

## MINUTES

### Nordic Kidney Group, 15th annual meeting

November 14, 2018

Clarion Hotel – opposite Copenhagen Airport

**1. Welcome by meeting chairman:**

Søren Schwartz Sørensen bid everybody welcome.

**2. Registration of participants and election of writer of minutes:**

List of participants:

Name	Yes	No
Søren Schwartz Sørensen – Copenhagen	x	
Alireza Biglarnia – Skåne sub by Ehab Rafael	x	
Marko Lempinen – Helsinki	x	
Lars Wennberg – Stockholm		x
Lars Mjörnstedt – Gothenburg	x	
Claus Bistrup – Odense	x	
Amir Sedigh – Uppsala sub by Bengt von Zur-Mühlen	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, Denmark	x	
KG Prütz – Kidney registry, Sweden	x	
Maria Stendahl, Swedish Renal Registry	x	
Mai Rosenberg - Estonian Kidney Registry	x	
STEP – Per Lindner	x	
STEP – Tommy Andersson	x	
NTCG – Øystein Jynge		x
STTG – Helle Brunsgaard	x	
Bo Hedemark Pedersen - Scandiatransplant	x	
Kaj Anker Jørgensen - Scandiatransplant	x	
Ilse Duus Weinreich – Scandiatransplant	x	
William Bennet – Liver group	x	

Kaj Anker Jørgensen was elected writer of the minutes.

**3. Approval of last meetings minutes (see [SCTP homepage](#)):**

Minutes approved.

**4. Further matters to the agenda:**

No further matters.

**5. Status from each center and registry (developments, phase-out, structural changes e.g.):**

Reykjavik:

Presumed consent has been approved by the Parliament. There is a high donation rate and there is good activity. The transplant surgeon, Jóhann Jónsson, from the USA, who has done the living donor transplants in Iceland, has now moved back to Iceland, and they are in the process of reorganizing.

Oslo:

Living donation OK. Normal activity. There has been a decrease in deceased donors.

Uppsala:

Activity is on average. There have been big changes in "manpower", and they rely on their colleagues from Oslo.

Stockholm:

Lower living donation rates. Otherwise activities as usual.

Gothenburg:

2018 seems to be a normal, maybe good year, better than 2017. The big problem in all Sweden is shortage of nurses. They have had to shorten the days in hospital after renal transplantation

Malmö:

2017 was an all times high and 2018 seems to be good.

Helsinki:

2017 was OK. They are now stepping up on living donor transplantations. The donor rate is a little lower in 2017.

Tartu:

Good for deceased donors. The cooperation with Scandiatransplant has been good for highly sensitized patients.

Aarhus:

The living donor program will be low this year. This is due to moving to new buildings and capacity problems in the operation theatres, where many non-cancer operations are postponed. Deceased donor rate is OK.

Odense:

Usual activity.

Copenhagen:

2017 was OK. 2018 the living donation rate is also decreased and shortage of surgical nurses have also been encountered. Deceased donors as usual.

**6. Announcement of NKG national key persons 2018-2019:**

National Key persons 2018-2019: Marko Lempinen (FI), Anna V. Reisæter (NO), KG Prütz (SE), Claus Bistrup (DK), Margret Andresdottir (IS), Jaanus Karhu (ES) Ilse Weinreich (Scandiatransplant). These are the same as last year.

**7. Kidney exchange compliance:**

The results of monitoring this had been sent out prior to the meeting by Ilse Weinreich. Deviations were discussed and accepted.

**8. Kidney payback overview:**

A new payback utility has been integrated in YASWA, and it seems that everybody, especially the coordinators, are very happy with this. The number of kidneys not paid back have increased from 49 (December 1, 2017) to 65 (November 1, 2018).

There is already today the freedom to negotiate a kidney payback with another kidney that may not be exactly age or ABO matched.

27 of 65 of the open cases had been waiting for payback more than 6 months. It was discussed to remove the six months for kidney payback and instead write that the next available kidney should go to payback.

The conclusion was that a small group should come forward with some definitions of donor/kidney quality groups and update the rules for payback. This group consisted of Lars Mjørnstedt from Göteborg, Claus Bistrup from Odense and Morten Skauby from Oslo.

**9. Nordic Kidney Registries, Annual data report:**

Søren Schwartz Sørensen showed a presentation, it will be placed on the Scandiatransplant [homepage](#). There was a discussion of making cox regression analyses, analyses by blood groups, center-based analyses and so forth. Ideas for analyses that could result in publications were requested.

**10. Suggestions for further analysis of NKG registry data:**

Discussed under point 9.

**11. Possible further parameters for the FU registry:**

○ **HLAi**

NKG recommends that all the tissue typing labs. initiates direct data transfer from Luminex/Fusion software to YASWA up and running, as this will make future identification of HLA incompatible transplantations possible.

○ **Parameters for Kidney donor risk index**

*Centres* are recommended to register diabetes, hypertension etc. on deceased donors in YASWA. This will make calculation of Donor Risk Index possible.

There was a discussion on cold ischemia time. It seems that most centres have these data either on a national level or centre wise. In Sweden it would be center-based. It was suggested that cold ischemia time was put into the script when data are imported from the uremic registries next year.

○ **Charlson comorbidity score**

The representatives from the uremic registries were asked to investigate it is possible to identify the data needed for comorbidity score and whether it is feasible to include Charlson score or another comorbidity score at time of transplantation to the yearly data import.

**12. STAMP and DPB1 matching, present status:**

Ilse reported that there had been problems with the algorithm that was initially suggested by the tissue typers and programmed into YASWA. A new agreement has now been reached in the tissue typer group, and YASWA reprogrammed accordingly. The immunologists now have to update current LAMP/STAMP patients with DPB1 acceptable mismatches. DPB1 matching is expected to be able to run by January 2019, so from this time point patients with HLA-DP antibodies can be enrolled in the program.

**13. Suggestions and recommendations from the tissue typers:**

Helle Bruunsgaard had sent these out in advance.

The first suggestion was to change the priority one and priority two in the exchange obligation list, meaning that STAMP patients become priority one. NKG approved of this suggestion.

The next suggestion was not to restrict type O-donors to type O-recipients and type B-donors to type B-recipients for STAMP patients. Minor ABO incompatibility matching on STAMP was accepted by NKG. Hopefully this will increase the organ offers for STAMP patients with blood group A and B without affecting the offers for blood group O patients in the STAMP program.

Both changes will be introduced when the Scandiatransplant office has done the necessary programming.

Based on last years discussion in the NKG group regarding decreasing the annual number of PRA testing we asked the tissue typer group for their view and this was discussed at this year's tissue typers' meeting. Helle Bruunsgaard reported that tissue typers' recommendation is that we keep on

testing for HLA antibodies every third month. Again there was a lengthy discussion about doing fewer investigations, but it was not decided to change this rule.

It was discussed if DSAs should matter in the priority list of non-STAMP patients. It is expected that this will be the case, when all patients have their antibody specificities registered in YASWA by direct data transfer from the fusion software.

**14. Evaluation of the kidney exchange rules ([see SCTP homepage](#)):**

See point 13.

**15. Contrast enhanced CT scan of all DD donors. Suggestion from the liver group:**

Contrast enhanced CT-scan of all deceased donors was suggested from the liver group. William Bennet from the liver group had sent out some material for this suggestion beforehand. At the meeting William Bennet gave a presentation on the background for the wish for contrast enhanced CT-scan of all deceased donors. His primary question to the kidney group was if this gave concerns in relation to contrast mediated nephropathy. The general opinion was that this problem is of little significance. The question was raised about false positive findings in a screening procedure. It was decided that William Bennet will work further on this matter and that it will be on the agenda for next year's meeting.

**16. Policy for transferring basic, anonymous clinical data from YASWA to other organisations and registries:**

Lars Wennberg was not present at the meeting, so this point was not discussed.

**17. Paired Kidney Donation Program (STEP), status:**

Per Lindnér reported on the first paired kidney donation in Sweden, which had been a three way-exchange involving two different hospitals (Stockholm and Skåne). Sweden have one more possible exchange under investigation. Ilse Weinreich then presented how far we were with the Scandiatransplant program STEP. It was decided last year that we would start with a two-way exchange, but this has already passed over by Sweden. The YASWA program will be up-dated in order to manage more than two ways pairing. However, this can be done quickly. There are still some unsolved problems in the clinical part of the protocol of STEP and Per Lindnér will update the protocol. Among these is a problem with Danish legislation on economical compensation for loss of income for the donors. Karin Skov, the Danish member of the STEP steering committee, is in contact with the Danish Health Ministry and hopefully this problem will be solved shortly.

**18. Reporting of SAE and SAR in renal transplantation - do people report?:**

Kaj Anker Jørgensen gave a short presentation of the reported SAE/SARs. There have been 13 from New Year until November 1.

**19. News from the SCTP board:**

Kaj Anker Jørgensen gave a short overview of board meetings and subjects dealt with.

He also presented the board's idea for a new logo after Tartu has become associated member.

**20. Any other business:**

None.

**21. Next meeting:**

It was decided to have the next meeting on November 13<sup>th</sup>, 2019 in Kastrup.

Kaj Jørgensen/Ilse Weinreich/Søren Schwartz Sørensen