

# Synapse

Volume 22, Issue 2

Spring 2019

*Newsletter of the Spastic Paraplegia Foundation*



## Spastic Paraplegia Foundation Annual Conference

**June 21-22, 2019**

**Learn More At  
SP-Foundation.org**

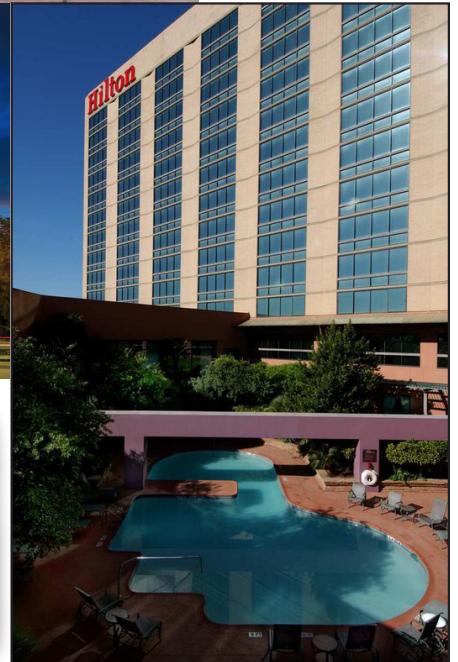
**Registration Open**



[www.morganswonderland.com](http://www.morganswonderland.com)



**#hspanapis**



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## SYNAPSE APPEAL

*Synapse* costs lots of money to print and mail, and we need your help to keep it going. If you or a loved one enjoyed this issue and would like to support it, please use the enclosed response envelope to make a donation.

*Every little bit helps.*



### Volume 22, Issue 2 - Spring 2019

*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, M.D..... Medical/Research Editor

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1605 Goularte Place  
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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John K. Fink, M.D., University of Michigan

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## Letter from the President



Dear Friends,

I have a wide variety of things I want to talk to you about today. First of all, I want you to know that a lot of exciting things are going on right now at the Spastic Paraplegia Foundation.

We are making final decisions on what research to support for the next two years. The manager of our all-volunteer Scientific Advisory Board, Dr. Martha Nance, has turned in the reports from all of the scientists that have reviewed and graded the research proposals submitted this year. There are some really exciting and promising projects soon to be underway. In May or June, you will receive our Annual Report where I will tell you what I can about recent and future research progress. Our researchers ask that we keep their projects confidential until they are complete so I can't give you all the details, but I do want you to know that they are all state of the art and on the cutting edge of the most promising and exciting find-a-cure research possible.

I also want to remind you again that every person that works for the Spastic Paraplegia Foundation does so on a voluntary basis. Our only costs are printing, postage and our Annual Conference (which is largely paid for by Conference Registration fees and sponsors) so almost every penny you donate goes to this incredibly valuable, cure-seeking research.

Speaking of our Annual Conference, this year's event, June 21 & 22 in San Antonio, Texas, will be one of our best conferences ever. If you look at our list of speakers this year, you will see that each one is a world leader in HSP or PLS research and knowledge. For the first time, this year we have both Dr. Craig Blackstone and Dr. Peter Baas on the agenda. I have been reading and following their long list of research reports for years and years and it is going to be very exciting for me to finally meet both of them.

What's more, Dr. Hiroshi Mitsumoto will be letting all of us know about the PLS Medical Symposium that will have taken place May 3-4, 2019, in Philadelphia, PA. This symposium, exclusively about Primary Lateral Sclerosis and partially sponsored by the Spastic Paraplegia Foundation, is a meeting of many of the top upper-motor neurologists from all over the world. It is mid-April as I write this letter and I am looking forward to attending and being one of the speakers at this Symposium. My role

will be to interview a panel of young neurologists about PLS as part of the whole presentation. This symposium will do wonders to create an energy about PLS knowledge and research among the whole community of neurological doctors worldwide and is long overdue. Again, Dr. Mitsumoto will tell us all about it and other PLS work they are doing at our Annual Conference in San Antonio in June.

Dr. Corey Braastad, a very valuable member of our Board of Directors for many years, is a PhD in Genetics and will be updating our audience about genetics. Corey is usually one of our most popular speakers because he is very good at explaining genetics in an entertaining and understandable way. He puts a lot of work into making sure that his presentation is up to date and very relevant for our audience.

We are also honored this year to have the president of our sister HSP organization in Australia, the HSP Research Foundation, Frank McKeown. Frank will speak to all of us about the exciting research they are doing with Dr. Allan McKay-Sim who won "Australian of the Year" in 2017. Our SPF is a major sponsor of this cutting-edge research and it will be exciting to get an update on the progress taking place.

Our most popular speaker is always my good friend and our medical advisor, Dr. John Fink. Dr. Fink has the fortitude to stand up in front of all of us who are so eager to learn and answer any and all questions. I honestly think he really enjoys doing so.

We also have times planned for break-out sessions where different groups – people with HSP, people with PLS, youth and caregivers – can meet separately and ask each other questions and share. Many people learn more from their fellow travelers on this journey than from the experts, so don't miss this.

The setting this year, in the historic and fun vacation city of San Antonio, will certainly be memorable. You will definitely, "Remember the Alamo!" There are numerous places to visit in San Antonio that you will read about elsewhere in this newsletter. Most of all, you will love the friendly people, the Hispanic heritage and the unique small town feel of the sixth largest city in the United States.

I really look forward to seeing you in San Antonio.

Sincerely,

*Frank Davis*

Frank Davis, President

## New Board Member, Carina Thurgood



Carina Thurgood is the Founder and CEO of The Maddi Foundation, a UK based charity that focuses on medical research for SPG15. She began this work after her teenage daughter, Maddi, was diagnosed with Hereditary Spastic Paraplegia. Since the beginning, Carina has dedicated her time to learn more about the condition and, with her strong fundraising drive, has been able to help finance relevant research projects; one of which is The Maddi Foundation partnering with SITraN at Sheffield University England. Her insight special fundraising skills will be a welcome addition to the Board. Her application to be a member of SPF's Board of Directors was approved by the Board in their March meeting.

Previously Carina was a successful businesswoman and a commercial florist working in some of London's Top Hotels including the world renowned Claridge's. She lives in Essex, England, some 30 miles North East of London, with her family, 2 daughters Madeleine and Alexandra and husband Paul.

## Connections

### Ottawa, Ontario Connection

*By Julie Ann Samson, SPF Ambassador- Ontario*

On Saturday, April 6th, we had our second get together in Ottawa, Ontario, Canada. We spent a few hours together and did a lot of chatting, and comparing different aspects of our lives and conditions. There were 4 HSPers, 1 PLSer, and 2 spouses. We are planning on getting together again on October 19, 2019 and continuing to do this twice a year.



*Left to right: Brian Green, Kathy Selst, Tara Tucker, Pieter Selst, Jean Brunet, Julie Ann Samson. Photo taken by Allan Ewen.*

### SPFillinois Connection, May 4, 2019

*By Sid Clark, HSP and Hank Chiuppi, PLS,  
Illinois SPF Co-Ambassadors*

Last week the skies were a dark battle ship gray with buckets and buckets of rain. Next week we are forecast to have storms and more soaking rains. On Saturday, May 4, we had our 20th SPFillinois connection under beautiful bright blue skies!!

With 25 attendees, we went around the room and discussed a wide range of items. including how long it takes to make a diagnosis of HSP/PLS and how unsure

it is. Many had examples of different doctors at many locations giving various conclusions at different times. Specific adaptive equipment recommendations were made for canes, ramps, lifts, and power chairs. Also discussed was the need to know how to use them safely and if you don't, how you can hurt yourself or do damage to the house. There was discussion of high cost of drugs. One person had found a high cost of one drug, Neudexta, could be reduced by a local pharmacy compounding it from two less expensive component drugs. We also discussed the need for jobs and opportunities that HSPers/PLSers can apply for and do. Exercise for the tongue were also demonstrated to help with PLS speech problems. An overall agreement was that laughter yoga was helpful. Do a hearty laugh at something everyday.

Pembe Hande Ozdinler, Ph.D., Neuroresearcher from Northwestern, explained what her lab is working on: the open source genetic lines they had developed; how the central cortex is involved with our diseases, communication within the cells and mitochondria; the findings and growth of knowledge is exponential. However, stem cells' health benefits, touted by some medical applications, have unclear definitions. She said not to believe all you read or hear. She also touched on the ethics of gene editing.

After the meeting, there was time for socializing. One person's daughter married recently and she brought a picture book of the beautiful wedding. Another ran and completed a 5K giant inflatable race.

Thanks to the many that brought treats to share.

*Continued on Page 18*

## Synapse Survey Results

By John Staehle, Senior Editor, *Synapse*

First of all, I want to thank all of you who took a few minutes in January to complete the *Synapse* Survey we conducted. Your responses will help us improve the quality and the content of future issues of *Synapse*. There were many excellent comments that we will use to guide our efforts to give you, the readers, a newsletter you will want to read cover to cover.

Earlier this year a survey was sent by email to more than 2,400 people on the SPF roster who identified with HSP or PLS. We received 147 responses, mostly within 3 days of the survey's distribution. Some of the significant results were:

- 24% of those that receive printed copies of *Synapse* also read it online;
- 68% would like *Synapse* to be published quarterly;
- The top 4 most-liked types of articles are Medical & Research, Features, General Interest and Personal Triumphs;
- 58% would be willing to pay an annual subscription fee for 4 mailed issues per year;
- Nearly 1/3 of responders read back issues of *Synapse*.

There were also other comments related to the availability of the newsletter. Here are instructions for accessing *Synapse* on the website, for removing your name from the mailing list and for adding your name to the mailing list.

- **To Access the Online Version of *Synapse*:** Go to the SPF website, [www.sp-foundation.org](http://www.sp-foundation.org) and click on the SYNAPSE NEWSLETTER link on the top banner. Alternately, you may type the following in your browser, <https://sp-foundation.org/news-resources/newsletter.html>.
- **To Remove Your Name from the Printed Copy Mailing List:** Go to the SPF website, [www.sp-foundation.org](http://www.sp-foundation.org) and click on the JOIN US link on the top banner. On the Join/Subscribe page, complete the required fields (marked with an \*) even if you are a current member and then select “*Synapse* (online version)” only. This will alert the SPF database manager to remove your name from the *Synapse* mailing list. Alternately, you may type the following in your browser, <https://sp-foundation.org/news-resources/stay-informed.html> to get to the Join/Subscribe page.
- **To Add Your Name to the Printed Copy Mailing List:** Go to the SPF website, [www.sp-foundation.org](http://www.sp-foundation.org) and click on the JOIN US link on the top banner. On the Join/Subscribe page, complete the required fields (marked with an \*) even if you are a current

member and select “*Synapse* (printed copy)” only. This will alert the SPF database manager to add your name to the *Synapse* mailing list. Alternately, you may type the following in your browser, <https://sp-foundation.org/news-resources/stay-informed.html> to get to the Join/Subscribe page.

There were several suggestions to have more articles about coping with the most common symptoms and/or complications associated with HSP or PLS. The best sources for these articles are you, the people who have experienced the impact these symptoms/complications have on their daily living and overall lifestyles. Sometimes these are very personal and there is a reluctance to discuss your “personal problems” in a newsletter like *Synapse*, but if you have solved one of these problems, sharing your solution with others who have HSP or PLS may resolve a troublesome condition that has affected their quality of life. If you wish to remain anonymous, specify that when you submit your article to me and your name will not be used in the newsletter article.

There were a few comments regarding the high-quality paper used for printed copies and the possible subscription fee for a printed and mailed quarterly newsletter, IF AND ONLY IF a subscription fee is established. The Winter 2017 issue was the first to have nearly all pictures and graphics printed in color. High-quality paper insures the color pictures are printed with no bleeding across color boundaries. The weight of the high-quality paper stands up to the rigors of bulk mail handling better than lighter-weight paper. As for the subscription fee, there is none right now. It's an option being explored to offset the cost of printing and mailing each issue. In 2017 and 2018 we printed a total of 6 issues at an average cost of \$3.11 per copy, including postage, mailing services and the donation envelopes stuffed in each copy. This cost/copy does not include the graphic artist's time to prepare the issues and get them ready for production, a cost the publisher generously donates. Subscription fees will be set to recover only our actual *Synapse* cost/copy and that will depend on the total costs and the number of copies printed and mailed.

Many of the questions and comments submitted by you may be answered by logging on to the SPF's website, [www.sp-foundation.org](http://www.sp-foundation.org) and clicking on “Resources.” There you will find a multitude of information about: current studies seeking participants; directories of doctors and SPF state ambassadors; government aid programs; helpful links to employment resources, genetic testing, travel and relationships; HSP & PLS forums; patient organizations for other neurological conditions; self-help guides; the *Synapse* newsletter archive; and the SPF Patients Insight Network.

# Fundraisers



## California Virtual Walk 'n Roll-athon

**Date:** Saturday, Oct. 5, 2019 11am-4pm

**Location:** St. James' Episcopal Church,

37051 Cabrillo Drive, Fremont, CA 94536

(corner of Cabrillo & Thornton)

**Registration:** \$15 (covers lunch)

**Contact:** Linda Gentner, (510) 651-5676


**E-mail:** lindagentner83@gmail.com

This is a virtual Walk 'n Roll-athon. Start getting your sponsors now (or donations) to support our effort. If interested, you can tour the 150+ year-old "Little Church" that is on campus (a very short distance). Bring your family and friends.

This will be the 18th year that we have met and re-connected. Our prior connections met for a weekend starting with Friday night dinner at a hotel. Out-of-towners stayed overnight. Saturday, we met for a real TeamWalk followed by a lunch and raffle for participants, friends and family. After so many years, we shortened our Connection to one-day event with lunch and our annual "Share and Compare" discussion. At this time, we form a circle and share and compare how we have progressed, or not, over the last year and offer tips to cope or just share our PLS or HSP stories. We also have a raffle and we ask participants to bring an item or two to raffle off – this is our annual fundraiser. Our theme is still "TEAMWALK for Our Cures" but now it's a "Virtual Walk."

IF YOU CAN'T JOIN US, PLEASE CONSIDER DONATING at [sp-foundation.org](http://sp-foundation.org) and stipulate CATW in the "honor of" space.

"If you can't figure out your purpose, figure out your passion. For your passion will lead you right into your purpose."

 BISHOP T.D. JAKES

## Potato Pants

### Helping to Fund HSP/PLS Research

Now is the time. As James Brown said, *Get Up Offa That Thing* (go ahead...look it up on YouTube...I dare you not to move!). For the 3<sup>rd</sup> year in a row, *Potato Pants* have made their presence known at the *Vienna Sports World* (VSW), the official sports fair of the *Vienna City Marathon* (VCM). Thanks to the hard work of 4 of my students and 15 helpers to organize and construct a professional looking display, they were able to speak to thousands of people, sell t-shirts, make potato stamps with kids and solicit donations



to fund HSP and PLS research in Europe. We not only had a stand at the VSW, the students also organized a group of 55 volunteers that helped at the Vienna City Marathon, April 7<sup>th</sup>, by serving runners energy drinks, water and small treats at the refreshment stations along the route. This year, we raised a total of €3,068 (\$3,486 US).



The concept of Potato Pants was developed in 2014. It demonstrates to able-bodied persons, with little or no knowledge of HSP or PLS, what walking is like with these two diseases. Since then, Potato Pants has helped raise over €31,000 (more than \$35,000 US) because it has been done in Italy, Scotland, England, the United States and Austria. It is a call to action for people to get busy and raise the money that will fund the research to find a cure. It doesn't matter where the research is performed as the development of better treatments and even cures for these rare diseases will benefit HSPers and PLSers world-wide.

Please go to our website to learn more about *Potato Pants* and what you can do to get active in order to help fund research to find a cure. [www.bit.ly/potatopantsonline](http://www.bit.ly/potatopantsonline)

*Submitted by Lori Renna Linton, HSP. Lori is from New York and has lived in Austria with her 2 children for 17 years where she teaches English to "fantastic students in grades 5 through 12." She was a featured presenter at the 2016 Annual Conference in Chicago and then spoke at one of the break-out sessions at the 2017 Annual Conference in Atlanta. Both times her subject was Potato Pants.*

# 2019 SPF Annual Conference

Registration Open



SAN ANTONIO

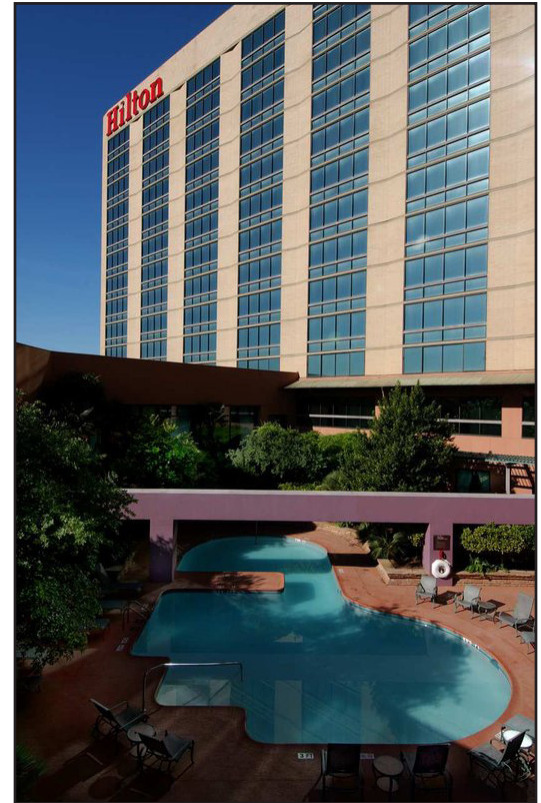
T E X A S

## Spastic Paraplegia Foundation Annual Conference

June 21-22, 2019

Learn More At

[SP-Foundation.org](http://SP-Foundation.org)



Hilton San Antonio Airport  
611 Northwest Loop 410  
San Antonio, TX 78216  
(210) 340-6060

### KRIS BROCCINI



Kris was diagnosed with PLS at UCSF in June 2003. After looking up PLS on the internet, she found the SPF and made plans to attend the Lexington, MA, Conference and TeamWalk in late September 2003 where she and her family were welcomed

with open arms. Questions were answered, stories were compared and a whole new world to think about was discovered. Frightening but informative. She thinks everyone needs to attend that first conference. Kris served on the SPF Board of Directors from 2007 to 2016. Her personal support of the SPF Annual Conference for the past 9 Conferences is the result of remembering how she felt when she first found the SPF community.



Each patient with a rare disease is a patient who needs to be heard and who deserves to be treated. And that is why Saol Therapeutics exists. We bring therapies for these serious and often life-threatening conditions to market and to the life of the patient who desperately needs it. Addressing the needs of patients with rare diseases and under-served neurological conditions are our passion and focus at Saol. Supporting patients with high un-met needs by offering promising treatment options is what drives us.

# 18<sup>th</sup> SPF Annual Conference

## THURSDAY, JUNE 20

Note: As of 4/29/19 and Subject to Change.

4:00PM - 6:00PM REGISTRATION DESK OPEN

## FRIDAY, JUNE 21

Note: As of 4/29/19 and Subject to Change.

7:30AM - 3:00PM REGISTRATION DESK OPEN

- 7:00AM - 8:00AM BREAKFAST (Served)
- 8:30AM Welcome and Introductions  
*Frank Davis, SPF President, and Tim Croghan, Conference Emcee*
- 9:00AM Work of the Foundation  
*Greg Pruitt, Esq., Co-Exec. Director*  
SPF Scientific Research Grant Process  
*Mark Weber, Esq.*  
Ambassador's Program & Recognition  
*Tina Croghan*
- 10:30AM Breakout Sessions:  
Men only  
Women only  
Children only
- 12:00PM LUNCH (Served, No Speaker)
- 1:00PM HSP Research Foundation Inc.,  
Australia  
*Frank McKeowen, President*
- 2:00PM Using mice to understand the cause of  
Hereditary Spastic Paraplegia and  
develop new treatments  
*Peter Bass, Ph.D.*
- 3:00PM Enjoy your evening in San Antonio!  
On Your Own: Tour the iconic San  
Antonio Riverwalk; Visit the Alamo  
(Closes at 7:pm); and dine at any one of  
the many San Antonio restaurants.  
Transportation and admissions on your  
own.

## SATURDAY, JUNE 22

Note: As of 4/29/19 and Subject to Change.

7:30AM - 3:00PM REGISTRATION DESK OPEN

- 7:00AM - 8:00AM BREAKFAST (Served)
- 8:00AM Welcome Back  
*Frank Davis, SPF President, and Tim Croghan, Conference Emcee*
- 8:15AM Research Advances in the HSPs  
*Craig Blackstone, M.D., Ph.D.*
- 9:15AM 1) PLS-specific functional rating scale,  
PLSFRS, and  
2) A report from the May International  
PLS Conference in Philadelphia  
*Hiroshi Mitsumoto, M.D, DSc*
- 10:15AM Summary and Updates on Gene  
Therapy  
*Corey Braastad, Ph.D.*
- 11:15AM Breakout States by Region  
Look for the USA map in your Welcome  
Bag and sit in your regional area.
- 12:00PM LUNCH (Served)  
Special Presentation
- 1:15PM HSP and PLS, Open Forum  
Discussion, Q & A  
*John K. Fink, M.D., SPF Medical  
Advisor*
- 3:00PM Social Mingle - Hotel Cash Bar  
Enjoy your evening in San Antonio!  
On Your Own: Tour the iconic San  
Antonio Riverwalk; Visit the Alamo  
(Closes at 7:pm); and dine at any one of  
the many San Antonio restaurants.  
Transportation and admissions on your  
own.
- 4:00PM Reception for Doctors, Donors, and  
to Sponsors  
5:00PM



## 18<sup>th</sup> Annual Conference Presenters



**Peter Baas, Ph.D.**, is a professor in the Department of Neurobiology & Anatomy at Drexel University College of Medicine. He is also director of the graduate program in neuroscience and an NIH-funded postdoctoral training program in the neurosciences. Dr. Baas is interested in all aspects of the neuronal cytoskeleton, with a particular emphasis on the regulation of microtubules in developing neurons. In recent years, his interests have expanded to include the underlying mechanisms by which flaws in microtubule-related proteins contribute to neurodegenerative diseases. Baas is frequently invited to present his work at national and international symposia, and has been consistently funded for three decades by federal agencies (NIH, NSF, DOD) as well as private foundations with missions related to treating neurodegenerative diseases and nerve injury.



**Craig Blackstone, M.D., Ph.D.**, is Senior Investigator and Cell Biology Section Chief within the NINDS Neurogenetics Branch and Director of the NIH MD-PhD Partnership Training Program. He received B.S./M.S. degrees from the University of Chicago (1987) and M.D./Ph.D. degrees from Johns Hopkins (1994). After a neurology residency in the Harvard-Longwood Neurology Program, Dr. Blackstone pursued clinical fellowship training in movement disorders at Massachusetts General Hospital and postdoctoral research training in neurobiology with Dr. Morgan Sheng at Harvard Medical School and Howard Hughes Medical Institute. In 2001, Dr. Blackstone joined the NINDS, where his group investigates the cellular and molecular mechanisms underlying the hereditary spastic paraplegias. He is an elected member of the American Society for Clinical Investigation (ASCI) and an elected Fellow and past Vice President of the American Neurological Association (ANA). He has held numerous other leadership positions in the ANA, including on its Executive Council and Professional Development Committee, and as Director of its Translational and Clinical Research Course and Chair of its Web Governance Committee. He currently serves on the editorial boards of the Journal of Clinical Investigation and the Journal of Neuromuscular Diseases. He received the NIH Director's Ruth L. Kirschstein Mentoring Award in 2012.

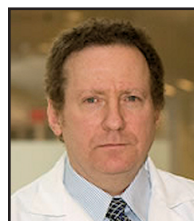
**Corey Braastad, Ph.D.**, is the Vice President and General Manager of Genomics at Covance Drug Discovery, part of LabCorp. Dr. Braastad has completed training, performed research, and developed programs in clinical trials, pharma research support and clinical genetic diagnostic products.



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



**Tina Croghan** 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 was a member of the conference planning committee for the 2017 conference in Atlanta and is again part of the 2018 planning committee for the Annual Conference in Pittsburgh. 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, M.D.**, 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

*Continued on next page*

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.



**Frank McKeowen** is the President of the HSP Research Foundation, Inc. in Australia, a position he has held for 9½ years. The HSP Research Foundation is an incorporated, registered Australian charity that facilitates and funds research to find a cure for Hereditary Spastic

Paraplegia - an inherited, degenerative disease affecting mainly the legs, causing muscle weakness, spasticity and severely impaired walking. It is also the community hub for about 1,700 HSPers in Australia, creating awareness and providing support and education. The role of the Foundation involves close working relationships with researchers and clinicians and support of the financial and management demands of sponsored research, while maintaining an informed and motivated HSP community from whom most of the funding comes. Global partnerships and collaboration with researchers and other spastic paraplegia support groups is also an important strategic element. For more information on the HSP Research Foundation, visit its website at <http://www.hspersunite.org.au/>.



**Hiroshi Mitsumoto, MD, DSc** is a Wesley J. Howe Professor of Neurology at Columbia University Medical Center and the Director of the MDA/ALS Clinical Research Center since 1999. In 1968, he graduated from Toho University School of Medicine,

Tokyo. Beginning in 1972, he pursued further medical and neurology training at Johns Hopkins University, Case Western Reserve University, Cleveland Clinic, and Tufts University. In 1983, he began working at the Cleveland Clinic as the Director of the Neuromuscular Section and ALS Center. He has since been involved with extensive research in ALS, including improving patient care/management and end of life issues, multiple clinical trials, biomarker development, and multisite epidemiological studies. He organized several large national and international ALS Conferences and is currently updating and developing the new International ALS Clinical Trial Guidelines. He has published more than 170 articles in peer-reviewed journals, mostly in ALS, in addition to reviews, chapters, and books. For more than a decade, his research interests have expanded to PLS.

**Greg Pruitt, Esq.**, SPF Co-Executive Director, served 26 years as Judge Executive, administering all facets of county government in his home county. While functioning in this capacity, he served on and chaired a number of



local, regional, state, federal, and multi-state organizations involving many areas such as tourism, health and social services, transportation, and economic development. He has been dealing with adult onset HSP since 2002. About a dozen members of his family over the past three generations have dealt with HSP.

Greg holds a Bachelor's Degree in Political Science and Business Administration from Murray State University and a Juris Doctorate Degree from the University of Kentucky. He lives in Mayfield, Kentucky, with his wife, Norma, who also serves as SPF Co-Executive Director. They have three children and five beautiful grandchildren.



**Mark Weber, Esq.**, 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 is an attorney and served for eleven years as a prosecutor in Massachusetts. He is currently 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, and has a son in college.

## Conference Leaders



**Frank Davis, SPF President**, [frank.davis@sp-foundation.org](mailto:frank.davis@sp-foundation.org), Frank was President of Pittman and Davis, a direct marketing catalog company specializing in the sale of gift packages of fresh fruit and other perishable gift food items before his retirement. From 2005 to

2011, Frank served as secretary for the Board of Directors. He was elected president in January of 2012. He holds a bachelor's degree in both business administration and sociology from Trinity University and a master's degree from Southern Methodist University. Frank has HSP and lives in Harlingen, Texas.



For the last twelve years, **Tim Croghan** has been a dedicated supporter of the Spastic Paraplegia Foundation. He and his wife, Tina (an SPF Board Member), focus all of their attention on advocating and raising funds to advance the research efforts to find a cure for HSP and PLS.

Tim has continued using his communication skills in assisting with the operation of the SPF Annual Conferences in St. Louis (2009 & 2013), Chicago (2016), Atlanta (2017) and Pittsburgh (2018). Tim will again be the Master of Ceremonies at the 2019 Annual Conference. He is excited about seeing everyone this June in San Antonio.

## Overflow Hotel Information

Thank you for booking your hotel stay early for the 2019 SPF Annual Conference in San Antonio. The conference Hilton Hotel has closed the block of rooms, as they have generously overbooked the block. A new overflow hotel has been secured at the San Antonio Marriott Northwest, 3233 NW Loop 410, San Antonio, TX, 78213-2866, (210) 377-3900, only 3.5 miles from the Hilton. Both hotels will provide shuttle services to and from the Hilton during the conference. Conference special room rates at the Marriott are the same as they are at the Hilton. If you are planning to attend the Annual Conference, please call ASAP to book a room at the San Antonio Marriott Northwest. The link to book rooms using Marriott's website is **Book your group rate for SPF 2019 ANNUAL CONFERENCE**. A friendly reminder, the last opportunity to get a discount on conference registration fees ends on May 31, 2019.



The graphic is a promotional announcement for the 2019 Annual Conference. It features a blue star on the left with the text 'SPF SPASTIC PARAPLEGIA FOUNDATION, INC. Research | Education | Support HEREDITARY SPASTIC PARAPLEGIA PRIMARY LATERAL SCLEROSIS sp-foundation.org'. To the right, the text reads 'Announcing Conference Hotel Sold-Out Overflow Hotel Marriott San Antonio Northwest 210-377-3900 San Antonio, TX 2019 Annual Conference'.

## To Do While in San Antonio

San Antonio is steeped in deep Latino roots, as well as a fusion of many cultures that have shaped the city today. This blending is evident in cuisine, architecture, music, special events, plazas, presidios, museums and missions. With its colorful history, Texas hospitality, cultural diversity, contemporary art and historic architecture, San Antonio is an excellent choice for a getaway. Plan ahead for a wonderful San Antonio experience. Visit the suggested itineraries at this link: <http://tourism.visitsanantonio.com/english/Trip-Ideas-Itineraries/Itineraries>

Before visiting the River Walk, download maps that show the location of ramps, elevators and accessible paths from the City of San Antonio's website. Often the most direct route is street level followed by an elevator. <https://www.sanantonio.gov/DAO/Publications-and-Maps/River-Walk-Maps-and-Accessibility>

## Some Places to Visit:

At the IMAX Theatre, watch a showing of "Alamo – The Price of Freedom". AMC Rivercenter 11 Theatres, located at 849 E. Commerce Street, Suite 800, San Antonio, Texas 78205, (210) 228-0351, <https://www.amctheatres.com/movie-theatres/san-antonio/amc-rivercenter-11-with-alamo-imax>.

Tour the Alamo. Journey to the heart of downtown San Antonio to find the Alamo, the cradle of Texas liberty. Originally a Spanish colonial mission, the Alamo is where 189 Texas defenders held 4,000 Mexican troops at bay for 13 days in their claim for Texas independence. Located at 300 Alamo Plaza, San Antonio, Texas 78205, Peak Season (May 25-Sept. 3) 9a.m.-7p.m. (210) 225-1391, [www.thealamo.org/](http://www.thealamo.org/)

Stroll along San Antonio's famed River Walk. Wheelchair accessible and elevators are located along the River Walk. An urban oasis that winds its way through the city's central business district, offering visitors respite from street-level activity. Meander the paths through quiet, park-like areas that lead to European-style passages with sidewalk cafes, galleries, boutiques and nightclubs amid high-rise hotels. The San Antonio River Walk is 15 miles long including the Downtown, Mission and Museum Reaches.

Cruise on the San Antonio River, or arrange a dinner cruise on the River (arrangements may be made by any restaurant, full-service hotel or caterer). You'll always remember having dinner on the river. River cruises provide the best view of the River Walk and reservations can be made to dine aboard. Choose catering from many great San Antonio restaurants. GO RIO Cruises, 202 E Nueva St., San Antonio, TX 78205, (210) 227-4746, <https://www.goriocruises.com/>

Morgan's Wonderland and Morgan's Inspiration Island! Both ultra-accessible™, non-profit parks in San Antonio, Texas, were designed with special-needs individuals in mind and built for everyone's enjoyment in an atmosphere of inclusion. Named in 2018 to the "World's Greatest Places" list by TIME Magazine. Located at 5223 David Edwards Dr., San Antonio, TX 78233, (210) 495-5888, <https://www.morganswonderland.com/>

## Other Must-See Places Include:

- Visit Main Plaza and San Fernando Cathedral, the oldest continually operating cathedral sanctuary in the United States.
- Lunch and shopping at Market Square, the largest Mexican Market outside of Mexico.
- Tour Mission Trail and enjoy the beautiful Spanish Colonial Missions. The largest is Mission San Jose, known as the "Queen of Texas Missions."
- Visit the San Antonio Zoo, the third largest zoo in the United States.
- Lunch at the San Antonio Botanical Gardens. Then tour the gardens and learn about the native flora and fauna of Texas.
- Visit the Institute of Texan Cultures, HemisFair Park and the Tower of the Americas.
- Enjoy dinner and a live theatre experience at the historic Majestic Theatre or the Empire Theatre.

## General Interest

### Cane or No Cane?

*A Public Service Announcement by Jackie Wellman*

Once you start asking yourself that question, it is probably past the point when you needed a cane. I have been there and now realize that using a cane makes sense. Having a broken ankle or arm is much worse than being seen with a cane.

For years I thought I was fooling everyone I saw. I just figured no one but my close friends and family knew something was wrong. On a visit to my brother's house in Seattle, I realized how stupid I was being. He had a full-length mirror at the end of the hallway. After watching myself walk, I thought, "Who do you think you are fooling?" It was obvious! I walked like I had a few drinks too many.

When I got back to Des Moines, I went to the medical supply store and purchased "it." I drove to a mall across town, where there was no chance of running into anyone I knew, to take it for a "test drive." Lo and behold, nobody stared at me. In fact, I got none of those looks of anger or pity from other folks thinking I was drunk.

### Where Are You?

*By Tina Croghan, Missouri State Ambassador, SPF Board Member*

"I have sent out numerous emails. I receive little to no response." This is a common complaint among State Ambassadors. At times, I doubt myself. Am I being heard? Am I inspirational? Why don't I hear back? Why can't I get more participation?

Having HSP, I know that sometimes it's easier to just stay home where I know where everything is. I know how to maneuver around. I have grab bars where I need them. I can wear comfy clothes—that's easy to access quickly for those urgent bathroom emergencies. The bathroom is close by and it's the right height!

To top it off, I don't drive. I'm dependent on someone else's schedule. They have to lift my rollator out of the car (I'm not strong enough to do it) or they have to put my scooter together. Plus, there needs to be room for Thunder, my service dog!

Well that explains the lack of participation, but it doesn't address the lack of communication. Communication, for someone with HSP or PLS, is a vital avenue to



avoid depression. It could be just a brief post on social media. Share a photo. I'm not asking you to post a picture of your face. Some of us are camera shy. Post something silly—like a picture of your feet.

Drop a line to your State Ambassador—just to say, "Hi." Don't know who your ambassador is? Look here: <https://sp-foundation.org/news-resources/directories/state-ambassadors.html>

Being a former high school teacher, when I retired, I received a gift. One of my former students, whose name I forget now, knew my love for quotes (I have them all over) and gave me a framed quote by Maya Angelou. It reads, "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

I use this quote to remind myself that, when I don't hear back from my email or get participation, I just need to remember that I never know who needs my communication right now.

Now it's your turn!

### KoolKape

Hi friends, I recently attended The Abilities Expo in Toronto, Canada. While there I discovered a new cape



*Donna flanked by John (L.) and Jenny*

called a KoolKape by Koolway Sports. Koolway Sports designs outerwear for people in motion, especially those who use wheelchairs and scooters, enabling them to achieve their maximum level of independence in all aspects of life. The quality of construction and the visibility you have while wearing their products are wonderful! Most of their products are available

in sizes for children and for adults. If you are interested and want to learn more, visit their website at [koolwaysports.com](http://koolwaysports.com). Jenny and John will custom design for you. It's fun to share what works! In motion with all of you, I am Donna Woodhead (I'm not affiliated with Koolway Sports).

## A *Synapse* Archive

By John Staehle, Senior Editor, *Synapse*

When I was compiling the responses to the *Synapse* Survey, I saw there were more people who read old issues of *Synapse* than I had expected. That got me to thinking about how far back we had copies of *Synapse* issues. After all, the Spastic Paraplegia Foundation was incorporated in the State of Massachusetts on January 15, 2002, so there ought to be newsletters that at least go back to 2002. I checked the SPF website and the oldest issue available there was Spring 2014.

I started to track down back issues of *Synapse*, hopefully all the way to 2002. Thanks to Jim Sheorn, Annette Lockwood, and Jim and Thurza Campbell, for keeping CDs, old hard drives and files buried in folders on home computers. With their help, I was able to acquire PDF files of *Synapse* newsletters back to the Autumn 2002 issue. Newsletters from August 2002 through Autumn 2007 were created in Word and had to be converted to PDF files for the archive. Jim Campbell also found one issue each from 2000 and 2001.

Here are some of the facts I discovered along the way:

- [*Synapse* was] “Established in June of 1997 by Joe Alberstadt for people with Primary Lateral Sclerosis, and their loved ones.” [From the September 2000 newsletter header]
- Joe Alberstadt explained why “*Synapse*” was chosen as the name of the newsletter: “*Synapse* means a means of connecting, and in so doing, nourishing the subjects (neurons) that are being connected by the mere fact that there is a synapse (a sort of connecting or communicating) taking place. -- William G. Figueroa, M.D. Relate this to our interactive communication support group, and it’s no wonder the name for our interactive communicating letter is befittingly called SYNAPSE. By interactive discussions, we can help each other. Neglecting to communicate can contribute to our attitudes, incentives, hope and spirits dying. Let’s keep these attributes alive through SYNAPSE. Thank you. Joe Alberstadt” [From the September 2000 newsletter header]
- The early newsletters were printed and mailed monthly to a comparatively small number of recipients.

- The senior editors of *Synapse* were:  
Joe Alberstadt, June 1997 – June 2000 (he preferred the title, “Messenger”)  
Mark Weber, June 2000 – Summer 2002  
Thurza Campbell, August 2002 – Winter 2011  
(None), Spring 2011  
Beth Anne Schulz, Summer 2011 – Spring 2012  
Annette Lockwood, Summer 2012  
Allen Bernard, Fall 2012 – Fall 2013  
John Staehle, Spring 2014 – Present
- The *Synapse* banner on each issue stated “Serving the Primary Lateral Sclerosis Community since 1997” until the Winter 2004 issue when, “Welcoming the SP Foundation since 2003” was added.
- In January 2008, *Synapse* was named the official newsletter of the Spastic Paraplegia Foundation.
- The first issue to be published by Gulf Business Printing in San Antonio was January 2008. They have published every issue of *Synapse* since.

As of this writing, the *Synapse* Newsletter page on the SPF website now has links to issues from January 2008 to the most recent issue, Winter 2019. There are 23 additional issues from Autumn 2000 through Autumn 2007 that will soon be added to the page. I will continue to track down additional copies of back issues, if any still exist. By the time you read this, the Spring 2019 issue will have been added to the Archive.

When the oldest issues have been added, take a look at the stories in those issues and you will see that some are just as relevant today as they were then. Others are just downright interesting!



*Charitable*  
**GIVING**

Please consider making a gift to  
the Spastic Paraplegia Foundation  
in your Will and Financial Plan.

## Surgical Anesthesia in HSP and PLS

By Malin Dollinger, M.D., SPG4

Recent chatroom discussions have uncovered a frequent lack of awareness of special anesthesia requirements in patients with HSP and PLS. This discussion is to set down medical information and comments about anesthesia and to offer references in the anesthesia literature that you can download and give to your anesthesiologist. Anesthesiology is a complex science, not just “putting someone to sleep for a few hours,” and a lot of research has been done and is continuing.

First, a brief classification of types of anesthesia: General anesthesia means you are “sound asleep” and unaware of anything, including what would otherwise be painful such as surgical incisions and cutting. In the “old days” this was a lengthy process, for example using open drop ether (used when I was six years old and underwent surgery). Later, things like sodium pentothal and lately, very effective agents such as Propofol are being used where you both “go to sleep” and “wake up again” in a very short time span. General anesthesia is the form of anesthesia which especially concerns us, not because of the anesthetic agent, but with the muscle relaxants commonly also used. Regional anesthesia will anesthetize only a part of the body, for example a spinal anesthetic for surgery on the legs, e.g. a hernia, local anesthesia for smaller areas, using the same type of anesthetic as the dentist, and other types of regional anesthesia, where larger nerves, e.g. in the chest, are numbed by local injection of anesthetic agents. Then there is “conscious sedation,” also called “twilight sleep,” where you are given intravenous drugs that make you unaware of your surroundings, but you can follow simple directions. It was often used for GI procedures such as colonoscopy, but nowadays Propofol is often used, since it works so fast, so well, and wears off so quickly without major side effects such as nausea and vomiting, both of which are problems with older anesthetics.

This topic became vitally important when people with HSP or PLS were given general anesthesia along with a long-acting muscle relaxant, such as succinylcholine, and unexpectedly became weak and unable to work

their muscles for several days or even a few weeks! Persons with PLS were especially vulnerable in this situation because their condition often includes involvement of the nerves at the base of the brain which control swallowing and breathing, both of which could be affected by the long-acting muscle relaxants. “Life support” might be needed in that situation until the muscle relaxant wears off. Other topics regarding surgery in people with HSP or PLS were offshoots of the above discussion. For example, how to improve leg muscle rigidity and tightness which might interfere with the planned surgery. A Synapse reader told me about receiving Botox injections in her leg muscles, a splendid solution to enable proper surgical positioning without the “tight legs” getting in the way. I once had prostate surgery and they couldn’t hold my legs apart. Finally, a nurse on each side held each leg outwards during the entire operation.

Now here are some details for you, and especially for your anesthesiologist, with some references you can download, print and give to her or him. These “pearls of wisdom” are from scientific/medical articles mostly written by anesthesiologists who deal with such matters every day. That’s the purpose of publishing medical research, so other physicians and their patients have the benefit of new and important advances in medical care. Suppose a doctor discovered a new antibiotic that worked against antibiotic-resistant bacteria. Wouldn’t it be vital, and sometimes life-saving for her to publish that information so we could all benefit? So here we are, about to discover and review what the anesthesiology researchers have to say about giving anesthesia to persons with PLS and HSP.

The following section is intended to be printed and given to your anesthesiologist at least several days before surgery and *not* the night before or the morning of surgery. I’ve quoted exact excerpts from some of the scientific articles and have not tried to edit out or translate the “doctorese.” Your anesthesiologist needs to hear the important message from the anesthesiologist who wrote the article using the correct medical language. These are for your direct benefit, thus better if exactly quoted. Print the following, including the references, for your anesthesiologist.

From the paper authored by J.A. Franco- Hernández, et al. (see reference 3), the use of neuromuscular blockers is complicated in patients with familial spastic paraplegia. Succinylcholine is contraindicated since it may induce hyperkalemia, and there should be caution in the use of non-depolarizing muscle relaxants due to the risk of exaggerated muscle relaxation. The literature sources have not shown whether regional anesthesia exacerbates the neurological symptoms. However, regional anesthesia is not always possible. Therefore, general anesthesia with non-depolarizing neuromuscular blockers would represent a safe alternative - particularly considering that there are drugs offering rapid and safe reversal of muscle block induced by rocuronium and vecuronium. In our two patients we chose general anesthesia because of the duration and complexity of both operations.

Great care is required at extubation in patients with FSP, particularly if neuromuscular blockers were administered during the operation. If possible, long-acting neuromuscular blockers should be avoided, with routine monitoring of neuromuscular relaxation throughout the operation, using a standard peripheral nerve stimulator. A TOF ratio of over 0.9 must be confirmed before awakening, accelerating patient recovery with neostigmine or drugs that selectively bind aminosteroid neuromuscular blockers, such as sugammadex.

Although the anesthetic management differed between the two operations (Total Intravenous anesthesia versus inhalatory anesthesia), agreement existed regarding the choice of muscle relaxant, i.e., rocuronium, due to the possibility of antagonizing its effects with sugammadex. Functional deficiencies being similar to those prior to general anesthesia, subsequent follow-up of both patients revealed no significant worsening of neurological signs.

**Conclusion:** The main interest of our study is that both patients were subjected to general anesthesia, with the use of a specific reversal agent for non-depolarizing neuromuscular block, followed by complete recovery and no worsening of the existing neurological disease.

Thomas, et al reported use of spinal anesthesia, in connection with an obstetric procedure, and spinal anesthesia worked well and normally.

Dizdarevic and Fernandes used a paravertebral nerve block and multimodal [several types] anesthesia for breast cancer surgery in a PLS patient. The

anesthesia was reliable and effective, she had Little or no pain postoperatively, and received no opioid pain medication.

Olmez and Topaloglu reviewed various reported types of anesthesia in HSP patients.

Kunisawa et al used nitrous oxide, oxygen and sevoflurane anesthesia in an HSP patient, and there were no anesthesia problems (article in Japanese)

References discussed:

1. Thomas, I., et al. Spinal Anaesthesia in a Patient with Hereditary Spastic Paraplegia: case report and literature review. International Journal of Obstetric Anesthesia. Vol 15: Issue 3, 254-256, 2006
2. Dizdarevic, A and Fernandes, A. Thoracic Paravertebral Block, Multimodal Analgesia, and Monitored Anesthesia Care for Breast Cancer Surgery in Primary Lateral Sclerosis. Case Report in Anesthesiology. Vol 2016, Article ID 6301358, 4 pages. <http://dx.doi.org/10.1155/2016/6301358>
3. Franco Hernández, J.A., et al. Use of Sugammadex in Strumpell-Lorain disease: a report of two cases. Revista Brasileira de Anestesiologia. Vol.63 No.1 Campinas Jan/Feb 2013
4. Olmez, A. M.D. and Topaloglu, H. M.D., Hereditary Spastic Paraplegia / Anesthesia Post 11.01.2012  
[http://www.medmerits.com/index.php/article/hereditary\\_spastic\\_paraplegia/P13](http://www.medmerits.com/index.php/article/hereditary_spastic_paraplegia/P13)
5. Kunisawa, T., et al. Anesthetic Management of a patient with Hereditary Spastic Paraplegia. Masui 2002;51:64-66.

Your anesthesia may be local, regional, or general, but in any event, a knowledgeable and expert anesthesiologist can create the same low risk of anesthesia as in people without HSP or PLS. Examples have been given, and especially important is the avoidance of the use of long-acting neuromuscular blockers, such as succinylcholine. There are other special measures for HSP and PLS patients, such as ways to “line up” crooked broken bones so they will heal properly using traction and Botox injections for a leg or arm fracture or using local Botox injections where a part of the body needs the spasticity reduced for the surgery.

*Continued on next page*

I suggest you copy this entire article to give to your anesthesiologist [or surgeon for transfer to your anesthesiologist] at least several days prior to your surgery. Of course, you will undergo the usual preoperative screening for everyone undertaking surgery, including checking for heart or lung disease, blood clotting abnormalities or any other medical issues that need to be known and dealt with to make the contemplated surgery as safe as possible.

## Why Getting A Gene Test Is So Important

*By Frank Davis, SPG4, President, Spastic Paraplegia Foundation*

If your family is anything like mine, you have all sorts of family traditions that are just part of who you are. HSP is a family disorder and so is often part of certain family traditions. One of those unfortunate traditions is the belief that, “HSP is just part of our family; it will never be cured; it is too expensive to find out what gene I have and there isn’t anything we can do about it”. Let me tell you, friend, that our Foundation and modern science is certainly kicking that tradition right out the window! We need your help to continue to do so!

Scientists and genetic companies, both large and small, using such new genetic technologies as CRISPR are popping up all over the world almost every day. They are coming to me and our Board of Directors to consider whether or not to apply their efforts and delve into actually curing HSP. They are currently curing many genetic blindness diseases and making strong efforts in the cure of Duchenne muscular dystrophy and other rare genetic diseases.

They ask us how many people in the US have each gene and how many we can contact. They don’t want to put the expense and effort into trying to cure a gene when there aren’t enough people with that gene for them to work with. For instance, SPG4 is the most common HSP gene. Scientists estimate that there are over 10,000 people in the United States with SPG4 HSP. In our data base, we only have 167 people in the U.S. with SPG4 HSP. However, there are over 2,600 people in our data base with HSP that don’t know what specific HSP gene they have. Finding out our genes can open huge doors for all of us. We need to be able

to contact more people with all HSP genes for these genetic companies to decide which HSP gene is the next rare genetic disease they want to cure.

We are currently making a big effort to reach out to neurologists nation-wide to ask them to please inform their patients with HSP and PLS about the Spastic Paraplegia Foundation. I encourage you to advise your family members who are not current members of SPF to please enter their contact information on our website. Since all family members with HSP are going to have the same HSP gene, sometimes they can get together and split the cost for one of the members to get their gene tested. Then other members of the same family who don’t know yet whether or not they have HSP can get tested for that one same gene for about \$100.00. You can’t beat that!

The cost of finding out what gene you have is coming down all the time. Right now, there are different gene tests that target different groups of genes at different costs, but it shouldn’t cost you more than \$1,200. Probably a lot less. If you participate in the CReATe project, with sites throughout the U.S., you will get your gene determined for free. Contact information for different gene testing companies and the CReATe project is on our website [www.sp-foundation.org](http://www.sp-foundation.org) [see the Editor’s Note below]. When you find out your gene or if you know it already and haven’t told us, please go to our website and enter your contact information and gene by clicking on the picture of the linked hands on the first page. Remember: Alone you are rare, together we are STRONG!

*[Editor’s Note: There are resources available on the SPF website to help you select a company to perform your genetic testing. On the SPF home page, select Resources, then Helpful Employment, Genetic Testing, Travel and Relationship Links, and Genetic Testing Links. There you will find links to several sources for genetic testing and an Excel file that compares what the various genetic testing companies offer and the cost of each test. I recommend you contact those companies for their current testing costs as test costs continue to decline. To access information on the CReATe project, click on Resources and select Current Studies Seeking Participants.]*



## Living with HSP / PLS

### Travel Turmoil

Compiled by Malin Dollinger, M.D., SPG4

This installment of Travel Turmoil recounts the troublesome travel experiences of Carol Barta and her husband, Randy, and those of Bob Gustafson. They also offer solutions to what otherwise might have discouraged future travels.

Carol was thought to have PLS at first, but then found she had “Stiff Person Syndrome” that was affecting her lower body. It is also an upper motor neuron disease with many similar symptoms as HSP and PLS. Consequently, the solutions she presents are likely to be applicable to the rest of us. Here is her story.

“**One of our first flights with my wheelchair.** I had gotten by with my walker and all was well. But now the disease/anxiety/stress has gotten worse so I use a wheelchair 99% of the time when I am in public places. I cannot walk if I think someone is watching me. My left leg doesn't bend at the knee and if I get really stressed, both legs are straight. We took a trip with Southwest Airlines. Before we left, I ordered two really nice canvas bags that have drawstrings for closing the open end. Then I bought a handicapped sign stencil and some blue paint. I painted the sign on **both** sides of each of the bags and used them to check my wheelchair and walker at check-in. I transferred to one of the airline's wheelchairs while at the airport.



“When we arrived at our destination, the bags were on the baggage claim conveyor belt and not at the oversized baggage claim area as they were supposed to be. My husband took the scratched

and dirty canvas bag off the wheelchair and...Oh my...it was badly bent and mangled. Thank goodness my walker was okay since I cannot replace it with the exact same one any longer. Southwest was **very helpful**. The lady apologized and started filing a claim. She said I could use their loaner chair for the week we were going to be there and they would send mine to

see if it was repairable or if they had to replace it. We both knew replacement was needed, but we were quite nice and agreed with her. I told her to not worry just so I would get a replacement similar to the one that was damaged. A mobility company they work with sent me photos of three options from which I could choose a replacement chair. We live in Texas where a plastic seat wouldn't work, so we chose a chair with a nylon seat. We had them ship it to my parents' house (near our home) and we would pick it up from them. We got there and all was well. What we learned is **DO NOT** check your personal wheelchair at check-in, **GATE CHECK IT** instead. That way it will be waiting at the gate and should be in better condition.

“**Cruise Lines.** We have taken a couple cruises and, in each case, the crew was wonderful to someone in a wheelchair. It's the tourists on board that can be rude. One time I got out of my chair and, with the help of a friend, struggled up one flight of stairs while my husband carried my wheelchair. People watched me struggle and just kept on going without even asking if we needed help. The cruise line personnel (we always cruise Princess ships) are always very, very nice and helpful. The nice thing about a cruise is you only unpack once and then travel from location to location for sightseeing day trips. It's really great! You do have to book early if you need an accessible room - they have a limited number on the ship.

“I have found everyone is very nice and helpful if you don't create a problem. I understand I could ask for special treatment, but I don't. I just explain I can't walk or stand without holding onto grab bars and have not had any problems so far. This summer will be interesting as there are 8 of us going to Ireland. This will be my first time for an overseas flight but we have an aide going with us as well as two other couples and another lady that can help my husband.

“I did purchase a wheelchair seat belt for the cobblestone roads and hilly areas we will be visiting. I don't want to fall out of the wheelchair if we hit a bump!

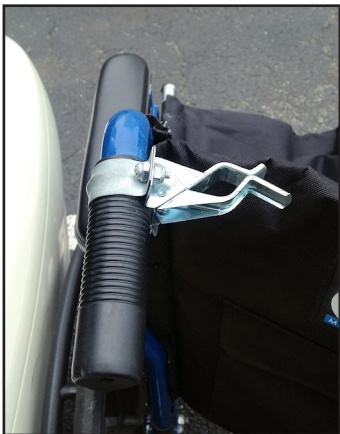
“Traveling is stressful enough and I try to make it as easy as I can on my husband and travel group (if we have one). Being nice and thanking people really goes a long way, even though some of the people really

*Continued on next page*

should be pushed aside and moved, but we don't worry about the small things."

Bob Gustafson is our other contributor. He lives in New York and describes his travel experiences going to California.

"I walk very slowly using Lofstrand crutches and for distances greater than 300 feet, I use a manual wheelchair. Transporting a wheelchair is more trouble than it is worth. So, with the ingenuity of someone at 101 Mobility, we invented a piece of hardware that can be attached to wheelchair handles into which I can insert the crutches. [Bob later told me all the parts needed to make the brackets were acquired from a local hardware store. Editor]



*Custom Bracket on Wheelchair Handle*



*Crutch Inserted in Bracket*

"So, when we went to California last summer, I removed the hardware from my wheelchair here in New York and took it with me. I traveled using nothing more than my canes and the airline wheelchairs made available to me at the airports. After I arrived at the hotel in Oakland, I rented a car from Enterprise because they pick you up where you are staying. I had pre-ordered a car with hand controls and drove to a place where I could rent a wheelchair. I attached the hardware to the handles of the wheelchair and I was off!

"The glitch was returning the car and getting on the return flight. I first returned the wheelchair to the place where I had rented it. I returned the car at the airport because the return flight to New York was a redeye, which meant that I had to take a bus from the car rental area to the terminal. The bus doesn't take passengers to the terminal. Instead passengers must cross an eight-lane road to get from the bus stop to the terminal. Well, cars just had to wait for me as I crossed the last three lanes while the traffic had a green light. Then there was the saga of wheelchairs at the airport.

Wheelchairs are the responsibility of the airlines and not the airport. I will spare you the details.

"Interestingly, JetBlue had some kind of ADA grievance filed against them which I found out about after I got home. It explained the unexpectedly good service I received once I was in a JetBlue wheelchair. A friend of a friend was aware of this grievance and I gave her a complete rundown of my experience. I pointed out to her that the security procedure was developed on the spur of the moment back in 2001 and hadn't been seriously re-examined since. And there is plenty of room for improvement. The *Synapse* article mentioned a TSA Known Traveler program. I will check that out."

That's it for this issue's Travel Turmoil. Thanks to Carol and Bob for sharing their own unique, important and helpful experiences. If you have examples of your own travel turmoil and how you dealt with them, email them to me at [malind@cox.net](mailto:malind@cox.net) so we can all benefit from your experiences and solutions in the next issue of *Synapse*.

## SPFillinois Connection, May 4, 2019



Starting upper left 1st picture - Keith & Diethard Beyer, Bryan Caspersen; 2nd picture - Hank Chiuppi, Dr. Ozdinler, Sid Clark; 3rd Center picture - Greg & BJ Irwin, Joan Morris, Carol Clark, Sara Karamer, Heidi & Kyle Swanson, Paulette Chiuppi, Mary Levi, Sue Sauer, Dr. Ozdinler, and in the middle Regina Potts; Bottom Right Picture - Steve Beutelspacher, Dr. Ozdinler; and the bottom left picture, left to right Heidi Swanson, Dr Ozdinler, Sara Karamer, Kyle Swanson, Stewart & Teressa Flemming. Not shown: Bob & Marlene Grens; and Mike Levi



# Spastic Paraplegia Foundation Annual Conference

**June 21-22, 2019**

## Join us

### Hotel Registration

#### HILTON SAN ANTONIO AIRPORT

611 N.W. Loop 410, San Antonio, TX 78216, Call 210-340-6060  
Free Self Parking, Complimentary Airport Transportation, and Wifi  
Mention "**SPASTIC PARAPLEGIA**" for discounted room rate of \$109  
The hotel is conveniently located only 2-miles from the San Antonio International Airport (SAT), 8-miles from downtown, and 8-miles from Morgan's Wonderland. Hotel offers a free shuttle service to destinations

### Conference Registration

Pay & Complete Registration Online at [SP-Foundation.org](http://SP-Foundation.org) or  
Make Check Payable: **SP-Foundation** Mail Payment & Registration form to: **SPF, 1605 Goularte Place, Fremont, CA 94539.**

### Registration Fees - No Refunds after May 31st

**\*To receive discount, payment must be received by SPF.**

Adult Early Discount, Must be Paid by April 15, 2019 .....	\$140	QTY: _____	Total \$: _____
Child Early Discount, Must be Paid by April 15, 2019 (under age 18) .....	\$100	QTY: _____	Total \$: _____
Adult Registration April 16th to May 31st, (Must be Paid by May 31, 2019).....	\$200	QTY: _____	Total \$: _____
Child Registration April 16th to May 31st, (Must be Paid by May 31, 2019) .....	\$160	QTY: _____	Total \$: _____
Adult Registration June 1st to Onsite.....	\$250	QTY: _____	Total \$: _____
Child Registration June 1st to Onsite .....	\$210	QTY: _____	Total \$: _____

#### Tentative Agenda

June 20, Thursday—Board of Directors Mtg

#### June 21, Friday

7:30am — Breakfast, plated  
8:30am — Welcome, General & Breakout  
12:00Noon – Lunch, plated  
1:15pm — General & Breakout Sessions  
3:00pm — Network on the Riverwalk  
[thesanantonioriverwalk.com](http://thesanantonioriverwalk.com)  
Dinner (on your own)

#### June 22, Saturday

7:30am — Breakfast, plated  
8:00am — General & Breakout Sessions  
12:00Noon – Lunch, plated  
1:15pm — General Session w/ Dr John Fink  
3:30pm — Network at Morgan's Wonderland  
[morganswonderland.com](http://morganswonderland.com)  
4:00pm — Donor & Sponsor Reception  
Dinner (on your own)

SUNDAY—NO SCHEDULED ACTIVITIES

Remember the Alamo—[thealamo.org](http://thealamo.org)

Enjoy your visit in historic San Antonio—  
[visitsanantonio.com](http://visitsanantonio.com)

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 at conference: (\_\_\_\_\_) \_\_\_\_\_ Text?: Y / N 2nd: Mobile: (\_\_\_\_\_) \_\_\_\_\_ Text?: Y / N

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

Are you driving or flying to the conference? \_\_\_\_\_ What aids are you likely to use a conference? Check all that apply:

Cane \_\_\_\_\_ Crutches \_\_\_\_\_ Walker \_\_\_\_\_ Scooter \_\_\_\_\_ Wheelchair \_\_\_\_\_ Powerchair \_\_\_\_\_ Animal \_\_\_\_\_ Other \_\_\_\_\_

Meal Requirement: Regular \_\_\_\_\_ Vegan \_\_\_\_\_ Vegetarian \_\_\_\_\_ Gluten-Free \_\_\_\_\_ Kosher \_\_\_\_\_

Food Allergies (List): \_\_\_\_\_ Other Allergies : \_\_\_\_\_ Other Comments \_\_\_\_\_

**Register Online & Book Hotel at [SP-Foundation.org](http://SP-Foundation.org)**

Questions, please email us [SPFKentucky@gmail.com](mailto:SPFKentucky@gmail.com)

1605 Goularte Place  
Fremont, CA 94539-7241



The Spastic Paraplegia Foundation has found an opportunity for you to get paid for your opinion and support our foundation at the same time!

Patients must be age 14 and caregivers (friends, family) of any disability, disorder, syndrome disease or condition are provided an opportunity to voice their opinions through surveys and interviews to improve medical products and services.

All you have to do is join the Rare Patient Voice community online and you will receive a \$5 Dunkin' Donuts, Starbucks or CVS gift card. When you do, the Spastic Paraplegia Foundation also receives \$5 for each qualified signup.

**IMPORTANT:** Your information is confidential, and your email address/name is never shared. You may be invited to participate in surveys from time to time, where you will earn cash.

**Type the link below into your browser and sign up today!**

<https://tinyurl.com/y63dhxnj>