

Minutes from the Nordic Pediatric Renal Study Group meeting,

Virtual meeting October 7, 2020

Host: Oslo, Anna Bjerre

Participants:

Denmark: Søren S. Sørensen, Ida Maria Schmidt, Hanne Nørgaard, Per Wittenhagen, Helle Thiesson, Søren Rittig

Estonia: Inga Vainumäe

Finland: Timo Jahnukainen, Juuso Tainio, Kira Endén, Janne Kataja

Norway: Anna Bjerre, Anders Åsberg, Ann Christin Gjerstad, Hjørdis Thorsteinsdottir

Sweden: Lars Wennberg, Helena Genberg, Felicia Kjaernet, Lisa Sartz, Zivile Bekassy, Susanne Westphal, Maria Herthelius, Marie Tranäng, Peter Barany, Åsa Norén

Scandiatransplant: Ilse Duus-Weinreich

Welcome

Anna Bjerre welcomed everyone to this first virtual meeting.

Approval of minutes

The minutes from last meeting were approved. Since last meeting, there was more information concerning ERN membership.

ERN: Stockholm has a full membership in ERN Transplant. Applications are under evaluation for Oslo, Copenhagen, Gothenburg and Helsinki. Odense has not been approved due few patients. Århus is a member of the ERK net.

NPRTSG National Key Persons 2019-2021

No changes have been announced

Denmark- Helle Thiesson

Estonia- Inga Vainumäe

Finland- Timo Jahnukainen

Iceland- Vidar Edvardsson

Norway- Anna Bjerre

Sweden- Lars Wennberg

The National key persons are responsible to keep an updated list of e-mail addresses from all the centers.

There have been some changes concerning the composition in the more extended NPRSTG group:

Chief Coordinator: Ilse Duus Weinreich is replacing Marie Tranäng.

Odense: Francois Baudier is replacing KE Larsen

Helsinki: H Jalanko has now retired, Timo J will investigate who will replace him

Oslo: a new member from the Surgeons Dept has to be announced, Anna will investigate this further

Gothenburg: Åsa Norén is replacing L. Mjörnstedt

Uppsala: Uncertainty if A Sedigh still is in charge

News from the SCTP

Ilse DW had a short presentation from the SCTP. Data entry in the FU forms were presented. Some data are still missing. The access to NPRSTG in YASWA is now possible for all the 11 centers (25 users).

The kidney exchange program was presented. STAMP has extended with matching on HLA-DRB3/4/5, DQA1 and DPA1 .

Exchanges between centers (2015-2019) , D < 50 years and R < 16 years: a total of 31. A total of 8/31 (26%) according to exchange priority 4. 2/31 (6%), according to exchange obligation.

Exchange obligations, D < 50 years, R < 16 years: a total of 10

Annual Registry Report

Søren S, Copenhagen and Anders Å, Oslo, have gone through the data from the last year. There was an improvement in LD numbers; the data are quite stable. There has been totally 31 ABOitx, and almost all centers have now performed these.

Ongoing studies from the Registry

1. Timo J: Variability in IS treatment after kidney tx- preliminary data.

Timo presented the differences between the centers. They have a vast data set which is under investigation. Publications are planned

2. Felicia K: The ABOitx study.

All formalities are now agreed on. The plan is to send out the CRFs to the centers and start the data collection.

Other presentations

Kira E, Helsinki: Transplantation during childhood increases the risk for malignancies.

This Finnish study has now been published in Pediatric Nephrology. Very interesting data from this National Finnish study. 233 SOT (137 kidneys, 53 liver, 43 heart) were enrolled and compared to a control group. Cancer was diagnosed at a median of 12 years after tx, no difference of tx type. HR was 14.7.

Zivilie B: Vaccination after tx

Zivile presented the differences in immunization after kidney tx in the Nordic countries, which was more or less similar. We had an interesting debate on immunization and what is the gain of influenza vaccine every year, and what immunological impact that this have in the long run. Zivile emphasized that during a life time a pediatric kidney recipient will have 50-60 flu shots.

Anna B: Experience of Covid 19 in ped tx in the Nordic Countries.

Few patients in the Nordic countries had been affected by the Corona virus. This is in concordance with other published surveys. Only one severely sick child was reported from Gothenburg (a child on dialysis and with an immunodeficiency).

Next meeting:

We have concluded to keep on with annual meetings. This is the only way to keep our Registry alive. At the moment we have two ongoing studies, we hope for more in the future.

Next meeting will be held in Finland, on October 13, 2021.

We all hope that this can be organized as an old fashioned meeting!!!

Thanks for attending