

Minutes 37.th NTTSG meeting

Clarion Hotel, Copenhagen Airport, October 12. 2017 10:00-14:30

1. FORMALITIES

- 1.1. MINUTES. The minutes from the 36.th meeting April 2017 were approved without comments.
- 1.2. ATTENDEES. A list for attendees to attest presence was circulated. It was reiterated that one representative of the transplant coordinators should be present as official representative of the coordinator group and appointed by this group. Additionally, coordinators may attend as observers upon invitation from their local board members.
- 1.3. ESTONIAN MEMBERSHIP. New associate members of Scandiatransplant were welcomed. Representing Tartu University Hospital were Arno Ruusalepp (cardiac surgeon) and Tanel Laisaar (general thoracic surgeon).
 - 1.3.1. Kaj Anker Jørgensen outlined the conditions for Estonian membership on Scandiatransplant as decided by the Scandiatransplant board.
 - 1.3.2. Tanel Laisaar presented Tartu University Hospital and the organ transplant activity there. Estonia has 1.3 million inhabitants, first kidney transplant was performed in 1967, first lung transplant in 2010 in collaboration with the centre in Vienna. So far, 22 Estonians have received a lung transplant. Heart transplants of Estonian patients are performed in Helsinki. The country has currently about 18 donors/mill inhab., lung usage about 20%. Currently, about 3 LuTx/year are performed, the five-year survival is 66% and five patients are currently on the wait list for lung transplant, including one Latvian citizen. There is no lung transplant program in Latvia, and more Latvian patients may be referred to Tartu in the future. UNANIMOUS DECISION: It was reiterated that the current Scandiatransplant rules regarding restricted organ offer to non member-state residents should prevail. However, it was unanimously decided that the Latvian patient who is already on the Estonian wait list should be treated as an Estonian patient, with all rights pertaining to the allocation of Scandiatransplant organs. It was acknowledged that this is an exception to the Scandiatransplant rule, but it was considered unethical to let this individual suffer because Tartu has joined the Scandiatransplant collaboration. Moreover, it would be a breach of the implicit contract between the individual and Tartu Hospital if the individual were excluded, and it might be held that when accepting Tartu into Scandiatransplant, this contract is one of the obligations included in the entry. Finally, the individual was accepted of compassionate reasons. However, it was strongly emphasized that this case is an exception, and that it may not serve as an example to any future individuals referred from Latvia or elsewhere outside the Scandiatransplant region. Any approaches regarding citizens of non-Scandiatransplant states must be handled by the Scandiatransplant board. Since the number of such referrals may be expected to increase, in particular from Latvia, the meeting urges the Scandiatransplant board to be prepared and pre-emptively clarify the proper procedures for such cases with Tartu.
 - 1.3.3. Since Tartu performs lung transplants but not heart transplants it was decided that Tartu should have two lung transplant program (?) representatives in the board of the NTTSG.

2. SCANDIATRANSPLANT REGISTRY

- 2.1. CURRENT STATUS. A brief and approximate overview of the status (completeness of entries) of the Scandiatransplant Registry (Yaswa) was given. Current efforts to improve the data entry were discussed. Kristjan Karasson, Ulla Nyström and others are working on this. It was decided that Are Holm should find out whom to contact at each centre to at least make sure that at least the entry of death was kept updated.

- There are on-going efforts to find solutions for automatic datafeed between local registries and Yaswa.
- 2.2. Scandiatransplant and the chair will keep an overview over data requests (for data of patients outside the own region), and at a minimum, the responsible individual, a project title, its purpose, and a confirmation that data protection regulations are OK will be demanded.
3. ORGAN EXCHANGE
 - 3.1. PRIO ACTIVITY. An approximate overview over activity in 2016 and 1.q. 2017 was shown. Main points are that number of prio 0 hearts is still reassuringly low, and wait list death for lungs is worryingly high. Concern was expressed whether our current system for allocating lungs for urgency is optimal. There seemed to be agreement that a revision of the urgency system is to big an issue for the regular NTTSG meeting, and that therefore a dedicated seminar would be desirable. Are will see what can be done.
 - 3.2. PRIO AND ROTA. According to current guidelines, when two centres compete for an urgent call, prio 0 should come before prio 1. If there is competition within the same prio status, the centres position on the ROTA-list decides. It was brought to vote whether time for the urgent call should decide instead (i.e., first called gets first). Six voted to keep current system, four voted to change it. The narrow margin indicates that the question should be re-discussed at a later time.
 - 3.3. URGENCY AND BLOOD GROUP. It was discussed whether organ claims due to prio 0/1 should just be blood group compatible (as presently is the case) or blood group identical. At present, blood group identity is not mandatory for prio. The current system puts recipients with group 0 at a disadvantage, and in kidney allocation, blood group identity is required. No change was decided, but we will return to the question.
 - 3.4. HLA-MATCHING. The possibility to assess HLA-antibodies per Luminex® may led to uncertainties. In some cases this may lead to delayed organ acceptance. The coordinators present are requested to bring this topic to their group and report back if this is an issue that may call for discussions within the NTTSG. Also, they are asked to discuss whether our current practice of sending serum for cross-match to other centres is adequate.
 - 3.5. TARTU AND ROTA. Despite the fact that Tartu caters for a population of only about ¼ of the population of the other centres, it was unanimously agreed that Tartu should get one full slot on the ROTA list, like the other centres. However, the arrangement will be reconsidered in one year (October 2018) and an alternative adjustment may be considered. One such possibility might be that all other centres get two slots on the ROTA-list while Tartu remains having one.
 - 3.6. TARTU AND PRIO. For urgent allocation of lungs, it was agreed that Tartu should have the right to claim one (1) prio 0 or prio 1 recipient per year, which corresponds to 1/3 of the number of the other centres. A suggestion that the quota might be 3 per 3 years was rejected.
 4. RESEARCH
 - 4.1. ScanCLAD. The status of the ScanCLAD-study was presented by Jesper Magnusson from Gothenburg. The representatives from Tartu asked whether it would be possible to participate, and they were asked to contact the principal investigator Göran Dellgren (Gothenburg). According to post-meeting discussions Tartu will not participate in ScanCLAD study as it would be too time consuming to get all approvals etc. for Tartu to participate.
 - 4.2. URGENT LUNG. Are Holm presented preliminary data from the Urgent Lung study.
 - 4.3. SURGERY FOR HEART FAILURE. Karl Lemström presented a proposal for a registry study of surgical treatment of heart failure (assist devices and transplant). The data from Finland are collected, and it was agreed that Karl should send a brief

- study description and a list of required data to the relevant contact persons at all centres.
- 4.4. COAUTHORSHIP. Rules for coauthorship: it was agreed that collecting data not necessarily merits coauthorship in a study, but that it is reasonable that all centres are represented in studies including data from all centres and that Scandiatransplant should be acknowledged in publications where data from the registry has been used.
 5. THE NAME NTTSG. Are Holm proposed that the name Nordic Thoracic Transplantation Group should be changed to Scandiatransplant Heart and Lung Group or Scandiatransplant Thoracic Group. The reason for a change was that NTTSG is a complicated name and that the group now actually is a subgroup in the Scandiatransplant system. It was unanimously agreed that the name of the group hereafter should be Scandiatransplant Heart and Lung Group.
 6. NEXT MEETING. It was agreed that the next meeting of the Scandiatransplant Heart and Lung Group (formerly NTTSG) should be held on **April 19, 2018**. The venue will be Kastrup Hotel if not otherwise arranged in due time.
 7. STS MEETING: The group was reminded that the next meeting of the Scandinavian Transplantation Society is to be held in Oslo on May 2-4, 2018.

Oslo, 20. October 2017

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