

**FROM THE EDITOR**

Hi Fellow PPS Managers.

An unusually high percentage of polio survivors went on to have successful careers, and many became famous. President Franklin D. Roosevelt, actors Lionel Barrymore, Donald Southerland, Mia Farrow, and Alan Alda, singers Neil Young, Dinah Shore, and Joni Mitchell just to name a few. Then, of course, there's violinist Itzhak Perlman. If you haven't seen him perform, you're in for a treat. He's a good sport and an amazingly talented man.

In this issue you'll find a short profile on jazz musician David Sanborn. I just happened to catch him on TV talking about his childhood polio experience.

In the last issue we covered the Medicare change that affected those of us with nighttime ventilators. In this issue is the continuing effort to understand polio related breathing problems and the solution: the bilevel ventilator.

Have fun....Rick VDL

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**By R.E. Van Der Linden**

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Letters and much more...



**Doris Starret**

# PPS MANAGER

## Victorville PPS Group Loses Matriarch

Doris turned ninety on January 22nd and passed away on March 19th. She was stricken with Polio in her early twenties and spent much time at Warm Springs. She met her husband Ed there as he had Polio also. He and Doris were active in the Post Polio Group here in the High Desert and Doris was responsible for running the group even after Ed died about ten years ago. She was our Matriarch and would get speakers for our meetings and keeping them going. The best speaker was Doris as she and Ed had an active life and many different interests.

A writer, Doris had some of her life stories published in magazines.

The group gave Doris a plaque last year in appreciation of her leadership and friendship. She will be sadly missed by all.

Bill Harold.

## Getting to Know Your Bilevel ST

By R.E. Van Der Linden

A few years ago, very few PPS people with breathing problems were being correctly diagnosed and treated. Things are improving rapidly. Thanks to the computer age, we have more and better information, and breathing machines are better than ever. According to predictions, next year they will even be able to adjust themselves to suit our needs. For the time being, however, most of us will have to deal with current technology. Today's bilevel ST machines still have to be set to suit the individual's complex needs.

In this article, I'll discuss what you can do to improve the effectiveness of your machine. If you don't have one but have considered even the most remote possibility of some day needing breathing assistance, you might want to hang on to this newsletter for future reference.

### **Sleep disordered breathing (SDB) can be very complex**

If you've had any pulmonary function tests (PFTs) or an overnight sleep study, you probably heard or read the resulting acronyms and numbers. There's no point in detailing them here, but what the numbers boil down to are the technician's best guess at how well your lungs are working. They measure not only your lungs' ability to transfer gasses, but also the strength of your breathing muscles. The numbers are helpful in presenting your case to your insurance company HMO or Medicare, but not very accurate in determining the necessary settings once you actually get a machine.

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## **Machines are complicated**

Manufacturers are constantly upgrading their machines to provide the best possible service to the widest range of patients. Unfortunately, along with more complex technology comes the confusion that often makes that very technology difficult to understand.

There aren't enough respiratory specialists in this country who are expert in providing long-term care for all the people with neuromuscular conditions. The training is quite specific, varies greatly among a half-dozen disorders, and can be extremely challenging. Fitting the machine and interface to the individual requires additional training, more follow-up visits, and special equipment to confirm proper results. Because of the high cost of training, and the U.S. health care situation (see "Medicare Changes" PPS Manager March 2007) it's unlikely we'll see an improvement any time soon.

## **Your doctor and respiratory therapist are very busy people.**

With multiple types and varying degrees of conditions that can contribute to SDB, there are innumerable combinations, and therefore the solution is not calculable or predictable by test results.

Few respiratory care specialists know how to handle neuromuscular problems. There are standard procedures for other respiratory conditions, but we offer a time consuming challenge. As usual, we have to look out for ourselves. The best thing we can do is to recognize our problems, identify solutions, and provide our caregivers with intelligent advice.

My objective in doing this work is to promote knowledge, understanding, tolerance, and communication between doctor and patient. Most doctors, however, speak a different language from their patients. The language of numbers, statistics, and complex concepts doesn't easily translate to how a breathing-compromised person feels when assisted by a machine. We have to look at breathing from the individual's point of view.

I've found that if you have a confident knowledge of yourself and your machine, you can win your doctor's respect, save office time, and improve the quality of your life. No one can do it better than you.

## **Understanding NPPV** (Noninvasive Positive Pressure Ventilation)

To understand positive pressure ventilation, one needs to first understand what happens when a person takes a breath. A normal breath is termed Negative Pressure Ventilation. That's because a negative pressure, or vacuum, is created by simultaneously using the muscles of the upper body, diaphragm, and abdomen to expand the lungs.

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## Step-by-step analysis of a breath:

- 1) Sensors detect too much carbon dioxide (CO<sub>2</sub>) or a need for more oxygen (O<sub>2</sub>) and send a signal to the breathing muscles. When you're awake, a little chip (to use a computer term) in the bulb-shaped brain stem (bulb-shaped, bulbar, ring a bell?) takes care of the manual operation. A chip next door takes over during sleep.
- 2) Inspiration (breathing in): The muscles respond by pulling at the lungs from the outside, forcing them to expand, creating a vacuum. (Imagine an un-inflated balloon. If you could pull it from the bottom, top, and all sides at the same time, it would expand while pulling air in through the stem.) Air rushes in through the mouth and/or nose.
- 3) Gas exchange: O<sub>2</sub> is transferred to the blood while CO<sub>2</sub> is removed from the blood. When enough air has entered the lungs, the "in" breath is terminated. How much air goes in normally depends on need as determined by the brain.
- 4) Expiration (breathing out): Breathing muscles relax and the natural elasticity of the lungs (again, think balloon) forces the air out.

## Breathing during Sleep:

It's important for a polio survivor (and people with other neuromuscular disorders) to understand that things change when we go to sleep. When we lie down, weak muscles have to work harder to overcome the weight of our intestines bearing down on the diaphragm, restricting proper ventilation by 30% or more.

Breathing weakness and sleep apnea often go hand-in-hand. Sleep-disordered breathing is the inability to sleep properly due to one or more of the following:

- 1) OSA (Obstructive Sleep Apnea) occurs when, during sleep, the airway collapses and air can't get through. Being overweight is the most common cause, but weak throat muscles can also be a factor.
- 2) COPD (Chronic Obstructive Pulmonary Disorder) Diseases such as emphysema and chronic bronchitis have a negative effect on normal airflow making it difficult for the lungs to do their job.
- 3) CHS (Chronic Hypoventilation Syndrome) is a condition in which the breathing muscles and/or the signals between the brain and the breathing muscles become too weak to fully inflate the lungs and therefore consistently maintain the proper balance of blood gases. It often comes on slowly over a period of years.
- 4) CSA (Central Sleep Apnea) is a malfunction of the chip in the brain stem that takes over breathing responsibility during sleep. The brain just "forgets" to send the "take a breath" signal. It can be a problem for polio survivors, particularly if you were diagnosed with bulbar polio.

## Treating Breathing Disorders

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There are two methods of treating sleep apnea and/or more serious breathing disorders: Negative Pressure Ventilation, and Positive Pressure Ventilation.

## **Negative Pressure Ventilation (NPV) – not to be confused with NPPV.**

Breathing is supplemented by expanding the lungs using a vacuum surrounding the body. A common example is the iron lung. Although the iron lung saved many lives during the polio epidemics, these days it's not a practical approach because of the cost and size of the device.

Smaller versions of NPV, such as the Porta-Lung, fit around the chest and connect to a vacuum pump.

## **Positive Pressure Ventilation (PPV)**

Noninvasive Positive Pressure Ventilation (NPPV) inflates the lungs by blowing air into the lungs through a mask or similar device connected by a hose to a small machine. Invasive Positive Pressure Ventilation (IPPV) delivers air through a tracheostomy, an opening surgically created in the windpipe.

PPV is delivered in two modes: bi-level (S), and bi-level (ST).

- 1) Bilevel (S): Bilevel refers to two pressure settings: one for inspiratory pressure (IPAP) and one for expiratory pressure (EPAP). It switches to high pressure for inhaling and low pressure for exhaling. The "S" stands for spontaneous. The change from high to low and back again is triggered by the user's input. The doctor prescribes the pressure settings based on patient needs.
- 2) Bilevel (ST): The same as bilevel S except for the "T" which stands for Timed. In addition to controlling inhale pressure and exhale pressure, this machine, also referred to as a bilevel with a backup rate, can be set to start a breath when the user fails to. The machine is set for a minimum number of breaths per minute. An S/T machine is necessary for the treatment of CSA and CHS. Generally, this is the treatment for polio survivors and some other neuromuscular disorders experiencing sleep-disordered breathing.

[Note: Constant Positive Airway Pressure (CPAP) is the usual treatment for common obstructive apnea only. CPAP is not considered a ventilator and is not effective treatment for mixed apneas.]

## **Your Settings:**

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### Definition of Terms

The simple bilevel “S” EPAP treats OSA by while IPAP treats CHS by Setting a bilevel S Often, the initial settings results, standards, charts, following suggestions are experience and are for the your caregiver.

**Low-pressure** – EPAP – expiration. Start with the increase it over time until mistake is to start out at cause claustrophobia or your head out the window Remember how it took take days or weeks to Observations by your bed machine’s computer your breathing has been without you knowing it.

**High-pressure** – IPAP – muscles during point is flat on your back, low setting – maybe 6 or feel suffocated. Try more

feeling. Then, relax and let the pressure do its job. You should feel the relief of getting enough air without painful or fatiguing effort. As you become more relaxed, observe the rise and fall of your abdomen and chest. They should rise evenly. (I have useless chest muscles. While lying on my back, without breathing support, when I breathe in my belly rises and my chest collapses. At IPAP 12.6 they rise and fall together.)

**IPAP** - Inspiratory Positive Airway Pressure.

**EPAP** - Expiratory Positive Airway Pressure.

**IPAP min.** - Minimum length of time machine remains at IPAP pressure. Measured in tenths of a second from beginning of the “in” breath.

**IPAP max.** - Maximum time allowed for inspiration. Measured in tenths of a second from the beginning of “in” breath.

**Rise Time (RT)** - The length of time it takes to shift from low to high pressure, measured in milliseconds.

**BPM** - Minimum breaths per minute allowed.

treats two causes of SDB. preventing airway collapse supporting weak muscles. is fairly straightforward. are made based on test and guesswork. The based on my personal purpose of discussion with

keeps the airway open during lowest possible setting, and snoring ceases. A common too high a pressure. This can worse. (Did you ever stick of a fast moving car? your breath away?) It could settle on the right number. mate, and downloads of the record (if available) will tell if stopping during the night

assists the weak breathing inspiration. A good starting relaxed. Again, start out at a 8. If it’s not enough you’ll until you no longer get that

### ST Machines are more complicated

In the case of the “ST” machine (commonly called by their trade names of BiPAP® or VPAP®), things start getting complicated because you’re adding the “timed” or back-up rate feature. Since it is able to tell you when to breathe, it must be able to take over every step of taking a breath including how deeply you breathe. Therefore, there are added settings, the functions of which kind of overlap one another. Let’s examine the settings of a VPAP® III ST machine, the unit I use.

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## HOW SPONTANEOUS AND TIMED MODES WORK:

### Starting a Breath:

An assisted breath is initiated spontaneously as you try to take a breath. The machine senses the pressure change and switches to IPAP, thereby helping to push air into the lungs. If you fail to start a breath soon enough, the Timed feature takes over and starts it for you. *The change from IPAP to EPAP would be abrupt if not for the RT setting which smoothes out the transition.*

One might compare rise time to letting out the clutch on a car with a manual shift. A long rise time is comparable to slipping the clutch, and a short rise time is like popping the clutch. Using this analogy, you may be able to visualize the importance of setting the rise time to match the difference between EPAP and IPAP just as you would the letting out of the clutch relative to the RPM of the engine.

### Continuing the in-breath:

When you think you have taken a deep enough breath and you stop trying to breathe in, the machine senses the pressure change and switches to EPAP. But, if you should get tired of trying to continue the in-breath, you may stop before you get enough air. In this case, the machine forces you to continue breathing in until IPAP min. is reached. Therefore, IPAP min. is an important part of your backup system, but may not be working for you all the time.

### Finishing the in-breath:

When you either get past IPAP min and stop trying to breath in, or you reach IPAP max, the machine switches to the lower EPAP pressure and the natural elasticity of your lungs begin pushing the air out.

### The out-breath:

Air is expelled from your lungs until either you try to take another breath, or the BPM limit is reached and the machine starts the next breath.

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Coming in the July issue of  
The PPS Manager Newsletter:

**One Breath – A breath taken while connected to the machine is carefully analyzed. How does the bilevel ST assist you every step of the way? What can be done to improve results?**  
**Medicare Codes – Make it easy for your doctor to help you order supplies.**

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Thanks to Judith Fischer, International Ventilator Users Network (IVUN) [www.post-polio.org/ivun](http://www.post-polio.org/ivun), for her editing expertise and excellent advice on this article, as well as the smiling spirit of Dr. Tony Oppenheimer. - Rick

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# PPS MANAGER

## UPDATE

### **Kaiser/San Diego's Neuromuscular Respiratory Program**

By Gladys Swensrud

For over a year, Kaiser/San Diego has been in the process of piloting a neuromuscular respiratory program totally unique to the Kaiser healthcare system. The trial period for San Diego included patients with respiratory weakness related to the following diseases: Post Polio Syndrome, Amyotrophic Lateral Sclerosis, Muscular Dystrophy, and Multiple Sclerosis. During this initial assessment phase, the program opened to also include patients with other neurologic diseases found to have a respiratory component, such as Myasthenia Gravis.

With meticulous planning, documentation and attention to detail, Kaiser/San Diego followed their prescribed treatment algorithm as each new patient was identified, tested and placed on a bi-level treatment protocol specific to their individual needs. And within one short year, proof of this pilot's success has been the complete integration of Kaiser/San Diego's Neuromuscular Respiratory Program into the departments of neurology and pulmonary care.

If you are a San Diego Kaiser, PPS patient with respiratory concerns, please contact your pulmonary care physician or neurologist for more information about this valuable program. If you are not yet linked to neurology or pulmonary care, you may call your primary care physician today for a referral to Neurology's Sleep Clinic to initiate the testing process.

For other Kaiser patients throughout the state and nation, feel free to contact me for information about our program at the following email address: [swensrud@pacbell.net](mailto:swensrud@pacbell.net) and/or telephone number: 858-271-9288. I would be happy to share how our program evolved and how you can request similar services in your local area.

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Polio Survivor Profile

## **David Sanborn**

By Rick Van Der Linden

One Saturday afternoon I got up from a nap, turned on the TV, and stumbled upon Smooth Jazz TV on NBC. Host Cameron Smith was interviewing Grammy Award winning saxophonist David Sanborn.

When asked what got him started playing the sax, David answered that he'd had polio [in 1948] at age three. He was paralyzed and spent some time in the iron lung. During rehabilitation, his doctor prescribed a wind instrument as physical therapy. He chose the sax because it was prevalent in much of the popular music he'd been hearing on the radio. He mentioned the song Tequila as one of his early favorites.

He went on to play with the Butterfield Blues Band for five years, performed at Woodstock, and played with many well-known Blues, Rock, and Jazz artists.

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Still recording and going strong, you can see him in Las Vegas May 4 and 5.  
Visit [www.davidsanborn.com](http://www.davidsanborn.com)

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## MEETING REPORTS

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### San Diego Post-Polio Support Group

For those who don't quite grasp the importance of networking within the polio community, the March San Diego PPS meeting would have been the perfect opportunity to see its advantages at work. We were fortunate to have two guest speakers address our members:

- Dr. Marty Becerril, the Patient Resource Program Coordinator for UCSD's School of Medicine's, Professional Development Center, **and**
- Sue Peeters, board member of the San Francisco Bay Area Polio Survivors

Dr. Becerril shared information on UCSD's *Help Train Your Future Doctor* Program, in which both Rick Kneeshaw and Gladys Swensrud have participated. She detailed what patients are able to do to help medical students learn about various health concerns. Rick and Gladys shared their experiences to reveal problems associated with PPS to young doctors in training; they hoped that by their efforts, new physicians exposed to their symptoms would at some point in the future consider a PPS diagnosis for someone exhibiting our neurologic symptoms.

Dr. Becerril, also a licensed chiropractor, explained the significance of her profession in terms of neurologic disease, and she spoke about some of the possible uses of alternative medicine. She quite easily straddles the line between chiropractic care and her position with UCSD. We were all very impressed with her presentation. And since several of the members from Escondido's PPS group were present, they used this opportunity to invite Dr. Becerril to speak at a future meeting as well. This was an example of PPS networking at its best!

Sue Peeters was visiting from San Francisco for a brace adjustment appointment with Marmaduke Loke, the owner of Dynamic Bracing Solutions, so she was delighted to have this opportunity to join us this month as well. She detailed some of the projects on which the San Francisco Bay Area Polio Group is working. Sue also shared her own experiences with the use of chiropractic care, and she supported Dr. Becerril's comments about the value it has for people searching for different way to look at health related issues.

Sue's connection to San Diego means that she returned to San Francisco and shared her experience. Once again, networking created an essential connection within our PPS circle.

Gladys Swensrud

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The speaker at our May 12th meeting will be Michele McLain, American Institute of Architects, who will speak on "Architectural Modifications for the Disabled."

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Michelle is a well-known and highly recommended and respected architect in San Diego County who has had previous experience modifying residences for person who are disabled.

At some point each of us will need to make some changes to our homes to make mobility and access easier. Now is the time to learn what might be possible, and how to select an experienced architect and contractor who can get the modifications done correctly at minimum cost.

Rick Kneeshaw

\_\_\_The next La Jolla meeting:\_\_\_

**May 12**

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](mailto:piecon@mindspring.com)

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

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## COACHELLA VALLEY POST-POLIO SUPPORT GROUP

Coachella Valley Post-Polio Support Group

Our March meeting was well attended thanks to the extra efforts of our phone committee gal, Rita Lack and the snail mail, e-mail guy Joe Camaya. Group support comes in a number of ways: from the mundane planning and preparations, publicity when you can find or make it, and the joyful sharing, learning and friendship of the support group members and guest.

At this meeting we had Red Cross pamphlets on "Preparing for a disaster for those with Disabilities and Special Needs". We discussed the types of natural disasters that we might experience here in the Valley and the need to be self-sufficient for perhaps more than 72-hours.

Joe Camaya and Barbara Hall collaborated on a bright yellow tri-fold flyer. "Polio?" headlined the three columns of information on polio, post polio syndrome that included information on our CVPPS meetings. Members are advised to take the flyer to various senior and community centers, waiting rooms at our doctors' offices and assorted retail stores. Keeping the word out in the public and continuing to grow our group.

For our April meeting, Joe Camaya double checked with our speaker from Community Access Center (CAC) and then contacted our 60 members to remind them to attend. Our Miss Rita Lack has already left the Valley for summer home in the Big Bear lake area.

Andi, our speaker from the Indio CAC, provided us with good information. The CAC has independent living services and programs in place and can be our business and personal advocate; they have grant programs for various needs and services too... There are 27

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Independent Living Centers in CA and CAC is State funded agency. If you call 211 it is our link to a 411 like service, just ask or explain your problem and the 211 operator will find the information or agency that can help you. CAC has a web site [www.ilcac.org](http://www.ilcac.org) or the Riverside office number is 1-951-274-0358 and they can help you find the CAC in the county you live in. The CAC has been providing services to people with disabilities in Riverside County since 1995.

**Summer break –  
*No meetings for July, August or September***

Barbara Hall

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

**May 11**

**June 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](mailto:stan-n-ollie@msn.com), (760) 365-3587 or Barbara Hall [whall233@aol.com](mailto:whall233@aol.com), (760) 329-9593

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## Escondido Post Polio Group

\_\_\_\_\_ **The next meeting:** \_\_\_\_\_

**June 14**

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](mailto:postpolio@cox.net)

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## HEMET AREA POLIO SURVIVORS

Hi Everybody.

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There were only a few of us at the March meeting. Bunny was unable to make her usual phone calls due to problems at home. I guess we need reminding now and then. It was a nice meeting anyhow. I played my guitar and we talked about normal stuff.

The April meeting was a little busier. The main subject was the Life Alert-type systems. You know, "I've fallen down and I can't get up" devices. It's a great idea if you live alone or are left alone for more than a few hours at a time. Turns out there are a few different manufacturers, various technical levels and options, and Medical assistance. I'll try to do a write-up for a future article. Thanks to Bunny for the information.

Life-Alert 800-360-0329

Lifeline 800-959-6989

HealthWatch 800-226-8100

Bunny and Betty are planning a party for Mid-July, so be prepared for another good time. Pot-luck and live music (In the works: a whole band playing 30's and 40's jazz/pop favorites.) Watch for particulars in the July issue.

Have fun ... Rick

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

**May 16**

**June 20**

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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

April 21, 2007

Eight of us gathered in person, plus two by phone, for our April meeting. We discussed the need to reduce stress – it is very important to have time to ourselves, especially if we are burdened with caring for other people in our home: grandchildren, aging parents.

Regina phoned (on her way to work). We all had a chance to talk with her. Last time she was interested in the discussion on swallowing difficulties. She has been following the guidelines in Dr. Bruno's *Polio Paradox* – small quantities, lots of meals. Certain foods are harder to swallow than others.

Focus Topic: Pauline had prepared copies of articles from three PPS publications, which she took last time to review. Article from Polio Health, reprinted by one of the other support groups (not available) was sufficient to fuel our discussion.

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**Assess Your Environment.** Get rid of clutter, clear space, improve lighting, use nightlights, no throw rugs or other items to trip over.

Riser for Toilet Seat – little by little we realize we need some of these things. Shower seats, too.

**Assess yourself** – do you wear shoes? Yolanda finds she has to wear shoes; Judy and shoes don't get along. Betty W wears a special innersole, which helps and reduces discomfort. Never goes barefoot. Years ago when she worked at Boeing, she wore “space” shoes, \$700 price tag at the time. They looked funny, and when children would stare, she would say, “Do you know what these shoes are? They are *space shoes!*” Ohhhhhhh! Their eyes would widen with delight!

Betty M mentioned attitude is important. If you start the day complaining, it guides the whole day. If you begin with cheery disposition, the day is much better. When taking medications, rather than read the possible side effects, she sets the list aside for reference in case she has any reactions. She knows of people who always get side effects after reading the list – the power of suggestion at work?

**Labor-saver:** robotic vacuum cleaner – Roomba – Both Betty M and Lorraine and have one. Lorraine says, “I never vacuum any more!” While she was laid up with surgery, she took the plunge.

**Walking.** Caution – if walking (or any exercise) causes pain, adjust and reduce the strain. Yolanda decided to walk more, and went for a walk without leg pain, but it drained her so much she is still having problems with breathing, stemming from that walking episode. “I hadn't realized my decreased lung capacity would be affected by the walking.”

Betty M took 5 years to recover from surgery. She began to get back into walking gradually – half a block at first, and increasing slowly.

**Talking** –Pauline and Yolanda observed that talking can be exhausting. Pauline suggested weakness in the diaphragm can be the source of problems exhaling.

**Posture and osteoporosis.** Betty M said heavy purse on the shoulder pulls you forward, slumping your shoulders and chin down.

Judy asked if others found it draining at times to hold your head up. Yes! Most of my reports are prepared on laptop, in bed, legs stretched out, head and back supported by pillows.

**Be as active as you can be.** Lorraine goes to Silver Sneakers at the Y – they sit on the chair and exercise. She illustrated the head rolling. Kaiser charges as much as \$30 a session, but the Y is free, and you may even get a Silver Sneakers T-shirt! She goes 3 times a week.

**Not everything is polio.** We often know “intuitively” when our fatigue or pain is polio-related, but not always. It's good not to assume it's polio, test for other things, like sugar level imbalance.

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Dr. Van Patten was recommended for polios (Kaiser), but Betty had cautioned you still have to be in charge. “You have to decide what path you choose. I tend toward ‘not polio-related.’ Things like joint pain – is it a polio pain or from rheumatoid arthritis?”

**Seek Expertise & Education.** Most of us do not seek healthcare professionals. Find ones who can assist you with appropriate exercises, orthotics, etc.

**Protect Yourself From Falling** – Consider having a personal alarm system, such as Lifeline (800-380-3111). Also, hip protectors have been shown to lessen the chance of damage to the hip if you do fall – garment worn under clothing providing extra padding in hip area to protect if you fall. ((Posey Hipster, Protecta Hip).

Having the article to focus our discussion and getting everyone’s experience on these issues helped to make this a very profitable meeting.

Judy Mahoney

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

**June 16**

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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](mailto:PPSRiverside@aol.com) (951)788-9310 or Betty McFarland (951)243-6991  
[bbooplink@aol.com](mailto:bbooplink@aol.com)

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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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## **High Desert PPS Group**

The passing of Doris Starret is the Victorville group’s focus these days, as evidenced by the front-page story and letters received.

Rick VDL

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

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**May 8**  
**June 12**

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Regular meetings: Second Tuesday of every month. Location varies.  
For information contact Vi at (760) 949-6775, or e-mail BillHerold@aol.com

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## Polio Survivors Plus

Polio Survivors Plus  
Orange County, CA

The second program in PSP's "Healthy Living" series will focus on the "**Newest PPS Findings and Hints For Handling Simultaneous Health Challenges**" this May 23, 2007 at 1:30 p.m. in Clubhouse 3 of Laguna Woods Village in Laguna Woods, CA.

With reservations, all are invited to attend this program that will feature **Physiatrist Sophia Chun, MD**, Chief of the Polio Clinic at Rancho Los Amigos National Rehabilitation Center.

If you would like to attend this meeting, but are unable to do so, feel free to send your questions prior to May 19th and they'll be presented on your behalf for an answer or feedback to your newest PPS concerns.

The last meeting of PSP featured **Attorney Nancy Rimsha** who addressed "**Managing Your Health Care and Medical Appeals.**" She advised everyone to consult their annually mailed benefits books BEFORE health care needs arise and to KEEP this valuable information for reference during those times when you believe you need to navigate through the challenges of your health care system. Each insurance provider has different procedures and if one needs help, HICAP representatives or specialists through the Health Consumer Action Network are available to help polio survivors.

At the same meeting, a special drawing took place and Laura M. won the luxurious white terry cloth robe and slippers. Polio survivors who find drying off after a bath or shower difficult, can don a terry cloth robe instead of toweling off to preserve one's physical energy.

Meeting attendees concluded the gathering by taking home the floral spring bouquets that were created as table centerpieces by Toshi I. and Barbara S. Special thanks also go to Barbara M., Sharon K. and Gladys B. who topped the green decked tables filled with sweets, fruits and beverages.

In April, Polio Survivors Plus, was applauded as a Gold Sponsor of the International Post Polio Conference in Miami, FL. In addition to providing a presentation on caregiving, PSP brought in a representative from the U.S. Department of Homeland Security to provide avenues for people with disabilities to become involved in their local communities through a program,

# PPS MANAGER

called CERT. The presentation concluded with the announcement that measures are being taken at this time to develop national disaster preparedness plans within the next 18 months for people who have disabilities. Conference attendees asked questions and provided input for this national plan's development.

Lastly, Polio Survivors Plus will be represented at the upcoming:

- State of California's Fourth Annual Consumer Advocacy Symposium, "Navigating the New Vision of Health Care," in Burbank, CA;
- The First "Emergency and Disaster Preparedness Program For Special Populations," held in two locations of Orange County; and
- "Transportation Awareness Day" that will feature the newest developments in fixed route and paratransit services by the Orange County Transportation Authority. New vans, taxi services, etc. have been added to the fleet, while door-to-door service changes will be put into effect this coming July 1, 2007.

For more information, contact:  
Sue Lau

Next meeting: \_\_\_\_\_

**May 23**

**June 27**

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 for gate entrance permit, contact: Sue Lau at (714) 639-7497 or e-mail Maliebchen@aol.com

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## LETTERS

Dear Rick,

The Post Polio Group of Victorville by resolution individually supports your PPS Manager newsletter in spirit in memory of the late Doris Starret.

She was the leader of our group and kept it functioning on a monthly basis.

We commend her in memory for her actions and support for our group.

Yours Truly,  
Nancy Snively.

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Dear Rick,

In the January issue, a visit to a kitchen store in San Diego was mentioned [by Gladys Swensrud] regarding products to make life easier for those with PPS (myself included).

We own a store in the Desert [called] Yes, I Can. We have many kitchen gadgets. The stores are set up as rooms in a house. Each room has products to make life easier throughout the day.

If anyone would like to visit , and want personal help from me, my cell is (760) 250-8923

We now have about 3,500 products. For our store brochure and an “in-home safety check” brochure, call (800) 366-4226

Lois Jackman

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Dear Rick,

Enjoyed the latest “PPS Manager” – as always!

Your article on pneumonia was undoubtedly of interest to all of us with breathing difficulties. Also, anyone with problems in swallowing: Are you aware of the “Cough Assist” machine? Technically its something called an In-Exsufflator, and is for use by those with weak coughs. Essentially what it does is cough for you by gradually applying a positive pressure to the airway, then rapidly shifting to a negative pressure. It’s made by the Emerson Co. (22 Cottage Park Ave., Cambridge, MA 02140-1691) – e-mail address is: info@jhemerson.com and web is www.coughassist.com. I have one and the great thing is its covered by Medicare. Luckily I haven’t had to use it for aspiration yet, but I think having one is a wise precaution because when a lung problem is building up to pneumonia there’s no time to be going through the lengthy: get a Dr’s appt. / maybe have to familiarize him or her about the machine (they aren’t apparently well-known if my experience is typical) / battle the insurance company / then maybe have to wait for the equipment company to get one in stock. I think these things could be real lifesavers.

Have you heard of anyone, especially among those of us who use bilevels, having trouble waking up with horrendously (and painful) dry mouths? I use a humidifier connected to my bipap (which ended the dry nose problem), but it doesn’t help as I use a face mask that covers only my nose.

We really need to get more public awareness of PPS. I noticed once again, when there was a recent wave of articles on stem-cell research on TV and the newspapers that PPS was never mentioned as a condition of relevance. There is always mention of ALS, MS, Parkinson’s, spinal cord injuries, etc., and never PPS. Yet, all tolled, there are probably more of us, and certainly more famous victims of childhood polio, who might be marshaled to make public service announcements for TV, etc. Of course, getting something like that organized would take more energy than anyone with PPS has!

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Keep up the good work, and watch out for all the winter germs.

Carolyn Moyer

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## THANKS

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

Special thanks to Sandy Van Der Linden for stapling and attaching the labels. Ann Howell for your graphics expertise. Thanks to Joe Camaya, Robert & Lois Jackman, Carolyn Moyer, Sally Seelman, Elesa Trisler, Claire Chessman, Betty Cameron, Richard Starret, Mary Larson, Betty Mabors, and Nancy Snively. Your contributions keep this thing alive.

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**Information contained in this newsletter is not intended to be a substitute for professional medical care.**