

Synapse

Volume 11, Issue 4 Autumn, 2008

Newsletter of the Spastic Paraplegia Foundation

Letter from the President



Jim Sheorn
President

This year's TeamWalks are winding down. By the time you receive this, all but a couple of TeamWalks will have been completed. Did you get to participate this year? Did you know that you can participate and raise much needed funds for research without attending an actual TeamWalk? The Walker by Proxy program is a way that you can help raise money from your home. Please log onto www.sp-foundation.org for details on how you can help. The best way to get donations is by asking family and friends for a personal donation. If that is uncomfortable for you, you can send a letter or email. The SPF website has several examples of letters that you can use as well as tips on how to be a successful Walker by Proxy. If you raise \$250 or more, you will get a TeamWalk t-shirt. The end of the year is soon approaching, so you will want to begin soon to collect donations before the holidays. You can also ask family and friends to help raise money as well. They can ask their friends and co-workers for donations and increase the fundraising efforts. Please let them know that if they raise \$250 or more, they will also get a TeamWalk t-shirt. Research is very expensive, therefore we need your help to continue the battle to find cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. If you have already participated with TeamWalk, THANK YOU! I hope that you will wear your t-shirt proudly.

The 2009 SP Foundation National Conference will be held in St. Louis the weekend of June 13th, 2009. Tina Croghan, who is a full time theater and film teacher, has agreed to be our chairperson. She is already working on ideas to make the conference successful. In the future, we hope to have the conferences in locations throughout the country. We want to give everyone an opportunity to join us and learn from the latest in research.

We are in the process of hiring a Development and Outreach Director. This will be a paid full time position. Advertisements were placed with several organizations that deal with non-profit professionals. So far, we have received 20 applications from well qualified candidates. Next, we will work with these candidates and those that may still apply to determine who is the best match for SPF. We hope to have someone hired by the first of the year, if not sooner.

Key responsibilities that we are looking for are a person who can:

- In coordination with the Board of Directors, develop a long-term strategy and annual work plans with measurable deliverables and timelines and corresponding organizational budget. This includes ensuring that the budget is met.
- Managing and implementing a year-round fundraising campaign including existing special events (e.g., Team Walks) and creating/executing new fundraising initiatives and events.
- Leverage the strengths, skills, and interest of each board member to build the strength and long-term viability of the SPF organization. Provide all volunteers with the information and support needed to accomplish their respective commitments.
- Identifying and creating relationships with donors and soliciting donations from other foundations, corporate and individual prospects/donors.
- Cultivating, coordinating, motivating and recruiting volunteers; creating new roles and opportunities for volunteers based on their interests/abilities.
- Strengthening and expanding SPF's marketing, public awareness, and outreach materials, including the Website, and direct mail.
- Developing a variety of cultivation activities to support/enhance fundraising and giving opportunities from existing donors.



Letter from the President (continued)

February will now be designated as PLS Awareness Month. Congressman Joe Baca from California introduced the legislation. It has been approved by Congress and signed by the President. We thank you for your efforts if you were able to get your Congressman to vote in favor of this bill. Sarah Roberts-Witt has agreed to be the Chairperson for this new opportunity and bring awareness about Primary Lateral Sclerosis. Please look for updates on the SPF website and the next edition of *Synapse*.

SPF has many opportunities for you to volunteer to assist the work of our Foundation. How do your skills fit these needs?

1. Contact people to verify information in the Reyerse data base – contact Mike Podanoffsky mike@sharecube.com
2. Become an SPF Ambassador in AR, HI, ID, KA, MI, NE, ND, RI, SD, UT, OR, WY – contact Linda Gentner lkgentner@aol.com
3. Sponsor a Connection – for ideas contact Linda Gentner lkgentner@aol.com
4. Become a part of the committee planning PLS Awareness Month – contact Sarah Roberts-Witt srwitt@yahoo.com
5. Help plan the 2009 SPF National Conference in St. Louis - contact Tina Croghan at: tinacroghan@yahoo.com
6. Join the SPF Board of Directors - information@sp-foundation.org
7. Use your graphic arts and web design skills –contact Annette Lockwood annette.lockwood@verizon.net

Thanks so much for your interest in the Spastic Paraplegia Foundation. We look forward to providing you with the latest information in future issues of *Synapse*. I hope that you have a great holiday season with your family and friends.

Jim Sheorn, SPF President



Volume 11, Issue 4 - Autumn 2008

The Spastic Paraplegia Foundation Inc. (SPF) is a national, not-for-profit, voluntary organization. It is the only organization in the Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).

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SP Foundation News

2008 SPF RESEARCH GRANT RECIPIENTS

Paola Arlotta, Ph.D., Harvard University, Massachusetts General Hospital Center for Regenerative Medicine, **“Directed Differentiation of Neural Progenitors and iPS Cells into Corticospinal Motor Neurons”**

\$60,000 for 1 year

Janine Kirby PhD, University of Sheffield, School of Medicine & Biomedical Sciences, **“Elucidation of upper motor neuron vulnerability in Primary Lateral Sclerosis”**

\$55,908 for 1st year, \$47,467 for 2nd year; total \$103,375

Yasushi Kisanuki, M.D., Department of Neurology, University of Michigan, **“Paraplegia in HSP Rat: Analysis and treatment”**

\$60,000 for 2 years; total \$120,000

Jeffrey D. Macklis, M.D., D.HST, Director, Massachusetts General Hospital – Harvard Medical School, Center for Nervous System Repair, **“Molecular-Genetic Controls over the Development, Connections, and Survival of Upper Motor Neurons”**

\$60,280 for 2 years; total \$120,560

THE FRANK REYERSE HSP/PLS DATA BASE

by Mike Podanoffsky

The Frank Reyerse HSP/PLS database project is a world-wide registry to help connect people afflicted with HSP, PLS, and ALS. Frank’s original dream established in the late 1990’s is sustained today by a special project of the Spastic Paraplegia Foundation and its many wonderful volunteers.

To participate in the database project, go to <http://sp-foundation.org/freyerse>. Click on ‘Search’ to view members in any area of the world. To add your name to the data base, select ‘Add’ and complete the information requested in form. You can search by zip or postal code, by state or province, or by country name. You can then scroll through the results.

How to Pan and Zoom the map:

a) when you place the cursor on the map, you will notice a vertical zoom bar on the left. Hit + to zoom in closer, hit the - to move further away.

b) you can double click on any region and you will zoom in on that region. Play around and try to zoom into your state.

c) you can pan the map. Position the mouse on the map, press the mouse button down and move the mouse in any direction. You will see how you have grabbed the

map and are repositioning it for a better view.

How to View Pictures

d) click on any entry to see the person’s name, state, and condition (if disclosed).

e) entries that show with a dot have pictures. click on any entry with a dot to see the picture.

Privacy is an important part of the Reyerse database effort. We only publish a person’s first name, first initial of their last name, state, any description provided for publication, such as onset, and a picture, if provided. The database does not publish personal identifying information and there is no way for an unauthorized person to “look up” anyone’s record. Last name, address, telephone number, or email address are never published.

One of the goals of Frank’s vision was to encourage and allow members to connect with each other. Members can control whether they want to receive messages. If a member allows receiving connections, a connect link is shown in the search results. The connect link goes to a send message page. The message is then sent privately without ever revealing a members email address. Members can choose to respond by email or phone.

The data collected by the Reyerse data base gives us a glimpse into the frequency of these diseases. The data base now dynamically shows case distribution on Google maps. You can select to view just HSP or just PLS cases or cases reported recently. We ask for date of birth and gender, but that data has not always been given.

Here are views of the data base for US and Canada and for the North East US.



There is more work to be done. The data base is imperfect. It contains only a fraction of known cases of these disorders. World wide, the data base contains slightly under 1,000 cases. But it is a start.

This data base would not have been a success if it had not been for the many years of tireless efforts of Frank Reyerse until his death. Since Frank’s passing, Jim Campbell has regularly maintained the database and recently encouraged the Spastic Paraplegia Foundation to take on this special project. Natasha Schaff volunteered to import the data from its original layout to a more computer friendly layout.

Events

MASSACHUSETTS PICNIC CONNECTION

July 20 - Lexington, MA

Submitted by Kathi Geisler

The annual Picnic Connection was held on the grounds of the lovely Lexington Visitor's Center. This year, ten people came. Each Picnic Connection includes a "Show and Tell" time where people can demonstrate or share something that is benefiting them. Bob Swain showed off Waldo, his new Canine Companion from NEADS. Joel demonstrated all the moves capable on his new, ultra-electric wheelchair. Leslie and Ken showed off their collapsible bikes. Maureen and Kathi shared about their biking and upcoming waterskiing. Kathi also shared about her kayaking.

I LIVE, I LEARN, I ACHIEVE CONFERENCE

August 8-10 - Warm Springs, Georgia

Submitted by Karen Johnson

We gathered at the Roosevelt Warm Springs Institute for Rehabilitation, the historic facility made famous by President Franklin D. Roosevelt. Because it was a polio treatment center, there are paved paths everywhere. We stayed on-site in rooms that were truly handicapped accessible and affordable (\$30 per person per night). They are joined around a big room (with fireplace) for meeting and socializing.

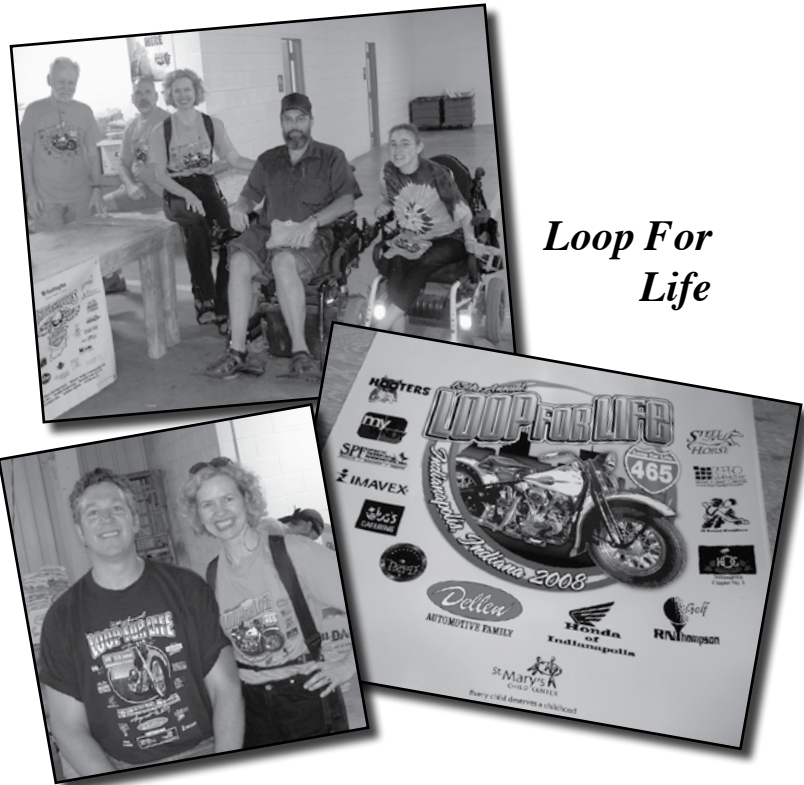
Nineteen attended. Presentations included "I Live" by Jane Anne King, "I Learn" by Ruth Kelley and "I Achieve" by Ben Free. After lunch, we had a demonstration of the MOTomed therapy machine and breakout sessions with an occupational therapist and a speech therapist. Next we enjoyed a tour of the facilities and pools. Many of us also toured The Little White House, where Roosevelt lived while at Warm Springs and where he died. Warm Springs is an accessible, affordable, charming place and I hope we meet there again.

LOOP FOR LIFE

August 23 - Indianapolis, IN

Submitted by Harvey Mover

The thirteenth Loop for Life Motorcycle Ride and Event took place at the Marion County Fair. The preliminary numbers indicate that nearly \$100,000 was raised, a portion of which will be donated to the SPF. The morning of the Loop for Life was consumed by breakfast and getting the nearly 2800 motorcyclists registered and arranged. About 100 volunteers helped with this task, including Karen Johnson and Steven Stuckey and his daughter. "The Loop" is I-465 around Indianapolis. The police block the exits and provide the escort for almost 10 miles worth of bikers. Lunch was provided to all riders, who also enjoyed the ride-in bike show. The event and turnout were extraordinary.



Loop For Life



Ken Dankel, Richard Wallace, Gary Krebs the instructor for ModeMed with Ben Free on the machine, Karen Johnson, Annette Lockwood, Cathy Wallace and her mom, Nora Wallace



Cathy Wallace, Debbi Thompson, Carolyn Dankel, Karen Johnson, David Lewis, Annette Lockwood, Ben Free, Gail Leasure, Ruth Kelley, and Jane Anne King



Gail Leasure, Debbi Thompson and Jane Anne King in the swimming pool that Pres. Roosevelt swam in for polio. The water feels like velvet.

Warm Springs

SOUTHERN CALIFORNIA CONNECTION

August 23 - Redondo Beach, CA

Submitted by Malin Dollinger

We held the third Connection at the HT Grill. We had the pleasure of dining together and spending three hours sharing our goals, our victories, and our challenges. Twenty-two attended from as far south as San Diego and as far north as the San Francisco Bay area. Cynthia Wagner demonstrated her Walk-Aide system. We shared and discussed medications, Baclofen pumps, new research, various medications, scooters and wheelchairs, travel problems, difficulty in establishing an initial diagnosis, and other unique problems and solutions. Malin explained that he has 57 grab-bars in his home so he always has something handy to move around and prevent falls. Will Bishop laid out the methods he has used to protect his scooter while traveling, and his efforts to create a collapsible scooter.



Malin & Lenore Dollinger, Will Bishop, Marilyn, Craig Gentner

Bonnie Brown, Cynthia and Steve Wagner



Jane & John Mitchell, Pat Dirkschneider, Deidre Maze, Philippa Green, Debbie Alexander, Norma Ard

AUSTIN PATIENT CONNECTION

August 30 - Austin, Texas

Submitted by Marlene Doolen

Twenty-two gathered at the Brick Oven for an afternoon of information, sharing, and learning from one another. Some drove in from locations three to four hours away. While visiting in Austin, one couple on vacation from England came to the Connection. They took away some ideas on how to hold their meetings in England. We Texas folks (who don't have Texas accents, of course) enjoyed listening to their English accents.

After lunch, Officer Tonya Normand of the Austin Police Department talked with us about ways to be proactive in protecting ourselves. Here are some of her tips:

Always be aware of your surroundings

Let at least one person know where you are going and when you will return

Carry pepper spray on your key chain

If you have a cell phone, carry it with you all the time

Have 911 on auto-dial on your cell phone

If you feel something is not right, trust your instinct

Always lock your car doors in or out of the car

Before ending the Connection, we had goodie bag drawings. Everyone took a little something as a reminder of the day. I told the participants that I hold the Connection each year because I remember the very first time I met someone else with HSP and what a difference that meeting made to my life.



A group of 22 gathered at the Austin Connection



Marlene Doolen, (head of the table) says a few words

MT. KISCO SALE DAYS

September 5-6

NEW YORK TEAMWALK

September 7 - Mt Kisco, NY

Submitted by Ann Lakin

On September 5th and 6th, the SPF participated in the Mt. Kisco Sale Days. We sold various SPF items, gave out brochures explaining PLS and HSP, and promoted our TeamWalk. The TeamWalk was September 7th. About 25 people participated. After the walk, we had raffles. Betsy Baquet was the big winner, however, she immediately donated her 50/50 winnings back to the SPF.

So many individuals and businesses gave so generously. Everyone was pleased with the lovely items that were raffled off. From the raffles we earned \$168, from registration we got \$155 and we received \$622 in donations. All in all, it was a very successful weekend.

*(L to R)
Helen Kienlen,
Chris Slagle,
Ann Lakin, and
Joe Kienlen*



*Ann Lakin and
friends man
the SPF table*

*Debbie Berish in
the wheelchair,
Ann Lakin, Betsy
Baquet and SPF
supporters*



QUEST FOR THE CURE SEMINAR

September 13

MAGNIFICENT MILE RACE AND NORTH CAROLINA TEAMWALK

September 14 - Raleigh, NC

Submitted by Sarah Witt

Things got rolling the morning of the 13th with the Quest for the Cure Seminar. Starting off the show was Dr. Nina Tang Sherwood of Duke University, who received a 2006 SPF grant for HSP research. She gave a fascinating presentation in which she discussed her research into *Drosophila* fly models of human disease such as AD-HSP and the role of spastin in the nervous system.

Next up was Wesley Reynolds, a doctoral student of PT at Elon College. Wes gave a fabulous talk on how water-based physical therapy and exercises can help those who suffer from spasticity. He also discussed the insurance issues patients are likely to encounter and how to get around them.

Last on the program was Dr. Richard Bedlack, director of the Duke ALS Clinic and a former member of SPF's Scientific Advisory Board. Dr Bedlack outlined the current barriers to PLS research, how they can be overcome, and some exciting research ideas he has for speeding up the diagnostic process.

Sunday the 14th proved to be a hot, sunny day typical of early fall in North Carolina. But that didn't stop more than 600 walkers, runners, and rollers from participating in the Magnificent Mile Race and the NC TeamWalk.



Racers at the starting line

The men's competitive mile race was thrilling. The winner zoomed down the straight-of-way to finish in 4:11. The women's race was equally exciting. Cece Russell gave her usual impressive performance—she finished her mile in 15 minute and 54 seconds on forearm crutches.

However, there's no doubt about who the stars of the day were. That distinction goes to four-year-old Nathan and 22-month-old Brady Rocheleau of Greensboro, NC. The sons of Jim and Shea, both boys have HSP and both ran their hearts out in the kids' 100-meter dash. The most beautiful moment of the entire weekend was the when the winner of the women's competitive race (*who clocked a 5:15 mile*) helped Brady cross the finish line.

NEW ENGLAND TEAMWALK CONNECTION
September 13 - Woburn, MA

Submitted by Thurza Campbell

Thirty people gathered around the picnic tables by the shore of Horn Pond to share tidbits of their own stories. We heard Pat tell of the wonderful outings she's found for her wheelchair bound son "T", including climbing a mountain and skiing. John Swain donned an English device, Musmate, to improve your gait. John also thanked Kathi Geisler warmly for all she has done and continues to do for SPF and especially those of us in New England. Following the sharing and lunch, we had our TeamWalk on the sidewalk along the Pond.



Cece Russell walks her mile!



Nathan Rocheleau proudly walks his mile!



Sarah Roberts-Witt (center), Chair of the Magnificent Mile and TeamWalk



NE TeamWalkers head out



Ed Geisler with John Swain demonstrating the Musmate



The NE group at the shore of Horn Pond

SUPPORT SPF WITH
ONE STEP A MONTH

Consider making a monthly donation to help SPF move a step closer to a cure. Our One Step a Month Program is a win-win! Recurring gifts allow us to plan ahead with confidence, making sure we take the best steps towards finding the cures for HSP and PLS. Plus, recurring donations allow you to give in a convenient, safe and secure way. Go to <http://www.spf-foundation.org/donate.htm>

Teamwalks & Connections

NORTHERN CALIFORNIA CONNECTION

October 3-4, 2008

Valley Community Church, Pleasanton, CA 94566

Linda Gentner: lkgentner@aol.com, 510-651-5676

A dinner is planned for Friday night at the Pleasanton Hilton. The TeamWalk and luncheon will be held on Saturday in Pleasanton.

IDAHO CONNECTION

October 4, 2008, 12:00 noon

Idaho Elks Rehab Hospital - Boise, ID

Patricia Bernhard:

patricia.bernhard@gmail.com, 208-888-4069

Dr. Robert Friedman will speak and answer questions and a representative from Medtronic will also participate in the meeting.

NORTHEAST OHIO LUNCH CONNECTION

October 11, 2008 – 1:00pm

Panera Bread 9587 Mentor Ave, Mentor, OH

Maryann Mayer: mayersms@oh.rr.com 440-257-1383

The first NE Ohio HSP/PLS Lunch Connection lunch will be held in the VIP Gathering Room at Panera Bread. Please join us for lunch so we can share our stories and get acquainted.

TAMPA BAY FALL FORWARD COOKOUT CONNECTION

October 18, 2008 12:00 - 3:00 pm

140 Chippewa Ave., Davis Islands (Tampa), FL

Bruce Maser: 813-649-8900

Gather at the home of Bruce Maser to exchange stories and concerns, and enjoy a cookout around the pool. Hamburgers and hotdogs will be provided. Bring a side dish or dessert to share with the group. The registration fee is \$5 per person. Make your check payable to SPF and mail to: Bruce Maser, 140 Chippewa Ave, Davis Islands, FL, 33606. Please register by October 3.

7TH ANNUAL AUTUMN IN CAROLINA AND SAWCAR RACE

October 18, 2008 - Rural Hall, NC

Don Wilson: don-wilson@earthlink.net,

336-969-6748

A Friday night dinner is planned and a hospitality suite is booked at the Holiday Inn Select for Friday evening. Autumn in Carolina will be held in the Fellowship Hall of Kingswood United Methodist Church on Saturday.

Weather permitting, the SAWCAR (Scooter and Wheel Chair Association of Racing) races will be held.

Those from North Carolina can register with the ALS Association and apply for a vacation grant for up to \$250. Discounted rooms (\$85/night) are available at The Holiday Inn Select. Call 1-800-553-9595 and ask for a room in the Autumn in Carolina block. Other motels in the area include:

Super 8 Motel 900-800-8000; Days Inn 336-744-5755; Quality Inn 336-767-9009; Motel 6 336-661-1588.

TENNESSEE TEAMWALK CONNECTION

November 1, 2008, 9:00 am - 12:00 noon

Centennial Medical Center, Nashville, TN

Jim Sheorn: jmsheorn@comcast.net

615-479-7369

The TeamWalk Connection will feature a video from the National Conference that was held in June. The meeting included a talk about Social Security Disability, Dr. Fink's speech about the latest on HSP and PLS, as well as a motivational talk.

TEXAS TEAMWALK

Cancelled - Houston, TX

Marlene Doolen: mdoolen512@aol.com

512-331-1953

Unfortunately due to the devastation caused by Hurricane Ike, the Houston TeamWalk is regrettably cancelled. Plans are to hold one in 2009.

RGM GOLF CLASSIC

Nov 8, 2008, 8am-6pm. Queenstown Harbor, MD

Sandie Heinicke: 301-352-7268

<http://rgmforespf.googlepages.com/home>

The 6th Annual RGM Golf Classic will be held at Queenstown Harbor (River course). This year's tournament highlights include a complimentary Bloody Mary bar, free beer and beverages all day, lunch served on the course, silent and live auctions, door prizes, and dinner.

SPRING FLING

May 1-2, 2009 - Berkeley Springs, WV

Ronnie Grove: frogrove@verizon.net

Details date will be released closer to the date.

A note from Ronnie: Mark your calendar for Spring Fling 2010. This will be Spring Fling number 10 and I intend to make it really special by having a "Homecoming Event" or a Ten Year Reunion. I hope to entice all who have attended over the years plus those who have wanted to.

Living with HSP/PLS

'Forever Friends Memorial Garden'

Created by and article written by Diana Montague-Jackson

Have you ever had a 'hunch' or 'intuition' that you have followed up on and then watched it grow into something quite unexpected and wonderful? That is how the 'Forever Friends Memorial Garden'- a tribute to those who have passed on from Motor Neuron Disease- started earlier this summer.

I suffer from Primary Lateral Sclerosis and belong to the PLS FRIENDS website for those with PLS and HSP. Over the late spring and summer several friends on the website passed away from complications of PLS and ALS. Deeply saddened and troubled, I decided, with the help of my roommate Sharon, to make a rockery in our small garden here on the acreage in Red Deer, Alberta, Canada. It was a way of helping me to grieve the loss of such wonderful people.

I suppose many large and beautiful projects begin this way: a small idea that catches the imagination of others and blossoms into something wonderful. And this is how the Memorial Garden came into being. I mentioned on the PLS FRIENDS website that I had planted a rockery. I also had an idea to expand this with a few more rose bushes and flowers. Someone on the website suggested that everyone send some soil from different American states, Canadian provinces and anywhere in the world where a 'Forever Friend' has passed on. Small donations began to come in along with photos of loved ones, sand, soil, clay and seashells from all over the world!

From then on, it became a 'team project'. The Garden was no longer mine, but 'ours', all of those wonderful friends on the website world wide. With the help of my 'Garden Volunteers' (roommate Sharon Race, my daughters Sarah and Heather Cornish and Heather's fiancé Jonathan Smith) the garden grew from a small section near the house to over a quarter acre and still growing! With the donations I purchased annual flowers, flowering bushes and shrubs, statuettes, bird feeders and much more. Jon, my muscular future son-in-law helped to dig lots of flower beds of various shapes and sizes, Heather and Sharon helped me with planting and weeding and Sarah, my 20 year old, donated a 5 foot tall statue of an angel which stands in the centre of the east Garden.

At the suggestion of another 'PLS FRIENDS' site member, I have laminated all the photos that were sent to me and they are out among the flower beds and bushes along with the soil from the person's state, province or country. In phase 2, to begin next spring, I will be attaching these photos to flat-faced rocks from the beautiful Alberta Rocky Mountains. Also in phase 2, if I can continue with my gift of convincing friends to get involved, there will hopefully be a garden pond and small water fall. Sharon is a genius with building little benches and plans to make one to go next to the pond: a place to sit and enjoy the peace.

The name? Again, it was a team effort among the PLS/HSP and ALS members. There were many excellent suggestions...I could have chosen at least 5 really good names! But 'Forever Friends' says it all I think. The Memorial Garden was never meant to be a place of sadness but one of joyful remembrance...a place to honor friends and family members who were courageous, loving and fun.

If you take a stroll through the garden, you will encounter not just flowers and bushes, but little smiling gnomes, ceramic butterflies, tiny angels and nymphs all nestled among the blooms. I especially love to wheel out there first thing in the morning, coffee in hand, and listen to the birds, watch the many and varied butterflies and bees flit from flower to flower. It is a magnificent and moving sight as the early morning sun begins to light up each part of The Garden.

My dream is that everyone could visit this spot and sit with me to enjoy the sound of the birds, the vibrant colors of the various blooms and remember with peace and love, those who have moved on and are now free. So, while I would love to take credit for 'The Garden', it truly has been a creation of all of us at the PLS/HSP websites. A joint effort and, I hope, a joint healing.



Memorial Gardeners Diana and Draven relax

For more information on the 'Forever Friends Memorial Garden', I can be contacted at dianamj100@hotmail.com or by mail: Diana Montague-Jackson, 3730 Spruce Dr., Red Deer, Alberta T4N 3N9, Canada.

All are welcome to visit and I would be happy to email photos to anyone who is interested. Also, if you would like a small tribute to a friend or family member to rest in the garden, feel free to contact me. Thank you friends, for helping to make this beautiful project a reality! Bless you all.

(Pictures of the 'Forever Friends Memorial Garden' and its creators are on the back page.)

New Feature in *Synapse*

Ed. Note: Dr. Fink has kindly offered to answer your disease-related questions in *Synapse*. You can submit your questions to him by clicking <http://www.spf-foundation.org/Synapse.htm>.

#1 Alcohol Consumption

Contributed by John K. Fink, M.D., SPF Medical Advisor

“Medical recommendations” (*advice from health care professionals*) regarding potential benefits of daily alcohol are controversial: Ask 5 doctors and you'll get 10 opinions! Here are a few opinions:

1. Clearly, excessive alcohol consumption should be avoided by everyone.
2. Clearly, combining alcohol with sedating medications (*including Valium*) should be avoided. Since Baclofen is chemically related to Valium, and since Baclofen may cause sedation, the same caution would apply (*particularly in individuals taking high doses of Baclofen*).
3. Dantrium (*which can cause serious liver disturbance*) should not be used in subjects who have chronic excess alcohol intake.
4. There are some types of HSP that also affect coordination (“*ataxia*”). I would predict that alcohol may make this symptom worse.

I have met several subjects with ataxia who have had marked worsening even from one or two glasses of wine.

5. Some cardiologists feel that one drink (*one ounce of alcohol, equal to one bottle of beer; one glass of wine*) is not injurious and may actually be beneficial.

6. For daily relaxation at bedtime, I would recommend “non-chemical” approaches (*including, reading, meditating, listening to music*) before I would recommend medications/chemical approaches (*including alcohol for “medicinal purposes”*).

PLSers Please Join Patients Like Me

Contributed by Emma Willey

In case you missed this August notice, Primary Lateral Sclerosis is now supported by PatientsLikeMe. Once we have sufficient numbers of PLS patients (*approximately 50 two- or three-star patients in each category*), we'll generate all-new don't have blue percentile curves for PLS. When we do, it will be the first data of its kind! Please go to <http://www.patientslikeme.com/about> to join.

Traveling with PLS/HSP

by Bonnie Guzelf

My husband and I have always loved to travel. When I was diagnosed with PLS in 1999 I was afraid that our traveling days might be over. Not so! With a little internet homework and a spirit of adventure (*and my travel wheelchair*) we have continued to have wonderful and sometimes exotic vacations. Some of the places we have visited since I've been “disabled”?

Kenya, England, The Costa Rica Rain Forest, The Panama Canal, Cruises to various Caribbean Islands and yes ... even Thailand. So my motto is, “Never say Never”.

Here are a few tips and resources that I've compiled over the years.

Traveling by Air with a W/C

Nowadays flying is not much fun for anyone, less so for someone traveling with a wheelchair. But it can be done with a little planning. First of all, understand that your wheelchair, walker or any medical equipment you need to take with you is NOT considered extra luggage and you will NOT have to pay extra to take it with you. As to how much regular luggage you can take, you need to check with your airline, as each airline has their own rules and exceptions are made for some Frequent Flyer programs.

I have a small power wheelchair I bought specifically for travel, The Go Chair.

I bought it on line at <http://www.spinlife.com/go-chair/spec.cfm?productID=74112>

The cost was under \$1500 and shipping was free. It was delivered quickly and in perfect shape This chair is lighter in weight and comes apart so it can be transported in the back of an SUV or in the trunk of a car without the need of a special lift.

When you make your reservation be sure to tell them you are traveling with your own wheelchair (manual or power). Confirm that this information is on record a day or two before your flight. If it is a power (motorized) chair they will ask you what kind of batteries it has. Most of the power chairs these days have closed dry cell batteries and are not a problem.

Be aware that some smaller airports may not have Jetways, but passengers must walk up stairs after crossing the Tarmac. Fear not. They have an elevator lift, much like a cherry picker that they will use to hoist you up to the plane, or a portable ramp for a wheelchair they will drive to the door. The elevator lift is actually kind of fun.

Accessibility...what it is, what it isn't

Be aware than even in the US where we have accessibility laws, the interpretation of Accessibility may vary. Older hotels may not have renovated their rooms to the highest standards. Apparently they only need to make "reasonable accommodation" during renovations. If the room is not on the ground floor, ask about elevators. The ideal accessible room should have

- 1) wide doorways that can accommodate a wheelchair.
- 2) No lip on the entrance doorway or bathroom doorway.
- 3) An accessible bathroom, meaning, wider doors, ideally a roll in shower with grab bars and a pull down shower seat.
- 4) Grab bars around the toilet area. Next best, if the room has a tub it should have grab bars, and they should bring you a shower chair to use.

ALWAYS, ask when you make a reservation what their definition of an accessible room is. I also have a portable grab bar of my own that I take along. You can use it anywhere and it is very helpful. If you get to the hotel and it does not meet your needs, ask to speak with the Manager. They should do everything they can to make it right, or find you somewhere else to stay.

Easy yet Exotic Trips - Cruise

If you haven't traveled much outside of the US one of the easiest ways to take that leap is to take a cruise. Cruise ships, especially the newer ones, are very user friendly for people with disabilities. For one thing, you only have to unpack once. You settle into your cabin and you are there. Everything you need or want is on the ship. All your meals, your entertainment, movies, shows, classes, pools spa, beauty salon, library, casino or virtually any activity you want is there for you. Or if you like, you can sit on deck and read a book. If you want an accessible cabin you need to book your cruise up to a year in advance.

You can cruise most anywhere these days. Short cruises to the Bahamas or Mexico, longer cruises to Europe, South America, Australia, or the Orient. My personal experience has found that Princess, Royal Caribbean and Celebrity seem to be the most "user friendly" for people needing a little extra help.

I recommend using a power wheelchair or scooter. The ships are huge and trying to walk around, even with a walker is exhausting. You can rent a chair or scooter. It will be delivered to your cabin on the ship and then picked up after the cruise is over. (*Note: I still bring along my walker to get around within the cabin.*) I have rented from:

Scoot Around America. <http://www.scootaround.com/>
Cruise Assist (*all types of disability aids for rent*)
<http://www.cruiseshipassist.com/>

Shore Excursions

At some ports they take you ashore via a small ship called a Tender. We informed the Purser's Office a day or two ahead of time of my special needs. We were pleasantly surprised when we got a phone call the night in our cabin the night before confirming where and when we should meet to exit the ship. They took my husband, me and my wheelchair onto the tender with the ship's crew who were going ashore to set things up to welcome the rest of the passengers. We were the first ones off the ship! We met our guide and we were on our way before anyone else had even come ashore. Many of Shore Excursions the ship offers are not accessible. As always, I take the pro-active approach. I usually Google "Shore Excursions" for the country or island I am visiting. I will find a private guide with an SUV or a van that can handle my chair. I tell them what

I want to do, where I want to go and then negotiate a price for the day. This way, I can take the sights at my pace and stay as long or as little at one attraction as I want to.

Non Cruise Adventures

Again, using the internet is a big help. I usually Google “Wheelchair Accessible Holidays” and then the country or area I want to visit. Here are a few websites that may be of help. I have not personally used all of these sites, so do your homework before you make any commitment.

Accessible Journeys

<http://www.disabilitytravel.com/>

Tour operator for people in w/c

<http://www.flyingwheelstravel.com/>

A list of w/c accessible tour operators:

www.disabledtravelers.com/tour_operators.htm

W/C accessible tours, Belize

www.experiencebelizetours.com/accessibletours.html

Israel 4 All - <http://israelaccessibletravel.com/>

Accessible Tours of Europe

www.accessibleurope.com/

Accessible Travel - Italy

www.accessibleescapes.com/destinations/florence/

Gimp on the Go - www.gimponthego.com/links.htm

Going it alone...

If you are not interested in a tour, and would rather go it alone, there are many sites that can help you plan your own accessible trip. You can rent an accessible home or villa in Europe or the US. You can even rent accessible motor homes here in the states.

The possibilities are endless! Have fun looking at all your options.

http://europeforvisitors.com/europe/planner/blp_accessible_countries.htm

W/C accessible resorts, homes, etc.

<http://www.disableds-resort.gr/links.htm>

<http://www.e-bility.com/disability-news/accessible-caravan-motorhome.php>

Things to be Aware of

1. Be aware that other countries do not have the ADA laws we have here in the USA, so their definition of “Accessible” may be different. For example, finding a ‘western style’ bathroom in Thailand was a challenge and then they were not usually w/c accessible.
2. Ask questions before you go. Be sure they understand your needs.
3. You may be better off with a manual chair.
4. Do be careful. Check out the company you are dealing with. Be sure they are licensed and insured if possible. Ask for references.
5. Lastly, don’t give up. Ask questions, confirm, and make your needs known.

Don't Give Up

All our dreams are gone, with a loss of faith.
We're still hanging on for another day.
It's so hard to see that it's going to get better,
And when will that be, it's hard to say.

We must believe; that if we give, we will receive.
Yes, we must believe, that it's going to get better.

Don't give up. Never give up!
We won't stop giving, giving all we got.
Now we're breaking away from what holds us down.

This could be the day that brings out the light.
Now we're marching on with the will of never giving up.
This time we'll have won without a fight.

We must believe...
Don't give up. Never give up!
We won't stop, giving all we got.

Forgive and forget don't hold on to the bitterness.
Filled with regrets we don't wanna go there again.
The glass is half full so lets get it on with togetherness,
And our number will grow we will prevail in the end.

Don't give up. Never give up!
We won't stop, Giving all we got.

Lyrics by Eagle Eye Cherry

(Pahl Rice read this at the MA TeamWalk)

WW II VETS RITA AND JOHN DICLEMENTE RECEIVE HONORARY TRIP

Contributed by Rita DiClemente

A year ago, we signed John up for a private organization honoring WWII vets, by flying *(those still alive)* to Washington DC to view the WWII Memorial, all expenses paid. I was able to go along because I am also a vet. The trip was September 12-14.



Caregiving

Ed note: This comprehensive list comes from Quest, the MDA magazine.

For caregiving information, or to connect with other caregivers, you may want to start with the following organizations:

Today's Caregiver (800) 829-2734 www.caregiver.com

Caring Connections (800) 658-8898 www.caringinfo.org

CaringBridge (651) 789-2300 www.caringbridge.org

US Government Caregiver Resources (800) 333-4636 www.disabilityinfo.gov

Empowering Caregivers (212) 807-1204 www.caregivers.com

Family Caregiver Alliance (800) 445-8106 www.caregiver.org

National Alliance for Caregiving www.caregiving.org
4720 Montgomery Lane, 5th Floor, Bethesda, MD 20814

National Family Caregivers Association (800) 896-3650 www.nfcacares.org

Share The Care (646) 467-8097 www.sharethecare.org

Strength For Caring (866) 466-3458 www.strengthforcaring.com

SUPPORT SPF WHILE YOU SEARCH

Raise money by using GoodSearch as your default **search engine** which will donate about a **penny per search** to SPF. You use it just as you would any search engine, and it's powered by Yahoo!, so you get great results. Just go to <http://www.goodsearch.com> and enter Spastic Paraplegia Foundation as the charity that you want to support.

SUPPORT SPF WHILE YOU SHOP

Shop online utilizing the SPF Shopping Mall at <http://www.spf-foundation.org/shopping.htm>. Buy For Charity and The ClubShop Mall feature a multitude of popular stores for all your needs. The percentage donated varies by store and appears on the website. There is no additional cost and you can still take advantage of sales and coupons!

Medical Research

For many of us, autumn marks the end of a carefree Summer, or the prelude to a cold and gray Winter. To quote the poet Hal Borland, "October is the fallen leaf, but it is also a wider horizon more clearly seen." There is much to see on the autumn horizon regarding advances in research. A harvest of discovery has been reaped by the scientific community that can benefit those living with HSP and PLS. Alliances are being made amongst experts in the field to further progress in the areas of stem cell research, disease mechanisms and drug therapies. Major discoveries in the area of ALS have far reaching effects that can help in developing potential therapies for the full spectrum of motor neuron diseases.

- Betsy Baquet, Medical Editor

HARVARD-COLUMBIA TEAM OF SCIENTISTS CREATES MOTOR NEURONS USING SKIN CELLS FROM ALS PATIENTS:

Harvard and Columbia scientists have been successful in extracting skin cells taken from ALS patients, transforming them into pluripotent stem cells (iPS cells), and then directing their differentiation into the type of motor neurons destroyed by ALS. Published in the journal *Science*, this breakthrough provides "proof of concept" that in the not-too-distant future, chronic diseases can be treated with stem cells created from patients' own adult cells.

The process of deriving stem cells from adult skin cells was discovered in November of 2007 by scientists in Japan and Wisconsin. This new process of creating stem cells bypasses many ethical and scientific barriers scientists faced with the use of embryonic stem cells.

Kevin Eggan, Principal Faculty member of the Harvard Stem Cell Institute, says, "No one has ever managed to isolate these neurons from a patient and grow them in a dish." "Now we can make limitless supplies of the cells that die in this awful disease. This will allow us to study these neurons, and ALS, in a lab dish, and figure out what's happening in the disease process," Eggan explains. Scientists can make comparisons between actual ALS motor neurons and healthy motor neurons, determine how they differ, and uncover the cause of degeneration. The same approach will work with different degenerative diseases, such as Parkinson's and Diabetes.

Scientists' ultimate goal is to treat chronic diseases such as ALS by reintroducing healthy stem cells into patients. However, many questions still exist. In particular, the degree of similarity between the contrived motor neurons and the patient's natural motor neurons needs to be determined. That, coupled with the safety issues that exist with the use of iPS cells, scientists predict the most immediate benefit from this discovery will be to determine the root cause of ALS, or other degenerative diseases, and screen for drugs that may provide life-saving benefit to patients.

SOURCES:

http://www.eurekalert.org/pub_releases/2008-07/hu-ncf072808.php

<http://www.technologyreview.com/Biotech/21157/?a=f>

GROUNDBREAKING STUDY SHEDS LIGHT ON THE CAUSE AND OCCURRENCE OF FAMILIAL ALS:

For the past three years, Brandeis chemist Jeff Agar and his colleagues have studied the rare, familial form of ALS (fALS) as a window into the sporadic form of ALS, which accounts for 90 percent of all cases. Researchers believe deciphering the mechanisms at work in inherited ALS will clear the way to understanding and treating sporadic ALS largely because clinical symptoms are identical in both forms of the disease.

The team's research demonstrated that two properties of the protein superoxide dismutase create toxic levels of the protein in motor neurons, causing fALS. They discovered that the unfolding and aggregation of increased protein are the major factors in fALS. In essence, the proteins clump together, amounting to what scientists call a "toxic gain of function," which leads to cell death.

The protein superoxide dismutase is normally a useful antioxidant. According to Agar, the protein "goes from Dr. Jekyll to Mr. Hyde when it clumps up," indicating that protein aggregation is toxic in ALS, "literally exploding the thread-like axons that transmit impulses from the cell."

Agar said the next step is to develop drugs that target key proteins and prevent them from clumping together.

SOURCE:

http://www.eurekalert.org/pub_releases/2008-07/bu-ppj072408.php

UMBILICAL CORD BLOOD CELL TRANSPLANTS MAY PROTECT MOTOR NEURONS:

Scientists at the University of South Florida (USF) demonstrated that transplants of human umbilical cord blood (HUCB) may help patients suffering from ALS. In this study, mouse models with ALS received HUCB transplants. Mice receiving moderate amounts of HUCB showed increased lifespan and reduced disease progression.

These results “demonstrate that treatment for ALS with an appropriate dose of HUCB cells may provide a neuro-protective effect for motor neurons,” said the study’s lead author Svitlana Garbuzova-Davis, Ph.D., DSc., of the Center of Excellence for Aging and Brain Repair at USF. The team had previously shown that HUCB transplants reduced inflammation and provided neuro-protection in models of stroke and Alzheimer’s Disease.

Garbuzova-Davis concluded that cell therapy may offer a promising new treatment, despite the diffuse nature of motor neuron degeneration.

SOURCE:

http://www.eurekalert.org/pub_releases/2008-06/uosf-ucb062408.php

SANGAMO BIOSCIENCE INITIATES PHASE II ALS STUDY ON ITS DRUG SB-509:

US-based Sangamo BioSciences has opened a Phase II clinical trial to evaluate its drug, SB-509, in subjects with ALS. Forty patients with ALS will be enrolled in this trial. Safety, tolerability and clinical measures will be taken, including lung function, muscle strength and progression based on the ALSFRS-revised. Each subject will receive a total of two treatments 3 months apart, and the study will be carried out over 11 months.

SOURCE:

<http://www.tradingmarkets.com/site/news/Stock%20News/1864236/>

COLLABORATIVE EFFORT TO SUPPORT TRIAL OF LITHIUM ON ALS PATIENTS:

In the Summer issue of *Synapse*, we reported that the Muscular Dystrophy Association will be supporting the first U.S. trial of Lithium on ALS patients. To further that effort, the ALS Association, along with the National Institutes of Health, the National Institutes of Neurological Disorders and Stroke (NINDS) and the ALS Society of Canada, will be funding a major

clinical trial of Lithium to determine if the approved, mood-stabilizing drug, can slow progression in early stage ALS patients.

“Lithium has generated a lot of interest in the ALS community,” according to Lucie Bruijn, Ph.D., Senior Vice President, Research and Development of The ALS Association. “This trial is vital for testing the efficacy of lithium in a well-controlled way.”

Lithium protects neurons in the brain in animal models of neurodegenerative diseases, including Alzheimer’s disease and Parkinson’s disease, and has been recently shown to do the same in a mouse model of ALS.

“Collaboration among researchers and funding agencies makes this trial possible,” Dr. Bruijn said. “All of us are working together to support this important research to find a new treatment for ALS.” Denise Figlewicz, Ph.D., Director of Research at the ALS Society of Canada says, “We welcome this opportunity to support the lithium clinical trial. The promising results from the Italian study data serve as the impetus for new research and new treatment strategies. This is very exciting news for the ALS community. We also welcome this opportunity to work together with our American colleagues. This collaborative approach between Canada and the United States will serve as a model for subsequent clinical trials.”

SOURCE:

<https://www.alsa.org/news/article.cfm?id=1337&ZFD=804963&ZTKN=4dbb1c332e29e0a-0BB68ACC-188B-2E62-80518E0F9BDE60C4>

ALTERED CHOLESTEROL METABOLISM PLAYS ROLE IN CAUSE OF HSP/ MOTOR-NEURON DISEASE:

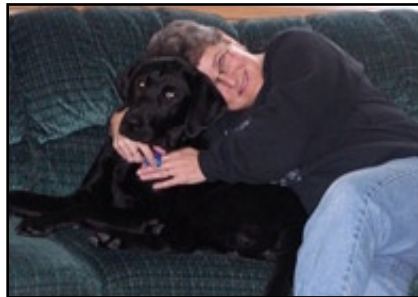
Although numerous mechanisms have been proposed in the HSP spectrum of degenerative diseases, the causes underlying neuronal loss are unknown. Analyses conducted on SPG5 identified sequence alterations in the cytochrome CYP7B1. In the liver, this cytochrome is critical in the degradation of cholesterol and also provides the primary metabolic route for the modification of the neurosteroid DHEA in the brain. These findings provide the first direct evidence of a pivotal role of altered cholesterol metabolism in the onset and progression of motor-neuron disease. This discovery also identifies a potential for therapeutic intervention in this form of HSP.

SOURCE:

<http://health.groups.yahoo.com/group/PLSers-NEWS/message/4506>

7700 Leesburg Pike, Ste 123
Falls Church, VA 22043

The 'Forever Friends' Memorial Garden



Top center: Diana and her service dog, Draven

from top left clockwise: Sharon, Jon Smith, Sarah, Heather