

## Minutes 36.th NTTSG meeting

Clarion Hotel, Copenhagen Airport, April 20. 2017

### Present representing the NTTSG board:

CPH: Michael Perch, Finn Gustafsson, Kaare Sander

GBG: Göran Dellgren, Gerdt C. Riise, Kristjan Karason

HE: Karl Lemström, Pekka Hämmäinen, Maija Holme, Jyri Lommi

ML: Hillevi Larsson, Johan Nilsson, Göran Rådegran, Per Wierup

OSL: Tom Hoel, Lars Gullestad

AAH: Hans Eiskjær

### Associate members:

Christian JK Møller, Hans HHL Schultz, Ulla Nyström, Petra Vestlund (tx. coord.), Einar Gude, Are Martin Holm (chair)

Jukka Lethonen (invited speaker), Anna Werther Evaldsson (invited speaker), Ilse Duus Weinreich (Scandiatransplant)

### 1. Formalities

- 1.1. There were no comments to the minutes from the NTTSG meeting in October 2016.
- 1.2. Names and emailaddresses of board members and associates were updated. It was agreed that we keep the definitions of board members and associate members informal and up to the centres discretion.

### 2. Scandiatransplant registry (Yaswa)

- 2.1. Current status of the registry was discussed. According to Ilse DW there is a highly variable completeness of data entry. It was suggested that a summarizing report of selected data from the registry should be extracted and distributed to NTTSG members and associates at regular intervals (annually or more often).<sup>1</sup> It was also encouraged that data lists generated in studies should, if possible, be sent to Scandiatransplant for integration into the registry. A suggestion by Lars G. to generate a randomizer in the registry for use in future studies was positively received but not brought to decision.
- 2.2. It was unanimously agreed that the board trusts Kristjan K. and Are H. to continue to work with a suggestion to reduce and improve the single data points of the registry. A final suggestion will be sent to board members for comments and approval before changes are made. Compliance with ISHLT registry should be sought.
- 2.3. The question how NTTSG or Scandiatransplant should be credited when data from the registry has been used in studies was discussed. It was agreed that some credit was desirable, either as co-authorship, acknowledgement or otherwise, as appropriate. Practices for using the acronym NTTSG or Scandiatransplant in the author list will be investigated (Are H.).
- 2.4. The data in the registry is to be considered the legal property and responsibility of the individual centre (hospital) from which the data originates. Data protection rules and ethical concerns are the responsibility of each individual centre, and may vary between countries. There are no formal rules for reporting from the registry at present. It was agreed that Are H. contacts

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<sup>1</sup> The form of this was not discussed in detail, but I suggest that Kristjan and I make a suggestion to get us started.

Scandiatransplant (Kai Anker Jørgensen or others) to clarify matters. Meanwhile, requests to extract multicentre data from the registry shall be forwarded to the chair as before, but the chair will then consult a steering committee to decide the matter. It was agreed that this committee should consist of one representative from each centre, and the following were appointed: Kristjan K, Johan N, Karl L, Hans E, Michael P, Are H. A log of each request should be kept.<sup>2</sup>

### **3. Status of Nordic organ exchange pr. April 2017**

#### **3.1. Donation timing for international offers**

There have been no major incidents in this matter. It was encouraged that involved persons at donor and recipient centres communicate after any case of disagreement. This is important in order to maintain the high level of mutual trust currently present in Nordic organ exchange practice.

#### **3.2. Status of Nordic organ exchange pr. April 2017**

Ilse DW presented the numbers of hearts and lungs exchanged between centres in 2016 and first q. of 2017. The worryingly high number of urgent hearts observed in 2015 has returned to normal and acceptable levels. The reason for the centre differences in the rate of import and export of organs was discussed. Possible reasons were varying thresholds for organ acceptance among evaluating surgeons, and the varying (and not really explained) differences between centres in length of wait list. The numbers of death on wait list were also discussed.

Tartu/Estonia have exported organs to the Scandiatransplant region, and Estonian patients have been transplanted (heart) in Helsinki (only Estonian donors, according to Karl L.). Lung transplants are performed in Estonia. Estonian representatives should be invited to the next meeting of the NTTSG. Are H. will ask Scandiatransplant for names (pulmonologist and surgeon).

#### **3.3. Donation after Circulatory Death**

A pilot project for abdominal organs has been successfully performed in Norway, and procurement of lungs is expected to start this year. Sweden is about to finish the preparations for the same, as is Denmark. In Finland, certain formalities remain to be cleared.

### **4. Studies**

4.1. Extra-corporal photopheresis (ECP): Michael P. suggested that a study on the efficacy of ECP for chronic lung allograft dysfunction (CLAD) should be done, along the principles of the current EPOS study. There were concerns about a possible conflict with the ScanCLAD study. It was decided that an ECP-study should be put on hold until everyone feels that the ScanCLAD study is going smoothly. Then, an ECP-study may probably be added as a study of rescue therapy within the frames of ScanCLAD. Michael P. will continue to prepare a protocol for such a study.

Hans E. reported that a study is currently running in Aarhus on ECP in patients with donor specific antibodies after heart transplantation (tx), examining cellular markers. It is not a controlled study.

The effects of ECP after thoracic tx remain to be proven in a controlled study. It was unanimously agreed that all centres should avoid using ECP until it may be done in a controlled study, as the Scandiatransplant area may well be the only region where such a study may still be performed.

4.2. Anna WE and Göran R presented the substudy of ScanCLAD examining heart function in patients receiving lung tx for pulmonary arterial hypertension. The substudy was positively received and will be coordinated with Göran D.

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<sup>2</sup> I will ask Ilse DW if this can be done centrally.

- 4.3. Cardiac sarcoidosis and giant cell myocarditis: Upon invitation from Kristjan K., Jukka L. from Helsinki gave an impressive presentation of the condition and of research performed in Helsinki. There was consensus to collect data from all Nordic centres for a collaborative study. Kristjan has started work with a CRF and will contact the other cardiologists of the NTTSG.
  - 4.4. Allocation for Urgency (lung): Hans HLS presented preliminary data from the study. Data collection is complete. Two publications are foreseen: the publication about the Nordic urgent call system will be written by Hans HLS and supervised by Martin Iversen/Copenhagen, the publication comparing allocation for urgency between various international centres will be done by Are H./Oslo. All contributors will be co-authors in both publications.
  - 4.5. EPOS (lung): inclusion in the EPOS study is still below expectations; currently 37 patients have been included. The steering committee will convene in August 2017 to decide how to proceed.
  - 4.6. Lung tx for pulmonary GvHD: Are H. reported that the study is completed, one paper has been published in the European Respiratory Journal this winter, the other is submitted to the Journal of Heart and Lung Transplantation.
  - 4.7. Aspirin for Heart tx.: An abstract presenting data from a similar study was presented at the ISHLT in San Diego two weeks ago. Hans E. will continue to explore the possibilities for this study and will discuss it with the other cardiologists of the group.
- 5. Other business**
- 5.1. Paediatric lung transplantation in the Nordic countries was discussed. Apparently, Gothenburg has by far the greatest experience, and a group from G. will go to Japan to study living donor lobar transplantation.
  - 5.2. The name NTTSG was discussed. It was probably coined before the group was formally incorporated into ScandiTransplant. Now being incorporated, however, the usefulness of renaming was discussed, without the intention to make decisions at present.
  - 5.3. Contributions to the current ISHLT work with guidelines for bronchioalveolar lavage after lung tx were discussed.
  - 5.4. The group was encouraged to submit proposals for symposia for the next ISHLT conference (Nice 2018), deadline June 1.<sup>3</sup>
- 6. Date for next meeting**
- October, Thursday 12. and possibly Friday 13. Are H. will (continue to) try to arrange this as a lunch-to-lunch symposium in Oslo, possibly cosponsored by the pharmaceutical industry (proposed topic: organ matching and allocation in thoracic transplant). If this fails, the meeting will be in the usual venue and Copenhagen airport, Thursday only.
- 7. Election of chair**
- Are H. was elected chair in 2015 and was unanimously re-elected for the coming two years (no other candidates announced).

21. April 2017  
Are M. Holm

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<sup>3</sup> The suggestions are to be submitted to the respective councils for heart, lung, MCS or other ahead of that. Check the ISHLT homepage.