

MINUTES from the Scandiatransplant Council of Representatives' meeting on May 25, 2011 in Copenhagen, Denmark

Kaj Anker Jørgensen welcomed all the representatives to Copenhagen

- Election of meeting chairman, writer of minutes and controllers of minutes 2. Søren Schwartz Sørensen was elected meeting chairman and Øyvind Østraat writer of minutes from the meeting. Arno Nordin and Allan Rasmussen were elected as controllers of minutes
- 3. Additional items or comments to the agenda including registration of the present representatives/substitutes/observers.

Scandiatransplant chairman Krister Höckerstedt gives additional items to the agenda and the present representatives were registrated. These were from

Helsinki: Lauri Kyllönen, Kaija Salmela, Hannu Jalanko, Arno Nordin and Carola Schaumann.

Stockholm: Bo-Göran Ericzon and Lars Wennberg and Gunnar Söderdahl Uppsala: Lars Bäckman

Skåne: Ragnar Källén, Johan Nilsson

Göteborg: Lennart Rydberg, Styrbjörn Friman, Vilborg Sigurdardottir and Gustaf Herlenius Oslo: Aksel Foss, Christian Naper, Odd Geiran, Karsten Midtvedt, Tim Scholz and Pål Foyn Jørgensen.

Copenhagen: Allan Rasmussen and Søren Schwartz Sørensen

Odense: Claus Bistrup

Aarhus: Øyvind Østraat

Iceland: No legal representative because of problems with the vulcano ash that stopped all the airplanes from Reykjavik.

Apart from the representatives the following were present: Krister Höckerstedt, Helena Isoniemi, Michael Olausson, Per Pfeffer, Kaj Anker Jørgensen, Margret B. Andresdottir, Niels Grunnet, Bo Hedemark Pedersen, Ilse Weinreich, Frank Pedersen, Christian Mondrup.

4. Approval of minutes year 2010 (see homepage):

Minutes year 2010 were approved.

The Chairman's annual report 5.

The chairman's annual report has been sent to all the representatives beforehand. Scandiatransplant now consists of 10 transplant centers, Lund Malmø is one center and Herlev Rigshospitalet is one center. The number of kidney transplants increased in year 2010 mainly because of living donor transplantations and the transplant waiting list was shortened.

6. Election of Scandiatransplant's board members and substitutes (enclosure) Per Pfeffer now leaves the Scandiatransplant board and the new member is Pål-Dag Line with Aksel Foss as the substitute. Grunnet thanked Pfeffer for his work in the board.

7. Accounts and economical balance fiscal year 2010. (enclosure): A review of accounts and economical balance fiscal year 2010 was given by Niels Grunnet with no further comments

8. Approved Budget for 2011 and proposal for 2012.

Niels Grunnet gave an overview over the approved budget for 2011 and the proposal for a budget of 2012. The fortune of Scandiatransplant increased in 2010 and we expect the income to balance the costs for 2011. The price for deceased donor kidney transplantation is 3000 DKK, and for a living donor kidney transplantation 700 DKK. The fees were accepted to be kept at the same level for 2012.

9. Report on the activities of Scandiatransplant 2010:

See Scandiatransplant's homepage www.scandiatransplant.org where also the Power Point pictures concerning the activities for year 2010 can be found.

These activities have been accounted for on Scandiatransplant's homepage www.scandiatransplant.org including a power point presentation on transplant performance. An overall review on the 2010 activities was given by Niels Grunnet. The overall number of deceased donors was 388 which is 15,23 per million population. There was an increase in the number of kidney transplantations. Most impressing was the increase of living donor transplantations in Denmark. For the first time in history there were more renal transplantations per million people in Denmark than in Norway. The report was approved by applause.

10. Developments related to the computer system:

Bo Hedemark Pedersen gave a short update. The file for reporting living donor renal transplantations was completed. The thorax transplantation report system was nearly finished, late mainly due to lack of programmer resources. Conversion to the new system for all organ transplantations was planned finished in 2014. Bo-Göran Ericzon wanted the living donor registry renamed to The Living Kidney Donor Registry, which was approved.

11. Report of activities. See link: http://www.scandiatransplant.org/board.htm

- The Reference group on prevention of transmission of infectious diseases from donors to recipients
- The Tissue typers' Group
- The Nordic Kidney Group (enclosure and 2 proposals for modifications of rules for exchange of kidneys from Deceased Donors)
- The STAMP Group Lars Wennberg, Stockholm
- The Nordic Liver Transplant Group
- The Nordic Thoracic Transplant Study Group Odd Geiran
- The Nordic Living Kidney Donor Database group One from Olso
- The Nordic Paediatric Renal Transplant group Hannu Jalanko, Helsinki
- The Nordic Transplant Coordinator Group Carola Schauman, Helsinki
- The pancreatic islet transplantations Lars Bäckmann, Uppsala
- The pancreas transplantations Per Pfeffer, Oslo
- The intestinal transplantations Gustav Herlenius, Göteborg

Firstly, Gustaf Herlenius reported on the activities in intestinal transplantations. Altogether 28 transplantations had been performed with patients from the Nordic countries. Of these 16 patients are still alive. Short term survival was 80% after 1 year. Long term survival data was incomplete due to the registration, but 50% of these patients die on the waiting list within the first year.

Lennart Rydberg reported from the the Tissue Typers' group. There still is no consensus on the cut of value of the luminex test. This is mainly due to the use of different luminex tests in the different centers. There is work ongoing trying to reach common methods for PRA measurements.

Styrbjørn Friman was reporting from the Reference Group on Prevention of Transmission of Infectious Deseases from Donors to Recipients. There were only small changes and the Guidelines were accepted.

Lauri Kyllönen reported from the Nordic Kidney Group. There were enclosure and two proposals for modifications of rules for exchange of kidneys from deceased donors. Highly immunized paediatric recipients were proposed added to the Stamp list right away instead of waiting time of at least one year on the normal list which is the rule for adult patients. They also proposed change in the rules of exchange of kidneys when another center has a recipient who is HLA identical but not immunized: If there is an age discrepancy between donor and recipient more than 30 years you don't have to send the organ (Approved). Lars Wennberg reported from the STAMP group. Before starting up of the Stamp programme the mean waiting time for these patients was 62 months. Now 25 renal transplants have been performed in 24 patients registered on the Stamp list.

Aksel Foss reported from the Nordic Liver Transplant Group. In 2010, 323 livers were transplanted and this is an all-time record. 284 patients received their first liver transplant. Vilborg Sigurdardottir reported from the Nordic Thoracic Transplant Study Group and there was no changes from the report of activities on the website.

Carola Schaumann reported from the Nordic Transplant Coordinator Group. Now the first transplant coordinator from one of the Nordic countries has passed the international transplant coordinator exam.

Lars Bäckman reported from the pancreatic islet transplantation group. There are still problems with the logistics and long ischaemia time which is followed by inferior results. In 2010, 156 pancreases were donated to the programme which have received altogether 1400 pancreases. 39 transplantations were performed in 2010 and altogether 278 transplantations have been performed.

Finally, Per Pfeffer reported from the pancreas transplantation group. 43 pancreas transplantations were performed in 2010. The results have been improved since 2003 mainly due to less rejections and fewer reoperations. Helsinki has started up and performed 2 transplantations in 2010, Oslo has a stable activity around 15 transplantations per year while Gothenburg has increased their activity and performed 10 pancreas transplantations in 2010. On the other hand the activity in Stockholm has decreased significantly.

12. Nordic Transplant Committee

Report from the Nordic Transplant Committee A short report was given by Krister Höckerstedt. There have been meetings between Scandiatransplant and representatives from the Nordic government authorities. There were no comments on the written report from the Nordic Transplant Committee.

13. International cooperation activities

a) EOEO:

Have been working on Directives on organ donation primarily. They have been working on a minimum data set and a complementary data set.

b) EU directive on Transplantation:

Several of the representatives had been contacted. Krister Höckerstedt commented that it is important to find a common language in communication with this EU organisation.

c) EFRETOS:

which is the European Framework for the Evaluation of organ Transplant. They are working on a European transplant registry, however it cannot be used for allocation purposes.

d) Council of Europe, Expert group of EDQM:

Per Pfeffer is our representative in this group (chairman). He gave a short report.

e) Scandiatransplant and Estonia:

Krister Höckerstedt gave a short update on the transplantation activities in Estonia. Estonia is the Baltic country which in their culture and even their transplantation activity is most similar to the Nordic countries. They have asked for further cooperation with the Scandiatransplant but more details are needed.

14. Grants:

- Travelling grants

There were travelling grants for 2011:

From Helsinki: Juha Peräsaari+Eeva Mainio were granted an amount of DKK 8,200.-

From Oslo: Are Martin Holm+Henrik Auråen were granted an amount of DKK 20,000.-From Stockholm:Öystein Jynge was granted an amount of SEK 7,000.-

From Oslo: Kristine Kloster-Jensen was granted an amount of DKK 20,000.-

- From Gothenburg: Kenneth Lindström was granted an amount of SEK 10,000.-
- The new Scandiatransplant Research Grant.

See link: <u>http://www.scandiatransplant.org/Scandiatransplant%20Research%20Grant%202011.doc</u> Three applications have been received. After a very careful and fair long discussion where each stone was turned it was decided to give the Scandiatransplant Research Grant 2011 to the group dealing with investigation of liver organ donors >75 years. Three countries out of five are involved in this project, it has a great deal of novelty, it is sizeable, it can be initiated within the next months, and it is predicted to have practical implication not only in the five Nordic countries i.e. Scandiatransplant, but also in the rest of the world.

15. Any Other Business:

Margret B. Andresdottir read a letter from the Reykjavik group concerning the problems with air traffic and vulcano ashes. During the period last year in which air traffic was closed, there were three possible donors and the similar period this year they had one possible donor. Normally, there is an agreement with the center in Gothenburg to harvest the organs, but the Icelandic group asked the permission to harvest the organs themselves for transplantation on Iceland if the air traffic is closed. In principle, this is up to the Icelandic group themselves to decide.

 Next meeting 2012. Suggestion Reykjavik on Wednesday May 9, 2012 in connection with the STS meeting May 9-11, 2012. Accepted.

May 31, 2011 Øyvind Østraat, Aarhus Writer of minutes Approved June 15, 2011

Controllers of Minutes:

Allan Rasmussen, Copenhagen Approved by e-mail date: June 24, 2011

Arno Nordin, Helsinki Approved by e-mail date: July 15, 2011

File: Council of Representatives' meeting May 25, 2011 Cph / MINUTES Repr May 25, 2011 Cph incl NGR comments and APPROVED by ØØ