

Minutes 38.th SHLG meeting

Clarion Hotel, Copenhagen Airport, April 19. 2018 09:30-14:30

1. Formalities

- 1.1. The minutes from the 37.th SHLG meeting were presented and approved.
- 1.2. The following board members were present: Göran Dellgren(s) GBG, Jesper Magnusson(p) GBG, Kristjan Karasson(c) GBG, Richard Ingemansson(s) ML, Johan Nilsson(s) ML, Hillevi Larsson(p) ML, Göran Rådegran(c) ML, Karl Lemström(s) HEL, Maija Halme(p) HEL, Arnt Fiane(s) OSL, Are Holm(p) OSL, Tanel Laisaar(s) TRT, Christian Møller(s) CPH.
Other attendees: Ilse Duus Weinreich, Scandiatransplant, Bo-Göran Ericzon, Scandiatransplant, Ulla Nyström, txcoordinator GBG, Petra Westlund txcoordinator GBG, Maria Engmann txcoordinator CPH.
- 1.3. **Tanel Laisaar** gave status from new Scandiatx-member Tartu: Four lung transplants have been performed since the last meeting of which one was an urgent call (donor from own center). Also, there have been discussions about two Latvian patients.
- 1.4. Chair of the Board of Scandiatransplant **Bo-Göran Ericzon** commented on the activities in Tartu: The guidelines of Scandiatransplant regarding deceased organ transplant for non-Scandiatransplant nationals must be respected (http://www.scandiatransplant.org/organ-allocation/GuidelinesforDeceasedorgantransplantationNonScandiatransplant_March2017.pdf). Donor neutrality in each case must be observed. At present, the Scandiatransplant board has no ongoing process aiming at inclusion of additional member centers outside the current region.
Holm expressed understanding for the pressure Tartu experiences regarding sick individuals from neighbouring non-member areas (ie. Latvia), but reminded of the position of the SHLG, referred in the minutes from the last (37.th) meeting.

2. Scandiatransplant Registry for Heart and Lung

- 2.1. No inventory of the current state of the registry was presented.
- 2.2. **Karasson/Weinreich**: An update of the work for a revision of the heart transplant was given. The suggested revisions require certain technical alterations that seem to take time to implement. Once this is done, a revision of the lung section may follow. Tartu will supply data on Estonian transplants.
- 2.3. A list of individuals who currently have access to the registry was shown (n=64). **Weinreich** informed that if the access is not used for 180 days, it will be lost. All board members were requested to keep track locally of who has access.
- 2.4. A list of data deliveries from the thorax registry since the last meeting was shown. It was agreed that current practice regarding delivery of identifiable data should be revised (Holm/Weinreich), and names and birth dates should probably not be delivered. Instead, individuals should be marked with their ScandiaID.
Currently, all member centres except Oslo and Stockholm have data processor agreements with Scandiatransplant. It was reiterated that it is the responsibility of each centre to comply with local data protection rules.
The Scandiatransplant Registry is in accordance with the new EU data protection regulation.

3. Organ exchange

- 3.1. **Weinreich** showed the activity and organ exchange status for 2017.
- 3.2. The trends for urgent priority are mainly as they have been before, and notably there is no sign of a dramatic increase in number of urgent priority for hearts.
- 3.3. **Holm** suggested that the next meeting of the SHLG should be held as a two day seminar focusing on allocation in order to allow time for a general revision of the allocation policies of thoracic organs. The suggestion was approved.

- 3.4. **Weinreich** showed data for utilization of thoracic organs. The utilization rate (numbers of heart or lungs used from converted donors) is low by international standards (25-30%) and varies between the Scandiatransplant centres.
- 3.5. **Holm** suggested that the SHLG board develop a donor check list akin to the Oto score for lungs (*Oto T, Levvey BJ, Whitford H, et al. Feasibility and utility of a lung donor score: correlation with early posttransplant outcomes. Ann Thorac Surg 2007; 83:257 – 263.*) and a similar score for heart donors, and that the coordinators are asked to diligently and without exceptions perform the registration in each converted donor whether thoracic organs are used or not. The data should be incorporated in the thoracic registry. It is assumed that the data points mainly are already in the registry, but that the actual registration may be improved. The suggestion was approved. **Nilsson** will assist in developing the list of required data for hearts. It is assumed that a diligent registration of such data will improve not only donor utilization but also be useful in organ exchange.
- 3.6. *Paediatric thoracic transplant*
 - 3.6.1. **Dellgren** told the meeting about his impressions from a recent visit to Kyoto to learn about living donor lung transplant. If this method should become an option in Scandiatransplant, the method is most likely to be used for paediatric recipients due to the scarcity of small size donors.
 - 3.6.2. **Fiane** gave an overview of heart and lung transplants to paediatric recipients in Scandiatransplant. For practical reasons, paediatric in this context was understood to mean <14-15 years of age. The volume of lung transplants in this age group has been low. The possibilities of a centralized function in Scandiatransplant for paediatric lung transplantation was discussed. This would probably require a Scandiatransplant priority for paediatric lung recipients. Therefore, Scandiatransplant allocation priority for paediatric recipients will also need to be discussed at the next meeting, where allocation will be specifically addressed. Whether paediatricians should be invited to the SHLG meetings was not discussed (but as before, each centre may invite whomever is felt to be relevant and notify the chair before the meeting).
4. *Research*
 - 4.1. **Dellgren** informed about the status of the ScanCLAD study. Currently, more than 200 patients are enrolled and 121 patients are randomized. It was suggested that when this study is completed, the process of inclusion and registration should continue for some other study, to keep the momentum. If so, the preparations for the next study should start soon.
 - 4.2. No status from the EPOS study was given.
 - 4.3. **Holm** showed the submitted manuscripts for the urgent allocation study and the donor age study, also including an abstract shown at this years ISHLT about size match in lung tx.
 - 4.4. No update on the activity of the Schedule study was given.
 - 4.5. **Karasson** informed about the status of the “inflammatory heart” study. Application to the ethical board has been submitted and a CRF been drafted.
 - 4.6. **Karasson** mentioned a suggestion for a study of the cholesterol lowering agent BSK9-inhibitor in heart transplant recipients. This study would be sponsored by Amgen. No one was present to inform about the study.
 - 4.7. **Nilsson** informed about the simulation study for heart allocation, showing that in a data set provided by the UNOS, allocation by criteria gives no advantage in survival benefit compared to allocation by wait time; however, allocation by “machine learning” yielded improved survival benefit.
 - 4.8. Other topics of interest for future studies were mentioned: age of heart donor, ex-vivo perfusion in heart tx, cardioplegia strategies.
 - 4.9. **Holm** showed a synopsis for a study of extra corporal photopheresis (ECP) for CLAD drafted by **Michael Perch** (CPH). It was decided that **Perch** and **Holm** continue working on such a study, and that the recommendation not to start using ECP at the Nordic centers until it can be done in a controlled study was

maintained. It must be cleared whether the study as drafted by Perch can be initiated while ScandCLAD is still active.

- 4.10. **Holm** presented a study suggested by Peter Jaksch of Vienna on ECP after antibody mediated rejection. It was decided that the study suggested by Perch should be given priority.
- 4.11. **Holm** presented a request from Erik Verschuuren of Groningen and Jens Gottlieb of Hannover of a study of oral ribavirin for upper or lower air way infections after lung tx. There was interest, but **Holm** will ask for written information about the study.
5. *Miscellaneous*
 - 5.1. A brief report from the recent ISHLT meeting was given. **Dellgren** was congratulated on his new position in the board of the ISHLT, and **Holm** on the position as chair in the International Exchange Committee of the ISHLT. The Nordic colleagues were recommended to engage in the respective councils of the ISHLT at the meetings.
 - 5.2. **Nilsson** informed about the new initiative of the ESOT to enhance its activity related to thoracic transplant. An ESOT meeting on thoracic transplant will be held in Munich in November.
 - 5.3. **Holm** reminded of the STS meeting which is to be held in Oslo on may 2.-4. 2018.
 - 5.4. Other business: **Ulla Nyström** will send an email to the board members about pregnancy in thoracic transplant.
6. The date for the next meeting (two day seminar in Oslo, see above #3.3) was set to November 8.-9. 2018. HOWEVER: after the meeting it became clear that this conflicted with the thoracic ESOT meeting (see above #5.2).
After email communications with board members, the date for this meeting has been set to Monday 5. November and Tuesday 6. November 2018. Details will follow.

Oslo, May 15. 2018

Are Martin Holm