

Eighth annual meeting

24th of November 2010 in Copenhagen Airport

Minutes of meeting



From left:

Magnús Bödvarsson, Runólfur Pálsson, Claus Bistrup, Lars Mjörnstedt, Søren Schwartz Sørensen, Ragnar Kallen, Lauri Kyllönen, Ole Øyen, Margareta Lundell, Lars Wennberg, Staffan Schön, Kaj Anker Jørgensen

Present:Nordic transplantation/nephrology departments:

Søren Schwartz Sørensen – Rigshospitalet
Ragnar Kallen – 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
Ole Øyen - Rikshospitalet

Nordic uraemia registries:

Staffan Schön – Svenskt Njurregister (SNR)
Runólfur Pálsson – Íslandsk Uræmiregister

Transplantation coordinator group:

Margareta Lundell - Malmö

Scandiatransplant:

Krister Höckerstedt
Frank Pedersen
Ilse Duus Weinreich

Absent:

Niels Grunnet – Scandiatransplant
Lars Bäckman – Akademiska sjukhuset/Svenskt Njurregister (SNR)
Torbjørn Leivestad – Norsk Nefrologiregister
James Heaf – Dansk Uremi register



1. Introduction

Søren Schwartz Sørensen was elected as chairman of the meeting. Scandiatransplant staff informed that the NKG meeting will form the basis of the next news letter from Scandiatransplant office.

2. Re-evaluation of the purpose of NKG

NKG was constituted in 2003 mainly focusing on publications and deceased donors. As years have gone by many different interests have arisen.

It was decided to keep the structure with one national key person appointed from each country. Responsibility of the key persons are to make sure that all the necessary persons in their own country are heard and involved. The key persons are not to decide and conclude themselves.

Furthermore one of the key persons is appointed as chairman. Responsibilities of the chairman is both to coordinate between the key persons, NKG and Scandiatransplant. A new chairman should be appointed every 2 year, however it's allowed to be re elected on time (total 2 x 2 years).

In addition one member of the Scandiatransplant staff is appointed to be part of the group.

The appointed persons are:

- Lauri Kyllönen (FI) – Chairman
- Torbjørn Leivestad (NO)
- Lars Mjörnstedt (SE)
- Søren Schwartz Sørensen (DK)
- Magnús Bödvarsson (IS)
- Frank Pedersen – Scandiatransplant

If necessary it's allowed for any of the appointed persons to find a substitute or be substituted by a new person from own country.

Definition of the main objective in NKG has to be discussed and written down by the key persons including the chairman within 3 months from this meeting. The proposition should be sent to all members of the NKG group for comments.

3. Status on “Kidney exchange compliance” 2009 and 2010

Kidney exchange compliance according to Scandiatransplants rules are continuously checked by the office by checking the donor search log and all deceased donor registered in Scandiatransplant. The results from 2009 (1st of March to 31st of December) and 2010 (1st of January to 31st of October) were presented.

- 2009 (10 months)
Total 330 searches – of which there were 53 exchange obligations
Exchange obligation in 16% of all searches performed
5,7% exchange not followed (3 out of 53)
- 2010 (10 months)
Total 311 searches – of which there were 48 exchange obligations
Exchange obligation in 15% of all searches performed
4,2% exchange not followed (2 out of 48)

The explanations for deviation from the exchange rules were presented.

It was agreed upon that it was actual errors but minor deviation and that the results from all centers shows that everyone does a very fine job.

Please look at attached power point (kidney exchange 2009+2010) for further details.

It was decided that the Tx. coordinator represented at the NKG meeting in the future should present the kidney payback balance. The coordinators decides themselves who is going to attend the NKG meeting from NTCG.

Scandiatransplant office is working at adding payback registering in the system.

4. Information on the present status of the EFRETOS activities

Krister Höckerstedt, Chairman of Scandiatransplant, presented the information about EFRETOS the registries of registries. The register concerns kidney, pancreas, heart, lung and intestines from deceased donors.

Four excel sheets were shown where the parameters EFRETOS wish the countries to deliver, are listed with priority 1, 2 and 3. One as the parameter that are mandatory and the least set of data that should be delivered.

- 104 parameters for 'recipients pre transplantation' are to be included in the register of which 11 parameters are mandatory for kidneys. (priority 1)
- 107 parameters for 'transplant and follow up until transplantation discharge' are to be included in the register of which 30 parameters are mandatory for kidneys.

- 100 parameters 'follow up after transplantation discharge' are to be included in the register of which 16 are mandatory for kidneys.
- 79 parameters for 'donor' are to be included in the register of which 11 are mandatory for kidneys.

The objective of EFRETOS is to enable the monitoring of patients and the evaluation of transplant results. Other underlying objectives were discussed - Political and economical reasons? The UNOS of Europe?

A letter written by Krister Höckerstedt to EFRETOS was shown.

All countries have to take a stand if they wish to be a part of EFRETOS or not. Krister Höckerstedt will draft a letter in the near future about EFRETOS and send it to Scandiatransplant board. Afterwards it will be send to all centers to give their statement.

5. Evaluation of the exchange rules

- Highly immunized Pediatric recipients go directly to STAMP (with waiting time<1 year) suggestion from STAMP steering committee.

An extraction from the database shows that it concerns approximately one child a year. The proposal was accepted and will be proposed to the Scandiatransplant Council of Representatives Meeting May 2011.

The question of why it is necessary for the adults to have been one year on waiting list before getting on STAMP, will be brought forward to the STAMP committee by Lars Wennberg.

- Age discrepancy between donor and recipient

An extraction from the database as a diagram of age difference between donor and recipient was shown. It was decided that the age difference should not be more than 30 years. This only concerns when a young donor kidney is offered to an old recipient and only in connection to exchange rule 5 - HLA compatibility.

This will be proposed to the Scandiatransplant Council of Representatives Meeting May 2011.

- Discussion of exchange rule no. 5 (HLA-A, -B, -DR compatibility) versus prolonged Cold ischemia time - pending on data import for comparison."

Further investigation is needed to decided on this issue. This will not be possible until new data import from the Nordic uremic registries is done.

6. Data from the Nordic uremic registries

Scandiatransplant is now in the end phase of creating scripts for data import data from the Nordic registries. The office will contact each register to see what data they have and in which format they can be delivered. The specifications for the import format can be found on http://wiki.scandiatransplant.org/?Renal_Tx_Registry_Bulk_Import

7. Status on

- NPRTSG – The incorporation of data

The incorporation of NPRTSG data into Scandiatransplant is done. The programming will form the basis of the import from the uremic registries of transplantation and follow up information on all patients.

- NLDR – Possible mandatory and voluntary fields

The current status of entering data into LDR were shown and talked about. Oslo, Odense, Malmö, Uppsala, and Stockholm uses LDR continuous with no problems. Århus and København are still a little shaky. Helsinki and Reykjavik asked for help with introduction to LDR from the Scandiatransplant staff. Göteborg would like as Malmö to import data from own system into Scandiatransplant. Further comments and status please look at the attached document. (ldr2009_2010)

The proposal about which fields that should be strongly recommended to enter made by Søren Schwartz Sørensen and Nils H. Persson were accepted. The mandatory fields are going to be visible color coded in the new LDR web version.

- STAMP

Lars Wennberg, member of STAMP committee, presented a STAMP status report with figures from the beginning (1st of March 2009) until today.

- 17 patients transplanted (18 transplantations)
 - 10 patients (11 transplantations) performed because of STAMP exchange obligation.
 - København – 1 patient
 - Oslo – 3 patients
 - Göteborg – 2 patients
 - Uppsala – 3 patients (4 transplants)
 - Stockholm – 1 patients

- 7 patients (7 transplantations) with STAMP record but not because of STAMP exchange obligation.
 - 1 exchange priority 1 (HLA identical) - Göteborg (1)
 - 6 no exchange, local donor - Göteborg (1) - Stockholm (1) - Helsinki (4)

Further details please look at the attached power point (STAMP NKG 2010)

- Intranet

Scandiatransplant office is still trying to sort out the best solution. In the near future a scheme that needs to be filled in with contact data will be sent by email to all Scandiatransplant related persons.(kontaktdatabase punkter.doc)

8. Definitions of words used within Scandiatransplant

Scandiatransplant office is asking for clear definitions of specific words. A short description of the problems were put forward and all attending the meeting were encouraged to look into the definitions. Look at attached document (definitioner.doc).

9. Next meeting and chairman of the meeting

23th of November 2011 – Magnús Bödvarsson will be chairman of the meeting which will be held in Copenhagen Airport.

Respectfully submitted by
Ilse D. Weinreich
2nd of December 2010