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MEDIA INQUIRIES CONTACT:

Norma Pruitt | Executive Director | 877-773-4483 |Information@SP-Foundation.org | Spastic Paraplegia Foundation, Inc

ANNOUNCING THE – SPASTIC PARAPLEGIA CENTERS OF EXCELLENCE RESEARCH NETWORK (SP-CERN): A COLLABORATIVE EFFORT WITH SPASTIC PARAPLEGIA FOUNDAITON, INC., TO ADVANCE RESEARCH AND TREATMENT FOR HSP AND PLS

[O'Fallon, Missouri, July 4, 2023] – The hereditary spastic paraplegia (HSP) and primary lateral sclerosis (PLS) communities have a reason to be hopeful as a groundbreaking research network, the SPASTIC PARAPLEGIA – CENTERS OF EXCELLENCE RESEARCH NETWORK (SP-CERN), is set to revolutionize the landscape of HSP and PLS research. A group of esteemed researchers and clinicians specializing in hereditary spastic paraplegia (HSP) and primary lateral sclerosis (PLS) have united with the Spastic Paraplegia Foundation, Inc., to establish this network to accelerate the understanding, diagnosis, and treatment of HSP and PLS, which collectively represent the most common cause of inherited spasticity and associated disability worldwide.

HSP and PLS are debilitating conditions characterized by the progressive dysfunction of long axonal tracts, resulting in muscle weakness, spasticity, and motor impairment. Despite extensive genetic testing, a significant number of patients remain undiagnosed. Furthermore, there are currently no therapies available to halt the progression of these disorders. SP-CERN aims to address these challenges by facilitating collaborative research efforts and establishing critical research infrastructure for children and adults with progressive spasticity.

To ensure the success of SP-CERN, the network will initially consist of nine Centers of Research Excellence (CERN) in the United States. These centers will serve as hubs for collaborative research, establishing a registry, a biobank, and a genome archive. By harmonizing efforts with similar consortia worldwide, SP-CERN aims to foster international collaboration, accelerate basic and clinical research, and overcome the challenges posed by geographically dispersed patient populations. SP-CERN will support critical research infrastructure for collaborative high-quality research on HSP and PLS in North America and beyond.

For media inquiries, please contact: Spastic Paraplegia Foundation, Norma Pruitt, Executive Director, 877-773-4483, Information@SP-Foundation.org.

About SP-CERN:

The Spastic Paraplegia – Centers of Excellence Research Network (SP-CERN) is a collaborative research consortium dedicated to advancing the understanding, diagnosis, and treatment of hereditary spastic paraplegia (HSP) and primary lateral sclerosis (PLS). Comprised of leading researchers and clinicians, SP-CERN aims to overcome the challenges associated with these debilitating conditions through collaborative research efforts, establishment of critical research infrastructure, and fostering international cooperation. Its ultimate goal is to improve the lives of individuals affected by HSP and PLS worldwide. For more information email or please visit SP-Foundation.org.