

Synapse

Volume 22, Issue 3

Summer 2019

Newsletter of the Spastic Paraplegia Foundation

San Antonio Success!



In This Issue

President's Letter..... 3

San Antonio Annual Conference

- Thank You for Making Our Conference
One of the Best..... 4
- Thanks to Our Conference Sponsors 4
- Summary and Updates on Gene Therapy 5
- An Effective Treatment for HSP..... 6
- Using Mice to Understand HSP and
Develop New Treatments 7
- An Interview with SPF Medical Advisor,
John Fink, M.D. 8
- Three Receive Award at Conference..... 8

General Interest

- The Total Cost of Synapse 9
- 1st Annual Canadian SPF Conference..... 9
- Dictus Bands 10
- Better Walking Aids..... 10
- A Mobility Aid for Maintaining Quality of Life.. 11
- Hard to Slide On & Off Your Driver's Seat? ...11
- I Believe..... 12
- My Journey to A Diagnosis 12

Living with HSP/PLS

- Tina's Tips..... 14
- Incontinence, A Male Perspective..... 14
- Upright and Smiling 15
- I Change My Focus 16
- My 3 Steps to Overcoming HSP 16

Fundraisers

- Punch-a-Thon Fundraiser..... 18
- 2018 Donations from Amazon 18
- California SPF Walk 'n Roll-athon 19

Connections

- West Virginia Connection 19

Other

- QR Code for Ease of Donations! 17
- SPF Earns Gold Seal of Transparency..... 17



Volume 22, Issue 3 - Summer 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

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

The SPF is a non-profit 501(c)3.

Tax ID # 04-3594491

Combined Federal Campaign CFC #12554

Send Correspondence & Donations to:

Spastic Paraplegia Foundation
1605 Goularte Place
Fremont, CA 94539-7241

Contact the SPF at:

(877) 773-4483

information@sp-foundation.org

or www.sp-foundation.org

SPF Board of Directors:

Frank Davis, President

Linda Gentner, Vice President

Jean Chambers, RN, Secretary

David Lewis, Treasurer

Members: Corey Braastad, PhD, Hank Chiuppi,

John Cobb, Tina Croghan, Greg Pruitt, Jim

Sheorn, Carina Thurgood, Mark Weber, Esq.,

Jackie Wellman

SPF Medical Advisor:

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

Disclaimer: The Spastic Paraplegia Foundation does not endorse products, services or manufacturers. Those that are mentioned in Synapse are included for your information. The SPF assumes no liability whatsoever for the use or contents of any product or service mentioned in the newsletter.

Letter from the President



Dear Friends,

“Better to Light a Candle Than Curse the Darkness”, is probably a good proverb for our foundation. I write this letter during a week that began with a blackout on the west side of Manhattan. Though it created plenty of challenges, many New

Yorkers found creative ways to find joy amidst the dying of the light. Some roasted hot dogs over candles, others decided to invite friends over and pop the cork on warming bottles of champagne and the casts of darkened Broadway shows entertained people with impromptu street performances. As the New York Times reported, “It’s a great New York story”, one West Sider said. “You may have a hardship through it, for a minute or two, but people come together.” It was a perfect reminder of how creative and inventive people can be, to come together, connect and make the best of an unexpected challenge.

Well, the New York West Side blackout is a great metaphor to illustrate some of the ways we all have been working together to face the challenges of HSP and PLS. This *Synapse* Newsletter is full of stories of our recent Annual Conference in San Antonio, Texas. Our Board of Directors and our Annual Conference chairperson, Norma Pruitt, did an excellent job of putting together and managing one of our best conferences ever in one of my favorite cities.

I am sorry to say that this was the first conference in 15 years that I actually had to miss. My father died that same week and his funeral was on the same day as our conference. My dad was a great man and a loving person who lived a full and successful life for 95 years. We worked together in a family business for 30 years. He actually went with me to my first HSP conference in the year 2000, right after I had been diagnosed. He did not suffer long.

Recently, many people in our SPF community have been creative and inventive with very successful and most appreciated fundraisers for SPF. Just one example, Vinay DSouza and his family held a nice brunch in New York in July where they asked their friends to make contributions to The Spastic Paraplegia

Foundation in honor of Vinay. I want to personally thank the entire DSouza family and all their friends immensely for their thoughtfulness and generosity.

I also want to thank you for your generosity and thoughtfulness because our fundraising efforts are now over twenty percent ahead of where we were this same time last year. We will be able to make incredible progress with this, but we can’t become complacent. I hope you all will help us maintain this momentum through the end of the year when over half of our annual funds are raised.

I want to close with another metaphor that seems to be beckoning from the sky. As we celebrate the 50th anniversary of the Apollo 11 moon landing this month, I’ve been reflecting on that historic image of Neil Armstrong and Buzz Aldrin planting the American flag on the lunar surface. On a personal level, the other night when I couldn’t sleep after my father’s funeral, I went outside to face a full moon. I was sure that the moon was beckoning me awake and it felt like my father was saying goodbye. I felt a deep spiritual connection, as though the moon was leading me somewhere. I also felt a sense of hope and trust in the path forward for The Spastic Paraplegia Foundation.

There’s a wonderful line in Walt Whitman’s poem “Miracles” that sums it up. He writes of the miracles all around us including, “... the exquisite delicate thin curve of the new moon in spring.” Tonight, I’ll be gazing up at the magnificent full moon, and I invite you to do the same. Like those astronauts did half a century ago, go beyond your comfort zone and dream of the possibilities that lie ahead. Let’s all look to the moon to find that next layer of courage to realize that a cure for HSP and PLS is indeed imaginable and together we can make it happen.

Sincerely,

Frank Davis

Frank Davis, President

2019 SPF Annual Conference

Thank You for Making Our Conference One of the Best

Your attendance was greatly appreciated at the 18th Annual Conference of the Spastic Paraplegia Foundation (SPF). This year almost the entire conference room of people in attendance raised their hands noting they were attending the conference for the first time. This year we had 215 adults and five children register to attend the event in San Antonio, Texas. We continue to see more new faces of people receiving a diagnosis of HSP or PLS or they are just finding out about the existence of the Foundation.

Every day the Foundation and its members are working to grow the awareness of the HSP and PLS rare diseases and, in doing so, we are urging everyone on social media to use the hashtag (#) symbol and typing hsp and pls together as a way to invite more people to learn about the Foundation - #hspandpls. These motor neuron diseases are closely related and together, we must press on to find cures or treatments for both. The conference is not a fundraiser but an outreach effort to connect with patients, families, advocates, researchers and doctors. We need everyone working together.

In the welcome bag this year, we distributed a survey requesting feedback for the event. More people completed the hand-written survey this year than the number of online survey submittals we received last year. Thank you to the forty-five people that completed their surveys providing comments, recommendations, and compliments. Even a thank you goes to the critics, whose comments help us to be more mindful at future events.

Let us please be reminded that we are all-volunteer members working to raise awareness and raise funds to direct toward more medical research. There may be a few travel & conference disappointments, but that too can be helpful to effectuate positive changes in our world of disability. We look forward to seeing you again and making new friends at the 2020 Denver Annual Conference.

Norma Pruitt

SPF Conference Coordinator

Thanks to Our Conference Sponsors



KRIS BROCCINI - The SPF Community would like to express our sincere gratitude and appreciation to you for the generous support and contributions you give to the Spastic Paraplegia Foundation. Thank You!



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 underserved neurological conditions are our passion and focus at Saol. Supporting patients with high unmet needs by offering promising treatment options is what drives us.



INVITAE

**PATIENT INSIGHTS
NETWORK
REGISTRY**

Invitae Corporation (NYSE: NVTX), one of the fastest growing genetic information companies, in collaboration with the Spastic Paraplegia Foundation, by expanding the network of rare and ultra-rare patient registries in its Patient Insights Network™ (PIN) program. Invitae is also working on a new program to allow patients to initiate their own medical genetic test. Invitae is connecting patients with rare genetic disorders to research, clinical trials and information on managing their conditions.



UNIVERSITY OF MIAMI
**MILLER SCHOOL
of MEDICINE**



A big thank you to the Spastic Paraplegia Foundation and all that came to support the CRiALS Biomarker research study of Dr. Michael Benatar and Joanne Wu at the University of Miami at the 18th Annual Conference. Danielle Sheldon and Anne-Laure Grignon collected participant's information as well as a blood samples to further research to identify biomarkers of neurological diseases such as HSP and PLS. A biomarker is an indicator of the disease that can easily be measured. Dr. Benatar's group is interested in markers that might be used to monitor response to treatments that are being examined in clinical trials. They had terrific success and 47 of you chose to participate in this valuable research. The team was extremely thankful for all of your support: science doesn't move without participants like yourself!

Don't forget to join the CReATe Connect Contact Registry (RDCRN.org/CReATeConnect) to get: (1) News about ongoing research studies; (2) A list of clinical centers where you may be able to participate in studies; and (3) Updates about what is being learned from studies.

2019 Presentation Summaries

The written summaries of the presentations by Drs. Pembe Hande Ozdinler, Craig Blackstone and Hiroshi Mitsumoto will be in the Fall issue of Synapse.

Summary and Updates on Gene Therapy

Presented by Corey Braastad, Ph.D., Vice President and General Manager of Genomics at Covance Drug Discovery, part of LabCorp.



Dr. Corey Braastad

The lecture began with a summary of his previously presented material. DNA is the genetic blueprint for every cell in the body, and there are trillions of cells. There are 23 pairs of chromosomes, thus a total of 46 in each cell. The genetic code, four bases, C A T and G, form the well-known DNA helix. Three consecutive bases, a triplet, called a codon, determines which amino acid occurs as the building blocks in the protein chain. Transcription, the first step of DNA-based gene expression (in which a particular segment of DNA is copied onto RNA), is followed by translocation, a process which results in an unusual rearrangement of chromosomes, thus building a protein that has structure and function. With about 23,000 different genes, there are this many different proteins. Various changes in DNA include deletion, inversion, translocation, and changes in a single gene. These gene changes may or may not cause a disease.

Clinical trials of new treatments are conducted in four phases. Phase I relates to safety of the new treatment, and phases II, III, and IV relate to efficacy, for example does the new treatment work, and if so, how does it compare with prior/standard treatments. [For more detail on the four phases of clinical trials, see “Lifecycle of Prescription Drugs” by Jim Sheorn, in the Spring 2018 Synapse, page 18. Ed.] With respect to HSP there have been many abnormal genes discovered, literally an “explosion.” Thirty to forty percent of HSP patients do not have a genetic diagnosis. Dr. Stephan Züchner identified a mutation, UBAP1, which causes HSP.

Dr. Braastad stressed the importance of the SPF leadership and the members, us, in creating the scientific advances. This is our foundation, and it belongs to all

of us. Together, we shape what is needed and should get involved! He commented on Frank McKeown’s notes about the work in Australia by Professor Alan Mackay-Sim on the olfactory stem cell model. He removed cells from the nasal membranes of HSP patients, those cells having the HSP mutation, and was able to repair specific HSP gene defects in these cells. He tested specific drugs that could repair these HSP gene defects. His research showed that tubulin-binding drugs restore acetylated alpha-tubulin and restore peroxisome function. These drugs include Noscapine and EpoD. (Scientific editor’s note: Noscapine has been used in an informal trial, by several dozen people with HSP in this country).

Dr. Peter Bass studied microtubules in mice, and commented that HSP has a series of similar phenotypes. Spastin severs microtubules of nerves. There are knock-out and knock-in mouse models for HSP/ SPG4 research. A knock-out mouse is genetically modified by inactivating or “knocking-out,” an existing gene, thus replacing it with an artificial piece of DNA. A knock-in mouse has had a one-for-one substitution of sequence information in a genetic locus, or the insertion of new genetic information at that locus.

There was an excellent discussion of HSP genetic causes. Dr. Pembe Hande Ozdinler studied the cellular and molecular basis of upper motor neuron vulnerability, itself a biomarker. Dr. Craig Blackstone commented that SPG11 and SPG15 are the most common forms of recessive HSP; they are complex phenotypes.

Dr. Hiroshi Mitsumoto worked on the COSMOS study, collecting data on PLS patients, and a new PLS scale was developed, very important to enable PLS treatments to be compared in different patients. There was a 2nd International PLS Conference in May 2019, a gathering of researchers and clinicians, to share and update research information and advances. They plan to meet every two years. The new PLS activity scale will eliminate the need for control groups and will improve the ability to interpret and to compare response of PLS patients to treatment. There was strong internal consistency between ratings of stage and performance by different researchers.

Continued on next page

Dr. Braastad's lecture concluded with a listing of gene and cell therapies, including antisense oligo (a temporary molecule that fits over the DNA to change its action), CAR-T therapy, especially in cancer, gene replacement, and gene editing, such as CRISPR gene editing. He discussed induced pluripotential stem cells, that are able to form a variety of tissues, just like our "natural" stem cells. Several important themes during the past few years have been directed to the current important question of how to get the genetic payloads to the right place in the body.

The video of Dr. Braastad's complete presentation may be viewed on the SPF website at https://sp-foundation.org/what_we_do/annual-conference-recap.html.

[This presentation summary was prepared by Malin Dollinger, M.D., Synapse Medical & Research Editor.]

An Effective Treatment for HSP ...What will it take?

*Presented by Frank McKeown,
President, HSP Research Foundation, Australia*



Frank McKeown

In 2005, the HSP Research Foundation was established as a registered charity in Australia. Foundation membership grew from the original 28 to its current level of 836, with around 100 of those from 21 countries on 5 continents. It is run by a committee of volunteers.

Ninety-nine cents of every dollar donated to the Foundation goes directly to fund HSP research.

The founder and first president (2005-2009) of the Foundation, Robin Bligh, provided the Foundation's vision and set its direction. He learned that there was no facility in Australia that was capable of gene testing. When donations reached the \$85,000 level, the Foundation awarded a grant to establish an HSP gene testing service in 2007. The research focus remains on the most common form of HSP, SPG4 (mutations of the SPAST gene). Frank followed Robin into the role of President in 2009 and remains in the position.

The Foundation has a dual mission: (1) be the hub for the HSP community providing information, education and support; and (2) facilitate and fund research to find an effective treatment for HSP. Its vision is to find a treatment that is highly effective (people with HSP believe the benefits are worthwhile having in their lives), widely available (globally to people with HSP) and readily affordable (no one with HSP cannot get the treatment due to its cost).

The HSP Research Foundation is not funding research to find a cure for HSP that corrects the genetic abnormalities at the root of the disease. Instead the primary focus is on finding an effective treatment that corrects impaired structures and functions in the neurons. Robin Bligh approached Professor Alan Mackay-Sim of the Griffith Institute for Drug Discovery at Griffith University, Brisbane, the Principal Investigator for the HSP Research Program, and matter-of-factly said to him, "Alan, I want drugs that work. What can you do for me?" At the time, Prof. Mackay-Sim was, and still is, recognized as the global authority on olfactory stem cells. He had been working on using these stem cells derived from nasal tissue to look at schizophrenia, Parkinson's and spinal cord injury. The stem cells are used to characterize the disease, to study it, identify what's impaired and not working properly for the purpose of drug discovery. Prof. Mackay-Sim was chosen as Australian of the Year 2017, Australia's highest national award, in recognition of his work on spinal cord injury.

The remainder of the presentation covers the process and findings of the research studies done using Prof. Mackay-Sim's technique, with two drugs discovered that repair the HSP defects in the neurons. His research showed that tubulin-binding drugs restore acetylated alpha-tubulin and restore peroxisome function. These drugs include Noscaphine and EpoD. Noscaphine is found in many cough medications but is not approved for use in Australia, the U.S and parts of Europe. It will likely require multiple successful clinical trials to gain approval. EpoD is not currently approved as a treatment for any condition. The video of the complete presentation, "An Effective Treatment for HSP" may be viewed on the SPF website at https://sp-foundation.org/what_we_do/annual-conference-recap.html.

[This presentation summary was prepared by John Staehle, Synapse Senior Editor.]

Using Mice to Understand the Cause of Hereditary Spastic Paraplegia and Develop New Treatments

Presented by Peter W. Baas, Ph.D.,
Drexel University College of Medicine, Philadelphia, PA



Dr. Peter Baas

Dr. Baas opened by discussing his background. His training was not as a neurologist, not in diseases but in basic science, basic developmental neurobiology. He's a cell biologist who is interested in cell mechanisms. He is most interested in microtubules. Microtubules are one of the structures that is very vulnerable and relevant to Hereditary

Spastic Paraplegia. He has studied microtubules and neurons for 35 years going all the way back to his graduate studies.

With HSP the main anatomical issue is the degeneration of cortico-spinal tracts in adults. A cortico-spinal tract starts with a neuron cell body in the brain, an upper motor neuron (UMN), that extends its elongated process down the spinal column where it synapses to another neuron. It's the upper motor neuron that principally degenerates in HSP. There generally are no developmental problems, however, sometimes there may be other issues.

Most diseases are defined clinically and not by basic scientists. Clinicians gather all the observed symptoms and then categorize diseases based on their symptoms. Basic scientists, on the other hand, would characterize diseases according to mechanisms rather than symptoms. That's how Dr. Baas got involved with HSP.

There are 93 genes associated with HSP and SPG4 (now known as SPAST) is the most common form of HSP with at least 40% of the known cases. Most of the 93 known genes are autosomal, meaning they come from the parents. Some may be sex-linked meaning they can only be passed on by the female parent or the male parent. They can be dominant, meaning only one gene from either parent causes HSP or recessive, meaning both parents have to pass on the recessive gene to their offspring. SPG4 is autosomal dominant. The focus of his presentation was on SPG4.

Genes encode proteins. SPAST (formerly known as SPG4) encodes the Spastin protein. Around 2002, Spastin was identified as a microtubule severing protein.

Suddenly, HSP was opened up mechanistically in a way it hadn't been before. Microtubules fill the long axon of the neuron cell body and are both structural, allowing the neurons to take on the long processes along the axons, and functional, serving as a "railroad" that allows nutrients, organelles and other items to move up and down the axon. Short microtubules are created when the long microtubules are severed by a protein like Spastin. There is a balance of long and short microtubules that make the axons function properly.

He started studying disease in his lab at Drexel University because, frankly, that was where the money for research was going and he needed to keep his lab going. The more important reason was the promise that one day, by doing all the years of basic research, we would be able to solve the mysteries of disease.

While studying disease he learned about the "loss of function" and the "gain of function" dichotomy. Loss of function occurs when an important protein is faulty, the cell can't do things right because it doesn't get what it needs for it to function properly. When you have one "good" SPAST gene and one "bad" SPAST gene it is called haploinsufficiency because the cell has half what it needs to work properly. Gain of function is much more common than loss of function. Gain of function doesn't mean you recovered a function you had lost; it means the mutant Spastin protein is misfolding and causing unexpected troubles. *[Protein folding is the physical process by which a polypeptide chain folds into its characteristic and functional three-dimensional structure from random coil. Source: Wikipedia.]*

Until a few years ago, the prevalent view of the geneticists and clinicians was haploinsufficiency (loss of function) was the reason there was not enough microtubule severing which made the axons "sick." Dr. Baas challenged that because there were key questions not addressed by that point of view. He theorized gain of function might better explain HSP.

SPAST has two start codons for the spastin protein and produces two forms of the protein. *[A codon is a specific sequence of three consecutive nucleotides that is part of the genetic code and that specifies a particular amino acid in a protein or starts or stops protein synthesis. Source: Merriam Webster.]* The initial start codon produces a long Spastin protein called M1. The second start codon produces a slightly shorter Spastin protein, M87. The M1 protein is prone to misfolding and proteins that misfold accumulate, don't go away and are troublemakers. M87 is the prevalent form of Spastin and is found throughout the body. M1 is detectable only in the spinal cord of adults.

Continued on next page

Experiments with flies and rats that were forced to express human mutant M87 and mutant M1 were performed. In all cases, mutant M87 had little affect and mutant M1 caused all the trouble. But to really test the impact of mutant M87 and M1, he needed a vertebrate model, a mouse model. Previous mouse models were “knock-out” models. One in which one or both of the spastin genes were removed. These were supposed to be the model for a mouse with HSP. There was some gait involvement but it was small, even when both genes were “knocked-out.” Dr. Baas’ research team made a “knock-in” mouse model to see if they could duplicate their prior findings using flies. This model did not remove the mouse’s spastin gene but overlaid a human mutant spastin gene on top of it. At one month old, the mouse walked normally. At three months, it has significant gait problems and some evidence of spasticity. They had created a mouse with adult onset gait deficiencies like the human patient. They made the mouse to test the gain of function hypothesis, which it did fairly well.

He is currently working on a cross between a knock-out mouse and a knock-in mouse. They want to show that both haploinsufficiency and mutant spastin proteins create the best model of HSP-SPG4. The knock-out mouse with haploinsufficiency will have a mutant human spastin protein laid on top. They have a couple of mice that are exhibiting symptoms consistent with SPG4 but it is very early in the investigation to draw any conclusions.

Dr. Baas corroborated a statement made by Frank McKeown in his presentation, that an “effective treatment corrects impaired structures and functions in the neurons.” Many millions of dollars have been spent on the development of drug therapies that don’t work because the wrong mechanism was targeted for treatment.

Lessons learned are: (1) Know your mechanism; (2) Basic science is the key to real answers; (3) Therapy requires the right tool to fix the problem; and (4) A good animal model is needed to test therapies.

The video of the complete presentation, “Using Mice to Understand the Cause of Hereditary Spastic Paraplegia and Develop New Treatments,” may be viewed on the SPF website at https://sp-foundation.org/what_we_do/annual-conference-recap.html.

[This presentation summary was prepared by John Staehle, Synapse Senior Editor.]

An Interview with John K. Fink, M.D.

SPF Medical Advisor, John K. Fink, M.D., Director of the Neurogenetic Disorders Clinic at the University of Michigan, Ann Arbor, was interviewed by Greg Pruitt, SPF Board Member and SPF Co-Executive Director. A 42-minute video of the interview is available for viewing on the SPF website, https://sp-foundation.org/what_we_do/annual-conference-recap.html.

Three Receive Award at Conference

The Spastic Paraplegia Foundation, Inc., Board of Directors recognized Dr. John K. Fink, Corey Braastad, Ph.D., and Ms. Kris Brocchini for their commitment and service to the Foundation as part of its annual conference in San Antonio, Texas, June 20-22.

Dr. Fink has been the Foundation's medical advisor since before its incorporation in 2002. Corey Braastad, who is involved in the ongoing research important to the Foundation, has served on the board since 2009 and is an annual presenter at each annual conference. Kris Brocchini is a former member of the board of directors who continues to contribute significantly on an annual basis to the success of the Foundation and its annual conference.

"The past contributions in so many different ways of these three, their current commitment to the vision of the Foundation, and our hope that they continue this important work with us into the future gives our board great incentive and reason to express to them our deepest appreciation," stated Greg Pruitt, SPF Board Member and Co-Executive Director, who made the presentations on behalf of the board.



Dr. Corey Braastad



Dr. John K. Fink



Ms. Kris Brocchini

General Interest

The Total Cost of Synapse

By John Staehle, Senior Editor, Synapse

I originally wrote an article for the Fall 2018 issue about the total cost to print and mail *Synapse* to those members that requested printed copies of SPF's newsletter. We've made some progress in our efforts to reduce those costs. We added a Summer issue this year and will control the size of each issue to 20 pages. We previously published three issues per year of varying size. The most recent three issues with varying page lengths totaled 80 pages of print, so you will get the same amount of print with four 20-page issues.

Postage and printing costs are a function of the number of copies mailed and the number printed respectively. Our printed subscription mailing list during the past year has been reduced to 1335 and we are continuing our efforts to reduce it more. Total postage and mail service costs have been reduced more than 27% and printing costs have dropped by more than 26%. Each 20-page issue that we mail costs about \$3.30 per copy. *Synapse* authors and editors are all volunteers and the publisher doesn't charge SPF for their graphic services.

We're asking all recipients of printed copies of *Synapse* to send a \$15 donation to SPF to cover the publishing and mailing costs for the four issues sent to them each year. A donation envelope is included with this issue. Please use it to send your donation to SPF and write "Synapse" on the memo line of your check. If you prefer to donate using a debit or credit card, please write "Synapse" on the inside flap of the envelope. **DO NOT SEND CASH.**

Your donation will allow SPF to increase its allocation of funds for research grants instead of diverting funds for the newsletter. Every donation, regardless of the amount, helps to make a cure for HSP and PLS more within our reach.

Alternatively, if you currently receive a printed copy of *Synapse* and plan to read future issues online at the SPF website, you can have your name removed from the mailing list by doing the following:

Go to the SPF website, www.spf-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. You may type the following in your browser, <https://spf-foundation.org/news-resources/stay-informed.html> to go directly to the Join/Subscribe page.

First HSP/PLS Canadian Conference

by Melanie Wade, SPF Ambassador for Central & Southwest Ontario and Eastern Canada

The first HSP/PLS Conference in Canada was held May 10-11, 2019 at the Community Living building in Brantford, Ontario. A total of 37 people attended the 2-day event.

Friday's activities included registration and a most rewarding several hours meeting and greeting each other, some meeting others for the first time who had the same disorder. We were also able to socialize with Saturday's guest speakers.

On Saturday, Dr. John Fink from the University of Michigan, spoke about Clinical and Genetic Aspects of HSP and Dr. Ziv Gan-Or from McGill University, Montreal, Quebec discussed an overview of the Genetics of HSP in Canada. There were separate breakout sessions for the men and the women followed by a question and answer session. Throughout the day, three women individually shared their journey to a diagnosis, how each dealt with the progression of their symptoms and the accommodations each had to make. These three women were also the conference committee: Martha Weavers, Jeanette McNeil and Melanie Wade.

It was great to meet other people from Canada and U.S.A.! Everyone agreed we should make this conference an annual event, so we are already planning next year's conference for May 1-2, 2020 - the location is yet to be confirmed.



Canadian Conference Group

Dictus Bands

By Jason Brown, HSP

Hi to all of the SPF community out there. The topic I am writing about is Dictus Bands.

I first got diagnosed by symptoms of HSP about 4 years ago. After noticing my unstable legs and foot drop, the rehab clinic that I initially went to in St. John's, Newfoundland, custom fit me with rigid Ankle Foot Orthotics (AFOs).

Not knowing much about AFOs at the time, I was quite eager and interested in using the AFOs to help with my gait and walking ability. However, after using the AFOs for a few months, I realized that other than their benefits for foot drop and stability, they were very restrictive and allowed me no flexibility at all from the knees down. On top of all that, they weren't at all user friendly. The restrictiveness was awful when trying to climb and descend stairs, and would allow for no action of the weak muscles. Needless to say, after a while, I used the AFO's less and less.

But just recently, after complaining about all the things I didn't like about my AFO's, the clinic recommended and gave me a prescription to buy Dictus Bands. I have to say that these bands have been the best combination of user friendly and effectiveness that I have used so far.

It is basically just a leather strap that goes around your ankle, with an elastic rubber ring which attaches to your shoe lace holes. It keeps your toes up to prevent foot drop, but also allows you to have, for the most part, additional ankle flexibility. Although I did combine a semi-rigid wrap-around ankle brace with it to give me better stability.



I am still as stiff as ever, but the combination of the Dictus Bands and the ankle braces do help quite a bit and are not nearly as bulky and restrictive as rigid AFOs. I now can get around more safely and more easily than I have in at least 3 or 4 years. My toes clear everything and I seem to walk with a more upright posture than before. Unlike the AFOs, I have no complaints about wearing them and I can wear them every day, all day when outside of the house.

Keep in mind that, for me, the semi-rigid wrap-around ankle braces make the Dictus Bands more

effective than when used by themselves. Don't expect phenomenal improvement with this, but it is a welcomed improvement over the rigid AFOs.

Better Walking Aids

By Jeremy Hines, HSP SPG7

I was diagnosed in July of 2018 with HSP SPG7. I began having symptoms in 2005 in a less severe form. I had a limp in my gait and I fell once every month or so. The symptoms manifested in my everyday gait in 2014. I saw many different doctors, all sorts of doctors, along the way to a diagnosis. I would be diagnosed by one specialist and then another specialist or test would refute that diagnosis. I had been diagnosed with MS, ALS, and Leukemia. Suman Jayadev, M.D., a board-certified neurologist at the University of Washington's Medical Center's Neurology Clinic, made my HSP diagnosis and is my current physician for HSP. I see her once per year.



Aluminum Poles

I live in Yakima Washington, about 2.5 hours from Seattle. We have ice and snow; we average about 2 feet of snow per year here. Yakima is on the east side of the Cascade mountain range that roughly divides our state in half. The eastern half of the state is a desert with rolling hills and sage brush for the most part. The hills have green cheat grass in April and early May, but are brown and dry by June.

I've had a pair of aluminum REI Co-op Traverse Power Lock Cork Trekking Poles for a while. I used rounded pole tips on them for everyday use. My wife found a deal at Costco and bought a single pair of carbon fiber Cascade Mountain trekking poles, including a variety of pole tips, for just \$30. They are also available from Amazon, just search for "carbon fiber Cascade Mountain trekking poles." [If you buy from Amazon, don't forget to use AmazonSmile and Amazon will make a donation to SPF based on the value of your purchases. Editor].



Carbon Fiber Poles

I have found that hiking poles with a wedge rubber tip are a great addition for walking on asphalt roads as they reduce the tap of a carbide tip and they help with using your arms to propel a longer stride which helps the gait be more normal. So, my carbon fiber poles have the wedge rubber tips on them. I have the snow basket tips but haven't had the need to use them yet.



Rubber Tips

The tips that REI sells for their poles slide on easily, but they wear through rather quickly. They don't have a metal ring on the inside so the carbide tip of the pole wears through the rubber on those tips. I found a set of pole tips that were compatible with my REI trekking poles that last much longer, though they are a little more work to slide on than the REI tips.

My father finished making a custom wooden hiking stick for me so it has been added to my choices for a walking pole. I keep the aluminum poles at the office and use them for my lunchtime walks. I use the wedge tips with them as the wedge gives a nice little reflexive boost just like your shoes do when you walk and roll off your toe. I keep the carbon fiber poles at home and use them for my walks when I'm home. I use the custom walking stick going to and from the office.

A Mobility Aid for Maintaining Quality of Life

By Richard Ahlquist, HSP (SPG7)

Before I was genetically tested and diagnosed with HSP (SPG7) at age 56, my wife Shelly and I spent many hours walking together. After all, a marriage of 32 years, raising a family, work, and being active, demands some togetherness. We talked a lot and solved "all the world's problems" on those walks. When I could no longer walk, there was a real void in our relationship. HSP was already enough of a challenge!



Bicycling seemed like the solution, however, there were two problems: 1) I could not bike alone, and 2) tandem bikes (front and back) were not conducive to talking. We solved the problem with a kit that connects two recumbent bicycles together, side by side. We bought two Sun EZ-Classic

21-speed recumbent bicycles as well as the Sun Side by Side Kit, including assembly. Although it comes with a motor assist and belt harnesses for a severely handicapped rider, I do not need that right now. I can sit up and pedal. Each rider has 21 gears of their own, so when I get tired, I simply let my wife pedal. However, the bikes do steer together, so whoever is stronger wins! It is quite unique and we get many comments from other people. The picture shows the two of us on the bike.

We love getting outside, talking, and exercising so much that the Minnesota winters have forced us to plan a move to Arizona! I just thought our newsletter readers would like to see how we have overcome one of the several HSP challenges.

[Editor's Note: For more information on the Sun EZ-Classic 21-speed Recumbent Bicycle and the Sun Side by Side Kit, go to <https://www.eriksbikeshop.com/> and search for each item.]

Hard to Slide onto and off Your Driver's Seat? Try this.

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

Over the years I've had several handicap vans, with the standard removal of the middle row of seats, so I could drive my scooter into the van and park it in the space behind the driver's seat. Then I would transfer to the driver's seat by pulling myself up, stepping forward, and sitting sideways on the inside of the driver's seat. Then came the difficult/awkward task of sliding onto the seat while rotating my behind, to face forward. Most driver's seats on the vans were rough and difficult to slide across. I tried adding seat covers, and even had one driver's seat reupholstered with the "slickest" fabric I could find, to slide across. It's still a struggle: my clothes always caught on the surface of the driver's seat, and it was very difficult to push myself onto the seat. No seat cover or upholstery was smooth and slick enough.

Enter the Ruby Slipper car seat cover, a very clever new idea to solve this problem. Nothing like it before. A nylon fabric seat cover, very slippery, covers the seat and another large piece of nylon is right on top (fastened at the back). To get on the seat, you pull the top nylon layer toward your standing position. If you enter the car or van from the driver's door or if

Continued on next page

you transfer from your scooter using the space between the driver's seat and the front passenger seat as I do, (in front of your parked scooter or wheelchair, see photo), you sit on the upper nylon layer and very easily slide across where you need to go, the two nylon sheets sliding over each other.



This can be used in either the driver's seat or the passenger seat. Installation took about 7 minutes, I also tucked the lower nylon sheet into the crease on the edge of the seat, and fastened the front edge of the lower nylon piece on the seat to the front of the seat with Velcro. This prevents the lower nylon piece from "wandering" while sliding into position.

To order, use www.rubyslippercarseatcover.com or call 1-877-855-3065. List price is \$79.95 and it comes in red, black, and gray. Tell them Malin sent you. It will save your muscles and all the strain you've had trying to slide onto and off the seat.

I Believe

By Lily Eve Nunez

I believe that disabilities are a blessing and not a curse. Some people look at a person with a disability and think of the things they cannot do instead of the things they can do. Even parents sometimes have a hard time of accepting the child's needs.

I have a health condition and have been in the hospital many times. My health problem makes it difficult for me to do certain physical activities and to learn as



fast or easy as others. I know how hard it is to have to go through hard times, but that doesn't mean the focus should be on the things I cannot do. Instead, I am glad to be who I am instead of being someone I am not.

People without disabilities can also have difficult trials in life yet people with disabilities may have even more complex problems in life. Although this has been true in my own life, I choose to focus on the positive rather than dwell on the negative. For example, when I see a yard filled with dandelions in the summer, instead of thinking they are bad, I see them as good and think, "Look at all the wishes!" Making the choice to think positively can help anyone see past the bad and notice the good.

[Lily wrote this when she was 14. She has epilepsy and is currently seizure free. She and her grandmother, Mary Ann Inman, share passions for the visual arts and writing. Mary Ann is a member of the SPF and currently serves on the Fundraising Committee. She has PLS and has been a contributing author in previous issues of Synapse. Editor]

My Journey to A Diagnosis

By Lalaina Skye Erlam, HSP (SPG11)

My name is Lalaina Skye Erlam, I am 21 years old and currently live in Harare, Zimbabwe. I have Hereditary Spastic Paraplegia and Arnold Chiara Malfunction. This is my story.

I had a normal childhood and met all my "milestones" as a child. I also loved dancing and did various types of dance from the age of 6 years old up to 16 years old.

In January 2016, when I was 18 years old, I moved to Cape Town, South Africa to study catering at a Chef School. Throughout the year everything was normal and then in November of that same year, I had a fall and injured my left set of ribs. I recovered quickly and didn't think anything of it until I returned home to Zimbabwe in December 2016 and my mother noticed that my walking had slowed right down and I was taking a lot longer to walk short distances. I told her that my right knee was hurting when I walked and this is where my long 2-year journey began.

During 2017, my grandfather took me to see a rehabilitation specialist at a nearby gym. The doctor who examined me told me that it was probably my ACL. He suggested I wear special shoes to help with my walking, which I did.

The soreness in my knee continued, so I visited my GP and she suggested I wear a knee brace to help stabilize

my knee. She also suggested I do some sessions with a Physiotherapist. I did ten sessions and wore the knee brace, but my walking did not improve and my knee was still sore.

I then visited a knee specialist and he did an MRI and an X-Ray on my knee. The doctor couldn't find anything wrong with my knee but suggested I try and lose some weight as I had a BMI of 33 and he felt that this was putting strain on my knee joints which was causing the pain. As I lost weight, I felt as though my walking was getting worse. I started doing personal training with a lady at my gym who specialised in rehabilitation but this also did not help with my walking, it only helped me with my weight loss.

One morning in October 2018, I was walking to the gym from the car park and my GP saw me. She hadn't seen me since our appointment a few months earlier and she was shocked at the way I was walking. She immediately made another appointment to see her where she did an ECG and a number of blood tests, as well as an X-Ray of my spine, hips and pelvis. She then suggested I visit a Neurologist in Johannesburg, South Africa as there was nothing showing up on the X-Ray or blood tests.

My mother and I flew down to Johannesburg to see a Neurologist in November 2018. I had a full body MRI and some more blood tests to rule out any deficiencies that I might have. I was started on a course of Bio-Baclofen and Valium. The Neurologist did not give a definite diagnosis of my condition.



Charitable
GIVING

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

We returned to Zimbabwe and visited another Neurologist in Harare, Zimbabwe in December 2018. She suggested further tests. I had an Electromyography and Nerve Conduction Test. These tests came back as "essentially normal" and the doctor suggested we look at Genetic Testing for HSP. She also set up a SKYPE appointment with some Professors at the Clinic of Pennsylvania. They asked me a lot of questions about how I was feeling and they also saw the way that I walked. Still no diagnosis was given.

In March 2019, I again went to Johannesburg, South Africa to see yet another Neurologist. He confirmed that I had Arnold Chiari Malfunction Type 2 and was adamant that I have genetic testing done. He organized an appointment for me to have blood tests at the Genetic Institute in Johannesburg. These blood tests had to be sent to America as they did not have the facilities to test the blood there.

In early April 2019 I received the results. It was a positive result for Hereditary Spastic Paraplegia, SPG11. I was devastated.

It has been a long journey, but I am glad that I now know what it is. I have decided to be positive and carry on as best as I can. I regularly attend Yoga classes (even though I struggle through them) and I have Biokinetics with a personal trainer at gym twice a week. I have also done a few sessions of counselling with an amazing lady who also specialises in MyoReformation (<https://myoreformation.com>) and the life-machine and right now, I am just taking one day at a time!



Come Join Us on Facebook for Friends, Fun and Support!

Spastic Paraplegia Foundation, Inc #HSPandPLS

SPREAD AWARENESS #HSPandPLS

Joined ▾ Notifications Share ... More

About This Group

Description

The SPF is the only organization dedicated to two groups of neurodegenerative disorders called Spastic Paraplegia (Hereditary and Apparently Sporadic)* and Primary Lateral Sclerosis (PLS). These spinal cord disorders cause pr... See More

GROUP BY

Spastic Paraplegia Foundation # 243 like this

Learn More

HISTORY

Group created on April 11, 2008

Name last changed on May 23, 2019

See More

Living with HSP/PLS

TINA'S TIPS

Get a Kick Out of Climbing Stairs

By Tina Croghan, Missouri State Ambassador and Board Member

Over the Mother's Day weekend, I got to visit with my son and daughter-in-law at their new apartment in Chicago.

My son had cautioned me that his apartment had 10 steps. He had scouted the situation and selected the back stairs as a better option. (See picture)



I did it! There was no real railing, so I held on to Tim while my son operated the feet. Each stair tread had an overhang and would catch my toes with each step. My son would have to pull each foot out from under the stair tread and place it on the next step. This we had to repeat until I got to the top.

The whole way, I kept thinking that there had to be a better way! I figured out that if I would swing or kick my foot back and tighten that Glute (butt-cheek) with each step up, I would avoid my toe catching on the overhang.

So, the next time you have to go up stairs, try kicking your leg back. It'll definitely help you up the stairs and tone your Gluteus, too, Ladies!

Incontinence, A Male Perspective

By John Staehle, HSP

In June 1999, I was diagnosed to have Familial Spastic Paraplegia, FSP, more commonly known as Hereditary Spastic Paraplegia. Several years before that, people close to me noticed my gait had started to change. I didn't notice it at first, but gradually that gait change became a limp and eventually I needed a cane to keep my balance while walking. It was then, I decided to find out what was happening to me. By the beginning of 1999, I used a walker if I had any distance to travel.

I discovered the Spastic Paraplegia Foundation website in 2003 and joined the HSP LISTSERV. The information on the website and the experiences

of HSPers provided me with a wealth of information on the symptoms of HSP, many of which I had not experienced yet. Unfortunately, there wasn't much about coping with the "private" symptoms. You know, the ones men don't discuss with anybody... like incontinence.

Urinary incontinence sneaked up on me. In the beginning, when I first got the urge to go, I could finish what I was working on before heading to the men's room (I was working then, at a sprawling aerospace manufacturing facility). The symptoms of my HSP progressed steadily from year to year. I began to have bladder spasms, but was able to get a prescription for oxybutynin to control them. It wasn't always as effective as advertised. I began to use male guards, a thick absorbent pad that would stick to the inside of my underwear, to provide protection if I leaked before getting to the men's room. While incontinence seemed to be "under control," my spasticity continued to make it more and more difficult to use crutches for long distances. So, I began to use a company-supplied 3-wheel factory personnel carrier that I could drive to just outside the entrances to office areas and park in designated areas. Unfortunately, most of those spaces were in the factory and I had to use crutches to get from the parking space to my destination in the office area.

My incontinence worsened. I had trouble emptying my bladder and it seemed like I was in the men's room more than I was at my desk. I couldn't make it through the night without soaking two male guards in my underwear. Strangely, I was thirstier than normal and was drinking more water which just compounded the problem.

I made an appointment with a urologist that was well-known for his work with incontinence and neurologic disorders. One of the early tests he performed was a urine retention test. Prior to taking the test, I had emptied my bladder in the men's room adjacent to the doctor's office. The first step was to insert a catheter to drain my bladder so it was completely empty. I didn't expect there would be much, but they drained 375cc! Then they slowly filled my bladder with a sterile saline solution and asked me to tell them when I felt my bladder was full. When I told them it was full, they had filled my bladder with 450cc of solution. I

started to understand why I was making frequent trips to the men's room.

The solution to my retention problem was to use a catheter to drain my bladder. The only catheters I knew about were the ones used in the hospital when you had surgery, the ones with a bag to collect the urine. I asked if that was what I was going to have to wear. It wasn't. They scheduled a training appointment where I was taught how to use and care for intermittent catheters. It was a little awkward at first but within a few days I was a pro.

For about a month, I had to record time of day and the volume each time I drained my bladder. For the next couple of months, the catheter was successful during the day, but I still had a problem with leakage at night. I was beginning to experience extreme thirst a couple times a day and always went to bed with 24 oz. of ice water on the night stand. Most nights it was empty by the time I got up for work. People noticed that I had lost some weight and was "looking good." I wasn't trying but, what the heck, I was actually losing weight! By now most of you recognized the telltale signs of diabetes, but I found out during my annual physical in the fall of 2007, when my blood sugar reading was 348. I had Type II diabetes. My doctor gave me a glucose meter and wrote me prescriptions for test strips, lancets to stick my finger and metformin to help my body produce more insulin. I took 1000mg of metformin before breakfast and another 1000mg before dinner. In just a few days, my seemingly insatiable thirst went away and my blood sugar readings came down to the low 100's. Best of all, the nighttime leakage was gone. Unfortunately, I stopped losing weight, too.

It is very important to not let your bladder get really full. It is a very flexible organ and can expand several times its normal size. The most I drained at one time was a little more than a liter. My urologist urged me to time my trips to the men's room so I would drain around 350cc each time. I've been self-cathing about 6 times per day since 2007 and I've been controlling my blood sugar readings to a range from 80 to 140 mg/dl with diet and medication (metformin). At least one time each day, after I have drained my bladder, I use a 60cc syringe filled with water to irrigate it. I attach the syringe to the end of the catheter and using the syringe's plunger, steadily push the water from the syringe into my bladder. This loosens any residue

left in the bladder. Then I slowly draw out the water and any residue until I can feel the bladder collapse on itself. This process is important to remove the accumulation of residue in the bladder that can become a breeding ground for infections.

If any of you men have specific questions about incontinence, email them to me at jstaehele@swbell.net and I will try to answer them based on my experience. Please understand that I am not a doctor and anything I say or write is not to be considered as medical advice in any way.

Upright and Smiling

By Steve Morrisey C.Ss.R., HSP

This is just to share a little bit about me, one who lives with and keeps on going whatever Hereditary Spastic Paraplegia dictates. Some days HSP can prove overwhelming, yet I keep on living.

In 1992 I took the Evangelical Council's vows of poverty, chastity and obedience. In addition to these three vows I also took a vow of perseverance. This 4th promise, this commitment of "stick-to-it-ness," keeps me faithful to the commitments that our founder, St. Alphonsus Liguori began back in 1732. This "stick-to-it-ness" is also very evident in my life in many ways. In 1996, I was ordained into the Roman Catholic Priesthood.

Over the past 30 years my dedication was fulfilled in many ways, but in particular through running. I have completed many 5k, 10k, half and full marathons. I am far from being super-fast but I am persistent. There are more marathons I have not completed than those I have finished (somewhat normal I've been told). I love the bonds of friendship that grow around running.



Steve Morrisey

In the early 2000's, I developed knee issues and was literally immobile for about a week. Eventually, after many years and a few mis-diagnoses, my issues led to a clinical diagnosis of Hereditary Spastic Paraplegia.

Continued on next page

HSP had entered my world and what was once a very comfortable 6-minute mile is now more like a 12-minute mile.

“Upright and Smiling” is an expression in the running community and it certainly describes me. I am always smiling and I will keep staying as upright as possible! These few words are just about one who lives with HSP yet keeps on going. I hope they can help others keep going as well.

I Change My Focus

By Molly St. James, SPG7

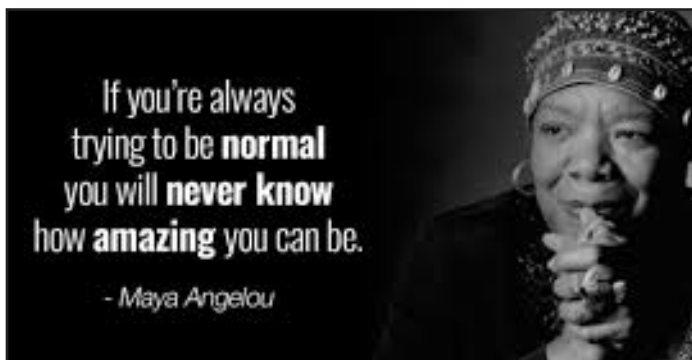
I have a “full” life. I have SPG7 and my husband is recovering from recent brain cancer treatment. We both currently work full-time jobs and have a soon to be 3-yr old to take care of. So, yes, there is never a dull moment.



St. James Family

The future outlook can be very depressing. When I feel myself starting to dwell on the negative parts of life, I have to mentally stop myself before I get sucked in and the snowballing effect occurs.

What I have found is that this helps me think positively. Please understand that I am by no means perfect so there are bad days at times. The best way for me to overcome these days is for me to have upcoming mini-events to look forward to. This allows me to have something to change my focus and distracts me from the doom and gloom of my medical situation. These mini-events can be a dinner at a restaurant, a visit to a park, a TV show premier (I was sad when Game of Thrones ended) or an upcoming trip. I am not saying this will work for everyone, but it definitely helps me.



MY 3 STEPS TO OVERCOMING HSP

By Shelton Norris, HSP



Shelton Norris

I started really being physically and emotionally affected by HSP when I was about 21 years old. Before then I was this quiet, goofy kid who enjoyed writing music and working out. I was an athlete for several years running track and playing football. One of my fondest memories is racing my dad to the car, trying to see who was the fastest. I first noticed a slight limp while I was in college. I tried to play it off like I had this cool “pimp walk.” Then it started to get more difficult and the pimp walk became less pimpish and more of a serious struggle. I started to feel like I didn’t fit in anywhere which caused me to isolate myself from the world around me. I didn’t know, and still don’t know, how to explain this condition easily, which made socializing a bit awkward. My sister thought I was playing around because it was so surreal to see someone who once was a runner, walking like a cripple out of nowhere. I stopped going to family gatherings because I just didn’t feel like myself. This condition was slowly sucking the joy out of my life. I was smiling on the outside, but secretly sad and broken on the inside. During my college graduation, my mom and friends had to convince me to walk across the stage because I was undoubtedly afraid of judgment by my peers and family. By this time, I began using a walking cane to support my unbalanced walk. Those dark and rainy days were long and strenuous, but I eventually found an umbrella. Today I am looking forward to lots of sunshine. Below are my three steps to overcoming the symptoms of HSP.

1. CUT OUT THE NEGATIVITY

I had this friend who decided to tell me I walked like a wounded veteran. I laughed off the comment, but it sort of hurt my feelings. I had another friend who said, “You need to get your legs fixed.” I smiled and said, “Yeah, I know,” but I really wanted to say, “Don’t you think I would have done so if I could, you idiot!” These people highlighted negative things instead of supporting me during this difficult time. As the condition progressed, I became intolerable of anyone or anything that wasn’t uplifting my spirit. I knew I needed to be surrounded with love in order to get

out of depression. I became very particular about who was in my circle and that made all the difference. I cut off some people and I connected only with people who poured great things into me. HSP is stressful enough. I have no room for any extra stress from anyone or anything.

2. LEARN THE POWER OF THE TONGUE

A good friend of mine sent me a text to get on this free conference call. After weeks of brushing it off, I decided to give it a try. Once I got on the call, this guy, who goes by the name Hazi Ali, was saying affirmations about success and a group of about 100 people enthusiastically repeated after him. At first, I was a bit skeptical, but I heard a lot of affirmations while watching the movie “The Secret” and my mom always told me that there is power in the tongue. Therefore, I tried it out. After about a week of saying affirmations like, “I love myself and I love my life.” I was completely sold. I realized that speaking affirmations out into the universe gave me extra confidence and made me feel empowered. I was inspired to come up with my own affirmations and implemented my affirmations into my morning prayer. Now that my circle is strong and my faith is stronger, I am ready to fight HSP and inspire others.

3. SPASTICITY EXERCISE

Physical therapy was too expensive, but while I was there, I learned many helpful exercise techniques. One thing that never changed was my love for working out, staying fit and eating healthy. One day while researching a cure for HSP, which usually makes me more depressed, I ran across an article that read, “the cure for spasticity is constantly exercise.” According to this research, enough reps of the right exercise could improve spasticity by retraining the muscles. This gave me so much hope. I thought to myself. “what if healing is all up to me, what if I can become my own rescuer?” Unfortunately, this article did not list the “correct exercises” to cure spasticity. So, I googled exercises for HSP, but I was unable to locate any results. I decided to come up with my own exercise routines by implementing effective exercises learned from physical therapy. I decided to create what I needed and it’s the most fulfilling thing I’ve ever done. Watch me take my life back from HSP with exercise routines, empowering affirmations, and nutritional information geared towards improving HSP by selecting the following YouTube link: https://m.youtube.com/watch?v=WMFT7FO6_P4.

SPF Earns GuideStar Gold Seal of Transparency

GuideStar USA, Inc. is an information service specializing in reporting on U.S. nonprofit companies.



It is a comprehensive database of every single registered nonprofit. It compiles publicly available information for more than 2.5 million organizations in the United States. That includes tax IDs, contact information, website links, and 990 tax returns. GuideStar was one of the first central sources of information on U.S. nonprofits and is the world's largest source of information about nonprofit organizations.

A GuideStar Seal of Transparency indicates that a nonprofit has provided key information in its Nonprofit Profile. By providing up-to-date information, nonprofits allow potential donors and funders to make educated decisions about the work they do to make the world a better place.

The Spastic Paraplegia Foundation has recently achieved the Gold Seal of Transparency. See <https://www.guidestar.org/profile/04-3594491> for details.

QR Code for Ease of Donations!

Using your smart-phone, scan this quick response (QR) code as a convenient tool for submitting donations to the Spastic Paraplegia Foundation. Scan it with your smartphone and a QR reader app and it will go straight to our donate page. Your contribution allows for medical research of Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS), together we are #hspandpls.



Fundraisers

Punch-a-Thon Fundraiser

By Jeff Holtz, Proud Father

A fundraiser held on May 19th, benefitting the Hereditary Spastic Paraplegia Foundation, raised approximately \$15,000. The event, initiated and organized by Reilly Holtz, started out as a Punch-a-Thon, where participants would take a 90-minute kickboxing class at the CKO Kickboxing gym in Freehold, NJ. However, as news of the event spread through social media and by word of mouth, support grew well beyond what Reilly had originally imagined. Before long, people from all over were reaching out, wanting to contribute in some way to the cause and the event became much more than just a Punch-a-Thon.

After many years of testing for MND's and visits to multiple MND specialists and neurologists, about 3 years ago, Reilly, a 19-year-old college student who, along with her older brother Conor, also a college student, was diagnosed through genetic testing with HSP SPG-11. The onset of the symptoms in both cases came in their teens and has dramatically changed their lives, but both Reilly and Conor were determined to live normal lives. In announcing the Punch-a-Thon, Reilly wrote on her Facebook page "I would never have envisioned myself at 19 years old on this uncertain journey, but I AM certain that I am going to do something about it..." and that something turned into the May 19th event.

As support for the event continued to grow, Reilly decided to add some raffles to the event for the participants. She went to local merchants to solicit donations and gift cards that she could raffle off following the Punch-a-Thon. Then people started to ask if they could make gift baskets to add to the raffle prizes. Soon the gift baskets started pouring in and

by the day of the event, there were over 75 gift baskets available for the raffle. At the same time, people started asking how they could make contributions to the Spastic Paraplegia Foundation. A link was added to Facebook and it resulted in over \$3,000 in donations. There were



Reilly Holtz

also friends and family around the country sending personal checks made out to the Foundation and many others contributed directly through the Foundation website. On the day of the event someone decided that a 50/50 raffle should also be held in addition to gift basket raffle. Amazingly, the 50/50 raised \$650 over and above what was raised through the other raffles and the participation fee for the Punch-a-Thon. The event itself was a day Reilly will never forget.

On the day of the event, well over 120 people came out to support the cause and contribute. The Punch-a-Thon itself sold out all 60 of the available spots for the workout and many others came to participate in the raffles and the 50/50, and most importantly, to show their support for both Reilly and Conor. It was a true testament to the selfless nature of both Reilly and Conor who always give back to the community. It is also likely to be just the start of something that will be ongoing in the future! A family friend is competing in an Iron Man Triathlon this coming September and will be riding in honor of Reilly and Conor to raise money and awareness for HSP. Reilly is already thinking of ideas for next year's fundraiser!



2018 Donations from Amazon

David Lewis, SPF Treasurer, reported that in 2018, Amazon electronically transferred over \$1,271 to SPF. Since the very first time someone bought something through amazonsmile and chose SPF as their designated charity, the Foundation has received more than \$4,563.



It's easy to sign up. Logon to www.smile.amazon and then select Spastic Paraplegia Foundation, Inc as your designated charity. From that point forward, every time you want to buy something from Amazon, if your browser isn't already on amazonsmile, type in amazonsmile and Amazon will donate to SPF 0.5% of the purchases you make. Remember, it costs you nothing. You still have all the benefits of Amazon Prime or full access to the Amazon website if you are not a Prime member. Please tell your friends and family about amazonsmile. Share it on Facebook, too.



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 and stipulate CATW in the "honor of" space.

Connections

West Virginia Connection, May 11, 2019

*By George Sprowls, West Virginia State Ambassador,
and Rev. Dr. Tracy Sprowls*

The genesis for this meeting occurred when George Sprowls was admitted to the Encompass Rehabilitation Hospital for physical therapy in February. During check-in, he mentioned he thought he had HSP and happened to be the SP Foundation's State Ambassador for West Virginia. Dr. S. Gibbs, the Medical Director of ERH, said she was very familiar with the disease and volunteered her facility and expertise if he wanted to schedule meetings there. Hence this meeting.

Response to invitations was sparse. Of 15 individuals invited in WV, only three responded; one requested to be removed from the contact list, one expressed interest but regretted being away that date and an HSP patient and caretaker from Palestine WV (Near Parkersburg), both of whom attended the meeting. The majority of the attendees (5) were associated with a single family in Fairmont.

Hank Chiuppi, Social Media Coordinator for SP Foundation, took the initiative to put news about our meeting on Facebook and sent the same to the SPF webmaster for inclusion on the website. As a result of his effort, one patient drove up from Virginia to attend and a phone call was received from Florida requesting any information provided about exercises.

Since Morgantown is just 7 hours from Pennsylvania, three emails and a personal phone call were made to the PA ambassador in an effort to get attendees from SW PA.

In the end, there were 8 people attending this meeting: 4 with HSP, three caregivers and a 48-year-old male who was not sure whether or not he had HSP.



Dr. Gibbs

Dr. Gibbs conducted a very informal meeting, welcoming questions and comments at any time. She started with the history of HSP and how it was discovered which included the original name of the disease and its prevalence. She then covered the clinical features

Continued on back page

1605 Goularte Place
Fremont, CA 94539-7241

Continued from page 19

of pure and complicated HSP and compared type one to type two. She spent considerable time on how the disease presents, what doctors are looking for in an examination, and she verified that genetic testing is the only absolute way to diagnose the disease. She emphasized how the disease can present in different ways in different people. At the conclusion of her presentation, Dr. Gibbs provided handouts of her talk, two pages of various exercises she recommends, and an article on HSP.

Following Dr. Gibbs, the Rev. Dr. Tracy Sprowls gave a 20-minute presentation on how yoga, particularly stretches, can enable continued mobility and even ease some of the pain of the disease. This information was received with interest and enthusiasm by the other participants.

Not only did Dr. Gibbs spend her valuable time

researching and preparing her excellent presentation, she surprised the participants with both breakfast before and lunch after the meeting. This generosity was certainly above and beyond the call of duty!

Everyone in attendance enthusiastically affirmed that Dr. Gibbs did a great job explaining our shared condition. In addition, it was unanimously agreed that there was a benefit in coming together and sharing our stories. It is clear that people with this disease can feel isolated and to know others are out there is important and even critical. The internet is of some help, but occasional face to face meetings are truly helpful.

We all agreed to meet again in the fall (including the lady from Virginia) when Dr. Gibbs will go over the different medication options and more time will be available for personal stories and interactions. We also exchanged email addresses so that we can keep in touch.

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.