

*Post-Polio Support Group of Orange County*

# Newsletter

18552 Cork Street  
Fountain Valley CA 92708

**NOVEMBER , 2013**

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

## **“Show & Tell” by Aleta Connolly**

We had the great privilege to have Dr. Donna Barris present at the September Post Polio meeting in Villa Park. Post polio survivors, family and friends who were able to attend this meeting at Villa Park City Hall experienced a special sharing with Dr. Barris who is herself a polio survivor who wears bracing and uses a unique power wheelchair.

Dr. Barris was very open and friendly. She started her presentation by talking about her early "formative" years recovering from polio. She addressed physical therapy and adjusting to daily living challenges.

Doctor Barris found that she had very good grades in school and decided to go to medical school but this proved to be difficult both because of post polio residuals and that she was a woman.. "In those days men were far more likely to become doctors than women were."

She completed her residency and the fact that she was a woman didn't stop her dream. In the early years, she started to work at Rancho Los Amigos with Dr. Jacqueline Perry or as she

called her "Jackie". She found her to be very knowledgeable and great to work with.

Doctor Barris told us about being a working doctor with Post Polio paralysis and learning to overcome many challenging barriers much as we all have experienced. The interesting and warm part of the Dr. Barris meeting was when she raised her pant leg to show us her brace and explained the special adaptations made for her. Soon other audience members joined in raising their brace coverings and sharing with each other their own bracing, support hose, crutches, caned, shoes and all the "latest and greatest" that enable us to be more mobile. The feeling in the room was helpful, productive and, believe it or not, fun.

After the meeting, Dr. Barris joined several of us for an early dinner at Rockwell's restaurant which is just opposite the meeting site.

Thank you, Dr. Barris for sharing and leading the "Show and Tell" experience. We hope to see you back again next year for another similar and fun event. I would also like to extend a special "Thank You" to Priscilla and Chuck Hiers for suggesting, inviting and providing transportation for her to bring us a very warm, friendly and interactive meeting.

I also hope to see you all in November for the HICAP annual and informative meeting which will explain all the changes in plans effective January, 2014. Please make the effort, if possible, to join us.

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**JOIN US IN NOVEMBER**

## **Meet Our Members**

### **Baldwin Keenan**

By Debbie Hardy

Baldwin Keenan will tell you that “living with polio shaped my world vision” - giving him a first hand understanding about what it feels like to be discriminated against and the abuse that people who are different are given.

Baldwin had polio in 1950, at two years of age. His mother told him that he couldn't get up from where he was sitting on the floor and she knew that there was something seriously wrong. Doctors in New Orleans, where his family was living, didn't know it was polio as they had not seen many cases of it in their area. Consequently, the diagnosis wasn't made until 5 months later. When he was 8, 9 and 11, he had a series of triple arthrodesis surgeries on his damaged leg to straighten tendons in the leg and weld bones to prevent ankle rotation and drop foot. Recovery was long and because of his orthopedic shoes, his grade school classmates teased him. In addition, he had to suffer the ignorance of a little league coach who berated him for being a pretty good hitter but not being able to run the bases.

His teen years were pretty much like that of any normal teenager. He studied, dated, hung out with his friends and swam and sailed competitively. When sailing, he would have to wear 35lb of wet sweatshirts on his body to attain the proper weight needed to race a physically demanding and challenging Olympic one-person class hull. Baldwin graduated from UC Irvine with a degree in Comparative Literature. Brown University offered him a spot in their graduate program but Baldwin declined. Having always had a great interest in the racial equality movement from listening to Dr. Martin Luther King, he accepted a position as volunteer labor organizer for the United Farm Workers that paid \$5 a week and all the food he could scrounge from community supporters.

While at UCI, he was taking a writing class from E.L. Doctorow, and a friend from class introduced him to Roni Whelan. Love blossomed and after their engagement and marriage, they took a year off and traveled to Europe, South America and parts of North Africa on \$5 a day. To save the money to pay for their year abroad, Baldwin worked as an apprentice carpenter. After returning home he completed his apprenticeship in the Carpenters Union. Carpentry is a very physical job and during his career, he would often carry 10 ft. metal I-beams on his shoulder. On weekends, he frequently did work on homeless shelters and other related projects. In 1982, he was elected to the position of Union Representative and Organizer, a position he held for the next 20 years. In consideration of being diagnosed with PPS in June 2000, he was assigned to office work for his final 18 month working for the Carpenters Union. He retired in 2002 but continued to supervise and help on projects for the disabled.

In 1999, referee-ing a soccer game, Baldwin turned and snapped his knee, tearing the meniscus and subsequently went into rapid physical decline. Doctors could not figure out why he couldn't recover from the injury. In 2000, he read an article written by Dr.

Perlman about PPS. Baldwin recognized the symptoms as the same he was experiencing and made an appointment to see Dr. Perlman who diagnosed him with PPS. He didn't take the diagnosis laying down and started collecting info on PPS – some of which he found conflicting. Before retirement he had joined PPSGOC and started helping out where he was needed. In 2003 diagnosed with periodic limb movement and found when his sleep improved immensely so did his pain and his health. In 2005, he became the editor and remained so until 2013. This task was challenging but rewarding. Baldwin did a superb job leaving enormous shoes to fill. On having PPS, Baldwin states "We have to accept our illness before we can rebound. We need to keep an optimistic view and we shouldn't presume that our limits are lower than they are." Although everyone's abilities are different, Baldwin subscribes to the theories of Dr. William DeMayo and finds that when he pushes himself a little farther than he thinks he can go, he often feels better – both physically and mentally. Usually he finds that he can live better extending further.

When Baldwin's wife, Roni, a Geriatric Physician, retired in November of 2012, they were all set to start off on another great traveling adventure – a 3-year RV trip across the United States but were sidelined by two things. The first was the birth of their first grandchild, Leo, and the second, in May of 2013, was a heart problem experienced by Baldwin. He attributed his problem to not drinking enough water with his medication, but due to a family history of heart problems, his health care provider didn't buy Bald-

win's theory and discovered a blocked artery that needed to be opened by a stent. Since the surgery, Baldwin has lost 25 lbs and is below the recommended BMI for his height. He feels much better and is able to walk easier and farther since the weight loss. When asked how he lost the weight, Baldwin says he used the "ELF" Plan (Eat Less Food) and usually, a glass of wine with dinner.

Baldwin and Roni's adventure commenced on June 13, 2013 and, soon they will park their RV and fly back to California to celebrate the holidays (and Leo's first birthday) with their family. They will resume their 3-year trip in January traveling thru the United States to the East Coast, across Canada, Alaska (maybe) and back down the West Coast. Along they way, they will be visiting with family, pinpointing national parks and enjoying the beauty of nature on a trip of a lifetime. Safe travels Baldwin and Roni! ###

### **Disability Travel Is Hit or Miss**

This article was in the travel section and thought it might be of interest to those of us who still travel on occasion.

Question: I'm a disabled traveler who makes hotel reservations about half a dozen times a year. I always reserve an accessible room, but recently it seems as if front desk staff does seem to know what that is. Two times in recent months, I have been put in rooms that didn't have grab bars. One hotel told me none of the toilets in it's accessible rooms had grab bars. Another clerk sent someone to check the bathroom before we went up and he comeback to say there was a grab bar in the shower but not by the toilet. That grab bar was actually a towel rack. I do not think it is unreasonable to expect that I will be

able to use the toilet in the room. What does the Americans With Disabilities Act mandate? And who trains hotel personnel?

Answer,: If you read the Justice Department's 2010 ADA Standards for Accessible Design, dated Sept. 15 and you are not a detail oriented person, you may be tempted to throw up your hands and screech, "just do the right thing, for heaven's sake". Then you read a letter like the one above and you understand that the mind numbing detail is necessary and very important. For specifics, go to the standards at [www.LAT.ms/lhJkJt](http://www.LAT.ms/lhJkJt) and read section 806 on "transient guest lodgings", with specific references to sections 603-610, including 609 which addresses grab bars in particular.

Critics of the original ADA, signed into law in 1990 by President George H.W. Bush, have said that the legislation was vague and that some issues could be resolved only by litigation. The 2010 ADA Standards provide a level of detail the original law did not and cover some of the issues in making a hotel reservation.

"Until the 2010 standards became effective on March 15 of this year, the responsibility of a hotel to provide and guarantee reservations was somewhat clouded", said Martin Orlick, a partner with Jeffers , Mangel, Butler and Mitchell Global Hospitality Practice and the leader of the ADA compliance and litigation team. "There was no specific requirement that a reservation, once made, guaranteed the room you reserved would be made available. The prior requirement when someone booked a specific room, was that room be "hard blocked" and available.". But how would you know you are getting a room that will actually work for you? The hotel must list it's accessible features, Orlick says. If grab bars are listed as a feature, the room is required to have them. One exception is: condo hotels. That is because the units are individually owned and cannot fall under a hotelier's umbrella. Knowing the difference between a grab bar and a towel bar goes beyond a compliance issue. But lodgings aren't left in the wilderness when trying to comply with the law. The American Hotel & Lodging Assn. "...provides training materials and tools that will help hotels", said Kevin Maher, senior vice president of governmental affairs for the lodging association. Hotel operators also know that making their properties accessible is just good business.

I think probably a successful hotel operator is going to understand this is a growing demographic with the population aging and with advances in medical treatment and mobility," Maher said. "You are ahead of the curve if you have a property that meets these requirements". Because of employee turnover, it behooves a hotel to keep training in the fore. And it behooves the customer to ask and ask and ask again about accessibility features just to be sure. Should it have to be this way? No, of course not. But until the world understands ... and this comes with knowledge and experience ... some of the education process belongs to the customer. The customer must impress upon hoteliers that he or she will give their business only to those places that go to the head of the class.

Travel/latimes.com

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### **Landlords Irked By Rent Watch Article**

In the July 14 column, Rent Watch advised that it would constitute housing discrimination for a property manager to discourage a potential tenant from seeking to rent a second-floor unit. We reached this conclusion even though the applicant had a disability that required her to use a cane to climb the steps to the second floor.

This answer resulted in several strong replies from landlords and owners. Here is a sampling, edited for brevity:

"I think you came down too hard on that landlord who suggested a first floor unit for the woman with a cane ... I was a landlord for many years, and I also use a cane ... I have also fallen down stairs when they were wet with rain."

"I can see it now ... The apartment manager allows the prospective "disabled" tenant to rent the upstairs apartment, then a year or so passes, the tenant requires more help, and requests (demands?) that the owner/manager provide an elevator or some kind of lift so she can continue to live in the upstairs unit. Where will it stop?"

"If the landlord rented an upstairs unit to a tenant who needed a cane to use the stairs, and if that tenant slipped and she fell, could she sue? Could he get her to sign a waiver saying she agreed to accept the liability herself?"

One of the principles at the heart of the fair housing laws is that all people, including those with disabilities, have the right to be free of discrimination in choosing where to live. In the context of this Rent Watch question and response, that right means the landlord is not the appropriate person to decide whether the disabled tenant is capable of navigating the stairs up to the second-floor apartment.

The renter, herself, is the one person in the best position to know what her physical capabilities and limitations are, not the landlord. Any assumptions or stereotypes the landlord may have about the abilities of this disabled tenant are not relevant. Furthermore, treating this tenant fairly will not impose an unreasonable burden on the housing provider, despite the fears voiced by several of the housing providers responding to the article.

If the tenant with the cane did move in and later asked the landlord to install a lift or elevator, that request would most likely be treated as a request for a reasonable modification under the Fair Hous-

ing laws, a reasonable modification is a structural change made to existing premises necessary to afford such person full enjoyment of the premises, such as installing a wheelchair ramp or an elevator. The installation would be at the tenant's expense.

As for concerns over whether the tenant might sue the landlord if she slipped and fell on the stairs, the landlord's best protection is to adequately maintain the stairs. A tenant would have to show that the landlord was negligent in maintaining the stairs before she could successfully sue for injuries she suffered in a fall on the stairs.

In most cases, Civil Code Section 1953 expressly forbids any attempt by a landlord to ask a tenant to waive liability for the landlord's negligence. Adequately maintaining the stairs in a safe condition, however, should protect the landlord from ultimate liability.

The bottom line here is that the law requires that the landlord treat this tenant exactly the same as he or she would treat a tenant without a disability. Making a unilateral determination that the disabled tenant is not capable of successfully living on the second floor is unfair to the disabled tenant. In most cases, Civil Code Section 1953 expressly forbids any attempt by a landlord to ask a tenant to waive liability for the landlord's negligence. Adequately maintaining the stairs in a safe condition, however, should protect the landlord from ultimate liability. ###

### State Takes Lead in Healthcare Law

Sam Thomas of Pasadena, an AARP volunteer, is one of hundreds of people around the state who have been training by community organizations to explain the benefits of the federal Affordable Care Act (ACA) to consumers. "They have just heard the stuff on television ... how terrible it is, how horrible it is, no one really wants it. It really isn't", said Thomas, 72, a retired executive director of the Leukemia & Lymphoma Society of Los Angeles. "I think they feel better after we have talked to them".

notwithstanding, California leads the nation in implementing the ACA: from setting up a new state agency that will help people find and enroll in health insurance plans to expanding Medicaid.

"California is going to be the shining example for other states," said Ron Pollack, executive director of Families USA, a nonpartisan consumer organization for health care.

State officials estimate that 5.3 million California residents who now lack coverage will be eligible to enroll in health insurance plans offered by thirteen companies and nonprofit groups selected by Covered California, the new state agency created to manage the ACA marketplace.

At least 2 plans will be available in every county within the state. Not all plans will be available statewide, but Peter V. Lee, executive director of Covered California, said consumers will have at least two plans to choose from in every county. An insurance marketplace, or exchange, will allow consumers to compare costs and benefits among insurance plans.

The plans cover doctor visits, prescriptions, hospital stays, maternity care, lab services, emergency services and other benefits ... and they place a ceiling of \$6,350 on out-of-pocket expenses.

While that might seem a lot of money, it is small potatoes indeed to people who have been treated and hit with \$10,000 or \$20,000 for an overnight hospital stay for a simple procedure as in the past, the plans come in four levels --- bronze, silver, gold and platinum --- with bronze considered

basic coverage, silver standard, and gold and platinum higher coverage with higher premiums. No one can qualified because of preexisting conditions.

Although coverage doesn't begin until January, Californians can begin enrolling as of October 1 at the agency's website, covered.com, or by calling 887-975-1142 toll-free. The lists of participating doctors has experienced the aforementioned glitches but Mr. Lee has promised it will be fixed shortly. Some insurance companies have a rather cavalier attitude towards notifying network doctors that they are or are not part of a specific network and if you call their offices to determine if they participate in a network, they really cannot tell you with any surety if they do or don't belong and the agency is having to verify the accuracy of the network lists they relied on originally posted on the website. This fix is in the works and promised by the end of October. Hopefully, those people who need this information to be accurate and current will still have adequate time to complete their enrollment during the Open Enrollment period so they are covered on January 1, 2014. The website includes an interactive chart where people can find out what plans are available and how much they cost. Individuals earning up to about \$46,000 and a family of four making up to \$94,000 annually are eligible for subsidies to help with the premium costs.

A wide range of organizations, churches and nonprofit groups have trained volunteers and paid staff ---

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Rancho Los Amigos Meeting

**No November Mtg.**

**Saturday , Nov 23, 2013**

**2 pm — 4 pm**

**Future Rancho SG Meetings**

**JOINT DOWNEY and OC**

**Christmas Party**

**December 7. 2013**

**2:00 PM**

**Orange County Meeting**

**HICAP—Changes in Health Plans for 2013**

**Saturday , November 9, 2013**

**2 pm — 4 pm**

**Future PPSG of OC Meetings**

**JOINT DOWNEY and OC**

**Christmas Party**

**December 7. 2013**

**2:00 PM**

**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: Patricia Hogate, Elizabeth Adams, Alice McCullough, Ralph Haskins, Rowland Rice, Jerry Walcher, and Mary Pat Toups.

*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 ????**

Please call Aleta at **949-559-7102** or email Priscilla: [prisofoc@aol.com](mailto:prisofoc@aol.com)

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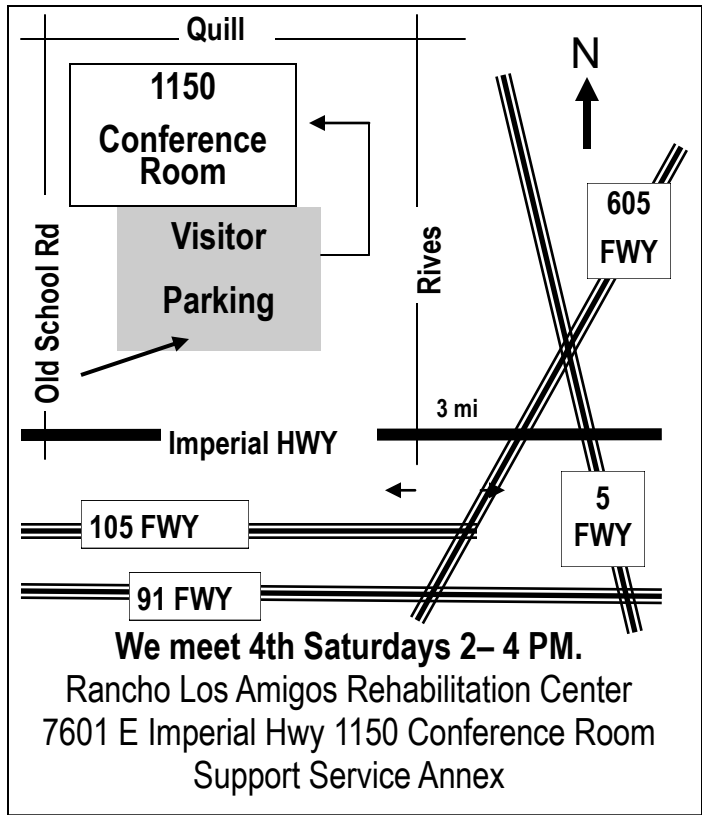
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**Rancho Los Amigos  
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**Orange County  
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