

Annual report from the Nordic Network on Usher Syndrome to the Nordic Leader Forum of Deafblindness, 2024

Coordinators:

Bettina Kastrup Pedersen (Coordinator) (Specialist Consultancy for the Deafblind), Rasmus Hougaard Pedersen (Specialist Consultancy for the Deafblind)

Members:

Sweden: Emma Varga (NKCDB), Maria Olander Nilsson (SPSM)

Denmark: Bettina Kastrup Pedersen (Coordinator) (Specialist Consultancy for the Deafblind), Rasmus Hougaard Pedersen (Specialist Consultancy for the Deafblind), Jackie Lehmann Hansen (chairman of Deafblind Denmark) representing DBNSK

Iceland: Steinunn Sævarsdóttir (Sjónstöðin), Estella Björnsson (Sjónstöðin)

Norway: Bodil Ballovara Olufsen (UNN)

Aim and purpose for the network

The goal of the Nordic network on Usher syndrome is to offer a platform for the sharing of knowledge and experience between professionals in the Nordic countries about living conditions and support for people living with Usher syndrome, and for parents who have children with Usher syndrome.

The network has different areas to focus on – both the practical field focusing on professionals, relatives, and people with Usher syndrome, but also focusing on research.

Status of the network

Though we were officially formed in 2023, the last year has still been focused on establishing ourselves as a network and turning our visions behind this network into reality with specific activities. In the application we mentioned that the network will have a rotating chair and in February Bettina became chair of the network and Rasmus became the deputy chair. Throughout the year we also had some changes in the composition in the network, and new and old members have entered the network while others have left the network. We are still looking for participants from Finland to cover all the Nordic region. We participated in the network meeting in Malmö and here we discussed the possibility of having a member representing DBNSK entering the network. In 2025 this has been done and Jackie is now a member of the network

Our last year has been focused on creating the first activity as a network. In November we had our first webinar about how people with Usher syndrome navigate in a digital world, and how technology both offers solutions and opportunity but also might pose some challenges. In 2025 we

are planning for a physical seminar on the life adjustment perspective. These activities are central in creating awareness about our network and Usher syndrome.

Meetings

Hybrid meeting in Lund and online – 1st of February 2024

- Chair of the network
- Going through the application of the network
- Structure of meetings and activities
- Prioritized list of themes for webinars
- Working method in the network
- Introduction for the website

Online meeting - 25th of March 2024

- Working with Usher syndrome and counselling perspectives in Denmark
- Website
- Discussion of the webinar and structure in November

Online meeting – 31st of May 2024

- Webinar
- The Nordic network meeting in November

Online meeting - 30th of August 2024

- Developing a course/seminar – an idea from Gøran
- Status on the webinar
- Looking at the timeline for the preparation of the webinar

Online meeting - 11th of October 2024

- Video analysis in preparation for the network days
- Preparing a network presentation
- Status on the webinar
- Two-days course in 2025

Meeting at the network days in Malmö - 6-8th of November 2024

- Preparing the presentation of the network
- Preparing the video analysis
- How can we integrate DBNSK in our network?

Activities

- Webinar 26th of November 2024 on Usher syndrome in a digital world – Tech talks from

the community.

Development of technology offers different kinds of solutions for everyday life. These solutions might pose both opportunities and challenges – especially for people with sensory impairment.

The webinar went well with 30 to 40 participants. Moa Wahlqvist represented the network and was a host of the webinar. Jenny Widmark has an ongoing ph.d.-project on technology and made a presentation about technology for people with Usher syndrome. Interviews were made in Denmark, Norway, Sweden and Iceland highlighting how people with Usher syndrome experience technology in everyday-life, and these interviews were used in a discussion between Moa and Jenny. The mix between the more theoretical aspects as well as aspects from everyday-life were good.

- Participation in the network meeting in Malmö 6-8th of November.
It was some very interesting days for this network. The Nordic Network on Usher syndrome is both relatively new compared to the other networks, it is the only network that solely focuses on acquired deafblindness. As an assignment for the network days, each network had to contribute with their perspective on a video clip. The video clip was about a boy with CHARGE syndrome and thus our network needed to be a bit creative on how we could contribute to the video analysis. However, during our discussion we focused on using the ICF model as a tool in the video analysis to focus on how to support activity and participation. This perspective was received very well from the other networks, and it contributed to the perspectives from the other networks in understanding the potentials of the boy in the video clip.

Plans and activities for the future

On November 12-13th 2025 we plan to have a seminar on the life adjustment perspective focusing on having perspectives from people living with Usher syndrome, perspectives from a research project on life adjustment model, and perspectives from professionals who have used the life adjustment perspective.