

Synapse

Volume 14, Issue 2

Spring, 2011

Newsletter of the Spastic Paraplegia Foundation

Our Thanks to Thurza



Thurza Campbell

We are reluctantly bidding goodbye to *Synapse's* editor – Thurza Campbell. In fact, Thurza has been the editor since 2004 which is two years before it became the SPF newsletter. In the words of her good friend, Linda Gentner, “It was definitely a labor of love to bring information to the PLS and HSP community members”.

In addition to coordinating the publication of *Synapse*, Thurza is also the author of *Carpé Diem: my five year journey with Primary Lateral Sclerosis* (she was diagnosed in 2001), and continues to be actively involved with her landscaping design business, Timeless Designs.

Both she and her husband, Jim, have poured heart, soul and countless hours of their time into both *Synapse* and the Spastic Paraplegia Foundation. Their efforts and dedication will surely be missed.



Thurza and Jim gathering notes for *Synapse*

COME JOIN US IN HOUSTON

SPF
Annual Conference
June 10-12, 2011
Hilton Americas-Houston, Texas

For more information
<http://www.spf-foundation.org/2011ac.htm>

Thank You to Our Sponsor!



Letter to the Editor,

I would just like to THANK YOU for the articles regarding stretching and "Understanding My Nerves" in the Winter 2011 newsletter. I originally donated and subscribed to the SP Foundation when we thought I might have PLS (or worst case scenario - ALS) in early 2009. I have since been diagnosed with Stiff Person Syndrome (March 2010). SPS is much like PLS in that it affects my UMN (Upper Motor Neuron) as well as it is an autoimmune disease due to the fact that my GAD₆₅ (Glutamic Acid Decarboxylase) antibodies are very high compared to a "normal" person (mine are at 93.8 U/mL - a "normal" person would have < 1.5 U/mL).

The *Synapse* articles in the Winter newsletter are great - they help confirm my going to physical therapy 3 days a week (for approximately 3 hours EACH session) and they also help me try to explain to my elderly parents and in-laws part of my disease. I HOPE insurance companies realize the need for the stretching - and PT - since there are many of the stretches and moves I can not do on my own. I have to have the therapist do some of the stretching and massaging my spastic muscles for me. Unfortunately this is a "lifetime" need. We are concerned that my insurance is going to realize I have been going to PT for 15 months now and start rejecting the claims. What they DO NOT realize is - the PT has kept me mobile. Without it and the botox injections into the calf and hamstring muscles I have received, I would not be walking today. They rejected the claim I sent in for the rollator...but it is also a necessity - I have fallen several times, luckily not breaking anything yet.

I realize SPS is not one of the diseases *Synapse* includes in it's information in general, but many of the spasticity issues are exactly what I have in my lower body. The research information you include is also of great interest to me. I will continue to support SP Foundation so that I can continue to receive the newsletter. I like the hard copies - it is much easier to share with my therapists and friends and family members. Thank you for all of the time and effort put in to publishing the newsletter. I greatly appreciate it!

Thank you again, and Happy 2011!

Carol Barta

TABLE OF CONTENTS	PAGES
SPF News from the Board	3
Upcoming Events	5
Living with HSP/PLS	6
Medical Updates	7
Emergency Preparedness.....	12

Synapse

Volume 14, Issue 2 - Spring 2011

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

Synapse Editors

TBDSenior Editor
Sarah Roberts-WittEvents
Beth Anne Shultz.....Medical Updates

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

The SPF is a non-profit 501(c)3.

Tax ID # 04-3594491

Combined Federal Campaign CFC #12554

Please Send Donations to:

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

Please direct correspondence to:

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

SPF Board of Directors:

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

SPF Medical Advisor:

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

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

SPF News from the Board

President's Letter:



Annette Lockwood
SPF President

The Spastic Paraplegia Foundation just turned nine years old. I am amazed at how far SPF has come since we first gathered in 2002. From that first year when we received four grant proposals and awarded \$80,000, to 2010, when we received four times that number and awarded \$433,000, shows a real commitment on behalf of our members to our organization.

Thanks to your generosity and the receipt of two \$100,000 Travelers Foundation grants in honor of Jim Brewi the funds available for research grants will be even higher in 2011. I am energized by the challenge of serving as your President once again.

The Annual Conference will be held in Houston on June 10 and 11, 2011. The agenda is available on the website at <http://www.sp-foundation.org/2011ac.htm>. Please register online or mail the registration form included in this issue of *Synapse*. I hope to see you in Houston!

SPF Board Transitions - SPF officer elections were held in late February. Jim Campbell's term expired this year, and he has elected not to serve another term. He will, however, continue to work on the NEALS initiative with Corey Braastad and Kris Brocchini (see update on page 4). Thurza Campbell has resigned as Senior Editor of *Synapse*. Her expertise will surely be missed. As many of you know, both she and Jim have done a tremendous

amount of work for SPF throughout the years. Our sincere thanks go out to both of them. Beth Anne Shultz will be joining the board. She has childhood-onset HSP, as does her father. Beth Anne received a degree in Special Education from the University of Alabama. She is an avid reader, an amateur gardener, and a "forever" student who enjoys studying Spanish, German, French and ASL.

I want to thank Mike Podanoffsky for the wonderful work he has done for SPF during his term as President. He worked hard to increase the visibility of our organization. As I take over, I look forward to continuing on with that which is in place as well as looking at other opportunities for growth.

Fundraising – Our major priority is to raise funds for research. We hope that you will help us by actively participating in fundraising events and activities. If you have any suggestions or recommendations on how we can raise more funds please send us an email at information@sp-foundation.org.

Website – Mike Podanoffsky has worked many hours on the updated look of our website. We hope you enjoy the new look and enhanced navigation.

Emergency Preparedness – Given the devastating events that are impacting Japan, an article with recommendations on preparing for an emergency situation can be found on Page 12.

Annette Lockwood
SPF President



Update from the Annual Conference Chairperson

The Annual Conference has an outstanding slate of topics presented by exciting individuals. Please take a moment to review the biographies of the speakers and presenters that were listed in the winter issue of *Synapse*.

The goal of the conference is to provide something of interest for everyone. Hopefully, this has been accomplished as evidenced by the wide array of topics being presented. The Friday evening speaker will provide current information on disability and the law. On Saturday morning, speakers will present research updates, and an explanation of the technical aspects of that research, in layperson terminology. During lunch, our speaker will discuss treatments for PLS and HSP. In the afternoon, participants will have an opportunity to attend a presentation about the following: exercise, acupressure, 21st century orthotics, service dogs, aquatic therapy, and/or visiting vendor exhibits.

The early interest, as indicated by the number of rooms reserved at the Hilton Americas, is exciting. It is an indication that the Annual Conference will be well attended. Those of you that have plans to attend are encouraged to reserve rooms as soon as reasonably possible. Hilton Americas, as with all hotels, has a limited number of ADA rooms. Early hotel reservations will ensure you get the proper room accommodations. There is no fee for making early hotel reservations.

Looking forward to visiting with you at the 2011 Annual Conference.

Sincerely,
Ashton Hecker
Conference, Chair



HSP / PLS NEALS Task Force

Submitted by Beth Anne Shultz

A meeting was held on Saturday, December 11th in Orlando, Florida. The following is a brief summary of the topics discussed.

Dr. Mitsumoto received a grant from the Spastic Paraplegia Foundation to study oxidative stress in 50 PLS patients. Samples of skin and blood were taken from patients both nationally and from abroad. Though, Dr. Mitsumoto is merging his efforts with existing registries, he is trying to improve recruitment into his study. He wants to include PLS sites and involve SPF in this endeavor. Dr. Rowland emphasized the lack of autopsy tissue for study in PLS. It was suggested that ADRC (Alzheimer's Disease Research Center) be contacted to see if they have collected any PLS cases. It was noted that an addition of as little as two tissue samples, would be of great help. A final proposal suggested involved taking all patients with pure UMN (upper motor neuron) disease, and noting certain specific symptoms such as swallowing difficulties and breathing irregularities, in order to determine if a prediction of ALS can be made accurately.

In closing, a small clinical trial involving HSP patients and the MS drug, Ampyra, is in the planning stage and hopefully will come to fruition. Ampyra (generic name dalfampridine), is an FDA approved drug that is currently being used with MS patients to improve walking ability. And lastly, another task force member is trying to get a HSP / PLS NEALS report published in *Neurology Today*, in the hopes that it will increase awareness and interest throughout the general neurology community.

SYNAPSE APPEAL

If you would like to help defray the printing costs for *Synapse* or fund medical research, please use the enclosed envelope to make a donation. Every little bit helps.

If you prefer to read *Synapse* online, please send an email to information@sp-foundation.org

New Website Launched

Submitted by Annette Lockwood

Thanks to Mike Podanoffsky, the SPF website has a different look. The navigation has also been improved. In addition to the simplified look, the goal was also to reduce the time needed to make updates.

If you are not already using GoodSearch as your search tool, please click on the box for it located on the right hand side of the home page. SPF earns money for every search made using GoodSearch when SPF is the selected charity. Since 2006 we have earned approximately \$700. If you tend to do your shopping online, please use GoodShop which is part of GoodSearch. On the GoodSearch home page, there is a Never Miss a Donation section where you can download the GoodSearch toolbar. What I like about using the toolbar is that now when I shop at different sites the toolbar will automatically tell me if there is a percentage donated to SPF and if there are any coupons available. In the past I would need to go to our website and click on the link for the store. SPF has earned \$350 through GoodShop. www.goodsearch.com



**9 DAY
FULLY ESCORTED**



ACCESSIBLE TOUR OF ISRAEL

Bonnie Guzelf is in the early stages of organizing a group tour of Israel for the spring of 2012.

This 9 DAY FULLY ESCORTED tour is for people with disabilities, slow walkers and wheelchair users and their companions.

The tour will include accessible hotel accommodations, two meals a day, transportation in a wheelchair accessible vehicle, an English-speaking tour guide and sightseeing. The tour will visit both Jewish and Christian sites.

The price will begin at \$2,570 per person, but the more people there are the lower the price. This price does not include airfare.

If you are interested or would like more information, please contact Bonnie at

480-838-1184

or e-mail me at bguzelf@cox.net



Upcoming Events

New England Spring Connection
Shrewsbury, MA Saturday, April 2, 2011
Jim Campbell, neconnection@sp-foundation.org

The NE Connection will be held at the Bucca di Beppo Italian Restaurant (7 Boston Turnpike Rd.) from 10am-2pm. The keynote speaker is Dr. Brown from the University of Massachusetts. Liz Wroblewski will also be presenting Chair stretching exercises.

Dallas-Fort Worth Spring Connection
Dallas, TX Saturday, April 9, 2011
John Staehle, jstaehle@swbell.net, 817-496-3137

Mark Saturday, April 9th on your calendar to attend the Spring Connection for HSPers, PLSers, spouses and friends who live in the Dallas-Fort Worth Metroplex and all of North Texas.

The Connection will be held in one of the private dining rooms at Buck n' Loons restaurant (funny name but great food), 3517 S. Cooper Street, Arlington from 12:00 PM to 3:00 PM. Cost is \$15.00 per person, payable in advance.

For more information and to receive the detailed Connection announcement, contact John Staehle at jstaehle@swbell.net or call 817-496-3137.

Spring Fling
Frederick, MD May 13-14, 2011
Jim Spencer, spencerfamily2@comcast.net,
301-634-4035

The 2011 Spring Fling will be held at Marriott Residence Inn (<http://tinyurl.com/46gdvjj>). Guests should identify themselves as part of the "Spring Fling Group" and a discounted rate will be provided. Dr. Andrea Corse, Director, Neuromuscular Pathology Laboratory at Johns Hopkins, will be the guest speaker. Please make plans to attend.

Southern California Connection Lunch
Hermosa Beach, CA August 2011
Malin Dollinger, malind@cox.net

Malin is organizing a Connection to be held during the week of August 15th. Please contact Malin at malind@cox.net or (310)378-4059 if you are interested in attending.

The Magnificent Mile Sept. 18, 2011
Hillsborough St, Raleigh, NC
Sarah Witt, srwitt@yahoo.com

The 6th Annual Magnificent Mile will be held on Sunday afternoon. If you are traveling to Raleigh for the event, 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.

California TeamWalk for our
Cures & Connection Weekend
Pleasanton, CA Sept. 30 - Oct. 1, 2011
Linda Gentner, lkgentner@aol.com, 510-651-5676

A Welcoming Dinner for people with PLS and HSP will be held Friday night -- pay for your own dinner. There will be discussion time with dessert and coffee following dinner. Get an early start on the weekend and stay at the hotel Friday night with no need to get up early on Saturday morning. The TeamWalk, lunch, and raffle will be at the Valley Community Church.

TeamWalks are also being planned for Mount Kisco, NY by Ann Lakin (alakin90@gmail.com) and one in Philadelphia, PA by her sister, Helen Kienlen (hmk17@comcast.net).

Friends of the Handicapped

*Blessed are those who take the time
To listen to difficult speech,
For you help me to know that
if I persevere, I can be understood.*

*Blessed are you who never bid me to hurry up
or take my tasks from me*

*For my failures will be outweighed
By the times I surprise myself and you
Blessed are you who asked for my help
For my greatest need is to be needed.*

*Blessed are you who understand that it is
difficult for me to put thoughts into words.*

*Blessed are you who with a smile
encourage me to try once more.*

*Blessed are you who never remind me that today
I asked the same question twice,
Blessed are you who respect me
and love me just as I am.*

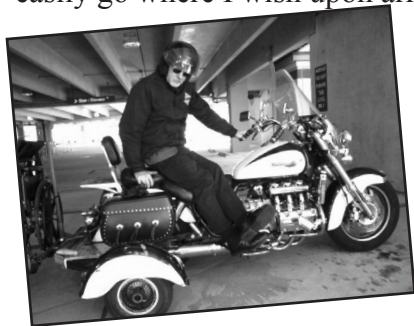
Author Unknown

Living with HSP/PLS

Let me introduce myself, my name is Jeffrey Litt, I live in Saint Petersburg, Florida. I have HSP, but I'm not going to let this disease rob my life of the things I love to do. Well, maybe there are one or two little ones that



I'm forced out of, kicking and screaming, but I am determined to continue to be involved in as much as I possibly can. Including continued employment (*I am a pharmacist*), travel (*often on my own but with family as well*), and not the least of which is riding my motorcycle while doing all of those things mentioned and more. I ride to and from work, I ride for fun and I ride on trips with a club. To accomplish these, I have made some modifications to the cycle that accommodate my disabilities. As you can see in the photo, the bike has a set of support wheels (*not unlike the training wheels on a child's bicycle*) to eliminate the concern of falling, I've reengineered the foot shifter to compensate a bit for what HSP has done to my feet, and I bring my wheelchair along in an aft carrier so I may easily go where I wish upon arrival at any destination.



I could write volumes about my activities, challenges and how I've overcome them, but space in this publication is limited.

[If you would like to contact me I can be

found on Facebook, or email to jefflitt@juno.com]

Endurance can be defined as the ability to do an activity for as long as you want. It is the heart's ability to deliver oxygenated blood to the working muscles as well as the muscles' ability to use that oxygen to generate repeated contractions for an activity. The current recommendation by the American College of Sports Medicine is for adults to engage in moderately intense exercise 30 minutes a day for 5 days a week. A moderately intense exercise is one which elevates your heart rate and results in a sweat. You should still be able to carry on a conversation during moderate intensity exercise. Google "rate of perceived exertion scales in exercise" for more information.

Diabetes, insulin resistance, cardiovascular disease and metabolic syndrome to name a few fall into the class of chronic noncommunicable diseases. Repeated contracting muscle (exercise!) secretes chemical mediators that lower the risk of developing these chronic diseases. We have to make a special effort to be active to contribute to our overall health.

Walking has the following qualities: weight bearing, weight shifting from one side to the other through trunk rotation, opportunity to vary speed and intensity to meet demands of the terrain and reciprocal muscle activity. This reciprocal activation with simultaneous relaxation of opposing muscles is inhibited by excessive muscle tone in the upper motor neuron syndrome.

What are good exercises for us? Exercises that will increase our endurance, lay the foundation for chronic disease management and allow to practice reciprocal relaxation in repetitive activity are ideal.

Consider using a stationary bike, a recumbent bike or enrolling in a spin bike class. The elliptical trainer is an excellent choice for weight bearing, weight shifting and trunk rotation. Treadmill walking at varied speeds and inclines is another good choice. Walking with a pair of Nordic poles incorporates all walking qualities listed above. If you have any concerns about your ability to participate in moderately intense endurance exercise, please consult your physician.

In summary, choosing endurance exercise will enhance your cardiorespiratory capacity, possibly mitigate chronic health conditions and give us the opportunity to work on mobility. I plan to elaborate further on this in future columns.

Remember! Exercise may not be fun, but it is certainly good for you.

Exercise And You: Why Exercise?

Contributed by Liz Wroblewski, MPT

Thanks to all who have been reading my columns in *Synapse*.

A comprehensive exercise program for PLS or HSP would include stretching, strengthening, balance, core work and endurance exercises. Don't forget breathing and posture both of which have been discussed in previous columns. What a tall order! This column is going to focus on the benefits of endurance exercises.

Medical Updates

Neuropsychological (Cognitive) Functioning in PLS: A Comparison with ALS.

Can J Neurol Sci. 2011 Jan;38(1):88-97. Grace GM, Orange JB, Rowe A, Findlater K, Freedman M, Strong MJ. Clinical Neurological Sciences and Psychological Services, London Health Sciences Centre.

Objective: In order to characterize the nature and extent of neuropsychological dysfunction in primary lateral sclerosis (PLS), we studied prospectively cognitive, emotional, and behavioral functioning in PLS, and compared performances to functioning in amyotrophic lateral sclerosis (ALS).

Methods: Eighteen patients with PLS and 13 patients with ALS completed a neuropsychological test battery assessing both cognitive skills and emotional/behavioral functioning. Results: Both PLS and ALS groups scored broadly within normal limits (mean T-scores greater than 40) on all cognitive measures and no significant between-group differences were found with the exception of one variable. However, when examined on a case by case basis, the data revealed considerable heterogeneity amongst patients in both groups. Overall, 39% of PLS patients and 31% of ALS patients were considered cognitively impaired. A higher than expected frequency of abnormal scores was noted for several tests of executive function in both groups, and a majority of PLS patients also exhibited abnormal behavioural symptoms. There was no relationship in PLS or ALS groups between cognitive functioning and disease duration, current site of disease, site of onset, functional status, and respiratory variables. Comparison between the PLS and ALS groups indicated virtually no differences in cognitive test scores and overall emotional/behavioural symptoms.

Conclusions: We observed deficits in cognition and behaviour in a significant proportion of PLS patients which were comparable to those observed in ALS cases. Although deficits were not in the range of frontotemporal dementia, both ALS and PLS cases demonstrated deficits most prominently on tests of executive functioning.

MRI Technique (DTI) Detects Neuronal Degeneration in PLS

A note from Mark Weber: Scientists first started experimenting on PLS patients with an MRI technique called diffusion tensor imaging (DTI) in the early part of this decade. Their goal was to be able to use DTI as a marker for PLS -- a way to distinguish PLS from other disorders with an objective test.

Br J Radiol. 2011 Jan;84(997):78-80. Tzarouchi LC, Kyritsis AP, Giannopoulos S, Astrakas LG, Diakou M, Argyropoulou MI. Radiology, Medical School University of Ioannina, Ioannina, Greece.

Objective: Primary lateral sclerosis (PLS) is a progressive degenerative disorder affecting upper motor neurons and requires a clinical diagnosis. Diffusion tensor imaging (DTI) is a quantitative method for assessing white matter fibre integrity. The purpose of the study was to evaluate the involvement of upper motor neurons by using DTI in PLS.

Methods: A patient with PLS was compared with eight age-matched controls. Differences in fractional anisotropy (FA) index were assessed using DTI on a voxel-by-voxel basis. Results: Decreased FA was observed in the proximal part of the pyramidal tract bilaterally, which indicated degeneration of the pyramidal cells. Conclusion: Voxel-based DTI could be used as an objective marker for detecting upper motor neuron degeneration in PLS.

Malfunctioning Gene Associated with Lou Gehrig's Disease Leads to Nerve-Cell Death in Mice

PHILADELPHIA— Lou Gehrig's disease, or amyotrophic lateral sclerosis (ALS), and frontotemporal lobar degeneration (FTLD) are characterized by protein clumps in brain and spinal-cord cells that include an RNA-binding protein called TDP-43. This protein is the major building block of the lesions formed by these clumps.

In a study published in the Journal of Clinical Investigation, a team led by Virginia M.-Y. Lee, PhD, director of Penn's Center for Neurodegenerative Disease Research, describes the first direct evidence of how mutated TDP-43 can cause neurons to die. Although normally found in the nucleus where it regulates gene expression, TDP-43 was first discovered in 2006 to be the major disease protein in ALS and FTLD by the Penn team led by Lee and John Q. Trojanowski, MD, PhD, director of the Institute on Aging at Penn. This discovery has transformed research on ALS and FTLD by linking them to the same disease protein.

“The discovery of TDP-43 as the pathological link between mechanisms of nervous system degeneration in both ALS and FTLD opened up new opportunities for drug discovery as well as biomarker development for these disorders,” says Lee. “An animal model of TDP-43-mediated disease similar to ALS and FTLD will accelerate these efforts.”

To determine the effects of misplaced TDP-43 on the viability of neurons, the researchers made transgenic mice expressing human mutated TDP-43 in the cytoplasm and compared them to mice expressing normal human TDP-43 in the nucleus of nerve cells. Expression of either human TDP-43 led to neuron loss in vulnerable forebrain regions; degeneration of part of the spinal cord tract; and muscle spasms in the mice. These effects recapitulate key aspects of FTLD and a subtype of ALS known as primary lateral sclerosis.

Next steps, say the researchers, will be to look for the specific genes that are regulated by TDP-43 and how mRNA splicing is involved so that the abnormal regulation of these genes can be corrected. At the same time, notes Lee, “We soon will launch studies of novel strategies to prevent TDP-43-mediated nervous system degeneration using this mouse model of ALS and FTL D.”

Two More HSP Genes Bind Together

Note from Mark Weber: The scientist who discovered the information below was previously funded by the Spastic Paraplegia Foundation.

Hereditary spastic paraplegia (HSP), a group of progressive neurodegenerative disorders that impairs the ability to walk, can be caused by mutations in more than 40 different genes. Despite this genetic heterogeneity, the pathologic features – degeneration of long axons in the spinal cord – are relatively uniform, suggesting that dysfunction of a common biochemical pathway might contribute to HSP. Peter Hedera and colleagues explored whether two proteins implicated in HSP – atlastin-1 and NIPA1 – are part of a common pathway....

(For the remainder of the article, please visit the link below.)

<http://news.vanderbilt.edu/2011/02/paraplegia-causing-proteins-pair-up/>

Two Project A.L.S. Studies Confirm Reliability of Human iPS Cells, Opening Door for ALS Modeling and Drug Screening

February 4, 2011 -In 2008, Time magazine named “First Neurons Created from ALS Patients” its #1 scientific and medical breakthrough of the year. While many were hopeful that iPS cells represented a giant step toward personalized medicine that would allow scientists to model human ALS and other diseases, iPS cell lines generated in several laboratories have exhibited instability and behavioral variability.

In two compelling studies published online today, a team of scientists from the Project A.L.S./Jenifer Estess Laboratory for Stem Cell Research, the Broad Institute, Harvard Stem Cell Institute, the Motor Neuron Center at Columbia University, and the Howard Hughes Medical Institute, among other institutions, announced that it has established reliable procedures for evaluating the efficiency of differentiated induced pluripotent stem (iPS) cell lines and embryonic stem (ES) cell lines, and have begun to use the cells lines to more reliably model ALS, a fatal neurodegenerative disease.

One study, the results of which were published in Cell, announced the creation of a genomic “scorecard,” designed for a comprehensive characterization of pluripotent cell lines. Led by Alexander Meissner and Christoph Bock, the team used genomic methods to compare and characterize 20 ES cell lines and 12 iPS cell lines. The scorecard will allow scientists everywhere to optimize and streamline the selection and monitoring of pluripotent cell lines.

The results of a complementary study appeared online in Nature Biotechnology. Kevin Eggen, Gabriella Boulting et al. authored the study, a rigorous and extensive characterization of 16 iPS cell lines. All 16 lines passed a stringent test of differentiation capacity. This thorough test will serve as an additional resource for all those interested in the application of pluripotent stem cells to human disease.

“Our team has created a toolbox that allows us to test the potential of stem cell lines created from a tiny sample of ALS patient skin,” said Valerie Estess, director of research for Project A.L.S. “In fact, the Project A.L.S./Jenifer Estess Lab is already using these well defined ALS patient lines not only to model ALS, but to screen for drugs that may slow or stop the human disease.”

Diseases in a Dish

by Stephen S. Hall 2011 Scientific American

– for full article go to <http://tinyurl.com/68n6fuw>

In June 2007, two elderly women with ALS agreed to donate some of their skin cells for an ambitious, but highly uncertain experiment. It took just a few minutes to perform the “punch biopsy” i.e., two quick nips of flesh from the inner arm. Thus began, in the USA, one of the exciting uses of Induced pluripotent stem cells (iPS cells) and the “disease-in-a-dish” phenomenon that is slowly transforming stem cell research and the politics that go with it.

So what, exactly, are iPS cells and why are they such an exciting step in stem cell biology? Simply put, iPS cells are cells that are converted to stem cells from skin tissue NOT from human embryos. This in turn, opens up numerous possibilities in the field of stem cell research and drug development that have been, up to now, severely hampered by the ethical questions and polarizing politics that accompany embryonic stem cell research. Let’s delve into the crux of the matter with regards to this article in “Scientific American”.

Once skins cells were obtained from the elderly women, the cells were chemically induced to become stem cells. The next step was to then reprogram the newly created stem cells into the motor neuron cells that control the muscles of the body, and are adversely affected by ALS. The results were amazing –the resulting tissue cultures exhibited the same molecular defects that gave rise to ALS in their human

donors! In essence, the researchers re-created the disease... in a Petri dish. This “Petri dish” focus allows stem cell research to head in an alternative direction. Rather than focusing stem cell research solely on “treatments”, which have produced agonizingly slow results, researchers are beginning to use stem cells to help screen for promising new drugs and to determine how disease specifically damages the body – all without the enormous time delay and the amount of red tape that comes when testing is performed on human subjects and embryos. For instance, the researchers in this article have already identified molecular pathways that seem to be involved in the death of motor neurons, which occurs when the cells are poisoned by another class of neurons known as astrocytes. With both motor neurons and astrocytes in a dish, scientists are now searching for potential therapeutic compounds that can either block the toxic activity of astrocytes or enhance the survival of motor neurons.

If met with continued success, iPS cells and the disease-in-a-dish concept has great potential in speeding up researchers’ understanding of many types of diseases, and lead to faster, more efficient screening of potential drug therapies. In addition, pharmaceutical companies, long wary of stem cell research, are starting to show real interest. It helps that this approach, in addition to reducing the negative aspects associated with stem cell research, compliments the traditional strengths of industrial drug discovery.

The scientific methodology described above is one of the research approaches Dr. Fink is using at his lab in Ann Arbor, MI. He adds the following comments. “In vitro” models (“disease in a dish”) are being used increasingly to study a wide array of disorders including hereditary spastic paraplegia (HSP) and primary lateral sclerosis (PLS). For more than 75 years, scientists have studied cells grown in the laboratory from individuals with various diseases to understand the disease and develop treatment. Until recently, these studies relied primarily on cells that could be obtained “conveniently” such as tumor samples, skin fibroblasts, lymphocytes, and less commonly through liver and kidney biopsy. With a few exceptions, human neurons (nerve cells) could be studied only in post mortem (autopsy) material. The inability to easily grow neurons in the laboratory from individuals with neurologic disorders has represented a stumbling block to directly studying biochemical processes and developing treatments for neurologic diseases.

As noted, however, this is changing. As this approach becomes optimized, investigation of these neurons promises to give investigators a method to directly examine molecular processes involved in HSP and PLS, and to test, in a high-throughput manner, potential treatments to reverse this process.

Understanding Biomarkers

QUEST Vol. 18, No. 1

A biomarker is any biological indicator that doctors or researchers can objectively measure and evaluate to determine the state of an individual’s health; confirm disease onset and progression; or gauge whether an experimental treatment is working or not. Some common, everyday types of biomarkers include body temperature, blood pressure, pulse, heart rate, and the presence or absence of particular proteins in the blood or urine. But in neuromuscular disease management and research, more specialized biomarkers are needed.

Diagnostic biomarkers help physicians identify, confirm or rule out a diagnosis, while prognostic biomarkers help determine the likely progression of the disease without treatment.

Predictive biomarkers tell physicians or researchers whether, or how well, an individual is likely to respond to a proposed therapy.

Pharmacodynamic biomarkers indicate how a drug behaves in the body (including whether, and how much of, a drug reaches its target; correlations between dose and response; and the presence or absence of various other intended or unintended effects).

In what may be their most important role, biomarkers help drug development teams to confirm in human clinical trials that an experimental therapeutic reaches selected targets within the body and produces the desired responses. Both prognostic and predictive biomarkers can serve as powerful patient selection tools by helping define the inclusion and exclusion criteria that determine clinical trial eligibility. Biomarkers also can help researchers ensure that randomized study groups within a trial are similar. Pharmacodynamic biomarkers give critical information about the experimental treatment’s activity and effects.

Researchers already use biomarkers in neuromuscular disease research, and are continually working on development of additional biomarkers. If the gene mutation underlying a disease is known, that mutation is a reliable diagnostic biomarker — if you have the mutation, you probably have, or will get, the disease. But what researchers really want are more prognostic and pharmacodynamic biomarkers — those that can reliably predict the course of the disease or indicate the biological activity of an experimental treatment.

Biomarkers will play a critical role in personalized medicine, in which treatments are based on an individual’s specific genetic makeup. Increased identification and use of biomarkers will help speed the pace of research and, ultimately, the development of safe and effective therapies.

History of Baclofen That You May Not Know

Historically baclofen was designed to be a drug for epilepsy. It was synthesized for the first time in Ciba-Geigy by the Swiss chemist Heinrich Keberle in 1962. The effect on epilepsy was disappointing but it was found that in certain patients spasticity decreased. Baclofen was and is still given orally with variable effects. In severely affected children, the oral dose is so high that side effects appear and the treatment loses its benefit. How and when baclofen came to be used in the spinal sac is not really clear but this is now an established method for the treatment of spasticity in many conditions.

Dr. Olivier Ameisen, a French-American associate professor of medicine and a cardiologist at Weill Cornell Medical College of Cornell University, reported in 2004 in the journal *Alcohol and Alcoholism* that he successfully used Baclofen to completely suppress his own alcohol addiction. In his paper, he called for randomized trials of high-dose baclofen to be conducted to test the therapeutic model he had proposed. He renewed his call for clinical trials in the *Journal of the American Medical Association (JAMA)*. His therapeutic model was reproduced by Dr. William Bucknam, who published a case report in *Alcohol and Alcoholism*, and by Roberta Agabio et al. who published another case in *Journal of Clinical Psychopharmacology*. Ameisen believes, based on his own experience and other anecdotal evidence, that Baclofen acts on some mechanism within the brains of addicts to suppress cravings brought on by addiction to various substances such as alcohol, cocaine, and heroin. Ameisen, who currently is a visiting professor of medicine at State University of New York Downstate Medical Center, authored *Le Dernier Verre (The Last Glass, titled The End of My Addiction and Heal Thyself in English)* to inform public opinion and physicians. Since his book has been released, hundreds of patients have been treated in academic centers and rapidly become “indifferent to alcohol”. Recently, based on Ameisen’s therapeutic model, some trials have been conducted in using Baclofen to treat cocaine addiction. People have said once they took Baclofen they felt their desire for cocaine plummet almost overnight. There is also a report that baclofen has beneficial role in the management of reflux disease.

<http://en.wikipedia.org/wiki/Baclofen> - cite note-14

Paying Less for Drugs in ‘Doughnut Hole’

Excerpts from article by: Patricia Barry from: AARP Bulletin January 13, 2011

Q. I hear the new health care law gives us a better deal in the Part D doughnut hole this year. How will this work?

Yes, 2011 begins the process of shrinking the gap in coverage — usually known as the doughnut hole — that has always been the biggest drawback for people enrolled in the Medicare Part D prescription drug program.

You fall into the gap if the total cost of your drugs since the beginning of the year reaches a certain level: \$2,840 in 2011. (*The “total cost” in this initial coverage period includes the amount you’ve spent yourself — your deductible, if your Part D plan has one, and co-payments — and the amount your plan has contributed.*)

2011 BRINGS NEW DISCOUNTS FOR DRUGS.

At that point, in previous years, you would have had to pay 100 percent of the cost of your drugs in the gap, unless you had other coverage. And only when you had spent a large amount out of pocket since the beginning of the year (*\$4,550 in 2010*) could you get out of the gap and qualify for low-cost catastrophic coverage until the end of the year.

But this year, under a provision of the new health care law, you’ll spend much less of your own money in the doughnut hole:

- You’ll receive a 50 percent discount on brand-name and biologic drugs, including insulin and vaccines, contributed by their manufacturers.
- You’ll receive a 7 percent discount on generic drugs and Part D-covered supplies used to administer insulin, through a subsidy from the federal government.

Over the next 10 years these discounts will get larger, so that by 2020 you will pay no more than 25 percent of the cost of any Part D-covered drugs in the doughnut hole.

Who Gets The Discounts?

Anybody who gets Part D drug coverage and falls into the doughnut hole is entitled to the discounts, including those who are enrolled in:

- A “stand-alone” Part D drug plan — the type mostly used by people in the traditional Medicare program.
- A Medicare Advantage health plan that provides drug coverage.
- A Part D drug plan or a Medicare Advantage plan that is sponsored by a current or former employer or union.

Will people who get Extra Help get the discounts?

No. People with limited incomes who receive low-cost prescription drug coverage under the government-subsidized Extra Help program already have year-round coverage without a doughnut hole.

How do I get the discounts?

You don't need to apply for them or fill out any paperwork. The discounts will be automatically applied at the pharmacy or, if you get your prescriptions through mail order, by your plan's mail-order service.

Does the discount apply to all Part D drugs?

Under the new law, drug manufacturers must provide the doughnut hole discounts on all their brand-name and biologic drugs as a condition for them being covered under the Part D program as a whole. According to Medicare officials, the manufacturers of more than 99 percent of the brand-name drugs used by Medicare beneficiaries have agreed to provide the discounts.

However, if one of your drugs is made by a manufacturer that declines to participate in the discount program, this means that your Part D plan won't cover it at all — not in the initial and catastrophic periods of coverage, not in the doughnut hole, and not in the Extra Help program.

Do the discounts mean it will take me longer to get out of the doughnut hole?

No. The limit on out-of-pocket costs that gets you out of the gap is still in effect — \$4,550 in 2011. But the calculation is different. What now counts toward the limit is everything you spent on drugs from the beginning of the year — your out-of-pocket costs (*deductible and copays*) during the initial coverage period and whatever you spent on drugs in the doughnut hole — plus the 50 percent discount on brand-name and biologic drugs provided by the manufacturers. The discounts are considered to be out-of-pocket costs even though you didn't pay for them. So if the total amount of all these components is high enough, you reach catastrophic coverage as quickly as you would have done without the discounts.

Example: You go to the pharmacy to fill a 30-day prescription for a brand-name drug while in the doughnut hole. The full price of the drug is \$100, plus a \$2 dispensing fee. The manufacturer's discount is applied, bringing the price down to \$50. You pay \$50 plus the \$2 dispensing fee. The discount does not cover this fee. But the whole amount of \$102 (*the full price of the drug plus the dispensing fee*) counts toward getting you out of the doughnut hole.

However, the discount on generic drugs (*7 percent in 2011*) that is provided by the government does not count toward the doughnut hole limit.

Also remember that, as in all previous years, what you spend on drugs in the doughnut hole only counts toward the limit if you buy them through your plan and from a pharmacy in your plan's network, except in emergencies and a few other circumstances that Medicare allows.

My plan doesn't normally cover one of my drugs but agreed to cover it because it was medically necessary for me. Will I get a discount for this drug in the gap?

Yes. If a plan grants coverage for a drug that's not on its formulary — usually in response to the patient's doctor's request for an exception to its rules — this drug is considered a covered drug for the purpose of discounts in the doughnut hole and counts toward the dollar limit that gets you out of the gap. But no exceptions can be granted for a drug made by a manufacturer that does not participate in the discount program.

What if my plan already gives some coverage for my drugs in the gap?

Your plan's coverage is applied first, and the discounts are applied to the remaining amount.

Example: You are enrolled in an "enhanced" Part D plan that covers 40 percent of the cost of your drugs in the gap. You go to the pharmacy to fill a prescription for a brand-name drug that costs \$100. The plan pays \$40 of this amount, leaving \$60 as your share. But after the manufacturer's discount is applied, you pay \$30 plus a dispensing fee of, say, \$2. The \$40 that the plan paid does not count toward the spending limit that gets you out of the doughnut hole. But the rest — the whole \$62 — does count.

What if I'm enrolled in a state pharmacy assistance program?

You still get the discounts in the doughnut hole. They will be applied to the price of your drugs before the state assistance kicks in. This is also true for other programs that provide help to pay for Part D drugs, except for Extra Help.

What if I already get assistance from a drug manufacturer?

You should check with the manufacturer's patient assistance program to see if its policy has changed.

How will I know if the proper discounts have been applied?

An explanation will be included in the regular statements you receive from your plan. If you have reason to think that you haven't received the correct discounts, call the number shown on your membership card. If you disagree with the plan's explanation, you can use the standard appeals process to resolve the issue. You can also call Medicare at 1-800-633-4227 or 1-800-633-4227 to file a complaint.

Patricia Barry is a senior editor with the [AARP Bulletin](#).

TIPS FOR PEOPLE WITH DISABILITIES AND MEDICAL CONCERNS

Reprinted with permission from: http://www.redcross.org/museum/prepare_org/index.htm

Establish a Personal Support Network

A personal support network can consist of friends, roommates, family members, relatives, personal attendants, co-workers and neighbors who will check in with you in an emergency to ensure you are OK and provide assistance if needed. Do not depend on any one person. Identify a minimum of three people at each location where you regularly spend your time: job, home, school, volunteer site, etc.

Personal assistance services (attendants) may not be available after a major disaster. Therefore, it is vital that your support network consist of people other than your attendants. If you employ one or use the services of a home health agency or other type of in-home service, work with them to develop an emergency plan. How will you get along for as long as seven days?

In spite of your best planning, sometimes a personal support network must be created on the spot. For example, you may find yourself in a shelter and in need of immediate assistance. Think about what you require, how you want things done and what kind of person you would select.

Seven Important Items to Discuss, Exchange and Practice with Your Personal Support Network

- Make arrangements for your support network to immediately check on you after a disaster and, if needed, offer assistance.
- Exchange important keys.
- Show them where you keep emergency supplies.
- Share copies of your emergency documents, evacuation plans and emergency health information card.
- Agree upon and practice a communications system (how to contact each other in an emergency). Do not count on the telephones working.
- You and your personal support network should always notify each other when you are going out of town and when you will return.
- The relationship should be mutual. Learn about each other's needs and how to help each other in an emergency.

Traveling

When staying in hotels, motels, etc., identify yourself to registration desk staff as a person who will need assistance in an emergency and state the type of assistance you may need.

Health Card

- An emergency health information card communicates to rescuers what they need to know about you if they find you unconscious or incoherent, or if they need to quickly help evacuate you.
- An emergency health information card contains information about your medications, adaptive equipment, blood type, allergies and sensitivities, insurance numbers, social security number, immunization dates, communication difficulties and preferred treatment, as well as contact information for your health providers, personal support network and emergency contacts.
- Make multiple copies of this card to keep in emergency supply kits, car, work, wallet (behind your driver's license or primary identification card), wheelchair pack, etc.
- Update this information every six months.

Emergency Contact List

- It is often easier to place an out-of-state call from a disaster area than to call within it. Ask relatives or friends who live outside your immediate area (approximately 100 miles away) to act as a clearing house for information about you and your family after a disaster. All family members should know to call the contact person to report their location and condition. The contact person should then relay messages to your other friends and relatives outside the disaster area. This will help to reduce calling into and out of the affected area once the phones are working.
- Besides emergency out-of-town contacts, your list should include your personal support network, equipment vendors, doctors, utility companies, employers, schools and day care centers.

Emergency Documents

- This includes important information typically needed after a disaster. Store emergency documents [such as your health card, family records (birth, marriage and death certificates), wills, deeds, family social security numbers, charge and bank accounts, insurance documentation, etc.] in sealed freezer bags in all of your emergency supply kits. If you feel comfortable doing so, give copies to your out-of-state contacts and the people in your personal support network. Remember to place a copies in a safe-deposit box. Be sure to update this information every six months as needed.

Conduct an Ability Self-Assessment

Evaluate your capabilities, limitations and needs, as well as your surroundings to determine what type of help you will need in an emergency.

1. Will you be able to independently shut off the necessary utilities (gas, water, electricity)?
 - Do you know where shut-off valves are? Can you get to them?
 - Can you find and use the right wrench to turn those handles?
2. Can you operate a fire extinguisher?
 - Have you practiced?
 - Will extended handles make these items usable for you?
3. Will you be able to carry your evacuation kit?
 - What do you need to do in order to carry it? How much can you carry? Do you have duplicates at other locations?
4. Have you moved or secured large objects that might block your escape path?
5. Write instructions for the following (keep a copy with you and share a copy with your personal support network):
 - a. How to turn off utilities (*color-code or label them for quick identification*).
 - Main gas valve, located next to the meter - blue; Electrical power circuit breaker box - red; Main water valve - green.
 - If you have a reduced or limited sense of smell, alert your personal support network to check for gas leaks.
 - b. How to operate and safely move your essential equipment. Consider attaching simple instructions to your equipment.
 - c. How to safely transport you if you need to be carried, and include any areas of vulnerability.

- d. How to provide personal assistance services.
 - Remind anyone who assists you to practice strict cleanliness. With limited water and increased health hazards, the possibility of infection increases. Keep a supply of latex gloves in your emergency supply kit and ask people assisting you with personal hygiene to use them.
 - List all personal care assistance needs (dressing, bathing, etc.) with instructions on how best to assist you.
 - Make a map of where to find medications, aids and supplies, and share it with your personal support network.
- e. How to evacuate. As much as possible, clear obstacles from aisles and secure large, heavy items such as bookcases that may fall and block your path. Plan alternate exit paths.

Communication: Practice Assertiveness Skills

Take charge and practice how to quickly explain to people how to move your mobility aids or how to move you safely and rapidly. Be prepared to give clear, specific and concise instructions and directions to rescue personnel: “Take my oxygen tank,” “Take my wheelchair,” “Take my gamma globulin from the freezer,” “Take my communication device from under the bed.” Practice giving these instructions with the least amount of words in the least amount of time. For example, the traditional “fire fighter’s carry” may be hazardous for some people with respiratory weakness. You need to be able to give brief instructions regarding how to move you.

Be prepared to request an accommodation from disaster personnel. For example, if you are unable to wait in long lines for such items as water, food and disaster relief applications, practice clearly and concisely explaining why you cannot wait.

“Carry-With-You” Supplies to Keep with You at All Times

Packing/Container suggestions: a fanny pack, back pack or drawstring bag which can be hung from a wheelchair, scooter or other assistive device.

- Emergency Health Information Card.
- Instructions on personal assistance needs and how best to provide them.
- Copy of Emergency Documents.
- Essential medications/copies of prescriptions (at least a week’s supply).

- Flashlight on key ring.
- Signaling device (whistle, beeper, bell, screecher).
- Small battery-operated radio and extra batteries

Disability-Related Supplies to Add to Regular Emergency Kits

Plan for enough disability-related supplies to last for up to two weeks (medication syringes, colostomy supplies, respiratory aids, catheters, padding, distilled water, etc.). If you have chemical sensitivities or a respiratory or cardiac condition, store towels, masks, industrial respirators or other supplies you can use to filter your air supply. Do not expect shelters or first aid stations to meet your supply needs. In an emergency, supplies will be limited.

Store supplies in areas you anticipate will be easy to reach after a disaster. If you are unable to afford extras, consider contacting disability-specific organizations, such as the Multiple Sclerosis Society, Arthritis Foundation, United Cerebral Palsy Association, etc. They may be able to assist you in gathering low-cost or no-cost emergency supplies and medications.

Medication

It is best to maintain at least a 7 to 14-day supply of essential medications (heart, blood pressure, birth control, diabetic, psychiatric orphan drugs, etc.) and keep it with you at all times. If this is not possible, even a three-day supply would be extremely helpful.

Work with your doctor(s) to obtain an extra supply of medications. Make several copies of your prescriptions and place one in each of your survival kits as well as your car kit and wallet.

Ask your provider or pharmacist how to store your medication. Ask how often you should rotate stored supplies to ensure the effectiveness does not weaken. If you are on medications that are administered by a clinic or hospital (*such as methadone, chemo or radiation therapy*) ask your provider how you should plan for a 3-14 day disruption.

If you are a smoker, be aware that smoking is not allowed in shelters. If getting to an outside smoking area may be difficult for you, consider stocking your evacuation kit with nicotine gum or patches.

Life in cramped, unheated shelters can increase the chances of pneumonia, influenza and colds. Stock your kits with vitamins or medications to guard against getting sick and to cope with being sick.

Equipment and Assistive Devices

Keep important equipment and assistive devices in a consistent, convenient and secured place, so you can quickly and easily locate them. Make sure such items as false teeth, hearing aids, prosthesis, mobility aids, canes, crutches, walkers, respirators, service animal harnesses, augmentative communication devices or electronic communicators, artificial larynx, wheelchair, sanitary aids, batteries, eye glasses, contacts and cleaning solutions, etc., are secured. For example, keep these items in a container attached to your night stand or bed post, secure your oxygen tank to the wall, keep your wheelchair locked and close to bed, etc. This helps prevent them from falling, flying or rolling away during a quake and makes them easily accessible in the event of an evacuation.

If you use a laptop computer as a means of communication, consider purchasing a power converter. A power converter allows most laptops to run from a cigarette lighter on the dashboard of a vehicle.

Checklist

Print out a copy of this list for your convenience and be sure to write down the completion date for each activity at it is accomplished.

- Establish a personal support network.
- Make an emergency health information card.
- Make an emergency contact list.
- Collect copies of your emergency documents.
- Store copies of your health card, contact list and emergency documents in your wallet, purse, supply kits and safe deposit box. Give copies to members of your personal support network as well as your out-of-area contact.
- Conduct an ability self-assessment.
- Collect “carry-with-you supplies” at all times.
- Compile disability-related supplies for emergency kits.
- Maintain a seven day supply of essential medications.
- Keep important equipment and assistive devices in consistent, convenient and secured places.
- Write out instructions for items you will need help with in an emergency.

Developed by Independent Living Resource Center San Francisco in cooperation with June Kailes, Disability Consultant, through a grant from The American Red Cross Northern California Disaster Preparedness Network.

©Copyright 2006, The American National Red Cross. All Rights Reserved.



Annual Conference Registration

June 10 – 12, 2011

Houston, Texas

The program includes the following talks:

Friday night:

- Binder and Binder – Disability Law
- NEALS update – Corey Braastad

Saturday:

- Featured speaker, Dr. John Fink - HSP and PLS Research Roundup
- Dr. Corey Braastad - Genetics
- Mark Weber - SPF Research Grants
- Dr. Jinsy Andrews – Treatments for PLS and HSP
- Dr. Lyn Litchke – Chair Yoga
- John Paul Liang – Acupressure and Acupuncture Treatments
- Kathi Geisler – History of Spastic Paraplegia Foundation

Friday night dinner = \$45.00 per person

Conference registration for Saturday = \$65.00 per person

If you prefer, register using Pay Pal at <http://sp-foundation.org/2011ac.htm>

----- cut here and mail -----

Sign up to participate in one of three Saturday afternoon break-out sessions:

Katie St. Mars - The Benefits of Water: Seen & Unseen Benefits of Aquatic Therapy _____

Tom DiBello – 21st Century Orthotics and WalkAide _____

Allie Keaton – Service Dogs _____

Name #1 : _____ Disorder: HSP ___ PLS ___ SP ___

Name #2: _____

Child/ren: Name: _____ Age: _____ Name: _____ Age: _____

Address: _____

Phone: _____ e-mail: _____

I will be using a: Cane _____ Walker _____ Scooter _____ Wheelchair _____

Friday night dinner: # _____ \$45.00 per person = \$ _____

Special Meal Requirement:

Conference: # _____ \$65.00 per person = \$ _____ _____ Regular _____ Vegetarian

SPF donation: \$ _____ _____ Gluten-free _____ Soft

Total enclosed: \$ _____

Please make your check out to SPF and send it with the registration form to:

Ashton Hecker, Conference Chair
1715 McDuffie Street, Houston, Texas 77019

7700 Leesburg Pike, Ste 123
 Falls Church, VA 22043

The screenshot shows the website interface with the following elements:

- Browser Header:** Mozilla Firefox, address bar: http://sp-foundation.org/
- Navigation:** File, Edit, View, History, Delicious, Bookmarks, Tools, Help. Search bar with "GO" button.
- Logo:** SPF SPASTIC PARAPLEGIA FOUNDATION, INC. with tagline "Research / Education / Support".
- Utility:** Phone number 1 (877) 773-4483, Home, Subscribe, Contact Us, Synapse on-line, Annual Conference 2011, and a red **DONATE** button.
- Form:** "Subscribe" section with an email input field, a "zip/post code" field, and a "GO" button.
- Menu:** Local Events, Volunteer, Shop Our Store.
- Content Grid:**
 - About the Disorders**
 - Our Research Mission**
 - Getting Assistance**
 - Giving and Getting Involved**
 - Guide**
- Featured Article:** "Chair Yoga" with a photo of people at a conference. Text: "Participants at the National Conference (Los Angeles, 2010) learning yoga from their chairs. Learn how to gently stretch and strengthen those muscles." Includes a "read more..." link.
- Other News:**
 - "Each year, the employees of Travelers Insurance hold a Golf fund raiser that draws 120 golfers, plus 60 other guests. read more..."
 - "Magnificent Mile combines a fun run with a USATF-sanctioned race. The event raises money for read more..."
- Footer/Right Side:** "Become a fan on Facebook" button, "Local Events" section listing "New England Connection (Worcester) April 2" and "Dallas-Fort Worth Spring Connection April 9".
- Bottom Left:** "Welcome" section with "SPF Vision...The day where all individuals with HSP or PLS are diagnosed, treated and cured." and a "Medtronic Pump Recall" section.