November 2024

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

RESEARCH | EDUCATION | SUPPORT

2023 ANNUAL REPORT

UNITY, THE NEW INSPIRATION

Through real unity, we can move mountains. People all over the world are watching.

2023 Message from the President

Greg Pruitt

Dear SPF Patients, Families, Friends, Supporters & Partners,

Once again as we review our financial and audit information for calendar year 2023, I have to express to you what an incredible difference you are making to the mission of the SPF discovering treatments and cures for both HSP and PLS! From year to year, so many new partners get positively involved in this mission, whether it be as a financial contributor, board member, SPF member, committee member, Scientific Advisory Board member, SPF Talks participant or in one of many other ways. Every dollar you contribute, every minute you spend working or participating, and every word of encouragement you give to others sharing this journey makes so much difference in reaching our goal. Last year's annual report focused on the growing **MOMENTUM** we all felt with the work of the foundation and the creation of the SPF Centers of Excellent Research Network. This year we are experiencing a great **UNITY** among all of us in this effort. Let us all continue to unify every individual and group in this process-the patients, researchers, clinicians, pharmaceutical companies, and government agencies to collectively and cooperatively hasten the accomplishment of our mission.

The 2023 financial information provided by our co-treasurers, David Lewis and Lorri Steiner, and audited by our auditing firm, affirms that we raised an amazing $1,244,568 in donations. When we add the other sources of income outlined in the table on page 13, our Total Support and Revenue for the year is $1,472,929! I believe this to be the greatest total support and revenue level ever reached if we look back at all twenty years of SP-Foundation history. That level of financial and personal commitment is vital in continuing the important research and partnering with every entity necessary to reach our goals.

There is much information in this report regarding both current and past medical research made possible only by the contributions you make. Please take time to become more familiar with that research work. We have diligently worked during this last year to find a way to better understand and pass on to you the positive results coming from that research. Many have been involved in that work, and I want to thank everyone for their work and volunteer hours in putting together this information. There is so much information that it would be a significant cost to put it all in this printed annual report, so we strongly encourage you to visit the foundation website, SP-Foundation.org, to find and become more familiar with much more of our research information.

We have just begun our second year in working with the SPF Centers of Excellence Research Network. I and other representatives of your board meet with those centers once

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a month to participate in their work to create clinical processes that we hope will result in quicker diagnosis and treatment for those who share our diseases. Our hope is that this process will move us more quickly to a point of preparation for any possible clinical trials that might be proposed in the near future. When the SPF-CERN started there were ten clinical sites involved. That has already increased to twelve, and we hope and believe there will soon be more added across the country and internationally.

CRITICAL PATH INSTITUTE

Your board has also just recently begun a collaboration with an organization based in Washington, D.C. called Critical Path Institute. As we looked far and wide to try to find ways to bring all the parties together to focus on expediting our work as I discussed above, one of our board members, Jackie Wellman, recommended we talk with CPATH. We invited them to our annual conference in Tampa. After much discussion with them, our board has agreed to work with them to assist in bringing all the parties to the table to accelerate our work and assist us in trying to apply and qualify for significant federal government funding and involvement in our work. Most recently with the support of CPATH, we are pleased to learn that a FDA Liaison has been assigned to assist the SP-Foundation in efforts focusing on HSP and PLS.

SPF was incorporated in 2002. There have been many who have played very important roles in the work and history of the organization. A few of them have been involved since the beginning. Some of them have now decided to retire from their board work and service. On behalf of every SPF member and board member, I want to tell them how much they mean to this organization. Their presence and commitment will be sorely missed, but each of them has pledged to keep in touch and assist when needed. Those board members retiring are:

Linda Gentner, who has been on the board since its inception and has served as our vice president for many years. We also want to say thank you to her husband, Craig. He has always been by her side and served many years as the emcee at our annual conference.

Mark Weber, who was the first president of the foundation in 2002, and who has served for as long as I can remember as our legal counsel and chair of our research committee.

David Lewis, who was one of the founding members of the foundation and has served as its treasurer since creation.

Dr. Corey Braastad, who has served the board for over twenty years and has been one of our very valuable researcher members and annual conference presenters.

Again, thank you to all four of you for the time, energy, and commitment you have so generously given that has built this foundation. We will forever be grateful to you!

We all will continue to work together in this work to find treatments and cures. We strongly believe that with the right combination of work, commitment, sweat, energy and **UNITY**, treatment and cures will be discovered and shared that can make an important difference in the lives of everyone who deals with hereditary spastic paraplegia or primary lateral sclerosis. As we have shared with you before, your board's goal is to reach **$1.5 million in 2024** contributions. It can be done. I believe it will happen. We need to finish the year strongly. Each year President Emeritus Frank Davis finds anonymous donors who agree to match contributions made to the foundation between November 1st to January 15th. He has done that again this year and **has $300,000 in matching donations committed. Thank you, Frank!** Please do all you can to assist us in getting every one of those matching dollars! Let's be **UNIFIED AND SUCCESSFUL** in reaching this goal and accelerating toward treatments and cures!

My Best Always,

Greg Pruitt

SP-Foundation President

IN SEARCH FOR A CURE

The SP-Foundation is the largest funding organization in the world focused on discovering disease-modifying treatments or cures for two rare diseases, HSP and PLS. The work of the SP-Foundation aims to convert donations into grant awards for researchers, scientists, and investigators to produce scientific research and therapies for patients. Grant awards will enable investigators to further uncover the biochemical processes that cause nerve degeneration and identify and test therapy targets.

The process consists of identifying researchers, requesting proposals, identifying the best-rated research proposals, and then funding the proposed research. This process is completed through the volunteer efforts of the SP-Foundation Research Grant Committee and SPF's Scientific Advisory Board. To put it in perspective, the SP-Foundation awarded two proposals for $40,000 each in 2003. Fast-forward for a 2023 update, and with the assistance of many donors, sponsors, and contributors, the SP-Foundation has collected $1,244,568 that will be made available for scientific research.

The SP-Foundation has historically funded investigators working independently, or in small collaborations. More objectives are achievable with existing technology, but only through a large-scale consortium of investigators working collaboratively. Through the generosity of many donors, the SP-Foundation actively seeks scientific proposals to initiate critical research that is driving science by systematic collection, interpretation, and evaluation of data. Through the essential function of the Research Committee, important contributions have been made to aid in the knowledge of HSP and PLS, including the description of cross-sectional clinical data, discovery of novel genetic causes, development of animal models, and clarification of the molecular biology of HSP-associated proteins, and detection of biomarkers for HSP and PLS. This groundwork of scientific knowledge paves the way for the development of medications for HSP & PLS clinical trials, necessitating a new level of inter-institutional collaboration for subject recruitment, natural history studies, and standardized assessment methods.

To date, nearly all our specific understanding of HSP pathophysiology has arisen from identifying causative genes and reliably classifying pathogenic variants. HSP encompasses over 80 rare monogenic disorders and collectively constitutes the most common cause of inherited spasticity worldwide, with an estimated combined prevalence of 5 to 10 cases per 100,000 individuals. In similarity, a gene for a very rare, familial form of PLS has been identified. Scientists are working to understand this gene and how mutations lead to upper nerve degeneration. Research is also being conducted regarding spasticity treatments and understanding neurological functioning. It is hopeful that treatments or cures discovered for other neurological conditions may prove to have similar pathways for those suffering with PLS and HSP.

To keep promising research projects moving forward funding is critical to initiate new research and uncover breakthrough treatments and/or medications that can change the lives of the children and families impacted by this devastating disease.

Many researchers provided encouraging updates on their research at the 21st Annual Conference in Tampa, Florida. Several are working with gene therapy. At least one has identified several medicines already approved for other diseases that may have a positive impact on HSP or PLS. Below are updates for 2023 highlighting the latest research funded by the SP-Foundation. The information is sorted below by years and investigators based on when the research proposal was approved and/or funded by the SP-Foundation. Please review SP-Foundation.org for additional medical research funded by your generous donations.

RESEARCH AND DEVELOPMENTS

2022

#1 The Spastic Paraplegia - Centers of Excellence Research Network (SP-CERN): "Promoting Clinical Trial Readiness For Hereditary Spastic Paraplegia": The SP-CERN is a collaborative research initiative covering both HSP and PLS, which is building a comprehensive program for diagnostic progress and clinical trial readiness to support the development of novel therapeutic approaches. The award illustrates the urgency of creating a consortium and international collaboration across the scientific community. This initiative will support the development of a registry and natural history study across all ages, a biobank for research biospecimens, and a genome archive for a cohort of individuals with HSP or PLS, along with the establishment of a platform for molecular testing for those with no genetic cause(s) yet identified. Principal investigator Dr. Ebrahimi-Fakhari - Boston Children's Hospital / Harvard Neurology Program, Boston, MA, expects that after the two-year Pilot Program, the SP-CERN will be eligible for funding from the National Institutes of Health (NIH) and network with more research sites. There are currently 12 research sites in the US. Find more information about these sites on SP-Foundation.org.

Peter W. Baas, PhD

#2 Peter Baas, Ph.D., Professor, Dept of Neurobiology & Anatomy, Drexel University College of Medicine, Philadelphia, PA. "Antisense Oligonucleotide Therapy for SPG4". Results: Dr. Baas sought to develop another therapeutic strategy that we could pursue alongside the gene therapy – namely antisense oligonucleotides (ASOs). He has been working on this project with Ionis Pharmaceuticals, the leader in the development of therapeutic ASOs. They created a new mouse model funded by The Lilly and Blair Foundation. In the second part of the grant from the SP-Foundation, Dr. Bass proposed to move the ASO work into affected mice to not only prevent the disease symptoms from occurring but also reverse the symptoms once they have begun. With plans underway, this will be done collaboratively with the world experts at the Marion Murray Spinal Cord Research Center at Drexel University, focusing on exercise therapy to enhance the sprouting of new axonal branches from healthy axons to reroute the nervous system to restore lost functions to patients who are already suffering gait deficiencies. The funding from the SP-Foundation has been essential to enabling Dr. Baas, together with Dr. Gerardo Morfini of University of Illinois at Chicago, to secure a five-year multi researcher grant from the National Institutes of Health (NIH). With this grant in its final year, they are continuing to seek additional funding from the NIH.

Dr. Stefan Barakat

#3 Dr. Stefan Barakat - Clinical Genetics, Erasmus University, Rotterdam, The Netherlands. Dr. Barakat's lab explores potential therapeutics for Hereditary Spastic Paraplegia *(HSP)* caused by a mutation in the AMFR gene *(autocrine motility factor receptor)*. AMFR is associated with SPG89, an autosomal recessive neurodegenerative disease with symptom onset in early childhood. One of the main findings in SPG89 is altered lipid metabolism, which is disrupted by the absence of AMFR. His lab uses zebrafish to characterize the disease mechanisms and potential therapies and also looks at AMFR mutations in stem cells.

Dr. Laura Civiero

#4 Dr. Laura Civiero - University of Padova, Italy. Dr. Civiero's lab focuses on ATP13A2-linked Hereditary Spastic Paraplegia (HSP) by testing anti-inflammatory drugs with potential ther-

apeutic effects. ATP13A2 is associated with SPG78, an autosomal recessive, adult-onset form of HSP. Dr. Civiero's lab also looks at ATP13A2 using CRISPR/Cas9 technology.


Dr. Matthias Kneussel

#5 Dr. Matthias Kneussel - University Medical Center, Hamburg-Eppendorf, Germany. Dr. Kneussel's lab uses mouse models to focus on the connections between tubulin post-translational modifications, tubular ER network integrity, and proteins such as spastin. Tubulin is a globular protein that polymerizes into microtubules, a major cytoskeleton component. Spastin microtubule binding and its dysregulation have been implicated in neurodegeneration. Dr. Kneussel's lab also investigates axonal endoplasmic reticulum (ER) using electron microscopy (EM), and the differences in axons based on the amount of spastin present. This is important because mutations in the SPAST gene cause SPG4.

#6 Dr. Claire Pujol - The Pasteur Institute, Paris, France. Dr. Pujol's lab focuses on mitochondrial dysfunction in Hereditary Spastic Paraplegia (HSP), namely the elucidation of mitochondrial dysfunction in HSP by unbiased imaging (specialized confocal microscopy) and pharmacological and genetic screening. Dr. Pujol hopes to find mitochondrial-modulating HSP therapeutic compounds (drug repurposing) and discover the mechanisms behind HSP to determine why there are so many phenotypic variations observed in patients.


Dr. Mukesh Gautam

#7 Dr. Mukesh Gautam - Northwestern University, Chicago, IL, USA. "Potential Role of cardiolipin in improving upper motor neuron health" – As presented during the SPF 2023 Conference, Dr. Gautam's lab focused on TDP-43 Pathology, which is detected in upper motor neuron diseases such as Hereditary Spastic Paraplegia (HSP), Primary Lateral Sclerosis (PLS) and Amyotrophic Lateral Sclerosis (ALS) and improving the health and function of upper motor neurons. TDP-43 pathology is a major factor behind neurodegenerative diseases. 97% of ALS patients have TDP-43, and it is also found in HSP and PLS. TDP-43 resides in the cellular nucleus, but in diseased conditions it migrates out and aggregates, getting stuck in the cell which in turn affects RNA metabolism and mitochondrial function. Defects in mitochondrial function are seen early in the disease process, specifically the inner mitochondrial membrane (IMM). The evidence of this can be seen in transgenic prpTDP-43 mouse models versus healthy wild type (WT) mice using electron microscopy (EM), as well as neurons from ALS patients with TDP-43 pathology. Both mice and humans with TDP-43 exhibit the same pathology and degeneration of the upper motor neurons.

Maintaining the health of the IMM is critical for mitochondrial function. One of the key factors in mitochondrial function and structure is cardiolipin, a lipid molecule which allows the membrane to properly fold due to its unique structure and is involved in mitochondrial metabolic processes. This is important because targeting the integrity and function of mitochondria could be an effective treatment strategy for upper motor neuron diseases. Results: Thanks to the support of the SP-Foundation as well as corroboration with Stealth Biotheraputics in Boston, two possible therapeutics have been identified: SBT-272 and cardiolipin nanoparticles. SBT-272 has been shown to bind to cardiolipin and stabilize it, thus improving the health and function of the IMM in upper motor neurons in transgenic prp-TDP-43 mouse models. SBT-272 also appeared to work better than other drugs currently approved for ALS. Dr. Gautam's lab is currently investigating the use of cardiolipin nanoparticles. Subsequent results show that cardiolipin nanoparticles also help improve the health of upper motor neurons. Studies are currently on-going.

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2021


P. Hande Ozdinler PhD

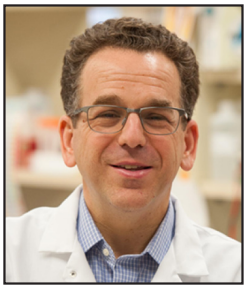
#1 Dr. P. Hande Ozdinler, Ph.D., Associate Professor, Northwestern University, Feinberg School of Medicine, Chicago, IL. "Investigation of NU9 and its impact on upper motor neurons diseased by spastin mutations in HSP." Dr. Ozdinler's lab is currently working with Dr. Richard B. Silverman on a potential treatment called NU9, the first reported compound that improves the health of upper motor neurons. Originally identified by Dr. Silverman, who invented the drug Lyrica *(pregabalin)* and formed the neurodegeneration and oncology-based company Akava Therapeutics, NU9 appears to overcome all four areas of identified cellular dysfunction and improves the function of upper motor neurons in diseased Spastin-UeGFP transgenic mice. Result: The Spastin transgenic mice were developed in corroboration with Dr. Peter Baas at Drexel University College of Medicine in Pennsylvania. This could be significant because decreased axon transport is an important factor in upper motor neuron diseases such as HSP and PLS, and it seems that treatment with NU9 helps reverse this phenomenon. Further research and quantification are needed but the early results are encouraging. Additionally, understanding the genetics behind the disease mechanism, as well as a patient's specific genetic mutation, is critical as the technology now exists to develop personalized gene therapy treatments, such as antisense oligonucleotides *(ASOs)*, AAV-mediated gene delivery *(adenovirus-mediated gene delivery)* and small RNAs, based on the known specific genetic mutation (e.g. SPG50). Whether HSP is inherited in an autosomal dominant manner *(one gene copy)* or autosomal recessive manner *(two gene copies)*, over 80 different mutations result in a protein not functioning and subsequent upper motor neuron degeneration. In 30-40% of HSP patients, the genetic mutation is unknown. In PLS, patients have mutations that also exist in ALS, but not HSP, and only about 10-15% of the genetics behind PLS is currently understood as the disease largely develops sporadically. Once the genetic domains and proteins are identified *(e.g. spastin and alsin)*, Dr. Ozdinler's lab began working on elucidating the mechanism and cause behind the specific disease process, the protein-protein interactions involved, and identify druggable targets based on those findings, thereby allowing patients to potentially be treated with known FDA approved drugs *(drug repurposing)* or allowing researchers to develop new ones using preclinical screening platforms based on transgenic mouse models. Additionally, proteomics and RNA gene expression analysis studies help enable the discovery of the disease mechanisms and understanding of why these upper motor neurons start showing signs of vulnerability. When the genetic mutation is unknown, her lab is working on identifying proteins that are critical for upper motor neuron health broadly *(e.g. UCHL1)*, thereby allowing for possible gene therapy treatment for the patients who do not have a genetic diagnosis. Dr. Ozdinler's UCHL1 research made the cover of Nature Gene Therapy due to its significance. These findings could ultimately allow physicians to treat patients with disease modifying drugs regardless of their genetic mutation rather than relying on a symptomatic-only approach to clinical care.


Emanuela Piermarini, PhD

#2 Dr. Emanuela Piermarini, Ph.D. Research Scientist, Department of Neurobiology and Anatomy, Drexel University College of Medicine, Philadelphia, PA "Gene therapy approach for SPG4 – based HSP". Results: The data collected is very promising, showing that gene replacement at pre-symptomatic age prevents corticospinal degeneration and the gait defects at 3- and 6-months of age of mice. Additional tests are ongoing to assess biodistribution, safety, and efficacy of the vector. The funding from SPF has allowed Dr. Piermarini to gather preliminary data to pursue a new mechanistic hypothe-

sis for SPG4. She is currently seeking funding from the National Institute of Health (NIH) as Principal Investigator to further study.

2020


Eric Morrow, MD, PhD

#1 Eric Morrow, M.D., Ph.D. Director, Center for Translational Neuroscience, Brown University, Providence, RI. "Dietary Supplements to Treat GPT2 Disease, a Metabolic Cause of Progressive Spastic Paraplegia".

Results: Using high doses of an amino acid called alanine prolongs the survival in the mouse model. High dose alanine also improves muscle, neuronal growth and nerve physiological measures. They would like to do another study by the end of 2025. They are also consulting with movement disorder colleagues to increase their natural history study which is critical to build future clinical trials.


Liang Qiang, MD, PhD

#2 Liang Qiang, M.D., Ph.D. Assistant Professor, Neurobiology & Anatomy Department, Drexel University College of Medicine, Philadelphia, PA. "How Defective Autophagy May be the Cause for the Nerve Dieback in Hereditary Spastic Paraplegia." Results: A grant from SP-Foundation allowed Dr. Qiang to identify several drug targets from high-throughput analyses, including single-cell transcriptomics and proteomics. One notable target is HDAC6. He tested a compound targeting HDAC6 in their mouse model for SPG4, yielding very promising results. He has been communicating with MERCK and Amylyx. Both have a portfolio of compounds targeting HDAC. He is also trying to expand the search in other companies that have HDAC drugs.

2019


Hiroshi Mitsumoto, MD, DSc

#1 Dr. Hiroshi Mitsumoto, M.D., DSc, Wesley J Howe Professor of Neurology, Eleanor and Lou Gehrig ALS Center, Columbia University Irving Medical Center. "The Second International PLS Conference". Results: Dr. Mitsumoto and his team felt that work from investigators outside of USA/Canada was needed because PLS is an exceedingly rare disease. The first international conference was held more than 10 years earlier. At the conference, a serious need for new diagnostic criteria was recognized. A group of the attendees volunteered to develop the consensus diagnostic criteria for PLS. The SP-Foundation is a primary sponsor of the International PLS Conference.

#2 Dr. Hiroshi Mitsumoto, M.D., DSc, Wesley J Howe Professor of Neurology, Eleanor and Lou Gehrig ALS Center, Columbia University Irving Medical Center. "Analyzing disease progress in patients with PLS to develop historical controls, which can be used for the first clinical trial in PLS in the near future". Results: This SP-Foundation grant supports a 29-multisite natural history study for the next PLS clinical trial. This is the first study ever conducted in PLS. The natural history study was originally planned to enroll 100 participants in total for both early and definite PLS cases. However, patient recruitment had been seriously delayed and potentially jeopardized by the 2020-2022 COVID pandemic. In 2022 Dr. Mitsumoto published a protocol paper which described the entire study. In Oct 2023, he needed to modify the target to two-thirds of the original target. He enrolled slightly more than 70 participants at the end of Oct 2024, at which time, he expects to complete a one-year natural history follow-up study. Dr. Mitsumoto will report results at the upcoming Third International PLS Conference in Montreal, on December 4, 2024. Dr. Mitsumoto certainly ex-

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pects multiple publications will be published out of this study. Most importantly this study will be the foundation for the next clinical trial which will be the first ever PLS planned trial. At the same time, he plans to request additional support from SPF for obtaining longer follow-up and survival data of already enrolled participants into this natural history study. It will be an unprecedented opportunity to study a long-term prognosis of arguably the best characterized PLS patient population.


P. Hande Ozdinler PhD

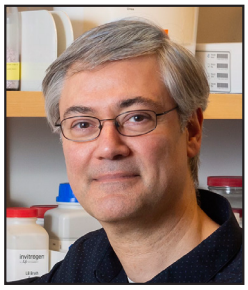
#3 Dr. P. Hande Ozdinler, Ph.D., & Dr. Nicholas Hatsopoulos, Ph.D., Associate Professor, Director, Les Turner ALS Lab II, Associate Professor with tenure, Department of Neurology, Northwestern University, Chicago, IL. "Directed Gene Therapy to Upper Motor Neurons." Results: Study is currently on-going.


Nicholas Hatsopoulos, PhD

2018


Darius Ebrahimi-Fakhari, MD, PhD

#1 Dr. Darius Ebrahimi-Fakhari, M.D., Ph.D. Boston Children's Hospital / Harvard Neurology Program, Boston, MA, & Mustafa Sahin, M.D., Ph.D., Co-Investigator, Director - Translational Neuroscience Center, Professor of Neurology, Harvard Medical School, The F.M. Kirby Neurobiology Center, Department of Neurology, Boston Children's Hospital, Boston, MA. "Generation of Human Nerve Cells from Children with AP-4-Associated Hereditary Spastic Paraplegia to Support a Search for New Therapies". Results: The purpose of the HSP Sequencing Initiative is to better understand the role of genetics in HSP and related disorders. The HSPs are a group of more than 80 inherited neurological diseases that share the common feature of progressive spasticity. Collectively, the HSPs present the most common cause of inherited spasticity and associated disability, with a combined prevalence of 2-5 cases per 100,000 individuals worldwide. In childhood-onset forms, initial symptoms are often non-specific, and many children may not receive a diagnosis until progressive features are recognized, often leading to a significant diagnostic delay. Genetic testing in children with spastic paraplegia is not yet standard practice. In this study, the investigators hope to identify genetic factors related to HSP. By identifying different genetic factors, the investigators hope that over time we can develop better treatments for sub-categories of HSP based on cause.


Mustafa Sahin, MD, PhD

Dr. Ebrahimi-Fakhari's lab completed a screening of approximately 3,000 small molecules and identified around 25 drugs that corrected the cellular properties towards normal. They are now embarking on a much larger screen of 35,000 small molecules with the hope to identify additional drugs that can be tested and ultimately developed into future therapies.

2017


John Fink, MD

#1 Dr. John Fink, M.D., Professor, Department of Neurology, University of Michigan "Primary Lateral Sclerosis: Biomarker Discovery." Results: The study is still in progress (2024). Investigators are analyzing stem cell derived neurons. The study begins with skin biopsies from individuals with PLS, transforms these skin fibroblasts into stem cells, and then selectively differentiates these cells into neurons. Prior attempts to create upper motor neurons specifically were very inefficient and did not permit biomarker analysis. Developments in the field did not yield high efficiency transformation into upper motor neurons, which greatly facilitates biomarker discovery.

Dr. Fink plans to submit a future grant application to SPF to continue to support this research.


Peter W. Baas, PhD

#2 Dr. Peter Baas, Ph.D. Professor, Dept of Neurobiology & Anatomy, Drexel University College of Medicine, Philadelphia, PA. "Cause of nerve degeneration in people with Hereditary Spastic Paraplegia." Results: Dr. Baas sought to understand if loss-of-function mechanisms are relevant to the disease, if not the primary cause. Dr. Baas, specially provided comments as follows: "First, we sought to determine if lowered functional spastin levels make the axon more vulnerable to the cytotoxic effects of the mutant spastin proteins. For this, we generated a new mouse model for SPG4-HSP that retained the two endogenous mouse SPAST genes while adding to them a human mutant SPAST gene. This mouse recapitulates the symptoms of the disease, demonstrating that gain-of-function mechanisms are necessary and sufficient for the disease, even without loss of functional spastin. When we crossed this mouse with a SPAST knockout mouse, the symptoms were notably worse, showing that loss-of-function of spastin is indeed an exacerbating factor. This work has been published. Second, we wished to begin breaking ground on therapies, starting with inhibitors of HDAC6, an enzyme that de-acetylates microtubules in the axon, and whose activity is increased by the mutant spastin. We are collaborating with Dr. Liang Qiang on this, with his lab currently taking the lead, using our mouse model and brain organoids generated in his lab from human induced pluripotent cells. Progress has been good, with positive benefits displayed in both model systems of HDAC6 inhibitors, and we hope to publish this work over the next several months. In my lab, we shifted our attention toward gene therapy, with subsequent funding from a grant from the SP-Foundation on gene therapy for SPG4-HSP to my colleague, Dr. Emanuela Piermarini."

2016


Hiroshi Mitsumoto, MD, DSc

#1 Dr. Hiroshi Mitsumoto, M.D., DSc, Wesley J Howe Professor of Neurology, Eleanor and Lou Gehrig ALS Center, Columbia University Irving Medical Center. "Development of a PLS-specific clinical rating scale, capable of evaluating the clinical functional state of patients with Primary Lateral Sclerosis in multi-site study." Results: Clinical observations of the participants in the PLS COSMOS study revealed ALSFRS-R, which we used because it is most widely and broadly utilized for ALS. research, was found to be not helpful for detecting the clinical progression in PLS. We realized that we needed a clinometric scale which was more sensitive to detect changes occurring in PLS. Thus, we developed a novel scale called PLSFRS.


Anjon Audhya, PhD

#2 Dr. Anjon Audhya. Ph.D., Associate Professor, Biomolecular Chemistry, University of Wisconsin Madison. "Identifying underlying causes of Hereditary Spastic Paraplegia and creating avenues toward the development of new therapeutic interventions." Results: Dr. Audhya created human induced pluripotent stem cells (iPSCs), which harbor the following mutations, all of which have been identified in patients suffering from HSP (both heterozygous and homozygous): SPG57 p.R106C and SPG3A p.S398F, as well as rat models of HSP expressing SPG57 p.R106C, SPG53 p.K382N, SPG57 p.R22W, SPG57 p.P285L, and SPG57 p.Q239STOP (forces an alternative splice donor to be selected). Dr. Audhya's lab developed several animal models and began assessing motor and gait phenotypes quantitatively. Was able to get medication from two different pharmaceutical companies. One medication worked. Very few people have SPG57 so it would be difficult to study them. More research is underway to develop a stem cell model for SPG4 and to try the medications in future patient trials.

SPF COMMITTEES – WORK OF THE SP-FOUNDATION

Get Involved - Volunteer on a Committee

SP-Foundation *has volunteer opportunities for you to provide input on one of any working committees. You may have personal experience, professional expertise, or just an interest in Advocacy, Education & Ambassadors, Fundraising, Marketing, and Research. If you have time and interest in any of these committees, email SPF at Volunteer@SP-Foundation.org, or join us virtually via Zoom by registering for our once a month call for the latest updates.*

Advocacy Committee

The Advocacy Committee seeks volunteers to support the SP-Foundation in its vision and mission, evaluating new and innovative ways to make our foundation a more active partner in both public and private sector networks. The committee discusses processes to assist our membership in more effectively communicating with both federal and state governments relating to policies and potential new legislation affecting the lives of people living with HSP and PLS. The SP-Foundation is seeking partnerships with similar organizations to amplify voices in creating awareness, ensuring access to care and treatments, accelerating drug development, and making positive changes for people affected by HSP and PLS. Engaging the spastic paraplegia population through storytelling, your journey is essential for outreach efforts to reach the ears and hearts of policy makers, state and federal legislators, and pharmaceutical companies.

Education & Ambassador Committee

The volunteers on the SP-Foundation Education & Ambassador Committee have a very important function. The primary focus of the SP-Foundation Education and Ambassador Committee is to spread awareness of HSP & PLS and to educate everyone about our rare diseases, specifically patients, families, caregivers, physicians/PT, and the general public. Ambassadors stay connected to members in their region as a liaison for the SP-Foundation. Ambassadors help individuals around the world every day offering critical support and information services online and at in-person gatherings. They raise disease awareness, enhance community building, and enrich relationships with people fighting HSP and PLS. They help members find disease information, educating everyone about HSP and PLS, including families and friends. Ambassadors may also assist by encouraging media relations, sharing their story, speaking before local groups, and helping with grassroots advocacy. Some are working with medical schools to show medical students firsthand what living with HSP or PLS looks like in the classroom. Committee members look for current and relevant information to update the SP-Foundation. Committee members also work with patients to compile a listing of doctors and physicians, movement clinics, and others in the medical field that are actively familiar with HSP and PLS.

Fundraising Committee

The Fundraising Committee seeks volunteers to help with planning, developing, and implementing fundraising strategies. The Fundraising team seeks your assistance in introducing SP-Foundation to your circle of influence to access potential donations and contributions. The Committee analyzes relationships with current and prospective major donors, funders, and corporate sponsors. It develops an individualized strategy and creates sponsorship packages to cultivate and strengthen those relationships. The foundation has the challenge of vying with other organizations for philanthropic dollars to best capture the attention, hearts, and funds of the community. Members should be knowledgeable about the mission of the SP-Foundation, in order to inform prospective donors of the many reasons they should strongly consider contrib-

uting to our important work. The Fundraising Committee seeks a listing from its membership about fundraising events throughout the year to share on SP-Foundation's social media pages in an effort to encourage fundraisers and donations. Another role of the committee is the brainstorming of new ideas, so others may implement and/or replicate them to help raise funds in their local communities. The Fundraising Committee also sponsors a few events via online platforms for friendly challenges among our membership, such as the SPF 5k Run Walk & Roll. Members review potential fundraising activities and make recommendations for innovative ideas for the new fiscal year. We are always seeking suggestions beyond traditional events such as golf tournaments, wine-tasting events, and 5Ks. Other potential fundraising activities may include incorporating volunteer projects, sponsorships at local restaurants, or favorite outdoor or seasonal activities. Also consider organizing gourmet cooking classes, holding a karaoke night, or sponsoring a brewery tour. The primary goal of the Fundraising Committee is to secure funding for disease research via scientific laboratory proposals to assist in finding a cure, therapy, or medications for patients with HSP and PLS.

Marketing Committee

The Marketing Committee communicates disease awareness, develops marketing messaging, and provides input for the purpose and vision of the SP-Foundation. The committee makes recommendations to the board to secure resources to advance the foundation's goals of research, education, and support. The emphasis has been to increase the presence and awareness of the SP-Foundation to physicians, scientists, researchers, and to individuals with HSP and PLS. The committee develops strategies and advertising campaigns to communicate with our membership, as well as current and potential donors. The committee also works to inform our community about events and happenings, such as fundraising events, webinars, and SPF TALKS via Zoom. The marketing committee's purpose is to decide how to communicate most effectively using all forms of media, including YouTube, Spotify, Instagram, X, and Facebook/Meta. If you have marketing or branding experience, we need your expertise to create messages, graphics, and memes. It is quite humbling to be a part of a community that so passionately tells its stories of enduring life with HSP and PLS. Our families, community and membership continue to grow, and our message and vision will continue to focus on "the day when all individuals with HSP or PLS are diagnosed, treated, and cured."

It is Essential to Register with the Spastic Paraplegia Foundation!

Medical researchers contact SPF to locate people with a specific gene mutation. Upon request, we provide a list indexing people with a specific gene mutation from the SPF database. If you are registered, then you may be selected for medical research or gene therapies.

Join at SP-Foundation.org/news-resources/stay-informed.html

SP-Foundation operates out of the strength of our patient community, caring family, friends, and sponsors. The Foundation is, all-volunteer based non-profit, made up of people affected by these diseases and our families. Your help makes a difference! The Fundraising Committee offers the following examples to expand your fundraising base to help you contribute financially to the SP-Foundation:

1. Online giving through SP-Foundation.org is the quickest, easiest, and most cost-efficient way for the Foundation. Set up a recurring donation plan or make a single contribution. Monthly or quarterly contributions can easily be setup and amended at any time with autopay on SP-Foundation.org. As soon as your online contribution is processed you will receive a quick response thanking you for the donation and providing an automatic tax receipt for your records.

2. Personal checks are always an option. Though it takes valuable time and resources to process checks to ensure the donation is properly coded in the system. It also takes volunteers to properly acknowledge your donation with a personal Thank You note. To be most efficient, the SP-Foundation prefers online donations if possible.

3. Honorarium and Memorial Contributions is a heart-felt way of acknowledging your loved one with a webpage specially created for them online through the SP-Foundation's "Memorial Giving Honoring Loved Ones in SPF Circle of Love". Please let us know if we should notify someone about your honorarium and memorial contribution by emailing Information@SP-Foundation.org with their contact information.

4. Facebook Fundraisers are another option for raising money for SP-Foundation. Creating personal fundraisers can bring people together and yet far-reaching in benefit for a great cause like the SP-Foundation.

5. Employer-Matching Programs may be available through your employer. Contact your human resource or personnel department to see if your employer has a program to match your charitable contributions. It is typically easy to sign up. Your gift may be matched by your employer, so let them know when and how much you plan to contribute to the SP-Foundation.

6. Planned Giving is another great way to contribute to SPF for medical research. It may be accomplished in several different ways. One option is including the SPF in your last will and testament. Making the SPF beneficiary of trusts or life insurance policies are other possibilities. Please check with your financial advisor and/or attorney to consider these types of contributions. In 2020 after we lost a hard-working member of our population, Mr. John Staehle, the SP-Foundation created "The Staehle Legacy League" in his honor so members can name the SP-Foundation in their will, trust, retirement plan, life insurance policy or annuity. For more information about planned-giving or if you would like to notify SP-Foundation that you are participating, please contact us at Information@SP-Foundation.org or call (877) 773-4483.

7. You can also donate Appreciated Securities, funds from 401Ks, or other financial investments. Check with your financial advisor regarding the proper process and timing should you desire to consider this type of contribution. Contact SP-Foundation for more information including wiring instructions.

8. Many businesses have foundations set up to help them save money while helping the community. If you have a connection with a business, please check and see if they make contributions to non-profits. If so, they might contribute to SP-Foundation in your honor. Contact SP-Foundation for assistance with the application process.

9. Corporate Sponsorships are another effective way to help raise money for SP-Foundation. Through the SP-Foundation Sponsorship Program we can partner to provide marketing opportunities for businesses and nonprofit organizations through SP-Foundation online resources. Contact SP-Foundation for assistance with the Sponsorship Program. There are several events, campaigns, and fundraising opportunities that happen year around. Details are communicated from the SP-Foundation via email, social media, and e-blasts.

FOREVER IN REMEMBRANCE

Memorial Giving Honoring Loved Ones in SPF Circle of Love

A memorial contribution is a heart-felt way of acknowledging your loved one on the SP-Foundation's "Circle of Love Memorial Giving" website. Honoring your loved one makes a wonderful living example of their journey on our website. During these difficult times, the SP-Foundation is heartfelt and sympathetic in memorializing your family members with HSP or PLS in our "Circle of Love". Send an obituary link to their funeral service by emailing Information@SP-Foundation.org.

Families are requesting remembrances be made in the form of contributions to the SP-Foundation in lieu of flowers. On the SP-Foundation website we have Memorial Cards to add the name of your family member that can be printed to share with family, friends, and the funeral home. We can help you set up a webpage created just for your family member in order to accept online contributions. When donations are received through your family's webpage, you will receive an acknowledgment of those donors from SP-Foundation.

With profound sadness, we said goodbye to many friends and family during this past year. Please consider making a donation to honor their commitment to finding a cure for HSP or PLS. With your help, we will persist in the vision of a world without spastic paraplegia where all individuals with HSP or PLS are diagnosed, treated, and cured.

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
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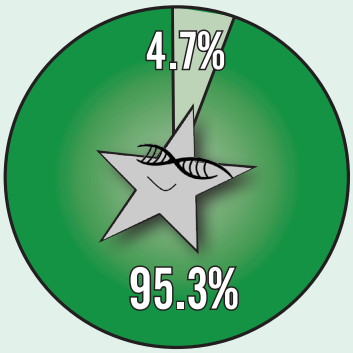
Visit: https://sp-foundation.org/get-involved/donate-here/memorial-giving-honoring-love-ones-in-spf-circle-of-love.html

Financial Activities

Where your dollars go



95.3% Mission

4.7% Management and Administration

REVENUE	**2023**
Donations	$1,244,568
Donated Services	36,760
Program Fees & Products	49,773
Interest and Investment Income/Loss	141,828
Total Support and Revenue	**$1,472,929**
DIRECT EXPENSES	
Management and General	64,738
(including non-cash Donated Professional Services Expense)	
FUNDRAISING	4,384
Program Expense - Education	126,314
(excluding grants)	
Program Expense - Grants Awarded	1,769,938
Mission	**95.3%**
Mgmt./Admin./Fundraising	**4.7%**
Total Non-Grant Expenses	**$195,436**
TOTAL ASSETS	**$3,308,442**
TOTAL LIABILITIES*	**$2,277,085**
NET ASSETS *(as of December 31)*	**$1,031,357**
GRANTS PLEDGED	**2,268,085**
(included in Total Liabilities)	

Note: SPF publishes annual audited financial statements and the IRS form 990 on our website as the information is finalized. To ensure complete transparency, the presentation above reflects categorization consistent with the audited financial statements.

**Financial Information provided by SP-Foundation Treasurer, David Lewis.*

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SPF SPASTIC PARAPLEGIA FOUNDATION, INC.
RESEARCH | EDUCATION | SUPPORT

6952 Clayborne Drive
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SPF EVENT CALENDAR

Register & Watch for SPF E-Blasts

Rare Disease Day	February 28th, Annually
SPF 5K Run Walk or Roll	May 1 – October 31, Annually
SPF Annual Conference	TBD – Join SPF for E-Blast Updates
HSP & PLS Awareness Week	August, Annually
HSP & PLS Awareness Day	August 27th, Annually
Golfing For Rare Disease Tournament	September Annually
Year-End Giving with Anonymous SPICY Match	November 1st to January 15th
Giving Tuesday	November, Annually
SPF TALKS	Join SPF for E-Blast Updates

PLS Support Group Zoom With Dr. John Fink – first Tuesday each month 5:00pm CST.

HSP Support Group Zoom With Dr. John Fink – first Tuesday each month 6:30pm CST.

See SP-Foundation.org > Events > for Zoom links.