

Founded in 1989

# The Post-Polio Support Group of Orange County NEWSletter

January 2009

## PRISON ESCAPE

### Increased Mobility with an Internal Lift

I was becoming a prisoner in my own home. Little by little my PPS was sapping my ability to be independent and go where I wanted or needed to go. My balance and the ability of my right leg to carry my weight became so fragile that I ceased working in my patio with my roses and camellias and even going to buy groceries was a challenge. I know that I am not alone in facing that, although I live alone. I have fallen so many times over the years that I often thought of myself as a bouncing ball. But, I am now in my late sixties and those falls have serious possible long term consequences. I cannot count on bouncing back any more. Hence, my prison status. If I stay inside my house, I have mostly carpeted floors, a much softer surface than concrete. Falls have less potentially destructive consequences. As I said, though, I also live alone. If I stay home all the time, how

(Cont'd to Page 4)

## Rancho Later Life Study

A two-day conference, Meeting the Challenges of Aging with a Disability: Lessons Learned from Post-Polio and Stroke, was held in Long Beach, CA, March 1993. The conference was the culmination of a five-year project (Polio Network News, Vol. 6, No. 3) funded by the National Institute on Disability and Rehabilitation Research (NIDRR), Department of Education.

Most persons with a physical disability, like the population at large, can now be expected to live a longer life. However, as they age, many start to experience the onset of new health problems and secondary complications which threaten to further erode their independence and well-being. Among those individuals who are vulnerable to these "secondary disabilities" are the survivors of the two leading causes of paralysis in the United States today – polio and stroke.

The five-year Later Life Study conducted at the Rehabilitation Research and Training Center on Aging at Rancho Los Amigos Medical Center involved individuals 50 years or older, and compared persons with early onset of polio and spinal injury, to those with a stroke occurring after age 50, and non-disabled controls.

A total of 265 individuals, ranging in age from 50 to 88, participated in the study. These included 120 polio survivors (60 stroke survivors and 60 non-disabled controls, plus an

### *Inside this Issue*

Internal car lift	Pg 1+4
Rancho Study PHI	Pg 1-2
Editor's Note	Pg 3
ADA Changes	Pg 3+7
Rejuvenated Muscle Study (LAT)	Pg 4-5
Why we are Called Survivors	Pg 6
Support Group info	Pg 7

Continued to Page 2

additional 25 persons with spinal cord injury who were not reported on during the conference). Each participant received a comprehensive medical exam, including laboratory analysis of EKG, blood chemistry and bone density testing for osteoporosis; a physical therapy evaluation; a psychological evaluation by a clinical psychologist, and a personal history interview by a medical sociologist.

Although not all of the data had been analyzed by the time of the conference, principal investigator Margaret L. Campbell, PhD, co-principal investigators Bryan Kemp, PhD, and Kenneth Brummel-Smith, MD, presented some preliminary information at the meeting. The final report will be completed by August 15, 1993.

The Rancho Later Life Study concluded, in part, the following: Polio survivors experiencing the greatest problem dealing with post-polio issues are those in the "sandwich" generation – individuals in their early 50s with responsibilities of launching children, aging parents and careers. This finding reinforces the idea that a "life course" perspective of disability will increase our understanding of how disability affects individuals and families.

The health evaluation found few statistically significant differences between the polio group and the control group, including no higher rates of obesity, cholesterol (actually lower), EKG changes (actually fewer), blood pressure and glucose levels. Age-associated diseases do not appear to be more common in polio survivors.

The study did show a higher rate of hypothyroidism in polio survivors. Routine health maintenance should probably include thyroid screening, particularly if survivors are experiencing symptoms such as fatigue, which, in some cases, could be alleviated if the hypothyroidism was treated.

For purposes of the study, depression was defined in two ways: One, by using clinical diagnostic criteria which included profound altered mood, six to eight symptoms (e.g., fatigue, thinking or sleep disturbances) and behavioral disturbances. The second definition of depression was based on clinically significant symptoms only and is less severe.

Overall findings indicate that polio survivors are somewhat less depressed than the non-disabled control group, although the mean differences were not statistically significant. However, among polio survivors, women reported significantly higher depression scores than men (although still within normal limits), and one group of survivors, those in their fifties who experienced acute polio after 1940, had scores consistent with clinically significant symptoms.

Funding was obtained to give one copy of the conference proceedings to each support group. They are being revised and will be available by July 1, 1993. Additional copies, as well as tapes from the conference, can be ordered. Contact Millie Sealana, Associate Training Director, Rehabilitation Research and Training Center on Aging, Rancho Los Amigos Medical Center, University of Southern California, 7066 Consuelo St., Downey, CA 90242 USA (310-940-7402, 310-940-8953).

The Center has been funded for another five years starting August 1993. It will continue its focus on aging and polio with an expanded sample of over 450 individuals, which will include a random sample of 60 individuals from the first five-year study, 300 from the Rancho Post-Polio Clinic and another 100 from the local community. Polio survivors are, of course, as susceptible to stroke as anyone else.

## FROM THE EDITOR'S DESK

Janet Renison

This month our newsletter has a multi-focused combination of topics which I found of interest and hope you will, as well. There are new decisions being made in interpreting the ADA and you need to know the direction in which things are moving. In addition, I found the information on a Rancho study to be pertinent as we age, as well as why we call ourselves PP "Survivors". There is appropriate precedent for this designation, learn why. Also, I found an interesting article that gives hope to those who follow in our footsteps. Maybe some of us will be around long enough to benefit from these efforts but it is movement in a direction that could really change many lives for the better. Read on. Hope you enjoy my mélange of thoughts. Pay special attention to the meetings in store in the New Year and mark your calendars.

We have a two-part series beginning in February (2/14) with a presentation by Ms. Teresa Gorman, Esq., a local attorney specializing in wills, probate, trusts, and Powers of Attorney. And in March (3/14), we are fortunate to have asked Ms. Susan Knopick, a certified trust management professional, to speak to us and who will focus on options for charitable giving, their potential tax consequences and how one might set up an annuity that will pay you benefits, save on taxes, and benefit others, long-term. You can make a gift using appreciated securities and realize larger tax savings than if you had used cash. You can make a gift that costs nothing during your lifetime. You can make a gift that pays you income for life. You can donate your house, take a tax deduction and continue to live in it rent free. You can use your IRA to make a gift. If you haven't already made your estate plans, don't miss the opportunity to learn how these matters can seriously affect the finances of your heirs and dependents.

###

## The ADA Amendments Act of 2008

Jacquie Brennan,

Southwest ADA Center, Houston, Texas, swdbtac@ilru.org

To understand what the ADAAA means, it's important to understand why the ADA needed amending in the first place. When it was passed back in 1990, the ADA had a definition of disability that was based on the definition used in the Rehabilitation Act of 1973. An individual with a disability has a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment, or is regarded as having such an impairment. Congress used the same definition because it had worked well.

The Supreme Court, in 1999, started to narrow the definition of disability in unexpected ways. In a case called *Sutton v. United Air Lines*, the court said that, when you determine whether an individual has a disability under the ADA, you have to consider the effects of mitigating measures - such as corrective lenses, medications, hearing aids and prosthetic devices - when deciding an impairment is substantially limiting. The Court did one other thing in *Sutton*. It essentially overturned an old Rehab Act case, *School Bd. of Nassau County v. Arline*. *Arline* had broadly viewed the part of the definition of disability that mentions having a "record of" an impairment. The Court in *Sutton* required a more restrictive view of that part of the definition, which practically eliminated it.

In 2002, in a case called *Toyota v. Williams*, the Supreme Court focused on the word "substantially" from the definition of disability; and said that it means "considerably" or "to a large degree." The Court also narrowed the scope of "major life activity," stating that it must be something that was of central importance to most people's daily lives. Eventually, the definition of disability was narrowed to such a degree that most cases became more about whether a

**On September 25, 2008 the ADA Amendments Act (ADAA) was signed into law and will become effective on January 1, 2009. The bill passed the House on a vote of 402 to 17 and unanimously passed the Senate**

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will I survive?

I found that this propensity for safety was taking over my life. So, I have tried some options to broaden that boundary. I live on a very fixed income (Disability Social Security for a time, now merely Soc Sec). It isn't very forgiving of major expenditures. So one uses the resources one has at the time your income disappears. I moved to a community that had homes with adaptive devices installed and a community bus system, complete with lifts on all buses. I got a power chair and I bought a lift to affix to my bumper for the few trips I had to take out of my community. But, the lift made my car, which is a lightweight sedan, bottom out going in and out of my driveway and every other driveway that I entered or left. So, rather than ruin or replace the car, I stayed home and used the community bus system when I had to go out. I may not have to go often but freezing in winter and dripping in the rain while waiting for a bus leaves a great deal to be desired. Especially when you must coordinate those trips with outside Access buses whose schedules are even less flexible and whose service areas are very limited. Finally, I realized I had no option but to use my limited resources to change the situation.

I purchased, after a great deal of research with car dealers, manufacturers and adaptive device purveyors, a "cross-over" small SUV with just enough room to accommodate an internal lift and my power chair. What a change in my ability to go and do. I cannot begin to tell you the freedom I feel. The internal lift allows me not to be concerned with the weather or the venue more than others would have concerns. Access is always an issue but that goes beyond the ability to get

someplace and we can't always control it. I can control, however, how much assistance I need to request (a difficult task for me). It was the most liberating action I have taken since I discarded my leg brace and orthopedic shoes in the eighth grade. I can sure recommend that, should your situation resemble mine, you call me to discuss my research and decision-making process in hopes it helps you break out of YOUR prison. ###

## PARALYZED LIMBS MOVE WHEN BRAIN SIGNALS ARE REROUTED, STUDY SHOWS

By Times Staff Writer, Denise Gellene  
Los Angeles Times, October, 2008

Though the study used monkeys, it shows that neurons can be trained to perform new tasks

Aided by external wires that rerouted signals from their brains, two monkeys regained control of their paralyzed wrists and played a simple video game, scientists said.

The study, published in the journal *Nature*, could one day lead to devices that allow people to regain some control of their limbs after suffering spinal cord, nerve damage and other forms of paralysis.

The research is part of a growing field in which scientists are harnessing the power of the brain to overcome paralysis. In a previous experiment, for example, scientists have demonstrated that people who have lost use of their limbs can control a cursor on a computer screen using only their thoughts.

In the latest research, scientists first trained monkeys to make a cursor reach targets on a computer screen by moving their wrists up and down. Beneath the monkey's skulls, scientists

had implanted electrodes into an area of the motor cortex responsible for hand and wrist movements. As the monkeys played the game, the electrodes recorded signals from individual brain cells so scientists could determine a firing rate.

Once the monkeys had learned the game, scientists implanted wires that ran from their electrodes into the muscles of each monkey's forearm. Researchers used an anesthetic to temporarily immobilize the animals' wrists.

A small battery operated device used the firing rate to convert brain signals into electrical stimulation to the monkeys' muscles. Thus, the animals continued to play the target practice game using their otherwise paralyzed wrists to move the cursors.

The monkeys' gaming skills improved with practice, researchers said, peaking at an average of nearly 15 correct hits per minute compared to an average of fewer than five hits per minute at the outset. Game playing sessions were limited by the duration of the anesthetic.

Researchers said they learned that only a single neuron was needed to control a pair of muscles, such as wrist flexors and extensors, and that cells in the motor cortex were capable of stimulating activity.

"Remarkably, every neuron we tested in the brain could be used," said Chet T. Moritz, a researcher at the University of Washington and an author.

The discovery that neurons can be trained to perform new tasks greatly expands the number of cells that the experimental devices may tap into, Moritz said.

"Clinical applications for the technology are at least a decade away", said Eberhard E. Fetz, a professor of physiology and biophysics at the University of Washington and also an author.

Methods for controlling multiple muscles must be developed, along with a reliable device, he said. The device used in the study pokes through the skull, which increases the risk of infection.

Dr. Andrew Schwartz, a professor of neurology at the University of Pittsburgh, who works on developing devices for paralyzed patients, said the challenges were huge.

What they have done is a very simplistic muscle activation with a single cell going to one or two muscles, Schwartz said. "It is a nice sort of glimmer of something, but in the real world you need many muscles acting simultaneously."

"The problem of translating this into a neural prosthesis is quite daunting," said Dr. Gerald Loeb, professor of biomedical engineering at USC, whose research is focused on reanimating paralyzed limbs.

Aside from the technical hurdles, cost also looms as an obstacle, Loeb said.

"These systems are going to be very expensive to build and implant, and they have to be fitted and adjusted to the patient, so the threshold of performance you have to achieve to justify the cost and risk is quite high", Loeb said.

"This is a difficult problem in terms of making a commercial device that insurance companies would pay for," he said.

###

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## WE CALL OURSELVES SURVIVORS

G.I.N.I. has been publishing since the 1950s. Copies of Toomyville Gazette, Toomey j Gazette, and the Rehabilitation Gazette reveal that through the years individuals who had polio have been called polio patients, wheelchair patients, polios, iron lung polios, multiplegics, respos, horizontals (severely disabled) vs verticals (non-disabled), upside down polios, polio quads, handicapped, physically handicapped, disabled, post-polio people, and polio survivors. The 1980 Rehabilitation Gazette (Vol. XXIII) contained the article "Watch Our Words" noting that 1981 would be the International Year of Disabled Persons, not "handicapped" persons, or "crippled" persons. The politically correct article argues against generalizing which impersonalizes, negative images which reflect small expectations, words which imply people with disabilities are asexual, and labels which assign superhuman qualities.

Since that time, G.I.N.I. publications have consistently used terms such as people with disabilities, ventilator users, and polio survivors, never accepting the euphemistic "physically challenged." Over the years a few readers have expressed their dislike for the term survivor. With a better understanding of what it means to be a survivor, they may change their mind.

In 1993, Al Siebert, PhD, published *The Survivor Personality* (ISBN 0-944227-06-6), in which he describes survivors and their qualities.

Dr. Siebert first became interested in survivors when he served in the Army in the early '50s. Part of his paratrooper training was conducted by individuals in a unit that had survived capture by communists in Inchon. He realized that these survivors had characteristics "which tipped the scales in their favor." He "decided to work backward. I look for people who had survived a major, stressful personal crisis which was surmounted in some way by their own personal effort, and which resulted in them being stronger and more capable than they were before."

Dr. Siebert interviewed "hundreds of people, survivors of the World War II Bataan Death March; Jewish survivors of the Nazi Holocaust; ex-POWs and Vietnam veterans; survivors of cancer, polio (11cTpoke with Ed Roberts and Dorothy Woods Smith), head injury, and other physically challenging conditions; survivors of co-dependency, abuse, alcoholism, and addiction; parents of murdered children...."

The following extended excerpt from his book describes what he learned:

"I learned that most survivors are ordinary people with flaws, worries, and imperfections. When people call them heroes they disagree. We just did what any reasonably sensible people would have done,' say two women who were lost for a week in the mountains during freezing winter weather. We aren't heroes,' they keep saying to people awed by their survival.

"I learned that a few good people are born survivors. They are the natural athletes in the game of life. Just as some people are born musicians, writers, artists, or singers, some people are gifted in living. The rest of us need to consciously work to develop our abilities. Just as we would have to take lessons and practice diligently to become artists or musicians, we have to work at learning how to handle job pressures, difficult people, conflict, negative situations, unwelcome change, and crises.

"I learned that some of life's best survivors grew up in horrible family situations, and that many of the people least skillful at coping with life's difficulties have come from ideal homes. Many of the best people in our world have been through experiences that no public school could get away with arranging. They have been strengthened in the school of life. They have been abused, lied to, deceived, robbed, mistreated, and hit by the worst that life can throw at them. Their reaction is to pick themselves up, learn important lessons, set positive goals, and rebuild their lives.

"I learned that people seldom tap into their deepest strengths and abilities until forced to do so by a major adversity. As Julius Segal, the distinguished survivor researcher has said, 'In a remarkable number of cases, those who have suffered and prevail find that after their ordeal they begin to operate at a higher level than ever before ... The terrible experiences of our lives, despite the pain they bring, may become our redemption.'

"Lt. Commander Charlie Plumb, for example, was a navy pilot shot down early in the Vietnam war. He was held in a prison in Hanoi for six years in a stone cell 8 feet by 8 feet in size. He had no window to look out and nothing to read. He was frequently hog-tied, repeatedly beaten, and subjected to grueling interrogations. Yet, in retrospect, when he talks about his experience as a POW he says 'It's probably the most valuable six years of my life. Amazing what a little adversity can teach a person .... I really felt there was some meaning to that, to my experience itself.' "

person met the definition of disability; rather than focusing on access or accommodation. The EEOC had regulations that defined "substantially limits" as "significantly restricts."

The ADAAA has new rules for the definition of disability. They include:

- The definition of disability is construed in favor of broad coverage to the maximum extent permitted; and
- The term "substantially limits" is to be interpreted consistently with the ADAAA; and
- An impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active; and
- Mitigating measures shall not be a factor when determining whether an impairment substantially limits a major life activity. The only mitigating measures that can be considered are or-

### 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**

Or email us:

**Rancho PPSG@hotmail.com**

dinary eyeglasses or contact lenses that fully correct visual acuity of eliminate refractive error.

- People who are regarded as being disabled are not entitled to reasonable accommodations or modifications. Previously, courts had debated whether the ADA required having to accommodate a disability that didn't actually exist.

The ADAAA is not some revolutionary new law. It simply attempts to bring the law back to what Congress intended it to be when it passed the ADA in 1990.

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[www.post-polio.org](http://www.post-polio.org)

### How to contact OC Support Group:

Call us for information:

Marte Fuller **562-697-0507**

Marilyn Andrews **714-839-3121**

### Newsletter co-editors:

*Baldwin Keenan* 949-857-8828

[keenanwhelan@cox.net](mailto:keenanwhelan@cox.net)

*Janet Renison* 949-951-8613

[renison@cox.net](mailto:renison@cox.net)

### Agenda ideas for PPSG of OC?

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

Special thanks to the following donors: Carol Demars, Walt & Margo Wilson, Helen Li, Lynn Coppel, Gertude Mikus, Janice Palmer and in memory of the late Janice Chin from Nina Tom and Carmen Fong. 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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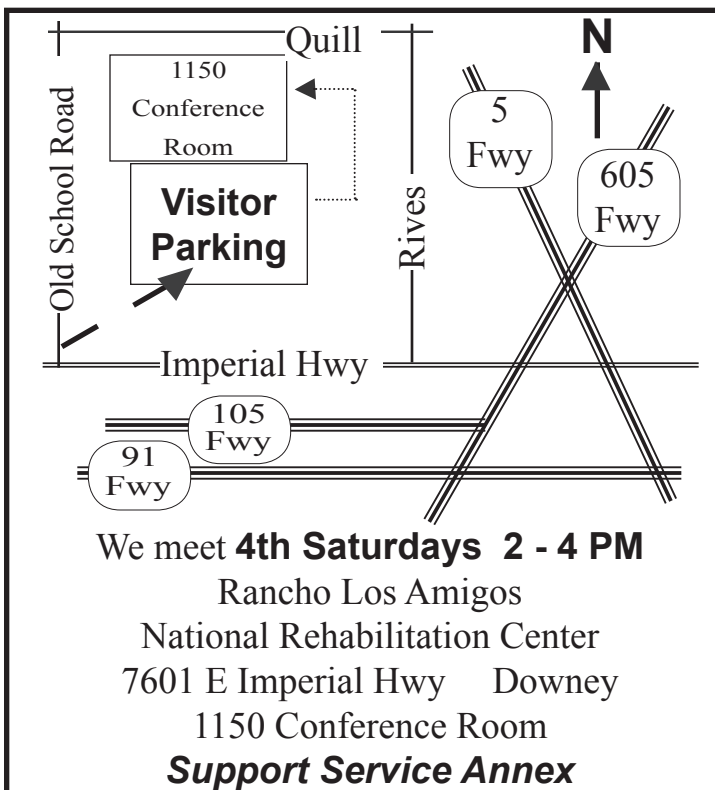


## Rancho Los Amigos Meeting

FOLLOW UP DISCUSSION  
of December Meeting Information  
January 24 2 PM - 4PM  
(See directions below)

### Future Rancho SG Meetings

Not available as of this date



## Orange County Meeting FINGER FOOD POTLUCK SOCIAL

**Saturday January 10** - Bring your favorite  
dish to share  
**2PM** in Villa Park City Council Chambers  
(See map below)

### Future PPSG of OC Meetings

February 14 Teresa Gorman  
**Probate, Wills, Trusts, Powers of  
Attorney**

March 14 Susan Knopick  
**Charitable Trusts, Annuities, Tax  
Saving Giving**

April 11 Mark Potter  
**ADA Laws**

