SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

#HSPandPLS

HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS

sp-foundation.org

CHAMPION CURES

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22ND ANNUAL CONFERENCE | October 22-24, 2025

HOLIDAY INN WASHINGTON CAPITOL-NTL MALL
550 C STREET S.W. WASHINGTON, DC 20024
202-479-4000

1.877.773.4483
INFORMATION@SP-FOUNDATION.ORG

SPASTIC PARAPLEGIA FOUNDATION, INC

PRESIDENT'S WELCOME

...and a Hello from the Executive Director

Welcome SPF Champions to Washington, DC!

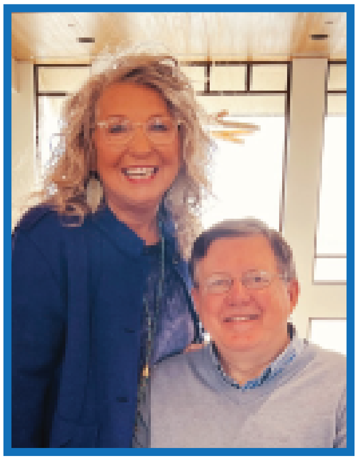
On behalf of the SPF Board of Directors, we welcome everyone to the 2025 SPF Annual Conference. We look forward to visiting with every member attending this event. We want all of us to get to know one another just a little better, sharing our life challenges, as well as our strong commitment to working together finding treatments and cures for both Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

Champion Cures, Cooperation, and Collaboration is our theme for this year's Annual Conference. You have been an important part in creating momentum in fundraising and bringing attention to the desperately needed interventions and therapies to make our lives better. Because of your work, generosity, and partnership, we were able to form a collaboration with a group of doctors and researchers to create a pilot program — the Spastic Paraplegia Centers of Excellence Research Network at the 2023 Annual Conference in St. Louis. We believe this network is the momentum toward accelerating clinical trial readiness, supporting therapy development, and increasing access to high-quality healthcare.

At the Annual Conference held in Tampa in 2024, we heard from representatives from Critical Path Institute. With CPATH we have a new partnership building a consortium of research clinicians, pharma, government agencies and our patient community to cross barriers and move much more efficiently and quickly toward finding treatments to improve our lives. This conference is about empowering this coalition in this very important work and process.

Thank you again for joining us at the 2025 Annual Conference. Washington DC is a beautiful and historic place to collaborate and see many national landmarks. We need everyone working together in this mission. Enjoy visiting with old friends and be sure to meet new ones! Help us in welcoming everyone. We look forward to meeting all of you over the next few days. Please let us know if we can do anything to assist you in any way.

Wishing You Our Best Always,
Greg and Norma Pruitt



2025 ANNUAL CONFERENCE SPONSORS

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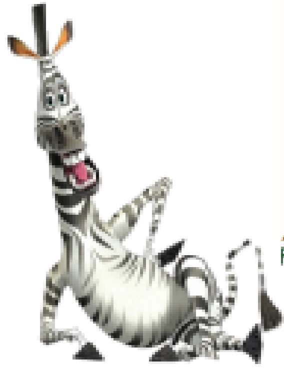

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WHIRLYBIRD

The Spastic Paraplegia Foundation extends its heartfelt thanks to the patients, families, and sponsors whose unwavering generosity, advocacy, and commitment fuel our mission. Your contributions—whether through time, donations, or personal stories—have been instrumental in advancing research, supporting community programs, and creating hope for those living with Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). Together, you help turn determination into discovery, and compassion into progress. We are deeply grateful for the trust you place in SPF and are honored to continue this journey with you. Thank you!

WEDNESDAY

9:00am SPF Board of Directors Meeting

2:00pm SP-CERN Kickoff Meeting

5:30pm-7:00pm Registration/Information Desk Open

THURSDAY

Enjoy breakfast on your own, See Hotel Food Options

7:30am - 5:30pm Registration/Information Desk Open

8:30am - WELCOME to WASHINGTON, DC., SPF WARRIORS | Capitol Ballrooms
SPF President Greg Pruitt Virtual Station Emcee & Tim Croghan In-Person Emcee

9:00am -9:45am Dr. Craig Blackstone, Mass General Brigham/Harvard Medical School

9:45am -10:30am Dr. Michelle Campbell, FDA Office of Neuroscience

10:30am -11:15am Overview of the SPF HSP/PLS Patient History Survey

11:15am -11:45am Javier Tuel | Tuel Shed Training |Inspiration, Motivation & Your Health

12:00pm Lunch (plated and served) in Congressional Ballrooms

1:30pm - 2:15pm Dr. Darius Ebrahimi-Fakhari |Boston Children's Hospital/Harvard
Medical School SP-CERN: Center of Excellence Research Network

2:15pm - 3:00pm Dr. Srikanth Ranganathan | NIH | NINDS, DHHS

3:00pm - 3:45pm Dr. Collin Hovinga |Critical Path Institute

3:45pm - 4:30pm Dr. Sheri Schully | NIH | All of Us Research

4:30pm - 5:00pm Members of Congress | Rare Disease Caucus

5:00pm Day 1 Wrap-Up & Reflections

5:30pm - REGISTRATION/INFORMATION DESK CLOSES

DINNER ON YOUR OWN & SOCIAL MINGLE: Gather on-your-own with Friends in the hotel restaurant. Or, head out for an evening in Washington, DC. Special Note: Everyone is welcome to gather after dinner, meeting old friends and making new ones.

Note Schedule is Subject to Change. Please See Registration/Info Table For Questions or Concerns.

Pause & Rest Up Tonight for Another Busy Day Tomorrow

Friday

FRIDAY

7:30am - 5:30pm	Registration/Information Desk Open
8:30am - 9:00am	Welcome Back - Tim Croghan
9:00am - 9:45am	Dr. Walter J. Koroshetz, Director, | NIH | NINDS
9:45am -10:30am	Dr. John Fink | University of Michigan
10:30am -11:15am	Dr. Peter W. Baas, Drexel University
11:15am -11:45am	Javier Tuel | Tuel Shed Training |Inspiration, Motivation & Your Health
12:00pm	Lunch (plated and served) in Congressional Ballrooms
1:15pm	Special Recognition and Quilt Auction | Capitol Ballrooms
1:30pm -2:15pm	Dr Hande Ozdinler | Northwestern University
2:15pm -3:00pm	Dr. Liang Oscar Qiang | Drexel University
3:00pm - 3:30pm	Dr. Richard Silverman |Northwestern University | AKAVA Therapeutics
3:30pm – 4:00pm	Dr. Richard Novak |Unravel Biosciences
4:00pm -4:30pm	Lindsay Perlman | Paralyzed Veterans of America
4:30pm -5:00pm	Members of Congress | Rare Disease Caucus
5:00pm	Closing Reflections & Call to Action
5:30pm	REGISTRATION/INFORMATION DESK CLOSES

DINNER ON YOUR OWN & SOCIAL MINGLE: Gather on-your-own with Friends n the hotel restaurant. Or, head out for an evening in Washington, DC. Special Note: Everyone is welcome to gather after dinner, meeting old friends and making new ones.

SPECIAL THANKS TO THE HOLIDAY INN & STAFF

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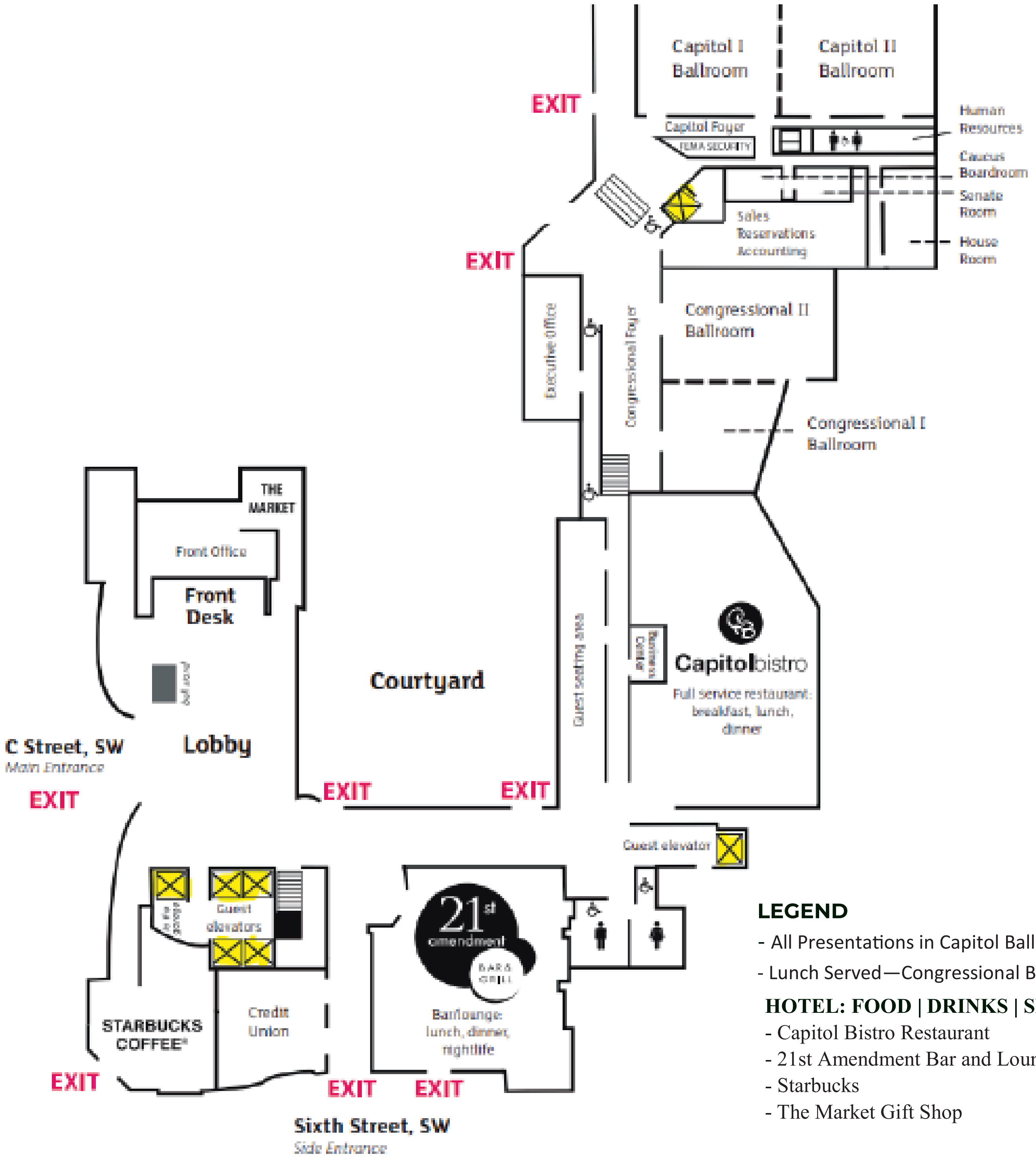
202-479-4000



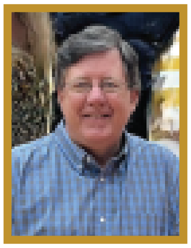
LEGEND

- All Presentations in Capitol Ballrooms I & II
- Lunch Served—Congressional Ballroom I & II

HOTEL: FOOD | DRINKS | SNACKS

- Capitol Bistro Restaurant
- 21st Amendment Bar and Lounge
- Starbucks
- The Market Gift Shop

SPF BOARD OF DIRECTORS & WORK OF THE FOUNDATION



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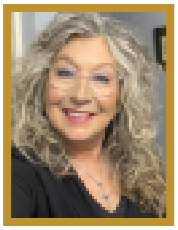
SPF Board Member

Sara Kramer
SPF Board Member



Norma Pruitt
Executive Director

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SPF Board Member

Dina Landphair
Co-Chair, SPF Education/
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SPF Board Member

Becki Cochran
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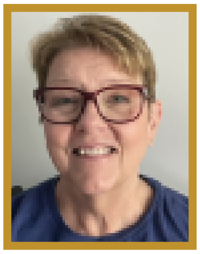
Vice President
Chair, SPF Fundraising
Former SPF President
SPF Board Member



Tina Croghan
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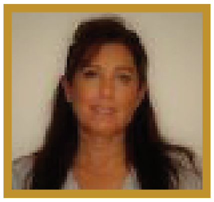
Advocacy
SPF Board Member



Carina Thurgood
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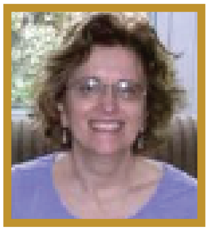
Frank Davis
President Emeritus
SPF Board Member



Jackie Wellman
Co-Chair, SPF Education/
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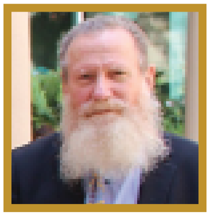
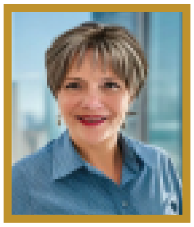
Lorri Steiner
SPF Treasurer, CPA



John K. Fink, M.D.
SPF Medical Advisor

Tim Croghan
Conference Emcee
Chair, SPF Marketing

Adam Futrell, ESQ
SPF Legal Counsel



Linda Arnold
Fundraising &
Relationship
Development Manager

Leonard Erskine
Co-Chair,
SPF Advocacy

LEGACY & PLANNED GIVING

Honoring a Lasting Legacy: $425,000 Planned Gift to Advance HSP/PLS Research

A BEACON OF HOPE

BARBARA (BARBI) ANN SEIPP SEIBERT

A devoted member of the SPF community whose foresight and generosity will accelerate the search for treatments and improve lives for generations to come.

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
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MAY 31, 1949- APRIL 29, 2024
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Legacy of Hope

Legacy Giving – Building a Future of Hope

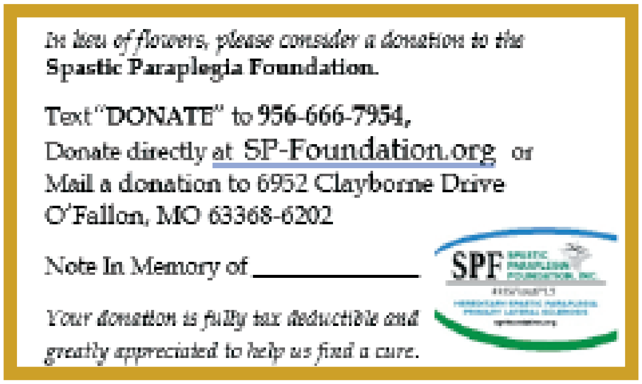
Leaving a gift to the Spastic Paraplegia Foundation (SPF) means joining our Legacy Circle, a community of visionaries who ensure progress in the fight against HSP and PLS continues far into the future. Planned giving is more than a financial contribution; it is a lasting expression of your values and commitment to advancing research, support, and education. SPF has become a trusted resource and strong voice for individuals, families, and children affected by HSP and PLS, and through legacy gifts, that impact will grow for generations to come. Whether through a bequest in your will, a trust, or another charitable planning tool, your gift secures a brighter tomorrow while also helping you achieve your own estate and financial goals. Together, we can ensure that the work of today builds the breakthroughs of tomorrow.

Through legacy giving, your impact doesn't end—it grows.

Memorial Giving

The Spastic Paraplegia Foundation invites you to honor the life of a loved one through our *Circle of Love Memorial Giving Fund*. This meaningful opportunity allows families to create a personalized tribute page that celebrates the legacy of someone special while advancing our shared mission to fund research for HSP and PLS.

Creating a memorial fundraiser through our Network for Good platform is simple, heartfelt, and impactful. We provide the tools, guidance, and resources to help you share your story and inspire others. Your support—whether in remembrance, gratitude, or hope, helps accelerate medical research and brings us closer to treatments and a cure.



In lieu of flowers, please consider a donation to the **Spastic Paraplegia Foundation.**

Text "DONATE" to 956-666-7954,
Donate directly at SP-Foundation.org or
Mail a donation to 6952 Clayborne Drive
O'Fallon, MO 63368-6202

Note In Memory of ______________

Your donation is fully tax deductible and greatly appreciated to help us find a cure.

Find this Donation Card on SP-Foundation.org
(877) 773-4483 | Information@SP-Foundation.org

MEMORIAL GIVING

bitly

Start by scanning the QR Code with your phone camera. We are here to assist you every step of the way.

Planned giving keeps hope alive—your legacy fuels research, support, and progress for generations to come.

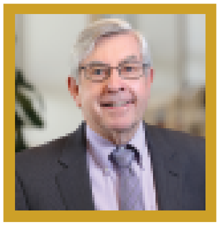
SPECIAL GUESTS

Michelle Campbell
U.S. Food & Drug Administration | fda.gov
National Institutes of Health

Michelle Campbell, is the Associate Director for Stakeholder Engagement and Clinical Outcomes in the Office of Neuroscience, Office of New Drugs (OND), Center for Drug Evaluation and Research (CDER), U.S. Food and Drug Administration (FDA). Previously, Dr. Campbell was the Senior Clinical Analyst, Center for Drugs Evaluation and Research (CDER), FDA. She also was the Senior Clinical Analyst for Stakeholder Engagement and Clinical Outcomes in the Office of Neuroscience, Office of New Drugs (OND) in FDA's Center for Drug Evaluation and Research. Dr. Campbell was a reviewer on the Clinical Outcome Assessments (COA) Staff and Scientific Coordinator of the COA Qualification Program in OND. Dr. Campbell's focus is on patient focused drug development and the use of patient experience data in the regulatory setting. Prior to joining FDA, Dr. Campbell spent more than 10 years conducting research in the academic clinical setting, including five years in a neurology and developmental medicine department. Dr. Campbell earned her BA in Biology from the College of Notre Dame, her MS in Health Science) from Towson University and her PhD in Pharmaceutical Health Services Research from the University of Maryland School of Pharmacy.

Collin Hovinga, PharmD, MS, FCCP,
Vice President of the Rare and Orphan Disease Programs
Critical Path Institute | c-path.org

Collin Hovinga oversees C-Path's Rare Disease Cures Accelerator-Data and Analytics Platform and the Critical Path for Rare Neurodegenerative Diseases public-private partnership. Dr. Hovinga completed his Bachelor of Science Degree in Biology and Doctor of Pharmacy degrees from Creighton University in Omaha, Nebraska. After which he pursued a Residency and Fellowship in Pediatric Pharmacotherapy with emphasis in Pediatric Neuroscience at the University of Tennessee, Memphis, LeBonheur Children's Medical Center. He has had a Fellowship at the Food and Drug Administration Office of Clinical Pharmacology and a Masters of Epidemiology from the University of Tennessee Health Science Center. Dr. Hovinga has been active in studying factors that influence the efficacy, safety, and the pharmacology of antiepileptic drugs in children, patient adherence to medications, and acute seizure management. Dr. Hovinga is recognized as an expert in neuropharmacology.



Walter J. Koroshetz, M.D.
Director of the National Institute of Neurological Disorders and Stroke
National Institutes of Health

Walter J. Koroshetz, M.D., serves as Director of the National Institute of Neurological Disorders and Stroke. He joined NINDS in 2007 as Deputy Director and has held leadership roles in a number of NIH and NINDS programs, including co-leading the NIH BRAIN Initiative, the NIH RECOVER Initiative in the study of Post Acute Sequelae of COVID-19, the NIH Blueprint for Neuroscience, the Traumatic Brain Injury Center collaboration between the NIH intramural and the Uniformed Health Services University, the NIH Helping to End Addiction Long-term® Initiative, or NIH HEAL Initiative®, and the Undiagnosed Diseases Network. He co-leads a number of the NIH Common Fund's programs including the Acute to Chronic Pain Transition programs, Somatic Gene Editing program, and the Accelerating Leading-edge Science in ALS (ALS2) initiative. Dr. Koroshetz was also instrumental in founding the NIH Office of Emergency Care Research.

Before joining NINDS, Dr. Koroshetz served as Vice Chair of the neurology service and Director of Stroke and Neurointensive Care Services at Massachusetts General Hospital (MGH). He was a professor of neurology at Harvard Medical School (HMS) and led neurology resident training at MGH from 1990 to 2007. Over that same period, he co-directed the HMS Neurobiology of Disease Course with Edward Kravitz, M.D., and Robert H Brown, M.D.

SPECIAL GUESTS

Richard Novak, PhD
Co-founder and CEO
Unravel Biosciences | Unravel.bio

Richard Novak, is a Termeer Fellow, bioengineer and entrepreneur dedicated to solving unanswerable questions through technology innovation. Prior to Unravel Bio, he was a Lead Engineer at the Wyss Institute for Biologically Inspired Engineering at Harvard University where he managed fast-paced programs in drug discovery, advanced disease models, human organ chips, and integrated automation and sensor systems. He has nearly 20 years of experience in technology and therapeutics development. He is a founder and president of the nonprofit Future Scientist and a founder and director of the sample collection automation company Rhinostics Inc.

Lindsey Perlman, MPH
Director, Research & Education
Paralyzed Veterans of America | pva.org

Lindsay Perlman is the Director of Research & Education at Paralyzed Veterans of America (PVA). PVA is a nonprofit Veteran Service Organization that is dedicated to helping Veterans with spinal cord injuries and disorders (SCI/D), and diseases like MS and ALS. The Research & Education team supports research grants in the SCI/D space, manages the development of SCI educational resources, and hosts one of the largest SCI/D, MS, and ALS educational conferences in the country.

Lindsay has been with PVA since 2019 and has a background in clinical research and global public health. She received her Master’s in Public Health from The George Washington University in 2016.

Srikanth Ranganathan, Ph.D.
Program Director
National Institute of Neurological Disorders and Stroke
National Institutes of Health

Srikanth Ranganathan is a Program Director in the Division of Neurodegeneration, Dementia, and Repeat Expansion Disorders (NDR) Cluster at the National Institute of Neurological Disorders and Stroke. He transitioned to NINDS from the Center for Scientific Review (CSR) where he served as an Scientific Review Officer (SRO) and Referral Officer at the Center for Scientific Review in NIH. In this role, Dr. Ranganathan managed the peer-review for the NIH Director's New Innovator Award (DP2) of the trans-NIH Common Fund high risk, high reward program before taking over the chartered study section of Musculoskeletal Tissue Engineering. In addition to the primary role as an SRO, he served as a Referral Officer for the Division of Receipt and Referral at CSR referring applications to the appropriate review branches. Dr. Ranganathan earned a Ph.D. in Cellular and Molecular Pathology (Neuropathology) from the University of Pittsburgh for investigating the molecular mechanisms of ALS and identifying mass spectrometry-based proteomic biomarkers, the latter resulting in an active patent as well as a biotech start-up. Following this, he completed a couple of post-doctoral fellowships, the first of which was in the Neurogenetics Branch of NINDS working on polyglutamine diseases (primarily mitochondrial dysfunction in SBMA) followed by a second fellowship on movement disorders (Huntington's and Parkinson's diseases) at the Wallenberg Neuroscience Center, Lund University, Sweden. After successful completion of the fellowships, Dr. Ranganathan served as a Chief Scientific Advisor and consultant in the biotech sector in Lund, Sweden before transitioning to CSR, NIH.

Dr. Ranganathan manages a portfolio of grants in basic mechanisms in neurodegeneration, including that of Spinal and Bulbar Muscular Atrophy (SBMA), Hereditary Spastic Paraplegia, Spinocerebellar Ataxias (SCAs), and Friedreich's Ataxia.

SPECIAL GUESTS

Sheri Schully, PhD
All of Us Research Program
Deputy Chief Medical and Scientific Officer
National Institutes of Health

Sheri Schully, Ph.D., is the deputy chief medical and scientific officer and the lead for ancillary studies in the All of Us Research Program at the National Institutes of Health (NIH). Through her leadership, she is establishing ancillary studies as a core and scalable capability of the program that will expand the cohort and deliver new phenotypic, lifestyle, environmental, and biological data to the All of Us Researcher Workbench. Dr. Schully has been involved with shaping the program and setting the scientific vision and strategy since its inception.

Before taking this role, Dr. Schully was a team lead and senior advisor for disease prevention in the Office of Disease Prevention (ODP). There she led the effort to systematically monitor NIH investments in prevention research and assess the progress of that research. She also served as the team lead for the Knowledge Integration Team, as well as a program officer in the Epidemiology and Genomics Research Program at the National Cancer Institute (NCI). She came to NIH as an NCI designated Presidential Management Fellow in 2005.

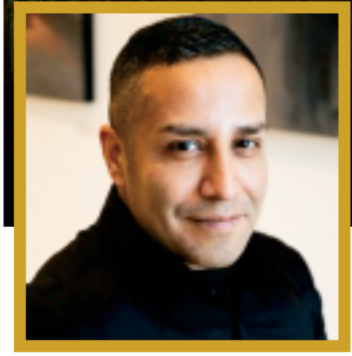
Dr. Schully's research interests include genomics, personalized medicine, and the integration of genetic and genomic information into clinical and public health practices. Her work has been published in numerous high-impact scientific journals. She earned both a PhD in biological sciences with a concentration in population genetics and a B.S. in zoology with a minor in chemistry from Louisiana State University.

Rick Silverman, PhD
Patrick G. Ryan/Aon Professor, Department of Chemistry, Department of Molecular Biosciences, Evanston, IL; Department of Pharmacology, Feinberg School of Medicine, Chicago IL
Northwestern University

Rick Silverman is a faculty member in the Department of Chemistry at Northwestern University, known for his research in organic chemistry and medicinal chemistry. His work can be summarized as investigations of the rational design, syntheses, and molecular mechanisms of action of potential medicinal agents. The primary focus is basic research into central nervous system disorders, including Amyotrophic Lateral Sclerosis, Alzheimer's disease, Parkinson's disease, Lewy body dementia, cerebral palsy, epilepsy, and neuropathic pain. Other therapeutic areas include cancer (melanoma and hepatocellular carcinoma). Numerous drugs are known to function as specific inhibitors of particular enzymes. For some enzyme targets, where potent reversible inhibitors are desired, computer modeling based on X-ray crystal structures initiates the research (high-throughput screening also may be used). For enzyme targets where inactivators are desired, mechanism-based inactivators are designed and synthesized, and inactivation and metabolism mechanisms investigated. The enzymes are isolated from overexpressed cells containing recombinant enzymes. Collaborations are developed in X-ray crystallography and preclinical studies. We have invented several drugs, one of which (Lyrica) is on the drug market, and three others have been or are in clinical trials.

SPECIAL GUESTS

Javier Tuel
Personal Trainer
Tuel Shed Training



Tuel Shed Training
12931 University Avenue Ste. 101
Clive, IA 50325
515-829-0068j tuel@tuelshedtraining.com

Javier is the owner and founder of Tuel Shed Training. He is a Certified Personal Trainer, Nutritionist & Senior Fitness Trainer with over twelve years of experience in the health and fitness industry. Javier's main goal is to help you BELIEVE in yourself and know you are worth reaching your goals. Along with personal training, Javier is a motivational speaker at corporate and private events, sharing his passion for health and fitness.

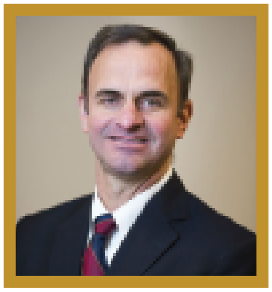
"My mission is to help transform bodies, boost their energy levels, and enhance overall performance in a fraction of the time normally spent in the gym. Flexibility, accountability, motivation and tangible results are the cornerstone of my approach. I take great pride in tailoring my services to suit the unique needs and goals of my clients, ensuring their success on their wellness journey."

I specialize in working with a diverse range of clients, including student athletes aiming to enhance their performance, individuals focused on fat loss and overall health, those seeking expert nutrition guidance, and dedicated individuals striving to reach their peak physique. My approach combines personalized workout plans, tailored nutritional advice, and unwavering support to help you achieve your specific fitness goals. Whether you're an aspiring athlete, on a weight loss journey, or building muscle, I'm here to guide you every step of the way. Let's embark on your fitness journey together and transform your potential into reality.

Scientific and Medical Leaders

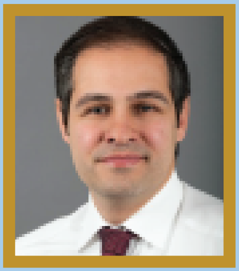
Peter W. Baas, PhD. | 215- 991-8298 | pwb22@drexel.edu
Professor, Department of Neurobiology and Anatomy
Director, Graduate Program in Neuroscience
Senior Editor, Cytoskeleton
Drexel University College of Medicine 2900 Queen Lane, Philadelphia, PA 19129
Webpage: http://drexel.edu/medicine/About/Departments/Neurobiology-Anatomy/Research/Baas-Lab/

Dr. Peter Baas 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 de-generative symptoms of SPG4-HSP in human patients.



Craig Blackstone, MD PhD | CBLACKSTONE@mgh.harvard.edu
Science Director, Mass General Brigham Neuroscience Institute &
Chief Movement Disorders Division (MIND), Massachusetts General Hospital,
Professor of Neurology, Harvard Medical School,
114 16th Street, Room 2005, Charlestown, MA 02129-4404

Dr. Craig Blackstone is Science Director at Massachusetts General Hospital and Professor of Neurology at Harvard Medical School. Previously, he was a Senior Investigator in the Intramural Research Program of the National Institute of Neurological Disorders and Stroke for nearly two decades. His research group investi-gates the cellular and molecular mechanisms underlying hereditary spastic paraplegias. He has published about 170 research and review articles and has presented about 180 invited lectures throughout the world. He is an elected member of the American Society for Clinical Investigation and Association of American Physi-cians, as well as an elected Fellow and former Vice President of the American Neurological Association (ANA). He has held numerous other leadership positions in the ANA, including on its Executive Council, Education Innovation Committee, Nominations Committee, Professional Development Committee, Transla-tional and Clinical Research Course Committee, Web Governance Committee, and Research Careers Reimag-ined Subcommittee. He has served for well over a decade on the editorial board of the prestigious Journal of Clinical Investigation. He received the NIH Director's Ruth L. Kirschstein Mentoring Award in 2012 and the NINDS Director's Diversity Achievement Award in 2018. In 2022, Dr. Blackstone was elected to the Nation-al Academy of Medicine, the pinnacle of recognition for outstanding achievement in the medical sciences.



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
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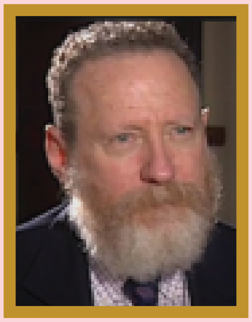
Dr. Darius Ebrahimi-Fakhari is a pediatric neurologist and neuroscientist at Boston Children's Hospital and Harvard Medical School. He leads the Movement Disorders Program at Boston Children's Hospital. His re-search interests cover childhood-onset neurogenetic and neurodegenerative diseases. His team 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.

Scientific and Medical Leaders



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University of Michigan
NCAC-Neurology | 2901 Hubbard Drive, Suite 2723 | Ann Arbor, MI 48109-2435
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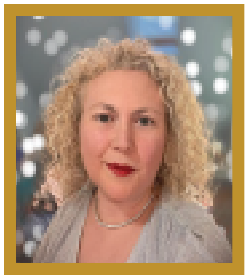
Dr. John K. Fink is a Professor in the University of Michigan Department of Neurology. Dr. Fink received his M.D. from the Medical College of Ohio in Toledo and completed Neurology Residency at the University of Virginia and postdoctoral fellowships in Developmental and Metabolic Neurology and Medical Genetics at the National Institutes of Health. Dr. Fink investigates inherited and degenerative neurologic disorders, partic-ularly hereditary spastic paraplegia and primary lateral sclerosis, and provides care and evaluation for individ-uals with these conditions. Dr. Fink serves as the Medical Advisor to the Spastic Paraplegia Foundation.



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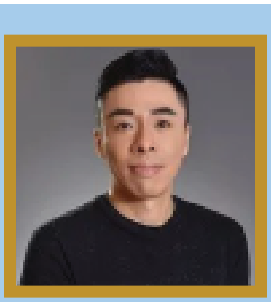
Northwestern University, Feinberg School of Medicine
Faculty, Chemistry of Life Processes Institute
Faculty, Les Turner ALS Center Faculty, Cognitive Neurology and Alzheimer's Disease Center
Faculty, Robert H. Lurie Comprehensive Cancer Research Center
303 E. Chicago Ave, Chicago, IL, 60611

Dr Hande Ozdinler 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 mecha-nisms responsible for their vulnerability and progressive degeneration. Prior to joining Northwestern Universi-ty, 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.



Liang Oscar Qiang M.D./Ph.D. | lq24@drexel.edu
Assistant Professor | Office: 215-991-8287; Lab: 215-991-8908
Neurobiology and Anatomy Department, College of Medicine,
Drexel University, 2900 Queen Lane, Philadelphia, PA 19129

Dr. Liang Oscar Qiang boasts a strong background in the research of neurodegenerative diseases. Having earned his MD and MS degrees from Nantong University in 2000 and 2003, respectively, he went on to complete his PhD at Drexel University in 2009. His doctoral thesis, "Functional Analyses of Microtubule Severing Proteins in the Central Nervous System," revealed his extensive knowledge and expertise in the field. Following his postdoctoral research on Alzheimer's and Parkinson's diseases at Columbia University Medical Center, Dr. Qiang joined Angriocrine Bioscience in 2013 as a principal scientist. He was a key figure in the establishment of an in vitro platform of the blood-brain barrier for drug screenings in the cen-tral nervous system, as well as a CNS-derived microvasculature environment to support neuronal repro-gramming. In 2015, Dr. Qiang returned to Drexel University and currently leads a research laboratory. The lab is committed to using human induced pluripotent stem cell (hiPSC) based technologies to develop in vitro and ex vivo cellular and tissue models. Their research focuses on studying several neurodegenerative disorders, including Tauopathies (such as Alzheimer's Disease and Frontotemporal Dementia) and Heredi-tary Spastic Paraplegia (HSP). The primary objective of Dr. Qiang's research is to elucidate the underlying etiology and causative mechanisms of these disorders and identify new molecular targets for treatment ther-apies through gene therapy and small chemical compounds. The lab is also devoted to preclinical testing of the therapeutic efficacy of cellular reprogramming-based strategies for treating CNS injuries and diseases.

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SP-CERN
The Spastic Paraplegia – Centers for Excellence Research Network
SP-CERN

Spastic Paraplegia – Centers for Excellence Research Network

Building on the Spastic Paraplegia Foundation’s catalytic support, the Spastic Paraplegia Centers of Excellence – Research Network (SP-CERN) was launched in 2023 and sustained in 2025 through Bridge funding, enabling ongoing recruitment and follow-up of patients with SPG4, SPG3A, SPG47, SPG50, and other trial-ready forms of HSP.

SPF’s investment served as a true catalyst, enabling the creation of a coordinated national infrastructure dedicated to advancing research, clinical care, and therapeutic development for hereditary spastic paraplegias (HSPs). Today, SP-CERN encompasses **11 leading academic institutions**, unified under a shared IRB (Institutional Review Board*1) protocol, a centralized REDCap*2 clinical database, and a coordinated biospecimen/genomic system. With **over 600 patients enrolled** in natural history studies (NCT04712812, NCT06553976), SP-CERN now provides the essential foundation for future interventional trials.

The primary goal of this consortium is to accelerate the development of therapies to the stage of clinical testing, while ensuring that individuals with HSP have access to both the highest standards of care and emerging, innovative treatment approaches.


The Spastic Paraplegia–Centers of Excellence Research Network (SP-CERN)
Clinical Trial Readiness for Hereditary Spastic Paraplegia
Abstract
Objectives
Methods
Results
Discussion
Spastic Paraplegia–Centers of Excellence Research Network

Find a copy of this Manuscript in your Welcome Bag and online here:
https://sp-foundation.org/research/sp-cern/

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*1 ”More than 130 countries and international organizations have developed independent committees to approve or deny research that involves human subjects. These entities are often called institutional review boards (IRB), ethical review boards (ERB), independent ethics committees (IEC), or research ethics boards (REC) (USAID, 2018). The institutional review board (IRB) is a research ethics committee that reviews and approves human subjects’ research. The IRB’s primary responsibility is to protect research participants’ rights, safety, and welfare, especially society’s most vulnerable groups (i.e., prisoners, children, educationally/economically deprived, critically/terminally ill, and individuals with mental disabilities) (Gallin, 2018). “ https://pmc.ncbi.nlm.nih.gov/articles/PMC10885741/

*2 “ Research Electronic Data Capture (REDCap) is a web-based application developed by Vanderbilt University to capture data for clinical research and create databases and projects.” https://pmc.ncbi.nlm.nih.gov/articles/PMC5764586/

SP-CERN LOCATIONS

The first round of the SP-CERN includes eleven centers as follows:

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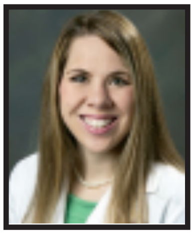

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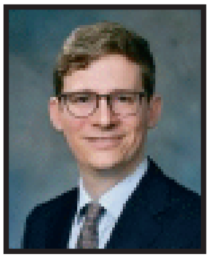

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Telephone: 901-595-1293

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SP-Foundation.org, 877-773-4483
Information@SP-Foundation.org

SPF & C-Path Collaboration: Aligning Strategy to Advance HSP/PLS Research

HSP/PLS CONSORTIUM

For over two decades, SPF has been relentlessly driving research, advocacy, and hope for families living with HSP and PLS. The Foundation has transformed hard-earned family contributions into scientific progress and compassionate action — funding research, advancing clinical readiness, and supporting every patient, investigator, and clinician on the journey toward real treatments.

For over two decades, **researchers and investigators** have worked tirelessly to decode the complex biology of HSP and PLS — translating patient-driven funding into fundamental discoveries, biomarkers, gene identification, and pathways to clinical trials.

For over two decades, **neurologists and clinicians** have led the charge in diagnosing, providing care, collecting data, and advocating for patients battling HSP and PLS — often in the absence of approved treatments, while relentlessly seeking better options.

For nearly two decades, **C-Path** has provided the legal, scientific, and regulatory infrastructure to create a unique, neutral environment for stakeholders in the medical product development ecosystem to collaborate.

This new SPF & C-Path Consortium will deliver solutions by uniting regulators, academics, pharmaceutical and biotech companies, and patient advocates, accelerating drug development and creating treatments for people living with HSP and PLS. HSP and PLS patients deserve breakthroughs, not barriers.

It's time to break down the silos, share knowledge, and unite around one goal: cures. For too long, discoveries have been slowed by fragmented efforts. HSP and PLS patients can't wait, neither should we, and who can argue against healthy children and families. Researchers, clinicians, regulators, and industry must collaborate, cooperate, and champion solutions — putting lives above prestige, profits, or politics. America has the ingenuity, resources, and drive to make breakthroughs; now is the moment to harness it for real impact.

SP-Foundation.org/SPF-Store

SHOP SPF-STORE
SCAN TO SEE
AVAILABLE
PRODUCTS

Visit Online the SPF STORE for Conference Swag and Products

Do you have a swag idea for a shirt or other products?

Send an email with your ideas, jpgs, or vector files to INFORMATION@SP-FOUNDATION.ORG. We'll upload them to our SPF Store to help raise awareness for #HSPandPLS.

Images must not have a copyright protection and must meet SPF graphic design standards.

SP-FOUNDATION ORGANIZATION

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

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

SEND CHECK DONATIONS TO:
Spastic Paraplegia Foundation,
6952 Clayborne Drive,
O'Fallon, MO 63368-6202

MAKE ONLINE DONATIONS AT:
SP-FOUNDATION.ORG

SPF MISSION:
The SPF is committed to providing information about two disorders, creating opportunities for mutual support, sharing, and funding and discovering the cures for HSP and PLS. The SPF is a non-profit 501(c)3. Tax ID # 04-3594491

SPF VISION:
The day when any individual with HSP or PLS is diagnosed, treated, and cured.

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

*Join us in our Mission and Vision at: SP-Foundation.org

BECOME A MEMBER:
*As a registered member of the SP-Foundation you will receive eblasts and updates to:
*Synapse Newsletter [printed]
*SPF Eblasts
*SPF Podcasts
*SPF TALKS a virtual outreach effort talking about subject matters of interest for people with HSP or PLS and their caregivers

Ideas or Questions Email:
Information@SP-Foundation.org

AWARENESS 2025 SPF HSPandPLS
MONTH: August
WEEK: August 24-28
WORLD DAY: October 17th

RESEARCH

How SPF Funds Research for HSP and PLS

The Spastic Paraplegia Foundation's primary mission is dedicated to advancing research and finding the cures and/or therapies for two closely related groups of neurodegenerative diseases termed Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). These conditions share the common pathologic feature of degeneration principally of the upper motor neurons.

Without research, there will be no cures. We are grateful to fund a new class of investigators every year with the support of our donors.

Learn more about the next generation of neuroscientists and their research projects at SP-Foundation.org

Scientists are unraveling 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. Animal models for these disorders have been developed and will enable investigators to uncover further the biochemical processes that cause nerve degeneration and identify and test therapy targets.

SAB | Scientific Advisory Board

The process is simple, time-consuming, but effective. SPFs work with a world-renowned group of scientists that are experts in the field of neurological disorders such as HSP and PLS. This group of scientists works with us on a volunteer basis. They live all over the world and we call them our Scientific Advisory Board (SAB). Every research proposal we receive is submitted to be reviewed, carefully analyzed, and graded by at least three members of the SAB. The SPF Board of Directors reaches out to the SAB and asks for recommendations. The manager of our SAB, Dr. Moretti, collects, compares and contrasts all of the SAB reports regarding each research proposal and turns in their report card with recommendations to the SPF Board of Directors. We generally follow their recommendations to support the very best HSP and PLS research in the world. The sad part of this process is that our SAB, in recent years, has graded several more of the research proposals as blue ribbon excellent than we have funds to support. Your donations are greatly needed and will be used in the most cost-efficient, effective method possible to fund the very best proposals.

Details available at: https://sp-foundation.org/the-foundation/scientific-advisory-board.html

FUNDRAISING

Every breakthrough in HSP and PLS research begins with one powerful spark: YOU. The dollars that drive cutting-edge studies, launch clinical trials, and move us closer to treatments come directly from the passion of families and friends who step up, speak out, and fundraise. Hosting a dinner, organizing a 5K Run Walk Roll, a birthday fundraiser, a Potato Pant Challenge, Rowing Event, Golfing for Rare Disease Scramble or simply asking your circle to give—it all matters. Fundraising isn't about asking strangers for help; it's about giving people the opportunity to be part of something bigger than themselves. When you make the ask, you'll be amazed at how many people are eager to join the fight for cures. Thanks to you and many volunteer hours, 93% of every dollar raised is transformed into research, progress, and hope for our community. Together, we are turning generosity into discoveries, and fundraising into life-changing science.

Fundraising Tools

Scan the QR Code wth the camera phone start a Fundraising page to tell your story today! Need help boost your Event, email Jim.Sheorn@SP-Foundation.org, visit SP-Foundation.org

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

RESEARCH | EDUCATION | SUPPORT

HEREDITARY SPASTIC PARAPLEGIA

PRIMARY LATERAL SCLEROSIS

#HSPandPLS

SP-FOUNDATION.ORG

The Spastic Paraplegia Foundation (SPF) is the world's leading nonprofit organization dedicated to advancing awareness, research, and patient support for two rare neurodegenerative diseases: Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). Together, we stand united as #HSPandPLS.

SPF serves as a trusted resource and strong voice for individuals, families, and children affected by HSP and PLS. As a patient-centered organization, SPF fosters collaboration among key opinion leaders, leading researchers, and innovators in medicine to drive the discovery of new treatments and improve quality of life for those living with these challenging conditions.

Since its founding in 2002, SPF has awarded over $12 million in research grants to more than 100 Ph.D. and M.D. scientists—funded entirely through the generous support and grassroots efforts of our dedicated community. Our incredible volunteers play a vital role in making this possible, giving their time and energy to organize fundraisers, connect with families, and spread awareness. Thanks to volunteer efforts, 93% of all funds raised go directly toward research grants, ensuring that every dollar truly makes a difference in advancing treatments and hope for those living with HSP and PLS.

SPF remains committed to accelerating progress through strategic initiatives, cutting-edge research, and partnerships that bring us closer to effective therapies and, ultimately, a cure.

Spastic Paraplegia Foundation, Inc.

SP-Foundation.org | Information@SP-Foundation.org | 877-773-4483

FUNDRAISING
Auction & Raffles

Visit Registration Desk for Additional Details.

All fundraising efforts directly benefit the mission of the Spastic Paraplegia Foundation.

INVITING BIDS FOR AN AUCTION-CALL ON FRIDAY IMMEDIATELY AFTER LUNCH.

VISIT REGISTRATION TABLE TO SEE THIS BEAUTIFUL QUILT! DON'T HESITATE TO BID BECAUSE YOU DON'T WANT TO FLY HOME WITH IT – WE WILL MAIL IT TO YOU

Special Appreciation to **Vicki Joines, sister-in-law to** SPF Board Member **Becki Cochran's,** for making and donating this beautiful quilt to support and to encourage SPF's Mission.

QUILT SIZE:
47.5"WIDE X 54" LONG

Why are zebra stripes associated for rare diseases—like HSP or PLS?

The zebra's stripes are used as a symbol for rare diseases due to a medical saying that advises doctors to look for common diagnoses first ("when you hear hoofbeats, think horses, not zebras"). Rare disease advocates have adopted the zebra as a symbol to represent the uncommon or rare conditions that many patients face, emphasizing that sometimes the "hoofbeats" are indeed from a zebra, not a horse. This symbolism highlights the need for increased awareness, research, and timely diagnosis for rare diseases.

DONATE AT THE REGISTRATION TABLE

Donate to 50/50 Raffle
50% Goes to SPF & 50% Goes to 1-Lucky Winner
$1.00 per ticket / $5.00 for 6-tickets

— Winner will be announced Friday during lunch
— Winner Must Be Present to Win!
— All credit card charges include a processing fee
— *All donations benefit the Spastic Paraplegia Foundation, Inc.*

SCAN TO PAY BY CREDIT CARD

SPF

50/50 RAFFLE

Donate to 50/50 Raffle, 50% Goes to SPF
& 50% Goes to 1-Lucky Winner
($1.00 per ticket / $5.00 for 6-tickets)

#HSPandPLS — SP-Foundation.org
Information@SP-Foundation.org

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OF EVERY WEBPAGE ON SP-FOUNDATION.ORG

Private Group

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QR-Code Center

SPF MEMBER REGISTRATION

ONLINE AGENDA

PHYSICIAN/CLINIC DIRECTORIES

AMBASSADORS

SPF TALKS

SPF EVENTS

Find More QR CODES Scattered Throughout the Conference Booklet

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SPASTIC PARAPLEGIA FOUNDATION, INC
SP-Foundation.org | (877) 773-4483
Information@SP-Foundation.org

October 17
WORLD DAY

Hereditary Spastic Paraplegia
Taking Steps Toward a Cure

HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS

#HSPPLSWorldAwarenessDay
#hspandpls #ChampionCures
#medicalresearch

SPF

ASL
HSP-FRANCE
Association Strümpell Lorrain

HSP Research Foundation

ASPEC
BRASIL

NEURO

naspa

HSP-Schweiz e.V.

HSP

TWS
TOM WAHLIG STIFTUNG

STOPP
HSP

Life4
HSP

SPIERZIEKTEN
NEDERLAND

V.I.P.S.

HEREDITARY SPASTIC PARAPLEGIA
funding • research • treatment

The
Mobili
Foundation

The
Hereditary Spastic Paraplegia
Support Group

NOTES

NOTES

QUICK AT A GLANCE SCHEDULE

WEDNESDAY

9:00am SPF Board of Directors Meeting
2:00pm SP-CERN Kickoff Investigator Meeting
5:30pm-7:00pm Registration/Information Desk Open

THURSDAY

Enjoy breakfast on your own, See Hotel Food Options
7:30am - 5:30pm Registration/Information Desk Open
8:30am - Welcome to Washington DC SPF Warriors
9:00am - Dr. Craig Blackstone
9:45am - Dr. Michelle Campbell
10:30am - HSP/PLS Patient History Survey
11:15am - Javier Tuel
12:00pm - Lunch (plated and served) Congressional Ballrooms
1:30pm - Dr. Darius Ebrahimi-Fakhari
2:15pm - Dr. Srikanth Ranganathan
3:00pm - Dr. Collin Hovinga
3:45pm - Dr. Sheri Schully
4:30pm - Members of Congress | Rare Disease Caucus
5:00pm - Day 1 Wrap-Up & Reflections
5:30pm - REGISTRATION/INFORMATION DESK CLOSES
DINNER ON YOUR OWN & SOCIAL MINGLE:

FRIDAY

7:30am - 5:30pm Registration/Information Desk Open
8:30am - Welcome Back
9:00am - Dr. Walter J. Koroshetz
9:45am - Dr. John Fink
10:30am - Dr. Peter W. Baas
11:15am - Javier Tuel
12:00pm - Lunch (plated and served) Congressional Ballrooms
1:15pm - Special Recognition and Quilt Auction
1:30pm - Dr Hande Ozdinler
2:15pm - Dr. Liang Oscar Qiang
3:00pm - Dr. Richard Silverman
3:30pm - Dr. Richard Novak
4:00pm - Lindsay Perlman
4:30pm - Members of Congress | Rare Disease Caucus
5:00pm - Closing Reflections & Call to Action
5:30pm - REGISTRATION/INFORMATION DESK CLOSES
DINNER ON YOUR OWN & SOCIAL MINGLE:

Thank You for Sharing your Time with Us Year Around and in DC!