

# SYNAPSE

*The Newsletter of The Spastic Paraplegia Foundation Inc.*

Volume 25, Issue 2

Spring/Summer 2022

## WHAT'S INSIDE

**Advocate! You Can Make A Difference**

*Page 8*

**Not just Lip Service: Tips for Making Yourself Heard**

*Page 10*

**Helpful Hints for Navigating Public Places**

*Page 12*

**Thinking of Getting a Service Dog?**

*Page 14*

**Cowboy Up, Volunteer, and Find Your Song**

*Page 17*

## Letter from the President



*Greg Pruitt*

Dear SPF Friends, Family, and Caregivers,

It is with MUCH EXCITEMENT and GREAT ANTICIPATION that I write my first President's letter to you! There

are so many wonderful things happening in our SPF work and world because of the hard work and commitment of so many of you!

Over these past couple of months, it has been my pleasure to communicate with many of you in a number of different ways. Two of the first questions many have asked me are, "What has you involved with the foundation?" and "What medical issues do you have?"

Those are great questions that help us get to know one another. I have HSP SPG4. After more family research, over the past three generations, about a dozen family members have displayed similar symptoms. For many years we were dealing with it alone, not knowing what "it" is. We didn't know any other family or person that had it. We had a very difficult time finding information about it. And then, as I began to have initial symptoms and began

researching, I discovered SPF on the Internet. With Dr. Fink's strong urging, in 2015, I was able to semi-retire, allowing time to focus on my own physical needs and to get more involved with the SPF board of directors. My greatest motivation in working with SPF is assisting in finding treatments and discovering cures, because I do not want to watch any children or grandchildren live with these conditions.

As a result of the hard work, commitment, and generosity of so many of you, SPF had an outstanding fundraising year in 2021! After raising \$888,986 in 2020, Frank Davis, our President Emeritus, told us in last year's spring *Synapse* that our goal for 2021 would be "a record total of one million dollars." Well pop the cork, cut the cake, blow the horn – whatever you do to celebrate a great victory, do it BIG! WE, WORKING ALL TOGETHER, raised \$1,186,202 by December 31. That's a 34% increase over 2020. And then, with that great momentum, some of our board and committee members quickly created a "Hot Pepper Challenge" to raise more contributions and matching donations. By our January 15, 2022 match deadline, those efforts and other

*Continued on page 3*

## In This Issue

	Page
President's Letter .....	1
<b>General Interest</b>	
Living Life with HSP .....	4
Changes.....	5
I Refuse to Give Up! .....	6
Celebrating KIDINS220 Awareness Day ...	7
Two Perspectives on Advocacy.....	8
<b>Medical and Health</b>	
Not Just Lip Service: Tips from a Speech- Language Pathologist's Point of View .....	10
<b>Living with HSP/PLS</b>	
Helpful Hints for Navigating Theatres, Auditoriums, and Other Public Places ....	12
Accessible You Say?.....	14
Getting a Service Dog: Insight into the Process.....	14
<b>Connections</b>	
SPF Illinois Connection March 2022.....	16
Abilities Expo in Dallas .....	16
<b>Other</b>	
Cowboy Up, Volunteer and Find Your Song .....	17
Tip of our Cowboy Hat to our 2022 Annual Conference Sponsors.....	18
Register Now for the 2022 Annual Conference in Nashville, Tennessee.....	19

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# SYNAPSE

## Volume 25, Issue 2 - Spring/Summer 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](mailto:synapsenewsletter.spf@gmail.com)

Therese Williams ..... Associate Editor

Donna Hinshaw ..... Designer

Katie Robinson.....Large Print  
Edition Production

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### Send Correspondence & Donations to:

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

### Contact the SPF at:

(877) 773-4483

[information@sp-foundation.org](mailto:information@sp-foundation.org)

or [www.sp-foundation.org](http://www.sp-foundation.org)

### Executive Director:

Norma Pruitt

[information@sp-foundation.org](mailto:information@sp-foundation.org)

### SPF Board of Directors:

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

Letter from the President - Continued from page 1

contributions resulted in total contributions of \$1,272,004 - a whopping 43% increase over 2020. CONGRATS on a FANTASTIC JOB!

Thank you to every contributor of any amount at any time of the year. We certainly thank the anonymous donors who graciously provide year-end match challenges, giving us great incentives to finish the year strong. Every contribution in every amount is important in reaching fundraising goals. All this effort gives SPF the ability to award more dollars to research. Our Scientific Advisory Board is currently reviewing more proposals than ever before to advise on which have the best potential to find needed information and move swiftly toward those cures.

Your fundraising committee and board of directors have set a challenging goal to raise \$1.5 million in 2022 to continue gaining in this needed research. Let's all work together to meet this new challenge! No doubt, we can move closer to those treatments and cures.

While medical research fundraising is an important goal, SPF is also vitally interested in creating a much greater awareness, connecting HSP and PLS with everyone from patients to doctors and the rest of our world. Join our newest outreach efforts with *SPF Talks* each month. Throughout the summer, watch and participate as we work to create more awareness and fundraising efforts.

Join us during our annual HSP and PLS Awareness Week which is August 21-28. We will meet daily to get to know others world-wide and extend our partnerships in this awareness effort. Please mark your calendars now and plan to participate.

I am also most excited to know that we will be gathering for our 19<sup>th</sup> annual conference this year, celebrating the 20th Year Anniversary of SPF. I have truly missed visiting with many SPF friends these past couple of years. The conference will be in Nashville, TN, July 22-24. It is always an important opportunity to meet with and hear doctors and researchers give us the latest research information while meeting, getting to know, and sharing with others who bear our challenges. I look forward to seeing many of you there!

More detailed information concerning all these activities can be found on our website at SP-

Foundation.org, in the monthly e-newsletter, and here in the *Synapse* throughout the year. Please use these resources often.

Let's all celebrate together our progress toward finding treatments and cures for both HSP and PLS. I want to thank every board member, committee member, volunteer, sponsor, and contributor. Every one of you is an essential part and ingredient to this very important effort. We still have much important work to do. THANKS SO MUCH!!

My best to you all,

  
Greg Pruitt, President



### Be Part of the Conversation!

SPF TALKS is our newest series addressing topics of interest to people with HSP or PLS. These Zoom meetings or webinars feature presentations or open forum discussions on how people with disabilities and caregivers can identify, obtain, and use helpful information.

SPF TALKS topics and event details are sent to members in advance of each session. If you are not a member yet, visit [sp-foundation.org/news-resources/register](https://sp-foundation.org/news-resources/register) or [CLICK HERE](#). If you have a topic you would like to present EMAIL US at [information@sp-foundation.org](mailto:information@sp-foundation.org) and enter "spf talks" in the subject line.

SPF TALKS are recorded and available on the SPF YouTube Channel, so be sure to check out past sessions on mobility assistive adaptive devices and disability lifehacks, tips and tricks.

## GENERAL INTEREST

### Living Life with HSP

By Anita Giesbrecht, HSP

**A**lthough I am not a writer, I do have an HSP story to tell. When I was born, my parents' main concern was the fact I only had one hand. I have a stump at the left wrist, but my parents wisely expected me to do almost everything myself. I didn't feel any different than other kids until first grade when kids wouldn't hold hands with me when we played "Ring around the Rosie." After finishing high school in 1966, I wanted a job. However, in those days, without further education, few jobs existed that didn't require typing. Unfortunately, I hadn't learned how to effectively do that with one hand. I did get a job in a Bible bookstore back in Chicago far from my home in Washington state. A couple of years later, I married a farm boy from Idaho, and we raised three healthy children.

In 1992, I started noticing how often I tripped over my own feet or anything my toes could find. Then I started dealing with visual migraines and numbness, vertigo, hyper reflexes, etc. We went to several doctors and even a physician in Salt Lake City, UT who specialized in Multiple Sclerosis (MS). He told me to come back in a year to confirm whether it was MS or not.

About 11 years later, after seeing several neurologists and having 17 MRIs, nothing had changed; it was not MS. Finally in 2003, I flew to the Mayo Clinic campus in Jacksonville, FL. Within 40 minutes of visiting the neurologist there, he said I had HSP. He was familiar with HSP having seen similar cases. Apparently, my missing hand had given him a clue. There was a genetic "mess up" before I was born, and HSP continued to mutate from there. At that time, there wasn't anything to do but treat the symptoms. Although the "H" stands for "hereditary," we weren't aware of any other family cases.

Over the years, the scissored gait took its toll on my back and led to sciatic pain which caused me to get a spinal cord stimulator implant that



*Anita looks forward to getting an early start on spring gardening.*

I have to this day. This has been a big help because I was taking over six Ibuprofen a day before the implant in 2010. Now

I only take pain medications on occasion.

As my gait was far from perfect, my right ankle eventually needed a brace to keep my foot forward. Later in 2020, my knee was getting very unreliable. When we found out the joint was bone on bone, I got it replaced. For once, my leg is straight and stable, but I still walk with support because of poor balance and spasticity. Physical therapy is just part of life now. It helped to have a physical medicine doctor familiar with HSP prescribe the right stretches and exercises, and now I can do them at home.

I like to trim bushes and putter in the yard using my tough Permobil wheelchair to get around. I use a cane for short distances on my husband's or friend's arm or a Go-Go chair for shopping. When our grandchildren were young, they loved to ride on my lap as I drove the wheelchair.

Lastly, my big issue is constipation and having to take "brew" to get relief, which requires time on certain mornings. I also use a self-catheter if I want freedom away from

a bathroom. After 18 years from visiting Mayo Clinic until today, I have ten grandchildren and no other known family cases of HSP.

I find strength through my faith in the Lord Jesus Christ. True to His word, He strengthens me (Philippians 4:13). He is key to helping me meet the many unpredictable situations as I walk through life with HSP (Psalm 73:23). My husband Jerry, my family, and friends are also a big support in helping where they can.

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## Changes

By Ryan Viola, HSP

*“One day you will tell your story of how you overcame what you went through and it will be someone else’s survival guide.” ~ Brene Brown*

**My** name is Ryan Viola, I’m 38 years old and a high school science teacher in Wasilla, AK. I was diagnosed with HSP in June 2021 at the Mayo Clinic in Rochester, MN. Getting to that diagnosis was a challenge with which many others with HSP can identify.

I started to notice changes in my balance, gait, walking up/down stairs and posture when I was 26 years old. At first, I thought these were problems related to getting older. My symptoms progressively got



*Ryan credits his trekking sticks for helping him stay active.*

worse as the years went by, even with frequent strength training.

When I was 33 years old, I’d had enough and went to neurologists and rheumatologists up here in Alaska. None of them could figure out what was going on with my health. As a result, some people were able to convince me that there was nothing wrong with me, that I was just clumsy.

Finally, my mental and physical health deteriorated so much that I travelled to the Mayo Clinic where I was finally diagnosed. I also received other beneficial help, including the advice to buy a good quality trekking stick.

When I first was diagnosed, I always “over did it” and would feel guilty about lying down/resting. I have learned that taking a break is very beneficial. If I can give any advice, it is this: NEVER “over do it.” Don’t feel guilty about lying down/resting. In fact, I feel a lot better when I take 30-60 minutes every day to lie down and rest. Also, consistently do your stretches and your physical therapy.

If there is one thing that I have learned in life it is the power of hope. Never give up; it took me 12 years to get diagnosed. Listen to your body. Respect everyone. Find someone to help you get through life. Finally, start each day with completing a task, e.g., making your bed. This gives you a small sense of pride and encourages you to do another task.

If you do these things, I can assure you that you will live a happier life. And living a happier life will lead to a better world.

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## Make a Visit to the SPF Store

If you haven’t visited the SPF Store lately, you haven’t seen all of the new items and designs

See all of the products, designs and colors by visiting [sp-foundation.org/SPF-STORE](https://sp-foundation.org/SPF-STORE) and then clicking on the yellow “SHOP” icon.



## I Refuse to Give Up!

### My Experience with HSP

By Jimmy Coliadis, HSP SPG4

I have HSP. The first time I heard about it was from a doctor I saw when I applied for SSDI (Social Security Disability Insurance). Then, one day I was unable to run and that's when I knew for sure I had HSP.

I have had some big challenges, but I refuse to give up. For years, I continued to seek employment and better treatments, even when things seemed stacked against me.

**Work/discrimination:** I'm very skilled in HVAC. When I searched for work, I got a lot of interviews based on my resume, but after the interview I would get a letter saying they found someone more qualified. I'm not saying that I'm the best, but after countless places "found someone more qualified" I suspected discrimination because of my disability. I couldn't prove it, so I let it go.

At one point, I got a job at a large facility as the Lead HVAC Tech and worked there for almost five years, getting on roofs carrying heavy things to get to the equipment I needed to work on. I even carried a 28' fiberglass extension ladder without trouble, but as time went on things got more difficult.

**Government benefits:** The first time I applied for SSDI I was denied, probably because there wasn't any medical documentation of my HSP. In 2013, I filed for SSDI for the second time. This time I was approved because I had lots of medical statements about my HSP.

**Treatments:** I've tried quite a few treatments. Some helped, some didn't.

**Reflexology:** A friend treated me to a couple of sessions of reflexology and that did wonders. The day after the first session I went to help a friend who lived on the second floor of an apartment building and I was easily able to climb the stairs.

**Aqua Therapy:** Also in late fall 2019 I started getting aqua therapy and that worked tremendously. I had to stop for quite a while because of a separate health problem, and then the pandemic, but started again in January 2022.

**Botox:** I tried Botox. The first time it went great. Once the first dose wore off I tried it three or four more times, but it was no longer any help.

**Muscle Relaxers:** I tried using various muscle relaxers to help my gait but they didn't help much and had terrible side effects, making me extremely sleepy.

**Baclofen Pump:** Finally, I tried the baclofen pump, which was a disaster for me!



*Jimmy strives to continue using his mechanical skills and expertise despite HSP.*

My physiatrist thought a baclofen pump might help me, but first I had to get a test sample injected into my spine to see how I would react. After the injection, I couldn't stay awake long enough to get home, and had trouble walking and climbing into bed. The next time I talked with them about a baclofen pump, I said there's no way I was going to do it - but I was talked into giving it a second trial at half the dosage. The second trial went better. I didn't sleep more than I regularly did, and I was able to walk, but I didn't have anyone staying with me to watch, so I can't say how my gait was.

The Monday after the second (1/2 dose) trial injection, I had a job interview at a very large facility doing HVAC/Refrigeration and other general maintenance. At the time I didn't know that the baclofen had worn off. During this interview they took me on a tour of the facility, including the attic where I had to step over things, which I could do easily. I assumed it was because of the baclofen, so I went ahead with getting the pump.

December 18, 2014 I had the pump installed. The morning after, I could barely lift my foot an inch off of the bed. When I tried to stand up, I fell backwards. They made some adjustments but there wasn't a huge improvement. At my next appointment I told the nurse practitioner

that it wasn't right, and she said that it was because of a progression of the HSP. I doubted it, because it seemed impossible for it to progress that much that fast, at the same time I got the pump, but I didn't know what I could do about it.

I experienced side effects from the baclofen, including:

- Sleep issues - Starting with the test injections, baclofen made me so tired that I slept most of the time. After the baclofen pump was installed, I developed severe central sleep apnea and also stopped having REM sleep (dreaming).
- Needing assistive devices - After the first test injection, I was unable to walk and had to use a motorized scooter to get around a store. When the pump was installed, they wouldn't release me from the hospital until I could go for a walk. I had to use a walker to do this, and prior to the pump I never used any assistive device. I now had to use an assistive device (forearm crutches, a walker, a knee scooter, or a motorized scooter) most of the time.
- Foot drop - I also developed terrible foot drop after getting the pump put in, which made stairs and ladders harder for me. I struggled, but I continued to do them if I needed to. I would not give up!

I had the baclofen pump removed January 15, 2021. What a world of difference! Immediately I could stand up without losing my balance. I could walk without an assistive device. My foot drop improved, and I can raise my foot up on stairs now. I had another sleep study done a month after removing the pump, and I don't have apnea anymore. I started to have REM sleep again, and dream frequently.

**My Current Life:** I depend on others for help with some things, but I am still able to do some things on my own and strive to do everything I can. I continue to do some HVAC and mechanical work. I still do jobs for friends, on a limited basis of course.

My message to you is Never Give Up! There have been lots of times people have watched me and said, "how is he doing that?" But like I've said, I refuse to quit! I may be slower because of HSP, but I REFUSE to give up.



## Celebrating KIDINS220 Awareness

By Tia Marie Bragg

**RARE.** It is a word that can be silencing, but as genetic testing becomes more common place, our KIDINS220 group has seen a spike in newly diagnosed children, teens, and even people in their mid-thirties when their own child is diagnosed. People who have been diagnosed with various conditions throughout their lives are finally finding the piece of the puzzle that puts it all together. We are a group of 27 families representing 30 cases; we also represent 30 of the 70 known cases in the world linked to HSP. Even though KIDINS220 is still vastly under diagnosed, we are growing fast!

In recognition of the progress made in shining a light on this incredibly rare disease, we celebrated our first KIDINS220 Awareness Day on February 25, 2022. We picked February 25 because the KIDINS220 gene is located at 2p25.1 on the short arm of chromosome 2 on the crick strand. It was our day to yell, "THERE ARE MORE THAN 3 CASES of KIDINS220!"

Families from around the world shared highlights of their day, which included: arriving at school and finding it decorated in black and white stripes to show their love and support, sharing a personal story of the KIDINS220 journey at a special all-school assembly, and celebrating KIDINS220 Awareness Day at Disney World with special signs and zebra pins to remind people to look out for other zebras!



*Michael (center), sisters Emmy (left) and Maddie (right), and mom Meghan show their stripes with their "Care for Rare" KIDINS220 Awareness shirts.*

*Continued on next page*



Rachel celebrating KIDINS220 Awareness Day.

Meghan Hagen, a highly visible and dedicated champion of KIDINS220 awareness and proud mom of Michael, was moved by the support shown for her son at a school assembly on KIDINS220 Awareness Day. "People who did not know me, who had never

met Michael, and had never even heard of this rare disease before, supported us like they have been walking this journey with us since the beginning," she said.



The Wexford, Ireland Fire department joined Ben (first row center), his dad James (left), and mom Nicola (right) to promote KIDINS220 Awareness Day on February 25.

Personally, I was blown away by the outpouring of love and support for my sweet Caleb on his first awareness day! From his family to his school, therapists and techs, it was amazing. We passed out stickers and zebra cakes everywhere we went. He thought the best part was when he got devour the leftovers at the end of the day!

A KIDINS220 mom, Ivet Licona Martinez, told me: "I was at the forefront of Fundación Danitos A.C (Mexico) for years before my son

Mathias was born, working with little ones with neuro developmental conditions. A doctor once said, 'when you hear hoofbeats you look for horses, not zebras.'" Well, our [KIDINS220] kids arrived with white and black stripes."

We look forward to celebrating our amazing Zebras each year with the Spastic Paraplegia Foundation at our side!



Caleb enjoyed his "zebra cake" with dad, Michael, and mom, Tia.

[Editor's Note:

In the Spring 2021 issue of Synapse, Tia Marie Bragg shared her journey of seeking a diagnosis for her son Caleb. In 2016 Caleb was finally diagnosed with KIDINS220 and its pathogenic variant resulting in SINO Syndrome (Spastic paraplegia, Intellectual disability, Nystagmus [repetitive, uncontrolled eye movements] and Obesity.) At that time, he was only the second child officially known to have KIDINS220. Through Tia's efforts, families and medical professionals are coming together to find each other and raise awareness.]



## Two Perspectives on Advocacy

By Tina Croghan, SPF Board Member, HSP SPG7, MO and Jackie Wellman, SPF Board Member, HSP, IA

### TOGETHER WE'RE STRONGER



Tina Croghan

**Tina:**

Recently I got to participate in Virtual Rare Disease Week on Capitol Hill. I joined RDLA (Rare Disease Legislative Advocates [www.rareadvocates.org](http://www.rareadvocates.org)), and I was kept up to date on the recent issues concerning rare diseases. There are more than 7,000 rare diseases out there, so getting our voices heard is challenging but rewarding. HSP and PLS is just a small string but when united with other strings, you now have a rope that is much stronger.





I didn't start out by having meetings with my legislators and talking about bills up for a vote. I started out by being me. I live, eat, and breathe this hand that has been dealt me—HSP. If I can't beat it, fight it, right? Everyone who comes in contact with me knows about SPF. Hey, I'm a "walking" billboard for HSP anyway! I let everyone know about HSP and upper motor neuron diseases. Sometimes I even educate the doctors! In a utopic world I wouldn't have to, but I'm taking control of this disease.

The first thing to do is get yourself a bunch of SPF swag. I wear SPF shirts everywhere. I've been around long enough to have acquired quite a complement. My husband wears SPF hats as well. Our car has a magnet promoting HSP and PLS.

When I was in the hospital with broken ankles, I kept a business card describing HSP; the flip side described the foundation. Everyone who entered my room got one. Whenever I post pictures on social media, I'm either wearing an SPF shirt or talking about HSP or SPF.

Next, educate yourself. Join all kinds of webinars. Dr. Fink has a neurological support group which meets the 1st Tuesday of each month. Check out the "events" on [www.sp-foundation.org](http://www.sp-foundation.org). You don't need to talk if you don't want to. Just listen.

Finally, speak out! When you join RDLA, you will receive links to particular legislative issues that pertain to our rare disease and sample form letters that you can use to send to your legislators. There will be a space where you are able to add your own thoughts. Tell them who you are and why their vote on this issue is vital to you. Remember, they work for you! They need to hear your voice before they can champion it. If you don't know who your legislators are and how they stand on rare disease issues—check out [www.everylifefoundation.org/rare-advocates/advocacy-tools/legislativescorecard](http://www.everylifefoundation.org/rare-advocates/advocacy-tools/legislativescorecard).



## BE THE CHANGE YOU WANT TO SEE



Jackie Wellman

### Jackie:

Two of the ways I deal with HSP are to always remain busy and to help to find a cure. I will do whatever I can to find a cure. My son has HSP. What better motivator is there than that?

Any of you can help.

Call your Senators and Representatives (if you do not know who they are, visit [www.usa.gov](http://www.usa.gov) or just Google it.) Ask them how to get Spastic Paraplegia Foundation research funding or ways to create awareness. I completely understand not wanting to or not having the time to do what I do. I could not do all that I do if I worked a full-time job. Plus, not everyone has an interest in politics like me, but each and every one of you can call or e-mail your legislators.



Besides my Spastic Paraplegia Foundation work, I dove headfirst into a way to get money for research and raise rare disease awareness. Politics is the way I choose. Each candidate I work with has a SPF connection.

Both of my connections in the Senate and in the House are helping with the most recent way I am hoping that SPF gets funding for medical research: a bill called Accelerating Access to Critical Therapies for ALS. This bill passed both the Senate and House and the President has signed it into law. It includes HSP and PLS, as well. The only thing done is the fact that it is a law. The way funds will be distributed is waiting to be decided. As we all know, government does not work really fast. My two connections in the US government are checking every little bit to see how this is going to work. I would love for SPF to get part of that money and be able to fund more research projects.

The only thing in life that you really have control over is your attitude. Are you going to do all you can to make the situation better or not?



## Not Just Lip Service!

### **Tips from a Speech-Language Pathologist's Point of View**

By Bethany Hetrick, M.S., CCC-SLP,  
UH St. John Medical Center  
and Larisa Kalinowski, B.S., Graduate Clinician



Bethany Hetrick



Larisa Kalinowski

When individuals hear the title “speech therapist,” or “speech-language pathologist,” they tend to generally assume that these professionals are responsible for simply teaching children how to talk properly. However, many speech-language pathologists (SLPs) specialize in working with adults, and with individuals with degenerative diseases, including hereditary spastic paraplegia or primary lateral sclerosis. According to the American Speech-Language-Hearing Association, SLPs can evaluate and assist

in developing a treatment plan if you present with any of the following symptoms:

- impaired coordination or increased weakness of the face or mouth,
- changes in voice,
- slurred speech,
- difficulty chewing and/or swallowing,
- trouble with word finding, or
- changes in cognition.

Various strategies to alleviate these symptoms are listed below; however, it is recommended that a certified SLP be contacted for a formal evaluation if any of these concerns arise.

**Having difficulty coordinating the muscles necessary for speech production?** Try modifying the speaking environment (e.g., *reduce background noise, ensure that the listener is paying attention to your message, decrease the physical distance between communication partners*). Be sure to communicate your needs and preferred method(s) of communication

and use strategies to repair communication breakdowns when they occur (e.g., *repeat, rephrase, use gestures, write*).

### **Experiencing increased weakness of the face and mouth or slurred speech?**

Consider trying various exercises that involve tensing the muscles affected. The muscles of the face and mouth work similarly to any other muscle and can be strengthened through intentional movement. These muscles respond well to exercises that involve resistance (e.g., *pushing tongue or pursed lips against a spoon or tongue depressor*). In addition to this, compensatory strategies can be implemented to promote better understanding between the speaker and listener. For example, prior to starting a conversation or switching topics, cue the listener by using one or two words related to the topic to provide the listener with the context of the message. For instance, if discussing plans for dinner, cue the listener with the word “dinner,” so that there is context prior to starting the conversation to improve overall understanding of the message. Furthermore, be sure to consciously speak loudly and slowly or try alternative methods of communication such as pointing, typing/texting, or writing.

**Noticing any changes in voice?** Attempt to determine patterns for conditions/situations in which your voice improves or worsens. Consider visiting an ENT doctor to rule out underlying pathologies. Voice intervention typically involves implementing a vocal hygiene regimen, providing education, determining the abilities of the current state of the anatomical structures and how they affect the voice, increasing awareness of perceptual factors (*vocal quality and muscle tension*), adopting compensatory strategies, modifying speaking environments, and suggesting accommodations and supports.

**Experiencing increasing trouble with word finding?** Try these strategies to trigger your memory or to communicate your message differently, but as effectively. If you find yourself “getting stuck” on a word, try instead describing the general idea behind

your message or substituting the word with another one that has a similar meaning. Or try using another modality to try to spark your memory of the word, such as making gestures or drawing a picture representation of the word. Furthermore, consider trying to say the first sound or syllable aloud, or saying words that are closely associated to the target word (e.g., saying "apple, banana, orange" to help remember the word "peach").

**Noticing changes in cognition (memory, attention, and/or executive functioning)?**

Try implementing a variety of internal cues and/or external cues to assist in alleviating the symptoms. Internal cues/reminders include rephrasing or repeating the important information, chunking information into categories or groups, connecting new information to previously learned information to build associations, and visualizing key details. External cues may consist of paper or electronic calendars or day planners, timers/alarms for reminders, designated permanent places for essential items (e.g., consistently leaving keys by the door).

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**IF YOU FIND YOURSELF  
"GETTING STUCK" ON A WORD,  
TRY SUBSTITUTING THE WORD  
WITH ANOTHER ONE THAT HAS  
A SIMILAR MEANING.**

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**Having difficulty swallowing?** Try to determine which foods and/or liquids are problematic or if any strategies improve or worsen the swallow. If you are experiencing symptoms such as increased coughing, especially when eating and drinking, a wet or "gurgly" sounding voice, weight loss, sensation of foods "getting stuck," or pain while swallowing, then consider a formal swallowing evaluation to determine the cause and develop a treatment plan. Strategies that

may help improve symptoms include taking small bites/sips, alternating consistencies (*taking a bite and then a sip and then another bite*), avoiding problematic foods/drinks, eating/drinking in an upright position, and using a slower rate when eating/drinking.

If you or anyone you know is exhibiting any of the symptoms described, consider contacting your primary care physician for a referral to a speech-language pathologist near you. For additional information on how a speech-language pathologist may be able to help you, please visit <https://www.asha.org>.



**Dr Fink's Neurological Support Group**

Join the Official SPF Group at:  
<https://www.facebook.com/groups/HSPandPLS/>

### Helpful Hints for Navigating Theaters, Auditoriums, and Other Public Places

By Malin Dollinger, M.D., HSP SPG4



Malin Dollinger, MD

Over the years, I have experienced firsthand how public places have varying degrees of accessibility. I also have learned that we must adapt our behavior and reconcile our specific type of disability and abilities with the challenges presented by our surroundings. We already

know how to open doors at home; navigate stairs, inclines, narrow pathways; and handle crowds and people who – thankfully for them – never had to deal with these situations. I’ve been in public handicap bathrooms so narrow that I had to choose between entering backwards in my scooter so I could close the door or entering forwards so I could access the toilet (*leaving the door open*), but not both, since I could not turn around in my scooter!

Here are some ideas that can help you deal with some of the challenges presented by public places.

#### Gaining Access

Those of us with HSP or PLS are used to special maneuvers and actions to enter public places, such as finding a stairway with handrails, if we can walk with help, or an entry ramp, if we’re using a handicap scooter, wheelchair, walker, or other mobility device. Sometimes the ramp is a late addition, resulting from new ADA requirements, and may be “around the corner” or harder to find. Added construction to an existing building often legally requires handicap remodeling, affecting not only ramps but bathrooms, doors, and other areas.

For older buildings, you may need to get in via a freight or loading dock, or the “back door.” By now you have figured out how to get through doorways. Electric scooter users have learned to push the door open with the scooter, or to adjust a scooter with twin motors to enter facing forwards or backwards, so the side of the scooter with the controller handle “matches” the side of the entry door that opens, opposite the side with the hinges. I’ve resorted

to some unusual behaviors in older facilities, like entering through the back or kitchen door, or sitting in an unusual place, like the Queen’s Royal Box at the Globe Shakespeare Theatre in England.

In this age of increased security and COVID-19 precautions, you’ll need to have your ID/driver’s license and your vaccination card handy when entering the building. Try to put your minimal “carry-in” items in a single container, perhaps with a strap to hang on you or the scooter, so you can remove it for inspection as needed. Many facilities do not wish you to bring food or water from the outside, but if you need either for control of blood sugar/diabetes, or to take medications, simply find a pocket in your scooter bag or some other “invisible” location.

#### Handicap or Regular Seating?

Find out about seating options ahead of time so you can purchase the correct tickets. The space for handicap seating may be “empty,” and a regular chair can be placed for your companion next to your handicap wheelchair or scooter. Sometimes there’s a theater chair alternating with empty spaces. If you purchase theater seating online, carefully inspect the seating diagram, so you have the correct number and type of adjacent seats.

You know the rules for handicap seating: a space for the wheelchair or scooter and an adjacent regular seat for your companion. If someone is sitting in your assigned seat, very politely and respectfully explain that you reserved this seat because you need to stay in your scooter and cannot transfer/sit in a regular seat. Show them your ticket. If the problem persists, you may need to call in the manager.

#### Things to Consider and Verify in the Age of COVID

- Is the seating standard/close or is there more space between seats (e.g., seating grouped in pods or with spacing all around)?
- Are vaccination cards and masks required, as well as an illness/travel question before admission?
- Does the facility have air quality improvements, such as HEPA filters?
- Are the performers, including musicians (except for wind instruments) in the

orchestra masked? Try to avoid sitting near the trombones, trumpets, and horns if you go to an orchestral concert.

- Try to obtain and wear N95 or KN95 masks, and go near a doorway or outside while waiting or during intermission.

### **Bathroom Strategies**

As soon as you enter a new theater or facility, find out where the handicap bathrooms are; you might even go inside to check out the handicap stall. The goal is to create a strategy before you need to use the bathroom.

A frequent challenge is encountering a line waiting to get into the bathroom. It's very important that you do *not* get into that regular line. There is likely only *one* handicap stall, and you are waiting *only for that stall*. So announce to everyone in line, in a loud and kind voice, "Excuse me. I can only use the handicap stall, so I need to be close to it when it becomes available." This is especially important for women, since the women's line is usually much longer than the men's line.

When you get to the handicap stall and the door is closed/locked, you and your bladder may be getting frantic! My favorite "kind" way of speeding up the process is to announce loudly, "Will the person using the *handicap* stall be out soon?" They may not know or respect that it's a handicap stall. If there is to be a long delay, you might decide to leave and come back in five or ten minutes. This situation is common at airports, often where a non-handicapped person has their luggage with them in the oversize handicap stall and is changing clothes while you wait.

Here's a new way of thinking about handicap bathrooms, as well as handicap hotels. I think of two different hotels – a regular one and a handicap one – being in the same building. For management's convenience, the small handicap hotel is inside the large regular hotel; just as the handicap stall/bathroom is inside the regular bathroom. So in that restroom line, you are actually waiting to get into the separate handicap bathroom, which happens to be inside the regular bathroom. Your job is to explain that you need to use *only* the handicap stall, and you are *not* trying to "buck the line."

Sometimes the handicap bathroom is not on the same floor as your seats. Some theatres have handicap elevators to get to the bathroom, but these may be small, and there's thus a waiting

line for the small handicap elevator during intermission. Using that elevator to get to the handicap bathroom and back may take up the whole intermission. One alternate plan is to take a regular elevator to a different floor and head for a less-used handicap bathroom.

Another strategy is to arrive early enough to use the facility bathroom before the performance and avoid competing for the bathroom line with other disabled people at intermission.

### **General Helpful Hints**

Be sure you bring everything you need for an enjoyable and safe experience:

- Water and a snack, to avoid going to the food counter during intermission.
- Medications and other medical items you might need, such as a sugar source for diabetics or extra hearing aid batteries.
- Vaccination cards and masks.
- Paper cups, hand wipes, hand disinfectant, eyeglass cleaner, and Kleenex.

When entering and being inside the facility, ask your companion to act as your "blocker" (like football) to:

- Clear the way,
- Remind people there's a wheelchair/scooter about to pass them,
- Open the lobby door for you,
- Run ahead and reserve the handicap elevator to the rest room,
- Press the button for the regular elevator, and
- Press the inside buttons if they are hard to reach.

Go ahead of you and open the doors to the hallway as you are leaving for intermission or at the end of the performance. Note: If you have a wider scooter, you may need to have the theater entry agent open "both" double entry doors.

*(Remember to buy an adjacent seat for your companion or helper!)*

If the parking garage is very full/busy, consider leaving as the audience applauds the final selection or the movie's credits appear. Doing so will give you the needed extra time to get to the garage and out of parking area before the crowd fills the garage and swarms around you.



## Accessible You Say?!

By Tina Croghan, SPF Board Member, SPG7

Recently, I had the opportunity to address a group of individuals that had no concept of what Hereditary Spastic Paraplegia is, much less what the term “accessible” really means to me. I have SPG7 and have flown many times to SPF Annual Conferences, doctor visits, and vacations.

We have all found out by unfortunate chance that “accessible” is a relative term when travelling. After booking a hotel room online, I found that the door is really heavy and hard to open. In the bathroom, the toilet is too low and the shower is a tub with only one grab bar and no seat. Although this room is technically accessible, it doesn’t meet my needs. I should have started with checking the hotel’s photo gallery, read online reviews and placed a phone call before booking the room.

Hotels have very few accessible rooms. Some of those rooms are designated hearing impaired, in which case the room is identical to a “regular” room but with flashing lights on the phone for an incoming call and one above the door in case of a fire.

If you are going to travel by air, try to get a direct flight. Always tell the airline you are a mobility-impaired person and you will get priority boarding. I recommend you use a wheelchair in the airport. Going through security is easy when using a wheelchair. TSA will usher you to a special screening area where you don’t need to take off your shoes. You will be able to take the wheelchair right up to the plane and be able to use the airplane’s aisle transport chair or walk with help from your caregiver or flight attendants. They will seat you automatically at the bulkhead (the first row of seats). I usually choose the aisle for the added legroom for my braces.

But first, I recommend going to the restroom before the flight boards. This is essential! Also, try to only fly three to four hours (or less) and limit liquid intake during the flight. I wear support socks and stretch often to avoid leg cramps during the flight. *(You’ll also need to do this if you’re in a car!)* Please note that

the airplane’s lavatory is impossibly small and difficult in which to maneuver. For added protection, I wear a disposable brief with a thick pad. After the flight, I use the airport’s restroom as soon as I get off the plane before going to claim my luggage.

I’m always the last to deplane. This gives the baggage handlers time to bring up my wheelchair from the cargo hold. If you are using airport services for a wheelchair, they will bring it down the gangway and have you deplane first. The flight crew is always good at assisting me during my travels.

If you travel by car, stop often to use the restroom and stretch. The biggest takeaway is don’t be afraid of traveling—just be prepared.



## Getting a Service Dog: Insight into the Process

By Tina Croghan, SPF Board Member, SPG7

Members of SPF often ask me what is the process of obtaining a service dog to help them with their HSP or PLS. I am fortunate to have a service dog, Thunder, whom I’ve had since 2015, and he has transformed my life by helping me become more confident and independent. I am a client of Duo Dogs, a non-profit organization located in St. Louis, Missouri, and I recently spoke with Duo’s Program Social Worker, Rebeca Hilleman, about the current process of getting a service dog. There are many other assistance dog programs available nationwide. This article describes how Duo Dogs handles the process since it is the organization with which I am most familiar.

Hilleman explains that the first step is to review their website, [www.duodogs.org](http://www.duodogs.org), and familiarize yourself with their organization and the



type of assistance dogs they train: facility, mobility, hearing and PTSD dogs (*currently only available to local veterans*), and then begin the initial online process.

The inquiry form is general in nature and is reviewed by Duo's Inquiry Committee to see if they feel that they can meet your needs. Hilleman points out that a Duo Dog is not able to provide bracing or transfer support. Prospective clients must not be active fall risks—meaning a dog cannot brace your fall or help you to stand.

If you meet the eligibility requirements, Duo will invite you by postal mail to complete a more comprehensive application that includes items such as verification of your clinical diagnosis of disability and your financial ability to care for the dog. Duo is also interested in the home environment in which their dog will be placed, as they want the dog to be successful in assisting you in your daily needs to ultimately become more independent in public.

Communication is the key to this process as it's your responsibility to understand what assistance you really need and what a Duo Dog can help you with. You must use the dog in at least three tasks to help mitigate your disability and also continue to follow Duo's rules and the training you've learned to keep the dog successful. While a service dog can provide a lot of assistance throughout your day, Hilleman tells people to remember that an Assistance Dog can never replace a human caregiver or a prescribed medical device.



*Rebeca Hilleman (left) counts Tina and Thunder among Duo Dog's many success stories.*

It is important to know that from each litter of puppies, on average only 35% of them make it through to graduation and that Duo invests \$40 thousand in their two years of training. Although Duo pairs clients and dogs without passing on this cost, the client is responsible for equipment fees, the cost of coming to St. Louis for two weeks of in-person training, and the cost of the dog's daily care once placed.

If Duo accepts your application for a service dog, you are then placed on the wait list, which is currently two to three years - the industry average. Hilleman notes that their training staff reviews your information and then compares that to the dogs they have in various stages of training and to which one would be best suited for you. Although it's a long wait for a service dog, Duo keeps in contact with you to see how you are doing and if any changes have occurred that could affect the outcome and timeline of the process. Stay positive as the wait is well worth it!!

I've been blessed these past seven years with Thunder's companionship, and I can't champion enough the efforts of Duo Dogs and the profound impact they've had on my life. I share this brief synopsis of what it takes to get a service dog to hopefully answer some of your basic questions. If you are really committed to the process, your future may have a service dog in it!



## SYNAPSE APPEAL

*Synapse* is an online and print publication for members and friends of the Spastic Paraplegia Foundation. If you or a loved one enjoyed this issue and would like to support it, please use the enclosed response envelope or go online at [www.sp-foundation.org](http://www.sp-foundation.org) to make a donation.

**EVERY LITTLE BIT HELPS.**

## SPF Illinois Connection March 2022

By Sid Clark, HSP and  
Hank Chiuppi, PLS

SPF Illinois had a Zoom Meeting in March. It was good to see those in attendance and welcome new members. It is hard to believe that Hank and Sid started meeting as SPF Illinois 10 years ago. We talked about how long we have had HSP/PLS and, in a round robin, we covered topics that included: baclofen pump; physical therapy; value of exercise (stretching, wheelchair exercises); Alinker bike (value and use of a non-motorized walking bike, cost); and the possibility of resuming meeting in-person late summer/early fall.



Attending the March Zoom were: (top row) Sid Clark, Hank Chiuppi, BJ Irwin, (middle row) Mary Levi, Carolyn Wright (not shown), Don Dahl, (bottom row) Steve Beutelspacher, Mary Schultz.

## Abilities Expo in Dallas

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

Tina Curfman, Jeana Fraser, Donna Matejka (SPG4), and Celyna Rackov with her husband Randy attended the Abilities Expo in Dallas in December.

Various businesses and organizations catering to disabled people were represented at the Expo, including groups such as "Disability Rights - Texas" that protect the rights of



L to R: Donna Matejka, Tina Curfman, Celyna Rackov, and Jeana Fraser.

the disabled, vendors who make and sell orthopedic devices and aids, and vendors who modify cars for your disability and sell pre-modified trucks and vans. There was even an organization that trains service dogs (*sorry, no service cats were represented!*)

There was also a rock-climbing wall configured so that anyone could reach the top, no matter how limited their mobility. We (Celyna and Tina) braved the climbing wall and agreed that, although the adaptive climbing wall follows all safety requirements, looking down was still a little scary; it was also exciting!

Physical benefits of climbing include strengthening hands, biceps, lower back, glutes, calves, and the cardiovascular system. Climbing can also have mental health benefits such as concentration, determination, and self-confidence.

Kim White from the Houston area was not at this event in Dallas, but she sent zebra pins for each one of us. She chose the zebra pin because it is the official symbol for Rare Diseases. Kim, thank you for your kindness and friendship! We hope we can all meet one day; probably at the 2022 SPF Annual Conference in Nashville.





Your attendance is greatly appreciated at the 19th Annual Conference, where we are celebrating the 20th Anniversary of the Spastic Paraplegia Foundation. Registration is open online as we plan to gather with friends, both known and new, on July 22-24, 2022, in Music City, Nashville, Tennessee. Learn about the latest in scientific medical research and share strategies for living with Hereditary Spastic Paraplegia and Primary Lateral Sclerosis.

The Spastic Paraplegia Foundation coordinates the world's largest annual Spastic Paraplegia gathering – the Annual SPF Conference. For two and one-half days, conference attendees meet and learn from world-leading researchers and clinicians, network together and reunite with old friends while making new ones. Many people – from patients, to caregivers, to medical professionals – travel from all over the world to attend the conference. The location moves each year, providing a broader opportunity for people to attend and travel. Accessibility accommodations are kept in mind when planning and choosing conference locations. Attendees get the opportunity to learn more about HSP and PLS regarding medical research, genetics, physical therapy, living challenged, coping, care-giving, and more.

Sessions at the conference will include the process of selecting researchers who receive scientific and medical research grants from the SP-Foundation. Researchers and doctors will share information about their work and updates on gene therapy. There will be breakout sessions for just men, just women, just children, and caregivers in which each group can talk openly with others about daily personal living issues. If you have a concern or a question that you would like to submit ahead of time, please let us know, and we will address it during the breakout session.

There will be informative sessions on clinical research and related disorders for therapeutic development, human genetics, and neurology. Dr. John Fink, who serves as the SP-Foundation's scientific medical advisor and is the Director of the Neurogenetic Disorders Clinic at the University of Michigan and Physician Scientist at the Geriatric Research Education and Clinical Center, will join us. On Sunday morning, we will have coffee and pastries with Dr Fink as he spends time speaking and answering questions from attendees. We will also recognize the State Ambassadors and Donors at the conference. Speakers include a Keynote Address from Darius Ebrahimi-Fakhari, and updates from researchers Peter Baas, Hande Ozdinler, Hiroshi Mitsumoto, Stephan Zuchner, along with others.

We celebrate the themes of Nashville, Tennessee as we focus on SPF. Nashville is "Cowboy Up", "Volunteer", and where better to "Find Your Song." Starting with **"Find Your Song."** Nashville is the capital of country music. Nashville is Music City where it's encompassing all music genres. Music isn't just part of the culture; it IS the culture. The humble center of all this activity is the thing that makes everything possible – the song. Writers often ask, "How do I get my songs to the right people? How can I get heard?" Comparably at the heart of SPF, we lift our voices often to ask, "When will researchers Find the Cure?" "When can this

*Continued on next page*

nightmare be over?" Like making a great song or finding a cure, how does it happen? The simple answer is a lot of hard work, planning, and reaching for your goals.

Next, you may know that Tennessee earned the nickname "the Volunteer State" after the state's overwhelming involvement in the War of 1812 when 3,500 men enthusiastically answered the recruitment call. Similarly, SPF is seeking assistance from every person willing to "**Volunteer**" helping with medical research fundraising and awareness of HSP and PLS.

Lastly, but listed first, "**Cowboy Up**" – it's not just a phrase, it's a lifestyle. Country music, cowboy boots and cowboy hats are a part of the country Americana culture.

Most cowboy hats are worn by tourists, and cowboy boots can be hot and uncomfortable wearing them all day. Like us with HSP and PLS, "**Cowboy Up,**" or "**Cowgirl Up**" for that matter, means you must get tough, make a determined effort to face and overcome whatever obstacle or difficult situation with a great deal of "grit and grace" every day, every way, and everywhere.

Say "hello" to me in Nashville!

*Norma Pruitt*

SPF Executive Director, Conference Coordinator

## Sponsors Thank You For Your Generous Contributions as SPF 2022 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 and contributions you give to the Spastic Paraplegia Foundation. —Thank You!



Christopher Falconer, CFP®, ChFC®  
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# 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](http://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.*

#### 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](mailto:SpasticConference@gmail.com) prior to the conference dates.

**Contact: Details at [SP-Foundation.org](http://SP-Foundation.org) - Email Comments/Questions: [SpasticConference@gmail.com](mailto:SpasticConference@gmail.com)**

**Call (877) 773-4483**

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**JULY**  
22-23-24,  
2022

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**#CureHSPandPLS**

Watch for  
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*Find Your Song*  
in **Music City, USA**  
**Nashville, TN**  
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**See Pages 18-19 for Latest Conference Details and Registration**