

Minutes from the Scandiatransplant Council of Representatives' meeting May 7, 2013 in Oslo, Norway

Present:

Finland:
Heikki Mäkisalo
Kaija Salmela
Marko Lempinen
Timo Jahnukainen
Pekka Hämmäinen
Jouni Lauronen

Sweden:
Bo-Göran Ericzon
Lars Bäckman
Ragnar Källen
Johan Nilsson
Styrbjörn Friman
Anne Flodén
Jan Holgersson
Marie Felldin
Marcus Gäbel

Norway:
Aksel Foss
Christian Naper
Arnt Eltvedt Fiane
Karsten Midtvedt
Tim Scholz
Truls Sanengen

Denmark:
Søren Schwartz Sørensen
Birgit Wolff (Substitute)
Lars Ilkjær
Øyvind Østraat

Iceland:
Runólfur Pálsson

Scandiatransplant board:
Krister Höckerstedt, Finland
Helena Isoniemi, Finland
Lars Wennberg, Sweden (representative)
Pål-Dag Line, Norway
Margrét Birna Andrésdóttir, Iceland
Finn Gustafsson, Denmark (representative)

Scandiatransplant office:
Kaj Anker Jørgensen
Bo Hedemark Pedersen
Ilse Duus Weinreich

Observers:
Carola Schauman, coordinator, Helsinki
Niels Grunnet, past Medical Director



Oslo 7th of May 2013

1. Welcome

Welcome by Scandiatransplant chairman Krister Höckerstedt and boardmember and host Pål-Dag Line

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

Meeting chairman: Tim Scholz

Write of minutes: Ilse Weinreich

Controller of minutes: Styrbjörn Friman and Aksel Foss

3. Additional items or comments to the agenda

Situation in Eurotransplant will shortly be commented under point '18. Any other business'

Registration of the present representatives/substitutes/observers

All present at the meeting are listed at the first page of these minutes

4. Approval of minutes year 2012

http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/Minutes_rep_2012_2.pdf

No comments, the minutes were approved

5. The Chairman's annual report (a written version will follow)

Presented by Krister Höckerstedt

In 2012 became a record year in terms of number of utilized deceased donors, thus the number of transplantations with organs from deceased donors were slightly higher compared with 2011. Due to a decrease in the number of transplantations with kidneys from living donors the total number of transplantations in 2012 was slightly lower than in 2011.

1st of November 2012 Niels Grunnet stepped down after having served as Medical Director in Scandiatransplant for 14 years. Kaj Anker Jørgensen has followed as the new Medical Director as half time employed at the Scandiatransplant office.

New board member 1st of November 2012 from Denmark is Finn Gustafson he is cardiologist in Copenhagen.

6. Election of chairman

Krister Höckerstedt has now served as chairman for the 1st period of three years. He was elected for the 2nd periode.

7. Election of Scandiatransplant's board members and substitutes

Helena Isoniemi and Margrét Birna Andrésdóttir will also countinue for another 3 years in the board.

Allan Rasmussen, Runólfur Pálsson and Lars Bäckman are new substitutes

8. New cooperation with Estonia

Presented by Krister Höckerstedt

Last year Estonia was recognised and accepted as an organ exchange origination, since then Estonia has sent out 3 offers on spare organs:

- The first offer on heart, lungs and liver from Estonia came the 20th of January 2013. However due to some technical problems with the mail server, that Estonia used, the

offer was delayed one hour and none of the organs were shipped to Scandiatransplant. The problem is now tested and solved.

- The second offer on heart and lungs came 22nd of February, it was accepted and retrieved by Gothenburg.
- The third offer was a heart which was accepted and retrieved by Helsinki. The patient whom was transplanted is doing fine.

So far all cooperation with the Estonia team has been positive and the coordination has run smoothly

9. Expansion of Scandiatransplant (Application by Estonia)

Presented by Pål-Dag Line

Last year at the representative meeting it was decided to form a working group to evaluate the issue.

A group was formed consisting of one person from each transplant center. The working group have had one meeting and regularly email correspondence. The work has resulted in a written report, which was signed April 19, 2013. The report has been sent to all representatives.

The group has processed two questions

- First - is it a good idea to expand?
- Second - what are the requirements?

In the report the working group has listed arguments in favour of expansion and possible disadvantages.

Some of the possible pros mentioned at the meeting:

Increased donor pool, help less developed countries, learn new things e.g.

Some of the possible cons mentioned at the meeting:

Organizational complexity, increased ischemia time, cultural differences e.g.

According to the Articles of Association for Scandiatransplant membership is limited to all hospital in the Nordic countries. The term Nordic is defined by The Nordic council as Denmark, Finland, Iceland, Norway and Sweden.

The working group decided that the question of expansion should be categorized as an organizational question and therefore according to the 'Articles of association' changes would require a 5/6 majority.

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If expansion is accepted the current set of articles needs to be revised.

Vote: Should Scandiatransplant expand to include centers from non-Nordic countries?

Result: 7 in favour of expansion and 14 against expansion

Conclusion: Scandiatransplant will not expanded

10. Developments related to the computer system

Presented by Bo H. Pedersen

Status on the conversion process

The organ offer form is almost ready:

- Offers on spare organs, internal and outside Scandiatransplant, can be done using the new user interface

- Built in data exchange with the existing system. For instance if a donor has already been registered in the database, data will automatically be transferred to the organ offer form
- Pdf- generation to preview data and used as attachment when the offer is sent by email. The functionality can in the future be used a lot of other places in the converted system to view or print reports.
- Draft-saving. If data registration has not been saved a draft will be saved and you will be able to bring forward the data and continue the registration.

Possibility to make statistics and diagrams directly in the database. This option will not be available to all users. To improve the facility feedback is need from the users.

Søren S. Sørensen suggested making a small group, consisting of people present at the meeting, this to help and give feedback about the developments in the system. Please report to Bo if you wish to be part of the group

11. Accounts and economical balance fiscal year 2012

Presented by Kaj Anker Jørgensen

The economical balance was explained in short, it shows a surplus of 600.000 dkr in year 2012. The balance has been signed by all board members and it was approved by the representatives.

12. Revised Budget for 2013 and proposal for 2014

Presented by Kaj Anker Jørgensen

The office would like to hire two new programmers to speed up the conversion process, why the budget is suggested increased. It is proposed not to raise the fees and instead use more than we earn the next 3 years. The cash balance is 8.9 million it would be reasonable to bring it down to approx. 5 million as this corresponds with one year of expenses.

The budget was accepted

Proposal: The chairman of Scandiatransplant should receive an annual 'salary' of 50.000 dkr

Conclusion: The proposal was accepted

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

Presented by Kaj Anker Jørgensen

The updated power point presentation is found on the Scandiatransplant homepage <http://www.scandiatransplant.org/resources/diasshows-and-others>

The main working task for the Scandiatransplant office is to run and maintain the core Scandiatransplant database (waiting lists, organ allocation and donor registration), further to:

Engage more programmers to convert the user interface to a more modern layout (YASWA) and future proof the server environment. And also to clarify and ensure legality aspects and future role of Scandiatransplant as consequence of EU-directives.

14. **Report of activities** (<http://www.scandiarttransplant.org/members>)

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

Message from Vanda Friman, Gothenburg:

The guidelines concerning transmission of infectious diseases from donors to recipients have been revised. The revision concerns the design and wording in terms of the Hepatitis section so that "Comment" is consistent with "Interpretation of positive reaction" It was a bit unclear earlier. These recommendations were proposed by the Scandiarttransplant working group on April 2013 and is a revision of previous recommendations from 2011.

<http://www.scandiarttransplant.org/organallocation/3April2013Scandtx.pdf>

The Tissue Typers' Group and STAMP

Presented by Christian Naper, Oslo

Christian Naper reported from the tissue typer meeting held 8th of February 2013.

http://www.scandiarttransplant.org/members/sttg/TTG_Minutes_2013.pdf

At the meeting in February two changes in the EFI standards were proposed concerning the way of reporting HLA types and virtual cross matching. Virtual cross matching was up for discussion, among others it is a problem that weak antibodies are detected with Luminex as they might not be relevant in transplantation. Further not all HLA antigens are present on the Luminex beads and the labs. do not as a routine type for DP. Virtual cross match is not optimal with regards to safety especially concerning HLA sensitized recipients.

STAMP activity

(<http://www.scandiarttransplant.org/members/stamp/STAMP13TTmeet.pdf>)

- 1269 active waiting kidney patients of these 210 are highly immunized and 68 have been included in the STAMP program
- A total of 41 transplantations have been made as a result of STAMP exchange obligation.
- The STAMP program increases the likelihood of transplantation as 41 patients has been transplanted due to STAMP exchange obligation vs. 7 exchanges due to priority 1 (1. Highly immunized (PRA ≥ 80%) patients who are HLA-A,-B,-DR compatible with donor.)

The tissue typers group reports problems with positive cross matches on priority 1 exchange obligations, this due to matching on board HLA types and not matching on HLA-C and DQ.

Proposal: The Tissue Typers Group propose to the Council of Representatives that exchange obligation 2 and exchange obligation 3 shift positions with regard to priority. However proper information was not sent out to all representatives before this meeting. The matter was discussed under 'The Nordic Kidney Group' presentation.

The Nordic Kidney Group

Presented by Lars Bäckman, Uppsala

The number of living donor kidney transplantations have increased and the number of deceased donor kidney transplantations seems to have leveled out.

Minutes from last NKG meeting:

<http://www.scandiatransplant.org/members/nkg/MinutesNKG2012.pdf>

Proposal: Exchange obligation 2 (Immunized patients (PRA \geq 10% but below 80%) who are HLA-A,-B,-DR compatible with donor) and 3 (Patient with STAMP-status) shift place.

Styrbjörn Friman pointed out again that all proposals must be sent out prior to this meeting.

Pros for accepting the proposal:

The outcome of STAMP looks very good, difficult to find suitable donor to highly immunized recipients, highly immunized recipient will be the top priority in the kidney exchange obligations, no major change in the number of exchange obligations

Cons for not accepting the proposal:

In theory it could decrease the 0-0 matches, but the amount of priority 2 exchanges are very small. In 2012 there were 4 exchanges, which equal 8% of all exchanges.

Conclusion: The proposal was accepted

The Pancreatic Group

Presented by Lars Bäckman, Uppsala

The number of pancreas transplantations have increased, last year 64 recipients were transplanted. A pancreatic group within Scandiatransplant has been form with the purpose to discuss donor selection and surgery.

The first meeting was held 6th of February 2013 at the meeting representatives from all the Nordic transplantation hospitals were present.

The group only deals with whole pancreas not islet. All centers are encourage to use all possible pancreas grafts.

Minutes from meeting:

<http://www.scandiatransplant.org/members/nordic-pancreas-group/MinutesofNPTGmeeting2013.pdf>

The Nordic Liver Transplant Group

Presented by Helena Isoniemi, Helsinki

The group has had two meetings in 2012, minutes from meetings:

March 2012

<http://www.scandiatransplant.org/members/nltr/MinutesfromNLTGmeetingMarch192012.pdf>

October 2012:

<http://www.scandiatransplant.org/members/nltr/MinutesofHelsinkiNLTGmeetingOct12.pdf>

The project with a common waiting list for segment 2+3 for pediatric recipients is still ongoing. The list still only serves as a reserve.

Discussed to increase the number of split livers by using donors with the following criteria (BMI <25, age <50, ICU stay < 3d, ALT <3 x normal).

When a center offered another center a split graft it has been decided that it should be refunded with a whole liver from the accepting center

Every spring the responsible persons for entering data in NLTR will be invited to have a meeting parallel with the NLTG meeting.

The Nordic Thoracic Transplant Study Group

Presented by Finn Gustafsson, Copenhagen.

The group has had two meetings in 2012

The group has discussed and revised the guidelines. The 3 urgent lungs per year will be maintained and the number of urgent heart is still a matter of urgency

NTTSG would like Scandiatransplant to support corporation between Helsinki and Estonia concerning heart transplanting Estonian heart patients with hearts from Estonian donors in Helsinki.

2 studies have been done using data from NTTSG, the corporation in NTTSG has made the studies possible. New studies are planned and research in LVAD therapy is ongoing.

The Nordic Transplant Coordinator Group

Presented by Carola Schauman, Helsinki

The group has had one meeting in 2012:

http://www.scandiatransplant.org/members/ntcg/MinutesNTCG_2013.pdf

At the last coordinator meeting one coordinator from each center was presented. At the meeting the effect of the EU directives was discussed. Further registration of tissue harvest and the corporation with Estonia were discussed.

When spare organs are offered from marginal donors it would be nice that it is written in the notes, not only as 'no recipient locally'.

Aksel Foss noted that 'marginal donor' is not the right term to use anymore, instead 'high risk organs' should be used.

The coordinators would like to know when meetings are held in the groups so they are able to send an observer.

The Pediatric Group

Nothing to report, next meeting will be held in autumn 2013.

The Pancreatic Islet Transplantations:

No reports on meetings or of forming an official group.

New way of calculating and paying for pancreatic islets transplantations. It has been decided by the board that each islet portion should count as a transplantation when it comes to payment. It is difficult to define how many portions that are related to each treatment.

15. Status of implementation of the EU-Directive 2010/53 in the Nordic Countries. Transplant Committee/Meetings with Health Authorities

Denmark: Finn Gustafsson

Has approved the law, but it is not fully been implemented yet.

Finland: Helena Isoniemi
EU directive was implemented 1st of May 2013, uncertainty about how to report SAE/AE.

Iceland: Margrét Birna Andrésdóttir
Not member of EU, has decided to implement the directive, however the ministry does not have it as a top priority.

Norway: Pål-Dag Line
Decided to implement the directive is working on a new law.

Sweden: Lars Wennberg
Legislation has been implemented, what SAE/AE to report and what will be done with the reports is unclear.

16. International cooperation activities

Estonia has sent a letter to the Finish Health Ministry were they apply of permission to transplant Estonian heart patients in Helsinki.

Similar incident in Copenhagen earlier this year, were a polish lung patient was transplanted with lungs from a polish donor.
Also ongoing discussion on a German recipient to be lung transplanted in Gothenburg, has not yet transplanted.

Discussion and arguments concerning transplantation of Estonian heart patients in Helsinki: EU suggested cooperation between member states.

NTTSG has by a letter to the board recommended corporation.

Doctors and administration in Helsinki and Estonia all supports the corporation.

Re-transplantation of hearts and lungs are very rare, why the risk of using 'Scandiatransplant organs' are very small.

The Estonians are not able to start a heart transplant program themselves as training and education is needed.

Can Scandiatransplant morally accept to have spare organs from Estonia and not allow Helsinki to help Estonia with transplantations?

The transplantation registration will not be done in Scandiatransplant as it does not involve Nordic patients or donors.

It is in accordance with the already written guidelines 'Deceased organ transplantation of non-Nordic nationals within Scandiatransplant.

<http://www.scandiatransplant.org/organ-allocation/Guidelinesfordeceasedorgantranspl....pdf>

Conclusion: Proposal accepted

17. Grants

Scandiatransplant Travelling Grant (total 100.000 dkr)

1 application was granted 15.000 dkr:

Visit to Hospital Clinic in Barcelona. The purpose is to study how immunological aspects are considered in the kidney allocation process.

Jouni Lauronen. MD, PhD, with laboratory personnel from the Blood Service, Finnish Red Cross, Helsinki.

Scandiatransplant Research Grant (total 40.000 €).

In total 4 applications, where the following two each were granted 20.000 €.:
 Liver Transplantation and cancer - a Nordic multicenter population based study.
 Principal investigator: Arno Nordin, MD, PhD, Transplant Surgeon, Helsinki, Finland.
 Participants from 4 centers in 3 Nordic countries.

Survival gap and premature death after liver transplantation - A Nordic population-based study.

Principal investigator: Helena Isoniemi, Head of the Transplantation and Liver Surgery Clinic in Helsinki, Finland. Participants from 5 centers in 4 Nordic countries.

18. Any Other Business

Articles of Association

Proposal: Article 8 in 'Articles of Association' the last three lines are no longer relevant, thus the lines can be removed

<http://www.scandiatransplant.org/about-scandiatransplant/organisation/Articles%20of%20association.PDF>

Conclusion: Proposal accepted

Eurotransplant business

A lot of unfortunate things have been going on in Germany, which have caused a lot of problems for the transplant centers and people involved. The German media has covered it thoroughly and legal consequences have followed.

STS congress 2013 in Copenhagen

The Scandinavian Transplantation Society XXVII Congress is to be held in Copenhagen, Denmark May 8th – 9th of May, 2014.

Please mark your calendars

19. Next meeting

May 7th, 2014 in Copenhagen before STS

Minutes are approved by controllers:

Aksel Foss, 3rd of June 2013

Styrbjörn Friman, 14th of May 2013

Minutes are respectfully submitted by Ilse D. Weinreich, 4th of June 2014