

Synapse

Summer 2007

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



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Synapse Editorial Troika Created

Contributed by Thurza Campbell

Beginning with this Summer, 2007 issue, two new editors have begun sharing their talents. Betsy Baquet has taken over Medical Research. Sarah Roberts-Witt is now in charge of Events. I will continue with SP Foundation, Living and Caregiving. Jim will, as always, refine the copy and post it at the website. I was thrilled when Betsy and Sarah said, "yes" to my request for help. My typing has slowed a lot as my disease has moved into my hands. I'm sure you'll enjoy their work.

EVENTS

Events Reports

Tales of a Spring Fling Newbie

Contributed by Sarah Roberts-Witt, editor

From my first forays onto PLS Friends, it was clear that this event called Spring Fling was something to behold. The same appeared to be true of its founder, the inimitable Ronnie Grove. Neither one disappointed upon my first trip to Berkeley Springs, WV, this April. Ronnie's Spring Fling is among the first, if not the first, organized gathering of PLS patients ever held, and this year marked its seventh anniversary. My traveling companion Kathy Dobbs and I had

barely rolled into the lobby of the Berkeley Springs Best Western, when a big friendly voice hollered "Are you Sarah?" As Ronnie gathered me up in a hug, I knew we had arrived. Ronnie's hug was the first of many wonderful moments that weekend. Seeing the familiar faces of Don and Bettie Jo Wilson and Bettie Jo's caregiver, Tracy, was of course a plus, as was making the acquaintance of many other PLSers, HPSers, and their family members and caregivers. In attendance this year were the following: Ed (PLS) and Carol Ames; Carolyn Sartain Anderson (PLS) and her daughter Sarah Oglesby; Martin (PLS) and Mary Ann Beckner; Vivian Crouse (PLS); Sarah Duncan (HSP); Ronnie Grove (PLS); David (PLS) and Lois Lehman; Annette (HSP) and Steve Lockwood; Lige Miller (PLS), his son Ben Miller, and his caregiver Dick Creamer; Jim (PLS) and Barb Spencer; Don and Bettie Jo (PLS) Wilson; Sarah Witt (PLS) and Kathy Dobbs; and Frank Young, the husband of Jeannie Young who died of ALS in August 2006. The festivities started with a getting-to-know-you dinner at Francis Asbury United Methodist Church on Friday night. Everyone reconvened Saturday morning at Wesley Chapel United Methodist Church where Annette Lockwood walked us through presentations made by researchers at SPF's national conference in Nashville. Of particular interest to the crowd of mostly PLSers were those from Dr. Richard Bedlack of the Duke ALS Clinic and Dr. Mary Kay Floeter of NIH (for more details on these, see the spring issue of Synapse). Once again, the women of the Methodist Church provided a fabulous meal and the attendees offered the fellowship. We gathered again that evening for dinner at a near-by restaurant. Though sharing food and finding out the latest research developments was terrific, for me, the highlight of Spring Fling was simply being around others who are struggling with the same issues that I am. Being able to converse with another person who, like me, no longer has the use of his or her voice is, as the commercials point out, priceless. Though others can empathize,

the only ones who can truly understand are those who must also use alternative means to communicate. The same goes for walking difficulties, hands that won't cooperate, the frustration of being confined to a wheelchair, and the myriad challenges that accompany motor neuron diseases.

But along with the tough stuff, there was much laughter, much positive energy, much sharing of useful information, and, above all, the example of Ronnie's fierce dedication to bringing people together. For that, I believe I can speak for all who made the trek to West Virginia with a heart-felt thanks.

The Southern California Connection

Contributed by Malin Dollinger

The Connection was held on Saturday afternoon June 16, at the Long Beach, CA Convention Center. There was a three-day Abilities Expo being held there, and we took advantage of that event. The Abilities Expo had, as usual, many exhibitors of accessible vans, wheelchairs, scooters, transfer devices, special items for children, lawyers who specialize in disability law, lots of special gadgets to aid walking, sitting, bathroom needs, sleeping, etc.

Our meeting began at noon on Saturday. We had about 25 people in attendance, including a family from Jordan with HSP. The meeting began with a description / discussion by Malin Dollinger of his own medical history. We had an opportunity to discuss the signs of upper vs lower motor neuron disease [former; muscles are spastic, reflexes are overactive, and Babinski's sign is present] [latter: muscles flaccid, reflexes decreased, and Babinski sign absent]. We then discussed the specific symptoms, nature, and progression of HSP and PLS, and the differences, and then some general discussion of genetics.

We had a presentation by Paul Webber, a very skilled therapist, of the Walk-Aide device, in which there is a sophisticated electrical device, about half the size of a pack of cigarettes, strapped to the leg below the knee. This "fires" the peroneal nerve/muscle, which lifts the toes every time a step is taken. The rest of the time

was informal.

I would like to thank all the participants, who made a great effort to be there and to share their experiences with us (as well as the donations), to Paul Webber, who made a great contribution by educating us about the Walk-Aide device, and to the Abilities Expo, who supplied the room and the setup/ chairs/ tables/ etc without any fee.

SP Connection, Norristown, PA

Dr Beister from the hospital of the University of PA was the featured speaker at this SP Connection. Dr Beister treats patients with neurological conditions and does research on brain activity with trauma, birth defects. She is also a psychologist.

Upcoming Regional TeamWalks

Walk with us today, so we can walk with you tomorrow

Linda Gentner, Coordinator

Please contact the coordinator of each walk for details. For a copy of the Sponsorship Form see the next to last page of this issue.

Toledo, OH TeamWalk

Aug 11, 10:30 am, Oak Openings Metropark, Mallard Lake Shelter
Moirra Franchetti: moirrafranchetti@sbcglobal.net, 419-865-0517

Orlando, FL TeamWalk Retreat Weekend

Held in conjunction with Living With A Disability Expo, Gaylord Retreat
Aug 25-27, Travelodge Hotel
Kathi Geisler: kathigeisler1@aol.com, 978-256-2673

Elysburg, PA Connection and TeamWalk

Sept 9, Knoebels Amusement Resort
Cassandra Scholzen: hotlips4041@yahoo.com

Waltham, MA Connection and TeamWalk

Sept 8, 10:30 am, Best Western TLC Hotel
Kathi Geisler: kathigeisler1@aol.com, 978-256-2673

Raleigh, NC TeamWalk and Magnificent Mile Race

Sept 16, 2 pm, downtown Raleigh
Sarah Witt: srwitt@yahoo.com

Norman, OK TeamWalk

Sept 22, 10 am, Andrews Park
Mark Dvorak: czechmarkmhd@yahoo.com, 405-447-6085

Long Island, NY TeamWalk

Sept 29, 12 noon, Wantagh Park
Betsy Baquet: ebaquet@optonline.net, 516-520-5906

Pleasanton, CA TeamWalk Weekend

Oct 5, 5:30 pm dinner, Hilton Hotel
Oct 6, 10 am, Valley Community Church
Linda Gentner: lkgentner@aol.com, 510-651-5676

Thomasville, GA TeamWalk

Oct 13, 11 am, Plaza Restaurant
Jane Anne King: gking@rose.net, 229-227-0558

Houston, TX Texas Two-Step TeamWalk

Oct 20
Brad Hendricks: 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, 615-479-7369
Terri McDonough:
terri.mcdonough@jeepthing.net, 615-278-0489

TBD

Annapolis, MD TeamWalk

Shannon Gregory: segregory20@verizon.net

Portland, OR TeamWalk

Cathy Cummins: ccumminsdc@earthlink.net

Other Events

Autumn in Carolina

Annual SAWCAR Race
Don Wilson: don-wilson@earthlink.net, 336-969-6748

SP FOUNDATION

Letter from the SPF President

The SPF has retained Edit Reizes as a Development Consultant on a part-time basis. Edit has over ten years of experience working with nonprofits in the development area. She will assist SPF solidify and increase our fundraising operations with a special focus on grants. As Fall approaches, many are busy getting ready for our major fundraiser events – TeamWalks. Right now there are 13 that are in some stage of preparation. TeamWalks are being held again in California, Georgia, Maryland, Massachusetts, New York, North Carolina, Ohio, Oklahoma, Oregon and Tennessee. Three new locations have been added this year – Florida, Pennsylvania and Texas. Please come join us at one of the TeamWalks if you can. If not, please join us in this effort as a Walker by Proxy. Simply collect donations in your name, just as though you were the one walking. If you'd like, you can hold your TeamWalk in your home or neighborhood while someone is walking for you in California. With more people participating, you will be surprised at how much can be raised during the TeamWalks. Participating in a TeamWalk or being a Walker by Proxy is just one way to help us raise money for medical research. SPF is now listed on MissionFish which is the nonprofit section of EBay. For those that sell products on EBay, a percentage of the final price can be donated to SPF. Saving Pennies for SPF is another opportunity to help SPF. Use www.GoodSearch.com as your Internet searching because every time you do, money will be donated to SPF. Also, the Combined Federal Campaign for government workers will begin in September, our code number is 12554. All of these donations will support Research Awards to find the cures for HSP and PLS. For those that were unable to attend the National Conference in Nashville, a DVD set is now

available. The video features the four keynote speakers, Drs. Richard Bedlack, John Fink, Mary Kay Floeter and Peter Hedera. SPF thanks the broadcasting department at Brentwood High School, Brentwood, TN directed by Mark Madison for volunteering to video tape this conference for us. The DVD set is available for \$20.00 and can be ordered online or by sending a check to the address below.

Recently, we mailed the 2006 Annual Report out. If you did not receive it and would like a copy, just let me know (contact information below). During the next few months, SPF will be re-organizing our committees. The committees in need of volunteer members are – Communications, Development (Fundraising), Educational Programs, Grant Writing and Research Grants. If you are interested in serving on a SPF Committee, please contact me. Annette Lockwood annette.lockwood@sp-foundation.org
7700 Leesburg Pike, Ste 123
Falls Church, VA 22043

Statement of Activities for the Year Ending December 31, 2006

		2005	2006
Revenue:			
	Donations	\$ 99,704	\$ 129,486
	TeamWalk	186,412	203,200
	Special Events	32,310	160,873
	Program Fees & Products	12,464	12,488
	Investment Income	12,449	18,362
	Total Support and Revenue	\$343,339	\$ 524,409
Expenses:			
	Fundraising	\$15,432	\$ 8,858
	Management and Admin.	11,655	50,413
	Program Expense	7,120	10,970

	Total Expenses	\$ 34,207	\$70,241
	Grants Pledged	\$512,930	\$422,07

Where your dollars go –

87% Mission

13% Management and Fundraising

The primary mission of the Spastic Paraplegia Foundation is to find the cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. It is therefore our intent to aggressively seek to minimize overhead expenses. SPF is managed and operated mainly by volunteers. All donations are fully tax deductible (Federal tax ID #04-3594491).

How to Find Sponsors for a TeamWalk

TeamWalks are a major fund raising annual effort for research. Everyone is encouraged to participate either as a Walker (by walking, or in your wheelchair) or as a Walker by Proxy (An assigned Walker will wear your nametag and walk for you in your honor in Pleasanton, California). How do you solicit financial support? Make a list of your friends and family members. Ask people directly, write a personal letter, telling people what you are doing and that you are asking for their support. Print out the Sponsorship Form and mail it and your donations to SPF TeamWalk, P.O. Box 1208, Fortson, GA 31808. You might also ask for sponsorships from your place of work, your civic group or religious organization, and places you do business.

Connection History

Contributed by Ronnie Grove

Back in "those days" connections were just starting and hardly any of us had met another person with PLS or HSP so it was a really big deal to get to a connection. From those humble beginnings there are now connections being held every where---some small, some not so small---so it just doesn't hold the same excitement as it did 5 or 6 years ago. Look at the number of new people signing up. And right away they get

information that took some of us years to attain. We pioneers thought we were the only people in the world that had this stuff. Now new people find out much quicker than we did that not normal is normal for PLS. As the ad says, "We've come a long way, Baby." and we did it is an awfully short period of time!!! I'm proud of all of us that were part of getting this big old ball rolling. It really is one of those situations "where you had to be there". I don't mean it is any less scary for any newcomer but because of all our accomplishments, we who were here from the beginning, can understand how it certainly is just not the same. I'm very happy about that. It means we are doing our job and getting better at it. I bet every time a new connection is held it encourages a couple more. Just think from the first small meetings in Florida with Joe Alberstadt to several small connections in Vienna, Va to the BIG one in CT to how many last year alone???? I think we should all be proud!

Contributed by Linda Gentner

We had a Large Connection in San Diego that Jennifer Thomson and I did which sparked the idea of the first International PLS Symposium. At the Connection, Drs. Siddique, Fink and Armon were present. The Connection was quite a weekend with people flying in from all over the country -- first time I met Bebe Leon and Linda Lordi from NY. The good old days when we were all so thirsty for education and camaraderie -- not that we still aren't, but nothing like the very beginning of our journey.

LIVING WITH HSP/PLS

Beach Advice

Ed. Note: Following is a compilation of beach advice prompted by Cathy West's questions. How will I walk in the sand? How will I get up when I fall? Is the ocean water going to knock me down? Should I go? From Maureen: I had extreme trouble walking on the sand, not because of balance but because of the "hot sand. Rule no.1 wear running shoes for

walking in hot sand.

Rule no 2. Don't go in the sea by yourself. I think that so long as you have someone with you that is strong enough to pull you up from the beach chair or towel and that same

person is able to help you in the surf, then you will be ok. We have to push our boundaries and not think, "oh its impossible for me to do that".

From Tawny: Many spots will have beach wheelchairs....at least here in FL they are required to have at least one that is first come first serve. Perhaps you could rent one while there so that you can at least experience the beach.

From Linda: My sister and my dad joined us and we went to a medical supply store in Myrtle Beach and rented a scooter for my dad. They had 2 beach wheel chairs for rent -- with the big balloon tires.

From Dennis: Cathy go to the beach. I use a walker with little skis on the legs so I do not sink in the sand. Have fun

From Eva: Go to the Beach! Cheapest thing to do is get a used folding walker for about \$15 and put tennis balls on the legs. Here at Daytona Beach several miles of the beach are set up for beach driving and parking right on the sand and right along the main hotel section. A handicap tag makes beach driving free AND gives the ability to park surfside (with caution !!) Four-wheel drive is NOT needed. I know other beaches such as Nags Head, NC have beach driving at remote areas that require four-wheel drive.

From Jerry: I found on a beach at least on the north Gulf of FL the sand is pretty packed. I used my cane with no problem. I saw a.few other people using crutch canes.

From Flora: GO and take the chance to have fun with life. Don't worry about the people staring at you. For years I let that keep me from doing the things I really wanted to do.....now I could care less!

From Jon: I have been going to the Shore..its how they say beach in Jersey...all my life. This is the first summer I really have been affected by PLS. Am I going this year? You bet. I will deal with all

the sand water issues when I get there. Hey if I can't get out of the water, my wife can just push me to the shore and I can crawl out lol....even if I just sit with a fishing pole in the water I am going..

Pool advice

From Colleen: I need to know from you 'poolies' out there if swimming makes you more spastic. I just got back from a couple of weeks of vacation and the last few days we had access to a pool. When I would get out of the pool (which required needing help), I could hardly move. Is it me? or does swimming knock your legs out? Of course, being in the pool feels so much better whilst actually in the water. I was such a water rat in my younger days.

From Sue Me: When hubby and I went away there was an outdoor pool and he "made" me go in it. It was cold but after I was immersed I could swim a little and I didn't seem to have problems when I got out so I am thankful for that. We went right into the hot tub and boy did that feel good!! We are going back in July for another conference and I am

looking forward to swimming with my boys!

From Maureen: If you are talking about a heated pool, I was told by the instructor that I could only stay in for about 30 minutes because when you get out your legs go all wonky and heavy.

From Tawny: I actually had to stop using the pool at my Y because the water wasn't warm enough and upon getting out i was just one big spaz. The water really helped my upper body and released the spasticity while in there. When I was in the heated pool during pt, it was almost immediate release upon entering.

From Thurza: I had PT in a 'therapy pool', heated to 100 degrees F. The directed exercises with 'wacky noodles' were liberating! I walked, pedaled in deep water, did stretches all unassisted. In chest deep or deeper water is the only place I can walk relaxed. Swimming is a thing of the past for me, a former swimming instructor, but now I focus on new ways of enjoying the water.

Access to Recreation

<http://www.accesstr.com/> 1-800-634-4351

Any of the products below can be ordered by calling the number above.

Most Popular Pool Lifts

PAL Pool Lift
Splash Pool Lift
IGAT-180 Pool Lift
Swim Lift Gallatin
PRO Pool Lift
The Spa Lift
Pro Spa Lift
Elkhorn Pool Lift
AG48 Pool Lift
Selway Spa Lift

Most Popular Beach Wheelchairs

Hippocampe -All-Terrain Power Wheelchair
TracAbout All-Terrain Power Wheelchair
Extreme 4x4 All-Terrain Power Wheelchair
Beach Cruzr Power Wheelchair
Landeex All-Terrain Wheelchair
De-Bug All-Terrain Wheelchair
Tremor All-Terrain Wheelchair

Most Popular Exercise Equipment

Equalizer 1000 Multi-Station Weight Training
Equalizer 6000 Single Station Unit
Easy Stand 6000 Glider
Challenge Circuit 7000 Fitness Center
Saratoga Family of Cycles

Encouraging words

Contributed by Ronnie Grove

Encouraging words are like attitude. Most of us are just about as happy as we make up our mind to be. It never ceases to amaze me at some of the stupid things doctors say to patients! It is like suspicion. All you need to do is plant a little suspicion in someone's mind and they will work in the rest of the story. Just ask someone at work, "Did you see who Missy was riding with this morning?" And by evening Missy and someone are going to be having an affair! If the doctor tells you you are doing great then you will. If he acts like this disease is a killer you will pick up that feeling!

When I was going to Wellness and Weight Management one of the things drummed into our

heads was that for years our computers (brain) had been taught that doctors were next to God and could do no wrong. We needed to re-set the computer. Doctors are not always right. Ask anyone in this group! And doctors don't necessary know more than we do about some things. Doctors are trained to heal you when you are sick. But learning to keep yourself well was the goal of Wellness classes. Doctor aren't taught to do that. We need to learn to do that for ourselves because we won't get that help in the doctor's office. For me, that starts with a healthy, positive attitude. I dare any doctor to tell my I'm dying. Shoot! We are all dying. That's the procedure. Birth, live, die. But I don't need a doctor to try to hurry things along by making it sound like it's going to happen real soon and I better be enjoying the time I have left. Find what makes you happy and stick with it. PLS just isn't all bad unless you let it be!!!!

Source for Assistive Devices

Tawny recommends

<http://www.activeforever.com/> 1-800-377-8033
for good prices on everything you might need. They carry home and gardening aids, nutrition supplements, mobility devices, and much more.

Make-a-Wish

Contributed by Sarah Roberts-Witt

Well this morning started with Kim, our family's long-term babysitter, taking herself, me, and our son to his preschool. She and I were "helping parents" and my son was the day's special helper. When we got home, the driveway was full of trucks and a van from the local NBC affiliate. Unbeknownst to me, Kim had e-mailed the station in regards to their make-a-wish foundation program months ago. She had explained my situation and how we needed a stairlift to get me up and down since I can no longer do stairs and my kids' bedrooms are on the second floor. The station decided to grant her's and our wish!!!!!! So I now have a brand-new stairlift to take me to the second floor of our house!!!! I was crying like a baby for all of Raleigh to see. It was such an incredible gift, I had to share.

Accessible Travel Resources

www.disabilitytravel.com 1-800-846-4537
www.disabledtravelers.com Jeremy Rynders;
P.O. Box 492; Yucca, AZ 86438
www.emerginghorizons.com *Emerging Horizons*
is a quarterly publication about accessible travel
for people mobility disabilities.
www.opendoorsnfp.org **773.388.8839**
www.travelguides.org 804-633-6752

www.sath.org 212-447-7284

www.universaldesign.com (301) 270-2470
<http://www.whenwetravel.com/> wheelchair
accessible hotels, restaurants and cruises

The Segway

Contributed by Kathi Geisler

When I was in FL, I took a Segway tour in Sarasota with Bruce, a gentleman with PLS who lives in Tampa. I had taken this tour about a year and a half ago. When I did it the first time, I was amazed at how well I could do it. I was worried about my balance, of course. But these things are like magic. They adjust immediately to your shifts in balance so you don't fall! In fact, I felt more stable on it than standing on the floor! It was a 2 hour tour and we went through the off-roads of Sarasota. The Tour Guide talked about the homes and history and since Bruce is an architect, he loved it. We made our way to the bay front where we took a rest and photos. Then we made our way back. Each time, we were standing about 40 minutes. As long as you can stand for that period, you could probably do a Segway.

On The Road to Being Disabled

Contributed by Jon Marino

Imagine for a minute being active your whole life. Camping, hiking, climbing mountains, body surfing in the ocean at the shore, scuba diving across the Caribbean and raising two children. Did I mention working for thirty three years hardly using a sick day! Then at fifty-six when all the hard work is supposed to pay off a sleeping demon in your brain awakens and changes your life forever. How can this happen, how does one cope and rationalize that life goes on. Yes, for

now it does but in this topsy-turvy life everything is different. I am now "disabled" and I have my state issued hang tag to prove it. How do people at work, friends, relatives and strangers react? What do they really think? Most are kind and concerned but there is a change in their interaction and there is pity in their eyes. You can't hide that. As I walk away I can feel them shaking their heads thinking what a shame. But this is reality and I intend to make the most of it, the other alternative is not an option.

The road to getting to this point is worth telling. It's a strange journey that I hope gives some insight into health care from a lay perspective. There is the good, the bad and the ugly. It was stressful, exhausting and time consuming. I am not anti-medical profession but I have come to realize a lot depends on who you happen to interact with as there is a wide gap of knowledge and interest. It has made me at times angry and confused. It may have fostered a bit of sarcasm but it is a coping mechanism, a defense in a very stressful situation. If any health professional could slip on a disabled persons shoes for one day health care would be very different, but I am a new comer and my views may change down the road. I am very fortunate to have the strong support of my wife without who I may be telling a very different story. This has changed her life as much as mine.

In 2005 I noticed something strange. The reflexes in my left hand were slower than my right. Tapping fingers together was slow as well as flipping hand over, palm up then down. It also felt a little weaker. I went to my Family Primary doctor on an unrelated issue and mentioned it. He shrugged it off and dealt with the problem at hand. A couple of months later I began to limp a little. He said to go see an Orthopedist. I again mentioned about the slow reflexes. Again he put nothing to it and sent me off. The Orthopedist sent me for an X-ray on my left knee. Found nothing unusual but told me to try Physical Therapy. So off I went to PT. The physical therapist was at a loss but had me exercise and go through the standard knee strengthening

exercises. Frustrated at seeing no results I went to another PT closer to home. There I was given a thorough exam by a young doctor who had a PhD in Physical/Rehab medicine. He immediately picked up that there was something neurological going on and told me to get a referral to a Neurologist. Neurologist #1, ordered MRIs and an EMG, all negative. Scratching his head he suggested I go see Neurologist #2. We talked a little and did the push pull exam. He said I should go see Neurologist #3. He suspected something but did not elaborate. Neurologist #3 was the head of the ALS Center at a teaching hospital. I immediately did a search on ALS. I could hardly finish reading as the tears blurred my vision. He did another EMG. The test went well with no pain. He explained he did not think it's ALS but PLS being Primary Lateral Sclerosis. He continued to say it could get better, could get worse or stay the same. I think that covered all the bases. Could it turn into ALS? Maybe. I did more research and found that PLS is not life threatening but it is life altering. Walking, speaking, cramping. Socially and emotionally life is now going to be quite different. I next went to see the Director of the MDA clinic where I work. She is the first person to give me cause for hope. She will not accept the broad term of PLS. Yes I have spastic muscles but she wants to know why. She is willing to try treatments. As long as I can walk I will, no matter how slow or off balance. He meant well but was way off base. I will deal with that issue when the time comes, but it's not now. So how does it feel to be disabled? As PLS affects the muscles my speech is slurred and slow. Communicating is labored and frustrating. I imagine the first impression is I had one too many. Sadly that's not the case. So how do they react? People act differently. Some show pity, some over compensate as if suddenly I am a five year old. Some just ignore it which I have mixed feelings about. Comments such as "that don't look like fun" referring to my walking and "you're too young to be this way" are true but insensitive. Most people give encouragement and are genuinely concerned which is appreciated.

One of the hardest things for me to overcome was using a cane. Its pride and embarrassment, it's a statement that I am indeed compromised. The first time parking in a disabled space was traumatic, it validates being disabled and it's hard to accept. There is also the whole issue for my wife as well as myself - dealing with denial. So many tests all negative. Is it real? Maybe I should just go see a psychiatrist. I wish it was that easy and a few sessions on the couch would do the trick. But unfortunately it's very real. The one genuine hope is stem cell research and treatment. Hopefully advances will come soon and rescue countless lives.

I recently went to California to my son's wedding and a weekend trip with four close friends. On both trips family and friends were helpful and supportive. They all accepted the cane, speech and disabled parking as part of who I am now. With my family and friends support as well as my Neurologist I will fight to stay strong and improve. My wife who I love and depend on cracks the whip having me do yoga, acupuncture, exercise and eat right. I thank God for her help and patience. Life will go on. I WILL swim in the ocean again!

Jane Ann King at NIH

The red noodle-looking thing is called a diffusion tensor image (DTI). It is a 3-D reconstruction of the corpus callosum that connects the left and right sides of the brain. This is an experimental technique for diagnosing PLS/HSP. This allows the radiologists to see bundles of axons as they leave the brain and descend the spinal cord. If there is degeneration in the axons, DTI may allow radiologists to see it. It is being used to diagnose MS and other conditions. Fortunately for the patient, unlike EMGs, the testing is painless - no needles!

Tour De Nez Criterium

Contributed by Geoff Kettling

Friday and Saturday, June 16-17 was the Criterium (how many laps can you do in allotted time) called the Tour De Nez. We had about 8 hand cyclists, 6 in the para division 2 in the quad

division. Friday in Truckee California I came in last in the para, and Saturday I came in 4th. Winner of both events was John Kirsch CEO of Sportif.

PatientsLikeMe

www.patientslikeme.com

Founded in 2004 by three MIT engineers whose collective experience spans from running the world's only non-profit biotechnology laboratory to large-scale online commerce applications, PatientsLikeMe is a privately funded company dedicated to making a difference in the lives of patients diagnosed with life-changing diseases. Our personal experiences with ALS (Lou Gehrig's disease) inspired us to create a community of patients, doctors, and organizations that inspires, informs, and empowers individuals. We're committed to providing patients with access to the tools, information, and experiences that they need to take control of their disease.

In 1998, a young carpenter named Stephen Heywood was diagnosed with ALS. The Heywood family began taking charge of Stephen's care, searching the world over for ideas that would extend his life and improve the way he lived. This set in motion a series of events that have led to PatientsLikeMe, a new system of medicine by patients for patients. We're here to give patients the power to control their disease and to share what they learn with others. We're here to help you.

Our goal is to enable people to share information that can improve the lives of patients diagnosed with life-changing diseases. To make this happen, we've created a platform for collecting and sharing real world, outcome-based patient data and are establishing data-sharing partnerships with doctors, pharmaceutical and medical device companies, research organizations, and non-profits. Contact us if you're interested in working together to achieve our goals.

Our operating costs will be covered by partnerships with healthcare providers that use anonymized data from and permission-based access to the PatientsLikeMe community to drive treatment research and improve medical care. We

only share anonymized data with trusted partners and all our patient information is kept safe and secure.

Ed. Note: SP has been in touch with PatientsLikeMe, inquiring whether/how patients with our disorders could be included in their data base. Right now, it would be cost-prohibitive. Some PLSers are included now under the ALS umbrella.

Genetic Nondiscrimination Act Passes in House

Contributed by Mark Weber

The U.S. House of Representatives passed the Genetics Non-Discrimination Act in late April by a vote of 420 - 3. (9 not voting) (For a list of every Congressman's vote, please see <http://clerk.house.gov/evs/2007/roll261.xml> .This could be the year for this important piece of legislation. The Senate passed it last year and its chances of passage there again seem very good. Further, the President has stated that he will sign the bill into law.

Congratulations to the Genetics Alliance and the Coalition for Genetic Fairness for the fabulous work they did over the past several years in getting this through the Congress.

CAREGIVING

Four Kinds of People

Don Wilson found this quote by Rosalynn Carter
"There are only four kinds of people in the world:
Those who have been caregivers;
Those who are currently caregivers;
Those who will be caregivers; and
Those who will need caregivers."

Continue Driving or Not?

Contributed by Jim Campbell

The decision to stop driving has to be one of the toughest choices to make in anyone's life. We associate driving with control, personal freedom

and what we see as a necessary convenience. The decision to stop has a degree of finality knowing it would be difficult if impossible to pass a drivers road test to renew the license. The decision also raises concerns over whether the patient's transportation needs will be met in timely fashion. These concerns make it too difficult for many patients to make or accept the decision when they should.

Both HSP and PLS often involve symptoms that hasten the need for a decision to stop driving. The symptoms often slow foot and leg movements thus increasing the stopping distance in a panic stop. Medications can affect alertness and judgment as well. But stopping driving before rather than after the symptoms become a significant liability is not easy to do.

As chief caregivers we can make the decision easier and help with the transition in several ways. Most importantly we can assure the person we will be ready and willing to take them on errands without question. This may mean regular trips to the grocery store, accompanying them to the beauty parlor and doctor's office, shopping for personal items for the person, offering to take them for sightseeing rides or to visit relatives or friends. Speaking personally, I know Thurza and I have some of our best talks in the car while driving on errands together where neither of us is distracted – except of course by the ever present cell phone.

The added driving responsibility can be shared with others besides the chief caregiver. Many friends and relatives are just waiting to know how they can help. You can suggest they call periodically to see what errands or rides are needed. Also most communities have a public transportation service that for a reduced fee will take someone handicapped to a local destination or medical appointment.

We can also help identify ways to replace the car such as businesses which include delivery in their regular services – local pharmacies, grocery stores, take out restaurants especially pizza. In addition we can introduce them to on-line shopping where virtually anything can be

purchased today including clothing, electronics, movie downloads and medications to name a few categories.

There's no doubt about it - the decision to stop driving does have an impact on both the patient and the caregiver. But you as the chief caregiver can go a long way in reassuring the patient that the change can be managed and maybe even bring some pleasant surprises along the way.

MEDICAL RESEARCH

Ed note, Betsy Baquet: Research and steady progress continues regarding the understanding of motor neuron disease onset, diagnosis, progression and treatment. Encouraging studies have been published or are underway regarding the roles of proteins and mitochondrial processes related to motor neuron disease. Exciting discoveries have been made regarding the creation of new motor neurons in the brain, and numerous potential therapies are emerging that may alter ALS disease progression.

SPF Funded Scientists' Work Published

SPF funded scientists have discovered proteins that can activate stem cells already in the brain to grow into motor neurons, which begin to develop axons that project down the corticospinal tract. This discovery refutes the theory that the supply of neurons in the brain are finite from birth. Massachusetts General Hospital /Harvard Medical School Center for Nervous System Repair, Departments of Neurosurgery and Neurology, Program in Neuroscience, Harvard Stem Cell Institute, Harvard University, Boston, MA Molyneaux BJ, Arlotta P, Menezes JR, Macklis JD

SOURCE: Nat Rev Neurosci. 2007 Jun;8(6):427-437

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?CMD=Display&DB=pubmed>

Biomarker for ALS & other disorders?

Despite genetic advances, the relationship of various motor neuron diseases is unclear. Except for rare familial forms of ALS, specific molecular or cellular markers that differentiate ALS from other motor neuron disorders have not been available. Recent studies have shown that a binding protein, TDP-43, has been shown to be present in ALS, and suggest that this protein may be a specific marker for ALS. This pilot study aimed to determine the value of TDP-43 in the differential diagnosis of motor neuron diseases. The results suggest that TDP-43 immunoreactivity is useful in differentiating frontotemporal lobar degeneration, motor neuron disease and ALS from other disorders associated with upper or lower motor neuron pathology. It also reveals subclinical motor neuron disease in a subset of cases of frontotemporal lobar degeneration when there is no clinical or pathologic evidence of motor neuron disease. Department of Neuroscience, Mayo Clinic College of Medicine, Jacksonville, FL Dickson DW, Josephs KA, Amador-Ortiz C SOURCE: Acta Neuropathol (Berl). 2007 Jun 14; [Epub ahead of print] <http://tinyurl.com/25psdy>

Repairing Defective Microtubules has Positive Effect in ALS Mice

Pharmacologic administration of a microtubule modulating agent alone, or in combination with a neuroprotective drug, to ALS mice reduced microtubule turnover, preserved spinal cord neurons, normalized axonal transport kinetics and delayed the onset of symptoms, while prolonging life by up to 26%. This data supports the hypothesis that hyperdynamic microtubules impair axonal transport and accelerate motor neuron degeneration in ALS. Measurement of microtubule dynamics provides a biomarker of disease activity and therapeutic response, and represents a new pharmacologic target in neurodegenerative disorders. KineMed, Inc., Emeryville, CA Fanara P, Banerjee J, Hueck RV, Harper MR, Awada M, Turner H, Husted KH, Brandt R,

Hellerstein MK

SOURCE: J Biol Chem. 2007 Jun 13; [Epub ahead of print] <http://tinyurl.com/37ullw>

Stem Cells:

Researchers may have come up with a new cell source using somatic cell nuclear transfer, also called therapeutic cloning. This will allow stem cells to take on the characteristics of a disease, an approach with promise for ALS drug discovery. <http://alsa.org/research/article.cfm?id=1134>

ALS Mutations in VAPB Gene Seen Only in Brazil

Janine Kirby at the University of Sheffield (United Kingdom) and colleagues reported in the May 29 issue of Neurology that according to their recent study, it is suggested that VAPB mutations do not significantly contribute to the genetic causes of sporadic ALS (SALS), where no mutation in the SOD1 gene was present. This was true for patients in the UK and Northern Europe. Similar findings were reported in 2006 after a study conducted on SALS patients in Southern Italy. It has been speculated that previous findings in a 2004 Brazilian study where VAPB mutation has been shown to cause familial ALS may stem from a shared Portuguese ancestor. <http://www.alsmda.org/research/news/070622vapb.html>

Origin of Viral Protein in ALS Elusive

A study in the May 29 issue of Neurology is the third to find that a viral protein known as reverse transcriptase is more frequently found in the blood of people with ALS than in those who don't have the disease. "The reason for the increased frequency [of reverse transcriptase] in ALS and its importance remains unknown," the authors of the 2007 study write. They note that no known retrovirus has so far been found to help explain the phenomenon, and they suggest further testing to see whether reverse transcriptase enzyme activity increases as ALS progresses. The ALS Therapy Development Institute (ALS TDI) in Cambridge, Mass., in partnership with MDA,

plans to use new technology to scan for viral and bacterial genes in blood and other tissues from ALS patients. <http://www.als-mda.org/research/news/070627viralprotein.html>

Mitochondrial Movements May Shed Light on ALS, Other Diseases

Watching the movements of mitochondria, the energy-producing miniature organs (organelles) inside cells, under a variety of conditions has just gotten easier, thanks to a new set of laboratory tools developed by Jeff Lichtman at Harvard University and colleagues. Deficient transport of mitochondria up and down nerve fibers is suspected of contributing to nerve cell loss in ALS. In the July issue of *Nature Methods*, Lichtman describes how the group developed and bred mice with fluorescent proteins that light up only the mitochondria. These "MitoMice" allow researchers to take time-lapse photographs of moving mitochondria in living animals. The researchers have already begun using the MitoMice to study nerve injuries, and they say the mice can also be used to study diseases. <http://www.als-mda.org/research/news/070619mito.html>

Emerging Disease-Modifying Therapies for the Treatment of Motor Neuron Disease/ALS

Significant gains have been made in understanding ALS. Mutations have been identified, animal models created, molecular pathways implicated and dysfunctional processes defined. All of this knowledge has led to an impressive pipeline of candidate therapies that offer hope for finally being able to alter ALS disease progression. There are over 35 potential therapeutic agents in this pipeline, with over 50% in either phase II or III of clinical trial for ALS. Fourteen of these agents are already approved and in use for other indications, such as Multiple Sclerosis, Stroke, Epilepsy, Alzheimer's, Parkinson's and others.

Duke University Medical Center, Durham, NC
Richard S Bedlack , Bryan J Traynor & Merit E Cudkowicz

SOURCE: Expert Opin. Emerging Drugs (2007) 12(2):229-252
http://www.dukealsclinic.com/downloads/emerging_therapies.pdf

Infantile Onset of HSP – New Genetic Mutation Found

Without a family history of HSP, it is difficult to reach a correct diagnosis of Infantile HSP. A misdiagnosis of Cerebral Palsy is common. A case of infant onset spastic paraplegia in three successive generations was presented, caused by confirmed de novo novel mutation 1537G>A (G471D) in SPAST. Several family members were previously diagnosed with Cerebral Palsy. Pediatric neurologists need to be aware of these mutations, and that HSP can present in infancy without a positive family history. Department of Neurology, Vanderbilt University, Nashville, TN
Blair MA, Riddle ME, Wells JF, Breviu BA, Hedera P
SOURCE: *Pediatr Neurol.* 2007 Jun;36(6):382-6.
<http://tinyurl.com/22s6s8>

Role of Certain Protein Within Mitochondria in HSP

Essential processes in mitochondria are critical to cell survival. Disturbances in these processes can lead to cell-specific neurodegeneration in mammals. ATP-dependent AAA proteases have versatile functions regarding mitochondria processes. Implications of these functions for cell-specific axonal degeneration in HSP will be studied. Institute for Genetics and Center for Molecular Medicine (CMMC), University of Cologne, Germany
Koppen M, Langer T
SOURCE: *Crit Rev Biochem Mol Biol*, 2007 May-June;42(3):221-42
<http://tinyurl.com/232gix>



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SP Connection held in Norriston, PA June 9th




Logo for this year's TeamWalks – see articles inside and application form on prior page



Jane Anne King undergoing painless Diffuser Tensor Imaging research testing at NIH



Geoff Kettling competing in Tour De Nez cycling race in Truckee, CA.

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