

## Scandiatransplant Pediatric Heart and Lung Group (SPaedHLG) meeting 2021

October 29th, 2021

Zoom-meeting at 3-4.45 pm Helsinki time

### Meeting participants:

Ilse Duus-Weinreich (Scandiatransplant office)

Timo Jahnukainen (Helsinki/Finland) – National Key Contact Person 2020-2022

Klaus Juul (Copenhagen/Denmark) - National Key Contact Person 2020-2022 – not present

Anu Kaskinen (Helsinki/Finland)

Thomas Möller (Oslo/Norway) - National Key Contact Person 2020-2022

Michal Odermarsky (Lund/Sweden) - National Key Contact Person 2020-2022

Jaana Pihkala (Helsinki/Finland)

Taisto Sarkola (Helsinki/Finland) – SPaedHLG Chair 2020-2021

Karin Tran-Lundmark (Lund/Sweden)

Håkan Wåhlander (Gothenburg/Sweden) - National Key Contact Person 2020-2022 (present from §7)

## Meeting minutes

1. Taisto Sarkola opened the meeting at 3 pm and kept minutes during the meeting.
2. Meeting participants were registered as listed above.
3. The agenda for the meeting was approved.
4. The minutes from the previous meeting (160421) were briefly reviewed.
5. SPaedHLG board
  - a. Change in SPaedHLG National Key Contact Person 2020-2022 for Denmark: E-mail from Jesper Reimers on July 12th that he is retiring and Klaus Juul (Klaus.Juul@regionh.dk) will take over.
  - b. Selection of SPaedHLG Chair 2022 – Taisto Sarkola was elected for 2022. A rotation system of the chair in the future was discussed. If autumn meetings are in the future arranged face-to-face in conjunction with the Nordic Pediatric Cardiology Meeting, then the chair rotation could be the same as for the NPCM meeting. NPCM 2022 is scheduled to be arranged in Gothenburg. For spring meetings virtual Zoom meetings seem convenient. Hybrid meetings could also be an option for participants not attending NPCM.
6. SHLG and Scandiatransplant office information.

- a. Annual numbers provided by Scandiatransplant office (SCTP, Ilse Duus Weinreich) of pediatric heart and lung transplantations in SPAedHLG area 2017-2021 was briefly reviewed and discussed. There was an in-depth discussion related with pediatric data entry into the Yaswa-database. There are currently differences between different centers data entry that is entered (more complete data from Gothenberg and Lund compared with the other centers) and in some centers the data is entered by persons handling adult thoracic organ transplantations. All centers have ethics approval for data entry. Retrospective information can also be entered. In the data entry process obligatory (and semi-obligatory) data fields can also be introduced in the Yaswa to aid in data entry completion. It was agreed among the centers that the pediatric data entry should be improved and that pediatric data entry could be managed by the pediatric centers (please see more information related with in following meeting §7). After the meeting Ilse Duus Weinreich sent the following links to data collection forms found on the Scandiatransplant webpage to be included in the minutes:
  - Htx pretransplantation form** ([http://www.scandiatransplant.org/organ-allocation/Heart\\_pre\\_tx\\_Nov\\_2017.pdf](http://www.scandiatransplant.org/organ-allocation/Heart_pre_tx_Nov_2017.pdf))
  - Htx transplantation form** (<http://www.scandiatransplant.org/organ-allocation/HTxDischargeNov2017.pdf>)
  - Htx follow-up form** (<http://www.scandiatransplant.org/organ-allocation/HTxFollowupNov2017.pdf>)
7. Report from studies within SPAedHLG region and projects in progress
  - a. An update of the ongoing Heart transplantations in Nordic countries between 1984-2020 was briefly presented by Michal Odermarsky. The variable list in the project has been modified (diminished) to improve data collection. Still, much of the data is not currently available in the Yaswa-database. It was agreed that this modified variable list will be sent to all National Key Contact Persons to review. This variable list should then be used to unify and streamline the pediatric data entry into the Yaswa-database both regarding retrospective as well prospective data. In the process, obligatory data fields in the Yaswa-database will also be agreed upon.
8. Suggestions for new joint studies within SPAedHLG – no studies to discuss.
9. Other business meeting presentations and proposals
  - a. Fragile pediatric Htx listed patients within Scandiatransplant – brief case presentations of recent and present challenging pediatric cardiology cases on mechanical circulatory support (ECMO and Berlin Heart/ BH EXCOR Active) as a bridge to Htx were provided by Taisto Sarkola and Karin Tran-Lundmark.
  - b. Currently, more than 12 months support on implantable long-term VAD (in-hospital or at home) is required for urgent HTx listing. For some critical patient BH-support provide beneficial recovery time as a bridge to HTx. However, the current long 12-month rule may impact on centers decisions regarding mechanical circulatory support type. Related with this, there was a proposal from Lund to change the pediatric 12-month listing rule to a 6-month listing rule to make the VAD-option more attractive. SPAedHLG is not responsible for organ allocation policies, this remains solely in the remit of SHLG. Thus, meeting participants are encouraged to

discuss this proposal with local surgeons and other key members involved in pediatric HTx for a consensus prior to forwarding this proposal to the SHLG board. The results of these discussions should be reviewed in the next SPaedHLG spring meeting with further actions regarding the proposal decided at this meeting.

10. Next meeting: April 22nd 2022 3pm as Zoom meeting.

11. Meeting was ended at 4.45 pm.