PLS Newsletter

Serving the Primary Lateral Sclerosis Community since 1997 - Autumn 2002

Editor's note: At Mark Weber's request, I have taken over as editor of Synapse. If any of you have computer access available, please transmit your e-mail address to me at SynapsePLS@attbi.com With use of a computer, you would have a much greater use of the resources. If you do not have your own computer, please inquire at your local library about Internet access for the public. Thurza Campbell

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RESEARCH UPDATES

National Organization for Rare Disorders (NORD)

How Our Brochure Came to Be

"Physician's Guide to Primary Lateral Sclerosis" by Linda Gentner

My husband retired from a (then high-flying) Silicon Valley company and they donated $100,000.00 for PLS research in my honor to be administered by NORD (National Organization for Rare Disorders). Our fund raising goal was $35,000 so this amount put us way over our goal. It was at that time, NORD asked me if I'd like to start an Education Fund to enable the publishing of a brochure to be sent to physicians. The PLS community felt education of physicians is of paramount importance, as even many neurologists have never heard of PLS. NORD said since the major donation came in my honor that I would be the contact person. So I took it on as my personal project. I thought it was a great idea and I earmarked $16,000 for the Education Fund. I dubbed it my **Leap of Faith** donation. As it turned out, the original amount that NORD proposed to publish this booklet was too low so others were urged to donate to our Education Fund since we had reached our Research Fund goal. That "Leap of Faith" donation has finally paid off and the brochure is now a reality. The general response thus far has been positive by most of the people on PLS- Friends who have received their copy. NORD will send the brochure to approximately 14,000 neurologists and 500 teaching hospitals. The distribution of these free brochures is a giant first step in further education of the medical community. Order your copy (more than one if you'd like) directly from NORD. Please take one to each of the physicians who care for you. The e-mail address is below. If you don't use a computer, the mailing address is also shown below.

NORD Addresses: E-mail address: http://www.rarediseases.org Postal Address Mary Dunkle Vice President of Communications National Organization for Rare Disorders 55 Kenosia Avenue PO Box 1968 Danbury, CT 06813-1968 Phone: 203.744.0100 Fax: 203.798.2291

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Northwestern University PLS Research Update

Contributed by Nailah Siddique

We have blood samples from 90 patients. We have 13 patient-parent sets, and 59 patient- sibling sets. There are 9 of these sibling sets that include the same patient as the patient-parent sets. We'd really like there eventually to be 2 discrete sets. So, we've certainly made progress! Long term we are trying to collect enough samples to do independent work on PLS. Ideally that would be 400 of each of these "sets"-- the patient-parent ones, and the sibling pairs. It will take a long time to obtain that many, so we are beginning work now. The goal is to find genes that increase a person's risk for developing PLS, which is really just a first step. The idea after that is to figure out how the proteins that those genes make act to produce motor neuron damage. Help could come from other quarters, maybe scientists working on those genes and proteins (who may or may not have any interest in motor neuron disease), or maybe even things like the Genome Project. Then we'd finally be getting to the good part, which would be a route in to the pathway of motor neuron support, so that we could figure out how things go wrong, and FINALLY have a target for a rationale treatment. We may get lucky and find some ways into this pathway from ALS research or even HSP research. We're hoping that we'll be able to do that with this alsin gene that we found in some consanguinous families, some of whom have kids with PLS and some of whom have kids with ALS. We're trying to make the transgenic mouse right now, and once that's done then some experiments can get under way. Right now the class of protein that alsin makes is known, but the real basics of how it works, and therefore what the mutant gene influences in the protein product aren't understood. But at least one mutation in this gene produces a type of PLS (very early onset), so it could very well get us in to this pathway we're so desperately looking for.

Another help could come from the sporadic ALS studies that we've started, using the same technique as we're collecting all these PLS samples for. We're further along in this, partly because we started quite a while ago, and partly because there are more ALS patients to be tapped. It would certainly seem likely that at least some of the same influences that produce ALS could influence the development of PLS, and that some of the eventual effective treatments might overlap.

PLS and HSP are very closely related

Contributed by Dr. John Fink

Neither PLS nor HSP are single disorders. There are several types of PLS and many types of HSP. We are dealing with a group of conditions that share similar symptoms and pathology. I feel that information gained by investigating any one of these conditions (a subtype of PLS for example), will advance our knowledge of other subtypes of this group of conditions.

NIH Office of Rare Diseases Intramural Research Program

Contributed by Sharon Neumann, a Health Paralegal and an SPF advocacy volunteer:

had the pleasure to once again participate n an NIH focus group session during recent meetings in Washington DC about rare disorders as part of the NORD annual conference. It is an exciting time for the entire rare disorder community because of the success in moving the two rare disorder Acts to the President's desk. When signed, these Acts will secure permanent annual funding ($50-million combined) for programs and services for rare disorders. A great deal of planning has already taken place to insure these funds will be put to use in the most meaningful ways possible. You will be interested and hopefully excited to know that the NIH Office of Rare Diseases (ORD) Intramural Research Program will be placing an additional focus on 130 existing and new NIH intramural "areas of emphasis" rare disease research programs. PLS and HSP are two of the 130 disorders included in this intramural research program! This is significant news for the emerging HSP and PLS communities when considering that there are more than 6,000 rare disorders. The NIH-ORD will be updating its website and databases. The NIH-ORD will be updating its Website and databases. You may wish to periodically check the NIH-ORD Website (http://rarediseases.info.nih.gov/) as well as http://www.clinicaltrials.gov for information on current programs and studies. Please contact the office of the President of the United States to make sure this gets passed. Don't be shy.

LIVING WITH PLS

Practicing Falling

Submitted by Galen Hekhuis

I suggest practicing falling. I practice "parachute landing" falls. They are a pretty good way to dissipate energy while doing a minimum of damage to yourself. I've almost pulled a bookcase on me doing a classic attempt at saving myself from falling. I think we all pretty much acknowledge that we go downhill after a fall, but I tend to think it is the injury we suffer falling, rather than the act itself, that is responsible. I still try to avoid falling whenever I can, but, at least for me, there seems to be a point when I'm pretty sure I'm going to fall over. When I reach that point, I pretty much give up and just try to steer for the soft spots as much as I can. This has resulted in some pretty spectacular falls, and I know many of my plants have suffered (I recently gave away all my cactus plants, I'm not crazy about plants that can fight back) but better them than me. Falls always have a habit of sneaking up on me. I try to anticipate things, which might cause them and try to avoid them, but try as I might, I still go over now and then. Crumpling up and tending to fall to the side seems to have saved me from serious injury so

far. I don't fall a whole lot less than I used to, just the consequences to me have been much less severe since I began practicing falling. When you get real good I hear you can put sharp objects to avoid in your practice area!

Advisory for Traveling with a Disability

The Air Carrier Access Act (ACAA) and the Department of Transportation's implementing rules prohibit discriminatory treatment of persons with disabilities in air transportation. Since the terrorist hijackings and tragic events of September 11, the Federal Aviation Administration (FAA) has issued directives to strengthen security measures at airline checkpoints and passenger screening ocations. In securing our national air transportation system, where much of FAA's efforts have been directed to date, steps were also taken to ensure that the new security procedures preserve and respect the civil rights of passengers with disabilities. This Fact Sheet provides information about the accessibility requirements in air travel in light of strengthened security measures by providing a few examples of the types of accommodations and services that must be provided to passengers with disabilities. The examples listed below are not all-inclusive and are simply meant to provide answers to frequently asked questions since September 11 concerning the air travel of people with disabilities. Check-in: Air carriers must provide meet and assist service (e.g., assistance to gate or aircraft) at drop-off points. The lack of curbside check-in, for certain airlines at some airports, has not changed the requirement for meet and assist service at drop-off points. Screener checkpoints: Individuals assisting passengers with disabilities are allowed beyond the screener checkpoints. These individuals may be required to present themselves at the airlines' check-in desk and receive a "pass" allowing them to go through the screener checkpoint without a ticket.

> Ticketed passengers with their own oxygen for use on the ground are allowed beyond the screener checkpoints with their oxygen canisters once the canisters have been thoroughly inspected. If there is a request for oxygen at the gate for a qualified passenger with a disability, commercial oxygen providers are allowed beyond the screener checkpoints with oxygen canisters once the canisters have been thoroughly inspected.

Commercial oxygen providers may be required to present themselves at the airlines' check-in desk and receive a "pass" allowing them to go through the screener checkpoint without a ticket. The limit of one carry-on bag and one personal bag (e.g., purse or briefcase) for each traveler does not apply to medical supplies and/or assistive devices. Passengers with disabilities generally may carry medical equipment, medications, and assistive devices on board the aircraft. All persons allowed beyond the screener checkpoints may be searched. This will usually be done through the use of a hand-held metal detector, whenever possible. Passengers may also be patted down during security screenings, and this is even more likely if the passenger uses a wheelchair and is unable to stand up. Private screenings remain an option for persons in wheelchairs. Service animals, once inspected to ensure prohibited items are not concealed, are permitted on board an aircraft. Any backpack or sidepack that is carried on the animal will be manually inspected or put through the X-ray machines. The service animal's halter may also be removed for inspection. Assistive devices such as walking canes, once inspected to ensure prohibited items are not concealed, are permitted on board an aircraft. Assistive devices such as augmentative communication devices and Braille 'N Speaks will go through the same sort of security screening process as used for personal computers.

Syringes are permitted on board an aircraft once it is determined that the person has a documented medical need for the syringe. Personal wheelchairs and battery-powered scooters may still be used to reach departure gates after they are inspected to ensure that they do not present a security risk. Any backpack or sidepack that is carried on the wheelchair will be manually inspected or put through the X- ray machines. Personal wheelchairs will still be allowed to be stowed on board an aircraft. Air carriers must ensure that qualified individuals with a disability, including those with vision or hearing impairments, have timely access to information, such as new security measures, the carriers provide to other passengers. For example, on flights to Reagan Washington National Airport, persons are verbally warned to use the restrooms more than a half an hour before arrival since after that point in time passengers are required to remain in their seats. Alternative formats are necessary to ensure that all passengers, especially deaf persons, understand new security measures such as the one at Reagan Washington National. Members of the public, who feel they have been the subject of discriminatory actions or treatment by air carriers, may file a complaint by sending an email, a letter, or a completed complaint form to the Aviation Consumer Protection Division (ACPD). ACPD's e-mail address is airconsumer@ost.dot.gov and its mailing address is: Aviation Consumer Protection Division, U.S. Department of Transportation, Room 4107, C- 75, Washington, DC 20590. Complaint forms that consumers may download and/or print are available at www.dot.gov/airconsumer/problems.htm.

Growing into Using a Cane Compiled from many of our experiences I was one who had a hard time beginning to use a cane along with a lot of others...right? Through conversations in the group, I gradually "grew" into a cane. I first started using it at home, getting used to its feel and how it could assist me. It is a s-l-o-w process to be able to use a cane in front of family; the hardest part for me was using the cane that first time at work. Now, it is a part of me and my constant companion...it even goes with me to the health club to workout. I am determined to do as much as I can and be safe. The cane helps stablize my balance and helps me walk with wobbly legs. The cane also doesn't make people stare as if I were a drunk from the way I walk without the use of the cane. Also, people are so generous in wanting to help with opening doors or helping in other ways. It is so nice to see the kindness in people. So keep an open mind about how a cane can assist you.

Arm Exercises Contributed by Ronnie

Grove For those of us getting along in years...here is a little secret for building your arm and shoulder muscles: You might want to adopt this regimen! Three days a week works well. Begin by standing outside behind the house, and with a 5-LB. potato sack in each hand, extend your arms straight out to your sides and hold them there as long as you can. After a few weeks, move up to 10-LB. potato sacks and then 50-LB. potato sacks, and finally get to where you can lift a 100 lb. potato sack in each hand and hold your arms straight for more than a full minute. Next, start putting a few potatoes in the sacks, but be careful not to overdo it at this level.

Assistive Aids and Technology

CATALOGS and specialty groups Ableware - "http://ableware.com/" Access to Recreation - www.AccessToRecreation.com Adaptability - www.snswwide.com at 800/243- 9232 AdaptAbility Catalog is 1-800-288-9941 Adaptivation Incorporated - www.adaptivation.com AliMed - www.alimed.com Assistive Technology Works, Inc. (Vienna, VA)

www.assistivetechworks.com Beyond Barriers - www.beyondbarriers.com Dynamic Living - www.dynamic-living.com Enrichments - www.ilp-online.com Functional Solutions - www.ncmedical.com Home Automation Systems, Inc. - 1-800-242- 7329 Independent Living Aids, Inc. - www.independentliving.com Key Technologies, Inc. - 1-888-433-5303 MaxiAids - www.maxiaids.com , 1-800-522-6249 MOMS Medical Supply- www.momsup.com National Easter Seal Society Making Life Better - www.easter-seals.org/ North Coast - 1-800-821-9319 Rubbermaid www.rubbermaid.com/ Sammons Preston - www.sammonspreston.com 1-800-323-5547 Science Products - 1-800-888-7400 Smith & Nephew, Inc. - www.smith- nephew.com HOUSING, HOME MODIFICATIONS STANDARDS Uniform Federal Accessibility Standards - 1-800- 872-2253 REGULATIONS/GUIDELINES ADA Accessibility Guidelines (ADAAG) - 1-800-514-0301 Fair Housing Accessibility Guidelines - 1-800- 343-3442 UNIVERSAL DESIGN AT BUFFALO IDEA web site: http://www.ap.buffalo.edu/~idea RERC web site: http://www.ap.buffalo.edu/~rercud RESOURCES FOR HOME MODIFICATIONS http://www.aarp.org/universalhome/ Good site for browsing ABOUT.COM http://disabilities.miningco.com/ From the NetLinks area choose "Accessible Homes". Choose Universal Design & Home Accessibility. Scroll down to the end of the page to "Remodeling Examples" and choose either "Bertha's Home" or Leona"s Home". Good Examples of modification projects with graphics and costs. (Iowa State

University) TOWARD A BARRIER-FREE HOME http://www.independentliving.org Type "housing adaptation" into search box. INFINITEC INC. - www.infinitec.org SPECIFIC MODIFICATIONS Image Management - dealer for Barrier Free Lifts and the Original Sling System: www.image-management.com ACCESS INDUSTRIES - stair glide, porch lift, bath lift, minivator, elevator: 1-800-925-3100 FUNDING ASSISTIVE TECHNOLOGY FUNDING RESOURSES FANNIE MAE - www.fanniemae.com/index.html HUD PROGRAMS - www.hud.gov/search.html NATIONAL FAIR HOUSING ADVOCATE www.fairhousing.com/resources/finder/ COMMUNICATION Enkidu Research - www.enkidu.net Synergy - www.speakwithus.com ACC SOLUTIONS - for a listing of 2000 Communications Aid Manufacturers Association ACC Workshops - www.aacproducts.org Voice Amplification Devices - www.brucemedical.com FOOD SUPPLEMENTS Thick It - to thicken liquids for those with swallowing difficulties1-800-333-0033 www.precisionfoods.com

The Senility Prayer Contributed by Jane Anne King God grant me the senility to forget the people I never liked anyway, the good fortune to run into the ones that I do, and the eyesight to tell the difference.

Stages of Grief Many events in life involve going through the steps of the grieving process: loss of a loved one, loss of a job, divorce, diagnosis of a debilitating disease, such as PLS. First stage: denial and isolation Second stage: anger Third stage: bargaining Fourth stage: depression Fifth state: acceptance Do these stages apply to you? Where do you find yourself?

Exercises for Weight Maintenance?

Contributed anonymously What kind of exercises do people do? How do you stay in physical shape? I find myself gaining weight even though I am not eating any more (of course I suppose I could eat less, but what fun is that). *Ed. note: e-mail suggestions if you'd like a feature on exercise soon.*

Puppies for Sale Submitted by Frank Cecere. A Storeowner was tacking a sign above his door that read "Puppies for Sale". The signs have a way of attracting children. Soon a little boy appeared at the sign and asked, "How much are you gonna sell those puppies for?" The store owner replied, "Anywhere from $30-$50." The little boy reached into his pocket and pulled out some change. "I have $2.37, can I look at them?" The storeowner smiled and whistled. Out of the kennel came his dog named Lady, running down the aisle of his store followed by five little puppies. One puppy was lagging considerably behind. Immediately the little boy singled out the lagging, limping puppy. He asked "What's wrong with that little dog?" The man explained that when the puppy was born the vet said that this puppy had a bad hip socket and would limp for the rest of his life. The little boy got really excited and said, "That's the puppy I want to buy!" The man replied "No, you don't want to buy that little dog. If you really want him, I'll give him to you." The little boy got upset. He looked straight into the man's eyes and said "I don't want you to give him to me. He is worth every bit as much as the other dogs and I'll pay the full price. In fact I will give you $2.37 now and 50 cents every month until I have him paid for." The man countered, "You really don't want to buy this puppy son. He is never gonna be able to run, jump and play like other puppies." The little boy reached down and rolled up his pant leg to reveal a badly twisted, crippled left leg supported by a big metal brace. He looked up at the man and said, "Well, I don't run so well myself and the little puppy will need someone who understands." The man was now biting his bottom lip. Tears welled up in his eyes. He smiled and said, "Son, I hope and pray that each and every one of these puppies will have an owner such as you." IN LIFE, IT DOESN'T MATTER WHO YOU ARE, BUT WHETHER SOMEONE APPRECIATES YOU FOR WHAT YOU ARE, ACCEPTS YOU AND LOVES YOU UNCONDITIONALLY

EVENTS

Connecticut Connection Gathering

Submitted by Dolores Carron A day long meeting of the CT Connection, a PLS/HSP support group, was held in Wethersfield, CT on Wednesday, June 5, 2002. Fourteen (5 new) PLSers and HSPers and their guests were in attendance. Attendees came from CT, MA, NH, NY, VT, NJ, and DE. The early arrivals met for dinner at an area restaurant on Tuesday night where we shared good food and conversation. The program of events for Wednesday began with a continental breakfast and socialization. Dr. Joyce Saltman, a professor of Special Education, spoke on the topic "Laughter: Rx for Survival". After lunch was served, Rita was presented with a birthday hat and carrot cake (that had been the subject of much cajoling between her and Frank C. on the PLS-Friends site). We had a good laugh about the presentation and cutting of the cake. Our afternoon speaker was Christine Kasinskas, professor of Physical Therapy, who presented "Use It or Lose t". Meeting old friends and greeting new friends is always a wonderful experience. We look forward to the next time with eager anticipation.

Please contact Dolores Carron, 139 Forest Drive, Newington, CT 06111 or d.carron@worldnet.att.net if you would like to be added to the mailing list for future gatherings.

The California Connection

Contributed by Jennifer Thomson The 3rd Annual PLS Conference was held in San Diego, Ca. on October 25-26, 2002. This was the largest gathering to date, with 26 PLS/HSPers along with their spouses, families and friends, making the total in attendance 54, inclusive of our speakers. The gathering started with a "Meet and Greet" on Friday evening. One thing was certain; we didn't have to worry about how to recognize a fellow PLSer! It was a good guess that anyone with a cane or wheelchair was "one of us". Saturday morning started with a continental breakfast and social gathering while Linda Gentner and I met with the 3 speakers, Dr. Armon, Dr. Fink, Dr. Siddique and Nailah Siddique. It was a fascinating breakfast meeting, more on that to come. Our meeting started with a talk by Dr. Carmel Armon, my neurologist and the author of the PLS chapter on eMedicine. Dr. Armon is the director of the ALS Multidisciplinary Clinic at Loma Linda as well as Professor, Dept. of Neurology, Loma Linda University School of Medicine. He is extremely compassionate and knowledgeable in the management of PLS. His talk was followed up with a lively Q&A from the audience. Next we heard from Dr. Teepu Siddique, Director of the Neuromuscular Disorders Program at Northwestern University, Professor of Neurology, Professor of Cell and Molecular Biology AND a recipient of the research grants funded by the PLS Community through NORD. In addition, he is also Nailah Siddique's husband, a definite point in his favor! Nailah has been a positive force in our community for a long time, and I was extremely excited to finally get to meet her, as well as their daughter Niaz. Dr. Fink, as most of you know, is the Spastic Paraplegia Foundation's Special Medical Advisor, as well as Associate Professor, Department of Neurology, University of Michigan AND also a recipient of the research grants funded by the PLS Community through NORD. Dr. Fink has been very active in the HSP community and is very interested in PLS as well. His talks are always interesting and informative, and he is never at a loss for words! After lunch, we gathered back in the conference room for individual introductions and a sharing time. All in all, it was an extremely interesting day. I want to thank Linda and Craig Gentner for all their help in making this Connection work! Without their help, and my husband's, it would have been a chaotic mess. Angela Dixon created the agenda once more, as well as nametags and raffle tickets for Ronnie's Santa. We will have a video of the conference available. Cost and ordering information will be available later. I am filled with hope and joy after our Connection. Something about meeting all of you gives me great inspiration. I hope every PLSer will get an opportunity to attend a PLS gathering, whether it be a large one like this was, or a small gathering of 3 or 4. As Dr. Armon finished up his talk, he emphasized this: Live Each Day!

Spastic Paraplegia Teamwalk

Contributed by Kathy Geisler The inaugural SPF TeamWalk chaired by Shellie Fischer and assistant Adam Roach September 13-15 in Chesapeake, Virginia was a terrific social and educational weekend as well as the first national fundraiser for the SPF. Thanks to the support of TeamWalk walkers and Walkers by Proxy from 38 states and Canada, corporate donors including Millipore Foundation, Medtronics and Pride Mobility, and the support of Target and Norfolk Naval Base, more than $88,000 has been raised to date. Contributions provided funds for the foundation's first research grants. Thank you! The Chesapeake Holiday Inn was the home base for the weekend. Friday offered a dinner social for twenty early birds arriving from nine different states. The chatting didn't end until nearly midnight, when all remembered that two busy days were still ahead of them. Saturday featured an informative conference for nearly thirty attendees. Jan Henderson, PT, provided a discussion and demonstration on the full range of orthotic devices; Attorney Eric Bauman gave an overview on tips for applying for disability and Peter Gaskell, PA-C, Duke University, presented a comprehensive program on HSP and PLS. Additionally, a representative from Medtronics talked about the benefits of the Baclofen pump (treatment for spasticity). Sunday's TeamWalk was held at Chesapeake City Park. More than eighty patients, family members and friends, Target workers, Norfolk Naval Base workers, and representatives from the University of Michigan alumni group gathered for an afternoon of fun and camaraderie. The festive day featured a hip-moving Elvis performance provided by popular Elvis impersonator Joe Searles. Elvis also serenaded Walkers and handed them stuffed bears as they head out for the walkathon. Nearly half of the attendees took part in the walk, each finishing whatever portion of the distance was comfortable, whether a block or the full three miles. Dr. Fink, the SPF medical advisor, not only walked in TeamWalk, but was available for short consultations. The Walker by Proxy program was a heart- warming hit. Walkers wore their own name tags, but also added the names of Walkers by Proxy who participated from afar by raising funds in their own spirits for TeamWalk. From all across the country, Walkers and Walkers by Proxy joined together in working for a cure for HSP and PLS and enhancing the daily lives of those affected by these disorders.

2002 Spastic Paraplegia community events - for PLS and

HSP patients and loved ones One of the focuses of the spastic paraplegia community (a community serving primary upper motor neuron disorders PLS and HSP) is to organize opportunities for patients and loved ones to gather to learn and help one another as well as hear from experts. There are a variety of formats, including large conferences featuring top experts, smaller conferences with local experts, support lunch or dinner gatherings for patients and loved ones and social outings. We are also involved in two monthly support groups that are open to people with other neurodegenerative conditions as well as PLS and HSP.

Here's a chronicle of 2002 completed and pending events: **February, Tampa, FL. Patient Connections Lunch** Twelve people gathered for a delightful luncheon at a Ramada Inn. Illness unfortunately kept another three people away. The event started with a round-table allowing everyone to share PLS or HSP stories as well as answer a get-to- know-you question for fun: "what is the one secret that most people don't know". Packets of educational and informational materials were distributed and everyone filled out a card indicating his/her "burning question". Cards were read and individuals shared their experiences and recommendations. Most of the discussion revolved treatment modalities and understanding the similarities and differences between PLS and HSP. It was the first opportunity for many to meet others, and hopes were high for a future meeting. (A meeting is scheduled in Ft. Lauderdale, Feb/03) **March, Ann Arbor, MI. Dinner with the Experts, Research Laboratory Tour**

A dinner gathering featuring Joan Mathay, R.N. and John Fink, M.D. of the University of Michigan PLS and HSP clinic and research laboratory brought twenty people from five states together at the Weber's Inn. Everyone enjoyed sharing stories and getting input from others as well as the experts. One of the round table questions – "What is the #1 best thing you do for yourself?" - provided a great opportunity to get motivated and set some personal goals. Packets of educational and informational materials were distributed. The next morning featured a tour of Dr. Fink's research laboratory where individuals could witness cutting edge research in action to help find the cure for PLS and HSP. **March, Ladner, BC, Canada. Patient Connections Dinner** Five people gathered for the first Canadian Patient Connections for a low-key, friendly dinner. Lots of sharing took place, with a major discussion around difficulties getting a diagnosis and various treatment methods. The small but mighty group hopes to have regular meetings and do outreach to other Canadians. The group feels that it is difficult to find experts knowledgeable about primary upper motor neuron disorders in Canada.

April, Seattle, WA. Lunch with the Experts Twelve individuals from several states and Canada enjoyed a luncheon at the Sante Fe restaurant featuring Thomas Bird, M.D., Department of Neurology, University of Washington. Attendees enjoyed swapping stories and getting real-life experience input from others. Dr. Bird answered numerous questions about treatment and cutting edge research in finding the cure. He conducts research on finding the cure for upper motor neuron degeneration. **April, Long Island, NY, Spastic Paraplegia Conference for HSP and PLS** Fifty people from nine states attended an informative national conference with non-stop presentations. The event featured keynote speaker John K. Fink, M.D., U. of Michigan, leading investigator and clinician for PLS and HSP. Local presenters were Mark Gudesblatt, M.D., a neurologist with extensive experience with PLS and HSP from South Shore Neurologic Associates; Joe Vlavka, P.T., Brookhaven Memorial Hospital; and Linda Bollinger, P.T., United Cerebral Palsy. Topics were symptoms, diagnosis criterion, physiology, treatment, and research as well as assistive technology. A Medtronic representative was available to discuss the Baclofen pump. The weekend also offered a Friday night arrival dinner and Saturday night Farewell Dinner for people to have plenty of time to chat with others. More than twenty people attended each dinner. **May, Chelmsford, MA: Luncheon Conference** Twenty people gathered on a beautiful spring day at Skip's Restaurant for a luncheon conference featuring Jo Ann Moriarity-Baron, P.T., expert on physical therapy for movement disorders. The afternoon began with a sharing roundtable and updates on community initiatives. Educational and information materials were available and the SPF Awareness Quilt was exhibited. Jo Ann presented a comprehensive program, stressing how individual the treatment modalities must be developed to meet very individual needs. Everyone is different, as much as they share spasticity, weakness, and balance difficulties. She demonstrated a number of great stretch routines and movement tips and helped the group try them out on their own. The big hit was a technique to get up out of a chair easier – just hold your arms straight out in from of you and raise them as you raise your body. **June, Cleveland, OH, Patient Connections Dinner** Seven people gathered at the Cleveland Holiday Inn restaurant for a low-key dinner featuring lots of sharing and instant bonding. For some, it was the first time meeting somebody else who had a similar disorder. **July, Salt Lake City, UT, Lunch with the Experts, Research Laboratory Tour** Twelve people, including one from NV and one from MA, swapped stories over a delicious Italian lunch at Tucci's restaurant featuring Kevin

Flanigan, M.D., expert on motor neuron disorders, and lab technician Emily Malouf, both from the University of UT research laboratories. Most of the discussion was sharing individual stories of symptoms and diagnosis. Emily's undergraduate thesis research under Dr. Flanigan resulted in the discovery of a new HSP gene locus. She and Dr. Flanigan talked about how making animal models of genes that cause neurodegeneration would hopefully lead to development of drugs to fix the biochemical process that has gone awry. After lunch, the group drove over to the laboratory for a fascinating tour of a research lab. **July, Memphis, TN, Quest for the Cure Conference Weekend** The national conference featured John K. Fink, M.D., U. of MI, leading investigator and clinician for PLS and HSP, who spoke at length about primary upper motor neuron disorders – their symptoms, classification, what’s happening in the body, and research for a cure. Other presenters included Mark LeDoux, M.D., U. of TN, who spoke about treatment (primarily drugs for spasticity), and Audrey Zucker-Levin, PT, U. of TN, and Ann Lindberg, OT, Germantown Rehabilitation Hospital, who spoke about physical therapy modalities and daily living aids. Additionally, Christy Hamilton from Handicap Unlimited set up a huge display of assistive devices including as assortment of various wheelchairs that people could try out. More than 80 people traveled from seventeen states and Canada for the conference as well as weekend social weekend events that provided plenty of time to meet others and share stories. About half the attendees arrived Friday night to enjoy dinner and chat and a good crowd headed out Saturday evening on a delightful dinner cruise on the Mississippi River. There was also an outing to Graceland on Sunday morning, which four people enjoyed. **September, Austin, TX, Dinner with the Experts** Seventeen attendees gathered at the Brick Oven restaurant for a Patient Connections dinner and physical therapy presentation and demonstration provided by Shawn Goodman, PT. A lively round table discussion to share stories and treatments was enjoyed by all. Educational and information materials were available. Additionally, an award was presented to the Austin Windsurf Club for running the first local fundraiser for the SPF (raised $700). **September, Pasadena, CA: Patient Connections Lunch** Three people gathered for a lovely chatty lunch in Beale’s Cafeteria. There was instant bonding and extensive sharing of stories and experiences. The group is anxious to attend a conference in San Francisco to be scheduled for spring 2003. **September, Boise, ID, Lunch with the Experts** Ten people joined at the Elks Rehab Hospital to share and learn from one another and hear from Robert Friedman, M.D., Physical Medicine. Dr. Friedman is also the medical director of Elks Hospital. It was a very lively and information afternoon and plans were made to meet annually. **September, Chesapeake, VA, TeamWalk Conference** The 2002 TeamWalk weekend featured a Saturday conference with several expert presentations as well as plenty of social time. Thirty people from numerous states attended. The morning provided plenty of time to meet and talk to others, as well as featured a representative from Medtronics who talked about the Baclofen pump. The afternoon held the formal presentations with Jan Henderson, PT, providing a discussion and demonstration on the full range of orthotic devices; Attorney Eric Bauman giving an overview on tips for applying for disability and Peter Gaskell, PA-C, Duke University, presenting a comprehensive program on HSP and PLS. Additionally, the SPF Awareness Quilts were displayed and there were plenty of educational and informational materials available. The local ABC news affiliate arrived and ran a feature on the conference and TeamWalk that evening on the news. There was a lot of excitement to watch it on television! A good group of people went out for a seafood dinner on the coast while others gathered for dinner at the hotel and yet others went their own ways. The conference day was a great prelude to the fabulous TeamWalk held the next day. **September, Boston, MA, Patient Connections Lunch and outing to the Abilities Expo** Six people met for a low-key lunch gathering and outing to the Boston Abilities Expo. The Abilities Expo is an annual exhibit of products and services for people with disabilities. The event also features a large number of free workshops, with the group enjoying one on Chair Exercises. Other workshops included presentations on claiming disability, parenting, car hand controls, speech aids, lifts, maneuvering the health care system, and others. **October, Baltimore, MD, Dinner with Dr. Fink** Fifteen people gathered with Dr. Fink, leading researcher and clinician from the University of Michigan at a Holiday Inn Restaurant. Individuals shared their personal stories of symptoms, diagnosis and treatment. Dr. Fink answered individual questions and talked about the various types of PLS and HSP. He also gave an update on current research to find he causes and cures for primary upper otor neuron disorders.

Upcoming: October, Baltimore, MD Dinner with the Experts" featuring Dr. John Fink and other experts

November, Chelmsford, MA, uncheon Conference Program eatures "Reflexology and other Alternative Healing Methods" with a hysical therapist and doctor. **December 7, Statham, GA, Patient Connections unch** Lunch gathering for patients and amily members.

Monthly Support Groups: **Bi-monthly support group, Ann Arbor, MI**

There is a bi-monthly support group meeting for PLSers, HSPers, and others with rare disorders (most attendees are PLSers and HSPers) every second Friday of the month from 6:30 pm - 8:30 pm at the Cancer Center Geriatrics Center, University of Michigan. Drop-ins are welcome. Call

Joan Mathay, R.N., for information: 734-936-3087 **Monthly support group, Norristown, PA** There is a monthly support group meeting for people with various neurodegenerative disorders on the second Saturday of each month from 10:00 a.m. - 12:30 p.m. at the Mercy Suburban General Hospital. Drop-ins are welcome. Contact Liz for more information: Lizout@aol.com

FUNDING

Major Grant Awarded

Linda Gentner, a PLSer and the PLS Communications Liaison for SPFoundation, congratulating Dr. Fink for being awarded the PLS Research Grant. Linda's husband, Craig’s, former employer donated $100,000.00 in honor of Linda. All of this donation went toward the awarding of two PLS Research Grants. The presentation occasion was the Memphis Conference.

ALS-PLS Research Foundation

http://www.als-pls.org/ This foundation has been formed by PLS patients, slow progressing ALS patients, and their families. With a goal of providing funds for research ttp://www.als-pls.org/contribute.htm , ecruiting participants for these studies ttp://www.als-pls.org/research.htm and roviding the latest information about these isorders, there is much work to be done. The ALS Research Fund was established at

Northwestern University Medical School in order to provide funding for research studies that will advance knowledge of Primary Lateral Sclerosis (PLS) and slow progressing forms of Amyotrophic Lateral Sclerosis (ALS), with the hopes of finding a treatment to stop or slow the progression of these diseases. Recently, Dr. Siddique and his colleagues at Northwestern University Medical School identified a gene mutation that is responsible for a rare, slowly progressive, early-onset motor neuron disease, called juvenile inherited ALS (ALS2). Another mutation, on this same gene, is also responsible for a juvenile onset form of Primary Lateral Sclerosis Further research is needed, and it is up to us, the patients and our families, to support Dr. Siddique's pioneering work on our behalf. **Address for donations:** NUMS ALS-PLS Fund Office of Medical Development Northwestern University Medical School Abbot Hall, Suite 1312

710 North Lake Shore Drive Chicago, Illinois 60611-3078 Or phone 312/503-8933 to make a credit card donation. To participate in research, please contact Lisa Dellafave MS, Genetic Counseling Email: 1-dellafave@northwestern.edu or Nailah Siddique, Clinical Nurse Specialist Email: nsiddique@northwestern.edu Phone 312-503- 2712 Or sign up from the website: http://www.als-pls.org/research.htm

ALS Therapy Development Foundation

http://www.als-tdf.org ALS Therapy Development Foundation uses entrepreneurial spirit and techniques to aggressively seek out, develop, and deliver promising therapies to slow, arrest, and cure ALS. We do this by identifying and filling gaps in the development process and defining and delivering the resources required to transform ideas into concrete therapies available to patients today. **Address for donations:** ALS Therapy Development Foundation 44 Glen Ave. Newton, MA 02459 Or if you would like to donate by credit card,

please call us at
617-796-8826

National Organization for Rare Disorders http://www.rarediseases.org

NORD has been working since 1983 toward the prevention, treatment and cure of rare “orphan” diseases. NORD created and recently published The Physician’s Guide to Primary Lateral Sclerosis. This project was funded through generous donations by the PLS community, launched by Linda and Craig Gentner and Redback Networks. **Address for donations:** Checks should be made payable to NORD/PLS Research Fund – be sure to specify this fund. National Organization for Rare Disorders 55 Kenosia Avenue PO Box 1968 Danbury, CT 06813-1968 Phone: 203.744.0100 Fax: 203.798.2291

Spastic Paraplegia Foundation

http://www.sp-foundation.org The Spastic Paraplegia Foundation was created to fund research to discover the cures for primary lateral sclerosis (PLS) and hereditary spastic paraplegia (HSP). In addition, we provide information and conferences about the disorders to patients, their caregivers, physicians, and the general public. We also provide support to patients and their families.Our goal is the day when all individuals with PLS or HSP are diagnosed, treated and cured. To learn more about the Spastic Paraplegia Foundation, please visit our web site at http://www.sp- foundation.org or call us at (860) 354-7071, or write us at 11 Pepper Pond Road, Sherman, CT 06784. Address for donations: P.O. Box 1208 Fortson, GA, 31808. E-mail: info@sp-foundation.org.

Project ALS http://www.projectals.org Since its inception**,** Project A.L.S. has been at the forefront of scientific research into finding treatments and a cure for ALS. Too often medical research is hindered by a lack of cooperation on the part of scientists who are forced to compete for critical funding. Project A.L.S. has broken this mold by bringing together a team of doctors from some of the most distinguished medical institutions in the world. These doctors and scientists are provided with the financial support to pursue their work in the most expeditious and efficient manner possible with the understanding that they share their findings and data with each other so that every possible path can be pursued until a cure is found. By fostering a spirit of cooperation, and by applying corporate expectations and timetables to the results, Project A.L.S. has established a new model for the funding and execution of medical research — one that has already produced remarkable results. **Address for donations:** Project ALS 511 Avenue of the Americas PMB #341 New York, NY 10011

Neurogenetics Disorder Clinic, University of Michigan Dr. Fink's laboratory has the largest PLS clinic in country. He is a top researcher of PLS and received one of the PLS grants for his study “Molecular Basis of Primary Lateral Sclerosis: Search for Alsin Binding Factors”, which studies the relationship between the proteins responsible for juvenile PLS and hereditary spastic paraplegias (HSP). **Address for donations:** HSP/PLS Research In care of: Ms. Lynette Girbach Department of Neurology University of Michigan 1500 East Medical Center Drive 5214 CCGCB Ann Arbor, Michigan 48109 - 0940

CAREGIVING

A Letter from Gary King, a Caregiver, posted 10-12-02 Hi to all, I just wanted to let you know how very much I appreciate your thoughts and prayers you wrote about Jane Anne's terrible pain she is going through. I have saved them all for her to read when she is able. It constantly amazes me that even though you too have this awful disease, you still take time to comfort others. I remember those years ago when we first learned the name of the disease Jane Anne had--- it was such a cruel, cold, unfeeling name. We had never heard of it (as had few Drs.) and were so terrified as to what the future would hold. We felt as though she was the only one in the world who had it. Then we discovered PLS-FRIENDS. There were only a few of us on then but what a relief to find there were others who understood what we were going through. We were able to share ideas, problems and even a laugh now and then. You are really a remarkable group--- I truly don't know if I would have the courage to face what you all do every day. I think all of us that try to care for you feel the same way. As we are not as brave as you, please forgive us if sometimes we get a little agitated or a little short with you--- we simply are so frustrated that we cannot take some of your pain on to ourselves, or make your legs work just a little better or make your hand hold that glass of water. Believe me, if we could, we would with no hesitation. So please be patient with us--- we too awake each day praying that maybe "today" will be the day that someone somewhere will find the cure for this devastating illness. Until that day comes (and it will) continue to stand together and share with all of us; because now we need no longer to fear this thing, but rather as a group, we can face it, challenge it, and someday defeat it. I know you are tired of reading this but lack of sleep tends to make me ramble on and on. Again, thank you for your thoughts and prayers. God bless you.

Educated Caregivers Videos

Contributed by Don Wilson The Educated Caregiver Series is a three-tape video set, which is directed to caregivers. The total run time is almost three hours. The first tape Coping Skills includes: Coping with the emotional challenges of caregiving; Gaining control over a demanding daily routine; Dealing with the natural feelings of helplessness, anger, resentment and guilt; Averting compassion fatigue; and Strategies to curb stress. At 80 minutes, this is the ongest tape of the set. Volume 2, Hands-On Skills includes: Hygiene, bed baths and nail care; changing an occupied bed; Observing for warning signs of medical problems; Patient transfer techniques; and Home safety. Volume 3, Essential Knowledge ncludes: Communicating effectively with healthcare providers; Giving and monitoring medicines and understanding drug nteractions; Preventing infections; Preventing pressure ulcers (bed-sores) and providing wound care; and Proper nutrition. I have reviewed all three

Volumes and find them helpful, especially Volume 1. I found the Series at Dynamic Living, www.dynamic-living.com (888) 940-0605. While the cost of the Series is not prohibitive ($50), I would be happy to loan the tapes for presentation at future gatherings.

Caregiving via Networking This fall, Dolores Carron coordinated a birthday blitz for a friend in a nursing home. Thanks to PLS Friends he received a total of 65 cards, representing most of the 48 contiguous states in the US, Canada, Australia, Europe, and India. A contingent of 3 CT and one NY PLSers visited and shared lunch, birthday cake and conversation with him. The joy he received clearly demonstrated the need for us to reach out to our friends who are unable to attend meetings or who don't have access to a computer.

About the Editor: I was diagnosed with PLS a year ago, in the fall of 2001, after having symptoms for about 3 years prior to my diagnosis. I am married to Jim, who is retired. We have three married children – a daughter here in Massachusetts where we live, two sons in Idaho and a total of 6.5 grandchildren. I feel very fortunate to have a career as a landscape designer which I love. I can continue despite speech impairment and mobility issues, thanks to my computer for designing and to wonderful people who install my designs. Prior to recognizing any PLS symptoms, I read Gail Sheehy's New Passages, and evolved a mission statement for my life. That mission is " to leave the world a more beautiful place." I look forward to compiling and editing information on PLS to share with all of you. I will always welcome input. I hope the efforts will provide the PLS community a sense of connection. . . be a synapse in your lives. Thurza Campbell 212 Farm Rd. Sherborn, MA 01770