

# SYNAPSE

*The Newsletter of The Spastic Paraplegia Foundation Inc.*

Volume 28, Issue 1

Spring 2024

*You're Invited!*

SPASTIC PARAPLEGIA FOUNDATION

21ST

ANNUAL

*Conference*

*You're Invited!*

SPF

SPASTIC  
PARAPLEGIA  
FOUNDATION, INC.



RESEARCH | EDUCATION | SUPPORT  
HEREDITARY SPASTIC PARAPLEGIA  
PRIMARY LATERAL SCLEROSIS  
#HSPandPLS  
SP-FOUNDATION.ORG

**JUNE 21-23, 2024**

**SP-FOUNDATION.ORG**

1.877.773.4483

INFORMATION@SP-FOUNDATION.ORG

**RENAISSANCE TAMPA**

**INTERNATIONAL PLAZA HOTEL**

**4200 JIM WALTER BOULEVARD**

**TAMPA, FL 33607**

**(813) 313-3289**

## HOW TO HELP

**We** operate out of the strength of our community, caring friends and sponsors. Your help makes a difference!

Please contact us at [volunteer@sp-foundation.org](mailto:volunteer@sp-foundation.org) to help in one of the areas below or to suggest another way you can get involved.

### SUPPORT RESEARCH TO SPEED OUR CURES BY VOLUNTEERING

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

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

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

**Conference Organizers:** SPF's conference coordinator gladly welcomes planning and organizing assistance from SPF members living in or near the metropolitan areas selected for annual conferences. These events feature speakers and programs on special topics of interest to our community and provide opportunities for individuals to meet others. Conferences can be half-day or full-day events.

**Communications:** Individuals with writing, research, website or graphic design skills are needed to assist with various communications initiatives.

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

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

# SYNAPSE

## Volume 28, Issue 1 - Spring 2024

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

Synapse is published quarterly. It is also available online at [www.sp-foundation.org](http://www.sp-foundation.org)

The SPF is a non-profit 501(c)3.  
Tax ID # 04-3594491

### Send Correspondence & Donations to:

Spastic Paraplegia Foundation  
6952 Clayborne Drive  
O'Fallon, MO 63368-6202

### Contact the SPF at:

(877) 773-4483  
[information@sp-foundation.org](mailto:information@sp-foundation.org)  
or [www.sp-foundation.org](http://www.sp-foundation.org)  
Norma Pruitt, Executive Director

### SPF Board of Directors:

Greg Pruitt, President  
Jim Sheorn, Vice President  
Hank Chiuppi, Secretary  
David Lewis, Treasurer  
Frank Davis, President Emeritus  
Mark Weber, Esq., Legal Counsel

Members: Corey Braastad, PhD, John Cobb,  
Tina Croghan, Dina Landphair, Carina Thurgood,  
Jackie Wellman

### SPF Medical Advisor:

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

Special thanks to Gulf Business Printing,  
Jim Burkhalter and Donna Hinshaw,  
for their assistance and support for the  
*Spring 2024 Synapse.*

*Disclaimer: The Spastic Paraplegia Foundation does not endorse products, services or manufacturers. Those that are mentioned in Synapse are included for your information. The SPF assumes no liability whatsoever for the use or contents of any product or service mentioned in the newsletter.*

# Letter from the President



Greg Pruitt

Hello, SPF Members & Friends,

**HAPPY NEW YEAR** to every member of the SPF community!! We hope your year has begun in a way that gives you and your family great hope for what 2024 may bring you.

On behalf of the SPF Board of Directors, we want to thank every one of you for your participation, support and assistance in making 2023 a very important year in our collective work to find treatments and cures for both PLS and HSP. Every dollar contributed and every minute spent in volunteering your work and time continues to move us toward that goal. Your generosity in giving and volunteering resulted in \$1,276,000 in 2023 fundraising. We particularly want to thank those who are part of providing that year-end matching dollar challenge. Every contributor at every level is an important part in helping fund essential medical research and in establishing the SPF Centers of Excellence program and process begun in 2023. It is our hope that this new work coordinating researchers will move us more quickly toward increased funding and research, with both public and private resources, accelerating the march toward treatments and cures.

We want to invite you all to be an important part of the SPF work and community in 2024.

Please register today for the 2024 SPF Annual Conference to be held June 21-23 in Tampa, FL. The early discount deadline is March 8, 2024. The discounted hotel room block will close on May 23, 2024 with no exceptions. The conference is always a fantastic place to meet and learn from both researchers and others who are dealing with the same life issues that may be challenging you. If you cannot join us in Tampa, please register for our simultaneous virtual presentation. You can still hear from every presenter and meet virtually others who attend and participate.

Finally, we want to say thank you so much to Linda and Craig Gentner for their twenty plus years of service to SPF. Linda was an original board member and has served as our VP for many years. Craig was always by her side and served in many ways, including as emcee at a number of our past annual conferences. While they have promised to stay involved and connected, Linda has recently stepped down from our board of directors. We genuinely thank them both for their service and contributions to this cause and wish them the very best in every way.

Again, thank you all for being part of SPF!! We look forward to working with you in 2024. Hope to see you in Tampa!!

*Greg Pruitt*  
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/>

# 2024 SP-Foundation Annual Conference Registration is OPEN

June 21-23, 2024

Early Discounted Fees Must Be Paid by March 8, 2024.

NO REFUNDS AFTER MAY 31, 2024.

## JOIN US IN TAMPA, FLORIDA



The Spastic Paraplegia Foundation invites you to the 21st Annual Conference to learn, share, network, spark collaboration, and have fun! Mark your calendars to join us beginning at 8:00am Friday, June 21st ending at Noon on Sunday, June 23rd, 2024.

Below are instructions to register for the conference, weblink to the hotel to book a room and a number to call for accessible transportation. The 2024 agenda will mix up a little different schedule than previous conferences, and is subject to slight changes based on speaker preferences and availability. However, the dates will not change. Please check back on this page as details are finalized, where we will provide the final agenda.

### PLEASE READ DETAILS BELOW PRIOR TO MAKING RESERVATIONS.

Any questions, please email us at [SpasticConference@gmail.com](mailto:SpasticConference@gmail.com) or call (877) 773-4483

### CONFERENCE REGISTRATION FEES

The SP-Foundation sponsors an annual conference bringing together leading doctors, scientists, researchers, clinicians, and families living with #HSPandPLS. SPF has hosted an annual conference since 2003. We look forward to uniting as a community supporting, strengthening, and learning about the latest advances in research and care, and most importantly helping the professionals see all of us together in various stages of disease progression.

Conference Fees are charged to cover the costs of the conference, including but limited to meals, breaks, room rental, audio-video equipment, videographers, and other expenses to conduct the conference. The fees charged per registrant do not actually cover all the expenses; and therefore, SP-Foundation must sponsor the balance from donations received from fundraising. If you, your family, or your guests are attending the conference each person must register and pay the appropriate rate, so we may plan accordingly.

The event is filled with a variety of workshops, general sessions with leading researchers, and more—plus informative events like our meet & greets with patients, investigators, and physicians. There are many opportunities to connect and interact with other SP-Foundation families and receive updates from doctors. We try to make accommodations for people with food allergies, other allergies, and try to keep the space safe for attendees. Please make note of any allergies on the registration form and make sure to remind the hotel staff when you are being served.

**A VIRTUAL OPTION** is also available for those that cannot attend in-person. Please watch our Spastic Paraplegia Foundation YouTube Channel to view the 2023 Annual Conference

**\$150 - VIRTUAL REGISTRATION ONLY** - Payment must be received by June 1, 2024

A non-shareable link will be emailed a few days prior to the Annual Conference. Please provide a complete, valid email address on the registration form or email [SpasticConference@gmail.com](mailto:SpasticConference@gmail.com) after you make your online payment.



## Early Discount—Payment must be received by March 8, 2024

- \$200 - 1st Adult Conference Fee Early Discount
- \$140 - 2nd+ Adult Conference Fee Early Discount
- \$100 - Child (under age 18) Early Discount

## Payment must be received between March 9 until May 23, 2024

- \$250 - 1st Adult Registration March 9 to May 23
- \$200 - 2nd+ Adult Conference Fee Early Discount March 9 to May 23
- \$100 - Child Registration March 9 to May 23

## On-site Registration

- \$300 - 1st Adult Registration May 24 to On-site
- \$280 - 2nd+ Adult Registration May 24 to On-site
- \$100 - Child Registration May 24 to On-site

## TWO WAYS TO REGISTER/PAY

- (1) Scan the QR Code to REGISTER online for the 2024 SPF Annual Conference in Tampa, Florida.  
OR
- (2) Print the Registration Form, Complete Form, Make Check Payable: SP-Foundation, then Mail Payment & Form To:  
SPF, 6952 Clayborne Drive, O'Fallon, MO 63368-6202



## HOTEL RESERVATIONS

The 2024 Annual Conference will be held at the: Renaissance Tampa International Plaza Hotel at 4200 Jim Walter Boulevard, Tampa, FL 33607 Phone (813) 313-3289.

## HOTEL RATE:

**Please Note \*\*May 23, 2024\*\* the room block ends and you are not guaranteed the group rate! Do not delay in making hotel reservations**

Mention **“SPF/Spastic Paraplegia”** to be included in the room block for discounted room rate per night of \$185 +applicable fees and taxes.

Check-In 4:pm/Check-Out Noon, Eastern Time Zone

Use hotel link provided to book your HOTEL SPF ROOM RESERVATIONS or call +1-813-877-9200.

## HOTEL HIGHLIGHTS:

SPF Hotel Guests receive free Wi-Fi and free self-parking. Available on-site is a restaurant, bar, pool, fitness center, and the hotel is adjacent to the Tampa International Mall (<https://shopinternationalplaza.com/>)

Renaissance Tampa International Plaza Hotel website: <https://www.marriott.com/en-us/hotels/tpaim-renaissance-tampa-international-plaza-hotel/overview/>

## ROOM ACCOMMODATIONS:

Please note all ADA Rooms have been reserved for our attendees but may be sold-out prior to your reservation. ADA rooms may be booked on a first-come basis.



**SHUTTLE:** Go to the airport-baggage-claim area to obtain shuttles. No appointment is necessary to transport to the hotel by shuttle. The Renaissance Hotel does not have an accessible shuttle but runs FREE Shuttles from 5am to 11pm. The AC Hotel has an Accessible FREE Shuttle available for SPF attendees found in the airport-baggage-claim area. AC Hotel is a neighboring hotel. Accessible appointments are only necessary to be dropped off at the airport by calling 813-350-4020.

**AIRPORT HIGHLIGHTS:** Hotel is located about 4-miles, or 7-minutes, from Tampa International Airport (TPA), <https://tampaairport.com/> **Airport Street Address:** 4160 George J. Bean Parkway, Tampa, FL 33607. **Airport Phone:** The Airport Information and Operations Center is staffed 24 hours a day, 7 days a week at (813) 870-8770.

**THINGS TO DO IN TAMPA, VISIT:** (1) The hotel is adjacent to International Plaza Mall—enjoy dining and the nightlife on Bay Street, a vibrant outdoor village filled with an exciting collection of restaurants and many shopping opportunities — <https://shopinternationalplaza.com/>

(2) Just minutes from downtown Tampa Bay, Raymond James Stadium, historic Ybor City, and the Westshore business district.

(3) Close to Busch Gardens, ZooTampa, Tampa Aquarium, the beach, the bay, lots of restaurants, waterfronts, and cool things to see and do! <https://traveler.marriott.com/tampa/>

**SPF CONFERENCE SCHOLARSHIP PROGRAM:** A Conference Scholarship Program is available to help low-income individuals and families with HSP or PLS attend the SPF Annual Conference. Because of generous donors, SPF will offer a limited number of Scholarships that will cover only the registration fees of the person with HSP or PLS. Applications will be accepted until February 10, 2024, 4:00pm CST. Applicants will be notified after all applications have been reviewed but no later than February 17, 2024. Please note the Early Discount Deadline is March 8, 2024. Request an Application by contacting Dina at [dinalandphair@sp-foundation.org](mailto:dinalandphair@sp-foundation.org) or submit a Scholarship Application online at <https://sp-foundation.dm.networkforgood.com/forms/spf-conference-scholarship>.



## 2024 SPF ANNUAL CONFERENCE TENTATIVE AGENDA (SUBJECT TO CHANGE)

### June 20, Thursday

Board Of Directors Meeting

### June 21, Friday

7:00am ..... Breakfast (*On Your Own*)

8:00am ..... Welcome

9:00am ..... General Session or Breakouts

10:00am ..... General Session or Breakouts

12:00noon ... Lunch, Plated (*Provided*)

1:30pm ..... General Session or Breakouts

3:00pm ..... General Session or Breakouts

5:30pm ..... Reception

7:00pm ..... Dinner (*On Your Own*)

### June 22, Saturday

7:00am ..... Breakfast (*On Your Own*)

8:00am ..... General Session or Breakouts

12:00noon ... Lunch, Plated (*Provided*)

1:30pm ..... General Session or Breakouts

6:30pm ..... Dinner Plated (*Provided*)

### June 23, Sunday

8:00am ..... Coffee & Pastries (*Provided*)

..... General Session or Breakouts

10:30am..... Dr. John Fink

12:00noon ... Adjourn, Lunch (*On Your Own*)

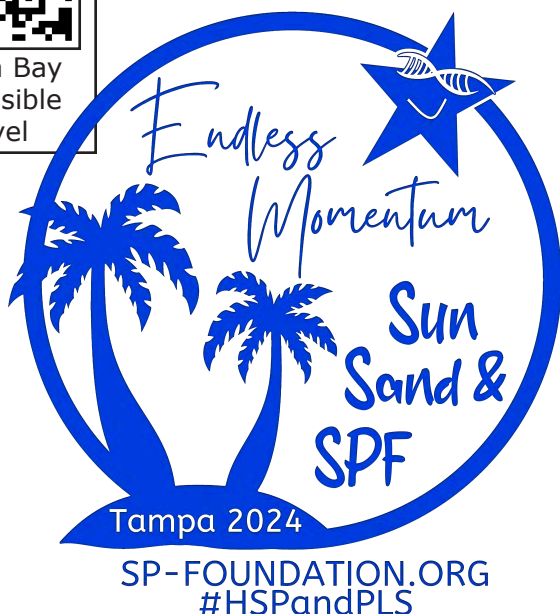
**IMAGE CONSENT POLICY:** By completing & submitting the Registration Form you acknowledge providing consent to use your image captured during the conference through live-video, photographs, or digital imagery, to be used by SPF in promotional materials, publications, and website and waive any and all rights to these images, unless otherwise revoked in writing to [Information@SP-Foundation.org](mailto:Information@SP-Foundation.org) prior to the conference.

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

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

**Important Dates:**

- 12/01/2023..... Registration Scholarship Application Open
- 12/01/2023..... Registration Annual Conference Open
- 02/10/2024..... Last Day – Conference Scholarship Applications
- 02/17/2024..... Notification of Scholarship Awards
- 03/08/2024..... Last Day - Early Bird Registration Pricing
- 05/23/2024..... Last Day - Advance Registration
- 05/23/2024..... Last Day – HOTEL BLOCK ENDS
- 05/31/2024..... Last Day – Request Refund Registration Fee In Writing



**Show Your Support and Get Geared up for the 2024 SPF Annual Conference!**

The Annual SPF Conference is around the corner, and what better way to show your support than a visit to the online SPF store, the official site for branded SPF merchandise, to help you 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 Annual Conference!

- 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](http://sp-foundation.org/SPF-STORE) and then clicking on the yellow "SHOP" icon.





## ***Hello, Sponsors, Advertisers & Friends;***

**We** are in full planning mode for the 2024 Annual Conference of the Spastic Paraplegia Foundation. The conference will be held in Tampa, Florida, June 21-23, 2024. The conference is an ideal platform in the disability community to market products, services, and extend your business name and logo to a national and international audience. Let us know of your interest in being a Sponsor, an Exhibitor, or perhaps you have items to include in our Welcome Bags, Raffles, or Door Prizes. Attached is a listing of our Sponsorship Levels. SPF has created many opportunities for sponsors to engage with the spastic community at the annual conference. There are options for every budget. We will work with you to meet your sponsorship and marketing needs.

The primary focus of the Spastic Paraplegia Foundation is funding medical research for scientists and medical investigators to find a cure, therapies, or treatments for two rare diseases HSP and PLS, that are variant-related to ALS. A secondary focus is locating everyone diagnosed with HSP or PLS, by growing awareness and outreach efforts. The annual conference is the largest gathering in the world of those affected by hereditary spastic paraplegia and primary lateral sclerosis, often stylized as #HSPandPLS for the purposes of hashtag activism. SPF has had conferences since 2002. The conference is not a fundraising effort but a platform for doctors and scientists to inform and educate patients and caregivers that are fighting these terrible diseases daily. Also, as an outreach effort, the conference is an opportunity to connect to families and people all over the world, bringing members together to support and learn about the debilitating symptoms and issues this population must live with every single day. The conference allows the physicians and investigators to see, in one place, disease progression of our patient population.

Please contact me with any questions at [SpasticConference@gmail.com](mailto:SpasticConference@gmail.com) by May 10<sup>th</sup>, 2024, so we can get logos and sponsorship information on our website, newsletters, and sponsor boards.

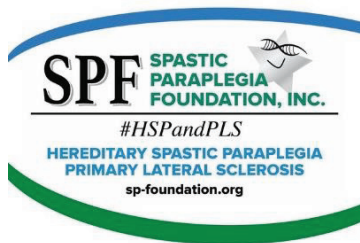
Best Regards,

*Norma Pruitt*

Norma Pruitt  
Executive Director  
Conference Coordinator  
[SP-Foundation.org](http://SP-Foundation.org)







## Sponsors Opportunities with SP-Foundation

Sponsorship Questions:

[Information@SP-Foundation.org](mailto:Information@SP-Foundation.org) or Call 877-773-4483

## CURE RARE DISEASES #HSPandPLS

### Sponsorship Levels Receive:

#### \$50,000 plus

- (1) Recognition of organization by linking corporate website to SPF website highlighting partnership for one year
- (2) Plaque of Appreciation recognizing company or individual contribution
- (3) Highest level of logo and brand recognition for your company, prominently displaying a large logo:
  - (a) on SP-Foundation website for 1-year,
  - (b) in the newsletter for 1-year
  - (c) on social media posts 1/month for 1-year
- (4) Annual Conference
  - (a) A 10-minute time slot on the conference agenda for a Speaking Role at the Annual Conference (date/time to be determined and content approved by conference coordinator)
  - (b) Exhibitor's Table provided (6-foot table with two chairs)
  - (c) Display literature at the Registration Table
  - (d) Distribute literature in the Welcome Bags
  - (e) Sponsorship Display Signage during the conference
  - (f) Two paid registrations to the Conference, includes meals/ reception
  - (g) Two free SPF shirts and awareness bracelets
  - (h) Logo in the conference program

#### \$25,000 plus

- (1) Recognition of organization by linking corporate website to SPF website highlighting partnership for fourth months
- (2) Plaque of Appreciation recognizing company or individual contribution
- (3) Highest level of logo and brand recognition for your company, prominently displaying a large logo:
  - (a) on SP-Foundation website for four months
  - (b) in the newsletter for four months
  - (c) on social media posts 1/month for four months
- (4) Annual Conference
  - (a) A 10-minute time slot on the conference agenda for a Speaking Role at the Annual Conference (date/time to be determined and content approved by conference coordinator)
  - (b) Exhibitor's Table provided (6-foot table with two chairs)
  - (c) Display literature at the Registration Table
  - (d) Distribute literature in the Welcome Bags
  - (e) Sponsorship Display Signage during the conference
  - (f) Two paid registrations to the Conference, includes meals/ reception
  - (g) Two free SPF shirts and awareness bracelets
  - (h) Logo in the conference program

#### \$10,000 plus

- (1) Recognition of organization by linking corporate website to SPF website highlighting partnership for one month
- (2) Plaque of Appreciation recognizing company or individual contribution
- (3) Highest level of logo and brand recognition for your company, prominently displaying a large logo
  - (a) on SP-Foundation website for one month
  - (b) in the newsletter for one month
  - (c) on social media posts 1/month one month
- (4) Annual Conference
  - (a) A 10-minute time slot on the conference agenda for a Speaking Role at the Annual Conference (date/time to be determined and content approved by conference coordinator)
  - (b) Exhibitor's Table provided (6-foot table with two chairs)
  - (c) Display literature at the Registration Table
  - (d) Distribute literature in the Welcome Bags
  - (e) Sponsorship Display Signage during the conference
  - (f) Two paid registrations to the Conference, includes meals / reception
  - (g) Two free SPF shirts and awareness bracelets
  - (h) Logo in the conference program

#### \$5,000 plus

- (1) Second highest level of logo/brand recognition for your company, medium-size logo:
  - (a) on SP-Foundation website for one month
  - (b) in the newsletter for one month
  - (c) on social media posts 3x prior to annual conference
- (2) Annual Conference
  - (a) Exhibitor's Table provided (6-foot table with two chairs)
  - (b) Display literature at the Registration Table
  - (c) Distribute literature in the Welcome Bags
  - (d) Sponsorship Display Signage during the conference
  - (e) One paid registrations to the Conference, includes meals/ reception
  - (f) One free SPF shirt and awareness bracelets
  - (g) Logo in the conference program

#### \$3,000 plus

- (1) Third level of logo/brand recognition for your company, small-size logo:
  - (a) in the newsletter 2x
  - (b) in the conference program
  - (c) on social media posts 1x prior to annual conference
- (2) Distribute literature in the Welcome Bags
- (3) Sponsorship Display Signage during the conference

#### \$1,000 plus

- (1) Small logo and brand recognition for your company displayed in the annual conference program.

● **Research**

● **Education**

● **Support**

● **SP-FOUNDATION.ORG**

The SPF reserves the right to accept/deny sponsors, increase/decrease the number of available sponsorships and update deliverables based on venue restrictions and SPF mission and focus.

# Spastic Paraplegia Foundation

2024 Annual Conference June 21-23, 2024

## Conference Registration Form & Fee Schedule



INSTRUCTIONS: (1) Complete Form Online & Pay by Credit Card at [SP-Foundation.org](https://sp-foundation.org) or (2) Print, Complete Registration Form. Make Check Payable: **SP-Foundation** and Mail Payment & Registration Form: SPF, 6952 Clayborne Drive, O'Fallon, MO 63368-6202. Your reservations are not complete or guaranteed until payment is received by SPF.

### VIRTUAL

#### VIRTUAL REGISTRATION ONLY - TOTAL \$150

-Payment must be received by June 1, 2024 Livestreaming, non-shareable link will be emailed 2-days prior to the Annual Conference. Livestreaming will include the meetings held in the main conference room, no breakout sessions will be livestreamed. Please provide complete email here: \_\_\_\_\_.

### IN PERSON

	Early Discount March 8, 2024			March 9th til May 23, 2024			May 24, 2024 to Onsite		
	QTY	RATE	TOTAL \$	QTY	RATE	TOTAL \$	QTY	RATE	TOTAL \$
1st Adult Conference Fee		\$200			\$250			\$300	
2nd+ Adult Conference Fee		\$140			\$200			\$280	
Child (under 18) Conference Fees		\$100			\$100			\$100	
<b>TOTALS</b>									

FAQ: (1)To receive a registration discount, payment must be **RECEIVED** in our office by the noted discounted deadlines. (2)**No Refunds after May 31, 2024, and must be requested by email.** (3)Bringing more guests, no problem, submit additional copies of this form. (4)SPF has put a hold on every ADA room in the hotel but may be sold out prior to your reservation. (5) **The hotel room block group rate ends \*\*May 23, 2024\*\*!** **DO NOT DELAY MAKING RESERVATIONS TODAY!**

Registrant Name #1: \_\_\_\_\_  
 Disorder: HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_ or None \_\_\_  
 Meal Requirement: Regular \_\_\_ Vegan \_\_\_ Vegetarian \_\_\_  
 Gluten-Free \_\_\_ Kosher \_\_\_ Other \_\_\_  
 Food Allergies (List): \_\_\_\_\_  
 Other Allergy Concerns : \_\_\_\_\_

Registrant Name #2: \_\_\_\_\_  
 Disorder: HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_ or None \_\_\_  
 Meal Requirement: Regular \_\_\_ Vegan \_\_\_ Vegetarian \_\_\_  
 Gluten-Free \_\_\_ Kosher \_\_\_ Other \_\_\_  
 Food Allergies (List): \_\_\_\_\_  
 Other Allergy Concerns : \_\_\_\_\_

Registrant Name #3: \_\_\_\_\_  
 Disorder: HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_ or None \_\_\_  
 Meal Requirement: Regular \_\_\_ Vegan \_\_\_ Vegetarian \_\_\_  
 Gluten-Free \_\_\_ Kosher \_\_\_ Other \_\_\_  
 Food Allergies (List): \_\_\_\_\_  
 Other Allergy Concerns : \_\_\_\_\_

Registrant Name #4: \_\_\_\_\_  
 Disorder: HSP \_\_\_ PLS \_\_\_ SP \_\_\_ ALS \_\_\_ Other \_\_\_ or None \_\_\_  
 Meal Requirement: Regular \_\_\_ Vegan \_\_\_ Vegetarian \_\_\_  
 Gluten-Free \_\_\_ Kosher \_\_\_ Other \_\_\_  
 Food Allergies (List): \_\_\_\_\_  
 Other Allergy Concerns : \_\_\_\_\_

Address: \_\_\_\_\_

Mobile Phone while at conference: (\_\_\_\_) \_\_\_\_\_ Text?: Y/N

2nd: Mobile: (\_\_\_\_) \_\_\_\_\_ Text?: Y / N

E-mail (primary): \_\_\_\_\_

Email (secondary): \_\_\_\_\_

Are you driving or flying to the conference? \_\_\_\_\_

What aids are you likely to bring to the conference? \* Check all that apply: Cane \_\_\_ Crutches \_\_\_ Walker \_\_\_ Scooter \_\_\_

Wheelchair \_\_\_ Powerchair \_\_\_ Animal \_\_\_ Caregiver \_\_\_ Other \_\_\_\_\_

\*This helps to determine how much room must be made available between tables and chairs, and walk-ways.

COMMENTS: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

#### DONATE TO SUPPORT A SCHOLARSHIP RECIPIENT TO AC

I would like to assist someone in attending the annual conference by donating to Scholarship Fund. Enclosed is my a check or I will charge by credit card online at:

<https://sp-foundation.networkforgood.com/projects/176811-sp-f-conference-scholarship>

\_\_\_ \$25 \_\_\_ \$50 \_\_\_ \$100 \_\_\_ \$200 \_\_\_ Other Amt \$ \_\_\_\_\_



SP-FOUNDATION.ORG #HSPandPLS



## 2023 Year End Totals

*Jim Sheorn, SPF Fundraising Chairman*

Happy New Year! It is time to celebrate! The Spastic Paraplegia Foundation had another one-million-dollar year in raising funds for medical research. Thanks to all that contributed and generated \$1,276,000. That is over \$50,000 from what was raised last year. We were also able to fully fund the second year of the Spastic Paraplegia Centers of Excellence. But the battle is not yet over, we still need to continue to raise money for future research grants. The Spastic Paraplegia Foundation Scientific Advisory Board will soon review the latest grant requests received from HSP and PLS researchers. We should be able to announce those grants by the Annual Conference in June. 2022 was the first year that SPF funded over \$1,000,000 in medical research. We should be able to fund another \$1-million in research from the money that was raised in 2023. A big Thank You to everyone that dug deep into their pockets to help generate significant money for research in 2023. Please continue to help by contributing what you can so that we can help find treatment options or even better, cures as soon as possible. We have many great ideas to create fundraising events, if you are interested please let us know.

Thanks to all those that helped SPF have a great fundraising year. If you choose to contribute online, you will receive an automatic emailed Thank You. If you prefer to mail a check, a thank you letter will be mailed to you. Using Facebook can be an easy way to raise money, but it can take up to four to six weeks before the contributions are sent to the SP-Foundation. Facebook no longer shares donors' names and contact information so we cannot celebrate the success of the fundraiser or thank those that make contributions to the SP-Foundation. Facebook is now charging a transaction fee, so money is lost. PayPal is another option to make contributions to SPF. Unfortunately, it can take a month or longer to get donations to SPF. The best and most efficient way to contribute to the Spastic Paraplegia Foundation is to contribute online using the following link. <https://sp-foundation.networkforgood.com/projects/22291-spastic-paraplegia-foundation>

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O'Fallon, MO 63368-6202

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