

Scandiatriansplant



Annual Scandiatriansplant Pediatric Heart and Lung Group (SPedHLG) meeting 2020

October 23rd, 2020

Zoom-meeting between 3 pm to 5 pm Helsinki time

Meeting participants:

Jesper Reimers (Copenhagen/Denmark)
Timo Jahnukainen (Helsinki/Finland)
Taisto Sarkola (Helsinki/Finland)
Jaana Pihkala (Helsinki/Finland)
Anu Kaskinen (Helsinki/Finland)
Maria Hurskainen (Helsinki/Finland)
Thomas Möller (Oslo/Norway)
Aslak W. Kristoffersen (Oslo/Norway)
Michal Odermarsky (Lund/Sweden)
Karin Tran Lundmark (Lund/Sweden)
Oscar van Der Have (Lund/Sweden)
Håkan Wåhlander (Gothenburg/Sweden)

Meeting minutes

1. Taisto Sarkola was elected to chair and keep minutes during the meeting.
2. Meeting participants were registered as listed above.
3. There were no minutes from previous meeting to review or approve (first official group meeting).
4. The modified agenda sent was approved.
5. Information from SHLG board chair Are Martin Holm (211020) was discussed. The modified pediatric subgroup bylaws have been sent to all pediatric Scandiatriansplant center surgeons to ensure consensus and agreement in the wording. The changes in wording of the pediatric subgroup bylaws made were briefly reviewed for approval by the group with no changes in the wording made, but discussed as follows:
 - a. The name of the group is "Scandiatriansplant Pediatric Heart and Lung Group" and the official acronym for the group is "SPedHLG". Approved.
 - b. Formation of local SPedSHLG groups. "Membership. Members of the group are representatives from Scandiatriansplant centers involved in thoracic transplantation who take care of pediatric heart and lung transplant recipients. Each center should

form a group of representatives who are professionally involved in the care of pediatric heart and lung transplant recipients. Each center appoints one contact person responsible for information sharing within the local center” (SPedSHLG bylaws). The group discussed including specifications of different local group representatives in the wording of the bylaws (e.g. transplant surgeon, cardiologist, pulmonologist, other transplant specialist, coordinators etc.), but the decision was made not to change the wording in order to avoid too much rigidity in the local group specifications in the bylaws. However, the meeting agreed on the importance of having the national key contact person and other key representatives involved in the care of pediatric heart and lung transplant recipients included in the local group. Also, as the number of representatives is not specified in the bylaws, the present wording provide excellent opportunity to cover representativeness as well. The meeting also decided that the national key contact person is responsible for information sharing within local SPedSHLG groups and to SPedHLG chair.

- c. SPedHLG chair. “Membership....The SPedHLG should appoint a chair (or similar) to be responsible for preparing meetings, follow up of meeting decisions and for communication with the SHLG” (SPedSHLG bylaws). Approved.
 - d. Venue of meetings. “The group meets at least once a year. The venue for each meeting should be decided at the previous meeting or agreed among the members between meetings.” Approved.
 - e. Participation in meetings. “Participation in SPedHLG meetings are open for anyone involved in the care of heart and lung transplants in pediatric patients at the Scandiatransplant centers.” Approved.
 - f. Publications and Scandiatransplant database. “Any member of the SPedHLG can make a suggestion on a topic for a research study using data from the Scandiatransplant thoracic transplant registry (Yaswa). Requests for data extract must be approved according to SHLG rules before delivery may take place. Requests should be sent to the Scandiatransplant office.” Approved.
 - g. The importance of local consensus and agreement on the SPedHLG group formation and activity was stressed during the meeting. No local issues related with this was presented by meeting participants.
6. Taisto Sarkola was elected chair for SPedHLG 2020-2021 to be responsible for preparing SPedHLG meetings during 2021, follow up of meeting decisions and for communication with SHLG. For the future, the models of restricting the annual re-election of a chair person from one center to a specified time (e.g. maximum chair duration 3 years per center), rotation of SPedHLG chair periods between the SPedHLG centers, and electing the chair annually based on the choice of the following meeting venue was discussed.
 7. Nomination of SPedHLG representative to attend SHLG meeting by invitation. The meeting decided that the SPedHLG chair represent the group in SHLG.
 8. The meeting nominated the following SPedHLG National Key Contact Persons for 2020-2022
 - a. Denmark, Jesper Reimers
 - b. Finland, Timo Jahnukainen
 - c. Norway, Thomas Möller
 - d. Sweden, Michal Odermarsky (Lund) and Håkan Wåhlander (Gothenburg)

- e. Island, as transplant clinical activity performed in Gothenburg Sweden, it was decided that representation in the local group will be offered to account for representativeness.
9. Annual numbers provided by Scandiatransplant office (SCTP, Ilse Duus Weinreich) of pediatric heart and lung transplantations in SPedHLG area 2016-2020 was briefly reviewed and discussed.
 10. Brief presentations on current and future clinical transplant activity within SPedSHLG.
 - a. Challenges with ABO incompatible transplantations and proposal for novel treatment modality by Karin Lundmark (Lund/Sweden)
 - b. Review of ABO incompatible transplantation activity in Helsinki by Timo Jahnukainen (Helsinki/Finland)
 11. Suggestions for new joint studies within SPedSHLG.
 - a. Heart transplantations in Nordic countries between 1984-2020 by Michal Odermarsky (Lund/Sweden). The project was presented and discussed. The meeting agreed on the sharing of information from the Scandiatransplant registry for the project. Ethical approval has to date been granted for Copenhagen (Aarhus information pending), Lund, Gothenburg, and Helsinki. Ethical approval from Oslo is pending. A variable list is currently under development and proposal will be sent to contact persons. All centers agreed to pursue with the project, with all centers represented among authors of scientific articles (names not specified at this stage), and with the presenter as principal investigator and last senior author.
 12. Other business meeting questions and proposals.
 - a. The SPedHLG meeting minutes will after meetings be circulated to all national key contact persons for approval prior to dissemination to SHLG and SCTP office.
 - b. Taisto Sarkola will contact the SCTP office to specify needs of subgroup activity reporting within Scandiatransplant. The suggestion is that SPedHLG reporting should be (in accordance with group bylaws) by publication of meeting minutes on Scandiatransplant webpage within the SHLG domain and as needed by SPedHLG chair to SHLG only.
 13. Next meeting is Friday April 16th 2021 in the afternoon by Zoom (or equivalent virtual venue).