

Minutes of Extra Council meeting May 7, 2015 from 11 to 12 o'clock in Stockholm at Nordic C Hotel

Bo-Göran Ericzon was elected as meeting leader and Kaj Anker Jørgensen was elected as Writer of minutes.

1. Welcome (Krister Höckerstedt)

Krister welcomed everyone and explained that this extra council meeting was demanded by the council last year. It was just intended to make a status report on how the working group on revision of the articles of Scandiatransplant (WGA) has been working. He presented the members of the working group:

Members of the Board

Krister Höckerstedt Fi, chair

Pål-Dag Line (N), Helena Isoniemi (Fi), Finn Gustafsson (Dk)

Margret Andresdottir (Ic) & Lars Wennberg (S)

Members of major expert groups:

Lars Bäckman, NKG

Allan Rasmussen, NLTG

Martin Iversen, NTTSG

Bjarne Møller, Tissue Typers

WGA secretary: Kaj Anker Jørgensen, Sctp

Database expert: Peder Nørregaard, Sctp

Lawyers: Rasmus Grønberg Jakobsen, Hospital Midt. Michael Sommer, Association legality.

2. Purpose of Scandiatransplant (Lars Wennberg)

Lars Wennberg then showed what the working group has come to regarding the purpose of Scandiatransplant:

Scandiatransplant is a collaborative non-profit organ exchange organization and managed by the member transplant hospitals.

The population in each member hospital's individual country is too low to enable optimal matching for transplantation or maintaining a reliable and efficient urgent waiting list for transplantation.

Thus, the main purpose of Scandiatransplant is:

Serve as a common organ exchange organisation and allocation resource for its member hospitals for kidney, liver, heart, lung, pancreas, pancreatic islet and multivisceral transplantation. This is done transparently, using ethical principles and in full compliance with the national legislation of the member's countries. Maintain and operate a common waiting list and database.

Maintain and operate follow-up registries of transplanted patients and donors.

Serve as a collaborative platform through specialized working groups and advisory boards to guarantee best practice recommendations and policies regarding organ allocation and transplantation outcomes.

Form a collaborative network for the member centers to promote research related to organ donation, allocation and transplantation.

There was some discussion on naming the exact organs which Scandiatransplant work with or if the wording should be a little less strict. There was a no conclusion on this, and the working group will work on with this matter.

3. Membership of Scandiatransplant (Krister Höckerstedt)

Krister Höckerstedt told about the work on the membership of Scandiatransplant. He first reviewed the cooperation Scandiatransplant has with other organ exchange organisations. He came with the following suggestion:

Full members

Transplant hospitals from the Nordic countries

Associate members

Transplant hospitals from other countries

They can take part in Scandiatransplant activities and shall follow the Articles and rules of Scandiatransplant

Organ exchange, activity registration, office, committee work, research

They have no voting right in the Council of Representatives

Board membership or not?

There was also discussion on this, some representatives expressed that it was difficult to overview the pros and cons of this suggestion. However, the majority accepted to work on these lines and also thought that an associate membership should be able to lead to a full membership. It is important that the articles are formed in a manner so Scandiatransplant decides who they want to have as associate members.

4. Groups in Scandiatransplant (Allan Rasmussen)

Allan Rasmussen then showed the work on groups. Groups are today the place where most professional works take place in Scandiatransplant, but they are not mentioned at all in the articles. Groups have been made very unsystematically, and their duties and rights are completely undefined. He then showed a suggestion for an article on groups:

Specialist in areas of transplantation employed at member hospitals can form groups with special interests. These groups can receive support from Scandiatransplant as decided by the board. They should give a report of their activities at the annual council meeting.

They are a forum for discussing matters of common interest and scientific activity. There are different types of groups.

*1) **Solid organ groups:** The group constitutes itself, but all member hospitals performing the particular organ must be represented. The group defines its own by-laws, leadership and meeting activity. The group must at all times have a contact person to the Office and Association. It is the responsibility of the group to keep the Office update on who is the contact person.*

a. Duties of the group:

- i. Decide rules for allocation of the particular organ and keep the Office updated on these rules.*
- ii. Govern compliance to the allocation rules.*
- iii. Governance of data in follow-up registries.*
- iv. Arrange meetings for the groups. Keep the office updated on meetings and produce minutes of the meetings for the home page. Preferably a coordinator and a member of the Office staff should participate in the meetings as observers without voting rights.*
- v. Form subgroups of with special interests. These groups refer to the main group.*

b. Rights of the group:

- i. Receive practical and financial support from the Office.*
- ii. Have the office staff work with a follow-up registry and scientific information.*
- iii. Be on the Scandiatransplant home page.*

*2) **Coordinators group:** This group constitutes of one coordinator from every member hospital. Their duty is to keep all coordinators updated on relevant information, specially rules and agreements on allocation and transport of organs for transplantation.*

*3) **Tissue typer group:** This group constitutes itself, but all tissue typing laboratories in the Scandiatransplant area should be represented. It defines its own by-laws, leadership and activities, but it should keep the Office updated on a contact person to the Association and the Office. The group gives recommendations for relevant tissue type information in the database and on recipient search procedures. The group acts as an expert advising committee for the organ groups.*

*4) **Advising committees:** These are committees of experts in a field relevant for organ transplantation. They advise the members and give guidelines the member hospitals. Their tasks are given by the Board.*

*5) **Official cooperation committees:** Committees consisting of representatives of the association and official authorities. The Board decides who is to represent Scandiatransplant.*

There was a short discussion on whether the “Islet Group” should be a subgroup of the “Pancreas group” or the other way around. WGA will work further on along these lines.

5. Legal memorandum on Scandiatransplant (Kaj Anker Jørgensen)

Kaj Anker Jørgensen then gave an overview of a memorandum made by lawyer Rasmus Grønborg Jakobsen, Central Region Denmark, together with Kaj Anker Jørgensen and programmer Peder Nørsgaard at Scandiatransplant. The main theme of this model is that the member hospitals own the data and are responsible for the data. Scandiatransplant is just a data processor working on instructions from the owners. The Region Midt IT is a subprocessor giving server capacity and service.

6. Article on Scandiatransplant Office.

Kaj Anker Jørgensen then presented an article on the Scandiatransplant office. There is no such article in the present articles. He suggested that it replaces the article on the Chief Executive in the current articles, which would become an article on:

The Scandiatransplant Office.

The main task of the Scandiatransplant Office is to manage the function of the IT-system according to instructions given by the members of the association. The Office also services all parts of the association, the general public, cooperating partners and relevant authorities with information. The Medical Director is responsible to the Board for the organisation of the Office and its activities.

Kaj Anker Jørgensen then went on to tell that the group would suggest that living donor transplantation and deceased donor transplantation should have the same weight both in payment and in counting representatives to the council. The council is increasing in size and it was suggested that counting to 50 transplantations should be replaced to counting to 75 transplantations.

The working group is planned to have a meeting on Oct. 5th, 2015. After this Kaj Anker Jørgensen will discuss the articles in a legal context with the private lawyer Michael Sommer. A new WGA meeting is thought to be held early 2016 before the suggestion is presented to the 2016 Council members in due time before decision at the Council meeting 2016.

Links:

1) Mandate:

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/MandateWGA.pdf>

2) Minutes WGA meetings:

[http://www.scandiatransplant.org/about-](http://www.scandiatransplant.org/about-scandiatransplant/organisation/MinutesoffirstmeetingWGA09.12.2014Cph.PDF)

[scandiatransplant/organisation/MinutesoffirstmeetingWGA09.12.2014Cph.PDF](http://www.scandiatransplant.org/about-scandiatransplant/organisation/MinutesoffirstmeetingWGA09.12.2014Cph.PDF)

[http://www.scandiatransplant.org/about-](http://www.scandiatransplant.org/about-scandiatransplant/organisation/MinutesWGA2onApril13Cph2015.PDF)

[scandiatransplant/organisation/MinutesWGA2onApril13Cph2015.PDF](http://www.scandiatransplant.org/about-scandiatransplant/organisation/MinutesWGA2onApril13Cph2015.PDF)

3) Memorandum from Lawyer in Danish and English

[http://www.scandiatransplant.org/about-](http://www.scandiatransplant.org/about-scandiatransplant/organisation/NotatomkonstruktionenbagdeserviceydelseSctpogRMtilbydersygehuseiNordenmedappendix.pdf)

[scandiatransplant/organisation/NotatomkonstruktionenbagdeserviceydelseSctpogRMtilbydersygehuseiNordenmedappendix.pdf](http://www.scandiatransplant.org/about-scandiatransplant/organisation/NotatomkonstruktionenbagdeserviceydelseSctpogRMtilbydersygehuseiNordenmedappendix.pdf)

[http://www.scandiatransplant.org/about-](http://www.scandiatransplant.org/about-scandiatransplant/organisation/LegalmemorandumonstructureofservicesSctpandRMofferNordichospitalswithappendix.PDF)

[scandiatransplant/organisation/LegalmemorandumonstructureofservicesSctpandRMofferNordichospitalswithappendix.PDF](http://www.scandiatransplant.org/about-scandiatransplant/organisation/LegalmemorandumonstructureofservicesSctpandRMofferNordichospitalswithappendix.PDF)

Kaj Anker Jørgensen