

SPF SPASTIC
PARAPLEGIA
FOUNDATION, INC.

RESEARCH | EDUCATION | SUPPORT
HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS

#HSPandPLS
SP-FOUNDATION.ORG



Cowboy Up!

Volunteer &
Find Your Song

#HSPandPLS
SP-Foundation.org

20th Anniversary

Spastic Paraplegia Foundation

#HSPandPLS

19th Annual Conference

SPF VISION

The day when all individuals with HSP and PLS are diagnosed, treated, and cured.

JULY 22-24, 2022

#HSPandPLS

NASHVILLE TENNESSEE

SP-Foundation.org

information@SP-Foundation.org

1-877-773-4483

Welcome from the President

Welcome to Nashville!

...and the Executive Director

FINALLY WE ARE HERE... at the 19th Annual Conference celebrating the 20th Anniversary of SPF. On behalf of the Spastic Paraplegia Foundation board of directors, Norma and I want to extend to you a very hearty welcome to the 2022 SPF Annual Conference. The challenges of the past two years have made our in-person conferences impossible. We had excellent virtual conference webinars with the participation and assistance of many of our research partners, physicians and members. We did, however, miss seeing you in-person and getting the opportunity to meet, know, and fellowship with others who live and care for those with HSP and PLS. We so much look forward to seeing friends we've known for a long time, while getting to know new friends we are meeting for the first time, in-person!

The conference is designed to accomplish a number of goals. We will hear from our doctors and scientists about cutting-edge research for HSP and PLS. We want to motivate you to meet and get to know others with whom we share life's daily challenges. We want to search and find everyone with HSP and PLS in the world. Lastly, the SPF board of directors wants to share the foundation's goals, organization and activities to inspire your involvement in this all-volunteer organization whose vision is *"The day when all individuals with HSP or PLS are diagnosed, treated, and cured."*



We need you. You need us. We all need each other as we live and work together in being victorious in the challenge before us. Please attend and participate in every session, and future meeting, when possible. Your participation and input is important to the success of this conference, our foundation, and our future!

Celebrating themes of Nashville, Tennessee as we focus on celebrating 20-years with SPF. Nashville is **"Cowboy Up"**, **"Volunteer"**, & where better to **"Find Your Song"**. Starting with **"Find Your Song"**. Nashville is the capital of country music. Nashville is Music City where it's encompassing all music genres. Music isn't just part of the culture; it IS the culture. The humble center of all this activity is the thing that makes everything possible – the song. Writers often ask, "How do I get my songs to the right people? How can I get heard?" Comparably at the heart of SPF, we lift our voices often to ask, "When will researchers Find the Cure?" "When can this nightmare be over?" Like making a great song or finding a cure, how does it happen? The simple answer is a lot of hard work, planning, and reaching for your goals.

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

Lastly, but mentioned first, **"Cowboy Up"**: It's not just a phrase, it's a lifestyle. Country music, cowboy boots and cowboy hats are a part of the country Americana culture. Most cowboy hats are worn by tourists, and cowboy boots can be hot and uncomfortable wearing them all day. Like us with HSP and PLS, **"Cowboy Up"**–or **"Cowgirl Up"** means you must get tough, make a determined effort to face and overcome whatever obstacle or difficult situation with a great deal of "grit and grace" every day, every way, and everywhere.

Welcome again! Please feel free to let us know any way we can be helpful to you. Thank you for your attendance and participation in this vitally important work!

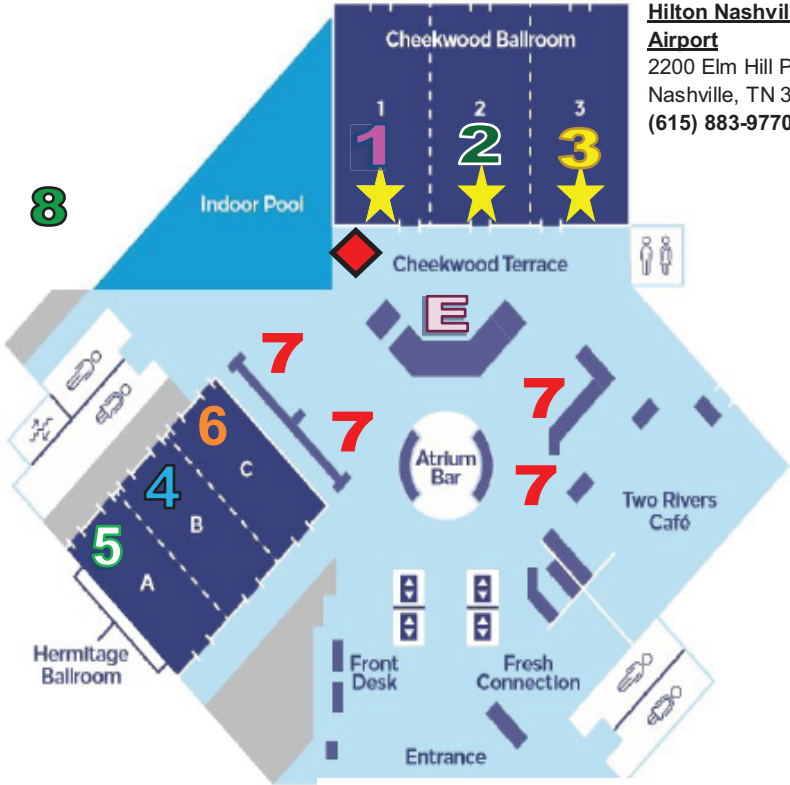
Warm Regards,

Greg and Norma Pruitt



Special Thanks to Hilton

**Hilton Nashville
Airport**
2200 Elm Hill Pike
Nashville, TN 37214
(615) 883-9770



- Info/Registration Desk/SPF STORE
- General Sessions/Meals
- Exhibitors

Breakout Sessions (States / Youth / Gender)

- Central States—Cheekwood 1
 - Southeast —Cheekwood 2
 - West—Cheekwood 3
 - Northeast —Hermitage B
 - Breakout Youth —Hermitage A
-
- Breakout Women Only Cheekwood 1
 - Breakout Men Only—Cheekwood 2
 - Breakout Caregivers —Cheekwood 3

- Orientation/New Members — Hermitage C
- Social Mingle/Atrium Bar
- Rolling Video Gaming in Parking Lot (Kids Only)



To strengthen the muscles of your heart, the best exercise is lifting someone else's spirit whenever you can.

Thursday

July 21, 2022

9:00am—4:00pm SPF Board of Directors Meeting

5:00pm – 7:00pm REGISTRATION/INFORMATION DESK OPEN

5:00pm – 7:00pm New Member Orientation Video Room is Open in Hermitage Ballroom C

FRIDAY

July 22, 2022 Patient Focus Day

7:00am—8:00am Lite Breakfast (Grab and Go, provided)

7:00am—5:30pm REGISTRATION/INFORMATION DESK OPEN

7:30am—12:15pm New Member Orientation Video Room Open in Hermitage Ballroom C

8:30—9:30am Breakout States by Region Ice See Breaker Questionnaire

Central states in Cheekwood 1 (Moderator: Greg Pruitt)
(IA-IL-IN-KS-KY-MI-MO-NE-WI)

Southeast states in Cheekwood 2 (Moderator: Jim Sheorn)
(AL-AR-FL-GA-LA-MS-NC-SC-TN)

West states in Cheekwood 3 (Moderator: Frank Davis)
(AZ-CA-CO-TX-WA)

Northeast states in Hermitage B (Moderator: Tim Croghan)
(MA-NJ-NY-OH-PA-VA-WV)

Youth in Hermitage Ballroom A (Moderators: Lauren Braastad, Marci Rudolph)

9:30am—9:45am Move to the next Break out session

9:45am—11:15am Breakout by Gender, Caregivers, & Youth, See Breakout Rooms

Women-only in Cheekwood 1 (Moderator: Tina Croghan/Dina Landphair)

Men-only Cheekwood 2 (Moderator: Jim Sheorn)

Caregivers Cheekwood 3 (Moderator: Melissa Sheorn)

Youth Hermitage A (Moderators: Lauren Braastad, Marci Rudolph)

11:15am Take Break Before Lunch, Allow the Hotel to Make a Room Change / Visit SPF Store Exhibitors, Visit New Member Orientation Video Room Open in Hermitage Ballroom C

12:15pm Lunch Served, (served plated, provided)

Welcome / Introductions / Happy Anniversary to SPF

SPF President Greg Pruitt

— Marketing Committee Chair & Emcee Tim Croghan

— Fundraising Committee Chair Jim Sheorn

— SPF Scientific Research Grant Committee Chair Mark Weber

— Education-Ambassadors Committee Chair Dina Landphair

— Ambassador Recognition

1:30pm-2:00pm Take Break After Lunch to Allow the Hotel to Make a Room Change

2:00pm—3:00pm Chelsea Burton, PA-C, Symptomatic Management of Spasticity

3:00pm -4:00pm Movement Matters, Angie & Jeremy McCord

4:00pm— Friday Wrap Up, Tim Croghan, Emcee

5:30pm —Registration/Information Table Closes

Social Mingle Gather on-your-own with Friends, or your SPG gene group in the hotel Atrium Bar. The Atrium Bar serves American and Southern cuisine, and the Fresh Connection is our casual spot for daily-made snacks and to-go bites, or the 24-hour snack shop in the lobby. Or head out for an evening in Nashville sightseeing or dinner in the iconic downtown area.

Breakout States By Region

<u>Central</u> gather in Cheekwood 1	<u>Southeast</u> gather in Cheekwood 2	<u>West</u> gather in Cheekwood 3	<u>Northeast</u> gather in Hermitage B	<u>Youth</u> gather in Hermitage A
IA	AL	AZ	Canada	A
IL	AR	CA	MA	
IN	FL	CO	NJ	
KS	GA	TX	NY	
KY	LA	WA	OH	
MI	MS	-40	PA	
MO	NC		VA	
NE	SC		WV	
TN	TN		-45	
WI	-57			



Icebreaker Tips and Questions

Keep it Simple—Have Fun— Express Yourself

- (1) In which state do you currently live?
- (2) Do you have HSP or PLS? If you have HSP what is your SPG gene, if known?
- (3) Do any other siblings or family members have HSP or PLS? Y/N, how many?
- (4) What age were you when you thought you had or was officially diagnosed?
- (5) Do you have children? Y/N, how many?
- (6) Do any of your children show signs of spastic paraplegia?











We're Glad You're Here!

Ribbon Colors

Find like Ribbon Colors for those with PLS or your specific SPG number from 3A to 58 to Unknown

-  PLS (Canary) - 4
-  SPG 3A (dk Brown) 2
-  SPG 4 (Hot Green) —26
-  SPG 5A (Ocean Blue) — 1
-  SPG 7 (Hot Pink) —18
-  SPG 11 (Ice Mint) —3
-  SPG 15 (lite Pink) — 4
-  SPG 31 (Sky Blue) -1
-  SPG 33 (Vegas Gold/Tan)- 1
-  SPG 49 (Kelly Green) —1
-  SPG 54 (Caramel)—1
-  SPG 58 (Maroon) —1
-  SPF Unknown (Lavender)—35

-  Ambassadors (Teal)
-  Board Members (Black)
-  Exhibitors (Orange)
-  Committee Chairs (Goldenrod)
-  President, Past President (White)
-  Speakers (Red)
-  Sponsors (Royal Blue)
-  Staff (Red White Blue)





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 the 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.

SATURDAY

Cheekwood Ballroom 1-2-3

July 23, 2022
Scientific Focus Day

7:00am — 8:00am Lite Breakfast (provided)

7:00am — 5:15pm REGISTRATION/INFORMATION DESK OPENS

7:30am — 4:00pm New Member Orientation Video Room Open, Hermitage C.

8:00am Welcome Back, Tim Croghan, Emcee

8:15am — 9:15am Keynote Speaker Dr Darius Ebrahimi Fakhari
Childhood-onset Hereditary Spastic Paraplegia:
Lessons learned from a translational approach to ultra-rare diseases

9:15am — 10:15am Dr. P. Hande Ozdinler, PhD.
Building Effective & Long-Term Treatments for UMN diseases: Time is Now

10:15am — 11:15am Dr. Hiroshi Mitsumoto, MD, DSc
PLS Natural History Study

11:15AM Take Break Before Lunch, Allow the Hotel to Make a Room Change /
Visit SPF Store, Exhibitors, and the Orientation New Members Video Room

12:30pm — 1:30pm Lite-Lunch Served (served plated, provided)

1:30pm—2:00pm Take Break After Lunch, Visit SPF Store, Exhibitors, and the New
Members Orientation Video Room / Door Prize Ticket Sales End

2:00pm — 3:00pm Dr. Peter Baas, PhD.
Mechanistic Route to Therapy for SPG4 Hereditary Spastic Paraplegia

3:00pm — 4:00pm Dr. John Fink, M.D., SPF Medical Advisor

4:00pm — 5:00pm Q&A Panel Discussion with Doctors

5:00pm — 5:15pm Saturday Wrap Up, Tim Croghan, Emcee
Please Clear the Room to Allow Hotel to Set Dinner

5:15pm REGISTRATION/INFORMATION DESK CLOSES

6:30pm — 8:00pm

Dinner (served plated, provided) / Special Presentations
Drawings, Door Prizes & Auction— Must be present to win!

8:00pm—Evening

Social Mingle Gather on-your-own with Friends, or your SPG gene group in the hotel Atrium Bar. The Atrium Bar serves American and Southern cuisine, and the Fresh Connection is our casual spot for daily-made snacks and to-go bites, or the 24-hour snack shop in the lobby. Or head out for an evening in Nashville sightseeing or dinner in the iconic downtown area.

Youth Itinerary

FRIDAY
July 22, 2022

Hermitage Ballroom A

8:30am— 11:15am Welcome / Introductions / Youth Ice Breaker
(Moderators: Lauren Braastad, Marci Rudolph)

11:15am Youth Returns to Families in Cheekwood Ballrooms

Icebreaker Tips and Questions

Keep it Simple—Have Fun— Express Yourself

- (1) Name, Age
- (2) In which state do you currently live?
- (3) What do you do for a living ? School, what grade; college, what degree?
- (4) How many siblings do you have?
- (5) Do you have HSP or PLS? If you have HSP what is your SPG gene if known?
- (6) Do any other siblings or family members have HSP or PLS? Y/N, how many?
- (7) What age were you when you thought you had or was official diagnosed?
- (8) Do you play sports or any music instruments?

SATURDAY
July 23, 2022

10:00am— 11:00am Youth Movement Matters in Hermitage A with
Angie & Jeremy McCord (Moderator: Lauren Braastad)

1:15pm — 3:30pm Youth Meet in Hermitage A to Walk Together to Activity
Nashville Mobile Video Game Theater in hotel parking lot
See #8 Location on Map
(Moderator: Lauren Braastad, Candise Pruitt)
(Security Team: Jimmy Reed & Trey Rudolph)

3:30pm—4:00pm Break in Hermitage A

4:00pm—5:00pm Youth Activity in Hermitage A
Science Guy Show and Workshop with Mr. Bond
(Moderator: Lauren Braastad)

5:15pm Youth Return to Families in Cheekwood Ballrooms

SUNDAY
July 24, 2022

No Scheduled Activities for Youth on Sunday.
Youth are welcome to enjoy Pastries and Coffee with Dr John Fink.

SUNDAY

July 24, 2022

7:30am – 10:30am REGISTRATION INFORMATION DESK OPEN

No Separate Scheduled Activities for Children on Sunday.
Children are welcome to attend Adult Program on Sunday.

7:30am Pastries and Coffee (provided) Cheekwood 1-2-3

8:00am — 10:15am Dr John K. Fink, Post Discussion Cheekwood 1-2-3

Quick Break to Pull Air Walls

10:45am — 11:45am SPF Committees

Join a Committee to Participate and Volunteer in the Work of the Foundation
Education/Ambassadors - Dina Landphair, Chair; Cheekwood Ballroom 1
Marketing – Tim Croghan, Chair; Cheekwood Ballroom 2
Fundraising – Jim Sheorn, Chair; Cheekwood Ballroom 3

12:00pm Adjourn—Registration Information Desk Closed

See You in STL 2023
Details at SP-Foundation.org



Donate At [SP-Foundation.org](https://www.sp-foundation.org)



Target
not the store but the
SPF Fundraising Goal for 2022
\$1,500,000

IF THE
Plan
DOESN'T
WORK
change the
PLAN
NOT THE
goal

Spastic Paraplegia Foundation

#HSPandPLS — SP-Foundation.org

SPF ORGANIZATION:

The Spastic Paraplegia Foundation Inc. (SPF) is a 501(c)3 national, not-for-profit, voluntary organization. It is the only organization in the USA Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).

SPF MISSION:

The SPF is committed to providing information about these disorders, creating opportunities for mutual support and sharing and discovering the cures for HSP and PLS. The SPF is a non-profit 501(c)3. Tax ID # 04-3594491 Combined Federal Campaign CFC #12554

SPF VISION:

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

SPF BOARD OF DIRECTORS:

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

Corey Braastad, PhD
John Cobb
Tina Croghan
Dina Landphair
Jim Sheorn
Carina Thurgood
Jackie Wellman

SPF MEDICAL ADVISOR: John K. Fink, M.D., University of Michigan

EXECUTIVE DIRECTOR:

Norma Pruitt Call: (877) 773-4483; Email: Information@sp-foundation.org;
Website: SP-Foundation.org

SEND CHECK DONATIONS TO:

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

SEND ONLINE DONATIONS TO:

[HTTPS://SP-FOUNDATION.NETWORKFORGOOD.COM/
PROJECTS/22291-SPASTIC-PARAPLEGIA-FOUNDATION](https://sp-foundation.networkforgood.com/projects/22291-spastic-paraplegia-foundation)

SCAN THE QR-CODE



SYNAPSE NEWSLETTER

Published quarterly; Contact: synapsenewsletter.spf@gmail.com Pamela Jordan-Handley, Editor; Therese Williams, Associate Editor; Donna Hinshaw, Designer; Katie Robins, Large Print Edition Production

SPASTIC WORLD Electronic Newsletter “*Connecting Spasticity Worldwide*”

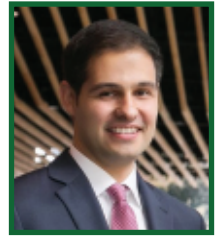
Contact: SpasticWorldInfo@gmail.com; Hank Chiuppi and Norma Pruitt

SPF TALKS SPF’s newest outreach effort talking about subject matters of interest to people with HSP or PLS. IDEAS & REQUEST ZOOM LINK EMAIL: Information@SP-Foundation.org

Doctors, Researchers, Special Guests

Keynote Speaker

Darius Ebrahimi-Fakhari, MD, PhD. | 617-355-8356
Movement Disorders Program
Department of Neurology, Boston Children's Hospital,
Harvard Medical School
300 Longwood Avenue, Fegan 11, Boston, MA 02115, USA
Laboratory: The F.M. Kirby Neurobiology Center
3 Blackfan Circle, CLSB 14060, Boston, MA 02115, USA
darius.ebrahimi-fakhari@childrens.harvard.edu



Darius Ebrahimi-Fakhari, MD, PhD, Department of Neurology, Boston Children's Hospital. Dr. Ebrahimi-Fakhari is a pediatric neurologist and neuroscientist at Boston Children's Hospital and Harvard Medical School. He leads the Movement Disorders Program at Boston Children's Hospital. His research interests cover childhood-onset neurogenetic and neurodegenerative diseases. His team is building a translational research program that aims to discover novel therapies for childhood-onset forms of hereditary spastic paraplegia and disorders related to the autophagy pathway. Current work covers two main areas: 1) Clinical trial readiness, and 2) the development of molecular therapies. Research projects in lab and clinic span gene discovery, natural history studies, disease modeling in iPSC-derived neurons and zebrafish, and high-throughput small molecule and functional genomics screens.

Peter W. Baas, PhD. | 215- 991-8298,
Professor, Department of Neurobiology and Anatomy
Director, Graduate Program in Neuroscience
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Neurobiology-Anatomy/Research/Baas-Lab/](http://drexel.edu/medicine/About/Departments/Neurobiology-Anatomy/Research/Baas-Lab/)



Peter Baas, Ph.D., Professor of Neurobiology and Anatomy at Drexel University College of Medicine, where he is also Director of the Graduate Program in Neuroscience and Director of the T32/NIH-funded Training Program in Spinal Cord Injury. Dr. Baas has studied *SPG4-HSP* for the past 15 years and has focused mainly on the underlying mechanisms of the disease. He has developed the first animal (mouse) model for the disease that includes both loss-of-function and gain-of-function components. With mechanistic insights and mouse models established, he is now primarily focused on developing novel therapies for prevention and treatment of the degenerative symptoms of *SPG4-HSP* in human patients.

John K. Fink, M.D. | Clinic 734-936-9020
Professor, Department of Neurology
University of Michigan
NCAC-Neurology | 2901 Hubbard Drive, Suite 2723 |
Ann Arbor, MI 48109-2435 | jkfink@med.umich.edu

John K. Fink, M.D., is a Professor in the University of Michigan Department of Neurology. Dr. Fink received his M.D. from the Medical College of Ohio in Toledo and completed Neurology Residency at the University of Virginia and postdoctoral fellowships in Developmental and Metabolic Neurology and Medical Genetics at the National Institutes of Health. Dr. Fink investigates inherited and degenerative neurologic disorders, particularly hereditary spastic paraplegia and primary lateral sclerosis, and provides care and evaluation for individuals with these conditions. Dr. Fink serves as the Medical Advisor to the Spastic Paraplegia Foundation.



Doctors, Researchers, Special Guests

Hiroshi Mitsumoto, MD, DSc | 212-305-2940 or 212-305-1319
Wesley J. Howe Professor of Neurology (at CUIMC)
Eleanor and Lou Gehrig ALS Center, CUIMC
hm264@cumc.columbia.edu



Hiroshi Mitsumoto, MD, DSc is a Wesley J. Howe Professor of Neurology at Columbia University Medical Center and the Director of the MDA/ALS Clinical Research Center since 1999. In 1968, he graduated from Toho University School of Medicine, Tokyo. Beginning in 1972, he pursued further medical and neurology training at Johns Hopkins University, Case Western Reserve University, Cleveland Clinic, and Tufts University. In 1983, he began working at the Cleveland Clinic as the Director of the Neuromuscular Section and ALS Center. He has since been involved with extensive research in ALS, including improving patient care/management and end of life issues, multiple clinical trials, biomarker development, and multisite epidemiological studies. He organized several large national and international ALS Conferences and is currently updating and developing the new International ALS Clinical Trial Guidelines. He has published more than 170 articles in peer-reviewed journals, mostly in ALS, in addition to reviews, chapters, and books. For more than a decade, his research interests have expanded to PLS.

P. Hande Ozdinler, PhD. | (312) 503 2774
Associate Professor, Department of Neurology
Northwestern University, Feinberg School of Medicine
Faculty, Chemistry of Life Processes Institute
Faculty, Les Turner ALS Center
Faculty, Cognitive Neurology and Alzheimer's Disease Center
Faculty, Robert H. Lurie Comprehensive Cancer Research Center
303 E. Chicago Ave, Chicago, IL, 60611



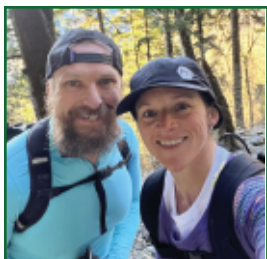
Pembe Hande Ozdinler, Ph.D., is an Associate Professor of Neurology at the Department of Neurology, Northwestern University, Feinberg School of Medicine, directing a research lab that focuses on understanding the biology of upper motor neurons. She received training in the fields of molecular biology, genetics, chemical engineering, biotechnology, cell biology, anatomy, neuroscience and neurosurgery. Her lab has generated and characterized numerous models that display upper motor neuron loss, and she is currently revealing the molecular mechanisms responsible for their vulnerability and progressive degeneration. Prior to joining Northwestern University, she was an Instructor at the Neurosurgery Department of Massachusetts General Hospital-Harvard Medical School. She is the recipient of Harvard Center for NeuroDiscovery Award for her ability to label, purify and study corticospinal motor neurons.

Chelsea Burton, PA-C | 734-936-7175
Physical Medicine & Rehabilitation Clinic | Burlington Building
325 E Eisenhower Pkwy Ste 100, Ann Arbor, MI 48108

Chelsea Burton MMS, PA-C, is a member of the Physical Medicine and Rehabilitation Spinal Cord Injury team at Michigan Medicine. Her medical practice focuses on treatment of spasticity, including managing the program's large intrathecal baclofen pump program. Additionally, she provides comprehensive training to medical students, residents and fellows on spasticity management through lecture, simulation and hands-on training.



Special Guests



JEREMY & ANGIE McCORD are co-owners of CrossFit since 2011. They have extensive training under well-known Team USA weightlifters and National Weightlifting Champions. Jeremy has achieved levels with USAW Nationally Qualified Weightlifter, CrossFit Level 2 Certified, USAW Weightlifting Certified, CrossFit Olympic Weightlifting Certified, CrossFit Kids Certified, CrossFit Movement & Mobility Certified, and Cross-Fit Gymnastics Certified. Angie has achieved levels CrossFit Level 2 Certified, World Ranked Master's Olympic Weightlifting Athlete, 2x CrossFit Age Group Quarterfinal Athlete, CrossFit Kids Certified, and Precision Nutrition Level 1 Certified.



Angie's favorite thing about being a coach is watching people accomplish things they didn't believe they could. "CrossFit is for everyone! Be prepared to try new things, push harder than you ever have, and be stronger and fitter than ever before!"

Let's give them a Shout-Out on Social Media! Crossfit of Murray, 1184 Poor Farm Road. Murray, KY 42071, ky.crossfitmurray@gmail.com, <http://crossfitmurray.com/>

Youth Itinerary



Rolling Video Games is a family owned and operated business located in Nashville, Tennessee. Our 32-foot mobile video gaming theater is available for parties, events, fundraisers, schools, corporate team building, festivals or anytime you want to get a group together to have a great time - We bring the mobile video gaming to you! We take your event experience to the next level with four widescreen HD-TVs, customized stadium seating, surround sound, and built-in vibration motors that are synched with on-screen action. Everything is linked so that 32 players can all play the same game - or against each other! Some of the consoles we have are Xbox One & Wii U, including all the latest games!

Let's give them a Shout-Out on Social Media! Owners James & Michelle Bacon | 629-777-9733 RVGNashville@gmail.com, <https://www.rvgnashville.com/>

Youth Itinerary



Mr. Bond's Science Guys' Mobile Science Lab is a great way to make science fun, cool and easy. Educational ways we can inspire with fun hands-on science experiments for kids and adults. Mr. Bond's Science Guys create wonderful demonstrations with science experiments that include explosions, dramatic chemical reactions and "shocking" special effects.

Let's give them a Shout-Out on Social Media! Owner Keith Trehy | 615.573.2702, makesciencefun@mrbondscienceguy.com, mrbondscienceguy.com

SPF Speakers



**Greg Pruitt | Pruitt@SP-Foundation.org
SPF President**

Greg was elected SPF President in January 2022. He served as volunteer SPF Co-Executive Director since the Fall of 2017. Greg is an attorney who served as Judge Executive for 26 years. In that capacity he served on and chaired a number of local, regional, state, federal, and multi-state organizations involving many areas such as tourism, health and social services, transportation, and economic development. Greg is a graduate of University of Kentucky College of Law. Greg and Norma have three children and five grandchildren. Greg and some in his family have HSP, SPG4



**Conference Emcee
Tim Croghan
Chair, SPF Marketing Committee**

Tim is dedicated in supporting the Spastic Paraplegia Foundation. Along with his wife, Tina (an SPF Board Member), they focus attention in advocating and raising funds to advance research efforts to find a cure for HSP and PLS since 2007. Tim serves as Chair of the SPF Marketing Committee and continues using his communication skills in assisting the SPF Annual Conferences.



**Dina Landphair | Dina.Landphair@sp-foundation.org
Chair, SPF Education and Ambassador Committee**

Dina joined the board in March 2021. Dina graduated from Iowa State University with a Bachelor of Architecture. She became a licensed Architect in 2002 and took early retirement after 25 years. Dina lives in Adel, Iowa with her husband and two boys. She was diagnosed with HSP in 2013. Dina is Co-Ambassador of Iowa and chairs the SPF Education Committee.



**Jim Sheorn | Jim.Sheorn@SP-Foundation.org
Chair, SPF Fundraising Committee**

Jim was a pharmaceutical sales representative for Daiichi Sankyo. He holds a bachelor's of science degree in marketing from the University of Tennessee at Chattanooga. Jim has HSP, SPG4 and lives with his family in Brentwood, Tennessee.



**Mark Weber, Esq. | Mark.Weber@sp-foundation.org
Chair, SPF Scientific Research Grant Committee**

Mark is one of the co-founders of the SPF and was its first president. Mark serves as the SPF's legal counsel and Chairs the SPF Research Grant Committee. Mark is an attorney and served for eleven years as a prosecutor in Massachusetts. He is currently in private practice in Connecticut concentrating in child abuse and neglect cases. Mark has been diagnosed with HSP. He lives with his wife, Andrea, in Sherman, Connecticut, and has a son in college.

SP Foundation'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!



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Raffle/Auction

Big Thank you to "Your Medical Store" for donating door prizes. Winner will receive these in the mail directly from "Your Medical Store". Please view <https://www.your-medical-store.com/> for more products.



Raffle Items: Get a raffle ticket for a chance to win one of the following door prizes for items #1 through #8. Drawing on Saturday after dinner.



#1
3 WHEEL
ROLLATOR
EURO NITRO
STYLE - ULTRA
LIGHTWEIGHT
VALUED AT \$207



#2
STRONGARM
COMFORT
CANE
REVOLUTIONARY
DESIGN,
VALUED AT \$80



#3
COMPLETE
TENS SYSTEM,
VALUED AT \$84



#4
NOURISH
MEMORY FOAM
ELEVATED
KNEE REST
BY AVANA
COMFORT,
VALUED AT \$84



#5
MULTI-
COLORED
BABY ALPACA
LUXURY
QUEEN
BLANKET,
VALUED AT \$129



#6
STEP2TUB
ADJUSTABLE
BATHTUB
SAFETY STEP
STOOL, VALUED
AT \$209



#7
ROHO MOSAIC
PREMIUM AIR CELL
WHEELCHAIR
CUSHION, VALUED
AT \$114



#8
STAND ALONE
TOILET RAIL
SAFETY
FRAME,
VALUED AT \$74



Auction Items:
The following two items will be offered by auction-call on Saturday after dinner.



#9
LEG
COMPRESSION
SYSTEM FOR
MASSAGE
THERAPY BY
VIVE HEALTH,
VALUED AT \$499



#10
THE PILOT
UPRIGHT
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WALKER
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VALUED AT \$239

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countrymusicshalloffame.org/



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(615) 244-3263 | www.musiciansshalloffame.com/



NATIONAL MUSEUM OF AFRICAN AMERICAN MUSIC

National Museum of African American Music
510 Broadway Nashville, TN 37203
(615) 301-8724 | nmaam.org



Tennessee State Library and Archives
1001 Rep. John Lewis Way N, Nashville,
TN 37219 | 615-741-2764 | free: sos.tn.gov/tsla



Tennessee Sports Hall of Fame
501 Broadway, Nashville, TN 37203
(615) 418-9595 | TSHF.net |
\$3 Adults/\$2 kids



Tennessee State Museum 1000 Rosa L Parks Blvd,
Nashville, TN 37208 | (615) 741-2692 | free
tnmuseum.org



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www.trolleytours.com/nashville/night-tour-music-city

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SPF AWARENESS MONTH: August
WEEK: August 20-28
DAY: August 27th



2022 UPCOMING EVENTS
 #CureHSPandPLS #HSPandPLS
 SP-Foundation.org



2022 SPF Talks
 Upcoming Meetings, Webinars, Zoom Talks Hosted by SPF
 Featuring Speakers/Members of the SPF Community
 Information presented on SPF Talks is not intended or implied to be a substitute for professional medical advice, diagnosis or treatment.



Visit the New Member Orientation Video Room in Hermitage Ballroom C. You may be a first-timer to the SPF Conference or perhaps new to HSP or PLS, or just learning about spasticity. Please

take a few minutes to watch our informative video presentation. Feel free to stop in, stay a minute, leave and return as the video loop will play continually throughout the weekend to help familiarize you with SPF, HSP and PLS.

SPF-Store

SP-Foundation.org/SPF-Store

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& Meaning
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wisely
YOU ONLY GET
SO MANY DAYS
Make them Count
FOR THE GOOD
OF THOSE IN
Your
Path



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- 1) Donate \$10.00 to receive your choice of Shirt
- 2) Donate \$2.00 for one rubber bracelet / \$5 for 3 / \$10 for 6 bracelets
- 3) Donate to 50/50 Raffle, 50% Goes to SPF & 50% Goes to 1-Lucky Winner (\$1.00 per ticket / \$5.00 for 6-tickets)
- 4) Donate to participate in Door Prizes (from Your Medical Store and others) (\$5 per ticket / \$10 for 3-tickets)

- Winners and Door Prizes will be announced Saturday after Dinner, July 23, 2022.
- Winner Must Be Present to Win!
- All credit card charges include a processing fee
- Colors and styles may vary while supplies last
- All donations benefit the Spastic Paraplegia Foundation, Inc.

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