Introduction

This fourth newsletter with information from Scandiatransplant office is the 'Annually status report 2010-2011'. It is the offices addendum to point 11 'Report of activities' on the agenda for the Scandiatransplant Council of Representatives' meeting May 25, 2011.

We would like to encourage those of you that needs to have information, related to Scandiatransplant, communicated to the whole organisation, to write to us. We will then include your information in the next newsletter.


On the web page, as a new initiative, you will also find a list with links to relevant courses supplied by you.

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 share 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

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1. Annually status report 2010-2011

1.1 The Reference group on prevention of transmission of infectious diseases from donors to recipients
We have not received any minutes from meetings or any enquiries from the group within the past year.

1.2 The Tissue typers' Group (including STAMP)
The annual meeting in the Tissue typers’ group was held in Göteborg, January 2010 with attendance from Scandiatransplant staff.  
This meeting and a STAMP meeting lead to the following list of wishes for additions to the system:

• Local STAMP – LAMP, same structure as STAMP, but patients does not need to fulfil all STAMP criteria and is only a locally priority patient.
• Quality control – antibody screentest
• Possibility to enter cause of temporarily withdrawal from STAMP
• Donor specific antibodies shown when doing searches
• Possibility to inactivate identified antibodies
• Automatically check of all STAMP criteria
• New antibody code – LI – low immunized used for patients with PRA 1-9% and identified antibodies with PRA 0%
• Donor pool with possibility for calculated PRA and transplantability

All these items are being programmed and tested. They will be introduced in details in the next newsletter.

1.3 The Nordic Kidney Group
The annual meeting was held in København with attendance of Scandiatransplant staff  
(http://www.scandiatransplant.org/members/nkg/MinutesNKG2010.pdf)
The next couple of pages shows the results of compliance to Scandiatransplant kidney exchange rules which are based on all kidney searches performed in connection with deceased donors for the year 2010.
This first diagram shows the activity on each center divided into the number of donor searches with and without exchange obligation.

The second diagram also shows the distribution of searches by centers with and without exchange obligation, but the number of donor searches are shown as a percentage comparison.
This last diagram illustrates the percentage distribution of all kidney searches performed in connection with deceased donors for the year 2010 divided into the compliance codes which are further described below.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Y</td>
<td>Checked - no exchange obligation</td>
</tr>
<tr>
<td>N</td>
<td>Not checked yet (default) – real/test/multiple searches to be verified/deleted</td>
</tr>
<tr>
<td>O</td>
<td>Open - Center answer pending (request have been send to a center for explanation)</td>
</tr>
<tr>
<td>T+</td>
<td>Transplanting Center - didn't transplant organ to the right recipient according to exchange rules - Acceptable explanation</td>
</tr>
<tr>
<td>D+</td>
<td>Donor Center - didn't send organ to (the right) tx center - Acceptable explanation</td>
</tr>
<tr>
<td>T-</td>
<td>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</td>
</tr>
<tr>
<td>D-</td>
<td>Donor Center - didn't send organ to (the right) tx center or made a wrong tissue typing result - Unacceptable explanation</td>
</tr>
<tr>
<td>E</td>
<td>Organ(s) exchanged according to rules</td>
</tr>
</tbody>
</table>

In 2010 a total of 676 patients were transplanted with kidneys from deceased donors. 361 kidney searches were performed in connection with the deceased donors.

58 of the 361 kidney searches resulted in a kidney exchange obligation.

*In 4 out of 58 exchange obligations the kidney exchange rules were not followed (6.9%)*
58 exchange obligations out of the total amount of 676 patients transplanted gives an overall exchange obligation rate for kidneys on 8.6%.

1.3.1. Comment to kidney exchange compliance and more

The results above were presented at the Nordic Kidney Group meeting November, 2010.

Section from the minutes:
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.

http://www.scandiatransplant.org/members/nkg/MinutesNKG2010.pdf

New import scripts for data from the Nordic Uraemia Registries is still an open issue.

1.4 The Nordic Liver Transplant Group

We have received the minutes from the Nordic Liver Transplant Group meeting held in København, November, 2010. Scandiatransplant staff were invited to participate, however we were notified very late, why it was not possible for any of us to attend.


The nicely written annual report made by Tom H. Karlsen is available on the web page


In 2010 a total of 308 patients were transplanted with livers from deceased donors.

42 of these transplants were performed with livers exchanged between countries (Urgency HU + T).
20 of these livers were exchanged to high urgent patients after which no centers were rotated according to the liver rotalist agreement.
1 liver was exchanged due to a kind request the receiving center was not rotated.
21 spare livers were exchanged between countries after which 16 centers were rotated according to the rotalist and 4 were not (of which 3 were split livers).

In 4 out of 21 exchanges of spare livers between countries the receiving center were not rotated (19%).
1.4.1. **Comment to liver exchange and rotation**

As an attempt to clarify and standardise the Scandiatransplant documents for organ exchange and rotation according to the roster list the Scandiatransplant office has from the originally documents (http://www.scandiatransplant.org/organ-allocation/Liver_rotation_manual_27jun2011Manualforliverorgan.pdf/at_download/file) tried to create a new and updated version. The draft is presented in the next section.

Furthermore an open issue still exists whether an exchange of liver due to kind request should result in rotation of receiving center. If no rotation has to be done the liver must be paid back.

The results above on exchange and rotation, the new document and the uncertainty about rotation in context with kind request, urges a respond from the leaders and members involved in the liver group. A way around the problems need to be found or the check of compliance by the office will not be possible.

1.4.2. **DRAFT – Liver exchange and rotation**

**Exchange and rotation rules regarding liver from deceased donor within the Scandiatransplant cooperation**

These exchange and rotation rules were agreed on , 2011 and is a supplement to the 'Manual for Liver Organ exchange in the Scandiatransplant area' from 2007.

All active liver recipients in the Scandiatransplant countries shall be registered in the Scandiatransplant database and actively sought for by the transplant coordinators when a compatible liver is available.

**Definition of liver patients**

- Urgency HU: Highly urgent – To be transplanted within 72 hours
- Urgency T: Transplantable patient
- Urgency NT: Currently not transplantable

**Exchange rules**

1. Own country urgency HU patients
2. Scandiatransplant urgency HU patients
3. Own country urgency T patients
4. Scandiatransplant urgency T patients to the center highest on the rotation list (defines a spare liver)
   - Only the accepting center is rotated.
   - Donor center is responsible for rotation a.s.a.p.

*Rotation has to be done when a spare liver is offered and accepted of another*
Elaborations

- When you have a spare liver all the other centers must be contacted
- All centers must respond positive/negative to the offer within 30 minutes
- Whether a spare live is offered as a hole or a split liver the accepting center must be rotated.
- Livers exchanged between countries due to urgent call must be "paid back" within 6 month. The organ offered in this way must be of identical blood group.

The above rules will be set in action from 2011 and inserted on Scandiatransplants homepage from the same day.

The practice of these exchange and rotation rules should be assessed by the NLTR meeting in the fall 2011

1.5 The Nordic Thoracic Transplant Group

The office have not received any minutes or been invited to any meetings in the thoracic group.

1.5.1. Heart exchange and rotation 2010

In 2010 a total of 130 patients were transplanted with hearts from deceased donors. 31 of these transplants were performed with hearts exchanged between countries (Urgency 0 + 2).
9 of these hearts were exchanged to patients with urgency 0 after which 5 centers were rotated according to the rotalist and 4 were not.
22 hearts exchanged to patients with urgency 2 after which 19 centers were rotated according to the rotalist and 3 were not.

In 7 out of 31 hearts exchanged between countries the receiving center were not rotated (23%).

1.5.2. Lung exchange and rotation 2010

In 2010 a total of 129 patients were transplanted with lungs from deceased donors. 13 of these transplants were performed with lungs exchanged between countries (Urgency 0 + 1 + 2).
5 of these lungs were exchanged to patients with urgency 1 after which 3 centers were rotated according to the rotalist and 2 were not.
8 lungs exchanged to patients with urgency 2 after which all 8 receiving centers were rotated according to the rotalist.

In 2 out of 13 lungs exchanged between countries the receiving center were not rotated (15%).

Number of used urgency tickets (Urgency 0 + 1) per center:
Skåne: 2
Helsinki: 3
Göteborg: 2
Oslo: 2
København: 3

1.5.3. **Comment to heart and lung exchange and rotation**

The results above together with several mails and phone calls to the office, proved doubts on how to interpret the exchange and rotation rules rules. In the Scandiatransplant office this let to making drafts from the originally document [http://www.scandiatransplant.org/members/nttr/Manual%20Thorax%20rota%2030%20apr%202009.pdf/at_download/file](http://www.scandiatransplant.org/members/nttr/Manual%20Thorax%20rota%2030%20apr%202009.pdf/at_download/file) as an attempt to clarify and standardise the documents on exchange and rotation.

These new documents were made as suggestions/drafts and only as a try to solve the interpretation problems of the rules.

In the office we very much need a respond from the leaders and members involved in the thoracic group. *A way around the problem need to be found or the check of compliance by the office will not be possible.*

1.5.4. **DRAFT – Heart exchange and rotation**

**Exchange and rotation rules regarding heart from deceased donor within the Scandiatransplant cooperation**

These exchange and rotation rules were agreed on , 2011 and replace guidelines of March 18, 2009.

All active heart and heart-lung recipients in the Scandiatransplant countries shall be registered in the Scandiatransplant database and actively sought for by the transplant co-ordinators when a compatible organ is available.

**Definition of heart patients**

- Urgency 0: Patient on short-term assist devices (ECMO, centrifugal pump), patient on paracorporeal or implantable blood pump with device failure or uncontrollable device infection, patients below 16 years on inotropic support or more than 12 months support on implantable LVAS.
- Urgency 2: Transplantable patient
- Urgency 3: Currently not transplantable

**Exchange rules**

1. Own country urgency 0 patients
2. Scandiatransplant urgency 0 patients to the center highest on the rotation list
3. Only the accepting center is rotated.
4. Donor center is responsible for rotation a.s.a.p.
5. Own country urgency 2 patients
6. Scandiatransplant urgency 2 patients to the center highest on the rotation list
7. Only the accepting center is rotated.
   • Donor center is responsible for rotation a.s.a.p.
   • Other European organ exchange organisations

Rotation has to be done when a heart is offered to another country and accepted to urgency 0 and 2 patient

Elaborations

- If both heart and lungs are offered from a single donor, only the center on top of the lung rota-list is entitled to have both organs for either a heart-lung recipient or a lung recipient. If a center accepts both heart and lung and dived the organs into two patients, rotation on both lists must be preformed.

- Blood group compatibility is only required for organ exchange. Donor–recipient match is the responsibility of the transplanting center

- A center that receives an organ offer should accept the organ within half an hour. The center has the right to decline the offer, then centers with patients of the same urgency, ranked by the “rotalist”, should be notified.

- Urgent call on urgency 0 patients shall be renewed weekly. Call should be closed immediately when patient status is changed.

The above rules will be set in action from           , 2011 and inserted on Scandiatransplants homepage from the same day.

The practice of these exchange and rotation rules should be assessed by the NTSG meeting in the fall 2011

1.5.5. **DRAFT – Lung exchange and rotation**

Exchange and rotation rules regarding lungs from deceased donor within the Scandiatransplant cooperation

These exchange and rotation rules were agreed on           , 2011 and replace guidelines of March 18, 2009.

All active lung and heart–lung recipients in the Scandiatransplant countries shall be registered in the Scandiatransplant database and actively sought for by the transplant co-ordinators when a compatible organ is available.

**Definition of lung patients**

- Urgency 0: Patient on extra-corporeal circulatory support (ECMO, Novalung or other device) or ventilatory support*.
- Urgency 1: Patient with a rapid progression of organ failure with poor prognosis in a short time defined by the responsible center*.
• Urgency 2: Transplantable patient
• Urgency 3: Currently not transplantable
* Each center has the right to claim urgency 0 and 1 for a total of three patients each year.

Exchange rules

1. Own country urgency 0 or 1 patients
2. Scandiatransplant urgency 0 or 1 patients to the center highest on the rotation list
   • Only the accepting center is rotated.
   • Donor center is responsible for rotation a.s.a.p.
3. Own country urgency 2 patients
4. Scandiatransplant urgency 2 patients to the center highest on the rotation list
   • Only the accepting center is rotated.
   • Donor center is responsible for rotation a.s.a.p.
5. Other European organ exchange organisations

Rotation has to be done when a lung is offered to another country and accepted to urgency 0, 1 and 2 patient.

Elaborations

• If both heart and lungs are offered from a single donor, only the center on top of the lung rota-list is entitled to have both organs for either a heart-lung recipient or a lung recipient.
   If a center accepts both heart and lung and dived the organs into two patients, rotation on both lists must be performed.

• Blood group compatibility is only required for organ exchange. Donor–recipient match is the responsibility of the transplanting center

• A center that receives an organ offer should accept the organ within half an hour. The center has the right to decline the offer, then centers with patients of the same urgency, ranked by the “rotalist”, should be notified.

• Urgent call on urgency 0 or 1 patients shall be renewed weekly. Call should be closed immediately when patient status is changed.

The above rules will be set in action from , 2011 and inserted on Scandiatransplant homepage from the same day.

The practice of these exchange and rotation rules should be assessed by the NTSG meeting in the fall 2011.
1.5.6. Thorax register web version
The Thorax conversion to graphical user interface is ongoing. Running parallel is programming a tool for us to change and improve the layout without involving a programmer.

1.6 The Nordic Living Kidney Donor Database Group
To our knowledge no official group exists. The first Scandiatransplant users have now been introduced to the new user interface and we have received some feedback. The “paper” registration form has been modified so it corresponds with the new layout and step by step more users will be included. A user manual is under preparation.

Import scripts from other databases are ongoing.

1.7 The Nordic Paediatric Renal Transplant Group
The office have not received any minutes or been invited to any meetings in the Nordic Paediatric Renal Transplant Group.

As already stated in a previous newsletter the programming and import of data from the Nordic Pediatric Renal Transplant Study Group (NPRTSG) database into Scandiatransplant is done. We have not heard from any interested in accessing, entering or extracting pediatric renal transplant data from Scandiatransplant except Marie Larsson.

1.8 The Nordic Transplant Coordinator Group
Two meetings have been held in the Nordic Transplant Coordinator Group one in September 2010 in Stockholm and the other one in April 2011 in Helsinki. Scandiatransplant staff has been invited and attended both meetings.

http://www.scandiatransplant.org/members/ntcg/Sctp_NTCG_08sep2010.pdf/at_download/file

One of the wishes from the group is to have the possibility to do extended registration of pay back for liver and kidney. In continuation hereof to get a balance report of pay backs between centers.

1.9 Pancreas and pancreatic islet transplantation
To our knowledge no official groups concerning pancreas and pancreatic islet transplantation exists.

1.10 Intestinal transplantation
To our knowledge no official group concerning intestinal transplantation exists. Specific waiting lists for intestine, hepatocyt and small bowel are on the offices 'to-do-list'.
2. Definitions of words used within Scandiatransplant

2.1 Definitions
Since the last newsletter the Scandiatransplant board has asked for the possibility to use three WHO definitions for deceased donors. You can see the revised definitions below. In generally we still like to hear from you with any comments and corrections you might have. Point 2.2 and 2.3 are still open issues.

Eligible donor (previous term 'Accepted donors'):
A medical and clinical suitable person with consent to donation who has been declared dead based on neurologic criteria as stipulated by the law of the relevant jurisdiction.

Actual donor (previous term 'Realized donors'):
Every donor from whom at least one solid organ has been retrieved for the purpose of transplantation.

Utilized donor:
An actual donor from whom at least one solid organ was transplanted

Multi organ donors:
Every donor from whom at least two different solid organs have 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:
3rd WHO Global Consultation on Organ Donation and Transplantation: Striving
2.2 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?

2.3 Pediatric recipients
How should pediatric recipients be defined?
ONT-newsletter <15, SCTP exchange obligation <16, internal danish rule <18