

**FROM THE EDITOR**

Hi Fellow PPS Managers.

Your response to last issue's call for help has been phenomenal. So good, in fact, that I had to abandon my original idea of sending a thank you card to each person and settle for a list of helpers instead. One, Sue Quillieute

**Feldenkrais practitioner** in Encenitas, actually paid for the full cost of this issue!

Also helping with this and future issues is Bob Doyle of Fast Posters in San Diego. He has generously offered to do the printing, folding and stapling at a discount.

Your gifts have been great but your good words have been even greater. Even though it's kind of embarrassing, (ah, shucks) I've included a few in the "letters" department.

In all, the experience has helped me to better understand your needs while greatly increasing my hat size. :-)

Thank you all very much.  
Have fun....Rick

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**HAPPY HOLIDAYS**  
and  
**MAY YOU HAVE A GREAT**  
**NEW YEAR**

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**Thanks to You**

The following is the 2002 list of those who have given money or goods for the support of this newsletter. Like yourselves, I get a great feeling from helping others. **Although this is the "Season of giving", the spirit of giving can benefit us throughout the year.**

**Remember, every gift, large or small, is for your good *and* the good of others.**

Beverly McGaugh, Guy McCutcheon, Virginia Burwell, William Kersteinerm, Henrietta Wahl, Marion Dore, Rick Kneeshaw, Judy Sander, Judy Mahoney, Marion Schoeller, Susan Berzon Turcotte, Rebecca Gigliotti, Dolores Masturzo, James Gauthier, Freida Marin, Joan Dolle, Edith Fuller, Dryscilla Luers, Bob Hudson, Alice Gowing, Rhonda Damsky, Irene English, Joyce Sapp, Rory Reidle, Bob Gorman, Annie Ehrlich, Beverly McGaugh, Susan Conley, Catherine Causey, Betty Thompson, Chris Kodama, Fred Munson, Jerry Lippett, Cynthia Fleri, Allan Downey, Dorothy Visnor, George Wiant, Arnold Oinonen, Carolyn Moorhouse, Mary Hargraves, Annamarie Villegas, Sylvia Cook, Lois Boxman, Joan Wesockes, Ken Edwards, Patricia Sampsell, Beatrice Weiss, Shirley Hueftle, Evelyn Shaw, Dale Kroker, Betty Cameron, Paula Chase, Mardell Wilson, Joanne Zeugschmidt, Judy Drum, Shirley Anne Rogers, all those who gave cash at the La Jolla meeting, Glenn and Marjorie Williams, Karen Kirkland, Edna Hogan, Agnes and Dr. Linsay Whitton, Lois Jackman...

**Your name here**

**... we are the instruments of one another's salvation, and only by the hope we give to**

others do we lift ourselves out of the darkness into light.

Dean Koontz

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## Escape Velocity

Scooters are great. I got my first one in 1995 following a year and a half of being virtually house bound. Being a former cyclist, the first thing I noticed was that even a little bit of wind in my hair is exciting. Kind of like being on a bland diet for a long time and then going out for Mexican food. Quite a rush.

Before buying a scooter, however, I did a little bit of homework and discovered that it's not just a matter of being able to buzz around the hardware store or the zoo or the mall, but it's also a matter of how well you can do it - a matter of speed and maneuverability.

## Maneuverability good.

My first scooter ride was at the San Diego zoo. It was early in my PPS years and I could get around without braces, could even walk a few blocks, but I knew the day would ruin me and spoil everybody's fun if I tried to walk the whole time. Lo and behold they had electric scooter rentals.

For twenty five dollars I got a new red four wheel scooter for the day. It was great cruising the paved paths, being able to park in the shade to rest and people watch, or hurrying to catch a program across the park. But problems arose when I got caught in a crowd at the snake house.

At six one, two hundred pounds, I was accustomed to towering over people but suddenly I became invisible. It was all I could do to avoid running over people's feet or catching them in the shins, and I was bumped

into several times by unaware snake gawkers before I finally escaped. It wasn't easy, though. The four wheeled tiller style scooter had an enormous turning radius, so every time I backed up to get a new angle the gap was filled with butts and legs and I had to wait or raise my voice to plead for room for another short move. I became frustrated and a little claustrophobic.

## Speed good.

My second experience was in a department store. Inside the door was a line of yellow bumper car looking things about the size of a VW and sprouting baskets front and rear. I was there to buy shoes and noticed the shoe department was at the rear, so I thought I'd give the bumper car a try. I'd call it a bad decision if I hadn't learned from it.

The first thing I noticed was that it was slow. If I had been sightseeing or window shopping it might have been alright, but I wasn't. I knew where I wanted to go, I felt self conscious, and I wanted to get the experience over with. Instead, it felt like I was caught in one of those "feet sticking to the railroad tracks and the train is coming" dreams. Big eyes followed me in slow motion, children pointed, I felt trapped.

Then another problem arose. Not only did I have to swing wide to make corners, but it had an electrical problem that resulted in a sudden stop every time I turned to the left. Only right turns, swing wide, don't hit that display, try to ignore the spectators... all in slow motion. It was terrible!

Well, eventually I got my own scooter and lift. Since I had to pay for it myself, I found a cheap used one and, being the mechanical type, I was able to rebuilt it and keep it in good running condition. It has three wheels (not as maneuverable as some, but better than many), an extended chassis to accommodate my size, and it has a top speed of six and a half miles per hour!

Six and a half miles an hour doesn't sound like much, but it's twice as fast as the average walking speed. This means that I'm in and out in half the time and if I get uncomfortable or feel the crowd closing in I can get out fast.

My old Pacesaver has served me well for over six years, but my next set of wheels will probably be very different - a power chair with joy stick control. One with four wheels. With the joy stick control you can rotate the vehicle in place for maximum maneuverability indoors. It doesn't have that cumbersome front tiller like a scooter, so it gets up close to tables and counters. And, if it can go at least six miles per hour I couldn't ask for more.

I looked at the six wheeled Jazzy but I doubt that it would suit me. I'm weaker in the upper body than in the legs and the Jazzy appears to bounce back and forth when stopping and starting which would require a strong neck if you don't want to bob around like a dashboard dog.

The Quickie looks pretty good. A rectangular tube frame, cool colors, shock absorbers... Best of all, in an informal parking lot speed trial Ann Corey's Quickie whipped me good. It's also very maneuverable indoors. Ann never has to back up and get a second shot at sharp turns the way I do.

Now all I have to do is talk my HMO doctor into prescribing one. But that's another story.

## **Shriner's Hospital Patients!**

Since 1922 Shriners Hospitals have been providing free care for disabled children through a network of 22 hospitals nationwide. Many people who read this

newsletter, like myself, are former patients of the Shrine Hospitals. If you are a former Shriner's patient, and would be willing to share your personal story of how the Shriners helped you, please contact Rick Kneeshaw (telephone 858-566-4016 or e-mail [polio@mindspring.com](mailto:polio@mindspring.com)) as I am assembling a series of presentations to thank the Shriners, and to assist them in their future fund raising for the Shrine Hospitals.

Thanks, Rick Kneeshaw [the other Rick]

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## **The State of the Heart.**

by REVanDerLinden

Recently, a young British student was attacked by a virus that began destroying her heart. She was minutes from death when surgeon Steve Westby at Oxford's John Radcliffe Hospital in England decided to try a mechanical replacement.

Instead of taking her heart out, they installed the pulseless pump beside it, leaving all the natural connections intact. It wasn't long before her tired heart recovered from the virus and, in the days that followed, started pumping again on its own. Apparently the short rest did the trick.

The mechanical heart was removed and her real heart is now functioning normally.

Let this be a lesson to anyone who might think that rest is not important enough to give high priority in your daily PPS management routine.

## **A Shock to the System**

by REVanDerLinden

He's a survivor. Initially he was paralyzed, couldn't swallow, was hospitalized for weeks. For

years he walked with a limp and was frequently in pain.

Now, years later, he has learned that he can expect sleep disturbances, panic attacks, memory problems, chronic pain in his arms and legs, cold one minute and hot the next, fainting spells, sleep disturbances, overreacting to stress, and a host of other disabling symptoms.

What happened inside him? An invader followed his nerves and spinal cord all the way to his brain, along the way killing some nerves instantly and leaving others damaged to the point that they are giving up before their time.

What came over him? Sounds just like Polio, doesn't it? Surprisingly he was struck by lightning!

I was shocked (pun intended) and amazed when I read the article, "When Lightning Strikes" by Pamela Grim in the August 2002 issue of Discover magazine.

According to the current understanding of polio, nerve cells were occupied by the virus which then started a family, quickly outgrew the cell, and busted out through the cell wall to send out offspring to settle in other nerve cells. According to the Discover article, a lightning strike can send DC current through the "wires" and pops little holes in the nerve cells. Besides the obvious "burnout" of the cell's components, nutrients and waste products can, over time, plug the cells pipes and leak out to the surrounding area. Amazing! Almost identical to Richard Bruno's explanation of poliovirus' horn cell damage.

While reading about it I was reminded of my own experiences with electrical shock, in my case AC current. Many years ago I received a 220 volt shock from hand to hand. It wasn't too bad. No burns or disabling after effects with one exception. Fatigue. For several hours my shoulders and arms felt like they do right now.

The point of this little story is that there are a lot of other things that can insult our bodies with the same or at least similar symptoms to Polio. In the March of Dimes booklet, Post-Polio Syndrome - Identifying Best Practices in Diagnosis & Care, there is a list of many neurological disorders we should be tested for in order to satisfy the PPS diagnosis by the process of elimination. Included are: adult spinal muscular atrophy, amyotrophic lateral sclerosis (ALS), cauda equina syndrome, cervical stenosis, chronic inflammatory demyelinating polyneuropathy, diabetic neuropathy, heavy metal toxicity, inflammatory myopathy, multifocal motor conduction block, multiple sclerosis, myasthenia gravis, Parkinson disease, peripheral neuropathy, radiculopathy, spinal cord tumor, and spinal stenosis. (That ought to give my spell check fits.) I guess we can add getting hit by lightning and who knows what else to the list.

What can be done? First, recognize the problem. Then, learn to live with it.

Although science is on the verge of prodding damaged nerve cells to regenerate, nature has not provided such a plan, so it's up to us to do the best we can with what we have. Managing PPS (and, apparently the after effects of being hit by lightning) means controlling our urge to do more than what we know we should do and learning to accept help from the medical community, assistive devices, friends and relatives...

Coming up in the PPS Manager: The story of a man who had polio as a child, had many good years, and then had new weakness and pain in his muscles but got over it. It wasn't PPS!

**\*\*\* ODYSSEY 2003 \*\*\***

by **Rory Riedle**

We've all heard the tried and true adage "Life is what happens while you are making other plans." When we experienced our original bout with

polio, many of us were too young to have made conscious decisions; others could not plan beyond the next grueling therapy. If goals and objectives were not assigned to us, we often set new ones ourselves. One established fact – our lives changed forever as we took the "road less traveled."

I always felt the term March of Dimes was so apropos. We marched, albeit to a different drummer, but march we did – with braces, crutches, chairs and limps. Our battle hymn became "We Shall Overcome." We became Survivors of the highest dimension. The inflexibility of our bodies was overshadowed by the flexibility of our spirits. Oh, what adventures we encountered long that road. Our senses were flooded with new sights, sounds and people. We tackled challenges, surmounted obstacles and achieved successes. We dreamed new dreams and restructured our lives. We continued to prioritize and then to re-prioritize. We lived the present and planned the future. The following reflection by Emily Pearl Kingsley has been loosely adapted to speak to the heart of the matter regarding the process of change on our journey with post-polio.

## WELCOME TO HOLLAND

It is like this...

When you are planning your future, it is like planning a fabulous vacation trip—to Italy! You buy a bunch of guidebooks and make your wonderful plans. The coliseum, Michelangelo's David, the gondolas in Venice! You even learn some handy phrases in Italian. It is all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland!!"

"Holland?" you say. "What do you mean, Holland? I signed up for Italy. All my life I've planned to go to Italy." But there has been a change in the flight plan to accommodate the threat of a post-polio attack and you were not consulted! You have landed in Holland and there you must stay. The important thing is that they have not taken you to a horrible, disgusting place full of pestilence and famine. It is just a different place. (Okay – so many days we can't exclaim "Viva la difference". So we may grieve, lament and bemoan our situation. We force ourselves or, should I say, life invites us to recognize both our limitations and our possibilities. We begin to ask, "What is the second best answer?" That answer usually proves to be both exciting and scary. You immediately retrieve your luggage and check its contents. The gifts you've been given and the skills you acquired are all intact. You are still in possession of your innate stubbornness, resourcefulness and imagination. Your wisdom, humor and sensitivity are all there. Most importantly, the indomitable power of your human spirit came through unscathed.) Now you must go out and buy new guide books and learn a whole new language. You will meet a whole new group of people you would never have met had you gone to Italy. It is a different place. It is slower paced and less flashy than Italy. But after you have been there for a while, you can catch your breath and look around and begin to notice that Holland has windmills, Holland has tulips and Holland even has Rembrandts. But everyone you know is busy, going to and coming from Italy and they are all bragging about what a wonderful time they have had there. And for the rest of your life you will say, "Yes, that is where I was supposed to go. That is what I had planned." The sacrifice of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the special and lovely things about Holland.

My hope and my prayer for all of us in 2003 is that as we forge ahead, we may keep the best and wisely let go of the rest to forever remain a passionate people. As passions abound in the heart of God and our genealogy goes back to God, odds are we'll succeed!!

A Happy New Year to All!

Rory Riedle

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## Breast Cancer and PPS

Breast cancer is more common than PPS, so it's certain that many ladies can have both. These days there are many treatment options and therefore some tricky decisions to make.

Loretta Blake, survivor of polio and breast cancer, is happy to share her experiences with others. If you need to talk about it, call her at (619) 337-6427

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## From the (e-)mail bag

### A sampling of the good words that accompanied just a few of the gifts.

Rick,

Thank you so much for putting together the newsletter --- I read every word of it and every time seems like there is something that applies to me. ... Dorothy

Hello Rick,

... Hope this will contribute to the continuance of info for all of us, through your good efforts. You certainly have done a great service and deserve our heartfelt appreciation.

Sylvia

Dear Rick,

... We surely were shocked to read about Easter Seals stopping to support our Post-Polio Syndrome groups. That is really sad. Especially now when so many of us really need the help we get from the newsletter. ...

We surely do appreciate all the work you are doing for all us "Polio Survivors"

Thanks so much.

Lois

Rick -

Thanks to you for a wonderful newsletter.

... I'm unable to attend meetings so I continue to feel "connected" whenever I receive it in the mail. It is so very informative and I'm so appreciative of all the effort you have given to this worthwhile service.

Joan

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Thank you for reading the PPS Manager Newsletter. And, thanks for your help and your words of encouragement.

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**The PPS Manager is published every other month by REVanDerLinden and is presented as management ideas and is not intended as a substitute for medical care.**

**To offer financial help mail to address below (make check payable to RE VanDerLinden)**

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