July 2025

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

RESEARCH | EDUCATION | SUPPORT

2024 ANNUAL REPORT

Champion Cures

It's Not Over If You Don't Quit.

2024 Message from the President

Greg Pruitt

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

It is with great thankfulness and excitement that I write this letter for the 2024 SPF Annual Report! Your board of directors and I are so grateful that the SPF community continues to work together so diligently in every way to move more quickly toward the day when there is a treatment that can improve the lives of all of us who deal with either hereditary spastic paraplegia or primary lateral sclerosis. Your board of directors needs your involvement and input in every facet of foundation work and activity. Raising funds for continued and progressing medical research is critically important, but your presence in this work through SPF Talks, committee meetings, and other processes is also vital. We need your personal touch and lived experience to help demonstrate to the world how devastating these diseases are for individuals and families, and how their partnership and commitment can make the difference in finding those life changing treatments.

THANK YOU to everyone who contributed to the fundraising work of SPF in 2024. As you can see from the numbers in this annual report, you played a part in this incredible financial growth, raising $1,597,571 during the year, an increase of 28.4% over 2023. THAT IS ABSOLUTELY AMAZING!! This funding will allow us to continue seeking the most on-point and important medical research to find interventions and therapeutics. As you may know, your board of directors is all volunteer, but we are working everyday meeting electronically with doctors, researchers, pharmaceutical representatives, federal government partners such as NIH and FDA, as well as other patient-based groups to push for aggressive approaches in finding the answers that will lead us to treatments that will make a positive difference.

As we move forward, we will continue working with our Scientific Advisory Board in evaluating research proposals for funding. Please take the time and opportunity to review the list in this annual report of all the research projects funded by SPF with your support from 2002 to 2024. We will also continue working with our SP-CERN to move toward opportunities for quicker diagnosis for patients and in support of their effort to obtain significant funding from NIH necessary to accelerate our research processes. As part of that effort, we are also working with Critical Path Institute in Washington, DC, to assist us in more quickly bringing together all parties in a pre-consortia necessary to the process of finding those treatments in a collaborative spirit and effort.

In short, thank you to every one of you who has supported and/or participated in any way in this very important work in 2024. Your presence and active participation will always be desperately appreciated and needed as we continue this work. I truly believe we are making significant strides, not only because of the medical research we are able to fund, but also because of the new relationships we are forging in the medical, research and regulatory arenas. We are committed to fighting this fight until we have found treatments that improve the lives of those who deal with these diseases now and in the future. Thank you for being a partner and warrior with us!

My Best Always,

Greg Pruitt

President | SP-Foundation

The SP-Foundation is the largest 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, determining the best-rated research proposals, and then funding the proposed research. This process is enhanced by the volunteer efforts of the SP-Foundation Research Committee and SPF's Scientific Advisory Board.

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 of 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 these 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.

SP-CERN

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

In 2023, SPF entered a collaboration with 10 initial research sites/investigators in the United States to form the Spastic Paraplegia - Centers of Excellence Research Network (SP-CERN), to bring together established physician-scientists and their multidisciplinary teams. At the end of 2024, a manuscript of this work was submitted for publication to Neurology Genetics dedicated to researching Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS) to create critical resources for the HSP and PLS community.

Researchers publish their manuscripts for research purposes for several key reasons. Dissemination of knowledge by sharing the findings of research being a top priority. The primary purpose of the research is to advance knowledge within a field, and submitting a manuscript for publication is the fundamental way to share those findings with the broader scientific community. Another purpose is to make contributions to the field. Published manuscripts have become part of the collective body of knowledge, serving as building blocks for future research and inspiring innovation. Another important focus involves peer review. Manuscripts undergo a rigorous peer review process in academic journals to help ensure the quality, validity, and credibility of the research. Publishing manuscripts helps in building a professional reputation. Publishing in reputable journals enhances researchers' professional standing and contributes to their academic recognition, which is crucial for career advancement, including promotions, tenure decisions, and securing funding. In essence, filing manuscripts for research purposes serves as a vital step in the research cycle, allowing researchers to share their work, gain recognition, improve their skills, contribute to the advancement of knowledge in their field, and most importantly gain validity to the research subject.

SP-CERN centered on creating a consortium and international collaboration across the scientific community, building a comprehensive program for diagnostic progress and clinical trial readiness to support the development of unique therapeutic approaches. 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.

(Note: The manuscript has been published in Neurology Genetics on February 21, 2025. There are currently 12 participating research sites in the United States. The collaboration has filed a U54 grant application for funding with the National Institutes of Health. Read the manuscript in its entirety and find more information about SP-CERN on SP-Foundation.org > Research > SP-CERN.)

BE READY FOR SERVICE

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 our 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 communities, email SPF at Volunteer@SP-Foundation.org, or join us virtually via Zoom by registering for our monthly Joint Committee Meeting for the latest updates

BE INSPIRED

2024 Grants

1. Critical Path Institute

Collin Hovinga, PharmD, MS, FCCP

Vice President of the Rare and Orphan Disease Programs – Tucson, AZ

Grant Award: $250,000

Research Target: Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS)

Formal Title of Project: Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS) Pre-Consortium Proposal

Title for Lay Persons: Pre-Consortium Collaboration

Specific Goals: In 2024, SPF entered a collaboration with Critical Path Institute, a Washington, D.C., based organization to form a pre-consortia to provide legal, scientific, and regulatory infrastructure to generate a unique neutral environment for stakeholders in the drug development ecosystem. This consortium can result in solutions that include clinical outcome assessment tools, clinical trial simulators and other quantitative tools, plus data resources and analytic platforms. These tools and platforms help de-risk decision making in the development and regulatory review process of novel medical products. In short, CPATH is assisting SPF in generating solutions to facilitate scientific and regulatory pathways to accelerate the development of therapies for patients with HSP and PLS.

2. EuroHSP

Federation of European HSP Associations

99 Rue Didot, 75014 Paris, France

Marina Zapparoli-Manzoni, President Euro-HSP

Gerald Fischer, PhD, Scientific Advisor Euro-HSP

The euroSPG4 Management Team: Lainate (Milano, Italy) / Völs (Tyrol, Austria) / STOPP-HSP/ Völs (Edlitz) / Austria

Grant Award: $11,000

Research Target: Hereditary Spastic Paraplegia SPG4

Formal Title of Project: euroSPF4 Project

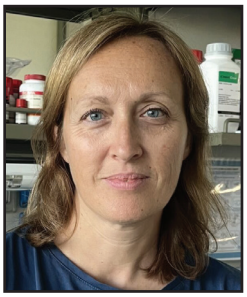
Title for Lay Persons: Development of a spastin recovery biomarker

Specific Goals: Euro-HSP and its member patient associations were funding this project in the past years.

In 2023 Euro-HSP established a consortium composed by patient representatives, basic researchers, clinicians, and industry for bridging the gap between promising findings in the laboratory and true treatments attempts. EuroHSP funded a first R&D year starting mid-2023 with a total of 60,000 Euro with contributions from patient associations in Austria, France, Italy, Switzerland, the Netherlands, the United Kingdom, and the Potato Pants Fund Vienna. EuroHSP is now planning a second research year starting mid-2024 which requires additional resources.

EuroHSP has a strong interest in supporting research activities which may lead to the development of a cure and aims to continuously raise money for promoting translation of HSP research into clinical application. In parallel to SPG4, EuroHSP is also setting up an SPG11/15 project, with a contract with the lab in Paris (180 kEuro over two years). SPF appreciates that the EuroSPG4 Project includes four (4) national Euro-HSP member associations that have formed a donator consortium. SPF is a strong advocate for open science and desires to solidify collaboration and international partnerships with our award to EuroHSP.

3. Investigators:



Chiara Vantaggiato

Chiara Vantaggiato, PhD. E. *Medea Scientific Institute - Associazione La Nostra Famiglia, Laboratory of Molecular Biology, Via d. L. Monza 20, 23842 Bosisio Parini, Lecco, Italy;* and **Genny Orso, PhD**, *Department of Pharmaceutical and Pharmacological Sciences, University of Padova, Largo E. Meneghetti 2, 35131 Padova, Italy;*

Genny Orso

[Update: Dr. Giulia Guarato from Padova University joined the research team after the recent passing of Dr. Genny Orso. Our condolences to Dr. Orso's family, friends and colleagues.]

Grant Award: $149,000

Research Target: Hereditary Spastic Paraplegia SPG11

Formal Title of Project: Therapeutic strategies for SPG11/ SPG 15

Title for Lay Persons: Therapeutic strategies for SPG11 / SPG 15

Specific Goals: This proposal brings together different expertise with multidisciplinary and complementary scientific background to cover different aspects that range from in vitro to in vivo animal studies. The research plan includes two main model systems: patient-derived fibroblasts and Drosophila models. The Primary Investigator, Chiara Vantaggiato, will perform lysosomal, endo-lysosomal and ALR analysis and rescue experiments in SPG11 patient's derived fibroblasts. The collaborator Genny Orso performed the experiments in the Drosophila models. Chiara Vantaggiato has been working on HSP for several years, and she has practical and theoretical expertise in autophagy, lysosomes and ALR. She demonstrated the role of Spastizin in autophagy, which mutations are associated with the HSP form SPG15, and characterized endocytic and autophagy defects in SPG15 and SPG11 cells. The Collaborator Genny Orso has successfully used the fruit fly models to identify the biological role of the HSP related proteins Spastin and Atlastin, when their functions were unknown. They recently performed the first combined in vitro/in vivo pharmacological screening in models of the SPG15 HSP from demonstrating that lysosomes are a key pharmacological target to rescue SPG15 phenotype and identifying potential therapeutic compounds (Vantaggiato et al., 2023).

Peter W. Baas, PhD

4. Investigator:

Dr. Peter Baas, PhD.
Professor, Department of Neurobiology and Anatomy

Director, Graduate Program in Neuroscience

Senior Editor, Cytoskeleton

Drexel University College of Medicine, Philadelphia, PA

Grant Award: $150,000

Research Target: Hereditary Spastic Paraplegia SPG4 - M1

Formal Title of Project: M1 monoclonal antibodies: A new tool for detection and treatment of SPG4-HSP

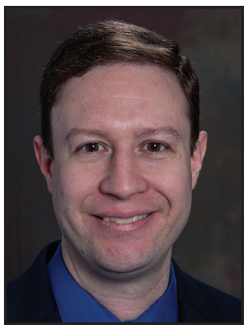
Title for Lay Persons: Antibodies for detecting and treating SPG4-HSP

Specific Goals: Hereditary Spastic Paraplegias (HSP) are diseases involving degeneration of the corticospinal tracts, leading to gait deficiencies. Mutations of the SPAST gene are the cause of SPG4-HSP, the most common variant of the disease. SPAST encodes spastin, a microtubule-severing protein with membrane-related properties. Corticospinal degeneration in SPG4-HSP results mainly from toxic properties acquired by the M1 isoform of spastin when it is mutated. M1 is difficult to defect in healthy cells but becomes more stable when mutated and accumulates in the corticospinal tracts. Because mutant M1 resists degradation, therapies that stop its expression may not be sufficient to impede the ensuing neurodegeneration. Investigating M1 and exploring potential ways of mitigating its toxicity have been hampered by the difficulty in detecting it. Developing monoclonal antibodies specific for M1 will provide an avenue for overcoming these obstacles, while also leading to a therapy for mitigating the toxicity of the accumulated M1 protein. In addition, if the accumulated M1 in the corticospinal axons enters the cerebral spinal fluid and/or the blood, such antibodies may enable M1 in these body fluids to become the first biomarker to assess disease progression in patients. For a variety of reasons, making M1-specific antibodies with the appropriate properties to accomplish these goals is challenging. Nonetheless, successfully doing so would be a game-changer in the HSP field. We have a good start on the process and are now requesting SPF funding in order to complete the production and characterization of these novel antibodies and to ascertain whether they can fulfill some or all of these urgent needs. For these studies, we will use a mouse model for SPG4-HSP developed in our lab.

BE GIVING

Donate to the SP-Foundation

Scan the QR Code with the cell phone camera and follow the prompts.



Anthony Donsante, PhD

5. Investigator:

Dr. Anthony Donsante, PhD.

Assistant Professor, Department of Neurology,

Emory University School of Medicine, Atlanta, Georgia

Grant Award: $150,000

Research Target: Primary Lateral Sclerosis

Formal Title: Modulation of Spasticity Using a Chemogenetic Approach

Lay Title: Reducing spasticity using a combination of gene therapy and small molecule therapy

Specific Goals: Spasticity is a consequence of many insults to the central nervous system, such as primary lateral sclerosis and spinal cord injury. The underpinnings of spasticity are not completely understood, but it involves the loss of descending innervation from the brain, increases in motor neuron sensitivity, and signaling through type Ia fibers.[1-3] Ultimately, this results in the unrestrained activation of motor neurons, leading to unwanted muscle contractions. This can lead to additional injuries, pain, and decreased quality of life.[4] Chemogenetics, which employs receptors engineered to respond to artificial ligands, can be used to reduce the activity of neurons, including motor neurons. In collaboration with CODA Biotherapeutics, we demonstrated that chemogenetics can be used to dampen motor output. However, CODA has since been acquired by another company, and it is not clear if we can pursue this research further with that receptor/ligand pair. This proposal will investigate two new chemogenetic systems and evaluate them in a rodent model of spasticity. [CODA Biotherapeutics]

Marcondes C. França Jr, MD, PhD

6. Investigator:

Dr. Marcondes C. França Jr, MD, PhD

Associate Professor and Head of Neurogenetics division

Department of Neurology, University of Campinas (UNICAMP) – Campinas/SP – Brazil

Grant Award: $118,000

Research Target: Hereditary Spastic Paraplegia SPG 7 and SPG11

Formal Title: Spinal cord morphometry and diffusion tensor imaging in hereditary spastic paraplegia: a one-year longitudinal study.

Lay Title: Advanced imaging to detect microstructural spinal cord changes in hereditary spastic paraplegia

Specific Goal: The disease takes a huge toll on patients, limiting activities of daily living. Treatment of HSPs represents an unmet medical need. Currently, the design of clinical trials for HSP is hampered by the lack of validated biomarkers. Although useful, clinical instruments – such as the Spastic paraplegia rating scale (SPRS) - lack sensitivity to track longitudinal changes, because HSPs are in general very slowly progressive conditions (Kessler et al, 2021). Several different biomarkers have been investigated in this context. Advanced brain neuroimaging emerges as one of the most promising candidates. For instance, corticospinal tract is a key structural target in the disease. Nowadays, volumetric and diffusion tensor imaging (DTI) techniques enable quantitative in vivo assessment of this tract. Indeed, recent studies uncovered the structural signature of brain alterations in specific HSP subtypes, helping us to understand the phenotypic spectrum in these conditions (Servelhere et al, 2021b). Spinal cord (SC) imaging looks even more promising, since this is the main target of neurodegeneration in most subtypes of HSP (Fink JK, 2023). There are interesting data on SPG4 showing the potential usefulness of advanced SC imaging in a cross-sectional setting (Navas-Sánchez et al, 2022; Servelhere et al, 2021a; Lindig et al, 2022). These studies have found cervical SC atrophy and diffusivity abnormalities in patients with SPG4 relative to controls (Navas-Sánchez et al, 2022; Servelhere et al, 2021a; Lindig et al, 2022). Moreover, these imaging parameters did correlate with disease severity, expressed by clinical scales. Despite these promising findings, longitudinal studies are scarce, particularly those focusing on SC morphometry and DTI.

SPF Historical Research

Year	Researcher	Institution	US or International?	HSP or PLS?	Topic	Grant Amount
2003	John K. Fink, M.D.	University of Michigan	US	PLS	A Molecular Genetic Analysis of Primary Lateral Sclerosis	$40,000
2003	Douglas A. Marchuk, Ph.D	Duke University	US	HSP	A Mouse Model of Hereditary Spastic Paraplegia	$40,000
2004	Vincent T. Cunliffe, Ph.D & Jonathan D. Wood, Ph.D	University of Sheffield	Intl. - UK	HSP (SPG4)	Modeling the neurodegenerative processes caused by mutation of the SPG4 gene in zebrafish and development of strategies for pharmacological intervention	$90,000
2004	Dr. Teepu Siddique	Northwestern University	US	PLS	PLS Registry	$90,000
2005	Michael R. Hayden, M.D., Ph.D and Blair R. Leavitt, Ph.D	University of British Columbia	Intl. - Canada		Revealing the mechanisms underlying ALS2, a form of hereditary spastic paraplegia, using ALS -/- mice	$149,896
2005	Brett Peter Lauring, M.D., Ph.D.	Columbia University	US		Analysis of Spastin and Atlastin in the cell biology of neurons	$96,701
2005	Peter Hedera, M.D.	Vanderbilt University	US	HSP	Invertebrate model of hereditary spastic paraplegia	$90,000
2005	Kendall S. Broadie, Ph.D.	Vanderbilt University	US	HSP	Mechanistic interactions among hereditary spastic paraplegia genes	$54,673
2005	Jeffrey Macklis, M.D.	Massachusetts General Hospital and Harvard Medical School	US		Molecular genetic controls over the development, connections, and survival of upper motor neurons	$121,660
2006	John K. Fink, M.D.	University of Michigan	US	HSP (SPG3A)	Developing treatment for childhood onset hereditary spastic paraplegia (SPG3A HSP)	$120,000
2006	Jeffrey Macklis, M.D. & Paola Arlotta, Ph.D	Massachusetts General Hospital and Harvard Medical School	US		Molecular Controls over the Development, Connections and Survival of Upper Motor Neurons	$125,000
2006	Nina Tang Sherwood, Ph.D	Duke University	US	HSP	Understanding the ameliorative effects of temperature in fruit fly models of AD-HSP	$120,000
2006	Kendall S. Broadie, Ph.D.	Vanderbilt University	US	HSP	Mechanistic interactions among hereditary spastic paraplegia genes	$57,070
2007	Bruce Horazdovsky, Ph.D.	Mayo Clinic College of Medicine	US	PLS	Development of a cell culture system to analyze defects associated with Primary Lateral Sclerosis	$58,000
2007	Peter W. Baas, Ph.D.	Drexel University	US	HSP (SPG4)	Mechanistic Basis of SPG4-based Hereditary Spastic Paraplegia	$140,000
2007	Stephan Zuchner, M.D.	Miami School of Medicine	US	HSP (SPG31)	Molecular and genetic analysis of the SPG31 gene REEP1	$135,561
2008	Paola Arlotta, Ph.D	Massachusetts General Hospital	US		Directed Differentiation of Neural Progenitors and iPS Cells into Corticospinal Motor Neurons	$60,000
2008	Janine Kirby, Ph.D, Christopher John McDermott, Ph.D, & Prof. Pamela Shaw	University of Sheffield	Intl. - UK	PLS	Elucidation of upper motor neurons vulnerability in primary lateral sclerosis	$103,375
2008	Yasushi Kisanuki, M.D.	University of Michigan	US	HSP	Paraplegia in HSP Rat: Analysis and treatment	$120,000
2008	Jeffrey Macklis, M.D.	Massachusetts General Hospital and Harvard Medical School	US		Molecular-Genetic Controls over the Development, Connections and Survival of Upper Motor Neurons	$120,560
2009	Hiroshi Mitsumoto, M.D., D.Sc	Columbia University	US	PLS	PLS Cohort Study of Multicenter Oxidative Stress (PLS COSMOS)	$120,000
2009	Elena I. Rugarli, M.D.	Istituto Nazionale Neurologico "C. Besta"	Intl. - Italy	HSP	Exploring alternative functions of paraplegin, a protein involved in autosomal recessive and sporadic HSP	$120,000
2010	Dong-Hui Chen, M.D., Ph.D	University of Washington	US	HSP	Next generation mutation identification: a paradigm for gene discovery in a new autosomal dominant hereditary spastic paraplegia	$73,194
2010	Susan K. McConnell, Ph.D	Stanford University	US		Elucidating the competence of upper motor neurons for corticospinal rewiring in transplantation paradigms	$120,000
2010	Robert D. Nicholls, D.Phil	Children's Hospital of Pittsburgh of UPMC	US	HSP	Gene Co-Regulation in the Hereditary Spastic Paraplegias	$119,779
2010	Dr. Teepu Siddique	Northwestern University	US	PLS	NTE-induced Upper Motor Neuron Degeneration in Primary Lateral Sclerosis	$119,979
2011	Paola Arlotta, Ph.D	Harvard University	US	Both	Molecular mechanisms of corticospinal motor neuron dysfunction in HSP and PLS	$120,000
2011	John K. Fink, M.D.	University of Michigan	US	Both	Natural history of primary lateral sclerosis and hereditary spastic paraplegia: establishing parameters for clinical trials	$120,000
2011	Nichole Hein, Ph.D	University of Michigan	US	Both	In vitro models of Primary Lateral Sclerosis and Hereditary Spastic Paraplegia	$120,000
2011	Sue-Jun Li, Ph.D	University of Connecticut	US	HSP	Elucidating the role of BMP signaling in HSP using patient-specific induced pluripotent stem cells	$120,000
2011	Melissa Rolls, Ph.D	Pennsylvania State University	US	HSP	Function of spastin in axon regeneration: a new role for the HSP protein spastin	$120,000
2012	Andrew Grierson, Ph.D	University of Sheffield	Intl. - UK	HSP	Pre-clinical assessment of histone deacetylase 6 (HDAC6) inhibition as a therapy for hereditary spastic paraplegia	$120,000
2012	Tina H. Lee, Ph.D	Carnegie Mellon University	US	HSP (SPG3A)	High throughput screen to identify small molecule facilitators of SPG3A function	$120,000
2012	Hiroshi Mitsumoto, M.D., D.Sc	Columbia University	US	PLS	Biochemical and Molecular Characteristics of Primary Lateral Sclerosis	$120,000
2013	Christina Fournier, M.D.	Emory University	US	PLS	Virginia Freer-Sweeney Clinical Research Training Fellowship in Primary Lateral Sclerosis	$200,000
2014	John K. Fink, M.D.	University of Michigan	US	PLS	Novel approaches to treating Primary Lateral Sclerosis	$120,000
2014	Andrew Grierson, Ph.D	University of Sheffield	Intl. - UK	HSP	Preclinical assessment of spastin gene replacement therapy as a treatment for hereditary spastic paraplegia	$120,000
2014	Professor Alan Mackay-Sim	Griffith University	Intl. - Australia	HSP	Patient-derived stem cells to develop drug treatments for Hereditary Spastic Paraplegia	$120,000
2014	Evan Reid, Ph.D	University of Cambridge	Intl. - UK	HSP	Defining a novel therapeutic--candidate pathway that modifies age at onset in HSP	$120,000
2014	Holger Sondermann, Ph.D	Cornell University	US		Molecular mechanisms and small-molecule targeting of atlastin	$120,000
2015	Benjamin F. Cravatt, Ph.D	The Scripps Research Institute	US	HSP	Brain lipid metabolism in hereditary spastic paraplegia	$94,914

Year	Researcher	Institution	US or International?	HSP or PLS?	Topic	Grant Amount
2015	Jonathan Rios, Ph.D & Mauricio Delgado, M.D.	Texas Scottish Rite Hospital for Children	US	HSP	Evaluating & Improving Personalized Genomic Medicine for Hereditary Spastic Paraplegia	$72,000
2015	Rebecca Schule, M.D.	University Hospital Tuebingen	Intl. - Germany	Both	Alliance for Treatment in HSP and PLS	$150,000
2015	Dr. Teepu Siddique	Northwestern University	US	PLS	Whole Exome Sequencing in Primary Lateral Sclerosis	$149,041
2015	Tobias S. Ulmer, Ph.D	University of Southern California	US		Structural basis of brain carnitine palmitoyltransferase 1 function	$150,000
2015	Sabrina Paganoni, M.D., Ph.D	Massachusetts General Hospital	US	PLS	Virginia Freer-Sweeney Clinical Research Training Fellowship in Primary Lateral Sclerosis, proposal Imaging of Inflammation in People with PLS	$200,000
2016	Jon Audhya, Ph.D	University of Wisconsin	US	HSP	Axonal trafficking and organelle dynamics in hereditary spastic paraplegia	$150,000
2016	Henry Houlden M.D., Ph.D and Viorica Chelban, M.D.	University College London	Intl. - UK	HSP	Development of the UK clinical research network and biobank in HSP	$54,200
2016	Hiroshi Mitsumoto, M.D., D.Sc	Columbia University	US	PLS	Multi-Site Test-Retest Reliability and Validity study of PLS-Specific Clinimetric Scale, PLS Functional Rating Scale (PLSFRS)	$150,000
2016	Emanuele Panza, Ph.D	Universita di Bologna	Intl. - Italy	HSP (SPG9)	Understanding Hereditary Spastic Paraplegia: in vivo models to identify pathogenetic mechanism and therapeutic targets for SPG9	$97,250
2016	Carolyn Sue, MBBS, Ph.D, FRACP, Alan Mackay-Sim, BA (Hons), Ph.D, Gautam Wali, M. Sc, Ph.D and Jin Sung Park, Ph.D	University of Sydney	Intl. - Australia	HSP (SPG7)	Patient-derived stem cell models to study disease mechanisms and screen drug candidates for SPG7 Hereditary Spastic Paraplegia	$150,000
2017	Mimoun Azzouz, Ph.D	University of Sheffield	Intl. - UK	HSP (SPG15)	Gene Therapeutic Strategies for Autosomal-Recessing Spastic Paraplegia Arising From Mutations in ZFYVE26 (SPG15)	$150,000
2017	Peter W. Baas, Ph.D.	Drexel University	US	HSP (SPG4)	Functional basis of SPG4-based Hereditary Spastic Paraplegia	$150,000
2017	John K. Fink, M.D.	University of Michigan	US	PLS	Primary Lateral Sclerosis: Biomarker Discovery	$150,000
2017	Gerardo Morfini, Ph.D	University of Illinois at Chicago	US		Mechanisms underlying the toxic effect of mutant M1 Spastin on axonal transport	$150,000
2017	Sabrina Paganoni, M.D., Ph.D	Harvard Medical School	US	Both	Imaging of Neuro-Inflammation in PLS and HSP	$150,000
2017	Giovanni Stevanin, Ph.D	Institut du Cerveau et de la Moelle epiniere - ICM (INSERM)	Intl. - France	HSP (SPG11)	Identification of the neuronal transcriptomic signature associated with lysosomal defects in spastic paraplegia 11	$150,000
2018	Ammar Al-Chalabi Ph.D, FRCP, DipStat and Alfredo Iacoangeli, Ph.D	Kings College London	Intl. - UK	PLS	A whole-genome approach to the study of the genetic and the epigenetic landscape of Primary Lateral Sclerosis	$134,000
2018	Darius Ebrahimi-Fakhari, M.D., Ph.D and Mustafa Sahin, M.D., Ph.D	Boston Children's Hospital	US	HSP	Development of iPSC-Derived Neurons from Patients with AP-4-associated Hereditary Spastic Paraplegia to Support an Unbiased Phenotypic Screening for Novel Therapeutic Targets	$149,998
2018	Xue-Jun Li, Ph.D	University of Illinois at Chicago	US	HSP	Rescuing axonal degeneration of human cortical neuron in spastic paraplegias by targeting mitochondrial dynamics	$150,000
2018	Holger Sondermann, Ph.D	Cornell University	US	HSP	Extrinsic Regulation of atlastin and its HSP variants	$150,000
2019	Siddarth Banka, Ph.D, Martin Peter Lowe, Ph.D, Anna Nicolaou, Ph.D	University of Manchester	Intl. - UK	HSP	Zebrafish models to understand and treat defects in the Kennedy pathway that lead to hereditary spastic paraplegia syndromes	$150,000
2019	Peter Bede, M.D., Ph.D	Trinity College	Intl. - UK	PLS	Development and validation of neuroimaging biomarkers for PLS: a longitudinal multimodal MRI study	$150,000
2019	Hiroshi Mitsumoto, M.D., D.Sc	Columbia University	US	PLS	Establishing the natural history of PLS for future clinical trials: Analyzing disease progression in patients with PLS to develop histori cal controls which can be used for the first clinical trial in PLS in the near future	$150,000
2019	Cahir O'Kane, Ph.D	University of Cambridge	Intl. - UK	HSP	Role of axonal endoplasmic reticulum architecture in neuronal vulnerability in HSP	$150,000
2019	P. Hande Ozdinler, Ph.D and Nicholas Hatsopoulos, Ph.D	Northwestern University	US		Directed Gene Delivery to Upper Motor Neurons	$150,000
2019	Carolyn Sue, MBBS, Ph.D, FRACP and Gautam Wali, M. Sc, Ph.D	University of Sydney	Intl. - Australia	HSP (SPG7)	Evaluating patient-derived stem cells from SPG7 patients carrying a variety of mutations to understand disease mechanisms and screen drugs	$150,000
2020	James R. Lupski, M.D., Ph.D	Baylor College of Medicine	US	HSP	Resolving the Genomics of Hereditary Spastic Paraplegia through Exome Sequencing and Long-Read Whole Genome Sequencing	$150,000
2020	Eric M. Morrow, M.D., Ph.D	Brown University	US	HSP	Pre-clinical Investigation of Dietary Supplements to Treat GPT-2 Disease, A Metabolic Cause of Progressive Spastic Paraplegia	$150,000
2020	Nicoletta Plotegher, Ph.D	University of Padua	Intl. - Italy	HSP	Unraveling the role of glucocerebrosidases and glucosyl-cholesterol in Hereditary Spastic Paraplegia	$50,000
2020	Liang Qiang, M.D., Ph.D	Drexel University	US	HSP (SPG4)	Elucidate impaired autophagy as one of the major contributors to SPG4-based Hereditary Spastic Paraplegia	$150,000
2020	Dr. Teepu Siddique	Northwestern University	US	PLS	Whole Exome Sequencing in Primary Lateral Sclerosis	$150,000
2020	Zane Zeier, Ph.D & Michael Benetar, M.D., Ph.D	University of Miami	US	PLS	Creation of Induced Pluripotent stem cells for primary lateral sclerosis modelling and identification of biomarkers	$121,000
2021	Hiroshi Mitsumoto, M.D., D.Sc	Columbia University	US		Abel grant	$46,000
2021	Peter Bede, M.D., Ph.D	Trinity College	vUK	PLS	Characterising infratentorial pathology in PLS: the longitudinal evaluation of spinal cord, brainstem and cerebellar pathology in vivo	$140,000
2021	Marka van Blitterswijk	Mayo Clinic College of Medicine	US	PLS	Revealing determinants of PLS with long-read sequencing	$150,000
2021	Dr. Frederic Darios and Professor Alexandra Durr	Paris Brain Institute (Institut du Cerveau, ICM)	Intl. - France	HSP (SPG4)	Modulation of mitochondrial function as a modifier of SPG4 physiopathology	$150,000
2021	Roberta La Piana	McGill University	Intl. - Canada	HSP	Identifying novel white matter diagnostic criteria and imaging biomarkers in Hereditary Spastic Paraplegias (HSPs)	$125,434
2021	Dr. Jonathon Howard (Joe)	Yale	US		Roles of alternate isoforms of spastin on function in vitro and in vivo	$149,775
2021	P. Hande Ozdinler, Ph.D	Northwestern University	US	HSP	Investigation of NU-9 and its impact on upper motor neurons diseased by spastin mutations in HSP	$150,000

Year	Researcher	Institution	US or International?	HSP or PLS?	Topic	Grant Amount
2021	Emanuela Piermarini, Ph.D	Drexel University	US	HSP (SPG4)	Gene therapy approach for SPG4-based Hereditary Spastic Paraplegia	$150,000
2022	Peter W. Baas, Ph.D.	Drexel University	US	HSP (SPG4)	Antisense Oligonucleotide Therapy for SPG4-HSP	$150,000
2022	Dr. Stefan Barakat	Erasmus MC	Intl. - Netherlands	HSP	Exploring therapeutic avenues for a new type of HSP caused by mutations in AMFR: a pilot towards therapy	$149,438
2022	Dr. Laura Civiero	Universita Degli Studi Di Padova	Intl. - Italy	HSP	Finding novel approaches to rescue pathological phenotypes in ATP13A2-linked Hereditary Spastic Paraplegia	$65,000
2022	Dr. Mukesh Gautam	Northwestern University	US	PLS	Revealing ultra-structural defects in the motor cortex of PLS patients with and without TDP-43 pathology	$150,000
2022	Professor Dr. Mattias Kneussel, Ph.D	University Medical Center Hamburg-Eppendorf	Intl. - Germany	HSP	Investigating Connections between Tubulin Post-translational Modifications, Tubular ER Network Integrity and Hereditary Spastic Paraplegia-Related Proteins in Axons	$150,000
2022	Dr. Claire Pujol	Institut Pasteur	Intl. - France		Molecular dissection of mitochondrial dysfunction in HSP by unbiased imaging-based pharmacological and genetic screening	$150,000
2022	Darius Ebrahimi-Fakhari, M.D., Ph.D and the F.M. Kirby Neurobiology Center	Boston Children's Hospital	US	HSP	Spastic Paraplegia – Centers of Excellence	$600,000
2023	Collin Hovinga, PharmD, MS, FCCP	Critical Path Institute	US	Both	Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS) Taskforce	$500,000
2023	Marina Zapparoli-Manzoni and Gerald Fischer	Federation of European HSP Associations	Intl. - France		euroSPF4 project; Development of a spastin recovery biomarker	$11,000
2023	Peter W. Baas, Ph.D.	Drexel University	US	HSP (SPG4)	M1 monoclonal antibodies: A new tool for detection and treatment of SPG4-HSP	$150,000
2023	Dr. Anthony Donsante, Ph.D	Emory University	US		Modulation of Spacticity Using a Chemogenetic Approach	$150,000
2023	Marcondes Franca, M.D., Ph.D	University of Campinas (UNICAMP)	Intl. - Brazil	HSP	Spinal cord morphometry and diffusion tensor imaging in hereditary spastic paraplegia: a one-year longitudinal study	$118,000
2023	Dr. Chiara Vantaggiato, Ph.D and Genny Orso, Ph.D	E. Medea Scientific Institute - Associazione La Nostra Famiglia	Intl. - Italy	HSP (SPG11)	Therapeutic strategies for SPG11	$149,000
2024	Dr. Ikjaei Lee, MD MSc	Columbia University	US	PLS	Extension of the PLS Natural History Study	$150,000
Total						**$12,641,498**

*Year based on contributions received during this year, actual award typically was communicated in the following year, but all SPF files are organized according to that particular year.

NOTE: Approximately 75% of SPF funds are raised in the last three months of any given calendar year. Those grant funds are then granted to researchers in the following year after proposals have been requested, received, evaluated by the Scientific Advisory Board and approved by the SPF Board of Directors. (i.e. the grants listed above for 2023 were committed with the funds raised in 2023 and approved by the SPF Board in 2024)

CHAMPION CURES

United We Stand & Roll

SPF

#HSPandPLS

SP-Foundation.org

JOIN US IN WASHINGTON DC

OCTOBER 23-24, 2025

The Spastic Paraplegia Foundation invites you to the 22nd Annual Conference to learn, share, network, spark collaboration, and have fun! Mark your calendars to join us beginning at 8:am Thursday, October 23rd ending at 5:pm Friday, October 24th, 2025.

Register online for in-person or virtual participation at https://sp-foundation.org/get-involved/events/spf-annual-conference/2025-annual-conference-copy.html.

Building community is important, especially for those within close proximity to the location of the annual conferences. Attendance, in DC this year, is vital to show disease progression in the young to the aged, so DC policy makers will begin to help us in forming the roadmap, pathways, and repurpose new therapies and interventions specifically for HSP/PLS.

Scan the QR Code with the cell phone camera and follow the prompts to Pay and Register for the 2025 Annual Conference.

2025 SPF Annual Conference Registration

BE PREPARED

Let Your Voice Be Heard – Complete the Survey

The Spastic Paraplegia Foundation, Inc., (SPF) is conducting a survey to collect valuable information about living with Hereditary Spastic Paraplegia (HSP) or Primary Lateral Sclerosis (PLS) from individuals and families directly affected by these chronic rare diseases. Your response is your patient-voice telling others about your challenges and the knowledge of your lived-experience that you face every day. Collectively we will build a clear and strong message for pharmaceutical stakeholder engagement, key opinion leaders, and more effective research teams.

The insights gathered from this survey will play a crucial role in shaping future conversations for interventions and therapeutics, starting with discussions at the 2025 SPF Annual Conference in Washington DC. The collective results will be available to everyone, including those capable of developing medical discoveries and researching treatments and therapies to improve the quality of our lives. These may include representatives from NIH (National Institutes of Health), FDA (Food and Drug Administration), C-PATH (Critical Path Institute) and others. By sharing your perspectives and lived experiences, you are helping to ensure that patient-voices are heard and considered in future research, development of treatments, and policy decisions.

Your participation is very important to all of us. More people taking this survey will result in stronger and more accurate statistics making a clear unified message that we do not have a therapeutic specifically approved for HSP/PLS. Please encourage as many families and friends as you know with HSP/PLS to complete this survey. Information from every family member is essential as personal impacts and symptoms vary among families and patients. Thank you for taking the time to contribute to this vital effort and helping progress toward patient knowledge for a treatment or a cure.

We will compile the survey results of all respondents, and there will be no personal identifiable information included. SPF does NOT sell or distribute your information. SPF will reach out to you directly when a researcher, physician, stakeholder, or a representative from NIH or other organizations are seeking specific information from you or are seeking participants for a clinical or drug trial or study.

Your being a member of our SPF community is essential in helping us get an accurate number of those struggling with HSP/PLS across the world, including those that do not know their SPG numbers, also known as "SPG Unknown".

SPF SURVEY

But, you don't have to be a member of the SPF to take the survey.

The benefits of joining SPF include finding like-minded people and long-lasting friendships that understand the struggles. We can talk about health issues and commonalities we face every day. As a member, you will receive updates through our newsletter eblast/emails. We send research news updates, scientific and medical publications, and opportunities to participate in events and upcoming meetings, including dates for the next SPF TALKS zoom events. If you are not a member of SPF, please consider registering at no cost.

The survey should take 25 minutes of your time. Please click on "TAKE SURVEY" button to begin. The Survey Deadline is July 20, 2025 to be included in the presentation for the Annual Conference, but we still need the statistics as we form grant requests and inquiries for therapies and interventions.

Please email any questions, comments or concerns to Information@sp-foundation.org, or should you need help completing the survey, we can schedule an appointment to help you complete it.

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

LEGACY PLANNING

Leave Your Legacy

Plan To Give by arranging for contributions to be made with financial or estate planning through your will or trust leaving a legacy to support the SPF. This enables you to make charitable gifts now and establishes provisions for gifts that will continue later, after you have provided for your loved ones. This approach may provide financial and tax benefits to you, your heirs, and makes a lasting impact for the Spastic Paraplegia Foundation, Inc., and for those suffering with HSP and PLS.

Gifts By Beneficiary Designation

Arrange for contributions to SPF by naming the Spastic Paraplegia Foundation, Inc., as a beneficiary on your various bank accounts, retirement funds, savings bonds, etc., upon your passing. Simply contact your bank, retirement plan administrator, insurance company, or other financial institution to request a beneficiary designation form.

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.
RESEARCH | EDUCATION | SUPPORT

Visit: https://sp-foundation.org/get-involved/donate-here/memorial-giving-honoring-love-ones-in-spf-circle-of-love.html

Fundraising for SP-Foundation operates out of the strength of our patient community, caring family, friends, and sponsors. The Foundation is an 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. It takes valuable time and resources to process checks to ensure the donation is properly coded in the system. 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 can be 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 memory 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 401(k)s, 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.

PLANNED GIVING

IN MEMORIAL OF LARRY J. HARDY

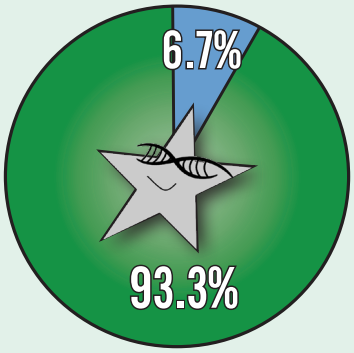
Larry J. Hardy
of Memphis, Tennessee
November 6, 1946 - April 29, 2023

The SP-Foundation expresses its deepest gratitude for the planned giving gift from Mr. Larry Hardy in 2024. Mr. Hardy died in 2023 and provided a planned and extraordinary gift in the amount of $250,000, which will be used in the SP-Foundation's medical research efforts. SP-Foundation also thanks Donna Wade, his dear friend and trustee, for her commitment and assistance in working with the SP-Foundation in fulfilling Larry's wishes and completing the planned giving process.

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

Financial Activities

Where your dollars go



93.3% Mission

6.7% Management and Administration

REVENUE	**2024**	**2023**
Donations	1,597,571	1,244,568
Donated Services	43,400	36,760
Program Fees & Products	37,315	49,773
Interest and Investment Income /Loss	99,959	141,828
Other income	5,684	–
Total Support and Revenue	**1,783,929**	**1,472,929**
DIRECT EXPENSES		
Management and General *(including non-cash Donated Professional Services Expense)*	81,604	64,738
Fundraising	37,811	4,384
Program Expense - Education *(excluding grants)*	213,750	126,314
Program Expense - Grants Awarded	602,174	1,769,938
Mission	**93.3%**	**95.3%**
Mgmt./Admin./Fundraising	**6.7%**	**4.7%**
Total Non-Grant Expenses		**195,436**
TOTAL ASSETS	**3,089,987**	**3,308,442**
TOTAL LIABILITIES*	**1,210,040**	**2,277,085**
NET ASSETS *(as of December 31)*	**1,879,947**	**1,031,357**
***GRANTS PLEDGED** *(Included in Total Liabilities)*	**1,194,086**	**2,268,085**

NOTE 1: Approximately 75% of SPF funds are raised in the last three months of any given calendar year. Those grant funds are then granted to researchers in the following year after proposals have been requested, received, evaluated by the Scientific Advisory Board and approved by the SPF Board of Directors. (i.e. the grants listed above for 2023 were committed with the funds raised in 2023 and approved by the SPF Board in 2024)

NOTE 2: 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.

This information was provided by SPF Treasurer, Lorri Steiner.

1 - 2024 included a 1x gift of $250,000

2 - most of 2023 investment earnings were unrealized gains, 2024 earnings are actual interest

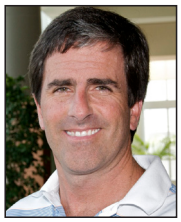
3 - 2024 expenses were coded to the respective category rather than utilizing allocations in prior years

4 - Because $511,000 of grants that were awarded in 2024 were not countersigned within the 2024 calendar year, they are not recognized in the 2024 financials. These grants will be recognized in the 2025 financials. Not including these grants in the 2024 financials give the appearance of a drop in funds being used towards the mission. This drop is a timing difference since the $511,000 of 2024 grants will be recognized in the 2025 financials along with grants awarded in 2025.

5 - SPF focused heavily on grant management in 2024 with proactive communications reminding researchers of due dates to keep the research and research payments on track as much as possible

2024 SPF Officers

Greg Pruitt
President



Jim Sheorn
Vice President

David Lewis
Treasurer

Lori Steiner
Treasurer

Hank Chiuppi
Secretary

Medical Advisor
John K. Fink, M.D.
University of Michigan, Ann Arbor, MI

Legal Counsel
Mark Weber, Esq.

Legal Counsel
Adam Futrell

2024 SPF Board of Directors

Greg Pruitt, President, *Mayfield, KY*
Jim Sheorn, Vice President, *Brentwood, TN*
David Lewis, Treasurer, *Fortson, GA*
Lorri Steiner, Treasurer, *Brentwood, TN*
Hank Chiuppi, Secretary, *Buffalo Grove, IL*
Mark Weber, Esq., Legal Counsel, *Sherman, CT*
Adam Futrell, Legal Counsel, Paducah, KY
Frank Davis, President Emeritus, *San Antonio, TX*
Corey Braastad, PhD, Member, *Southampton, MA*
John Cobb, Member, *Berkeley, CA*
Tina Croghan, Member, *O'Fallon, MO*
Dina Landphair, Member, *Adel, IA*
Carina Thurgood, Member, *Essex, England (U.K.)*
Jackie Wellman, Member, *Des Moines, IA*
Norma Pruitt, Executive. Director (Volunteer), *Mayfield, KY*

2023-2024 SCIENTIFIC ADVISORY BOARD - SPASTIC PARAPLEGIA FOUNDATION, INC.

SAB Chair: Paolo Moretti, MD, Chief, Division of Sleep and Movement Disorders, Department of Neurology, University of Utah, Salt Lake City, UT

Corey Braastad, PhD, Vice President and General Manager of Covance Genomics Laboratories, Springfield, MA

Andrew Crosby, PhD, Professor of Human Genetics, University of Exeter Medical School, RILD Wellcome Wolfson Centre, Royal Devon & Exeter Hospital, NHS Foundation Trust, Exeter, UK

Nicholas Alonzo Frost, MD, PhD, Assistant Professor, Department of Neurology, Division of Cognitive Neurology, University of Utah, Salt Lake City, UT

Mark Gudesblatt, MD, South Shore Neurological Associates, Long Island, NY

Michael Kruer, MD, Director, Pediatric Movement Disorders & Neurogenetics Programs, Barrow Neurological Institute, Phoenix Children's Hospital; Associate Professor, Child Health, Neurology & Genetics, University of Arizona College of Medicine; Programs in Neuroscience and Molecular & Cellular Biology, Arizona State University, Phoenix, AZ

Mark S. LeDoux, MD, PhD, Professor, Department of Psychology and School of Health Studies, University of Memphis; President, Veracity Neuroscience LLC, Memphis, TN

Colum MacKinnon, PhD, Associate Professor, Department of Neurology, Institute of Translational Neuroscience, Director of the Movement Disorders Laboratory, University of Minnesota, Minneapolis, MN

Niamh O'Sullivan, PhD, Assistant Professor, School of Biomolecular and Biomedical Science, University College Dublin, Ireland

Melissa Rolls, PhD, Associate Professor of Biochemistry and Molecular Biology; Chair, Molecular, Cellular and Integrative Biosciences program; Director, Center for Cellular Dynamics; Associate Director of the Penn State Hershey MD/PhD program, Penn State, University Park, PA

Jacinda Sampson, MD, PhD, Associate Professor of Neurology, Stanford University, Stanford, CA

Filippo M. Santorelli, MD, Director, Department of Molecular Medicine & Neurogenetics, IRCCS Fondazione Stella Maris, University of Pisa, Calambrone-Pisa, Italy

WE DID IT TOGETHER!

You played an incredible part in this extraordinary financial growth, raising **$1,597,571** during the year, an increase of **28.4%** over 2023.

Thank you!

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

2024 DONORS

THANK YOU FOR SUPPORTING THE SPASTIC PARAPLEGIA FOUNDATION

Platinum $50,000-99,999+

Baker Hughes Foundation
Frank Davis
Michael & Carol Dollinger
Larry Hardy Trust
Dr. William & Teresa Reed

Gold $25,000-49,999

Kris Brocchini
Stephen & Shari Holtzman
Michael & Mary Levi
Caroline, David, Molly, Meg & Peter Marren
Susan Parkinson

Silver $10,000-24,999

Jim Brewi
The Albert & Rina Brocchini Family Foundation
Tamara & Joseph Anthony Chan
Matt & Lauren Conlin
Beverly Fuchs
Tilia Gode
Google Google
Carin Gurliaccio
Dr. Mario, Elsa, J.Taylor & Feliciano Gutierrez
Robert & Michelle Hanes
HNR Foundation
SPF KY Golfing for Rare Disease
Annette Lockwood
Lawrence & Caitlin Riley Malone
Tami & Patrick Moynihan
Ellen ONeal
Leonard Podolin
Nancy Shuman Hock Foundation
Veronica Snyder
Dr. Edward & Janice Sparks
Carol Staehle
Ed Starr
Amy Stevens

Marathoner $5,000-9,999

Jody Ames
Wayne Britt
Gary Corsmeier
Walter & Carolyn Crager
Dee Davis
Edward & Suzann Duffy
Tom Egan
Elleaire Fore Golf Tournament
Dr. Michelle & Richard Fox
Patrice & Beth Anne Gorup
Matthew Hardin
Sally & Silvio Ingui
Rebecca Joines Cochran
Dina & Chris Landphair
Gary Lee
Joyce Lofmark
Richard & Genine Macaluso
The Merck Foundation
Marlene & Robert Patton
JC Penney
Eric Schwartz
Daniel Sullivan
United Parcel Service
Dr. Deborah Warden

Sprinter $2,000-4,999

Monika Aldridge
Julie Allison-Conlin
Kathy & Allen Angel
Battleview Orchards Inc
Brookfield
Cara Mia Kids Foundation
Leonard & Catherine DiSanza
Jennifer DiTillio
Double Good Popcorn
Howard & Anne Elsberry
Ever Loved, Inc
Cliff, Deidre, Donovan & Kendall Fiore
Russell & Joy Fisher
Michael Franken
Linda & Craig Gentner
Give Lively Foundation
Adli Hagen
Mitzi Haggard
Dr. Daniel & Madelyn Hajjar
Martha Hoffheimer
Tracy & Ron Hood
Roger & Lorri Kaufman
Kathy, Joe & Shane Kelley
Debra & Douglas Kerr
Chad & Andrea Kloberdanz
Dr. Nelson & Louisa Levy
Judith MacCrate
Mary Ann & Paul Milhous
James & Heather Moynihan
Jennifer Offman
P. Hande Ozdinler, PhD
Pampered Chef
Chris, Katherine & Jessica Prouty
Greg & Norma Pruitt
Brian Robinson
Jeffrey & Wendy Robinson
Johanna Rothman
Shannan Rumsey
Salesforce
Susan Sedita-Parker
Nancy Shaidnagle
Thomas Smith
Jeff Stern
Ellen & Erland Stevens, Jr.
Julia Lee Taubert Foundation
Christopher White

Runner $1,000-1,999

David Albrice
Kristopher & Suzie Altis
Larisa & Robert Antonisse
Kendall Ayers
David Barber
Cathy & Charles Benson
Douglas & Cathy Boleyn
Gary Bopp
Eric Boyer
Brian Carroll
Paula & Robert Clawson
John & Marjorie Cobb
Mary & Bob Cole
Terri Crews
Tina & Tim Croghan
Jim Dahlin
Anne & Clifford Davis, Esq.
Sheila Eby
Patricia & Daniel Egbert
Christopher Falconer
Fidelity Charitable Gift Fund
Karla Fisher
Pamela & Robert Flanigan
Ann & Steve Flechter
Anthony Fortino
Franklin Templeton
Donna Freer-Stannard
Michael Frieband
Kevin & Wendy Gallagher
Neil & Cynthia Garroway
Eric & Ronnie Gast
Robert & Lily Giffin
Glow Natural Wellness
Anne & Cameron Gongwer
Dr. Joseph, Daniel & Amanda Hajjar
David Hawthorn
Hearst Hearst
Doug Heffelfinger
Ami Hindia
Francis & Carolyn Hinkle
Elizabeth Holden
Patricia & Joe Holden
Carol & Scott Isbell
Heather Jorajuria
Sherry & Jerry King
Sandra Knotts
Vamsi & Maurya Koduri
Lisa & Daniel Kunz
Edward Latimer
Lighthouse Financial Advisors
Alice Lissow
George Lowrie, III
Craig & Connie Luigart
Ann Maher
Dr. Lionel & Catherine Mailloux
Peter Manhard
Bernard & Seane Marren
Elizabeth Marren
Annie, Patrick & Felicity Martin
Marcie McCleary
Mary & John McCormick
Susan McGlumphy
Karen Moreau
Joseph & Rhonda Morley
John & Emily Moynihan
Christy, Taylor, Harrison & Joseph Nemelka
Carol Ostrander
Michael & Melanie Padilla
Laura Pearl
JT Pendergraft
Pfizer Foundation Matching Gift Program
Celyna Rackov
Renaissance Charitable
Eliza Riley
Mary Beth Riley
Debby & Barry Rosen
John Rosendahl
Philip & Rhonda Ross
John & Laurie Schoepf, III
Richard Schultz
Andy & Caroline Scott
Seymour & Wendie Serebnick
Jim & Melissa Sheorn
Maria Simili-Croteau
Daniel & Francean Slavin
Remington Smith
Mark & Robyn Strayer
Albert & Kay Stutzman
Harry & Ann Tennant
Ann Thompson
TIAA Insurance
Colleen Tillman
US Ecology Holdings
David Waldo
Dr. John & Ann Warden
Jess & Rosalinda Weiner
Richard & Lucille Weiss
Jackie Wellman
Brett White
Julie & Charles Williams
Daniel Winston
Brett & Linda Wolters

Race Walker $500-999

Diana Abler
John & IIona Ahramjian
Monica & Carl Albers
Bank of America Employee Giving Program
Roger Barney
Cheryl Barnum
Monica Bernheim
Steven Bielman
Craig Blackstone, MD, PhD
Curtis & Barbara Blom
Amy Bockelman
Terryl Bollinger
Linda & Michael Brown
Karen Bruch
Wally & Linda Chase
Hank Chiuppi
David Christian
Combined Federal Campaign
James & Judith Corbett
Ursula, Greg & Annelisa Crabtree
Matt & Kimberly Cultrera
David DeBello
Linda Doctor
Paul Ebeling
Sarah Edge
Glenn & Clairice Ellisor
Enterprise Bank & Trust Foundation
Carey Fanzone
Kathleen Fenton
Carol Fitzgerald
Terry Foster
Jay Fry
Albert & Cynthia Geerders
Edward Geisler
Molly Gray
Janet Green
Steve Greenberg
Guardian
Barbara Hendrickson
Renae Hermann
Robert Hewitt
Joyce & Ronald Hood
Frank & Mary Hosick
Hilary Hrutkay
Tom & Lori Huling
Humana
Kathryn Jastrzembski
Nancy & Thomas Keiser
Wendy Kerr
Daniel Kilfoil
Carol King
Blair King
Michael Klotz
Mark Konietzko
Elizabeth & Robert Kottmann
Carolyn Kroger
Jason, Arlene & James Kurtz
James & Judy Labit
Karen & Philip Levy
Jacqueline Malinski
Kristine & Scott Maly
Fred Martin, Jr.
Justine Moreau
Bruce Munster
Sandra Pappas
Marsha Perkins
Debbie & David Phippen
Karen Prior
Gavin Reid
Mary & Arch Reid
Mike & Kathy Robinson
Andrea & Craig Rosenblum
Crystal & Dale Rustigian
John Sartain
Debbie, Larry & Dillon Sexton
Nick Shakra
Doug Smith
Stone Harbor Pools
Fred & Nicole Strauss
Therese, Thomas & Tiffany Streng
Deborah Travaille
Tricia Ujvagi-Culotta
Emma Wade
Susan Walker
Christopher Wallace
Margaret & John Walsh
Cindy Wesselman
Gary Wiederhorn
Elise Wilkins

SP-Foundation is diligent in its efforts to accurately account for all donations. Please notify Information@SP-Foundation.org of any errors or omissions.

SP-Foundation gratefully acknowledges the generous support of all anonymous donors whose contributions continue to advance our mission and vision.

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

6952 Clayborne Drive
O'Fallon, MO 63368-6202

NONPROFIT ORG.
U.S. POSTAGE
PAID
SAN ANTONIO, TX
PERMIT NO. 1001

BE WATCHING

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
HSP & PLS Awareness Week	August, Annually
HSP & PLS Awareness Day	August 27th, Annually
Golfing For Rare Disease Tournament	September 6, 2025
SPF Annual Conference	October 22-23, 2025, Washington DC
Year-End Giving with Anonymous SPICY Match	November 1st to December 31st
Giving Tuesday	November, Annually
SPF TALKS	Join SPF for E-Blast Updates

MONTHLY MEETINGS

SPF JOINT COMMITTEE MEETING first Thursday each month 7:00pm CST.

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.