

**Minutes 35.th NTTSG meeting**  
**Hilton Hotel, Copenhagen Airport, October 27. 2016**

Present representing the NTTSG board:

*CPH: Kaare Sander, Richard Ingemansson, Finn Gustafsson, Michael Perch*

*Aarhus: Hans Eiskjær*

*GBG: Göran Dellgren, Kristjan Karason, Gerdt Riise*

*LUN: Johan Nilsson, Per Wierup, Göran Rådegran, Hillevi Larsson*

*HLS: Karl Lemström, Peter Raivio, Jyri Lommi, Maija Halme*

*OSL: Tom Hoel, Are Martin Holm*

*Observers: Ulla Nyström, Petra Vestlund, Jesper Magnusson*

*From Scandiatransplant: Kai Anker Jørgensen*

1.1 The minutes from the NTTSG meeting April 2016 were approved.

1.2 List over board members with email addresses were updated.

2.1 The meeting was informed that the status of the registry is mostly as presented by *Ilse Weinreich* at the last meeting: pretty complete regarding pre-tx and tx data, weak on follow up data and somewhat patchy regarding death data for the last few years.

2.2 A brief orientation from each centre about who enters data to the Scandiatransplant registry. The tx-coordinators were important in most centres.

2.3 *Ulla Nyström* informed about the workshop held in Aarhus earlier this month for tx coordinators to train in data entry and use of the registry.

2.4 Possibilities for mutual data exchange between Scandia-registry and local registries were discussed.

2.5 Possibility for upload from data from the CRFs in the ScanCLAD study to the registry was discussed. The topic will be discussed with data responsible when the ScanCLAD-study is running.

2.6 Pruning of the registry: *Karason, Nyström and Eiskjær* have produced a visually more condensed and slightly altered registration form for data regarding heart-tx.

*Karason* has emailed it to all and will revise according to feedback, thereafter contact *Ilse Weinreich* for implementation. *Johan Nilsson, Michael Perch, Ulla Nyström and Are Holm* will do a similar process for data related to lung-tx.

2.7 *Kai Anker Jørgensen* presented the changes in the Scandiatransplant bylaws and legal status. Importantly, the registry is now considered property of each of the owning hospitals, where each hospital has rights pertaining to data from their centre. The proper crediting in publications was not discussed.

2.8. The ethical status of the registry could not be clearly presented at this meeting, and must be cleared by each centre. Until further notice, the NTTSG assumes that necessary ethical approvals for the current use are in accordance with local regulations. Therefore, as before, each centre may use data about their own centre according to local regulations. Use of aggregated data for all centres must be requested from the Scandiatransplant office (*Weinreich*), which normally will consult the chair of the board as to whether the request shall be permitted or should first be brought before the board of the NTTSG or other instances.

3. It was agreed unanimously that a representative for the tx.coordinators and a representative for the tx.nurses should be invited to each NTTSG meeting.

4. The decision regarding donation timing for international organ offer discussed at the previous meeting was presented. Work to determine how a larger part of the available organ pool may be exploited will continue. *Holm* will initiate work to evaluate the suitability of a scoring system for organs to improve assessment and increase comparability. This discussion will continue at the next NTTSG meeting.

5. Updated figures for urgent heart (prio 0) were presented, showing that the sharp increase observed this spring, had reversed. *Finn Gustafsson* suggested that there should be audits in case of a strong increase in the use of urgent hearts. It was agreed that number of urgent hearts should be audited at each meeting.

6.1. A change of the wording in the current guidelines, merging the definitions of prio 0 and prio 1 was rejected. The majority considered it desirable to maintain the current practice that if two “urgent calls” for lung are valid at the same time, a patient on ventilatory support or ECMO should have priority over an earlier call not on support.

6.2. It was made clear that “kind request” exchange calls does not exist in thoracic transplantation in ScandiTx. There was agreement that should it be introduced, then it would have to be linked to an organ pay-back system. It was generally opined that such a pay-back system would be problematic due to the low number of transplanted organs pr. year (about a tenth for hearts or lungs compared to the annual number of kidney transplants). It might also be problematic due to concerns about variations in organ quality. There was therefore an agreement that “kind request” or pay-back systems should not for now be introduced for thoracic transplantation in ScandiTransplant.

7. The use of extra-corporal photopheresis (ECP) to treat chronic rejection after thoracic transplantation (CAV/CLAD) in the Nordic countries was discussed. Most centres now have available facilities, and some centres have started treatment on a few patients. It was agreed that it is desirable to refrain from such treatment in the Nordic countries until it can be done within the context of a controlled study. *Holm* will discuss this with representatives from the providing company (Therakos) on the 11.11. this year.

8. The legal and practical status of use of organs from donation after circulatory death (DCD) was discussed. No centre is currently using it. In Oslo, a pilot project was done in 2015 regarding abdominal organs, and thoracic organs may follow. The legal status in some other countries was unclear. Further work on this topic is encouraged.

9.1. *Göran Dellgren* presented the current status of the ScanCLAD study. Inclusion has started. The need for a protocol regarding antibody-mediated rejection was noted. Legal issues regarding blood sampling from the donor for research that are parallel with organ retrieval were discussed as this is relevant in one of the sub studies. A final clarification is needed.

9.2-3 and 5. *Holm* briefly mentioned current status of the “Allocation for urgency in LTx study” (data collection nearly completed), the “CLAD/RAS/BOS-study” (manuscript in preparation) and the “LTx for pGvHD study” (one manuscript published, the other in preparation). All of the studies are results of collaborative efforts within the NTTSG.

9.4. *Michael Perch* gave a briefing about the EPOS study, where inclusion has been disappointing, highlighting the difficulties to define the inclusion criterion (BOS). P.t. Copenhagen has included 5 patients, Gothenburg 3, Oslo 1, Lund 0, Helsinki 0.

9.6. Jukka Lethonen who should have given a presentation about the “Inflammatory Heart study” was not present, and the topic is postponed to the next meeting.

9.7. Eiskjær gave a presentation suggesting a study about acetylsalicylic acid after heart tx. Great interest in such a study was expressed, and he will develop a synopsis which will be further discussed.

9.8. Lund is planning a registry of thoracic transplants that are blood type incompatible.

10. No additional topics were discussed.

**11. The next meeting will be on the 20. April 2017, also at Kastrup Hilton, Copenhagen Airport.**

Oslo, 22. December 2016

Are Martin Holm

*Department of Respiratory Medicine*

*Oslo University Hospital*

*Chair NTTSG*