

Synapse

Volume 11, Issue 3 Summer, 2008

Newsletter of the Spastic Paraplegia Foundation



Jim Sheorn
President

Letter from the President

We just completed the SPF National Conference in Valley Forge, PA. There were 150 people from 24 states and 2 countries that attended. That makes the largest SPF Conference to date.

The conference started off with a welcome reception and dinner on Friday night with guest speaker, Patricia Leisner Clements. She shared the latest on "Medicare and Disability Benefits". It was very informative.

Saturday we were joined by Peter Baas, PhD, Mary Kay Floeter, MD, PhD and John Fink, MD who gave overviews of HSP and PLS and then updated us on the latest research. Dr. Fink may start some human trials soon. He said that it may be hard to design trials that will be of help, but he and his staff are dedicated to find a way. Look forward to upcoming SPF E-News and *Synapse* for updates.

Later that afternoon, Rosette Biester, PhD gave an interesting presentation on "Living with a Chronic Disorder". During the Patient Forum we heard about the Baclofen pump from Susan Johnson with Medtronic and about WalkAide from Gregg Beideman, DTP with Innovative Neurotronics. Craig Gentner led the Caregiver Forum. We had some very interesting presentations, which inspired a lot of questions. I apologize to those that attended about limiting the number of questions. I was trying to keep us on schedule so that all the speakers could present before our time was up. We will do our best to allow more time for questions and answers in the future.

We heard lots of compliments and are looking forward to reading the evaluations so that we can see where we can improve for next year.

The conference was video taped and we hope to make it available to those interested in the near future. Please look forward to updates on the SPF website.

Our next big project is TeamWalk. This is the biggest fund-raiser for SPF. The money it raises is almost 3 times more than any other event. If you have implemented a TeamWalk in your area, we hope that you will do so again. If you are interested in putting one together, we hope that you will. It actually doesn't even have to be a walk event. You could have a Connection Meeting and allow participants to turn their money at the same time. Some Connections have guest speakers like researchers and others just offer a place for affected people to meet and learn from each other.

The SPF website has many ideas on how to raise money. One of the easiest is to send a letter or email to family and friends. There is a sample letter available on the website. In our first year, my wife and I wanted to raise \$1,000. We were amazed that we collected nearly \$7,000. Please make sure that you start early. It sometimes takes awhile to collect all of the donations.

Last year, \$503,000 was raised over all. We hope with your help that we can raise even more this year. If you have questions or need help, just let us know. We will do our best to help you support the SPF mission, which is to find the cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. Please remember that all donations are tax deductible and that many companies have a Matching Gift Program. It is a great way to double your fund-raising efforts.

Thanks in advance for your support.

Sincerely,

Jim Sheorn, SPF President



Volume 11, Issue 3 - Summer 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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CORRECTIONS TO SPRING SYNAPSE

Ed. Note: We're sorry for these errors and omissions.

Annual Report Donors

Missing from Runner category....\$1,000-\$1,999
Joel and Bobbie Seidman

P. 12 - National Respite Network

The 800 number listed is incorrect. Please use the website as listed.

P. 15 - Ambassador Corrections

NM, Shellie Fischer, shellfischnm@hotmail.com
(505) 499-9277

MO, Mike Church, churchmike@sbcglobal.net
(417) 873-9656

Thanks and Welcome New Ambassadors!

Ambassador Additions

CO, Dennis Morales, dipnote@msn.com
303-333-0878

IL, Lewis S. Clark, lscmc@yahoo.com
(847) 566-5979 (northern IL)

IL, Al Taylor, papa-al@sbcglobal.net
(618) 465-4611 (western IL)

LA, Patti Prudhomme, pmp55mat@yahoo.com

MD, Joel Fastow, jsfastow@aol.com (301) 652-2707

MN, Jim Dahlin, jdahlin@comcast.net (763) 520-7123

NJ, Joanne Gooley, joanne056@optonline.net
(732) 866-5152

VA, Beth Anne Shultz, farley1165@aol.com
(540) 788-1798 (*co-ambassador*)

WI, Dennis Strangstalien, uffda2@centurytel.net
(715) 538-4167

Canada -- Jim Langedijk, jlangedijk@rogers.com -
(519) 823-8346

Canada -- Monika Scholze, scholzie1@sympatico.ca
(416) 284-0422

Events

EVENT REPORTS

New England Spring Seminar and Connection

March 29, 2008

Submitted by Jim Campbell; edited by Jeffrey Macklis

“Growing, Protecting or Repairing Corticospinal Motor Neurons”

Dr. Jeffrey Macklis, M.D., D.HST - Director, MGH-HMS Center for Nervous System Repair, Massachusetts General Hospital & Harvard Medical School; Department of Stem Cell and Regenerative Biology, Harvard University

Dr. Macklis has for the past 15 years been engaged in research on “projection neurons” of the brain, most centrally “corticospinal motor neurons”, more commonly known as “upper motor neurons” (UMNs). Malfunctions of UMNs, whose cell bodies are located in the cortex portion of the brain with axons extending through the spinal cord, are the cause of symptoms in both PLS and HSP. To describe the size of just one UMN and understand its complex purpose, he had us look at the movie screen we were watching in a hotel in Waltham. We were about 12 miles from Boston. If the movie screen represents one cell body, we were to imagine a communication cable that was directed by that cell body to run all the way to Boston to a specific hotel, find the correct room in that hotel, then make the appropriate connections. Each of many thousands of UMNs must send their axons a long way, and be properly programmed to function properly.

He believes that developmental neurobiology and precursor / “stem cell” biology can lead to both understanding of and therapies for our diseases. By utilizing early and adult stem cells from mice, his lab has deeply investigated the development and growth of UMN cells and isolated about 35 genes that control that development. They have already recruited new UMNs in mice with UMN degeneration, from stem cells already in the brain. With the understanding of the UMN cell development he believes it is now feasible to increasingly precisely control and repair UMNs in adult mice. He noted that mice are an excellent model for studying UMNs because mice are mammals with much simpler brain making them easier to study, yet they have genes that are 95% or more similar to humans. He also observed that repair and rebuilding of neurons similar to UMNs is a natural phenomenon

in some birds. Songbirds repair their UMNs to perfect their mating calls and canaries actually build new brain circuitry each season.

In responding to audience questions he noted the criticality of front-end funding such as that generated by our own SP Foundation. This has allowed him to pursue ideas that are high risk/high reward given NIH’s cost constraints and attendant reluctance to fund concepts that are not yet proven. He said that he has used recent SP funding to develop tools to modify the UMN control genes.

When asked about when this research might help those of us with PLS and HSP, he shared the following three part prediction: Near term (next few years): Cell models will soon be available to test potential drugs to slow degeneration of UMNs thought to be in the area of a mouse brain causing HSP. Mid Term (3-5 years): Availability of drugs to slow UMN degeneration in humans. Actual repair of UMNs in mice that may permit subtle improvements.

Longer Term (within the next decade): Actual repair of UMNs in humans that will permit subtle improvements in PLS & HSP patients.

The 60 HSPers, PLSers and caregivers present were appreciative of Dr. Macklis’ presentation that was informative, easy to understand and hopeful. We are all grateful for his important research efforts on our behalf.

Oklahoma Connection

Submitted by Mark Dvorak

We had a great time at the Tulsa Connection on April 12, 2008. Eleven people met at the Delta Cafe for lunch and had a wonderful get together. The attendees came from Ponca City, Claremore, Broken Arrow, Norman, OK, and Springfield MO. After lunch, we listened to a speaker from The Center for Individuals with Physical Challenges (www.tulsacenter.org). There are only three centers like this in the United States and one of them is in Tulsa. It is very much like a YMCA but it is designed for people with physical challenges. There were many questions asked and answered about the center.

After the speaker, we had a discussion about the various ways we cope with our situations. Many things were

learned from each other's experiences. For instance, Mike Church brought some shoes he had customized. He put a tip on the sole that allows the toe to slide as opposed to catching on the ground when walking. He gave us the "how to" knowledge so now we can do it ourselves.

Spring Fling 2008

Submitted by Don Wilson

Spring Fling in West Virginia without freezing winds, torrential rain, or snow! Who would have thunk it? This time Ronnie Grove ordered special weather to highlight her ninth annual event.

Guests began arriving early Friday, and the motel lobby soon became a greeting place for friends old and new--Carolyn Sartain Anderson and her daughter Sarah Oglesby, Martin and Mary Ann Beckner, Dorothy Cockrell and friend Donna Suchmann, Sarah Duncan and her son Zach, David and Lois Lehman, Annette and Steve Lockwood, Jim and Barb Spencer, and Bettie Jo and Don Wilson along with care provider Traci Stanley.

After getting squared away at the motel, everyone gathered for dinner at Francis Asbury United Methodist Church and a fine meal it was. After dessert, the group lingered a bit before returning to the motel. There, some set up camp in the motel lobby for conversation and sharing.

On a bright Saturday morning, Janet Hawbaker and friend Carol Ralston, along with Gene and Anna Knicely, joined the gathering to make the Connection complete. Counting Ronnie, the Connection comprised six PLSers and four HSPers, representing seven states. It was "old home day" as everyone in the room moved from one welcoming to the next.

Robert Polander from the Bethesda, MD, Hanger office was introduced. He explained and demonstrated the Walk-Aide, the newest aid to enable users to walk. He attached the Walk-Aide and was able to program the equipment to demonstrate the effect of stimulating the correct nerves to result in better walking, and much less toe drop. It helped some more than others.

We always eat well in West Virginia. Lunch was served, followed by drawing of tickets for all sorts of goodies. Ronnie followed tradition by sharing a meal for dinner at the Park-N-Dine in Hancock, MD. Did I mention that West Virginia food is great? And across the Potomac River, the food is almost as good.

The Spring Fling 2008 report would not be complete without mentioning that Ronnie dedicated the Connection to Annette Nussey, who died on the first day of this year. Annette, a very pleasant, caring, classy lady came to her first Spring Fling in 2003, and she and her dedicated husband and caregiver, Stan, attended every year, the last in 2007.

Connecticut Connection

Submitted by Dolores Carron, CT Connection Organizer and Coordinator

The 26th meeting of the CT Connection was held on June 4, 2008, at the NEAT (New England Assistive Technology) Marketplace in Hartford, CT. The day's activities began with an arrival coffee hour. Our morning speaker, Officer Michael Webster, talked to us about safety and security of person and home. As part of his presentation, he demonstrated the use of a taser gun. Attendees were given numerous printed handouts describing measures to take to ensure their safety.

Jennifer Baker, Program Director at NEAT, then gave a talk and showed a large variety of 'gadgets and gizmos' which can be useful for a variety of handicaps and used in various areas of the home. She also described the myriad resources available at NEAT. If you are unfamiliar with NEAT, check out their website at www.neatmarketplace.org. It is a truly remarkable organization.

Following our lunch and conversation break, Mira Binford, a CT PLSer and internationally acclaimed film maker, presented her award winning Holocaust documentary, "Diamonds in the Snow". Mira is a Holocaust survivor herself. She presently is on the faculty at Quinnipiac University in Hamden, CT. It was a somber and emotional way to end the day, but everyone was pleased to have shared the fruits of her talent. As Mira quipped, "what are the odds that I'd be among the small number who survived the Holocaust and among an equally small number afflicted with PLS?" Talk about odds!

There were two PLS newcomers to the group--one a newly diagnosed woman from CT and another woman and her husband who recently moved to CT. As always, it was nice to renew old acquaintances as it was to meet and welcome new faces.

TEAMWALKS AND CONNECTIONS

Yes, it's that time again. TeamWalks are coming your way. Below is a list of TeamWalks and Connections currently on the docket. Some of these are still under construction, so keep checking the calendar section of www.sp-foundation.org for the latest information. Or feel free to email or call the contact person listed for the event you're interested in attending. If you've never walked the walk or made a connection, take that step in 2008. You won't regret it.

New England Connection Picnic

July 20, 2008, 11:00 am

Lexington Visitor's Center, Lexington, MA

Kathi Geisler: kathi@kgeisler.com, 978-256-2673

For those who are interested, there will be a planning meeting for the September 13th New England TeamWalk immediately after the picnic.

Kentucky Connection

July 21, 2008, 12:30 pm

The Majestic Restaurant, Mayfield, KY

Jane Anne King: gking@rose.net, 229-227-0558

The first Kentucky Connection will be held at the Majestic Restaurant (270-247-2541), 700 South 6th Street, in Mayfield, Kentucky. The meeting will start at 12:30pm. The deadline for registration is June 27th.

Iowa Connection

July 26

Des Moines, IA

Jackie Wellman: hopywell@aol.com, 515-223-7275

Austin Patient Connection

August 3, 2008

Brick Oven Restaurant, Austin, TX

Marlene Doolen: mdoolen512@aol.com, 512-331-1953

**Warm Springs Retreat: I Live, I Learn, & I Achieve
August 8-10, 2008**

Warm Springs, GA

Jane Anne King: gking@rose.net, 229-227-0558

The first Warm Springs Retreat will be held August 8-10 at the Roosevelt Warm Springs Institute for Rehabilitation. The Institute is a state-operated comprehensive rehabilitation center located in Warm Springs, GA, on a beautiful 950-acre campus. Founded

by President Franklin D. Roosevelt in 1927 to treat persons affected by polio, the Institute remains true to its original mission "to empower individuals with disabilities to achieve personal independence" as a living legacy to FDR. In addition to its continuum of rehabilitation services, the Institute also offers the fully-accessible Camp Dream, which is enjoyed by 2,000 disabled campers each year. Cabins for two are available for \$30/person per night and are equipped with a handicap-accessible bathroom. Breakfast will be about \$6.00/person and lunch is \$12.00/person. The group will go out for dinner on Saturday night for some scrumptious Southern food (self-pay). Much more is planned, all of which is FREE.

2008 Loop for Life

August 23, 2008, 9 am

Indianapolis, IN

Harvey Mover: loopforlife@gmail.com, 317-815-2549

This year's Loop for Life will be bigger and better than ever. Sara Lee and Kroger will provide breakfast; Jug's Catering will provide lunch; Kinetico Water and RN Thompson will provide beverages; and live music all day provided by Blonde Sonja. Hooters is sponsoring the Bike Show and will award cash prizes as well as serve delicious wings.

You can save \$5 by pre-registering at www.loopforlife.org. That \$5 can be donated to your HOG Chapter Group, Rider's Club/Group, or other 501(c)(3) organization when registering. The first 3,000 registered are guaranteed a commemorative t-shirt.

Satellite rides will be available from Harley-Davidson of Indianapolis, 4146 East 96th Street, Indianapolis, IN 46240 and Southside Harley-Davidson, 4930 Southport Crossing Place, Indianapolis, IN 46237 with a police escorted ride to the Marion County Fairgrounds.

Southern California Connection

The HT Grill

August 23, 2008, 12 pm to 3 pm

Redondo Beach, CA

Malin Dollinger: malind@cox.net, 310-378-4059

This connection will be held at the HT Grill, 1701 S. Catalina Ave, Redondo Beach, CA 90277, 310-791-4849. Enjoy a time of discussion, support, socializing, a chance to ask others with similar problems for their solutions, and an opportunity to

make new friends. Malin will present a brief summary of the national meeting in Valley Forge, PA, including “what’s new” on the research and practical aspects of HSP and PLS.

Cascadian Connection

September 5-6, 2008

Portland, OR

Jean Chambers: jeanchambers@shaw.ca

604-990-1060

A Friday evening dinner is planned with a “We are the Experts” gathering afterwards. On Saturday, there will be a WalkAide demonstration and Dr. T.D. Bird of the University of Washington, Seattle, will speak. The Saturday night event is a concert that will star two women--one has HSP and the other is a spinal cord injury/neurological disorder specialist with the Oregon Vocational Rehabilitation Centre.

New York Teamwalk

September 7, 2008

Mount Kisco, NY

Ann Lakin: Alakin90@aol.com

914-242-9321

New England TeamWalk Connection

Woburn, MA

Sept. 13, 12:00 - 3:00

Kathi Geisler: kathi@kgeisler.com 978-256-2673

The TeamWalk will be at beautiful Horn Pond. A picnic table area is reserved for the Connection. The TeamWalk will be on the sidewalk that goes around the pond. There are plenty of benches to enjoy vistas, plenty of parking, and an accessible bathroom

Magnificent Weekend

NC Quest for the Cure Seminar and NC TeamWalk and the Magnificent Mile Races

Raleigh, NC

September 13-14, 2008

Sarah Witt: srwitt@yahoo.com 919-848-0582

Saturday’s Quest for the Cure Seminar will be held at the Clarion Hotel, 320 Hillsborough St, Raleigh, NC. Registration is \$25 per person, which includes lunch and refreshments. Featured speakers are Dr. Nina Tang Sherwood, an assistant professor of biology at Duke University and recipient of a 2006 SPF grant for HSP research;

Dr. Richard Bedlack, director of the Duke ALS Clinic and a former member of SPF’s Scientific Advisory Board; and Jeffrey B Weisler, DPT, of Aquatic PT and Beyond whose specialty is aquatic physical therapy and treatments for impaired balance.

The NC Teamwalk and the Magnificent Mile Races will be held on Sunday at 2 pm. They start one block from the Clarion Hotel. Registration is \$10 per person. Food, fun, and sun are the highlights of this event. Last year, more than 800 runners, walkers, and spectators came out to support our cause.

Discounted rooms (\$79/night) are available for Friday and Saturday nights at the Clarion Hotel. Call 919-832-0501 and ask for a room in the Magnificent Mile block.

Pennsylvania Connection and TeamWalk

Sept 20, 2008

Knoebels Amusement Resort, Elysburg, PA

Sue Meholick: momofboysonly@yahoo.com

814-590-4673

Northern California Connection

October 3-4, 2008

Pleasanton, CA

Linda Gentner: linda@gentner.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.

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. The program is being formulated. Weather permitting, the SAWCAR (*Scooter and Wheel Chair Association of Racing*) races will be held on Saturday. Racers should start planning strategy and remember that it takes lots of expensive technology to maintain those racing machines, so sponsors are needed. All sponsor donations will go to the SP

Foundation and ultimately to PLS and HSP research. Everyone is invited to share a meal at another nearby restaurant Saturday evening.

With the current fuel situation, there is no telling how much a gallon of gas will cost by October. Those from North Carolina should register with the ALS Association and apply for a vacation grant, which can be as much as \$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. Rooms in this block will be held until midnight on September 18. Other motels in the area include: Super 8 Motel, 1-800-800-8000; Quality Inn, 1-336-767-9009; Days Inn, 1-336-744-5755; Motel 6, 1-336-1588.

Arizona TeamWalk

November 2008 (exact date still to be determined)

Tucson, AZ

Erika Annis: ArizonaMommyOf3@aol.com

520-822-1936



Kathi and Maureen on a bike outing



The Spring Fling Gang!

OTHER EVENTS

Abilities Expo

Abilities Expo showcases the latest products and services to enhance the lives of people with disabilities. The exhibit hall is packed with vendors, live equipment demonstrations, and special events throughout the weekend.

Minnesota - September 12-14, 2008

Northeast Passage (NEP)

NEP promotes adaptive skiing, golf, cycling, water sports, and hiking programs. Visit www.nepassage.org for more information.

July 19, Paddling in Petersborough, NH, 1:00-4:00 (canoe), \$20

July 22, Water-skiing (boarding) in Merrimac, MA, 5:00 p.m. to dark (\$30)

August 9, Water-skiing (boarding) on Cape Cod (\$30)

Movement for Living free Teleconferences and Seminars present information on spasticity management

Medtronic's Movement for Living Seminars feature information about the Baclofen Pump. The seminars are designed to educate people about severe spasticity and ITB Therapy (*Intrathecal Baclofen Therapy*) as a treatment option. During the two-hour seminar, you will hear from an experienced physician who manages spasticity and a Movement for Living Ambassador who is receiving treatment for his or her spasticity. The 2008 teleconferences are listed below.

Register: www.medtroniceducation.com/kma/www/itb_mfl/3.listing.html

or call 1-888-743-8348

2008 Teleconferences - 7:00 p.m. EST

July 8

August 12 (Multiple Sclerosis)

September 9

October 14 (Pediatric Focus)

November 11

For information on the Baclofen Pump, visit the Journal of Neuroscience Nursing, April 2006 article to read "Intrathecal Baclofen Therapy: Ten Steps Toward Best Practice" www.medscape.com/viewarticle/547425

SP Foundation News

SP Board Notes from the June 6, 2008 Meeting

Jim Sheorn

The most exciting news is that we have begun the process to find a professional to help. We hope to have someone hired within six months.

We also began developing a list of companies that we will try to build strong relationships with to help us grow. If anyone knows of a company, please let us know.

Cosponsors of PLS Awareness Month - H.RES.896

Title: Recognizing the need to pursue research into the causes, a treatment, and an eventual cure for primary lateral sclerosis, supporting the goals and ideals of the **Hardy Brown Primary Lateral Sclerosis Awareness Month**, and for other purposes.

Sponsor: Rep. Joe Baca [CA-43] (introduced 12/19/2007)

Co-Sponsors: (120 as of 6/9/08) Contact your Rep. today if he/she is not on the list.

Latest Major Action: 12/19/2007 Referred to House subcommittee. Status: Referred to the Subcommittee on Health.

Whole Foods Market Selects SPF to be Featured for Donations

Thanks to Sarah Rogers-Witt's efforts, the Spastic Paraplegia Foundation has been selected to be the featured organization for Whole Foods Market, Raleigh's Community Spotlight during the month of August 2008. This means that all of the money that is collected in the donation boxes located at our cash registers in August will be donated to SPF. Nancy Halberstadt of Whole Foods Market, Raleigh hopes that the funds raised through the August Community Spotlight program will make a significant contribution to the support of the Magnificent Mile Race 2008. Sarah, you continue to inspire everyone.



Dr. M.K. Floeter speaking at the SPF National Conference

COSPONSORS(120), ALPHABETICAL
[followed by Cosponsors withdrawn]:
Rep Allen, Thomas H. [ME-1] - 5/8/2008
Rep Andrews, Robert E. [NJ-1] - 5/8/2008
Rep Arcuri, Michael A. [NY-24] - 5/8/2008
Rep Baird, Brian [WA-3] - 5/8/2008
Rep Baldwin, Tammy [WI-2] - 3/3/2008
Rep Barrow, John [GA-12] - 5/14/2008
Rep Bartlett, Roscoe G. [MD-6] - 4/1/2008
Rep Bean, Melissa L. [IL-8] - 5/8/2008
Rep Becerra, Xavier [CA-31] - 3/10/2008
Rep Berkley, Shelley [NV-1] - 3/31/2008
Rep Berman, Howard L. [CA-28] - 5/8/2008
Rep Berry, Marion [AR-1] - 5/8/2008
Rep Bishop, Sanford D., Jr. [GA-2] - 5/8/2008
Rep Bono Mack, Mary [CA-45] - 4/15/2008
Rep Bordallo, Madeleine Z. [GU] - 2/12/2008
Rep Boren, Dan [OK-2] - 5/8/2008
Rep Boswell, Leonard L. [IA-3] - 5/8/2008
Rep Boyd, Allen [FL-2] - 5/8/2008
Rep Boyda, Nancy E. [KS-2] - 5/8/2008
Rep Brady, Robert A. [PA-1] - 3/10/2008
Rep Brown, Corrine [FL-3] - 5/8/2008
Rep Butterfield, G. K. [NC-1] - 3/10/2008
Rep Calvert, Ken [CA-44] - 3/10/2008
Rep Capps, Lois [CA-23] - 5/14/2008
Rep Cardoza, Dennis A. [CA-18] - 3/3/2008
Rep Carson, Andre [IN-7] - 4/16/2008
Rep Chandler, Ben [KY-6] - 5/7/2008
Rep Christensen, Donna M. [VI] - 2/12/2008
Rep Clarke, Yvette D. [NY-11] - 5/8/2008

Rep Clay, Wm. Lacy [MO-1] - 3/4/2008
Rep Cleaver, Emanuel [MO-5] - 5/8/2008
Rep Clyburn, James E. [SC-6] - 5/8/2008
Rep Cohen, Steve [TN-9] - 3/31/2008
Rep Conyers, John, Jr. [MI-14] - 5/8/2008
Rep Cooper, Jim [TN-5] - 5/8/2008
Rep Costa, Jim [CA-20] - 5/8/2008
Rep Cramer, Robert E. (Bud), Jr. [AL-5] - 5/8/2008
Rep Crowley, Joseph [NY-7] - 5/8/2008
Rep Cuellar, Henry [TX-28] - 5/8/2008
Rep Cummings, Elijah E. [MD-7] - 5/8/2008
Rep Davis, Artur [AL-7] - 5/8/2008
Rep Davis, Danny K. [IL-7] - 2/27/2008
Rep DeGette, Diana [CO-1] - 5/8/2008
Rep DeLauro, Rosa L. [CT-3] - 5/8/2008
Rep Dicks, Norman D. [WA-6] - 5/8/2008
Rep Donnelly, Joe [IN-2] - 5/8/2008
Rep Doyle, Michael F. [PA-14] - 5/8/2008
Rep Ellison, Keith [MN-5] - 3/12/2008
Rep Ellsworth, Brad [IN-8] - 5/8/2008
Rep Emanuel, Rahm [IL-5] - 5/8/2008
Rep Farr, Sam [CA-17] - 1/29/2008
Rep Fattah, Chaka [PA-2] - 3/31/2008
Rep Filner, Bob [CA-51] - 5/8/2008
Rep Frank, Barney [MA-4] - 5/8/2008
Rep Gonzalez, Charles A. [TX-20] - 3/12/2008
Rep Green, Al [TX-9] - 3/4/2008
Rep Green, Gene [TX-29] - 4/10/2008
Rep Grijalva, Raul M. [AZ-7] - 2/28/2008
Rep Gutierrez, Luis V. [IL-4] - 3/12/2008
Rep Hall, John J. [NY-19] - 5/8/2008

Rep Harman, Jane [CA-36] - 5/13/2008
Rep Herseth Sandlin, Stephanie [SD] - 5/8/2008
Rep Hinojosa, Ruben [TX-15] - 3/4/2008
Rep Inslee, Jay [WA-1] - 5/7/2008
Rep Jackson-Lee, Sheila [TX-18] - 3/4/2008
Rep Jefferson, William J. [LA-2] - 3/31/2008
Rep Johnson, Eddie Bernice [TX-30] - 3/13/2008
Rep Jones, Stephanie Tubbs [OH-11] - 6/4/2008
Rep Kagen, Steve [WI-8] - 5/8/2008
Rep Kilpatrick, Carolyn C. [MI-13] - 3/31/2008
Rep Larson, John B. [CT-1] - 5/8/2008
Rep Lee, Barbara [CA-9] - 3/10/2008
Rep Lewis, Jerry [CA-41] - 2/28/2008
Rep Lewis, John [GA-5] - 3/31/2008
Rep Maloney, Carolyn B. [NY-14] - 3/5/2008
Rep McGovern, James P. [MA-3] - 3/31/2008
Rep Meek, Kendrick B. [FL-17] - 3/3/2008
Rep Meeks, Gregory W. [NY-6] - 5/8/2008
Rep Moore, Gwen [WI-4] - 5/6/2008
Rep Murtha, John P. [PA-12] - 5/8/2008
Rep Napolitano, Grace F. [CA-38] - 3/4/2008
Rep Norton, Eleanor Holmes [DC] - 3/31/2008
Rep Obey, David R. [WI-7] - 5/8/2008
Rep Ortiz, Solomon P. [TX-27] - 3/4/2008
Rep Pastor, Ed [AZ-4] - 3/4/2008
Rep Payne, Donald M. [NJ-10] - 4/9/2008
Rep Perlmutter, Ed [CO-7] - 5/8/2008
Rep Rangel, Charles B. [NY-15] - 3/31/2008
Rep Reyes, Silvestre [TX-16] - 4/14/2008
Rep Rodriguez, Ciro D. [TX-23] - 5/8/2008
Rep Ross, Mike [AR-4] - 5/14/2008

Rep Rothman, Steven R. [NJ-9] - 5/8/2008
Rep Roybal-Allard, Lucille [CA-34] - 4/10/2008
Rep Rush, Bobby L. [IL-1] - 5/13/2008
Rep Salazar, John T. [CO-3] - 5/8/2008
Rep Scott, Robert C. "Bobby" [VA-3] - 3/31/2008
Rep Serrano, Jose E. [NY-16] - 3/31/2008
Rep Sestak, Joe [PA-7] - 6/4/2008
Rep Sherman, Brad [CA-27] - 5/8/2008
Rep Shimkus, John [IL-19] - 5/8/2008
Rep Shuler, Heath [NC-11] - 5/8/2008
Rep Sires, Albio [NJ-13] - 3/12/2008
Rep Snyder, Vic [AR-2] - 5/8/2008
Rep Solis, Hilda L. [CA-32] - 3/3/2008
Rep Stupak, Bart [MI-1] - 5/14/2008
Rep Sutton, Betty [OH-13] - 3/10/2008
Rep Terry, Lee [NE-2] - 5/22/2008
Rep Thompson, Bennie G. [MS-2] - 5/8/2008
Rep Thompson, Mike [CA-1] - 5/8/2008
Rep Tierney, John F. [MA-6] - 5/8/2008
Rep Towns, Edolphus [NY-10] - 2/6/2008
Rep Udall, Mark [CO-2] - 5/8/2008
Rep Udall, Tom [NM-3] - 5/8/2008
Rep Velazquez, Nydia M. [NY-12] - 5/8/2008
Rep Walz, Timothy J. [MN-1] - 5/8/2008
Rep Waters, Maxine [CA-35] - 3/31/2008
Rep Watson, Diane E. [CA-33] - 3/3/2008
Rep Watt, Melvin L. [NC-12] - 4/2/2008
Rep Weiner, Anthony D. [NY-9] - 5/14/2008
Rep Wynn, Albert Russell [MD-4] - 4/2/2008

Living with HSP/PLS

Jane McCord Gives of Herself for Research

Jane McCord has passed on. Jane gave the penultimate gift to the PLS community – she directed that her brain and spinal cord be donated to the Feinberg School of Medicine @ Northwestern University Neuromuscular Disorders Program for PLS. This is only the second such donation given. The greatest hope for unraveling the cause of PLS is through autopsy.

Contributed by Carol Liquori and Ruth Watkins

Jane and her family are most grateful to: NWU, SPF, and Hope Hospice, in Fort Myers, FL. All of these organizations have served Jane well since she was diagnosed in 1999. They have provided medical information, support, connections to others with PLS, dinners, tours and obviously caregiving. Three wonderful organizations which our family endorses! Please help in some small way, if you can.

May 21, 2008 -- The Genetic Information Nondiscrimination Act is signed by the President.

The Genetic Information Nondiscrimination Act (GINA) paves the way for the responsible use of genetic information while protecting against discrimination with respect to health insurance and employment. GINA:

- Prohibits group health plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.
- Prohibits issuers of Medigap policies from adjusting pricing or conditioning eligibility on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.
- Prohibits employers from firing, refusing to hire, or otherwise discriminating with respect to compensation, terms, conditions or privileges of employment. Employers may not request, require or purchase genetic information, and may not disclose genetic information. Similar provisions apply to employment agencies and labor organizations.

ALS Society Grants and Loaners

Contributed by Deanna Babcock

Recently my mom and dad had some big problems with mother's care because my dad had 3 surgical procedures in 2 months and was unable to lift her to transfer to the bathroom and bed. Mom has PLS. I moved in with them, took some time off and they hired a private aide to help in the day. Someone suggested we contact the ALS society as PLS falls under the diagnosis of ALS support. They came out to discuss her condition, and had me complete a respite care grant application. They will give her about 4 hours a week for a care giver break. She has used the grant to hire a bath lady once a week so I won't have to spend every Sunday afternoon doing it with her. Now we can spend our free time on more fun stuff. They have a wonderful loaner closet with supplies -like shower chairs, cushions wheelchairs etc that they can supply people with.

Third Grade Wisdom

Contributed by Mark Fischer, Grade 3

I don't really care about having HSP.

I feel great and don't worry about it.

I can fix things.

I help my classmates because I get done the fastest.

I am smart and I can spell.

I have great aim when I shoot my air rifle.

I also fish and drive a really cool go-cart.

My mom, brother and sister all have HSP.

They don't care about having HSP.

We have other stuff to do.

PatientsLikeMe

By Paul Wicks

PatientsLikeMe.com is an online community where patients can share data about their progress, treatments, and symptoms with one another. The first PatientsLikeMe community was for sufferers of the condition ALS (Amyotrophic Lateral Sclerosis) and has now grown to over 2,000 members. In May 2008 a range of new features were launched to welcome patients with PLS (*Primary Lateral Sclerosis*) into the ALS community. When patients with PLS join the site they will have their own patient representation ("*stickman*") and we've made it easier

to find another patient like you with PLS. We're also collecting data on the progression rates of PLS patients so that we can generate percentile curves for your chart to add context into how your PLS is progressing. Since its launch the PLS community has grown to almost 50 members with PLS; the largest sample of PLS patients gathered for published clinical research was just 26 patients so we are confident that we will be able to learn much more about this rare condition. Please go to www.patientslikeme.com/user/signup to signup.

HSP / FSP Support Group (UK): A Sister Group across the Pond

Contributed by Ian Bennett

The HSP/FSP Support Group helps people diagnosed with Hereditary Spastic Paraplegia [*also known as Familial Spastic Paraparesis (FSP)*]. It is a UK based Registered Charity and began as a 'self-help' group in 1989 by Stephanie Wyatt to support her affected husband and son. We now have over 300 members in the UK. We hold regular meetings, run a help-line and provide our members with funding to purchase mobility aids or other equipment that may help improve quality of life. We support UK based research teams both financially and by providing HSP affected volunteers. We are trying to reach more people with the condition in the UK, but this remains a problem due to the rarity of diagnoses.

Please check out the website www.hspgroup.org and read our newsletters.

Ronnie's Story

Contributed by Ronnie Grove

Nineteen years ago this past February I had the worse case of the flu I've ever had. I was so sick my eyelashes hurt. Shortly after that, as I started a walking program, I realized something was wrong with my left foot. I would stumble or my toes would drag

In July of that year (1989) I started a new job. That's when I noticed other symptoms. Being tired, left hand sluggish, my left leg felt like it was in a hip wader filled with concrete. In December I began to see a series of doctors. The diagnosis came at University of Virginia in April of 1990 and was told I had PLS...whatever that was.

The doctor told me, "It is very rare and we know very little about it. Normally it progresses very slowly compared to ALS. Each case is different. You could

be in a wheel chair a year from now or you might still be walking twenty years from now. I just can't tell you what to expect". It is now going on twenty years and I am still walking. Tippy and slow, yes, but walking!

I did the usual running to different doctors until I heard from Frank Levy and then Joe Alberstadt. A small PLS meeting was put together at Vienna, VA and I met my first PLS people in June of 1998...I think. It was here that I met Ed Ames who insisted that I needed a computer and encouraged me until I got one. That led to finding PLS Friends and changing my whole life.

Talking about that small gathering in Vienna is probably what kicked off the great first large Connection in CT where so many of us that had met on line gathered to meet face to face. I think that was one of the greatest experiences of my life. Coming home, a 7 hour trip by car, I decided that was what I wanted to do with my life. I left with such a wonderful feeling that I thought there could be nothing greater than to bring together other PLSers to experience the same thing.

Thus, Spring Fling was born. With nothing formal in mind I simply went to Frank Reyerse's Data base and sent hand written invitations to about sixty-five people that I thought were within maybe 200 miles. I like to think that Joe Alberstadt was the creator of these random connections: Vienna lead to the one in CT and that started Spring Fling and Autumn in Carolina.

Spring Fling has definitely been a success. Those attending Spring Fling on a regular basis have really formed a family relationship. Somewhere along the line HSPers began joining us for the WV Connection and we have become one big happy family. Thanks to the United Methodist Women at my church our social hall and restroom are now accessible for our annual Friday night kick-off dinner.

I have gotten so used to having PLS that I suppose there are times I even forget it is there. I call that acceptance. I am now using my walker full time in the house and my scooter for anything outside. Looking back, I feel the first couple of years were the worst. Adjusting to new ways of doing things, grieving for the me that used to be, worrying and wondering what was going to happen to me, feeling all alone and scared to death I was dying and worse than that, it seemed no one cared. Add to all this the fact that I am, for all practical purposes, deaf.

I was working at a bank when diagnosed. I had two supervisors, both of whom were wonderful. They

would very subtly adjust my work so that I could stay and work. It was with great anguish that I finally filed for and received SS Disability last year.

I'm putting an addition on my house for my 85 year old mother. You (*the editor*) asked about my current challenges and biggest sources of joy. I guess they are the same. Get this house finished and put back together and get the Fling planned and get my mother moved and still be alive to talk about it! (*both have been successfully completed now*)

I often say, "It's not easy being me", but I think it is a personal choice how we handle PLS and what we do with our lives. I credit a lot of my abilities to continue doing what I can't do to two things: Growing up, my mother would always say, "There's no such word as can't" and I firmly believe, "most people are just about as happy as they make up their mind to be."

Need Help Finding a Neurologist?

There are several good sources of information regarding physicians who diagnose and treat PLS and HSP.

First, try the Muscular Dystrophy Association's list of clinics and research centers at www.als-mda.org/clinics/alsserv.html#n.

Also try the ALS Association's list of both certified centers (<http://tinyurl.com/42suz2>) and regional clinics (<http://tinyurl.com/4765jb>).

Lastly, try the physician directory at We Move (<http://www.wemove.org/TCD/adult.asp>) for adults and (<http://www.wemove.org/TCD/> for children.)

"Renewal and Awakening"

By Mari White

"The day scales were removed from my eyes-suddenly light was able to seep in, my life began to slowly take on color- the day my sons were born. It's a slow moving process. It is up and down, back and forth; clouds come and go, some days are more pristine than others. My understanding, ever changing, comfort and no comfort, past present, and future blend and blur life's hues. Experiences blur and blend. Often we don't recognize it when it is in front of us. It can be disguised to us as the winged angel. Life is so vitally alive, if you only look. Everyone is to be celebrated. God does not make mistakes. Things do not just happen.

One must look outside the blinders, the box, take risks, and make mistakes. One cannot avoid fear. One must celebrate fear because knowledge comes from fear.

I would never change my sons yet I have learned to change myself. Hopefully the sun will rise in them and they will celebrate their uniqueness. Life is an open, infinite, ever changing opportunity. One must remove their scales to see it, to feel it, to experience it. One must be willing to wear fluorescent pink in a dark world. One must shimmer and shine like dew drops first thing in the morning. It is the dew that washes away the darkness of night and awakens the soul. It is the willingness to laugh at (and with), accept, and celebrate our own life and that of all other people everywhere."

Learning to Fall Song and Video

Contributed by Tom Connolly

Musicians Lowen and Navarro have been together for years. Eric was diagnosed with ALS some years back. He is an incredible singer and songwriter, as is Dan Navarro. The video is a party they held at their recording studios in Santa Clarita, and the chorus of patients, family and friends they put together to record this song. Every time you click on the link or send it to a friend who clicks on it, \$2 is contributed to Augie's Quest and ALS research (*that would be ALS TDI*). So click on it. You are not charged anything, but it is logged and the gift comes from the site. Keep clicking. <http://www.whatkindofworlddoyouwant.com/videos/view/id/88461>.

Committee on Disability Issues North of Vancouver, BC

Contributed by Jean Chambers, Canada

I have been a member of our Advisory Committee on Disability Issues on the North Shore since Oct. '05. The first week of June is National Access Awareness week, with Saturday, June 7 being the really big Access Awareness Day. We arranged an Access Awareness event last year for the mayors and councilors of our three municipalities - it was terrific - held at a local bus depot. For mobility, the mayors and councilors had to use a motorized wheelchair to get on and off a bus. Then they had to do it again with a blindfold on. They listened to a recording that was distorted and try to answer a questionnaire on what they heard (very little) - then they heard the same recording adjusted to sound as it would in a room with 'looping' installed. They tried to speak with a mouthful of marshmallows, to read a sentence that had been distorted with joined words, differing texts etc;

to mimic learning disabilities or cognitive impairment; they went in and out of the washroom in a motorized chair and then again with a blind fold. All these things were done with dried beans in their shoes, to mimic chronic pain.

It has been such an eye opener for me to work with people of such varied disabilities.

Miami Institute for Human Genomics Genetic Studies of HSP

The Miami Institute is looking for individuals and their families who would like to participate in Hereditary Spastic Paraplegia (HSP) research. The purpose of the research study is to identify genetic factors that contribute to (HSP). Any individual with a Hereditary or Familial Spastic Paraplegia (HSP/FSP) diagnosis and, if willing, selected family members of the individual; can participate. Participation is free of charge. Travel to the University of Miami is not required.

Trained staff from our team will perform a family and medical history interview, focused neurological exam, review of your medical records related to HSP, and a small blood sample (*about 2 tablespoons*). We maintain the highest standards of confidentiality for all. If you are interested in participating, please contact the HSP study coordinators at 1-877-6UM-MIHG (877-686-6444) (toll free). You may also email us at mihgHSP@med.miami.edu Please visit our web site at www.mihg.org for more information.

Opportunity to Participate in Research

Massachusetts General Hospital is seeking individuals to participate in a specimen collection study enrolling under the direction of Drs. Merit Cudkowicz and Swati Aggarwal. MGH has asked both persons with HSP, PLS, and controls to participate.

The purpose of the research study is to collect blood samples from healthy subjects, and both blood and cerebrospinal fluid (CSF) samples from people with amyotrophic lateral sclerosis (ALS), pure lower or upper motor neuron diseases, as well as other neurological diseases that may mimic motor neuron disease. Through comparison of these samples, the researchers hope to learn more about the underlying cause of ALS and find unique biological markers that could help develop new therapies.

Participants must be at least 40 years of age and be able to answer brief questions about their medical and family history, as well as be willing to have blood and/or CSF drawn for the study. If interested, please contact one of our coordinators at 617-726-0563 or e-mail us at groyce-nagel@partners.org . Interested participants may also contact the Massachusetts General Hospital Neurology Clinical Trials Unit for more information about this study at mghneuroclinicaltrialsunit@partners.org or toll free at 1-877-458-0631.



Bob Swain and Waldo



Debbie Berish, SP Chat Room Facilitator

Caregiving

Good Days/Bad Days: A PLS Spouse's Perspective

Contributed by Doug Brand.

My wife is a PLS person and a classic example of how grit and fierce determination are valuable coping mechanisms.

Flora began to exhibit symptoms in the mid-90's and like many of you, we began the arduous and frightening task of trying to zero in on exactly what was wrong with her. As this was about 15 years ago, finding a physician who could even spell PLS was a challenge. For the first few years, she bravely endured all the tests, pokes, scans and second-guesses involved in arriving at a differential diagnosis. We bounced from one specialist to another until we landed with Dr. Mike Franklin who made the call. During this period, we were filled with the usual mix of emotions and unanswered questions. Was it fatal? How long did she have to live? How was this going to impact our future? Were we going to be able to get through this together?...and thousands of other mind-spinning notions. For certain, life as we knew it was changed forever and we were facing a huge adjustment in the years to come.

We both dealt with these feelings in different ways. After all, we had just hit a brick wall as 90 mph. However, as things began to settle in we landed on a very basic, simple fact of life..." it is what it is". She has it, it's not going away, it most likely will get worse and (at present) there is no cure. This is all defined in one word-ACCEPTANCE.

I have a tendency to jump in when not invited, do things Flora would prefer to do herself, make decisions for her that are contrary to what she wants or needs and a host of other stupid blunders. I need to be reminded that she wants to embrace as much of her independence as she can, and my involvement in her business and daily routine denies her those simple pleasures. Sooooooo, I try as best I can to remain on the periphery of her world and await the nod if she needs my help. Another hard lesson in acceptance

Flora gives up nothing without leaving claw marks. Ordinary tasks that used to take a few hours, now may take a day. That's OK. She's managed to modify her routine to match her abilities and find inventive ways to accomplish just about anything she tackles. Only through acceptance has she been able to make the best of a very difficult situation.

We still have our moments and battle over trivial things. That's mostly due to pent up frustration and anxiety. Patience wears thin and feelings get hurt-I guess that comes with the territory. I for one, wound easily and heal slowly, so I understand the "acceptance pill" is tough to swallow at times. When I replay the tape, 99% of the time it's something I did that shouldn't have been done...or something I should have done, but didn't do...and so it goes.

We are all casualties in this life changing event and the survivors are the ones who accept their limitations and make do with what they have. True acceptance will help identify what you can do and new ways to do it...and what is completely and totally beyond your control. I suggest leaving the second part to medical science and your higher power, so you can concentrate on what is manageable in your life. Pity Parties? Those too come with the package. I've found the key in not to stay in them. Stomp your feet, scream out loud, kick the couch and punch the pillow...and as has happened to me...hand someone their head if necessary. Release it, get it out, get over it and move on. Easier said than done? Yes, of course. I don't mean to downplay any of this. But accepting the "givens" can reshape thinking, attitudes, stress levels and maybe make the day a little more tolerable.

Caregiving Insight from the National Conference

Contributed by Craig Gentner



Approximately 30 people attended the Caregiver Session hosted by me. This was an open forum intended to share concerns, issues, feelings and helpful ideas. I used a few poems from Thurza Campbell's book Carpe Diem to stimulate conversation.

The more we talked the more we all realized that regardless of the disorder of our spouse, or friend we all have similar issues, concerns and feelings. Some look at it from the negative side--why me? While others look at it from the positive side--how can I help? The open discussion by the group of both positive and negative comments, helped in the process of understanding of how to improve one's role as a caregiver.

Medical Updates

Betsy Baquet, Editor

Since the last issue of Synapse, new milestones in research have been reached, with one of SPF's own scientists leading the charge to further understand the cause of motor neuron disease and to develop new drug therapies to slow progression or prevent onset. A clinical trial is underway using a drug already approved by the FDA, while results on another clinical trial have been reported. Stem cell researchers set the bar higher with alliances forming between industry leaders to empower scientists to speed up delivery of potential drug therapies for motor neuron disease.

SPF Funded Scientist, Dr. John Fink, Discovers

New HSP Gene:

Dr. John Fink, Dr. Shirley Rainier and their colleagues at the University of Michigan discovered a gene associated with a complicated form of autosomal-recessive HSP that causes wasting of the muscles of the hands and feet, accompanied by the usual symptoms of HSP. The name of the gene is NTE, neuropathy target esterase. The protein expressed by the gene is involved with a type of chemically caused neurodegeneration. This lends further support to the theory that organophosphorus compounds contribute to motor neuron disease. This discovery provides another avenue for better diagnosis, as well as research for effective therapies.

Source: <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4451>

Dr. John Fink Leads Team of Scientists in Discovery of Possible Link Between Motor Neuron Disease and Toxic Substances:

A team of University of Michigan scientists, led by Drs. John Fink, Shirley Ranier and James Albers, has gotten a step closer to figuring out the cause of some motor neuron diseases (MND), which can lead to the development of therapies to treat or prevent MND.

During the team's recent discovery of the NTE gene's role in the cause of a previously unknown type of Hereditary Spastic Paraplegia, an even more intriguing discovery was made. They found that mutations in the NTE gene also caused changes in a protein that is already known to be involved in MND resulting from exposure to environmental toxins called organophosphates. These neurotoxins are commonly used in solvents, insecticides and nerve gas agents.

According to Dr. John Fink, "We speculate that there may be gene-environment interactions that cause some forms of motor neuron disease....Our findings support the possibility that toxic organophosphates contribute to motor neuron disease in genetically vulnerable people." He believes the results suggest that altered activity of the gene found in patients in the study may also contribute to other motor neuron diseases, possibly including ALS. The findings are an exciting first step in uncovering a possible link between the environment and motor neuron disease, says Dr. Shirley Rainier.

Dating back to the 1930's, there have been numerous incidences of neurological disease directly linked to exposure to toxic organophosphates. Most notable is the "Ginger Jake" incident when over 50,000 people developed neurological disease after consuming a beverage called Ginger Jake, which contained organophosphates. More recent cases, numbering in the tens of thousands, have been reported in Fiji, India and Africa due to accidental consumption of oils containing these neurotoxins. Although scientists don't yet know the exact manner in which toxic organophosphate exposure leads to progressive and permanent nerve damage, they have learned that this process involves disturbance of the enzyme, NTE, contained within nerves.

Next, Fink and his team want to learn if mutations in the NTE gene happen in other types of motor neuron disease such as ALS, and if the mutations make a person more vulnerable to neurological damage from organophosphate exposure. Fink's lab is currently using fruit flies as a model to study the NTE mutations, with the goal of finding treatments for people with motor neuron disease.

SOURCE: University of Michigan Health System (2008, March 21). "Motor Neuron Disease and Toxic Substances: Possible Link?" Science Daily. <http://www.sciencedaily.com/releases/2008/03/080320163109.htm>

Muscular Dystrophy Association (MDA) Supports First U.S. Trial of Lithium in ALS:

A MDA-supported clinical trial of Lithium is set to begin with ALS patients. Lithium carbonate is an existing medication currently used to treat bi-polar disorder. This trial follows reports from a study conducted in Italy that Lithium may dramatically slow the progress of ALS.

The goal of the U.S. study is to confirm or refute the findings of the Italian trial conducted by Francesco Formai and the University of Pisa. The result's Dr. Formai's study showed the Lithium dramatically delayed progression all 16 trial participants who were given daily doses of Lithium.

The MDA trial will enroll 100 participants who will take daily doses of Lithium for 12 months. During and after the trial, scientists will compare changes in the ALS Functional Rating Scale (Revised), or ALSFRS-R, to those patients who participated in a recent ALS study that received a placebo. By using historical placebo data, it enables all participants in the Lithium study to receive the drug.

"The results of the Italian Lithium study were the most positive findings ever reported for ALS," says Dr. Robert Miller who is the lead investigator on the U.S. study and Director of the Forbes Norris MDA/ALS Research Center at California Pacific Medical Center in San Francisco. "We really need to know that it's real, and this study should give us that answer."

SOURCE: http://www.als-mda.org/research/news/080507als_lithium_trial.html

Blood-Spinal Cord Barrier Breaks Early in ALS:

MDA research grantees M. Kerry O'Banion, University of Rochester Medical Center, and Severine Boillee, University of California-San Diego, has found that leaks in the blood vessels of the spinal cord precede damage to the nervous system in ALS mice. Where SOD1 genes were mutated, there was a disruption in the barrier between the spinal cord and the bloodstream that normally protects the central nervous system from toxins and injury.

“Genetic or pharmacologic intervention targeted specifically to the lining of blood vessels (endothelium) will help to determine both the causality between the blood-spinal cord barrier leakage and motor neuron degeneration and how such damage may delay disease onset and/or progression,” the researchers note. (These experiments were conducted in mice with SOD1-related ALS. Their meaning for ALS resulting from other causes is unknown.)

SOURCE: www.als-mda.org/research/news/080408blood-spinal_cord_als.html

Reprogramming Stem Cells with Drugs:

Last year, scientists from Japan and the U.S. revolutionized stem cell research when they demonstrated that adult skin cells could be reverted to an embryonic state through genetic alteration. This diffused the ethical debate on the collection and use of embryonic stem cells for scientific research and cell replacement therapies. One drawback to the research was that by genetically altering the adult cells, it limits the cells' potential use in humans.

Scientists are now reporting that they can use drugs rather than genes to revert adult skin cells to their embryonic state. Doing so eliminates the need to use viruses and the cancer gene to revert skin cells. Dr. Sheng Ding, Associate Professor and stem cell biologist at Scripps Research, believes that chemical cocktails will be used someday to reprogram cells for cell-based therapy.

SOURCE: “New Research Brings Stem Cells One Step Closer to Clinical Use.” Emily Singer. *Technology Review*, MIT, June 5, 2008. <http://www.technologyreview.com/blog/editors/22082>

Clinical Trial of High Dose CoQ10 in ALS Yields Disappointing Results:

Two of the contributing factors in the progression of ALS are impaired mitochondrial function and the accumulation of free radicals. CoQ10 was thought to be a promising treatment for ALS because not only is it a mitochondrial co-factor, but it is also a powerful antioxidant with the capability of neutralizing free radicals.

The Neurological Institute of New York Columbia University, funded by the National Institute for Neurological Disorders and Stroke (NINDS), conducted a Phase II Trial of CoQ10. Although it is only during a Phase III trial that scientists can conclusively determine whether the potential drug is an effective treatment; Phase III trials are very large, very expensive and take a very long time. Therefore, it was

decided that a Phase II trial would better enable scientists to obtain preliminary answers quickly and determine whether a Phase III trial is worthwhile.

The primary results suggested that CoQ10 at 2700 mg. daily is not promising enough to warrant further studies as a treatment for ALS. The differences between the CoQ10 group and the placebo group were not significant enough. This suggests that a Phase III trial would yield the same results.

These results are disappointing, but are still helpful to the ALS community. Because a Phase II trial was conducted, less research dollars and resources were used, making them available for more promising drug trials. This information will also help ALS patients to rethink their needs for CoQ10, which can be expensive.

Source: <http://cpmcnet.columbia.edu/dept/als/newsletter/spring-08/coq10.html>

ALS Patient Advocacy Groups Team Up with Biotech and Drug Companies to Use Stem Cells in the Fight Against ALS:

California Stem Cell (the biotech company), the ALS Association and BioFocus, a U.K. subsidiary of Galapagos, the Belgian drug discovery company, have joined forces in the fight against ALS. With funding from the ALS Association of up to several million dollars, this collaboration will use motor neuron cells already created from embryonic stem cells to speed up the discovery of new drugs.

California Stem Cells ability to deliver large quantities of human motor neuron cells is “a valuable new tool to use in the drug discovery process,” says Dr. Lucie Brujin, Science Director at the ALS Association. “We’re very excited about what this can do for us.” The research process should take about a year, and should allow BioFocus to come up with a handful of drug targets. The next steps would be to determine if they translate into good drugs and, if so, develop a drug aimed at one or more targets.

Also collaborating are New York based charity Project ALS, Columbia University and the Harvard Stem Cell Institute. The Columbia and Harvard researchers have already made billions of motor neurons from embryonic stem cells and hope to begin using them in drug screens this year, says Valerie Estess, Project ALS Research Director. Project ALS and Harvard cellular biologist Kevin Eggan are also making progress reprogramming the skin cells of ALS patients to become motor neurons.

The use of motor neuron cells from human embryonic stem cells, as opposed to using motor neurons from mice or rats, will provide scientists with much better disease models that represent human disease more accurately and will allow them to screen drugs more effectively.

SOURCE: “How Stem Cells Could Fight Lou Gehrig’s Disease.” Kerry A. Dolan and Robert Langreth. *Forbes.com*, May 28, 2008. - http://www.forbes.com/2008/05/28/stem-cells-als-biz-healthcare-cz_kd_rl_0528medtech_als.html

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Annette Lockwood*



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*Marlene, Kathi, Sue Me,
and Jean Chambers*



*Linda Gentner
with a Tote Bag*



*Kris Brocchini
with Ben Franklin!*



*Conference Planner,
Anna Bonnani*



Dinnertime!