

Annual report from the Nordic CHARGE Network to the Nordic Leader Forum of Deafblindness, 2022

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Members:

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

Meetings:

10th September -11th September 2021 (a video meeting hosted by Frida Racksäter Nerback, Mo Gård, Sweden)

Due to the Covid-19 pandemic we could not travel to Sweden in the May as planned and chose to postpone until September. But still we could not travel and we met online again which worked out well.

The Network continued the work with our upcoming publication and looked at the template from NVC and decided that the different chapters will be maximum 10 pages long. The focus in the publication 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. Ásta presented her case for the coming book.

The template for the chapters works well we think and we sorted out the different chapters with a starting chapter with information on CHARGE and the ethical perspective of the publication, an ending chapter with a discussion of the content and finally a resource section.

The timeline for the publication is that all the drafts for chapters will be ready in May 2022, and the first draft of the content in the NVC template is made for November 2022 and we hope for publishing in spring 2023.

We had a visit from Emma Jensen who has CHARGE syndrome and she showed us a film she made for Dbi international CHARGE network and we had the possibility to ask her a lot of questions about what support she needs from the professionals in her life.

We also decided to invite Andrea Wanka from Dbi to an online meeting to share our networks thoughts on the R in CHARGE with her as they also have the same discussion in their group and with youngsters with CHARGE in Germany.

We will make a presentation of our network in Dbi Review in 2022. We will also take part in the NVC conference in Finland in September 2022 and use the free networking time, 45 minutes, to do a presentation. The content will be decided in Reykjavík in May.

Summary of our online meetings, 3 during 2021 and 1 in the spring of 2022

A lot of focus has of course been on the publication and we have met more often to keep the momentum. A couple of case presentations has been done and we discussed possible adaptations and support for the different cases.

Other topics has been CHARGE and CVI – a case presentation, CHARGE and Autism – discussion about getting both diagnosis is it common that individuals have both diagnoses or is it misconception of behaviour/symptoms? We also have the ongoing discussion about the R in CHARGE where we collaborate with Dbi Charge Network.

We also have shared news from the different counties where Denmark is active on a book about CHARGE and sexuality, Sweden with a webinar series about CHARGE to parents and professionals on 4 different subjects including a new presentation video from Specialpedagogiska skolmyndigheten, the story of being a parent, social and physical surrounding adaptations and finally about self-regulation and behaviours. Norway work with support to families and new information material and a translation of the educational checklist.

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 book.

Future plans

We will continue our work with the book based on cases in 2022-2023.

We will continue to meet online 3 times a year and for 2 days in may 2022 in Reykjavik, Iceland.

We will make plans for webinars based on the video case project and we hope that we can do this in connection to the release of the book in 2023.

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.

We will present our network and our work in Dbi review and on the NVC conference in Finland in September 2022.

/Frida Racksäter Nerback, Mo Gård, Sweden, April 2022.