

SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.

Volume 23, Issue 1

Winter 2020

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Letter from the President



Dear Member of the SPF Community,

I'm not sure when you will read this letter but as I write it, in early January, "Happy New

Year!" is still very appropriate. I hope 2020 is off to a great start for you and your family. Our team is very busy working on exciting plans for 2020 and we want to share some announcements with you as we kick off the year.

First of all, if you haven't already heard, thanks to you, our fundraising broke a record in 2019. We raised 32% more than we did in 2018, just over \$870,000. Thank you So Much!! As you know, our mission is to support research to cure HSP and PLS and it is just a matter of time and money before we get to those cures. Time before a cure is fortunately always decreasing. I wish I could say the same about the demand for money. Your contributions continue to make incredible progress possible as we head ever stronger toward that goal of a cure.

Every year our world renowned Scientific Advisory Board of the top experts on HSP and PLS carefully study the dozens of research proposals we receive from all over the world and rank them from

worst to best. The very, very best are ranked as Excellent and Very Promising (EVP). As science is blasting forward with ever increasing speed, for the last several years, there have been many more EVP proposals than we could afford to support. This year, we will be able to support far more of them than we ever could before. This just might be the year that one of the EVP proposals makes a fantastic ground breaking discovery that changes everything for the rare, upper motor (HSP & PLS) disease community.

It goes without saying, I hope, that we remain deeply committed in 2020 to furthering our mission to develop treatments and a cure for HSP and PLS. Thanks to you, we were able to direct \$623,808 to research in 2019. Our plans for 2020 include further expanding our research portfolio by growing the number of pharmaceutical/biotech partners, launching exciting new gene therapy projects, expanding and directing more funding than ever before to translational research initiatives that will lead to treatments for our community. Stay tuned for some major announcements from us in the coming months!

We are dedicated to serving the SPF community; to improve the quality of life for everyone living with HSP and PLS. This, of course, includes our youth. In 2020, we plan to

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SYNAPSE

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The Spastic Paraplegia Foundation Inc. (SPF) is a national, not-for-profit, voluntary organization. It is the only organization in the Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).

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President's Letter (continued)

initiate an SPF Youth Council. Our Youth Council will not only assist our Board of Directors to further the needs and wishes of the HSP and PLS Youth Community but will also work together to share ideas about how best to live with HSP and PLS under the age of 25. Alex White has agreed to be the director of our new Youth Council and he will soon invite several other members to join him from all around the country. If you, your son or daughter would be interested in joining our SPF Youth Council, please send me an email to let me know (frank.davis@sp-foundation.org).

In 2019, our chief medical advisor, Dr. John Fink, initiated a monthly computer video meeting on the first Tuesday of every month. It is a completely open forum and Dr. Fink enjoys answering your questions. You can find out about the next scheduled meeting and how to connect under "Events" on our website.

In 2019, we began a partnership with Dr. Pembe Hande Ozdinler of Northwestern University to open a new Upper Motor Neuron Initiative (UMNI). This facility will greatly facilitate the study of Upper Motor Diseases such as HSP, PLS and other diseases like ALS, Spinal Cord Injury, stroke,

Multiple Sclerosis and Huntington's Disease which also have upper motor neuron problems.

The mission of UMNI is to understand the biology of upper motor neurons and to reveal the underlying causes of pathology so that they can develop effective and long-lasting treatments. SPF and Dr. Ozdinler insisted that they generate an inclusive and collaborative environment to expedite research efforts and discoveries. The UMNI will enable upper motor neuron scientists to have a platform where the flow of knowledge will be facilitated via joined projects, multi-PI grant applications, sharing of resources, and regular meetings among members. I hope you share in the excitement and hope that UMNI will be a great benefit to our community!

With your help, we continue to march forward to the day when people with HSP or PLS can be quickly diagnosed, treated and cured. I thank you again for making all of this possible!

All the best,



Frank Davis, President

Thanks for the Privilege of Working With You

By John Staehle, Senior Editor

Malin Dollinger began his role as the Medical/Research Editor for *Synapse* on the Fall 2015 issue. From the very beginning he has been a superbly competent colleague. In November of last year, he asked to be relieved of his editorial duties that in his own words, "I cherished my role as scientific and medical editor." I fully understood his reasons for stepping away from the editor's job and reluctantly accepted his wishes.

I am pleased he will continue to submit articles for *Synapse* as time permits. His medical articles, written so non-medical readers like me can understand them, have been appreciated many

times. Also, I always enjoy reading his poems and the "unusual" articles from his pets and scooters.

Frank Davis added, "I just want to offer a very generous thank you for all the incredible work and time you have devoted to our Foundation over lots and lots of years. I think you are making a wise decision and I wish you and Lenore the best of health and happiness."

Even though I never met Malin in person, working with him and sharing personal communications for four years, I'm proud to call him a friend.

Best wishes, my friend, and thank you for allowing me the privilege of working with you.

A New Look for Synapse

By John Staehle, Senior Editor

I hope you noticed this issue of *Synapse* looks a lot different than previous issues. The format you are used to seeing has been in effect since the Spring 2008 issue. This Fall we decided it was time to update the format of our official newsletter. You are seeing the product of the hard work of the graphic artist at Gulf Business Printing, Donna Hinshaw, who turned my limited set of requirements into what you're seeing today.

I would like to hear what you think about the new look. Email your comments to me at staehjo@gmail.com.

REGISTRATION FOR THE 2020 ANNUAL SPASTIC PARAPLEGIA FOUNDATION CONFERENCE IS OPEN

The Spastic Paraplegia Foundation invites you to attend the 2020 Annual Conference to learn, share, network, and have fun! Mark your calendars to join us in Nashville beginning with a Welcome Reception Thursday evening, June 25th continuing through Sunday noon, June 28th, 2020.

The Spastic Paraplegia Foundation sponsors a conference to bring together the leading SPF researchers, clinicians, and families living with #HSPandPLS. SPF has hosted the Annual SPF Conference since 2003. We look forward to reuniting as a community at this year's conference in order to lend each other support and strength, and to learn about the latest advances in research and care.

The conference is filled with a variety of workshops, keynote sessions with leading researchers, a family-friendly research poster session and more. There are many opportunities to connect and interact with other SPF families and to receive firsthand updates from the researchers.

You have three options to register online for the 2020 Annual SPF Conference: by clicking the Annual Conference bar at the top of the SPF home page OR by going to <https://form.jotform.com/90107997584167> OR by using this direct link <http://bit.ly/SPFAC>.

REGISTRATION

[By the time this issue of Synapse was printed and mailed, the Early Discount deadline may have passed. Editor]

Each person who is attending any portion of the conference must register, including attendants. The conference registration fee gives access to all sessions. See the registration form on page 19 for rates and deadlines for discounts.

PAYMENTS

SPF has two options to assist in registering and paying for the annual conference registration fees. First option is to make a personal check payable

to "SPASTIC PARAPLEGIA FOUNDATION" or "SPF" and earmark the Memo Line: "2020 AC". Print and complete the registration form (available on the SPF website and on page 19 of the Winter issue of *Synapse*) and mail it and your check before the early discount deadlines, to: Spastic Paraplegia Foundation, 1605 Goularte Place, Fremont, CA 94539.

The second option is to Register for the Conference online at <http://bit.ly/SPFAC>. Once the registration form is submitted online, pay the registration fees by credit card online at: <https://sp-foundation.networkforgood.com/projects/22291-spastic-paraplegia-foundation>. You can also find this information online at sp-foundation.org.

Visit sp-foundation.org and on the very top line, click on the green tab labeled "Donate by Credit Card" to submit your fees online. The link will open another box where you can **enter the Dollar Amount** for the registration fees and type **2020 Annual Conference** on the next line labeled "Your Note for the Donor Scroll". The "donation" will be earmarked as the registration fees for the conference. Screens will open to allow you to register your name, email address, and credit card information.

Hurry as the first early discount ends February 17th. Any questions, please email us at SpasticConference@gmail.com.

After you complete the conference registration process, please remember to book your hotel room at the link below. Hurry the discounted rate hotel room block ends on June 1st.

ANNUAL SPASTIC PARAPLEGIA CONFERENCE POLICIES

EARLY DISCOUNT DEADLINE

Please note in order to receive the early conference discounts, a registration form must be submitted and paid by the designated dates on the registration form.

REFUND POLICY

There are no refunds of registration fees for cancellations received after May 31, 2020. To cancel a registration, you must email your notification to SpasticConference@gmail.com prior to May 31, 2020. Otherwise your fees will be directed as a donation to the Spastic Paraplegia Foundation or you may send an alternate in your place for no additional cost. Advanced notification of alternate is required by May 31, 2020, so we may adjust the registration and customize their badge accordingly during check-in.

IMAGE CONSENT POLICY

By attending the 2020 Annual Spastic Paraplegia Foundation Conference you give your consent to use your image and any video recording captured during the conference through video, photographs, or digital imagery, to be used by the Spastic Paraplegia Foundation in promotional materials, publications, and web site and waive any and all rights to these images.

FILMING/RECORDING POLICY

The recording of any audio and/or video recording of conference sessions or at any venue of the annual conference is forbidden without prior written approval of the SPF. PowerPoint presentations will be available on the website after the completion of the annual conference. Attendants at the annual conference expect, and deserve, the right to privacy. The SPF does photograph and record at the annual conference and will make photographs and other media available for news, educational, and promotional purposes.

SOLICITATION POLICY

Soliciting funds for organizations other than the Spastic Paraplegia Foundation or for individual benefit is prohibited at SPF events. Any materials distributed seeking funds for other organizations or for individual benefit will be removed.

HOTEL RESERVATIONS

The 2020 Annual Conference will be held in the **Hilton Nashville Airport Hotel** in Nashville, Tennessee, located at: 2200 Elm Hill Pike, Nashville, TN 37214. The hotel is only two miles from Nashville International Airport (BNA).

Below is a link that you may use to book reservations. You may also call the reservations line at 844-886-4136 and use the group code SPF to obtain the rate. The cutoff date for the room block and discounted group rate of \$154 ends June 1st.

<http://bit.ly/2020SPFACHotelReservation>

HOTEL HIGHLIGHTS

- Close to Briley Parkway and I-40 for quick movement around Nashville
- Complimentary shuttle from BNA Airport (6:00 am - 11:00 pm daily)
- 382 renovated guest rooms, all with complimentary WiFi
- Heated indoor pool and well-equipped fitness center
- Hotel On-site Dining Options and Convenience Shop

A hearty breakfast, a casual lunch, post-work snacks and drinks—you'll find what you crave at the hotel. Two Rivers Cafe offers a breakfast buffet and a la carte items, and the Atrium Bar serves tasty American dishes and your favorite cocktails. Fresh Connections and room service are also available.

About Nashville: Welcome to Music City

So synonymous is Nashville with music, it's almost hard to describe the place without bursting into song. It's been dubbed the Country Music Capital of the World and is often referred to more colloquially as Music City – however you choose to refer to it, the country connections are clear. In recent years though, Nashville has worked hard to broaden its horizons – and it now matches its world-renowned live music scene with a cultural offering that takes in superb cuisine, artistry and more. It makes for a special place to stay – you'll leave with your toes tapping for sure.

Local Attractions

- Grand Ole Opry
- Ryman Auditorium
- Country Music Hall of Fame and Museum
- Nissan Stadium, home of the Tennessee Titans
- Bridgestone Arena, home of the Nashville Predators

Resilience Matters – Part Two Why Resilience is Important

By Kathi Geisler, President of Life's Still Good



Kathi Geisler

Building resilience is shown to improve the quality of life. People with high levels of resilience have better long-term physical and emotional health and lower risks of physical and emotional illnesses and conditions.

Resilient people also tend to have healthier relationships as well as greater self-esteem and self-confidence, which often leads to new positive life opportunities.

Everyone has adversities in life. People with higher levels of resilience are shown to manage adversity better and to grow from the experience – learning things about themselves, what they value and a greater confidence to meet future challenges.

People with chronic and progressive conditions such as HSP and PLS can especially benefit from building their resilience because of the ongoing, unpredictable changes they face in their health, abilities and self-image. This unpredictability can lead to a sense of loss of control over one's life – a feeling that can spiral into depression, poor management of disease or negative changes in relationships.

But by learning new ways to look at their situations, individuals can discover there is much they can control about their lives – and that sense of self-efficacy is one of the primary contributors to resilience. Self-efficacy is having the confidence that you can do what you need to do and manage what comes your way.

People with self-efficacy tend to be happier and more resilient, managing both life and their health conditions better. Being resilient is particularly helpful when there's progressive change in one's health condition and functioning.

Researchers have outlined three stages that people typically work through on the road to developing greater resilience. Learn about these in the next Resilience Matters Column "How to Build Resilience" in the Spring issue of *Synapse*.

Food for Thought:

1. What is a positive outcome of having your condition?
2. What important thing have you learned about yourself?
3. Is there a new pleasurable activity or hobby that you now enjoy that you otherwise would not have?

Kathi Geisler is a Co-Founder of the Spastic Paraplegia Foundation and a former Vice President of the SPF. She has HSP and lives in Massachusetts.



First Brazilian Hereditary Spastic Paraplegia Symposium

Prepared by Jailson Mouzinho, HSP, ASPEH-Brazil President, SPF member; Michelle Detoni, HSP, ASPEH-Brazil Director, SPF member; Celyna Silva-Rackov, SPG4, SPF State Ambassador, North Texas Region

In Brazil, it is estimated that Hereditary Spastic Paraplegia (HSP) may affect about 10,000 people which represents 10% of the known affected world population. With such rareness there is little awareness of this disease in the country. Even many health professionals have never heard of it. As with any other rare disease there is a scarcity of pertinent information available for both health professionals and for families of those affected.

In order to make pertinent information available to Brazilians in Portuguese, *Associação de Paraparesia Espástica Hereditária do Brasil (ASPEH-Brazil)* which translates to Association of Hereditary Spastic Paraparesis – Brazil, was founded in December 2017. ASPEH-Brazil founders were strongly inspired by the SP- Foundation.

On December 14th, 2019 ASPEH-Brazil held the *First Brazilian Hereditary Spastic Paraplegia Symposium* in the city of Sao Paulo, Brazil. An audience of approximately 200 people heard motivational speakers and received information on legal, health and public policy topics from qualified professionals. In addition, one of the greatest values was meeting other people with the same challenges.

The event began with a lecture by para-athlete Fernando Aranha, who is a Paralympic champion in the triathlon sport in Brazil. He spoke about motivation and overcoming through sports.

Similarly, Marília Castelo Branco, president of the *Síndrome do Amor*, an Association of rare syndromes that gives emotional support to affected families, spoke about learning to embrace a positive perspective in the face of life's limitations. Regina Prospero from the *Vidas Raras* Institute gave an overview of the issue of public policies for rare disease patients in Brazil.

Four attorneys presented on topics of great interest to families and people affected by HSP, including the legal rights of people with HSP, such as the procurement of medicines by Brazilian Health Unique System, tax exemptions and public policies. What made these presentations more meaningful was the fact that three of the four attorneys have HSP and the fourth has spinal muscular atrophy.



The audience was led in doing arm stretches.

Health speakers included renowned professionals and researchers Dr. Marcondes França and Dr. Acary Bulle along with additional speakers for

neurology, genetics, psychiatry and physiotherapy from important institutions such as University of Campinas (UNICAMP), University of Sao Paulo (USP) and Federal University of Sao Paulo (UNIFESP). They addressed topics that included the genetics of HSP, HSP and related diseases, drug and non-drug therapies for HSP.

Dr Fernanda Bittar, who attended the SPF Annual Conference 2019 in San Antonio, Texas, USA, presented a summary of the conference with emphasis on the worldwide importance of the Spastic Paraplegia Foundation's work in HSP and PLS research.

The First Brazilian Hereditary Spastic Paraplegia Symposium concluded with great success through its dissemination of reliable applicable information derived from qualified sources such as UNIFESP,



Post-conference gathering of Medical Doctors, Symposium Committee (in orange) and relatives

UNICAMP and the SP-Foundation. The impact of this information to affected people and their families brought hope through effective therapies that improve quality of life, medical treatments to slow and reduce the effect of the disease and progress toward an eventual cure.

Staying Active with HSP

By Tina Curfman, HSP

I was first diagnosed with HSP in 1991. I started showing symptoms in my late teens.

I've always been very active. Playing sports in school and then running/walking every morning before work. Of course, with HSP you never know how you're going to feel or what your body will



Tina and Coach Brandon

let you do that day. I am thankful that I am still able to work full time and that I am able to walk a little over two miles a day. It's not a "pretty walk" but my neurologist assures me that my gait is normal for my condition. For me, walking on the treadmill or my routine walk through my neighborhood was getting boring. I wanted to try something different.

My 14-year old son plays tennis. I signed him up for lessons when he was 11. He really enjoys playing and as I watched people come for the adult classes, they all looked like they were having fun. So, I talked to my son's coach, Brandon, and asked if he would be willing to work with me. I told him that I had HSP and sent him a link to read about my condition. He said he would. We started out slow, very slow. I did not know if I could really move to hit the ball. I'm excited to say that I am still taking lessons and that I've also joined the Adult Beginner Class. I've found the more I move the better I feel. I have more mobility now than when I first started in November 2018. My Neurologist, who has always encouraged me to stay active, told me I no longer need to do physical therapy. She said I am doing my own therapy with tennis and walking. She did say as long as I can play safely and I am not falling or losing my balance, she thinks it's great!

Tennis has been great for me, both mentally and physically. I do still have bad days, where I am not able to walk due to the spasms or pain, but I just try and work through it. The support from my

Continued on next page



Tina's Adult Beginner Class

family and all the new friends I've made through tennis has completely changed my life. Always be willing to try something new!

Reflections

By Susan Parkinson, FSP (a.k.a. HSP)

Seventy-three years went by rather quickly. I have times that I reflect on those years with a little smirk on my face, some with smiles, and some with frowns. I think I've had a full life with lots of adventure: some bad and some good. But I like to think I'm grateful for the good and the bad because it has helped me learn more about the world, and people, as well as myself.

I loved being a mother and watching them as they grew and changed; grateful that I was there to watch as they weaved their way into adulthood. I wove myself out of a twenty-two-year marriage, thrilled that I could live my future life with happiness, free of an abusive relationship. I was free and I was ready to fly.

But life throws us surprises sometimes. Mine came as I was walking across a rough lawn, carefully holding a large plate filled with food for a picnic. Suddenly I was on the ground with those tasty morsels thrown in every direction. I got up and didn't think much more about it - until the next time and the time after that. I finally went to my doctor who had no idea why I was tripping. After a few months of tests and no answers he suggested I go to the Mayo Clinic in Rochester. That is where I found the diagnosis of Familial Spastic Paraplegia. I felt so relieved that I finally knew what it was. It could have been something much worse and I tucked my prescription in my pocket and flew home. This progressive disease wasn't going to be progressive with me!

This diagnosis came when I was fifty, and I'm now 73. Baclofen never worked for me and I have tried a large variety of medications, all with the

same result. I worked at keeping a schedule of exercises. I now use my walker full time. I can no longer walk without it. I don't travel anymore and seldom go out in the winter where I have to fight with the snow and ice. I really limit myself, afraid of falling and breaking a bone.

I don't like this disease that has robbed my body of things it once loved to do. But I try to stop and tell myself how fortunate I am that it's not a horrid disease that is taking my life. My mind is in place (I hope) and there are lots of things I can do. I can still paint, read books, enjoy family and friends, and plant a few things in a garden box outside in the Spring. No, it's not convenient like it once was and I hate to hold people up when we go out. I'm embarrassed at being so slow and I feel like a burden. But I think they understand. We are friends. I would do the same for them.

I don't pretend that it's easy and sometimes I get so tired of it. Why does this happen? I want to run down a beach with my grandchildren, or something as small as taking a little walk in the lawn, or go fishing which I always loved to do. It makes me mad!

Then I have to talk to myself. "Susan, you can't do lots of things you wish you could. But there are lots of people who don't even have half the choices you have. You have to keep on trying to do what you can and work to discover new things." I discovered a slow cooker the other day which is much easier than trying to stand over a stove. People will help and serve themselves, and they seem to like the helping. I would like to help someone that was having difficulty serving a meal. Or needed help shopping, or getting something fixed. I have a disease that makes lots of things difficult. I know there isn't anything I can do about stopping it right now, but I know I can work on living my life today. It's a choice.

Importance of a Strong Support Network

By John Boucher, HSP SPG7

HSP is hard enough to live with, having a strong support network is key. An appropriate network should include a medical team and family members.

Medical Support Team: An HSP patient must have the support of a quality medical care team that will work together. It's very important to have a neurologist that has HSP specific knowledge (they're not easy to find!). This is important because he or she will be able to prescribe the appropriate medication in the correct dose. You

and your neurologist have to work together to find what works best for you since so little is known about HSP. The neurologist will also be able to recommend a good therapist.

Physical therapy is really important to those suffering HSP. The therapist can help you to learn exercises and stretches that you can tolerate and will benefit you specifically. Exercise is key to being at your best. The therapist and/or neurologist will be able to send you to see an Exercise Physiologist that can recommend and teach you how to properly do exercises appropriate for the HSP patient.

It is also important to have in your support network mental health professionals. There is no shame in admitting that you see someone for mental health issues related to what you are going through. Let's face it, we're not who we used to be; we can't do all of the stuff we used to do at all or at the same level/intensity. It's only natural that as your particular HSP case progresses, you may become susceptible to depression and/or other mental health issues. Your neurologist will be able to recognize these issues and refer you to the appropriate mental health professional.

Family Support Team: It is key to have the support of your family - husband/wife, children, parents, in-laws and your brothers and sisters. They each need to have varying levels of understanding what you are going through. If you're married, your spouse should have a detailed understanding of your disease. They will need to know what you're going through and what to expect so that they can provide the appropriate level of support. If you have children, the disease will have to be explained to them - the level of detail will depend on their age. They will need to understand their chances of inheriting the disease also. This is very important so that they can help to support you. Parents, in-laws, brothers and sisters will only need to know about the disease on a tangential level so they can help you and support you.

If you are building a support team, the most effective one will have both a medical and a family component.

Party of More Than One When You Have More Than One Disability

By Katie Robinson, HSP

Upon my conception, I decided I wanted to try more than one genetic condition. I was born with Oculocutaneous Albinism type 1a; albinism causes the body to produce little to no pigment and

causes varying degrees of vision loss. My HSP presented very mildly as a teenager and became more evident in my early 20s. HSP has caused sensorimotor polyneuropathy and I have difficulty regulating my autonomic nervous system (likely from neuropathy). I am prone to tachycardia and difficulty with my heart rate jumping around and my blood pressure tanking and jumping back up. This has also caused mild gastroparesis and slow colon motility. HSP affects my bladder as well. My diet is very bland and carb based with a side of laxatives. In addition, I have Mast Cell Activation Syndrome, a condition that causes the MAST cells in my body to leak histamine inappropriately when exposed to strong scents, certain foods, medications and temperature changes.

My Albinism is a more severe type, so I am very pale and my vision is on the worse end of the spectrum at about 20/600. I have always known visual impairment, so I have always had a disability to compensate for. Acquiring additional disability from HSP has been more difficult for me to accept and has really tested my ability to adapt on the fly. I have always known how to be blind; I have not always known how to be blind with a physical disability. I can say it is easier to be born with a disability and not know what you are missing vs. acquiring a disability and remembering what used to be. I do mourn for what I used to have and what I used to be able to do. I allow myself to feel those feelings, but then I pick up and keep going. I find new ways to do old things and find new things to do. I try to keep my world ever expanding, not shrinking.

I currently walk with AFO's and a cane for the blind or I use a custom manual wheelchair for distances. Using a wheelchair with a significant visual impairment has been a learning curve. I received Orientation and Mobility (O&M) lessons as a child but those lessons were as a walking blind person, not a wheelchair using blind person. O&M teaches people with vision loss how to safely



Katie doing a wheelie

travel independently in all types of environments. I've fallen off edges, bumped into walls, corners, furniture, and people. I've scraped up my frame and tested my seatbelts ability to keep me in the chair. I can also kick a pretty sweet wheelie and move faster than I moved before. I

Continued on next page

can go shopping and enjoy myself and shop for much longer. From a seated position, I see more items on lower shelves I cannot see standing up. I've participated in some wheelchair sports. I can go out with friends and play Pokemon Go for longer stints with no pain.

Currently, I am 29 and work full time as a Braille Transcriber and Large Print Production Specialist; I am a Certified Literary Braille Transcriber. This means I make braille and large print textbooks and educational materials. I speak to university students twice a year about my experience as a blind person in the education system, so they can be better teachers for disabled and abled students. I also talk life as an independent working adult, inclusion, and how to avoid ableism and tokenism.

For fun I like to read (audio, braille and large print), mostly non-fiction or realistic fiction. I loom knit hats, headbands and scarves. I make lotion for myself and for family and friends. I own an albino corn snake named Mini Me. I like to watch anime and cartoons. I consider internet browsing a hobby. Up next, I have set my sights on learning to use a sewing machine to make dresses and skirts and to explore making clothing to help conceal incontinence products while still looking fashionable.

I do not know what my future holds. So far, I have not heard of another patient like me. But I am who I am, for better or worse. I deal with the difficulties head on, feel my feelings and keep moving. Dry humor has been a major coping method. Good friends, and staying busy, and enjoying the small things. I am content in my ever-changing world.



This Is Not All About Me

By Lisa Kubek, PLS

I was diagnosed 10 years ago and quite honestly, it's still surreal. Never did I think when I was playing baseball that I would someday be confined to a wheelchair.

The progression of my symptoms has proven to be challenging to say the least. I've lost use of my legs, my hands and arms, and worst of all, my ability to speak.

But enough about me. I often think about the affect this is having on my family. I couldn't ask for a better caregiver than my husband Joe. When we married a little over 30 years ago, he hadn't signed up for this. I guess this is part of the "in sickness and in health" of our vows. Most

assuredly I still do my share of laughing...I laugh a lot thanks to Joe! That is why I fell in love with him from the start and our laughter and love has grown stronger despite PLS!!!

Also, my son, Joey, has shown repeatedly that he'll do anything, and I mean anything, for me. He is our joy and we try to let him go to live his life. He's shown us his devotion time and again. Of course, Joe's sister, Sue, and my sister, Mary, have been more than generous with their ongoing help for our family.

Last but not least, I need to thank our friends who will stop in or call to see if we need anything. At times they'll take me out or sit home with me which gives Joe a well-deserved break. Unfortunately, I'm unable to join them for some things we used to do, so some of those relationships have severed. That's okay though because I know if I called any of them, they'd be here in a nano-second to help.

I would like to give props to my champion, Dr. Tomas Holmlund, Neurologist from the Dent Institute. He originally diagnosed me and remains in my corner 10 years later.

My future is PLS and every day my family and I are learning to live with it. We are forced to be prisoners of our bodies for the rest of our lives. Disabled, no treatments, no cure (yet).



My Long Search for A Diagnosis

By Tracy Taylor

In the late 1980's, when I was in my mid 20's, I became aware of a nasal sounding voice. I thought nothing about it for a while and no one ever said anything about it. While living in Tampa, I visited an ENT and he thought I had some kind of sinus issue, so I had sinus surgery. After surgery, when my nose was filled with cotton, my voice sounded normal. Once the cotton was out, the nasality was still there. He sent me to speech therapy, which helped a bit, but the nasality was still there.

In the early 90's, while living in Miami, I went to another ENT about my nasal sounding voice, he sent me to speech therapy, which helped a lot. While in therapy, my voice was a lot clearer, but still not 100%. Insurance only pays for therapy for so long and the few months of therapy helped, but it was over. The ENT also sent me to see a neurologist. He had me do numerous tests, a MRI, CT scan, etc.; all tests came back negative. He had mentioned a few diseases, one being ALS, but nothing came of it.

Then a friend of my mom recommended seeing a plastic surgeon that maybe I had a paralyzed palate. I had an appointment with a team of doctors – plastic surgeon, dental, neurologist, social worker, gene therapist, etc. They concluded that I had a paralyzed palate and that having pharyngeal flap surgery would be good for my condition. I had the surgery in the early 2000's and a touch up in 2002 followed by speech therapy. Again, my voice got better with therapy, but once it stopped, it went back to being nasal. During most of this time speech therapy helped, but when I stopped, it would get worse.

I was also sent to see a Prosthodontist who fitted me with a retainer type of product that pushed up the palate area. I wore this for a few years but it did damage to my teeth. It seems everything I did helped a little but nothing major. At this time, my speech was still understandable but very nasal.

In the late 2000's I went to a new neurologist who diagnosed me with Myasthenia Gravis and put me on a steroid and another medicine and to speech therapy. Again, it helped a little, but when I stopped, it went back to normal.

In 2006, I started to notice I would stumble a lot or trip over things; my neurologist diagnosed it as drop foot and I starting using an AFO on my right foot. This seemed to help with my tripping.

Finally, in 2010, under the pressure from my best friend, I went to Cleveland Clinic, saw a new neurologist, again MRI, CT scan of brain, thyroid test, etc. and they all came back negative, including tests for Myasthenia Gravis and ALS. My new neurologist took me off the steroid, which let me lose about 20 pounds, and the Mestinon. At my re-evaluation with the neurologist, she told me that they did not have a diagnosis, but probably it was PLS. Again, I was sent to speech therapy and again it worked a little, but it had to end so you know what happened.

About 6-8 months after discontinuing the Myasthenia Gravis medication, I noticed my balance was a bit off. I go back to the neurologist at Cleveland Clinic every year for follow up and a checkup. Went to physical therapy twice and speech therapy twice at Cleveland Clinic.

To this day, my voice is still very nasal and is sometimes not understandable over the phone. The speech therapist spoke to me about banking my voice, but I do not think I am mentally there yet. Strategies I use to help with my PLS, if that is what I have are:

1. Walk with a cane when I walk far;
2. Walk around my home or patio without cane; do not want to become dependent on it;
3. Work out in the gym at least 4 times a week, arms but mainly leg strength;
4. Talk slowly so that my voice is somewhat more understandable;
5. Neurologist gave me a handicap decal for my car.

After seeing numerous doctors and therapists over the years, I still have no conclusive answers. I try to keep myself physically and mentally strong, which is another story as I also have PBA.



Still Searching for A Diagnosis

By Ann Dapice, PhD (Lenape/Cherokee), Director Education and Research, T.K. Wolf, Inc., a 501(c)(3) American Indian organization Skiatook, OK

Some 15 years ago I began having troubles climbing stairs. I had been active and able to run up and down stairs all my life. For a time, a neurologist in Tulsa did some tests ruling out MS, MG, ALS, and it was decided that I should go to a surgeon who performed decompression surgery in 2009. Neither my climbing and walking problems nor low back pain were helped. I was then diagnosed with Sjogren's in 2014. I learned that along with other head to toe symptoms of this autoimmune disease, there were neurological problems as well which often preceded Sjogren's diagnosis. After several different sessions of physical therapy that did not help and an additional neurologist who said he didn't know what the problem was, my walking, talking, swallowing, and dropping things were worsening. So I went to the Sjogren's neurology clinic at Johns Hopkins in late 2017. The neurologist there said that he saw some spasticity in my walking and after tests, said he did not think Sjogren's was the problem, but instead, I had PLS. I had not heard of PLS so I began researching it, saw clinical trials for rare diseases and as a long-time researcher, I wanted to aid in the research.

So I signed up for trials in San Francisco in November 2018 and at the NIH in Bethesda in January 2019. In San Francisco, after brief examination, I was told I had "PLS light." Then last March I was told that the Bethesda research showed I had no PLS and perhaps was having problems related to aging. Over the years I have become older while trying to find out what the problems were, but I am quite active physically, socially and academically in numerous ways. I was left in confusion. It felt somehow

Continued on next page

embarrassing. I did not make up the diagnosis. While I had to pay for transportation and the hotel for the trip from Tulsa to San Francisco, NIH footed the bill in Bethesda. I sent all my medical records, MRIs and other test results to Bethesda, including those from Johns Hopkins. I would not purposely have taken up their time and resources had I not been diagnosed with PLS at Johns Hopkins. It is confusing to family and friends as well as those who wish to be helpful.

I know that neither Sjogren's nor PLS have a cure. In some ways nothing is changed. My symptoms that appeared to be PLS remain. The medical field is still determining what testing clearly demonstrates PLS and Sjogren's. Meanwhile, perhaps we need a section for research of symptoms that don't fit current testing.



My Road to Become an SPF Ambassador

By Tara Ames, HSP unknown variant



Tara Ames

My name is Tara and I am 46 years old. I live in Canada, about an hour away from Vancouver and I have HSP though it's an unknown variant of type 4. I began to show symptoms around the age of 35. HSP runs strong in my family. I am the first in my generation to show symptoms, however some cousins have been asking a lot of questions lately. My

mom had it as did six of her siblings and their father.

Initially upon diagnosis I was kind of back and forth with support groups. I even turned off my notifications for months to avoid seeing posts because, honestly, they scared me! A LOT!! I always knew there was a chance I would inherit this, but I just blocked it out as a coping mechanism.

My first visible symptoms started with my gait. I didn't even notice it, but my friend who I hadn't seen for a long time mentioned it to me. Slowly my gait disturbance progressed. My feet started to drag; I would stub my toes a lot. I noticed when I was stressed or anxious, my walking would be different, maybe rigid. I then started to have muscle spasms which also increased in frequency. Sometimes my legs would just give out and basically collapse. Then I slowly lost the feeling in my legs. The farther down I go towards the foot area the less feeling I have there. I always have cold extremities. When it is cold, I find it is much

harder to walk because my stiffness increases. I find my left leg to be weaker than my right. I stumble a lot and have to hang on to my husband's arm for balance and I have had a few falls. My legs are very rigid and sore, more so in the evening. I find stretching them before I sleep helps a bit. I have had depression on and off because of this disease. Some days I am stronger than on other days.

I would likely still be blocking out this diagnosis if we weren't at the point we are now with science. Before with this diagnosis, not much was known, if anything, and you just had to accept it and live your life the best you could.

I strongly believe things are different today and there IS finally hope! There are many researchers working on gene therapy and CRISPR for a variety of rare genetic diseases and, thanks to the SP Foundation, there are a few working on gene editing for HSP and are funded by SPF research grants.

Now I am at the point in my journey where I want to take on a different role and get more involved and make a difference. The kids are now grown up and in University which allows me more time - so here we are!

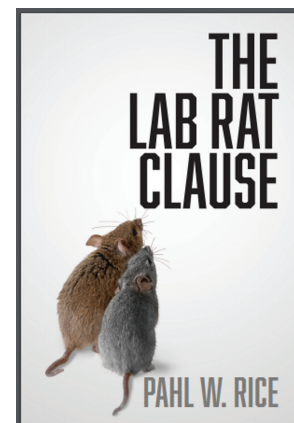
I am very happy to say that I'm taking on the role of SPF Ambassador for British Columbia and Saskatchewan. I look forward to getting to know each of you and I encourage you to reach out to me at Tara.ames@yahoo.ca or (604) 908-6869 should you have any questions. I will be learning as I go, but have some visions in mind. I would like to hold regular get togethers so we can keep connected, share our stories, wisdom and ideas as we navigate this journey together.



The Lab Rat Clause

Society believes that people with disabilities cost society too much and should be eliminated; so they kill the people with disabilities. The main Character, Ben, has disabilities and faces the challenges put before him by this culture in an effort to survive. Those in charge of the executions are making every effort to be sure he does not survive.

Pahl Rice has HSP and is a member of the SPF. He wrote the book based on some of his own experiences with HSP. The e-book is now available on Amazon at a very reasonable price.



Problems with Your Bladder?

By Ann Darrah

I have HSP, SPG4. Looking back, I think I had symptoms of HSP for years, but I had no idea that the symptoms were hints of what was to come. At around 50 years old, the tripping started and I started having trouble lifting my legs to walk. In my 50's the bladder problems kicked in, the immediate urgency to go the bathroom, and the inability to get to a bathroom quick enough. The additional problem, of getting up four times during the night to go to the bathroom, and then having a small amount of urine come out.

I went to a bladder doctor and he suggested the Interstim, an electronic bladder stimulator, which I got. It really didn't help me and it caused my legs to cramp while sleeping. I eventually just turned it off.

When I could see that the Interstim wasn't going to help me and I was at the end of my rope as far as fixing my bladder problems, I started more research. There are physical therapists that specialize in bladder issues. Men and women have bladder issues and I saw both men and women in the office that I went to.

What I learned in the office made a huge difference in my life and I hope you will get the same benefits that I have. Traditionally, doctors say to do Kegels, but if you are not doing them right, they are doing more harm than good. I was told that a muscle that supports the pelvis, the transverse abdominis, needs to be engaged while doing the Kegel. The transverse abdominis supports the bladder. Explanation:

1. Lay down on the floor with your knees bent and feet flat on the floor, you might need a flat pillow under your head.
2. Take a deep breath of air, feel your stomach fill up with air.
3. Blow out the air, and push your lower back into the floor. While the back muscles are pushed into the floor, use the muscles that stop urine flow. In other words, a Kegel. I'm not sure what term is used for a man, but women are probably all familiar with the term Kegel.
4. Hold the Kegel for a count of 6, release and go through the entire process again. If you can't hold for 6, then do 1 or 2, then try it again.
5. It's really hard at first, but really think about it, after you do it, it's easier the next time.

6. Start by holding the muscle for a count of 6, then work up to holding for 20. Then hold for a count of 20, 10 times.
7. If you have trouble getting the muscles to engage, go to a physical therapist, they have electronic devices that can get your muscles to wake up. I would call and ask questions before I make an appointment, this is not just any physical therapist, this office specializes in the pelvis and bladder problems.

I hope this helps you as much as it has helped me. My bladder is not perfect, but I can sleep all night without getting up and although I don't leave the house without a pad, my bladder function has greatly improved. There are more exercises to help the bladder, but this muscle is the main one to start with. I would be happy to send the other exercises that I was given. But just doing these has helped me. If you have any questions, my name is Ann, madann@frontier.com.

Bridge to Sleep

By Michael Isber, HSP SPG7

I was diagnosed over six years ago with HSP SPG 7. I am 64 and I'm told it's expected that I can be up two or three times a night to urinate which is probably due to an enlarged prostate. I don't expect this is due to HSP as other men over 60 have similar symptoms. However, getting up and walking to the washroom while my body is still half asleep can be precarious. I have been getting up at night for the last few years which is getting tougher as walking is more laboured.

I had visited a Naturopath about two years ago who had recommended a natural supplement called Uro-Pro that was quite helpful in reducing the symptoms of getting up and making for shorter visits to the john. It can take my body a couple of minutes to wake up and start "going". The only problem I really have with this is that I may not get back to sleep after a 4 a.m. rising which makes for a short sleep and a tired day after. My walking is quite a bit worse when I am tired.

I added bridge exercises into my daily routine a couple of months ago: my back on the floor, knees up and feet flat on the floor; raise hips up so straight body from shoulders to knees and back down. I do two or three sets of 40 daily.

Continued on next page

Surprisingly, I mostly don't get up through the night much anymore and when I do, it is only once. My water consumption is the same and there are no other changes that might account for this improvement. I asked my therapist if this change might be due to the bridge exercise and she commented that the bridge exercise was probably strengthening the muscles around the prostate. I had started doing bridges to help strengthen my glutes, but this was an added benefit. And now my sleep is much better!



Winter 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.

I live in Yakima Washington, about 2.5 hours from Seattle. We have ice and snow; it averages 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 with 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 found these Snowboot Crutch Tips (for Ice and Snow) on Amazon and they work well on ice and snow (they do wear out after a while). They also help give my custom walking stick (as it uses a cane tip) good traction in winter weather. Be sure to take them off your cane tip once you get inside as they are very slick on tile and other solid surfaces (they are alright on carpet).



Snowboot Crutch Tips

Go to the following website to purchase these directly from the manufacturer: <https://yaktrax.implus.com/products/traction/>. You can also buy these from Amazon for \$5 to \$10 less than the MSRP prices shown above.

Yaktrax Traction Cleats (PSP).



I keep a set of yaktrax under the seat in my truck and a set by my door at my house as they give me better traction with my regular shoes. I have used the Walk and Pro versions of the yaktrax and both work well. The Pro version stays on your feet better if you are using a snow shovel or a snowblower or if you are going to be doing a lot of walking outdoors. However, the Walk version is easier to slide on an off your feet as they don't have a strap.

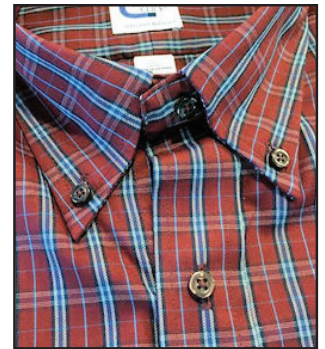
[Remember, if you buy from Amazon, don't forget to use AmazonSmile and Amazon will make a donation to SPF based on the value of your purchases. Editor].



Magnetic Buttons

By Jim Brewi, PLS

My daughter bought me these adaptive shirts for Christmas and I love them, so I thought I'd share. They use magnets under the buttons and were easy for me to put on!



The manufacturer is Magna Click, www.magnaclick.com

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

Annual SPF Fundraiser, Mt. Kisco, NY

By Ann Marie Lakin, HSP SPG7



NY Fundraiser,
Ann Marie Lakin

On October 18, 2019 I organized and hosted my annual SPF fundraiser in Mt. Kisco, NY. The event was well attended - over 75 people came to the fundraiser this year. A lot of friends and family attended as well as fellow SPF members. Dinner was pot luck and we had a great variety of food from chili and lasagna to brownies and homemade cookies for dessert.

Entertainment was provided by two bands who were terrific and had us dancing and singing along with them. The first band we heard from was Gray Matters. They sang a lot of oldies and with five members had some great harmonies.

When Gray Matters finished their act, I welcomed everyone and spoke about how much money this event has raised for research over the years. Since I started having fundraisers in 2008, approximately \$13,000 has been raised at the event, excluding donations that were mailed to me separately. One of the ways I announce the fundraiser is to email a letter to family and friends describing the event and explaining what HSP and PLS are. I also directed them to the SPF website for additional information on these two rare diseases.

I then talked about some of the research that has been done. Through research many gene mutations causing HSP have now been identified as well as a gene responsible for PLS. My brother-in-law, who does research at the University of Pennsylvania, told me how important it is to



NY Fundraiser Some Attendees

have fundraisers for research. The reason that fundraisers are so important is research is very expensive. Every dollar raised is needed to move research for HSP and PLS forward and bring us closer to the cures. He also told me, "Doing standard experiments on any particular day, can cost \$1,000/day or more and as much as \$240,000/year. There are other expenses such as DNA analyses to look for mutations, costing approximately \$750/sample, and pictures to archive data costing about \$300/hr. Scientific research is quite costly; therefore, fundraisers are important to move the science forward."

After that, we heard from the next band, Bedside Manor. They were a real rock 'n' roll band that had us moving and shaking.

We raised over \$1,700 that night. I asked people to make a \$15 suggested donation at the door and I also had a number of items for a silent auction. Local vendors donated gift cards or items I could use for the auction. I am always surprised at the generous response I get from the different stores. People are so helpful and anxious to contribute.

It was a fun evening. Not only did I raise at least \$1,700 that night but I also raised another couple thousand in mailed donations. In total, over \$3,000 was raised for research. When people heard I was having a fundraiser, they often wanted to make a donation even though they couldn't attend the event.

If you are considering having an SPF fundraiser of some sort, I really encourage you to do so. Someone once asked me how mine started. I replied that I had wanted to participate in a fundraiser, but there were none nearby so I started my own. It takes very little effort to have a fundraiser. So many people are willing to help and, like I said before, fundraisers are very important because research is so expensive. I know one day we will find cures for HSP and PLS and I am glad I am making a contribution.

CARS FOR SPF?

Frank Davis has been working with a company that handles vehicle donations for charities. They profit by taking 30% of the sale's proceeds. The charity gets the 70% balance. *More to come.*

The Rosella Vigliotta Golf Tournament, July 26, 2019

By Meredith Gattuso, PLS



Meredith Gattuso

The 9th annual Rosella Vigliotta Golf Tournament took place on Friday, July 26, 2019. Every year we hold the tournament at the Rock Hill Golf and Country Club in Manorville, New York on Long Island. This year we had 85 golfers participate and 100 additional people came for the dinner and raffles. Each year the tournament becomes a bigger success and we are able to make a greater donation to SPF. In past years we sent our donations to the Foundation under my cousin's name; however, this year it was sent under the tournament's name.

Rosella Vigliotta is my paternal grandmother. She passed away in 2009. Grandma was an incredible person. A mother of seven children, she also found time to volunteer at the local hospital and with her church. She had a wonderful sense of humor and was known for her kindness and generosity as well as her loving spirit.

My aunt and her daughter were looking for a way to honor Grandma's memory by helping someone in need. With medical bills to treat my PLS and costs for the equipment and transportation to keep me mobile, my family was having a very rough time financially. When my aunt and cousin approached me and my husband and the rest of my siblings to propose the fundraising tournament to help us and to raise money for the Spastic Paraplegia Foundation, it was an answer to our prayers.

My grandmother continues to inspire generosity and love. This year, in addition to raising money for my family, we donated \$8,500 to the SPF and were able to give more than \$1,200 to a local family in need of a van to transport their wheelchair dependent son. We are always on the lookout for ways to provide hope and to help others. That's why we call our tournament The Rosella Vigliotta "Hope in One" Tournament.

Meredith Gattuso was diagnosed with PLS nearly 16 years ago at the age of 33. Within 6-8 months her symptoms had progressed enough that she was forced to step away from a job she loved, as an aide for disabled children in preschool and kindergarten classrooms.



Golfers Ready To Take The Course

Dropping

I drop things quite often that's just what I do
 The top scoop of ice cream falls right on my shoe.
 My hands are so clumsy and a little bit weak
 So grapes in my hands are going to be free.
 Deviled eggs are the devil to get in my mouth
 They'll drop to the flooring without a damn doubt.
 So don't hand me money if you owe me some change
 You'll just see some heads roll; I'll say you're to blame.

Hugh Fenlon 2019

Time

*Time is short, we need to cherish the moments together
 before we die
 We need to reach out for a hand to hold on to life
 To always have a friend who can help us to move
 upwards and forward
 We need to stand together as one to cherish the moments
 together as friends
 That is really the meaning of time together as friends ...*

Kathleen Kienlen, 2007

Kathleen is Ann Marie Lakin's sister. She recently passed away in January from cancer at the age of 50. Kathleen had HSP SPG7 and Down syndrome. Even with these, she worked 5 days a week for 32 years at the Philadelphia Navy Yard.

SPF Illinois Connection, October 26th, 2019

By Hank Chiuppi, PLS, SPF Board Member, SPF Co-Ambassador for Illinois

Braving the cooler weather, we had 29 participants come from all around the Chicago area plus visitors from Rockford and Paxton Illinois. We also had a Wisconsin state ambassador, Mary Ann Inman, and her husband, Tom Inman, from Clinton, Wisconsin. Special guests were Dr. P. Hande Ozdinler, from Northwestern University and her friend, Dr. Ulupinar, Professor of Neurology and Neuroanatomy. Adding to our guests was Deborah Rose who is a medical candidate in 2020 studying Neurology at Loyola University. I met her through the Global Genes Rare Compassion Project, <https://globalgenes.org/compassion/>. This project matches medical students with rare disease patients. By doing this, medical students have an opportunity to learn firsthand about diagnosis as well as the unique challenges faced by patients every day and the means to connect with the rare disease community. Sid Clark, my co-ambassador and good friend for many years, was missing due to being in rehab after surgery.

The group discussed a number of topics including, falls, CBD oil and cannabis, current TV shows that portray patients seeking a diagnosis, ways to deal with pain, and medications. We also talked about state programs that might help people with disabilities. Above all we had a good time with positive energy in the room sharing thoughts and suggestions.

Dr. Ozdinler told us about her research which is focusing on upper motor neurons because she feels they are the key to a number of neurological diseases. Upper motor neurons are responsible for voluntary movement. She is also collaborating with Dr Fink from the University of Michigan.



Attending were 8 HSPers, 6 PLSers, 12 caregivers and 3 guests.

Making Connections in Ohio

By Pamela Jordan Handley, HSP SPG7, SPF Ohio State Co-Ambassador

Autumn rain didn't dampen spirits as 23 Spastic Paraplegia Foundation (SPF) members, HSP patients and guests from all over the state gathered



OH Rismiller Presentation

in September in Gahanna, Ohio, a suburb of Columbus. The occasion was a special event sponsored by neurologist Yasushi Kisanuki, M.D. of The Ohio State University Wexner Medical Center and co-sponsored by SPF Ohio State Ambassador Pamela Jordan Handley. For some attendees, the half-day event was the first time they connected with other HSPers. For others, it was an opportunity to keep the conversation going after attending the SPF Annual Conference in San Antonio. For all, it was a welcomed opportunity for sharing and support.

In his opening comments, Dr. Kisanuki thanked his patients and the SPF for being driving forces behind the day's event – adding that their questions and areas of interest helped shape the agenda. An early highlight of the agenda was Sara Rismiller, PT, MPT, NCS, a board-certified Physical Therapist specializing in Neurologic and Orthopedic Rehabilitation at Wexner Medical Center. Ms. Rismiller discussed the importance of a daily stretching program for managing spasticity. She also offered tips for a successful exercise program, including:

- Do an exercise or activity that you enjoy, whether it's water aerobics, chair yoga or a home exercise program.
- Enlist a buddy to keep you motivated. It's harder to skip exercising when someone is counting on you to be there with them.
- Remove barriers that keep you from exercising. Strapped for time? Start with five or ten minutes of activity at a time and build up to at least 150 minutes a week.
- Make "SAM" your best friend when setting exercise goals: **S**pecific, **A**chievable and **M**asurable goals are the keys to success.

Another area of interest was choosing assistive mobility devices. Ms. Rismiller emphasized that different situations may call for different devices.

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OH Breakout Session

What works for getting around the house might not be enough for getting around the community. There are many “tools in the toolbox” with ambulatory aides such as canes, crutches, rollators and walking sticks and mobility devices such as manual and electric wheelchairs, scooters and other power-driven mobility devices (OPDMD). Choosing the right tool for the right activity can have a positive impact on daily living.

By the time the group split into breakout sessions, conversations were in full swing! There were so many stories, best practices and questions to share, the sessions lasted nearly twice as long as expected – and probably could have gone longer except for the lengthy drives home facing many of the participants.

As the afternoon drew to a close, the most frequent comments were: “It is so reassuring to meet others who understand what it is like living with HSP. When can we get together again?” Initial plans are underway for 2020 events in Ohio, and ideas for Ohio locations, topics and activities are welcome! Send your suggestions to Pamela Jordan Handley at jordanhandley.pamela@gmail.com.



Ottawa Ontario Connection, October 19, 2019

By Julie Ann Samson, SPF Ambassador - Ontario, Canada

We had our third Ottawa connection on October 19th. Twelve people attended and once again we compared notes, everything from our doctors to our meds and different treatments. We also chatted about our everyday lives and the traveling some of us have been doing. We also talked about the annual conference that was held in San Antonio this past June. All in all, everyone had a great time and we’ve set the next get together for April 25, 2020.



L to R: Brian Green, Christine Hall, Tara Tucker, Jacques Collin, Deb Collin, Cathy Bergeron, Kathy Selst, Pieter Selst, Julie Ann Samson, Mike Wood and Laura Wood. Taking the photo was Allan Ewen

Sarasota, Florida Connection

By Gene Levin, PLS, SPF State Ambassador - West FL

I hosted an SPF meeting for the west coast of Florida members on Wednesday, November 13, 2019. Four members and one spouse from the Sarasota area met for lunch to share and learn from each other’s experiences. Of the four, one used a cane or her husband’s arm, one a rollator, one a walker and one a scooter.



We each took some time to share parts of our lives before and after diagnosis. The names of meds currently being taken or that had been previously used included Valium, Tramadol, Baclofen, CBD along with supplements believed to be beneficial. Individual results were actually all over the place, but I don’t recall any one med that stood out. In an effort to limit or stop disease progression, the following activities are being used: weeding the lawn, working out at local gyms, swimming, stretching, etc. are in play. Being the most limited, I intently focus on transferring, getting up when seated and visualization.

We spent some time discussing the search for GOOD neurologists, which gene is the “baddie” we deal with, the specific HSP type, studies known to be underway or getting specific bloodwork done to have more detailed information and to add to the national registry. As a PLSer, my entire focus has been on dealing with my current limitations so I’m able to remain as active as possible, be positive and not be a burden for as long as possible.

Bruce and I shared our favorable results from being fortunate to work with ALS and MDA centers. Here is a summary of how I was dealt with at the MDA center I attended in Sarasota. I, having PLS since 1980, met with my neurologist, who runs the center for the MDA, about 3 times yearly. After vitals are taken by a nurse, a young paper-pushing high school student doing a study, two breathing specialists who did a pulmonary function test and reminded me of the importance of using my cough suppressant device, a social rep with MDA to make suggestions or what needs I might have and then my neurologist for a discussion and Q & A session. The entire visit takes 1.5 to 2 hours, sometimes longer.

Bruce was similarly impressed by the specialized attention given by the ALS Clinic at USF Tampa, where options and alternatives were discussed, including gene testing and Botox injections. Being a teaching hospital, he got two neurologists’ opinions for the price of one!

We also had a connection in early January and plan to have another one in March.

NASHVILLE



June 26-28, 2020

Annual Conference



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Registrant Name#1: _____

Disorder: N/A ___ HSP ___ PLS ___ SP ___ ALS ___ Other ___

Registrant Name #2: _____

Disorder: N/A ___ HSP ___ PLS ___ SP ___ ALS ___ Other ___

Must be under age 18 to register as child

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Disorder: N/A ___ HSP ___ PLS ___ SP ___ ALS ___ Other ___

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What aids are you likely to use a conference? Check all that apply:

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Powerchair ___ Animal ___ Other _____

Meal Requirement: Regular ___ Vegan ___ Vegetarian ___

Gluten-Free ___ Kosher ___ Other _____

Food or Other Allergies (List): _____

TENTATIVE AGENDA *

Thursday, June 25

9am-5pm - Board of Directors Mtg

5pm-6pm - Welcome Reception

Friday, June 26

8am-4pm – Registration Open

9:am-11:30am – Pre-Conference Discussion w/ Dr Fink

10am-12pm Pre-Conference Video

1pm - 5pm General & Breakout Sessions

6pm-8pm - Welcome Dinner

June 27, Saturday

7am – Lite Breakfast Provided

8:am-5:pm - General & Breakout Sessions

12Noon – Lunch, plated

1:15pm – General Session w/ Dr John Fink

3:30pm – Breakout Session

5:00pm – Donors, Doctors & Sponsors Reception

Dinner (on your own)

Sunday, June 28

Breakfast (on your own)

9:am – 11:30p – Breakout Sessions

11:30am – adjourn

***Subject to Change Without Notice**

Hotel Registration

Follow #hspandpls, #TeamSPFHilton

Hilton Nashville Airport, 2200 Elm Hill Pike, Nashville, Tennessee, 37214, 844-886-4136 Mention “**SPF**” for discounted room rate of \$154, Room block ends Juen1st. Free Self Parking, Complimentary Airport Transportation, and Wifi, The hotel is conveniently located only 2-miles from the Nashville International Airport (BNA), 6-miles from downtown.

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Questions, please email us at: SpasticConference@gmail.com

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2020 Annual Conference
June 26-28, 2020
Nashville, Tennessee



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