Minutes

Meeting No.: 69
Time: May 6-7, 2014
Place: Copenhagen, Denmark

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)

The meeting was held according to the distributed preliminary agenda. Krister Höckerstedt welcomed everybody to the board meeting.

1. Agenda and format:
   Accepted.

2. Approval of minutes of board meeting in Copenhagen Feb.17, 2014:
   No comments.

3. Since last board meeting:
   a. Status at the Scpt office.
      The Heartbleed bug had not had any influence on the accessible Scandiatransplant systems. It had however shortly affected the sms-system for organ offers due to Scandiatransplant's e-mail provider. KAJ gave an update on the status at the office.
   b. Status on YASWA.
      The work is progressing, but we cannot say when the conversion from the old system to YASWA will be finished. It is an ongoing process. The big step will be taken when the recipient search module is working in clinical practice.
   c. Scpt participation in meetings.
      KAJ gave an overview of the meetings that Scandiatransplant has participated in.

4. Minutes distributed as link to homepage:
   The board accepted that in the future, minutes of meetings can be distributed as links to the homepage.
5. Suggestion for SAE/AE definitions. Suggestions for next NTC meeting in fall (LW):
During the meeting Lars Wennberg sent all board members his suggestion, which he had
sent out earlier (February 2014). The board members were urged to give comments so that
the board can have a proposal ready for the NTC meeting in fall.

6. Relations with Estonia:
The new application for a preliminary membership from Estonia was discussed. Krister told
the board that he had already answered Estonia saying that the question of membership
could not and will not be taken up at this representatives’ meeting. It has to wait till later.
The guidelines for non-Nordic citizens was discussed. The board concluded that the point
2b is to be removed. The council will be told, that the board has removed point 2b.
The case in Stockholm where an Estonian mother gave a split of her liver to her child,
which subsequently urgently needed a new liver and got a liver from Göteborg in response
to kind request after the child had been entered on the high urgent list, was discussed. It
was decided that Krister Höckerstedt should write to Stockholm telling them that such a
liver should not have been on the high urgent liver list.

7. National Person Identification Registries and Scandiatransplant:
The board had this point for discussion about a year ago, but the discussion was dismissed
due to lack of time. The board finds it a good idea to compare Scandiatransplant with
national personal identification registries where this is needed to ensure that patients who
are dead are also registered as dead in Scandiatransplant. This led to a discussion of the
living donor registry. There is now an EU directive and law in each country saying that
there has to be a living donor registry. The board therefore asked the Nordic Kidney Group
to decide minimal mandatory data that must be entered into the living donor registry. KAJ
is to write to the NKG demanding them to take on this task.

8. Any other business:
No issues. FG told us about the STS congress which seems to be a success with over 270
registered participants at this moment, good speakers, over 100 abstracts, and the logistics
seemed well planned.

9. Next meeting, time and place:
Next meeting will be in connection with the next NTC meeting in Stockholm on September
30th. The board meeting will therefore be on the 29th and 30th September 2014.

10. Council meeting May 7th, 2014 (see separate agenda):
   a. Søren Schwarz Sørensen as leader of the meeting.
      Finn Gustafsson had asked Søren Schwartz Sørensen if he would be the leader at the
      Council meeting, and Søren Schwartz had accepted. Søren Schwartz Sørensen
      therefore participated in the last hour of the board meeting.
   b. Election of board members and substitutes.
      Pål-Dag Line was the only board member on election this year. He was willing to
      continue, and it would be the board's proposal that he continues as the Norwegian
      member of the board.
c. Proposals for the council’s decision, timing of council meeting.

There was a discrepancy between the timing which on the summoning was set from 13-16 hrs., while in the STS 2014 programme it was set from 13-17 hrs. It was decided that we had to follow what was written in the summoning.

The proposals sent to the representatives were discussed.

i. Mandate for work group on the Articles.

Krister Höckerstedt showed his chairman's report which would focus on the purposes of Scandiatransplant according to the articles, demonstrating that the articles in many ways did not reflect what Scandiatransplant is today. It was decided that KAJ would come with a proposal after he had delivered his report on the activities in Scandiatransplant the last year. Krister Höckerstedt would give the second part of his report to the board emphasizing the relation to the EU directives and EU commissions under point 15 in the agenda of the council meeting.

ii. NPG on pancreas donors.

Lars Bäckman should present this proposal to the council.

iii. Non-Nordic guidelines.

It was decided that the board has the authority to make and change the guidelines. They could be discussed on the council meeting, but the board decided to remove the point 2b in the current non-Nordic guidelines, and primarily inform the council that this had been done. This would be done under point 16 in the council meeting. It was decided that KAJ would tell the council about who received the research and travel grants this year.