Founded in 1989

The Post-Polio Support Group of Orange County Newsletter

March 2009

A CLARIFICATION OF NON-PARALYTIC POLIO

By Ernest W. Johnson, MD

For many years, most physicians have understood that non-paralytic is a loose clinical term implying that neither the patient nor the clinician-examiner reported functional weakness.

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Attorney to discuss ADA laws in April

Our reprinting of the PHI article on the new regulations concerning the **Americans with Disabilities Act** has generated considerable discussion, (See pages 1 and 4) We are very happy to have Mark Potter of the **Center For Disability Access** join us again. Although he is very clear that there are times and places when only a lawsuit will do, he will stress to us that our goal is to remove the barriers to accessibility. Mark will discuss ways in which we can talk to businesses — to explain, to persuade. If that fails he will tell us how to bring in the power of laws.

Inside this Issue

ADA Provisions and Clarifications

by Janet Renison, co-editor PPSG of OC

Questions about our re-print of the Post Polio Health ADA article in our January newsletter helped to generate a response from the author, Jacquie Brennan, to say that the wording in that article WAS correct. She goes on to say: "The ADA covers people who meet the definition of having a physical or mental impairment that substantially LIMITS ONE OR MORE MAJOR LIFE ACTIVITIES". For those who are regarded as having an impairment, but possibly do not actually have a disability, there is no "reasonable accommodation" available because they do not actually have a disability. This comes up most often when discussing facial disfigurements or burns. The person doesn't have a disability, is not limited in a major life activity but may be "regarded as" having a disability by, say, a potential employer. But, because the person does not have a disability, there is no need for a reasonable accommodation.

Which brings us to the issue of what is considered a "reasonable" accommodation. Businesses with fewer than 15 employees are not covered by the employment provisions of the ADA. Moreover, a covered employer does not have to provide a reasonable accommodation that would cause an "undue hardship." Undue hardship is defined as an action requiring significant difficulty or expense when considered in light of factors such as an organization's size, financial resources and the nature and structure of its operation. This may vary from employer to employer because of circumstances of doing business. What one employer might be willing to do may be cost prohibitive for another and the law has held that if there is a significant negative monetary impact on the employer, they do not have to make all accommodations requested. It also is important to note that this issue applies more to large employers rather than small "mom and pop" businesses. If an employer is of sig-

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This determination was often made without the understanding that 50% of the motor units can be lost before a manual muscle grade of four occurs. This means that many patients with acute polio were labled non-paralytic incorrectly, but certainly in a well-meaning way.

When the polio virus is in the gastrointestinal tract of an individual and causes symptoms, the term abortive polio has been used. This is the condition that confers immunity on the individual and also prevents the carrier state. This is why the Sabin (attenuated, live poliovirus) vaccine prevents the invasion of the poliovirus into the central nervous system, but not the poliovirus from living in the gastrointestinal tract. In those individuals whose immune systems, for whatever reason, permit the invasion of the central nervous system by the poliovirus, a population of anterior horn cells will die. The number of these cells that die will determine whether the clinician will be able to identify paralysis.

In the late 1950s, our electromyographic studies suggested that in all patients who experienced the invasion of the central nervous system by the virus, pain, meningismus, and positive spinal fluid findings revealed abnormal irritability (fibrillation and positive waves) in many muscles that were clinically "normal". It should be absolutely understood that patients who were told that they had nonparalytic polio did, in reality, have polio which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affected other persons with post-polio syndrome.•

Dr. Johnson is editor of the American Journal of Physical Medicine and Rehabilitation. He is a well recognized expert on Post-Polio Syndrome.

MEDICARE BACKS DOWN ON ASSISTIVE DEVICE RESTRICTIONS !

Late last year the Medicare Improvements and Providers Act of 2008 reversed a Medicare provision which would have made it difficult and expensive for us to get assistive devices specifically designed. We would have been forced to accept the lowest priced "off the shelf" equipment.

Internet Study

Health Promotion for Women Aging with Physical Disability: The Baylor College of Medicine Center for Research on Women with Disabilities (CROWD) is testing an online self-help, interactive health promotion program called the "Garden of Wellness."

This creative Internet program is designed to increase knowledge about exercise, nutrition, stress management, and the use of health care services; to improve health behaviors; and to reduce isolation and increase connectedness for women with functional impairments. The Principle Investigators are Drs. Margaret A. Nosek and Susan Robinson-Whelen.Eligibility is being a woman who is at least 45 years of age, who has access to a computer with a high-speed Internet connection about 2-4 hours per week and who likes learning to use computers, and who has had a physical limitation, disability, chronic illness or health condition that limits activities for at least one year. Participants will be randomly assigned to two groups – an online intervention group for 8 weeks or a control group (that will not have access to the program until 6 months later). All participants will complete some surveys and receive payment for participation in either group.

Interested? Reply to **cathyc@bcm.edu** or call 713-523-0909. CROWD staff will call you back to tell you more about the study and conduct a telephone interview to confirm your eligibility.

My Favorite Mask: FlexFit™ 407

Gladys Swensdrud, San Diego, California
swensdrud@pacbell.net

Merriam-Webster defines a mask as "a cover or partial cover for the face used for disguise." That definition instantly conjures up images of the Lone Ranger's classic black mask. However, for those of us dependent upon bilevel or CPAP support, the function of our masks serve an equally noble purpose - aiding us in safe, restful sleep.

There are almost as many nasal and full face masks available today as there are sizes and shapes of faces. Finding the perfect mask to allow me to sleep in comfort throughout the night required a bit of experimentation. Fortunately, during that critical period I was under the care of the sleep professionals at Progressive Medical in Carlsbad, California. The therapist assigned to help me make this decision was Kelly. She fitted me for three or four different styles and brands. But as soon she hit upon one that matched my requirements, I was finally able to sleep peacefully, both through the night and when resting or sleeping during the day.

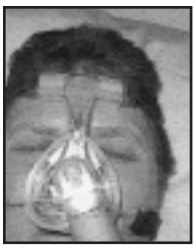
Each person's comfort requirements are slightly different. I needed a mask that had a light touch against my forehead and sinus cavities. I wear glasses throughout the day, so I did not want to go through nights as well as days with pressure against those same facial areas.

After sleeping with the FlexiFiCM 407, manufactured by Fisher & Paykel Healthcare (www.fphcare.com). I concluded that their size small nasal mask worked best for me. There are multiple reasons for my success with this particular model:

■ A foam cushion sets into the silicone seal to protect my face from undue pressure. It feels secure, yet comfortable, against my skin.

■ The silicone seal pops off (and back on) easily for cleaning, so I am more apt to wash it daily, preventing skin irritation and skin oil buildup.

■ A glider strap lets me turn my head while I sleep, but it keeps the mask stationary on my face.



■ A well-designed air diffuser vents air away from my body, so I am never bothered by air blowing down at my chest.

■ Once it has been adjusted to my head size, the headgear generally only needs to be replaced once a year. I set it and basically forget it!

■ The headgear disconnects from the mask for easy cleaning. I just put my headgear periodically in the washer on gentle cycle, and let it air dry afterward on top of the dryer.

■ The headgear has a stretchy band at the rear for additional comfort at the back of my head.

■ The easy slide hooks make it simple to disconnect and/or reconnect my headgear in the dark if I should need to get up in the middle of the night. •

Polio Survivor Gladys Swensrud is co-facilitator of the San Diego Polio Survivors support group. She was instrumental in helping to create Kaiser/San Diego's Neuromuscular Respiratory program, which is presently in the process of seeking expansion throughout Kaiser Permanente in Southern California. With her nasal mask, she uses a RedMed VPAP®III (ST) bilevel machine at settings of IPAP/12, EPAP/5 and a back up rate of 9 Breaths Per Minute (BPM).

ADA Clarifications from Pg 1

nificant size there is a tendency to require that SOME accommodation be made. However, once again the issue of what may be considered "reasonable" comes into play. If a person is hearing impaired, for instance, and the employer is able to purchase a phone that enhances the audio for such an individual, this would be reasonable. Some employers might even be willing to help defray listening device cost in part or in total to accommodate this disability. If a person's is sight impaired, there are devices that augment computer text sizes (ZoomText for one) or machine that magnifies the size of print of documents. The cost would probably be considered "reasonable". Some magnification equipment cost $300 - $500, but other machines run into the thousands. The reasonableness of the request for accommodation is based on the size of the employer and the cost of such purchase(s) on the financial well being of the company. If other employees would have to be terminated or have work shifts reduced to accommodate these purchases, it is generally unlikely that such requests would prevail. The interpretation of the law is reduced to specific and individual instances.

The foregoing does not imply that people who utilize or seek access to any company's facilities cannot ask that such access be considered. One can always bring such issues to the attention of a business with a suggestion that their client base could grow as a result of minimal changes that create greater access. Those suggestions are generally encouraged, especially in economic times when business is down. If it doesn't take much to change something that brings in MORE business, most businesses will surely give it consideration. Businesses tend to view that as part of the cost of doing business and many times accommodations for the disabled will be made. Sometimes, unfortunately, in the final analysis, businesses will determine the necessary changes to be cost prohibitive.

There has been a lot in newspapers lately about individuals who use the ADA legislation to intimidate businesses to "settle" potential lawsuits threatened by requests for reasonable accommodation. One recent example was a man who went to the door of a small single owner business and visually "inspected" the premises and who later, with his attorney's collusion, threatened to file a lawsuit because a counter was ½" (one-half-inch) too high to meet the ADA requirements. This person was, according to the report, NOT even a customer of the eating establishment so clearly had not been denied service nor did he require ANY accommodation. This seems to be a form of legal extortion which was the surmise of the owner of the restaurant. The individual, along with another who had brought or initiated some 4,000 suits was making a six-figure income AS WAS HIS ATTORNEY for doing this. A judge has "enjoined" (refused to allow further such actions) from one or both of these gentlemen. There was not any attempt made, apparently, to request that changes be made to accommodate the disabled, it was merely a ploy to earn a rather handsome income. These types of litigants make it VERY difficult for people who truly wish to effect change to do so.

Based on no response from readers from my request in the February newsletter, we cannot assume that there is rampant discrimination. However, I, personally, was told many years ago that because I could not physically lift and carry a "sixth grade" student who might be injured, that I was unable to perform the task of teaching in an elementary school. This experience, in light of a crying need for teachers in that district which had many under performing schools was one of the major motivators for me to go into Human Resource work. This type of blatant and ridiculous assumption (if a child were injured, one would not move them at all but, rather, call for professional medical assessment before doing so) and further a woman of my size, even an able bodied one, would have a very difficult time doing so if the student were of any size. Does this mean, then, that small well educated women should be prohibited from teaching anything other than preschool or primary grades?? Of course not. However, these decisions and many like them are still being made by people, not only in this country but elsewhere in the world. It does not help when some folks abuse what is clearly a well-intentioned law aimed at preventing such silliness. All those of us who fight daily to live in a world that is not particularly sensitive to disabilities can do is to work collaboratively where we can to make the types of SUBSTANTIVE changes that really make the lives of our disabled brethren easier.•

PPS and Diabetes

By Rick Van Der Linden
www.ppsmanager.com

What is Diabetes?

The pancreas produces the insulin our cells need to process glucose. If the pancreas fails to make enough at the right times or if for any reason the cells are unable to use the existing insulin, the blood sugar (glucose) level can rise dangerously high and we become very sick. The disease, if ignored, can kill quickly or it can slowly destroy the entire body.

There are two basic types of diabetes.

Type 1 used to be called juvenile diabetes because it usually strikes before 30 years old. Today it is called Insulin Dependant Diabetes Mellitus and, as it's name suggests, insulin injections are necessary to manage blood sugar level. It can come on very quickly, often after an illness such as the flu. Symptoms include frequent urination, extreme thirst, increased hunger, and weight loss.

Type 2 diabetes is the one we are most familiar with because it comprises about nine out of ten cases of diabetes. It is sometimes called adult-onset or Non-Insulin-Dependant Diabetes Mellitus. As suggested by the names, it comes on later in life and insulin injections are not necessarily required.

This is a sneaky disease because it can come on slowly as blood sugar rises and remains high. Over time, blood vessels and nerves may be damaged, causing eye, heart, blood vessel, nerve, and kidney disease.

Type 2 diabetes is the one we'll look into here.

A Lot of People Get Diabetes These Days.

Diabetes costs our health care system $130 billion a year. That's because there are 18 million diabetics. And, not only do diabetics require frequent checking of blood sugar level, but many are on drug or insulin therapy as well. And, each year 40 thousand get kidney disease, 24 thousand go blind, and 82 thousand have amputations.

There are also 41 million people who are prediabetic. That may explain the prediction that in 25 years the number of diabetics is expected to double.

Why?

It's partly genetic. Early people were hunter/gatherers. Because the available foods varied seasonally, it was feast or famine. The human body developed the ability to store food internally in times of feast so they could survive the times of famine. They did this by regulating insulin to facilitate storage and burning of fat deposits as needed. Throughout most of the world these days, with all kinds of food available all the time, it's always feast season. If you are a recent descendant of hunter/gatherers (this includes Native Americans, Africans, Islanders, and South and East Asians) there is an increased risk of diabetes.

But, it's mostly lifestyle. It's too easy for us to grab a snack and sit down. Television, computers, even books (of course, this does not include the PPS Manager newsletter), when coupled with super-sized cokes and fries, potato chips, and double latte cappuccinos from the drive through can add up to disaster.

What are the signs?

Those of us with Post Polio Syndrome will recognize many of the signs of diabetes. They include: Excessive thirst, frequent urination, blurred vision, increased hunger, irritability, tingling or numbness (called neuropathy) in the hands or feet, and fatigue. These symptoms can come on slowly and may go unnoticed until after the damage is done.

Other factors that may be associated

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to the overall problem are high blood pressure and high cholesterol – both conditions commonly linked to excessive weight.

For us, there is the added danger of attributing these symptoms to PPS and doing nothing about it.

What can YOU do?

The main cause of diabetes is too much of the wrong kinds of food (mostly sugars) and not enough exercise. It's true that there are thin diabetics, but sick people often lose weight as a result of being sick.

If you are overweight, can't exercise, and have a few of the warning signs, see your doctor. As with any disorder, early detection and treatment will increase your chances of a long, healthy life. Simple blood tests can detect the problem, and early treatment is also simple and very effective, starting with diet and exercise.

If you can't exercise, and diet alone doesn't work, your doctor might prescribe pills or insulin injections. There are new things coming along all the time.

Whether you think you have diabetes or not, why not commit yourself to a better diet? Although it would be good to eliminate French fries, cokes, mashed potatoes and gravy, etc. you could actually eat the same foods as before, just eat less. Think about it. If you wanted to reduce fats and sugars by 50%, all you have to do is eat half as much.

Oh, and if you smoke, you're asking for all kinds of trouble.

The good news according to WebMD: "Modest weight loss of as little as 5% to 10% of your body weight can lower your body's resistance to insulin and increase its ability to use insulin more effectively."

For more information visit www.diabetes.org, www.idf.org and ask your doctor. •

In Passing January 22, 2009

Grace R. Young received her B.S. in Occupational Therapy from Washington University in St. Louis and her M.A. in Occupational Therapy from the University of Southern California. For years she was prominent in OT at Kaiser Permamente She has published and lectured extensively on disability issues and worked closely with PHI she will be missed as well as her blog.

This may help you ...

I have found a source for repairing wheelchairs. He is wonderful. He will come to your house to repair manual as well as power wheelchairs and chair lifts.His name is Michael Gross. His business name is:

A & T WHEELCHAIR
15559 Graham St.
Huntington Beach, CA 92649
Phone: 714 402-0411
Fax: 714 892-4892

I hope this information will be helpful to our group. *Betty Killeen*

As always the PPSG of OC does not endorse nor certify the quality of the service of any vendor. We provide the above as information only from a polio survivor who wants to help others.

California High Court:

Doctors Cannot 'Balance Bill' To Collect Fees

SACRAMENTO, Calif. — Billing disputes over emergency medical care must be resolved between the emergency room doctors and health maintenance organizations and the doctors cannot "balance bill" the patient for the disputed amount, the California Supreme Court held Jan. 8 (Prospect Medical Group Inc., et al. v. Northridge Emergency Medical Group, et al., Prospect Health Source Medical Group v. Saint John's Emergency Medicine Specialists Inc., et al., No. S142209; Calif. Sup.).

From December 7, 2008 at PHI

The Office of Disease Prevention and Health Promotion (ODPHP) launched a completely redesigned healthfinder.gov making changes to the home page, including the addition of a link to the new 2008 Physical Activity Guidelines for Americans.
The Quick Guide to Health Living section provides easy-to-understand information on key prevention issues.

Healthfinder .gov

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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**

Or email us:
Rancho PPSG@hotmail.com

How to contact OC Support Group:

Call us for information:
Marte Fuller **562-697-0507**
Marilyn Andrews **714-839-3121**

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renison@cox.net

Agenda ideas for PPSG of OC?
Please call Aleta at 949-559-7102 or email Priscilla at prisofoc@aol.com

We accept donations. 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.

Rancho Los Amigos Meeting

Safety in the Home

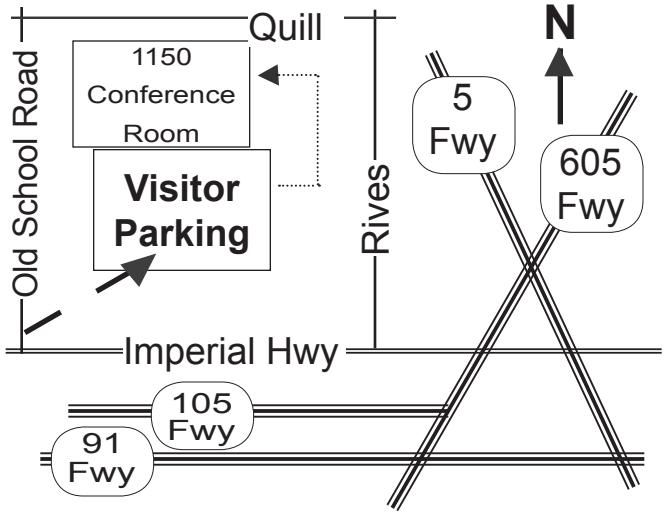
by **Deborah Levan**

Saturday March 28

2 - 4 PM

Future Rancho SG Meetings

To be announced



We meet **4th Saturdays 2 - 4 PM**
Rancho Los Amigos
National Rehabilitation Center
7601 E Imperial Hwy Downey
1150 Conference Room
Support Service Annex

Orange County Meeting

Susan Knopick

Annuities and Charitable Giving

Saturday March 14
2 - 4 PM

Future PPSG of OC Meetings

- **Saturday April 11** **Mark Potter**

ADA LAWS

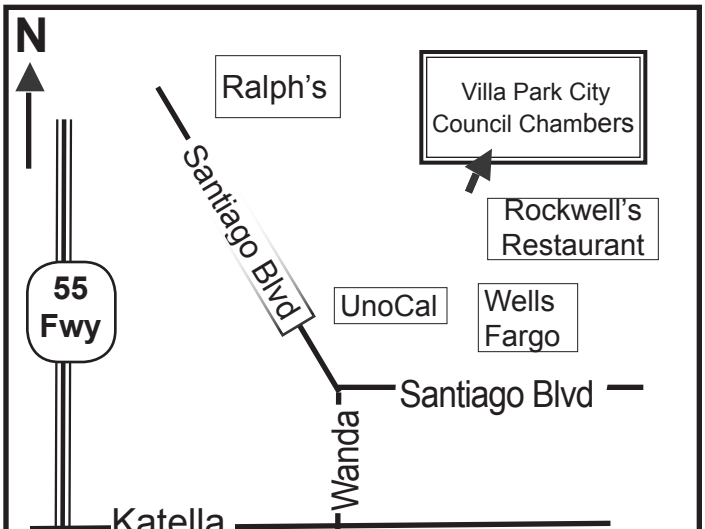
- **SUNDAY MAY 17th**

Dr. Susan Perlman

Post-Polio Syndrome Update

- **Saturday June 13th**

OPEN SHARING of ideas, concerns, gadgets & Suggestions in a relaxed setting.



We meet **2nd Saturdays** 2 - 4 PM
Villa Park Council Chambers
17855 Santiago Blvd. Villa Park
May meeting usually 3rd SUNDAY
December at Rancho in Downey