
**SCANDIATRANSPLANT
COUNCIL OF REPRESENTATIVES' MEETING
MAY 11, 2016, STOCKHOLM, SWEDEN**



Helsinki:

Arno Nordin
Marko Lempinen
Johanna Savikko
Kethe Hermunen
Illkka Helanterä
Hannu Jalanko
Antti Nykänen
Jouni Lauronen

Stockholm:

Torbjörn Lundgren
Bo-Göran Ericzon
Lars Wennberg
Helen Erlandsson

Uppsala:

Vivian Hellström
Helene Malm

Skåne:

Johan Nilsson
Lars Algotsson

Reykjavik:

Runólfur Pálsson

Gothenburg:

Per Lindnér
Jan Holgersson
Markus Gäbel
Petra Vestlund
Maria Castedal
William Bennet
Gustaf Herlenius

Aarhus:

Ulla Møldrup
Hans Eiskjær

Norway:

Anne Varberg Reisæter
John Torgils Vaage
Arnt Eltvedt Fiane
Karsten Midtvedt
Morten Hagness

Copenhagen:

Allan Rasmussen
Søren S. Sørensen
Kåre Sander

Scandiatransplant board:

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

Scandiatransplant office:

Kaj Anker Jørgensen
Bo Hedemark Pedersen
Peder Chr. Nørgaard
Torben G. Helligsø
Tito Phiri
Ilse Duus Weinreich

Observers:

Dan Hauzenberger, Stockholm
Carola Schauman, Helsinki
Fatma Bergqiust, Gothenburg
Lars Bäckman, Uppsala
Are martin Holm, Oslo
Bengt Gustafsson, Gothenburg



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: Torbjörn Lundgren

Writer of minutes: Ilse Duus Weinreich

Controllers of minutes: Arno Nordin and Morten Hagness

3. 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 2015

http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/Minutes_council_2015_May_7.pdf

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/MinutesofExtraCouncilmeeting7thMay2015Stockholm.PDF>

No comments, the minutes were approved

5. Chairman's Report

Presented by Krister Höckerstedt

Krister Höckerstedt gave a report from his 6 years as Scandiatransplant Chairman including what has been going on in Europe, some of the main points were as follows

- Number of deceased donor rate in Scandiatransplant has increased in all countries
- Number of patients on the waiting list and transplanted patients have also increased
- EU-project of setting up a European Transplant Registry – EFRETOS (European Framework for evaluation of Organ Transplantation).

The amount of data that were asked for was enormous and it was not clear for what purpose the data should have been used, who owned the data etc. The project ended in 2012, as it was no longer financially supported.

- EU-directive 53/2010 – safety and quality of organs.
The member states needed to adjust their national laws, select the appropriated data to be collected and have a registry, which resulted in an interest in the activities in Scandiatransplant.
- Problems in Germany with misinformation reported from some of the transplant centers to Eurotransplant
- Regularly meetings in the 'Nordic Transplant Committee', the national Health Authorities have shown more interest in these since the EU directive.
- Transplantation outcome has constantly improved > 50 % of patients live more > 20 years

6. Work on a new model for the legality and responsibility of data in Scandiatransplant.

Presented by Kaj A. Jørgensen

Scandiatransplant has worked on a new model for data legality as it is not clear today and it has to be dealt with due to the interest shown by the competent authorities.

In the current model Central Region Denmark is the data responsible authority and therefore the owner of data, this is not according to how it works in Scandiatransplant.

The suggested new model consists of a signed agreement between Scandiatransplant and each transplant center. The agreement gives the responsibility and ownership of the data to each center and furthermore it gives the possibility to comply to each countries data legality.

The work to come is to write such data processor agreements and have them signed by each transplant center.

7. Conversion to YASWA completed

Presented by Bo H. Pedersen

A landmark was reached in 2015/2016 as there is no old hardware left the database is now running on virtual servers.

There are now 4 fulltime programmers employed, which makes the system much less vulnerable. Among others security and speed has been improved, collaboration with other registries/system interfaces has been extended and output from the system improved.

8. Activities/News from Scandiatransplant Office in Aarhus

Presented by Ilse D. Weinreich

Information about the progress and developments in the system has been sent out regularly in newsletters. Though the system has been converted there is still a lot of open issues as the converted parts needs to be adjust and there is a long list of new wishes.

One of the top priorities at the office is to attend the meetings within the groups in Scandiatransplant. This close cooperation is very important to the office as it supports information sharing. The activities in the groups and in the transplant centers are thereby reflected in the work that is done at the office.

Key figures from the Annual data report was presented please read more at:

<http://www.scandiatransplant.org/resources/AnnualScandiatransplantdatareport2015.pdf>

Suggestion on ways of presenting data and what data to present are more than welcome

9. Revised Articles of the Association “Foreningen Scandiatransplant”

Presented by Kaj A. Jørgensen

The articles written in 1992 does not reflect how Scandiatransplant works today. The groups, medical professionals, database and office is not mentioned, some issues are obsolete and some articles are not followed.

At the representative meeting in 2014 it was decided to give mandate to a working group (WGA) with the assignments of reviewing the Articles and coming up with suggestions for a thorough revision.

Detailed description of mandate and meeting minutes are found on the homepage:

<http://www.scandiatransplant.org/about-scandiatransplant/organisation/working-group-on-articles>

The WGA has completed their work and a draft for new articles was sent to all representatives prior to the meeting. The major changes being rewriting of the purpose of Scandiatransplant, changing how the composition of the council is calculated, medical decisions are placed in groups, addition of an article on the office, groups and possibility of associate membership.

Suggestion: Can the revised articles be approved?

Conclusion: All representatives approved the new articles and they will become effective

<http://www.scandiatransplant.org/about-scandiatransplant/organisation/ArticlesofAssociationforForeningenScandiatransplant.pdf>

10. Election of chairman

Krister Höckerstedt has been chairman for the maximal 2 x 3 years and he was thanked for his work.

The candidate suggested by the board Bo-Göran Ericzon was presented and elected as new chairman for the next 3 years.

11. Election of Board Members

Margrét Andrésdóttir (Iceland) and Helena Isoniemi have been on the Board for the maximal 2 x 3 years.

| | Today | | Suggestion | |
|---------|----------------------|------------------|------------------|----------------------|
| | Board | Substitute | Board | Substitute |
| Finland | Helena Isoniemi | Heikki Mäkisalo | Arno Nordin | Marko Lempinen |
| Sweden | Lars Wennberg | Lars Bäckman | Lars Wennberg | Helen Malm |
| Norway | Pål-Dag Line | Aksel Foss | Pål-Dag Line | Bjarte Fosby |
| Iceland | Margrét Andrésdóttir | Runólfur Pálsson | Runólfur Pálsson | Margrét Andrésdóttir |
| Denmark | Finn Gustafsson | Allan Rasmussen | Finn Gustafsson | Allan Rasmussen |

The suggested candidates for the board and substitutes were accepted

12. Accounts and Budget

Presented by Kaj A. Jørgensen

Annual payment from the transplant centers to Scandiatransplant has previously been based on whether it is a deceased donor transplantation, which costs 3000 DKK or and living donor transplantation, which costs 700 DKK.

Suggestion: No difference in payment, each transplanted patient should cost 2600 DKK

Conclusion: Payment was accepted

Suggestion: To increase the 2016 budget with 400000 DKK

Conclusion: 2016 budget was accepted

Suggestion: To increase the future research grant from 300000 DKK to 450000 DKK

Conclusion: Increase in research grant was accepted

Suggestion: Total 2017 budget 5700000 DKK

Conclusion: 2017 budget was accepted

13. 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

During the last year two issues have arisen, the outbreak of Zika virus in Latin America and Strongyloides infection transmitted from a donor to two kidney recipients. For this reason, a special addendum for Zika virus has been included and information concerning Strongyloides infection has been added to the guidelines.

Guidelines:

<http://www.scandiatransplant.org/members/prevention-of-transmission-of-infections/ScandtxInfGuidelines20April20162.pdf>

Tissue Typers' Group and STAMP

Presented by Dan Hauzenberger, Stockholm

Dan Hauzenberger reported from the last Tissue Typers meeting held in Stockholm January 2016 <http://www.scandiatransplant.org/members/sttg/MinutesTissueTypersMeetingStockholm20160129.pdf>

488 searches were done for potential kidney recipients in 2015, 75 (15%) of these resulting in exchange obligations. In 6 of 75 the exchange rules were not followed.

At the annual meeting and in the STAMP committee changing the inclusion criteria for patients entering the STAMP program has been discussed. It has been decided to work towards using a Transplantability Score instead of the PRA as inclusion criteria.

Furthermore new solutions for patients not transplanted despite a long waiting time on STAMP is being investigated.

An article is on the way presenting the results of the STAMP program

Nordic Kidney Group

Presented by Søren S. Sørensen, Copenhagen

Annual import from the national kidney registries into Scandiatransplant has been completed, which means that transplant outcome can be analyzed. The follow up report is published on the homepage each year:

<http://www.scandiatransplant.org/members/nkg/registry-survey>

Until now there have been two kidney groups one mainly concerning pediatric recipients and one focusing on adult recipients. With the new articles the future structure needs to be discussed.

Nordic Pediatric Renal Transplant Study Group

Presented by Lars Wennberg, Stockholm

The group have had annual meetings, presented abstracts and recently published an article in the journal 'Pediatric Transplantation'. Work is ongoing with revising the report forms and transferring the registry to the new Scandiatransplant interface YASWA.

Patient survival is good, there is a significant difference in graft survival between kidney graft from living and deceased donors, however the outcome has improved over the years. Long-term graft survival is superior among the youngest recipients.

The waiting time is longest for pediatric patients between 2-5 years.

Nordic Liver Transplant Group

Presented by William Bennet, Gothenburg

The group has been evaluating and working with the liver exchange, payback rules and a common waiting list for pediatric patients. Furthermore, the group has defined criteria for split liver donors and there is now an ongoing follow up and registration on the donors that meet the criteria but where the liver was not split. Updated guidelines has been made and the changes has been included in the Scandiatransplant database.

A lot of different studies are ongoing

Nordic Thoracic Transplant Study Group

Presented by Are Martin Holm, Oslo

First Are Martin Holm presented some of the annual figures available on the homepage:

http://www.scandiatransplant.org/members/nttr/NTTSG_2015.pdf

The number of single lung and heart-lung transplantations have gone down, while the bilateral lung transplantations have gone up. It is like this in all countries as bilateral lung transplantations have proven to give better results over time. The number of lung and heart transplantations has gone up since the 1980's, however the activities seem to be stable over the last 4-5 years.

Second there is ongoing discussion in the group on how to increase the organ usage, currently only around 30% of the heart and lungs are used.

Timetable and procedure in relation with organ offers has been discussed in the group. The conclusion was that the donor center must be the master, which means that the donor center sets the timeframe. However one must also consider using as many of the organs as possible.

Furthermore the rising number of urgent heart patients and the fixed number of maximum 3 urgent lung patients is regularly discussed.

Many different studies are ongoing for instance the multicenter study ScanCLAD, which has help align the treatment protocols in the Nordic counties.

The Nordic Transplant Coordinator Group

Presented by Carola Schauman, Helsinki

The transplant coordinators have had two meetings, at the meetings kidney and liver balance is discussed every time. Some of the kidneys are difficult to payback as they are from very young donors, the centers are aware of this problem.

Scandiatransplant allocation rules for pancreas does not yet exists, however NTCG would like such written rules.

The amount of samples that need to be included when shipping organs differs a lot between the center. NTCG has asked the Tissue Typers Group to look into this.

Nordic Pancreas and Pancreatic Islet Transplantation Group

Presented by Bengt Gustafsson, Gothenburg

Previously there has been two separate groups the 'Nordic Pancreas Transplantation Group' and 'The Nordic Network For Clinical Islet Transplantation', they have now merged into one group as the group of patients and the organ of interest is the same.

The objectives are to achieve somewhat similar surgical procedure and immunosuppression protocols. Furthermore to create a registry for follow up in the Scandiatransplant database and to make common research.

14. Grants

Scandiatransplant Research Grant

| Applicant: | Title | Granted |
|---|--|----------------|
| Allan Rasmussen, Copenhagen, Denmark | Donor Specific HLA alloantibodies in Liver Transplantation: a prospective blinded multicenter prognostic study | 220.000 DKK |
| Hans Eiskjær, Skejby, Denmark | Platelets, coagulation and cardiac allograft vasculopathy after heart transplantation | 150.000 DKK |

Scandiatransplant Travel Grant

| Applicant: | Purpose of study travel: | Granted |
|---|--|----------------|
| Hans Henrik Schultz, Copenhagen, Denmark | The first purpose is supported: to visit the Oslo Lung transplantation unit. | 12.500 DKK |
| Carina Lund Sørensen, Copenhagen, Denmark | For the Donor Specific HLA alloantibodies in Liver Transplantation Study. All of the five Scandinavian Liver transplant Centers will participate in the Study. As a head study nurse of the project it will be necessary to for me visit the individual centers approximately twice a year. | 24.000 DKK |
| Hege Vibstad and Anna Maria Riddervold Nordin Oslo, Norway | At hospitere på Univerity of Virginia Health System (www.healthsystem.virginia.edu) og Medical College of Virginia (http://www.vcuhealth.org) for å øke vår kompetanse med fokus blant annet på donasjon og transplantasjon. | 29.000 NOK |
| Timo Saarinen, and Anne Polvi, Helsinki, Finland | Histocompatibility Testing Laboratory, Department of Immunology, Uppsala University | 13.000 DKK |
| Petra Vestlund, Göteborg, Sweden | Study and learn from our colleges in Oslo and Stockholm/Uppsala to learn more about the coordination process. | 9.600 SEK |

15. Any Other Business

Krister Höckerstedt thanked Kaj Anker Jørgensen for his effort and greatly appreciated work within Scandiatransplant.

16. Next meeting

May 10, 2017 in Helsinki

Minutes are approved by controllers:

Arno Nordin, May 19, 2016

Morten Hagness, May 27, 2016

Minutes are respectfully submitted by Ilse D. Weinreich,