste" error on my part, the main Bag of Toys story was left out of Mary Ann's letter. It is such a good story – one many of us can relate to – I have to make it right. So here it is.]

Rick,

Thank you so much for including such a thought-provoking letter as the story of a polio experience - "Dead Flies." I hadn't thought about those memories of my hospital stay till it jogged my memory.

...

The memory that stayed with me since I was nearly three and in the ward about 6 months, is not being able to reach a netted sack of toys hanging on the outside of our cribs. I could see all of the toys in it but unable to set up or use my legs, it was a real challenge to get it over the side of the crib.

If the nurses had time they would hand it to me, but most days I just lay there watching other kids playing with their toys. One day I decided to work the string that held it, up the side till I could nab it. Several times I would loose it as they slipped from my grasp, then on about the 10th try I found my tiny fingers able to slowly pull the string up clear to the top of my footboard.

I began to get excited about the prize that waited at the end of that string. The top of the sack appeared, and then it caught on something! I was determined not to lose this time.

Rolling over on my back I pulled for all I was worth and my reward came raining down over me and the bed like Christmas time in a bow! I had succeeded in getting something I really wanted by not giving up!

That was the beginning of my getting well again, my whole outlook turned to the positive in nature. No more sighing and feeling bad when others had their toys, now I could get my own.

I went on to become a nurse, and finally an X-Ray tech, even though it took me three times as long as anyone else to get through school, that is what I wanted so I was going to earn it. I didn't care if it took me 10 years, I would get there.

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I got to work for 16 years at a job I just loved before PPS hit in my 50s. Within a year I could no longer remember the X-Ray techniques I had done for years. What a jolt of reality!

Still in all, I did get to enjoy life a lot more because of the determination that all started with that little bag of joy that created a strong will and a positive outlook. In many ways I had a better life due to overcoming polio.

Thanks for the memories  
Sincerely Mary Ann Hayes

[The editor further notes: Judy responded that she too remembered the bag of toys and her struggle to regain strength and independence. If you have a story about how polio contributed to the person you are today, we'd love to hear it.]

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Hi Rick,

[Judy viewed the videos on [www.poliotoday.org](http://www.poliotoday.org), one of which showed your editor talking about PPS, using his bilevel ST, and playing the guitar while singing and playing the harmonica.]

Great Video of you !!! I guess I never really knew what you looked liked. And you certainly can play the guitar. Keep up the good work, and the newsletter.

Judy

[Learn about Judy Hoit at <http://www.myaccnow.info/pakkie/hoit.htm> And, see many more of your fellow PPS folks at [www.poliotoday.org](http://www.poliotoday.org)]

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Dear Rick,

Thank you for all the info you have given me for the past few years.

I want to direct this info to Elizabeth Gerdes. I am a 66 yr old with PPS. I started with the same visual symptoms [as Elizabeth. See PPS Manager 9/09 LETTERS column.]. Please visit your Ophthalmologist to have him assess if you do need cataract surgery. I was at the point of not being able to drive. I had my left eye operated on in Jan. 2009 in Redlands. I was an outpatient. I was given a mild sedative as you must be awake. This procedure took less than 30 min. for me. The next day, when my Dr. took off my patch, I was in awe of the bright colors and clear vision. I had my other eye done in March. I can drive at night now. I am so grateful for this surgery.

I started experiencing PTSD in the last three months. I wake up and I can't feel my legs, it takes a few seconds for me to realize it's not 1952.

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Josie Short

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Hi Rick -

I just watched your 4-minute video on the polio today web site. I need to make a video and submit it with my story.

My PPS has been taking me further down in the past year. I will be 58 this December and I can feel my legs and feet and sometimes my entire body weakening. Thank goodness I have my scooter, it gives me my freedom and Independence.

I have a lot of fatigue and sometimes trouble breathing is more of an effort than it used to be. I am seeing my MD Thursday to go over a bunch of issues. He is so interested in trying to help me and was honored I gave him a copy of Dr Bruno's book.

I need to look into having a test to see if I need a breathing machine for sleeping. Is there a test for this Rick? If so, I need to pursue it. You really woke me up in the video talking about protecting your organs, etc. Plus it is letting your body rest!

If you could give me some steps I need to take, I would appreciate it. It might be as easy as asking my doctor. I am with Sharp Rees Stealey Pacific Care HMO in San Diego.

Thank you Rick again for all you do for me and so many others.

Your friend,  
Paula

Hi Paula,

You are describing a probable PPS breathing problem. How much help you get depends on your doctor and health plan.

Right now there are three places that I know of offering the right tests and treatment in Southern California. Kaiser's Neuromuscular Respiratory Program, and two private services. Progressive Medical in Carlsbad does testing and supplies machines. Dr. Bradley Schnierow at the San Diego Sleep Clinic in La Jolla is a Neurologist and Psychiatrist who understands the problem and can prescribe proper machine through a reputable service. Both accept direct Medicare and private insurance. Sometimes an HMO will refer you to services outside of their group. It's worth asking.

Testing:

PPS breathing problems get 30% worse when we lay down, so sleep is always affected. Most

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doctors want to do an overnight sleep study, though it is not always necessary for the treatment of neuromuscular breathing deficiency. Medicare guidelines (which are the standards they all generally go by) say that you are eligible for a machine if you are below 50% breathing capacity. This can be proven by a simple in-office pulmonary function test or PFT.

The proper way to do a PFT is lying on your back. If they do it with you sitting up, the results will show that you are much better than the true test of how you breathe laying down trying to sleep. PFT tests include how much air you can hold, how fast you can push it out, how hard you can blow, and something else -- I forget.

It should be noted that when we (PPS folks) take these tests we often try too hard and go home sore from the effort. If you take the test, be honest with yourself and don't try too hard. When they say blow, blow, blow, more, more ... Stop before it hurts. Don't do anything that hurts or might cause fatigue. You know what I mean.

The Machine:

The proper machine is a bilevel ST or the new ST automatic. It supports your breathing muscles just as a scooter or leg braces support your legs. (The ResMed VPAP III ST works perfectly for me.) A CPAP or bilevel S won't do. Supplemental oxygen is bad unless you have a serious lung disease of some sort. (PPS neuromuscular hypoventilation is not a lung disease; it's muscle weakness affecting blood gas levels.)

Hope this helps. Let me know if there's anything else I can do.

Rick V, PPS Manager

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**THANKS**

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

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# PPS MANAGER

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