

# SBONN – Rare Diseases Nordic Network of organisations representing people living with a rare disease

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## Introduction

Rare diseases are not uncommon. Although there may be only a handful of individuals living with one specific rare disease in a given country, there are between 4 – 6% people worldwide living with one of the more than 6.000 rare diseases known today. Thus, connecting beyond national borders is essential for people living with a rare disease. Both to find individual support from professionals and patient associations, but also to raise our voice as one advocacy group to drive societal development, striving towards open societies that are accessible for all people. On the Nordic level, Denmark, Finland, Iceland, Norway and Sweden cooperate on rare diseases in several ways. SBONN is the cooperation between umbrella organisations and networks and speaks the voice of people living with rare diseases in the whole Nordic region since 2014.

## Rare SBONN: Sällsynta Brukarorganisationers Nordiska Nätverk

SBONN was formed in 2014 by umbrella organisations and networks representing people living with rare diseases in Denmark, Finland, Iceland, Norway and Sweden. The purpose of SBONN is to promote the exchange of ideas, knowledge, learning and understanding of living with a rare disease and/or disability across national borders in the Nordic region. It is also an ambition to act as speaking partner for all rare people at the Nordic political and professional level.

## SBONN today

As per 2020, SBONN represents 277 rare disease patient organisations with all together 55.000 rare people as members:

- Sällsynta Diagnoser Sverige (Sweden)
  - [sallsyntadiagnoser.de/in-english/](https://sallsyntadiagnoser.de/in-english/)
  - 68 member societies and 1 group for individual members
  - representing 15.900 rare people, covering 150 rare diagnoses
- Sjældne Diagnoser Danmark (Denmark)
  - [sjaldnediagnoser.dk](https://sjaldnediagnoser.dk)
  - 56 member societies and Network for Ultra Rare Diseases (NURD)
  - representing 12.500 rare people, covering 400 rare diagnoses
- Harso Finland, Harvinaiset-verkosto
  - [harso.fi](https://harso.fi), [harvinaiset.fi](https://harvinaiset.fi)
  - 20 umbrella members with 107 member societies
  - representing more than 10.000 rare people, covering 850 rare diagnoses
- Funksjonshemmedes Fellesorganisasjon (Norway)
  - [ffo.no](https://ffo.no)
  - 84 member societies (where more than 30 represents one or more rare diseases)
  - representing 17.500 rare people, covering 300 rare diagnoses
- Einstök börn-stuðningsfélag (Iceland)
  - [einstokborn.is](https://einstokborn.is)
  - 415 children with rare diseases and their families, covering more than 200 rare diagnoses

**SÄLLSYNTA  
DIAGNOSER**  
RARE DISEASES SWEDEN

**Rare Diseases Denmark**

**HARSO** THE FINNISH NETWORK FOR RARE DISEASES

**FFO**

**einstök  
BÖRN**

## Lessons to be learned

To establish a successful regional network across borders, a formal structure and some funding is necessary:

A circulating chairmanship is implemented, so that SBONN is chaired by the national or-organisation/organisations of one country for a period of one year at a time.

A Steering Committee has been constituted, meeting twice a year. Internal rules have been formed and a "Letter of intent" has been agreed and disseminated.

NWC/Nordic Council has partly funded the SBONN-activities.



## Contact us!

SBONN is the only Nordic network across diagnosis representing rare people. SBONN welcome and encourage contact from professional organisations, authorities and other stakeholder groups who share our vision for better care, better treatment and better lives for people with rare diseases.

## Contact information

SBONN may be reached through the participating organisations:

- Denmark: Sjældne Diagnoser: [mail@sjaldnediagnoser.dk](mailto:mail@sjaldnediagnoser.dk)
- Finland: Harso: [sihteeri@harso.fi](mailto:sihteeri@harso.fi), Harvinaiset-verkosto: [harvinaiset@harvinaiset.fi](mailto:harvinaiset@harvinaiset.fi)
- Iceland: Einstök börn-stuðningsfélag: [einstokborn@einstokborn.is](mailto:einstokborn@einstokborn.is)
- Norway: Funksjonshemmedes Fellesorganisasjon: [post@ffo.no](mailto:post@ffo.no)
- Sweden: Sällsynta diagnoser: [info@sallsyntadiagnoser.se](mailto:info@sallsyntadiagnoser.se)

## Letter of intent

SBONN has managed to perform accordingly to the tasks from the SBONN "Letter of intent":

- Advocate for Nordic cooperation within rare disease care, treatment and research
- Offer a unified patient voice at Nordic rare disease conferences when needed
- Be the self-evident collaborative and speaking partner when systems, structures and policy affecting people with rare diseases and their patient organizations are being discussed and decided upon within the Nordic countries.

