

Annual report from the Nordic CHARGE Network to the Nordic Leader Forum of Deafblindness, 2023

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Statement of goals

The target of the Network is to collect, share and spread the knowledge of CHARGE syndrome. To have contact within the network and get benefits from the projects in the different countries.

To be part of, and conduct, projects aiming to collect data in the different countries and to share the results for example through publications, conferences and webinars.

Meetings:

Iceland 23- 24th of May 2022

The days in Reykjavik focused mostly on our upcoming publication and the structure of it.

There will be chapters with case-presentations and interviews in between them. The publication topic is psychosocial development and transitions with a focus on self-regulation in children, youth and adults with CHARGE with case descriptions and suggestions for adaptations and support.

We used time to plan our network presentation at the NVC conference in Tampere, Today's knowledge for tomorrow's action. The presentation will be a celebration for the networks 20 year's celebration.

We decided to send in a post about our network, the upcoming conference and the 20 years of action to the DBI newsletter. This was part of the summer issue.

We had a visit from parents to a child with CHARGE that shared their story from birth until present day and gave us the possibility to ask many questions. The dialogue inspired us all in the work with looking over the presentations of CHARGE that is given to new parents in the Nordic countries.

Summary of our online meetings between April 2022 and April 2023

Professor Andrea Wanka from the University of Heidelberg joined us for one meeting to have an informal discussion about the R in the acronym. She shared the thoughts from CHARGE network in Germany and we shared our Nordic networks thought. Children with CHARGE have given the acronym new meaning, for example in the Dutch publication "You taught me". As the acronym is

based on the old diagnose criteria there is a need for medical professionals to get involved in this. To get on with this Andrea will contact David Brown and check if students at the university in Heidelberg would be interested in writing their master thesis on the topic. We will also get in contact with families and people with CHARGE for further discussions in our different networks both international and national.

The timeline for the publication was reviewed in the autumn of 2022 together with NVC and was, once again, postponed for a couple of month. In early 2024 we hope it all will be wrapped and ready. The reason for this is the change in members in the network, the pandemic and the workload that we all faced when restrictions was lifted.

We've formulated an interview guide to use for the publication, which we have spread in some of the national workgroups to collect answers from as many as possible.

Today's knowledge for tomorrow's actions – a Nordic perspective on Deafblindness

NVC gave a conference in Tampere, Finland, in September. We used our 45 minutes of networking time to present our network and the work we do. We did a short presentation of CHARGE and how the diagnose criteria have changed during the years, from definition up until today, and on the aspects of Self-regulation and the impact it has on individuals with CHARGE. We showed a slideshow with pictures from daily life with CHARGE. In focus was the different ways to self-regulate and to enjoy life. We also took time to celebrate the Networks 20 years of action with a Q&A and shared candy from our different countries.

Tasks of the network:

- * Continue our work of collecting, sharing and spreading knowledge of CHARGE syndrome.
- * Contribute to seminars for both professionals and family members, arrange courses/webinars and prepare conference presentations.
- * Collect and present our experience regarding psychosocial development with a focus on self-regulation in children, youth and adults with CHARGE syndrome in a publication.

Future plans

We will continue our work with the publication based on cases and interviews in 2023. After the publication in 2024, there will be webinars based on different chapters.

We will continue to meet online 3 times a year and in May 2023, we will meet in Bergen, Norway.

We will maintain contact with the CHARGE Network of Deafblind International and with the Nordic countries national workgroups.

We also plan to make contact with the Nordic workgroup on self-regulation to share knowledge.

/Frida Racksäter Nerback, Mo Gård, Sweden, April 2023.