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**SCANDIATRANSPLANT  
COUNCIL OF REPRESENTATIVES' MEETING  
MAY 2, 2018, OSLO, NORWAY**

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**Helsinki:**

Helena Isoniemi  
Marko Lempinen  
Johanna Savikko  
Hannu Jalanko  
Jouni Lauronen

**Stockholm:**

Gunnar Söderdahl  
Henrik Gjertsen

**Uppsala:**

Tomas Lorant  
Vivian Hellström

**Skåne:**

Johan Nilsson  
Alireza Biglarnia

**Reykjavik:**

Margret B. Andresdottir

**Gothenburg:**

Markus Gäbel  
Petra Vestlund  
Marie Felldin  
Gustaf Herlenius

**Aarhus:**

Karin Skov  
Lars Ilkjær

**Norway:**

Pål-Dag Line  
Jon Sponheim  
Christian Naper  
Anne Varberg Reisæter  
Karsten Midtvedt

**Copenhagen:**

Allan Rasmussen  
Søren S. Sørensen  
Michael Perch

**Scandiatransplant board:**

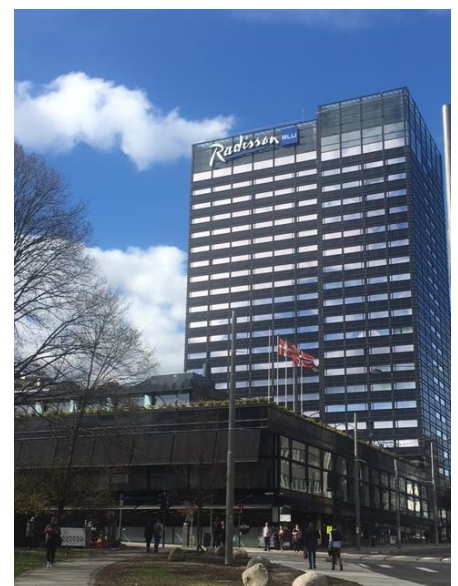
Bo-Göran Ericzon, Sweden  
Arno Nordin, Finland  
Lars Wennberg, Sweden  
Morten Hagness, Norway  
Runólfur Pálsson, Iceland

**Scandiatransplant office:**

Kaj Anker Jørgensen  
Bo Hedemark Pedersen  
Poul Kruse-Hansen  
Tito Phiri  
Ilse Duus Weinreich

**Observers:**

Are Martin Holm, Oslo  
Bengt Gustafsson, Gothenburg  
Øystein Jynge, Stockholm  
Vanda Friman, Gothenburg  
Virge Pall, Tartu  
Tanel Laisaar, Tartu  
Peeter Dmitriev, Tartu



## **1. Welcome**

Welcome by Scandiatransplant board member Morten Hagness, Oslo

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

Chairman of the meeting: Pål-Dag Line

Writer of minutes: Ilse Duus Weinreich

Controllers of minutes: Gunnar Söderdahl and Marko Lempinen

## **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 2017**

<http://www.scandiatransplant.org/about-scandiatransplant/scandiatransplant-representatives/MinutesSCTPRepresentative2017.pdf>

No comments, the minutes were approved

## **5. Chairman's Report**

Presented by Bo-Göran

The board has worked on the collaboration with Tartu before, under and after they were accepted as associated members in Scandiatransplant by the Council of Representatives.

At the representatives meeting last year the board was given the task to reorganize *'The group on prevention of transmission of infectious diseases from donors to recipients'*, which have resulted in a new working group. The results will be presented later in this meeting by Vanda Friman.

Bo-Göran has, as an observer, taken part in meetings in the Council of Europe. Moreover he has participated in numerous meetings in the different organ groups within Scandiatransplant.

Presently the board is working with the arrangements for the Scandiatransplant 50-year jubilee, which will take place 9th of May 2019 in Aarhus.

## **6. Status on Data Processor Agreements**

Presented by Kaj A. Jørgensen

9 member hospitals have now signed the data processor agreements with Scandiatransplant, two hospitals are still pending – Stockholm and Oslo.

## **7. Serious adverse events/serious adverse reactions (SAE/SAR)**

Presented by Lars Wennberg

According to EU directive EU 53/2010 all member states must have a system for reporting SAE/SAR.

A substantial part of the data/information required for reporting is already available in YASWA, which will probably increase the completeness, make the reporting easier and less time consuming. Reporting of events will go through existing communication systems/channels. The Scandiatransplant SAE/SAR system has been accepted by all the national competent authorities.

It is the transplantation units that have the responsibility to report, not Scandiatransplant. It is not possible to specify in details what to report, however if in doubt it is better to report – better safe than sorry.

Helena Isoniemi commented, that FIMEA in Finland does not want SAE reports from other countries, this will be discussed at the next NTC meeting.

The report system might need improvement and modification, please send feedback and suggestions to the Scandiatransplant office.

## **8. Activities/News from Scandiatransplant Office in Aarhus**

Presented by Kaj A. Jørgensen

Status on staff at the Scandiatransplant office since last year is that Programmer Peder Nørgaard left the office and a new programmer Lorraine Mortensen and new student programmer Poul Kruse-Hansen have been employed.

Numerous updates have been made within the it system YASWA, among others Tartu has been incorporated, SAE/SAR was introduced and a new registration system for kidney and liver payback has been launched. At the moment the top priority is to do the necessary programming for the STEP program.

Figures are presented in the annual report on the homepage:

<http://www.scandiatransplant.org/resources/AnnualScandiatransplantdatareport2017.pdf>

## **9. Election of Board Members and substitutes**

Lars Wennberg, Sweden, has been on the Board for the maximal 2 x 3 years. Sweden suggested Tomas Lorant as new board member and Amir Sedigh as his substitute.

Suggested candidates were approved

## **10. Accounts and Budget**

Presented by Kaj A. Jørgensen

Kaj presented the account for 2017 and the budget for 2017 and 2018, all the documents were sent to the council prior to the meeting.

A little less than expected was used in 2017, this was due to two things, a programmer left the office and it was not possible to transfer one of the research grants within the year it was granted.

The board suggested same budget for 2018 as accepted last year (5.9 mill DKK), a budget for 2019 of 6 mill DKK, and the same payment of 2.600 DKK per transplanted patient.

Budget and payment were approved

## **11. Scandiatransplant 50-year jubilee**

The board has decided that celebration of the 50-year jubilee should be divided in two events. The internal scientific celebration will take place at STS 2020 in Helsinki. The other event is an external event directed against awareness in the society, this will take place next year in Aarhus, May 9<sup>th</sup> 2019. The event in 2019 will firstly take place at the Town hall in Aarhus, with a ceremony focusing on patient stories and how Scandiatransplant is involved in organ allocation, this will be followed by a dinner at the AroS museum.

Suggested budget: 500.000 DKK

Budget was approved

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

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

Presented by Vanda Friman, Gothenburg

As decided on the Council of Representative meeting last year the working group has been reorganized.

The group has worked on some changes regarding Hepatitis C and B.

Previously Hep. C positive donor organs were not accepted for transplantation, however this procedure is suggested changed as treatment of Hep. C is much better today and antiviral treatment can be initiated right after transplantation. The Anti-HCV text in the guidelines is separated in two, liver and non-liver organs, it was commented that this separation is not relevant.

It is suggested that Hep. B positive livers are used for antigen positive recipients and in urgent cases as the Hep. B treatment is not as effective as the Hep. C treatment. Non-liver organs can be given to all recipients in urgent cases.

The recipients must be informed and give consent to receive these types of infected organs prior to transplantation.

In general, the Nordic guidelines will be more in line with the European guidelines when it comes to hepatitis.

The number of donors coming from tropical areas are increasing and the working group is looking into what to recommend concerning organs from these donors.

New updated guidelines will be distributed when they have been finalized.

### **Nordic Kidney Group**

Presented by Søren S. Sørensen, Copenhagen

Meeting minutes: <http://www.scandiatransplant.org/members/nkg/minutes>

Outcome of transplantation, activities etc. is found in the annual report:  
<http://www.scandiatransplant.org/members/nkg/registry-survey>

The STEP program has been the main issue in NKG, the program will hopefully be launched in Scandiatransplant within this year. Furthermore, including HLA-DPB1 matching in the STAMP program has been up for discussion.

### **Nordic Liver Transplant Group**

Presented by Helena Isoniemi, Helsinki

Meeting minutes: <http://www.scandiatransplant.org/members/nltr/minutes>

During the last year the liver rota list was changed, so that Sweden now only has one common position on the rota list. Furthermore, the payback rules have been modified to make them simpler. Both initiatives will be evaluated.

The total annual number of transplantations might have reached its top level as the number in 2017 (410) was almost the same as in 2016 (419), Sweden and Norway doing the most transplantations PMP. At the same time entries on waiting list seems to have stabilised. Number of deaths on the waiting list is going down. Median waiting time is lowest in Finland and Norway, however all countries are on an acceptable level now. Overall patient and graft survival are improving.

### **Scandiatransplant Heart and Lung Group**

Presented by Are Martin Holm, Oslo

Meeting minutes: <http://www.scandiatransplant.org/members/nttr/minutes>

Three topics are discussed at each meeting; registry, organ allocation and research. Regarding the registry discussions are ongoing concerning improving data entry and revising the registry. When it comes to organ exchange it is on the same level, however one worry is that the

lung and heart utilization rate is rather low, it varies between 24-40% depending on center. This will probably result in introducing a donor score calculation, so that numbers can be compared. Among others the ScanCLAD research project is ongoing and all lung transplantations will be enrolled.

### **Nordic Pancreas and Pancreatic Islet Transplantation Group**

Presented by Bengt Gustafsson, Gothenburg

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

Last year the group managed to agree on a common protocol both for immunosuppression and prophylaxis, which gives a good foundation for future studies.

January 1<sup>st</sup> 2017 new exchange recommendations were effective, these have since been up for discussion.

At the last meeting it was decided that each country should only have one entry on the rota list, leaving the possibility to use the pancreas within own country before it is offered to other countries on the rota list. This change will be effectuated as soon as the minutes from the meeting has been finalized. In addition, it has been discussed whether the recommendations should be rules and if it should be obligatory to offer a kidney with the pancreas, if there are no other kidney exchange obligations / local urgent patients. This work is ongoing.

The group has also agreed upon a common follow up registry that will be incorporated into YASWA. The hope is that results can be presented at ESOT in Copenhagen 2019.

Ongoing research projects in islet transplantation

### **Tissue Typers' Group and STAMP**

Presented by Christian Naper, Oslo

Meeting minutes: <http://www.scandiatransplant.org/members/sttg/minutes>

The STEP program was on the agenda at the last meeting and Tommy Andersson gave a presentation based on the program launched in Sweden in 2016. A corresponding program is now being developed by the Scandiatransplant office.

Since last year the STAMP inclusion criteria have changed, the inclusion is done based on the Transplantability Score and not on PRA  $\geq$  80% as previously and the patients don't have to wait one year before they can be accepted to STAMP.

Work with introducing HLA-DPB1 matching in STAMP is ongoing

Graft survival for STAMP and HLA-A, -B, -DR matched is on the same level, maybe even a little better for STAMP. The STAMP patients transplanted with DSA do significantly worse.

Discussion about what to do with patients that have been on STAMP for a long time is ongoing.

## **The Nordic Transplant Coordinator Group**

Presented by Øystein Jynge, Stockholm

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

Discussions in the group reflects the role of the coordinators as they concern logistic, organ allocation and payback. Introduction to the new payback registration in YASWA has been given, it is up and running and the centers aggress on the balance.

### **14. Grants**

#### **Scandiatransplant Research Grant**

<b>Applicant:</b>	<b>Title</b>	<b>Granted</b>
<u>Göran Dellgren</u> (Gothenburg):	Sub-study on donor specific antibodies in the ScanCLAD study	370,000 DKK

#### **Scandiatransplant Travel Grant**

<b>Applicant:</b>	<b>Purpose of study travel:</b>	<b>Granted</b>
Sini Puputti, Helsinki	Support to visit Toronto General hospital	12,500 DKK
Ingebjørg Kvangarsnes, Oslo	Support to visit Edinburgh and observe the use of perfusion in controlled donation after cardiac death.	19,500 DKK
Carina Lund Sørensen, Copenhagen	Support to visit the centers in a liver transplant study	36,000 DKK

Members of the board are looking into changing the application rules for the Research Grant, please contact Morten Hagness (Norway), Finn Gustafsson (Copenhagen) and/or Arno Nordin (Finland) if you have any suggestions for changes.

### **15. Any Other Business**

*Short status report by Tanel Laisaar, Tartu*

Thanked for the acceptance of Tartu as an associated member last year. Joining Scandiatransplant has been useful, Estonia has received 3 livers for urgent patients and 1 pair of lungs. Moreover, it has made it possible to cooperate with Helsinki concerning heart transplantation and one Estonia child has been kidney transplanted in Helsinki.

*Thank*

Lars Wennberg was thanked for his great job in the Scandiatransplant board.

### **16. Next meeting**

May 9<sup>th</sup> 2019 in Aarhus held before the celebration of Scandiatransplant 50-year jubilee

Minutes are approved by controllers:

Gunnar Söderdahl, May 9<sup>th</sup> 2018

Marko Lempinen, May 17<sup>th</sup> 2018

Minutes are respectfully submitted by Ilse D. Weinreich,