

## **Minutes 42.nd SHLG meeting**

Virtual Board meeting, October 12. 2020 15:00-16:45

#### **Present by videolink:**

- 1. Göran Rådegran
- 2. Finn Gustafsson
- 3. Maija Halme
- 4. Tanel Laisaar
- 5. Karl Lemström
- 6. Peter Raivio
- 7. Michael Perch
- 8. Einar Gude
- 9. Hillevi Larsson
- 10. Hans Eiskjær
- 11. Arnt Fiane
- 12. Kristjan Karasson
- 13. Johan Nilsson
- 14. Are Holm (AMH)
- 15. Ilse Duus Weinreich

#### **Formalities and Governance**

- 1.1 Minutes from the 41.st Board meeting, and summons and agenda for this meeting were approved
- 1.2 Update of member lists: A list of members of the Board and associate members <u>will be circulated by AMH</u> to all by email (along with these minutes) and shall be returned corrected to AMH who will compile an updated list for final circulation.
- 1.4 Bylaws PedSHLG: The suggested bylaws for the paediatric subgroup of the SHLG as submitted by Sarkola Taisto (Helsinki) and Michael Odermarsky (Lund) were discussed. There were two concerns. The first was that there was uncertainty about the involvement of paediatric surgeons in this process. It was decided that <u>AMH send the suggested bylaws to the leaders of the heart and lung transplant programs at each center</u> for them to forward to local pediatric surgeons for comment. The comments shall be returned to AMH who will incorporate them into a revised version of the bylaws for the paediatric group. If the changes are deemed to be insubstantial, AMH will send the revised bylaws to the members of the SHLG board for approval by email. If the revisions are significant, the approval must be deferred to the next meeting of the Board of the SHLG. The second concern was the name of the subgroup and it was decided

The second concern was the name of the subgroup, and it was decided that it should be Scandiatransplant Paediatric Heart and Lung Group, acronym SPaedHLG.

1.5 Common clinical protocols: For lung transplantation, the ScandCLAD study group will continue to be the forum for discussions of alterations in clinical treatment guidelines, to ensure optimal alignment across our

centres. For heart transplantation, the study group of the Involved-study will have the same role.

1.6 Articles of the SHLG: The suggestions as circulated before the meeting by AMH were approved, except the final suggestion about the necessity of unanimous decisions which was left unchanged and will be discussed at future meetings. <u>The revised Articles are attached</u> and are sent to the Scandiatransplant office for publication on the website. The most important change was the introduction of an executive board, consisting of two Board members in addition to the chair. These two

consisting of two Board members in addition to the chair. These two individuals should not have the same professional specialty (being either surgeon, cardiologist, or pulmonologist) as the chair and all three members of the Executive Board (Exec.B.) should be from different centres. The exact time to serve was not decided and is not written in the Articles, but for now, the two additional persons will serve for one year in the Exec.B.

# **Registry and Organ exchange**

- 2.1 Ilse Duus Weinreich presented the transplant and organ exchange activity for heart and lungs in Scandiatransplant for 2020, including a special presentation of the effects of the COVID-19 pandemic. Notably, apart from a short dip in April, the pandemic does not seem to have affected transplant volume in our region. Publishing these observations was suggested (AMH).
- 2.3 The group appointed at our last Board meeting to work on improvement of the Scandiatransplant Registry (Yaswa) was reactivated (lead: Sandra Ingemansson, members: Kristjan Karasson, Göran Dellgren, Karl Lemström, Michael Perch, Are Holm). These minutes will serve as a notification to reactivate.
- 2.4 The rules for data delivery from the registry were briefly discussed. It was emphasized that each center owns data regarding their patients and must defer to local regulations. It was decided that the Exec.B. decides how to handle data requests. In uncomplicated cases, the Exec.B. may allow data delivery without further proceedings. In more complicated cases, all involved centers must be contacted for approval. As before, the Scandiatransplant office shall keep a list of all requests.
- 2.5 <u>AMH shall invite the members of the group</u> that will discuss the need for a revision of the organ exchange rules to a virtual meeting. A <u>doodle poll to</u> <u>determine time will be sent soon</u>, and the meeting will presumably take place in November.

## Studies and other business

- 3.1 ScanCLAD: Jesper Magnusson reported about satisfactory progression of the ScandCLAD study.
- 3.2 EPOS: Michael Perch reported about satisfactory progress og the EPOS study.
- 3.5. ECP: Michael Perch sends email to each center asking for interest in developing a study. If there is no study, at least a thorough data registration should be established.
- 3.3 Pulmonary hypertension-study: AMH briefly presented the outline of this study as described by Arne Andreassen, Oslo. The idea is to collect data on

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all PH patients regarding listing time, transplant time and death for all Scandiatransplant centers. The results will be reported in a paper with first and last authors from Arnes group in Oslo, additionally there will be participants from each center according to agreements made between the participating centers and Arne. <u>Arne will send an email to each center</u> asking about who should participate and be local representative.

- 3.4 Inflammatory Heart Study: Kristjan Karasson reminded of the study and <u>will contact local participants</u> for acquisition of data.
- 3.5 Election of members of the Executive Board: Johan Nilsson (Surgeon, Lund) and Hans Eiskjær (Cardiologist, Lund) were elected.

## **Next SHLG Board meeting**

4. The next meeting (spring 2021) will be virtual, and hopefully the meeting in the fall of 2021 may be in person. If so, AMH will explore the possibilities for a meeting over two days. Regarding the next meeting, <u>AMH will send a Doodle poll in February</u> to agree a suitable time for the virtual meeting.

21. October 2020 Are Holm