Founded in 1989

Post-Polio Support Group of Orange County

Newsletter

MAY 2013

18552 Cork Street
Fountain Valley CA 92708

Website: **ppsupportoc.org**

COMING EVENTS

Dr. Susan Perlman

Joint OC & Downey

Groups meet in Villa Park on

***SUNDAY,* - May 19, 2013, 2:00-4: PM**

(Note Day and Joint Mtg.)

Downey

Saturday, June 22, 2013 -

Annual Picnic

Orange County

Saturday, July 13, 2-4 PM

Annual Indoor Picnic

Inside this issue:

Meet Our Members
Aleta Connolly

When the Space Shuttle recently made its return to California, Aleta Connolly felt a lump in her throat and a pride that very few of us will experience. She had worked as an aerospace inspector on parts of that shuttle. When she first joined the workforce, Aleta found it difficult to get jobs because people couldn't see past her disability. Having contracted polio as an infant, she used crutches to ambulate and felt that "some people equate disability with a lack of intelligence." She started working in manufacturing and worked her way up to supervision. Like most post polio survivors, Aleta had to do more and try harder than others because of her disability. "Because I needed a wide road to succeed in life, I also wanted to give that to other people. We all need a chance."

Born in Los Angeles, Aleta contracted polio when she was 7 months of age. She received treatment at Orthopedic Hospital, had many surgeries and lots of physical therapy as a child and used a KAFO brace and crutches to walk. In her younger years, her family relocated to Riverside and the Bonds family were neighbors. They were very competitive and good in all sports, but Aleta has the distinct advantage of being a champion in the game of jacks against Barry Bonds' aunt, Rosie. Around 18 years of age, Aleta stopped wearing the brace because of hip pain and ambulated using the crutches alone.

After a fall in December of '94, Aleta had to retire on disability. Her new retirement job including having to learn to be disabled and how to accept help when she needed it. Being retired gave Aleta the time to pursue her love of travel. She has taken many cruises including Hawaii, Australia and Spain, as well as achieving a life-long dream of going to the Vatican. She co-owns a home in Irvine with her sister and is very close to her nieces and nephews whom she helped raise. Aleta was also instrumental in making the pool in her association accessible for the disabled. She was moved to see it being used by grandparents who could now access the pool and enjoy it with their grandchildren. She drives and is able to put her own wheelchair on the rack on her car.

Aleta joined the PPSGOC in 1987. She feels the group has helped her so much and that “we walk in each other’s braces” by sharing information. She stressed that the group has good energy and is comprised of successful people working with the same type of physical issues. “I’ve no complaints. I have a good life and have met some wonderful people because of polio.”

If you are interested in having your story printed in our newsletter, please contact Debbie Hardy at ppsstoryeditor@gmail.com

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DISABILITY INSURANCE IN PERIL

Disability Insurance (DI) is one of the least known and least understood programs within Social Security. It is also the worst funded and facing an immediate crisis. And you may have read that Social Security's trust fund will be be exhausted in the 2030's, at which point benefits would have to be cut or taxes raised. That is still conjecture. But there is almost no doubt that the Disability program's trust fund will run out in 2016, three years from now. At that point, disability payments, unless congressional action takes place, will have to be cut by about 20%. For those of us who rely on those monies for survival, a one-fifth cut in benefits is a huge loss. The insolvency of DI comes at a very bad time, politically, and could affect 8.8 million disabled Americans and their 2 million spouses or dependents. Congress seems disinclined to even debate the near-term fixes including reallocating more of the Soc. Security payroll tax to the DI fund or raising the tax to shore up the program. Instead, Washington is concerned about the supposed growth of the program. It deems the program "out of control". Since the program covers relatively few recipients, the Disability program has always been a prime target of myths and misperceptions. It's beneficiaries have been mislabeled and portrayed as "slackers" gaming the system whiling away in indolence eating chocolates and being couch potatoes. In March of this year, a program on NPR described the DI program as a "deal 14 million Americans have chosen for themselves" as though the typical recipient has chosen whatever medical condition which reduced us to subsistence living on the average monthly check of $1,130.

The NPR report suggested that the caseloads of Soc. Sec. Disability and it's means-tested cousin, SSI, have "skyrocketed" because they have evolved into "hidden" substitutes for traditional welfare programs. In fact, as the social policy expert, Harold Pollack, has pointed out, the percentage of low-income children on SSI (the main beneficiaries) has remained fairly constant since the 1996 welfare reform. What has skyrocketed is the number of children in poverty in the US. AND the failure of all government relief programs to serve them adequately. As a disabled person whose disability required earlier retirement than originally planned, I didn't realize that my PPS made me a freeloader. Who knew? Clearly, I didn't. My 45+ years in the workplace paying into the system don't count to those who share this mindset. NPR was merely the latest in a long line of news sources who do not seem to understand the Disability Insurance program.

Last year, New York Times columnist, Nicholas Kristof, claimed that rural families were pulling their kids out of school so their illiteracy would keep them qualified for DI. He couldn't and didn't actually identify anyone doing this and, moreover, illiteracy and school attendance or it's lack aren't considered disabling conditions in and of themselves qualifying one for benefits but that didn't seem to bother him. The year prior, the Boston Globe reported that parents were placing their kids on ADH drugs so they would qualify for such benefits. However, government investigators found just the opposite. Kids on the hyperactivity drugs tended to be denied DI or SSI monies. In the 1990's, the media frenzy was over parents "coaching" their kids to act crazy, adding "crazy checks" to the political lexicon. Again, without ANY real substantiation. These claims are all variations on the theme of the undeserving poor and "welfare queens" living on six-figure handouts. The goal of this misinformation campaign is to rationalize cuts in benefits by portraying recipients as morally repugnant.

The picture of disability as an easy and undeserved exit from the workplace has never been accurate but it lingers close to the surface and antipathy to the program seems to run in cycles. The cycle of hostility to the program is back.

The truth of the matter is that Social Security's disability standards are stringent. To be eligible, you must have worked at least one-fourth of your adult life, typically (and unlike early beginners like me) from age 22 on, and been employed in at least the last five of the previous 10 years. Children qualify under SSI, and workers younger than age 31 have to show employment in half of the years since they turned age 22. In addition, you have to be too impaired to earn even $1,040 per month on your own. Just barely over one-fourth of those who apply are approved initially. An additional 13% or so will win benefits after appealing that initial denial so in all, about 41% of all those who apply end up with the big $1,100 per month payoff, on average. Piece of cake, right, welfare queens and kings???

When one considers that the US population is growing older, the ratio of those age 50 to 64 increased by one third from 1980 to 2010, going from 15% of the population to 20% in the US. Let's face it, the general population are twice as likely to become disabled at age 50 as at age 40, and twice again more likely to become disabled at 60 as at age 50. Add to that economic and work-place conditions, wherein productivity requirements have increased multiple times with fewer and fewer people doing the workloads once carried by many. A study done by the Center for Economic and Policy Research found that 45% of workers age 58 and older held jobs that were physically demanding or involved difficult working conditions. In West Virginia, which has the highest disability rate, 150 of every 1,000 jobs involve transportation, hauling, construction, or mining. In California, those jobs those categories account for 95 of every 1,000 jobs. Also, with employment running nearly 9 million jobs below what it was using pre-2008 criteria for the workplace in manpower and productivity levels, it is hardly a surprise that more workers are becoming disabled. People can only do so much before they are physically or mentally affected adversely. It is a fact that most of those who have had lifelong disabilities have encountered discrimination while seeking employment to begin with. Multiply that in a distressed job market where any kind of employment is hard to find and the challenges are increased.

Most of the solutions for the crisis in Social Security Disability involve shifting it's costs to employers, workers, or state governments. These are all either not-gonna-happen options or formulas for the increasing impoverishment of the disabled. Characterizing us as layabouts who should "just get a job" is cruel. Forget the debt ceiling and the deficit, this program is at a crossroads and millions of lives are at stake. It is time for Congress to take action. But the real question is, will they be eartless or humane in their solution?

Source: LAT, March 2013, M. Hiltzik

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DEAR JR

Dear JR: I had polio as an infant. All my life, I have used a leg brace. Now in my late 50's, I have noticed that I am gradually cutting things out of my life because of the distance required and pain caused when I walk. I think the time has come to get a scooter, but I am embarrassed to ask my physician for a prescription. How do I ask and what can I counter with if he says I don't need it when I know that I do?

JR: If your physician tells you that you don't need a scooter to be more mobile as your capabilities decline, you need a more empathetic doctor. We are far more aware of what we can accomplish than anyone else. If you THINK it would make your life easier, ask for the prescription. Please do not be embarrassed. This will enable you to go and do things that you are cutting out of your life, needlessly. There comes a time when all of us face that may be forced to face that choice. It is far better that you ask than struggle to do things and enjoy your life.

Dear JR,

All my life, people have stared at me because of my limp from polio. Why now, as an older adult, have I not gotten used to this and let it still embarrass me?

JR: Being the object of curiosity or ridicule is normal and it takes strength of character to ignorance. But, sometimes it is merely well-intentioned curiosity. Do NOT be embarrassed. If it is merely curiosity, consider it is an opportunity to educate by sharing your knowledge base. I have found most people are kind and will say something along the lines of , "Oh, I know "X" who also had polio. I should have them contact you/PPSG/ PPsupportOC.org, etc. If they are ignorant dcorks, consider the source and ignore them.

Dear JR,

When I need help doing something physically and people offer, I always say no thanks when I really need it because I'm embarrassed that I do need it. What is a gracious way to accept help without feeling embarrassed about it?

JR: I have no idea why you would feel embarrassed to allow people who would be happy to help you when you need it. I often do. Most people do, disabled or not. LET THEM and say Thank You with a smile. It makes everyone's day brighter. They feel good and you are not stressed to do something for which you need help. Go for it!!

Editorial Note:

For the lady who called asking about the article on ANESTHESIA, please go to Post-Polio.org and look under the article by Dr. Calmes from UCLA. I believe this is what you need.

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AN ACT OF KINDNESS

The other day while doing errands my lift ceased working. There I was in the parking lot of the market with the chair suspended about four inches off the ground and hanging out of the back of my CRV. None of the controls were operational at all I was about 7 miles from home and an equal distance to the new location of The Mobility Center which I wrote about in the last issue of the OC newsletter. I remembered that they have inaugurated a new mobile service to provide repairs to equipment in the comfort of your home and it occurred to me that they might have a technician in the area who could take my chair into their shop for repairs. I called and explained my situation to Sommer., who with her brothers, Ali and Omar, manage the technical and sales aspects of the business,. They are all very knowledgeable and service oriented. Sommer transferred my call to Ali. I asked if they had a technician who might be in the area who could help me get the chair to the ground or somehow help me. I envisioned myself driving the 7 miles to their facility with the chair hanging outside, banging against the rear of the car , my rear lift door also open, etc., Especially as the drive passes directly in front of the local DMV office. Ali listened, asked questions about my location and said he would have a technician there as soon as possible. Within a half hour Ali arrived.. Within minutes he had the controls working, the lift inside my car and explained what had happened to cause the controls to cease working. I was able to go on my way .There are failsafe options built into my Bruno lift that I knew nothing about but luckily the techs at The Mobility Center DO know all about them. Since I am a small woman, even with the help of another person, there is no way I could manually lift and reposition that chair, but it was enormously helpful to know that should this happen again, there are ways to get the chair into the car through manually executed controls until you can get it into the Center for service. Not being particularly technically oriented, I later went with my son, who IS a tech kind of guy, and Ali spent a half hour showing us all the ways that could be used in the future should I ever find myself in a like fix. The peace of mind knowing that even I, dummkopf that I am, can get myself on my way should the need arise is tremendously empowering.. That capability gives me great comfort. Folks, I have to say that even though I know there are many, many good people in this world who are generous with their time and energies, the number of Alis who will give up their lunch hour, drive across town, fix the lift of someone they don't even know PLUS spend time later giving instructions on the equipment features to a novice, are few and far between. But that is their service mindset at The Mobility Center. I encourage readers to avail yourselves of these folks, their many skills, equipment and service options whenever you have a need.

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A HERO(INE) TO US ALL

Judith E. Heumann is an American disability rights activist and an internationally recognized leader in the disability community. After 30-plus years working as an activist, Heumann advocates that “Disability only becomes a tragedy for me when society fails to provide the things we need to lead our lives—job opportunities or barrier-free buildings, for example. It is not a tragedy to me that I’m living in a wheelchair.”(1) She continues to be one of the world’s leading voices focusing on the rights and independence of all persons with disabilities. Heumann's commitment to disability rights stems from her personal experiences. Having contracted polio at age 18 months, she was the eldest of three children born in Brooklyn to German-Jewish immigrants. After Heumann graduated from Long Island University in 1969, she was denied her New York teaching license because the school board did not believe she could get herself or her students out of the building in case of a fire; she took the case to court—and won. The media was happy to tell the story of a qualified teacher up against bureaucracy with the headline *"You Can Be President, not Teacher, with Polio"*(2) Heumann became the first person in a wheelchair to teach in New York City and taught elementary school there for three years.

Heumann also gained a Master of Science degree in public health at the University of California, Berkeley in 1975. She has been awarded honorary doctorates by Long Island University in Brooklyn, the University of Illinois at Urbana-Champaign and the University of Toledo. She was the first recipient of the *Henry B. Betts Award* from the Rehabilitation Institute of Chicago (later awarded jointly with the American Association of People with Disabilities). Using a wheelchair all her life, Heumann had to fight repeatedly to be included. Her distinguished dedication to the rights of the disabled includes founding Disabled in Action (D.I.A) in 1970 which focused on securing the protection of the disabled population under civil rights laws. She quotes the group's philosophy as "…to address our problems in a forthright, political way, to show that we were not helpless and disempowered."(3) She served as legislative assistant to the chairperson of the U.S. Senate Committee on Labor and Public Welfare, and in 1974 helped develop legislation that becamethe *Individuals with Disabilities Education Act*. As an early leader in the Independent Living Movement, she served as deputy director of the Center for Independent Living in Berkeley, California. She organized sit-ins at the U.S. Department of Health, Education and Welfare (HEW) offices in San Francisco and around the U.S., ultimately resulting in the signing of the *Rehabilitation Act's Section 504* regulations (mandating that no program receiving funds from the federal government could deny access, services, or employment to someone solely on the basis of their disability From 2002 to 2006 she served as the World Bank's first Advisor on Disability and Development whose projects allowed disabled people around the world to live and work in the social and economic mainstream of their communities. She was also Lead Consultant to the Global Partnership for Disability and Development. After the change of power to the Republican Party, she stayed in Washington, DC, as the Director of the Department of Disability Services for the District of Columbia. Since 2010, Heumann has been the Special Advisor on International Disability Rights for the U.S. State Department. She has worked with governmental and non-governmental (NGOs) organizations to develop human rights legislation and policies to benefit children and adults with disabilities.

Heumann now lives in Washington, D.C. and is married to Jorge Pineda.

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Rancho Los Amigos Meeting

VILLA PARK-JOINT MEETING—May 19 , 2 PM Dr. Perlman

“State of the Polio Research”

Sunday, May 19, 2-4 PM

Orange County Meeting

SUNDAY, MAY 19, 2013

Dr. Susan Perlman

State of the Latest in Polio Research, Villa Park, 2 PM

Future Rancho SG Meetings

Saturday, June 22, 2013, 2-4 PM

Annual 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, Racho 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 : Betty Charron, Betty McFarland, Winifred Hyson and Barbara Smith.. Thank you 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

For add additional information please call Richard at 562-862-4508

Email: **RanchoPPSG@hotmail.com**

How to contact OC Support Group

For information call:

Marte Fuller	562-697-0507
Marilyn Andrews	714-839-3121

Editor: Janet Renison 949-951-8613

renison@cox.net

Agenda ideas for PPSG of OC ????

Please call Aleta at **949-559-7102** or email Priscilla: **prisofoc@aol.com**

Post-Polio Support Group of Orange County

18552 Cork Street
Fountain Valley CA 92708

Website: ppsupportoc.org

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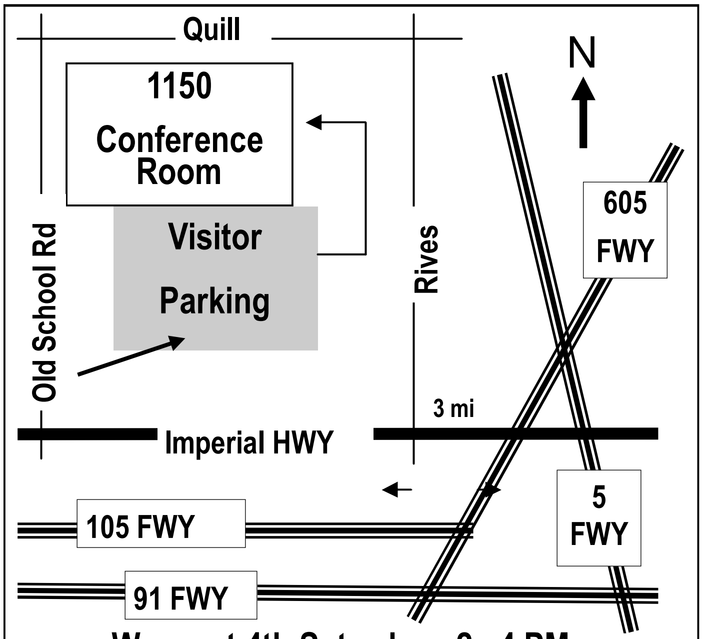
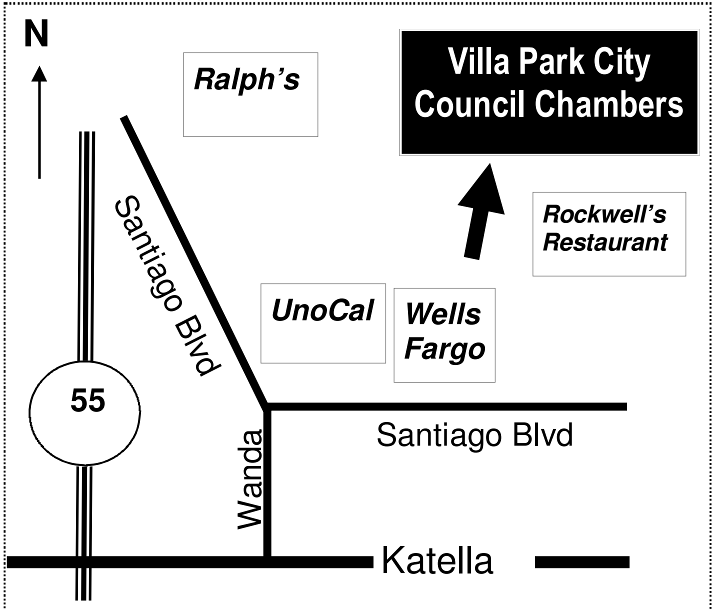
Rancho Los Amigos
Support Group Meetings



We meet 4th Saturdays 2– 4 PM.
Rancho Los Amigos Rehabilitation Center
7601 E Imperial Hwy 1150 Conference Room
Support Service Annex

Orange County
Support Group Meetings



We meet **2nd Saturdays**   *2 to 4 pm*
Jan. March, July, Sept. Nov.
Villa Park City Council Chambers
17855 Santiago Blvd., Villa Park, CA.
May meeting usually 3rd Sunday