

# *Nordic Transplant Committee*

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*/ Nordic Transplant Committee / Minutes meeting No. 14 Sept 22, 2009 Stockholm*

## MINUTES OF MEETING

Meeting No: 14<sup>th</sup> meeting in the Nordic Transplant Committee  
Time: Tuesday, Sept. 22, 2009 at 12 - 4 p.m.  
Meeting place: The National Council for Organ and Tissue Donation (Donationsrådet)  
The National Board of Health and Welfare (Socialstyrelsen)  
Primusgatan 18, Lilla Essingen, Stockholm, Sweden

### **Meeting participants:**

#### *National Health Authority representatives:*

- (JS) Jorunn Svendsen, (Helsedirektoratet) Norwegian Directorate for Health, Oslo,  
jorunn.svendsen@helsedir.no  
(ACB) Anne Christine Breivik, (Helsedirektoratet) Norwegian Directorate for Health, Oslo,  
AnneChristine.Breivik@helsedir.no  
(PF) Per Fauchald, (Helsedirektoratet), Norwegian Directorate for Health, Oslo,  
p.fauchald@c2i.net  
(TH) Terhi Hermanson, Ministry of Social Affairs and Health, Health Department, Finland,  
Terhi.Hermanson@Stm.Fi  
(ÅW) Åsa Welin, The National Council for Organ and Tissue Donation (Socialstyrelsen  
Donationsrådet), Stockholm,  
Asa.Welin@donationsradet.se  
(MN) Maria Nilsson, Health Care Division, Ministry of Health and Social Affairs, Stockholm,  
maria.nilsson@social.ministry.se  
(BUK) Bjørn Ursin Knudsen, Sundhedsstyrelsen (Health Authority), Copenhagen,  
bjk@sst.dk

#### *The board of Scandiatransplant:*

- (AJ) Arnt Jakobsen, Oslo  
(PP) Per Pfeffer, Oslo  
(LK) Lauri Kyllönen, Helsinki  
(MO) Michael Olausson, Göteborg  
(SSS) Søren Schwartz Sørensen, Copenhagen  
(MB) Magnús Bødvarsson, Reykjavik

#### *Apologies received from:*

- (SM) Sveinn Magnússon, Ministry of Health, Reykjavik

#### *Medical director, Scandiatransplant:*

- (NGR) Niels Grunnet, Aarhus

**1. Welcome:**

By the host Åsa Welin (ÅW) followed by welcome by the chairman of the board of Scandiarttransplant Arnt Jakobsen (AJ). There was a short presentation round. Maria Nilsson (MN) is head of section under Health Care Division, Ministry of Health and Social Affairs. She is engaged in the work with the EU directives on organ transplantation especially during the Swedish chairmanship of EU until 01.01.2010. Per Fauchald has recently been appointed as the leader of a newly established national advisory group on organ donation in Norway.

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

Arnt Jakobsen elected as chairman of the meeting and Niels Grunnet (NGR) elected as writer of the minutes.

**3. Approval of minutes from meeting No. 13 in Copenhagen on Sept. 23, 2008:**

Approved. There was a remark on the percentage of multiorgan donors in deceased organ donation. The percentages are 65-65-85-90-100 % (the last one in the two deceased donors in 2008 in Iceland).

The figures can be seen in the newsletter Transplant, vol. 14, No. 1, Sept. 2009 on data concerning 2008. This publication is distributed to participants at the meeting not already having had this.

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

A report from Norway on the newly established national advisory board on organ donation ("Nasjonalt fagråd for organdonasjon") (see new point 8), and report from Finland (see new point 9).

**5. Status regarding organ transplantation in the Nordic countries in 2008:**

NGR presented selected dias on this issue. All the power point pictures can be found on the homepage of Scandiarttransplant: [www.scandiarttransplant.org](http://www.scandiarttransplant.org). In short: The total number of deceased donors in the Scandinavian area was 398 deceased donors, this has never been that big. The number of deceased donors per million population has in 2008 compared to 2007 increased in Norway and Sweden, but decreased a little in Denmark and Finland. Iceland has considerable variations from year to year. Overall the number of kidney transplantations using deceased donors and living donors has never been as big as it was in 2008. Only approx. 5% of kidneys from deceased donors are exchanged between centers due to the obligatory exchange rules, and due to the rule of back delivery the overall exchange of kidneys is 10% in 2008 the same as the previous years. Organ exchange deals with more than 30% of the hearts, approx. 18% of the lungs, and approx. 13% of livers apart from the 10% kidneys. Despite the increase in the transplantation activity within the Scandiarttransplant association more patients have entered waiting lists during 2008 concerning the organs kidney, heart and lungs with a little decrease in the number of patients waiting for liver transplantation. So, in total for all the waiting lists for organ transplantation within Scandinavia, the year 2008 ended up with a few more patients on waiting lists for all the organs been transplanted.

There is a discussion on the number of kidney transplantation with living donors especially in Finland where several initiatives will be supported not to create unnecessary limits for this treatment.

**6. The Danish Centre for Organ Donation:**

The leader of this institution Helle Haubro Andersen should have been invited to this meeting, but it was not done due to a mistake of who should send the invitation. It is decided that the minutes from this meeting will be sent to Helle Haubro Andersen in addition with an invitation to participate in the meeting next year. The activity can be seen on [www.organdonation.dk](http://www.organdonation.dk). In short: There has been a new setup of donation responsible key persons. The organisation of coordination of organ transplantation is done in three centers being in contact with 47 intensive care units in Denmark. There has been a description of the

organ donation organisation in relation to the organ transplant centers in Denmark. Some regional meetings have been planned, for example one for Middle and North Jutland in October 2009. There has been launched a wish to create a clinical database, but there are some critical comments to this due to questions on the feasibility.

**7. Experience with the Swedish Donasjonsrådet:**

Statistics and key figures for organ donation in 2008 in Sweden is given and a report in Swedish is distributed to the participants. In this there is an interesting flow diagram of the flow and issues on patients that died in intensive care units until status as potential organ donors and further on to realised organ donors being 144 deceased donors in Sweden in 2008 out of 209 potential donors out of 3429 deaths in intensive care units. The goal in Sweden has been announced to be 200 deceased organ donors per year. In 2009 so far there has been 152 organ donors. Donor specialists are now appointed at all donation hospitals in Sweden and education programs have been established.

There will be several activities on the Organ Donation Day. In relation to the EU directives ÅW is participating in two working groups to figure out details in the action plans, and Maria Nilsson works very actively in connection with the EU directive and action plans in conjunction with the Swedish chairmanship of EU this half year. There is a discussion on the problem with the decreased number of beds in intensive care units, but the focus on patients in intensive care units has been intensified. The necessity of legal frames is stated to make a no hindrance of potential organ donors to be realised donors. There had been concern of giving treatment to patients with no chance of recovery giving not enough time to elaborate if the patient could be a potential organ donor.

In some European countries use of non-heart beating donors is increasing. It is answered that this shall be investigated. It is a question how the training is done of a donation responsible person, and there is a request from Iceland to get a copy of how the training program has been organised.

Information can be found on the homepage: [www.icuregswe.org/sv/](http://www.icuregswe.org/sv/) and [www.donationsradet.se](http://www.donationsradet.se) where there is a link to "første års sammenstälningen til möjlige donatorer i Sverige 2008".

**8. "Nasjonalt fagråd for organdonasjon" in Norway:**

Per Fauchald (PF) is appointed as leader of this newly established national advisory group on organ donation. Per Fauchald is nephrologist and professor in renal medicine, Rikshospitalet, Oslo, but now retired. The newly founded advisory group has had one meeting at which they decided to concentrate on the situation on the donor hospitals and plan for several measures in order to increase the donor detection rate and to discuss and increase the quality of donor preservation, death diagnosis and contact with the family. A lot of other issues were also raised at the first meeting.

The advisory group consists of 2 transplanted patients, 1 media expert, 2 doctors appointed as donor responsible at major donor hospitals, 2 nurse transplant coordinators, 2 transplant surgeons from Rikshospitalet and 1 primary health doctor. The mandate for the group is to assist the health directory in reaching the goal of increasing the number of organ donors. The group shall deal with all aspects of organ donation including national and international directives and guidelines, local medical guidelines, educational and medical teams at the donor hospitals, public information on organ donation and shall initiate and evaluate new initiatives. Also issues connected to organ donation from living donors and the capacity on the transplant center in relation to the organ donation rate can be dealt with. PF stated that perhaps the most important aspect of the national advisory group will be the continued, permanent and near contact with the donor hospitals, the patient organisations and the transplant center on the one side and the health authorities on the other side. PP raised the question that one urgent topic is to revise and make a new description of the criteria for

brain death in Norway because the present description demands wellknown established diagnostic methods like cerebral angiography. Nowadays, several new techniques are available for functional image diagnostics ("billeddiagnostiske").

This has also been an issue in other Nordic countries for example Sweden.

**9. From Finland:**

According to the Finnish statutes, a clinical investigation of the brain death criteria is sufficient with no special radiographic investigation necessary. Terhi Hermanson (TH) will send criteria for brain death diagnosis in Finland to the meeting participants. Finland reported that there is a bill in the legislature for changing the present law towards presumed consent in organ donation from deceased donors. Today, it is not specified who are the relatives or intimate ones whose opinion about organ donation should be asked. TH reported that activities are taken to facilitate "a more smooth process" meaning that if it is known that the deceased person was against organ donation, then organ donation is not allowed. Otherwise the relatives would only be informed about the donation process. In Finland they have had 9 living kidney transplantations in 2008 which is the highest number in recent years in Finland and also here some initiatives are taken to facilitate the possibility of using living organ donor for kidney transplantation in Finland. An adjustment of the law complex concerning transplantation in Finland is planned.

From Norway there is a tendency to a more active attitude from the nephrologist to raise the question to the patient if there are any family members that could be relevant for a living kidney donation. Michael Olausson stated that it is very crucial how the approach to relatives is done concerning the question of organ donation from a living donor. Anne Christine Breivik (ACB): It is a matter of legislation versus praxis and to have these rules clarified. The refusal rate of relatives to organ donation from deceased donors differs for example in Spain between different regions from 15% to 50%.

These issues are very important and an important issue in all the 5 Nordic countries in the dialogue between the national health authorities and the organ transplant community. All participants recommend analogue set of rules in all 5 Nordic countries.

**10. The IT situation in Scandiatransplant**

**- the present status**

**- the development project with Oracle**

**- personnel**

The computer system of Scandiatransplant is the engine driving the system. The present IT system is from 1994 with some modifications during the years. It is of great importance to modernise the IT system used of all the users in the Scandiatransplant association. Therefore a process had been started and the company Oracle Danmark was involved in a project that cost a lot of money, time and frustrations. This cooperation has been stopped and now we have employed a new programmer and we have already made some changes i.e.

- adjustment of the licence agreement for the computer programmes

- a clarification of how to recreate the datasystem

And now we are in a phase of an enthusiastic work process towards a new system beginning with a web-based version of the database for living kidney donors. It is planned to be released before the end of this calendar year and after that other parts of the datasystem will be renewed.

So far this has been financed by the economy of the Scandiatransplant association itself.

**11. Activities within the CoE, EU and other organisations:**

PP is functioning chairman for the expert group on transplantation in The Council of Europe (later elected as chairman from 02.10.09). This group has existed for more than 20 years but has now been reorganised under the auspices of EDQM and thus belongs under partial agreement with 27 nations as partners plus the rest of the states as observers. The group (called CD-P-TO) functions as a "think tank" reaching more universal recommendations due

to the fact that the observer states also have the right to speak during the meetings and therefore decisions (which traditionally are unanimous) can be made on the broadest and best basis. CD-P-TO has published a "Guide to safety and quality assurance for the transplantation of organs, tissues and cells" which now has been revised in an updated version taking into consideration the latest information about tumors in the potential organ donor. The chapter about infections is presently being updated. This book is a practical tool used throughout the transplant community in many countries. In addition the Newsletter Transplant is published under the auspices of Council of Europe. Newsletter Transplant has shown its very high usefulness with accurate data on donation and transplantation in Europe and many other countries. A joint Council of Europe/United Nations study on trafficking in organs, tissues and cells and trafficking in human beings for the purpose of the removal of organs has been prepared. The meeting will take place at the United Nations in New York on Oct. 13, 2009 to coordinate the activities of different international organisations. CD-P-TO deals mainly with European issues, but has not only members from the 27 EU states but also includes all the other European states and especially East European states that are now establishing legal transplant programs and where illegal transplant activity has been known to take place. Member states of CD-P-TO also helps these new states, from implementing new transplant laws to practical help in training of hospital staff. The latest example of a CD-P-TO initiative, is focusing on "double listing" on waiting lists in different countries, which is known to exist .

The initiative from Denmark about a move to WHO Europe instead of staying in the auspices of the Council of Europe had been taken away from the table again, which is appreciated by all. All meeting participants in the Nordic Transplant Committee could agree that it is necessary not to do double work, but that it can be necessary with more discussions of the purpose of each organisation by itself and in relation to each other.

**On the EU directives:**

From Socialstyrelsen Sweden a text of approx. 70 pages had been seen by the board members of Scandiatransplant although Scandiatransplant was not put on the sending list in the beginning. By reading this text it is seen that the word "organ" is mentioned somewhere. This issue was thoroughly discussed and it is decided that Scandiatransplant sends a letter to the general directorate of Socialstyrelsen to clarify the high demand for common rules in all the 5 countries of Scandiatransplant so that Scandiatransplant can continue to work as it has done during the last 40 years (the letter was sent after this meeting, a copy is enclosed these minutes). It is necessary to have EU directives on blood, other directives on tissues and cells and then wait for the new directives for organ transplantation not for the time being finished with the relative clarification of the content of the directive itself and the national action plans. It is of great importance not to mix tissue and cells with the rules that will be set in action in the area of organ transplantation although some of the aspects of quality assurance can be applied to the area of organ transplantation. MN stated that it is expected that the EU directive on organ transplantation will be finished within the next year, probably during the leadership of EU where this is under chairmanship of Spain. Expected closing time June 2010. From several of the meeting participants it was stated that what is in the EU directive is minimum standards which is binding whereas action plans are national action plans not binding in the same way as the directive in itself.

**EOEO:**

This organisation has earlier on worked out policy on exchange of organs between organisations (done some years ago), but now this forum will await the faith of the EU directive, and then it will be judged if it has to be laid down or it shall exist in some way or another.

**EFRETOS:**

It had been possible to get some funding to some European projects for example EFRETOS in which Scandiatransplant has an observational status.

Due to many commissions and working groups and activities in Europe on organ transplantation it is questioned if it is possible to get an overview of which of the national health care persons and which of the Scandiatransplant persons are involved in which activities in the European co-work context. It is decided that each member of the Nordic Transplant Committee try to send these information to the secretary in Scandiatransplant: Susanne Sønder (e-mail: [scandiatransplant@scandiatransplant.org](mailto:scandiatransplant@scandiatransplant.org)) and then the Scandiatransplant office will try to make an overview of who is active in which context. This information can then be shared between the representatives from the national health authorities and the Scandiatransplant board and the council of representatives.

**12. How to align the responses to questions from CoE, EU, WHO from Nordic Health Authorities with the response from Scandiatransplant? Is it advisable or even possible?**

From the board of Scandiatransplant it is stated that it is necessary to coordinate the activities. EU had in its working groups been very receptive to the comments from the experts also including representatives from Denmark, Sweden and Finland. The chairman of the board of Scandiatransplant had had function of observer and participated in discussions in the working groups.

EU had worked with a new directive on patient mobility within the European Union and in this it has been possible to take out issues on organ transplantation based also on recommendations from several of the Nordic experts.

**13. Any other business:**

No issues.

**14. Next meeting 2010:**

It is decided that following the rotation principle, the time has come to ask Reykjavik, Iceland. The next meeting is decided to be on September 7, 2010 in Reykjavik with a Scandiatransplant board meeting the day before also in Reykjavik.

Encl.:

- Letter sent to the Swedish Health Authority (Socialstyrelsen).
- 10 dias presented under item 5
- Comments on item 11 received from Bjorn Ursin Knudsen, Sundhedsstyrelsen (Health Authority), Copenhagen, based on investigations made after the meeting.

Writer of minutes: Niels Grunnet