



**SPIERZIEKTEN**  
**NEDERLAND**



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# Spierziekten Nederland

*(neuromuscle diseases Netherlands)*

*Since 1967*

<http://www.spierziekten.nl/>





## Charity and Patientorganization:

together we are strong



# HSP in the Netherlands

- 9 in 100.000 have HSP, about 1700 people
- 320 are members
- Age 0-12            8
- Age 13-18        12
- Age 19-30        21
- Age 31 and over 279

# Tasks

- Information and support
- Promote diagnostic - specific information in medical, technical and psycho-social area for our members
- Signalize, contribute to and manage all interests in those areas
- Signalize and contribute to improving the quality of diagnose-specific care and management
- Stimulating research
- Provide national awareness and knowledge of our association and the represented diagnoses
- Represent, advocate and lobby Neuro Muscular Diseases in meetings with authorities, politicians etc.

## Some activities

Magazine “Contact” 4 x a year  
Diagnose newsletter 2 x a year

- also digital on website
- Websites, various subjects
- Leaflets and brochures
- E-learning : online courses





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## Websites

The collage consists of four overlapping screenshots of websites:

- Top-left:** A screenshot of the VSN Ouders website. The header includes 'VSN Ouders' and navigation links like 'Home', 'Nieuws', 'Agenda', 'Links', 'Contact', 'Over', 'Dobbel', and 'Vrij'. The main content area features a large photo of children and a section titled 'Actueel' with a sub-heading 'Stuurgroep Paspoort Ouders'. A sidebar on the left lists categories like 'Opvang', 'Dien en omgeving', and 'Spelen en vrije tijd'. A search bar is visible on the right.
- Bottom-left:** A screenshot of the moov.nl website. It features a red header with the 'moov.nl' logo and a navigation menu. The main content area includes a 'Profiel' section with a registration form and a 'Laatste profiel' section with a profile picture.
- Top-right:** A screenshot of a website with a blue header and a large photo of a child. The main content area has a 'Zoeken' bar and several orange buttons for navigation, such as 'Nieuws op het forum' and 'Nieuws op de site'.
- Bottom-right:** A screenshot of a website with a yellow header. It features a 'Profiel' section on the right and a 'Nieuwste Media' section at the bottom. The main content area includes a 'The Club' section with a list of items and a 'Doe mee!' section with a list of activities.

# Mutual Contact

websites  
meetings  
facebook



## Contact

- Contactperson for website
- Regional theme meetings: tiredness, laws, work, how to deal with your disease, etc.
- Meetings 2x a year
- Annual meetings with themes
- ‘Some-one like me’ : [www.iemandzoalsik.nl](http://www.iemandzoalsik.nl)
- ‘Myocafé’ community :  
[www.myocafe.spierziekten.nl](http://www.myocafe.spierziekten.nl)
- Facebook



# Yearly conference

- Diagnostic - specific lecture programs;
- Meet and greet with the lecturers
- Research market;
- Information market;
- Myocafé live;
- Children (circus);





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# Quality of care and stimulating research

## Other activities

- Network of caregivers
- Centres of excellence
- Guidelines and standards of care
- Best care ?





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## ZORGWIJZER SPIERZIEKTEN



Dokters met verstand van  
uw spierziekte

**Starten >**



#### Vaststellen van een spierziekte

**Ik zoek een specialist die kan vaststellen of ik een spierziekte heb en welke spierziekte ik heb**

Zoek de beste neurologen met verstand van spierziekten voor het vaststellen van een spierziekte. Ik wil controleren of bij mij de juiste spierziekte is vastgesteld (second opinion).



#### Medische zorg

**Ik zoek een specialist (bijvoorbeeld een neuroloog of cardioloog) met verstand van spierziekten**

Zoek de beste neurologen (spieren en zenuwen), cardiologen (hart), longartsen, orthopedisch chirurgen (botten in rug, handen en voeten), maag-darm-leverartsen en kinderartsen met verstand van spierziekten.



#### Revalidatie

**Ik zoek een specialist die mij helpt te leven met mijn beperkingen**

Zoek de beste revalidatieartsen, fysio- en ergotherapeuten, psychosociaal medewerkers, diëtisten en logopedisten met verstand van spierziekten.



#### Ademhalings-ondersteuning

**Ik zoek een arts met verstand van ademhalingsondersteuning bij spierziekten**

Zoek de centra voor thuisbeademing.



#### Advies over erfelijkheid

**Ik zoek een specialist op het gebied van erfelijkheid voor onderzoek of advies**



## Situation in The Netherlands:

- There is no registration for HSP
- SGP 4 -7 -3A - 8 -11 - 17 - 31- 53 + VCP gen
- Nijmegen is the expertise centre for HSP
- DNA research (looking for new genes)
- Rehabilitation research for better quality  
of life



**My personal vision**

**and**

**own experience**

# Integrated Personalized Medicine for people with HSP

**See: Sino-Dutch Centre for  
Preventive and Personalized Medicine**

# Integrated Personalized Medicine for people with HSP

- Health is a dynamic process being expressed in the ability to adapt and self management.
- Practically it means stimulating of health as far as possible and where necessary fight the disease.

## Integrated Healthcare:

- Sets the therapeutic relation between client and social worker central
- Looks at the whole human being
- Bridges the different philosophies underlying Western and Chinese Medicine based on scientific biochemical language, following a Systems Biology approach.
- Makes use of the base of science and research for all useful therapeutic approach, care professionals and disciplines to come to optimal healthcare and optimal recovery
- The self healing possibility is essential in the healing process

## HSP Symptoms :

- Spasticity, restless legs
- Gait, Balance, Muscle weakness
- Falling
- Sensitivity problems
- Depression
- Pain (back, feet, legs, buns under feet)
- Cognitive problems: concentration, foggy head
- Bladder problems
- Bowel problems
- Sexual problems
- Sleeping problems
- Breathing
- Other??

# DNA

- Difference between the genes
- Symptoms of the different genes
- What triggered these genes ?
- What is the link between these genes ?
- What is the reason that it starts earlier in the next generation ? How can we prevent this ?
- What is the influence of the epigenetics ?
- Is there a link between HSP and arthrosis (embryological it develops from the same tissue)?

## Research

- What kind of research has been done ?
- What kind of research is going on in every country ?
- Is it useful to organize a meeting with experts to reach a consensus about where it goes wrong in the neuron ?
- What is the influence of aging ?
- Which effect has the neuron problem on the function of the total body ?

# Treatment

- Rehabilitation
- Treatment of spasticity:
  - Good walkers with mild spasticity
  - Difficult walkers with mild spasticity
  - Bad walkers with severe spasticity
- Motion score in lab
- Mobility analysis
- Physiotherapy : what kind of exercise is good ?
- some HSP-ers can do a lot, others are easily tired
- Hydrotherapy
- Walking aids, Falling therapy



- Medicine
- Ergo-therapy
- Speech-therapy
- Social worker
- Children
- Homecare givers
- Work
- Insurance
- School
- Education
- Relations
-

- Genetical research, heredarity,
- Family planning
- Prenatal screening?

- Earlier diagnosed, less misdiagnosed

# Complementary

- Biochemical: Fatty acids, neurotransmitters, heavy metals, vitamins, minerals, liver-detoxification: Glutathione, SOD microbiome
- TCM - acupuncture + Chinese herbs
- Homeopathy
- Orthomolecular
- Phyto-therapy, Ayurveda
- Nutrition / life style
- Aroma therapy
- Osteopathy, Stress release therapy  
Yoga, mindfulness, tai Chi, Bowen therapy  
BodyTalk, Quantum touch

## What is the preferred future for people with HSP

- A roadmap to therapy and develop a specific scale for quality of life
- Participation in patient registrations system in Europe and internationally
- We have to follow the European Federation of Pharmaceutical Industries and Associations (efpia) guidelines

## Future

- By working together we want to speed up the process and get to a therapy
- Create an international research agenda for all the aspects.
- Look how SMA, Pompe, Mitochondrial diseases did this (there is a lot of experience)
- Who is a good registering partner for us: Eurordis, Neuronomics, RaRe connect, NMD? are they interested in us??