

Nordic Transplant Committee

/ Nordic Transplant Committee / Minutes meeting No. 19 Sept 30, 2014 Stockholm

Oct. 3, 2014

MINUTES OF MEETING

Meeting No: 19th meeting in the Nordic Transplant Committee

Time: Tuesday, Sept. 30, 2014 at 12:00-16:00

Meeting place: Nordic C hotel, Vasaplan 4, Stockholm

Meeting participants:

National Health Authority representatives:

Norway: **Sverre Harbo, Eldrid Byberg**, Norwegian Directorate for Health, Oslo

Finland: **Jaakko Yrjö-Koskinen**, Ministry of Social Affairs and Health.

Sweden: **Carin Franzén, Josefina Eggertsson Meyer**, The National Board of Health and Welfare.

Olof Högrell, Utredningen om donations- och transplantationsfrågor,
Regeringskansliet, Stockholm,

Denmark: **Bjørn Ursin Knudsen, Anne Cathrine Bollerup**, Danish Health and Medicines Authority, Copenhagen.

Iceland: **Jórlaug Heimisdóttir**, Directorate of health, Reykjavík (*absent*).

The board of Scandiatransplant:

(KH) Krister Höckerstedt, Helsinki

(HI) Helena Isoniemi, Helsinki

(LW) Lars Wennberg, Stockholm

(PDL) Pål-Dag Line, Oslo

(MA) Margret Andresdottir, Reykjavik

(FG) Finn Gustafsson, Copenhagen (*absent*)

Scandiatransplant:

(KAJ) Kaj Anker Jørgensen, Aarhus, Medical Director.

(PN) Peder Nørgaard, Aarhus, programmer

A G E N D A

1. Welcome:

Krister Höckerstedt welcomed everybody to the meeting.

2. Election of chairman of the meeting and writer of the minutes:

Krister Höckerstedt was elected chairman of the meeting and Kaj Anker Jørgensen writer of minutes.

3. Approval of the minutes from meeting No.18, 2013:

The minutes were approved.

4. Additional issues for the agenda from the participants:

None.

5. EU Action Plan and Scandiatransplant (Kaj Anker Jørgensen):

Kaj Anker Jørgensen showed the presentation that had been shown to the meeting with the EU Commission in September 2013. The presentation is attached to the minutes.

6. Living Donor Database (Kaj Anker Jørgensen):

Kaj Anker Jørgensen gave a short presentation indicating that each country needs a living donor database. It seems that the competent authorities in the countries are not going to make the database, but in some countries like Norway and Finland, the hospitals have a living donor database. Everybody at the meeting agreed to use the Scandiatransplant living database and accepted the proposed obligatory fields as well as the amount of follow-up.

7. Plans for Scandiatransplant in the near future (Kaj Anker Jørgensen):

Kaj Anker Jørgensen told about the work that is starting in Scandiatransplant where they are going to revise the articles and bring them up-to-date with what they are doing today.

8. What has happened in the last 12 months in each country.

• **Main transplantation and administrative issues including the EU-Directives.**

Denmark: The three transplant centers had been the notified parties according to the EU-directive. The Parliament has decided to start an action plan to increase organ donation. The action plan has six bullets.

Norway: All donor hospitals have been officially recognized. They are implementing new guidelines for living donation. The national council for organ donation may probably soon be reorganized. They are still implementing the very large plan for treatment of a chronic kidney disease. A new law on organ transplantation is on its way.

Sweden: The people from Socialstyrelsen showed a presentation on the update in Sweden. There is a government inquiry regarding donation and transplantation which ought to be finished in 2015.

Olof Högrell from Utredning om donation- och transplantation updated on this work and told us that the legal problems that he told us about one year ago are now being solved. The annual report on organ donors in Sweden 2013 has been published in June, and guidelines for donation responsible doctors and nurses was published in April 2014, and now they are working on new guidelines to increase organ donation in Sweden. These publications can be seen on the website of Socialstyrelsen.

Finland: Donation doctors and nurses have been identified in all donation hospitals. They are trying to increase living donation primarily by using next of kin. There has been a recommendation for a steering committee at national levels which should be independent from the transplant centers. The guidelines for braindeath are being renewed.

Iceland: Jórlaug Heimisdóttir from Iceland was absent. Margret Andresdottir had received a mail from her and told that the Directorate of Health has taken over the tasks of the Icelandic Transplant Committee from the Ministry of Health and Welfare. The Directorate of Health has appointed an advisory transplant steering group. There is a website under construction where people can register their position/wishes regarding organ donation. A bill on presumed consent was proposed but turned down in the Parliament. They are however still working on this bill. The EU directive will be implemented, but is not completely implemented yet.

9. SAE/SAR reporting (Lars Wennberg):

Lars Wennberg showed a suggestion from the Scandiatransplant. Scandiatransplant has many of the data that are needed for SAE/SAR reporting and registration. The proposition

from Scandiatransplant is therefore that SAE/SAR are reported and registered in Scandiatransplant. Scandiatransplant should then automatically send these reports to the relevant competent authorities. The proposition is attached these minutes. It was agreed that each country should report to the Scandiatransplant office by January 31st, 2015 if they accepted this proposition.

10. Letter from Lithuania (Krister Höckerstedt):

Krister Höckerstedt told that a letter had been sent to all the competent authorities in EU countries from Lithuania asking some questions about organ transplantation.

Question 2 was if foreign recipients can come on the national waiting list for organ transplantation. The Finnish competent authority has asked Krister Höckerstedt to give an answer to this since Finland follows Scandiatransplant rules. Krister had made a proposal for an answer to this question and had discussed it with the board of Scandiatransplant where everybody agreed. The answer was shown at this NTC meeting and everybody agreed upon the answer. The answer is attached to these minutes.

11. Any other business:

None.

12. Next meeting September 2015 (CPH, Sept.15th, 2015?)

Next meeting will be on September 15th, 2015 in Copenhagen.