

**FROM THE EDITOR**

Hi Fellow PPS Managers.

It's always interesting to hear other polio survivors' stories. Sometimes I'm overwhelmed by how much we all have in common. Three recent events have driven this point home for me: the film, "A Fight to the Finish" viewed on video at the Hemet meeting and many other PPS group meetings (reviewed in this issue), the book "Speck" (also reviewed in this issue), and the article "The Shadow that Lurks in Recovery..." included in this newsletter. Personally, I thought I had almost no recall of being hospitalized and the rehabilitation that followed yet, since being involved in PPS groups, surfing the internet, reading books and personal polio stories, and seeing films on the subject, many memories have come back - often the same memories shared by other polio survivors. Maybe you'll find some enlightenment too.

The Post-Polio Letter received from Dr. Richard Bruno and signed by Mia and Thaddeus Farrow is intended as information for family, friends and medical professionals who may be in need of some education regarding PPS.

Mia Farrow is one of many famous people who had polio. Her adopted son Thaddeus is also a polio survivor. We are fortunate that she is becoming active on our behalf.

Other famous people who had polio include Alan Alda, Joni Mitchel, Neal Young, Itzhak Perlman, Arthur C. Clark, Judy Collins, Francis Ford Coppola, Jack Nicklaus, Dinah Shore, Donald Southerland, Franklin Delano Roosevelt, and you. You can find Jann Hartman's complete list at:

<http://www.geocities.com/arojann.geo/poliopeople.html>

Finally, check out the upcoming PPS events.

Have fun....Rick

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IN THIS ISSUE:

**Speck**

**THE SHADOW ...**

**The Post-Polio Letter**

**Letters and more**

**Book Review:**

**Speck**

The self published autobiography of Donald "Speck" DeVore.

From the Preface:

"This story depicts events over a period of time from 1948 to March of 1954. The struggles and disappointments this little boy faced while fighting for a normal life again, and recovering from the crippling disease called Polio, are an example of what courage and determination can accomplish."

The story of a scrappy red-headed nine year old from a broken home, "Speck" is loosely written in the third person as if his life was being observed by someone else. He did "manage to maintain the Texas flavor, and manner of speaking..." in exploring his personal relationships with his family, friends, and doctors while overcoming the anger and frustration of being treated "different" by a sometimes intolerant society.

Donald DeVore was a March of Dimes poster child, famous in his home town, and went on to be a community leader.

I was amazed that DeVore remembered so much about his experiences. He brought back many memories I thought I had forgotten.

Donald R DeVore  
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## Film review:

### **A Fight to the Finish: Stories of Polio**

a Mandel/Harring film

Presented by Texas Scottish Rite Hospital and Ken Mandel Productions.

“... weaves together history and personal stories to create a unique documentary portrait of the human spirit.”

Included are interviews with local heroes Dr. Jaquelin Perry and polio survivor Richard Daggett. A must see for polio survivors wishing to relive the experience. May be seen at your local PPS group meeting.

## **THE POST-POLIO LETTER**

**Basic facts about PPS for polio survivors, doctors, family & friends.**

### **Dr. Richard L. Bruno**

Chairperson, International Post-Polio Task Force

Director, *The Post-Polio Institute* and The International Centre for Post-Polio Education and Research

Englewood (NJ) Hospital and Medical Center,

USA\*

## **WHAT ARE POST-POLIO SEQUELAE?**

Post-Polio Sequelae (PPS, "Post-Polio Syndrome," The Late Effects of Poliomyelitis) are the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness,

muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, as well as difficulty swallowing and breathing -- that occur about 35 years after the poliovirus attack in 75% of paralytic and 40% of “non-paralytic” polio survivors. There are about 2 million North American polio survivors and 20 million polio survivors worldwide. The existence of PPS has been verified by articles in many medical journals, including *The Journal of the American Medical Association*, the *American Journal of Physical Medicine and Rehabilitation* and *The New England Journal of Medicine*.

**WHAT CAUSES PPS?** PPS are caused by decades of “overuse abuse.” The poliovirus damaged 95% of brain stem and spinal cord motor neurons, killing at least 50%. Virtually every muscle in the body was affected by polio, as were brain activating neurons that keep the brain awake and focus attention. Although damaged, the remaining neurons compensated by sending out “sprouts,” like extra telephone lines, to activate muscles that were orphaned when their neurons were killed. These oversprouted, poliovirus-damaged neurons are now failing and dying from overuse, causing muscle weakness and fatigue. Overuse of weakened muscles causes muscle and joint pain, as well as difficulty with breathing and swallowing.

**HOW ARE PPS DIAGNOSED?** There is no diagnostic test for PPS, including the electromyogram (EMG). PPS are diagnosed by excluding all other possible causes for new symptoms, including abnormal breathing and muscle

twitching that commonly disturb polio survivors' sleep, a slow thyroid and anemia. Other neurological or muscle diseases are almost never the cause of PPS symptoms.

**ARE PPS LIFE THREATENING?** No. But because of damaged brain activating neurons, polio survivors are extremely sensitive to - and need lower doses of - gas and intravenous anesthetics and sedative medication. Polio survivors can have difficulty waking from anesthesia and can have breathing and swallowing problems, even when given a local dental anesthetic.

**IS PPS A PROGRESSIVE DISEASE?** PPS is neither progressive nor a disease. PPS is caused by the body tiring of doing too much work for too long with too few poliovirus-damaged, oversprouted neurons. However, polio survivors with *untreated* muscle weakness were found to lose about 7% of their remaining, overworked motor neurons each year.

**IS THERE TREATMENT FOR PPS?** Yes. Polio survivors need to “conserve to preserve,” conserve energy and stop overusing and abusing their bodies to preserve their abilities. Polio survivors must walk less, use needed assistive devices - braces, canes, crutches, wheelchairs - plan rest periods throughout the day and stop activities *before* symptoms start. Also, since many polio survivors are hypoglycemic, fatigue and muscle weakness decrease when they eat protein at breakfast and small, more frequent, low-fat / higher-protein meals during the day.

**ISN'T EXERCISE THE ONLY WAY TO STRENGTHEN WEAK MUSCLES?** No. Muscle strengthening exercise adds to overuse. Pumping iron and “feeling the burn” means that polio-damaged neurons are burning out. Polio survivors typically can't do strenuous exercise to condition their hearts. Stretching can be helpful. But whatever the therapy, it must not trigger or increase PPS symptoms.

**IS TREATMENT FOR PPS EFFECTIVE?** Yes. The worst case is that PPS symptoms plateau when polio survivors stop overuse abuse. Most polio survivors have significant decreases in fatigue, weakness and pain once they start taking care of themselves and any sleep disorders are treated. However, because of emotionally painful past experiences related to having a disability, many polio survivors have great difficulty caring for themselves, slowing down and especially with "looking disabled" by asking for help and using assistive devices.

**WHAT CAN DOCTORS, FAMILY AND FRIENDS DO TO HELP?** Polio survivors have spent their lives trying to act and look “normal.” Using a brace they discarded in childhood and reducing overly-full daily schedules is frightening and difficult. So, friends and family need to be supportive of lifestyle changes, accept survivors' physical limitations and any new assistive devices. Most importantly, friends and family need to be willing to take on taxing physical tasks that polio survivors may be able to do but should *not* do. Doctors, friends and family need to know about the cause and treatment of PPS and listen when polio survivors need to talk about how they feel about PPS and lifestyle changes. But friends and family shouldn't take control of polio survivors' lives. Neither gentle reminders

nor well-meant nagging will force polio survivors to eat breakfast, use a cane or rest between activities. Polio survivors need to be responsible for caring for their own bodies and ask for help when they need it.

*For more information about the cause and treatment of PPS go to [www.postpolioinfo.com](http://www.postpolioinfo.com)*

**(The Post-Polio Letter cont.)**

**Whether you had polio or not, please COPY and MAIL this letter to your doctors. With your help every doctor will learn about the cause and treatment of PPS and give polio survivors the care we so desperately need. Thank you!**

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Mia Farrow and Thaddeus Farrow, polio survivors

Co-Chairperson, The POST-POLIO LETTER Campaign  
Co-Chairperson, The POST-POLIO LETTER Campaign

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## **THE SHADOW THAT LURKS IN RECOVERY:**

**MY EXPERIENCE WITH POLIO AND POST-POLIO SYNDROME**

By Susan H. Conley

Yes, I am a polio survivor, and I have always known that I was "One of the lucky ones". I was able to walk away from the experience into a relatively normal life. My first memories are of FEAR: Fear...Pain...and feelings of Isolation. I capitalize these because I remember them so very strongly.

The scare of the summer plague known as Polio was over. It was the first week of September 1952, and I was eight years old. The school year was just starting, and I was ill. The doctor thought that I had the flu, but my mother had been reading about polio, and sensed that she should get another opinion. Overnight (it seems to me) I could not lift my legs to put my jeans on. I remember calling out for my mother and crying. My legs hurt so much. What was happening? The summer was over...this couldn't be the dreaded polio!

My life was about to change dramatically, and as a family unit, we could never have been prepared for this experience and the effect that it would have on each of us. I can only speak for myself, and I can tell you that I was terrified! My parents drove me to the County Hospital in Los Angeles, which was about 30 miles away from our home in the San Fernando Valley. County General was where polio patients were taken at that time. This was before freeways, so it seemed to take forever to me, lying in the back seat of the car and looking out of the back window at the streetlights going by.

We arrived at the emergency room, and all I remember is the spinal tap. To say that I was scared to death would be an understatement! After the ER, I was separated from my parents, and placed in a ward in this huge hospital, set aside for people like me. The life I had known with my mother, father, and younger brother, had come to an end. I was on my own in a very strange and isolating environment.

I spent three days at County in that ward. I became afraid to go to sleep at

night, because when I did, I would awaken with sounds of another patient being rushed out of the room surrounded by loud voices and banging of the metal beds against each other. Later, that person would be brought back with a hole in his throat! I believed that if I stayed awake, that might not happen to me. I also remember that whenever anything fell from the bed onto the floor, the nurse would take it away to burn it, because it was then considered contaminated. I lost a stuffed animal that way. So, when the picture I had of my family hit the floor, I cried and pleaded with the nurse not to take it away and burn it. Thankfully, she placed it in a nearby window, where I could see it but could not reach it. I remember my mother visiting, all covered up, and unable to touch me. All I could see was her eyes. I had never before been separated from my family, and could not understand why my mother could not hold me.

After the three days I was transferred to a polio rehabilitation hospital in Santa Monica, where I stayed for almost four months. Four months can be a long time for anyone. For an eight-year-old, it is an eternity!

I was placed in a ward, surrounded by other children also scared and alone. It did not take long for me to be fit into the routines of the hospital. There were treatments at that time that I believe now, certainly saved my muscles:

The Sister Kenny treatment: staff would come in rolling a big metal bucket on noisy casters filled with steaming hot blankets inside. We would each be

placed on a plastic sheet on our beds, and watch the attendant go from bed to bed, lifting the steaming blanket with long wooden sticks to wrap our bodies with. I could not understand, how it was too hot for them to touch, but not too hot to wrap around my small body.

Pool therapy: lifted down on a stretcher into the water for therapy. I could not swim yet, and had so little strength in my legs, that I feared drowning on a daily basis at first. I soon learned to trust the strong arms in the pool to keep me safe.

Whirlpool baths: I was so embarrassed to be almost naked in front of others.

Physical therapy: countless sessions with heavy weights on my legs. These were very tiring, but I do not remember disliking this part. As some of my strength came back in my legs, I received positive feedback because I had been such an athletic child before polio. It was felt that this helped me tremendously in my recovery.

Electric muscle stimulation: so frightening that I was found hiding in a linen closet one day, trying to avoid this.

The nights were the longest. Many of us cried ourselves to sleep, seemingly, day after day, and night after night. Was this to last forever? But again, I was one of the lucky ones!

I came home just before Christmas. I do not remember going home, except in a picture taken of me soon after. In it I am wearing my new Blue Bird uniform (a junior level of Camp Fire Girls), looking so very pale, with hundreds of freckles standing out next to my dull looking, dark eyes. I look like I had been put through the ringer, obviously

exhausted from the experience. Thankfully, I had a loving family, with lots of support at home. My next year was filled with intense physical therapy until my strength returned, and my activity level and stamina became that of other nine-year-olds.

As a teenager, I began to put this experience behind me, and began excelling in sports in school again. I was once again the tomboy in the neighborhood, jumping hedges, climbing trees, and first picked by the boys for the baseball games. I worked hard to appear normal, and to fit in. However, when I would overdo, and get tired, my left leg would give out very suddenly and I would fall. I remember falling in the hallway in school; papers and books would fly everywhere, and the other kids would laugh.

I would trip over unseen objects. It felt like I excelled in stumbling. At other times I felt strong and agile. I majored in physical education in college, and even joined the women's track team for awhile. I was never a runner; I did not have any speed to speak of, but put a discus in my hands, and watch out!

So on into my adult years, I did not even think about polio. In fact, although I was quite young when I was hospitalized with polio, I had such unpleasant memories of that experience that for decades I blocked it out totally. It had happened in a different lifetime and as if to a different person. I actually had few memories of my childhood. I studied Nursing, became an R.N., and even specialized in Pediatrics for a few years.

I felt as if I really identified with the children and their separation anxiety. I believe that I was of some help in that way. So I developed my career, married, gave birth to two children, and divorced, all in about ten years. Stress had become a major factor in my life, and I did not handle that well at all. I seemed to internalize everything, never feeling good enough to the task at hand, yet always striving toward goals. Yes, I fit into the mold of the A-type personality, so common in polio survivors.

Then, in my forties, I began to limp when I became tired. It seems that I was beginning to drag my left leg a little again, and began to tire more easily. In 1988, at the age of forty-four, I began experiencing shooting pains down my left hip and leg, radiating from my lower back. It became painful to lower my left heel to the floor when I walked.

One day, at the hospital where I worked as a Nursing Administrator, I had the opportunity to hear a physician, an orthopedic surgeon, speak on the topic of Post Polio Syndrome. I was so very fortunate to have gone to that lecture. I spoke to him afterwards, then called for an appointment to be evaluated by him for my leg and back pains. The most traumatic moment of all, was when I was on the exam table, with two physicians leaning over my legs, looking at my feet, and mumbling to each other.

Suddenly, I was eight years old again! I was frightened as I flashed back to all of those feelings I had when I was a child, and was separated from my family. I felt overwhelmed as the doctor scheduled

surgery and explained what was happening to me.

I cried for two days after that, and could not sleep for many days. All that I had stuffed deep down in my past, far behind me, came flooding back. Insecurities abounded.

I soon was able to put things into perspective, and again moved on with my life. The surgery, and a support in my left shoe, seemed to manage the problem for a few years.

Then, three years ago, my tripping and stumbling began in earnest, and again my left leg would give way without warning, and down I would go. Just like back in school 35 years before. Then it happened. I fell down a few stairs when my leg gave way once again, badly injuring my right knee. That was my "good" leg. The injury required surgery and many weeks of physical therapy. I talked to my present doctor about Post Polio Syndrome. He believed that I needed to exercise more to strengthen my weakened muscles. He did not seem to know about PPS.

By then I was using a cane for support whenever I was outside. I began doing my own research, getting a computer for that specific purpose, finding local PPS support groups, and discovering wonderful newsletters. I was not alone. I was not crazy and just feeling sorry for myself. I was going to be okay. I could do this! My life was changing, and not in a way that I would have chosen. Who knew that we would have to go through this again? I grieved for awhile, but I am an adult now, and I have choices. I can

educate myself, and learn the best way to cope with this. This certainly is the challenge that I will deal with for the rest of my life. I still believe that I am one of the lucky ones.

I came to the conclusion that I needed an expert medical opinion and evaluation. I had read about the Post Polio Clinic at Rancho Los Amigos Rehabilitation Hospital in Downey, California. I had read articles by Jacqueline Perry, MD, and was already receiving the Rancho PPS newsletter in the mail. I called, and waited the requisite six months for an evaluation. I will be forever grateful that I ended up at that clinic, being evaluated by Dr. Perry. By that time, fall of 2001, I was significantly weakened on my entire left side. Even my right arm and leg were measurably weakened. Dr Perry and her professional team were very understanding and supportive of the effort my life had become. The weakness and the chronic fatigue were now having a major impact on my life. I could no longer walk around the block without major effort. I tired quickly when gardening. I became exhausted and irritable at the end of each day. I was aging before my time, and before my eyes.

Dr. Perry ordered a brace for my left leg, and talked to me about resting three times each day, and to pace myself to lessen the demands in my busy life. It was suggested that I sit or lean on a stool while preparing meals in the kitchen, and to feel free to ask others in my life to help me. I have found that there is a lot of gray area between dependence and independence that I need to explore further. I see this as another challenge in my life; to accept my physical

limitations, as well as to do whatever I can to pace my activities, rest frequently during the day, and stay as optimistic as possible.

So, I wear my brace, use my cane, and have even added "Scooter" to my life recently.

Scooter is an electric scooter that I find already is worth its weight in gold.

Wearing my brace has removed much of my daily pain, and along with my cane, has kept me from falling. Using the scooter is not only a godsend when I have to travel distances "by foot", but I find that riding it is a lot of fun. Actually, I feel very independent when using it.

I cannot underestimate the importance of a support system, as well as education in PPS, and a doctor who understands PPS and can help me. As my life evolves, I am energized by these changes. The more I know the more I grow, preserving the nerves and muscle strength that I have left. I am ready for the next chapter in my life.

Susan H. Conley - [colbys@pineknot.com](mailto:colbys@pineknot.com)

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Thanks, Rick, I found this issue [JAN/FEB] to be particularly helpful and interesting.

For my cold sensitive feet and legs during the winter, my wife and I have modified a heated bed blanket that works better than anything else I have tried for warmth sitting in my recliner.

We had a queen size blanket with dual controls. We first tried the entire blanket and this was a lot to work with. So we cut the blanket in half to yield two

1/2 blankets each with a set of controls. This worked much better and I had one for my family room chair and one for my bedroom chair.

Later we created a "pouch" for me to insert my legs into that worked even better. My wife folded about 1/3 of the blanket's length under and sewed the sides. Now I slip my feet into the pouch, the underside comes up to about mid-thigh-enough to cover the open space between the foot rest and the chair seat when I have my feet elevated.

Regards,  
D. Mark Arnold

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Hi! Rick, I would like to introduce myself. My name is Sandra Snorek, and I am a PPS survivor among other problems. I am about to turn 60 in April and the doctors think that I contracted Polio from a cousin of mine, that died from Polio. They guess that I must have been somewhere around 3. At that time I lived with an Aunt whose adult daughter was a nurse in a Pediatric Ward, which is where she contracted Polio. Her Polio centered in her lungs and that is before they knew about the iron lung (I think), hence she died. I also was born with both hips dislocated. When I was 6 some men, in the small town that I was born, who were Masons. They were able to get my mother and I as interview at the Shriners Hospital in Philadelphia, where I was accepted. I had 4 surgeries in the space of about a year and a half. When I was released I had to walk with crutches and sleep in a brace. I had school while in the hospital, so when I returned home I started

back in the 3rd grade. Thanks to my mother, she made me a very independent person. I never dreamed I'd be facing anything like this again. (only worse) I am married and have 2 children. I am on Disability but can't seem to admit how hard it is for me to work. I do work for the Cleveland National Forest, in Corona. I work 20 hours a week. 8 to 1:30, 4 days. I do enjoy dealing with the public and the Fire Fighters.

I have enjoyed reading your news letter and passing it on to friends and to my Doctors. I haven't been able to attend any of your meetings because of working, but some of the information in your paper has been very helpful. Recently I had some surgery on my knee, but since then I have had to walk with a cane and am in enormous pain. I do have pain killers, but only take them when I can't take it any more.

... A fan of your Newsletter, Sandra Snorek

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Dear Rick,

Thanks so much for the great job you do on the newsletter. I read every bit of it

May I suggest you put your address and/or phone number on the masthead?

... Henrietta Wahl

Editor: Thanks for the idea....Rick

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## Regarding home spas:

In an e-mail (which I lost) Judy Sander reminds us that many people are allergic to chlorine and bromine.

A Jacuzzi tub may be the best alternative. It's smaller and uses the water once,

so you can add scented oils and such for a full on relaxing experience. It may fit in your bathroom, replacing your existing tub.

They cost much less than a spa but installation could be pretty expensive. If used daily, the cost of operation will probably be more than a spa.

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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 Henrietta.

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

## Important Coming Events

**April 27** Technonogy Fair for Disabled Persons  
3939 13th St, Riverside 909-880-7695

**May 9** PPS Regional Group Leaders Meeting  
At Rancho Los Amigos in Downey  
call 562-862-4508

# PPS MANAGER

10

**May 9** 7:00 to 8:30 **Dr Gold** in Palm  
Desert

Dr. Gold is a top ranked Pulmonologist  
treating  
patients with neuro-muscular  
conditions.

760-340-3220

**May 19** 1:00 to 3:00 **Dr. Susan Perlman** at  
Apollo Park Senior Center across from Rancho  
Los Amigos in Downey. Call 714-968-1675

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**ADMIT ONE**  
**2002 ABILITIES EXPO/SO.**  
**CALIFORNIA**  
**Long Beach Convention Center**  
Friday, **June 7**, 2002, 10am-5pm  
Saturday, **June 8**, 2002, 10am-5pm  
Sunday, **June 9**, 2002, 11am-5pm

Name:

Address:

City:

State:

Zip:

Email:

Bring completed form for free  
admission.

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## Post Polio Symposium

€**Susan Perlman, M.D.** - Recent Advances in  
Treating Post Polio Syndrome

€**Sam Pfaff, Ph.D.** - Using Secrets From  
Embryonic Development To Treat Disease

€**Lindsay Whitton, M.D., Ph.D.** - Persistent  
Virus Infection and PPS

Sunday, **June 23**, 2002 1 to 4 PM

Schaetzel Center - Scripps Memorial Hospital

9890 Genessee Ave

760-741-5075

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