

Minutes of the Nordic Pediatric Liver Transplant Group (NPLTG) Meeting

Copenhagen, October 22nd, 2014, 9:00 – 14:00

Allan Rasmussen introduced the principle about the Nordic Shared waiting list for pediatric patients on the waiting list, prepared the day before at the Nordic liver transplantation group meeting. Everyone is looking forward to get started and no new comments were added. A updates from the coordinator meeting next-door report that they are positive and can get started within 2 weeks.

Each centers reported about the activity within pediatric liver transplantation. A comment was made due to the Tyrosinemia cases with HCC (Copenhagen has transplanted 1 this year) and Antal Nemeth suggested that we might should publish the data of children with tyrosinemia and HCC despite treatment with NTBC. Marianne HJ will make a suggestion for the presentation of the cases for the next NPLTG meeting and mail it around.

Silvia Malenicka presented the main findings for the BA study. It is now ready for publication; Pediatric transplantation will be the first choice. SM will mail to centers for final comments. Lesson learned from the study was that the data set was pure concerning follow up data.

Silvia also presented suggestions about working groups within vaccination, nutrition and renal failure to discuss differences and similarity between centers. The possibility to develop guidelines for treatment of children was discuss. The first topic will be, to discuss a vaccination program of children pre and post liver-Tx. Silvia Malenicka will be chairman for this group, Marianne Hørby Jørgensen and will take part as well. We will try to recruit a pediatrician from each center and find some pediatrician with special interest in vaccination to participate in the working group. The next 3 month there will be literature search and there will be a meeting during the liver week in Stockholm in February.

In order not to overwhelm people with work, working groups within nutrition and renal failure was not established on this meeting. It was decided that a new working group within nutrition should be a priority.

William Bennet presented the different immunosuppression protocols for children both within the Nordic liver transplantation group and between pediatric centers in general. The strength of a common protocol was discuss. This will be of great value in future research project that we are as similar as possible, adding the pediatric population from all 5 centers together can be comparable to the big centers. William Bennet will put together a working group with 2 participants from each centers. The same working group will look into a shared protocol for anticoagulation for children.

As Silvia M discovered lack of data within the pediatric data in the database. We discuss the possibility to improve the database; ESPGHAN might have some suggestion already how to improve the pediatric data in the European database. William Bennet and Silvia will contact ESPGHAN members and we will discuss this on the next meeting.

Other ongoing studies in each center was briefly discuss and the possibility to gain forces is there.

The possibility to meet again during the Liver Week in Stockholm was highlighted. There will be a pediatric session the 12th of February: <http://www.leverveckan.se/sv/program>

We decided that a meeting list within pediatric hepatology should be made and that it should be possible to briefly review highlights from the meetings.

Next NPLTG meeting will be fall 2016 in Stockholm. The date will come after the next NLTG meeting in Gothenburg April 11'Th.

Things that already has been decided to discuss at the Stockholm meeting:

- Center-wise updates
- Reports from working groups:
 - Vaccination guidelines in liver transplanted children in the Nordic contries
 - Shared immunosuppression protocol within the Nordic contries
- Improvements of the database with pediatric data
- Updates from relevant international pediatric meetings.

Marianne Hørby