



Dear Board Members and HSP Organizations,

World HSP Day 2026 is just over one month away.

On Saturday, 17 October 2026, the second World HSP Day will unite people around the world to raise awareness of Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS)—two rare neurological disorders that have a profound impact on the daily lives of patients and their families.

We are asking all HSP organizations around the world to take action and help make this day a powerful global movement. Please share the information below, the video, and the World HSP Day website with your members, patients, families, healthcare professionals, and supporters. Encourage them not only to read or watch, but to join, share, participate, and take action.

World HSP Day 2026

At present, there is no treatment that can stop the progression of HSP or PLS. That is why greater awareness, better understanding, and increased scientific research are urgently needed.

World HSP Day brings together patients, families, healthcare professionals, researchers, and organizations with one shared goal: To accelerate research, pave the way for better treatments, and ultimately build a future without HSP and PLS. In the days leading up to 17 October, and on World HSP Day itself, everyone can make a difference.

Join this global movement by:

- Sharing the World HSP Day message on social media
- Taking part in the international webinar
- Organizing or supporting awareness activities
- Sharing your personal story
- Encouraging others to get involved
- Supporting scientific research through a donation

Every voice matters. Every action counts. Together, across borders, we can raise awareness, strengthen research, and create real change.



Join the Global Awareness Campaign

On 17 October, we invite everyone living with HSP or PLS to share their story on social media. Post a short video or photo showing how you move—whether walking independently, using mobility aids, or a wheelchair. By sharing these personal experiences, we can show the world what HSP and PLS mean in everyday life.

Then share this message by your video/photo:

“Dear everyone, for me, walking is a major challenge. For you, helping is just a small step. Will you join the fight against HSP? Visit www.worldhspday.com and make a donation. Every euro goes directly to research.”

Please use the hashtags:

#hspplsworldawarenessday #hspandpls #eurohspfederation #life4hsp #research

Please also tag your national HSP association, EUROHSP, and Life4HSP.

The success of the first World HSP Day showed what we can achieve when patients and organizations around the world stand together.

On 17 October, let's unite once again and show that the global HSP and PLS community speaks with one voice.

Watch and Share the World HSP Day Video

Please share the video with your members and networks:

<https://youtube.com/shorts/LNGJAHlvOhc?is=MpnI5OoJza13861L>

International Webinar

As part of World HSP Day, EUROHSP, Life4HSP, and Spierziekten Nederland will host an international webinar.

Saturday, 17 October 2026

11:00 AM – 3:00 PM (CEST – Central European Summer Time)

Registration:

<https://schoon-producties.webinargeek.com/world-hsp-day-webinar/join/cuxlu3wn>

During the webinar, host Alex Sijm and Emmelie Zipson will welcome new guests every 30 minutes.



Neurologists from Radboud University Medical Center, researchers, volunteers, patients, and representatives of HSP organizations from around the world will discuss the latest scientific developments, inspiring initiatives, and the importance of international collaboration.

The first two hours will be conducted primarily in Dutch with English subtitles. The final two hours will be in English with Dutch subtitles, enabling participants from both the Netherlands and abroad to fully engage with the program.

Participants will also have the opportunity to ask questions and join the discussion through the live chat.

International HSP Congress in Amsterdam

Around the time of World HSP Day, the International HSP Congress will take place in Amsterdam from 16 to 18 October 2026. Nearly 40 representatives of HSP organizations from around the world will come together to exchange knowledge, share experiences, and build new international partnerships.

The congress will focus on:

- Fundraising
- Patient participation
- International projects
- The latest developments in scientific research
- Strengthening international collaboration
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In addition to inspiring keynote presentations and lectures, the program will include workshops, interactive sessions, and networking opportunities for patient organizations, researchers, and healthcare professionals.

The congress is organized by Life4HSP and represents an important step toward stronger international collaboration. By combining knowledge, experience, and research across borders, we increase the chances of developing new treatments and, ultimately, achieving a future in which HSP and PLS can be stopped.

Together We Make the Difference

World HSP Day is more than a day of awareness. It is a global call to stand together and take action.

A call to show everyone living with HSP or PLS that they are not alone. Join the movement. Share your story. Share the message. Watch the webinar. Support research. Encourage your community to take action.



We especially call on HSP organizations worldwide to actively mobilize their communities in the weeks leading up to 17 October. Share this email. Share the video. Ask your members to participate. Encourage people to tell their stories. Promote the webinar. Raise awareness. And, where possible, support research. Every voice raised, every story shared, every donation, and every action strengthens our collective fight.

Together, we can drive research forward, accelerate the search for better treatments, and build a future without HSP and PLS.

Together, we can set the world in motion.

With kind regards,

Gerald Fischer
EUROHSP

Wouter de Vries
Life4HSP

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