

Minutes

Meeting No.: 84
Time: 1. Oct., 2018 at 09:30-13:00
Venue: V Spa Hotel & Conference Center, Tartu, Estonia

Participants: The board of Scandiatransplant:
CHAIRMAN: Bo-Göran Ericzon, Stockholm
SWEDEN: Tomas Lorant, Uppsala
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

Agenda:

1. Welcome:

Bo-Göran welcomed everybody to the meeting and gave a special welcome to the new member of the board Tomas Lorant.

2. Approval of minutes from the last Board Meeting (83th, 2nd May, 2018, Oslo):

http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-board/Minutes_Board_No_83_Oslo_2_May_2018.pdf

The minutes were approved.

3. Status at the Office:

– a. Personnel:

Lorraine Mortensen started in the office in May 2018. Her strength in the office is in documentation and systematization of the programmers' work.

The office will have a seminar at Hotel Fru Larsen on Nov. 26-27. The main topic will be GDPR.

– b. GDPR:

Kaj showed a power point presentation of this issue prepared by Ilse Weinreich. The main conclusion of this presentation was that the GDPR was a regulation which means that it is the same law in all member states and it replaces a directive where all the member states made their own interpretation of the directive. This is an advantage for Scandiatransplant as all members now apply to the exact same regulations. The goal of GDPR was to balance protecting the rights and privacy of personal data and reducing barriers by facilitating free movement of personal data. Regarding the consent needed it is important that the hospitals are the data controllers and

Scandiatransplant office is the data processor, which means that the responsibility for consent lies with the hospitals who are the data controllers. It is essential for the GDPR as it was for the directive, that we have data processor agreements with all the member hospitals. Scandiatransplant does not delete data as data are used to approve future practice and needed if patients need a re-transplantation, but data access is restricted in Yaswa. Scandiatransplant have developed a standardized report if a data breach occurs. In the conclusion we are pushing hard to get data processor agreements in place with all hospitals, we are working on improving documentation through ISO 2701+27002 compliance, and data protecting is the basis of all the structures in the it-system and will be a fundamental part of all new developments. So seen from a Scandiatransplant view we are well on the way, however it will be and should be an ongoing project.

– c. STEP:

The programming is now finished in the sense that we have made the program and coded it as well as possible, but we are waiting for the immunologists before it can be correctly tested. The big job in this sense has been the direct import from Luminex and that the tissue typers have decided that in the STEP program the tissue types have to be with four digits.

4. COM/CA meeting Brussels June 27-28th, 2018:

– EDITH, transparency register, perfusion machines:

Kaj participated in this meeting on June 27th, was not able to participate in the meeting on 28th. There was again laid pressure on Scandiatransplant to participate in some of the workshops of the EDITH project. Kaj had told the commission and the CAs that this issue had been debated at least at two board meetings and for the time being Scandiatransplant does not want to participate in this project.

The commission has realized that there is something called perfusion machines and they will be looking into if this increases the risk of criminal activity in transplantation.

The EU has made a registry called the transparency registry for people who want to influence the work in the EU (primary lobbyists). It has become clear that Scandiatransplant cannot participate in the COM/CA meetings, if they do not register in this registry.

Scandiatransplant has therefore been registered in the transparency registry in the EU.

5. Balttransplant ?:

Kaj had raised this question because there is still in the it-system of Scandiatransplant reminiscence of the Balttransplant. It is now clear, that Balttransplant does not exist. According to the Latvian database of enterprises, Balttransplant was closed on the 24th of January 2008. There is therefore no organisation called Balttransplant anymore.

6. Scandiatransplant LOGO:

The board discussed the different suggestions put forward by Steffen Ellebæk Petersen after decisions of the board last time we discussed this. The board was in favour of his suggestion No. 6 showing overlapping shields and with the four last shields showing increasing transparency. The Board asked for a new suggestion, where the letters in Scandia were raised a little or decreased in size so they don't collide with the shields. The shields should stay in the same height as they have on the suggestion. The title must be changed to: Founded in 1969 by the Nordic Council. The title that it was founded by the Nordic Council of Ministers is not logic since the Nordic Council of Ministers was created in 1972. Kaj will deliver this message to Steffen Ellebæk Pedersen and ask if he will try to

make a new proposition following this suggestion. Virge Pall was asked if she was satisfied with this suggestion, and she had discussed it with her colleagues, and they were satisfied and they had concluded, that the shields were more important than the sail, when it actually comes to combat.

A follow-up on the answer we gave to Lithuania's application 2 years ago was discussed. It was decided should give them a response stating, that it was still to early consider further enlargement of Scandiatransplant. It was also thought that it was to early to make a status on how the membership of Estonia has worked out.

7. NTC meeting:

The board went through the agenda and a power point presentation that Kaj had prepared, which will be shown in the NTC meeting, and the points were discussed on roles and who is to deliver the message at the NTC meeting.

8. Cornea bank application:

Application from the cornea bank in Aarhus representing all Denmark. Pernille Koefoed-Nielsen had sent an application to Scandiatransplant for permission to put a donor search into Yaswa so it would be easy and replace a lot of manual work to search for an HLA matching donor when a special cornea recipient needed such a donor. It was estimated that the work would be one week of programming work and one week of testing by Ilse and it would cost Scandiatransplant 25.000-30.000 DKK. The eye bank was willing to pay this. This point was discussed heavily in the board because corneas are outside the purposes of Scandiatransplant laid out in article three. On the other hand Scandiatransplant would like to support the use of the data and the programming we have in Scandiatransplant for other matters. There was a lot of discussion if donor recipients should be registered in Scandiatransplant and therefore the hospital should pay Scandiatransplant for such a transplantation. There was no agreement on this subject. The conclusion was that the applicants should be asked for an exact manual of how this should work in practice and what they want.

The board would be positive for a pilot study of this within Scandiatransplant limited to Aarhus, but of course if it works, it should be able to be used at all Scandiatransplant member hospitals. Each board member should investigate what is the current situation of cornea transplants in their countries. Pernille Koefoed-Nielsen should be invited to present the application and explain to the board exactly how this is going to work at the next board meeting on March 5th at Clarion hotel Kastrup Copenhagen in 2019. One board member questioned if there at this time is good evidence that HLA matching improves the survival of these special cornea grafts.

9. Next Board Meeting (March 4th & 5th, 2019. Århus?):

It was decided to have the next board meeting on March 5th 2019 at Clarion hotel in Kastrup as a one-day meeting. The major issues will of course be:

1. Revision report, signing of these and budgets.
2. Grants
3. 50 year jubilee

10. Any other matter: None