

Minutes of the board of representatives meeting in Malmø, April 15, 2009.

1.
Ragnar Källén started with wishing welcome to Malmø. Arnt Jakobsen (AJ) opened the meeting.
2.
The following elections for the meeting were done: Styrbjørn Friman (SF) – chairman, Anna Varberg Reisæter - writer of minutes, Ole Øyen and Ragnar Källén controllers.
3.
Michael Olausson (MO) articulated memorial words about Hans Brynger and the meeting passed one minute in silence in Bryngers memory.

A call for attending representatives, substitutes and observers was done. Attendee list enclosed.
4.
The minutes for 2008 were approved without comments.
5.
A thorough annual report by the chairman was circulated with the meeting documents. Several of the issues were on the agenda later in the meeting. Krister Høckerstedt (KH) commented that the report was useful and informative.
6.
Election of Scandiatransplant's boardmembers and substitutes.
MO was re-elected by applause. The other members of the board will serve until 2010 or 2011. The supplants were also re-elected.
7.
Accounts and economical balance fiscal year 2008 was presented by Niels Grunnet (NG). For the year 2008 less was spent than was planned in the budget, among others on salaries and IT development. The account for 2008 was audited by the accountancy firm and approved by the Council of representatives.
8.
The budget for 2009 and 2010 was presented by NG.
An increase in spending on salaries for 2009 and 2010 was suggested. The suggested budgets had a negative balance of approx. ---. However, Scandiatransplant has funds in bank accounts, approx 4,6 mill D.kr. and the deficit will be covered from these funds. The fees were proposed unchanged from 2008 in the years 2009 and 2010, (DKK 3100 for transplantation with deceased donor and DKK 800 for living donor) this was approved by the Council of representatives.
9.
A report on the activities in Scandiatransolant was given by NG.
The slide with this information are found at www.scandiatransplant.org

The year 2008 we experienced an all high transplant activity with 398 deceased donors. Also the highest yearly number of living donor transplantations was performed in Scandiatriplant. Exchange of organs was dominated (in percentages) by heart, followed by lung, then liver and kidney

10.

AJ gave a short status for the developments related to the computer system.

Six years ago it was decided to go for a new IT system and offers from Oracle and Miracle received. The board decided for Oracle and IT Skejby was given the responsibility to run the project. The total costs for the total project so far are not known, but an estimate is approx. 2 mill DKK has been spent so far. There have been severe problems in the project. The management has been weak, with poor continuity with several changes of IT director at IT Skejby hospital, and also personnel in Oracle. The board has not been satisfied by work done and deliveries from Oracle. The participation of Oracle and IT-Skejby in the developmental project has been brought to an end.

A highly qualified IT associate was employed in November 2008, Bo Hedemark Pedersen (BHP).

Based on a limited Oracle database the IT personnel at Scandiatriplant will perform the IT developments themselves. It turned out that Scandiatriplant has overpaid licenses to Oracle for a system that had more capacity than the needs of Scandiatriplant. This has now been ruled out.

Frank Pedersen (FP) demonstrated how to enter data in the present Living donor registry. This is laborious and knowledge of the system is necessary.

BHP demonstrated the screens for a new system based on Oracle database with a service layer – web-service (SOAP, XML). This system is scheduled to be ready for use in 2-3 months time.

The plan is to further develop and renew other parts of the system, among other things to make an automatic quality control system. The system must be developed to be independent of developer, i.e. give the system standard formats. A test-group will be established for the production version.

Pål-Dag Line asked why not use an open source database. FP and BHP answered that a limited version of Oracle database has been taken in use and the licence fee is acceptable and function Ok.

Bo-Gøran Ericzon asked if the Living donor registry only includes kidney donors. What about living liver donors? This matter will have to be discussed by the liver group.

AJ thanked the IT personnel for positive development lately.

For the last 3 months FP has been looking up on exchange obligations for kidney donors to see if they have been followed. If the obligations were not followed he has inquired about the reasons. There has been negligible non-compliance. N Persson (NP) commented on who should decide what is a good explanation for non-compliance. AJ commented that violations should be reported to the board.

11.

There was no comments on the written report from the tissue typers (sent out in advance).

12.

A short report from the Nordic kidney group was given by Lauri Kyllönen. The group has discussed STAMP, the IT system and diagnostic coding. There was an initial discussion whether to put more follow-up data into the system. A discussion group on internet for problem patients was suggested. FP informed us that this has been looked into and can be made available in the Scandiatransplant IT system.

13.

A report about STAMP was given by Bjarne Møller. Last year in May a steering group was elected. Criteria for inclusion in the program were established and now the IT functionality is running in the Scandiatransplant datasystem. The program started March 1, 2009. One transplant has been performed 6 weeks after entering the program. All centres agreed to join the program, by now 2 centers have entered patients.

14.

Nordic Living Donor Database group. There is an ongoing renewal of the system. Ole Øyen (OØ) informed that otherwise there was nothing to report.

15.

Nordic pediatric group----
The most recent meeting of the group was in Oslo and yearly meetings are planned. There project has included 506 children in a database. The funding has been from Huddinge Hospital, but there are no available resources there any more. So far the registry is on a personal computer. There is a need to import this registry to Scandiatransplant.

SF urged the board to incorporate this registry into Scandiatransplant. FP informed that this has been discussed and that much of the data are already in Scandiatransplant.

16.

SF reported on the Nordic liver group. 4393 patients has been entered into the registry. The registrations are now done by Tom Henning Karlsen in Oslo. There were 285 liver tx last year. There has been an increase, especially in Norway. Both recipient and donor age has increased; still there is a good survival, however poorer in hepatitis C patients. There have been many projects based on the registry resulting in publications.

SF informed about the exchange rules for livers. There is a Rota system; the centre that received a liver will be put at the bottom of the list. If a recipient has not received a liver within 3 days on urgent call a kind request can be posted and a pay back can be done later. This will be irrespective of the Rota system.

17.

Nordic Thoracic transplant study group
The report was given by Martin Iversen (MI). Two clinical studies have been performed, and the studies are soon to be published.

Odd Geiran and MI had the task to suggest new exchange rules. The rules for heart and lung are different. New guidelines were agreed upon March 18, 2009 in Gothenburg and replace rules of Nov 25, 1996. The rules will be implemented May 1, 2009.

AJ asked about the European paediatric heart waiting list. MI answered that this will be discussed within the group.

18.

A short report from the Nordic Transplant Coordinator group was given by Ann-Christin Croon. Per Arne Bakkan, Oslo, is leader of the group. The last meeting was in Oslo in the spring 2008.

19.

Chairman of the "infection group" Vanda Friman was not present. SF presented the report. There have been some changes. Organs from donors with septicaemia can now be used under certain circumstances at the judgment of the surgeon.

AJ asked whether these rules are different from recommendations from the European Council. SF states that these is not rules but guidelines. OØ has been on an European committee and stated that there are no big discrepancies

20

Pancreatic islet report

No comments

21

Nordic Transplant Committee (see written report sent out in advance).

There are annual meeting with the Nordic health authorities.

AJ underscores the importance of cooperation with the Nordic authorities and that the policies are congruent in the Nordic countries. It is the responsibility of the board to forward this.

NP points out that at a national level it is useful to refer to Nordic policy.

22

International cooperative activities

AJ pointed out that from the start of his office as chairman he set out to participate and be active in meetings internationally in order to have the Scandinavian points of view heard. He reported on this activity. EOEO is European Organ Exchange Organisations.

European Union is working on a directive for organ transplantation. This is a soft directive. Each member state is stimulated to make own action plans. There are many working groups and initiatives.

Per Pfeffer participates in an expert group within the Council of Europe. He stated the importance of Scandiatransplant's participation in the discussions. We will be obligated by EU directives.

Krister Høckerstedt reported on discussions in the European Union. It is important to be aware that action plans can be very different from the original directives. Stated by KH and PP that it is very important to participate in these EU meetings.

23

Travelling grants presented by NG: In 2009 8 applications, 6 supported financially ~ 60,000 DKK

24

The Istanbul declaration about organ trafficking was published in Lancet July 2008. Scandiatransplant recommends that the national societies endorse the declaration. No objections were posted.

25

ISBT 128 for Tissue and Organs

Bar codes have been used for blood products. This can be an instrument for labelling in connection with organ donation and transplantation.

26

Helena Isoniemi invited the delegates to the next meeting May 19, 2010 at Finlandia Hall in Helsinki. In 2011 the meeting will be in Copenhagen.

AJ thanked the participants and closed the meeting.

Minutes of the meeting are based on the enclosures sent in advance to all the participants on 23/3-2009 by e-mail.

Anna Varberg Reisæter
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Writer of minutes

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Controller

Approved by e-mail on April 23, 2009

Ragnar Källén
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Controller

Approved by e-mail on May 4, 2009