

# Nordic Meeting for spina bifida and hydrocephalus 2021

*13-14 of March 2021*

Due to the Covid 19 restrictions, we had this year's Nordic meeting digitally on Teams.

## **Participants**

**Hans Christian Norseth**, Norway, VP of the Norwegian association for SB&H, has spina bifida himself

**Heidi Anita Rahm**, Norway, Chair woman of the Norwegian association for SB&H, has spina bifida herself

**Ida Rönnblad**, Sweden, board member of Spin-Off, has spina bifida herself and a son with SB

**Kirsa Segerhard**, Denmark, representative of the Danish association for SB&H, mother of two children with spina bifida

**Ammi Andersson**, Sweden, has a daughter with SB, member of RBU Sweden, and active in ERN Europe

**Elisa Ósk**, Iceland, has a daughter of 2 with SB

**Gerda Lindholm**, Sweden, member of RBU Stockholm, mother of daughter with SB&H

## **Iceland - an introduction**

This is the first time we have a representative from Iceland participating! A big, warm welcome to Elisa Ósk!

The Icelandic members don't want to start their own association, because they are so few and now they are members of the rare diagnoses association in Iceland.

There are currently 9 children under the age of 19 in Iceland. 40-50 with spina bifida total in the whole of Iceland. There is no SB medical team in the hospitals. A regular children's surgeon closed the spine on Elisa's daughter after she was born and she has heard of children who have had their shunts put in by regular children's surgeons as well. Doctors in Iceland don't know how to care for children with SB.

There are two main hospitals in Iceland and one of them houses the children's hospital - Barnaspítali Hringinsins.

<https://www.landspitali.is/>

Elisa's daughter has had 18 urinary tract infections since August and she is worried about her daughter's kidneys. Her bladder is overactive, cramping. They are doing a reflux check and isotope investigation. Her daughter is in much pain from not getting all the poo out of her intestines. From her description we all agree she needs professional help to have a proper irrigation plan.

We discuss the possibilities of contacting specialists in other countries. Hans Christian has already sent some information to Elisa.

### **Kidney examination:**

Heidi informs us that to get a right answer about the kidney function from a blood test of someone with a lot of paralysis in the body, you have to check the **Systein C** (in Swedish Cystain C), not the usual Kreatinin – Kreatinin could show the wrong answer for a person with spina bifida.

## **How do we connect in the future?**

We decide to start a What's App-group for the Nordic countries, for more direct interaction, and close the Facebook-group we started last time, since it is harder to notice when something is updated there. Ammi starts the new What's App-group and Gerda discontinues the Facebook-group.

## **What we have been up to in 2020?**

**Spin-Off (Sweden)** has hosted some webinars that have been popular, so they will arrange more.

**Denmark** has had many hard lock downs due to covid and has had to cancel their summer camp.

**Norway** has cancelled the youth camps in 2020, and even the youth camp for 2021. They have digital meetings with specific topics, which is very useful because everyone in the country can join.

People with spina bifida often don't get the right treatment by their local doctors and the Norwegian association puts a lot of focus on this question, how to educate local doctors.

Hans-Christian has done a lot of work with folic acid.

Norway has had lots of digital meetings with the local districts of the association.

There is a new name of the organization - RH-forening to include "hydrocephalus" (R for ryggmarksbrokk and H for hydrocefalus) and a new homepage, [rh-foreningen.no](http://rh-foreningen.no)

They had several meetings with the Rare diagnosis association about what SB is, what to take action on and what challenges people with SB face. This will, among other things, be a valuable tool for getting funds for research in the future.

Norway has had a project with Bulgaria to educate them about the transition phase, assisting adolescents in the process towards becoming independent adults.

**Iceland** The rehabilitation center had a summer camp for children with different diagnoses, where they had training, tips and social get-togethers.

**RBU** (Sweden) has cancelled social meetings for 2020 and board meetings have been done digitally.

## **Shunts**

We discuss our experiences of shunts, hydrocephalus and the ETV surgery.

Nowadays, if you wait and see, only 40-50 % of children with SB will need a shunt. Earlier 80-90 % of children had a shunt very early for precaution, but now more and more of the doctors wait.

Elisa tells us that in Iceland, the regular children's surgeons perform the shunt surgeries, which has led to maltreatments.

## **Information to expecting parents**

We talk about what information you are given as a parent who is expecting a child with spina bifida and hydrocephalus. In every country we have the same experiences, that the doctors inform parents of all the worst case scenarios of medical complications that may occur. Many parents feel pressed to terminate the pregnancy, for various reasons. It is a very hard decision to make.

We discuss the opportunity in society for assistance and what you get to read in the media about how people with disabilities are treated and what assistance they receive or don't receive. This makes it an even harder decision to keep a baby with a disability for the expecting parents.

### **Initiative to spread our own information**

We discuss if we could make an initiative to inform expecting parents with positive examples and showing real people who actually live with spina bifida. To be a kind of counterweight to the health care point of view and give expecting parents a broader picture of the reality of living with spina bifida.

One suggestion to get positive examples out there, is to be more open on facebook and Instagram – if you make a post, tag it with #spinabifida, so that people get to see more real people and how their actual lives are, when they search the internet and social media for spina bifida.

### **Putting the information together**

If we put some inspirational/educational material together, should we produce our own material or collect material that is already out there? There is much information already produced and many social media accounts talking about spina bifida - maybe we should focus on collecting existing material and "packaging" it?

### **Getting the information out**

How do we reach the expecting parents? Do we make booklets or do we make the information available online? Perhaps both should be the focus.

A problem for all our organizations is that we don't get high up on google search, so we have to work on this.

We discuss when we can reach expectant parents – when they make the first ultrasound – is it week 12 or 18-20? Is it at the major hospitals? Should we distribute our booklets only to the major hospitals. If you find out in a minor/local hospital, you are probably referred to a bigger hospital.

We have some discussions about fetal surgery and how effective they are. Should we include information about that or is it hard enough to make a decision as a parent anyway? Maybe that is too much information.

### **What should it contain?**

We should add information about rights for parents and children after the child is born – general

human rights, rights of persons with disabilities and rights in the various countries and inspirational stories that tells stories without pretending that there are no challenges.

### ***Action/conclusion:***

- We decide to go forward with this initiative to create a collection of information for expectant parents. The information should consist both of “hard facts” about the diagnosis and also inspirational stories about actual living with spina bifida, from a parent’s perspective as well as the perspective of a person living with spina bifida.
- The goal is have both a booklet and one also have information available online.
- We want to make a working group within the Nordic community to work with this.
- We will start with a version in English first, then translate in the Nordic languages, if we have enough money.
- Hans-Christian and Heidi will book a follow-up meeting after the summer.
- Hans-Christian and Heidi will set up a document where we can add examples we find. Perhaps create a group in Teams where we have documents for this that everyone has access to.

**Homework for everyone:** Collect inspirational stories from the internet and Social Media. Eurordis may have some stories, Ammi will check.

### **ERN - ITHACA**

Ammi Sundqvist holds a presentation about ERN ITHACA and the working group for Spina Bifida (see separate power point in Teams group)

### **Covid 19 experiences**

What have we heard from our members on this topic? Has there been any big problems for our members?

**Norway:** Many have complained about lacking physiotherapy, difficulties to receive doctor’s appointments and treatments. Harder to have regular personal assistants, due to quarantine restrictions (they must stay at home if there are any signs of a cold, e g). Many are lonely and show signs of depression.

TSN (Norwegian competence center) says that the only link between SB and being in a risk group if you have acquired some kidney problem.

**Iceland:** It takes longer time to get supplies like shoes and continence materials. Hard for parents of children who have surgeries, when you can only be one parent accompanying in the hospital.

**Sweden:** Same as Norway, also people who have assistance in their homes are afraid the assistants could bring covid into their homes.

**Denmark:** All education is from home, which is especially hard if you are beginning a new school or need assistance in school.

The main issue for most people with SB in all of our countries in regard to covid seems to be problems with loneliness.

## **Ageing with spina bifida and hydrocephalus**

There has been a lot of research done lately on people 50+ with spina bifida. Both in Europe (IF), Norway, Sweden and in the US.

One of the conclusions is that there is a new “survivor group” of people with spina bifida. People with spina bifida who are 50+ are usually “high functional”, both physically and cognitively. Earlier, more “vulnerable” people usually didn’t survive into adulthood. But now there are some new generations reaching adulthood and many of them have more severe medical and cognitive challenges than the people who are 50+.

We see a clear need for something like a “life coach” that aids the person with keeping check on health status, doctor’s appointments, job applications, social support applications and so forth.

Perhaps this could be a topic for a future Nordic meeting?

### **IF study:**

<https://www.ifglobal.org/our-work/working-group-on-ageing-with-sbh/>

**Swedish study** performed by Hanna Gabrielsson:

[https://oru.diva-portal.org/smash/record.jsf?aq2=%5B%5B%5D%5D&c=8&af=%5B%5D&searchType=SIMPLE&sortOrder2=title\\_sort\\_asc&query=Gabrielsson&language=sv&pid=diva2%3A1474392&aq=%5B%5B%5D%5D&sf=all&age=%5B%5D&sortOrder=author\\_sort\\_asc&onlyFullText=false&noOfRows=50&dswid=1998](https://oru.diva-portal.org/smash/record.jsf?aq2=%5B%5B%5D%5D&c=8&af=%5B%5D&searchType=SIMPLE&sortOrder2=title_sort_asc&query=Gabrielsson&language=sv&pid=diva2%3A1474392&aq=%5B%5B%5D%5D&sf=all&age=%5B%5D&sortOrder=author_sort_asc&onlyFullText=false&noOfRows=50&dswid=1998)

Norwegian study of gait in older people with SB:

<https://www.sciencedirect.com/science/article/pii/S0003999320312168>

Norwegian competence center for rare diagnoses:

<https://www.sunnaas.no/fag-og-forskning/kompetansesentre-og-tjenester/trs-kompetansesenter-for-sjeldne-diagnoser/sjeldne-diagnoser/ryggmargsbrokk>

Norwegian competence center for rare diagnoses:

<https://www.sunnaas.no/seksjon/trs>

## **Digital meeting, our experiences so far**

Everyone agree that this form of meeting is the second best option for the Nordic meeting, when we can’t meet in person. Next year we all want to meet in person again, but until then it is also good that everyone has experience of digital meetings and knows how to use these digital tools. It also gives us the opportunity for shorter follow-up-meetings (also in smaller working groups) to collaborate on initiatives we want to work on. This has been a challenge earlier, when we only met once a year. We see opportunities for new ways to work together more efficiently!

### **Next Nordic meeting**

The next Nordic meeting should take place spring-summer of 2022. We all want to go to Iceland! And Elisa has gracefully volunteered to host it.

We inform Elisa that we apply for the funds for the meeting from Nordens Välfärdscenter. We are all happy to assist in the application process.

<https://nordicwelfare.org/en/disability-issues/the-funding-scheme/>