

Scandiatriansplant Pediatric Heart and Lung Group (SPaedHLG) meeting Fall 2024

September 19th, 2024

Hurdalsjoen Hotel and Zoom at 17:00 – 19:00 Central European
summertime (GMT +2)

Meeting participants:

Klaus Juul (Copenhagen/Denmark) - National Key Contact Person 2023-2024 (Zoom)
Michal Odermarsky (Lund/Sweden) - National Key Contact Person 2023-2024 (Zoom)
Oscar Van Der Have (Lund, Sweden) (Zoom)
Tiina Ojala (Helsinki, Finland)
Thomas Möller (Oslo/Norway) - National Key Contact Person 2023-2024 (SPaedHLG chair
2024) (host of the meeting)
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)
Maria Hurskainen (Helsinki, Finland)
Marie Bartos (Gothenburg/Sweden)
Katarina Övermo Tydén (Stockholm/Sweden)
Katharina Lannering (Gothenburg/Sweden)

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.
5. The minutes from last meeting (9 April, 2024) was approved by the participants.
6. News or protocol updates since last meeting:
 - a. Gothenburg is currently working on the dd-cfDNA setup.

- b. Oslo has written protocols for cellular and antibody-mediated rejection.
- 7. SHLG and Scandiatransplant office information:
 - a. Ilse Duus-Weinreich (Scandiatransplant office) not present. Will join the spring meeting.
 - b. Updates on YASWA as a Nordic protocol and document sharing platform.
 - i. Guidelines not yet uploaded.
 - ii. Discussed if some can be uploaded to Scandiatransplant website (official) and some to Yaswa (restricted access)
- 8. CAV surveillance
 - a. The group discussed regular CT vs photon CT and root angio versus selective coronar injection.
- 9. Long-term mechanical support
 - a. All centers now have a VAD-program including Berlin heart EXCOR, except Oslo. Oslo currently doing a mini-method evaluation of Berlin heart EXCOR.
 - b. Anticoagulation: The group discussed the use of Warfarin versus Bivalirudin. All centers except Helsinki use Warfarin. Will an oral anti-thrombin inhibitor (dabigatran) be an alternative in the future?
- 10. Organdonation in infants in Norway
 - a. Thomas is leading a national working group in Norway that recently presented their [report](#) on the needs and improvement opportunities regarding organ donation in children in general and infants in particular. The background for this is the lack of infant donors from Norway.
- 11. Research:
 - Report / update from studies within SPAedHLG region and other projects in progress
 - a. MRI and CT coronaries in pediatric HTx follow-up (Ojala)
 - b. Nordic Heart Transplant Study (Odermarsky / Van Der Have)
 - i. Oscar presented updated data. Stratified on three eras. 598 patients listed, 462 reached transplant. 14 listed for re-transplant, 11 reached re-transplant. Most active centers Helsinki and Gothenburg. Presented listing outcomes (death ratio, transplant, withdrawal). Presented post-transplant survival numbers. Will get data on re-transplant from adult data. Will get data on the number of liver transplants among transplanted Fontan population.

- c. Swedish dd-cfDNA study. Is in manuscript. Will be submitted soon. Jens will defend his thesis on December 13th.
- d. Suggestions for new joint studies within SPaedHLG:
 - i. Mortality study of the cohort from the Nordic Heart Transplant Study.

12. Other:

- a. The group discussed the age-criteria for heart patients on continuous inotropic support to qualify for the Priority 0 category in the Scandiatransplant thoracic exchange guidelines. The group will propose for the Scandiatransplant to raise the age limit from 16 to 18 years.

13. Next meeting:

- a. Spring 2025. Zoom meeting, preliminary Friday April 11, 15:00-17:00 CET
- b. Discuss if we should have shared meetings where we discuss transplant candidates.
- c. Finland will provide a summary from the national Fontan meeting.