

Nordic Transplant Committee

/ Nordic Transplant Committee / Minutes meeting No. 15 Sept 21, 2010 Århus

MINUTES OF MEETING

Meeting No: 15th meeting in the Nordic Transplant Committee

Time: Tuesday, Sept. 21, 2010 at 1 p.m. - 4.15 p.m.

Meeting place: Aarhus University Hospital, Skejby

Meeting participants:

National Health Authority representatives:

(JS) Jorunn Svendsen, (Helsedirektoratet) Norwegian Directorate for Health, Oslo, jorunn.svendsen@helsedir.no

(PF) Per Fauchald, (Helsedirektoratet), Norwegian Directorate for Health, Oslo, p.fauchald@c2i.net

(RA) [Raija Asola, Ministry of Social Affairs and Health, Health Department, Finland. \[raija.asola@Stm.Fi\]\(mailto:raija.asola@Stm.Fi\)](#)

(CM) [Charlotte Möller, The National Council for Organ and Tissue Donation \(Socialstyrelsen Donationsrådet\), Stockholm. \[charlotte.moller@socialstyrelsen.se\]\(mailto:charlotte.moller@socialstyrelsen.se\)](#)

(BUK) Bjørn Ursin Knudsen, Sundhedsstyrelsen (Health Authority), Copenhagen, bjk@sst.dk

(LB) [Lone Bøgh, The Danish Centre for Organ Donation, Aarhus, Denmark. \[lone.boeg@rm.dk\]\(mailto:lone.boeg@rm.dk\)](#)

The board of Scandiatransplant:

(KH) Krister Höckerstedt, Helsinki

(HI) Helena Isoniemi, Helsinki

(MO) Michael Olausson, Gothenburg

(PP) Per Pfeffer, Oslo

(KAJ) Kaj Anker Jørgensen, Aarhus

(MA) Margret B. Andresdottir, Reykjavik

Apologies received from:

(SM) Sveinn Magnússon, Ministry of Health, Reykjavik. sveinn.magnusson@hbr.stjr.is

Medical director, Scandiatransplant:

(NGR) Niels Grunnet, Aarhus

From the Scandiatransplant office participation of:

(FP) Frank Pedersen

(IW) Ilse Weinreich

A G E N D A

1. Welcome:

By the chairman of the board of Scandiatransplant: Krister Höckerstedt followed by a short presentation round.

2. Election of chairman of the meeting and writer of the minutes:

Krister Höckerstedt elected as the chairman of the meeting and NGR elected as writer of the minutes.

3. Approval of minutes from meeting No. 14, 2009:

The issues were shortly gone through by KH. Minutes approved.

4. Additional issues for the agenda from the participants:

None.

5. Presentation of the scope and capability (see also issue 6c) of the Scandiatransplant organisation and office:

NGR showed selected slides from the Sctp dias series 2009. Scandiatransplant is an association running a common waiting list for each organ and operating a database on organ donation and transplantation to communicate information from the database to the association's members. However at present not all information is available in the Scandiatransplant database. Some parameters have to be imported from other registries for example Uremic Registry of each country.

Since last year Herlev Hospital in the Copenhagen area have ended doing organ transplantations of kidneys at August 1st, 2010. In 2009 again we have seen a rise in the number of organ transplantations both using diseased donors and living donors. Overall the organisation Scandiatransplant is yearly involved in more than 1600 organ transplantations in the 5 Nordic countries. In a year (2009) despite tendencies to an increased demand for organs for organ transplantation the transplantation centers in total have been able to keep the numbers on waiting list at the same level as previous years. This is in contrast to what is seen in other organ exchange organisations in Europe where there has been an ever increasing number of patients on waiting lists for organ transplantation. FP gave a short review of Scope of Scandiatransplant and which data we can deliver from the Scandiatransplant data system. 200-250 users in Scandinavia have access to the system. Search function within the system was demonstrated for the meeting participants. Several subregistries have been integrated in the Scandiatransplant datasystem such as Liver Registry, Thoracic Registry, Living Donor Registry and registration of follow-up data. The latest branch in the system has been Paediatric Renal Registry.

What has happened in the last 12 months in each country:

DENMARK: Danish Center for Organ Donation was founded in 2007. Now they have created an online database which from the 1. of April 2010 shall contain information on all deaths in Intensive Care Units both of brain death and heart death to try to find out potential actual and realized organ donors. On all intensive care units a doctor and a nurse have been given the function as a contact person being responsible for all activities in relation to organ donation. The center run courses and do questionnaire investigations from which one can say that especially nurses now are more positive in the attitude to organ donation than 10 years ago. Focus is on the relatives to donors. In some part of Denmark there has been increase in the donation rates.

NORWAY: Work on a new transplantation law for Norway. This will be written with close relation to what is let down in the EU Directive on Organ Donation and Transplantation. Regional meetings have been held. 2009 has been with the highest number of organ transplantations ever in Norway. This means that patients are on the waiting list in a shorter time, but there has been a tendency to process a less number of living kidney donor procedures maybe because the work load for several individuals are much higher in clarifying if there is an available living kidney donor or not compared to just setting a

kidney patient on the waiting list in the ScandiTransplant data system for a kidney from a diseased donor.

SWEDEN: Since 01.01.2010 Charlotte Möller has taken the place instead of Åsa Welin in Donationsrådet of Socialstyrelsen. There has been a change in the structure of the organ donation center. 2009 has not been that good year for Sweden with regard to diseased donor organ transplantations. Therefore the number of patients on the waiting lists are now increasing which gives a lot of concern in Sweden. The total Health Care System is under pressure with personnel and resources and the number of ICU beds have gone down in Sweden. Some of these factors can influence the total outcome.

FINLAND: Raija Aisola has got the present position in the Ministry of Social Affairs and Health since February 2010 instead of Terhi Hermanson. A new transplantation law was set in action on August 1, 2010 on transplantations stating that Finland now has presumed consent for organ donation. It has been a process of 18 months with many discussions and debates, but with a very positive attitude from the population, decision makers and the media. As a consequence of the new law, relatives and next of kin cannot deny donation if it is clear that the person in question as potential organ donor has not been against organ donation as such. It will be interesting to follow the influence of this new law. In Helsinki they have done their first small bowel transplantation in 2009 and the first pancreas transplantation in 2010.

ICELAND: December 2005 living donor kidney transplantation programme was started. In Reykjavik they have a special nurse taking care of many of the elements. A new booklet on organ donation etc. has been prepared. There is a systematic follow up of living organ donors in Reykjavik. Diseased donor transplantations are done in cooperation with Gothenburg, Sweden.

In general it is the impression that it is not enough to look at what is happening with the problem of organ donation in intensive care units, but also to look at all hospitals especially in the emergency room, because some may die there before they get to the intensive care unit but where a situation of a potential diseased organ donor could have been on the scene without being observed or referred in the health care system.

6. EU directive on organ transplantation

a) National Action plans

b) Implementation in the member states

c) The role of the ScandiTransplant office in the management of the Action plans as a consequence of the EU directive.

Notice added on Oct. 6, 2010: The EU Directive on Organ Transplantation has changed number from 2010/45/EU to Directive 2010/53/EU.

There are no changes in the text, it is only the number of the document that has been changed.

On Sept. 6-7 was held the first meeting of the competent authorities for organ donation and transplantation at EU in Brussels. Raija Asola, Charlotte Möller, and Bjørn Ursin Knudsen, KH, and NGR participated in this meeting. 14 slides with the main aspects of the EU directive were shortly discussed. The directive shall be set in action at the latest by August 27, 2012 in member states. The 2 countries Norway and Iceland are not members of EU but are so closely related to ScandiTransplant that it is a hope that the set of rules, data registration etc. will be administered in a very analogue way. From Sweden we heard that the first meeting had already been held and maybe it is not necessary to make a special new transplantation law in Sweden due to this EU directive, but that legislation documents have to be created. The same attitude concerns Finland. At the time of the meeting it is not clear if a special law has to be written in Denmark. As a consequence of the EU directive national action plans have to be defined and realized in a period up to year 2015. From the meeting in EU we have got 60 slides covering the subjects donation/waiting list/allocation/transplantation/health outcome/health resources.

These slides were partly shown and discussed, especially the diagrammes and tables giving figures or percentages concerning the 5 countries participating in the Scandiatransplant association. Some of the slides contained obvious errors which the Board of Scandiatransplant have decided must be corrected. These selected tables/diagrammes will be checked by FP and IW to see if data in the Scandiatransplant database can clarify the numbers. If not possible, the individual transplant centers being members of Scandiatransplant will be asked for the right figures and information. All in this meeting agreed on the relevance of indicators for activity in transplantation but there is also an agreement to reduce these parameters and to concentrate on those giving meaningful information.

KH summarized that this is the first exercise to have a common European overview of transplantation figures for the individual organs. As such it is a positive initiative. The next exercise will be in April 2011. Before that we will have to clarify who is going to give data to these registrations. Scandiatransplant is not "a national body". It is the individual countries being these national bodies and thereby responsible for sending data to the common EU registrations. Scandiatransplant office creates a report of transplantation statistics and waiting list statistics for each organ four times a year supplemented with a yearly report. These data are validated and checked in several ways both at the Scandiatransplant office and at the individual transplant centers (the members of Scandiatransplant).

All the representatives of the national health authorities present at this meeting are encouraged to get together by mail or meetings in an attempt to agree on the implementation elements of the EU directive in each country, hopefully ending in very analogue procedures for all 5 countries.

7. Activities within the CoE, EOEO and others:

PP gave a report of a recent meeting in the auspices of Council of Europe (see minutes from last year's meeting).

Guide for Quality and Safety of Organ Transplantation is now in a final process of a new version that will be available January/February 2011 covering new chapters on several issues.

Transplant Newsletter concerning 2009 has just got out on ONT's homepage and in the paper copy all the figures from Scandiatransplant in that publication are sent from the Scandiatransplant office so it is validated data.

The CoE group (CD-P-TO) has also looked at several aspects of organ trafficking either by the organs themselves or by human beings from whom organs can be transplanted. The next meeting will be held in Georgia in the city of Tbilisi with the purpose especially to help those countries that have a need of help in establishing organ transplantation programmes. This initiative is supported by WHO, ONT and the international transplantation society. Other initiatives are to hold a European Donation Day and a World Transplantation Day. In the auspices of UEMS (The European Society of Medical Specialists) a new section for transplantation surgery has been created three years ago and they have now exams in modules and have initiated audits of transplant centers to accreditate/qualify a whole transplantation center. So far, four centers have had this audit/inspection, namely: Essen, Oslo, Budapest and Groningen.

Ad EOEO: No specific information on future meetings in this regi.

Efretos: It is a European project funded by EU-support chaired by Eurotransplant and with eight working groups working fast and eager. The problem is to try to find a reasonable level of registration at the European level. The challenge for the five countries within the Scandiatransplant association is to try to push the middle and southern European initiatives in a way so the number of parameters and the amount of reporting can get a reasonable level. It is better to have fewer data but validated than an enormous amount of data not validated enough. The last situation is without meaning.

8. Rapid Alert systems (EU office):

At the EU office in Brussels this rapid alert or vigilance function has been created and regularly some messages are sent out to all health representatives and to Scandiarttransplant. Within the Scandiarttransplant association we have a working group creating guidelines for prevention of transmission of infectious diseases from organ donors to recipients. Last version of this guideline dated March 23, 2009 was given in a paper copy to the representatives from the national health authorities. The working group within Scandiarttransplant will discuss new issues Autumn 2010 and adjust the guidelines if necessary.

- a) **Action plan for protecting the Blood System etc. against WNV (West Nile Virus) in Greece** (referred to the working group on infectious diseases).
- b) **Q-fever in the Netherlands and potential impact for substances of human origin** (referred to the working group on infectious diseases).

9. Any other business:

The working group on liver transplantation within Scandiarttransplant named Nordic Liver Transplant Group (NLTG) will have its next meeting November 11, 2010 as a 25th anniversary in Copenhagen. The results of this cooperation has been more than 30 research publications and a forum for exchange of information and defining rules for exchange of organs between the member states. Scandiarttransplant has in addition different groups of experts on kidney transplantation, on paediatric kidney transplantation, on thoracic organ transplantation, and a group for tissue typing. All these working groups involve very many of the actively working persons within the field of organ transplantation and is thereby working out recommendations and rules for cooperation and for activity within the field of organ transplantation. PP mentioned that in Europe we have had several resolutions. First the Amsterdam resolution on living donor transplantation, then the Istanbul resolution on diseased donor and issues of trafficking within the transplantation area, and third a Madrid resolution on the responsibility of each nation with the goal that each nation can reach selfsufficiency with regard to organs for organ transplantation.

It would create great damage if somebody in the EU or in the individual countries' national health authorities think of a common waiting list for the whole EU. This could damage the conditions for treating patients with organ transplantation due to a demotivation factor. Today within the Scandiarttransplant cooperation we have very much work with motivation of all involved in the area of organ transplantation and this is very important for the success. We will not get more organs for transplantation by sending organs from one country to another country. Countries can help each other by sending organs to which there are no appropriate recipient in own country or to fulfill some special requirements for patients on for example urgent lists. In the cooperation between the five Nordic countries this has been worked to nearly perfection with the relative distribution in each center, in each country, and between the countries in the Scandiarttransplant association. About 1600 organs are transplanted annually in the five Nordic countries. Only less than 1% of organs did not find a suitable recipient in our countries and were therefore sent to another European organisation. It is therefore the hope that we can keep this high standard and continue with the brilliant example of defining rules for cooperation to help most patients possible in the best way defined by clinical medical evaluations.

In April 2010 the EU funded project "living organ donation in Europe" (EULOD) has started. Where the goals of the project is to collect legislation from European countries on living organ transplantation and organ trafficking. In EU-papers now, it is stated that organ transplantation with living donors should be considered supplementary to organ transplantation with the use of a diseased donor. This matter should be changed into having equal status. Even countries with very few living donor transplantations as for example Spain also begin to look at possibilities for using living organ donors in relevant cases.

10. Next meeting 2011 (Reykjavik):

Scheduled to be held in Reykjavik in September 2011. Of practical reasons on Monday September 19, 2011 with home travel Tuesday September 20, 2011. This means that all shall travel to Iceland (Reykjavik) on Sunday September 18, 2011. All the meetings can then be held on Monday September 19, 2011, Board meeting in the morning and Nordic Transplant Committee meeting in the afternoon.

Writer of minutes: Niels Grunnet