Minutes

Meeting No.: 68
Time: Feb. 17, 2014
Place: Copenhagen, Denmark

Participants: The board of Scandiatransplant:
CHAIRMAN: Krister Höckerstedt, Helsinki (KH)
SWEDEN: Lars Wennberg, Stockholm (LW)
FINLAND: Helena Isoniemi, Helsinki (HI)
NORWAY: Pål-Dag Line, Oslo (PDL)
ICELAND: Runolfur Palsson, Reykjavik (RP)
DENMARK: Finn Gustafsson, Copenhagen (FG)

Director of Scandiatransplant:
DENMARK: Kaj Anker Jørgensen, Aarhus (KAJ)

Leader of meeting: Krister Höckerstedt (KH)
Writer of minutes: Kaj Anker Jørgensen (KAJ)

Welcome: Krister Höckerstedt welcomed everybody.
1. Agenda and format:

   No comments.

2. Approval of minutes of board meeting in Oslo September 23rd and 24th, 2013:

   The minutes were approved.

3. Since last board meeting
   a. Status at the Sctp office:

      KAJ had sent a report to the board just after New Year on conflicts ongoing at the office.
      He updated on what has happened since then. KAJ is working on a solution together with the HR-Department at Aarhus University Hospital. The board fully supports the actions taken by KAJ and KH.

   b. Status on YASWA (Peder Nørgaard at 11.30):

      Peder Nørgaard (new programmer at the office) attended this part of the meeting. He gave an overview of why we have to change to the new system. He then showed some diagrams on the complexity of the programming in Scandiatransplant, and an overview of what has already been set into function, what is very close to coming to the stage where it can be set into function, what parts they have not started to work with, and
finally which elements are being discussed if the facilities should be placed under the new system since they have hardly ever been used by the users. Peder would not promise anything, but thought that there was a good chance that we could bury the old Solaris system by the time of the next STS Congress in May in Copenhagen. The boards comment was, that it was “looking good”. FG suggested some kind of accreditation for users. It could be some kind of on-line test the users should pass before gaining access. The reason for this was to reassure the competent authorities and others on the quality of our working procedures. The board again complained on the layout of the reports of activity on the home page. KAJ will take these items up at the office.

c. Meetings with other authorities and groups:

KAJ gave an overview of EU meetings and meetings in committee groups where the Scandiatransplant office had participated.

4. Import and export of organs to and from Scandiatransplant countries 2013:

A document produced by Ilse Weinreich had been sent to the board members before the meeting. 25 organs had been imported, all from Estonian donors. 5 organs had been exported, 4 to Germany and 1 to Holland. The continuing import of organs from Estonia and not exporting any is an ethical problem which Scandiatransplant will have to deal with at some time. However, after the rejection of Estonia's application for membership at the latest Council meeting with reference to Articles of the Association Scandiatransplant, the board does not feel that it is the right time to take this discussion yet. FG pointed out that officially we have the same kind of cooperation with Estonia as we have with Eurotransplant, UK Transplant and others, yet for practical reasons we have chosen to use a Scandiatransplant system (the rota list) to find the correct recipients for Estonian livers.

Regarding the transplantation of hearts from Estonian donors to Estonian recipients in Helsinki, none had been done yet. HI told about some concerns with possible private stakeholders gaining access to transplantation. It was decided, that all the other countries should find out what model they are using for the payment of transplantation of foreigners. These models should then be compared to the Finnish model to see if there is a problem. Scandiatransplant will be seriously concerned if areas of transplantation are going to private, non-public stakeholders.

5. Classification of death cause in SCTP registry (Helena Isoniemi):

HI had made an overview of deceased donors' death causes in different registries and sent them to the board members before the meeting. The issue was discussed and it was decided that HI should come up with a suggestion of causes of death in deceased donors. KAJ gave a short overview of causes of death in the Scandiatransplant system for recipients of organs. KAJ has received complaints on the causes of death in the living donor registry. He proposed that the NKG should be asked to prepare a list for this, but this suggestion was turned down by the board. The board wants the list of death causes in the living donor
registry to be the ICD codes built up in their hierarchy. KAJ will discuss this with the programmers.

6. **Suggestion for SAE/AE definitions (see minutes of NTC meeting September 24th, 2013).**

Krister Höckerstedt asks each board member to send out beforehand to all of us the standing of this issue in their respective countries.

LW had sent out an overview of the legislation in the different Nordic countries before the meeting. This overview had been sent out earlier. HI showed us the legislation that had just come into place in Finland. The legislations in Norway, Sweden and Denmark are quite similar, while the Finnish is much more loose. The board still thinks that Scandiatransplant should come up with suggestions and offer to register these events. The logic is that there has to be traceability and it is in the Scandiatransplant system that the donor and the recipient are coupled. Ideally, such a system should be able to automatically report such events to the relevant competent authority, so that they only had to be reported in one place. LW will work some more on suggestions and these will again be taken up with the competent authorities at the next NTC meeting in the fall of 2014.

7. **Accounts and budget:**

The written annual report 2013 and the long-form audit report and financial statement for 2013 were signed by all board members. These reports had this year been written in both Danish and English and the amounts were in both Danish kroner and Euros. FG pointed out that there had been quite large increase in the point called board duties, meetings, hotels, travels, etc. KAJ should explain at the Council meeting that items like user education, committee meetings and compensations are all in this sum.

8. **Travel and Research Grants:**

Research Grants:

There were 2 applications:

FG was biased for the discussion of research grants and left the room while the board decided the grants.

One from Jouni Lauronen, Juha Peräsaari, Jan Holgersson and Christian Naper. The board discussed this application and turned it down due to the fact that there were no permissions from the ethical committee.

Application No 2 was from Kari Nytrøen, Marianne Yardley, Finn Gustafsson and Kristjan Karason. The board decided to award 40,000 € to this randomized controlled study entitled: Effect of exercise after heart transplantation – short term and long term.

Travel grants:
Grant No 1 was an application from Einar Gude to visit Toronto General Hospital and Copenhagen. The board decided to grant him the amount applied for, namely DKK 23,500.

Application No 2 from Per Arne Bakkan. The application was for 3 transplant coordinators from Oslo to visit Bristol and 2 unnamed donor hospitals in London or in the area nearby. The board decided to grant DKK 15,000 to this application.

Application No 3 from Åsa Svärd and Tanja Hölvold, two transplant coordinators from Stockholm to visit Oslo. The board decided to grant these applicants DKK 10,000.

Application No 4 from Hans Henrik L. Schultz who applied for 2 months' stay in Leuven, Belgium. The board was of the opinion that this was outside the scope of the travel grants, but awarded him DKK 10,000 for travelling expenses.

Application No 5 from Margret B. Andredottir to visit Rikshospitalet in Oslo was awarded DKK 7,900.

Application No 6 from Ilkka Helanterä from Finland to study living kidney transplantation in Rotterdam was awarded DKK 15,000.

9. Changes in articles:

The board adopted the suggestion from KAJ to form a group to investigate the need for a major update of the articles and to come with suggestions for changes. It was suggested that such a group should comprise of one person from each transplant center, KAJ as secretary, a programmer from Scandiatransplant and a lawyer from Region Midt. KAJ was asked to prepare a mandate for such a group so that the suggestion could be set forward at the next Council meeting in May 2014.

10. Any other business:

FG gave an overview of the present status of the organisation of the next STS congress, it looks like everything is working out fine. The website is well-functioning and it looks like the participation will be at least as good as former years, and that there will be both international speakers and participants.

11. Next meeting, time and place:

The next board meeting will start at 16:00 at the Copenhagen Island hotel on the 6th of May 2014.

Kaj Jørgensen