

the Southern California
PPS MANAGER

DECEMBER Dedicated to being our best with Post Polio Syndrome

1999

FROM THE EDITOR

Hi fellow PPS managers.

Post-Polio Syndrome is a neuromuscular disorder. It affects our whole body from the inside out. Our attention is drawn inward as we focus on things like fatigue, muscle pain, brain weariness, and the frustration of not being able to function as before.

To combat the downward spiraling state of stress that PPS can cause we must constantly attempt to understand and control what PPS is doing to our lives. We ask ourselves: What damage did polio do? What exactly is the scientific definition of PPS? What can I do about my current greatest symptom or challenge? It's a constant battle and the battlefield is inside us. To surrender means to become lost in the dark, cold sea of fear and worry of depression.

As we face the holiday season we are confronted with the combined challenges of Winter's cold and shorter, darker days, overactivity and under activity. It's no wonder that the holiday messages of "Peace" and "Joy to the World" are so popular. We need it.

In "JOY!" I attempt to find a place of comfort and peace.

Have fun....Rick

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JOY!

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JOY!

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

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

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

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

Stay warm and relaxed. Rest often. Lay flat or sit in a recliner. Wear an insulated body suit in the winter. Get yourself in hot water. Become a snow bird. Get a lap dog or cat. Don't worry. If you can't fix it, forget it. Enjoy being alone.

Listen to soft music without words.

Concentrate on your breathing. Never try to run someone else's life. Don't force a decision when you're too tired to think. Be childlike.

THE OPPOSITE OF STRESS IS...

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

I remember a time when I woke up every day with a joyful feeling. The smell of the morning air, the promise of things to come, new things to discover... Why can't life be like that every day? Now I often wake up and feel

the aches and weakness that should have gone away with a night of rest. Can we have a blissful life in spite of this physical challenge? The answer is, "Heck, why not!"

GO BEYOND MANAGING YOUR PHYSICAL WORLD

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

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

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

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

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

I wish you true peace and joy.

FROM POLIO TO POST POLIO SYNDROME

By Delmer G. Ross

It began one afternoon when I got a headache. It was 1957, and my family had

recently moved from the cool, highland city of Quezaltenango, Guatemala, at an elevation of more than 7,000 feet above sea level, to hot, humid, tropical lowland Managua, the capital of Nicaragua, with an elevation of less than 200 feet. An active youngster, not quite fifteen years old, I spent weeks, walking miles and miles every day, exploring the nooks and crannies of our new home base. Although I did a lot of sweating, the unaccustomed heat didn't bother me.

But the afternoon I got the headache, it was different. I felt hot and was sweating profusely even though I was at rest in the cool of our living room. My mother checked, and sure enough, I had a high fever. Not long after that, my headache having worsened considerably and my fever gone even higher, my father called the doctor.

Soon I was hospitalized, and a day or two later the first signs of paralysis began to appear. Somewhere during my wanderings about the city, I had contracted polio. Mine was only the second or third case of a half dozen or more that were diagnosed during the course of a little more than a week. The Nicaraguan government, fearing the outbreak of a polio epidemic, had a large supply of the Salk vaccine flown in from the United States, and many thousands of children in Managua were vaccinated. A few more children came down with the disease, but the program of vaccinations effectively stopped the epidemic. That help, unfortunately, was too late for me. I was partially paralyzed from my neck down.

When I failed to regain the use most of the affected muscles, my parents sought information on polio recovery programs in California, our home state, and decided on Glendale Adventist Hospital. After months of physical therapy, including a lot of hydrotherapy in a violin-shaped Hubbard tank, I was able to walk again with a cane. My right

leg was still largely paralyzed, as were many of my trunk muscles.

Despite my handicap, I managed to live an active and often exciting life. After graduating from college, I earned masters and Ph.D. degrees, then put them to use teaching at four different colleges and universities, including La Sierra University where I currently am a professor of history. I traveled extensively throughout the United States, Canada, Mexico, and Central America. When I married Karen Gibson, our honeymoon was an automobile trip through Mexico, Guatemala, El Salvador, and Honduras, to Nicaragua, where I also did research on the history of Nicaraguan railroads. We bought a four-wheel-drive Blazer which we used to explore remote places in the Mojave and Colorado deserts. I wrote books. To supplement our income – teaching is far from a high paying profession – Karen and I began buying "fixer-upper" houses, which we would remodel and sell. We put together a crew and for a time purchased houses that were to be relocated, moved them onto lots that we had bought, then sold them.

It was while I was teaching at Loma Linda University, and doing remodeling work during my spare time, that I noticed the first symptoms of post polio syndrome. We had a heavy, 20-ton capacity, hydraulic jack that we used to level floors. It weighed close to fifty pounds. One day in 1982 or 1983 I noticed that I was having trouble carrying it. At about the same time I began to experience difficulty swallowing; if I wasn't careful, I could choke on perfectly well chewed food. When I told my doctor, his response after briefly checking me over was, "things happen to us as we age." Over the next several years I experienced a number of additional symptoms: difficulty keeping my balance, sleep apnea, sensitivity to cold, unreasonable fatigue, and muscle pain, especially in my arms and shoulders.

By the early 1990s I was fairly certain that I had PPS, but when I approached my

doctor on the subject he said he knew nothing about it. Nor did he know of anyone who did. He offered several suggestions, each of which I followed up, but without success. A friend of ours, a pediatrician who had contracted polio during early childhood and who guessed he was suffering from PPS, told me he thought I probably had it. He suggested that I do what he planned to do, travel to visit an expert in Ottawa, Canada. That seemed like a long way to go.

I contacted Rancho Los Amigos, but whoever I spoke to on the phone told me tersely, "We don't have anyone here who can help you," and abruptly hung up on me. My wife and I contacted more than one hundred physicians and medical groups in the Riverside-San Bernardino area with no better results. We probably should have continued searching, but work schedules and other matters made it inconvenient.

By 1998, though, I couldn't walk more than two or three blocks without experiencing extreme fatigue. Climbing stairs often made my good leg and arms hurt for hours afterward. Periodic bouts of mild depression led me to start taking St. John's Wort. A trip to Ottawa began to look more reasonable! Then, shortly before the beginning of the 1998-1999 school year, I was walking in our bedroom when I fell for no apparent reason except that I somehow had lost my balance. One week later, on the very first day of classes, I fell again, in exactly the same spot while performing exactly the same maneuver. This time, though, I broke my ankle in two places. Apparently some of my trunk muscles had become seriously weak.

My problem just had to be caused by more than simple aging! Again, my wife and I began searching for an expert on PPS. Karen, who is a nurse, explained the problem to another nurse at the hospital where they both work. The nurse said that she had a friend who had PPS, and gave my wife her telephone number. We called. The lady we talked to was

very gracious and recommended that I go to Dr. Ronald Bailey, a neurologist at the Riverside Medical Clinic.

I was able to obtain an appointment with him. When he saw me, my orthopedist had just authorized me to put my full weight on my mended ankle. Dr. Bailey listened carefully to my list of symptoms, then examined me. He then told me what I already suspected: I had post polio syndrome. Later, he did an electroneuromyographic study on me, which helped to confirm his diagnosis and to rule out certain other possibilities I might have concurrently with PPS. I wanted to get back to walking with my cane again, but he cautioned me that I might not be able to. He prescribed some physical therapy to try to strengthen my muscles, but warned me emphatically to stop at the first hint of pain. He also gave me a folder full of literature on PPS.

Dr. Bailey told me that, as far as he knew, aside from some limited physical therapy, there was little or nothing that could be done to help me recover my strength. On the other hand, there was a medication that might slow the deterioration of nerve endings. He said it appeared to help some, but not all, PPS sufferers. He would prescribe it if I wished. Needless to say, I wished. So I started taking 100 milligrams of Neurontin twice a day, and gradually built up to 400 mg three times daily. Considering how rapidly my condition was worsening before starting it, I believe it may be helping.

Because my office and the classrooms I used were on the third floor of a building that has no elevators, I had to quit teaching for a term. La Sierra University, though, soon provided me with an office and classrooms on the ground floor. It also pulled out some shrubs and paved a new parking space that is less than fifty feet from my office. Reserved for my sole use, it is exceptionally wheelchair accessible. Everyone at the university has been very helpful and understanding. So, I am back at work again.

Today, at the turn of the century and the millennium, I have been forced to slow down considerably. I can walk some 20 or 30 feet at a time using a walker, but I can run five-miles-per-hour races with my electric wheelchair! Moreover, I can still explore old, often abandoned, four-wheel-drive roads to nowhere in the desert. God willing, I hope to continue to do so for years to come.

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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 soooooo 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.

NetClips

Going on disability has been the best thing I ever did. Now there is time for me. Time to shop, time to visit with grand kids, time to write a card to someone who is hurting. Time to teach a Bible study class. We call ourselves the "Women of Encouragement". We pray together and study God's word, and this is

better than medicine. loisanne
[BobMacSale@aol.com]

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IT WORKS FOR ME

_____So far I have not been able to lose weight. If you have found a way that works for you please write or call the PPS Manager and share your success.

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THANKS

Thank you for reading the PPSManager. Your words of encouragement mean so much to me.

Thanks for your help Catherine.

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MEETING REPORTS

HEMET AREA POLIO SURVIVORS

At the latest meeting we looked at a video made by Dr. Clinton Maxwell of Texas. Dr. Maxwell started studying PPS years ago when one of his patients started having

symptoms. Since then he has seen hundreds of PPS patients which he says is the way he learned the most about the illusive syndrome.

Some of the points he made are:

PPS is a new disease (not preexisting) and should be presented to insurance companies as such.

PPS support groups know more about PPS than 99% of doctors.

The average time between the onset of serious PPS symptoms and the first doctor visit is 3 to 5 years.

Patients normally go through periods of denial, depression and then recovery as they learn to cope with the life altering situation.

About 85% of his patients benefit from psychological evaluation and counseling.

To properly manage PPS you must give yourself permission to "put me first".

To get started on a management program the first thing to do is set aside two weeks to do only "have to" activities. This means not doing any activity that isn't absolutely necessary. After this period "want to" activities can be added a little at a time until pain or fatigue returns. By doing this we can determine our base level of activity.

To get a copy of Dr Maxwell's video call (972)964-0666

Next HAPS meeting December 8

Call Rick VDL (909)929-8208

San Diego Polio Survivors

11/11/1999
Sander

by Judy

Judy Sander welcomed everyone and made several announcements. Several new informative articles from the Internet were available. Judy then asked the 4 new members present to introduce themselves and share their PPS history. Kay Meers had polio in '56 and was diagnosed with PPS in '91. Kay has a service dog which travels with her in her fifth wheel. Henrietta Wahl had polio at 18 months

in NYC. Richard Willebonn had polio in NYC in '55. Regular members then introduced themselves and made guess's on a mystery present. Marilyn Salisbury was the winner after many tries.

Dr. Jim Donovan reported the National Institutes of Health (NIH) in Bethesda, MD is accepting PPS patients for participation in clinical research. They will provide medical, surgical or other hospital care. For information contact Dr. Marinos Dalakas of the NIH Institute of Neurological Disorders and Stroke (301) 496-0079.

Dr. Donovan related these PPS issues to the Steering Committee for the March of Dimes International Conference on PPS, May, 2000:

- 1) PPS should be included in medical school and nursing curriculum.
- 2) The World Health Organization should address polio and its future PPS complications.
- 3) More assistive devices should be available for independence.
- 4) Pursue more research with neural stem cells.
- 5) More active involvement from Fred Gage at the Salk Institute with his research of neurotrophin 3 that stimulates growth in damaged nerves, from John O'Brien of UCSD with his research of neurodys and lipidoses and from Mark Tuszynski, also from UCSD with his research on spinal cord injuries.
- 6) Research from Washington University, St Louis on a protein molecule (SLIT) that directs developing nerve cells and transplants neurons to the site that needs them.

(Thanks Dr. D. for the above. We are proud that Easter Seals picked you to have on their conference call.)

After a short break, Judy Sander and Steve Goldman lead discussion of "What works for me." Many ideas were exchanged. Steve was the only one that brought his index card with his idea. He has designed and built a great carrying tray for his wheelchair. This tray rests on two extensions from the feet supports. He can carry all of his luggage, plus

his able bodied friends, onthis device. Many other ideas were shared and our January meeting will be of the same title. Please bring your ideas on an index card. Please!

Marilyn Salisbury brought her service dog to the meeting. His name is Bailey. Marilyn Salisbury and Betty Svare have moved and their new number is 858-485-5976. Marty Bloom is busy nearly every night singing in the Master Choral and more. Give him a call for information on times and places to hear the wonderful Messiah and other Christmas music. 858-459-7598

Virginia and Nick Nichols again did a wonderful job of greeting each member upon arrival. They also always come early and help set the room up and make the coffee. Refreshment were their treat. Please sign up for refreshment in January. Call Judy Sander, 858-454-9615

Next meeting: January 13

For info call:(619)220-2152

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EAST SD COUNTY PPSG

This San Diego sharing group is now meeting on the last Saturday of every month at the El Cajon Library from 2 to 4 PM. Call Sammy D at (619)464-5364

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NORTH COUNTY PPSG

Facilitator Marilyn Salisbury was in the process of moving to a new home so she could not attend the December 4 meeting which was lead by Rhoda and Mary Clare. Since Marilyn usually writes this column there will be no formal report this time.

Next meeting is scheduled for February 5.

Call Marilyn Salisbury (760)738-1177 or: Betty Svare (858)485-5942