

Minutes

Meeting No.: 80
Time: 2nd Oct., 2017
Venue: Scandic Park Hotel Helsinki, Finland

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

Invited associate member representative:
ESTONIA: Virge Pall, Tartu

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 to the meeting in Helsinki.

2) Approval of minutes of last Board Meeting (79th, May 9th and 10th, 2017, Helsinki):

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-board/MinutesBoardNo79Helsinki910May2017.pdf>

Minutes were approved.

3) Status at the Office:

Kaj informed the board about the personnel at the office. At the last board meeting the situation was that important persons were on sick leave. Everybody is now working full time again. Peder Nørsgaard has resigned and has left the office. On September 21st the office was visited by Bo-Göran who told that he was happy to see that the office was working well. The office had a theme day on September 6 and 7. The focus was on how we do the work with special focus on the programmers. The use of bugzilla was discussed, also documentation of the Yaswa system and possibilities to make parts of Yaswa open source.

We have hired a new student programmer 10 hours a week. His name is Poul Kruse-Hansen, he is on his next last years before taking his master in computer software science. We have plans to hire a new programmer on full-time who can use some of his time on how to make parts of Yaswa open source. We will not advertise for this before we have room for more Scandiatransplant personnel which we have been promised. There has been discussion of hiring a programmer at another transplant center maybe Tartu, but all board members agreed that this was not a good idea for the time being.

4) Update on Data Processor Agreements, STEP and deceased donors' death causes:

The data processor agreement with Tartu is now ready for signing, and we therefore have seven of the eleven hospitals with data processor agreements. Oslo, Stockholm, Uppsala and Skåne are still missing. It was decided that we should send a reminder to the directors of the remaining Swedish hospitals about this. Morgen Hagness told of special difficulties in Oslo, but he had been told by Pål-Dag that there will soon come a development .

Regarding STEP: Kaj told the board that the size of the job to integrate STEP into Yaswa has proved to be much larger than anticipated in March. At that time we thought we could use what was in STAMP. It has taken some time to get an agreement between the tissue typers on how the immunological matching is to be done. It seems like they have agreed on a meeting on September 23rd 2017. They want readouts directly from the Luminex, and it seems like they want all data put into Yaswa and not just the final assignment. The data for STEP will therefore be kept completely separated from the STAMP and other data. This means that the job in programming is large, but the hope is that if it succeeds and works well in STEP it may also be used in STAMP and maybe later for all patients. Some preliminary programming adjusting Yaswa to STEP has been done.

Deceased donors' death causes: The revised deceased donor causes have now been implemented in Yaswa. In the old codes about 10% were grouped in "other causes" and after translating the old codes to the new one, about 35% are in the group "other causes".

5) SAE/SAR:

The program is close to being complete. It has been tested by Lars Wennberg and he has suggested some alterations which will be made soon. Lars Wennberg will demonstrate the program at the NTC-meeting tomorrow. The board will tell the NTC-meeting that we expect the program to be up and running by Januar 1st 2018.

6) Hepatitis C, Group: "Prevention of transmission of infections":

The council meeting in 2017 gave the board the job of reorganizing this group so they could become more effective. Bo-Göran has contacted Vanda Friman who is still willing to lead the group and she has contacted the previous members if they want to continue. Copenhagen and Sweden have members who want to continue, and Bo-Göran has asked the board members from the other four countries to find new candidates. These are Morten Hagness from Norway, Mar Kristjansson from Iceland, Veli-Jukka Anttila from Finland and Anne Kallaste from Estonia. Bo-Göran will ask Vanda Friman to form the group and to hold a new meeting to get the group working effectively. Scandiatransplant will support this meeting economically.

7) EDITH – Participation in EU-funded projects:

There was a quite thorough discussion of this matter but the conclusion was that Scandiatransplant does not want to be a partner in this project. The reasons are that in Scandiatransplant we have the registries and we prefer to use energy in making these better than in projects that we do not think will be of benefit for the patients in the Scandiatransplant area. There is not resources and time to do the work needed for these projects. The board will discuss this at the NTC-meeting and tell them the opinion of the Scandiatransplant board, but it is of course up to the CAs to decide whether their country should participate in these projects.

8) Estonia now associated. LOGO?:

It was discussed if we should have a new logo. It was finally suggested that there should be three shields on the Viking ship. The first shield should be in Estonian colours and the next two shields should be black. Kaj will try and find out if the one who designed the logo has comments or maybe can do this. This led to a discussion of the exact Scandiatransplant history. It was decided that we have to contact Arnt and try to get a clearcut description of the 1969 meeting which is supposed to be the start of Scandiatransplant. It was suggested that the very few people who were active in this and who are still living should be contacted or maybe even get together and clear up this matter. The 50 years jubilee of Scandiatransplant in 2019 was also discussed. There were many suggestions in place. We will discuss this further at the next board meeting. The suggestion that was most in favour was that the jubilee was held in the spring of 2019 in Aarhus in conjunction with the council meeting and that the 2020 STS meeting in Helsinki should continue this celebration.

9) NTC meeting:

The board went through the agenda of the NTC-meeting and discussed how to go through the points and present them for the competent authorities.

10) Next meetings (Tuesday Dec. 4th & 5th, 2017, Tartu?; March 5th & 6th, 2018, Aarhus?):

It was decided that the next board meeting should be on the **9th of January 2018** in Tartu.

The following meeting should be on **March 5th and 6th 2018** in Aarhus.

11) Any other business:

Under this point Bo-Göran had sent out a document from the European council on registration of patients transplanted abroad. Kaj was to find out if a transplantation with an unknown donor could be registered in Scandiatransplant and also if this cannot be done, how much work it would take to make it possible. The question will then be discussed again at the next board meeting in Tartu.

Kaj Jørgensen