

Minutes

Meeting No.: 78
Time: 1-2 March, 2017
Venue: Day 1: Hotel Fru Larsen, Østergade 1, Laurbjerg, 8870 Langå
Day 2: Aarhus University Hospital, Skejby

Participants: The board of Scandiatransplant:
CHAIRMAN: Bo-Göran Ericzon, Stockholm
SWEDEN: Lars Wennberg, Stockholm
FINLAND: Arno Nordin, Helsinki
NORWAY: Pål-Dag Line, Oslo
ICELAND: Runolfur Palsson, Reykjavik
DENMARK: Finn Gustafsson, Copenhagen

Director of Scandiatransplant:
DENMARK: Kaj Anker Jørgensen, Aarhus

Leader of meeting: Bo-Göran Ericzon

Writer of minutes: Kaj Anker Jørgensen

AGENDA

Day 1: Hotel Fru Larsen, Østergade 1, Laurbjerg, 8870 Langå, www.frularsen.dk,
Tel.: +45 86468388, Lunch at 12.00, Meeting at 13.00-18.30, Dinner at 19:30

1. Welcome:

Bo-Göran Ericzon bid everybody welcome and told that he was very happy with joining this group.

2. Approval of minutes from the last board meeting (December 7th, 2017, Copenhagen):

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-board/MinutesBoardNo77Cph.7.dec.2016.pdf>

Minutes were approved. The NKG-group has responded to the mail on the use of organs from DCD-donors, answers from the other groups are pending.

3. Status at the Office:

Kaj informed the board of the status at the office. The application from Alicja Janicka was discussed. We primarily thought that it would be very good to have her help in developing the cross kidney donation program. After we have had the meeting with professor Tommy Andersson, we have found out that this help is not needed. She clearly has some statistical skills that we could use at the office. It is concluded that we cannot give her any position in the office, but if she is willing we can use her as a consultant in statistical matters.

4. How should Scandiatransplant register "face transplantation" (Helsinki):

It was concluded that this should be registered in Scandiatransplant similar to other organs. This requires a change in the articles. The board suggests that we add "composite graft" to the text in the articles. The word "cellular" in §3 in the articles should be changed to "liver cells". The suggestion for changes will be put forward to the council meeting in May 2017.

5. Status on Data Processor Agreements:

We have signed agreements with Helsinki, Aarhus and Odense and signed sub-dataprocessor agreement with Region Midt-IT. The office has received papers from Rigshospitalet, Copenhagen. There are a few questions and some things to be filled out, but this can be signed very soon. Uppsala has replied that they are working on it. Bo-Göran has pushed Stockholm and they are working on it now. Bo-Göran has asked Per Lindnér and Ragnar Källén to activate their hospitals. He will contact these two doctors again, and then Bo-Göran and Kaj will decide how to proceed. Oslo is working on it, and Reykjavik has received a suggestion and Runolfur Palsson will push the administration take action on the matter.

6. Status on the work with “Deceased Donors Death Causes”:

Runolfur has together with the working group come up with a suggestion which was discussed. A complete agreement has not yet been reached. It is concluded that it is more important to generate a usable system for the future than a system which incorporates all the death causes that have been registered until now. The system should be simple to understand, it should not be possible to have overlapping causes. It was discussed to have principal codes for the actual cause of death and sub-groups describing mechanism leading to fatal injury. We finally decided that if we time allows this point would be taken up tomorrow together with the staff at Scandiatransplant office. Runolfur Palsson got some input from the board for the work.

7. Recommendation document on Tartu Hospital:

The recommendation document had been circulated among board members and since everybody agreed this was signed and can now be sent out to the representatives before the next council meeting. It was decided that Bo-Göran should present this to the council. The office was asked to investigate the age of the donors in Estonia from which organs were transplanted in Scandiatransplant. The result should be presented to Bo-Göran.

8. Accounts 2016 – Budget proposal 2017 & 2018:

The account documents for 2016 had been sent out to the board. They had no comments to these and all the documents were signed by all board members. The budget for 2016 was kept quite exactly. It was decided to keep the budget of 5.7 million DDK that the council had given us for 2017 and to ask for an increase of 200.000 DKK for the budget in 2018, which would then be 5.9 million DKK.

9. Travel grants:

Application from Carina L. Sørensen was not accepted because she received a grant last year and has not sent in the obligatory report on how the grant was used.

Catarina Lindqvist received 13.030 DKK

Selma Mariusdottir received 15.000 DKK

Fatma Bergquist received 7.000 DKK

Carl Jorns received 42.000 DKK

Andreas Rostved received 50.000 DKK

Per Bakkan and Monica Storrø received 15.541 DKK

A total of 142.571 DKK. The rest 7.429 DKK was transferred to the research grant.

10. Research grants:

The application from Kristin Wisløff-Aase was rejected since it was only from one Center. An application from Göran Dellgren was rejected because the project description was not attached.

It was decided to grant Bjarne Møller 148.686 DKK.

Silvia Malenikca received 308.743 DKK

Both applicants should only receive a grant if there was an answer from the ethical committee.

The application from Greg Nowak was also rejected since it only came from one transplant and two donor Centers.

It was decided that we should rewrite the guidelines and make sure that it says that the applicant needs approval or a response from the ethical committee before a grant can be transferred to the applicant. The application form should also be changed so that it specifies the status of the ethical application (submitted or approved).

Day 2: Aarhus University Hospital, Skejby, room 25, at 9.30–14.30 (lunch at 12.00-13.00)

11. Welcome to Scandiatransplant Office:

The board was bid welcome with 20 minutes of entertainment by Tito Phiri and Kaj Jørgensen.

12. Presentation of Staff:

The board met the staff at the office at the place they work. The board also witnessed their working conditions at the time being. There is much noise due to reconstruction at Skejby Hospital. The noise was so bad that the board meeting had to be moved to a room distant from the Scandiatransplant office.

13. SAE/SAR:

Tito Phiri presented the work he has done until now in creating the user interface for reporting these events. The board commented that he had done a very fine job. They had a few suggestions. Thereafter the export from the SAE/SAR registry was discussed. Each SAE/SAR should be reported directly to all the competent authorities. It would be on a secure mail with an attached pdf-file. A coordinator on the hospitals involved would receive an e-mail. When a button on the reporting form was activated, coordinators on hospitals involved should get an SMS warning and an e-mail is sent telling them to go on YASWA and see the SAE/SAR. Once yearly a report should be made on SAE/SAR from every country and sent to all competent authorities and to the coordinators.

14. Kidney cross donation program (STEP?):

After some discussion it was concluded to keep the name STEP for the time being. The STEP is under the NKG and in the NKG they know what STEP is about. Bo Pedersen presented an estimate of time needed for programming, but this was very uncertain until the office knows exactly how the immunological matching should be performed. Ilse is in touch with Mats Bengtsson on this matter and we believe that it would be clarified soon. Kaj told the board that he has been contacted by both Søren Schwartz Sørensen at Rigshospitalet in Copenhagen and Anna Reisæter at Rikshospitalet, Oslo concerning some uncertainty in the NKG about this program in other countries than Sweden. Lars Wennberg confirmed that Sweden is very interested in other countries joining and that Sweden will go together with the other countries as soon as the program is available in YASWA. The programmers did not promise an exact time when they can have the program running, but they do expect it to be within one year. The uncertainty lies on how much extra programming that has to be done in relation to the immunological matching. It was decided that KAJ should inform the NKG of these matters and the status.

15. Discussion with staff at Office:

Several items were discussed as those in point 13 and 14 and also those in point 16.

16. Any other business:

- a. Organ offer form: Ilse presented a wish from some coordinators to be able to differentiate between which OEOs outside Scandiatransplant were offered organs

which could not be used within Scandiatransplant. This is because a few coordinators do not use the Scandiatransplant offer form, but send the old fax to the OEO they prefer. The reason for this is that they say they get very many very disturbing phone calls when the organ offer form is sent out to the many OEOs. It was therefore decided that the button on the organ offer form that sends the offer to the EU organisations was changed to two buttons, one that sends to Swisstransplant and Eurotransplant, and one that sends to the rest. Ilse Weinreich showed that for the last five years only Eurotransplant and Swisstransplant had accepted organ offers from Scandiatransplant. Ilse also told the board that the organ offer form, which was developed when the old fax system broke down, will now be integrated in the “deceased donor” part of YASWA. This is logic and will do away with copying many values from one part of the IT-system to another. It will also spare the coordinators from putting in the same information twice.

- b. Causes of death of deceased organ donors. The working group had sent several questions to Ilse regarding the relative occurrence of a different cause of death codes in the Scandiatransplant database. The proposal of a new system was discussed, particularly if there should be two layers of codes, one for the cause of death and another one for the mechanism leading to this. Runolfur Palsson got additional input for the working group.
- c. Scandiatransplant guidelines for non-Nordic citizens. The text in this was changed to guidelines for deceased organ transplantation of individuals from a non-Scandiatransplant member country performed within Scandiatransplant and the use of organs from such countries for Scandiatransplant recipients. The text of these guidelines was accepted by the board and will be put on the homepage where they replace the guidelines for non-Nordic citizens. This is necessary since the articles now open a possibility for associate membership for hospitals from non-Nordic countries.

17. Next Board meeting (May 9th, 2017, Hilton at Helsinki Airport):

The next board meeting will be on May 9th 2017 at Hilton Hotel at Helsinki airport. We should look at the flight plans and plan a two to three hour meeting at the end of the day. There should then be a continuing board meeting the next day in the morning before the council meeting in the afternoon on the 10th of May. Arno Nordin will bid welcome to the council meeting and will find a candidate for the leader of the meeting to be suggested by the board.