

Spierziekten Nederland – Who we are & what we do

Who we are

Spierziekten Nederland is the Dutch Neuromuscular Patient Association, founded in 1967. We represent people with neuromuscular diseases in the Netherlands, including mitochondrial disease.

With 8,500 members and many dedicated volunteers, we work closely with partners such as the Prinses Beatrix Spierfonds and Spieren voor Spieren, as well as with medical experts and researchers across neurology, rehabilitation and allied health disciplines.

What we do

We support people with neuromuscular diseases, their families, and healthcare professionals by focusing on three key areas:



Knowledge & information

We provide reliable, up-to-date information via our website, magazine, newsletters, brochures, online courses, webcasts and social media.



Events & (digital) meetings

We organise 50+ meetings per year, including the Neuromuscular Disease Conference. We also facilitate peer exchange through our online platform Myocafé.



Advocacy

- We ensure optimal quality of (para)medical care
- We stimulate relevant scientific research
- We stimulate drug development and better access to medication
- We fight for appropriate intramural care and care at home and good (access to) medical supplies and home adjustments

We collaborate with a broad network of clinicians, researchers, expertise centres, insurers, pharmaceutical companies and government bodies to achieve this.