

Minutes from the board meeting Tuesday 22 March 2011 at Nordatlantens Brygge in Copenhagen

Present: Göran Elinder
Lotta Knutsson Bråkenhielm, *secretary*, from 11.30¹
Grethe Foss
Firouz Gaini
Ásgeir Haraldsson
Gunhild Isfeldt
Thomas Jensen
Titti Mattsson
Anne Myhr
Salvör Nordal
Janne Rothmar Herrmann
Sirpa Soini
Aaro Tupasela, *chair*

1. Opening of the meeting

The chair opened the meeting.

2. Approval of agenda and of minutes from the Committee meeting on the 4th of February

Miscellaneous was added to the agenda after country reports.

Minutes, corrections:

Country reports, Faroe Islands: The mentioned condition is not just a Faroese disease, but accumulated there. Registered partnerships are **not** allowed.

3. Joint meeting with Nordic bioethics committees - debriefing

- Good beginning and collection of ideas. Next meetings should be concrete and much more focused, possible pairing between committees. We need to define our role in this process.
- Possible topics for cooperation: arrange joint meetings in conferences (e.g. breakout workshops), such as biobanks, prioritization in healthcare, alternative medicine, new tech hype, research on children and personal integrity, public trust in science.
- Concrete actions based on meeting:
 1. Update the document on bioethics committee (1999)
 2. Make a participant list and mailing list
 3. Produce official statements on some topics: e.g. biobanks, bringing out the pros and cons, different views
 4. Draft a report based on the meeting to be published (Aaro)

¹ The minutes are partly based on notes made by Aaro.

4. Conference on *Biobanks*

Chairs for sessions: Göran (Biobanking today), Janne (Biobanking and legislation), Asgeir (Autonomy), Anne (Trust and privacy), Gunhild (Individual rights), Grethe (Biobanks and the future).

Speakers for Individual rights session: John Harris, Heidi Torstensen, Veikko Launis, Helena Siipi. (Göran will contact them in that order.)

Enquire about interest to organize a biobank workshop in the fall from other committees.

5. *Public Health: Summary and Publication*

Deadline for submitting manuscripts for the report is extended until mid-April. Planned publication: May.

Sirpa will draft a summary and send to the committee for comments.

6. *Prenatal Diagnosis: Summary and Documentation*

Grethe presented a summary in Norwegian that is going to be published on Bioteknologinemndas web page. She will also write an English version and send it to the committee for comments. Sirpa promised to write a very short legal summary.

7. Conference on *Mental Health*

An updated programme was presented by Aaro. The content was discussed and suggestions for speakers were made. The importance of focusing on and clarifying the ethical issues and dilemmas, was stressed.

8. Conference on “*Mammals*”

Gunhild presented the ideas behind the programme, possible speakers and some topics. The meeting also discussed possible locations.

9. Other plans

- Issues with children (research and clinical trials, individual rights, compulsory care, well being), fall 2012?
- Vaccination (and screening?)
- Trust in science and science ethics; fraud possible topic for joint meeting with ethics committees

10. Information material

The meeting discussed the four versions available of the Leaflet presenting the Committee. The text is ok, but need smaller changes. Picture suggestions: Molecules that are real, glacier, child in tunnel, field of something (wheat), pipette. Lotta continues the collaboration with Publication at Nordic Council.

11. Country reports

Denmark

- Sperm donation: there is a debate on a proposed legislation that will make it possible for doners to choose whether you are anonymous or non-anonymous
- Abortion: there is a debate on what should happen with the foetus once aborted, e.g. if there should be a funeral; hospitals handle it in different ways.
- Genetic self-testing debate, Genome Denmark (100 mil dkk) in coop with Beijing, 250 Danes are being sequenced, leading to discussions on biobanks and informed consent.
- Fierce debate on scientific integrity following the unravel of a case of fraud and scientific dishonesty.

Faroe Islands

- Sea Shepards and other organizations have announced that they will come there to protest against whale hunting.

Finland

- Biobank Bill relapsed due expiration of the Parliament's mandate. There will be elections on April 17, after which is expected that the new government will present the Bill to the New Parliament.
- The register for healthcare personnel still contains names of people who have been convicted of crimes and should, therefore, not be listed in the register.
- Public response to adoption of new 95 E10-biofuel has not been as successful as hoped because people have concerns over how well it works in their cars.
- Nuclear energy: there is a debate after what's happened in Japan (an earthquake causing damages on a nuclear power station) recently.

Iceland

- Surrogacy has been publicly discussed and now there is a proposal at the Parliament to compose a bill to allow it. The idea is legalize full surrogacy, for altruistic reasons.
- GM plants: Orf (private company) growing GM corn for pharma purposes.

Norway

- There is a debate about ultrasound and Down syndrome.
- Surrogacy debate has started, e.g. about "old" peoples "right" to have children .
- There is a debate on gene doping and enhancement (endurance and speed).
- There is an evaluation of biotech law.
- Lack of sperm donation is a problem payed attention to.
- There is a discussion on genetic self-testing and the whole genome sequencing.

- There is a "healthism" (healthy eating) trend and campaign ongoing.

Sweden

- There is a debate on the inequalities on access to health in breast cancer.
- There has been cases of over medication in elderly care.
- Investigation in youth care: people that have been mistreated during compulsory care claim an official excuse from authorities and 250 000 sek.
- New legislation for biobank is open for comments, could start in Jan 2012.

12. Miscellaneous

Sirpa informed the meeting that the work with setting up the archive for NCBio documents now is completed. The minutes since 2000 are stored in the Finnish National Archives. There are also most of the publications even from the early days at the end of 1980s. Sirpa is writing a paper on the Committee to an anthology of the Nordic Network on Research in Biomedical Law. Documents of the early days may be scattered around different countries as there were many secretaries. In the future all material shall be submitted to the archives after three years (a full mandate). Lotta shall contact Helena von Troil and ask if she knows where the documents before her time might be. Minutes and other documentation between 1992 and 1998 would be interesting, and in particular documents relating to the establishment of the current committee in 1996.

13. Next meetings

- May 3, 2011 at 9-13, in Uppsala
- August 29, 2011 in Copenhagen or Faroe Islands
- October 31, 2011 morning, in Helsinki

Stockholm, 2011-04-04

Lotta Knutsson Bråkenhielm, secretary