Winter 2022 Newsletter

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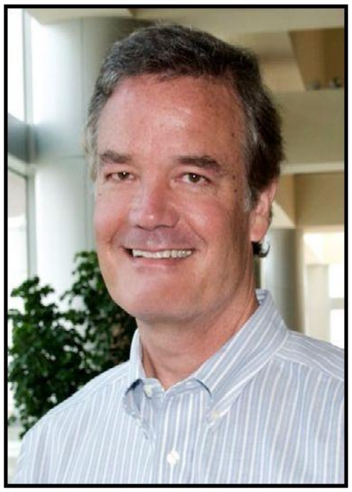
SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.

Volume 25, Issue 1 Winter 2022

WHAT'S INSIDE

Letter from the President



Frank Davis

Dear Friend,

“I have two things: HSP and Hope” was how a recent note from a donor read. That message seemed profound to me because those two things are what many of us hare; they also sum up the mission of our foundation.

That hope blossomed lately because together we surpassed great fundraising goal, raising over one million dollars for 2021. Our anonymous donor had a mid-January deadline for making a matching donation up to $200,000, so by mid-January we reached $1.2 million. Hurray and thank all of you so much for making our 2021 goal happen! Whether you chose our foundation as your AmazonSmile charity; participated in a run, walk and roll-a-thon; or donated via Facebook or any of the other convenient ways to give, you played an important part in getting us to our 2021 goal and passing the $1 million mark. This is about 25% more than we have ever raised and will help us get ever closer to the day when everyone with HSP or PLS can be quickly diagnosed, treated, and cured.

Each two-year research project that we sponsor receives $150,000, so $1.2 million will allow us to support eight leading edge HSP and

PLS research proposals ranked as "Excellent" and "Very Promising" by our Scientific Advisory Board (SAB). Our SAB is made up of leading scientific experts on HSP and PLS. Every research proposal we receive is carefully studied by at least two SAB members and graded on several qualities. Those detailed grades are turned over to the manager of our SAB, Dr. Martha Nance, who then ranks them from best to worst. We only sponsor research proposals graded "Excellent" and "Very Promising" by our SAB so we can reach cures as soon as possible and not waste a penny of your donations.

Every year the knowledge about HSP and PLS becomes ever more clear. As the knowledge grows, so does the excitement within the scientific community, as evidenced by the quality and quantity of research proposals submitted from all over the world.

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Special thanks to Gulf Business Printing, Jim Burkhalter, and Maximum Accessible Housing of Ohio for their assistance and support for the Winter 2022 Synapse.

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SYNAPSE

Volume 25, Issue 1-Winter 2022

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 Team

Pamela Jordan-Handley- Editor synapsenewsletter.spf@gmail.com
Therese Williams- Associate Editor
Donna Hinshaw- Designer
Katie Robinson- Large Print Edition Production

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1605 Goularte Place
Fremont, CA 94539-7241
Contact the SPF at:
(877) 773-4483
information@sp-foundation.org or http://www.sp-foundation.org/
Executive Director:
Norma Pruitt SPFKentucky@gmail.com

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I have appreciated the opportunity to be your SPF president. After serving for ten years, I decided to pass the presidential baton to someone who has been on our Board of Directors for many years: Greg Pruitt. I will stay busy on our Board of Directors so the transition will be smooth. Greg has served 26 years as Hickman County (Kentucky) Judge Executive, administering all facets of county government. He has served on and chaired various local, regional, state, federal, and multi-state organizations involving areas such as tourism, health and social services, transportation, and economic development. He has been dealing with adult onset HSP since 2002. About a dozen members of his family tree over the past three generations have dealt with HSP. Greg holds a bachelor’s degree in Political Science and Business Administration from Murray State University and a Juris Doctorate degree from the University of Kentucky. He lives in Clinton, Kentucky, with his wife, Norma. Please join me in warmly welcoming Greg Pruitt as our new SPF President.

Sincerely,

Frank Davis

Frank Davis, President Emeritus

Dear SPF Members and Friends,

It is a great honor to be asked to serve as President of the Spastic Paraplegia Foundation. First, I want to say a big thank you to Frank Davis for his dedication and commitment as SPF president for the past ten years. His stepping back a bit, no doubt, will leave some holes that we will work hard to fill. We appreciate that he has agreed to continue as a board member. Thank you so much, Frank-stay close to the phone and computer. We will be calling you!

I began serving on the SPF board of directors in 2014. My wife, Norma, has been coordinator of the SPF annual conference since 2016. She and I have served as co-executive directors of SPF since 2018 and count it a privilege to work with the SPF board of directors and committees. We look forward to getting to know many more of you as SPF continues to grow in our work and mission.

Greg Pruitt

SPF had a successful, innovative, and productive 2021, setting new records with webinars and fundraising. THANK YOU TO ALL WHO WERE PART OF THAT! Additionally, our Ambassadors, Education, and Marketing committees once again rose to the challenge.

My vision for SPF’s future is that we have ultimate success in finding treatments and cures for HSP and PLS. I believe the way to reach this is to build on the history of this great organization by increasing commitments from so many people willing to give of their time, talent, and resources. We live in a world that is different from even two years ago, and we commit to pursuing new and different opportunities to set even more new records in 2022.

Looking toward the future, I want to remind you of two important upcoming opportunities: Rare Disease Day, and the 2022 SPF Annual Conference.

- Rare Disease Day, February 28, is a time to raise awareness and generate change for those of us living with a rare disease and our families and caregivers. Share your story with others, such as your local community, media, and government representatives and help spread the word about HSP and PLS.
- You are invited to the 2022 SPF Annual Conference, July 22-24, in Nashville, Tennessee. This conference is a fantastic opportunity to meet others in the SPF community and hear from doctors and scientists focusing on research of motor neuron diseases. We always look forward to meeting new friends, seeing existing friends, and having the opportunity to know you better. See you in Nashville!

Cordially,

Greg Pruitt

Greg Pruitt, President

GENERAL INTEREST

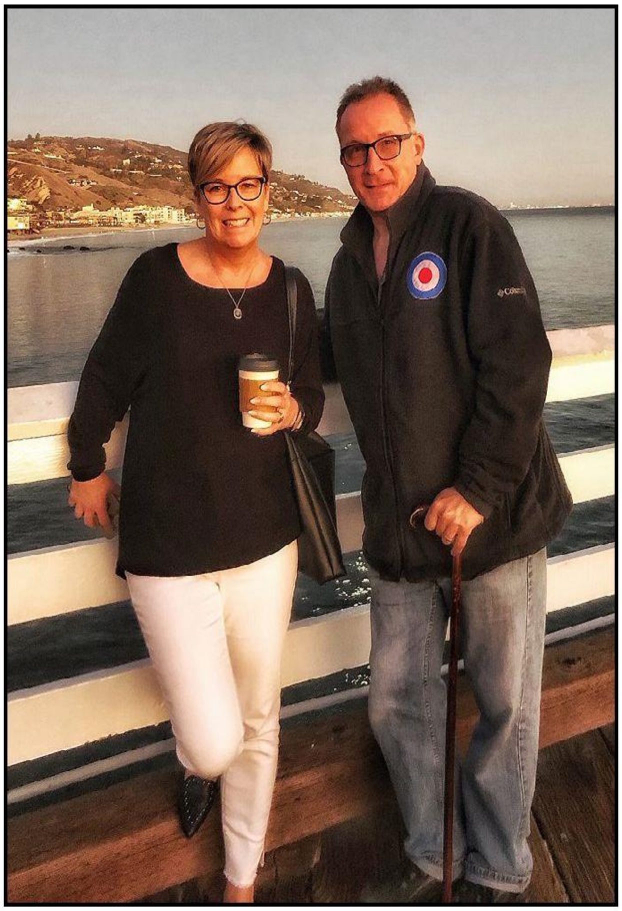
Traveling the SPG4 Highway

By Craig M. Renwick, HSP SPG4

It’s early morning, you’re lying there in bed and the first shreds of sunlight are filtering in for a new day. The weight of the blankets, however, is comforting and all you want to do is roll over and get just a little more sleep. All is ok, but then the clarion call of the alarm pierces the peacefulness and you must rise out of the bed to face the world that we call HSP.

Then once you are out in this "world" you can get the ambiguous "look"—you know the one—from people that try to figure out what's wrong with you. Did you have an injury and that is why you walk funny and use a cane? When will you get better and walk without assistance? I usually try to cut it off in the pass by sharing with them the name, Hereditary Spastic Paraplegia, which then elicits another look—this one confusion.

They have never heard of HSP before, and you need to underline that is why it is a rare neurological condition. Now comes the fork in the road of conversation. Do they ask any further questions or, because of the earlier mentioned confused look, do they move on from there? Typically, I get that. They say they are sorry and hope I feel better. I know, I know...they think this will go away.



Craig and his "discovered" sister, Sandy, catch up on family history and the prevalence of HSP among family members.

But for those who do have an inquiring look, I tell them that because of alien DNA from the planet Strumple being accidentally injected into my body, this is the result. Now of course, with an even more confused look on their faces, I smile and tell them the truth. This lovely condition that gives us a grab bag of stiff legs, spasticity, sudden jerking, frequent bathroom trips, and, for some like me, 24/7 pains with little or no relief was first described in 1880 by a German neurologist named Adolph Strumpell. It has been generally called Strumpell-Lorrain disease, but Hereditary Spastic Paraplegia was coined by neurologist Anita Harding in 1983. With some still puzzled looks, I hit them with the bottom line: there is no cure and no treatment other than band-aids like Baclofen, etc. That usually elicits another round of "I'm sorry" to which I am generally polite and, out of habit, say "thank you." Then there is that even more inquisitive person who raises the issue of heredity. They ask, "If this is hereditary why didn't you expect this?" Or they ask, "Is there another member of your family who would have given you an idea HSP might be in your path?" I share with them I truly didn't know. You see, I have lived with the life of the unknown because I was adopted as an infant.

If you asked me whether I had an interest in my biological past before I was officially diagnosed in 2014, my answer would have been a flat-out "no." But that story changed around two years ago with the results I received from a certain DNA site. I opened up the results and there, at the top of the page, it indicated that a certain female client in their database shared an almost 100% match with me and would be my sister. What!!??

To be completely honest, as I have already stated, I had no interest in trying to find my biological family. As far as I was concerned, I was adopted into a wonderful family with many aunts and uncles and cousins and I have had a good life. I confess, though, that there were times that I did have a little curiosity. However, it never went too far and remained tucked away—until that day I received those results.

I don’t know too many people who, after 60 years, get to meet their sister and family that they never knew about. Fortunately, I did and I discovered that I am not the only HSPer in the family. It appears that my HSP came from my mother’s side of the family and she is of German descent which connects us all back the neurologist I referred to earlier, Adolph Strumpell. In fact, several members of my biological mother’s side of the family have been members of this HSP club. My younger sister Sandy told me that when she was around 10 years old many members of our mother’s side were tested for HSP. Our cousin Rick (son of our mother’s sister, Bonnie) was part of this testing and was found to have possible symptoms but never showed until he was in his 30s. And not too long ago, his son Andrew, who is in his late 20s, shared with me his diagnosis of HSP.

I was talking to my therapist the other day and trying to explain what it is like for me on this HSP highway. I said when you are sick with a cold or the flu, sprained your ankle, or cut your finger there is the initial hurt and aches, but eventually, the healing begins and we get better. I told her I have always tried through this journey to keep the attitude of “it’s okay, I’ll be fine and I can handle it.” However, the more I have lost the ability to walk and have 24/7 pains in my legs, I have been getting discouraged. This is not a nick in the finger that will heal. This is a thief in the night that has robbed me, you, and the thousands around the world of one of our most basic abilities: to walk. Sure we can be depressed, we can have anger, we can cry, we can be sad—but other feelings need our attention as well, like laughter, love, curiosity, and gratefulness. I know those are much tougher to retain on days when we have the more difficult times, but we must not allow that thief to take away everything.

> **“I DON’T WORK IN A WORLD OF LIMITATIONS; I THINK OF THEM AS MODIFICATIONS FOR OUR WELL-BEING.”**

With nothing to do but slap band-aids on it until there is a discovery, it can be a little depressing. It is here, where being a member of this “club” that I did not want to be a part of, that I have reached out to the services of a therapist. No, the therapist does not have a cure, but it certainly helps to talk things out from the tough days. A therapist can be objective and help with coping mechanisms because, if you are like me, your family and friends have heard about it a thousand times and like everyone else can only provide empathy seeing what you are going through.

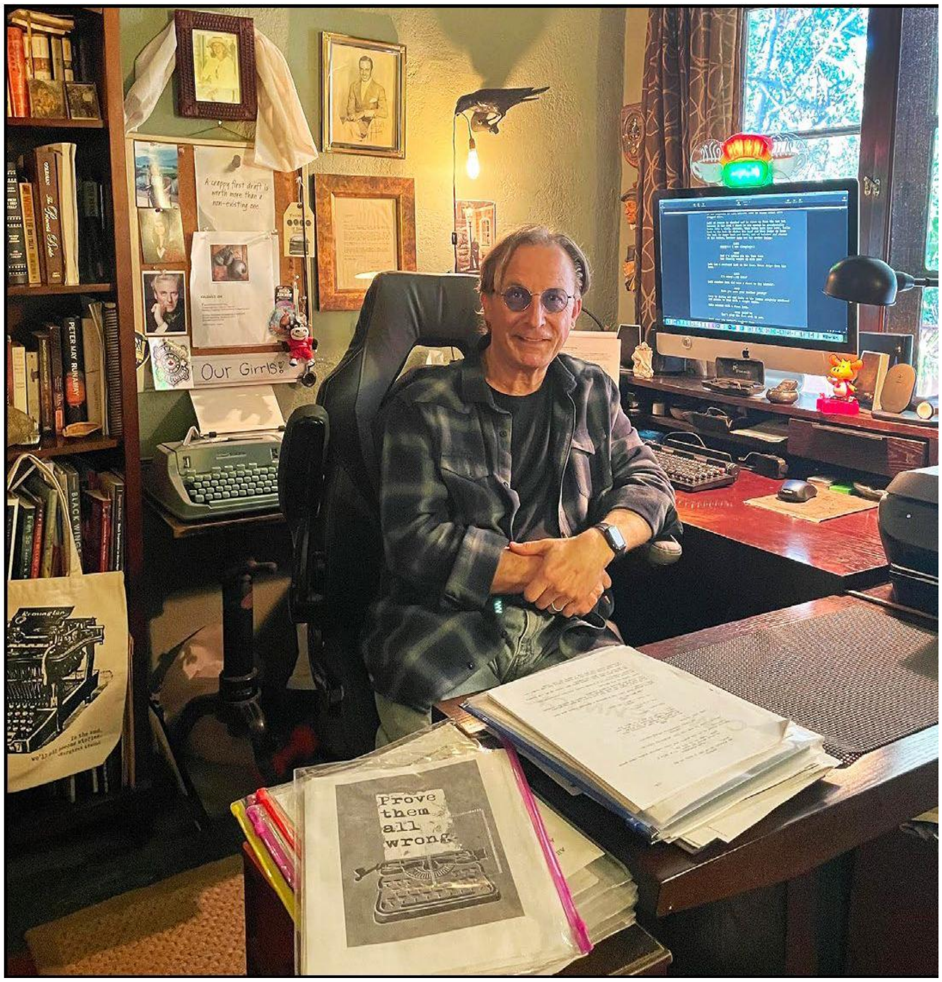
For Craig, living with HSP means moving beyond what he can no longer do and focusing on what he can do, such as pursuing his passion as a musician.

My therapist has given me some ways of dealing with it mentally. She stresses not being defined by HSP, but rather to stack the probabilities, not the possibilities, of our lives.

While it is a challenge every day, I have found some things that I can do that do not allow the thief to rob me blind—things like playing guitar and drums, a little gardening, taking care of my birds, some art, and writing scripts. In this forum, I am trying to write stories that are engaging and entertaining. As a result of these adventures, it creates a place for me personally where I can develop worlds where I am not dependent on a cane, or a walker, or a wheelchair to maneuver.

Because I am 63 years old and well versed in the film classics of the greats like Frank Capra, Preston Sturges, Billy Wilder, and others, I am, of course, not choosing stories where things are blowing up every five seconds. Instead, I am choosing interesting (at least for me and others who have read my scripts so far) stories that are quite diverse, trying to emulate the hero writers to me: William Goldman, Larry Gelbart, George S. Kaufman, Morrie Ryskind, David Mamet and other scribes. In my time behind the keyboard, I have written:

- A ten-episode series based on the lives of the women pilots from around the world that ferried fighter and bomber planes in the UK during WW2*;
- A modern-day genie story;
- A true story of the richest black girl in the world in 1916;
- A fun vampire series that takes place in Transylvania, Louisiana;
- The march of 20,000 WW1 vets on DC in 1932 lobbying for the bonuses promised to them; and
- One that is a celebration of books, Norse gods, and the powers of imagination.



These stories are a few among 25 others and growing.

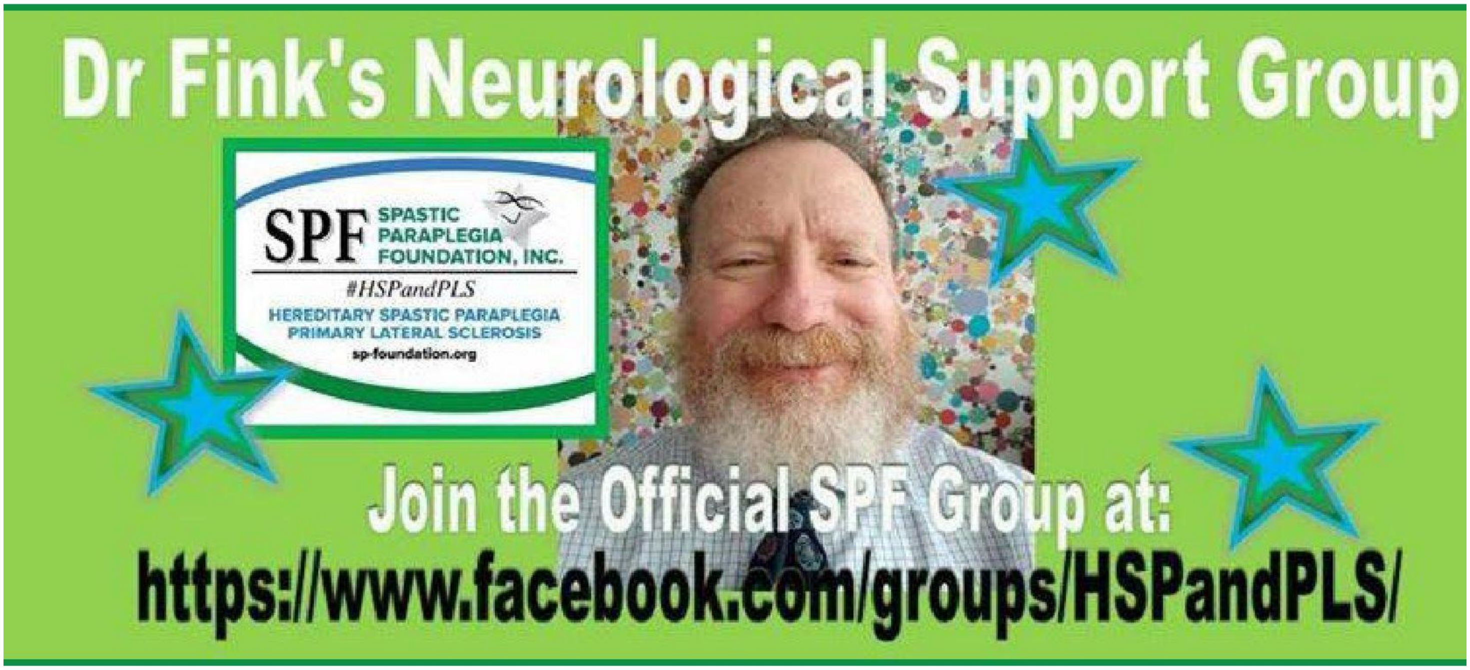
Not a writer? There are so many other things that we HSPers can do. Now with technology, we can explore new areas and take courses online. Perhaps there is an area of interest that can be entertained, given what each of our present limitations are at this time. Of course, I admit that I have never liked the word limitation. It conjures up what you can't do instead of what you can do. I don't work in a world of limitations; I think of them as modifications for our well-being.

Perhaps we find it difficult to do the 25 things we used to do; so maybe we focus on the ones we can do and have fun and enjoy those. We only get one ticket for this ride folks and we on the HSP highway have a few extra challenges to deal with while driving. But we can do it.

Sure it can be tough, and many days feel like we are pushing a boulder uphill. The positive is that we have a supportive HSP community that provides an empathetic base for each other. We can all share taking the wheel on this HSP highway and help each other on the journey to finding a cure.

* If anyone is curious and would like to read the first episode of the "SEVEN SISTERS" WW2 women pilots story I have written, you can go to this link: http://www.sevensisters.tv/

Craig credits scriptwriting for providing a creative outlet where he can develop worlds that transcend the need for a cane, walker, or wheelchair.



RAREDISEASEDAY.ORG
28 FEBRUARY 2022

Rare Disease Day Is February 28

By Therese Williams, SPG7, SPF Co-Ambassador for California, Synapse Associate Editor

Rare Disease Day is celebrated all over the world, and it's coming up February 28. The celebration creates energy and focus to support rare disease advocacy work on local, national and international levels. It's a platform to:

- De-stigmatize being "different" because of a rare condition;
- Get policymakers' and researchers' attention;
- Help all of us who live with rare diseases to find community and break out of isolation.

Rare Disease Day is about raising awareness and creating change for the 300 million people worldwide living with a rare disease, and for their families and the people who care for and about them. RDD started in 2008, and picks up steam every year. Last year, there were thousands of events in 106 countries, worldwide.

Therese Williams

WHAT CAN YOU DO?

Send a message of solidarity by sharing your story on rarediseaseday.org.

Light up your town. You can send an email to your civic leaders, requesting that they illuminate landmarks at 7 p.m. on Feb. 28. (Note: some towns are already planning something-double-check if yours is one of them!) Every town is different-but some good places to illuminate are bridges, courthouses, monuments, stadiums, main streetlights, bell/ water towers, and hospitals. And you can light up your own home; it doesn't take permission from anyone! Rare Disease Day colors are magenta, green, purple, and blue-you can find ready-made tools, logos and colors on the Rare Disease Day website (http://www.rarediseaseday/.org/downloads/).

Find and join an event near you, from Virtual Run/Walks and photography competitions to meetings aimed at publicizing research on rare diseases-or create your own event.

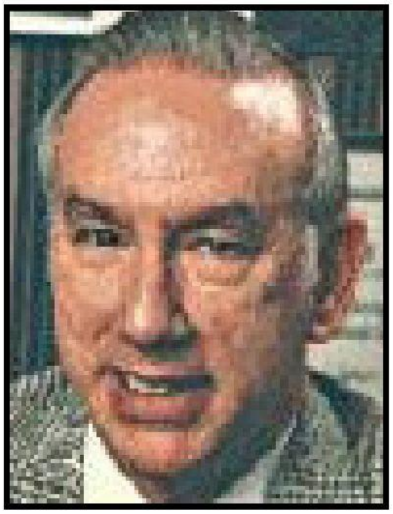
You can also use this day to call on policymakers and shine a light on people living with rare diseases, as two SPFers, Tina Croghan and Mary Brigid Schultz, have done. Tina and Mary visited their state legislators and set up table exhibits with Rare Disease info. In 2020, Tina was able to participate in Rare Disease week on Capitol Hill, including a tour of the NIH. The 2022 event will be virtual. SPF has been involved with RDD for half a dozen years now. It's a great platform for getting the word out about HSP and PLS; let's use it!

Tina and Tim Croghan, accompanied by their sociable service companion, Thunder, at the U.S. Capitol for Rare Disease Day 2020.

LIVING WITH HSP/PLS

Hospitalization and You: Part Two
Planning for a Hospital Stay

By Malin Dollinger, MD, HSP SPG4



Malin Dollinger, MD

A hospital stay, whether scheduled or unexpected, can be stressful. Advance planning can help make your experience more comfortable and reassuring. As a physician and a patient, I have seen the hospital experience from both sides. Here are some tips that I've learned along the way.

Make sure you can navigate the room safely and easily. Handicap-accessible rooms are not always designed with function in mind. In my last few hospitalizations, the handicap shower had a moat-a raised platform at the entrance-preventing anything with wheels from entering. I also tore off the toilet seat trying to turn my scooter in a too-small bathroom.

The placement of larger objects like a utility table, chair or trash can create barriers to getting around.

My advice is to check out the room immediately, before "unpacking," especially if you use a mobility device, scooter, wheelchair, etc., that requires more space. Ask to be transferred to a different room if the bathroom is too small for your wheelchair or scooter, the toilet is too low, the shower is inaccessible, or there are large objects that can't be adequately moved and pose tripping hazards.

If a different handicap room is not available, switch to Plan B. Sometimes, the best handicap bathrooms are the public ones in the hallways. If all else fails and the public bathroom is nearby, you could try using it.

Pay attention to grab bars, handrails and alternatives. Grab bars and handrails can also be an issue; not enough or not in the right places. It’s unlikely the toilet will have a handrail on both sides of the toilet. The usual single wall handrail is insufficient to support you when sitting down, and especially is not enough to hold onto when you get up. You need two different places to hold onto.

One choice, if you are alone, is to move your scooter/wheelchair next to the toilet, set the brakes, and use one side arm or arm rest, along with the grab bar already on the other side, to help pull yourself up. If you use your scooter side arm to push yourself up, you then need to be able to move the scooter in front of you and facing you, so you can easily sit down on it and move out of the bathroom.

Alternately, you may need to ask for assistance when it is time to get up. A useful technique is to extend both of your arms and hold onto each other’s wrists. This “double hold” at the wrist is safer than just clasping hands-think of circus aerialists!

These techniques also can be useful when getting up from a chair or the bed.

Get Ready for Bed. Getting in and out of bed needs to be engineered by you for each hospital bed/room. The bed should be as low as possible, so your feet touch the floor before standing. You will need to have the nurse adjust the side rails up or down to give you room to sit and hold on, while you swing your legs from the bed onto the floor through the empty space created by lowering that side rail.

Intravenous (IV) lines are often present, connected to a pole next to you, and may be awkward. These need to be disconnected when you get out of bed for trips to the bathroom, unless someone rolls the IV stand into the bathroom with you. It is advisable to have a strategy in place for moving these before you need to go. Same for a cardiac monitor or other lines, e.g., suction lines, fastened to you.

Meals are another issue that needs planning. Have the food table and the bed adjusted so you do not need to reach for the food “over there,” and be sure everything you ordered is on the tray before the delivery person leaves. You should always have drinking water nearby, as well.

Also, check to see that there is a call device for the nurse, a remote for the TV, and a telephone and be sure they are where you can reach them while you are in bed. You might want to have their cords secured around something, so they do not fall on the floor.

Have a strategy for keeping on your routine medication schedule. Depending on the time of day, or night, you get admitted, you might bring with you the first/immediate dose of crucial medications, such as heart medicine, antibiotics you already started for a current infection, etc., until the hospital pharmacy can “catch up” with your medication needs and schedule.

If you are taking diabetes, heart, lung, or other medications that require a specific time, try to arrange for the hospital meds to be given to you according to your regular schedule during your stay. Also, when you are given medication, ask what medication it is. You need to carry out your role in being sure there are no medication errors.

Know Your Care Team and Be Their Coach. In this era of separate care team job functions, it is important for you to keep track of what is going on. Different people will admit you to the hospital, move you to your room, make your bed, give you your meds, provide radiology tests, take your vital signs (blood pressure, pulse, and temperature), draw your blood, enter data into the computer, and so on. You need to keep track of the timing and nature of what is going on, especially with the need to avoid missing something important.

Some may have limited experience with taking care of people with disabilities. You might need to coach them on how to move you/help you move, and importantly, what things you can do and cannot do. With severe leg muscle spasm, I cannot get into and out of bed myself, get to the sink or bathroom, or even lift myself onto a bedpan.

Regarding your care team, while private physicians still can care for their patients in the hospital, you might have your hospital-based physician care provided by a “hospitalist”-a physician specializing in hospital care (also known as a nocturnalist when providing overnight care.) They are an important member of your care team, though you may have never met them before.

Avoid Slippery Situations. The universal tile floor many hospitals use is slippery, especially when wet. For that reason, it is best not to use the bathroom in your bare feet. Instead, opt for the special socks with abrasive rubber on the soles, provided by most hospitals, to keep your feet from sliding. I also bring pieces of rubberized pads, which can be rolled up for storage and unrolled on the bare floor where I need to stand. Don’t try to stand on a rug, anywhere. Rugs can slip out from under you, and down you go! Last time for me, the nurses put towels on the floor to solve the wet floor problem. No good! Towels simply slide out when you step on them. And if you use a walker, especially one provided by the hospital, have someone with you to be sure it does not slip on the floor.

Prepare for Going Home. Figure out ahead of time how your discharge will work and how you will get home. Can you be in a regular car or do you need a handicap-accessible vehicle that accommodates you sitting in your scooter or wheelchair? Arrange for your own driver to bring the vehicle to the discharge area. Make sure they know where you left the keys and can operate your scooter or fold your wheelchair.

Review home-going instructions and followup services, such as physical therapy or home nurse visits, and know who is responsible for making arrangements. Be sure any new prescriptions given to you on discharge can be filled somewhere before you need to take them at home.

Also, make sure you have the durable medical equipment that you need when you arrive home. Can't go upstairs to your bedroom? Rent a hospital bed and have it delivered so it is waiting for you at home.

My best advice to you is don't hesitate to advocate for what you need! Remember, you are the most important person.

Editor's Note: For tips on preparing for emergency care, and for a handy checklist of what to bring to ensure your personal necessities are with you during a trip to the hospital, check out "Hospitalization and You: Part One: Planning for Hospital Emergency Care" in the Autumn 2021 Synapse.

Taking Control of Incontinence

By Dina Landphair, HSP SPG7, SPF Board Member

I’ve had bladder problems for years, but it was really bad the last couple of years. I finally went to see a Urologist who specializes in female incontinence. I found out there are two types of incontinence: stress and urgency. After a Urodynamic test, it was determined that I had both types. I tried treatment with medicine first, but it didn’t help at all. I also tried physical therapy to help coordinate the muscles of the bladder through muscle training exercises such as Kegels, but it didn’t help either.

I had surgery in December 2020 for my stress incontinence. A mid-urethral sling was added and now I could do things such as cough, sneeze and lift stuff without peeing my pants. But I was still having urgency issues. My options were to have Botox injected in my bladder every three to six months, a nerve stimulation treatment called Percutaneous Tibial Nerve Stimulation (PTNS), or surgery to implant a Sacral Neuromodulation System (InterStim^{TM}). I decided to try PTNS.

PTNS works by indirectly providing electrical nerve stimulation to the nerves responsible for bladder function. The treatments are 30 minutes each for 12 weeks. It worked well, but I still had some minor issues. The next option was having surgery or Botox.

I decided to do a trial for the Medtronic InterStim^{TM} implant (the Baclofen pump also is by Medtronic), and I was happy with the results. Therefore, I elected to have the surgery. The implant stimulates the Sacral nerve which is thought to normalize communication between the bladder and brain and between the bowel and brain. The surgery is outpatient and takes 1-1/2 hours. The device is about 2 inches square by 1/8 inch thick and is implanted in the right side of my butt.

I had a choice of a regular battery (lasts approximately seven years) or rechargeable (lasts 15 years). I chose rechargeable, so for 20 minutes once a week I wear a recharger belt that goes around my hips and positions the recharger over where the implant is located to recharge the neurostimulator battery.

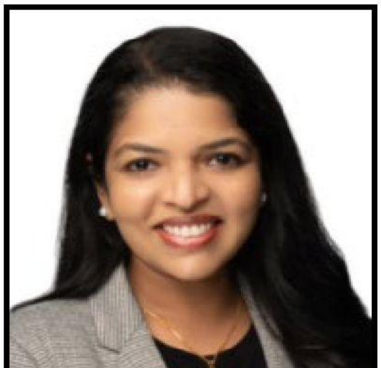
Also, I can control the intensity and the programs of the implant. There are seven different programs and each one has a range of intensity. The best way to explain it is each program is like a different medicine and the intensity is the dose. I control it all myself. I typically don’t feel the impulse, but I do sometimes if I’m standing or sitting a certain way. It feels like a spasm. It’s weird. I must remind myself what it is, but I’m getting used to it.

I had the surgery in September 2021 so I’m still figuring out myself, but it’s going well so far. I now only need to see the doctor once, maybe twice, a year.

Move Better in 2022!

By Priya Karakkattil, PT PhD CBIST

Assistant Professor, Doctor of Physical Therapy, University of St. Augustine for Health Sciences



Priya Krakkattil

If you are thinking about a new year resolution to improve your mobility and are wondering who can help you achieve that, consider consulting a physical therapist. A physical therapist is a movement specialist who can help you improve your quality of life through prescribed exercise, hands-on care, and patient education. Here are a few ways a physical therapist can help someone with Hereditary Spastic Paraparesis (HSP).

Managing spasticity: A physical therapist can help teach you specific stretching exercises to manage your spasticity. While medication helps with spasticity, doing specific stretching exercises will help you manage the spasticity and preserve the range of motion at your joints in your legs to help you move better.

Improve strength: Along with spasticity, you may also experience weakness in your legs. During my clinical practice, my clients with HSP reported the first symptoms as feeling as though they are walking through mud. Physical therapists can do specific assessments to identify which muscles are weak and can then guide you with appropriate exercises.

Improve your balance and decrease your fall risk: Falls are a common cause of fractures and brain injury in people with neurological diagnoses. Physical therapists can use various assessments to identify your fall risk and teach you specific strategies to improve your balance and decrease your fall risk.

Prescription of assistive devices: Maintaining independent walking is one of the most common goals of my patients with HSP. Physical therapists can prescribe the most appropriate assistive devices, such as a walker, cane, forearm crutches, etc., and teach you the most appropriate way to use those devices based on your individual needs. They can also work with Orthotists to identify the most appropriate ankle foot orthoses to manage foot drop for safe walking.

Energy Conservation: It can be very difficult to walk or even do a sit to stand transfer when you have foot drop or when you have spasticity and weakness in your legs. Physical therapists are trained to teach you how to move efficiently by teaching you proper body alignment techniques and using different adaptive devices based on your needs.

Pain management and prevention of overuse injuries: During my clinical practice, patients with HSP also had pain in their shoulders and arms from overuse of their arms with transfers and walking with a walker. Physical therapists can help you manage the pain by using manual therapy treatment and various taping techniques. They can also help you prevent these overuse injuries from developing by teaching you proper body alignment with functional movement.

Caregiver education: Physical therapists don’t just help the person with HSP; they also help their caregiver. If the person with HSP needs assistance with their transfers, the physical therapist can educate the caregiver on the best way to transfer the person with proper body mechanics to avoid back and neck injuries.

Maintain general health and wellness: The American Heart Association recommends 30 minutes of moderate intensity exercises five days a week to maintain your general wellness. It is difficult to figure out the best exercises to perform when you have difficulty with your mobility. A physical therapist can help you figure out the best exercises that you can do regularly to maintain and improve your general health and wellness.

Now that you know how a physical therapist can help you improve your mobility, let’s talk about how you can get that help. You can start by asking your primary physician or your neurologist for a referral to be evaluated by a physical therapist. In some states you may even be able to see a physical therapist without a referral.

When you contact a physical therapy clinic, make sure the physical therapist has clinical expertise with treating patients with neurological disorders. Just as doctors have different clinical specialties, physical therapists also have different clinical specialties. The American Physical Therapy Association has a board certification in neurology, so you should ask whether the physical therapist is a Neurology Certified Specialist (NCS) or has other certifications in the field of rehabilitation of neurology patients. The physical therapist will then do a detailed evaluation to identify what specifically they can do to help you improve your safe mobility.

I hope in this new year you be able to improve your functional mobility and quality of life through the help of a physical therapist.

Simply Having an Accessible Wintertime!

By Mara Layne and Beth Glas, Maximum Accessible Housing of Ohio

Whether the weather is cold, or simply temperate, winter brings accessibility challenges to every household. Read along for tips from Maximum Accessible Housing of Ohio’s (MAHO) accessibility experts.

Light It Up In the dark winter months, adding more light is always a bright idea. This winter, make it your mission to add one more source of light to your home.

Solar powered landscape lights placed along your home’s entry and travel path both prevent falls and add home security. Models vary in size and cost (starting at $10 for a set of 2+) and won’t increase your electricity bill.

Night-lights don’t just scare the monsters away: they can help prevent falls. In addition to traditional plug-in night-lights, new light switch and outlet covers have integrated LED guide-lights that replace your existing covers for simple, streamlined light.

We spend so much time in our kitchens in the winter. Increasing lighting sources can help us stay safe when preparing food. Light helps us hone-in on color contrast and limits shadows, which can help us avoid accidents and injuries. Task lighting on the underside of upper kitchen cabinets can make what we’re preparing on our counters that much easier to see. You can have it professionally installed or choose to add battery-powered tap-on lights or plug-in LED strips. Task lighting is helpful throughout the home: inside closets and medicine cabinets, under the sink...the possibilities are endless!

Under cabinet task lighting can help make food preparation easier.

Eliminate Tripping Hazards Even in temperate climates, cooler winter weather means we spend more time indoors, which can lead to more clutter. Eliminating safety hazards and prioritizing proper storage can be a literal lifesaver.

Keep your outdoor travel path and entry safe from ice with a heated walkway mat. Be sure to remove planters, gardening tools, outdoor decorations and other trip and slip hazards, as well.

Concrete travel paths can be improved by creating a lip or barrier on either side of the walkway to prevent mobility aids from rolling over the edge and into the grass or landscaping. Running a rake through wet concrete at a perpendicular angle to the walkway can help provide some traction for future users, especially if the path is wet or icy.

Secure steps and stairs by bolting down loose floorboards and railings, increasing lighting, and clearing off all clutter. Add traction to steps with anti-slip traction tape; transparent traction tape is available for indoor applications.

Indoor decorations and clutter can quickly become trip hazards. Prioritize keeping travel paths clean and clear to reduce the risk of falling, with at least 36” of clearance to and around furniture. This may mean removing a rug or stair runner, rearranging furniture, keeping books and decor items tucked out of the way, and taping down power cords.

Clearing clutter from our floors is just the beginning of what we can do to minimize risks. Traditional metal transition strips between flooring materials can pull up over time; if a transition strip is unavoidable, consider going with a wide rubber transition strip that is secured with adhesive to the floor. Carpet might look nice, but thick carpet can inhibit the movement of wheelchairs and walkers. Consider replacing high-pile carpet with a laminate or wood floor that is consistent throughout the home to create seamless transitions and increase mobility.

Rethink Your Storage Implementing a one-year rule throughout the house can help you re-prioritize storage to minimize reaching and bending. The one-year rule is simple: if you haven’t used it, and especially if you haven’t thought about it, in over a year, it is time to give that item to a new home. Local Facebook groups like “Buy Nothing (your city here)” are a great way to make sure these items go directly to someone who will love them! Once cleared out, you can prioritize everyday items in the spots closest to your reach range.

It’s a Lock Cooler weather can exacerbate arthritis and stiff muscles. New technology can make it easier to accomplish tasks that traditionally require a strong grasp, long reach, and robust upper body strength.

Electric locks can require no pinching, grasping, or turning of a key. A useful “smart lock” can be opened in several ways: via an app on your phone, a pin pad, or key fob. Some options hide the technology inside of a traditional-looking lock, and will blend right in with your current hardware, while others make their technology clear for easy use. Pairing an electronic lock with a lever door handle will make using entry-ways easier for everyone, even someone with limited dexterity in their hands.

Smart locks can help make entry-ways easier for people with limited dexterity in their hands.

Go Touchless Robot vacuums remove the effort and strength required to clean the floor. A staple for many years now, advancements have improved the sensors of robot vacuums and mops. Newer models can be operated through an app on your smartphone.

Electric options for trash cans and soap dispensers are easy to use and improve sanitation in your home. Trash cans with motion and voice activation open with no physical effort; these plug into your wall and respond to a simple wave or voice command. Motion-sensor soap dispensers are battery-powered and look great on your bathroom or kitchen sink.

Control Your Temperature Temperature is relative! Where 45° Fahrenheit (about 7° Celsius) might feel like a lovely spring day to someone in Cleveland, Ohio, it would feel freezing to someone in Los Angeles, California. The same is true for our skin as we move from the outdoors to the indoors in the winter months. Regulating the temperatures our bodies experience indoors can be achieved with some simple solutions.

Water temperature is hard to control, and even harder to tell just by touch. Setting the maximum water temperature on your furnace or boiler to 120° can help reduce risk of scalding and burns.

Replace an older faucet with one featuring simple red and blue temperature indicators to help everyone set the water temperature regardless of cognitive ability, memory, or language spoken. Select a model with a single lever handle for easier use by people limited dexterity or hand strength; a single lever also allows for more accurate temperature adjustment.

Smart thermostats employ the principle of “set it and forget it.” Once set for the ideal temperature, they can be adjusted from your phone, or voice if you have a smart speaker, which means no fumbling with switches and buttons in the middle of a chilly night. Some smart thermostats can sense if you’re home and will turn the temperature down to avoid wasting energy. Place your thermostat within reasonable reach range of someone seated, about 36” to 48” from the ground to accommodate present or future wheelchair users.

Can’t Wait to Go? The Restroom Access Act Helps Make Life Easier

By Pamela Jordan-Handley, HSP SPG7 SPF Co-Ambassador for Ohio, Synapse Editor

Those of us with HSP and PLS know only too well that sinking feeling of needing a restroom NOW. While I’ve lost count of the times I’ve had to make a mad dash (relative term!) to find a restroom, one incident stands out.

I’d ventured out to one of my long-time favorite stores. While heading to the fitting room, my bladder gave me the 30-second warning. Desperate, I flagged my sales person and pleaded to use the in-store restroom. She hesitated and then informed me that I would need to use the public restroom in the main part of the mall citing their store policy to not allow “the general public” to use the store’s bathroom.

I willed myself to make the trek, only to discover that the one bathroom that could accommodate my walker also housed the diaper-changing table. Two weary moms with babes in strollers and fidgety toddlers in tow already were waiting in line. Disaster!

When I finally composed myself and headed back to the store, I turned my humiliation into a fervent vow to make sure their restroom policy changed and the staff never again treated another person with such indifference. After a quick search online, I learned a young woman named Ally Bain beat me to it.

In 2004, Ally was a 14-year old with Crohn’s Disease who experienced swift and painful abdominal symptoms while shopping with her mother. Despite her apparent urgent need, she was denied access to an employee-only restroom-resulting in a very public and humiliating incident. As a result, Ally became an activist who succeeded in getting the Illinois Restroom Access Act (Ally’s Law) drafted and passed into state law in 2005. Since then, a version of the law has passed in 17 states:

Pamela Jordan-Handley

- Colorado
- Connecticut
- Delaware
- Illinois
- Kentucky
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- New York
- Ohio
- Oregon
- Tennessee

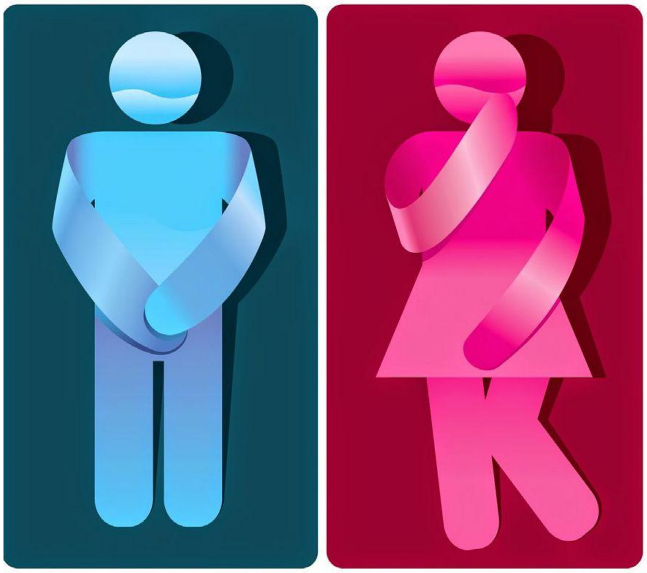
- Texas
- Washington
- Wisconsin

This law requires retail establishments to make their employee restrooms available to people with medical conditions requiring immediate bathroom access if no public facilities are immediately available and they need to go.

Per the law, proof may be required in the form of a document signed by a medical professional stating that the person has a condition requiring immediate use of a restroom. Additionally, in some states, an identification card issued by a relevant national nonprofit organization may also be presented.

If you live in one of the 17 states currently covered under Ally's Law and are turned away after presenting a letter from your medical care provider, you can report noncompliance to your local law enforcement agency. Punishment for not complying varies from state to state, but ranges from $100 fines to warning letters and civil infractions.

If you live in a state without Ally's Law, having a letter from your medical care provider doesn't guarantee compliance; yet most people are understanding and willing to help when presented with the letter. It's also worth voicing your support and asking about any progress your state is making toward passing a bill similar to Ally's Law. You can find your state's legislators at http://www.usa.gov/.



As for my experience, it eventually had a positive resolution. I contacted the store's corporate headquarters in Massachusetts, where they were very aware of Ally's Law-even if some of their stores were not. They assured me that not only were they committed to complying with the law, they were committed to a culture of compassion. To ensure the entire company was living that commitment, a review of Ally's Law and the company's national policy of making their employee restrooms available to people with medical conditions requiring immediate bathroom access was added to their national and regional managers' meetings.

To help avoid future situations, though, the letter from my physician is securely tucked in my handbag-ready to open new doors!

Being a SPF Ambassador can be Life Changing!

Ambassadors raise awareness of HSP and PLS, connect HSP and PLS patient communities, and let patients and caregivers know they are not alone.

As a SPF Ambassador, you can become as active as your schedule allows.

- Arrange or host a local or state Connection event to bring those with HSP and PLS together;
- Be a SPF liaison to new and current members by sending welcome emails and updates on SPF news and happenings;
- Support fundraising and friendraising activities;
- Help with grassroots advocacy efforts;
- Assist with media relations;
- Build relationships and provide HSP and PLS information to health care professionals, medical schools, and related organizations.

Learn more about becoming a SPF Ambassador at https://sp-foundation.org/get-involved/ambassadors/

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.

CONNECTIONS

North Texas Luncheon Connection

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

SPF members in the North Texas region held a Luncheon North Texas Connection on November 6, 2021 at Olive Garden Restaurant in Grapevine, Texas. The meeting started with introductions and a welcome to Donna Matejka, the new North Texas SPF member. Next, members shared their experiences about diagnoses, ageonset, medications, walk-aids, working hours, disability, retirement, and other topics. For those who work full time and have PLS or HSP, the importance of balancing work time with taking time for stretching and exercises was highlighted, considering that these activities are currently the most effective treatment for those who have any of these diseases.

Tina and Jeana shared their awesome experience of the climbing event at Enchanted Rock in Fredericksburg, Texas. The other attendees were so excited after hearing their experience that Donna recommended a walk at Arbor Hills Nature Preserve in Plano on November 20. We also agreed to meet again at the Abilities Expo in Dallas on December 4.

Attending the North Texas Luncheon Connection were: (L to R) Celyna and Randy Rackov, Tina Curfman, Jeana Fraser, Donna Matejka

Virtual Brazil Connection

By ASPEC-Brasil

December 2021, the Association of Correlated Spastic Paraparesis of Brazil (ASPEC Brasil) celebrated four years of foundation. Created in 2017 as the Hereditary Spastic Paraparesis Association of Brazil (ASPEH Brasil), the organization originally served people with hereditary spastic paraparesis (HSP) and similar diseases. Since September 2020, the organization’s focus expanded to include patients with tropical spastic paraparesis, primary lateral sclerosis (PLS), Stiff Person and Sjogren Larsson Syndrome.

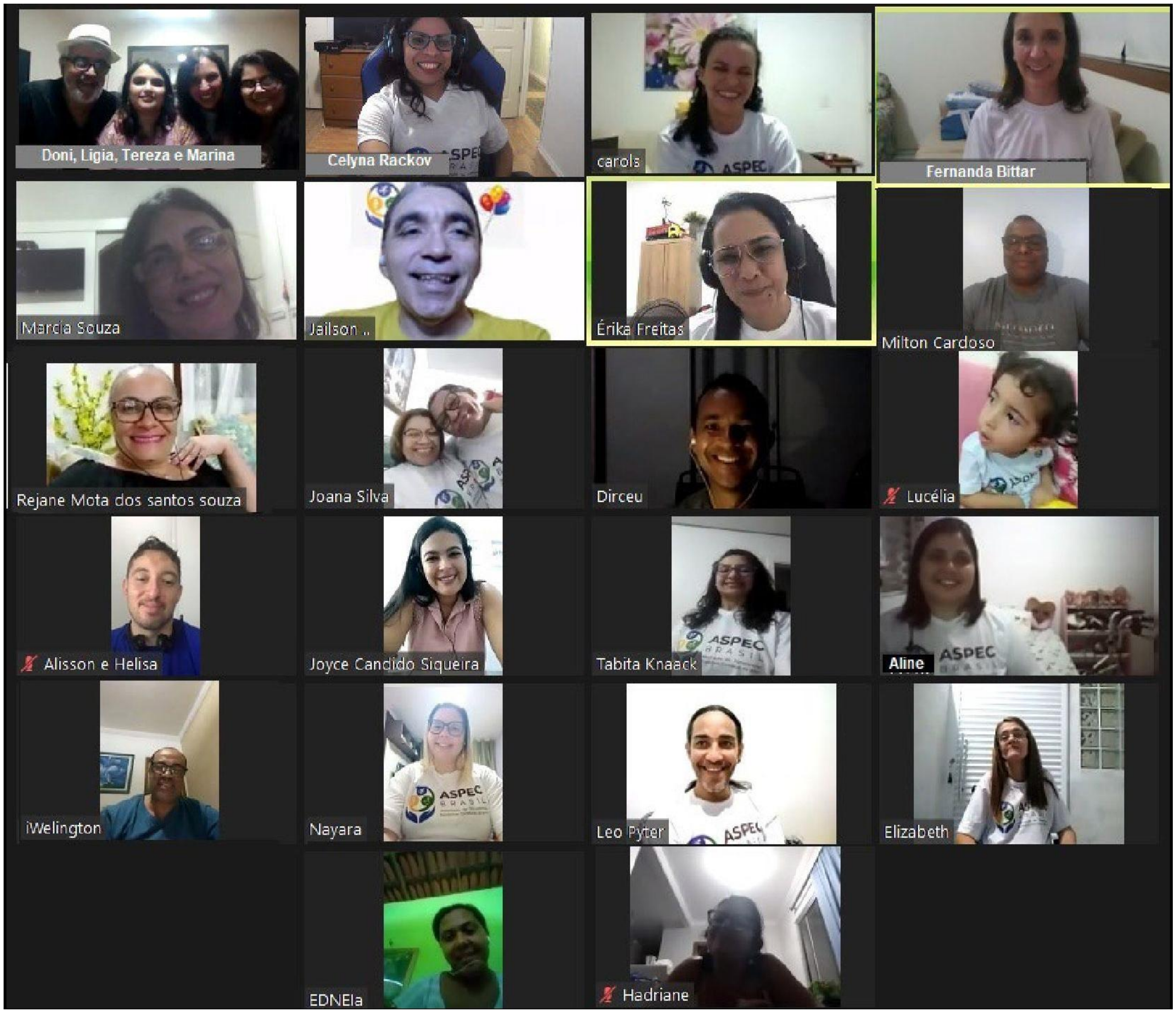
The anniversary of ASPEC Brasil was celebrated on December 4 via a virtual Zoom meeting and was the organization’s third EVIP-Encontro Virtual de Paraparesia, which translates to Virtual Meeting of Paraparesis. This EVIP was specially dedicated to commemorating the Association’s fourth anniversary and was attended by approximately 30 members from Brazil and Texas in the United States.

The event’s program included exciting testimonies from members of the Association followed by moments dedicated to music, with performances by the Freitas Family from Sao Paulo (Sao Paulo), Leo Pyter from Capela do Alto (Sao Paulo) and Joyce Siqueira from Igarassu (Pernambuco). During the virtual commemorative meeting, kits with gifts from ASPEC Brasil with t-shirts and mugs were raffled.

Also, as part of the Association’s anniversary celebrations, Dr. Fernanda Bittar, researcher at the State University of Campinas (Unicamp) and Spastic Paraplegia Foundation (SPF) ambassador in Brazil gave a talk on some of the SPF-funded research around the world centered on finding treatments for patients with HSP and PLS.

For ASPEC Brasil, which is inspired by the work of SPF, it is important that its members are aware of the work of SPF and the need to register in the worldwide database maintained by this important international foundation dedicated to promoting research on HSP and PLS.

We are all together!



Take a Hike! Conquering Enchanted Rock

By Jeana Fraser, HSP, and Tina Curfman, HSP SPG4 SPF Co-Ambassadors for North Texas

October 2021, Tina Curfman, Laura Forgey, and Jeana Fraser, who all have HSP, hiked Enchanted Rock. When we arrived, we met Justin Forgey, another HSPer and Founder of Worn Souls (https://wornsouls/.org), a hiking ministry with a passion to help people engage, challenge, hike and overcome.

After receiving our Worn Souls t-shirts, we broke off into three teams, Team Jeana (which included David Fraser), Team Tina and Team Laura. Each team went at their own pace. The trek was a bit difficult, especially at the foot of Enchanted Rock where larger pieces of rock had sloughed off through weathering and erosion and fell to the bottom. The hike took 40 minutes to one hour to reach the summit, where there were magnificent views and vernal pools in which you can see fairy shrimp if you look closely.

Jeana Fraser and Tina Curfman trek to the summit of Enchanted Rock.

At the highest point a U.S. Coast & Geodetic Survey Reference marker indicated the height, latitude, and longitude of Enchanted Rock. It is an 1,825-foot granite dome and is the visible, small part of the huge underlying batholith that spans over one hundred square miles.

We’re grateful to Justin and his Worn Souls volunteers for helping us learn firsthand that sometimes you have to step out of your comfort zone to get comfortable with yourself!

Don’t miss this three-day event, filled with a variety of workshops, keynote sessions with leading researchers, and more! Plus, informative events like our meet & greet and social mingles, There are many opportunities to connect and interact with other SPF families and to receive updates from doctors. The Spastic Paraplegia Foundation sponsors a conference to bring together the leading doctors, scientists, researchers, clinicians, and families living with HSP and PLS (#HSPandPLS). SPF has hosted the Annual Conference since 2003. We look forward to reuniting as a community at this year’s conference to offer each other support and strength, and to learn about the latest advances in research and care.

2022 SPF ANNUAL CONFERENCE AGENDA

(Tentative Agenda Subject to Change)

Thursday, July 21 Board of Directors Meeting
Friday, July 22

7:00am Breakfast (lite/grab & go, provided)
9:00am Welcome
9:30am General Session with Dr. Corey Braastad

10:30am Breakout States by Region
Noon Lunch (plated, provided)
1:30pm Breakout by Gender/Caregivers/Youth
3:00pm GeneralSession with Dr. John Fink
4:30pm Dinner (on your own)

Saturday, July 23

7:00am Breakfast (lite/grab & go, provided)
8:00am General Sessions
Noon Lunch, lite & plated (provided)
1:30pm General Session w/ Doctors/Researchers
6:00pm Dinner (plated, provided)

Sunday, July 24

8:30am Coffee & Pastries with Dr. John Fink
10:30am SPF Committees
Noon Adjourn, Lunch (on your own)

HOTEL REGISTRATION

Hilton Nashville Airport-(615) 883-9770 2200 Elm Hill Pike,
Nashville, Tennessee 37214

You must mention SPF/SPASTIC PARAPLEGIA to receive the discounted room rate of $159/Night. Check-in: 4PM / Check-out: Noon. The hotel is located 4 miles from Nashville International Airport (BNA), 8 miles from downtown. Free shuttle service (non-accessible) to destinations within 2 mile radius of the hotel 6AM-11PM. SPF Guests at conference hotel receive free self-parking and WiFi. Restaurant, bar, indoor pool, fitness center, and airport shuttle (non-accessible) are available on-site. For accessible shuttle service, please see information below for PrimeCare.

Please note, All ADA Rooms have been reserved for our attendees but may be sold out prior to your reservation. The hotel has a total of 17 ADA Rooms (All King-Beds); 6 ADA Rooms with Roll-in Showers, and 11 ADA Rooms with Stand-up/Step-in Showers (approx. 2” step-up to enter shower). The hotel has 150 King-Beds with Stand-up/Step-in Showers and 150 Double-Beds with bathtubs. Please let the hotel know if you need a shower chair when you book your reservations either online or by calling.

PrimeCare Assisted Transportation: To reserve a ride, call (615) 933-6363 and mention “SPF”. PrimeCare offers non-emergency transport for seniors and disabled, including rides to/from airport and leisure trips.

<u>FILMING/RECORDING POLICY:</u> Recording of any audio/or videotaping of conference sessions, or at any venue of the annual conference, is forbidden without prior written approval by the SPF. Conference presentations will be available on the website after the completion of the Annual Conference. Attendees at the Annual Conference expect, and deserve, the right to privacy. SPF will photograph and record at the Annual Conference and will make photographs and other media available for news, educational, and promotional purposes as deemed appropriate by SPF.

<u>SOLICITATION POLICY:</u> Soliciting funds for organizations, or for individual benefit, other than donations directed to the Spastic Paraplegia Foundation is prohibited at SPF events. Any people or materials soliciting funds for other organizations or for individual benefit will be removed or asked to leave the conference.

Spastic Paraplegia Foundation

Registration for 2022 Annual Conference
July 22-24 in Nashville, Tennessee

INSTRUCTIONS: (1) Complete Form Online & Pay by Credit Card at **SP-Foundation.org**, or (2) Print, Complete Registration Form. Make Check payable to **SP-Foundation** and mail payment & registration form to: **SPF, 1605 Goularte Place, Fremont, CA 94539.**

Registrant Name #1: ____
Disorder: ☐HSP ☐PLS ☐SP ☐ALS ☐Other ____________________ ☐None
Meal Requirement: ☐Regular ☐Vegan ☐Vegetarian ☐Gluten-Free ☐Kosher ☐Other __________
Food Allergies *(List)*: ____________________ **Other Allergy Concerns:** __________

Registrant Name #2: ____
Disorder: ☐HSP ☐PLS ☐SP ☐ALS ☐Other ____________________ ☐None
Meal Requirement: ☐Regular ☐Vegan ☐Vegetarian ☐Gluten-Free ☐Kosher ☐Other __________
Food Allergies *(List)*: ____________________ **Other Allergy Concerns:** __________

Child Name #1:____________________________________ **Age:** _____
Disorder: ☐HSP ☐PLS ☐SP ☐ALS ☐Other ____________________ ☐None
Meal Requirement: ☐Regular ☐Vegan ☐Vegetarian ☐Gluten-Free ☐Kosher ☐Other __________
Food Allergies *(List)*: ____________________ **Other Allergy Concerns:** __________

Child Name #2:____________________________________ **Age:** _____
Disorder: ☐HSP ☐PLS ☐SP ☐ALS ☐Other ____________________ ☐None
Meal Requirement: ☐Regular ☐Vegan ☐Vegetarian ☐Gluten-Free ☐Kosher ☐Other __________
Food Allergies *(List)*: ____________________ **Other Allergy Concerns:** __________

Mailing Address: ____
Mobile Phone #1: (____)____________ **Text?:** Y / N **Mobile Phone #2:** (____)____________ **Text?:** Y / N
Email: ____
Are You Driving or Flying to the conference? ☐Driving ☐Flying
What Aid(s) are you likely to bring to the conference? *(Check all that apply)*: ☐Cane ☐Crutches ☐Walker
☐Scooter ☐Wheelchair ☐Powerchair ☐Service Animal ☐Caregiver ☐Other:______________

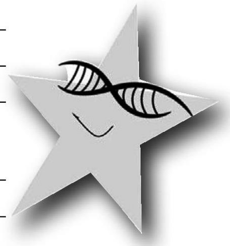
We try to make accommodations for people with food allergies and other allergies to help keep spaces safe for attendees. Please make note of any allergies on the registration form and make sure you remind the hotel staff when you are being served.

EARLY REGISTRATION DISCOUNT: ***Payment Must be Received by: February 25, 2022***
1st Adult Conference Fee Early Discount..................$150 Qty: _____ **Total $**__________
2nd+ Adult Conference Fee Early Discount ....$130 Qty: _____ **Total $**__________
Child Registration Early Discount (under age 18) ......$100 Qty: _____ **Total $**__________

EARLY DISCOUNT!

OPEN REGISTRATION (February 26-May 31, 2022): ***Payment Must be Received by: May 31, 2022***
1st Adult Conference Fee..$250 Qty: _____ **Total $**__________
2nd+ Adult Conference Fee.......................................$230 Qty: _____ **Total $**__________
Child Registration (under age 18)..............................$150 Qty: _____ **Total $**__________

DOOR REGISTRATION (June 1-Onsite):
1st Adult Conference Fee..$300 Qty: _____ **Total $**__________
2nd+ Adult Conference Fee.......................................$280 Qty: _____ **Total $**__________
Child Registration (under age 18)..............................$200 Qty: _____ **Total $**__________



FAQ: (1) To receive a registration discount payment must be **RECEIVED** in our office by the noted discounted deadlines. (2) **No Refunds after May 31, 2022.** (3) Bringing more guests? No problem. Submit additional copies of this form. (4) SPF has put a hold on every ADA room in the hotel but may be sold out prior to your reservation. (5) *IMAGE CONSENT POLICY:* By completing and submitting your registration form, you acknowledge providing consent for SPF to use your image captured during the conference through video, photography, or digital imagery to be used in SPF promotional materials, publications, and website and waive any and all rights to these images, unless revoked in writing to SpasticConference@gmail.com prior to the conference dates.

Contact: Details at SP-Foundation.org - Email Comments/Questions: SpasticConference@gmail.com
Call (877) 773-4483

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PRIMARY LATERAL SCLEROSIS
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Early Discount
Deadline
February 25, 2022

Conference Details & Registration Inside See page 18-19!