
SCANDIATRANSPLANT
COUNCIL OF REPRESENTATIVES' MEETING
MAY 7, 2015, STOCKHOLM, SWEDEN

Finland:

Heikki Mäkisalo
Marko Lempinen
Jouni Lauronen
Karl Lemström
Minna Räsänen
Fredrik Åberg
Tiom Jahnukainen

Scandiatriansplant board:

Krister Höckerstedt, Finland
Helena Isoniemi, Finland
Lars Wennberg, Sweden
Pål-Dag Line, Norway
Margrét Andrédóttir, Iceland
Finn Gustafsson, Denmark

Sweden:

Gunnar Söderdahl
Bo-Göran Ericzon
Lars Bäckman
Clara Paul
Ingrid Skog
Per Lindnér
Marie Felldin
Maria Castedal
Petra Vestlund
Torbjörn Lundgren

Scandiatriansplant office:

Kaj Anker Jørgensen
Bo Hedemark Pedersen
Frank Pedersen
Ilse Duus Weinreich

Observers:

Dan Hauzenberger, Tissue Typers Group, Stockholm
Carola Schauman, Transplant Coordinator Group, Helsinki

Norway:

Morten Skauby
Christian Naper
Tom Nilsen Hoel
Karsten Midtvedt
Anne Varberg Reisæter

Denmark:

Allan Rasmussen
Ulla Møldrup
Søren Mellekjær



1. Welcome

Welcome by Scandiatransplant board member Lars Wennberg

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

Chairman of the meeting: Bo-Göran Ericzon

Writer of minutes: Ilse Duus Weinreich

Controllers of minutes: Gunnar Söderdahl and Marie Felldin

3. Registration of the present representatives/substitutes/observers

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

Margrét Andrésdóttir, whom is a member of the Scandiatransplant board, was the only person representing Iceland and it is a tradition that board members have no voting right.

From the articles (<http://www.scandiatransplant.org/about-scandiatransplant/organisation/ArticlesEnglish2013.pdf>):

The Council of Representatives shall only form a quorum when all member countries are represented at the meeting by a representative who is entitled to vote or who is in other ways entitled to participate in the decisions.

Margrét Andrésdóttir was approved by the council as representative from Iceland.

4. Approval of minutes year 2014

http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/Minutes_2014_rep.pdf

No comments, the minutes were approved

5. Report on the activities of Scandiatransplant last year

<http://www.scandiatransplant.org/resources/AnnualScandiatransplantdatareport2014.pdf>

Presented by: Krister Höckerstedt, Kaj Anker Jørgensen and Ilse Duus Weinreich

Krister Höckerstedt: It has been tradition that the Chairman presents an annual report each year, however this has now been replaced by a new annual report made by the office.

Kaj Anker Jørgensen: The structure of the organization and current composition of Scandiatransplant board members and office staff were presented.

Scandiatransplant office have participated in meetings within EU, with competent authorities, working group for articles, Aarhus university hospital and Scandiatransplant group meetings.

Some meetings with user education as main focus have also been completed. It is expected that the number of this kind of meetings will increase, as introduction to the new user interface will be needed.

Ilse Duus Weinreich: Throughout the years quarterly and annually waiting list and transplantation statistics have been provided in a compressed excel format, together with an annual updated slideshow. This year a new way of presenting the activities within Scandiatransplant has been introduced in an annual report. The main focus in the annual report is to present the annual

figures in a not so compressed way. The report presents data in various ways as raw numbers, numbers per million population and with graphical illustrations. It was suggested to add more notes to explain the data, such suggestion and ways of presenting data and what data to present are more than welcome.

6. Status on the IT-system

Presented by Bo H. Pedersen

Central region of Jutland, who maintains the hardware have informed the office that hardware support of the servers is no longer possible through their suppliers. Due to these new circumstances they cannot maintain their support-level.

As a result of this the different parts of the system have been divided into 4 levels of criticality, which have significant impact for prioritization of the work.

Security and access to data will be tightened up, with balance between constrains and access to data.

Turning point: The most critical parts of the system have been converted and in case of a hardware crash the new system can be up and running against the virtual servers in a matter of minutes.

7. Election of chairman

No election needed as Krister Höckerstedt has one year left, which means that the position as Chairman is up for election next years. It is the board that needs to come up with new candidates and the election is done by the Council of Representatives.

8. Election of Scandiatransplant's board members and substitutes

Board member Lars Wennberg and his substitute Lars Bäckman were up for election, both were re-elected.

9. Accounts and economical balance fiscal year 2014

Presented by Kaj A. Jørgensen

There have been some changes this year as the accountancy firm has merged with another firm. The economical balance was explained in short, the result was within the budget and showed as expected an overspending of 216.000 dkr in year 2014.

Conclusion: 2014 revision approved

10. Budget for 2015 and proposal for 2016

Presented by Kaj A. Jørgensen

The 2016 budget was presented, only change was an extra 100.000 dkr, compared with the 2015 budget. The extra money is added to the category 'Consultant' as further help from a private lawyer to clarify legalisation is expensive and still needed in the group working with the Scandiatransplant articles.

Conclusion: 2016 budget approved

11. Report of activities (<http://www.scandiatransplant.org/members>)

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

Email from Vanda Friman

The guidelines have been revised:

- Hepatitis B and C section has been clarified
- Anti-CMV IgG test has been moved to the section 'Samples taken before donation but analyzed later'
- Ebola risk is now included in the section 'Addendum', the text follows the EU guidelines

New version of the guidelines:

http://www.scandiatransplant.org/organ-allocation/ScandtxInfGuidelines2015inclEbola_5.pdf

Tissue Typers' Group and STAMP

Presented by Dan Hauzenberger, Stockholm

Dan Hauzenberger reported from the last Tissue Typers meeting held in Reykjavik January 30, 2015 <http://www.scandiatransplant.org/members/sttg/TissueTypersMeeting2015Minutes.pdf>

- Kidney exchange obligations 2014
 - Total 93/473 (20 %) searches with exchange obligations
 - In 4/93 (4,3 %) the exchange rules were not followed
- Great variance between the centers in the proportion of highly immunized (PRA > 80%) patients put on the STAMP list
- In order to make the number of patients on the STAMP-list more equal between centers the possibility of reporting antibody specificities, and not PRA%, and let Scandiatransplant calculate the PRA% on the basis of antibody specificities, has been discussed.
- A frequency calculator is available in Scandiatransplant, which give a calculated estimate of matching donors. Only 23 patients (26%) have an increased calculated frequency of finding a suitable deceased donors kidney 'with STAMP' compared to 'without STAMP', so not all patients can be helped by STAMP.
- Discussion on new approaches for the highly immunized patients is ongoing.

Nordic Kidney Group

Presented by Lars Bäckman, Uppsala.

A report was given from the two meetings held in 2014

April 30, 2014 – main topic Paired Kidney Exchange Program

Paired Kidney Exchange Program for immunized and /or ABO incompatible recipient – donor pairs were discussed. The goal is to maximize the number of transplanted patients.

It is the intention to do the first simple match runs in Sweden in 2015 and maybe the first transplantations in the fall of 2015. Later on whole Scandiatransplant will be included, but there are still some legal and financial things to sort out.

November 19, 2014

<http://www.scandiatransplant.org/members/nkg/MinutesNKG2014.pdf>

- Deviations from kidney exchange obligations were presented, evaluated and accepted

- Presentation of a new a update registry survey with data from Scandiatransplant <http://www.scandiatransplant.org/members/nkg/Scandia14.pdf>
- The Nordic Living Kidney Donor Registry contains possibility to registry a broad range of parameters. It was decided which data should be mandatory to register for instance age, blood group, blood pressure, complications.

Suggestion: Exchange obligation 1 (highly immunized + HLA-A, -B,-DR compatible) and obligation 2 change place (STAMP)

Conclusion: Not approved, further investigations are needed in the tissue typers group. It was suggested that a person from the tissue typers group should be invited to the next Nordic Kidney Group meeting.

Nordic Pancreas Transplantation Group

Presented by Lars Bäckman, Uppsala

Lars Bäckman reported from the last meeting held in the group

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

- Discussions on what to do about the unutilized pancreas (islets) donor potential
- Copenhagen has received the final approval and are now allowed to do pancreas transplantations
- The group have composed and approved guidelines
- The possibility of making a pancreas registry and which parameters to included have been discussed
- Collection of immunosuppressive protocols from each center

Nordic Pediatric Renal Transplant Study Group

Presented by Lars Wennberg, Stockholm

Data on 810 pediatric kidney transplantations performed in Scandiatransplant the last 20 years (1994 – 2014) was presented.

http://www.scandiatransplant.org/members/nprtsg/NPRTSG1994_2014.pdf

- 59% of the transplantations have been done with kidneys from living donors.
- Age distribution of renal transplantations in Nordic children illustrated differences. An underlying genetic disease is the explanation for the large proportion of very young children in Finland
- The number of small children (< 2 years) seems to be increasing
- A new article has recently been published

The challenged with transfer/transition from pediatric to adult were addressed, this will be brought up at future meetings.

Nordic Liver Transplant Group

Presented by Helena Isoniemi, Helsinki

Two articles have been published where the studies have been supported by the Scandiatransplant Research Grant. Many other studies are ongoing.

Helena Isoniemi presented key numbers and statistics from the Nordic Liver Transplant Registry made by Espen Melum

http://www.scandiatransplant.org/members/nltr/NLTR_2014.pdf

- Waiting time in each country is almost the same
- Number of transplanted patients is increasing steadily. Around 60% of the transplanted patients are between 30-60 years old.
- The primary listing diagnosis are Hepatocellular carcinoma and Primary sclerosing cholangitis (38,5%)
- Donor age gradually increasing, mean donor age in 2014 were 52 years
- Patient survival has improved in the most recent 5-year period

The annual report will soon be available on the homepage.

Nordic Thoracic Transplant Study Group

Presented by Karl Lemström, Helsinki

Karl Lemström reported from the last two meetings held in the thoracic group

<http://www.scandiatransplant.org/members/nttr/MinutesNTTSGApril302015.pdf>

<http://www.scandiatransplant.org/members/nttr/ReferatNTTSGmeetingNovember6th2014.pdf>

Ongoing discussions about the background and the current lung allocation rules including if it is okay to have a fixed number of maximum 3 urgent lung patients on the waiting list per center per year. Different alternatives have been discussed: Payback rule? An extra urgent call per year? Review Board reviewing 4th and 5th patients "applying for urgent call"? The centers have had less than 3 entries each year and the entries are spread throughout the year, why it at this time point has been decided to keep the current rules unchanged. Many different studies are ongoing for instance the multicenter study ScanCLAD, which have just started.

The Nordic Transplant Coordinator Group

Presented by Carola Schauman, Helsinki

The transplant coordinators have had two meetings, the latest one combined with a visit to Estonia.

http://www.scandiatransplant.org/members/ntcg/MinutesNTCG_2014_2.pdf

<http://www.scandiatransplant.org/members/ntcg/MinutesNTCGapril2015.pdf>

At the meetings some of the following subjects have been discussed; Kidney & Liver balance, sending of blood for cross match, the new YASWA interface, cooperation with Estonia, reimbursement for transportation.

The coordinators had a very nice visit to Estonia, where they were presented to the Estonian activities and got a 'tour' around the facilities at Tartu University Hospital.

Estonian key figures: In 2014 they had 23 actual donors with mean number of procured organs 3,7 per donor, only one living kidney donor. At the time of the visit the following

number of patients were on the waiting list, 55 waiting for kidneys, 1 waiting for combined-kidney pancreas, 1 waiting for liver, 10 waiting for lungs, 2 waiting for hearts. The main challenges in Estonia are to get urgent, pediatric and highly immunized patients transplanted based on their very small population.

The Pancreatic Islet Transplantations

Presented by Torbjørn Lundgreen, Stockholm

The Nordic Network for Clinical Islet Transplantation has existed since 2001, with two to three meetings each year. At the moment there are two labs, which can do the isolation of islets, Oslo and Uppsala.

¼ of the pancreas where islets are isolated are used for transplantation, some countries are not allowed to export organs if they ‘only’ are used for research.

Sweden and Norway are some of the largest contributors in Europe when it comes to islets used for research, which is one of the important results of the cooperation.

In Scandiatransplant between 20-40 islets transplantations are done per year

13. International cooperation activities

Presented by Krister Höckersted and Kaj A. Jørgensen

The European Committee (Partial Agreement) in Organ Transplantation at Council of Europe have elected a new chair. The new chair is Bernadette Hasse from Netherlands.

The indicator excises, which has been running for 4-5 years collecting a variety of data, will stop this year as the quality of data was to poor.

ACCORD project which has a sub-group on living donors with a registry of registries. In agreement with the board, this has not had top priority, as the focus should be to get the centers to use the Nordic Living Registry. The ACCORD project will also stop now a new project will probably be suggested.

14. Grants

Scandiatransplant Travel Grant

Applicant:	Purpose of study travel:	Applied for (and granted)
Hildigunnur Friðjónsdóttir coordinator Reykjavik	Visit to the University Hospital in Nottingham, UK. The purpose of the visit is to learn about the clinical practice of nurses in the field of transplantation at their hospital	DKK 10,000.-
Sif Hansdottir MD, PhD Reykjavik	Visit to Sahlgrenska University Hospital's Transplant Center, Sweden to build on my knowledge fund and to further strengthen the relationship.	DKK 4,600.-
Thordis Hrafnkelsdottir MD, PhD, Reykjavik	Study visit to Gothenburg transplantation center to investigate possible heart transplant recipients, perioperative management and postoperative problems, and to meet the caregivers.	1050 € (=DKK 7,875)

Carola Schauman coordinator Helsinki Chair of NTCG	NTCG want to visit Tartu University Hospital, meet our colleagues and doctors to achieve and share knowledge in the field of transplantation.	3050 € (=DKK 22.875)
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Scandiatransplant Research Grant

Applicant:	Title	Granted
<u>Taina Jaatinen</u> , Helsinki	Comparison of HLA antibody testing methods in highly sensitized patients.	DKK 20,000 €.
Hans Henrik L. Schultz, Copenhagen	Priority for urgency in lung transplantation – Scandiatransplant Urgent Call compared with the Lung Allocation Score.	DKK 20,000 €.

15. Any Other Business

Last year it was decided that renewal of death causes on deceased donors in Scandiatransplant was needed. It was decided that one person from each center had to contact Helena Isoniemi, to take part in this work.

This has not happened, why it was proposed by Helena Isoniemi, that she will contact a person on each center.

The Scandiatransplant office would like to be part of this work to find the best solution between clinical practice and the IT system.

16. Next meeting

May 11, 2016 in Stockholm in connection with STS

Minutes are approved by controllers:

Gunnar Söderdahl, May 21, 2015

Marie Felldin, May 23, 2015

Minutes are respectfully submitted by Ilse D. Weinreich,