

FROM THE EDITOR

From Ten Years Ago

Hi Fellow PPS Managers,

In this issue is a reprint of "PTSD and PPS" from ten years ago. As I was putting this issue together, I happened to spend some time with Dr. Bradley Schnierow as he was preparing to speak to my local support group on the subject of fibromyalgia, ventilation, and sleep disorders. Little did I know, Dr. S is a neurologist and psychologist. What better training for handling polio and the PPS mindset.

I was impressed by Dr. S's unique insights into the PPS mind and body. Hope to hear more from him in the future.

As an illustration of how we come about this crazy way of dealing with things, two special stories:

Michelle's Story was originally published along with the PTSD story in 1999 and it seemed appropriate to include it again. Also included was a story by Judy Sander. It is our good fortune that Judy has shared a newer story of her polio experience - "Dead Flies."

Anyone who doesn't understand why PPS folks resist returning to braces and other assistive devices should see the light after reading this issue.

Fortunately, we're able to rise above it.

Rick VDL

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IN THIS ISSUE:

PTSD and PPS by RE Van Der Linden

Michelle's Story

Dead Flies by Judy Nieman-Sander

Meeting Reports, Letters, and much more...

PTSD and PPS

Once called "shell shock", Post Traumatic Stress Disorder can result from a traumatic and/or life threatening experience. PTSD has been diagnosed in people who were in the battlefield, suffered violent attack, or had a life threatening disease including polio. In fact, one poll found that about ten percent of polio survivors are also being treated for PTSD.

What is PTSD?

There are many manifestations of PTSD including: Flashbacks, anxiety attacks, depression, paranoia, memory loss and difficulty forming new memories.

Although it is usually considered to be a psychological disorder, recent studies have shown that there is also a physical component. An MRI of the PTSD brain shows that the hippocampus (the part of the brain responsible for making memories) is, on the average, 25% smaller than expected. This suggests that in an effort to forget the details of the incident the brain has modified itself, perhaps destroying the area responsible for storing or retrieving the offensive memory.

PPS MANAGER

In the process, future memory manipulation is partially disabled.

Flashbacks, anxiety and paranoia could be the result of being "haunted by a ghost" – although the offensive memory is buried, but the grave can't be hidden.

Could I have PTSD?

Two people can have the identical experience and react differently. It's not what happens to us, but our reaction that makes the difference - we all react to things with different intensities. Therefore it stands to reason that in the case of polio survivors PTSD can be non-existent, extreme, or anywhere in between.

What can I do about it?

There is a recent scientific study suggesting that the hippocampus may be able to rebuild itself, while other areas of medical research are making historic advances in the area of nerve cell regeneration. This is good news, but until the technology is widely available we have to keep doing our best by applying good management practices.

If you think that you are being "haunted" it might be a good idea to get a professional opinion. Counseling and/or medication are very effective in treating PTSD.

MICHELLE'S STORY

I got polio in 1959 while living on the island of Guam. The people in the naval hospital didn't know what to do with me, or even what was wrong with me until after they had me in isolation and tied down (at 18 months old) for 6 weeks, while they waited for test results to come in from Japan. When they found out it was polio, everyone went into shock...and my parents never allowed anyone to know that I had polio.

When we came back to the states to live, my father made a contraption that was supposed to make me learn how to walk without a limp. Every time I limped, it would dig a nail into my ankle... I would either walk without limping or have bloody ankles. I believe this is where my "hiding" of my polio started.

I myself didn't know why I wasn't allowed to limp, until I reached my teens and started having nightmares about the spinal taps... and my parents finally had to fess up to me that I had polio when I was younger.

I was originally paralyzed for over a year and was paralyzed on the right side of my body head to toe. I recovered extremely well, and when I was in my teens and twenties, you would NEVER have known that I ever had a neuromuscular problem

PPS MANAGER

at any time. I was a hiker (Appalachian trail), swimmer (swim team at FSU), bicyclist (didn't have a car), and a Girl Scout leader (the most physically demanding of anything else!).

I refused for several years to use the little scooter carts provided at grocery stores, because I was so embarrassed, and was afraid someone would get mad at me for using one when I didn't look disabled at all. I was unable to grocery shop for over 2 years, so all of this "adjusting" that I am doing now is very, very new, and very emotionally scary. However, I am lucky to have my significant other be a PPS'r as well, and he helps me through, and we understand each other's needs... My life has been a very good one, and now I just have to learn to make adjustments!

Michelle in Arizona

P.S. I am a "power-user" on the computer, so at least I am in a sedentary work environment! That certainly helps!

Editor's note:

Michelle has been active in the PPS community for many years. She has been receiving professional treatment for PTSD and, as you can tell, she's doing an excellent job of managing PPS. Thank you, Michelle, for sharing.

Rick Remembers

One thing I remember from my recovery days in the hospital was how the girl in the cage next to me would cry and scream when her parents left after a visit. It's sad and frightening when Mom and Dad go away and leave you behind again, but she would scream and cry until the nurse came and yelled at her... I just lay there accepting the fact that there was nothing I could do. I may have been too paralyzed to react to the stress as she did, or it didn't bother me... I just don't remember.

Sometimes I wonder how deeply I may be scarred by those days of separation anxiety and fear of death.

Later, when I came home from months in the hospital, it was as if I was a stranger in my own home. My brothers shunned me, my bed had been converted into a slab (doctors orders), I had painful stretching treatments over and over ... I felt unwelcome.

I had changed. I would never be the same person I was before polio.

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Seen on a bumper sticker:
**"It's never too late to have
a happy childhood."**

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PPS MANAGER

DEAD FLIES

By Judy Neiman-Sander - copyright 2005

Two more minutes have passed since I pushed the black call button on my bed. I watch the big hand on the clock above the doorway to the hall, move from one little mark to the next little mark. It snaps each time like someone flicking dead flies off a table. It's not the first time I've thought of dead flies today.

There are fourteen patients in our room with white folding screens between us. On the oatmeal-colored wall above me are two pictures. One's a naked baby crying. The other is a smiling little girl about my age, in a pale-yellow dress dragging a brown teddy bear. She's opening a tall blue door. I think she's happy because she can leave.

This morning when they pulled a gurney past my bed with two-year-old Suzy under a thin white sheet, I didn't react. I didn't cry. I just stared at the gurney and listened to the squeaky wheels as it passed through the hall door. I thought of dead flies.

It's getting dark outside. Earlier, large snowflakes fluttered past the window across from me. Now the wind's blowing grey-white swirls against the glass. It makes me shiver and I pull my blanket tight around my neck.

I have to pee so bad it hurts. I push the buzzer once more even though I know it will anger Nurse Stitz, with her bright red hair in her perfect white uniform. In my head, I call her Nurse Shit. I never say it aloud. Katherine, who used to be in bed number three, slipped once and said it right to her face. Nurse Stetz didn't say anything, but the next day they took Katherine to a box in the room next door. I hear her crying sometimes, above the pumping sounds.

Every time they push my wheelchair down the hall, I gaze into the box room. It looks the same as ours except there are no windows or pictures. Long metal boxes sit off the floor about as tall as I am. They make loud sucking sounds. Children lay on their backs inside with only their heads sticking out. One girl has been in a box for a long time. Her dark-brown hair has grown so long it falls to the floor.

Nurse Stetz is coming. I recognize the sound of her quick, angry steps on the dented, yellow-green linoleum in the hall. I've been here a long time and I know at night, during the week, Nurse Stetz is in charge.

She tells her staff to ignore the first buzzer when they're busy. Anyway, that's what Nurse Peach told me. However, if we ring more than once, we get into trouble sometimes. I don't know what to do.

When I think of Nurse Peach, it makes me smile. She cares about us and is sad when someone has to go into a box or the closet— or away forever. I saw her cry this morning as she helped push Suzy's gurney out the door. Big tears fell out of her dark eyes onto her chocolate-brown skin.

Nurse Stetz breezes into the room with a wall of perfume around her. "Cindy, don't push the buzzer again tonight. We have others to take care of, you know."

Raising my lifeless legs up, she shoves the bedpan under my skinny hips. I leak a few drops onto the bed. She sighs. I notice she's wearing silver earrings with red diamonds. I say something nice so she'll like me. "Your earrings are beautiful."

"I'll have someone change your bedding. You're five, Cindy, not a baby. Perhaps you should stay in the closet tonight."

I try to go in the pan but it won't come out. The thought of staying all night in the

PPS MANAGER

closet makes it difficult to breathe, let alone pee.

"Cindy, you're wasting my time." She leans close to my head. "Pee."

Oh no, I feel tears flow down my cheeks. Crying is not allowed on the sixth floor. If we complain, cry, wet our beds or call a nurse a bad name, we go into the closet or to a box next door.

"Finally! But you wet the bed. You're such a bother."

I turn my head away from her and look to the far corner of the room. The closet door is open. I see cleaning supplies, wheelchairs, crutches, trash and a bag full of dirty linens. I've stayed in there three nights in the last few months, with the door shut and lights turned off. Two times because I cried and I don't know why the other time. It smells terrible. A monster lives in there at night. Kathleen told me his name is Argus. I saw him once when his yellow eyes came down from the ceiling and I screamed so loud Nurse Peach came. She pushed my bed out of the closet and told me not to tell anyone. I never did.

I wish Mom or Dad would believe me when I tell them about the closet, but they don't. They say it's my imagination or the polio. It's been eight days since they've come to see me. Well, eight is when I quit counting. Oh, I can count to a thousand but after eight, it doesn't seem to matter anymore.

Nurse Stetz left without saying another word. Maybe she'll forget to put me in the closet tonight. I stare up at the light globe and count the dead flies inside. There are eighteen, one more than yesterday.

John, who's fourteen, is trying to say something. His bed is at the end of the room. He can't move his arms or his legs. He's making a wheezy noise.

"John, do you want me to push the buzzer?" No answer. "Sally, is John okay?" I

think Sally is pretending to be asleep. Whoever rings the buzzer will be in big trouble. I grit my teeth and push it.

I hear Nurse Peach coming. Thank God, she didn't wait for two rings. She waddles when she walks. The sound of her footsteps coming down the hall is a relief.

"Hi pumpkin. Guess what? I get to change your bedding and tell you a story at the same time."

"John needs you."

She hurries to John's bed at the end of the room and calls for help. Two others come quickly with a gurney and a few minutes later, John's limp form is pushed out the door and into the room next door. I hear a metal lid close on a box. I wonder what he did wrong.

I look up at the ceiling and count the dead flies inside the light globe above me. Eighteen. The same number as this afternoon. Good.

My eyes shift to the clock on the wall. I watch the big hand snap as it clicks the seconds away. Tonight I'll dream I'm the little girl in the pale-yellow dress with the teddy bear. I'm going to open the tall blue door and fly away.

[Editor's note: Judy is one of the co-founders and former leader of the current San Diego PPS Support Group. She is a published writer now residing in Sedona, Arizona.]

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**We are not creatures of circumstance;
we are creators of circumstance.**

Benjamin Disraeli (1804-1881)

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PPS MANAGER

MEETING REPORTS

San Diego

Post-Polio Support Group

Salk Institute Reaches out to the PPS

Community

By: Gladys Swensrud

On May 4, 2009, local post-polio support group leaders were invited to the Salk Institute for a unique roundtable and info sharing session. The invitation was graciously extended by Salk's Rebecca Newman/Vice President of Development and Communications, Cheryl Dean/Senior Director of Planned Giving, and Susan Trebach/Senior Director of Communications. Our Salk hosts, already familiar with poliovirus basics, were particularly interested in gleaning all they could learn about specific problems we face as survivors living with Post-Polio Syndrome.

The Salk Institute, established by Dr. Jonas Salk nearly 50 years ago, is a research center dedicated to biological studies. Molecular Biology and Genetics, Neurosciences and Plant Biology are their major areas of emphasis.

While aging polio survivors face the sobering reality that there is only miniscule attention being paid by researchers worldwide to PPS health related struggles, there remains hope that ongoing study within a wide spectrum of other motor neuron diseases could, theoretically, spill over to help us find answers. Ms. Newman mentioned two specific projects (one on Amyotrophic Lateral Sclerosis and the other on Spinal Muscular Atrophy) being spearheaded at this time by Dr. Sam Pfaff, which highlighted his continued dedication to finding answers on behalf of those stricken with motor neuron disease. The following quote, taken directly

from the Salk Institute website (www.salk.edu), explains Dr. Pfaff's focus:

"The main objective of Samuel Pfaff, a professor in the Gene Expression Laboratory, is to discover how nerve cells are formed and wire up correctly, focusing on the fetal development of the spinal cord.

Of special interest to him is how motor neurons develop and make connections between the spinal cord and muscles in the body, since these connections are necessary for all body movements. Spinal cord injuries lead to paralysis because motor neuron function is disrupted. Degenerative diseases such as ALS (Lou Gehrig's disease), spinal muscle atrophy and post-polio syndrome result from the loss of motor neurons."

Speaking for polio survivors everywhere, we expressed our appreciation to Dr. Pfaff and his peers for their persistent investigation geared toward finding solutions for all people living with motor neuron disease.

The Salk Institute's representatives were intensely interested in understanding the present dilemma of polio survivors both locally and nationally. We offered a plethora of topics ripe for discussion, which initiated more and more in depth conversation about ways in which Salk might interface more closely with the post-polio community. It was clear dialogue going forward presents great opportunity to build a close relationship.

Watch the PPS Manager Newsletter for future developments.

___ **The next San Diego meeting:** ___

July 11

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>

PPS MANAGER

COACHELLA VALLEY POST-POLIO SUPPORT GROUP

No report submitted

_____The next meetings:_____

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2nd Fridays at 10 AM at Portola Community Center, 45-480 Portola Ave, Palm Desert CA Park in rear.

Victorville PPS Group

The High Desert Group met at a The Pizza Place in Spring Valley Lakes on May 15th with a great turn out and discussions ensued in regards to PPS suffering through the heat and winds of summer! On June 10th we had a potluck picnic in Hesperia attended by VERY strong winds, but a great lunch. Information was passed to everybody about the "Disability Access issue: Sidewalks" that had been forwarded by Rick Kneeshaw. It was also decided that we will go DARK for July and August while our members are on vacation.

Kay Mears

_____Next meetings:_____

**No meetings in
July and August**

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

For information contact Vi at (760) 949-6775, or Bill at (760) 243-6242

Escondido North County Post Polio Support Group

John Hagee led the group meeting on June ninth in Marilyn's absence as she was attending her grandson's graduation in Illinois. John reports that there were four new polio survivors who attended the meeting. It is great to know that we are reaching new people. They, like all of us, were in search of answers and adequate care with the onset of post polio. John's presentation was on the Warm Springs conference that he and Glenda attended in April so he wove in the information with the questions. More information to follow. I look forward to meeting the new people at our August meeting.

Four of the group leaders met at Salk Institute with three Salk representatives. Salk Institute is very interested in how our groups function and in our personal stories. They have also expressed an interest in helping us get the post polio message out to the general public. We look forward to a new relationship with the institute. Gladys Swensrud has written a more substantive report on the meeting. (see the San Diego meeting report)

On a personal note, I finally made an appointment at the Kaiser respiratory clinic. I have been denying my breathing problems to myself for a while now. At my first appointment, I was given a sleep apnea test (which I flunked!) and then a muscle and air output test (which I also flunked!) and was immediately given a bipap machine. I now have my very own machine and am in the process of getting the settings just right. For quite sometime I have been surviving on very few hours of sleep and battling my weight problem.

PPS MANAGER

I am happy to report that I now get from six to nine hours of sleep per night and have lost twenty pounds in the process. I have more energy and I think less pain. So if any of you even think that breathing may be an issue, please have your physician give you a referral or contact one of the qualified sleep clinics.

Our August 11th will welcome Dr. Bradley Schnierow who will update us on new developments in the respiratory field. Everyone is welcome.

Submitted by Marilyn Loba

_____The next meeting:_____

August 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)

Hi Everybody.

We had a lively “sharing” meeting in May. We discussed everyday life with PPS, doctors, medications, assistive devices ... the usual.

Guest speaker **Dr. Bradley Schnierow** made the June gathering very interesting. Here’s my report:

The first half of Dr. Schnierow’s presentation dealt with fibromyalgia. First and foremost, he

believes in the existence of the disorder. Secondly, he has learned that in most cases improved sleep the cure.

After elaborating on the mystery and importance of sleep, he focused on the problems that arise when sleep is interrupted. To illustrate this, he noted past scientific studies in which college students were deprived of sleep and tested for their pain tolerance levels. The findings clearly revealed that, even among otherwise healthy college students, the longer one goes without proper sleep, the more the perception of pain increases.

Dr. Schnierow then went into detail as to what constitutes proper sleep. People with chronic pain can often think they have been sleeping well when, in fact, they are not going all the way to sleep and therefore are unaware of the problem. In people with a sleep related pain problem, this can be revealed with an overnight sleep study – often done at home with a small device.

In the case of fibromyalgia, a test can record a brain wave pattern abnormality during sleep. Dr. Schnierow is among a small number of physicians prescribing the drug Xyrem to treat this anomaly with a high rate of success.

According to Dr. Schnierow, unlike other drugs used to treat fibromyalgia, Xyrem has only minor side effects such as very relaxed muscles that may require the support of a CPAP or bilevel vent for some people, and an increase in sodium. Compared to the side effects of other remedies such as Lyrica and Cymbalta these are very minor.

Things that don’t help fibromyalgia are those drugs used for other types of pain. Dr. S found that people using those drugs were able to reduce by half, or eventually eliminate the drugs after treating the sleep component.

The second half of the presentation switched to PPS breathing. It was a slow transition,

PPS MANAGER

however, because so many of the questions dealing with fibromyalgia-like pain and the sleep/breathing connection seemed to relate to both fibromyalgia and PPS. With this in mind, the use of a ventilator to treat pain is the logical next step.

His usual test is not an overnight sleep study, though he does have a sleep lab for those who exhibit signs of common obstructive apnea. Instead, a pulmonary function test and maybe an overnight home study ("a little gizmo, like a watch, another that fits around your chest, another that fits under your nose.") to determine if you could benefit from the use of overnight ventilation.

Throughout the presentation Dr. Schnierow answered specific questions about pain and pain medications.

Comments included a testimony from two of Dr. Schnierow's patients. One person who had FMS so bad she couldn't stand being touched, tried other remedies to no avail, but found immediate relief with Dr. S's treatment. Her husband, who suffers from PPS and other disorders, received a VPAP SV vent which has greatly improved his quality of life.

Another commented that he uses a VPAP III ST to treat polio weakened breathing muscles, but in reality it's a pain treatment in that the first indication of the need to "hook up" is muscle pain. Though the pain starts in the chest area, it would soon spread throughout the body if not for the ventilator. He uses it overnight (during sleep – nap, too) and a 20 or 30-minute treatment if needed for overexertion or a visit to a high elevation.

For more information contact San Diego Sleep Medicine at (858) 623-3266 or visit www.sandiegosleep.com

Bunny and Betty are planning the July picnic. We'll do the usual indoor potluck, live music, and fun at Valley Wide Recreation on Esplanade in San Jacinto. Sunday July 12, 12:30 to 3:30 PM. Setup begins at noon. For more info, call Bunny at 766-7118

Our next **HAPS** meetings are: _____

July 12 - PICNIC
August 18

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

Big Bear PPS Group

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

Polio Survivors Plus

"Think Big" is the theme of the Orange County Fair and anyone who wants to join in the fun can "Think Big" with a complimentary entrance ticket that includes free parking for this coming Wednesday, July 15th at 9:30 a.m. to 12 noon.

As in years past, there will be complimentary events, which will include carnival rides and special programs for a few hours when the fair is open by invitation only. It's an ideal time to come to the OC Fair because people who use wheelchairs, walkers, canes and other POVs can ambulate freely without the worry of a crowd "stampede." The OC Fair opens to the public at 12 noon, but everyone is welcome to

PPS MANAGER

stay to enjoy all of the rides, exhibits, demonstrations and more until the facilities close.

Also in July, Polio Survivors Plus (PSP) will focus the attention of the July 22nd's meeting on everything that one needs and could want to know about the process of getting custom made shoes. Mina Nakhaee, a board certified pedorthist, will be the featured guest speaker.

PSP's past speaker was Marmaduke Loke who hails from South Africa and who is the president of Dynamic Bracing Solutions. By using multitudes of measurements, it is possible to have a lightweight, proper fitting brace or two that can help to support the use of nonfunctioning muscles, while providing ample support so additional crutch or cane requirements can be reduced, helping polio survivors to conserve and preserve their upper body strength. This program was videotaped and anyone is welcome to request a copy of it for home viewing.

The Board of Polio Survivors Plus will host a pool-side barbecue on Saturday, September 5, 2009, to celebrate polio survivors and nine years of supporting each other with the challenges of PPS. Come to enjoy a scrumptious menu, live music and good company. Save-the-date and join us with your RSVP

Sue Lau

_____ **Next meetings:** _____

July 22
September 5

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 efmind1@cox.net (949) 830-9347

Riverside PPS Group

PPS Meeting Riverside June 20, 2009

Several Post Polio Support Groups send us their newsletters, and we have found it profitable to select an article or two from these to guide our discussions. This month everyone got a different newsletter, and we were going to see what headlines popped out. Pauline gave us a great amusing opening by reading "My Mother Taught Me ...," from the May 2009 issue of *The Second Time Around*, Boca Area Post Polio Group's newsletter.

Lorraine Hartik had attended the Hemet PPS Meeting and brought a pile of "Discover Sleep" brochures. Dr. Bradley Schnierow (see Hemet report) used examples from nature and from studies to illustrate the importance of sleep. In one study, students plunged their hands into ice water and were given a dollar for every minute they could stand it. The same students were then deprived of sleep, then given the ice water test again. There was a marked difference: lacking sleep, they couldn't endure. If you are tired during the day, you aren't getting enough sleep.

Regina, who is still working full time, had taken time to create gifts for everyone, "just because..." – beautiful crocheted butterfly magnets. Regina, you are a treasure and we love you.

PPS MANAGER

Much of our discussion centered around Lorraine's report and the relationship between lack of sleep and pain.

We enjoyed lunch together, and all were invited to July 4 barbecue at Mahoneys' (5pm-10pm), and reminded that our annual barbecue will be August 15th. We passed out information for Rancho's annual Picnic.

Calendar: August 15th, Barbecue (dogs & burgers provided), bring side dish, dessert, drink, or just come as you are – all welcome!
October 17th, and December 19th Holiday Party

___The next Riverside PPSG meeting:___

August 15
BBQ

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 bbooplink@aol.com

Letters

Rick,

Your March PPS Bulletin was very interesting. You are to be admired for the efforts put forth with PPS, etc. etc. Thank You.

I was a polio patient in 1940. Light case, legs and left arm. I "got over it" 90%, then PPS about 2 years ago. I use a walker and get tired - no pain. I can't complain. Am a little grouchy and impatient with myself, etc.

Don

Hi Don,

Thanks for the note and the encouragement.

Some observations if you don't mind ...

First: PPS hit me 15 years ago. I consider myself lucky to be among the roughly 50% of PPS folks who DO experience pain. Pain is a useful tool. It tells me to stop hurting myself. I credit pain for saving my joints and extending the life of my feeble muscles.

Second: Walkers, canes, manual wheelchairs, and crutches turn your arms into legs, and they aren't strong enough for the task. Wrists, hands, elbows, and shoulders break down under the stress. Scooters and power chairs save more energy and preserve your hands and arms for more important activities of daily living.

Also, I'm most impatient with myself when I find myself in a bad situation because I failed to use an assistive device. For example: Walking through the hardware store, then getting home to find I don't have energy left to continue the project because I didn't take my scooter or use one of those supplied by the store. My pride pulled the rug out from under me again!

One more point: The condensed version of your "Culture Template" suggests to me that you have a book to write and very important things to say. I found that using assistive devices, particularly overnight ventilation, enables me to express my creative self about as well as I could ever hope to. Without them my body could not support my mind.

Rick

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Hello Rick !

Just finished reading your May newsletter,

PPS MANAGER

which I always enjoy.

I attended the *Warm Springs April Conference* in Georgia, which was quite enjoyable. It 'moved' me to see so many Post-Polio Survivors in one place. I never see fellow survivors, which leads you to think you are all alone sometimes. It did my heart good.

Remember my trouble finding *SPRINGS* for my old walking brace? The *Brace Shop* at Warm Springs had all the answers that no local orthotist could offer. I visited Blanchard Hall between two great seminars where they identified the brace maker as the German manufacturer 'Otto Bock'. I contacted their offices in Minnesota. A dozen springs are on their way, and so will I!!!

Keep up the good work that you are doing.
Warmest Regards, Rick Z. from Miami Florida

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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. 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.

**To give financial help
Make check payable to:
R.E. Van Der Linden
34711 Lyn Ave
Hemet, CA 92545**

To submit ideas, writings, or commentary, write to above address, E-mail PPSman@roadrunner.com, or call Rick at (951) 926-5492

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