

# Synapse

Volume 19, Issue 2

Spring 2016

*Newsletter of the Spastic Paraplegia Foundation*

## THERE'S STILL TIME TO REGISTER!!

<http://www.jotform.us/form/60216341480143>

*Come on Research, Why don't we find a cure*

*And dance that jazz*

**SPF 16th Annual Conference**

**CHICAGO**

**June 24-26, 2016**

**Renaissance O'Hare**

## 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!*

## 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](mailto: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 TeamWalk. 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.



### **Volume 19, Issue 2 - Spring 2016**

*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

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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](mailto:information@sp-foundation.org)

or [www.sp-foundation.org](http://www.sp-foundation.org)

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

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## Letter from the President



Dear Friend,

Today, I want to tell you about how life is giving us both an incredible gift and an exciting challenge. When it comes to HSP & PLS, we look at the thorns on the rose

too often and overlook the flower altogether.

The flower, or gift, you and I should focus on is the hope that lies in the mind-boggling speed that genetic and neurological science is moving today. Our research for the cure for HSP and PLS is thriving and making spectacular progress. The challenge is that these phenomenal opportunities demand support. It is like a fast moving train and we'd better stay on.

You and I don't give to The Spastic Paraplegia Foundation because we want another text book to be written. We want a cure to happen yesterday so our friends and family with HSP and PLS can find relief from their suffering. A cure will be found but the question is whether we want it to happen in the next ten years or the next fifty.

I wrote you just recently, in our Annual Report, about just some of the highlights of the progress that is taking place toward a cure for HSP and PLS. (If you haven't read it yet, it is available on our website, [sp-foundation.org](http://sp-foundation.org).) It is truly exciting.

I want that research progress to come home with a cure for over 100,000 people world-wide with HSP and PLS. We owe all of our past progress to your generosity and we are so grateful but I want to add a challenge. Please try to be extra generous with your summer donation. I'M GREEDY FOR A CURE because I know we can do it!

What we can accomplish is limited only by the dollars we can afford to spend for research. There is so much promise in what research is doing, it is like everything is a bargain. The cure is so close, you can almost taste it. This is not something that we can just let other people pay for. It is right within reach but we are the ones that have to do the reaching. You may say that you can only afford to give a small amount so your gift can't make any difference. Well, Bernie Sanders is an example of how small gifts add up. He claims to be funding his entire campaign for the Democratic presidential nomination with donations that averaged just \$27. Your gift to SPF, no matter what amount, will make a world of difference!

We keep reaching new plateaus but we could be doing so much more. I challenge you to help SPF set a new donation record by the time of our Annual Conference in Chicago in late June. I look forward to hearing from you.

Sincerely,

*Frank Davis*  
President

# Rare Disease Day

## “Dining to Donate” Fundraiser at Applebee’s Restaurant: One SPF Ambassador’s Experience

By Jeff Stern

SPF State Ambassador, Maine

Western Maine is a long way from anywhere. The nearest city, Portland, Maine’s largest at 67,000 people, is a 1¼ hour drive distant – in good weather – over twisty, narrow roads. In some of the lonelier stretches, encountering a moose might be a more likely outcome than seeing another vehicle. Beyond Portland, the small, dispersed communities that dot this heavily forested region almost on the Canadian border are among the poorest in the United States.

So why choose such an out-of-the-way, down-on-its-luck place to hold a fundraiser? Well, I’ve lived here 16 years and over this time developed fairly deep roots. I feel a deep affection for the people and landscape. Plus, I wanted to mark Rare Disease Day (RDD) by staging an event to raise community awareness. After all, HSP and PLS are considered rare diseases. I took heart from a line in Frank Sinatra’s song New York, New York: “...if I can make it there I’ll make it anywhere...” But could I?

The focal point for my RDD fundraiser was the Oxford, ME, Applebee’s Restaurant. Applebee’s has a program called “Dining to Donate”. It’s a way for the chain to give back to the communities it serves. On a Dining to Donate night, Applebee’s will contribute 15% of meals (less tax and tip) to a charitable organization. The upside to SPF could be huge; after all, there are more than 2,000 Applebee’s Restaurants nationwide. Even if there isn’t an Applebee’s in your town there may be other local restaurants that offer something similar. Pulling together one of these events takes planning, and a moderate investment of time. Here’s how I did it.

Rare Disease Day is an annual commemoration that comes along at the end of February. (The originators of RDD are obviously from a warm climate where there is no danger of disruption to events due to blizzards or ice storms!) Despite the risk of inhospitable weather I nevertheless contacted my local Applebee’s in early January. There are online forms to fill out; nothing too complicated. But it is best to register early so you’re more likely to get the date you want. In my case, Feb. 25 was the nearest I could get to Rare Disease Day, which this year was Feb. 29.

To qualify for the fundraiser, patrons need to present a flyer to their server before ordering their meal. So the next item on my “to do” list was to line up a local agent where people

could pick up flyers. I live outside of town and wanted to make it as convenient as possible for people to participate. I targeted the local book store, a hub of the community, and visited with the owner. Going in, I had concocted an elaborate sales pitch the climax of which was the idea that getting people in her store to pick up Dining to Donate flyers might boost book sales as well. But I never got that far; she cut me off half way through my spiel and said she was more than willing to act as the local repository. This was in late January.

Now that I had a local distributor of flyers lined up I could write my press release. SPF allowed me to use foundation letterhead. I kept it as brief as possible, explaining HSP and PLS in layman’s terms, Rare Disease Day, the role of SPF, and why it’s important to raise money to fund research into a cure. I told readers they could either visit the book store to pick up flyers or get them from me by calling or emailing.

Before sending the press release out to the world I ran the draft by Applebee’s and the book store; since it mentioned their names I figured I owed them this courtesy. Once I received their blessings I sent it to area newspapers and the local country radio station in early February. I also wrote a letter to the editor that I sent to the largest newspaper (in terms of readership) at about the same time.

I know that some people hate writing. If this describes you, please contact me and I will gladly share my press release and letter to the editor. You can use them as you see fit. Feel free to tailor them to your situation. There’s no sense reinventing the wheel!

Also in early February, I began sending personal emails to friends. I included the flyer and press release as attachments. But people lead busy lives and many were going to be out of town the night of the fundraiser. This I expected; there’s always a mass migration of Mainers to warmer, sunnier places in February and March. Others who were sticking out the Maine winter already had previous meetings scheduled. Still, the one-on-one contacts were useful because most folks agreed to contribute even if they couldn’t attend in person.

I sent several emails to my list of SPF members in Maine – about 30 people – on the off chance they would be passing through western Maine that evening. I realized this was a long shot because of the distances involved but thought I’d put it out there anyway. As it turns out, I was thrilled to see that one SPF member (and her friend) from several towns over WAS able to attend!

*Continued on next page*

In mid-February, the weekly local newspaper sent a reporter to interview me after receiving my letter to the editor. This was a big help in publicizing the event. As the result of this article, I received a call from a person who suffers from a related condition. Although different from HSP and PLS, her Spastic Hemi-Plagia has created severe mobility issues similar to what SPF members deal with. She was pleased to learn there was someone else in the community who could relate to her challenges. Others didn't have a clue about any of this until they saw the article. It was a genuine "teachable moment".

I also advertised the event in the community calendar on the public radio station and on the SPF Facebook page. I continued with personal emails and calls all the way up to the big day.

February 25 finally arrived. I was relieved to see the weather was a few degrees above freezing with no major storms in sight. Snow or ice would not be a problem. I felt like I had done all the prep work I could. But would it be enough? I didn't know what to expect when I pulled into the restaurant parking lot. I took a deep breath and entered...

Once inside I saw familiar faces all over the place. This was extremely heartening. Way more people attended than I dared imagine in my wildest dreams. Patrons can participate in Dining to Donate any time from 4 – 9 p.m. I arrived at 6. I had previously reserved a large table for this time and invited some of my closest friends to join me. We enjoyed ourselves and stayed several hours. I encouraged people to run up big bills. My girlfriend and I even ordered dessert; something we usually avoid.

The truth is it's hard to raise a lot of money solely this way. Even though my Dining to Donate night generated almost \$1,000 in revenue for the restaurant, SPF pocketed just \$138. But I believe that is only part of the story. Holding an event like this presents something tangible around which to organize and educate the public. People felt good about donating while enjoying an evening out. Before the fundraiser many people did not have a clue about HSP, PLS or Rare Disease Day. The press release, letter to the editor, feature article, one-on-one contacts, and Dining to Donate night itself all spread the word far and wide. How can you put a price tag on that?

In the end, contributions from those who couldn't attend Dining to Donate pushed SPF's total "take" for my event to more than \$800. Dining to Donate gave me an excuse to hit up people for a donation instead of just calling them out of the blue. I was overwhelmed by the community's generosity. I followed up with a letter to the

editor that thanked all those who participated, both in and out of the restaurant.

That's my story. I'm not saying the way I did it is the only way, or even necessarily the best. Nor will it fit all situations. But I believe "Dining to Donate" dinners at restaurants like Applebee's across the country, combined with direct solicitation, can have substantial educational benefits and at the same time raise needed funds for SPF's quest to cure HSP and PLS.



Rensselaer County Men Bowling League  
c/o Olympic Lanes  
5 Elmwood Road  
Menands, NY 12004-2403

Spastic Paraplegia Foundation, Inc.  
Frank Davis, President  
1605 Goularte Place  
Fremont, CA 94539-7241

March 8, 2016

Dear Mr. Davis:

In anticipation of Rare Disease Day 2016, I informed my Monday night bowling league, Rensselaer County Men, at Olympic Lanes, of the significance of the day. Together with that occurrence, I asked bowlers to opt to wear jeans that night in recognition of the Jeans for Genes project, given that a majority of Rare Diseases, including Hereditary Spastic Paraplegia, originate in such manner. In response, one member, Joe Bifaro, created several denim ribbons from old jeans that were distributed to and worn by several bowlers that night.

To my surprise and beyond that gesture, Joe, in consultation with our league vice president, Scott Rogers, announced that they would be taking a collection to be donated to the Spastic Paraplegia Foundation on my behalf, in recognition of my continuing to bowl despite having Hereditary Spastic Paraplegia, together with my work as secretary of this league of 144 members and substitutes.

Their collection resulted in \$387.00, to which I added \$13.00 to make the end donation an even \$400.00, for which a check is enclosed.

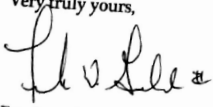
With this submission, you have the league's permission to use its name, together with my permission to use my name in any appropriate missive, which may include the [spfoundation.org](http://spfoundation.org) website, Facebook or other social media, and any appropriate print publication that would be of the board's choosing.

Hereditary Spastic Paraplegia does present multiple challenges, and I am pleased to submit this contribution on behalf of the Rensselaer County Men bowling league as a token of support for all contributing to research and other projects to learn more about this and other neuromuscular conditions, with the hopes that one day either a cure or improved treatment may one day arise out of these efforts.

As I will be unable to attend the annual conference in June, please share my warmest regards with the members of the board and other attendees.

On behalf of the members, substitutes, and guests of the Rensselaer County Men, I remain

Very truly yours,



Frank W. Goebel II (HSP SPG-4)  
Secretary, Rensselaer County Men  
encl.

# 2016 Annual Conference

Chicago, Illinois  
June 24-June 26

## Program for Friday Evening June 24, 2016

5:00 – 7:00	Registration - Foyer of Ballroom
5:00 – 7:00	Cocktail Reception & Cash Bar Sponsored by MetLife
7:00 – 8:00	Plated Dinner
8:00 – 8:30	Speaker: Corey Weiser, MetLife
8:30 – 9:00	Entertainment by “Erasing the Distance”

## Program for Saturday, June 25, 2016

7:00 – 9:00	Registration and Breakfast Sponsored by Invitae
9:00 – 9:15	Welcome & Introductions – Frank Davis
9:15 – 10:15	Dr. Teepu Siddique
10:15 – 11:00	Dr. Sabrina Paganoni
11:00 – 12:00	Dr. John Fink
12:00 – 1:00	Plated Lunch
1:00 – 2:00	Dr. Kirsten Tulchin-Francis
2:00 – 3:00	Dr. Corey Braastad
3:00 – 4:00	Lori Renna Linton, “Potato Pants”
4:00 – 5:00	<b><u>BREAKOUT SESSIONS</u></b> Q&A with Dr. Fink – Main Ballroom “Tissue Donation” Susan Garcia- Hagen – Jazz Breakout Room

## Program for Sunday, June 26, 2016

9:00	Board busses at hotel for Abilities Expo
10:00	Group picture outside of Abilities Expo
10:00 – 1:00	Tour vendors (lunch on your own)
1:00	Board busses to return to hotel
2:00	Arrive at hotel

SPF 16th Annual Conference

CHICAGO  
June 24-26, 2016  
Renaissance O'Hare

## 16th Annual Conference Speakers



**Corey Braastad, PhD**  
*cbraastad@athenadiagnostics.com*  
Senior Scientific Director  
Genomics Core Lab and  
Bioinformatics  
AthenaQuest Diagnostics

Corey Braastad has been a member of the SPF board of directors since 2008. He is a Senior Scientific Director at Athena Diagnostics, part of Quest Diagnostics, specializing in developing new clinical genetic tests. Corey earned his PhD in Molecular Biology, Biochemistry and Biochemistry at Brown University in the field of mechanisms of DNA repair. He completed a post-doc at UMass Medical School working on cell cycle regulated gene expression.

*Continued on next page*



**John K. Fink, M.D.**  
*Neurogenetic Disorders Program,  
University of Michigan*

Dr. Fink is board-certified in both Neurology and in Medical Genetics. For more than 20 years, Dr. Fink's research and clinical activities have focused on understanding the causes and developing treatments for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. Dr. Fink directs the Neurogenetic Disorders Program at the University of Michigan and Fink serves as the Medical Advisor to the Spastic Paraplegia Foundation.



**Susan Garcia-Hagen**  
*Social Media Manager and Project  
Manager, University Relations  
University of Minnesota; Patient  
Services Director, National Ataxia  
Foundation, Minneapolis, MN*

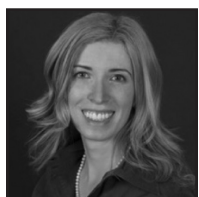
Susan Garcia Hagen currently serves as a Communications Consultant for the University of Minnesota-Twin Cities' Office of Undergraduate Admissions, where she oversees the social media strategy for the office. Susan serves as Patient Services Director for the National Ataxia Foundation in Minneapolis, MN.



**Lori Renna Linton**  
*High School Teacher, HSPer,  
Klosterneuburg, Austria  
lorilinton@potatopantshsp*

Working together to raise awareness of hereditary spastic paraplegia.

Lori Renna-Linton was born in Borough Park, Brooklyn but lives in Kritzendorf, Austria with her husband and 2 children, Jack and Bella. She is a teacher at a high school in Klosterneuburg where she teaches English to fantastic students in grades 5-12. Over the last 15 years she has acquired extensive teaching experience in both the private and public sectors.



**Sabrina Paganoni, MD**  
*Board-certified in Physical Medicine  
and Rehabilitation, Neuromuscular  
Medicine, and Electrodiagnostic  
Medicine*

Dr. Paganoni is an Assistant Professor at Harvard Medical School and faculty at the Massachusetts General Hospital Neurological Clinical Research Institute. Her research focuses on therapy development for motor neuron diseases including the use of neuroimaging studies in early clinical trials. As the recipient of the 2015 Virginia

Freer-Sweeney PLS Fellowship, she is currently working on a molecular neuroimaging study to characterize neuroinflammation in PLS and is spearheading a national PLS registry.



**Teepu Siddique, MD**  
*Northwestern University, Departments  
of Neurology  
and Cell and Molecular Biology*

Dr. Siddique has had a long term interest in diseases of the neuromuscular system, particularly diseases that affect the motor neuron, such as ALS, PLS and HSP. His research has focused primarily on the molecular genetics of ALS (amyotrophic lateral sclerosis) and ALS with dementia. Dr. Siddique credits the enthusiasm of four members of the SP Foundation, Thurza Campbell, Angela Dixon, Linda Gentner and Jennifer Thompson, affectionately nicknamed the Fab Four, with reigniting his research interest in PLS and spurring the development of a Registry of samples and clinical information that will now allow his group to employ exome sequencing to look for genes that may increase the risk for developing sporadic PLS. The SPF has most generously funded this project, about which he will speak at the June SPF Annual Conference.



**Dr. Kirsten Tulchin-Francis**  
Dr. Tulchin-Francis is director and senior bioengineer in the Movement Science Laboratory at Texas Scottish Rite Hospital for Children, TSRHC. She also serves as a clinical assistant

professor for the Prosthetics and Orthotics Program in the School of Health Professions at The University of Texas Southwestern Medical Center at Dallas. Her research interests include foot and ankle biomechanics, functional outcomes in hip pathology, lower limb deficiencies and scoliosis, and understanding the movement patterns of children with orthopaedic and neuromuscular conditions.



**Cory Weiser, CIMA®, CMFC®,  
CRPC®, MBA**  
*cweiser@metlife.com  
www.coryweiser.metlife.com*  
Financial Services Representative,  
Special Needs Planner, Investment

Advisor Representative for Bridge Financial Group, an office of Metlife.

# DISABILITY LAW: CRISPR Patent Litigation

By Mary B. Schultz



Dr. Malin Dollinger's recent article in the *Synapse* was a very informative and understandable narrative about scientific advances in genetic neurologic diseases, like HSP and PLS in general, and CRISPR in particular. Because of that article, I concluded it would be suitable in

this instance to deviate from my analysis of basic disability law, to discuss how a legal battle over the patents and licenses for CRISPR affects the application of that exciting gene editing biotechnology to our diseases.

CRISPR is an acronym for "Clustered Regularly Interspaced Short Palindromic Reports". CRISPR has been described by Antonio Regalado in the MIT Technology Review as "molecular scissors", allowing DNA to be cut and disabled, replaced, or edited with precision and ease. CRISPR might well be the most significant development in biotechnology in the last century. Personally CRISPR gives me much hope as a potential for gene therapy. CRISPR/Cas9 would allow the use of the enzyme "Cas9" to re-write DNA sequences by disabling, replacing, or otherwise changing genes. In other words, as I understand it, CRISPR is a simple and versatile technology that would enable scientists to edit genes.

However, I regret to report that lawyers and the legal system are interfering with scientific progress that could directly and dramatically affect us. A law school classmate of mine, who worked for a high-brow law firm in New York City, reported that when a senior partner had him research a legal ethics question that affected that lawyer personally (and professionally) the lawyer told my classmate: "This ain't no \*#@!! moot court problem." Well, no legal issue is a sterile, abstract, academic issue to the people that are directly affected by our legal system. The CRISPR dispute is no exception. I'll step off Mary's soap box now... Unfortunately, a legal battle over patents for CRISPR technology would restrict the use of CRISPR, and affect the terms of its use. Does our

hope and the promise of CRISPR biotechnology come with a price tag?

Numerous patents relating to the biotechnology of CRISPR have been issued. However, there is a legal dispute about a fundamental patent relating to the use (and application) of CRISPR biotechnology. On March 15, 2013, a team of biologists at the University of California – Berkeley, Jennifer Doudna and Emmauella Charpentier—now at the Max Planck Institute for Infection Biology in Berlin, Germany and Umea University in Sweden, filed a patent application relating to CRISPR/Cas9 technology with the USPTO (United States Patent and Trademark Office). Significantly, the Doudna-Charpentier patent application was filed the day before the first-to-file rule went into effect at the USPTO.

About six months later, in October of 2013, another team of scientists from across the country, led by Feng Zhang of the Broad Institute (MIT and Harvard) and an investigator at the McGovern Institute for Brain Research at MIT, filed a patent application relating to CRISPR/Cas9 technology with the USPTO. Zhang also filed an Accelerated Examination Request. The second patent application, the Zhang application, was approved by the USPTO first, before the Doudna-Charpentier patent application. The first patent application, the Doudna-Charpentier patent application, remains "under review" by the USPTO. Zhang's patent that is now in heated dispute is Patent No. 8,697, 359 ("the 359 patent").

In April of 2015, the first group, the Doudna-Charpentier group, requested the USPTO to commence an "interference proceeding" that would declare which group was first to invent CRISPR technology, and filed "Suggestions of Interference". In December of 2015, the USPTO issued an initial "Interference Memo", recommending that the PTAB (Patent Trial and Appeals Board) conduct an "interference proceeding". Such an interference proceeding before the PTAB would be similar to a trial. In January of 2016, the PTAB issued "Document No. 1 'Notice to Declare Interference', often referred to as "the count". All motions before the PTAB are to be filed by May 6, 2016.

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Both Doudna and Zhang are expected to file what are called Rule 131 Statements. (Rule 131 Statements are based on 37 C.F.R. §1.131.) Such Rule 131 Statements were likened by Jacob Sherkow, an Associate Professor of New York Law School, to watching Nobel Prize winners in traffic court. The parties have until September 16, 2016, to request oral argument before the PTAB relating to the interference proceeding on the CRISPR patent. If oral argument is granted, it will be on November 17, 2016. Whichever group wins the interference proceeding before the PTAB would have the power to require that any use of the CRISPR technology, even for research, be licensed by the patent holder (presumably for a fee).

If you read this article, you are hereby bestowed a virtual JUNIOR LAW DEGREE. I will personally give you your own personal virtual plastic badge at the SPF Annual Conference.

Mary Schultz is a partner in the law firm of Schultz & Associates LLP, [www.sl-lawyers.com](http://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 Schultz 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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## Tek Robotic Mobilization Device, Part II

*By Malin Dollinger, M.D./SPG4*

The Tek Robotic Mobilization Device, Tek-RMD, is everything it set out to be. My goal is to spend at least an hour or two a day in the Tek-RMD, being upright and thus helping my bone and calcium metabolism and my leg muscles. Some users have spent six or eight hours a day in the Tek-RMD. I've mentioned the reliability and dedication of the Innovations Health Company (<http://www.innovationshealth.com/tek-rmd/>) and how they not only need to determine if the Tek-RMD is right for you before they will let you purchase it, but also after purchase they stand ready to help you if any questions or problems occur. The process begins with a practical education on how to get on and off the Tek-RMD and how to use the controls and adjustments. This is after the factory has pre-set all the adjustable parts of the Tek-RMD: knee braces, foot mounting enclosures, height of the handle assembly, and other essential adjustable features. The company CEO has been to my home at least five times in the past two months since I purchased the Tek-RMD, and this is from his office 400+ miles away. On the latest visit he spent two hours watching me get on and off and offering practical advice and help. He fine-tuned the factory adjustments that were already made according to my own measurements. It seems I'm the "beta-tester" for new Tek-RMD ideas.

One very important aspect is determining the best seat/bed/scooter/chair to use to get onto and off the Tek-RMD. The placement of your body, where you sit on the chair or scooter, is a key factor in making an easy transition from sitting to standing and back again. The company CEO "walked me through the process" [now there's a new unused disability pun!] and he made marks on my scooter seat showing exactly where to place the "launch pad," and also marks on the pad itself showing where my body should rest, at the beginning of the standing maneuver. That way I can be in exactly the right place every time. There is the need to have the holding ("launch") pad at the right height behind my pelvis, so it rides up properly to be in the correct support position when standing in the Tek-RMD.

We discussed the pathways for obtaining the Tek-RMD. He has sold over 55 Tek-RMDs so far, all over the country, and he is training local representatives in many communities, so assistance when needed is local. Thus, there

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is already a new technical expert / representative in Los Angeles. There is a great demand for the Tek-RMD in Canada, and sales are just beginning there. We also went over insurance and other sources of financial help. Medicare requires a “code” for every medical/surgical procedure, as well as for every device, e.g. wheelchair, heart pacemaker, diabetes insulin pump, etc. There is no code yet for “Vertical Mobility Device,” so Medicare will not yet cover the cost of the Tek-RMD. However, there are other pathways/organizations that have been helpful in covering the cost. Vocational rehabilitation agencies have been of assistance, as have Veterans organizations, providing the paraplegia occurred while in the service. There is a lot of effort underway to facilitate third-party/insurance coverage, but since this is a new type of mobility device, there is no precedent for coverage. Paraplegia due to spinal cord injuries may make third-party/insurance coverage much more available. Some patients with “no-fault auto insurance” have obtained coverage, and some workmen’s compensation cases, which are job-related injuries, have obtained coverage.

Clearly, the third-party payment situation is evolving, and we will need expert help to discover what pathways might exist for partial or full payment, in particular for us paraplegics who do not have an injury or external cause for our disability, and thus a potential responsible party or agency that might assist with payment.

Now some practical considerations: The Tek-RMD unit is constructed to be able to be used by persons weighing up to 265 pounds. There are, however, slightly heavier persons who have been able to use it. A number of HSP people have asked me about themselves or persons in their family. Of course the company representative needs to carefully evaluate each prospective user. However the unit is designed for persons with spinal cord injury/disease levels of T4 and below. There are people with T2 level injuries that have been able to use the Tek-RMD. In my own case, my “spinal cord equivalent injury level” is T8, and I believe the vast majority of HSP people have an equivalency level below T4. The key to using the Tek-RMD, if you have no one assisting you, is the ability to help the unit lift you from a sitting position to a standing one, while attached to the Tek-RMD. It doesn’t take a lot of strength, but you need to be able to squeeze the hand-grips [or for those who have a helper/assistant, they need to squeeze the hand-grips for you]. On squeezing the hand grips, the next step is to pull yourself up, attached to the Tek-RMD, to a vertical position. Almost all of the “pulling” is done with springs inside the Tek-RMD, so your own effort is minimal. I weigh 165 pounds; ordinarily I would have difficulty pulling

myself up from a sitting to a standing position, since I also have injuries to both shoulders. However, just like being on the moon at one-sixth gravity, with the Tek-RMD spring helping, I really weigh, in effect, about 10 pounds in terms of pulling myself up in the Tek-RMD. That spring can be replaced with a different strength, if required, and our next experiment for me is to try a different one to see if it makes the process even easier.

One important requirement is the ability to use your hands to grip the handles to pull yourself up and down, getting on and off. Now it doesn’t take much “pull,” the spring mechanism in the Tek-RMD does 98% of the work; but the hands still need to be able to squeeze the handles to enable the spring mechanism to work. There are two kinds of situations for using the Tek-RMD: 1) the disabled person carries out the entire operation by herself/himself without assistance, and 2) there is a capable person/family member/friend, who helps the person, especially getting on and off. Both situations work well, and this decision determines the type of training needed. The Tek-RMD has also been used by patients who need 100% assistance.

The Tek-RMD has been used by lots of patients with multiple sclerosis and spinal cord injuries and it has been very helpful, but when used by a few with Parkinson’s disease, it was not so beneficial. It appears I am the first HSP patient to use the Tek-RMD. So I’ve now had the Tek-RMD for a couple of months, and I have fine-tuned my experience and use, and have become more adept and confident at getting on and off. I have not yet added available attachments so I can read, write, and use a laptop computer while standing in the Tek-RMD. I can certainly reach a lot of things on tall shelves now.

The Tek-RMD is approved by the FDA for use on level ground/floors. You can go up or down very gentle inclines, but you need to observe certain rules. You can place yourself in jeopardy climbing or descending without taking necessary precautions, i.e., standing fully upright when climbing and reclining slightly when descending, and not getting sideways on a slope. Your “center of gravity” needs to remain inside the wheelbase [which applies of course to your scooter as well!]. The Tek-RMD has a very small footprint, a great advantage, and the user needs to know how to operate it safely. The company will review your own situation with you in detail. For example, I have one “very gentle” ramp inside my home, which we tested with me on the Tek-RMD, and it was quite safe.

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Now a few comments about my own experience; I've included some photos which should be helpful, taken by the CEO, Dan Niccum during our last session. In Figure 1, I am standing upright on the Tek-RMD, held by a pad [I call it my "launching pad"], which I first attach the holding straps with the two metal bars at the ends, through the openings in the pad, one on each side, and I then sit on the pad placed on the seat of my scooter. The pad, with me attached, is then pulled up by motors in the Tek-RMD so I am then standing, with the pad behind me. There is an additional chest strap, shown in the photo, which is optional, in case you need extra support.



In Figure 2, I am standing, just after getting on the Tek-RMD from my scooter. You can see the scooter fitting nicely into the footplate of the Tek-RMD, so I am close enough to stand smoothly and easily from a sitting position in my scooter [a Jazzy]. The process is reversed when getting off the Tek-RMD. There is some experimentation



needed to be sure the front of the scooter fits closely into the Tek-RMD frame. Dan Niccum, the CEO, modified the height of my Jazzy scooter footplate, and the small front wheels, to obtain the needed proximity. Some scooters are better-suited than others. The Tek-RMD company reps would assist you with this process. Of course, from a bed or chair it's easy. You can bring the Tek-RMD right in front of you using the remote control. I have placed markings on the scooter seat and the pad, so I will sit in the right place and thus the pad will ride up with me when I stand, instead of riding down.

As I mentioned earlier, there are a few personal, disability, and medical situations and problems that might not make the Tek-RMD a possibility or good idea for you. I've prepared a listing of such considerations in Table I.

The issues with hand, arm, and shoulder strength, for example, may not apply if you have a helper to assist you. Some people have been able to use the Tek-RMD with that assistance, who otherwise would not have been able to use it. The Innovations Health Company representative will guide you through the evaluation and decision process.

In the words of CEO Dan Niccum, "We are not selling a product, primarily. We are establishing a life-long relationship with mobility-impaired people." Having been here at least five times to help me, I truly believe him. They have other handicap/mobility products as well, as are illustrated along with the Tek-RMD on the inside front cover of most current paraplegia magazines. In fact when I told him that the SPF Annual Conference for 2016 planned to take the participants to the Abilities Expo on Sunday, June 26th. He said his company, Innovations Health, would be there to demonstrate the Tek-RMD, for all of you who have asked me and are interested in seeing it up close and trying it out. This would be a unique opportunity for those who attend the annual conference, without requiring additional travel expenses.

In summary, the Tek-RMD should be considered by all of us who have, like myself, been sitting all day and evening for years, with resulting disuse and atrophy of leg muscles, changes in calcium and the leg bones, with resulting stiffness, scar tissue, contractures [which you may recall prevented me from using the recently invented exoskeleton walking devices], and with resulting further inability to walk with crutches or other mobility aids. It is a unique, novel, and seminal solution to many of our paraplegia-caused problems. It has a small footprint, fits about anywhere, can be parked with a hand control in the corner when not in use, and later this year a new pathway - it can be remotely parked and brought to you with your cell phone. There is a whole educational process, but didn't we all go through a "negative" educational process "learning how to be a paraplegic?" This will be a positive education process. For the record, I do advise the Tek-RMD people about new ideas and pathways as a way of helping them. I have no financial interest whatsoever in the product. I'm simply here to help all of us.

To summarize my message, "Time to get off our butts!"

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Table 1

### Concerns Regarding Suitability for Using The Tek Robotic Mobilization Device

Please contact Innovations Health if any of the following situations is present in the prospective purchaser

- Difference in leg length more than 5 cm [2 inches], which cannot be corrected with appliances/shoe lift
- Restrictions in hand function sufficient to interfere with operation/control of the device, specifically to squeeze the hand grips and pull yourself up, if you need to use the TEK by yourself without another person to help
- Restrictions in force or range of motion in the shoulders and arms sufficient to interfere with the ability to sit up in the device
- Severe contractures of the hip, knee or ankle joint that prevent standing up in the device. There should be at least 70% of the normal range of motion of these joints
- Significant osteoporosis in lower legs or spine, that would thus significantly increase risk of fracture
- Presence of autonomic dysreflexia, hypotension [low blood pressure] or significant dizziness, uncorrected by medication
- History of epilepsy, uncontrolled by medication, or a seizure during past year
- Cognitive impairment sufficient to interfere with the safe use of the device
- Pregnancy
- Major visual impairment that would interfere with the ability to safely use the device

***You should speak with the TEK representative, as well as your personal physician, if there is uncertainty regarding any of these concerns.***

## 2016 Pediatric HSP Family Conference

Texas Scottish Rite Hospital for Children, 2/13/2016

*From edited notes taken by Frank Davis, President, Spastic Paraplegia Foundation*

The meeting began at 9AM. Scottish Rite Hospital began in 1921 as a treatment hospital for polio with a goal to treat families regardless of their ability to pay.

Dr. Mauricio Delgado, director of Neurology at TSRHC, began by speaking of the history of HSP. Adolph Stumpell (1853-1925) was the first doctor to write about HSP and so it was first called Stumpell disease in 1883. It was later studied by in France by Maurice Lorrain who was born in 1867 and so it was later called Stumpell-Lorrain disease. Paresis means weakness. Plegia means paralysis. So, HSP should more correctly be Hereditary Spastic Paraparesis. It may be progressive.

People with HSP can have a very similar walk to those who have Cerebral Palsy. The main difference is that people with CP have scarring in their brain from birth that appears in an MRI which people with HSP do not have. The prevalence of HSP is 4.3 to 98 per 100,000 people population. People with CP are at least 400 times more prevalent than HSP which is why many people with HSP are initially diagnosed with CP

Dr Delgado said that the majority of people with HSP do not have any prior family history. The three forms of inheritance are Autosomal Dominant, Autosomal Recessive and X-Linked. Another way that HSP is classified is either Complicated or Uncomplicated. Dr. Harding came up with this distinction in 1981. It is also broken down by either early or late onset. There are 76 loci and 59 genes sequenced for HSP - 65% are dominant, 17% are recessive, 18% are sporadic and X-Linked is very rare.

Why would anyone care to know their HSP gene? This information helps to provide information to neurologists about the prognosis and prevents burdensome costs in the diagnosis and evaluation. It also allows for better genetic counseling and potential selection in a clinical trial.

HSP treatment is mostly for tone management. The main problem is weakness and so tone management can sometimes reveal even more weakness. Baclofen is the main spasticity drug but Dr. Delgado has also tried Kepra with mixed results. There can be behavioral problems with Kepra. A physical therapist asked if people with HSP can be overworked and Dr. Delgado said no. The stronger the better.

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The next speaker was Jonathan Rios, PhD, Staff Scientist, Division of Molecular Genetics at TSRHC. He promised to not talk about science as he wanted to talk in more understandable language. He went over the evolution of genetic diagnosis. He then went over the goals of Whole Exome Sequencing (WES). Goal 1 is to evaluate the success of WES diagnosis for pediatric HSP. Goal 2 is to perform a detailed reanalysis of clinical WES data. Goal 3 is to develop an approach to improve WES.

Currently with WES, 70% of the time there is no significant finding, 7% of the time there is a change in the diagnosis, 3% of the time there is another diagnosis and 13% of the time HSP is confirmed. The limitations of WES are: 1. it only considers genes linked to HSP; 2. it is not clear what genes might be missed; and 3. information from other family members is rarely considered. Maybe the entire family should receive WES. Many people have a family history of this movement disorder but they still can't find the gene.

Dr. Rios spoke about how Dr. Zang at UT Southwestern is taking skin cells from a patient and creating stem cells from those skin cells and using those stem cells to have induced motor neurons.

The next speaker was Amy L. McIntosh, MD. Her topic was Orthopedic Management of HSP. There are 18 pediatric orthopedic doctors at Scottish Rite. She broke up movement disability into 5 levels. Level 1 is almost normal with slight limping. Level 2 is a person that will need to use a cane and hand rails when walking up the stairs. Level 3 are people that use a combination of walkers and a wheel chair on occasion. Level 4 are people that use a walker and a wheel chair most of the time. Level 5 are people that use a wheel chair and need to be assisted.

They have a gait and posture lab at Scottish Rite where they put motion sensors all over a person's body and then film them walking. She spoke about different types of HSP walking. They were prolonged hip extension, knee extension, ankle plantar flexion and a few others.

She prefers to do a single event multi-level surgery so that there is only one recovery time. This surgery is often done as a team so they can turn a 6 hour surgery into a 3 hour surgery to minimize blood loss. They will treat multiple joints, muscles in one surgery. There was some talk about how children who will later go through a large growth spurt after puberty need to have this planned into their surgery. She will over or under do some corrective measures knowing that a large growth spurt will change what they have done. I left her talk thinking that this kind of experience and knowledge would be so wanted and

needed if I was bringing my child in for corrective surgery. She has done some training with a doctor in Australia who is interested in HSP. There is a technique that they have incorporated called the Melbourne Technique. Another perk she said they have at Scottish Rite is that she has a Physical Therapist and a child psychologist working with her all the time.

The next speaker was Julie Rogers, a social worker at Scottish Rite. She said that it is important for parents to know about community resources for their children. She gave the Dr. Seuss quote: "The more that you read, the more things you will know. The more that you learn, the more places you'll go."

The agencies she listed were:

- Partners Resource Network
- US Dept of Education Parent Training
- partnerstx.org
- parentcenterhub.org
- Department of Assistive and Rehabilitation Services. Vocational Training. [www.dars.state.tx.us](http://www.dars.state.tx.us)  
<http://usajan.org/cgi-win/typequery.exe?902>
- Centers for Independent Living under DARS umbrella. Goal to help youth with disabilities prepare for adult life by linking them with knowledge, skills and resources.
- Disability rights of TX. <https://www.disabilityrightstx.org> ndrn.org.
- A social worker. Julie Rogers phone number 214-559-8604 Jill Johnson phone number 214-559-8337. Jill is head of the family resource center.

The next speakers were Rebecca Hart and her parents. Rebecca was the first to speak after they played the YouTube film that we played at our AC. Rebecca said that she is now a 7-time national champion. She does not like to define life in the negative. You just have to learn to play the cards you are dealt. It can be a world of opportunities. She talked about going through an anger stage when she was growing up. She remembered as a little girl thinking that if she put on certain outfits like a ballerina outfit that her problem would disappear and she would just dance away. Her mom later talked about a time that they went to dance class when Rebecca was a little girl and she tried to dance in front of the other girls with her new outfit and it didn't work. Rebecca decided to not go back to dance class. Rebecca said that horses did give her that new lease on life. She could get on the horse and walk. She talked about that one time that she asked

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her dad to pull over to ride some horses for a fee when she was about 6 years old. She remembered getting on that horse and it was wonderful. It became both a mental and physical outlet for her. It was her mom that got her into the Paralympics movement. Para means same or parallel to able-bodied Olympians. She currently trains with a German athlete who has no legs. With her she learned how to ride the horse without any straps or stirrups. Her mom later told me that the stirrups would often make her legs jerk or jump and that would make her unknowingly kick her horse. She was speaking to the young people in the audience and she said you have to accept yourself, look at the cards you've been dealt and make life good. Practice makes perfect. Rebecca is now 31 years old.

Her mom spoke about how they had to learn to trust themselves when dealing with doctors and not be afraid to move to another doctor when they felt it was needed. Once they were asked to do a Dorsal Rhizotomy in a hospital where the culture was parents don't ask questions. They went to one doctor when Rebecca was in her early teens and the doctor asked Rebecca's mom questions about Rebecca's mental abilities as though Rebecca was not there. This doctor said they will never be able to make Rebecca "normal" to which Rebecca spoke up and said that she was normal, just unusual. There is a difference between "normal" and "usual".

Her mom said she remembered once when Rebecca was 5 and she was being bullied. One child was mimicking her walk behind her and Rebecca turned around and said something like "if you are trying to walk like me, let me tell you that you are not doing a very good job." There were a number of other moving stories of her childhood and parenting of a disabled young daughter. Rebecca now works for Starbucks who is one of her top sponsors.

They then had a group of young people come to the front and sit around a table where they had a discussion with an adult facilitator. The young people were Kaitlan Aniol from San Antonio who is 14, Adriana 18, Sedrick 6, Noah Taylor 9 and Alex White from Kansas who is 13. The question was what makes a good day? Answers were: having friends, doing something interesting or memorable, and being with people that are understanding, aware and appreciate their independence. Nothing was said about material things. The facilitator reminded parents to try to gear their child's life in this way. Other points made were that doctors should be reminded that the child is not her or his condition. Let them have ownership of what and when to share.

Another question was what makes a good friend? Answers were having things in common, being trustworthy, kind and being able to laugh at themselves. Alex said that some teachers at school wanted to put him into low math class just because he couldn't walk. Rebecca Hart said that a technique she uses is she looks at herself every morning in the mirror and plans what she will do that day to make life better. Any negative self talk is to be put in the mental garbage can.

Another question was what could teachers do better? Alex said they should not give him such special treatment. The facilitator said "make inclusion as seamless as possible." Kaitlin talked about something her teacher did that was helpful. The teacher was told that Kaitlan needed to stand so many times a day, so the teacher arranged it where everyone in class needed to do a standing and stretching that many times during the day so Kaitlan didn't stand out as different. Parents should make themselves familiar with the I.P. and then just remind the teacher what they might pay attention to make the child be successful.

They then had several parents come to the front to share a conversation. The parents were Bob Aniol, Mari White and Sarah Taylor. Bob said it is important to them that doctors work to coordinate their efforts and not work separately. He said it is important that the doctor care. Someone said they should not use a cookie cutter approach. When you have seen one patient with HSP, you have seen one patient with HSP. Mari said that she liked it when Dr. Delgado suggested that she trust herself when she did not like a doctor. It is OK to find another doctor. It is important for the parent to be a part of the team to educate themselves. The parent should know what the child is entitled to and claim it. Learn everything involved in both the state and federal level and then you will know it better than the school does. There is a difference in OI or Orthopedic Impairment and OHI or Other Health Impairment. The second will open more doors. You can get OHI with HSP. Go to the Disability Rights Web site. Mari said she is learning to step back and let Alex self advocate.

The next speaker was Courtney Warren, Physical Therapist.

Physical Therapy is "transforming society by optimizing movement to improve the human experience." She spoke about episodic care which is an improvement over constant care. It is focused intervention targeting emergent need with a beginning and an end. It is task specific.

The day ended with a BBQ dinner where everyone enjoyed sharing conversation and good Texas BBQ.

## CASE REPORT

# Thoracic Paravertebral Block, Multimodal Analgesia, and Monitored Anesthesia Care for Breast Cancer Surgery in Primary Lateral Sclerosis

Anis Dizdarevic and Anthony Fernandes: Anesthesiology and Pain Management, Columbia University Medical Center, 622 West 168th Street, PH 5, New York, NY 10032, USA

Correspondence should be addressed to Anis Dizdarevic; ad2689@cumc.columbia.edu

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**Objective.** Primary lateral sclerosis (PLS) is a rare idiopathic neurodegenerative disorder affecting upper motor neurons and characterized by spasticity, muscle weakness, and bulbar involvement. It can sometimes mimic early stage of more common and fatal amyotrophic lateral sclerosis (ALS). Surgical patients with a history of neurodegenerative disorders, including PLS, may be at increased risk for general anesthesia related ventilatory depression and postoperative respiratory complications, abnormal response to muscle relaxants, and sensitivity to opioids, sedatives, and local anesthetics. We present a case of a patient with PLS and recent diagnosis of breast cancer who underwent a simple mastectomy surgery uneventfully under an ultrasound guided thoracic paravertebral block, multimodal analgesia, and monitored anesthesia care. Patient reported minimal to no pain or discomfort in the postoperative period and received no opioids for pain management before being discharged home. In patients with PLS, thoracic paravertebral block and multimodal analgesia can provide reliable anesthesia and effective analgesia for breast surgery with avoidance of potential risks associated with general anesthesia, muscle paralysis, and opioid use.

**Conclusion.** Patients with primary lateral sclerosis and other similar neurodegenerative disorders presenting for surgery may be at increased risk for surgery and anesthesia related complications and should be carefully assessed perioperatively by all healthcare professionals involved in their care. Special emphasis should be paid to respiratory function, aspiration risk, and muscle dysfunction. Thoracic paravertebral block, along with multimodal analgesia, can provide reliable anesthesia and effective analgesia for breast surgery, with avoidance.

For the complete report, go to Hindawi Publishing Corporation, Case Reports in Anesthesiology, Volume 2016, Article ID 6301358, 4 pages, at <http://dx.doi.org/10.1155/2016/6301358>.

## MNDs and UTIs

*By Jackie Wellman*

Just last week I had the second person in my family die from urinary tract infections that was caused by having HSP and it went systemic. Yes, die from a urinary tract infection that went systemic. The first was in 2000 and it was my Grandma. She died from a chronic urinary tract infection that went systemic. Last week my 63 year old Uncle John was the second.

This article is to warn you that urinary tract infections are nothing to mess around with. If you have bladder issues with your HSP or PLS, like urgency, then chances are you have to go all the time because you are not emptying. Our bladders just do not work right; therefore they do not empty completely. Even though you may feel like it is. If you have to urinate within the next hour it is because there is too much in there....because it did not empty completely. Think of a pond that does not get drained...it gets gross. Unpleasant things start growing in it. Same thing with the bladder...not green algae, but nasty bacteria. Those bacteria can become resistant to antibiotics and then you are in trouble.

I used to get UTIs frequently. The doctor talked me into trying to self-cath morning and night. I have not had an infection since. That was about ten years ago. I now get bladder Botox and self-cath about six times a day. Every day. Yes, I would much rather not do it but the alternative is to die...at least in my family.

The bladder Botox is painless also. I feel normal for 6-9 months. It's worth it in every way to me. Before doing Botox I was visiting the bathroom every fifteen minutes.

I urge you, if you are debating about whether or not to start self-cathing, to bite the bullet and do it. It is painless and easy. Not the most convenient thing but better than the alternative.

## Brain Donation

*by Tina Croghan*

I want to contribute SOMETHING to this life! The feeling of uselessness is quite strong in all of us with an upper motor neuron disease. Some are better at dealing with it than others. I'm not rich. I can't walk or drive.

One way I have dealt with this feeling, is by putting a plan in place to contribute my brain and spinal column to research. (Hey, when I'm dead, I won't be needing it!) I found a

*Continued on next page*

place that will accept my donation. I contacted Sue Hagen at the National Ataxia Foundation, who directed me to the University of Miami's Brain Endowment Bank which is a National Institutes of Health (NIH) NeuroBioBank, one of six designated brain and tissue biorepositories in the nation. "There are no costs to the family for brain donation when working with the University of Miami." Hagen goes on to say, "Brain retrieval should take place within 24 hours after death. No matter where you live, you can put a plan in place for brain donation."

While the National Ataxia Foundation's focus is on ataxia, they have a strong relationship with the University of Miami Brain Endowment Bank to refer potential brain donors. However, you can contact the University of Miami directly for answers to all of your questions like, "Do I have to be cremated or buried? Can I have an open casket?" There were many questions I had. I'm sure you do, too.

The main thing... I'm able to DO something!

For more information go to: [www.brainbank.med.edu](http://www.brainbank.med.edu), Brain Endowment Bank at Miller School of Medicine.

The Brain Endowment bank encourages brain donation to support medical and scientific researchers, who study the human brain in search of better medication and treatments, and ultimately, a cure for brain diseases and disorders.

Donating tissue for medical research is an important and deeply personal decision. Proper planning can help ensure that wishes are accounted for and honored at the time of you or a loved one's passing.

## Hip Flexor Pain or Spasms?

*Jackie Wellman*

If you have hip flexor pain or spasms this should change that. They hurt and spasm because they are so weak. Mine used to spasm so hard if I was laying down, on either my stomach or back, they would actually flip me over. When this happen the pain was intense. I punched my husband once in bed....unintentionally.

My Pilates instructor had something she thought might work. We tried it and it helped. The first time I could only last about thirty seconds and then my hip flexors would spasm so hard that I would be thrown to the floor. Get a half foam roller about 36 inches long and 6 inches in diameter. Lay the foam roller on the floor, butt on one end and head on the other, so your spine runs the length of the roller. Feet should be flat on the floor and knees bent. You can feel your core and hip flexors tightening to keep you balanced. Start with your hands at your side. Now raise your hands up in the air, one at a time and then both. Move your arms around challenging your balance. Raise them above

your head. This is also a great stretch for your upper back and shoulders.

After you master this, try adding light weights. Now try crunches and leg lifts one at a time. Now both at the same time. Now arms, legs and crunches at the same time.

I try to do this for 1/2 an hour a night while watching television. At first I could only manage staying on the roller 30 seconds and that was just lying still...arms and feet planted on the floor. That was very hard and hurt when a spasm ended my balancing act. Pain can be worked through. Just because something hurts or is hard does not mean we should not do it.

I used to have painful spasms at least every few hours and sometimes during the night. No more. This really works.... is very easy to do....and inexpensive. I got my half-roller from Amazon (using Goodshop.com, of course) and it was about \$20.

## TREAT YOUR FEET!

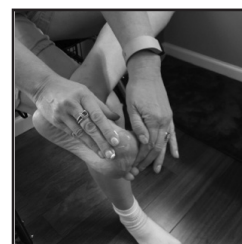
*By Tina Croghan*

Don't forget about those all-important feet! "Check them every day," says Keith Smith of Orthotic and Prosthetic Labs of St. Louis, MO. "Especially if you have neuropathy, you might not feel a wound until it gets really bad!"



1. I massage my feet every day as a part of my shower routine. Not only am I inspecting them but it feels good, too. I put lotion on those calloused toes. Check them for "new" callouses, abnormalities or pressure sores.

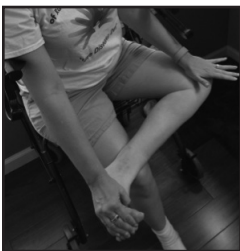
Inspect your toenails, too. Check for ingrown nails or discolorations. No cause for alarm but let your doctor know next time!



2. I sit with one ankle atop the other knee, A quite natural pose for me. Start with your LEFT ankle and your RIGHT knee. (We'll do the other side later.) I then use that time to give my feet an added stretch. I gently pull me toes on that foot toward that shin, stroking the bottom of the foot with lotion at the same time.

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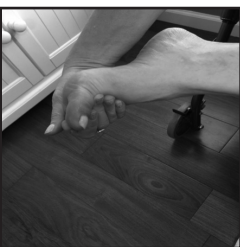
3. Now take your LEFT hand and place it on your LEFT knee. Push gently down while that knee is trying to raise up. Kind of like chewing gum and walking, but you'll get the hang of it!



4. Lean slightly forward—breathe deeply as you go. You'll feel a stretch in your I.T. band in your glute and piriformis if its tight. (your bum!)



5. Take your RIGHT hand and bring the toes of your LEFT foot down (or back) while trying to resist and bring your toes up. Do this 10X then reverse it.



6. Cup your foot and toes with your RIGHT hand try to resist while you try to push your foot and toes into you hand to the floor or



6a. a lateral ankle movement.  
Now do all of the above again on your other side.

Remember, your feet will be slippery from the lotion! I always put my socks on no matter the temperature.

Now you are ready for that next step of your day. You've treated your feet and stretched them, too!

*The more difficulties one has to encounter, within and without, the more significant and the higher in inspiration his life will be.*

—Horace Bushnell

## A Tribute to My Dad, Malin Dollinger with HSP, focus on The Orange County Marathon May 1, 2016

By Marc Dollinger and Malin Dollinger

### Why I'm Running A Marathon [from my Facebook post]

By Marc Dollinger

In 1977, at age 13 and at the height of the Frank Shorter-inspired marathon craze, I decided to run the Palos Verdes Marathon, then the second-oldest marathon in the country after Boston. I'm sure I jogged around the block at least twice in preparation for the big day. I started the course. It was an extraordinarily long experience. Only the kindness of a grandpa-aged runner who insisted on finishing last in the 2,000 runner field saved me from middle-school athletic shame. (My time, for those who understand these things: 6:47).

Inspired by the effort, my dad, in a great moment of parental pride and support, proclaimed that he would join me for the next year's effort. Alas, it was not to be. My dad, Malin Dollinger, was eventually diagnosed with Hereditary Spastic Paraplegia (HSP), a congenital nerve disease that, over time, robbed him of the ability to walk. In fact, the last time he stood upright was as he walked me down the wedding aisle to the huppah. HSP, a disease with a 50% chance of passing to one's children, skipped me and, with that, skipped my children too. So, even as Shayna and I have been overwhelmed with support, love, and respect for our ambitious goal, we've also (enjoyed) our fair share of friendly pushback: why, on earth, would you do something like running a marathon? I'm running a marathon to honor my dad who can't. I think of him, of his strength, courage, and endless endurance navigating an able-bodied world from a scooter. He gives me more strength than I could ever need on the long training runs. I've got nothing on him. Our family has been involved with the national HSP charitable foundation focused on supporting research that we hope will get HSP legs moving again. While I am focused on supporting Shayna's outstanding marathon fundraising efforts for AJWS, I will be making an additional contribution to HSP research. It is not impressive to run a marathon nor is it a fancy of folks who have lost all perspective. With my fitbit, I figure to take over 50,000 steps tomorrow. And every single one is, fundamentally, a privilege, a blessing, and a gift. Off we go...

*Continued on next page*

Malin's Facebook response to Marc's post: "Marc, I am deeply touched by your love and support. I may not run with my legs, but by your example, I can run with my mind, my enthusiasm, and my love of life, yours as well as mine."



Speaking of responses to Marc's Facebook post, in the first 24 hours after his post, he has received 127 "likes" and 26 comments!

After the race, Marc wrote: "The first 20 miles was a standard run; the last six miles were a glimpse of why Heaven is the favored someday destination! We were exhausted, and happy to have accomplished our purposes, the milestones each of us had envisioned. The "time" was not important, it was the realization of our spiritual and humanitarian goals. Malin's favorite charitable destination was again the beneficiary of our efforts.

"Our goal, of course, was just to finish. We trained for 16 weeks in preparation, with our longest training run a 20-miler. We initially planned on running in Sacramento until a weather forecast of 95 degrees sent us, at the very last minute, on a flight to Orange County! Remarkably, we kept pace, finishing the first half of the course in 2:31 and the second, and far more challenging half, in 2:38, crossing the finish line, hands held together over our heads, in 5:09. Of special note...at about mile 23.... with both my legs locked up with muscles that would not move...my music ear buds randomly started playing "Lean on Me" with the lyrics, *"Sometimes in my life, we all have pain. We all have sorrow. But if we are wise, we know that there's always tomorrow. Lean on me when you're not strong and I'll be your friend. I'll help you carry on."* What can I say? I thought of Dad and just burst into tears. He carried me those last 3 ever-so-painful miles. Our Marathon journey today began very early...Sunrise...and ended very late...Sunset. Swiftly went the day, but not the forever devotion to my father and our family, and to you and all of your families with HSP and PLS."

Malin's mindset on their marathon experience:

"Witness the love and devotion of my son, Marc, who was spared the scourge of HSP, and is ever-mindful of the life-changing effects of HSP on me, his father, Cynthia, his sister, as well as all those worthy folks who are similarly affected. He attended Linda and Craig Gentner's North California TeamWalk, along with his parents, and understands first-hand the life-changing effects of HSP and PLS. So it was no surprise, and also in fact a great surprise, for Marc's father, Malin, to read the Facebook page about Marc's dedication of his running the Orange County Marathon to his father's fight to overcome HSP, personally and professionally. He and daughter Shayna finished in a little over five hours."

## Malin's HSP Story

*By Malin Dollinger, MD, SPG4*

Long ago I had this terrible nightmare, about losing my ability to stand and walk. When I woke up, the nightmare was still there, and it took a long time for me to realize in fact it would never go away. Since then, some 25 years ago, my life has been a complex, necessary, and fulfilling adaptation to my unwelcome discovery that during my remaining life I would always be sitting down. I decided I could not stand for this, so I adapted everything to my needs. A special medical office, a new rebuilt home with every conceivable device, a handicap-accessible minivan, many home-made devices and tools to get me dressed, functioning all day, able to travel all over the country in my work, and to pretend that things did not change. I've been so busy proving that things have not changed that I have been able to forget how significantly my life did change. I spent some years on the Board of Directors of the Spastic Paraplegia Foundation, until other medical problems supervened, limiting travel. I'm still active, "from home," as is true in many/most of my life interests. Non-standing and non-walking has become my new normal, or as I've realized, not so new at all. I've had the blessings of help and understanding from my wife, family and close friends, who have enabled me to successfully pretend that nothing has changed. I get into my scooter at bedside every morning, and get out again every bedtime, as if this is "just the way things are now!" It no longer occurs to me that to get from "here" to "there" I might need to stand up.

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Enter my two biologic children, one of whom, my daughter, was visited by "Gene," an unwelcome friend, and the other, my son, was spared. I wrote a poem about Gene, who will be vanquished from our family by my daughter:

### **The Departure of Gene, Our House Guest**

*Gene came to visit us in 1960  
More specifically he entered my Mother's home  
He was in disguise, so we did not recognize him at first  
About 1985 he removed his disguise and came to my home  
Then he visited my daughter Cynthia as well  
And has been with her as well ever since*

*He was some kind of strange novelty, at first  
The more you got to know him the more obnoxious he became  
Since he would not leave, we needed to put up with him  
Drastic changes in our lives, and in the lives of our loved ones  
We became used to his daily annoyance  
His nickname was SPG4  
But he was an enemy, not a friend*

*Enter the incredible wisdom and determination of Cynthia  
Who vowed to expel Gene from our family  
Once and for all  
Alissa and Sarah became part of our family  
There was no longer any room for Gene*

*Gene will become a ghost  
Only a memory for future generations  
Hardship he created will someday no longer exist  
Our family will walk the path of normalcy  
Thanks to Cynthia, to Alissa, to Sarah*

### **NEW MOBILITY: THE MAGAZINE FOR ACTIVE WHEELCHAIR USERS**

[www.newmobility.com](http://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.

## Connections

### **SPF Georgia Connection February 13, 2016**

*By Elizabeth Woolridge, Georgia State Ambassador*

The latest meeting with Georgia chapter was held at Texas Border Grill yesterday (2/13/16) from 1-3. There were a total of 12 people in attendance. It was great just talking with each other and sharing some experiences. We briefly discussed having regional representatives. I really want everyone to have a chance to get together and meet some others that are local. I can take care of North Georgia and Metropolitan Atlanta, but if anyone is interested in helping out in their area, it would be great. I need to find someone to help out in the Macon area, Columbus area, and South Georgia area, please private message me. Thank you to Randy Hortman and Rick Thompson for telling me about Texas Border Grill. It was a great place to meet, but without their help I would have had no clue since I don't live in that area. I was thinking if you want to keep it small and personal, you could host it at your home, and if you wanted to have a speaker, you could go to the public library, a church, etc. . .



### **SPF Louisiana Connection April 8, 2016**

*By Natasha Schaff, Louisiana State Ambassador*

On April 8th, SPF members from Louisiana met at Drusilla's restaurant in Baton Rouge. We had thirteen members in attendance from all across the state. All who attended either had HSP or were caregivers of family members with HSP.

Our first speaker, Stephanie Patrick from the Advocacy Center of New Orleans, spoke about the benefits this agency has to offer our group. She discussed the different means in which the center protects, empowers, and advocates for individuals with physical disabilities.

Johnette Magner, a SPF member from Shreveport, shared a video of her current physical therapy regimen as well as other tools she utilizes for home therapy. Her physical therapist, Dr. Suzanne Tinsley of Louisiana State University Health Sciences Center, has a Masters Degree in Physical Therapy and a PhD in Neuropharmacology. As part of Johnette's therapy, Dr. Tinsley employs a product developed by Bioness that sends electrical signals to activate and contract specific leg muscles. Bioness is a company that produces devices to help people regain functionality in their hands or legs due to some type of central nervous system disorder. Everyone was impressed with the video of Johnette's therapy and some planned to make an appointment with Dr. Tinsley to see how she could help them.

We are very thankful for the beneficial information that Stephanie and Johnette shared with our group. I would also like to send a big thank you to Tammy Nolan. Without her, I could not have coordinated this Connection.

*Members at our meeting shown in the collage include: Steve Beutelspacher, Hank & Paulette Chiuppi, Lewis "Sid" & Carol Clark, Candy Cotsiomitis, Frank & Phylis Madrigali, Joan Morris, Ed & Anne Sopala, Lynn Staudacher, Carolyn & Sara Wright, Richard Fairbairn, Ann & Ken Robb.*

## SPFillinois Connection

April 17, 2016

*By HSP: Sid Clark and PLS: Hank Chiuppi*

We held our spring connection Saturday under a beautiful blue spring sky. We had a productive and fun get together. With 17 present, it is hard to believe this was our 11th SPFillinois connection. We discussed that it is a very good idea to have a Key Lock box installed for your home in case EMTs need to get in your house in a hurry. Do check with your local fire/police before putting one up as they may have specific requirements for your area. We reviewed whole genome sequencing; what it is and what it can do for you. Several members talked about their results. We also had a handout (thank you Candy) on medical coverage for Home Health Services. Some of the coverages you need to request / insist on. You need to know the requirements and be your own advocate. Our connection also covered: Medical Drugs e.g. CBD Oil, Ampyra, and medical cannabis; Speech Problems; and Handicap Aids; (Canes, Walkers, Scooters, Chairs, others). After our box lunches we talked about the upcoming convention. We made HSP/PLS Survival Kits to be given out to each of the convention attendees as a welcome from SPFillinois. See you at the convention!



# Tina's Tips...

Compiled by Tina Croghan

## “Necessity Is the Mother of All Invention” at the Chiuppi House

Recently, I went to visit Hank & Paulette Chiuppi (IL State Ambassador) and took some pictures of his garage entrance. Hank has PLS and his inventiveness coming up with some unique and low-cost solutions to improving accessibility in his garage and home is worth showing you. Maybe you will find these “Tips” helpful!

Hank calls these his “monkey bars.” They are actually distribution rings used to hold low voltage cables, like network and fiber optic cables, to the wall. He uses the 3-inch size aluminum rings as handholds to help him get around obstacles (like a parked car) in his garage. Hank strongly recommends attaching these rings, with screws in all four mounting holes, to a solid wood surface or to a building stud. A word of caution - DO NOT install them using wall anchors. For more information and pricing, go to <http://www.showmecables.com/product/3-inch-metal-distribution-ring.aspx>.



This grab bar with the pipe insulation is along the garage wall on the driver's side of the car. He uses it getting in and out of the car. The bar is only 3/4" in diameter and got cold in the winter, so Hank put pipe insulation on it. The pipe insulation not only keeps the cold off his hands but also gives the bar a soft cushion.

Hank also used pipe insulation to prevent those knicks and scratches caused by his rollator.



I know that in a previous edition of “Tina’s Tips” Mike Church told how he had installed off-set hinges in his home, but I was so impressed with Hank’s installation, I took some pictures so that you could see again how really cool they are! The hinges made the bathroom doorway about 2 inches wider so Hank could get through the door using his walker. In his case, he used a handyman to do the work.



## “Top Shelf Grocery Shopping”

When trying to get an item off the shelf that I can't reach, and Thunder (my service dog) can't reach either, I try to ask for help. There's usually someone in the aisle with me.

I asked on the SPF Facebook page and received one comment saying that they use their cane to “fish” the item out. Another comment rendered an interesting reply. This person recommends a lightweight foldable grabber that has a magnet on the end!

I found one on Amazon.

[http://www.amazon.com/Ez2care-Lightweight-Folding-Reacher-Magnetic/dp/B008HA0E0Q/ref=sr\\_1\\_11\\_a\\_it?ie=UTF8&qid=1459432333&sr=8-11&keywords=grabber](http://www.amazon.com/Ez2care-Lightweight-Folding-Reacher-Magnetic/dp/B008HA0E0Q/ref=sr_1_11_a_it?ie=UTF8&qid=1459432333&sr=8-11&keywords=grabber)



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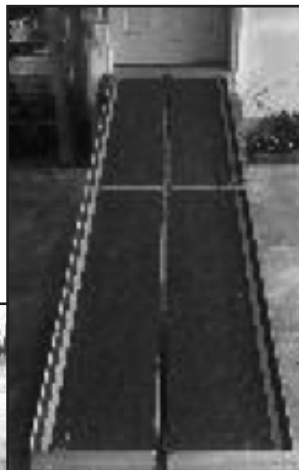
John Staehle writes, The weakest part of a lightweight folding grabber is the point where it folds. I had a 24" folding grabber that broke when trying to pick up a heavier object. There also are limitations on the size and weight of the object being "grabbed." I have a couple of non-folding grabbers at home, one 24" and one 32" and they serve most of my reaching needs and the magnets on the end are a great addition. However, I wouldn't use them in the grocery store to get something off an out-of-reach shelf. For that, like Tina, I'd first ask for assistance from someone shopping nearby. If there are none, I'd use a jaws-type grabber, especially if you need to reach a can or jar. Links to examples of this style grabber are on the same webpage as above.

Be sure to use [www.goodshop.com](http://www.goodshop.com) if you plan to buy them on Amazon!

Of course Lewis "Sid" Clark, SA from IL, swears by tongs, too!

## "Ramps"

Lewis "Sid" Clark, SA from Illinois, writes: Since I can no longer walk, we put a permanent ramp in our house which we could not do without. It is important to stay active and involved, so I recommend it. I did get a portable ramp for our son's house for family events (see photos). However, portability is in the eye of the beholder. We need his help in putting it up, but any lighter it would not hold up. I have heard of some who got a cheaper, lighter ramp only to have it bend. Being on a ramp and having it fail underneath me is not something I would want to happen or experience. If you need a ramp to stay active, get one and stay active.



Tina writes: I need some help from you, the readers. I do not have much knowledge nor have I had much experience with portable ramps other than to make sure that they're not too steep! Follow the ADAs recommendations when rehabbing your own home with a ramp. Don't think that the run of your ramp will be the same distance as your steps were! Too many times, I have found this to be the case on existing construction. I remember in my teaching days when I directed a show and was building the set. Now these students were not disabled, but they did have to sing and dance or just traverse a ramp under the glare of the bright lights, I wanted "Dick" and "Jane" to be safe. According to the ADA, the "rise-and-run" of a ramp should be 1" rise for each 12" of run. Check out: [www.disabilitysystems.com](http://www.disabilitysystems.com) for various examples of portable ramps.

John Staehle adds: If you plan to buy one, be sure that it meets ADA guidelines and has a weight capacity sufficient for you and your mobility device. A power chair, depending on its features, can by itself weigh close to 400 pounds!

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](mailto:tinacroghan@yahoo.com).

## *Understanding Disability*

*by Brenda Asbury*

- It's not about intent, it's about interpretation.
- From a legal standpoint, that's the bottom line.
- From a moral, ethical, professional belief system, when you pity people, you dis-empower them.
- It's not right to take away someone's choices.
- If they can't do it, they'll let you know, otherwise, you have to respect both them and the law.
- Good intentions can still make people feel terrible.

# SPASTIC PARAPLEGIA FOUNDATION 2016 ANNUAL CONFERENCE REGISTRATION FORM



**Friday, June 24<sup>th</sup>**

Corey Weiser, MetLife  
Potato Pants – The Race!  
*Erasing the Difference* – Theatre Group

**Saturday, June 25<sup>th</sup>**

*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 26<sup>th</sup>**

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](http://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**

1605 Goularte Place  
Fremont, CA 94539-7241



See you in Chicago!!