

PRESS RELEASE

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NIH Awards \$8.4 Million Grant to Fund First-Ever U.S. Spastic Paraplegia Research Consortium

SPF Donors Helped Lay the Groundwork for This Landmark Initiative

[October 23, 2025, Washington, D.C.] The Spastic Paraplegia Foundation (SPF) is proud to share exciting news that the **National Institutes of Health (NIH)** has approved an **\$8.4 million U54 grant** to fund major research initiatives for **Spastic Paraplegia Centers of Excellence Research Network (SP-CERN)** — the first national research consortium dedicated to **Hereditary Spastic Paraplegia (HSP)** and **Primary Lateral Sclerosis (PLS)**.

This landmark grant represents a major step forward for our community and for all those living with HSP and PLS. **Your donations to SPF (Spastic Paraplegia Foundation), unwavering support, and commitment helped lay the foundation for this achievement** in 2022 at the SPF Annual Conference in Nashville, Tennessee.

“The formation of the first Spastic Paraplegia research consortium in the United States—SP-CERN—is excellent news for patients,” said **Dr. Stephan Züchner**, University of Miami. “This will greatly improve access to quality care and, by design, create the largest resource of clinical and genetic research data from HSP patients and families. SP-CERN will set the stage to discover the missing genetic causes of HSP, develop biomarkers, establish standards for clinical trials, and much more. With growing momentum in neurological therapies, we believe the time is right for breakthrough advances in HSP.”

Dr. Darius Ebrahimi-Fakhari of Boston Children’s Hospital added, “SP-CERN aims to revolutionize medical research on HSP and PLS by establishing a foundation for groundbreaking clinical studies and fostering collaboration, study enrollment, and data sharing. By bringing together dedicated physician-scientists and multidisciplinary teams, SP-CERN empowers patients to actively shape the future of treatments. Together, we’re building a comprehensive clinical trial readiness platform that paves the way for innovative therapies and a brighter future.”

As part of the consortium’s onboarding process, **Dr. Ebrahimi-Fakhari and the SP-CERN leadership team selected the Spastic Paraplegia Foundation** to serve as the **primary Patient Advocacy Group (PAG)** representing the consortium on the **Coalition of Patient Advocacy Groups (CPAG) Steering Committee** of the **Rare Diseases Clinical Research Network**

This appointment ensures that the voices of HSP and PLS patients will be represented at the national level in shaping rare disease research priorities and clinical study designs. SPF has

confirmed that Norma Pruitt, SPF's Executive Director, will serve as the organization's representative on the CPAG Steering Committee.

SP-CERN brings together eleven leading academic centers and clinician-researchers to accelerate discovery, unify data collection, and prepare for the first clinical trials in HSP and PLS, and provides for a greater expansion of locations across the country. The consortium will serve as a central hub for genetic discovery, biomarker validation, and patient engagement.

The Spastic Paraplegia Foundation congratulates all the investigators involved and extends sincere gratitude to our donors and community members whose commitment makes this progress possible.

“Every dollar given to SPF moves the field closer to real treatments,” said Norma Pruitt, SPF Executive Director. “We are grateful that your donations helped make this moment possible—and this is just the beginning. Funding early-stage projects, building investigator collaborations, and sustaining advocacy efforts will lead directly to greater milestones.”

About the Spastic Paraplegia Foundation (SPF)

The Spastic Paraplegia Foundation is the only organization in the U.S. dedicated to funding research and supporting individuals with Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). Through partnerships with researchers, clinicians, and global collaborators, SPF is driving innovation toward treatments and cures.

Learn more and support research at:

<https://sp-foundation.org>

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