



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - January - February 2019

My Experiences with Polio

By James "Jim" Morgenstern

Our family loved to camp out on weekends. Our favorite place was at Boulder Creek in the Santa Cruz coastal range of northern California. We were about 200 miles away from our home in Fresno.

I was just 6 years old in 1949. I had persuaded my parents to bring my new tricycle along on this trip. One morning, probably Saturday, I got up and anxiously wanted to ride my trike, but my legs just wouldn't move. My parents thought I was faking, as I did like to pull off stunts in order to see my parents panic. My legs just did not work.

My father was a physician who was trained in oral surgery at the finest medical university in the world for 1930, the University of Vienna. He didn't know what to do. Our family packed up and drove to the nearest city, probably Santa Cruz. There, the physician that we were able to find said that he was familiar with the polio epidemic, and he had heard about a British Army nurse by the name of Sister Elizabeth Kenny. She had experimented with polio victims in Australia with leg conditions. Neither the doctor nor Sister Kenny believed that leg braces should be the first choice for treatment.

My parents were instructed to take me home to Fresno, at a time of year when the daytime temperatures often exceeded 100 degrees. I was placed on a chaise lounge in the hot sun, only clothed in shorts, and my legs were covered with hot, wet cloth compresses. That "medical procedure" continued all summer. Between treatments, I would try to exercise my legs by walking a little. It did not work. Just on our block, three of us were afflicted and one of my young neighbors had to live in an iron lung.

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The information presented at our meetings and/or contained in this newsletter is solely for information. It is not an endorsement of any product, medication, or individual.

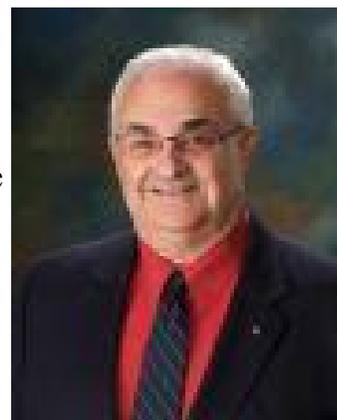
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My family did not treat me special, nor did they make any bigger deal of this than they did when I contracted measles, mumps, chicken pox, or anything else. My older brother was off with his high school buddies and I seldom saw him. By the time school started in the fall, I was able to walk without any assistance, even though I think that I moved slower than my friends. Nobody seemed to care. At school, probably in the first grade, I remember having a wonderful and uneventful year. Occasionally, when very tired, my right leg would hurt and my parents would take turns massaging that leg.

About a year ago, at age 73, I noticed that my left leg (not right leg) would often ache and that sometimes I felt so weak that I would have to lift that leg up when entering my car. My hip and knee would ache and the inside muscle on my left leg even kept me awake at night. I went to see my doctor for a routine checkup and to “complain” about getting old. He did not have any ideas as to why my leg was causing problems, so he sent me to physical therapy for 6 weeks. I was directed to increase my physical strength and learn hard line aerobics. My condition got worse to the point that I could hardly walk between treatments. We were “pushing” to get stronger, not working to “maintain” and gently build up what was lost many years ago.

With the help of my “surfing skills” on the internet, the Pennsylvania Polio Network popped up, and wow, I heard of this thing called “Post-polio syndrome.” My internist knew nothing, the neurologists around Santa Barbara County knew nothing; no one seemed to know or care. I read dozens of papers from The Network and I was both impressed and shocked at the same time. Unable to find anyone in our area, I called a physical therapist acquaintance from Rotary Club. He not only knew of the syndrome, he had treated numerous people, mostly seniors.

Michael did a three hour assessment, measuring everything that could be measured. From that assessment and subsequent treatment, I have not only maintained, but I have gotten back some lost strength. One article I read spoke of brain damage to the hypothalamus that occurs in virtually all polio patients. There is a direct effect on one’s ability to stay awake in the day, and that sleep apnea is a real possibility. I participated in an overnight sleep study, and sure enough, I have some “really weird” sleep patterns. With the help of a specialty dentist, I now wear a sleep appliance insert at night, and my snoring is gone. Happy wife, happy life! My daytime sleep issues cost me my part-time retirement job. Even with letters from my physician, the dentist and the therapist, my employer refuses to reconsider rehiring me. Each of us may have and could experience discrimination in one or more ways.



All of this has caused me to further consider how “fearfully and

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wonderfully” we are made and how much a disease or condition can change things in a hurry. I have learned not to worry, but just listen to God, to others, to myself, and to my body. I have made some new friendships, some of these are professional and some social. I have been able to share post-polio articles with caregivers. It has become an exciting “ride” and I look forward to seeing and experiencing the future.

NOTE: This is another in our series of first person stories on the polio experience. In a future newsletter we will include a narrative by Sandy Tackett. If you have a story to tell (actually, we all have a story) please consider sharing it with us.



We Have a New Meeting Location

Yes. We are still meeting at Rancho Los Amigos National Rehabilitation Center, but we have been given the opportunity to meet in Rancho’s newest building. This complex includes the out-patient clinics, a new wellness center, and some of the administration offices.

Because many of those who attend our meetings have ambulatory issues, we have been given permission to park directly in front of the main entrance. This entrance is located next to the tall spire in the photograph above. We have included a map with directions on page 5.

If you live in driving distance of Downey, California, we encourage you to attend our monthly meetings. We share our stories and concerns in a friendly and supportive atmosphere. We also try to include some fun. Please join us.

Are you up-to-date on your vaccinations? These are the CDC recommendations for everyone over fifty. Vaccines for influenza, pneumonia, and shingles are very important!

Vaccine	Who and how often
Influenza (flu)	Everyone ages 6 months and older; once a year at the start of the flu season (early fall, winter).
Pneumonia (pneumococcal polysaccharide)	Two types of pneumococcal vaccine are available. Everyone ages 65 and older should get both one dose of PCV13 and at least one dose of PCV23. Adults 19–64 should receive the vaccine depending on their health.
Tetanus, diphtheria, pertussis (Td/Tdap)	If you were never vaccinated against these diseases, get one dose of Tdap. All adults ages 19 and older should receive a Td booster every 10 years. Women should get one dose during every pregnancy.
Herpes zoster (shingles)	Two types of zoster vaccine are available. You should get two doses of recombinant zoster vaccine (RZV) at age 50 or older (preferred) or one dose of zoster vaccine live (ZVL) at age 60 or older, even if you had shingles before. People with a weakened immune system should not get ZVL.
Varicella (chickenpox)	Anyone who has never had chickenpox; two doses during your lifetime.
Measles, mumps, rubella (MMR)	For adults born in 1957 or later who have not had these childhood diseases; one to two doses per lifetime. People born before 1957 are likely to have immunity from the measles.
Hepatitis A	Anyone at risk if they've never been vaccinated, such as travelers to regions where hepatitis A is common; two doses per lifetime.
Hepatitis B	Anyone at risk if they've never been vaccinated, such as travelers to high-risk areas, adults with multiple sex partners, partners of infected people; healthcare workers; three doses per lifetime. A combination hep A and B vaccine is available.
Meningococcal	For some overseas travelers and certain other at-risk groups. Two types of meningococcal vaccine are available; you may need one or both depending on your health; one or more doses per lifetime.
Haemophilus influenzae type B (Hib)	Anyone with certain medical conditions, including persons who don't have a spleen, have sickle cell disease or HIV, or have had a bone marrow transplant.

Meeting Notice

Rancho Los Amigos Post-Polio Support Group

Saturday, March 23, 2019 - 2:00 p.m. to 4:00 p.m. - “Official” Open House

Saturday, April 27, 2019 - 2:00 p.m. to 4:00 p.m. - **Annual Pot-Luck**. This was moved from our regular February date. Please bring an easy to serve, and easy to clean-up dish you want to share.

May - We will have no meeting at Rancho in May. That month will be a joint meeting with the Post-Polio Support Group of Orange County. Please see announcement on the next page.

Saturday, June 22, 2019 - 2:00 p.m. to 4:00 p.m. - **Annual Picnic**

Saturday, July 27, 2019 - 2:00 p.m. to 4:00 p.m. - **To Be Announced**

Contact us at: RanchoPolioGroup@gmail.com or Diane at: **562-861-8128**



Please save this page. This side has the map to our new meeting location. The other side of this page has a map to the new location for the Orange County Group. Our two groups work together, and share information that can improve the lives of polio survivors.

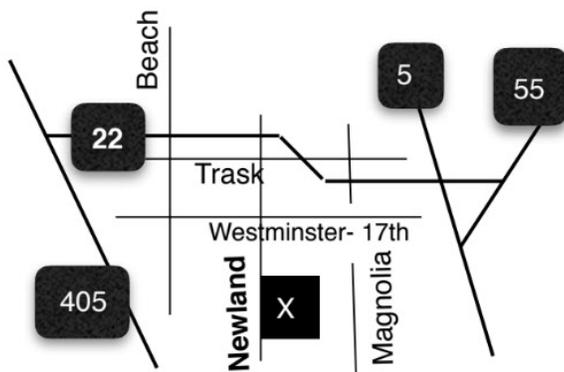
Meeting Notice

Post-Polio Support Group of Orange County

Sharing Ideas to Live Well with PPS

Saturday March 9th, 2019 2 - 4 pm

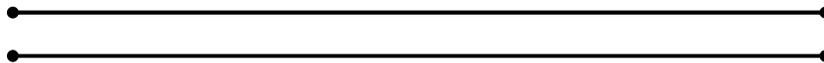
↙
Newland Street Church of Christ
13852 Newland Street Garden Grove CA



For detailed driving directions see your printed or emailed copy of July 2018 newsletter or go to MAPS in MEETINGS link at ppsupportoc.org

Dr. Perlman is scheduled to make her annual presentation on a Sunday (not Mothers Day) in May.

Meetings are every two months. Contacts are Priscilla at: prisofoc@aol.com, Aleta at: 949-559-7102, or Marilyn at.: 714-839-3121



The **Rancho Los Amigos Post-Polio Support Group** and the **Post-Polio Support Group of Orange County** survive on year round donations from our readers. Small donations from all readers will ensure that our newsletters and meetings will continue to provide information on what polio survivors want to know. Please mail your donation to Support Groups' Newsletters at 12720 La Reina Avenue, Downey, CA 90242. Make your check out to PSA—Support Groups, and write newsletters in the memo area of the check. The Rancho Los Amigos group publishes on even numbered months and the Orange County group publishes meeting notices on the odd numbered months. We share the same mailing list, and all donations are shared equally. All donors are acknowledged at the end of the year, but amounts are never listed.