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SCANDIATRANSPLANT  
COUNCIL OF REPRESENTATIVE'S MEETING  
MAY 10th, 2017, HELSINKI, FINLAND

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1) Welcome

Arno Nordin (Helsinki) wished everyone welcome.

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

Krister Höckerstedt (KH, Finland) was elected chairman of the meeting.

Lars Wennberg (LW, Stockholm) was elected writer of minutes.

Anne Varberg Reiseater (Oslo) and Margret Andresdottir (Iceland) were elected controllers of minutes.

KH concluded that the Representative's meeting had been duly summoned and the agenda was accepted. Kaj Anker Jørgensen (KAJ) added one announcement to "other issues".

3) Registration of the present representatives/substitutes/observers.

LW called all representatives and substitutes/alternates.

In the Scandiatriansplant (SCTP) Representative Council 2017, there are 34 votes totally distributed amongst 10 transplant centers (Helsinki 6, Stockholm 3, Uppsala 2, Skåne 2, Gothenburg 5, Oslo 7, Copenhagen 3, Odense 2, Aarhus 2 and Iceland 2).

At the meeting there were 25 delegates present (only 24 allowed to vote). No observer was present.

Helsinki: 6/6 present - 6 representatives (Isoniemi, Lempinen, Mäkisalo, Jalanko, Lemström, Lauronen) and 1 substitute (Helanterä, not allowed to vote).

Stockholm: 2/3 present - 2 representatives (Sölder Dahl, Gjertsen).

Uppsala: 2/2 present - 1 representative (Hellström) and 1 substitute (Sedigh).

Skåne: 1/2 present - 1 representative (Nilsson).

Gothenburg: 5/5 present - 3 representatives (Holgersson, Gäbel, Vestlund) and 1 substitute (Felldin). One representative (Lindnér) was represented by "power of attorney" (Gustafsson).

Oslo: 4/7 present – 3 representatives (Reisaeter, Naper, Holm) and 1 substitute (Hoel).

Copenhagen: 1/3 present – 1 representative (Sørensen).

Odense: 0/2 present

Aarhus: 2/2 present – 2 representatives (Ilkjær, Møldrup).

Reykjavik: 1/2 present – 1 representative (Andresdottir).

Present from the SCTP Board: Bo-Göran Ericzon (BGE, Chairman), Kaj Anker Jørgensen (Medical Director), Pål-Dag Line (PDL, Norway), Finn Gustafsson (Denmark), Arno Nordin (Finland), Runolfur Pálsson (RP; Iceland), Lars Wennberg (Sweden)

#### 4) Approval of minutes of last Council meeting May 11<sup>th</sup>, 2016, Stockholm.

Minutes from the meeting in Stockholm May 11<sup>th</sup>, 2016 (previously sent out to all representatives/substitutes) were approved.

#### 5) Chairman's report.

a) BGE gave a brief overview of the SCTP organization, purpose, and background.

b) BGE reported on SCTP activities since the previous meeting in Stockholm (2016) with special focus on contacts/meetings with the National Competent Authorities (CAs), a new system for SAE/SAR reporting and the Estonia issue. SCTPs upcoming system for SAE/SAR reporting was outlined briefly by LW. BGE had indicated to the CAs that the new reporting system would be active in October 2017. At present, there is a preliminary version of the new reporting system, but some computer programming remains to be done at the SCTP Office in Aarhus.

c) BGE showed a few slides on the transplantation activity in 2016. More information on SCTP activities is available at the SCTP web-page.

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

KAJ presented the status in obtaining data processor agreements with the 10 different

hospitals within SCTP. Of 10 agreements pending, 5 were signed (Helsinki, Iceland, Copenhagen, Aarhus, Odense). Regarding the remaining 5 agreements, the 4 Swedish centers were close to signing and discussions were ongoing in Oslo.

#### 7) Tool for reporting SAE/SAR.

Discussed under point 5

#### 8) Activities/News from Scandiatransplant Office.

KAJ presented Ilse Duus Weinreich report on SCTP Office activities regarding YASWA.

a) YASWA launched 2016, continuing improved with reports, quality controls, and changing fields.

b) NPRTSG incorporated in YASWA, organ offer form integrated in Deceased Donor menu, SMS and email notification of urgent patients introduced.

c) Work done with import/export of data.

d) Upcoming activities: STEP program, SAE/SAR system, Estonia/Tartu, revision of thorax and liver registry plus a lot of other minor projects.

c) More information on SCTP activities is available at the SCTP web-page

#### 9) Election of Board members and substitutes.

Pål-Dag Line from Oslo is leaving after 6 years on the Board. PDL presented Morten Hagness as the new Oslo representative and he was accepted by the representatives.

#### 10) Revision of Article 3 in the Articles (Composite graft added to article 3).

KAJ suggested a minor revision of Article 3, adding “composite grafts” to the list of organs SCTP deals with (previously sent out to all representatives/substitutes). This suggestion was accepted.

#### 11) Revision of Deceased Donors Death Causes .

RP presented the working groups suggestion for revised registration of deceased donor death causes in the SCTP database (previously sent out to all representatives/substitutes). After specifying "infections" as "CNS-infections", this suggestion was accepted.

#### 12) Acceptance of Tartu as an associate member of Scandiatransplant.

- a) BGE briefly summarized the background to the recent revision in the SCTP articles allowing associate members and the Board's evaluation of Tartu University Hospital following the application for associate membership in 2016.
- b) BGE presented the SCTP experience so far in collaborating with Estonia and Tartu University Hospital. In total, 68 organs have been imported from Estonia and 1 organ has been exported to Estonia.
- c) BGE presented the Board's recommendation (previously sent out to all representatives/substitutes) to accept Tartu University Hospital as associate members of SCTP.
- d) Tartu University Hospital was unanimously accepted as associate members of SCTP.
- e) Tartu was accepted as an associate member from May 10th 2017. However, some preparatory work (including computer programming and educational efforts) remains before Tartu can become active in SCTP (i.e. participate in SCTP organ exchange), this activation date will be set by the SCTP Board. From this date, all Estonian transplantations must be performed within SCTP and according to SCTP rules and regulations. No transplantations will be allowed in Estonia outside the SCTP collaboration.
- f) BGE explained that the only difference between associate members and full members of SCTP was that the former has no voting rights in the SCTP representative. Apart from this, associate members have the same rights and obligations as full members of SCTP. Associate members are entitled and expected, to participate in all SCTP activities and working groups and to follow all SCTP rules and regulations.

#### 13) Accounts and Budget.

KAJ presented the accounts for 2016 and the budget for 2017 and 2018 (previously sent out to all representatives/substitutes). After questions on increased costs for consultants, the accounts and budget were accepted. KAJ commented that some revisions to the budget may become necessary as a result of Tartu becoming an associate member.. There was no suggestion of changing the fee for transplantations, which therefore remain at 2600 DDK per patient transplanted.

#### 14) Report of activities from groups.

##### a) Transmission of Infectious Disease:

Vand Friman's email to the Board, describing a non-functional working group, was presented. She presented a suggestion regarding anti-HCV positive donors in the view of hepatitis C treatment. The last 2-3 years, she has had no response from the other members of the group. KH asked if the Council of Representative could instruct the Board to re-organize this working group and this suggestion was accepted.

##### b) NKG:

Søren Schwarz Sørensen (Copenhagen) presented the activities of NKG (well functioning import of clinical patient data from national renal registries, STEP, new clinical follow-up report recently published in Pediatric Transplantation, revision of NPRTSG forms finalized).

##### c) NLTG:

PDL (Oslo) presented the activities of NLTG (numbers, results, waiting times, changes in ROTA-list, exchange of splitable livers).

d) NTTSG: Are Martin Holm (Oslo) presented the activities of NTTSG (organ exchange with imports/exports, urgency listing, which had "normalized", post-tx mortality, DCD (Oslo), and the ScanCLAD study).

##### e) Tissue Typers group/STAMP:

Jouni Lauronen (Helsinki) presented the activities in TTG/STAMP (technical issues, results of STAMP, new acceptance criteria for STAMP with Transplantability score vs PRA%, and the group's publication in HLA).

##### f) NπTG:

Bengt Gustafsson (Göteborg) presented the activities of the NπTG. The 2 groups have merged to one group. They have 2 meetings per year. They discussed exchange recommendations, surgical procedures, common protocols, creating a follow up registry, and research.

g) NTCG: Ann-Christin Croon had become ill, so there was not given a report from the coordinators group.

15) Research and travel grants.

a) BGE showed a slide of the people, who had received the Travel Grant: Catarina Lindqvist (Stockholm), Selma Mariusdottir (Reykjavik), Fatma Bergquest (Göteborg) and Carl Jonas (Stockholm). A total of 142,571 DDK.

b) He then showed a slide of the recipients of the Research Grant: Bjarne K Møller (Århus) for "Epitope-mapping of Anti-HLA class I and II Antibodies in highly sensitized patients by machine learning", and Silvia Malenicka (Stockholm) for "Evaluation of vaccination practices in liver transplanted children in the Nordic countries". A total of 457,429 DDK.

16) Any other business.

BGE and KAJ thanked Pål-Dag Line for his work in the Board the last six years. His administrative skills have had a big impact on the changes the Association has gone through during these years. KAJ also complemented PDL on his knowledge in IT matters. PDL received a small gift as a reminder of all these years.

17) Next meeting (Oslo 2018 in connection with STS).

PDL welcomes everybody to the 29. Congress of the Scandinavian Transplant Society to be held at Radisson Blu Scandinavia, Oslo, 3-5 May, 2018. The next Council meeting will be held just before start of the Congress in the afternoon of May 3rd, 2018.

Lars Wennberg/Kaj Anker Jørgensen