

# Synapse

Volume 20, Issue 2

Spring 2017

*Newsletter of the Spastic Paraplegia Foundation*

## Letter from the President



Dear Friend,

This is the time of the year when tradition, culture and my responsibilities with The Spastic Paraplegia Foundation call me to experience a roller coaster of thoughts and emotions. In the Lenten season I try to do my personal, reflective, spiritual spring cleaning. Moreover, Easter and Passover are times of thankfulness and celebration.

Believe it or not, these same roller coaster feelings of inner reflection and joyful gratitude are part of our work at the Spastic Paraplegia Foundation. Inner reflection is taking place as we put together our 2016 Annual Report, which will be completed and mailed soon. It summarizes what has been accomplished in the past year. Of course, looking back helps us to look forward with more purpose and clarity.

It is wonderfully exciting to see how your donations are making such incredible progress toward a cure for HSP & PLS. Our research is no longer just filling up text books about HSP and PLS. Most of our sponsored studies are now working on actual drugs that will soon be getting to clinical trials for HSP and a first of its kind PLS Patient Registry that scientists, the world over, are excited about.

Talk about exciting - I'm thrilled with what our Conference Chairman, Norma Pruitt, is putting together for our 2017 Annual Conference in Atlanta GA, June 23rd to the 25th. The speakers and topics will be very helpful and informative, but the part I enjoy the most is how we all seem to learn from each other as we talk and share stories,

tips and techniques. The speakers will be some of the leaders in the field of HSP & PLS research and if you have questions, they will happy to answer them.

I also want to take this opportunity to once again Thank You for your generous contributions to this cause. It is only because of you that we are stepping closer every day to the day when a CURE CAN BE ANNOUNCED. Yes, a cure is within reach and your big-hearted donations are doing that reaching. **THANK YOU SO MUCH!!!**

Frank Davis, President

*Frank Davis*  
President

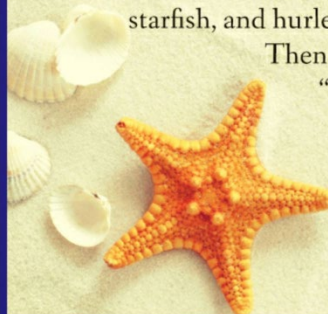
A young girl was walking along a beach upon which thousands of starfish had been washed up during a terrible storm. When she came to each starfish, she would pick it up, and throw it back into the ocean. People watched her with amusement.

She had been doing this for some time when a man approached her and said, "Little girl, why are you doing this? Look at this beach! You can't save all these starfish. You can't begin to make a difference!"

The girl seemed crushed, suddenly deflated. But after a few moments, she bent down, picked up another starfish, and hurled it as far as she could into the ocean.

Then she looked up at the man and replied, "Well, I made a difference to that one!"

— Adapted from The Star Thrower  
by Loren C. Eiseley



GodNine.com

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Volume 20, Issue 2 - Spring 2017

*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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Fremont, CA 94539-7241

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(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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## Fundraising

### Quinn Family Virtual Fundraiser

By Melinda Quinn

Our brother Darrin (we are five siblings) was diagnosed with HSP twelve years ago. He is the only one in our family that has symptoms of HSP. He had the genetic testing. We do have a large family on both parents sides. None of the cousins that are our age have HSP that



we know of. We wanted to come together as a family to support not only Darrin but also the SP Foundation's incredible work and research. The surviving members of our large family consist of 14 nieces and nephews, five siblings, my two step children, their spouses and my grandchildren. Unfortunately, we all live a fair distance from one another so getting together for a physical event to raise money is difficult.

We decided to start small and let each individual family work to contribute via various projects dedicated to our family fundraiser effort. We collected each family's contributions through "Go Fund Me" which made it a bit simpler and more efficient for us to manage over the Internet.

This year's event began on March 31<sup>st</sup>. Our goal is to raise \$450 and to hopefully grow this effort in the coming years ahead. Most importantly, it will help to raise awareness within our own family about HSP and all the work that the Foundation does to support our family member, Darrin. We hope to have all the monies in and over to the SP Foundation by May 15<sup>th</sup>. As of April 21<sup>st</sup>, we have collected \$675!

Darrin has an incredible spirit (see photo with his son). Two years ago he began riding an electric



(part manual/part electric) around his town of Baltimore. This has been a truly liberating experience for him as all adaptive sports are for those who have some physical challenges.

2017 SPASTIC PARAPLEGIA FOUNDATION  
*15<sup>th</sup> Annual Conference*

As of April 29, 2017 (Subject to Change)

**FRIDAY, June 23, 2017**

11:30AM - 6:00PM Registration  
1:00PM - 1:15PM Welcome and Introductions  
Frank Davis, SPF President &  
Tim Croghan, Conference MC  
1:30PM - 5:15PM Breakout Sessions

**GROUP I:**

1:30PM - 2:15PM **Concurrent Sessions**

- *NEALS PLS Registry* -  
Sabrina Paganoni, MD
- *Powerful Tools for Caregivers* -  
Brenda Russell, CTRS
- *CRISPR, the New Tool that Edits DNA* -  
Corey Braastad, PhD

*[15-minute Break]*

2:30PM - 3:15PM Repeat Group I Concurrent  
Breakout Sessions

*[15-minute Break]*

**GROUP II:**

3:30PM - 4:15PM **Concurrent Sessions**

- *SPF Scientific Research Grant Process* -  
Mark Weber, Esq.
- *Balance and Lifestyle Adjustments* -  
Brenda Russell, CTRS
- *Education, State Ambassadors & Who to  
Talk To* - Tina Croghan & Laurie LeBlanc
- *Fundraising Ideas - Golfing, Walks, Trivia  
Night, Potato Pants* – John Cobb

*[15-minute Break]*

4:30PM - 5:15PM Repeat Group II Concurrent  
Breakout Sessions

5:30PM - 6:15PM Welcome Reception  
(Cash Bar)

6:30PM DINNER (Served)

**SATURDAY, June 24, 2017**

7:30AM - 8:15AM BREAKFAST (Served  
Home-Style)

8:30AM - 11:45AM General Session

8:30 - 8:45 Welcome and Introductions:  
Frank Davis, SPF President &  
Tim Croghan, MC

8:45-9:30 Jeffrey Statland, MD  
*CReATe Consortium*

9:30-10:15 Sabrina Paganoni, MD -  
*Research Updates in PLS*

10:15-11:00 Christina Fournier, MD,  
Emory University, Atlanta VA  
Medical Center

11:00-11:45 Corey Braastad, PhD  
Covance Drug Discovery

9:00AM to 3:00PM (Back at Hotel)

**KID'S DAY EXCURSION TO  
THE ATLANTA ZOO (Includes Lunch)**

<http://www.zooatlanta.org/home/experiences>

12:00PM - 1:00PM LUNCH (Served)

Speaker Brenda Russell, CTRS -  
*Life and Significance*

*[15-minute Break]*

1:15PM – 4:45PM **Continuation of General  
Session**

1:15 - 2:00 Representative from Children's  
Healthcare of Atlanta (CHOA)  
*Multidisciplinary Approach to  
Reduce and Control Spasticity*

2:15 - 3:15 John Fink, MD - University of  
Michigan, - *HSP and PLS*

*[15-minute Break]*

3:30 - 4:45 John Fink, MD - Open Forum  
Discussion, Questions and  
Answers

5:00PM - 6:00PM Social Mingle

6:00PM - DINNER (On Your Own)

**SUNDAY, June 25, 2017**

MEALS ON YOUR OWN

9:00AM – 3:00PM (Back at Hotel)

**EXCURSION/TOUR - GEORGIA AQUARIUM**  
<http://www.georgiaaquarium.org/experience/visit>

2017 SPASTIC PARAPLEGIA FOUNDATION

15<sup>th</sup> Annual Conference

PRESENTERS

**Cory Braastad, PhD**



Dr. Corey Braastad is the Vice President and General Manager of Genomics at Covance Drug Discovery, part of LabCorp. Dr. Braastad has completed training, performed research, and developed programs in clinical trials, pharma research support, and clinical genetic

diagnostic products. Dr. Braastad is a published author who has many years of experience in senior team leadership, lab operations, and R&D. Dr. Braastad is a member of the board of directors for the Spastic Paraplegia Foundation and Cure SMA. He is a Member of: The Human Variome Project; American Society of Human Genetics; American College of Medical Geneticists; American Academy of Neurology; American Society of Cell Biologists and Radiation Research Society. He has a Ph.D. in Molecular and Cellular Biology and Biochemistry from Brown University School of Medicine. He also has his B.S. in Biology - Magna Cum Laude from University of Massachusetts at Dartmouth.



**John Cobb**



John was elected to the SPF Board in May of 2013. He is from Alexandria, VA and graduated from the College of Charleston in 2009 with a Bachelor of Science in Economics before entering the Financial Services Industry. After three years with Morgan

Stanley he transitioned to Edelman Financial Services, a financial planning firm headquartered in Fairfax, VA. He was diagnosed with HSP in early 2003 and is the second in his family with the condition. He has successfully organized and conducted three golf tournament fundraisers benefitting SPF.

**Tina Croghan**



Tina is a retired teacher who still stands by the motto that she greeted each student as they entered her classroom with, "What we learn with pleasure, we never will forget." With a Master of Arts in Theatre and a Master of Fine Arts in Directing

from Lindenwood University – St. Louis, Tina uses her performance and people skills to inform, advocate and fundraise for the Spastic Paraplegia Foundation. Tina has HSP and was clinically diagnosed in late 2002. She has since received her genetic diagnosis of SPG7, and now looks forward to upcoming patient drug trials. Tina has been part of the SPF family since 2006 and has been the Annual Conference Chairperson for 2009 & 2013 (St. Louis) and 2016 (Chicago). She is again excited to a part of the 2017 Annual Conference in Atlanta. Tina became a member of the SPF Board in 2012 and has continued her efforts in finding a cure for HSP & PLS. Tina lives in O'Fallon, Missouri with her husband Tim and her support dog, Thunder.



**John K. Fink, MD**



Dr. Fink is the Director of the Neurogenetic Disorders Clinic at the University of Michigan, Ann Arbor. He's also a Professor in the university's Department of Neurology and is a Physician Scientist at the Geriatric Research Education and Clinical Center, Ann

Arbor Veterans Affairs Medical Center. His research interests are analysis of inherited and degenerative disorders of the nervous system (including hereditary spastic paraplegia, primary lateral sclerosis, inherited movement disorders, schizophrenia) and regulation of neuronal development.

Dr. Fink received his M.D. from the Medical College of Ohio in Toledo. He did his residency training in neurology and genetics at the University of Virginia, Charlottesville. At the National Institutes of Health in Bethesda, Maryland, he did a post-doctoral fellowship in the Developmental and Metabolic Neurology and Medical Genetics departments.

### Christina Fournier, MD



Dr. Fournier graduated from Emory University with a BA in mathematics, attended medical school at the Medical College of Georgia, and completed neurology residency training at Tufts University. She then returned to Emory for fellowship training in clinical

neurophysiology and neuromuscular disorders and subsequently joined the neurology faculty at Emory University as a board-certified neurologist. She also completed a Master of Science degree in clinical research. Dr. Fournier is an Assistant Professor with the Emory University Department of Neurology and is the co-director of the Emory ALS center. Dr. Fournier also runs a neuromuscular clinic and ALS program at the Atlanta VA Medical Center. Her research interests are in the field of motor neuron diseases, particularly Amyotrophic Lateral Sclerosis (ALS) and Primary Lateral Sclerosis (PLS).

### Laurie LeBlanc



Laurie is an Account Executive for an IBM Business Partner who specializes in IBM hardware and services. She completed her Bachelor's Degree in Management at Franklin Pierce University. Laurie

was diagnosed with HSP in 2009 and became the New Hampshire State Ambassador for The Spastic Paraplegia Foundation in 2010. She has helped with New England fundraising activities and has organized local gatherings. When not working, Laurie enjoys spending time with her family and her dogs. Her goal is to find a cure to prevent her children or grandchildren from having to suffer with HSP in the future.

### Sabrina Paganoni, MD



Sabrina Paganoni is an Assistant Professor of Physical Medicine and Rehabilitation (PM&R) at Harvard Medical School, Spaulding Rehabilitation Hospital. She obtained her MD degree at the University of Milan in Italy and a PhD in Neuroscience at Northwestern

University (Chicago, IL). She completed her medical training in Boston (residency in PM&R at Spaulding Rehabilitation Hospital and fellowship in EMG/Neuromuscular Medicine at Brigham and Women's Hospital/Massachusetts General Hospital (MGH)). She is Board-certified in Physical Medicine and Rehabilitation, Neuromuscular Medicine, and Electrodiagnostic Medicine. She is currently working at Spaulding Rehabilitation Hospital and at MGH in the Amyotrophic Lateral Sclerosis (ALS) clinic. She is faculty at the MGH Neurological Clinical Research Institute and her research focuses on ALS and PLS therapy development. She is the Principal Investigator (PI) of three ALS clinical trials, site Investigator of one PLS clinical trial and two PLS observational trials. She leads the NEALS PLS Registry and is using novel neuroimaging techniques as pharmacodynamic biomarkers for clinical trial development. She is also passionate about developing innovative assistive technology tools that can improve quality of life for people with ALS and PLS.

### Brenda Russell, CTRS



Brenda Russell currently serves as the Aging Services Program Coordinator for Fulton County Government, Atlanta, Georgia. She is certified in Certified Therapeutic Recreation and as a BLS for Healthcare Providers and is a Certified Powerful Tools for Caregivers Class Leader.

Brenda is a graduate of the University of North Carolina, Chapel Hill with a BA in recreation and an MS in recreation administration.

*Continued on next page*

## Jeffrey Statland, MD



Dr. Statland is an assistant professor of neurology at the University of Kansas Medical Center with both clinical and research training in neuromuscular diseases. His primary research interest is in FSHD, one of the most prevalent adult muscular dystrophies. Recent advances in

our understanding of the genetic mechanism behind FSHD have led to the identification of potential therapeutic targets, resulting in a pressing need to develop sensitive, disease-relevant outcome measures for clinical trials. Development of outcomes measures was recognized as a priority at a number of international FSHD meetings and workshops. Effective outcomes research is at its heart a collaborative effort. Together with his collaborators, he hopes to develop the institutional infrastructure and tools to run high-quality, efficient clinical trials.

### CReATe

Clinical Research in ALS and Related Disorders for Therapeutic Development (CReATe) Consortium will enroll patients with sporadic and familial forms of amyotrophic lateral sclerosis, frontotemporal dementia (FTD), primary lateral sclerosis (PLS), hereditary spastic paraplegia (HSP), and progressive muscular atrophy (PMA). The goals of the CReATe consortium are to advance therapeutic development for this group of neurodegenerative disorders through study of the relationship between clinical phenotype and underlying genotype, and also through the discovery and development of biomarkers.

## Mark Weber, Esq.



Mark Weber is one of the co-founders of the SPF, and was its first president. He serves as the SPF's legal counsel, and chairs its research grant committee. Mark also started and maintains the PLS-Friends email group. He is an attorney and served for eleven years as a prosecutor in Massachusetts. Currently, he is in private practice in Connecticut concentrating in child abuse and neglect cases. Mark has been diagnosed with HSP. He lives with his wife Andrea in Sherman, Connecticut.

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### DISABILITY LAW: The CRISPR/Cas9 Patent Litigation Will Go On...

By Mary B. Schultz



In the Spring 2016 issue of the *Synapse*, I wrote a column about patent litigation involving CRISPR/Cas9 bio-technology. CRISPR is an acronym for “Clustered Regularly Interspaced Short Palindromic Repeats.” CRISPR/Cas9 holds much promise as a gene therapy for our diseases, and

might be the most significant bio-technology of the last century. CRISPR was named a Science Magazine “Breakthrough of the Year” in 2015, and was awarded the Gruber Genetics Prize and the Japan Prize. Cory Braastad, PhD, made a fantastic presentation on CRISPR at the 2016 SPF Annual Conference in Chicago. A video recording of that presentation is available on the SPF website, [www.sp-foundation.org](http://www.sp-foundation.org). I also recommend Ellen Jorgensen’s TED talk about CRISPR. 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, CRISPR/Cas9 is a simple and versatile technology, genetic scissors, which would enable scientists to edit genes. Very promising for those of us with genetic diseases. Like all members of SPF, I am eager for therapeutic application of CRISPR/Cas9. However, a year ago, I reported that lawyers and the legal system are delaying the therapeutic application of CRISPR/Cas9 bio-technology, affecting each and every one of us. A patent dispute has delayed that application and could affect the cost of CRISPR/Cas9 bio-technology. Unfortunately, what initially appeared to be light at the end of the tunnel proved to be illusory.

A summary of the patent dispute follows. As a preliminary matter, here is a description of the parties. The two parties are the UC-Berkeley team and the Broad Institute/Zhang team. The UC-Berkeley team consists of a team of biologists at the University of California-Berkeley headed by Dr. Jennifer Doudna and Dr. Emmanuella Charpentier. Dr. Doudna is still at UC-Berkeley, and was recently elected to the National Academy of Sciences and the Institute for Medicine. In

2015, Dr. Doudna gave a TED talk about the bioethics of CRISPR. Dr. Charpentier became a member of the Max Planck Institute in Germany, leader of research at the MIMS (Molecular Infection Medicine – Sweden), a professor at Umea University in Sweden, and a visiting professor at UCMR (Umea Centre for Microbial Research). The Broad Institute/Zhang team consists of another team of biologists led by Feng Zhang of the Broad Institute (MIT (Massachusetts Institute of Technology) and Harvard) and the McGovern Institute for Brain Research (at MIT). In March of 2013, the UC-Berkeley team applied to the USPTO (U.S. Patent and Trademark Office) for a patent for CRISPR/Cas9 bio-technology. The UC-Berkeley application was not specific to particular types of cells, and so was general for both prokaryotic (cells without a nucleus, i.e., bacteria) and eukaryotic cells (cells with a nucleus, i.e., animal (including human) and plant cells). The UC-Berkeley team had been able to apply CRISPR/Cas9 bio-technology in a test tube, but not to eukaryotic cells. The UC-Berkeley team submitted its application **THE DAY BEFORE THE FIRST-TO-FILE RULE** went into effect. About six months **AFTER** the UC-Berkeley team applied for a patent, in October of 2013, the Broad Institute/Zhang team applied for a patent relating to CRISPR/Cas9 bio-technology for use in eukaryotic cells. (The Broad Institute/Zhang team was successful in applying CRISPR/Cas9 to eukaryotic cells.) The Broad Institute/Zhang team also filed an accelerated examination request. The second patent application, the Broad Institute/Zhang application, was approved **BEFORE** the UC-Berkeley patent application. Patent no. 8,697,359 (usually called the “359 patent”), granted by the USPTO to the Broad Institute/Zhang team, is specific to use of CRISPR/Cas9 bio-technology in eukaryotic cells. The UC-Berkeley team’s patent application has not been granted by the USPTO yet and remains “under review” by the USPTO. The UC-Berkeley team initiated “interference” proceedings, arguing that the 359 patent issued to the Broad Institute/Zhang team interfered with any patent that will eventually be issued to the UC-Berkeley team.

*Continued on next page*

On February 15, 2017, the PTAB (Patent Trial and Appeals Board) ruled that the 359 patent issued to the Broad Institute/Zhang team does not interfere with a patent application by the UC-Berkeley team. The PTAB decision of February 15, 2017, was significant, but it might not end the CRISPR/Cas9 legal proceedings between the UC-Berkeley team and the Broad Institute/Zhang team in the United States. Professor Jason Sherkow described the PTAB decision as “one battle in a larger war, but it’s a very big, important battle.” On April 13, 2017, the UC-Berkeley team appealed the decision of the PTAB to the U.S. Court of Appeals for the Federal Circuit. Although it is impossible to predict the outcome and duration of further legal proceedings in this case, it is helpful to know about Federal Circuit cases generally. Although the time that appeals remain pending in the Federal Circuit has been decreasing overall, the average remains about nine months. About two-thirds of appeals to the Federal Circuit are eventually affirmed, about one-third affirmed in total and another one-third affirmed in part and reversed in part. About one-third of appeals to the Federal Circuit are reversed and remanded (or sent back to the trial court, in this case the PTAB, for further proceedings). Of course, the CRISPR/Cas9 patent dispute might be resolved informally, by settlement agreement, at any time.

In the meantime, because the Broad Institute/Zhang team prevailed in the interference proceeding before the PTAB, it now has the power to require that any use of the CRISPR/Cas9 technology in eukaryotic cells, even for research, be licensed.

The UC-Berkeley team put a positive spin on its loss before the PTAB, suggesting that the recent PTAB decision clears the way for its patent to be issued by the USPTO. Dr. Doudna said that she was “delighted” with the PTAB decision, and that the UC-Berkeley team’s patent would be like a patent for all tennis balls and the Broad Institute/Zhang patent is like a patent just for green tennis balls.

Unfortunately, I fear that license fees might render the promise of CRISPR/Cas9 bio-technology very costly. So far, the legal fees alone exceed \$20 million. With the appeal, legal fees will inevitably be much higher. There is another reason I am braced for large costs in connection with CRISPR/Cas9 research and therapy. Many start-ups have business plans that are CRISPR-based. Editas Medicine licenses Broad Institute/Zhang patents. Editas’ stock rose almost 30% after the recent PTAB decision was announced. Assuming the UC-Berkeley team is ultimately granted a U.S. patent, businesses that might apply CRISPR/Cas9 bio-technology for therapies, including therapies for HSP and PLS, will be required to secure licenses from BOTH the Broad Institute/Zhang team AND the UC-Berkeley team, driving up the cost.

In the meantime, there has been another development. The EPO (European Patent Office) approved the same patent application by Dr. Doudna on Friday, March 24, 2017. The EPO will issue the patent on May 10, 2017. Although this is big news in Europe, it has no impact whatsoever on the UC-Berkeley team’s patent application that remains pending in the USPTO.

*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 since 2012.*

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## SYNAPSE APPEAL

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# YOUR WHEELS ARE YOUR LEGS – Part II

## Electric Scooters and Wheelchairs: How To Be “On A Roll” Safely And Efficiently

By Malin Dollinger, MD, SPG4, S.D.\*\*

\*\*Doctor of Scooters

*[Editor’s Note: Throughout this article, the author uses the term “scooter” to include motorized 3- and 4 wheeled mobility devices with handlebar-style steering as well as motorized chairs that are joystick controlled and may range from low-cost minimal function devices to special purpose, multifunction rehab devices.]*

### Handicap Parking

The laws of each state incorporate the national ADA rules and requirements, and a complete description can be found on the following websites:

<http://adata.org/factsheet/parking>

<http://legalbeagle.com/6019155-handicap-parking-rules-meter-parking.html>

<http://legalbeagle.com/5992684-american-disabilities-handicap-parking-requirements.html>

**T**hese rules state there is a width requirement for the adjacent blue-hatched access aisles. Access aisles are no parking zones. The usual requirement is five



feet wide, but this may not be enough room for the ramp, as well as the scooter exiting the ramp. That’s another reason to use a smaller/shorter scooter, when you travel in your car. Eight feet of adjacent access aisle is

necessary for “van-accessible” parking places.

There are two kinds of electric ramps: one kind is hidden under the floor when not in use and goes in and out by pressing hand controls. Mine was modified by the dealer to be able, on command, to not extend outwards the full distance. Since I park next to my home, a full extension would not allow me enough room to ride down the ramp and then turn toward the house door. The other kind of ramp is a folding ramp, where the ramp is hinged in the middle and is fastened to the threshold of the van’s sliding door. When stowed, the ramp is folded in front of the closed sliding door. It’s inside the passenger space and is

always visible. It automatically unfolds and extends out from the car when you operate the ramp controls. This type of ramp is difficult to “make shorter” to fit a narrow adjacent space, your home or garage in particular. However, if you are fortunate enough to find a parking space with a curbed sidewalk on the ramp side of your van, the fold down ramp can be used as a bridge between your van and the sidewalk. Make sure you shut off the “kneeler” mechanism that lowers the back of the van to reduce the ramp angle. Otherwise the bridge may go uphill.

A handicap blue-hatched access aisle (5 feet adjacent) is required for every 25 parking spaces in the parking lot or garage, and one of every six accessible parking spaces must be van-accessible (8 feet adjacent). A parking lot for 25 cars or less only needs one handicap space and it must be van-accessible. There are other requirements such as level ramp space, proximity to various businesses and the acceptability for one blue-hatched access space between two handicap spaces. My own wish is that handicap drivers in ordinary cars not use van-accessible spaces, simply because they are available, but instead, if available, use a “regular” handicap parking space with a narrower blue-hatched access aisle.

I sometimes need to park in a regular diagonal space, with an empty space next to me on my right (ramp) side. I have an orange cone that I place in the adjacent empty space, to discourage parking there, so I have room for my ramp and my scooter. In tight parking situations, it is safer to exit the car with the scooter going forward down the ramp, rather than backing down the ramp, so you can see not to bump the adjacent (close) car.

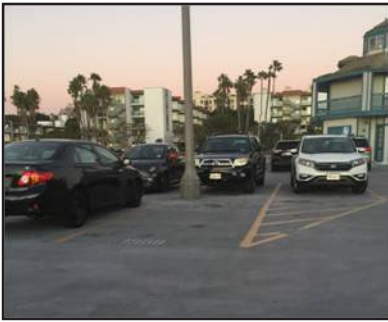
The width of the adjacent blue-hatched access aisle varies, and side-ramp handicap vans need the most space. The trick is to park as close to the left-hand edge of the space as possible (be sure the



adjacent car is not so close as to prevent them from opening the adjacent door and denting your car!). This is where a smaller scooter is nice; there is less difficulty turning at the bottom of the ramp and avoiding bumping the adjacent

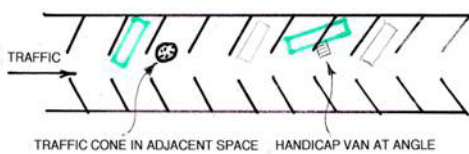
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car. Sometimes a different car has been parked adjacent to mine, when I return from shopping and is too close for me to deploy the ramp or is even occupying part of the blue-hatched access aisle. I may need to ask another driver-person to back my car up far enough so I can deploy my ramp in a clear space, and then drive my scooter into the car while someone watches for incoming traffic, while my car's back end is in the traffic lane. If all else fails, and a regular handicap space is not available, there are two other options. One is to look for an "end space," a regular parking space



that happens to be the last one in line, next to a traffic lane, or to park diagonally occupying two spaces. My use of this latter method has resulted in police warnings as well as nasty notes left on my car commenting on my

parking stupidity and my mother's background. I have a large window sticker on the ramp door explaining the large space needed next to the car, for the ramp and the exiting maneuver. Handicap auto dealers have these stickers. City road crews often put the blue-hatched area on the



PARKING IN REGULAR SPACES

left side of the van accessible parking space. In that case you need to back into the space, so the right-side door/ramp is on

the same side as the blue-hatched accessible aisle. Some handicap vans are modified with the entry ramp on the back of the vehicle rather than the side. This solves the "adjacent space" problem, but creates the need to watch for moving cars behind you in the traffic lane.



The ADA rules and regulations are sometimes ignored by non-handicapped people, who "park only for a minute" in a handicap spot, to "go in and get the cleaning" or whatever. I forcefully tell them that the minute they were there is the exact same minute I could not find a handicap place to park, because they were in it. Some drivers simply ignore the blue-hatched access area and park there. I called the police about the pictured car that parked in the blue zone on a daily basis.

## Suggestions about Restaurants

Usually a table is better than a booth, particularly if you have trouble getting up and down and changing "seats." If you transfer to a booth, there is the problem of matching the scooter seat height with the table seat height. If you do sit in a booth, position the scooter so the control handle and off/on switches are next to you, and not on the other side, away from you. It is often easier, simpler, and safer to sit at a table, on your scooter, where a chair has been removed. Avoid the center of the room and near the entrance; people, waiters carrying food or with rolling carts of food will need to get by you. If you know you need to transfer to a chair (e.g. your scooter won't work at a table, because the control arms are in front and you can't turn the seat to sit sideways on the scooter and face the table), you might bring a fold-up walker or your favorite cane or walking aid, to get from the parked-nearby scooter to the table. Sitting in your scooter to eat at a table also has the advantages of not having the scooter moved somewhere else by the staff, because, "it is in the way." In case you sometimes need to get to the bathroom quickly, not having to have someone "fetch your scooter" is a big plus.

## Cost of Scooters

Only general comments can be made here. New *wheelchairs* cost a few hundred to a few thousand dollars, the latter often being racing or athletic chairs. Scooter prices can range from several hundred to many thousand dollars, depending on its complexity, attachments, range of positions and adjustments, and special features, such as the ability to raise and lower the seat. A fairly well-equipped scooter often costs a few thousand dollars, whereas a complex one, e.g. with a stand up feature or a multi-function rehab chair, can be very expensive. You need to thoroughly investigate your insurance coverage, especially Medicare, so your purchase corresponds to what is covered. Often, part of the cost will be covered (basic needs), but your wish to be able to move your seat up and down, for example, will be on your own dime (and this dime is worth several hundred dollars).

A key thinking and discovery process involves comparing different models/companies, attending local events like the Abilities Expo, visiting large scooter stores, and comparing brands, features, and prices. There is a plentiful market for used scooters usually costing far less than new ones. When you own a scooter, you need to identify a reliable local repair person, who is available to promptly fix things that go wrong with it. This is one life activity you cannot "put on hold" for several days or a few weeks. My own repair person appears the next day after I call him to tell him, "I broke the *name of part*, can you bring and install a replacement?"

Your doctor needs to use the correct language when writing the scooter prescription to get maximum insurance coverage, especially with Medicare (who pays only for a scooter for indoor use!). For example, in previous years, the prescription had to have the specific words, “wheeled mobility platform,” rather than “scooter,” to be covered.

## Avoiding Risks during Scooter Use

Getting on/off your scooter or transferring to or from the toilet, shower, or bed is always a risk. It’s a good idea and a major safety item to install some sort of handicap handrail where transfers take place that allow you to hold during the transfer. I have such handrails near the toilet, inside the shower and near my bed. I discovered a remarkable vertical floor-to-ceiling grab bar, with several grab points halfway up, which I have placed at key and important transfer points in my home. These are especially useful where I move back and forth between my scooter and anywhere else (see <http://stander.com/products>).



Whenever I sit down on my scooter, I have a standard path and sequence of movement. I know where I am going to grab and lean on the scooter arm rest (with the power off), and I always rotate clockwise to turn and sit down. It doesn’t matter what *your* sitting action plan is, but a standard well-thought-out plan and sequence makes your sitting action safer and standard and reliable.

How you handle getting on and off elevators obviously depends on your specific situation. Two-motor scooters can go in forwards, turn around (unless the elevator is full of people), and face outwards to be ready to leave the elevator. Many of us feel safer going forward into an elevator, to be sure not to hit someone already there. That makes it awkward to find the floor buttons so you ask someone to press the one for your floor. If there’s no one else in the elevator, then it is safe for you to turn around and help is unnecessary pressing the desired floor button.

## A Stuck Scooter

There is one “emergency difficulty” that requires special handling, a “stuck scooter.” If you are going through a doorway, or up or down a ramp in your car, or brush your scooter’s side against a fixed object, or fall into a hole or depression, or go over a speed bump in a parking lot, your scooter may suddenly become “stuck” in that spot. The wheels may be jammed in a hole or turned at an odd angle, the joystick controller assembly may have been displaced and the joystick cannot be moved.

What do you do to rescue the scooter and yourself?

1. Turn off the scooter power. You don’t want more strange and unpredictable scooter behavior.
2. Assess the stability of the scooter. Will it “stay put” while you figure this out, or is it unstable/ teetering/ wobbling back and forth? If unstable, call for help to hold the scooter and keep it from tipping or rolling/sliding somewhere.
3. Once there is temporary control, and you realize that turning the scooter back on, with you on it will create a new scenario requiring the rescue of the scooter and yourself, **GET OFF THE SCOOTER!** It’s our extra weight sitting on the scooter that makes it impossible to fix things. This also removes you from the risk of sudden scooter shifting, and facilitates moving the now much lighter scooter to its usual, safe place, out of the rut, the wheels and joystick facing the correct direction. Sometimes, you may need a helper or two to pick the scooter up slightly and move it to a good, stable place where you can get back on and drive it away.

A few times I have caught the joystick assembly on the edge of a doorway. The joystick got twisted at the wrong angle so it became inoperable. I then turned off the scooter, released the brakes [there’s a handle or lever somewhere to do this], and had a helper move the scooter out of the doorway, so I could then push the joystick assembly back where it belonged. I could then re-engage the brakes, turn on the scooter and keep going.

Recently as I was entering my van, riding up the ramp, I got too close to the ramp edge, and a front wheel dropped two inches down into a recess in the ramp mechanism. No amount of power was going to lift that wheel up. I realized that my weight was the problem. I managed to lift myself off the scooter onto the back seat of my van, then called my wife to come out and be there, “just in case.” When I turned on the empty scooter power, it easily rose out of the wheel rut, went a foot forward back onto level car floor, and everything was fine. The important action in these predicaments is to quickly turn off the power and then figure out a safe and realistic way to fix the problem.

## Shoulder Injuries and Scooters

Many of us have had shoulder injuries. That makes the whole handicap situation more complicated and difficult, including with scooters. We need our arms and shoulders to get up and down, to transfer, and to support ourselves while standing (holding on). You might injure one shoulder, which in a “normal” person might be able to be surgically repaired; you can stand, walk, and move about, and you have the other arm and shoulder to do those tasks involving the use of your arm(s). However, as a paraplegic, your

*Continued on next page*

shoulders have a lot more strain and possibility of injury because they bear much more of your weight in your daily routine. So if you injure one shoulder, you might then injure the other shoulder as well, from having the other “good” shoulder “take up the slack” of supporting your entire body. Surgeons often do not wish to repair one broken shoulder in a paraplegic, since that makes an injury more likely in the one remaining “good” shoulder from all the extra stress. This happened to me, and now I have two bad shoulders [injuries] and two bad legs [HSP/SPG4 gene]. My physical medicine doctor told me I’m functionally equivalent to a quadriplegic, even if there are now two different causes of my disability rather than a single cause. So think carefully about everything you do and everything you grab onto, go step-by-step when transferring, on/off the toilet, in and out of the shower and to and from your bed, so you do not suddenly have all your weight on one arm and shoulder. Consider using a transfer board where the situation allows it. You slide on the board rather than having to raise your body up to make the transfer. When transferring from the scooter, I’ve found it helpful to pull myself up with one hand holding onto a handrail while using my other hand to push up on the scooter armrest. Both arms share in the work.

## Segways and iBOTS

Some of these are clever two-wheeled devices commonly used by security personnel/police inside large facilities, such as factories or airports. They are of limited use by us, since a) you can’t sit down, b) it’s difficult to carry items with you, c) many of us have difficulty standing and moving for a period of time, and d) you need to be able to walk when you get to your destination. Some years ago there was a multiple-wheeled Segway/iBOT for handicapped people, but it is no longer being marketed. iBOTS are 4-wheeled devices for handicapped people, that can go up and down stairs and curbs, as well as “hover” on two wheels, so the occupant is up at eye-level. The next generation iBOT 2.0 will be introduced this year and represents a great improvement. It is a “four-wheel-drive wheelchair that can climb up and down stairs and curbs, roll across varied terrain, raise a seated user to eye-level standing height by rising up and balancing on two wheels” (New Mobility magazine, November 2016).

## Stand-up Scooters/Wheelchairs

Several manufacturers produce complex heavy-duty scooters which permit standing, and traveling in a standing position, such as Permobil. Most are quite heavy, to produce a safe situation when you are standing and all of your weight is concentrated above a small area. Most are “sitting scooters” as we are used to, which also allow the occupant to stand. The Permobil does this and other brands, such as Karman, Redman, and Corpus, do the same. The newest

innovation is the TEK-RMD device (I described this in two previous *Synapse* articles) which differs from all previous “standing wheelchairs and scooters” in that it is designed to move you only when standing, rather than sitting, and to allow you to carry out normal standing life functions while in the device. Mine does this rather remarkably.



A new small scooter, the Whill Model M, has a different type of steering mechanism, has high and low back supports and an arm support. Another new scooter, UPnRIDE, from Israel, allows riding while standing. It awaits marketing here in the U.S.



Incidentally, there are various wheelchair-securing devices to secure your empty wheelchair/scooter in your van; most require a tie-down device on the floor of the van. New ones instead have a quick and easy mechanical attachment to the scooter.

## Scooter Ideas

- If finances permit, having two different scooters may be useful. For example a smaller one for the car, outside the home and public places with narrow spaces and a larger one for inside the home, where it would be more stable when transferring to the toilet or shower, or during eating or performing other home activities. You need to carefully research the insurance/Medicare requirements, specifically the need for a letter from your doctor regarding medical necessity.
- Be sure your intended scooter can fit into your home without damaging furniture, doors, and walls, and especially that it can fit into your car/van and maneuver inside. This is especially important if you need to drive your scooter into an empty space behind the steering wheel and steering column, to drive from the scooter.
- If you need to change a scooter tire, how do you raise that tire off the ground? Your auto jack appears to be too large and Charles Atlas may not be available. The method I use is to create what are called “pillow blocks,” a method to easily raise a very heavy object a short distance. You find a bunch of pieces of wood, which when stacked together, are high enough to raise the object to a specific height. Books will also work. With a crowbar [or a

heavy 2 x 4], you lift the scooter just far enough to insert the first piece of wood. You keep adding pieces of wood, with the crowbar, until the bad wheel clears the floor. The last piece of wood can be a wedge, as shown, which you find in hardware stores; you drive it in with a hammer. When done, simply reverse the process and lower the new wheel back down. Buy some wedges now; they're quite handy to move things a little bit and "take up slack."



## Manual Wheelchairs

If you have read this far and use a manual wheelchair, you know that many of these principles and guidelines also apply to you. You have your own specific rules, like putting the wheel brakes on whenever you get up or down from the wheelchair and use of the foot supports (which are often adjustable). You can easily reverse direction in one spot, e.g. an elevator, and you know that in many situations, like going up or down steeper ramps, you may need someone else to be with you, for safety. Opening doors and holding them, while you enter and leave (in particular business and commercial building doors with door closers), often requires a helper to hold the door open while you pass through. There are special trays and platforms for manual wheelchairs, to hold things, and these can also be used for electric scooters. There are special rims to hold onto, that are easier on the hands, and there are also new efficient "cranks" that attach to both sides of the wheelchair, that make it much easier to move the chair, compared to your needing to turn the wheel rims.

## Changes to Scooters You Can Make:

There are improvements that can be made by retrofitting scooters. Some examples are:

1. Buy a small inexpensive rug or mat and cut out a piece to fit over the top of the hard footplate and fasten it with Velcro. It is easier on your shoeless or bare feet. If the footplate is small, make a larger footplate to better fit your feet and fasten it with screws to the smaller one that is already there. You can also add a rubber bumper on the edge of the footplate (cut open a rubber hose made for washing machines).
2. Invent/buy/fasten some carrying bags to the side arms. Don't use duct tape. There is no known solvent that will clean its adhesive off later, except for "Goof Off." Velcro is very handy for attachment and "industrial" Velcro holds better than regular Velcro. Another idea is to fasten carrying bags to both edges of a rectangular

piece of heavy fabric and place that assembly under a pad that you sit on, on top of the scooter seat. This allows you to move the bag assembly from one place to another, e.g., from one scooter to another.

3. Create specialized methods of carrying needed items, like canes and drinks. These attachments are also sold commercially and can be used as is or adapted.
4. You may want to get an extra pad for the seat if it is too hard. When we are in chairs for years, our gluteal ("behind") muscles atrophy and you may be more comfortable with an extra pad or cushion that conforms to us from Soho, Temperpedic or Java.
5. Make instruction cards for airline, train, or bus personnel, and fasten them to the scooter...how to fold the scooter, turn it on and off, and how to find and operate the brake release. Take photos of the scooter, also, in case you need to find a lost scooter or prove the damage is new. Take the photos with you when you travel. Put sticky labels on your scooter, with your name and identifying information/address/phone and also another label near the brake release telling how to set and release the brakes (airline personnel in particular). If you fly with your scooter, and you have a stopover, if you want your scooter to appear only at your final destination (avoid risk of waiting at the intermediate stop for your scooter, and missing your subsequent flight), place large labels on your scooter.



6. Certain items are needed to be with you and easily accessible whenever you use your scooter: scooter keys, car keys, wallet or purse, personal items, medications. Consider buying a small container and fastening it to your scooter. I bought a small plastic storage container with a lid, about 3 x 5 inches, and screwed it onto the side of my scooter by drilling two holes in its side. Industrial Velcro would also work to attach the container. Into that container goes all my "stuff."



7. You need to be sure that you carry the battery charger with you, when you take your scooter outside your home. I have a canvas bag behind the scooter seat

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which contains the charger, charge cables, and a few tools to manipulate important fasteners and devices. I also have a COPY of the scooter instruction manual in this same pocket. I once had to call a scooter service to install new batteries when I was 3000 miles from home. I have also needed to consult the manual to answer new and unfamiliar questions when travelling, such as how to reassemble the scooter when an airline decided to convert it into smaller parts.

8. If there are specific adjustments, such as moving the side armrests in and out, keep tools, such as the specific Allen wrenches, in that same bag. I carry a small all-purpose tool set with me “just in case.” That Phillips screwdriver is handy to take covers off to change batteries or make adjustments. Take with you the special/specific tools you need for your scooter.
9. A light on the scooter is very useful at night. These can be purchased and installed separately.
10. The ‘horn’ supplied with the scooter is usually a “joke,” often audible only in a quiet room. I have a hand-operated bicycle bulb horn that I use in necessary places, such as airports, to warn people.

Your scooter IS YOUR LEGS, and this complex mechanical device becomes, in a sense, a “living thing” that is a part of you. This article and Part I in the Winter issue of Synapse have been concerned with the “care and feeding” of this part of you.

### Something about My Attitude

*By Hugh Fenlon, PLS  
hughblue@yahoo.com.*

I have a sclerosis  
That's really atrocious  
It makes me clumsy as hell  
I fall down the stairs  
On tables and chairs  
And places I'd rather not 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.

And yet I still do  
As when putting on shoes  
And doing those everyday tasks  
Although it gets done  
It's never much fun  
In fact, it's a pain in the ass!

## Selective Dorsal Rhizotomy for Hereditary Spastic Paraparesis in Children.

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### Abstract

#### PURPOSE:

The aim of this study was to determine the outcomes for children who underwent selective dorsal rhizotomy (SDR) for the treatment of spasticity related to spinal pathology.

#### METHODS:

We performed a retrospective review of all cases of SDR at our institution over the last 30 years and identified patients in whom spasticity was attributed to spinal rather than cerebral pathology. We gathered demographic information and recorded functional status and spasticity scores pre-operatively and over long-term follow-up.

#### RESULTS:

We identified four patients who underwent SDR for spinal-related spasticity. All four had hereditary spastic paraparesis (HSP). All patients had reduced spasticity in the lower limbs after SDR, which was maintained over long-term follow-up. Two patients had a more severe and progressive subtype of HSP, and both these patients exhibited functional decline despite improvement in tone.

#### CONCLUSIONS:

Our findings suggest SDR is a reasonable option to consider for relief of spinal-related spasticity in uncomplicated hereditary spastic paraparesis. However, SDR for the treatment of complicated HSP seems to carry more risks and have a less predictable outcome. Overall, SDR is probably best reserved for pathologies that are relatively stable in their disease course.

Source: US National Library of Medicine, National Institutes of Health (PubMed.gov) and National Center for Biotechnology Information (NCBI).

# Activities and Opportunities for Kids With Special Healthcare Needs

By Mari and Ray White

As parents of two very fantastic children, both of whom have special healthcare needs, we have learned a great deal. However, with that said, they are not abnormal as society would have you think. Alex is now 14, in the terrible hormonal teens, and happens to use forearm crutches, a manual wheelchair on occasion, and a service mobility dog. Our 25-year old has Asperger Syndrome. Both are unique, both have quirks, both are otherwise like any other sibling match, and both cause laughter, despair, and bring love to our family.

One of the major things we as parents have done is to instill a sense of identity, a selfless love of humanity, a creative and can-do attitude, and most of all, a sense that they do not have to hide. We have tried to teach them that their “disease” does not define them. We go out of our way to have the same expectations as any parents have such as ownership of mistakes, working to their full capacity, trying their best, chores, responsibility, and faith in themselves and humanity. I like to call this Hope. It is a tough world out there, especially now in the political arena, but we want them to know that despite the societal low expectations and attitudes towards persons who have different mobility needs, different learning styles, differing abilities, that does not mean they are less than. We have purposefully attempted to engage both boys in all kinds of community activities, cultural and artistic activities and other opportunities so that they could start to dream. Along the way, we have gently nudged them along to keep an open mind and to be as well rounded as they can be. It is not easy and there are many emotional and financial barriers, time commitments, many, many doctors’ appointments, and often times, pain, fear, and tears, but we want our boys to feel comfortable with who they are. We always joke, “**Be yourself, everyone else is taken.**”

Along the way, Ray and I have found over the years many, many opportunities for both boys to explore the world and their abilities.

## **1. Theater camps, community civic theater, community arts groups.**

Most communities have these activities available to its residents or they have reciprocity agreements with nearby communities that do have them. Please use your favorite search engine (use GoodSearch.com and benefit SPF) to find the locations for these activities that are nearest to you.

**2. Space Camp.** We have one of the best space camps in Hutchinson, Kansas that is sponsored by N.A.S.A. and it is for all ages, all abilities. They even have child/grandparent camps. This is at the Cosmosphere. They have day camps and they also offer week-long camps for kids starting around 7<sup>th</sup> grade. Each year, the camps progressively get more elaborate as the participants learn leadership, teamwork and travel to places like the Johnson Space Center in Houston and Cape Canaveral in Florida where they actually run real space missions and work with kids from all around the United States. Scholarships are available. Some of the camps teach scuba diving and how to be a pilot. *Did you know that one can easily fly a plane with hand controls?*

**3. Muscular Dystrophy Camp.** This is open to kids from age 6 to 17 and is for any child with a neuromuscular disability. They are usually paired 1:1 or 1:2 with counselors and do all the same things that other kids do at camp, but they can relax because everyone else uses wheelchairs, have traches, have feeding tubes, wear braces or have service dogs and are like them. They also have a full healthcare team on site. The volunteers are trained to do stretching and other P.T. things. These are FREE.

**4. Challenge Air** is a free national program all over the United States that offers any child from age 6 to 21 with any kind of special healthcare needs, even the most severe, an opportunity to have fun with science experiments, learn about flight, and best of all, have the opportunity to fly



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a real airplane, if they so choose, or at least go up in an airplane. The planes are all donated by pilots for the day and each pilot is paired with one child and a parent and often even a best friend. The pilots take the kids, including those who use wheelchairs, up in their planes where they teach them about the plane and flying. The kids sit in the co-pilot's seat. Once they reach altitude, the pilot will often turn the plane over to the child and allow them to steer. The flights usually last about 30 minutes. Food is free, cheerleaders are free, and everything else is free. They often have special adult guest speakers who have had major disabilities and have adapted and gone on to live very successful lives. One such speaker was Jessica Cox who was born without arms but is a pilot, has 2 black belts, and scuba dives. She goes around speaking to kids and groups about her growing up and being expected to see herself as normal. As frustrating as that was, she learned she could do it. She does everything with her feet, drives a car, flies a plane, and writes prettier than I do.

**5. Boy Scouts or Girl Scouts** are great ways to interact and learn how to be good citizens, how to trust in themselves, and how to have fun. Most scout troops are adaptable to kids who have different mobility needs.

**6. Mid-America Games is a National Paralympics-like sports group** that allows all children from age 6 and up to compete and participate in activities like track and field, archery, skiing, soccer, and whatever other sports are available. These have very minimal costs. These are similar to Special Olympics but are geared more to kids and adults with neuromuscular differences. I absolutely hate the word disabled because to me, that tells kids they are broken. At these events, they often have a real live Paralympian athlete talk to the participants about what it takes to be a Paralympian.

**7. Music** of any kind is near and dear to our hearts. Although Alex has mobility issues, he sings well and is in a national touring choir called the Lawrence Children's Choir. They have gone all over the world for the past 25 years. Alex has been involved for the last 7 or 8 years and they are like family. They actually have 6 different choirs starting at age 3 and going to age 90+, but the bulk of the choir is the touring choir which is made up of kids from grades 5 through 9 with an occasional 10<sup>th</sup> grader. The choir practices just one day a week and you don't have to know how to sing. They can make singers of anyone. Last year, Alex had the opportunity to travel to Costa Rica which was a real mind-opening trip. Dondo, his service dog, participates

in all the concerts and travel (except Costa Rica) and is considered a choir member. Alex also participates in the summer advanced Choir camp. Alex plays cello and again, Dondo goes everywhere and sits or sleeps through all concerts on stage. A benefit I learned about singing and cello playing is that they help build core muscles and balance as well as provide a common interest with other kids. Alex travels with his school choir and has been a member of the community orchestra. He does all of this and is totally accepted, dog and all, with and without wheelchair or crutches.

**8.** Most communities have **wheelchair sports** (and you DO NOT need to use a wheelchair) and other adaptive sports from skiing, to ballroom dancing, to baseball and basketball. You name it, literally, and they have an adaptive sport for it, even fencing and mountain climbing! If you ever have the opportunity to meet Rebecca Hart, one of our own from SPF, go for it. She has had HSP her whole life and has been part of the Paralympics in Equine Dressage which is essentially horse ballet. She has traveled and competed in 3 different National Paralympics, the last being in Rio De Janeiro. She speaks to groups all over about her journey to where she is, how very angry she was as a youth at HSP and how she channeled that anger into the equestrian sports. For Alex, this was very important for him to hear that it was ok and acceptable to be angry at the disease.



**9. Service Dogs.** I will be writing a much more lengthy report on service dogs in the next issue of *Synapse*, but I wanted to get out there that these are fabulous companions for our kids (and adults). They are highly trained to do just about anything a person needs help

with from dressing to getting things from the refrigerator to assisting with mobility and helping with falls. They can pick things up off the floor, help with laundry, help pull laundry baskets, open doors and elevators, and even pay with a credit card if a person cannot reach the cashier from the chair. (I am, of course, in hopes that the kids do not have credit cards). The dogs are usually around 2 ½ or 3 years old when matched with the person. With children, the parents are involved with the last steps of training.

Once a puppy is born or donated to a training organization, they are immediately immersed into a sense of life experiences, textures, smells, and places. Once weaned,



they are placed with puppy trainers for the first 18 months or so of their lives. Here they are exposed to all kinds of things and are taught basic obedience. These trainers are volunteers. Then the dogs usually go to an intermediate training facility for about 6 months. In our area, they go to the Women's Correctional Center which is a win-win for both as they learn to trust and love. Finally, they go to what is essentially Doggie University where they spend about 6 months doing advanced training. By that time, they are fully screened health and temperament wise and matched by personality to their perspective person. The matched pair then spend two solid weeks in an on-site, duplex-like housing unit learning all kinds of things and commands. Once they pass an international exam, they take the dog home and start a life of love and companionship. Alex takes Dondo just about everywhere with him. We will occasionally give them breaks from each other because as Alex says, "Mom, it's like a married couple, and sometimes I just need a break in the bathroom away from him."

Just because a dog starts out in training does not mean it will end up being placed. Some puppies just have too much of a wild imagination and/or a love of squirrels and some have health issues. Dogs can also be trained to be guide dogs for the blind, emotional support dogs, mobility dogs, school and therapy dogs, courtroom dogs, diabetic dogs, military dogs, PTSD dogs, seizure dogs and search and rescue dogs. Some become breeding dogs for a while. There are multiple places throughout the United States that train these. Some are much better than others. The best ones require the international testing and continued training throughout the life of the dog and most require continued health checks as well.

There are many perks to having a service dog such as free or reduced costs on vet bills, supplies, entrance to amusement parks/rides (front of the line for most rides), lowered food costs, and of course in Alex's case, the "Chick Factor" with girls. For shy kids, service dogs often allow them to be seen and understood and help with socialization. One additional perk is that these dogs and all medical bills, food, toys, travel, etc. are tax deductible as medical expenses. These dogs, once matched will go through mourning if they are separated from their "person." It is a lengthy process to get placed depending upon the facility and availability of dogs. For most, it is around two years. So, get an application in early. They do not mind if you have other dogs or other pets in the home, in fact, most places encourage it. Once a dog is out of the harness, they can be just a dog. It's amazing the difference between when they are on duty

and off duty. Being able to play ball with a dog can often strengthen muscles, build balance, and help with self-esteem. Many, many of the service dogs are essentially free of charge for the life of the dog. A few organizations will charge a fee with an expectation that one go through fundraising or a community group, like the Lions Club, to raise the money. There are red-flag places to avoid and should anyone need to know more about these or which ones are more child-friendly, I would be glad to discuss them with you.

## **10. Equine Facilitated Counseling**

The horses are trained much like service dogs to pick up tiny emotional signals from the rider and will let the social worker running the program know so he can slowly draw things out of the rider. Often times the rider does not even know that it is happening.



Medicaid will pay for this under counseling and we also see a psychologist which can be billed under family therapy. It's a great program. It really helps with balance and muscle strength. The social worker's wife is a physical therapy assistant by trade and she has a list of suggested stretches from Alex's physical therapist.

**11. Other Activities.** Find other activities, such as chess club, gaming, Wii Sports, bowling, debate, spelling bees, warm water swimming/therapy, and so many other things, that they can do with class mates who do not have altered mobility.

In closing, I would be in hot water if I did not mention the various online support groups and SPF State Ambassadors that exist. Several of the older kids have their own chat spaces and pages and there is a very large and active SPF parent and caregiver support group. There is a National Pediatric Conference held every two years in Dallas at Texas Scottish Rite Hospital for Children. The next one is scheduled around February 2018. There, families and children with HSP can get together for a day and get to know each other. They have a few speakers, but mostly it is social. And it is free.

We have many, many funny and not so funny tales of experiences that we have had with both boys and my husband, who also has HSP. Should we ever meet, I would love to share them with you. We believe strongly as a family that we need to allow our kids to experience and to fail. Out of failure comes growth and redetermination.

By Tina Croghan

# LEG CRAMPS!

This article all started from a suggestion received in a letter from Paula Thompson of Tigard, OR:

### **Try Pickle Juice!**

*My husband [Ken] is afflicted with HSP and we have found the articles in [Synapse] helpful in many ways. I did want to relate one possible remedy we have used which we have not seen anything about since receiving the newsletters. One of the symptoms my husband dealt with in the past was leg spasms at night. When we spoke with his neurologist about this he suggested he try drinking pickle juice! I could hardly believe an educated person was suggesting such a silly thing, but he said he had read where people were relieved of leg pain if they drink pickle juice regularly. So, we gave it a try. Each night around 5:00 pm my husband has a "cocktail" of either pickle juice or a bottled product called "Gut Juice" from a health food store. It was suggested that he swirl the juice around in his mouth so that the juice can affect his taste buds, which then causes sublingual absorption. His spasms stopped, but on the night when I forgot to give him anything they reoccurred. If any other patients suffer from nightly leg spasms, I suggest they give pickle juice a try!*

This works for Ken Thompson, but there may be many more solutions to Leg Cramps. So I posed the question, "What do you do for leg cramps before bed?" on the SPF Facebook page. I thought it would be a simple, straightforward question that would be answered with a few suggestions. To my surprise, I received a multitude of responses. I've tried to compile them all.

It seemed like everyone said that they swear by their remedy. Basically, I found that there isn't one thing that works for everyone. Like each one of us is different, each of the remedies is just as unique. This column is meant to give suggestions of what might work for you, too!

- Linda Gentner said that her husband, Craig, drinks 1 tablespoon of apple cider vinegar in juice (if not straight).
- An Amish recipe also uses raw apple cider vinegar this time with the juice from the ginger plant along with garlic juice. It didn't include any specific amounts, just a list of ingredients.
- The common denominator I found was the use of vinegar (mildly acidic), whether it be in the form of pickle juice or concocting your own "cocktail" using apple cider vinegar.

- Most people suggested stretching — STRETCHING — STRETCHING. Especially before going to bed. A suggestion of stretches for us can be found at: <https://www.youtube.com/watch?v=mz2sISsJ8hg>.
- Another reader suggested body placement — the angle of your legs. Bending your legs in a fetal position along with a pillow placed between your legs, is supposed to keep the leg cramps from even beginning.
- Some of the prescription drugs mentioned were gabapentin, tizanidine and diazepam.
- Some of the over-the-counter remedies were: Voltaren Gel (available in Canada), Biofreeze, Lidocaine (sold in patches) and a restless leg cream commonly found at your local Wal-Mart.
- Most agree that common water—tap, bottled, or sparkling can't be beat in heading off the dreaded "Charlie Horse" leg/foot cramps.
- Someone posted her recipe for "jazzing up" her water by making it into a lemonade drink: 3 lemons, 3 Tablespoons sugar, ½ teaspoon salt and 2 L water
- I subscribe to this diet, too—I only drink one (or so) cups of coffee and the rest of the time I drink sparkling water. Speaking of tonic, someone suggested that you drink tonic water or a kind of electrolyte corrective liquid like Pedialyte, Gatorade, etc.
- I eat half of a banana everyday and put the other half in a baggie for tomorrow. One suggestion I received was to take an over-the-counter Potassium supplement.
- Something I had never heard of, but it makes sense, is a hot pack or weighted body shawls found at: [www.grampasgarden.com](http://www.grampasgarden.com). I had heard of the benefits of weight on spastic muscles. Thunder, my service dog, lies on my legs when they start their "jumping."
- One of the more bizarre remedies was to place a bar of Ivory soap in the sheets at the foot of your bed! I don't know if this works on leg cramps, but your sheets will smell good!
- Most agree the over-the-counter supplement of Chelated Magnesium really helps to avoid leg cramps. What varies is the daily intake. The response was anywhere from 100mg to 500mg.

Once again, there is no agreement—only that everyone is different! The takeaway — there's no one solution to the night leg cramps problem. Choose the one that works best for YOU.

Remember, if you have a tip or suggestion, send it to [tinacroghan@yahoo.com](mailto:tinacroghan@yahoo.com).

The topics for the next Tina's Tips column are "*closing a door*" and "*ramps and lifts to get into and out of the house.*" Please submit your ideas and/or pictures to me at the above email address. Thanks in advance for your help!

# SPF 2017 ANNUAL CONFERENCE

## June 23 - 25

Save the Date

ATLANTA AIRPORT MARRIOTT GATEWAY  
2929 CONVENTION CENTER CONCOURSE,



# ATLANTA, GA

**Hotel Registration:** Mention "SPF" for discounted room rate of \$119 and \$8 self-parking, Call (404) 763-1544 Atlanta Airport Marriott Gateway. **Conference Registration:** Pay Online or Make Check Payable: SP-Foundation Mail to: 1605 Goularte Place, Fremont, CA 94539. Questions, please email SPFKentucky@gmail.com

# SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

Research / Education / Support

## HEREDITARY SPASTIC PARAPLEGIA PRIMARY LATERAL SCLEROSIS

www.sp-foundation.org

### Tentative Agenda

**June 23, Friday**

- 1:pm Welcome
- 1:30pm - Breakout Sessions
- 5:30pm – Welcome Reception (cash bar)
- 6:30pm – Dinner, plated

**June 24, Saturday**

- 7:30am – Breakfast, plated
- 8:30am – General Session, Panel
- 9:00am - Kid's Day Excursion to Atlanta Zoo
- 12:Noon – Lunch, plated
- 1:45 pm – General Session, Breakout Sessions
- 5:00pm Social Mingle (on your own)
- 6:pm – Dinner (on your own)

**June 25, Sunday (Add-on Cost)**

Excursion to Georgia Aquarium (must prepay, preregister, para- transportation provided by MARTA)

Registrant Name#1: \_\_\_\_\_ Disorder: N/A \_\_\_ HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_

Registrant Name #2: \_\_\_\_\_ Disorder: N/A \_\_\_ HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_

Child Name #1: \_\_\_\_\_ Age: \_\_\_\_\_ Disorder: N/A \_\_\_ HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_

Child Name #2: \_\_\_\_\_ Age: \_\_\_\_\_ Disorder: N/A \_\_\_ HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_

Address: \_\_\_\_\_

Mobile Phone while in ATL: (\_\_\_\_) \_\_\_\_\_ Text?: Y / N 2<sup>ND</sup>: Mobile: (\_\_\_\_) \_\_\_\_\_ Text?: Y / N

E-mail: \_\_\_\_\_

(1) Are you registered in your home state with para-transportation services? \_\_\_\_\_ If yes, ask your local paratransit services to fax "Visitor's Status" information to ATL MARTA Mobility at 404-848-6900 if you are attending the Zoo (child) \_\_\_\_\_ (y/n) or Aquarium (Adult/Child) \_\_\_\_\_ (y/n). (2) If not previously registered with para-transit services, while in Atlanta, are you attending the Zoo (child) \_\_\_\_\_ (y/n) or Aquarium (Adult/Child) \_\_\_\_\_ (y/n). (3) Will a companion join you? \_\_\_\_\_, If yes, please attach a registration form for the companion. (4) What aids are you likely to use in ATL? Check all that apply: Cane \_\_\_\_\_ Crutches \_\_\_\_\_ Walker \_\_\_\_\_ Scooter \_\_\_\_\_ Wheelchair \_\_\_\_\_ Powerchair \_\_\_\_\_ Animal \_\_\_\_\_ Other \_\_\_\_\_ (5) Meal Requirement: Regular \_\_\_\_\_ Vegetarian \_\_\_\_\_ Food Allergies \_\_\_\_\_ (6) Are you driving or flying to ATL? \_\_\_\_\_

**Registration Fees: SPF Donation** ..... \$ \_\_\_\_\_

**QTY: \_\_\_\_\_ @\$100 per adult (\$110 after 5/20/17) (1-day rate \$80)**.....\$ \_\_\_\_\_

**QTY: \_\_\_\_\_ @\$70 per child (age <18-yrs old) (\$80 after 5/20/17)**.....\$ \_\_\_\_\_

**(Conference Fee includes: Friday Dinner; Saturday breakfast, lunch, and snacks during breaks)**

Saturday Kid's Day Excursion to Atlanta Zoo includes lunch & para-transit (must pre-register)

QTY \_\_\_\_\_ @\$0 Child (3-11) / QTY \_\_\_\_\_ @\$21 Adult (12+).....\$ \_\_\_\_\_

Sunday Optional Excursion: Georgia Aquarium includes para-transit

Adult QTY \_\_\_\_\_ @\$32 /Children(3-12)QTY \_\_\_\_\_ @\$27 /Seniors(65+)QTY \_\_\_\_\_ @\$29 .....\$ \_\_\_\_\_

**Total Fees Enclosed** .....\$ \_\_\_\_\_

1605 Goularte Place  
Fremont, CA 94539-7241

## Para-Transportation by MARTA

If you plan to attend the 2017 Annual Conference, MARTA, the Metropolitan Atlanta Rapid Transit Authority, can provide para-transportation services for handicap persons at a reduced cost, however customers must be registered with MARTA to use this service. If you are already registered with a paratransit service in your area, you can ask your local paratransit service to fax "Visitor's Status" information to MARTA Mobility, 404-848-6900. If you are not registered with a local service, it is very important to answer all the questions on the Conference Registration Form. A copy of the form can be found at the end of this newsletter. Your information will be provided to MARTA to meet their registration requirements.



*California Connection - Fremont, CA*

St. James' Episcopal Church (same as last year)  
Contact: Linda Gentner - linda.gentner83@gmail.com

**Abilities  
EXPO**

The event for the  
disability community

**CHICAGO EXPO**  
June 23-25, 2017

**HOUSTON EXPO**  
August 4-6, 2017

**BOSTON EXPO**  
September 8-10, 2017

**SAN MATEO**  
October 27-29, 2017

For more details, [www.abilities.com/expos/](http://www.abilities.com/expos/)