

*Post-Polio Support Group of Orange County*

# Newsletter

18552 Cork Street  
Fountain Valley CA 92708

**JULY 2013**

**Website: [ppsupportoc.org](http://ppsupportoc.org)**

## **MEET OUR MEMBER MARILYN ANDREWS**

If you ever visit Marilyn Andrews, be sure to notice the antique butter churn that is on the top of her hutch. That churn is the very one that Marilyn used to make butter with for her family when she was a young girl. Being the second child in a family of five and the oldest girl, Marilyn used to help her mother with many things including canning. Her family lived in Garden Grove, CA and in addition to growing a large variety of fruits and vegetables, they raised their own beef and chickens.

In 1948, just a few days before her 11<sup>th</sup> birthday, Marilyn contracted polio. A week later, her younger brother also came down with the disease. Both were hospitalized at Orange County General Hospital where they were kept in quarantine. Her younger brother recovered quickly with no residuals affects, but Marilyn was paralyzed from the neck down for four months. After 2 weeks in the hospital. She

came home. The county furnished a steam table for the hot packs that enabled her mother to continue the Sister Kenney treatments at home. For the first year after contracting polio, she and her brother shared a tutor. A physical therapist would also come and teach her mother how to do the exercises that Marilyn needed. Gradually she improved and, although she wore short leg braces on both legs, the following school year, she rode her bike for a mile to get to school. "Times were different then, you weren't bullied or shunned because you were different and people offered assistance."

When she was in high school, Marilyn threw out her braces. In her junior year, her physician made her start wearing a brace again because of a drop foot but eventually, she threw that away too. After high school, Marilyn went to work for the Santa Ana Register in the Circulation Department. She left that position after a year to get married and start a family. She raised 4 children, 3 sons and a daughter. Some of her fond memories include the family trout fishing in the Eastern Sierras and one of those trips even included rain and snow in August.

In 1972, Marilyn went to work for the Pacific Life Company. She worked there as an account clerk. The braces that she discarded when she was a teenager, made a reappearance in her life in 1992. "I started falling at work and scaring my coworkers, so I knew I had to do something." In May of 1999, she retired on disability.

Today, short leg braces and a forearm crutch help Marilyn ambulate. When going out, she also uses a scooter for trips to the mall or places that require walking a long distance. She feels that often people are "in denial about using aids because they fear

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that having to occasionally use them will make them permanently dependent upon them and they will lose their ability to walk. But that doesn't have to be."

In addition to being a grandmother of 4, a great grandmother of 7 (with one on the way) and a great-great grandmother of a baby girl born May 31st of this year, Marilyn belongs to the Ladies Bible Study Group and is an avid animal lover. Her current menagerie (both of whom are rescues) includes Tara, her 11 year-old German Shepherd lab mix and Smokey Jo, an 8 year-old cat that she bottle fed as a kitten after it was abandoned, as well as her 8 desert tortoises.

As member of both OCPPSG and the Rancho Group, when asked about living with a disability, Marilyn says, "You adjust when you need to" and she is evidence of that.

To volunteer your story for this column, please contact Debbie Hardy at [ppsstory-editor@gmail.com](mailto:ppsstory-editor@gmail.com) or (562)693-6265.

## **Dr. Susan Perlman Speaks to Support Groups**

Dr. Susan Perlman gave her annual state of Post-Polio Research presentation to Orange County on Sunday, May 19, in Villa Park. A copy of the presentation can be found on the <http://PPsupportoc.org> website for those who wish to review it in greater detail. Because of aggressive vaccination programs throughout the world, we grow ever closer to a time when wild polio is no longer the virulent epidemic it once was. The resistance to aid workers and a fear that the vaccination workers are channels for espionage has made the programs in these three countries very difficult and dangerous. She gave a rundown on the studies which were implemented or findings reported during the past year, some of which

were follow on studies to those discussed in past addresses. The efficacy of IVIG treatments continues to mount and the results show far longer benefits than were shown in prior studies. It appears that multiple infusions of the IVIG over several days can produce results lasting a year or more. This is very encouraging. However, the price for such treatments is still very high. As the evidence mounts as to the benefits, it will be much easier to make a case to insurance companies that the benefits outweigh the costs. It does not require continuous infusions to demonstrate positive results.

Some of the studies identified significant risk factors for individuals who were likely to suffer from the late effects of polio. One study indicated that females are more prone to develop the condition, which other studies dispute. They all seem to agree upon the fact that the level of destruction of nerves in the initial acute stage was a strong factor in the development of PPS. Other factors suggested are age at the onset of the acute phase.

In addition to the research studies implemented or reported over the past year, Dr. Perlman included two case studies that were indicative of new information about the potential late effects of post polio on patients. The second covered concerns of anesthesia on post polio patients and her recommendation that even minor surgeries that include minimal amounts of anesthesia be done in hospital rather than as outpatient procedures as a precaution. There is ample evidence available that such procedures can result in prolonged unconsciousness and she will no longer agree to such procedures for her patients unless they are admitted at least overnight for observation and monitoring.

The first case study involved bladder muscle failure of autonomically enervated muscles, which in the past have not generally been associated with post polio syndrome. However, after a review of the literature over several decades, there is evidence,

Perlman (continued)

albeit rare, of such muscular failure which affects the bladder or its support system causing the condition described.

These case studies generated considerable discussion. Much of it focused on individual experiences, mainly negative, with anesthesia for even simple dental procedures, as well as, other usually benign routine periodic health checks such as colonoscopies. It is advised that should your physician recommend such a procedure, he and his anesthesiologist be given a copy of Dr. Calmes article on the deleterious effects of anesthesia. The discussion also included experiences with physicians who have limited knowledge of post polio or insensitivities to the special requirements that might be necessary to treat us. There are occasions when it might be imperative to seek out someone who has greater knowledge of the condition, which is always preferable. However, should you feel it is incumbent to continue with a physician who has limited experience or knowledge of post polio, there is enough material online that can provide a minimal knowledge base for any doctor. In CA, we are especially fortunate in that there is a recommendation by the state medical board for basic information requirements for treating such patients. That requirement to be minimally informed on the condition can translate into increased liability for adverse effects during treatment of post polio patients. Not all states have the same requirements that California does. One final caveat expressed by Dr. Perlman is that however many specialists you are seeing, it is imperative that you have one person that is your "gatekeeper" coordinating your care with all health providers so that there are no conflicting treatments or medications and that everyone knows and understands the desired outcomes and protocols being implemented. It can be your general practitioner or one of your Specialists but it should be someone with whom you are comfortable. You should feel you can be very candid and open with this person and confident that they are the leader of your "team".###

**DON'T MISS OUR JULY INDOOR PICNIC. Join us on Sat, July 13 , 2-4 PM. Villa Park City Hall . Bring a finger food to share.**

**Dear JR**

JR, I have always been too embarrassed to ask as this is a an embarrassing subject, but I often have severe constipation. Is this common to people with post polio? Concerned

Dear Concerned, I don't believe that this is a PPS problem per se. There could be a number of reasons that this is a problem for you. I have read that liquid intake can effect this problem and activity as well. Since many PP folks have limited activities, it could exacerbate the condition. If you are diligent about your liquid intake of 6-8 glasses of water a day and this is still a problem for you, embarrassed or not, you need to discuss this with your physician. There could well be an obstruction in the bowel or other physical condition creating or affecting your ability to evacuate easily. Ask your doctor. He or she is your greatest defense against unwanted problems which could decrease your enjoyment of life.

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## San Francisco Challenges Kaiser Healthcare Hike

While workers have been willing to accept pay cuts, furlough days and increasing percentages of their retirement costs, it appears one city has had it with the year after year rise in healthcare premiums. In what one can only hope is the beginning of a trend in California and elsewhere, the City of San Francisco and its unions have banded together to tell their health insurance carrier, Kaiser Permanente, no to their latest rate hike for 2014. They are calling for an alternative proposal that caps profits, links rates to the use of services and provides far greater transparency. That means, to wit, explaining whether rising costs are a result of potentially avoidable complications such as hospital infections, and the breaking down to specifics just what the city is paying for in a ballooning category known as "other medical services/integrated care management."

The showdown introduces local political muscle into the national push, under the Affordable Care Act, to make the healthcare industry more responsive to consumers. Sally Covington, a spokeswoman for the Oakland-based Community Campaigns for Quality Care, a nonprofit that has guided unions nationwide to press health plans for accountability, is working with the San Francisco labor unions. She sees this coalition as a huge opportunity. "What we are seeing unfold here is very unusual. We do not know of any other instance where these kinds of forces have been aligned in this manner."

Final contracts must be approved by the San Francisco Board of Supervisors which is watching the negotiations closely. So is Ed Lee, the Mayor, whose spokesperson indicated he was "confident that the parties would work toward a proposal that will serve our employees and protects the fiscal health of the city."

In a statement, a Kaiser Permanente spokesperson said the 2014 proposal was "fair and competitive", adding that the organization would continue to meet with city representatives "to explain our renewal pricing and cost structure."

For years, city administrators and labor union leaders have bristled at the rate hikes. Now they have Ed Lee's support. "If you are going to get people healthier, it has to translate into a reduction in cost for employers, employees and taxpayers," said Rebecca Rhine, executive director of the Municipal Executives Association and a part of a coalition of labor groups pushing for change. "We began talking about how they all fit together."

When health service system Deputy Director Lisa Ghotbi analyzed the data, she found that overall, Kaiser's San Francisco members have been using fewer services because of the enrollment of families with young children, who tend to have fewer health problems. Yet, while their use of hospital, doctor and prescription services has trended down by as much as 16% since 2011, plan costs had risen by 11%.

(Kaiser proposed a 5.5% rate hike for next year).

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## San Francisco vs. Kaiser (cont'd)

Wendy Sack, vice president of underwriting for Kaiser, responded that its pricing structure was "put together to compete in the marketplace" and was not directly tied to utilization of services. Hospital patients are sicker overall, she said, and more surgeries are performed on an outpatient basis. Commissioners called her answers "confusing" and directed Kaiser officials to return for further discussion at a board meeting later that week. "You have to come forward with much better explanations for those fees", health Commissioner Jean Fraser told Sack. "You're losing a PR battle."

In response to an inquiry from The Times, a Kaiser spokeswoman later said that the organization stands apart from competitors because it is fully integrated ---with its own hospitals, medical groups and so on. That means "other medical services" and "integrated care management" --- which account for 29% of the company's proposed 2014 premium proposal --- include services that other healthcare plans either don't provide or bill for separately. Examples include injections given during medical visits, secure email communication with doctors, health education classes and disease management.

"It is absolutely untrue to suggest that these categories are used for any purpose other than to classify and account for tangible services delivered to members," Gerri Ginsberg, director of communications said in a statement. Ginsberg also noted that as a not-for-profit, Kaiser's margin" is needed for "investments in new hospitals, medical offices, equipment and technology."

Brent Fulton, a healthcare market expert at UC Berkeley, said the public pressure on Kaiser was an interesting development, but that the company --- which long has underpriced competitors --- probably had the negotiating advantage. "It's like going to Walmart and saying, "You're making too much profit" he said. "Wal Mart will say, Okay, go shop someplace else."

Still, as a "large employer with so many customers", San Francisco is well positioned to press for change, said Mark Farrell, who is also a health system commissioner. "You're starting to see it at the federal level, you're starting to see it at the state level and I am certainly going to push for it at the Board of Supervisors here at the city," he said.

###

## **Three Companies Sit Out 2014 Health Exchange**

While many of our members receive health benefits through Medicare or an employer, there are still many of our number who do not. So having choices within the Affordable Care Act is of premium importance. Three of the major companies to offer plans in California in the past are electing to sit out year one (at the very least) of the implementation of the new healthcare law beginning January 1, 2014. This does not mean that they necessarily will offer no plans to Californians, it does mean that they can continue to ignore some of the requirements that the California Health Exchange, called "Covered California", in whatever plans they do offer. There will be mandates invoked by the Affordable Care Act by which they must abide, but there will be some offerings they will not have to include if they do offer plans. So, for those of you currently enrolled in plans with United Health, Aetna or Cigna, beware. Also, if you are in need of federal subsidies to help you pay premiums, you will need to find a plan that is being offered in the state Health Exchange. This might well mean a far more limited group of offerings. We in California are a key testing ground nationally for a massive coverage expansion under the federal healthcare law regardless of the number of plans being offered.

## Insurers (continued)

The biggest insurers in the state, Kaiser Permanente, Anthem Blue Cross and Blue Shield, are all expected to participate in the state-run market for individual health coverage. The winning bidders and proposed rates were announced last month by Covered California and approximately five million residents are expected to shop for coverage starting next year.

The state has picked a group of health plans for each of the 19 regions across California. The insurers will be selling policies with uniform benefits packages in four broad categories of coverage. For the first time in the individual market, consumers will be able to make easier price comparisons among companies. However, there is major concern about the potential for much higher premiums in next year's revamped market. Policy makers cannot risk the alienation of too many middle-income, healthier customers who will be needed to offset the increased costs of covering sicker, poorer people who have essentially been shut out of the healthcare system for years.

United Healthcare, Aetna and Cigna are small players in the individual healthcare market in California. Most of their business has focused on large employers where the majority of Californians currently get their health coverage. They are taking a wait and see approach on the new government run marketplaces. I believe they may be waiting to see if, and how many, companies who now offer coverage to their employees will elect to get out of the business of offering coverage to their employees at all, a trend that has been growing in the past decade. Together, these three companies have only covered about 7% of California's individual health insurance market. The other 87% has been the province of Kaiser, Blue Shield and Anthem Blue Cross, a unit of WellPoint, Inc. and the nation's second-largest health insurer. Peter Lee, executive director of Covered California, has rejected any criticism that diminished competition could or would lead to higher premiums and limited choices. "There will be plenty of price competition for California consumers. They will be benefiting from robust competition."

According to a spokesman for Minnesota-based UnitedHealth said, "We are simply taking the time to carefully evaluate and better understand how the exchanges will work to ensure we are best prepared to participate meaningfully in their development." Joseph Mondy, a spokesman for Connecticut-based Cigna indicated that the company chose to participate in exchanges in only half of the states where it currently sells individual policies. Those states include Arizona, Colorado and Florida. "We will continue to offer individual plans going forward, but we've decided not to participate in Covered California in 2014," Mondy stated. Aetna, the nation's third-largest health insurer, also based in Connecticut, has elected to suspend offering individual policies in California permanently.

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Rancho Los Amigos Mitg.

**Saturday, July 27 2-4 PM**

**Open/ Sharing  
Discussion**

**Future Rancho SG Meetings**

Saturday, July 27 2-4 PM

Open/Sharing

Saturday, August 24 2-4 PM

“Gadgets & Tips”

Saturday, Sept. 28 2-4PM

“Academy Med. Equipment”

**Orange County Meeting**

**Saturday, July 13 2-4 PM**

**INDOOR PICNIC**

**Future PPSG of OC Meetings**

Saturday, July 13, 2013 2-4 PM

Indoor Picnic

Saturday, Sept. 14, 2013 2-4 PM

HICAP

Saturday, Nov. 9, 2-4 PM

Dr. Barnes, Rancho Los Amigos

**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. Thanks this month go to Didi Dodson, Lilli Jones, Fred & Rose Mary Yarak, Cecelia May and John Tully. Thank you all for your generosity.

*How to contact Rancho Support Group*

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

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**Agenda ideas for PPSG of OC ????**

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email Priscilla: [prisofoc@aol.com](mailto:prisofoc@aol.com)

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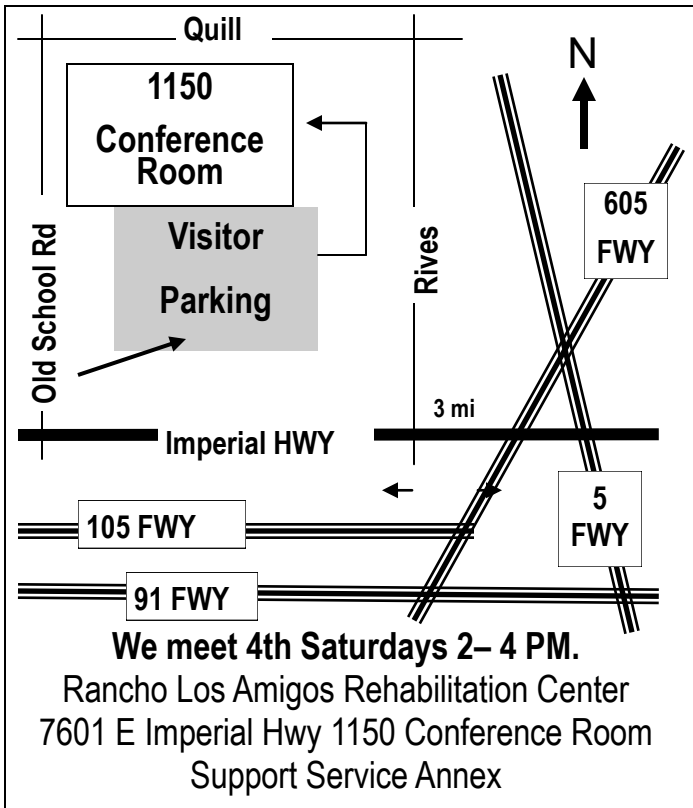
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