

SPP Warrior



STLMO

Gateway of Hope

SPASTIC
PARAPLEGIA
FOUNDATION

20th Annual
Conference

SP-FOUNDATION.ORG

INFORMATION@SP-FOUNDATION.ORG

1-877-773-4483

June 23-25, 2023

SPF VISION

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

#HSPandPLS

Welcome from the President ...and the Executive Director

Welcome to St. Louis **SPF Warriors!**

On behalf of the SPF board of directors, we want to welcome everyone to the 2023 SPF Annual Conference. It's our 20th Annual Conference. We all look forward each summer for the opportunity to gather with friends, both old and new, to share with one another in our personal and collective battles and strategies in dealing with hereditary spastic paraplegia and primary lateral sclerosis.



Everyone here is a warrior in this important fight. Those of us who have one of these diseases fight the physically limiting symptoms every day. Our family members and caregivers who love and assist us in so many ways fight with us to make everyday more enjoyable and most productive. Our doctors, researchers and health care providers are also warriors working daily to find treatments and cures we so desperately need. Those who contribute financial resources, both large and small, are warriors for medical research in providing resources to help us wage this war. Just one of the beauties of this annual conference is bringing together all of these warriors to share with each other and strategize how to collectively take the next important step leading to finding treatments, therapies, and/or cures for everyone who suffers from either HSP or PLS!

Thank you again for joining us at the annual conference and continuing our battle in the Gateway City. It is because of the collective work of all our different warriors that we stand at this "Gateway of Hope" and look forward to working with everyone in winning this battle. Enjoy visiting with old friends and making new ones! We look forward to meeting you all over these next few days. Please let us know if we can do anything to assist you in any way.

Our Best Always,

Greg and Norma Pruitt



SPFoundation's Annual Conference Sponsors



Kris Brocchini

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



Classic Dentistry

Joseph L. Skradski, DDS



KODURI

VAMSI, YASHODHA,
MAURYA & DISHA

Exhibitor



Saint Louis Zoo

Animals Always®

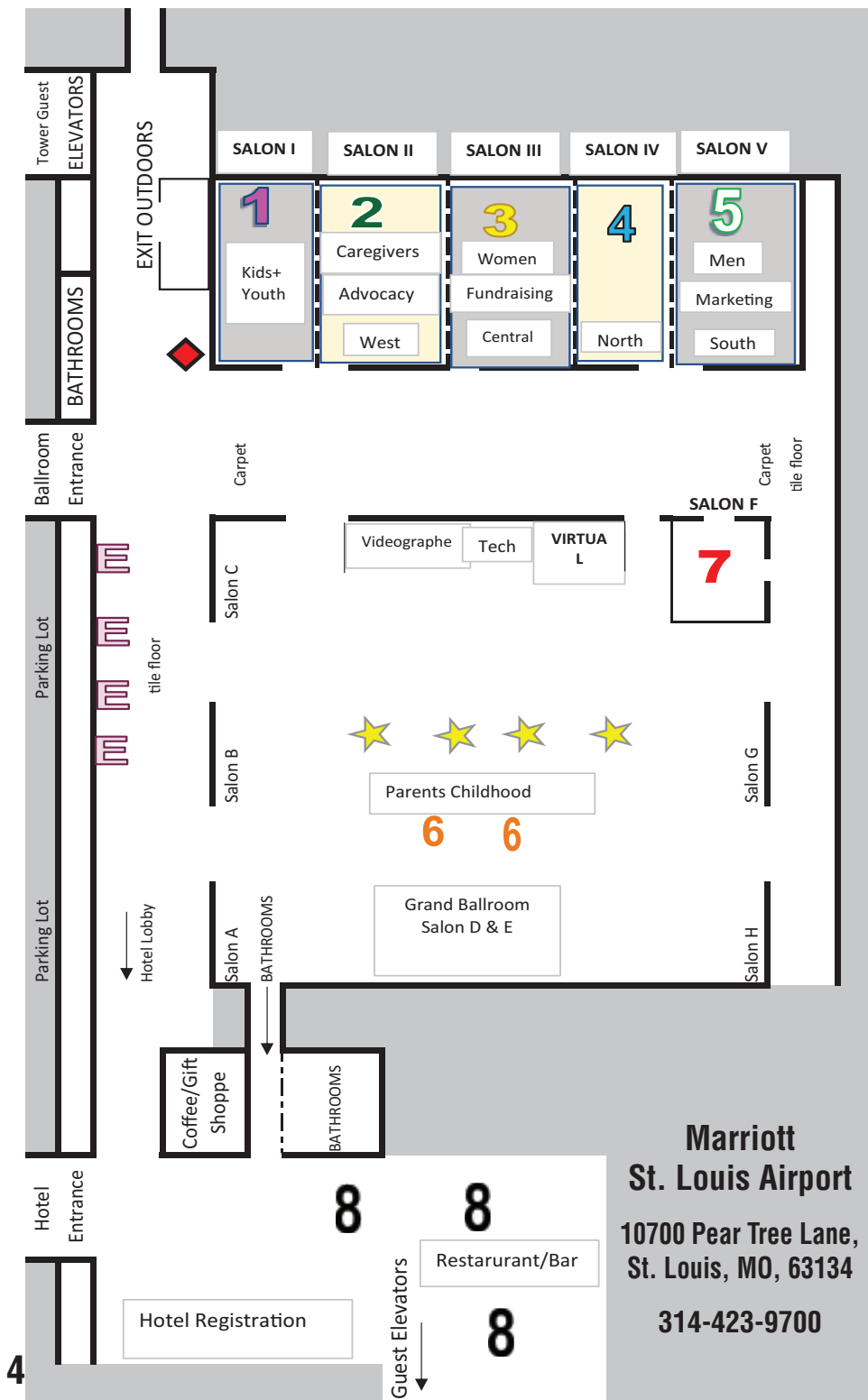
Exhibitor



Your Medical Store

Exceptional Products For You





We're Glad You're Here!

 — Info/Registration Desk/SPF STORE

 — General Sessions/Meals

 — Exhibitors

8:30-10:30am - Breakout Sessions Gender & Caregivers

1 — SALON I — Kids+Youth Activities

2 — SALON II — Caregivers

3 — SALON III — Women-Only

4 — SALON IV — Vacant

5 — SALON V — Men-Only

6 — SALON D & E — Parents Childhood Onset

2:pm - Breakout Sessions SPF Committees

1 — SALON I — Kids+Youth Activities

2 — SALON II — Advocacy Committee

3 — SALON III — Fundraising Committee

4 — SALON IV — Vacant

5 — SALON V — Marketing Committee

6 — SALON D & E — Parents Childhood Onset

3:00-4:30pm - Breakout Sessions States -Regions

1 — SALON I — Kids+Youth Activities

2 — SALON II — West States

3 — SALON III — Central States

4 — SALON IV — North States

5 — SALON V — South States

6 — SALON D & E — Parents Childhood Onset

7 — SALON F — Dr Darius Fakhari Assessments (by Appt)

8 — Social Mingle/ Restaurant/ Bar

Ribbon Colors

Find like Ribbon Colors for those with PLS or your specific HSP, SPG number from SPG 3A to SPG 11 to SPG Unknown

 PLS (Canary) — 10

 SPF Unknown (Lavender)—16

 SPG 3A (dk Brown) — 2

 SPG 4 (Hot Green) —23

 SPG 5A (Ocean Blue) — 3

 SPG 7 (Hot Pink) —10

 SPG 11 (Ice Mint) —1

 Ambassadors (Teal)

 Board Members (Black)

 Exhibitors (Orange)

 Committee Chairs (Goldenrod)

 President, Past President (White)

 Speakers (Red)

 Sponsors (Royal Blue)

 Staff (Red White Blue)

Numbers may vary due to late registrations



Thursday - June 22, 2023

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

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

5:30pm—6:30pm Ambassadors Pre-Conference Mentoring Matchup—Salon II
(Moderator: Dina Landphair) As an SPF Ambassador join this session to learn how to meet and greet with conference attendees from your state or region.

Friday - June 23, 2023

Patient Focus Day

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

Enjoy breakfast on your own in the Marriott Restaurant. Room service is not available.

8:00—WELCOME TO ST LOUIS SPF WARRIORS — Salon D & E
SPF President Greg Pruitt Virtual Station Emcee & Tim Croghan In-Person Emcee

8:30am —10:30am BREAKOUT SESSIONS—See Breakout Rooms Below
GENDER, CAREGIVERS, PARENTS & KID+YOUTH

—Kids + Youth — Salon I (Moderators: Sandy Lakey and Kelly Barban)

—Caregivers — Salon II (Moderators: Lloyd & Sarah Small, WA Ambassador)

—Women-only — Salon III (Moderators: Sue Duffy & Christine Hendrickson)

—Men-only — Salon V (Moderator: Jim Sheorn)

—Parents of Childhood Onset — Salon D & E

Diagnosis to Hope: Life as a Parent Caregiver — Hear from parent caregivers across multiple sessions as they share their journey of 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.

11:00am—WORK OF THE SP-FOUNDATION PRESENTATIONS — Salon D & E

— Marketing Committee — Chair & Emcee Tim Croghan

— Fundraising Committee — Chair Jim Sheorn

— Advocacy Committee — Chair Leonard Erskine

— Education & Ambassadors Committee — Chair Dina Landphair

12:00pm Lunch Served, (served plated, provided) — Salon D & E

12:00pm-12:30pm—Special Guest Hint: Who is the St Louis Blues Hockey Mascot? Hint: **LOUIE** is the mascot of the St. Louis Blues. He was introduced on October 10, 2007. On November 3, 2007, the fans voted on his name on the Blues' web site. Louie is a blue polar bear and wears a Blues jersey with his name on the back, and the numbers "00". Please welcome him as he helps to bring awareness to SPF, HSP and PLS!

1:00pm CRISSY SMITH WITH DUO DOGS — Salon D & E

Friday - June 23, 2023 (Continued)

2:00pm BREAKOUT SESSIONS SPF COMMITTEES & OTHER SESSIONS

See Breakout Rooms Below

- **SPF Kids + Youth** — Salon I (Moderators: Sandy Lakey and Kelly Barban)
- **Advocacy Committee** — Chair Leonard Erskine — Salon II
- **Fundraising Committee** — Chair Jim Sheorn — Salon III
- **Marketing Committee** — Chair & Emcee Tim Croghan — Salon V
- **Parents of Childhood Onset** — **Open Forum Q&A Panel** — Salon D&E with Dr Darius Ebrahimi-Fakhari, MD, PhD and Dr. Daniel Calame, MD, PhD

3:00pm — 4:30pm BREAKOUT SESSION BY STATES & REGIONS & OTHER SESSIONS

See Breakout Rooms and Ice See Breaker Questions

- **SPF Kids + Youth Group** — Salon I (Moderators: Sandy Lakey and Kelly Barban)
- **West states** — Salon II (Moderator Frank Davis)
- **Central states** — Salon III (Moderator: Mary Shultz and Mari White)
- **North states** — Salon IV (Moderator: Linda Lafontaine)
- **South states** — Salon V (Moderator: Jim Sheron)
- **Parents of Childhood Onset** — with Dr. Daniel Calame, MD, PhD & Parent Wrap-Up — Salon D&E
- **Dr Darius Ebrahimi-Fakhari** — **Child Assessments by Appointment** — Salon F

5:00pm REGISTRATION/INFORMATION DESK CLOSES

DINNER ON YOUR OWN & SOCIAL MINGLE: No Room Service Gather on-your-own with Friends, or your SPG gene group in the hotel Marriott Restaurant or The Bar. Enjoy excellent sandwiches, as well as steak and seafood, in a casual contemporary environment. The Bar serves American and Southern cuisine, and the The Market offers coffee and snacks. Or, head out for an evening in STL sightseeing or dinner in the iconic downtown area. Special Note: SPG7 will gather at 7:pm in The Bar. Everyone is welcome.

Breakout States By Region

Numbers may vary due to late registrations

Salon II	Salon III	Salon IV	Salon V
West States	Central States	North States	South States
(AZ-CA-CO-TX-WA)	(IA-IL-IN-KS-KY-MO-NE)	(CT-MD-ME-MI-NJ-NY-PA-VA-WV)	(AR-GA-FL-NC - SC-TN-Canada - United Kingdom)
		CT - 2	
AZ -1	IA - 2	MD -2	AR - 2
CA - 7	IL - 5	ME - 1	GA -10
CO -2	IN - 3	MI - 9	FL -7
TX -11	KS -7	NJ - 5	NC - 2
WA - 9	KY - 2	NY - 3	SC - 1
	MO - 17	OH - 1	TN - 2
	NE -2	PA - 4	UK - 1
		VA - 2	
		WV - 2	
		Ontario -2	
30	38	33	25

7:00am — 5:15pm REGISTRATION/INFORMATION DESK OPENS
Enjoy breakfast on your own in the Marriott Restaurant. Room service is not available.

**8:00am WELCOME BACK, TIM CROGHAN, IN-PERSON EMCEE &
GREG PRUITT, VIRTUAL STATION EMCEE**

**8:15am SPF SCIENTIFIC RESEARCH GRANT COMMITTEE — Chair John Cobb
SPF SCIENTIFIC ADVISORY BOARD — Chair Dr Paolo Moretti, MD**

9:00am KEYNOTE ADDRESS: Showcasing the latest advancements, priorities and future directions in three crucial domains, fostering a sense of unity and collaboration within the HSP research community. **EXPLORING RESEARCH FRONTIERS IN HSP: GENOMICS, BIOLOGY, CLINICAL RESEARCH**

—**GENOMICS:** Dr Stephan Züchner, MD, PhD, FAAN

—**BIOLOGY:** Dr Craig Blackstone, MD, PhD

—**CLINICAL RESEARCH:** Dr Darius Ebrahimi-Fakhari, MD, PhD

11:00am Dr Hiroshi Mitsumoto, MD, DSc — PLS Natural History Study

12:00pm Lite-Lunch Served (served plated, provided)

**1:00pm — Thomas (Thom) J. Hart, J.D., C-Path Institute
Drug Development Process and Patient Advocacy Communities**

1:30pm — 2:15pm — Dr Daniel Calema, MD PhD—Undiagnosed Pediatric HSP: A Tale of Gene-Disease Validity, Mimics, and Phenotypic Expansions

2:15pm — 3:00pm — Dr. P. Hande Ozdinler, PhD— Developing the clinical trials for upper motor neurons: biology, pathology and biomarkers

3:00pm — 3:30pm — Dr. Mukesh Gautam, PhD— Potential role of Cardiolipin nanoparticle in improving Upper Motor Neuron health
(15-min break)

3:45pm — 5:15pm Open Forum Q&A Panel Discussion with Doctors

5:15pm—5:30pm Saturday Wrap Up, Tim Croghan, Emcee

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

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

8:00pm—Evening

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

7:30am – 10:30am REGISTRATION INFORMATION DESK OPEN
No Separate Scheduled Activities for Children on Sunday.
Children are welcome to attend Adult Program on Sunday.

7:30am Pastries and Coffee (provided)

8:30am — Education-Ambassadors Committee Chair Dina Landphair

9:00am — 9:45am — Dr. Peter Baas, PhD
Mechanistic Route to Therapy for SPG4 Hereditary Spastic Paraplegia

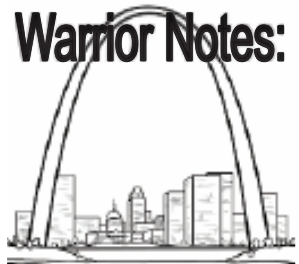
9:45am— 10:15pm — Dr. Emanuela Piermarini, PhD
Gene Therapy approach for SPG4-based Hereditary Spastic Paraplegia

10:15am—10:45am — Dr. Liang Oscar Qiang, MD, PhD
Unveiling HDAC6: A Promising Therapeutic Target for SPG4: Insights from Human and Animal Models

(15-min break)

11:00am — **Dr John K. Fink, MD — Q&A**

12:00pm — Adjourn



PEP'S *Kids + Youth* **Activities** **Salon I**

FRIDAY

June 23, 2023

8:30am - 9:30am Welcome/Introductions / Ice Breaker Kids+Youth — Salon I
(Moderators: Tina Croghan and Thunder, Sandy Lakey, Kelly Barban)

9:30am -10:30am..... World Bird Sanctuary - Salon I

10:30am - 11:30am..... Alinker - Christine Hendrickson — Salon I

11:45am Kids + Youth Return to Families in — Salon D & E

12:00pmLunch Served, (served plated, provided) — Salon D & E

1:00pm Crissy Smith with Duo Dogs — Salon D & E

2:00pm - 3:30pm Missouri Botanical Garden — Salon I

4:30pmKids+Youth Return to Families in — Salon D & E

SATURDAY

June 24, 2023

8:00amWelcome Back — Salon I
(Moderators: Tina Croghan and Thunder, Sandy Lakey, Kelly Barban)

9:am - 10:00amStretching and Movement — Salon I
(Moderator: Sandy Lakey, Kelly Barban, Amber Croghan)

10:00am - 11:30amSt. Louis Zoo Lia Reilly & Shayle Wigger, Zoo Staff —Salon I

11:30amBath Room Break—Return to Families in — Salon D & E

12:00pm - 1:30pmLite-Lunch Served (served plated, provided) — Salon D & E

2:00pm - 3:30pmMagic With Jeff Lefton — Salon I
(30-minute break)

4:00pm - 5:30pmAdaptive Recreation Adventures - Shayle Wigger—Salon I

5:30pmKids+Youth Return to Families in — Salon D & E

6:30pm - 8:00pm.....Dinner (served plated, provided) — Salon D & E

SUNDAY

June 25, 2023

No Scheduled Activities for Kids+Youth on Sunday.

Kids+Youth are welcome to enjoy Pastries and Coffee in Salon D&E

Special Guests & Kids+Youth Activities



Crissy Smith, 314-997-2325
Director Canine Operations
Duo Dogs, Inc.,
10955
Linpage Place,
St. Louis, MO 63132
|csmith@duodogs.org
duodogs.org



Crissy works closely with all canine health, breeding and whelping operations, in addition to dog training programs, such as assistance dog

training, building skills for handlers and dogs for placement with mobility, hearing, PTSD, and facility clients.

Crissy facilitates puppy classes for Volunteer Puppy Raisers and assists in Touch Therapy and Obedience programs.

Crissy has been training dogs for nearly twenty years. To date, Crissy has placed close to sixty assistance dogs across the country.

THUNDER



Help me wish my humans
—Tim and Tina Croghan —
a Happy 30th
Wedding Anniversary!



**MISSOURI
BOTANICAL
GARDEN**

Missouri Botanical Garden, 4344 Shaw Blvd, St. Louis, MO 63110, (314) 577-5100, www.mobot.org; Jeanne Carbone, Supervisor, Therapeutic Horticulture 314-577-9473 ext. 76455 — missouribotanicalgarden.org/learn-discover/therapeutic-horticulture—Explore the textures, scents, and colors of a variety of sensory plants. We will use the plants to create art and the children will leave with a plant of your very own! Jeanne Carbone is Supervisor of the Therapeutic Horticulture team at the Missouri Botanical Garden. Therapeutic Horticulture is the practice of encouraging participants to use nature to improve well-being. Activities are designed to experience the natural world through sensory engagement. The



**WORLD BIRD
SANCTUARY**
Preserve, Protect & Inspire.

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

Jeff Lefton
Comedy Magic Show!



Lefton Comedy Magician LLC

Jeff Lefton, 30 Wydown Terrace, St. Louis, MO. 63105, (314) 608-6547, leftoncomedymagician.com—Enjoy a Comedy Magic Show, take-home a trick for participants from the Magic Workshop, and take-home a balloon creation from Animal Balloon Workshop.

Spastic Paraplegia Foundation

#HSPandPLS — SP-Foundation.org

SPF ORGANIZATION:

The Spastic Paraplegia Foundation Inc. (SPF) is a 501(c)3 national, not-for-profit, voluntary organization. It is the only organization in the 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 discovering the cures for HSP and PLS. The SPF is a non-profit 501(c)3. Tax ID # 04-3594491 Combined Federal Campaign CFC #12554

SPF VISION:

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

SPF BOARD OF DIRECTORS:

Greg Pruitt, President
Linda Gentner, Vice President
Hank Chiuppi, Secretary
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Frank Davis, President Emeritus

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

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

EXECUTIVE DIRECTOR:

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

SEND CHECK DONATIONS TO:

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

SEND ONLINE DONATIONS TO:

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

SCAN THE QR-CODE



***SYNAPSE NEWSLETTER**

Published quarterly; Donna Hinshaw, Designer

***SPASTIC PARAPLEGIA WORLD** Electronic Newsletter “*Connecting Spasticity World wide*” Contact: SpasticWorldInfo@gmail.com; Hank Chiuppi and Norma Pruitt

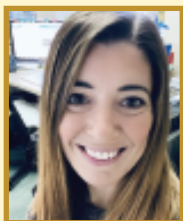
***SPF TALKS** SPF’s virtual outreach effort talking about subject matters of interest to people with HSP or PLS. IDEAS AND TO REQUEST ZOOM LINK EMAIL: Information@SP-Foundation.org

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/>



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.



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

Emanuela Piermarini 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.

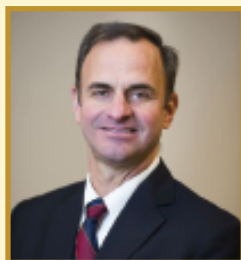


Liang Oscar Qiang M.D./Ph.D. | lq24@drexel.edu
Assistant Professor | Office: 215-991-8287; Lab: 215-991-8908
Neurobiology and Anatomy Department, College of Medicine,
Drexel University, 2900 Queen Lane, Philadelphia, PA 19129

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 Angiocrine 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.

Craig Blackstone, MD PhD | CBLACKSTONE@mgm.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



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
Baylor College of Medicine, Molecular and Human Genetics
6651 Main St, Ste F320 Houston, TX 77030 | texaschildrens.org
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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 *ENTPDI* 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.

SPF Medical Advisor

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

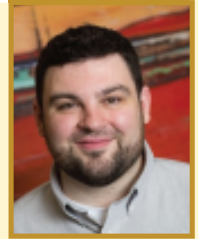


John K. Fink is a Professor in the University of Michigan Department of Neurology. Dr. Fink received his M.D. from the Medical College of Ohio in Toledo and completed Neurology Residency at the University of Virginia and postdoctoral fellowships in Developmental and Metabolic Neurology and Medical Genetics at the National Institutes of Health. Dr. Fink investigates inherited and degenerative neurologic disorders, 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.

Thomas (Thom) J. Hart, J.D., | 305-439-0684 | thart@c-path.org
C-Path Institute, Director of Outreach, 1840 E. River Rd., #100,
Tucson, AZ 85718, 520-547-3440, c-path.org



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.

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



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

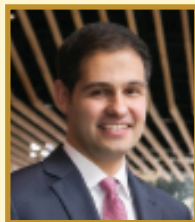
SPF SCIENTIFIC ADVISORY BOARD CHAIRMAN

Paolo Moretti, MD | 801-585-7575 | paolo.moretti@hsc.utah.edu
Associate Professor, Department of Neurology
University of Utah, 175 Medical Drive N, Salt Lake City UT 84132
Staff physician, Neurology - George E. Wahlen VA Medical Center
500 Foothill Boulevard, Salt Lake City, UT 84148



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.

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



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



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.

Warrior Notes:



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



Pembe 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.



Mukesh Gautam, PhD. is a research assistant professor in the department of Neurology, Northwestern University Feinberg School of Medicine, Chicago Dr. Gautam's research interests are to understand underlying mechanisms of upper motor neuron (UMN) degeneration, and developing therapeutic approaches to improve UMN health. His research has shown that mitochondrial defects are an early and converging phenomena in UMN degeneration.

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



KIDS+YOUTH Icebreaker Tips and Questions

Keep it Simple—Have Fun—Express Yourself

- (1) Name? Age? What state are you from?
- (2) Do you have siblings? How many do you have?
- (3) Do you play sports, any musical instruments, what do you do for fun when you are home?
- (4) Do you have HSP? If you have HSP do you know your SPG gene?
- (5) Do any other siblings or family members have HSP?
- (6) What age were you when you discovered you had HSP or were officially diagnosed?

Adult Icebreaker Tips and Questions

Keep it Simple—Have Fun—Express Yourself

- (1) Name? What state are you from? In which state do you currently live?
- (2) Do you have HSP or PLS? If you have HSP do you know your SPG gene?
- (3) Do other siblings or family members have HSP or PLS? How many?
- (4) What age were you when you thought you had HSP or PLS or were officially diagnosed?
- (5) Do you have children? Y/N, How many? Do any of your children show signs of spastic paraplegia?
- (6) Are you still employed? What do you do for a living? or
- (7) Are you in college? What grade are you in? What degree are you perusing?



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GOAL \$1,500,000



SPF Speakers



Greg Pruitt | Pruitt@SP-Foundation.org

SPF President

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



Tim Croghan | [ConferenceEmcee](mailto:ConferenceEmcee@SP-Foundation.org)

Tim.Croghan@SP-Foundation.org

Chair, SPF Marketing Committee

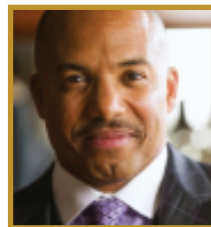
Tim is dedicated in supporting the Spastic Paraplegia Foundation. Along with his wife, Tina (an SPF Board Member, HSP, SPG7) live in Missouri. They are a dynamic team focusing attention on advocating and raising funds to advance research efforts to find a cure for HSP and PLS since 2007. Tim serves as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



John Cobb | John.Cobb@SP-Foundation.org

Chair, SPF Research Committee

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 live in Oakland, CA and just welcomed their son Jamie, born in November of 2022!



Leonard Erskine | Leonard.Erskine@SP-Foundation.org

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 dog-gie dad to Gizmo and Gracie, his beloved Shi Tzu's. Leonard serves as Chair of the SPF Advocacy Committee. Leonard is diagnosed with PLS.



Dina Landphair | Dina.Landphair@sp-foundation.org

Chair, SPF Education and 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, Iowa, 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.



Jim Sheorn | Jim.Sheorn@SP-Foundation.org

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.

Raffle/Auction

The Upper Motor Neuron Stargaze



ARTWORK MADE POSSIBLE THROUGH
A GENEROUS DONATION FROM
**DR. P. HANDE
OZDINLER**



SP-FOUNDATION VALUES DR. P. HANDE OZDINLER AS AN EXTRAORDINARY FRIEND TO THE SPASTIC PARAPLEGIA COMMUNITY. SHE IS ALSO A SCIENTIST, A PHOTOGRAPHER AND A PAINTER. 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, AFTER LOOKING AT THE DISSOCIATED CULTURES OF MOTOR CORTEX FOR A LONG TIME. THE GFP LABELED CELLS ARE UPPER MOTOR NEURONS, THE RED LABELED CELLS ARE ASTROCYTES AND THE BLUE MARKS THE LOCATION OF THE NUCLEUS. THE SIZE OF THIS STUNNING PHOTOART IS 30" BY 30".

Inviting bids during the Auction Call Saturday evening.

All donations benefit SPFoundation medical research grants.

Raffle/Auction

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



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



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



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



#3
COMPLETE
TENS SYSTEM,
VALUED AT \$84



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



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



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



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



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



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



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



#10
THE PILOT
UPRIGHT
FOREARM
WALKER
ROLLATOR,
VALUED AT \$239

SEE REGISTRATION TABLE FOR LISTING OF OTHER DOOR PRIZES.

Raffle/Auction

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



Barbara Lawrence from Alabama has HSP, SPG Unknown, made this quilt as a fundraiser for SPF, HSP and PLS. It is a series of different shades of green ribbons, since green is the color for HSP and PLS. The ribbon in the center of the quilt is zebra stripes to represent all Rare Diseases. Barbara Lawrence organized a GOFUNDME fundraiser for the quilt and Dina Landphair from Iowa, was the lucky winner. Dina says, "even though I LOVE the quilt, I want to donate it to the SPF Annual Conference to raise more money for the foundation." Dina has HSP, SPG7. The size of quilt is 60"x84" or 5'x7'.



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

SPF AWARENESS 2023
#HSPandPLS
MONTH: August
WEEK: August 20-27
DAY: August 27th



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Meet the Author Onsite:

Vamsi Koduri, father to Maurya Koduri, narrates his heart warming and heart wrenching experiences with his first born, a 'special child' Maurya Koduri while navigating the other aspects of his life. Vamsi has a MBA, PMP, CSM, ITIL certified, is a Project Manager working for a top technology company that develops and markets software as a service (SaaS) for clinical trials. As a clinical IT professional, he has over 15 years of experience in the Health Sciences Industry. He is an accomplished short film maker and is well versed with film making.



Thank you Vamsi for your dedication and support.

All proceeds from book sales are donated to SPFoundation

Author | Film Maker | Digital Creator | Rare Disease Advocate | Project Manager, HealthCare Industry



Special Guests & Kids+Youth Activities

Lia Reilly, Educator,
(314) 646-4589 | lreilly@stlzoo.org
Saint Louis Zoo, One Government Drive,
St. Louis, MO 63110, 314-646-4677



Saint Louis Zoo
Animals Always®

stlzoo.org | The Education Department at the Saint Louis Zoo believes that everyone has the right to learn. We believe that by collaborating with organizations of all kinds, we are stronger and more effective conservation educators. We believe it is our charge to inspire wonder and encourage curiosity. To accomplish this, we provide experiences that are conservation focused, learner-directed, inclusive and creative. Lia has been with the Saint Louis Zoo since September 2022. She has a Bachelor of Science degree in Elementary Education from the University of Missouri-Columbia. Before coming to the Zoo, she was a classroom teacher for Kindergarten, 1st, and 2nd grades.

Shayle Wigger, CTRS, 404-863-1829, Swigger1@live.com, Zoo Education Administrative & Inclusion Specialist, 314-646-4537; Shayle is a nationally certified recreation therapist of 25 years, having graduated from University of Georgia with a BS Education-Therapeutic Recreation. She has enjoyed working with children, teens, and adults experiencing traumatic injuries, developmental/intellectual disabilities, behavioral health, or medical and acquired conditions; in a variety of clinical and community settings and roles from teaching preschool and directing camp programs, to managing adaptive recreation departments and agency disability inclusion services. Currently, Shayle provides accessibility/inclusion and administrative support for The St. Louis Zoo and Girl Scouts of Eastern Missouri. Born in Missouri and having lived internationally and throughout the US - from east coast to west coast – Shayle's now back home and getting reacquainted with Missouri.



Visit **STLMO** **EXPLORESTLOUIS.COM** Restaurants Near The Hotel ((Not Walkable))

Golden Pancake

Golden Pancake 10216 Natural Bridge Rd., St Louis, MO 63134; **314-427-0420**, goldenpancake.com
5-minutes from Hotel | Fri-Sat 7am-8:pm; Sun 7:am-3:pm



Bandanas BBQ

10800 Pear Tree Lane, St Ann, MO 63074
314-426-9955
bandanasbbq.com
2-minutes from Hotel | Opens 11:am -10:pm



Lombardo's Italian Restaurant

10488 Natural Bridge Road, St. Louis, MO 63134
314-429-5151
lombardosrestaurants.com/
5-minutes from Hotel | Opens 3:pm –9:pm

Visit Online the SPF-Store



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



SP-Foundation.org/SPF-Store

DONATE AT THE REGISTRATION TABLE

- 1) Donate \$15.00 to receive your choice of a Shirt
- 2) Donate \$2.00 for one rubber bracelet / \$5 for 3 / \$10 for 6 bracelets
- 3) Donate to 50/50 Raffle, 50% Goes to SPF & 50% Goes to 1-Lucky Winner (\$1.00 per ticket / \$5.00 for 6-tickets)
- 4) Donate to participate in Door Prizes (from Your Medical Store and others) (\$5 per ticket / \$10 for 3-tickets)

—Winners and Door Prizes will be announced Saturday after Dinner, June 24, 2023.

—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.*