

Synapse

Volume 18, Issue 3

Fall 2015

Newsletter of the Spastic Paraplegia Foundation



Letter from the President



Dear Friends,

This is a really exciting time for The Spastic Paraplegia Foundation. The scientific research we are sponsoring keeps turning up ever more encouraging hope for a cure or treatment. It feels like I can smell a cure in the air, like bacon in the morning.

You may remember that our Annual Report this past Spring listed 4 pages of just the highlights of the incredible progress taking place in HSP and PLS research. In the last *Synapse* Newsletter, I told you about the Tom Wahlig symposium in Graz Austria in May. This is an annual meeting of scientists from around the world each presenting their latest research about HSP. The excitement about all of the progress taking place was so invigorating, it felt like you could cut it with a butter knife.

Since I last wrote you, I attended an international HSP/PLS meeting in Madrid, Spain in June. It was exciting to meet and share with each of the many HSP Foundations from Australia, Germany, Spain, Italy, The Netherlands, Sweden, France and UK. We each made a presentation about our foundations and the incredible research many of us are sponsoring. We agreed to work together on an international HSP/PLS publicity campaign.

Also in June, The Spastic Paraplegia Foundation had a very successful Annual Conference in Seattle, WA. This *Synapse* will have many stories about our conference. We enjoyed meeting and reuniting with old friends as well as touring the beautiful city and surroundings of Seattle Washington. I want to again thank our largest Annual Conference Sponsors, Athena Corp, Invitae Corp and Met Life.

Our Board of Directors are currently working with our Scientific Advisory Board to rate the latest round of research proposals. Each proposal is ranked by several of the volunteer expert scientists on our SAB. The reports and rankings are compared by our SAB Administrator so we are sure to support the very best research in the world. Let me tell you, the science is moving along so fast that we are faced with the dilemma that there are many more top rated research proposals than we have been able to afford to support.

Please know that all of this is only possible because of your past generous support and I want to thank you so much.

Sincerely,

Frank Davis

President

PS: Everyone on our hard working Board of Directors is a volunteer and all travel expenses are self paid. We do not have any paid staff.

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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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July 1, 2015

Rebecca Schule, MD
Hertie Institute for Clinical Brain Research
Department of Neurodegenerative Disease
Otfried Muller Str. 27 72076 Tübingen

Dear Dr. Schule:

We the undersigned, as the leaders of groups representing people with HSP in 8 countries, collectively endorse and enthusiastically support your research project “**Genome Studies in Hereditary Spastic Paraplegia – beyond the exome**”.

We are convinced that a multi-site program for gene discovery in Mendelian disease, as described in the project plan, is essential in identifying new therapeutic targets for many diseases, including HSP. We will communicate the nature and importance of the project to our respective HSP communities and facilitate the recruitment of participants to it.

We wish for a positive outcome with the funding grant application and also wish you and the team every success with the exciting work to come on this project. We look forward to our future collaboration on this important work.

With our best regards,



Foreningen for ATAKSI / HSP



Marcos Guadalupe
Vicepresidente de AEPEF, Spain



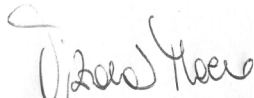
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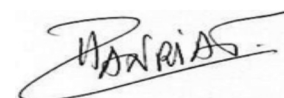
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Board Business

Compiled by John Staehle, Editor

In May, the SPF Board approved the allocation of \$600,000 for grant awards this year. Since we increased our grant amounts to \$150,000 over a two year period, that allocation will allow us to award 4 grants this year.

Board member Greg Pruitt reported he and his brother are planning a golf tournament fundraiser in Kentucky on September 19. John Cobb plans to conduct his second annual “Cobb Classic” tournament on November 7.

Frank Davis reported he will be attending the HSP Support Groups International Meeting (at no expense to SPF) in Madrid, Spain the beginning of June. The meeting, being organized by Frank McKeown of the HSP Research Foundation of Australia, will follow the Eurodis Rare Disease Conference. Representatives and leaders of several European countries’ HSP organizations are expected to be there.

The June Board of Directors meeting was held in Seattle on Friday, June 26, prior to the start of the Annual Conference. Topics discussed by the board included the Scientific Advisory Board’s Role in the Grant Award Process, during which Dr. Fink suggested that recipients of SPF grants be advised that they must serve on the SAB for two years as a condition of receiving the grant (this is the process used by NIH). The Board also discussed ways to improve our grant application process and the status of the whole genome screening projects by HLI (Human Longevity Inc.) and ViaGenetics and the myriad of issues that must be addressed in this rapidly expanding field of research. Additional topics discussed were the need to identify our time-phased research priorities and to increase our political outreach to our congresspersons to get their support for those priorities; the idea of creating a medical “Journal of HSP” which would become the official journal of the SPF; the possibility of creating a TED Talk about SPF, though the general feeling was it would be an enormous undertaking that would not likely happen; and Frank Davis’ attendance at the HSP Support Groups International Meeting in Madrid earlier in June, specifically the discussion about creating an international patient registry

for research, especially when research reaches the clinical trials stage.

Actions taken at the June meeting were:

- Greg Pruitt moved the chair appoint a committee to determine long range planning and strategic objectives; seconded by Mark Weber; motion carried. Volunteer members of the committee are: Mark Weber, John Fink, John Cobb, Corey Braastad and Frank Davis. Frank agreed to chair the committee.
- Jean Chambers moved to authorize Greg and Norma Pruitt to prepare and submit to the federal government an application for grant funding to be used toward the expenses of the SPF meeting currently being planned for 2016 in Chicago and to authorize them and our officers to execute any documents necessary to complete and submit such application; seconded by Jackie Wellman; motion carried.
- Kris Brocchini moved to reimburse HSP Australia for SPF’s share of meeting expenses paid by HSP Australia for Rebecca Schule’s flight from Miami to Madrid and her hotel costs so she could attend the HSP Support Groups International Meeting. This would be about \$300. Mark Weber seconded and the motion carried.

At the July Board meeting, a suggestion made by Dr. John Fink at the Annual Conference to “invite big donors to SPF’s Annual Conference,” was discussed with regard to what specifically the invitation would include. After exploring several alternatives, Kris Brocchini moved that we invite them and a guest to be our special guests at dinner on Friday night. Tina Croghan seconded and the motion carried.



Standing L to R: Corey Braastad, John Fink, Greg Pruitt, Frank Davis, Kris Brocchini, Linda Gentner, John Cobb, Seated L to R: Jean Chambers, “Annie”, Tina Croghan, Jackie Wellman, Mark Weber. Not pictured: David Lewis, John Staehle.

Dear SPF Family,

I would like to thank every sponsor, vendor, attendee and speaker who helped in making the 2015 SPF Annual Conference such a success.

There were so many who contributed time, money and so much effort in bringing the conference to a fun and absolutely informative event! We were so fortunate to have some of the most knowledgeable doctors on both HSP and PLS attend and speak at the conference.



A sincere thanks goes out to Craig Gentner for once again being our Master of Ceremonies. It is not an easy job to keep everything on time and running smoothly. Actually, I now know that it's almost impossible!

Thank you to all the wonderful doctors who took time away from their busy schedules to come to Seattle and share their knowledge with all of us in attendance. Dr. John Fink, Dr. Christina Fournier, Dr. Leo H. Wang and Corey Braastad, PhD.

Thanks to Angela Dixon for being able to hear and visualize the concept for "Dancing in the Rain". Her artwork went above and beyond. Angela and James provided not only the artwork but donated their time and talent to provide the programs for the conference.

Thanks to Cory Weiser & Kelly Placenti with MetLife who were our speakers Friday night. Thanks for MetLife for again sponsoring our conference.

We sure want to give a special thanks to Terry Hart & Sue Dobson, Rebecca's parents, for their very lively and touching presentation about Rebecca's growing love and skill with horses from the very first time she asked her dad to stop the car at a carnival so she could take a pony ride.

Thanks to all the sponsors this year. Without this group of sponsors there would have been no wonderful fun times and great meals, and the "best of the best" speakers. So a special thanks goes out to: Kris Brocchini, Ned and Dee Davis, MetLife, Mike & Ann McLelland, Athena Diagnostics, Invitae Corp., Erik Linstrom and Frank & Claudia Davis.

There is a saying that "it takes a village" and this is especially true when putting on a conference. I could not have ever done this job without the help of my family, friends and the volunteers from the SPF community. I would like to thank Linda Gentner, who had to put up with an amazing number of emails from me asking way too many questions.

Thanks to all who helped make the 2015 Conference such a wonderful experience for me. I can honestly say I had a great time meeting everyone and being the conference coordinator. Thanks to everyone who made up the "village". I look forward to our 2016 SPF Annual Conference in Chicago!

It is truly a learning experience doing this job. Hopefully, next year I will have more of "my ducks in a row." Thanks for your patience.

Sincerely,

Claudia Davis

*2015 SPF Conference Coordinator
claudiadavis6@yahoo.com*

FEDERAL EMPLOYEES ARE WILLING TO SUPPORT SPASTIC PARAPLEGIA FOUNDATION

The Combined Federal Campaign or CFC is a fundraising campaign the Federal Government offers its employees to participate with each year. It is like a United Way campaign where employees pick which non-profits they would like to support. The CFC starts the end of August and usually runs through December.

Each year **Millions** of dollars are raised through the CFC campaign. The bad news is that the Spastic Paraplegia Foundation doesn't get much of the money raised.

Your help is needed to ask Federal employees you know to pick the Spastic Paraplegia Foundation to contribute to. The best way to get a commitment is to ask personally. If that is too uncomfortable, feel free to send a letter or email. The Spastic Paraplegia Foundation CFC number is **12554**. Federal employees will need to know that so they can designate the SPF.

The following are examples of Federal employees: law enforcement, mail personnel, VA or Veteran's Administration employees, Medicare, Medicaid, military and many types of governmental jobs. If donors want to know more, please have them log on to www.sp-foundation.org.

Many federal locations have CFC Fairs during the Fall. They allow representatives from organizations to visit with employees and provide information. If you hear about one in your area and would like to help inform federal employees about the SPF, please let me know. I can get you the materials you will need. All you will need to do is provide the time and a friendly attitude. If you have any questions, suggestions or would like to help with a CFC fair, please contact Jim Sheorn at jmsheorn@comcast.net or 615-479-7369.

Please help us generate more resources for research.

Singing In The Rain In Seattle

2015 SPF Annual Conference, Seattle, Washington, June 26-28, 2015

Each of the following five articles summarizes one of the presentations made by Saturday's speakers. To view the entire presentation (recommended) go to the SPF website, sp-foundation.org, click on What We Do and then select ANNUAL CONFERENCE RECAP. There is no video of the presentation made by Rebecca Hart's parents. The video on the website was produced in 2014, but it is still very much worth watching. Ed.

AN UPDATE ON PLS AND FUTURE DIRECTIONS FOR RESEARCH

Christina Fournier, M.D., MSc, Emory University, Department of Neurology

Dr. Fournier began her presentation by describing PLS as a "pure upper motor neuron" disease. With PLS, only the upper motor neurons are damaged, In contrast, with ALS, both upper and lower motor neurons are damaged. Early symptoms of ALS and PLS are similar and generally, if symptoms remain those of upper motor neuron damage only, then a diagnosis of PLS can be confirmed.



There is an open question whether ALS and PLS are on the same continuum or are they two distinct diseases. There is no clear answer yet, but there are muscle biopsy and EMG test results that indicate there may be some degree of overlap of the two diseases.

More research is needed to reach a definitive answer to the continuum question.

PLS behaves differently than ALS. Median survival after symptom onset is greater than 15 years while ALS median survival is around 3 years. Median age of onset for PLS is 47-54 and for ALS it is late 50's. PLS has a slower progression and different patterns of spread from ALS.

Because of the rarity of PLS, it is difficult to get enough participants to conduct clinical trials at any one research center. That prompted NEALS (Northeast ALS consortium) to create a UMN Disease Registry. The goals of the registry are to establish UMN disease clinical trial feasibility, characterize clinical and EMG characteristics, and determine if minor EMG differences predict clinical differences. The registry has 233 patients from 20 different sites; 217 of them had EMG data. Their mean age is 62, 51% are male and the mean duration of their disease is 84 months.

Dr. Fournier then reviewed clinical data gathered from these 217 patients. The following are slide images of these data taken from her presentation:

	Normal EMG n=140	Minor Denervation on EMG n=77	Total n=217	p-value
Legs (%)	84%	86%	85%	0.736
Arms (%)	40%	31%	37%	0.221
Bulbar (%)	24%	30%	26%	0.388

	Normal EMG n=140	Minor Denervation on EMG n=77	Total n=217	p-value
Legs (%)	98%	99%	98%	0.841
Arms (%)	84%	95%	88%	0.018*
Bulbar (%)	62%	64%	63%	0.736

	Normal EMG n=140	Minor Denervation on EMG n=77	Total n=217	p-value
Walks unassisted	29%	26%	28%	0.551
Walks with assistance	74%	77%	75%	0.482
Use of cane	21%	16%	19%	0.338
Use of walker	37%	34%	36%	0.675
Use of wheelchair	34%	47%	38%	0.047*

	Normal EMG n=140	Minor Denervation on EMG n=77	Total n=217	p-value
Spasticity	97%	92%	95%	0.097
Abnormal walking	94%	95%	94%	0.853
Slurred Speech	68%	67%	68%	0.994
Pain	43%	43%	43%	0.839
Sleeping Difficulty	36%	33%	35%	0.851

	Normal EMG n=140	Minor Denervation on EMG n=77	Total n=217	p-value
Fatigue	30%	41%	34%	0.108
Depression	32%	34%	33%	0.727
Pseudobulbar Affect	33%	31%	32%	0.86
Increased Saliva	28%	32%	30%	0.45
Shortness of Breath	26%	30%	28%	0.504
Anxiety	23%	19%	21%	0.666

The result of the UMN Registry is that with 233 PLS patients at 20 participating sites, the population is large enough to conduct clinical trials, thereby accomplishing one of its goals.

Future research will include a Longitudinal UMN Disease Registry that will look at patients' histories on a timeline to see if a model of disease progression can be developed that will ultimately help physicians counsel their PLS patients on what to expect and when.

Future research would be greatly improved with the identification of PLS and ALS biomarkers that are diagnostic or that measure disease progression. If ALS and PLS share similar biologic pathways, then PLS patients could benefit from inclusion in ALS trials. If PLS has unique biologic pathways, then biomarkers could help separate PLS from ALS earlier and PLS biomarkers could identify treatment targets. Biomarkers can also be used as outcomes in clinical trials. The Ongoing Longitudinal Biomarker Study involves: recruiting PLS and ALS patients; collecting clinical measures, cognitive testing, blood, and spinal fluid every 4 months for up to 2 years; looking for biomarkers that predict disease progression to use in clinical trials; and exploring diagnostic biomarkers for PLS and/or upper motor neuron disease. The six sites participating in this study are:

- Massachusetts General Hospital, Boston, MA
- Emory University, Atlanta, GA
- Mayo Clinic, Jacksonville, FL
- U MASS, Worcester, MA
- U of Pittsburgh, Pittsburgh, PA
- Barrow Neurologic Institute, Phoenix, AZ

“GENETICS AND GENOMICS OF HSP AND PLS”

Corey Braastad, PhD, Athena/Quest Diagnostics

Once again Dr. Corey Braastad guided us through the myriad pathways of genetics and genomics. I say “once again” because things are changing so radically that Corey can spend an hour bringing us up to date. He started off with a brief



history of the study of genetics: in the 19th century, Mendel described the units of inheritance. In 1900 blood was ‘typed’ as A, B, 0 and in 1940 the Rhesus factor was introduced. Modern genetics is only 50 years old. From 1980 to 2000 progress was made in describing, among other disorders, Cystic Fibrosis, Huntington’s Disease, Marfan Syndrome, Fragile X Syndrome, Cancer typing of BRCA1 and BRCA2, Familial Retinoblastoma and Lynch Syndrome.

We inherit 23 pairs of chromosomes – 23 from our mother and 23 from our father. The genes we inherit from our parents are ‘packaged’ inside the chromosomes and arranged like beads on a string. The genes are the recipes – the instructions for the body in the making of proteins. Each rung on the DNA double-helix “ladder” is a nucleotide which is described by one of four letters: A, T, C or G. Three nucleotides (i.e., three rungs on the ladder) define a specific amino acid. A string of amino acids builds a specific protein. Mutation is a failure of DNA to repair a disruption to the creation of a protein. In the living cell, DNA undergoes frequent chemical changes, especially when it is being replicated. Most of these changes are quickly repaired. Those that are not repaired result in mutation. Dr. Braastad demonstrated this process using 14 participants from the audience. Each participant was identified as an amino acid and all 14 amino acids made up a specific protein. One participant represented an amino acid which had one of its nucleotides missing. The reading of nucleotides in groups of three was altered and a variant protein was created. Sometimes the result is a benign polymorphism that does not disrupt or alter the function of the protein product. A pathogenic variant (a mutation) is one that disrupts or alters the functional protein and causes disease. There are several types of DNA mutations:

- Point mutations
- Insertions or deletions
- Splice site mutations
- Repeat expansions (*important for ALS but not for HSP*)
- Somatic mutations (*not passed on to offspring*) vs germline mutations (*every cell within offspring will contain the mutation*)



The two most common inheritance patterns in HSP are Autosomal Recessive and Autosomal Dominant. In Autosomal Dominant one gene in the pair contains the mutation. All individuals with the mutation are affected by or predisposed to develop the condition. Each offspring has a 50% chance of developing HSP. Male and females are equally affected. Examples of Autosomal Dominant HSP: SPG3, SPG4, SPG 6, SPG 8 and SPG 31. In Autosomal Recessive both genes in a pair must contain the mutation. Individuals with ONE mutation are carriers and are not affected. There is a 25% occurrence rate for offspring with both parents are carriers. Males and females are equally affected and examples are SPG 7 and SPG 11.

Dr. Braastad defined Genetics as, “The study of inheritance patterns of specific traits,” and Genomics as, “The study of genes and their function.” The National Institutes of Health (NIH) has been spearheading the Genome Project, a research and technology-development effort aimed at mapping and sequencing the genome of human beings and certain model organisms.

The geneticist’s approach to reaching a diagnosis involves the analysis of hypothesis-driven data. Steps typically taken are to (1) examine patient and family history, (2) develop a differential diagnosis, (3) order appropriate confirmatory tests, and (4) refine hypothesis, if necessary, and repeat step (3). These are the steps taken by an informed neurologist. If not familiar with HSP, the neurologist may order a panel of tests that searches for a gene match.

On the other hand, the genomicist’s approach is to test data-driven hypotheses. Steps taken are to (1) get whole genome or whole exome sequence, (2) use sequencing data to develop differential diagnosis and (3) attempt clinical correlation to confirm diagnosis.

Dr. Braastad’s presentation summarized by Jean Chambers, SPF Secretary and SPF Board Member.

ADVANCES IN HSP AND PLS SMALL STEPS AND BIG STRIDES

John Fink, M.D., Director of the Neurogenetic Disorders Program University of Michigan

Dr. John Fink, Director of the Neurogenetic Disorders Program at the University of Michigan and medical advisor to the SPF Foundation, spoke to the conference on Saturday morning about the significant progress being made in research for both HSP and PLS. He described the work over the past year to be making incremental progress, but emphasized that many small steps made in the right direction will ultimately result in big strides that make the difference for those who suffer with HSP and PLS.



According to Dr. Fink, the word “paraplegia” overstates the condition. Most who suffer with HSP do not have “paralysis”. The proper term is “paraparesis”, which describes different degrees of immobility from subtle to severe. The spasticity causing the impaired immobility is caused by an upper motor neuron disturbance in the nerves that extend from the brain through the spinal cord. Just as patients have varying degrees of paraparesis, they also have varying degrees of weakness. Some of his patients show little change in strength and weakness over a ten to fifteen year period, while others show significant weakness more quickly. Spastic gait is a complex symptom, involving the upper motor neuron deficits and subserving bilateral lower extremities and can include increased muscle tone, slowed movements, decreased precision and weakness.

For those who may be considering the use of an intrathecal baclofen pump, Dr. Fink indicated that the pump can be very helpful in dealing with the spasticity component of spastic gait; however, it would most likely not be very helpful for those who have more muscle weakness issues. The baclofen would cause the weakness to be more pronounced, interfering with the balance between spasticity, tone and weakness that is important for us to consider as we deal with the progressive symptoms.

Dr. Fink reminded the group how important exercise and physical activity/therapy is in dealing with the



condition. “The way we walk is training the way we will walk,” he stated. If we sit down at a piano and play a musical key the wrong way only three times, it makes it much more difficult to play it correctly. He also shared the story of a college student with HSP who walked to classes using arm crutches. When he came home for the summer, he spent much time on the couch, walking only 100-200 steps per day, significantly affecting his mobility in a negative way.

Dr. Fink indicated that the therapeutic use of stem cell transplantation to treat nervous system disorders (e.g. ALS) is currently under investigation. He indicated the process is moving forward very slowly and that it is very expensive. Studies to understand molecular processes and potential treatments for both HSP and PLS are being done to look at possible steps for stem cell treatments. Next generation and whole genome sequencing for large numbers of PLS subjects is available and could provide transforming insights in the causes of PLS. Finally, some clinical trials are underway such as the use of ampyra for HSP patients and drugs for neurodegenerative diseases are a global pursuit.

While we continue to find new gene mutations (now more than 80) that cause HSP, that is not enough. We have to discover why that mutation causes the problem in order to identify potential “small molecule” drug treatment that can successfully correct the problem.

In closing, Dr. Fink discussed our research priorities. He said we must 1) invest carefully; 2) do what we do best; 3) think creatively and work smarter; 4) aim at fundamental problems (yielding transformative advances) rather than easier, short-term objectives; and 5) lead, inspire and encourage others to participate.

During the afternoon question and answer session, Dr. Fink made a number of important points:

- SPG7 is highly variable. One in 23 PLS patients have this mutation, but that does not mean that SPG7 patients will morph into PLS. Other mutations are very variable (e.g. SPG4 has 600 different variations).
- Dorsal rhizotomy (cutting fibers from the spinal cord to decrease spasticity) - he said this can work, but he is “not so excited” about it. If the spasticity is profound and untreatable he would consider it, but prefers the use of a baclofen pump first. This process could result in significant weakness.
- In regard to a baclofen pump trial, the question is not are your legs more limber, but does it improve your walking?
- With balance issues, the motor sensory nerves are affected. Weighted belts or vests might be helpful with the loss of motor response. If interested, see your podiatrist or physical therapist. Also, do dedicated balance exercises.
- Increased reflexes in the arms and hands are very common in HSP patients.
- Environmental factors – He is not aware whether agent orange creates upper motor neuron problems.
- Regaining lost muscle strength will take long-term exercise and commitment.
- Hearing loss can occur with some forms of HSP.
- Try to gradually increase your exercise or walk, but do not try to do too much too quickly.
- Long-term upper motor neuron problems can result in or cause later lower motor neuron symptoms to appear.
- In regard to achilles lengthening surgery, try physical therapy, more physical therapy, botox and more before doing any surgery, particularly achilles lengthening.
- PLS does not morph into ALS, but an early correct diagnosis may be difficult. The longer your PLS symptoms exist, the less likely that you have ALS.
- No cure is just around the corner. Just work to stay as healthy as you can through exercise and therapy.
- Ampyra helps a few HSP patients, but not many. Researchers are working on other drugs for HSP/PLS that are similar to ampyra.

Dr. Fink’s presentation and Q&A session summarized by Greg Pruitt, SPF Board Member.

Primary Lateral Sclerosis

*Leo H. Wang, M.D., PhD, Assistant Professor,
Department of Neurology, University of Washington*

Dr. Wang's presentation addressed the symptoms of PLS, the problem in PLS, causes of PLS, what the PLS patient can expect and ways to manage PLS.



Early symptoms of PLS have been described as “usually begins slowly and insidiously...with a sense of weight, dragging and slight feebleness in one or the other leg, without pain. The condition progresses just as slowly as it begins. The legs become stiffer...and the gait more labored.” Wilhelm Heinrich Erb, MD, 1902. PLS is a clinical diagnosis. Criteria that point to PLS are adult onset, no family history of a PLS-like disorder, insidious onset and a gradual increase in spasticity, symptoms that have been present for 4 or more years and all clinical findings are limited to corticospinal tract dysfunction. Criteria that exclude PLS as a diagnosis are known causes of spasticity: ALS; cervical spinal stenosis; MS; HSP; infections like Lyme disease, human T-cell lymphotropic virus (HTLV) Types I and II and syphilis; abnormal brain MRI; or metabolic conditions, toxins or vitamin deficiencies.

The cause or causes of PLS are still unknown, but there are areas of focus that require more study. One is that PLS is a variant of ALS and they have a common cause. Another is that PLS is a heterogeneous disorder that can have different causes. For example, subsets of PLS have causes similar to ALS while others are more similar to HSP. And finally, PLS is caused by environmental factors that affect people who may have genetic risk factors.

Patients diagnosed with PLS can expect their symptoms to progress rapidly for 5-8 years and then slow down or stop. Based on a study done by the University of Western Ontario ALS Clinic on 661 ALS and PLS patients,

- 45% will need help with mobility
- 30% - 40% will need help with cleaning, cooking, dressing and personal hygiene
- 16% will remain independent
- Half will retire
- 32% will change jobs
- 68% will make changes to their households to increase accessibility and safety

PLS is a rare disease – estimates place the total number of PLS patients in the U.S. between 600 and 1800. Being

such a small population, funding for research is limited. In the meantime, PLS patients have to learn to manage the symptoms and consequences of their disease with physical therapy, speech therapy, occupational therapy and alternative medications. There are medical treatments for spasticity, stiffness, muscle spasms, pseudobulbar affect and excessive salivation. There also are physical treatments such as rehab and physical therapy, orthotics and assistive devices, neural prosthetics and brain-computer interfaces. Some solutions to the poor nutrition consequence of PLS symptoms are breathing support, eating aids, high calorie/high protein diet, modified food consistency, feeding tubes. For dealing with cramps, solutions include massage, hot baths, stretching, carbamezepine and baclofen, mexiletine, quinine sulfate (small amounts in tonic water if cannot get prescription quinine sulfate).

Managing spasticity requires finding the right balance between too stiff and too loose. Medications include baclofen, diazepam, dantrolene, memantine, and tizanidine. In addition there is an implanted pump available for a more specific and controlled delivery of liquid baclofen. Botox is also available for focal control of spasticity. Most recently, the use of medical marijuana has been shown to be an effective control for spasticity in MS patients, but because of drug laws in the U.S., its availability is very limited and tightly controlled.

The two most active ingredients in the marijuana plant are the psychoactive tetrahydrocannabinol (THC) and the non-psychoactive cannabidiol (CBD). These two are the major components in medical marijuana. In the United Kingdom, a double-blind randomized placebo-controlled study was conducted using 572 MS patients. Results of the study showed a significant difference at reducing spasticity between patients receiving THC/CBD and those receiving the placebo. THC/CBD is approved for use in Europe to treat MS. THC/CBD is currently being evaluated by the FDA for treatment of MS in the United States. If it can be shown that spasticity in MS and HSP/PLS have similar sources, then approval for its use with HSP/PLS can be pursued.

Dr. Wang has seen mixed results with his patients that have taken medical marijuana. Some benefit from it and others do not. He doesn't believe patients should be on medications that don't help them.

Future challenges are to develop disease-directed therapy. To achieve this, a specific target needs to be identified. When identified, challenges for the target will be in the areas of disease onset (prevention), progression and repair and regeneration.

PUTTING THE “ABLED” IN DISABLED...YOUR PERCEPTION IS EVERYTHING

Sue Dobson and Terry Hart, Proud Parents of Rebecca Hart

“I AM ALREADY NORMAL!” cried a 13 year-old Rebecca Hart to an insensitive doctor. “I am unusual!”

Rebecca’s love for horses began when she was 5 years old. Sitting in the back seat of a car she cried, “Top! Top! Top!” to her father who screeched the brakes thinking something tragically was wrong. You see a young Rebecca Hart had trouble saying her “S’s”.

“I want to go on the pony ride!” she squealed.

Thus began her seeming inseparable love for horses. Her parents, Sue and Terry Hart, nurtured that love. Becca has HSP but was called then, Familial Spastic Paraplegia, which her father has, too.

Rebecca defied the doctors with an unknown self-therapy—riding horses, hippotherapy. She didn’t know it was therapeutic—she just did it to be with horses! It challenged her balance as well as mobility but is not widely found in most stables in the United States. In Europe, this is a different picture, where therapeutic riding is widely available and many countries support monetarily their high level athletes with disabilities just as they do their non-disabled athletes. The United States is not quite, there, yet,” says Sue Dobson, Rebecca Hart’s mother.



Rebecca mounts the horse with a special staircase that she had constructed. Her legs stretched astride the horse and special Velcro straps keeps them in place. She steers and guides the horse with her shoulders and posture in the saddle.

Rebecca went on to compete in Dressage (ballet on horseback) in numerous competitions including the Paralympics in London and Beijing with her horses, Norteassa and Lord Lugar. PARALympics simply means PARALLEL Olympic rules. Nothing is made easier because of her disability.

“That’s somewhat from SPECIAL OLYMPICS. The competitors there usually have developmental difficulties,” stated Sue Hart.

The reason she would not be in attendance this year was because she was busy placing Third in France and then 2nd in Germany with her new horse, Romani.

Since the conference, we found out Rebecca placed 1st in Dressage in England at the prestigious Hartpury Competition.

Rebecca has continued to be an inspiration for all—not just the young, misunderstood girl, who longs to feel free finally on the back of a horse.

Summarized by Tina Croghan, Missouri SPF State Ambassador and SPF Board Member.

“Disability is not a brave struggle or ‘courage in the face of adversity.’ Disability is an art. It’s an ingenious way to live.”

– Neil Marcus

Connections

SPF Illinois Connection July 18, 2015

HSP: Sid Clark PLS: Hank Chiuppi

We tried a summer meeting and the results were good. We had 17 in attendance and covered a number of topics of interest. We evaluated the recent Abilities Expo held in Chicago and the various equipment vendors there. How you qualify for wheel chair either hand push or power was also discussed. We mentioned that the SPF conference would be in Chicago with information to come. Then we talked about various drugs and the experiences with them: drugs like Ampyra, Keppra, Baclofen, Gabapentin, CBD oil, THC, and Botox.



One of the group showed us her hand controls and what is needed to qualify for them. A good time was had and we learned by open honest sharing. For lunch we ordered from Corner Bakery boxes and had the driver take the connection picture. Importance of keeping a positive attitude was discussed. Carolyn led us in a chorus of Zip-A-Dee-Doo-Dah. Our voices were not bad – but we are keeping our day jobs.

The date for the fall meeting has not yet been set but will be the end of September or early October. By each of us sharing we have learned a lot. For information on future meetings email us at SPFIllinois@gmail.com.

Austin Patient Connection August 29, 2015

The Austin, Texas, Patient Connection, held August 29, 2015, was a great success with 13 people in attendance. There were many comments and questions about Hereditary Spastic Paraplegia amongst the group. There were no attendees with Primary Lateral Sclerosis this year. Attendees left with new friends and new information from this Austin Patient Connection.

Marlene Doolen
Texas Ambassador
Spastic Paraplegia Foundation



Iowa Connection August 29, 2015

A small group but we really enjoyed our long lunch.

Jackie Wellman
Iowa SPF State Ambassador and SPF Board Member



*Back row...
Colette Ergenbright,
Dina Landphair,
Dave Statezni, and
Kimm Richman.
Jackie Wellman sitting.*

TeamWalk 'n Roll for our Cures

Saturday, September 19, 2015

By Linda Gentner, SPF State Ambassador, Northern California and Vice President, SPF Board of Directors

Festivities began at Friday night's dinner. A good time was had by the 20 attendees.



On Saturday, a group of about 65 of us met for our Walk 'n Roll in Pleasanton, California. The weather was picture perfect although a bit hot (95), but better than too cold or rainy. Registration began with pastries, juice and coffee to get us going to begin our Walk 'n Roll. Our walk ended at a Farmer's Market which all our members truly enjoy. We met back at the church for our lunch and raffle. Everyone in attendance had a great time meeting new people and re-connecting with "old" friends. This year, as always, we had a few new members. Our fund raising amounted, so far, to \$30,000.



REBECCA HART FINISHES EUROPEAN TOUR WITH THREE TOP FINISHES AT CPEDI3* HARTPURY FESTIVAL OF DRESSAGE

HARTPURY, ENGLAND – July 15, 2015

Rebecca Hart and Schroeter's Romani continue to succeed on their whirlwind European tour, proving nothing will stand in their way on the road to the 2016 Olympics in Rio de Janeiro. The duo gave it their all to finish third Friday in the Grade II Freestyle at the CPEDI3* Hartpury Festival of Dressage in England with a score of 73.95 percent.

Hart will conclude her successful visit to England with top ribbons in each test: a team test score of 72.706 percent for the win on the opening day, and the individual test score of 71.409 percent earning her a strong second as the first to ride down the center line. Hart narrowly missed the blue on the final day for the Freestyle, which was won by two-time Para-Olympic gold medalist Natasha Baker with a score of 75.600 percent.

"It is very exciting to end our European tour with such great results, more than I ever could have hoped for," Hart described. "To hear our national anthem played the opening day was a dream that I have always had, come true. To have it played in England, at Hartpury, made it that much more special. It is the first time I have ever heard it in European competition, and it is such a huge honor to have my horse rise to the occasion for me. It was really nice for me to give back to the people who have supported me; it was nice to be able to share that moment with them. There has been a really nice progression to have everything come into fruition from January during the CPEDI in Wellington to now."

Hart and Romani recently broke their personal records, riding to their first European scores over 70 percent at the CPEDI3* Überherrn 2015. Hart just came off of a trio of top finishes during the Mulhouse CPEDI3* in France two weeks prior to her exceptional rides in Germany. She admitted that she is feeling more confident than ever before with Schroeter's Romani, the international competition, as well as the venues and atmosphere.

"I found it very interesting that Becca, over the three competitions, got better and better. The more challenging the competitions and the better the horses, the better she performed and she earned higher scores," trainer Todd Flettrich said. "Their success is accredited to both of them performing as a team. Romani is a fantastic horse, she has a wonderful demeanor with quality gaits. They have overcome their weaknesses, and the feeling that Becca has with the mare truly shows, therefore they shine. I think she really stood out among all those other horses in England with their harmony and their rapport."

Rebecca Hart and Schroeter's Romani concluded their European Tour with the first, second and third place finishes during the Hartpury Festival of Dressage. Photo By: Kevin Sparrow

The Hartpury Festival of Dressage marked the final leg of Hart and Romani's European campaign, and the duo will return to the United States to continue competing on the road to Rio.

Flettrich commented, "I am proud of Becca and the mare, both of them are fantastic. To have won in Great Britain, or anywhere, against a gold medalist is a wonderful feat. We were the only other anthem played during the awards ceremony on the opening day. The first day is the most difficult day because of your nerves and settling into the environment. For me, to win the first day is the most important. I was extremely proud. I wasn't proud just because she won. Becca made all the corrections we talked about to improve the test. Our goal is Rio, we still have room for improvement, but she is getting better and better every day-it is a journey."

Hart would like to thank her generous sponsors, donors and owners who helped her finance the European-tour. She gives all credit to those supporters, especially Margaret Duprey and Cherry Knoll Farm, Sycamore Station Equine Division, Barbara Summer, the Ruffolos, and Will and Sandy Kimmel, all part-owners of Romani, attributing her success at the events, at an international competition of such high-caliber and with a horse that understands Hart's rare progressive genetic disease, Familial Spastic Paraplegia (FSP), would not be possible without them.

"I want to give a big thank you to Todd [Flettrich] for holding my hand through everything, as well as Hannah Hassinger for always making Romani look the best she can," Hart concluded.

Hart's name is a familiar one in the dressage sphere, earning the title of National U.S. Paralympic Champion in 2006, 2008, 2009, and 2010. She competed last year at the World Equestrian Games for the United States Equestrian Team, and has also shown in two Paralympics for the USA. She now has her sights set on the Rio 2016 Paralympic Games.

Hart returns to the United States on Tuesday, where she and Romani will be based out of Wellington, Fla. They will prepare for the Nationals at the end of September in Texas and then return to Florida for the final two qualifiers for Rio in January.

For more information on Rebecca Hart and Cherry Knoll Farm, please visit www.cherryknollfarminc.com.

Living with HSP/PLS

PLS ... GETTING SPEECH BACK?

By Eleanor Kane

What WAS that word I was trying to say? I can't remember what the word was, but it probably had an "s" sound which still gives me trouble. I do know that I couldn't pronounce the word, and that was when, nearly ten years ago, I suspected that I had a problem, a problem which prompted me to see a Neurologist at Kaiser Permanente, my health provider. About three years later, he was finally able to give me a diagnosis: Primary Lateral Sclerosis. It's a rare neurological disorder, which I happened to know about because my sister's husband had had it. Readers of Synapse know that it affects the upper neurons that control balance, speech and other functions which may vary from patient to patient.

I must use a Walker when I walk and because of poor balance, I fall frequently, and that is perhaps my main concern. But for a big part of each day, my inability to speak clearly is perhaps my most frustrating problem. I've had speech therapy, which didn't help. I've had machines (including a smart phone) and am about to be given instruction on a new, improved Tobii talking machine, called Dynavox. I will type on a sort of iPad. The machine will speak what I type. Hopefully, I will at least be able to communicate better than I can now. In my autobiography class which I've taken for at least

fifteen years, our teacher starts us off with a prompt which may be a paragraph or poem she reads to us. Last week she said: "Write what's it's like to have a conversation with someone who only speaks a different language". Then we go around the class reading what we've written aloud. Since the class cannot understand me, my seat-mate Anne reads my stories to the class. She does it well. Last week, she even sang a phrase from the Beethoven Minuet in G, a piano piece which I mentioned playing at a recital when I was about ten.

My speech is an increasing problem. Do I use the Telephone? I have the California Relay Service. An operator speaks what you type to whomever you are phoning, but I find that complicated and difficult. I use email when I can. My caregiver sometimes makes calls for me.

It's interesting for me to see how individual people have different ability to interpret imperfect speech. Some can understand me quite well and some not at all. Some will try to "translate" what I am saying and not come close! My friend Edith and I usually have a good laugh at what she thinks I am saying, but it is far afield. At times it is extremely frustrating when it is far from what I am trying to say.

As with so many things in life, it helps to have and keep your sense of humor!

Speech Generating Devices

By Don Wilson

SPF NC Ambassador

You may recall that Medicare made changes in funding for SGD equipment and limitation the equipment to being a dedicated SGD only, never be able to connect to the Internet or any other purpose. With your help along for the ALSA and MDA, over 200 signatures were added to a "Dear Colleague" letter which resulted in CMS withdrawing the "Coverage Reminder" which placed the limitations on what SGD's could do other than generate speech. However, that action did not remove the equipment from the "Capped Rental" DME group, which could not have worked in any case.

Believe it or not, Medicare and the Legislative branch were both working to bring about changes. Changes were required in the Social Security Act, in the body of a new National Coverage Determination (NCD) for Speech Generating Devices. After the Dear Colleague" letter,

a new NCD was published calling for any comments. That period for comments was 30, and after that time, comments were reviewed and the new NCD would be published I have not received notice of the adoption of the new NCD, however everything was positive.

In addition, the Steve Gleason Act of 2015 made its way through the House and was passed by a voice vote in the Senate. The Act is very short and well pointed: "To amend title XVIII of the Social Security Act to provide Medicare beneficiary access to eye tracking accessories for speech generating devices and to remove the rental cap for durable medical equipment under the Medicare Program with respect to speech generating devices."

On July 30, 2015, President Obama signed the Act into law. This means that "Capped Rental" will officially end on October 1. Anyone with a capped rental device at that time will be converted to a full purchase immediately. The ability for devices to be unlocked is effective immediately.

ADA at 25

By Marian Vessels, Director, the Mid-Atlantic ADA Center

Eating out. We Americans love to eat out! We enjoy having someone else cook for us, exploring different cuisines, sharing a congenial meal with family and friends or enjoying the ease of a quick meal. It seems that even the smallest of towns has a café, coffee shop or restaurant where folks go to eat, but often more importantly, socialize.

Travel. Americans also are known to travel for work, pleasure or family events. We enjoy seeing new sights, experiencing adventures, traveling for business or to celebrate, mourn or connect with family and friends. These activities often require one or more nights in a rented room. Staying in a hotel, motel or other lodging is a staple for many of those who travel.

Over the last quarter century, diners and travelers with disabilities have benefited from substantial improvements in their ability to enjoy these venues since the Americans with Disabilities Act (ADA) became law and continues to be woven into the fabric of American life.

We are now eagerly anticipating the 25th anniversary of the signing of the ADA. This is a monumental step for the civil rights of those with disabilities. President George H.W. Bush stated at the signing of the ADA on July 26, 1990, "Let the shameful walls of exclusion finally come tumbling down." Unfortunately, we are still a long way from full inclusion in the hospitality industry. Many owners, operators and staff are still not aware of the broad requirements of the ADA and their application. Simple features such as accessible parking, a clear path of travel from parking areas or the street to entryways, accessible entrances, accessible lower front counters and clear routes through main areas of properties are often not provided or maintained. Concerns by front-line staff about how to interact with a person with a disability are as prevalent now as they were twenty-four years ago.

I love to eat out and enjoy travel for pleasure, work and for family events. I am also a diner, a traveler and a family member who has used a wheelchair for the last 40 years. I have seen significant changes since the signing of the ADA. I sometimes forget to call ahead to ensure that an unknown restaurant will accommodate me independently. I presume that my hotel room is truly accessible and will accommodate my needs.

I assume that I will be treated with dignity and respect by hotel and restaurant staff. Unfortunately, that is not always the case. Waiters still address my dining companions, asking for my dinner selection (instead of asking me directly) and many hotel rooms still do not allow me to move around, change the temperature or open the drapes independently.

There remains a great need in the industry to be more knowledgeable about the provisions of the ADA and provide inclusive customer service for their patrons with disabilities. The ADA National Network (ADANN) recognized this need and developed ADAhospitality.org, a website dedicated to providing the hospitality industry with information, resources and training on the application of the ADA. ADAhospitality.org has free downloadable staff ADA training materials, facts sheets and a myriad of other resources. ADANN, a network of 10 regional centers, can also provide customized, confidential information on the application of the ADA via a toll free phone line: 800-949-4ADA (4232).

The demands of a growing disability community (over 54 million in 2012) and an aging affluent baby boomer population (an estimated 84 million persons 55 years and older in 2010) requires the industry to be ready and willing to meet their needs. Find out how the ADA applies to your business, to you as person with a disability, or as a concerned individual. Review resources, tax credits and deductions and other materials to become more knowledgeable. YOU can make a difference in ensuring that all who dine or use lodging facilities are included. When restaurants and hotels welcome guests with disabilities, they are welcoming not only those individuals, but their families, friends and colleagues who dine and travel with them. Implementing the provisions of the ADA is a great business decision for all!

Marian Vessels is the Director of the Mid-Atlantic ADA Center, a project of TransCen Inc. Serving in this role since 1996, she has been the liaison with entities and disability coalitions in the six-state Mid-Atlantic region (D.C., Del., Md., Penn., Va. and W.V.). The Center is one of 10 regional centers comprising the ADA National Network, which is funded by the U.S. Department of Education, providing information, guidance and training on the Americans with Disabilities Act (ADA). Among her primary areas of expertise are training and guidance on the ADA as it relates to employment, state and local government and hospitality.

Up Close and Personal

Important Things To Know about Getting A Service Dog

By Mari White

Kansas State Ambassador

There is a lot of thought that needs to be put into the acquisition of getting a service dog and when well researched and thought out, the end benefit is a lifelong friend that becomes in tune with you as a person. Once the bonding takes place these dogs become an extension of you and can do so much to help. But, there is service dog training and then there is proper service dog training. There are huge differences and many things that need to be considered. Following is an intro to what the typical process is and things to ask when researching an organization.

A person planning on getting a service dog needs to anticipate a wait time of up to 2 or 3 years to make it through the process. The sooner they get on the list the sooner the training organization can start looking for the right match. A lot goes into that decision of the right match. A legitimate organization takes into consideration your personality, your city, your living arrangements, your mobility needs, your support system, and several other things. Then they look at the personality of the dog, the health, the size, and what the dog has been exposed to training wise. If they know that you are one that goes out into the community or travels a lot or goes to the theater, they will work with the dog to acclimate the dog to those situations.

Each organization is a little different as to how they train the dogs. Some use only certain breeds or certain pure breeds and work with an international breeding program to ensure quality. Others work with shelter dogs and other mixed breeds. Some train exclusively in the community and some use prisoners to help train

the dogs. Some charge the person for the dog and some have grant funding for the cost of training and do not pass that cost on to the person.

Typically, a dog will start training as a puppy in the community (8 weeks old) with what they call a puppy raiser. These are individual families that do basic obedience and will work with people skills in the community. Many take the puppies to work. At this point no one knows if the puppy will actually make it to the final program. A legitimate program will be watching growth, eyes, hips, etc. and personality to see if they will be better at being a mobility dog, a therapy dog, a guide dog, a seizure or diabetic dog. Dogs can be trained for all kinds of medical issues, even post-traumatic stress for the veterans.

Puppy trainers are all volunteers. They typically work with the puppy for about 18 months. Once they reach

18-20 months, the puppies are returned back to the training facility for essentially college level training where they work with wheelchairs, kids, crutches, stairs, retrieving things, etc. They usually do this for at least 6 months. Throughout this time they continue to be studied for personality, strength, hips, eyes, etc. If they pass all the necessary tests then the next phase is meeting the potential

owner and a rigorous two weeks of individualized training. If all goes well and the final test is passed, then the person gets to keep the dog and they then start training in the home of the individual. Typically a legitimate agency will continue to work with and support you for over a year before they finally release all responsibility and ownership of the dog. A good agency will continue to be involved and help where necessary as problems come up for the life of a dog and they will help with issues of retirement of the dog, too.



(Continues next page)

On average and this varies from agency to agency, it costs upwards of \$30,000 to train the dogs and to do a good job. Some, like I said, do not pass the cost on, others do. Many community agencies like the Lions Club, the Kiwanis Club or the Optimist Club will help cover the cost of a dog. Many times the new partnership can do volunteer work for the agency which becomes a win-win for both the agency and the dog. It gives exposure and practice for the dog and it gives identity to the agency when the public sees a well-trained team. I know in our area, we have what they call puppy training which is a support group of all puppies in training in that area and they get together to train and to socialize. We take the service dog to that as a role model and as a social group and its good practice even for the older service dog.

A legitimate organization will belong to the International Service Dog Association and will use their testing curriculum in making sure the dogs are ready to work in the public. By being a member, you get a lot of support legally, free products and discounts, and support. They have testing standards that must be met. It is expensive for an agency to belong and those that are willing to spend the money are doing it to ensure the quality of the dog.

Follow up is incredibly important. An agency should be willing to be available after the placement to guide and help where necessary as problems crop up. There is no way a dog can be 100% trained to each individual before the match. It takes time. Being available for support is very important. Again, a legitimate agency will continue to work with you.

Some agencies have a facility with dorms or duplexes where you go and live for two weeks during the training and some will train with you in your home community. Some do both. We trained for two weeks with the first dog, and my son did a week of one on one training with the second dog at their facility. Then the trainer came to his school and spent a day or two working with the school and being available for questions. She is also coming back in the fall and working with the junior high when he transitions to the new school.

Some agencies work with all kinds of service dogs, others primarily do mobility or guide or therapy. Not all agencies work with children and this is really

important because with kids the training and the dog has to be customized for kids. Not all dogs are the proper size for kids or can deal with kid activity and energy levels. Our son went on the waiting list when he was 7 and got his first dog when he was 9. After he lost his first dog to an unfortunate freak accident he just got his second dog at 11½. It will take approximately 18 months to really truly bond with a dog so that the dog can think for you. Training goes over just not the mobility needs but also care for the dog, parasites, vet care, grooming, first aid, etc. With children, we as parents have to understand it, but we have to not get too involved because the dog needs to know who the “boss” is and know who to bond with. It is frustrating to see our son struggle sometimes but it is very early on in this new relationship.

I am more than glad to answer individual questions at anytime. [Send your questions to Mari at alex72302@gmail.com Ed.]

You Can Make Money for SPF by Just Lifting (and Pressing) Your Finger

HSPers and PLSers....along with your friends and families.

The Online Shopping season is approaching. To donate to the Spastic Paraplegia Foundation without costing you a penny please use goodshop when you shop online. In fact, whenever you have that online shopping urge, go to **goodshop.com**. Enter Spastic Paraplegia Foundation as your charity of choice and then enter in the blank your favorite store...Amazon, Kohl's, Target, Barnes and Noble, Land's End, etc...hundreds of stores. If you enter the store's website this way, the retailer will donate from 1% - 6% (and sometimes more) of your purchases to SPF. Donating without costing you a penny more and requiring only about 5 seconds of extra time...how can you beat that? Please do this and pass this information on to everyone you know.

Also if you ever search the Internet (who doesn't?), use **goodsearch.com** and a penny will be donated to SPF for every search. Goodsearch is powered by YAHOO!. Just think, if everyone reading this, including their friends and families, used **goodsearch.com** and **goodshop.com**, SPF would have enough money for more research grants or for more clinical trials.

Tina's Tips . . .

JUST BREATHE

Just like the song says, “Just Breathe.” Sometimes we need to stop... stop trying to rush (it just makes us stiffer!). Stop holding on to the cane or rollator handles for dear life...just bring the elbows in to your sides and **just breathe!**

I'd asked for ideas for “tips” and got a unique one that I'm sure will help!

Mary Schultz (MO - SPG 7) says that, “For me, nutrition is key to fighting HSP. One thing that has helped me is to adhere to a gluten-free/vegetarian/paleo diet.”

When I asked her to explain she replied, “Basically, I eat no processed sugars and no meat no white flour or canned beans.”

Tina: Where do you get your protein?

Mary: “I use my Nutra-Bullet (blender –or rather an extractor) every day to make a smoothie with my protein powder.”

Tina: Is that all of your protein?

Mary: I also keep a stash of nuts at my desk when I get the “munchies” instead of chips or microwave popcorn. The nuts are high in magnesium, which is good for my leg cramps!

Tina: Why gluten-free?

Mary: I eat gluten-free because that's what is recommended for Multiple Sclerosis. I figure, why not?!

Tina: Where do you shop? Do you have any products that you like?

Mary: Not really. Gluten-free bread can be notoriously crumbly. I found some really great-tasting bread at Trader Joes, but I can't remember the brand. I look at the labels and see what's really in things. I especially notice the amount of salt or sodium in a product. Sometimes a regular

brand at Trader Joes has less sodium than an organic brand! The lesson here is to **READ** the label!

Mary went on explaining that she has no sensation of hunger. If she doesn't eat regularly, she forgets and finds herself with a headache, increased spasticity and experiencing vertigo.

Tina: I've never had that happen to me! Matter-of-fact, I wake each morning planning out my entire day around food!

Mary: Well, this is what I have found works for me. I have found that when I eliminate processed sugars and eat gluten-free, I “feel” better—balanced—less stiff.

Mary goes on to include mild exercise to her regimen.

Mary: Just do what you can, where you can. I can only attest to how exercise and stretching make me feel. I know I feel much better—less spastic—less stressed. I use the time to allow my mind to wander. It's “me time.” You know my mother had a sneaky trick she used on us kids. Instead of immediately reaching for an aspirin, she made us drink a glass of water first and lie down. After 20 minutes, my headache would usually be gone! Now it's important for me to drink a glass of water, lie down or just stop and take a mental survey. What have I done or not done today? Have I stretched? Have I eaten? What have I eaten? By that time, my headache is usually gone! Thanks Mom for teaching me to **JUST BREATHE!**

Remember, if you have a tip or trick that makes life easier for you, I want to hear about it! Email me at: tinacroghan@yahoo.com.

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