

**Tenth annual meeting**

**21<sup>st</sup> of November 2012 at Copenhagen Airport**

**Minutes of meeting**

**Present:**

**Nordic transplantation/nephrology departments:**

Søren Schwartz Sørensen – København

Clara Pählman – Skåne

Magnús Bødvarsson – Reykjavik

Lauri Kyllönen – Helsinki (+ Finish Kidney Registry)

Lars Mjörnstedt – Göteborg

Claus Bistrup – Odense

Lars Bäckman – Uppsala

Anna V. Reisæter – Oslo

Kaj Anker Jørgensen – Aarhus

**Nordic Kidney Registries:**

Torbjørn Leivestad – Norsk Nefrologiregister

Runólfur Pálsson – Islandsk Uræmiregister (+ Landspítali, Reykjavik)

James Heaf – Dansk Uremi register

KG Prütz – Svenskt Njur Register

**Nordic Transplantation Coordinators Group:**

Pernille van Houten - København

**Scandiatransplant:**

Frank Pedersen – Scandiatransplant

Ilse Duus Weinreich – Scandiatransplant

**Absent:**

Lars Wennberg – Stockholm

- **Welcome by meeting chairman Lars Bäckman**

- **Approval of last meetings minuts**

<http://www.scandiatransplant.org/members/nkg/Minutes%20NKG%202011.pdf>

Accepted without further comments

- **Status from each centre and registry (developments, phase-out, structural changes e.g.)**

Uppsala more recipients transplanted with kidneys from deceased donors this year, 106 until today.

Göteborg same donor frequency. Living donor increasing including ABO incompatibility

Helsinki more living kidney donors 10 this year and 6 pancreas transplantations. Lauri Kyllönen will go on pension soon, but he will keep working with the Finish kidney registry.

Odense low number of deceased donors this year, why most transplantations are with kidneys from living donors.

Scandiatransplant new medical director Kaj Anker Jørgensen – keeping the old database up and running, while we are also working on the new user interface. The fax serve breakdown and the making of a new and more modern solution has taken quiet some time.

Aarhus collaboration with Oslo about combined Kidney-Pancreas transplantations.

Reykjavik 6 living kidney donor transplantations. - 6 recipients transplanted in Göteborg with kidneys from deceased donors 2 of these through the STAMP program.

Oslo last year was the best year ever with 302 transplantations with kidneys from deceased donor transplantations. Documentary television broadcast might have been the reason why the numbers went up. Due to the amount of kidneys from deceased donors (approx 70% of the kidney transplantations) living kidney donor transplantations (30%) has gone down

Copenhagen number of deceased donors have gone down. It might be do to a documentary about 'Pigen der ikke ville dø'. (The girl who wouldn't die)

Skåne kidney and thoracic department were suppose to merge but without success

In all countries initiatives to get higher numbers of deceased donors have been initiated, however the impact of these actions seems to be small. This lead to a talk about the following topics:

What is the difference between Norway and rest of the Nordic countries?

Resources at intensive care unit, donor responsible doctors, attitude, ethics, training  
Norway or Spain as a role model?

- **Announcement of NKG national key persons 2012-2013**

- Lauri Kyllönen (FI)
- Anna V. Reisæter (NO)
- KG Prütz (SE)
- Claus Bistrup (DK)
- Runólfur Pálsson (IS)
- Ilse Weinreich (Scandiatransplant)

- **Approval of the main objectives of NKG**

A few corrections were made and the by laws were accepted

<http://www.scandiatransplant.org/members/nkg/by-law>

- **The possible role of NKG members to report to competent authorities**

*Directive 2010/53/EU*

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

*'standards of quality and safety of human organs intended for transplantation'*.

Scandiatransplant has implemented the missing parameters according to appendix A, however the role of Scandiatransplant is still unknown.

*New directive 2012/25/EU*

<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2012:275:0027:0032:EN:PDF>

*'laying down information procedures for the exchange, between Member States, of human organs intended for transplantation'*.

This directive concerns serious adverse events and reactions, which at the moment is a matter for the national health authorities.

- **Status on 'Kidney exchange compliance'**

In the first 10 months of 2012 a total of 351 searches for recipients in relation with a deceased donor were done in the database.

In 14% (48 of 351) of these searches exchange obligation(s) occurred.

In 2,1% (1 of 48) the exchange rules was not followed, due to a minor deviation, which was accepted.

Conclusion: Compliance to the kidney exchange rules has improved over the years and the figures are very satisfying.

- **Kidney payback overview**

Each centre has its own way to register kidney import and export, which makes it quiet difficult and time consuming to check the balance. However, with great effort it was possible to get an import/export balance between the centres and it seemed to be in a good state.

It might be possible with some extra programming and registration to extract the balance from the Scandiatransplant database.

- **Evaluation of the exchange rules**

- Priority 1-5.

Suggestion: Exchange obligation 2 (Immunized patients (PRA  $\geq$  10% but below 80%) who are HLA-A,-B,-DR compatible with donor ) and 3 (Patient with STAMP-status) shift place.

Conclusion: All accepted the proposal. Lars Bäckman will send a written proposal to the Scandiatransplant office and will present it at the Council of Representatives Meeting May 2013.

The kidney exchange rules have been updated by adding HLA-C in the STAMP priority according to what was decided at the Council of Representatives Meeting May 2012.

<http://www.scandiatransplant.org/organ-allocation/Engelskriterierudvekslingnyrerfraafdddonorrepr9maj2012.pdf>

- **Status on**

- Nordic Kidney Registries - format and possibility of import/export (meeting held 17<sup>th</sup> of October 2012).

In which format to import data from the renal registries was decided at the meeting held 17<sup>th</sup> of October 2012. Last date of import is 1<sup>st</sup> of April 2013. The aim is to use Torbjørn Leivistads earlier report with figures from the registry year 1995-2006 as a template for an annual report. All are welcome to bring forward new suggestions for an annual report.

The 'old' report: <http://www.scandiatransplant.org/members/nkg/NKGmay08.pdf>

- NLDR (Donor relation codes)

Torbjørn Leivestad presented the present list of donor-recipient relation codes and the distribution. The question was if all the codes are necessary and meaningful. As an example the two categories 'mother' and 'father' could be narrowed down to one called 'parents'. However gender is not mandatory and if it is decided to narrow the codes down it will not be possible to go back again. Sibling and haplo spec. is not correctly registered in all cases, however this can be deduce from the tissue types.

The group was asked to consider pro and cons about narrowing down the number of relation codes.

- STAMP

Since the beginning there has been 11 positive cross matches (2009:1; 2010: 4; 2011: 6; 2012: none by Oct.). Since the beginning HLA DQ and lately Cw have been added in the donor typing and the STAMP matching algorithm.

7 STAMP recipients have been transplanted due to exchange obligation priority 1 (Highly immunized and HLA-A,B- and DR compatible) and not the STAMP program.

40 STAMP recipients have been transplanted due to exchange obligation priority 3 (STAMP).

16 STAMP recipients have been transplanted locally against DSA.

*Conclusions on the STAMP program so fare*

Too many positive cross matches, however the number seems to be decreasing.

Post transplantation graft survival: acceptable; > 90% 1 year graft survival

Post transplantation rejections: acceptable; ~20%

Not all patients can be helped by STAMP, however not all that can be helped by STAMP are on STAMP.

- Homepage

The new layout of the homepage were shown and all were encouraged to take a look at it. NKG has its own menu with by-laws, guidelines and minutes from meeting.

- **Proposal: Nordic exchange of survival data from the ERA-EDTA**

Sweden reports renal data to ERA-EDTA and Scandiatransplant. ERA-EDTA delivers two reports an annual report and a survival report. The survival report compares Sweden with other participating European countries on a variety of parameters and it is considered confidential. Internal Sweden comparisons are done between counties. The question is if it is correct and valid to compare figures between the countries included in the report. The mentality and ways of reporting are comparable in the Nordic countries. KG Prütz asked if the people attending the meeting had the mandate to allow such comparison between the Nordic countries. This was not the case, KG Prütz will contact the relevant persons directly.

- **Donations from patients with multiple sclerosis**

The background for this topic was an incident in Copenhagen where a possible donor with multiple sclerosis was declined due to multiple sclerosis (MS). In some countries blood donation from people with MS are allowed in others not. No one at the meeting had experienced a case where MS had been transmitted from donor to recipient. The final statement was that it is never without risk to receive a kidney transplantation.

- **Possible pretreatment of donor/recipient with Rituximab as prophylaxis for passenger lymphocyte syndrome**

The prophylaxis use of Rituximab for the treatment of passenger lymphocytes syndrome was discussed it seems that Rituximab may be an effective therapy though the experience is limited.

- **Upcoming Tissue Typers Meeting – Copenhagen 2013**

The Tissue Typers Group will be informed and asked about their opinion on the proposal concerning exchange obligation 2 and 3 shifting priority.

- **Next meeting**

20<sup>th</sup> of November 2013 at Hilton, Copenhagen Airport