

Minutes

Meeting No.: 74
Time: 29. Feb.-1. Mar., 2016
Place: Copenhagen, Denmark

Participants: On Feb. 29. Item 1-10:

The board of Scandiatransplant:

CHAIRMAN: Krister Höckerstedt, Helsinki
SWEDEN: Lars Wennberg, Stockholm
FINLAND: Helena Isoniemi, Helsinki
NORWAY: Pål-Dag Line, Oslo
ICELAND: Margret Andresdottir, Reykjavik
DENMARK: Finn Gustafsson, Copenhagen

Director of Scandiatransplant:

DENMARK: Kaj Anker Jørgensen (KAJ), Aarhus

On March 1. Item 11-13 apologies from:

DENMARK: Finn Gustafsson, Copenhagen

Leader of meeting: Krister Höckerstedt

Writer of minutes: Kaj Anker Jørgensen

1. Welcome:

Krister Höckerstedt welcomed everybody to the meeting.

2. Approval of minutes of last board meeting (Sept. 21-22nd, 2015, CPH):

Minutes were approved.

3. Status at the office:

a. SC15 shut down, change to YASWA successful:

On Dec.10th, 2015 access to SC15 from the outside was closed down (SSH-secure shell). Everything was then running on YASWA except the kidney pediatric registry. We had beforehand received acceptance that it was ok to have the pediatric registry closed down for 3-4 months. There were hardly any problems at all and people seemed to have been warned in good time and have understood it. On Jan. 20th 2016 between 01:25-01:35 a.m. the database was moved from SC15 to SC30. At 02:05 the first real user logged on to the system and it went well. In conclusion the transition has given fewer problems than we had expected and has gone well.

b. Personnel:

KAJ gave a status on matters related to the personnel at Scandiatransplant office. This included some private matters related to the Medical Director. He told that Peder Nørgaard was now working full time, but has achieved a so-called §56 agreement for his chronic illness.

The office had a workshop on Friday 13th of Nov. 2015 where they discussed priorities, and the board was told that a system for priorities was made primarily by Bo Pedersen and Ilse Weinreich, but which everybody in the office can contribute to.

c. Questions to/from the office:

i. Audit of Scandiatransplant ?

This question was discussed in depth. The conclusion was that Scandiatransplant will not be pro-active in seeking an audit, but the right to audit Scandiatransplant at any time from the member hospitals will be put into the agreement between Scandiatransplant and every member hospital when we are fulfilling the model of the legal memorandum.

ii. Expense for donor procedures (Malmö coordinator)

The proposition sent to the board by Kerstin Karud from Malmö and the question was discussed. The board was of the opinion that things are working according to the suggestion made. The board has difficulties in understanding exactly what the problem is. Lars Wennberg will contact Kerstin Karud and try to sort out exactly what the problem is.

iii. Transport payed to coordinators meeting / one from every hospital?

The board concluded that things should stay as they are now that Scandiatransplant pays for 1 coordinator from each country to these meetings. The board cannot accept the difference it would make if countries with many small transplantation centers are supported more than countries with one large transplant center. The board discussed completely removing this support to the coordinators to their group meetings since no other groups get their transport paid by Scandiatransplant to group meetings. The conclusion was, however, that things stay as they are now.

iv. Issues that have come up after change to YASWA

KAJ told the board the he had discovered that Scandiatransplant is on very few occasions asked to change the entry date of the patient. This is done when a patient has been waiting for a living kidney donor, and it turns out that there will not be a living donation and the patient is put on the deceased donor's waiting list. Scandiatransplant is then requested to change the entry date backwards to the date when the patient actually was transplantable. The board finds that changing the entry date backwards is unacceptable. The question is related to how different centers use Scandiatransplant in relation to using Scandiatransplant as a work-up area before the patients are transplantable, and the practice of putting the patients on the deceased donor waiting list while investigating possible living donor donation. The board asked KAJ to contact the NKG and ask them to discuss this question at their next meeting in November.

KAJ also told the board that according to the old system, donor hospitals could see information on the recipient, while in the new system, donor hospital can only see the Scandiatransplant number, the organ, the blood type, and the tissue type of the recipient after the recipient has been transplanted. The office has had very few questions on this matter, but the response has been and that is the way it is now. The board endorses this answer.

4. Answer from NTTSG on suggestion from Sahlgrenska on machine perfusion of lungs:

This answer from the NTTSG group was discussed and approved by the board. KAJ is to write to Sahlgrenska and give them the answer from the NTTSG and also write to NTTSG that the board acknowledges their answer to the questions asked by the board.

5. Status on the SAE reporting project:

The suggestion made by Lars Wennberg was approved. The board approved of the examples, but they should be translated to English. Lars Wennberg will work on this document and send it to the Scandiatransplant office which will send it to all the participants of the last NTC-meeting and ask for their comments.

6. Further work in line with the "legal memorandum" – Agreements with hospitals:

KAJ told the board that he had no reactions from the participants of the last NTC-meeting, who promised to give him an e-mail address from every country of people participating in the further discussions within two weeks. KAJ had therefore made a suggestion for a scheme for a data processor agreement with every hospital. This scheme has been sent out to the board. The status is that Norway and Finland (Rikshospitalet Oslo and Helsinki University Hospital) are working on this agreement. KAJ should send this scheme to the hospital director of the university hospital in Reykjavik, to the competent authorities in Sweden, and to the directors of the three transplant hospitals in Denmark.

Helena Isoniemi will send a copy of the suggestion for the agreement that follows the data processor agreement when a suggestion for this is made in Helsinki.

7. Scandiatransplant and the EU FOEDUS project, the new horizon project from Leiden (Claas).

KAJ showed a presentation of how the "Organ Offer Form" works in Scandiatransplant, and told the board that he thinks the only way we can participate in the Foedus project is to send data directly to the Foedus portal, when they are marked "Send to others (EU)" in the Organ Offer Form. KAJ told the board that on the last EU-CA meeting he felt there was a pressure from the EU commission wanting Scandiatransplant in some way to be a part of this project. The board discussed this matter and it was concluded that the board was very doubtful about the whole project and cannot see how it can benefit Scandiatransplant. Krister Höckerstedt will participate in the next EU-CA meeting and deliver this message. Scandiatransplant programmer Bo Pedersen will participate in this meeting so that any questions arising from how the Scandiatransplant Organ Offer Form works can be addressed.

Scandiatransplant has been asked about new horizon project seeking EU funding with the aim of being able to transplant kidney patients for which you cannot find an acceptable match in Scandiatransplant by increasing the donor population to all of Europe. The project has been briefly discussed in the STAMP group, the tissue typers group, the NKG, and the board. KAJ has given the answer to professor Claas that Scandiatransplant cannot commit itself to such a project before we know more about it. Bjarne Kuno Møller, who is both in the STAMP group and the tissue typers group has accepted to be the Scandiatransplant contact person to this project and the board accepted this.

8. Scandiatransplant participation in EU-CA meetings:

KAJ informed the board about some communication with the leaders of the EU/CA meetings about Scandiatransplant participation in the meetings. KAJ had suggested that Scandiatransplant participates in these meetings as observers with 2 people, one from the board and one from the office. The board endorsed this suggestion.

9. Accounts and budgets:

The annual reports and the long-form audit report from the Ernst & Young revision company had been sent to the board before the meeting. The documents were accepted and signed by all board members. The costs in 2015 had been a little bit less than the budget approved by the council, and there was a positive balance since the income has increased due to an increasing number of transplantations. KAJ intends to ask the council to increase the approved budget for 2016 mainly because Tito is now working full time at the office. KAJ also sees an increased pressure on help to group meetings and other meetings, and it is also the intention of the board to increase the grants, so he will ask the council for a budget for 2017 to increase to 5.7 million Danish kroner.

10. Travel and Research Grants:**Travel Grants:**

No 1 Jytte Graarup. The application falls outside the scope of what the grant should support.

No 2 Thomas Kromann Lund. The application falls outside the scope of what the grant should support. The grant is not for congresses, symposiums and the like, and the board feels that this course falls under this category.

No 3 Hans Henrik Schultz. There was actually an application for two purposes. The first purpose was supported with 12,500 DKK. The second purpose of the application is outside the scope of what the travel grant should support.

No 4 Carina Lund Sørensen. The board grants this application 24,000 DKK on the condition that the project will be effectuated.

No 5 Helge Vikstad and Anna Nordin. This application was accepted and is granted 29,000 NOK.

No 6 Timo Saarinen. The application accepted and granted 13,000 DKK.

No 7 Brian Brikdal Løgstrup. This application was found to be outside the scope of the Scandiatransplant travel grant. It was therefore rejected.

No 8 Petra Vestlund. Application accepted and granted 9,600 SEK.

Research Grants:

No 1 Karin Nystrøm. This study has received 40,000 Euros in 2014. The board acknowledges that it is an important and very good study, but concluded that they will not support it this year.

No 2 Allan Rasmussen. The board finds this a very good study according to the Scandiatransplant research grant, and it was granted 150,000 DKK plus the unused amount from the travel grant (70,000 DKK).

No 3 Hans Eiskjær. The board also found this to be a good study, but only with participation from two Scandiatransplant centers. It will be supported by 150,000 DKK.

The board asked KAJ to put a point on the agenda for the next council meeting to increase the total grants to 600,000 DKK. KAJ asked for grants to be given and registered in DKK in the future. This is due to the legality of the association being Danish, and the exchange rates for Euros vary a little from time to time. This was accepted by the board.

March 1st board meeting:**11. Preparations for the meetings in Stockholm May 2016:**

Lars Wennberg told us that the planning of the meeting is going forward as planned. They have 80 abstracts. The program is almost finalized, they have symposiums and they have international speakers. The dinner will be at Skansen. Support from industry is in place.

12. Any other matters:**a. The board after next council meeting:**

Sweden has suggested Bo-Göran Ericzon as the next chairman of the board of Scandiatransplant. The board supports this suggestion. New board members from Finland have not been elected yet, but will be elected before the council meeting. From Iceland Runolfur Palsson will be the next board member. From Denmark Finn Gustafsson will continue for 3 more years.

A complaint from Gothenburg regarding time tables from a donation process from Finland was discussed. KAJ was asked to request the NTTSG to make guidelines for steps and especially acceptable time limits in the organ donation process of thoracic organs. The opinion of the board is that when the donor operation starts the time table must be set and all discussions about it must stop. It is also the opinion of the board that the donor center is the master in this process, the recipient center must adapt. Krister Höckerstedt went to the Eurotransplant meeting in October 15-16, 2015 and gave the board an overview of his impressions from the meeting. The board again discussed if there was a possibility for fraud to happen within Scandiatransplant like it has in Eurotransplant. We should be very alert to make sure that similar things cannot happen.

13. Next board meeting:

The next board meeting will be in Stockholm on May 10th, 2016 in the afternoon and will continue in the morning of May 11th. The council meeting will be in the afternoon of May 11th. The big issue is to get the suggestion for new articles passed. According to the present articles this need 5/6 majority. In Finland and Oslo they will have a kind of symposium explaining their representatives of the situation. KAJ said he would be very disappointed and would find working conditions for the Medical Director very difficult, if the articles are not changed.

Kaj Jørgensen