

**Minutes**

**Meeting No.:** 82  
**Time:** 5-6 March, 2018  
**Venue:** Hotel Fru Larsen/Aarhus University Hospital

**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 (BGE):**

Bo-Göran Ericzon bid everybody welcome to Hotel Fru Larsen. Board meeting March 5<sup>th</sup> was held at Hotel Fru Larsen in Laurbjerg and the second part of the board meeting (March 6<sup>th</sup>) was held at Aarhus University Hospital together with the staff at Scandiatransplant.

**2. Approval of minutes from the last Board Meeting (KAJ):**

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-board/MinutesBoardNo81Tartu89Jan.2018.pdf>  
The minutes were approved.

**3. Status at the Office (KAJ):**

Scandiatransplant has advertised for a programmer. There have been 7 applicants, but only 3 which may be of interest. These 3 will come to interviews on Friday March 9<sup>th</sup>.

**4. Status on Data Processor Agreements and STEP (KAJ):**

There is now a signed data processor agreement with Skåne University Hospital. We are now only lacking Oslo and Stockholm. Status on the STEP was given by Ilse Weinreich in the second part of the meeting on March 6<sup>th</sup>. Ilse Weinreich showed each task and status on these in relation with incorporating STEP into YASWA. There has been a lot of work on the antibody registration and import of bead raw data from the fusion software in the Luminex. Test runs are ongoing and it is quite close to be finished. The enormous amount of data from the Luminex will be kept and treated in a PostgreSQL database. When this is accomplished it will be possible to make the medical match and continue with the algorithm given to us by professor Tommy Andersson.

**5. Accounts 2017 – Budget 2018 & 2019 (KAJ):**

The board had received all the documents from the revision company Ernst & Young before the meeting. The documents were signed. Kaj explained that the main reason for using less money in 2017 than anticipated was that our programmer Peder Nørgaard had left us and also, that a big research grant could not be paid within the 2017 budget, but will be paid in 2018. For this reason Kaj will stick to the budget for 2018 that the council accepted last year and will ask for a small increase in wages for the budget for 2019.

In the document from the revision company on page 6 it states *“Every Nordic country shall have at least one member. Members of the Association can be all hospitals/hospital units in the Nordic countries which perform transplantation and which are economically responsible”*. This wording is copied from the articles of the Association Scandiatransplant article 4. The wording cannot be used in context of the annual report and should be changed. Kaj will circulate a suggestion for new wording to the board, and when we agree we will ask the revision company next year to use a new phrasing.

**6. Travel Grants:**

There were 3 applications.

1. Sini Puputti asks for money to visit Toronto General hospital. Was granted 12,500 DKK.
2. Ingebjørg Kvangarsnes from Oslo wanted to visit Edinburgh and observe the use of perfusion in controlled donation after cardiac death. A grant of 19,500 DKK was given.
3. Carina Lund Sørensen asks for money to visit the centers in a liver transplant study. She was granted 36,000 DKK.

Since the total amount for the grants is DKK 150,000, DKK 82,000 will be added to increase the grants next year.

**7. Research Grants:**

There were 3 applications, but 2 of them were projects conducted in one country only, and are therefore outside the scope of what the grant can support.

Göran Dellgren from Gothenburg was awarded 370,000 DKK for a sub-study on donor specific antibodies in the ScanCLAD study.

Since the total amount for granting is 450,000 DKK, 80,000 DKK will be transferred to next year's grants.

The board discussed that this year and in preceding years there had been very good projects which could not get support due to the rules for granting that we have at this time. Since Scandiatransplant is an association of hospitals and not of countries we should have a thorough look at the rules and at the application forms. Finn Gustafsson, Morten Hagness and Arno Nordin will do this and come up with a suggestion to the board, hopefully in time so that we can send it out to the representatives and it can be discussed at the council meeting.

**8. Council meeting May 2<sup>nd</sup>, 2018 in Oslo:**

- a. New Board member from Sweden (LW, BGE)

Lars Wennberg will leave the board and Sweden must find a replacement and also a replacement of the substitute. No other board members or chairman are up for election.

**9. STS 2018 Oslo (MH):**

Morten Hagness demonstrated the scientific program and told that the number of people registering for the congress is very satisfactory.

**10. Tartu/Latvia cooperation in lung transplantation (VP):**

There was a general consensus that the draft for an agreement complied with the Scandiatransplant guidelines. There was a little discussion of what the teaching element should fulfill. Paying for transplantation should come from public funding and not from patients paying themselves. It should therefore be stated, that transplantation of Latvian patients in Tartu must be financed by public funding. Virge Pall will edit the agreement accordingly before the next Board meeting. There was still however a quite critical attitude to accepting such an agreement. The main concern was that this was in some way making Latvia some kind of member of Scandiatransplant at a stage where we know very little of the system in Latvia, and if it can comply with Scandiatransplant rules. The board will briefly discuss the revised agreement at the next board meeting and plan to ask the opinion of the Scandiatransplant heart and lung group.

**11. Registration of recipients transplanted outside of Sctp (BGE):**

One of the very important features in the YASWA system is to have complete traceability from donor to recipient. For these reasons some basic donor information is necessary to register a transplantation. If we are to register patients, where we have no basic information about the donor, we would have to violate this principle. Ilse Weinreich demonstrated how the system works and how it might be possible to make such registrations in different situations. It ended with two possibilities being discussed.

1. One should be able to make a tick in a check box and then you can register a donor with no basic information or very little basic information.

2. The other suggestion was that this could only be done at the office of Scandiatransplant. After a lengthy discussion it was decided to make it possible for the office personnel to register a donor with none or very little basic information. This means that when the departments wish to register such a transplantation they have to contact the office. We believe there will be very few registrations, and in that way we would not jeopardize the main system. Bo-Göran Ericzon said that the main reason for wanting to do this is to ensure that SAE/SAR that occur in such recipients can be reported to the competent authorities. He thought it would be best for us to be proactive and have such a possibility rather than waiting for the competent authorities to come and ask us to do it.

**12. Scandiatransplant 50 year celebration (KAJ):**

The board had received a document from Kaj stating the status of what had been done until now for this. The plan A is to have a ceremony from 14:00 – 16:00 in the Town Hall of Aarhus. We are not 100% sure that this will be possible, but we think it will be possible and it will be clarified soon. This should be followed by a dinner at the ARoS museum at 18:00-22:00.

When the royal mourning is over in Denmark, the patient associations for heart and kidney patients will ask their protector Crown Princess Mary of Denmark, if she could participate on this occasion. Lars Wennberg has asked Prince Daniel of Sweden if he can participate. He has not given an answer, but is considering this. The main reason for wanting royal participation is to attract the press and the media. Visit Aarhus has offered to help making a video and also to pay for it with an estimated amount of 40,000 DKK if the video is produced this year. They suggest we use a company called Click Film and a journalist called Michael Johnsen, who has previously made similar videos for Aarhus University Hospital. The focus of such a video should be on the patients and what Scandiatransplant has done for the patients. It was

suggested that the video was made in chapters with each chapter having a certain focus. The chapters could then be used as independent videos or be shown in a sequence as a long video. The total time should be about 15-20 minutes and it should be shown at the ceremony. It was concluded that the board needs a meeting where they discuss exactly this video and nothing else, and it was decided that this meeting would take place Friday afternoon after the STS in Oslo, since it was very difficult to find an alternative date. Before that each board member should find two or three patients who have a very interesting story which can appeal to the media and the press. The journalist Mikael Johnsen should be invited to participate in this meeting in Oslo.

After that there was a lengthy brainstorming on who to invite to the ceremony and the dinner. Kaj had prepared a list just to start the discussion. It was concluded that the board members should think and make a list, and that we should have a meeting early in August and decide who to invite, who to pay for travel, accommodation, and both travel and accommodation. It was decided that we need some kind of registration. To try to avoid misuse, there should be a low registration fee and this was set to 200 DKK. Kaj will ask Visit Aarhus if they have someone who can take care of such things. Bo-Göran Ericzon stressed that we should invite 250-300 people if we want a participation of about 200 people. Then the program was discussed shortly. There should be a little bit about the history of Scandiatransplant, maybe 15 min. with focus on how it started, and we thought Erik Thorsby could give such a talk as the only living person from the start of Scandiatransplant. The main focus should be on patient stories and the video. If we have royalties participating, it was suggested that we ask them if they could accept being ambassadors for Scandiatransplant representing both the patients and the Nordic cooperation, and then part of the ceremony would be to give them something to remind them of this and the day. There should also be a presentation but very short of what Scandiatransplant is today and a thank you to Aarhus University Hospital for hosting Scandiatransplant through all these years. It was discussed if there should be some music both at the ceremony and also at the dinner. The arrangement at the dinner as proposed was to start with a welcome drink walking around the museum and see the exhibition they have. Then there should be a first and a main course of the dinner where there should be a few speeches from people, who have been asked to give them. Then there should be a walking dessert where people could walk around the rainbow in ARoS and also around the art exhibition.

**13. Any other business:**

The was no point for this.

**14. Next Board meeting in Oslo May 2<sup>nd</sup>, 2018, 9.00-12.00:**

Next board meeting will be in Oslo May 2<sup>nd</sup> 2018 from 09:00-12:00