

Minutes

Meeting No.: 67
Time: Sept. 23-24, 2013
Place: Oslo, Norway

Participants: The board of Scandiatransplant:

CHAIRMAN: Krister Höckerstedt, Helsinki (KH)
SWEDEN: Lars Wennberg, Stockholm (LW)
FINLAND: Helena Isoniemi, Helsinki (HI)
NORWAY: Pål-Dag Line, Oslo (PDL)
ICELAND: Runolfur Palsson, Reykjavik (RP)
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)

1. Welcome:

KH welcomed everybody.

2. Agenda and format of the meeting:

The agenda and format were approved.

3. Approval of minutes from board meeting No. 66:

Minutes approved.

4. Since last meeting:

a) Status at the office: New people, room facilities, seminars:

KAJ presented the two new programmers employed at the office this summer. Peder Christian Nørgaard and Torben Grøn.Helligsø. He expressed great expectations for the work they will be doing together with Bo Pedersen.

They both work very well with the whole staff. A drawing of the rooms we have at the Department of Clinical Immunology was shown and the working place of each employee at the Scandiatransplant office was demonstrated. On August 23rd 2013 the whole office participated in a one-day seminar with Henning Winther from N3 Security Aps. Henning Winther took us through the ISO standards in the morning and in the afternoon we practised on examples related on how it could work in the Scandiatransplant office. It was a very good seminar which has set us on the correct track in working with data security. The first step is to agree on a security policy. The office has produced a document on information security policy, and this document was approved by the board. It will now be placed on the homepage. On September 12th and 13th all the Scandiatransplant office staff except the student programmer Tito Phiri and Christian Mondrup participated in a seminar on collaboration (samarbejdsseminar) in the office. In the seminar we had both focus on personal abilities to cooperate and on methods to work at the office to come

around different practical matters. The seminar was generally well evaluated and we decided to have such a seminar twice a year, but to make it only a one-day seminar. The common priorities are to bury the old server as quickly as possible and get the new YASWA system working. We must however at the same time be sure that the Scandiatransplant system is working 24 hours every day.

KH reported on his visit to the office. His general impression was that there had been quite a big change in the office and that these changes had been to the better. He had talked to both the new and the old staff and was satisfied that the programming part of the office had been strengthened considerably. The board still finds it difficult to accept that Scandiatransplant cannot pay its employees as it decides due to the organisation in Region Midtjylland. KAJ was encouraged to challenge these regulations when necessary.

b) EU competent authorities meeting:

The meeting in the commission with the competent authorities was held in Brussels on the 17th and 18th of September. The meeting in the working group for indicators, which should have been held earlier, was cancelled. Scandiatransplant participates in the meetings as an observer and KH, KAJ and Frank Pedersen participated. KAJ had given a presentation on how Scandiatransplant can help the Nordic countries comply with the EU Action Plan 2009-2015. KH reported from the meeting. The board especially discussed how data including numbers given to the requested issues at the meeting reached the commission. Many numbers seem to be wrong. The Board members were encouraged to check data from their own country. It was discussed if numbers regarding the waiting lists should be kept anonymous due to the fear of patients travelling to countries where the waiting lists are short. The general assumption in the board was that we cannot go against these numbers being publicly known, but we will not encourage it. There will be a meeting in Madrid on 16th and 17th of October on the ACCORD Project where Scandiatransplant participates in WP4 on living donor registries. KAJ will participate in this meeting. The EU has also organised a journalist workshop in Brussels on Oct. 7th, but Scandiatransplant will not participate here.

c) SAE/AE reporting to competent authorities (LW e-mail 07.07.13):

LW has as decided in the former board meeting sent an e-mail to the board members asking how the national guidelines were. He also sent a mail with some Swedish suggestions and guidelines. After some discussion the board concluded that Scandiatransplant should make its own guidelines. These are necessary because the organ transplant activity crosses borders where the national guidelines may be different. It was decided that LW should make a short presentation at the competent authorities' meeting the next day and suggest, that the board of Scandiatransplant would make a suggestion of which SAE/AE should be reported. When this list was made it should be approved by the competent authorities. After that there was a suggestion made that Scandiatransplant could be a good place to log these events.

d) Cross-border procurement rules:

KH reported that the first suggestion for "Principles related to the activity of foreign organs procurement teams in Member States" had been produced by an Austrian lawyer at the last EU meeting in March and given it to KH. The board wanted two minor changes in the suggestion. KAJ will put these suggestions in a document and send it to the board for approval. KH will thereafter send it to the lawyer. It should be discussed at the next EU meeting. In the Nordic countries there are actually no laws on these matters.

e) The Estonians:

KAJ presented that 23 organs from 7 deceased donors had been imported to Scandiatransplant from Estonia while no organs had been exported. The activities had been ok. KH referred to a letter sent last week from from Tartu to Scandiatransplant

saying that they were still wanting to apply for full membership, and they were asking methods of how the cooperation between Estonia and Scandiatransplant could be improved.

5. Travel and Research Grant. Missing reports ?:

It was discussed how to treat grants which had not been used and also missing reports of how grants had been used. It was concluded that grants given which had not been used must be paid back, and that reports on how the projects were progressing and how the money is used must be sent to Scandiatransplant at one year.

The board decided that point 6 in the travel grant guidelines stating that a possible surplus on the Scandiatransplant account for travel sponsorship is transferred to the next year's granting of travel sponsorships, should be removed. The grants should every year be what appears in the budget.

6. Document on Scandiatransplant:

The document had been sent out and had been commented by the board. It was also sent out to the competent authorities who were to participate in the next meeting. It was presented and the board was satisfied with the document which shall be used in negotiations with the competent authorities. There was a minor change in the document related to that it may not always be ten hospitals who are transplanting in the Nordic region. The document is now put on the homepage.

7. Discussion on using each country's person identification registry number:

This was a project intended to be a kind of quality control for the data in Scandiatransplant. KAJ presented such a comparison of death and date of death between Scandiatransplant data and the Danish CPR-registry. Due to time no conclusion was made if Scandiatransplant should go further with such project, and we will continue to discuss it later.

8. NTC meeting September 24th, 2013 (see separate agenda):

The meeting was discussed. LW would present a suggestion on the SAE/AE. Bo Pedersen participated in the board meeting under this point, and showed the presentation he would show at the NTC meeting regarding the data security of the Scandiatransplant datasystem.

9. Evaluation of the Council of Representatives Meeting 2013. Discussion of 2014:

The council meeting May 2013 was generally satisfactory. It was decided that the 2014 meeting should last for four hours and start one hour earlier than what was now in the STS 2014 programme. FG will change this.

10. STS 2014 Copenhagen. (FG):

FG told about the organisation of the STS 2014, the scientific programme and also the problems that had come up because Denmark had won the European Song Contest. It is important that people book rooms through the congress or else rooms will be very expensive if they can be found at all. It was decided, that all board members should participate in STS 2014.

11. Discussion of the future structure and activities of Scandiatransplant.

Changes needed in the "Articles of the Association Scandiatransplant":

KAJ opened this discussion about how Scandiatransplant should be run in the future, and also if it was time to revise the articles. The articles are not clear on how allocation rules should come forward. There is no mention of committees and groups, the rules they should follow and their responsibilities. These are now important parts of the Scandiatransplant organisation. The database is only mentioned very lightly in the articles. There is nothing about security policy, ownership and responsibility of data and the homepage. It was concluded that members of the board should think over which changes are needed in the articles of the association. The deadline for coming forward with the results of these thoughts should be January 17th. KAJ should e-mail the board members on

this subject. We can then discuss it at the next board meeting, and maybe present something for the next council meeting.

12. Process of implementation of the EU Directives in each country:

Sweden: No change.

FINLAND: FIMEA is now the authority responsible for the quality of the organs. Administrative regulations will come soon and also how to report SAE/AE. Valvira personnel will inspect the hospitals and be responsible for statistics.

Denmark: The law is in place and the directive has been implemented in May 2013, but information on how this is to work in practice has not reached the clinicians.

Norway: No change.

Iceland: No change. However the Directorate of Health has now taken over the responsibility as a competent authority.

13. Patient Mobility Directive and Transplantation:

KH reported on the appendix of the EU DIRECTIVE 2011/24/EU on the application of patients' rights in cross-border healthcare:

“15) Given their specificity, access to and the allocation of organs for the purpose of organ transplantation should fall outside the scope of this Directive. “

Although access to and the allocation of organs and transplantation are excluded from the patient mobility directive, the commission is discussing the meaning of this. It seems like the commission is of the opinion that it is only allocation that is outside the directive, the directive may imply other aspects regarding transplantation. As we understand it, this is still being discussed. The Nordic CAs will be informed about this at the meeting today. We should be alert for any extra suggestions, which might endanger the organ donation and transplant activity in the Nordic countries.

14. Any other business:

None.

15. Next meeting time and place:

Next meeting February 17th 2014 as a one whole day meeting at Hilton hotel in Copenhagen airport. The deadline for seeking the grants should be January the 17th.

On behalf of the board.

Kaj Anker Jørgensen