

**Minutes from the board meeting, Monday 31 October 2011 9.00 -11.30
at The House of Science and Letters in Helsinki**

Present: Göran Elinder
Firouz Gaini
Ásgeir Haraldsson
Gunhild Isfeldt
Thomas Jensen
Lotta Knutsson Bråkenhielm, *secretary*
Titti Mattsson
Salvör Nordal
Janne Rothmar Herrmann
Sirpa Soini
Aaro Tupasela, *chair*

Not present: Grethe Foss
Anne Myhr

1. Opening of the meeting

The Chair opened the meeting.

**2. Approval of agenda and of minutes from the Committee meeting on
the 29th of August**

There had been the opportunity to send in comments in advance and this will also be possible a short period after the meeting. After that the minutes will be sent to all members for final approval before publishing it on the web and sending it to other partners.

Miscellanea were added to the agenda.

3. Conference on *Mental Health*

There was a brief run-through before the conference.

4. Conference on “*Mammals*”

Gunhild Isfeldt presented ideas, suggestions and a preliminary programme that the organising committee had worked with. The following decisions and comments were made:

- A specific focus is important to attract people and to draw attention.
- The focus on this conference will be “whales”, and the organisers shall come up with a “catchy” title as soon as possible.
- As soon as more details are decided a “flyer” will be put on the web site.
- The specified focus will not exclude the speakers to widen the topic.

- Vilhjálmur Árnasson will continue to work with the organising committee and he is not claiming any fee for that. He will be invited as speaker and/or to chair a session.
- Maybe we will have a follow-up meeting in Copenhagen a week after the conference with invited politicians and other relevant decision makers.
- The committee has contacted the proposed venue (The Hall at the Nordic House in Torshavn). Firouz Gaini will visit them and explain our purpose further.¹
- The organising committee will probably work together with other partners, who must be included in the working group and be given the opportunity to influence the agenda. (Working group so far includes Gunhild Isfeldt, Firouz Gaini, Aaro Tupasela, Anne Myhr, Asgeir Haraldsson and Vilhjálmur Árnasson.)

5. Conference on “Child Issues”

Titti Mattsson presented her ideas for the conference. She is in charge and will work together with Göran Elinder, Janne Rothmar Herrmann, Grethe Foss, Asgeir Haraldsson and Sirpa Soini. The following decisions and comments were made:

- The conference will take place in Lund in October 2012: on the 11th-12th or 4th-5th.
- Titti Mattsson will contact the Swedish Barnombudsmannen.
- The organising committee will contact the Nordic Council group for clinical trials.
- Different angels on the topic are discussed in all Nordic countries so the theme is most relevant.
- Since the topic is of important concern the possible impact/outcome must be stressed. One possible outcome could be a recommendation for every country to initiate a Barnombudsman (or similar).
- The topic could be a starting point that could be developed in other events and activities related to “children – health – ethics”.
- If possible we will organise a press conference in relation to the conference.

6. Continued collaboration with other Nordic committees

Lotta Knutsson Bråkenhielm has asked the Nordic bioethical (or similar) committees if they are interested in continued collaboration. There seems to be a certain interest in collaboration on specific themes. “Child Issues” could be such a suitable theme. Aaro Tupasela will draft a letter to the committees on the issue.

7. Dissemination of our material, webpage, Newsletter?

We will continue the discussion on how to do this and also how to strengthen the secretariat in general.

¹ After the meeting the contact person at Nordic House has given a positive response, but not for the suggested dates.

8. Economy

Lotta Knutsson Bråkenhielm gave a brief report. There seems to be less money left than expected.²

9. Other plans

- The European Medicines Agency (EMA) has sent an invitation to the committee for its members to attend a meeting it is holding in London in early December 2011. The topic of the meeting is 'Ethical consideration in paediatric trials.' The committee asked its members if there was interest to participate. Committee members Asgeir Haraldsson and Göran Elinder have indicated an interest to participate. Members will also try and develop links in relation to our up-coming meeting next year in Lund on 'The rights and protection of children'
- NCBio received an unofficial invitation from the Finnish Association of Science Editors to organize one or two sessions at the up-coming World Congress of Science Editors that is to be held in Helsinki in June 2013. The committee has tentatively agreed to help organize and partly fund such a cooperative effort. Further planning will take place during 2012.

10. Miscellanea

- Thomas Jensen, a long time member of NCBio will be leaving the committee as his second term is coming to an end at the end of 2011. The committee wished to express its deep gratitude for his excellent work during the past six years and hopes that it will be able to use his expertise in the future as well.
- Sirpa Soini reported on her travel to the Third European Conference on Health Law which she attended in Leuven 6-7.10.2011 (see appendix for her report) ???

11. Country reports

There had been the opportunity to send in comments in advance and this will also be possible a short period after the meeting.

Denmark:

- Use of stem cells from Ukraine in the treatment of muscular dystrophy.
- Case of young transgender patient.

² After the meeting it was discovered that Nordic Council of Ministers so far has paid approx 30 000 less than what was budgeted for which fits well for the sum that was "missing". These sum will be transferred.

Faroe Islands:

- The issue of whole genome sequencing has been discussed with 100 Faroese having being sequenced thus far. The discussion is currently on whether the whole population will/should be sequenced.
- The prohibition of Puffin hunting has also been an issue since in some areas the Puffin population has been decreasing.

Finland:

- Biobanks. Finland does not have a specific law on biobanking. After many years of waiting and revisions the proposal for the law on biobanking has been sent to the Parliament and is being discussed during week 43.
- Surrogacy. Surrogacy is currently illegal in Finland, but the Ministry of Justice has asked the National Advisory Board on Social Welfare and Health Care Ethics (ETENE) to write a comment on the ethical issues related to surrogacy. The Ministry is therefore taking a closer look at this law and whether there is reason to change it.

Iceland:

- The issue of surrogacy and whether it should be allowed in some form is being discussed in the Parliament.
- The issue of cutting the costs is being discussed in health care.
- The misuse of ADHD drugs has been in the news.
- A discussion of the environmental impact of geothermal power plants has been debated.

Norway:

Benefits and risks of GMOs in food/feed production and in aquaculture have been debated in several newspapers. The Ministry of Environment has announced that a political decision soon will be made on two marketing applications of GM plants in Norway, which if approved will be the first GM plants intended for food and feed production in Norway.

Sweden:

- The paediatrician that was accused of killing an infant was acquitted of all charges.
- Compulsory care for drug abusers is being discussed

12. Next meeting (and plans for next year)

January 10 2012, business meeting in Copenhagen

Working dinner Sunday 30 October, 18.00-21.00 at Brasserie Kämp

Present: all except Anne Myhr, Grethe Foss and Firouz Gaini

13. Report from the meeting in Copenhagen 17 October

Aaro Tupasela gave a short presentation of the meeting with Helene Norberg at Nordic Council of Ministers with the purpose of discussing the development for the work and mandate of the committee.

14. Discussion on mission and tasks

Aaro Tupasela presented a draft for mission and tasks based on the discussion at the meeting. This document will be sent out as a working material to all members. Before the 15th of November the elaborated document will be presented for NCM.

Djursholm 2011-12-01

Lotta Knutsson Bråkenhielm