

MØDEREFERAT

- Møde nr.:** 59
Tid: 24.01.2011
Sted: Hilton Hotel, Kastrup lufthavn, København, Danmark
- Deltagere:** Scandiatransplants bestyrelse:
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|----------|------------------------------------|-------|
| FORMAND: | Krister Höckerstedt, Helsinki | (KH) |
| SVERIGE: | Michael Olausson | (MO) |
| FINLAND: | Helena Isoniemi, Helsingfors | (HI) |
| NORGE: | Per Pfeffer, Oslo | (PP) |
| ISLAND: | Margrét B. Andrésdóttir, Reykjavik | (Ma) |
| DANMARK: | Kaj Anker Jørgensen, Århus | (KAJ) |
- Scandiatransplants direktør:
- | | | |
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| DANMARK: | Niels Grunnet, Århus | (NGR) |
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- Mødeleder:** Krister Höckerstedt (KH)
- Referent:** Niels Grunnet (NGR)

1. Velkomst

By KH. Globalisation has now also come to Scandiatransplant which has given a lot of extra work both at the office in Aarhus and for KH himself. The extra activities are e-mails, European meetings and other contacts.

2. Mødets dagsorden og format:

Will be held mainly in English.

Extra items to the agenda: Lars Bäckman, (Uppsala), Per Wierup (Lund) will come at 2 pm. to inform the board on the situation for heart transplantations in Sweden.

Extra item to the agenda: Accreditation of transplant centers (under agenda item 15)

Extra item to the agenda: Information by PP on activities in Council of Europe (agenda item 15).

3. Godkendelse af referat fra bestyrelsesmøde nr. 58:

Minutes of board meeting No. 58 approved. KH gave a short summary of the issues and several of them will be dealt with also in this meeting. Minutes from the last meeting November 2010 in the Liver Group has not yet arrived, but there were some new decisions on exchange of livers and reimbursements for liver transplant between centers. Some issues have to be approved at the Council of Representatives' meeting in May 2011 to be formally set in action.

4. EFRETOS present status and the relation to Scandiatransplant:

Handouts sent to the board members:

- Letter from KH to Arie Oosterlee/Eurotransplant on the relation between Scandiatransplant and Efretos.
- Report on a dedicated data dictionary deliverable 7 concerning which data to be registered in register for registries in European context.

KH showed a power point presentation of the comments from Frank Pedersen on availability of data in the present Scandiatransplant system. Some data had got a green colour, some a yellow and some a red. Those with green colour are part of the Scandiatransplant present registration and can be drawn out, those with red colour are not available at the time being, those with yellow colour has a question mark.

The board states that the EU Directive is a document for member states and not in itself for an interest organisation as the Scandiatransplant association. However, all the board members agree that the present way we do it in Scandiatransplant is the way that we will recommend that we can continue to report also in the context of the EU directive and future demands for registrations in the EU context. However, it is the member states (that means Socialstyrelsen/Sundhedsstyrelsen/Ministry of Health/Helsedepartementet/Sundhedsministeriet) that have to state what they would like to have in their registers in relation to organ transplantation both from living donors and from deceased donors. It is decided that KH will write a draft to a letter, circulated to the board members, and then the board can finalize a common text to be used by each board member to use in the dialogue with the health authorities to get a commitment of what the member states will require in the registrations in the context of donation and transplantation. If it is possible to synchronize the demands from all the countries from within the Scandiatransplant organisation and it is feasible with respect to what we have in Scandiatransplant now, then we will stand on a much better firm ground in the dialogue with the rest of Europe.

KH reported that the meetings during 2010 in the kidney group and the liver group all were hesitating and think that the way we do it now in Scandiatransplant is sufficient. So EU member states have the decision of how they want data registered, but Scandiatransplant have the data as it is today.

Another document in the handouts: Variables for Efretos registry when non-standard risk donors are used for transplantation. See above.

- At the meeting a handout from KH of four pages titled: EU-arguments for live kidney donation in Europe 2010. The document has been prepared with the participation of Arnt Jakobsen, Norway and Charlotte Møller, Sweden. The document is an effort to try to find out how could live kidney donations be increased in European countries (the document will be in the enclosures to this minutes).

Arnt Jakobsen has now an affiliation to HelseDirektoratet in Oslo and can probably continue to work on issues with for example live kidney donation/transplantation issues. So far, the board of Scandiatransplant are satisfied with the state of the issue on living donation in the European context.

Cont. on Efretos connections: MO has been affiliated with the working party. He is in dialogue and we will have more information later on.

Several sources in Europe are not satisfied with the enormous set up in the Efretos regi, for example Germany has been very critical.

The board discussed the present status of Scandiatransplant with traceability with availability of 70-80% of "tier one data". Some in Efretos are very active and have written to parliament member and do a lot of lobbyism.

During the autumn of 2010, Scandiatransplant is listed as one of the seven partners in the Efretos project. KH has clearly indicated for the chairman of Efretos and in oral communication with Arie Oosterlee and Axel Rahmel that Scandiatransplant is hesitant to what level the demands of registrations will end.

There is the impression that some Efretos people have a dream of creating a "European Unos". Apart from Germany, England is also hesitant, so Sctp will continue to express

attitudes on the line of German and the UK to try to define an appropriate level for these registrations which shall be in place August 2012 for each member state within the EU Union. For the continuing story see agenda item 6.

5. Re: Estonia. New suggestion from Tartu Hospital on collaboration with Sctp.:

An enclosure dated January 21, 2011 from Virge Pall, Director, Transplantation Center, Tartu University Hospital. This is an announcement so that the board of Scandiatransplant can know that a new transplantation center Tartu University Hospital has been founded in January 2011, see the enclosure for transplantation figures etc. The Tartu director proposes a contact with Scandiatransplant to discuss the possibilities towards collaboration with the Scandiatransplant association. Several board members have visited Estonia. KH last time in May 2010. One major problem is that the laboratory services in Estonia are not formally accredited so they cannot show a paper that their standards and quality is at a standard which is demanded in 2011.

KH will write a letter together with NGR with an official reply to the letter of January 21, 2011.

6. EU Directive 2010/53/EU on Organ Donation and Transplantation

- Workshop in Luxembourg 19-20 Jan. 2011 on Joint Actions?:

Had participation of Arnt Jakobsen as a representative of Helsedirektoratet, Oslo. KH had been in telephone contact with AJ after the meeting and we have had a short minutes indicating that the outcome of the meeting was very limited. Minutes from AJ enclosed.

- Next meeting of the Competent Authorities 28. feb. og 1. marts 2011 i Bruxelles:

KH will participate and NGR thinks he can participate together with Bjørn Ursin Knudsen, representing the Danish Health Authorities. The meeting is regarded as very important. The content is on a set of national priority actions, joint actions etc.

7 a. Allokeringsregler hjerte/lunge og lever

b. Rota princippet ved hjerte/lunge samt lever

Præcision (clarification needed):

The board confirms that the individual working groups define the rules. The present guidelines for exchange and rotation rules regarding lungs from deceased donor are from September 29, 2010 on the NTSG meeting.

Guidelines for heart from deceased donor were also agreed on Sept. 29, 2010 on the NTSG meeting. However, some transplant coordinators have had some difficulties in managing these rules because they are to some degree complex. From the Scandiatransplant office we have written to the two chairmen Martin Iversen (Copenhagen) and Odd Geiran (Oslo) to ask for some clarifications, however we have not had a formal reply with clarifications.

If there are difficulties in understanding the precise way of handling the rules, then the transplant coordinator group should have a dialogue with the chairmen of the Thorax Group.

We have not yet received minutes from the last two meetings, the meeting in the Thorax Group and the meeting in the Liver Group, both held in the autumn of 2010.

We will try to get the minutes. For the Liver Group a new system should be in action here from 2011 according to oral information from some of the meeting participants.

8. Newsletter from Scandiatransplant Dec. 2010.

(different issues incl. definitions):

From KH there is a handout concerning the WHO Global Consultation on Organ Donation and Transplantation meeting in Madrid March 2010 in which they have produced a fig. 2 also indicating definitions of a

- potential deceased donor,
- eligible deceased donor,
- actual deceased donor, and
- utilized deceased donor.

It is a wish from the board that we have three columns of deceased organ donors.

According to the Scandiatransplant office, we can fulfill data on

- eligible,
- actual and
- utilized donor,

but not on potential donor (we have not this information in the Scandiatransplant data system). There is a discussion on the differences between the Northern and Southern European countries because in the Northern part you have only an organ donor if you have a recipient, that means that you have transplanted one or several organs. In other parts of Europe you maybe have registration of a deceased organ donor and sometimes there are no corresponding recipients in the actual data registrations.

In the diagram over transplantation figures, the Scandiatransplant office will adapt the terms eligible donor, actual donor and utilized donor.

The transplant centers within Scandiatransplant will be informed in a newsletter in the spring of 2011.

9. IT systemet/status mht. webversion/øvrige emner:

In the Newsletter item 2 you can see the present status. NGR gave a handout from Bo Hedemark Pedersen (BHP) on the status.

The kidney follow-up will be ready for testing within a few weeks and the personnel on IT-issues in Skejby are working on getting something to be presented at the Council of Representatives' meeting. As stated in the notes from BHP we have a current setback in programming resources due to lack of competence and working efficiency by the last employed programmer. He had been at Scandiatransplant as a student programmer in the first half of 2010, then he was educated as datalogue from the University, but during the autumn of 2010 it has become clear that he cannot work with our issues. Therefore, after several formal talks and involvement of the human resource department at Skejby, the last employed programmer has been referred to dismissal by the end of January 2011. He will have the right to salary for three months, and we tried to see if he can have some very simple things to work with. For the time being he is ill, and we have not seen him at the office for some time.

It is the hope of BHP and others that we can have a new student programmer, but all at the Scandiatransplant office feel that it is very necessary to stimulate what can be stimulated, and try to deliver parts of the new web version as soon as possible.

- Concerning the Nordic Children Kidney Registry (NPR TSG), data for the year 2010 has now been sent to Scandiatransplant. Christian Mondrup has indicated some errors and repaired these, and therefore the data are now integrated in the Scandiatransplant data system. However, we still need contact to the chairman of the Kidney Children Group, Hannu Jalanko.
- Marie Larsson from Karolinska, Stockholm asks if she could have access to data from all transplant centers. The answer is no, she has to go through the Scandiatransplant office.
- January 20, 2011 we have had a request from Oslo concerning data on kidney transplanted women that subsequently have been pregnant. It is an epidemiologic study involving data from Oslo and Gothenburg. It is OK to deliver data to them if we have accept from the two involved centers namely Oslo and Gothenburg.

10. Præliminært Regnskab for 2010:

At Skejby Hospital we cannot have the final accounts before in February 2011, but preliminarily one can say that we have used approx. 3.5 million DKK during 2010. We have a budget of 4.5 million DKK and we expect income for a little more than 4 million DKK for the year 2010 to be collected after the meeting of Council of Representatives in May 2011. There has been a regulation of the extra fee taken from Oslo for 2009. It has been taken away from the 2010 accounts. For the next meeting of the Council of Representatives there is possibility for 34 persons (representatives), i.e. two less than the year 2009 due to closure of Herlev and five instead of six from Gothenburg. According to decisions earlier on, the fee for a deceased donor transplantation is 3000 DKK, for a living donor transplantation 700 DKK. The final accounts will be finished in February 2011 and circulated to the board members.

11. Suggestions for budget 2012:

For the year 2011 we have decided to have a budget of 4.59 million DKK. We shall have regulated the amount for travel grants to 100,000.- DKK, and we have to have an extra line for the Scandiatransplant research grant of 20,000.- Euro corresponding to 150,000.- DKK. A suggestion for the budget for 2012 will be circulated later on to the members of the board.

12. Scandiatransplant Grant (the new one)**Proposal and decision on statutes:**

A preliminary definition of statutes and application form was discussed. The statutes will be changed by PP. MA will make proposal to application form and MO will write down simple rules for having support for this grant. It is decided to give the grant once a year.

13. Rejsestipendier:**a. Skema til rejsestipendierappporter:**

The proposal was discussed and a new version will be made by MO. The report should be of max. total of 500 words with focus on report and evaluation of what came out of the grant.

b. 5 ansøgninger om rejsestipendium 2011 modtaget:

1. Juha Peräsaari (joint application with Eeva Mainio) Helsinki, Finland:
8,200 DKK
2. Are Martin Holm, Oslo, Norway:
20,000 DKK
3. Öystein Jynge, Stockholm, Sweden:
7,000 SEK
4. Kristine Kloster-Jensen, Oslo, Norway:
20,000 DKK
5. Shinji Yamamoto, Uppsala, Sweden:
Could not be supported.
6. Kenneth Lindström, Göteborg, Sweden:
10,000 SEK

14. Planned meeting: Meeting on Vigilance and Surveillance of Substances of Human Origin (not blood) arranged by WHO/CNT/SOHOV&S, Bologna, Italy Feb. 7-9, 2011.01.10:

We will see what will come out of this meeting.

15. Øvrige emner/meddelelser:

- There has been an agreement between the Danish Center for Organ Donation and Scandiatransplant to deliver data on deceased organ donors. A formal agreement has been signed by the Danish board member Kaj Anker Jørgensen and the leader of the Danish Center of Organ Donation, and it fulfills all criteria for data handling in Denmark.

- We have had a report on certification at the European Transplant Coordinator meeting in Cardiff 2010 by Käthe Meyer, Oslo sent out in advance.
- KH informed that Oslo has been accredited for kidney, liver and pancreas transplantations in the UEMS regi. They got very good points. In addition other centers in Europe: Essen, Budapest and Groningen (only liver) have been accredited.
- The board had a visit of two surgeons from Sweden, see above. They informed the board about Rikssjukvårdsnemnet in Sweden had decided only to have two centers for doing heart transplants and two centers for doing liver transplants. For heart transplant it will be Gothenburg and Lund. For liver transplant it will be Gothenburg and Stockholm
There are some minor clarifications of which recipient/patient area versus donor area is covered by the different centers, but the dialogue is ongoing and the medical personnel is highly involved in trying to find out working rules.
- PP informed on Council of Europe meetings in CD-P-TO. PP has suggested a future recommendation on standards for European examination of transplant surgeons, transplant coordinators and transplant nephrologists. Under the European Board of Surgery (UEMS), Section for Transplant Surgery there is already examinations and until now 130 transplant surgeons have gone through these exams. Also under UEMS transplant coordinators have also formed an European examination. A system for nephrologists will follow. PP declared that it is not a double activity, but under the regime of Council of Europe one would like to set up certain standards in the area of organ transplantation for whole Europe where UEMS is a good example of how this can be implemented in practical terms.
The fourth edition of the Guide to Safety and Quality Assurance for the Transplantation of Organs, Tissues and Cells is now just before release, also in an electronic version. An expert group chaired by France is trying to find out how many patients go abroad to be transplanted in another country. By questionnaire they will try to investigate this area and try to see if one can get some reliable information.

16. Evt.:

Nothing.

17. Næste møde tid og sted:

Copenhagen, Hilton hotel, Kastrup May 24, 2011 board meeting and May 25, 2011 board meeting in the morning and Council of Representatives' meeting 1-5 pm. It has been decided not to have any board meeting before May, but that all relevant things are discussed via e-mail or telephone.

In September 19-20, 2011 it is planned to have board meeting and meeting in the Nordic Transplant Group in Reykjavik, Iceland. The board travel to Iceland on Monday Sept. 19 arriving at ca.15:30. Have the board meeting at 17-20 followed by a dinner. Meeting with NTC at 8-11 am. on Tuesday, Sept. 20, and leave at 13:20 via Copenhagen.

