

Nordic Transplant Committee

/ Nordic Transplant Committee / Minutes meeting No. 13 Sept 23, 2008 Copenhagen

MINUTES OF MEETING

Meeting No: 13th meeting in the Nordic Transplant Committee

Time: Tuesday, Sept. 23, 2008 at 12 - 16 hrs

Meeting place: Sundhedsstyrelsen (Health Authority)
Islands Brygge 67
2300 Copenhagen S
Denmark

Meeting participants:

National Health Authority representatives:

- (JS) Jorunn Svendsen, (Helsedirektoratet) Norwegian Directorate for Health, Oslo
- (ACB) Anne Christine Breivik, (Helsedirektoratet), Norwegian Directorate for Health, Oslo
- (TH) Terhi Hermanson, Ministry of Social Affairs and Health, Health Department, Finland
- (ÅW) Åsa Welin, The National Council for Organ and Tissue Donation (Socialstyrelsen) Stockholm
- (SM) Sveinn Magnússon, Ministry of Health and Social Security, Reykjavik
- (BUK) Bjørn Ursin Knudsen, Sundhedsstyrelsen (Health Authority), Copenhagen

The board of Scandiatransplant:

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

Apologies received from:

- (MO) Michael Olausson, Gothenburg

Medical director, Scandiatransplant:

- (NGR) Niels Grunnet, Aarhus

1. Welcome:

By the host Bjørn Ursin Knudsen (BUK) followed by welcome by the chairman of the board of Scandiatransplant Arnt Jakobsen (AJ). There was a short presentation round. Terhi Hermanson (TH) has a background as medical doctor. Anne Christine Breivik is lawyer.

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

Arnt Jakobsen elected as chairman of the meeting and NGR elected as writer of the minutes.

3. Approval of minutes from meeting No. 12 in Oslo on Sept. 18, 2007 :

Approved. AJ had the comment that Sctp earlier on had received 400.000 DKK from the Nordic Council of Ministers that there had been no application in the year 2008 and we will investigate if it is feasible to make an application for 2009 to get financial support for the Scandiatransplant datasytem's technical update.

4. Additional issues for the agenda from the participants:

Lauri Kyllönen (LK) will present some appropriate pictures on the situation in Finland for deceased donors and kidney transplantation.

2 extra items will be dealt with under agenda item 10. One on trafficking the other on control of living kidney donor from third party countries used in context with patients in one of the five Nordic countries.

5. Status regarding organ transplantation in the Nordic countries in 2007:

NGR showed a power point presentation on transplantation figures for 2007. The pictures evoked a fruitful and lively discussion concerning the differences between the high per million population rate of living kidney donor transplantation in Iceland versus Finland. A difference due mainly to cultural issues. Finland made living kidney donor transplantations in the beginning, then in 1971 Finland was the first of the Nordic countries accepting the brain death, and since focus had been mainly on kidney transplantations from deceased donors. The Iceland representatives were asked by the Finnish representative from the Ministry how to secure that living kidney donor transplantation is done for altruistic reasons. Of course this is difficult to prove but in case of a doubt or uncertainties, a psychologist or a psychiatrist is involved in the decision making of a potential kidney transplantation using a living donor in Iceland. It is the plan to continue with this high rate of kidney transplantations from living donors in Iceland. From LK we are informed that there are an increasing pressure on the use of living kidney donors in Finland due to the relative decrease in the available kidneys from deceased donors during the recent time. NGR is asked from Åsa Welin(ÅW) if we can see the mean number of organs transplanted from each deceased organ donor within Scandiatransplant. We have in Scandiatransplant a relatively high degree of multiorgan donors. Frank Pedersen at the Scandiatransplant office will be able to find the figures for Sweden.

Newsletter Transplant September 2008 concerning 2007 figures was made available for those participants not already having got this publication. It is very valuable in many aspects. From Sweden it is said that the figures on tissues were missing in this issue due to an editorial error. Liver transplants have increased in Norway since 2005 and this was commented on by PP.

Then we had a round where each country commented on issues in transplantation the last year. In Denmark we have changed from counties to 5 regions and we are looking forward to the activity of the Danish Center for Organ Donation, see below. It is expected to have fewer donation hospitals in the future which may make the organ donation process more efficient. From Finland it was reported on a new project with pancreatic islet cells plus stem cells in a special protocol since the summer 2007. So far six patients have been involved in

this programme. From an analysis made by LK over the last 18 months it is seen that there is a decrease in the number of actual deceased donors for kidneys in Finland, in the same period there is an increase in the unrealised deceased donors for kidneys. However, if you look at all potential organ donors for kidney transplantation there is a steady state. These figures will be followed intensely and analysed. It was questioned if this fall in realised organ donors could be due to a higher number of refusals from family members. In Iceland in 2007 eight kidney transplants were done with living related donors; it has been very well functioning.

In Norway there is a growing age of the population. There is a 10% rise in the number of uraemia patients per year. They try to establish "the Spanish model by donor responsible doctors". Since the 1st of January 2008 there has been a reimbursement system of actual costs to the donation hospital using the DRG-system. The reimbursement is only given if there is a realised organ donor not for those being cancelled for various reasons during the process. The government in Norway had set up the goal to double the number of deceased organ donors for transplantation. In order to try to fix how to reach this goal, a national and advisory committee for organ transplantation has been set up to help facilitating an increase in the number of deceased organ donors in Norway. It is by training purposes, capability of treatment at Rikshospitalet in Oslo etc. There had been a case with a non heart beating donor in Norway where organ donation was questioned who was diagnosed correctly before admission to hospital so organ donation was not realised. However, the case gave some debate in the press. In Norway there is a suggestion of finalising a continuous treatment of disease that will not bring the patient to recover, that means to turn off the respirator in a patient where hope for the future is lost. A process is now going on to get authorisation for doing such things with everything made ready for transplantation before turn off of the respirator in these very special patients. The refund according to the DRG codes for a donation is between 70.000-100.000 NOK but only if the donor is realised. In Sweden there has been a slight increase in the number of kidney transplantations. In Uppsala the team working with pancreatic islet transplantations chaired by Olle Korsgren had had great funding from a research fund of 50 million SEK in addition to the great fundings given from United States. They had performed more than 1100 islet isolations in Uppsala and it is a very interesting research area collecting elegant research results. In Oslo there has been a process of processing the islets for transplantation quickly after removal of pancreas from the deceased person. This is a factor that could higher the motivation factor in the surgeon for participating at this.

6. The Danish Centre for Organ Donation:

BUK reported on the relatively low figures for organ transplantation in Denmark. The institution with contact persons at hospitals had been tried, but with no satisfactory efficiency. Two years ago patient organisations went to the government and it was realised to get funding on the state project to create a national center for organ donation. The leader Helle Haubro Andersen (lawyer of education) is intended to be invited for future meetings in the Nordic Transplant Committee. They work with 3 projects mainly: education, data collection and organisation. It is a project of approximately 9 million DKK per year. In connection with the 4 neuro centers in Denmark (Aarhus, Aalborg, Odense and Rigshospitalet) several models are investigated to evaluate how one could set up some organ donation teams. The home page www.organdonation.dk was in the air August 22, 2008. There will be a monitoring of the activity of organ donation. EDHEP-course is continued in the auspices of this new organ donation center. In the future there will be an education for medical students during their pregraduate period and one will try to develop some e-learning courses. It was questioned if it is mandatory to make a registration of potential organ donors at intensive care units (ICU). This is not yet fully implemented but some investigations have been done.

7. Experience with the Swedish Donasjonsrådet

ÅW presented the national survey of potential heart-beating solid organ donors in Sweden, an investigation presented at the Scandinavian Transplantation Society meeting in Oslo May 2008. From this it was clear that only 59% of potential donors became actual organ donors. The goal after this study has been to increase it to 90%. Today Sweden has approx. 135 heart-beating solid organ donors per year. The goal is to have these increased to 200 per year. Maybe there are more potential donors in Sweden than the 247 which were registered in this investigation. There was a general discussion concerning that several of the Nordic countries put several million kroner in different projects of analysing, collecting and stimulation the number of organ donors, and it is clear from the discussion that it is mandatory for all the five Nordic countries to have an increase in the number of deceased organ donors. This will cost money and therefore health authorities have to focus on cost efficient investments. From the data from Finland and elsewhere it is seen that there are seasonal differences in the number of deceased donors. There are variations between areas in each country and between countries. In Spain they have family refusals between 10-50% depending on where it is in the country. In Norway it is normally 20-30% and in Denmark and in UK it is 50% family refusals to deceased organ donation.

8. The IT situation in Scandiatransplant

- the present status

- the development project with Oracle

- personnel

Our present IT-system is from 1994; therefore we went into a project with Oracle. There has been a turn of project management from Skejby-IT and from Oracle Denmark and this had created misunderstandings. There was a clearing-up meeting at July 1, 2008. At the moment we have one full-time and one part-time (3/4) IT-persons at the office. From November 1, 2008 a new IT-programmer and projectleader has been employed at the Scandiatransplant office, Skejby. This gives a new situation and we hope that we can manage to speed up the developmental project of the datasystem for Scandiatransplant. The possible help by lawyers is discussed but this aspect has been dealt with. From the health authority persons very great support is expressed to the Scandiatransplant system. It is very critical if the Scandiatransplant datasystem is not functioning because all the health authorities have their data, their numbers and figures from this source. The representatives of the health authorities present at the meeting express their willingness to support Scandiatransplant as much as possible in its process of keeping the datasystem in a living, functioning and modern form. It was questioned if the Scandiatransplant datasystem is a simple datasystem, but it was illustrated from Finland and others that the issue of creating a well-functioning datasystem concerning organ transplantation parameters is not an easy one, but a complicated issue.

9. Activities within the Council of Europe (CoE), EU and other organisations

PP reported on CD-P-TO: a document of living kidney donor from non-genetical related donor had been approved spring 2008 after many discussions and changes in the wordings. The European day for organ donation is October 18, 2008 in Ljubljana, Slovenia. At this meeting there will also be a look at the next issue of the guideline for organ transplantation which in 3 earlier editions have been published from Council of Europe. The Transplant Newsletter is also under the auspices of the Council of Europe. It will now come in an electronic version in addition to the printed version. Per Pfeffer has been functioning chairman for this group also trying to set up documents that could be at help for countries not fully developed within the organ transplantation area. PP points on that a representative from Denmark has not been participating in these CD-P-TO meetings the last times. BUK

will have a look on that and it was agreed that it is very necessary that the Nordic countries are present at these meetings to stress the Scandinavian attitudes and way of handling, which in some aspects are less bureaucratic than in Southern Europe.

Concerning activities in the EU there had been three expert group meetings since our last meeting and there is now a process in defining a directive for organ transplantation in a soft version plus some actions plan in the annexes which make it possible at national levels to make an adoption to the national rules and set-up. Terhi Hermanson (TH) told that there had been an intense debate in the commission whether the directive should be soft or strict and she told that the presentation may be delayed (it was promised that the directive would be presented before Christmas). She stressed that it will be on the donation side and not so much on the transplant side. Organ transplantation is practice of clinical medicine in a higher degree than blood transfusion where it is more a matter of production of components. All participants agreed that the directive should not be so regulating that it will make changes in the organ transplant activity.

With respect to Europe and EU several projects are on the scene, former on Alliance-O, now it is EFRETOS including 6 organ transplant organisations including Scandiatransplant and ESOT. There have been an application to EU and they have said that they will give 750.000 Euros which create some working groups. The money are not for the development of datasystems but it is very necessary to create some best practice documents to help for upcoming countries.

10. Any other business

Trafficking.

The declaration of Istanbul on organ trafficking and transplant tourism. It was distributed to the health care representatives and discussed.

The other issue concerning living kidney donors living in foreign country donating to relatives or associates being a citizen in Denmark. SSS distributed a letter of three pages created by the four university departments doing kidney transplantations in Denmark. The issue is discussed, a reply from the Danish National Board of Health has not been published yet. Although the absolute number of these cases is low it is of great importance to have a clear set of handling these cases. From Norway it is stressed that you have different ethical aspects in the obligations of the legal system, the medical system and the hospital. A practice in Oslo seems to be appropriate according to legislation (the point of view from a lawyer) that Norwegian laws and guidelines are in action in Norway but not in other countries meaning that an organ donor from a third party country who is sent back to the primary country is equipped with a letter stating what has been done and which regime for follow-up and care of the organ donor is recommended and will be followed if the person is in Norway. This could fulfil the legal requirements. This issue could not be solved at this meeting, but now the problem has been raised and we will come back to a discussion and clarification of what is done in each country within Scandiatransplant and if we can create a common set of rules.

11. Next meeting (2009 Stockholm)

Was decided to be on September 22, 2009 at The National Council for Organ and Tissue Donation (Socialstyrelsen), Stockholm.

Writer of minutes: Niels Grunnet