Annual report from the Nordic network ”CHARGE syndrome” to the Nordic leadarship forum of deafblindness 2017

**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 3th and 4th 2017 in Tromsø, Norway.

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, an outline of the lecture that will be given at the preconference in Aalborg and future goals of the network 2018.

**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.

**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 å 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.

\* Lecture at the European Conference in September 2017.

\* Writing a description of the network on NVC's website.

**Next meeting:**

- 9 January on skype.
- 8 to 9 May 2018 Lund, Sweden. Nordic meeting.

- October or November 2018, Oslo, Norway. Professional Day.

 Tromsø, may 23th 2017

Mona Andreassen Hellebust