Synapse

Volume 19, Issue 1 Winter 2016
Newsletter of the Spastic Paraplegia Foundation

2016 ANNUAL CONFERENCE

Our 2016 Spastic Paraplegia Foundation Annual Conference will be in the Windy City, Chicago, Illinois on

June 24-26, 2016

The Renaissance Chicago O'Hare is 4.5 miles east of The Chicago O'Hare International Airport and there is a shuttle service to the hotel. The special rate is $119.00 per night.

Renaissance Chicago
O'Hare Suites Hotel
8500 W Bryn Mawr Ave.
Chicago, IL. 60631

We'll see you there!

Warmest regards,
Tina Croghan
SPF Conference Coordinator
MO State Ambassador & Board Member
(314) 497-8540
TinaCroghan@yahoo.com

How to Help

We operate out of the strength of our community, caring friends and sponsors. Your help makes a difference!

Please contact us at volunteer@sp-foundation.org to help in one of the areas below or to suggest another way you can get involved.

Support Research to Speed Our Cures by Volunteering

Below you'll find information on some of the ways you can help SP Foundation in their search for a cure to PLS and HSP.

Raise Funds: The primary focus of SPF is to raise funds to support research to find the causes, treatments and cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. Our major fundraising activity consists of a Team*W*alk. Individuals can help organize local fundraisers. People are also needed to secure corporate sponsorships and help with grant applications.

Patient Connection Programs: Organizing a Connections gathering for people to meet, share stories and help one another is a great service. Events can be as simple as meeting for coffee! In areas with large patient populations, SPF seeks to establish Chapters.

Conference Organizers: The SPF seeks event coordinators in or near metropolitan areas who can work with us to organize Conferences for our community. These events feature speakers and programs on special topics of interest to our community as well as provide the opportunities for individuals to meet others. Conferences can be half-day or full-day events.

Communications: Individuals with writing, research, website or graphic design skills are needed to assist with various communication initiatives.

Ambassadors: Ambassadors raise awareness about our disorders as well as enhance community building and industry relationships. You can assist with media relations, share your story, speak at local groups or help with grassroots advocacy.

Business and Administrative Support:
Volunteers with business and administrative skills can play a valuable role in administering the work of the SPF. Most of the help is coordinated through email correspondence and uses popular Office applications.

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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).

Synapse Editors
John Staehle..Senior Editor
Malin Dollinger................. Medical/Research Editor

Published three times a year, Winter, Spring and Fall, for the HSP/PLS community. It is also available online at www.sp-foundation.org

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Send Correspondence & Donations to:
Spastic Paraplegia Foundation
1605 Goularte Place
Fremont, CA 94539-7241

Contact the SPF at:
(877) 773-4483
information@sp-foundation.org
or www.sp-foundation.org

SPF Medical Advisor:
John K. Fink, M.D., University of Michigan

Letter from the President

Dear Friend,

I am so grateful to you for your loving, giving generosity. As you know, our year end fundraising goal was to reach $125,000. Our anonymous donor had promised to match every gift, up to that amount, dollar for dollar. Well, we not only reached that goal but we surpassed it. Our total amount raised, with the match, was just over $300,000, 15% more than last year. This will truly do a world of good in the quest for a cure for PLS & HSP.

We live in a time when science is really cooking up incredible discoveries every day. We just need to keep fighting to stay on the front burner. When I say "fighting", I mean that we first need the financial support from you, without which nothing else happens.

Everyone that works for our Foundation "fighting" to find a cure, does so on a volunteer basis. This includes not only all of our Board of Directors but also our Scientific Advisory Board and Ambassadors in almost every state of the union. But, we would all be just spinning our wheels if it weren't for your support to finance the research that is so vitally important to reach our goal of ending the suffering of almost half a million people worldwide with these two insidious diseases, HSP & PLS.

Melodie Beattie once said "gratitude unlocks the fullness of life. It turns what we have into enough, and more. It turns denial into acceptance, chaos to order, confusion to clarity. It can turn a meal into a feast, a house into a home, a stranger into a friend." So, with my gratitude, I hope to welcome you as a friend. You give me hope for a better world for all of us.

Sincerely,

Frank Davis

President

SYNAPSE APPEAL

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

Board Business

Board Business, August 2015 – December 2015
(Compiled by John Staehle, Senior Editor)

In October, Greg Pruitt reported the Kentucky Golf Tournament raised $8,000 for SPF. Linda Gentner reported the California Team*W*alk was attended by 70 and raised $30,175 for SPF.

Frank Davis reported that the Renaissance Chicago O'Hare Suites Hotel was selected as the site for the 2016 SPF Annual Conference, June 24-26, 2016. The special room rate for conference attendees is $119/night.

The Board approved the Minnesota Supplement to the Unified Registration Statement (URS), an annual task required by the State of Minnesota that allows SPF to do fundraising in their state. All other states in which we fundraise accept the URS without supplemental documentation.

At a special meeting in November, the Board approved funding five research grant requests totaling $622,000. One grant was for a HSP & PLS project, one was for a PLS project and three were for HSP projects. See related article in the Medical & Research section for additional information.

In December, Frank clarified that the deadline for matching gift contributions will be January 15, 2016.

Tina Croghan, Conference Coordinator reported that negotiations continue with the Renaissance Chicago O'Hare Suites Hotel on prices and charges for the facilities and services needed for the June Annual Conference.

A Poem about PLS:

I have a sclerosis that's really atrocious
It makes me unsteady as hell
I fall down the stairs, on tables and chairs
And places I never will tell.
But though I have bruises
I don't make excuses
And otherwise feel really fine
For though I could bitch
And curse like a witch
It never seems useful to whine.

Hugh Fenton, Nov. 2015

Connections

North Texas SPF Connection
November 14, 2015

John Staehle, North Texas SPF Ambassador, hosted the Fall North Texas SPF Connection on Saturday, November 14th in the Gathering Room at Advent Lutheran Church in Arlington. Our group for this Connection numbered twelve including three first-time attendees. Instead of meeting at a restaurant for lunch, each attendee brought a snack to share as part of this trial format suggested at our last Connection in May. After introductions, John updated the group on the number of SPF contacts in the North Texas region, a total of 84, of which 62 have either a diagnosis of HSP or PLS or are a spouse/caregiver/family member of someone diagnosed with HSP or PLS. Twenty-one of the 62 have PLS and 15 live in or very near the Dallas-Fort Worth area.

As Editor of SPF's newsletter, *Synapse*, John asked those in attendance to consider writing something for a future issue about an experience, good or bad, they or one of their children have had because of their condition (HSP or PLS). Personal stories are well-liked by the readership. They can send their articles to him anytime via email at jstaehle@swbell.net.

Subjects discussed included the 2016 SPF Annual Conference to be held in Chicago, June 24-26, 2016. Details on the hotel and when they'll start taking reservations for the event are forthcoming - we were urged to check the website, www.sp-foundation.org, regularly for updated Annual Conference information. Also discussed were post-implantation issues with baclofen pumps; various medications we take and their side effects; questions raised by caregivers present at the meeting; personal experiences; and where to find good physical therapists who understand our diseases and can develop exercise routines for our specific condition.

Those present liked the format and would like to continue using it at the same location for the next Connection tentatively scheduled for May 2016. One comment was that it was so quiet (compared to restaurant noise) we could actually hear each other talk. John will check availability of the room and reserve it for a Saturday afternoon next May.

Standing L to R: Cathey Petrey, Michael Petrey, Noah Taylor, Sara Taylor, George Owen, Annette Bos, Lucy Owen, Nikki Holmes, Jerry Holmes. Seated L to R: John Staehle, Frank Davis. Not Pictured: Avery Taylor.

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SPF Illinois Connection
October 17, 2015

HSP: Sid Clark   PLS: Hank Chiuppi

We met at the Buffalo Grove Arboretum clubhouse. For lunch, we ordered from the Corner Bakery and had the driver take the Connection picture. We had 17 in attendance at this our fall meeting.

As we have been doing, we went around the room to discuss the questions and concerns that may be of interest. Among other things we discussed:

SPF 2016 Annual Conference: June 24-26 is tentative Renaissance Chicago O'Hare Suites Hotel, (Conference information to follow and it is the same dates as the Chicago Abilities Expo);

What is new with Stem cell research and HSP/PLS, especially the Israel Stem treatment that is beginning a new trial phase;

Handicapped Parking Spaces;

What is required to get insurance to help pay for medical equipment like Power Chairs and Wheel Chairs;

Drugs that have been tried and the results like Medical Marijuana and Ampyra;

Genes – how do you know your SPG Number and what is whole Exome Sequencing.

Continued on next page

Tim & Tina shared SPF wristbands with the group. In addition, Joan Morris surprised us with HSP/PLS Survival Kits (see contents below). Thank you.

The meeting concluded with Carolyn Wright leading us in a chorus of Zip-a-dee-doo-dah, zip-a-dee-ay.

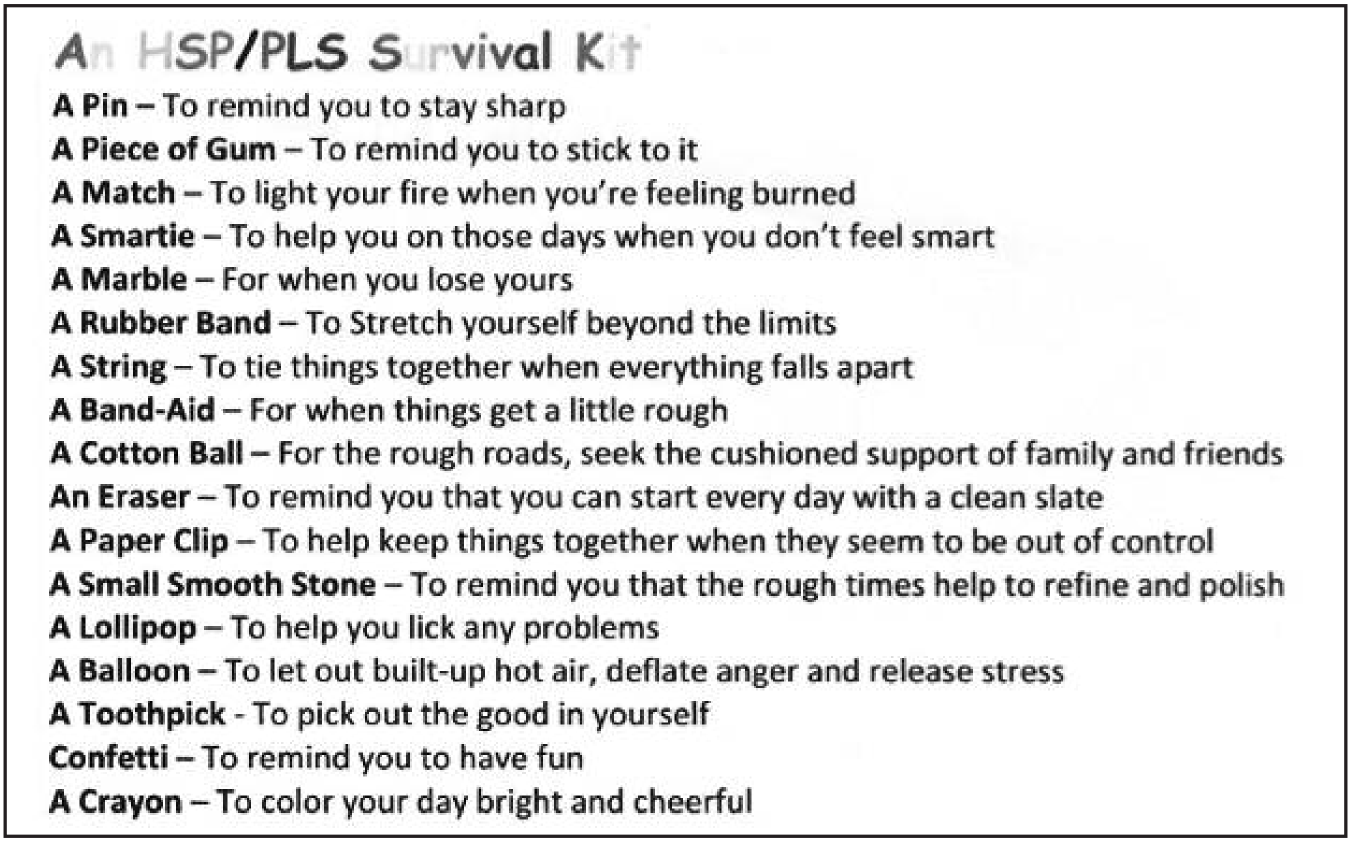
Excellent Meeting. We never have enough time to cover and share all that we want. For the next meeting we are looking for suggestions on topics to be discussed. By each of us sharing, we learn a lot. Our next meeting will be in Spring.

Included in the Picture are: Across the back L-R: Hank Chiuppi, Carol Clark, Steve Beutelspacher, Frank Madrigali, Rich Fairbairm, Sarah Wright, Paulette Chiuppi, Joan Morris, Andy & Candy Cotsiomitis, Rich, Tim and Tina Crogham. On the inside of the table, L-R, we have Sid Clark, Phyllis Madrigali, and Carolyn Wright. Ed and Ann Sopala are not shown, nor is Thunder, Tina's service dog which is under the table.

Imagine the day. . .

By Annette Lockwood

A day without the friendly stares,
Or the more often unfriendly glares.
A day of dancing to the wee hours,
And climbing stairs in the tallest towers.
A day to fall head over heels in love,
Instead of face down on the rug.
A day of walking without any worries,
And not being pushed aside by those in a hurry.
A day of walking like most,
Being able to walk both up and down the coast.
A day without doctors, tests or pills,
Or denied insurance claims and bills.
This day will come,
And what a beautiful day it will be.
But for now we must wait,
For research will determine our fate.



An HSP/PLS Survival Kit

A Pin – To remind you to stay sharp
A Piece of Gum – To remind you to stick to it
A Match – To light your fire when you're feeling burned
A Smartie – To help you on those days when you don't feel smart
A Marble – For when you lose yours
A Rubber Band – To Stretch yourself beyond the limits
A String – To tie things together when everything falls apart
A Band-Aid – For when things get a little rough
A Cotton Ball – For the rough roads, seek the cushioned support of family and friends
An Eraser – To remind you that you can start every day with a clean slate
A Paper Clip – To help keep things together when they seem to be out of control
A Small Smooth Stone – To remind you that the rough times help to refine and polish
A Lollipop – To help you lick any problems
A Balloon – To let out built-up hot air, deflate anger and release stress
A Toothpick - To pick out the good in yourself
Confetti – To remind you to have fun
A Crayon – To color your day bright and cheerful

10 Things You Should Know about Emergency Preparedness

From: *Disability Connection Newsletter* -
September 2015 edition
Published by: Disability.gov

America's PrepareAthon. More than 21 million people across the U.S. are participating in preparedness activities – are you one of them? It's not too late to sign up for America's PrepareAthon, which takes place on September 30th and marks the end of National Preparedness Month. This nation-wide event includes activities in every state to make sure citizens know how to get ready for an emergency. Leading up to America's PrepareAthon, learn about common hazards and download resources that can help you prepare for earthquakes, floods, hurricanes, tornadoes, wildfires and winter storms. Read stories about individuals, organizations and communities participating in this important initiative. Find PrepareAthon activities or add your own and help spread the word. Register online and be empowered to get prepared.

Inclusion in Emergency Planning. Since one in five people in the U.S. has a disability, this population must be considered when planning for emergencies. The Administration for Community Living recently called for the inclusion of people with disabilities in emergency preparedness planning. If you haven't seen it already, watch the Federal Emergency Management Agency's (FEMA) "We Prepare Every Day" public service announcement (PSA) and learn about emergency preparedness for people with disabilities. "The Importance of Preparing Every Day for the Unexpected," a recent Disability.Blog post by guest blogger Marcie Roth, director of the Office of Disability Integration and Coordination at FEMA, further drives this point home. The National Organization on Disability has also developed a guide for emergency managers, planners and responders about planning for people with disabilities in a disaster. Preparing in advance and creating a support network allows people with disabilities to be included from the start in emergency planning. Disability.gov's Guide to Emergency Preparedness provides additional resources.

What to Have on Hand. Stocking up on essential items that may not be readily available during a disaster is a central part of emergency preparedness. Make sure to have at least a three-day supply of food, water and medicine for each person in your household. Choose non-perishable items such as canned and dry goods and have a gallon of bottled water per day available for each person in your household. Wheelchair users are advised to keep a manual wheelchair or cushion available. Store extra medication and medical supplies in your emergency kit. Your medications may be affected by things that happen during an emergency, such as exposure to high heat or contaminated water, so always check to make sure it's safe to take the stored medications. Special precautions may be required for insulin. If you have a Medicare Prescription Drug Plan (Part D) and you live in a place where a state of emergency has been declared, Medicare can help with getting the medications you need. To avoid any confusion, keep copies of your prescriptions in your emergency kit for reference.

Planning for Your Service Animal. People with disabilities who rely on service animals must also consider the animal's needs when planning for an emergency. You'll want to include emergency supplies, such as food and water, a first aid kit, medications and important documents, among other items. If you must evacuate to an emergency shelter, know your rights as a person with a service animal – service animals must be allowed in shelters, but you are responsible for its behavior. Under the Americans with Disabilities Act (ADA), emergency shelter workers can only ask if the service animal is required because of a disability and what tasks it has been trained to perform. They can't ask for documentation or certification for the service animal. Although geared towards pet owners, tips from the Humane Society and the ASPCA can also benefit people who use a service animal. For information about service animals and accommodating the needs of people with disabilities read "Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities."

Workplace Preparedness. Having an emergency preparedness plan at your place of work is just as important as having one at home. Under the ADA, an emergency plan at work may be considered a reasonable accommodation. Together with your employer, you can create a plan that accommodates your specific disability. The U.S. Equal Employment Opportunity

Continued on next page

Commission has guidelines for employers about how to talk with their employees in a non-discriminatory way about accommodations that may be needed in an emergency. Once an emergency plan is in place, employers and employees should hold emergency drills as practice to determine if any changes should be made to the plan in order to ensure safety.

Shelters and Accommodations. When an emergency strikes, your local emergency shelter may be the best option to stay safe. The ADA generally requires shelters to provide equal access to the many benefits that shelters provide: safety, food, services, information and a place to sleep. All parts of a shelter, from its parking and entrances to restrooms, sleeping and dining areas, medical units and beyond, must be accessible to people with disabilities. Shelters should use this checklist of ADA requirements in order to understand how to best serve people with disabilities. When preparing to go to a shelter, complete this shelter checklist, which will help you communicate about your accommodations and medical or other needs you may have once you arrive. You can find open shelters through the American Red Cross.

Communicating during an Emergency. Emergency situations require quick, clear and accessible communications. One critical part of our emergency communications system is the 911 network. You can call 911 from a home or mobile phone; if you have a hearing impairment, you may use the TTY service. In some areas, you can also send a text message to 911. The Federal Communications Commission (FCC) has developed a guide about text-to-911 communications from landlines using TTY, as well as mobile phones, and how you can expect that to work. Another form of disaster communications, the Emergency Alert System (EAS), gives national, state and local governments the ability to share emergency information with the public via broadcast, cable and wireless cable systems. All EAS broadcasts and emergency information from broadcast television and radio are required to be accessible by audio and visual means. The FCC has specific requirements for the accessibility of disaster information and what must be provided to be people with disabilities.

First Responders. Emergency responders and law enforcement officers must understand the needs of people with disabilities when responding to a disaster. When communicating with someone who is deaf or hard of hearing, when an interpreter is not available, there are other ways to communicate effectively. The Autism Society offers tips for communicating with children and adults with Autism or other sensory disabilities. You may also want to check out these tips for first responders that focus on many other types of disabilities. This guide from the Inclusion Research Institute details ways that emergency personnel can best serve people with disabilities during a disaster. Watch a clip from a video called "Disability Awareness Training for Law Enforcement" that can help you communicate with and support people with a range of disabilities. The Substance Abuse and Mental Health Services Administration's (SAMHSA) Behavioral Health Disaster Response Mobile App helps behavioral health responders organize and share disaster preparation, response and recovery resources. It includes a directory of behavioral health service providers in affected areas.

Current Events. You should have an emergency preparedness kit and emergency plan ready for a wide variety of hazards and emergency situations. Learn about emergency situations affecting the U.S. right now and how you can prepare for and handle them. Hurricane season in the Atlantic lasts through November; in the Pacific, it lasts until December. Keep track of approaching hurricanes with the American Red Cross' Hurricane app. In addition to your emergency kit, prepare yourself and your home: clean up your yard, store outdoor items that could be blown away by high winds and board your windows. Always evacuate your home if instructed to do so. California in particular has experienced many wildfires this year. Although the area is known for these occurrences, wildfires can happen anywhere at any time and dry conditions increase their likeliness. As with all emergencies, it's important to be prepared. If you live where wildfires occur, you must be ready to leave at a moment's notice. Make sure you respond appropriately – have two ways out, a place to stay once you leave and take needed supplies with you. Power outages can happen at any time, too. Turn off or unplug lights that aren't being used anymore. Limit how many times you open your refrigerator so food stays cool longer. When it's time to cook, use perishable foods from the fridge and foods from the freezer first – then use your non-perishables. If you want to use a generator, never use it in an enclosed space, like a garage, and follow these safety tips. Learn about what to do during power outrages if you use medical devices that require electricity.

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Recovering from a Disaster. Disasters can take a toll on your mental and emotional wellbeing; your personal recovery is an important part of the process of overcoming a disaster. Emotional and mental health recovery takes time. A key resource for support is SAMHSA's Disaster Distress Helpline. Call 1-800-985-5990 (TTY: 1-800-846-8517) or text TalkWithUs to 66746 to speak with a trained crisis counselor. Remember, everyone responds to a disaster differently, so it is important to understand how to cope and help others cope during difficult times. Parents can read "Helping Children Cope with Disaster" for information about how to help young children who are experiencing emotional issues related to a disaster. Situations such as missing family members, returning home or finding a place to stay may also contribute to post-disaster stresses. Financial assistance is also available. Visit DisasterAssistance.gov or use FEMA's Disaster Recovery Center Locator to find help. You can also apply for FEMA disaster assistance online or by calling 1-800-621-3362. The Small Business Administration's Home and Property Loans are low-interest loans that help homeowners and renters in declared disaster areas whose home or personal property has been damaged by a disaster. Even if you're not a small business owner, you can apply for up to $200,000 to replace or repair your primary residence. And remember, your state's emergency management agency can help you prepare for, and recover from, an emergency or disaster.

cafemom
the meeting place for moms

CALLING ALL MOMS!!!

Check out a new web site

www.cafemom.com

Do you have a child suffering from any type of spastic paraplegia? HSP? PLS? Then this is the site for you.

www.cafemom.com/group/116957

A place where moms can come together – to share, encourage, and support one another!

Come Check Us Out!

Created by: Jessica Barlow-Anderson

Applebee's

IMPORTANT:

HELP Applebee's Restaurants to Cure HSP & PLS

Frank Davis, President, 01/05/2016

We're organizing a national fundraiser around Rare Disease Day with Applebee's Restaurants to build awareness of Hereditary Spastic Paraplegia and Primary Lateral Sclerosis and raise funds for future research.

Participating is simple:

1. Call your local Applebee's to find out if they participate in the "Dining to Donate" program. If so, pick up and fill out the form they require and return it to the General Manager. Find your local Applebee's here: http://www.applebees.com.
2. Applebee's will contact you to schedule a date and time for your fundraising event, ideally on or around February 28.
3. Applebee's will provide you with an invitation for your fundraising event to reproduce and distribute.
4. Promote the event in your community and pass out the invitations to as many friends, family members, co-workers and neighbors as possible.
5. On the event date chosen, your guests should present their personal invitations to the Applebee's server before service, and Applebee's will donate a percentage of the invitation holder's food and beverage purchases to the Spastic Paraplegia Foundation.
6. At the event, you will have the opportunity to raise awareness of HSP & PLS and the challenges faced by patients and families as well as the importance of Spastic Paraplegia Foundation research.

Spastic Paraplegia Foundation is a 501(c)3 charitable organization:
1605 Goularte Place, Fremont CA 94539-7241
Tax ID#: 04-3594491

More information about Rare Disease Day can be found here: http://rarediseaseday.us.

Please contact us at information@sp-foundation.org with any questions, and thanks for participating!

On the Web: sp-foundation.org

How I Got My Service Dog

By Tina Croghan, MO State Ambassador & SPF Board Member

On March 6, 2015, I was blessed to receive my support dog, Thunder. He "gets" a multitude of things I drop; he opens and shuts doors, drawers and cabinets—sometimes slamming it with a little teen-age attitude. But now I suddenly feel the responsibility of another life. I no longer am just thinking about how far I have to walk, but more of the intimate restroom schedule and feeding of another. I am squished out of bed most nights and lulled to sleep by a cacophony of choruses of snoring by my husband and support dog. All of the little inconveniences are minor compared to the warm rhythmic breathing of this furry companion who needs me as much as I need him.

When I think back on it, I was first introduced to the notion of a support dog in 2010 when Canine Companions gave one of the presentations at our Los Angeles Annual Conference. At the time I thought, "A dog would be nice, but not for me! A support dog is really only for a person who is paralyzed or blind."

I didn't think about it again until September 2013 when I did a Combined Federal Campaign event for SPF at Scott Air Force Base in Illinois. That day was the first day I used my scooter. The event was held outdoors on the base parade grounds. I had to bring several boxes of brochures, t-shirts and (of course) candy. This would be too far for me to walk and too many trips with my rollator. The ground would be uneven and on grass (for those of you that understand, this whole prospect made me shudder with dread). My husband convinced me to conserve my energy (and his!) by making one trip and loading up my scooter. I'm so glad I did!

With my new-found-freedom, I toured the ENTIRE CFC grounds. I stopped at several of the tables and found out that HSP/PLS was rare among the rare diseases. A support dog program was there that day and I remember they had a puppy Labrador Retriever that sat/laid quietly on a little cot display they had. I stopped at the support dog booth and commented on the dog's calm behavior, and after chatting with them, I was made aware of the many uses a support dog could accomplish to make my life easier.

Some months later I Googled "Assistance Dogs St. Louis" and I came upon Support Dogs, Inc. I read their website pouring over each page. On a whim I filled out their 26-page application and sent it in. After a few months, I got a phone call from SDI for a face-to-face interview on March 9, 2014. During the lengthy and comprehensive interview I was told that it would be another year or 18 months before I could be placed with a service dog, but that I was now officially on the list. I was overjoyed!!

During the summer of 2014 my mobility declined and my then 84 year-old mother came to live with us (my father had passed away the year before) so we began the process of having our basement turned into an apartment for her.

In October, the very day that construction started on our basement, Support Dogs Inc. called. . .they wanted me to start training in a few weeks! They had a litter of dogs ready for placement, and an individual had dropped out of the program making a sudden opening. I was next on their list!

I was instantly flooded by several emotions. I was ecstatic, scared and then came instant dread. I realized just what was going on in my life right then. Training would take two weeks of full 9-5 days. There was no way I could juggle one more thing PLUS deal with the stiffness that I was sure to experience during training. My husband assured me that I was doing the right (and humane) thing by passing on this opportunity at this time.

I called back Support Dogs, Inc. and through tears I explained my situation. After being very positive and supportive, SDI assured me that I hadn't jeopardized my chances of getting a service dog and they would put my name back on the list.

Continued on next page

Then, a few months later in February 2015 I got another call from SDI. This time I said yes--Yes—YES!!!

When I showed up for the training session, I was introduced to the "group" of dogs that would be placed with us. There were four other disabled individuals from across the United States at the training and we all had no idea which dog would be ours. There was one wiry-looking yellow lab, Tackle, who had springs for legs who kept jumping with excitement. I think the each of us said the prayer, "Please don't let me get that dog!"

As the day progressed, the pairing assignments were made and Tackle was placed with a young girl in a power chair that had as much energy as he did. Then the rest of the dogs were paired up and I was the last one to receive my assignment. I was given Thunder. Thunder is a BLACK Lab! I had always thought that I would get a YELLOW lab. And Thunder was a BOY! I thought that I would get a GIRL. My heart sank. Then I opened the door of his kennel. His thumping tail and big brown eyes greeted me. Instantly all of my preconceived notions of the "perfect" dog were immediately changed to Thunder!!

ALL of the dogs were expertly placed by SDI that day. Through their process of having clients fill out a comprehensive application and having an extensive interview with the staff of Support Dogs, Inc., their long history of working with disabled individuals gave them the ability to place the "perfect" support dog with me. Their dogs are "trained" with a basic set of skills; some were trained with a more unique set of skills than others. The two weeks were basically so WE could learn the commands and bond with our new partners.

After the third day of training I brought Thunder home! Oh, what exhilaration and trepidation! The feeling of bringing home a newborn was refreshed. Here I have this living and breathing life that is totally dependent on me for everything—food—water and toileting! Thunder explored his new home with excitement and I could tell he was very happy to be placed with me. We work together everyday and he has helped me become more confident and independent as I battle my disability. As I'm writing this article, my service dog – Thunder - sleeps on my feet (keeping them warm, incased in a black fur cocoon) with constant rhythmic breathing while he waits for our next challenge together.

Ostrich: SPF Offers Support Even When Loved Ones Don't "Get It"

By Mary B. Schultz

My own story is similar to so many other members of SPF. After a decade of misdiagnoses, I finally received a diagnosis of "hereditary spastic paraplegia". I had not even HEARD of HSP until I was diagnosed with it.

I have had two major "game changing" moments since my HSP diagnosis. The first was going to the SPF Annual Conference in St. Louis where I saw other people that walked just like me. (I discovered that I was not alone!) The second was more recent. I learned that other people, again just like me, are struggling with close friends and family – loved ones – who have good intentions but just don't "get it". Frankly, I am frightened by the progress of the disease – so many unknowns about HSP as a biologic "card" I've been dealt – the progress of HSP in my own body, the progress of research on HSP, whether there will be a treatment or cure any time soon, whether future generations are in peril, on and on... I am frightened by my increasing need to rely on close friends and family for support who do not seem to "get it".

My disability is invisible, so to close friends and family I look the same as I have always looked, except of course older. They assume or expect that I am able to "do" at 55 with HSP, pretty much the same as what I did (and loved doing) at 45 or 35 or even 25 (Ha! I wish…). Loved ones do not see that I am "hiding" pain, frustrated, and scared. I routinely hear things like: "But you LOOK good…"; "If only you would try harder…"; "Everybody gets cold…"; "We're talking about someone who is REALLY sick…." I muddle through and respond as well as I am able "on the spot" and I suspect that others with HSP or PLS have encountered similar scenarios. We might learn from each other's experiences. On the other end of the spectrum are well-intentioned loved ones who "walk on eggshells" around me, and assume I am unable to "do" things that I have always done and continue to be able to do.

I want to "rally" the members of SPF, particularly on this second issue. Our membership in SPF should be "active", so we can share how we each confront and deal with our many fears and problems. DO NOT BE AN OSTRICH! In other words, do not "bury your head in the sand". Ignoring problems won't make them go away and we can and should learn from each other.

Continued on next page

As initial steps, I ask two things of you. First, I invite HSPers and PLSers to contact me at mschultz@sl-lawyers.com, on the HSP listserv, on the SPF Facebook page, or by PM (Personal Message), with stories of loved ones who have inadvertently said or done (or NOT said or NOT done) hurtful things and how you responded. I will compile those stories, and attempt to create a "short list" of responses for those awkward circumstances which I will make available to you in the next issue of *Synapse*. Second, I ask that you actively take advantage of your membership in SPF. It was so important to me personally to learn that I was not fighting my battle with HSP alone – that other members of SPF share in my experience with loved ones who have good intentions but just don't "get it". Please help SPF help YOU!

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"My disability has opened my eyes to see my true abilities."

Robert Michael Hensel

NEW MOBILITY: THE MAGAZINE FOR ACTIVE WHEELCHAIR USERS

www.newmobility.com

"New Mobility" encourages the integration of active-lifestyle wheelchair users into mainstream society, while simultaneously reflecting the vibrant world of disability-related arts, media, advocacy and philosophy. Our stories foster a sense of community and empower readers to:

- Participate in all areas of life, including education, work, love, sex, home ownership, parenting, sports, recreation, travel and entertainment;
- Be informed of and take charge of health concerns;
- Obtain appropriate technology; and
- Assert legal rights.

New TEK Mobility Device - Part I

By Malin Dollinger, M.D., SPG4

We are all used to various kinds of scooters and wheelchairs, motorized and manual, three wheels and four wheels, walkers, canes, and various simple and complicated devices to allow folks who are handicapped to get from place to place. We see our disabled friends, and store displays, with a wide variety of such devices. All are based on a single premise and method, which is: we hold onto some kind of handle(s) while we walk slowly [e.g., a walker], or we sit in some kind of special chair with wheels, with or without a motor, and we then go somewhere by "rolling" the chair forward, while we are sitting in it. When we get to our destination, we may stay in the chair or we might transfer to a regular seat, a seat in the car, a toilet, or wherever else we may wish to sit.

It's been that way for many years. No one has thought of a different, better way to get from here to there. Until now, that is. Enter the TEK mobility device, introduced and sold by Innovations Health in California [with nationwide access]. It was invented and is manufactured in Turkey, and has already been on the market in Europe. Having just received FDA approval, it is now being sold in the U.S. If you receive any disability magazines, their two-page ad spread is on the inside front cover. Their website is www.innovationshealth.com.

After first investigating this new device in early 2014, I received in December 2015 one of the first ones to be sold in the United States. The distribution company, Innovations Health, is firmly committed to supplying this TEK device to those who need it, anywhere in the country. They are also committed to being sure that this device is the right one for each handicapped person. A doctor's prescription is needed, and more importantly, they insist on a personal demonstration and trial before agreeing to supply the TEK to a prospective purchaser. It must be correct and useful, and usable, to each new purchaser or they will not sell the unit to that person. It is customized for each user. They are thus extremely ethical and also very supportive once you have the unit.

How does it work so differently? Using a small hand-held remote control, the TEK is moved in front of you while you are sitting in a chair or on a scooter. You move it to you from wherever you parked it last, all by use of the remote control. You transfer onto a firm pad with a large opening near each end and then attach straps to each side of the pad (Fig. 1). Then, by operating the controls, the straps tighten and pull the attached pad up, with you on it, to a standing position (Fig. 2). The straps hold you there, standing, during the entire time you are using it. Your knees are inside special pads and there is another pad touching your lower chest so you are comfortable (Fig. 3). Each TEK is custom built for each person after many body measurements are taken and recorded.

You are then able to ride around in the standing position anywhere you wish to go and reach things you could not reach otherwise (Fig. 4). You reverse the process to sit back down on your scooter or in a chair. The big difference from all previous mobility devices is that you ride around in the standing position rather than sitting. My big plus, and yours also, is that you can avoid/reverse the bone/calcium loss and muscle atrophy, not to mention leg swelling, that happen when you spend all day sitting. The unit is rather small so it would fit anywhere - doorways and tight spaces are not a problem. The width at the wheels is 16.5" and at the handle bars, it is 19.5".

When done for the day, you simply park it in a corner somewhere. When you need it next, you use the hand control to bring it back to wherever you are. It is extremely well-engineered and constructed and took years to develop.

Part II will appear in the next issue of *Synapse*. In it, I will provide you with much more information about my personal experiences with the TEK unit, including additional photos, comments on its advantages and disadvantages for paraplegic people with specific commentary on who might benefit most from the unit and who are unlikely to be helped at all. I will offer a candid discussion of my own experience and recommendations that, hopefully, will help you determine whether or not you should consider the TEK unit for yourself or your loved one. I'll also discuss the all-important price and insurance information.

Photos courtesy of Brandon Schaefer.

(Fig. 1)

(Fig. 2)

(Fig. 3)

(Fig. 4)

What does HSP mean to me?

By Gary Lockwood

Faded hopes and weakened knees?
The hardships of dulling limbs.
Frustration grows as movement dims.
Or is it a temporary setback,
Until our strength gets back.
It's not clear to see,
What will fate bring the next day?
Will answers come as I pray?
Even though it breaks our stride,
We must not let it diminish our pride.
And although worries fall like hail,
I know that the Heart Surely Prevails.
That's what HSP means to me.

Be Your Own Best Advocate

Disability Law: §504 Rehab Act

By Mary B. Schultz

I am a lawyer. I have been practicing for over 30 years. I also have HSP. My symptoms first became apparent when I was in my 40s. After a decade of misdiagnoses, I finally received a diagnosis of Hereditary Spastic Paraplegia when I was in my 50s.

Like so many of us with HSP, I had not even HEARD of the disorder until I was diagnosed as having it. I had my physician write down ”hereditary spastic paraplegia” so that I could later look it up.

I have been practicing law, primarily in Missouri and a little in Illinois, since 1985. I have devoted much of my practice to access to public information, libel defense, and civil rights law in the context of freedom of speech and the First Amendment. One of the legal weapons in my arsenal has been what lawyers refer to as §1983 (a/k/a “civil rights act”). Since my fairly recent diagnosis, I have become interested in applying what I know about civil rights law in the context of freedom of speech to civil rights in the context of disability law. My education has not only been about neurology and cell biology, but also about disability law. I would like to share what I’ve learned.

As we all struggle with our own disease individually, there is a social struggle for disability rights. To my surprise, the legal framework for advocacy for disability rights is fairly new. I hope to facilitate our discussion of social equality for those with disabilities, and frame part of that discussion in the growing body of law that supports disability rights.

I intend to “jump right in” to discuss §504 of the Rehabilitation Act of 1973. The statute in only about 40 words in length, but was landmark legislation in that it provided civil rights protection for people with disabilities in programs and activities that receive federal funds. Recipients of federal funding are barred from discriminating against people with disabilities.

Section 504 of the Rehab Act provides in part:

No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

The Rehab Act was amended in 1974 to define “Individuals with Disabilities” to be:

any person who (A) has a physical or mental impairment which substantially limits one or more of such person’s major life activities, (B) has a record of such an impairment, or (C) is regarded as having such an impairment where “Major life activities include caring for one’s self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks and learning.”

Each federal agency has a set of §504 regulations that govern its own programs. Federal agencies that provide financial assistance to local programs also have §504 regulations. Common to all of the regulations is a requirement there be “reasonable accommodation” for employees with disabilities, program accessibility, effective communication with people who have hearing or vision disabilities, new construction that is accessible. Section 504 is effective by and large through regulations, as the regulations specify how the recipients of federal funding are barred from discriminating against people with disabilities.

§504 of the Rehab Act may be enforced by the particular agency at issue, or in private litigation.

Early Section 504 court decisions did not favor disability rights. For example, the 1979 United States Supreme Court decision in Southeastern Community College v. Davis, and a decision of the United State Court of Appeals for the Second Circuit (sitting in New York City) in American Public Transit Association (APTA) v. Lewis.. These two early decisions allowed public entities to thwart compliance with §504 of the Rehab Act if compliance was not economically practical.

The facts presented in Southeastern Community College v. Davis, decided by the U.S. Supreme Court in 1979, have been summarized as follows:

Frances Davis sought admission to the nursing program at Southeastern Community College, which received federal funds. Davis also suffered from a hearing disability, and was unable to understand speech without lip-reading. Davis’ application was denied. She asked for reconsideration,

Continued on next page

and her application was again denied. Davis filed suit in United States District Court for the Eastern District of North Carolina, which ruled against her. The United States Court of Appeals for the Fourth Circuit overturned that decision.

In a unanimous decision of the U.S. Supreme Court, the decision of Southeastern Community College, which received federal funds, was upheld in Southeastern Community College v. Davis. Justice Powell wrote that an "otherwise qualified handicapped individual" specified by the Rehab Act meant one who meets all the program's requirements "in spite of his handicap" as opposed to "in every respect except as to limitations imposed by their handicap." The court reasoned that, even with an improved hearing aid, Davis still required lip-reading to understand speech, and therefore was not "otherwise qualified." The court concluded that since Davis could not be admitted to Southeastern's program without substantial changes to admission requirements, Davis' rejection did not constitute unlawful discrimination. Id.

One of the first victories for disability rights in a court decision was the decision of the United States for the Second Circuit (sitting in New York City) in Dopico v. Goldschmidt. In Dopico, disability rights attorneys successfully argued that newly acquired vehicles, and newly constructed or newly altered facilities, must be accessible. (In previous cases, disability rights attorneys argued unsuccessfully for accessibility in existing vehicles and facilities. Courts allowed noncompliance justified by economic limitations. In Dopico, disability rights attorneys successfully argued for required accessibility limited to new vehicles and facilities.) Dopico led to other victories in Section 504 cases. (For example, in a landmark decision of the entire court, sitting en banc, the United States Court of Appeals for the Third Circuit (Philadelphia) in ADAPT v. Skinner the court's reasoning in Dopico was adopted and affirmed.)

Mary Schultz is a partner in the law firm of Schultz &Associates LLP, www.sl-lawyers.com , 640 Cepi Dr., Suite A; Chesterfield (St. Louis), Missouri 63005, (636) 537-4645. Mary B. Schultz graduated from Northwestern University Law School more than 30 years ago, in 1985, and has been practicing primarily in Missouri ever since. Mary B. Schultz is admitted to practice in Missouri and Illinois.

Mary was diagnosed with HSP in 2012 and through genetic testing has learned that her gene mutation is in SPG7. Mary has been a member of SPF and has benefited from friendships and support she has received from SPF.

This column is intended to provide general information only. It does not constitute, nor should be relied upon, as legal advice or a legal opinion relating to specific facts or circumstances.

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Medical and Research

SPF Board Awards Grants Worth $622,000

At a special meeting of the SPF Board of Directors, held on November 20, 2015, five research proposals, requesting a total of $622,000, were approved by the Board to receive grants from the Spastic Paraplegia Foundation.

In total, twenty-three proposals were received, reviewed and ranked by SPF's 12-member Scientific Advisory Board. Fourteen proposals were designated by the applicant as relating to HSP, six to PLS, and three to both HSP and PLS.

The top-ranked proposal was one related to both HSP and PLS:

Rebecca Schule, M.D., Hertie Institute for Clinical Brain Research, University of Tuebingen, Tuebingen, Germany, "Alliance for Treatment in HSP and PLS."

The top-ranked HSP-specific proposals were:

Benjamin Cravatt, Ph.D., Professor & Chair, Department of Chemical Physiology, The Scripps Research Institute, La Jolla, CA, "Brain lipid metabolism in hereditary spastic paraplegia."

Tobias Sebastian Ulmer, Ph.D., Associate Professor of Biochemistry and Molecular Biology, Zilkha Neurogenic Institute, Keck School of Medicine, University of Southern California, Los Angeles, CA, "Structural basis of brain carnitine palmitoyltransferase 1 function."

The top-ranked PLS-specific proposal was:

Teepu Siddique, M.D., Professor, Departments Neurology, and Cell and Molecular Biology, Northwestern University Feinberg School of Medicine, Chicago, IL, "Whole Exome Sequencing in Primary Lateral Sclerosis."

In addition, the Board also approved from the SAB's list of other highly-rated proposals, the following:

Jonathan J. Rios PhD, Assistant Professor in Pediatrics, University of Texas Southwestern Medical Center, Dallas, TX, and Assistant Professor in the McDermott Center for Human Growth and Development, Texas Scottish Rite Hospital for Children, Dallas, TX, and Mauricio Roque Delgado-Ayala, MD, Medical Director, The Carter Center Initiative for Childhood Motor Disorders, and Texas Scottish Rite Hospital for Children, Dallas, TX, "Evaluating & Improving Personalized Genomic Medicine for Hereditary Spastic Paraplegia."

Scientific Advances in Genetic Neurologic Diseases, Such as HSP and PLS: What Is CRISPR?

by Malin Dollinger, M.D., SPG4

Let's first consider the scientific pathway, over a long time, which led us to the present. We've come a long way since my genetics class in college (1955), where we were mostly concerned with inheritance of dominant genes (need one copy [allele] to inherit the trait, such as brown eyes) and recessive genes (need two copies to inherit the trait, such as blue eyes). Then there are x-linked genes where the females are the carriers and the males get the disease. These genes were studied not only in humans, but in primitive animal species, such as the fruit fly [Drosophila] and molds such as Neurospora [Dr. Tatum won the Nobel for this in the Stanford lab next to mine]. Then along came inherited HSP, and no surprise that there were the common dominant forms, like the most-common SPG4 that my daughter and I have, the uncommon recessive forms, and the rare x-linked forms. A variety of PLS appears to be inherited as well.

Then amazing research took off in genetics in general and inherited neurologic disorders, HSP in particular. The human genome was unraveled and defined, with three billion base pairs that determine virtually every trait and characteristic of each one of us. Shortly thereafter, there followed the identification of many DNA abnormalities that were associated with many specific diseases. Now we can even send a sample of our DNA to diagnostic laboratories to discover what diseases and conditions may lie ahead for us. We can identify trisomy-21 [Down's syndrome, three copies of chromosome #21 instead of two] before birth and even cure most patients with a form of previously incurable chronic leukemia by using therapy that targets an abnormality/mismatch where portions of chromosomes #9 and #22 trade places. Those of us with suspected or clinically diagnosed HSP can send a blood sample to Athena Diagnostics to study our DNA and diagnose which of dozens of different HSP gene defects we personally have. Someone once asked me how long I've had HSP, and I told him that it began when my mother's egg was fertilized with my father's sperm. I was then one-cell old.

All well and good. Enter the field of stem cells. All of us start life as a single fertilized egg. That new chromosome/DNA mixture, a hybrid of both our parents' DNA, has all the instructions for every cell in our body to be used during our lifetime. After millions of cell divisions, some cells become the lining of the stomach, and secrete gastric juice. Others determine our eye color. Others form bone to hold our body together. And every instruction for every cell in our body is contained in our DNA. Those billions of inherited DNA base pairs tell every cell in the body what to do, how to do it, and when. Somewhere in the DNA there are the instructions to heal a cut or wound or to stop bleeding when we injure ourselves. There are instructions to create a structure in our kidneys, called the nephron, which gets rid of waste and conserves water and minerals; and instructions for every single part of our body as well.

That very first cell, and many subsequently-derived cells, are stem cells, meaning they can become [differentiate] whatever kind of cell is needed. Some make bone or cartilage; others make skin or lung tissue, still others become nerve cells [neurons] and the cells that surround and support the nerve cells. In HSP, as well as multiple sclerosis and many other neurologic diseases, something goes wrong with the nerve cell DNA. When our cells divide, so does the DNA, so each divided cell gets the same complete set of DNA. There is often an error or mistake so the resulting DNA is abnormal. The body has specific mechanisms [e.g. the p53 gene] to find these mistakes and correct them or to eliminate that "bad cell" so it cannot divide and make identical bad cells and cause trouble. Incidentally, that's how cancers begin; one bad cancer cell is accidently formed with "cancer DNA" that is not eliminated by the body's defenses, and then goes on to make many more cancer cells.

Research workers are vigorously trying to discover, in the case of HSP, exactly what goes wrong in the nerve cells, beginning with the abnormal DNA, which in this case involves structures in the nerve cell called microtubules. There are already animal models that give us an important clue and research tool to discover what goes wrong. The tiny zebrafish is transparent, and an HSP-equivalent zebrafish model can be studied under a microscope, and we can actually see the nerves up close. A mouse HSP model can be "treated" and we can see how the affected mouse walks with the treatment.

There has been much research with stem cells, at first an effort to not only collect them but also to convert mature cells back to the primitive stem cells that started the whole process in the first place. Many have been successful; many have not. We are still facing two major problems: 1) assuming we can create or collect stem cells, how do we teach them to make the kind of mature cell we need and how do we get these new cells to the right place?

Already we can put cardiac stem cells into the heart to build new heart muscle and can make new blood vessels and gland tissue; 2) there is superimposed the ethical, legislative, and governmental oversight as to exactly what is permitted and what is not. Use of aborted fetal tissue, rich in stem cells, is a current area of great debate and concern. Large research institutions have been created (e.g. Stanford's stem cell research center) to explore this great scientific and medical breakthrough. Our personal fantasy goal would be to create some sort of nerve stem cell that would create "normal" nerves/neurons, and thus fix the DNA abnormality/abnormal cell in HSP.

With any form of treatment for HSP, and inherited PLS, we must distinguish between fixing somatic cells, the cells all over our bodies that do all these tasks, and germ cells, the ones in eggs and sperm that combine to make new people. "Germ cells" are the cells that start the reproduction process. A germ cell from the mother combines with a germ cell from the father to create an embryo that grows into a person. For living souls, fixing the germ cells is a worthwhile goal, which might thus prevent our offspring from inheriting the HSP gene. Our abnormal HSP "gene pool" would end with that type of treatment. However, fixing our germ cells would not help us personally, the suffering living. Just as important is the idea that we could somehow fix all the bad nerve cells we already have so we, the sufferers, could be helped.

That's where a new breakthrough, CRISPR, may come in and save the day. It's still very early and we need a lot of research to discover just what role this new technique may have for affected people. A very few persons, children with neuromuscular conditions in particular, have had such treatment, with amazing results. We are anxiously awaiting the research progress to include HSP in the group of potentially treatable patients.

Just what is CRISPR? This is a method of editing genes, to change abnormal genes to normal ones, in the somatic cells [cells all over the body, muscles and nerves in particular], as distinguished from germ cells that transmit genetic information, defects especially important to us and to our offspring. CRISPR stands for Clustered Regularly Interspaced Short Palindromic Repeats. A virus vector, which finds and attaches to muscle or nerve tissue, is used to deliver the CRISPR/Cas9 system to the correct target, where it modifies and corrects the abnormal places in the chromosome that cause the disease. The viral vector is a "smart bomb," in that it knows what target it is looking for, and finds and attaches to that target.

A few of the many important recent research studies:

Long et al [Science 10:1126/5725 December 2015] studied a mouse model of muscular dystrophy, a disease where there is a gene mutation involving the protein dystrophin. Treatment with CRISPR/Cas9 "allows precise modifications of the genome and represents a potential means of correcting disease-causing mutations." They used a viral carrier (vector), which seeks and binds to muscle tissue, to deliver gene-editing components. They noted that not every muscle cell needs to be "fixed" to create improvement and they estimated that even low levels of repaired dystrophin can protect against injury to skeletal muscles. There was concern expressed, when human trials begin, about "off-target" mutations. In other words, changes to genes other than those intended. Whole genome sequencing was mentioned as a way to assure future safety of this type of treatment approach.

Nelson et al [Science 10, 1126, 5143] used a virus vector to deliver the CRISPR/Cas9 system in a mouse model of Duchenne muscular dystrophy to remove a mutated portion of a chromosome containing the dystrophin gene. That gene was again expressed and functional dystrophin protein was partially recovered. Muscle force improved significantly. Thus, this form of gene editing and modification has great potential for treating genetic disease, especially those involving muscle and nerves.

Similar restoration of function of dystrophic mouse muscle and muscle stem cells was reported by Tabebordbar, et al [Science 10, 1126, 5177]. They emphasized that perfect DNA correction was not required for recovery of muscle function. Targeted gene modification was successful in their diseased mouse model, even after administration of only one dose of the agent.

So stay tuned! In our lifetimes, dedicated researchers will apply this muscular dystrophy treatment model to inherited nerve diseases, such as HSP. In particular, just like muscular dystrophy, in HSP we also know the specific site and type of the responsible mutation. Let's use a viral vector/delivery system [for once a good use of a virus] to administer the specifically designed CRISPR system to our genetically-diseased nerve cells. Nerve cells are very different from muscle cells, so a lot of research needs to be done before they will have the correct, and safe, human delivery system to treat genetic viral nerve disease.

I'll be in line, waiting, with great interest and expectation.

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[The following is an alternate source for information about your motor neuron disease and may provide answers to questions you may have about your specific conditions. Participation in this closed Facebook group requires approval by one of the two group moderators – see details in the article. Ed.]

Research Group on Motor Neuron Disorders

By Rita R. Handrich, PhD

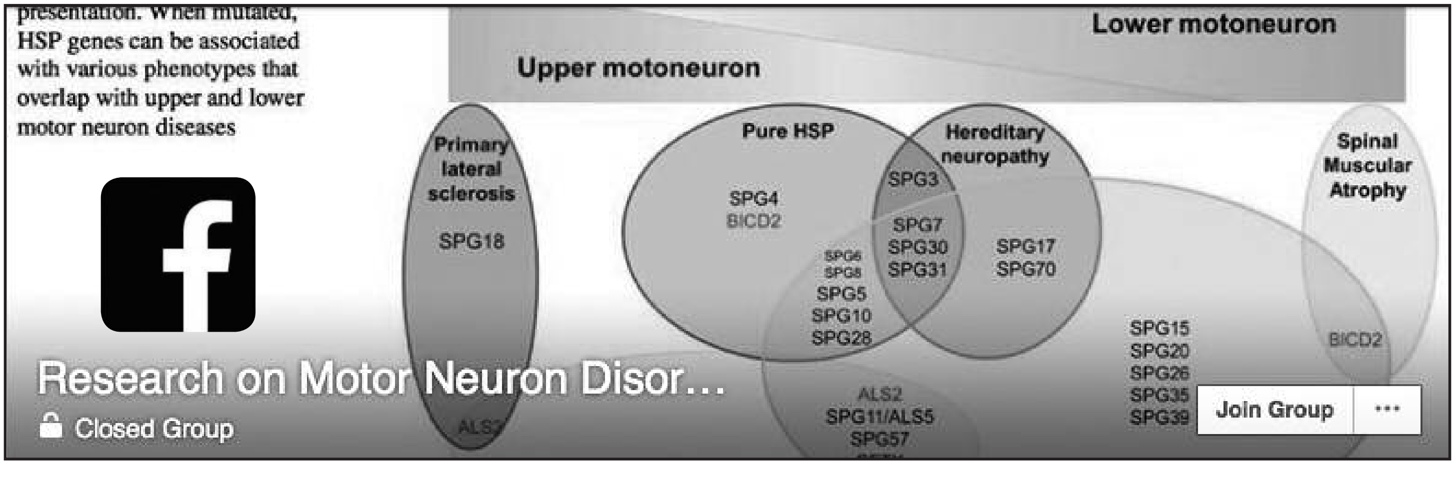
This is a very exciting and hopeful time for motor neuron disorders. Things are picking up again after the holidays with more on stem cells, new treatments for neurodegeneration (aka progression) that draw from existing medications and supplements, and more on how exercise is not only good for you but can help you grow NEW brain cells. (Oh my.)

About six months ago, we created the Research Group on Motor Neuron Disorders on Facebook at URL https://www.facebook.com/groups/1480906428886694/. To join the group, click on the JOIN button and then watch your Facebook Messages folder for a question as to why you want to join. We don't approve anonymous profiles if we cannot verify who you are in real life. We also do not approve anyone unless we can establish a direct Messages link with them because of how the group operates. We've had several members tell us the Research Group is "the best and most well-moderated group on Facebook". We don't know about that, but we do our best. If you'd like to join the group, use Facebook Messenger to message me or Lisa Dang, who lives in Hawaii. We won't send you our postings via email (it's too much work), but we are happy to have you join us on Facebook.

This group is intended to offer you ACCURATE and CURRENT information on emerging new research in motor neuron disorders. While there are multiple support groups for these conditions (ALS, HSP/SP, PLS), there is no central place to obtain good information on research and support groups are filled with inaccurate information that can be confusing. The Research Group makes every effort to vet information and to remove inaccurate information so that what you read here is information you can count on. To that end, this group will post new research on three motor neuron disorders: Spastic Paraplegia, Primary Lateral Sclerosis, and Amyotrophic Lateral Sclerosis. In the recent past, these three were investigated separately, but newer research has begun to see they are inter-related. This is a place to keep up on the newest research as we all wait for treatments beyond symptom-relief to emerge.

The expectation in this group is for civil and respectful discussion, even in disagreement. Group members who insult, harass, or make fun of others in posts, comments or private messages, will be warned privately by one of the moderators and the uncivil/disrespectful note will be deleted from the group. If, after being warned, there is a second incident, the offending group member will be removed from the group. This is done in order to keep the group emotionally "safe" for all group members.

We invite you to join us and we know we are not for everyone. But if you are the sort of person who wants to understand more about your chronic health condition, wants to be in a group that stays focused and is not repetitive, and enjoys reading a diverse range of plain language articles and some research articles specific to your areas of interest—we probably *are* for you.



presentation. When mutated, HSP genes can be associated with various phenotypes that overlap with upper and lower motor neuron diseases

Tina's Tips...

I have been fortunate to have several ideas or tips sent in that could make life a little easier whether you have HSP, PLS or not!

On my recent visit to a connection with the group from Illinois, I can't remember who brought it up, but someone suggested a backpack or fanny pack to put things in to help us carry items.

One tip sent in by Linda Gentner *(PLS from California and VP of the SPF)* is a great idea for icy steps. She added that she doesn't know first hand if this works because where she lives it never freezes! She got this tip from her cousin in Indiana.

> For icy steps and sidewalks in freezing temperatures, mix 1 teaspoon of Dawn dish washing liquid, 1 tablespoon of rubbing alcohol, and 1/2 gallon hot/warm water and pour over walkways. They won't refreeze.

I particularly like this idea because it is better for dogs' paws than rock salt!

Another idea was sent in from Mike Church *(HSP Springfield, MO)*. Mike writes,

> "I finally found out how to cleanup cat messes without getting on the floor, a dust pan and a 12" squeegee from Lowes. I added the handle to fit the squeegee. Now I can clean up anything our cat, Smokey can throw up and do it from my power chair!

Mike has also added PVC "tubes" to the back of his Jazzy scooter in order to put his canes. *(see picture)*

And here is yet another tip from Mike Church:

I just finished replacing door hinges in one of our rooms. New hinges give me another 2 inches doorway width. Got the hinges at Lowes, swing clear full mortise hinges 3½" (88mm). Backsets on doors and frames should be increased by the amount of the additional door thickness. A tool that works well for making the hinges fit is a oscillating multi-function power tool, mine is from Harbor Freight. In my case I had to use the tool to cut out the hinge area to accommodate the square corners of the hinge. If you're not handy with tools get a relative who is to help you. [Better yet, hire a professional handy-man with carpentry skills to do the work for you. Ed.]

Fig. 1 - New (top) and Old Hinges

Fig. 2 Close up of New Hinge

I (Tina) have an idea that I use all the time! I put one of those plastic grocery bags on the handle of my rollator. I put a roll of paper towels and cleaning supplies in the seat basket of my rollator. That way if I find trash or recycle or something that needs cleaning or dusting, I'm not making several trips!

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.

SPASTIC PARAPLEGIA FOUNDATION
2016 ANNUAL CONFERENCE
REGISTRATION FORM

Friday, June 24th
Corey Weiser, MetLife
Potato Pants – The Race!
Erasing the Difference – Theatre Group

Saturday, June 25th
Speakers include: Dr. John Fink, University of MI,
Dr. Teepu Siddique, Northwestern University
Dr. Kirsten Tulchin-Francis—Scottish Rite Hosp. & Univ. of Southwestern Texas Medical Center, Dallas, TX
Dr. Corey Braastad, Athena
and lots more in break out sessions!

Sunday, June 26th
Abilities Expo
Schaumburg, IL *(transportation provided!)*

Friday Night Dinner - $50
Children - $15 *($55 for adults and $20 for children after 5/17)*
Saturday Conference $70 *($75 after 5/17)*
Sunday Abilities Expo $20 per person (*not available after 5/17)*

Hotel reservations for the Renaissance Chicago O'Hare Suites Hotel call: 773-380-9600

Register online at: www.sp-foundation.org

Name #1:____Disorder: HSP____ PLS ____SP____

Name #2: ______________________________ Name #3:______________________________________

Child/ren: _________________________ Age: _____ Name:__________________________ AGE:______

Address: ____

Phone: (_______)_________________________ E-mail: _______________________________Text?: Y / N

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

Friday Night Dinner: QTY:_____@ $50.00* pp = $_______

Saturday Conference: QTY:_____@$70.00* pp = $_______

Abilities Expo: QTY:_____@$20 pp = $______

Special Meal Requirement

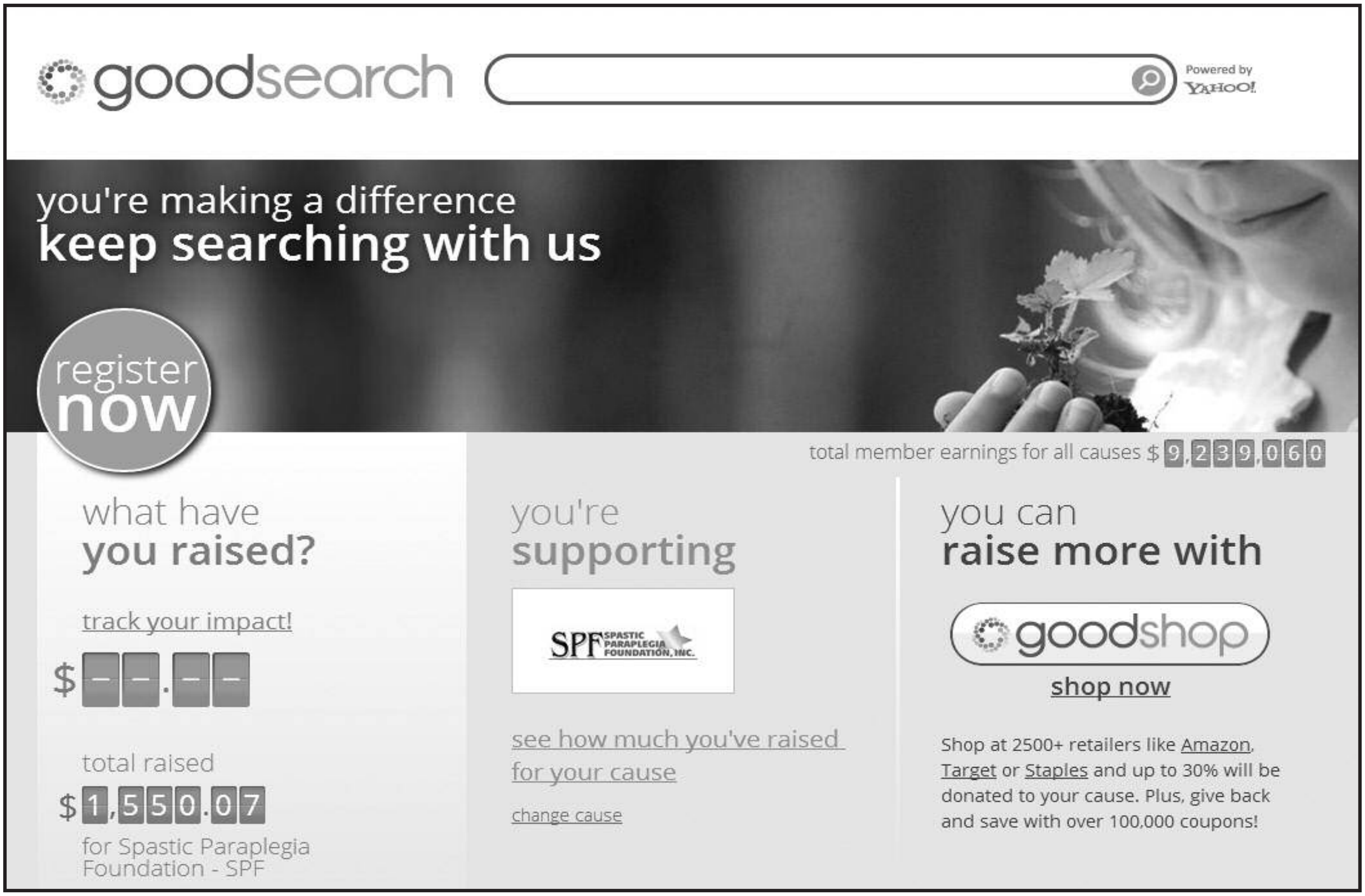
__________ Regular _________ **Vegetarian** _________ Soft **SPF Donation:** $_________

Total Enclosed: $__________

Early registration price before May 18, 2016

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
Research / Education / Support

1605 Goularte Place
Fremont, CA 94539-7241



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