Scandiatransplant

Minutes of NLTG April 19, 2021

Teams meeting Helsinki April 19, 13:30 – 17:30

Arno Nordin opened and welcomed participants to the digital video meeting.

Due to the Covid-19 pandemic this meeting was held digital. All liver transplant centers were well represented.

Action points are marked with XXXX

1. Minutes from last NLTG-meeting in Stockholm October 10, 2020.

The minutes were approved.

2. Center wise update

Oslo: Regardless of the Covid-19 pandemic the year 2020 was close to normal. In total 88 liver transplantations, **6** pediatric transplantations. One new surgeon.

Helsinki: In 2020 in total 75 liver transplantation, **8** pediatric transplantations, **1** pediatric re-transplantation. All time highest annual number of liver transplantations regardless of the Covid-19 pandemic. In 2021 22 liver transplantations so far.

Tartu: In 2020 in total 12 liver transplantations, constant level compared to previous years. **2** pediatric transplantations.

Copenhagen: In 2020 in total 66 liver transplantations, **7** pediatric transplantations of which 3 were with living donors

Gothenburg: In 2020 some 10 liver transplantation less than in 2019.
In total 80 liver transplantations, 8 pediatric – 8 received split grafts, 1 domino. Long waiting list with mean waiting time approximately 60 days.

Stockholm: In year 2020 in total 92 liver transplantations. 1 DCD liver transplantation, 10 pediatric.

3. NLTR annual report, *Espen Melum*

Espen gave a presentation of the 2020 NLTR annual report. In summary total of 413 liver transplantations were performed – very impressive number given the Covid-19 pandemic situation.

Number of patients listed as highly urgent was reduced by 50%. The number of re-transplantation was 40, somewhat lower than in year 2019 when the re-transplantation number was 55. Waitlist mortality remained low, < 5%; in 2020 record low relative number of deaths on waiting list.

PSC was back as the leading indication for liver transplantation in the Nordic countries, closely followed by alcoholic cirrhosis and HCC.

The two last 5-year periods (2010-15 and 2016-20) have similar survival. Increased survival in the most recent 5-year period for retransplanted patients is seen.

4. Suggestions for the new DEA (dead on waiting list) definitions, Espen Melum

As pointed out in previous meetings centers register dead on waiting list differently. There are large differences in causes for permanent withdrawal. Due to this, it is hard to define if there is actual clinical differences or is it more matter of different registration practices. In order to measure properly the performance of liver transplant programs in Nordic countries it is important to know if the patient was actually on the waiting list when she dies. Do we manage to offer the patient a graft before death? In addition, obvious lack of registration of death or wrong permanent withdrawal classification as not-transplantable and patients with worsened condition lives on for decades.

According to Espen's suggestion, not-transplanted outcomes on the waiting list should be defined either as DEA (dead on waiting list) or (PW) permanent withdrawal. Causes for PW should be defined as:

1) Improved condition (CI) *e.g. lives or re-listed later*
2) Worsened condition (CW) *e.g. cancer progression, worsening of liver failure*
    - patient is expected to die within a medium to short time-frame
3) Not transplantable (NT) *e.g. clinical condition makes it impossible to go on with transplantation*
    - *patient is expected to die within a short time-frame*
4) Other (OT) *e.g. patient's wish, logistical challenges etc.*
    - difficult to make estimates regarding anticipated survival

These definitions should also be in YASWA. To ensure the proper use of these definitions all centers should check the CW and NT patients that are still registered as alive. It was suggested that there should be a quality control check 3 months after the waiting list withdrawal. After discussion it was accepted that in every January all these patients should be listed and the data should be cleaned by every center.

5. Update from Scandiatransplant, *Ilse Duus Weinreich*

a. Payback and balance

In April 2021 there is 16 livers which are not paid back. Six of these depths are more than 6 months old.

In the balance sheet, it is of notice that Stockholm owes 8 livers, while Helsinki is waiting for 5 livers to be paid back and Copenhagen 4 livers.

It was discussed and pointed out that Stockholm transplants most livers but it simultaneously owes most livers to other centers. In addition, there is a feeling that Stockholm offers and sends poor quality livers to other centers causing lack of confidence with other centers.

Based on that more emphasize should be put into transparency and trust, as it is everything in organ exchange. As there is feeling that you are not receiving a normal liver as a payback, improvement is needed in defining normal liver. Pål-Dag Line, Oslo suggested that a proposal of revised definitions should be put into next meeting agenda. It should also be defined how the normal/abnormal liver offers are documented in YASWA.

b. Minor revision of liver payback guideline (Suggestion for new version of payback guidelines, document attached)

The suggestion that a payback can be performed with a liver of another blood group if mutually agreed on between centers was discussed and approved. The other suggestion of limited number of payback offers was discussed more, see below section 7.

c. Update on extending YASWA with more split/pediatric liver information (Suggestion for optimization of the 'Pediatric liver and multivisceral waiting list', document attached)

This suggestion was discussed. It was noted that section 1 is already in use and it was accepted. The section 2 with offering split donors to all liver centers at the same time generated more discussion. The basic idea is to decrease the workload of coordinators. However, there is also fear of more work for coordinators,

together with more technical matters involved in the process. This point still needs further evaluation.

6. Status on ELTR data export, *Ilse Duus Weinreich*

A data exchange authorization letter between NLTR and ELTR has been signed by Oslo, Gothenburg, Stockholm, Tartu and Copenhagen. January 31, 2017 first test export of data to ELTR. Adjustment of extraction, complete data extraction from NLTR shared with ELTR September 4, 2019

Helsinki agreed to export core/basic data. Data was included the first time September 2020. All centers (data controllers) that enter/collect data into a registry must have a data processor agreement with this registry (data processor). The responsibility of this agreement lies with the data controllers (each transplant center).

The current situation of "the Joint data processor agreement". The 1st proposal has been prepared and sent to all centers. In the agreement two things have been toned down:

1) Backup requirements, as we have data in NLTR, loss (=deletion) of data in ELTR is not a problem for us/you
2) Audit visits, is mentioned as an option but not in that many details as you will probably not go to ELTR for an inspection

Otherwise, the agreement is a standard data processor agreement.

First draft of such an agreement prepared and shared with you in late 2019. Data controls (=the centers) are legal responsibility for data, data processing and export of data.. Here the requirements of GDPR have to be taken into account.

7. Revision of the liver exchange and payback rules and proposition of guideline on how to cancel a payback after certain number of offers, *William Bennet*

William gave a presentation of how payback rules should be re-defined. He suggested that after five declined payback offers to a center who has potential compatible recipients on the waiting list the payback will be cancelled. A payback offer is only counted if the liver is transplanted by another center after being declined by the center to receive the payback.

It was discussed of pros and cons of this proposal. It was pointed out that small countries are likely to have problems with this revision and it was not accepted. In addition, it was again emphasized that there is no problem if a normal liver is offered, but better criteria should be

developed for a normal liver.
No decision was made in relation to suggestion on number of declines

8. Parameters for Nordic pediatric liver transplant registry, *William Bennet*

William gave a presentation of current situation of this registry. More information will be given in the autumn meeting when the pediatric transplant section is also with.

9. DCD liver transplantation

There was discussion and center wise update of DCD liver transplantation. Helsinki is not yet planning DCD with livers, DCD program is starting with kidneys in autumn 2021. Stockholm and Gothenburg are having a national DCD program; 2 DCD livers are done in Stockholm, after summer Gothenburg is having NLP readiness. Copenhagen is having a DCD protocol according to NLP British protocol. Oslo has performed 8 NLP liver transplantations earlier with results similar to normal liver transplantations but currently waiting for approval to continue with DCD program.

10. Ex vivo liver perfusion

This topic was only shortly stated as the presentation scheduled by Antonio Romano was not yet available.

11. Transfer of donor CT radiology between centers (Sectra), *Magnus Sjöberg*

Magnus gave a presentation of Sectra Image Exchange Portal which is a proposal for CT scan data transfer between different liver transplant centers in Scandiatransplant. According to Magnus, this system is simple, convenient and cost efficient. This same solution could be used basically for all image exchange. In this platform email address and mobile phone number are used to create the connection between the sender and the data user destination.

It was discussed that by using an external firm there are challenge with data protection and that there are many other companies in the market providing similar platforms. It was stated that more discussion and evaluation are needed before deciding which platform will be chosen. However, there was clear consensus that the digital solutions in image transfer should be improved.

12. Ongoing studies
    a. DSA study, *Allan Rasmussen*

Andreas Avendtsen Rostved gave a presentation on the current situation of this study. 921 patients with study samples are enrolled into the study. Total of 756 of these patients are in follow-up with minimum follow-up of 365 days. Nearly 70% samples are analyzed, the newest data is still missing from the transplant centers with rejection rates and protocol biopsies. CRF completion from all centers is needed, but there is no need for new patients as the power of the study should be fulfilled clearly.

b. Comparison of results from the different LTx centers during the last 10 years, *Espen Melum*

Espen gave a presentation of this data analysis of the NLTR registry data for the first time ever as the attitude towards this suspect has opened. There was a agreement in NLTG meeting October 2020 to evaluate and discuss center differences internally although this procedure should be part of the annual report. For a proper evaluation of the current practice the last 10 years seems to be a reasonable cut-off.

Based on this evaluation there are considerable differences in center activity in the 10 year period:

- 3 centers 800-900 (Oslo, Gothenburg, Stockholm)
- 2 centers 500-600 (Helsinki, Copenhagen)
- 1 center 100 (Tartu)

Diagnostic spectrum varies clearly between centers. Waiting time is low at all centers. Mean recipient and donor age are lowest in Denmark.

c. Factors associated with waiting time and waitlist mortality, *Carl Jorns*

Carl stated shortly that the progress of this study has slowed down, and no new data is yet available.

d. Results of Hepaticoduodenostomy in Norway/Denmark, *Morten Hagness/Allan Rasmussen*

No new data of the study is yet available. It will be presented in the next meeting.

e. Evaluation form of CT examination in deceased donors, *Ulrika Samuelsson, William Bennet*

William gave a presentation including 109 donors. More than 95% were evaluated with CT scan. 12.3% of donor procedures were aborted due to findings of CT scan.

In 9,4% of the cases malignancy was detected. In 26,2% of the cases this examination was useful in size matching. Based on this preliminary study cost benefit is marked.

It was discussed that currently Helsinki, Copenhagen and Oslo are using CT imaging of donors nearly routinely. Again, it was pointed out that there is a need for standardizing the measurement of liver grafts before having a sharing platform and measures are more important than pictures itself. Here too, Pål-Dag Line, Oslo will take responsibility for the standardization process. It was decided that the CT-scan study should be expanded with participation from all centers.

f. Study proposal: "Rescue hepatectomy prior to liver transplantation in Scandinavia ", *Erika Laine/Greg Nowak*.

No presentation was shared at the meeting but Greg Nowak sent an email later, that this study has been done as a single center study.

g. PSC and immunosuppression, *Fredrik Åberg/Arno Nordin*

Fredrik presented a study proposal where tacrolimus vs cyslosporine were studied in three different study arms to investigate the role of these different regimens in the outcome of PSC liver transplanted patients. The topic was discussed and it was concluded that more background data should be gathered in other studies before RCT to support the idea. Helsinki center will come back with this idea later.

h. Further study proposals - **no**

13. No other business

14. Next meeting Tartu/Tallinn 5th, October
– the meeting is planned to be virtual depending on the pandemic situation

List of meeting participants

Scandiatransplant, Aarhus
Ilse Duus Weinreich

Oslo University Hospital
Espen Melum, Pål-Dag Line, Monika Olofsson Storrø

Helsinki University Hospital
Arno Nordin, Johanna Savikko, Marko Lempinen, Ville Sallinen, Aki Uutela, Ines Beilmann-lehtonen, Carola Schauman, Heikki Norio

Tartu University Hospital
Andres Tein

Sahlgrenska University Hospital
William Bennet, Bengt Gustafson, Gustav Herlenius, Ulrika Samuelson, Kristin Persson

Copenhagen University Hospital, Rigshospitalet
Allan Rasmussen, Nicolai Schulz, Christian Ross, Andreas Arendtsen Rostved, Ulla Plagborg, Carina Lund Soerensen

Karolinska University Hospital
Carl Jorns, Antonio Romano, Gunnar Söderdahl, Erika Laine, Greg Nowak, Øystein Jynge, Marie Tranäng, Björn Fischler