

Scandiatransplant Pediatric Heart and Lung Group (SPaedHLG) fall meeting 2025

October 17th, 2025

Zoom at 15:00 – 17:00 Central European summertime (GMT +2)

Meeting participants:

Klaus Juul (Copenhagen/Denmark) - National Key Contact Person 2024-2025

Thomas Möller (Oslo/Norway) - National Key Contact Person 2024-2025 (extended
SPaedHLG chair period until fall 2025)

Michal Odermarsky (Lund/Sweden) - National Key Contact Person 2024-2025

Taisto Sarkola (Helsinki/Finland) – National Key Contact Person 2024-2025

Karin Tran-Lundmark (Lund/Sweden)

Håkan Wåhlander (Gothenburg/Sweden) part of the meeting

Aslak Widerøe Kristoffersen (Oslo/Norway)

Tiina Ojala (Helsinki, Finland)

Oscar Van Der Have (Lund, Sweden)

Meeting Minutes

1. Welcome

2. Registration of meeting participants

Centers present: Meeting board present: Copenhagen, Lund, Oslo, Helsinki, Gothenburg (parts of the meeting)

3. Adjustment and approval of agenda for present meeting

No suggestions for changes

4. Approval of minutes from last meeting (April 11, 2025)

Minutes from last meeting were approved

5. SPaedHLG board

a. Any news from the board?

Karl Lemström (Helsinki/Finland) – SHLG chair

Timo Jahnukainen (Helsinki/Finland) – National Key Contact Person 2024-2025

Klaus Juul (Copenhagen/Denmark) - National Key Contact Person 2024-2025

Thomas Möller (Oslo/Norway) - National Key Contact Person 2024-2025

(extended SPaedHLG chair period until fall 2025)

Michal Odermarsky (Lund/Sweden) - National Key Contact Person 2024-2025

Håkan Wåhlander (Gothenburg/Sweden) – Second national Key Contact Person 2024-2025

b. Chairperson for upcoming meeting - spring 2026.

Klaus Juul from Denmark will take over as chairperson as the next annual Nordic Pediatric Cardiology Meeting will be in Copenhagen. The next SPaedHLG-meeting will be during the annual AEPC meeting in Padova 13th-16th May 2026. We plan for the details (date/time/room/hybrid platform) for the meeting when we have the conference program.

6. SHLG and Scandiatransplant office information

a. Data on Nordic and national waiting list mortality:

Michael shared the latest numbers including country specific figures.

Overall waitlist mortality 1986-2023:

-Approx 75% survival at 500 days.

No age stratified numbers presented.

No data on numbers of procured organs/donors presented.

b. Other (annual numbers are presented in the SPaedHLG spring meeting)

7. Update on national / center-wise paediatric heart transplant follow-up protocols within SPaedHLG

a. Major changes (effectuated or planned)

None

b. New about sharing of protocols?

No

c. Discussion about Nordic patient-specific conferences pre-listing and listing policy alignment (KJ)

It may be useful to discuss individual patients either formally in the group meetings or more informally via email correspondence. One option would be to review patients who have been listed since the last meeting every six months. There is consensus in the group that whether a patient should be listed or not should have to be decided by each center individually and not through a “democratic” joint process in SPaedHLG. Another issue that arose was whether we need formal consent from the patient and family in order to discuss patients collectively in this way or by electronic communication.

8. Mechanical support – status and recent developments

a. Status for method evaluation of Berlin Heart EXCOR in Norway (AWK)

We have for several years attempted to raise the issue for establishing a VAD program for children, specifically introducing the Berlin Heart. There has been some skepticism, especially among former surgeons. Last year we agreed to perform what is called a mini-method assessment (Hospital-based Health Technology Assessment) of the Berlin Heart EXCOR where we have assessed the clinical effect and safety of the method, costs, whether the method will replace an old method or be an addition, and organizational changes or consequences. The assessment was completed last week and published on the Norwegian Institute of Public Health’s website. Thanks to our colleagues from Lund, Gothenburg and Kiel for their peer reviews. The final decision on whether the method will be implemented is made by the involved clinics and may be escalated to the highest level of the health trust. The document is intended to provide a well-founded knowledge base so the health trust can make a correct decision. An assessment like this of the Berlin Heart EXCOR has not been made in the other Nordic countries.

9. Research

Report / update from studies within SPaedHLG region and other projects in progress

a. Nordic heart transplant study (MO / OvdH)

Update: The single ventricle study moves forward. Manuscript draft expected ready in the beginning of 2026. There will also be a spin-off quality-of-life study with data both pre- and post-transplant from Sweden.

b. Suggestions for new joint studies within SPaedHLG?

No suggestions for joint studies.

10. Other business meeting questions and proposals

a. Status for SPaedHLG suggestion for increasing of age limit to 18 years for pediatric urgent call criteria (KTL)

The group discussed the drafted document from Karin and agreed to improve the text and strengthen the argumentation with some numbers/evidence. Taisto will continue the work.

11. Next meeting. Planned as a hybrid meeting during AEPC in Padova in May 2026.