

Synapse

Volume 12, Issue 2 Spring, 2009

Newsletter of the Spastic Paraplegia Foundation

President's Letter:

AN EXCITING YEAR AHEAD!



Mike Podanoffsky
SPF President

We are in a very busy and exciting period for the Spastic Paraplegia Foundation. I have a great deal of good news to share with you, none of which would have come about without your generous donations.

The National Convention will be held in St. Louis on June 12 and 13, 2009. We have changed the focus to be more about you the patient and less about the medical research. Register before May 1 to save money (see links below). I hope to meet many of you at the National Convention

SPF Board Transitions - SPF held officer elections at its March board meeting. Jim Campbell was elected to the board. All of you know the wonderful work that Jim and Thurza Campbell have done for SPF throughout all of these years. Long time board member Annette Lockwood, which I am sure many if not all of you know from her long and wonderful work with SPF has decided to not remain on the board. She wants to pursue other interests. I want to thank her for her distinguished and selfless dedication to SPF. Jim Sheorn retired as President. I want to thank Jim for the wonderful work he has done for SPF while he was President. As the new president, you can read a brief bio of my experience on the SPF web site (see links below).

Fundraising - We are going to place an emphasis in revitalizing fundraising in order to achieve the foundation goals of funding research, providing support, or education. We will do this by increasing our visibility and improving how we raise money. We will focus on revitalizing TeamWalks as well as look at other ways in which we can raise funds.

(continued)

2009 National SPF Conference June 12 - 13, 2009

St. Louis is centrally located and rich with history and culture. People affected by PLS and HSP will contribute to that experience and enjoy the sights and sounds of a uniquely American city during the 2009 National Conference of the Spastic Paraplegia Foundation, June 12-13.

Conference participation this year is expected to approach 200. In addition to scientific discussions, Conference Chair, Tina Croghan, and Program Chair, Jim Sheorn, promise plenty of social opportunities and sessions that are entertaining and interactive.

Keynote speaker John K. Fink, M.D., of the University of Michigan will talk about research and how new discoveries may improve the lives of people with PLS, HSP, and related disorders. Dr. Fink serves on the SPF Medical Advisory Board and is a recipient of SPF research awards.

The conference will begin with Friday night with the SPF Welcome Dinner. Cocktails will begin at 6 p.m. and dinner at 7. The evening will have a limited program, allowing plenty of time to relax and mingle. The dinner is \$35.

Conference presentations and exhibits on Saturday will include the latest on HSP and PLS research, physical rehabilitation, spasticity management and treatment options, and adaptive/assistive devices.

The conference fee is \$55-65 per person, which includes the conference, handout materials and lunch. Check-in will begin at 8 a.m.

After the conference, some participants will head to a Saturday dinner outing at a local restaurant while others will make their own evening plans.

The Renaissance St. Louis Hotel Airport has a limited number of fully accessible rooms with roll-in shower areas. Early registration is strongly encouraged for those with special needs. To register, visit www.sp-foundation.org, or mail in the registration form which is in your flyer.

President's Letter Continued

Grants -The core function of the SPF is its research grant awards. This year, the board has determined that it will award approximately \$300,000 for research. This is roughly the same amount that was awarded in prior years.

Updates on important happenings – Please read the detailed articles on pages 3-5 which report on February 2009 PLS Awareness Month, how you can help pass H.R. 804 which would provide \$2,000,000 to National Institutes of Health with respect to PLS in 2010 through 2014, and enjoy reading about Annette Lockwood's attendance at the National Press Club.

Upcoming therapy trial – The first article in the Medical Updates on page 13 describes the human trial which is to be funded in part by SPF. This is what all of us have been waiting and hoping for, the day when therapies would be available. To be both cautious and realistic, this is the first of its type of therapies. We hope for the very best success for the patient.

Funding Synapse - I am going to ask that each of you who reads this publication to help defray the costs of printing and mailing. This is a wonder information tool and none of us want to see its costs take away from research. If you have not made a donation to the SPF in 2009, please make a donation today, using the enclosed envelope.

*Mike Podanoffsky,
SPF President*

For links mentioned in this publication, go to:
<http://sp-foundation.org/synapse/0309>.

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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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Published quarterly for the HSP/PLS community
Available online at www.sp-foundation.org

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SP Foundation News

PLS Awareness Month

This February marked the first-ever Congressionally-designated PLS Awareness Month. Throughout the month of February SPF members across the country increased outreach efforts in social networking, media exposure, additional support from other not-for-profit organizations and Congressional meetings in Washington, D.C. Here are success stories from the 2009 PLS Awareness Month:

Media Coverage



*The media coverage on PLS Awareness Month surpassed our expectations. We developed a press release that received worldwide publication. Our PLS Awareness Month media kit provided background information on PLS and SPF, encouraging local media outlets to tell the

PLS story and recognize February as PLS Awareness Month. Many SPF representatives across the country distributed these media kits to their local media outlets.

*SPF also developed thirty-second Public Service Announcements that aired nationwide on the CBS Television Network. These PSAs were produced by Atek Media at no charge thanks to Cheryl Brown (Thanks Mrs. Brown!).

*The SPF logo makes its big debut in Times Square!
*SPF's Oklahoma Ambassador Mark Dvorak was interviewed about PLS Awareness Month on TV station KSBI. Mark did a fantastic job advocating on behalf of PLS.

*Hardy L. Brown, co-publisher of Black Voice News, helped promote SPF and PLS Awareness Month through the Brown Publishing Company and Blackvoicenews.com ran several articles on behalf of SPF to promote PLS Awareness Month. Mr. Brown is constantly working to promote awareness of neuromuscular diseases and we are grateful for his dedication to SPF.

SPF Expands Social Network

SPF's social network significantly grew during PLS Awareness Month. We re-invigorated our SPF group on the popular social networking website Facebook enabling more members to communicate via Facebook about PLS. The PLS Awareness Month cause now has over 560 members. Be sure to tell your friends to join the cause on Facebook.

Not-for-profit Supporters

The National Education Association provides educational information for teachers to use as a resource when developing educational lessons for their students. In conjunction with Black History Month, National Education Association posted information on PLS and Hardy Brown, the honoree from PLS Awareness Month. Both the American Neurological Association and the American Academy of Neurologists posted information on their website about PLS Awareness Month. During the month of February, the American Academy of Neurologists posted a link on their homepage highlighting PLS as the Disorder of the Week.

SPF Board Member Meets with Congress on Capitol Hill

On Thursday, February 19th, 2009 SPF Board member Larry Asbury and members of the Tiber Creek staff held a series of meetings on Capitol Hill to garner support for H.R. 804 from new sources and to use our old friends to continue to advance the cause of SPF in Washington and nationwide. H.R. 804 directs the National Institutes of Health to increase research into Primary Lateral Sclerosis by \$2 million over the next 5 years and requires the director of NIH to "expand, intensify, and coordinate research activities."

Our initial meeting was with Laura Hooper-Broyles of Congressman Mel Watt's office. Mel Watt (D/NC), is a subcommittee chairman on Financial Services and a member of Congress since 1993 who has experience on a broad array of issues. His staff seemed very receptive to our requests and she said she will discuss sponsorship of Congressman Baca's bill with her boss upon his return to DC.

We then met with Lisa Salerno of Congressman Jim McGovern's office. Congressman McGovern (D/MA) is the Vice-Chair of the House Rules Committee.

Lisa was great, very helpful and concerned about the needs of our organization. Congressman McGovern is already a cosponsor of our bill and Lisa was very helpful offering to take the lead speaking with other members of the MA delegation and providing assistance on an as needed basis.

We had a significant meeting with Brenda Villanueva of Congressman Baca's (D/CA) office. We don't need to tell you how instrumental he has been to our cause. We spoke extensively about creating letters for programs which increase SPF awareness as well as the Congressman's efforts to further connect with other members on the House floor.

Finally, we met with Congressman Van Hollen's (D/MD) office and spoke with Ray Thorn. Ray was very interested in our issue since their district holds NIH. Congressman Van Hollen is a member of Democratic Leadership and carries a lot of weight with freshmen and newer members. We hope that Ray will pass along a favorable recommendation to his boss that will lead to his support.

It was an effective legislative activity day. Larry represented the board very well and we look forward to implementing the ideas brought up yesterday and seeing these members sign onto our bill.

Please Help Get Cosponsors for H.R. 804

Now that Congressman Baca (D-CA) has introduced H.R. 804, and that Larry Asbury from the SPF Board has gone with the Tiber Creek staff to Capitol Hill to advocate for support, it's our turn to advocate. We encourage SPF members, patients, friends and family members to contact their representatives in Congress to support this bill. H.R. 804 directs the National Institutes of Health to increase research into Primary Lateral Sclerosis by \$2 million over the next 5 years and requires the director of NIH to "expand, intensify, and coordinate research activities."

As of this writing these Reps. Have become cosponsors:

Rep. Barrow, John [GA-12] - 3/3/09
Rep. Bordallo, Madeleine Z. [GU] - 3/3/09
Rep. Connolly, Gerald E. "Gerry" [VA-11] - 2/23/09
Rep. Green, Gene [TX-29] - 2/10/09
Rep. Grijalva, Raul M. [AZ-7] - 3/5/09
Rep. McGovern, James P. [MA-3] - 2/10/09
Rep. Meeks, Gregory W. [NY-6] - 3/3/09
Rep. Scott, Robert C. "Bobby" [VA-3] - 2/23/2009

If your Rep. isn't on this list please go to <http://www.sp-foundation.org/events-HR804.htm> or click on development@sp-foundation.org. for the complete details of how to locate your U.S. Rep. as well as suggested letters to write. Your personal stories and experiences are important. Share them. Be as personal as you feel comfortable. And remember that each of these Senators and House Members owe their current position to the people who elected them. They work for you.

Making Rare Diseases Common Knowledge

February 28th, 2009, marked the first observance of Rare Disease Day in the United States and the second for Europe. A disease is considered rare if it affects fewer than 200,000 people. As we all know, HSP and PLS fit that bill. Currently, there are more than 6,000 rare disorders that, taken together, affect some 25 million Americans.

The focus for this year's Rare Disease Day was quality, patient-centered care. The European Organization for Rare Diseases published a book entitled "The Voice of 12,000 Patients". It explores the patient's perspective, offers anecdotes, and provides the results and analysis of data collected through the EurordisCare2 and EurordisCare3 surveys. An executive summary of the surveys is available at www.rarediseaseday.org.

Stateside efforts were organized by the National Organization for Rare Diseases or NORD. Thanks to its efforts, more than 220 organizations, agencies, and companies signed on as Rare Disease Day Partners to promote awareness of rare diseases. In addition, NORD asked those affected by rare diseases to contact their governor's offices to request that February 28th be declared Rare Disease Day in their home states. In an impressive inaugural effort, 38 of the nation's 50 states came through, along with the cities of Chicago and Wooddale, Illinois.

Jane Anne King of Georgia, who has HSP, was SPF's point person on this initiative. Thanks to her support and cajoling, our community was responsible for 13 of the 38 state proclamations:

Connecticut—Dolores Carron and Mary Lau
Georgia—Jane Anne King
Indiana—Lisa Sorg
Iowa—Jackie Wellman
Kansas—Mari White
New York—Virginia and Skip de Leonard
North Carolina—Sarah Witt

Oklahoma—Mark Dvorak
South Carolina—Owen Bridgeman
Tennessee—Jim Sheorn
Texas —Marlene Doolen
Virginia—Joan Westbrook and Annette Lockwood
West Virginia—Ronnie Grove

Annette Lockwood at the National Press Club



SP Foundation Board Member Annette Lockwood attended a landmark conference on Friday, February 13th at the National Press Club discussing the new administration. The event was hosted by the Georgetown University

College of Continuing Studies.

As the United States experiences a historic change of administration, Annette submitted questions and listened to speakers from both sides of the aisle sharing valuable insight on the key issues that face all Americans during the transition into a new administration.

Topics included:

- The 100 day agenda
- Foreign policy changes
- Response to the financial crisis
- The new domestic agenda
- The goals and priorities of the 111th congress

Annette sat at a head table as she listened to comments from Maryland Congressman and Majority leader Chris Van Hollen, a unique insight from the Editorial staff of The Politico Newspaper, perspectives from Capitol Hill presented by California Congressman Dan Lundgren and a keynote address by former White House Press Secretary, Senior Advisor and Media pundit George Stephanopoulos.

The highlight of the event was clearly Annette's introduction to Mr. Stephanopoulos in the VIP room. As Annette was introduced, Mr. Stephanopoulos expressed interest in the efforts by the Spastic Paraplegia Foundation. Annette represented the organization very well as she discussed the mission and the vision of the group while highlighting the successes as well as the need for more media support and promotion towards finding a cure.

Michael Hayden named Canada's "Researcher of the Year"

By *ANDRÉ PICARD, Globe and Mail*

Ed. Note: Dr. Hayden was the recipient of SPF funding several years ago to be used in research in PLS.



When Michael Hayden was named Canada's "Researcher of the Year" by the Canadian Institutes for Health Research it was hardly a surprise. He is, after all, one of the world's most renowned geneticists, having identified the genes responsible for a number of disorders - including

Huntington disease, amyotrophic lateral sclerosis (ALS or Lou Gehrig disease), type 2 diabetes, and pain — and the founder of three successful biotechnology companies.

But it is what Dr. Hayden, director of the Centre for Molecular Medicine and Therapeutics at the University of British Columbia, did with the \$500,000 prize money that surprised and inspired his colleagues: He donated the entirety to a charity that will train aspiring doctors and researchers, particularly those from Africa.

"At first, I wasn't aware money came with the prize," Dr. Hayden said in an interview. "But when I found out there was half a million dollars, I decided that I have to be a curator, I have to use this to honour the opportunities that have been given to me and help provide opportunities to others." Using the prize as seed money (*and having raised almost \$3-million more in the past six weeks*), he has created a foundation called Ripples of Hope. The foundation will bring trainees to Canada to study in four areas: global health (HIV-AIDS and tuberculosis in particular), mental health, rare diseases, and biotechnology and entrepreneurship.

"Each of these awards reflects an aspect of my past and encompasses the future," Dr. Hayden said.

SYNAPSE APPEAL

Synapse costs lots of money to print and mail, and we need your help to keep it going for another year. Please use the enclosed response envelope to make a donation. Every little bit helps.

Events

Edited by Sarah Roberts-Witt

Salt Lake Valley, UT, Lunch Connection

Submitted by Linda Gentner

The snowy afternoon of December 14, 2008, provided the perfect backdrop for the first Salt Lake Valley Luncheon Connection. We had a lively communication session with newcomers asking many questions about HSP and the SPF. Connie Duran and Geneva Miera fielded their HSP questions, and Linda Gentner talked about the SPF, its web site, and the 2009 National Conference. She also did a short presentation on 2008 events and the 2008 National Conference. Linda's husband Craig provided more details about previous conferences. By the end of lunch, Connie and the Larson family had started making plans for holding a TeamWalk or some other kind of a fund raiser next summer in the Salt Lake City Area. Pictured here are Curt & Katie Brown,

Jonnie Larson (from Idaho), Mrs. Larson (from Spoke, WA), Linda & Craig Gentner (from CA), Geneva Miera, Connie & Roy Duran; and Dr. John Larson.



St. Petersburg, FL, Lunch Connection

Submitted by Kathi Geisler

A lovely Lunch Connection was held at the home of Jeff Litt on February 15, 2009. We were fortunate to have two exciting opportunities: an Ask the Doctor session, featuring Jeff and Flora's neurologist, Dr Michael Franklin; and an Ask the Pharmacist session, featuring Jeff, who is a registered Pharmacist. There was a lot of discussion about PLS and HSP as they relate to one another and to ALS, as well as sharing about personal stories, treatments and managing life with these conditions.



Windsurfing Fundraiser Surpasses its Goal

Contributed by Darran Rolls

In early March the Austin Windsurfing Club race committee headed off to Florida to attend the Calema Midwinters.

The Midwinters is one of the best international race events in the northern US. It's on the official US National Windsurfing Race Tour and hosts some of the best windsurfers in the world. It's a true windsurfing festival with demos, freestyle, formula, SUP and Kona class racing to boot.

To make the trip worth while, we've decided to try and raise some money for the Spastic Paraplegia Foundation on the way. We'll be covering all our own travel and event costs, but ask that you all join us in raising \$\$ for this charity. When the \$1,000 goal was met by February 20, the goal increased to \$2,000. The donation amount is now at \$1,415!! Many thanks to Marlene Doolen for all of her SPF work with the Austin Windsurf Club.

<http://www.austinwindsurf.org/>



Upcoming Events

New England Spring Forward Seminar

April 4, 2009, 10:30 am – 3:00 pm

Sheraton Hotel, 1657 Worcester Rd.

Framingham, MA

Kathi Geisler: kathi@kgeisler.com, 978-204-7432

The New England Spring Forward Seminar will feature Rob Redden, MD, who is a primary care physician with HSP. Rob will share his story of managing life with HSP and will also facilitate a Q&A session around symptom management. In addition, Mary Cooper will lead a chair yoga session. Mary took the Chair Yoga certification class at Kripalu and has been an Adapted Physical Education teacher for 25 years. Registration is \$24 per person. Lunch will be served.

(Continued next page)

Spring Fling
May 1-2, 2009

Berkeley Springs, WV

Ronnie Grove: frogrove@verizon.net

Program details are currently being worked out. For those interested in attending, rooms are available at Best Western for \$69/night. Call 304-258-9400 and ask for a room under Spring Fling.

A special note from Ronnie: Make a special mark on your calendar for Spring Fling 2010. This will be Spring Fling number 10 and I hope to make it really special by having a "Homecoming Event" or a Ten Year Reunion. I hope to entice all of those who have attended over the years plus those who have wanted to attend. This should be a very special Connection so I am giving you plenty of time to plan. I may even recruit a few of you if you aren't on the volunteer list, so be prepared.

2009 National Conference

June 12-13, 2009

St. Louis, MO

Plans are well underway for the 2009 SPF National Conference. Dr. John Fink from the University of Michigan will share the latest information on HSP and PLS as well as the interesting research that he is doing. We plan to bring you more interactive ways to learn and share than in the past.

A special note on accommodations: The conference will be held at the Renaissance St. Louis Airport Hotel. Call 314-429-1100 for reservations; mention the SPF National Conference for special rates. A limited number of handicap accessible rooms are available. Please call Daphne at 314-890-3151 to book one.

Magnificent Weekend

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

Raleigh, NC

September 12-13, 2009

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 as of now are Dr. Colin Bishop of the Wake Forest Institute of Regenerative Medicine; and Brian Kramer, MS, L.Ac, Dipl.Ac, CPT, of Kramer Acupuncture, who will

explain the use of acupuncture in spasticity and pain management.

The NC TeamWalk and the Magnificent Mile Races will be held on Sunday at 2 pm. They will 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.

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: https://www.medtroniceducation.com/kma/www/itb_mfl/3.listing.html or call 1-888-743-8348

2009 Teleconferences -

7 pm Eastern, 6 pm Central,
5 pm Mountain, 4 pm Pacific

April 14 - Focus on Pediatrics

May 12 - Focus on Stroke

June 9 - All Indications

July 14 - All Indications

August 11 - Focus on MS

September 8 - All Indications

October 13 - Focus on Pediatrics

November 10 - All Indications

Abilities Expo

April 17 - 19, 2009

New Jersey Convention and Expo Center
97 Sunfield Ave, Edison, NJ

May 29-31, 2009

Anaheim Convention Center
Anaheim, CA

Abilities Expo showcases the latest products and services to enhance the lives of people with disabilities.

Living with HSP/PLS

Dr. Fink Answers your Questions

Explain Differences between our Diseases

Q. *What is the difference between HSP, complicated HSP, PLS, Hereditary ALS and childhood onset ALS. Also, how much do we know about genetic causes of Cerebral Palsy? - Mari White*

A. Hereditary spastic paraplegia (HSP) refers to a large group of disorders that affect primarily the ends of upper motor neurons (nerve cells in the brain motor cortex that send their long axons down the spinal cord). To a lesser extent, there is degeneration at the ends of long sensory nerves that transmit vibration and position sensation from the feet. HSP is classified as “uncomplicated” when symptoms and signs are limited to weakness and tightness of the legs (“*spastic paraplegia*” or “*spastic paraparesis*”) often accompanied by mildly decreased vibration sensation in the toes and urinary urgency.

HSP is classified as “complicated” when, the inherited syndrome includes involvement of other areas of the nervous system (*such as epilepsy, peripheral nerve involvement, mental retardation, dementia*) or other systemic disorders.

Primary lateral sclerosis (PLS) affects the same nerves as HSP (*upper motor neuron*) but has three important differences: PLS is only very rarely an inherited disorder (as far as we know now) whereas HSP is usually (*not always*) an inherited condition; PLS affects the arms, speech, and swallowing (*these are very rarely affected in HSP*); PLS does not appear to affect the long sensory nerves that transmit vibration and position sensation from the feet.

Amyotrophic lateral sclerosis (ALS) is occasionally inherited (*10% of the time*). ALS also affects the upper motor neurons (that are affected in HSP and PLS); but in addition, affects motor nerves that begin in the spinal (“*spinal motor neurons*” or “*lower motor neurons*”). For this reason, ALS is associated with wasting or atrophy of muscles (*which may also occur in complicated forms of HSP*).

Cerebral palsy (CP) is a descriptive term indicating non-progressive motor impairment (*spastic weakness*) that is first noted in early infancy or childhood. There

are many causes of cerebral palsy including genetic disturbances in brain and spinal cord development; pre- and peri-natal infection; prematurity; very young maternal age; difficulty with the birth process; inadequate brain blood flow and oxygenation during delivery. At least one form of HSP (*due to mutations in the SPG3A/atlastin gene*) causes early childhood/infantile onset gait disturbance (*first manifest as “toe-walking”*) that usually does not worsen significantly and resembles spastic diplegic (*affecting both legs*) cerebral palsy.

How do Tests Help Diagnose HSP

Q. *Information on diagnostic tests being used to assist in diagnosis of HSP, or to rule out other disorders. - Sandra Williams*

A. Diagnosing HSP requires exclusion of other disorders including structural abnormalities of the brain and spinal cord, infections (e.g. HTLV1), vitamin deficiency (e.g. B12), and other degenerative disorders including multiple sclerosis. The exact nature of diagnostic tests depends on individual features (*for example, if lower extremity spasticity is associated with numbness in the feet*), the neurologist may obtain electromyography (EMG) and nerve conduction studies (NCS) to consider the possibility of peripheral neuropathy, either as a co-existent condition or as a feature of HSP.

Diagnostic testing for HSP is improving and can presently diagnose approximately 75% of subjects with dominantly inherited HSP; and an increasing number of subjects with recessively inherited HSP (*affecting siblings only*) and those with no previous family history of HSP. Genetic testing panels for HSP are available at Athena Diagnostics Laboratory (Boston), Medical Neurogenetics Laboratory (Atlanta), and Demours Clinic (Delaware, for PLP gene testing).

Might my Child be a Carrier

Q. *My husband and daughter both have HSP. We also have a son and two nephews with no signs/symptoms. Should there be concern that they may be carriers & may show up as they start families? - Dee Bromley*

A. If your husband and daughter have HSP, the condition is most likely dominantly inherited, although X-linked inheritance can not be excluded (*unless genetic testing identifies the causative gene mutation*).

For dominantly inherited conditions, there is a 50% chance that each child (*your son, for example*) can inherit the gene mutation. Usually (*not always*), individuals with HSP gene mutations eventually manifest some symptoms. Genetic testing may (*not 100% certainty*) be helpful: if the type of HSP in your family was diagnosable by gene testing, this information could be used to a) determine if your son had the gene mutation; and b) if so, for prenatal genetic testing if desired.

Wheelchair Tennis Anyone?

By Nancy Haggerty, *Poughkeepsie Journal*



Debbie Berish HSP remembers that first time. She sat in her car in the parking lot outside Sport & Wellness in Hopewell, stuck in one of those, “What am I doing?” moments.

But minutes later she was inside because the 43-year-old Fishkill resident long ago decided ‘doing’ is what she’s all about. Now, nine months later, Berish is happy that 80 percent of her serves are in but she’s working on developing more wrist snap to make those serves harder and, in turn, more elusive. Getting to balls is still a challenge but that’s challenging for many ambulatory people and Berish is still getting the hang of all this from a wheelchair.

Seven years ago, the mother of two was finally forced to use a wheelchair. Thank Sport & Wellness tennis director Carol Levine and thank the Women’s Sports Foundation and Eastern Tennis Association for that. The two groups, big backers of the wheelchair game, gave Levine a \$500 grant in September 2007 to start a free wheelchair tennis program.

Last May, Levine, who coaches Kyle, convinced Berish to become the program’s first player. For both Berish and Levine, a 30-year coach and 46-year player, this is all a learning process. Wheelchair rules are identical to

regular tennis, except that players may hit the ball off the second bounce. This provides added time to maneuver the chair, which is a difficult task since players hang onto their racquet with one hand while using both hands to wheel themselves to shots. “The hardest part is getting to the ball. Once I get there, I really can hit it good,” said Berish. Sports wheelchairs don’t have brakes, making stopping a problem. But Berish learned how to grab a wheel to stop and to turn.

Another early challenge was recovering from shots, since the chair will turn in the direction of any hard arm movement - a right-hand forehand, for instance, turning the chair left. So now, Berish simply follows through, spinning the chair 360 degrees with every shot, while pivoting her head “owl”-like, she explains, so she doesn’t lose track of the ball.

Berish, who characterizes her disability as “sort of a gift” because, rather than occurring in an instant, it came on slowly, allowing her to accept it, said playing shows her son that even though “Mom is in a wheelchair, she can still do things.”

Levine characterizes Berish, who runs a support group for HSP and PLS sufferers at Our Savior Lutheran Church in Fishkill, as someone who lives life to the fullest. “I love teaching anyone the game. It just inspires me,” said Levine. “And I want to give back to the game... especially to someone who I just admire.”

“With my disability, you have to fight every day,” Berish said, adding, “I don’t let it get the best of me.” Because you’re disabled doesn’t mean you can’t go out and play sports,” said Berish. “You can’t sit home feeling sorry for yourself. You’ve got to go out there and enjoy the world.”

Helping your Neurologist Help You

Contributed by Steven Stuckey - Indiana

I received my ‘Synapse’ this week and was looking through it and had a semi-bright idea. My neurologist says any time I get something new on my disease to bring it in for him to look at. With all the great information in the ‘Synapse’ this time, I put it in my bag of things I take to my neurologist to share with him.

For a little history I told my neurologist last year that I was going to go to Philly for the SPF Conference and

(continued)

asked him if I could share any information. He then told me yes and took copies of my notes. He did mention that Dr. Fink was very good (which we already knew) and anything he said we would try to implement. I also take to each appointment a journal of any thing related to my disease, Internet posting related specifically to me or my condition, my medications, and my general well being.. The better informed you are the better informed you can make your doctor.

Fiberglass Tub Cutout

Contributed by Ruth Havener

I was getting afraid I would fall stepping over the edge of our bathtub. The cutout cost was \$410 and took about six hours. A local independent guy that has done a lot of fiberglass



work did the job. He first makes a pattern sketch of the area we wanted cut and goes back to his shop for the materials. He cut the side of the tub as you can see and then reinforced the bottom edge of the tub floor with wood and epoxy that in place. From there he put in the bottom and side pieces. We had to let the epoxy set-up for a couple days before using the tub. Of course it is only for showers now and it works great.

Transitioning to a Wheelchair

by Linda Wheeler Donahue

Adapted for HSP/PLS and edited by Thurza Campbell

When actor Christopher Reeve sustained his spinal cord injury in a horse riding accident, he went immediately from Superman to Man in Wheelchair. In contrast, we HSP/PLSers usually go through a lengthy, angst-ridden decision-making process before we plunk ourselves down in a wheelchair.

We listen to the recommendation of our physicians and we sheepishly explore the idea with our loved ones. We recognize that using a wheelchair would keep us from tripping and falling. It would help us conserve our limited energy and sure would make daily life a lot easier. Why, then, is this decision so emotionally intricate and agonizing?

You now use a cane for support in walking; possibly you were fitted for a brace and/or forearm crutches. You may find that motorized shopping carts at the grocery store are a colossal help to you. But life is still much more difficult with HSP/PLS.

You may be declining activities that involve walking. You sit back and reluctantly stay home, unable to do some of the activities you once enjoyed due to increased weakness, pain, fatigue, fear of falling and lack of endurance. You stay home.

Did you once savor the fun of cruising the mall with your daughter-in-law? You stay home. You and your HSP/PLS medical professionals recognize that the time has come for you to use a wheelchair for most of your mobility needs. However, the thought of appearing in public in a wheelchair fills you with dread. You realize on a rational level that using a wheelchair would be very liberating. But that rational base is overpowered, indeed almost buried, by the negative emotional overtones that shout: "No! No! No wheelchair for me!"

Let's examine the underlying origin for this resistance. Society places an inordinately high value on walking. The wheelchair makes it virtually impossible to be a "passer," that is, to pretend you are able-bodied. Indeed, it is the image of a wheelchair that is the universal symbol of disability. Much of your self-esteem is wrapped up in the fact that you are still able to walk.

Almost universally, people who are not totally wheelchair dependent make too little use of the wheelchair, if they are willing to use it at all. Likewise, people who are gait impaired but not crutch dependent make far too little use of crutches, if they are willing to use them at all. "I'm not that disabled. I don't need it/them," are considered sufficient reasons to forego the enhanced function, ease, safety and health benefits they could have from selective use of adaptive aids.

When a HSP/PLSer chooses to use a wheelchair, he/she faces emotional, interpersonal and social issues that can be deeply troubling and anxiety producing. How my heart pounded with dread and self-consciousness the first semester I wheeled into the faculty meeting. That wheelchair gets the credit for "outing" me. I now had to admit to the world that I was, indeed, a Person with a Disability. But ever since that day... oh, the liberation that has been mine!

(continued)

It is an important healing step to act on the belief that it is OK to be you. Know that the consumerist driven, stereotyped images of “attractive” and “popular” are oppressive falsehoods rather than the truth. Consider this thought: it is stunningly appealing for a person with a disability to exhibit confidence and self-acceptance. People are not used to seeing this in someone who is disabled. When you perceive others’ positive responses and you realize these responses are to you, as you are, you will be freed.

The good news is that the stigma is diminishing. Societal attitudes about people with disabilities are vastly more accepting today than they were in the doo-wop era of the Fifties. You can trade in your negative thought patterns for powerful, new, positive beliefs. You can liberate yourself and claim your rightful place in society. If you love the comfort and ease of using your chair in private but dread the thought of using it in public, you can use the power of your human consciousness to restructure your perceptions and free yourself. Picture yourself on a swift mobility scooter at the shopping mall with your favorite friend, scooping up bargains. You can shop ‘til you drop and still have energy left over to go out to dinner at the end of your day.

Linda Wheeler Donahue is a polio survivor, Professor Emeritus of Humanities and President, The Polio Outreach of Connecticut. As a result of her grassroots advocacy work, President George Bush, Sr., invited Linda to the White House Rose Garden signing of the Americans with Disabilities Act on July 26, 1990.

Professor Donahue has published numerous articles on subjects of positive living, disability dignity and increasing happiness through conscious choices. She welcomes feedback and can be reached at LinOnnLine@aol.com



Rita DiClemente's off to shop in the new Lift-bus in Hollis, NH

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Thurza Campbell, "Synapse" editor, enjoying skiing again.

Caregiving

Expectations and Stress

By Kelly Brunn

People often ask, “What is the most stressful part about being a well spouse?” My initial reaction is “It depends on the day.” The truth is the smallest most insignificant thing can completely stress me out while things that you would think would be the most certain stress factors sometimes pass without much affect.

In evaluating why that’s the case, I discovered it all boils down to my expectations and experiences.

I get the most stressed when my expectations for the task, day, or week don’t line up with reality. Sometimes that’s because reality can be extremely overwhelming when you’re a caregiver.

Many times the “cure” for minimizing stress is reassessing the expectations and correcting them or evaluating what my control factor is in the situation.

Things that I have experienced numerous times as a well spouse, I have a much better handle on and become “routine” in my day rather than stressful. It’s the new unexpected twists that can set me off. Unfortunately, sometimes that can be an emotional reaction my husband expressed that hadn’t been present in previous situations.

I’ve learned over the years of being a caregiver that getting stressed out over things I have absolutely no control brings me down the most. Obviously the extreme vulnerabilities of being a caregiver mixed with emotional reactions can make a situation unbearable regardless of the cause.

Sometimes it’s being the wage earner in the family and feeling trapped by extreme financial obligations to provide the best care for my spouse possible.

Sometimes it’s having the lost dreams staring me in the face with an unclear view of what the “replacement dreams” might be.

Sometimes it’s feeling like a single parent when “technically” I’m not one.

Sometimes it’s knowing on a Friday night that the most excitement I can count on is television re-runs and my

spouse falling asleep at 7:30 which leaves me sitting there feeling like I’m at the end of my life rather than in the middle of it.

I’ve learned over the years of being a caregiver that getting stressed out over things I have absolutely no control brings me down the most.

Finding a quick mitigating strategy for the stress is important, regardless what the underlying source of the stress might be. What has worked for me?

- Physical relaxation (*for me a warm bubble bath at the end of the day*).
- A walk with headphones to escape the mental drain while allowing some release physically can also redirect my energy.
- A glass of wine or just a few moments alone with my journal to release the feelings can be the cure.
- Finding people to socialize with helps me feel like I’m still a whole person.

I don’t think as a well spouse we ever find a constant balance, but recognizing when the scales are tipping far too much on one side is a step in relieving the stress.

There’s no one way to endure this caregiver journey; it’s one day at a time and sometimes one hour at a time.

Kelley Brunn’s husband, Bill, suffered from multiple sclerosis. He passed away in July 2006.

Share your caregiver journey...

Send us your story or contact us about volunteering to be interviewed.

Also, we welcome submissions of drawings and poetry.

Email us-at mainstay@wellspouse.org

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WSA-Mainstay,

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Medical Updates

Betsy Baquet, editor

Scientists are geared to “spring” into action as a new presidential administration injects funding and hope into the accelerating field of medical research. Groundbreaking discoveries have been made in the fields of genetics, molecular biology and stem-cell research. Experts have advanced their understanding of molecular mechanisms and processes, and how they overlap between different neurodegenerative diseases. Regenerative therapies have been successful in animal models, and human cell models have been developed. The use of a RNA interference (RNAi) delivered via intrathecal pump has been successful in treating mice with familial ALS, and private fundraising efforts are underway for a human trial in the very near future. Advances in research show that we are firmly rooted for a period of rapid growth towards treatments and cures for many neurodegenerative diseases.

PHASE 0 HUMAN TRIAL TO BEGIN THIS SPRING



Lisa Krivickas, MD, a nationally-recognized expert in physical medicine and rehabilitation, including Amyotrophic Lateral Sclerosis (ALS), was herself diagnosed with ALS last year. In a particularly difficult and ironic turn of events, Lisa has been stricken with the very disease to whose treatment and cure she has devoted so

much of her professional energies. Dr. Krivickas has the SOD1 gene mutation, which brought about her familial ALS. Patients stricken with this particular form of ALS usually succumb in 18 months.

One gene therapy currently under development, however, has shown such promise that its creators, Craig Mello, MD, of the University of Massachusetts Medical School and his partner, Andrew Fire, PhD, of Stanford University, received the 2006 Nobel Prize in Medicine for it. The therapy, known as RNA Interference (RNAi), has been very successful in mice and is now ready for its first human test. Lisa Krivickas has courageously volunteered to be the first human test subject for RNAi. Dr. Robert H. Brown, Jr., PhD, MD, now at University of Massachusetts Medical School, as well as Dr. Merit Cudkowicz of MGH are diligently working together with Dr. Mello. This Phase 0 clinical trial, which involves surgical implantation of an intrathecal pump for continuous

infusion, could provide proof of concept for the therapy’s use in humans, paving the way for further clinical trials. If successful the RNAi trial may be the first step toward developing a cure for ALS and perhaps even the means of preventing onset for those who are at risk of developing it. After genetic forms of ALS are tested in this manner, trials could expand to other forms of neurodegenerative disease.

A SECOND MND GENE MUTATION IN ONE YEAR SIGNIFIES RAPID RESEARCH PROGRESS

A collaborative research project, involving medical experts from the U.S., Canada, the U.K. and Australia, has discovered that a mutation in a gene called “fused in sarcoma” (FUS) causes familial ALS. FUS is the second gene to be identified as a cause of ALS in less than a year, and is one of four discovered over the past 20 years. Its discovery on the heels of the TDP-43 gene is testament to the acceleration of research into the cause and understanding of disease mechanisms.

Professor Christopher Shaw of King’s College London explained, “The new gene, called FUS, is a very important clue as to what causes motor neurons to degenerate. It links in with TDP-43, which is deposited in motor neurons in 90% of all people with MND.” “The genetic pieces of the jigsaw puzzle are beginning to fit together leading us in new and exciting directions of research. There are also major implications for diagnosis and treatment.” “We are very excited about this latest discovery and the collaboration between the Boston and London research groups has been crucial in this breakthrough. It is only by understanding the fundamental disease mechanisms that we will find a cure.”

Normally, FUS protein molecules stay in the nucleus and don’t clump together. However, FUS protein molecules made from mutated FUS genes are more likely to be located in the cytoplasm, where they tend to clump together. This type of clumping (aggregation) has been correlated with degeneration of nerve cells in ALS and other conditions. In fact, the clumps are similar in appearance to those found in another rare form of familial ALS that’s caused by mutations in the TDP-43 gene.

This latest discovery will not only help doctors to counsel those families at risk of MND but crucially aid researchers to develop better models of disease. The gene FUS is shown to be related to the TDP-43 gene found by Professor Shaw’s team last year. Thanks to this development, scientists now have two more genes with which to map out the origins of this dreadful disease and develop drugs to combat it.

SOURCE: http://www.eurekalert.org/pub_releases/2009-02/kcl-asm022509.php
<http://www.als-mda.org/research/news/090227als-fus-gene.html>

RESEARCHERS SHAKE UP SCIENTIFIC THEORY ON MOTOR PROTEIN

An international team of scientists led by the University of Leeds has shed new light on the little-understood motor protein called dynein, which is thought to be involved in progressive neurological disorders such as motor neuron disease. These findings dispute existing ideas regarding the mechanisms that drive dynein's movement and function. Working with researchers from the University of Tokyo, the Leeds team has for the first time identified key elements of dynein's structure, and the mechanism by which it moves. Dynein is the largest, but least understood of the three families of motor proteins, yet it is responsible for many key processes, including the transporting of molecular cargo within cells such as motor neurons.

Dynein is poorly understood, partly because it is difficult to engineer for experimental studies and because the usual imaging techniques for determining the structure of a molecule have been unsuccessful. However, working with a synthetic molecule of dynein engineered by Japanese researchers, the Leeds team was able to identify key points within the motor and gain a better understanding of the "fuel" that drives it. Scientists were also able to view the core of the molecule. These findings will enable researchers to correct previous mistaken ideas, and determine what goes wrong and why.

Lead researcher, Dr. Stan Burgess from the University of Leeds' Faculty of Biological Sciences, says: "Motor neurons have a very complex transportation system. While the nuclei of motor neurons lie within the spinal cord, they have branches that can run the entire length of a limb, say from the spine to the big toe. This branch is like a highway for molecular motors such as dynein. If there's a disruption to the traffic, it can lead to cell death and eventually to muscular weakness, characterized in diseases such as motor neuron disease." Dynein can carry its cargo up to a meter in humans - the equivalent of humans walking about forty thousand kilometers.

The international team will build on these findings, as well as their expertise in the engineering and imaging of dynein. "By examining the structure and mechanism of dynein while it's moving, we hope to learn more about how the protein works in the cell, so we can better understand what happens when it goes wrong," says Dr Burgess.

SOURCE: http://www.eurekalert.org/pub_releases/2009-02/uol-rsu020309.php

MAYO CLINIC: BRAIN DISORDER SUGGESTS COMMON MECHANISM MAY UNDERLIE MANY NEURODEGENERATIVE DISEASES

A Mayo Clinic-led international consortium has discovered a genetic defect for a rare disorder known as Perry Syndrome, and the mechanism implicated may help explain the origins of a variety of neurodegenerative disorders, such as ALS and Parkinson's.

Researchers report that people with Perry syndrome have mutations in a subunit of the dynactin complex (DCTN1; p150glued), which is essential to the movement of molecular "cargo" inside brain cells, or neurons. In this case, the mutations meant that the cargo was being driven on a "train" that essentially had faulty brakes. And because Perry syndrome resembles many other neurodegenerative diseases, the findings suggest breakdowns along the cell's interior transportation grid may be a common mechanism underlying neurodegeneration.

Researchers say these findings on Perry syndrome may shed light on other neurodegenerative disorders. "Understanding why distinct neurons are selectively vulnerable to neurodegeneration in different brain disorders is one of the greatest puzzles in neuroscience," says the study's lead investigator, Matthew J. Farrer, Ph.D., a professor of neuroscience at Mayo Clinic. "These findings suggest that trafficking of specific cargoes inside brain cells may be a general problem in a variety of neurodegenerative diseases, depression, and other disorders."

SOURCE: http://www.eurekalert.org/pub_releases/2009-01/mc-mcb010909.php

GENETIC RISK FACTOR FOR ADULT ONSET PLS DISCOVERED

Mutations of the lipid phosphatase FIG4 are responsible for the recessive peripheral-nerve disorder Charcot-Marie Tooth 4J (CMT4J). We now describe non-synonymous variants of FIG4 in 2% (9/473) of patients with amyotrophic lateral sclerosis (ALS) and primary lateral sclerosis (PLS). A specific mutation of FIG4 (heterozygosity for a deleterious allele) appears to be a risk factor for ALS and PLS, extending the list of known ALS genes and increasing the clinical spectrum of FIG4-related diseases.

SOURCE: <http://health.groups.yahoo.com/group/PLSers-NEWS/message/4616>

HOPE FOR RESTORING INJURED NERVES: BIOLOGISTS ID GENE, PATHWAY FOR NERVE REGENERATION IN WORMS

University of Utah scientists identified a worm gene that is essential for damaged nerve cells to regenerate, and showed they could speed nerve regeneration by over-activating the gene - a step toward new treatments for nerves injured by trauma or disease.

The new study focused on regeneration of motor neuron axons - the wiry part of every nerve cell that transmits signals to other nerve cells or to cells such as muscle. The research team developed a "genetic screen" to look for genes involved in nerve regeneration. They mutated a worm gene that produces a protein named beta spectrin, which helps keep nerve cells flexible. Mutant worms lacked beta spectrin, so their nerves broke as they crawled around a culture dish.

The scientists used a method named RNA interference to suppress the functioning of 5,000 of the 20,000 worm genes - one at a time. People also have those 5,000 genes. They found the *dlk-1* gene was crucial for regeneration because every time the scientists blocked it, nerve regeneration was halted. When scientists overproduced the *dlk-1* gene, they saw an improvement in regeneration.

“We discovered a molecular target for a future drug that could vastly improve the ability of a neuron to regenerate after injury,” either from trauma or disease, says biology Professor Michael Bastiani, leader of the research team and a member of the Brain Institute at the University of Utah. “In the future, we would like to develop drugs that could activate this chain of molecular events in nerve cells and stimulate regeneration of diseased and injured nerve cells. At this point, we can’t do that. But this study gives us hope that in the future, we will have a rational approach for stimulating regeneration.” says study co-author and biology Professor Erik Jorgensen.

SOURCE: <http://www.physorg.com/news151589222.html>

ALS TDI AND ASKLEPIOS COLLABORATE ON DEVELOPMENT OF VIRAL GENE THERAPY TO TREAT ALS

ALS Therapy Development Institute (TDI) is working in collaboration with Asklepios BioPharmaceutical, Inc. on a viral vector treatment for ALS. The custom constructed Biological Nano Particle (BNP) vectors are designed using proprietary technology developed by Asklepios. ALS TDI will evaluate the BNP vectors in a tightly-managed mouse colony that is based on mutations in a specific mutated protein, which is a cause of a genetic form of disease. BNP vectors are of interest to drug development scientists because they generally do not elicit as aggressive an immune response often associated with other viruses, and have been clinically tested.

“This project is an aggressive and proactive effort to develop the safest alternative therapeutic delivery options available today,” reported Dr. Steve Perrin, Chief Scientific Officer at ALS TDI after a recent conference call with more than 140 members of the ALS community, “By focusing on developing therapeutic strategies while operating the largest discovery biology program for this disease, we are preparing to rapidly move potential therapeutics through the drug development process with today’s patients in mind.”

“Our main objective is to resolve issues that have limited successful gene delivery approaches to ALS in the past, and I look forward with a great deal of optimism to offering this initial step toward progress for the ALS community,” said Jude Samulski, Ph.D., President and Founder of Asklepios BioPharmaceutical, Inc.

SOURCE: <http://www.als-mda.org/research/news/090120als-new-therapeutic-delivery.html>

RESEARCHERS GENERATE FUNCTIONAL NEURONS FROM SOMATIC CELLS

In a new study, researchers were able to generate functionally mature motor neurons from induced pluripotent stem (iPS) cells, which are engineered from adult somatic cells and can differentiate into most other cell types. This potential new source of motor neurons that does not require human eggs or embryos could be an enormous boon to research into conditions such as amyotrophic lateral sclerosis (ALS) and spinal cord injury and could open the door to eventual treatments.

This study is the first to use human iPS cells to generate electrically active motor neurons, a key hallmark of functional maturation that is essential for any future application of iPS cells. “To our knowledge, our results present the first demonstration of the electrical activity of iPS-derived neurons and further suggest the feasibility of using these cells to explore how changes in motor neuron activity contributes to the degeneration of these cells underlying these disorders,” the authors state.

SOURCE: <http://www.physorg.com/news154698681.html>

OBAMA LIFTS STEM CELL BAN AND PLEDGES TO RESTORE “SCIENCE INTEGRITY” AS PART OF STEM CELL SHIFT

President Barack Obama reversed the U.S. government’s ban on funding stem-cell research and pledged to “use sound, scientific practice and evidence, instead of dogma” to guide federal policy, an adviser said. Obama will ask the White House Office of Science and Technology to create guidelines to incorporate ‘scientific integrity’ into decision-making by U.S. agencies. The order involving embryonic stem cells will reverse a decision by former President George W. Bush to ban federal support for all but 21 cell colonies created before 2001. This action on stem cells may help speed research into cures for major illness.

SOURCE: <http://www.bloomberg.com/apps/news?pid=newsarchive&sid=a69RDbSnmkCQ>

NIH RECEIVES SIGNIFICANT BUDGET INCREASE IN OBAMA STIMULUS PACKAGE

NIH received an astounding \$10.4 Billion, or 34 percent increase, to its budget thanks to the Obama Administration’s Recovery Act, signed on February 17, 2009. This component of the stimulus package represents a striking act of generosity and confidence on the part of our elected leaders. Most of this money is slated to go to universities and other research institutions around the country.

SOURCE: <http://www.niaid.nih.gov/ncn/recovery/default.htm>

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