

FROM THE EDITOR

Hi Fellow PPS Managers.

As predicted there have been a couple of months of spring beauty around here. The wildflowers came in abundance and are slowly fading; a couple of months of blazing glory, then they're gone. Actually, that's a whopping 20% of the year.

We often have flashes of blazing glory too, but ours spread out over the year. Our moments of glory can come at any time. Plan on them.

Preservation, Conservation and Imagination came together about six years ago with a regular PPS Manager feature called "It Works for Me." I figured that it took so long for me to solve each PPS related problem, maybe I could save someone some time.

What works for you? Who knows? I may be one of the lucky humans benefiting from *your* life-improving secret. Hopefully, the next issue will include a lot of good ideas.

Have fun....Rick

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IN THIS ISSUE:

England on a Roll by Carole Carsey
It Works for Me

Travel, Stress reduction, pain relief, efficiency.

Summary of Anesthesia

Issues for Post-Polio Patients

And more...

"England on a Roll:

A Wheelchair Adventure in London and the West County"

Book review by Rick Van Der Linden

Carole Carsey is a polio survivor and a brave traveler. Now she has added "author" to her list of credits.

In her first book this feisty Texan artfully takes her readers on an armchair tour of London and the countryside around Somerset as seen from the seat of a power chair which she controls with a left hand joystick. The rest of her body has been pretty much out of order since polio at the age of twelve.

Accompanied by her husband, Willie, she managed to see many of the major sights of London, enjoyed bird watching in the countryside, and visited old and new friends.

A few years after her trip she became a PPS Manager and decided to share her experience by putting her notes and pictures into book form.

I found the book suspenseful, exciting and educational. I really enjoyed being taken away to another country; another world. That's saying a lot from a guy who thinks travel means taking the wife and dogs camping in the desert for the weekend.

In the "It Works for Me" travel department, "England on a Roll" is a great resource for disabled travel information, and a fun way to visualize the trip you just might be able to take after all.

1st Books Library - www.1stbooks.com

1(800) 839-8640

IT WORKS FOR ME!

Stress Reduction

[Stress tightens muscles and generally wears us down, so peace of mind is an important tool of the ever-diligent PPS manager. At the March HAPS meeting, days before the war in Iraq started, the question was asked, "What do you do to reduce stress in these troubled times?" Although the question brought up a lengthy discussion about current events, there were approaches that seemed to show positive results. Ed]

The Spiritual Approach. By Anne Corey

I'm not in a position to know all the details over there, so I trust God to guide our leaders. I don't have the answer to the problems of the world, but God does. It's not a defeatist attitude because I feel that prayer really works.

The Bible has all the answers, so I go there often for comfort and assurance.

Two Views Better Than One?

by Dale Gerdes Condensed from phone interview.

Like so many things in our [PPS] lives, we have to be aware of the things that stress us out so that when we see it coming we can turn the other way.

No one likes war but sometimes it has to be done. You really can't ignore what's going on because it's history happening. What I do is watch the war news for a while in the morning, but not at night. I don't want to go to bed with those images in my mind.

Another thing is - I keep my mind off of the war and my personal problems by

transferring my attention to more pleasant things like gardening, woodworking, and listening to music. You have to trust someone else to handle big things like that, and just let it go.

[I read Anne's point of view to Dale. Ed]

I agree with Anne. What better way to "let go of it" than to put it in God's hands?

It's Not My Job by Rick Van Der Linden

Worrying takes a lot out of me. It makes me tense up... hurt more. The result: physical fatigue followed by mental fatigue and the classic PPS symptom: The "I'm not qualified to make a decision" complex.

I'm certainly not qualified to handle political/international problems, or stop terrorism. I have to trust the people who *are* informed, intelligent, and brave enough to decide who is a threat to worldwide peace and freedom - I trust the men and women trained and willing to fight for my freedom to be the peace lover that I am.

I limit my daily war news, any news for that matter, to thirty minutes maximum, but if I find it's causing anxiety I shut it off and do something else.

Music, writing, reading, napping, hobbies... these things don't help *world* peace a whole lot, but they do contribute greatly to mine.

Pain Relief Department

Manage the Pain By Anne Corey

I had the paralytic and bulbar polio throughout my body like a marble cake, though some areas weaker than others. Fortunately I was able to obtain my records from Children's Hospital in Akron, Ohio.

I was left with very little at on the onset of my polio and I have since worn out the neurons that took over for the dead ones. After having children and the continual overuse I was eventually diagnosed with PPS at the Rancho Los Amigos Medical Center in Downey.

With the help of Doctor Perry I've been able to compensate for the muscle loss with support devices. A back brace and power chair have allowed me to remain independent and prevent further damage.

Before I used a back brace I had a lot of back pain and lower abdominal and groin pain. I also had many bladder and kidney infections because my bladder was not emptying properly.

The brace helps support my very weak lower back muscles and provides support to my posture. It also provides compression for my missing abdominal, intercostal and diaphragm muscles, and keeps me upright in my chair and able to breath properly. Without this brace I would tend to sag and my internal organs would not be able to function the way they are suppose to.

Without bracing, I believe that my remaining muscles would have given out by now because of the abuse that would have been put on them.

My brace was custom made by a company in Cypress, California. and I wear an elastic top that holds the brace in place so it doesn't continually ride up.

Whatever may come I know that God will provide the strength and endurance I need to be smart enough to not abuse my body any more then I already have, and to live out my life as an independent individual.

Efficiency Department

I took a hint from Bob Warnock and made a reaching stick.

You get a wood dowel or a broomstick and put a soft tip on one end for pushing things away, and a screw-in metal hook on the other end for pulling things towards you. Bob has several heavy-duty sticks in various locations instead of carrying one with him all the time.

I made one for my desk. A one half inch diameter wood dowel, two feet long, with a rubber cane tip on one end and a cup hook on the other. Easy stuff to get at the hardware store. I went early, found a young man to help me. A few minutes and one dollar were all it took.

I whittled on the rubber tip and bent the cup hook to make each end suited for particular tasks depending on which way it is rotated - turn knobs, push buttons, operate the printer controls with no reaching required. Very handy.

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PPS on TV

On April 27, 2003, Lifetime network aired an episode of the original one hour drama, "Strong Medicine", in which one of the three rare and dramatic medical challenges was PPS.

At the military medical facility, the good Doctor Major Andy (Patricia Richardson) helped a young woman in the early stages of PPS train for the ROTC.

The grouchy, by-the-book instructor didn't want to accept the girl because of her weak arm. The referred neurologist broke the news as gently as possible with a detailed explanation of polio damage and it's late effects. Doctor Andy faithfully supported her patient in her attempt to pass the ROTC entry test.

Thanks Lifetime for your well-researched presentation. It was over-dramatized, but surprisingly accurate and at times painfully blunt.

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SUMMARY OF ANESTHESIA ISSUES FOR POST-POLIO PATIENTS

By Selma H Calmes, MD

Polio results in widespread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience of these patients.

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is due to central neuronal changes, especially in the Reticular Activating System, from the original disease.

2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the polio virus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intra-op helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

3. Succinylcholine often causes severe, generalized muscle pain post-op. It's useful if this can be avoided, if possible. There is no experience with Raplon yet.

4. Pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.

5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel).

This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilator function post-op, and some patients who have not needed ventilation pre-op have had to go into a ventilator (including long-term use) post-op. The marker for real difficulty is thought to be a VC & 60; 1.0 liter. Such a patient needs good pulmonary preparation pre-op. Another ventilation risk relates to obstructive sleep apnea in the post-op period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

7. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass of tendons.

For more information contact (Dr. Calmes) at 818-364-4350, e-mail shcmd@ucla.edu

Special Events

May 18, 2003: Dr Susan Perlman, MD, Neurologist and director of the UCLA Post Polio Clinic will speak on the late effects of polio.
2 to 4 PM at St. Mark's Presbyterian Church, 2100 Mar Vista, Newport Beach.

Annual Picnic

Riverside Polio Survivors Support Group will have their annual picnic on **JUNE 28, 11 am-?** at California Citrus State Historic Park located at Van Buren Blvd & Dufferin Ave in Riverside.

Activities include BBQ by Dale and friends.

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San Diego Polio Survivors La Jolla Group

The next meeting of the San Diego Polio Survivors, La Jolla Group, will be at 10 AM May 8, 2003 in the Community room of La Jolla Village shopping center.

Steve Goldman will moderate one of his excellent annual "What Works for You" discussions so bring along all the great ideas you can share with the group that will assist anyone that is surviving polio. A no host lunch will follow the meeting in the Sports Bar.

_____ **The next meeting:** _____

May 8

What Works for Me With Host Steve Goldman

Regular meetings are on the second Thursday of odd numbered months at: **La**

Jolla Village Square Community Room, west of I-5 on Nobel.

For more information call **Rick Kneeshaw @** 858-566-4016 e-mail piecon@mindspring.com

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San Diego Polio Survivors North County Group

_____ **The next meeting:** _____

June 24

Regular meetings on the forth Tuesday of even # months from 1:00 to 3:00 at Joslyn Senior Center, Dorothy Boeger building, 728 Broadway, Escondido
For more info. call Mary Timmons 760-738 0560
or e-mail LaRosa1234@aol.com

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COACHELLA VALLEY POST-POLIO SUPPORT GROUP

_____ **next meetings** _____

May 9

June 13

Portola Community Center, 45-480 Portola Ave,
Palm Desert CA

For information, contact
[Linda Dempster@aol.com](mailto:LindaDempster@aol.com) or (760) 772-5556

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HEMET AREA POLIO SURVIVORS

Hi Everybody.

At the March meeting we discussed access ideas for our new library. Your efforts in sending in the questionnaires paid off and the grant was issued. I'll keep you updated.

We also had an "It Works For Me" discussion, the subject being "How do you stay

calm in these troubled times?" I've included some of the ideas in the article of the same name in this issue.

The discussion prompted Anne Corey to suggest that we have a meeting dedicated to home made ideas that make life a little simpler for us. Good idea, Anne. Everybody, bring something you'd like to share at a future meeting.

New member Ray Schneider suggested we have a meeting every month. Also, we might want to consider having a meeting at a different time and/or day for those of you unable to make it on mid day Wednesday. Please tell me what you think.

Bill Neff is still looking forward to getting his new wheels, but I'm sure that his scheduled back surgery will keep him out of trouble while he waits. Charlotte Levangie is also had to deal with surgery. It's a big challenge to have plot complications like that when PPS is bugging you. It's a good thing we're used to challenges.

Dale Gerdes made a video of the recent Social Security presentation at the Riverside PPSG, and we should be able to watch it at our May Meeting. Thanks Dale.

Have fun....Rick

Our next meeting is:

May 21

Social Security Video

Regular Hemet meetings are at 11 AM to 12:30 on the third Wednesday of odd numbered months at: Sun West, 1001 N. Lyon, Hemet for more info call Rick VDL (909) 926-5492

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Riverside PPS Group

At the April meeting we decided to standardize our meeting schedule to the 3rd Thursday of the month. After the June picnic we will meet only on even-numbered months.

We are in the process of outlining the purpose and scope of our PPSG, with a view to sharing responsibilities and being more effective. The May meeting will be Thursday May 15th at 11 am at Mahoneys'... 3465 Ramona Dr Riverside (909) 788-9310 PPSRiverside@aol.com.

Agenda for May 15th meeting:

- 1-Group Organization
- 2-Discussion of Picnic plans
- 3-Books & Videos available at discounts
- 4-Opens Discussion

June 28 - Picnic (11 am-?) at California Citrus State Historic Park located at Van Buren Blvd & Dufferin Ave in Riverside. Contact Judy (909) 788-9310 or PPSRiverside@aol.com for more info or food suggestions.

The next meetings: _____

May 15

open discussion at Judy's

June 28 - Picnic

Future: August 21 and October 16

Book & Video Offers _____

Safe at Home

23 Minutes, Color, VHS/NTSC

Produced by the International Rehabilitation Center for Polio at Spaulding Rehabilitation Hospital (polioclinic.org). Sponsored in part by Rhode Island Infantile Paralysis Foundation.

Safe at Home is the just-released video narrated by Bob Vila featuring special segments on making accessibility modifications to KITCHENS, STAIRS, and BATHROOMS - key areas for independent living.

"Whether you are completely remodeling your home or using some of the readily available low-cost adaptive products, creating a safe, comfortable and accessible environment is not planning for disability - it's planning for continued independence." Bob Vila of Bob Vila's Home Again.

The Riverside PPSG is offering to order the "Safe at Home" video for Southern California PPS managers at the special discount price. Neither Judy nor the PPSG intend to profit from sales. To get the video at half price we must have a minimum of 10 orders. Deadline to order: June 15th 2003.

To order, send \$11 (\$9.95 + estimated shipping & handling) to:

Judy Mahoney
3465 Ramona Dr
Riverside, CA 92506

The Polio Connection is offering for a limited time:

1) Post Polio Syndrome: A Guide for Polio Survivors and Their Families, by Julie K Silver MD - \$10

2) Managing Post Polio: A Guide to Living Well With Post-Polio Syndrome by Dr. Lauro S. Halstead - \$8

[Note: prices include tax and shipping]

To order, send check to:

Polio Connection
PO Box 182
Howard Beach NY 11414

For more info. call: Judy Mahoney (909)788-9310 or Betty McFarland (909)243-6991

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Yucca Valley PPSG

Potluck meetings: Feb, Apr, Jun, Oct and Dec. on the 3rd Saturday at 3:00 p.m. Contact Joan Giesing, P.O. Box 681, Joshua Tree, 92252 Phone: 760-366-8729.

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Big Bear PPS Group

For information contact Marsha at
(909) 878-3092

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Victorville PPS Group

For information contact Doris at
(760)245-9058

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Thank you for reading the PPS Manager Newsletter. And, thanks for your help and your words of encouragement. Special thanks to LaVerne Torok, Andy and Jane Bellomo, Grace Huff, Anita Irazari, Bunny Smith, Sandy Van Der Linden, Pat Sampsell, Ray Schneider, Phil Black, Marion Dore, Rick Kneeshaw, Pat Sampsell again, Pat McKinney, Anne Corey, Dale Gerdes, Richard Mull, Bob Doyle

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