



## Annual Meeting 2025

November 18th,  
Kastrup, Copenhagen 10:30-15.30

### Minutes of Meeting:

**1. Welcome by** Zivile Bekassy

**2. Writer of minutes** Maria Herthelius

**3. Minutes from the last** meeting were approved in their current form. Zivile Bekassy noted that the document on steroid withdrawal from ERN Transplantchild, promised at the previous meeting, is now in its final stage.

**4. Presentation of participants**

- The list of participants is provided at the end of the document.
- Mailing list updated: country representatives are responsible for keeping the list updated.

**5. All key persons were reelected.**

- Helle Thiesson (DK)
- Inga Vainumäe (EST)
- Timo Jahnuainen (FIN)
- Vidar Örn Edverdsson (ISL)
- Ann Christin Gjerstad (NOR)
- Lars Wennberg (SWE)
- Søren Schwartz Sørensen (NKG)

**6. Annual report:**

Søren Schwartz Sørensen presented completed data from the registry. No major changes or clear trends in any direction were observed for 2024 compared to previous years.

The report is available:

[Nordic Paediatric Renal Transplant Study Group \(presenting year 1995 - 2024\)](#)

#### **7. Data completeness NPRTSG:**

Ilse Duus Weinreich presented how well different centers have registered follow-up data. Unfortunately, Stockholm, unlike most other centers, had not registered any follow-up data at all.

#### **8. Status on ERN TransplantChild and PETER Registry (LW online):**

Lars Wennberg provided information about ERN Transplantchild and encouraged all centers to be active within this ERN by discussing patients via the Clinical Patient Management System (CPMS 2), contributing to work on guidelines and training, or alternatively making use of the available material. Stockholm is most active to include patients in PETER registry so far. No news regarding cooperation among different EU registries under ERN. Consent is mandatory but varies between Nordic countries.

#### **9. Discussion about exchange obligation 4.**

Helle Charlotte Thiesson raised the question of whether the age of a pediatric recipient in “exchange obligation 4” in the Scandiatransplant exchange program (i.e., that a kidney from a deceased donor younger than 50 years with mismatch 2-0 should be offered to a pediatric recipient) should be increased from 16 to 18 years, and whether the kidney should be offered even if there is more mismatch. Helena Genberg pointed out that not only the number but also the type of mismatches matters. It was also noted that if there is a living donor, a more pronounced mismatch can be considered compared to a deceased donor. It was approved that Søren S. Sørensen should bring forward the suggestion to NKG to increase the age from below 16 to below 18 years of age and to further discuss the HLA matching.

After lunch, two highly appreciated lectures were held (attached):

**10. Kidney transplantation for severely neurologically compromised children – ethical considerations** (Anders Castor, Chair of the Medical Ethics Delegation within the Swedish Society of Medicine)

**11. Intellectual disability – what does it mean?** (Maria Forsgren, pediatric neurologist, Lund)

Following this, four cases were presented concerning children with significant intellectual disabilities and severe kidney failure, where we discussed the pros and cons of kidney transplantation. It seems that we have similar ethical considerations and difficulties in decision making for this growing group of patients (Sweden, Denmark and Finland).

We concluded that difficult cases can be discussed in this NPKTSG to gain more experience and support for decision making.

**12. The date for the next NPRTSG meeting was set for November 10<sup>th</sup> 2026, and Finland will host this meeting.**

The meeting was adjourned.

**Meetings:**

**2027:** Oslo

**2026:** Helsinki 10th November

**2025:** Sweden (Skåne)

**2024:** Copenhagen

**2023:** Stockholm

**2022:** (COVID)

**2021:** Helsinki

**2020:** Oslo

251209 Maria Herthelius and Zivile Bekassy

**Meeting participants:**

Søren Schwartz Sørensen, Copenhagen

Maria Herthelius, Stockholm

Kajsa Åsling Monemi , Stockholm

Åsa Laestadius, Uppsala

Timo Jahnukainen, Helsinki

Line Aas Mortensen, Odense

Åsa Norén, Gothenburg

Inga Vainumäe, Tartu

Ida Maria Schmidt, Copenhagen

Hanne Nørgaard Line, Copenhagen

Line Thousig Sehested, Copenhagen

Helle Charlotte Thiesson, Odense

Astrid Aakmann, Copenhagen

Tobias Axelsson, Gothenburg

Sartz Lisa, Skåne

Zivile Bekassy, Skåne

Ilse Duus Weinreich, Scandiatransplant

Rebecka Hermansson, Skåne

Marita Bladh, Stockholm

Anne Karin Sandberg, Stockholm

Gisella Suala, Stockholm

Helena Genberg, Stockholm

Lars Wennberg, Stockholm (online)