

Founded in 1989

# The Post-Polio Support Group of Orange County Newsletter

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## May 2009

### Polio Survivors Ask...this month's article from PHI.

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, (n.carter@cox.net)

Q: I just remodeled my kitchen and found non-slip tile that is called "ADAtile." The label helped me narrow the possibilities, but I wasn't sure if that was a good use of "ADA." What do you think?

A: That's the point of having the Americans with Disabilities Act (ADA), isn't it? Now there's a standard. We're no longer forced to go whistling in the dark. Want non-slip tile on the floor? Check the ADA criteria: Coefficient of friction of 0.6 or greater on flat surfaces, 0.8 on ramps or inclines. Voila! How easy could it be! And how helpful!

We're smart to question how we use "ADA." We don't want people thinking of these letters as silly government gibberish. The ADA is not simply a meaningless pile of rules and measurements. Those guidelines translate into our freedom.

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In fact, the ADA is the most comprehensive antidiscrimination legislation ever devised for those of us with disabilities. This civil rights law, our shot at equality, is our passport to accessing life in a way never possible before. We count.

For years our participation often came riddled with impossible barriers, physical and otherwise. We, society's outcasts, stood in the shadows, waiting our turn. (Pg 2, C 2)

When President George H. W. Bush signed the ADA into law in 1990, he said "Let the shameful walls of exclusion finally come tumbling down." The ADA lets us IN—figuratively as well as literally over the curb, up the steps, through the door, into the room, down the aisle, whatever. We get our chance. The ADA offers us the fresh breath of spring—it brings precious ACCESS.

So when we say that something is "ADA accessible," (whether that be jobs, public accommodations, commercial facilities, government services) we know that pains have been taken to follow ADA regulations. The question isn't "Can I reach the credit card processing machine on the counter?" The question is "Can everyone reach the credit card processing machine on the counter?" The ADA shows us how to answer that question equitably.

We do not judge accessibility by what we, alone, need. The ADA has taught us to look around us and consider usefulness, workability for the entire disability community be-

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## February and March Speakers Offer Advice and Information on Financial Matters

On February 14, our speaker, attorney-at-law Teresa Gorman, came to present information on the many aspects of estate planning from a legal standpoint. She is a certified Financial Planning Legal expert and, as such, offers services for preparation of Wills, Trusts, Powers of Attorney for Financial Matters or Health Care issues, can oversee or appoint a conservator for elders who no longer can handle their own financial matters and work with families to implement the various provisions of such documents when the time comes that they are needed to distribute estates. She made clear that trusts were not essential in every instance. Sometimes estates are better served by merely having a will if many of the estate assets are such that the law already determines their distribution, etc., or that may be held in vehicles that preclude being placed in a trust. She tried, and I believe was successful, it hitting most of the highlights on this topic. She indicated timeframes, costs and the major differences in each of these legal documents. It was quite informative and I, personally, found a hole in my own estate planning that had not been considered which needed to be addressed so even when you think it is all done and taken care of, you may find that the law has changed and you must update your documents to take that into account or you find, as did I, that there is a small unlikely but possible event that could change things as currently planned that you must give consideration and on which you must take action.

In March, we had Susan Berkman, J.D., Asst. Vice President for University Development at California State University, Long Beach.

(Cont'd)

She focused on the other portion of estate planning: if you want to give some or all of your estate away, what are some options available, what are the tax implications and what types of benefits can you derive, before and after your death so that those gifts are protected or magnified. The benefits of timing annuity purchases so you can continue to draw income or be able to retain use of assets during your lifetime were discussed at some length and, still, she merely touched on all of the possibilities available. We were fortunate to have Susan address our group after the stroke suffered by the speaker originally scheduled. She stepped into the breach and gave us all a wealth of information and food for thought. ###

### PHI Asks -Cont'd from Page 1, C. 2

fore we brand anything as accessible.

For instance, I don't require grab bars in order to transfer from my chair to a toilet seat. However, some folks with disabilities do. Therefore, all it takes is the absence of grab bars to make a public toilet stall inaccessible.

It's not OK to lift wheelchair users up the steps to a business establishment. Hoisting is no more a substitute for ramps than flip-flops are for winter boots. No ramp? The building is inaccessible.

It's not OK to corral wheelchair users in an isolated section of a theater or stadium, away from their companions and other spectators. Seating plan isn't integrated? It's inaccessible, not to mention unacceptable.

Let there be no excuses. Remember: We no longer have to accept the unacceptable.

Yes, yes, I know—numbers of exemptions let these groups or those buildings off the ADA hook. I've read the regs. I hope you have,

## More Discussion on ADA Issues

By Janet Renison

I did receive some feedback on my request for experiences and limitations encountered by our members regarding ADA issues. Unfortunately, it arrived in my e-mail inbox AFTER the last issue of our newsletter went to the printer in February (March 1 issue). I felt, however, that the views and experiences expressed were so germane to our discussion I wanted to share them with you this month. It certainly indicates that we in California are much advanced than some states in making the environment "user-friendly" for the disabled. Since this is not at all the case, even in a university area, we have a great deal of awareness-raising still to do.

Rebecca from Durham/Chapel Hill writes: 'Living in "Dixie" is different from living in California. People are still "hiding in their homes" even this close to our nations capitol because they are made to feel or perceive that it is "not appropriate for them to be seen. ' This is a sad sad commentary on the vaunted southern hospitality of which one frequently hears. She goes on to share some experiences that certainly give one pause for thought.

While standing at a local farmer's market peach stand, the vendors sold to customer after customer while ignoring her. After the final customer was served, the vendor turned away without serving her. Finally, she got rather vocal asking if they did not wish to sell her peaches because she was standing there in braces and on crutches or is there some other reason? The question generated a certain amount of interest in passersby which caused the vendors to explain that they didn't know she wished to buy any because they didn't think she had money for such a purchase. In their minds, apparently, braces

and crutches equaled poverty or destitution.

Another time, needing to purchase a birthday cake for a bone marrow transplant patient. She stopped at the local bakery. After all other customers had been served and left the store, she stepped forward to be served. After an additional fifteen minute wait, she still had not been served. When another customer got in line behind her, she was asked to move out of the way so they could serve the new customer. She was then asked to move to a different counter where "someone" would serve her, where she had already waited for a long period. In a loud voice, she suggested to the manager (who had asked her to move) that her wait in the other line had been fruitless as the store employees failed to serve her, and it seemed to suggest a very bigoted attitude towards disabled customers.

While trying to register her son in a local drigin school whose office was on an inaccessible (except for stairs) second floor, she heard the woman in the registration office. who was dealing with her son who had stated that his mom was at the bottom of the stairs, berating him because of his request that she go down the stairs where his mother was, stating that "just because your mother is too fat to make it up the stairs doesn't mean that she was going to take the forms down to her". Rebecca's response to that outrageous statement was to yell up at her with a threat to take her complaint two doors down to the mayor's office and returning with her attorney. The woman began cursing as she stomped towards the stairs where, upon seeing Rebecca's disability, her attitude underwent a remarkable transformation and she apologized.

At a local theater production, seating was on a floor reached by stairs. When the tickets

were being purchased, it was made clear to the theater folks that one of the purchasers was disabled and they needed to accommodate that need. The building did have an elevator. Upon arrival at the theater on the evening of the performance and when asked for use of this elevator, it was denied by ushers who stated it was not for general use. After assuring the usher (while standing there on crutches) that it was for just such people as Rebecca that the elevator had been installed. Rebecca was then told that she had only two options. One would be to sit alone on a bottom floor seat or to climb the stairs. Rebecca informed the usher that, should she fall in making that climb, the usher would be personally named in any subsequent lawsuit. Strangely enough, it was found that the VIP elevator could be used for such people as Rebecca after all.

A personal friend, a magna cum laude graduate of UNC Chapel Hill, was hired by the nearby Duke University campus as a computer manager. The interviews had been held in various locations around the university campus which is not very accessible. He found, upon reporting for work the first day, that he had been assigned an office and the entire computer system were both on the third floor and the building had no elevator to ANY of the universities administrative offices.

One final experience of note happened at the US Post Office in Chapel Hill. One would think the US government, who authored the ADA legislation, could get its act together but, apparently not. Since she had a number of packages to mail, she assumed that she would have extra forms to complete, which was the case. After balancing packages, crutches, purse, etc. on the counter, she was asked to please hurry as there were customers in line. Having given the clerk the

international package first, I received back a customs form which she began to complete as the clerk started the actions for the remaining packages. Having nearly completed the form, the transactions on the remaining packages were complete and the clerk asked her to move away so that she could serve others. Rebecca responded that she could not do that as her purse was there and her crutches, etc, leaned against the counter. The clerk was quite indignant and told her she MUST do as she was told. The man who was immediately behind her told the clerk he would be happy to wait. She was told to move. At that point, Rebecca tried to explain it is not just that easy to go to another counter in the midst of these multiple transactions and that was why she was using the window designated for the disabled. The clerk continued to repeat that she did not care, that Rebecca must do as she had been told and the clerk stated she would not mail that package. After requesting to speak with the clerk's supervisor and another five minutes of wait time, Rebecca explained the situation, what the process of occurrences had been and was told that, since the clerk was from Korea, she did not know any better and that Rebecca should not have been rude to her, which was not the case. Luckily for Rebecca, the man in line behind her was an attorney who took note of the whole incident and supported Rebecca's explanation, and volunteered to carry the information on the situation up the chain of command, there and then, which he did.

University Mall in Chapel Hill has stickers on their entries (you know, the blue wheelchair accessibility insignia) showing they are accessible by chair. This is great if you have someone with you to open doors. Otherwise, you had best be prepared to wait until the

next person comes along to open the doors for you. After sixteen years living in the area and repeatedly bringing the issue to the attention of the city “fathers”, it still is the same. Even places like the State Fairgrounds are a menace to the disabled. Just make sure you NEVER have to use one of it’s restrooms.

The continuous exposure to these experiences can be exhausting. We deal with the normal post polio fatigue anyway and these instances can become the proverbial straw to a camel’s back. We need to remember that it is incumbent upon ALL of us to get out the message, to be active and proactive in making our needs known and we must, further, share these experiences with ALL of our friends, family and colleagues, because, only with raised awareness (and some possible legal interventions) will any of this change. And like Rebecca, who tends to offer assistance to other disabled people when the opportunity arises, we all need to look around us to see if there is something we can do to help others whose needs are greater than our own or whose limitations make things even more difficult and them more “invisible”. Do not be afraid to speak up and speak out. You CAN make a difference even in places like “Dixie”. ###

## **There is a Whole World Out There – Even for Us.**

Quite often as we age with our various levels of disability, we shrink our own area of exploration – usually because it is easier -- but sometimes because we are a bit apprehensive of the problems encountered when we DO exceed our usual environs. There are, however, people who look at their limitations as a challenge rather than a hindrance. One such individual is Scott Rains. Many years ago, just after qualifying as a certified ski instructor, Scott was paralyzed and has been confined to a wheelchair from that time. This did not quench his desire to expand his world and even to see the larger one. However, he recognized that there were some serious difficulties for those of us who share his limitations. Scott’s response was to develop a website and a business that is “in the business” of alerting others as to the user friendliness and accessibility of various places and companies throughout the world with an eye to enhancing the ability and quality of travel for all of us. It has been in existence for over a year now.

His site – Tour Watch – originally focused on providing a digital forum on Inclusive Tourism aimed at travel agents and he provided them with a venue for information for their clients. It serves those who offer a specialized travel related business or are trying to start one. Now, however, Scott has broadened that site to include others who need to know where facilities can be found and services rendered that make travel for all of us possible. Tour Watch is the public face of his on-going work, the Rolling Rains Report ([www.RollingRains.com](http://www.RollingRains.com)). It is available by subscription, and he offers consultation, research services and training to individuals, businesses, govern-

Welcome to New members:

Linda Klinkert, Diane Lopez, Laura Dickson, and Mimi Vu

ment and other not for profit entities. They can and do help clients develop tours or manage a destination experience. Some considerations are: How desirable is the destination already to the non-disabled traveler? What are the characteristics and limitations of transportation systems to and from and operating around the destination? What are the relevant national and local standards for building accessibility? What are the numbers and distribution of FULLY ACCESSIBLE rooms for rent or lease? Or, partially accessible rooms? What are current trends or pending legislation which will affect Inclusive Tourism in a particular country? How is UNCRD being implemented in a country? What would make a specific location a “destination-of-choice” for people with disabilities? Who, if anyone, in a specific geographical area is already taken a leadership role in serving people with disabilities? What might be a reasonable market share of traffic for people with disabilities in that geographical area?

Sites like Scotts have also sprouted some specific businesses that can be found on his website. If you are considering travel, regardless of where, there are resources that can be found to help you plan your trip and KNOW, not just guess, what you will find. One such site is that founded by Lindsey Young, Accessible Travel Adventures Inc. She is particularly concerned about the many disabled people who miss out on extraordinary and exhilarating experiences because of their disabilities. Their business mission statement is “to create accessibility reference guides written by disabled people FOR people with disabilities.” She is especially pleased with the standards of accessibility for the new cruise ships who have much better accessibility than the Caribbean resorts for instance. She particularly laments the

fact that there are no universal or international standards for accessibility. Each guide will require individual ON-SITE inspections. When you travel, even though you may have requested an accessible room, many hotels will not guarantee that it is available when needed.

While Lindsey focuses mainly on the Western Hemisphere, in Europe there are others who provide similar services, depending on the specific limitation. There is a European Organization based in Athens, Greece, with many members throughout Europe. They have a website as well: ENAT@accessible-tourism.org. Or, one may contact specific providers such as www.EurpoeforAll.com to gather information and make plans.

One does not need to suffer apprehension or limit your environment simply because of your disability. There is a big world out there for you to see and enjoy. SO GO FOR IT, FOLKS!!!! ###

### **PHI Asks** (cont'd -from Page 2, Col 2)

too.

We must continue to focus on compliance. I'd thank that establishment for carrying “ADA tile.” I'd tell others about it and encourage their doing business with that company. For those who still refuse to comply with the ADA, I'd start with a gentle reminder.

People fought a tough battle for US to be the ones to define accessibility. We do that through the ADA. I want to keep things that way; I'm going to insist on it.

How about you?

Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

## In memorium - Lee Holloway

A very dear member of our group passed away in March. Lee was stricken with polio which left her with weakness in both her upper and lower body. In recent years she had respiratory difficulties. She and her husband Dan did much to build our group. Lee took on the responsibility for getting notices of our meetings in the newspaper, which was the only way some polio survivors found out about us. Until very recently, Lee made a point of talking with every new person who came through the door to make him or her feel welcome and to make sure that his or her concerns were met. Lee's passing is a profound loss and all of us extend to Dan our caring and support.

## Dr. Perlman to speak at May 17 Meeting

Please mark your calendars and arrive early to guarantee yourself a chair when Dr. Susan Perlman makes her repeat visit to give us an update on the latest research in Post Polio. She and her colleagues are always in the forefront of that field and she makes time in her impacted schedule to come share that information with our membership. The Board would appreciate a significant show of members to welcome Dr. Perlman. **SUNDAY, May 17, 2:00pm** at the Villa Park City Council Chambers.

## 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 additional information please call Diane @ (562) 861-8128 or Richard at **562-862-4508**

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Special thanks to the following

donors: Conrad Villanueva, M/M Jmes Hall, (Lee Holloway's brother) and Barbara Smith.

We mention donations but not the amount, as all donations make our support group possible. Please write checks to **Polio Survivors Association** and write "Orange County" in the memo section. Please **mail checks to** Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708.

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## Rancho Los Amigos Meeting

**Saturday, May 23**  
**Sharing & Open Discussion**  
**2pm - 4 pm**

**Future Rancho SG Meetings**

**Saturday June 27**  
**Annual Picnic**

**Saturday July 25**  
**Rancho's Model Home Tour**  
**and Center for Rehab Tech.**

## Orange County Meeting

**Sunday May 17**  
**Dr. Susan Perlman**  
**Update on PPS**  
**2 pm -- 4pm**

**Future PPSG of OC Meetings**

**Saturday June 13**  
**Open Sharing**

**Saturday July 11**  
**“Laughter Yoga”**

