

Minutes from the Scandiatransplant Council of Representatives' meeting May 7th, 2014 in Copenhagen, Denmark

Present:

Finland:
Heikki Mäkisalo
Marko Lempinen
Jouni Lauronen
Hannu Jalanko
Ilkka Helanterä
Johanna Savikko

Sweden:
Gunnar Söderdahl
Lars Bäckman
Ragnar Källen
Johan Nilsson
Jan Holgersson
Markus Gäbel
Per Lindnér
Helena Genberg

Norway:
Aksel Foss
Christian Naper
Arnt Eltvedt Fiane
Karsten Midtvedt

Denmark:
Søren Schwartz Sørensen
Allan Rasmussen
Martin Egfjord
Claus Bistrup
Lars Ilkjær
My Svensson

Scandiatransplant board:
Kristen Höckerstedt, Finland
Helena Isoniemi, Finland
Lars Wennberg, Sweden
Pål-Dag Line, Norway
Runólfur Pálsson, Iceland
Finn Gustafsson, Denmark

Scandiatransplant office:
Kaj Anker Jørgensen
Bo Hedemark Pedersen
Ilse Duus Weinreich
Frank Pedersen
Peder Chr. Nørgaard
Torben Helligsø

Observer:
Carola Schauman, coordinator, Helsinki



Copenhagen, 7th of May 2014

1. Welcome

Welcome by Scandiatransplant chairman Krister Höckerstedt

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

Meeting chairman: Søren S. Sørensen

Writer of minutes: Ilse D. Weinreich

Controller of minutes: Heikki Mäkisalo and Marcus Gäbel

3. Additional items or comments to the agenda

The Nordic Pediatric Renal Study Group will report about their activities - point 14

Revision of Scandiatransplant brain death causes? - point 18

Registration of the present representatives /observers

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

4. Approval of minutes year 2013

http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/Minutes_2013.pdf

No comments, the minutes were approved

5. The Chairman's annual report

Presented by Krister Höckerstedt

The main content and status of the Association's objectives were presented:

1. Intermediary in the exchange of human organs
In 2013 both the waiting list and the number of transplantation increased.
Exchange between the Scandiatransplant centers has consolidated to around 13-19%.
2. Operate a database + communication
Registration of donor, recipient and transplantation information is ongoing and done by all centers. As is also the exchange of organs and data between the Nordic countries
3. To maintain a dialogue with the Nordic health authorities
The SCTP office is working on improving and documenting the data security,
Definitions of SAE and AE are discussed and a new suggestion will be presented by the board at the Nordic Transplant Committee meeting in September.
4. European cooperation
35 organs have been imported from Estonia in the period from 1.1.2013 to 16.03.2014
In the same period 8 organs have been exported to other EOEO's (non to Estonia).
5. Promoting the provision of human organs and tissue
Is done by some of the committees by making guidelines for donor criteria for specific organs.
6. Support scientific activities
Committees/groups which are central in this matter are not mentioned in the articles.
The receivers of research and travel grants this year are listed under point '15. Grants'.

The full length of the articles are found on the homepage

<http://www.scandiatransplant.org/about-scandiatransplant/organisation/ArticlesEnglish2013.pdf>

It was questioned if it is a modern democratic process, that the council has to agree 100% before medical matters, can be adopted. There is a need for a revision of the articles.

A written version of the chairman's report will not follow this year, the slides showed at this meeting will replace the document.

6. Election of chairman

No election needed.

Krister Höckerstedt was elected as chairman last year for his 2nd period and will serve as such for two more years.

7. Election of Scandiatransplant's board members and substitutes

Pål dag Line was re-elected for his second period.

Runólfur Pálsson is now in the board instead of Margrét Birna Andrésdóttir.

8. Developments related to the computer system

Presented by Bo Hedemark Pedersen

Bo presented his two new colleagues Peder Chr. Nørgaard and Torben Helligsø

Status on the conversion process:

Already in production

- Organ offer from + offers from EOEO
- Rotations-lists (lung, heart and livers)
- Living Kidney Donor
- File-upload/processing

Next in line

- Urgent waiting-list
- Search for kidney recipients
- Recipient
- Donor
- STAMP
- NTTR, NLTR, pediatric/Renal
- GUI (graphical user interface) to old export scripts

9. Accounts and economical balance fiscal year 2013

Presented by Kaj Anker Jørgensen

The economical balance was explained in short, it shows as expected an overspending of 500.000 dkr in year 2013 and a cash balance of 8.4 million dkr.

The balance has been signed by all board members.

10. Budget for 2014 and proposal for 2015

Presented by Kaj Anker Jørgensen

The transplantation fees for living and deceased transplantations was suggested kept on the same level

The final item for meetings and user education has been increased compared to former years. It replaces several items on former years budgets, but more money has been spend due to the fact that each committee can apply for 15000 dkr twice a year in connection with meetings (meeting room and eating). Scandiatransplant staff has and will travel more to assist users and program development.

Conclusion:

Budget was accepted

11. Report on the activities of Scandiatransplant/News from the office in Aarhus Presented by Kaj Anker Jørgensen

Activities

The power point presentation containing Scandiatransplant activities has been updated with 2013 figures and is to be found on the Scandiatransplant homepage
<http://www.scandiatransplant.org/resources/diasshows-and-others>

Office staff

Special thanks to Christian Mondrup, whom will retire this summer, for his great effort with developing and maintaining the database.

Welcome to the two new programmers Peder Chr. Nørgaard and Torben Helligsø

The strategy has been to emphasize the programming to support the conversion process and the data security.

Legal aspects

Quiet some work has been put into investigating legalities aspects in relation with Scandiatransplant. The conclusions are that Scandiatransplant is legal in Denmark, the other countries need the service and legality must be solved by each country according to their national laws.

ArticlesProposal:

The board proposes a major revision of the articles as many of our activities are not covered by the articles

Detailed description of the mandate is found on the homepage

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/MandateWGA.pdf>

Conclusion:

Revision was accepted by the representatives

Comments:

Should there be an intermediate meeting with the possibility for others to give input to the working group?

It was decided to prolong the representatives meeting next year (2015) to discuss the status, give input and ideas.

Is it a problem if not all centers are represented in the working group?

No, as long as all centers are present at the intermediate meeting and in the final decision process.

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

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

Message from Vanda Friman, Gothenburg: We plan to revise the "Guidelines for prevention and transmission of infectious diseases from organ donor to recipients" every second year. A revision was made 2013 and we plan a new revision 2015.

The Tissue Typers' Group and STAMP

Presented by Jouni Lauronen, Helsinki

Jouni Lauronen reported from the last tissue typer meeting held in Oslo January 31, 2014
http://www.scandiatransplant.org/members/sttg/TTG_2014_v2.pdf

The donor HLA-typing has improved significantly and is now acceptable. Of the 491 searches performed in 2013 most of them were done with split antigens. Further it was discussed if donors should be DPB1 and DQalfa typed and also changing the ABO exchange criteria.

Scandiatransplant Acceptable Mismatch Program (STAMP):

72 recipients have been transplanted due to STAMP, the 1 year graft survival is acceptable (~ 90%) and so is the post transplantation rejection incidences (< 20%).

It was discussed if STAMP should become priority 1 kidney exchange obligation, this will be brought up for discussion at the next Nordic Kidney Group.

The Nordic Kidney Group

Presented by Lars Bäckman, Uppsala

The 2013 kidney transplantation figures were presented and around 30% of the transplantations were with kidneys from living donors.

Two meetings have been held in the Nordic Kidney group. One ordinary meeting was held 20th of November 2013 <http://www.scandiatransplant.org/members/nkg/minutes>

Further a meeting was held April, 2014 with the theme 'Paired kidney exchange program'. 2-way, 4-way, listed and undirected exchange was presented and the mathematically and logistic challenge were shortly explained.

In the beginning the focus will be on immunized patients and will not include ABO incompatibility. A meeting will be held in Lund 4th of June 2014 where Al Roth (Nobel laureate 2012) will give a talk.

The Nordic Pancreatic Group

Presented by Lars Bäckman, Uppsala

The group has got off to a good start and two meetings have been held in the Nordic Pancreatic Group since last year <http://www.scandiatransplant.org/members/nordic-pancreas-group/minutes>

Especially donor criteria and potential has been discussed, but also a possible follow up registry.

Recommendation:

Please consider pancreas/pancreas islet procurement on all relevant donors

The Nordic Pediatric Renal Study Group

Presented by Hannu Jalanko, Helsinki

Data on 720 pediatric kidney transplantations performed in Scandiatransplant from 1994 – 2013 was presented. Of the total amount of transplanted pediatric recipients 17% are <2 years, 20% between 2-7 years and the largest amount 63% is in the age group 7-16 years. The data illustrates that the youngest group of recipients transplanted with kidneys from living donors has a better graft survival compared to the other two age groups.

The latest presentation of the pediatric transplantation figures are found on the homepage: http://www.scandiatransplant.org/members/nprtsg/NPRTSG_1994_2012.pdf

The Nordic Liver Transplant Group

Presented by Aksel Foss, Oslo

It has been decided that the Annual report this year will be published as an article. The common shared Nordic waiting list for pediatric recipients waiting for segment 2+3 is still effective. If you split a liver and exported it you have the right to get a full size liver as payback.

Recommendation:

Please consider splitting livers on all relevant donors

A special meeting concerning pediatric liver recipients has been held this year.

The Scandiatransplant liver rotation list is used when livers are offered and accepted from Estonia. This arrangement has been effective from December 1, 2013. Since then two livers have been accepted and the rotation list has been used correctly.

A little child from Estonia was LD transplanted with liver from her mother in Stockholm. Unfortunately complication arose and re-transplantation was needed. All centers in Scandiatransplant were phoned and the child was put on the Scandiatransplant high urgent list.

The liver group found this case not to be complicated as Scandiatransplant has received around 8 free livers from Estonia.

The board has discussed the case as it is a matter of principals and has concluded that the recipient should only have been sent out as a kind request.

The Nordic Thoracic Transplant Study Group

Presented by Finn Gustafsson, Copenhagen.

The Thoracic Group has discussed the exchange and rotations rules no changes have been made. Each center still has the right to claim Priority 0 and 1 for total of three lung patients each year. The number of urgent call for hearts has decreased from 2012 to 2013.

Most of the work and effort in the group is related to research among others an article has been published: 'Three decades of heart transplantation in Scandinavia: long-term follow-up'.

The Nordic Transplant Coordinator Group

Presented by Carola Schauman, Helsinki

Carola reported from the last two meetings

<http://www.scandiatransplant.org/members/ntcg/minutes>

At each meeting the liver and kidney exchanges are balanced and the fact is that it is not always possible to payback within ½ year especially concerning organs from young donors. All centers have started to register the reason for refusals on offered payback organs.

The coordinators are happy with using the rotation list when livers are offered and accepted from Estonia. They hope the same agreement will be sorted out with the thoracic organs. A flow-chart has been made, which describes the working procedure:
http://www.scandiatransplant.org/organ-allocation/Liver_rotation_Estonia.pdf

The group has some wishes concerning layout alterations in the pdf of the organ offer form and the possibilities to do printouts.

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

Presented by Krister Höckerstedt

Slides shown at the last EU meeting, March 11-12, 2014, were presented. The slides compared the number of transplantation performed in 2009 with 2012 divided on living and deceased donations in the EU countries both in relation with kidney and liver transplantations.

14. International cooperation activities

The representatives was informed that the board has decided to delete line 2.b. in the following document http://www.scandiatransplant.org/organ-allocation/GuidelinesforNonNordic_may_2013.pdf

The update version has now been placed on the homepage
<http://www.scandiatransplant.org/organ-allocation/GuidelinesnonNordicnationalsMay2014.PDF>

15. Grants

Scandiatransplant Travelling Grant (total 100.000 dkr)

Application No 1 was from Einar Gude to visit Toronto General Hospital and Copenhagen. The board decided to grant him the amount applied for, namely DKK 23,500.

Application No 2 from Per Arne Bakkan. The application was from 3 transplant coordinators from Oslo to visit Bristol and 2 unnamed donor hospitals in London or in the area nearby. The board decided to grant DKK 15,000 to this application.

Application No 3 from Åsa Svärd and Tanja Hølvold, two transplant coordinators from Stockholm to visit Oslo. The board decided to grant these applicants DKK 10,000.

Application No 4 from Hans Henrik L. Schultz who applied for 2 months' stay in Leuven, Belgium. The board was of the opinion that this was outside the scope of the travel grants, but awarded him DKK 10,000 for travelling expenses.

Application No 5 from Margret B. Andresdottir to visit Rikshospitalet in Oslo was awarded DKK 7,900.

Application No 6 from Ilkka Helanterä from Finland to study living kidney transplantation in Rotterdam was awarded DKK 15,000.

Scandiatransplant Research Grant (total 40.000 €)

For the research grant there were 2 applications, which have been evaluated by the board. The board decided to award 40,000 € to:

Kari Nytrøen, Marianne Yardley, Finn Gustafsson and Kristjan Karason.

For a randomized controlled study entitled: Effect of exercise after heart transplantation – short term and long term.

16. Any Other Business

Revision of Scandiatransplant brain death causes?

Helena Isonemi presented an overview of brain death causes used in different registries.

Proposal:

To revise the list of brain death causes registered in Scandiatransplant.

Conclusion:

Revision was accepted by the representatives

Comments:

At least one person from each center must send an email with the name of a contact person to Helena Isonemi within one month. A proposal will be ready for the next council of representatives meeting

17. Next meeting

May 7th, 2015 in Stockholm

STS 2016 will be a joint venture between Stockholm and Uppsala

Minutes are approved by controllers:

Heikki Mäkisalo 13th of June 2014

Marcus Gäbel 2nd of June 2014

Minutes are respectfully submitted by Ilse D. Weinreich,