

The Swedish ED-association was founded in May 27th 1999 and works in the belief of everybody's equal value and is religiously and non-political independent. The work of the association aims towards its members' participation and equality in all areas of the society.

The purpose of the Swedish ED-association is

- to ensure and guard members' interests
- to spread knowledge and information in order to make the diagnosis ED known to healthcare and society
- to get in touch with as many ED carriers in Sweden as possibly
- to help and support new diagnosis carrier
- to help and support people with ED in their contacts with dentists, healthcare and others.
- to provide support and advise, elaborate structure and procedures in dealing with the authorities, insurance companies and Försäkringskassan.
- to establish contact and exchange experience with ED organizations in other countries.

The Swedish ED-association is a small organization with 140 members at the present. One third is estimated to be ED carriers. At least six different ED diagnoses are represented in our association. Our members usually find us via information from dentists and healthcare, via the Swedish Social Boards information bank or our website Our activities are financed by funds, contributions and membership fees.

The Swedish ED-associtaion holds a big gathering in August every year, spending a weekend together with activities and fun. Every other year we arrange with lectures on subjects related to ED. The annual meeting is held in the conjunction with the August meeting.

We are seven board members and our board meetings are held on the phone seven times a year and other communication via e-mail. None of the board members charge any fee and work is done voluntary.

The Swedish ED association are members of a large umbrella organization – Rare Diagnoses, Sweden – together with many other small associations. Rare Diagnoses, Sweden works to disseminate information and to help improve conditions of life for people with rare diagnoses. We participate in several of their projects.





<u>www.svenskaed.se</u> (The Swedish ED association website) <u>www.socialstyrelsen.se</u> (The Swedish National Board of Health and Welfare) <u>www.sallsyntadiagnoser.se</u> (Rare Diagnosis, Sweden) <u>www.forsakringskassan.se</u> (The National Social Insurance, Sweden)

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