Minutes from the Nordic Liver Transplant Group (NLTG) meeting in Oslo 0310, 2011(proposal)

Present:
Silvia Malenicka (ST), Annika Bergquist (ST), William Bennet (GO), Bengt Gustafsson (GO), Gustaf Herlenius (GO), Maria Castedal (GO) Susan Malmros (GO), Bo-göran Ericzon (ST), Gunnar Söderdahl (ST), Aksel Foss (OS), Tim Scholz (OS), Tom Hemming Karlssen (OS), Kirsten Muri Boberg (OS), Erik Schrumpf (OS), Christian Ross (CP), Helena Isoniemi (HE), Arno Nordin (HE), Styrbjorn Friman (GO). Krister Hockerstedt (Sctp), Per Lindnér (GO),Truls Sanengen (OS), Trygve Thorsen (OS), Kathe Meyer (OS).

Aksel Foss welcomed the participants

1. The minutes from the Gothenburg-meeting was approved

2. Center reports
   - Copenhagen: Aiming at approx 40-50 Ltx for 2011 and probably a further rise in activity for 2012.
   - Gothenburg: The successor of prof. Olausson as chairman of activity will soon be decided. The liver program is unchanged in number of transplants.
   - Stockholm: A substitute for the leave of dr. Gjertsen is called for by surgeon from Miami. Size of liver program is unchanged
   - Helsinki: The professorship is still pending. Activity as usual.
   - Oslo: Donor rate is up nearly 40%, targeting 30 pmp. The Livertx numbers are as last year, mainly due to lack of recipients. Net export of livers Q1-3 is 25. Covering of retrieval costs will secure maximal utilization of available donor livers in the Nordic area. Modern financial hospital management call for an urgent decision on reimbursement of costs for free livers. Resumed discussions on this matter is initiated in Sctp. and this issue will appear on the agenda of the upcoming NLTG meeting in March 2012, with the aim of ratifying retroactive reimbursement of free liver retrieval from Jan. 2011.

3. Krister Höckerstedt (Sctp) was specially invited to update NLTG of the status of transplant regulations and registries in the EU and other aspects regarding Sctp position vs. the EU. Currently updated information of the dynamics and regulations of transplantation and donation in EU is of uttermost importance for professionals in the field of transplantation.

4. Tom Hemming Karlsen reported on NLTR. Again topics regarding harmonization Sctp/NLTR and the EU were referred. The group discussed how the data in the register can be properly validated and if we need an external audit/validation of the registry. Any consensus on this point was not achieved. Further, the need for scheduled meetings between NLTR and personnel involved in data collection to the registry was discussed and approved. Tom stressed the importance of including responsible physicians at such meetings. The importance of regular (i.e. once a year) NLTR-meetings are obvious as quality control of the data input to the registry. Delegates to participate in these meeting shall be appointed by the responsible livertx program person at each center. Scheduled NLTR meetings were proposed to be a responsibility of Sctp, who has both the

authority and the financial strength to implement it. The chairman of Sctp (Krister) was strongly encouraged to promote and to decide on this issue with the aim of planning for a NLTR-meeting in Copenhagen early 2012.

5. William Bennet and Gustaf Herlenius proposed a shared and mutual Nordic wait list for seg. 2+3 liver recipients (children) and for multivisceral recipients (children and adults). In 2010 less than 20 of 323 Ltxs (4.9%) were performed in children less than 5 years according to the NLTR annual report. Based on donor demographics in the Nordic countries, perfect deceased liver grafts (seg. 2+3 splits) for all children are available. Consequently, it is only a matter of organization and allocation to ensure perfect livers to children (without the use of live donors). The group agreed on making a common wait list within Sctp for patients in need of seg. 2+3 liver grafts and for children awaiting intestinal or multivisceral grafts. To ease the implementation of a shared inter-nordic list for children, GO agreed to establish routines and update such a list (the first couple of years). Thus, when patients are in need of seg 2+3 William or Gustaf may be contacted for listing. When a suitable donor appears the involved two centers should communicate and decide about the spliting procedure and offer opportunity of the other center to take part in the spliting.
   - Example 1. If we in OS have a perfect organ available and there is a seg. 2+3 recipient on the inter-nordic shared wait list at another center, the most suitable approach for us will be to split the liver ex situ in OS and then ship the seg. 2+3 to the other center.
   - Example 2. Recently, an urgent child in OS got a perfect whole liver from GO according to established NLTG rules. An ex situ split was performed here and the seg 4-8+1 was shipped back to GO and transplanted with CIT< 10 h. (several successful full left-full right split has also been performed, although this is not the issue of the new NLTG agreement).

   Suitable donors for children awaiting intestinal and multivisceral on the inter-nordic wait list, is requested to contact the center treating the patient (at present GO and HE).

   Concerning adult multivisceral recipients, the picture is a bit more complicated. Most centers have long waiting list for livers and thus few multivisceral donors available. OS is preparing for increasing the PA-program substantially. Internationally, there are differences in the preference: multivisceral vs. intestinal tx for adults. If more adult multivisceral patients could manage with intestinaltx only, a nordic shared list for intestines to adults could be adopted, since there is a large potential for suitable intestinal donors in the Nordic donor pool.
   Gustaf gave a brief update on the existing Nordic multivisceral program. Totally, 30 patients have undergone multivisceral/intestinal tx, 23 of these procedures have been performed in Gothenburg. The 1 year survival rate is very good, approx 80%. The program is growing, but slowly, due strict criteria for tx and lack of suitable donors.

6. Update on studies:
   - *LTx and cancer study (*Arno Nordin) – Needs license from the ethical committee in Denmark and Sweden. Norway and Finland are ok and ready to go.

- *Pediatric Ltx study (Silvia Manicka)* - Presented update on the study and a list of data still missing. The missing data list will once again be sent to the responsible contact persons at each center and lacking information is expected to be completed within the next few months. Silva is prepared to help with data collection at each center if manpower is needed.
- *Ltx and use of alcohol-study* – The PI Knut Stokkeland was unfortunately not present. There are several concerns about the study. Both the lack of objective measures of alcohol use and the size of the study was discussed. Already at the NLTG meeting in Oslo, April 2008, when the study was proposed, Oslo rejected to participate due to concerns about sample size and originality of the study. NLTG urge the PI to take action to speed up the study progress. For further support by NLTG it is very important that PI is available and reports substantial progress on the study at the next meeting (March 2012)
- *Colorectal neoplasia in IBD patients after Ltx study* – (Kirsten M Boberg). The first paper of the study is completed and submitted for publication. The group discussed a potential study performing MRCP on the patients to explore recurrence of PSC or to perform a prospective study on the topic.
- *Life expectancy after Ltx in the Nordic countries* – (Helena Isoniemi) Long term life expectancy after Ltx has not improved significantly over the latest decades. Helena et al want to investigate this using NLTR data and national health registries, of which are open for public use. The concerns of the group were whether one can rely on the information (cause of death) in the registries. However, the study was encouraged to be carried out.
- *The use of donor livers above 75 years/under 6 years, Scandiatransplant Research Grant Study* – (Aksel Foss/Trygve Thorsen). The group agreed on performing both studies, defined in two separate papers. Contact person(s) at each center has been appointed. Study protocol for the use of donors > 75 and list of patients have been distributed. Protocol for donors < 6 years is to be completed. Final proposal of study parameters will be sent to participants ASAP. OS and GO will define the project as quality control studies (IRB approval). ST want approval by the ethical committee. Other responsible contact persons (Helena, Frans, Allan/Christian) is urged to decide the need for local approval. Aksel/Trygve will design a project description: the use of extreme aged donors in liver transplantation to use for approval applications. The grant is in total 20.000 Euros, and is of course available for all participants. We have invested app 1000 Euros in a study specific PC. According to time scale the study reports is to be submitted by the end of 2012.

7. Leif Eriksson reported on Astellas pipeline drugs.

8. This proposed minutes is mailed to the present NLTG mailing list. When you reply please check the validity of the mailing list.

9. Next meeting will be hosted by Bo-Goran in Stockholm: March19 (monday), 2012.

Trygve Thorsen
Aksel Foss