

# SBONN – Rare Diseases Nordic Network of Patient Organisations

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## Introduction

For many years, Nordic countries such as Denmark, Finland, Iceland, Norway and Sweden have cooperated in a number of ways and around a number of topics. This is also the case when it comes to rare diseases. And some diagnosis specific rare disease patient/user-organisations have a tradition of networking and more at the Nordic level. However, this has not been the case for the “umbrellas” of the diagnosis specific organisations.

If the voice of the Nordic rare people - rare disease patients and their relatives - are to be taken into consideration, also the umbrellas and alike has to network and cooperate at the Nordic level. That is why SBONN was formed in 2014.

## SBONN

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 Nordic borders. It is also an ambition to act as speaking partner for all rare people- at the Nordic political and professional level.

## SBONN:

### Sällsynta Brukarorganisationers Nordiska Nätverk

SBONN was formed in 2014 by the national alliances and rare people network on the “umbrella level” from Denmark, Finland, Iceland, Norway and Sweden.

## SBONN today – the results

As per 2016, SBONN represents 277 rare disease patient organisations with all together 55.000 rare people as members:

### • Sällsynta Diagnoser Sverige (Sweden)

- [sallsyntadiagnoser.se](http://sallsyntadiagnoser.se)
- 62 member societies and 1 group for individual members
- representing 13.200 rare people, covering 120 rare diagnosis

**SÄLLSYNTA  
DIAGNOSER**  
RARE DISEASES SWEDEN

### • Sjældne Diagnoser Danmark (Denmark)

- [sjaeldnediagnoser.dk](http://sjaeldnediagnoser.dk)
- 52 member societies and Network for Ultra Rare Diseases(NURD)
- representing 12.500 rare people, covering 370 rare diagnosis

 Rare Diseases Denmark

### • Harso Finland, Harvinaiset-verkosto

- [harso.fi](http://harso.fi), [harvinaiset.fi](http://harvinaiset.fi)
- 17 umbrella members with 107 member societies
- representing more than 10.000 rare people, covering 850 rare diagnosis

 HARSO RY THE FINNISH NETWORK FOR RARE DISEASES

### • Funksjonshemmedes Fellesorganisasjon (Norway)

- [ffo.no](http://ffo.no)
- 55 member societies
- representing 17.500 rare people, covering 300 rare diagnosis

 FFO

### • Einstök börn-stuðningsfélag (Iceland)

- [einstokborn.is](http://einstokborn.is)
- 270 children with rare diseases and their families, covering 110 rare diagnosis

 einstök  
BÖRN

## 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.



## 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 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.

So far, the NWC/Nordic Council has 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@sjaeldnediagnoser.dk](mailto:mail@sjaeldnediagnoser.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)
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