

Minutes from the NLTG meeting in Gothenburg October 21, 2013

1) The NLTG minutes from meeting in Copenhagen April 22, 2013 were revised. The second to last sentence under the 5th point of the minutes (*"Furthermore it was decided that all "splittable" liver should be splitted unless there is an explanation why not."*) will be revised and changed to:

"Furthermore, splitting of livers which fulfill the splitting criteria established will remain voluntary, however, the reason for deciding not to split such a liver should be documented in order to enable valuable follow-up data regarding the potential availability of segment2+3 grafts for paediatric liver transplantation".

The new versions of the minutes from the NLTG in Copenhagen April 22, 2013 are attached (Appendix 1).

2) An update from each centre was given. In general, no major changes at any center. Denmark has had a sharp decline in donors following a diagnosis error in a donor who recovered. They seem, however, to slowly recover both public trust and donor frequency.

3) William Bennet presented information regarding ongoing collaborative work between local registries and the NLTR, and the NLTR and ELTR in an attempt to eventually establish a link for direct data transfer between the registries. Tom Hemming Karlsen is coordinating this activity. A letter of intent, signed by representatives from each center will be needed for this agreement for the case of NLTR as well as the ELTR. William Bennet will write a proposal (Appendix 2) which will be circulated to the representatives from each center and with the aim that a document is ready by the next NLTG meeting (Oslo, march, 2014). Oslo will establish a pilot project to test direct transfer data opportunities into the new NLTR and will present an update on this in Oslo 2014. The following representatives were chosen and agreed to be the contact person from their center with regards to this work and legal as well as quality aspects of data entries into the the NLTR:

Copenhagen	Allan Rasmussen	(allan.rasmussen@dadlnet.dk)
Gothenburg	Michael Olausson	(michael.olausson@surgery.gu.se)
Helsinki	Helena Isoniemi	(helena.isoniemi@hus.fi)
Oslo	Axel Foss	(afoss@ous-hf.no)
Stockholm	Bo-Göran Ericzon	(Bo-Goran.Ericzon@ki.se)

Furthermore, it was decided that there is a need for written guidelines regarding data request from the NLTR and subsequent publication rules regarding data extracted from the NLTR. William Bennet and Styrbjörn Friman will draft such guidelines to be presented at the next NLTG meeting. The studies will thereby be published as a study supported and endorsed by the NLTG/NLTR.

The Annual NLTR Report for 2012 is still not published but is to be expected shortly (?)

4) William Bennet gave an update regarding the current status of the Common Nordic waiting list for paediatric segment 2+3. The following criteria were established as initial screening criteria for livers which should be considered for segment 2+3 splitting (in the absence of unfavourable factors such as listed below):

- Age \leq 50yrs
- BMI \leq 25
- ICU \leq 3days
- ALAT \leq 3 x normal

It was also agreed on, that livers fulfilling these criteria that are not split a reason for this decision should be quoted in order to enable valuable follow-up data regarding the potential availability of segment 2+3 grafts for paediatric liver transplantation. Potential reasons include hemodynamic instability, > 1 inotropic drug, history of trauma, steatosis >20%, S-Na⁺ > 160, size/anatomical reasons, logistical problems, no recipient on common waiting list or any other reason of choice.

Furthermore, it was agreed on that:

- In **non-high urgent case** the donor center decides if to offer only segment 2+3 or the whole liver to a center with a child on the common waiting list.
- In **high urgent case** the recipient center decides and is entitled to the whole liver graft.
- As **pay-back** the donor center of segment 2+3 will receive a whole liver in order to encourage split-liver sharing between centers. In case a whole liver fulfilling the splitting criteria is offered then a similar liver fulfilling the splitting criteria should be used as a payback.

5) We also discussed payback rules for other livers and it was agreed on that a center can decline an "adequate" pay-back offer no more than 2 times. At the 3rd decline (within a 6 month period) the pay-back will be cancelled and removed from the pay-back list.

The criteria and pay-back rules will be added onto the ScandiTransplant pay-back rules.

6) William Bennet introduced the concept of possibly implementing a Donor Risk Index score into the NLTR. The purpose would be to better compare donor quality within the Nordic countries and trends over time. All agreed that this is of importance and interest to all of us. A group consisting of Christian Ross Pedersen, Per Lindner, Axel Foss and William Bennet volunteered to investigate existing scoring systems and provide a proposal for a system suitable for the Nordic population at the next NLTG meeting.

7) Liver offers from the Baltic countries were discussed. Both Oslo (2 livers), and Stockholm (2 livers) and Helsinki have thus far accepted and retrieved excess livers from Estonia and have been impressed by the logistics and service at the donor hospital. Helena Isoniemi mentioned that in their case there is an ongoing investigation regarding a potential transfer of hepatitis B from their Baltic donor to the Finnish recipient. We await the results of this investigation. Apparently there is/are laboratories certified for viral screening with the Baltic region. Nevertheless, the group decided that any liver offers from the Baltic states will enter the existing rotation list (ROTA) and be handled just like any other surplus liver within the ScandiTransplant region. The practical aspect of this was also discussed and outlined at the most recent

NTCG meeting in Copenhagen, following this NLTG meeting. The standard operating procedure (SOP) of the allocation of livers from the Baltic region is attached (Appendix 3)

8) An Update on-going Nordic multicentre studies:

Liver transplantation and cancer - Nordic Multicenter Study (*Arno Nordin*)-
data analysis ongoing-

Pediatric Liver transplantation (*Silvia Manicka/Björn Fishler/Anthal Nemeth*):
No update given

Alkohol study after Liver transplantation (*Knut Stokkeland*)- ***Maria C gave an update- recruitment into the study is slow, only Sweden participating although Copenhagen was planned to participate- Allan R was unaware of this and will look into the reason for withdrawing from the study.***

Genetiske studier av rejektion vid levertransplantation (*Tom Hemming Karlsen*)- ***Not reported but apparently ongoing !***

Donors above 75 years and less than 6 years, Scandia TX research grant study (*Aksel Foss/Trygve Thorsen*) : ***Final data analysis and manuscript to be prepared and ready during 2014.***

9) Future Studies were discussed. We all were urged to think of future collaborative studies. Bo-Göran Ericzon mentioned that it could be interesting to study outcome after liver transplantation for α -anti trypsin deficiency. A plan for such a potential study will be presented at the next NLTG.

10) Collaboration in the field of clinical hepatocyte transplantation was discussed and Prof Stephen Strom, from Karolinska, urged centers to if possible provide excess livers /tissue for clinical studies. He also has a special interest in studying hepatocytes from explanted liver from recipients with metabolic liver diseases. Prof. Strom will possibly present the field of hepatocyte transplantation at the next NLTG meeting and to discuss the possibility of a Nordic collaborative study in this field. Stockholm has full equipped with a GCP lab for clinical hepatocyte transplantation and Prof. Strom has extensive experience in this field from his work and research at the University of Pittsburgh, USA.

11) Next NLTG meeting will be in Oslo on March 31, 2014 followed by the first meeting of a Nordic Pediatric Liver Transplantation Group (NPLTG) on April 1st, 2014 at the same venue.

12) Dinner

William Bennet

Appendix 1

Minutes from NLTG meeting in Copenhagen April 22. 2013

- Minutes from meeting in Helsinki October 22, 2012 were approved
- The new director of Scandiatransplant, Kaj Anker Jørgensen introduced himself to our group.
He gave an update about the current status in Scandiatransplant, and he gave information regarding the challenges, and his visions for Scandiatransplant
- Aksel Foss presented data from the annual report.
- An update from each centre was reported.

William Bennett gave an update regarding the current status of the Common Nordic waiting list for pediatric segm 2+3. There was a very good discussion and general agreement that steps should be made to encourage the exchange of segment 2+3. It was decided that there in the future will be a payback for the segments. A centre sending a segment 2+3 for transplantation in another centre will receive a full liver of the same blood group as a payback. *Furthermore, splitting of livers which full fill the splitting criteria established will remain voluntary, however, the reason for deciding not to split such a liver should be documented in order to enable valuable follow-up data regarding the potential availability of segment 2+3 grafts for paediatric liver transplantation.* How we shall manage this in the future has to be clarified.

- There was a discussion about how to manage “splittable” livers in urgent calls. There was general agreement that the recipient centre “owned” the liver, and the recipient centre could split the liver and use both grafts in their own centre if they wished to do so. As a consequence of this system, the payback of a liver fulfilling the criteria for being splitted, obviously should be a liver fulfilling the same criteria.
- Helena Isoniemi presented the rapport by the group under Scandiatransplant who has handled the Estonia application for membership of Scandiatransplant. The rapport from the group was circulated before the meeting. The group recommended, the application to be turned down. Pro’s et con’s were given.
- Gustaf Herlenius chaired a discussion regarding the implementation of a Nordic Intestinal Failure and Transplant Registry. No final discussion was made.
- An Update on-going Nordic multicentre studies
 - Liver transplantation and cancer – A Nordic Multicentre Study by Arno Nordin
 - Donors above 75 years and less than 6 years, Scandiatransplant research grant study by Trygve Thorsen
 - Causes of premature death in the long term after liver transplantation – a population-based study in the Nordic Countries by Fredrik Åberg
 - Further discussion on downstaging TACE study for HCC by Magnus Rizell
- The RAD 2304 study, a multicentre study on Certican was presented by Bo-Göran Ericzon

- Parallel to the NLTG meeting, there was a meeting for the register responsables from each centre and Scandiatransplant. Frank Pedersen gave a raport from this meeting.
- Next NLTG meeting should be in Gothenburg October 21, 2013.
- Dinner

ALLAN RASMUSSEN

Appendix 2

Letter of Intent

Data transfer between the Nordic Liver Transplant Registry and the European Liver Transplant Registry

The undersigned representatives of the Nordic Liver Transplant Registry (NLTR) have agreed on developing and establishing an agreement between NLTR and the ELTR with the purpose to:

1. establish a framework for cooperation between the ELTR and NLTR in order to facilitate the exchange of donor, recipient and follow-up liver transplant data of patients, as a service for the transplantation centers;
2. define the rights and obligations of the Parties and ensure information exchange between Parties;
3. provide a framework for the alignment of the datasets and the data exchange between the databases of ELTR and NLTR.

The NLTR is owned by the Nordic liver transplant centers and has its operational seat in Oslo, Norway. The operational head and current NLTR custodian, by appointment, is the Dr. Tom Hemming Karlsen, MD, PhD. With the consent of all centers the goal is to develop and enhance cooperation within the field of data exchange regarding liver transplantation data. The parties have also agreed that Dr. Tom Hemming Karlsen has authority on behalf of its NLTR members to draft and formulate the conditions and an agreement between the NLTR and ELTR regarding this. A representative from each center will subsequently sign this agreement.

Signed in fivefold on 2013-XX-XX

Prof Aysel Foss MD, PhD
Oslo University Hospital
Oslo, Norway

Prof. Michael Olausson MD, PhD
Sahlgrenska University Hospital
Gothenburg, Sweden

Prof. Bo-Göran Ericzon MD, PhD
Karolinska University Hospital
Stockholm, Sweden

Prof. Helena Isoniemi MD, PhD
Helsinki University Hospital
Helsinki, Finland

Prof. Allan Rasmussen MD, PhD
Copenhagen University Hospital
Copenhagen, Denmark

Appendix 3

Standard Procedure for allocation of liver offers from the Baltic Region/States

A phone chain between the ScandiTransplant liver transplantation centers forms the basis of this solution, where the order of the centers in the phone chain is defined by the current liver rotation list.

When a liver is offered from the Baltic states the center with the highest position on the ScandiTransplant liver rotation list evaluates if they can use the liver for one of their recipients.

- If the center accepts the liver, they must inform all other centers in ScandiTransplant that they have accepted the offer, furthermore only the accepting center will phone the Estonia coordinator. The accepting center must be rotated and the accepting center itself is responsible for the rotation a.s.a.p. Cause of rotation is 'OE: Organ accepted from Estonia'.

- If the center does not accept the liver, they must inform the next center on the rotation list. Then this center will have to decide if they can use the liver. This procedure continues until a center accepts or all centers have declined the offer.

This standard operating procedure will become effective from **December 1st, 2013**.

At the next NTCG meeting (March 27th, 2014) the outcome will be evaluated. The Estonian team will be informed about this change in procedure

Copenhagen, 2013-10-23

Carola Schauman (NTCG chair) & Ilse D. Weinreich (ScandiTransplant)