

## Annual report from the Nordic CHARGE Network to the Nordic Leader Forum of Deafblindness, 2021

Coordinator: Frida Racksäter Nerback

### Members:

Frida Racksäter Nerback, Jessica Jägryd, SE

Jette Noergaard, Annette Soelgaard DK

Kirsten Costain (coordinator nov 2019-feb 2021), Hege Krog Francke NO

Ásta Bjornsdottir, Estella Bjornsson, IS

Maria Creutz, NVC

### 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. There are also projects that have been collecting data in the different countries and the results have been shared in different ways.

### Meetings:

**5th May -6th May 2020** (a video meeting hosted by Kirsten Costain, Statped)

Due to the Covid-19 pandemic we could not travel to Norway and instead we met online which worked out well.

The Network continued the discussion of the case project about psychosocial development with a focus on self-regulation (based on the model described by Hartshorne and Nicholas) in children, youth and adults with CHARGE with video case descriptions that illustrate the topic. Frida presented her case for the coming book. The case is focused on adaptations made to the surroundings, both physical and social, to facilitate for an individual with CHARGE syndrome to take part in a group activity in a new location.

The template that will be used for all case descriptions was reviewed and became more detailed. This also led to the realisation that it will become a book and not a pamphlet with shorter articles. Deadline for this book project was from the beginning set to the autumn of 2021 and a decision for shorter online meetings more often than previous years was made to make this happen.

A related topic for this meeting was CHARGE and sexuality with a presentation by Jessica Jägryd of her work in this area.

We also discussed ideas for implementation at the centres of a new publication, *A New medical care program, CHARGE Syndrome* by Claes Möller:

<https://publikationer.nkcdb.se/produkt/medicinskt-vardeprogram-for-charge-syndrom-2/>

We had time to look at the Educational Checklist by Hartshorne et al as well as a booklet about CHARGE intended for new parents by Kirsten Costain which will be submitted for consideration for distribution to the National Centre of Expertise on Deafblindness, Norway (NKDB).

## Summary of our online meetings, 2 in the autumn of 2020 and 1 in spring 2021

A lot of focus has been on the ethical aspects of making the book due to the fact that a lot of the individuals in the cases have difficulty for example their age or cognitive and/or communicative challenges to give their consent to participate. We will therefore make the presentations anonymous and not use video or photos where the persons can be identified.

Due to the Covid-19 pandemic all of us have had restrictions regarding meeting the individuals with CHARGE syndrome the work with our cases have been delayed and we have postponed the date for the book to be finished to 2022.

There has been another challenge for some members to get the time needed for working with the Nordic network and the writing of their chapters that may affect the outcome of the book.

To keep us inspired we booked a presentation of Ástas case to the first meeting in the spring of 2021.

We also have done a lot of work with the page for the Nordic CHARGE network on NVC:s website with useful links to lectures, publications and websites where people can find more information about CHARGE.

## 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 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 book.

## Future plans

We will continue our work with the book based on the video cases in 2021– 2022. We will continue to meet online but hope to actually meet in November 2021 in Sweden.

We will make plans for a possible online course or seminar based on the video case project and we hope that we can do this in connection to the release of the book in late 2022 or early 2023.

We will continue to work with the topic of psychosocial development and CHARGE.

We will maintain contact with the CHARGE Network of Deafblind International and also with the Nordic countries national workgroups activities for spreading knowledge regarding CHARGE syndrome.

/Frida Racksäter Nerback, Mo Gård, Sweden, April 2021.