

# HSP/PLS Pathway to the Gateway



St. Louis 2026

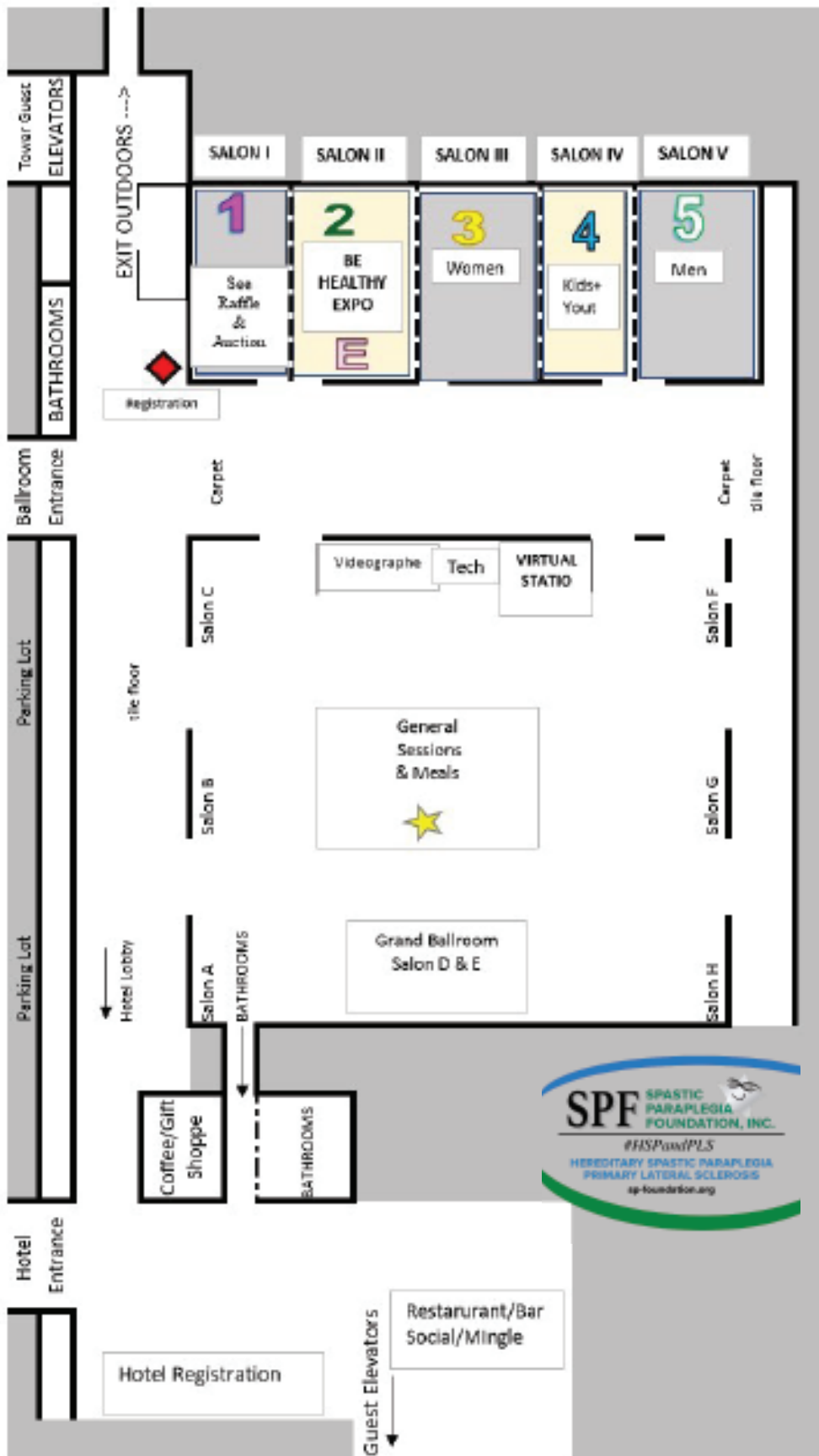
#HSPandPLS  
SP-Foundation.org



SPASTIC PARAPLEGIA FOUNDATION, INC  
INFORMATION@SP-FOUNDATION.ORG  
#HSPandPLS  
877-773-4483



# SPECIAL THANKS TO MARRIOTT HOTEL & STAFF



**Marriott St Louis Airport**  
 10700 Pear Tree Lane  
 St Louis, MO 63134  
 314-423-9700

**HOTEL: FOOD | DRINKS | SNACKS**

- **THE RESTAURANT** (6:00AM-2:00PM)  
 enjoy sandwiches, steak and seafood

- **THE BAR**  
 (2:00PM-1:30AM)

- **THE MARKET**, coffee house  
 (5:00AM-10:00PM)

**LEGEND:** All Presentations & Meals  
 in Grand Ballroom (Salons A-H),  
 except noted for Breakout Sessions  
 of Women and Men as noted on map.



**SP-FOUNDATION.ORG**

The Spastic Paraplegia Foundation Inc. (SPF or SP-Foundation) is a U.S. based 501 (c)3 international not-for-profit organization. It is the only organization in the world dedicated to both Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). Tax ID # 04-3594491

**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 and research funds to two neurodegenerative disorders, creating opportunities for mutual support, sharing, and funding the discoveries of therapeutics for HSP and PLS.

**SPF VISION:**

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

**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

# PRESIDENT'S WELCOME

*... and a big Hello from the Executive Director*

*Welcome* to the 2026 SPF HSP/PLS Conference in St. Louis, Missouri—where hope, science, determination, and community come together with a shared purpose: accelerating the path toward treatments, therapies, wellness, and ultimately cures for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

This year's conference theme, "**Pathway to the Gateway: A Roadmap to Health, Therapies, and Wellness,**" reflects something extraordinary happening across our community and around the world. For many years, families affected by HSP and PLS were told these diseases were too rare, too complex, and too difficult to solve. While we recognize that many challenges still remain, we also know this: the science has changed, the global collaboration has changed, and the momentum has changed.

Today, researchers are identifying converging biological pathways, developing new biomarkers and outcome measures, building global registries, advancing gene and pathway-based therapies, and creating the infrastructure needed to launch meaningful clinical trials. Across the United States, Europe, Brazil, Korea, and beyond, scientists, clinicians, industry leaders, regulators, and patient organizations are beginning to work together in ways that were almost unimaginable just a few years ago.

Most importantly, this progress is happening because of you.  
Because patients shared their stories.  
Because families participated in studies and registries.  
Because caregivers continued showing up through the hardest days.  
Because clinicians and researchers refused to give up.  
And because this community continued believing that progress was possible—even when the road felt long and uncertain.

Over the next several days, we hope you will feel encouraged by the remarkable scientific advances now emerging, energized by the collaboration taking shape across the field, and strengthened by the friendships and support found within this community. Whether you are newly diagnosed, a longtime advocate, a caregiver, researcher, clinician, industry partner, or supporter, your presence here matters deeply.

Our June 15 SPF Global Regulatory & Scientific Forum on HSP/PLS marks an important turning point as leaders from around the world gather to help align endpoints, registries, biomarkers, and clinical trial readiness with both U.S. Food and Drug Administration and European Medicines Agency perspectives. The goal is simple but powerful: to move from fragmented efforts toward coordinated action that accelerates therapies for the people waiting for them.

On June 16–17, our broader conference community of patients, families, caregivers, clinicians, researchers, and supporters will come together to learn, connect, share experiences, and continue building hope for the future. We know there is still much work ahead. But for the first time in many years, the field is no longer standing still. Real pathways are emerging. Real therapeutic strategies are being explored. Real global coordination is beginning to take shape. And real reasons for hope are growing stronger every day.

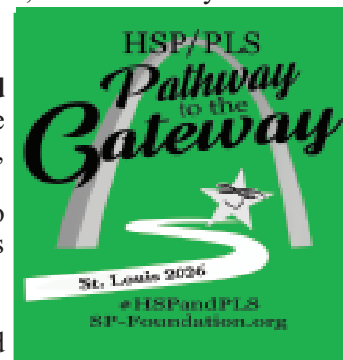
Thank you for being part of this journey with us. Thank you for your courage, your advocacy, your partnership, and your belief in what is possible. Together, we are helping build the roadmap forward—not only toward therapies and treatments, but toward greater health, independence, wellness, and hope for generations to come.

Welcome to St. Louis. Welcome to the Gateway. And welcome to the next chapter in the future of HSP and PLS.

With gratitude and hope,

**Greg Pruitt**  
President  
Spastic Paraplegia Foundation, Inc.

**Norma Pruitt**  
Executive Director



# 2025 SPF HSP/PLS CONFERENCE

# SPONSORS

## *Thank You!*



## Saint Louis Zoo

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!





**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 \$13 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 their efforts, an impressive 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

**9:00am—12:noon SPF Board of Directors Meeting**

Coffee, Tea, Water and Drinks Available All Day

**1:00pm—6:00pm Grand Ballrooms**

**SPF Global Regulatory & Scientific Forum on HSP/PLS: From Data to Approval**



- ▶ Opening Remarks
- ▶ Accelerating Therapeutic Development for HSP & PLS
- ▶ Measurement That Matters: Regulatory-Grade Endpoints
- ▶ Global Convergence on a Regulatory-Ready Data System
- ▶ Closing Remarks

SPF is convening a strategic working session—not a traditional scientific meeting. Building on the Global Convergence discussions, it brings together clinical, scientific, and regulatory leaders who are actively shaping the path to therapies for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). We are at a crossroads with a focus is on accountability, alignment, and execution: clarifying what we already know, exposing where the gaps remain, and defining the concrete steps required to move from data to regulatory approval. There are many researchers and clinicians across the world familiar with HSP and PLS. These participants represent the core infrastructure progress of HSP and PLS, including registries, natural history studies, outcome assessments, digital health technologies, biomarkers, and emerging therapeutic strategies.

This Forum is structured as a closed working meeting to allow invited experts to engage in deep, focused discussion rather than broad audience Q&A. With support from the Critical Path Institute and engagement across both U.S. Food and Drug Administration and European Medicines Agency perspectives, this session is designed to move the field beyond fragmented, academic siloed efforts toward a globally aligned, regulatory-ready framework for HSP and PLS drug development. The goal is not simply discussion but coordinated action: to harmonize data across networks, refine and validate meaningful endpoints, clarify what U.S. regulators need to see, and build a reliable pathway that enables sponsors to move into HSP and PLS trials with greater confidence. This is where global expertise is translated into accountable plans and where those plans become real therapeutic opportunities for individuals and families living with these neurogenerative movement disorders.

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

DINNER ON YOUR OWN & SOCIAL MINGLE: Gather on-your-own with Friends in the hotel restaurant. Or, head out for an evening in STL, MO. 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**



**Michelle Campbell**  
**Associate Director, Stakeholder Engagement and  
Clinical Outcomes, Office of Neuroscience**  
**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) in FDA's Center for Drug Evaluation and Research. Dr. Campbell joined the FDA in 2014 and previously 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 in patient-focused drug development and the use of patient experience data in the regulatory setting. In Dr. Campbell's current role, she engages in discussions and reviews considerations in using novel endpoints including using digital health technology data. 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.



**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 a 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.



**Collin Hovinga, PharmD, MS, FCCP,  
Vice President of the Rare and Orphan Disease Programs  
Critical Path Institute | [c-path.org](http://c-path.org)  
[chovinga@c-path.org](mailto:chovinga@c-path.org)**

Collin Hovinga serves as Vice President of the Rare and Orphan Disease Programs at the Critical Path Institute overseeing 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 and Doctor of Pharmacy degrees from Creighton University in Omaha, Nebraska. Subsequently, 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.

Critical Path Institute has been a trusted nonprofit that generates solutions to facilitate scientific and regulatory pathways that accelerate the development of therapies for people with unmet medical needs. C-Path forms collaborative work groups comprised of diverse stakeholders to identify specific barriers to developing safe and effective therapies for a given disease, and then creates tools and solutions that help drug developers overcome those barriers.



**Megan B. Miller, PhD  
Director of Outreach  
Rare/Orphan and Pediatric Diseases  
Critical Path Institute | [c-path.org](http://c-path.org)  
[mmiller@c-path.org](mailto:mmiller@c-path.org)**

Megan Miller leads community engagement and advocacy efforts for Critical Path Institute's Rare Neurodegenerative Disease program. A neurobiologist by training, she has spent the last decade working at the intersection of science, policy, and community engagement to advance research and improve health outcomes. She joined C-Path from the National Institute on Aging, where she led engagement with federal and international partners, advocacy organizations, and the U.S. Congress. She also has experience leading rare disease advocacy and advisory initiatives, partnering closely with disease communities and ensuring that lived experience is integrated into research and development efforts. Earlier in her career, she managed international research collaborations at USAID, supporting global multi-stakeholder partnerships and evidence-informed decision-making.

Megan holds a B.S. in Biology and Microbiology from The Ohio State University and a Ph.D. in Biomedical Sciences from the University of Connecticut. She completed a postdoctoral fellowship at Yale School of Medicine and a Science & Technology Policy Fellowship through the American Association for the Advancement of Science (AAAS).



**Heidi Grabenstatter, PhD**  
**Scientific Director, RDCA-DAP**  
**Rare Disease Cures Accelerator-Data and Analytics Platform**  
**Critical Path Institute | [c-path.org](http://c-path.org)**  
**[hgrabenstatter@c-path.org](mailto:hgrabenstatter@c-path.org)**



Heidi Grabenstatter, Ph.D., is the Scientific Director of RDCA-DAP. She has previously served as the Science Director of the International Foundation for CDKL5 Research (IFCR) managing the research portfolio for the organization. Heidi worked closely with IFCR's Board of Directors, MSAB, Centers of Excellence, and International CDKL5 Clinical Research Network (ICCRN) to ensure all projects were scientifically vetted and met patients' needs. She received a B.S. in Microbiology in 2001 and a MSc in Biomedical Sciences focusing on Neurobiology and Anatomy in 2003 from Colorado State University. Heidi completed her PhD in Molecular, Cellular, and Integrative Neurosciences in 2007 at Colorado State University. Her research focused on the molecular and physiological mechanisms underlying epilepsy and rationale therapy development. Her postdoctoral appointments were in adult and pediatric neurology departments at the University of Wisconsin School of Medicine and Children's Hospital Colorado, respectively. She later led an independent lab at University of Colorado- Boulder. As an epilepsy patient herself, Heidi promotes patient-driven research and caregiver engagement in the development of new tools that impact treatment development. Her commitment to rare disease patient advocacy is strengthened by her personal understanding of the extreme challenges that people with epilepsy face and experience as a caregiver to her mother and sister, both of whom passed from rare cancer diagnoses. Dr. Grabenstatter's unique experience positions her to act as a conduit between patients and caregivers with unmet needs, industry, and regulatory communities to foster innovative drug development solutions.

## 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.

# SPF 2026 SCIENTIFIC PATHWAY

## From Discovery to Independence

Science. Hope. Innovation. Wellness. Community.

A TWO-DAY JOURNEY

Uniting world-class science, innovative solutions, and real-world support to transform the future for individuals and families affected by Spastic Paraplegia.

### SCIENCE, DISCOVERY & PATHWAYS TO THERAPEUTIC READINESS

1

#### UNDERSTAND THE DISEASE



Uncovering the biology and mechanisms behind HSP/PLS

- **Darius Ebrahimi-Fakhri**, SP-CERN and Collaborative Research Networks  
How collaborative networks are accelerating HSP/PLS progress.
- **Craig Blackstone**, Disease Mechanisms and Therapeutic Targets  
Understanding disease biology and emerging therapeutic opportunities.
- **Harold Oudier**, Motor Neuron Biology and Spinal Disease Mechanisms  
Foundational overview of motor neuron vulnerability across HSP, PLS, and related neurodegenerative disorders.

2

#### BUILD THE PATH TO THERAPIES



Creating the framework to move discovery into treatment

- **John K. Fink**, Clinical Translation and Therapeutic Readiness  
Bridging scientific discovery into real therapeutic pathways.
- **Colin Heulings**, Regulatory Science and Clinical Trial Frameworks  
Clinical trial readiness, regulatory collaboration, and pathway development.
- **Srinivath Rangayathian**, NH Research Priorities and Emerging Opportunities  
Federal priorities, research opportunities, and future direction.

3

#### IGNITE HOPE THROUGH INNOVATION



Spotlighting emerging therapies through breakthrough possibilities

- **Michael Pacold & Claire Miller**, SPQRS Research Progress and Emerging Possibilities  
Presenting research developments and future therapeutic opportunities.
- **Anne Gridley & BE ARIK**, Watch Me Walk! Production Overview & Special Guest Experience  
Storytelling, innovation, mobility, neuroscience-based sound healing, and quality-of-life technologies.

4

#### WHOLE-PERSON WELLNESS



Strengthening body, mind, resilience, and long-term health

- **Eric Neptune**, Integrative Health, Functional Medicine & Whole-Body Healing Strategies  
The 7 Stages of Disconnection: The Truth About Health No One Ever Explained to You
- **Eric Neptune**, Toxicity: The Silent Health Crisis
- **Christi Laro**, Practical Self-Compression: Sustainable Caring & Emotional Resilience  
Practical emotional support and caregiving sustainability strategies.
- **Javier Tuel**, Inspiration, Motivation & Your Health  
Movement, mindset, and personal empowerment.

5

#### DEEPER SCIENCE & DISCOVERY



Exploring cellular mechanisms, neural health, and neurobiological function

- **Peter W. Bess / Liang Oscar Qiang / Emmanuel Parmentier / Cellular Mechanisms & Axonal Integrity Panel**  
Topics include axonal transport failure, cytoskeletal instability, intracellular trafficking, and convergence of cellular stress pathways.
- **Claire Pajal (Virtual)**, Molecular Dissection of Mitochondrial Dysfunction in HSP  
Linking cellular dysfunction to mitochondrial pathology and therapeutic opportunity.

6

#### TRANSLATE TO THERAPIES



Accelerating the pipeline from laboratory discovery to real-world treatments

- **Rajul Sachdeva & Micaëla Franco**, Neurostimulation & Functional Neurology  
Neurostimulation mechanisms, emerging intervention strategies, and clinical applications.
- **SPF Research & Collaborative Discussions**  
Advancing translational science, collaborative initiatives, and future therapeutic strategies.

7

#### INNOVATE & EMPOWER



Leveraging technology and tools to enhance mobility, function, and independence

- **Sherry Brady & Stephanie Osville**, with CHORC  
Mobility Innovation & Functional Independence  
Featuring wearable technologies, gait assistance innovations, adaptive mobility tools, and patient-centered functional solutions.
- Includes demonstrations/discussions including:
  - **Dryas Exoskeleton**
  - **CHORC Electro-Stim Leg Suits**
  - **Mobi Electro-Stim Suit**
  - **SmartCuffs Blood Flow Restriction Cuffs**
  - **ACE Ex Spinal Cord Stimulation**
  - **Galileo Vibrations Plus**

8

#### CARE, SUPPORT & DAILY LIVING



Practical strategies for symptoms relief, independence, and quality of life

- **Kyle Moynihan**, Palliative Care Basics: Practical Support, Symptom Relief & Quality of Life  
Communication, symptom management, emotional support, and improving daily living.
- **Nancy Carlson**, Adaptive Strategies for Daily Living  
Balancing personal, environmental, and occupational factors to maintain independence and satisfaction in daily life.
- **Lorri Steiner**, Key Findings & Historical Research Perspective  
Reflecting on SPF's research journey, progress, and future direction.

Every discovery brings us closer. Every connection strengthens us. Every step forward creates a future of hope.



#### THE PATH FORWARD



**COLLABORATION**  
Living researchers, clinicians, industry, and the HSP community



**INNOVATION**  
Fostering science and creative solutions



**TRANSLATION**  
Turning discoveries into real-world impact



**EMPOWERMENT**  
Supporting individuals and families with knowledge and tools



**WELLNESS**  
Promoting whole-person health, resilience, and well-being



**COMMUNITY**  
Stronger together—today and for tomorrow

Patient & Family Conference—Science, Hope, and the Future of Therapies—Conference Focus:  
Building the scientific foundation, connecting patients to the therapy pipeline, and creating a day structured around discovery, hope, resilience, and practical next steps.

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

Enjoy breakfast on your own, See Hotel Food Options / Coffee, Tea, Water and Drinks Available All Day

**8:00–8:30 AM Welcome & SPF Opening Vision Greg Pruitt & Tim Croghan**

**8:30–9:00 AM Darius Ebrahimi-Fakhari: SP-CERN and Collaborative Research Networks**

How collaborative networks are accelerating HSP and PLS progress.

**9:00–9:30 AM Craig Blackstone: Disease Mechanisms and Therapeutic Targets**

Understanding disease biology and emerging therapeutic opportunities.

**9:30–10:00 AM John K. Fink: Clinical Translation and Therapeutic Readiness**

Bridging scientific discovery into real therapeutic pathways.

**10:00–10:30 AM Collin Hovinga: Regulatory Science and Clinical Trial Frameworks**

Clinical trial readiness, regulatory collaboration, and pathway development.

**10:30–11:00 AM Srikanth Ranganathan: NIH Research Priorities and Emerging Opportunities**

Federal priorities, research opportunities, and future direction.

**11:15–12:00 PM Javier Tuel: Inspiration, Motivation & Your Health #1**

**12:00–1:00 PM Lunch with Special Guest: STL Cardinals Mascot Fredbird**

Meals plated and served, please remind wait-staff of allergies by placing allergy card on table

**1:15–2:00 PM Rahul Sachdeva & Marcondes França (Virtual): Neurostimulation & Functional Neurology**

Topics include: neurostimulation mechanisms, functional neurology, emerging intervention strategies, clinical applications

**2:00 –2:45 PM Michael Pacold (Virtual) & Claire Miller (Virtual): Hope—SPG83 Research Progress & Emerging Possibilities**

Promising research developments and future therapeutic opportunities.

**3:00–4:15 PM Eric Nepute: Integrative Health, Functional Medicine & Whole-Body Healing Strategies**

The 7 Stages of Disconnection: The Truth About Health No One Ever Explained to You

**4:15–5:00 PM Christi Lero: Practical Self-Compassion: Sustainable Caregiving & Emotional Resilience**

Practical emotional support and caregiving sustainability strategies.

**5:00–6:00 PM Breakout Sessions: Women's Session & Men's Session**

Peer support, shared experiences, and end-of-day reflection.

**5:30PM REGISTRATION/INFORMATION DESK CLOSES**

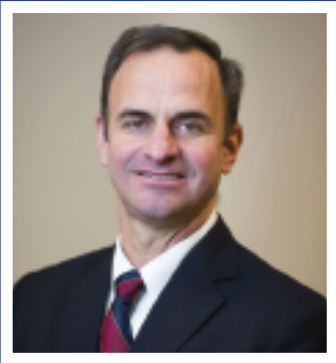
**6:15 LAST CALL FOR RAFFLE TICKET SALES**

**6:30 PM DINNER, RAFFLE & AUCTION BANQUET**

Meals will be plated and served to each registered attendee. For those with allergies, please place your allergy card on the table in front of you and remind your wait-staff of your allergies.

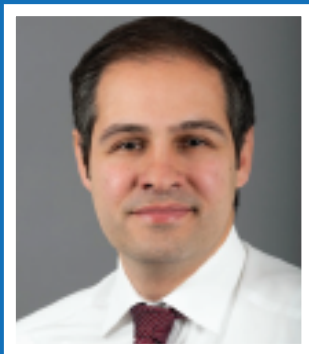
SOCIAL MINGLE: Everyone is welcome to gather after dinner, meeting old friends and making new ones, in the restaurant/bar area.





**Craig Blackstone, MD PhD | [CBLACKSTONE@mgh.harvard.edu](mailto: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 investigates 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 Physicians, 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, Translational and Clinical Research Course Committee, Web Governance Committee, and Research Careers Reimagined 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 National 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  
3 Blackfan Circle, CLSB 14060, Boston, MA 02115, USA  
[darius.ebrahimi-fakhari@childrens.harvard.edu](mailto:darius.ebrahimi-fakhari@childrens.harvard.edu)



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 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.



**SPF Medical Advisor**

**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](mailto:jkfink@med.umich.edu)**

John K. Fink, M.D., is a neurologist, medical researcher, and professor in the Department of Neurology and director of the Neurogenetic Disorders Program in the University of Michigan Medical School based in Ann Arbor, Michigan. He is widely recognized for his pioneering work on hereditary spastic paraplegia (HSP), primary lateral sclerosis (PLS) and other inherited neurodegenerative disorders. He directs basic science laboratory research focused on identifying genes and mechanisms responsible for age-dependent neurologic degeneration and on developing treatments for these conditions.

Fink is affiliated with the University of Michigan Health System, where his laboratory investigates the molecular basis of inherited neurologic and psychiatric disorders. His clinical expertise focuses on inherited and degenerative disorders of the nervous system. Dr. Fink evaluates individuals of all ages, from infancy through senescence with these disorders, which include lysosomal storage disorders (such as Gaucher disease, Niemann-Pick disease and Fabry disease), ataxias (including Friedreich's ataxia), leukodystrophies (such as Krabbe, CADASIL and adrenoleukodystrophy), familial dystonia, primary lateral sclerosis, Wilson's disease, familial motor neuron disease (including familial amyotrophic lateral sclerosis), familial dementia, and a group of inherited spinal cord disorders known collectively as the Hereditary Spastic Paraplegias (HSPs).

Dr. Fink came to the University of Michigan in 1990 as an assistant professor of neurology and director of the Neurogenetic Disorders Clinic. The program provides care and evaluation for individuals and families with inherited and degenerative neurologic disorders and clinical and molecular laboratory training for physicians and scientists studying these disorders. He was promoted to associate professor in 1996 and professor in 2005.

Board-certified in neurology and medical genetics, Dr. Fink received his medical degree in 1980 from the Medical College of Ohio in Toledo. Following internship at the Mayo Clinic in Rochester, Minnesota, he completed a neurology residency in 1984 at the University of Virginia in Charlottesville. Subsequently, he trained in developmental and metabolic neurology and medical genetics at the National Institutes of Health.

Research focus: Fink's research centers on identifying genes and molecular pathways responsible for hereditary spastic paraplegia, primary lateral sclerosis and related motor neuron diseases. His team studies how specific genetic mutations cause axonal degeneration in the corticospinal tract, the major pathway controlling voluntary movement. These investigations aim to clarify disease mechanisms and develop targeted therapies.

Clinical role: As a neurologist, Fink evaluates and manages patients with complex movement disorders, particularly hereditary and spastic gait conditions. He combines clinical practice with translational research, ensuring that genetic discoveries inform diagnostic approaches and patient care strategies.

Contributions and impact: Fink is regarded as one of the foremost authorities on HSP/PLS. He has authored numerous scientific papers and contributed to defining the genetic classification of HSP subtypes. His work has helped shape international diagnostic standards and foster collaboration between research and patient advocacy organizations focused on rare neurological diseases.

Affiliations and recognition: Within the University of Michigan community, Fink is associated with both the Department of Neurology and the university's neurogenetics research initiatives. His ongoing studies continue to influence the understanding and management of hereditary motor disorders worldwide. Dr. Fink has served as the Medical Advisor to the Spastic Paraplegia Foundation since its establishment (2002), and serves as ad hoc reviewer for numerous journals and NIH study sections.



**Javier Tuel & Justine Bast**  
**Tuel Shed Training**  
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Clive, IA 50325  
515-829-0068  
[jtuel@tuelshedtraining.com](mailto:jtuel@tuelshedtraining.com)  
[justine@tuelshedtraining.com](mailto:justine@tuelshedtraining.com)

**Javier Tuel** 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.

# BELIEVE STRONGER

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- No Guesswork



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- Chair-Based Workouts
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- Power + Stability Tracks



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- Weekly Challenges
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*Movement should not cost you access.*



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**Justine Bast & Javier Tuel**, co-owners of Tuel Shed Training created the **Believe Stronger App**. It is a free fitness platform designed for real people, real limitations, and real life. Javier has years of hands-on experience working with individuals with neurological disorders, injuries, disabilities, and those who need extra support. This app was built from that work.

**Designed for every body.** ■ Seated. Modified. Power. ■ Because you can do this. ■ Whether you are on your own or doing it with someone you love.

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- ✓ Structured daily workouts that are guided and easy to follow
- ✓ Multiple tracks including stability, strength, and chair-based options
- ✓ Short, effective sessions that remove overwhelm
- ✓ A supportive community environment
- ✓ Designed for beginners, older adults, and anyone needing modifications

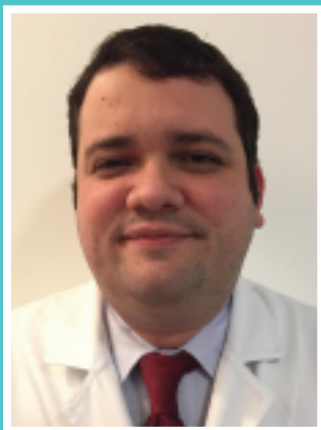
Our goal is simple: To help people hold onto their independence for as long as possible. To help them keep doing the things that matter. Getting up on their own. Moving with confidence. Staying strong enough to live life on their terms. Because for many, this is not just about working out. It is about slowing decline, building confidence, and giving them a way to keep showing up for themselves every day. This is not meant to replace what you do. It is meant to support it.

Everyday, tell yourself you believe in yourself. If that is hard for you, find us at Tuel Shed Training and on the Believe Stronger Community. **Believe.**



**Rahul Sachdeva, PhD**  
Assistant Professor  
University of Kentucky  
Office Phone: +1 859 257 4888  
rahulsachdeva@uky.edu  
Physical Medicine & Rehabilitation, 2050 Versailles Road, Lexington, KY 40504  
Spinal Cord and Brain Injury Research Center (SCoBIRC)  
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741 S. Limestone Street Lexington, KY 40536

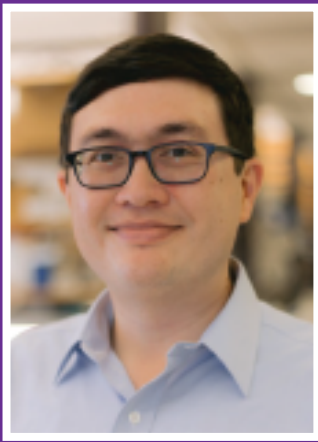
Rahul Sachdeva, PhD, is an Assistant Professor at the University of Kentucky in Lexington, where he conducts both preclinical and clinical research in neurological disorders such as spinal cord injury and cerebral palsy. Supported by the Spastic Paraplegia Foundation, his current work is expanding into hereditary spastic paraplegia (HSP). A major focus of his research is the use of noninvasive transcutaneous spinal cord stimulation to enhance functional recovery and improve quality of life for individuals with neurological conditions.



**Marcondes C. França, Jr., MD, PhD**  
Professor Titular / Professor Doenças Neuromusculares e  
Neurogenética / Neuromuscular and Neurogenetics  
Depto de Neurologia / Dept of Neurology  
Faculdade de Ciências Médicas / School of Medical Sciences —  
UNICAMP  
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<https://www.researchgate.net/profile/Marcondes-Franca-Jr>



Marcondes C França Jr is a clinical neurologist with particular interest in neurogenetic disorders. He obtained a PhD in 2008 working on peripheral nervous system involvement in SCA3 at the University of Campinas (UNICAMP) in Brazil. He is currently the director of the neuromuscular and neurogenetics research groups at the university. He manages large neuromuscular and neurogenetics clinics that includes patients with motor neuron diseases, peripheral neuropathies, myopathies, spastic paraplegias, motor neuron diseases, hereditary spastic paraplegias, and ataxias. His research interests focus in the characterization of the natural history of these diseases, the identification of non-motor manifestations and the search for modifier genes.



**Michael E. Pacold, MD, PhD**  
**Michael.Pacold@nyulangone.org**  
**NYU Langone Neurology Associates**  
**222 East 41st Street, 15th Floor, New York, NY 10017**  
**212-263-7744**  
**<https://nyulangone.org/doctors/1841327293/michael-e-pacold>**



Michael Pacold is an Associate Professor of Radiation Oncology at NYU Langone Health. He received dual Bachelors' of Science degrees in Chemistry and Biology from Indiana University, a PhD in Molecular Biology from the University of Cambridge, and an MD from Harvard Medical School in the Health Sciences and Technology Program. He completed his internship in internal medicine at the MGH and residency in radiation oncology in the Harvard Radiation Oncology Program. His postdoc was at the Whitehead Institute and the Dana-Farber Cancer Institute. He runs a lab that is interested in discovering fundamental processes in metabolism and in targeting these processes to treat disease. He also maintains a limited clinical practice in central nervous system radiation oncology.



**Claire Miller, MD, PhD**  
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**NYU Langone Neurology Associates**  
**222 East 41st Street, 15th Floor, New York, NY 10017**  
**212-263-7744**  
**<https://nyulangone.org/doctors/1861806515/claire-miller>**



Dr. Claire Miller is a pediatric neurologist at NYU Langone Health whose work bridges clinical care and translational research. Inspired early in her career by working with children with cerebral palsy, she pursued medicine with the goal of improving movement and communication for children with neurologic disabilities. She earned her dual MD-PhD degree at the University of Illinois and completed residency training in Child Neurology, followed by a Movement Disorders Fellowship, at NYU Langone Health. Dr. Miller is currently a Clinical Associate Professor, and her research focuses on rare neurogenetic disorders including HPDL deficiency and DRPLA.

# Take the First Step Toward Better Health.

You aren't broken—you're blocked. You aren't diseased—you're disconnected. Take the first step toward real answers and a personalized plan built around your body's unique needs.



**Dr. Eric Nepute, DC, DNM, DPC / Founder BioLimitless | 314-544-5600**  
**<https://neputewellness.com/shop> | 4225 Bayless Ave | St. Louis, MO 63123**  
**A Disruptive Voice for Root-Cause Health and Human Potential**

Dr. Eric Nepute is a Primary Care Provider and a leader in root-cause health care. He holds the credentials of Doctor of Chiropractic (DC), Doctor of Natural Medicine (DNM), and Doctor of Primary Care (DPC). In addition, he has earned a Master's Degree in Clinical Nutrition, three Bachelor's degrees in health-related sciences, a Fellowship in Functional Neurology, a Fel-



lowship in Functional Medicine, and a Diploma in Kinesiology. These diverse educational achievements allow Dr. Nepute to approach health from a truly integrative perspective—combining structural health, neurological function, nutrition, and lifestyle medicine into one comprehensive model of care focused on identifying and correcting the root cause of disease.

Dr. Eric Nepute is a pioneering healthcare leader, educator, and entrepreneur who has dedicated his life to challenging the traditional disease-management model and helping people rediscover their body's innate ability to heal. As a Doctor of Chiropractic, Doctor of Natural Medicine, and practitioner of functional medicine and functional neurology, Dr. Nepute has become known as a bold and disruptive force in modern healthcare—one who is committed to empowering individuals to move beyond symptom management and address the true root causes of illness.

Born and raised on a working farm in the small town of Carlinville, Illinois, Dr. Nepute learned early in life the values of discipline, resilience, and hard work. As a young athlete, he excelled in football and eventually earned a college football scholarship. However, a significant sports injury changed the trajectory of his life. What initially seemed like a setback ultimately became a defining turning point—introducing him to chiropractic care and sparking a lifelong fascination with the body's remarkable ability to heal when properly supported.

Driven by that experience, Dr. Nepute pursued extensive education in the health sciences. His academic journey includes degrees in sports medicine, human anatomy and physiology, chemistry, and clinical nutrition, culminating in a Doctorate of Chiropractic and a Doctorate of Natural Medicine. This broad scientific background allowed him to view health through a more comprehensive lens—one that integrates structure, nutrition, neurology, and lifestyle into a unified model of healing.

Over the past two decades, Dr. Nepute has built a reputation as a clinician who refuses to accept the idea that chronic disease is simply inevitable. As the founder and CEO of Nepute Wellness Center, he has developed systems of care designed to uncover and correct the underlying imbalances that drive illness. Rather than focusing solely on treating symptoms, his approach emphasizes identifying root causes such as inflammation, neurological dysfunction, metabolic imbalance, toxic overload, and lifestyle stressors.

This philosophy has positioned Dr. Nepute as a leader in the rapidly growing fields of functional medicine and functional neurology. His work focuses on restoring communication within the body—between the brain, nervous system, immune system, and metabolism—so that the body can return to balance and perform the way it was designed to.

# BioLimitless

You're Not Broken — You're Blocked

The 7 Stages of Disconnection: The Truth About Health No One Ever Explained to You

Toxemia: The Silent Health Crisis

How Lymphatic Congestion and Toxic Overload Are Draining Your Energy



(continued: Dr. Eric Nepute)

Beyond clinical practice, Dr. Nepute is also a passionate educator and communicator. Through television appearances, radio programs, podcasts, live events, and global speaking engagements, he has reached millions of people with a message of hope and personal responsibility for health. His ability to simplify complex scientific concepts into common-sense strategies has made him a sought-after speaker in the wellness community.

At the heart of Dr. Nepute's mission is a powerful belief: that true health is not achieved by suppressing symptoms, but by restoring the body's natural systems of healing. His work continues to inspire individuals around the world to rethink what health really means—to question outdated models of care and to take ownership of their well-being through education, testing, and lifestyle transformation.

Today, Dr. Eric Nepute stands as a catalyst for change in modern healthcare—a physician, innovator, and advocate for a new era of medicine that prioritizes truth, personal empowerment, and root-cause healing. His message is simple but profound:

You are not broken. Your body is not diseased. It may simply be blocked—and when those blocks are removed, the human body is capable of extraordinary healing.

KNOWLEDGE IS POWER, BUT...

**WISDOM**

is applying it to your life.

BioLimitless is built on that truth. We believe wisdom begins when knowledge is applied—so we make advanced science and health education personal and practical. Through breakthroughs in *biotechnology*, *nutrigenomics*, *neuroscience*, and *AI-powered technologies*, we give you the tools to understand your body genetically, cellularly, and holistically—so you can truly *CARE* for your *SELF*. *Wise choice.*

Innovation, Technology, Practical Care & Wellness Conference Focus: Translating scientific discovery into practical therapies, technologies, wellness strategies, and real-world tools that improve function, independence, and quality of life.

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

7:30am - 8:30pm - Fruit, Pastries, Coffee, Teas, Water and Drinks Available for 1-hour

**8:00–8:30 AM Hande Ozdinler: Motor Neuron Biology and Shared Disease Mechanisms**

Foundational overview of motor neuron vulnerability across HSP, PLS, and related neurodegenerative disorders.

**8:30–9:30 AM Peter W. Baas / Liang Oscar Qiang / Emanuela Piermarini: Cellular Mechanisms & Axonal Integrity Panel**

Microtubules, Axonal Transport & Cellular Stress in Neurodegeneration. Topics include: axonal transport failure cytoskeletal instability, intracellular trafficking, convergence of cellular stress pathways

**9:30–10:00 AM Claire Pujol (Virtual): Molecular Dissection of Mitochondrial Dysfunction in HSP**

A capstone science session linking cellular dysfunction to mitochondrial pathology and therapeutic opportunity.

10-11:00 AM Snacks Refresh—Fruit, Coffee, Teas, Water and Drinks Available for 1-hour

**10:00–10:30 AM Lorri Steiner (Virtual) SPF Accountant: Key Findings, Historical Research Perspective**

**10:30-11:15 AM Nancy Carlson: Adaptive Strategies for Daily Living**

Highlighting the need to balance personal factors, environmental components, and occupations to maintain independence and satisfaction in daily life.

**11:15–12:00 PM Javier Tuel: Inspiration, Motivation & Your Health #2**

**12:00–1:00 PM Lunch with Special Guest: STL Blues Mascot Louie Bear**

Meals plated and served, please remind wait-staff of allergies by placing allergy card on table

**1:00–1:45 PM Anne Gridley: Watch Me Walk Production Overview w/Virtual Special Guest**

**BE Alink (Virtual):** A powerful patient-centered storytelling experience exploring resilience, mobility, identity, and hope through performance and lived experience. BE Alink will share perspectives on mobility, wellness, neuroscience-based sound healing, and innovative approaches to improving quality of life and independence for individuals living with neurological conditions.

**2:00–2:45 PM Kyle Moylan: Palliative Care Basics: Practical Support, Symptom Relief &**

**Quality of Life:** Practical guidance for symptom management, communication, emotional support, and improving quality of life.

2:30—3:45 PM— Afternoon Snacks Coffee, Teas, Water and Drinks Available for 45-minutes

**3:00–4:15 PM Eric Nepute: Toxemia - The Silent Health Crisis**

**4:15–5:30 PM Sherry Brady & Stephanie Ovalle with Cionic Mobility Innovation & Functional Independence**

Session Featuring: wearable device demonstrations, adaptive mobility technologies, gait assistance innovations, patient-centered functional solutions, real-world independence strategies, audience Q&A and engagement pertaining to: Dnsys exoskeleton, CIONIC electro-stim leg sleeves, Mollii electro-stim suit, Smart Cuffs blood flow restriction cuffs, ACE Ex spinal cord stimulation, Galileo vibration plate

**5:30pm - REGISTRATION/INFORMATION DESK CLOSSES**

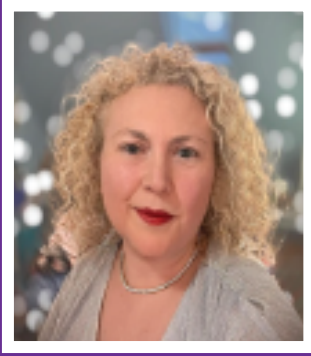
**DINNER ON YOUR OWN & SOCIAL MINGLE:** Gather on-your-own with Friends in the hotel restaurant. Or, head out for an evening in STL, MO. Special Note: Everyone is welcome to gather after dinner, meeting old friends and making new ones in the hotel bar mingle area.



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

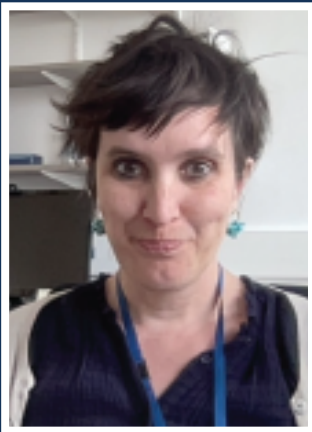
**Thank you for joining us!**





**P. Hande Ozdinler, PhD. | (312) 503 2774 | ozdinler@northwestern.edu**  
**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**

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 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.



**Claire Pujol**  
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**claire.pujol@pasteur.fr**



## **Molecular dissection of mitochondrial dysfunction in HSP by unbiased imaging-based pharmacological and genetic screening.**

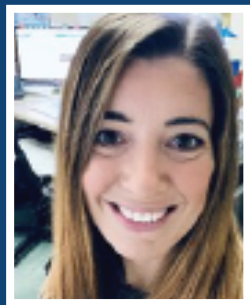
Claire Pujol is a CNRS researcher at Institute Pasteur specializing in mitochondrial biology, neurodegeneration, and rare inherited neurological disorders. Her research combines cellular and in vivo models, including zebrafish, *C. elegans*, and mammalian systems, to investigate the molecular mechanisms underlying hereditary spastic paraplegias and mitochondrial diseases. She has contributed to the identification and characterization of novel disease genes and pathogenic mechanisms associated with mitochondrial dysfunction, neuroinflammation, and metabolic defects. Her current research focuses on understanding how mitochondrial dysfunction contributes to the clinical heterogeneity observed in hereditary spastic paraplegias and related neurodegenerative disorders. She combines high-content imaging, genetic screening, proteomics, and patient-derived cellular models to identify molecular pathways and genetic modifiers that influence disease severity and phenotypic variability, particularly in SPG7-associated disease.



**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**



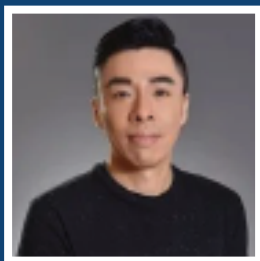
Peter Baas, PhD, Professor of Neurobiology and Anatomy at Drexel University College of Medicine, where he is also Director of the Graduate Program in Neuroscience and Director of the T32/NIH-funded Training Program in Spinal Cord Injury. Dr. Baas has studied *SPG4*-HSP for the past 15 years and has focused 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.



**Emanuela Piermarini, Ph.D. | (215) 991 8311 | ep477@drexel.edu**  
**Research Scientist, Department of Neurobiology and Anatomy**  
**Drexel University College of Medicine, 2900 Queen Lane,**  
**Philadelphia, PA 19129**



Emanuela Piermarini, PhD, is a Research Scientist in the Neurobiology and Anatomy Department at Drexel University College of Medicine. She was born and raised in a small town close to Rome, Italy. She earned her Ph.D. degree in Biochemistry and Molecular Biology at University of Rome "Tor Vergata"/Children's Hospital and Research Institute IRCCS "Bambino Gesù" in 2016, where she studied the role of oxidative stress in the context of Friedreich's ataxia, a rare neurodegenerative disease affecting children. In 2016, she joined Dr. Peter Baas laboratory as a postdoc and recently as a Research Scientist, where she studied SPG4-based Hereditary Spastic Paraplegia by using a novel mouse model. She characterized behavioral deficiencies and anatomical changes to better characterize the disease progression and understand the mechanisms of neurodegeneration in order to apply therapies.



**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, MD, PhD, 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 Angriocrone 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 central nervous system, as well as a CNS-derived microvasculature environment to support neuronal reprogramming. 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 Hereditary 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 therapies 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.



**Nancy Carlson, Ph.D. OTR/L CAPS**  
 Associate Professor of Occupational Therapy  
 717.361.1174 | [carlsona@etown.edu](mailto:carlsona@etown.edu)



Dr. Nancy Carlson, an occupational therapist, with 40 years of experience, will share insights on living with HSP and PLS, emphasizing the importance of adapting environments and activities to maintain independence. Dr. Carlson discussed strategies for managing spasticity, exercises to maintain mobility, and the role of occupational therapists in providing holistic care. She will highlight the need for a multidisciplinary approach to health management, including working with specialists like urologists and cardiologists. The session also covers practical tips for daily living, such as modifying homes for accessibility and using assistive devices like grab bars and mobility aids. Participants can learn about finding occupational therapists, managing specific health issues, and staying active in wheelchairs. The discussion will underscore the importance of proactive health management and community support for individuals with HSP and PLS.

	Ankle Exercises		Handibar
Home Fit Evaluation		Driver's 65	



Anne Gridley  
anne.gridley@gmail.com



## WATCH ME WALK

Anne Gridley is a two time Obie award-winning actor, dramaturg, artist, and has HSP SPG8. As a founding member of Nature Theater of Oklahoma, she has co-created and performed in critically acclaimed works including *Life & Times*, *Poetics: A Ballet Brut*, *No Dice*, *Romeo & Juliet*, and *Burt Turrido*. In addition to her work with Nature Theater, Gridley has performed with Pan Pan, Chameckilerner, Jérôme Bel, Caborca, *7 Daughters of Eve*, and Big Dance, served as a Dramaturg for the Wooster Group's production *Who's Your Dada?*, taught devised theater at Bard College, and comedy at Northwestern University. Most recently, she performed her original piece *Watch Me Walk* at Soho Rep.

*Watch Me Walk* is performed by Gridley with Alex Gibson and Keith Johnson. It's "the show [Anne] never wanted to write"—about her experiences since being diagnosed with Hereditary Spastic Paraplegia (HSP), a rare degenerative neurological disease which her mother and grandmother also had. The play is part observational comedy, part bonkers family history, part critique of our trainwreck of a healthcare system.

*Watch Me Walk* has garnered widespread critical praise, with Hilton Als of *The New Yorker* calling Gridley an "incredible performer" and the play "a prime example of what we get when autobiographical theatre works: intelligence, and the ability to laugh at oneself, with one's heart, as always, in both the wrong and the right place." Chris Bonanos of *New York Magazine* deemed *Watch Me Walk* "the best cultural experience I had last week," and Dan Rubins' *Theatermania* review proclaimed, "Every step has meaning in Anne Gridley's *Watch Me Walk*," and "Gridley's wry, warm delivery and her oft-mischievous grin allow her to bring the storytelling to very dark places and then lead us back to the light." Loren Noveck, in *Exeunt*, described the show as "breathhtaking"; Alisa Solomon, in *Jewish Currents*, called it "hilarious"; and Tony Marinelli, writing for *TheaterScene*, observed, "Gridley gives us a reckoning with a life that has learned, stubbornly and brilliantly, how to keep moving. She is in complete command—of her balance, of the moment, of the uneasy tenderness she has coaxed from the room—and, more to the point, of us."



**BE Alink**  
My memoir: [www.bealink.world](http://www.bealink.world)  
The Alinker: [www.thealinker.com](http://www.thealinker.com)  
whatsapp +1 778 228 9618



BE Alink is a Dutch designer, architect, humanitarian, musician, composer and frequency /neuroscience-based soundscape recording artist creating frequency and sound healing compositions. and inventor of the Alinker. The Alinker story started with a comment of BE's aging mother- Antonia Esman. While passing some elderly people with walkers and scooters, she said: "over my dead body will I ever use one of those!". BE set out to design something better for her mum, but soon realized what was truly needed was a vehicle for social change, challenging our assumptions about people with mobility challenges. After all, we are all aging, but instead of dreading what's to come, now we can stay active, be energetic, and experience freedom and joy with The Alinker!"

**BE  
ALINK**

The Alinker was first introduced to the Dutch market via a crowdfunding campaign in 2014. In 2016, the Alinker was launched in North America through another highly successful crowdfunding campaign. The Alinker team is proud to have created something worth talking about, but most of all, the team is thankful for all the support from customers and Alinker champions in the community. The Alinker isn't just for him or her, it's for all of us.



### **Alinker!**

Use code **SP200** on <https://www.thealinker.com/> when you buy an Alinker and to get:

- \$200 OFF your Alinker
- \$50 donated to the Spastic Paraplegia Foundation (SPF)
- \$50 donated to Soho Rep, the theater behind Watch Me Walk

This partnership grew directly from the impact of "*Watch Me Walk*"—a powerful, funny, and deeply honest performance about disability, mobility, and dignity. Please share this with friends, family, and clinicians who support the HSP/PLS community.

*Watch Me Walk* offered something clinicians almost never get in their formal training: a deep, lived, "client side" perspective on disability, HSP, mobility, and how everyday interactions—including medical ones—can either empower or harm. As participants noted, it would be an ideal part of education programs for physiotherapists, doctors, kinesiologists, and other rehab professionals, because it combines humor, storytelling, and gut-wrenching honesty to expose common assumptions and biases.

**Kyle Moylan, MD, FACP**

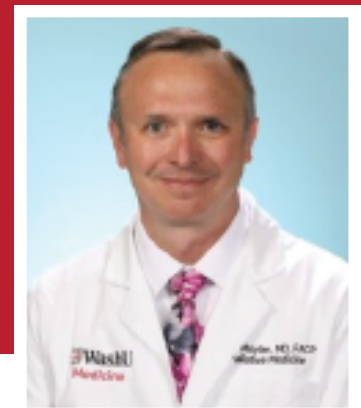
**Associate Professor of Medicine, Palliative Medicine**

**WashU Medicine Division of Palliative Medicine**

**John T. Milliken Department of Medicine Education:**

**314-454-7376 Clinical: 314-747-5361**

**[moylankylec@wustl.edu](mailto:moylankylec@wustl.edu)**



## Palliative Care Basics

Dr. Kyle Moylan joined the Department of Medicine in the Division of Palliative Medicine as an Associate Professor in July of 2025. Dr. Moylan is board-certified in Internal Medicine, Geriatric Medicine and Palliative Care. After completing his internal medicine residency and geriatric fellowship at Washington University, he served as chief resident before joining the Division of Geriatrics faculty. He then took a position as a hospitalist at the University of Missouri in Columbia. While at the University of Missouri, he served as Associate Program Director of the internal medicine residency program, Program Director for the Geriatric Medicine Fellowship Program and as the Director of the Division of Hospital Medicine. He left academic medicine to spend 13 years as a geriatric-focused primary care physician in private practice while also spending 3 years as medical director for an area hospice program. His key interests are Parkinsonian disorders, Palliative care, Polypharmacy, quality improvement and patient safety projects, and medical education.



**Christi M. Lero, MSW, LCSW | PhD Candidate**

**NIH T32 Predoctoral Fellow,**

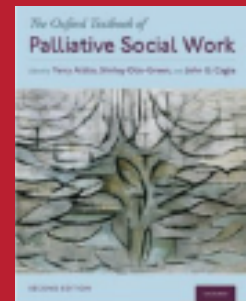
**National Institute of**

**Mental Health (NIMH)**

**Brown School of Social Work**

**Washington University in St. Louis**

**[c.lero@wustl.edu](mailto:c.lero@wustl.edu)**



## Palliative Practical Self-Compassion: Small Shifts for Sustainable Practice

Christi Lero, MSW, LCSW, is a doctoral candidate at the Brown School of Social Work at Washington University in St. Louis, where she was awarded the Mark S. Wrighton Award on Aging in 2024 for her research on family caregiving in the context of neurodegenerative disease. Ms. Lero earned a Master of Social Work from the University of Missouri in 2016 and subsequently worked as a hospice and palliative care social worker, supporting patients and families affected by a broad range of life-limiting illnesses, including ALS, Alzheimer's and dementias, Parkinson's, heart disease, and cancer, among others. Clinically, she provides psychotherapy for individuals navigating family caregiving, grief, loss, and traumatic bereavement. A National Institute of Mental Health (NIMH) T32 fellow, Ms. Lero has published widely in academic and medical journals on death and dying, neuropalliative care, caregiving, and ethics. Her research focuses on end-of-life caregiver wellbeing and neuropalliative care, with particular attention to caregivers of people with neurodegenerative diseases at the end of life and into bereavement.

### **Practical Self-Compassion: Small shifts for sustainable practice.**

Caregivers of people with neurodegenerative illnesses dedicate years of their lives in service to ensuring dignified, respectful, and compassionate care to those they love. The substantial effort put into that care can lead to physical, mental, emotional, social, and financial distress. Self-compassion is a powerful tool that can be practiced and strengthened to ensure caregiver wellbeing, even in challenging times. This talk will provide information about self-compassion, and practical tools to practice and strengthen caregiver self-compassion.



**Sherry Brady**  
 SPF State Ambassador (Vista, CA)  
 Patient Advocate | Educator | Technology Explorer  
 HSP-sandiego.org  
 hsp-sandiego.com  
 hsp-sandiego@sonic.net  
 sbrady1@live.com  
 707-322-9737

Sherry Brady lives in Southern California with her husband and serves as the SPF Ambassador for San Diego. A retired elementary educator, she continued her passion for teaching through science and nature education with the Escondido Creek Conservancy. Living with Hereditary Spastic Paraplegia (SPG4), Sherry is dedicated to exploring emerging therapies and technologies aimed at reducing spasticity, improving mobility, and maintaining independence. Combining her background in education with lived experience, she helps make complex therapeutic tools more practical and understandable for the HSP community. A certified yoga instructor and active advocate for wellness and adaptive living, Sherry also created HSP-SanDiego.org to support and connect others on their HSP journey. Her presentation will share practical insights into mobility and neurostimulation technologies and their potential to improve function, independence, and quality of life.

**PATIENT LIVED EXPERIENCE: Technology, Neurostimulation & Mobility, Practical Tools for Managing Spasticity**

Cionic Neural Sleeve with Stephanie Orvalle

Dnsys Exoskeleton-

Ottobock Mollii Suit

Vibration plate

Arc Ex spinal cord stimulation

SmartCuffs BFR cuffs

Cryoneurolysis procedure

Dnsys Exoskeleton



**Stephanie Ovalle, MSAES**  
 Mobility Specialist  
 CIONIC | 415-993-4179  
 Stephanie@cionic.com



Stephanie Ovalle is a Mobility Clinical Specialist – Sales at CIONIC, a company dedicated to improving mobility and independence through innovative bionic clothing technology. Stephanie holds a master’s degree in Applied Exercise Science with an emphasis in Exercise Physiology, and is passionate about combining clinical knowledge with cutting-edge rehabilitation solutions. Stephanie enjoys educating others on emerging mobility technologies and helping connect individuals with tools that can support greater movement, confidence, and quality of life.

# SP-CERN LOCATIONS

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



Darius Ebrahimi-Fakhari, MD, PhD  
Boston Children's Hospital  
300 Longwood Ave., Fegan 11  
Boston, MA 02115  
Telephone: 617-355-6388



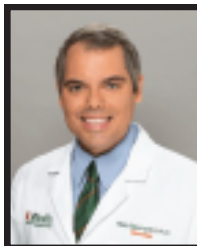
Michelle Christie, MD  
Scottish Rite For Children  
2222 Welborn St  
Dallas TX 75219  
Telephone: 214-559-7830



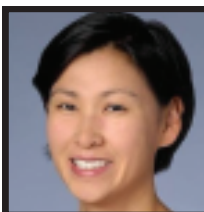
Stephan Züchner MD, PhD &  
Hussman Institute for Human Genomics  
Biomedical Research Building (BRB)  
Room 616, LC: M-860  
1501 NW 10th Avenue  
Miami, FL 33136  
Telephone: 305 9897835



Daniel Calame, MD, PhD  
Baylor College of Medicine,  
Texas Children's Hospital  
One Baylor Plaza, Room 604B,  
Houston, TX 77035  
Telephone: 832-492-4843



Mario Saporta MD, PhD  
Hussman Institute for Human Genomics  
Biomedical Research Building (BRB)  
Room 616, LC: M-860  
1501 NW 10th Avenue  
Miami, FL 33136  
Telephone: 305 9897835



Marie Davis, MD, PhD  
UW Institute on Human  
Development and Disability  
1959 NE Pacific  
Seattle, WA 98195  
Telephone: 206-598-4030



Craig Blackstone, MD, PhD  
Mass General Neurology  
55 Fruit St.  
Boston, MA 02114  
Telephone: 866-934-3881



John Fink, MD  
University Of Michigan Neurology  
1500 E Medical Center Dr Fl 1-C,  
Ann Arbor, MI, 48109  
Telephone: 734-936-9020



Michael Shy, MD  
University of Iowa Health Care  
2007 RCP  
200 Hawkins Drive  
Iowa City, IA 52242  
Telephone: (319) 356-7199



Donald Gilbert, MD  
Cincinnati Children's Hospital  
Medical Center  
3333 Burnet Avenue ML 2015  
Cincinnati, OH 45229-3039



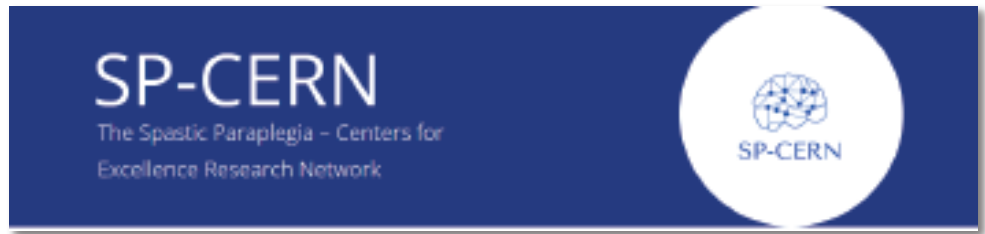
Matthew Harms, MD  
Columbia University Irving Medical Center  
710 West 168th Street  
New York, NY 10032  
Telephone: 646-426-3876



Joshua Burns, PhD  
St. Jude Children's Research Hospital  
262 Danny Thomas Place  
Memphis, TN 38105  
Telephone: 901-595-1293



Spastic Paraplegia Foundation, Inc  
SP-Foundation.org, 877-773-4483  
Information@SP-Foundation.org



## 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.**



\*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](https://www.usaid.gov/our-work/ethics)). 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://pubmed.ncbi.nlm.nih.gov/articles/PMC10885741/)).” <https://pubmed.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://pubmed.ncbi.nlm.nih.gov/articles/PMC5764586/>

Find a copy of this Manuscript online here:  
<https://sp-foundation.org/research/sp-cern/>



# LEGACY & PLANNED GIVING A BEACON OF HOPE

Honoring a Lasting Legacy: \$337,000 Planned Gift to Advance HSP/PLS Research

## JOSEPH (JOE) A CARLISLE, JR



Not Your  
Average Joe

[www.nya-joe.com](http://www.nya-joe.com)

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



1938-2024  
LAWRENCEVILLE, GA

# 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](http://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](http://SP-Foundation.org)  
 (877) 773-4483 | [Information@SP-Foundation.org](mailto:Information@SP-Foundation.org)

MEMORIAL GIVING



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.*

#HSPandPLS — [SP-Foundation.org](http://SP-Foundation.org)  
[Information@SP-Foundation.org](mailto:Information@SP-Foundation.org)  
 (877) 773-4483

# FUNDRAISING = RESEARCH GRANT AWARDS

**Progress for a cure depends on continued investment in research.**

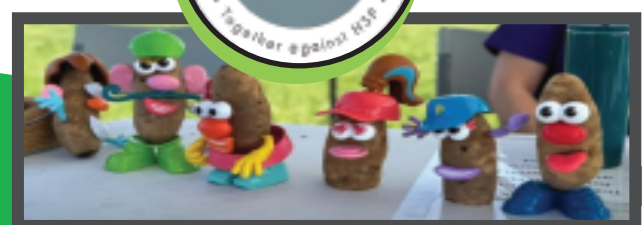
Fundraising is the engine that turns mission into momentum for the Spastic Paraplegia Foundation. It fuels the research we pursue for treatments, the programs we deliver, and the support we provide to individuals and families who rely on our work. Every dollar raised is more than a contribution, it's an investment in hope, progress, and meaningful research.

Fundraising is never the work of one person or one organization alone, it truly takes a community. When individuals, families, sponsors, and volunteers come together, their collective impact multiplies. It's through shared passion, commitment, and participation that we are able to extend our reach, deepen our impact, and ensure that no one has to travel this journey alone.

This year, we're excited to expand that sense of community by helping you create "My Personal SPF Fundraiser". Through our peer-to-peer fundraising platform we provide you with the tools to make a successful event. From fun and creative ideas like Potato Pants to more traditional efforts like a 5K Run, Walk, or Roll, there are many endless ways to raise disease awareness and to get started today.

You Make it Meaningful. You Make it Manageable. Together We Make it Ours. We are grateful for our contributors and for the many anonymous donors helping to build pathways and bridges for HSP and PLS. We welcome your suggestions and for a list of current fundraising ideas scan the QR code below. Our goal is to make this easy and fun, questions can be directed to [Jim.Sheorn@sp-foundation.org](mailto:Jim.Sheorn@sp-foundation.org).

Special Note: Starting January 2026, an updated tax receipt process has been implemented for SPF donations made by personal checks. All financial and in-kind contributions will receive a personalized year-end summary statement, instead of receiving a receipt for each donation. No change to credit card donations. Those contributions receive an email acknowledgement after each donation. For example, all donations made in 2026 will be summarized and sent in January 2027.





## MARK YOUR CALENDAR

Follow events by going to [SP-Foundation.org](http://SP-Foundation.org)

- March:* Check out our updated website & Plan a P2P Fundraiser
- April:* Sign Up for Monthly Giving Program: "Partners In Hope"
- May 1-Oct 31:* 5K Run, Walk or Roll – Gather your circle
- May 2:* Elleaire Fore Golf Tournament
- June 15-17:* 26<sup>th</sup> Annual Conference in St Louis
- July:* Watch your mailbox for the 2026 Annual Report
- August:* Pampered Chef
- August:* Make A Will Month – Join our "Legacy Circle of Love"
- August:* Summer Synapse Edition with Conference Photos
- August 23-29:* HSP & PLS Awareness Week
- September 12:* Golfing for Rare Diseases
- October:* Fall/Winter Synapse Edition
- October 17:* World Awareness Day
- November 1- December 31:* Year End Fundraiser Match

WEAR PROUDLY  
YOUR  
HSP and PLS  
SPF  
AWARENESS  
SWAG



SCAN TO DONATE  
BY CREDIT CARD



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

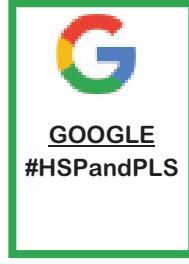
Send an email with your ideas, JPGs, or VECTOR files to:

[INFORMATION@SP-FOUNDATION.ORG](mailto: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.

FIND, FOLLOW, LIKE, COMMENT & SHARE  
FIND SOCIAL MEDIA LINKS ON THE BOTTOM  
OF EVERY WEBPAGE ON SP-FOUNDATION.ORG



SHOP SPF-STORE  
SCAN TO SEE  
AVAILABLE  
PRODUCTS

#HSPandPLS — [SP-Foundation.org](http://SP-Foundation.org)  
[Information@SP-Foundation.org](mailto:Information@SP-Foundation.org)  
(877) 773-4483

# Giving, Bidding & Building Hope Together: Starts at the SPF Registration Table

## Raffle Baskets and Auctions:

See all Baskets, Quilts & Many Items in the BE HEALTHY EXPO Salon I & II  
Winners will be drawn Tuesday evening after the Dinner Banquet  
All donations & purchases benefit the *Spastic Paraplegia Foundation, Inc.*

### BIG NEWS for the SPF 2026 HSP/PLS Conference in St. Louis!

This year, we are excited to make participation more accessible than ever before. For the first time, portions of our conference raffle and auction experience will be expanded through the conference livestream, allowing more members of the HSP and PLS community to participate and support SPF research from anywhere.

Over the years, generous families, businesses, organizations, and supporters have donated incredible products, adaptive devices, wellness tools, artwork, gift baskets, and mobility-related items to help raise funds for the **Spastic Paraplegia Foundation's research mission**. Previously, attendees needed to be physically present to participate and win. This year, we are opening new opportunities for both onsite and virtual engagement.

Throughout the conference, attendees may purchase raffle tickets and place them into the drawing containers beside the specific baskets or items they hope to win. This allows participants to choose which prizes they would most like the chance to receive while directly supporting SPF's mission to advance therapies, research, health, and wellness for individuals and families living with **Hereditary Spastic Paraplegia (HSP)** and **Primary Lateral Sclerosis (PLS)**.

Featured raffle baskets will include themed favorites such as:

- ✦ “Sip Happens” — wine and entertaining collection
- ✦ “Spa Night” — luxurious self-care and relaxation items
- ✦ “Red, White & Blue” — celebrating America's 250th Birthday
- ✦ Your Medical Store Baskets
- ✦ Additional wellness, therapy, adaptive living, and specialty baskets

In addition to the raffle experience, **Tuesday evening after the Annual Banquet Dinner** will feature a special **Live Auction Call**, where select high-value and one-of-a-kind items will be auctioned live in front of attendees and livestream participants. Featured items may include beautifully handcrafted quilts, artwork, specialty gifts, adaptive products, and other unique donated treasures from our incredible community supporters. (Visit the Registration Desk for complete details.)

Thanks to the livestream and virtual engagement opportunities, individuals who are unable to attend in person may still:

- ✓ Coordinate bidding through friends or family onsite
  - ✓ Participate remotely in select auction opportunities
  - ✓ Support SPF research from home using a credit card
  - ✓ Arrange shipment of many items if traveling or attending virtually
- To participate virtually, please make arrangements in advance with a friend attending to help you place a bid or participate in the ticket sales for the Basket Raffles.

To help celebrate our generous supporters and build excitement within the community, raffle and auction winners are also agreeable to allow their names and photos to be shared through SPF's website and social media platforms. Most importantly, every raffle ticket purchased, every auction bid placed, and every donation made directly supports SPF's efforts to accelerate research, therapies, education, and hope for families affected by HSP and PLS. This is more than a fundraiser — it is a celebration of resilience, community, innovation, and the pathway forward toward health, therapies, and wellness.

♥ Thank you for helping us create hope together.

SEE DETAILS AT THE REGISTRATION TABLE  
INFORMATION WILL BE SHARED DURING THE LIVE STREAM FOR VIRTUAL PARTICIPANTS

### Purchase Raffle Tickets!

\$1/1

\$5/6

\$10/13

\$20/28

\$50/70

\$100/150

All credit card charges  
include a nominal  
processing fee

SCAN TO DONATE  
BY CREDIT CARD



# Basket Raffle

Big Thank you to "Your Medical Store" for donating raffle prizes. Winners will receive these in the mail directly from "Your Medical Store". Please consider supporting "Your Medical Store" in appreciation of their generous support of the SPF community and families living with HSP and PLS, visit <https://www.your-medical-store.com>.



**Raffle Items: Purchase raffle ticket for a chance to win one of the following prizes. The drawing will take place after the dinner on Tuesday evening.**



LIGHTWEIGHT  
2 WHEEL WITH  
SWIVEL  
WHEELS AND  
PADDED SEAT  
VALUED AT \$59



ULTRA  
LIGHTWEIGHT  
HEIGHT  
ADJUSTABLE  
3 WHEEL  
ROLLATOR WITH  
SEAT  
VALUED AT \$139



COMPLETE  
TENS SYSTEM,  
VALUED AT \$59



STRONGARM  
COMFORT CANE  
REVOLUTIONARY  
DESIGN  
VALUED AT \$69



ORIGINAL  
LONG U  
WHEELCHAIR  
CUSHION,  
VALUED  
AT \$129-\$149



STEP2TUB  
ADJUSTABLE  
BATHTUB  
SAFETY STEP  
STOOL, VALUED  
AT \$134



MEMORY FOAM  
BODY PILLOW  
FOR SIDE  
SLEEPERS  
BY AVANA  
VALUED AT \$69



COLD  
COMPRESS  
THERAPY  
WRAPS &  
COOLING UNIT  
VALUED AT \$139



PATIENT LIFT SIT TO  
STAND TURNER  
VALUED AT \$279



WHEELCHAIR  
EARLY RISE  
CUSHION  
VALUED AT \$42



Visit onsite the "Be Healthy Expo" in Salon I & II to see Raffle and Auction Items & Other Vendors



FOR VIRTUAL PARTICIPANTS INTERESTED IN:  
BIDDING ON AUCTION ITEMS, OR  
BUYING RAFFLE TICKETS:

THEN  
(1) MAKE ARRANGEMENTS IN ADVANCE WITH A FRIEND ONSITE ,  
OR

(2) SEND A MESSAGE TO SPF FUNDRAISING CHAIR  
JIM SHEORN AT 877-773-4483 BY 2:PM TUESDAY, JUNE 16, 2026  
TO MAKE ARRANGEMENTS



# AUCTION ITEMS

## Quilts & More

See these beautifully displayed quilts  
and other items in the  
BE HEALTHY EXPO Salon I & II



**HSP/PLS T-SHIRT BLANKET**  
Donated by  
**Christine & Andrew Hendrickson**  
Made with 16-shirts cut into panels  
on grey plush backing  
making it 4.5ft x 4.5ft in size.



**HSP/PLS WARRIOR QUILT**  
Made and donated by **Vicki Joines**.  
The 60" wide by 67" long pattern  
is called **Labyrinth**.  
All materials are 100% cotton.



**Classic Irish Chain Quilt**  
Made and donated by  
**Annette Lockwood and family**  
Queen Size 108" x 80"



**"Imagine the Day"**  
Made and donated by  
**Annette Lockwood and family**  
10x8 print in a 12x10 frame



**Baby Quilt 48"x40"**  
Made and donated by  
**Annette Lockwood and family**.



# "Be Healthy Expo"

Visit with Vendors and see Raffle Baskets, Quilts and many other items in Salon I & II

## Dr John K Fink Gait Analysis



Javier Tuel & Justine Bast  
Tuel Shed Training  
Discuss & Download the Free  
"Believe Stronger" Training App

Visit with Stephanie Ovalle, MSAES  
Mobility Specialist and  
Sherry Brady Technology Explorer

DEEP TISSUE MASSAGE  
BY  
RAY PRESNELL  
314-882-8383  
ptaray2001@yahoo.com  
CALL TO SCHEDULE AN  
APPOINTMENT SOON



Visit with those that brought their own Alinker



[Find More QR CODES Scattered Throughout the Conference Booklet](#)

SPASTIC PARAPLEGIA FOUNDATION, INC

[SP-Foundation.org](http://SP-Foundation.org) | (877) 773-4483

[Information@SP-Foundation.org](mailto:Information@SP-Foundation.org)

## QR-Code Center

DONATE BY CREDIT CARD



SPF MEMBER REGISTRATION



ONLINE AGENDA



PHYSICIAN/CLINIC DIRECTORIES



SPF TALKS



SPF EVENTS



**17** **1**  
Countries Global Day

**United for Awareness**  
**WORLD HSP & PLS DAY**  
**October 17**

Hereditary Spastic Paraplegia and Primary Lateral Sclerosis affect thousands worldwide. Together, we're making our voices heard.

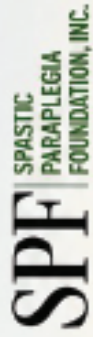
**One voice. One day. Global impact.**

**#HSPandPLS**  
**#HereditarySpasticParaplegia #PrimaryLateralSclerosis**  
**#SpasticParaplegia**

**SP-Foundation.org**

# A JOURNEY TO HEALTH, THERAPIES & WELLNESS

## THE SPF ROADMAP: DRIVING DISCOVERY. EMPOWERING LIVES. TRANSFORMING THE FUTURE.



**SPF AS THE ARCHITECT**

Convening Global Experts

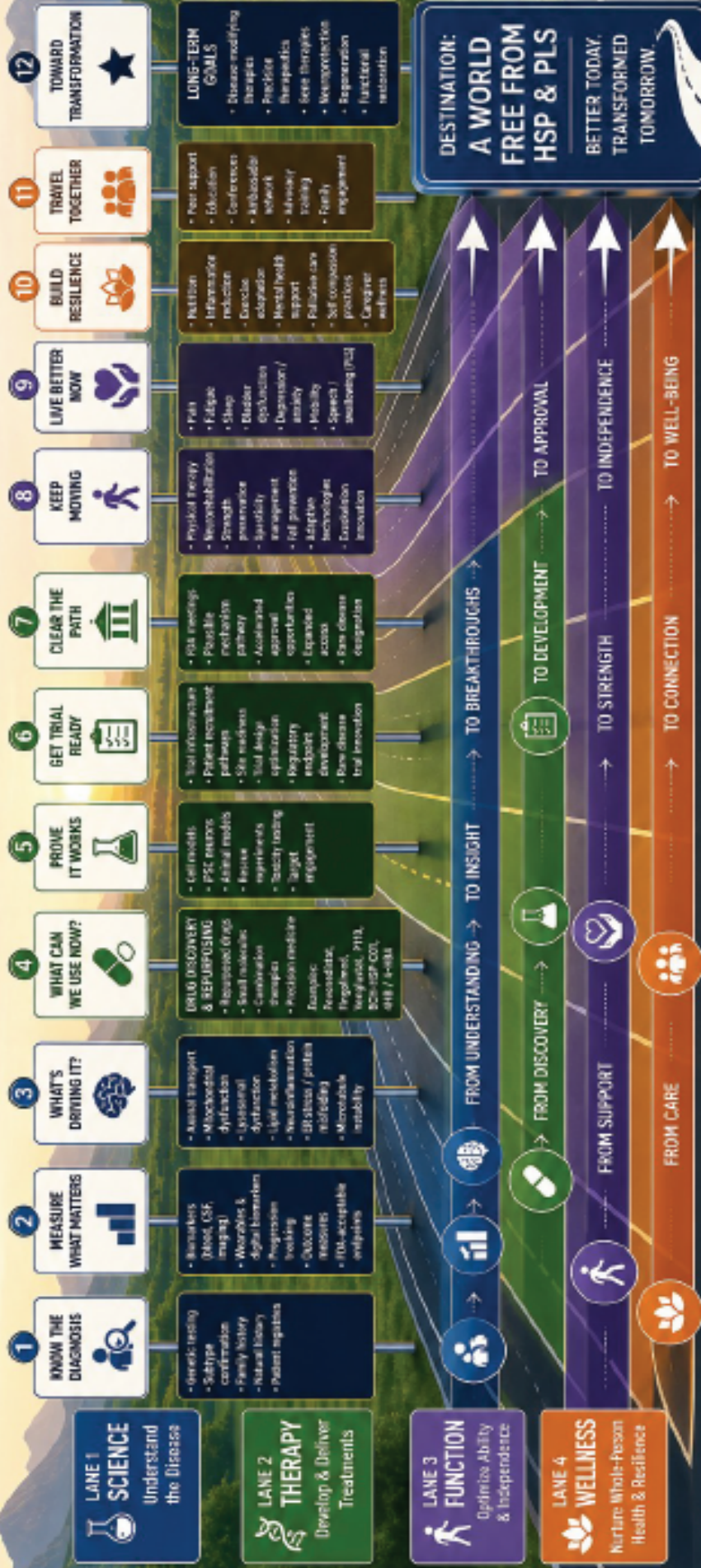
Funding Priority Science

Building Regulatory Bridges

Amplifying the Patient Voice

Accelerating Therapies

Guiding every step of the journey for a world free from HSP & PLS



PATIENTS & FAMILIES AT THE CENTER OF EVERY DECISION



TOGETHER, WE ARE ACCELERATING HOPE AND CHANGING LIVES.

JOIN THE JOURNEY. SUPPORT THE MISSION. TRANSFORM THE FUTURE.

*We don't just hope for a better future— we build it.*

# SPF BOARD OF DIRECTORS & WORK OF THE FOUNDATION



**Greg Pruitt**  
SPF President  
SPF Board Member



**Hank Chiuppi**  
SPF Secretary  
SPF Board Member



**Sara Kramer**  
SPF Board Member



**Norma Pruitt**  
Executive Director



**John Cobb**  
SPF Board Member



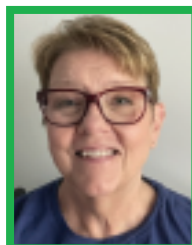
**Dina Landphair**  
Co-Chair, SPF Education/  
Ambassador  
SPF Board Member



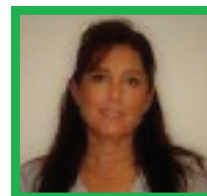
**Becki Cochran**  
SPF Board Member



**Jim Sheorn**  
Vice President  
Chair, SPF Fundraising  
Former SPF President  
SPF Board Member



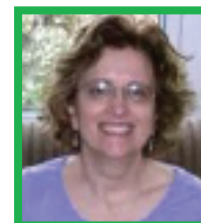
**Tina Croghan**  
Co-Chair, SPF  
Advocacy  
SPF Board Member



**Carina Thurgood**  
SPF Board Member



**Frank Davis**  
President Emeritus  
SPF Board Member



**Jackie Wellman**  
Co-Chair, SPF Education/  
Ambassador  
SPF Board Member



**Lorri Steiner**  
SPF Treasurer, CPA



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



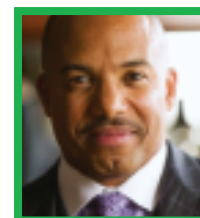
**Tim Croghan**  
Conference Emcee  
Chair, SPF Marketing



**Adam Futrell, ESQ**  
SPF Legal Counsel



**Linda Arnold**  
Fundraising &  
Relationship  
Development Manager



**Leonard Erskine**  
Co-Chair,  
SPF Advocacy

SPF KIDS-TEENS



**TUESDAY JUNE 16, 2026**

- 8:00—8:30 AM \*Grand Ballroom — Welcome
- 9:30-10:30 AM **Salon IV—World Bird Sanctuary**
- 10:30-11:10 AM **Salon IV— Adaptive Living (Carlson)**
- 11:15–12:00 PM \*Grand Ballroom — Inspiration, Motivation & Your Health 1 (Tuel)
- 12:00–1:00 PM \*Grand Ballroom —Lunch with Special Guest STL Cardinals Mascot Fredbird
- 1:15–1:45 PM \*Grand Ballroom —Rajul Sachdeva & Marcondes França Neurostimulation & Functional Neurology
- 2:00-3:00 PM **Salon IV—Missouri Botanical Garden**
- 3:00–4:15 PM \* Grand Ballroom — 7 Stages of Disconnection, The Truth About Health No One Ever Explained (Nepute)
- 4:15–5:00 PM \*Grand Ballroom —Christi Lero Practical Self-Compassion —Grand Ballroom
- 5:00–6:00 PM Free Time and/or Attend Breakout Sessions Women’s Session & Men’s Session

Many Thanks to SPF Assistants  
Onsite Helping With NextGen! Students:

- Judy Hejnal
- Blair Sheorn
- Susan Parker
- Avery Parker

**WEDNESDAY JUNE 17, 2026**

- 8:00AM \*Grand Ballroom —Welcome / Free Time or Return to family
- 10:00-11:30 AM- **Salon IV—St Louis Zoo**
- 11:30–12:00 PM \*Grand Ballroom —Inspiration, Motivation & Your Health 2 (Tuel)
- 12:00–1:00 PM \*Grand Ballroom —Lunch with Special Guest STL Blues Mascot Louie Bear
- 1:00–1:45 PM \*Grand Ballroom — Watch Me Walk Production Overview & Alinker (Gridley, Alink)
- 2:00-3:30 PM **Salon IV—Magic with Jeff Lefton**
- 3:30–4:15 PM \*Grand Ballroom —Toxemia: The Silent Health Crisis (Nepute)
- 4:15–5:30 PM \*Grand Ballroom —Cionic, Mobility Innovation & Functional Independence (Brady & Ovalle)

\* Free time or Return to hear the speaker in the Grand Ballroom



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



**Saint Louis Zoo**  
Saint Louis Zoo  
One Government Drive,  
St. Louis, MO 63110  
314-646-4677  
stlzoo.org



**Missouri Botanical Garden**  
4344 Shaw Blvd, St. Louis,  
MO 63110, (314) 577-5100,  
www.mobot.org;  
314-577-9473 ext. 76455  
missouribotanicalgarden.org



**Lefton Comedy Magician LLC**  
Jeff Lefton,  
30 Wydown Terrace,  
St. Louis, MO. 63105,  
(314) 608-6547  
leftoncomedymagician.com

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

# NOTES

# NOTES

# QUICK AT A GLANCE SCHEDULE

## MONDAY

9:00am—12:noon SPF Board of Directors Meeting

1:00pm—6:00pm SPF Global Regulatory & Scientific Forum on HSP/PLS: From Data to Approval

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

Dinner on your own & Social Mingle

## TUESDAY

7:30 AM - 5:30 PM Registration/Information Desk Open

Enjoy breakfast on your own / Coffee, Tea, Water and Drinks Available All Day

8:00–8:30 AM Welcome & SPF Opening Vision Greg Pruitt & Tim Croghan

8:30–9:00 AM Darius Ebrahimi-Fakhari

9:00–9:30 AM Craig Blackstone

9:30–10:00 AM John K. Fink

10:00–10:30 AM Collin Hovinga

10:30–11:00 AM Srikanth Ranganathan

11:15–12:00 PM Javier Tuel

12:00–1:00 PM Lunch with Special Guest: STL Cardinals Mascot Fredbird

1:15–2:00 PM Rajul Sachdeva & Marcondes França (Virtual)

2:00 –2:45 PM Michael Pacold (Virtual) & Claire Miller (Virtual)

3:00–4:15 PM Eric Nepute

4:15–5:00 PM Christi Lero:

5:00–6:00 PM Breakout Sessions: Women's Session & Men's Session

5:30PM Registration/Information Desk Closes

6:15 PM last call for raffle ticket sales

6:30 PM Dinner, Raffle & Auction Banquet

Social Mingle

## WEDNESDAY

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

7:30am - 8:30AM Fruit, Pastries, Coffee, Teas, Water and Drinks Available for 1-hour

8:00–8:30 AM Hande Ozdinler

8:30–9:30 AM Peter W. Baas / Liang Oscar Qiang / Emanuela Piermarini:

9:30–10:00 AM Claire Pujol (Virtual)

10-11:00 AM Snacks Refresh—Fruit, Coffee, Teas, Water and Drinks Available for 1-hour

10:00–10:30 AM Lorri Steiner (Virtual)

10:30-11:15 AM Nancy Carlson

11:15–12:00 PM Javier Tuel

12:00–1:00 PM Lunch with Special Guest: STL Blues Mascot Louie Bear

1:00–1:45 PM Anne Gridley and BE Alink (Virtual)

2:00–2:45 PM Kyle Moylan

2:30–3:45 PM Afternoon Snacks Coffee, Teas, Water and Drinks Available for 45-minutes

3:00–4:15 PM Eric Nepute

4:15–5:30 PM Sherry Brady & Stephanie Ovalle

5:30pm - Registration/Information Desk Closes

Dinner on your own & Social Mingle



Thank You for Sharing your Time with Us <sup>Year Around and</sup> in STL, MO!

