

FROM THE EDITOR

Hi Fellow PPS Managers,

The days are growing short and the temperature is dropping. There's a definite shift in PPS management style. It's time to stay inside, check out the new TV season, football, good books, favorite tea ... If we do it right, we'll be thinking about everything but PPS because we'll have it under control.

Would you like to share your special winter management tip? Go ahead, write.

In the meantime:

We revisit The PPS Brain, an article from the May, 1999 issue. It's fun to look back at what I wrote nearly 10 years ago and explore what I've learned since. Maybe you will too.

Also, donations to the newsletter have been terrific! We now have well over two years of funds.

See a tribute to Phil Black in the HAPS report.

THIS IS IMPORTANT!

Please look at the address label on front of this issue. If there is a * after your name, you have contacted me and will remain on the mailing list. If not, you must call or write in order to receive future newsletters in the mail. Remember, you do NOT have to donate money. It's free. I just need to know if you want to keep receiving it.

Rick VDL

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IN THIS ISSUE:

**The PPS Brain (revisited) by Rick VDL
Dr. Benditt
Meeting Reports, Letters, and much more...**

THE PPS BRAIN

by Rick Van Der Linden

[Originally published in The PPS Manager May 1999.]

WHAT THE VIRUS DID

To better understand how the damage caused by the poliovirus is affecting us today, we need to get a rough idea of how the brain is wired for action. Every action message sent out by the conscious or unconscious brain passes through the base of the brain. This primitive area of the brain which controls our basic animal functions (moving, breathing, sleeping, etc.) is connected to the top end of the spinal column. This structure, the brain stem, is shaped like a light bulb, the Medulla (socket area) topped off with the Bulbar region.

When the poliovirus enters the nervous system it causes an infection in the gray matter of the spinal column disrupting the signal from the brain to the muscle cells. Lesions (scars) from this infection can be detected by autopsy or by MRI and are seen as speckles throughout the gray matter. The resulting Paralytic Polio is partially overcome in rehabilitation but the lesions remain. In most cases (or perhaps all, but to varying degrees) these lesions continue upward beyond the spinal column and into the brain stem where sleep, breathing and swallowing are controlled - Bulbar Polio.

Usually the heaviest concentration of lesions is in the spinal column and they thin out as they progress upward into the brain stem with very few in the rest of the brain.

PPS MANAGER

Doctor Richard Bruno has described the polio-damaged brain stem as looking like it was shot with a miniature shot gun.

THINK AND ACT

Often we have trouble finding words, concentrating, staying awake and aware, remembering things. It's enough to make you think you're losing your mind. But why should this happen if the virus only damaged the action part of the brain?

To answer that question think about this: We are experts at compensating for weakness. If a muscle is weak, the one next to it works harder. It stands to reason that if an area of the brain is overworked, a nearby area tries to take up the slack. To put it in computer parlance, we create a much less efficient software solution in the thinking part of the brain to fix a faulty hardware problem in the action part of the brain. The result is a computer that is straining its capacity - Central Fatigue.

DO YOU REMEMBER?

"So," you ask, "If polio didn't directly hurt my thinking brain why do I have memory problems?" I can think of three reasons. Fatigue, poor quality or quantity of sleep, and PTSD.

FATIGUE: When I overuse my body, my brain is short changed in the energy department (see **THINK AND ACT**) and the resulting Central Fatigue causes loss of awareness. I can't remember things I never noticed.

SLEEP DISORDERS: Memories of the day are set in place during the three hours of REM sleep. This important segment of sleep can be interrupted by jumpy legs, side effects to a drug you're taking (including alcohol and caffeine),

aches and pains, and so on. If, for example, during REM sleep you are reviewing my face and name and you suddenly wake up because... say you quit breathing... you may forget me.

PTSD: The third reason is perhaps a little more controversial. Post Traumatic Stress Syndrome (PTSD) can cause you to forget a particularly stressful event and make it hard to make new memories. We don't all respond to stress in the same way, but there could be a small percentage of us who suffer from PTSD. Next issue of the PPS Manager we'll take a closer look at PTSD. [July 1998 issue of The PPS Manager newsletter.]

CONCLUSION

Although the poliovirus invaded and damaged part of the brain it was only the action parts that were damaged. The higher functions should work just fine if we manage PPS properly.

"The best we can do" involves saving our energy for creativity. Sing, paint, make photographs, write, garden ... share your vision. Even if it's just for a few minutes a day, it's the most human thing you can do. Being creative is better treatment than any drug. It lifts you above your mortal problems and brings you closer to a purely spiritual state. I'm thankful every day that, although polio hurt my brain, my mind was left untouched.

UPDATE – NOVEMBER 2008

In the above article I touched on the connection between mental function and sleep apnea. At the time, I had not yet learned of the effect weak breathing muscles has on sleep quality and therefore mental abilities. Here's more on that:

PPS MANAGER

PPS remains the same strange and often illusive disease, though our understanding of it seems to keep evolving. Since writing “The PPS Brain” nearly ten years ago, I’ve added a very important piece to the puzzle. That piece is the negative effect of hypoventilation, which I later wrote about in an article called “Barely Breathing.”

To summarize: many of us (some say “most of us”) suffer from breathing muscles weakened by the poliovirus. Over years of slow deterioration of these nerve/muscle connections, we breathe less and less as we compensate for the weakness. Year after year it goes unnoticed as we learn to survive on less oxygen (O₂) while carbon dioxide (CO₂) builds up in our blood. As years go by CO₂ is stored in our muscles and organs. The presence of excessive CO₂ interferes with normal function, so we end up with things like high blood pressure, failing kidneys, liver failure, and so on.

Of particular interest to this article is the effect on the brain.

CO₂ IN THE BRAIN

I’m not a doctor and I don’t know all the hows and whys, but I am an expert in the area of first hand experience in this matter. It happened to me.

I had polio at in 1953, PPS diagnosed in 1994. I’m now (2008) 61 years old. At the time of my diagnosis I was told that I may have been experiencing PPS symptoms as long as 10 or 15 years before problems became serious enough to cause me to seek treatment. At first I found it hard to believe. Now I see things differently.

My mind was changed by the fact that now, after five years of overnight ventilation, I still find improvement in certain mental abilities.

It seems that vent therapy corrects blood gas balance right away. After all, simply hyperventilating over the stress of having an ABG (arterial blood test for level of CO₂ in the blood) test at the hospital can remove a good portion of built-up CO₂ in the blood. However, the longer hypoventilation continues, and the more severe it is, the more CO₂ collects deep within body tissues. It takes time to clean up the mess.

Some of the early improvements included a clearing of the fog - I could actually think again. My memory seemed to improve, too. Depression was no longer such a problem as the increased endurance allowed me to accomplish more and therefore feel more useful. Decision-making is no longer a problem.

The most surprising delayed improvement is in the area of problem solving. I’m a Mr. Fixit. A machinist, a writer, a musician, plumber, electrician, carpenter, mechanic, inventor ... and yet, there are a lot of little glitches in daily activities I’ve put up with for years. In the last two years I’ve come up with several simple creative ideas to make repetitive tasks (or every day activities) easier or more efficient. On every one of these occasions I’ve asked myself, “Why didn’t I think of that 20 years ago?” These are not complicated problems with complex solutions, they’re little things that have bugged me or wasted time, and the solution was always something easy, cheap and only required a few minutes and materials on hand. The only answer I come up with is, “I must not have been thinking straight.” And only two things have changed. I’m over 60, and I’m on overnight ventilation. I doubt that being over 60 could be the reason for this unexpected improvement so, by the process of elimination, I assume it has something to do with the latter.

PPS MANAGER

Dr. Benditt, Vent Specialist

If you live in the great northwest and you have a neuromuscular breathing problem, you're in luck. There's someone in your area who can help.

Dr. Benditt is well versed in the ins and outs of vent use. This fact is made clear in his video, "Non-Invasive Assisted Breathing" produced by University of Washington TV's Talk Medicine program.

The main subject, serving as an example of neuromuscular breathing disorder in the video, is a young man with Duchene Muscular Dystrophy (DMD). A patient for ten years, Jesse started with an overnight BiPAP machine and eventually advanced to full time NPPV using a daytime sipper and overnight mask. Because of a very weak cough, he also uses a cough assist machine.

Discussed are details of thirty-one year old Jesse's decision to not have a tracheostomy and his reasons for that choice.

Jesse says that he has not been hospitalized with pneumonia in the ten years since NPPV.

Jesse demonstrates the use of his positive pressure sipper to "breath stack" to produce a better cough. Then his respiratory assistant discusses the use of the cough assist machine.

Basic bilevel machines are demonstrated along with the mask styles available. In Jesse's case, a bilevel machine works well for overnight, but during the daytime, a volume vent, which he uses by way of a sipper attachment, is attached to his power chair.

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Now available in paperback "Polio: An American Story" by David Oshinsky Oxford University Press

The Pulitzer Prize winning account of the scientific and political struggle to develop the polio vaccine and get it to the people.

"A riveting, detailed story of the battle between the Sabin and Salk camps.

David Oshinsky did a heck of a job."

Rick VDL

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NEW DRUG FOR THE TREATMENT OF PPS

In August 2008 Pharmalink, a Swedish pharmaceutical company, released information regarding a new product for the treatment of PPS.

Years ago, studies showed that intravenous immunoglobulin (IVIG) could reduce the inflammatory cytokines found in the cerebrospinal fluid of PPS patients. As a result, a slight reduction in pain and fatigue was noted in most study subjects.

The new drug replaces the delivery method of several expensive intravenous treatments with one shot every nine to twelve months.

Studies are now under way in the US to see if it will be made available to us.

For more information, check out:
<http://www.i-sites.net/ppsrl/IVIg.html>

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PPS MANAGER

MEETING REPORTS

San Diego Post-Polio Support Group

September 13, 2008

Note taker: Gladys Swensrud

Stand-in facilitator, Steve Goldman, did his normally gifted, fill-in routine for Rick Kneeshaw who was “on the road” with Lenora somewhere in middle America. Word has it wherever they looked from their RV windows they saw cornfields, cornfields and more cornfields. We missed you, team Kneeshaw!

Today’s meeting was free form and filled with lots of useful information. During the first 15 minutes, Gladys Swensrud read the letter she and Don Baisch prepared and submitted on August 19, requesting the expansion of Kaiser/San Diego’s successful Neuromuscular Respiratory Program throughout Southern California. They are presently awaiting a response to their request. We discussed the importance of carefully wording any appeal to for help asked from an HMO or PPO. Gladys stressed the need to be very specific in your wording. A few suggestions would be to:

- State names of everyone who is making the request (person/people).
- Identify the person/group of people who will benefit from the change of policy for which you are asking.
- Clearly state the problem you wish to see resolved in easy to understand terms.
- Give background/supplemental data to support your point of view.
- Offer a solution you feel is a workable option and explain why you take this stance.

- Detail what you have already done on your own behalf, and list specific names of those you have personally contacted in your hunt for solutions.
- Summarize how your request will impact not only you but others similarly situated.

We briefly discussed testing of a newly introduced, potential treatment for Post-Polio Syndrome, Xepol. The Phase III study involving 142 patients was announced on August 26, 2008, in Stockholm, Sweden by the specialty pharmaceutical company, Pharmalink. According to their press release, “The follow-on results strengthen the position of this novel treatment modality for PPS by demonstrating a reduction of inflammatory cytokines in the cerebrospinal fluid and a significant reduction of symptoms of PPS while also showing that Xepol is safe and well tolerated with few or no side-effects.” Needless to say, we will be following the details of this study as it progresses. Watch for future information on this topic.

Steve next announced a new legal decision in which the San Diego Polio Survivors were involved via Rick Kneeshaw. Steve explained that following Rick and Gladys’s San Diego Zoo mobility challenge success in December of 2006, Rick took a position on the Board of the Disability Rights Legal Center (DRLC), who represented Rick and Gladys in their lawsuit. According to the DRLC description on the web, their mission “...is to promote the rights of people with disabilities and the public interest in and awareness of those rights by providing legal and related services.” They fulfill that mission through each of the cases they represent.

Because of his close connection to the DRLC, Rick stays abreast and involved with a

PPS MANAGER

variety of legal issues. He was recently emailed notification about a case in which the San Diego Polio Survivors signed onto an amicus (a Latin term meaning "friend of the court") which had a great outcome. In the case of Robert Miller v the California Speedway Corporation, the 9th Circuit court of appeals held that **in newly constructed venues accessible seating has to provide line of sight over standing spectators.** Simply put, this means that when a disabled person buys a ticket to any event, he/she has the same right to actually *see* the event they are paying for as much as the person in front of them who stands to get a better visual vantage point or to cheer on their favorite team. We send out a big cheer from the San Diego Polio Survivor team to the Disability Right Legal Center and to our in-house advocate, Rick, for the work they do on behalf of all disabled citizens!

Upcoming events

SDPS meetings are held at: Kaiser Permanente's Hospital located at 4647 Zion Avenue, in Classroom 2.

November 8 meeting – Tentatively scheduled is a guest speaker on protection/service dogs

December 13 meeting – Holiday Party

___The next San Diego meeting:___

December 13 Holiday Party!!!

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

Oct. 10th. Reported by Bob Braddy

We had a short business meeting before the guest speaker spoke. We received some help for postage from those present and it was decided that we did not need refreshments at the meetings.

Lois Jackman of Yes I Can was our guest speaker. She gave a very interesting and lively report of her experiences with Dr. Richard Bruno and the Post-Polio Institute. They had just recently opened their services to reach beyond the local area in New Jersey and offer evaluations to people all over the US. The evaluation process is extremely thorough. It begins with a multi-paged set of forms that you fill out and return to the institute. There are extensive blood tests, MRIs, Cat scans and you take those with you to your appointment. The appointment starts with an exhaustive interview with Dr. Bruno (2 hours) and moves on to a physical therapist who evaluates your current strengths and weaknesses during which they tell you which parts of your body are too weak to exercise. Then you move onto a complete physical exam by an MD. After all this after a couple of weeks you will receive the evaluation with recommendations for you to follow.

Lois said that Dr. Bruno is the ultimate expert on Post Polio Syndrome but that he is also a very warm and caring doctor who is very laid back and friendly.

A lively discussion came as members asked many interesting questions. A recommended book was "How to Stop Being Vampire Bait" by Dr. Bruno

Sally Saban, MS, RD, has agreed to speak at our November meeting. She is a registered Dietician and the Clinical

PPS MANAGER

Nutrition/Patient Services Manager at Eisenhower Medical Center. It should be a very interesting presentation.

_____ **The next meeting:** _____

November 14
December 12

2nd Fridays at 10 AM at Portola Community Center, 45-480 Portola Ave, Palm Desert CA Park in rear. For information, contact **Bob & Kathy Braddy at 1(800) 242-4111 or (877) 938-8267 or email rbraddy@dc.rr.com**

Escondido North County Post Polio Support Group

Reported by Marilyn Loba

Our October meeting was held on the 14th at the Escondido Joslyn Senior Center. The time was changed to begin at 12:30 pm to allow more time for discussion and still finish by 3pm. The time change will afford an informal discussion time for those who are available to begin earlier. Our regular programs will, as always, begin at the 1pm time.

We began our meeting by discussing suggestions for future meetings. Many good topics and speakers were discussed as we begin to set up for next year's meetings. John brought DVD copies of our August meeting with Dr. Bradley Schnierow to share with the group and to add to our library. Two new books are also available for checkout.

Our speaker for this meeting was Allison Blaha, C. Ped, of The Foot Comfort Store in Vista (www.footcomfortstore.com).

Allison began the program with a discussion about the ten tips for getting a proper fit.

1. Foot size changes as we get older – get your foot measured each time and shop at the end of the day when your feet are the largest.
2. Fit your largest foot – polio survivors especially may have feet of different sizes.
3. Select shoe by fit, not by marked size.
4. Select a shoe that is shaped like your foot.
5. Make sure there is enough toe room in a standing position.
6. Make sure ball of foot fits into the widest part of shoe.
7. Do not expect shoes to stretch – buy shoes that feel comfortable.
8. Your heel should fit comfortably with a minimum of slipping.
9. Even if the shoes are comfortable at the store, wear them on the carpet at home to make sure that they fit and feel right.
10. Shoe uppers should be made of soft, flexible materials. Soles should provide solid footing and not be slippery. Thick soles cushion your feet. Low-heeled shoes are more comfortable and safer.

The discussion continued about ways to customize shoes to fit the foot. There are a variety of lifts, insoles and arch supports available over the counter that can improve the fit and comfort of the shoes. Custom orthotics and lifts are also available. Shoes can be built up on the outside in the soles. For severe fitting problems, special sizes can be ordered from some manufacturers or custom shoes are available.

Much information about wear patterns and support needs can be determined by examining the insoles of worn shoes. An expert in fitting

PPS MANAGER

can determine foot problems and modification needs.

Many post polio survivors have feet that are different sizes. Up to approximately 1 size difference there can be adjustments made to the shoe but 2 sizes or more may require purchase of two pairs to provide a comfortable safe fit. Some higher end department stores such as Nordstroms will split sizes for their customers.

Fit and support are the most important way to purchase shoes. Try to find a store that provides sales people that are experts in shoe fitting. Have your foot measured each time that you shop for shoes. Purchase shoes by fit not style. Make sure that your socks or stockings are comfortable and wear them when your shop for shoes.

Allison finished her presentation by taking questions from the group. We thank Allison for her informative and lively presentation. The Foot Comfort Store is located 1611-B South Melrose Drive in Vista, (760) 598-3668.

We finished our meeting with general discussion.

For our December 9th meeting, we are pleased to have Dr. James Marino, orthopedic surgeon who also has PPS, as our speaker. The subject will be "Living with Post Polio."

The next meeting:_____

December 9

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 info. call Marilyn Loba (760) 745-2787 or email ppsnorthsd@cox.net.

HEMET AREA POLIO SURVIVORS (HAPS)

Hi Everybody.

The September and October meetings were both open discussion, less than a dozen folks at each meeting.

The September meeting was the last one for Phil Black. Phil passed away a couple of weeks before the November meeting. Phil has been a regular member of HAPS for a good eight years. He was always helpful, caring, thoughtful, and he will be missed.

Though it's sad to lose a good friend, it must be said that had it not been for the PPS group, I wouldn't have had the opportunity to meet Phil and all the other great people I've been lucky to get to know since coming down with PPS fifteen years ago. And I do mean "great" people.

I meet a lot of people. Folks I play music with and for, friends and family ... but PPS folks are special. Not just by the things we have in common. We've talked about our drive to achieve, our tendency to excel, but I'm referring to the fact that each of us seems to have a special skill that goes beyond the physical - something that sets each of us apart from everyone else. I see the same sort of individuality in everyone I meet, but there seems to be a higher peak reached by polio survivors.

I'm proud to be part of this group – proud to be a PPS manager – and I thank Phil for helping me see it.

We've scheduled this year's Christmas party for December 7 from 1 to 3 PM (we'll have the room from 12 to 4) at Valley Wide Recreation facility in the general-purpose room as usual. Live music by one of Rick's bands,

PPS MANAGER

pot-luck, fun ... Call Bunny to coordinate menu items.
(951) 766-7118.

Have fun...Rick

Our next **HAPS** meetings are:

November 18

December 7

Christmas Party!!

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 766-7118

Big Bear PPS Group

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

Victorville PPS Group

Call for information

Next meetings:

November 12

December 10

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

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

Riverside PPS Group

Reported by Judy Mahoney

October 18, 2008

We were very happy to hear from Dale Gerdes by phone during the week, who reported he was found cancer-free (after much prayer and chemo). More tests soon to determine if follow-up is necessary, but you know Dale – always cheerful, rejoicing in the Lord in all circumstances.

Betty tried to be in three places at once but wasn't able to manage that, so we missed her. But we did have three new people! It was joy to welcome Joe & Marilyn, and we were honored also to have sculptor of note John Edward Svenson. He shared about his work, and of course we were all in awe. (Google his name or try <http://www.oma-online.org/svenson.html> for a nicely done website.)

Several shared experiences of world travel, going with a group, walking versus taking a chair. We talked at length about using assistive devices in general to conserve, but it is difficult to overcome the stigma associated with riding in a chair – power or manual.

And the question often arises, "If I go to a motorized chair, will I lose even more function from lack of use?" Far from it – using a chair when you can still walk will help keep you walking longer, because you conserve your muscles. It very unlikely that once you get a motorized chair you will even use it as often as you should. It just seems unnecessary, and it's a bother. But you ease into it. It's a mental process.

We used the analogy of making investments. Let's say you have a 401k (your body). While you are still working (still able to walk), you tuck money away into your 401k so that when you retire, you'll have a supply to help you

PPS MANAGER

when you are older. Be wise – invest in your muscles by conserving them today so they will be there for you tomorrow.

We thank Lorraine Hartik for the PPS “We’re Still Here” buttons, and for informing us of Southern California’s November 13 earthquake-drill, “The Great ShakeOut.” See

<http://www.shakeout.org/>

Holiday Party: Saturday, December 20th – 11 am at Mahoneys’ – 3465 Ramona Dr, Riverside (951) 788-9310. ppsriverside@aol.com. Great music (“Rick n Eddie”), delicious food, joyous fun.

2009 meetings – Begin at 11 am, third Saturday – February, April, June, August (BBQ), October, December (Holiday Party) at home of Bryan & Judy Mahoney.

___The next Riverside PPSG meeting:___

December 20 Holiday Party!!

Riverside PPSG Meetings: third Saturday of even # months at 11 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 bboopl@aol.com

Polio Survivors Plus

With PPS, that's Passion, Persistence and Selfless determination, PSP's October Speaker Gladys Swensrud, (San Diego Polio Survivors co-facilitator), shared what fueled her efforts to make a difference for persons with disabilities

and people who are challenged with neuromuscular conditions.



Taking a question from the audience, (L) is San Diego Polio Survivors' Co-Facilitator Gladys Swensrud and in a front row seat is (R) Mildred Urban.

Her presentation focused on the importance of all polio survivors getting involved in some phase advocacy; how she influenced changes in San Diego's Kaiser (HMO) system; what resulted as Kaiser's Neuromuscular Respiratory Program; the founding of San Diego's Neuro Network (that is comprised of 14 organizations); and how she navigated the legal system with San Diego's Rick Kneeshaw to ensure those who use motorized mobility aids don't have to sign liability waivers as an entrance requirement (in the federal law suit Kneeshaw v. Zoological Society of San Diego, Case No. 05-CV-2127-IEG DT [POR], covering the world famous San Diego Zoo and Wild Animal Park).

While one may think that such accomplishments of advocacy are only pertinent to the San Diego area, the results are more far-reaching. The judicial case that compelled the San Diego Zoo and the Wild Animal Park to suspend their waiver of liability

PPS MANAGER

policies was viewed by zoos all over the world.

Now, any Kaiser patient can make a request of their physician to be referred to the Neuromuscular Respiratory Program, by contacting Guillermo Friederichsen, RRT, or Phyllis Walker, RRT, in the S. CA Permanente Medical Group (phone: 619-516-6514; fax: 619-516-6567) for testing and treatment. If one is not a Kaiser member, testing can still be done by contacting Helen or Melanie at Progressive Medical in Carlsbad, CA, at 800-491-2292.

So, how do you know if you have compromised respiratory muscles? If you are a polio survivor; have a nighttime breathing deficit; use nighttime mechanical ventilation (like a CPAP or Bi-PAP machine); have frequent sighing; fading voice while speaking; headaches when awakening; gasp for air at night; have multiple bathroom visits each night; have excessive daytime drowsiness; have overwhelming fatigue from the dawn of beginning a new day; don't recall dreams at night; and prefer not to make plans for the days that lie ahead, then you might want to be tested for a Bi-Level S or Bi-Level ST ventilation machine.

She also advised everyone to keep ventilation machines properly maintained by replacing the headgear every six months; the mask, every three months; and the tubing, monthly.

Reference Medicare, Medi-Cal and/or your own insurance's coverage for replacement guidelines and placing supply orders via the proper health care provider.

In addition to Gladys's presentation, quick update notes are that: (1) the Social Security Administration announced that monthly checks, as of January 2009, will reflect a 5.8% COLA hike with (2) no increase in Medicare Part B premiums. (3) Open enrollment for Medicare

Part D is rapidly approaching with any changes made from November 15 to December 31, 2008, so compare the plan in your area to make sure that you're with the one that can optimally serve you with the best prescription coverage.

(4) If you have not yet received a stimulus check, it may not be too late to file a tax return for 2007. See the "Senior Action Required" section at <http://seniorark.com/index.htm>

All polio survivors are invited to attend in Clubhouse 3:

-- November 21, 2008, Friday from 10-11:30a: "**COPS**," a presentation on advocacy through the "Community Organizing Project" by the Dayle McIntosh Center (and* with the LW Vision and Hearing Club);

-- December 12, 2008, Friday from 2-4p*: **Holiday Gift Fare**, featuring gift ideas for people with disabilities from more than 15 vendors and service providers.

-- January 28, 2009, Wednesday from 1:30-3:30p: **The Reversal of Disuse Atrophy - Is the Reversal Worth It?**, presented by Marney Eulberg, MD, of Denver, CO.

Next meetings:

November 21
December 12

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

PPS MANAGER

Letters

Dear Rick,

I want to thank the PPS Manager and the Hemet Area Polio Survivors for the years of support and comradeship my husband Phil enjoyed with your group. Thanks to those who attended his memorial service and for the card and donation to his favorite charity.

I would like to sell Phil's van, as I have no disability myself. It's a 1990 Ford Econoline XLT Super with a 5.4 liter V8, hand controls, a Bruno Sr. hoist, tow package, and running boards. It's well cared for, so there are plenty of good miles left in it. His scooter is included. I know it's worth more, but I'm only asking \$5000.00 for it.

Kathy

[contact Rick. Info at the end of the newsletter]

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Hi Rick,

Just a quick personal comment regarding you retiring your editing and "producing" the newsletter.

I think you need to do what is best for yourself. I can sense that you are doing that and that if you do "retire", it will be because it's better for you. And we all are in the same boat and we all will understand it and never try to second-guess any decision you make. I retired (a few years early) a year ago and I feel bad for the people still working, but they knew it was time for me to retire, and they don't criticize me for my decision.

BTW, I only want the Internet version of your newsletter. I get a lot of information now about PPS, so if you retire the editing part of your life,

I personally will be fine. With that said, I enjoy getting the newsletter and I always at least scan it. For instance, there were several references to stress and PPS, which is an area I have special interest in. I pick up little jewels once in a while in your newsletter. And from an emotional point of view, I take strength from knowing I'm not alone in my PPS problems.

Thanks for your service Rick.

As a Combat Vet (Vietnam), I am thanked for my service by others and I appreciate that, but I know I will no longer be able to do what I did back in the 60's. I decided a long time ago that I need to leave certain things to the next generation.

Larry Julius

Washington State

Larry,

I always take time to thank a Vet.

THANKS, Larry. And thanks for the advice, too.

Rick

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Rick and all,

I have a condition some others may share. Around ten years ago I started having a spasming esophagus during my evening meals, where my esophagus simply locked up with little or no warning, and food being eaten loads up on top of the blockage. The only relief was to induce vomiting, which was easy because the food to be gotten rid of was not yet in the stomach.

After several years the incidence of spasming was interlaced with what I called my

PPS MANAGER

stomach locking up with gas increasing (again at an evening meal) to the point it was severely painful and difficult to breathe. A sneeze was a major event. When this gastric distress began in earnest, the condition with the esophagus diminished, then went away. I have just found what has caused the entire sequence of events.

Having had polio in 1949, post polio began to ease in (at least to my awareness) around six years ago and I found it necessary to discontinue singing with a master chorale because I could no longer sustain a note as before. This of course, was due to a weakening of the muscles that operated the diaphragm.

Now back to the stomach problems. The esophageal specialist showed me photographs taken of my stomach from the inside that showed a huge hiatal hernia with the sphincter muscle apparently vaporized. The doctor explained that surgery was available to correct the condition, but that due to my age (76), coupled with the fact that I had polio, the operation was strongly to be avoided. He then explained that the scenario leading to this mess was that with the diaphragm weakened from polio, this led to the hiatal hernia, which then led to the stomach conditions. A delightful scenario.

Because I have too much stomach acid, the doctor prescribed Protonix twice daily, and for me to sleep with my head on several pillows (what joy) to hopefully reduce these delightful incidents where I feel I would be better off if I simply croaked.

At any rate, I seem to be doing better, and hope that if some of you experience these same symptoms they are a tad more understandable.

Larry K.

--

Hi Rick:

... I'm glad to hear that people are supporting

this both physically and monetarily - I will send you another check when I make them all out next week. You do a wonderful job and I can't imagine anyone else taking it on! Being of service to others!

I can't remember what all I wrote to you last time around but I think I did ask if you had ever heard of PPS connected with going deaf and I think you wrote no. It clearly is, at least according to UCLA where I got my Cochlear Implant. The little 'nerve hairs' in your ears that allow for hearing start to shut down, never to return, and once they all go bad, that's it for hearing anything. In a normal hearing person, those nerve hairs do start to shut down as you get older but it's a rare thing indeed for someone to go totally deaf. Hard of hearing, yes, but the kind hearing aids can fix.

For us, the process goes much more quickly and starts at an earlier age; therefore, when I went deaf at age 59 I was shocked because no one had prepared me for this news or that it could even happen. Certainly, not everyone with PPS and hearing LOSS will go deaf but at least at UCLA they know what can happen with us and are not totally clueless about PPS, which is a true relief. ...

Thanks - Holly B.

--

Rick,

Your September issue is delightfully informative. I laughed when I read "Dear Doctor". You had the bad doctor dialogue so familiar I could hear my doctor's voice back in 1983.

Fortunately for me when he referred me to a physical therapist it was to one that had her training at UCSD. She told me she had seen a TV news item reporting on the Salk Institute at UCSD getting information on the late affects of polio. This led to finding others in San Diego

PPS MANAGER

area and starting a support group.

What you do keeps us connected. I am glad you reported on the stress of putting out the newsletter. We tend to get wrapped in our own world of coping and neglect being sensitive to what it "costs".

...

Thank you, Virginia

--

Grace Young is still out there!

Hi Rick,

I would like to continue receiving your informative newsletter. I also want to let you know that I just started a web log on disability issues, titled Grace R. Young OT

If you would like to use any of the articles in your newsletter, that is fine as long as they are reprinted in their entirety.

...

Warm regards, Grace

[Visit her site at www.graceryoung.com]

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Hi, Rick,

Thanks for putting me back on the PPS Manager email list. Just to let you know, the online version is fine with me. I will try to put at least a small check in the mail for you to help out with expenses.

I do have a question, though: on page 12, in your response to Joe Marsh, you write, "The two most likely causes of early death are doctor related. One is treatment with painkillers and antidepressants..." So I went online to see if I was harming my health by taking Celexa, an antidepressant that works extremely well for me. In the Sept. 2001 Post-Polio Forum in New

Mobility magazine, Dr. Bruno says that there is no reason for polio survivors not to take an anti-depressant if they really need it, and says that Celexa is one that has fewer side effects than some of the older ones. Has something else come to light in the meantime (since 2001)? Also, what was this about painkillers? Maybe since I've been off the PPS Manager email list for a while I've missed these articles.

I did get a hoot out of a "quiz" I found online, and if you haven't seen it, you should take a look. It's called, "So You Think You Are a Polio Survivor? A Holiday Quiz." It's located at:

<http://www.newmobility.com/articleViewIE.cfm?id=306> .

While in general I always do the second choice, much to my husband's disgust, I always want to do the third choice! You'll see. I laughed when I read this.

So I'll continue my online research.

Thanks, Joanne

Hi Joanne,

In my opinion there's nothing wrong with antidepressants when taken in conjunction with counseling and with a particular goal in mind. The problem I see over and over is the combination of opiates and antidepressants. Strong drugs are sometimes prescribed to treat PPS pain, then when it's unsuccessful, more painkillers, and then antidepressants on top of that. The lack of success as I see it is due to the fact that the pain killers take away our most valuable tool in managing PPS neuron loss, and that is pain itself. The end result often includes joint destruction as well.

As a support giver, the most frustrating calls I get are from polio survivors who have been on Vicodin or Percoset plus antidepressants. The average is about six years

PPS MANAGER

before the trouble really sets in and I get the call. They're looking for alternatives, usually more or stronger drugs. They usually have worn out tendons and joints, are in untreatable pain, slur their words, and usually are unable to get around.

I know that good doctors recommend non-steroidal anti-inflammatory drugs (NSAIDS) like Advil and some of the newer and better kind, but I find that I have to be careful even with Advil. It works fine for me except for the side effect that when I use it I need more, and more.

I have successfully treated PPS pain (which I found unbearable in 1993) with assistive devices and time management and my life has been very active and good. I average one or two Advil per month and that's it - and I only take them when I'm through with activity for the day. And, I did take the antidepressant Paxil during 1998 or thereabouts. That doesn't mean that my current plan will work forever, but it's worked for fifteen years without a hitch.

On the other hand, I understand that everyone has the right to handle things their own way. I just try to give my opinion based on fifteen years of successful PPS management, and the good and bad experiences of others I have observed.

I'm sorry to be so frank about this stuff, but I don't know how else to deal with it.

Rick

--○○○○○●○○○○--

We're all different, but it's our similarities that bring us together.

Rick VDL

THANKS

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Pat and Tom Sampsell
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