

# Minutes for the Nordic Pediatric Renal Study Group meeting, Copenhagen, October 9, 2019

Venue: Clarion Hotel, Copenhagen Airport  
MT, LW 2019-10-17

## Participants:

Denmark – Søren S. Sørensen, Line Thousig Sehested, Ida Maria Schmidt, Hanne Nørgaard, Mette Christensen, René Frydensbjerg Andersen, Per Wittenhagen, Helle Charlotte Thiesson, Mette Neland

Estonia – Inga Vainumäe

Finland – Timo Jahnukainen

Norway – Anna Bjerre, Ann Christin Gjerstad

Sweden – Lars Wennberg, Helena Genberg, Kajsa Åsling Monemi, Zivile Békassy, Lisa Sartz, Nilüfer Kayihan Kuru, Felicia Kjaernet, Marie Tranäng, Åsa Norén

Scandiatransplant – Ilse Duus-Weinreich

## Welcome

Søren SS welcomed everyone to the meeting. He also mentioned that the register was founded in 1994 which means we are celebrating the 25th anniversary this year. Marie Tranäng from Stockholm announced here forthcoming retirement and were acknowledged for her life-time achievements within NPRTSG

## Approval of minutes

The minutes from the last meeting was approved. They can be found on the Scandiatransplant website

## NPRTSG National Key Persons 2019-2021

Denmark – Helle Charlotte 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. The list should also include names on pediatric nephrologists at each center

## Present and future structure of NPRTSG

Up to now it has been possible to report to the registry in two ways, either on paper forms or electronically directly in YASWA. From now on everybody must report electronically and those who not yet have a log in to YASWA can contact Ilse Duus Weinreich at Scandiatransplant. In addition to reporting data, it is also possible to export your own data. In that way you can check the status of your own reporting.

A special report should be produced annually. The National Key Persons are to decide what should be included in the report – **deadline before Christmas 2019**. The annual report you can do without any permission from the reporting centers but for a publication you need approval from all centers.

It was decided that Anders Åsberg from Oslo and Søren SS from Copenhagen, presently in charge of producing the annual report for the Nordic Kidney Group, will take over the production of the annual NPRTSG report when Marie Tranäng retires.

Discussion regarding the reporting, differences in how some variables are reported. The National Key Persons were commissioned to go through the forms in YASWA to see what could be improved. They should also go through the drop-down menus and check that everything is ok.

#### **GFR method**

'DPTA' has now been added under GFR methods in YASWA production

#### **News from the SCTP office**

Ilse DW gave a short presentation of the organization of Scandiatransplant and the SCTP office.

#### **Registry report**

Marie T presented data from NPRTSG. The registry was founded in 1994 (by professors Gunnar Tydén and Ulla Berg at Huddinge Hospital) and the first meeting was held in April 1994 at Arlanda airport. Simplified retrospective data was collected for the time-period 1982 (start of the use of Cyclosporine) – 1993 and full registration started in 1994. The presentation can be found here:

<http://www.scandiatransplant.org/members/nkg/nprtsg>

#### **ICD-10 diagnoses reference group**

Timo J gave a report from the reference group that was formed at the last meeting. The working group has not experienced any problem with the new coding system (ERA-EDTA codes) that was implemented some years ago.

A comparison was made between the diagnoses distribution in the two articles published from the registry and the last two-year period (2016-2018) and there has been a change over the years. There was a proposal to look deeper into this and report at the Scandinavian Transplantation Society meeting in Helsinki in May 2020

#### **Special reports from the registry**

Ida Maria S gave a report on combined liver-kidney transplantation. ARPKD and oxaluria are the main diagnoses. Finland has the highest number of combined LKtx, no patient with ARPKD transplanted in Sweden

Søren SS gave a country comparison on HLA mismatch for DD pediatric renal transplantation. In addition to the kidney exchange obligations Denmark has its own rule. The question came up on how many kidneys has been exchanged the last years. The answer from Ilse below:

#### **Kidney exchange obligations prio. 4**

In the 5-year period from 2014-2018 there has been 30 exchanges between Scandiatransplant centers where the organ donor was <50 years of age and transplanted recipient was <16 years of age counted from time of registration.

5 of the 30 exchanges were according to pediatric kidney exchange obligation number 4 between the following centers:

Oslo to Malmö

Copenhagen to Gothenburg

Uppsala to Helsinki  
Stockholm to Helsinki  
Helsinki to Stockholm

2 of the 30 exchanges were according to STAMP kidney exchange obligation between the following centers:

Oslo to Gothenburg  
Malmö to Stockholm

### European network (ERN):

Lars W gave a short presentation of the ERN network TransplantChild and the web-based clinical patient management system (CPMS). There will be a new possibility to apply for membership in ERNs coming up soon. More information could be found on <https://www.transplantchild.eu/en/>

### Report from NPRTSG studies

Felicia K summarized the results from the ABOi study

Lars W reported from the study on viral infection where nothing regrettably has happened yet. New attempt to initiate the study.

Discussion about ambiguities and uncertainties on which permits that are required for 1) studies based only on registry data only (such as NPRTSG) and 2) studies based on registry data in combination with retrospective data retrieved from patient hospital records/files. Ethical permits, other permits, one permit only, individual national permits, etc. ? There also seems to be some differences between the different countries in SCTP. Since clarification of this issue will be of vital importance for almost all future studies performed within NPRTSG (or SCTP), the national key persons in NPRTSG were asked to investigate the requirements within the individual countries and report back

### Different presentations

Helle T presented a case report: Broad immunization in a non-transfused pediatric renal transplant candidate

René A presented a Danish study on Nephrotic syndrome

Helle T gave a presentation on TDM for MMF

### Pediatric renal transplantation in Estonia

Estonia became an associated member of Scandiatransplant in 2017. Inga V gave an overview of the past and present status of renal transplantation in Estonia

### Suggestion new study

Timo J suggested a study on immunosuppression – a continuation on previous studies (the 2 publications), deadline is the Scandinavian Society meeting in Helsinki in May 2020. Authors of the study are Timo J, Søren SS, a Ph student + one author from each center.

### Next meeting:

Frequency of NPRTSG meetings were discussed. Since 4 years, meetings have been held bi-annually. It was decided to return to annual meetings for the next NPRTSG event and to evaluate and discuss

this issue also at the next meeting. Next meeting will be hosted by Norway in one year from now.  
Suggested date is October 7, 2020