

Scandiatransplant Nordic Transplantation Coordinator Group Meeting – 12-13 april, 2012, Aarhus

Minutes of Meeting

Present:

Carola Schauman: Helsinki
Ann-Christin Croon: Stockholm
Bente Kaxe: Odense
Charlotte Lowén: Göteborg
Ewa Björklund: Uppsala
Käthe Meyer: Oslo
Margareta Lundell: Skåne
Dorte Matiassen: Aarhus
Else Marie Tram: Aarhus (observer)
Helle Madsen: Aarhus (observer)
Frank Pedersen: Scandiatransplant
Ilse Weinreich: Scandiatransplant

Absent:

Pernille van Houten: København

1. Welcome by Carola Schaumann

2. Kidney exchange and payback balance between centers

A few cases needed further investigation, the centers involved agreed to look into these.

3. Liver exchange and payback balance between centers

The same as point 2

4. Thanks – mail/fax

When an organ is exported to another center, the receiving center must report back to the donor center without due delay, whether everything went as expected and with a 'thank you' for receiving.

5. Board of Transplant Coordinators (BTC) and certification

Quote: 'The main objectives of the BTC is to guarantee the best standard of care in organ and tissue donation and transplant coordination in Europe by establishing homologous standards of practice and ensuring that training in donation and transplant coordination is maintained at the highest level by accrediting and examining transplant coordinators on their knowledge and practice.'

Next application deadline: 30th of May 2012

For further information about schedule and application:

<http://www.uemssurg.org/index.jsp?documentid=444B4D3D859D3491C125783400447729&form=Dokumente&parent=5A336F55332DA53EC12573A2005F8D8F&submenu=AD15E35AD0969DCBC125783400448ACF>

6. BTC and Scandiatransplant

Käthe Meyer has been appointed as Treasurer in BTC and will represent Scandiatransplant

7. Coordination, logistics and information about the time schedule

Please inform your colleagues if the time schedule changes considerable when exporting organs

8. Organ transportation

It became clear that there is major problems in all Nordic countries with getting organs transported between countries in a secure and fast way.

Among others this is related to the possible courier firms, airport customs, filling out various customs and shipment forms. The courier firms does not seem very co-operative and does not want to take responsibility.

As this has a large impact upon the quality (CIT) of the exported organs it was decided to bring this issue forward at the Representative Meeting May 9th 2012. Carola Schaumann will write to Susanne Sønder, at the Scandiatransplant office, to get the issue added to the agenda.

The proposal for the agenda was sent to Susanne Sønder and Krister Höckerstedt 16th of April 2012 by Carola Schauman.

9. Quarterly figures form Scandiatransplant to be clarified

The figures were shown and explained in short.

The plan is to add more details to the yearly figures e.g. not only the number of actual donors but the number of retrieved organs per donor.

10. Organ offers and urgent patients present and future

Present:

A total of 12 organ offers have come form Europe since the new mail and SMS system were implemented.

In two cases problems occurred in the system, these problems have been solved and will not happen again.

However it is still not possible for the Scandiatransplant staff to predict all that can go wrong.

In the light of this more surveillance have been added to the system.

Further the staff would like to send an organ offer test through the system to all coordinators ones a month. The test will be send out the first Wednesday in each month at 12 o'clock.

Ilse has received contacted with the following European Organ Exchange Organizations (EOEO):

Countries/organisations	The countries that would like a phone call along with the organ offer:
Poland	
Switzerland	X
Italy	X
Eurotransplant	
UK	X
Spain (OCATT)	
Czech Republic	

France is not ready to send or receive organ offers by email and Portugal has yet been unreachable.

The countries/organisations know now that we can only receive organ offers (urgent calls) by email.

Remember when you have spare organs, that can not be used within Scandiatransplant, you can email the filled in organ offer form as an attachment to the EOEO's.

Three countries have asked for a phone call along with the email. The structure of Scandiatransplant has been explained and no promise as to this has been made. Only an appeal to the Scandiatransplant coordinators to do so has been promised.

Current:

Bo and Ilse are working on the organ offer form to be used for organ offers inside and to the EOEO's.

The organ offer form will be linked to the 'old system', this means;

- that if the donor has already been registered in the database, it will draw the

existing information into the form

- and if you have not registered anything at all in the database beforehand you will create the donor record in the database when saving data in the organ offer form.

The organ offer form will very soon be accessible for the coordinators in NTCG at a specific test point, you will be informed about this later.

Future:

To incorporate that a message will be send out when a new urgent patient comes on the list. When a patient is stated as urgent in the database an email+SMS will automatically be generated and send out.

11. Liver

NLTG meeting 19th of march 2012

Ann-Christin reported from the meeting. Among others she told that the coordinators entering data into the follow-up registry will be invited to join the next NLTG meeting

Liver – exchange and rotation

The figures for 2011 were shown:

20 high urgent exchanges between countries – 1 wrongly rotated

42 surplus/payback exchanges between countries – 9 out of 42 were not rotated. The ones not rotated might be due to payback, however then the right export causes were not used in the database.

The rotation and payback rules in short:

* Exchange obligation to high urgent patients

Rotation: No – Payback: Yes

* Kind request no obligation to send liver

Rotation: No – Payback: Yes

* Spare liver (surplus) to the accepting center highest on the rotation list.

Rotation: Yes – Payback: No

If Scandiatransplant is expected to do the liver exchange and payback balance between centers the export causes used must be correct.

20 out of 62 (32%) export causes in 2011 were either lacking or wrong.

Explanation of export causes in the database:

1. Matching or other exchange criteria = Exchange due to High urgent call

2. Obligation (repay) = Payback for high urgent/Kind request. (The guiding text in Scandiatransplant has been changed April 19th 2012 to 'Payback')
3. No recipient locally = Surplus livers
4. No resources locally = Surplus livers
6. Response to "Kind Request" = Kind request
7. Liver used for liver cells = The new liver cell infusion
8. Local agreement = Agreements between centers e.g. kidneys between OFO. Were the export is not done due to exchange obligation, payback, kind request or surplus liver (This export cause has been added April 19th 2012)

12. Thorax

NTSG meeting 15th of march 2012

Charlotte Lovén reported from the recent meeting, she told:

- That the group will send minutes from meetings to Scandiatransplant
- That 'Guidelines and manual for Thorax Organ exchange in the Scandiatransplant area' was discussed and revised at the meeting. Odd Gerian would rewrite the document according to what was decided at the meeting:
 1. Ranking of priority 0/1 - It was agreed that priority 0 must have advantage over priority 1.
 2. Blood group compatibility and identity was discussed. It was agreed to maintain blood compatibility
 3. The rules as they were adopted in 2010, number of urgent lungs (n = 3), is not included in the guidelines on scandiatransplants webpage. The guidelines will be modified according to this.

Ilse will get in contact with Odd Gerian and send him the documents that the Scandiatransplant office has worked on.

Heart and lung – exchange and rotation

The figures for 1st of January 2011 until 10th April 2012 were shown:

- 24 heart exchanges between countries – 3 not rotated
- 28 lung exchanges between countries – 2 not rotated

The rotation rules in short:

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

13. Kidney – exchange

In 2011 422 donor searches were performed out of these there were 64 exchange obligations (15%)

In 6,3 % the exchange rules were not followed (4 out of 64)

Like for the liver export causes the payback balance for kidneys can only be made by Scandiatransplant if export causes are used correct.

41 out of 139 (29%) export causes in 2011 were either lacking or wrong.

14. EU-directive - quality and safety

EU-directive

Frank referred to the meetings held between the Nordic Health Authorities and Scandiatransplant. The situation and the effect of the directive on Scandiatransplant is still very unclear. But one thing is certain that the foundation and organisational structure of Scandiatransplant need to be described and be formalised.

Especially the situation in Sweden were discussed as the lawyers in the Health Authority seems to be very far from the practical and clinical perspective.

The next meeting between the Nordic Health Authorities and Scandiatransplant will be held Monday, April 16, 2012.

Human Tissue Authority (HTA) in Britain has made various initiatives to deal with the directive. One of the very short and precise slide shows were shown.

<http://www.hta.gov.uk/bodyorganandtissuedonation/euoddevents.cfm>

(Organ donor directive → EUODD → EUODD in a practical perspective)

Security seal

The new security seals were shown and handed out to each center. A short manual is attached to the minutes.

The use of the seals will start 1st of May 2012. After the first 1-2 months the seals will be evaluated. The office will send out an evaluation form.

15. Articles for the group

In the light of the EU directive and to formalise the meetings, the office encouraged the NTCG to write down the groups main objectives.

16. Questionnaire

Before the meeting a questionnaire with two questions were sent from the office to the coordinators:

- The purpose of Scandiatransplant in your aspect (what do you expect from us)
- Your tasks within Scandiatransplant database (what can we expect from you?)

This as an attempt to match expectations and to make it more clear what is expected of Scandiatransplant as an organisation.

5 out of 9 returned the filled in questionnaire, the answers were shown one by one and further explanations were given.

A common thread was clear through the first answers, about the purpos of Scandiatransplant, to sum up:

- Office/organization: Fair, safe & secure organ allocation
- update and maintenance of database
- Activity reports
- Quality assurance and assistance
- Cooperating with organizations outside Scandinavia
- Link between the Scandinavian centres
- Further development of the database to ensure usable data
- Education of transplant coordinators
- Exchange of experience
- Guidelines for organ exchange, rotation and payback
- A transparent database
- Support for database
- Information about new initiatives, changes etc.

The answers for the second question, concerning the coordinators own work tasks, clearly indicated that the coordinators uphold very different roles at each center.

17. Existing quality controls (QC) and need of new ones

Suggestion and talk about a possibility to sign for done registration on a deceased donor and also a QC for mandatory data according to the new EU directive (appendix A).

18. Next meeting

April 11, 2013 in Copenhagen airport

Scandiatransplant, 25. April 2012