

## **Minutes NTTSG 19. October 2015**

**Meeting number 33, Place: Hilton, Copenhagen, Denmark**

### **Participants:**

Oslo: Are Holm; Inga Leuckfeld; Tom Hoel; Arnt Fiane

Helsinki: Karl Lemström; Maija Halme; Jyri Lommi, Peter Raivio

Lund: Ingrid Skog; Hillevi Larsson; Johan Nilsson; Göran Rådegran

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

Copenhagen: Michael Perch; Peter Skov Olsen, Kåre Sander, Hans Henrik Schultz

Aarhus: Hans Eiskjær

Scandiatransplant: Ilse Duus Weinreich

Minutes: Hans Henrik Schultz (Ilse Duus Weinreich did the minutes from the ScanClad study)

### Welcome and presentation.

On behalf of the current chair Martin Iversen, Göran Dellgren lead the meeting.

Göran Dellgren welcomed everybody, and gave a brief overview of the structure of Scandiatransplant. Ilse Weinreich added that the tx coordinators have a strong wish to have a representative attending the NTTSG meeting. It was briefly discussed and unanimously agreed to invite a representative from the transplant coordinators for the next meeting.

Ilse Duus Weinreich gave a presentation of a test version of the new interface on Scandiatransplant. If anyone experiences any problems to login to the database they can contact Scandiatransplant to get help. The user interface is much more user friendly than earlier, enhancing the opportunity to see input and extract data from the database. The interface is expected to be ready within a month.

There were questions about feedback to each center. There is an opportunity for each center to get feedback on the data, and center specific mandatory values required to proceed in the database system. Some variables are required variables that are submitted to the ISHLT. But generally the submission of variables is patchy.

Johan Nilsson suggested that a feedback system could be implemented at the Scandiatransplant website behind a secured login.

Ingrid Skog suggested that we discuss this issue with the transplant coordinators at the next meeting, and Are Holm suggested that next chair could check statuses at each center to find out what the problem is at each center. It should be one of the tasks of the next NTTSG chairman. All supported and agreed on the latter 2 suggestions.

Are Holm presented the "Urgency in lung transplantation study". It consists of two studies: one to evaluate the Scandiatransplant Urgent Call system, and the other to internationally compare systems that give priority to urgency in lung allocation. The first is lead from Copenhagen (Martin Iversen and Hans Henrik Schultz), the second is lead by Are Holm from Oslo. The data collection is overlapping, and a list of desired variables has been sent out and return of data requested by December 11<sup>th</sup>. If there are any problems obtaining data by the deadline please contact Are or Hans Henrik.

Ilse Duus Weinreich presented the heart urgent call data from the first 9 months in 2015. The rotalist data was also presented. All heart exchanges have been done correctly according to the rotalist rules. The data from the lung urgency system were also presented, as well as the rotalist exchanges. There was a general discussion of the figures and especially the heart figures. This year, Helsinki has used 7 urgent calls for heart. For the next meeting Ulla Nyström and Ilse Duus Weinreich will prepare a slide showing the organ exchange (heart) for the last 10 years.

Göran Dellgren presented a proposal from Sahlgrenska University Hospital to Scandiatransplant regarding non-used marginal lungs being reconditioned by EVLP and offered to patients outside the Scandiatransplant countries. Currently, if organs are turned down locally and by all Scandiatransplant centers, they could be offered for Eurotransplant or other Organ Procurement Organizations (OPO). It is unknown how often such offers are made, probably not very often. The question is what could be done with such organs should they be developed (reconditioned) by EVLP and considered good enough for transplantation, and if such organs then could be given to patients outside normal Scandiatransplant waitlist. Scandiatransplant has requested the NTTSG to give a statement on the matter. There were extensive discussions in the group of NTTSG. Several questions were raised: Should lungs reconditioned in Gothenburg be re-offered within Scandiatransplant or can they be offered to other patients, such as non-Nordic patients or patients that have been turned down from other transplant centers. No evidence suggests that ischemia time (for transport time within Scandinavia) after successful EVLP is a problem. It was pointed out that other countries have a limit of 5% of transplantations that may be performed to non-resident patients (USA). Göran Dellgren also pointed out that pediatric lung transplantation recipients from Sweden have been sent to Hannover, and asked why we should not accept e.g. German patients for transplantation in Sweden. It was suggested that an organ reconditioned in Gothenburg should be re-offered first to Scandiatransplant and thereafter to the other transplant organizations in Europe. No final agreement was reached. Göran Dellgren will write a proposal for an NTTSG statement that will be circulated among the board members and put forward to discussion and final decision at the next meeting.

## **Lunch**

### Election for the NTTSG Chairman ship.

Ilse Duus Weinreich, Scandiatransplant lead the meeting for this point.

Three Candidates had announced their candidacy:

- Göran Dellgren, Göteborg, Sweden
- Are Holm, Oslo, Norway
- Johan Nilsson, Lund, Sweden

There was a short discussion whether it was ok to send a suppliant instead of the board member and that was unanimously agreed. Each candidate gave a short introduction before the election. Ballots were distributed to board members or the suppliant. Ballots were thereafter collected and counted by Ingrid Skog and Ilse Weinreich.

Are Holm got 9 votes and Göran Dellgren got 7 votes and Johan Nilsson got 2 votes. New elected chairman was Are Holm from Oslo.

Göran Dellgren took over the leadership of meeting again. The guidelines for organ exchange in the Scandiarttransplant area were examined. There were no comments and no suggestions for changes.

Ulla Nyström proclaimed the wish to make a follow up study to the “Pregnancy in heart- and heart/lung recipients can be problematic.” Ulla will contact the responsible person at each center to get the follow up data. Are Holm will contact the first author of the previous study (dr. Estensen in Oslo). All agreed to encourage this study .

Göran Dellgren presented the Scanclad Study.

ScanCLAD Proposed sub-studies – (notes to page 53)

- DSA - Jan Holgersson, immunologist, is preparing a protocol
- NODAT - Mads Hornum will get a reminder on writing a protocol
- Molecular - Karl Lemström will write a protocol with suggestion for a molecular study
- Two of the substudies include EBV and immune monitoring, so there seems to be an overlap.. The substudies are ‘Immunosuppression equipotency (Holm, Oslo) ‘ and ‘EBV-PCR monitoring (Riise, Gothenburg)’. Holm and Riise agreed to coordinate their proposals
- CLAD, will Martin Iversen take part?
- Pharmacokinetic – protocol has been forwarded (Leuckfeld/Holm, Oslo)
- RV failure - PAH – interest in the study was discussed
- New suggestion: Donor risk factors and its correlation to CLAD and PGD, Ravio et al.
- New suggestion: Blood products/transfusions (trc/erythrocyt), Ravio et al.

Other issues:

Arnt Fiane (Oslo) asked everyone to keep in mind to try keeping the time limit within 30 minutes when responding on an organ offer.

Next meeting

April 14, 2016 in Copenhagen, Hilton (maybe together with the coordinators involved in entering data in the registry).