

Minutes from the board meeting on the 29th of August 2011 at Hotel Admiral in Copenhagen

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

Not present: Thomas Jensen
Anne Myhr

1. Opening of the meeting

The Chair opened the meeting.

2. Approval of agenda and of minutes from the board meeting on 3rd of May

The agenda and the minutes were approved with some revisions.

The following decisions were made:

- The revised version shall be sent to the other secretaries in the Nordic bioethical committees.
- The minutes shall not be sent to persons outside the committee until they have been approved.
- From now on (2011) all minutes will be published on our web site. Chair and secretary will go through the minutes for improvements; e.g. the points under “Country reports” must be more clearly elaborate.

3. Debriefing of the evaluation process

The ongoing evaluation process will be finished with a report to Nordic Council of Ministers around September 1, where after we will receive a copy. So far the process is proceeding well, and all interviewed committee members felt comfortable answering the questions, questions that are very useful in our work.

The following comments/decisions were made:

- We should start to discuss our tasks and the working processes of the committee
- We will engage a consultant to help us with a SWOT analysis.

- We must improve our possibilities to be more “visible”, to disseminate information and do PR about our events and to learn more about media strategies.
- We could contact a science communicator for this purpose

4. Debriefing and summary on *Biobanks*

We have received many positive responses after the conference. There has also been at least one article published on the event; the meeting decided that we should try to link this article to our web page.

Göran presented a draft for a summary that he will continue to work on, together with Aaro,

5. English summary *Prenatal Diagnosis*

Grethe presented a draft for a summary. All comments will be sent to her by the members.

6. Summary and Publication on *Public Health*

Those who want more copies of the report will contact Lotta.

7. Conference on *Mental Health*

Gunhild presented the programme draft, and names were discussed. So far nine speakers have agreed to participate, we expect answers from four persons, and we still lack approximately five. Names were suggested and discussed. All members will try to come up with names and inform the organising committee. Lotta will contact the speakers conc. practical matters.

Chairs: I. Aaro, II. Gunhild, III. Sirpa, IV: Göran, V. ?

We will invite four guests from each country at the expense of the committee; they will also be invited to the conference dinner.

We decided to try a new form of conference documentation (besides putting presentations on the web page): to engage a science communicator to “cover” the conference and produce a publication with a photographer. Lotta will contact Lotta Eriksson at SMER for advice.

8. Conference on “*Mammals*”

The conference on “Marine Mammals” was discussed. Among other things the focus: marine mammals or wild animals in general; (e.g. there are similarities between the Swedish and Norwegian debate about wolfs and the debate in The Faroe Islands about whales).

A draft letter to three other committees in the Nordic Council was discussed. Gunhild will send this letter to see if there is interest concerning cooperation.

There are many interesting ethical questions on either topic, of which some were discussed at the meeting. The organising committee is applying for cofinancing, but it was the opinion of the meeting that this is not necessary (even if welcomed).

Organising committee is Gunhild and Firouz (in charge) together with Anne, Aaro and Asgeir. The former member Vilhjálmur is also part of the group; Salvör and Asgeir will contact him conc. fee arrangement.

Suggested time schedule, 2012:

- Sunday May 20: committee arrives
- Monday May 21: board meeting; conference participants arrive
- Tuesday May 22: conference full day
- Wednesday May 23: conference half day; departure
- N.B. there are three daily flights from Copenhagen

9. Clinical Trial/Kliniska multicenterstudier

Nordic Council of Ministers has given us the opportunity to, before October 1, make comments on the current project on a Nordic coordination of clinical research: “Nordiskt samarbete om kliniska multicenterstudier”. Aaro will make a draft on this and send to the committee for comments.

10. Continued collaboration with other Nordic committees

The meeting discussed the possibility of having a satellite meeting in connection to the “Mammals” conference on Faroe Island with representatives from the Nordic bioethical committees, or having a separate meeting in Copenhagen in March. We will investigate the interest of having such a meeting.

11. Dissemination of our material, webpage

At the moment the following materials are available: a small folder about the committee, summaries on Medical Tourism, Genetic Self Testing and Public Health. Some copies have been sent to TSV in Helsinki, and we will investigate again of the possibility on having them exposed at “Norden” in Copenhagen.

We will also have a separate headline on the webpage were members could put reports on current issues with relevant links.

12. Economy

At the moment there is approximately 83 000 € on our account. Lotta will investigate the possibility to transfer a surplus to next year. The committee needs to take into account the added costs that will be incurred related to the development process of the committee as suggested by the evaluation report, e.g. by engaging consultants. Cfr. issue 3.

13. Other plans

We decided to start making plans for a conference on “child issues” to take place in Lund (probably at the university) during fall 2012. Organising committee: Titti (in charge), Janne, Göran, Grethe and Asgeir.

14. Miscellanea

- Sirpa has written an article about the committee to be published in a report on Health Law (editor: Elisabeth Rynning). We will try to get permission to put the article, full text or abstract, on our web page.
- Aaro has an invitation to a conference on ethics and stem cell research, which will take place in Geneva, Switzerland December 1-2. The meeting decided that he should attend the conference at our expense. He will write a report on the meeting.

15. Country reports

Denmark

- There are private stem cell banks that offer their services in an “aggressive” way, which has caused attention in media.
- There is a new law coming, e.g. on the possibilities of doing research on unconscious people.
- There has been put attention to cases of severe child abuse and why nothing has been done to detect these.

Faroe Islands

- Sea Shepard was in the Faroe Islands with two boats this summer trying to prevent pilot whale hunting. But there were no pilot whales in the islands at that period. Despite this fact Sea Shepard wrote on their home page that they prevented whale killing in the Faroe Islands this summer.

Finland

- There is a discussion on whether the costs for narcolepsy should be paid by the government.
- The biobank act that has been discussed in parliament is being reviewed. Researchers hope that the new government will give a proposal for a biobank act soon; last proposal lapsed in spring 2011.
- There has been attention on serious criminals that relapsed into criminality shortly after being released, as well as those who have left of their own volition in so-called ‘open’ rehabilitation programs.
- Most private health insurers will not offer any health insurance if one has a history of depression or mental disorder.

Iceland

- There is an ongoing debate on surrogacy, but no decision in parliament yet.
- The continuing cuts in the health care systems cause debate.

- There is a discussion on the environmental consequences of constructing more power plants, both for hydroelectric power as well as geothermal power.

Norway

- The debate on how to handle surrogacy is ongoing. In some cases, children of gay couples have been registered in Norway with two male parents, which is not according to the Norwegian law. These families may now have to go through an adoption procedure.
- The newborn screening programme, which was to be expanded from July, is postponed due to the debate on whether these blood samples should be used for biobank research and under which conditions.
- The debate on the newborn screening programme has revealed that the opt-out system for biobank research on biospecimens without consent is not well known and hence not working according to the health research act.
- There is a new health care law from January 2012, which has more emphasis on preventive health.

Sweden

- There are public discussions and media attention after the massacre at Utøya.
- There are also discussions on ethical matters in connection to the military involvement in Libya and on the “Murdoch affair” in UK.
- Attention has been put on child poverty.
- Sweden have been criticized for putting “children”, i.e. 15-17 years old, in custody; there are app. 200 cases per year.
- There is a new “patient safety law” from January 1 which makes it easier for patients to report maltreatment.

16. Next meetings

- A Working dinner Sunday October 30, 18-21, and a morning meeting Monday October 31, 9-11 (?) in Helsinki
- Board meeting January 10 2012 in Copenhagen
- A two days strategy meeting in February
- (Maybe) a meeting with Nordic bioethical committees in March
- Board meeting May 21 in Faroe Islands

2011-09-16

Lotta Knutsson Bråkenhielm, secretary