Policy Plan Life4HSP Foundation

2025

Introduction

Hereditary Spastic Paraplegia (HSP), also known as hereditary spastic paraparesis, is a rare neurodegenerative disorder primarily characterized by progressive stiffness and weakness in the lower limbs. HSP comprises more than 80 genetic variants that collectively account for a wide spectrum of symptoms, ranging from mild motor impairments to severe neurological complications.

The prevalence of HSP is estimated at approximately 1 to 9 per 100,000 people, depending on the region and the genetic diversity of the population. Although rare, the condition affects tens of thousands of people worldwide, significantly impacting their quality of life and that of their families. The rarity of HSP makes research and awareness particularly challenging, as it often receives less priority compared to more common conditions.

Due to the genetic diversity and rarity of HSP, collaboration at European and international levels is essential. Only by pooling knowledge, resources, and expertise can researchers make significant progress in the development of diagnostics and treatments for this impactful disease.

The Life4HSP Foundation is fully committed to promoting this collaboration and supporting research to make a difference for HSP patients around the world.

1. Mission

The mission of the Life4HSP Foundation is to accelerate scientific research into the degenerative condition HSP (Hereditary Spastic Paraplegia) through fundraising and partnerships. The aim is to improve diagnostics and treatment options for patients with HSP.

Slogan version:

1. Delay neurodegeneration in HSP mutations
2. Translate research to cure.
3. Bring the cure to all patients.

2. Vision

The foundation strives for a future in which effective treatments are available for HSP patients. Through collaboration at the European level, Life4HSP combines knowledge, expertise, and resources, thereby significantly strengthening research into this rare condition.

3. Strategic Objectives

Life4HSP identifies four key goals:

- **Fundraising:** Generating financial resources through campaigns, donations, and collaborations with companies and individuals.
- **Research Support:** Financially supporting research institutions such as hospitals and laboratories that are active at the European level.
- **Awareness:** Increasing public knowledge about HSP and encouraging engagement in the fight against this condition.
- **Collaboration:** Building and strengthening relationships with European doctors, partners, donors, and sponsors.

4. Target Groups

Life4HSP broadly distinguishes three target groups in its communications:

1. All residents of the Netherlands and beyond whom we seek to motivate through Life4HSP to make a donation.

2. Patients and their families, who indirectly benefit from improved diagnostics and treatment options.
3. Research institutions and scientists who receive funding for their work on HSP-related research.

5. Organizational Structure

The foundation's board consists of:

- Wouter de Vries – Chair
- Jan Pieter Bevelander – Treasurer
- Alexander Cornelis Petrus Sijm – Marketing and Communications
- Edwin Kats – General Board Member
- Antoinette Boleij – Organization and Communications

The board members combine their expertise to effectively lead the foundation and achieve its objectives.

6. Funding

The foundation raises funds through:

- Donations from individuals and businesses
- Sponsorships and collaborations with organizations
- Targeted campaigns and events
- Limited operational costs, such as necessary administrative expenses and marketing activities.

7. Communication

Life4HSP focuses on:

- **Campaigns:** Developing targeted fundraising campaigns.
- **Online visibility:** Active use of social media and an informative website.

- **Events:** Organizing gatherings to raise awareness and funds.

8. Management and Allocation of Funds

The foundation manages its assets carefully and transparently. Income is managed by the board, aiming for a responsible distribution between direct expenditures on research projects, activities, and reserves for future projects.

Allocation of funds:

- Financial support for HSP research.
- Organizing activities such as education and peer support.
- Awareness campaigns and initiatives about HSP.

9. Remuneration Policy

The board members of Stichting Life4HSP receive no remuneration for their work. They are only entitled to reimbursement of expenses incurred.

10. Publication Requirement

To comply with the publication requirements of an ANBI, Stichting Life4HSP publishes the following information annually on its website:

- The policy plan.
- An overview of activities from the past year.
- Financial accountability, including the annual accounts.
- The names and functions of board members.

This information is presented clearly and accessibly for donors and interested parties.

11. Other Information

For transparency and identification, the foundation also publishes the following data:

- RSIN (Tax Identification Number): 867465438
- Chamber of Commerce number: 96091517
- Bank account number: NL43 RABO 0101 9276 57
- Contact details: Wouter de Vries, info@life4hsp.com