

Minutes

Meeting No.: 73
Time: 21-22 Sept., 2015
Place: Copenhagen, Denmark

Participants: The board of Scandiatransplant:

CHAIRMAN: Krister Höckerstedt, Helsinki
SWEDEN: Lars Wennberg, Stockholm
FINLAND: Helena Isoniemi, Helsinki
NORWAY: Pål-Dag Line, Oslo
ICELAND: Margret Andresdottir, Reykjavik
DENMARK: Finn Gustafsson, Copenhagen

Director of Scandiatransplant:

DENMARK: Kaj Anker Jørgensen, Aarhus

Leader of meeting: Krister Höckerstedt

Writer of minutes: Kaj Anker Jørgensen

1. Welcome:

Krister welcomed everybody.

2. Approval of minutes from last board meeting (May 6-7th, 2015, Stockholm):

Minutes were approved without comments.

3. Status at the Office:

a. YASWA:

KAJ informed that the CORE of YASWA now is implemented. There is only lacking a little of the thoracic registry and the pediatric registry. In all, the implementation has gone well so far. There are not many users to test the system, but we feel that as a whole, the users are accepting the system well. Suggestions and complaints are being dealt with.

For some users there has been a change in the privileges of accessing the system. Accessing the system via the old system has been closed for the liver and will soon be closed for the rest. The programmers are eager to move the database from SC15 very soon for reasons of security and stability, but also because the new system will work much faster at user level when the database is moved to the virtual servers.

b. Theme day:

The office will have a workshop on Nov. 13th. It will be led by a psychologist Line Hvilsted Hansen from Region Midt. We will discuss how to do the work at the office more efficiently, and how to make priorities for our work.

c. Personnel, Tito now full time:

KAJ also informed that Tito Phiri, who has achieved his bachelor degree in the computer software science, now is employed full time at the office. He also informed the board that Peder Nørgaard is now working 5 hours a day, but is very efficient and valuable when he is at work, and he has been very important in launching YASWA. KAJ is following the absence policies of Region Midtjylland and we still believe, that he will recover so that he can fill out the fulltime position.

d. Priorities after YASWA:

The method of making priorities of tasks at the Scandiatransplant office was discussed. When making priorities it is of course important for the office to estimate how long time a given task will take. It may be necessary to involve the groups in Scandiatransplant and the board of Scandiatransplant in making priority decisions dependent on the character of the tasks.

4. Scandiatransplant history, Arnt Jacobsens project?:

The short Scandiatransplant history has now been accepted by the board members and can be put on the homepage.

Regarding the history to be written by Arnt Jacobsen it was decided that Krister Höckerstedt should contact Arnt Jacobsen advising him to telephone the country representatives in the board on who he should contact regarding the history, and about what can be found. Necessary funding for trips paid by Scandiatransplant can be decided by Krister Höckerstedt.

5. Suggestion from the Tissue Typer Group (presented to the board by Ilse Weinreich):

It was suggested that all donors must have their HLA type made and that this should be done at the donor center. The suggestion was accepted by the board. The board does not think that this needs confirmation in the council. KAJ can therefore inform the tissue typer group that their proposal is accepted and should now be implemented.

6. Suggestion on machine lungs from Göteborg:

All board members have seen the suggestion and have accepted the answer from Scandiatransplant, so there were no further comments. We are waiting that the question is discussed in the thoracic group and for answers from Gothenburg.

7. Scandiatransplant Office and follow-up on persons without Person Identification Numbers:

The board had an extensive discussion on this subject. We are aiming at giving the hospitals the responsibilities for what they do, so it is not the responsibility of the Scandiatransplant office to monitor and look for any foul play. If people are missing the last digits in a person identification number, Scandiatransplant should persue the matter if it has any influence on data quality. Otherwise the office should not put too much time into this. KAJ would clarify with the programmers if there is any influence on data control quality if the last digits in the person identification number are missing.

8. WGA meeting October 5th, 2015:

KAJ has sent out the articles of Scandiatransplant corrected according to what we have agreed on until now. He will send this out to the WGA-group again. KAJ is of the opinion that we should take into consideration if a group cannot agree on a matter or if a matter, which involves different groups, cannot be settled. It was also said that there are some groups discussing financing of subgroups, and maybe this should be clarified. KAJ said that he hoped that the medical matters in the WGA could be finished on the meeting of Oct. 5th. He would then work together with the lawyer who has a specialty in associations to make it legally correct. We should then have a WGA meeting early in 2016 where the WGA could accept the articles, which then should then be sent out to the council in good time before the next council meeting.

9. Scandiatransplant at transplantation meetings, example ESOT:

Krister Höckerstedt took up the subject because some people think Scandiatransplant is quite invisible at these meetings while for example Eurotransplant is very visible. There was a discussion on this matter but the general feeling is that things are ok as they are. If groups or people in Scandiatransplant have something they want to present, they should present it. Scandiatransplant will make priority on the STS-meetings. KAJ informed the group that the office will achieve the statistical programme STATA 14, so that we can also give some statistical estimates when replying to requests. The programmers prefer the open source programme R and there is a wish at some time to build some statistical features into YASWA. If that is the case, they will use the programme R.

10. NTC meeting September 22th, 2015, Sundhedsstyrelsen, Copenhagen.**a. SAE:**

Lars Wennberg would take this point up on the NTC meeting. He would repeat what he offered last year and see what the competent authorities would say.

b. Legal memorandum on the structure forming the basis of the services which Scandiatransplant and Region Central Denmark offer hospitals in the Nordic countries:

KAJ showed a power point presentation telling the status of legality now demonstrating the access rights in different situations to the Scandiatransplant database and then finally presenting the legal memorandum waiting for comments from the competent authorities. Pål-Dag Line suggested forming a working group to get things to work faster between Scandiatransplant and the competent authorities.

We have learned from previous meeting that when we only meet once a year things progress very slowly if they progress at all.

11. The board after May 2016: Krister, Helena and Margret elected in 2010:

This point was just information for the board members.

12. Any other matter:

Krister had asked that the subject of “organ donation and transplantation of refugees” should be taken up under this point. There is a big pressure on Europe of refugees right now. This could also have an impact on transplantation and organ donation in the Nordic

countries. It will be important for the competent authorities to know how things are handled, if these questions arise. Scandiatriplant has guidelines on Non-Nordic recipients and donors, but these guidelines cannot overrule the laws of any Nordic country. It was decided to take this point up at the NTC meeting later on and Pål-Dag Line will start the discussion.

13. Next meeting:

It was decided that the next meeting should be on February 29th at Hilton Hotel Copenhagen. We should try to arrange it so that we have both a board meeting and a WGA meeting on this day.