

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 as a way to further collaboration between our groups.

The mission of the Rare Diseases Nordic Network of Patient Organisations is to strengthen the exchange of ideas, knowledge, learning and understanding between the rare disease patient organizations in the Nordic countries.

The Rare Diseases Nordic Network of Patient Organisations represents 197 rare disease organizations 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 organizations 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 the Rare Diseases Nordic Network of Patient Organisations will rotate among member countries annually.

We welcome and encourage contact from professional organizations, authorities and other stakeholder groups who share our vision for better care, better treatment and better lives for people with rare diseases.

“Through the (name), patient organizations 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

Rare Diseases Denmark – www.sjaeldnediagnoser.dk

Harso Finland - www.harsofinland.net

Finnish Network for Rare Diseases - www.harvinaiset.fi

The Norwegian Federation of Organisations of Disabled People – www.ffo.no

Association of children with specific diseases in Iceland - einstokborn.is

Contact information regarding the the Rare Diseases Nordic Network of Patient Organisations can be found on the each member organization’s website from august 2014.