SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.

Volume 27, Issue 3
Fall/Winter 2023

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2023 SPF Annual Conference Photos & Recap

HOW TO HELP

We operate out of the strength of our community, caring friends and sponsors. Your help makes a difference!

Please contact us at volunteer@sp-foundation.org to help in one of the areas below or to suggest another way you can get involved.

SUPPORT RESEARCH TO SPEED OUR CURES BY VOLUNTEERING

Below you'll find information on some of the ways you can help SP Foundation in their search for a cure to PLS and HSP.

Raise Funds: The primary focus of SPF is to raise funds to support research to find the causes, treatments and cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. Our major fundraising activity consists of a TeamWalk. Individuals can help organize local fundraisers. People are also needed to secure corporate sponsorships and help with grant applications.

Patient Connection Programs: Organizing a Connections gathering for people to meet, share stories and help one another is a great service. Events can be as simple as meeting for coffee! In areas with large patient populations, SPF seeks to establish Chapters.

Conference Organizers: SPF's conference coordinator gladly welcomes planning and organizing assistance from SPF members living in or near the metropolitan areas selected for annual conferences. These events feature speakers and programs on special topics of interest to our community and provide opportunities for individuals to meet others. Conferences can be half-day or full-day events.

Communications: Individuals with writing, research, website or graphic design skills are needed to assist with various communications initiatives.

Ambassadors: Ambassadors raise awareness about our disorders as well as enhance community building and industry relationships. You can assist with media relations, share your story, speak at local groups or help with grassroots advocacy.

Business and Administrative Support: Volunteers with business and administrative skills can play a valuable role in administering the work of the SPF. Most of the help is coordinated through email correspondence and uses popular Office applications.

SYNAPSE

Volume 27, Issue 3 - Fall/Winter 2023

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 is published quarterly. It is also available online at www.sp-foundation.org

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Send Correspondence & Donations to:
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O'Fallon, MO 63368-6202

Contact the SPF at:
(877) 773-4483
information@sp-foundation.org
or www.sp-foundation.org
Norma Pruitt, Executive Director

Special thanks to Gulf Business Printing, Jim Burkhalter and Donna Hinshaw, for their assistance and support for the *Fall/Winter 2023 Synapse.*

Letter from the President


Greg Pruitt

Hello, SPF Members & Friends,

WOW!

The 2023 Annual Conference in St. Louis, Missouri, was another fantastic event for the Spastic Paraplegia Foundation. It was such a pleasure to see so many long-term SPF Friends and meet many new warriors. The SPF Board also announced the formation of a new research project - the SP-CoE, Spastic Paraplegia- Centers of Excellence. The SP-CoE is an effort with our physicians and investigators to establish initially nine CoE's to help accelerate the process of finding treatments and cures for both HSP and PLS. Many of you, both at the conference and from home, are meeting the challenge to raise more research dollars when one, little, young man initiated the first donation on Friday afternoon. By the end of the conference, everyone collectively raised $165,000! What an amazing group committed to our common mission, vision, and goal.

I want to say "Thank You" once again to every board member, committee member, volunteer, and contributor who assisted in the work of the conference. A very special thank you to our St. Louis area members who helped with so many details. Finally, we cannot thank our sponsors enough for their contributions which make the conference possible and that provide the financial basis on which to build a great conference!

Please take the time to look at all the great pictures and information about the 2023 conference. We are currently working hard on the details of the 2024 Annual Conference. As soon as we have the details available, we will get them to you. We truly believe it is essential for our researchers, investigators, and physicians to see us collectively in person to have a broader understanding of the suffering we endure with HSP and PLS. We truly hope you all will find a way to join us in the 2024 SPF Annual Conference in Tampa, Florida! LET'S KEEP GROWING SPF MOMENTUM TOWARD TREATMENTS AND CURES!!

Until next time,

Greg Pruitt

Greg Pruitt, President

CHECK IT OUT!!!

The Gutierrez Family had an ***Amazing Turnout*** *for their 2nd Annual 5K Run, Walk, and Roll!*

Read the full story on page 10

SP-CoE -- SPASTIC PARAPLEGIA CENTERS OF EXCELLENCE

With your charitable support to the SP-Foundation, you are enabling researchers to take important steps distinguishing and characterizing HSP and PLS. Recently, a team of investigators submitted a grant request to the SP-Foundation with a proposal forming an inaugural North America network for HSP and PLS, titled "Spastic Paraplegia Centers of Excellence (SP-CoE)". This innovative concept brought these outstanding doctors and scientists together to help us in a collaborative effort forming Multi-Stakeholder Consortiums. The central hypothesis is the SP-CoE will successfully enroll 100 individuals with HSP and PLS under shared regulatory data, and sample infrastructure over a two-year period. The team is comprised of renowned investigators, who have contributed to the understanding of HSP and PLS on a clinical or molecular level. The establishment of SP-CoE is a critical step towards creating clinical trial readiness for HSP and PLS and accelerating the development of improved diagnoses and therapies.

In an effort to support the funding of the SP-CoE, we were astonished by a young man that started a fundraising challenge with a $93 contribution and then just as quickly an anonymous donor stepped forward to pledge up to $70,000 as a match to any funds raised during the 2023 Annual Conference weekend. It was literally kicked off with a $93 contribution and within 26 hours, the momentum and energy helped to raise $86,000. To date, we have raised $95,000. The SP-CoE grant will cost $300,000 for the first year and an additional $300,000 for the second year. With your help we hope to raise an additional $300,000 this year so that funding the SP-CoE will not take away from funding our annual grant awards that are evaluated by the Scientific Advisory Board. With the $95,000 raised, along with the $70,000 match, we need your help raising $135,000. Please donate directly to SPF by clicking the red Donate button on our homepage at SP-Foundation.org.

BIG THANK YOU TO SPONSORSHIPS TO OFFSET CONFERENCE COSTS

SPFoundation's Annual Conference Sponsors

Kris Brocchini

The SP-Foundation and community would like to express our sincere gratitude and appreciation to Kris Brocchini for the generous support, contributions, and friendship you give to us and the Spastic Paraplegia Foundation. Thank You!

THE CONLIN FOUNDATION

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MISSOURI BOTANICAL GARDEN

Brittany Kasaba and Christopher Falconer hosting a connection get-together at the NY Yankees minor league team. We had a blast and are looking forward to making it an annual event at the Somerset Patriots Park in Bridgewater, NJ.

SPF Team Events – North Texas

North Texas – Connections – 2023 – Tennis and Luncheon

By Tina Curfman (HSP), Celyna Rackov (SPG4), and Jeana Fraser (SPG4) SPF Co-Ambassadors in North Texas region

On Saturday, June 17, 2023, some of our North Texas HSP/PLS members got together for a little tennis and lunch. Celyna Rackov (SPG4), Jeana Fraser (SPG4), Trevor Taubert (HSP) and Tina Curfman (HSP) along with some family members for support met at Goldfield Tennis Center in Denton, TX.

Once again, Coach Brandon spent a little time with each of us working on our strokes and volleys. He started with Margaret Ann (Trevor's daughter) she had great footwork and was fast on her feet getting to the tennis balls. Then Trevor took his turn. He played well in his tennis chair and was able to move fluidly around the court returning tennis balls. Jeana was next and she had great form when returning volleys. Celyna played next with the help of her husband Randy. She did a great job of hitting the balls back and keeping her balance. I think she remembered some of the strokes that Coach Brandon taught her in 2021. Tina was last. She hit a few backhands and forehands. We then broke off into teams and had a little rally with Coach Brandon feeding the balls in, and the five of us keeping the game in play.

After playing tennis that morning, Tina Curfman, Jeana and David Fraser, Celyna and Randy Rackov, Roberto and Joana Silva (Celyna's parents), Sue (HSP) and Gary Rudd, Romina (PLS) and Mack Amin attended a late luncheon at Olive Garden restaurant in Fort Worth, TX. At this lunch meeting, members shared their experiences about their diagnoses, age of onset, medications, braces, supplements, diets, neuropathy and other upper motor neuron (HSP & PLS) symptoms. We also discussed physical activities such as Pilates, swimming, horse therapy, and tennis.

Continued on next page

Tennis Picture: L to R: Brandon, Celyna, Tina, Margaret Ann, Trevor, and Jeana

Lunch picture: L to R: David, Jeana, Tina, Roberto, Joana, Gary, Sue, Randy, Celyna, Romina, and Mack

All in all, it was a great day! We met new North Texas members and their family members. Celyna's parents from Brazil were there to support Celyna and cheer for all of us! They also snapped some photos and video of us so that we could make our North Texas HSP/PLS 5K fundraising video.

We looked forward to meeting again for the Virtual Texas Connection in a week prior to the 2023 HSP and PLS Awareness Week.

North Texas – Connections – 2022 – Luncheons

The group in North Texas shared information on two Luncheon Connections in 2022 by Celyna Rackov (SPG4), Donna Matejka (SPG4), Jeana Fraser (SPG4), and Tina Curfman (HSP) SPF Co-Ambassadors in North Texas region.

On April 23, 2022, the SPF Co-Ambassadors Celyna Rackov (SPG4), Donna Matejka (SPG4), Jeana Fraser (SPG4), and Tina Curfman (HSP) were joined by Celyna's husband Randy and her parents Roberto and Joana Silva for the North Texas Connection luncheon at the Olive Garden in Grapevine, TX.

On July 16, 2022 another luncheon was held which included: Jeana Fraser, Donna Matejka, Jeff Janak, Celyna and Randy Rackov, Jolene and Harv Weisblat, again at the Olive Garden Restaurant in Grapevine, TX.

The North Texas team also met again in a Virtual Texas Connection just prior the HSP and PLS Awareness week August 2022, and in person again in November 2022.

Our SPF Ambassadors know the value of pulling members together to chat, meet in person, and share experiences related to living with HSP. In both meetings SPF members shared their experiences about diagnoses, age-onset, medications, walk-aids, supplements, Botox, genetic testing, spastic paraplegia symptoms, and physical activities such as Pilates, swimming, tennis were also discussed. If you'd like to meet with others with HSP and PLS that live near you, why not host a luncheon or a meeting at your local library or a coffee shop. If you aren't aware of folks in your area that have HSP or PLS – reach out to your SPF Ambassador for some help in locating neighboring members. It is an excellent way to connect, especially if you haven't been able to attend an Annual Conference.

North Texas Connection; April 23 L to R: Randy Rackov, Roberto Silva, Joana Silva, Celyna Rackov, Tina Curfman, Jeana Fraser, and Donna Matejka

North Texas Connection; July 16th L to R: Harv and Jolene Weisblat, Donna Matejka, Jeff Janak, Jeana Fraser, Celyna Rackov.

2023 SPF EVENTS CALENDAR

--**Year-End Giving** Nov. 1st thru Jan. 15th

--**Giving Tuesday** - Tuesday, Nov. 28, 2023

--**Neurologic Disorders Support Group with Dr. Fink** -*See dates/times on SPF Events Calendar*

--**SPF TALKS** - *TBD – Become an SPF Member for E-Blast Updates*

--**RARE DISEASE DAY** Feb. 28, 2024 - Annually

Do you have events to share with SPF to help raise awareness? Please send the date of your event and your graphics so we can upload them to our Events Calendar.

Walking for a Cure!

By Tracy Hood

I'm excited to share my journey in getting involved with the SP-Foundation this year! I participated in Christine Hendrickson's (SPF FL Ambassador) 5K in late May this year. It was refreshing for me to make a human connection with someone in my local area who also shares this journey of HSP. It was also a test for me to see if I could actually complete a 5K. Funny story, before even embarking on considering this 5K, I had a personal goal to train for and complete a 5K by June of 2023 (mission accomplished). Meeting Christine and Kathy Angel at Christine's 5K also led to friendships and my attendance at the SPF Annual Conference in St. Louis, MO in June 2023. I was so inspired by the people I met – those afflicted with HSP and PLS, and those life partners, spouses and caregivers who are just as passionate about the search for a cure. I was energized by the neurologists and researchers who presented their research focus toward a cure. I knew that weekend that I needed to be more engaged and involved in helping to drive SPF's mission to find a cure.

My Background Story … I experienced disease onset and was diagnosed with HSP in 2015, with confirmation through genetic testing in the summer of 2016 – SPG5A. I learned that both of my parents were symptomless carriers. Like a lot of us, I had never even heard of HSP before my diagnosis. I'm sure you can all attest that this has been a journey like no other. My disease onset also came with secondary afflictions of hypothyroidism, acute onset high blood pressure and asthma.

Planning to host my first SPF Run, Walk or Roll 5K … I planned my 5K to happen on Saturday, September 23rd, my birthday, to host my first SPF Run, Walk and Roll 5K in Seminole, FL (Pinellas County). I selected my birthday on purpose – I could not think of a better way to spend my birthday than to challenge myself and create awareness and fundraise for the SP Foundation. Having never hosted a 5K before, I spent time looking into setting up my fundraising page. I'm sure I was overthinking it, telling my story, and sharing it with my friends and family. Being a new FL Ambassador for SPF, I also sent out Emails to others afflicted with HSP and PLS in my tri-county area. At first, my fundraising felt like it was off to a slow start. BUT… my friends and family also started spreading the word, sharing my story and my fundraising link. By race day, I had more than doubled my goal of $2,000. I still have some funds coming in, but I expect to be over $5,000!

Tracy Hood, HSP

On the day of my walk, I had about 30 attendees. It was a beautiful fall Florida morning. I had relatives that flew in from other states to walk with me and support me. I can honestly share I was so humbled and so grateful for everyone that attended and supported me through donations. I made sure to share with attendees before the walk started to thank them for their attendance and their generosity. I also let them know that my time would be slow, so we took a "before" picture, in case some peeled off if they finished before me. With my trusty stick (cane) in one hand and holding my husband's hand with the other, I walked the full 5K in one hour and twenty-eight minutes. It was such an important goal for me personally to physically challenge myself to complete this walk. I believe that this is the start of something special – we will host another event next year and we'll see how we can grow this movement! Thank you, SP-Foundation, for creating a platform where we can be part of the mission to find treatments, therapies and, one day, a cure for HSP and PLS!!


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City of Saint Louis
Proclamation
I'm with THAT spaz
I'm with THIS spaz
FINDING A NEW NORMAL
Smith Family Home
House Plans
Views of the Home
KANSAS
FRIENDS
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KANSAS
SPF WARRIOR

North Texas Connections Go Around the World

By Jeana Fraser and Celyna Rackov

Aspec Brasil is the Brazilian spastic paraplegia organization which supports five different diseases (HSP, PLS, TSP-Tropical Spastic Paraplegia, Sjorgren Larsson Syndrome, and Stiff Person Syndrome).

ASPEC
BRASIL
Associação de Paraparesias
Espásticas Correlatas do Brasil

One of SPF's North Texas Ambassadors, Celyna Rackov, is a founder and Vice President of Aspec Brasil along with Rejane Mota, also a founder, Honorary President, and Director for Associated Support Board Member for Aspec Brasil. Rejane has three adult children, in their 30's, two of her children (one of the sons and a daughter) have severe SPG 11 with cognitive impairment and juvenile ALS.

Celyna asked Dr. John Fink to provide a virtual presentation for their first Aspec Brasil webinar in 2020 while simultaneously being translation into Portuguese. Dr. Fink conducted a fantastic presentation about HSP and PLS. Celyna also asked Dr. Hande Ozdinler in 2021 to provide a similar Portuguese translated presentation as a second webinar for Aspec Brasil. As expected, Dr. Ozdinler provided a presentation about the NU-9 compound research.

Aspec Brasil was so grateful to Dr. Fink and Dr. Ozdinler for speaking to them. Rejane's son with SPG11 gave a decorated mug along with a t-shirt and other branded Aspec Brasil items to Dr. Fink and Dr Ozdinler because Rejane as well as Aspec Brasil were so grateful to the Doctors for speaking to them. Rejane said, "in spite of the difficulties for our family, we decided to turn the focus from the pain/negative to something positive". Her family tapped into Felipe's and Camila's artistic abilities in recognition of Dr. Fink and Dr. Ozdinler. Find inspiration, hope, and additional information in SPF's Winter 2022 *Synapse* about a previous Virtual Brazil Connection. These hand-made items from Rejane were given to Dr. Fink and Dr. Ozdinler at the 2022 SPF Conference in Nashville by Jeana Fraser, Texas Ambassador on behalf of Celyna, Rejane, and Aspec Brasil who was unable to attend.

GOLFING FOR RARE DISEASE RAISES MORE THAN $17,000

SPF-Kentucky hosted the 9th Year Golfing For Rare Disease Scramble raising more than $17,000 for the Spastic Paraplegia Foundation. The golf scramble fundraiser was held on Saturday, September 9, at Drake Creek Golf Club in Ledbetter, Kentucky. Beautiful weather, teams, friends, and more than thirty sponsors combined to raise funds for research to find treatments and cures for hereditary spastic paraplegia and primary lateral sclerosis. SPF Kentucky thanks every golfer and sponsor who played an important part in the success of this annual event. SPF-Kentucky invites golfers to put it on your schedule now and plan to be a part of our 10th annual event on September 7th, 2024!

5K RUN WALK ROLL

Starting in May of this year, many teams and people gathered in person to kick off a 5K Run Walk or Roll to raise money for medical research. This year, we have participants that have run, walked, rolled, swam, played tennis, used mobility devices and one person used a Peloton device. It is easy. You pick the physical activity, set up your personal fundraising page on the SPF website and raise money for the Spastic Paraplegia Foundation. All those that register and raise or contribute at least $100 qualify for a 100% cotton 5K t-shirt.

To date, 42 participants have raised over $50,000 towards our goal of $75,000. Challenges for Fundraising for the 5K Run, Walk or Roll will continue through Oct 31, 2023. Several participants will host their events in the coming weeks as the weather transitions to Autumn. For specific information to register, because it's not too late, use this link: https://sp-foundation.org/get-involved/events/5k-run-walk-or-roll.html

★ ★ ★ ★

The Gutierrez Family hosted our second annual 5K Run, Walk, and Roll on Sunday, October 15. We had a fantastic turnout of over 75 participants. We had two HSP members as our honorees, Francesca Harris, and J.Taylor Gutierrez. The 5K Event took place in Oakwell Farms Subdivision. This year we had three Sponsors for our event. A big thank you to

Hassinger's Hair Salon, Randolph Brooks Federal Credit Union, and Vision Source of Alamo Heights and MacArthur Park.

Our morning started with a welcome speech that informed our participants about HSP, PLS, and the SP-Foundation. Shortly after that, the participants got to run, walk, or roll throughout Oakwell Farms' beautiful trails. After the 5K, participants met in the clubhouse to enjoy a light breakfast and took part in a raffle. Prizes consisted of a $50.00 gift certificate by Hassinger's Hair Salon, a $50.00 gift certificate from Boss Bagels, caps with the SP-Foundation Logo, and two pairs of sunglasses donated by Vision Source of Alamo Heights and MacArthur Park. Everyone left the event with a participant's certificate, a gift from Vision Source, and a pamphlet about our SP-Foundation.

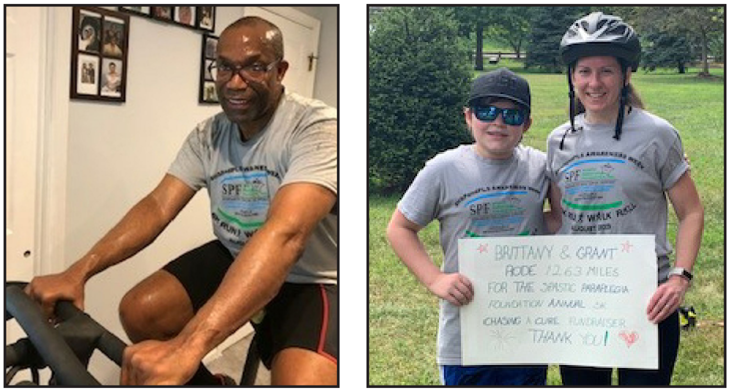
The Gutierrez Family, Patton Family, and the Harris Family felt very honored and blessed to have received so much support and love from our friends, family, and the Oakwell Farms Community. We had a fabulous time!

★ ★ ★ ★

Brittany and her son hosted a SPF 5k Awareness event as a bike ride together on the Columbia Trail, beginning in High Bridge, NJ, riding 12.63 miles. "My son riding with me was a birthday present since we did this over my birthday weekend. Along the way, we greeted others enjoying the trail to bring awareness to our matching SPF shirts. At a water break, we were approached if we were riding for a cause, which opened up a nice conversation about SPF and the support that is needed during an important growth opportunity for our community. My family and I are looking forward to making this an annual event."

Bob and Julie Conlin also pumped out over 100 miles during August to raise $10,900. Bob ran and Julie rode her Segway. Mary Schultz rode her Alinker and also swam as part of her event. She has raised $988.

Christine and Andrew Hendricksons and Trace and Ron Hood participated in their 5K in May. The Hendricksons had six people participate, raising $350. They had 6 people participate. The Hoods completed their 5K event, raising $4621. They had 30 participants.



Christopher Falconer hosted a fundraiser challenge on his Peloton bike, riding over 100 miles, and raising just over $15,000. He is a member of the NJ Ambassador team. Brittany Kasaba is also part of the NJ Ambassador team. She and her son, Grant, rode their bikes -10 miles, raising $9,035. The NJ Ambassador team also had an awareness event at a local professional baseball game. Go! #TeamSPF!!

Golfing is good to help train for balance and loosen hip flexors.

YEAR END FUNDRAISER & GIVING TUESDAY CAMPAIGNS

Each year, we focus fundraising efforts on a Year End Matching campaign. SPF has a dedicated and anonymous group of matching donors that has contributed in 2022 $300,000 that is used to match your contribution starting November 1st until January 15, 2024. All donations received during these dates up to the matching amount will be doubled. Our Year End Giving campaign also includes Giving Tuesday, which is a National Day of Giving. It happens on Tuesday, November 28th. Eblasts and emails will be sent to our membership before Giving Tuesday to provide additional details and the total amount of funds the matching donors will contribute in 2023.

Our goal in 2023 is to raise a total of $1,500,000. So far, we have raised $500,000. During the 2022 Year End Campaign over $600,000 was generated. Please do what you can to help us reach our year end goal by making a personal contribution and asking family and friends to support our efforts. Many employers have a matching gift plan, so contact your employer to see if your contribution can be matched and double your impact.

Using Facebook is also an easy way to generate funds for SPF. However, the issue is that it can take up to four to six weeks before the contributions are sent to the SP-Foundation. Facebook no longer shares donors' names and contact information so we cannot celebrate the success of the fundraiser or provide a thank you to those donors. The best and most efficient way to contribute to the Spastic Paraplegia Foundation is to contribute online by clicking the red Donate button on our home at SP-Foundation.org.

Thanks to all those that have contributed so far this year!

thank you!

Additionally, thanks to a group of anonymous donors that generously give to the Spastic Paraplegia Foundation, your donation, until January 15, 2024, will be matched. We are grateful for these anonymous donors, and we are thankful for the many generous donors like yourself who remain steadfast in the support of our vision. Yes, it's our vision– "The day when all individuals with HSP or PLS are diagnosed, treated, and cured." Everyone has something to give and every act of generosity counts.

Holiday Shopping is a Click Away at the SPF Store

This year, give a gift that keeps giving! When you choose to give a gift from the online SPF store, the official site for branded SPF merchandise, you help raise awareness of HSP and PLS. Plus, a portion of every purchase benefits medical research through SPF.

If you haven't visited the SPF Store lately, you haven't seen all of the new items and designs - just in time for the holidays!

- T-shirts, Hoodies and other logo wear for men, women and children
- Tech Accessories such as Phone and Tablet Cases
- Tote Bags and Backpacks
- Mugs for Home, Office and Travel
- Stationary and Stickers
- Plus so Much More

See all of the products, designs and colors by visiting sp-foundation.org/SPF-STORE and then clicking on the yellow "SHOP" icon.

MOMENTUM

STRENGTH OR FORCE GAINED BY MOTION OR BY A SERIES OF EVENTS

Momentum is Growing and Thank You for Making the SPF Conference One of the Best

The Spastic Paraplegia Foundation (SPF) greatly appreciated your attendance at the 20th Annual Conference in St Louis, Missouri. Again, this year many attendees in the conference room raised their hands noting they were attending the conference for the first time. This year we had approximately 163 total people register: eight children, 12 people with PLS, and 60 people with HSP. We continue to see more people receiving a diagnosis of HSP or PLS, or they are just finding out that a Foundation exists to support the HSP and PLS community.

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 to invite more people to learn about the Foundation - #HSPandPLS. These motor neuron diseases are closely related, and we must press on together to find cures or treatments for both.

The conference is not a fundraiser. It's an outreach effort to support and connect with patients, families, advocates, researchers, and doctors. However, in 2023 we experienced energy and momentum during the conference like nothing we have ever seen before. A simple act of wanting to desperately find a way to a cure, one little boy donated less than $100 during a meeting, and it grew to over $165,000 by the time the weekend conference had ended. As you can see, we need everyone working together.

In the welcome bag this year, we distributed a survey requesting feedback for the event. Thank you to everyone that completed the 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 for 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 in Tampa, Florida in 2024. More details will be made available as soon as we select a hotel and execute a contract.

Norma Pruitt

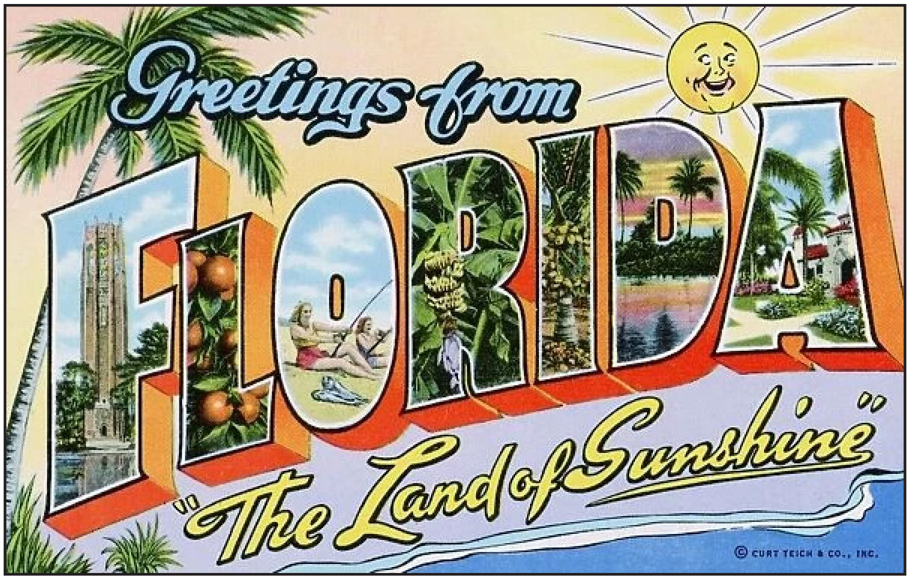
SPF Conference Coordinator

2024
SPF CONFERENCE
TAMPA, FLORIDA

(Dates & Details to Come!)

Don't Miss Out!

www.visittampabay.com/accessible-travel



REACH OUT TO SPONSORS HELPING SPF

By Sue Duffy Ambassador, FL

Visor Tags – Ideal Holder for your Handicapped Parking Tag

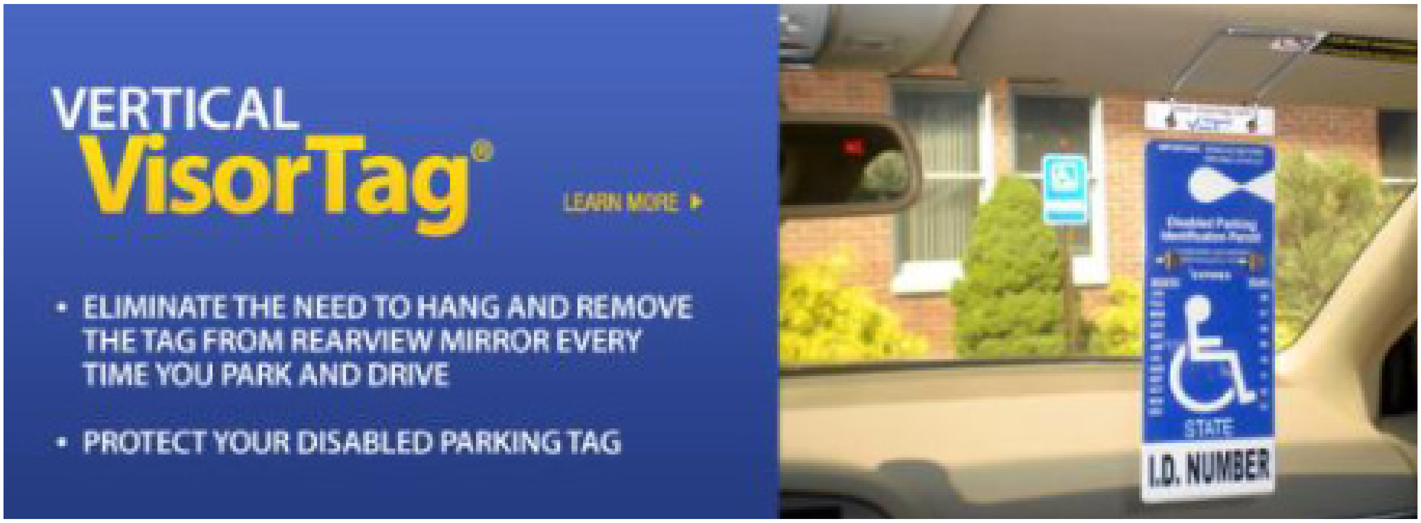
JL Safety
safety made easy

I was in a friend's car and noticed a device on her visor that held her Handicapped Parking Tag. This device has a means to flip down when needed. When not in use, you flip it back up where it is magnetically held up to the visor and out of the way. Plus, you are no longer in violation of laws in all 50 states that prohibit leaving the tag hanging from your rear-view mirror when the vehicle is moving.

Well, I got the details and went right on line to order one. I also looked up information on the company – JL Services. They are located in Matthews, NC and their products are made in the USA. They have multiple versions of the Visor Tag and other types of holders which can been seen on their website: www.jlsafety.com

I reached out to their "Contact Us" link and mentioned our foundation and that we represent over 20,000 people in the US, and most of us have the Handicapped Parking Tags, and would love a few to raffle at our upcoming conference. Their President replied and sent me 10 Visor Tags and also a discount code that all of us can use to order this or any of their other products from their website, with a 20% discount. **The discount code is SPF20**.

JL Safety was a sponsor whose donation to the SPF helped us in raising over $2,000 at the Annual Conference in St Louis. This is an amazing product that can make a day out in the car a bit easier, and with the generous discount they have given us, this cool tag holder is less than $20 and shipping is included.



Your Medical Store
Exceptional Products For You

YOUR MEDICAL STORE

Many thanks to "Your Medical Store" (YMS) for sponsoring SPF Annual Conference in 2023 and 2022. YMS is a premier medical online store, providing state of the art medical equipment, devices, rehabilitation products, and much more. YMS offers valuable products for people with diseases such as HSP and PLS. Type this URL in your favorite search engine, just make sure you use the dashes (-) in between the names of the company: https://www.your-medical-store.com . For questions about YMS search out Christine Patrick Hendrickson, ARNP, SPF Ambassador, Florida. Christine became an ambassador for YMS in 2022.

SILVER LININGS

By Christine Patrick Hendrickson, ARNP

Hereditary Spastic Paraplegia (HSP) has closed some doors in my life, but it has also opened a loft of windows. I have made priceless friendships and had countless opportunities.

In 2018, after 18 years of specialist visits, painful tests and misdiagnoses, I was finally diagnosed with HSP, SPG7. I found myself a single mom and a busy nurse practitioner- NOW WHAT? One of those opportunities came in a place that I least expected-with the staff at your-medical-store.com.

In 2019, I was on vacation with my husband and I saw a woman with a stand-up walker. I was curious and said "I would like to try one of those." When we got home my husband (the computer geek) went online to look at stand-up walkers. That is when he came across your-medical-store.com. They were advertising - "if you become a brand ambassador for us and post you using this stand-up walker we will send you for free". I thought "a lot of people probably applied, they will never choose me," but I will apply. Then much to my surprise, they chose me. The stand-up walker came the following week, and my relationship with the staff of your-medical-store.com was born.

Over the next several months Your Medical Store would send me medical products to review. I would review them and make videos about them to be posted to various social media platforms. I could review the products from the perspective of a healthcare professional and from a patient with a neuro degenerative disease perspective (HSP).

As the 2022 Spastic Paraplegia Foundation (SPF) annual conference in Nashville approached I mentioned the event to the Your Medical Store owner. I asked him if he would be interested in attending. He couldn't attend but he would donate a 'few' items. (I thought that he was going to send some pens or magnets.)

Was I surprised and thrilled that he donated many pieces of medical equipment, worth hundreds of dollars to be raffled and auctioned off at the conference. After the conference my relationship with Your Medical Store continued, with my participation as a brand ambassador.

As the 2023 SPF conference approached, I asked the owner of Your Medical Store to once again be a sponsor. He unfortunately could not attend, but once again generously donated hundreds of dollars of medical equipment.

I continue to work with YMS as a brand ambassador. I love to try all of the medical equipment. I hope that my relationship with Your Medical Store continues for years to come and they continue to support the Spastic Paraplegia Foundation. A relationship between myself and the people at Your Medical Store would most likely have never developed if it wasn't for HSP!

Unfortunately I have a neuro-degenerative disease, but now I have relationships that will last a lifetime. When one door closes, another one opens!

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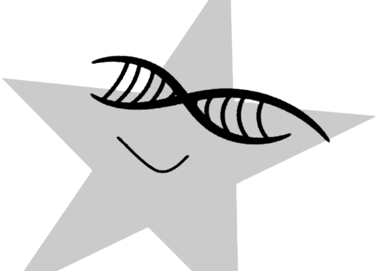

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