

Minutes from NTLG meeting in Stockholm 22 October 2014

1. After a short welcome and introduction of the program we also discussed future meetings. Order of hosting centers is Helsinki, Copenhagen, Gothenburg, Oslo and Stockholm. NTLG meetings are scheduled twice a year and each autumn meeting is in connection with PNLTG meeting. Next meeting will take place in Helsinki, 25th of March 2015. Spring meetings are in connection with coordinators meeting and include yearly reports from NTLR.
2. Center reports.
 - a. Helsinki: 100 donors; 50 years celebration of kidney transplantation program
 - b. Copenhagen: slow recovery in organ donation; 50 liver transplantations per year expected; pancreas transplantation program starts
 - c. Gothenburg: turbulent times due to changes in coordinators team; expected 85-90 liver transplantation; 2 intestinal and 1 multivisceral transplantation this year; records in lung transplantation
 - d. Oslo: two new surgeons in the team; 100 liver transplantations expected; longer waiting list
 - e. Stockholm: 40% increased production in organ transplantation; expected 85 liver transplantations; pediatric transplantation center at Transplantation Department (6 beds)
3. Report from NTLR Scandiatransplant given by Espen Melum who is in charge of the registry. Plan to update registry with possibility to get information on donation, intention to treat, registration of patient without permanent stay in Scandinavia. Data analyses were presented and it was discussed how they should be presented; at least yearly reports should still be presented on Scandiatransplant's website and a "bigger" overview could be presented in Scand J of Gastroenterology, etc. Ilse Weinreich was presenting updates on data transfer local→Scandia→ELTR. The aim is that it should be enough to transfer data to Scandia and the rest will be "automatically" updated. Right now there is a pilot project in Oslo (not finished but implemented with possibilities to synchronize database with Scandia). The system seems to be pretty compatible with other platforms. New ready interface for registration in Scandia was presented, and update on its implementation will be presented in Helsinki during the next NTLG meeting. It should also be discussed if we want to send the data to ELTR automatically? Should it be optional or mandatory for Scandia centers to send these data to NTLG?
4. William Bennet presented a revised version of NTLR guidelines for data request and publications. Six points of the guidelines are accepted. Projects using "data request" must be presented during NTLG meeting (project involved original data analyses). When it is only a question of using "copies" with results it should be approved by NTLR only.

5. Rota list: it was discussed if Scandia should not prioritize Estonia if livers are sent outside of Nordic countries, due to significant import of organs from Estonia to Scandia. It should, however, be discussed on Scandia Tx level.
6. Greg Nowak presented a proposal for a Scandinavian retrospective study on results after liver transplantation in patients with alfa-1-antitrypsin deficiency. All centers agreed to participate in the study, and Greg is in charge of contacting them as soon as the final proposal for the study protocol is ready (the protocol is going to be discussed with A1AT group in Sweden).
7. Christian Ross presented updates regarding Donor Risk Index Score Scandinavia. Potential data needed for the index calculation are available from NTLR, however it is surprising how low quality of data is in the donor registry. An update on the subject should be presented in Helsinki.
8. Arno Nordin presented updates on the Nordic multicenter study on liver transplantation and cancer. They are still missing data from two centers. Representatives of these two centers are in charge to contact local investigators and to check up why there is a delay in data transfer. Update on the study will be presented in Helsinki.
9. Per Ståhl presented updates on the Alcohol study in liver transplanted patients. The update was mainly on the study progress (patient inclusion in Gothenburg and Stockholm) and the main update will be presented in Helsinki by principal investigator Knut Stokkeland.
10. Tom Hemming Karlsen presented studies on genetics and rejection (importance of matching donor-recipient). Update on the study will be presented in Helsinki.
11. Professor Rene Adam from France gave a presentation on Advagraf vs. Prograf in liver transplantation. Already 3 years after transplantation there is a difference in graft survival between Advagraf (85%) and Prograf (74%) with patient survivals 89 vs 81%, retrospectively. Non compliance problems occur in up to 62% of patients. The presented study was discussed, and a separate video recording with Professor Adam was performed the same day by Astellas.
12. Allan Rasmussen presented protocol for study on switching from CNI to Sirolimus. Despite a positive answer from different centers, it is still unclear if there will be financing for this (findings from Novartis?). The update on the study will be presented in Helsinki.
13. Lina Lindström presented a Nordic study on recurrence of PSC after Liver transplantation which we observe in ca 23% of liver transplanted patients (6-60% in literature, 30% in Sweden, 40% in Norway). To complete the study additional data are needed from Helsinki and Copenhagen. Both centers are positive for participation in the study, and Lina will contact them directly. Update/results from the study should be presented within one year.
14. Miscellaneous:
 - a. Markus Gäbel email should be added to the mailing list
 - b. Krister Höckerstedt informed about the letter of intention from Lithuanian. This will be discussed at Scandia Tx level.

c. Many of the participants are staying for the PNTLG meeting tomorrow and will attend the Transplant Symposium tomorrow at KI Solna to celebrate the anniversaries of transplantations in Stockholm including 40 years of liver transplantation in Sweden.

d. List of participants based on signed form:

Jens Hillingsoe	Cph
Allan Rasmussen	Cph
Per Lindner	Gbg
Gunnar Söderdahl	Sthlm
Markus Gäbel	Gbg
Gustaf Herlenius	Gbg
William Bennet	Gbg
Styrbjörn Friman	Gbg
Christian Cahlin	Gbg
Bengt Gustafson	Gbg
Henrik Gjertsen	Sthlm
Tim Scholz	Oslo
Helena Isoniemi	Helsinki
Arno Nordin	Helsinki
Krister Höckerstedt	Helsinki
Ilse D Weinreich	Scandiatransplant
Frank Pedersen	Scandiatransplant
Espen Melum	Oslo
Christina Wibecke	Gbg
Per Stål	Sthlm
Lina Lindström	Sthlm
Antal Nemeth	Sthlm
Christian Ross	Cph
Greg Nowak	Sthlm