



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - October 2016

EDITORS NOTE: This issue is in memory of Jose Cedeño, a long time member who passed away recently. He was a frequent contributor to our newsletter with his column "It Works", where he shared helpful ideas and gadgets he created to assist polio survivors in day-to-day living. Jose also participated in the yearly Art of Rancho exhibit, where he displayed and sold some of his beautiful paintings. Jose suggested we try to forget about polio and enjoy the rest of our life, so it will be the best of our life. This personal story tells how he did that.

A personal story by Jose Cedeño



Instead of writing my life story, I decided to tell it to my friends at the Rancho Los Amigos Post-Polio Support Group meeting in September 2004.

I was born in Cuba and had acute polio at age two-and-one-half. This left me paralyzed from the waist down, but by age six I was walking and later was able to participate in sports when in high school.

Following graduation I went to Havana, Cuba to study at the School of Architecture and Fine Arts. I worked as an architect in Havana until Fidel Castro came into power. Then I knew that I had to leave Cuba.

In 1960 I fled to Miami first and then, after a few months, on to California. When I became a

(Continued on page 2)

No article in this newsletter may be reprinted without written approval. **No** article may be edited. The full text of an article, including most graphics, can be obtained by request. Please send requests to: RanchoPPSG, 12720 La Reina Avenue, Downey, CA 90242 or **RanchoPPSG@hotmail.com**

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.

(Continued from page 1)

United States citizen, my life changed. I am proud to be an American. I call the rest of my life, the best of my life.

During a visit to the local mountains in 1961 I fell. Unfortunately I broke my femur and required surgery. During convalescence I had to use two canes to ambulate, but this was difficult to do while carrying architectural drawings under my arm. Then I had another fall while working and this time I broke both knees. As you can imagine, I was in terrible shape to be doing construction work, and nobody wanted to hire me. So in 1968 I started my own architectural firm.

In 1985, I heard Dr. Albert Sabin, discoverer of the oral polio vaccine, and Richard Bruno, PhD being interviewed on the radio. I then began to associate everything that was bothering me with polio. But I later learned that the pain in my neck was not due to polio. It was arthritis. To myself, I denied polio and continued working ... all while using crutches and living in a two-story house.

In 1989, Dr. Jacquelin Perry diagnosed me with post-polio syndrome. She recommended that I adjust my work schedule and my lifestyle so that I wouldn't overdo. She advised me not to use crutches because my rotator cuffs could tear. I began attending post-polio support group meetings and learned more about adaptive equipment and saving my muscles. I started using a scooter and then, in 1996, I began to use a motorized wheelchair.

At the end of 2003, I thought I was having a heart attack, but it actually was a panic attack. I had been suffering from depression without realizing it. Fortunately, medication has helped treat this condition. I began reading some of the reports on PPS talks given by Dr. Perry and by sociologist Dr. Margaret Campbell. What they had said finally made sense to me. I realized I had two choices; either change my life for the better or die.

As a child my uncle always told me to get up when I fall, to go forward, and to not look back. Once again in my life, his words echoed in my head. I realized my freedom was in books and in learning, and they have worked for me.

I read many books, but want to recommend these especially: "The Rest of your Life is the Best of your Life", by David Brown; "Aging Well", by James F. Fries; "Instant Meditation for Stress Relief", by John Hudson

Every day, both morning and evening, I thank God for the day. I also thank Dr. Perry for the guidance I have received from her. I recommend that other polio survivors set aside two hours daily just for themselves.

(Continued on page 3)

(Continued from page 2)



The funds from a reverse mortgage on my house have been like winning the lottery. I am now remodeling my house so that it is 100 percent wheelchair accessible, including wall plugs at wheelchair height (24 inches from the floor).

I have a new wheelchair that reclines and enables me to elevate my feet to help reduce leg swelling during the day. I have purchased a new mini-van with a ramp and this is providing me with newly found freedom.

I love all kinds of music. In my home I listen to Mozart most of the day, but in my car I listen to loud heavy metal music. In my car I can scream as loud as I want without disturbing others.

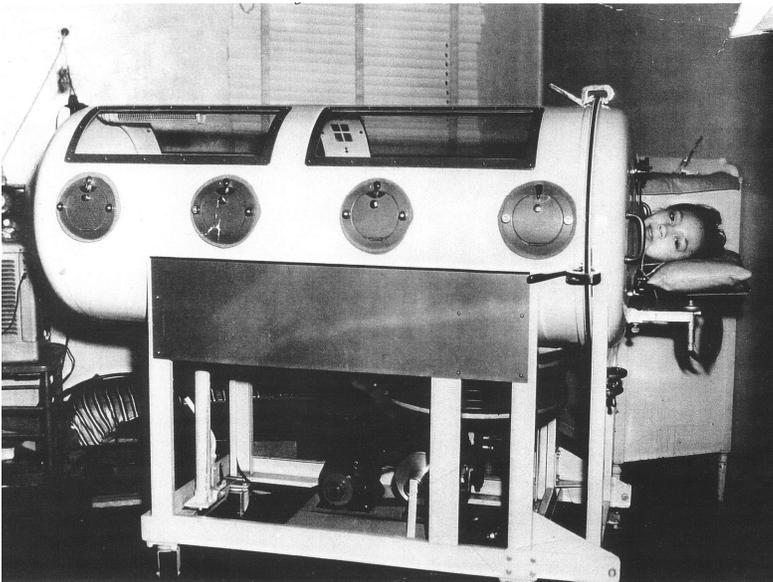
I talk aloud to myself asking how I can make myself better. One thing that I do is go out every day and interact with others, either to the mall or out with friends. I try to dress nicely, smell good, and be friendly.

People in wheelchairs can intimidate others, so I try to treat everyone with kindness. If you are nice to people, you will be remembered kindly. Do the best you can to forget about polio and enjoy the rest of your life, so it will be the best of your life.

~ Jose

August and September Meetings at Rancho

The August and September meetings of the Rancho Los Amigos Post-Polio Support Group were special. In preparation for the August meeting people were asked to bring photographs that illustrate their early polio experiences. Diane was a March of Dimes poster child. She had many photographs relating to this that were protected in an album. This is an excellent idea. Our polio experiences were a unique and important part of 20th century history. We endured, and overcame obstacles that those people born after the polio epidemic years might not be able to fully understand. Photographic evidence of these experiences should be preserved.



Emma Eivers



Richard Daggett and his father

Emma and Richard brought photographs showing them in “iron lungs”. Many others brought photographs and newspaper clippings from their early childhood. We plan to devote an entire newsletter to these photographs.

The September support group meeting took place in Richard Daggett’s backyard. It was a very, very warm afternoon, but Richard’s covered patio and an additional large shade sail provided protection from the direct sun. The group enjoyed conversation, an anatomy word game, and plenty of food.

Post-polio support groups sometimes become overwhelmed by post-polio and related issues. It is helpful sometimes to step out of the support group regimen and gather as good friends.

The Rancho Los Amigos Post-Polio Support Group is an active and friendly gathering of people who share many of the same challenges. We invite the telling of individual stories, and we allow time to discuss problems and solutions. Please join us for our monthly meetings.

Polio Anniversary

The year, 2016, marks the 100th anniversary of the first large polio epidemic in the United States. The northeastern U.S. was hit hardest. The Brooklyn Eagle newspaper for September 19, 1916 carried this article:

REPORT INDICATES PARALYSIS INCREASE

Slight Jump in Figures in Epidemic Announced by Health Board

NINE NEW CASES IN BOROUGH

Brooklyn Also Has Six Deaths in Day

The article continues: The report of the Board of Health on infantile paralysis today showed an increase of 20 new cases over yesterday and an increase of 4 deaths. There were 35 new cases reported today and 10 deaths. The total number of cases is now 8,800, and the total number of deaths is 2,197.

This epidemic “officially” began on Saturday, June 17, 1916, when an announcement of the existence of an epidemic polio infection was made in Brooklyn, New York. That year, there were over 27,000 cases and more than 6,000 deaths due to polio in the United States, with over 2,000 deaths in New York City alone. The death rate was about 25%. The names and addresses of individuals with confirmed polio cases were published daily in the press, their houses were identified with placards, and their families were quarantined. Placards were placed in windows of residences or nailed to the front porch. Violating the quarantine or removing the placard was punishable by a fine of up to \$100, the equivalent to \$2,700 today.

ANTERIOR POLIOMYELITIS!

INFANTILE PARALYSIS

“Act of Assembly approved May 14, 1909, provides that anyone violating the provisions of this Act, upon conviction thereof may be sentenced to pay a fine of not less than \$10.00 or more than \$100.00, to be paid to the use of said county, or to be imprisoned in the county jail for a period of not less than ten days or more than thirty days, or both, at the discretion of the court.”

BY ORDER OF THE BOARD OF HEALTH.

Health Officer.

Address.

Support Group Meetings

Rancho Los Amigos Post-Polio Support Group:

Saturday, October 22, 2016 - 2 p.m. to 4 p.m. - **Gadgets and helpful tips.** This is always a popular meeting topic. Please bring any helpful “gadget”, tool, or idea that makes your life easier.

Rancho has no Meeting in November. We suggest you attend the Orange County meeting listed at the bottom of this page.

Saturday, December 3, 2016 - 2 p.m. to 4 p.m. - **Polio History.** This year is the 100th anniversary of the first large polio epidemic in the U.S. We will have a real iron lung and other historical displays at this meeting. This is a joint meeting at Rancho with the Post-Polio Support Group of Orange County. (please note early December meeting date)

Saturday, January 28, 2017 - 2 p.m. to 4 p.m. - **Disaster preparedness.** Are you ready for “the big one”? This is important for everyone, but there are special considerations if you have a disability.

Saturday, February 25, 2017 - 2 p.m. to 4 p.m. - **Annual Anniversary Potluck.**

For meeting information, please call Diane at (562) 861-8128

For newsletter comments, please send an e-mail to: ranchoppsg@hotmail.com



Post-Polio Support Group of Orange County:

Saturday, November 12, 2016 - 2 p.m. to 4 p.m. - **The 2017 Changes in Medicare and Affordable Care Act by Health Insurance Counseling and Advocacy Program (HICAP)**

For meeting information, please call Aleta at 949-559-7102
or send an e-mail to Priscilla at prisofoc@aol.com