

MØDEREFERAT

Møde nr.: 58
Tid: 20-21 sept. 2010
Sted: Århus Universitetshospital, Skejby, Danmark

Deltagere: Scandiatransplants bestyrelse:

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:

DANMARK:	Niels Grunnet, Århus	(NGR)
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d. 21.09 fra Scandiatransplant office:

Bo Hedemark Pedersen	(BHP)
Jörn Hajek	(JH)
Christian Mondrup	(CMO)
Frank Pedersen	(FP)
Ilse Weinreich	(IW)

Mødeleder: Krister Höckerstedt (KH)

Referent: Niels Grunnet (NGR)

1. Velkomst

Ved KH, hvorefter hver enkelt præsenterer sig. Dette er første møde i den nye bestyrelse med 4 nye bestyrelsesmedlemmer.

2. Mødets dagsorden og format:

Held partly in English and partly in Scandinavian language.

3. Godkendelse af referat fra bestyrelsesmøde nr. 57:

Minutes from board meeting No. 57 approved, comments on the Madrid resolution which several of the board members had not seen (we will get it and send it). PP recommended that the board of Scandiatransplant could express its support to this document. NGR gave a brief summary on the IT-personnel at the Scandiatransplant office, CMO is working mainly on the old system. 2 programmers BHP and JH make developments on the new web-based system which subsequently is tested by FP and IW who also take care of the daily management of the Scandiatransplant IT-system in connection with the many users. There has been quite an increase in the number of requests to the office. There is still a need of guidelines for answering these requests and sending out data.

It is stressed that the owners of the data within the Scandiatransplant system are the transplant centers = the members of Scandiatransplant. The office produces a quarterly table on all performed organ transplantations within Scandiatransplant and another table with figures for waiting lists concerning each organ.

Chairman of the working group for the Paediatric Kidney Group is Hannu Jalanko, Helsinki. HI will take contact to him again.

4. EU Directive on organ transplantation. National Action plans.

Rapport fra møde 6-7 sept. 2010 og forberedelse til mødet i Nordisk Transplantationskomité 21.09.2010. See minutes from this meeting.

5. EU-registry on organ donations and transplantations - should the Nordic countries and Scandiatransplant contribute with data? Se punkt 8/Efretos:

On Sept. 10, 2010 discussion in a telephone conference on Efretos with many working groups and efforts to create registry of registries, definition of numerous amounts of parameters to be reported.

There is a great applause to ELTR European Liver Transplant Registry, which has been very useful and well functioning, but there is a great deal of scepticism within the board on all the activities initiated in the regi of Efretos. There is a wish to put on "brakes" on the end results of the Efretos activities. There is an agreement that it is very important for Scandiatransplant as an organisation and for the transplant centers within Scandiatransplant to be affiliated with the different European activities and that also means the projects under Efretos. In USA you have UNOS which seems to work very professionally and has a very extended service in answering requests on data, but the problem is the quality of the data in the system, especially follow-up data.

EU would like to have some sort of quality control of what is going on in the organ transplantation area and for that purpose they would like to have registries. These issues will be taken with the meeting with the health care authorities.

6. Questions are raised back to the reference groups and after their reply there shall be an information to the transplant coordinators how to understand the guidelines.

6. a. Allokeringsregler hjerte/lunge og lever:

Rules for allocations of the organs heart/lung and liver. Exchange rules for these organs are defined and decided by the working/reference groups for each organ. The rules defined by these reference groups have to be followed. It is clear that the rules are not static because they are influenced by medical judgements.

b. Rota princippet ved hjerte/lunge samt lever:

Rota principles for heart transplants, lung transplants and liver transplants. Although the reference groups have defined written rules there are a wish that these rules are more precise in their wording and kept as simple as possible so that it is possible for transplant coordinators and others to administer the rules correctly and to manage movements on the rota list for each organ. It is a wish that we under the point "guidelines" in the Scandiatransplant homepage can put one single page for each organ (heart/lung/liver) as we know it concerning the mandatory exchange rules for kidneys.

c. Balance in exchange of livers (Back delivery/"Pay back"):

Oslo has a need to use all own donor liver organs due to more patients on the waiting list for liver transplantation in Oslo.

It is concluded that if there is not a surplus of donor livers then allocation is in own country. There is questions to the Scandiatransplant newsletter from June 2010 with diagrams on compliance with exchange rules. The diagrams will be explained in the board meeting Sept. 21, 2010.

Again the board members expressed a judgement that the rules for exchange of heart and lung organs seem to be very complicated and that can stimulate confusion so there is a wish of simpler rules. It is stated that 90% compliance for example for livers is quite good. The deviations can be explained by each center. The question of

back delivery of livers will be referred to Nordic Transplant Liver Group on their next meeting on November 11, 2010 in Copenhagen. The main statement is that those rules we have within the Scandiatransplant cooperation shall be followed.

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

On the IT system BHP reported our activities since May 2010 especially use of web services as system interface.

- A new thorax module will be available hopefully ultimate 2010.
- Database skills
- Minor living donor registry updates
- Security updates also in co-application
- XLM files can be imported to the database

CMO reported on a paediatric kidney register to the Scandiatransplant database in cooperation especially with Maria Larsson. It is finished and data put in in August 2010. In the children registry there shall also be an import from the Uremic Registries. The Paediatric kidney group has not seen the present version, but HI will take contact to Hannu Jalanko to claim the need of precision of what the group wants. Earlier on data were put in the children's kidney register via paper, but that is not necessary now in the Sctp version.

CMO stated also that we are in a process of seeing if it is possible to go from the Oracle database as the base system and go to open software instead.

BHP reported on the renewal of the license from Oracle database where there have been some complications due to a bill sent to a wrong e-mail address in Scandiatransplant office (not received). The error was due to personnel at Oracle office in Ballerup, Denmark.

Then we had a short discussion on how to put reports of travel grants on the homepage and all agreed on the idea of having a simple form of max. 1A4 page to be used for the reporting (see below under 9.).

8. Internationalt: Nyt vedr. CoE, EOEO, Efretos og andet EU relevant:

- **Efretos:** EFRETOS is led by Eurotransplant and chaired by its chairman AO. Its Board wants to make a registry of the registries in Europe. The 8 working parties are working hard and fast. Their purpose is trying to compare and to see number of complications etc. Some in the working groups want to have data collection to be obligatory, but the commission stated that it should not be obligatory.

Scandiatransplant has had a low profile so far, but in May, 2010 it is suddenly stated in a protocol that Sctp is now a partner. This is a problem.

September 1, 2010 MO participated in a working party with very detailed discussion of variables. The working group is chaired by a Dutch statistician. It is necessary to have a definition of which data should be put in and what the purpose is for this and what shall be extracted.

KH has only been involved in this Efretos activity from the summer 2010. The individual centers within Scandiatransplant have no clear information on what some of these working parties expect of them. So, KH shall discuss with the centers if they will deliver data. There is a support to use Scandiatransplant as a body to state what we think in Scandinavia to set a line for done or not done. It is decided that FP and IW shall check what we can and what we cannot, and the very detailed EFRETOS-schemes in their present form will be sent from KH and MO to the Scandiatransplant office so that we can have a discussion on it and define the level of data delivery. Then the Scandiatransplant shall comment on this in a letter to all the national authorities.

- **CoE:** PP is chairman of a working group and he mentioned that the Transplant Newsletter published by ONT just has come out with new figures for 2009. In a business meeting on Sept. 17, 2010 in Strasbourg work was done on Guide to Safety and Quality in Organ Transplantation with the purpose to fulfill the new edition so that it could come out in January-February 2011. There are more on infection, quality assurance requirements and a reference list is put in with a promise to update this every second year. Another issue is traffic in organ transplantation for organs there are as it seems now not enough laws and rules within the European states which is the case for trafficking concerning human beings. In Norway they have a perfect system to find out the size of the problem with trafficking and the number is 6 patients over the years. In France they have contacted transplant centers, dialysis centers and nephrologists to make a clear figure of the size of the problem. A lot of countries have not answered a questionnaire sent out on this issue of trafficking in organ transplantation. Another issue is a double listing of patients on waiting lists. There is an agreement between North Italy and Belgium and in Italy you have a waiting list for the north, the middle, and the south part of the country. These problems will be further discussed. The problem of double listing was discussed and it is stated that there is no doublelisting in the Scandiatransplant database.
- **New issue:** the speciality in UEMS (The European Organisation for Medical Specialists) of transplant surgeons, officially the Division of Transplantation / European Board of Surgery / UEMS. 100 surgeons from different European countries are now approved for a speciality in transplantation surgery. The exams are in four models concerning multiorgan transplantation, kidney transplantation, liver transplantation and pancreas transplantation. This year a new project has been initiated as 4 transplantation centers so far have been audited for accreditation of teaching in kidney-, liver- and pancreas transplantation. Oslo is one of them. The audit reports will be presented at the Division meeting in October 1st.

9. Rejestipendier:

- *Rapport fra studietur til Rikshospitalet, Oslo 2010 fra Jakob Stenman, MD PhD, Dept. of Liver and Transplantation Surgery, Helsinki.*
- *Rapport fra studietur til Rotterdam 2010 fra Kerstin Fredriksson, Fil mag i socialt arbete, Transplant Institute, Göteborg.*

There has been a discussion of putting these travel reports on the homepage, but not all are very well shaped for this purpose. The board agrees on that MO would make a suggestion for a form being on 1 page only covering for example 250-300 words. Then travel grant recipients could fill in this form and we could put that on the homepage. The suggestion from MO will be sent to the rest of the board for comments before it is finalized.

10. a. **Action Plan for Protecting the Blood System against WNV in Greece (etc.)**

In the guidelines for prevention of transmission of infectious diseases from organ donors to recipients made by the reference group in the Scandiatransplant association chaired by Vanda Friman, last version March 23, 2009. State on West Nile Virus: The risk is too low to justify testing. Exclusion of donors may rarely be considered on the basis of possible recent exposure and clinical picture. So far no cases have been reported from the Nordic countries. The reference group will look at the issue for Scandinavia at their contacts in autumn 2010.

b. **Q-fever in the Netherlands and potential impact for substances of human origin ("smitte-arbejdsgruppen"):**

Not considered a problem in the Scandinavian countries, but it is also reported to the reference group for their contact in autumn 2010.

11. Brug af Sctp kapital til støtte af research projects i relation til Scandiatransplant og Nordisk aktivitet (Scandiatransplant Grant):

At the Scandiatransplant council of representatives' meeting May 2010 Helsinki: Aksel Foss raised a proposition that Scandiatransplant should encourage the use/extraction of data from the Scandiatransplant database both by logistical and economical means. The issue is discussed and the board decides to one big prize for research on the amount of 20,000 Euro once a year. It is decided that PP and Aksel Foss in cooperation with MO will write the rules and guidelines for this grant. The guidelines should be written before the end of November 2010 and the issue will be discussed at the next board meeting. This economical support should especially be given to start up of a new project involving at least 2 countries within the Scandiatransplant association involving a cooperation between several members of the Scandiatransplant association. If no suitable candidate can be found then it is the decision by the board to postpone the delivery of this Scandiatransplant Grant.

12. Øvrige emner/meddelelser (Any Other Business)

During the meeting on Sept. 21, 2010 also BHP, CMO, FP, JH, IW were present. After a short presentation of each participant we continued with the agenda item 4: EU directive on organ transplantation national action plans with reference to the meeting in Bruxelles 6-7 Sept., 2010, 60 slides were presented and discussed. These 60 slides were a result of the first exercise in the regi of EU on data presentation. There were comments on the following slides: 23, 24, 28, 29, 30, 33, 37, 39, 40, 44, 45, 50, 54, 58, 59. It was clarified that the data used in these slides were not delivered from the Scandiatransplant office but probably taken from Transplant Newsletter and some maybe other sources from each country. In general one can state:

EU wants traceability which is supported by the board. For several of the slides it is not quite clear how the figures were created and what numbers were counted. It was obvious from the participants that in several slides there were a lot of errors concerning the Scandinavian countries. These reported data are preliminary data. The data are owned by the members states. Thus, the member states should have the final responsibility for their accuracy.

It is decided that FP and Ilse will go through these 60 slides so that we can clarify the figures so that we can comment on them to the Health Directorate in EU, Bruxelles. There is a wish to write short guidelines for Scandiatransplant/each country for getting on a waiting list for organ transplantation of a given organ. As for all registries it is obvious that "if you put garbage in you will have garbage out". So it is very necessary to have corrections done by the Scandiatransplant office and supplemented with input from all relevant transplant centers within Scandiatransplant. The way to do this is requests to the heads of the individual transplant center to get correct figures because then it is the responsibility of the chief that the correct person answers the questions. Discussion of this first exercise on national action plans: Sctp is not member of EU ! Nations are responsible for the data helped by Scandiatransplant in cooperation with individual centers. Validated data today is quarterly figures from Scandiatransplant and the yearly report on organ transplantation for each organ and waiting list statistics by the end of the year. In addition we have our slide versions for some of the parameters for each country and for the Scandiatransplant association as such. It is asked how many of these 60 slides can be filled with data from the present Scandiatransplant system and the present activities. FP, IW and NGR will make a report on this. Any other data should in principle be given to the EU-authorities by the European member states. The next exercise will be in April 2011.

13. Evt.:

Nothing.

14. Næste møde (Århus?) tid og sted.

At Hotel Hilton, Kastrup Airport as a one-day meeting from 1 p.m to 5 p.m. beginning with lunch on Monday, January 24, 2011.