

Annual report from the Nordic CHARGE Network to the Nordic Leader Forum of Deafblindness, 2020

Coordinator: Kirsten Costain

Members:

Frida Racksæter, Jessica Jägryd, SE
Monika Estenberger (until November 2019), Sonja Friberg (until November 2019) SE
Jette Noergaard, Annette Soelgaard DK
Kirsten Costain, Mona Andreassen Hellebust (Coordinator until November 2019) NO
Ásta Bjornsdottir, Estella Bjornsson, IS
Maria Creutz, NVC

Statement of goals (the same as last year)

Meetings:

26th November 2019, Hovseter, Statped sørøst (video meeting)

The topics discussed at the previous meeting (Aalborg, May 2019) are also included in the general theme of psychosocial health and development in people with CHARGE syndrome.

The Network continues in 2020 – 2021 with a video 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. The form of these descriptions and their distribution is still a matter for discussion. Burdens of work for the members as well as changes in structure and shifts in personnel at several of the centres has delayed the progress of the project. The Corona pandemic has of course also had an impact. We will finalize the plan for progress in 2020-2021 at the Network meeting in May 2020.

We will finalize a template for case presentations of self-regulation, body image and positioning. The coordinator has contacted the leader of the Deafblind International CHARGE Network, Andrea Wanka, about the possibility of a cooperative effort to publish a pamphlet. We have received a positive initial response and will return to this cooperation after we have collected case descriptions for publication.

An important consideration for the group is the ethical considerations connected with this presentation and publication of case descriptions and anonymity arising in connection with

small professional environments, vulnerable and small groups of people with CHARGE, the sensitivity of the subject, and other considerations. One suggestion under discussion that would resolve these issues is the use of constructed cases based on several actual cases. We will also have to apply for approval from the relevant ethics committees in the respective countries, and this demands that we write a project plan that demonstrates how we will approach ethical challenges. In connection with this, letters of information and consent will be developed for the people with CHARGE themselves (in cases in which the person has the capacity for consent) or for the parents/guardians of the person with CHARGE to read and sign. The coordinator of the group has research training and experience and will write a draft of the project plan for distribution to the group and to the Leader Forum before application for ethical approval for the project.

The project has no fixed date for conclusion regarding the publication of a pamphlet, but results of work on the project in progress will be used as the base for a streamed course on the topic of self-regulation and related issues within psychosocial health and development of people with CHARGE planned for autumn, 2021.

The next meeting of the Nordic CHARGE Network, Tuesday, the 5th May - Wednesday 6th May (a video meeting hosted by Kirsten Costain, Statped)

In addition to the continues discussion of the case description project, the network members will discuss a related topic regarding CHARGE and sexuality with a presentation by Jessica Jagryd of her work in this area. We will also discuss 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-varprogram-for-charge-syndrom-2/>. In addition, the Educational Checklist, Hartshorne et al., will be discussed, 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).

Tasks: (the same as the previous year)

Plan for the future

We will continue our work on the video case project in 2020 – 2021.

We will make plans for a possible course on self-regulation and CHARGE based on the video case project (planned for autumn, 2021). We will continue to work with the topic of psychosocial development and CHARGE.

CHARGE booklet for new parents will be submitted to the National Centre of Expertise on deafblindness, Norway (NKDB).

We will maintain contact with the CHARGE Network of Deafblind International regarding publication of the video case project.

Kristen Costain, Statped, NO, April 2020