SCANDIATRANSPLANT NORDIC TRANSPLANTATION COORDINATOR GROUP MEETING – APRIL 23, 2015, TARTTO, ESTONIA MINUTES FROM MEETING

<u>NTCG:</u>

Carola Schauman (CS): Helsinki

Bente Kaxe (BK): Odense

David Den Hartog (DDH): Göteborg

Nadine Weidenberg (NW): Uppsala

Ingebjörg Kvangarsnes (IK): Oslo

Dorte Matiassen (DM): Aarhus

Pernille van Houten (PH): København

Frank Pedersen (FP): Scandiatransplant

Ilse Duus Weinreich (IDW): Scandiatransplant - writer of minutes

Coordinators from Stockholm and Skåne were not present

Observers from Estonia:

Virge Pall

Anni Küüsvek

Hele Nurme

Janika Kuus



1. Welcome by Carola Schauman

NTCG expressed their thankfulness to the Estonians for their help and hospitality

2. Kidney and liver balance

In most cases agreement on balance was reached, only a few cases needed follow up by mail. Skåne was not present, why balance has to be checked by email.

3. Thoracic organ transport box

Current ways of packing the thoracic organs were shared and discussed.

4. Transport box for liver

Stockholm and Uppsala have started to use new transport boxes for livers. The boxes are not expensive so they do not need to be returned/re-used. They find the usage of the box very convenient. It is possible to order the boxes from:

- Schaumaplast Reilingen GmbH / Industriestrasse 5 / 68799 Reilingen
- reilingen@schaumaplast.de
- +49 6205 9774-0
- <u>www.schaumaplast.com</u>
- Minimum order 15 pieces price 70 SEK per box

5. Vascular pancreas, exchange?

There is no official Scandiatransplant guidelines of how and when to offer spare pancreas. How should it be handled in practice and are the retrieval teams ready/willing to retrieve 'only' pancreas? NW and IK will ask responsible persons at their centers and contact chair of the pancreas Group, Lars Backman. Local guidelines might need to been changed and made to Scandiatransplant guidelines.

6. Pay back

Sometimes suggested pay back is <u>not</u> an organ of same quality, why is this?

The problem were addressed and discussed. Keywords were; doctors decisions, lack of knowledge, different views on quality, different work procedure.

7. New user interface (YASWA)

• Evaluation of organ offer form and rotation lists

It works well, possibility to print current rotation list status is a wish.

Urgent waiting lists and 'search for suitable kidney recipient' are now also available in production through the new user interface. Time of urgency listing will be added to the display.

It is still a strong wish to have updates to the urgent lists by email and sms. Furthermore it is a wish to have an automatically 'countdown' on high urgent liver patients, which will change the patient status to kind request after 72 hours.

• Recipient administration (All recipients)

Has been and still is in test. It is strongly recommend that all give it a try as the office is depended on feedback from the users to make a good and well-functioning system.

• New developments

The very first screens for deceased donor registration were shown, they still need some work before being released for user testing. Deceased donor transplantation registration is also on the way.

The user administration and logging module were demonstrated

To follow the developments please read the news letters from the office.

http://www.scandiatransplant.org/news/newsletters

8. Urgent call thorax and liver, when several recipients are listed at the same time

For hearts and lungs it is the rotation list and not the time of registration that counts:

Prio 0/1 organs should first be offered locally.

If there is no prio 0/1 patient locally, the organ should be offered to the centre at the top of the rotalist (ie, independently of the time prio 0/1 was registered in the database or when a fax was sent).

This view is in accordance with #3 in the guidelines, and applies to both heart and lungs.

http://www.scandiatransplant.org/organ-

allocation/GuidelinesforThoraxOrganExchangeintheScandiatransplantArea.pdf

Rotation has to be done when a heart/lung is exported to another country and transplanted to a prio 1, 2 or 3 recipient.

For livers it is the time of registration that counts:

If several HU call exist at the same time, the first one registered in the database has priority over later HU call and that this also is true if the second center has a local donor.

Rotation has to be done when a spare liver is exported to another country and transplanted.

http://www.scandiatransplant.org/organ-allocation/liver_rotation_manual_27jun2011.pdf

9. Fax for urgent call/ reminder

Shared waiting list should be sent by email not fax. The procedure of sending the list once a week and when there are changes (in daytime) will stay unchanged.

Reminders on high urgent still kept as it is each Monday.

10. Reimbursement for land transports

As it was decided at the last meeting Kerstin Karud and CS have written a letter, which they have sent to the Scandiatransplant board. The board has not responded.

Administration is also a cost and land transportation is not that expensive.

NTCG decided to leave it as it is for now.

11. Organ offers from Estonia

Estonia should not keep track of the Scandiatransplant rotation lists, this is a take home message to all coordinators. The flowchart is to be followed. <u>http://www.scandiatransplant.org/organ-allocation/Liver_and_thorax_rotation_Estonia.pdf</u>

Estonia should not wait 1½hours to get an answer of evaluation, if extra evaluation time is needed, please contact and inform the Estonian team.

To use and keep track of the rotation lists when numerous organs are offered is demanding, however there is no better solution at the moment.

12. Other matters

• Spare liver offers

If receiving center needs to procure the liver themselves, please write it on the organ offer form.

No one is obligated to offer anything, some centers do not offer livers that they would not use for their own patients.

• Urgent call for liver from Estonia

The Estonian coordinators wanted to discuss, how to approach Scandiatransplant when they have urgent patients. They were asked to send these enquires to Scandiatransplant as kind requests. Kind request has no time limit, why it is not necessary to send out a reminder. A withdrawn should be done, when transplanted or if not transplantable anymore.

• Feedback between centers on organ donors

Feedback on organ donors should be sent to the 'group'-email addresses instead of to a single person.

• Refusal from relatives

It was discussed how this is registered at each center.

• Difficult to find transportation

If the receiving center has trouble with transportation, please contact the donor center as they might be able to help. Please notice that Oslo have a special agreement with a private company 'Hesnes Air'.

• Scandiatransplant Council of Repatensive meeting

CS will present a short status on behalf on NTCG

13. Next meeting will be held in Copenhagen, Kastrup, Hilton October 22, 2015