

Annual report from the Nordic Network on CHARGE to the Nordic Leader Forum of Deafblindness, 2025

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Aim and purpose for the network:

The target of the Network is to collect, share, and spread knowledge of CHARGE syndrome.

- **Collect knowledge:** We keep each other updated within the network with, for example, reports from the national CHARGE networks and DBI CHARGE.
- **Share experiences:** We emphasize sharing all aspects of knowledge and experience within the CHARGE syndrome. This is important because we have a relatively small population in the Nordic countries, and CHARGE itself is rare.
- **Spread knowledge:** We work on disseminating what we learn and the voices of people living with CHARGE.

Meetings:

Since April 2024, we have met online five times. The first meeting focused on evaluating the publication work and the launch webinar. The subsequent meetings were mostly for preparing for the seminar in Malmö, including video analysis and a network presentation. During the network seminar, we made plans for future work in our network. The following two meetings have mostly been about planning a physical meeting in May in Enköping/Stockholm, Sweden, where we will record webinar lectures regarding our publication re-CHARGE.

Activities (courses, publications, webinars, other):

Nearly all members participated in the Nordic network seminar in Malmö, Sweden. There, we presented our network and a bit about CHARGE, advertised our publication, and worked with video analysis together with all the other deafblind networks.

Plans and activities for the future:

We will:

- **Continue to work with re-CHARGE:** One part of this is to present the chapters from re-CHARGE in different groups in our Nordic countries, for example, the interview with the mother in parent groups. We will also create webinars about the publication and what we have learned through working with cases and interviews.
- **Include people with CHARGE more:** We want to amplify the voices of people living with CHARGE.
- **Create a welcome pack for parents:** This will include a letter, toy, information for parents (book), and the interview chapter with the mother from re-CHARGE.

- **Create a welcome pack for doctors and nurses:** This will be for BVC and healthcare professionals.