SCANDIATRANSPLANT
COUNCIL OF REPRESENTATIVES’ MEETING
MAY 19, 2021, VIRTUEL MEETING

Helsinki:
Heikki Mäkisalo
Eija Tukiainen
Ilkka Helanterä
Johanna Savikko
Timo Jahnukainen
Karl Lemström
Jouni Lauronen

Odense:
Claus Bistrup
Francois Baudier

Copenhagen:
Søren S. Sørensen
Michael Perch
Nicolai Schultz

Stockholm:
Carl Jorns
Lars Wennberg
Gunnar Söderdahl

Reykjavik:
Margrét B. Andrésdóttir

Uppsala:
Tomas Lorant
Amir Sedigh

Tartu:
Tanel Laisaar, Tartu (observer until point 7)
Astra Västrik, Tartu (observer until point 7)

Skåne:
Alireza Biglarnia
Oscar Braun

Scandiatransplant board:
Bo-Göran Ericzon, Sweden
Allan Rasmussen, Denmark
Arno Nordin, Finland
Morten Hagness, Norway
Johan Nilsson, Sweden
Runólfur Pálsson, Iceland
Virge Pall, Estonia (full member after point 7)

Gothenburg:
Marie Felldin
Jan Holgersson
Markus Gäbel
Petra Vestlund

Scandiatransplant office:
Kaj Anker Jørgensen
Ilse Duus Weinreich

Aarhus:
Lars Ilkjær
Ulla Møl hdrup

Observers:
Helena Isoniemi, Helsinki
Øystein Jynge, NTCG, Stockholm
Kaie Lokk, STTG, Tartu
Hanne Scholz, NPITG, Oslo
Vanda Friman, Infection group, Gothenburg

Oslo:
Kristine Fasting
Morten Skauby
Anna V. Reisaeter
Christian Naper
Are M. Holm
Anna K. Bjerre

Invited speakers:
Jurijs Bormotovs, Latvia (took part in point 8 and 9)
Marius Miglinas, Lithuania (took part in point 8 and 9)
1. Welcome
Welcome by host and Scandiatransplant board member Arno Nordin, Helsinki

2. Election of meeting chair, writer of minutes and controllers of minutes
Chair of the meeting: Helena Isoniemi
Writer of minutes: Ilse Duus Weinreich
Controllers of minutes: Carl Jorns and Jouni Lauronen

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 2020
Kaj A. Jørgensen gave a short presentation of the minutes from last year

The minutes were approved without any comments

5. Report of activities
Presented by Bo-Göran Ericzon

A short overview of the daily working tasks at the office were presented together with some of the general transplantation figures.

Further information on waiting list, donation, organ exchange and transplantation figures is found in the Annual Report on the homepage
http://www.scandiatransplant.org/resources/AnnualScandiatransplantdatareport_2020.pdf and also in the annual power point presentation
http://www.scandiatransplant.org/resources/sctp_slideshow2020.pptx

Last year a voluntary registration of patients infected with Covid-19 post transplant was introduced in YASWA, the numbers are updated every 2nd week and found on the homepage:
http://www.scandiatransplant.org/data/covid-19-status-in-scandiatransplant

Late April around 750 transplanted patients have been registered Covid-19 positive post transplant and around 12% has died with the infection. 2/3 of the total infected patients are from Sweden. The data from Sweden and Estonia are more or less complete, whereas data from the other countries might be more uncertain.

SAE/SAR reporting has gone down from 15 cases reported in 2018 to 5 cases in 2020. The reporting is important for the trust between the Competent Authorities and Scandiatransplant. Everyone is encouraged to be more aware and to report all cases, if you are in doubt whether you should report or not, then please report.

The transplant coordinators have a central position in the donation and transplantation process and they were asked to support the reporting.
Scandiatransplant Research Grant

<table>
<thead>
<tr>
<th>Primary applicant</th>
<th>Purpose of study</th>
<th>Granted:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bente Jespersen</td>
<td>EVITA study – Epstein-Barr Virus Infection monitoring in renal transplant recipients.</td>
<td>200,785 DKK</td>
</tr>
<tr>
<td>Lilia Martinez de la Maza</td>
<td>Bile composition and its regulatory pathways as predictors of liver function in liver transplantation</td>
<td>150,000 DKK</td>
</tr>
</tbody>
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Scandiatransplant Travel Grant

<table>
<thead>
<tr>
<th>Primary applicant</th>
<th>Purpose of travel</th>
<th>Granted:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caroline Stolt, Skåne</td>
<td>Visit Scotland (Edinburgh transplant center)</td>
<td>22,000 DKK</td>
</tr>
<tr>
<td>Lene Ugilt Pagter Ludvigsen, Aarhus</td>
<td>Visit Oslo</td>
<td>21,000 DKK</td>
</tr>
</tbody>
</table>

Fewer grant applications this years, maybe due to the difficulties with the pandemic. Next announcement by e-mail will be followed by a poster made by Kaj A. Jørgensen.

6. Accounts and Budget

Presented by Kaj A. Jørgensen

Documents from the independent auditor had been distributed to all prior to the meeting. The expenses were lower than the income in 2020, with a difference of 847,888 DKK, which means that the assets have gone up. The decrease in expenses were mainly due to a reduction in wages and meetings. The budget for 2020 was 6,100,000 DKK the total expenses were 5,020,112.

Suggested revised budget for 2021 was 5,550,000 DKK

*Suggestion was accepted by the Council*

Suggested budget for 2022 was 6,300,000 DKK

*Suggestion was accepted by the Council*

7. Tartu membership and changes in the articles of ‘Foreningen Scandiatransplant’

Presented by Helena Isoniemi and Kaj A. Jørgensen

Tartu has been an associated member of Scandiatransplant for 4 years, during this period they have imported around 50 organs and exported around 130 organs. The application from Tartu of becoming full member of Scandiatransplant and suggested changes to the articles by the board have been distributed to the Council before the meeting.

The 3 suggested changes in articles 4, 8 and 12 were presented to the members.

*Suggestions were accepted by the Council*
Application from Tartu of becoming full members of Scandiatransplant.

Application was accepted by the Council

Tanel Laisaar and Astra Västrik from Tartu are now members of the Council. Peeter Dmitriev and Kaie Lokk are their substitutes.

8. Presentation of organ donation/transplantation in Latvia
Presented by Jurijs Bormotovs

The Paula Stradina University Hospital in Riga is the only hospital in Latvia with license to do solid organ transplantation under the Ministry of Health founded by the National Health Service. The first kidney transplantation was done in 1973, the heart program was started in 2002 and the liver program was started in 2018. The heart and liver programs are very small, with approx. 2 liver and 2 heart transplantation per year. The first simultaneous kidney–pancreas transplant was performed in 2008, however the procedure has been infrequent and there is currently no active program. The HLA lab. tests have been ISO accredited since 2017 excepted for Luminex. The lab. is not EFI accredited yet, however they are working towards packed A accreditation in year 2023. It is a challenge to have their pediatric patients and the HLA immunized patients transplanted.

9. Presentation of organ donation/transplantation in Lithuania
Presented by Marius Miglinas

Lithuania has 2 transplant centers placed on the University Hospitals in Vilnius and in Kaunas, where heart (10 txs in 2020), kidney, liver (14 txs in 2020), lung and simultaneous organ (pancreas-kidney, heart-kidney, liver-kidney, and heart-lungs) transplantations are performed. The first kidney transplantation was performed in Vilnius in 1970. Organ transplantation is mainly funded by National Health Insurance Funds. DCD was approved in 2015 and the first kidney transplantation from a donor after cardiac death was performed in Kaunas in 2016. Organs are allocated according to a strictly regulated system based on blood group, HLA compatibility, waiting time, sensitization and age (for kidneys and pancreas) and disease severity (for heart, lung, and liver). The HLA lab. does not hold an EFI accreditation. The waiting list with HLA immunization kidney patient is increasing due to a small donor pool. The challenges with allocating well matched kidneys is also reflected on the graft survival, as no significant improvement has been seen over the years. An increased donor pool will also help the urgent heart, lung and liver patients. Potential challenges in the collaboration could be expenses related to transportation and prolonged cold ischemia time.
**Board suggestion for a Working Group on Latvia and Lithuania**
Presented by Kaj A. Jørgensen

The board suggested to form a working group to look into the following points:
- Describe how organ donation and transplantation is organized
- Identify any problems with medical/technical standards
- Identify how transplantation/donation is financed
- Identify any legal and/or ethical and/or organizational problems
- Write a report to the Council evaluating criteria and possibilities for membership

*Suggestion was accepted by the Council*

The board suggested that the group should consist of the following persons:
- NKG/Denmark: Søren Schwartz Sørensen
- SHLG/Norway: Are Martin Holm (also accepts to chair the working group)
- STTG/Sweden: Mats Bengtsson
- NTLG/Finland: Heikki Mäkisalo
- NTCG/Finland: Carola Schauman
- Estonia: Virge Pall
- Iceland: Runólfur Pálsson
- Chairman of Scandiatransplant: Bo-Göran Ericzon
- Medical Director of Scandiatransplant: Kaj Anker Jørgensen (Secretary for the group)

To be contact persons for the working group the two countries have appointed one person from their competent authorities, one from transplantation and one from donation.

*Suggestion was accepted by the Council*

A preliminary report from the working group is expected to be given 31st of August 2022 in Iceland.

10. **Election of Board Members and substitutes**
Presented by Helena Isoniemi

No of the present board members were up for election.
Virge Pall was suggested as board member from Tartu and Tanel Laisaar will be her substitute.

*Suggestion was accepted by the Council*
11. Report from the groups

**Nordic Liver Transplant Group**
Presented by Carl Jorns, Stockholm

Meeting minutes: [http://www.scandiatransplant.org/members/nltr/minutes](http://www.scandiatransplant.org/members/nltr/minutes)

At the meetings exchange and payback rules are discussed, clarified and adjusted. Some of the current and ongoing activities are refinement of the liver quality groups, ABOi livers for pediatric patients, optimization of the ‘Pediatric liver and multivisceral waiting list’ and possibilities of sharing of donor CT radiology files.

Each year the registry data are summarized in a report made by Espen Melum. Since 2020 center specific outcome measures have been made for internal comparison to improve sharing of knowledge and quality.

A variety of studies are ongoing

**Nordic Kidney Group**
Presented by Søren S. Sørensen, Copenhagen

Meeting minutes: [http://www.scandiatransplant.org/members/nkg/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](http://www.scandiatransplant.org/members/nkg/registry-survey)

Data is collected in several sub-registries within YASWA, which gives a good material for studies. STEP (living donor exchange program) has had an increasing activity with several match runs and with trying to solve the new work procedures. Ongoing research projects are ABOi project, Imlifidase protocol and STAMP a publication. The Nordic Kidney Group has a pediatric sub-group, which have existed for many years. The group has separate meetings and several studies are also going on.

**The Nordic Transplant Coordinator Group**
Presented by Øystein Jynge, Stockholm
Meeting minutes: [http://www.scandiatransplant.org/members/ntcg/minutes](http://www.scandiatransplant.org/members/ntcg/minutes)

Issues that are discussed on a regular basis is the coordination activity, experiences and cooperation along with the organ exchange and balance especially in relation to new guidelines. Ongoing is developing YASWA as a possible coordination tool and sharing the experiences with introduction of DCD.
**Scandiatransplant Heart and Lung Group**
Presented by Are Martin Holm, Oslo
Meeting minutes: [http://www.scandiatransplant.org/members/nttr/minutes](http://www.scandiatransplant.org/members/nttr/minutes)

At the regular board meeting the registry, organ exchange practice and studies are discussed. Furthermore the bylaws of the group has gone through a slight revision. In the last year a pediatric heart and lung sub group (SPedHLG) was established, they have their own meetings and have had their own bylaws. Work is done on restabling data transfer to ISHLT after the introduction of GDPR. A Covid specific mini-webinar was held online in February 2021 with good attendance.

**Scandiatransplant Tissue Typers' Group**
Presented by Kaie Lokk, Tartu
Meeting minutes: [http://www.scandiatransplant.org/members/sttg/minutes](http://www.scandiatransplant.org/members/sttg/minutes)

In STAMP matching on DRB3, DRB4, DRB5, DPA1 and DQA1 was introduced in April 2020. Furthermore Tartu became member of the STAMP steering committee and several updates in YASWA has been introduced to improve the evaluation process. Ongoing work with a STAMP publication.

**Nordic Pancreas and Pancreatic Islet Transplantation Group**
Presented by Hanne Scholz, Oslo
Meeting minutes: [http://www.scandiatransplant.org/members/nordic-pancreas-group/minutes](http://www.scandiatransplant.org/members/nordic-pancreas-group/minutes)

Lower activity in 2020 for solid pancreas and islet transplants. Entrance of the patient on islet waiting list is decreasing probably due to patients trying new technologies. Due to the access to islet isolation facility, Stockholm, Uppsala, and Oslo are offering total pancreatectomy with islet auto-transplantation (TPIAT).
In February new chairs of the group was elected: Torbjörn Lundgren, Stockholm with co-chair: Hanne Scholz, Oslo. 
Nordic Islet Registry is being moved from MedSciNet to Scandiatransplant and discussion is ongoing to open up for DCD donors for islet isolation and to develop a protocol for Simultaneous Islet Kidney Transplant.
The group on prevention of transmission of infectious diseases from donors to recipients
Presented by Vanda Friman, Gothenburg

This year the main focus has been on Covid-19 in relation to this the guidelines have been updated twice.
Vanda Friman has been chair of the group for 14 years and now wished to step down. It has been decided that Morten Hagness will chair and form a new group consisting of persons that have interest in this field.

12. Any Other Business
No issues were brought up

13. Next meeting
Short virtual meeting May 11th, 2022
Face-to-face meeting August 31st, 2022 together with STS in Iceland

Minutes are approved by controllers:
Carl Jorns, 24th of May, 2021
Jouni Lauronen, 24th of May, 2021

Minutes are respectfully submitted by Ilse D. Weinreich