

## *Nordic Transplant Committee*

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*/ Nordic Transplant Committee / Minutes meeting No. 12 Sept 18, 2007 Oslo*

### MINUTES OF MEETING

Meeting No: 12<sup>th</sup> meeting in the Nordic Transplant Committee  
Time: Sept. 18, 2007, Oslo, Norway  
Meeting place: The Directorate for Health and Social Affairs, St. Olavs plass /  
Universitetsgata 2, Oslo

#### **Meeting participants:**

##### *National Health Authority representatives:*

(CD) Cecilie Daae, (Sosial- og Helsedirektoratet) Social- and Health Authority, Oslo  
(KT) Kåre Tønnesen, (Sosial- og Helsedirektoratet) Social- and Health Authority, Oslo  
(ACB) Anne Christine Breivik, (Sosial- og Helsedirektoratet) Social- and Health Authority, Oslo  
(MK) Mervi Kattelus, Ministry of Social Affairs and Health, Health Department, Finland  
(ÅW) Åsa Welin, The national council for organ and tissue donation, Stockholm

##### *Apologies received from:*

(SM) Sveinn Magnússon, Ministry of Health and Social Security, Reykjavik  
(BUK) Bjørn Ursin Knudsen, Sundhedsstyrelsen (Health Authority) , Copenhagen  
(HG) Håkan Gäbel (Socialstyrelsen), consultant at The National Board of Health and Welfare, Stockholm

##### *The board of Scandiatransplant:*

(AJ) Arnt Jakobsen, Oslo  
(LK) Lauri Kyllönen, Helsinki  
(PF) Per Pfeffer, Oslo  
(SSS) Søren Schwartz Sørensen, Copenhagen  
(MB) Magnús Bødvarsson, Reykjavik

##### *Apologies received from:*

(MO) Michael Olausson

##### *Medical director, Scandiatransplant:*

(NGR) Niels Grunnet, Aarhus

The meeting followed the previously submitted agenda.

**1. Welcome**

By the host by Anne Christine Breivik (ACB) and Cecilie Daae (CD)

This was followed by a short summary of the organisation of the association for organ transplantation at university hospitals within the 5 Nordic countries named Scandiatransplant. We now have 12 members, 12 hospitals which in principle are the owners of this association Scandiatransplant. Scandiatransplant set the standards for organ transplantation in Denmark, Norway, Sweden, Finland and Iceland.

Each participant presented himself/herself shortly. Cecilie Daae (CD) is director, herself medical doctor, specialist in general practice referring to Hans Petter Aarseth, and Anne Christine Breivik is lawyer and responsible for organisation of the new system for organ donation in Norway. Kåre Tønnesen (KT) has been civil servant at Sosial- og Helsedirektoratet for many years.

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

AJ was elected as chairman of the meeting and NGR was elected as writer of the minutes.

**3. Approval of minutes from meeting No. 11**

Approved

**4. Additional issues for the agenda from the participants**

None

**5. Organ transplantation activity in 2006 in the five Nordic countries**

Newsletter Transplant, vol. 12, No. 1, Sept. 2007 concerning 2006 transplantation data from Europe was distributed to the participants. It is printed and paid by ONT under the auspices of Council of Europe. In the near future, another way of financing this publication may have to be found. All the participants are recommended to take a closer look at the figures and diagrams in the publication. Within Scandiatransplant, approximately 4 organ transplants are performed each day; Finland is the country best in organ retrieval or organ donor procurement especially with the kidneys; Denmark is unfortunately the country with the lowest frequency of organ retrieval from deceased donors.

In addition, it is recommended for all the participants to look at the Scandiatransplant home page: [www.scandiatransplant.org](http://www.scandiatransplant.org). Here it is possible to see some local numbers, and in addition several guidelines including the new rules on investigation of organ donors for infectious markers.

**6. - European Union**

Directive for tissues and cells

Directive for organ transplantation ?

Since the 1980's Council of Europe has started a work of defining recommendations by a group of experts. This has resulted in now the 3. edition December 2006 of Guide to Safety and Quality Assurance for the transplantation of organs, tissues and cells (ISBN 10:92-871-6037-6 CoE). A 4. edition is now going to be edited. Approximately 2 years ago there was reorganisation within the Council of Europe which resulted in revitalizing of the area covering the majority of the countries of the in total 48 nations under the auspices of Council of Europe. The new European Committee on Organ Transplantation was affiliated to EDQM (European Directorate for the Quality of Medicines and Health Care). This group also has participants from WHO and EU for the coordinating purposes. So it is a so-called "Think Tank".

At the international level one know of some dark sides within the field of organ transplantation such as trafficking. Many topics are on the agenda for the next meeting to be held in Dublin, Ireland in October 2007. The European Union (EU) has increasingly been interested in the area. First, EU Directives have been set up for blood, then there was an EU Directive on Tissues and Cells, and now a consultation process is ongoing to find out if an EU directive for organ transplantation can be defined, or it has to be written as guidelines or recommendations. There was the first expert meeting of the member states on July 13, 2007 in Brussels. Observers from WHO, Council of Europe and from the 2 supernational organ transplantation organisations Scandiatransplant and Eurotransplant were also present. The minutes from this meeting came Sept. 14, 2007 and was distributed during this meeting for information purposes. The next meeting is going to be held on November 20, 2007. In particular, the issues are quality and safety principles for organ transplantation. One think that there will be set up some "minimum criteria" under the auspices of EU. Some of the participants could not see the negative in getting an EU directive on organ transplantation. However, other participants are very concerned about how it will be formulated. Within the medical profession there are some worries. It is the impression that concerning the EU directive on tissues and cells, Denmark in particular has chosen a very pragmatic way of practising the directive for tissues and cells, and it is a wish from the board of Scandiatransplant that these rather simple rules can be conferred to the other Nordic countries. At the time of the meeting there had not been a clearcut harmonizing of the rules for tissues and cells (for Scandiatransplant that is pancreatic islet cells in particular) from the health authorities, especially in Norway it is stated that the way the legislation is implemented in the Nordic countries will give problems if it is not uniform within the area of Scandiatransplant. This is agreed on from the board of Scandiatransplant. During the meeting, the participants are informed of a meeting in September 2007 between health authorities in the Nordic countries concerning how to practise the EU directive on tissues and cells. (Added after the meeting, NGR had contact to the Danish Medicines' Agency (DMA) in Denmark and was informed that pancreatic islet cells was not on the agenda for this meeting, but DMA is very interested in discussing the subject with representatives of Scandiatransplant to secure no particular limiting factors in this area). The meeting in Dublin 11-12 October 2007 is in connection with European organ donation day. From Sweden Bo-Göran Ericzon (Huddinge) will participate. From Norway, Per Pfeffer (PF) will participate as a co-chairman in the group under EDQM. AJ will participate on behalf of Scandiatransplant.

**- Council of Europe**

**A new organisation is set up**

See above.

**- Alliance-O activities and EURO CET**

Alliance-O is an EU supported project with several working parties. They are now in their final stage and a "white paper" has come out and will be presented as the final document in Paris later this autumn. Then one wonder how the experience from Alliance-O can be continued. The project of Alliance-O has been driven by the French organ transplant organisation named Agence de la Biomedicine. Scandiatransplant together with Eurotransplant has had a position as observers.

Another international cooperative activity is European training programme for transplant coordinators, and as a new activity, an examination of transplant surgeons is set up in Prague this autumn in connection with ESOT meeting (European Society of Transplantation), and in connection with UEMS (Union Européenne Médicale Spécialiste) one can apply for examination in the surgical aspects within kidney transplantation, liver transplantation, pancreas transplantation or organ donation as separate fields. This examination has been organized by the physicians themselves and is regarded as an activity to maintain and define the level of quality within organ transplantation.

**7. European Organ Exchange Organisations (EOEO)**

Representatives of the individual organ exchange organisations meet once a year within this context. The last meeting was held in Bern, Switzerland discussing several topics in particular rules for allocation in the different countries or organisations in Europe.

**8. Scandiatransplant's datasystem; status regarding the renewal and financial situation.**

Scandiatransplant has got a financial support from the Nordic Council of Ministers with an amount of 400.000 DKK in the recent year. We will apply again. Scandiatransplant differs from the other transplant organisations within Europe where the majority of these are financed directly by their governments. This is not the case for Scandiatransplant which do not get money from the governments in the 5 Nordic countries. It is financed by fees from the members that is transplant centers at university hospitals in the 5 countries. One can say that it is indirectly financed by the health authorities. However, the demand for some renovations of the data system creates a need for money to finance this process of modernizing the data system which is the core of the Scandiatransplant co-work and organisation. Now we are near the end of a so-called phase 1 in this renovation process. However, the total costs to get a new system is presently unknown, therefore Scandiatransplant asks for funding possibilities and is in the process of investigating this. From the health authorities it is asked what is the purpose of the Scandiatransplant database, and the answer is that the database is the essence of Scandiatransplant or "the nerve". With this datasystem one can run a common waiting list for patients in need of a transplant with a kidney, a liver, a lung, a heart or a pancreas.

From the health authorities in Norway it is stated that one could write a letter to them asking for funding. For the time being there is a public awareness in Norway on the area of organ transplantation.

Several very fruitful outputs of the cooperation within Scandiatransplant is mentioned. For example the possibility to get a liver for transplantation due to the fact that the background population is a little more than 24 million inhabitants within the Scandiatransplant area and that you have the possibility to come up with an organ donor donating a liver for a patient in great need within the area of Scandiatransplant. In fact approximately 30% of all livers are exchanged from one center to another. From Norway it is stated that the Scandiatransplant system in addition can be used to communicate information concerning living kidney donor programme through the secure internet connections. The availability of this datasystem facilitates the communication both within each country and between countries.

**9. Scandiatransplant's application for financial support from the Council of Nordic Ministers**

See above.

**10. Pancreatic islet transplantations in the Nordic countries**

The board of Scandiatransplant presented that the center in Uppsala is outstanding within this area. NIH (National Institutes of Health) has by a big grant funded research projects being realized within the Scandiatransplant area.

**11. Rules for allocation of organs for transplantation within Scandiatransplant**

The allocation rules in Scandiatransplant are practised in another way than in for example Eurotransplant. In Eurotransplant you use a point system that is a sort of a mathematical way of defining who is going to be the recipient of a given available organ. In Scandiatransplant we have a system with medical issues on the top. The whole idea is to have a common waiting list which will create a greater chance for patients to be transplanted if they are possessing antibodies. In Scandiatransplant we have a system that is well adapted. It functions very well. A problem could be the case if politicians would have a point system. A point system could for some persons look as if it is more justified, but taking medical issues in the talk with well-educated doctors and nurses in the health care system of the Nordic

countries will in an ethical way secure the best use of the organs being available. The board of Scandiatransplant express the need of keeping the rules simple. To have rapid communication with a limited number of kidney organs crossing the borders. If one has complicated systems it can take longer time to get the individual organ transplanted because you have a longer allocation procedure and transportation period. This can indirectly be read in the number of kidneys with a primary function which for example is about 50% in the New York area, but approximately 90% in Norway. In Norway there has been an investigation indicating that by a statistical study there was a fair distribution of kidneys transplanted in each region of Norway. It is mentioned that in some other countries outside Scandiatransplant complicated rules create situations where some patients have zero chance of being transplanted.

It is stated from the board that each center is looking at describing their rules for allocation of organs.

- The problem of organ trafficking or organ tourists was discussed. The problem of a kidney patient coming to a clinical department in a Nordic country with a scar indicating an operation done somewhere in a foreign country is a phenomenon that is seen 5-6 times per year in Denmark. Maybe 20 of such persons have been seen in Sweden, and only a very few in Norway and Finland. Åsa Welin reported that she was called upon to the Japanese embassy in Stockholm to report on the legislation in Sweden in an attempt to help the Japanese in creating a new law system, so transplant tourism can be minimized or eradicated. In a majority of countries we know that organ trafficking is forbidden by law. However there have been some problems of Japanese going to the Philippines to get an organ for transplantation.

The board drew the attention on the fact that Scandiatransplant has written guidelines on non-Nordic residents in relation to organ transplantation. The guidelines can be seen on the homepage of Scandiatransplant. The issue discussed here is under great observation from not only the professionals within the transplant area in the Nordic countries, but also by EU, Council of Europe, EOEO and WHO.

**12. Other issues**

None.

**13. Next meeting 2008**

Next time the meeting is going to be held in Denmark, so we suggest Copenhagen on Tuesday, September 23, 2008 at 12-16 p.m. NGR has contacted the Danish health authorities to ask if they can host the meeting that day which has been accepted.

**14. Any other business**

Nothing.

Writer of the minutes: Niels Grunnet