

Annual report from the Nordic CHARGE network to the Nordic leadership forum of deafblindness 2019

Members

Monika Estenberger/ Sonja Friberg/ Frida Racksäter Nerback (Sweden)

Estella D. Björnsson (Iceland)

Annette Sølgaard / Jette Nørgaard (Denmark)

Mona Andreassen Hellebust/ Kirsten Costain (Norway)

The target of the Network is to collect, share and spread knowledge about CHARGE syndrome. The network members report on and disseminate results from projects, conferences and publications with relevance for the field from their respective countries. Distribution of knowledge from projects and other initiatives is through seminars, conference presentations and written reports/publications. An important aspect of the work of the network is discussion of video analysis of case examples in relation to themes with a general relevance for those working with individuals with CHARGE.

Web seminar arranged by NVC in cooperation with Statped Norway

On the 7th November 2018, the Nordic CHARGE network held a web seminar with 150 participants that was streamed to 4 countries. The topic was social-emotional development and the perspectives of children and young people with CHARGE. There were contributions from 9 presenters from across the deafblind and related fields. The participants were professionals with an interest in CHARGE and parents of children with CHARGE. The evaluation of the seminar was extremely positive with regard to the utility and significance of the presentations and discussions.

Meetings

We held a videoconference meeting on the 13th December 2018 during which we evaluated the video seminar held on the 7th November 2018. We prepared the topic of the next meeting, self-regulation and CHARGE and the booklet, *Self-regulation in individuals with CHARGE Syndrome*, (Hartshorne, & Nicholas, Deafblind International) was selected as the basis for the video analyses.

May 14th and 15th 2019 in Aalborg, Denmark.

The main annual network meeting is a working meeting over two days with an agreed agenda. Topics covered during these two days are news from each country and case presentations with video clips in relation to a selected topic. This time the focus was on self-

regulation and CHARGE. Inge Mogensen from CDH Denmark presented data from a continuing project on CHARGE and stress. Maria Baerentsen, Communication consultant participated on the afternoon of the first day and recorded notes for an article on the work of the group. From this year on, the group will record the video case discussions in reports after each meeting that will be published on the national websites and on the NVC website. These reports will form a basis for future discussions, seminar topics and conference presentations.

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.

Future plans:

- *We will be collaborating with Hans-Erik Frölander, Phd., Psychologist on an interview study with young adults with CHARGE with the theme of mentalization / theory of mind.
- *We will continue to encourage professionals in the field to conduct interviews with individuals with CHARGE with the long-term goal of developing educational tools to support social-emotional development in this group.
- *We will also have a focus on self-regulation in CHARGE Syndrome based on the model Timothy S. Hartshorne and Jude T. Nicholas have developed presented in the booklet: *Self-Regulation in Individuals with CHARGE Syndrome*.

Next meeting:

The network will have a video conference in November, the 26th. The focus will be on the strategies people with CHARGE use to self-regulate. The discussion will be based on new video case examples.

Our second meeting will be at Hovseter, Oslo, 5th – 6th may 2019. We will continue to discuss the topics of self-regulation and social-emotional development with the goal of writing reports for distribution to the field. We will also begin planning another streamed seminar on self-regulation to be held in 2021.

Tromsø, April 1th 2019

Mona Andreassen Hellebust