

<p>Network Name: The Nordic Network of CHARGE Syndrome 2017</p>
<p>Contact Person: Mona Andreassen Hellebust, Regionsentret for dövblinde, UNN, Tromsø, Norway</p>
<p>Other People involved: Monika Estenberger, Nationellt Kunskapscenter för dövblindfrågor, Sweden Sonja Friberg, Specialpedagogiska Skolmyndigheten, Resurscenter Dövblind, Sweden Lynn Skei, Signo, Norway Anette Sølgaard, Center för Dövblindhed och Høretab, Denmark Jette Nørgaard, Region Nordjylland, Denmark Päivi Vataja, The Finnish Federation of Hard of Hearing, Finland Estella D Björnsson, National Institute for the Blind, Visually Impaired, and Deafblind, Iceland Brynja Brynleifsdóttir, Midstod, Iceland</p>
<p>Address of contact person: Regionsenteret for dövblinde, UNN Postboks 88 9038 Tromsø, Norway</p>
<p>Phone number of contact person: +47 777 55830/91566399</p>
<p>Email of contact person: Mona.andreassen.hellebust@unn.no</p>
<p>Name of deputy contact person: Sonja Friberg</p>
<p>Address of deputy contact person: Sonja.friberg@spsm.se Specialpedagogiska Skolmyndigheten Box 12161, 10226 Stockholm Sweden</p>
<p>Phone number of deputy contact person: +46 (0)10 4735459</p>
<p>Describe the purpose of the project/ network 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.</p>

<p>Why do you feel this network needs to be formed? There is limited knowledge about CHARGE syndrome in all kinds of professional environments and therefore also for parents. It affects the persons with CHARGE syndrome very much. By focusing on educational – psychologically consequences and behavioural aspects in CHARGE syndrome the participants of the network have increased their knowledge and understanding regarding CHARGE syndrome. The possibility of meeting people across the Nordic borders has</p>
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this fare made a big difference. We have shared experiences and encouraged each other in forming national networks, projects, and different ways to implement the knowledge in daily practice.

What is the relevance to the Nordic countries?

Each year there is a meeting, alternating in the different countries. In the meeting the participants agree on a topic, such as pain, communication or interview guide, to focus on in the coming year and at the next meeting two or three case presentations are given considering the topic of the year. If possible there is an expert invited to have a lecture regarding CHARGE syndrome during the meeting. The time in between the meetings the members have contact by mail, video conference and share knowledge and also use each other for consultation. The network is useful for the professionals in their daily work.

How do you intend to work to answer on this?

Keep on as planned.

What activities do you plan to organize as a network? Have you undertaken any activities already?

The network is contributing to the pre-conference in Aalborg with a presentation from Denmark. We will have our yearly meeting, next year in Sweden. We will have a video conference meeting in January 2018. We are planning a webseminar from Statped Hovseter, Oslo in November 2018 presenting the work with interviewing youngsters witch is ongoing in each country.

2006 and 2010 the network has contributed and participated in big family meetings. Members of the network also attend meetings with the international network of CHARGE (DbI) when possible.

What materials and documents do you plan to produce? Have you produced any yet?

We are planning to write an article about our experiences with interviewing youngsters who have Charge syndrome.

How will you plan to finance your activities and publications?

The different resource centres/institutions are paying for travel and living costs for their employees participating in the network meetings.

How will people become members of your group?

In each country there is a national working group/network choosing 1 – 2 contact persons attending the Nordic network for CHARGE syndrome.

How do you plan for members to communicate with their national colleagues?

There are national networks in each of the Nordic countries.

How do you plan to communicate with NVC?

We send a summary to Nordic leadership forum every year and a more detailed summary is presented in the website of NVC.

New knowledge are spread in the different countries by the national networks to parents and professionals through courses and consultations in local networks, pamphlets etc. It is an ongoing process.

How will you set up a way for members to communicate with each other?
We use e-mail and video conferences

When will this project/ network start and when will it end?
It started in 2002.

When will you evaluate?
We evaluate the need for and outcome of this network at our Nordic annual meeting.

How much time do you expect every member to use in this project/ network?
There are two days of meeting in the Nordic network, the host country have preparations and after the meeting there will be written a report. In addition the members are using some time in the national working groups/networks to prepare case presentations and discuss different topics regarding CHARGE syndrome.

How will you collaborate with international networks about the same subject?
We meet at conferences and share knowledge and information.