Minutes:

First meeting of the Working Group on Revision of the Articles of the Association Scandiatransplant (WGA).

Hotel Hilton, Kastrup, Copenhagen, December 9th, 2014.

Participants:

The board of Scandiatransplant:

- Krister Höckerstedt, chairman (KH)
- Pål-Dag Line, Norway (PDL)
- Helena Isoniemi, Finland (HI)

Apologies from Finn Gustafsson (Denmark), Margret Andresdottir (Iceland) & Lars Wennberg (Sweden)

Member of major groups:

- Lars Bäckman, Nordic Kidney Group (LB)
- Martin Iversen, Nordic Thoracic Transplantation Study Group (MI)
- Allan Rasmussen, Nordic Liver Transplant Group (AR)
- Bjarne Møller, Scandiatransplant Tissue Typer Group (BM)

WGA secretary: Kaj Anker Jørgensen, Scandiatransplant (KAJ)

Database expert: Peder Nørregaard, Scandiatransplant (PN)

Lawyers:

- Rasmus Grønborg Jakobsen, Central Denmark Region (RGJ)
- Michael Sommer, Expert on association legality (MS)

The meeting followed the agenda, which had been sent out beforehand, but in a loose structure giving room for discussions and presenting point of views.
1. **Welcome**: KH opened the meeting bidding everyone welcome and shortly gave the background for the meeting. He asked for further matters to the agenda, there were no such matters at this time.

2. **Election of meeting leader and writer of minutes**: KH was elected leader of the meeting and KAJ writer of minutes. KAJ already was the secretary of the group according to the decision at the last council meeting.

3. **Presentation of the members of the group**: All participants presented themselves and their position in relation to the WGA.

4. **Presentation of mandate and over-all timetable**: KAJ gave a presentation showing the way Scandiatransplant was organized and functioned today. He pointed out where the current articles seemed to be out of line with today’s Scandiatransplant. The deadlines given by the council were presented.

5. **Comments around the table on the questions sent out before**: The following discussion started with the questions sent out, but led to many other important issues.
   
   a. It was generally agreed to keep the structure of the organization with hospitals / council / board / office. It was discussed if Scandiatransplant was a private or public organization. It is a matter of “wording”. MS explained that Scandiatransplant is a private organization according to Danish law meaning that it is not regulated by a specific law in Denmark or by the Constitution. It was agreed that Scandiatransplant should stay an association (forening) situated in Århus, Denmark. This means that the original articles (vedtægter) have to be in Danish which shall be translated to English. We should, however, try to write the articles in such a manner that Scandiatransplant could be situated in any of the countries which own Scandiatransplant.

   b. The current articles (article 3) say “human organs and tissue”. It was agreed that Scandiatransplant should not deal with all tissues, and formulations such as “organs and cellular derivates of organ function” were discussed. It was concluded, that the best would be to state in the objectives of the association precisely which organs and tissues the association should deal with.

   c. It was agreed that the payment for living donor and deceased donor transplantations should be the same. The work load for Scandiatransplant is becoming more similar in both donor types.

   d. The composition of the Council of Representatives was discussed. AR suggested that it should be a representative from each center and a representative from each group. The current composition gives the large centers more power. KAJ argued that there is some logic in that the ones who pay the most also have the most to say. This is to be further discussed in group b (see below).

   e. It was agreed that there was no need to have the possibilities for sanctions.
f. There is a problem concerning the ownership of the data. RJG found some difficulties in Central Denmark Region being responsible for data, while they are owned by the member hospitals. PDL and RJG will prepare some suggestions for solving this (see below).

g. KAJ gave a short overview of relations we have with authorities and also other people with interest in Scandiatransplant affairs and data. It was concluded, that there is no need for specific article on these matters, but that they should continue to be treated as they are today. It should be stated in the objectives in general terms. It should also be mentioned in the objectives, that we should stay updated in matters on transplantation of interest for the members.

h. One question sent out beforehand to think about was: “Can new members join?” LB pointed out, that since we have accepted and handled at least one application, new members can join. The next question was. “How do we cooperate with non-Nordic countries?” PDL suggested that the problem was the word non-Nordic. It should be removed. We should in principal say that any country can join and then specify what the requirements should be. The experience with the application from Estonia was that many members of the council did not know very much about Estonia at the time the council decided to reject their application. It was therefore suggested to have a “trial period” for new members, so the association could be confident with their situation before they became full members. Each application should be looked at individually and not rejected/accepted from general terms.

6. Working method for the continuing work: It was decided to form two groups to further discuss matters. As their work might be influenced by the objectives of Scandiatransplant, it was suggested that any member of the group could voluntarily send suggestions for the objectives to the secretary (KAJ). The deadline was set to 31st of December, 2014. The secretary will gather the suggestions and send them to all the members of WGA shortly hereafter. The two groups formed were:

a. A group discussing the membership and cooperation with non-member transplant units.
   i. Krister Höckersted. Contact person. (krister.hockerstedt@hus.fi)
   ii. Lars Wennberg (lars.wennberg@karolinska.se)
   iii. Finn Gustafsson (finng@dadlnet.dk)
   iv. Pål-Dag Line (pline@ous-hf.no or pg@line.name)
   v. Margret Andresdottir (mband@landspitali.is)

b. A group discussing council, board and groups.
   i. Allan Rasmussen. Contact person. (allan.rasmussen@dadlnet.dk)
   ii. Martin Iversen (martin@iversen-net.dk)
   iii. Lars Bäckman (lars.backman@akademiska.se)
   iv. Helena Isoniemi (Helena.isoniemi@hus.fi)
   v. Bjarne Möller (biamoell@rm.dk)

c. Data governance and ownership.
i. Pål-Dag Line will make a suggestion.
ii. Rasmus Grønborg Jakobsen will make two alternative suggestions.
iii. KAJ will gather the suggestions and comment on them together with the office. Whereafter they will be sent to the whole WGA.
d. The task of removing elements which were no more relevant from the articles was given to KAJ.
e. KAJ will together with the Office look at suggestions for the articles regarding the Scandiatransplant Office.

The groups should give a report to the secretary (kajoerg@rm.dk) on February 15th, 2015 at the latest (one week before next board meeting).

Kaj Anker Jørgensen,
Skejby 10.12.14