

SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.

Volume 24, Issue 4

Autumn 2021

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Letter from the President



Frank Davis

Dear Friend,

The fourth quarter of the year is when the Holiday Spirit prompts everyone to be kind and generous to their fellow man and I am very

excited that we will all be working together to break our fundraising record. Our anonymous donor has again agreed to match everyone's donations received between mid-November and mid-January, up to \$200,000.

This also marks the end of my tenth year as the president of The Spastic Paraplegia Foundation and the end of my 17th year being on the Board of Directors of SPF. When I first took on this volunteer presidential responsibility, I remember feeling trepidation. I was stepping into the very big shoes of Annette Lockwood who had carried out this role so excellently for many years.

SPF was founded in 2002. I joined the Board of Directors as secretary in 2004 and became president in 2012. The decades keep rolling by. To say a lot has happened in our SPF research efforts, upper motor neurological science,

and genetic science in the last decade has to be an understatement. When I started, our Foundation had all sorts of less effective software which has been greatly improved on or replaced. We can now easily keep track of you, communicate with you, and be personally acquainted with you. I am glad that we can stay in touch. The people on our Board of Directors and our ambassadors keep getting stronger in their abilities and resourcefulness and we keep becoming stronger as a Foundation and as a patient advocacy group as a consequence.

In 2012, the total donations given through us to facilitate the very best find-a-cure research on this planet was about \$458,000. This year, with your help, we stand a very good chance of raising over one million dollars, which is about a ten percent growth over last year's total. We may all have to try just a little bit harder this year in our giving to get us there, but I feel confident that together we can do it. Getting over one million dollars will allow us to expand our support of research ranked as "excellent" and "very promising" by our expert Scientific Advisory Board. Every year our research efforts get us ever closer to

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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 to make a donation.

SYNAPSE

Volume 24, Issue 4 - Summer 2021

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

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achieving our mission of having everyone with HSP or PLS be able to be quickly diagnosed, treated and cured. This could be the year that a groundbreaking discovery is made.

Since this is my tenth year as president, I thought I would review how science has moved forward by leaps and bounds over the past decade. It was in 2009 that the first whole exome sequencing opened up a new wave of gene discoveries. Between 2010 and 2022 dozens of new HSP gene discoveries were made. This greatly narrowed the HSP diagnostic gap. Today, many more HSP patients receive a diagnosis than could have just a few years ago.

In the last decade, the genetic and biological overlap of HSP with related disorders, such as ataxia, neuropathies and ALS, has been born out and is influencing research. Large scale genetic data sharing has accelerated gene discoveries. Key databases such as the GENESIS database in the USA and RD-Connect in Europe have brought many more scientists and doctors together to greatly facilitate getting to our cures. It was in 2013 that the Spastic Paraplegia Foundation supported the creation of the TreatHSP Consortium and it was also in 2013 that the start of the Human Brain Project was announced. In 2014 John O'Keefe, Edvard Moser and May-Britt Moser shared the Nobel Prize for their discoveries about cells that constitute a positioning system in the brain.

In 2017 the first gene replacement treatment called Luxturna was approved by the FDA for a genetic eye disorder. In 2019 P. Hande Ozdinler, Ph.D. developed a drug (NU-9) that shows great promise for helping people with HSP and PLS. NU-9 will soon go through clinical trials. In 2020, the Nobel Prize for CRISPR gene editing was awarded to Emmanuelle Charpentier of the Max Planck Unit for the Science of Pathogens and Jennifer Doudna of the University of California, Berkeley.

Technologies such as optogenetics and single-cell RNA sequencing were widely adopted by the neuroscience community in the last decade. Optogenetics allows researchers to control neurons with light, even in freely moving animals going about their lives. Add to that, a whole list of rainbow-colored proteins to tag active cells. Single-cell RNA sequencing is the queen bee of deciphering a cell's identity, allowing scientists to understand the genetic expression profile of any given neuron.

There has been a great brain-mapping effort, producing map after map at different resolutions of various animal brains. The upcoming years will see individual brain maps pieced together into comprehensive atlases that cover everything from genetics to cognition, transforming our understanding of

brain function from paper-based 2D maps into multi-layered Google Maps.

The human brain alone contains around one hundred billion neurons and one hundred trillion synapses; it consists of thousands of distinguishable substructures, connected to each other in synaptic networks whose intricacies have only begun to

be unraveled. At least one out of three of the approximately 20,000 genes belonging to the human genome is expressed mainly in the brain.

Scientist after scientist has told me, excitedly, in recent months that the next couple of years will reveal all sorts of discoveries that will step us ever closer to finding those cures. It is only because of you and your generous giving that this progress is taking place, so Thank You So Very Much! I hope you will please do your best to be generous this coming holiday season. Help us to use every penny of that \$200,000 matching donation.

Sincerely,

Frank

Frank Davis, President

SPF Vision - The day when all individuals with HSP or PLS are diagnosed, treated and cured.

GENERAL INTEREST

Learning to Live Our Best Lives with HSP

By Louise Roux

Bonjour!

We are two sisters, Mary (6 years) and Olivia (8 years) who live in the south of France. We both have SPG4.

About me, Olivia: my symptoms are quite mild. I get fatigued when walking too long, and sometimes I fall.

About me, Mary: my symptoms are more pronounced. I walk on tiptoe and I often fall.

We both go to the physiotherapist together twice a week where we do stretching and some exercises in order to improve our balance. We also have psychomotricity sessions with breathing exercises and relaxation. We also swim to relax our muscles.

We go in the same school and our teachers adapt sports lessons for us. It's great because we can participate in the same activities as our friends. Soon we will even have an adapted tricycle.

Sometimes, though, HSP makes us sad because we can't walk and run like other children. For example, when children are playing ball or skipping rope we are often afraid of falling when they jostle us. It makes us feel alone on the playground.

We very much hope that a treatment will cure us and all HSPers around the world. Until that day, we make the most of life and we keep smiling!

Au revoir!



Olivia and Mary brighten the day with their smiles!

Evan Austin Honored To Go To Third Paralympic Games

By Karen Price, United States Olympic & Paralympic Committee

Swimmer Evan Austin is at his third Paralympic Games, and he can still remember that moment when he learned he was going to his first Games back in 2012.

"There was that immediate feeling at the team announcement when they just said my name," he said. "And I'd heard my name a million times before; I'll hear my name 10 million times later in life, but that was one so significant moment."

When Austin heard his name for a third time following the U.S. Paralympic Team Trials in Minneapolis in June, it was no less special. He trained differently and prepared differently this go-around, and now at 28 years old the Terre Haute, Indiana, native is hoping to snag his first Paralympic medal. "To come back and be on the doorstep of going to a third Games, and one that I think I'm maybe best prepared to bring home some hardware for, it's a huge honor," he said. "I'm just super thankful and grateful that I have this community and village that supports me and allows me to keep doing this."

Austin was a resident at the U.S. Olympic & Paralympic Training Center in Colorado Springs, Colorado, leading up to the Paralympic Games Rio 2016 and as recently as the summer of 2019. But that fall he decided he needed a change, so he moved back to Indiana and began working and training with the Purdue women's swim team. He became the official volunteer assistant coach for the 2020-21 season and not only helps head coach John Klinge but also trains under him as well.

"New coach, new system, it's a different style," said Austin, who has spastic paraplegia and will compete in the S7 50-meter butterfly, S7 400-meter freestyle and SM7 200-meter IM in Tokyo. "And now I'm the only adaptive sport athlete and I train exclusively with college-age women on the Purdue swimming and diving team. So the environment's certainly

different. I like it. On meet days I'm on the pool deck saying this is how we can do better, this is how we can perfect strokes and things like that. And then the next day I'm right back in the water with them. It's been an interesting dynamic that's definitely changed my mindset and my mind frame."

Austin admitted he wasn't so sure coming into the situation how he'd be received. He was really, truly scared, he said, about what the women on the team would think and how they would react. "Like, here's this guy who knew the (former) assistant coach (Molly Belk) coming in and saying, 'Hey, I'm here to help you guys get better, and also I'm going to train with you,'" he said. "I didn't know if they'd have some walls or some reservations about that, and they could not have been more welcoming. From day one I felt like I was a member of the family there and the bond has only grown in the last two years."

Serving as a coach has changed Austin's training significantly. For one, he said, he believes he's more coachable now, and has a different attitude toward criticism and critique.

"You talk amongst coaches about a swimmer's technique, and then when somebody's talking to you about your technique it's like, OK, I have this new level of understanding of where that's coming from and what he's trying to accomplish and what he's trying to say," Austin said. "He wants me to get better. I think it's given me more patience and more perspective as an athlete."



Evan Austin's powerhouse performance at this year's Tokyo Paralympic Games was golden!

Photo courtesy of the United States Olympic & Paralympic Committee



Evan Austin celebrates his golden moment on the podium at the Paralympic Games Tokyo 2020.

Photo courtesy of the United States Olympic & Paralympic Committee

In Austin's Paralympic debut, he finished sixth in the 100-meter breaststroke and in the 34 pt. 4x100-meter freestyle. In 2016, he was again sixth in the 34 pt. 4x100-meter freestyle and the 34 pt. 4x100 medley and eighth in the 100-meter butterfly and 100-meter breaststroke.

Then the fall of 2019 he had a breakthrough performance at the world championships, winning the title in the 50-meter butterfly. "I really was looking for that benchmark moment in my career to say that's when I knew I was the real deal," he said. "Not a lot of people get to say they were world champion in anything."

Despite the interruptions of 2020, Austin set two lifetime bests at the Para Swimming World Series stop in Lewisville, Texas, in April, winning the 50-meter butterfly and 400-meter freestyle and setting American records in the 200-meter and 400-meter freestyle.

"I really didn't expect to do that, and as a 28-year-old that was fantastic news," he said. "It was a perfect example of the training and hard work at Purdue putting us on the right track."

EDITOR'S NOTE: Congratulations to Evan Austin for his stellar performance at the Paralympic Games Tokyo 2020 held in August 2021. Austin was the gold medalist in his favorite event, the 50-meter butterfly, bronze medalist in the 400-meter freestyle, and claimed 5th place in the 200-meter individual medley.

I'M DONE!

By Tina Croghan, HSP SPG7, SPF board member

I'm done!

On August 16, 2021 I was discharged from physical therapy. I had been doing PT for my ankle that I broke in October 2020. It was exactly 10 months. I guess I should be happy, but I am a bit scared. It's now up to me. I know all of the exercises to get me stronger. I just have to do it. But ... what am I so worried about? I have started and stopped this article several times.

What if I fail? There. That's it. What if I do everything and I don't get back to how I was before? Dr. Fink assured me that I could, but I'm still in a wheelchair and I still have difficulty lying on my back or stomach. I have gained weight, and it's humiliating to need my husband to do everything for me that I used to do for myself. Is this as good as it gets? Is this my new normal?

That has been my frame of mind for the last 10 months. It wasn't until this 2021 HSP and PLS Awareness Week that my outlook changed. If



Tina sporting her new wheels

you have never tuned in to the 1:00 p.m. Zoom gatherings, you're sadly missing out. One of the people (I don't remember who) said, "This is just your Earth suit; [you need] to find joy every day and decide what your mission's going to be."

I know that these are all Hallmark sayings, but something in me clicked. I'm going to get myself up out of this pity party and do my stretching and exercising and get my legs stronger. If my life is going to be from a wheelchair, so be it. I'm going to find the joy and happiness every day.

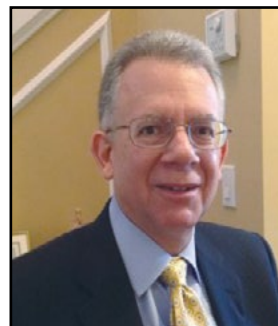


Your Donations: Money with a Mission

By Jim Sheorn, HSP, SPF Board Member and Mark Weber, Chairman, Research Grant Committee



Jim Sheorn



Mark Weber

The way members and friends choose to donate to the Spastic Paraplegia Foundation is as unique as they are. From donating by check, credit card or PayPal to arranging Planned Giving through financial or estate planning. From designing their own virtual fundraiser to hosting a golf outing or hotdog sale. From shopping online at AmazonSmile to selecting SPF as their charity of choice if they are eligible for the Combined Federal Campaign for Federal employees.

The one thing they all have in common is their desire to make every dollar count.

Which is why SPF has a rigorous process in place to ensure that your donation dollars make the biggest impact possible toward reaching SPF's mission of advancing research in support of finding cures for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

The SPF Medical Research Grant Process

Each year, the Spastic Paraplegia Foundation sends a request for proposal (RFP) to all researchers who have published articles about HSP and PLS. Up until 2020, requests went out to just over 300 highly specialized researchers. In 2020 that number grew by 100. This past summer, yet another 100 researchers were added, resulting in a record-breaking 534 RFPs sent. Even more exciting is what this signifies: HSP and PLS research is accelerating, with more than 150 research papers published in the past year!

Investigators have approximately two months to submit proposals to SPF. Once received, Mark Weber, SPF Research Grant Committee Chair forwards a list of all grant proposals received to Dr. Martha B. Nance, chairman of the 12-member SPF Scientific Advisory

Board (SAB). Dr. Nance then assigns each SAB member specific proposals to review and Weber distributes the proposals to the reviewers.

The SAB is made up of highly trained scientists and neurologists knowledgeable in HSP and PLS. Depending on how many grant proposals are received, each SAB member receives several grants to review and rank. Every proposal is reviewed by at least three different SAB members to help give a fair and balanced review. Once the review process is completed, all grant reviews are returned to Dr. Nance. She then examines the reviews and prepares a report ranking the proposals starting with the best, most promising proposals. The list is then submitted to the SPF Board during the spring for its funding deliberations.

Your Donations Determine the Number of Grants Awarded

Each research grant is usually awarded for two years and totals \$150,000. The SPF Board determines the research grant budget based on the amount of funds raised during the previous year. Your donation has a direct impact on the number of research studies that receive grants from SPF. Once the budget is set, the SPF Board uses the SAB ranking report as a guide to determine which grants are funded. Even though there are usually more HSP proposals than PLS, the SPF Board tries to allocate equal amounts of money on HSP and PLS. Sometimes that is not possible, though, because of a lower number of PLS research studies seeking funding.

Transparency in Sharing the Funding Story

SPF has earned the GuideStar Gold Seal of Transparency for nonprofit organizations. We do our best to share with you the results of research trials that receive SPF grants. Some trials take longer than two years to complete. Once completed, it takes additional time to analyze the data before it is ready to share.

If you are a registered SPF member, you will receive these updates and other important information regarding HSP/PLS and what SPF is doing to find cures and spread awareness. The SPF Annual Report is a valuable source of such information. [The 2020 Annual Gratuities Report](#) was distributed via email this summer, as well

as posted on the SPF web site for downloading from the "Corporate Documents" section.

In August, the SPF Board approved six top ranked research proposals. More can be found about each grant on the SPF website under the "Research" tab.

The Journey Starts with You

We are working to raise \$1 million this year – a new milestone for the Foundation. Every dollar raised helps us fund more research, which could lead to breakthroughs and – ultimately – treatments and cures for HSP and PLS. Your support is crucial. To learn how you can support SPF, please visit sp-foundation.org. If you have questions, contact us at information@sp-foundation.org or call 877-773-4483.



SPF Needs Your Assistance to Reach Federal Employees During the 2021 Combined Federal Campaign



The Combined Federal Campaign (CFC) is one of the largest fundraising campaigns in America. It is available for all Federal employees. Now through January 15, 2022, Federal employees can select which charities they would like to contribute to for the following year.

Do you know any Federal employees? They include postal workers, military personnel, police, and many others. If you do, please reach out to them. Let them know about your disease and the work SPF is doing to find a cure for HSP and PLS. Then ask them to choose Spastic Paraplegia Foundation during the 2021 pledge process. **Our CFC number is 12554.**

Please help us with this great opportunity. We challenge each of you to recruit and get a commitment from at least one Federal employee. With your help, they can be the face of change.

2021 HSP and PLS Awareness Week Highlights

By Therese Williams, SPG7

SPF celebrated HSP and PLS Awareness Week Aug. 22-28, 2021. Lots of fun was had – but Awareness Week also had two serious and important goals:



Therese Williams

- To build awareness and understanding of these two rare conditions, and
- To raise money to fund research that could lead to a cure.

There were so many exciting things happening that week, it's hard to cover them all – here are a few highlights:

Adli's Cookout

For the third year, 9 year-old Adli, who was diagnosed with HSP SPG3A at age 5, had a cookout fundraiser, involving her local fire station and supported by almost one of every five people from her home town in Iowa.



Adli sends a heartfelt thanks to everyone who volunteered and supported the third annual cookout fundraiser!

This event has become a regular highlight for the town, starting small in the first year: Adli and her family served 100 hotdogs from their garage, raising over \$1600 for SPF through free-will donations. The next year, the event grew and the local fire station got involved, serving 240 hamburgers and hotdogs. The event was so popular that they ran out of food – twice -- and raised \$4400. This year was the biggest yet: Adli, her family, the local Fire Department and volunteers served 283 burgers and hotdogs, and raised \$5961 at last count. The event lasted two hours, and Adli and her crew never slowed down.

Adli had a great time, standing up and serving for an hour, wearing a big smile, before taking a short rest. Adli's family -- and the town that supports her -- hopes to keep doing this event for many years to come. What a great way to raise awareness and funds to help find a cure!

SPF Virtual Conference Series: Dr. Corey Braastad



Dr. Corey Braastad

You've probably had the experience of sitting in a doctor's office, or reading a medical report, and feeling like you need to look up every third word. It can seem like information about HSP and PLS is in another language – but we need to understand the words to understand our condition, and to effectively advocate for ourselves and our community.

One of the many highlights of Awareness Week was an excellent presentation by Dr. Corey Braastad, a long-time SPF Board member, and prolific researcher into genetic neurological diseases. In addition to his work in genetics, Dr. Braastad has a special interest in helping a broad audience understand this complex topic. As he put it, we need to be our own experts, ask the right questions, and be able to contact the right people for answers.

In his virtual session on August 28, he gave us a few more tools to do just that. He covered three areas:

1. A general overview of genetics.
2. A peek at the wave of research, trials, and likely FDA approvals for cell and gene therapy treatments coming over the next five years. Spoiler alert: Dr. Braastad expects 10-20 approvals per year by 2025!
3. A review of the key points from two of this year's earlier virtual conference talks: Dr. Sabrina Paganoni's "What's New in PLS" and Dr. Hande Ozdinler's "Building Effective Treatment Strategies for Upper Motor Neuron Diseases."

If you want to understand more (*without the reference books*) on any of these topics, I encourage you to watch – or re-watch – Dr. Braas-

tad's talk. It, along with other informative Virtual Conference presentations, is on the SPF YouTube channel, at SPF Virtual Conference Series #4 with Dr. Corey Braastad.

Run Walk & Roll

People all over the country participated in Run Walk & Roll events to raise awareness and funds for researching HSP and PLS. Participants showed a lot of creativity – including one member who swam her 5K – ultimately raising almost \$40,000.

Dina Landphair and Jackie Wellman, SPF Board members and Iowa co-ambassadors, worked together to organize a 5K. They got the word out by emailing all SPF members in Iowa, then asking them to contact their friends and family. They set up fundraising pages and sent out e-vites, signing up more than 50 participants and 88 donors.

On race day, participants gathered at the start line, ready to run, walk or roll the 5K distance to raise awareness and funds for HSP and PLS research. It was a beautiful day, sunny with temps in the 80s and a little wind, and by the end of the event, they had raised a total of \$8600. Way to go, Jackie, Dina and everyone who participated or donated to the event!

Dina and Jackie plan to do the event again, and are happy to share their experiences and advice with anyone who wants to do the same in their communities. Their advice to first-timers: start small, and you can change or add things over time. *Just get started!*



The Iowa weather cooperated and brought together runners, walkers and rollers of all ages to raise awareness and funds for SPF.



L to R: Brandon L'Heureux, Tina Curfman, Jeana Fraser, Celyna Rackov, and Randy Rackov

North Texas Home Court Advantage

By Tina Curfman, HSP, SPF Co-Ambassador for North Texas

Living with HSP can be difficult and challenging, both mentally and physically. Having a support system is very important. Meeting up with fellow HSPers is a great way to exchange stories and to let off some steam. HSP is a disease that progresses and affects people differently, so it never hurts to challenge yourself a little, as long as you are safe.

Tennis is a sport that requires a lot of directional change. Dr. Fink has mentioned that we consider trying things, when possible, that require a prompt change of direction within our ability to do so. On Saturday, July 31 Celyna Rackov, Co-Ambassador for North Texas, her husband Randy, (he came for support), Jeana Fraser, Co-Ambassador for North Texas, and I met with Coach Brandon L'Heureux for a modified tennis lesson. He worked with us individually first and then worked with all three of us hitting the ball back and forth. We had a great time and are looking forward to our next tennis lesson.

QR Code for Ease of Donations!

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



Hospitalization and You: Part One Planning for Hospital Emergency Care

By Malin Dollinger, MD, HSP SPG4



Malin Dollinger, MD

Many hospitalizations are relatively sudden decisions by us or our family, that being in the hospital right now is vitally necessary. Some hospitalizations are emergencies; others are elective and you have more time to plan. But either way, you need to plan

ahead and gather all the personal things you will need while there. Especially in emergencies, there's no time to start gathering these things, even more so if you are handicapped and have trouble walking, hearing, seeing, or have some other special need.

A key part of my advance planning is my bright-red "ER Go Bag," which contains all the things I need to have while I am in the hospital. This bag is in plain sight, and my family knows where it is and what it is for. I also have a plan for how to get to the hospital, and what needs to be done on the home front while I'm away, such as caring for my pet. If you have children or other dependents, create a plan ahead of time for who takes care of them.

I won't list all the reasons to go to the hospital, but basically it's the place to be for serious illness or unexplained major symptoms during off-hours (*like chest or abdominal pain, high fever or other major symptoms*).

When you need hospital care, it's usually not a good idea to drive yourself there. Not only are you ill to begin with, your driving ability may be impaired and could result in an accident. The real question is whether to have someone drive you to the hospital or whether to call an ambulance – 911. Going by ambulance can get you there more quickly, bypasses most of the usual delaying factors during the trip, and, especially when you get to the ER, usually bypasses the waiting room and associated delays. Your decision depends on several factors, including:

- the nature of your medical problem,

- how urgently you need to be there, and
- in the world of HSP or PLS, your possible need for mobility devices while there (*e.g., walker, wheelchair, scooter.*)

If there is a real time-crunch emergency, call 911 and get an ambulance. Grab your ER Go Bag and bring it with you. If you choose the pathway of having someone drive you, determine ahead of time which people are available to drive you. I make sure that my potential drivers know how to operate my vehicle and load my scooter into my handicap van. I leave a set of keys in a known location.

Be sure your designated person who either drives you or later brings your stuff knows what you need, where it is, and how to operate your vehicle. Make sure he or she knows where you keep your clothes, your medications, your bulky "handicap stuff," or anything too large to place in your ER Go Bag. Even though your ER Go Bag is already filled with most things you may need, your driver/helper might need to secure a few additional items that you routinely use, and thus would not be in your ER Go Bag. Remember to put some kind of ID on everything.

Another planning aspect before you go to the hospital: If you think you have an infection and have not seen a doctor for it, do not start taking some leftover antibiotics you happen to have on hand. The hospital will obtain cultures to discover the kind of infection you might have and which antibiotics will work. If you already have taken antibiotics, the cultures may not grow anything to help diagnosis and treatment, but the infection is still there. If you somehow believe that surgery might be needed, do not take aspirin or non-steroidal anti-inflammatory drugs (NSAIDs), like Advil, Motrin, etc., since they impair blood clotting. Plain Tylenol is usually safe.

Dr. Dollinger's bright red "ER Go Bag" ensures his personal necessities are always ready in the event of a trip to the hospital.



If you are taking antibiotics prescribed by a physician for a current infection, going on right now, she or he may have already done the appropriate cultures, so don't stop taking these antibiotics as prescribed. Be sure to tell the nurse about this as soon as you get to your hospital room. In addition, a printed medication list is essential; the nurse will ask you.

And finally, be sure to bring all your insurance cards and information, along with any pertinent medical records the hospital might not have already -- especially for the type of illness causing you to be hospitalized. An

important medical record is your card proving you've been vaccinated against COVID-19. If you've not received the vaccine, other special precautions may be necessary.

As a physician with HSP, I've seen both sides of the situation and can attest that all of these plans and measures will put you in more control of how well you do while in the hospital.

Please look for the Winter 2022 Synapse for Hospitalization and You: Part Two Planning for Hospital Inpatient Care

Hospital / ER Go Bag Checklist

- | | |
|---|---|
| <ul style="list-style-type: none"> _____ Medical insurance card(s) and driver's license/legal identification card _____ Copies of pertinent medical records _____ COVID-19 vaccination card _____ Comfortable clothes for daytime; plus one basic set of clothes, including underwear _____ Slip-on shoes or slippers (<i>avoid shoelaces</i>) _____ Pajamas, athleisure wear, scrub outfit _____ Slipper socks/warm socks _____ Sweater or sweatshirt _____ Robe _____ Necessary toiletries (<i>no perfume/ cologne or scented deodorant</i>) _____ Flushable wipes _____ Stationery/blank paper and pens _____ Music playlist on laptop, tablet or cell phone; earbuds or headphone _____ Family pictures _____ Your favorite pillow (<i>bring a container in which to store it, in case the hospital won't allow you to use your own pillow</i>) _____ Business cards _____ Reading material _____ Current medications in original prescription containers, with 3+ days of medications (<i>remember to bring refrigerated meds, e.g., insulin or eye drops</i>) | <ul style="list-style-type: none"> _____ Printed list of medications, dosage and schedule _____ Rubber or synthetic floor pad/roll up, to prevent slippage when standing on hospital floor _____ Glasses and hearing aids with spare batteries _____ Spare syringes/alcohol sponges for injectables _____ Test equipment (<i>e.g., blood sugar</i>) _____ Calendar/schedule for reference or to make needed changes _____ Cell phone and charger _____ Special handicap equipment (<i>e.g., grabber, sock devices, etc.</i>) _____ List of key phone numbers (<i>e.g., close family and friends, physicians, clergy</i>) <p>OTHER: Review your daily routine and think of things that you specifically need and use that are not on this list (<i>e.g., gloves, pad for wheelchair seat, cane or other walking device, etc.</i>)</p> <p>TIP: Be sure you clean and identify any items that the hospital may not want you to bring, such as your own pillow, or certain inadvisable items, such as your own supply of medications, or essential things that you need and the hospital may not have.</p> |
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My Lower Back Surgery during COVID

By Deborah Warden, MD



Deborah Warden, MD

I recently had back surgery unrelated to my PLS, yet my PLS affected every stage of the process: the planning, hospital stay, and inpatient rehabilitation. As a physician, I thought I knew what to expect since medical systems are very familiar to me. I found,

however, that many surprises awaited me, requiring flexibility and perseverance.

First, choosing a surgeon and determining the specific surgery I needed was surprisingly difficult. I consulted two orthopedic surgeons and a neurosurgeon before deciding who to trust with my body. My diagnosis was spinal stenosis, a narrowing of the spaces where the spinal nerve roots exit the vertebral column on their way to the appropriate muscles.

My spinal stenosis caused severe pain in my left buttock, especially when I turned over in bed or made certain movements during the day. Epidural injections did not help enough. X-rays showed that my spinal stenosis was complicated by a forward slippage of L4 over L5, called spondylolisthesis. The trusted anesthesiologist who had

administered my epidurals referred me to the orthopedist who had operated on his wife—a good sign, I thought!

Dr. A recommended “limited surgery,” a laminectomy, because he incorrectly thought I had ALS. When I corrected Dr. A and told him I had PLS, he said, “Oh, I still wouldn’t do more surgery on you.” He predicted an 80% improvement of my pain. Something didn’t seem completely right about this assessment, and I chose not to schedule an operation date then.

When a friend who works in a large hospital recommended another orthopedic surgeon,

I decided to see him. It was summer 2020, and although the clock was ticking toward the anticipated winter surge in COVID cases, I had enough time to be confident in my surgeon!

Dr. B showed me the X-ray of my spine, pointing to the spondylolisthesis, and calmly explained that a minimally invasive laminectomy was not a good choice. In fact, my chances of relief without a second surgery later were only 50:50. He said that only cutting the vertebrae could make the slippage of L4 over L5 worse. He explained that the lumbar vertebrae would have even less support, and because I have a neurologic illness, my core muscles are less able to support my spine.

He said though it seems counterintuitive, he has to be more aggressive in neurologic patients due to our compromised ability to activate our own muscles. He recommended laminectomy with fusion (screwing a rod into both sides of the three vertebrae, L3, 4, and 5, for more

support.) Because I have osteoporosis, he would use a special cement when placing the screws.

He asked me to send my last DEXA scan, a measure of osteoporosis severity, and I mentioned that the DEXA had shown improvement over the past three years while I was taking medication.

I spoke to my neurologist about the different recommendations for surgery. He then spoke to Dr. B, and called me to say he

agreed with the reasoning for the more involved surgery—the fusion—remarking on how many patients in his group practice had experienced good results with Dr. B.

I was 99% sure of choosing Dr. B when I went to my pain anesthesiologist for a repeat epidural injection. He winced at the mention of fusion because of the longer recovery time required, though initially he had been concerned that minimally invasive surgery wasn’t possible due to my spondylolisthesis. Still, he had high regard for Dr. A and his recommendation for laminectomy that could spare me a longer recovery.

**“AS A PHYSICIAN, I
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The anesthesiologist and I agreed to try for a tie breaker, and he referred me to a neurosurgeon, Dr. C, who had an excellent reputation. Dr. C agreed with the need for fusion, but said he didn't like cement, so depending on my osteoporosis severity, he might recommend doing the surgery through my abdomen in order to place cages around the affected three lumbar vertebrae, though this approach is more invasive and requires the assistance of a vascular surgeon.

Dr. C. spoke at length about a prior patient with ALS and the difficulty of removing him from the ventilator after surgery. I assured Dr. C that I had PLS, no breathing difficulties, and had, in fact, been practicing Qigong by Zoom since the pandemic began seven months earlier. As the appointment ended, Dr. C also told me that Dr. B is a superb surgeon and his friend. He added that, if ever he needed spine surgery, he'd choose Dr. B to do it. High praise indeed!

I felt overwhelmed by the range of recommendations and the idea of back surgery at all. When I considered waiting until spring for surgery, my neurologist recommended an EMG to see if waiting was a good choice. However, the EMG showed muscle irritation from the most affected nerve root meaning my muscles would get weaker from the spinal stenosis. He recommended surgery without waiting further.

I chose Dr. B for his reasoning of the required surgery and because he was the only doctor who was not distracted by past experiences with someone with ALS. He was able to see me clearly as a patient with PLS. My neurologist's and Dr. C's recommendations of Dr. B as a top surgeon were also reassuring.

The surgery went well. The medication controlled my pain even though I was uncomfortable in bed. My PLS and the incision made it more difficult to change positions, and often the new position would be comfortable for only a few minutes. My husband was permitted to stay with me, but because of COVID precautions, he

had to remain in my room for my entire stay. His presence was such a gift to me!

On the second day, the Pain Service doctors discontinued my Baclofen, thinking I was on Baclofen for post-op pain control. The pain doctors had not read my home medication list, which was in the computer, so they didn't know I'd been taking Baclofen at home. In fact, I'd been on Baclofen for more than 13 years!

On the third day, I felt my muscles becoming stiffer. While in Radiology for a routine post-op X-ray, I had difficulty standing, even with a walker. My husband and the Radiology Technician steadied me during the brief X-ray. The X-ray tech didn't even take the time to get herself a lead apron; she decided to remain supporting me during my X-ray.

“I WROTE ON A YELLOW FOLDER, “I HAVE PRIMARY LATERAL SCLEROSIS x 17 YEARS” AND HELD IT UP EVERY TIME SOMEONE NEW INTERACTED WITH ME...”

That evening we discovered the medication error when I requested my “as needed” extra Baclofen; the nurse replied that no one had ordered Baclofen. My husband asked to see the orders and found the Baclofen still under the “as needed” medication, so I was able to have a tablet then. At that point, routine, daily Baclofen was reinstated to

the medication orders, but the lapse in taking Baclofen and worsening of my spasticity could have resulted in a fall.

Additionally, neither my husband nor I recalled a visit from the Pain Service, so they were managing my pain medication solely by reading my computer record. I was angry that such a mistake had happened, underscoring how necessary it was to follow my own care closely. Silver linings do occur, in this case an X-ray technician named Angela (of course!) whose actions touched me as well as kept me safe.

Yet another challenge arrived with my transfer to inpatient rehabilitation. I learned quickly that no one in the rehab unit, including my new physician, knew I had PLS, or even that I'd had fusion surgery. My record revealed only

Continued on next page

that I was a "laminectomy patient." Because I have dysarthria (difficulty speaking clearly) and because we were all wearing masks, trying to reset their expectations of me was as difficult as it was necessary.

I arrived in the late afternoon and PT was not able to see me then. I was not permitted to use a walker until PT had prescribed the correct height for my new walker the next day. That would be fine except that I still had to get to the bathroom! The aides expected me to be more capable than I was, but we compromised on using my scooter to get to the bathroom. Additionally, my aide was insistent that the hospital socks with adhesive were adequate for my transfers. I explained I needed my shoes, realizing she had to put them on for me, as I wasn't permitted to bend over. She repeated that the socks were specially treated, but I held steadfast. Finally, she agreed.

Hastily, I wrote on a yellow folder, "I have Primary Lateral Sclerosis X 17 years" and held it up every time someone new interacted with me, knowing they wouldn't know what PLS is, but hoping they would be less resolute in their interaction with me, knowing I had a mystery medical condition.

After the first few days, the nurses and aides learned what I could do. Still, lack of awareness crept in. At one point, an occupational therapist was training me to stand with a walker and use one hand to throw her a ball. "Soon," she said, "you'll be doing this without holding on to the walker!" "That's great," I replied, "I haven't been able to do that for 10 years!"

To make my hospitalization and acute rehabilitation easier, I relaxed at night by listening to a familiar recording of the "Medicine Buddha Mantra." I took earphones with me and played the chant on my phone when I was uncomfortable or during stressful times, for example, urinating after the catheter was removed after surgery. Especially because I was in a new place with unpredictable sounds, listening to the Medicine Buddha chant was very relaxing and productive!

Five months after the operation, I'm very grateful for the surgery. The pain I had is completely gone, and my walking short distances has progressed from using a walker to my forearm crutches.

I'm still emerging from the drama of the events the surgery created and grateful that the intensity has diminished. Clearly, preparing for and recovering from surgery was a multiphase process requiring grit, perseverance, a touch of humor and optimism, and the contributions of many.

Deborah Warden, MD, a retired neurologist and psychiatrist, specialized in Traumatic Brain Injury. "A Life in Progress," a 20-minute documentary about her living with PLS, has just been completed. A five-minute version, "The Amazing Journey of Doctor Deborah Warden," won its class at the 2017 Neurology Film Festival and is available on YouTube and the SPF web page.

Dr Fink's Neurological Support Group

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

Houston Abilities Expo

By Kim White, HSP SPG4 and Jeana Fraser, HSP, SPF Co-Ambassadors for Texas

The Houston Abilities Expo on August 6, 2021 in Texas was an enjoyable experience for Kim and Robert White, Jeana and David Fraser, and Cullen Domangue and his mother Leah.

There were many booths for a variety of different needs. One booth had a TrueStim electrical muscle stimulator that helps activate the nerves and muscle of the anterior tibialis which helps lift your toes, decreasing the risk of falls from foot drop. Jeana tried the MiraColt, a horse-riding simulator used as a complementary device in physical, occupational, speech and behavior therapy. The device helps with neuromuscular control, core strength, postural balance, and gait, which can be issues for people with HSP and PLS.

We also tackled the Adaptive Climbing Wall, which was fun. The wall can be climbed using your arms and legs or while seated, by pulling down on a handlebar which lifts the person in the chair. Jeana climbed up with her arms and



Kim White tackles the Adaptive Climbing Wall at the 2021 Houston Abilities Expo.

legs. Kim used the seated/handlebar method.

While at the Expo, we handed out Spastic Paraplegia Foundation (SPF) cards to the staff of quite a few of the booths, and they seemed to appreciate

them. We were so glad we were able to do that. To promote SPF and raise awareness of HSP and PLS, we also wore T-shirts purchased from the online SPF Store. Kim did a great job organizing our get-together at the Houston Abilities Expo, including purchasing green ribbon pins from Amazon for us to wear on our T-shirts to represent our need for a CURE!

Your Words Can Change Lives

Words of encouragement. Words of wisdom. Words of inspiration. Words of support. Words of joy. YOUR words.

Synapse, the Spastic Paraplegia Foundation's quarterly publication, reaches people across the country and around the world. Readers are eager to hear from others with Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

You don't have to be a professional writer or photographer! You just need a passion for sharing what keeps you going and growing while living with PLS or HSP.

Articles can be any text format; photos can be any picture format.

Popular topics include:

- Ways you keep doing what you love – modifications you make to keep active and stay in the game.
- Technologies and devices that can help make life easier.
- Tips for stretching, exercising, balancing and staying as physically active as possible.
- How you keep your sense of humor and view the absurdities of life.
- Fundraisers, Connection get-togethers and other events you do to promote awareness and support the Spastic Paraplegia Foundation's mission of finding a cure.

To submit an article or discuss your ideas contact synapsenewsletter.spf@gmail.com

WE ARE THE HSP and PLS
WARRIORS!

Please Get Out of Your Car

By Malin Dollinger, MD, HSP SPG4

Lately there have been some examples of the need to be prepared to deal with law enforcement officers, emergency medical service (EMS) personnel, even auto repair or towing services. They are all trying to do a good job, safely. For those of us with disabilities, responding to requests to present our driver's license or get out of our vehicle can be challenging, and even hazardous. I believe it would be helpful to have a small "card" to carry with you to repeat verbally or hand to people as needed. While a traffic stop, accident, or need for roadside assistance usually is unexpected, being prepared can make the situation safer and easier.

The information below can help you create your own "explanation card" to inform law enforcement professionals, EMS staff or others who are not familiar with HSP or PLS when you need to comply with their requests.

- I am paralyzed.*
- My legs are paralyzed due to a rare neurological disease.
- I cannot walk or stand unassisted, or simply get out of my car.
- I want to comply with your request to get out of my vehicle. To do so, I need to use my walker/wheelchair. I can get it or explain how you can get it for me so I can get out of the car.
- Also, I'll be glad to provide my driver's license. It is in the _____ (e.g., *pocket of my wheelchair, purse on the back seat, etc.*) and I need help getting to it.
- (Ask for Officer/EMS input on the best way to proceed.)
- I am keeping my hands in your sight at all times. I want both of us to be safe.
- [If applicable] Although I am unable to walk unassisted, I am legally allowed to drive as long as I use a vehicle with hand controls, instead of foot pedals, and steering balls on the steering wheel. My vehicle complies with that.
- Although my disability IS a challenge to my exiting my vehicle, please know that I am trying my best to comply with your direction and appreciate your understanding and willingness to assist me. Thank you.

***NOTE:** Be sure to say "I am paralyzed" instead of saying "I am a paraplegic" or "I have paraparesis" since not everyone understands those terms. People usually understand the term "paralyzed."



Holiday Shopping is a Click Away at the SPF Store

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

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

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



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



SPF Illinois Connection: October 2021

By Sid Clark, HSP and Hank Chiuppi, PLS

SPF Illinois has had a number of Zoom connections over the last two years. While we had hoped by now to be back with in-person, face-to-face meetings in Buffalo Grove, IL, our October 3 Connection, was held via Zoom. SPF Illinois attendees were fortunate to have special guest Dr. P. Hande Ozdinler, from Northwestern University, update us on many areas of current research, including:

- Gene Therapy for upper motor neurons - This refers to a gene therapy approach for the diseased upper motor neurons. Genetic materials will be introduced primarily to the degenerating upper motor neurons, so that they will begin to make the necessary proteins or the proteins they could not previously make because of the mutation. This is a very promising avenue for therapeutic interventions, especially for rare diseases.
- Drug discovery platform using upper motor neurons - Ozdinler Lab is developing a novel drug discovery platform, which utilizes diseased upper motor neurons so that their cellular responses to drug treatment can be used as an outcome measure. This is

particularly important for upper motor neuron diseases, because so far none of the compounds that moved into clinical trials have ever been tested for their ability to improve the health of diseased upper motor neurons.

- The need for good biomarkers - Biomarkers are required for clinical trials. We need to find out whether treatment improves the health of diseased upper motor neurons. Ozdinler Lab is developing biomarkers that identify the timing and the extent of upper motor neuron loss, and this information will be critically important for developing clinical trials for upper motor neuron diseases.
- The need for rare disease groups to be in constant communication with the FDA - Doing so can help the expanded access programs get more recognition and access. The need to recruit hundreds of patients, especially to Phase 3 clinical trial is very challenging, particularly for rare diseases. FDA and rare disease groups need to have better conversations to improve the current state of drug discovery.

We encourage the various SPF state groups to reach out to members in their areas and get together, if not in person, then by Zoom.



Attending the October Zoom were: (top row) Norma & Greg Pruitt, Hank Chiuppi, B J Irwin, Steve Beutelspacher, (2nd row) Joan Morris, Rich Fairbairn, Dr. Ozdinler, Steven Newhouse, (3rd row) Mitch Udowitz, Sid Clark, Celyna Rackov, Mary Schultz

Virtual Texas Connection

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

Our Virtual Texas Connection happened on August 14 at 1 p.m. via Zoom. Carol Real (HSP), Tina Curfman (HSP), Jeana Fraser (SPG4), Celyna Rackov (SPG4) from North Texas, along with Justin Forgey (HSP) from Austin, Timothy West (SPG5A) from El Paso

and Kim White (SPG4) from the Houston area participated in the meeting.

The meeting started with introductions and social conversation. Next, we shared our experiences with Botox, baclofen pump, physiotherapy, Pilates, tennis, swimming, WalkAid, CBD, and other herbs. Genetic testing to obtain HSP subtypes and the main difference between dominant and recessive subtypes were discussed.

Tina Curfman spoke about the "Awareness Week 5K Run, Walk or Roll" that would happen in the coming week. She gave details about the event and the daily challenges. Then she talked about Justin's organization called Worn Souls (<https://wornsouls.org/>). The organization's main focus is making the impossible, possible! Wornsouls.org helps people realize their dreams.

Celyna Rackov talked about the Texas Team fundraising for the SPF and the 2021 Texas 5K Team video available at the Spastic Paraplegia Foundation YouTube channel (<https://www.youtube.com/channel/UCsZIM577T5rKs8hRj-ToucZA>).

Kim and Jeana shared their experiences at the Abilities Expo in Houston. We all look forward to meeting at the Abilities Expo that will be held in Dallas, December 3-5, 2021.



Attending the Virtual Texas Connection were:

(Top Row) Jeana Fraser, Celyna Rackov, (2nd row) Tina Curfman, Kim White, (3rd row) Carol Real, Timothy West, (4th row) Justin Forgey

GIVING TUESDAY

BE THE GOOD ON NOVEMBER 30!

GivingTuesday is a global day of generosity that will take place on November 30, 2021. It was created in 2012 as a simple idea: a day that encourages people to do good, be it a donation of time or money. Over the past nine years, this idea has grown into a global movement that inspires hundreds of millions of people to give, collaborate, and celebrate generosity. SPF asks that you make a contribution on GivingTuesday to help us kick off our End-of-Year Fundraising Campaign to support the needed research for a cure for HSP and PLS. Please help us to reach our \$1 million goal for 2021!

We can't predict where life will take you, but we can help you plan for it



Be sure your financial goals align with your long-term needs

When it comes to family health care costs, you may have some needs that are more pressing than others. We can help. We'll work closely with you to help create a financial approach that's designed for you and your loved ones. To learn more, please give us a call today.

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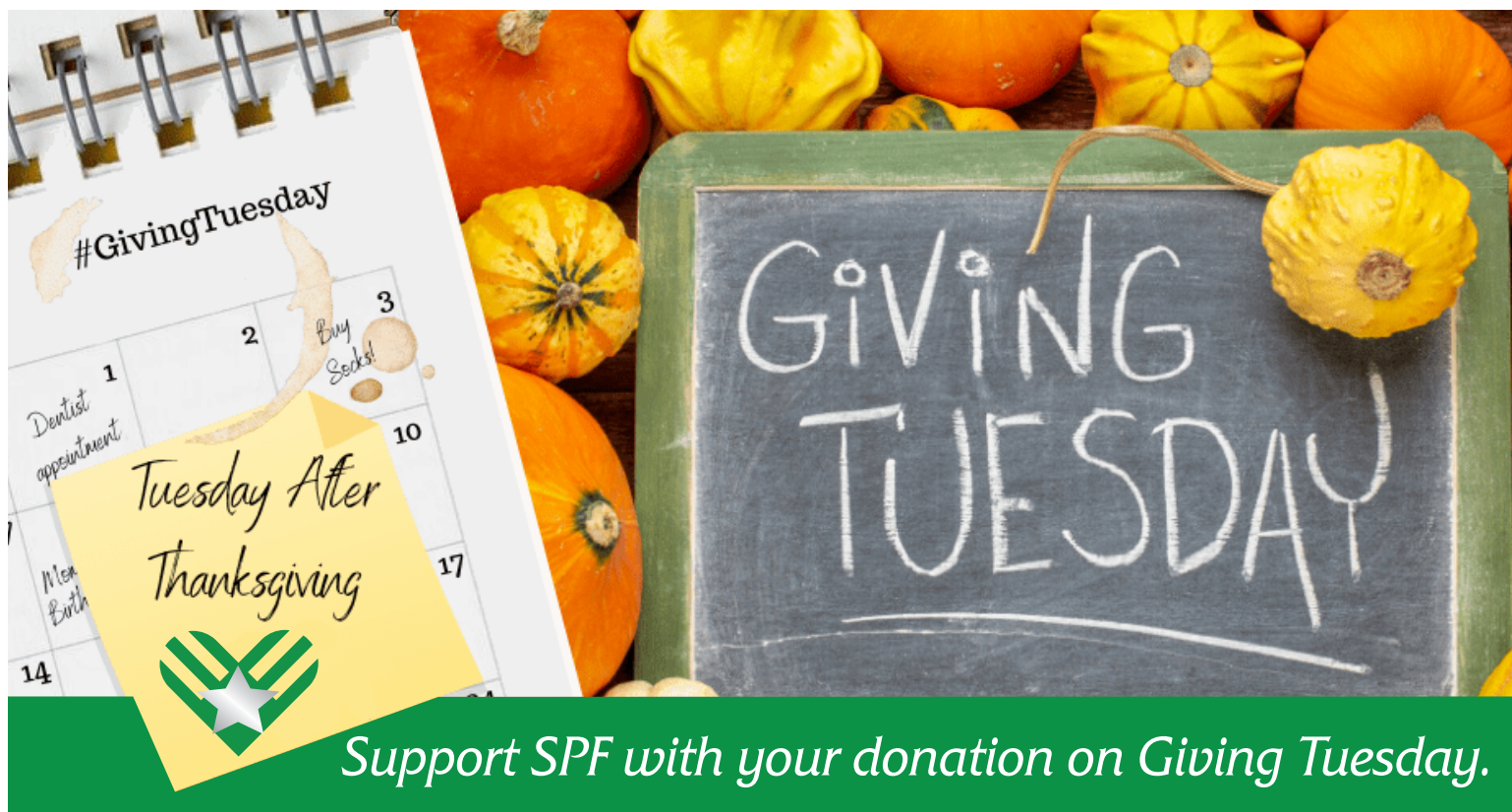
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BE THE GOOD ON NOVEMBER 30!



Support SPF with your donation on Giving Tuesday.