

The Southern California

July

PPS MANAGER

2007

Dedicated to being our best with Post-Polio Syndrome

FROM THE EDITOR

Hi Fellow PPS Manager,

Summer is officially here. Hopefully you are among the PPS Managers who feel better this time of year.

If you are convinced that you have strong breathing muscles and you sleep just fine, you are probably getting tired of hearing all the complicated details about bilevels. There's hope. Getting to Know Your Bilevel, Part 2 should simplify things. I just wanted to make sure that my hard learned lessons are passed along to those in need. That's my job.

Of course, the ever-popular Gladys Swensrud is always working on new things. She never stops.

In upcoming issues, I'd like to hear more from you. I already have a few very good letters saved up, but it would be great if you could let me know what's on **your** mind, too.

Have fun....Rick VDL

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IN THIS ISSUE:

Getting to Know Your Bilevel ST

Pt 2 by R. E. Van Der Linden

Advance Health Care Directive

by Gladys Swensrud

And much more...

**Getting to Know Your
Bilevel ST**

Part 2

By R.E. Van Der Linden

In the May 2007 issue we discussed a problem faced by many polio survivors: sleep disordered breathing (SDB). We also explored the commonly prescribed treatment: the bilevel ST machine.

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SDB is a complex problem with an even more complex solution. So, it's no surprise that many people miss out on the chance for a better life because they gave up after the first few attempts at using a machine.

It took me several months to figure this thing out, but in the end, it literally saved my life. Hopefully, you can learn from my experience, improve communication with your doctor, and have a fulfilling bilevel experience.

Part 2 is a step-by-step look at one breath. It analyzes the details from the inside out – a view unseen by your doctor or therapist.

A quick recap:

The Problem: Complex (mixed) sleep apnea. Sleep is constantly interrupted by the following possible conditions: closing of the throat, too tired to breathe, brain forgets to automatically send “breathe” signal, etc.

The Solution: Bilevel ST machine. Pressurized air delivered via hose and mask supports weak muscles, and times breaths in case you “forget” to breathe on your own, insures adequate ventilation.

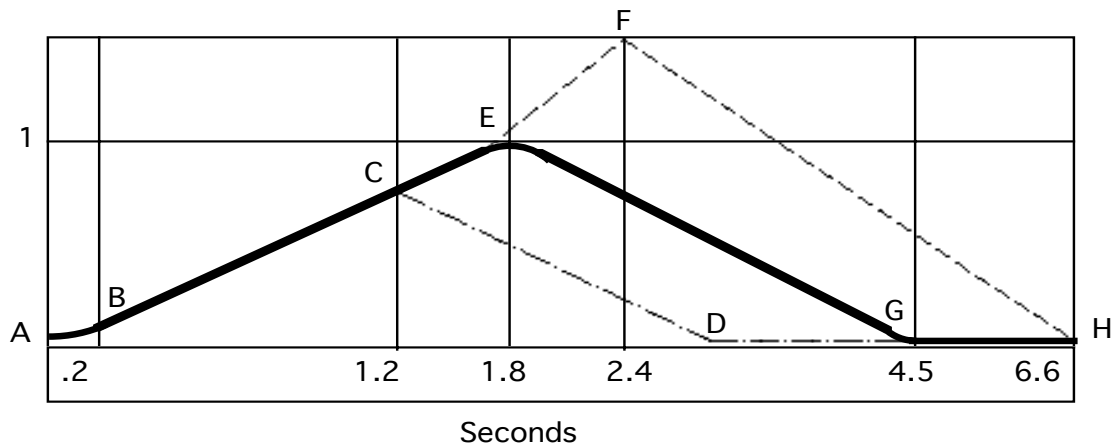


Figure A: The above graph is designed to help analyze a breath step-by-step. The dark line starting at point A and ending at point E represents the flow of air into the lungs. Point E to point G represents the flow of air out of the lungs. Line GH represents the time between breaths. Numbers represent intervals in seconds.

One Breath

The following is a step-by-step analysis of one breath assisted by a VPAP® III ST.

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The person whose numbers are used in this example suffers from a neuromuscular breathing disorder (NBD) being treated for mixed apnea. The asterisk indicates prescribed machine setting. Horizontal line 1 = one liter.

Line AB: * Rise Time.

At point A, the switch from EPAP to IPAP begins. At point B, full pressure is reached.

If Rise Time is too short, the abrupt pressure change can be uncomfortable and cause the user to try too hard to stay ahead of line BC thereby increasing muscle pain and fatigue.

If it's too long, the delay can cause the user to depend on IPAP to "get up the hill." In this case, there is more likely to be a drop off at point C; breath is shortened; dwell time is increased. The user has to either: 1) use tired muscles to start a breath earlier (increase BPM) or, 2) in the case of a Central Sleep Apnea (CSA) event, wait for time to expire and have the next breath started by the machine.

Point B: End of Rise Time

If the user is comfortable with the Rise Time setting, the transition from line AB to line BC will go by unnoticed.

Point C: * IPAP min.

Point F: * IPAP max.

Line BCEF: The Hill

Air enters the lungs until one of three things happen:

At Point C (IPAP min.), if the user has allowed IPAP to push up the hill, the sudden pressure drop to EPAP begins the out breath. This point represents the smallest breath allowed. In the event of a machine-initiated breath, inadequate ventilation will result unless the combined IPAP, IPAP min., and BPM settings meet minimum needs at the time.

At Point E, the ideal breath ends. The user has inhaled enough and user input initiates EPAP spontaneously; the user exhales, and has two seconds to initiate the next breath.

Line EF: IPAP max. setting allows user time to sigh. Machine switches to EPAP at set time.

Point E: Top of Breath

The Top of the Hill is the critical area. *If Rise Time and IPAP are correct, a light effort from even the weakest muscles will carry the user past point C to point E, and the most natural ventilation possible will result.*

Line EG: Normal, spontaneous exhalation.

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Line EF: Sigh time allowance.

* **BPM: Breaths Per Minute**

The prescribed minimum time allowed between the start of one breath and the start of the next.

For example: at 10 BPM, one breath will take 6 seconds. The S/T machine allows the user to increase BPM by spontaneously starting a breath earlier, but not later than ten seconds. More breaths per minute = fewer seconds per breath.

If IPAP is stopped too soon at IPAP min., then either a spontaneous increase in BPM is necessary for adequate ventilation, or a deep sigh will soon be needed to make up for the loss.

Line D/G/H: Dwell Time.

Dwell time = time spent at EPAP. Or, time allowed for the user to start a breath spontaneously.

If the user's lungs are sufficiently emptied, the lowering of the lungs natural elastic stress makes it easier for weak muscles to spontaneously start the next breath. A higher EPAP setting discourages spontaneity.

Areas of Tolerance:

The time between IPAP min. and IPAP max., and the Dwell Time allow the user the flexibility needed to make breathing as natural as possible.

Up and Over the Hill

A Further Explanation of One Breath on NPPV

Think of it this way:

You're walking up to the bottom of a steep hill that you plan to run to the top of. The weaker your muscles, the steeper the hill seems.

Start Rise Time:

As you meet the rise, you get a push from behind to help you up the hill.

If the push starts with a collision from behind, you may not get your feet under you until you reach the top (IPAP min.) and end up stumbling over the top. On the other hand, a gentle increase, until full push is reached allows time to get moving, and you fly over the top – you go beyond IPAP min. and start floating down when nature takes its course.

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If the assistance comes on too slowly (long Rise Time), you struggle to get started and waste energy. There's also a short period of uncertainty that causes discomfort. "Will help arrive in time?"

End Rise Time:

IPAP:

You are being pushed up the hill.

If the push is too weak, you struggle all the way up and fall off at IPAP min. Not only do you have to work too hard, but you also don't get as far.

If the push is too hard you get the feeling you're going to fall forward. Although it's a minor discomfort, it discourages you from using your own muscles and may, over time, decrease muscle tone. Other problems can arise as a result of too much IPAP, such as: mouth leaks, ear discomfort, sinus over-inflation, mask leaks, and so on.

If pressure is just right, you don't even know it's there. The top of the hill (the dark line on my graph) is where sufficient ventilation is attained.

End IPAP.

Start EPAP:

You get to parasail down the other side with a little breeze coming up from below. How far you sail depends upon how heavy the (EPAP) breeze is.

Start Dwell Time:

The length of Dwell is governed by two factors:

Start of Dwell depends on where you land, which is a result of everything that's happened from the time you started up the hill.

Length of Dwell also ties in with the BPM setting.

BPM sets the maximum distance between hills.

The magical part of this analogy is that you can bring the next hill closer and start up when you feel ready. You have a moment to rest until you feel like starting up again.
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When everything is set right, the increase in pressure blends in with the angle of the hill, and you hardly notice the push. IPAP min. goes by unnoticed. Then, you breathe out smoothly, rest for a second (more or less) and start the next breath.

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Problems and Solutions

Detailed descriptions of your sleep/breathing problems are very important. Without your knowledgeable input, the doctor and respiratory therapist won't know what to do. Once you get used to the mask and machine, breathing should feel natural and normal.

It should be noted that the purpose of Bilevel ST is to treat the symptoms (morning headache, claustrophobia, short breaths, dizziness, and snoring) caused by a medical condition such as under-ventilation. If symptoms persist, minor adjustments can make a major difference.

PROBLEM	TRY
Morning headache, daytime sleepiness, frequent urination during night,	Increase IPAP. Increase BPM. Improve mask fit. Balanced settings
Mask leaks	Improve fit/adjustment. Increase rise time. Decrease IPAP.
Throat/mouth leaks, air in stomach	Decrease IPAP. Increase rise time.
Discomfort with sudden pressure impact when a breath begins	Increase Rise time.
Claustrophobia	Increase IPAP. Decrease EPAP. Decrease rise time.
Difficulty getting timed with machine	Increase I min. Increase I max. Decrease BPM.
Inability to sigh	Increase I max. Decrease BPM.
Short breaths (panting)	Increase I min. Decrease I max. Decrease BPM.
Dizziness	Decrease IPAP.
Dry throat/nose	Need humidifier, or humidifier empty.
General ineffectiveness	Increase IPAP. Increase difference between IPAP and EPAP. Increase BPM. Decrease rise time.
Machine's starting more and more breaths for you as days go by	Increase I min. Increase I max. Decrease BPM. All of above.
Snoring, anxious awakenings, night sweats	Increase EPAP. Increase IPAP.
Hammering effect at top of breath	Decrease I min. Increase IPAP. Decrease BPM. All of above.

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The Mask

1) Nasal mask:

This is the most commonly used mask. It covers the nose and is held in place by straps around the head. Sometimes an additional chinstrap is used to keep the mouth closed.

2) Full-face mask:

This covers the nose and the mouth.

3) Nasal interface:

This is sometimes called nasal pillows. Air is delivered directly into the nose by way of two pads that seat into each nostril. A moisturizer is used to avoid irritation where it touches the inside of the nostrils. Sometimes an additional chinstrap is used to keep the mouth closed.

Some doctors recommend that you have at least two types on hand in case one creates a problem and/or you have an upper respiratory infection.

Most masks require that you use a pure soap (I use Ivory bar soap) to clean your face and the contact surfaces of the mask before each use. It may take a few minutes for the mask to warm up to body temperature before leaks stop.

With masks, it's important that you adjust the straps so that the mask is neither too tight nor too loose. Either situation can cause leaks, but too tight can result in soreness and skin breakdowns. Any sore spot must be addressed immediately. It may be necessary to switch to a different size mask, or sometimes it can be customized.

The machine must be adjusted to the type of mask you use. For example, the rise time setting that is comfortable for a full-face mask may be extremely uncomfortable if you switch to a nasal pillows system. Your respiratory therapist can help you with this problem.

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Thanks to Judith Fischer, International Ventilator Users Network (IVUN) 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.

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Do I Need a Heated Humidifier?

The short answer is: you may not always need it, but you should have one.

A few facts:

Moisture in the air you breathe aids oxygen absorption in the lungs.

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A bilevel pressure of 12 or higher can (according to Melanie Arledge of Progressive Medical) reduce humidity.

Dr. Bach recommends warm, moist air with your bilevel.

Dry air can swell sinuses and restrict breathing.

If you get a cold or cough, a humidifier can help thin out secretions and make coughs more productive, thereby reducing the possibility of pneumonia.

Medicare's Replacement Schedule

To prevent disease and maintain proper function, it's best to replace expendable parts (supplies) on a regular schedule.

Most HMOs adhere to the Medicare guidelines, but it may be up to you to call and remind them to send your supplies.

The following is a list of Medicare approved supplies showing HCPCS (Medicare) code #, part description, and allowed frequency of replacement.

A7032, nasal cushion, two per month

A7033, Nasal pillows (pair), two per month

A7034, Nasal interface, one per 3 months

A7035, Headgear, one per 6 months

A7036, Chinstrap, one per 6 months

A7037, Tubing, one per month

A7038, Disposable filter, one per month

A7039, Non disposable filter, one per 6 months

Bilevel Battery Backup

Now that you have your bilevel all figured out, you're getting a full 8 hours of sleep in an 8-hour night, and your half-hour nap revives you for a more productive afternoon. Your brain is functioning normally, your body is able to run a little longer than before, and you're getting things done.

You think about that camping trip you've been putting off, or that all-day trip to your favorite far away place, but you're worried about taking your machine along.

What if you need to recharge yourself and can't find a 110-volt AC outlet near a bed? OR, what if the power goes out?

Some, but not all, machines have a 12-volt DC port that plugs directly into your car's power port (cigarette lighter) via a cable available from the manufacturer (or your local electronics store, but be very careful to get the right positive and negative configuration).

If you have a machine without a built-in 12-volt DC option, you can use an inverter. ResMed, the manufacturer of the VPAP III recommends using a 300-amp pure sine wave inverter. (About \$150.00 at invertersrus.com.) You can find a 75-amp-hour deep cycle 12-volt

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RV battery for \$80 to \$100 locally. You can buy an inexpensive battery charger at Sears or any large auto parts store.

If you have a heated humidifier, you must remember to empty it before moving your machine. When running on battery power, just leave the humidifier in the off position (“0”) and your battery should last for a few nights before recharging.

Advance Health Care Directive

By Gladys Swensrud

Throughout our lives we make many important legal and financial decisions. For years prior to retirement, we faithfully contribute to Social Security and/or we sock whatever money we can spare away into retirement portfolios. Along life’s path, we work hard to maximize savings and investments. Our hope is that if we play by all the rules, we can live comfortably into our golden years, relatively worry free of serious money concerns.

For additional safety, we purchase insurance for our house and cars to lessen the anxiety of unforeseen accidents. We buy healthcare and long-term care insurance to help with expected and unexpected costs related to illness, injury or disability. We try to plan for every contingency in life, however sometimes the most obvious are the easiest to overlook. And for some, neglecting to complete an Advance Health Care Directive might be an important missing piece to future preparedness.

My first exposure to an Advance Health Care Directive was placed in my lap prior to carpal tunnel surgery in 2002. Tucked inside my surgery folder pockets, along with other paperwork requiring my signature, was a form titled: *Advance Health Care Directive*. My HMO has always stressed the individual’s need to participate in making sound, personal, healthcare choices, and I do recall having seen *Advance Health Care Directive* among the pages of past informational guidebooks. And at this time, although I didn’t understand the actual significance of an Advance Health Care Directive, with surgery pending, I dutifully looked it over and quickly filled it out, really giving little forethought to my answers. The only exception to that was I realized I had become acutely aware that should a problem arise during surgery, which would prevent me from speaking for myself, my husband, as my designated agent, would have the authority to make my healthcare decisions.

The way I had lightly brushed the Advance Health Care Directive aside in 2002 must have preyed on my mind because I went back and updated it in 2003, giving it slightly more consideration the second time around. It wasn’t, however, until I attended the last in a four part series of Financial and Legal Wellbeing Workshops presented by the Parkinson’s Disease Association of San Diego (PDASD) that I was given a totally new perspective on this important subject.

The guest speaker for the final meeting in PDASD’s sequence of well presented workshops was Luann Beberman, Esq. Ms. Beberman focuses her practice on Elder Law, with a special emphasis in Wills, Trusts, Probate and Conservatorship law. As she explained, an Advance Health Care Directive is a very powerful document. It not only tells the names of

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agent(s) you might like to have address your healthcare decisions should you not be able to speak for yourself, but it tells your doctors, family members and friends how you feel about end of life treatments, diagnostic tests, and surgical procedures you may or may not want done. It can also cover such far reaching topics as cardiopulmonary resuscitation, authorization for an autopsy, organ donation and burial wishes.

Unlike a Durable Power of Attorney dealing with financial matters, which must be notarized, the Advance Health Care Directive becomes legal in the state of California once it is signed by two witnesses. Ms. Beberman cautioned us that laws vary from state to state, so should you move outside of California, you must review the laws in your new locality. Additionally as important, she reminded us that this document should be reviewed frequently since individual situations change over time and your wishes will undoubtedly change as well.

The following are few of the many suggestions I noted from this meeting:

- Always keep your original Advance Health Care Directive in a safe place.
- Make sure your designated agent(s) has a copy.
- Give a copy to your doctor for your chart.
- Be sure to take a current copy with you should you go to the hospital for any procedure.
- Provide a copy to your dentist.
- Be sure your agent understands the terms you specify about your decisions, and if you should have multiple agents or co-agents, be sure they also understand your wishes and will abide by them should you require their intervention.
- When you update your Advance Health Care Directive, you should ask that prior forms be destroyed. However, the one with the most recent date will be the one honored.

Like all other legal documents, the objective of your Advance Health Care Directive is to simply lay out your long range healthcare plans, which hopefully will keep you from ever becoming entangled in the court system. Having a plan now will help to avoid problems down the line!

By the looks on faces around the room, it was clear that all attendees came away from this workshop with an understanding of Advance Health Care Directive and the part it should play in healthcare planning. We also realized that this is a topic you can and should research and learn more about. Although I am not a lawyer, I left feeling comfortable that I could and should redo my own Advance Health Care Directive since it has been four years since its last update. I vow to do that for myself within the next few weeks, and I believe it would be a wise move for others to consider as well. Long term it might benefit you in more ways than you can imagine.

Detailed information on Advance Health Care Directives within the state of California can be found by going to California State's website:

http://www.ag.ca.gov/consumers/general/adv_hc_dir.htm

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Contact information for our presenter, Luann Beberman, Esq. is:
Beberman, Stoffel and Beberman
7676 Hazard Center Drive (Suite 850)
San Diego, CA 92108
619-297-4900 or email her at: lcb@bsblaw.org

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MEETING REPORTS

San Diego Post-Polio Support Group

May 12, 2007, Meeting Report-back

Notetaker – Gladys Swensrud

In the absence of our fearless leader, Rick Kneeshaw, the meeting facilitator once again this month was Steve Goldman. Steve began with an appropriate icebreaker: How is the escalating price of gas impacting you and your family? It was evident from the responses that our driving habits are in the process of changing as the price goes up, but there were also a few good “belly jiggers” in the lot. The following suggestions might be of use to you as well:

- Drive less
- Drive slower (we are noticing more and more traffic in the slow lane)
- Use an AARP credit card because it gives gas credit.
- Using a Costco credit card gives cash back to spend on gas or goods.
- Switch to an economical car like a Toyota or Honda hybrid.
- If you have two cars, drive the one that gets the best mileage.
- Use air conditioning less often.
- Buying gas in Mexico saves about fifty cents a gallon.
- Consider relocating closer to town and/or work to save time and gas.

The comedians in the group suggested ideas such as reciting a few choice words (preferably in a foreign language) each time you reach for the pump handle; or make sure your spouse rides his/her bike more often, which naturally means no sacrifice on your part whatsoever.

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In summary our group indicated at this point the increase has not yet impacted our lives too dramatically. Steve suggested that we revisit this issue when the price of gas is in the vicinity of \$4.50 a gallon.

Our guest speaker this month was architect Michele McLain, AIA. Her program, “Accessible Living for the Physically Challenged,” was a great combination of slide presentation and handout. Michele began her visit by noting that each person is an individual, so our needs are uniquely individual as well. In home building and/or remodeling, the home owner generally tries to anticipate future physical challenges to incorporate into their plan. Michele explained that by using an architect, the professional can suggest many useful additions which should make your planning process flow much smoother.

Michele added that those experiencing PPS are pioneers in the art of aging. As polio survivors, we are facing many early limitations, which the general population will also encounter as they age. She mentioned that “Universal Design” is a fairly new buzz word, but Michele felt we were the originators of that term because our needs prefaced its use.

Some remodel ideas are basic, like adding handicapped toilets and grab bars, but there are many, many ideas that could be combined with your plan to help you live more comfortably in your home for as long as is physically possible. An architect can assist you in anticipating some of your unique needs and goals, thereby eliminating potential future barriers.

A few of the many suggestions Michele had to offer were:

- A five foot turning radius at the entry to your home so you can turn and close the door.
- Use a swing clear hinge on interior doors to gain the width of the doors for entry and exit.
- Trash bins that tilt out toward the user
- Installing lever handles on all doors makes for easier use for everyone in the home.
- Flooring thoughts –
 1. Ceramic flooring should be non-skid.
 2. Use resilient flooring that is not too light to show scuff marks or too dark to reduce visibility.
 3. Vinyl is good for people who wear braces.
 4. Carpeting should have a thin pad or none at all so as not to impede wheelchairs or walkers.
 5. Carpets should be glued down or stapled in place.
- In kitchens, entertain 48” isle widths for easier maneuvering.
- A wheelchair user might consider a 34” counter top a better access height.

Some parting thoughts Michele shared were:

- As you begin planning for that remodel, you might want to allow twenty to thirty percent for overruns and project costs, which you may not anticipate.

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- She encouraged everyone beginning a redo project to find and watch *Mr. Blandings Builds His Dream House*. It is a 1948 comedy in which a man (Cary Grant) and his wife (Myrna Loy) decide they can afford to have a house in the country built to their specifications. It ends up being a lot more trouble than they think!
- Being disabled doesn't trump zoning, so Michele suggested checking all zoning regulations prior to entertaining a remodel.

Michele McLain's territory covers most of San Diego County, but she generally services the north county. You can reach her at:

Michele McLain, AIA

P.O. Box 905

San Marcos, CA 92079

Telephone number – (760) 743-1955

Fax number – (760) 743-1919

She can also be reached by email at: mclainaia@aol.com

___The next San Diego meeting:___

July 14

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

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

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

COACHELLA VALLEY POST-POLIO SUPPORT GROUP

At our May meeting, we shared with some of our attendees that were unable to make the April meeting, what we took away from the presentation from Andi of the Indio Community Access Center (CAC). The Braddys are looking into the CAC existing grant program for a voice-activated computer. Kurt Sipolski reminded us of the wonderful service provided by Neiman-Marcus if you need two different shoe sizes, buy one and get one free!

At the June meeting we welcomed new member Robert Golden to the last meeting of the season. Joe Camaya is working on an order of books for the group, "Managing Post-Polio: A Guide to Living and Aging Well with Post – Polio. This is the second edition of the book "Managing Post-Polio". Joe should have price for us by the time of our next meeting in October. Kurt Sipolski was on vacation in Australia. May also brought the Braddy Bunch an

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adventure in trying to find June vacation rentals for special needs. Bob reports that find wheel chair accessible vacation rentals near the beach that also will accept the family dog was a challenge. But, we are happy to report the Braddys are vacationing in Oregon.

I would like to take this opportunity to encourage each of you to attend your city and county events, such as; Senior Forums, Abilities Expo, Health and Safety Fairs and Community Partners Preparedness. These are wonderful venues to receive information on services, changing needs and issues affecting seniors and adults with disabilities. You can also take this opportunity to educate your community and fellow attendees on Post - Polio Syndrome.

We wish a cool and carefree summer to all of you. No meeting for the CVPPSG in July-August – September. See you on the second Saturday of October that's the 12th from 10 Am – 12:00 noon, at the Portola Community Center 45-480 Portola Avenue Palm Desert, CA
Barbara Hall

Summer break –
No meetings for July, August or September

_____The next meetings:_____

October

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, (760) 365-3587 or Barbara Hall whall233@aol.com, (760) 329-9593

Escondido Post Polio Group

"Sleep Disorders and Chronic Pain"

Dr. Bradley Schnierow is a specialist board certified by the American Board of Sleep Medicine, as well as the American Board of Psychiatry and Neurology. Dr. Schnierow is Assistant Clinical Professor at the U.C. San Diego School of Medicine and Director of the UCSD Sleep Disorder program. Also he is a staff physician at Scripps Memorial Hospital.

Dr. Schnierow will discuss sleep disorders and pain from post polio syndrome, fibromyalgia and chronic fatigue.

<http://www.sandiegosleep.com/staff.html>

_____The next meeting:_____

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August 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

HEMET AREA POLIO SURVIVORS

Hi Everybody.

Our May meeting was intimate and relaxing. Thanks to Lucille, we are now serving coffee, and members are bringing baked goods. Now if that doesn't get you out of your easy chair on a Wednesday morning, I don't know what will.

The June meeting featured special guest, Gladys Swensrud. Gladys drove up from San Diego to talk to us about her recent success in helping start and maintain a neuromuscular breathing program at Kaiser. She encourages everyone to fight for your right to proper care within your HMO.

In coming months, Gladys will be delivering her message at PPS meetings throughout Central and Southern California.

Don't miss the second annual polio survivors' pot-luck

HAPS Summer Picnic

Sunday, July 15

Valley Wide Recreation

On Esplanade, San Jacinto

12:30 to 3:30

Food, fun, live music

Air conditioned, easy access.

Bluegrass/country/spiritual music by **The Lincoln Street Band** – Rick VDL and friends.

You don't have to be a HAPS member to attend. Bring your friends and family.

For more information, what to bring, etc. call Bunny at 766-7118 (call after 11 AM)

Have fun ... Rick

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___Our next HAPS meetings are:___

July 15 - Picnic
August 15

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

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Riverside PPS Group

Dale Gerdes underwent surgery to remove cancerous lymph nodes June 13th. He will undergo chemo as soon as insurance approves medication necessary to begin. The cancer is widespread. Dale's outlook is as always, "I trust the Lord, and He is allowing this for a reason. It will be all right." That cheerful sparkle which characterizes his voice is not the least diminished. If you care to drop him a note:

His address:
PO Box 5312
Salton City CA 92275

Dale, we love you!

Speaker Gladys Swensrud will be speaking to our Riverside group Saturday, August 18th. The meeting starts at 10 am, and will be followed by a barbecue. "Optional potluck" - we supply the meat and drinks. All welcome!

Judy M.

___The next Riverside PPSG meeting:___

August 18

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

Big Bear PPS Group

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

Victorville PPS Group

Next meetings: _____

July 10

August 14

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

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

Polio Survivors Plus of Orange County

Next meetings: _____

July 25

August 22

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

Letters

Hi Rick;

First let me tell you what a great resource you bring to the polio community.

I have a question that I would like to ask the readers of your newsletter. I had polio when I was very young 1947/48. I don't remember it at all. Lucky me. I had drop foot and walked on my toes until the age of 14 when I had surgery to correct it. I had a triple arthrodesis operation and they moved a ligament from the back of my leg to the front top of my foot, followed up with a leg cast up to the top of my thigh for four months. This brought my foot up to near normal, although with limited movement (13 degrees).

PPS MANAGER

I had minimal pain until the late 80s when arthritis set in. I had a brace made and used it for several years until it wore out and I was too stubborn to go and have a new one made. My friend Mr. POST POLIO came to visit me shortly after and in 1994 I was disabled. I have been going down hill every since with all the typical (if there are typical) symptoms of post polio.

The major problem I am having right now is my foot is starting to curl back under as it was when I walked on my toes. My foot and toes are starting to bend inward which makes my foot twist outward when I walk. Very painful.

I have been using a cane for about 10 years and now I think I will have to switch over to crutches.

I guess I should quit rambling on and ask my question.

Is any one else going through this? If so what are they doing about it.

Thanks so much for any info you can provide.

Don Kesling

Hi Ricky,

Thank you for the detailed, informative, and clear explanations in your article from the March, 2007 newsletter article entitled, "Medicare Change Takes Full Effect." I too was rather confused after receiving the first one page letter from Progressive Medical instructing me to decide by a deadline if I choose to purchase my NPPV.

I did phone Melanie Arledge at Progressive Medical and she did ease my confusion somewhat. Thanks to your article, I feel much more informed.

As a post-polio editor once upon a time, I appreciate how much time you must devote to compiling information and all the thought processes involved in putting a volunteer newsletter together. There is so much you must do "behind the scenes," in order for me (and everyone else) to receive and read the finished product. A big fat, K U D O S to you and all your assistants.

I feel the post-polio newsletter is the one informative, true, and honest publication I can rely on these days. That is so rare anymore.

Here is an unrelated question I have for you. What do you know about the mobility aids that polio people with problems walking can purchase to wear in their shoes or on their weakened leg besides an AFO or brace? Something like the artificial limb which people who have lost a leg can wear. Sorry I know I have not explained this very well. But I would appreciate any feedback.

Sincerely,

Marion

[If you can advise Don or Marion, please write or call Rick VDL]

PPS MANAGER

THANKS

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

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