

FROM THE EDITOR

Hi Fellow PPS Managers,

The grass is green, the sky is blue,
I'm sick of PPS, how about you?

That just about sums up what I have to say this time around.

Yes, it's beginning to look a lot like springtime around here. The wildflowers are starting to bloom, rain once a week keeps them happy, not too cold ... soon all those beautiful flowers will amount to nothing more than weeds and I won't have the energy to manage the situation without hurting myself.

It's always something.

Well, at least I got the newsletter done – late again thanks to a bad cold that attacked my throat and chest. Quick with the antibiotics, expectorant, and decongestant to prevent gunk from building up and ease removal. Rest, rest, rest, liquids galore. I'll live. At one point I thought I might need to go to the hospital but thought I'd rather risk living at home than dying at the hospital. It was a gamble. I won.

Enough about me.

Rick VDL

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IN THIS ISSUE:

From Ten Years Ago

VENT!

Meeting Reports, Letters, and much more...

VENT!

Definition:

Often used as a short form of the word ventilate.

Verb:

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- 1) Letting in fresh air – allowing for air exchange.
- 2) Verbal release of pent up feelings
- 3) Short for ventilate – to provide breathing assistance

Noun:

- 1) An opening or duct designed for the purpose of providing air exchange into or out of an enclosed space.
- 2) Short for ventilator – a device used to assist or support weak or incapacitated breathing muscles.

In this article, we'll explore the relevance in the lives of PPS folks of two particular forms of the word VENT.

Vent – Short for Ventilate

You're in a closed-up room. Over time, the air has become stale and you're feeling claustrophobic, dizzy, and nauseous. What do you do? You open a window. Better yet, you open two windows - on opposite sides of the room. There's a light breeze outside. At the up-wind opening, fresh air enters. At the down-wind opening, the used air (exhaust) is forced out. Ahhh, relief.

Vent – Short for Ventilator

Ventilators are assistive devices. For PPS folks, bilevel ST ventilators go by names like BiPap ST, VPAP ST, and Volume Ventilators. They improve our blood gas balance by compensating for weak breathing muscles. More oxygen in the blood (via fresh air), and less CO₂ in the blood (exhaust) = Ahhh, relief.

Vent – Verbal release of pent up feelings

“I'm sick and tired of post polio! I'm mad as hell at not being able to do what I want to do! I try to get something done, and get pain in return for my efforts or I get so tired I can't stand it! It's just not fair. I didn't ask for this.”

How's that for venting?

I guess I could go to that open window and yell as loud as my weak diaphragm and chest muscles are able, but who would hear me? Who would even care? Good question.

Even if no one listened, I suppose it's good to just let off steam. Releasing the pressure can reduce stress for a little while. That's a good thing. Do you remember primal scream therapy?

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What if someone did listen? If the person hearing me was someone who has the same problems, I might get the response, “I know how you feel.” That would make me feel less alone. I would no longer feel like a “lonely little petunia in an onion patch.” Validation can be soothing.

And then there’s the opposite extreme: “Quit feeling sorry for yourself. Whining won’t help.” I got that from my brothers. It did me no good at all.

Well, maybe whining does help.

Here’s another thought: What if someone said that I was just reinforcing the negative? Why am I not yelling: I can still think! I can listen to music! I can still go to church (or watch it on TV)! I can still read and write! I can watch my grandchildren grow up!

Maybe the best venting involves both. Have a good screaming and crying session, count your blessings, and then carry on.

GOOD VENTING, EVERYBODY!

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Out with the bad, in with the good. Hmmm, which “vent” was I talking about?

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New at PPSManager.com

Rick recently added a PPS Breathing page to the PPS Manager web site.

You’ll find the basic information on breathing problems – how to recognize and treat hypoventilation - illustrations, videos, links, and frequently asked questions.

This is an ongoing project, so check back now and then for the latest updates.

Go to → www.ppsmanager.com and click on the “PPS Breathing Page” button.

FROM TEN YEARS AGO

PPS MANAGER

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

A little understanding works wonders.

SPREADING THE WORD

The big story for me this issue is the publication of a PPS story in the local county-wide newspaper, the Riverside Press Enterprise. In the article staff health writer Mike Schwartz did an excellent job of describing what polio and post-polio are. He interviewed me and Dr. Jaquelin Perry, he researched the work of Dr. Halstead and he included a very good illustration of the motor unit's damage and "recovery".

At the forefront of the article was the fact that many are misdiagnosed and mistreated by physicians who do not understand or accept PPS.

In a follow up story he covered the methods of managing PPS and included my phone number as a referral to those in need of help.

[After the article was published] I was on the phone for three weeks solid. It's been two months since the article came out and I still get a call every other day.

Some highlights of the experience:

Misdiagnosis:

About two out of three calls were from people who told their doctor that they had had polio and yet were being treated for other things, mostly Fibromyalgia Syndrome (FMS). The usual treatment of FMS is exercise and a diet high in fruits and vegetables. As a result of this treatment most people with PPS (who normally need little or no exercise beyond necessary daily activity and a high protein diet) will have an increase in pain and fatigue for which the doctor prescribes pain killers, antidepressants, and then more exercise.

We have a lot in common:

In the past six years I've talked to hundreds of polio survivors at local meetings and on the Internet and I know that polio survivors have a lot in common but it didn't really sink in until I started hearing the same story over and over again.

The big difference between us [myself, having learned to manage PPS and the callers just beginning the process] is the level of acceptance (or knowledge) of the condition and therefore the ability to calmly manage PPS without serious medications.

How many Americans have PPS?

In the article Mike Swartz used the lowest estimate of 300,000, or roughly one in four or five polio survivors who have or will get PPS. The highest estimate I've read is 1.6 million had polio and 90% have or will have PPS. That's nearly one and a half million people! [The current average estimate is around 700,000 – ed, 02/10]

Out of seventy calls only one was from someone who had polio over forty years ago and had no noticeable symptoms of PPS.

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I started HAPS (Hemet Area Polio Survivors) over a year ago. In that time I located about a dozen polio survivors in my local area. After the article that total has increased to over thirty. That's almost triple! [In 2009, the list has topped 100]

Learning to manage PPS:

A well-informed, open-minded doctor will prescribe assistive devices and a minimum of invasive medications or surgeries. They will also suggest that you join a support group and change your lifestyle. Those who trust their doctor to "fix it" are suffering the worst pain, fatigue, depression and mental confusion.

Several of the calls were from people who seemed to have a sixth sense about the effects of polio. They intuitively know that pain-causing activity is bad, rest and relaxation is good. One particular man comes to mind. His advice: Accept and understand the situation. Use relaxation, hot water therapy, assistive devices as needed and when you feel the stress or pain take a deep breath of fresh air in through your nose and blow it slowly out your mouth.

The most obvious roadblock to good management is the mindset that only the doctor can help you. You also have to help yourself.

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[From December 1999]

## **PPS HUMOR**

**The New Chair** by Jen Williams

We have two grandsons, 6 and 8, Devin and Nicholas, and they have never known grandma when she didn't have a cane, walker or manual wheelchair.....

Well, I had just gotten my new electric power wheelchair and they both thought this was just sooooo cool ... the little one, 5 then, walked around and around it and inspected it closely and kept looking underneath it several times.....I asked, what was wrong, since he had a very concerned look on his face. He stood up, thought a moment, put his hands on his hips and said, "GranMa, where are the blades to your ridermower?"

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IMPORTANT NOTICE

The test for Carpal Tunnel Syndrome may show a false positive due to PPS nerve loss. Your neurologist should be aware of this before scheduling CTS surgery.

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[From PPS Manager 02/2000]

**Rick:**

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Eddie, I heard about Chiari (Dysautonomia) on TV and was impressed by how similar the symptoms are with PPS (extreme fatigue as result of standing, balance problems, neck pain, etc.).

Is it possible that some PPS symptoms may result from the flow of spinal fluid being restricted by any or all of the following:

- 1) Scoliosis or slumping
- 2) The enlargement of the horn cells in the spinal column
- 3) Damage to the brain stem

[Note: Chiari is a rare condition in which some lobes along the lower part of the brain enlarge or slip out of place and restrict the flow of spinal fluid to other parts of the brain. These lobes are, coincidentally, right along side the brain stem which is known to have been affected by polio]

## **Eddie:**

I'm not surprised by similarity of symptoms. For example, just about any insult or malfunction of the body results in fatigue. Its almost a universal symptom. For PPS we don't have balance problems and we do have extraordinary local muscle fatigue which can generalize to the entire body. Another example would be CFS and Fibromyalgia. I read yesterday that many people start with unbearable fatigue with CFS but after a few years it turns to muscle pain and cognitive (memory) problems start. This is very similar to PPS and has been attributed by some to brain damage from the virus. But that may not be the cause. So pain and fatigue can be from sunburn, PPS, infections, trauma, and a host of problems ... At least that's how I see it now. It is simply the way the body reacts to insult.

So many people have PPS that I doubt if scoliosis is part of it for all of them. For some it certainly exacerbates the problem. There have been numerous autopsies of polio patients after they have died of other causes and no one has talked about enlargement of the horn cells. There would be other paths for spinal fluid flow if that did happen. As to #3...There was damage to the brain stem in polio. The question is did it heal. The brain is extremely plastic in its ability to substitute and heal. Brain scans of monkeys infected with polio virus show abnormal brain scans which clear up after they recovery phase. So all of your questions are valid but the answer is nobody exactly knows why PPS occurs. The most accepted theory is the "wear out" theory that motor units are overtaxed and wear out. Personally, I think muscles would wear out first. There is probably a place in the development of polio where old polio virus particles exacerbate the problem (because they are present in the spines of PPS patients) either by antibody attack against them (most likely) or by virus damage itself. [see "New Model PPS"]

Spinal fluid nurtures the Central Nervous System because there is a blood brain barrier, which prevents direct contact with blood into the brain. The capillaries are sewn tight. This prevents the brain from coming into contact with diseases and toxins that could wreak havoc.

## **NEW MODEL PPS**

In his "New Model PPS" Eddie Bollenbach stated that he believes there is a good possibility that PPS is the result of mutated polio virus. He cited a recent French study in which certain polio virus related RNA fragments were detected in PPS patients.

The theory goes something like this:

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When we had polio, the virus (PV) gets into a motor cell and reproduces until the cell explodes. This releases thousands of PVs - about ten percent of which are mutated and unable to reproduce. The un-mutated PVs infect healthy cells and repeat the cycle while an unknown number of mutated PVs infect healthy cells but do not reproduce and therefore don't do significant damage at that time. About 33 years later the cell gets tired of carrying the extra load and poops out. PPS is the result.

This seems to make more sense than the "overused muscle" theory of the cause of PPS onset because there are many cases of polio with no PPS later, as well as cases of very active people getting PPS at about the same time as people who have been relatively inactive.

## IMPORTANT NOTES

It's important to understand that this theory does not see PPS as the result of the poliovirus in its original form, but a mutation, which is unable to reproduce and spread. We are not infectious and therefore cannot give it to others.

This theory is an effort to understand how PPS gets started and in no way changes our need to conserve what we have by following a careful management program.

[Edward Bollenbach is a well known microbiologist and fellow PPS person. His research into PPS continues today.]

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## MEETING REPORTS

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### San Diego Post-Polio Support Group

#### San Diego Polio Survivor January 9, 2010 Meeting Report Notes by: Gladys Swensrud

Our first meeting of the New Year was started on a very high note with the introduction of new members and re-welcoming of old. How exciting it has been to watch our membership grow over the past year as more and more people discover our location and take time out from their busy Saturday schedules to attend. Kaiser arranged a larger room for us for 2010 to accommodate our growing size, which is a huge bonus. We plan to continue offering topics of interest and value, so keep your eyes peeled for meeting notices on the *Events* page at [www.PolioToday.org](http://www.PolioToday.org).

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We had another phenomenal January *What Works for You* discussion! Steve Goldman led the way with creative uses for grabbers of all shapes and sizes. He reminded us that the important thing about mobility problem solving is to identify the problem at hand and think divergently about ways of resolving it using every day items, either things from around the house or items that can be easily purchased. Steve took a simple handheld mirror from his pile of goodies, and set to work explaining how handy a mirror could be for peering over the top or under the bottom of things. He covered everything from taking clothes from a dryer on the top level of a stackable washer/dryer combo to looking under the bed for items that have rolled away and out of sight. I believe we all left this meeting with our brains in better problem-solving gear.

We had other really creative ideas surface, like an old-fashioned wooden shoe stretcher to keep the toes of tennis shoes from curling too tight for those with drop-foot or feeling too tight, either when new or after washing. We had all forgotten this old-time tool, which our grandparents and parents often used before the days when you could buy a new pair of shoes and have them stretched at the store to fit more comfortably. Along with being a creative solution, it provided an opportunity for a fun walk down memory lane.

We were reminded to:

- Go to [www.canesgalore.com](http://www.canesgalore.com) to purchase such useful items as right or left handed canes, and handy gadgets like clip-on cane holders, specialty cane heads or walking-stick toppers.
- Use a creative approach to foot pain by reversing an ankle support and wearing it long side on the foot/short side up the ankle to support painful foot muscles when they aren't comfortably confined in a shoe.
- Review creative ideas on the web and in stores before remodeling a kitchen or bathroom.
- Use grab bars strategically placed and securely fastened anywhere in the house where extra support is required for safety.
- Buy simple knee socks to roll down over the top of braces to keep them from chafing your calf.
- Etc., etc., etc!

The most memorable part of this month's gathering though will be remembering the friendships forged and information shared. We spent considerable time just talking and sharing memories and ideas. We hope to see all polio survivors within the San Diego metropolitan area attend a San Diego Polio Survivor meeting in 2010. And our doors are always open to polio survivors both far and near.

March 13, 2010 - Mr. Paul Bielman, Manager of Library Services at Kaiser Permanente's San Diego Medical Center will speak to us on the resources available on-line and through Kaiser Permanente.

\_\_\_ **The next San Diego meetings:** \_\_\_

## March 13

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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](mailto:piecon@mindspring.com)

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

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## Victorville PPS Group

The High Desert Group wishes everyone happy & hopefully healthier 2010!

Our January and February meetings have been luncheons held at local restaurants with some lively discussions on how to support all those 'New Year' resolutions and how to make them come true. Lots of literature from the PHI Gazette was passed out, along with all the website info for those interested! We've ordered the bumper stickers for our wheelchairs, scooters and cars to promote PPS. In addition we passed out the business cards with "Yes We Are Still Here" header made up for all members to pass out to any and all, with our meeting dates, times & contacts phone numbers for locations. Also still working on a list of physicians in the area who are knowledgeable about PPS.

We are really looking forward to our March mtg. as we finally found someone, besides our own Mr. Rick Van Der Linden, who is willing to take on the daunting task of driving up the hill to Victorville to talk to our group about Post Polio. Kathryn SanMartino from Casa Colina is coming up and will talk about 'Rehab and post polio, home safety and modifications and adaptive equipment and wheelchairs'!

The next mtg. then is March 10th at 'Lil Bit a Country' on Hesperia Rd. in Victorville. We invite any and all to join us.

Our April 14th meeting will be held at The Sizzler on Main St. in Herperia. In the future, we hope to have Dr. Shubin a neurologist from the Casa who has expressed an interest in coming to speak to us.

Next meetings: \_\_\_\_\_

**March 10:**

**Kathryn SanMartino from Casa Colina**

**April 14**

**Regular meeting**

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Regular mtgs. Second Wednesday of every month, dark on July & August.  
Location varies!

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For information, contact Vi @ (760) 949-6775 or email Kay @ calamity@sonic.net

## Escondido North County

### Post Polio Support Group

Our December 8<sup>th</sup> meeting included a discussion time along with a celebration of the Christmas holidays with food and fun. We also watched the video "The Final Inch" after a few technical problems. It was a nice time to catch up with our progress and spend time with friends both new and old.

At our February 9<sup>th</sup> meeting, we welcomed Dr. James Marino to speak to us. He spoke about how PPS is affecting us as time goes by along with a review of the disease and the development of the polio vaccine. After the presentation, we had a lively discussion in a question and answer time. We did use my new video camera to record most of the presentation before the battery died. Unfortunately, the discussion session was not part of the video. I should be able to make DVD copies of the presentation to share with groups who would like to see the presentation. As I learn how to use the video camera, I hope to be able to offer future presentations. You may contact me at mloba@cox.net if you are interested. I am hoping that those of us who find it impossible to attend our meetings can be reached through this media.

Marilyn Loba

\_\_\_\_\_The next meeting:\_\_\_\_\_

**April 13**

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

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## HEMET AREA POLIO SURVIVORS (HAPS)

January 2010

We started off the year rainy and cold, so there were just a few of us at the January meeting. A new member told her polio story, and that was good. It reminded me of the early days when we would each introduce ourselves and take a few minutes to tell our story.

The February meeting featured guest speaker Ron Eitzen, Advance Planning Councilor for Miller-Jones Mortuary. Rick started the meeting by introducing Mr. Eitzen and the subject he would be discussing, **Getting Your House In Order**. Rick pointed out that, properly managed PPS is not likely to cause early death. However, there is comfort in knowing you are prepared in such a way as to not leave a burden for you children.

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Mr. Eitzen pointed out that the cost of dying increases at an astounding rate but buying a burial or cremation policy fixes the cost at today's price. Not only that, the money spent is not an asset so it's not taxed as such, your wishes are sure to be fulfilled, it prevents emotional spending by your heirs, and you have peace of mind.

Ron's presentation included information on Veteran's benefits, Social Security benefits, wills, trusts and some information on Riverside National Cemetery. A Q and A session preceded lunch.

With 40 years experience, Ron Eitzen is very knowledgeable in these matters. He is available for free private consultation in the Hemet/San Jacinto and Menifee/Sun City areas by calling (951) 765-6417

We discussed a few options for future guests including a local vendor of a new type of scooter, and a person to advise us on how to apply for public services.

If YOU have an idea or a particular need for information, let me know and we'll see if we can get someone to enlighten us.

Have fun,  
Rick VDL

\_\_\_\_ Our next **HAPS** meetings are: \_\_\_\_

**March 16**

**April 20**

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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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## **Big Bear PPS Group**

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

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## **Polio Survivors Plus**

"Ergonomics in Daily Life" was the topic of the last meeting of Polio Survivors Plus, (PSP).

Registered and Licensed Occupational Therapist Carol K. John, who is also a certified ergonomic evaluation specialist, flew in from New England to make this presentation and to provide many useful tips.

While it's sometimes defined as the science of fitting the work to the user instead of forcing the user to fit the work, ergonomics is a discipline focused on making products and tasks comfortable ... efficient for the user. "It's so important for polio survivors 'to preserve to conserve,'" Ms. John repeatedly stated.

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She provided handouts to all meeting attendees. Within that provision is a list of "principles of safe body mechanics," which advises PPSers to:

1. Keep the load close to the axis of movement
2. Use the largest muscles and joints possible
3. Use mechanical devices whenever possible
4. Do not use body parts as tools
5. Pushing is safer and more effective than pulling loads
6. Prepare for work: warm up a bit, plan how you will perform difficult tasks, and do not rush through hard tasks.

To enable a person to do this, there is also a method to simplify work. Work simplification is possible if one plans, organizes, performs and evaluates tasks with an ongoing basis. An avenue to accomplish this end is to consider all daily tasks with:

1. Planning
  - a. Determine the necessity of performing the task
  - b. Determine who should perform the task
  - c. Determine what steps are involved
  - d. Plan the sequences of steps involved
  - e. Determine the work place
  - f. Determine the best time of day to perform the task
  - g. Reexamine individual jobs periodically for possible improvement in the process.
2. Organizing
  - a. Determine the preparation required (get tools and equipment ready)
  - b. Store equipment and tools where they are used (have multiple tools in a two story house)
  - c. Store tools where they are easily accessed (access does not require bending, stooping or reaching)
  - d. Eliminate unnecessary details or motions (keep frequently used information handy)
  - e. Consider eliminating the entire activity if it is too hard to do
  - f. Have the work area laid out to allow good postural alignment
3. Performing
  - a. Do hard tasks when you are rested
  - b. Alternate hard tasks with easy ones
  - c. Rest before you are tired, plan for frequent rests
  - d. Do not start a task that cannot be interrupted or put on pause for a rest
  - e. Use correct tools that are well maintained (sharp knives)
  - f. Always position yourself in correct postural alignment and strive for symmetry in your movements.

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## 4. Evaluating

- a. Take a moment to consider if the task just performed was worth it?
- b. Did it need doing? Did it contribute to your overall well being?

The Board of Directors for Polio Survivors Plus voted to share this helpful program with any post polio support group in Southern California, making a written request before the close of this calendar year. Along with this AV recording, handouts can also be made available. For more information and to have this request answered, write to: Board of Directors; Polio Survivors Plus; P.O. Box 645; Lake Forest, CA 92609.

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

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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

## Riverside PPS Group

Meeting Report February 20, 2010

After personal interaction, general discussion and lunch, we reviewed a presentation by Dr. Richard L. Bruno, at the 1991 PPS Forum, Arlington VA on Post Polio and Stress.

Dr Bruno began with what we have all been able to relate to: that we're tired of being told by our doctors that we're fatigued because we're lazy, fatigued because we're crazy, or fatigued because we're just getting old. Even though his presentation was made in 1991 when post-polio awareness was in its relative infancy – and happily we don't hear that annoying mantra quite as consistently now – Dr Bruno's introduction still struck a chord with everyone.

### **Polio Survivors Perform Well ...**

Dr Bruno gave statistics that showed polio survivors work full-time more than other disabled groups; have a higher percentage of education above high school than the general population; are "more married" than the general population. "What does this mean?" he asks. "Polio survivors are harder-working, are brighter than everybody else, and are more socialized than everybody else. In short, people who had polio are better than everybody else in the country!" (Laughter.)

He went on to say that while polio survivors have been the embodiment of the American Dream, this performance record has wreaked havoc on the survivors themselves. Physical and emotional

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stress are two leading causes of post-polio problems. “Your being so great has been great for everyone else, but at this point not so hot for you.”

## **Damage to Reticular Formation**

The three types of polio virus caused basically two kinds of problems: polio that paralyzes skeletal muscles, compromising mobility; and “bulbar” (located in the brain). In the 1940s David Bodian, neuropathologist at Johns Hopkins, discovered that the polio virus went into the bloodstream before it went into the central nervous system. In a summary of the research he had done, Bodian said (1949) (excerpts, and slightly rephrased by Dr. Bruno), “In all cases of poliomyelitis, inflammation of the spinal cord, damage to the gray neurons in the spinal cord, an ...encephalitis exists [brain inflammation], whether symptoms of the poliomyelitis are present or not, whether there’s paralysis or not... Lesions in most of the brain stem centers, and the reticular formation, are very common and often severe... Symptoms due to this damage would be more often observed if they were not overshadowed by paralysis of skeletal muscles...” (We were worried that you couldn’t walk, or your diaphragm wasn’t working – not about the reticular formation.)

What do the hypothalamus and reticular formation do, and if these centers are affected, if the neurons that run your diaphragm are affected, are there other areas that are affected?

Dr Bruno brought up sketches of the brain showing the hypothalamus and reticular formation. The thalamus is the turntable from the brain. It takes information coming up through your brain and sends it to the part of the brain that processes information over myelinated neurons – neurons insulated with myelin. The thalamus, hypothalamus, and other parts of this cluster constitute the reticular activating system. The RAS keeps your brain awake. It tells your brain to process information. The polio virus damaged – from mildly to severely – the centers that correspond to the RAS.

What kinds of symptoms would you expect to see? A 1990 National Post Polio Survey looked at people reporting new fatigue and found that 96% reported difficulty with concentrating, 85% trouble with long- and short-term memory; 82% trouble with attention; 80% had word-finding difficulty; 71% had trouble staying awake, and 70% had trouble thinking clearly.

## **It’s Up to You**

About 1990 they started doing MRI’s on polio survivors’ brains, and found significant lesions in the reticular formation, evidence of damage done years before. They found a correlation between these and the complaint of fatigue.

Is there, then, a way to deal with our fatigue? Yes. We have to deal with emotional and physical stress. In the studies Dr Bruno’s group was doing, there appeared to be a primary correlation in

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complying with therapeutic recommendations. People who don't comply continue to decline; patients who comply get better.

You are your own therapist. You have to go to people who know what they are talking about. But if you don't do what they recommend, you aren't going to get better. If you comply, you will get better.

Obstacles to compliance: depression and criticism to failure. It's totally and completely in your hands. You have to deal with the psychological realities of your condition, and take the recommendations to heart – and you will feel better.

Next meeting: April 17, 11am. Luncheon provided. Topic of discussion to be decided.

Reported by Judy Mahoney

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

**April 17**

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](mailto:PPSRiverside@aol.com) (951)788-9310

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## Letters

From the editor:

### Did you get your polio records?

Throughout the years, I've had several requests for information on how to go about getting hospital records of your polio visit.

The most obvious first step would be to write or call the hospital. If they are still in existence, they may have a dungeon with records on paper, and you may be able to pay someone to search for yours.

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Often the records of a hospital that went out of business are transferred to another hospital or some kind of accounting firm, so there may be a bit of a run-around involved in that case.

Or, the hospital may have burned down, the records lost forever. I've heard of this happening.

I've heard of cases where old records were transferred to microfiche and easily found and printed for a minimum fee.

In most cases it's safe to assume that fifty-year-old records (if they still exist) will most likely be on paper and it will be difficult to get someone to look for them and costly to have them copied.

Having your polio record might be enlightening, particularly if you don't remember much about the experience.

So I'm asking you, the reader, if you got your records, was it difficult and costly? Did you benefit from having the information? Was it worth the effort?

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Dear Rick,

Happy New Year! Thank you for sending this newsletter out. You know I read each and every word. You do so much for so many!

I opened a store on Cafe Press to sell items to polio folks like us. I am wearing my leg braces now and folks ask me if I broke my legs! I was thinking what if I wore a shirt that said, "Polio Survivor"? It would let folks know what is wrong, without asking me point blank. And it would bring about awareness to folks that we are still here!

So I opened my store and a guy just purchased a water bottle! I purchased a tee shirt and a baseball cap. Now, the reason I am telling you all this is because I would like to donate a portion of each sale to the Hemet post polio group.

Why? Because my entire family is back in Ohio and I was going through all of this alone. And thank goodness I found you on the Internet -- and because of you and the Hemet & Riverside groups, I know how to take care of myself.

# PPS MANAGER

Now, I need to get the word out -- and if you'd like to put something in the next Newsletter, great! I just want to let you know why I started this store -- and how I want your group to benefit.

It should at least help with some of the costs that you incur monthly!

Take care and please say hello to your wife.

I am doing great, going on auditions and resting when I can.

Hugs,

Lisa Zion

<http://www.cafepress.com/69442395>

[Lisa has a promising career as an actress. Watch out for her, she's a pistol! – Rick]

--

On 1/6/10 8:53 PM, "Richard Daggett" <[richarddaggett@ca.rr.com](mailto:richarddaggett@ca.rr.com)> wrote:

Rick -

I was reading the article you wrote for your latest PPS Manager, "Assisted Breathing for PPS folks: Some New Thoughts."

It is a good article and has some very helpful information. I did, however, find a couple of things that might be a little confusing to your readers.

You indicated that using a volume ventilator might lead to dependence and eventually the need to "graduate" to invasive (trach) ventilation. I have seen no evidence that indicates using assisted breathing devices, invasive or non-invasive, will hasten dependence. On the contrary, most people who have hypoventilation because of polio residuals have more energy and endurance once they start using assisted ventilation, either bi-level or volume.

Some people do "graduate" to assistive breathing devices that provide more support, but this is more often a result of decreased pulmonary function due to polio residuals. You also write, "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." This is often not the case. Unfortunately, many polio survivors still lack informed medical advice. Too often their physician will prescribe a CPAP instead of a bi-level device because it is easier to get approved (or they don't know any better), or oxygen via nasal cannula because they are uninformed, or lazy, or stupid.

# PPS MANAGER

You, and those other polio survivors who keep themselves informed, know how to tweak the machines to suit your individual needs. Many people are not as well informed, or are afraid to question their medical "authority figure."

You also include some information that would indicate that a bi-level device gives, "a better sense of muscle rest and blood gas exchange with the bilevel" over a volume vent. These results were noted in COPD patients. While some polio survivors might have COPD in addition to weakened breathing muscles, COPD is not the same. You conclude that paragraph with, "People with COPD have to work harder to breathe, so there is a reasonable comparison to the muscle weakness of PPS." Actually, there is very little comparison. The "O" in COPD stands for obstructive. People with COPD work harder to breathe because their airway is obstructed or their lungs are diseased. We don't breathe harder, we just don't breathe enough.

And, one minor, nit-picking comment. You spelled the nickname of a tracheostomy as "trache" with an "e" on the end. Many in Great Britain do, indeed, spell it this way, and pronounce it "trachee." Those of us on this side of the pond spell it without the "e" and pronounce it with a long a, just like the full name but without the "eostomy."

You conclude your article with very good advice. One of the biggest problems we face when trying to advocate and offer support, is the reluctance of many polio survivors to accept any assistive device.

Keep up the good work.

Richard Daggett  
richarddaggett@ca.rr.com  
or Richard@polioassociation.org  
www.polioassociation.org

To: Richard Daggett <richarddaggett@ca.rr.com>  
Subject: Re: Assisted Breathing for PPS folks: Some New Thoughts

Hi Richard,

Thanks for your careful study of my article and your positive comments.

First let me say that I started the article several months ago when I realized that my partners in setting up the Salk Symposium chose not to include the psychological factors involved in getting a PPS person to use a vent - something I consider to be half the battle. I would have preferred to call the article "Important Things Not Included in the Salk Breathing and Sleep Symposium", but that just didn't sound right.

# PPS MANAGER

The limitations of the new AV (assure volume) machines was another subject I didn't expect to hear mentioned, though Louis Boytano did, in passing, say that he finds the machine useful to break a person in on the mask, then later set it to ST mode for more precise control. It's as if he read my mind. (See the video at <http://poliotoday.org>)

I discussed the AV machine with a ResMed engineer at their San Diego headquarters a year before any local PPS person received one. As a vent user with over 30 years of engineering experience, I had my doubts about the new technology then as I continue to now.

I should note that both the ST and the AV machines are, in effect, very similar to VVs in that they produce a regulated volume of air over a given period of time. The main differences are the flexibility provided by the vented mask, and the "volume first or pressure first" methods of titrating. And of course the price tag.

The similarity is the time/pressure connection, which can be set to fully control breathing, or set to work with the user as needed. My intention in the article was to point out the fact that an ST, AV, or VV machine might be improperly set in such a way to as to encourage [muscular] underuse syndrome and promote muscle atrophy. I don't think I missed the mark on making that point, though it's not unusual that my wording is sometimes mistaken by some individuals. I hope you will be the only one to be confused by my writing method. [So far that has held true – ed]

There's no doubt that initial use of a vent brings with it a certain level of recovery. I tell people "Bilevel is like a brace for your breathing muscles. You can rest your legs, but you can't stop breathing. Once you have a chance to rest your breathing muscles, you'll breathe better all day long - just as you can walk better if you use a scooter part-time."

As for the CPAP thing, I've written repeatedly about the "less than useless" CPAP, and chose not to include the word "CPAP" in this article because it sticks out on the page. My thinking is that: people in need of breathing help are usually fuzzy brained. When an ignorant doctor says, "You need a CPAP," they might think, "Hmmm I read something about that in the PPS Manager." No, I'd rather accentuate the positive by repeating words like bilevel and ST.

Regarding a person's ability to set their machine: Yes, it's true that most people are not able to figure it out. A few years back I wrote a detailed article about how to understand the individual settings and how they relate to one-another, and I doubt that 1 of 100 people got it, though my RT was fascinated by it. My overall intention is to get people who are on vents to think about how the elements of time and pressure are affecting them, and then relate that to their technician. It's an ongoing challenge.

The perceived effectiveness of the ST over the VV was a bit of a [pleasant] surprise to me. I could only figure it had something to do with the comfort of having a vented mask and therefore a less forceful connection to the pressure received. In other words: a sense of personal control.

# PPS MANAGER

You said, "Actually, there is very little comparison. The "O" in COPD stands for obstructive. People with COPD work harder to breathe because their airway is obstructed or their lungs are diseased. We don't breathe harder, we just don't breathe enough."

Actually, you're confusing cause with effect. True, the cause is completely different, but the effect is the same – it's hard to breathe, so the victim breathes less. Actually, most pulmonary doctors, even those with PPS experience, list neuromuscular breathing weakness under the "obstructive" heading, though you and I might think of it as being in a class of its own.

As for the spelling of trach(e): thanks for the lesson. I've read the word in various books and articles and probably picked the spelling at random without regard to its correctness in America, though my newsletter is read in all English speaking countries. I'm not too concerned about it, however, because it's a word that is not likely to be used in future articles since it's going the way of the CPAP.

Again, thanks for writing.

Rick Van Der Linden - editor, PPS Manager  
[www.ppsmanager.com](http://www.ppsmanager.com)

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## Neighborhood Meetings

Eileen Howard would like to organize a neighborhood meeting group for PPS folks in the Carlsbad/Oceanside area. For more information call her at (760) 729-1022

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Rick,

Thanks for such a great job in regularly producing such interesting and informative issues.

Adrienne, Alice, and Deborah

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Dear Rick,

Thanks for your dedication and years of perseverance helping your fellow polio survivors.

Thanks,  
Paul

--

Thank you for so much information on PPS. I had polio at age 32 and will be 90 in 2010. I use a wheel chair for right leg weakness and bi-level for weak chest wall weakness.

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# PPS MANAGER

## 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: Donald & Carol Baisch, Carl & Virginia Nichols, Bonneta Doshier, Sally Laberteaux, Grace Huff, Patrick Keane, Jean Cullinan, and A.M. Marks. Your contributions keep this thing alive.

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The PPS Manager is published every other month by R.E. "Rick" Van Der Linden and is presented as management ideas.

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