

May 22, 2010

## Minutes of Scandiatransplant Council of Representatives Meeting on May 19<sup>th</sup> 2010 in Helsinki, Finland

### 1. Welcome

- Meeting invitation (*enclosed <0>*) had been sent to all representatives by E-mail; with 26 attachments/accompanying documents included (*<0-24>*).
- Lauri Kyllönen started with wishing welcome to Helsinki.
- Helena Isoniemi gave further practical instructions regarding the venue.
- Arnt Jakobsen opened the meeting.
  - Axel Rahmel, director of EuroTransplant, was greeted welcome as observer.

### 2. Election of meeting chairman, writer of minutes and controllers of minutes

The following elections for the meeting were effectuated:

- Krister Höckerstedt as meeting chairman.
- Ole Øyen as writer of minutes.
- Styrbjörn Friman and Lars Ilkjær as controllers.

### 3. Additional items or comments to the agenda including registration of the present representatives/substitutes/observers

- Please find enclosed documents/listings marked *<3>*; *3 documents*.
- There were no specific comments to the agenda.
- A call for attending representatives, substitutes and observers was performed. The present attendees have been listed.

### 4. Approval of minutes for year 2009

The minutes for 2009, *enclosed <4>*, were approved without comments.

### 5. The Chairman's annual report

A thorough annual (written) report had been prepared by the chairman of Scandiatransplant Arnt Jacobsen; *enclosed <5>*. Delegates did express their judgement of the report as useful and informative.

Arnt Jacobsen gave a short and comprehensive review. Several of these issues were part of the the agenda later in the meeting. :

- 98% of the explanted organs had been used within Scandinavia
- The economy was healthy
  - In this regard Arnt mentioned particularly the efforts of Bo Hedemark Pedersen, when coming into the organisation. He decided to terminate a number of dubious IT engagements, thereby saving a lot of money.

- More IT people had been employed (altogether 5 at present); a highly necessary step in renewing/fulfilling the database requirements; particularly the implementation of a WEB-based version.
- The recently introduced STAMP program was well underway.
- Follow-up of Living Donors from third world countries was emphasized, according to the intentions of the 'Istanbul Declaration'.
- There should be prepared written guidelines on the extraction/use of data from the Scandiatransplant database.
  - Aksel Foss raised the proposition that Scandiatransplant should encourage the use/extraction of data, both by logistical and economical means.
- A letter from Scandiatransplant to Socialstyrelsen (Sweden), regarding the jurisdiction on 'organs' versus 'tissues and cells' had not yet been replied.
- The history of Scandiatransplant should be written and published
  - Sören Schwartz Sørensen proposed Arnt to be the editor-in-chief for this project.

6. **Election of Scandiatransplant's board members and substitutes**

*Enclosed <6>*. Arnt Jacobsen had been chairman of Scandiatransplant for the allowed two periods (2 x 3 years).

- Krister Höckerstedt was elected as new chairman, unanimously by applause.
- Board members: Helena Isoniemi replaced Lauri Kyllönen. Kaj Anker Jørgensen replaced Sören Schwartz Sørensen. Margret Andresdottir replaced Magnus Bodvarsson.
- Suppleants: Magnus Bodvarsson replaced Margret Andresdottir. Heikki Mäkisalo replaced Helena Isoniemi.
- The other members and substitutes of the board (not mentioned above) will continue to serve until 2011 or 2012.

7. **Accounts and economical balance fiscal year 2009**

A brief review was presented by Niels Grunnet; *.enclosed <7>; 4 documents*.

- The economy was in a good condition
- Net surplus: DKK 1.5227.29 Capital pr. Jan. 1., 2010: DKK 6.653.463
- For the year 2009 less was spent than was planned in the budget, particularly on salaries and IT development.
- The account for 2009 had been audited by the accountancy firm KPMG (Ringkøbing) and was approved by the Council of representatives.
- It was decided to still make use of KPMG in future.
- Styrbjörn Friman asked if the intention was still to increase the capital in future. He was answered that this was not the case, and that the present level of capital reserve seemed reasonable. Furthermore, the income fees from the Tx centers would be decreased by DKK 100 per transplantation in 2010 and 2011 (Cfr. point 8).

8. **Budget; revised for 2010 and proposal for 2011**

The budget for 2010 and 2011 was presented by Niels Grunnet; *enclosed <8>*.

- In the 2011 budget the salary expenses had been increased by DKK 450.000 (to DKK 2.900.000), due to the employment of more IT-related people.
- Øyvind Østraat proposed to increase the stipendium expenses. This was agreed upon, and it was approved by the Council to increase the stipendium contribution from DKK 60.000 to DKK 100.000.

- The fees for both DD- and LD-transplantations were decreased by DKK 100 per patient. This raised a discussion on whether these money rather should be invested in the stimulation of research projects utilising the Scandiatransplant registry data. However, the proposed decrease in income fees was finally approved.

#### 9. **Report on the activities of Scandiatransplant during 2009**

These activities have been accounted for on Scandiatransplant's homepage [www.scandiatransplant.org](http://www.scandiatransplant.org), including Power Point presentations on transplant performance.

An oral review of the 2009 activities was given by Niels Grunnet.

- There was an all high overall transplant activity with 407 deceased donors (16,09 per million population (pmp)).
- An increasing number of Kidney Tx's had been performed, with Norway reaching 60 pmp. Also regarding living donor Tx's an all high number had been performed within Scandiatransplant.
- The number of Pancreas-Tx's had also increased significantly during 2009, reaching the highest volume since 1990. During 2009 Gothenburg started up a Pancreas-Tx programme, and Helsinki made their first Pancreas-Tx a few months ago (2010).
- Regarding Heart-, Lung- and Liver-Tx there was overall a steady state scenario.
- The rate of organ exchange between Scandinavian Tx-centers was highest for Heart, followed by Liver, Lung and Kidney.
- There had been an efficient retrieval and use of organs per deceased donor, at an increased rate during recent years (in 2009: 3,7 organs from deceased donors aged 0-29).
- Five STAMP recipients had been transplanted.
- Frank pointed out that there were now 15 years of Tx data, available for extraction, in the Scandiatransplant database.

#### 10. **Developments related to the computer system**

Bo Hedemark Pedersen gave a short status report for the developments related to the computer system; *enclosed <10>*.

- He explained the reasons for escaping the Oracle contract/licenses and starting all over; with YASWA (Yet Another Scandiatransplant Web-Application).
- The new web-application was presented shortly. (Demonstration was later on afforded at the Scandiatransplant Congress stand).
- Total conversion, of all components of the database, have been planned finished during 2014.
- Oracle has still not been supportive regarding advice.

#### 11. **Report from the Tissue typers's group**

Torbjørn Leivestad gave a short presentation; *enclosed <11>*; *2 documents*.

- There was no particular comments on the written report from the tissue typers.
- It was pointed out that the centers had the option to refuse organs; if judged inferior due to donor age etc..
- There have been made changes in the Scandiatransplant database system; based on topics from Tissue Typers Meeting 2010 and an internal meeting with Torbjørn Leivestad (Cfr. separate enclosed document).
- The next meeting has been scheduled to Jan. 2011 in Gothenburg.

12. **Report from the Nordic kidney group (NKG)**

A short oral report was given by Lauri Kyllönen; *enclosed <12>*.

- The group has particularly discussed STAMP, the development of the IT system and diagnostic coding.
- There was no comments on the written report from NKG.
- Frank Pedersen has been included in NKG, as IT-consultant.
- The next meeting is scheduled to Nov. 2010.

13. **Report on new kidney exchange rules within Scandiatransplant**

A report about the introduction of STAMP (ScandiaTransplant Acceptable Mismatch Programme) was given by Jussi Merenmies *enclosed <13>; 2 documents*.

- 32 patients had been accepted and waiting-listed for STAMP.
- 5 STAMP transplantations have been performed without immunological complications.
- HLA-DQ matching has been included.
- The Council approved to upgrade STAMP patients to priority 3 on the 'kidney exchange rules list' - while HLA-A,-B and -DR compatible was reciprocally moved to priority 5.
- Axel Rahmel (EuroTransplant) argued in favour of even higher STAMP priority; but the decision described above was maintained.
- There was a discussion about defining a maximal age difference between donor and recipient (20 years?/30 years?). No exact difference-limit was agreed upon, but representatives suggested that this will be the task for the new board for a proposal at next year's representatives' meeting. However, there seemed to be a general understanding about the importance of age-matching in the recipient selection process; by individualised judgement taking all factors into regard.

14. **Report from the Nordic Living Donor Database group**

Ole Øyen gave a brief report.

- The implementation of the WEB-version of the Living Donor Database had now been finalised; as the first section of the Scandiatransplant database. Bo Hedemark Pedersen assured that this was now in 'production mode'.
- There had been a visit from Austria regarding our Living Donor Database; *enclosed <14>*.
  - The Austrian Coordination Office for Transplantation and Transfusion (ÖBIG) had been asked by the Austrian Ministry of health to develop a living kidney donor registry in Austria.
  - They concluded that Scandiatransplant had the most developed registry, among 3 european registries.
  - This led to a meeting between ÖBIG and Scandiatransplant on Dec. 7.-8., 2009 in Aarhus. The Austrians expressed satisfaction with this exchange of information.
- Krister Höckerstedt asked if Living Liver Donors were to be included in the database. Answer: The design of the database is not yet prepared for this; but adaptations to meet these demands will be sought in future.

15. **Report from the Nordic Paediatric Renal Transplantation Study group**

- Yearly meetings are planned.
- The preexisting pediatric database at Huddinge has now been imported/included in the Scandiatransplant database.

16. **Report from the Nordic Liver Transplant group (NLTG)**  
Styrbjörn Friman gave a short review; including the NLTG meeting in Helsinki in Oct. 2009 ; *enclosed <16>*.
- Most issues are accounted for in the above document
  - Two meetings are planned each year; next meeting in Copenhagen in Nov. 2010.
17. **Report from the Nordic Thoracic Transplant Study Group.**
- Odd Geiran reported about various Tx-thoracic studies going on.
  - It was pointed out that new rules for urgent lung recipients had been introduced, similar to the liver-Tx rota-list.
18. **Report from the Nordic Transplant Coordinator Group**  
Käthe Meyer gave a brief report:
- She urged that changes in rules regarding urgent recipients should be communicated to the coordinators as early as possible.
  - The introduction of a digitalised Tx-coordinator communication system (instead of fax) was discussed. Already, communication by an electronised fax version to cellular phones is available – and reported as very serviceable by coordinators.
  - ESOT/ETCO had now provided European certification of Tx-coordinator; *enclosed <18>*.
- 19 **Report from the reference group on prevention of transmission of infectious diseases from organ donors to recipients**  
There was nothing new to report regarding these guidelines, which were revised and approved in 2009.
20. **Report on pancreatic islet transplantations**  
Aksel Foss reported on the new global study on Islet Tx; by now 6-7 patients had been transplanted in Scandinavia.
21. **Nordic Transplant Committee**
- A meeting with national health authority representatives (from Finland, Denmark, Sweden and Norway) was conducted in Stockholm in Sep. 2009; *enclosed <21>*.
  - The need for uniform Scandinavian legislation was once again underscored.
  - The next meeting has been scheduled to Sep. 2010.
22. **International cooperation activities**  
Arnt Jacobsen gave a short review of these international activities.
- The contact with the EU organisations EOEO and EFRETOS will be maintained.
  - Council of Europe, Expert group (CD-P-TO); within the framework of EDQM.
    - CD-P-TO has one member from each European country, while Scandiatransplant has observatory status.
    - The CD-P-TO ‘Guidelines for the prevention of transmissible Tx diseases’ will be revised during 2010.
    - Furthermore, CD-P-TO has been involved in the issues of ‘Trafficking’ and ‘Double-listing’.
  - The EU directive about organ transplantation has recently been approved, after lots of amendments.
    - There has been a huge discussion about the wording regarding living donation

versus deceased donation; “LD subsidiary to DD” has been changed to “complementary”.

-- Axel Rahmel (EuroTransplant) elaborated further on this dispute, and pointed out that all will depend on how the directive is implemented.

- Dr Höckerstedt informed about the activities of the Division of Transplantation, Section of Surgery of the UEMS, founded in 2007.

Individual transplant surgeons have the opportunity to undergo an exam in four modules and those who pass receive authorisation in the European countries. The modules are: kidney transplantation, liver transplantation, pancreas transplantation and multiorgan donation. Among the examiners are surgeons from Finland, Denmark, Norway and Sweden. Surgeons from the thorax organs have not participated. As a new activity also transplant centers may apply for "Accreditation for training in transplantation surgery". Four centers have applied, among them is Oslo. The audit will be performed shortly. It is done by three surgeons, two from the Division of Transplantation Surgery and one surgeon requested from ESOT.

### 23 Travelling grants

DKK 60.000 had been distributed among 12 applicants.

- The Council approved (Cfr. point 8) increasing this contribution to DKK 100.000.

### 24. Other matters

- In Madrid in march 2010 an important international Tx meeting was arranged by EU in cooperation with WHO; *enclosed <24>*.
  - 61 countries were represented
  - An amendment (sent in by Ole Øyen on behalf of Scandiatransplant), on the complimentary nature of DD versus LD Tx will be included in the final resolution.

### 25. Next meeting in 2011: Copenhagen

- Suggestion: Week 21, May 25 at Hilton Hotel, Copenhagen airport.
- Søren Schwartz Sørensen invited the delegates to the next meeting in Copenhagen.

### 26. Tributes were made to the departing chairman Arnt Jacobsen

- His essential contributions to transplantation activity in Scandinavia was made clear by Per Pfeffer, particularly regarding international cooperation.
- Very warm retirement greetings were communicated.

Tributes were made to the other departing members of the Board: Lauri Kyllönen, Magnus Bodvarsson and Søren Schwartz Sørensen.

The minutes of the meeting are partly documented by the enclosures sent in advance to all the participants.

May 22., 2010

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|--------------------------------|----------------------|---|
| Ole Øyen<br>Oslo               | Writer of<br>minutes | New wording of last issue in item 22 above approved by e-mail on June 13, 2010.   |
| Styrbjörn Friman<br>Gothenburg | Controller           | Approved by e-mail on June 10, 2010.<br>New wording of last issue in item 22 above approved by e-mail on June 18, 2010. |
| Lars Ilkjær<br>Aarhus          | Controller           | Approved by e-mail on June 6, 2010.<br>New wording of last issue in item 22 above approved                              |

by e-mail on June 19, 2010.