

Minutes for the Nordic Pediatric Renal Study Group meeting, Stockholm, October 10, 2017

Venue: Clarion Hotel, Arlanda airport

Participants:

Denmark – Søren Schwartz Sørensen, Per Wittenhagen, Helle Thiessen, Mia Faerch

Estonia – Inga Vainumäe

Finland – Timo Jahnukainen, Juuso Tainio

Norway – Anna Bjerre, Rune Horneland, Trygve Thorsen, Bjarte Fosby, Ann Christin Gjerstad

Sweden – Lars Wennberg, Gustav Friman, Helena Genberg, Kajsa Åsling Monemi, Mia Herthelius, Rafael Krmar, Susanne Westphal Ladfors, Zivile Békassy, Lars Mjörnstedt, Nilüfer Kuru, Tim Scholz, Marie Tranäng

Welcome:

Lars W started the meeting by introducing Estonia as a new associate member of SCTP and by remembering Professor Gunnar Tydén, co-founder of NPRTSG, who passed away in 2017

NPRTSG registry:

Søren SS gave a short presentation of the organization of Scandiatransplant with specialist groups for the main organs kidney, liver, thoracic organs, pancreas and intestine. NPRTSG is a subgroup of the Nordic Kidney Group (NKG). There is a possibility to receive financial support (20.000 DKK/year) from Scandiatransplant for meeting facilities and food etc. to conduct group meetings one or two times per year.

Previous NPRTSG meetings have been supported by the industry and there was a discussion if we should continue to receive support from the industry. Since the rules and regulations have been changed both in industry and in health care the meeting decided to change and to apply for funding from SCTP in the future, and not from the industry. To facilitate adequate funding, it was decided to arrange NPRTSG meetings every second year in the future. However, NPRTSG reports will be issued annually, also on years without a NPRTSG meeting. Meetings will continue to rotate between the SCTP member countries, including Estonia.

Marie T presented the recent data from NPRTSG. Now all registration is electronic through Scandiatransplant/YASWA. It is up to each center to decide if they want to register themselves or if they want to report on paper forms and send to Marie T. Access to the pediatric registry in YASWA could be obtained by contacting Scandiatransplant or Marie T. Except for registering own data it is also possible to extract data on you own patients from the registry.

A reference group for diagnoses was formed with one member from each country: Sweden – Mia Herthelius, Norway – Anna Bjerre, Finland – Timo Jahnukainen, Denmark – Mia Faerch, Estonia – Inga Vainumäe, Iceland – Vidar Edvardson. If there are any uncertainties about diagnostic codes, you can contact the reference group for advice (for e-mail addresses see enclosed contact list).

European network (ERN):

Lars W gave a short presentation of the ERN network TransplantChild. More information could be found on www.transplantchild.com

Study proposals:

ABOi transplantation

Helen G presented data on ABO-incompatible transplantation; what is done world-wide, different protocols and results. Then she presented survival data from the NPRTSG on 30 ABOi transplantations with a proposal of a study on these patients. Anyone interested to take part in this study could contact Helena Genberg (helena.genberg@sll.se).

Viral issues

Gustav F presented a proposal on a retrospective, descriptive study on viral complications after transplantation. Anyone interested to take part in this study could contact Gustav Friman (gustav.friman@sll.se)

Any other study?

Suggestions on new projects/studies are welcome

Next meeting:

Next meeting will be hosted by Denmark in two years from now. Suggested date is October 9, 2019