

Minutes

Meeting No.: 76
Time: 19-20 Sept., 2016
Venue: Reykjavik, Iceland

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

1. Welcome:

Bo-Göran Ericzon welcomed everybody and presented himself. This was followed by a presentation from everybody around the table.

2. Approval of minutes from last board meeting (May 10th & 11th, Stockholm):

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-board/MinutesBoardNo75Stockholm1011May2016.pdf>

Minutes accepted.

3. From the Office:

a. Missed organs from EUROTRANSPLANT (Intestine & Child Lung):

KAJ oriented the board of the missed organs due to some problem in the format Eurotransplant had used for an e-mail. It is corrected so this format will be received, but if it happens again we will contact Eurotransplant. KAJ also told the board that there is a dialogue between Bo Pedersen and programmers in Eurotransplant because they are running into problems similar to the problems we have had.

b. Personnel:

KAJ oriented the board about the present situation with the personnel at the Scandiatransplant office.

c. Guidelines for support to group meetings:

The guidelines sent previously to the board members for support to group meetings was accepted. The board wants the expenses used for invited participants for non-group members at group meetings to be monitored and reported to the council. This to increase the awareness of this possibility.

d. Registration of Non-Nordic Transplantations:

The board has earlier decided and confirmed that all transplantation at Scandiatransplant hospitals should be registered and paid for by the hospital performing the transplantation.

e. Revision of Deceased donor death causes:

The board had previously received a suggestion prepared by Ilse Weinreich and KAJ for revision of the donor death causes in Scandiatransplant. The board felt that a major revision is necessary and there was a lot of discussion. The conclusion was to form a group

to come up with a suggestion for revision of these events/diagnoses. Each board member should nominate 1 person from each country to participate in the group looking at this problem. KAJ should nominate 1 person from the office, and Runolfur Palsson will participate as a board member and a key person for the group. Pal-Dag Line will send a suggestion for a mandate for the group to the board members. The board members can then comment on the mandate. This working group should be formed by October 15th and they should have a suggestion for the council meeting in Helsinki in May 2017.

4. Status for Data Processor Agreements and Membership agreements:

KAJ gave the board a status. He has signed agreements with Helsinki and Aarhus, and a completed but not yet signed agreement with Odense. There is a lawyer working with the agreement in Copenhagen. KAJ will send the agreements we have to all the board members. Tomorrow we will discuss with the competent authorities how to continue in the other countries.

5. Membership application from Estonia:

Bo Göran Ericzon had visited Estonia and was quite impressed by their hospital. Some specific issues were discussed as for example transplantation of Estonian hearts to Estonian recipients in Helsinki. We think that if Estonia becomes an associate member, they will have to make an agreement and do it in the same model as Iceland does. The council meeting in May in Helsinki will decide if Tartu can become an associate member. The board should produce a document to be sent out to the council before the council meeting stating the board's recommendation. The board members should now think about this document, and we will discuss it again at the next board meeting.

6. SAE/AE proposal:

A new document made by Lars Wennberg had been sent out prior to the meeting, and it was discussed and accepted. There was some discussion of how such a program feature should work. It was discussed that some SAE/SAR should go as alert in a similar manner with SMS and e-mail system as the organ offers do. It was concluded that the matter would be further discussed at the NTC meeting later.

7. NTTSG reply to the board:

The question about time frames for decision of accepting thoracic organs which had been put to the NTTSG was discussed. The answer from the NTTSG indicates, that they accept the guidelines put down by the board namely that when the donor operation starts, all discussions of who is the recipient should be over, and secondly that the donor center is the master in these cases. Thus the need for extended time frames must always be acceptable for the donor center. The NTTSG is concerned about losing organs due to too rigid time frames and has not yet decided an exact time frame, but is going to investigate the matter further.

8. Prepare for NTC meeting:

The board went through the agenda for the NTC meeting and agreed on the role of the different board members and director in presenting issues at the NTC meeting.

9. Any other matter:

1. Finn Gustafsson told a case story about a Polish patient moving to Denmark where the real cause was to get an expensive medicine in Denmark for lung disease. Eventually the lung disease progressed to the stage where lung transplantation was discussed. The board accepts that you have to follow a country's legislation in these matters even if there is a risk of organ tourism.
2. KAJ presented questions sent out to the NKG group in November to help answer the question raised by the board regarding how the renal transplant centers use scandiatransplant when putting patients on the waiting list.
3. Lars Wennberg told the board about the status of the STEP (Scandiatransplant Exchange Program). The group is preparing to start in Sweden and will visit other centers in Denmark

and Oslo offering them participation. KAJ stated that the program is at a stage, where Scandiatransplant Office should be involved and this will be discussed at the NKG meeting in November.

10. Next meeting:

It was decided that the next board meeting should be on December 7th, 2016 in Kastrup as a 1-day meeting, and that the following meeting should be a 2-day meeting on March 1st and 2nd, 2017 held in Aarhus including a presentation of the office and the personnel there.

Kaj Jørgensen