

Synapse

Volume 13, Issue 1

Winter, 2010

Newsletter of the Spastic Paraplegia Foundation

**TeamWalk summaries
begin on Page 7**



**Houston
TeamWalk**



**Sarah and Ronnie Face
Off in SAWCAR Race**



LA Nov 21 - Entire Group



**Mark and Fred
2009 OKTW**



The Autumn in Carolina, Gang's All Here



**Socializing at
Autumn in Carolina**

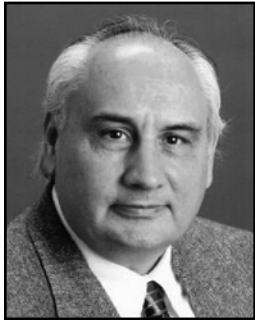


2009 Oklahoma TeamWalk

Editor's Note: I welcome all Letters to the Editor, please e-mail me synapsePLS@comcast.net. I will always print your letters in the next issue.

President's Letter from Mike Podanoffsky

The Tipping Point and National Conference 2010



In this issue you will read about the terrific plans we have for the National Conference 2010. It will be held at the LAX (Airport) Hilton in Los Angeles, May 21 – 23, 2010. The conference will be focused more on you and less on research, although all presentations are important. I look forward to meeting each and every one of you there.

This past summer I read The Tipping Point: How Little Things Can Make a Big Difference (by Malcolm Gladwell). The book has been out for some time now. It describes how a small effort can create a ripple effect that turns a tide. One example is how neighborhoods improve. It starts with a few people who care. They set an example and others follow. At some point the idea is so contagious that it is unstoppable.

The Tipping Point reminds me of the ripple that the Spastic Paraplegia Foundation has started. A small research project here, some ideas that need more work, a lesson learned here and there, all set the stage for future research.

In The Third Wave and in Future Shock (by Alvin Toffler), a futurist thinker of some note, the pace of new discoveries grows, accelerating with each new innovation. This can be seen everywhere you look. The work of one scientist sets the foundation for many scientists to follow, and their work sets the foundation for the scientists that follow them.

As this issue of *Synapse* goes to press it is December. You'll read it in mid to late January. When you do, it is a great time to reflect on these examples. The role of the SPF is to keep the progress of research growing.

Want to change the SPF? Want it to serve you better? We'll publish the best ideas next issue. Send me email at ideas@sp-foundation.org.

For links mentioned in this publication, go to <http://sp-foundation.org/synapse/1209>.

TABLE OF CONTENTS	PAGES
National Conference Roundup	3-5
SP Foundation News	6
Event Reports	7-8
Living with HSP/PLS	9-12
Caregiving	12
Medical Reports	13-15



Volume 13, Issue 1 - Winter 2010

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).

Synapse Editors

Thurza Campbell Senior Editor
Betsy Baquet Medical Research
Sarah Roberts-Witt Events

Published three times a year for the HSP/PLS community Available online at www.sp-foundation.org

Corporate Address:

Spastic Paraplegia Foundation
212 Farm Rd.
Sherborn, MA 01770-1622

Please Send Donations to:

Spastic Paraplegia Foundation
P.O. Box 1208
Fortson, GA 31808

Please direct correspondence to:

Spastic Paraplegia Foundation
7700 Leesburg Pike, Ste 123
Falls Church, VA 22043
(877) 773-4483
information@sp-foundation.org
www.sp-foundation.org

SPF Board of Directors:

Mike Podanoffsky, President
Linda Gentner, Vice President
Frank Davis, Secretary
David Lewis, Treasurer
Members: Larry Asbury, Corey Braastad, PhD,
Kris Brocchini, Jim Campbell, Jean Chambers, RN,
Malin Dollinger, M.D., Ashton Hecker, Jim Sheorn,
Mark Weber, Esq.,

SPF Medical Advisor:

John K. Fink, M.D., University of Michigan

Disclaimer: The Spastic Paraplegia Foundation does not endorse products, services or manufacturers. Those that are mentioned in Synapse are included for your information. The SPF assumes no liability whatsoever for the use or contents of any product or service mentioned in the newsletter.

National Conference Roundup

FRIDAY, MAY 21, 2010

3:00-5:00pm – Registration

5:00-5:45pm – Welcome cocktail reception cash bar and simple hors d'oeuvres

5:45-6:00pm – Welcome and Introductions by *Craig Gentner*

6:00-7:00pm – Dinner, including dessert

7:00-7:15pm – Break

7:15-8:15pm – “Welcome to the Convention You’d Rather Not Qualify For” by *Malin Dollinger and Craig Gentner*

8:15pm – Instructions for Saturday

8:15pm – Meeting rooms available for meet/greet/social time. You may take this opportunity to meet new people, to discuss challenges and victories, and to get help with day-to-day living

SATURDAY, MAY 22, 2010

8:00-9:00am – Registration Desk Open

9:00am – Welcome by *Craig Gentner*

9:15-10:15am – Keynote Address by *Gary Karp* “Life on Wheels”

10:15-11:00am – “Genetics and HSP/PLS Testing” talk by *Dr. Corey Braastad*, Athena Diagnostics and SPF Board Member

11:00-11:15am – Break

11:15am-12:00pm – *John Fink, M.D.* “Current research and understanding of HSP and PLS--What’s New and Exciting”

12:00-1:30pm – Lunch Exhibitors meet and greet

1:30-2:30pm – “Get Fit Where You Sit®” Talk and Demonstration of Chair Yoga.

2:30-3:00pm – “SPF Research Grants, Funding, and Our Scientific Review Process ~ How Contributions Will Become the Cure” by *Mark Weber, Esq.* SPF Board Member

3:00-3:15pm – Break

3:15-4:00pm – “Adaptation to Disability” by *Gary Karp*

4:00-4:45pm – Simultaneous Breakout Sessions

- ◆ Stress Relief by Acupressure by *Dr. Lenore Dollinger*
- ◆ Caregivers’ Time by *Jim Campbell*
- ◆ Maximizing Your Abilities



5:00pm – Entire group gathers for closing remarks by *Craig Gentner*

Dinner on your own – (There are 3 restaurants in the hotel and others nearby.)

7:00pm – Meeting rooms available for meet/greet/social time.

SUNDAY, MAY 23, 2010 9:00-11:00am

7:30am – State Ambassadors breakfast meeting led by *Linda Gentner*

9:00am – Greeting by Craig and outline of today’s schedule

9:15-10:00am – Simultaneous Breakout Sessions

- ◆ Stress Relief by Acupressure by *Dr. Lenore Dollinger*
- ◆ Caregivers’ Time by *Jim Campbell*
- ◆ Maximizing Your Abilities

10:00-10:45am – “Physical Therapy to Get You Moving”

10:45-11:00am – Closing Remarks by *Craig Gentner*

11:00-11:30am – Check Out

11:00am-12:30pm – Lunch on your own

1:00pm – Start of bus tour for those signed up for tours

Saturday 1:30 p.m.

Special Interactive Program, Bruce Binder

Chair Yoga“Get Fit Where You Sit®”

Lakshmi Voelker Chair Yoga offers you the ability to improve your health through an amazing form of adaptive exercise. You sit in a chair or your wheelchair so you can receive yoga’s healing and restorative benefits that have been known for thousands of years. Yoga relaxes your body and mind, improves your musculoskeletal fitness and flexibility, and elevates your overall health and well-being. Lakshmi Voelker created Lakshmi Voelker Chair Yoga in 1982 and was joined by Bruce Binder in 2003. He manages the business while Lakshmi spends her time certifying teachers around the US (including the Mayo Clinic). There are over 350 certified teachers in the US, Canada, and Japan. Their teacher training emphasizes contraindications including an entire section on wheelchair yoga. They will explain Chair Yoga and then have everyone present who wishes participate in a group experience and demonstration of “Getting fit while you Sit”.

Saturday 2:30 p.m.

Mark Weber will explain to us the way our research grants are evaluated by our Scientific Advisory Board, a group of neurology specialists who tell us which research proposals are most worthy of our funding. He will also explain how the Board of Directors then selects those grants that will be funded.

Mark is a founding Board member, co-chaired the Foundation Steering Committee and served as the first SPF President. He is an attorney with eleven years experience as an Assistant Attorney General and Assistant District Attorney. Mark has been an active SPF community leader since 1999, launching and managing PLS Friends, and serving as editor of a PLS newsletter. Mark holds a BA in economics and psychology and a JD. Mark and his wife and two boys live in Sherman, CT. Mark serves the SPF as Legal Counsel and also chairs the Research Committee.

Synapse Appeal

Please use the enclosed envelope to make a donation. Thanks to everyone who donated in 2009 to help offset the printing and distribution expenses.

LAX Hilton room reservation instructions:

Call Loretta Baker at the LAX Hilton Hotel, phone number (310) 410-6143, and request a room reservation. Specifically mention the “Spastic Paraplegia Foundation, SPF” to get the special room rate of \$95/night, and confirm with Loretta that you will receive that rate. Reserve your room by April 15th for this SPF special room rate. Do not call after hours or in the evening, or the 1-800 Hilton reservation number. **Speak only with Loretta.**

TYPES OF ROOMS:

There are four types of rooms available. Please read this carefully, and request the “simplest” kind of room that you actually need. That will allow the more handicapped people, who need more special rooms, to have them. The rooms, listed here from simple to complex, are:

REGULAR ROOM [not handicapped]. For non-handicapped people or people with handicaps who can do OK with a regular room. If you’d prefer to use the Hilton LAX a web/ e-mail reservation address, use this only for regular rooms. If you use this method, be sure you are quoted our special rate of \$95/night.

“S” [as in “Simple”] **HANDICAP ROOM**. There are 15 of these. They have a hand-held shower, and “easy” controls for lights, drapes, towels, but no other special handicap facilities, e.g. no bars, extra room in bathroom, or wide doors.

“A” [as in “Accessible”] **HANDICAP ROOM**. There are 15 of these. They have an accessible shower with handrails, rails by the toilet, “easy controls,” and an accessible chair. There is a bathtub with a chair in the tub. **This is the usual type of “ordinary” handicap room at most hotels.**

“R” [as in “Roll-in Shower”] **HANDICAP ROOM**. There are 4 of these. They have all the above amenities as well as a roll-in shower, but no tub. Please request this only if you need a roll-in shower, and can’t use a bathtub with a tub-chair.

Regarding the length of your stay, remember that there will be a 2-hour Sunday morning session, 9 to 11 AM, which will include a community interaction, three different breakout sessions, and a State Ambassador breakfast meeting. We will have recommended tours and activities for Sunday afternoon.

Any questions/problems, call Malin at 310 378 4059 or e-mail: malind@cox.net

SP Foundation News

Constituent Outreach Task Force (COTF) Launched by SPF Board

Jim Campbell, Chairman

In October the SPF Board created a task force to examine how to better serve and communicate with our constituents. Our focus is to identify the issues and services that are of interest to our SPF patient and caregiver community.

Only a small minority of our 2400 SPF community members (under 200) attend any of our regional events - social get togethers called Connections or participate in our fundraising TeamWalks. Many members join our on-line support groups PLS-Friends and HSP ListServ soon after being diagnosed, then seem to fade away. On a typical day only a couple dozen or so contribute email inputs. We have a data base of SP patients and caregivers first established by Frank Reyerse years ago, yet only about one sixth of our 2400 members have entered their personal data. So you can see there is significant room for increased participation by our community members.

The COTF thinks the answer to improving our SPF organization's effectiveness may lie in altering both the content of our offerings and the way in which they are delivered. Regarding the content of our offerings and services we plan an every member survey sometime in the first half of 2010. Much has changed since the prior survey was done over 7 years ago in 2002.

We believe *Synapse* is an effective way to communicate nationally on a periodic basis, but here also we want to find out how it could better fill a need. We see email as our most cost effective and quickest way to communicate important announcements, yet we currently have email addresses for only 80% of the *Synapse* subscribers.

We think the State Ambassadors have the potential to strengthen our organization by bringing the national agenda to the state level and adding a personal touch. Presently the COTF is contacting our 40 or so current state ambassadors to see what ideas they have and whether they are amenable to increased visibility and a larger role in the SPF program.

The COTF is just beginning to look for new ideas and approaches to improving the SPF organization's outreach. If you would like to contact us before the every member survey is published please send us an email at cotf@sp-foundation.org.

The COTF is comprised of SPF State Ambassadors Marlene Doolen (TX), Judy Johnson (NH) and Mari White (KS) and Board members Jim Campbell, Jean Chambers, Frank Davis and Ashton Hecker.

PLS Grant Update

Hiroshi Mitsumoto, MD, D.Sc., Director, Eleanor & Lou Gehrig MDA/ALS Center, The Neurological Institute, Columbia University College of Physicians and Surgeons, New York, NY was awarded a two year SPF research grant. It was announced in the Autumn *Synapse*, titled "Multicenter Prospective PLS Natural History Study". Dr. Mitsumoto has lined up 11 ALS centers to participate in his PLS study. There are at least 5 full time centers with the rest being satellite centers. His prospective study will follow newly diagnosed patients with PLS for 5 years and checked on them each annually.

The project as now written is funded primarily with a large NIH grant. Dr. Mitsumoto will be applying for an approximately million dollar grant for the PLS component of the project. His team will be taking specimens and sending them to Dr. Teepu Siddique where he will look for abnormal proteins.

This will be the first major PLS study. It will categorize PLS patients better than has been possible in the past. What we are giving is just seed money for a much larger NIH funding. He suggests that we approve this project as amended. Our project is \$60,000 for first and \$60,000 for the second year. It will be amended for a new start date from Sept 2009 to Sept 2010.

In contrast to this project, Dr. Mary Kay Floeter's PLS project has 23 people in it while this one will have between 100 to 150 patients. Everybody in her project, she diagnoses with PLS. Every center in Dr. Mitsumoto's project will use the same diagnosis criteria. Both will follow patients for good number of years.

Event Reports

Sarah Roberts-Witt, editor

Norman, Oklahoma – October 2nd-3rd

Mark Dvorak, Chair

Report submitted by Michael Petrey

On Friday evening, we met at the Stephenson Research and Technology Center at the Oklahoma University Genome center, toured the building, and saw the Bion Model. My whole family, including my 9-year old grandson, found the Model fascinating. We were able to easily understand it's similarities to our own nerve sensors (such as touch and smell) and how the stimulation is communicated across our bodies and to our brains.

The Bion Model consists of hundreds of tiny glowing, chirping three-dimensional sculptural forms called bions. Each bion is a synthetic "life-form" that's fitted with an audio speaker, blue LEDs, and multiple sensors. The bions are arranged at different elevations and are suspended by fine gage wires. The wires are connected to panels on the ceiling, which form the Bion Model's "brain". Each bion has the ability to communicate with the others and with viewers who enter the space. For example, when we approached a Bion cluster, one of the bions immediately detected our presence. We watched the lights ripple along the model as that information was communicated up through the swarm of bions to the brain.

On Saturday, we met for the Oklahoma TeamWalk at an indoor gym-track at the First Baptist Church. Approximately 25 individuals were present, including several HSPers and PLSers, one individual with Ataxia, and caregivers. After the TeamWalk, we met for lunch and conversation. This was my first SPF function so I bent everyone's ear by asking about issues we all experience, commonalities, and medications. I found this working session very helpful and am extremely thankful to Mark and his family for putting the event together.

Hartford, Connecticut – October 3rd

Contributed by Dolores Carron, Chair

The 29th meeting of the CT Connection was held at the N.E.A.T. Marketplace in Hartford. The informative program included presentations by Liz Wroblewski, a PT who was diagnosed with HSP in 2004; Jennifer Della Ruffa, a Dynavox representative; and Ride-Away sales associate Roland Grundmann.

Liz spoke about helpful exercises that can be used to prevent/delay the progression of complications caused

by the spasticity and contractures of PLS and HSP. She, her assistant, and my student PT gave an extensive demonstration of the stretches and exercises, and answered questions afterwards.

Lunch was next, a time when old friendships were renewed and new ones were made. We also conducted a free raffle of donated items. After lunch, Jennifer Della Ruffa of Dynavox discussed the wide variety of Augmentive Alternative Communication (AAC) equipment as well as voice banking. Roland Grundmann (www.Ride-Away.com) was next with a discussion of the available vehicle conversion options. He also demonstrated the features of a handicapped modified minivan he had brought. On behalf of his company, he gave gift certificates to meeting attendees entitling them to a \$1,000 reduction in the price of a new or used minivan from Ride-Away.

I am looking forward to the 30th CT Connection in the Spring. By popular demand, we will be welcoming back Keith Mullinar, a trainer of helper dogs. He will bring a dog to demonstrate some of the tasks helper dogs are capable of. Our meetings are not limited to CT residents. If you'd like to attend, watch for the announcement online or email me at d.carron@sbcglobal.net.

Autumn in Carolina Rural Hall, NC – October 17th

Don Wilson, Chair

Report submitted by SAWCAR champion Ronnie Grove

Well, it's like this. Jane Ann King and I ran the scooter race. I was on a scooter and she was riding a bulky mule. You know how she likes horses. Someone must have switched her steed for a mule so I just ran away from her. Then the wheelchairs raced. Sarah Roberts-Witt ran away from the crowd. She was waaay out front the whole way-flying a jet plane and spreadin' sparks. She was running so fast her wheels were wobbling! I was thinking I'd be eatin' dust just like two years ago when I trailed Annette by two states in the finals. But this time my scooter came through with a championship. The only thing I can figure is Sarah's fingers froze in place. It could have been the snow and ice on the track because we had 90 mph winds and temps below zero. And if that's not the truth, all I can say is it sure felt like it. Anyway, the deed is done, the tears have been shed, the name-calling is over, the blood has been removed, and we all left friends. . . I think. And for \$24.95 you can view my trophy at the 10th Annual Spring Fling in Berkeley Springs.

A few words from Don

Bettie Jo and I were happy to welcome more than 35 old and new friends to Autumn in Carolina this year. We talked of those who came to our first event in 2001, and here we are eight year later. Our goal has always been to send folks home with good memories. I doubt that anyone will forget people running around the room pretending to be lawn-mowers or trimmers. Or Martin Beckner's glee upon finding the "gold" in his treasure chest. Who could forget the joy on Sarah Witt's face as she won the power chair division of the SAWCAR 280, and the same huge smile as she followed Ronnie across the finish line in an attempt to win the title of Grand Champion. We provided the location and opportunity, but each and every attendant made the event a success.

Houston, Texas - November 7th

Contributed by Ida Park, Chair

Twenty-five adults and teens and five young children participated in this year's Texas TeamWalk. The location was Bear Branch Park, The Woodlands, which is northwest of Houston. We walked or rolled through a beautiful wooded area with a wide cement sidewalk. The walk through the forest showed how powerful Hurricane Ike was last year and why it forced us to cancel in 2008.

SPF board member Ashton Hecker invited Colby Brotherton of Dynamic Orthotics and Prosthetics to talk about foot and leg braces. Colby also showed us a variety of brace types. A selection of freshly made sandwiches and soft drinks were donated by Valero Retail Holdings for us to enjoy after the walk. Thanks goes to everyone who participated in the walk and to those who contributed in raising funds for research to find the cures for HSP and PLS.

Queenstown, Maryland - November 7th

Contributed by Chair, Joan Heinicke

The 7th Annual RGM fore SPF Golf Classic was held at the Queenstown Harbor Golf Course. The River Course was used, which is the premier course at that location with expansive views of the Chesapeake Bay. Some 140 golfers participated, including many members of the Milbourne family. The morning was chilly but the day turned out to be sunny and pleasant. Coffee, donuts, and a bloody Mary bar were provided at registration, and lunch stations were set up throughout the course. Pit beef and turkey, chili, clam chowder, hot dogs, and fresh shucked oysters were among the many foods offered. During the dinner banquet, a fifty-fifty raffle, and live and silent auctions were held, which helped bring in a nice sum for the SPF. The tournament is held in memory of Richard G. Milbourne, whose three children have HSP. The event has raised more than \$120,000 for SPF since it began.

Santa Ana, California - November 21st

Contributed by Malin Dollinger, Chair

The Southern California Connection was held at the Embassy Suites Hotel in Santa Ana. We had 15 people for lunch, and for a discussion of our goals, problems, victories, and solutions. A family from Australia--Sue, Jari, and Jesse Holopainen—told us about the health care situation "down under" and the problems of the very few people there diagnosed with HSP. When they shared their problems and their solutions, we were impressed by how universal these "facts of life" are, no matter what country people are from. In addition to the Holopainen family, we were joined by Craig and Linda Gentner, John and Jane Mitchell, Hoyt Johnstone, Barbara Hardwick, Deidre Maze, Philippa Green of Australia, and Will and Marilyn Bishop.

Lenore Dollinger discussed some specific aspects of exercise. She emphasized the need for upper body conditioning in particular, since we use our upper body muscles more than most to help us navigate and move around. Lenore will speak at our national meeting on how to use acupressure to manage stress. She is a registered nurse who practiced that specialty for many years. Informal polling disclosed that everyone present had seen many different physicians before their diagnosis was established. The record was set by Jane Mitchell, who saw 10 different doctors!! There were also some subjects mentioned as possible topics for our annual meeting.

UPCOMING EVENTS

Spring Fling #10 in 2010

May 7-8, 2010 - Berkeley Springs, WV

Contributed by Ronnie Grove, frogrove@verizon.net

Make plans to attend a very special WV Connection with lots of specialists—namely, you. No one knows PLS and HSP better than we do. I'm still working on many of the details but I do have a speech pathologist lined up. She would like to know what you are interested in learning more about, i.e., augmentative communication, speech or other? Also, let me know via email if any of you are interested in an extra day of meetings. For example, we could start on Thursday and leave Sunday, or come in Friday and leave Monday. I am open to your suggestions

Rooms are available at Best Western-Berkeley Springs Inn for \$59/night. To make reservations, call 304-258-9400 and ask for the Spring Fling block. Handicapped rooms at the Inn are scarce, so call early. However, many other motels are nearby. So mark the date for Berkeley Springs and remember, this is the place where all the women are gorgeous and the men are lucky.

Living with HSP or PLS

Two Spinal Cord Injury Foundations Have Merged

On what would have been Christopher Reeve's 57th birthday, Life Rolls On Foundation (LRO) and the Christopher & Dana Reeve Foundation have announced a merger. Effective immediately, Life Rolls On Foundation, based in Los Angeles, will serve as the West Coast headquarters and division of the Reeve Foundation. The Reeve Foundation is a national, non-profit organization dedicated to finding cures and treatments for spinal cord injuries and improving the lives of people living with paralysis. Life Rolls On, founded by Jesse and Josh Billauer, is dedicated to improving the quality of life for young people affected by spinal cord injury (SCI) and utilizes action sports as a platform to inspire infinite possibilities despite paralysis. Both organizations' mission and focus will remain the same. LRO will continue to produce unique quality of life programs, including its award-winning, adaptive surfing program, They Will Surf Again, as well as education, motivation and awareness initiatives.

Ed. Note: The Christopher & Dana Reeve Foundation supports SPF financially. I now have its 2009 Paralysis Resource Guide. Sixteen diseases or conditions are covered in the Guide. I'll be including information from this valuable guide in this and future issues.

Legislation Introduced in U.S. Congress Regarding Clinical Trial Participation

Contributed by Lynn Holmes

Both houses of Congress have bills in Committee (as of 12/13/09) regarding Clinical Trial Participation. The "Improving Access to Clinical Trials Act of 2009" would allow patients with a rare disease to participate in clinical trials without losing their eligibility for government health benefits. Current rules for Supplemental Security Income (SSI) and Medicaid eligibility require that compensation for participation in a clinical trial be counted as income. This bill would allow individuals with a rare disease to disregard up to \$2,000 of compensation when calculating income, thereby allowing more Americans receiving public assistance to participate in clinical trials.

S. 1674: Improving Access to Clinical Trials Act of 2009

H.R. 2866: Improving Access to Clinical Trials Act of 2009

To track the progress of these bills, contact your Senator or Representative, or go to www.govtrack.us/congress/bill.xpd?bill=h111-2866&tab=related

A Letter to the Editor



Hi Thurza,

I just wanted to say I enjoyed your article about giving up one's driver's license. This has been one of the most frustrating things for me - but I know it is the right thing to do. All of the medications I am on would be the equivalent of driving while ability impaired (not to mention might have me fall asleep at the wheel). The AFO on my right foot would make managing the pedals difficult. My heightened startle response would no doubt contribute to an accident.

I never owned a car in my life - I always used public transportation - but I did rent cars (and in Seattle flex cars which you could use by the hour) and really enjoyed the freedom of being able to drive when I wanted. Sometimes I feel like a child again. This Sunday, in fact, I am going to a concert 15 minutes away - paratransit does not go there - and my mom has to drive me. It's better than me ending up injured/dead or injuring or killing someone else.

Thankfully where I live there is public transportation and paratransit (the ADA stipulates any town/city that has public transportation must have a paratransit system for the disabled so as to not discriminate). Paratransit has been a life saver for me - otherwise I would be stuck at home except on weekends when my mom is not at work - OR I'd be spending an exorbitant amount of money on taxis.

I always appreciate your insightful contributions to *Synapse*.

Sincerely, Christina Buck

An Opportunity to Give

Contributed by Jane Anne King

Jerry Simmons gave me a wheelchair to give this man Jerry Mullins in Kentucky. He was so appreciative of the wheelchair. Jerry Simmons said this was an omen since the other man was named Jerry. We all should try to make other people happy with gifts of things we do not use anymore.



Let's Exercise Together!

Contributed by Christina Buck



Yesterday I rode my tricycle 3 miles! I needed a 3 hour nap to recover, but it was well worth it. When I first bought the trike I could barely ride it and thought I had made a mistake. Now I am riding like a pro and loving every minute of it. I highly recommend it as a wonderful, no fall down way to exercise. It is very freeing. I am also doing well with my weight loss. I have lost 20 pounds! I am working hard on this and still feeling very motivated. My goal is to lose 10 more pounds by the end of the year. I will have lost over 10% of my body weight, which will have reduced my chances of getting diabetes by 58%. I'm exercising at least 30 minutes daily (with weights at least 2X a week) and I feel really good.

I hope that my journey can help inspire others. I am highly motivated to not get diabetes (having PLS is enough) and I get a lot of my motivation from watching Dr. Oz on TV, too. I bought my trike from an independent cycle shop. It cost \$400.

What an inspiration! Here are some comments –

"I am joining up with you girlfriend and see if I can lose 20 lbs toooooo so let's do it together dawling so I can tap dance better. We will report our weight loss ever so often...ok?"

"Way ta go Christina! You have inspired me! I have been working on the mind/spirit part of my 'journey' a lot. But I crave exercise. Before I got PLS I used to be a runner, body sculptor etc. I am trying to lose 20 pounds right now. Lost 5 so far. Good for you my friend! Hugs!"

"I have started some exercises, but oh MAN my muscles hurt later on...real cramping. Guess I pushed too hard."

Challenges are what make life interesting; overcoming them is what makes life meaningful.

-Joshua J. Marine

Rare Disease Day February 28, 2010

Why Rare Disease Day?

- Because we constantly need to raise awareness on rare diseases among decisions makers, health professionals and the general public. Information is key to improving living conditions for rare disease patients; raising awareness is therefore one of our primary goals.
- Because acting simultaneously in many places and in many countries can ensure the voice of rare disease patients is heard by more people.
- Because rare diseases are a public health priority today in the European Union.
- Because a day focused on rare diseases can bring hope and information to people living with rare diseases, their caregivers and their families.
- Because we want equity in access to care and treatment for rare disease patients in Europe and beyond.
- Because we need an action that can bring all stakeholders of the rare disease community together with the same goal.
- Because we need more funds for research and care, and more research and efforts directed towards rare diseases.
- Because we need to keep fighting for rare disease patients.
- Because we need to coordinate policy actions at national level and at the international level.

More specifically, this year we are seeking to achieve the following objectives:

- Promote research interest in the field of rare diseases.
- Promote collaboration between patients and researchers.
- To shape public policy and the research agenda.
- To empower patients as actors in research.
- To define research needs and priorities for rare diseases.

For more information about how you can participate, please go to www.rarediseaseday.org.

PatientsLikeMe

PatientsLikeMe (PLM) tracks disease progression and medications for PLS patients who choose to share their information. You only post what you want, and never your name. If you choose, you can insert your picture. As of mid-December, worldwide 230 PLSers have posted their information. Please check it out www.patientslikeme.com/home

Below is more information from their website on how PLM works.

Is sharing data on PatientsLikeMe safe?

When sharing information about an illness or disease in any community, there is always a risk that someone could use this information against you. We also believe that openly sharing information is an important way to improve medical care. Ultimately, it is your decision to make about how to balance these risks. We do not display your name or email address and you control what information you enter and, therefore, share.

What is Openness and what about Privacy?

We believe privacy has hindered the effective development of new treatments and shared understanding of how to manage disease. We're embracing a new model founded on the belief that openness is a good thing. We believe openness can save lives and improve care for everyone. It is at the core of who we are as a company. Understanding privacy is important too. Our website can only work if we build trust with our patient communities. Without the trust of our members, we would not be able to accomplish our mission to improve healthcare. Privacy is also a legal term and we have worked hard to develop a good policy. The entire privacy policy is on the website.

Does PatientsLikeMe sell my information?

Our goal is to create partnerships between patients and the companies that are developing products to help them. To do that we will take the information you entrust to us and sell it--in an anonymous, aggregated and individual format--to the companies that can use that data to improve or understand products or the disease market. We will not sell your personally identifiable information (like your name or contact information) for marketing purposes or without your expressed permission.

Editor's note: Right now, PLM is the most comprehensive PLS data base and information source in the world both for patients and researchers. Thank you to the 230 who've signed up. To all of the others with PLS, please add your data today.

Dealing with Anger

From the Reeve Foundation's [Paralysis Resource Guide](#)

You can't eliminate anger, and it wouldn't be a good idea if you could. Life will always bring you your share of frustration, pain, loss, and the unpredictable actions of others. You can't change that; but you can change the way you let such events affect you, especially if anger is an issue.

Simple relaxation techniques, such as deep breathing and pleasing imagery, can help calm down angry feelings. Try this:

- **BREATHE DEEPLY**, from your diaphragm; breathing from your chest won't relax you. Picture your breath coming up from your "gut."
- **SLOWLY REPEAT A CALM WORD OR PHRASE** such as "relax," or "take it easy." Repeat it to yourself while breathing deeply.
- **USE IMAGERY**; visualize a relaxing experience, from your memory or your imagination. Practice these techniques daily and remind yourself that the world is "not out to get you."

Source: American Psychological Association; www.apa.org

Legal Basics: Job Hunting with a Disability

From the Reeve Foundation's [Paralysis Resource Guide](#)

By Harriet McBryde Johnson, Attorney at Law

Note: This article offers general information about law and is not intended as a substitute for individual legal advice.

Under the best of circumstances, job hunting is probably the hardest job you'll ever have. For anyone, it requires energy and dogged persistence--keeping at it in the face of rejection. A disability can make it even tougher. Functional limitations may make some jobs impossible. You may need to find a unique job that will accommodate your unique situation. Instead of merely adapting to the workplace, you may need a workplace that adapts to you.

Added to all of this is that ugly fact of life we'd like to forget: discrimination. Despite some real progress, many employers still have trouble seeing people with disabilities as part of the workforce. In your job hunt, you're likely to encounter unfounded myths, fears, and stereotypes. The good news is that the law, particularly the Americans with Disabilities Act, offers some help. It hasn't leveled the playing field. It hasn't made job hunting easy. But you can improve your chances of winning the job that's right for you by being armed with a little knowledge of how the laws work.

Job Hunting with a Disability (cont.)

Q: Are all employers covered by the ADA?

A: No, only those with 15 or more employees. Some states have comparable laws covering smaller employers, but in most states disability discrimination is legal in very small business.

Q: Does the ADA guarantee me a job?

A: No, it only protects your right to compete. If you are qualified and able to do the job, you cannot be denied the job just because of your disability. Moreover, if you're able to do the job with an accommodation, the employer must provide "reasonable" accommodation to your disability.

Q: Do I report my disability when I apply for a job?

A: You are under no obligation to do so. Under the ADA, employers may not inquire about disabilities until after a "conditional offer" of employment has been made. That means you should be evaluated initially the way other people are evaluated, based on your education, experience, and skills.

Q: What if I want to report my disability?

A: It's your call but disclosure does carry a lot of risk. For most employers, disability is still a definite negative. If you bring it out too early, employers may decide to avoid an uncomfortable situation simply by not selecting you for an interview.

Q: What about job interviews?

A: Even in an interview, ADA employers may not ask about disabilities; they may ask about your ability to perform essential job functions. For example, if driving is part of the job, you can be asked if you have a driver's license.

Q: What is a "conditional offer of employment."

A: Basically; under the ADA, the employer should first evaluate your qualifications without considering disability. Before asking medical questions, the employer must tell you that you're selected, contingent on your satisfying medical requirements. This means you should have a job offer, with all important terms like what you'll be doing, how much you'll be paid, and when you'll start. After the offer, you are subject to the same medical screening that applies to all applicants: you should not be singled out for special scrutiny because of your disability.

Caregiving

Internet Resources for Caregivers

From the Reeve Foundation's [Paralysis Resource Guide](#)

FamilyCare America hopes to improve the lives of the caregivers by creating a highly accessible resource for caregivers. FamilyCare America also serves corporate needs through specialty publishing and human resource programs. See www.familycareamerica.com.

Shepherd's Centers of America (SCA) is an interfaith, not-for-profit organization that coordinates nearly 100 independent Shepherd's Centers across the United States to help older adults remain independent. See www.shepherdcenters.org

Hiring and Management of Personal Care Assistants for Individuals with SCI is a downloadable, 26-page booklet in PDF format from the SCI Project at Santa Clara Valley Medical Center. Covers everything from locating and hiring, to training and paying personal assistants. Includes forms, checklists and resources. See www.tbi-sci.org/pdf/pas.pdf

Paralysis Community, a resource of www.paralysis.org, the homepage of the Christopher & Dana Reeve Foundation Paralysis Resource Center. This is a safe and secure online social networking site with a robust discussion area on many areas of paralysis, including caregiving. Join us: Write a blog; connect with friends. Click on Community Forums at the top of the www.paralysis.org home page; registration is quick and easy to access the many community features.

CareCure Forum for caregivers. Active and helpful message board for loved ones and caregivers of people with paralysis. On the Internet see www.sci.rutgers.edu and click on the "Caregiving" section.

Nursing Home Compare, sponsored by Medicare. Information about the past performance of most nursing homes in the U.S. Also features A Guide to Choosing a Nursing Home and a nursing home checklist. See www.medicare.gov/NHCompare/home.asp.

In Memoriam

In the fall of 2009, a courageous physician lost her personal battle with a devastating familial form of ALS. Her personal, courageous decision to participate in a clinical trial was not in vain. Everyone in the SPF community can join together knowing that what her research colleagues learned from her experience will enable the field to move ahead more quickly to stop this insidious disease.

Both the SPFoundation and some individuals in our patient community contributed to this exciting RNAI project. The Neurology Departments at the University of Massachusetts and the Massachusetts General Hospital, the Angel Fund, the Spaulding Rehabilitation Hospital and the Northeast ALS Consortium all collaborated on the groundbreaking research and funding which made the trial possible.

Medical Reports

Betsy Baquet, editor

Discovery of HSP related protein functions

Troyer Syndrome is a form of HSP caused by a mutation in the SPG20 gene encoding spartin protein. The cellular function of spartin and the knowledge about spartin interactors is very limited. A study was conducted to identify novel spartin binding proteins and characterize potential spartin binding proteins. 94 potential spartin-binding proteins were identified, and interactions with nucleolin proteins, GRP78 And GRP75 were confirmed, as well as interaction with ubiquitin and ligases protein. These studies suggest that spartin is a multifunctional protein and, for the first time, it suggests a role for spartin in protein folding and turnover both in mitochondria and endoplasmic reticulum. It also shows, for the first time, interaction between spartin and a nucleolar protein, nucleolin.

SOURCE: <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4709>

Study in Determining the Function of the Atlastin-1 Protein

Mutations in the SPG3A gene causes juvenile onset HSP. Atlastin-1 is the protein product of that gene. A study was conducted to better understand this protein's function and role in the Endoplasmic Reticulum (ER), which is an organelle that forms a lacey network of tubules, vesicles and cisternae in the motor neuron cell. It was concluded that atlastin-1 might be implicated in membrane tabulation and vesiculation, and also participated in the formation and function of the ER. This shows significant progress in determining the functions of the Atlastin protein in neurons, which is a factor in understanding disease onset and developing a cure.

SOURCE: <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4710>

Frequency and phenotype of SPG11 and SPG15 in complicated hereditary spastic paraplegia.

A recent study was conducted to compare the frequency of SPG11 and SPG15 mutations in patients with early onset complicated HSP. It was found that thinning of the corpus callosum was considerably higher in patients with SPG11. Additionally, several new variants were identified for SPG15. It was concluded that thinning of the corpus callosum is the best predictor for SPG11 and SPG15, and that there are no clinical features that could discriminate between SPG11 and SPG15. Therefore, priority of genetic testing should be driven by mutation frequency that appears to be substantially higher in SPG11 than in SPG15.

SOURCE: <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4723>

Dementia is a Feature in SPG4 HSP

Thirteen members of a family with SPG4 HSP known to have a deletion of exon 17 in the spastin gene were cognitively assessed over a seven year period. Six out of the 13 members showed cognitive decline. Two genetic deletions were identified in 12 out of the 13, and in five members, there was a deletion in SPG6. Four members

had deletions in SPG4 and SPG6, of which two showed cognitive impairment. One member with SPG6 deletion alone had neither HSP nor cognitive impairment. It was concluded that cognitive decline and dementia is a feature of SPG4 HSP due to a deletion of exon 17 of the spastin gene.

SOURCE: <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4729>

Axonal Transport is Key Factor in Spastin Mutation HSP

It has been determined that the most common cause of HSP is mutations in the spastin gene. However, how this mutation induces the disease is still unclear. Spastin's function plays a significant role in axonal transport, deficits in which may underlie part of the disease process. Since there is no direct evidence supporting this, axonal transport was analyzed in a mouse with spastin-induced HSP. It was found that mutant spastin disrupts transport of mitochondria and membrane-bound organelles in neurons. Where axonal swelling was present, this disruption was exacerbated. These results strongly support that defective axonal transport due to spastin mutation plays a direct role in the development and disease process of HSP.

SOURCE: <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4731>

New "Antisense" Experimental Therapy Clinical Trial Announced for Familial ALS

The ALS Association is preparing for a clinical trial of a drug therapy in patients with familial ALS later this year. Using an approach known as antisense, a drug is designed to shut down the RNA (Ribonucleic acid) that is responsible for the production of disease-causing proteins. Initial research in rat ALS disease models demonstrated that the antisense drug inhibited the mutant SOD1 protein, resulting in prolonged life of the rats. Researchers hope that this therapeutic approach will provide a similar therapeutic benefit in people with familial ALS due to mutations in the SOD1 protein. The antisense approach could also prove valuable in treating other neurological disorders, such as Huntington's disease.

SOURCE: <http://www.alsa.org/research/article.cfm?id=1525&CFID=4864788&CFTOKEN=6788674f2572fe0d-7E372CC4-188B-2E62-8097B94AAD541D0A>

Two ALS Drugs Show Early Promise

Two experimental compounds under development by different drug companies have shown encouraging early results, according to reports given at the 20th International Symposium on ALS/MND. They are identified as KNS760704 and SB509.

According to Knopp Neurosciences of Pittsburgh, PA, KNS760704 appears to protect nerve cells under stress. The experimental drug is a molecular mirror image of pramipexole, a prescription medication approved for the treatment of Parkinson's disease and restless legs syndrome under the trade names Mirapex and Sifrol. The company says these two mirror-image molecules have very different properties. In phases 1 and 2 of the trial, patients showed a trend of slowed disease progression. The rate was slowed

more at higher doses, and at the highest dose, there was a trend toward survival benefit. The drug was found to be safe and well-tolerated. Knopp is currently preparing for a phase 3 trial.

A report given at the symposium about trials of the experimental compound SB509 suggests the substance is safe and well tolerated and also may have a positive effect on function in people with ALS. Approximately 30 percent of people treated with the drug had improved manual muscle function and showed improvement on the ALS Functional Rating Scale. Jeffrey Rothstein, who directs the MDA/ALS Center at Johns Hopkins University in Baltimore, said the ability to maintain muscle strength or delay its deterioration could have a significant impact on quality of life for people with ALS. Sangamo Biosciences, located in Richmond, CA, is the drug developer, and is preparing for a phase 3 trial.

SOURCE: <http://quest.mda.org/news/two-als-drugs-show-early-promise>

“Toxic Desert Dust” Linked to ALS in Gulf War Vets

In 2001, a government-funded study showed that military personnel serving in the 1990-1991 Gulf War were nearly twice as likely to have developed ALS as were military personnel who had not served in that war. New findings suggest a possible link between dust-dwelling bacterial toxins and an elevated incidence of ALS in Gulf War veterans. The study blames cyanobacteria, microorganisms that live in desert sands and which can be inhaled when they're kicked up in dust, such as when a convoy of military vehicles rumbles by. Cyanobacteria are common throughout the world in salt water, fresh water and soil. The new findings generally support the theory that ALS may be caused by a combination of genetic predisposition and environmental exposures.

SOURCE: <http://quest.mda.org/news/als-research-poison-dirt>

After a two-year review, the FDA approves reopening a clinical trial of the experimental compound arimoclomol.

A clinical trial of an experimental drug for ALS -- halted almost two years ago due to safety concerns -- has been given the green light to continue with a revised protocol, says CytRx Corp. of Los Angeles, the drug's manufacturer. The U.S. Food and Drug Administration placed a hold on the phase 2b trial of arimoclomol in January 2008, saying it wanted to see more toxicity data from previously completed animal studies. CytRx announced on Dec. 2, 2009, that it had received FDA permission to continue human testing. The new trial is not yet officially open, but it soon will begin recruiting participants. Arimoclomol represents a new strategy in ALS — enhancement of molecules called “chaperones,” which help regulate cellular repair. According to CytRx, arimoclomol can detect proteins that are misfolded and potentially toxic and refold them into their correct, nontoxic shapes. A different phase 2-3 study of arimoclomol already is underway, focusing on the SOD1-related form of familial ALS. It was not affected by the halting of the phase 2b arimoclomol trial in ALS.

SOURCE: <http://quest.mda.org/news/als-drug-trial-restarted>

Smoking Raises Risk of ALS

A new review of the medical literature confirms that smoking significantly raises the risk of developing ALS. A new analysis says that smoking, already suspected of being a risk factor for amyotrophic lateral sclerosis (ALS), definitely is one. Carmel Armon, professor of neurology at Tufts University School of Medicine in Boston and chief of neurology at Baystate Medical Center in Springfield, Mass., analyzed the medical literature published on smoking and ALS between 2003 and April 2009. He initially identified 28 studies, only two of which were considered reliable enough to be included in the final results, which were announced Nov. 17, 2009, in the journal *Neurology*. In the two studies announced, smokers increased their risk of developing ALS by 1.6 to 1.89 times the average. Also, the longer an individual smokes, the more likely they are to develop the disease. Those who smoked more than 33 years had more than a two-fold increased risk of getting ALS compared with those who never smoked.

SOURCE: www.mda.org/publications/Quest/extra/nov09/stop-smoking.html

First Human Embryonic Stem Cell Lines Approved for Use Under New NIH Guidelines

NIH Director Francis S. Collins, M.D., Ph.D., announced on December 2 the approval of the first 13 human embryonic stem cell (hESC) lines for use in NIH-funded research under the NIH Guidelines for Human Stem Cell Research adopted in July 2009. Dr. Collins said. “In accordance with the guidelines, these stem cell lines were derived from embryos that were donated under ethically sound informed consent processes. More lines are under review now, and we anticipate continuing to expand this list of responsibly derived lines eligible for NIH funding.”

More than 30 NIH grants funded in the 2009 fiscal year totaling more than \$20 million proposed to use hESCs. This group of grants includes research using hESCs for the therapeutic regeneration of diseased or damaged heart muscle cells, developing systems for the production of neural stem cells and different types of neurons from hESCs in culture, and developing a cell culture system for the large scale production and self-renewal of hESCs.

SOURCE: www.nih.gov/news/health/dec2009/od-02.htm

Scientists encouraged by new mouse model's similarities to human ALS

St. Louis, Oct. 9, 2009 — A new mouse model of ALS closely resembles humans with the paralyzing disorder, researchers at Washington University School of Medicine in St. Louis report. The new genetically engineered mouse has a mutation in the gene for a protein called TDP-43. Researchers at the University of Pennsylvania linked TDP-43 to inherited forms of ALS in 2006. Like humans with ALS, the mouse develops progressive paralysis; loses muscle mass and specific types of motor neurons, and dies of the disorder.

“As far as we know, this is the first mouse model that recapitulates ‘typical’ ALS to be produced in more than a decade,” says senior author Robert Baloh, M.D., Ph.D.,

assistant professor of neurology. “That could make it very helpful for our efforts to better understand and identify treatments for this terrible disorder.” He further states “TDP-43 is only the second gene to be linked to an inherited form of ALS that appears clinically identical to sporadic ALS, and it’s very promising that this similarity allows the symptoms of sporadic ALS to be accurately modeled in mice.”

The new mouse model may also provide an important tool for screening new drugs, according to Baloh. Scientists already have another mouse model of ALS with a mutation in SOD1, the first gene to be linked to an inherited form of ALS with typical symptoms, but, according to Baloh, it hasn’t always been the best tool for predicting if treatments will work in humans. “If we use the two models together to test potential treatments, though, that might provide us with a much finer screen,” says Baloh. “This could help relieve some frustration in the field, because there are a number of new drugs ready to be tested in humans, and we urgently need ways to determine which should be tried first.”

SOURCE: www.eurekalert.org/pub_releases/2009-10/wuso-seb100909.php

Compound shows potential for slowing progression of ALS

A chemical cousin of a drug currently used to treat sepsis dramatically slows the progression of ALS in SOD1 mice. In a paper published online Oct. 19 in the *Journal of Clinical Investigation*, scientists studied the use of a form of an enzyme known as activated protein C, or APC, to slow the cell death that occurs in ALS. They were able to extend the lifespan of mice with an aggressive form of the disease significantly, by about 25 percent. The compound also extended the length of time that the mice were able to function well despite showing some symptoms of the disease, and it reduced the pace of muscle wasting that is a hallmark of ALS.

While the investigators say that more research must be done before the enzyme is tested in people with the disease, they are encouraged that the work involves a compound that has already been proven to be safe and is currently given to patients via a common injection for another condition. The team hopes to test a treatment in patients within five years.

SOURCE: www.eurekalert.org/pub_releases/2009-10/uorm-csp101509.php

Heavy metal paradox could point toward new therapy for Lou Gehrig’s disease

New discoveries have been made about how an elevated level of lead, which is a neurotoxic heavy metal, can slow the progression of ALS—findings that could point the way to a new type of therapy.

The results surprised researchers, since lead is also a known risk factor for ALS. This paradox is still not fully understood, and at this point would not form the basis for a therapy, as lead is toxic for the nervous system. But scientists say the

phenomenon may lead to promising alternative approaches to the gene therapies that are now a focus of study.

The research was just published in *Neurobiology of Disease*, a professional journal, by researchers from the Instituto Clemente Estable and the University of the Republic in Montevideo, Uruguay, and at Oregon State University. The research has been supported by the National Institutes of Health. “We know that environmental exposure to lead is a risk factor for ALS,” said Joseph Beckman, holder of the Ava Helen Pauling Chair in the Linus Pauling Institute and director of the Environmental Health Sciences Center at OSU. “That’s why it’s so surprising that, according to studies done with laboratory animals, higher levels of lead appear to significantly reduce motor neuron loss and progression of ALS.” The levels of lead that were therapeutic in the mice have toxic risk in adult humans, the researchers pointed out. However, as more is learned about how lead is affecting ALS, alternatives to lead might be found to accomplish the same goal.

SOURCE: www.eurekalert.org/pub_releases/2009-11/osu-hmp113009.php

Tiny molecule slows progression of Lou Gehrig’s disease in mice

Researchers at UT Southwestern Medical Center have found that a molecule produced naturally by muscles in response to nerve damage can reduce symptoms and prolong life in a mouse model of amyotrophic lateral sclerosis (ALS).

“We believe we can apply this research toward drug development,” said Dr. Eric Olson, chairman of molecular biology at UT Southwestern and senior author of the study, which appears in the Dec. 11 issue of *Science*.

As muscles are damaged in ALS, they can “re-innervate” themselves by prompting healthy nerves to send new branches their way. The molecule responsible for this is microRNA-206 (miR-206), but can only work for so long. “While miR-206 initially prompts nearby surviving nerves to send new branches to the muscles, it only delays the inevitable,” Dr. Olson said. “Our findings correlate with the observation in ALS patients that the disease is nearly asymptomatic until a large fraction of motor neurons has died, at which point the few remaining ones can’t compensate sufficiently. These results provide a new perspective on the mechanisms of ALS,” he said. “MiR-206 seems to sense nerve injury and promote regeneration.”

“Because miR-206 only exists in skeletal muscle, a drug based on it might not affect other tissues. That limits its risk of side effects and is a key part of its appeal as a potential therapy.”

In collaboration with a company he co-founded, called miRagen Therapeutics, Dr. Olson is developing potential drugs based on miR-206.

SOURCE: www.eurekalert.org/pub_releases/2009-12/usmc-tms120309.php

7700 Leesburg Pike, Ste 123
Falls Church, VA 22043

Reserve your room at the LAX Hilton Today!!!



**SPFoundation National Conference - May 21-23, 2010 - Los Angeles, CA.
Call Loretta Baker at the LAX Hilton Hotel (310) 410-6143**