

Minutes

Meeting No.: 71
Time: 24.02.2015
Place: Copenhagen, Denmark

Participants: The board of Scandiatransplant:

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| CHAIRMAN: | Krister Höckerstedt, Helsinki | (KH) |
| SWEDEN: | Lars Wennberg, Stockholm | (LW) |
| FINLAND: | Helena Isoniemi, Helsinki | (HI) |
| NORWAY: | Pål-Dag Line, Oslo | (PDL) |
| ICELAND: | Margret Andresdottir, Reykjavik | (MA) |
| 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)

AGENDA

Welcome

Krister Höckerstedt welcomed everybody to the meeting.

1. Agenda and format:

No comments.

2. Approval of minutes of board meeting no. 70 on Sept. 29-30 in Stockholm 2014:

The minutes were approved but there should be a change in point 3a, line 10 where it should read: *The 10 Nordic hospitals*, instead of just the 10 hospitals.

The opened matters from the last meeting would be addressed at the present board meeting.

3. Status at the office:

KAJ told that the office had had a theme day on the theme how we could get YASWA finished as quickly as possible. We are also under pressure from the Region Midt IT to become independent of the old Solaris server SC15.

KAJ has had MUS (medarbejderudviklingssamtaler) with all the employees, and they have received new descriptions of functions. Ilse's and Frank's title has been changed from "System Administrator" to "Clinical Data Manager". Ilse Weinreich has been appointed substitute for the Medical Director when he is not present, so her title has become "Clinical

Data and Office Manager”. The new descriptions of functions emphasize cooperation and good documentation.

KAJ told the board that our programmer Peder Nørgaard has been ill for some time. He had therefore been on and off at work. This has caused considerable delay in the development of YASWA. We are optimistic that the correct diagnosis and therefore the correct treatment can be given. We are looking forward to having him back to the office at work. KAJ promised the board to keep them updated of the situation at the next board meeting in May.

4. Revised accounts (2014) and budget proposal (2015/2016):

The annual report for 2014 and a long-form audit report for 2014 together with a long-form audit report document on responsibility and objective of the audit were all accepted and signed by all board members. A copy of each document was also signed, as was the documents translated into English, 12 documents in all. KAJ will propose to the health representatives, that the budget for 2015 should be the one accepted by the council in 2014, and the suggestion for the budget for 2016 would be the same as 2015 except that it was expected to use 100.000 DKK more on consultants. This is mainly to expected expenses to the hired lawyer in connection with the major revision of the articles.

5. SAE suggestion to CA. Sweden, Finland, Denmark:

In Sweden the reporting of serious adverse events has been changed from Socialstyrelsen to a new body called IVO. Lars Wennberg is in dialogue with this new body. Lars Wennberg will report to the office, who we are to invite to the next NTC meeting in Copenhagen in September. In Sweden they will not give us any answer before their investigation of transplantation is finished.

In Finland these are reported to a body called FIMEA. At this time we should invite the same persons from Finland to the NTC meeting as we have done before. Helena Isoniemi will inform the office, if we are to invite some other persons.

Denmark. Denmark has sent an e-mail asking why the serious adverse events in the Scandiatransplant suggestion are not named exactly the same as in the text of directive. KAJ has given them an answer, but also told them that at least Sweden will not answer yet, so Denmark is also waiting.

Norway. In Norway they think these reactions should be reported as any other reactions. It seems that they would accept if Scandiatransplant is the place where serious reactions in relation to transplantation are logged.

Iceland. There is no answer from Iceland.

The conclusion was that Scandiatransplant board and office should and cannot do anything regarding this matter before the next NTC meeting in September.

6. EU “Indicators” Exercise. CA meeting in Brussels March 11-12:

KAJ had beforehand sent a mail to the board regarding these Indicators Exercise as part of the “Action Plan on Organ Donation and Transplantation” which has run from 2009 and will end in 2015. At the meeting in Brussels it will be decided how to continue after 2015. The working group on these indicators has received some options for continuation. The first option is to stop collecting these data. All board members agreed that this was the preferred option. Scandiatransplant will advise the competent authorities of the

Scandiatransplant countries to vote for this option if they are present at the meeting. The main reason for wanting to stop collection of these data is that the board members cannot see the reason to collect them, the quality of the data already collected is very questionable, and collecting the data involves a lot of work for the involved parties.

7. Grants:

Travel grants: There were 4 applications. All the applicants were granted the money they applied for.

| Applicant: | Purpose of study travel: | Amount applied for: |
|---|--|----------------------------|
| No 1 Hildigunnur Friðjónsdóttir coordinator Reykjavik | Visit to the University Hospital in Nottingham, UK. The purpose of the visit is to learn about the clinical practice of nurses in the field of transplantation at their hospital | DKK 10,000.- |
| No 2 Sif Hansdottir MD, PhD Reykjavik | Visit to Sahlgrenska University Hospital's Transplant Center, Sweden to build on my knowledge fund and to further strengthen the relationship. | DKK 4,600.- |
| No 3 Thordis Hrafnkelsdottir MD, PhD, Reykjavik | Study visit to Gothenburg transplantation center to investigate possible heart transplant recipients, perioperative management and postoperative problems, and to meet the caregivers. | 1050 € (=DKK 7,875) |
| No 4 Carola Schauman coordinator Helsinki Chair of NTCG | NTCG want to visit Tartu University Hospital, meet our colleagues and doctors to achieve and share knowledge in the field of transplantation. | 3050 € (=DKK 22.875) |
| | | |

Research grants: There were 3 applications.

No1 Mitra Rashidi, Oslo: *Surgical complications in the (post) cardiac transplant patient.*

This application was rejected. The board found that the application was not good enough, but the researcher can apply again with an improved application including either permission from ethical committees or considerations if approval of ethical committees is not necessary.

No 2. Taina Jaatinen, Helsinki: *Comparison of HLA antibody testing methods in highly sensitized patients.* This project was granted 20,000 €.

No 3. Hans Henrik L. Schultz, Copenhagen: Priority for urgency in lung transplantation – Scandiatransplant Urgent Call compared with the Lung Allocation Score.

This project was also granted 20,000 €.

Under this point, two other matters were discussed. First the NTCG had asked the board if they could have their annual meeting in Estonia this year. They wished to visit this country because they have had many contacts with Estonia due to the many organs exported from Estonia to Scandiatransplant. The chairman of the NTCG Carola Schauman sent this request addressed to the board in a mail to the chairman of the board and the medical director. After consultation between the chairman and the director the NTCG was granted permission to have their annual meeting in Estonia. This decision was unanimously approved by the board. It was emphasized that this was just an ordinary, annual meeting in the NTCG, and cannot be taken as any political statement from the Scandiatransplant organisation

The other matter discussed under this point was brought forward by Finn Gustafsson. He asked if it was time to reconsider the way Scandiatransplant supports research. He had a suggestion that Scandiatransplant maybe should put more money into one PhD-project which could bear the Scandiatransplant logo and increase the profile of Scandiatransplant in research. This was discussed with pros and cons. The current method has only been applied for a few years. It was therefore decided to evaluate and give an overview of the projects that had been supported until now. KAJ was given this task of making this overview.

8. Minutes of first WGA meeting December 9th, 2014:

KAJ gave an overview of the suggestions and conclusions made at the first meeting.

9. The work in the Scandiatransplant WGA (Allan Rasmussen will join the meeting at 14⁰⁰):

Allan Rasmussen joined the board meeting at 14 o'clock.

The objectives of Scandiatransplant were discussed. First the suggestion from Pål-Dag Line and then additions and thoughts put forward by Lars Wennberg and Margret Andresdottir. It was concluded that KAJ should come with a suggestion using Pål-Dag's suggestion and incorporating practical suggestions made. This suggestion for objective should be sent out to the board who should comment on it within 1 week. Thereafter it could be sent out to the whole WGA. Applying high ethical standards should be put into the objectives some place. Krister Höckerstedt presented some ideas for a way for Scandiatransplant to be able to expand. He thought that new members could be associated, alternatively they could have a trial period before becoming full members. He felt it was important to look at applicants for membership or association individually and not make any rules that would make Scandiatransplant obliged to accept new members, if Scandiatransplant does not want to. Krister's group has not discussed his proposal yet, but they will discuss it further and see if they can present some conclusions at the next meeting in the WGA.

Allan Rasmussen had also made a suggestion regarding the council, the board and also the groups to the group he is leading. They had not had time to discuss his suggestion yet. It was discussed in the board, and the decision was that the election of the council and the

election of the board are functioning satisfactory, and it would be impractical to make major changes. They will therefore concentrate on defining the groups, their responsibilities, and their requirements to the organisation. They will also see if they can present some more details and maybe suggestions to the next meeting in the WGA.

It was felt that there should be an article on the Scandiatransplant office. KAJ will work out such a suggestion together with the people working at the office.

The next meeting time in the WGA was discussed. KAJ was asked to arrange a 1-day meeting at Hilton Copenhagen airport on Monday, April 13, 2015 from 10-16 hrs.

10. Any other business:

The matters had already been discussed under the preceding points.

11. Next meeting, time and place (May 7, 2015 in Stockholm):

The next board meeting will be late in the afternoon on May 6th, 2015 in Stockholm. The board meeting will continue in the morning of May 7th. On May 7th, an extraordinary council meeting on the WGA will be held as promised. It is planned to take place on May 7th, 2015 from 11-12 o'clock and then the ordinary council meeting to take place at 13-15.30.

Kaj Anker Jørgensen