Asociación Española de Paraparesia
Espástica Familiar, Strümpell Lorrain (AEPEF)
Declarada de Utilidad Pública
Premio Sociedad Española de Neurología versión social

Declaration of October 17 as World Day for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS)

STATEMENT

We, the patient associations and entities committed to raising awareness and providing support to individuals affected by both Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS), hereby declare our firm support for the **official recognition of October 17** as **World Day for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis**. This day will be dedicated to **awareness, education, support, and the promotion of research** on these two diseases.

The choice of this date pays tribute to **Camillo Golgi** and **Santiago Ramón y Cajal**, who, in October 1906, were awarded the Nobel Prize in Physiology or Medicine for their groundbreaking contributions to the study of neuron structure. Golgi's discovery of dictyosomes and his innovative staining method enabled Ramón y Cajal to develop the neuronal theory, thus laying the foundation for the neuron doctrine. For this reason, Santiago Ramón y Cajal is considered the father of neuroscience. Their contributions were fundamental to the modern understanding of neurological diseases, including **Hereditary Spastic Paraplegia and Primary Lateral Sclerosis, both of which are associated with alterations in neuronal structure and function**. Therefore, this date highlights the importance of continuing research and providing support to those living with these conditions.

Context and Objectives of World HSP and PLS Day

Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS) are **neurological disorders** affecting many individuals and families worldwide. However, their **rarity and complexity** have contributed to widespread lack of knowledge, limiting the support and resources available to those living with these conditions. We believe that proclaiming a joint **World Day for both diseases** is a key step towards:

1. **Raising awareness in society**: Inform and educate the general public about the effects of **HSP/PLS**, as well as the needs and challenges of those affected.
2. **Consolidating a Support Community**: Promote a global support network for patients, families, caregivers and health professionals.
3. **Promoting Scientific Research**: To promote the interest and commitment of the scientific community to advance the study and treatment of this disease.
4. **Facilitating International Collaboration**: Strengthen cooperation between associations, scientific entities and health systems to improve the quality of life of people with **HSP/PLS**.

Invitation to Join

We invite all patient associations, scientific committees, health professionals and organizations around the world to **join this initiative** and commit to the declaration of this World Day, under the principles of cooperation and mutual support **to improve the situation** of those affected by these diseases.

By adhering to this statement, the signatory organizations demonstrate their commitment to the aforementioned objectives and support AEPEF's proposal to

proclaim October 17 as World Day for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

Signatories

	Stopp-HSP – Austria
	HSP Research Foundation – Australia
	Aspec – Brasil
	Hereditary Spastic Paraplegia Funding Research Treatment – Canada
	Foreningen for ATAKSI/HSP- Denmark
	Association Strúmprell Lorrain – France
	HSP Selbsthilfe – Germany
	TWS Tom Wahlig Stiftung – Germany
	ViPS ETS – Italy
	Spierziekten – Nederland

	Life4HSP – Nederland
	NASPA – Norway
	AEPEF Asociación Española de Paraparesia Espástica Familiar - Spain
	HSP Schweiz – Swiss
	Neuroförbundet – Sweden
	HSP Support Group – UK
	The Maddi Foundation – UK
	SPF Spastic Paraplegia Foundation Inc – USA
	The Lilly and Blair Foundation – USA

We have de support of Federacion de Enfermedades Raras and Federacion Española de Enfermedades Neuromusculares

Please sign and return this form of support to the addresses provided to contribute to the proclamation of October 17 **as World Day for Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).**

Together, we can make a meaningful difference for people with HSP/PLS and their families around the world.

VºBº **AEPEF**

Asociación Española de Paraparesia Espástica Familiar Strümpell-Lorrain

Fdo.
Marcos De Guadalupe Villanueva

VºBº **ASL HSP-FRANCE**

Jean BENARD, Président

VºBº HSP - SCHWEIZ

Fdo. Contact Person

VºBº The Maddi Foundation

Fdo.
Carina Thurgood CEO

VºBº

Spastic Paraplegia Foundation, Inc.

Fdo.
Greg Pruitt, President

VºBº ViPS ETS

Alessandra D'Andrea
President

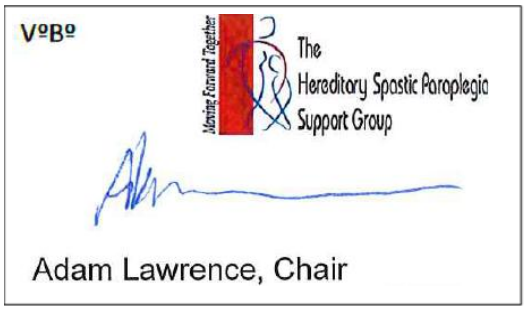
Fdo.


VºBº
NEURO
Fdo.
Katarina Gustafsson, Chief secretary


VºB
Linda Lafontaine
HSP patient advocate
HEREDITARY SPASTIC PARAPLEGIA
funding • research • treatment


VºBº
STOPP-HSP.at
AUSTRIA


ASPEC Brasil
ASPEC
BRASIL
Celyna Rackov
President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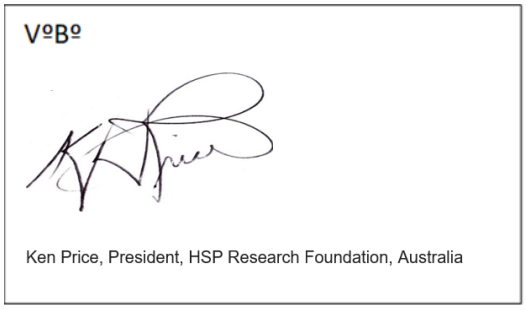
Moving Forward Together
The
Hereditary Spastic Paraplegia
Support Group
Adam Lawrence, Chair


VºBº
Vereniging Spierziekten Nederland
Jovanka Vis, director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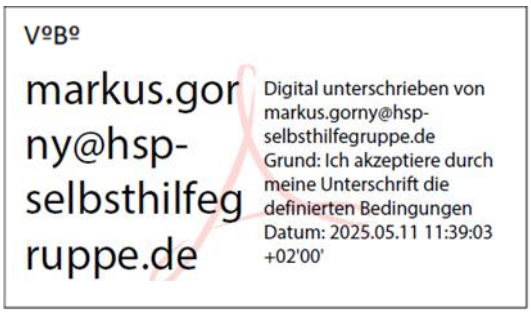
Ken Price, President, HSP Research Foundation, Australia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markus.gorny@hsp-selbsthilfegruppe.de
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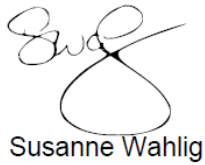

Susanne Wahlig
Tom Wahlig Stiftung, Deutschland
(Tom Wahlig Foundation, Germany)

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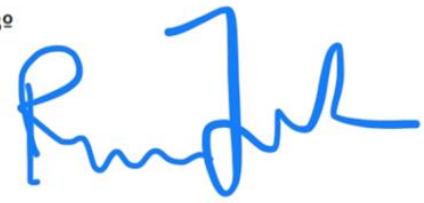

Rune Johansenn (NORWAY)

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Lars Bøje Christensen (DENMARK)

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VºBº Federación ASEM

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Life4HSP - Netherlands
Wouter de Vries

VºBº

Katie Gregg
Co-founder, The Lilly and Blair Foundation

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