

## Minutes 40.th SHLG meeting

Clarion Hotel, Copenhagen Airport, April 25. 2019 10:00-14:30

### 1. Formalities

1.1. The minutes from the 39th SHLG meeting and the summoning for the present meeting were presented and approved.

1.2. *The following board members were present:*

Göteborg: Göran Dellgren(s), Gerdt Riise(p), Kristjan Karasson(c)

Lund: Sandra Lindstedt Ingemansson(s), Johan Nilsson(s), Hillevi Larsson(p), Göran Rådegran(c)

Helsinki: Karl Lemström(s), Maija Halme(p), Peter Raivio (s), Markku Pentikäinen(c)

Oslo: Tom Hoel(s), Are Holm(p)

Tartu: Tanel Laisaar(s)

København: Michael Perch(p)

Aarhus: Lars Illkjær(s)

*Other attendees:*

Ilse Duus Weinreich, Scandiatransplant, Ulla Nyström, coordinator GBG, Petra Vestlund tx coordinator GBG, Maria Engmann tx coordinator CPH, Jesper Magnusson(p) GBG

### 2. Report from Estonia

2.1. **Tanel Laisaar** gave a brief report about lung transplant activity in Estonia and current status about cooperation with Latvia.

### 3. Scandiatransplant Registry for Heart and Lung

3.1. **Kristjan Karasson** and **Ilse D. Weinreich** gave a report about the revision of the registry regarding data for heart tx. The revision is partly implemented: preTx-forms are implemented, Tx will be before summer, follow-up will be in the fall. Lung revision will start when heart is finished, drawing lessons from the process to ensure smooth and adequate revision.

3.2. **Karl Lemström** oriented about the Collaborative Transplantation Study (CTS) based in Cologne, Germany. Helsinki report data there.

3.3. **Weinreich** and **Holm** informed about the process in the ISHLT registry to adapt to the GDPR. Work is ongoing, but will have no immediate consequence for the SHLG and our registry. Currently data is not uploaded to ISHLT registry.

3.4. There was a general discussion about the quality of our registry. There was agreement that the registry is valuable to all, in addition to the fact that it is required by law to keep a registry that enables tracing of donors and (more recently) that registers certain adverse events. Everyone will continue efforts to use and improve the registry.

3.4.1. It was suggested that reminders to enter data could be sent to the centers, and the possibilities of introducing fees for failure to enter were also discussed. No decision was made.

3.4.2. Upon a suggestion by **Lemström**, it was decided that **Holm** should write a formal letter as chair of the group to all centers informing about the importance (and legal obligation) to maintain a good registry, and asking each center to dedicate necessary efforts to comply with this obligation.

3.4.3. Following a suggestion by Holm, **Sandra Lindstedt Ingemansson** took it upon herself to get a picture of how the data is currently entered into the registry at the different centers, and to chart possibilities of bringing the work forward. She will collaborate on this with **Holm** and **Weinreich**, and possibly others as the work proceeds.

3.5. **Weinreich** and **Holm** oriented about the status regarding data processing agreements between transplant centers and Scandiatransplant. Oslo is currently the only centre that does not have any agreement.

### 4. Organ exchange

- 4.1. **Weinreich** showed the activity and organ exchange status for 2018 and the previous years.
- 4.2. For heart, pediatric transplants are indistinguishable from other urgent transplants. Separated data will be presented henceforth.
- 4.3. A work group for revision of the organ exchange guidelines was appointed and the meeting in November in Oslo. Their work is not finished. It was decided that **Holm** should suggest and find a date and convenient location where the group could meet and finish their work of drafting a suggestion for a revision of the organ exchange guidelines. Most likely, it will be at Kastrup end August or primo September.
5. In a follow up of discussions at previous meetings, it was decided that SHLG should create a check list of data about donors that would enable the calculation of a donor score. This will be done in collaboration by **Holm** (lung data, akin to the Oto score), **Nilsson** (heart data), **Vestlund** (coordinator issues) and **Weinreich** (implementation in Scandiatransplant registry). The aim is to register the data for all donors in Scandiatransplant, and agreement with the coordinator group must be negotiated.
6. *Research*
  - 6.1. **Karasson** informed about the status of the “inflammatory heart” study.
  - 6.2. **Karasson** mentioned a suggestion for a study in collaboration with Astra Zeneca using the SGLT2-inhibitor, which appears to have certain beneficial metabolic effects. He will follow the topic further and come back to it at later meetings.
  - 6.3. **Dellgren** informed about the status of the ScanCLAD study. It is coming along nicely and the inclusion is on schedule. The great potential of maintaining a common Nordic protocol in continuous research projects was emphasized.
  - 6.4. **Perch** gave an update of the status of the EPOS study, which will soon be concluded.
  - 6.5. **Perch** presented an update on the progress of a study of the effects of Extracorporeal Photopheresis for CLAD. The importance of such a study was emphasized. Costs were discussed. Perch will continue to work with this.
  - 6.6. **Lemström** asked for information about the EVOLVED-study, but the engaged individuals were not present and it will instead be discussed at the next meeting.
  - 6.7. No update on the activity of the Schedule study was given.
7. *Miscellaneous*
  - 7.1. A brief report from the recent ISHLT meeting was given. A sentiment that the ISHLT is dominated by members from the US was expressed by several attendees. **Dellgren** encouraged all to get involved in the organization, as it is the worlds leading organization in the field. **Holm** showed data about membership distribution in the ISHLT and also encouraged engagement in the respective councils and other fora of the ISHT at the meetings. Policies of the organizations towards collaboration with China in matters involving solid organ transplantation were discussed, including review of papers.
  - 7.2. **Nilsson** informed about the activity of the ESOT targeted at thoracic transplantation and encouraged participation.
  - 7.3. **Perch** informed briefly about the LTx subgroup in the European Respiratory Society.
  - 7.4. The possibility of changing the start time of the SHLG meeting to better comply with those who travel from Finland and Estonia was discussed. It was agreed that current times should be maintained. Also, it was agreed that the standard three topics for the agenda of *registry, exchange and research* should be kept.
8. The date for the next meeting was set to November 7th 2019, at Kastrup Airport as usual.