SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.
Spring/Summer 2026

Momentum is building, and you can feel it across the pages of this issue of SYNAPSE. Around the world, researchers are pushing new ideas forward, partnerships are opening important doors, and families affected by HSP and PLS are coming together with renewed determination and hope.

Inside this edition, you'll discover how those efforts are taking shape. Promising research is advancing, collaborations are strengthening, and the voice of our community is helping guide the path toward therapies that were once only imagined. Every story reflects the power of a community united around one mission: accelerating progress for people living with HSP and PLS.

Whether you have been part of the SPF family for many years or have only recently found your way here, thank you for being part of this journey. Your support, advocacy, and belief in this mission are helping turn scientific momentum into real hope for the future.

YOUR SUPPORT IS ACCELERATING RESEARCH | EDUCATION | SUPPORT

The collaborative work, efforts and financial support led by Spastic Paraplegia Foundation (SPF) and SP-CERN (Spastic Paraplegia - Centers of Excellence Research Network) along with that of C-PATH (Critical Path Institute), is vital in creating opportunities for mutual support, sharing, and discovering the cures for HSP and PLS by funding medical research.

Additional information on SP-CERN and C-PATH can be found on page 4.

RESEARCH

- $750,000 Seed Investment by SPF to launch SP-CERN.
- $8.4 Million NIH U54 Grant was awarded by NIH to build on SPF's seed funding. The purpose of the grant is to expand a multi-center natural history study of HSP across the age span through SP-CERN.
- Global Research Collaboration with SP-CERN investigators connecting international research efforts studying HSP genetics and disease mechanisms.
- Advancing Therapy Development by working with C-PATH to advance the scientific and regulatory groundwork needed for future HSP and PLS therapies.

Advances in research and support programs are possible because of YOU

EDUCATION

- 36 SPF Talks & Educational Programs and discussions in 2025.
- 142 average registered participants per SPF Talk, reflecting strong interest and demand for expert-led education within the HSP & PLS community.
- October 17, we collaborated and celebrated the first annual World Awareness Day. Global awareness amplifies understanding and advocacy.
- February 28, Rare Disease Day brings global attention to people living with rare diseases. SPF hosts open conference call, welcoming our community to share experiences and connect.
- 308,000 Average web visits monthly to the SPF Website.
- 22 Years of Annual Conference hosting delivering research, therapy, and wellness education.

SUPPORT

- 145 Eblasts in 2025, spotlighting community and family support, resources and education for individuals and families impacted by HSP & PLS.
- Volunteer & Advocacy engagement mobilizing advocates to advance awareness and research funding.
- Accessible Information and resources supporting patients and caregivers at every stage.
- Forming partnerships, like CPATH that drive impact in collaboration with researchers, clinicians, and advocacy partners worldwide.

YOUR donation makes research, education, and support possible

We invite you to consider a gift today and help carry this work forward for today, tomorrow and the next generation. More than 90% of SPF donations directly fund medical research advancing treatments for HSP and PLS.

SPF -- MY PERSONAL P2P FUNDRAISER

Turn your story into momentum for research – Start with just one page.

Every member of the SPF community has a story – one of resilience, determination, and hope. Through Peer-to-Peer (P2P) fundraising, you can share that story while helping accelerate research for HSP and PLS.

Creating your own “My Personal Peer-to-Peer Fundraiser” page on the SPF Network for Good platform gives you a place to tell your lived experience in your own words. Many supporters dedicate their page to a personal journey: living with HSP or PLS, honoring a loved one, celebrating a milestone, or simply raising awareness about these rare conditions. When you share that story with friends, family and colleagues, you invite them to become part of the mission.

Getting started is easy—and even fun. SPF provides simple tools, step-by-step guidance, and read-to-share links so you can quickly create a personalized fundraising page and invite your network to support the cause.

And it works. In 2025, our community raised more than $150,000 through P2P pages from over 1,000 individual donations – each one helping to advance promising research and to move us closer to better treatments.

Your fundraiser doesn’t have to be large or complicated. Some people organize small events, others share their page during birthdays or special occasions, and many simply tell their story online and invite others to give. Every page created and every dollar raised helps move the science forward, and reminds families everywhere that they are not alone.

If you would like help getting started, email Jim Sheorn, SPF Fundraising Chair at jim.sheorn@sp-foundation.org. He is always enthusiastic to assist. You can also visit our website for ideas and inspiration using the QR Code below, or if you have an idea for a fundraiser we’d love to hear it and share with others in our community.

Scan Here to Help Host a Fundraiser

SPF TALKS

Inspiration, Insight & Connection

Your next spark of insight is just a Zoom away!

SPF TALKS brings our mission of Research, Education, and Support directly to you—wherever you are. These engaging Zoom sessions and webinars give individuals, families, and caregivers affected by HSP and PLS a chance to gain trusted information, practical guidance, and real connection with others navigating the same journey.

From medical updates and emerging research to mobility, caregiving, wellness, and everyday life tips, every session is designed to empower you with knowledge that supports confident, informed decision-making. Hear from expert speakers, join discussions, and connect with a community that truly understands. These aren’t just presentations—they’re opportunities to learn, share, and be inspired, with unique chances to connect firsthand with clinicians and research scientists—all from the comfort of your own home.

Upcoming SPF TALKS are posted on our website, social media platforms, and invitations are SPF EBLASTED to members in advance. Not a member yet? Join today and stay connected. Have a topic you’d like covered? We’d love your ideas. Can’t make a live session? Most all recordings are on the SPF YouTube channel, building a growing library of on-demand education.

Visit the QR Code below to see the schedule and register today! With SPF TALKS, no one facing HSP or PLS has to navigate it alone—knowledge, resources, and support are always within reach.

Scan Here for Upcoming Talks

Miss a Talk?
Want to listen again?
YouTube

STAYING CONNECTED — It Matters!

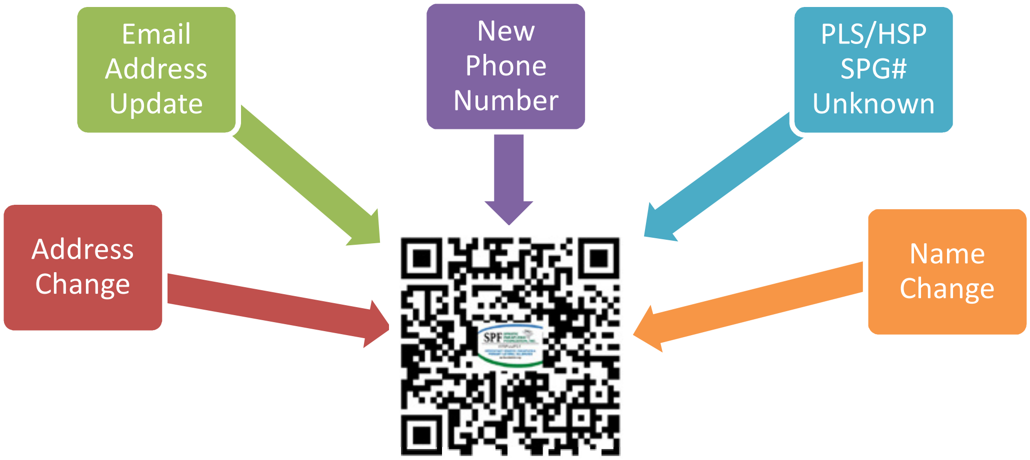
Stay Connected in 30 Seconds

Why Staying Connected Matters

Research moves quickly. **Make sure we can reach you when it does.**

Keeping your contact information current ensures you receive important updates from SPF—whether it's the latest research progress, new **SPF TALKS** programs, advocacy opportunities, community events, or resources designed to support individuals, families, and caregivers living with **HSP and PLS**.

As research accelerates, the ability to communicate quickly with our community becomes more important than ever. Staying connected allows SPF to share timely information that may directly impact care, research participation, and opportunities to engage with the community.



Why Your Information Matters

When you update your profile, you also help strengthen the power of our community. Knowing whether members are living with PLS or HSP—and, if applicable, their SPG subtype or SPG Unknown—helps SPF better understand our community and connect individuals with the most relevant research updates, programs, and opportunities.

Why Email Matters

Printing and mailing materials is costly and limits how quickly we can communicate. Email allows SPF to share **timely research news and program announcements** more frequently, while directing more resources toward what matters most—Research, Education, and Support.

Your Privacy Matters

SPF never sells, shares, or distributes your personal contact information. De-identified information may be shared with researchers and partners to advance scientific understanding—but **never in a way that could identify you personally.**

NEED HELP?

If you do nothing else today, please update your contact information.

Scan the QR Code above

Email Your Contact Updates to: Information@sp-foundation.org

Call Us for one-on-one updates 877-773-4483

SPF ADVOCACY

Your Voice Can Help Change the Future of HSP and PLS

Advocacy is one of the most powerful ways our community can accelerate progress toward treatments for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

The **SPF Advocates Program** empowers members of our community to raise awareness, share their lived experiences, and help drive momentum for research and support. Whether speaking with a policymaker, sharing your story, participating in educational outreach, or helping spread reliable information, **every action strengthens the voice of our community.** As Celyna Rackov, SPF Texas Ambassador and President of ASPEC Brazil, reminds us: **"Information generates awareness. Consciousness generates change."**

Advocates help bring attention to the needs of individuals, families, and caregivers living with HSP and PLS while supporting the broader effort to advance research, improve understanding, and encourage collaboration among clinicians, scientists, and policymakers.

You don't need special training or experience to make a difference. **Everyone is an advocate.** Every conversation, every shared story, and every effort to raise awareness helps move us closer to better treatments and a stronger, more informed community.

Take Action in Minutes -- One of the simplest ways to advocate is by contacting your elected representatives about issues that impact the HSP and PLS community. Scan the QR code to visit the SPF Advocacy page, where you can quickly send emails to your Members of Congress regarding current policy issues and campaigns that affect rare disease research, patient support, and healthcare access.

The most powerful voice for change is the one that shares the truth of lived experience. **YOURS.**

For more information about becoming an SPF Advocate or getting involved in outreach efforts, scan the QR Code, visit our website or email information@sp-foundation.org.

Scan here for Advocacy Info

SPF, SP-CERN, and C-PATH

Three Organizations. One Shared Goal: Accelerating Progress for HSP and PLS

Launching SP-CERN (2023-2027)
SPF provided $750,000 in seed funding to establish the Spastic Paraplegia – Centers of Excellence Research Network (SP-CERN). This initial investment created the core research infrastructure, including a centralized clinical trial protocol and IRB, a shared biobank, and a pilot study enrolling more than 100 participants focused initially on SPG4 and SPG5A.

Expanding Research Through NIH Support (2025-2030)
Building on this foundation, the National Institutes of Health (NIH) awarded an $8.4 million U54 grant to expand SP-CERN's multi-center natural history study of HSP across the lifespan. The network is coordinated by Principal Investigator Dr. Darius Ebrahimi-Fakhari (Boston Children's Hospital) with Dr. Stephan Züchner (University of Miami) serving as Co-Principal Investigator and Administrative Director.

Global Collaboration
SP-CERN investigators now collaborate with international research partners studying HSP genetics and disease mechanisms. These partnerships strengthen genetic analysis, expand data sharing, and accelerate discoveries that can lead to future therapies.

Advancing Therapies with C-PATH
SPF is also working with the Critical Path Institute (C-PATH) to advance the scientific and regulatory groundwork needed for future HSP and PLS treatments. This collaboration supports clinical trial readiness, promotes data sharing, and helps identify meaningful outcome measures that can move therapies to patients faster.

SPF is pleased to announce that **Norma Pruitt, SPF Executive Director**, will represent the Foundation on the SP-CERN CPAG (Coalition of Patient Advocacy Group) Steering Committee.

Expanding SP-CERN to Support a Future PLS Initiative
Building on the infrastructure established through SP-CERN, SPF is exploring the opportunity to expand the network to support a dedicated Primary Lateral Sclerosis (PLS) research initiative at existing SP-CERN clinical sites. Leveraging these established centers could accelerate patient enrollment, strengthen data collection, and help lay the groundwork for future PLS clinical studies and therapy development.

Scan here for more SP-CERN Info

PARTNERS NEEDED

Together, we are building a roadmap to treatments, stronger support systems, and hope for today, tomorrow, and the next generation. Advancing research, strengthening support programs, and bringing the HSP and PLS community together requires collaboration. Progress happens when individuals, families, caregivers, foundations, and corporate leaders choose to stand together as partners."

These partnerships help drive the work that matters most, accelerating research toward treatments, expanding patient and caregiver support, and building a community where no one faces these rare diseases alone.

Partnership opportunities are available to support SPF's mission year-round or the 2026 Annual Conference in St. Louis, where researchers, clinicians, patients, and families gather to share knowledge, spark collaboration, and inspire hope. We welcome partners at every level—from community supporters to corporate leaders. Partnership opportunities range from $500 to $50,000 and can also be customized to align with your philanthropic or corporate engagement goals.

Leadership and community partners are helping accelerate progress for HSP and PLS.

Leadership Partners

Gateway Champion Partner | $50,000
Pathfinder Partner | $25,000
Trailblazer Partner | $15,000
Navigator Partner | $10,000

Scan For Partner Info

Community & Mission Partners

HOPE Partner | $5,000
Waypoint Partner | $2,500
Community Partner | $1,000
Friend of SPF | $500

Customized Partnership Recognition & Engagement Options

All SPF sponsorships are customized to create mutually beneficial partnerships. We work with each sponsor to design recognition opportunities aligned with your brand, mission, and goals while supporting the work of SPF. Examples include, website & digital recognition, social media & newsletter highlights, event signage, on-site recognition, & dedicated program space.

SPF QUICK LINKS -- SCAN TO LEARN MORE

SUPPORT
Community support of our families and friends with HSP/PLS.

RESEARCH
Advancements in Research available for your review.

ADVOCACY
Your voice can change the future of HSP and PLS.

PEER- to-PEER FUNDRAISING
Turn your story into momentum for research.

SPF TALKS
View upcoming SPF Talks and stay in the know.

YOUTUBE
Watch any missed SPF Talks on our SPF YouTube channel.

PATIENT HISTORY SURVEY
Published results of our 2025 patients speak survey.

SP-CERN
Moving forward for HSP & PLS. Learn who SP-CERN is.
.

SPF Swag
Order your custom tee shirts for the 2026 Conference.

ANNUAL CONFERENCE REGISTRATION
Registration for the conference and hotel information can be found here.

PARTNERSHIPS NEEDED
Scan here for more information on Corporate and Community Partnerships.

JOIN AND/OR UPDATE INFO
The most important thing you can do, is to update your personal contact info.

DONATE
Keep Research moving, a quick scan pops up our secure donation platform.

WE ARE ALWAYS HERE TO HELP – YOU ARE NEVER ALONE!
With your phone camera scan any of the codes above.
Email us: Information@sp-foundation.org Call us: 877-773-4483

HSP/PLS
Pathway to the Gateway
St. Louis 2026
#HSPandPLS
SP-Foundation.org

2026 SPF Annual HSP/PLS Conference

Pathway to the Gateway: Roadmap to Health, Therapies & Wellness

June 15-17, 2026 | St Louis, MO

SPF is thrilled to invite you, your family, and friends to join us in St. Louis, Missouri, June 15-17, for the **2026 HSP/PLS Annual Conference**, a special opportunity to learn, connect, and strengthen our community.

More than a meeting, the SPF Annual Conference is a gathering of patients, families, caregivers, clinicians, researchers, and industry partners working together to advance progress for HSP and PLS. It is a place where experiences are shared, questions are welcomed, and the voices of our community help shape research, treatment, and care priorities.

When our community comes together, something powerful happens. Individuals and families who often navigate these rare conditions in isolation become part of a **visible, united community**, helping researchers and healthcare professionals better understand the urgency and impact of HSP and PLS, **and realize You are not alone!**

The conference is about connections and offers practical tools for living well today, including sessions on wellness, movement, nutrition, and supportive technologies, while highlighting the latest research and innovation aimed at tomorrow's treatments.

And of course, there will be time to enjoy **St. Louis**, a vibrant city filled with family-friendly attractions, great food, and iconic experiences.

Mon, June 15: Scientific Forum

Open to All Attendees - The conference begins with a half-day Scientific Forum Research Roundtable, held from 1:00–5:00 PM, designed to be open, accessible, and engaging for all attendees, including patients, families, and caregivers.

This session will feature a roundtable-style discussion with leading clinicians and scientists who are deeply informed about HSP and PLS.

Monday meals are on your own.

Tues & Wed, June 16–17: Patient & Family Conference

The heart of the conference focuses entirely on you, the patients, families, and caregivers, with something for everyone.

Session's are 8:30-5:00 each day. Topics include:

*Educational sessions in plain language
*Wellness and assistive technologies
*Health, and daily-living support
*Opportunities to connect with other families who are on the quest for therapeutics and cures
*Space for hope, resilience, and community

SPF will host a Dinner banquet on Tuesday evening.

The following page offers information for conference & hotel registration.

Questions? Email: Spasticconference@gmail.com

Early Bird Registration Discount is being extended until April 30, 2026!

Scan me!

For FAST, EASY, SAFE Registration

We ask that you go online and complete and pay for registration.

https://sp-foundation.org/get-involved/events/spf-annual-conference/2026-annual-conference.html

CONFERENCE REGISTRATION

April 30, 2026

Early Bird Registration: January 15 – ~~March 31, 2026~~ (Best Value)

$225 – First Adult **|** $175 – Additional Adult(s) **|** $125 – Youth (under 18 years)

Standard Registration: April 1 – May 31, 2026

$275 – First Adult **|** $225 – Additional Adult(s) **|** $125 – Youth (under 18 years)

Late / On-Site Registration: Beginning June 1, 2026

$350 – First Adult **|** $300 – Additional Adult(s) **|** $125 – Youth (under 18 years)

Scan me!

Virtual Registration: January 15-June 14, 2026

$150 -- Provides Virtual Access for one attendee -- A non-shareable link will be emailed June 14th

Registering by mail, complete 1 registration form per person (make copies if necessary) and include appropriate payment.

_____ First Adult **_____Additional Adult(s)** **____Youth (under 18)** **____Virtual Registration**

Full Name ____ **Phone Number** _________________________

Email Address ____ **Is this Your First Conference** ___Yes ___No

Relationship __Family Member ___Patient ___Caregiver ___Sponsor/Exhibitor ___Staff ___Other _____________

Disorder for this Registrant ___None ___PLS ___HSP Type # _____ ____Other ____________________

Aids will you be bringing (Used to determine space for seating and walkways), please check all that apply:

__ None __Animal __Cane __Crutches __Powerchair __Scooter __Walker __Wheelchair __Other _____________

Transportation ___Driving __Flying __Unknown **Hotel:** ___Yes __No __Unknown __Sharing a Room __Other

Meal Preference: ___Regular ___Vegetarian ___Vegan ___Gluten-Free ___ Kosher ___Halal __Allergies ________

Allergies other than food ____

Consent to having your name, state and email published for sharing with fellow attendees? __Yes __ No __Other

HOTEL REGISTRATION

Marriott St. Louis Airport Hotel | 10700 Pear Tree Lane | St. Louis, MO 63134
Reservations: 314- 423-9700
Website https://www.marriott.com/en-us/hotels/stlap-marriott-st-louis-airport/overview/
MUST Book by Sunday, May 31, 2026 to secure SPF Annual Conference
Group Rate $139 night+ applicable fees & taxes). This rate is good June 11-June 21, 2026

Hotel guests receive free parking and Wi-Fi. Available on-site is a restaurant, bar, coffee shop, indoor pool, fitness center, and an airport shuttle (non-accessible). This hotel is near St. Louis airport and 15-minute from downtown.

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
Research / Education / Support

6952 Clayborne Drive
O’Fallon, MO 63368-6202
EIN: 04-3594491

MARK YOUR CALENDAR

Follow events by going to SP-Foundation.org

March: Check out our updated website & Plan a P2P Fundraiser
April: Sign Up for Monthly Giving Program: *“Partners In Hope”*
May 1-Oct 31: 5K Run, Walk or Roll – Gather your circle
May 2 : Elleaire Fore Golf Tournament
June 15-17: 26th Annual Conference in St Louis
July: Watch your mailbox for the 2025 Annual Report
August: Pampered Chef
August: Make A Will Month – Join our *“Legacy Circle of Love”*
August: Summer Synapse Edition with Conference Photos
August 23-29: HSP & PLS Awareness Week
September 12: Golfing for Rare Diseases
October: Fall/Winter Synapse Edition
October 17: World Awareness Day
November 1- December 31: Year End Fundraiser Match

SPORT SPF SWAG!

Order your selection of personalized items from SPF Redbubble store. A small percentage of purchase proceeds goes to SPF. Please note that shirts will **NOT** be available at this year's annual conference. **Order your 2026 Annual Conference tee shirts in advance.**

Need A Tee?

OUR MISSION

The Spastic Paraplegia Foundation (SPFoundation) is a national, non-profit organization incorporated in February 2002. It is the only organization in the world dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP). SPFoundation is committed to providing information about these rare diseases, creating opportunities for mutual support and sharing, and discovering the cures for HSP and PLS by funding medical research. These closely related upper motor neuron diseases, variants similar to ALS, affect some 30,000 children and adults across the United States and internationally.
The SPF is dedicated to finding cures for these conditions and providing education and support services.