

the Southern California
PPS MANAGER

DECEMBER Dedicated to being our best with Post Polio Syndrome

2000

FROM THE EDITOR

Hi fellow PPS managers.

Genetic research is on the verge of awesome discovery. With every passing day we are closer to understanding and controlling the most basic yet the most complicated aspect of nature - what makes living things grow.

To most people genetic research is a curiosity, but to those of us with damaged nervous systems this research is especially important. We can mend a broken bone, patch up cuts and repair many internal parts by growing new cells, but for some reason nature has failed to provide us with a means of repairing nerve cells. We have to rely on science to find a way to change that.

I have great respect and admiration for the exceptional people, in laboratories around the world, working on a way to fix our damaged nerve cells, and I hope to be there when that dream comes true. In the meantime, I intend to do everything I can to preserve the rest of me. To that end this newsletter is dedicated.

There is hope for a cure, but in the meantime preserve all you can.

Have fun....Rick

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Dennis Rohrig, PT

11/15/2000, HAPS group, Hemet CA
Physical Therapist Dennis Rohrig spoke on "Joint and Muscle Education".

A PT in Hemet since 1977, Dennis Rohrig got some of his early training in the treatment of patients with neurological damage or disorders at Rancho Los Amigos under Dr. Perry.

Mr. Rohrig pointed out that:

1) When a muscle or connecting tissue injury occurs serious disintegration starts after three days, so it's best to see your doctor as soon as possible. A partially torn muscle is very painful, but a complete tear is painless and evidenced by a bulge and/or loss of function.

2) In the case of weak muscles, joints don't stay fully seated and irregular wear is likely. A good PT can not only give you exercises to strengthen suspect muscles, but he can also teach you mobility tricks to help save the joints when muscle strengthening is limited.

3) An OT who is familiar with neuromuscular disorders best treats swallowing problems. There are exercises and techniques that may help.

4) He demonstrated exercises aimed at relieving lower back pain and improving digestion. Included were suggestions for people who spend a lot of time in wheelchairs.

5) Transferring techniques vary depending on which muscles are weak.

6) After fifty years old, the loss of a couple of inches in height is normal. More than that may suggest other problems.

7) Scoliosis usually stops progressing at a certain point. Bracing, casting, and surgery usually produce no overall improvement.

8) While Chiropractors (particularly those trained at the Palmer method) can be helpful, there is a danger of serious damage. A PT can actually teach you to treat yourself.

9) Glucosamine is sometimes helpful in rebuilding the soft tissue between joints. You should talk to your doctor and/or pharmacist about it.

10) Stay with one Pharmacist who knows your history. He can help you avoid bad interactions between your prescription drugs and over-the-counter supplements.

11) DMSO, often used for joint and other problems, increases the incidence of kidney failure ten times.

Dennis Rohrig, PT
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Meet Taylor Fritz

I am 51 years old, had polio at age 6 in Ft. Worth, Texas. Was affected (both legs paralyzed) in both legs and my upper left side (weakness only). 3 1/2 years of rehab left me with a slight limp as the only outward sign of the polio. Started having trouble when I was in my mid 30s with fatigue, falling, etc. I left my job in 1993 when I thought I needed a rest. Being a type AA personality, as we all are, I was an avowed workaholic. Since 1993 I have been unable to take an outside full time job due to extreme fatigue. I use a scooter for outside the house, have a long leg brace (KAFO) on my left leg for back-knee and a short leg brace (AFO) on my right leg for toe drop.

I started going to our local support group in late 1993 and have been a board member of our group ever since. Lee Seitz's Polio Survivors Foundation [18700 Sherman Way #104, Reseda, CA 91335 (818)996-8733] gave me my scooter in 1994.

I recently lost my telecommuting job and decided it was time to publish my books.

The following is the bio that is on my web page:
<<Physically disabled from post-polio syndrome, Taylor Fritz is in her fifties and into a second career. Taylor's first career was computers, a programmer and consultant for over 30 years. During her years working in computers she had toyed

with the notion of writing a combined cookbook and biography of an old "show-biz" couple that befriended her after the 1971 Earthquake in Southern California. The woman was a great cook and all the recipes were from her junk drawer. In 1994 Taylor wrote "Judy's Junk Drawer Cookbook". (Unpublished at this date.) Her recent disability caused her to rethink her priorities and as an avid mystery reader, she realized how much she enjoyed writing and turned her attention to mystery novels. Married to a retired policeman, she has a built-in reference for police procedures and cases. >>

"Take A Byte Out Of Crime" is the first in a new mystery series named "ByteLady Mysteries." I have two additional titles completed and am in the middle of the fourth and fifth books. (Type AA personalities die hard.)

I work every day (old habits die hard!) Since I work at home and at my computer, I can manage pretty well. I have a friend who works with me at ByteLady Publishing, who does all of the running around for me.

Right now I am spending 99% of my time doing the publishing end of the business in an effort to launch the books. I hope to be able to get back to actual writing in a month or so. The plan is to set up a schedule of writing for 2 - 4 hours every day and for me that is more than doable. The rest of the time I will be doing the publishing, selling end of things. The only thing that might get in the way is my old bugaboo - fatigue. I currently take

meds that help with the problem but want to eventually get off of them (hope springs eternal!)

When I get in my writing mode I can spit out a 350 page novel in about a month or two. In addition to the three completed novels and the two I am working on, I have 15 more outlined (I am prolific if nothing else!)

If the publishing business does not take off and provide me with a living I will have to find another means of support. My husband works as Chief of Security at California Lutheran University but we still have two children, aged 20 and 19, to support through college. I can always fall back on my computer skills but find it impossible to actually get out to find another job. My PPS is controllable as long as I don't actually have to leave the house. (Good thing I don't suffer from wonderlust as well!)

ByteLady Publishing
3885-J Cochran St #326
Simi Valley, CA 93063
866-298-3523
bytelady@earthlink.net
<http://www.bytelady.com>

Editor's note:

I found "Take a Byte Out of Crime" entertaining, and I learned a few things. If I hadn't known that the author is a polio survivor, I might have guessed when her main character recalled childhood events that affected her as an adult. From beginning to end Taylor Fritz seemed to

grow as a writer. I'm looking forward to her next book.

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In Defense of HMOs

by Rick Van Der Linden

A recent installment of Bill Kurtis' Investigative Reports entitled "Managing Your HMO" featured lawyer and polio survivor Bob Provan and his fight to help HMO (Health Maintenance Organization) patients get needed care. I taped the program looking forward to seeing "one of us" on national television. After watching it I was left with an empty feeling. I wasn't sure why, so I watched it again and this time I felt disappointed. The third time I took notes.

Mr. Provan made some very revealing statements. When his client, who is recovering from joint repair surgery, received her new wheel chair, he angrily complained that she had not gotten the chair she wanted. Wanted, not needed! What arrived was the standard issue model instead of the much more expensive lightweight model she *wanted*.

Mr. Provan is also involved in a possible class action suit against the HMOs. A suit that he admits would cost the HMOs millions of dollars and may even force them out of business.

The segment on the doctor who quit working for HMOs was more to my liking. However, the program was missing an important feature - the patient's contribution to the potential success of his or her HMO.

So, what's the problem?

An HMO is a business. They provide a needed service and deserve to make a reasonable profit as regulated by the US government. No problem - it's the American way.

The HMO gets a fixed amount of money each month for the health care of each subscriber. If all goes well, the excess funds from the healthier members counter balances the higher cost of the sick members. Problems arise if there are too many cases involving expensive treatments, and/or if too many people abuse the system. Then the HMO may have to spend more than it takes in. When this happens, the cost overrun can be taken out of the doctor's pay. As a result, some doctors - those who are less efficient, greedy, or just unlucky enough to have a high ratio of expensive patients - tend to be stingy with their prescriptions and referrals. This bottom line consciousness can cause a potentially good doctor to go bad.

In the case of an often hard to prove disability such as PPS, this situation can put pressure on a doctor to prove that you are not disabled.

For example: I've been with an HMO for about four years. During that time I've had two Primary Care Physicians (PCP). I told my first PCP - let's call him PCP1 - that two well-known PPS specialists had diagnosed me with PPS, and I provided him with the backup documentation. (He later would say, "Of course they're going

to say you have it. How else are they going to keep their clinics going." Some attitude, eh?) He sent me to several specialists including a Neurologist, two Orthopedists, a pulmonary specialist and a Physical Therapist. They were all capitulated with my HMO (on their list of local service providers who work on the high volume principal). Two of them had first hand experience with PPS. On the referral forms, PCP1 wrote, "I don't believe that Mr. Van Der Linden has Post Polio syndrome." Two said that I was uncooperative and one said that I don't have PPS. Of the two doctors with PPS experience, one said that I have the classic symptoms and should be treated as such (PCP1 told him he was wrong). The other suggested that my lung function was still acceptable, but annual testing was recommended (six years previous I had tested at 68% lung capacity and I've gone down hill since then).

After trying (and failing) to prove that I had one of a number of other conditions PCP1 finally told me that he believed I simply don't have PPS and if I wanted a doctor to agree with me, I should find another doctor. So, after a year and a half of beating my head against the wall I fired him.

This time I shopped around before choosing a doctor and it was time well spent. My new PCP (PCP2) respects me and believes what I say. (One time she said, "You know yourself very well.") She knows that I'm aware of the HMO challenges, and that I am as concerned as she is about the cost of treatment, so I

won't make any unnecessary or frivolous requests. We work together for my best possible health, and her success as a healer. The relationship has worked wonders for me while costing less.

Through all of this I kept the same HMO. I never once felt that Secure Horizons was in any way responsible for the physical and emotional setbacks I suffered. It was the doctor's decisions and nothing more.

I believe that the way to get good HMO care is to have a doctor who believes in you and will fight for you. You must also do your part by letting your PCP know that you intend to do your best to help yourself.

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How and Why Did I Get Polio?

I've often wondered why I got polio and my three brothers didn't. I know that I had contracted just about every childhood disease that came along, so I must have had a weak immune system. I had my tonsils removed before I got polio. I wondered if this could be a factor. Doctor Jim Donovan, retired pediatrician and polio survivor says it's not. He also said that it's "rare to see more than one case of polio in [a] family." He went on to explain that each of us has a different "genetic immunity".

At a recent PPS meeting one of the members stated that she thinks she got polio from migrant farm workers - either from the produce they handled or from a

contamination of the water supply when a flash flood that carried the virus from the local canyon where they camped. Since she lived in a very small community not far from the Mexico border, and contact with the outside world was minimal, this scenario seems plausible.

Could they have been carrying the virus without being sick? According to Doctor Jim a person can be a carrier - that is, a person who can transmit the disease without having symptoms.

Following the invention of the microscope, people became aware of the "wretched beasties" sharing our world - bacteria were discovered and later viruses was identified. As a result of these discoveries, milk was pasteurized, bacteria were harnessed for the making of wine, and disinfectants were invented. Eventually middle and upper class people sanitized their environment by killing or avoiding contact with many bacteria and viruses.

Before long we learned that some people got sick and some didn't because they had strong natural defenses and/or they had become immune to diseases through repeated low level infection. This insight led to the development of the vaccine responsible for nearly ridding the world of polio (the World Health Organization predicts that the world will be rid of polio by the year 2002).

Could we have "de-immunized" ourselves? Doctor Jim agrees that without regular contact with the virus or the

vaccine people would be more vulnerable to serious infection.

I got polio because I somehow ingested an enterovirus (see definition below) that, for some reason, my immune system was unable to fight. But the question still remains unanswered: Why is it that I go to PPS meetings and see only intelligent, good-looking people?

--ooOoo--

ENTEROVIRUS

The American Heritage Dictionary defines enterovirus as "Any of a subgroup of picornaviruses, including polioviruses, coxsackieviruses, and echoviruses, that infect the gastrointestinal tract and often spread to other areas of the body, especially the nervous system."

DEAR EDITOR

I am a polio survivor and now have MS. Have you heard of anyone else developing serious diseases after having polio so long ago?

Cathi

Cathi,

Yes. There's no reason to believe that just because we have PPS we wouldn't also have another condition. In fact, it's important to be tested for any condition that has similar symptoms. Hypothyroidism is the most common of these.

There is, however, a situation we have to look out for. Often people have a trusted doctor who is unfamiliar with Post Polio. In this case improper treatment might mask some symptoms while increasing others. Since PPS is a rare syndrome (a group of specific symptoms and conditions), this is not an unlikely scenario.

Your best bet is to go to a PPS clinic for a complete evaluation.

Rick

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The only thing I exercise is caution.

Doris Starrett

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For many years, Doris Starrett has donated her energy as the group leader in Victorville. Doris met her husband (also a polio survivor) at Warm Springs.

Thank you Doris.

Taking pain pills can be like not paying your taxes. Eventually you'll pay with interest and penalties.

Rick Van Der Linden

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Life is full of obstacle illusions.

Grant

Fraiser

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THANKS

Thank you for reading the PPS Manager. Your words of encouragement mean so much to me. Special thanks to Bev and Bill

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Merry Christmas
Happy Hanukkah
Feliz Navidad
Happy New Year
and so on....

May your holidays be warm and friendly.

See ya next year....Rick

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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.

Written by REVanDerLinden unless otherwise stated.

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or: E-mail PPSman@aol.com or call Rick at (909)929-8208

Meeting Reports

HEMET AREA
POLIO SURVIVORS

Thanks to **Bunny Smith, Anita Irazari, Phil Black,** and everybody.

Let's have us great year.

Our next meeting is:
January 17, 11 A.M.

After meeting go-to-lunch at local restaurant?

Regular Hemet meetings are at 11 AM on the third Wednesday of odd numbered months at: Sun West, 1001 N. Lyon, Hemet
for more info call Rick VDL 929-8208

COACHELLA VALLEY POLIO SURVIVORS
GROUP

Thanks to **Bob Warnock** for getting the group going and thanks **Linda Dempster** for all the help you give. Keep up the good work.

For information contact Bob at (760)345-5800

Victorville PPSGroup

Thank you **Doris Starrett.**
You are a very special lady.

For information contact Doris at (760)245-9058

Easter Seals Riverside
PPS Group

Betty McFarland is the party responsible for lighting the fire that got the Riverside group going in 1998. You may have heard her voice on the phone or maybe you got an e-mail from her. Betty, we wouldn't be here without you.

Judy Mahoney is the energetic organizer and snack bringer. You may have heard her voice on the phone and maybe you saw her lead a meeting or two. Judy, we're lucky. Your energy rubs off on everyone.

Thanks **Mary Brennan** for hanging on to the dough.

Thank you **Beverly McGaugh,** previous leader of the Riverside PPSG, for sharing your PPS experience with us.

This should be a very exciting year!

Next meetings are:

January 18, 2001

February 15, 2001

Regular Riverside meetings are the third Thursday of each month at 1 PM at: Eden Lutheran Church, 4725 Brockton, Riverside (two blocks south of 14th St.)
For more info. call:
Judy Mahoney (909)788-9310 or Betty McFarland (909)243-6991

Big Bear PPSGroup

Thank you **Marsha Hart**.

For information contact Marsha at
(909)585-6106