The
Stiff Person Syndrome
Research Foundation

THE 2024 ANNUAL REPORT

Powering Tomorrow's SPS Research, Today

MAY 2025


The SPS Symposium


Rare Disease Awareness


The SPS Funsraiser


Moira Papp, Moira's Mission, interview with NBC channel 5

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Welcome from Our Founder

Dear Friends,

When I was diagnosed with Stiff Person Syndrome, I faced a diagnosis that few had heard of, with no roadmap, no effective treatments, and no clear answers. Like so many others, I encountered the isolation and fear that come with a rare disease—and I realized that had to change.

I founded The Stiff Person Syndrome Research Foundation not just as a patient, but as a mother, a dentist, and an advocate—driven by a sense of urgency and the unwavering belief that we could do better. Better for the next person searching for a diagnosis. Better for those navigating a life-altering condition. Better for the researchers working toward a cure.

In just a few years, we've made real progress. We've raised critical awareness. We've funded meaningful research. We've helped build a community that spans continents and connects patients, caregivers, clinicians, and scientists alike. We're proud to partner with leading institutions like Johns Hopkins and the Chan Zuckerberg Initiative, and we're leading national efforts such as the Consensus on SPS Diagnostic Criteria Initiative to reshape how this disease is understood and treated.

But we are just getting started.

This work requires all of us. It requires shared vision, bold collaboration, and sustained support. Your belief in our mission fuels what comes next—new studies, new connections, and ultimately, new hope.

Thank you for standing with us. Together, we will change the future of SPS.

With gratitude and determination,

Tara Zier
Founder & CEO, The SPSRF
SPS Patient

The SPSRF Board of Directors

The SPSRF is guided by a dedicated Board of Directors, each bringing unique expertise and personal commitment to our cause. Their collective leadership ensures that our strategic direction aligns with our mission to support research, raise awareness, and provide resources for those affected by SPS.

Tara Zier, DDS
FOUNDER & CEO

James Weiss, MD
BOARD MEMBER

Lara Vujovic, PhD
SECRETARY

Helena Zec, PhD
BOARD MEMBER

Our Board brings wisdom, accountability, and compassion, and keeps us relentlessly focused on our mission to end Stiff Person Syndrome.

Vidyashankar Krishnan
TREASURER

Our Mission:

The Stiff Person Syndrome Research Foundation envisions a world where all people with Stiff Person Syndrome (SPS) receive a prompt diagnosis, compassionate care, effective treatments, and a cure

We exist to raise awareness of SPS and to support research for better treatments and a cure for SPS while strengthening our community through education and collaboration.

Our Team:

Tara Zier
CEO

David Axelrod,
Associate Director

Camryn Wells,
Development

Neil Mathis,
Marketing &
Communications

Jacqueline Kraska
SPS Global Registry
Manager

Medical Advisory Board

James Weiss, M.D.
CHAIR

Marinos Dalakas, M.D.
BOARD MEMBER

Duarte Machado, M.D.
BOARD MEMBER

Andrew McKeon, M.B., B.Ch., M.D.
BOARD MEMBER

Scott Newsome, DO, MSCS, FAAN, FANA
BOARD MEMBER

Amanda L. Piquet, MD, FAAN
BOARD MEMBER

Isharat Yusuf, Ph.D.
BOARD MEMBER

The collective expertise of our Medical Advisory Board accelerates our journey toward innovative SPS treatments.

The SPSRF Patient Advisory Committee

Lahoma Nachtrab
PAC CHAIR

David Axelrod
PAC MEMBER

> "Our Patient Advisory Committee ensures the lived experiences of those with Stiff Person Syndrome are at the heart of every decision we make."

Tom Wilson
PAC MEMBER

Mynde Smith
PAC MEMBER

Khita Whyatt
PAC MEMBER

Davin Persad
PAC MEMBER

Jane Hunter
PAC MEMBER

What is SPS?

SPS is a life-altering neurological disease – often misdiagnosed, misunderstood, and under-researched – but not invisible anymore.

Stiff Person Syndrome (SPS) is a progressive, autoimmune neurological disorder that affects the central nervous system. Marked by severe muscle spasms, rigidity, chronic pain, and heightened sensitivity to external stimuli, SPS can dramatically impact mobility, breathing, and quality of life. Though rare — affecting a few people per million (estimated) — the condition often remains undiagnosed or misdiagnosed for years. For many patients, the path to a correct diagnosis is long, confusing, and emotionally exhausting.

SPS doesn't just attack the body — it isolates people from their work, their families, and often, their sense of identity. It takes years to diagnose on average, and by the time it's identified, irreversible damage may have already occurred.

> "It feels like your muscles are turning to stone while your nerves scream beneath the surface. It's terrifying — and for too long, people thought it was in my head."

Clinical Snapshot

Definition: SPS is a spectrum of neurological diseases with autoimmune features that disrupt normal muscle control and motor function.

Symptoms Include:

- Rigid muscles
- Spasms that can be moderate, intermittent, or debilitating.
- Sensitivity to touch, sound, stress, or movement
- Chronic pain, anxiety, and unsteadiness

Onset:

Most commonly appears between ages 30–50, though it can affect children and older adults.

Diagnosis:

Often delayed; many patients wait 7+ years and see numerous specialists before receiving an accurate diagnosis.

Misdiagnosis:

Sometimes mistaken for degenerative disc disease associated with cervical or lumbar spondyloarthritis, as well as Parkinson's, anxiety disorders, fibromyalgia, multiple sclerosis, or conversion disorder.

The information provided in this section, reviewed by Dr. Yujie Wang and based on published peer-reviewed medical journals, is for informational purposes only and is not intended to substitute for professional medical advice, diagnosis, or treatment.

Understanding SPS

For many patients, the path to an SPS diagnosis is long, confusing, and emotionally exhausting.

WHAT IS STIFF PERSON SPECTRUM DISORDER?

Stiff Person Spectrum Disorder (SPSD), also known as Stiff Person Syndrome (SPS), is a neurological disease with autoimmune features. Usually progressive over time, SPS symptoms include severe muscle spasms, rigid limbs and body, debilitating pain, and chronic anxiety.

SPS AFFECTS

A few per 1,000,000

PEOPLE

ON AVERAGE, IT TAKES

7 YEARS

TO BE DIAGNOSED WITH SPSD.

SPS CAN OFTEN BE MISDIAGNOSED AS OTHER DISEASES, RESULTING IN DELAYED TREATMENT PLANS FOR PATIENTS.

TODAY, THERE IS NO CURE FOR SPS.

THERE IS AN URGENT NEED FOR BETTER TREATMENTS.

OCCURRENCES OF SPS:

- Females are affected twice as often as males.
- Patients most commonly develop symptoms between the ages of 30-50.
- 5% of cases of SPS are reported in children.

PATIENTS CAN BE DISABLED, UNABLE TO WORK, OR CARE FOR THEMSELVES.

The information provided in this section, reviewed by Dr. Yujie Wang and based on published peer-reviewed medical journals, is for informational purposes only and is not intended to substitute for professional medical advice, diagnosis, or treatment.

The Role of The SPSRF

Turning Urgency into Action

We are the engine behind awareness, research, and support for a disease that most people – including many doctors – have never even heard of.

The Stiff Person Syndrome Research Foundation (The SPSRF) exists for one reason: to change the reality of living with Stiff Person Syndrome. Founded by a patient, powered by a global community, and guided by leading scientists and physicians, The SPSRF is the only U.S.-based nonprofit solely focused on improving outcomes for people living with SPS.

We fund critical SPS research.
We connect patients to care.
We educate healthcare professionals.
We create community.

And we're not stopping until there is a cure. In a rare disease landscape often marked by invisibility, inaction, and misinformation, The SPSRF serves as a strategic, trusted, and deeply human force for change.

What We Do

- **Fund Research That Moves the Field Forward**
- **Build Awareness That Leads to Diagnosis**
- **Support Patients with Resources and Community**
- **Convene and Collaborate with Global Leaders**
- **Advocate for Equity in Rare Disease Care**

Bold, Focused, and Built for Impact

Our Key Initiatives

We invest deeply in the most critical, high-impact areas to shift the entire landscape of Stiff Person Syndrome — from diagnosis to treatment to quality of life.

Each of our initiatives addresses a core need identified by patients, clinicians, and researchers alike. These programs are not only strategic — they are urgent, coordinated, and guided by our Medical Advisory Board and global collaborators. Whether driving the development of diagnostic criteria or convening the international SPS community, our initiatives are designed to generate lasting change.

The SPS Symposium

Our annual global gathering of patients, caregivers, clinicians, and researchers — offering education, connection, and real-time insights into the latest science and strategies for living with SPS.

The SPS Global Registry

A centralized, secure platform for collecting real-world data from patients around the world — empowering research, clinical trials, and future drug development.

The Consensus on SPS Diagnostic Criteria

A global collaboration of leading neurologists to establish standardized, evidence-based diagnostic criteria — eliminating the years-long diagnostic delay most patients face.

The SPS Biorepository

A powerful new initiative in partnership with Combined Brain — collecting and securely storing biological samples from individuals with SPS to support cutting-edge research and accelerate drug development.

Educational Resources & Support Tools

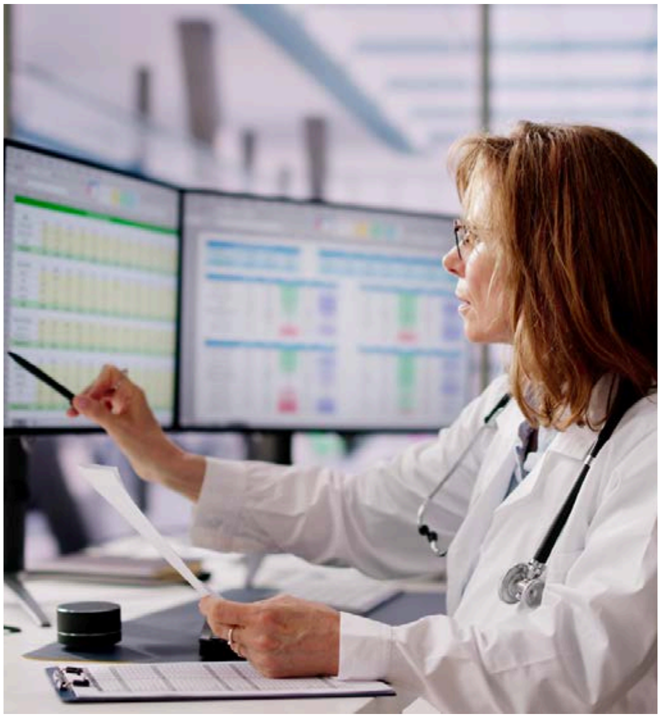
From physician directories to patient literature to webinars, we're building a knowledge infrastructure to empower every person impacted by SPS — from diagnosis to daily life.

The SPS Global Registry

A First-of-Its-Kind Platform to Accelerate SPS Research

The SPS Global Registry is a cornerstone initiative of The SPSRF. This secure, patient-driven platform is designed to collect, organize, and share high-quality, anonymized data to accelerate scientific discovery and improve clinical outcomes for people living with Stiff Person Syndrome.

Launching in 2025, the Registry captures real-world information about disease progression, symptom variability, treatment response, and quality of life — information that's often missing from traditional studies.



Why It Matters

- Clinical trials require data. Researchers need robust, real-world patient data to design studies, identify participants, and validate outcomes.
- Patients want to help. The Registry empowers individuals with SPS to actively participate in research — safely, securely, and meaningfully.
- Equity in research begins with inclusion. This global registry ensures that diverse voices and experiences are represented in the future of SPS care.

Progress Highlights

- Platform Launch: Core infrastructure developed
- IRB & Ethics Approval: Secured review and compliance structure to ensure safe, ethical operation.
- Survey Design & Programing: With survey designs approved and system programming completed, optimization is currently underway.
- Community Outreach: Early outreach campaigns have been reviewed and approved by IRB panel.

The SPS Symposium

The SPS Symposium proves what's possible when knowledge, compassion, and action come together.

Held in Windsor Locks, Connecticut — and broadcast globally — the 2024 Stiff Person Syndrome Symposium marked a major step forward in education, connection, and collective action for the SPS community. Over the course of two days, nearly 100 in-person attendees and 300 virtual participants from more than 20 countries came together to share knowledge, hear from leading experts, and build meaningful support networks.

2025 Information

July 19–20 - Windsor Locks, CT & online

Registration opens May1, 2025 online at:
stiffperson.org/2025symposium

Why It Matters

The SPS Symposium is the only dedicated, multi-stakeholder event focused entirely on SPS, giving patients and caregivers access to leading experts, while also creating space for shared experiences and practical learning.

2024 Key Highlights

Global Reach

- 20+ countries represented
- 300+ virtual participants

Expert-Led Presentations

- Dr. Scott Newsome on the state of SPS research
- Dr. Amanda Piquet on stem cell transplantation
- Dr. Duarte Machado on SPS diagnosis and care
- Updates on patient registry, awareness, and research strategy

The Consensus on Stiff Person Syndrome Diagnostic Criteria

The Consensus on SPS Diagnostic Criteria Initiative is a groundbreaking effort led by The Stiff Person Syndrome Research Foundation to establish standardized, evidence-based diagnostic criteria for Stiff Person Syndrome. This initiative brings together the world's top neurologists and SPS experts to solve one of the greatest barriers in rare disease care: recognition. By unifying how SPS is defined and diagnosed across research, clinical practice, and patient experience, this initiative aims to shorten diagnostic delays, improve care pathways, and make high-quality research possible.

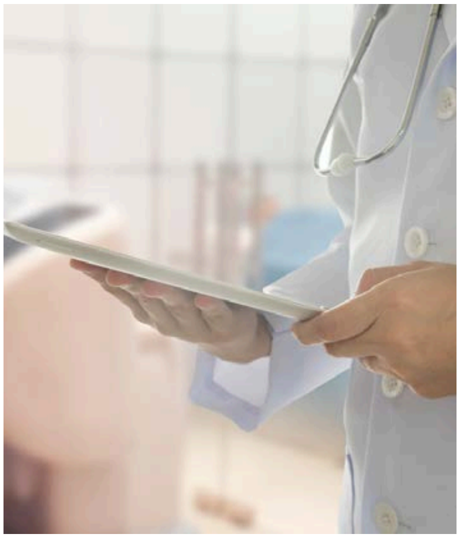
> **Without a clear way to diagnose SPS, patients stay lost in the system. We're fixing that!**

Why It Matters

- On average, SPS currently takes 7+ years to diagnose and is often misdiagnosed. Patients frequently go through countless tests and see multiple specialists before receiving an accurate diagnosis.
- There are no universal clinical standards. The absence of agreed-upon diagnostic criteria leads to uncertainty, inconsistent treatment, and missed research opportunities.
- Diagnostic confusion leads to suffering. Delays in diagnosis and inappropriate treatments often result in irreversible physical damage, emotional trauma, and financial strain.

Progress Highlights

- Expert Leadership Secured: A distinguished steering committee composed of global SPS experts has been formed to lead the initiative.
- SPS Experts Identified: The world's top neurologists and SPS experts have been identified for the panel to get consensus on the diagnostic criteria.
- Scientific Rigor Ensured: Two dedicated methodologists have joined the team to guide evidence-based processes.
- Review Process Underway: The team is actively developing a standardized approach to assess and synthesize scientific literature.



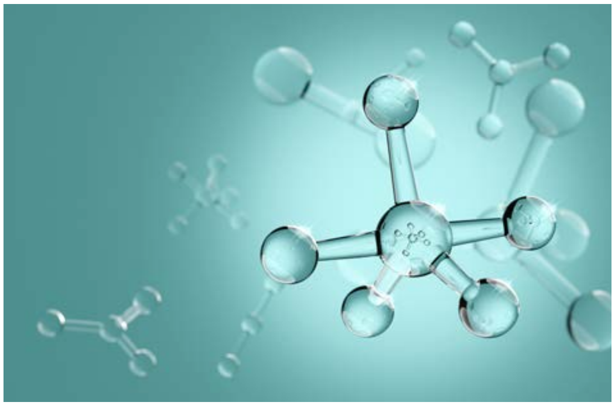
The SPS Biorepository

A Critical Link Between Patient Data and Scientific Discovery

The SPS Biorepository is a new initiative from The Stiff Person Syndrome Research Foundation in partnership with Combined Brain — a collaborative consortium advancing research across rare neurological diseases. This initiative provides a secure and standardized way to collect, store, and distribute biological samples from individuals with SPS, including blood, saliva, and other biospecimens.

By linking these samples to the clinical and real-world data in The SPS Global Patient Registry, we are creating a comprehensive research resource — one that empowers scientists to uncover biomarkers, study disease mechanisms, and accelerate the development of targeted treatments.

With expert oversight and rigorous protocols, the Biorepository gives SPS patients a meaningful way to directly contribute to scientific progress — from anywhere in the world.



Why It Matters

- Paired with clinical data, biosamples can reveal critical clues about how and why SPS develops and progresses.
- The Biorepository helps remove a major barrier to research: access to consistent, high-quality patient samples.
- It enables faster, smarter clinical trials — and brings us closer to precision medicine for SPS.
- Participation is voluntary, secure, and designed with patient empowerment at its core.

Every donated sample is a building block for breakthrough science in SPS

What the Initiative Includes

- Powered by Combined Brain: Leveraging proven infrastructure to securely manage, process, and distribute biosamples to qualified researchers.
- Integrated with The SPS Global Registry: Clinical context meets molecular data, offering a 360-degree view of SPS.
- IRB Oversight & Informed Consent: Ensuring ethical integrity, transparency, and patient safety at every step.
- Accelerates Research: Supports genetic studies, biomarker discovery, and therapeutic development efforts.

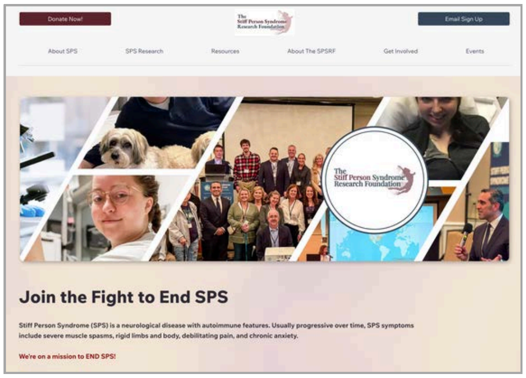
Organizational Advances

Progress isn't just what we do – it's how we operate. In 2024, we laid the groundwork for deeper reach, smarter engagement, and stronger partnerships.

New Website & Expanded Tools

We introduced a redesigned digital experience, making it easier than ever for patients, caregivers, and clinicians to access essential information and connect with the global SPS community. The new site features:

- The SPS Literature Library — a curated, searchable archive of clinical research
- A Global Physician Directory to help patients find SPS-aware specialists
- A growing collection of online resources for education, self-advocacy, and support



Join the Fight to End SPS

Stiff Person Syndrome (SPS) is a neurological disease with autoimmune features. Usually progressive over time, SPS symptoms include severe muscle spasms, rigid limbs and body, debilitating pain, and chronic anxiety.

We're on a mission to END SPS!

400%+ growth in subscribers in one year

Published the 2023 Stewardship Report

In June 2024, we released our most comprehensive financial and programmatic summary to date: The SPSRF 2023 Financial Stewardship Report. This report gave our community unprecedented visibility into:

- How our funding is sourced
- Where every dollar is going
- How we measure impact

The SPSRF

Comprehensive Financial Stewardship Report 2023

Contact

E: info@stiffperson.org
W: www.stiffperson.org

4000+ views in the six months.

Launched the Industry Partnership Program

In 2024, we formalized a new strategic pillar: the SPSRF Industry Partnership Program — a structured initiative to engage with pharmaceutical companies, biotech labs, and clinical trial sponsors. Our goal is simple: To build collaborative relationships that accelerate treatment development, expand access to research data, and align industry investment with real patient needs.

Our first partnership finalized 3-months post launch.

IGNITION

PARTNERSHIP OPPROTUNITIES

01 Raising Awareness for Clinical Trials through the SPS community
02 Bring the voice of the SPS community into industry
03 Offer the voice of the SPS community to industry discussions

Awareness Changes Everything

SPS & The SPSRF IN THE MEDIA

In 2024, the world started paying attention – and we made sure the message was clear: Stiff Person Syndrome is real and in urgent need of answers.

I Am: Celine Dion Documentary

Celine's courage in sharing her diagnosis opened the door for countless patients to feel seen.

Good Morning America

A dedicated segment brought SPS to national morning television in the U.S. — reaching millions.

National Geographic Coverage

An in-depth feature highlighting the science behind SPS and the frustrating journeys for patients.

NATIONAL GEOGRAPHIC

New England Journal of Medicine

Featured in the NEJM — underscoring a shift in how the scientific community is prioritizing the disorder.

The NEW ENGLAND JOURNAL of MEDICINE

Numerous Radio Shows & Podcasts

Appearances on Fierce Biotech (8/15), It Happened to Me (7/17), and the the Cam Wells Show (3/15).

Community-Led Fundraisers

Every community-led fundraiser is more than an event – it's a declaration that this fight matters

Moira's Mission

March 2024 | Chicago, IL

Organized by friends and family of Moira Scully Papp, this inaugural event brought together loved ones with one shared goal: to raise funds for the launch of The SPS Global Registry. Moira's Mission raised both awareness and essential research dollars to help accelerate the understanding of SPS.

Swing For A Cure

August 2024 | Middletown, RI

Hosted at Wanumetonomy Golf & Country Club, this charity golf tournament was organized in honor of 5-year-old Isla Marcellus, one of the youngest known SPS patients. The event drew a full roster of golfers, community sponsors, and supporters eager to take a swing at rare disease fundraising.

Community-Support

These initiatives directly support research, patient resources, and advocacy efforts, moving us closer to better treatments.

The SPS Marketplace

Launched 2024 | Online at stiffperson.org

In 2024, we launched The SPS Marketplace, a dedicated online portal showcasing ongoing community-led fundraising initiatives. From custom apparel to benefit raffles, this page highlights the creativity and dedication of our community in mobilizing resources for SPS research.

Celine Dion Inspired Fundraisers

Multiple Events | 2024

Celine Dion's public journey with SPS inspired a wave of grassroots fundraising efforts across the U.S. and beyond. In 2024, four community-led fundraisers were hosted by fans and advocates moved by her courage. These events not only raised money but helped introduce SPS to thousands of new people.

Corporate Supporters

The Power of Giving: Every Contribution Moves Us Forward

In 2024, we saw an unprecedented outpouring of support from individuals, families, foundations, and businesses who share our vision of a world where SPS is no longer an overlooked disease. Their contributions have allowed us to exceed our fundraising goal, fund groundbreaking research, and expand patient access to vital resources.

Hartford HealthCare

nufactor®
A SPECIALTY INFUSION COMPANY

IVX HEALTH

Homewatch CareGivers®
Homewatchcaregivers.com/Newhaven

CHAN ZUCKERBERG INITIATIVE

NORD®
National Organization for Rare Disorders

Jim & Beverly Gibbons

Donor Stats

Our donors aren't just supporters – they are partners in the fight to transform the future of Stiff Person Syndrome.

The progress we make is only possible because of the generosity and belief of those who stand with us. Every donation — whether from a longtime supporter, a new advocate, a corporate partner, or a community fundraiser — fuels critical research, provides patient resources, and amplifies awareness of Stiff Person Syndrome.

884

First-Time Donors in 2024

$386K

Donations by First-Time Donors

123

2023 Repeat Donors in 2024

$232K

Donations by Repeat Donors

23

Recurring Donors in 2024

$43K

Donations by Recurring Donors

36

Corporation & Foundation Donors in 2024

$98K

Donations by Corporations & Foundations

SUMMARY OF FINANCIAL PERFORMANCE

January to December 1, 2024

2024 Financial Summary

In 2024, thanks to the generosity of our donors, sponsors, and community fundraisers, we exceeded our annual goal and raised $619,544 - allowing us to accelerate key research initiatives, expand patient resources, and strengthen our operational foundation for long-term sustainability.

Our commitment to transparency and impact-driven spending ensures that funds are directed where they matter most: advancing research, increasing awareness, and supporting the SPS community.

We are setting even bolder goals for 2025 — focusing on increasing research funding, expanding patient education tools, and securing new collaborations with pharmaceutical and biotech partners.

2024 Financial Highlights

We connected directly with over 400 individuals—patients, caregivers, clinicians, and donors—through in-person events.

In 2024, we committed $82,295 toward the development of The SPS Global Registry Initiative, a centralized, patient-informed resource to drive breakthroughs in diagnosis and treatment.

In 2024, 67% of funds raised were unrestricted. This flexible funding allows us to respond quickly to emerging needs and invest in innovation.

Since our founding in 2019, The SPSRF has raised more than $2 million. Every dollar represents a step toward our shared vision: a world where all SPS patients have access to accurate diagnosis, compassionate care, effective treatments, and, ultimately, a cure.

THE SPSRF FINANCES AT A GLANCE

$847,989*

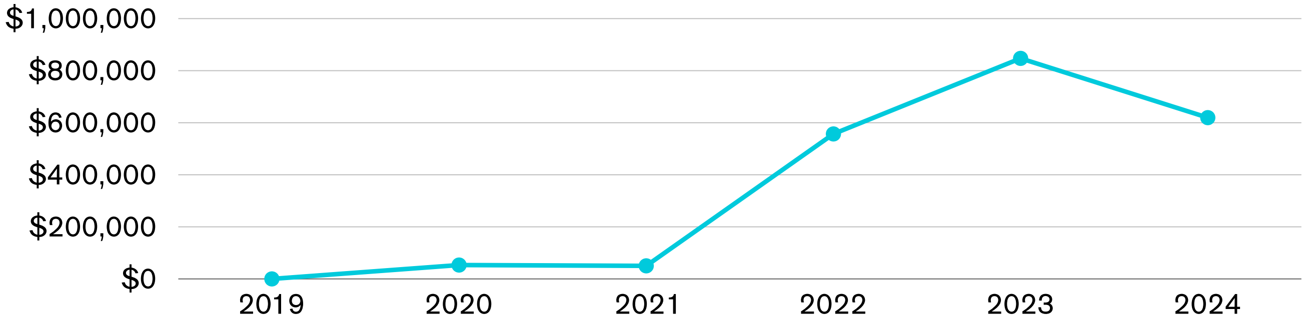
Donations Raised in 2023

** Includes final CZI grant funding*

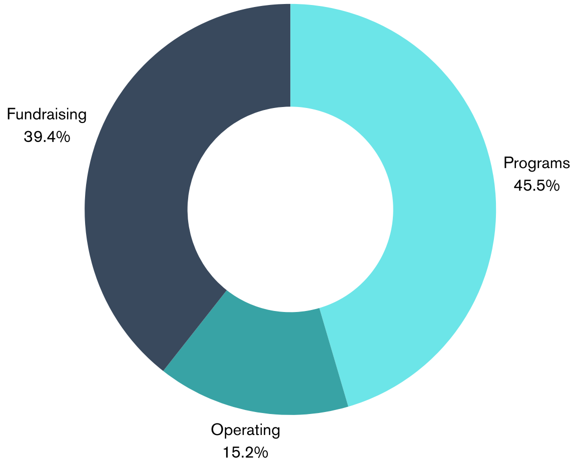
$619,544

Donations Raised in 2024

Donations & Grants Received by Year



2024 Expenditures (%)



2024 Expenditures ($)

Patient & Research Programs:	**$ 167,252**
• Build the Registry:	$ 82,295
• Neurologist Awareness:	$ 33,410
• Brand and Awareness:	$ 51,547
Fundraising	**$ 144,706**
Administration	**$ 52,141**

JOIN OUR MISSION!

The progress we seek will take all of us. Whether through donating, advocating, fundraising, or sharing our mission, every action makes a difference.

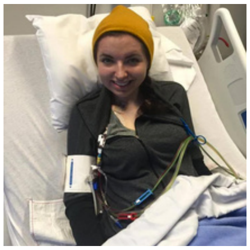
Support Research:
Help fund groundbreaking SPS studies.

Raise Awareness:
Share our mission with your network.

Get Involved:
Host a fundraiser, volunteer, or connect with our team.

Visit stiffperson.org to learn how you can be part of this movement.





LOOKING AHEAD TO 2025 AND BEYOND

2024 was a defining year for The Stiff Person Syndrome Research Foundation. We made measurable progress in research, awareness, funding, and community-building—but our work is far from over.

If this year has proven anything, it's that momentum creates more momentum. The more we push, the more doors open—for faster diagnoses and better treatments.

As we look ahead to 2025, our vision remains clear: to accelerate research, expand access to resources, and elevate SPS on the global stage.

With the unwavering support of our donors, partners, and advocates, we are ready to go further than ever before.

The
Stiff Person Syndrome
Research Foundation

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A 501(c)(3) organization
EIN 84-2291780