



# Newsletter

**MEETINGS SITE**  
**First Saturday of Month**



**11:00 AM**

**3520 Auburn Boulevard**  
**Sacramento, CA 95821**  
**916-481-1357**  
**At I 80 & Watt Avenue**

**OFFICERS**

**President:** Leslie D. Smith  
**V. President:** Wil Nuckolls  
**Treasurer:** Jim Munro  
**Secretary:** June Basco  
**Bd. Member:** Carolyne Reed

**SPPSG**  
**PO BOX 3043**  
**Citrus Heights, CA 95611**

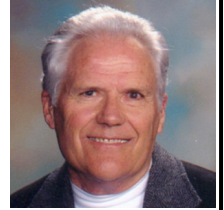
**Email:**  
**leslie@sacramentopolio**  
**survivors.com**

**Website:**  
**www.poliosurvivors.com**

**MORE INFO?**  
Leslie D. Smith  
916.725.4077  
1-800-215-0318

**FROM THE PRESIDENT...*Leslie D. Smith***

I trust all you members of SPPSG had a wonderful Thanksgiving with family and friends. Truly every day we are alive we can be thankful and to have a special day set aside to remember all our blessing is truly wonderful.



The first monthly meeting at our new location of Denny's Restaurant went well. I received complements from individuals as they did not have to prepare pot luck dishes for the meeting or toil to set up and clean up after the meeting. There was some confusion about where to exit I 80 at Watt Avenue to arrive at Denny's on Auburn Boulevard. You that come from Auburn or Roseville direction need to stay in the right hand lanes of Interstate 80 and go on Business 80 (Capital City Freeway) before exiting on Watt Avenue. For the January 7, 2012 meeting I will again go over the directions in the Newsletter to arrive at the Auburn Boulevard Denny's. Plan on being there!

On the back cover (page 10) of this Newsletter you can still participate in our Annual Christmas Luncheon, Saturday, December 3, 2011. Make the phone call to Jim Munro at 916-487-7168 or Leslie Smith at 916-725-4077 and we will reserve a place for you at the Back Forty. Bring a raffle prize for our Raffle.

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**LOCAL POST POLIO  
PHYSICIANS**

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Dr. TeSelle, M.D.  
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4860 “Y” Street  
Suite 1700  
Sacramento, Ca. 95817-2307  
U. C. Davis Med Center

.....  
Doctor’s listed here are for information only. Please continue to see your own primary care physician (PCP) for polio and other health issues.

You will notice that this Newsletter is two pages longer. First, the article from the PPS Manager, Fall 2011 issue pages 4, 5 and 6 was longer than some articles published in past newsletter issues and I needed extra space. Secondly, Post-Polio Health International (PHI) emails communiqués each month and I had missed publishing one, therefore to be up to date you will find both on pages 7, 8 and 9 two short communiqués. In all these articles you will find some very helpful information for polio survivors. Pleasant reading!

I extend to you the blessing and joy at this season of the year to all of you. Merry Christmas!

*Leslie*



**MISSION STATEMENT**

**Our Goal is to help post-polio survivors;**

**To be informed of the changes that are occurring after thirty plus years of the onset;**

**By providing information from the medical community;**

**And the shared experience of one another.**



**BIRTHDAYS**

Dave Coy	Dec. 2	George Russell	Dec. 29
Ray Menebroker	Dec. 11	Barbara Driggs	Dec. 30
Richard Bleau	Dec. 15	Leslie Smith	Dec. 30
George Scharmacher	Dec. 15		

*Ideas and suggestions printed within this newsletter are those of the individual writers and should not be considered “Medical Opinions or Advice.” Please consult your primary physician for your health issues. SPPSG Editor*

## SACRAMENTO POST POLIO SUPPORT GROUP:

Meets the **first** Saturday of the month at **11:00 am** at **Denny's Restaurant**, 3520 Auburn Boulevard (At Business 80 and Watt Ave.) Sacramento, CA

**December 3, 2011:** Christmas Luncheon and Raffle. 11:00 am. Back Forty Texas BBQ, 1201 Orlando Avenue, Roseville, CA 95661. Phone 916-726-4040

**January 7, 2012:** Speaker Michael Beman of Safe Inheritance Corp.

**February 4, 2012:** Speaker Dr. Peggy Portwood. PPS Physician.

**March 3, 2012:** Speaker Ken and Jenifer Dawid of Security Network.

**April 7, 2012:** Submit your ideas for this meeting.

## SIERRA HILLS [AUBURN] PPS GROUP:

Meets the **second** Saturday of each month at **9:00 am** at **Denny's Restaurant**, 2400 Grass Valley Highway (Highway 49) Auburn, CA.

**December 3, 2011:** Christmas Luncheon and Raffle. Both the Sacramento and the Auburn groups will meet for the luncheon. See

above announcement for SPPSG.

**January 14, 2012:** Regular meeting. We will be sharing tips and helps with one another over a delicious breakfast.

**February 11, 2012:** Save this date!

## Polio Place [www.polioplace.org/](http://www.polioplace.org/)

Post-Polio Health International continues to add information to Polio Place. If you haven't been there lately, visit again. You will notice that we added options to make the type bigger and darker. We invite you to look around to learn and to think about what you could add from your life experiences.

Post-Polio Health International is

committed to reaching survivors worldwide, and we'd like your help with a new project. PHI invites any polio survivor living in Central or South America who has an interest in post-polio issues and services (or lack of services) to send a letter of introduction for consideration for a committee to guide our work to [director@post-polio.org](mailto:director@post-polio.org) or to PHI, 4207 Lindell Blvd, #110, St. Louis, Missouri. Additionally, if you speak Spanish and English, are tech savvy, and would like to assist PHI, too, contact [director@post-polio.org](mailto:director@post-polio.org).

## FROM TEN YEARS AGO

It's become a custom lately to include something from the issue of the PPS MANGER newsletter published ten years ago. This time I'd rather talk about it.

The two big stories in the September/October 2001 issue were a short article on the emotional effect of the attack on the Twin Towers, and a report by Mary Clark Atwood on the late Dr. Edward Oppenheimer's March 2001 presentation, "Assistance for Breathing Problems of Polio Survivors."

Then, the Atwood article was a very thorough summary of state of the art [in 2001] medical knowledge and technology available regarding PPS breathing problems as presented by, in this reporter's opinion, the best PPS "lung doc" ever, Dr. Oppenheimer.

The article (readers can write for a copy) contained all the information I needed to get started in the right direction, and to share with readers of this publication.

Dr. Oppenheimer retired from the practice of medicine, but continued supporting the PPS community [myself included, Rick] via email. Then we lost him in 2005. I consider myself one of his humble disciples, carrying on his work.

Dr. Oppenheimer's 2001 presentation included information on the treatment of PPS via bilevel noninvasive support. He also mentioned that the future held the possibility of a machine that would automatically adjust to the patient's needs. That dream came true then faded away as the preset bilevel ST became today's standard.

I still feel guided by the great Dr. O as I work to help my fellow PPS folks breathe better.

Dr. O advised me to advocate for myself, to take control because nobody is going to do it for me. I've learned from others and from experience, and I've worked to pass that information along to others.

Roughly half of the folks in breathing distress accept help. The other half has been receiving the wrong treatment from their doctor so long that they don't know how to get out of the rut created by drugs, CPAP, and supplemental oxygen.

Still, the first requirement to sustaining life is breathing in and out, and that's something most of us find challenging without mechanical help.

The following article was written by someone whose doctor told her that she would have to be on supplemental oxygen [O<sub>2</sub>] for the rest of her life, and that a "BiPAP" machine can't help remove carbon dioxide [CO<sub>2</sub>] from your system. Following the guidelines of Dr. Oppenheimer and one of his disciples, she proved her doctor wrong and changed her life.

Janet is a fine example of the right way to do it.

Rick Van Der Linden, Editor: PPS MANGER NEWSLETTER. The PPS Manager is published every other month by RE "Rick" Van Der Linden and is presented as management ideas.

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### SDB – SLEEP DISORDERED BREATHING By Janet Whitworth

Polio survivors often experience SDB because they have weak breathing muscles. Frequently when they visit the doctor complaining of fatigue a sleep study reveals sleep apnea. This is a condition where a

person stops breathing for a short while and then they wake and start breathing again but they may not realize that they are doing this because usually they do not awaken fully. In the morning they do not feel rested.

Sleep Apnea is a common medical condition. Usually patents with this condition are over weight but not always. During REM sleep our bodies are paralyzed and if we have diaphragm or upper chest muscle weakness we may experience hypoventilation. This is breathing so shallow one is hardly getting any oxygen. Over time this causes carbon dioxide to build up in the body, which can lead to very negative problems in the body especially the heart and the brain.

Doctors usually prescribe a CPAP machine to treat sleep apnea. The patient wears a mask connected by a hose to the CPAP machine, which provides a continuous air pressure (determined by a sleep study) to prevent soft tissue closing the airway. Once patients adapt to the equipment they notice they are refreshed and feel better. The pressure may be changed over time as the condition changes. Now Auto machines are pretty popular because the patient receives the pressure they seem to need and this makes the equipment more comfortable. Treatment does not require close monitoring by the clinicians and when downloads are done they mainly focus on mask leaks and hours of use. If the patient experiences a high percentage of mask leaks then the fit should be checked. It may just require straps be adjusted, or perhaps a different brand or style of mask should be tried. Typically there is the nose mask, nose pillow mask and the full-face mask, which covers the mouth as well as the nose.

Polio survivors are not successfully treated with the CPAP machine because their weak

breathing muscles make it hard for them to exhale against the continuous air pressure. Post polio survivors with SDB should be treated with a bi-level VPAP ST, which provides two pressures: one higher to help inflate the lungs and one lower to enable the patient to exhale more easily. There is no cure for post polio syndrome – the best treatment is to try to rest the part of the body affected and eat a protein rich diet in the first half of the day to feed the weakened muscles. (No pumping iron – the muscles are breaking down from overuse so PPS patents need to reserve the strength they still have.) Focusing on SDB it would seem then that the bi-level machine settings are critical for restful sleep.

The ResMed VPAP ST has the following features:

IPAP: (inspiratory positive airway pressure)

The pressure for Inspiratory breath

EPAP: (expiratory positive airway pressure)

The pressure for Expiratory breath. Some machines lowest level is 4 but the ResMed goes as low as 3

Rise Time: Is how quickly the machine kicks into the set IPAP pressure in milliseconds (mine is at 300 mS)

Ti Max: This is the maximum time the machine stays in IPAP pressure in seconds (mine is at 2.0 s)

Ti Min: This is the minimum time the machine stays in IPAP pressure in seconds (mine is at 0.8 s)

Trigger: This is the sensitivity level and the range is Very High to very low. My machine is set to High

Cycle: High

BPM: Breaths per minute setting. If the patient does not initiate breath the machine will kick in per the setting to initiate a breath.

If neuromuscular patients have difficulty exhaling against pressure one might wonder why the bi-level machine does not go to zero.

The reason is that some air has to flow to clear the air or the patient may breathe in the air they just exhaled. However, there is now a more sophisticated machine [at about 10 times the cost – editor] that does allow an EPAP setting of zero that has two tubes going to the mask. It is a volume ventilator and has many more features than the ResMed VPAP ST.

Carbon dioxide levels should not be above 45. A blood gas draw is required to test for one's carbon dioxide level. This test is usually done in a hospital because the technician needs to draw from an artery in the wrist. Oxygen level tests can be part of this blood test but it is much easier to test for oxygen level with a finger monitor. I believe that as the oxygen level goes down the carbon level may also be going up. If supplemental oxygen is added the patient's impulse to breathe more deeply is suppressed and consequently the blood gas levels continue to go in the wrong direction. Hypoventilation needs to be treated with the bi-level machine set to encourage better ventilation while resting the patient during sleep.

It is important to have a pulmonologist who knows [that] the treatment for patients with weak breathing muscles may differ from those with lung disease. My doctor was willing to tweak the setting on the bi-level equipment to gently increase the IPAP and lower the EPAP to the lowest setting to provide a wider spread, thus allowing a deeper breath in and ability to fully exhale. Over-night oximetry tests were run to check oxygen levels with and without supplemental oxygen and a follow up with a blood gas test can determine the CO<sub>2</sub> level.

Supplemental oxygen may still be required for people with weak breathing muscles in

certain circumstances. One example would be when flying. Oxygen levels are at about 80% of normal air, which is adequate for normal breathing at rest but not sufficient for a person with weak breathing muscles. Passengers requiring supplemental O<sub>2</sub> help need to take their own pre-approved battery operated portable oxygen generator with them, or for some longer flights arrange on-board oxygen with the airline.

I would like to give credit for this article to personal web research and experimentation, the support of Group Health and Apria, and to some very special polio friends namely: Hilary Boone, Gladys Swensrud and most of all Rick Van Der Linden.

Contact Janet at [janhatt55@comcast.net](mailto:janhatt55@comcast.net)

*Two boys were walking home from  
Sunday school  
after hearing a strong preaching on the  
devil.  
One said to the other, 'What do you think  
about all this Satan stuff?'  
The other boy replied, 'Well, you know  
how Santa Claus turned out.  
It's probably just your Dad.'*

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*An elderly woman died last month.  
Having never married, she requested no  
male pallbearers.  
In her handwritten instructions for her  
memorial service, she wrote,  
'They wouldn't take me out while I was  
alive,  
I don't want them to take me out when  
I'm dead.'*

## Post-Polio Thoughts

Nancy Baldwin Carter, BA, M Ed  
Psych, Omaha, Nebraska,  
([n.carter@cox.net](mailto:n.carter@cox.net))

### THAT OLD FEELING

It got their attention—our friend Mac wheeling along in his power chair, lugging three two-by-fours and a standard toilet stool into the City Council meeting.

He'd been there before, our friend Mac, and had made no headway trying to describe why the city government building restrooms made it impossible for people like him in wheelchairs to use those facilities.

This night he *showed* them. Plopped down his two-by-fours to square off the dimensions of a stall, arranged the toilet stool in the center, and proceeded to demonstrate, tastefully, why this does not work—and then made clear what needed to be done. By the end of Mac's show, he had a unanimous vote for change, and the city government building had accessible restrooms within weeks.

Lesson One in Making the ADA Work For You.

But that was 20 years ago. Enthusiasm ran high among those of us with disabilities back then. We saw a world of freedom beckoning. Suddenly there were buildings we could get into, pathways we could sail through, reachable drinking fountains. We spread the word, touted the universal importance of accessibility.

We talked with city planning directors, property owners, parents watching children frolic in the park. We shared our vision, and it became theirs. We showed them how—and why. What spectacular results!

But time marched on. As with other initiatives to great social change, after outstanding bursts of accomplishment, efforts began to wane, and today public response to the ADA remains “a work in progress.”

A local polio survivor serves on a committee dealing with housing units being built in a retirement community. “Management” tells her they want to comply with ADA regulations. Only, apparently, not too often—a pitiful one in fifty of the independent living apartments currently under construction is accessible. Could they possibly believe that those of us with disabilities cannot also be independent?

*They* say budget concerns cause ADA cuts; they can adapt later if they need to. Besides, they say, people are turned off by apartments that look as if the purchasers, themselves, might be disabled some day.

Indeed, the retirement village's resort-like ads project, through appealing photos, the image of a mecca for active aging folks. The relatively affluent. The non-disabled. Nary a wheelchair, scooter, or walker in sight. Can it be this describes the typical retiree?

Who are “the disabled,” anyway? Our fathers, putting up with debilitating

arthritis all these years? Niece Amy, living with MS since she was 35? Beloved Uncle Ralph, using a walker after recovery from a stroke? Our sweet old neighbor, still baking cookies as she did when we were kids, in spite of her frequent need for oxygen? Thousands of veterans returning home scarred and maimed from defending us in wars? These people couldn't possibly be independent?

Surely we have not become so outrageously biased as to suggest relegating them all to an invisible society. Who today would be offended by the sight of a wheelchair? A brace? An artificial limb? Are there actually those who do not accept people who are disabled as viable members of a community?

Let's find out. Get people's attention again. Let's remind them of the tune they danced to twenty years ago when they began to embrace the ADA. The kindness in their hearts. The way they felt when they made room for one more imperfect soul in their world. Let's start shouting from the rooftops as we did before. Only this time the message is: WE'RE STILL HERE!

Let's see how it goes. I'm betting on *us*.

*Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

## **Post-Polio Thoughts**

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

### **CLOSE ENCOUNTERS OF THE POST-POLIO KIND**

It's not as if we polio survivors never run into a glitch or two in a day. Let's face it—dealing with the unexpected has become part of everyone's routine. Developing the finesse to do that smoothly and successfully—well, that may be a different matter.

Consider Alice, a former nurse with serious arm weakness. Alice just returned home from two weeks at a rehab center where she was evaluated by a PT, an OT, and her personal physician, all of whom concluded that she needs a power chair.

Congestive heart failure and weakness in her legs make it difficult for Alice to walk around the house, and she finds it impossible to be independent when it comes to such things as getting to the bathroom. She needs the power chair.

So the rehab center folks contact a power chair supplier and arrange for them to meet with Alice to work out the details for finding the right chair.

Meantime, Alice (now home and renting a power chair) engages a home health agency to provide the PT her doctor orders. And herein lies the problem.

The PT, seeing Alice only once, decides he will be a miracle worker, says he'll

have her up and walking in no time, and puts the kibosh on the power chair. Without consulting anyone, he calls the power chair outlet, switches them to his own questionable evaluation of Alice's condition, and declares that only a manual chair is indicated for our weak-armed Alice. Trouble ensues.

Time for Alice to jump into action.

We all have options. We do not have to sit passively and watch others take over our lives. This doesn't require shouting angrily in indignation, loudly stirring the pot with wild demands or accusations. A calm, quiet, "I'm in charge here," will do.

Alice could:

1. Start by firing the PT (if not the home health agency) and hire one that will honor the perfectly acceptable existing evaluations already attained. Check the qualifications of workers sent by any agency and be clear on job descriptions. Everyone must understand that our health care decisions are up to us—we do not casually hand over our authority to every individual who stumbles into the picture.
2. Speak up. If we have already been through a certain process and have no intention of doing it again, we have merely to say so. If someone insists on our participation when we know this to be wrong for us, we refuse. The word "NO" comes to mind. And if this is more than we can handle, then we'd best find

ourselves a "NO-man" to carry along with us to utter the word.

3. Work with experts. For instance, see an assistive technology professional to get exactly the fit and the kind of chair needed. Don't settle for anything less. Discover what works for us. Don't allow a salesman with extra scooters in his inventory to decide that would make a better purchase than the chair we want. Who knows our bodies better than we do?

Of course it isn't just Alice. Lots of people need to realize it's OK to act on the courage of their convictions. You know how it is. Jack makes an appointment with his doctor. When he arrives at the office, he learns he will be seen by a nurse only. Fine, if that's what he wants. If not, he needs to say so. Firmly, but calmly, he must insist a pinch-hitter is not acceptable. Next time he can avoid this situation by confirming this when calling to get on the schedule. Nothin' to it.

Easy enough—no whining or complaining. We simply gather up our polio pluck and make our lives work for us. What could be better than that!

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))



# ***Annual Christmas Luncheon***

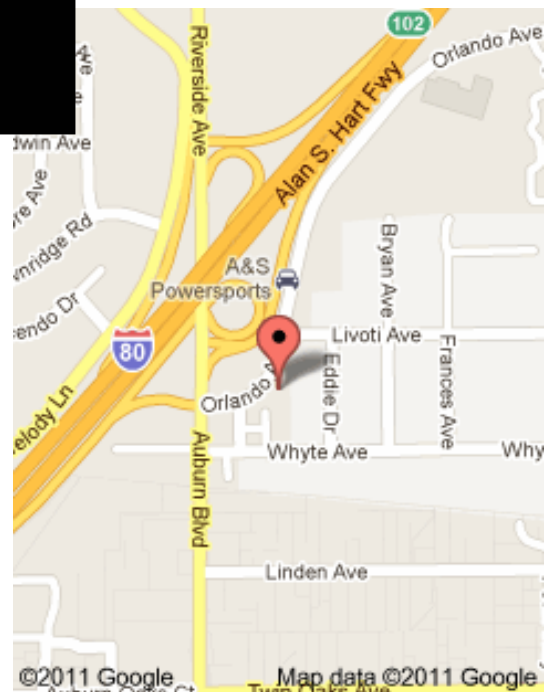
***December 3, 2011 11:00 am***



We ask you to bring a raffle prize to share in our Raffle to support our Post Polio Support Groups. The raffle prize can be a useful item or store gift card. At past luncheons many have gone home with some very nice items. Thank you for your bring a raffle gift, Saturday, December 3.

Please contact Jim Munro at 916-487-7168 or Leslie Smith at 916-725-4077 for reservations. You will be able to order directly from the menu and pay for your meal individually. The menu is available on line at [www.backfortyroseville.com](http://www.backfortyroseville.com). The price per person will range from \$6.49 for salad to \$22.99 for rib eye steak, plus your refreshment drink. Your choice. Please make the call to Jim or Leslie.

**1201 Orlando Avenue**  
**Roseville, CA 95661**  
**916-726-4040**



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**EASTER SEALS SUPERIOR CALIFORNIA** for contributing postage costs.