

Scandiatriansplant



Scandiatriansplant Pediatric Heart and Lung Group (SPaedHLG) meeting 2024

April 26th, 2024

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

<https://uio.zoom.us/j/64064980928?pwd=YldXME13OW4rSmRSRHE1RFRVdmpuZz09>

Meeting participants:

Ilse Duus Weinreich (Scandiatriansplant office)
Timo Jahnukainen (Helsinki/Finland) – National Key Contact Person 2023-2024
Klaus Juul (Copenhagen/Denmark) - National Key Contact Person 2023-2024
Thomas Möller (Oslo/Norway) - National Key Contact Person 2023-2024 (SPaedHLG chair 2024) (host of the meeting)
Michal Odermarsky (Lund/Sweden) - National Key Contact Person 2023-2024
Taisto Sarkola (Helsinki/Finland)
Karin Tran-Lundmark (Lund/Sweden)
Håkan Wåhlander (Gothenburg/Sweden) National Key Contact Person 2023-2024
Aslak Kristoffersen (Oslo/Norway) (kept meeting minutes)
Tiina Ojala (Helsinki, Finland)
Maria Hurskainen (Helsinki, Finland)
Oscar Van Der Have (Lund, Sweden)
Kathrine Sutter (Pediatric Radiologist, Oslo, Rikshospitalet)
Anu Kaskinen (Pediatric nephrologist, Finland, Helsinki)

Meeting minutes

1. Host of the meeting, Thomas Möller, welcomed everyone with a brief introduction.
2. All participants introduced themselves.
3. Registration of meeting participants as above.
4. The agenda for the meeting was approved with adding a discussion on organ procurement to the discussion list.

5. The minutes from last meeting (Oct 10, 2023) was approved by the participants.
6. SPaedHLG board.
 - a. The SPaedHLG National Key Contact Persons for 2024 listed above were confirmed.
7. SHLG and Scandiatransplant office information:
 - a. Scandiatransplant will have their annual meeting in Gothenburg next week.
 - b. Duus Weinreich presented the SHLG annual numbers.
 - i. Heart and lung from the Scandiatransplant region, including Estonia and Iceland, included;
 - ii. Heart:
 1. Mean number of entries to the waiting list over the last years has been 24.
 2. 3 patients were withdrawn from the list last year; 1 died on the waiting list, 2 were permanently withdrawn for other reasons (Oslo and Gothenburg).
 3. 10 children and 7 adults were listed as urgent.
 - iii. Lung:
 1. On average 4 patients/year added to the lung transplant list.
 2. On average 3 lung transplants per year. Gothenburg is doing the most lung transplants.
 3. No withdrawals last year
 - iv. The Scandiatransplant office would prefer annual digital updates on patient survival from the Scandinavian countries. Due to regulatory issues there has been difficulties in receiving exchange data from Norway and Sweden this way.
 - v. The registry data is grouped by age, waiting time, survival curve by era (currently 5-year survival is 86%; 10-year is 80%).
 1. Comments from the group:
 - a. The patients should be group by age as done by ISHLT (0-1 years instead of 0-4 years, and then 2-5 years, 6-10 years).
 - c. YASWA as a Nordic protocol and document sharing platform was discussed.
 - i. Möller suggested that all the Scandinavian pediatric heart and lung transplant centers should upload their protocols to YASWA, with joined access for all SPaedHLG participants.

Could also include read and edit access to database/registry data. The group agreed to give access to all participants of today's meeting.

- ii. Jahnukainen asked about the different Scandinavian centers participation in the ERN TransplantChild as they also have a digital system for protocol sharing. Copenhagen report their pediatric heart data to ERN, Gothenburg has also managed to participate, but Lund and Oslo have not. The overall problem for many of the SPaedHLG members is dedicated time to contribute into the ERN TransplantChild, and most of the participants of today's meeting are prioritizing the SPaedHLG instead of ERN TransplantChild

8. Research:

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

- a. MRI and CT coronaries in pediatric HTx follow-up (Ojala)
 - i. Tiina presented her work in CMRI and rejection screening. High negative predictive value. Suggests combination of MRI and cell-free DNA for the future.
- b. Nordic Heart Transplant Study (Odermarsky / Van Der Have)
 - i. Oscar presented updated key numbers, tentative manuscript layout and a time plan. There are some uncertainty whether children from Estonia and Iceland are included. In total 601 patients listed for a heart transplant during this period. 465 patients had a primary heart transplant.
- c. Swedish dd-cfDNA study (Jens Böhmer). Lund tell they will support further study in Gothenburg and continue to send samples.
- d. Suggestions for new joint studies within SPaedHLG
 - i. Thomas mentioned his thoughts for a study on echo myocardial work combined with dd-cfDNA as a screening tool for rejection. Thomas has already discussed this with Jens Böhmer.

9. Update on paediatric heart transplant follow-up protocols within SPaedHLG

- a. Major changes (effectuated or planned)
 - i. Finland: No major changes last year. More or less stopped protocol biopsy after the first year. Instead, they use coronary CT and MRI. For heart rate reduction, they use

beta-blockers for the younger patients and Ivabidrin for those above 12 months.

- ii. Denmark: Are working on reducing the numbers of EMB. For low risk patients they now do four biopsies the first year.
 - iii. Lund: No major changes since last time. They do biopsies until 5 years post TX. They do no angio, only CT. They do some undersized heart matching (down to 80% weight)
 - iv. Gothenburg: No significant changes over the last year. Still do biopsies first year. Planning to reduce the number of biopsies when they have dd-ccDNA up and running.
 - v. Norway: Down from 7-8 biopsies per year to five biopsies for children older than 1 year. Only one biopsy for infants.
10. Organ donation procurement: Möller informed the group about the ongoing process in Norway with a Working Group remaking the National organ donation protocols. He hopes that this will culminate in also including infant donors.
11. Mechanical support – status and recent developments. There was only time for a very short update. Denmark did one Berlin Hearts last year. Finland has been preparing to restart their program. Juul commented that organ prioritizing is closely related to ventricular assist device support and that it is necessary to discuss this further.
12. Other business meeting questions and proposals was postponed due to limited time.
13. Next meeting. The group agreed to arrange for a hybrid meeting during the Nordic meeting in Oslo in September