

**We're Still Here ...  
But Too Many Others Still Don't See Us**

By Janet Renison

Interestingly enough, at just the time I received an announcement from Post Polio Health touting the week of October 9-15 as a focus on generating awareness that "We're Still Here", I had an experience which brought home rather sharply that, although we still struggle to make our lives all they can be, the world is still peopled by the unconscious. They not only do not see us, do not hear us, but apparently consider us irrelevant in running their businesses. It has been many years since the ADA was enacted and most businesses GET IT!!! But others, either because they came through that time frame under the radar or they argued they could not afford major repairs to their facilities. Consequently, they have never given our space needs or their facility configuration a whole lot of comprehensive thought. *To wit:* After eating a fine meal with a large group in an area which was accessible, though without a lot of extra width for my power chair, I

decided I needed to hit the ladies room prior to the hour-long return car ride. My ex-husband with whom I am very friendly, and who had similar thoughts followed me to the designated area. However, when we reached the thin route between tables which was the only approach to those facilities, it was blocked by a young man in a manual wheel chair who had been seated with his family in a booth that required him to sit at the table end IN THE AISLE fully blocking entry or egress to the needed rest rooms. This was a very large restaurant which has numerous seating areas, including the lovely patio which accommodated my group. But, of course, it only made good business sense to someone (my assumption was that this individual decision-maker is brain dead) to place the man and his family in the ONLY aisle to the rest rooms (for those who do not know me well – that was "gallows humor"). Making it worse, the rest room designated for ladies was so small that it did not accommodate my chair, nor allowed turning to go out forward. Furthermore, the way one had to open the door to exit was a challenge. I could never had managed at all but for the good graces of my ex-husband. God forbid that someone try it solo. The young disabled man, whose chair was in the aisle, had no other option but to maneuver his chair all the way out of the dining area into the restaurant foyer, not once, but twice to allow me to get to and from. This is a well-

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populated, pricey restaurant, doing a considerable business on a Saturday evening and yet, they were totally oblivious to the concerns of ANY disabled patrons.

But they are, unfortunately, not alone in that oblivion. Earlier this year, a federal judge ruled that Taco Bell violated the ADA and California law in Oakland. They have 220 stores here in California alone that need remediation to meet appropriate standards for access and services for disabled patrons. As a result of complaints made about one San Pablo, CA store and a week long trial because of their failure to provide handicapped parking, adequate access and other such accommodations, the entire chain within California are being assessed for compliance. Regrettably, it took litigation filed in December 2002 and taking all these subsequent years to wind slowly through the legal system to raise that awareness. This does not begin to count the cost investment made to bring this to resolution.

So, while we are “still here”, there is unfortunately a lot more work to do to raise awareness of that fact. •

## **The Disabled Lost a Hero in the Passing of Steve Jobs**

by Janet Renison

With the recent death of Steve Jobs, we have heard how much of a genius he was and how he made such changes in the world of technology. But one of the areas of technology that has not gotten much “air time” is those end user adaptations which most effectively make the world better for us, the disabled and challenged by everyday living. The one who made this clearest is Stevie

Wonder, who as a person with no sight, has been challenged in ways that I have only recently come to appreciate to any degree. Steve Job’s devices also greatly impacted those who are deaf with his push button, speech or visual icon driven applications. Wonder stated that Jobs “...has affected not just my world, but the world of millions of people who, without that technology would not be able to discover the world”. He added further, that his company was the first which created technology that was accessible, made the world accessible and without screaming that out loud that “this is for the blind, this is for the deaf”. For those of us who struggle mightily to just be accepted as one more person on the planet, albeit with a minor (or major) limitation, THIS IS HUGE.

I believe I can say with confidence that most of us don’t want to be treated as “different” and nor does Stevie Wonder. Although with his tremendous talent, it is not easy to think of him as “everyman”. He isn’t. Jobs incorporated assistive devices, which were not really special except to special needs folks and made them an integral part of the devices he developed. This incorporation into the device lets the user decide if he will use it or not, but it is available to those that need it.

It is to be hoped that there are others, like Jobs, who can envision ways that technology can help those who need it but continue to build the wealth of other wonders into their technological devices that people will sit out side store for 48 hours just to get the first one sold. Thanks, Mr. Jobs. You are a hero to lots of us who never had a chance to say:

“THANK YOU” for opening up our world. •

## **Promoting Positive Solutions**

(from *Post Polio Health*,  
Summer 2011 Issue)

**Question:** *As a group leader, I sometimes feel I come across as too “pushy” when suggesting that (sic) a polio survivor try out an assistive device. How can I get someone who obviously needs to use a new device to try it without appearing to be too pushy?*

### **Response from Rhoda Olkin, PhD:**

Sometimes it is easier for someone else to see what a person needs than it is for that person him/herself. But what do you do with that knowledge? Let me tell you how I first went from being a crutch user to a scooter user as a way of introducing how hard this transition can be. I was teaching at a university, and one day I arrived to find a scooter parked outside my office. I was told, “Oh, the Dean thought you could use this on campus to get around”.

Well, it seemed churlish to refuse, so I started using the scooter. And lo, and behold, I found I went places I hadn't gone before because they were too far, and I conserved energy. But at first I limited my scooter use to on campus, that is, I was okay with being a “scooter user” in my professional life. Then I got a scooter for home and began to use it with friends. Suddenly I could go to big box stores, museums, the park – the scooter expanded my world. The last place I used the scooter was with family. That was the harder transition – both for me and for my parents – bringing up lots of feelings in all of us. Our identity shifts when we go from being upright to a seated position; I get that, it's hard.

But you know the moral of the story. It is the one every new scooter or wheelchair user can recite: You don't realize how much you have limited your world until you get wheels and can expand it again. Then you feel a sense of freedom that you couldn't have predicted, and you would never go back again to not having wheels. But how do you impart this moral to someone who is not there yet? I have a few suggestions.

Have a questionnaire for people to fill out and discuss with each other. Ask questions like: Are there stores you don't go to because they are too big? How long can you stand in line? How active do you envision yourself being in the next five years? Have you fallen in the past six months?

Plan an outing at a place that is easy to get to by scooter, but difficult on foot. Make scooters available for those who don't usually need them.

Have small group discussions about self-image as a person with a disability and what it means to be a crutch user, or scooter or wheelchair user.

Have timed treasure hunts in the facility where you meet. Have clues spread out in the facility so that walkies have to go all over. Offer scooters for use as needed.

Put wheelies on one side of the room and walkies on the other and have them talk about what is easy and hard about their mode of transportation.

Remember, you can lead the horse to water; but only the horse can make itself drink. •

**Question:** *I am a caregiver of a polio survivor. At times I feel taken for granted. How can I handle this situation without hurting my partner?*

**Response** from Stephanie T. Machell, PsyD:

Caregivers, like parents and spouses and others we love and depend on are often taken for granted. No matter how much someone appreciates your care, in the daily routine that caregiving becomes, the person may forget the importance of expressing appreciation and gratitude.

It's hard to be a caregiver, especially for a spouse or partner. It changes the relationship and can create inequalities and resentments. There is ambivalence for both partners about their new roles. The one receiving the care may be appreciative of what is given but fears becoming a burden and resent not being able to do what he or she once did. The one providing the care may be happy to help but resent the extra work and loss of freedom. Both may long for the carefree earlier days of the relationship.

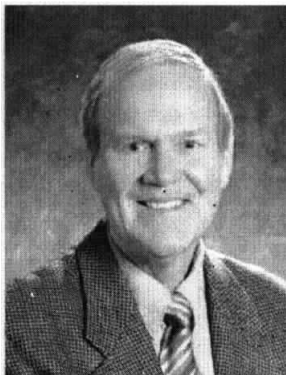
It's especially hard for polio survivors to receive care. Being taken care of may bring up memories of the original polio, which may include negative experiences of caregivers who were anything but caring. Or it may bring up feelings of helplessness and dependence that can be hard to handle for someone who has always believed it was essential to be fully in charge and independent. Expressing appreciation for care, even when it's felt, might make the polio survivor feel more vulnerable.

Can you talk with your partner about how you feel? Couples often fail to discuss such sensitive issues until they come up in indirect ways or in angry and hurtful words – or until the caregiver becomes ill and unable to carry on. Such a serious and important discussion would be best held at a calm and neutral time. You might start by asking your partner how he or she feels about the way things are going in your relationship. Or you could talk first about what you value about being able to care for your partner, or ask what it is like to receive care. You could ask your partner how he or she feels about what you are doing and if there is anything he or she especially likes or dislikes.

This may be a chance for your partner to express gratitude or appreciation for all you do. If not, you can let your partner know how you feel and see how he or she responds. If talking about it doesn't work, or your partner can't or won't do so, there may be less direct ways he or she expresses appreciation that you can observe.

For instance, he or she might look more comfortable or smile at you when you have done something helpful. You might also notice the positive effects of what you do for your partner, like having more energy.

Feeling taken for granted could also be a sign that you need a break. It's important to care for yourself so that you can care for your partner. Find a way to take time out. If no family or friends can help, there are resources available for respite care. Use them and take time to do something that will replenish you. You will return refreshed and revived and better able to care for your partner. •



*Ask*  
**Dr. Maynard**

**Question:** *My physiatrist says that paraplegics have a lot more diabetes, so I started wondering how post-polio and spinal cord injury compare with regard to the disease.*

**Response** from Frederick M. Maynard, MD:

You are right that people with chronic spinal cord injury paralysis do develop glucose metabolism abnormalities and diabetes (by criteria) more often than their age cohorts. I attended a 90-minute course on this topic and obesity among people with spinal cord injury at a recent meeting of the American Academy of Physical Medicine and Rehabilitation. The new information reminded physicians how important muscle is to insulin utilization and, therefore, to serum glucose levels.

During the lecture, I was thinking about people who had polio, with their extensive muscle atrophy, because I expect the same issues exist for them. Not only are people with extensive muscle paralysis (paraparesis and quadriparesis, independent of causation) predisposed to obesity because they cannot move and exercise as much to burn up calories, they also are predisposed to store fat because they cannot move and exercise as much to burn up calories, they also are predisposed to store fat because the relative lack of muscle mass (as a proportion of the

body) leaves high circulating levels of insulin which combines with serum glucose to store fat.

A recent study of body composition among polio survivors in Taiwan found a higher proportion of fat, independent of body weight as considered from the standard of Body Mass Index (BMI). Normally a BMI (calculated from height and weight) of 25 to 27 is considered “overweight” and over 30 as “obese”. Almost all polio survivors studied, even those not overweight /obese by BMI, had an increased proportion of fat by body composition measurements, a proportion that would typically be expected only in overweight obese individuals.

I would expect there is a correlation between glucose metabolism abnormalities and increased fat proportions of body composition.

**Question:** *My father-in-law is 88 years old and has post-polio syndrome. He has had trouble sleeping for the past several years, and he claims that it “takes more medication for people with post-polio syndrome”. My wife is his caregiver and controls his medications so he will not overdose. What is your professional opinion?*

**Response:**

Your father-in-law is mistaken about need for higher medication doses for post-polio people. Generally, they are more sensitive to medications and require lower doses because their bodies distribute medications differently through body tissues and fluids

due to reduced muscle mass. I would be very careful with sleeping medication doses, in particular, because of their potential to affect breathing during sleep (suppression) and the likelihood of creating dizziness/balance problems on awakening (leading to greater falls risk) – both greater problems among polio survivors than the general population.

Encourage him to keep talking to his doctor about what is and is not helping and to try several different types of medications or other techniques to attain “good sleep” without just dangerously taking higher doses of prescribed sleeping pills.

**Question:** *I have a severe rotator cuff tear and an orthopedic surgeon has recommended a shoulder replacement because of the severity of the tear and the presence of significant arthritis. I had polio in my right leg and use my left leg and to lift/stabilize myself on crutches. Apparently the increased dependency has weakened my arms and, perhaps injured them. The surgery may help or may create complications. Can you share any knowledge to help me make an informed decision?*

**Response:**

You raise several important issues to the pros and cons of shoulder replacement in

polio survivors. First of all, if you had any significant residual weakness in your shoulder muscles as part of your original polio, then it is unlikely that your shoulder problems are, anatomically at least, related to polio. You may have worn them out and/or injured them as you suggested, and the shoulder problem can be surgically treated like anyone else's.

Definitely get a second opinion whether the best treatment is arthroplasty (replacement). In addition to a second opinion from a shoulder surgeon specialist, I recommend a second opinion from a non-surgeon, such as a physical medicine and rehabilitation specialist in post-polio. That person cannot only advise about non-surgical alternatives for the shoulder problems, but also advise you on preparations for the post operative period, if you do elect to have the shoulder replacement.

Certainly, you should at least practice transferring and walking and caring for yourself with only one arm, since you will not have much use of the arm after surgery for at least three months. You are facing a difficult and important decision. Don't make a hasty one, especially if you are not suffering severely. Take all steps possible to inform yourself about the pros and cons. •

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**Agenda ideas for PPSG of OC?**

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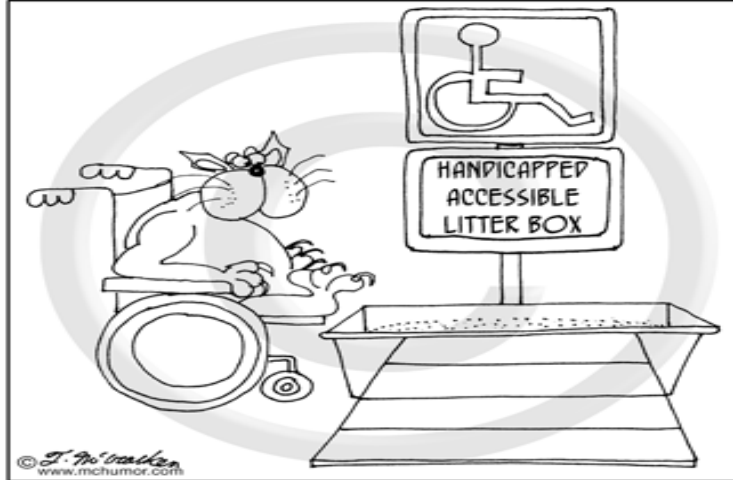
**Webpage: ppsupportoc.org**



Special thanks to the following donors: Barbara Wood, Carol Purington, Betty Thompson Anita Berlacher, Winifred Hyson, Bertram Justus, Helen Li, and the Walcher Family. 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**

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## 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 Richard at **562-862-4508**

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**Webpage: polioassociation.org**



# Rancho Los Amigos Meeting

**No Rancho Los Amigos MEETING IN NOVEMBER 2011**

## Future Rancho SG Meetings

**Saturday December 3rd 2 pm**

# TENTATIVE

Dr. Vance Eberly, orthopedist, who is part of the Rancho Los Amigos Post-Polio team will provide his insights into some of the challenges we encounter in living well with PPS

**This will be a JOINT MEETING with Orange County PPSG.**

WATCH NOVEMBER MAIL FOR CONFIRMATION AND MORE DETAILS

## Orange County Meeting

**NEW DIGITAL AUDIO PLAYERS** are available to us from the Braille Institute. Presentation by Nancy Stanton, Braille Institute Librarian on how we can easily access all recorded books and other publications of the Library of Congress.

**SATURDAY 2 PM NOVEMBER 12, 2011**

**Post Meeting BONUS !!!**  
*Dan Holloway of HICAP will likely return to help us with Medicare Plan decisions.*

## Future PPSG of OC Meetings

**SAT. DECEMBER 3rd 2pm Joint Meeting with Rancho Group**

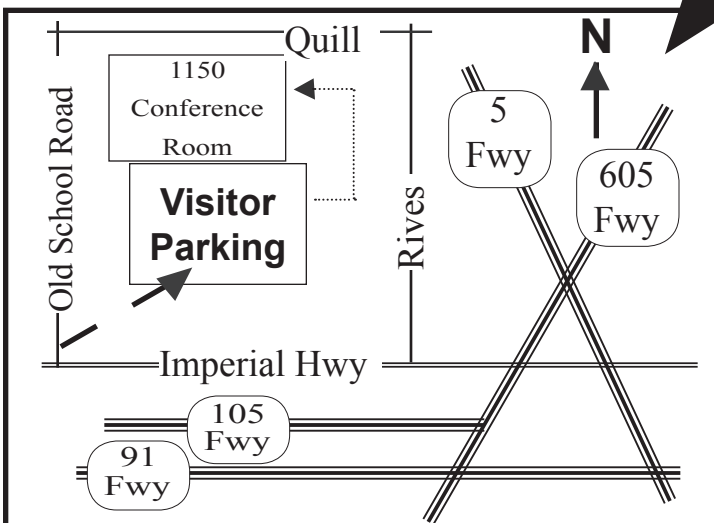
**Dr. Vance Eberly**

**SATURDAY**

**January 14, 2012**

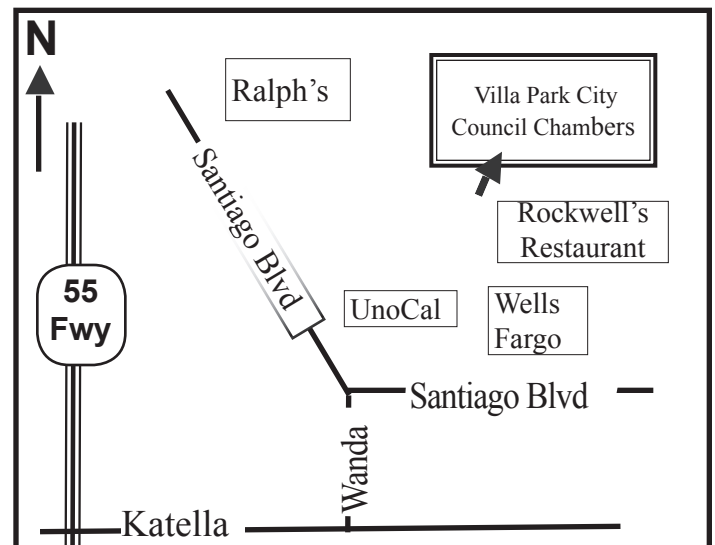
**Finger Food Indoor Picnic**

Tentative Date



We meet **4th Saturdays 2 - 4 PM**

Rancho Los Amigos  
National Rehabilitation Center  
7601 E Imperial Hwy Downey  
1150 Conference Room  
**Support Service Annex**



We meet **2nd Saturdays 2 - 4 PM**  
**Villa Park Council Chambers**  
**17855 Santiago Blvd. Villa Park**

**May meeting usually on a SUNDAY**  
**December at Rancho in Downey**