

## Minutes NTTSG April 14<sup>th</sup> 2016

Meeting number 34,

Place: Hilton, Copenhagen, Denmark

Participants

**Oslo:** Are Holm; Inga Leuckfeld; Arnt Fiane

**Helsinki:** Karl Lemström; Maija Halme

**Lund:** Hillevi Larsson; Johan Nilsson; Göran Rådegran

**Gothenburg:** Göran Dellgren; Gerdt Riise; Kristjan Karason Ulla Nyström;

**Copenhagen:** Martin Iversen; Michael Perch; Hans Henrik Schultz, Kåre Sander

**Aarhus:** Elisabeth Bendstrup

**Transplant Coordinators:** Petra Vestlund, Göteborg; Catharina Yesil, Helsinki; Carina Lund Sørensen, Copenhagen; Urs Christen, Oslo; Jenny Warheim, Lund.

Scandiatransplant: Ilse Duus Weinreich; Torben Helligsø.

Minutes: Hans Henrik Schultz

### Arrival and Welcome

Are Holm welcomed everybody and gave a brief introduction of today's program. A short introduction round was performed.

### Scandiatransplant registry

Ilse Weinreich gave an overview of the status of the Scandiatransplant registry. The pretransplant data from all centers seems completely submitted from most centers. Transplant and follow up forms seem to lack from most centers. There was a discussion of the need for a Scandinavian registry. Reporting the 35 variables that Scandiatransplant submit to ISHLT seems necessary. Additionally, a registry would be essential for joint research projects. There was agreement about the need for the registry. However, there was also an agreement to evaluate the specific data points in the registry aiming to trim/reduce the number of variables. A group should be established to look into the parameters. Kristjan Karason, Ulla Nyström, Are Holm and Petra Vestlund volunteered, additional persons may be necessary and will be contacted by the group. Several local registries exist in all centers. These could be merged into Scandiatransplant.

### Donation timing for international offer

In a correspondence from director of the board of Scandiatransplant Kaj Anker Jørgensen, the NTTSG has been asked to comment a complaint from one center on the timeframe given from a donor center. According to Scandiatransplant guidelines, all discussion must be over when the donor operation starts and the donor center is the master. There was a discussion that the response-time is not always upheld. It was also emphasized that some organs might be wasted because of a rigid timeframes. Scandiatransplant data were presented, showing that lungs and hearts are currently used in only 30-40% of the realized organ donors in the Nordic countries. There is no information about the role of rigid time frames in this possible under usage.

NTTSG states that a timeframe should be made early, and if there is a need for more time one should ask for it. To investigate the extent of this problem (time consumption vs. organ loss), a registration of relevant data will be initiated. Are Holm will contact the transplant coordinators with a suggestion for such a registration at all centres. The results of this registration will be discussed at the coming NTTSG meeting. Also, Are Holm will write an answer to Scandiatransplant,

emphasising that the NTTSG will strive to increase the numbers of donor organs used thereby minimizing organ waste and that the two points stated by Scandiatransplant should be respected. Furthermore, the NTTSG will investigate the extent of the problem stated.

#### Prio 0 and 1, specify or change guidelines for organ exchange?

Ilse Weinreich gave an overview of the exchange rate for heart. There has been an increase in prio 0 use, from 15 in 2006 to 33 in 2015. A suggestion by Are Holm to evaluate the need for restrictions of prio 0 usage for heart transplant was rejected, but there was agreement of the importance of continuously monitor the number and discuss the prio 0 usage at forthcoming meetings.

There was a discussion of the use of urgent call in lung transplantation. A “running year” vs a calendar year of the limited numbers was discussed. The registration for an “urgent call” (of which each centre has 3/year) could be when an organ is actually exchanged (and a patient transplanted) and not when the patient is listed for “urgent call”. It was agreed upon that the current system should be interpreted as to mean number of “urgent call” listings, but that the matters should rest for now, and that the discussion should be continued at the next meeting in October. Specifically, for the remains of this year, this means that patients who die without receiving a lung while waiting for an “urgent call” should still count, and that the count should apply for the year when they were listed, not the year the actual exchange took place.

#### Minutes October 2015

The minutes from the last meeting was examined. There were no comments.

#### Diagnosis codes ISHLT and Scandiatransplant

There have been some questions about codes for diagnosis mainly regarding heart transplantation. Ilse gave an overview of current diagnosis in both the ISHLT and the Scandiatransplant. There is some discrepancy between ISHLT and Scandiatransplant. There has been made some changes and there a need for more changes. Ilse Weinreich will forward the list to all for revision.

#### Current studies.

The Allocation for urgency study was presented by Are Holm and Hans Henrik Schultz. These studies are making good progress, aiming for a presentation of a manuscript later this year.

LTX for pGvHD was presented by Are Holm. There is good progress with this study, and the first paper is accepted with minor revisions.

ScanCLAD was presented by Göran Dellgren. Summary: OD Tacrolimus vs Cyclosporin BD. 242 patients needed. Prospectively randomized 1:1 before transplantation.

Primary Endpoint is chronic lung allograft dysfunction (CLAD), secondary endpoint GFR at 3 months. Main protocol finished. Ethical application was approved in Sweden. Finland likewise. Norway and Denmark still in evaluation/submission process. Clinical trials acceptance is anticipated. E-CRF interface is finish and was presented. Budget and funding was presented. There is a still a need for further funding. There has been established a data and safety monitoring board. The study will hopefully start within a few months in Sweden and a few months later in the other centers. Minor adjustments to the protocol was discussed and proposed. Data/medical applications from Sweden will be forwarded to all centers.

Michael Perch presented the EPOS study. Inclusion criteria and progress was presented. Amendments were presented.

A suggested heart study: "HTx due to Inflammatory Cardiomyopathy" was presented by Kristjan Karason, Gothenburg. The literature in inflammatory heart muscle disease was reviewed and found to be quite sparse. A Scandinavian retrospective data collection on patients with HTx due to giant cell myocarditis or cardiac sarcoidosis was proposed with the aim of a joint publication.

#### Other topics

Ulla Nyström asked for data on pregnancy after thoracic transplantation as a follow up. A CRF will be sent out.

Johan Nilsson suggested a study for induction therapy in heart transplantation and post-transplant malignancy. A synopsis will be made for the next meeting.

#### The next NTTSG meeting

The time and date for the next meeting: October 27<sup>th</sup> 2016 Kastrup Hilton. The possibility for an overnight seminar was discussed and could be arranged if funding can be found. Are Holm will investigate this, suggestions are welcome. Possible topics for the seminar could be allocation of organs for thoracic transplantation.