

Minutes from the Scandiatransplant Council of Representatives' meeting May 9, 2012 in Reykjavik, Iceland

Present:

Finland:

Lauri Kyllönen
Heikki Mäkisalo
Kaija Salmela
Karl Lemström
Hannu Jalanko
Jouni Lauronen

Sweden:

Bo-Göran Ericzon
Lars Bäckman
Alireza Biglarnia
Clara Pålman
Johan Nilsson
Styrbjörn Friman
Göran Dellgren
Jan Holgersson
Marie Felldin
Anne Flodén
Heidi Stensmyren (Socialstyrelsen)

Norway:

Aksel Foss
Odd Geiran
Arne Andreassen
Karsten Midtvedt
Tim Scholz
Ole Øyen

Denmark:

Allan Rasmussen
Finn Gustafsson
Søren Schwartz Sørensen
Claus Bistrup
Øyvind Østraat
Martin Egfjord

Iceland:

Runólfur Pálsson
Magnús Bodvarsson

Scandiatransplant board:

Krister Höckerstedt, Finland
Kaj Anker Jørgensen, Denmark
Helena Isoniemi, Finland
Michael Olausson, Sweden
Pål-Dag Line, Norway
Margrét Birna Andrésdóttir, Iceland

Scandiatransplant office:

Niels Grunnet
Frank Pedersen
Bo Hedemark Pedersen
Christian Mondrup
Ilse Duus Weinreich



Reykjavik, Iceland, May 2012

1. Welcome

Welcome by host and board member Margrét Birna Andrésdóttir

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

Meeting chairman: Magnús Bødvarsson

Writer of minutes: Ilse Duus Weinreich

Controller of minutes: Aksel Foss and Lauri Kyllönen

3. Additional items or comments to the agenda

HLA-C included to the STAMP program

Formal Pancreas and Pancreatic Islets Group within Scandiatransplant

4. Registration of the present representatives/substitutes/observers.

5. Approval of minutes year 2011

http://www.scandiatransplant.org/Sctp_rep_2011.pdf

Minutes accepted without comments.

6. The Chairman's annual report

Presented by Krister Höckerstedt

The Report had been sent to the Council members prior to the meeting

The day-to-day working tasks at the office have intensified, along with this the personnel has assisted the board, committees and groups, improved the data system and produced three Newsletters. They have also solved an emergency situation with the fax-server breakdown (caused by the introduction of a new telephone system at the Skejby hospital) in connections with organ offers from and to European OEOs.

The chairman has had discussions with the personnel on their specific working tasks. A formal work description on each employee must be made by the end of 2012.

It might be necessary in near future to move the office to another location in the Aarhus area.

In the Nordic countries the total number (10) of transplant hospitals was maintained.

The Scandiatransplant Research Grant of 20.000€ was launched in 2011 and the same sum will be given this year. In 2013 the sum of the Research Grant will be raised to 40.000€, effective from 2013. Other main issues of the report are discussed in §13 and §14.

<http://www.scandiatransplant.org/Chairman's%20report%202012.pdf>

7. Election of Scandiatransplant's board members and substitutes

Presented by Niels Grunnet

Michael Olausson has served for two periods (2 x 3 years) in the board, he was thanked for his work and acknowledged with applause and a small present.

Lars Wennberg was elected as new board member for Sweden and Lars Bäckman as his substitute.

Chairman:

Krister Höckerstedt, Finland

Board members:

Kaj Anker Jörgensen, Denmark

Helena Isoniemi, Finland
Lars Wennberg, Sweden
Pål-Dag Line, Norway
Margrét Birna Andrésdóttir, Iceland

8. Accounts and economical balance fiscal year 2011

The economical balance was explained in short, it shows a surplus of 1 million dkr in year 2011. The accounts has been signed by all board members and it was approved by the representatives.

9. Approved Budget for 2012 and proposal for 2013

Changes in 2013 budget:

- The Scandiatransplant Research Grant increases from 150000 dkr to 300000 dkr
- Telecommunication decreases from 30000 dkr to 20000 dkr.

Further the following text was added May 2012:

Depending on today unknown extra costs due to adjustments according to implementation of the EU Directive 2010/53 (extra employed personnel and etcetera) it can be necessary to regulate the budgeted costs in several areas for 2012 and 2013.

It was argued why 1 million dkr is added to the budget and that this money could be spend on the expert committee meetings. It was clarified that money is already put aside in the budget for these meetings. An example: At the coordinators 2-day meeting and workshop in Copenhagen in April, the costs of coordinators from all Nordic transplant centers were reimbursed. The amount for each group is 15.000 dkr per meeting, however only few of the committees take advantages of this opportunity to get a financial supplement. To get the money granted you need to send an application to the Scandiatransplant office.

It was also stated that it is necessary to have surplus as there is uncertainty about the cost of implementing the EU directive and also moving the office location.

10. Report on the activities of Scandiatransplant/News from the office in Aarhus

Presented by Niels Grunnet

Please take a look at Scandiatransplant' homepage (www.scandiatransplant.org) where the Power Point presentation concerning the transplantation and waiting list activities year 2011 are available.

Scandiatransplant is now paying 40000 dkr. per year to University hospital, Aarhus for keeping accounts, administrative help etc. according to an agreement signed April 2012.

8 employees at the office (total manpower = 5, thus 6 out of 8 are part time employees):
1 Medical director and daily leader (Niels Grunnet), 2 system administrators (Frank Pedersen and Ilse D. Weinreich), 2 programmers (Christian Mondrup and Bo H. Pedersen), 2 student programmers (Camilla Pedersen and Tito M. Phiri), 1 secretary (Susanne Sønder).

11. Developments related to the computer system

Presented by Bo Hedemark Pedersen

Status on conversion to new user interface YASWA :

Living donor is in production, soon access through the old system will be closed down.
Thorax is almost ready for testing.

Besides the conversion process, time has been used for establishing an email and SMS notification system for surplus organs between EOEO's. In relation to this time has been used on

producing a new web based organ offer form.

A new possibility to make diagrams and downloads in YASWA have also been developed which was demonstrated at the meeting.

YASWA includes a web service technology. Web service is a software system that makes it possible to communicate between two electronic devices over the web (internet), thus avoiding to enter data more than one place. It is a goal from the programmers in the future to establish more cooperation between the local center systems and Scandiatransplant.

11. Report of activities

The Reference group on prevention of transmission of infectious diseases from donors to recipients

Message from Vanda Friman: No changes this year – the group will revise the guidelines every second year. Revision expected 2013.

The Tissue typers' and STAMP Group

Presented by Jouni Lauronen

At the annual meeting this year there were no talk about lab. techniques. Instead Torbjørn Leivestad presented the latest data on STAMP and gave a presentation of quality controls in the Scandiatransplant database. New facilities implemented in relation to STAMP were shown in the database by Ilse Weinreich.

It was decided that when adding acceptable mismatches to an already accepted patient the patient record must be re-evaluated by the STAMP committee.

The STAMP committee reported problems with patients having antibodies against the HLA-C antigens. It was suggested to include HLA-C in the donor typing.

Proposal: Changes regarding the STAMP protocol by adding HLA-C in the donor typing
The proposal was accepted by the Representatives

The Nordic Kidney Group (NKG) including pancreas and the pancreatic islet transplantations

Presented by Lars Bäckmann

In 2011 779 patients were transplanted with a kidney from a deceased donor and 381 with a kidney from a living donor. This is the highest amount of kidney transplants in Scandiatransplant's history. The exchange rate between the centers are stable at around 15%.

At the yearly meeting the Nordic Kidney Group has been working on their By-laws, to get a more formal description in the light of the EU directive. Further results of the kidney exchange compliance was presented, there were no severe mistakes.

In 2011 pancreas transplantations increased: 35(Sweden) 20(Norway) 1(Finland) = 56 pancreas transplantations in total (43 of these transplantations were combined kidney-pancreas transplantations).

In 2011 total number of islet transplantations were 19 keeping the same level as previous years.

Proposal: "That issues of pancreas transplantation are dealt with in the Nordic kidney group".
This is no longer relevant as it is a plan to form two new separate groups one for whole pancreas and one for pancreatic islet.

The Nordic Liver Transplant Group (NLTG)

Present by Bo-Göran Ericzon

The group has had two meetings last year, the subjects of these meetings were:

1. Differences in tx. rate between centers
2. Key persons related to Nordic Liver Transplant Registry (NLTR) – urgent wish to arrange a meeting. In connection with each NLTG spring meeting, the persons that enter data will have a workshop around NLTR.
3. Scheme C (Follow-up of transplanted patients) is not used by all centers, this is up for discussion.
4. “Pay back” – seems to work. Realised that the centers did not manage to pay pack within 6 months, this might be solved with more sharing of information.
5. Research program related to the registry – 8 studies are ongoing at the moment.
6. The atmosphere in this group is very good.
7. Next meeting will be held in Helsinki 22nd October 2012

The Nordic Thoracic Transplant Study Group (NTTSG)

Presented by Odd Gerian on behalf of Martin Iversen

1. The NTTSG has been a loose informal working group and was started based on the possibility to make population based studies. The group has an appointed chairperson (Martin Iversen at the moment), whom is responsible for the contact with the Scandiatransplant administration in Aarhus.
2. The EU directive requires a more formal structure and a proposal for by-laws are in preparation
3. The guidelines for exchange of hearts and lungs, have lately (March 13 2012) been slightly revised to clarify the rotation rules.

<http://www.scandiatransplant.org/Guidelines%20for%20Organ%20Exchange%20in%20the%20Scandiatransplant%20Area%20-%20revised%202012.pdf>

4. The group has 2 yearly meetings. The two recent meetings have been held in Helsinki and Gothenburg, together with steering committee meeting for studies on aspects of immunosuppression. These studies are run by researchers in the group, but not by the group itself.
5. The database have given the background for a follow up study after three decades of heart transplantation in the Nordic countries, and a scientific paper has been submitted. A clean up of the database is under way and will create the platform for an update of survival and risk factors.

The Nordic Transplant Coordinator Group (NTCG)

Presented by Carola Schaumann

The yearly coordinator meeting was this year extended with a course held by Frank Pedersen and Ilse Weinreich. The main items were the database, the EU directive and the new security seals.

May 2012 is the last change to apply for honorary 'Certification of European Transplant Coordinator (CETC)'.

There is major problems in all Nordic countries with getting organs transported between countries in a secure and fast way. Among others this is related to the possible courier firms, airport customs, filling out various customs and shipment forms.

As this has a large impact upon the quality (Cold Ischemia Time) of the exported organs, NTCG propose that the Scandiatransplant board should approach the responsible authorities in each country with this problem.

The board replied that they had already discussed the matter. To work with this problem, NTCG needs to produce a list to the board, which specifies the scope of the problem. (Which airports and courier firms and specification of the problems).

The Nordic Living Kidney Donor Database group (NLDR)

Presented by Ole Øyen

Not much new to report, all centers are using the database.

The intestinal transplantations

Nothing to report

12. Nordic Transplant Committee/Meetings with Health Authorities of the Nordic countries

Presented by Krister Höckerstedt

In the EU53/2010 Directive on organ donation and transplantation some parameters are mandatory and some are not. The Competent authorities of the Nordic countries are in charge how the member states (plus Norway and Iceland) must organise the implementation of the Directive. A national registry of organ donation and transplantation should be ready in all Nordic countries by August 27, 2012. The tasks can be delegated to a competent body (Competent body: Organ exchange organisations or transplant center).

It differs from country to country how the 24/7 duty to report Serious adverse events/ Serious severe reactions will be solved. Definitions of these terms have been discussed and when to report and when not to. This was commented at this meeting: One should react responsible – as we have always done.

There have been held not only one but 3 meetings between the Nordic health authorities and Scandiatransplant Board on how to organise what is described in the directive 2010/53/EU. Data security has been a big issue especial in relation to Sweden and a text has been provided which describes the levels of access and users of the system.

It is a paradox to have anonymity on the recipients and still keep traceability in the database and this important issue has to be solved.

13. International cooperation activities

a) EU directive on Transplantation and implementations

Is covered under item '12.Nordic Transplant Committee/Meetings with Health Authorities'.

b) Council of Europe (EC), Expert group of EDQM

Presented by Ole Øyen

Two initiatives regarding living donor registries are running simultaneously

1. EU directive: Quality and safety

2. Initiative made by Ole Øyen

Per Pfeffer is chairman of the Transplant Committee. A document is submitted by Ole Øyen with the Scandiatransplant database as a template

Collaboration between the two projects must be considered.

c) Scandiatransplant and Estonia

Presented by Krister Höckerstedt

In 2011 the Tartu University Hospital declared that it represents Estonia in organ donation. In 2012 this statement has been confirmed by the Estonian Ministry of Social Affairs.

In Tartu all accreditations have now been performed by official European organisations and all donor and recipient-tests and transplantations are performed here.

Tartu, Estonia is now an official organ exchange organisation.

The head of the Transplant University Hospital Urmas Siigur has sent a letter to Scandiatransplant in which he expresses that Estonia would like to be a full member of Scandiatransplant. As this would be a fundamental change in the Scandiatransplant articles and activities, it has to be discussed by the users and owners of Scandiatransplant.

Thus the final answer lies in the hands of the Scandiatransplant Council of representatives.

To get more knowledge about Estonia a power point presentation made by Estonia was shown:

Estonian figures 2011 (all patients have been transplanted in Tartu):

53 potential donors from 4 hospitals – 22 became actual donors.

40 kidneys transplanted (4 LD + 40 DD)

8 livers transplanted

3 lungs transplanted

In total Estonia has made:

931 kidney transplantations

25 liver transplantations

5 lung transplantations

The whole presentation can be found here:

<http://www.scandiatransplant.org/Estonia%20Tx%20presentation,%20May%203,2012.%20V%20Pall..pdf>

A strong collaboration between Tartu and Helsinki has been ongoing since 1990 concerning the liver program and for many years the Estonians have had an independent national programme. Also in kidney transplantation the Helsinki center has given many ways of help and assistance already from the 1970-ies..

Krister Höckerstedt presented a strategy for the Estonian issue, which has been discussed by the Board. There are two different approaches to consider:

1. Would it be possible to recognise Estonia as an official exchange organisation in line with the other European organisations like Eurotransplant, Francetransplant, Poltransplant and others?

They have fulfilled the European OEO criteria, thus they should be recognised as an exchange organisation.

After an active discussion all agrees to recognise Estonia as an official exchange organisation.

2. Estonia as full member of Scandiatransplant?

This question brought up an intense discussion, here are some of the arguments.....

“Do we wish to include any countries at all, do we wish to expand? This should be asked before talking about Estonia.”

“This is not a question about including any country in Europe, this is about Estonia which lies close to the Nordic countries.”

“Why should we include non Nordic countries, what is the motivation for Estonia?”

“We should be open to changes.”

“Many of the other European Organ Donation Organisations have undergone changes and some

have been enlarged to contain new EU-countries, particularly from the former Eastern European countries.”

At the end of the discussion Krister Höckerstedt suggested that a working group should be formed to evaluate this issue: Should Estonia become a member of Scandiatransplant or not.

The suggestion underwent a vote

Agrees of making a group: 26

Against making a group: 4

Conclusion: A working group should be formed

Krister Höckerstedt declared himself as biased in the further handling of the Estonian question, since he had for more than 20 years been a teacher and consultant for the Estonian liver team. Pål Dag Line was suggested to represent the board in the group, he accepted. Further the group must consist of one member from each center (the owners of Scandiatransplant) and cover all areas of organ transplantation. Pål Dag Line was elected chair of the group.

Karl Lemström, Finland, raised a question: Can we help transplanting an Estonian heart patient in Helsinki with an Estonian heart graft?

It was concluded that this is unclear and involves some unsolved questions.

15. Grants

- ***Scandiatransplant Travel Grants***

6 applied – 5 granted (Lars Bäckman, Kirstine Andreasson, Emma Högström, M. Lempinen, Lonnie Rasmussen.

- ***The Scandiatransplant Research Grant 2012***

After careful evaluations the project with principal investigator Lars Bäckman was chosen. This project integrates all transplant centers within Scandiatransplant. The project has been approved by the local ethic committees in the different countries. The project: "Analysis of the true incidence of post-transplant malignancies in renal transplant recipients. Initiation of a Nordic project on post-transplant malignancies". It will be supported with 20.000 €.

16. Any Other Business

Proposal:

- The Scandinavian network for Islet transplantations will become an official working group of Scandiatransplant
- A working group for pancreas transplantations will also be formed

One member from each hospital performing pancreas-transplantations or intended to start a program should be included in the group.

The group will workout the details regarding the connection between pancreas transplant group and other groups within Scandiatransplant.

Lars Bäckman will chair the pancreas-group during this early phase.

No objections: The groups can be formed.

17. The next Representatives meeting will be held in Oslo, early May 2013

Minutes are approved by controllers:

Aksel Foss, 29th of May 2012

Lauri Kyllönen, 12th of June 2012

Minutes are respectfully submitted by Ilse D. Weinreich, 13th of June 2012