Minutes of the Pediatric and Nordic liver Transplant Group
Helsinki 3 - 4thOctober, 2017

Venue:
Scandic Park Hotel,
Mannerheimintie 46
Helsinki

Minutes of the Nordic Pediatric Liver Transplant Group (NPLTG) Meeting
Helsinki 3rd October, 2017

Welcome *Hannu Jalanko*
Hannu Jalanko welcomed everybody to Helsinki by telling that the first pediatric liver transplantation in Helsinki was performed 30 years ago (19.10.1987) and the fifth hundred pediatric patient received organ transplantation two weeks before the NPLTG meeting.

Minutes from pediatric NPLTG meeting in Oslo 24 October 2016 *(Pål-Dag Line)*
Pål-Dag Line presented the minutes from NPLTG meeting in Oslo 24th 2016. The use of CT scans to evaluate the size of the donor liver aroused a lively discussion. This procedure is now a routine in some centers.

The status of pediatric liver transplantations and waiting list was presented by Ilse Duus Weinreich. Thirteen patients were listed on September 8th 2016, and 39 new entries were reported by September 8th 2017 with a total number 52 listed patients. 42 of them were transplanted and 6 patients were permanently withdrawn from the list (2 deaths). The median waiting time was 46 days which had shortened during the last years (67 days on 2014). The number of listed patients fluctuated (4-11) during the year and was only 4 patients on September 2017. The number of donors fulfilling the criteria for split liver was 41, and 13 of them (32 %) were used for pediatric recipient. Reasons for not splitting were variable (not procured 4, no matching recipient 5, logistics 7 etc.).

Center wise annual pediatric update reports
Each center briefly presented their patients who had received liver transplant during the last year.

Management of biliary atresia patients in Scandinavia.
Mikko Pakarinen presented the results of the management of infants with biliary atresia in Nordic Countries. The report was based on a recent publication: Pakarinen et al. Outcomes of biliary atresia in the Nordic Countries – a multicenter study of 158 patients during 2005-2016. J Pediatr Surg 2017; epub ahead of print .Hannu Jalanko presented the results of combined liver-kidney transplantation in Helsinki.

Combined liver-kidney transplantation.
Helsinki experience was presented by Hannu Jalanko. So far, 13 simultaneous combined transplantation have been performed and 11 are alive. Long term renal function of these children is better than in patients with kidney transplant only.

A common pediatric immunosuppressive protocol in the Nordics? *William Bennet*
William Bennet proposed to consider common immunosuppressive protocol in the Nordics and presented the pediatric liver transplantation results in Gothenburg. He emphasized that despite improvements in patient and graft survival during the past 15 years there is still need for further improvement in graft survival especially in the early period after pediatric liver transplantation. Strategies to reduce early graft loss must be further developed such as improvements in preventing & managing vascular complications (e.g. HAT). Bleeding and biliary complications must be reduced to overcome the high post-operative morbidity which is often presented in this particular population.

Based on this report from Gothenburg it was proposed that data on the early post-op problems should be collected from NPLTG centers. Planning of this project was started.

NPLTG will be arranged once a year and the next will be arranged in Copenhagen in Autumn 2018.

Hannu Jalanko

Minutes of the Nordic Liver Transplant Group (NLTG) Meeting
Helsinki 4th October, 2017, 10.00-14.30

Welcome *Helena Isoniemi*
Helena Isoniemi opened the meeting and welcomed everyone to Helsinki. Tartu as an associate member of Scandiatransplant was invited to NLTG meeting. Toomas Väli from Tartu was especially welcomed.

Minutes from NLTG meeting in Stockholm 4th April 2017 were written by *Greg Novak* and approved in the meeting with one note which was accepted to add to these minutes. According to EU recommendations Scandinavian Registry for living liver donors will be introduced as extension of the living kidney registry. Decision was to use the same format as ELTR. It has been implemented by Ilse Weinreich and co-workers at the Scandiatransplant office.

Center wise update reports in October 2017 *(all centers)*
Helsinki: Liver transplantations about the same amount than year ago. Two new positions for transplant surgeons.

Oslo: 77 liver transplants. 7 DCD donors of which 3 livers transplanted. There was discussion if separate consent or the recipient for DCD liver is needed. Machine perfusion used. Oslo is asking consent. Cancer patients are candidates for DCD livers.

Copenhagen: Numbers are improving, target about 70

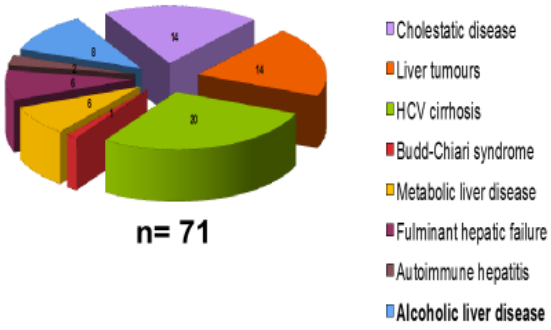
Stockholm: 62 transplants, good results, blood group O waiting list is growing, while waiting 4 died 6 withdrawn from list and died

Gothenburg: 75 transplants (6 children, no living), about 40 patients on waiting list and >25 blood group O

Greetings from Tartu liver transplant program and donor organization
Toomas Väli from Tartu presented their liver program. Before clinical program they did 50 experimental liver transplantations. First successful liver transplantation was performed 1999 with the help of Helsinki team. Between 1999-2017 a total of 71 liver transplantations is done and main indications are hepatitis C cirrhosis (20), liver tumor (14) and cholestatic disease (14). Results are good with one-year survival 82% and 5 yr. 70.2%. Toomas presented treatment protocols and also complications after transplantation. Rejection frequency was low 8%, artery thrombosis 3%, biliary complications 37%. Donor screening for infectious disease follows the Scandiatransplant guidelines. Between 2013-2017 Tartu has offered 25 livers to Scandiatransplant and received from Scandiatransplant only one. Some key slides of presentation are included.

CURRENT SITUATION

Indication of liver transplantation in Estonia



n= 71

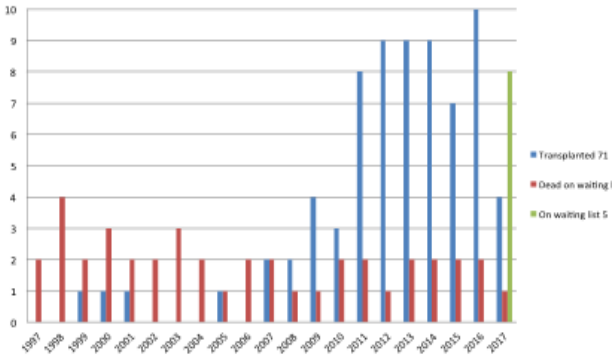
CURRENT SITUATION

Donor screening for infectious diseases

Mandatory minimum by national legislation	TUH criteria for organ donors
HIV-1,2 Ab	HIV-1,2 Ag+Ab; HIV1,2 RNA
HBs Ag, HBc Ab	HBs Ag+Ab; HBc Ab; HBc IgM; HBV DNA
HCV Ab	HCV Ab; HCV RNA
T pallidum Ab	T pallidum Ab
HTLV-1,2 Ab (where appropriate)	HTLV-1,2 Ab (where appropriate)
	CMV IgM + IgG
	EBV IgM + IgG

CURRENT SITUATION

Liver waiting list in Estonia 1997 -2017



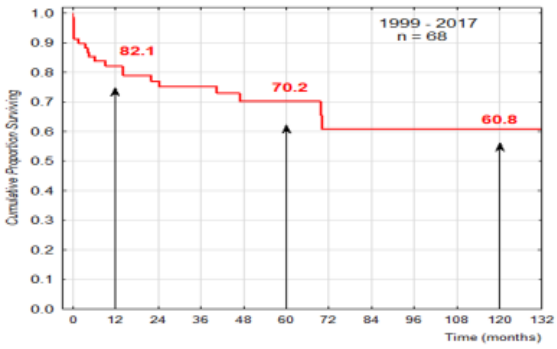
CURRENT SITUATION

Organ donation with special respect to liver donation in Estonia 2013 -2017

	2013	2014	2015	2016	2017
Organ donors accepted	35	24	21	26	13
Liver accepted and harvested	15 (43%)	15 (63%)	13 (62%)	16 (62%)	6 (46%)
Liver transplanted in Tartu	9	9	7	10	4
Liver offered to Scandiatransplant	6	6	5	6	2
Liver received from Scandiatransplant			1		

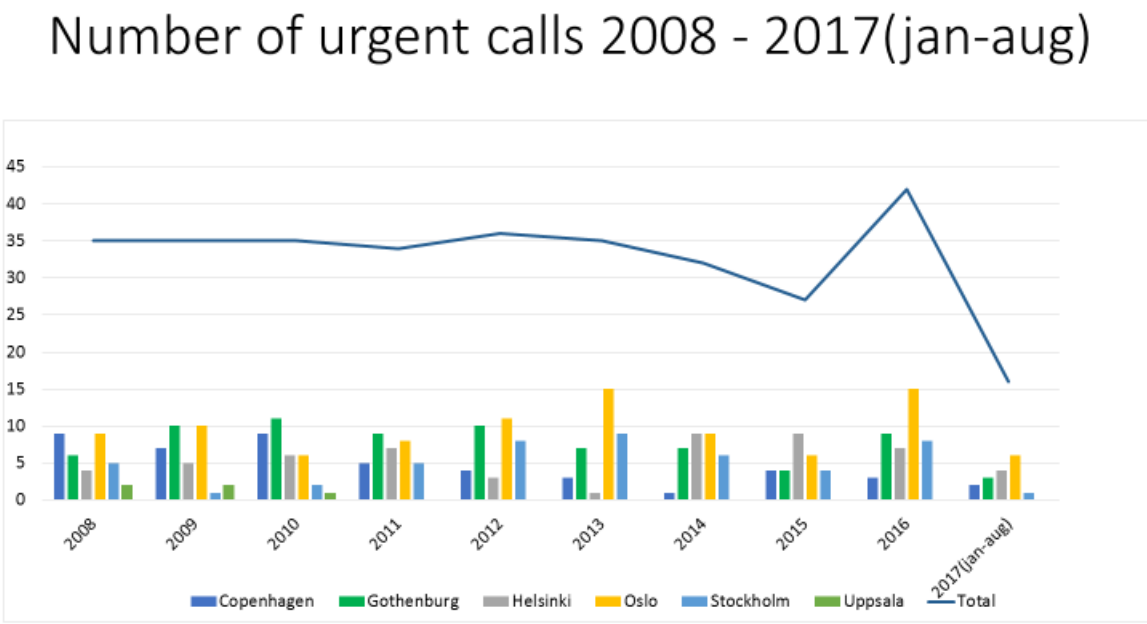
CURRENT SITUATION

The Kaplan-Meier estimate of survivor function for 68 OLT patients



Other presentations and discussions

- Statistics from Scandiatransplant: *(Ilse Duus Weinreich)*
    - A) Demonstration of Living Liver registry in YASWA
      ELTR parameters are used for living liver registry
    - B) Urgent calls
      Ilse presented statistics of urgent calls 2008-2017 in Scandiatransplant.



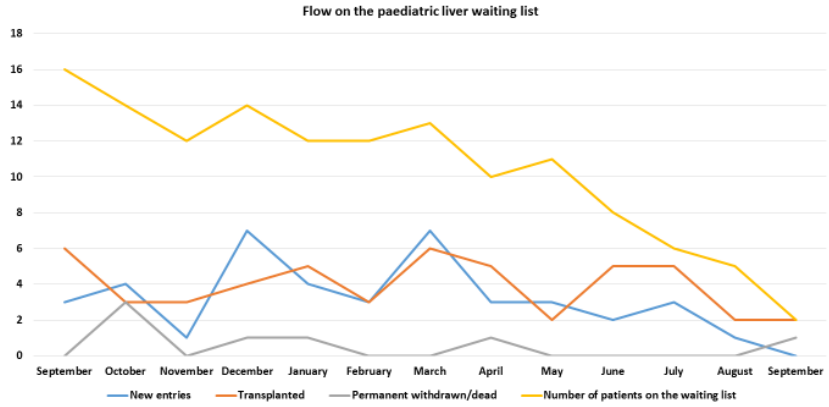
Import/export of livers for urgent calls

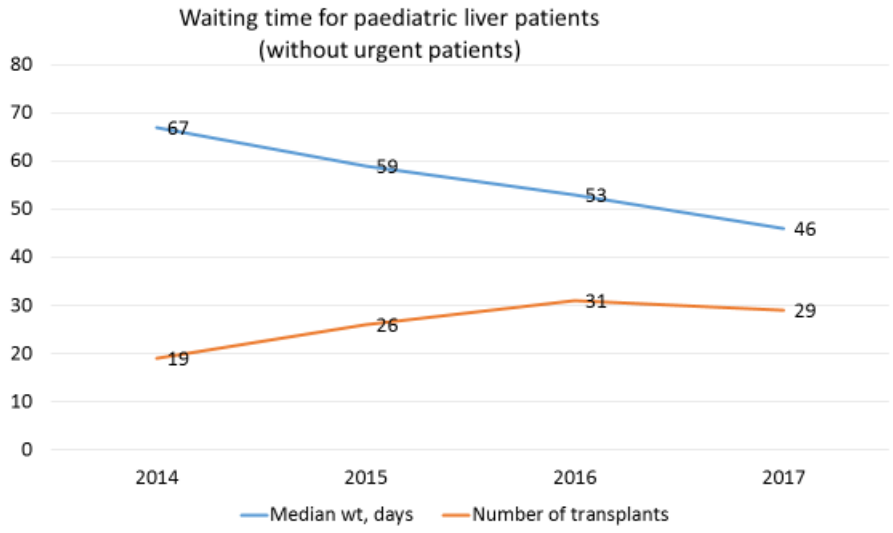
Donor center → Recip. Center ↓	Aarhus	Copen-hagen	Odense	Gothen-burg	Skåne	Stock-holm	Uppsala	Helsinki	Oslo	Tartu	Total
Copenhagen	6	5	2	5	3	3	1	8	8	0	**41 (15,0%)**
Gothenburg	3	5	2	9	1	2	4	13	23	1	**63 (23,0%)**
Helsinki	4	3	3	3	1	0	1	21	11	0	**47 (17,2%)**
Oslo	3	5	3	11	2	7	6	11	30	0	**78 (28,5%)**
Stockholm	4	2	1	5	4	3	6	5	11	0	**41 (15,0%)**
Uppsala	0	0	0	1	0	1	1	0	1	0	**4 (1,5%)**
Total	**20 (7,3%)**	**20 (7,3%)**	**11 (4,0%)**	**34 (12,4%)**	**11 (4,0%)**	**16 (5,8%)**	**19 (6,9%)**	**58 (21,2%)**	**84 (30,7%)**	**1 (0,4%)**	**274**

S: 39,4%

DK: 18,6% S: 29,2%

- C) Shared waiting list (multivisceral patients and pediatric) any changes in waiting time or in the length of waiting list. Ilse presented statistics from Scandiatransplant and this was discussed already in NPLTG meeting.





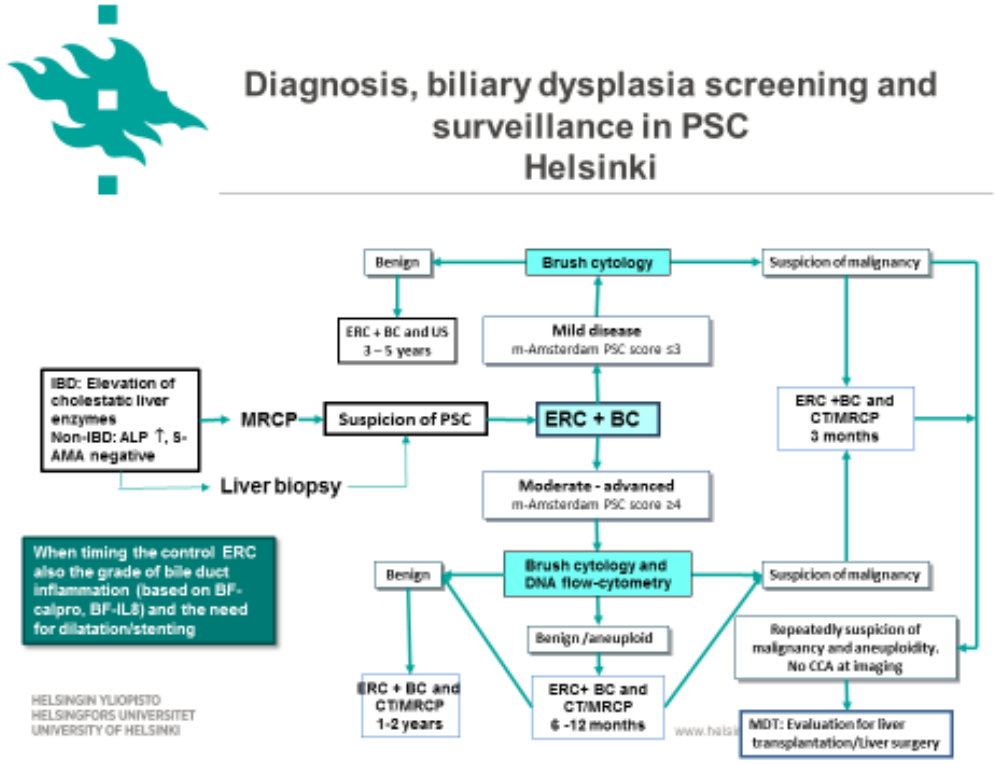
- **Discussion of allocation and pay back rules – any need for simplification** *B-G Ericzon*
B-G E opened the discussion to simplify pay back rules. These rules were recently (2015) renewed and there was also opinion that these rules should not so often to change. B-G E felt that our pay-back rules with 4 donor categories are too complicated. However final decision was that we will test new rules: It was decided that the receiving centre has to offer pay back with the first available AB0 blood group identical normal liver ≤ 65y.It is allowed to reject the liver offer, however rejection cause will be noted. Ilse will prepare new rules with centers before these are published on webpages. Pål-Dag Line had left before this discussion and of course Oslo must approve new rules before publication.

- **Where are we now with NLTR→ELTR data transfer**:
  Espen Melum have informed by email: Agreement with ELTR on which variables we need to implement and which can be mapped. Integration of the variables into YSWA have been done for some (already in production) while some still needs to be programmed. When this is finalised we will confirm that everything needed by ELTR is in place. Then new paper forms will be distributed. For the old data, we have offered Vincent access to everything we have buy have stressed that harmonising all old data is not feasible and not a burden that should be put on the centers. Such an effort would have limited scientific value.

- **Use of generics in the Nordic centers** *(all centers)*
  All centers are using generics except Helsinki at moment but there are also in Finland in the near future available generics which we will start to use.

- **Cholangiocarcinoma treatment in different centers, common protocol?** *(Heikki Mäkisalo and others)*
  Heikki presented background information of indications and treatment protocols in CCA in different centers. He also showed own center experience in CCA, mainly incidental or PSC patients where hilar CCA was diagnosed only from the explanted liver. He also presented that many studies have shown that adjuvant treatment only is not enough in hilar CCA. There was discussion to plan common protocol in hilar cholangiocarcinoma

- **PSC surveillance and revised LTx indications in Helsinki** *(Isoniemi/Färkkilä)*
  Isoniemi presented the biliary dysplasia screening and surveillance protocol in PSC by M Färkkilä. PSC patients are followed regularly and if there is repeatedly biliary dysplasia and/or aneuploidy finding in DNA flow cytometry, the case will be discussed in MDT meeting to decide if there is indication for liver transplantation.



- **Update on present studies**
    - ***Last accepted NLTG publication and future plans from available cancer data***. Our article "Decreasing incidence of cancer after liver transplantation – A Nordic population-based study over three decades" is published in Am J Transplantation. Helena Isoniemi was proposing another cancer study, an analyse of the incidence and types of posttransplant cancer among pediatric and young adults. Study material is collected from all Nordic centers and cancer registries and mainly analysed. New study proposal was accepted and manuscript will be rotated in every center including paediatrician. Third study from cancer material: the effect of pretransplant malignancies outside the liver was also decided to analyse. This study needs more information to be collected from each center (11-20 cases per center) and contact persons from every center are needed. Helsinki will prepare proposal for extra parameters to be collected.

    - ABO compatibility in Liver Transplantation: a Nordic Liver Transplant Registry-study *(Andreas Arendtsen Rostved)* AAR was not present but Allan informed *study is progressing*
    - Donor Specific HLA alloantibodies in Liver Transplantation: a prospective blinded multicenter prognostic study *(Andreas Arendtsen Rostved &Allan Rasmussen)* Study is running nicely.
    - Molecular Diagnostics of Acute Rejection and Chronic Pathologies after Liver Transplantation *(Andreas Arendtsen Rostved)* Protocol will be send
    - A1AT study *(Ahmad Karagadi Ph.D student)*
    - Survey on donor operation technique *(Antonio Romano)* No report

New study proposals. New protocol for hilar cholangiocarnoma and a study in the NLTG group. Other new proposal was that we should use the cancer study material to also find out reasons for the unexpected low risk for prostate and breast cancer among our liver transplanted patients Is it related to males receiving female liver and vice versa

Other: Helena Isoniemi proposed during the meeting that minutes should be written within two and rotated and accepted in every center. The final minutes should be at Scandiatransplant before six weeks passed after the meeting. However this was not successful this time.

Next meeting was proposed to be on 13th March in Tartu and Toomas Väli invited NLTG welcome to Tartu

Helena Isoniemi

List of participants based on signed form

Helena Isoniemi helena.isoniemi@hus.fi
Heikki Mäkisalo heikki.makisalo@hus.fi
Eija Tukiainen eija.tukiainen@hus.fi
Leena Toivonen leena.toivonen@hus.fi
Caola Schaumann carola.schauman@hus.fi

Eero Hartikka eero.t.hartikka@hus.fi
Siv Ansa siv.ansa@hus.fi
Krister Höckerstedt ext-krister.hockerstdt@hus.fi
Allan Rasmussen allan.rasmussen@dadlnet.dk
Nicolai Schultz nicolai-schultz@dadlnet.dk
Per Lindner per.lindner@vgregion.se
Monica Olofsson monica.olofsson@ous-hf.no
William Bennett william.bennet@vgregion.se
Maria Castedal maria.castedal@vgregion.se
Pål-Dag Line pline@ous-hf.no
Toomas Väli toomas.vali@kliinikum.ee
Bo-Göran Ericzon bo-goran.ericzon@ki.se
Carl Jorns carl.jorns@ki.se
Gunnar Söderdahl gunnar.soderdhl@sll.se
Ilse Duus Weinreich ilse.duus.weinreich@scandiatranplant.org