SPASTIC PARAPLEGIA FOUNDATION

21ST ANNUAL *Conference*

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

RESEARCH | EDUCATION | SUPPORT

HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS

#HSPandPLS

SP-FOUNDATION.ORG

JUNE 21 - 23, 2024
SP-FOUNDATION.ORG

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INFORMATION@SP-FOUNDATION.ORG

RENAISSANCE TAMPA
INTERNATIONAL PLAZA HOTEL
4200 JIM WALTER BOULEVARD,
TAMPA, FL 33607
(813) 313-3289

President's Welcome

...and a Hello from the Executive Director

Welcome SPF Warriors to Tampa!

On behalf of the SPF Board of Directors, we welcome everyone to the 2024 SPF Annual Conference. We look forward to visiting with every member attending this event. We want all of us to get to know one another just a little better, sharing our life challenges, as well as our strong commitment to working together finding treatments and cures for both primary lateral sclerosis and hereditary spastic paraplegia.

Endless Momentum has been our theme for the past two years. We all have been an importantpart in creating momentum in fundraising and bringing attention to the desperately needed medical research for a cure. Because of your work, generosity, and partnership, we were able to form a collaboration with a group of doctors and researchers to create a pilot program named the Spastic Paraplegia Centers of Excellence Research Network at the 2023 Annual Conference in St. Louis. We believe this network is the momentum toward accelerating clinical trial readiness, supporting therapy development, and increasing access to high-quality healthcare.

Thank you again for joining us at the 2024 Annual Conference. Tampa is a beautiful place to celebrate and enjoy the Sun, Sand and SPF!! We need everyone working together in this mission. Enjoy visiting with old friends and be sure to meet new ones! Over 50% are first-time attendees! Help us in welcoming everyone. We look forward to meeting all of you over these next few days. Please let us know if we can do anything to assist you in any way.

Wishing You Our Best Always,
Greg and Norma Pruitt

Endless Momentum
Sun Sand & SPF
Tampa 2024
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SP-FOUNDATION'S ANNUAL CONFERENCE
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KB
KRIS BROCCHINI

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

MATT HARDIN

THE CONLIN FOUNDATION

Joshua COCHRAN Toby - Becki

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WELCOME RECEPTION

Friday, June 21, 2024

6:00PM - 7:30PM

Catch up with old friends, make new ones, and meet physicians and researchers

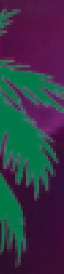
RENAISSANCE Tampa Internation Plaza Hotel
LaFuente Courtyard

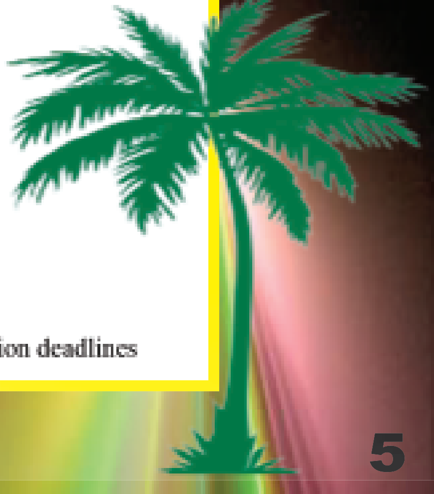
Find Like Ribbon Colors for those with PLS or HSP specific SPG number from SPG 3A to SPG 11 to SPG UKNOWN (numbers may vary slightly based on late registrations)

AL	1
AR	2
AZ	2
CA	4
CT	7
DE	2
GA	10
FL	33
IL	11
KY	2
MD	2
MI	5
MO	8
NC	7
NE	4
NH	2
NJ	6
NV	2
NY	5
OH	4
PA	4
SC	6
TN	3
TX	18
UT	4
VA	7
WA	5
WI	3
WV	3
WY	2
....	
UK	3
Canada	2

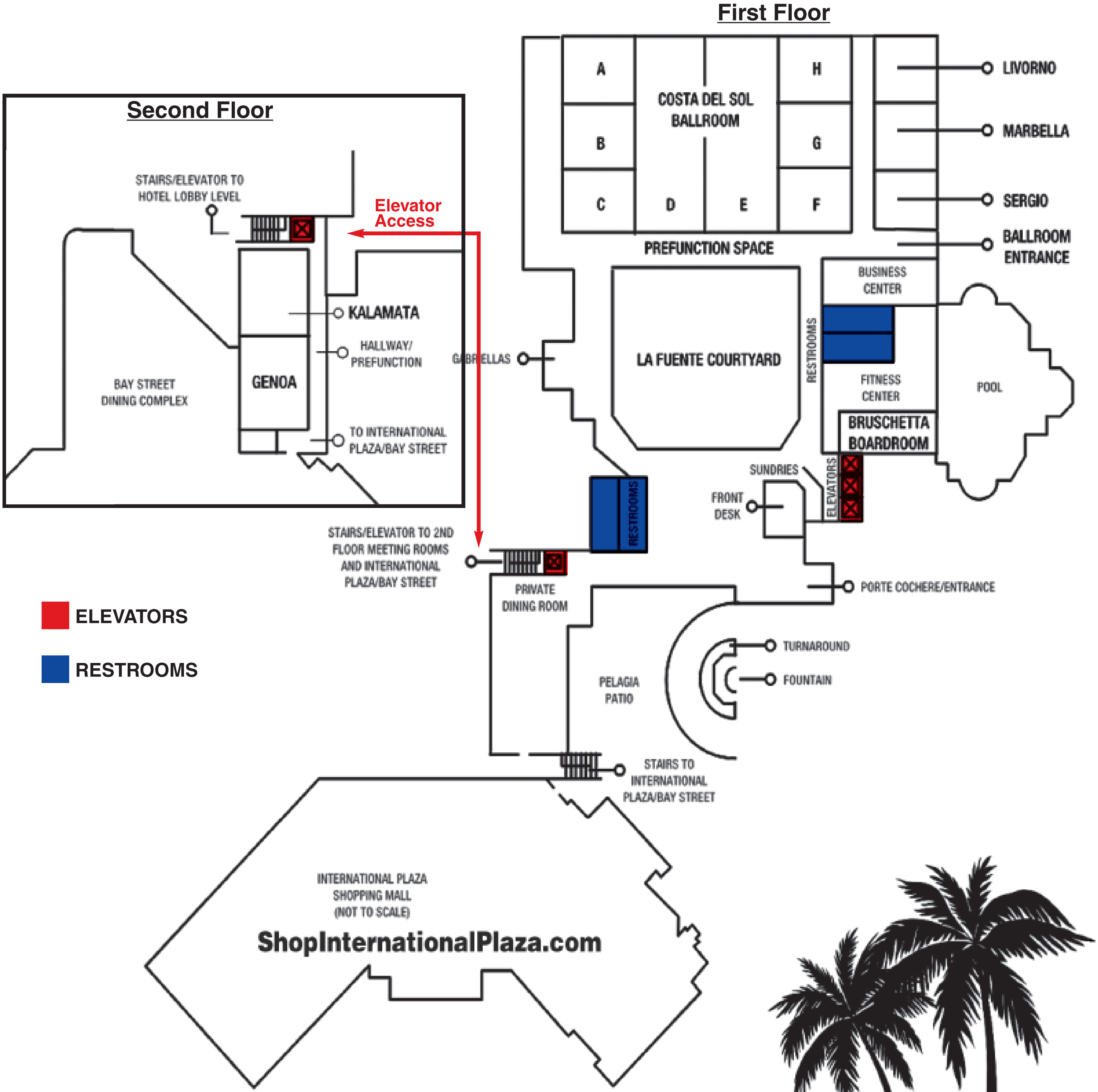
- 🟨 **PLS** (Canary) — 18
- 🟦 **ALS (Ocean Blue)** — 1
- 🟪 **SPF Unknown** (Lavender)—27
- 🟫 **SPG 3A** (dk Brown) — 2
- 🟩 **SPG 4** (Hot Green) —22
- 🟥 **SPG 5A** (Burgundy) — 3
- 🟥 **SPG 7** (Hot Pink) —18
- 🟧 **SPG 8** (Copper) —2
- 🟩 **SPG 11** (Ice Mint) —1
- 🟪 **Student+Youth** (dk purple, eggplant)— 8
- 🟥 **Parents** (Burnt Orange) — 17
- 🟩 **First Time Attendees** (dk green) — 96
- 🟩 **Ambassadors** (dk Teal)
- ⬛ **Board Members** (Black)
- 🟧 **Exhibitors** (Orange)
- 🟨 **Committee Chairs** (Goldenrod)
- ⬜ **President and Past Presidents** (White)
- 🟥 **Speakers** (Red)
- 🟦 **Sponsors** (Royal Blue)
- 🟥⬜🟦 **Staff** (Red White Blue)

Numbers may vary due to registration deadlines





SPECIAL THANKS TO STAFF AT RENAISSANCE



Doctors, Researchers, Special Guests

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

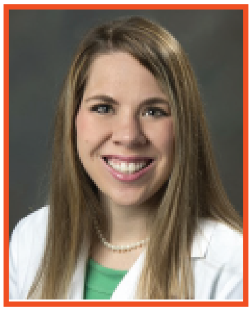
Dr. Peter Baas Professor of Neurobiology and Anatomy at Drexel University College of Medicine, where he is also Director of the Graduate Program in Neuroscience and Director of the T32/NIH-funded Training Program in Spinal Cord Injury.
Dr. Baas has studied *SPG4*-HSP for the past 15 years and has focused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

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

Dr. Craig Blackstone is Chief of the Movement Disorders Division at the 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.

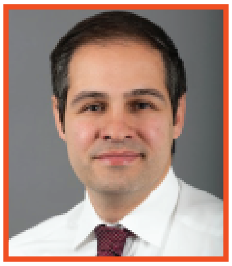
Daniel Calame, MD, PhD | (832) 826-7500 \ Daniel.Calame@bcm.edu
Baylor College of Medicine, Molecular and Human Genetics
6651 Main St, Ste F320, Houston, TX 77030 | texaschildrens.org

Dr. Daniel Calame is a Clinical Instructor at Baylor College of Medicine. He is a pediatric neurologist specializing in rare neurogenetic conditions including hereditary spastic paraplegia and established an Undiagnosed Neurogenetics Clinic at Texas Children's Hospital. He works with Prof. James R. Lupski, MD, PhD, DSc (hon) and is a member of the Baylor College of Medicine GREGoR Research Center (Genomics Research Elucidates the Genetics of Rare diseases), a research program devoted to "solving the unsolved" in rare Mendelian disease. The BCM-GREGoR is one of five institutions within the NHGRI-funded GREGoR consortium which applies cutting-edge multi-omic technologies including short- and long-read whole genome sequencing, transcriptomics, methylation studies, and metabolomics to find genetic diagnoses for undiagnosed patients. His work, supported by an SPF grant to Prof. Lupski, led to an *Annals of Neurology* publication establishing gene-disease validity for the ATP-ADP ectonucleotidase gene *ENTPD1* as a cause of SPG64. He will discuss this work as well as unpublished work demonstrating the importance of phenotypic expansions, allelic series, and HSP mimics in solving the unsolved in pediatric HSP.



Michelle R. Christie, M.D. | 214-559-7830 | Michelle.Christie@tsrh.org
Director of Neurology and Rehabilitation Medicine at Scottish Rite for Children
Director of Clinical Neurophysiology at Scottish Rite for Children
2222 Welborn Street Dallas, Texas 75219

Dr. Michelle R. Christie received her undergraduate degree from the University of Texas at Austin and doctorate from the University of Texas Health Science Center at Houston where she completed her general pediatric and pediatric neurology training. After residency, she completed a fellowship in clinical neurophysiology, becoming an expert in performing neurologic procedures such as electroencephalogram, nerve conduction studies/ electromyography and intra operative neurophysiological monitoring in pediatric patients. She is double board certified in neurology with special qualification in child neurology and clinical neurophysiology. She enjoys treating all neurologic disorders but has special interest and research in hereditary spastic paraplegia (HSP), holoprosencephaly (HPE) and Charcot-Marie-Tooth disease (CMT). Her professional associations and affiliations include the American Academy of Neurology, The American Association of Neuromuscular and Electrodiagnostic Medicine, and the American Academy for Cerebral Palsy and Developmental Medicine. She is an assistant professor in the Department of Pediatrics and Neurology at UT Southwestern Medical Center and practices at Scottish Rite for Children. Christie has been included in D Magazine's Best Pediatric Specialist list (2020).



Darius Ebrahimi-Fakhari, MD, PhD. | 617-355-8356
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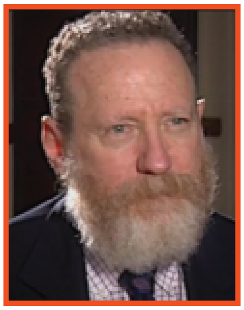
Dr. Darius Ebrahimi-Fakhari is a pediatric neurologist and neuroscientist at Boston Children's Hospital and Harvard Medical School. He leads the Movement Disorders Program at Boston Children's Hospital. His research interests cover childhood-onset neurogenetic and neurodegenerative diseases. His team 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 zebra fish, and high-throughput small molecule and functional genomics screens.



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

Hiroshi Mitsumoto, MD, DSc | 212-305-2940 or 212-305-1319
Wesley J. Howe Professor of Neurology (at CUIMC)
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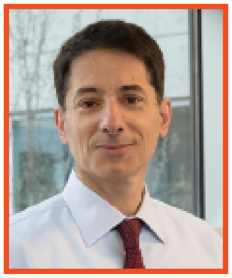
Dr. Hiroshi Mitsumoto is a Wesley J. Howe Professor of Neurology at Columbia University Medical Center and the Director of the MDA/ALS Clinical Research Center since 1999. In 1968, he graduated from Toho University School of Medicine, Tokyo. Beginning in 1972, he pursued further medical and neurology training at Johns Hopkins University, Case Western Reserve University, Cleveland Clinic, and Tufts University. In 1983, he began working at the Cleveland Clinic as the Director of the Neuromuscular Section and ALS Center. He has since been involved with extensive research in ALS, including improving patient care/management and end of life issues, multiple clinical trials, biomarker development, and multi site epidemiological studies. He organized several large national and international ALS Conferences and is currently updating and developing the new International ALS Clinical Trial Guidelines. He has published more than 170 articles in peer-reviewed journals, mostly in ALS, in addition to reviews, chapters, and books. For more than a decade, his research interests have expanded to PLS.



SPF Scientific Advisory Board Chairman
Paolo Moretti , MD | 801-585-7575 | paolo.moretti@hsc.utah.edu
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Staff physician, Neurology - George E. Wahlen VA Medical Center
500 Foothill Boulevard, Salt Lake City, UT 84148

Dr. Paolo Moretti is an Associate Professor of Neurology and the Division Chief of Movement Disorders and Cognitive Disorders at the University of Utah. He is also a staff neurologist at the Salt Lake City VA Medical Center. Dr. Moretti received his MD from the University of Padua, Italy, and he completed Neurology Residency at the University of Michigan. He also completed a Clinical Genetics Fellowship at Baylor College of Medicine, and postdoctoral research fellowships at Columbia University and Baylor College of Medicine. His clinical and research interests are in movement disorders and genetics of neurological disorders. He evaluates and treats patients with movement disorders at the University of Utah and the Salt Lake City VA and he runs a neurogenetics clinic at the University of Utah. Dr. Moretti is an Co-Investigator in the Undiagnosed Diseases Network and he leads an active research and clinical trials program in movement disorders.

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Northwestern University, Feinberg School of Medicine
Faculty, Chemistry of Life Processes Institute
Faculty, Les Turner ALS Center
Faculty, Cognitive Neurology and Alzheimer's Disease Center
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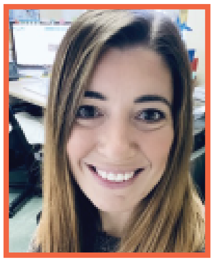
Dr Hande Ozdinler is an Associate Professor of Neurology at the Department of Neurology, Northwestern University, Feinberg School of Medicine, directing a research lab that focuses on understanding the biology of upper motor neurons. She received training in the fields of molecular biology, genetics, 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.



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

Dr. Emanuela Piermarini 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 then 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,
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Dr. Liang Oscar Qiang boasts a strong background in the research of neurodegenerative diseases. Having earned his MD and MS degrees from Nantong University in 2000 and 2003, respectively, he went on to complete his PhD at Drexel University in 2009. His doctoral thesis, "Functional Analyses of Microtubule Severing Proteins in the Central Nervous System," revealed his extensive knowledge and expertise in the field. Following his postdoctoral research on Alzheimer's and Parkinson's diseases at Columbia University Medical Center, Dr. Qiang joined Angriocrine Bioscience in 2013 as a principal scientist. He was a key figure in the establishment of an in vitro platform of the blood-brain barrier for drug screenings in the 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.

Luca Schierbaum, Ph.D. | luca.schierbaum@childrens.harvard.edu
Department of Neurology, Boston Children's Hospital
300 Longwood Avenue, Boston, MA 02115
Email: luca.schierbaum@childrens.harvard.edu

Dr. Luca Schierbaum is a researcher with a passion for translational research focused on genetic diseases. During her pediatric rotations, Luca developed a keen interest in congenital diseases, which ultimately became the focus of her doctoral thesis. She was awarded a one-year research stipend from the University of Bonn to investigate copy number variations in patients with posterior urethral valves. Her genetic interest led her to Boston Children's Hospital as a research student, where she conducted Whole Exome Sequencing (WES) analysis in patients with congenital anomalies of the kidney and urinary tract (CAKUT). Her work was supported by the DAAD biomedical education program. She graduated medical school at the University of Bonn in 2021, before starting her pediatric residency at the same institution. Luca then chose to broaden her research scope, eventually finding her passion in hereditary spastic paraplegia. In January 2024, she returned to Boston Children's Hospital and joined the Ebrahimi-Fakhari lab as a postdoctoral fellow, where she leads the HSP Sequencing Initiative for patients with undiagnosed movement disorders, including children and young adults with progressive spasticity. Her research is funded by the Walter Benjamin Scholarship. Ultimately, Luca's long-term goal is to increase the diagnostic yield of genetic testing in patients with movement disorders by developing a comprehensive standard pipeline for identifying genetic diagnoses, as well as expediting the development of personalized gene-modifying therapies.

Amy Tam, BS | 617-355-2698 | amy.tam@childrens.harvard.edu
Clinical Research Specialist, Department of Neurology,
Boston Children's Hospital (BCH), 300 Longwood Avenue
Boston, MA 02115, Mailstop: 1 Autumn Street, Room AU418

Amy Tam coordinates the research studies around hereditary spastic paraplegia led by Dr. Darius Ebrahimi-Fakhari at BCH. She trained through the Computational and Systems Biology undergraduate program at UCLA and worked with Debbie Marks, PhD, at Harvard Medical School to predict protein and variant function using evolutionary information before moving into the translational and clinical research spaces. At BCH, she worked with gene discovery in the context of bioinformatics and clinical research. She now works with Dr. Fakhari toward clinical trial-readiness and molecular therapies through work spanning natural-history studies, gene discovery, and patient advocacy. Amy is also preparing to pursue further training through an MD-PhD program so that she can more effectively advance molecular therapies.

Stephan Züchner, MD, PhD, FAAN | 305-243-2281
Professor for Human Genetics and Neurology, Chief Genomics Officer, Miller School of Medicine
Chair Emeritus, Dr. John T. Macdonald Foundation Department of Human Genetics, John P. Hussman Institute for Human Genomics | University of Miami Miller School of Medicine, Biomedical Research Building (BRB) | Room 616, LC: M-860, 1501 NW 10th Avenue, Miami, FL 33136

Stephan Züchner is a Professor of Human Genetics and Neurology in the role of Chief Genomics Officer at the University of Miami Miller School of Medicine. He received his degrees from the University RWTH Aachen, Germany and an honorary doctoral degree from the Semmelweis Medical School in Budapest. His research interests are focused on identifying strong genetic variation associated with disease. His lab been involved in identifying nearly 100 neuromuscular disease genes, including for spastic paraplegia and related disorders. He also leads the GENESIS genome database for rare neurological diseases, which is widely used in rare disease genomics studies. To further enhance the ability to identify pathogenic variation, his team has recently developed machine learning tools that have successfully supported gene identification. All this is directed towards the genomics-to-therapy concept, whereby progress in genomics will directly, and at times rapidly lead to therapeutic options to be tested in clinical trials. Other relevant roles include his leadership in the ClinGen efforts, the Board of Undiagnosed Disease foundation, and advisory roles to the Muscular Dystrophy Association, the Charcot-Marie-Tooth Association, and the HSP Research Foundation.

Thomas (Thom) J. Hart, J.D., | 305-439-0684 | thart@c-path.org | c-path.org
C-Path Institute, Director of Outreach, 1840 E. River Rd., #100, Tucson, AZ 85718

CRITICAL PATH INSTITUTE

Thom Hart has spent nearly two decades advocating for individuals with lived experience in navigating healthcare and addressing barriers to access related to poverty, health care access, and discrimination. Thom has worked closely stakeholders from across the industry to inform the projects and programs impacting health and ensuring the voice of lived experience is reflected in research and policy decisions.

Thom has a BA in Bioethics from Wittenberg University and a JD from the University of Miami School of Law, where he earned honors as a Senior Fellow at the school's Center for Ethics and Public Service. Thom has also clerked for the Supreme Court of the Navajo Nation and served as Minnesota Justice Foundation Staff Attorney at the University of Minnesota Law School. Thom's background includes state and federal health policy advocacy for a Fortune 50 company, global strategy design and execution for new drugs in the pharmaceutical space and developing inclusive recruitment and engagement tools to improve health outcomes. Recently, Thom co-authored an article in Harvard Law School's Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics on ADA accommodations for mental health conditions.

Natalie Downs, MS, CGC | natalie@rarebase.com
Senior Project Manager, Genetic Counselor | rarebase.com

Rarebase

Rarebase is a genetics-focused therapeutics startup based in Palo Alto, CA. Using high-throughput screening of thousands of compounds in vitro, their premier drug discovery engine maps molecular structure and drug action to the whole cell transcriptome, revealing therapeutic candidates that impact gene expression to treat disease. Sr. Project Manager Natalie Downs is a board certified genetic counselor who draws on her clinical perspective and genetics expertise to oversee complex drug discovery partnerships for Rarebase. She is dedicated to Rarebase's mission of delivering novel therapies to patients impacted by genetic disease.

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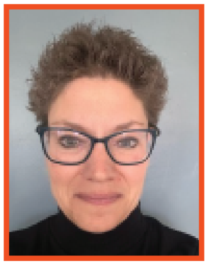
https://www.youtube.com/channel/UCFyXndBSFVaVaaB1Ah-Q5LQ

Dr. Lauren Leiva is a multidimensional Doctor of Physical Therapy who merges ancient divine wisdom with modern medicine. Connecting the mind, body, spirit, and heart, Dr. Leiva truly embodies sacred healing; healing that addresses and pinpoints every patient need. Dr. Leiva identifies both the physical and energetic forces of the human anatomy in her Physical Therapy work. Combining both physical and energetic medicine has supported her large variety of patients, from hometown families to NFL players. Mom, wife, daughter, sister, yogi and Doctor of Physical Therapy, are only titles that express the nurturing capacity of Dr. Leiva. Dr. Leiva is more than a title, she is love personified. Her healings, teachings, and expressions, all serve the bigger picture of being the voice for the new generation of highly intentional doctors that are emotional, energetic, AND intellectual. Her capacity to overcome all odds is just as inspiring as her clinical work. Anything you need will be met with compassion at The Excerscience Center, Tampa, Florida. From hospital bed to successful Doctor of Physical Therapy, Dr. Leiva is the living example of the healer that had to heal first to shed wisdom into the world. Welcome Dr. Leiva!

ZACHARY LIPSON | zlipson1999@gmail.com
Adapthletics | https://adapthletics.com/

Zachary Lipson is an adaptive personal trainer committed to showcasing the incredible capabilities within our community. As someone who personally navigates hereditary spastic paraplegia, he embraces a unique perspective on life-all aimed at dismantling the misconception that disability defines us. Despite the challenges, he has transformed his journey into one of resilience and achievement, with a passion for helping individuals of all abilities reach their fitness and wellness goals. It is his mission to reshape the perception of disability. He will share fitness and yoga techniques like chair yoga, stretching, and even adaptive boxing.

His focus is on celebrating achievement and tailoring exercises to match your unique needs. Consciously stay away from a focus of limitation- and instead celebrate your strength through positive progress. By nurturing an inclusive environment, he work with you to embrace your abilities and surpass the beliefs of what you think to be possible. Starting when he interned with an adaptive fitness organization, which transformed into the adaptive fitness coordinator at the YMCA of Delaware, he has spent years refining his approach to make adaptive fitness accessible and enjoyable for individuals of all diverse abilities. Now based in South Florida, he has immerse myself in the world of disability culture! Welcome Zachary!



Linda LaFontaine (spg7)
President, Hereditary Spastic Paraplegia Canada
Ottawa, ON, Canada | lindajlafontaine@gmail.com

HEREDITARY SPASTIC PARAPLEGIA
funding • research • treatment

Living with Hereditary Spastic Paraplegia (HSP) for almost 20 years, the questions and answers I had at the beginning of my HSP journey, are pretty much the same ones I have now. So in an effort to change that and generate more information, I am working to advance research and ultimately to find a cure. I partnered with the NEURO at McGill University in Montreal (Québec, Canada) to create a patient driven HSP cohort. This cohort will populate the different pathways of the disease to benefit the entire HSP community regardless of nationality. I'm doing that by using the power of Open Science. Linda is now working on adding to the PLS cohort within C-BIG in the same way. She strongly believes that all rare diseases need to stick together. Linda is married to James McLaren who adds a touch of humor to her nerdy endeavors. James is my rock!

James McLaren— With a degree in Physics although he currently teaches math, chemistry, and biochemistry at Algonquin College in Ottawa, Canada. James has made a career of devising ways to explain difficult concepts in memorable ways. James is married to Linda Lafontaine who has been a member of SPF for three years. This is his third SPF Conference, including last year in St Louis where he memorably drove his actual Chevy to an actual levee. (Okay, it was Linda's Chevy, but close enough! It wasn't dry either.) In his spare time James goes camping, attends SPF Conferences, paddles, and cycles. He also enjoys sky gliding, hang diving, and authoring biographies with suspicious penultimate sentences. He is old enough to not want to tell you how old he is.

MORPH'D
Presented by PAR

THE FLORIDA AQUARIUM

THE FLORIDA AQUARIUM

701 Channelside Drive, Tampa, FL 33602
P:813-273-4015 | flaquarium.org

Terrestrial Animal Ambassadors - Meet a variety of The Florida Aquarium's animal ambassadors in this informal education program. The animal ambassador collection may consist of baby alligators, lizards, snakes, turtles, and toads.

MOSI
KEEP DISCOVERING

MUSEUM OF SCIENCE & INDUSTRY

4801 E. Fowler Avenue, Tampa, FL
Office: 813.987.6000 | MOSI.ORG

Cryo-Cool Workshop - MOSI scientists use liquid nitrogen to demonstrate super cool science at subzero temperatures, with investigations into solids, liquids, and gases. Students will have the chance to take a closer look at heat transfer and what effect the flow of energy has on states of matter.

US YOUTH SOCCER

FYSA TOPSOCCER: WWW.FYSA.COM/TOPSOCCER
USYS TOPSOCCER : WWW.USYOUTHSOCCER.ORG/TOPSOCCER

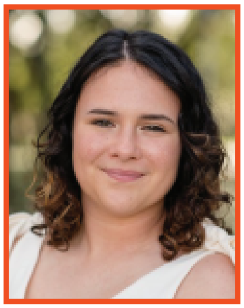
Jennifer DiTillio's remarkable dedication to the Florida Youth Soccer Association TOPSoccer Committee includes three years as Chairperson and seven years of prior service. Her contributions have fostered inclusivity in soccer within Florida and at the national level as the South Region Representative for TOPSoccer on the United States Youth Soccer Association. Jennifer's leadership led to supporting existing programs, establishing new ones, and implementing a grant program for equipment. Her passion for inclusivity in soccer is evident through her impactful initiatives, serving as an inspiration to the soccer community. Email: jsmith.tops@outlook.com

Bob Stover embarked on his soccer journey four decades ago, initially as a player. His dedication extended to coaching, leading to active participation on the FYSA Board of Directors. During his tenure on the board, Bob expanded his engagement by contributing to TOPSoccer. Drawing from his involvement with Special Olympics, Buddy Break, and A Night to Shine, Bob enriched the TOPSoccer program. Presently, Bob plays a pivotal role in the TOPSoccer committee, assuming the position of Program Trainer. He has participated in numerous national events and organized three USYS TOPSoccer events in Florida. Questions Email: flsoccerbob@gmail.com

Susan Kessel | staceykemp80@gmail.com
Canine Companions® | Southeast Region | www.canine.org

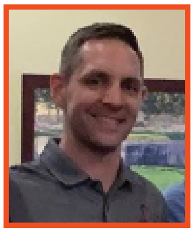
The Central Florida Chapter of Canine Companions serves the Central Florida area. Our chapter includes graduates, volunteers, puppy raisers and donors who are enthusiastic about supporting the mission of Canine Companions – providing expertly-trained assistance dogs for people with disabilities, and free of charge.

Leah Frohnerath | MS, CCLS, CEIM,
Certified Child Life Specialist Facility Dog Handler
P 727-767-7877| C 727-287-1965 | allkidscanines@jhmi.edu
Johns Hopkins All Children's Hospital Child Life Department
501 6th Avenue South, St. Petersburg, FL 33701
www.HopkinsAllChildrens.org| Insta: allkidscanines



Ainsley Basham| Director of Operations and Education
4113 Henderson Blvd & 4110 W Estrella St, Tampa, FL 33629
Direct 813-957-3320 | Plant & Gift Shop 813-755-9579
Conservatory 813-551-2359 (Bfly)
www.ButterflyTampa.com www.LittleRedWagonNativeNursery.com
www.TampaBayButterflyFoundation.org

Through education and outreach, our goal is to increase awareness about the importance of pollinators and our natural environment. We aim to inspire people about the ease and joy of natural gardening for homes, businesses, schools, and farms. We intend to work with our city, and neighboring cities, to do the same in the hope of helping to reverse the ongoing destruction of butterfly and pollinator habitats in our local areas by providing a place to experience and understand nature and beauty."



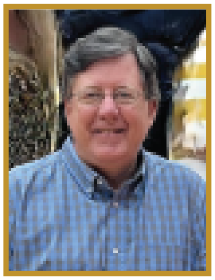
Parents of Childhood Onset

Hear from parents as they share their journeys navigating their new normal. Focusing on the years from early childhood to young adulthood, discussion topics will include diagnosis and the grieving process, building your medical team and exploring treatments, current reports and research information and ways to effect change. Join us for conversation and connections with other parents that "get it" and learn how to move from acceptance to action. Parents: Chris Lorek, Katie Gregg, Bridget Lassig

NOTABLES

COMMITTEE WORK OF

SPF President



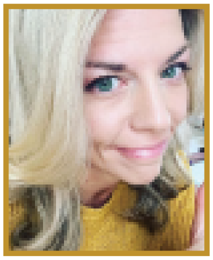
Greg Pruitt | SPF President
Pruitt@SP-Foundation.org |

Greg was elected SPF President in January 2022. He started as a board member in 2014 and served as volunteer SPF Co-Executive Director since the Fall of 2017. Greg is an attorney and served as Judge Executive for 26 years. In that capacity he served on and chaired a number of local, regional, state, federal, and multi-state organizations involving many areas such as tourism, health and social services, transportation, and economic development. Greg is a graduate of University of Kentucky College of Law. Greg and Norma have three children and five grandchildren. Greg has HSP, SPG4.

Marketing

Tim Croghan | Conference Emcee |
Chair, SPF Marketing Committee
Tim.Croghan@SP-Foundation.org

Tim is dedicated in supporting the Spastic Paraplegia Foundation. He, along with his wife, Tina (an SPF Board Member, HSP, SPG7) lives in Missouri. They are a dynamic team focusing attention on advocating and raising funds to advance research efforts to find a cure for HSP and PLS since 2007. Tim serves as Chair of the SPF Marketing Committee and continues using his communication skills in assisting the SPF Annual Conferences.



Kim Sanchez | Florida Ambassador
SPF Marketing Committee Member
SPF Podcaster

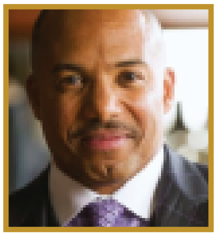
I share my journey with PLS, the highs and the lows, via my social media accounts “My Spastic Life”. After several years of strange symptoms, I was diagnosed with PLS (primary lateral sclerosis) July 2022. Kim lives near Dallas, TX, with two wonderful teenagers and has a great career in customer experience. I love drawing, music, cooking, being outdoors, smiling, working out (modified of course!), and living every moment of life to the fullest.

Research

John Cobb | SPF Board Member
Chair, SPF Research Committee
John.Cobb@SP-Foundation.org

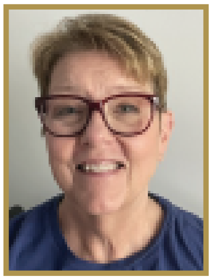
John has been a member of the SPF board since May 2013. He is passionate about furthering research for HSP and PLS. He and his wife, Jody, chair the Research Committee working with the Scientific Advisory Board to facilitate the funding of research grants. John is a data analyst at Slack Technologies, a popular workplace communication hub owned by Salesforce. He and Jody, and little Jamie live in Oakland, CA.

Advocacy



Leonard Erskine | Leonard.Erskine@SPFoundation.org
Co-Chair, SPF Advocacy Committee

Leonard is a graduate of Ohio State University and has been in the Pharmaceutical and Biotech Industry for over 30 years, where he has worked in sales, marketing, leadership, and market access.Leonard has been married to his college sweetheart, Liz, for almost 27 years. He is the father of three great kids and doggie dad to Gizmo and Gracie, his beloved Shi Tzu’s. Leonard serves as Chair of the SPF Advocacy Committee. Leonard is diagnosed with PLS.



Tina Croghran | SPF Board Member
Co-Chair, SPF Advocacy Committee

Tina Croghan is a retired teacher who still stands by the motto that she greeted each student as they entered her classroom with, “What we learn with pleasure, we never will forget.” With a Master of Arts in Theatre and a Master of Fine Arts in Directing from Lindenwood University – St. Louis, Tina uses her performance and people skills to inform, advocate and fundraise for the Spastic Paraplegia Foundation. Tina has HSP and was clinically diagnosed in late 2002. She has since received her genetic diagnosis of SPG7, and now looks forward to upcoming patient drug trials. Tina has been part of the SPF family since 2006 and has been the Annual Conference Chairperson for 2009 & 2013 (St. Louis) and 2016 (Chicago). She was a member of the conference planning committee for the 2017 conference in Atlanta and is again part of the 2018 planning committee for the Annual Conference in Pittsburgh. Tina became a member of the SPF Board in 2012 and has continued her efforts in finding a cure for HSP & PLS. Tina lives in O’Fallon, MO, with her husband, Tim, and her support dog, Thunder.

Education-Ambassadors

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

Dina joined the board in March 2021. Dina is a graduate of Iowa State University with a Bachelor of Architecture. She is a licensed architect, but took early retirement after 25 years of service. Dina lives in Adel, IA, with her husband and two boys. She was diagnosed with HSP, SPG7 in 2013. Dina is Co-Ambassador of Iowa and chairs the SPF Education-Ambassador Committee.

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

Jackie worked as a Medical Assistant until she was diagnosed with Hereditary Spastic Paraplegia in 1997. When diagnosed she opened her own business. She has volunteered in many ways, including a civil rights march in Georgia, working at a no-kill animal sanctuary in Utah, being a Big Sister, and worked on several political campaigns. She is currently the SPF Ambassador for Iowa. Her first book, Spiritual Clarity was published in 2005. Jackie spends many hours a week studying reports on medical research, communicating with others who are similarly involved, and looking for ways to raise money for SPF. She was named to the board in 2013. Jackie lives in Des Moines, IA, a with her husband, son, and two dogs.

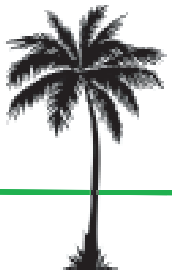
Tracy Hood | Florida SPF Ambassador
SPF Education/Ambassador Committee Member

Tracy Hood 52, resides in Seminole, FL, with her husband, Ron; they have 2 children, ages 25 and 21. Tracy experienced HSP symptoms in Spring 2015, confirmed as SPG5A through genetic testing at Mayo Clinic in summer of 2016. Tracy continues to work full-time, leading a technology Change Management team for HSN / Qurate Retail Group. Tracy is passionate about controlling what she can with HSP, by regular workout sessions with a personal trainer, yoga, walking, swimming and biking. Tracy & Ron attended their first SPF A/C in St Louis in 2023. Tracy immediately felt she could positively contribute to SPF by becoming an ambassador for FL. Tracy is actively engaged in SPF, through the ambassador program and is excited to connect with current and potential ambassadors at this year'sannual conference in Tampa!

Fundraising

Jim Sheorn | SPF Board Member
Chair, SPF Fundraising Committee
Former SPF President

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



SP-FOUNDATION ORGANIZATION

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

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

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

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

SPF Board of Directors:
President: Greg Pruitt
Vice President: Jim Sheorn
Secretary: Hank Chiuppi
Treasurer: David Lewis, Lorri Steiner
Legal Counsel: Mark Weber, Esq
President Emeritus: Frank Davis
Members: Dr. Corey Braastad, John Cobb, Tina Croghan, Dina Landphair, Carina Thurgood, Jackie Wellman

SPF Medical Advisor:
John K. Fink, M.D.
University of Michigan

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

Send Check Donations to:
Spastic Paraplegia Foundation,
6952 Clayborne Drive,
O'Fallon, MO 63368-6202

Send Online Donations to:
SP-FOUNDATION.ORG
* As a registered member of the SPFoundation you will receive eblasts and updates to:
* Synapse Newsletter [printed]
* Spastic Paraplegia World Newsletter [electronic]
* SPF Podcasts
* SPF TALKS a virtual outreach effort talking about subject matters of interest for people with HSP or PLS

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

How SPF Funds Research for HSP and PLS

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

Scientists are unraveling many of the riddles regarding the complicated biochemistry of these diseases. Many HSP genes have now been discovered as well as a gene for PLS. Animal models for these disorders have been developed, and will enable investigators to further uncover the biochemical processes that cause nerve degeneration and identify and test therapy targets.

SAB | Scientific Advisory Board
The process is simple, time-consuming, but effective. SPFs work with a world-renowned group of scientists that are experts in the field of neurological disorders such as HSP and PLS. This group of scientists works with us on a volunteer basis, they live all over the world and we call them our Scientific Advisory Board (SAB). Every research proposal we receive is submitted to be reviewed, carefully analyzed, and graded by at least 3 members of our SAB. The SPF Board of Directors reaches out to the SAB and asks them for their recommendations. The manager of our SAB, Dr. Moretti, collects, compares and contrasts all of the SAB reports regarding each research proposal and turns in their report card with recommendations to the SPF Board of Directors. We almost always follow their recommendations to support the very best HSP and PLS research in the world. The sad part of this process is that our SAB, in recent years, has graded several more of the research proposals as blue ribbon excellent than we have funds to support. Your donations are greatly needed and will be used in the most cost-efficient, effective method possible to fund the very best proposals.

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

NOTABLES

Spastic Paraplegia – Centers for Excellence Research Network

The Spastic Paraplegia – Centers for Excellence Research Network (SP-CERN) is the first Spastic Paraplegia Research Consortium in the United States.

Investigators dedicated to researching Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS) from around the United States have come together to create critical resources for the HSP and PLS community. The SP-CERN (Spastic Paraplegia Centers of Excellence Research Network) establishes a network of ten initial centers in North America. These centers bring together established physician-scientists and their multidisciplinary teams. SP-CERN will support the development of a registry and natural history study across all ages, a biobank for research biospecimens, and a genomic archive. These efforts will lay the groundwork for numerous opportunities to improve diagnosis and clinical trial readiness. Our objective is to harmonize this effort with similar consortia in Canada, Europe, Asia, South America, and Africa, to accelerate basic and clinical research on HSP and PLS globally. SP-CERN will provide critical research infrastructure for collaborative, high-quality research on HSP and PLS in North America and beyond.

The goal of the SP-CERN is to create clinical trial readiness, support therapy development, and increase access to high-quality healthcare for individuals with hereditary spastic paraplegia (HSP) and primary lateral sclerosis (PLS). Physician-scientists and their multi-disciplinary teams from ten different research centers across the United States will collaborate to develop a framework for translational research for HSP that will ultimately improve the lives of children and adults affected by HSP and PLS.

RESEARCH GOALS:
The initial phase of the SP-CERN aims to establish the center of excellence sites and organize national and international collaboration. The network will establish research infrastructure, will harmonize research protocols with international partners, connect patients and families affected by HSP/PLS, and build collaborations with partners in the biotechnology and pharmaceutical industry. The central infrastructure includes a prospective, longitudinal natural history study, a comprehensive repository of biospecimen and cell lines, and a state-of-the art genomics platform.

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
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HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS
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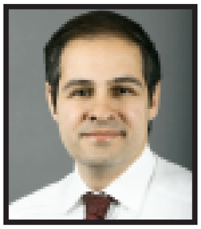
SP-CERN LOCATIONS



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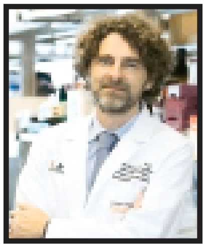
Telephone: 617-355-6388



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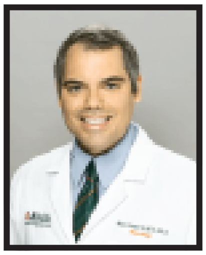
1501 NW 10th Avenue
Miami, FL 33136
Telephone: 305 9897835



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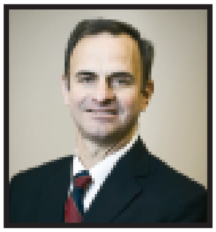
Telephone: 305 9897835



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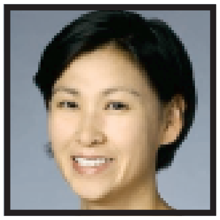

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Cincinnati, OH 45229-3039

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

ADVOCACY COMMITTEE

The main goal of the Advocacy Committee is to spread awareness of our diseases HSP and PLS through social media, press and TV media, and State and Federal legislators. We meet via Zoom once a month. If you would like to serve on the Advocacy Committee or would like to provide ideas or feedback, please contact us at Volunteer@sp-foundation.org.

HOW TO BECOME AN ADVOCATE FOR HSP/PLS

Research who are your legislators are:

— Openstates.org

— Join/monitor these websites for what's new:

- Everylifefoundation.org
- — Rarediseases.org (NORD—National Organization for Rare Disorders)

RESEARCH HOW YOUR STATE VOTES ON DISABILITY ISSUES

https://everylifefoundation.org/rare-advocates/advocacy-tools/legislativescorecard/

— Rarepatientvoice.com

— globalgenes.org

— Patientslikeme.com

MyID

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Many health conditions require more than a few words to explain. MyID has many features that a traditional medical ID does not. It allows you to easily access, store, manage, and share an unlimited amount of medical information on a secure platform that you can quickly access at the tip of your fingers.

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MYID will donate 10% of all sales from the code back to SP-Foundation! Use SPF20 at checkout to receive a 20% discount off your purchase!

ADVOCACY

WHAT ARE HEREDITARY SPASTIC PARAPLEGIA (HSP) & PRIMARY LATERAL SCLEROSIS (PLS)?

- HSP and PLS are progressive motor neuron diseases sharing common symptoms, weakness and spasticity. HSP is a genetic disease that many times affects several members of the same family in which symptoms can occur at any age. Although hereditary, anyone may be the first to experience the genetic mutation in a family. PLS Symptoms usually begin in the legs but may also start with the tongue or hands. Scientists believe that PLS is not hereditary.
- HSP and PLS are chronic neurological disorders that affect balance and the ability to walk, may cause pain, muscle spasms, stiffness, slurred speech and or neuropathy. Symptoms may begin anywhere from birth to middle age. There are currently no treatments or cures. One variant of HSP has a life expectancy in the first decade of life and there are children that are beginning life with no current option beyond wheelchairs.
- HSP and PLS are often misdiagnosed as ALS (Amyotrophic Lateral Sclerosis), MS (Multiple Sclerosis), Parkinson's Disease or Cerebral Palsy.

Spastic Paraplegia Foundation (SPF) Overview:

- The Spastic Paraplegia Foundation, Inc. is the only organization in the world that raises funds for medical research and is dedicated to finding cures for HSP and PLS. Since SPF's creation in 2002, SPF has raised and funded over $11 million in research grants.
- SPF is a nonprofit corporation (501(c)3), and donations to SPF are tax deductible.
- SPF has a Scientific Advisory Board (SAB) which conducts peer reviews of grant proposals from doctors and scientists around the world for medical research on HSP and PLS.
- In 2023, SPF agreed to fund a pilot program and work with an alliance of physicians and scientists to establish Centers of Excellence at top tier Universities, to support the development of a registry and natural history study across all ages, a biobank for research biospecimens, and a genomic archive. These efforts lay the groundwork for numerous opportunities to improve diagnosis and clinical trial readiness. Our objective is to harmonize this effort with similar consortia throughout the world to accelerate basic and clinical research on HSP and PLS globally. These efforts are important steps towards clinical trial readiness, significant funding, and working with agencies like the National Institutes of Health (NIH) and pharmaceutical companies towards finding treatments and cures.

Other Priorities:

- Working though our Advocacy team to get Compassionate Allowance support to enable expedient access to Disability Benefits for those with HSP and PLS.
- Raising awareness (Education) about these diseases for early recognition and to help prevent misdiagnosis.
- Early diagnosis (genetic testing, screening, orphan drug incentives) especially to determine which of over 100 known variants of HSP is present. Many cases remain undiagnosed.
- Accessibility including physical and travel accommodations, access to health care and medications.
- Helping our members with support – finding doctors, treatment centers, and other specialists, or just a friend that understands.

Contact:
Spastic Paraplegia Foundation, Inc., 501c3, *EIN: 04-3594491*
SP-Foundation.org | *877-773-4483* | Information@SP-Foundation.org

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PRIMARY LATERAL SCLEROSIS
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Two Rare Diseases That Should Be Included On The Compassionate Allowances Listing

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

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

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

Please contact your two U.S. Senators and your members in U.S. House of Representatives to help support the spastic paraplegia community by adding HSP and PLS to the Compassionate Allowances Listing for expedited and automatic approval of Social Security Disability Insurance.

Your action on this issue can help the 30,000+ people living with HSP and PLS rare diseases across the United States.

Contact:
Spastic Paraplegia Foundation, Inc., 501c3, *EIN: 04-3594491*
SP-Foundation.org | *877-773-4483* | Information@SP-Foundation.org

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EDUCATION AMBASSADORS

SPF EDUCATION & AMBASSADOR COMMITTE

The main goal of the Education and Ambassador Committee is to spread awareness of HSP & PLS and educate everyone of our rare diseases, specifically Patients, Family, Caregivers, Physicians/PT, and the General Public. The SPF Education & Ambassador committee meets once a month via Zoom. The agenda is sent prior to the meeting and meeting minutes/notes are sent afterward so everyone on the committee and the Ambassadors know what the meeting is about and can review it on their own time if they cannot attend. In addition to education, the committee is a place for Ambassadors to share ideas on how to contact SPF members and ways to get them involved. Ambassadors and Education Committee members should know where to find information on the SPF website to help educate others. See more details about the Role of the Ambassador at SP-Foundation.org.

Welcome FIRST TIME ATTENDEES to the
2024 SP-Foundation Annual Conference

Greetings and welcome to our SPFteam! Feel welcome among friends, families, and caregivers traveling on this journey with HSPandPLS. We're so glad you've joined us, and we're looking forward to meeting you and hearing about your experiences. We hope you make new friendships that you can keep for a lifetime.

It is essential for the attending doctors and researchers to see us as individuals fighting these rare diseases. They have a unique opportunity to watch disease progression annually, across all ages of patients, and your presence is important at these conferences for this reason. It's also an opportunity for you to interactive with so many physicians, doctors, and researchers — all in one place.

SPF aims to provide you with all the essential details you'll need for a productive and enjoyable conference. Please let us know at Registration/Info Table you need anything.

NOTABLES

AMBASSADOR VOLUNTEER INFORMATION

AMBASSADOR VOLUNTEER DESCRIPTION Ambassadors raise awareness about our disorders, as well as enhance community building and industry relationships. You can assist with media relations, share your story, speak at local groups, help with grassroots advocacy, or create a fundraiser. Please maintain respect for everyone with HSP or PLS in your area at all times, hold the Spastic Paraplegia Foundation in high regard and follow the guidelines presented by the Board of Directors. Both HSP and PLS must be represented equally at all times. Please use hashtag #hspandpls when posting online. If you are asked any questions by your membership group that you are not confident in answering, please direct them to the Board of Directors by emailing the question to volunteer@sp-foundation.org.

ESTABLISH A NETWORK AND LOCATIONS OF PEOPLE Ambassadors will receive, upon request, an Excel spreadsheet of contact information for people in their state known to have HSP and PLS. The number of people will range from a few to many, and the information will range from just names and emails to full mailing addresses.

YOUR ROLE AS AN AMBASSADOR

●Ambassadors receive information about new people in their area who join our SPF community. It is essential to send them a "Welcome" email. Depending upon the area, this may be 1-12 people over the course of a year.

●Let people who live within reasonable proximity to one another know they are "neighbors" and encourage them to meet.

●Send out periodic emails as needed to maintain the regional network.

●Hold periodic group support meetings, formal events, or assist with fundraising activities.

●Try to obtain current contact information if the information provided on the original spreadsheet is incorrect as you talk with new members. Report updated information to SPF database coordinators at volunteer@sp-foundation.org.

●Encourage participation in annual conferences and monthly meetings.

CRITERION FOR AMBASSADORS

●Be one with an SPF disorder (HSP or PLS), be related to, or be a caregiver to someone who does.

●Be one who seeks to enhance the quality of life for individuals and brings energys and commitment to the SPF.

●Be comfortable with email, internet searches, Excel and Word applications.

●Make a commitment of one year.

●Respect and maintain the confidentiality of SPF members and not share personal information outside of SPF initiatives. Additionally, Ambassadors will respect the desire of individuals who do not want any further contact.
●Ambassadors and Education Committee members should know where to find information on the SPF website to help educate others.

HOW TO REACH OUT TO MEMBERS IN YOUR STATE/REGION Reach out to volunteer@sp-foundation.org to obtain a list of members in your region. Then use the sample welcome letter to send an email to the members in your state, which is found at: **HTTPS://SP-FOUNDATION.ORG/GET-INVOLVED/AMBASSADORS/**

WHAT TO EXPECT AS AN AMBASSADOR Participate in the monthly SPF Education Committee and Ambassador Meetings. Send a monthly email to members in your region with important updates from the monthly education committee and ambassador meeting. Stay connected to members in your region as a liaison and support member, giving them information they may need to feel connected in the SP community .

HOW TO STAY CONNECTED TO SPF MEMBERS
●Be a listener! Give suggestions and know who to contact for different requests.
●Be well versed in the SPF website. Visit it often to see what's new.
●Be a liaison! Know whom to contact and make sure to follow-up!
●Be a conduit! Especially for newly diagnosed people who don't know where to begin or what to ask. "Where do I start?"
●Be an example! (Practice what you preach!) If you are recommending stretching or other forms of exercise, make sure you are doing it, too.
●Send out periodic emails. However often—you decide. Be excited! Send pictures and short videos. Share what's happening with you.
●Update your contact information at least once a year. Let SPF know of a change. It costs money, in returned postage, that could be spent on research.
●Hold periodic group meetings. This can be formal (a connection with an agenda or speaker) or informal (a simple "let's meet for coffee!") as you like!

RESOURCES ON THE WEBSITE

WAYS TO DONATE: HTTPS://SP-FOUNDATION.ORG/GET-INVOLVED/DONATE-HERE/

AMBASSADOR RESOURCES:

HTTPS://SP-FOUNDATION.ORG/GET-INVOLVED/AMBASSADORS/

MEMBER RESOURCES:

HTTPS://SP-FOUNDATION.ORG/NEWS-RESOURCES/

FUNDRAISING

Ways to Support the Spastic Paraplegia Foundation

By Jim Sheorn, SPF Fundraising Chair

Credit Card Donations Online through the SPF website is the safest, easiest and fastest way to donate to SPF. One can make a single contribution or set up to participate with a Recurring Plan, giving monthly or quarterly, automatically by setting it up on the SPF website. It can be cancelled at any time. Our Recurring Donors are known as our "Partners in Hope". Once you give online, you will receive a Thank You by email. Those that mail in personal checks, will receive a thank you letter via the USPS mail. See the QRCode Center in this booklet to Donate by Credit Card.

Also, one can give online via PayPal, Facebook, and many other giving platform. Unfortunately, AmazonSmile is no longer contributing to non-profits. However, it may take several weeks after the contribution before we are notified. Donor data is not usually transmitted to SPF so we can't thank these donors for their contributions. The quickest, most efficient way to contribute to SPF is on the website under Get Involved, Donate Here on this link and QR Codes in the booklet: https://sp-foundation.networkforgood.com/projects/22291-spastic-paraplegia-foundation

Personal Checks must be mailed to 6952 Clayborne Dr, O'Fallon, MO 63368. The mailing address changed last year. Tim and Tina Croghan are now handling the check process for SPF. We would like to thank Linda and Craig Gentner for handling this process for many years. It takes time and resources to process the checks. If you can give online, it is much more efficient, safe, and does not require as many volunteers to manage.

Memorial/Honor - One can make contributions in Honor or in Memory of someone. If you would like SPF to notify someone about your gift, please let us know when setting up your contribution. There are also donation cards available on the website to download as a way to donate in lieu of flowers.

Facebook - It is easy to set up a Facebook fundraiser so that all your friends can participate. Please let SPF know if you do this so we can celebrate with you. Make sure to thank all your donors when doing FB fundraisers. FB does not provide SPF donor contact information, so we cannot thank your donors unless they are already in our database.

Matching - If you are employed, contact your human resource department to see if it might match contributions. It is usually easy to sign up. Let them know when and how much you contributed, and your gift may be doubled up to a limit your employer may have set.

Planned Giving is a great way to include SPF in your will. As kids get older and on their own, one could plan to include SPF in one's will. Please check with your financial planner on how to set this up.

Stock Transfer - If you are limited in cash, but have a 401K or other financial investments, you can make a stock transfer. Check with your financial planner for details and ask what is needed to make the contribution. Also, please notify SPF of the transfer so that we can make sure it is received.

Grants - Many businesses have foundations set up to help them save money while helping the community. If you have a connection with a business, inquire and see if it makes contributions to non-profits. If so, it might contribute to SPF in your honor. SPF can help with the application process.

Sponsor - Please see the full list of sponsors for the Annual Conference. We have sponsorship levels available for every budget.

Body to Science - You can contribute your body to science. If you have any interest, please let us know. Plans would need to be set up in advance. The body would need to be received by the researcher in less than 24 hours after death.

Time - You can donate time. Each state has Ambassadors that help communicate with those in their area. They are knowledgeable of SPF and provide updates. There are also four committees that need your participation. Marketing, Education/Ambassador, Advocacy, and Fundraising are the working committees. If you have a special talent that you would like to share with SPF, please stop by the registration table, or let a Board member know.

Fundraising Campaigns - There are several events/campaigns each year that SPF hosts. Details are communicated via email, eblasts, and on social media. The following is a list for the remainder of 2024:
(1) 5K Run, Walk or Roll. You can run, walk, roll, and raise money. You can set up your own fundraising page on the website and then share it with family and friends. Please look under Get Involved and Events for more details. So far, 32 past participants have committed to participating this year. Our goal is to raise $80,000. Feel free to do your own fundraiser and help spread awareness. You can do your event any time now though Oct 31st. Can't run, walk, or roll? Pick your own form of exercise and make it happen. See the QRCode Center in this booklet to update your information—use the 5K-Run-Walk-or-Roll Setup QRCode.
(2) The Annual Report is usually available in early July. It is an opportunity for us to share financial successes with our donors. Many make contributions during this time.
(3) HSP & PLS Awareness Week is August 26-31, 2024. Please share your story with all those around you. Reach out to the media in your area and see if you can set up an interview. Please keep us in the loop with your exposure. I can provide talking points about SPF if you like.
(4) Giving Tuesday is a national day of giving held the first Tuesday after Thanksgiving, Dec 3, 2024. Many SPF donors contribute to this campaign. This will be promoted with social media and emails.
(5) Year-End Appeal begins the first week of November. SPF sends a Year-End Appeal letter to everyone in our database. Most non-profits raise more than 50% of their money with a year-end appeal letter. Last year, SPF raised almost $500,000 during this time. Contributions through Jan 15, 2025 will be counted for 2024. Last year, about $1.3 million was raised, the most ever! This year, with your help, we hope to raise $1.5 million. The Spastic Paraplegia Foundation is your foundation. We are going to need everyone here along with family and friends to reach our goal. Please don't forget to check with your employer about getting your contribution matched. You could double your investment in SPF.

The money collected from the annual conference registration fees, unfortunately, does not go toward funding research. SPF underwrites the cost of the conference, because the costs far exceed all collected fees. Help us reach our goal of raising $1.5 million dollars this year by making a personable contribution, reaching out to family, friends, and business associates. Our #1 goal is to help find treatment options and better yet cures. We cannot do that without YOUR financial support!

Please keep your SPF account updated. Making sure SPF has the correct mailing and email addresses are key to communicate with you. Also please provide whether you have HSP or PLS and your specific spgene if known. Also ask family members that are affected to registered. Having more people identified will help when medical companies are interested in doing research. Your personal information will never be sold or shared. See the QRCode Center in this booklet to update your information—use the SPF Member Registration QRCode.

POTATO PANTS FUNDRAISING & AWARENESS

POTATO PANTS EVENT

TOOLKIT: FOR YOUR OWN FUNDRAISER

PG. 1

1 YEAR TO 6 MONTHS BEFORE

Starting a fundraiser is easy to do, and it's fun!

1 *Choose a date, time and location*

Enlist schools. Schools host a Sport's Day or a Field Day at the end of the year for the children to engage in fun activities.

A Boy-Scouts or Girl Scouts of America facilities or camps.

A sports-center or park.

A shopping mall.

Be creative with other potential ideas.

2- 3 MONTHS BEFORE

You got this!

2 *Make at least seven pairs of Potato Pants*

The size of your pants will depend upon your audience: large enough for any adult body type and smaller pants for children!

3 *Make "potatoes"*

Tutorial For Step 2 & 3.

How to make "Potatoes" & Potato Pants

4 *Prizes*

can be as elaborate as a gift card or as simple as a plastic potato attached to a ribbon.

5 *Organize donation boxes*

6 *Decide entrants/racers tickets cost*

7 *Advertise the event*

Contact all your local media. Create flyers, posters, email, text, and don't forget to advertise on social media. Create individual fundraisers using Facebook, SP-Foundation, or other sources.

8 *Connect with the community*

Enlist the assistance of a good public speaker or even a DJ and add music to the Potato Pants Event.

Create a fact sheet describing the happening of wearing Potato Pants. Help others understand who SP-Foundation is in their quest to raise funds for medical research to Find a Cure. The speaker or DJ should help to motivate the crowd.

1 TO 2 MONTHS BEFORE

Your Almost There!

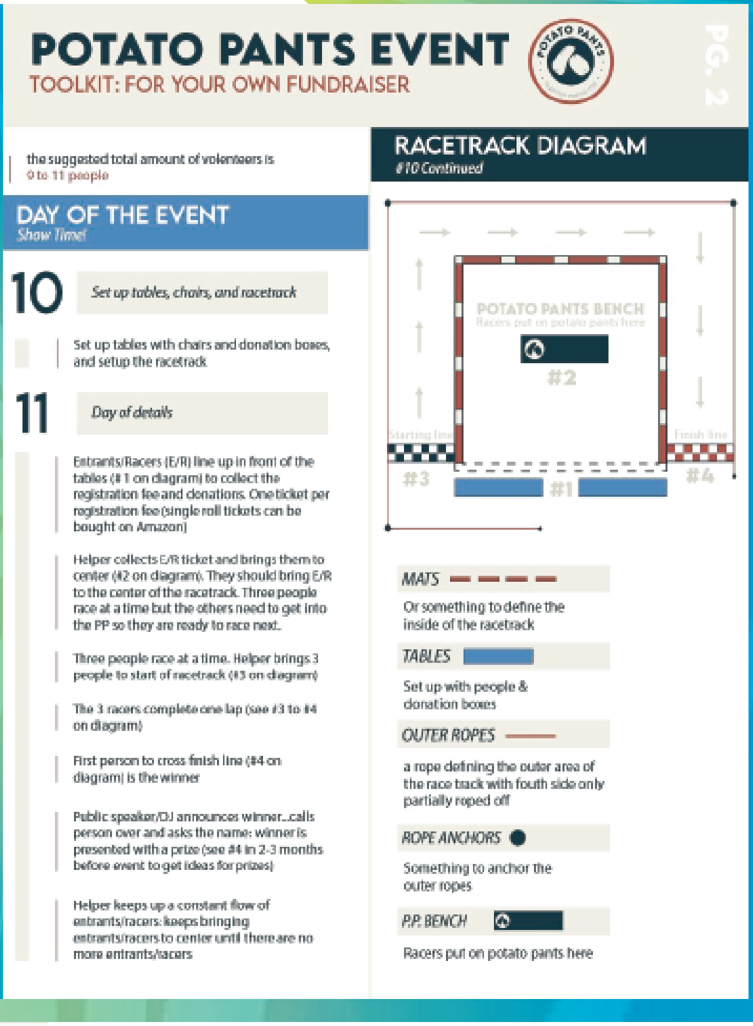
9 *Recruit valenteers*

4 people to help set up/break down racetrack
(4 people)

Secure 2-4 tables and chairs for helpers to collect registration fee from entrants to race
(2-4 people)

2 volunteers to help people get on the Potato Pants and to transition them to the starting line
(2 people)

1 public speaker/DJ
(1 person)



POTATO PANTS EVENT

TOOLKIT: FOR YOUR OWN FUNDRAISER

PG. 2

the suggested total amount of volenteers is
9 to 11 people

DAY OF THE EVENT

Show Time!

10 *Set up tables, chairs, and racetrack*

Set up tables with chairs and donation boxes, and setup the racetrack

11 *Day of details*

Entrants/Racers (E/R) line up in front of the tables (# 1 on diagram) to collect the registration fee and donations. One ticket per registration fee (single roll tickets can be bought on Amazon)

Helper collects E/R ticket and brings them to center (#2 on diagram). They should bring E/R to the center of the racetrack. Three people race at a time but the others need to get into the PP so they are ready to race next.

Three people race at a time. Helper brings 3 people to start of racetrack (#3 on diagram)

The 3 racers complete one lap (see #3 to #4 on diagram)

First person to cross finish line (#4 on diagram) is the winner

Public speaker/DJ announces winner...calls person over and asks the name: winner is presented with a prize (see #4 in 2-3 months before event to get ideas for prizes)

Helper keeps up a constant flow of entrants/racers: keeps bringing entrants/racers to center until there are no more entrants/racers

RACETRACK DIAGRAM

#10 Continued

MATS ▬ ▬ ▬ ▬

Or something to define the inside of the racetrack

TABLES ▬

Set up with people & donation boxes

OUTER ROPES —

a rope defining the outer area of the race track with fouth side only partially roped off

ROPE ANCHORS ●

Something to anchor the outer ropes

P.P. BENCH ▬

Racers put on potato pants here

RESOURCES LIST

Total price $295.46

1 *Plastic potatoes (for prizes)* - *$13.99*
Purchase: this depends on how many entrants you think you'll have - there are 30 potatoes in an order

2 *Satin Ribbon* - *$9.99*
Purchase: this or a similar blue

3 *Tickets* - *$ 6.95*
Purchase: we were not able to find less than a pack of 500 single roll raffle tickets but if you do, then purchase

4 *Brown Packing Tape* - *$20.88*
Purchase: one roll should be enough to make enough "potatoes" for 1.5 pairs of pants but there are 6 rolls in an order

5 *Plastic Storage Bags* - *$21.99*
Purchase: one order should be enough for to make "potatoes" for 7 pair

6 *Webbing* - *$17.99*
Purchase: 25 yards = 900 inches = enough for 7 pairs

7 *Buckles* - *$7.05/each pack of 6*
Purchase: 2 orders

8 *Scrubs* - *$13.47/ pair*
Purchase: this color or similar blue (2 pair for each PP so 14 in total)

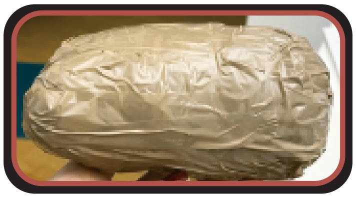
9 *Fabric* - *$6.99*
Purchase: whatever pattern delights you but just make sure that they are 20" x 20" (50 cm x 50 cm)

AND FINALLY...

Make sure to enjoy the race!

INFORMATION AVAILABLE ONLINE AT:

https://sp-foundation.org/get-involved/events/potato-pants.html



MARKETING

Synapse Newsletter -
Review Online or Download at:
https://sp-foundation.org/news-resources/newsletters/

<u>Spastic Paraplegia World</u> Electronic Newsletter
"Connecting Spasticity Worldwide"
Contact: SpasticWorldInfo@gmail.com

FIND—FOLLOW– LIKE– SHARE
SPF ON SOCIAL MEDIA

Facebook Pages
https://www.facebook.com/SpasticParaplegia
https://www.facebook.com/groups/CureHSPandPLS/

Twitter: @SpasticWorld AND @SpasticParapleg

Instagram: @SpasticParaplegia

Linked In: @spastic-paraplegia-foundation/

YouTube: https://www.youtube.com/channel/UCsZIM577T5rKs8hRjTouczA

Google: <u>#HSPandPLS</u>

Pinterest: @SpasticParaplegia

<u>SPF TALKS</u> SPF's virtual outreach effort talking about subject matters of interest to people with HSP or PLS. Ideas and to Request Zoom Link email: SPFTALKS@gmail.com

<u>SPF PODCASTS</u>
See at : https://sp-foundation.org/podcasts/

Register online has a member at SP-Foundation.org to receive eblasts and updates!
Questions Email Information@SP-Foundation.org

Visit Online the SPF STORE

SP-Foundation.org/SPF-Store

SHOP SPF STORE

SCAN TO DOWNLOAD

Check back often as more products will be added.
Ordering Issues Contact SpasticWorldInfo@gmail.com

SP-FOUNDATION.ORG
#HSPandPLS

Do you have a swag idea for a shirt or other products. Send an email to INFORMATION@SP-FOUNDATION.ORG with your ideas, jpgs, or vector files. We 'll upload them to our SPF Store to help raise awareness for #HSPamdPLS. Images must not have a copyright protection and must meet SPF graphic design standards.

SPF
AWARENESS 2024
#HSPandPLS
MONTH: August
WEEK: August 26-31
DAY: August 27th

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

WAVE YOUR AWARENESS FLAG

DONATE TO
Get Shirts,
Get Bracelets,
& Participate In
Door Prizes
and Raffles

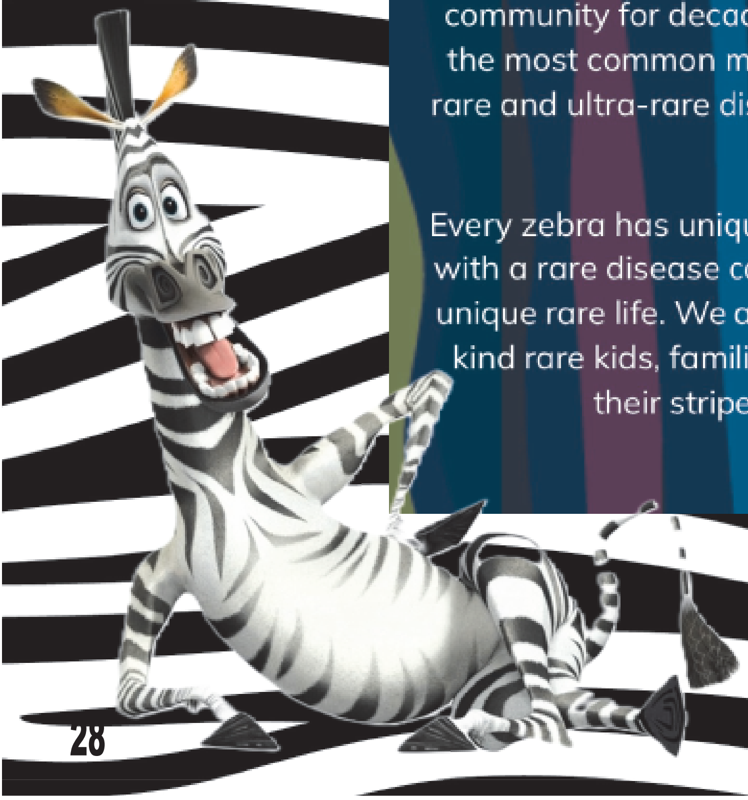
WHY ZEBRAS?

The zebra is commonly known within the rare disease community as the mascot for rare disease. In the 1940s medical professor Dr. Theodore Woodward made the statement to his interns,

"When you hear hoofbeats, think of horses not zebras."

This quote has been shared in the medical community for decades to guide doctors to look for the most common medical conditions first - but for rare and ultra-rare disease families we really are the zebras!

Every zebra has unique stripes, just like every person with a rare disease can have a unique mutation and unique rare life. We are proud of all of our one-of-a-kind rare kids, families, and supporters who show their stripes to care about rare!



SPF PODCASTS

MEET SPF SOCIAL MEDIA INFLUENCER

KIM SANCHEZ

Visit with Kim at the Exhibitor's Booth

Podcasting is a great way to share your journey and experience to the world. Podcasting is an increasingly popular medium for sharing ideas, telling stories, and information about rare diseases HSPandPLS.

SEE MORE DETAILS AS WE BUILD OUT THE WEBPAGE
SPF PODCAST—https://sp-foundation.org/podcasts/
SCAN QRCODE...

bitly

SPF Podcast

"This event is very educational. The agenda includes a wide variety of presentations. The conference addresses opportunities, challenges, and current events. We especially like meeting our old friends and making new ones. Little do my friends know, they're helping me every time we hangout together. Fixing the heart they didn't break and a life they didn't mess up, but just them understanding the journey is key. I may not say this enough but I appreciate you guys more than you could ever imagine." - past conference attendee

SPF
SPASTIC PARAPLEGIA FOUNDATION, INC.
#HSPandPLS
sp-foundation.org

SPF & Art

DONATE TO:
SP-FOUNDATION.ORG

Art
/ärt/ noun
the expression or application of human creative skill and imagination...

What is in your imagination?

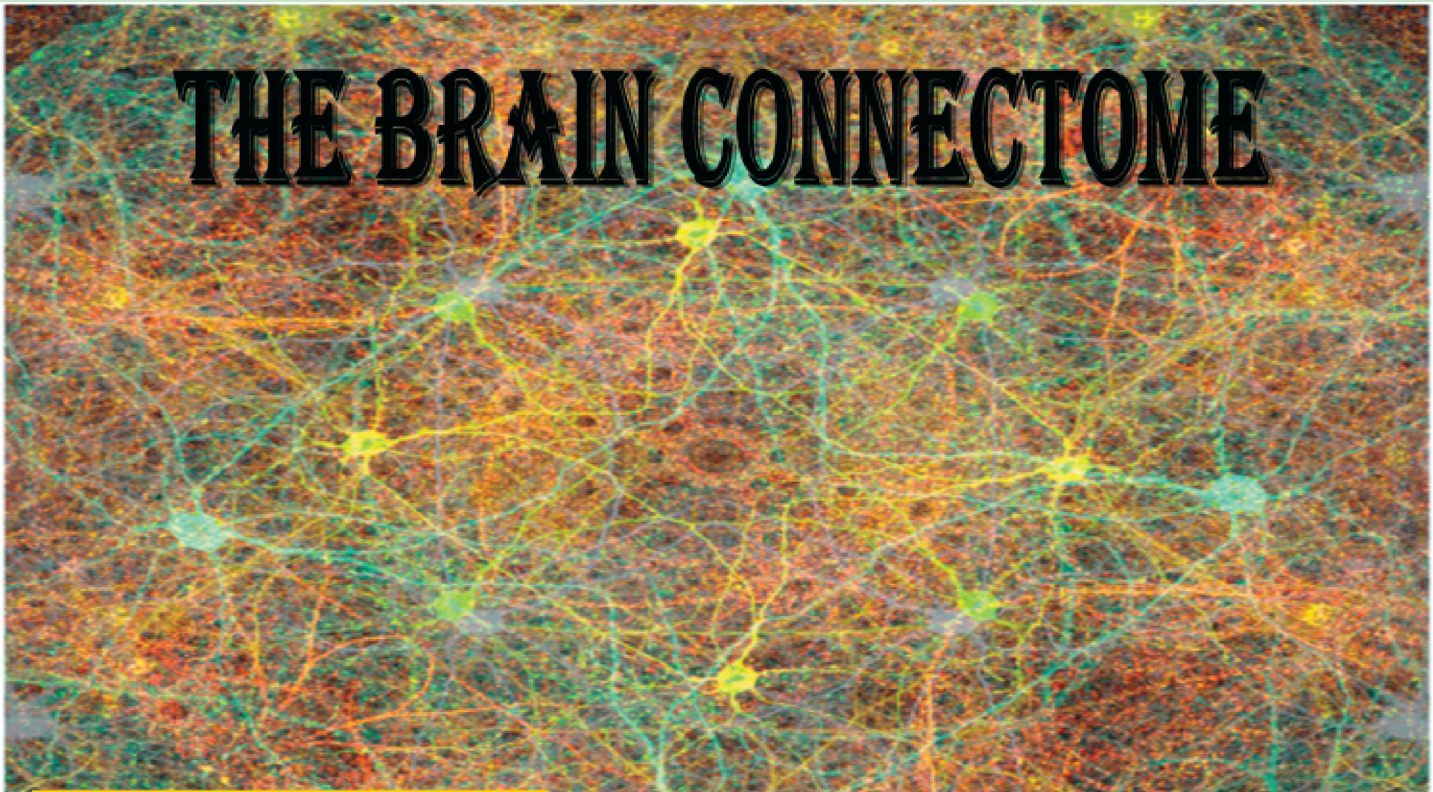
CURES & THERAPEUTICS,AND A MEDICAL REVOLUTION
LET'S CURE THE WORLD

What Happens in TAMPA Let's Tell the World!

email photos of you hanging out with friends at the conference to:
SpasticConference @gmail.com

#HSPandPLS Awareness

THE BRAIN CONNECTOME



Artwork made possible through a generous donation from

Dr. P. Hande Ozdinler

Dr. Ozdinler is a scientist, founding director of the Ozdinler Upper Motor Neuron Lab at Northwestern University, and the inventor of OzdinART, a new form of painting. She blends colors in such a way that they retain their identity and yet join in harmony. This is a photoART from Dr. Ozdinler, originating from an image she took with the microscope. This shows the brain connectivity and complexities. The large GFP neurons are the upper motor neurons. The size of the stunning photoART is 20" by 20".

The SP-Foundation values Dr. P. Hande Ozdinler for her commitment to scientific research and as an extraordinary friend to the Spastic Paraplegia community.

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
RESEARCH | EDUCATION | SUPPORT
HEREDITARY SPASTIC PARAPLEGIA
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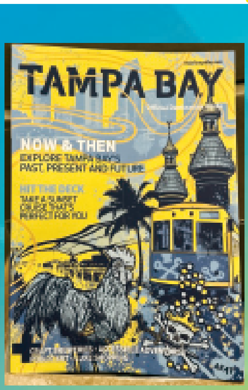
We're Glad You're In Tampa with SPF



VisitTampaBay.com

ShopInternationalPlaza.com/map#

Boasting 1.26 million square feet on two levels, over 200 specialty shops, 15 full service restaurants, and a luxurious four diamond hotel, this mall has something for even the most refined tastes. Its anchor's include such landmarks as Nordstrom's, Neiman Marcus, Dillard's, and Robb & Stucky Interiors. If all this shopping starts to overload your feet, and your purse, they offer a sunny, 125,000 square foot outdoor plaza to relax in before venturing back into the fray. In addition they offer excellent packages, that include hotel accommodations, relaxing amenities, and special savings. Thu/Fri/Sat:10:00AM-9:00PM / Sun:11:00AM-6:00PM / **Phone:(813) 342-3790**

NOTABLES

QR-Code Center

5K-Run-Walk-or-Roll Setup

SPF MEMBER REGISTRATION

SPF EVENTS

SPF TALKS

PHYSICIAN/CLINIC DIRECTORIES

SPF STORE

AMBASSADORS

ONLINE AGENDA

DONATE BY CREDIT CARD TO SPF

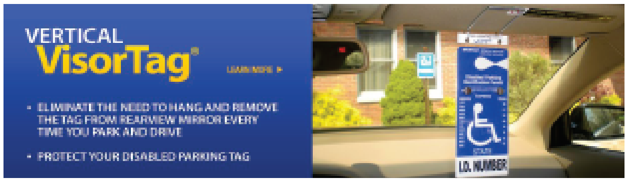
I'm an
HSPANDPLS
Advocate
I WORK TO #FUNDHSPANDPLS RESEARCH

I'm an
HSPANDPLS
Fundraiser
I WORK TO #FUNDHSPANDPLS RESEARCH

Auction - Door Prizes - Raffles

Please Visit Registration Desk for Additional Auction, Raffle, &/or Door Prize Items That May Be Available for Viewing Including These Below and the OzdinART:

Quilt Donated by Vicki Joines, sister in law to **Becki Cochran**. The size of the quilt is approximately 50"x52".



JL Safety
safety made easy

JL Safety | 1513 Waybridge Way | Weddington, NC 28104, 980-339-5334, www.JLSafety.com

Use Discount Code: "**SPF20**" to receive 20% off on all store products

Massage Envy Gift Cards

CADENSE
ADAPTIVE SHOES

INVITING BIDS FOR AN AUCTION CALL ON SATURDAY EVENING—SEE REGISTRATION TABLE FOR DETAILS ON WHICH ITEMS!

All funds raised benefit the Spastic Paraplegia Foundation

Raffle/Auction

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

Your Medical Store
Exceptional Products For You

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

#1 3 WHEEL ROLLATOR INNO DELUXE 11LB EURO STYLE VALUED AT $199

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

#3 COMPLETE TENS SYSTEM, VALUED AT $84

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

#5 YOUR MEIDCAL STORE UNO MEMORY FOAM SNUGGLE PILLOW FOR SIDE SLEEPERS BY AVANA (your-medical-store.com)

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

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

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

Must Be Present To Win!

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

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

#10 YOUR MEDICAL STORE DELUXE UPRIGHT FOREARM WALKER ROLLATOR BY MOBO (your-medical-store.com)

SEE REGISTRATION TABLE FOR LISTING OF OTHER DOOR PRIZES.

DONATE AT THE REGISTRATION TABLE

1) Donate $15.00 to receive your choice of SHIRT

2) Donate $2.00 for one rubber or beaded bracelet /
$5 for 3 bracelets / $10 for 6 bracelets

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

4) Donate to participate in Door Prizes (from Your Medical
Store and other items) — $5 per ticket / $10 for 3-tickets

—Some Items will be available to win by Auction
(see details at the Registration/Info Table)
— Winners and Door Prizes will be announced Saturday
after Dinner, June 22, 2024.
— Winner Must Be Present to Win!
— All credit card charges include a processing fee
— Colors and styles may vary while supplies last
— *All donations benefit the Spastic Paraplegia Foundation, Inc.*

SPF

SCAN TO PAY BY CREDIT CARD

Donate $15.00
to receive an
SPF Shirt

50/50
RAFFLE

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

Donate $2.00 for one rubber
or one beaded bracelet
—$5 for 3 bracelets or
—$10 for 6 bracelets

DONATE TO
Get Shirts,
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Thursday & FRIDAY

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

DAY ONE

THURSDAY, JUNE 20, 2024

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

5:00pm— 6:30pm REGISTRATION/INFORMATION DESK OPEN

5:30pm— 6:30pm Pre-Conference Matchup/Meeting —[Livorna Breakout Room / (Moderator: Tracy Hood]

- Come join a short introduction to SPF Ambassadors and other attendees in this informal meet-n-greet welcome.

FRIDAY, JUNE 21, 2024

7:30am –5:30pm REGISTRATION/INFORMATION DESK OPEN
Enjoy breakfast on your own in the hotel restaurant.

8:00am –Welcome to Tampa SPF warriors – [Ballroom]
SPF President Greg Pruitt Virtual Station Emcee & Tim Croghan In-Person Emcee

BALLROOM

9:00am – 10:00am–KEYNOTE ADDRESS: DR P. HANDE OZDINLER – [Ballroom]
-Developing Effective Treatments for UMN Diseases: The Future is NOW

10:00am– 10:45m–DR DARIUS EBRAHIMI-FAKHARI – [Ballroom]
- SP-CERN | Spastic Paraplegia Center of Excellence Research Network Update
-The Dawn of Translational Research in Hereditary Spastic Paraplegia

11:00am– 11:45am–DR LAUREN LEIVA, The ExerScience Center – [Ballroom]
-Inspiration and Movement, including a mini-stretch

12:00pm Lunch Served, (served plated, provided) – Private Dining, First Floor

BALLROOM

1:30pm–2:15pm– THOMAS (THOM) J. HART, CPATH | Critical Path Institute
–Fast Tracking HSP and PLS

2:15pm–2:45pm– NATALIE DOWNS, Rare Base Genetic Counselor, Senior Project Manager
–Delivering Novel Therapies to Patients Impacted by Genetic Disease

2:45–3:00pm – Mini Stretching with Zachary Lipson –[Ballroom]

BALLROOM

3:00pm–3:30pm–DR HIROSHI MITSUMOTO– PLS Natural History Study and PLS International Meeting

3:30pm- 4:00pm– DR CRAIG BLACKSTONE–New Therapeutic Approaches for the HSPs

4:00pm–4:15pm–Mini Stretching with Zachary Lipson –[Ballroom]

SMALL GROUP BREAKOUT SESSIONS (PICK ONE)

4:30pm– 5:30pm SMALL GROUP & BREAKOUT SESSIONS (pick one)
(1) Caregivers with DR LAUREN LEIVA–[Livorna Room / Moderators: Melissa Sheorn & Mary Kay Robinson

(2) Women-only – with DR HANDE OZDINLER AND DR EMANUELLA PIERMARINI– [Kalamata 2nd Floor / Moderators: Sue Duffy & Christine Hendrickson]

(3) Men-only with DR JOHN FINK AND Dr PETER BAAS – [Genoa 2nd Floor / Moderator: Jim Sheorn]

(4) Parents of Childhood Onset – DR DARIUS EBRAHIMI-FAKHARI [Ballroom]

6:00pm– 7:30pm–WELCOME RECEPTION FOR EVERYONE– [LaFuente Courtyard]
Unity is the new Inspiration

DINNER ON YOUR OWN & SOCIAL MINGLE: Gather on-your-own with Friends in the hotel restaurant or at any one of the 24 restaurants at the International Plaza Mall adjacent to the hotel. Or, head out for an evening at a Tampa Landmark on Your Bucket List. Special Note: Everyone is welcome to gather after dinner at the Bar or in the LaFuente Courtyard, meeting old friends or making new ones. https://shopinternationalplaza.com/dining

Pause & Rest Up Tonight for Another Busy Day Tomorrow

SATURDAY

DAY TWO

7:30am –5:15pm REGISTRATION/INFORMATION DESK OPENS
Enjoy breakfast on your own in the hotel restaurant.

8:30am– 9:30am SMALL GROUP & BREAKOUT SESSIONS (pick one)

(1) DR PETER W. BAAS - [Ballroom] – Development of an M1-spastin antibody for diagnosis, study and treatment for SPG4 Hereditary Spastic Paraplegia

(2) DR HIROSHI MITSUMOTO with PLS Community – [Livorno Breakout Room]

(3) Parents of Childhood Onset – [Kalamata 2nd Floor / Moderators: CHRIS LOREK, KATIE GREGG, BRIDGET LASSIG

SMALL GROUP BREAKOUT SESSIONS (PICK ONE)

10:00am – 10:30am– DR EMANUELA PIERMARINI– [Ballroom]
-Beyond Gene Therapy, Can We Promote Functional Recovery of SPG4-patients?

10:30am- 11:00am– DR LIANG OSCAR QIANG - [Ballroom]
- Advancing Hereditary Spastic Paraplegia Research: Insights from Human Stem Cell Models

BALLROOM

11:00am–11:30pm–Mini Stretching with ZACHARY LIPSON–[Ballroom]

12:00pm Lunch Served, (served plated, provided) – Private Dining, First Floor

1:30pm- 2:00pm–LINDA LAFONTAINE [Ballroom]
- The HSP cohort within C-BIG at the NEURO at McGill University in Montreal, Canada

2:00pm–2:30pm– DR STEPHAN ZÜCHNER –[Ballroom]
- Updates on spastic paraplegia genetics and opportunities ahead

2:30PM–3:00PM– DR Daniel Calame– [Ballroom]
- Genetic Mechanism Underlying Undiagnosed Pediatric HSP

BALLROOM

3:00pm- 3:30pm– DR LUCA SCHIERBAUM– [Ballroom] - Genetic Sequencing

3:30PM–3:45PM –Mini Stretching with Zachary Lipson–[Ballroom]

4:00pm– 5:00pm SMALL GROUP & BREAKOUT SESSIONS (pick one)

(1) Parents of Childhood Onset–DR MICHELLE CHRISTIE– Multidisciplinary Care for Pediatric Hereditary Spastic Paraplegia – [Kalamata 2nd Floor]

(2) Adaptive Fitness w/ZACHARY LIPSON– [Genoa–2nd Floor]

(3) PLS Community – [Livorna / Moderator Patrice Gorup]

(4) Podcasts and Social Media w/KIM SANCHEZ – [Ballroom]

SMALL GROUP BREAKOUT SESSIONS (PICK ONE)

5:30pm REGISTRATION/INFORMATION DESK CLOSES
(Last chance to buy shirts and items from SPF Store)

6:30pm – 8:00pm - DINNER PROGRAM (served plated, provided) / Special Presentations Drawings, Door Prizes & Auction – Must be present to win!

8:00pm–EVENING **SOCIAL MINGLE:** Gather on-your-own with Friends in the hotel restaurant/outdoor court. Or head out for an evening at a Tampa Landmark on Your Bucket List. Special Note: Everyone is welcome to gather after dinner at the Bar or in the LaFuente Courtyard, meeting old friends or making new ones.

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Pause & Rest Up Tonight for Another Busy Day Tomorrow

SUNDAY

DAY THREE

7:30am - 10:30am REGISTRATION INFORMATION DESK OPEN
No Separate Scheduled Activities for Students+Youth on Sunday.
Everyone is welcome to attend Ballroom presentations on Sunday.

7:30am Pastries and Coffee (provided)

8:30am – 9:30am COMMITTEE WORK OF THE SP-FOUNDATION – [Ballroom]
– Advocacy Committee – Leonard Erskine, Chair
– Marketing Committee – Tim Croghan, Chair
– Fundraising Committee – Jim Sheorn, Chair
– Education & Ambassadors Committee – Tracy Hood, member
– Research Committee–John Cobb, Chair

9:30am–10:00am–Break to Checkout

10:00am – 11:30am DR JOHN K. FINK – Q&A - [Ballroom] BALLROOM

12:00pm – Adjourn

Thank You for Participating in this Wonderful Weekend

NOTABLES

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****SEE REGISTRATION/INFO TABLE FOR DETAILS ****

Child Assessments By Appointment with Dr Darius Ebrahimi-Fakhari and Ms Amy Tam

Conducting onsite assessments for the Registry and Natural History Study for Early-onset HSP, including collection of clinical data and blood / skin samples from patients who exhibited onset of HSP symptoms at 18-years old or younger. The objectives are to document the clinical and biological aspects and form a natural history for early onset forms of HSP. The goal is to facilitate an early diagnosis, enable counseling and anticipatory guidance for affected families, and help define clinically meaningful endpoints for future interventions.

SPF Students + Youth

Marbella

FRIDAY, June 21, 2024

8:30am - 9:00am …….. Welcome/Introductions / Ice Breaker Students +Youth — [Marbella Breakout Room]

9:00am -10:00am…….. Dr Lauren Leiva—Inspiring Minds of Tomorrow The ExerScience Center

10:00am - 11:00am…… The Florida Aquarium Terrestrial Animal Ambassadors

11:00am ……………… Kids + Youth Join Families—Return to Ballroom with Dr Lauren Leiva

12:00pm ……………….Lunch Served, (served plated, provided) — Private Dining Room

1:30pm ………………. Free Time

2:00pm - 3:00pm ……... Dr Lauren Leiva —Movement

3:00pm ………………… Free Time

3:30pm - 4:30pm ……… TOP Soccer with Jenn DiTillio

4:30pm - 5:30pm.……….Canine Companions with Stacey Kemp & Leah Frohnerath

5:30pm …………………Students+Youth Return to Families—Ballroom

6:00pm—……………….Welcome Reception Everyone Invited

SATURDAY, June 22, 2024

8:30am …….…………Welcome Back Students + Youth — [Marbella Breakout Room]

9:00am - 10:00am ...…. Dr Lauren Leiva — The ExerScience Center

10:00am - 11:00am …...MOSI—Museum of Science and Industry

11:00am ……………… Kids + Youth Join Families— with Zachary Lipson —Return to Ballroom

12:00pm ……………….Lunch Served, (served plated, provided) — Private Dining Room

1:30pm - 2:30pm ……...Butterfly Tampa with Ainsley Basham

3:00pm - 3:15pm ………Zachary Lipson—Movement & Fitness

3:30pm - 4:30pm ………CPR + First Aid

4:30pm—5:30pm ………Health + Nutrition

5:30pm …………………Students+Youth Return to Families—Ballroom

6:30pm - 8:00pm.……….Dinner (served plated, provided) — Ballroom

SUNDAY, June 23, 2024

No Scheduled Activities for Students +Youth on Sunday.
Students +Youth are welcome to enjoy Pastries and Coffee—Ballroom

QUICK AT A GLANCE WEEKEND SCHEDULE

THURSDAY

9:00am—4:00pm—SPF Board of Directors Meeting
5:00pm—6:30pm—Registration/Information Desk Open
5:30pm—6:30pm—Ambassadors Meeting Livorrna

FRIDAY **

7:30am-5:30pm Registration/Information Desk Open
8:00am-9:00pm Welcome Conference Begins Ballroom
8:30am-9:00am Students+Youth Welcome Marbella
9:00am-10:00am Students+Youth Dr Lauren Leiva Marbella
9:00am-10:00am Keynote – Dr Hande Ozdinler Ballroom
10:00am-11:00am Students+Youth The Florida Aquarium Marbella
10:00am-10:45am Dr Darius Ebrahimi-Fakhari Ballroom
11:00am-11:45am Dr Lauren Leiva, MiniStretch, including Students+Youth Everyone in the Ballroom
12:00pm-Lunch served in Private Dining Room—everyone
1:30pm Students+Youth Free Time (30-mins)
1:30pm-2:15pm Thom Hart, CPATH - Ballroom
2:00pm-3:00pm Students+Youth Dr Lauren Leiva Marbella
2:15pm-2:45pm Natalie Downs Rarebase Ballroom
2:45pm-3:00pm MiniStretch Break Zachary Lipson
3:00pm Students+Youth Free Time (30-mins)
3:00pm-3:30pm Dr Hiroshi Mitsumoto Ballroom
3:30pm-4:00pm Dr Craig Blackstone Ballroom
3:30pm-4:30pm Students+Youth with TOPSoccer Marbella
4:00pm-4:15pm— MiniStretch Break Zachary Lipson
4:30pm-5:30pm Students+Youth Canine Companions Marbella
<u>4:30pm-5:30pm ADULTS Small Group (pick one)</u>
4:30pm Caregivers Dr Lauren Leiva Livorna
4:30pm Women-Only with Dr Ozdinler + Dr Emanuella Piermarini Kalamata 2nd Floor
4:30pm Men—Only w/Dr John Fink and Dr Peter Baas Genoa 2nd Floor
4:30pm Caregivers Dr Lauren Leiva Livorna
4:30pm Parents Childhood Onset Dr Darius Ebrahimi-Fakhari Ballroom
6:00pm-7:30pm Welcome Reception Courtyard Center
—Everyone Welcome

**Child Assessments By Appointment with Dr Darius Ebrahimi-Fakhari and Ms Amy Tam. For details see Registration/Info Table

SATURDAY**

7:30am-5:15pm Registration/Information Desk Open
8:30am-9:00am Students+Youth Welcome Back Marbella
<u>8:30am-9:30am ADULTS Small Group (pick one)</u>
8:30am Dr Peter Baas Ballroom
8:30am Dr Hiroshi Mitsumoto Livorno
8:30am Parents Childhood Onset w/Lorek, Gregg, Lassig Kalamata, 2nd Floor
9:00am-10:00am Students+Youth Dr Lauren Leiva Marbella
10:00am-11:00am Students+Youth Museum of Science & Industry Marbella
10:00am-10:30am Dr Emanuella Piermaria Ballroom
10:30-11:00am Dr Liang Oscar Qiang Ballroom
11:00am-11:30am MiniStretch Break Zachary Lipson including Students+Youth Everyone in the Ballroom
12:00pm Lunch served in Private Dining Room everyone
1:30pm-3:00pm Students+Youth Butterfly Tampa Marbella
1:30pm-2:00-pm Linda LaFontaine Ballroom
2:00pm-2:30pm Dr Steven Zuchner Ballroom, Zoom
2:30pm-3:00pm Dr Daniel Calame Ballroom, Zoom
3:00pm-3:30pm Dr Luca Schierbaum Ballroom
3:00pm-3:15pm Students+Youth Zachary Lipson—Marbella
3:30pm-3:45pm Adult Break MiniStretch Zachary Lipson Ballroom
3:30pm-4:30pm Students+Youth First Aide+CPR Marbella
<u>4:00pm-5:00pm ADULTS Small Group (pick one)</u>
4:00pm Dr Michelle Christie—Kalamata 2nd Floor
4:00pm Zachary Lipson —Genoa 2nd Floor
4:00pm PLS Community—Livorna
4:00pm Kim Sanchez—Ballroom
4:30pm-5:30pm Students+Youth Health+Nutrition Marbella
5:00pm Pause Refresh for Dinner
6:30pm- Dinner Program

**Child Assessments By Appointment with Dr Darius Ebrahimi-Fakhari and Ms Amy Tam. For details see Registration/Info Table

SUNDAY

7:30am-10:30am Registration/Information Desk Open
7:30am Pastries and Coffee, Everyone is Invited
8:30am-9:30am The Work of the SP-Foundation
9:30am-10:00am Break to Check Out
10:00am-11:30am Dr John K Fink
12: Adjourn

Year Around
and
Thank You For Sharing Your Time With Us In Tampa