

## Letter of intent

### Rare Diseases Nordic Network of Patient Organisations

In the spring of 2014, Nordic rare disease patient organizations created the Rare Diseases Nordic Network of Patient Organisations (SBONN) as a way to further collaboration between our groups.

The mission of SBONN is to strengthen the exchange of ideas, knowledge, learning and understanding between the rare disease patient organisations in the Nordic countries. SBONN represents 197 rare disease organisations and more than 49,000 members in five countries. As a result, we have the capacity and desire to:

- 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 partner when systems, structures and policy affecting people with rare diseases and their patient organisations are being discussed and decided upon within the Nordic countries
- actively collaborate with health care and research stakeholder groups to encourage and further innovation and quality improvement
- develop a shared agenda for a Nordic cooperation within a European context
- become a collaborative Speaking Partner in the Nordic countries.

The administration of meetings, seminars and other activities of SBONN will rotate among member countries annually.

We 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.

***“Through SBONN, patient organisations representing people with rare diseases in the Nordic countries can work together to ensure that people with rare diseases receive the best care and treatment regardless of where they live. People with a rare disease in the Nordic countries can raise their voices together.”***

- Rare Disease Sweden – [www.sallsyntadiagnoser.se](http://www.sallsyntadiagnoser.se)
- Rare Diseases Denmark – [www.sjaeldnediagnoser.dk](http://www.sjaeldnediagnoser.dk)
- Harso Finland - [www.harsofinland.net](http://www.harsofinland.net)
- Finnish Network for Rare Diseases - [www.harvinaiset.fi](http://www.harvinaiset.fi)
- The Norwegian Federation of Organisations of Disabled People – [www.ffa.no](http://www.ffa.no)
- Association of children with rare diseases in Iceland – [www.einstokborn.is](http://www.einstokborn.is)

Contact information for the Rare Diseases Nordic Network of Patient Organisations can be found on each member organisation’s website from september 2014.

**SBONN** is acronym of the Nordic spelling of Rare Diseases Nordic Network of Patient Organisations: ***Sällsynta BrukarOrganisationers Nordiska Nätverk***