Synapse

Winter 2007

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

SP FOUNDATION

Plan Now to Come to the SP National Conference and our 5th Birthday Celebration!

When: April 13-14 in Nashville, TN
Where: Embassy Suites 10 Century Blvd, Nashville, TN 37214. Rooms at $109/night can be reserved by calling 615-871-0033. Complimentary cooked-to-order breakfast and free parking are included with the room. Make your reservations today.
Keynote Speakers: Dr. John Fink of the University of Michigan, Dr. Peter Hedera of Vanderbilt University, and Dr. Mary Kay Floeter of NIH will be the keynote speakers.
Program Notes: There will also be information on Physical Therapy, Assistive Devices, and the Baclofen Pump.
Registration: Meeting registration forms will be available in the near future.

Anniversary Celebration

Formed in February 2002, we will celebrate our five year anniversary at the meeting. To celebrate and recognize those who have made significant contributions to SPF, we will be honoring people by inducting them into the **SPF Hall of Fame.**

President's Message –Annette Lockwood

Happy New Year! The Spastic Paraplegia Foundation had a very good year. **Donations** received last year totaled over $450,000, by category the results are as follows:

Category	Total
TeamWalk	220,123
2006 Year End Appeal Letter	65,258
Unrestricted	36,713
Exxon-Mobil Workplace Giving	33,754
Loop For Life Event	24,000
Annual Report 2006	19,374
Memorials	18,959
RGM Memorial Golf Classic	18,095
Pennies	10,671
Miscellaneous	7,175
Carolyn`s Southampton Benefit	5,655
Program Fees	1,213
Grand Total	**460,991**

We met our goal for the 2006 TeamWalks which was to raise $220,000. Thanks to everyone who obtained sponsors and participated in the TeamWalks. A special thanks to all of the TeamWalk organizers and helpers. Thanks to everyone for your help and support of our mission throughout the year.

SPF Hall of Fame. This new Hall of Fame will have these categories - 'Shakers & Movers', 'Never to be Forgotten', 'Behind the Scenes' and 'The Brain Power'. Please send your nominations to information@sp-foundation.org. or to SPF, 7700 Leesburg Pike, Ste 123, Falls Church, VA 22043. If you like, donations can be made in their honor. SPF Hall of Fame members will be honored in Nashville at our Celebration Dinner on Saturday night.

If you are interested in serving on the **SPF Board of Directors**, please complete the application that can be found on the SPF website home page. A new two-year Board term begins in 2007. The applicant must be able to attend the 2007 Board meeting on April 13 in Nashville, TN.

We are always looking for **new ideas to raise money for medical research**. If you have any ideas, please submit them the Board of Directors using the Fundraiser Event Form that can be found on the website - http://www.sp-foundation.org/how-to-help.htm

Executive Director Resigns Cathy Wilkes, Executive Director, has decided to resign from the Spastic Paraplegia Foundation. She felt that her skills would be better utilized at a larger foundation.

Committees Forming – Looking for Volunteers We are in the process of forming three committees – Fundraising Events, Program Events and Grant Proposals. If you are interested in participating on one of the committees, please contact Annette Lockwood or Linda Gentner.

Potential Joint Meeting with the United Spinal Association The United Spinal Association is holding a two-day conference that will offer in-depth presentations on critical issues affecting people with spinal cord injuries, MS, Spina Bifida and other disorders (such as HSP and PLS) with clear, easy-to-understand seminars. The conference will be held in Orlando, FL on August 27-29. They will also be hosting a wide variety of nationally-known vendors showcasing the latest in products and services for people with disabilities. I have been in contact with the Association to discuss SPF participation in this conference. A TeamWalk could be held on the Sunday, August 26 prior to the conference. I believe this is an excellent opportunity to engage and interact with others that deal with similar difficulties as we do. If this is of interest to you, please contact Annette Lockwood who would like to see if this is worth pursuing. For more details,

go to http://www.sciconference.org/
Hope to see you in Nashville,
Annette M. Lockwood

Help Make the SP Foundation Database Complete

Contributed by Linda Gentner

SP Foundation has a secure and confidential database. The system keeps track of the finances of the Foundation, and contact information for donors and our patient community. This database is used to send out information from the Foundation. Annette and I are trying to update the database to have the most current information as possible on everyone, including who has a baclofen pump.

When people join the HSP-L Discussion Group or SP E-News, contact information is added to the database. There is not a system in place to capture similar contact information when people join PLS-Friends.

Here's how you can help make the SP database complete. Please keep in mind that the database is strictly confidential. Please inform us whenever any of your contact information changes. Even if you think we have your current information, please send it anyway so I can verify.

Please send your contact information to my direct email address lkgentner@aol.com or mail it to:
Linda Gentner- 1605 Goularte Pl.-Fremont, CA 94539.

Name:_______________________
Address:______________________
Phone Number/s:________________
Email/s:________________________
PLS, HSP, SP or ______
Affected person/spouse/parent/caretaker/medical personnel/researcher/other _______
Your neurologist (for our Patient Directory):_______________________
Baclofen pump user, date of implant:______________________________
E-News Subscriber Y/N ______________
Any additional information you send will be included in "notes".

LIM Coalition Awards Grant to SPF

Letter from LIM shared by Annette Lockwood

Thank you to all Life in Motion Coalition organizations that participated in the Letter-writing Campaign! Eighteen member organizations of the LIM Coalition elected to participate in the Letter-writing Campaign. Of the total 4,000 letters generated, these 18organizations accounted for 2,729 of the letters sent to Congressional representatives. Three organizations were responsible for driving over one third of the letters generated by participating organizations, representing over 50% of the effort toward the campaign initiative (as measured by percentage of declared membership involved in the campaign).

Congratulations to….
#1 Tremor Action Network
#2 Spastic Paraplegia Foundation
#3 National Spasmodic Torticollis Association

These three organizations will receive grant recognizing their efforts in driving their membership/constituency to participate in the Letter-writing Campaign.

Diagnosed With the Rare Disease He Studied for Years, Dr. Olney Struggles to Find Donors for ALS

Excerpted from an article by Amy Dockser Marcus

Ed. Note: I've included this article so the reader can see that SP is not the only body challenged by fundraising difficulty.

Like many patients who get diagnosed with a rare disease, Richard K. Olney set out to raise awareness and money after learning in 2004 that he has ALS.

Few people seemed better poised than Dr. Olney to draw attention to the fatal neurological disease. Dr. Olney, a neurologist, was already a prominent researcher on ALS. In 1993 he founded the ALS Treatment and Research Center at the University of California, San Francisco, and turned it into one of the top ALS research facilities in the country. Dr. Olney and his family set up the Richard Olney Endowment with the hope of raising $10 million to find a cure and to support the ALS center, which had a $500,000 debt when he was diagnosed. Despite the widespread publicity and outpouring of sympathy, Dr. Olney says he has raised only $200,000. Some of the money went to pay down the center's debt, leaving around $100,000. Since the endowment follows a practice of spending only 5% of total funding each year, this means just $5,000 is available for spending. Dr. Olney's efforts highlight one of the big difficulties for patients with rare and lethal diseases. With a tightening economic climate and so many other competing and worthy fund-raising causes, even people who can put a prominent face on a disease often have trouble raising money.

There are, of course, instances of success in fund raising for rare illnesses. Project A.L.S., founded in 1998 by Jennifer Estess, who died of ALS, and her family and friends, raised $3.77 million in fiscal 2006, $1.46 million of which came from an annual benefit. This amount pales in comparison to the money that major foundations for diseases such as breast cancer are able to give out. Well-meaning families can find that the disease "maxes out favors from your friends," Olney's daughter says. "It's hard on top of that to say, 'By the way, you've been so kind in making us dinner once a month, do you also want to donate to ALS?' "

EVENT REPORTS

IN – Indianapolis, August 19. Loop for Life
Harvey Mover, Loop for Life Chairman and Founder, organizes a motorcycle ride in Indianapolis called Loop for Life to raise funds for SPF and St. Mary's Child Center. Loop for Life events over the past ten years, has raised over one million dollars with more than 25,000 people attending. On August 19, 2006, over 1,000 motorcycles hit the road raising money for the Loop for Life. Harvey has presented SPF with a check for $24,000. Our sincere thanks to Harvey and all Loop for Life participants for their generosity and support.

MD – Queenstown, November 4. Fourth Annual RGM Memorial On November 4, 2006, the fourth annual Richard G. Milbourne Memorial Classic golf tournament was held in Queenstown, MD. Despite the chilly weather, 144 golfers enjoyed the three contest holes and several food stations that were scattered throughout the course. Dinner with live entertainment and auction followed the golf. With the $18,000 raised this year, the tournament has provided over $70,000 to SPF.

NC - Raleigh, November 4. Magnificent Mile and TeamWalk

Organized and reported by Sarah Witt

The Connection and TeamWalk were held at NC State University's Centennial Campus - Sarah also organized the Magnificent Mile race for athletic runners as part of the event

The morning of November 4th dawned clear, crisp, and cold and stayed that way as set-up got rolling for Raleigh's first annual Magnificent Mile Races and TeamWalk. Volunteers began gathering in force around 8:00 am and by 9:00 am the plaza at NC State's Centennial Campus was hopping. The 402 registered participants, who ranged in age from 2 to 60-something, were picking up their packets, enjoying delicious goodies from Great Harvest Bread and Bruegger's Bagels, and trying to stay warm.

At 10 o'clock sharp, the thermometer jumped to

38 degrees Fahrenheit and the 95 competitive milers headed down the hill of a very fast course. At 10:04, Russell Slade broke the tape with a winning time of 4:16. Shortly after, my good friend Heather Davis came flying across the line, handily winning the top female spot with a time of 5:09.

As the last miler came across the line, preparations started for the non-competitive mile and TeamWalk. The gang of 257 runners, joggers, walkers, and "rollers" embarked on an out-and-back mile course at 10:30 am. Within this group were several representatives of SPF: Jim and Thurza Campbell and extended family; Cece Russell and her daughter Jessie; Don, Bettie Jo, and Matthew Wilson and their gang; Judith West and husband John Skau; Dana Brower; and the Corsmeier crew, which included mom Linda, son Scott, and daughter Amy Petrucci. For the record, Cece took the SPF speed-demon award as she finished her mile in a flat 16:00.

The kids races were enjoyed by every one of the 40 children who registered.

After the races were run, all parties reconvened on the plaza to watch the awards ceremony and to listen to a moving speech given by Dr. Richard Bedlack, head of the Duke ALS Clinic. Dr. Bedlack, who participated in the non-competitive mile, talked about the history of motor neuron disease, the research strides that have been made in the last 10 years, and the importance of events like this one to raise awareness as well as funds for research. And raise funds we did thanks to the generosity of 23 corporate sponsors (platinum sponsors were The Athlete’s Foot, Ascolese Enterprise, Inc. Lenovo, Love2Run Coaching, North Raleigh United Church, and Second Look Pressure Cleaning), the hard work of our SPF folk, and numerous individual donors. A few checks yet to be counted and race proceeds still to be calculated, but right now we are at $22,500 raised.

MA- Burlington, December 2

Organized and reported by Kathi Geisler

We had a fabulous Lunch Connection Seminar, Enhancing Mobility. 28 participated, including some first timers. We gathered at 11:00 and started off with a Round Robin where we shared a Top Tip, Technique or Tool that we use to enhance our mobility. Exercise programs, my new travel electric scooter, a new walker that doesn't have a seat but a big pouch to carry things and a Service Dog were all shared or demonstrated. We had two people from Hanger Orthotics for our Program. One was an Orthotist and the other was a PT. They brought different types of AFOs and talked about them and passed them around the room. They did a PowerPoint program on WalkAide. Then anyone who wished was tested to see if he/she were a candidate.

VA- Fairfax, December 7. ExxonMobil Supports SPF

For the past 4 years, ExxonMobil has held an Employee Favorite Charities Campaign (EFCC) at their Fairfax, VA facility. This program replaced the United Way Campaign. Employees are can make donations by payroll deductions during the year to one or more of their preferred charities. ExxonMobil then compliments the donations with a matching amount based on the employee designations. ExxonMobil pays for all administration expenses so the charities receive 100% of the donations. The Spastic Paraplegia Foundation is one of over 300 charities on the EFCC list. Annette Lockwood, now retired from ExxonMobil received the matching check of approximately $6,100 on December 7, 2006. Co-workers and friends of Annette donated over $20,000 to SPF for the 2007 campaign. Since this program began, SPF has received over $150,000 from the ExxonMobil Employee Favorite Charities Campaign.

Upcoming Events

Feb. 24 Tampa FL Connection

Contact Kathi Geisler kathi@kgeisler.com or phone1-978-256-2673.

A Casual Connection with the Manatee-Sarasota Sierra Club Group. A in the group woman who uses an electric wheelchair who organizes a monthly Roll & Stroll outing for slow walkers and riders. "Roll & Stroll to Tampa Electric's Manatee Viewing Center at Apollo Beach. Saturday, Feb. 24, 2:00 - 5:00 p.m. Visit the education center and view manatees seeking warm discharge waters." Please contact me if you'd like to meet for lunch first and then go to the outing together.

March 24 Phoenix AZ Connection
Contact Bonnie Guzelf or phone-1-480-838-1184
Details are taking shape for the 2007 Phoenix Lunch Connection. The location will be the Bada Boom Pasta Room, on 48th Street and Warner Rd., Phoenix AZ. Please let Bonnie know if you plan to attend. We need to have an idea of how much space we will be needing. More details will follow. By the way, if any of you are coming in from out of town, we go every year to the AZ Renaissance Fair which will also be open that weekend. We go every year, and its lots of fun.. (I take my power chair and have not problem!). Please contact me if you'd like to join the 17 people who are already signed up.

April 27-28 Berkeley Springs WV Spring Fling
Contact Ronnie Grove 13 Erin Ln. Berkeley Springs, WV 25411
Rooms are set aside at Best Western-Berkeley Springs Inn under PLS-Spring Fling Connection. Call: 1-304-258-9400 to reserve a room.

June 15-17 Long Beach, CA Connection + Abilities Expo
Contact Malin Dollinger, M.D. in Los Angeles. malind@cox.net or call me at (310) 378-4059.
We will be having a get together meeting, "Sharing Struggles and Success," for those with PLS, HSP, and others with paraplegia who wish to join us, AND their spouse, friend, or significant other, on Saturday morning, June 16. We are not sure if the meeting will be a half day or all day, and that depends on feedback from those who will join us. It will be an important opportunity to meet new friends, to share our struggles and triumphs, and to have a chance to network. There may also be a talk or two on pertinent subjects by health care professionals. This timing will allow you plenty of time to attend the Abilities Expo the day before or the day after (or both). There may be some time on Saturday as well. The Expo is at the Long Beach Convention Center. The closest hotel is the Hyatt Regency Long Beach, which is next door, which will give us a room rate of $209 a night (usually $259). That is somewhat pricey, and there are other hotels a little further away which are cheaper. I am checking these out. It would be useful for me to know how many people are interested in possibly coming. Later on we'll get to a definite time schedule and plan for the day, once I have feedback and a more definite idea re who will be here. If you would like to be on the planning committee, or help with arrangements, check in, or other key activities, please let me know.
Please send me an e-mail malind@cox.net or call me at (310) 378-4059. I don't need a guarantee or a commitment, just an early idea of how many are interested.

More Spring and Early Summer Events.
Details later
Vancouver, Canada; March, contact Jean Chambers jeanchambers@shaw.ca
Norman, OK: March, contact Mark Dvorak czechmarkmhd@yahoo.com
Indianapolis, IN: March 31, contact Brandy McKibbin bmckibbin@mail.com
Burlington MA: April or May, contact Kathi Geisler kathigeisler1@aol.com
NY Metro, NY: April or May, contact Janet SILVRMAVEN@aol.com
Thomasville, GA: May 18, contact Jane Anne King gking@rose.net
Philadelphia, PA: June 16, contact Liz Nussear. lizout@aol.com
Austin, TX: June 2, contact Marlene Doolen MDoolen512@aol.com

TeamWalks in late Summer and Fall. Dates to be announced. Look for the dates in Spring Synapse in April, SP-E-News or contact Linda Gentner - 1605 Goularte Pl.-Fremont, CA 94539.

TN -- yes
OH -- probable
OK -- yes
CA -- yes
MA -- yes
NY -- yes
NC – yes, probably first weekend in Nov.
GA -- yes
OR -- probable
MD -- probable
TX -- Brad Hendricks -- Texas Two Step -- October 20 in Houston
FL – possibly in connection with the National Spinal Ass'n. Conference in Orlando in August.

LIVING WITH HSP or PLS

Raleigh Reflections

By Sarah Roberts-Witt

I just wanted to share a couple of things with you about our Raleigh event. I am pleased to report we had a tremendous show of report from my daughter's school. We signed up 83 kids and parents! My husband I went into the 3rd grade classes (my daughter is in 3rd grade there) and talked to them about PLS and motor neuron disease, and how we need more research. We also showed them all my gadgets. I can't speak any more so am using Next Up software on a laptop--they loved it!!! And my electric wheel chair and my walker and my grabber. The best part was these children were so compassionate and had so many good, insightful questions. The principal saw this as whole event as a terrific educational tool and I think he's right. We got thank you cards from the kids and you wouldn't believe what they remembered!! Many of them included PLS in their cards and said they were so happy to be racing or walking to help us find a cure. It was very, very touching. I just wanted to let you all know about that. I had to take a big breath to make myself do it but I'm so glad I did.

We did a similar thing at my husband's company, which is a sponsor. Not as much fun but a little easier. I also wrote an article for a local sports magazine to tell my story and promote the event.So overall, organizing this event has turned into a wonderful experience that has helped me to grow and I'm very grateful for that. Even though I am ready for it to be over!

Grolls

Contributed by Galen Hekhuis

Ever wonder why you trip so much? Ever wonder why when you look to see what made you fall often you can't find anything? It is because of grolls. Grolls are sort of a cross between a gnome and a troll, but mostly they have big feet. Most important, they are invisible, you can't see them. Grolls are mischievous little critters, and they love to come stand on something important that you have dropped. They have very large feet, and so easily can cover most anything you drop, and, of course, being invisible, you can't see them or what they are standing on. How many times have you dropped something and not been able to find it, even when you should be able to? Proof a groll was standing on it. Sometimes you can distract the groll by dropping something even more important, causing the groll to go stand on that. This allows you to recover what you first dropped, but has the disadvantage of losing the even more important item. The tactic also doesn't work very well if the groll has a friend, and being social critters, they usually do. What has been recently discovered is that PLS/HSP types give off a scent that, while undetectable by humans, grolls find irresistible. We just attract grolls, by the bunches. Like I say, grolls are invisible, so this was never noticed before. All this time we've been thinking we walk funny, when in reality we've just been tripping over grolls. There's probably a groll sitting near you while you read this. Go ahead. Drop something important.

Patient Café

Patient CAFÉ (http://www.patientcafe.com) is a public portal for patients with any medical condition to exchange information and provide support and inspiration to others. Key Features of Patient CAFÉ include:
Knowledge Base: Share and read information about resources like medical and rehabilitation facilities, treatments, support groups, assistive devices etc
Story: Tell your story and inspire others
Snippets: Share a few laughs and smiles
Blog: Start your own Blog on Patient CAFE

We Move

Contributed by Judith Blazer, MS
Executive Director, WE MOVE
http://www.wemove.org/
Written by Susan Popp, West Virginia
Living with PD & Cervical Dystonia

We move.
  How ironic is that?
To be the name
  Of our favorite chat.
When most of us either move
  More than we should,
And others would gladly move
  If only they could.
But diversity of symptoms
  Makes us unique.
Some cannot walk,
  Others can't speak.
But near every night
  We come together for talk,
And usually stay
  Till well after dark.
PD, dystonia,
  Or even msa,
It's into wemove,
  In the foyer we stay
For regardless of title
  It's really the same,
We are all just players
  In this disorders game.
Just names on a wall?
  I'd rather say..NOT
When I think of the support
  From the friends that we've got.
When one hurts, we all do,
  As it should be.
For life sometimes deals us
  More than need be.
But your heartache is something
  That we can all share,
For this chat room called 'WEMOVE'
  Should be renamed ' WECARE'

Accessible Travel Story – Panama Canal

Contributed by Bonnie Guzelf

Phil and I celebrated our 20th Anniversary by taking an 11 day cruise of the Panama Canal. It was wonderful. We went on the Royal Caribbean Cruise Line ship" Brilliance of the Seas". I had purchased a small power chair specifically made for travel. We booked an accessible room with a balcony. The ship was wonderful and totally accessible for me. I was very impressed. My homework showed that RCCL and Princess are the most user friend for people with disabilities so keep that in mind if you decide to cruise. Also, the newer ships on those lines were usually built to be more accessible. I was able to go anywhere on the ship with no problem. They even have a special lift at the pool to help you get in (I didn't need to us it but it's nice to know they have it for people who do).

In Panama and Costa Rica we booked private shore excursions because the cruise tours were giving me a hard time about whether or not I could take the chair.

I booked private tours and they were wonderful. Picked us up in an SUV or van and had no problem with my chair. They took us everywhere I wanted to go ...all day and it was not any more expensive than the ship's tours. We got to see things that the other tours did not. Our tablemates were very impressed. I would highly recommend this option.

Next year Phil and I have planned a private accessible tour of Thailand. There is a wonderful tour company run by Tom (British) and his wife who is Thai. She has MS and that is how he got into it. The tour provides a wheelchair accessible van, a private driver a private guide, all 4 & 5 star hotels, all meals and all sightseeing. We are going for 18 days next December. If anyone is interested in the details, let me know and I'll send you the information. Tom has sent me some DVD's to distribute to people or organizations who may be interested.

I am a PLSer

By dldl@bellsouth.net

I am a PLSer something that I cannot change,
each one of us varies at a different range.
It's important for us to take one day at a time,
tomorrow will take care of itself, so keep this in mind.
Each step we take and word spoken can be a chore,
our inner strength will be there as we take on more.
Think on things that you can do instead of what you cannot,
otherwise you'll find yourself uptight in a big knot!
A positive attitude is important for all of us each day,
it will keep us focus as we make our way.
We are a rare breed of people chosen to carry this disease,
we will encourage others by the lives we lead.
No time for self pity, no room in our hearts for that,
too all PLSers I tip my hat!

US House Passes Bill to Expand Stem Cell Research

On Thursday, January 11, the House of Representatives passed *The Stem Cell Research Enhancement Act*, HR 3, by a vote of 253 to 174. This tremendously exciting news for all advocates of the promise of stem cells would not have been possible without the support and dedication of all of our advocates in keeping this issue front-and-center in the national agenda. The *Stem Cell Research Enhancement Act* expands the number of stem cell lines that are eligible for federally funded research, thereby accelerating scientific progress toward cures and treatments for a wide range of diseases and debilitating health conditions. Under the current federal policy on human embryonic stem cell research, only those stem cell lines derived before August 9, 2001, are eligible for federally funded research. This bill lifts that restriction.

Tell Them You Love Them

By Gary Lockwood

Have you ever laid awake at night?
Just thinking about those few people,
Those few people you can't do without.
How many of those times have you,
the next time you saw them,
Honestly told them what they mean to you?
Insecurities aside,
Open your minds, open your hearts,
Open your souls.
One man is no one,
Without love,
Without the passion that leads him,

Leads him to within.
Where he finds portraits of friends,
Portraits of family.
Look within yourself and find those people.
And tomorrow,
and the next day,
Tell them how much they mean to you,
Tell them you love them.

Tips for Dealing with Insurance Companies

Contributed by Valerie Wilson
<valerielynnwilson@YAHOO.COM>

I work at an insurance company. I have an enormous amount of trouble getting my claims paid correctly. I'm somewhat of a problem client because I know how they are supposed to be paid. The general public, who are less aware, just accept what the insurance company tells them and never questions it.

Okay here are some tips:

1. Get a copy of your policy and read it. It's the law. They have to provide it to you. There are all sort of riders that can give you headaches.
2. You usually have a right to file a Grievance and Appeal. Most of the time that will put a stop to incorrectly paid claims. Look on the back of your EOB and it will explain the process for filing a Grievance & Appeal. If your Grievance & Appeal is denied it will usually go to your state's Department of Insurance. Most insurance companies don't want it going there because you will be opening up a can of worms for the insurance companies. They pay you instead.

Relative Gravity

By Cathy Wolf

I eavesdrop on young women in the gym
Their perfect bodies glistening with sweat—
No, perspiration
Those ethereal bodies could never sweat
Sweating is for pigs
And ugly people
A blonde says to another
"I need to lose two inches here"
Pointing to her muscular, womanly thighs
The other blonde replies
"I must tone this"
She pats her pancake belly
"It’s disgusting"
I am more than twice their age
Crippled with muscle wasting disease
Each week I set the machines to a lighter load
Measuring my progress
Watch muscles transmogrify
Into some foreign, gelatinous substance
I want to shout with the wisdom of my colored hair
"Enjoy life!
Don’t worry about such trivial things!"
But they would only stare, open mouthed
Revealing perfect pearls of whitened teeth
And take me for an old fool

Helping Friends Relate

By Geo Anderson

Just for a moment think back way before you got this Yucky Disease. Did you go out of your way to find out about one of your friends who had some kind of cancer or other disease? No, probably not, because you didn’t really want to know .For one very big reason. Its called Disassociation for fear of what we don’t know. Fear of getting something is real. Being around someone who is ill is not easy. They may wonder if they are wanted but want to help their friend. You need to tell them how you want them to treat you. Now they all know if I really need them I'll hold out my hand and ask for help. They all mean well. So forgive them for not knowing how to relate.

By Galen Hekhuis

I think we may threaten folks, for two reasons. First, we represent an "it could happen to anyone, even me" type of situation to people. Second, our ability to manage, even smile at times in spite of our infirmity threatens
some folks in that it sets a bar they themselves might not measure up to should they have to face what we do. People respond to feeling threatened in a lot of strange ways.

CAREGIVING

Caring for a Loved One with PLS or HSP

Contributed by Jim Campbell

For the last five years I have been the primary caregiver for my wife Thurza (Synapse editor) who was diagnosed with PLS in 2001. During that time I have been searching for some meaningful advice for caregivers dealing with loved ones that have our diseases. Because PLS has some of the symptoms of ALS she and I attend a monthly ALS support group in our area. Much of the care giving discussion at those meetings seems to focus on caregiver burnout – usually brought on by physical exhaustion of the caregiver.

Although it’s dangerous to generalize, my observation is that PLS and HSP diseases impair but do not totally disable our loved ones. Certainly mobility, dexterity, energy, strength and some times speech and swallowing are reduced, but the patient often can still accomplish most of the six Activities of Daily Living, but more slowly. Therefore, the demands on most of the male caregivers dealing with a PLS or HSP patient are time consuming rather than physically exhausting. As a result the common caregiver admonition to "make sure you get a respite or physical break" hasn’t been all that helpful to me. That’s why I was particularly pleased with the Caregiver Breakout session at the SP Foundation National Convention on Long Island this past September. The session leader, Dr. Jean Elbaum, a psychologist specializing in neuro-rehabilitation, asked a room full of caregivers the following questions about being a caregiver to a loved one:

1. What’s the hardest thing about being a caregiver?
2. What do you think helps you keep going?
3. What do you do when the patient takes out frustration on you?
4. What is the value of focusing on the present rather than the past or future?
5. What positive strategies help you get through stressful times?
6. What advice would you give to a caregiver just starting to give care to a loved one?

As you might expect the leader got a wide variety of answers to these questions with some of the answers in disagreement. I encourage each of you to take the time to answer each of the six questions for your own unique situation. Here are my answers to get you started:

1. Slowing down is the most difficult challenge for me as a caregiver – walking slower, taking time to listen carefully before responding, eating more slowly and in general recognizing that the pace of life has slowed for Thurza and for me if I am to support her. Thurza has lost the ability to speak and now must use a computer with voice synthesizer or sign language to communicate with me. Both options take time and patience on both our parts.
2. My love and admiration for my wife keeps me going. These diseases may have taken away the more active physical activities we used to enjoy – skiing, swimming and hiking, but they can’t take way the joy of recalling the many special moments we have already shared or the opportunities for more sharing and planning together.
3. I often struggle with how to deal with frustration including my own as a caregiver. I think the key to dealing with frustration is to take time out – to stop and listen to one another before the frustration escalates. (I wish I could always remember that advice!)
4. I think it’s healthy to share happy memories and to spend time planning or anticipating future events like trips or family reunions. But the main focus should be on the present - living each day

to its fullest by appreciating the opportunity to share whatever life brings without trying to control or manipulate it all.

5. Our most stressful times have come when we have not been communicating and are out-of-synch. Usually that’s my fault for thinking I am too busy, too burdened to stop and communicate. We have found daily "meetings" where we each share what needs to be done that day as well as how we are feeling about things to be a great way of minimizing the occurrence of stressful times.

6. My advice to someone starting as a caregiver is to realize you are at the start of journey in a new direction for both of you. Many others have taken this journey, but it has no well-defined road map or known destination. One thing you can count on is "change" including your role as a partner in the relationship. As independent and capable as your loved one might have been, your role now calls for more support and involvement in the life of your loved one. You will become someone to lean on in multiple ways – physically an arm to lean on, mentally an interested observer to suggest aids and alternate strategies when needed and emotionally a cheerleader to encourage, to understand and, most importantly, to listen.

In summary, it’s not my answers but the ones that you come up with that will be most meaningful to you and to your loved one. I urge you to take the time to jot down your own answers to these important questions.

MEDICAL RESEARCH UPDATES

Human Stem Cells Found in Amniotic Fluid

Source: Nature Biotechnology, reported in the Boston Globe

Stem cells nearly as powerful as embryonic stem cells can be found in the amniotic fluid that protects babies in the womb. They used them to create muscle, bone, fat, blood vessel, nerve and liver cells in the laboratory and said they believe the placenta and amniotic fluid can provide one more source of the valued cells, which scientists hope will someday transform medicine.

"I feel these cells are pluripotent like human embryonic stem cells." Atala said in a statement. Pluripotent means the cells can give rise to any type of tissue in the body -- blood, nerve, muscle, and so on. Adult stem cells, found in the tissues and blood of fetuses, babies and adults, are already partly differentiated and are less adaptable.

They used discarded samples from amniocentesis, a test used to check fetuses for birth defects. Tests in mice showed the stem cells could be used to replace damaged brain cells, and could be "printed" onto structures using technology similar to that seen in inkjet printers to make bone tissue. Atala said a bank with 100,000 specimens of the amniotic stem cells theoretically could supply 99 percent of the U.S. population with perfect genetic matches for transplants.

Growing Motor Neuron Axons Using IGF-I

Nat Neurosci. 2006 Oct 22

Note from Mark Weber: Dr. Jeffrey Macklis received SPF research grants for his work both this year and last year. He is revolutionizing the field of nervous system repair in the central nervous system.

Ozdinler PH, Macklis JD.

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University, Boston, Massachusetts 02114, USA. Corticospinal motor neurons (CSMN) are among the most complex CNS neurons; they control voluntary motor function and are prototypical projection neurons. In ALS, both spinal motor neurons and CSMN degenerate; their damage contributes centrally to the loss of motor function in spinal cord injury. Direct investigation of CSMN is severely limited by inaccessibility in the heterogeneous cortex. Here, using new CSMN purification and culture approaches, and in vivo analyses, we report that insulin-like growth factor-1 (IGF-I) specifically enhances the extent and rate of murine CSMN axon outgrowth, mediated via the IGF-I receptor and downstream signaling pathways; this is distinct from IGF-I support of neuronal survival. In contrast, brain-derived neurotrophic factor (BDNF) enhances branching and arborization, but not axon outgrowth. These experiments define specific controls over directed differentiation of CSMN, indicate a distinct role of IGF-I in CSMN axon outgrowth during development, and might enable control over CSMN derived from neural precursors.

Restless Legs Syndrome in Hereditary Spastic Paraparesis.

Anne-Dorte Sperfeld, Alexander Unrath, and January Kassubek
Department of Neurology, University of Ulm, Ulm, Germany.
SOURCE: Eur Neurol, November 14, 2006; 57(1): 31-35.
http://tinyurl.com/yc69by

This study was designed to investigate the prevalence and determinants of the association of restless legs syndrome (RLS) and hereditary spastic Paraparesis (HSP). Therefore, 132 patients with HSP were evaluated concerning the symptoms of RLS by a standardized questionnaire. In 27 patients, the diagnosis of RLS was established. The data of this screening for RLS provided evidence that patients with HSP are particularly susceptible to develop RLS. Consequently, special emphasis should be put on the diagnosis criteria of RLS in HSP patients.

Scan of Human Genome Finds New Clues to ALS

http://www.mda.org/disease/als.html

The Muscular Dystrophy Association (MDA) and the Translational Genomics Research Institute (TGEN) announced that a comprehensive scan of the human genome has identified more than 50 genetic abnormalities in people with sporadic ALS. The most common of these abnormalities have never before been shown to play a role in the disease.TGEN researchers identified the differences by screening DNA samples from over 1,200 people with and 2,000 people without sporadic ALS using state-of-the-art microarray technology by Affymetrix of Santa Clara, Calif. "Our findings indicate these genes produce a sort of molecular glue that attaches motor neurons to muscle. It appears that in ALS the nerve is able to peel off the muscle and, when that happens repeatedly, the nerves die,"said Dietrich Stephan, TGEN director of Neurogenomics and the study’s principle investigator.

"There is a revolution going on in research, and this study is a perfect example of how things are changing," said Sharon Hesterlee, MDA vice president of translational research. "New technology is letting us look at the genome at a level of detail that was unthinkable just a few years ago and, as a result, costs are coming down, results are coming much faster and we’re seeing breakthroughs in diseases that have baffled researchers for decades."

According to MDA and TGEN, the next steps center around high-throughput screening for drugs that act on the biochemical pathways identified by the DNA screen.

Nonviral Gene Delivery Comes of Age

http://www.mda.org/publications/als/als-curr.html#age

Delivering genes to the nervous system or muscles using a patented high-pressure injection system may be the "next big thing" in gene therapy, if MDA grantee Jon Wolff’s hunch is correct. Wolff, an MDA grantee at the University of Wisconsin-Madison, has been working with Mirus (www.mirusbio.com), a Madison biotechnology company, to develop gene delivery methods that don't require the use of viruses.

In October, Mirus announced it has a European patent on its gene-delivery approach, known as Pathway IV, which stands for "intravascular." The company received a U.S. patent for the technique in 2003. Wolff says that, although the nonviral technique Mirus has patented can get genes into a large number of cells, "one of the concerns has been its safety, since it requires high intravascular pressure in order to be effective. However, we have conducted an extensive number of safety studies, and the technique appears to be very safe." In ALS, candidates for gene therapy include genes for neurotrophic (nerve-nourishing) factors, such as VEGF and IGF1, and compounds that block toxic genes, such as SOD1 genes with ALS-causing mutations.

Project ALS Research News

Stem Cell Progress

Stem cells, the source of all cells in the body, have the intriguing ability both to self-renew and to transform themselves into specialized cell types. For this reason, stem cells hold great promise in treating brain disease in which large numbers of nerve cells are lost.

In 1999, Project A.L.S. pioneered the use of stem cells in ALS research. Now, in the space of seven years, the Project A.L.S. stem cell team has achieved several milestones.

- 2000 Project ALS stem cell team transplants a variety of stem cell types in to the SOD1 mouse, a laboratory model of ALS.
- 2001 Project ALS-funded scientists devise method for directing the differentiation of embryonic stem cells (ES) into functional motor neurons, the very cells that are targeted for destruction in ALS.
- 2003 Rats paralyzed with an ALS-like syndrome regain significant motor function after receiving an infusion of stem cells into the spinal fluid.
- 2004 Project ALS team demonstrated that ES cell-derived motor neurons can establish appropriate connections with target muscles in a live animal.
- 2005 Scientists develop strategies for recruiting endogenous stem cells – or stem cells already residing in the body- to the ALS spinal cord.
- 2006 Project ALS opens the Jenifer Estess Laboratory for Stem Cell Research, the world's first privately-funded lab devoted exclusively to the study of stem cells and ALS therapies.

Jenifer Estess Laboratory for Stem Cell Research opened in May, 2006, in New York, as the first privately-funded laboratory devoted exclusively to the study of stem cells, ALS, and therapeutic approaches to the disease. A joint venture between Project A.L.S. and Columbia University, the Project A.L.S. Lab does not accept federal funding.

Named after Project A.L.S. founder, Jenifer Estess, the Laboratory unites leading stem cell experts from Columbia University, Harvard University, Memorial Sloan Kettering Cancer Center, Johns Hopkins University, and additional collaborators to focus together on specific scientific and clinical goals.

Short-term goals of the laboratory:

1. Create large numbers of human stem cell-derived motor neurons. This is our first chance to examine up close the properties of functional human motor neurons. Scientists will use these human motor neurons to test drugs that may slow the course of disease.
2. Create patient-specific stem cell lines. We will obtain DNA from the skin cells of ALS patients. This DNA will be transferred into human stem cell lines. Scientists will then differentiate these lines into motor neurons with ALS. These living ALS-motor neurons will offer us

new insights into the disease process and will provide an accurate new screen for ALS drugs.
3. Transplantation studies.

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Genetics of ALS and PLS

While approximately 5% of ALS cases are due to a mutation of the gene superoxide dismutase-1 (SOD1), most ALS cases do not appear to run in families, and are known as *sporadic*. The presumption with sporadic ALS is that a constellation of normally occurring gene variants acts in concert with environmental triggers to cause the disease.

Whether considering cancer, heart disease, infection, or brain disease, a person's genetic make-up variously affects his or her susceptibility to disease, the course of the disease, and response to treatment. Until now, however, no one has identified the gene variants that may predispose to ALS.

In partnership with the Harvard Medical School, Project A.L.S. has recently undertaken the first comprehensive analysis of the genetics of ALS susceptibility.

The Project A.L.S.-Harvard Medical School partnership is an unprecedented study that will analyze DNA from patients worldwide and guide the development of new treatments. Data generated from this project will be freely shared with the public via the Web. If technology has given us the tools to identify relevant genes, it has also given us new tools for manipulating them—for turning them on or off. Project A.L.S. supports investigations utilizing cutting-edge technologies including rapid DNA sequencing, gene therapy, and RNA interference, toward altering gene expression.

According to Diane McKenna-Yassek, who works with Dr. Robert H. Brown on this genetic project, data collection is complete. Samples of 1,100 patients and 1,100 controls are being analyzed. Results will differentiate between definite ALS and probable (this category will include PLS). In addition, the survey will sort environmental and geographic questions.

Event Photos

Travel Tips	**Massachusetts Connection - 12/06**	**Massachusetts Connection - 12/06**
		
Annette Lockwood receives Exxon Mobil's donation to SP Foundation	Over 20 attended this connection with the focus on mobility.	Joel Seidman is tested for a new device that electrically stimulates the leg nerve
NC TeamWalk – 11/06	**NC TeamWalk – 11/06**	**NC TeamWalk – 11/06**
		
Dr. Richard Bedlack spoke to a large crowd about medical progress.	Event organizer, Sarah in center along with fellow TeamWalkers	Six and unders in the 100 yd. dash
RHG Golf Tournament – 11/06	**RHG Golf Tournament – 11/06**	**Oregon TeamWalk – 9/06**
		
Ron Throwbridge, Paul Johnson, Julian Samuels & Tom St. Clair	Coed Foursome – Henry Hornbeck, Len Levitt, Carol Ellis and Dick Goldberg	Over 40 attended this TeamWalk organized by Karen Long (center)
Loop for Life – 8/06	**Loop for Life – 8/06**	**Accessible Travel**
		
Over 2,500 people were at the start of the Loop for Life around Indianapolis.	Elizabeth Johnson, SP Board Member Karen Johnson, event organizer Harvey Mover, Karen's brother Greg and Harvey's wife Debra	Bonnie Guzelf at the helm navigating the Panama Canal