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

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<thead>
<tr>
<th>Name</th>
<th>Yes</th>
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<tr>
<td>Søren Schwartz Sørensen – Copenhagen</td>
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<td>Alireza Biglarnia – Skåne sub by Carl Raihle</td>
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<td>Marko Lempinen – Helsinki sub by Ilkka Helanterä</td>
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<td>Lars Wennberg – Stockholm</td>
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<td>Åsa Norén – Gothenburg</td>
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<td>Claus Bistrup – Odense</td>
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<td>Amir Sedigh – Uppsala sub by Bengt von Zur-Mühlen</td>
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<td>Kristian Heldal – Oslo</td>
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<td>Karin Skov – Aarhus</td>
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<td>Margrét Birna Andrésdóttir - Reykjavik</td>
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<td>Jaanus Kahu – Tartu</td>
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<td>Anders Åsberg – Kidney registry, Norway</td>
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<td>Nina Ask – Kidney registry, Finland</td>
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<td>Ólafur Skúli Indrason – Kidney registry, Iceland</td>
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<td>Kristine Hommel – Kidney registry, Denmark</td>
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<td>Maria Stendahl - Kidney registry, Sweden, sub by KG Prutz,</td>
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<td>Mai Rosenberg - Kidney Registry, Estonian</td>
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<td>STEP – Per Lindner</td>
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Kaj Anker Jørgensen was elected as writer of minutes.

3. Approval of last meetings minutes
   (http://www.scandiatransplant.org/members/nkg/Minutes_NKGmeeting_16th_November_2022_Copenhagen.pdf) - Søren Schwartz Sørensen

   Minutes were approved.

4. Further matters to the agenda - Søren Schwartz Sørensen
   Anders Åsberg had a point about the ABOi study, which will be taken under point 10.

5. Status from each centre and registry (developments, phase-out, structural changes e.g.)
   Reykjavik: Less transplantations in Iceland, but more in Gothenburg. They are working on increasing living donors. Younger doctors are taking over in the clinic.
   Oslo: Kristian Heldal has taken over after Anne Reisæter. They have done their first STEP transplantation. They have more deceased donors and are a little bit a head of last years, but there are too few living donors. The leadership in Oslo is undergoing reorganisation.
   Uppsala: Fewer living donors, but they will reach record high deceased donors this year. Thinks this is due to DCD.
   Stockholm: Have passed the all-time high, due to DCD. Otherwise, things are the same as last year.
   Malmø: DBD has gone down and LD decreased. They have done 2 STEP. They are implementing NRP for DCD.
   Helsinki: Record high number of transplantations. DCD is now approved at 3 donor hospitals. Living donor follow up data and quality of life data are being gathered.
   Tartu: Working to increase living donor. Deceased donor very good.
   Gothenburg: A little less living donors.
Copenhagen: Very good year for deceased donors. Fair for living donors. DCD started in Denmark.

Odense: Have had their first DCD. DGF both kidneys. Donor situation slightly better than last year.

Aarhus: On the average of last year. One third LD transplantations. Announced the STS next year in Aarhus. STS 2024 29th-31st of May 2024, Aarhus

Søren Schwartz Sørensen will make a template to facilitate for this point for next year.

The present software platform for the Danish Uremic Registry, that also includes kidney transplantations, will be closed by the authorities. The functionalities/facilities of the of replacing platform is not yet known.

Living donors will go into the national kidney registry in Sweden.

6. Announcement of NKG national key persons 2023-2024:
   (National Key persons 2023-2024: Marko Lempinen (FI), Kristian Heldal (NO), Lars Wennberg (SE), Claus Bistrup (DK), Margrét Birna Andrásdóttir (IS), Jaanus Kahu (ES), Ilse Weinreich (Scandiatransplant))

7. Kidney exchange compliance (will be circulated before the meeting) – Ilse Weinreich
   Ilse Weinreich went through the presentations, that had been sent out before the meeting. The deviations were few. The cases where the rules had not been followed were accepted. It was stated that there should be a call to the potential recipient centre when there is deliberate breach of rules. It was emphasized that if there is a positive x-match in STAMP, the patient should be taken off STAMP immediately until the reason is clarified and that search for potential exchange obligations must be done right before donation, not 3-6 days in advance.

8. Kidney payback overview – Ilse Weinreich and Ulla Plagborg
   Ilse Weinreich went through the presentations, that had been sent out before the meeting. Ilse Weinreich was asked to look into if the tightening of the rules introduced a few years ago has had any effect.
9. Suggestion from liver WG regarding new definitions for reasons for permanent withdrawal  - Ilse Weinreich

The suggestion from the liver group had also been sent out before the meeting. The consensus was not to accept these suggestions, but to try and make better definitions of the current list. The national Key persons will look into definitions of permanently withdrawn and give a response by March 2024.

10. Nordic Kidney Registries, Annual data report – Anders Åsberg, Søren Schwartz Sørensen

Søren Schartz Sørensen showed and commented on the presentation, which can be found on the Scandiatransplant homepage.


- Preliminary analysis of waiting list data from Norway – Anders Åsberg

  Data from Norway show that something happened from 2012 till now with increased survival of waitlisted patient not transplanted. It was decided to extend these analysis with data from Denmark since the necessary data are already in YASWA.

- Suggestions for further analysis of NKG registry data – all

  No suggestions put forward.

- Report from the WG on comorbidity index – Margret Andrésdóttir

  Margret Andrésdóttir presented the work that had been done looking at the different comorbidity indices. Based on preliminary inquiries it seems that all centres will be able to collect data for the Baskin-Bay index. The conclusion at this meeting was that the Baskin-Bay should be used and hopefully included in YASWA retrospectively as well as prospectively. Field definitions will be made before Christmas 2023 by the WG. The ambition is to present analysis results next year.

- ABOI project: More data are needed if a publication is to be made. It is only DK, S, and N. Oslo will proceed to get necessary data to make a publication.
11. and 14. Suggestions and recommendations from the tissue typers group – Helle Bruunsgaard

Points 11 and 14 on the agenda were taken at the same time. Helle Bruunsgaard proposed on behalf of the STTG.
1. Proposal: Investigate if the number of epitope mismatches predict the outcome (de novo DSA, graft survival, rejection episodes) in STEP?
The suggestion was approved. Project lead will be the STEP steering committee.
2. Should more immunological risks be taken in STAMP? – It was decided to let the STAMP committee look into this.
3. Procurement of more data on 86 STAMP patients transplanted outside STAMP. This was accepted by the NKG, which felt that this might give some useful information. Project lead will be the STAMP committee.

12. News from the Coordinator group – Ulla Plagborg

Ulla Plagborg pointed out that blood samples are sent together with the organ, and usually not before. There is a wish for a ROTA list for kidneys and the NKG confirmed that this should be made. The SCTP Office will start to do the necessary programming next year.

13. Paired Kidney Donation Program (STEP) – Per Lindner, Ilse Weinreich

Ilse Weinreich showed the status of the STEP now. Per Lindner encouraged the centers, to include altruistic donors into STEP as one altruistic donor often in STEP gives rise to several transplantation.

Per Lindner also reported that simulations have shown that one extra pure ABOi pair included theoretically should result in 0.7 more matches. Based on this offering STEP to ABOi pairs should also be encouraged. Per Lindner showed the Gothenburg model, where ABOi pairs go into STEP first for one match round with an already fixed data for direct ABOi transplantation shortly after the match round if no match is found. He recommended this model that could be a benefit both ABOi pairs as well as increasing number of matches for HLAI in STEP.
There has been an application to EU for a European KEP. Per Lindner represents Scandiatransplant and will participate in WP 3, if the money is granted.

14. SCTP acceptable Mismatch programme (STAMP)
   - News from the STAMP committee – Søren Schwartz Sørensen
     This point was taken under point 11.

15. Should imlifidase treatment be centralised in SCTP? – Kristian Heldal
    Kristian Heldal had sent out a document before the meeting asking if Imlifidase treatment could be centralized to one center within Sctp. The price is unknown and there will probably be problems getting the permission in some countries.

    Søren Schwartz Sørensen informed that the company Hansa has offered to sponsor a FU meeting. The offer was discussed and the conclusion was that presently there is no need for a FU meeting.

17. News from SCTP board – Kaj Anker Jørgensen
    Kaj Anker Jørgensen presented an overview of the meetings and the issues that had been taken up in the Board since the last NKG meeting.

18. Any other business
    None

19. Next meeting: 13.11.2024