

PPASS Times

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On the Web at [Http://www.ppassmn.org](http://www.ppassmn.org)

From Where I Sit

By Nancy Gosz, Chair

Nancy had this column turned in in plenty of time to meet a December publication date. However, your editor was busy unwinding from his November cruise, dealing with the holidays, and computer issues and so didn't get around to publishing until now. I apologize! I trust that Nancy's sincere holiday wishes are not too late. May I also add my wishes for a very prosperous New Year? Incidentally, I have also decided to do a double issue to close out 2006 and start 2007 on schedule.

I wish there was a way for this column to be interactive because I really wonder how many of you share my feelings. Right now they are something like this:

- ◆ Wow! The holidays are here.
- ◆ I love Christmas!
- ◆ I love bringing in the New Year.
- ◆ I have so much fun "decking the halls," filling our home with the sights, smells and sounds of the season"!!
- ◆ I get more excited every day.

Yes, all of that is true. I really feel that way. But I guess I've developed a multiple personality disorder. There is, within me, another whole set of feelings. Something like this:

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Post Polio International Conference

April 9 – April 11, 2007

(Begins April 9 at 12:30 pm and concludes April 11 at 4:00 pm)

Radisson Hotel Miami Downtown

1601 Biscayne Blvd., Miami, FL 33132

Reservations: (800) 342-7499 or (305) 374-000

www.radisson.com/miamifl_downtown

"Partnering for a Better Tomorrow"

- P Partnerships to enhance quality of life
- P Pride in our history and power to improve our lives
- S Strength to survive

Hosted by:

The Post Polio Assn. of South Florida

&

The International Post Polio Support Organization

Speakers Confirmed to date:

Dr. Carol Vandenakker, Post-Polio Clinic at UC Davis Medical Center, California
Dr. Khema Sharma, Medical Dir., University of Miami Post Polio Treatment Education, & Research Centre

Dr. Ashok Verma, University of Miami Neurology, PPS Clinic

Dr. Andrew Sherman, University of Miami Rehabilitation Medicine, PPS Clinic

Cynthia Henley, P.T. & Kat Wollam P.T., PPS Clinic

Ginger Irving, St. Catherine's Rehabilitation Hospital Administrator, PPS Clinic

Mike Kossove, Professor of Microbiology, Touro College, NY

Dr. Hubert Rosomoff, Medical Dir., Rosomoff Comprehensive Pain Center

Ann Lee Hussey, Rotarian Action Group for Polio Survivors and Associates

Bill Norkunas, ADA Help, Inc.

Phyllis Resnick, ADA Access Now

Linda Wheeler Donahue, Polio Outreach of Connecticut

Kimberley Dowds, Associate Director, Polio Canada

Reserve Hotel Rooms Early!

We have reserved a block of rooms at the Radisson at a special Conference Rate of \$119.

Ask for "Post Polio International Conference" block room rates.

Rates are based on availability and are good for 3 days before and after the conference.

Additional information available on our web site www.ppassmn.org

From Where I Sit

(Continued from page 1)

- ◆ Oh heck (or worse) the holidays are here.
- ◆ I can't stand Christmas-all the work! Shopping, wrapping, blah, blah, blah.
- ◆ I'm not awake long enough to bring in the New Year. And then do we have to have some kind of celebration the next day? I'm too tired!!
- ◆ I wish I didn't have all this decorating stuff (or worse) I don't know what to do with it all! Too much work! I'm too tired! And it all has to be put away in a couple weeks! Ugh!
- ◆ I get more depressed every day.

Yes, all of that is true too. I really have both sets of feelings, although the second list is increasingly surpassing the first. Crazy? No, just plain old PPS rearing its ugly head for the holiday season. Sure, I've cut back on all of the shopping, wrapping, decorating. And, it would be just about enough to cause my husband a heart attack if he came home to the smells of Christmas treats baking in the oven. Nope, he gets by now with the water I keep heating on the stovetop providing moisture to the dry winter air, with a few holiday smells thrown in. My new Christmas cookie recipe: 1 pot steaming water, a few cloves, 2 cinnamon sticks. I really wish I could find molasses sticks. Not very appealing but a whole lot easier than the smell of cookies baking.

And, however the splendid concept of name-drawing for Christmas gifts began, I will be eternally grateful. My family adopted that

idea a long time ago, thankfully since I have a very large family. Mike's family just came around a couple years ago, up until then we provided gifts for 19 Gosz's! (Not really as bad as it sounds, since we gave gift cards to the adolescents.) But, the wrapping alone was an overwhelming task. Now, of course we buy many less gifts. And, whoever invented gift bags to replace wrapping has my utmost respect and admiration.

Now we rejoice that we have become grandparents. But oh, oh. Some things have to be changed back to the old ways. Though we skipped putting up a tree two years ago, it's not an option anymore. Up goes the tree, the monogrammed stocking hangs from the bedecked mantle, the house is again filled with lights, music and of course, the Santa collection is once more spread all around. My biggest fear? - will there come a year when the little one asks Grandma why there aren't any cookies?! Likely we'll then see one more standard lowered; store bought, probably relatively tasteless goodies will be festively laid out on my Spode Christmas cookie plate. Oh, and of course the shopping is increased again - but such a fun little person to shop

for! And wrap seems more toddler oriented than bags. Its okay, he doesn't care about fussy bows, just slap 'em on. I can't complain about the extra work at all, just musing.....

Wow, all this holiday thinking has worn me out. I think I'll go plug in my electric tea kettle, turn on the gas fireplace, and sit back for a cup of Christmas tea. Sure wish I had a cookie to go with that tea.

Happy Happy Holidays to each of you!



Chapter Happenings

Owatonna

By Dick Baumer

The Owatonna Chapter held its last formal meeting on December 18. It had been announced in November that the chapter would disband after the annual Holiday Party in December. Declining attendance was due to a number of reasons but a general lack of interest was the main reason given in a survey conducted earlier in the year. Two members of the group passed away during the groups short existence. The small group that met



Those who attended the Holiday Party from left to right are Barb DeReus, Char Brage, Clarence Brage, Phyllis Otterness, Cheston Otterness

regularly agreed to get together on an informal basis in the spring or summer.

A fruit basket has been a door prize each year and was awarded by drawing a name out of a hat. Char Brage won it again this year. Everyone brought a dish to pass so as usual we ate too much.

Since this will be the last report from the Owatonna Chapter I will take this opportunity to thank everyone who supported the group from PPASS MN, the membership, including those that may have not become members but attended at least one meeting, and those in Owatonna that helped get the word out that a support group was being organized. Those folks and groups include Todd Hale, The Owatonna Today Show, The Owatonna People's Press, Senior Place, the two Rotary Clubs, and word of mouth by local friends and acquaintances.

St. Cloud

By Gale Erdmann

The Independent Living Center *Independent Lifestyles* is no longer providing a facilitator for our meetings. Toni Reif will send a thank you to them for their assistance over the last two years. Lin Holder and Gale Erdmann, from District 742 Community Education, are taking over the coordinating and facilitating responsibilities in the future.

The December meeting will be a Holiday get together at G-Allen's in Sartell. The topic for the meeting will be a discussion on what do we want to do next year? Members should bring ideas.

The book *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome* by Lauro S. Halstead has helped many, especially with a new diagnosis in the beginnings of PPS. We now have a 2nd edition in our Post Polio library.

Our speaker for the November meeting was Arnie Tilleson from the St. Cloud Hospital. He spoke on the two different types of pain and what pain medications work for each. There is:

1. Localized or acute pain such as wounds - use aspirin or opiates
2. Neuropathic pain - use antidepressants

Neuropathic pain is an actual disease, a breakdown of the nervous system which can be caused by a number of different sources, including post polio syndrome. He also discussed the questions:

- ◆ How long you can be on an antidepressant
- ◆ Why some people are so sensitive to these medications (especially the elderly)
- ◆ What happens when going on or coming off an antidepressant,
- ◆ And the reason why some individuals are so sensitive to pain.

Note:

Gale Erdmann has been working for the St. Cloud Area District 742 Community Education Adults with Disabilities Program for 20 years. The program provides educational and recreational activities for people with disabilities, resource referral and assistance to organizations serving people with disabilities. The program has been providing support to the St. Cloud Area Post Polio Group for several

years in the form of hosting the meetings in their building, sending out meeting reminders and membership notices, typing up minutes and anything else the group may need.

West Metro

By Larry Kohout

November was our traditional end of year or holiday party. Once again we met at the Cherokee Sirloin Room in West St. Paul. While your reporter couldn't be there (he was sailing in the Caribbean at the time) he understands that a wonderful time was had by all. The Cherokee Sirloin Room is wonderfully accessible to those of us using various mobility devices, and they always provide us with a private room.

In December we had Russ Drangeid and Ken Ottum from Reliable Medical Supply come in to talk to us about the use of various breathing aids: like machines such as both the Continuous Positive Airway Pressure (CPAP) devices and various ventilators, and oxygen (O²) in all of its delivery methods. One of the biggest problems with all this type of equipment is that when a patients first go on the equipment in the hospital they are given no training or even given any kind of choice. There are almost always several different types of machines that will do the same job and one or another of the machines may well be a better choice for the patient. People need to know that they have a choice in equipment types and styles and they have a choice of suppliers. They also need to get

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Chapter Happenings West Metro

training from a supplier about their choices and then how to use and do any needed maintenance.

The first types of equipment that Russ talked about were those dealing with oxygen. The very first misconception that he wanted to address is that O² does not burn. It greatly enhances a fire that is started but by itself it does not burn.

He then talked about the different types of equipment available. An O² concentrator is a machine that takes the O² out of the room air and uses it to deliver to the patient. This machine needs a power source as it runs on electricity. These machines are always comparatively large and therefore not very portable. Having said that there are some that run on DC electricity and so can run off of a battery or the power in a person's car.

Then there are the portable tanks in many different sizes and cost levels. Portable tanks are filled from another source and then can be carried around fairly easily. Some are mere O² cylinder that are fairly big and don't allow a great deal of time away from the main filling source. Others are very small and can be carried on your hip. One of the things that determines the amount of time that a portable tank can be used is the regulator. There are continuous flow regulators that are less expensive but use the O² faster. Then there are on-demand regulators that are more expensive and also conserve the O² better.

Then there is liquid O² that is used

to fill the portable tanks. The liquid O² produces pressure as it warms and this is used to fill the portable tanks. If the liquid tank is just sitting for a period of time there will be an audible hiss as the pressure is vented off the tank.

Lastly, there are the interfaces that deliver the O² to the patient. These can be in the form of a cannula, the device that sits under the patient's nostrils and allows the O² to flow directly into the nose. Masks can fit just over the nose or just over the mouth or it may cover both the mouth and nose. Finding a good fit shouldn't be a problem since both the cannulas and the masks come in a variety of styles.

We then moved on to the class of machines that are loosely grouped under the heading of ventilators. The CPAP was the first machine covered and this, strictly speaking, is not a ventilator. As the name implies this machine delivers a continuous flow of air to keep the patient's airway passages open to allow breathing. This is most often used to treat sleep apnea, a condition in which the patient spontaneously stops breathing, either from obstructive apnea or from central apnea. The next machine is a Bilevel Positive Airway Pressure machine (BiPAP). This is the first machine actually classified as a ventilator. Unlike the CPAP, the BiPAP gives an inspiration flow of air and the drops its pressure for the expirational air flow. This is used when a patient has such weak breathing muscles that they cannot exhale against the continuous flow of air at the higher pressure. Additionally, there are several varieties of BiPAPs some with a fixed Ipap (inspirational

positive airway pressure) and a fixed Epap (expirational PAP), and then there are a number of machines referenced as ST for spontaneous/timed. These deliver an air flow according to the patient's inspiration and expiration but when the patient does not breathe for a fixed time period, the machine steps in and delivers a breath anyway.

The next class of ventilators are all positive pressure ventilators. There is also a class of ventilators that works on negative pressure (like the iron lung) but these are mostly obsolete and were not discussed. Ventilators deliver a breath to a patient depending on the doctor's prescription. The volume and rate of breaths are both adjustable, and the machines have a wide range of sensing devices and alarms. Ventilators can deliver breaths to a patient either through a mask interface or through a tracheostomy depending on the patient's needs and the amount of time that the ventilator is used each day.

Some of the issues raised during the presentation were:

- ◆ How did I end up with the company I had when I left the hospital?
- ◆ I paid for a week of therapy thinking that I'd learn what I learned today.

What we each need to know is that there are almost always choices and that we need to speak up and make it clear to our doctors or the technicians in the hospital that we want to clearly understand what we are dealing with and what exactly our choices are.



One Psychologists Perspective on the Polio Experience: Emotional Intelligence: An Introduction

By Margy Hull, Ph.D

Last time, I presented ideas about the “perky, plucky, patient persona” as something that I, and many others who have had polio, have adopted as a way to cope with others and our own feelings. It occurs to me that our direct or indirect role model in this may have been FDR. Hugh Gallagher describes him this way in his book *FDR’s Splendid Deception*:

The characteristic tilt of his head; the famous smile; the infectious, hearty laugh; the jaunty cigarette holder; the military cape; the old, floppy fedora – it was by such means that he was able to project and enlarge his presence (p. 213).

Is that perky and plucky or what? Even for those of us who had no memories of his time as president, his influence has been felt through the tremendous effect he had on the whole rehabilitation movement. The expectation that all disabled people can improve their lives if they meet the challenge with zest and hard work replaced the earlier expectation that those who were crippled should stay out of sight and out of mind.

I’ve been thinking a lot about FDR since my book group recently chose *No Ordinary Time* by Doris Kearns Goodwin which describes the way Franklin and Eleanor led us through the harrowing period of the Second World War. She described the

impressions of people who had known Franklin Roosevelt before and after he had contracted polio at age 39, and often they described a profound change in his personality. The following is a summary of some of these descriptions:

Yet the paralysis that crippled his body expanded his mind and his sensibilities. After what Eleanor called his “trial by fire”, he seemed less arrogant, less smug, less superficial, more focused, more complex, more interesting. He returned from his ordeal with greater powers of concentration and greater self-knowledge. “There had been a plowing of his nature,” Labor Secretary Frances Perkins observed. “The man emerged completely warmhearted, with new humility of spirit and a firmer understanding of profound philosophical concepts.”

There were other qualities that might be perceived as less positive, his apparent inability to get close to anyone, his love of gossip and small talk, his occasional tendency to use people to further his own ends without regard to their own well-being and to tell them what they wanted to hear, even to put them in competition with each other to see what would happen. Some of these good and bad qualities were undoubtedly an exaggeration of quirks in his personality that were inherent in the temperament he was born with and the family environment in which he grew up. But the exigencies of living with polio also seem to have had an effect.

The complexities of these influences are a good reminder not to over generalize about people, that we are all individuals and vary in our temperaments, our childhood experiences, the age at

which we contracted polio, the severity of the initial disease and post polio symptoms, and the kind of environment in which our treatment and recovery occurred. It is endlessly fascinating to me the varied ways that we have reacted to these experiences. Indeed, many of us have invested much energy in passing as normal, outdoing our colleagues at every opportunity, and thus can be accused of having Type A personalities. Many of us have experienced varying degrees of rejection or abuse that have cost us injuries to our self-esteem or made us more anxious. Still there are also ways that many of us have been made stronger, more resilient, more empathic toward others who have suffered.

Indeed, many of us have invested much energy in passing as normal, outdoing our colleagues at every opportunity, and thus can be accused of having Type A personalities.

I would like to begin a new series of articles looking at some of these varied influences through the lens of emotional intelligence. This is a concept that has received a great deal of attention since the book by that name written by Daniel Goleman came out in 1995. General intelligence has been looked at from all angles and described in many ways by psychologists over the last 200 years, yet it is still difficult to give a succinct definition. Often we say in frustration “it’s what

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One Psychologists Perspective

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intelligence tests measure.”

Howard Gardner breaks it down into seven domains: verbal, mathematical-logical, spatial, kinesthetic, musical, intrapersonal and interpersonal.

Goleman lumps the last two together and calls them “emotional intelligence”. He is talking about those qualities that use information from the emotional centers of our brains that enable us to determine personal relevance and the most effective ways to achieve our goals in relationship to other people in the real world. Briefly, these qualities are insight, the ability to manage emotions, motivation, empathy, and skill in handling relationships. He presents evidence from case studies of people with brain injuries that, contrary to conventional wisdom, integrating emotion with reason makes us not less, but more wise. Without emotional intelligence, you may be the smartest mathematician, the most agile basketball player, the most articulate writer, the most visionary architect, but your efforts are at risk of coming to naught.

Daniel Goleman’s first book has led to a large number of other books and workshops describing emotional intelligence in the workplace, in management, in relationships and many other venues, and prescribing ways in which this quality can be increased. Although other aspects of intelligence may be more in-born and dependent on early life

experiences, emotional intelligence seems to be more amenable to enhancement once we understand what it is and how it works and what experiences can make it grow.

In my next series of articles, I would like to explore, one at a time, each of the five qualities that make up emotional intelligence in terms of the varied ways that the experience of polio has influenced each of them. In doing this, we will again look back at what we can learn from FDR as our exemplar, and also think about ways that we can further develop each quality to the extent that development would be beneficial.

Margy Hull Ph.D. is a Psychologist who formerly worked in a community mental health center in Atlantic County,



Post-Polio Forum

By Richard Bruno Ph.D.
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Dr. Richard Bruno is Chairperson of the International Post-Polio Task Force and director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center. E-mail him at ppsforum@newmobility.com.

Note: This column is for information purposes only and is not intended as a substitute for professional medical advice.

Last month, I described the upset caused by the publication of a Mayo Clinic 2006 press release and paper, describing a 15-year follow-up study of 38 polio survivors that generated the media headline, *People*

Who Survive Polio In Childhood Will Not Suffer Further Effects Later In Life. In spite of their admitting that they failed to include a control group of non-polio survivors of the same age, Mayo researchers nonetheless stated that post-polio subjects lost a "normal" number of motor neurons over 15 years, that is, 45 percent. Because of that "normal" loss of neurons, the authors concluded that post-polio subjects' reports of progressive muscle weakness and a measured 18 percent decrease in muscle strength were caused by "aging alone," and that polio survivors therefore "did not age any differently than a normal population."

Last month, I described the upset caused by the publication of a Mayo Clinic 2006 press release, describing a 15-year follow-up study of 38 polio survivors that generated the media headline, *People Who Survive Polio In Childhood Will Not Suffer Further Effects Later In Life*.

What the Mayo press release and paper didn't tell you was that the 2006 article was the last of three articles by the same authors. The first paper was published in March 2005 in the journal *Neurology*. That paper noted the 18 percent increase in muscle weakness on subjective muscle strength tests and the 45 percent loss of motor neurons. But, it also reported the results of quantitative tests of muscle strength, measured objectively by machine, plus hand and finger dexterity measured using

standardized tests. Those tests found polio survivors had an overall decrease in muscle strength of 21 percent: 8 percent in the thighs, 14 percent in the muscles that lift the feet, 25 percent in the upper arms, and 31 percent in grip strength. What's more, subjects had a 25 percent decrease in hand dexterity and a 55 percent decrease in finger dexterity.

As opposed to the 2006 article, the authors admitted in the March 2005 paper that "We did not include a normal control group," and stated, "In the absence of a normal control population, the effects of aging ... cannot be commented on. How the changes identified in our polio (subjects) compare with those of a normal aging population remains unknown." This article did not conclude that "the decline in our polio survivors is aging alone" or that "people who survive polio in childhood will not suffer further effects later in life." In fact, the authors stated, "The syndrome of progressive weakness late after paralytic poliomyelitis was quite common."

Then, in September 2005, the authors published their second study of the same subjects in , this time describing "adaptive equipment use." In 1987, 13 percent reported using a brace or "gait aid" (presumably a cane or crutch), 16 percent had been forced to change jobs and 13 percent had modified their homes due to muscle weakness.

Fifteen years later, an additional 12 percent had to modify their homes or move because of weakness, and there had been a 100 percent increase in subjects using a brace or aid. What's more, 40 percent of those originally using

just a brace or aid were now using wheelchairs.

The 2005 studies -- presenting objective findings of progressive muscle weakness, loss of function and increased assistive device use -- certainly do not support the 2006 declaration that polio survivors "will not suffer further effects later in life." Why did the authors ignore their own published findings of muscle weakness and loss of function from the 2006 paper and change their conclusion from how polio survivors bodies "compare with those of a normal aging population remains unknown" to "our polio survivors did not age any differently than a normal population?" I haven't a clue. And I don't think it's important to know. What is important is the fact that studies of thousands of polio survivors -- not just "the Mayo 38" -- show that the PPS are real and are not "normal" again.

It's also important, in this age of the 24-hour news cycle and the Internet, that we become extremely cautious when medical research is "published" via press release and the media. Medical "facts" change in the media from week to week. Chocolate causes obesity, then it fights cancer; a daily glass of wine leads to alcoholism, then it prevents heart disease. For PPS -- or for any condition -- we need to do the hard work of reading the actual research studies, not just newspaper articles or press releases, to understand what's really happening to our bodies and know how to care for ourselves.



Background – San Diego Zoo

Editor's Note: Some time in 2003 or 2004 the San Diego Zoo and Wild Animal Park began a policy of stopping all people using motorized transport (wheelchairs and scooters) and asking them to sign a liability waiver.

As one of two plaintiffs in the Kneeshaw vs Zoological Society of San Diego lawsuit, I spent the greater part of two years wondering what on earth would have possessed the San Diego Zoo and Wild Animal Park to institute such a discriminatory, flawed entrance policy. When asked by Larry to give a *brief* summary (brevity not being my long suit) of the Zoo's thinking process, I found myself scraping the bottom of the proverbial barrel looking for any reason with merit. In my estimation, there was none. ADA laws were introduced for one simple reason: the eradication of discrimination against persons with disabilities. In simple terms, it is **not** okay to single out the disabled and treat them differently than you would the able-bodied.

Long before searching for a lawyer to represent this issue, Rick Kneeshaw tried to personally correspond via letter with the Zoo requesting that they stop this hurtful policy. He explained that as a long time member of the San Diego Zoo he found this new policy upsetting. The policy was to pull from line anyone using a motorized scooter (or wheelchair) and ask them to sign legal documents as a condition of entry. The Zoo felt they were justified in

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Background – San Diego Zoo

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treating the mobility challenged differently, and according to their statement by their spokesperson, Christina Simmons, printed in the San Diego Union-Tribune article dated November 16, 2005 (the day our lawsuit was filed in Federal Court), the Zoo stated the following: "...the zoo's policy on motorized vehicles applies to all people who use them in the parks, not just disabled people."

It was, however, the disabled entering the park on personal assistance devices: power wheelchairs and motorized scooters, who were being singled out, pulled from line, embarrassed and humiliated by questions at the busy entrance turnstiles, while others filed by staring and wondering what we had done wrong. Then we, different from other visitors entering through the turnstiles, were asked to sign waivers as another condition of entry stating we would be taking responsibility for anything that should occur while in the park on our power wheelchairs/motorized scooter, whether or not we were at fault. This was the ultimate insult. Even those, such as I, who refused to sign, were not exempt. Wording in the waiver stated that if you received the waiver, agreement to the terms was implied whether you signed or not. The fact that so many people blindly signed those documents/waivers was rather frightening. As our lawyer put it, this is an example of how easy it is for people, without understanding the consequences, to just give up their rights.

San Diego Zoological Society Settles Discrimination Case Entrance Policy for People with Mobility Disabilities at the San Diego Zoo and Wild Animal Park

Editor's Note: The following is a press release from the Disability Rights Legal Center in San Diego California

SAN DIEGO (NOVEMBER 29, 2006) – The Disability Rights Legal Center (formerly Western Law Center for Disability Rights) announced today that it has reached a settlement with the Zoological Society of San Diego to end what it alleged were discriminatory practices against people with mobility disabilities. The settlement was reached in the federal suit *Kneeshaw v. Zoological Society of San Diego*, Case No. 05-CV-2127-IEG DT (POR), and covers both the World Famous San Diego Zoo and the Wild Animal Park.

As a result of the settlement, the Zoological Society will permanently discontinue its policy of asking people who use motorized mobility aids, such as motorized scooters and wheelchairs, to sign liability waivers or any document regarding their use of such aids in the Zoo or Wild Animal Park. As for previously signed waivers already on file under its prior entrance policy, the Zoological Society has agreed to void all such waivers and never enforce them. In addition, it will notify those who have signed or been deemed to have signed the waivers by putting a notice on its website, its maps, its accessibility guide, and via letters to those who had been subject to the previous

policy.

"We are extremely pleased that we were able to reach a resolution with the Zoological Society" said Shawna L. Parks, Director of Litigation at the Disability Rights Legal Center, the nonprofit legal organization that represented the plaintiffs. "The settlement allows people with mobility disabilities to once again enjoy their visits to the Zoo without hindrance or discrimination. The Zoo agreed to do the right thing here."

As a result of the settlement, the Zoological Society will permanently discontinue its policy of asking people who use motorized mobility aids, such as motorized scooters and wheelchairs, to sign liability waivers

Named plaintiff Gladys Swensrud, a long time member of the Zoological Society, was very pleased with the result. "Although I'm sad about the time I lost at the Zoo, I eagerly look forward to resuming my visits to the Zoo with my friends and seeing the animals together," she said.

The settlement represents a major victory for people with mobility disabilities who use motorized scooters and wheelchairs. In November of 2005, plaintiffs Rick Kneeshaw and Gladys Swensrud, both polio survivors, motorized scooter users and long time members of the Zoological Society, filed the lawsuit against the Zoological Society claiming that the entrance policy, which mandated that motorized wheelchair and

scooter users sign a liability waiver in order to enter the Zoo, unlawfully discriminated against people with mobility disabilities.

Under the Zoo's policy, persons who used motorized wheelchairs and scooters were pulled from line, presented with a series of documents, and required to sign a waiver and indemnification agreement before being allowed to enter the Zoo. The waiver placed all liabilities and risks on the person with a disability for incidents at the Zoo involving the mobility device, even if the Zoo or its employees were at fault. No other Zoo patrons were subjected to this treatment or forced to sign such waivers in order to visit the Zoo. The suit alleged that the Zoo violated the Americans with Disabilities Act and California civil rights laws, and sought a court order to remove the illegal and discriminatory policy and waiver requirement.

"I'm glad that we were able to convince the Zoological Society that it is the right thing to do to stop this policy. I just wanted to bring my granddaughter to the Zoo. She was looking forward to seeing the elephants, and I was so embarrassed to be pulled out of line, and treated like a criminal in front of my granddaughter," said Mr. Kneeshaw. "I'm glad I got to show my granddaughter that it is important to stand up for our rights and make a change for the better. I can't wait to go back to the Zoo."

The plaintiffs were represented by the Disability Rights Legal Center, a thirty year old non-profit organization that protects the civil rights of individuals with disabilities.



Popular Heartburn Drugs Linked to Hip Fractures

Nexium, Prilosec may make it harder for body to absorb calcium, study says

Information derived from reports on MSNBC, Fox News, and NPR

A large study in Britain, and reported in a recent edition of the *Journal of the American Medical Association* found that taking such popular heartburn drugs as Nexium, Prevacid or Prilosec for a year or more can markedly raise the risk of a broken hip in people over 50,

The study raises questions about the safety of some drugs taken by millions of people. These are some of the most widely used and heavily promoted prescription drugs on the market. According to IMS Health, a corporation that tracks drug sales all over the world, Nexium is one of the most popular drugs in the world, second only to the cholesterol drug Lipitor. Sales of Nexium totaled \$4.6 billion in 2005.

Researchers speculated that reducing acid in the stomach also makes it more difficult for the body to absorb calcium. Since calcium is a bone-building mineral, this can lead to weaker bones and fractures. The authors of this study suggest that when proton pump inhibitors decrease the acid content of the stomach, the body may lose some of its ability to absorb calcium, which can potentially lead to weaker bones and teeth.

Since hip fractures are one of the leading causes of death in the elderly, doctors should make sure their patients have good reason to stay on heartburn drugs long term.

The study also indicates that another class of drugs that is used to suppress the discomfort of heartburn - known as H2 blockers - also poses a similar but smaller risk of paving the way to developing hip fractures. The most popular H2 blockers on the North American market are Tagamet and Pepcid.



Stairs – They Are A Hurdle!

By David Holland

Norah and I have lived in our home, here in Langley, since June of 1980. Our two children, Fraser and Julee, grew up here, went to school and college from here, and of course we have had numerous gatherings of both family and friends join us in our home. Throughout the years we have made our home to suit our needs, and are comfortable here. During the course of the last few years we have looked on many occasions for a single storey rancher due to the stairs becoming more and more of a hurdle – PPS for me and Spinal Stenosis for Norah. Ranchers that would accommodate our furniture (including my model railway!), be situated on a secluded ¼ acre lot backing onto a salmon creek, and be within easy reach of stores, doctor, dentist, pharmacy and post office were not

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Stairs – They Are A Hurdle!

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available – what were we to do?

In 2004 and again in 2005, AG-37 Langley organized a mini trade show and symposium to which various medical equipment suppliers were invited, and several exhibited their products. In 2004 I obtained information from Terry Lock of Shoppers Home Health on stair-lifts (with Norah's needs in mind). In 2005 the same situation occurred, but this time Norah obtained the information from Terry, but with my needs in mind this time! Terry drew up a quotation, including various options, and we pondered. By 2006 our needs were becoming more pressing, so we took the plunge and finalized the order.

The process of ordering the stair lift was very simple due to Stannah having a specialized template system that is photographed in-situ using a digital camera, the file is then e-mailed to Stannah (in England), layout plans were then produced within 10 days and e-mailed back. These were then checked for accuracy at the job-site, and signed off for approval. The unit was then manufactured according to the layout plans, and shipped within 6 weeks. Our installation took two men approximately a day and a half to install, with very little fuss or mess. I might add that the entire unit is attached to the stair treads NOT the banisters, so can be removed with very little or no damage to the stairs. Last but not least, the chair is battery powered with the battery being charged every time

the chair reaches the upper or lower park positions, resulting in it being operational during any power outage.

We know one thing – it is a lot less stressful and cheaper to install a stair lift than having to go through a house move! We'll be here for the duration!



Stair lift at top of stairs on landing



Stair lift at lower station with stairs in view

Kaiser/San Diego's New Respiratory Program

By Gladys Swensrud

Reprinted from *The Southern California PPS Manager* by permission

With tremendous gratitude to Don Baisch, my breathing buddy. Without his help, this goal may never have been realized. We learned through our shared experience that there is, indeed, strength in numbers...even when that number is as small as TWO.

For over three years I founded (I say that lovingly) my HMO, Kaiser/San Diego, to recognize that they had little understanding of the neuromuscular respiratory component related to my motor neuron disorder, Post-Polio Syndrome. As early as 2002, I knew the Continuous Positive Airway Pressure (CPAP) therapy, which had been prescribed by my neurologist the year prior, was not improving the symptoms I was experiencing. Those were: excessive fatigue from the moment I awoke in the morning, awakening in the night gasping for air, voice falling away when I tried to speak, etc. I could sense that my condition was continuing to deteriorate.

After much research and reading, I shared my concerns with my pulmonary care doctor that CPAP might not be the right treatment for me as a patient with issues of old polio; I suggested I should probably be using Noninvasive Positive Pressure Ventilation (NPPV) delivered through a bi-level machine instead. I was not, however, able to identify how the

change in machines would most benefit me. He kept testing me, yet through the traditional testing methods, my results continued to indicate everything was “within the normal range.” Thus a change to bi-level treatment was not indicated at that time.

I was still on the uphill side of the learning curve, so as they say, I did not yet know what I did not know in order to help myself. Thus I used my CPAP, faithfully night after night, hoping for improvement.

With information supplied by . . . PPS Manager, Rick Van Der Linden, in September of 2003, and through the educated coaxing of Helen Kent, owner of Progressive Medical, I began to search outside of my healthcare system for answers and solutions. Helen understood the mechanisms involved in neuromuscular respiratory compromise. She and her staff took me under their wing, created a program to meet my respiratory needs, and their intervention was instrumental in not only improving my quality of life, but I actually credit them with having saved my life.

Shortly after my breathing needs were back on track, I began requesting that my HMO investigate this new program and incorporate it into my care. I knew if Progressive Medical held a special key to understanding neuromuscular respiratory issues, then certainly Kaiser/San Diego would want the same level of understanding to share with clients and patients. I knew through my interactions with Progressive Medical that they were also servicing the breathing requirements of other disorders like Amyotrophic Lateral Sclero-

sis (ALS), Muscular Dystrophy (MD), Multiple Sclerosis (MS), and Parkinson’s disease (PD). The fact that each of these neuromuscular/neurological disorders had a respiratory component similar to Post-Polio Syndrome intrigued me.

By spring of 2004, I was still actively writing letters and sending my concerns to everyone I could connect with inside Kaiser/San Diego. I kept reiterating that neuromuscular breathing problems were different than normal Obstructive Sleep Apnea (OSA) issues, and the care of patients with this problem should be recognized and treated differently; the status quo was not working for me, and it likely was not working for others experiencing breathing symptoms of old polio.

Coincidentally, at this same time, through my alliance with the San Diego Neuro Network as the post-polio representative, I became closely aligned with reps of ALS, MD, MS, and PD. I became more and more aware that clients from their agencies had the same serious potential as survivors of polio for respiratory compromise. With this additional information, my focus widened at how I needed to impress upon Kaiser/San Diego the need for a respiratory strategy to cover these groups as well. If their situation was at all like mine, their respiratory problems could be widespread and equally as important to their overall health.

Although I am sure that scattered bi-level care might have been prearranged for specific individuals, I could see that, in general, Kaiser/San Diego, like all HMOs/PPOs of which I am aware, had no plan in place for this cluster of people

struggling with breathing issues related to a respiratory component complicating their neuromuscular conditions. My personal doctors had been in tune and involved in my breathing progress. But even as I won my personal breathing battle by receiving an outside agreement between my HMO and Progressive Medical to carefully monitor my breathing care, and even with the interest and support of my pulmonary care physician, I could not impress upon Kaiser/San Diego’s “powers that be” that there was merit to the thinking that all neuromuscular patients might need the same pulmonary support I was eventually afforded.

Over a three year period, I took my breathing concerns to my local membership services representatives, to regional membership services, to Kaiser/San Diego’s mediation process departments at the highest levels, and I challenged their thinking at the state level twice by appealing to the Department of Managed Health Care. Each complaint or appeal was denied. However with each rejection, I gathered more and more information to present the next time I made an appeal, so I continued to press forward with my concerns. What I found through this process was that Kaiser’s employees were well informed on the issues and often wanted to be of further help, but until the wording of my request was even clearer and more concise, they could not assist me in moving forward to a successful outcome.

Finally, on December 30, 2005, I decided to bypass all the middlemen, and I wrote a letter explaining my plight, and that of my dear

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Kaiser/San Diego's New Respiratory Program

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friend, Don Baisch, who had joined me a bit later in this challenge, to the Medical Center Director, who himself is a neurologist. Much to my amazement, by February 9, 2006, a meeting had been arranged for Don and me to present our concerns to a panel, which included the Assistant Medical Center Director, an administrator in the Department of Neurology and an ombudsman mediator. It was my one big chance to express the specific issues I had been voicing for three years to someone who might have the power to actually create change. I meticulously prepared my presentation, and I, with the support of Don, presented it with a no holds barred approach. The end result is that Kaiser/San Diego listened, and they, indeed, heard.

The domino effect has been startling. Kaiser/San Diego developed a pilot, neuromuscular respiratory program that was up and running by the end of June, 2006. They have asked for and used Don's and my experience as they moved forward with development of their program. They will begin slowly, but all patients with PPS, ALS, MD, MS, and PD will be screened for a respiratory element to their disorder. The Neurology and Pulmonary Care Departments will be linked so any patient coming to or diagnosed by a neurologist or a pulmonologist for one of the above disorders will be automatically assigned to a pulmonary care physician for respiratory support.

The testing process has been specifically redesigned to identify neuromuscular ventilatory issues. If a patient does not immediately show signs of need, the system (through this initial testing) will have a baseline to begin monitoring them should they become symptomatic at a later date. And from the point of diagnosis, patients will be screened incrementally, about every 6 months, to watch for signs and symptoms of respiratory distress.

Those who are already in need of breathing support will move into an individualized program, which offers the professional attention of a Registered Respiratory Therapist (RRT) paired with a pulmonary care doctor. These patients will be prescribed a bi-level (S/T) machine with heated humidification therapy, set to values which meet their personal specifications. And as a topper to all of this, Don and I were informed that Kaiser/San Diego has hired a pediatric pulmonary care physician, who will join them in July of 2006, to care for the respiratory concerns of their youngest patients with Muscular Dystrophy.

As you can guess, I am still in awe that it has all unfolded so quickly. Naturally "quickly" is not quite the correct term since it took three years of work to bring this to fruition. However in my estimation, Kaiser/San Diego stepped up to the plate big time with their plan, and if they implement it as it was designed to be implemented, they will meet Don's and my greatest expectations. It should be noted that this is a work in progress, and Kaiser's progress will be measured slowly as they develop the program. Don and I respect that

this stairway to success will not happen in a day, but the plan and treatment algorithm that Kaiser/San Diego has put into place assures us that it can be successful, and all neuromuscular patients within their realm of care could greatly benefit by this newly instituted program.

As we can see, Kaiser/San Diego's new program has implications far beyond just the bounds of this specific HMO. Don and I are very excited to watch it all unfold; it validates our multi-year commitment to see this change occur, and it finally takes us down the long pathway to a successful outcome.



Editor's Note: In early December I got the following note. It is reprinted here with Sally's permission.

Larry,

I met you several years ago at a PPASS meeting off HWY 280. I first attended by myself & then attended again with my sister, Mary Kay Holasek. I came across several copies of the PPASS Times at Mary's home this past week. Mary passed away last Wednesday, November 29. After battling polio & post polio for 50 years, we never dreamed that inflammatory breast cancer (IBC) would take her life. She was diagnosed with cancer in October & we have learned that by the time one is diagnosed with IBC, most times the cancer has already spread too far.

I know Mary did not attend your meetings much but the group & newsletter were a source of support for her. Thank you for that...

Sincerely,

Sally Flesland

Telephone Tax Rebate

Editor's Note: The following information regarding a tax deduction was passed along by our trusty accountant, Art Sauter. Art suggests that you not use more than the recommended amounts unless you have receipts for everything. There have already been IRS examinations of those who have.

FS-2007-1, January 2007

This year, telephone customers can request a one-time refund of taxes they paid on long-distance and bundled telephone service. Individuals, businesses, and tax-exempt organiza-

tions can request this refund as a credit on their 2006 federal income tax returns.

Over 146 million individuals and more than 14 million businesses and tax-exempt organizations are expected to request the refund. This includes millions of people and organizations who don't normally file returns, for example, low-income individuals (many of them senior citizens), churches, and small charities. The government estimates that telephone excise tax refunds totaling \$10 billion will be paid to individuals and another \$5 billion to businesses

and tax-exempt organizations.

The refund covers the three-percent tax paid on long-distance and bundled service billed after Feb. 28, 2003 and before Aug. 1, 2006. Several recent federal court decisions held that the tax does not apply to long-distance service as it is billed today. For that reason, the government stopped collecting the tax on service billed after July 2006 and authorized refunds of the taxes billed during the previous 41 months.

The federal excise tax continues to apply to local-only telephone ser-

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In Memory

of

Mary Kaye Hosasek



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Telephone Tax Rebate

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vice. Likewise, various state and local taxes and fees paid by telephone customers are unaffected and thus, not eligible for the refund.

Federal long-distance excise taxes paid on land line, cell phone, fax and Voice over Internet Protocol (VoIP) service qualify for the refund. This includes bundled service - local and long-distance service provided under a plan that does not separately list the charge for local service. Bundled service includes, for example, phone plans that provide both local and long-distance service for either a flat monthly fee or a charge that varies with the time for which the service is used.

Taxpayers can base their refund requests on the actual amount of tax paid. To do this, they must fill out Form 8913, Credit for Federal Telephone Excise Tax Paid. Individuals and businesses should attach it to their regular 2006 income-tax returns. Tax-exempt organizations should attach it to Form 990-T.

But many people don't want to dig through 41 months of old phone bills or lack the records they need to figure the actual amount of tax paid. For that reason, the government created a standard amount that individuals can use to request the telephone excise tax refund. The amount is based on the number of personal and dependency exemptions an individual is eligible to claim on their tax returns. The standard amounts are:

1 exemption - \$30;

2 exemptions - \$40;

3 exemptions - \$50; or

4 exemptions - \$60.

The standard amount is optional. To choose it, taxpayers fill in one line on their federal income tax returns. The line, labeled "Credit for federal telephone excise tax paid," is:

Form 1040, Line 71;

Form 1040A, Line 42; or

Form 1040EZ, Line 9.

For millions of people not required to file a regular income-tax return, the IRS has created a special short form for requesting the telephone excise tax refund. It is Form 1040EZ-T and is used exclusively for this purpose. Form 1040EZ-T can also be filed electronically for free via the Free File link on IRS.gov beginning in mid-January.

Form 1040EZ-T can be used to request a refund with either the actual amount of tax paid or the standard amount. Those choosing actual amounts must attach Form 8913.

The IRS wants to make it as easy as possible for taxpayers to get the refund they deserve. Accordingly, the agency has created a page on this Web site devoted entirely to the refund. To get answers to frequently-asked questions, download forms and get other helpful tips, visit the federal excise tax refund link.

Related Item: Telephone Excise Tax Refund

Advances in Neurologic Research as They Relate to Post-Polio Syndrome

With Susan L. Perlman, MD

Reported by Mary Clarke Atwood

Editorial Assistance by V. Duboucheron and S.L. Perlman, MD

This report is based upon Dr. Perlman's presentation to a joint meeting of the Rancho Los Amigos Post-Polio Support Group and the Post-Polio Support Group of Orange County on May 19, 2002.

As part of Dr. Perlman's efforts to educate others about PPS, she has recently completed an article on Post-Polio Syndrome (PPS), which has been reviewed and approved for Continuing Medical Education credit. It will be published shortly in the geriatric medicine literature. The focus of the article is to educate physicians about post-polio -- what to do, what not to do, what to look for, what post-polio is, and what it is not. This is her first of this type of article and she hopes more will follow.

Currently, Dr. Perlman divides her time at UCLA Medical Center between patient care, teaching, and research in genetic and neuromuscular diseases. Since 1985 she has seen more than 700 PPS patients in her Post-Polio Clinic at UCLA and credits them for helping her learn how to treat patients with PPS. This clinic has been on hiatus since July 2001 due to budget and staffing constraints. In her general neurology clinic there is very limited capacity to see new PPS patients, for one time only, to consult with staff and communicate with that person's outside doctor and try to develop a treatment plan.

Current Literature

Dr. Perlman cited thirty-two pieces of PPS-related literature that have appeared since May 2000. They focus on:

1. Causes of Post-Polio Syndrome



2. Fatigue
3. Brainstem Neuronal Injury
4. Drug Trials
5. Animal Models
6. Stem Cell Research
7. What Polio Survivors Continue to Need (and can't get in our current healthcare environment)

This report looks at some of those studies and Dr. Perlman's interpretation of them.

Understanding Post-Polio Syndrome

Noted neurologist Theodore L. Munsat, MD, in his 1991 book *Post-Polio Syndrome*, diagrammed a summary of what is occurring in some polio survivors. He uses a drawing of three interlocking circles of dysfunction that could possibly be presenting as complaints:

- ◆ The Signs and Symptoms of Neurologic Dysfunction
 - ◆ Probably 33-50% of polio survivors with new problems have some neurologic dysfunction that can be measured, defined, and treated.
- ◆ The Signs and Symptoms of Orthopedic Dysfunction
 - ◆ Others have mainly orthopedic problems: old orthopedic issues, surgeries, orthopedic deformities they have been living with, arthritis, and other problems that are mainly orthopedic in nature. Their neurologic system is exactly the same but their bones and joints are not holding up.
- ◆ The Signs and Symptoms of

Non-Polio Medical Dysfunction

Polio survivors are not immune to other medical conditions. It is quite common for a new complaint in a polio survivor to be a new medical problem. Dr. Perlman has seen neuropathies and complications from other medical illnesses affecting, for instance, breathing, while underneath these symptoms the polio issues have not changed at all.

The criteria for diagnosing PPS are: a history of polio, a 30-year average period of stability following recovery, gradual or sometimes apparently abrupt onset of new problems, which are usually fatigue and pain. But the hallmark is new atrophy and weakness.

A physician's evaluation might include an EMG that should show evidence of old polio; newer refined techniques will show changes that are associated with PPS also. Other medical or orthopedic conditions that might cause these same problems need to be excluded.

Newer research suggests...

These criteria may be too restrictive. There are polio survivors who had non-paralytic polio but are now having fatigue and pain that is indistinguishable from a person who had paralytic polio and is consistent with PPS. Thus the criteria for diagnosing PPS could be dangerous because a person might be sent to a psychiatrist for aches and pains that in reality are PPS and deserve further evaluation.

In May 2000, the Third Interna-

tional March of Dimes Conference on PPS tried to redefine those criteria and make them more realistic and usable. There will probably be more clinical research to define the best way to identify polio survivors who are having new symptoms.

Risk Factors

Marinos Dalakas, MD, a premier researcher in post-polio and other neuromuscular diseases, listed the risk factors more frequently associated with the earlier onset of post-polio syndrome. They are:

- ◆ Severity of residual disability -
 - people who had less to lose or had less initial recovery were more likely to feel it if they did lose a motor unit.
 - ◆ Somebody who had reasonable recovery with many residual motor units might be less expected to have problems further down the line.
- ◆ Individuals who had residual bulbar or respiratory signs are more sensitive to the later onset of symptoms affecting those areas. These people are strongly represented in the post-polio population.
- ◆ People who were older at the time of the original polio were thought to have less good recovery. If you were in your teens or in your 20s during the acute stage, you are more likely to develop PPS now.
- ◆ Individuals with recent injuries or falls, people who were immobilized in a cast for a while, or had weight gain are highly represented in the polio population with new complaints. This suggests some

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Advances in Neurologic Research

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physical stress on those motor units.

Another research project involved individuals who, during their plateau of normal adult activities, had been involved in exercise, sports, or work-related activities that caused pain in their polio limbs. It suggested that these individuals were more likely to have PPS symptoms 5 or 10 years later. This suggests that there was overuse or metabolic stress on those fragile recovered motor units.

Complaints of Post-Polio Individuals

Studies of more than 4,500 PPS individuals and their complaints show that the most bothersome symptoms are fatigue, weakness, usually in previously affected muscles, but sometimes in muscles not known to be affected, diffuse muscle pain, joint pain, cold intolerance, and muscle atrophy. The functional areas that people complain about the most are walking, stair climbing, and dressing. These are areas that rely heavily on the legs, tend to resist gravity, and demand a lot of energy to accomplish.

Newer Literature Adds PPS Knowledge –

What Post-Polio Muscle

Atrophy (PPMA) Is and Is Not

1. Causes of Post-Polio Syndrome

◆ Post-polio does not seem to have a genetic basis. The gene that affects Spinal Muscular

Atrophy, which affects the health of anterior horn cells, was not found to be abnormal. There is at this time no known genetic disposition to post-polio or to polio itself. (Bartholdi et al., SMA gene is normal Neuromuscular Disorders 10:99, 2000)

◆ There is accumulating evidence that there is a process going on that does not allow a recovered nerve to last forever -- that recovery may be only temporary when it does occur. A similar delayed progressive decline in survivors of other spinal cord related processes has been observed. This was reported on a person who had a spinal cord injury, experienced some recovery, and years later began to have a decline with new atrophy and weakness -- similar to what you would expect to see in a polio survivor. This has also been reported in survivors of Guillain-Barre syndrome.

(Narayanaswami et al., J Neurol Sci 184:11, 2001)

◆ An article about Taiwanese polio survivors suggests that PPS is not just normal aging of the motor units. There seems to be something intrinsic to the healed nerve that is causing it to fail sooner. These survivors are 10-20 years younger than their Western counterparts. (Chang et al., Spinal Cord 39:526, 2001)

◆ During the last two years no publications addressing the role of the immune system have appeared -- although several researchers at the March of Dimes Conference suspect

that the immune system could be playing a role and PPS could be an immune mediated disease. Dr. Perlman believes that the immune system will be an important area of future research.

What about persistent polio virus?

Dr. Dalakas at the NIH thinks that leftover pieces of the old virus may still be present in the nervous system, causing an immune reaction, but not an ongoing infection.

Girard, et al., have shown in mice that viral RNA does not replicate and infect, but may persist in an altered form. (J Gen Virol 83:1087, 2002)

2. Fatigue

One of the most bothersome symptoms of PPS is fatigue. There are many causes of fatigue in PPS -- primary neurologic fatigue that comes from the nerve itself. There could also be other neurologic diseases and non-neurologic factors that could be contributing to fatigue in an individual with PPS that need to be ruled out. Some of the most common conditions found are sleep disorders, depression, and the use of medications that contribute to fatigue, tiredness, and sleepiness.

There has been a lot published about central fatigue, peripheral fatigue, and brain fatigue. Richard Bruno, PhD, is the main researcher into central (brain) fatigue pathways. There are activating pathways for nerves in the brain that keep us awake, keep us energized, and focused. If the original polio affected these areas, obviously persons with PPS will be tired, sleepy, less focused, etc.

Most other research has been done on peripheral fatigue. Over the last 15-20 years there has been a lot of well-documented evidence that there are changes at the nerve endings -- changes at the nerve/muscle connection where a peripheral nerve turns into nerve endings and directly connects to muscle structures. In polio survivors with new fatigue those nerve endings are not as firmly attached as they might have been a few years ago; they seem to be dying back. On the muscle side, the nerve connection and the muscle membrane underneath it are never going to be the same as before polio. There are changes in the way the muscle membrane is activated; it is activated electrically and activated by calcium, which stimulate the proteins in the muscle to contract and give the muscle its strength and ability to perform as a muscle. All of these factors -- the activation, the ability to contract and generate strength, and the ability to relax -- are altered in polio survivors. The original thought was that the problem was the spinal cord or a nerve. It is now known that there are components in muscle performance that also are not what they originally were before acute polio and certainly not what they were during the plateau before PPS became a problem.

In order to determine where the fatigue is coming from and to develop strategies to treat it, researchers must investigate from the brain all the way down to the muscle and seek ways to intervene at every level. Many drugs and rehabilitation strategies that have been in use for PPS fatigue are aimed at all levels. More research needs to be done to learn if better

agents can be developed.

New Research on Fatigue

While not the hallmark of PPMA, fatigue is by far the most common symptom (>80%).

In a study of 120 patients, Klein, et al., reported decreasing strength, at a rate higher than normal aging, in upper extremities and flexors of the leg (stepping muscles, not weight-bearing). (Arch Phys Med Rehabil 81:1059, 2000)

One explanation could be that when you are weight bearing and your leg is extended, it is not repetitive motion. The stepping muscles go through an arc: they lift, they stand, they stretch, and they come down. So there is more repetitive movement in the stepping muscles as opposed to the weight-bearing muscles. Repetitive motion is more fatiguing.

Swedish researchers Sunnerhaagen, et al., discuss several types of fatigue in PPMA (Acta Physiol Scand 171:335, 2001). They looked at central fatigue, emotional fatigue, fatigue from deconditioning, and augmented peripheral fatigue. When a person is weak or fatigued he tends to exercise less and do less, then gets deconditioned, which adds to fatigue. Some of the recent research in exercise showed that aerobic and conditioning exercise can be well tolerated by polio survivors. Exercise can improve endurance, if done without fatiguing a person. Studies have shown that polio survivors will even benefit from very small amounts of conditioning exercise.

Most people involved in polio treatment and research think that

the majority of the fatigue that can be identified is called augmented peripheral fatigue. It results directly from expanded, enlarged muscle fibers that have fragile membranes and fragile nerve connections that activate more slowly, contract less well, or recover abnormally. This has been noted in studies of PPS fatigue. The things that would relieve fatigue in a non-polio survivor, like going for a walk, tend to make fatigue worse. Recovery from normal muscle activities takes longer in a polio motor unit.

3. Brainstem Neuronal Injury

(This is the basis of much of Bruno's work.)

- ◆ Non-paralytic polio did cause neuronal lesions and these survivors are at risk for PPMA (14-42%) (Bruno Am J Phy Med Rehabil 79:4, 2000)
- ◆ Word-finding difficulties in 79% of survivors with fatigue were documented by psychological testing and associated with decreased brain dopamine, a neuro transmitter that is involved in activating the brain.

(Bruno, et al., Am J Phy Med Rehabil 79:343, 2000)

New Technologies

At the national neurology meetings in April 2002 Trojan, et al., reported on the use of Magnetic Resonance Spectroscopy (MRS), a form of computerized imaging to assess the number of nerves and their metabolism in various areas of the brain. In this group of fatigued polio survivors Dr. Trojan found neuronal loss and dysfunction.

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Advances in Neurologic Research

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tion in the reticular activating system of the brainstem. There are many centers for activation in the brainstem: a fatigue center, blood pressure regulators, heart rate regulators; respiratory pathways begin there. So this certainly gives more evidence for central factors contributing to some of the features seen in PPS -- fatigue, maybe cardiovascular problems, and perhaps pulmonary problems.

The temporal lobes, which are a higher part of the brain involved with thinking and language, were actually normal in this particular study, thus discounting a generalized brain problem as a cause of PPS fatigue.

4. Review of drugs used for PPS fatigue

In theory the nerve/muscle junction should be enhanced by the drug pyridostigmine (Mestinon) because that is where it works.

Central dopamine related drugs amantadine, selegiline, noradrenaline-enhancers, and others have been used with some symptomatic success. People feel better, but how can that be documented? In evidence-based medicine it must be shown in black and white.

Many controlled trials have been started, so there has not been a lack of interest or creativity to find drugs to stimulate nerve pathways. The first well-controlled study on Mestinon had disappointing results (no major benefits seen), but lessons were learned from it.

“WHY DRUGS FAIL IN PPS”

Lessons from a Clinical Trial,
Marinos C. Dalakas, MD
(Neurology 1999; 53:1166)

- ◆ Unstable neuromuscular junctions are present in all PPS muscles, but not all cause symptoms. Improving junction stability may have no effect on symptoms. Maybe what was measured wasn't sensitive enough to show improvement; maybe Mestinon wasn't strong enough.
- ◆ PPS nerve fiber sprouting is already at its maximum, so that growth factors that induce more sprouting may be redundant or even harmful to the overextended nerve.

There is a need for better-controlled drug studies but it is difficult to design a drug for a condition with so many unknowns. The causes of PPS are not known; it is not known how nerves grow, connect, maintain connections for years; and aging is not understood. So it will be difficult to generate a drug to work on a system when all the components are not known.

Developing Drug Trials

At the April 2002 national neurology meetings, Nollet, et al., reported on another randomized, double blind, placebo controlled study of pyridostigmine (Mestinon 60 mg four times per day). The subjects were 67 patients with abnormal single-fiber EMG studies. Results were assessed at five and fourteen weeks.

- ◆ Subjective fatigue, isometric strength, and EMG did not improve.
- ◆ Timed walking performance improved about 5-6% on Mes-

tinon, mainly in patients with normal sized motor units (“wiring was there, but connections were faulty”). Dr. Perlman commented that this is a really small improvement when considering that placebo effects can be in the 30% range.

This confirms a report by Trojan (Neur 53:1225, 1999) that Mestinon could be helpful, but there is not compelling evidence to put all polio survivors on it. However some doctors will continue to prescribe Mestinon because symptomatically it could be helpful.

This confirms a report by Trojan (Neur 53:1225, 1999) that Mestinon could be helpful, but there is not compelling evidence to put all polio survivors on it.

Trojan, et al., in a study of 112 survivors, found insulin-like growth factor (IGF) levels did not correlate with strength and decreases in IGF may not be a cause of fatigue in PPMA. (J Neurol Sci 182:1107, 2001)

Magnetic Resonance Spectroscopy can detect levels of lipids, creatine, and carnitine in muscle fibers and may be useful in trials of new drugs or rehab, and in studies of the causes of PPMA. (Jagaannathan et al., Mag Reson Imaging 20:113, 2002)

5. Animal Models

6. Stem Cell Research

Researchers at the San Diego Symposium presented these two

topics in June 2002. This information will be summarized in a separate publication.

7. What Polio Survivors Continue to Need (and can't get in our current healthcare environment)

More publications indicate that polio survivors are best served in multidisciplinary clinics staffed by knowledgeable professionals. "One stop shopping" is the best kind of follow-up; this helps conserve the patient's energy and prevents conflicting recommendations or good ideas falling through the cracks.

How are polio survivors doing? Polio survivors still report poorer functional status and health-related quality of life. They are not feeling as good as they should.

Healthcare providers have not adequately addressed the life-altering effects of PPMA, but it is

possible to work within the system.

Building a Network

International Polio Network, a Gazette International Networking Institute (GINI) group, is a wonderful resource of PPS doctors, clinics, medical personnel, and support groups -- both in the United States and internationally. Dr. Perlman frequently refers queries to them.

In Southern California we have a post-polio network that has been growing. Sometimes local physicians have questions regarding treatment of a patient who is a polio survivor and often contact Dr. Perlman. "Is this something with which she is familiar? Can she answer a question? Does she have to see the patient?"

This network can continue to grow only with the help of polio survivors. If you are seeing a pri-

mary doctor, an orthopedist, somebody who wants to work with you, somebody who is dealing with a particular medical concern but has a question about the role of post-polio, give them the literature that you have, indicate that there are people nationally and locally who might be resources for them.

Let's continue to network and spread the knowledge about post-polio. According to the 2001 March of Dimes physician paper on post-polio, we need to educate more health care professionals in proper ways to approach a polio survivor.

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Our support group feels an exchange of information between groups is important, and it is our hope for the future that all groups will join those of us who take the time and effort to research, contribute, and educate responsibly

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