

Seventh annual meeting  
**25-Nov-2009 in Copenhagen**

Minutes of meeting

**Present:**

Nordic transplantation/nephrology departments:

Søren Schwartz Sørensen – Rigshospitalet  
Ragnar Kallen – Universitetssjukhuset MAS  
Nils H Persson – Universitetssjukhuset MAS  
Magnús Bödvarsson – Landspítali  
Lauri Kyllönen – Helsingin Yliopistollinen Keskussairaala  
Lars Wennberg – Karolinska Universitetssjukhuset  
Lars Mjörnstedt – Sahlgrenska Universitetssjukhuset  
Kaj Anker Jørgensen – Århus Universitetshospital, Skejby  
Claus Bistrup – Odense Universitetshospital  
Jan Carstens – Odense Universitetshospital  
Lars Bäckman – Akademiska sjukhuset  
Anna Varberg Reisæter – Rikshospitalet

Nordic uraemia registries:

Torbjørn Leivestad – Norsk Nefrologiregister  
Runólfur Pálsson – Islandsk Uræmiregister  
James Heaf – Dansk Uremi register

Transplantation coordinator group:

Charlotte Sick Nielsen - København

Scandiatransplant:

Frank Pedersen  
Ilse Duus Weinreich

**Absent:**

Arnt Jakobsen – Scandiatransplant  
Niels Grunnet – Scandiatransplant  
Staffan Schön – Svenskt Register för Aktiv Uremivård  
Jesper Melchior Hansen – Herlev Hospital

## **1. Presentation of the last two additions to the Scandiatransplant staff**

- Frank Pedersen presented the Scandiatransplant staff and afterwards there was a quick presentation of all attending the meeting.

## **2. The present state of the incorporation of the NPRTSG schemes into Scandiatransplant**

- Presentation of the NPRTSG schemes that are to be incorporated into Scandiatransplant.
- Concerning the questionnaire all attendees received in advance. The questionnaire shows what we already have in Scandiatransplant and what is going to be incorporated with NPRTSG. As much data as possible will be imported from the Nordic uraemia registries.

## **3. Revision of additional data that can be collected from the Nordic uraemia registries**

- Diagnosis: Scandiatransplant is preparing the system for importing ICD10 and EDTA codes. The possibility to enter the diagnosis in Scandiatransplant will be removed. The reason is that the field often is lacking information or is filled in with – 99 Other renal disorder. The diagnosis will be imported from the Nordic uraemia registries. .
- Infection serology: A list already exists in Scandiatransplant; this is the one that will be used in the follow-up part in the system.
- Dialysis date: Definition is lacking– day of first dialyse?
- Dialysis form: Only the last form of dialysis should be entered.
- CIT: We expect this to be imported from the Nordic uraemia registries. A difficult parameter to get correct data on.
- Date of onset: Definition is not clear.
- S-Creatinine at tx: Only relevant for patients not on dialysis
- S-Creatinine at follow-up: Date must be attached
- Immunosupp.: Many don't have information about dosage. Why there must be a possibility to chose between YES/NO/NI (NI = not investigated)
- Rejections: There was talk about if classification of rejections is needed. No decision was made.

## **4. Election of leader and leader group for NKG**

- The leader group was re-elected and a member from Scandiatransplant was added

Lauri Kyllönen (FI) – Chairman  
Torbjørn Leivestad (NO)  
Lars Mjörnstedt (SE)  
Kaj Anker Jørgensen (DK)  
Magnús Bödvarsson (IS)  
Frank Pedersen - Scandiatransplant

## **5. STAMP Scandiatransplant Acceptable mismatch program – the first 8 months.**

- There are right now 20 patients on STAMP – 5 STAMP patients have been transplanted.

## **6. Presentation of the first 8 months of TOTAL control of “exchange compliance”**

- **Remember:** Scandiatransplant needs an email with an explanation of why a kidney is not exchanged even though there were exchange obligations, as well as if an exchanged kidney is given to another patient for any reason.
- If Scandiatransplant finds a case where exchange obligations are not followed and there is no explanation, it was decided that they should contact: Donor centre, recipient centre and the chairman of NKG.
- Is the compliance as good as it could be? Should there be 100% compliance? What to do with the cases where age difference is given as explanation?
- Everybody agreed that work will be done to try to eliminate the 1.8 % where the exchange obligation was not followed.

## **7. Evaluation of the exchange rules.**

- Lauri Kyllönen presented a power point show that showed that many factors might have effect on the success of kidney transplantation.
- Keep all rules, but in another order? PRA above everything?
- Lauri Kyllönen will present 3 suggestions for the tissue typing meeting
  1. Rule 3 and 5 changes place = Higher priority to STAMP exchange patients
  2. Patients who are HLA-A,-B,-DR compatible with donor, possibly with some definition of age compatibility.
  3. HLA compatibility on split level (concerning all existing rules)
- Age difference donor/recipient is a difficult question - no decision was made.
- The ongoing existence of STAMP also has to be accepted by the representatives.

## **8. Who is to present NKG and with what, at the upcoming STS 2010?**

- Nordic kidney transplant registry survey 1995-2008 should be updated, and presented at the meeting by Torbjørn Leivestad. NKG members are welcome to suggest analyses to be performed and presented.

## **9. Status for “Forum for discussion of problem cases”**

- Scandiatransplant is working on this issue. The solution is probably an Intranet site with individually and group log on.

## **10. Status on reworking of NLDR**

- The new screen layout was shown.
- There is an EU directive stating that there must be a registry containing follow up data on all living kidney donors. The directive does not state anything precisely about what kind of data it should contain.
- Possible mandatory and voluntary fields were presented by Søren Schwarts Sørensen and Nils H. Persson. They will evaluate the fields again.

## **11. Other matters**

- Transplantation of CLL patients – Nils H. Persson. - A lot of responses not many had experience with this problem. Few cases with CLL that have been transplanted – most seemed to have had bad outcome.
- EFI and the number of annual antibody screen tests - Should Scandiatransplant write down a rule?  
10 years ago it was decided in a tissue typing meeting that patients should be screened every 3 months. Now some in the group wants it done only every 4 month. A proposal will be presented to the tissue typing meeting in Århus 2010.
- Lars Wennberg will replace Nils H. Persson in the STAMP group

## **12. Next meeting**

- 24<sup>th</sup> of November 2010 in Copenhagen

Respectfully submitted by Ilse D. Weinreich