Nordic Kidney Group, 21th annual meeting
November 13th, 2024, 10:00-15:00 CET
Copenhagen Airport, Denmark
Minutes

1. Welcome by meeting chairman – *Søren Schwartz Sørensen*

   Søren Schwartz Sørensen bid everybody welcome.

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

   Anders Åsberg was elected as write of minutes

Søren Schwartz Sørensen – Copenhagen
Alireza Biglarnia – Skåne
Marko Lempinen – Helsinki
Lars Wennberg – Stockholm – participation online
Åsa Norén – Gothenburg sub by Gustav Hagberg
Claus Bistrup – Odense
Amir Sedigh – Uppsala sub by Tomas Lorant participation online
Kristian Heldal – Oslo
Karin Skov – Aarhus
Margrét Birna Andrésdóttir - Reykjavik
Jaanus Kahu – Tartu
Anders Åsberg – Kidney registry, Norway
Kristine Hommel – Kidney registry, Denmark
KG Prutz - Swedish Renal Registry, Sweden
Maria Stendahl - Swedish Renal Registry, Sweden
Mai Rosenberg - Estonian Kidney Registry
Jānis Jušinskis – Observer from Latvia
NTCG – Ulla Plagborg
STTG – Pernille Koefoed-Nielsen – participation online
Ilse Duus Weinreich – Scandiatransplant

3. Approval of last meetings minutes (https://www.scandiatransplant.org/members/nkg/Minutes_NKG23.pdf) - *Søren Schwartz Sørensen*
   Minutes were approved.
4. Further matters to the agenda - *Søren Schwartz Sørensen*

   Representative from Malmö wanted to add *ABOi STAMP transplantations*
5. Status from each center and registry (developments, phase-out, structural changes e.g.)

   Iceland: Lack of donors, refusal from DD relatives. One potential donor where the cause of death was stabbing where the police stopped the donation. DCD donation learning from Gothenburg upcoming. New surgical training in Gothenburg possibility coming up. Registry no news.

   Oslo: Marked increased LD, DD somewhat less than 2023, will include LD:s in the Norwegian Renal Registry for better follow-up.

   Uppsala: DCD has increased organ availability a lot. Apart form that no big news.

   Stockholm: 1/3 DCD, LD going down.

   Gothenburg: Good number of transplants, LD reducing, LD session at "regional kidney days", DCD a good part of the donors.

   Malmö: Last year bad year, not that many DCD.

   SE registry: Problem with economy but registration new data is working well, register LD, all time high kidney Tx last year mostly due to DCD, 61% KRT is Tx (prevalence)

   Helsinki: Last year record year, LD steady maybe a bit lower (good according to Finish standards). DD lower than last year, a few DCD, staring other organs DCD next year by NRP. Registry as usual, have possibility to electronic reporting but many use paper.

   Tartu: Last year was a good year. No big clinical changes. Chief immunologist left the team – no major impact on activity! Registry: >50% of all KRT is Tx. Active contributing to ERA registry, Tx rate stable the last 10-15 yr. No funding for registry, Mai is doing it as one of her university obligations – risk for registry but no chance getting funding since registry is only 3rd national level priority!

   Aarhus: Good year 2024 so far, only few DCD (started this year, only kidney). No change on LD.

   Odense: Good year Tx, somewhat down on LD, DCD saves the DD protocol. New surgeons needing training and hence higher surgical complications. First laparoscopic LD nephrectomy.

   Copenhagen: Slightly behind last year. DCD saves the DD protocol, LD as last year but capacity for LD is not fully used. No change in organization. RCT of robotic kidneyTx started and will be finished in 2025.

DK Registry: Potential disaster! The official organization for clinical quality monitoring organization has, due to budget cuts, closed the usual and well tested database and are instead offering a cheaper registry platform without the facilities from the old platform. Flat structure platform with the inherent limitations. No historic data in the new platform. Tx part of the registry will be least affected, hopefully! The historic dataset is secured but local sites cannot see the historic data.

Søren: Maybe make a registry forum to discuss issues like the DK case? Help each other with strategies to quality check data in the registries.

6. Announcement of NKG national key persons 2024-2025:

   (National Key persons 2023-2024: Marko Lempinen (FI), Kristian Heldal (NO), Lars Wennberg (SE), Claus Bistrup (DK), Margrét Birna Andrésdóttir (IS), Jaanus Karhu (ES) Ilse Weinreich (Scandiatransplant))

   No changes.

7. Kidney exchange compliance (see attachment) – *Ilse Weinreich*

   Ilse went through the presentation that had been sent our beforehand. The situation has been unchanged the last 4-5 years, if excluding late searches. So far in 2024 a small reduction (2.2%) is seen. Different rules at the different centers on how long before donations that the search are allowed. Tissue typers have no common decision on this but there is a recommendation to do a re-search during the last 24 hours window. A STAMP patient may appear in the meantime for example.

   No systematic signs of any center avoiding sharing organs.

8. Kidney payback overview – *Ilse Weinreich + Ulla Plagborg*
   Payback data presented by Ilse. Open cases only 31 this year, previously around 40 annually. Nothing that indicate that the payback system does not work, and all centers obey the rules. Payback deviations will be presented at the coordinators meeting next week.

   Malmö representative comment: should we have a higher focus to accepting kidneys offered? It is not nice to be in the situation to owe kidneys.

9. SAE/SAR registration overview of practice – *Ilse Weinreich, Søren Schwartz Sørensen*
   Relatively few reports of SAE/SAR potentially due to underreporting through this system. It is important that we use the YASWA based system that was built to comply with the EU directive. The YASWA system is governed by the competent authorities.

   Ilse presented an overview of SAE reports for both DD and LD in the WASWA system. Looks like too few reports so we need to reinforce the reporting. We must revisit/re-evaluate the guidelines for what we need to report, guidelines that already presently can be found in the SAE module in YASWA and on the website. We must make it as easy as possible for all centers to know what they are expected to report through the YASWA SAE system.

The group decided to set up a working group within NKG evaluate if the list/guideline in YASWA needs clarification/expansion and on how to increase awareness of the list. The group is composed of Wennberg (Sweden), Schwartz Sørensen (Denmark), Lempinen (Finland), Heldal (Norway), Andrésdóttir (Iceland) and Rosenberg (Estonia). Marko Lempinen will make sure to invite all to the first online meeting Q1/2025. The annual report to the competent authorities is sent by Scandiatransplant. All centers can see all reports in YASWA.

10. Suggestion for change to exchange obligation 5 (see attachment) – *Karin Skov*

    Karin presented the suggestion to change obligation #5 to only apply for recipients <60 years. No objections to this suggestion so it will be implemented.

    Iceland: neutral
    Norway: positive
    Uppsala: positive
    Stockholm: positive
    Gothenburg: positive
    Malmö: positive (also for lower age)
    Helsinki: positive (also for 50 yr)
    Tartu: positive
    DK: positive

    An upfront warning that next year it can come a question to shift children threshold to 18 years also for "obligations". The NKG group should take this into account and discuss this in time for the NKG meeting 2025.

11. Nordic Kidney Registries, Annual data report (https://www.scandiatransplant.org/members/nkg/registry-survey) – *Anders Åsberg, Søren Schwartz Sørensen*

    Søren presented the data that is already available online. More than 30,000 Tx now! DCD looks like it has made a major impact, it will be interesting to see how it turns out in the long run.

    a. Should SCTP/NKG report center/country specific waiting time – *Søren Schwartz Sørensen*

       A question has been raised in Sweden and Denmark about how to calculate/express waiting time? Søren presented four different methods as an example. There are several questions that needs to be defined, e.g. Should LD-transplantations be excluded from the analysis or censored at time of LD-Tx?
       Heldal (Oslo): Would be good to have a standard method for this in order to make good comparisons within Scandiatransplant.
       KG (Sweden): Suggests that Ilse provide data to each so they can do their own analyses.

Wennberg (Stockholm): Replies that after starting this annually benchmarking analysis the difference in waiting time between the Swedish centers have decreased.
It was agreed to include that this kind of analyses, comparing different countries, in next year's registry analysis. Using the Kaplan-Meier method presented by Søren, excluding patients that has been LD-Tx. Analysis could include subgroup analyses for ABO-groups, High immunized patients etc,.

b. Suggestions for further analysis of NKG registry data – *all*

The waiting list analysis as mentioned above was the only additional analysis suggested.

c. Update from the WG on comorbidity index – *Margret Andresdottir*
Margret presented the project. As of now the only risk factor in the database is age. The variables to implement Baskin-Bey has now been included in YASWA. It should be possible to get retrospective data back to 2010 from most centers and Ilse can batch import them. Centers with data longer back in time should provide these as well. From now on these data should be prospectively including in YASWA.

d. Update on the ABOi project – *Anders Åsberg*
Anders presented what has come out of the project so far. We need ethical approval at each center to collect the additional variable to be able to prepare a good scientific paper on this topic. We also need a new leader for the project since Anna Varberg Reisæter is retired and no longer have the capacity to lead this project. We will need data transferal agreement between the centers to continue the project. Lars Wennberg asks Helena Genberg if she wants to lead the project as she has done something similar for the NPRTSG.

12. Suggestions and recommendations from the tissue typers group – *Pernille Bundgaard Koefoed-Nielsen*
Pernille presented from the tissue-typers that they are discussing split-type matching for obligations 2, 3, 4. Most labs register split-types. Not many actual transplantations with split mm. It will therefore not have any big influence on the lists.
They also questioned if we should have the same internal ranking with the different obligations than STAMP to decide who to get the kidney if there are two (or more) possible recipients?
A question was also raised about searched many days before the actual transplantation since there may have come a new candidate on the list in the meantime. Should there be mandatory to perform a new search when the transplantation is not performed within 24 hours from the previous search?

13. News from the Coordinator group – *Ulla Plagborg*

    a. Practical issues with the rota list (see attachment) – *Ulla Plagborg*

       If both surplus kidneys are offered, they should go to two different countries. Coordinators have meeting next week. They will finalize this suggestion and send it to National key persons that decide if OK or not by e-mail voting.

14. Paired Kidney Donation Program (STEP) – *Ilse Weinreich, Karin Skov*

    Ilse present STEP an overview of the program so far. In total 19 match-runs has been performed, resulting in a total of 78 Tx and 60% broken cycles.
    An application for a EU-program has been sent and STEP is part of WP3 (guidelines). Per Lindner og Ilse has made a questionnaire for centers that will be presented for the EURO-KEP. Kick-off meeting EURO-KEP January 2025.

    Søren: ABOi pairs, can they be prioritized in order to get them into the program for at least one cycle? By now 38% ABOi are in STEP. Karin says that the prioritization has been analyzed and discussed, but it has not resulted in any changes.

15. SCTP acceptable Mismatch program (STAMP)

    a. Analysis HLAi transplantations – *Søren Schwartz Sørensen*

       Søren presented data Tx within STAMP vs Tx outside STAMP for these patients. dcGS is somewhat poorer but maybe acceptable? In all 99 Tx; 17 with only historic DSA, 77 with DSA at time of Tx, 4 without both DSA at Tx and historic DSA (?). Of the 77 with DSA many had multiple DSA (8 as max). Desensitization: 5 Imlifidase, 2 PE, 9 IVIG+Ritux. Historic DSA did not affect outcomes negatively, 43% of those with DSA at time of Tx got ABMR (TCMR 13%)

       Ilse has tried to find the same data in YASWA that Søren had in his files from the centers but it is clear that there is a need for a common definition. Many different definitions and everything is not reported in YASWA.

16. Should we give priority on the waiting list to previous donors - and how should we do it – *Kristian Heldal, Anders Åsberg*

    Kristian presented Norwegian data about previous LD that end in KRT and the algorithm for organ allocation used in Norway. The question was if these LD should get some kind of priority and in Norway it has been discussed to give them points comparable to one year on the waiting list. The other centers do not have an algorithm like this and Søren replied that in Denmark these patients would probably be put on the LAMP list.

17. Causes for permanent withdrawal from the WL – *National Key Persons*

    This point was discussed during the last meeting and centers should investigate this during the last year. Is this worth the job or only “nice to have”? Should *kidney* use the same options as *liver*?

    Decision: Leave as is now!

18. Donor variables necessary for optimum organ allocation – *National Key persons*

    This is a question/task from the SCTP board to the different organ groups. Søren presented a preliminary list of minimum DD-data that Ilse have prepared. Claus will call for a meeting amongst National Keypersons. Results should be reported to the board.

19. Is it time for mandatory registration of method of preservation in YASWA? – *Claus Bistrup*

    Presented by Claus. It is important to monitor the outcome of machine perfusion to see if it makes the expected difference. Also, it is most likely the competent authorities will, at some point in time, ask for data on kidney preservation method used for DD transplantation. The field to report this is already in YASWA. Ilse can perform a batch in YASWA of historic data. Data on a YES/NO/Unknown form only. Centers using pumping devices said they have the data and can deliver these to YASWA.

20. Any other business

    a. *ABOi STAMP transplantations*

    Malmö: Will ABOi-STAMP Tx increase Tx-rates for these patients? Malmö give rituximab but no immune absorption. Malmö will present their protocol and results so far at the next NKG meeting. If any of the other centers have done the same they should also present data at next meeting.

21. Next meeting

    November 19th, 2025 in Copenhagen