

## Minutes

**Meeting No.:** 60  
**Time:** 24-25.05.2011  
**Place:** Hilton Hotel, Kastrup airport, Copenhagen, Denmark

**Participants:** The board of Scandiatransplant:

CHAIRMAN: Krister Höckerstedt, Helsinki (KH)  
SWEDEN: Michael Olausson (MO)  
FINLAND: Helena Isoniemi, Helsingfors (HI)  
NORWAY: Per Pfeffer, Oslo (from evening of May 24) (PP)  
ICELAND: Margrét B. Andrésdóttir, Reykjavik (Ma)  
DENMARK: Kaj Anker Jørgensen, Århus (KAJ)

Director of Scandiatransplant:  
DENMARK: Niels Grunnet, Aarhus (NGR)

**Leader of meeting:** Krister Höckerstedt (KH)

**Writer of minutes:** Niels Grunnet (NGR)

**1. Welcome:**

With the chairman of the board KH.

**2. Agenda and format for the meeting**

Accepted with no comments.

**3. Approval of minutes from board meeting No. 59**

Approved with no comments.

**4. Transplant center changes (NG, KH, all)**

Denmark has now 3 organ transplant centers, namely Rigshospitalet, Odense University Hospital and Aarhus University Hospital.

Malmö and Lund have merged to Skåne University Hospital.

In Helsinki all transplantation activity has moved to the main University Hospital, Meilahti Hospital.

So, Scandiatransplant now has 10 centers/10 members.

**5. EU Directive 2010/53/EU on Organ Donation and Transplantation, follow up (KH, NG and all)**

KH presented the directive 2010/45/EU of July 7, 2010 on standards of quality and safety of human organs intended for transplantation. Later in 2010 the number of directive was changed to 53 without no changes in the text. So, now we refer to 2010/53/EU. The directive shall now be integrated in the law system in each member state. The content of the directives annex A is presented and discussed. This will not give problems for Scandiatransplant. Annex B is "the dark horse". Discussions are now in progress to define to which degree data shall be reported.

The directive says that each member state shall have one national donor registry. Law work has been initiated in Denmark and Finland and probably also in Sweden. The board of Sctp agreed on the necessity and importance of each board member to be in

contact with relevant individuals in the national authority to secure a proper process and that the decisions will be reasonable and manageable by the transplant community and Scandiatransplant. Some of the board members have been in contact with their representative in the Ministry or Health Authority, but others have not. It is unclear to which degree the five countries' Health Authority persons at the moment try to coordinate and synchronize the content of the law text in each country to become a common voice. It is stated that it is very important that we are active in this process. At the meeting with Nordic Transplant Committee in September 2011 in Reykjavik it is a very essential part of the agenda.

**6. EFRETOS present status and the relation to Scandiatransplant, (KH, NG and all)**

At May 17, 2011 there was a closing meeting of the EFRETOS-project in Bruxelles, Belgium. KH, AJ and NG were present.

KH showed the Board a presentation given by Jacqueline Smits, statistician from Eurotransplant, concerning the arguments and the status of the process to make "register of registries" concerning organ transplantation within Europe. KH will present a shortened version at the Council of Representatives's meeting May 25, 2011. So Efreto is now closed and what to do? It is clear, at least at this stage, that a European register for registries shall not be used for organ allocation, because it is not an online registry registration.

Scandiatransplant has functioned as partner during this 2½ period in which the project has been running. This has been unclear in the beginning due to former statements that Scandiatransplant only wanted an observational role and not partnership. However, to have some travel money refunded, the administration of Efreto and EU demanded a signature from the medical director representing the institution/association. This was done only with one signature not with two which normally is the procedure in Scandiatransplant to have a formal binding effect. The text of the contract for each of the partners in the Efreto project was very voluminous (app. 82 pages). Present status: Key persons in Eurotransplant are very much in for "registry of registries" in Europe and that this shall have a management board and an ethical board and other administrative bodies. They will try to continue the work from Efreto in an attempt to create a "registry for registries" of organ transplantation in Europe. However, the future financial situation is unclear. EU will only give money for projects not for running a registry, that is up to the member states. The board of Sctp again stated the differences between the system we have in the Nordic countries within Scandiatransplant compared to the American system in UNOS and also that in Eurotransplant.

KH mentioned that the EFRETOS-project has received criticism not only from the Board, but also from Germany. The main chief surgeons of the largest transplant centers and also Günter Kirste, the chairman of DSO (Deutsche Stiftung Organtransplantation) have expressed their concerns at meetings.

The board of Scandiatransplant stressed the necessity of being aware of what is going on in the further process.

**7. ACCORD Project (NG, KH, others) (enclosure (obs. 32 pages) Joint Action application form from ONT)**

Another EU economically supported project to be started named ACCORD: Achieving Comprehensive Coordination in Organ Donation throughout the European Union. The organisation for coordination and application is ONT, Spain. They have invited several countries to participate including the five within Scandiatransplant. They have phoned and e-mailed the Scandiatransplant office att. Niels Grunnet very eagerly during the last weeks. The Norwegian Ministry of Health and Care Services have in a letter of May 13, 2011 stated that Norway would like to participate in the joint action of organ donation

and transplantation in this ACCORD project. Norway will only take part in the working group concerning living donation. The ministry has nominated dr.med. Per Fauchald leader of the national advisory group on organ donation in Oslo to represent Norway. Sweden has according to information from ONT in Madrid also said that they would be partner although we have had no information at the Scandiatransplant office specifically on this. The dialogue with ONT namely Beatrice Dominguez-Gil on the role of Scandiatransplant and the member states ended with the following wording: "Following our conversation by phone please let us confirm that Norway and Sweden will be involved in the joint action as associated partners, this means that they will receive specific budget for the development of the project. It could be possible that the same expert attending on behalf of Norway represents also Scandiatransplant and that your institution is involved as collaborating partner". This has been agreed by NGR after dialogue with KH. This means that Scandiatransplant has no economical relationship with the ACCORD project and that we can be informed via the representative from Norway. The concern in the board is of course if the evolution in Europe could create any restrictions against the living donation then it is a very bad thing for the Nordic area and that is for Scandiatransplant. Therefore, it is important to be alert and aware of what is happening. It is important that the representatives from one to two countries report to Scandiatransplant. NGR will write a letter to Per Fauchald and Charlotte Møller concerning this (done May 27, 2011).

**8. The Estonian question (KH)**

In the part of the chairman of Scandiatransplant's report for the period (May 2010 to May 2011) the background is given: A new transplantation center at Tartu University has been founded. This functions as an organ donation organisation therefore a suggested similar collaboration between Scandiatransplant and the organ exchange organisation (OEO) in Estonia could be established analogue to the agreement with other organ exchange organisations in Europe if the following conditions are met: 1. The Transplantation Center at Tartu University Hospital represents the OEO of Estonia. 2. Formal accreditation of activities related to transplantation of this center and the donor hospitals in Estonia is shown. Both of these things shall be fulfilled and stated in a letter by the competent authority of Estonia. This was agreed on by the board of Sctp. KH sends a letter on this decision to Virge Pall, the director of the Transplantation Center at the Tartu University.

**9. Newsletters from Scandiatransplant (Ilse/FP/NG)**

May 25, 2011 with the participation of Ilse Weinreich (IW), Frank Pedersen (FP), Christian Mondrup (CMO), Bo H. Pedersen (BHP). The last newsletter from May 2011 was discussed in details and some suggestions done on how to clarify some of the uncertainties. The newsletter is very appreciated by the board and some of the questions will be discussed during the council of representatives's meeting. Ad issue 1.6 on Living kidney donor registry: A name and a person to be the contact person is asked for. It is decided that it is a group that shall be integrated in the kidney group, but that Ole Øyen also in the future is the man to contact with special questions. Ad 1.7 the contact person is Hannu Jalanko representing the working group. From CMO it is stated that for the paediatric patients a template for kidney transplant follow-up has been made and this should also be implemented concerning adults. The data to the Nordic paediatric renal registry should/can nearby be sent as shear import to the Sctp data system. Ad 1.8 The coordinator group has a wish to have a **security seal** on boxes for organs being sent from one country to another. A proposal has been made by IW. This is supported by the board.

FP brought up the question that the requested data to Transplant Newsletter published by ONT yearly ask for a new way to report the data. They want only patients on the active waiting list not those being temporarily inactive. In earlier years it had been active plus inactive. From several board members it is stated that this has not been discussed in all relevant fora in Europe. It is very necessary to have an indication of actual donors versus utilized donors and this should be clarified throughout Europe. Organ donors are donors with the purpose to have at least one organ transplanted. The problem is that some countries in Europe register some organ donors from which they have transplanted no organs. The plan is now that FP will set up the figures for Scandiatransplant and the five Nordic countries, send it to the board, who then send the data to ONT. It is stated by the board of Sctp that it shall be discussed on EU meeting and also on Council of Europe meeting. Concerning 1.9 and 1.10 we have no official working groups, but activity is registered in the data collection of Sctp. Ad 1.11 New recommendations have been received from chairman of the reference group namely Vanda Friman in the beginning of May 2011. It will be presented at the Council of Representatives's meeting, and thereafter the Guidelines can be entered on the Sctp homepage.

Extra: The annual report from the chairman of the board of Scandiatransplant shall not be entered on the homepage of Scandiatransplant in the form it was sent to the representatives of the council of Sctp. KH will in a dialogue with FP edit that version that can be entered on the homepage.

**10. Preparation of the Council of Representatives' meeting on May 25, 2011. (NG, KH and all)**

The different issues have been gone through and subjects distributed.

**11. The IT system/status of (BHP/others from the office) webversion/other subjects**

The best estimate by BHP is that approx. 25% of the system is ready in the web-version. Members of the board concluded there is still a lot to do. BHP gave an overview and the issues were dealt with and discussed. The estimate is that in some months major parts will be ready for testing. By the IT-personnel it is stated that the old system is still in action for example related to tissue typer issues (i.e. the STAMP system etc.).

Concerning economics of IT-development we have the resources. We have one position available for the right IT-person (programmer) if it is possible for us to find such one. We also search for student helpers, but have not yet succeeded in getting one to two relevant persons. The word "super users" was discussed. It is the aim that some daily users of the Sctp data system can be educated and test parts of the new web version and give their comments for further improvement and finalizing the new web version. There has been a set back situation because the employment of the last associated programmer was terminated due to several reasons.

In a period the number of mean working hours for BHP has been increased from 24 to 31 working hours per week. This will continue until at least autumn 2011.

**12. Accounts for 2010 (NG)**

All the documents are signed and approved.

**13. Proposal for budget 2012 (NG)**

The word "superbruger = super users" is not clearly defined. The language of this budget form is in Danish and an English version is wanted by the board also with the Danish Kroner calculated in an estimate in Euros to facilitate the overview of the single elements of the budget, then it was approved.

**14. Activities of the different groups (All)**

See above under issue 10 and the minutes from the Council of Representatives' meeting.

**15. Scandiatransplant Research Grant (the new one), applications? (NG and all) (deadline May 10, 2011)**

Three applications have been received. The board should under normal circumstances decide who is going to have the nomination. If it is difficult, then one can consult external evaluation. After a very careful and fair long discussion where each stone was turned it was decided to give the Scandiatransplant Research Grant 2011 to the group dealing with investigation of liver organ donors >75 years. Three countries out of five are involved in this project, it has a great deal of novelty, it is sizeable, it can be initiated within the next months, and it is predicted to have practical implication not only in the five Nordic countries i.e. Scandiatransplant, but also in the rest of the world. According to the rules set up for this Grant it should be given only to one project and only once, and the board should normally decide who will get it, however it can be very difficult to make this decision. The two other projects have the possibility to send in a new application next year, so in summary the reason to select application No. 1 on Liver Organ Donors >75 years are:

- Several countries within Sctp involved
- Relatively simple
- Using Sctp data
- Lot of practical input
- New project with new information.

It is impressive that it had been possible for the community of Scandiatransplant departments and medical personnel to set up three applications with a very short time for sending in proposals after the announcing of this new grant.

**16. Travel Grant Report Form (NG)**

The one that had been circulated has been approved by the board and can be entered on the homepage and be used for reporting in the future.

**17. Other subjects/information**

We have had a phone call and e-mail to the office concerning an eventual involvement in a project about technical assistance for alignment in organ donation in Turkey. The board decided that it is not relevant for Scandiatransplant in the way it has been presented. NGR will answer them (done May 26, 2011 in a telephone conversation).

**18. Any other business**

None to be reported.

**19. Next meeting time and place:**

**Sept 19 and 20, 2011 in Reykjavik, Iceland.**

Monday Sept.19 arrival at approx. 15.30.

Board meeting from 17-20 at hotel Holt, Bergstadastræti 37.

Tuesday Sept 20 Nordic Transplant Committee meeting 08-11 in the morning at the Ministry of Health, Reykjavik, Iceland.

Departure 13.20 if via Copenhagen.

