Minutes of Scandiatransplant Council of Representatives Meeting on May 14th 2008 in Oslo, Norway

- 1. Per Pfeffer, Oslo opened the meeting. Arnt Jakobsen, Oslo, welcomed the representatives.
- 2. Dagfinn Albrechtsen, Oslo was elected as chairman of the meeting. Øystein Bentdal, Oslo was elected as writer of the minutes. Lars Wennberg, Stockholm, and Jussi Merenmies, Helsinki were elected as controllers of the minutes.
- 3. Additional points. Afterwards the representatives/substitutes/observers were presented (Attachment). The invited visitor Eduardo Fernandez-Zincke, Medical officer, Brussels was welcomed and the presentation were given as the next issue on the agenda.
- 9. Presentation by Eduardo Fernandez-Zincke on EU activities towards an EU Directive on organ donation and transplantation was given, followed by a discussion. Each country can decide whether to participate in areas where established systems and registers are well functioning. Rapid response systems on serious adverse events (SAE) are developing. The Directive on organ donation and transplantation is going to be approved by the EU Commission later in 2008. More info can be found on http://ec.europa/health/index_en.htm
- 4. The minutes from 2007 were approved.
- 5. The chairman of Scandiatransplant, Arnt Jakobsen, Oslo, presented the annual report for 2007 (Attachment). A thorough presentation was given of the finances at Scandiatransplant and the situation around the development of the new computer system which was later discussed under 11 on the agenda. The board applied in 2006 for a grant from the Nordic Council of Ministers to support the development of the IT-system. A grant of DKK 400,000 has been received. The board has discussed applying for another grant at the end of 2007, but has been informed by the Secretariat of the Nordic Council that there is no money available for health related projects for 2008/2009.

Transplant tourism is an increasing problem especially in the south of Europe, with *non residents* seeking access to the transplant waiting list. The trafficking by *residents* in Scandinavia to countries outside Europe has also been reported in recent years: Denmark 45, Sweden 10, Norway 3-5 and Finland 3.

The annual report was approved with applause.

The report will be available on Scandiatransplants web site www.scandiatransplant.org

- 6. Election of Scandiatransplants board members and substitutes. Per Pfeffer, Oslo, was reelected as board member with applause.
- 7. Niels Grunnet, Scandiatransplant, Århus, presented the accounts and the financial balance for 2007 is satisfactory, DKK 2.954.243. The account has been signed by all board members. On recommendation of the accountants KPMG Statsautoriseret Revisionspartnerselskab, Århus, the financial report was approved by the representatives.
- 8. The budget for 2008 was presented. There will be a deficit of DKK 130,000 due to expenses in development of the new computer system. The budget proposal for 2009 was approved. The budget is based on the anticipation of a steady number of transplantations. If this number should be lower than anticipated, the possibility of charging the centers for the deficit based on the number of transplantations was approved by the representatives. This has been the practice during recent years. The charge for each recipient transplanted with organs from diseased donors (DD), DKK 3.100 and from living donors (LD), DKK 800 should be unchanged in 2009 compared with 2008.

10. Report on the activities of Scandiatransplant presented by Niels Grunnet, Scandiatransplant, Århus. Totally 1259 DD and 286 LD transplantations were performed (recipients according to fee calculations).

See Scandiatransplant's homepage <u>www.scandiatransplant.org</u> where also the Power Point pictures concerning the activities for year 2007 can be found.

- 11. Developments related to the computer system was presented by the chairman. A hand out dated May 9th 2008 was given to the representatives on the progress of the recent software upgrading performed by Oracle. The quality of the IT work has not been satisfactory, but it is difficult to evaluate the present status until phase I is finished. Gunnar Tufveson,Uppsala recommended the Board to write a letter to the Global Director of Oracle. Yves Vanrenterghem suggested that increased cooperation between Scandiatransplant and Eurotransplant concerning IT, could be to benefit for both in the future.
- 12. Report from the Tissue typers's group was given by Jussi Merenmies, Helsinki. (Attachment.)
- 13. Report from the Nordic kidney group was given by Lauri Kyllönen.
- 14. Proposal to a new kidney exchange rule within Scandiatransplant: ScandiaTransplant Acceptable Mismatch Programme (STAMP) by the Scandiatransplant working group on AMP and presented by Nils H Persson, Malmø and Torbjørn Leivestad,Oslo (Attachment). Superior results have been reported in highly immunised recipients in Eurotransplant with the Leiden protocol. There was no representatives which had any objections against STAMP. It is however, optional for each transplant center whether to participate in STAMP. According to Frank Pedersen, Scandiatransplant this new exchange rule can be implemented within 2 months

Exchange priority will follow Scandiatransplant rules and placed as priority 5:

Patient with STAMP-status when all donor HLA-A,-B, -DR antigens are either shared with the recipient or are among those defined as acceptable.

- 15. Report from the Nordic Living Donor Database group was presented by Ole Øyen, Oslo. More optional parameters were requested by Søren Schwartz Sørensen.
- 16. Report from the Nordic Paediatric Renal Transplantation Study group. A meeting was arranged in Copenhagen in October, 2007.
- 17. Report from the Nordic Liver Transplant group. A rotasystem has now been implemented in liver transplantation similar to the well established system in cardiac transplantation. User meeting will be arranged in Århus 15-16/9 2008.
- 18. Report from the Nordic Thoracic Transplant Study Group by Folke Nilsson, Gøteborg. Urgent lung transplant recipient has been agreed upon and will soon be implemented in the exchange rules.
- 19. Report from the Nordic Transplant Coordinator Group by Monika Olofsson, Oslo. (Attachment.)
- 20. Report from the reference group on prevention of transmission of infectious diseases from organ donors to recipients. Enclosed New Updated Guidelines.

- 21. Report on pancreatic islet transplantations by Gunnar Tufveson. Three clinical protocols have been approved. In Uppsala 1000 islet islations have now been performed.
- 22. Nordic Transplant Committee. (Attachment.)
- 23. International cooperation activities:
 - a) EOEO c) Alliance-O (Attachment.)
 - b) Council of Europe, Expert group (within the framework of EDQM) (Attachment.)
- 24. Travelling grants. (Attachment.)
- 25. Other matters. Certification of transplant surgeons in Europe have been implemented in 2008 and Michael Olausson, Gøteborg recommended all transplant surgeons to apply for certification. It is possible for experienced surgeons to be certified without exams, but formal applications are required.
- 26. Next meetings:

2009: Malmø (22/4) 2010: Helsinki + STS 2011: Copenhagen 2012: Reykjavik + STS

Oslo May 23th

Øystein Bentdal Writer of minutes

Oslo

Lars Wennberg Controller

Stockholm

Jussi Merenmies Controller

Helsinki

Accepted by e-mail with a few added corrections.

Re: (Attachment) mentioned above: This refers to the documents sent together with the agenda to the representatives and the board. If anyone needs these attachments please contact Susanne Sønder by e-mail: scandiatransplant@scandiatransplant.org

List of attendants at the meeting is enclosed.