

Minutes

Meeting No.: 63
Time: May 8-9, 2012
Place: Reykjavik, Iceland
Participants: The board of Scandiatransplant:

CHAIRMAN:	Krister Höckerstedt, Helsinki	(KH)
SWEDEN:	Michael Olausson	(MO)
FINLAND:	Helena Isoniemi, Helsinki	(HI)
NORWAY:	Pål-Dag Line, Oslo	(PDL)
ICELAND:	Margrét B. Andrésdóttir, Reykjavik	(MA)
DENMARK	Kaj Anker Jørgensen, Aarhus	(KAJ)
Director of Scandiatransplant:		
DENMARK:	Niels Grunnet, Aarhus	(NGR)

Leader of meeting: Krister Höckerstedt (KH)

Writer of minutes: Niels Grunnet (NGR)

1. Welcome:

With the chairman Krister Höckerstedt (KH).

2. Agenda and format of the meeting :

Information given by Margret Andresdottir (MA).

3. Approval of minutes from board meeting No. 62:

Some corrections:

Issue 4: 5 instead of 7 individuals have been interviewed, not the studentprogrammers.

Minutes approved.

4. Since last meeting Feb. 20, 2012 at Rikshospitalet, Oslo:

- March 15, 2012 a new student programmer Tito Phiri was hired 10 hours per week. His main objective is at the beginning to create a more modern version of the homepage.
- The follow-up meeting between the Sctp organisation and representatives of the national health authorities in Copenhagen April 16, 2012 was a very good meeting, informative and in a cooperative spirit. Minutes from this meeting enclosed.
- After the meeting an elaboration of the data security of using the Scandiatransplant datasystem was asked for by the Swedish lawyer. A text was worked out and sent to her on April 30, 2012 (text: "Some information on the Scandiatransplant datasystem" enclosed these minutes).

- Ilse Weinreich (IW) has had her hourly working time increased from 30 to 37 hours per week from May 1, 2012. There are still negotiations with the HR department on regulation of salary to IW and on an economical bonus to Bo Hedemark Pedersen.
- A newsletter from the Scandiatransplant office was sent out in March 2012.
- Meetings in Brussels on March 1 and 2 and again on April 24, 2012 ended especially on April 24 with an understanding from the Brussels people that "a delegated body" also can be a transplant center and not only a transplant organisation.

- So at the office we now have 8 persons affiliated: 2 programmers, 2 system administrators, 2 studentprogrammers, 1 secretary and NGR.
- A process has been started to create a text for "data treatment agreement" between the Region of Central Denmark and the Scandiatransplant organisation.
- An agreement with Aarhus University Hospital on account services / HR etc. has been signed. Sctp will then have to pay 40,000 DKK annually for these services.
- The time has been busy since last board meeting. KH has had a working load (1.1.2012) of around 1.5 working days per week, and NGR has had 18 working hours per week.

5. Process of implementation of the 2010 EU 53/Directive:

KH presented the steps and the process and the very positive developments although some issues are still unclear.

6. Preparing of the Council of Representatives' meeting on May 9, 2012:

All the agenda issues were discussed and dealt with and it was clarified who will do what, see separate minutes from this meeting.

The Estonian application to become a member of Scandiatransplant was for the first time on the agenda. KH presented the action strategy, which was approved by the Board members.

7. Any other business:

None.

8. Next meeting time and place:

Board meeting in Helsinki September 17, 2012 with Nordic Transplant Committee meeting on September 18, 2012.

Writer of minutes: Niels Grunnet

Enclosures to the minutes May 8-9, 2012**SCANDIATRANSPLANT April 2012****Some information on the Scandiatransplant datasystem.**

The present datasystem of Scandiatransplant was set in operation in 1994. Personnel that are allowed access to the datasystem are given a user name and login managed from the Scandiatransplant office, Aarhus, Denmark. All personnel that are given these admittances are employed at public health departments at University Hospitals in one of the five Nordic countries namely the members of the Scandiatransplant association.

All these personnel have during their employment signed a promise of professional secrecy according to the secrecy act in each country.

The personnel are nurses, medical doctors, technicians, secretaries, IT-personnel employed at one of the ten public hospitals doing organ transplantation in the five Nordic countries. The transplant centers are: Stockholm, Uppsala, Skåne (Malmö-Lund), Gothenburg, Reykjavik, Aarhus, Copenhagen, Odense, Helsinki and Oslo. Those personnel that we have listed belong to one of three categories:

B = only the right to look at data

A = to look at and update data

X = system administrators = four IT-professionals at the Scandiatransplant office in Aarhus (Frank Pedersen and Ilse D. Weinreich: System administrators, Christian Mondrup and Bo Hedemark Pedersen: Programmers).

In the use of category B we presently have 53 names of which 35 are active users and 18 are not active users (= former users kept on the list due to traceability in the system log).

In the user category A we have 174 names of which 27 are not active users (former users).

33 have only the right to read. The remaining 114 users in category A have the right to update data to the core system. Some of these 114 have special supplementary rights to for example update data in the thoracic register (actual 29) or/and in the liver registry (actual 33). Apart from these rights, a few of the active users have got the rights to interact some minor registries and a new version of the system.

During all the years since 1994, the Scandiatransplant datasystem has operated according to a license of the Danish data surveillance system.

The Scandiatransplant datasystem has been created with the purpose only to give personnel right to look or update data in relation to relevant management: That is to deal with patients entered on waiting list for one organ transplant. This is very relevant to fulfill the goal of exchange of organs between centers and the five countries whose transplant centers are members of Scandiatransplant. Access to data is limited to relevant behaviour according to the purpose to help patients to be transplanted with an organ.

Since 1994 misuse of user rights to access data in the Scandiatransplant datasystem has never been seen. The system is under constant surveillance of experienced users, both at the transplant centers but also to a high degree at the Scandiatransplant office. From the office of Scandiatransplant in Aarhus any symptom of an irregularity will call attention and be corrected in a dialogue with the specific decentral user.

Summary: The Scandiatransplant datasystem is a secured system with extensive surveillance of the behaviour of all users with prompt correction and supplementary education in case of any sign of

irregularity for example erroneous registration of data by any of these users all being licensed health care personnel (doctors, nurses, technicians, secretaries) at the public health departments surveyed by national health authorities in each of the countries Norway, Sweden, Finland, Iceland and Denmark.

On behalf of the Scandiatransplant office.

Niels Grunnet

Medical director