

SYNAPSE

The Newsletter of The Spastic Paraplegia Foundation Inc.

CONFERENCE EDITION

Summer 2023

SPP
Warrior



#HSPandPLS
SP-Foundation.org

Gateway of Hope

STL MO 2023

Letter from the President



Greg Pruitt

Dear SPF Members & Friends,

Well, here we are nearly halfway through 2023, and the important work of the SPFoundation moves forward. Your board of directors is so thankful for all of you who are involved and supportive in so many ways. Your work, your financial contributions, and your

advocacy is collectively making such an important difference in moving our research possibilities forward toward meaningful treatments and cures.

As I write this, we are working and planning daily for our 2023 annual conference in St. Louis. Our agenda is full of so many opportunities to learn more about current research, meet new and old friends in this journey we share and focus on how we can collectively improve our future together. If you are able to join us at this year's annual conference, I want to encourage you to do at least three things. First, learn all you can about the research that is focused on finding a treatment and/or cure that would improve your life. Secondly, make at least one new friend with whom you can maintain contact as you return home in order to share encouragement, information and strength in this fight. Finally, determine the best way you can become more involved and effective in helping in the SPF mission. Every year we meet new members who get positively involved in some capacity, including becoming a member of one of our working committees. Please

share with us any interest or experience you might be able to give to strengthen this work important to us all. Thank you so very much to everyone who makes any contribution to this work. Every dollar contributed helps us fund this important research. In 2022 we were able to fund seven more research projects. Our Scientific Advisory Board and board of directors are currently evaluating proposals for the 2023 funding and hope to make those awards in the very near future. We will share information about those awards on our website when those decisions have been made.

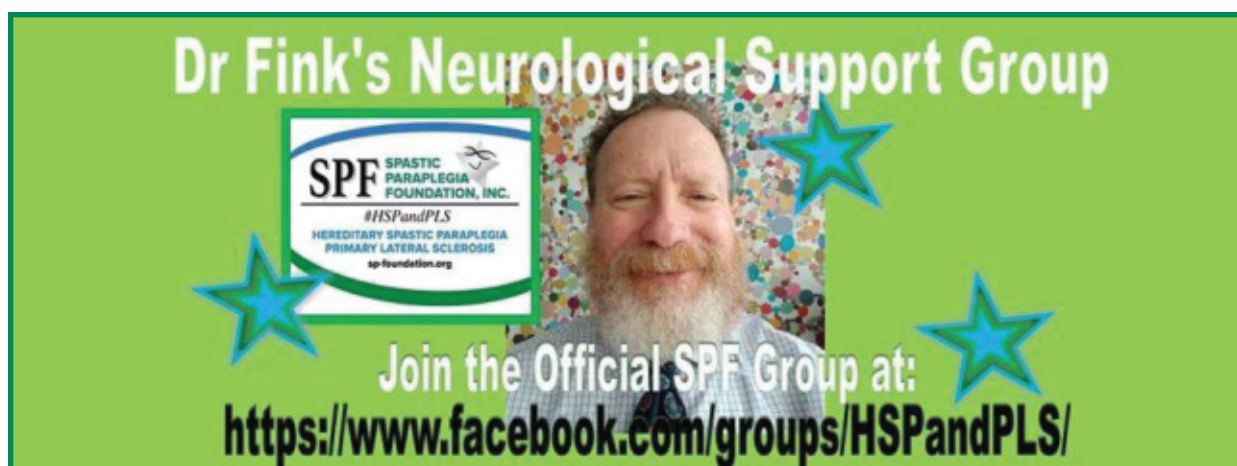
Finally, I want to thank our sponsors for the 2023 annual conference. Your investing in our work and conference makes possible this focused effort in moving forward in bringing doctors, researchers, scientists, individuals, and families who deal with these diseases and all other interested parties together to accomplish our mission. Without you and your support, this would be much more challenging. We appreciate your support in every way.

Norma & I look forward to seeing and meeting you all. Please let us know anything we can do to assist you at the conference or in any other way throughout the year.

Sincerely,



Greg Pruitt, President



Dr Fink's Neurological Support Group

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
#HSPandPLS
HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS
sp-foundation.org

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

SPF COMMITTEES – WORK OF THE SPFOUNDATION

AMBASSADORS AND EDUCATION COMMITTEE

The primary focus of the SPFoundation Education and Ambassador Committee (E&A) is to spread awareness of HSP & PLS and educate everyone about our rare diseases, specifically Patients, Family, Caregivers, Physicians/PT, and the General Public. The E&A Committee meets via Zoom on the third Wednesday of each month at 7:00pm CST. An agenda is sent prior to the meeting so others may prepare their input for additional discussions. Afterwards, the meeting minutes are sent to the E&A members so they can follow up on discussions, helping with the importance of educating and supporting our community.

In addition to education, the committee is a place for Ambassadors to share ideas on how to contact members of our community and discuss ways to get more people involved. The Ambassador role is evolving as more people are interested in becoming an ambassador. With input from our population, an informational pamphlet for “Your Role as an Ambassador”, was created and can be found along with additional resources online at SP-Foundation.org.

A great deal has been accomplished, created, and discussed since the Education Committee was formed in 2018. Many accomplishments include the following highlights:

- Obtained corporate sponsors for the annual conference
- Solicited donations of medical equipment for the annual conference for raffles and door prizes
- Updated SP-Foundation.org and adding testimonials from our population
- Updated SPF members information on Network for Good (NFG) platform
- Updated a listing of the recommended doctors familiar with HSP or PLS on SPFoundation.org
- Updated welcome letter for new members to SPFoundation
- Added a letter that outlines the SPF website
- Created a SPFoundation Informational “business” card
- Recommended to the SPFoundation Board the signing of a petition from World Health Organization (WHO) to proclaim October 17 as World Hereditary Spastic Paraplegia Day
- Wrote an introductory letter and sent to Movement Disorder Clinics, medical schools, and clinics to spread awareness of HSP, PLS, and SPFoundation
- Compiled an introductory letter to ALS Clinics and sent information to them to spread awareness of HSP and PLS

- Developed a list of addresses for ambassadors to help connect and provide outreach efforts within the ambassador family of the SPFoundation

Here are some of our usual discussion items:

- SPF Annual Conference
- SPF Webinar Series – Monthly presented by doctors
- SPF Talks – Monthly, Subject-Matter Experts and Patient discussions
- SPF Awareness Week
- Fundraisers and Events
- SPF Synapse and Spastic World
- SPF YouTube Channel
- SPF End of Year Giving Campaign
- SPF Hot Pepper and Hot Wing Challenge
- Giving Tuesday
- Abilities Expo
- SPF Patient Insight Network

If you would like to serve on the SPFoundation Education and Ambassador Committee or would like to provide ideas or feedback, please contact Dina Landphair at Dina.Landphair@sp-foundation.org

Being a SPF Ambassador can be Life Changing!

SPF AMBASSADORS

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

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

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

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

FUNDRAISING COMMITTEE

THANK YOU to every member, partner, contributor, and donor for your effort and participation with SPFoundation in 2022. On behalf of the SPFoundation Fundraising Committee, we simply want to say, “We Appreciate You!” Last year, over \$1 million was raised through all our efforts. This is the most ever raised!

Your direct efforts and contributions are assisting the SPFoundation in raising more resources than ever before. Resources that increase important research to move us closer to the treatments and cures that are so very important to those of us who must daily handle and endure HSP or PLS.

Fundraising Committee work is accelerating with the assistance of more new members and contributors. With growing awareness, the committee enthusiastically recommended a 2022 fundraising goal of \$1.5 million to the SPF Board of Directors early in the year. Without hesitation and with great commitment, the Board unanimously adopted the expanded goal and is working with the various committees to ensure that medical research continues moving forward at an accelerated pace.

The Fundraising Committee offers the following examples to expand your fundraising base to help you contribute financially to the SPFoundation:

(1) Online giving through SPFoundation.org is the quickest, easiest, and most cost-efficient for the Foundation. Make a single contribution or set up a recurring plan. Monthly or quarterly contributions can easily be setup and amended at any time with autopay on SP-Foundation.org. As soon as your online contribution is processed you will receive a quick response thanking you for the donation and providing an automatic tax receipt for your records.

(2) Personal checks are always an option, but it takes valuable time and resources to process checks to ensure the donation is properly coded in the system, and ensure the donor is properly acknowledged with a Thank You letter. To help assist our volunteers to be most efficient, the SPFoundation prefers online donations if possible.

(3) Honorarium and Memorial Contributions is a heart-felt way of acknowledging your loved one with a webpage specially created for them online through the SPFoundation’s “Memorial Giving Honoring Loved Ones in SPF Circle of Love”. Please let us know if we should notify someone about your honorarium and memorial contribution by emailing Information@SP-Foundation.org.

(4) Facebook Fundraisers are another great option for raising money for SPFoundation. Creating personal fundraisers can bring people together yet be far-reaching in benefit for a great cause like the SP-Foundation. Facebook makes it easy to create and share so family and friends can easily donate securely through Facebook.

(5) Employer-Matching Programs may be available through your employer. Contact your human resource or personnel department to see if your employer has a program to match your charitable contributions. It is usually easy to sign up. Let them know when and how much you contribute to SPF, and your gift may be matched by your employer.

(6) Planned Giving is another great way to contribute to SPF for medical research. It may be accomplished in several different ways. One option is including the SPF in your last will and testament. Making the SPF beneficiary of trusts or life insurance policies are other possibilities. Please check with your financial advisor and/or attorney to consider these types of contributions. In 2020 after we lost a hard-working member of our population, Mr. John Staehle, the SPFoundation created “The Staehle Legacy League” in his honor so members can name the SPFoundation in their will, trust, retirement plan, life insurance policy or annuity. For more information about planned-giving or if you would like to notify SPFoundation that you are participating, please contact us at Information@SP-Foundation.org or call (877) 773-4483.

(7) You can also donate Appreciated Securities, funds from 401Ks, or other financial investments. Check with your financial advisor regarding the proper process and timing should you desire to consider this type of contribution. Contact SPFoundation for more information including wiring instructions.

(8) Many businesses have foundations set up to help them save money while helping the community. If you have a connection with a business, please check and see if they make contributions to non-profits. If so, they might contribute to SPFoundation in your honor. Contact SPFoundation for assistance with the application process.

(9) Corporate Sponsorships are another effective way to help raise money for SPFoundation. Through the SPFoundation Sponsorship Program we can partner to provide marketing opportunities for businesses and nonprofit organizations through SPFoundation online resources. Contact SPFoundation for assistance with the Sponsorship Program. There are several events, campaigns, and fundraising opportunities that happen year around. Details are communicated from the SPFoundation via email, social media, and e-blasts.

SPFoundation operates out of the strength of our community, caring friends, and sponsors.

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

SUPPORT RESEARCH TO SPEED OUR CURES BY FUNDRAISING & VOLUNTEERING

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

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

Patient Connection Programs: Organizing a Connection or a gathering of people to meet, share stories and help one another is a great service. Events can be as simple as meeting for coffee!

Conference Organizers: SPF's conference coordinator gladly welcomes planning and organizing assistance from SPF members living in or near the areas selected for annual conferences. These events feature speakers and programs on special topics of interest to our community and provide opportunities for individuals to meet others. Conferences are normally a 3-day event. Individuals can also help gather items to auction or raffle for fundraising at the conference. People are also needed to secure corporate sponsorships and other corporate donations.

Communications: Individuals with writing, research, website, or graphic design skills are always welcome to assist with various communication initiatives.

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

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

Please keep your email updated with SPFoundation so you can be informed of upcoming activities. We need everyone, along with family and friends to help to reach the fundraising goal this year and raise awareness to reach more people with HSP or PLS.

Please help us reach our 2023 goal of raising \$1.5 million dollars by making personal contributions, reaching out to family, friends, and asking business associates. Questions or comments about the Fundraising Committee contact, jim.sheorn@sp-foundation.org. Jim Sheorn SPF Fundraising Committee Chair.

MARKETING COMMITTEE

The SPFoundation's Marketing Committee began in 2018 at the Annual Conference in Pittsburg. The SPF Board of Directors combined all communication and marketing efforts into one committee to advance its goals of research, education and support. The emphasis has been to increase the presence and awareness of the SPFoundation to physicians, scientists, researchers, and to individuals with HSP and PLS. Members of the SPFoundation and community have listed as their number one issue, their being misdiagnosed for many years as they are enduring symptoms and effects of HSP or PLS.

The challenge before the Marketing Committee is to develop a creative message that communicates the SPF mission to physicians, the medical community, and others. The Marketing Committee is communicating who we are, what symptoms we have, and directing people to our website. To this point, it is also essential to carry the message to researchers and investigators that the SPFoundation has a scientific grant award program available to assist them in their efforts to study HSP and PLS.

In 2019, the Marketing Committee created a targeted geo-fence campaign that afforded us the ability to target our message specifically to neurologists attending the American Academy of Neurology (AAN) Conference in Philadelphia, PA. We had a geo-fence, or a virtual fence, set-up around the physical location of the conference site via an internet provider, that sent our message/advertising directly to those in attendance via their laptops and mobile devices. Our messages included a combination of "Question and Answer" graphics designed to engage the viewer to click-through to the SPFoundation website for more details and videos explaining HSP and PLS conditions. The internet provider reported that our advertising plan exceeded expectations by exceeding the

national average of user engagement and click-thru rates bringing viewers to our website. During the AAN conference, our website analytics almost doubled from the previous month. With this success, we targeted the American Neurology Associations (ANA) conference in St. Louis, MO., later in 2019, aiming our message to researchers. As before, our ads exceeded expectations, with increased website visits and it contributed to an increase in the number of grant Request for Proposals (RFP) from researchers.

As 2020 rolled in and out, we expanded our capacity focusing to reach our audience without the ability to meet in-person. The Zoom video conferencing service allowed us to virtually create our first Virtual Annual Conference with an aggressive list of speakers, physicians, and medical researchers, all of which can be viewed on the SPFoundation You-Tube channel. The Zoom service also helped to bring us together for HSP and PLS Awareness Week.

The process of reorganizing the SPF website, cleaning up duplicated and outdated information, etc., was a huge task, but now we are immensely proud of the volunteers that took on the challenge to make the website even more user friendly. We encouraged members to participate in our HSP and PLS Awareness Week in late August 2020 and our social media platforms began exploding with our members' activities and fundraising events.

Continuing with our successes into 2021, the Marketing Committee expanded the SPFoundation's global presence. Our series of seven webinars over four months was heavily attended, bringing members from around the world together to hear from our researchers and doctors. Participants attended our Zoom webinars from 26 countries. With a renewed energy and presence, our membership is growing, participation is increasing, fundraising goals are exceeding initial expectations, and more people are creating personal campaigns each year. We are also pleased to note the addition of the SPF Store which allows a creative flair for a message of enduring life with HSP or PLS, promoting the SPFoundation, and making new items available to raise awareness while providing residual revenue to the SPFoundation.

Fast-forward for a 2022 update, as technology continues to advance, the Marketing Committee worked through an internet provider to develop the ability to not only focus our message to the AAN Conference in Seattle, WA., in April, but also to send the attendees our ads for an additional 30 days after they returned home. Plus, we were able to target the Top 10 research universities in the United States with our ads. The SPFoundation now has more than 500 researchers in our database to receive our message that grants are available through the SPFoundation to research HSP and PLS, and we

are currently evaluating over 30 proposals. During 2022, we also hosted an in-person annual conference in Nashville, TN and are looking forward to the 2023 conference in St Louis, MO.

It is quite humbling to be a part of a community that so passionately tells its stories of enduring life with HSP and PLS, along with those with complicated and unknown variants. Our families, community and membership continue to grow and our message and vision will continue to focus on "the day when all individuals with HSP or PLS are diagnosed, treated, and cured." Be a part of the Marketing Committee to help us support the SPFoundation. If you have any questions or comments about the Marketing Committee please reach out to us at Information@SP-Foundation.org, Tim Croghan SPF Marketing Committee Chair.

RESEARCH GRANT COMMITTEE

The mission of the SPFoundation Research Grant Committee is aimed at converting donations into grant awards for researchers, scientists, and investigators to produce scientific research and therapies for patients with HSP and PLS. The process consists of identifying researchers to send a request for proposal, identifying the best research proposals, then funding the proposed research. This process is completed through the volunteer efforts of the SPF Research Grant Committee (RGC) and SPF's Scientific Advisory Board (SAB).

To put it in perspective, the SPFoundation awarded two proposals for \$40,000 each in 2003. In 2021, the SPFoundation had pledged grant awards of \$771,000 to research across six distinct proposals. Scientists have unraveled many of the riddles regarding the complicated biochemistry of these diseases. Many HSP genes have now been discovered, as well as a gene for PLS, but much more research is essential.

Fast-forward for a 2022 update. With the assistance of many donors, sponsors, and contributors, the SPFoundation set a record in fundraising, collecting \$1,300,000 that will be made available for scientific research. Further at the 2022 Annual Conference, Dr. Martha Nance, who is stepping down as Chair of the SAB, was honored with an award from the SPFoundation, acknowledging our appreciation for her 19-years of commitment and service to the SPFoundation. Also, Mark Weber was awarded for his service as the SPFoundation RGC Chair. He is stepping back as committee Chair but will remain active with the committee.

The SPFoundation has a remarkable team of people who are constantly accepting the challenge to utilize their experience and talents. John and Jody Cobb, the new RGC co-Chairs and

Dr. Paolo Moretti, our new SAB Chair, are proceeding quickly to build on what Dr. Nance and Mark Weber have accomplished over the past 20 years. Due to these shifts, the grant review cycle was delayed, but a plan was formulated to get the 2022 grants funded before the end of the year.

Please help us reach our goals. Questions or comments about the Research Grant Committee contact John Cobb, SPF Board of Directors, Research Grant Committee Co-Chair at john@sp-foundation.org or Jody Westbrook Cobb, PhD Research Grant Committee Co-Chair at jodi@sp-foundation.org org.

SPF ADVOCACY COMMITTEE

The SPF Advocacy Committee has just recently organized and is evaluating new and innovative ways to assist in making our foundation a more active partner in both public and private sector networks. The committee has met over the past six months and has discussed processes to assist our membership in more effectively communicating with both federal and state governments relating to policies and potential new legislation affecting our members. It has also considered putting together an application to the Social Security Administration to get both hereditary spastic paraplegia and primary lateral sclerosis added to the compassionate allowance listing in regard to the application for social security disability benefits. Applicants who have medical diagnoses of any of the listed diseases/conditions are generally able to be determined eligible for SSDI benefits much quicker. SPF member Leonard Erskine has agreed to serve as chair of the committee and would certainly welcome input and support. For more information email Information@SP-Foundation.org, Leonard Erskine, SPF Advocacy Committee Chair.

Legislative Asks

- *1. Ask your members of congress to INCLUDE HSP and PLS on the COMPASSIONATE ALLOWANCES LISTING.** (* – get started on this first!)
2. Ask your members of congress to **JOIN THE RARE DISEASE CAUCUS.**
3. Ask your legislators to **JOIN A CONGRESSIONAL SIGN-ON LETTER TO THE FDA** requesting the formation of an internal FDA Task Force to review and inform agency-wide rare disease activities.
4. Ask your members of congress to **SUPPORT RARE DISEASE APPROPRIATIONS.**
5. Ask your legislators to **COSPONSOR the BETTER EMPOWERMENT NOW TO ENHANCE FRAMEWORK and IMPROVE TREATMENTS (BENEFIT ACT)**

COMPASSIONATE ALLOWANCE

Help support SPFoundation to elevate the awareness of HSP and PLS to encourage the inclusion of these diseases on the “Compassionate Allowances Listing” for expedited and automatic approval of Social Security Disability Insurance. In November 2022, the “SSA Medical Consultants and Policy Analysts [had] previously completed comprehensive reviews of medical literature and information on Hereditary Spastic Paraplegia and Primary Lateral Sclerosis.” “We [SSA] concluded that these conditions are not candidates to include on the CAL list. At this time, we [SSA] have determined that cases involving these conditions are best handled through our [SSA] standard disability claims process. The purpose of this letter is to inform you that the submitted conditions do not meet our [SSA] criteria for expedited handling under the CAL initiative.” SPF wants this changed to help people struggling with HSP or PLS.

Now is the time to reach out to every Congressional Senator and Representative to include HSP and PLS on the Compassionate Allowances Listing. Rare Across America is a means to help you contact your congressional members in person or virtually between August 7-18, 2023



RARE
ACROSS AMERICA
EVERY VOICE, IN EVERY DISTRICT, MATTERS
August 7-18, 2023
Details at: <https://everylifefoundation.org/rare-advocates/rare-across-america/>

Rare Across America is the opportunity to meet with your Members of Congress at their in-district offices and educate them on the issues that are most important to the rare community.

Where? All Senate meetings will be scheduled virtually, and House meetings will be in person at your Member's in-state, in-district office. Rare Disease Legislative Advocates (RDLA) will schedule meetings for you and help you to prepare. No prior advocacy experience is necessary.



Join a Congressional sign-on letter to the FDA requesting the formation of an internal FDA task force to review and inform agency-wide rare disease activities.

Overview

Forty years ago, The Orphan Drug Act (ODA) created a designation, incentives, and other processes to spark rare disease therapy development. The FDA has issued more than 1,100 orphan-designated approvals, but 95% of the more than 10,000 rare diseases still have no FDA approved treatments.

Time is the most precious commodity for the rare disease community. Each time a promising therapeutic target faces delays or demise due to the complexities in rare disease and the strain on the existing regulatory infrastructure, lives and investments are lost -- and future scientific promise remains unfulfilled.

Small populations to study, limited natural history knowledge and long diagnostic odysseys are just a few of the challenges inherent in rare disease therapy development. In addition to these challenges, the community experiences numerous regulatory obstacles to successful therapy development including:

- ✓ Changes in acceptable clinical trial endpoints
- ✓ Application of the accelerated approval pathway standard in rare disease
- ✓ Disparities in the use of real-world evidence and real-world data in regulatory decisions
- ✓ Decisions regarding the development of therapies for small populations
- ✓ Missed opportunities for sharing experience and knowledge across centers

The FDA has developed multiple programs to help strengthen their rare disease infrastructure, especially within CDER. However, the impact of those new initiatives is not yet consistently felt by the community.

The Proposal

An internal FDA task force should be created to evaluate and inform the agency's rare disease activities and the processes that are in place to ensure they benefit the entirety of the agency. Better information for therapy developers, clinicians, and patient communities regarding the basis for FDA decisions, especially advice on good practices, and applying shared learning across all relevant divisions and centers would lead to significant process improvements and help translate the remarkable scientific and technology advances into better outcomes for this generation of rare disease patients.

Please join the Co-chairs of the Congressional Rare Disease Caucus in a sign-on letter to the FDA requesting the formation of an Internal FDA task force to review and inform agency-wide rare disease activities.

To join the letter, please contact:

Sen. Klobuchar's office: Ruth_Mcdonald@klobuchar.senate.gov;

Sen. Wicker's office: Sally_Thompson@wicker.senate.gov;

Rep. Bilirakis' office: Chris.Jones@mail.houes.gov; or

Rep. Matsui's office: Jackie.Weinrich@mail.house.gov

Two Rare Diseases should be included on the Compassionate Allowances Listing

About SPF: The Spastic Paraplegia Foundation (SPF) is the only foundation in the Americas dedicated to finding cures and treatments for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS) by funding early-stage, medical and scientific research projects. Through education and community, SPF strives to help people affected by these conditions live fuller and more productive lives with the latest scientific and medical developments. (SP-Foundation.org)

Diseases: HSP and PLS are two progressive, degenerative upper motor neuron diseases affecting mobility, balance, speech, swallowing and muscle atrophy. These conditions are also known as Familial Spastic Paraplegia or Paraparesis (FSP) and Strumpell-Lorrain Syndrome. They are cousins to Amyotrophic Lateral Sclerosis (ALS).

Problem: A disabled individual with HSP or PLS cannot file for Social Security Disability Insurance without being denied (usually several times) whereas individuals with ALS are automatically approved because Amyotrophic Lateral Sclerosis is recognized as a rare disease by the Compassionate Allowances Listing. SPF applied on 11/18/2022, to the Compassionate Allowances Listing using practically the same language, as did ALS. CAL denied our request on 11/20/2022 with the response, “. . .We have determined that cases involving these conditions are best handled through our standard disability claims process.” And “. . .the submitted conditions do not meet our criteria for expedited handling under the CAL initiative.”

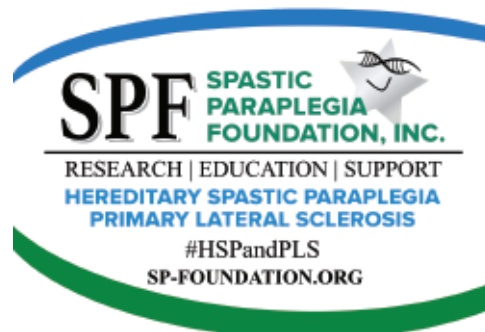
Please help support the Spastic Paraplegia Foundation by adding HSP and PLS to the Compassionate Allowances Listing for expedited and automatic approval of Social Security Disability Insurance.

Your action on this issue can help over 2000 of your Missouri constituents and the 30,000 others with these rare diseases across the United States.

Please contact:

Norma Pruitt, Executive Director,
Spastic Paraplegia Foundation, Inc.,
(877) 773-4483

Information@SP-Foundation.org





Please support important rare disease FY 2024 appropriations priorities involving NIH, FDA, and Ultra-Rare

Request 1:

Bill: Agriculture, Rural Development, Food and Drug Administration, and Related Agencies

Section: Food and Drug Administration, Office of the Commissioner, Office of Orphan Products Development

Request: Provide \$30 million for the Orphan Products Grant Program to reflect the full authorized funding level, and support the following language:

***Developing Products to Treat Rare Diseases.** The Committee is aware of the increasing number of therapeutics in development for rare disease patients, but there still remain significant gaps with 95 percent of rare diseases not having a FDA-approved treatment. As such, the Committee recognizes the importance of the Orphan Products Grant Program which supports development of products to treat orphan or rare diseases including the programs to support clinical trials, natural history studies, and the new authority to fund grants addressing regulatory science challenges. The Committee provides the fully authorized funding in this bill to reflect the critical need to support this program and the documented economic burden of all rare diseases.*

Request 2:

Bill: Health and Human Services, Education, and Related Agencies

Section: National Institutes of Health, National Center for Advancing Translational Sciences

Request: Provide \$969.465 million for the National Center for Advancing Translational Sciences, and support the following language:

***Rare Disease Research:** The agreement encourages NCATS to leverage the investments made in NCATS rare disease research to accelerate the development of new treatments for the 95% of rare diseases with no approved treatment, to strengthen the innovation of diagnostics to shorten the average 6.3 year long diagnostic odyssey, and to lower the nearly \$1 trillion annual economic burden of rare diseases. The Committee has provided an increase in funding for NCATS to increase funding for rare disease research, helping to grow the newly created Division of Rare Diseases Research Innovation.*

Rare Disease Research Background:

- Investments into rare disease research benefit everyone.
 - A 2022 study showed that the conservatively estimated impact of rare diseases in the U.S. in 2019 was nearly \$1 trillion. Discovery of treatments for the more than 95% of rare diseases with no FDA approved therapy – and investments into opportunities to improve health outcomes -- is a societal priority.
- For many rare diseases, treatments are now within reach.
 - Advances in the understanding of rare diseases and novel technology platforms have transformed many disease pipelines. Yet we must ensure that incentives and regulatory pathways exist for all rare diseases to make development financially viable for companies.

Rare Disease Research Agency Background:

- The FDA's Office of Orphan Products Development administers provisions of the Orphan Drug Act to promote development of therapies for rare disease patients. OOPD manages two vital and successful grant programs - the Orphan Product Clinical Trial Grants Program and Natural History Grants Program.
 - Orphan Product Clinical Trial Grants Program supports new and continuing extramural research projects that test the safety and efficacy of promising new drugs, biologics, devices, and medical foods through human clinical trials in extremely vulnerable populations often with life-threatening conditions.
 - Natural History Grants Program supports studies that advance rare disease therapy development through characterization of the natural history of rare diseases and development and/ or validation of clinical outcome measures.
- The National Center for Advancing Translational Sciences (NCATS) houses the Division of Rare Diseases Research Innovation (formerly known as ORDR) which helps to facilitate and coordinate NIH-wide rare disease related research activities. It oversees critical rare disease research programs such as the Rare Diseases Clinical Research Network (RDCRN), Platform Vector Gene Therapy (PaVe-GT), and Therapeutics for Rare and Neglected Diseases program.

Request 3:

Bill: Health and Human Services, Education and Related Agencies

Section: Office of the Secretary

Request: Support the following language:

***Defining Ultra Rare Diseases:** The agreement includes \$1,500,000 to fund the National Academy of Sciences to produce a report within 18 months that identifies the ideal process to determine a definition of ultra-rare diseases. Developing a therapy for conditions occurring in very small populations involves overcoming unique regulatory and research hurdles due to their small patient populations. A scientifically valid definition of ultra-rare may be needed to inform additional process reforms to orphan drug development. The report development would include a public workshop convening rare disease expert stakeholders including scientists, federal agency representatives, patient advocacy leaders, clinicians, therapy and diagnostics developers, and regulators. The report would address questions such as what data is needed to define ultra-rare, who are the critical stakeholders required for the determination, where are the gaps in data to aid in determining the definition, are there opportunities to define ultra-rare outside of population size, appropriate frequency for updating the definition, and what are the benefits and downsides of creating a definition.*

Background:

- The ODA reshaped the rare disease landscape, yet more remains to be done.
 - The incentives within the Orphan Drug Act brought helped to exponentially increase the number of FDA-approved rare disease therapies.
 - Small, rare disease populations (ultra-rare diseases) still face significant challenges in the development of new therapies and may require additional policy and regulatory considerations to address the unique complexities of therapy development.

For more information contact: Director of Policy, Dylan Simon at dsimon@everylifefoundation.org.

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

www.EveryLifeFoundation.org



Join the Rare Disease Congressional Caucus

The bipartisan and bicameral **Rare Disease Congressional Caucus** is led by Representatives Doris Matsui (D-CA) and Gus Bilirakis (R-FL) and Senators Roger Wicker (R-MS) and Amy Klobuchar (D-MN) to promote awareness of rare disease issues.

Background: There are over 10,000 rare disorders that together affect more than 30 million Americans and their families. Rare or orphan diseases are defined as diseases affecting fewer than 200,000 people in the United States. Many rare diseases are considered ultra-rare; some affect fewer than 100 people. Rare diseases include genetic diseases, rare cancers, tropical or neglected diseases, and many pediatric diseases. Many of these diseases are life-threatening and have no treatment options.

The Orphan Drug Act was enacted in 1983 to incentivize pharmaceutical companies to develop therapies for diseases that have relatively small patient populations. Despite the success of the Orphan Drug Act, 93-95% of rare diseases still do not have a treatment approved by the Food and Drug Administration.

The science exists for many of these diseases to be treated; however, treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment. Additionally, while relatively few treatments have been approved, patients struggle with health insurance reimbursement and other coverage barriers that prohibit access to potentially lifesaving treatments.

Solution: The Rare Disease Congressional Caucus helps bring public and Congressional awareness to the unique needs of the rare disease community (including patients, physicians, scientists, and industry), and creates opportunities to address barriers to the development of and access to life-altering treatments. The Caucus gives a permanent voice to the rare disease community on Capitol Hill. Working together we can find solutions that transform hope into therapies and cures.

For more information contact: Senior Director of Advocacy, Shannon von Felden at svonfelden@everylifefoundation.org.

To join the Caucus contact: Sen. Klobuchar's office: Ruth.Mcdonald@klobuchar.senate.gov; Sen. Wicker's office: Sally.Thompson@wicker.senate.gov; Rep. Bilirakis' office: Chris.Jones@mail.houes.gov; or Rep. Matsui's office: Jackie.Weinrich@mail.house.gov.

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers.

RARE DISEASE LEGISLATIVE ADVOCATES (A PROGRAM OF THE EVERYLIFE FOUNDATION)
1012 14TH STREET NW, SUITE 500, WASHINGTON DC 20005
OFFICE: 202-697-RARE (7273) WWW.RAREADVOCATES.ORG @RAREADVOCATES

Ensure Patient Perspectives Are Included in FDA Benefit-Risk Assessments: Cosponsor the S. 526/H.R. 1092 the Better Empowerment Now to Enhance Framework and Improve Treatments (BENEFIT) Act

Overview

Congress and the Food and Drug Administration (FDA) have made considerable progress in driving forward policies and procedures to ensure the patient perspective is considered by FDA reviewers evaluating candidate drugs and other medical products. As a result of numerous provisions of both the Prescription Drug User Fee Act (PDUFA) authorization of 2012 (known as FDASIA) and the 21st Century Cures Act passed into law in 2016, the FDA now has programs and policies in place to evaluate the benefits and risks of potential therapies and to gather and assess the patient perspectives.

But while much progress has been made, some significant gaps remain. One such gap is the lack of a requirement in law that the FDA include patient experience or patient-focused drug development (PFDD) data as part of its risk-benefit framework. Examples of patient experience data include:

- *Patient reported outcomes* (how a drug impacts activities of daily living ie: whether they can feed themselves, be independent etc.)
- *Patient testimonials* (qualitative data/patient stories of “living with”)
- *Patient preference data* (how much risk patients are willing to take)
- *Natural History Data* (the natural progression of the disease without intervention)

The agency’s signature tool for evaluating risk-benefit of a drug does not currently explicitly include data from the patient perspective that could be critical to informing the agency’s evaluation and, ultimately, decision on whether or not to approve a product.

The BENEFIT Act

To address this gap, Senators Roger Wicker (R-MS) and Amy Klobuchar (D-MN) and Representatives Doris Matsui (D-CA) and Brad Wenstrup (R-OH) have introduced S. 526/H.R. 1092 the Better Empowerment Now to Enhance Framework and Improve Treatments (BENEFIT) Act.

Currently, FDA indicates whether it receives submitted patient experience data – including information developed by a product sponsor or a third party such as a patient advocacy organization or academic institution – but not whether or how it was used in the review process. **This legislation will amend the Food, Drug and Cosmetic Act (FDCA) to require that FDA include in the risk-benefit framework a description of how submitted patient experience data and information were considered.** This action will enhance transparency and accountability, sending an important signal to all stakeholders that patient experience data will be incorporated into the agency’s review process, encouraging such entities to continue developing and refining scientifically rigorous and meaningful tools and data.

Conclusion

The nascent field of patient engagement in drug development continues to flourish thanks to a continued interest and focus by Congress. The BENEFIT Act will continue this evolution by filling a sizeable gap by ensuring such data is fully considered as part of the FDA’s risk-benefit assessment. **Advance patient engagement by cosponsoring the BENEFIT Act today.**

Senate: Support S. 526 the BENEFIT Act (Wicker-Klobuchar)

Contact: sally_thompson@wicker.senate.gov or Ruth_McDonald@klobuchar.senate.gov

House: Support H.R. 1092 the BENEFIT Act (Matsui-Wenstrup)

Contact jackie.weinrich@mail.house.gov (Matsui) or kelsi.wilson@mail.house.gov (Wenstrup)



Senate Co-Chairs: Senators Roger Wicker (MS) and Amy Klobuchar (MN)
House Co-Chairs: Representatives Doris Matsui (CA-7) and Gus Bilirakis (FL-12)

HOUSE

Mark Amodei NV-2
Jake Auchincloss MA-4
Don Bacon, NE-2
Andy Barr KY-6
Joyce Beatty OH-3
Ami Bera CA-7
Donald Beyer, Jr. VA-8
Gus Bilirakis* FL-12
Sanford Bishop, Jr. GA-2
Lisa Blunt Rochester DE
Suzanne Bonamici OR-1
Julia Brownley CA-26
Vern Buchanan FL-16
Michael Burgess TX-26
Ken Calvert CA-42
Salud Carbajal CA-24
Andre Carson IN-7
John Carter TX-31
Sean Casten IL-6
Judy Chu CA-27
David Cicilline RI-1
Emanuel Cleaver, II MO-5
Steve Cohen TN-9
Jenniffer Gonzalez-Colon PR-AL
James Comer KY-1
Gerald Connolly VA-11
Jason Crow CO-6
Sharice Davids KS-3
Diana DeGette CO-1
Rosa DeLauro CT-3
Suzan DelBene WA-1
Mark DeSaulnier CA-10
Debbie Dingell MI-12
Lloyd Doggett TX-37
Tom Emmer MN-6
Anna Eshoo CA-18
Brian Fitzpatrick PA-8
Lizzie Fletcher TX-7
Ruben Gallego AZ-7
John Garamendi CA-3
Josh Gottheimer N-J5
Garret Graves LA-6
Raul Grijalva AZ-3
Brett Guthrie KY-2
Kevin Hern OK-1
Jim Himes CT-4

Richard Hudson NC-8
Jared Huffman CA-2
Hank Johnson GA-4
Dusty Johnson SD-AL
David P. Joyce OH-14
Marcy Kaptur OH-9
Ro Khanna CA-17
Derek Kilmer WA-6
Andy Kim NJ-3
Raja Krishnamoorthi IL-8
Darin LaHood IL-18
John Larson CT-1
Bob Latta OH-5
Susie Lee NV-3
Teresa Leger Fernandez NM-3
Debbie Lesko AZ-8
Mike Levin CA-49
Ted Lieu CA-33
Zoe Lofgren CA-19
Blaine Luetkemeyer MO-3
Stephen Lynch MA-8
Nancy Mace SC-1
Nicole Malliotakis NY-11
Kathy Manning NC-6
Brian Mast FL-18
Doris Matsui* CA-6
Michael McCaul TX-10
Jim McGovern MA-2
Cathy McMorris Rodgers WA-5
Grace Meng NY-6
Barry Moore AL-2
Seth Moulton MA-6
Richard Neal MA-1
Joe Neguse CO-2
Donald Norcross NJ-1
Ralph Norman SC-5
Eleanor Holmes Norton DC
Frank Pallone NJ-6
Jimmy Panetta CA-20
Chris Pappas NH-1
Bill Pascrell NJ-9
Donald Payne, Jr. NJ-10
Scott Peters CA-52
Dean Phillips MN-3
Chellie Pingree ME-1
Katie Porter CA-45
Bill Posey FL-8
Mike Quigley IL-5

Jamie Raskin MD-8
David Rouzer NC-7
C.A. Dutch Ruppersberger MD-2
John Rutherford FL-4
Maria Elvira Salazar FL-27
Mary Gay Scanlon PA-5
Jan Schakowsky IL-9
Brad Schneider IL-10
David Scott GA-13
Mikie Sherrill NJ-11
Mike Simpson ID-2
Elissa Slotkin MI-8
Adam Smith WA-9
Chris Smith NJ-4
Jason Smith MO-8
Lloyd Smucker PA-16
Darren Soto FL-9
Melanie Stansbury NM-1
Chris Stewart UT-2
Marilyn Strickland WA-10
Eric Swalwell CA-15
Glenn Thompson PA-5
Rashida Tlaib MI-13
Paul Tonko NY-20
Lori Trahan MA-3
Jeff Van Drew NJ-2
Juan Vargas CA-51
Nydia Velazquez NY-7
Ann Wagner MO-2
Debbie Wasserman-Schultz FL-23
Bonnie Watson Coleman NJ-12
Bruce Westerman AR-4
Jennifer Wexton VA-10
Susan Wild PA-7
Joe Wilson SC-2
Robert Wittman VA-1

SENATE

John Barrasso WY
John Boozman AR
Mike Braun IN
Maria Cantwell WA
Shelley Moore Capito WV
Christopher Coons DE
Tom Cotton AR
Steve Daines MT
Charles Grassley IA
John Hoeven ND
Cindy Hyde-Smith MS
James Inhofe OK
John Kennedy LA
Angus King ME
Amy Klobuchar* MN
Edward Markey MA
Jeff Merkley OR
Jerry Moran KS
Markwayne Mullin OK
Alex Padilla CA
Gary Peters MI
James Risch ID
Kyrsten Sinema AZ
Jeanne Shaheen NH
Tina Smith MN
Debbie Stabenow MI
Chris Van Hollen MD
Raphael Warnock GA
Roger Wicker* MS

FUNDRAISING IDEA - LIVE LIFE HAVE FUN

People With disABILITIES Just Want To Have Fun!

- by Christine Patrick Hendrickson, ARNP, SPF Ambassador, Florida

Did you know that laughing increases your heart rate, can reduce stress and fights infection.

Making time to have fun is SO important. HSP has so many physical symptoms, we shouldn't forget about the mental symptoms, even though we can't see them. Having fun is good for our mental health. Those of us with "physical challenges" are often guilty of putting "fun" on the back burner.

When I was first diagnosed with HSP, I made a "to do" list of things I wanted to do, but I kept putting them off.

One of those things was to do a Disney World 5k.

I couldn't do it like a "regular" person, but Disney worked with me. (now HSP and the Alinker are in the employee training manual).

In 2020 I finished my 1st 5k (with the help of my walking assist-the Alinker). It was so much fun! (now I'm up to having completed twelve 5k events.)

We have annual passes to Disney now.

I have a disability pass, which lets me skip lines, gives me reserved seating, and lets me take my walking assist right up to the ride. At the races I start earlier and get transportation to the race. I go to Disney about twice a month. It not only gives me physical exercise (walking with my Alinker), vitamin D from the sun, but I have FUN!

It gives me hope to know that even though I have HSP, I can have fun like a "regular" person.

During the 5k races that I run at Disney I post a link to donate on my SPF website. Just another way to get awareness and donations!



#HSPandPLS AWARENESS WEEK

SPF SPASTIC PARAPLEGIC FOUNDATION, INC.
RESEARCH | EDUCATION | SUPPORT
HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS
#HSPandPLS
SPFOUNDATION.ORG

5K RUN WALK ROLL
AUGUST 2023
TShirt Logo

5K

RUN, WALK, & ROLL

SPF Fundraiser

MAY TO OCTOBER 2023

Compete in your own event, recruit family and friends to participate, or plan an in-person event for others in your area. See details online at [SP-Foundation.org](https://sp-foundation.org)

Registration online
<https://sp-foundation.networkforgood.com/projects/186302-5th-annual-spf-5k-run-walk-roll-2023>
If you would like to host a 5K event or have questions, please email Jim.Sheorn@sp-foundation.org

EXERCISE & STRETCH

How About A Foot Massage!

By Sue Duffy, SPF Ambassador, Florida

I have attended a community fitness class over the past year focused on balance and posture – and the key to improving my balance and posture is dealing with tight muscles – something just about all of us with HSP and PLS deal with.

At one session, our instructor brought in a Reflexology diagram of the bottom of our feet and a racquet ball. Well, it was incredible to learn how a little blue ball can change my day.

I stand behind a chair, near a counter or a balance bar and press my foot on the ball with a series of motions and the results are amazing. It was clear to realize every muscle in our bodies is connected so the exercise on my feet helped reduce the spasticity up and down my legs. This can also be done sitting down.

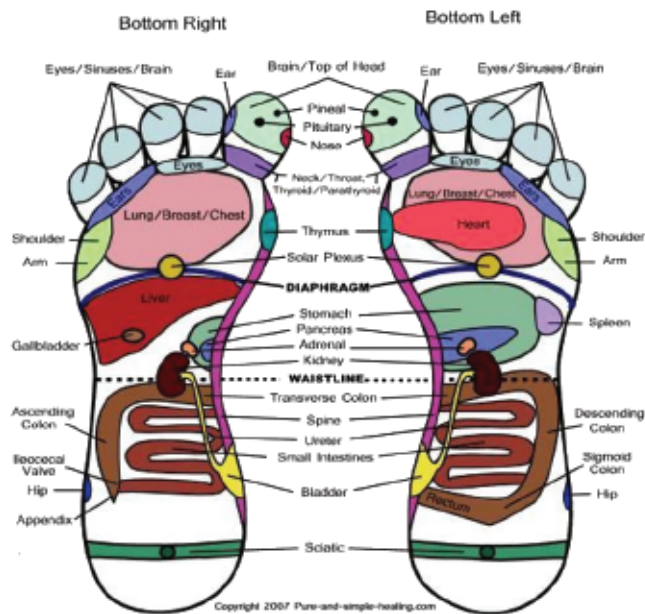
Here is what we did in our class:

- 1) Press down on the ball using the arch of foot, press on and off, 3 times
- 2) Press down on the ball of the foot, on and off, 3 times
- 3) Press down at each toe, starting at big toe (like curling your toes around the ball)
- 4) Press down side of foot – ball, mid and then heel
- 5) Press down other side of foot – heel, mid, and then ball
- 6) Press down on the ball of foot
- 7) Brush down foot – racing stripes 5 times, then do starting under each toe going from toe to heel, from the big toe to little toe
- 8) Place ball at lower arch before your heel, sheer from side to side
- 9) Same as above, more pressure, smaller movement, side to side
- 10) Side brush up and down foot
- 11) Squiggle around foot and stay on tender areas

If you are able to stand, see how fluffy your feet feel. And you should feel more stable standing and have less tightness in your calves. It is like a foot massage and clearly shows how the muscles in your feet reach up to your legs and actually tie into your back and shoulders.

Another use of the racquetball is sitting on the floor or exercise table with legs straight in front or have a chair in front of you that you can place your legs on. Put the ball under your leg at the lower part of the calf muscle, press down on the ball and move up and down a bit along the leg and then side to side, moving upwards as you go toward your knee. This, as with the feet, is like a massage. Always consult your doctor before starting any new exercises.

FOOT REFLEXOLOGY CHART



REACH OUT TO SPONSORS HELPING SPF JL SAFETY

Visor Tags – ideal holder for your Handicapped Parking Tag
by Sue Duffy, SPF Ambassador, Florida

I was in a friend's car and noticed a device on her visor that held her Handicapped Parking Tag. This device had a means to flip down when needed but otherwise is magnetically held up to the visor.

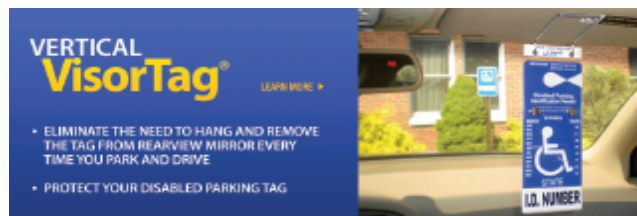


And, when not in use you flip it back up and you are no longer in violation of laws in all 50 states that prohibit leaving the tag hanging from your rear-view mirror when the vehicle is moving.

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

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

What an easy way to get a donation to the Foundation and a very useful tool in our day-to-day lives. If you see something cool – reach out, there are many generous folks out there!!!





It helps to know you're not alone.

Facing new responsibilities as a family caregiver can be a challenging role and likely one that you haven't been trained to undertake or anticipate. You can provide loving, effective care without sacrificing yourself in the process with the right help and support. Learn as much as you can about an illness or disability. The more you know, the less anxiety you'll feel and the more effective you'll be in helping your family.

Seek out other caregivers. It's comforting to give and receive support from others who understand exactly what you're going through. Trust your instincts. You know your family member best. Don't ignore what doctors and specialists tell you, but listen to your gut, too. Encourage your loved one's independence. Caregiving does not mean doing everything for your loved one. Be open to technologies and strategies that allow your family member to remain as independent as possible. Know your limits. Be realistic about how much of your time and yourself you can give daily. Set clear limits, and communicate those limits to doctors, family members, and other people involved.

Tip 1: Accept your feelings - Caregiving can trigger a host of difficult emotions, including anger, anxiety, fear, grief, guilt, helplessness, and resentment. It's important to acknowledge and accept what you're feeling, both good and bad. Don't beat yourself up over your doubts and misgivings. Having these feelings doesn't mean that you don't love your family member—they simply mean you're human.

Tip 2: Find caregiver support - It's not always easy to ask for help, even when you desperately need it. Perhaps you're afraid to impose on others or worried that your request will be resented or rejected. But if you simply make your needs known, you may be pleasantly surprised by the willingness of others to help. Many times, friends and family members want to help, but don't know how.

Tip 3: Really connect with your loved one - Caring for a loved one can bring meaning and pleasure—to both you, the caregiver, and to the person for which you are assisting. Staying calm and relaxed and taking the time each day to really connect with the person you're caring

for can release hormones that boost your mood, reduce stress, and trigger biological changes that improve your physical health. And it has the same effect on your loved one, too.

Tip 4: Attend to your own needs - If you're distracted, burned out, or otherwise overwhelmed by the daily grind of caregiving, you'll likely find it difficult to connect with the person for which you are caring. That's why it's vital that you don't forget about your own needs while you're looking after your loved one. Caregivers need care, too.

Tip 5: Take advantage of community services - Many communities have services to help caregivers. Depending on where you live, the cost may be based on your ability to pay or covered by the care receiver's insurance or your health service. Services that may be available in your community include adult day care centers, home health aides, home-delivered meals, respite care, transportation services, and skilled nursing.

Tip 6: Provide long-distance care - Many people take on the role of designated caregiver for a family member—often an older relative or sibling—while living more than an hour's travel away. Trying to manage a loved one's care from a distance can add to feelings of guilt and anxiety and present many other obstacles. But there are steps you can take to prepare for caregiving emergencies and ease the burden of responsibility.




Duo Dogs, Inc.,
10955 Linpage Place,
St. Louis, MO 63132
csmith@duodogs.org
duodogs.org
Crissy Smith,
Director Canine Operations
314-997-2325



**MISSOURI
BOTANICAL
GARDEN**

Missouri Botanical Garden
4344 Shaw Blvd,
St. Louis, MO 63110
(314) 577-5100
www.mobot.org
Jeanne Carbone, Supervisor

2023 SPF EVENT CALENDAR

RARE DISEASE DAY	February 28th , Annually
SPF 5K Run Walk or Roll	May 1, 2023 – October 31, 2023
SPF Annual Conference	Friday, June 23 - Sunday, June 25, 2023
Rare Across America	August 7-18, 2023
HSP & PLS Awareness Week	Saturday, August 20 – Saturday, August 26, 2023
HSP & PLS Awareness Day	August 27th, Annually
Golfing For Rare Disease Tournament	Saturday, September 9, 2023
Year-End Giving	November 1st to January 15th
Giving Tuesday	Tuesday, November 28, 2023
SPF TALKS	TBD – Join SPF for E-Blast Updates

NEUROLOGIC DISORDERS SUPPORT GROUP ZOOM WITH DR JOHN FINK

- Tuesday, September 5, 2023 @ 6:30-8:00pm EST
- Tuesday, October 3, 2023 @ 6:30-8:00pm EST
- Tuesday, November 7, 2023 @ 6:30-8:00pm EST
- Tuesday, December 5, 2023 @ 6:30-8:00pm EST
- Tuesday, January 2, 2023 @ 6:30-8:00pm EST
- Tuesday, February 6, 2023 @ 6:30-8:00pm EST
- Tuesday, March 5, 2023 @ 6:30-8:00pm EST

SPFoundation's Annual Conference Sponsors



Kris Brocchini

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



Lia Reilly, Educator,
(314) 646-4589
lreilly@stlzoo.org
Saint Louis Zoo
One Government Drive
St. Louis, MO 63110
314-646-4677
stlzoo.org



The Education Department at the Saint Louis Zoo believes that everyone has the right to learn. We believe that by collaborating with organizations of all kinds, we are stronger and more effective conservation educators. We believe it is our charge to inspire wonder and encourage curiosity. To accomplish this, we provide experiences that are conservation focused, learner-directed, inclusive and creative. Lia has been with the Saint Louis Zoo since September 2022. She has a Bachelor of Science degree in Elementary Education from the University of Missouri-Columbia. Before coming to the Zoo, she was a classroom teacher for Kindergarten, 1st, and 2nd grades.



World Bird Sanctuary,
125 Bald Eagle Ridge Road
Valley Park, MO 63088,
(636) 225-4390,
worldbirdsanctuary.org

YOUR MEDICAL STORE

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



Meet the Author Onsite:

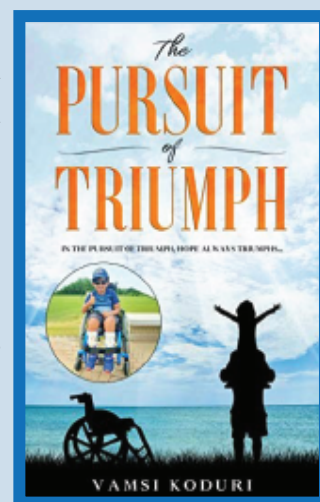
Vamsi Koduri, father to Maurya Koduri, narrates his heart warming and heart wrenching experiences with his first born, a 'special child' Maurya Koduri while navigating the other aspects of his life. Vamsi has a MBA, PMP, CSM, ITIL certified, is a Project Manager working for a top technology company that develops and markets software as a service (SaaS) for clinical trials. As a clinical IT professional, he has over 15 years of experience in the Health Sciences Industry. He is an accomplished short film maker and is well versed with film making.



Thank you Vamsi for your dedication and support.

All proceeds from book sales are donated to SPFoundation

Author | Film Maker | Digital Creator | Rare Disease Advocate | Project Manager, HealthCare Industry





SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

RESEARCH | EDUCATION | SUPPORT
HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS

#HSPandPLS
SP-FOUNDATION.ORG



SHOP

sp-foundation.org/SPF-STORE

Get Your
Favorite Item
with an SPF Logo

- **Shirts**
- **Hoodies**
- **Blankets**
- **Phone Cases**
- **& many more products**