

News from Scandiatransplant office December - 2010



Introduction

You have here the third newsletter with information from Scandiatransplant office. This time the main theme is based on the Nordic Kidney Group (NKG) meeting held the 24th of November 2010 in Copenhagen. Among other things NKG, at the yearly meeting, evaluate kidney exchange rules and other official Scandiatransplant related politics and documents. This close cooperation with NKG is greatly appreciated by Scandiatransplant office.

Furthermore this newsletter contains news from the programmers written by Bo Hedemark Pedersen and news from Director Niels Grunnet.

All newsletters you'll find on the web page www.scandiatransplant.org under <http://www.scandiatransplant.org/news/newsletter-2012>

Meetings held in 2010:

1. Minutes from Scandiatransplant board meeting March 2010
www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/Sctp_board_nr_56_Goteborg_3_marts_2010.pdf
2. Minutes from Scandiatransplant board meeting May 2010
www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-board/Sctp_board_nr_57_Helsinki_18-19_may_2010.pdf
3. Minutes from Scandiatransplant board meeting September 2010
<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/Sctp%20board%20nr%2058%20Aarhus%2020-21%20sep%202010.pdf/>
4. Minutes from the Scandiatransplant council of representative meeting may 2010
http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/Sctp_rep_2010.pdf
5. Minutes from Nordic Transplantation committee
<http://www.scandiatransplant.org/members/ntc/minutes>
6. Minutes from NKG meeting 2010
<http://www.scandiatransplant.org/members/nkg/minutes>
7. Minutes from NTCG meeting September 2010
<http://www.scandiatransplant.org/members/ntcg/minutes>
8. Minutes from Tissue Typers Meeting January 2010
<http://www.scandiatransplant.org/members/sttg/minutes>
9. Minutes from NTTSG meeting September 2010 – not received yet
10. Minutes from NLTR meeting September 2010 – not received yet
11. Minutes from NPRTSG meeting – not received yet

Purpose

By this information letter we wish to communicate to you about the office status and progress within the system, collaboration with groups related to Scandiatransplant and ongoing working projects.

We hope that you will read it and shared the information with whom it might concern.

As always don't hesitated to contact us for further information, ideas, problems and help.

Both Frank and Ilse receives a mail when writing to:

help@scandiatransplant.org

Frank Pedersen

frank.pedersen@scandiatransplant.org

Ilse Duus Weinreich

ilse.duus.weinreich@scandiatransplant.org

Scandiatransplant
Århus Universitetshospital, Skejby
DK - 8200 Aarhus N
Denmark
Phone +45 8949 5308

Content

- 1 Theme NKG
 - 1.1 History and purpose of the group
 - 1.2 Kidney exchange rules
 - 1.3 Kidney exchange compliance
 - 1.4 Follow up
- 2 News from programmers (Bo Hedemark Pedersen)
- 3 News from the directors office (Niels Grunnet/Susanne Sønder)
- 4 Definitions of words used within Scandiatransplant
- 5 Ongoing working projects
- 6 Season greetings from Scandiatransplant office

... and in further details

1. Theme NKG

1.1 History and purpose of NKG

NKG was constituted in 2003; surgeons, nephrologists, representatives from the Nordic uraemia registries, representatives from Scandiatransplant and observers from NTCG and Tissue Typers Group, have since then met yearly. The attendance of people from all these different fields gives an important understanding of what is going on at the moment, and makes developments and changes to the system possible.

The main objectives of the group are to discuss and evaluate data sharing and politics, publications, research and kidney exchange rules.

1.2 Kidney exchange rules

On the agenda every year is the evaluation of the kidney exchange rules which are written and easily accessible to all at [www.scandiatransplant.org/about-scandiatransplant/organisation/Rules for exchange of Kidney from deceased.pdf/](http://www.scandiatransplant.org/about-scandiatransplant/organisation/Rules%20for%20exchange%20of%20Kidney%20from%20deceased.pdf/).

Any suggestions about new rules or changes to existing rules are discussed and if possible an extraction from the database is made beforehand to illustrate the effect of the change. The proposals which are decided on at the meeting will be presented at the Scandiatransplant Council of Representatives Meeting and here the final decisions are made.

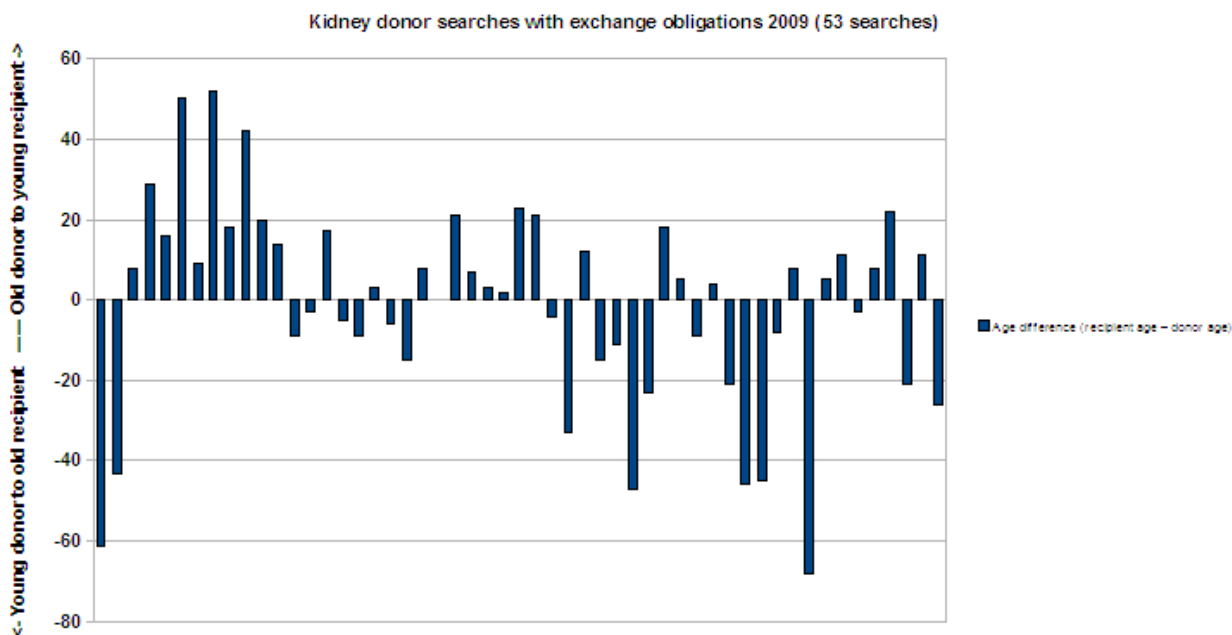
At previous meetings some of the topics up for discussion have been the implementation of acceptable mismatch program (STAMP) and payback. This year the following 3 proposals were discussed.

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

An extraction from the database showed that it concerns approximately one child a year. The proposal was accepted by NKG.

- Limit on age discrepancy between donor and recipient

Below you can see an extraction from the database as a diagram of age difference between donor and recipient in 2009 (10 months) in relation with exchange obligations (all rules).



It was decided by NKG that the age difference between organ donor and recipient should not be more than 30 years. This will apply only when a young donor kidney is offered to an old recipient, and only in connection to exchange rule 5 (HLA compatibility in PRA-negative recipient).

- Discussion of exchange rule no. 5 (HLA-A, -B, -DR compatibility) versus prolonged Cold ischemia time

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

1.3 Kidney exchange compliance

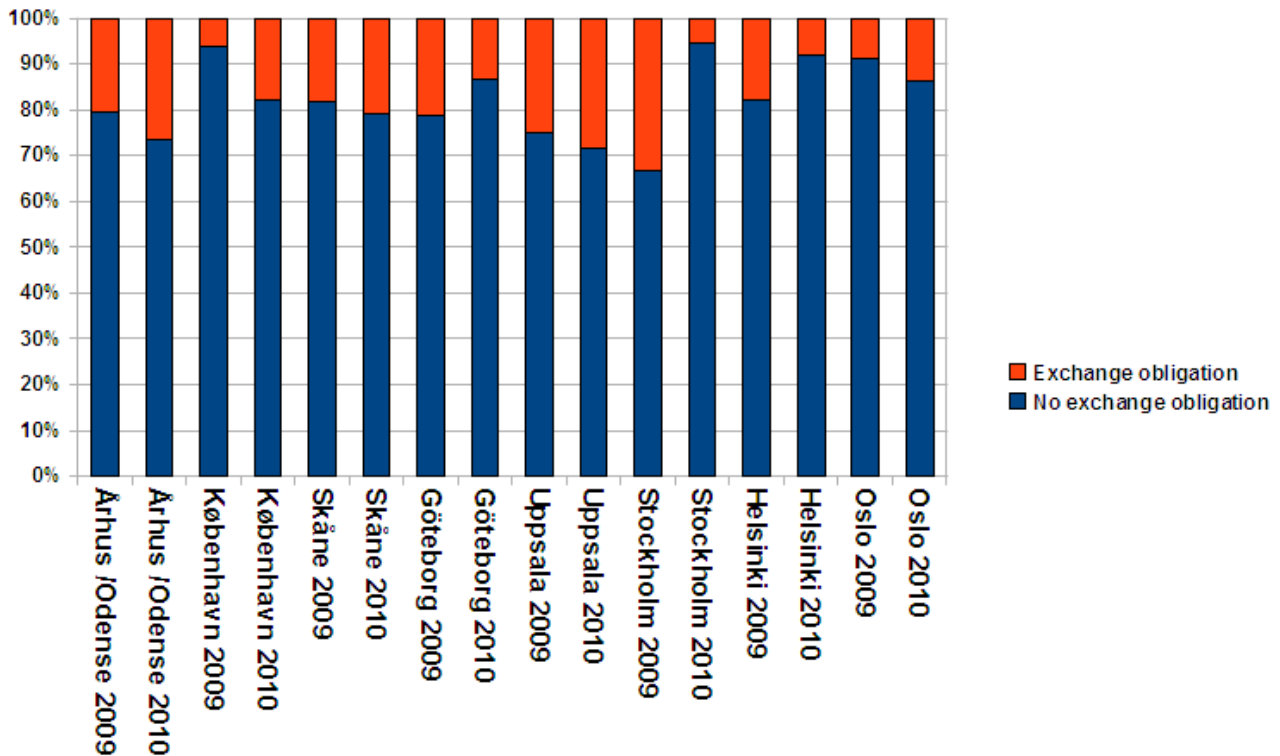
Kidney exchange compliance according to Scandiatransplant rules are continuously checked by the office by checking the donor search log and all deceased donor registered in Scandiatransplant.

- 2009 (1st of March to 31st of December – 10 months)
Total 330 searches – of which there were 53 exchange obligations.
This gives exchange obligation in 16% of all searches performed.
In 5,7% of the cases the exchange obligations were not followed (3 out of 53)
- 2010 (1st of January to 31st of October - 10 months)
Total 311 searches – of which there were 48 exchange obligations.
This gives exchange obligation in 15% of all searches performed.
In 4,2% of the cases the exchange obligations were not followed (2 out of 48)

The explanations for deviation from the exchange rules were presented and discussed at the meeting. It was agreed that actual errors had occurred but the deviations were minor and that the results from all centers shows that

everyone does a very fine job.

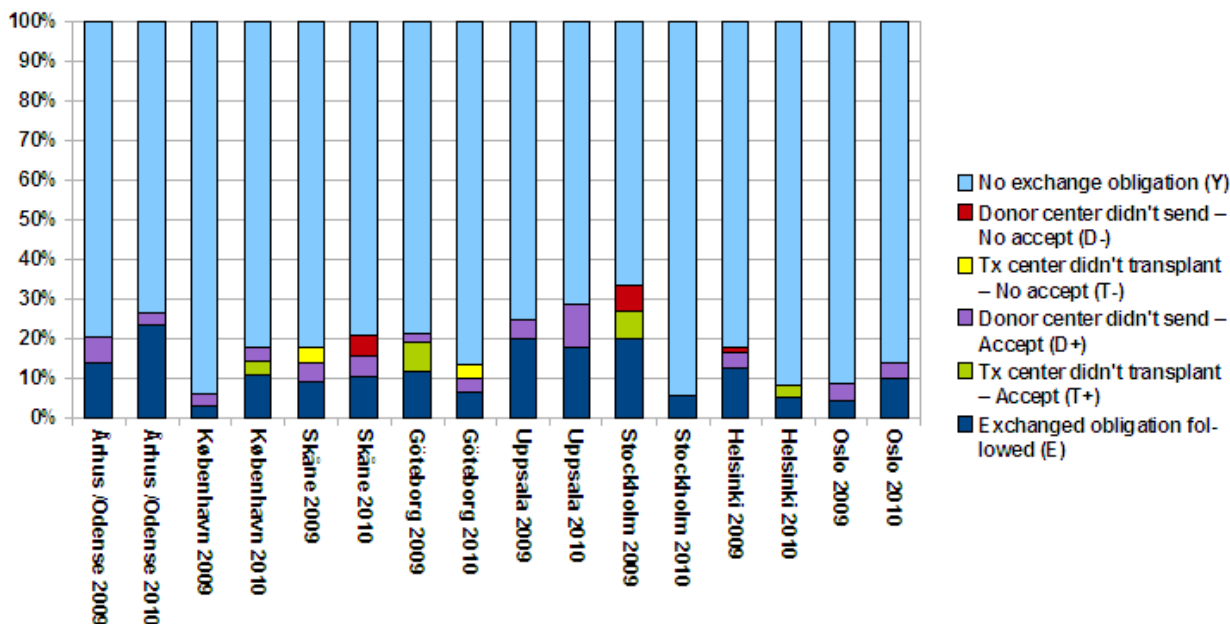
The diagram below shows the distribution of searches by centers with and without exchange obligation. It is a percentage comparison based on all kidney searches performed in connection with deceased donors.



In the previous newsletters we have presented the search compliance log. As you might remember, we mark every kidney search performed with one of the following codes.

| | |
|----|---|
| Y | = Checked - no exchange obligation |
| N | = Not checked yet (default) – real/test/multiple searches to be verified/deleted |
| O | = Open - Center answer pending (request have been send to a center for explanation) |
| T+ | = Transplanting Center - didn't transplant organ to the right recipient according to exchange rules - Acceptable explanation |
| D+ | = Donor Center - didn't send organ to (the right) tx center - Acceptable explanation |
| T- | = Transplanting Center - didn't transplant organ to the right recipient according to exchange rules or forgot to take patient off waiting list after transplantation - Unacceptable explanation |
| D- | = Donor Center - didn't send organ to (the right) tx center - Unacceptable explanation |
| E | = Organ(s) exchanged according to rules |

The diagram below illustrates the grouping into these codes with all the searches mentioned earlier.



1.4 Follow up

Living Donor Register (LDR)

The current status of entering data into LDR were shown and talked about at the meeting.

Oslo, Odense, Malmö, Uppsala, and Stockholm use LDR continuously with no problems. Århus and København still have some data on paper that needs to be enter into the system. Helsinki and Reykjavik asked for help with introduction to LDR from the Scandiatransplant staff.

Göteborg would like, as Malmö, to import data from own registry into Scandiatransplant.

It was decided which parameters are strongly recommended to be entered. These parameters are going to be colour-coded in the new LDR web version.

Follow up on kidney transplant results

The follow up information in the system on kidney recipients has until now been at a minimum set of data.

However the incorporation of Nordic Pediatric Renal Transplant Study Groups (NPRRTSG) data into Scandiatransplant is done and the programming will form the basis of the import from the uraemia registries of transplantation and follow up information on all patients.

2. News from programmers

During autumn the IT-resources have been spend on:

- New servers are (almost) established to make sure we have mechanical backup, when or if the old servers gives up on us.
- Surveillance on servers regarding configuration and administrative setup in general. These are necessary steps towards a robust and developing environment, so that we can add new features and keep the various communication-channels securely updated, without disturbing the users.
- Functionality to restart and swap the application between servers is one of the time-consuming additions that will allow us to make changes beyond usual system-windows.
- Thorax conversion to web are still not polished enough to show off. But we have been through all the data-elements, which have also revealed issues in the existing system to be dealt with.
- Due to reduced man-powers we still have some issues with the living-donor parts in the new web-system; and we're still working on how to expand the technical staff.
- New time-lines are being estimated and discussed to be exposed in the middle of January.

3. News from the directors office

Scandiatransplant travel grants 2011

Frist for ansøgning er d. 10. jan. 2011

Ansøgning bedes sendt til e-mail adr.: scandiatransplant.office@rm.dk.

You will find the application form and guidelines at www.scandiatransplant.org under 'Scandiatransplant travel sponsorship for 2011'.

4. Definitions of words used within Scandiatransplant

4.1 Definitions

Scandiatransplant office is asking, on behalf of our users, for clear definitions of specific words well knowing that definitions are tricky. We would like to encouraged you to look at the definitions and respond to us with any comments and corrections you might have. The final document will be presented to the Scandiatransplant board and Council of Representatives.

Accepted donors:

The following issues have to be fulfilled and accepted: Consent to donation, certified dead according to existing laws, donor evaluation, medical and clinical examination.

Realized donors:

Every donor from whom at least one solid organ has been retrieved for the purpose of transplantation.

Multi organ donors:

Every donor from whom at least two different solid organ has been retrieved for the purpose of transplantation.

Vascularised organs:

Arrangement of tissue which, if wholly removed, cannot be replicated by the body

Solid organs:

A differentiated and vital part of the body, formed by different tissues, that maintains its structure, vascularisation and capacity to develop physiological functions with an important level of autonomy.

For instance kidney, liver, heart, lung, pancreas and small bowel

Microorgans:

Cells when bound by a form of connective tissue.

For instance pancreatic Islets cells

Tissues:

All constituent parts of the human body formed by cells.

For instance bone, corneas, cardiovascular tissues (including heart valves)

Cells:

Individual cells or cells when not bound by any form of connective tissue.

For instance hepatocytes

Sources:

Council of Europe, Guide to safety and quality assurance for organs, tissue and cells, 3rd edition, 2006

Newsletter Transplant 2009, ONT

The voices off Scandiatransplant members

4.2 Transplantation?

What do members of Scandiatransplant consider and agree on as a transplantation, what should be counted in the statistic and payed for, solid organs and microorgans?

4.3 Pediatric recipients

How should pediatric recipients be defined?

ONT-newsletter <15, SCTP exchange obligation <16, internal danish rule <18

5. Intranet

Scandiatransplant office has now sorted out a solution for an intranet. The first developments will be to create a contact database and a forum for discussion. In the near future a scheme that needs to be filled out with contact data will be send by email to all Scandiatransplant related persons.

6. Listing of ongoing working projects

LDR web version – final phase

Thorax register web version

Import scripts - LDR (Göteborg)

Import scripts - LDR follow up (Göteborg+Malmö)

Import scripts - Nordic Uraemia Registries

Development of intranet with contact database and forum for discussion

Various extractions

Registration of kidney payback

Registration of liver payback

Hepatocyt/intestine/small bowel waiting list and transplantation

Clarification of rotation and exchange rules concerning liver

Clarification of rotation and exchange rules concerning heart

Clarification of rotation and exchange rules concerning lung

7. Season greetings from Scandiatransplant office

Finally we wish you all a Merry Christmas and a Happy New Year

