



Dwarslaesie
Organisatie Nederland

A short description of

Dwarslaesie Organisatie Nederland Dutch Spinal Cord Injury Association (Dutch SCIA)

Who we are

"Dwarslaesie Organisatie Nederland" is the Dutch Spinal Cord Injury Association (Dutch SCIA). Members of the association aim to assist each other and non-members with a similar handicap, through exchange of experiences and through pursuing common interests. At this time (2011) our association has approximately 1,300 members, consisting of people with SCI and/or relatives.

The association's reasons for existence

Spinal cord injuries (SCI) are usually the result of an accident or a complication associated with an illness. From one moment to another, people are seriously handicapped and encounter significant problems in their daily life. The rehabilitation centre is usually the place where one will master the initial adjustments required to deal with the new reality. Although this is an excellent first step, back at home one will encounter many more problems that need to be solved. "At home things really get real". Dutch SCIA consists of people who have personally experienced this process after suffering SCI and who also have first-hand experience with problems associated with SCI. They want to share their experiences amongst themselves and with others (including family members and friends) who have only recently suffered SCI.

What we do?

- We organize and promote contact between people with SCI. Members assist and inspire each other and exchange information.
- We provide information to people with SCI and all people involved with them (i.e. family members, friends, physicians, therapists, researchers, students, etc.)
- We protect the interests of people with SCI in all areas of concern.

The Association's organizational structure

Only people with SCI and/or their immediate family members may join as regular members. Others – such as SCI professionals – are registered as donors. The association is governed by the General Assembly and a national Board of Directors, accountable to the General Assembly with regard to activities performed and new activities proposed. The association consists of five regional groups, each with their own regional Board of Directors. In addition, the association supports a number of National Committees focusing on issues such as incomplete spinal cord injuries, youth issues, and issues specific to parents and partners of people with SCI.

Contact amongst people with SCI

All regional groups and National Committees organize one or two meetings annually. During these meetings, members are informed about topics such as treatments, rehabilitation and issues of daily living of interest to people with SCI. The meetings are organized in such a way that there is ample room for contact with fellow people with SCI.

Dutch SCIA. (the national association) organizes an annual contact and information event, called the "Schakeldag" ("schakel" being a "link in a chain", symbolizing the relationship between its members). Around 80 to 100 members typically attend this annual event. In addition to this annual event, chat/discussion groups on www.dwarslaesie.nl ("Het Forum") play an important role in further facilitating contact amongst members.

Over time, the many activities of the association have resulted in the establishment of a large scale informal networking system. Members inform, inspire and encourage each other and protect each others interests. In doing so, members make full use of each other's experience and expertise.

Information provisioning

- Dutch SCIA publishes a bi-monthly magazine "De Ketting" (the chain).
- Dutch SCIA has a telephone Help Line (0031(0)900 20 21 229) operated by people with first-hand experience in living with SCI. They interact with callers on the basis of their own experience and have access to the enormous amount of accumulated knowledge and experience of other members of Dutch SCIA.
- Dutch SCIA has published several books and a video on topics of importance to people with SCI.
- The website www.dwarslaesie.nl contains an abundance of information and expertise.
- Dutch SCIA is represented at numerous trade fairs and similar events. An important trade show is the bi-annual "Support" trade fair in the city of Utrecht.
- In addition, Dutch SCIA responds to numerous requests for information and assistance from healthcare professionals, civil servants, politicians, journalists, students, researchers, etc.

Advocacy of interests: support of members on an individual basis

On a regular basis, Dutch SCIA members meet with people in rehabilitation centres who have recently incurred SCI. For these people, a one-on-one conversation during the rehab period or during a visit to their home not only provides practical information, but is also inspiring. These one-on-ones often significantly reduce fear for the future and help with finding the necessary courage to complete the demanding process of rehabilitation.

Many questions are received through the Help Line and the website, often from family and friends of persons who recently incurred SCI. Callers do not only look for factual information, but also for someone who is willing to listen. Dutch SCIA makes sure that people with a long experience with (or living with) SCI are the ones who are answering these questions.

Advocacy of interests: supporting collective needs

Dutch SCIA is a regular participant in a number of governmental and steering committees (i.e. regarding (medical) resources, mobility, accessibility and living circumstances). The association also participates in work groups of the "Nederlands Normalisatie Instituut" (Dutch Standardisation institute), several universities, research institutes like Vilans, TNO and LEVV as well as work groups of the European Fortune Project focusing on increase of quality and distribution of resources/tools at a European level.

Dutch SCIA is a member of the CG-Raad (The Dutch Council of the Chronically ill and the Disabled, the umbrella organization, consisting of associations of people with a chronic illness or a disability) and of the European Spinal Cord Injury Federation (ESCIF). ESCIF consists of 24 European national associations of and for people with SCI.

Many projects with regards to collective needs come up unexpectedly, for instance as a result of complaints/questions from members. Dutch SCIA lobbies governments and other institutions and also participates in short term projects with the objective to remedy the complaints.

Becoming a member

People with SCI and/or their family and friends may become members of Dutch SCIA. By becoming a member you will participate in supporting the needs of people with SCI. Dutch SCIA is active in the following areas: distribution of experience and expertise, mutual assistance, provision of resources, mobility, information, rehabilitation, healthcare, social legislation, living circumstances, creating options for vacations, medical developments as well as the encouragement of research (scientific, "cure" and "care").

In addition:

- You will receive the magazine "De Ketting" 6 times per year with the latest information about all developments with regards to living with SCI.
- You have access to the association's information sources and Help Line.
- You have the opportunity to exchange experiences with other people with SCI. They may or may not have a SCI for a longer time, or may have specialized knowledge in certain areas.
- You will receive assistance when requesting a Person Specific Budget (PGB).
- You will be able to use, without charge, Dutch SCIA's legal aid service (Juridisch Steunpunt)
- You are entitled to ordering, amongst other things, prepared foods as well as vitamins at a reduced rate from "De Roode Roos"
- You will receive a discount on a "care" insurance with for example Agis Zorgverzekeringen
- You are entitled to participate in the association's annual information and networking day ("Schakeldag")
- You are entitled to participate in regional events and work groups.
- You have the option to rent a cottage from the Beatrixfonds for a vacation in the off-season.

Donations.

Dutch SCIA is an association of volunteers. Financial contributions come from members and from donations from third parties. Financial support can be given by remitting money to the treasurer of Dwarslaesie Organisatie Nederland in Leeuwarden on ING bank account 947 39 33.

Contact	
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Visit our website: www.dwarslaesie.nl