

MINUTES

Nordic Kidney Group, 14th annual meeting

November 15, 2017

Clarion Hotel Copenhagen Airport

1. Welcome by meeting chairman – Søren Schwartz Sørensen

2. Registration of participants and election of writer of minutes – Søren Schwartz

Sørensen:

List of participants:

Name	Yes	No
Søren Schwartz Sørensen – Copenhagen	X	
Alireza Biglarnia – Skåne	X	
Marko Lempinen – Helsinki	X	
Lars Wennberg – Stockholm	X	
Lars Mjörnstedt – Gothenburg	X	
Claus Bistrup – Odense	X	
Amir Sedigh – Uppsala		x
Tomas Lorant - Uppsala	x	
Anna V. Reisæter – Oslo	X	
Karin Skov – Aarhus	X	
Margrét Birna Andrésdóttir - Reykjavik	X	
Jaanus Kahu – Tartu	X	
Anders Åsberg – Kidney registry, Norway	X	
Nina Ask – Kidney registry, Finland		x
Runólfur Pálsson – Kidney registry, Iceland	x	

James Heaf – Kidney registry, Iceland	x	
KG Prütz – Kidney registry, Sweden	x	
STEP – Per Lindner	x	
NTCG - Ingebjørg Kvangarsnes	X	
STTG – Helle Brunsgaard	X	
Bo Hedemark Pedersen - Scandiatransplant	X	
Kaj Anker Jørgensen - Scandiatransplant	X	
Ilse Duus Weinreich – Scandiatransplant	X	

Kaj Anker Jørgensen was elected writer of minutes.

Approval of last meetings minutes (see SCTP homepage) - Søren Schwartz Sørensen: Minutes approved.

4. Further matters to the agenda - Søren Schwartz Sørensen:

Søren Schwartz Sørensen will tell something about the pediatric group.

5. Status from each center and registry (developments, phase-out, structural changes

e.g.):

Stockholm: New organisation. Donation rate is good in Stockholm it has actually doubled the last two years.

Uppsala: Also new organisation. Donor rates are good.

Gothenburg: No changes.

In Sweden they are discussing a DCD project which they expect to start in February. They will give the NKG a report on this.

Malmø: There is a generation shift among the doctors. The donation rate is high.

Oslo: The falling living donor kidney transplantations the last two years has now been turned around and the number is increasing. They have done 16 DCD donors in their project.

Helsinki: The number of donors has fallen and they are looking at this. They are trying to do more living donors.

Aarhus: Same as last years, they are educating young surgeons.

Odense: Business as usual. The last two years they have increased their donation rate for deceased donors but the living donor rate is decreasing.

Copenhagen: Time consuming process of implementing their new IT-system in the hospitals. Their pancreas programme is now really taking off. There will be inspections from the competent authorities very soon.

Tartu: They usually do about 50 kidney transplantations per year but this has been a little less. About 10 % are living donors. They are increasing the pancreas transplant program.

Reykjavik: Business as usual. A very high donor rate. Their transplant surgeon will be moving back to Iceland, but is has not been decided yet how much he is going to work.

KG Prütz asked if there were separate registries for pediatric patients in the other uremic registries. All countries use the same register for pediatric patients as for adults. The pediatric registry in Scandiatransplant has been redesigned and incorporated into YASWA.

6. Announcement of NKG national key persons 2017-2018:

National key persons will be: Marko Lempinen (FI), Anna V. Reisæter (NO), KG Prütz (SE), Claus Bistrup (DK), Margret Andresdottir (IS), Ilse Weinreich (Scandiatransplant) and Estonia will within one week announce who will be the key person for Estonia.

7. Kidney exchange compliance (attached) – Ilse Weinreich:

Ilse Weinreich presented the kidney exchange compliance which had been sent out before. It was accepted.

8. Kidney payback overview – Ingebjørg Kvangarsnes:

Transplant coordinator Ingebjørg Kvangarsnes presented 2016 figures for kidney exchange obligations and whether payback was done within 6 months. Around 1/2 is not paid back within the 6-month limited. A facility for following payback refusals and payback time is being incorporated into YASWA and will be running soon.

9. Nordic Kidney Registries, Annual data report – Søren Schwartz Sørensen:

Søren Schwartz Sørensen went quickly through the annually analysis made by Torbjørn Leivestad and Søren S. Sørensen. <u>(see SCTP homepage)</u> It was again discussed if they could show centers specific data, but it was not decided at this time

10. Suggestions and recommendations from the tissue typers (attached) – Helle Bruunsgaard:

Helle Bruunsgaard reported from the Tissue Typers' meeting. Suggestions had been sent out before.

The first suggestion was to accept candidates in the STAMP programme without waiting for one year. Suggestion was adopted and will be put in action from December 1st, 2017.

Suggestion No. 2 was to include HLA-DPB matching in the STAMP program. This was accepted and can be implemented when the YASWA program has been changed for it, and when all laboratories do HLA-DPB typing on deceased donors.

There was also a subject for discussion whether it should be obligatory to exchange two kidneys if they could be used in the STAMP program. The NKG could only accept this suggestion as a voluntary rule. It is recommended that both kidneys are sent to STAMP patients if they comply with two STAMP patients.

11. Evaluation of the kidney exchange rules (see SCTP homepage) – All:

Firstly, STAMP/LAMP guidelines should be corrected according to the suggestions adopted in point ten.

NKG would like the Scandiatransplant Tissue Typers Group to work through the current exchange obligations and come up with a new and up-to-date suggestion for Kidney exchange obligations within Scandiatransplant. The suggestion must be ready and discussed at the next NKG meeting.

12. Paired Kidney Donation Program (STEP), status - Per Lindnér:

Per Lindnér showed an overview of how the system should work and how far they are in Sweden. Ilse Weinreich showed the progression at the Scandiatransplant office in making this possible within Scandiatransplant, the project will be finalized in 2018. The committee formed as a STEP steering group should work on the practical matters.

13. Reporting of SAE and SAE in renal tranplantation, role of SCTP – Lars Wennberg: Lars Wennberg demonstrated the soon coming facility in YASWA to report SAE/SAR. It was emphasized that this is not a report made by Scandiatransplant, but it is a tool for the hospitals to report SAE to the competent authorities. The competent authorities have accepted receiving the reports in this way. It is expected that it can be running by the start of 2018.

14. Should we report/be able to identify HLAi Tx in our registry? – Søren Schwartz Sørensen:

Søren Schwartz Sørensen asked if it was possible to identify HLA antibody incompatible transplantations in the registry. Currently this information cannot be extracted as all

centers do not enter HLA antibody specificities. This calculation will be possible when direct data import from the Luminex to YASWA is up and running.

15. Suggestions for further analysis of NKG registry data – *Claus Bistrup:*

Claus Bistrup wondered what all the data we put in are used for. There was some discussion on this matter and people should look into wishes for the annually statistical report. In principle YASWA contains fields for the data necessary to make a kidney donor risk index, but it is dependent on people putting these values into the system. Cold ischemia time is reported directly into the Scandiatransplant system by some centers (time of tx (reperfusion) – time of cold preservation start = CIT), but others have it in their own local systems, and they would like to import it. Work is going on in relation to this matter.

16. Living Donor Follow up-register – Still of value? – Claus Bistrup:

Use of the data in the Living Donor Follow Up registry depends on what people have put in. Ilse Weinreich showed center based grafts, which illustrated the usage of the registry . It was mentioned that the living donor registry should be compared with the civil registration registries of the countries to ensure that living donors who have died are registered as dead in the database. According to EU directive there has to be a follow up system for living donors.

17. Work-up on living donors across transplant centres – KG Prütz:

KG Prütz wanted a discussion if work on living donors could be done in other centers. This was a complicated matter and it showed that the center which performs the transplantation has to have the last word. There was no consensus on what could be done in remote centers.

18. News from SCTP board – Kaj Anker Jørgensen:

Kaj went through some matters that the board had worked on in the last year. First Tartu had become an associate member. The deceased donor death causes had been revised and are now in production. SAE/SAR reporting has been discussed earlier. Kaj told about participation in the EU commission meetings and especially the EDITH project. The board and the Nordic CAs are reluctant to participate in the project, but will keep monitoring how these projects in the EU move forward. There are now data processor agreements with eight of the eleven hospitals in Scandiatransplant. We are still lacking Stockholm, Skåne and Oslo. The board has asked all the main organ groups what thoughts they have about DCD donors. Only the NKG has replied. The board has discussed the STEP program and given it highest priority in the programming. The board is also in the phase of discussing registration of patients transplanted outside of Scandiatransplant. This will not be discussed at the next board meeting, but at a board meeting in March.

19. Any other business:

Søren Schwartz Sørensen asked the NKG to accept that the pediatric group receives economical support for meetings from Scandiatransplant. This is in line with the declining possibilities for external sponsorship.

Malmø asked who was using basiliximab for normal transplant patients. This was discussed. It seems that most centers use it, but are not sure that it is of supplementary benefit. This is because the implementation of basiliximab was about the same time as many other changes in the immunosuppressive protocols.

20. Next meeting:

Next meeting will be held on Wednesday 14th of November 2018 at Clarion Hotel, Kastrup, Copenhagen, Denmark.