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Board meeting No. 99 on 8th Dec. 2022

Minutes

Meeting No.: 99

Time: 8. Dec., 2022

Participants: The board of Scandiatransplant: CHAIRMAN: Allan Rasmussen, Copenhagen DENMARK: Michael Perch, Copenhagen

NORWAY: Pål-Dag Line participated instead of Morten Hagness, Oslo

SWEDEN: Johan Nilsson, Lund

FINLAND: Marko Lempinen, Helsinki

ESTONIA: Virge Pall, Tartu

DENMARK: Medical director:

Kai Jørgensen

Absent:

ICELAND: Jóhann Jónsson, Reykjavik

Leader of meeting: Allan Rasmussen

Writer of minutes: Kaj Anker Jørgensen

1. Welcome:

Allan Rasmussen bid everybody welcome to this first meeting where he was chairman. There was a special welcome for the new members: Michael Perch and Marko Lempinen

2. Issues for any other business:

Kaj had three issues he wanted the board to discuss, see point 9.

3. Minutes of last Board meeting: (http://www.scandiatransplant.org/about-

scandiatransplant/scandiatransplant-

board/Minutes Board No 98 30.Aug.2022 Reykjavik.pdf).

Minutes were accepted.

4. Status at the Office:

Kaj told that there had been many group meetings in this fall where Ilse and Anne had participated. The programmers were besides the usual work doing more work on removing Oracle to Postgresql.

On Oct. 27, 2022 there was a break down of the total network in Central Region Denmark. The reason was two fire walls competing, and it took seven hours before the network became stable again. Ilse sent a mail to all coordinators on duty to call her if there was something urgent. Our mail server is on a server outside the Central Region Denmark's IT-system. There was also put a message on the homepage, and also on Yaswa when it was accessible.

Kaj told that he had held a webinar on transnational transplantation cooperations for DTI, and this had led to an invitation to participate in a MENA conference in Abu Dhabi. In both cases he had presented how Scandiatransplant is organized and works, and there was quite a lot of interest on this, especially from countries like Pakistan, India, Egypt and Syria, but also from the Emirates.

5. Yearly check of "alive status" in Scandiatransplant database with the countries' person number registries:

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Such a yearly comparison of the alive status in Yaswa with the person number registries of the countries would be an improvement of the data quality in Yaswa. The office did it for Denmark in 2013 and found quite a number of patients who were alive in Yaswa, but really were dead. In Denmark it is a very simple thing to do this. All agreed that we should try to see if we can do this exercise every year, and that it would be an improvement of the data in Yaswa. The board members from Sweden, Finland and Estonia thought it would be quite simple to do this, and Pål-Dag also thought it would be possible in Norway. Kaj was authorized to try and find out if and how this can be done.

- 6. Further plans for Riga after Council meeting decision (WG follow-up attached):
 Kaj presented the text of the council meeting decision put in the further work on the
 Scandiatransplant board. He also went through the points from the follow-up of the work
 group. It was suggested to invite Are Martin Holm to the next board meeting and to take up
 this point at the next board meeting.
- 7. Better definition of the group "Prevention of transmission of infectious disease" in article 12?: (http://www.scandiatransplant.org/about-scandiatransplant/organisation/ARTICLESsigned amended2021May19 repr Helsinki.pdf.). Morten Hagness was ill and could not participate. He had asked to get this point postponed until next meeting. Kaj and Allan had discussed this and replied that we would take a short general discussion of the problem and not make any decisions at this meeting, and that specific questions and decisions would be taken at the next meeting. The board decided that there should be a new point in article 12 defining the mandates and the relation to the other groups in Scandiatransplant for this group. It was decided that when Morten was well enough, he and Kaj could work on a draft for this to present to the next board meeting.
- 8. Should Sctp Office be more active in inviting CA to see the Office?:

 It was emphasized that good relations to the CAs is very important and that we should keep this relationship at the level it is today. It would be OK and the board would support if the office invites the CAs of the country to come to Aarhus and be presented for what Scandiatransplant is and how it works. This question came up after two successful meetings with Socialstyrelsen from Sweden. The board thought that generally Scandiatransplant is well known, and we do not have to advertise more about Scandiatransplant, but if we are

invited to give a talk on what Scandiatransplant is, we should participate if possible.

9. Any other business:

A)

Kaj asked if we should have stated somewhere on the Scandiatransplant homepage that you can only be on one waiting list. The board decided that it should be so. Kaj was to find out where it was best to have it. The wording should be that you can only be on one waiting list for each organ.

B)

Kaj asked if Scandiatransplant should ask for documentation of accreditation for immunology and infection labs? This question had been raised from different sources and had been actualized in our discussion asking for such documentation in relation to accepting new members in Scandiatransplant. It was decided that Scandiatransplant office should ask the relevant laboratories for copies of their accreditations once a year.

C)

Case of misuse of Scandiatransplant. Kaj described a case of misuse of Scandiatransplant in the Swedish newspaper Dagens Nyheter. The board agreed that there was a clear case of misuse of the Scandiatransplant name and brand. The board was of the opinion that the damage had been done, and that the best would be that Scandiatransplant does not do

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anymore about this right now. Johan Nilsson explained to the board the background for the incident, and this is beyond the work of Scandiatransplant.

10. Next meeting:

- a. Two day face to face meeting March 16 & 17^{th} , 2023 in Aarhus.
- b. A ZOOM meeting January 26th, 2023 at 17:00 CET.