

Minutes

Meeting No.: 81
Time: 8-9 Jan., 2018
Venue: Hotel London, Tartu, Estonia

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 bid everybody welcome to the board meeting.

2. Scandiatransplant's 50 years' celebration (bus ride):

There was an open-minded brain storming on how this should be, and what we should do for the Scandiatransplant 50 years' celebration in 2019. It was agreed that we will have an event in Aarhus in May with a council meeting in the morning and an event in the afternoon and in the evening. It was concluded that the event should be in two parts, first a form of symposium in the afternoon and then later a galla dinner or reception. The target for this event would primarily be the general public, the media, patient organisations, and health authorities. We expect participation of about 200 people. The symposium should have something about the start of Scandiatransplant and the history, but it should also focus on what Scandiatransplant does and has done through the years. It was discussed who to invite to participate and it was mentioned that maybe Lars Wennberg could ask prince Daniel of Sweden if he would participate, and Kaj would explore the possibility to have crown princess Mary of Denmark, who is the protector for both the kidney patient organisation and the heart patient organisation. We agreed on trying to make a video of about 15, max. 20 min., showing what Scandiatransplant does and having short statements from patients from all the countries. All the board members believed that they had good video material from different sources, and they will find this. Bo-Göran and Lars Wennberg will try to make a manuscript for this video. It was then discussed to contact a professional company to make the video, or maybe try to go to the media school, if somebody there could help make the video.

It was also mentioned that Erik Thorsby, who probably is the only living person, who

participated in the first meeting in Scandiatransplant in 1969, should give a presentation on the early history, but he should discuss this with Arnt Jakobsen, who is writing the history of Scandiatransplant. We should contact the Nordic Council and ask if they have any wishes to influence the event, or to support it. It was discussed to invite competent authorities or health ministers, but the pros and cons for this actually did not reach a conclusion at this meeting. The budget was discussed, and this would of course depend on how much responsibility for the event that the Århus University Hospital or Aarhus Kommune (municipality) would take for the event. The budget between a half and one million crowns was discussed, but some felt that this was too high and could be difficult for the council to accept. We also thought that there should be some kind of registration with a symbolic fee to participate. In conclusion Kaj was given the task of approaching the journalists and PR-service of Aarhus University Hospital and ask them for advice and also find out how much Aarhus University Hospital would support the event. Kaj should also try and find out if the mayor of Aarhus was willing to support. It was discussed to have it in the hospital, but it was also discussed to have the event out in the city of Aarhus, maybe the town hall or maybe the Aros museum, this depending on how much Aarhus Kommune (municipality) was interested in investing in the event. For the time being the whole board will be the group in charge of the event. After Kaj has made some research in the hospital and in the Aarhus Kommune (municipality) we will discuss this at the next meeting in March and then try to make a budget which we can get the council to accept in May.

3. Approval of minutes of last Board Meeting (Oct. 2nd, 2017 in Helsinki):

http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-board/MinutesBoardNo80Helsinki2Oct2017_KAJ2.pdf

Kaj went through the minutes and these were approved. The last points in the minutes regarding registration of patients treated at Scandiatransplant centers, but who were transplanted outside of Scandiatransplant, was not discussed at this meeting, but was postponed until the meeting in Aarhus in March, because Kaj feels it was important to have the Scandiatransplant personnel to take part in this discussion due to the way Yaswa is built up and works.

4. Status at the Office:

Kaj shortly told the board that we will very shortly advertise for a new high-level programmer. We should have half-time of his job to document and prepare Yaswa or parts of Yaswa for open source.

5. Short update on Data Processor Agreement, SAE/SAR, STEP, EDITH, Sctp logo, and the group "Prevention of transmission of infections":

We now have a data processor agreement for Uppsala, we are still lacking Stockholm, Oslo and Skåne. It seems that for at least Stockholm and Oslo we just have to wait. The SAE/SAR functionality is now in Yaswa and running. It was decided that Bo-Göran Ericzon should write a short letter to encourage people to use this SAE/SAR reporting facility and this letter should be mailed to all our users. Kaj told them that the EDITH project people are still asking why we do not want to participate in this project, and the board agreed that we have exactly the same reasons for this as we have given them previously.

Scandiatransplant logo: This was discussed with the examples that had been sent out from Steffen Ellebæk Pedersen. It was decided that Kaj should ask Steffen to try and make a logo with just one shield in the Estonian colours, or with six or seven shields where one was in

Estonian colours and the others were semi-transparent. This suggestion should be sent out to the board, and we will look at it in March and see, if we have a suggestion ready for the council meeting in May. The group for prevention of transmission of infectious diseases: The group has now been reformed and they will hold their first meeting in April. The office will help in arranging this meeting.

6. STS congress 2018:

As the tradition is all the board will participate. We also agreed that we will have a board meeting in the morning of May 2nd at 09:00-12:00, and not have a board meeting late on May 1st as the tradition is, this is because we think we can do it in a short time when we just have had a two-day meeting in Aarhus in March. Morten Hagness told us that the work with the arrangement for the STS is going forward nicely as planned.

7. Visit transplantation team at Tartu University Hospital:

This was the main issue of this board meeting. The board was first presented to people performing the different types of transplantations in Tartu, and they gave an overview of the history and the status. After that the board went on a tour of the hospital seeing the laboratory, the immune laboratory, the intensive departments, the operating theatres, and the wards. All board members were impressed by the very good facilities and working conditions the hospital had.

8. Any other business:

Kaj asked the board if they had suggestions for subjects or issues they wanted presented in the annual report. This quickly led to different suggestions. One was looking at the age of the donors over time for the different organs, it was suggested to give the donors as donor per ten thousand deaths in the country. It was suggested maybe to look at the donor death causes since this has been revised, and there was also suggestion of a comparing for example age or death causes with other international figures. It was concluded that Kaj would discuss this with Ilse and see what was feasible and this suggestion would be sent out to the board who were to comment within one week, if they had further ideas.

Virge Pall had announced that they want to work on some kind of twinning agreements with Latvia on lung transplantation. They would put something in writing, and this should be sent to Kaj at the office in Aarhus, and he will send it out to the board, so they can discuss and comment, and we can have a serious discussion of it on the meeting in March in Aarhus.

9. Next meeting already decided: 5th and 6th March, 2018 in Aarhus:

Next meeting had already been decided.

10. Use of Scandiatransplant resources for non-Scandiatransplant tasks (bus ride):

This point was not discussed or taken up at all. It quickly proved that it was impossible to have any reasonable communication on the bus rides.

Kaj Jørgensen