

Synapse

Autumn 2004

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



TeamWalks - 2004

Massachusetts August 29



Ohio September 18



Arkansas September, 18



California October 2



Table of Contents	pages
Fund Raising	2
Events	2-8
Medical Updates	8-12
Caregiving	12
Living with PLS/HSP	13-19
Event Photos	20



Lead Sponsor of the Synapse Newsletter

The Spastic Paraplegia Foundation is dedicated to finding the cures for Primary Lateral Sclerosis and Hereditary Spastic Paraplegia through research funding, information and support programs.

<http://www.sp-foundation.org> * email: info@sp-foundation.org
Phone: 703.495.9261

FUND RAISING

Fund Raising as of mid October

2004 has been a record fundraising year for all of us. Last year, we raised \$148,600.00. The most recent tally for 2004 is \$247,000.00 and rising. Each of you should pat yourself on the back for a job well done. As you know, SP Foundation made a contest for highest numbers of sponsorships (donations). Here are the winners:

Winner of the Scooter for the most sponsorships: Kris Brocchini, CA
Winner of the Lift Chair for second most sponsorships: Thurza Campbell, MA
Third place winner of the Panasonic portable DVD player - Joel Seidman, MA

In addition, many of you bought chances on a scooter raffle. The winner of the Scooter from the drawing is John Fitzner.

Memorial Donations to SP Foundation

SP Foundation is happy to accept and properly acknowledge donations given in memory or in honor of friends and loved ones. You may feel moved to give a gift to SP to acknowledge a significant effort of a friend or loved one. Often a death needs to be memorialized, and the family does not have a favorite charity. You can make SP Foundation the recipient of memorials, by sending checks to the SP Treasurer, David Lewis, PO 1208, Fortson, GA 31808.

End of Year Donations of Appreciated Stock to SP Foundation

Start planning now for end of the year donations to SP Foundation. Have you considered taking advantage of the opportunity to donate appreciated stock to SP Foundation? Donating appreciated stock is a bonus for both you the donor and the SP Foundation. You avoid capital gains tax, are credited with the

charitable contribution at the appreciated value and SP sells the appreciated stock to add to our dollars for research. SP Treasurer David Lewis is making all necessary arrangements with the bank that has the SP Foundation account. We will post detailed instructions for you ASAP on the stock transfer process. You may also contact David directly at PO 1208, Fortson, GA 31808.

EVENTS

First Australian Connection, August 24, 2004 Gladesville, New South Wales *Contributed by Janet Monaghan*

On Tuesday Adriana, Maureen and I (Janet) met for the 1st Oz Connection. It was great to meet and compare notes. Very quickly we were like old friends, and I felt a real bond. They coped well with me using a lightwriter to communicate. I felt like we were war buddies - which in a way is true. I had never previously met another PLSer. Adriana and I have been diagnosed PLS, and Maureen believes she has sporadic spastic paraplegia. It was interesting to note the differences in our conditions. Adriana lives 3 states and thousands of miles away, and Maureen is maybe 1 hrs drive from me. We had a nice long lunch get-together.

Contributed by Maureen It was wonderful meeting up with Janet and Adrianna!! I felt that we were buddies within the first few minutes of meeting each other. Janet describes us as war buddies and that is exactly so!! We have all gone thru so much and therefore were so in tune with one another. It was the first time with me also that I had met others with very similar symptoms to myself. To Janet and Adrianna, you are 2 truly beautiful people and it was a pleasure to meet you both.

SP Foundation National Conference and MA TeamWalk, August 27-29, 2004

Contributed by Thurza Campbell

Friday evening The fourth annual SP Foundation **National Conference and TeamWalk 2004** began with Registration and dinner Friday evening, August 27. Our evening speaker was Elmer Bartels, the Commissioner on Rehabilitation in Massachusetts. Mr. Bartels became a quadriplegic 40 years ago as the result of an ice hockey accident. At that time there was no ADA! Barriers abounded. In telling his story, he told us how we can be advocates for the disabled – how we can work to change laws and make things happen.

Saturday National Conference The lead off speaker at the Research and Beyond Conference was Terry Wise. Her husband died of ALS. During the four years his disease progressed, she was his caregiver. All help was refused for too long. Terry's message to us was that we must ask others to help us – patients and caregivers alike. For excerpts from her book which chronicles her experiences, go to www.terrywise.com

We heard and saw an informative, easy to understand presentation entitled: "Promises of Stem Cell Research and Regenerative Medicine". Drs. Paola Arlotta and Bradley Molyneaux are researchers at Harvard in its Center for Nervous System Repair. They explained what embryonic stem cells are and that they can form all cell types in the body. There are ethical, moral and religious concerns regarding the use of human embryonic stem cells. They went on to explain the advantages and disadvantages of the use of adult stem

cells in regenerative medical research. Their research involves unraveling the secrets of how corticospinal motor neurons (CSMN) develop. They hope in the short term to understand the signals that direct upper motor neuron development. In the long term, they hope that by understanding the genes of the CSMN that they might eventually manipulate the genes in vitro to induce stem cells to become CSMN for therapy. Their work is with mice. Transferring their learning to human therapies is many years and many research dollars away.

After lunch Mark Weber, SP Foundation President spoke, updating the audience on all that has been going on in SP Foundation. He and Kathi Geisler, VP of the Foundation presented special Community Service Awards. Two afghans were presented in person – to Thurza Campbell for her work with Synapse, and to Dr. John Fink for his dedication as SP Medical Advisor. In absentia awards were announced to Ronnie Grove, organizer of Spring Fling and to Shellie Fisher, who chaired the first two TeamWalks.

Dr. John Fink spoke on "PLS and HSP Similarities and Differences". He introduced us to another acronym, ASUSP or Apparently Spastic Uncomplicated Spastic Paraplegia. This clinical presentation has no known familial occurrences, no bulbar involvement, and only affects legs. Dr. Fink explained current medications recommended for our diseases. These include: Baclofen, Xanaflex and Botox injections for spasticity; Ditropan to relieve urinary urgency. He went on to list the following as experimental therapies: Rilutek, Copaxone, and antioxidants including Vitamin E and

CoQ10. Current treatments he recommends for all of us all fall in the category of exercise: Cardiovascular fitness/aerobic conditioning; reduce osteoporosis; improve flexibility (stretching); improve strength (resistance exercise); balance exercises; and speech and swallowing therapy.

The final portion of the afternoon was divided into two separate breakout elements. First, we divided by disease and had the opportunity to hear the current SP Foundation research recipients speak on finding causes and cures. The session leaders were Dr. Fink, recipient of the SP Foundation research grant for PLS and Dr. Douglas Marchuk recipient of the 2003 SP Foundation research grant for the HSP. We then regrouped into patient and caregiver groups. Bebe Leon led the patient discussion; Craig Gentner led the caregiver group.

The majority of the attendees had dinner together Saturday evening. It's always nice to have lots of opportunities to visit with old friends and make new ones.

Sunday TeamWalk The day for TeamWalk dawned HHH (hazy, hot & humid) – one of the four days all summer that Boston went over 90°. JoAnn Moriarty led us in stretching to the rhythms of the All New Old Brown Pigeon Jazz Band. Despite the weather, quite a number of determined patients and their teams walked the one mile loop in Lexington, led by four of the Jazz ensemble! Others socialized under the tent. The weekend ended with lunch, and announcement by Kathi Geisler, of the total collected to date: over \$130,000. and growing.

Thanks go to Chair of the weekend, Kathi Geisler for her superb leadership

and enthusiasm. Everyone in SP will benefit because of her efforts. The best news for all of you who were unable to attend is that Gene Secor (PLS) professionally videotaped the entire weekend. We'll let you know when his DVD is ready. You'll hear the speakers, meet lots of patients, hear the band and see the walk. We're all indebted to Gene for his efforts on our behalf.

Arkansas Satellite TeamWalk, September 18, 2004

Contributed by Sue Huskey

This was a wonderful event. Including the children, we had about 36 attendees. The walkers arrived early and we had time to chat and get to know one another. It was nice to see lots of my relatives that I had not seen in a long time. I was delighted to see Eddie Adcock from Kentucky, who drove about six hours to attend, and that just lifted my spirits. About 2:00 P.M. we watched the 30 minute video of Kathi Geisler and Joel Seidman. We had a large group of walkers who walked for those that could not walk. Two of my distant cousins brought golf carts to ride and carried one of our signs. Everyone had fun, and we had some folks to stop and ask what was going on. After the walk, we had our drawing for the raffle prize, a \$300.00 John Deere Backpack Blower donated by: John Deere Equipment. The winner was Melanie Hutchison's husband, Ron. We gave away four gift certificates donated by two Wal-Mart stores, and a box of the beautiful SPF note cards. We had time to chat some more before we headed out to Hardee's restaurant, who had donated burgers, fries and a drink for everyone and they let us bring our donuts with us. Krispy Kreme in Memphis, TN had

donated, (I ate two, but didn't gain any of my weight back that I had worked so hard to lose) LOL. This summed our day up, I think everyone had a great time, and I didn't expect to raise over \$2,000, but we raised \$4,000!

Ohio Satellite TeamWalk, September 18, 2004

Contributed by Sue Huskey

We arrived a little early for the arrival dinner at the hotel restaurant. Moira, her two children, Tim and Brynn, Tim Kolhoff, his two brothers, Rick and Dan, and their mother and Dan's wife, were there. Also, Maryann, my Dad, myself and David Jewell and Vicki Dyer. We had a nice visit and got to know each other a little better. It was an enjoyable evening!

There were 37 total at the walk on Saturday, a cool, breezy sunny day by the Maumee River in a park. We enjoyed the beautiful scenery. There were women, men, children and 4 deer and 1 blue heron in attendance and Sharon's dog. We all enjoyed hot coffee, donuts, cold water and bagels and apples donated by two local vendors.

Total raised by this event was \$3,644.00.

California Satellite TeamWalk, October 2, 2004

Contributed by Jennifer Thomson

70 attendees of the Satellite TeamWalk and Connection, held October 2 in Pleasanton, California, walked and rolled the final stretch of the 2004 TeamWalk for our Cures.

The efforts of the Craig and Linda Gentner and Ken and Julie Auer made this an event to remember. We started Friday evening with a "meet and greet" gathering at the Hilton Hotel, followed by dinner. I was able to catch up on news from old friends and make some

new friends. It is amazing how warm and friendly our community is. There is no such thing as a stranger among our group.

The next morning I accompanied Craig and Linda to the Walk site, the fellowship hall of their church. Coffee and pastries, as well as apples with caramel dip, made for a pleasant morning of socializing prior to the walk. After stuffing ourselves on the best bakery items I've ever tasted, we were ready to walk and roll through the town that is aptly named Pleasanton. It is truly a pleasant town. The weather was perfect and the company was even better. This was the most fun I've had at any event I've attended. Something about walking (well, rolling for me) along the tree lined streets with friends made me feel wonderful. Life is good!

After the walk we gathered again at the fellowship hall, where we had a wonderful lunch and visited some more. After the walk we gathered once more at the fellowship hall for a great lunch and more socializing. Then Craig Gentner and Julie Auer conducted the raffle. There were so many wonderful items to raffle off, we actually ran out of raffle tickets. Ken and Julie Auer tirelessly approached businesses for donations and or sponsorship for the raffle and food. The success of their efforts was apparent by huge number of raffle tickets sold. They deserve a big Thank You. I feel blessed that people like the Kris Brocchini, and her beautiful and caring family, share company with me in fighting this disease. Kris and her family silently worked hard to make the California event the success that it was. She deserves a big Thank You.

And Craig and Linda, what can I say. They sure know how to make an event that takes lots of hard work and creativity look like a walk in the park. Craig and Linda deserve more than a Thank You. They do so much for our communities. More than we all know. Linda and Craig, thanks for a truly wonderful, memorial event. I can't wait for next year!

Contributed by Linda Gentner, CA

To All the Wonderful Hardworking People in Both Communities, the fourth and the Grand Finale' of the Satellite TeamWalks was beyond my expectation. Being a bit proud at the moment, I'm absolutely ecstatic to report that we brought in almost \$100,000 just in California. I most definitely will continue with the slogan after my name!!!

"Together we CAN do so much!!!"

Contributed by Jean Chambers, Vancouver

I can't let another moment pass without a huge "thank you" to Linda, Craig and the Auers for all their work on the incredible Teamwalk. It was really great and especially nice to meet so many of the west coasters. We had wonderful weather, the pleasure of the company there, the very pleasant walk and the (I'm a "foodie!") excellent coffee, muffins and lunch for the walk.

Contributed by Donna Sampson, CA

The CA TeamWalk was GREAT!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!! This was my first experience at such a function and not the last I can assure you. Also in my 56 years on this earth I had never met anyone other than my family members with HSP or PLS. I just want to take this opportunity to give Linda Gentner and her husband Craig, as

well as Ken and his wife, Julie a great big thank you for all of the work they did. It was very much appreciated by me and everyone else. We all met up in the bar Friday night before dinner then had a very nice dinner. We immediately liked each other. We all have something in common, besides the fact that we are all funny, outgoing, friendly nice people. The walk on Saturday morning was great. The 2 mile walk didn't seem like 2 miles. The lunch we had was great with some veggie trays with the most wonderful exotic vegetables I've ever seen.

I just have to urge you all to try to attend a TeamWalk or a Connection when there is one in your area. It is such a rewarding experience to meet other people who are going through or have gone through many of the same things as you. It is so nice not to feel so alone or isolated. I can't say enough good about the weekend and don't think this piece even expresses how much I enjoyed the weekend and the opportunity to meet so many wonderful people.

Footnote to the CA TeamWalk:

QuakeMagic is calling upon its readers for donations towards the Team Walk For Our Cures Walkathon. Lynn Holmes, cousin of QuakeMagic founder Nick Arellano and a sufferer of PLS will be a participant in the event."Although there is currently no cure, I have a lot of hope because research is finally accelerating," Holmes told MAGIC. "Please HELP fund research efforts by donating what you can - \$5, \$10 or \$25 or you name it," Holmes continued. "I realize that there are many charities that vie for your attention but any contribution, large or small, will be greatly appreciated."

SP Connection - Boise, ID October 9

Contributed by Bob and Jone Brown

Patricia Bernhard put out the information about the connection and attended with her daughter Gabby. Also Nancy Michael attended. We received some great information from Dr. Robert Friedman of Idaho Physical Medicine and also Physical Therapist Barbara Kerr of St. Luke's Hosp in Boise. This was our first attendance at a PLS/HSP gathering and it was very informative. It was great to exchange information about how each functioned and to meet someone who has a Baclofen pump and how they like it. Maybe next year there will be more PLS and HSP people attending. I feel that if the word gets out about the different gatherings the more we can learn and share and support each other. It was well worth the 6hour drive for information as well as making new friends. Thanks again Pat, Gabby, Nancy and especially Dr. Friedman and Barbara Kerr for their time.

Autumn in Carolina Featuring the First Annual SAWCAR Races, October 9, 2004

Contributed by Don Wilson, organizer par excellence!

At each connection or gathering there is always some activity focused on adding a few dollars to the research war chest of the SP-Foundation. We have participated in auctions and raffles, but wanted to do something a little different. I thought that racing scooters and powerchairs would be fun.

The races were planned as the closing part of the day of activities at Autumn in Carolina III SAWCAR, Scooter and Wheel Chair Association of Racing,

sanctioned the races. As with all the larger sanctioning bodies, NASCAR, ARCA, IRL, there must be officials. We had a Chief Steward, Arthur Neely; Inspector, Brenda Asbury; Honorary Starter, Sarah Duncan; Safety Inspector and Trophy Girl, Jessica Russell; Chief Scorer, Doug Brand; and Official Starter Sheri Mercer.

There were four competitors in each division, scooter and wheelchair. The schedule called for racing in each division, then the two winners would race to determine the Power Champion.

The drivers lined up for the first race. "Florida" Flora Brand started on the inside pole position with Martin "Mad Dog" Beckner beside her. Vaughn "Pathfinder" Hickman was a substitute driver for Ronnie Grove in a bright red three-wheeler. He started third and Jean "Smiley" Mills in her Number 1 Flyer lined up on the outside. Starting positions were determined by drawing.

Sarah gave the command to turn on the motors and flag person Sheri Mercer waved the green flag. They were off; "Smiley" Mills made a quick jump to the front but was soon overtaken by the rest of the field. When the racers came to the first turn, spectators could see who could best maneuver their scooters. "Smiley" went wide while "Mad Dog" Martin and "Florida" Flora stayed tight to the inside. "Pathfinder" Hickman was already noting that he was overmatched. As they came down the backstretch into the third turn, "Mad Dog" opened up a lead and easily held it through turn four. He crossed the finish line first as the checkered flag waved. "Florida" Flora was second, "Smiley" third, and poor "Pathfinder" Vaughn was a respectable fourth in a field of four. "Florida" Flora

received a ribbon for her second-place finish. "Pathfinder" was presented with a "Good Sport" ribbon.

The second race was for the Powerchairs. Starting positions for this race were also determined by drawing. Cece "The Shot" Russell lined up on the inside with "Green Thumb" Bettie Jo on the right with her Penske Racing/Ryan Newman Special. "Dancing" Donna started third and Barbara "Stormy" Neely lined up on the outside. As the green flag waved, the drivers shoved their joysticks forward and rocketed toward the first turn. "Green Thumb" Bettie Jo had a gear problem at the start and fell behind. "Stormy" Barbara clearly had the fastest machine as she came out of the second turn with "Dancing" Donna close behind. "Green Thumb" and Cece "The Shot" were side by side fighting for position as they drove down the backstretch, almost rubbing tires. "The Shot" gave way and "Green Thumb" moved into third position. The racers finished in that order as "Stormy" Barbara took the victory. "Dancing" Donna received a ribbon for finishing second.

The final race of the day was between the winners of each division, "Mad Dog" Martin in his steel gray scooter and "Stormy" Barbara in her Storm Powerchair. "Stormy" started on the pole as determined by a coin toss. They looked like an even match as the green flag waved; however, "Stormy" slid wide in the first turn as "Mad Dog" moved to the inside, holding tight in the turns. "Mad Dog" had a sizable lead as they raced down the backstretch and into turn three. "Stormy" put the pedal to the metal and began gaining ground. She was almost on "Mad Dog's" rear bumper at the finish line. "Stormy" commented

in a post race interview that she "could have taken him if the race were only 100 feet longer. Just wait until next year". "Mad Dog" was gracious as always in Victory Circle as each received a trophy and Team Walk T shirt for winning their division races. "Mad Dog" received a plaque proclaiming him Power Champion of the 2004 Autumn in Carolina.

The promoter (Don Wilson) thanked the officials for their fine job and the mechanics who had tuned the racers, and especially the sponsors who helped make everything possible.

MEDICAL UPDATES

Snippets of Research

"Efficient Generation of Neural Stem cell-like Cells from Adult Human Bone Marrow Stromal Cells". Journal of Cell Science, September, 2004 <http://jcs.biologists.org/cgi/content/abstract/117/19/4411> Clonogenic neural stem cells (NSCs) are self-renewing cells that maintain the capacity to differentiate into brain-specific cell types, and may also replace or repair diseased brain tissue. NSCs can be directly isolated from fetal or adult nervous tissue, or derived from embryonic stem cells. Here, we describe the efficient conversion of human adult bone marrow stromal cells (hMSC) into a neural stem cell-like population (hmNSC, for human marrow-derived NSC-like cells).

StemCells Inc.

<http://www.stemcellsinc.com/tec/index.html> Stem cells are rare, undifferentiated cells that can both duplicate themselves ("self renew") and produce differentiated (functionally specialized) cell types that constitute the various tissues or organ

systems of the human body. The potential for manipulating stem cells to repair or replace diseased or damaged tissue has generated a great deal of excitement in the scientific, medical, and biotechnology investment communities. StemCells, Inc. is engaged in identifying and isolating stem cells from a variety of medically important tissues, including the brain, liver and pancreas. Working in collaboration with StemCells founders Drs. Fred Gage (The Salk Institute) and Irving Weissman (Stanford Medical Center), the team at StemCells, Inc. led by Dr. Nobuko Uchida, has succeeded for the first time in finding markers for human brain stem cells. Using these markers and state of the art cell sorting, we have been able to purify stem cells away from the other cells in the brain tissue. The purified stem cells have been expanded using proprietary cell culture systems and transplanted back into host mouse brains.

“A Novel Locus for Pure Recessive HSP”. Original article in Annals of Neurology
<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&listuids=15455396&dopt=Books> We performed linkage analysis on an autosomal recessive pure HSP family and mapped the disease to chromosome 10q22.1-10q24.1, a locus partially overlapping the existing SPG9 locus. We have either identified a novel locus for pure recessive HSP (SPG27), or we have found the first case of allelic disorders with different mode of inheritance in HSP. If the disorders are indeed allelic, our results have reduced the SPG9 interval by 3Mb with D10S536 and D10S1758 as flanking markers.

“Causes of slowly progressive neurodegenerative disorders”. Original

article in Nature Medicine
(<http://www.nature.com/nm/>)
<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&listuids=15272266&dopt=Abstract>

The molecular bases underlying the pathogenesis of neurodegenerative diseases are gradually being disclosed. One problem that investigators face is distinguishing primary from secondary events. Rare, inherited mutations causing familial forms of these disorders have provided important insights into the molecular networks implicated in disease pathogenesis. Increasing evidence indicates that accumulation of aberrant or misfolded proteins, protofibril formation, ubiquitin-proteasome system dysfunction, excitotoxic insult, oxidative and nitrosative stress, mitochondrial injury, synaptic failure, altered metal homeostasis and failure of axonal and dendritic transport represent unifying events in many slowly progressive neurodegenerative disorders.
SOURCE: Nat Med. 2004 Jul;10(7 Suppl):S2-9.

“Intrathecal baclofen withdrawal syndrome” Mohammed I, Hussain A. Department of Internal Medicine, Mercy Hospital of Pittsburgh, Pennsylvania 15219

BACKGROUND: Intrathecal baclofen pump has been used effectively with increasing frequency in patients with severe spasticity, particularly for those patients who are unresponsive to conservative pharmacotherapy or develop intolerable side effects at therapeutic doses of oral baclofen. Drowsiness, nausea, headache, muscle weakness, light-headedness and return of pretreatment spasticity can be caused by intrathecal pump delivering an incorrect

dose of baclofen. Intrathecal baclofen withdrawal syndrome is a very rare, potentially life-threatening complication of baclofen pump caused by an abrupt cessation of intrathecal baclofen. CASE PRESENTATION: A 24-year-old man with a past medical history of cerebral palsy and spastic quadriplegia developed hyperthermia, disseminated intravascular coagulation, rhabdomyolysis, acute renal failure and multisystem organ failure leading to a full-blown intrathecal baclofen withdrawal syndrome. Intrathecal baclofen pump analysis revealed that it was stopped due to some programming error. He was treated effectively with supportive care, high-dose benzodiazepines and reinstatement of baclofen pump. CONCLUSION: The episodes of intrathecal baclofen withdrawal syndrome are mostly caused by preventable human errors or pump malfunction. Educating patients and their caregivers about the syndrome, and regular check-up of baclofen pump may decrease the incidence of intrathecal baclofen withdrawal syndrome. Oral baclofen replacement may not be an effective method to treat or prevent intrathecal baclofen withdrawal syndrome. Management includes an early recognition of syndrome, proper intensive care management, high-dose benzodiazepines and prompt analysis of intrathecal pump with reinstatement of baclofen.

Entire article available for free at <http://www.biomedcentral.com/1472-6904/4/6> .

“Stem Cells Promote Axonal Regeneration”. Original article in Experimental Neurology.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list>

[uids=15380475&dopt=Abstract](#)
Regeneration in the peripheral nervous system is impaired after prolonged periods of denervation. Currently, no interventions exist to alter the outcome after prolonged denervation. To examine the role of transplanted neural stem cells (NSC), we prepared chronically denervated distal tibial nerve segments. After 6 months of chronic denervation, we transplanted vehicle, C17.2 mouse NSCs, or C17.2 mouse NSCs engineered to overexpress GDNF to the distal tibial nerve and performed a peroneal nerve cross-suture. This is the first successful demonstration of regeneration through a chronically denervated nerve. These findings suggest that improved regeneration in the PNS can be accomplished by combining neurotrophic factor support and removal of axon growth inhibitory components in the extracellular matrix.

The web site of the national organization of the ALS organization contains a wealth of information. The home page, <http://www.alsa.org/> outlines the breadth of resources for you through ALSA. Find a chapter near you. See their suggestions on how to become an advocate. Find out the latest avenues of hope using stem cell research.

Update on Stem Cell Research and Potential Treatments for ALS

Stem cell research is receiving increasing attention, particularly in many public forums and in the current debates leading up to the November presidential election. The staff and volunteers of The ALS Association share the sense of urgency to develop effective treatments for ALS and we are encouraged by what is being learned from stem cell research. ALSA is in contact with investigators to advance the efforts toward appropriate

stem cell clinical trials as the body of scientific knowledge about stem cells grows. In addition, excitement about the potential of stem cell replacement in ALS was heightened with recent reports about a stem cell treatment for ALS patients in China . It is important to realize that within the scientific investigator community the excitement and research efforts into stem cells is continuous with many new studies initiated by different laboratories and top investigators. ALSA has recently funded two new studies in stem cell research and continues to fund leading investigators in different areas of stem cell biology. For more information, view these two articles on ALSA's web site.

<http://www.alsa.org/research/grant.cfm?id=448>

<http://www.alsa.org/research/grant.cfm?id=453>

These projects include the use of a variety of different stem cell sources which will be emphasized in the following brief report. Laboratory results are encouraging but scientists recognize the need for rigorous pre-clinical research to move the field forward and increase the potential for success as a therapy for ALS.

Current ALSA-Funded Stem Cell Research

Autologous Stem Cell Therapy for ALS

Martin, Lee , PhD

Johns Hopkins School of Medicine,
Baltimore , Maryland

<http://www.alsa.org/research/grant.cfm?id=137>

Recruitment of Replacement Corticospinal Motor Neurons via Induced

Neurogenesis and Enhanced Survival

Macklis, Jeffrey D., MD, DHST
Harvard Medical School and
Massachusetts General Hospital, Boston,
Massachusetts

<http://www.alsa.org/research/grant.cfm?id=134>

Regulation of the Expression of the Proneural Gene Neurogenin2 in the Adult Spinal Cord

Guillemot, François, PhD
Division of Molecular Neurobiology,
NIMR, London, England

<http://www.alsa.org/research/grant.cfm?id=111>

Generation of Human Motor Neurons from Stem Cells

Su-Chun Zhang, MD Ph.D.

University of Wisconsin, Madison, WI

<http://www.alsa.org/research/grant.cfm?id=166>

Stem Cell Therapy for ALS

Clive Svendsen, PhD

University of Wisconsin , Madison ,
Wisconsin

<http://www.alsa.org/research/grant.cfm?id=183>

NORD PLS Booklet

Contributed by Linda Gentner

The PLS Community first started out raising research funds through NORD (National Organization for Rare Disorders). This was before the PLS and HSP communities joined to form the SPF We were very successful and through us, NORD was able to issue 3 PLS research grants -- Dr. Fink, Dr. Siddique and Dr. Talbot (latest one, he is in England). My husband's former employer gave a sizable donation, so I became the contact person at NORD. I was approached and asked if we'd be

interested in funding an educational guide for physicians. NORD mailed the brochure to approximately 14,000 neurologists and to over 500 teaching hospitals and also to medical libraries. The booklet is available free at:

<http://www.rarediseases.org/programs/freebooklets> . Since the booklet is a couple years old, some changes need to be made before giving out the booklet now. For example, the PLS Awareness Site is no longer in existence (Jennifer closed it when we joined with SPF) and also Frank Levy no longer publishes the PLS Newsletter. The Synapse newsletter has a different address that is www.synapsePLS.org

Another thing of interest that people may not be aware of is NORD has a Networking Program. You need to be a NORD member (basic membership is \$30) and you have to fill out a Networking Registration form and they will add you to the list and your signature grants NORD permission to provide your name and address to others registered in our disease-specific network. This is held in strict with one exception: if NORD has a member organization for your specific rare disorders, your name may be forwarded to that organization. (I copied that from their flyer.) This is only for you, or a member of your family. If you interested in being listed in the NORD Networking Program, contact: NORD, P.O.Box 1968, Danbury, CT 06813-1968 (Attn: Networking Coordinator)

Research Project in Australia

Contributed by Janet Monaghan

I am going to participate in a research project at the request of my neuro. It is not a therapy or treatment. I will have a skin and nasal mucosa biopsy

"Dr. Dominic Rowe and Dr. Carolyn Sue are seeking patients diagnosed with Motor Neurone Disease, to participate in research project for stem cells. The purpose of the research is to look at whether we can grow cells from patients with MND. "

"Title of Project: Characterisation of the role of mitochondrial dysfunction in cell lines

derived from patients with ALS."

The purpose of this study is to try to identify whether abnormalities in a certain part of the cell (called mitochondria) are involved in causing motor neurone disease.

The long-term goal of our research is to discover ways to treat people with motor neurone disease based on modifying mitochondrial abnormalities in affected patients."

EmCell Experience in the Ukraine

These links open articles chronicling the experience of a family which traveled to the Ukraine for stem cell treatment for their son.

http://www.boston.com/news/globe/health_science/articles/2004/09/26/desperate_parents_chase_a_stem_cell_miracle/

http://www.boston.com/news/local/articles/2004/09/26/absence_of_data_on_clinics_therapies_provokes_skepticism/

CAREGIVING

Resource for California Caregivers & Financial Asst.

Contributed by Lynn Holmes

I found a group that has provided co-pay assistance for my power wheelchair, agreed to fund and find a contractor to remodel my bathroom for shower chair access.

"The purpose of the California

Foundation for Independent Living Centers (CFILC) is to collaborate with and increase the capacity of California's Independent Living Centers to create access and integration for people with disabilities. CFILC's mission is to support independent living centers in their local communities through advocating for systems change and promoting access and integration for people with disabilities. CFILC is a statewide, non-profit organization made up of more than two dozen Independent Living Centers. Through unified action, CFILC envisions civil rights for all people with disabilities. "

<http://www.cfilc.org/directory/index.htm>

1

They help with:

Assistive Technology
Workforce Inclusion
In Home Supportive Services
Transportation
Deinstitutionalization
Universal Design & visitability
SSI/SSP
Mental Health
Violence Against People with Disabilities

LIVING WITH PLS/HSP

Proactive Patient Checklist

Contributed by Dolores Caron

Print out this guide, bring it with you to your doctor's appointment and chart your progress.

Find a good doctor and medical facility

__ Get a recommendation from a friend, family member, neighbor, healthcare professional, or co-worker.

__ Do a background check on the American Medical Association website.

__ Query the doctor's office for patient load, waiting time, and insurance concerns.

__ Query the medical facility about specialties, number of procedures performed, and services provided.

__ Be prepared and ask questions

__ Research health issues online and through non-profits & government agencies.

__ Bring reference materials with you to doctor's appointments.

__ Bring past medical records and test results to a new doctor when possible.

__ Ask questions, questions, and more questions.

Questions to ask your doctor about medicines he/she prescribes.

__ What is the name of this medicine (brand name and generic alternatives)?

__ How does this medicine work?

__ When and how long should I take this medicine?

__ What foods and drinks should I avoid when taking this medicine?

__ What are the possible side effects of this medicine and how do I cope with them?

__ How do I know when this medicine is working/not working?

__ Are there possible interactions with other prescription or non-prescription drugs?

Questions to ask your doctor about a medical test or procedure.

__Please explain this test/procedure from start to finish.

__Why is this test/procedure necessary?

__Will this test/procedure require a hospital stay? If so, for how long?

__What side effects/risks are possible with this test/procedure?

__What is the estimated length of recovery from this test/procedure?

__Is follow-up care necessary?

__When will results of the procedure be available? (Be sure to follow up on this).

__How many of this particular test/procedure have you (the doctor) performed?

__Are there alternatives to this test/procedure?

When test results are returned:

__What do these results mean?

Specific Questions that you would like answered. (Write down your questions before your doctor's appointment and then write down the answers for future reference.)

Transition Garden – for Laura

Written by Bettie Jo Wilson, 2004 (For Laura, was written when a close friend was waiting for the results of a suspected recurrence of cancer, which finally came back negative.)

Transitions have never been my best thing. I prefer to have things move from one to the next in an orderly fashion, although this is rarely the case. This morning I was anticipating the arrival of guests, none of whom had ever been to my house before. I gazed at my front

yard in dismay. Gone was the springtime splendor of blooming phlox, daffodils, and clematis, yet to be replaced by summer blooms. I fretted over how to get things "company ready" given that I am no longer able to do the work myself. As I rehearsed a variety of excuses to tell my guests a thought came to me. I realized that my garden is in transition, the most miraculous time of all. Both phlox and Clematis have gone to seed, already preparing for next year's blooms. We allowed for extra seedtime as we have begun saving seeds of these heirloom varieties to share with others. The daffodils are storing nourishment from their leaves as their bulbs develop underground. Spider plants are ready to be divided some to go in hanging baskets, the rest to be shared with others. What appears to be chaos is in reality an orderly transition of seasons.

I could take a lesson from my flower garden. My life is in transition as well. As PLS progresses I have to reassess my priorities. I sometimes think to myself that things are falling apart. What I fail to realize is that things are in order even if I can't see the whole plan.

Caregiver - For Don

Written by Bettie Jo Wilson, 2004.

When I think about it, this has been a rough year. I had two surgeries, I smashed my toe and could not wear my shoes, had modifications to my chair that took some getting used to, and more little things than I can remember. I had the easy part. Don took care of me. He lifted me when I could not bear weight, spent the night in my hospital room, and wore himself out. In short, he does all that it is humanly possible to do, and then a he does some more. I wrote a poem for him, and ask you to keep him in

your prayers.

My heart aches for you.

I know how hard it is and my heart aches for you.

I know because I can remember,

Being up at night with babies,
And going to work the next day,
But I was young then.

So my heart aches for you.

My heart aches for you.

I see weariness in your eyes, plodding steps and I remember,

Caring for little ones, who could not walk, could not talk,

Guessing what was wrong,
cleaning messes, wiping spills,

But children gain independence with every day that passes,

So my heart aches for you.

I remember having a full time job,

Driving carpools,
Doctors appointments,
Broken ankles, mono,
But this was temporary,

Unlike PLS and struggling to stay afloat,
So my heart aches for you.

New Group for Parents with Physical Disabilities

Contributed by Bonnie McIsaac

There is a new Yahoo group for Parents who also have physical disabilities. For anyone interested, or if you know someone who may benefit, - the link is <http://groups.yahoo.com/group/physicallydisabledparents>

E-mail address is

physicallydisabledparents@yahoogroups.com

Exercise for the Disabled

Dr. John Fink, at the August 28 National Conference of the SP Foundation, urged the patient community to exercise. The Mayo Clinic has a detailed article on

exercise for persons with disabilities.

<http://www.mayoclinic.com/invoke.cfm?id=SM00042>

This link begins by listing reasons why persons with disabilities should exercise, including: to lower your risk of developing heart disease, stroke, type 2 diabetes and osteoporosis, to lower your blood pressure, to help you manage your weight, to help you improve your cholesterol level, to improve your ability to cope with stress, and to provide psychological benefits, such as improved self-image and self-confidence, better sleep and a more positive outlook on life.

Ed. note: The article is copy write protected, so persons reading the print version of Synapse should go to their local public library to download the article in its entirety.

Book of our HSP/PLS Stories to be Printed

Contributed by Cheryl Huskins

I'm hoping to get an abbreviated book printed (by SPF) to raise funds, and find a publisher for a bigger, better book that can raise more funds to find cures for PLS and HSP. We need your story in the book.

Please read the following list from Kathi Geisler and start writing! Even if you don't have Word or can't type, please send me your documents in other formats (even handwriting) and I'll convert them to a usable format and/or type them. After I edit, I will send your story back to you for your final edit. Some basic questions for you to answer when telling your story:

1. Introduce yourself and your family members - name, spouse, siblings, kids, etc., where you/they live.
2. Do you have PLS or HSP. If HSP, are there other family members with it?

3. Your story of how your symptoms began - if it's HSP, then did other family members have problems walking so you were watching for it?
 4. Your story of diagnosis - some people have a confusing and long diagnosis story!
 5. About you - do you work? Hobbies? What do you do for fun?
 6. What keeps you positive?
 7. What treatment helps you the most? Do you use assistive devices?
- I look forward to "hearing" from all of you. My email address is:
ihusk888@adelphia.net.

My street address is: 666 Finson Road
#188 Bangor, Maine 04401

Assistance Dog Financial Aid

Contributed by Lynn Holmes

<http://www.assistancedogunitedcampaign.org/>

The Assistance Dog United Campaign (ADUC) is a health and human welfare organization which provides financial assistance to individuals who have the need for an assistance dog but have difficulty in raising the necessary funds and to people and programs whose purpose is to provide assistance dogs to people with disabilities. The chart which follows gives you names and phone numbers of agencies for assist dogs in most states

<u>4 Paws for Ability, Inc.</u>	Xenia, OH	937-374-0385	Service, hearing, guide, social/therapy, search & rescue
Adler Assistance Dogs	Denver, CO	303-722-0327	Service
Alaska Assistance Dogs	Wasilla, AK	907-357-1657	Service, hearing, social/therapy, facility
<u>All Purpose Canines</u>	Aberdeen, SD	605-225-1131	Service, hearing, social/therapy, facility
<u>All Ways Pawsitive Pet Behavior & Training</u>	Mesa, AZ	480-529-7947	Service, hearing; trains personal dogs in clients' homes
<u>Amazing Tails, LLC, Inc.</u>	Oxford, PA	717-529-6875	Service, hearing, seizure alert
Angel's Alley Assistance Dogs	Sandy Valley, NV	702-723-1921	service, social/therapy
<u>Animal Protective Asso of MO</u>	St. Louis, MO	314-645-4610	Social dog training for individuals
<u>Assistance Dog Institute</u>	Santa Rosa, CA	707-537-1960	Service
Assistance Dogs for Freedom	Chicago, IL	312-543-8395	Service
<u>Assistance Dogs of America</u>	Swanton, OH	419-825-3622	Service, hearing
Assistance Dogs of the West	Santa Fe, NM	505-986-9748	Service
<u>Blue Ridge Assistance Dogs</u>	Manassas, VA	703-369-5878	Service, social/therapy
Calif. Canine Academy/Assistance Dogs	Merced, CA	209-723-2777	Service, hearing, social/therapy
Canine Assistants	Alpharetta, GA	770-664-7178	Service
Canine Capabilities	Monroe, WI	608-325-8253	Service, hearing, social/therapy
<u>Canine Co-Pilots</u>	Flagstaff, AZ	877-596-6366	Service, hearing, social/therapy
Canine Golden Opportunities	Hamilton, MT	406-375-0174	Service
Canine Helpers for the Handicapped	Lockport, NY	716-433-4035	Hearing, service, therapy
Canine Inspirations	Ventura, CA	805-671-9633	Service
<u>C.anine O.pportunity P.eople E.mpowerment</u>	New Lowell, Ontario, Canada	705-424-9692	Service, social/therapy
<u>Canine Partners for Life</u>	Cochranville, PA	610-869-4902	Service

Canine Partners of the Rockies	Denver, CO	303-399-4575	Service
Canine Specialty Training	Independence, MO	816-796-6444	Service
<u>Canine Support Teams</u>	Temecula, CA	909-301-3625	Service
Canine Working Companions	Waterville, NY	315-861-7770	Service, hearing
Capitol City Independence Dogs	Citrus Heights, CA	916-723-0124	Service, hearing, social/therapy
Companion Animals Meeting People	Westminster, CA	714-896-0062	Social/therapy visits
<u>Delta Society</u>	Renton, WA	425-226-7357	Asst dog info, so/th training
Discovery Dogs	San Rafael, CA	415-479-9557	Service, hearing, social/therapy and works with clients' own dogs
<u>East Coast Assistance Dogs</u>	Torrington, CT	860-489-6550	Service
<u>Emotional Retrievers</u>	Wilmington, NC	910-792-0560	Social/therapy
<u>Florida Guide Dogs for the Deaf</u>	Bradenton, FL	800-520-4589 V/TDD	Hearing, service
Freedom Guide Dogs	Cassville, NY	315-822-5132	Guide
Friends for Folks	Lexington, OK	405-527-5676 #2630	Social/therapy
Golden Dogs Academy	Mount Vernon, OH	740-393-0758	Service
Great Plains Assistance Dogs	Jud, ND	701-685-2242	Service, seizure alert, hearing, social/therapy
Hearing and Service Dogs of Minnesota	Minneapolis, MN	612-729-5986 V 612-729-5914 TTY	Service, hearing
Helping Paws of Minnesota	Hopkins, MN	612-988-9359	Service, social
K-9 Search and Rescue	Murray, NE	402-235-3148	Service, social/therapy??
Kids and Canines	Tampa, FL	813-975-7355	Service
<u>Lone Star Assistance Dogs</u>	Benbrook, TX	817-249-8585	Service, social/therapy
<u>Loving Paws Assistance Dogs</u>	Santa Rosa, CA	707-586-0798	Service
Midwest Assistance Dogs	Southbend, IN	574-272-7677	Service, hearing

<u>My Wonderful Dog</u>	Portland, ME	207-799-9792	Service
New England Assistance Dog Service	West Boylston, MA	978-422-9064	Service, seizure response
New Hope Assistance Dogs	Warren, PA	814-726-1620	Service
New Horizons Service Dogs	Orange City, FL	386-456-0408	Service, social/therapy, facility
New Life Assistance Dogs	Lancaster, PA	800-995-9581	Service
<u>Olympic Assistance Dogs</u>	Port Ludlow, WA	360-437-0490	Service
<u>Paws and Effect</u>	Charlotte, NC	260-417-1825	Service, hearing, social/therapy
Paws and Think	Indianapolis, IN	317-577-1688	Service, social/therapy, facility
<u>Paws'itive Teams</u>	San Diego, CA	858-674-0845	Service
People and Animals Working in Sync	Alda, NE	308-382-7182	Service
<u>Power Paws Assistance Dogs</u>	Scottsdale, AZ	480-945-0754	Service, hearing, guide, social/therapy
Prison Pet Partnership	Gig Harbor, WA	206-858-4240	Service
<u>Pro-Train</u>	Vista, CA	760-749-0897	Service, hearing, guide, social/therapy
Rainbow Animal Assisted Therapy	Northbrook, IL	773-283-1129	Animal-assisted therapy
<u>Spoke N' Paws Assistance Dogs</u>	Oceanside, CA	760-754-0818	Service, hearing, guide, social/therapy
Summit Assistance Dogs	Anacortes, WA	360-293-5609	Service, hearing
<u>Susquehanna Service Dogs</u>	Harrisburg, PA	717-599-5920	Service, hearing, social/therapy
<u>Texas Hearing and Service Dogs</u>	Austin, TX	512-891-9090 V/TDD	Hearing, service
<u>WI Academy Graduate Service Dogs (WAGS)</u>	Windsor, WI	608-250-9247	Service, social/therapy, companion
Working Class Dogs	Johnsburg, IL	815-759-3962	Service, hearing, guide, social/therapy

North Carolina SP Gathering



Green flag at Start of SAWCAR



Bettie Jo Wilson wife of SAWCAR organizer Don Wilson



Race winner Mad Dog Martin down the home stretch

California TeamWalk



TeamWalk organizer Linda Gentner with husband Craig and grandson William
Arkansas TeamWalk



TeamWalk registrar and scooter winner Kris Brocchini



On Main St. in Pleasanton

Australia Gathering



Sue Burges, Helen Garner & Sonny Garner getting ready for walk



TeamWalk organizer Sue Huskey (right) with her supportive family



Maureen, Adrianna & Janet gather 1st ever SP gathering in Australia

Massachusetts TeamWalk



Bottled water for walkers – a must for a hot day



Synapse editor Thurza Campbell with her grandchildren



SP President Weber assisted by VP Kathi Geisler wrap up the day