

Minutes from the Nordic Liver Transplant Group (NLTG) meeting in Stockholm, March 19, 2012.

The meeting took place at S staholm Hotel & Conference situated between Arlanda and Stockholm.

Present: Erik Schrumpf (O), Tom Hemming-Karlsen (O), Trygve Torsen (O), Aksel Foss (O), Jorgensen (O), Tim Schultz (O), Henryk Wilczek (S), Bo-G ran Ericzon (S), Antal Nemeth (S), Gunnar S derdahl (S), Annika Bergquist (S), Lina Lindstr m (S), Carl Jorns (S), Knut Stokkeland (S), Silvia Malenicka (S), Rafal Dlugosz (S), Allan Rasmussen (K), Marianne H rby-Jorgensen (K), Helena Isoniemi (H), Arno Nordin (H), Michael Olauson (G), William Bennet (G), Lars B ckman (U), Maria Castedal (G), Bengt Gustafsson (G).

1. Bo-G ran Ericzon welcomed everyone to Stockholm and gave a brief history of S staholm as being the late retirement place for Swedish movie stars previously.
2. Minutes from the NLTG-meeting in Oslo in October 2011 were shortly commented on; the participants list was not fully correct and will be updated by Aksel Foss for the archive. Helena Isoniemi asked to comment on the Estonian application to Scandiatransplant and Lars B ckman wanted to inform about EU-directives in organ donation and the effect on the Swedish organization (see below).
3. At the centre-wise update; Gunnar S derdahl in his new position as deputy director for the Department of Transplantation Surgery in Stockholm, reported on good liver transplant activity last year reaching 73 liver transplants. He also informed about the present discussions in Stockholm related to the placement of the department in the future when the new Karolinska Solna hospital will open. Decision regarding whether Department of Transplantation will remain at Huddinge or at the new hospital will be decided during 2012. Aksel Foss, Oslo reported an unchanged and high liver transplant activity, 89 transplants, the same as 2010, and so far this year already 26 liver transplantations had been performed. Donor situation remains excellent in Oslo with approximately 25 per million inhabitants. Helena Isoniemi reported 56 liver transplants last year and 13 so far this year. Some concerns were raised about the low donor activity with Helsinki being inferior to the rest of the country. Actions were taken to improve the situation. Liver and kidney transplant patients are kept together in the same department and pancreas and small bowel transplantation are also included in this program. William Bennet, Gothenburg reported 83 liver transplants last year and 15 so far this year. Per Lindn r has just been announced as the new head of the Department of Transplantation in Gothenburg. Lars B ckman, Uppsala informed about their ambition together with the plastic surgeons to start a program for composite tissue/face transplantation with a formal announcement of this on Monday 26 of March, 2012 with invited lecturers and presentation of the program. Marianne H rby-Jorgensen, Copenhagen reported a growing pediatric liver transplant activity in Denmark and a stable number of liver transplants over all.
4. NLTR-update was given by Tom Hemming-Karlsen. Information on number of transplants as well as number of re-transplants were given for each country and also listing the most frequent indication for liver transplantation. Survival after re-transplantation seems to be improving (see separate NLTR-report for full information-presently being processed). Aksel Foss commented on the high re-transplant rate in

Gothenburg seen last year, as well as previous years and asked for comments on this. William Bennet however was not prepared to give a comment at this meeting but would be able to provide further information on this later. It was decided that next meeting should have this topic on the agenda, discussing re-transplantation at individual centers, attitudes, need for etc. Antal Nemeth, Stockholm raised a question why the pediatric population was limited to patients less than 16 years, rather than 18 years. According to the group different definitions of pediatric patients exist worldwide, but Nemeth insisted that the international pediatric community have favored the definition of children as being younger than 18 years of age. In Oslo, pediatric patients are transferred to the adult system for follow up at the age of 16. In Helsinki the corresponding age is 15. Overall it is obvious that individual patients are transferred at different ages between pediatric monitoring and adult monitoring post transplantation. Some patients may even be taken care of by the pediatric hepatologists up to ages well above 20. Nevertheless, and at least for publication matters a common definition in the NLTR as of what age a patient is regarded as pediatric or adult should be decided on. The present age of 16 could easily be changed to age under 18 according to Tom. Since Tom was willing to change the definition for the new report and since this did not cause any concern from the group, consensus was reached to change the definition of pediatric patients in the register to patients less than 18 years of age. Another matter of concern according to Tom was that form C in NLTR is only used and updated in Norway and Sweden. The reason for Finland not using form C is that it represents double work with their own register, since electronic transfer of the data cannot be done and only paper transfer is functioning properly. However, Helena Isoniemi was willing to update also the Finish patients with form C for NLTR. It was decided that Tom Hemming during the next meeting will report data from form C to the group even if not all centers would use this form. This was regarded as important since data registered should come to some use, or otherwise be deleted from the registry. Next meeting should therefore contain reports also related to form C, and discussion whether this form should be kept and used by all centers or potentially be deleted.

5. A workshop/meeting for those who in practice is accumulating and reporting the data to NLTR has been long wanted from several of those involved. Unfortunately a long time has elapsed since such a meeting was held. Tom responded that it had been difficult to motivate the transplant coordinators for such a meeting. According to Tom, transplant coordinators wanted to discuss this at their meeting in April 2012. Bo-Göran Ericzon commented that organization for education of this group, should not be left to the transplant coordinators since the function is organized differently at the various transplant centers. Therefore NLTR/NLTG should take responsibility for repetitive education of the "data manager" for NLTR at the different sites. Ericzon suggested that once per year in parallel with the NLTG-meeting in springtime, the site representative data managers could take part in the NLTR updating, but otherwise work in a separate room for their own needs in parallel with the NLTG-group meeting. Although this was planned for spring, it was decided that the first such meeting should take place this coming autumn (in Finland) in order to meet the needs from the group to get together as soon as possible.
6. Lars Bäckman reported about the Swedish concerns for using Scandiatransplant as a formal registry for Swedish patients. Both Norway and Finland are optimistic for using the already existing Scandiatransplant register for this purpose. One problem

may be the need to register adverse events related to organ donation and transplantation which is within the new EU-directives and may not be properly taken care of by using the Scandiatransplant register. Ericzon informed that Karolinska Institutet was asked by the government to comment on the new need for registration related to the EU-directives and that Karolinska Institutet has responded positively to not double register but use existing Scandiatransplant register as much as this is possible also for the Swedish situation.

7. NLTG-liver exchange rules. Ann-Christin Croon reported on payback situation between the different centers, although the data were not complete. It was clear that several livers had not been paid back within the 6 month rule, and one explanation to this may be that the information was not clear as how this practically should be taken care of, especially when new transplant coordinators were not properly informed about the system. The liver doctor on call needs to be reminded by his/hers transplant coordinator at the time of organ donation that the specific center needs to pay back a previously received liver. It was discussed whether an obligatory payback of the next available blood group identical liver is present should be the rule. Anyhow, it was the general feeling amongst the centers that some flexibility in this payback system should be maintained, and therefore the present guidelines should be kept. However, better information locally needs to be in place for the transplant surgeon to make decision on whether the liver should be used locally or as a payback liver each time a donor is available. The general opinion was that the payback should be done as soon as possible after having received a liver, and definitely within the 6 months time frame.
8. Aksel Foss suggested a modification of the phrasing in the text describing when "urgent call for liver" can be used. He suggested that "no prior liver disease" should be replaced by "no underlying liver disease". Although several including Schrumpf and Wilczek meant that a change could be done since it at least did not do harm, and that it may indeed represent some advantages, it was considered by others to be at risk to lose the strict guidelines and thereby cause a more expanded use of the high urgent call. The possibility of "kind request" and the generally positive attitude to help each other was regarded as sufficient enough, and therefore the phrasing was left unchanged.
9. Helena Isoniemi reported that the board of Scanditranplant has accepted an application from Estonia regarding membership to Scandiatransplant that will be discussed in Reykjavik in May 2012. Helena expressed concerns about expanding Scandiatransplant to Estonia, partly related to safety and efficacy in blood testing for instance hepatitis C etc. Michael Olausson responded that for organ exchange Estonia has to be within Scandiatransplant. Schrumpf wanted first of all to have a discussion whether at all Scandiatransplant should be expanded, and later discuss potential details for this. Aksel Foss suggested that the Baltic States should organize between themselves a transplant organization similar to Scandiatransplant before considering being part of Scandiatransplant. Aksel also felt that the size of Scandiatransplant presently is optimal. Allan Rasmussen supported this feeling of optimal size as it presently is. Ericzon was not negative to increase collaboration with Estonia and seriously discuss participation in the Scandiatransplant organization. The Baltic States are individual states and efforts previously by Scandiatransplant to help the Baltic states to form their own organization, even by supporting computer services etc, did not seem to improve the collaboration in organ donation and transplantation between

the Baltic States. Ericzon therefore felt that if one country would rather collaborate with Scandiatransplant, this should be considered carefully with a positive attitude. However, Ericzon felt it would be less likely possible to come to decision already at the Reykjavik meeting since this needs careful consideration in each of the Scandiatransplant countries. Tim Schultz also meant that it is important to see the difference between collaboration and membership, and that there would be no problem with careful collaboration, but found a formal membership as less interesting. Bäckman meant that there should be other factors than donor exchange to enter a collaboration like the Scandiatransplant collaboration.

10. William Bennet displayed their data on reduced steroid use after liver transplant patients showing low incidence of insulin dependent diabetes mellitus short term after liver transplantation.
11. Carl Jorns gave an overview of the organization for hepatocyte transplantation in Stockholm, and informed about two pediatric patients on the actual waiting list for this procedure. These patients are also listed on the new lateral segment sharing list. He also pointed out that neonatal donors, too young and small to donate for liver organ transplantation would be ideal for preparation of hepatocytes for these clinical pediatric cases. Collaboration on this was highly appreciated.
12. Update on NLTG present studies.
 - A:** Genetic studies of rejection in liver transplantation (Tom Hemming-Karlsen). This is now a one-center Norwegian study and is not a part of the NLTG-group studies.
 - B:** Colorectal neoplasia/PSC, presentation done by Erik Schrumpf. This study is now under review in Scandinavian Journal of Gastroenterology.
 - C:** Recurrent PSC in NLTG. Lina Lindström gave an update of this study. The study contains a very high number of patients and the group agreed that additional patient history as well as extra blood sampling, and even some new liver biopsies should probably be performed in order to have as correct data as possible, and avoid high number of missing data.
 - D:** Aksel Foss presented the status of the study related to donors above 75 or less than 6 years. Appropriate control groups were discussed; also the material should be extended to also include 2011. Several ways to have a control group was discussed and Aksel will consider the alternatives and come back with a suggestion to the group. Original no control group were described.
 - E:** Helena Isoniemi reported from the life expectancy study. There are 100 patients with missing data. Stockholm, Oslo and Helsinki have done an update, data from Gothenburg are still missing but they now promised to update.
 - F:** Alcohol and liver transplantation. Update was given by Knut Stokkeland. This study is now just about to start to include patients in Stockholm, Gothenburg and Copenhagen.
 - G:** Pediatric liver transplantation. Update by Silvia Malenicka. Major concerns relates to the fact that data is not completely accurate and sites visits are needed. It was decided that Silvia will visit each site and help to have correct update, with or without the combination of a separate group meeting for this study, independent from the NLTG-meetings to advance in data accumulation. This was expected to be done before the summer 2012, with start of data analysis early in autumn, and update at the next meeting were all relevant data should be at hand and missing data will have to be accepted in order to proceed. An update of the data by including patients more

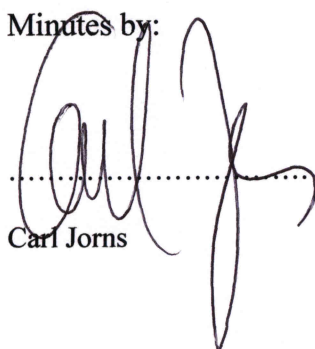
recently transplanted has also delayed the progress. No new patients after 2011 should be included in this study.

H: Arne Nordin reported on the study liver transplantation and cancer in Scandinavia. Wilczek has submitted an ethics committee application valid for Stockholm and Gothenburg, and are currently waiting for the response, the same is true in Denmark. Following this, data from the cancer registries will be asked for and sent to Helsinki for analysis. A preliminary evaluation of such data should be possible to have at the next NLTG-meeting.

13. Next meeting was decided to take place in Helsinki, Monday October 22, 2012 was suggested but Helena Isoniemi will come back to confirm this.

Stockholm, June 4, 2012

Minutes by:



Carl Jorns



Bo-Göran Ericzon