

Minutes of NLTG meeting in Helsinki 25th March, 2015.

Venue: Scandic Hotel, 8th floor meeting room Pavilion, 11.15-16.30

1. H Isoniemi opened the meeting and welcomed everyone. Minutes of the NLTG meeting in Stockholm 22.10.2014 were accepted with minor revisions. It was decided that the center responsible to organize NLTG meeting will send the accepted minutes from last meeting to the Scandiatransplant office, where after the minutes will be placed on the webpage (<http://www.scandiatransplant.org/members/nltr/minutes>).

2. Center reports:

- a) Copenhagen: Pancreas transplantation program is just starting. Negative publicity in tv-program resulted in a period with less donors than usual..
- b) Gothenburg: 97 liver transplantations last year, two LDLT for pediatric recipients. 2 patients waiting for intestinal transplantation, 2 more will be listed in near future. Problems with coordinators fixed by employing new staff, should work better and better all the time.
- c) Oslo: Start of the year has not been good, with only 20 donors and only 19 livers done this year. First three DCD kidney transplantations done.
- d) Stockholm: 85 transplantations last year, good and relevant number of doctors in the unit. Started a pediatric unit at the department of transplantation surgery Huddinge. Hepatocyte study running, and in next meeting some preliminary results of A1AT study will be presented.
- e) Helsinki: 120 donors and 59 liver transplantations done last year – also 240 kidney, 15 combined pancreas transplantations done last year. No intestinal transplantations, 2 patients listed. This year already 28 donors and 14 livers (50 kidneys, 4 pancreas) done so far. The two wards have been united into one level of the new hospital, having now 50 beds for abdominal transplantation patients together with nephrological and hepatological patients.

3. Espen Melum presented the NLTR report up to 31. January, 2014

Registry holds data of 6437 patients of which 5492 had first liver transplant, 590 more than one Tx, and 99 more than 2 transplantations. 570 patients are pediatric. Waiting list had 418 patients of which 96 are active, 10 died on the list, and 17 were withdrawn. There was a discussion about some discrepancy between these groups “dead” and “withdrawn” since some of the withdrawals are actually dead on the list and it was asked is the reason for withdrawal also recorded? Some data exists but not exactly all and this could be analysed. It was hoped that in the next meeting there would be more thorough report on these things.

Deaths on waiting list have actually decreased since 1990 to 2014. Waiting times have increased in Helsinki and Oslo, however, these centers are still leading in short waiting time figures. Gothenburg waiting time has decreased slightly. It was commented that patient selection affects these results, as for example hepatologists may list more easily the patients increasing the waiting time arbitrarily (Allan). Hepatocellular cancer is the most common indication for LTx, followed by PSC etc. The recipient age increases in all centers as well as the donor age which is now 52 years (mean). The oldest donor was 86 years. Overall and patient survival have still improved. But Nordic countries have excellent survival results as compared to other centers in the world. The MELD score have decreased slightly obviously due to the increased number of HCC patients listed. The prognosis of various MELD groups would

be important since the score is used in patient selection (Ericzon) and it was wished that the analysis should be done according to MELD classes as well. The NLTR report is available on Scandiatransplant website.

http://www.scandiatransplant.org/members/nltr/NLTR_ANNUAL_REPORT_2014.pdf

Styrbjörn asked also for the slides on website.

http://www.scandiatransplant.org/members/nltr/NLTR_2014.pdf

The data entry systems was also presented by Espen. The idea is that each center fill data on line to NLTR/Scandiatransplant. Connection with ELTR is hopefully coming soon. Scandiatransplant in Aarhus is the data collecting center. Some details for example histological data, immunosuppression data etc. were discussed. Patients transplanted abroad or patients without papers should also be included in the register to maintain transparency of transplantation programs. Scandiatransplant seems not to register them at the moment and this matter will be checked in the future.

4. Ilse Weinreich from Scandiatransplant reported on the status of converting NLTR to the new Scandiatransplant user interface.

5. NLTG rules and guidelines

NLTG would need a contact person that would answer for data request by Scandiatransplant. At the moment KA Jorgensen does not know whom to contact in such situations. It was decided that the chairman of last meeting will be in charge until next meeting. Chairman will also rotate the minutes for acceptance before next meeting, preferably as early as possible.

6. Guidelines for publication of NLTG studies. These are under work and not presented now, perhaps in the next meeting. Last time six point rules were accepted but the rules are not distributed for final acceptance. After final acceptance rules are on SCTP webpage.

7. Krister Höckerstedt presented the ideas and changes proposed by a newly formed working group of new Articles 2014-2015 in Scandiatransplant. The issues under work are for example the overall structure of the organization, the owners, councils and boards, groups and committees, and the office. And also the fact who owns the data, what are the relations to authorities, what countries would join the Nordic group etc.

8. LICAGE proposal. Espen presented the LICAGE initiative of collecting peroperative data. This study is in its early stage and no center has been involved yet. The data collection was very extensive and at least in Finland no-one is interested to do this. The proper protocol and more detailed information should be available before deciding this proposal.

9. The NLTR diagnosis conversion by Ilse Weinreich. The NLTR have 2 different sets of diagnose codes, the historical NLTR diagnosis and diagnosis used in ELTR. It would be better to have one set. The cause of deaths is also inadequately recorded but it was pointed (Isoniemi) that the information is in ELTR data and is available to all. Ilse proposed that Scandiatransplant could access this data for each center, send the files to each for correction and check-up. The new system description and user manuals will be sent.

10. Ongoing studies

a) Allan Rasmussen presented *a new study on DSA in liver transplantation*. The analysis of DSA and complement activation would be done in Copenhagen which has the funding. Some of the details of the protocol were discussed including the blindness as the study would go on for 2-3 yrs. Also MRI+MRCP was suggested to be added in the protocol (at one year). Allan will arrange investigator meeting in Copenhagen for more details to be discussed.

b) Arno Nordin reported that the final analysis of the *Nordic cancer study* will start when the last data has been collected.

c). Knut Stokkeland was unable to come to the meeting. Informed by email 9th March: *The alcohol study* will soon end the enrollment period – early March more than 170 patients enrolled and hopes continued support

d) Christian Ross reported about the DRI score. We have altogether 5193 donors from the year 1995. The data is not properly recorded, CIT is recorded in only 77% of cases, the number of splits is small, the organ allocation cannot be used as indicator and it was decided not to go on with such study.

e) Christian ? presented also a study of *optimization of anti-CD25 use induction* in liver transplantation. Lot of theoretical points for the study were presented and also available publications. Discussion about blood samples and protocol for ethical application

f) *The recurrence of psc study* was not reported.

Latest NLTG studies published:

1) Fredrik Åberg et al: Differences in long term survival among liver transplant recipients and the general population: a population-based Nordic study. *Hepatology*. 2015 Feb;61(2):668-77

2) Trygve Thorsen et al: Transplantation with livers from deceased donors older than 75 years. *Transplantation* 2015 Apr 24

17. A new study by Åsa Noren, Gustaf Herlenius and Styrbjörn Friman was presented: the preliminary study is going on in which kidney biopsy is taken from liver transplantation recipients in order to look for the reasons for kidney failure post liver Tx. The first results will be presented in the next meeting and then the study could be widened to other centers.

18. The next meeting was decided to be on 21st October 2015 in Copenhagen.

List of participants based on signed form:

Helena Isoniemi	Helsinki
Mikaela Viss	Stockholm
Bo-Göran Ericzon	Stockholm
Greg Nowak	Stockholm
Eero Hartikka	Helsinki
Leena Toivonen	Helsinki
Siv Ansa	Helsinki
Carola Schauman	Helsinki
Stein Foss	Oslo
Hannu Jalanko	Helsinki
Ilse Weinreich	Scandiatransplant
Christian Ross	Copenhagen
Allan Rasmussen	Copenhagen
Gustaf Herlenius	Gothenburg
Krister Höckerstedt	Scandiatransplant
Styrbjörn Friman	Gothenburg
Arno Nordin	Helsinki