



## MINUTES

### Nordic Kidney Group, 16<sup>th</sup> annual meeting

November 13<sup>th</sup>, 2019, 10:00-16:00

Copenhagen Airport Kastrup

Clarion Hotel – Meeting Room Medium Airport Terminal 3

**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	x	
Marko Lempinen – Helsinki	x	
Lars Wennberg – Stockholm	x	
Lars Mjörnstedt – Gothenburg	x	
Claus Bistrup – Odense	x	
Amir Sedigh – 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 Lindnér	x	
NTCG –Ulla Plagborg	x	
STTG – Helle Brunsgaard	x	
Kaj Anker Jørgensen - Scandiatransplant	x	
Ilse Duus Weinreich – Scandiatransplant	x	

Writer of minutes: Kaj Anker Jørgensen

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

These were approved.

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

Søren Schwartz Sørensen had one point about the pediatric sub-group.

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

Iceland:

Iceland have performed their first transplantation from deceased donor. They actually performed two in the same weekend. They have had a donation day where they have had people from Gothenburg come and tell them about DCD. Margret Andrésdóttir is now the chief of the department.

Oslo:

Things are as they have been the previous years. There has now been signed a data processor agreement between Oslo University Hospital and Scandiatransplant. Now all member hospitals have a data processor agreement with Scandiatransplant.

Uppsala:

There was nobody present to tell about new developments in Uppsala.

Stockholm:

Their budget has gone down. They have done their first DCD donors after the pilot project. They were using ECMO. They have a new hospital director who actually comes from Reykjavik.

Gothenburg:

The DCD program has started, but they haven't done any transplantations after the pilot project. They claim even lower budget while the number of transplantations is increasing. They will exceed 200 transplantations this year.

Malmö:

They are working on living donor registrations in Scandiatransplant. Beside budget their main problem is lack of nurses. They have done their first DCD and they started pancreas transplantation last year.

Helsinki:

Arno Nordin is now chief of the abdominal transplantation department. They have many donors and are transplanting many kidneys. Have used their first donor over 80 years. They claim very low budget and few surgeons. They have done 36 kidney-pancreas transplantations

Tartu:

They are discussing DCD. They have many immunized patients and 20% of their waiting list is on STAMP.

Aarhus:

Did their first STEP transplantation last week which was with Stockholm. Everything went well. They have a big problem with operations rooms which means that there are big difficulties in planning living donor operations.

Odense:

The number of living donors has also gone down. They have very many DCD donors and are the center in Denmark doing most kidney transplantations right now. They have received the Life Port.

Copenhagen:

Denmark is working on introducing DCD after the Parliament has decided that Denmark should do DCD. They have had to cancel quite a number of living donor transplantations due to acute disease in both recipients and donors. They have had a hit in STEP but the transplantation has not taken place yet.

## **6. Announcement of NKG national key persons for 2019-2020:**

These are unchanged: National Key persons 2019-2020: Marko Lempinen (FI), Anna V. Reisæter (NO), KG Prütz (SE), Claus Bistrup (DK), Margret Andresdottir (IS), Jaanus Karhu (ES) Ilse Weinreich (Scandiatransplant).

## **7. Kidney exchange compliance:**

Ilse Weinreich had sent a document on this before the meeting. It was discussed and accepted by the NKG. It was stated that Acceptance of kidney (obligation and payback) by recipient center is binding. All changes in acceptance of kidneys late in the process should be reported to Ilse Weinreich.

## **8. Kidney payback overview:**

Ilse Weinreich gave a presentation of the payback overview. There had been 95 pay-backs since last year, median time to payback was 140 days (range 3-1424). As of November 1<sup>st</sup> 2019, there were 66 cases of pending paybacks with a median waiting time of 189 days, and this had improved compared to preceding years. Exactly 50% of the pending paybacks have been waiting for more than six months. A detailed description of the pending paybacks was shown. It was investigated if paybacks had been possible last years and it showed that sometimes it is very difficult and takes a long time to be able to give a payback.

## **9. Suggestion for new rules for time delay before payback:**

Last year a group (Lars Mjörnstedt, Claus Bistrup, Morten Skauby) was appointed to come up with new rules for payback. These had been sent out before the meeting so people were prepared. Lars Mjörnstedt presented the principles the group had worked on and the conclusion they arrived at. This was discussed, minor changes were suggested and the group has incorporated these so the new rules for payback are:

- Kidneys, which are exchanged on basis of the above-mentioned obligatory exchange rules, must be "paid back".
- Payback should be offered with the ***first*** available ABO blood group identical kidney with a quality comparable to the primarily received kidney.
- Kidneys from a donor aged  $\pm 15$  years, compared to the age of the primary donor, are eligible for payback. The cause of not offering such kidneys must be noted.
- Kidneys outside this age range and in other blood groups may also be offered.
- The kidney offered as payback must be of a quality acceptable to the recipient center. The receiving center is allowed to reject any payback offer. The cause of this rejection must be noted in all cases.
- In rare cases two kidneys will have to be paid back from the same donor. Thus, it will not be possible to always keep one kidney in the retrieving center. However, the primary exchange obligations above, based on HLA-matching, are always in priority before the payback/return obligations. This priority rule applies also when you optionally chose to send both kidneys in the primary exchange.
- If there is a suitable recipient for a kidney transplantation combined with any other organ, i.e. pancreas liver, heart, intestine, this may also be prioritized and regarded as an acceptable reason for not paying back a kidney.
- If there are other extraordinary reasons for not following the payback obligations, this must be agreed after personal contact with the responsible physician at the receiving center.

It was also decided that these rules can be implemented at January 1<sup>st</sup> 2020. The group wanted registration of reasons not to offer the kidney, if decided by the payback center, to be registered in YASWA and an automatic listing of all kidneys that had not been paid back displayed for the coordinators. This latter part will need some programming in YASWA which may not be ready by January 1<sup>st</sup> 2020, but the needed data can be found manually through the 'Payback status' menu in YASWA.

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

Søren Schwartz Sørensen argued that the menu name 'Registry Survey' on the Scandiatransplant homepage should be changed to: Annual report. This was accepted and changed. He then showed some selected slides on graft survival curves, kidney donor index etc. Some of the slides will appear on the homepage when they are ready, some will not be presented because the lack of data makes the conclusions very insecure. Data cleaning is important in the process and improves the quality of data. It was suggested to make a validation in YASWA when doing deceased donor registration of the parameters included in the donor risk index. This was decided.

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

See point 12.

**12. Possible further parameters for the Follow Up registry:**

To be able to identify transplantations with donor specific antibodies we are waiting for direct import of Fusion data from all centers. The group therefore encourages Helsinki and Oslo to start this process. A group consisting of K.G. Prütz, Margret Andresdottir and Anders Åsberg was to look in recipient comorbidity index. They should look into which are best and which are possible.

**13. Suggestions and recommendations from the tissue typer group:**

Helle Bruunsgaard presented two suggestions from the tissue typer group.

Point 1 was that the STAMP committee should be supplemented with a representative from Estonia. NKG agreed with this.

Point 2 was called 'Time for the Next Step in STAMP'. The suggestion was that the STAMP program should be updated to include matching for HLA-DRB3/4/5, DQA1 and DPA1. This suggestion was also accepted by the NKG. It will be implemented when programming is done and existing STAMP/LAMP patients have been updated by each center.

There was raised a question about how efficient the STAMP committee is working. Some said they don't know how the STAMP committee works. It was stated that the issue had been discussed in the tissue typers' meeting. Ilse had made a suggestion to make the status of each patient as to coming on the STAMP list much more visible. The NKG supported this suggestion and stated that this is a focus area for the NKG.

**14. News from the Coordinator group:**

Ulla Plagborg reported on the Coordinator group's meetings. The new suggestions for the payback rules had been discussed and accepted and the coordinators' group had given supplements to the NKG group working with this issue.

**15. Evaluation of the kidney exchange rules:**

There were no suggestions for changes.

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

Per Lindnér gave a presentation of the runs and the exchange transplantation within the Swedish and later the Scandiatransplant STEP program. In the first 18 months there will be 20-22 transplantations. The transplantations have gone smoothly, there have been more transplantations than

expected and the workload for the coordinators has been larger than expected. It has now been decided to:

- 4 yearly match runs, January, April, August and October
- Maximum 3 months between match run and transplantation
- If a living donor is accepted in the local center it can be included in STEP
- Altruistic donors should go into STEP
- ABO-incompatible pairs should be encouraged to go into STEP

**17. Exchange of DCD donor kidneys, time to make our prior statement official:**

The board asked NKG in 2017 how it thought that DCD kidneys should be exchanged. The answer to the board was accepted at this meeting as the official statement.

The official statement is:

The DCD kidneys should be included in the exchange obligations in exactly the same way as the DBD organs. It is by the discretion of the receiving center to accept such organs. They can always say no. Pay-back of a DCD kidney must be done in the way that the center can, meaning that centers that have accepted a DCD kidney must pay back according to the pay-back rules whether it is a DCD or a DBD kidney. The recipient centers should remember this when accepting a DCD exchange kidney for one of their patients. Using a DCD kidney to pay back for an earlier exchange of a DBD kidney will always be at the discretion of the receiving center that always can say no if they feel that the offered kidney does not match the exchanged kidney.

**18. Should we aim for machine perfusion during kidney exchange?:**

This was discussed but there was no conclusion. It seems like there will be some logistic problems when transporting kidneys in other ways than by land or by an aircraft hired just for this reason. Sending kidneys being perfused in the Life Port would need a lot of cooperation with aircraft and transport companies. People were however encouraged to try to make some projects, that will show the benefit of using the perfusion machines for transport.

**19. New from SCTP board:**

Kaj Anker Jørgensen gave a brief summary of the Board meetings last year and then he gave an overview of the SAE/SAR reports in 2019. Reports are all given as SAE, but for the competent authorities, it is important that they are given correctly as SAE or SAR.

**20. NKG – Should we have a logo:**

This was also discussed and there was not complete conclusion, but Steffen Ellebæk Petersen will be asked if he has a good idea for such a logo.

**21. Any other business:**

Søren Schwartz Sørensen presented the NPRTSG as an official sub-group under the NKG. As a subgroup of NKG the NPRTSG work under the bylaws of NKG

**22. Next meeting:**

It was decided that the next meeting will be November 11th 2020 at Clarion hotel in Kastrup.

Kaj Anker Jørgensen/Ilse Weinreich/Søren Schwartz Sørensen