

Ninth annual meeting

23rd of November 2011 at Copenhagen Airport

Minutes of meeting

Present:

Nordic transplantation/nephrology departments:

Søren Schwartz Sørensen – Rigshospitalet, København

Clara Pålman – Universitetssjukhuset MAS, Skåne

Magnús Bödvarsson - Landspítali, Reykjavík

Lauri Kyllönen – Helsingin Yliopistollinen Keskussairaala, Helsinki

Gunnela Norden – Sahlgrenska Universitetssjukhuset; Göteborg

Kaj Anker Jørgensen – Århus Universitetshospital, Skejby

Claus Bistrup – Odense Universitetshospital

Lars Bäckman – Akademiska sjukhuset/Svenskt Njurrregister (SNR), Uppsala

Nordic Kidney Registries:

Torbjørn Leivestad – Norsk Nefrologiregister

Runólfur Pálsson - Islandsk Uræmiregister

James Heaf – Dansk Uremi register

Staffan Schön – Svenskt Njurrregister (SNR)

Nordic Transplantation Coordinators Group:

Carola Schauman, Helsinki

Scandiatransplant:

Bo H. Pedersen

Ilse D. Weinreich

Absent:

Lars Wennberg – Karolinska Universitetssjukhuset, Stockholm

Anne V. Reisæter – Rikshospitalet, Oslo

Frank Pedersen - Scandiatransplant

1. Welcome by meeting chairman Magnús Bödvarsson

2. Approval of last meetings minutes

<http://www.scandiatransplant.org/Minutes%20NKG%202010.pdf>

Minutes approved without any comments

3. Further matters to the agenda.

Exchange of Blood group incompatible kidney? – Torbjørn Leivestad (Was discussed under 'Status on STAMP')

4. (Re)election of NKG leader group - chair and national key persons 2011 – 2012:

Chairman for the next 2 years:

- Lars Bäckman

National Key persons:

- Lauri Kyllönen (FI)
- Anne V. Reisæter (NO)
- Lars Mjörnstedt (SE)
- Vacant (DK)
- Runólfur Pálsson (IS)
- Ilse Weinreich - Scandiatransplant

5. Definition of the main objectives of NKG

First draft made by Lauri Kyllönen was discussed and corrections were made. The leader group will work on the document, circulate it and put it up for approval next year at the NKG meeting.

Leader group tasks: NKG defines at the annual meeting each year what tasks should be looked into the next year.

It is necessary to specify how and for how long the key persons and chair should be elected. It was suggested that each country, before the annual meeting, agrees on whom is going to be the national key person.

Chairman candidates should be announced at least one week before the meeting. There is, to the groups knowledge, no formal pancreas group. It was suggested that matters concerning solid pancreas tx. could be included in the NKG, this was positive received by the group. The suggestion will be brought forward at the Representatives Meeting in may 2012 by NKG.

There is no limit of how many people that are allowed to attend the annual meeting. At least one representative from each center.

6. Information on the present status of 2010/53/EU

An overview was made by Søren S. Sørensen among others he explained about 'Delegates acts' that have not yet been clearly described, but might influence on the daily clinical practice. He encourage all to read the directive to be informed.

<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2010:207:0014:0029:EN:PDF>

7. Status on “Kidney exchange compliance” 2010 vs. 2011 and kidney payback balance

The *kidney exchange compliance* for 2010 (10 months) and 2011 (10 months) based on donor searches performed was presented.

- 2010

Total 311 searches of which there were 48 exchange obligations

Exchange obligation in 15% of all searches performed

In 2 out of 48 cases the exchange obligation was not followed (4,2%)

- 2011

Total 370 searches of which there were 52 exchange obligations

Exchange obligation in 14% of all searches performed

In 4 out 52 cases the exchange obligation was not followed (7,7%)

The 4 'new' cases were presented in details to the NKG. The deviations was accepted with no further actions.

Kidney payback overview was presented by Carola Schauman.

Return obligation:

Kidneys, which are exchanged on basis of above-mentioned criterions must be "paid back", and the return is aimed at being effected within six months, and if possible by a kidney of the same blood group as the one received. The organ offered in this way must be of a quality acceptable to the recipient center, regarding for instance technical quality, donor age and time of ischaemia.

It is difficult to make strict payback rules, because there is very different views on what good quality is. The problem cases, where a payback has not been possible/accepted for several years, are not increasing.

8. Evaluation of the exchange rules. Priority 1-5.

- The two adjustment suggested last year were approved at the representatives meeting in May 2011. They were set in action September 2011.
- It was discussed if adults should wait one year before acceptance to STAMP.

9. National Renal Registries - format and possibility of export.

Bo H. Pedersen informed about the format and possibilities for data import.

It was discussed why and what an import could be used for.

It was agreed upon that the only parameters that should be included from the beginning are patient death/alive and graft function/loss. Future additions to the import should be parameters that are registered in all Nordic registers.

The registries will send the data in Excel format, but the sctp staff encourage to consider the future export formats 'HL7', 'web-services'.

The Renal Registries should send data as soon as possible no later than 1st. of Marts 2012.

The dataset should included transplantations from 1995 to 31st. of Dec. 2010.

10. A future group on discussion of exchange rule no. 5 (HLA-A, -B, -DR compatibility and CIT) ?

Not relevant until data has been imported from the National Renal Registries.

11. Status on

- **Scandiatransplant staff**

The current situation was presented. In short the staff has an increasing workload and is still in need of more manpower.

- **Newsletters**

The office encourage all who needs information distributed throughout the organisation, to send it by email, then it will be brought in the next newsletter.

- **NLDR – Mandatory and voluntary fields + overall use of the registry.**

Mandatory fields should be mandatory, a possibility to save an unfinished record as a draft is going to be made.

- **STAMP**

Torbjørn Leivestad gave an update on STAMP which started April 2009.

By November 22, 2011, 53 patients are listed (36 transplantable; 17 temporarily

Withdrawn) *AR:2, CP:5, GO:12, HE:13, OS:8, ST:10, UP:3*

STAMP Transplants performed:

Exchanged: 19 (+ 2 matched on priority 1)

Local: 15 (4 "STAMP", 11 "non-STAMP")

Local Living Kidney Donor tx.: 1 (*AR* – not followed).

Exchanges with positive X-match: 8.

Permanently withdrawn: 3 + ?

Exchange of Blood group incompatible kidney

Is not relevant at the time being due to different AB0 titration techniques/levels.

- **Temporarily withdrawn (one year, NT reconfirmed else PW)**

The quality control in Scandiatransplant was shown 'Main menu -> Quality control -> KI patients long-term Not Transplantable'. The NKG stated that it is not practical possible to reconfirm NT.

12. Changes in Scandiatransplant statistics

Two adjustments have been made:

- By inspiration from the definition diagram 'The Critical pathways for organ donation' the Sctp board decided to change the deceased donor definition.

The definitions used are eligible donor (prev. term accepted donor), actual donor (prev. term realized donor) and Utilized donor.

<http://www.scandiatransplant.org/SCTP%20News%20May%202011.pdf>

- PMP is only presented for each country, because it is difficult to find the correct number for each center.
- Retrieved organs per donor will be presented as an addition when the statistic for 2011 have been made. Probably ready for presentation at STS congress 2012.

13. Scandinavian Transplantation Society XXVI Congress

The planning is ongoing and Magnús Bödvarsson welcomes all to attend the congress

<http://congress.is/STS2012/homepage.aspx>

14. Upcoming Tissue Typers Meeting - Uppsala Monday 06-Feb-2012

No comments

15. Next meeting

Kastrup, Copenhagen Airport, November 21, 2012.

Chairman will be Lars Bäckman.

Minutes are respectfully submitted by

Ilse D. Weinreich

1st of December 2011