Scandiatransplant Nordic Transplantation Coordinator Group Meeting – 11th of April, 2013, Copenhagen

Minutes of Meeting

Present:

Carola Schauman: Helsinki Ann-Christin Croon: Stockholm

Bente Kaxe: Odense

Charlotte Lovén: Göteborg Ewa Björklund: Uppsala Käthe Meyer: Oslo Ann Boklund: Skåne Dorte Mathiasen: Aarhus

Pernille van Houten: København

Kaj Anker Jørgensen: Scandiatransplant Ilse Duus Weinreich: Scandiatransplant

1. Welcome by Carola Schaumann

2. Kidney exchange and payback balance between centers

A few cases needed further investigation and the centers involved will follow up on these cases.

3. Liver exchange and payback balance between centers

The same as point 2

4. Initiatives made in the Nordic countries in connections with the EU directive – effect on our work

All countries are working on fulfilling the EU directive

The coordinators in Sweden have experienced a lot of changes especially concerning traceability and documentation. They must follow checklists and work plans and everything must be documented. All this has resulted in a lot of paperwork and once a year a report must be send to Socialstyrelsen.

Denmark, Finland and Norway have not experienced much of a change yet.

5. Tissue banks – EU directive

Dialog about registration of tissue harvest in Scandiatransplant, with the possibility to register to which tissue bank it has been send to.

Tissue is not within the normal work frame of Scandiatransplant, however if there is a general wish to register information concerning tissue harvest, the proposal can be put forward to the Scandiatransplant board for evaluation.

There is still a lot of open issues with retrieval of pancreatic islet where usage have not been

registered. Ewa will receive information from Ilse and look into the open cases.

6. The role of Scandiatransplant today

Kaj Anker Jørgensen presented his view on Scandiatransplant as Medical director in Scandiatransplant since November $\mathbf{1}^{st}$, 2012.

The main working tasks for the Scandiatransplant office are to run and maintain the core Scandiatransplant database (waiting lists, organ allocation and donor registration), further to:

Engage more programmers to convert the user interface to a more modern layout (YASWA) and future-proof the server environment.

Clarify and ensure legality aspects and future role of Scandiatransplant as consequence of EU-directives.

Priorities the incoming work tasks

7. Prioritisation of Scandiatransplant office work tasks

The conversion to the new user interface has the highest priority, however if other tasks in the old system need to be solved the office need to hear the voice of the users. Time used on new facilities in the old system is not wasted, as it will ease the conversion process. Fax of high urgent/kind request between centers and kidney/liver balance were mentioned as examples of such earlier suggested work tasks, which have not yet been solved. Both examples were evaluated by the coordinators and the conclusions were that these tasks are not critical and they can be put on hold.

Next and upcoming conversion to YASWA will be the heart, lung and liver rotations lists.

8. Education of the Tx coordinators in the Nordic countries

The question asked was if there is any common education strategic in the centers. This is not the case there is no common education besides the European certification BTC.

9. Organ offers from Estonia

The Estonia team has paid Helsinki a visit and Carola pointed out the following things to be aware of:

There are two donor hospitals in Estonia one in Tallinn and one in Tartu. This is important to know as the Tartu airport is closed from 22.00 to 11.00 and there is a 1 hour and 40 minutes' drive between Tallinn and Tartu.

Concerning lab. results etc. please be aware that Tartu University Hospital is the official and certified organ exchange hospital.

10. New solution after fax server break down

Organ offers from/to EU – The system is working and offers are received without problems. Organ offers from/to SCTP – In previous test runs the form showed performance problems in Internet Explorer, the screens took a long time to load as all fields and tabs were loaded right after login. To improve the performance this has been reprogrammed, so the fields under each specific tab are not loaded until the exact tab is chosen.

The office would very much like the users that have experienced problems to test the new

version. The users that would like to test please send an email to Ilse.

Until the form is set in action eoeo email address can still be used to send spare organ offer to all other European organisations.

Urgent patients - ?

The high urgent patients can still be displayed in Scandiatransplant database and as stated in point 7 the fax routine will continue.

11. Notes on why the organ was not accepted in own center/country

It is important to register why the organ cannot be used for own recipient, if it is due to the fact that the donor is considered a marginal donor in own center, please write this as organ offer cause.

It was discussed if organs that you will not use for own recipients should be offered, the limit of what to offer and what about borderline cases.

12. Feedback on recipient after organ import - system?

It was decided that recipient center must report back to donation center within 3 days with details about the primary organ function.

13. Shipping problems, has it improved?

There are still problems in the Nordic countries with getting organs transported in a secure and fast way. Carola collected information last year from each center about the specific problems and have forwarded this document, however she has not received any response.

The document might have been missed as it has not been view by the board. Carola will send the document for refreshment to the group and will afterword forward it to the Scandiatransplant board again.

14. Security seals – status

The seals are used in most cases when sending an organ. The firm that produces the labels has send a new type of label, which should have better glue on the backside and should still be removable without leaving traces on the container. Käthe will try the new labels and report back to Ilse with the results.

15. Liver

Information from the liver group meeting

http://www.scandiatransplant.org/members/nltr/MinutesofHelsinkiNLTGmeetingOct12.pdf

The project with a common waiting list for segment 2+3 for pediatric recipients is still ongoing. The list still only serves as a reserve.

The rotation and payback rules in short:

* Exchange obligation to <u>high urgent</u> 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

Compliance to rotation rules liver 2012

- 47 livers send between countries
 - 3 rotations done without reason
 - 3 rotations not done
 - (2 rotated with export cause matching or other criteria recipients 'only' registered as transplantable in Scandiatransplant, remember to register recipients as high urgent)

16. Thorax

Information from the thorax group meeting

No one has been invited or attended the last meeting and no one has seen the minutes from the meeting.

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.

Compliance to rotation rules hearts 2012

- 14 hearts send between countries
 - 7 high urgent (urgency 0)
- All rotated correctly

Compliance to rotation rules lungs 2012

- 27 lungs send between countries
 - 10 high urgent (urgency 0+1)
- 4 not rotated

Number of claimed priority 0 and 1 lungs patients 2012

- 2 Gothenburg
- 3 Helsinki
- 3 Copenhagen
- 2 Oslo

17. Kidney – exchange

In 2012 421 donor searches were performed out of these there were 65 exchange obligations (15%)

In 4,6 % the exchange rules were not followed (3 out of 65). The three cases were recipients, that should have been put 'on hold' on the waiting list.

18. Other matters

Organ form - Deceased donor

Ann-Christin presented suggestions for changes to the organ offer form.

Additional fields: Signature - Transpl. Coord., DCD/DBD, Into ice box/ Machine Perfusion (life port) in hours.

Removal of recipient information as detailed recipient information must not be presented together with deceased donor information on the form.

New

RECIPIENT:				
Scandia no:	Initials:	Date of birth (year):	Date of transplant:	
Old				
RECIPIENT:				
Scandia no:		Name:		
Date of birth:		Date of transplantation:	Date of transplantation:	
Revascularization:	ddmmyy	Cold ischemia time:	ddmmyy	

Ann-Christin will bring forward a new suggestion including revascularization, cold ischemia time, HLA-C and DQ

Donor number on domino liver

It is a problem that it is not possible to get a living liver donor Scandia number before the transplantation is registered in the database as the number is needed on the organ form. The registration cannot be made as the transplantation has not yet been performed. As the domino donor has a unique recipient scandia number, this is suggested used as initial identification.

Overview of infection screen test made at each center

Ann-Christin has prepared an overview, were each center must fill in which laboratory infection screen tests are made at their center.

The works is not ready yet, please send information to Ann-Christin.

Definition of actual deceased donor

Ewa brought up that the definition for actual donors

http://www.scandiatransplant.org/news/News ticker 1.pdf and the Scandiatransplant figures is misleading. Ilse will work out on a more clear an precise definition.

Coordinators as observers at meetings

It was discussed why the coordinators are not invited to all Scandiatransplant committee meetings as it was decided at the Council of Representatives Meeting 2010 in Helsinki, Finland (OBS the decision is not written in the minutes). Carola will write a letter to the board and also bring it up at the Council of Representatives Meeting on 2013 in her presentation.

Withdrawal of urgent/kind request

Charlotte suggests that the withdrawal of urgent/kind request by fax is not done in the night time. There is no reason why all coordinators should be woken by the fax or phone, due to withdrawal. Please do the withdrawal first thing in the morning.

19. Next meeting

October 24th, 2013 in Copenhagen airport March (week 13), 2014