

FROM THE EDITOR

Hi Fellow PPS Managers,

Another holiday season has passed, and a new decade has begun. It's hard to believe. Ten years ago people were worried about the millennium bug. "From Ten Years Ago" was actually from the previous century. And here we are: looking forward to another spring.

Here at the ranch, welcome rains have brought a hint of green to the long brown fields and hills, and with it the promise of wild flowers and warmth. Real hope, not vague suggestions of unsubstantiated change. Only nature can do that.

So let's all do the Charlie Brown/Snoopy dance in our hearts and stay warm any way we can until nature turns up the heat.

In this issue is a quick review of the Salk Breathing Symposium. When attempting to write about it, all I could think was, "You had to be there." Well, you can. Online at poliotoday.org

There's a load of info in the Meetings and the Letters departments, so take your time, enjoy, and learn.

Rick VDL

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IN THIS ISSUE:

From Ten Years Ago
Review of the Salk Symposium
Some New Thoughts Re: Assisted Breathing
Meeting Reports, Letters, and much more...

FROM TEN YEARS AGO

[The following was first published in the December 1999 issue of the PPS Manager newsletter. – Editor]

JOY

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Most polio survivors agree that stress increases the fatigue and pain we experience. To understand what this means we need to define the stress we're talking about.

Mental (or emotional) stress is worry and anxiety. Physical stress is tension or pressure. We feel it in our muscles when we are opposing gravity, trying to stay warm, or experiencing emotional stress.

If we can control or eliminate stress we can greatly improve our quality of life. That may mean we have to concentrate on relaxation.

Here are a few of the thousands of dos and don'ts you might try when stress threatens:

- Stay warm and relaxed.
- Rest often.
- Lay flat or sit in a recliner.
- Wear an insulated body suit in the winter.

- Get yourself in hot water.
- Become a snowbird.
- Get a lap dog or cat.
- Don't worry.
- If you can't fix it, forget it.
- Enjoy being alone.
- Listen to soft music without words.
- Concentrate on your breathing.
- Never try to run someone else's life.
- Don't force a decision when you're too tired to think.
- Be childlike.

THE OPPOSITE OF STRESS IS...

So far we've relied on the fact that the opposite of stress is relaxation, and in a physical sense it is. But in order to really get a grasp on it we have to take it a step further and look at stress from the purely human aspect - the spirit. From that standpoint the opposite of stress may very well be joy.

I remember a time when I woke up every day with a joyful feeling. The smell of the morning air, the promise of things to come, new things to discover... Why can't life be like that every day? Now I often wake up and feel the aches and weakness that should have gone away with a night of rest. Can we have a blissful life in spite of this physical challenge? The answer is, "Heck, why not!"

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GO BEYOND MANAGING YOUR PHYSICAL WORLD

Every day we learn a little more about how to manage our PPS symptoms. We improve our quality of life by bracing and pacing, better understanding of the mechanisms of polio damage to our bodies, taking carefully prescribed medications, modifying our diets and so on. All these techniques and procedures confront the physical foe but what about the spiritual?

A few years ago (after about four years of PPS 101) my wife, Sandy, said to me, "All you ever think about is Post-Polio. There's more to life than that."

At first I felt guilty and foolish because I had not noticed that it had become an obsession but after giving it some thought I replied, "I have to get control of this thing if I'm ever going to get my mind back on track. If it takes all of my energy then that's what I have to do."

Since then I've put in place a lot of little habits that allow me to successfully manage PPS without thinking about it and therefore giving me more time to relax and concentrate on further reducing stress. This newsletter is one of the results of that quest. Why?

I discovered that to be happy we need to turn our attention outward. The happiest people I've met in our little PPS community are those who do one or more of the following things: Volunteer, go to church, help others, make people laugh, touch people's hearts, create, love. It's a joy thing - the opposite of stress. And it really works.

I wish you true peace and joy.

Rick Van Der Linden

Breathing and Sleep Symposium at the Salk Institute

On November 1, 2009, The Salk Institute presented the Breathing and Sleep Symposium. This is a summary of events and observations by Rick Van Der Linden.

Part 1

Rebecca Newman, VP of Development and Communication at Salk Institute, opened the symposium with the interesting history of the Salk Institute, outlining the important work done by world-renowned scientists there today.

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Research includes plant biology studies aimed at more efficient crops, and finding ways to turn skin cells into stem cell for the ultimate cure of a host of disorders. For more information, visit <http://www.salk.edu/about/>

Dr. Geoffery Sheean, Director of Neuromuscular Division UCSD, was then introduced by MC Judith Fischer.

Part 2

In his presentation “Respiratory Muscle Weakness in Neuromuscular Conditions” Dr. Sheean talked in detail about how normal breathing works, and how neuromuscular disorders such as polio can disrupt the process.

Part 3

Noah Lichtzin Assistant Professor of Critical Care Medicine at Johns Hopkins University of Medicine, Baltimore Maryland then presented “Breathing and Sleep: What’s the Problem? What Tests Are Needed?”

Part 4

Finally, Dr. Lichtzen was joined by Registered Respiratory Therapist Louis Boytano. Mr. Boytano works with Dr. Josh Benditt at Northwest Assisted Breathing Center, University of Washington Medical Center, Seattle, Washington. Their presentation, “Solutions to Breathing and Sleep Problems: Finding the Right Ventilator for the Right Problem at the Right Time” covered the wide variety of problems and solutions in dealing with neuromuscular breathing weakness.

Observations

In April 2005 The Salk Institute celebrated the 50th anniversary of the Salk vaccine. At that celebration, I was honored to spend a few minutes with Dr. Peter Salk, Dr. Jonas Salk’s son, and his wife Ellen. I was delighted to hear stories of life around the house with Dr. Salk and his friends. Most impressive was his philosophy regarding the affect he had on the world at large, and the sense of responsibility that remained after the fact.

This year the Salk Institute celebrates its 50th anniversary. After spending a few hours with the good folks at the Institute, it’s obvious the spirit of Dr. Salk lives on as research continues to save lives and advance quality of life worldwide.

This symposium was the brainchild of Gladys Swensrud. The idea came to her only a few months before the event took place and, thanks to the great effort of the folks at the Institute, it became a stellar event – one that will live on for many years to come.

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The information presented is truly state-of-the-art. The neurological details of polio's damage to the breathing muscles and the methods of testing and administering treatment are remarkably accurate and complete. The hands-on experience of Louis Boytano cannot be topped.

Hope

The word has been frivolously tossed about these days. Used in an obscure, somewhat meaningless way, but this symposium does offer real hope.

As one who has experienced PPS breathing problems for nearly 20 years, read every book on the subject, counseled hundreds of PPS folks, and lived the bilevel ST experience for nearly a decade, one could say I know a thing or two about it. Several people asked if I learned anything new at the symposium. My answer: I learned that there are professional people out there who really know and understand PPS breathing problems.

In this article, I didn't try to include all the details of the symposium, just an overview and opinion as to its importance. You can see it in its entirety at <http://poliotoday.org>. Some folks have watched it 10 times and still learn from it. If your doctor isn't as well informed as those you see on the videos, learn all you can, and teach your doctor.

If you don't have a computer, visit a friend who has one, go to the library and use their computer, or see the poliotoday.org videos at your local PPS meeting. There's no substitute for the real thing.

Also: Janet Renison and Baldwin Keenan of the Orange County PPS Support Group have been working on an excellent multi-part article. You can contact me for a copy. If I get enough requests, I'll reprint it in future issues of the PPS Manager. (Also available at ppsupportoc.org)

Assisted Breathing for PPS folks: Some New Thoughts

Thoughts, research, and ideas by Rick Van Der Linden 8/20/09

The Pressure is on

The latest innovation in bilevel breathing support is the **assured volume bilevel** machine. A few major manufacturers have jumped on the bandwagon in recent years replacing the manually titrated (pressures and times set by a technician according to doctors prescription) with the automatic titrating machines. Simplified, the technician sets the machine to deliver a prescribed volume of air per minute prescribed by the doctor, presumably based on body size or other chart derived factors. Because the machine adjusts to the users volume requirements, it's easier for the doctor/technician to find a setting the patient can tolerate. The result is a higher rate of **patient compliance** but is it the best-long term treatment?

The Positive

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First-time users of the new generation (automatic) machine report success within the first day or two whereas the previous generation of machines were too often initially set wrong, so success was hit and miss – mostly miss. A high percentage of people gave up because of wrong settings. That doesn't seem to happen with the new, automatic machine.

The Negative

However, those of us with older, manually adjusted machines have an added advantage, assuming we (or our technical assistant) are wise enough to know what we need and are able to set the inspiratory pressure (IPAP) to respond to our minimum requirement. The timed functions are then used to control volume. This allows us to get no more muscle support than we absolutely need. The end result, over time, is that we are less likely to suffer atrophy of the breathing muscles – a loss that would force us to “graduate” to a trache (vent support delivered through a tube surgically inserted in the neck) and/or full time volume vent perhaps years before it may otherwise have been necessary - if at all.

In other words: The new machine is aimed at delivering a set volume (assured volume) of air per minute which means it's a “volume first, pressure second” approach. This is done by setting a prescribed volume of air per minute. Then the machine automatically adjusts to the patient's requirements by adjusting the IPAP and (perhaps) timed functions. The IPAP is what actually supports (braces) our weak breathing muscles. If we have careful control of the IPAP number, we have the best chance of conserving our muscles over time. The “volume first” method of setting up the machine gives that control to the machine.

Volume vent vs. bilevel

There is some confusion over what, exactly, is a volume vent. Traditionally, a volume vent was a special ventilator used in cases of total vent dependency, such as paralysis, coma, etc. The doctor could set the machine to deliver a particular volume of air in and out every minute, and check blood oxygen level to confirm the correct settings. Note the use of the words volume and time. To create the conditions for volume over a period of time, the machine must have control of not only air pressure, but also the time periods that pressure is on and off.

What is NOT a volume vent? A breathing support machine without a timed function such as a CPAP or a Bilevel S cannot be considered a volume vent.

CPAP = one constant pressure.

Bilevel S (sometimes called a BiPAP) operates at two pressures – high for inhaling, low for exhaling. The pressure change is triggered spontaneously (that's what the “S” stands for) by the user's input. Try to breathe in and it switches to high, etc.

Realistically, the bilevel ST machine can be considered a volume vent because of its timed feature. It's a combination of spontaneous and timed (ST) functions much the same as a traditional volume vent. There is a difference, however.

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In a recent study comparing bilevel ST to the volume vent approach, volume preset is not always better than pressure preset.

(<http://www.labmeeting.com/paper/23493435/lien-2000-comparison-of-bilevel-positive-airway-pressure-and-volume-ventilation-via-nasal-or-facial-masks-in-patients-with-severe-stable-copd>)

In the study, people with severe COPD experienced (and tests supported) a better sense of muscle rest and blood gas exchange with the bilevel. For comparison to those of us with PPS it should be noted that muscle rest was a key factor in the study. People with COPD have to work harder to breathe, so there is a reasonable comparison to the muscle weakness of PPS.

So what makes a volume vent worth four to five times the cost? Generally, they're designed for full time use and 100% dependency, so they're, theoretically, better built. Some have a built in back-up battery, bells, and whistles ...

To further complicate the issue, most volume vents have the option of "pressure first" setting making them more like the bilevel ST machine when that setting is selected. So, it's not just a matter of what machine you have, it's also a matter of how it is set. Obviously, in the above test, a standard bilevel ST (not a newer volume assured bilevel) was compared to a volume vent using "volume first" settings.

It should be noted here that in the Salk presentation, Louis Boytano explained that, since the new AV machine is also equipped to be set as a CPAP, Bilevel S, or Bilevel ST, he sometimes chooses to start a patient on the AV setting then, after an adjustment period, reset the machine to ST mode at the average settings indicated by the previous AV experience. This sounds like the perfect procedure.

Dependency

You might wonder, how dependant does one need to be to require a trache and/or a volume vent?

I use a bilevel ST overnight and at naptime. Through most of my life, my favorite sleep time per day has been about 9 hours. Now, my average time on machine is about 9-1/2 hours per day. Seems pretty normal. My IPAP (inspiratory pressure – a good gage of how much assistance the machine is providing my breathing muscles) setting is 13.6. If I were on a volume vent 24 hours a day, set at 36 (or whatever pressure my muscle-less chest required), I would be 100% dependent. I'm around 1/3 pressure dependent for 40% of the day. I guess that works out to roughly 35% dependent.

In reality, I'm 100% dependent, because without it I would have been completely dead ten years ago.

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As with my legs, I've learned to "conserve to preserve" as cautioned by Dr. Jacqueline Perry. So, metering the IPAP only as needed (as previously discussed) allows me to preserve my breathing muscles. I may remain at 35% for the rest of my life or I may lose the normal 1 or 2 percent per year.

At least I know I'm doing the best I can do for the long run.

Ain't no good if you don't use it

Another issue involving the use of assistive devices has to do with Post Traumatic Stress Disorder or PTSD. [see PPS Manager, July 2009]

Basically, a traumatic event (a near death experience, for example) might cause the victim to suppress the memory or, the other extreme, be tormented by the unforgettable event. In either case, the bad memory becomes a serious problem when it causes a person to make bad decisions or disrupts the person's life.

In the case of post polio, for example, a person might have a fear of ventilators because of his or her childhood experience with the iron lung. Thirty or forty years later, when PPS pops up, this fear may prevent the use of a simple life saving bilevel ST.

In fact, it's not uncommon within the PPS community to see people refuse to use braces and/or power chairs, taking pain meds instead, resulting in early muscle loss and joint disintegration. Often, this failure to make the right decision is based on doctor advice, but fear of returning to the assistive devices of the past – the helplessness of that polio-stricken child – is all too often a factor.

In my case, I resisted braces and I put off bilevel assistance for years after I knew it was the right thing to do. I called it hard-headedness. I'm convinced I'd be better off today if I hadn't waited until my muscles got "bad enough."

Help is on the way

In this decade, researchers have developed a new understanding of how memories are formed, stored, and retrieved. Studies have shown that memories are not hardwired into our brains. They're changed every time we retrieve them. New drugs in combination with simple therapy may soon be available. These new drugs have been shown in tests to reduce horrible memories to merely uncomfortable memories. One of the stumbling blocks to patient compliance will have fallen away.

All it takes is a little understanding and a little knowledge, and the desire for a better life -- unreasonable fears can be overcome.

Sooo

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In conclusion, the new volume assured machines are great for patient compliance but may not be the best long-term solution. And, if you're not using assistive devices because you "don't want to think about it" though a little voice way down deep inside tells you otherwise, a simple solution is on the way. You just need to reach out and grab it.

We're known for tenacity. Let's all work to maintain that stereotype.

MEETING REPORTS

San Diego Post-Polio Support Group

November 14, 2009 and December 12, 2009 Meeting Reports

Notes by: Gladys Swensrud

Our 2009 Christmas party was a large gathering of friends, old and new. The yearly holiday meeting provides us with a unique time to just sit and talk, share friendships and chat about any topic we wish. Along with a wonderful potluck spread, we had the musical accompaniment of Mike Blazick's extraordinary talent on the violin. And our White Elephant gift exchange didn't disappoint in the entertainment department either...be sure to ask Steve Goldman about the beautiful enamel bracelet someone "stole" from him at the last minute. We are sure he is still in tears over that one ☺!

Our November meeting had a sobering side as we viewed the documentary *The Final Inch*. For anyone who has not yet seen it, it is a **must** see! The 38-minute film documents the continuing quest to eradicate polio throughout the world. From a total of 350,000 cases of polio reported worldwide in 1988, the numbers declined to approximately 2,000 in 2007, which was detected mostly in children under the age of 3 in the countries of India, Nigeria, Afghanistan and Pakistan. To complete the eradication process, the film details the need to find and immunize every child.

A portion of the film focuses on the difficulty of convincing community leaders within the deepest slums of those nations that they will be saving lives and quality of life for their citizens by allowing their children to be immunized. It chronicles how Muslim leaders, so distrustful of America, must be convinced it is not a plot to undermine their country by allowing mass immunization.

Anyone interested in purchasing *The Final Inch* should be able order it from Amazon.com for \$7.50 a DVD. It comes within a couple of days, and would be well worth planning a group meeting around. Our talkative group was left speechless after watching it. Part of the quiet was realizing that people throughout the world are still suffering the ravages of polio...and the other part was reliving our own experiences through the vivid images the film portrayed.

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____The next San Diego meetings:____

January 9

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

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

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

COACHELLA VALLEY POST-POLIO SUPPORT GROUP

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

Victorville PPS Group

No report filed. Contact Vi or Kay for information.

____Next meetings:____

January 13

February 10

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

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

Escondido North County

Post Polio Support Group

____The next meeting:____

February 9

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

HEMET AREA POLIO SURVIVORS (HAPS)

In November, we had our normal meeting - PPS talk and friendship.

Our Christmas party was fun and warm thanks to the swell facilities at Valley Wide Recreation. About twenty polio folks and their family members exchanged gifts and food, and listened to some live music during the two-hour get-together.

For the January meeting, you can expect the usual sharing with some whining about the cold weather thrown in for good measure. Okay, I'll do the whining to save you the trouble.

No Free Lunch?

February 16, 2010, 11 AM Sun West Village

Getting Your House In Order: A presentation by Ron Eitzen

Included: Veteran's benefits, Social Security benefits, wills, trusts and some information on Riverside National Cemetery. There should be plenty of time to allow for Q and A.

Lunch will be provided (chicken, potatoes, gravy and all the trimmings.) free of charge.

Everybody is welcome, so bring friends and family.

RSVP required if you want to eat: (951) 926-5492 or email rickvdl@roadrunner.com

___ Our next **HAPS** meetings are: ___

January 19

February 16

Getting Your House in Order

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

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Riverside PPS Group

December 19, 2009 Holiday Party

Networking is a good thing. We form a “Human Web.” According to Wikipedia, “six degrees of separation” refers to the idea that everyone is, at most, six steps away from any other person on Earth.

When my friend Barb, whom I know by networking with my high school alumni association, emailed me to ask about a possible connection between PPS and ALS, I immediately connected her with Gladys Swensrud. Now the two have a wonderful dialog going on. It came about by a sad circumstance, though. Barb’s friend, a polio survivor, was diagnosed recently with ALS, and passed away.

Barb (whose husband has ALS) sent me a great article by Cheryl Carter New about the kind of personality and attitude found among people who survive ALS beyond the initial three- to five-year sentence. As I read Cheryl’s article, I felt there are similarities and differences in how we respond. The majority of polio survivors are not faced with a life-threatening disease. Additionally, our condition is not a sudden new thing, out of the blue; we fought the polio battle before; we “overcame” once before. Also, doctors haven’t been willing to acknowledge there is such a thing as PPS – it is sometimes difficult not to be in denial ourselves! Anyway, here are some subheadings from Cheryl’s piece. See how they apply to you, or where you might adopt a new approach!

http://www.alsindependence.com/The_Survivors.htm

- ***Survivors draw emotional stability and mental strength from outside themselves.*** – Our faith in God, our friendships.
- ***Survivors are universally stubborn skeptics when it comes to the “facts” about ALS.*** (With PPS, we find it’s the doctors who are stubborn skeptics. We must network to get the facts to each other, because improving quality of life depends on our applying what is known!)
- ***Survivors will try almost anything.*** Uh-oh. We on the other hand tend to avoid trying those assistive devices, for fear of the “handicapped” label – but we ought to be more proactive!
- ***Survivors are problem solvers.*** Take for example Rick Van Der Linden teaching us about using bi-level breathing; and Gladys Swensrud, enlisting Kaiser to the cause, not only in San Diego, but working on getting it state-wide.
- ***Survivors communicate.*** – Post Polio Support Groups, Newsletters, Emails, PolioToday.org!
- ***Survivors stay mentally active.*** “Type A” people!
- ***Survivors have somebody they love and who loves them.***
- ***Survivors are relentlessly positive.*** (Those who aren’t are not very popular!)
- ***Survivors allow people to help them.*** Hint, hint.
- ***Survivors help others.***
- ***Survivors have a wicked sense of humor and never lose it.***

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Our holiday party was quieter this year than in past years, as several of our regulars were unable to attend due to illnesses or other circumstances. Did I say "quieter"? We could barely hear Rick and Sandy singing to us those great songs over the din of our many conversations. We are a gabby group. (It's great!) Gladys came up from San Diego and added to our joy. We celebrated the value in getting to know each person's unique beauty of soul. Regina outdid herself with lovely handcrafted gifts and greeting cards. It was good to see Edward again (he was also at the Salk Symposium) with his daughter, Nicole, who is majoring in Neurosciences, and is planning to take the MCAT soon and apply to medical school in either 2010 or 2011. He is very blessed to have such a sweet, intelligent daughter!

Some communicated by mail and email their best wishes for the holidays, and we count them as having been with us in spirit, if not in body. We didn't get cards signed to you, but please know we appreciate and love you. Get well soon, Dale G. and Mary B. Hang in there, Yolanda and Eddie, caring for elderly parents. Your labors of love count.

Reported by Judy Mahoney

___The next Riverside PPSG meeting:___

February 20

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

Big Bear PPS Group

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

Polio Survivors Plus

PSP Report

Polio Survivors Plus has a meeting at 1:30p on Wednesday, January 20, 2010 in Clubhouse 3 of Laguna Woods Village in Laguna Woods, CA. Any and all attendees need to RSVP to obtain gate clearance.

Our January speaker, Carol John is flying in from Ithaca, NY, to make a presentation on "Ergonomics - Energy Saving Ideas for PPSers." She has taught occupational therapy courses at Ithaca College and has worked as an occupational therapist.

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Our past PSP speaker was Mina Nakhaee, a Board Certified Pedorthist. Ms. Nakhaee currently serves the Southern California community and is conveniently located at "The Shoe Specialist" on El Toro Road, (just off of the 5 Freeway) right beside Mother's Market in Laguna Hills, CA.

Pedorthics involves the design, manufacture, modification and fit of shoes and foot orthoses to alleviate problems caused by disease, congenital condition, overuse or injury. Pedorthics is a well-established allied health profession which makes an invaluable contribution to public health. Ms. Nakhaee's presentation was titled, "How the Proper Shoe Fit Can Help with Stability While Walking." Ms. Nakhaee illustrated the factors that must be considered when individuals with stability issues, such as how polio survivors, choose their walking shoes. This is critical information for anyone challenged with avoiding falls while walking. She also answered a plethora of audience questions and recommended that everyone should support their feet all of the time with the shoe that has the perfect fit.

Reported by Sue Lau

Next meetings: _____

January 20

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

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Letters

Letters 1/10

To PPS Manager and all Contributors,

I have a very strong testimony regarding the info gained from the newsletter.

I copy it twice to give to doctors in Utah. One has PPS. He saved my eyesight. He is an ophthalmologist. I had emergency eye surgery while visiting my son in Utah.

I won't linger with all you have provided for me and mine. Thank you is not adequate to explain my appreciation.

PPS MANAGER

Please continue to send me the newsletter. I will try to help with expenses as I can.

My friends and family are grateful to you.

Sincerely, Gloria Y.

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Dear Rick,

Thank you so very much for keeping me on your mailing list. I save all of your newsletters.

Best regards, Richard A.

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Dear Rick,

... Our last year or so has been filled with many joyous experiences but has dealt us difficult challenges along the way. Such is life. But we do applaud you for all you are doing.

Thank you, Beverly and Bill McGaugh

PS: I've had two out-patient appointments this year at Rancho Los Amigos clinic. They're wonderful. I couldn't recommend them more highly.

Question: Do you ever get information regarding spinal curvature and/or deterioration of the arms? I'd love to hear input.

[Can you offer information for Beverly and others who have similar problems? Please write or call Rick at the newsletter. - Ed]

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Rick,

I am still enjoying the newsletter. I always appreciate your continuing efforts to see that all of us are able to make good decisions regarding our health

I was particularly interested in the Casa Colina piece regarding FMS drugs and anti-inflammatory meds. And the info re: the H1N1 nasal spray flu vaccine.

Thank you so much,

PPS MANAGER

Joan

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[Response to the 9/09 issue of the PPS Manager newsletter]

Dear Rick,

Just thought I'd answer to Sylvia Smith's letter regarding PTSD.

The jumpiness and fear may be a reaction to her own adrenaline. According to my pulmonologist – one of the few MDs I found who is knowledgeable about PPS – “Anecdotal research indicates many with PPS are highly sensitive to epinephrine (the synthetic form of the body's natural adrenaline).”

He advised me to wear a Medic Alert pendant, and to give every doctor I see a copy of the letter from the allergist who originally diagnosed my having the condition. It can be a very serious allergy, one which, in extreme cases, can kill.

I first learned of it when I had a bronchial infection and used some of my sister's Primatine Mist. Within 15 minutes I was lying on the floor in a public restroom surrounded by EMTs – then on my way to the ER. I remember in the ambulance hearing them say my blood pressure was 60 over a number I don't recall, and they couldn't find a pulse.

In answer to Elizabeth Gerdes' inquiry on cataract surgery: I had the surgery almost a year ago. It's an easy procedure nowadays. Mine was done by ultra-sound here in Riverside [California], apparently the newest technique.

The surgeon was great. Wish I could say the same for the anesthetist. I'd given the surgeon the article by Dr. Susan Calmes of UCLA, and asked him to forward another copy to the person who'd be handling the anesthesia. When I arrived for the surgery it was obvious she hadn't read the article and had no intention of using a topical and the doctor had talked about. Instead, as soon as I sat down her assistant grabbed my arm, tied it down, and began injecting something. Whatever it was I wasn't fully awake for about 12 hours. But the surgery itself is great – the sight in that eye is perfect. Now the cataract in my right eye needs to be done, but I've put it off for fear of the anesthesia.

We shouldn't have to live this way! I also have some serious dental work that needs to be done, but keep postponing it for the same reason.

Speaking of dental work, I have a copy of the notice to tell your dentist to use the “old fashioned” numbing stuff. We tried the “new and improves” local which is to wear off by the time the patient leaves the office – only in my case it wore off in a matter of 2 or 3 minutes. The dentist and I experimented around with it by giving me several injections in different areas of my mouth, but each time it lasted no time at all.

PPS MANAGER

One more problem of a similar kind – one I'd really like to ask your readers if they had. I've had nitrous oxide (isn't that what the dentists use to "put you out?") 3 times, and except for one time it's worked well. The second time, however, it didn't affect me at all. Two weeks later we tried again and it worked perfectly.

Keep well, and take care of yourself this winter.

Carolyn Moyer

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Dear Rick,

Thank you so much for all your hard work in the Polio Newsletter. I know my husband really appreciates the information you're able to gather.

His doctor is always trying to learn more about the disease. I would like her to get a subscription also. [Address included]

My husband would attend your meetings, but he still works. Three more years and, hopefully, he will be able to retire and not be totally disabled.

Thanks for all your hard work.

Chris.

Hi Chris,

Three things I'd like to comment on. First: you obviously understand and support your husband in his battle to live with PPS. You play a very important part in his long-term health. He's lucky to have you on his side.

Second: You are so right to educate his doctor. The best doctor is one who already knows about PPS. Second best is one who is willing to learn. Most PPS folks have a hard time finding either one.

Third: It's a very common dilemma for us PPS folks – when do we give up our regular job and become a full time PPS manager? An unusually large percentage of us go through that "two more years" thing for three or four years until we can no longer function and are forced by circumstances to go on disability. The key is to make a move before serious damage is done to the joints, and/or muscle atrophy has gone too far. It's also important to do it before you start losing pay by going part time or missing work. This causes your last 40 quarters average pay to decline, therefore reducing monthly income after retirement.

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Hope this helps,
Rick.

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[The following was an email forward from Carol Thompson of Blue Whale]

DALLAS – Nov. 25, 2009 – Physicians at UT Southwestern Medical Center soon will begin implanting a new device designed to improve breathing in patients with upper spinal-cord injuries or other diseases that keep them from breathing independently.

UT Southwestern University Hospital – St. Paul is only one of only two sites in Texas and one of 25 in the country currently equipped to implant the device, called the NeuRx Diaphragm Pacing System.

The device is designed to give patients more freedom and to help slow respiratory decline. Patients who have diseases or injuries that affect breathing muscles, such as the diaphragm, are more prone to lung infections because of their weakened ability to inhale and exhale sufficiently, said _Dr.

Michael DiMaio_

(<http://www.utsouthwestern.edu/findfac/professional/0,2356,36393,00.html>), associate professor of cardiovascular and thoracic surgery at UT Southwestern.

“Patients who have high-level spinal-cord injuries are unable to breathe efficiently because the nerve signals no longer function,” Dr. DiMaio said.

The diaphragm separates the abdomen and chest cavity and contributes to 80 percent of respiration. Nerve signals from the brain tell it when to expand and contract. When it expands, pressure inside the chest is reduced and air rushes into the lungs. When the diaphragm relaxes, the lungs and chest wall push air out. People with spinal-cord injuries that interfere with breathing are typically placed on external mechanical ventilators that support breathing through positive pressure via a tube placed directly into the airway through the front of the throat.

The implantable device, manufactured by Ohio-based Synapse Biomedical, was approved by the Food and Drug Administration in 2008. The NeuRX system includes four electrodes that are implanted directly into the diaphragm. Electrical signals from an external control device induce impulses from the phrenic nerve, which runs from the spine to the diaphragm. Once those signals reach the electrodes in the diaphragm, the muscle is stimulated to expand and contract. This action more closely simulates normal breathing than external ventilators. “This device has some advantages over traditional ventilators,” Dr.

DiMaio said. “Patients have more mobility because they don’t have an external ventilator to carry around, and the surgery to implant the device is less invasive than previous treatments.”

Researchers said they hope the new device can improve quality of life and decrease incidents of infections that can affect patients who are on external ventilators. Prior generations of phrenic nerve stimulators were inserted by making an incision in the neck and chest. Electrodes were then placed directly on the nerve, rather than the diaphragm.

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“Although phrenic nerve stimulation as a way to induce breathing in these patients isn’t a new concept, we think the NeuRX will alleviate some symptoms present with previous stimulators,” said Dr. Jose Viroslav

(<http://www.utsouthwestern.edu/findfac/professional/0,2356,64711,00.html>), professor of internal medicine at UT Southwestern and pulmonary and critical care specialist. “One of the problems that arose before was scarring and fatigue of the phrenic nerve. This stimulator is placed on the diaphragm, and the pulses are more diffuse.”

Dr. Viroslav said another major advantage with the NeuRX device is that it helps with speech.

“Patients on diaphragmatic pacers have more of a normal ventilation, and their vocal cords are not bypassed therefore they can talk,” he said. “

Breathing with the diaphragm is normal, and if you can do it with implantable electrodes, you are closer to breathing normally with the advantages of speech, less infection, and more mobility.”

Patients who are interested in the NeuRX device should first consult with their physician to determine whether they might be eligible.

For additional information, please contact the research coordinator at UT Southwestern by calling 214-645-5337.

Visit utsouthwestern.org/heartlungvascular to learn more about heart, lung and vascular clinical services at UT Southwestern.

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This winter remember to:

Dress in layers

Take a nap

Stretch

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Take a nap

Drink water

Take a nap

Look forward to spring

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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 and Ann Howell. Special thanks to: Kathleen Murphy, Joan Wesockes, Bill & Beverly McGaugh, Richard & Mildred Atchison, Kenneth & Marilyn Edwards, Gloria Yates, Holly Beam, Patrick Keane, Paul P.Pickering, Wayne & Suzanne Gesiriech, D. MacKinney, Nona Atkins, Lorraine Hartik, Betty McFarland, Joseph & Marilyn Grande, and the entire Riverside PPS group. 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