

Annual report from the Nordic network "CHARGE syndrome" to the Nordic leadership forum of deafblindness 2018

Members

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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

May 8th and 9th 2018 in Lund , Sweden.

The arrangements for the meetings is that the network meets for two days and work together, with an agreed agenda. Themes of this two days were news from each country, case with video clips, interviews with persons with CHARGE syndrome- How can we use their ideas to improve services?, Semi- Structured interviews with youths with CHARGE about psychosocial concerns and experience. We planned the webseminar at Statped Hovseter, Oslo in November 2018 presenting the work with interviewing youngsters witch is ongoing in each country.

Tasks of the network:

- * Continue our work of collect, share and spread knowledge of CHARGE syndrome.
- * Contribute at seminars, family gatherings and arrange courses.
- * Have focus on semi-structured, qualitative and interpretive interviews with older children, youth and young adults with CHARGE.
- * We will also have focus on Self-regulations in CHARGE Syndrom

Future plans:

* Our goal is to perform semi-structured, qualitative and interpretive interviews (using interview guides developed by the different local interviewers) that reflect the respondents' perspectives and cultural settings, etc.) With older children, youth and young adults with CHARGE. A qualitative analysis of this material will be conducted in the early part of 2018 and the results of this work will be presented at the planned Professional Day on CHARGE and psychosocial aspects under the direction of the CHARGE Nordic Network group in November 2018. Our aim is to explore the voices of the children and youths themselves in

relation to psychosocial aspects of living with CHARGE and having a CHARGE diagnosis, but mostly also being a young person with challenges related to the effects of the syndrome with relevance for psychosocial issues and development. We are concerned with developing knowledge both about *how to access* the voices, experiences, emotional life and ideas of this group and *knowledge of what these* experiences and ideas are. A more general, long-term goal is to develop a psycho-educative pedagogical complement aimed at helping this group to learn about and reflect over their own feelings and emotional lives, strengthen self-esteem and identity, and understand themselves and others in relationships, among other topics.

*We will also have focus on Self-regulations in CHARGE Syndrom and based on the model Timothy S. Hartshorne and Jude T. Nicholas has developed. The model is written in The book "Self-Regulation in Individuals with CHARGE Syndrom" .

Next meeting:

- December 2018 on skype.
- 15 to 16 May 2019 Aalborg, Denmark. Nordic meeting.
- 7 November 2018, Oslo, Norway. Professional Day.

Tromsø, May 11th 2018

Mona Andreassen Hellebust