

## Minutes 41.st SHLG meeting

Clarion Hotel, Copenhagen Airport, November 7. 2019 10:00-14:30

### 1 Formalities and governance

- 1.1 The minutes from the meeting in April 2019 were approved.
- 1.2 A list for update of board members and associates was circulated.
- 1.3 Election of board chair. No other candidates had announced their interest, so Are Holm was reelected for the final two years (until fall 2021) as chair of the SHLG board.
- 1.4 A suggestion to establish a Pediatric subgroup for the SHLG was discussed. Pediatrician Taisto Sarkola (Helsinki) presented the plans which were discussed at the Nordic meeting for pediatric cardiology. Representatives for pediatric cardiology from all Nordic centers that perform pediatric heart transplants were involved. The planned subgroup shall also include pediatric pulmonology. The plans were positively received, and it was decided that the pediatricians should continue their work of forming a subgroup to the SHLG. A suggestion for bylaws that must be aligned with the rules of SHLG and Scandiatransplant shall be drafted, under the initiative of Taisto Sarkola, and presented to the SHLG board in due time (at least two weeks) before the next meeting, and then be forwarded for final approval at the next meeting of the SHLG. It was emphasized that decisions about organ exchange and registry remain the responsibility of the SHLG board.
- 1.5 Common protocols in SHLG: through the ScanCLAD study and before that the SCHEDULE study, the protocols for heart tx and lung tx have, to a large extent, been aligned at all Nordic centers. It is desirable to encourage that future protocols are kept aligned. It was agreed that the principal investigators of ScanCLAD and of the cardiac EVOLVE study should discuss measures how to maintain this. Specific suggestions to ensure such maintenance may be presented at the board meetings of the SHLG.
- 1.6 The SHLG bylaws are somewhat outdated on certain topics. Are will (conservatively) propose suggestions for revision that will be communicated with a working group consisting of Kristjan Karasson, Hillevi Larsson, Peter Raivio, Tanel Laisaar, and Hans Eikjær. A proposal will be forwarded will be sent to the members of the board at least two weeks before the next meeting and will be subject to vote at that meeting.

### 2 Organ Exchange

- 2.1 Ilse Duus Weinreich presented the figures for organ exchange for the last years and for 2019. No significant changes compared to the previous situation were noted.  
Heart: Sweden is a net “exporter” of hearts (+6) while Norway and Denmark “import” (-4 and -3). The number of urgent calls for heart has remained stable.  
Lung: As before, Finland is a net “exporter” (+5), while “imports” are evenly distributed, with Norway no longer the main “importer”. For lung, there was still a high number of death on wait list or permanently withdrawn (24 so far this year).
- 2.2 Presentation and discussion of the suggestions for revision of organ exchange guidelines: The suggested changes for the organ exchange guidelines that had been sent to the board members prior to the meeting were not unanimously accepted, and thus rejected. There was a thorough discussion of the subject.  
There was agreement that we need a system that grants *flexibility, transparency and accountability*.  
Urgent lung: Some advocated a criteria based urgent allocation with no limited number (similar to the UK system). It was held that all patients on mechanical ventilation or ECMO should have access to urgent allocation (prio 0), with no number limitation, while there should be no status corresponding to the current prio 1 (where urgency may be decided at the discretion of each center), as it was felt that a non-criteria based center discretion system was not transparent. Others suggested a system without limited numbers but with a mandatory organ pay-back, similar to the Scandiatx-system for liver allocation. Precisely when and how this pay-

back should take place was not discussed. It was countered that this could mean a great increase in cross-border organ exchange, which might be unfortunate since our current system for cross-match of imported organs is not ideal. Another question was how pay-back should be handled between the Swedish centers.

Urgent heart: There were no concerns about the current criteria. No opinion against introducing a limit to the maximum number of prio hearts was voiced, but the decision to introduce such a ceiling was nevertheless postponed.

Increased flexibility for counting the limited numbers: no clear opinion was voiced against increasing the term from one calendar year to three calendar years, but this decision was also postponed.

It was decided that Are should arrange a meeting of the "Allocation-group" that was appointed a year ago. The meeting should be over two days and should take place in January or February 2020. The aim is to formulate a suggestion for revision of the organ exchange guidelines that may be forwarded to vote at the next SHLG meeting.

### 3 Scandiatransplant Registry

3.1 Ilse gave an overview of the current status of the registry. The entry levels are variable, with particularly low completion of entries for follow up data.

Kristjan Karasson reported on the revision of the forms for registration of heart data.

3.2 There is now a data processing agreement with Oslo, meaning that all member hospitals now have such an agreement with Scandiatransplant. This means that work may now start to develop automatic data exchange systems with local registries. Also, a better user interface for mobile phones will be developed for Yaswa. This may make the wait lists more accessible and safe.

3.3 Sandra Lindstedt Ingemansson presented the results of her work to chart what registries are currently used for heart and lung tx at Scandiatransplant centers. She showed that most centers have more than two systems, and there is presumably a lot of overlap. The overlapping data entry contrasts with the previous presentation by Ilse showing that data entry is highly incomplete.

It was decided that Sandra should lead a working group that continues to work to survey the various registry related activities at all centers, and strive to find solutions in or continuous efforts to improve registries. The following expressed interest to join this group: Kristjan Karasson, Göran Dellgren, Karl Lemström, Michael Perch, Are Holm. These and all other interested will contact Sandra and she will take lead in the process. Results and progress will be presented at the next meeting.

3.4 Demonstration of database software Prjcts: Transplant surgeon Einar Martin Aandahl (Oslo) is part of a group that have developed a new software called Prjcts®. It integrates functionality for database, statistic analysis, and graphic illustration. It was given room for presentation at the SHLG meeting because of the vast plethora of programs currently used for registries at our center, and because software such as this may represent a solution for some. Einar Martin may be contacted at [einarmartin@leididi.no](mailto:einarmartin@leididi.no). (Note: the software is a commercially available product from the company Ledidi (ledidi.com) in which Einar Martin has commercial interests.)

3.5 Are very briefly informed that donor data necessary to create a donor check list has now been promoted to "validation status" in Yaswa, meaning that it probably will be more completely entered hereafter. Results will be presented at later meetings.

### 5 Miscellaneous

5.1 News from ISHLT: without giving any details, Are mentioned that a major reorganization of the ISHLT is under way, but that it might not have immediate consequences that would be noticed by the common members.

5.2 ESOT: Michael Perch gave a brief report from the recent ESOT congress in Copenhagen

ESHLT: The Wengen meeting was mentioned.

6 Next meeting: The next meeting will be on TUESDAY 31.st of March 2020, presumably same venue and time as usual: Clarion Hotel Kastrup, 10:00 to 15:00, unless otherwise announced.

### 7 Research

## Scandiatransplant Heart and Lung Group

Emil Bluhme ([emil.bluhme@sll.se](mailto:emil.bluhme@sll.se)) from Karolinska presented a study on neonatal organ transplantation and was interested in collaborating partners.

After this, there was a separate meeting for cardiologists arranged by Lars Gullestad to discuss the EVOLVE trial.

ScanCLAD (lung): Göran Dellgren gave an update of the status of ScanCLAD study. Inclusion is completed.

EPOS (lung): Michael Perch gave an update of the EPOS study. An abstract is planned for the ISHLT 2020.

ECP study: Michael Perch discussed the previously suggested ECP (photopheresis for CLAD) study. There is current inclusion for a very well-funded US trial of ECP for CLAD. This raises concerns about whether we should initiate a similar trial.

Moreover, Andrew Fisher of Newcastle has plans for a UK ECP trial, primarily with functional (immunological etc.) endpoints. Michael will keep following this and will come back with more later.

Oslo, November 10. 2019

Are Holm