



**TeamWalk Photos from around the Country (see back cover for more)**

90 people attended the walk in the bright California sunshine  
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**California** TemWalk organizer  
Linda Gentner with family.

20 people participated in the fundraiser for SP Foundation  
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**Florida** Organizers Rick & Janet  
Green, Kathi Geisler & Bruce Maser

Malin Dollinger seated with wife  
He is congratulated by Angela &  
son

Williams with his mother,

**Georgia** Some of the 29 participants The Sheurings with Canine Assistant dog Jerry Simmons entertains

# Autumn

# 2007

## **Serving the Primary Lateral Sclerosis Community since 1997 Welcoming the SP Foundation since 2003**

paradise on the edge of Toledo. Included in our group of Ohioans and Michiganders (and yours truly) were newby Robert Ellison, Herb and Betty Hipp, Tim Kolhoff, Rita and Jeff Stenzel and their clan, and, of course, Moira's husband, kids and sister. We did some chatting, sharing, and snacking, and then took a stroll around the lake where folks were fishing and sun bathing. All in all, it was a lovely day.—*Karen Johnson*

**Orlando, FL - August 25-27** The first TeamWalk event in Florida drew 34 people from around the nation. The weekend featured an arrival dinner, a Retreat Connection with educational and inspirational programs, a TeamWalk, and an outing to the Spinal Cord Association Disabilities Expo and Conference. Several people from the Ataxia Foundation joined us as well. One of the featured Retreat Programs was presented by Tom Clouse, MD, who has ataxia. He has created a dynamic treatment program called “Walking with Ataxia” that may be of benefit to people with SPF conditions as well. In addition,

representatives from Florida Mobility demonstrated numerous assistive devices including canes, walkers, scooters, and wheelchairs. They also gave this important Medicare tip: be sure you acquire devices in a progressive order. Once a more advanced item is acquired, you can't get approval to order a less advanced item. —*Kathi Geisler*

**Waltham, MA - September 8** Two dozen people met at the Best Western Hotel in Waltham for the TeamWalk Connection and lunch. The event featured three excellent speakers. Rob Park, from the Boston Center for Independent Living, shared his story

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**Table of Contents pages**  
Events 2-6 Living with  
HSP/PLS 6-14 Caregiving  
14-17 Medical Updates  
17-20 SP Foundation 20-22

**Events: 'Tis the Season. . . Ed.**  
*note: For TeamWalks, that is. So far, nine SPF TeamWalks have been held around the country, along with Don Wilson's Autumn in Carolina. These events have ranged from intimate get-togethers to sprawling street fairs. They've connected people from Vancouver to Florida and many spots in between. However, regardless of size or location, each TeamWalk has been driven by a common set of goals: to bring together those affected by HSP and PLS, to educate ourselves and our communities about the diseases and related issues, and to raise*

Synapse – Autumn 2007 Edition Page 2  
about managing life despite challenging disabilities. Rob was born with severe cerebral palsy and is legally blind. Yet that has not limited him. His current goal is to finish his undergraduate degree in Criminal Justice and go on to law school. Lori Gillen, a Red Cross volunteer, spoke about disaster preparedness and special considerations for the disabled. She stressed the importance of discussing disaster preparedness with your family and creating a plan. Michael Schleipfer, President of Alternative Care Designs, spoke about the importance of participating in grassroots advocacy. He also

*money for research. The TeamWalks held to date have raised more than \$80,000. And we still have a couple more to go. Below you'll find the highlights of this year's gatherings to date. Remember as you read, it's never too early to start planning your own TeamWalk. Sarah Roberts-Witt*

**Toledo, OH - August 11** Moira Franchetti started the SPF TeamWalk season off strong with her third Ohio TeamWalk. A nice bunch of people came together under the covered Mallard Lake shelter of the beautiful Oak Openings Metropark, a birder's

demonstrated an assortment of mobility devices and aids for independent living and gave assistance to a number of people who had concerns with their assistive devices. After the programs, people headed to the nearby Prospect Hill Park for the TeamWalk. --Kathi Geisler

**Raleigh, NC - September 16** The Magnificent Mile Race and TeamWalk were held for the second year, with a few minor improvements. First, it was warm. Second, the course was flat. And third, it was the state championship race for the mile. In other words, it

was fast. The winner of the men's race man finished in 4 minutes and 12 seconds; the winning woman ran it in 5 minutes flat. But the real story was Cece Russell. Cece lives in South Carolina and has HSP. Last year, she walked the mile in 16 minutes. This year, she did it in 15 minutes and 30 seconds...on forearm crutches!! Loads of people were there to witness Cece's feat. Between runners, walkers, rollers, and spectators, we had nearly 1,000 people out supporting us. The finishing touch was having both Annette Lockwood and my doctor, Richard Bedlack of the Duke ALS Clinic, speak to the crowd about how we can vanquish motor neuron disease. A few checks are still straggling in, but looks like the grand total from North Carolina will be upwards of \$36,000.—*Sarah Witt*

**Elysburg, PA - September 22** The PA TeamWalk was held at Knoebel's Amusement Resort. The weather was perfect and we had a get to know you dinner the night before at a local restaurant and we had around 13 attending. We enjoyed good food and lots of laughs!

Synapse – Autumn 2007 Edition Page 3  
bigger and better next year. It was a fun walk in the park! —*Sue Me*

The day started out with everyone coming to the pavilion to register and getting a chance to meet some others that they had never met before. There were a few who had never met anyone else with the disease that attended so that was great to see.

We had a catered lunch at the pavilion and everyone ate well and then shortly after everyone was done eating, I introduced Annette as the SPF president and presented her with a lighted jack o' lantern and said that Annette was like a jack o' lantern--that even when she felt like everything was taken out of her, her light still shines through and she still has a big smile on her face! I meant that sincerely!

We started the walk with around 75 people or more and had a designated route to follow. I got to ride the Big Ferris wheel--three times--once by myself!! It was awesome! We raised almost \$12,000. I want to thank all who participated, all those who donated and my family and friends. I am hoping to make this an annual event at Knoebels and make it

**Norman, OK - September 22** We

had a blast at the Oklahoma TeamWalk. The weather was beautiful and the wind was calm. We had a great group of 33 people who came from as far as South Carolina to share in the fun. Everyone raised money for research from their network at home and brought it to the park. For that day alone, we managed to raise \$4093.55 for the SPF-- --WOW! After the TeamWalk, six of us went to the Oklahoma University Advanced Center for Genome Technology. We were given a tour by the Specialty Coordinator, Joshua Maxey. He took us through several labs, including the Zebra fish lab which contained more than one million fish. Next year, I plan to set up a tour of the National Severe Storm Laboratory, which is across the street from the genome center. I want to encourage everyone to participate in a TeamWalk. Every penny does add up. You won't regret it if you do!  
–Mark Dvorak

**Long Island, NY - September 29** The third annual Long Island TeamWalk took place at Wantagh Park in Wantagh, NY. The 65 attendees enjoyed sunny skies, temperatures in the mid 70s, and a wonderful ocean breeze. The festivities began with a casual lunch. Participants enjoyed delicious food and great company, while children had fun with crafts and face painting. The

weather was perfect for walking as we began our ceremonial march. The kids led the way, carrying our TeamWalk banner. Bystanders from neighboring events applauded our parade

as we walked by, instilling pride and determination in our mission to find a cure. Attendees were amazed by the exciting prizes displayed at our raffle table. Items donated included golf equipment and apparel, wine and spirits, plus an Apple IPOD Nano. About 20 prizes were awarded, including a 50/50 cash prize. The day ended with my expression of sincere thanks and appreciation. All who participated responded with optimism, support, and encouragement. –*Betsy Baquet*

**Pleasanton, CA - October 5-6** This marked the fourth year of our California TeamWalk for our Cures. Friday night, 30 people came out for dinner and discussion; both PLS and HSP were equally represented. Patients and caregivers were given the opportunity to talk, which took quite a while. But no one felt they were alone with their disorder after leaving the meeting. In addition to sharing our stories, we celebrated Dr. Malin Dollinger's birthday with a special TeamWalk cake. Saturday was a picture-perfect day. About 90 people attended the TeamWalk, compared with 65 last year. Participants came from Arizona,

Vancouver, Seattle, West Des Moines, Boston, and southern California. We also had musical accompaniment for our trek. Kathi Geisler and myself were serenaded multiple times by Malin Dollinger. I'm sure we weren't the only ones. After

lunch, we held our raffle, which Julie and Ken Auer were in charge of. I brought home more than \$1,300 in cash, primarily from the raffle! My guess is that the California TeamWalk has added

Synapse – Autumn 2007 Edition Page 4  
at least \$30,000 to our research fund so far.--Linda Gentner

### **Thomasville, GA - October 12-13**

What do you get when you take one funny, clever guy and add a beauty pageant contestant? The Georgia TeamWalk, of course. Jane Anne and Gary King hosted quite a shindig down in Thomasville this fall. On Friday night, a group of eight met for dinner. Then came Saturday, which was chock-full. About 29 of us lunched in a restaurant near town, shared our stories, and enjoyed three presentations. Kristine Riggs of the American Red Cross talked about the history of her organization and provided important emergency and disaster tips for handicapped folks. Debbie Sheuring, her daughter, and her daughter's Canine Assistant dog put on a terrific show. This is one incredible dog! He knows 90 different commands, including "kiss" and "snuggle". Even more amazing, he knows 20-30 minute beforehand when Debbie's daughter

is going to have a seizure and can alert her parents with different barks for different types of seizures. Our third presenter was Dr. Tom Clouse. He demonstrated how we can learn to move better through basic, simple improvements like lifting our knees. Next we went to a sweet park and did a walk to our shaded area. Jane Anne had collected lots of fabulous raffle items. Cold drinks and ice cream added to the festive atmosphere. But that's not all. After dinner came live music. Jane Anne's son Timothy and his buddy James Eldridge played guitar, the professional group "Newport South" added a terrific performance, PLSer Jerry Simmons did a guitar set as well. We had a nice crowd. In addition to the TeamWalk folks, lots of locals came in

to hear the good music, including Dr. Pope of Texas A & M, and her partner (part of the effort through Jane Anne's recent visit there for the students to see and learn about our conditions). *–Karen Johnson*

**Upcoming Regional TeamWalks**  
**Walk with us today, so we can**  
**walk with you tomorrow** *Linda*  
*Gentner, Coordinator*

**Houston, TX Texas Two-Step**  
**TeamWalk** Oct 20 Brad  
Hendricks:  
[treeman1@houston.rr.com](mailto:treeman1@houston.rr.com),  
713-416- 6604

**Nashville, TN Two-Step to a Cure**  
Oct 21, The Wild Horse Restaurant  
and Bar Jim Sheorn:  
[jimsheorn@comcast.net](mailto:jimsheorn@comcast.net),  
615-479-7369 Terri McDonough:  
[terri.mcdonough@jeepthing.net](mailto:terri.mcdonough@jeepthing.net),  
615- 278-0489

### **SAWCAR Lives! Autumn in**

Synapse – Autumn 2007 Edition Page 5

foam and closed gel cells. He also fielded general questions about wheelchairs and funding. Sue Humphries, Director of Patient and Family Services of the Catfish Hunter Chapter, ALS Association, was our afternoon presenter. Sue informed the group that PLS was recognized by the ALS Association throughout the country. In addition to general services, each Chapter offers patient grants for such necessities as respite care, travel, wheelchair repair, and assistive technology. For those in the area

**Carolina - October 13** Folks began arriving in SAWCAR country on Friday afternoon, and by Saturday morning seven PLSers and three HSPers were on hand for the sixth annual Autumn in Carolina. The PLS group included Martin Beckner, Ronnie Grove, Donna Isenhour, Rich Jodon, Lynn Petch, and Bettie Jo Wilson. Sarah Duncan, Annette Lockwood, and Wilburn Swaim made up the HSP contingent. The morning speaker was Todd Ferrell, founder and president of The Wheelchair Company. Todd demonstrated the different types of rehab seats available, including the newest combination of live

served by the Catfish Hunter Chapter, the combination of grants may equal \$5,000 per person. When Sue completed her presentation, the crowd felt the need for speed— RACING TIME! Scooter and power chair drivers donned shirts and hats representing NASCAR drivers Ryan Newman, Kurk Busch, Dale Earnhardt Jr., Paul Menard, Clint Bowyer, Kevin Harvick, and Jeff Burton, and were transformed into stars of the SAWCAR (Scooter and Wheel Chair Association of Racing) circuit. The scooter race was first.

Martin Beckner, Sarah Duncan, and Ronnie Grove lined up for the green flag. Martin took the early lead and held on for the first lap. However, Ronnie, in her new blue racer, overtook him on the back stretch of the second lap and never looked back. The power chair division fielded five racers: Donna Isenhour, Annette Lockwood, Lynn Petch, Barbara Neely, and Bettie Jo Wilson. Annette demonstrated the power of her machine by taking the lead and running away from the field. The Championship race pitted Grove against Lockwood. Once again, Annette took an early lead. Even though Ronnie

challenged her at every turn, Lockwood managed to hold on for the win. Annette also handily won a challenge race against Don Wilson, who was driving Bettie Jo's Invacare. Ronnie and Annette entered the Winner's Circle and received their plaques and awards, after which the gathering began to break up. Though many headed home, the Beckners, Lockwoods, Neelys, Wilsons, and Petchs, along with Ronnie and cousin Jackie, shared a meal of genuine Lexington-style barbecue.—*Don Wilson*

## **Living with HSP or PLS**

**Each Day** *Contributed by Ruth Havener, "I found this saying on the back of a tea box. Wouldn't it be great if we could really do this. "*  
"Finish every day and be done with it. You have done what you could; some blunders and absurdities crept in---forget them as soon as you can. Tomorrow is a new day. You shall begin it well and serenely, and with too high a spirit to be encumbered with your old mistakes and nonsense." Ralph Waldo Emerson

**An HSP Love Story** *Told by Marie Swain* Bob and I want to tell you our story about making the choice of not having children because of the possibility of passing on a hereditary medical disorder, Hereditary Spastic Paraplegia (HSP). We knew from the moment we started to date in 1980 that we would become soul mates. We also recognized mutually shared communication between one another was the cornerstone of any lifelong relationship. We both still have all this love and respect for one another

Synapse – Autumn 2007 Edition Page 6  
as we celebrated our 25th Wedding Anniversary this year. Before we

married Bob and I did discuss at length about having children. I was

brought up in a very strict Roman Catholic family where you get married and you have children. It was as simple as that. I am now more convinced that deliberately not having children is a serious moral issue and that many Christians are deeply confused about the topic. I see marriage as a personal connection. A person choosing not to have children comes with its fair share of critics; many people do not understand your decision. I have always felt people think just because you don't have children you must be a very cold person. And I resent having people feel that way about us. I see from couples who have children that the relationships can become more strained with so much going on in their lives so to bear a child with the possibility of knowing they could be affected with a hereditary disorder you really need to make a sound decision. I also feel children should not be the only motivation to get married. I was adopted, because my parents could not conceive children so I think my parents were expecting Bob and me to have children of our own. I have an older brother who currently has 3 beautiful children. Bob was somewhat adamant in not wanting children because of the hereditary (HSP) disorder that runs in his family. His grandmother was diagnosed with MS but we now think it was a form of HSP. His father and

two uncles also were diagnosed with this disorder and Bob also was quite sure that he would develop this disease as well. Bob states he grew up seeing his father always having a tough time walking, but he also remembers his father being very independent and a very successful stock broker for many years with a very pleasant demeanor. As Bob's HSP progressed it became more apparent that our decision not to have children was well-founded. I understand all the pains and hardships that have come into play for Bob, living with the medical disorder HSP. In closing we encourage others to discuss this topic openly and thoroughly. Come to a mutual agreement. Have respect for one another's decisions. Don't let friends and relatives influence your decisions concerning your lifelong commitment with one another.

### **Most Inspirational Camper Award**

*Contributed by George Lepper* Liz Lepper was awarded the "Most Inspirational Camper Award" at the University of California at Santa Barbara Junior Wheelchair Camp. They did everything from scuba diving to mountain climbing (being hauled up the wall on a rope). Liz has complex HSP. She has recently lost hearing, speech and continues to deteriorate in her ability to stand and transfer. Photo on back.

## **Supporting Each Other**

*Contributed by Jean Chambers* Do what we do best...lift each other up. It made me think of the geese that fly in a "v" formation. Each goose, in flight, gives a "lift" to the goose behind him - when the front goose gets tired, he slips back and they

reform in their V -flying much further and faster than a single goose would be able to do, flying alone. We are like this with our community and our Foundation.

## **Conversion Van Selection**

Synapse – Autumn 2007 Edition Page 7

*Jim Campbell* Minivans with built in ramps bear little resemblance to the wheelchair vans of as recent as 15 years ago. Advances in minivan conversion technology have given today's converted van both space and amenities to safely transport the entire family in comfort. With the conversion van's increasing popularity today there are several options for conversion vans both as to ramp style and vehicle features.

This article suggests some factors to consider before purchasing a conversion minivan. Today conversion power ramps or lifts are installed in Chrysler, Dodge, GM, Ford, Toyota, and Honda minivans. These conversions are usually done at companies that specialize in the installation using either new vans or fleet rental vans with low mileage. There are two major suppliers of power ramps: Braun,

[www.braunmobility.com](http://www.braunmobility.com) (800-THE-LIFT) and VMI, [www.vantagemobility.com](http://www.vantagemobility.com) (800-348-

VANS). These two companies sell their conversions exclusively through local dealers. A list of van dealers can be found at [www.nmeda.org](http://www.nmeda.org) (800-833- 0427) the website for the National Mobility equipment Dealers Association. In addition there are a number of companies including Rollx, Liberty Motor, Freedom and Vision that sell their conversion vans on line. Ramp minivans have the floor lowered about 10" to facilitate chair & scooter entry headroom. Typically both passenger and driver elevated modular seats can be removed and replaced by the wheelchair if desired. Vertical lifts are only available with full size vans which account for about 20 to 30% of conversion van sales. Most consumers prefer the minivan for its more maneuverable smaller size and better gas

mileage. For the minivan two power ramp options exist – a fold out ramp and an under-floor slide out ramp.

The underfloor ramp has the

advantage of taking up no interior space and not blocking the door for other passengers in the back. When in the folded position the foldout ramp version projects into the van about 6" and because it is stored inside the van has the advantage of less exposure to road salt and sand. Hence about 95% of the vans sold in northern states have fold out ramps, whereas underfloor ramps are more popular in southern states. To help you consider which van and ramp are right for your situation, Liberty Motor has the following list of questions with amplifying detail on their website [www.libertymotorco.com](http://www.libertymotorco.com) (888-578-8886):

- How tall is the wheelchair user while seated in their wheelchair?  
Typical door entry height without

Synapse – Autumn 2007 Edition Page 8  
need to be accommodated at one time?

- Is there an assistant and/or primary caregiver that can facilitate ingress and egress?
- How long do you plan to keep the vehicle?
- What is your typical driving environment and what type of parking facilities do you plan to

modification is 45". Typical interior height is 48". Liberty Motor lowered-floor minivans provide a typical door entry height of 56". If a height of greater than 56" is required, this will generally rule out the use of minivans, limiting your choices to full size (e.g. Ford E-Series) vans.

- Is the wheelchair user willing and able to transfer to a regular car seat?
- Is it necessary that the wheelchair user be in their wheelchair in either the driver or front passenger position?
- How many ambulatory and/or non-ambulatory passengers will

utilize? For those who want to pursue the nuances of van and ramp selection a site <http://www.wheelchairjunkie.com/> by wheelchair user Mark E. Smith discusses ramp selection as well as ways to improve van suspension if needed.

*Ed. note: This summer lots of good information was on PLS Friends on vans – pros and cons. Below, the information has been compiled and*

*edited. No editorial endorsement should be implied.* Three years ago we bought a 2000 Dodge Grand Caravan with a Rollx conversion. The big problem is that it rides very rough. We have had it checked out at least by a dozen places (Truck, Dodge, suspension and two conversion places) and spent \$900 having a 5th leaf spring added (it helped a little). But it kills me to ride in it, (shaken not stirred) My question is, how is the ride in your conversion vehicle? *Dale*

I have a Chrysler Braun conversion van, it's was a new 2006 when we bought it on July last year when I got my powered wheelchair. It rides as smoothly as I expect, but the rattle it makes is annoying. I don't mind the noise, as it IS a conversion. *Bob Sexton*

We started off with a 1999 Plymouth Voyager. It had been a "program" van that Braun purchased (had 22,000 miles on it). All the modifications, including kneeling, were new when we bought it in 2000. The ride was rough. We had to creep over speed bumps and often hit bottom where driveways joined to streets. Last year we traded for a 2006 Dodge Grand Caravan, modified by Braun (Entervan). I was surprised at the extra room. The ride

was smooth enough for me to sleep in the back seat while the PCA drives. I still take it easy over speed bumps but that is more habit than anything else. The Dodge Entervan does quite well, and I do not have any rattle in the ramp. *Don Wilson*

I bought a used 2005 Dodge Grand Caravan Rollx conversion van. It has a power driver's seat that rotates 180 degrees and slides back into the cargo area. It drives like a farm truck, steers like a farm truck, bounces over any bump in the road like a farm truck! It is still under warranty with Rollx and Dodge but there are issues they conveniently pass the buck on. It gets between 17-18mpg. *Eva*

I just bought a 2006 Dodge Caravan. It has the Braun conversion and it is brand new. Other than a little rattle from the fold out ramp we have no complaints. It's wonderful and we love it. No problems with speed bumps or dips in the road. *Pat Croom* I am in the process of purchasing a 2002 Chrysler Town & Country Wheelchair van. It only has 19,000 miles with a VMI conversion on it. I am having the Van fitted to me. . . everything from transferring my hand controls to having an Ez-dock installed so that I can drive

sitting in my power chair. I have yet to see how the '02 will compare to a traditional Dodge van. *John S. Adams*

I would like insight to how I will EVER get a van. With no insurance and little outside financial help, I feel pretty helpless in more ways than one! I am on disability and will not be eligible for Medicare til Jan '09. *Trish Stone Ed. note: As an economical means of transportation I suggest you consider local medical related transportation services which are less expensive than leasing or purchasing a conversion van and then insuring it.*

I traded my '99 Chrysler with fold out ramp, kneeler, turning passenger seat, and lowered floor when it had 104,000 miles on it, for a 2007 Toyota. I did go to a different ramp style to get rid of the noise on the fold out ramp. Both conversions are made by Braun. The ramp I have now is under the floor of the van and power slides out. What I liked about this ramp is 1. you don't have ramp making noise when driving, 2. you can open the ramp sliding door without the ramp opening and walk right in on either side of the van 3. When the ramp is out it doesn't take up quite as much room on side as the other does. We do like the Toyota. I have been getting 19mpg around home and should get 24 to

27 on the open highway. *M. David Lehman*

We bought a 2006 Chrysler Town & Country with a Braun conversion -- I regained some independence, so it's been worth every dollar we paid. *Virginia*

I have had two vans, both of which had a side platform lift that folded up in behind the wheelchair once you have

parked your chair in the van. My current van is a 2004 Dodge Grand Caravan with an Entervan conversion by Braun with side ramp and lowering kit. It squats about 10 inches, I bottom out unless I take bumps, dips and heaves extremely slowly. I have put in extra struts and heavy duty shocks. There is one drawback to side ramp minivans, as people have a tendency to park too close to the right side of your van. The new trend is installing the lift in the back of the van. This eliminates people parking too close to the side of the van. The only problem I see with this setup is how to get from the wheelchair to the front of the van. *Gary Norton*

My full sized van "Gladi" is a '95 Chevrolet Gladiator Conversion van. I chose the following options, so I won't have to update it or add to it in the near future as my condition worsens. 1. The door opens

automatically from the outside with a hand held remote, which also lowers the Ricon lift. 2. It has a swivel driver's seat. That I can still drive this is a God send, because I don't have to depend on anybody when I go on my own. 3. I have e-z lock tie downs for the chair. 4. I have controls on the dash to open and close the doors and release the lift from the inside. Every time I use the valet parking at our local hospital, they think it's such a cool van. I love

my van. It also has a TV for the kids and the backseat turns into a bed, lots of fun. *Rita DiClemente*

I think when you're talking about converted minivans you need to consider obstacles you encounter. You are your own best advocate! Regulations require only 2% of the overall parking needs to be dedicated to the current specifications for van parking. The regulations in MA

Synapse – Autumn 2007 Edition Page 10

have recently changed and currently are giving handicapped van owners the needed space that one needs to properly exit the vehicle. This year I had to petition my property managers to construct a proper handicapped parking I needed for our complex because it did not exist. Our complex is fairly new three years old and this was overlooked by the town during its construction. My condo complex put in speed bumps after my purchase of the minivan. Because ramp minivans have lowered floors, ground clearance becomes a problem when traversing speed bumps. Currently there are no legal specifications in MA regarding the height of speed bumps. However, in MA it is the obligation of the property owner to remove obstacles that impede a handicapped person's access. I

have currently just won the argument to have the speed bumps lowered so my van could pass over the speed bumps properly without scraping. This mediation with the state and town officials took four months to resolve - a very slow process. Many hospitals and other heavily trafficked areas control the speed of vehicles using speed bumps. *Bob Swain, MA*

**Tips for Living Well with Disabilities** *Ed. note: Rob Park 33, one of the speakers at the MA TeamWalk this fall is an inspiring motivational speaker and advocate for the handicapped. Here are a few of his gems of advice to anyone disabled:*

- do all you can for yourself ➤
- never have reduced

expectations

because of your disability >  
being married is just like normal  
couple - sometimes pain in neck  
and sometimes wonderful >  
persevere in the ongoing  
struggle

to be with people not separate  
and isolated > negotiate deals  
with professors -

oral exams, computer tests  
(legally blind, he is currently  
going to Salem State law school  
at night working full time days)  
> there are no better advocates  
for

the handicapped than the  
individuals themselves > don't  
let status quo stand in way >  
anger can be a constructive a  
motivator for change > life is  
not about falling it's about  
getting up > plan for worst  
case scenario and

come up with strategies for what to  
do if it does happen > don't live in a  
box Rob concluded his talk by  
asking the audience, "What good

things do our disabilities give us?" A  
lively discussion followed. What  
could you answer?

### **Two Inform Physical Therapy Class about HSP and PLS Ed.**

*note: I hope this report and the  
accompanying pictures will inspire  
many of you to team up to help  
spread the word about our diseases,  
and help therapists enhance how  
they help us. Jane Anne King, HSP*  
Dr. Mary Pope asked to me to come  
to her PT class and talk about HSP. I  
of course told her yes. I was so  
honored to do this. I arrived at the  
A&M University. There were 10-15  
students all seniors. They took my  
vital signs, pulse, blood pressure,  
respiration rate check the sensation,  
flexibility etc. They wrote a report on  
me and we talked about how HSP  
started on me, how I deal with it,  
what type of medication I was on. I  
am on such a HIGH. I had one of the  
best times I have had in a long time.  
We made a video which is two hours  
long..

Synapse – Autumn 2007 Edition Page 11

They loved the SPF Foundation  
pages and Dr. Pope said they got  
lots of information off of it for their  
students. They also went to Dr. Fink  
article and was helped a lot in  
learning about HSP. They were so  
happy that we would do this for

them. But I told them after all they  
are the first people that have asked  
us to participate in anything like this.  
*Jerry Simmons, PLS* A day at A&M  
University for me and Zeke !!!It was  
a great experience for me! and I am  
sure I gave the students an earful.

Having worked in the prison system 20 years of my life, I am pretty straight forward....But always try not to offend or hurt feelings.... I would like to thank Dr Peggy Pope for invitation and the students for the free physical going over ..... Photo on back.

**Making Marriage Work with PLS** *Contributed by Rita DiClemente*

John and I just celebrated our 46th wedding anniversary. We went out and had a nice dinner, and while we were talking I realized that most of my married life I have had PLS- for at least 35 years. I never thought about it that way before, so I started to put my thoughts together and want to share them with you, as to why a combination of PLS and marriage can work without too much difficulty. 1. Respect the marriage vows, and respect the person who has to be your caregiver, as he or she is also a victim. 2. Accept the disease regardless of how devastated you are when you are told you have it. 3. Try to lead as normal a life as you can, and when obstacles come along pertaining to this disease, deal with them as best you can. This disease isn't going away, so one day at a time. 4. Don't dwell on the fact you have PLS.

Stress is an enemy of any disease, and it doesn't do any good for you physically or mentally. People don't

want to be around people who whine all the time. 5. Get rid of the people in your life that drag you down with them (this not easy to do) and surround your self with positive vibes. 6. Yes, there are so many things we can't do any more, but there are so many new adventures out there, you just need to go to find them out. I used to climb trees and pick apples, now I use my chair and pickup the drops. I still make a mean apple pie. 7. If you're frustrated over a situation, be it physical or personal, talk, talk! You'd be surprised how good you feel when you get the garbage out of your life. A clergy, a doctor or somebody you can count on, helps. 8. Meet other PLSer's and their caregivers as it is such a rewarding experience. I have been blessed to have met so many PLSer's, Mark, Dolores, Ronnie, Galen and I could go on and on. Last but not least, having a wonderful person as my John to help me thru the bad times and still tolerate me and my PLS is a gift from God.

**Living with Speech Loss** *Ed note: Sandy Ciresi posted her situation and asked for help.* Like everyone else, I have the mobility problems, but the thing that is really messing up my life is my voice or lack of it. Does anyone with speech problems take any medication that helps restore or strengthen the vocal cords? It is amazing how shut off

from the world you are when you can't make a phone call or answer the phone. Going in public is the worst. When I am out by myself and

am spoken to by the store clerks, they don't take a nod for an answer. They always

Synapse – Autumn 2007 Edition Page 12  
speak louder, and I want to say, “I'm not deaf just dumb”. I never thought I would lose my voice, but then again I never thought I would not be able to walk without a rollator. Please tell me how you manage.

recommend seeing a Speech pathologist. They have the tests linked to computers that can immediately tell where the problem is, and then suggest a program for you. *Eva*

*She received these replies.* Bulbar issues can manifest differently in each of us: Dysarthria (makes the speech muscles and chords very stiff so you work hard to make words that are on the croaky side), Increased nasality (when the air you take in to speak escapes in large quantities thru the nose due a weak soft pallet), Poor articulation (tongue and muscles controlling the lips and mouth get stiff - had to make the difference between consonants), Dysphagia (problems with swallowing) which has many subgroups - problems with mouth and tongue organizing food for swallow, or delayed initiation of swallow reflex or gag reflex initiating too far forward in the mouth or too far back (food is already in the airway before you can swallow) and severe throat dryness which is very common in MND (food or pill sticks to throat lining after it is swallowed). I

You definitely need a Lightwriter or similar device. I couldn't survive without mine - it goes with me absolutely everywhere!! I never use it to speak for me as I find that people have problems understanding it because the speech is robotic. All I do is have it set to scroll at easy reading pace and let people read it from either of the two screens. Have been doing that for about 10 years now and never had a problem - I find people are very patient and understanding. Whenever I am going into a shop or somewhere and know what I am going to ask for I type it up beforehand and save it so when I get in there I don't have to waste their time and mine typing something up while they wait. There are plenty of memory keys so plenty of room to save favorite phrases and pre-save sentences as described above. For phone

calls you should be able to use one of the relay services set up for deaf and/or dumb people. It works very well, although is limited by the speed with which you can type.

*Gary C.*

Computer technology unlocks the world for those of us who've lost our speech. Sure, there are many frustrations still, but with patience and perseverance, you can communicate in the speaking world. My current device is Words + on a Panasonic Toughbook.

[http://www.words-plus.com/website/products/syst/f2kliteP\\_series.htm](http://www.words-plus.com/website/products/syst/f2kliteP_series.htm) Previously I'd had an

Enkidu for over 3 years. It had served me well, but due to mergers of companies, service became an issue. My most important message to you and others in the U.S. is, do not buy one!! Go through your neuro and PCP. Get an Rx for an Augmentative Communication Device, then order it through a rehab facility where the paperwork will be handled. If you are 65, Medicare covers alot; then your secondary; finally MDA picked up the remainder. If you're younger, your insurance should also cover it if the Rx is well written. The process can take up to four months, but it's worth it. *Thurza*

Synapse – Autumn 2007 Edition Page 13

I am one of those people that can speak just fine, I have no problem whatsoever understanding what I am saying, although I have noticed that other folks seem to have difficulty understanding me. Being the selfless type of person that I am, I have spent some time looking into devices that might enable others to also understand what I'm saying. I've found that virtually everything I have tried requires me to type what I want to say, and it is easier for me just to get people to look over my shoulder at what I am writing, so I wind up not using the speech synthesis part of

whatever device I select. Having people read isn't always possible though, and the neatest little program I've found is e-triloquist. <http://www.etriloquist.com/> It's free, though a donation won't be rejected. You can pre-program phrases for it or just have it say things as you type. You can now have it play music. You will need a laptop that will run it (Windows). *Galen Hekhuis*

**Caregivin  
g**

**Caregiver and/or Wife Contributed**

*by Lenore Dollinger* As a caregiver I have had two awarenesses that are very important to me. A few years ago Malin and I were at a handicap expo. I was sitting at a table resting and a woman, my age, came and sat across from me. She looked at me and said "When did this happen to you?" My immediate thought was, it didn't happen to me it happen to Malin, but I responded "11 years ago." We talked for a long time about the changes in our lives. How we loved to travel and the older we were getting the more difficult it was for us to lift the luggage, keep up with the scooters etc. It was the first time I had ever talked about how I was affected. On the way home I started telling Malin about my experience and just started to cry. I think I cried 11 years worth of tears. I felt terrible crying in front of Malin. He gently touched me to let me know it was O.K. More recently, I became aware of how I was taking away Malin's independence. I'm a nurse and I live with Malin 24/7. I know all about how to help him and I want desperately to make his life easier for him. Yet, he will go to a physical therapist weekly but not let me assist him with his physical therapy at home. He will struggle and struggle

to get his socks on and will not let me help him. He won't even let me pick a paper clip off the floor for him. I perceived this as a personal rejection and felt very hurt. "Why doesn't he want me to help him once in a while?" or "I'm just trying to help him - why is he taking his frustration and anger out on me". One day he looked at me and said, "Lenore you are trying to take my independence away from me and I want to be independent" It's not easy for me to stand back and watch him struggle, after all, I was born a helper, but I got it! I'm not his therapist, I'm his wife.

**Caregiver Guide** from  
<http://www.caps4caregivers.org/guide.htm>

Caregiving can be complicated. Finding resources and making decisions is not an easy task. The entire family should be addressing caregiving issues. If elderly parents or chronically ill loved ones are capable, by all means, involve them in an open discussion of issues directly related to their future. If they seem reluctant at first, persist. It's far better to

Synapse – Autumn 2007 Edition Page 14

"air" their fears and yours now, while they are still capable. Be sure

to involve all siblings in the discussion even the "long distance"

children. If they can't be there, keep them well informed, preferably in writing. Informal letters serve well.

*General Issues* Who will be the principal caregiver? What involvement will siblings have? Which responsibilities can be shared? By whom? (Supervising medications, shopping, doctors, day care, etc.) Is communication open and honest between caregiver and elderly person or chronically ill loved one? Do family members share feelings and information?

*Financial and Legal* What is the person's financial situation? Is there a list of assets, their value, their locations? Is there a private pension? Is it mailed directly to a bank? Which one? What is the social security amount? Is it directly deposited? Where? Are there other sources of income? Annuities, stocks, interest, IRA's, CD's, safe deposit box? What are the debts? Mortgages, car payment? Is there a need to apply for SSI, Supplementary Security Income? Is medical coverage adequate? Is there a prescription plan? Long term care insurance? Medicare? Medicaid? Has anyone consulted an eldercare attorney? Has the elderly person or chronically ill loved one transferred any assets? What is the "time frame" in your state for transferring assets before being qualified for Medicaid? Is there a will, a living will, a power of

attorney, a durable power of attorney

that lasts beyond incapacitation?

Where are they kept? Is there an insurance policy? Where is it kept?

*Housing* What housing options are possible? Can the elderly person or chronically ill loved one live alone?

What about an assisted living facility? Is a nursing facility or a personal care facility needed? Is senior housing or shared housing an option? Is a life care community feasible? Has the person or family any "up-front money" available for some period of personal pay in a nursing home?

*Physical Condition* Has the person had a recent physical? Is there a family doctor?

What medications are being taken? By prescription? Over the counter? Ask the pharmacist or doctor if any medications interactions should be avoided. Ask if any meds should not be taken together. Any foods avoided?

*After Death* Are there any pre-paid funeral expenses? Any specific funeral wishes? What funeral home? A viewing? A family plot? Cremation? Any specific desires? Can you discuss death with the person for whom you are caring? Why not? Most of the elderly or chronically ill do not fear discussion of death.

**Resources for Caregivers AARP**  
A multifaceted resource for caregivers that offers information in

many forms. Visit AARP.org's Caregiving section at [www.aarp.org/caregiving](http://www.aarp.org/caregiving), or call 888- OUR-AARP (687-2277).

**Children of Aging Parents A** nonprofit group that provides support

Synapse – Autumn 2007 Edition Page 15

and information, including member's quarterly newsletter, to caregivers of the elderly or chronically ill. Visit the organization's website at

[www.caps4caregivers.org](http://www.caps4caregivers.org), or call 800-227-7294. **Eldercare Locator**

at the local level Sponsored by the U.S. Administration on Aging.

Specializes in putting caregivers in touch with resources in their own communities. Use the service's

website at [www.eldercare.gov](http://www.eldercare.gov), or call 800-677-1116. **National Family**

**Caregivers Association** An activist organization that supports,

educates, and represents those caring for chronically ill, aged, or disabled loved ones. Visit the

organization's website at [www.nfcacares.org](http://www.nfcacares.org), or call 800-896-3650. **Medicare**

The official government contact for all questions about Medicare and Medicaid

eligibility and coverage. Visit the Centers for Medicare & Medicaid

Services' website at [www.cms.gov](http://www.cms.gov), or call 800-MEDICARE (633-4227).

**The Care Dividend** *Excerpted from* Caring for Your Parents: The Complete AARP Guide *by Hugh Delehanty and Elinor Ginzler,*

*published by AARP Books/Sterling, 2005.* The rewards of caregiving are many and profound. Not only does it give you an opportunity to repay someone who gave you life and nurtured you when you were a child, it can also bring you closer to estranged loved ones and resolve long-standing emotional conflicts. As author Beth Witrogen McLeod writes, caregiving "has the potential to alter us at the core of our being, opening our heart's capacity to live fully even in the midst of loss." In a recent survey

researchers asked caregivers to describe their feelings. "Worry," "sadness," and "frustration" came up a lot, but the words they used most frequently were "loving," "appreciated," and "proud." What kind of caregiver will you be? Many people when they're starting out tend to think of caregiving as a fix-it project, says clinical psychologist and Buddhist meditation teacher Tara Brach, the author of *Radical Acceptance: Embracing Your Life with the Heart of a Buddha*, but that perspective has serious limitations. "If you think you're just doing a job, fixing a person who is weaker than

you, there will always be a wall between the two of you," she says. "But if you approach it with the point of view that the person you're taking care of is going through a natural process, a profound connection begins to grow. Trust occurs when somebody's vulnerable and lets you in—and you show up," says Brach. "It often isn't until we're sick and dying that we open up and let that happen." Caregivers who have the easiest time shifting perspective, says Brach, are those who aren't locked into patterns of denial. "If you're in the habit of avoiding uncomfortable situations, you will

probably take the position that something's wrong," she says. "But if you've developed a habit of honestly recognizing your own insecurities, then you'll probably find a place in yourself to tolerate it when someone else is experiencing pain and suffering." The key is self-forgiveness. Caregivers often punish themselves for not being perfect. But what does "perfect" mean in this situation? "Caregiving is painful," says Brach, "because you can't take away the other person's pain. You can't make everything okay. All you can do is love that person. And the deepest

Synapse – Autumn 2007 Edition Page 16

expression of love is paying attention. The more you're just being with the person, and not trying to fix him or her," says Brach, "the more you'll be able to see them as what Thomas Merton calls, 'the divine that comes through all life.' " Caregiving is a humbling experience. It forces you to move beyond narcissism to a more inclusive identity. "We spend so much of our time thinking 'How am I going to make myself comfortable?' 'How am I going to handle this future situation?' " says Brach. "But there's a tremendous amount of freedom that comes when you widen the circle of what you're paying attention to and include someone else." It's possible, of

course, to find this kind of liberation in other ways. But the day-to-day rigors of caregiving give you direct experience of the alchemy of selflessness. It helps you see, says Brach, that "there's more reality in togetherness than any idea of a separate self."

### **Medical Research Ed.**

*note: This Autumn issue of Synapse brings with it much information in the areas of research. Discoveries in the areas of mitochondrial involvement, environmental factors, disease models and SPG mutations have given scientists an even greater understanding of cellular dynamics,*

*disease onset and drug therapy. The PLS Registry continues to grow as a reliable sample for future research. With registry funding expiring in April, 2008, it is critical that all PLS patients enroll! (Details on registering are included below.) As you will see by the article briefs below, there is much reason for hope and celebration as we enter this holiday season! -- Betsy Baquet*

**ADVANCE IN REPAIRING LOWER MOTOR NEURONS OF RATS:**

Yan J., Xu L., Welsh A.M., Hatfield G., Hazel T., Johe K., Koliatsos V.E. Department of Pathology, Division of Neuropathology, The Johns Hopkins Medical Institutions, Baltimore, Maryland, United States of America. Recent findings dispute the notion of a spinal cord that is unfavorable to neuronal repair. Restoration of spinal cord circuitry in degenerative and traumatic disease may be more realistic than previously thought. Human neural stem cells were recently grafted into the spinal cord of normal or injured adult rats. Observations included large scale differentiation into neurons, forming

axons and synapses, and established extensive contacts with host motor neurons. Major challenges remain, especially with respect to the establishment of neuromuscular connections. SOURCE: PLoS Med. 2007 Feb;4(2):e39 <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4374>

**JOINT PROJECT BRINGS EXPERTISE TO BEAR ON ALS**

**AXON DYNAMICS:** ALS experts Raymond Roos, M.D, University of Chicago, Richard Morimoto, Ph.D., Northwestern University, and Scott Brady, Ph.D., University of Illinois, Chicago, will collaborate in an effort to model the disease in simple laboratory systems, such as rodent, worm and squid tissues. Their research will build on recent advances, and use new techniques in disease models. The focus of their efforts will be on the abnormal dynamics of material transport along nerve fibers. According to Dr. Raymond Roos, this

Synapse – Autumn 2007 Edition Page 17  
exciting collaboration “brings together individuals with very different backgrounds and expertise, different labs, and different institutions. This kind of interdisciplinary collaborative

approach provides a synergy to move the research along as quickly as possible.” Modeled mice with mutant SOD1, the protein altered in some inherited cases of ALS, provide a way to find out what goes

wrong in the disease and a way to test therapies. But simpler model systems, such as worms and squid tissues complement this established ALS model. Their transparency makes it possible to view changes in axonal transport more easily. Dr. Roos will also work with viruses in all three models to identify models that interact with mutant SOD1, preventing it from working normally. The new collaborative project will undertake the goals of finding out if existing drugs can counter the change in material traffic along nerve fibers (axonal transport) induced by mutant SOD1. If so, this could provide a platform for therapeutic investigation. As drugs already exist to affect kinases, including some in clinical testing in other diseases, the collaboration could yield rapid progress towards new therapeutics for ALS. SOURCE:

<http://www.alsa.org/news/article.cfm?print=1&id=1170&9/21/07>

### **A HEAVY TOLL FROM DISEASE FUELS SUSPICION AND ANGER A**

Middleborough, Massachusetts community await a report later this year that could reveal whether an elevated occurrence of ALS around a downtown industrial area is being caused by pollution. The cases are located within a mile of a densely settled neighborhood, Everett Square, which is adjacent to the town's former "factory row." The

federal Agency for Toxic Substances and Disease Registry are funding the study, which will be followed by the creation of a statewide registry to track cases of the disease. Town Selectman Wayne Perkins said: "For years, there's been a fear that something was here creating more of an instance of A.L.S. I'm concerned. I've always been concerned. It can't be undone, but it can be cleaned up." Suzanne K. Condon, director of the state's Center for Environmental Health, said an environmental link may emerge from the report. "About 10 percent of the time we do these types of cluster investigations we tend to see that the environment may have played a role," she said. SOURCE:

<http://www.nytimes.com/2007/10/07/us/07middle.html?ex=1192593600&en=d09677971b4796d0&ei=5070&mc=eta1>

<http://health.groups.yahoo.com/group/PLSers-NEWS/message/4382>

### **GENES AND ENVIRONMENT AND SPORADIC ALS**

"Paraoxonase cluster polymorphisms are associated with sporadic ALS" Saeed M., Siddique N., Hung W.Y., Usacheva E., Liu E., Sufit R.L., Heller S.L., Haines J.L., Pericak-Vance M., Siddique T.

Davee Dept. of Neurology and  
Clinical Neurosciences, Feinberg  
School of Medicine, Northwestern  
University, Chicago, IL 60611, USA.  
Researchers working with Teepu  
Siddique, M.D., Northwestern

University, Chicago, show that a risk  
to develop ALS is associated with  
mutations in the genes coding for a  
set of enzymes that detoxify nerve  
gas agents

Synapse – Autumn 2007 Edition Page 18

and chemically similar pesticides  
and insecticides called  
organophosphates. This association  
might explain why the veterans of  
the Gulf War have been reported to  
be at a possible two-fold increased  
risk of developing ALS. Soldiers  
serving in that war may have been  
exposed to high doses of such  
chemicals, researchers have  
speculated. Genetic variations in the  
enzymes coded by the paraoxonase  
gene cluster are associated with a  
strong susceptibility for ALS, the  
investigators demonstrated.

SOURCE: Neurology. 2006 Sep  
12;67(5):771-6

<http://tinyurl.com/yrhlm6>

<http://health.groups.yahoo.com/group/PLSers-NEWS/message/4365>

### **MUTANT SOD1 REDUCES AXONAL MITOCHONDRIA**

**CONTENT** De Vos K.J., Chapman  
A.L., Tennant M.E., Manser C.,  
Tudor E.L., Lau K.F., Brownlees J.,  
Ackerley S., Shaw P.J., McLoughlin

D.M., Shaw C.E., Leigh P.M., Miller  
C.C., Grierson A.J. MRC Centre for  
Neurodegeneration Research,  
Institute of Psychiatry, King's  
College, London, Denmark Hill,  
London SE5 8AF, UK. In model  
mice, mutant SOD1 damages the  
transport of both mitochondrial and  
membrane-bound organelle's  
(MBOs), but the precise details of  
this damage are specific to each.  
MBO transport is reduced in both  
the anterograde (forward) and  
retrograde (backward) directions,  
whereas mitochondrial transport is  
selectively reduced in the  
anterograde direction, resulting in  
depleted mitochondria in axons.  
Mitochondria in mutant SOD1 also  
showed features of damage. These  
factors combined are likely to  
compromise axonal function. These  
alterations represent some of the  
earliest pathological features so far  
reported in neurons of mutant SOD1  
transgenic mice. SOURCE: Hum  
Mol Genet. 2007 Aug. 28; [Epub  
ahead of print].

<http://tinyurl.com/2mjoc>

v

<http://health.groups.yahoo.com/group/PLSers-NEWS/message/4338>

**A NOVEL FORM OF AUTOSOMAL RECESSIVE HEREDITARY SPASTIC PARAPLEGIA CAUSED BY A NEW SPG7 MUTATION**

Warnecke T., Duning T., Schwan A., Lohmann H., Epplen JT, Young P. Dept. of Neurology, University of Munster, Munster, Germany The new SPG7 gene mutation leads to a novel complicated autosomal recessive hereditary spastic paraparesis phenotype that widens the spectrum of different brain systems that are optionally affected in hereditary spastic paraplegia

(HSP). In this novel phenotype, spastic paraparesis is related to cerebral damage of corticospinal tracts. Impairment of attention and executive functions is due to white matter loss in frontal lobes. Furthermore, supranuclear palsy is caused by white matter damage in the midbrain. This multisystem affection, which was detected by the use of diffusion tensor imaging, may reflect a mitochondrial dysfunction that contributes to the underlying pathogenesis of SPG7-HSP. SOURCE: Neurology, 2007 Jul. 24;69(4):368-75

**THE GENETICS OF HSP AND IMPLICATIONS FOR DRUG THERAPY**

Synapse – Autumn 2007 Edition Page 19

Zuchner S. University of Miami Miller School of Medicine, Miami Institute of Human Genomics, Miami, FL 33101, USA. szuchner@... Hereditary spastic paraplegia (HSP) comprises a group of clinically and genetically heterogeneous diseases that affect the upper motor neurons and their axonal projections. A total of 30 chromosomal loci have been identified for autosomal dominant, recessive and X-linked HSP. The underlying genes for 15 of these loci

have been described. The molecular dissection of the cellular functions of the related gene products has already greatly advanced our understanding of the most critical pathways involved in HSP. It is hoped that in the foreseeable future this knowledge will begin to translate into novel pharmacological approaches for this devastating disease.

SOURCE: Expert Opin Pharmacother, 2007 Jul 8(10):1433-9 <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4338>

[up/PLSers-NEWS/message/4347](http://PLSers-NEWS/message/4347)

**PARTICIPANTS NEEDED !! PLS Registry at Northwestern University Continues**

**Recruitment:** Program goal to include virtually all people in country who have been diagnosed with PLS The Neuromuscular Disorders Program and Neurogenetics Laboratory at Northwestern University, under the direction of Dr. Teepu Siddique, continues to recruit patients and families to be part of a PLS Registry for a study of sporadic or non-inherited PLS. Because the cause of PLS is unknown, we are trying to determine whether genetic factors may predispose an individual to developing sporadic PLS. The research team suspects that sporadic PLS may be the result of not one, but

several, genetic factors coming together and interacting with environmental influences to produce disease. Recent advances in the field of statistical genetics make it possible to answer such questions if there are sufficient study participants available. Based on one estimate of a possible 400-500 PLS patients in the country, it could be possible to anticipate the participation of most of these individuals in the PLS Registry, resulting in a high statistical power for these studies. To date the program has registered (meaning a

person has donated a blood sample and signed a registry consent form) 216 people who have reported a diagnosis of PLS. Many family members have also participated, and spouses have donated blood samples as controls. Blood samples are processed and DNA is stored so that analysis can begin when we have obtained a sufficient number of samples. Patients are also requested to complete a medical release form, family history questionnaire, and a soon-to-be- completed environmental exposure questionnaire. For those who are willing, the registry is also making arrangements for collection of spinal fluid samples and assisting with advance directive planning for tissue donation after the time of death. The registry covers expenses for obtaining samples locally and shipping them by FedEx to our laboratory. We encourage inquiries and hope soon to reach our goal of including virtually all the people in the country who have been diagnosed with PLS. To inquire about participating, please contact Grace Carlson-Lund, RN by phone at 312-503- 0160 or by email at [gcarlsonlund@northwestern.edu](mailto:gcarlsonlund@northwestern.edu). For additional information you can also visit the Neuromuscular Disorders Program website at

[www.neurogenetics.northwestern.edu](http://www.neurogenetics.northwestern.edu)

u or the ALS-PLS website at

[www.als-pls.org](http://www.als-pls.org). -- Grace

Carlson-Lund

## SP Foundation

### News

#### Quarterly Letter from the SP

**President Annette Lockwood** This year is going by way too fast for me. Only two TeamWalks – Houston and Nashville – are yet to be held. My sincere thanks go out to all of the TeamWalk coordinators and organizers. Thus far we have raised \$129,034 from TeamWalks and \$276,113 overall. It is never too late to join in fundraising for SPF whether it is participating in a TeamWalk, the Pennies Campaign or just raising money to fund research. It is up to each of us to do whatever possible to support the SPF mission of find the cures for PLS and HSP.

**Initiatives Amount TeamWalks**  
**\$129,034.00** Unrestricted **\$64,105.00**  
Annual Report 2007 **\$27,425.00**  
Miscellaneous **\$22,750.00** 2007  
Conference **\$17,465.00** Exxon-Mobil  
Workplace Giving **\$11,199.00**  
Pennies Campaign **\$4,135.00** Grand  
Total **\$276,113.00**

The 2007 research grant awards have been announced. Please refer to the Grant Chart below, prepared by Thurza for the details.

A committee has been formed to formalize the 2008 and beyond research grant process. The members of the committee are Thurza and Jim Campbell, Jean Chambers, Malin

Dollinger, Mark Weber, Don Wilson and Sarah Roberts-Witt. We look forward to the results of their efforts.

*Mark your calendar* - The 2008 National Conference will be held on April 18-19, 2008 at the Crowne Plaza hotel in Valley Forge, PA (near Philadelphia).

If you are interested in participating on the Development/Fundraising or Communications committee or volunteering, please contact me at 703- 495-9261 or

[annette.lockwood@sp-foundation.org](mailto:annette.lockwood@sp-foundation.org) . As we approach holidays, please remember to use the SPF shopping website if you shop online. Walk with us Today so we can Walk with you Tomorrow!

**A SPF Grant Recipient Publishes**

**his Work Contributed by Mark Weber.** The Spastic Paraplegia Foundation awarded Kendall Broadie, Ph.D. from Vanderbilt University two, one-year grants in 2005 and 2006 for work concerning HSP. May 15 of this year, he published an article in the Journal of Neuroscience Methods based on part of his work. He developed a new scientific technique to actually see

what he and others believe to be the cause of HSP caused by mutations in the SPG4/Spastin gene. (The cause is theorized to be a disruption of microtubule dynamics.) He then sought to prove that the technique was correct. He applied one of 2 drugs to fruit flies—one to stabilize microtubules and one to disassemble them. His technique worked as predicted.

Synapse – Autumn 2007 Edition Page 21

**SPF Grant Summary**

**Year Recipient Title Amount Of Grant**

**Final report**

**For**

**2003** John K. Fink, M.D., Director,  
Neurogenetic Disorders Clinic, University of Michigan

**Duration Of Grant** \$40,000 1 year yes PLS

Douglas A. Marchuk, Ph.D., Associate Professor of Molecular Genetics and Microbiology, Duke University  
"A Molecular Genetic

Analysis of Primary Lateral Sclerosis".

\$40,000 1 year yes HSP

**2004** Vincent T. Cunliffe, Ph.D. and

Jonathan D. Wood, Ph.D., Centre for Developmental Genetics and the Academic Neurology Unit of the University of Sheffield, UK

"A Mouse Model of Hereditary Spastic Paraplegia"

\$90,000 2 years yes HSP

Dr. Teepu Siddique, the Director of the Neuromuscular Disorders Program at the Feinberg School of Medicine at Northwestern University

"Modeling the neurodegenerative processes caused by mutation of the SPG4 gene in zebrafish and development of strategies for pharmacological intervention".

PLS

**2005** Michael R. Hayden, M.D., Ph.D. and

Blair R. Leavitt, Ph.D., Center for Molecular Medicine and Therapeutics, University of British Columbia, Vancouver  
"PLS Registry" \$90,000 3 years Due

spring 2008

HSP and PLS

Brett Peter Lauring, M.D., Ph.D., Department of Pathology, Columbia University College of Physicians and Surgeons, NYC

"Revealing the mechanisms

\$149,896 2 years Due underlying ALS2, a form of

fall hereditary spastic paraplegia,  
2007 using ALS -/- mice".

HSP

Peter Hedera, M.D., Department of Neurology, Vanderbilt University, Nashville

"Analysis of Spastin and Atlastin

\$96,701 2 years Due in the cell biology of neurons".

fall 2007

HSP

Kendall S. Broadie, Ph.D., Department of Neurobiology, Vanderbilt University, Nashville,

"Invertebrate model of hereditary

\$90,000 2 years Due spastic paraplegia"

fall 2007

HSP

Jeffrey Macklis, M.D., Director of the Massachusetts General Hospital-- Harvard Medical School Center for Nervous System Repair, Boston

"Mechanistic interactions among

\$54,673 1 year Due hereditary spastic paraplegia

fall genes"

2007

PLS

**2006** John K. Fink, M.D., Director,

Neurogenetic Disorders Clinic, University of Michigan

"Molecular genetic controls over

\$121,660 2 years Due the development, connections,

fall and survival of upper motor

2007 neurons"

HSP

Jeffrey D. Macklis, M.D., D.HST Dir. of the Harvard Stem Cell Institute, MGH-- Harvard Medical School Center for Nervous System Repair. Paola Arlotta, Ph.D., Assistant Professor at the Harvard Stem Cell Institute and the MGH

Center for Regenerative Medicine

"Developing treatment for

\$120,000 2 years Due childhood onset hereditary

fall spastic paraplegia (SPG3A HSP)"

2008

PLS

Nina Tang Sherwood, Ph.D. Assistant Research Professor, Duke University

"Molecular Controls over the

\$125,000 1 year Due Development, Connections, and

fall Survival of Upper Motor Neurons"

2007

HSP

Kendall S. Broadie, Ph.D., Department of Neurobiology, Vanderbilt University, Nashville

"Understanding the ameliorative

\$120,000 2 years Due effects of temperature in fruit fly

fall models of AD-HSP"

2008 "Mechanistic interactions among

\$57,070. 1 year

Due

HSP hereditary spastic paraplegia

extention

fall genes"  
of '05 grant  
2007

## Synapse – Autumn 2007 Edition Page 22

**For Year Recipient Title Amount Of Grant 2007** Bruce Horazdovsky, Ph.D., Associate Dean of the Mayo Clinic College of Medicine, and senior consultant to the department of biochemistry and molecular biology and the Mayo Clinic Cancer Center (Rochester, MN)

### Duration Of Grant

PLS

Peter W. Baas, Ph.D., a professor in the departments of neurobiology and anatomy, in the College of Medicine, at Drexel University (Philadelphia, PA) "Development of a cell culture

\$58,000 1 year Due system to analyze defects

fall associated with Primary Lateral

2008 Sclerosis"

"Mechanistic Basis of SPG4-

HSP based Hereditary Spastic Paraplegia"

Stephan Zuchner, M.D., the director of the Center for Human Molecular Genetics at the Miami Institute for Human Genetics in the Leonard M. Miller School of Medicine (Miami, FL)

\$140,000 2 years Due

fall 2009

HSP

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"Molecular and genetic analysis

\$135,561 2 years Due of the SPG31 gene REEP1".

fall 2009

## Synapse – Autumn 2007 Edition Page 23

### Final report

## TeamWalk Photos

Continued



**Massachusetts** “T” with his service  
dog and mother Pat led us on the  
Walk

Mallard  
Lake

people had a good time participating **Ohio** TeamWalkers relax at the

**North Carolina** Organizer Sarah Witt Walk in Raleigh underway **SAWCAR** racers at the starting line  
walk on Long Island  
izer Mark Dvorak  
brafish  
ter

Phil playing guitar before start  
of TeamWalk  
Phil playing guitar before start  
of TeamWalk

**New York** SP banner leads the

**Pennsylvania** Registration Organizer Sue Me and family Some of the 75 participants

**PT** – Jane Anne King at therapy **PT** – Jerry Simmons at therapy **CampAward winner** – Liz Kepper