

Bylaws of Scandiatransplant Paediatric Heart and Lung Group (SPaedHLG) as adopted by the board of SHLG in October 2020

Name

The name of the group is “Scandiatransplant Paediatric Heart and Lung Group” and the official acronym for the group is “SPaedHLG”. The group is an official subgroup within Scandiatransplant Heart and Lung Group (SHLG).

Objectives

To promote clinical and scientific collaboration between the transplantation centres who are in charge of paediatric thoracic organ transplantation in Scandiatransplant.

To ensure that specific paediatric requirements within heart and lung transplantation are covered by Scandiatransplant documents and regulations.

Membership

Members of the group are representatives from Scandiatransplant centres involved in thoracic transplantation who take care of paediatric heart and lung transplant recipients. Each centre should form a group of representatives who are professionally involved in the care of paediatric heart and lung transplant recipients. Each centre appoints one contact person responsible for information sharing within the local centre. The SPaedHLG should appoint a chair (or similar) to be responsible for preparing meetings, follow up of meeting decisions and for communication with the SHLG.

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.

SPaedHLG meetings are open for anyone involved in the care of heart and lung transplants in paediatric patients at the Scandiatransplant centres.

Annually numbers and follow-up data from paediatric heart and lung transplantations in Nordic countries are presented and discussed during meetings. SPaedHLG is not responsible for organ allocation policies, this remains solely in the remit of SHLG.

Paediatric research projects involving heart and lung transplants within Scandiatransplant are discussed at SPaedHLG meeting.

Minutes shall be kept of SPaedHLG meetings and these are published on the Scandiatransplant webpage in conjunction with SHLG.

One representative, yearly nominated within the SPaedHLG during the autumn meeting, may be invited to every SHLG meeting. SPaedHLG will appoint a deputy representative on short notice if necessary. SHLG board members are welcome to attend SPaedHLG meetings.

Publications and Scandiatransplant database

Any member of the SPaedHLG 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. Research proposals are discussed in SPaedHLG meetings with projects and

authors from different centres agreed upon. Authors shall be those who significantly contribute to produce the article in agreement with journal author guidelines. All publications and reports using other country or centre data must be presented to and accepted by all involved centres.

Approved by the SHLG Board February 2021