



Fact Sheet

What is SPF?

The SPF is a volunteer driven, non-profit organization dedicated to finding the cures for two groups of upper motor neuron disorders called Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

What are HSP and PLS?

HSP and PLS are caused by degeneration of the upper motor neurons in the brain and spinal cord. They are related to Amyotrophic Lateral Sclerosis (ALS, Lou Gehrig's disease). They can begin at any age, causing progressive loss of the use of the legs. Balance difficulties and pain are common. In PLS, arm and voice muscles also become affected although this can take some time. In rare forms of HSP, additional neurological symptoms also occur. HSP is hereditary while PLS only rarely occurs in families. HSP is thought to affect some 20,000 individuals and PLS some 500 people in the U.S. However, the rate could be much higher. HSP is often diagnosed for conditions including Cerebral Palsy, Multiple Sclerosis, Ataxia and in mild cases, arthritis. Researchers believe the estimated incidence rate for PLS is too low as well.

The HSP and PLS Patient Communities

HSP and PLS are rare. Until the SPF, there was no organized effort to help people, leaving individuals with a sense of isolation and limited information. That began to change in 1996 and 1999 when people affected by these disorders created websites and online email support groups to help themselves and others.

Active, online communities formed. Soon, people began to organize meetings and conferences. They also began raising funds for research. By 2001, it was clear that a handful of patients could not meet the growing demands and desires.

As rare conditions, the only disorders caused primarily by degeneration of the upper motor neurons, and so closely related clinically that they are often diagnosed as one another, leaders of each community began to discuss forming one foundation with a common focus: finding the cure for upper motor neuron disorders.

In January, 2002, the Spastic Paraplegia Foundation was launched. National headquarters are in Massachusetts. The SPF has no paid staff, its Board of Directors is comprised of individuals affected by the disorders and its work is carried out by them and other volunteers. The SPF Medical Advisor is John K. Fink, M.D., University of Michigan, leading investigator of HSP and PLS. The Scientific Advisory Board is chaired by Martha Nance, M.D., Minnesota and comprised of leading experts across the country.

SPF Vision

The day where all individuals with HSP and PLS are diagnosed, treated, and cured

SPF Mission

We are committed to:

- Discovering the cures for HSP and PLS by promoting research
- Providing accurate information about these disorders
- Creating opportunities for mutual support and sharing

Board of Directors

Mark Weber, Esq., President; Kathi Geisler, Vice President; David Lewis, Treasurer; Marlene Doolen, Secretary; Annette Lockwood, Member; Carolyn Sartain Anderson, Member; Paul Brockman, Member; Linda Gentner, Member

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