

Newsletter

MARCH 2014

18552 Cork Street
Fountain Valley CA 92708

Website: ppsupportoc.org

COMING EVENTS

In March, we will have a speaker from HICAP whose area of expertise is ELDER ABUSE. She will discuss how to recognize it and what to do if you believe you or a family member is the object of abuse. She will discuss resources for aid and how to notify the proper authorities if appropriate.

In May, after Mother's day, we will have our annual research and treatment update presented by Dr. Susan Perlman. This is a joint meeting of Rancho and Orange County held at Villa Park.

GOOD THOUGHTS

As this is intended to be a vehicle of support to our members, I have been trying to find ways to add personalized support rather than just medical and polio related articles. While important, most of us do not need to be reminded we have had polio. Trust me, we know it. We live it on a daily basis. But we are more than our polio experiences and memories. We have all had times and things in our lives that are beautiful.

One such, for me, is the remembrance of visiting my maternal grandparents home on Murray Street in Placentia during the summers. When they lived there, Orange County still had many, many orange groves. In fact, across Murray St., it was all orange groves for blocks. My grandparents were quite elderly as my mom was the youngest of seven and her oldest sibling was nearly 20 years her senior. Like most children, we tended to get noisy, and in the summer evenings most of the time, we were banned to the front porch so our noise wasn't so bothersome. My grandpa HAD to listen to Walter Winchell on Sunday evenings without fail and his hearing predicated that his ear be within a few inches of the radio. (Yes, that was pre TV time and people actually relied on radio and newspapers).

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Meet Our Member

Jerry Daniel

By

Debbie Hardy

At my Grandparents, summer evenings we children spent outside. The scent of the orange blossoms from all those orange trees would waft through the evening breeze. I don't think I have ever smelled anything in my life more wonderful than the orange blossoms filling the air at my grandma's house in the summertime. It was truly wondrous and a wonderful memory.

Do you have a special positive memory that you would like to share with our readers? I would be happy to print some uplifting stories if you do wish to share them. Send me a note by snail mail to Janet Renison, 3454-A Bahia Blanca West, Laguna Woods, Ca 92637 or by e-mail to Renison@lagunawoodsvillage.net

SURVEY RESULTS

As you know, I asked the question in last issue, **“Should Disabled People be Able to Use Modified Guns That Accommodate Their Disabilities?”**

We didn't have a big response, unfortunately, but it was quite unanimous. Our members feel that gun modifications would not be as likely to provide disabled people the protection they feel they should have. In fact, it was felt that guns would provide a FALSE sense of security and being aware of ones surroundings and using common sense approaches to safety, especially at night, would offer more protection than a gun. I'd like to thank those who took the time to respond.

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Just after Jerry Daniel turned 10 years old, his life changed forever. He was taken by ambulance to Seaside Hospital in Long Beach where a spinal tap was performed. He and his parents were informed that he had both spinal and bulbar polio. Jerry was then transferred to County General Hospital in Los Angeles because they were equipped to handle polio cases and spent the next six weeks in an iron lung. After receiving treatment at County General, Jerry was told that he was going to a really nice place with green grass and lots of trees named Rancho Los Amigos in Downey. At the time, Rancho was taking the most disabled polio patients for rehabilitation. When Jerry arrived at Rancho Los Amigos, he did see lots of trees and green grass, but the buildings were very old and run down and had been formerly used to house the indigent.

Following a year of treatment and rehabilitation at Rancho Los Amigos, Jerry's parents decided they wanted their son home. Back at his home in Long Beach, Jerry received physical therapy and schooling. When it was time for high school, Jerry decided that he wanted to go to a regular school and entered Poly High in Long Beach. Once there, Jerry learned that things were much harder for him physically and emotionally than he thought. Having been home schooled for so long, Jerry found it was difficult to communicate and make friends. Students that he had been friends with in grammar school passed him

in the halls without so much as a hello or any sort of acknowledgment other than the recognition in their eyes. At the time, the Long Beach School District provided taxi service to take him to and from school; that, coupled with his physical disability, helped to ostracize him even more from his classmates.

As he got older, Jerry's spine was becoming more and more crooked and was affecting his breathing. He returned to Rancho Los Amigos, which now had beautiful new buildings, for treatment. In his senior year of high school, after viewing an x-ray of his lungs, his doctor told him that his lung was partially collapsed and he needed to come in immediately for treatment. After several doctor conferences to discuss his condition, Jerry was told that he needed a spinal fusion and that he had only a 50% chance of surviving the surgery. The surgery was done in 5 stages and took almost a year. Needless to say, Jerry survived and spent his recovery in a body cast from the top of his head to just below his knees with cutouts for his face, ears and stomach. Jerry also had to be in an iron lung for recovery. After lying flat for almost a year, Jerry experienced many moments of joy when once again he was able to sit and walk. He is proud of the fact that he graduated with his class from a regular school instead of receiving his diploma from a handicapped school.

Jerry continued his education at Compton College but was a poor student. He found it difficult to sit still and be confined to a classroom after all he had been through. He had his first car, a 1957 Ford, with an automatic transmission and power steering and he wanted to be out enjoying life. He was interested in electronics and he enrolled in National Technical School to study and did very well. Because of problems caused by his spinal fusion, Jerry needed to work from home. He was employed servicing home care ventilators. UPS would bring the ventilators to Jerry and pick them up when he had finished his repairs. He just recently retired from this occupation as the weakness in his arms now makes it difficult for him to lift and turn the machines.

In 2009, Jerry started experiencing pain in his stomach. Medical tests revealed that Jerry's colon had started deteriorating. It was twisted and deformed. Surgeons untwisted as much as they could and patched it with mesh but Jerry had to have a colostomy. Eight months ago, Jerry developed pneumonia. After a few days in the hospital, Jerry was ready to return home when his doctor informed him that he had had aspirational pneumonia. Because of his lung problems, when he was swallowing food, no matter how well he chewed, little particles of it were going into his lung. This is a deadly condition and he was told that he would need a feeding tube surgically implanted into his stomach. Jerry cannot eat food normally as he can no longer swallow. All of his nourishment is delivered through a GI tube in his stomach via a Kangaroo pump which feeds him 24/7. "Not being able to eat is a big loss. My wife is a chef and catered to me with food."

(Daniels cont'd)

Jerry met his wife, Rena, who is originally from Maine, through a polio friend. They have been married for 45 years and have a daughter and a son, as well as three beautiful grandchildren (twin boys and a girl). In 1980, Jerry and Rena, migrated north from sunny Southern California to Vancouver, Washington. Jerry's friends were against the move; worrying that he might not be able to get the medical care he needed in Washington. Jerry has had 20 orthopedic surgeries and has used a ventilator since he contracted polio (with the exception of 5 years). He has had no problems receiving excellent medical care in Washington. In 1984, Jerry returned to using a wheelchair after developing a staph infection from a hip joint replacement. Now, he uses a power chair for 6 hours a day and spends the rest of the time in bed because of the ventilator and GI pump. Currently, one of his projects is writing his memoirs of his polio experience.

Jerry feels honored that his children have chosen to remain close to him and raise their families in the same town and says that he has "a great family and has lived his life as close to normal as possible – whatever 'normal' is."

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CUTTING COSTS FOR PRESCRIPTION DRUGS

When Maggie Helm had a recurrence of ovarian cancer a year after her initial treatment, her oncologist suggested she take what, in his opinion, was a life saving drug. There was just one problem; her insurance wouldn't pay for it. The 59-year-old Hermosa Beach resident inquired about the cost at Cedars-Sinai where she received care. She was told that the drug, Avastin, would cost her about \$50,000/mo. But that was simply not an option for her. She needed to take Avastin two times per month at \$25,000/treatment.

Specialty drugs used to treat complex or rare conditions like Helm's has are getting pricier, even as growing numbers with serious illnesses such as, Helm's cancer and multiple sclerosis, are using them. In 2010 for instance, Medicare paid \$216,833 a year for each patient taking the drug Recombinant to treat hemophilia and \$26,000 a year per person for Herceptin, another cancer-fighting drug. Genentech Inc., maker of Avastin, sells the drug wholesale for up to \$10,000 a month, but a company spokeswoman noted that the company provides price reductions for customers who can't afford the drug. Health insurance policies, particularly those offered at work, typically cover most routine drug costs. But with specialty drugs prices continuing to escalate at exponential rates, employers are becoming more assertive in managing those costs. To curb costs, employers are using economic incentives such as tiered prescription benefit plans that cost employees more money for specialty drugs and require a "step therapy process" whereby employees must try less expensive medications before gaining approval for pricier drugs. Some people with life threatening

(Cutting costs for Rx cont'd)

disease just don't have the time to use this process.

However, whether you are on high-cost specialty drugs or drugs for more common conditions like high blood pressure, there are ways you can explore to save money.

- Participate in clinical trials.

Helm solved her cost problem by joining a clinical research trial studying a new treatment works for patients. The one she found offered Avastin treatments for her ovarian cancer for free.

A website titled "ClinicalTrials.gov" is a clearinghouse maintained by the NIH.

- Shop around and negotiate

As much as you may dislike this approach a recent poll by Consumer Reports found wide variation in the price of commonly used prescription drugs. The cost for generic Plavis, for example, ranged from \$15 at Costco to \$180 at CVS pharmacies. Even should your insurance company require you to use a specific pharmacy chain, you may find your out-of-pocket costs are less by using another pharmacy and paying for the drug in total. There are often other affordable alternatives. In many cases, there are cheaper generic choices or simply less expensive drug alternatives. Often, you have to ask to find out. "Appeal to your doctor to find another treatment that is covered by your insurer" suggests Lisa Gill at Consumer Reports.

- Appeal the decision of your insurer and even Medicare.

This option worked for me when I found I could not find a pharmacy who sold the one generic out of more than 12, that worked for me. Not all generics are created equal regardless of what the pharmaceutical companies profess. They allowed me to purchase the brand name even though it wasn't on their formulary as covered. If you make a strong case, sometimes you can prevail.

Federal law now gives most consumers the right to challenge their insurance company decision to deny medical care. Your health plan MUST provide guidelines on how to appeal care that has been denied. To increase your chances for success, ask your doctor to intervene on your behalf and advocate for use of that drug specifically. For help fighting an insurer's decision, Californians with HMOs can contact the Dept. Of Managed Care at healthhelp.ca.gov or by calling (888) 466-2219. If you have a PPO plan, try the Dept of Insurance at (800) 927-4357. If you get your insurance through work, ask your HR Dept for help in overturning the decision. You also have the right to appeal when Medicare denies coverage.

If you have Part D Medicare Rx coverage or a plan through Medicare with drug coverage, also consider appealing directly to the private insurance company's administering your Medicare benefits.

- Look for patient assistance programs

Typically aimed at the poor and uninsured, patient assistance programs help people cover their medication costs. Some are offered by pharmaceutical manufacturers. Others are diagnosis-specific and available through nonprofit organizations and state governments. They may have financial asset restrictions but it doesn't hurt to ask.

There are a number of good clearinghouses that provide information about programs and how to apply. NeedyMeds.org has information on thousands of programs, more than 10,000 free or low cost or sliding scale clinics, drug discount coupons and nearly 1,000 application assistance programs which will help consumers navigate the application process. RXAssist.org offers a database of pharmaceutical company programs.

States also can provide financial help. In all, 22 states -- but not California -- offer state pharmaceutical assistance programs that help residents pay drug costs. Some coordinate with Medicare benefits programs. You can see what is available at Medicare.gov. Even if you don't meet the exact qualifications listed, apply anyway.

Plead your case, pull heartstrings if you must and do whatever it takes to make them consider you. There is always some "wiggle room" in such programs.

The job of finding and getting the right drug can be daunting and complicated as well as frustrating, but success is priceless according to Helm, the Hermosa Beach resident. "I am doing pretty well so far," she said. That thought makes the effort more than worth it for many.

Excerpted from LATimes.com

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**Don't forget the coming meetings.
See list on Pages one and eight.**

Disclaimer: Information provided in our newsletters and at our meetings is provided by the PPSG of OC and Rancho Los Amigos Support Group solely as information. It is not to be taken as an endorsement of any product, individual, medication, or treatment. If you have personal medical problems, please consult your own physician knowledgeable in the late effects of Polio. Unless otherwise stated, the articles in this newsletter may be reprinted provided that they are reproduced in their entirety, and the author, the original source, and the PPSG of OC and/or the Rancho Los Amigos Support Group are acknowledged in full.

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Rancho Los Amigos Meeting

BULBAR ISSUES

Saturday , MARCH 22, 2014

2 pm — 4 pm

Orange County Meeting

ELDER ABUSE

Saturday , MARCH 8, 2014

2 pm — 4 pm

Future Rancho SG Meetings

Saturday, March 22, 2-4 PM

Pulmonary and Other Bulbar Issues

Sunday, May (TBD) 2 PM

Dr. Susan Perlman @ Villa Park

UPDATE on PPS Research

Future PPSG of OC Meetings

Saturday, March 8, 2014

HICAP — Anne Gray

Sunday, May (TBD), 2 pm

Dr. Susan Perlman

Donations needed year round! Note that we mention donations but not the amount, as all donations make the OC and Rancho groups possible. Please write checks to Polio Survivors Association and write "Newsletter" in the memo section. Please mail checks to Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork St. Fountain Valley, CA, 92708.

How to contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association

For add additional information please call Richard at 562-862-4508

Email: RanchoPPSG@hotmail.com

How to contact OC Support Group

For information call:

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Marilyn Andrews 714-839-3121

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renison@lagunawoodsvillage.net

Agenda ideas for PPSG of OC ????

Please call Aleta at **949-559-7102** or email Priscilla: prisofoc@aol.com

**Post-Polio Support Group
of Orange County**

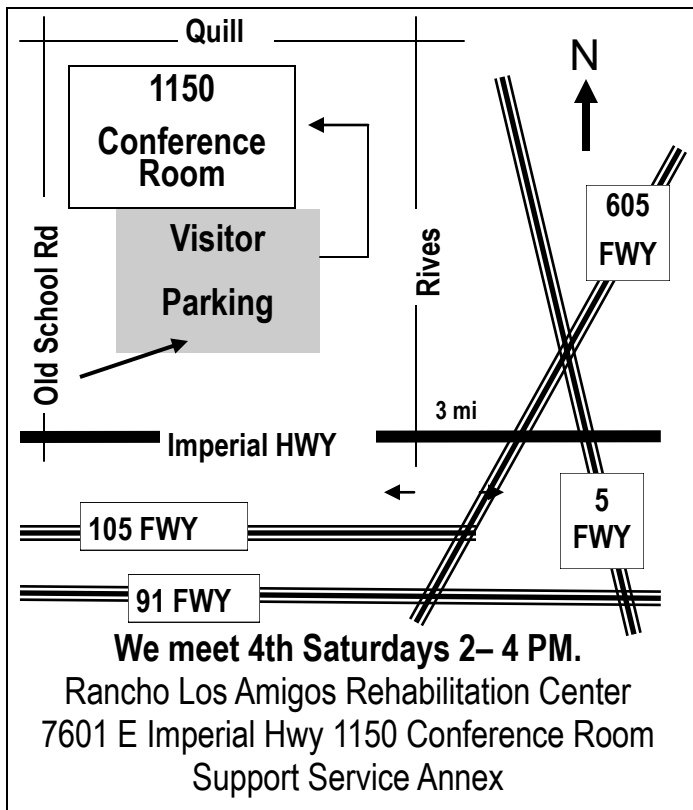
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**Rancho Los Amigos
Support Group Meetings**



**Orange County
Support Group Meetings**

