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Board meeting (Hybrid) No. 94 on 27th-28th Sept. 2021 at Huddinge

Minutes

Meeting No.: 94

Time: 27-28 Sept., 2021

Hybrid meeting: From Huddinge Hospital, Sweden

Participants: The BOARD of Scandiatransplant:

Present are:

CHAIRMAN: Bo-Göran Ericzon, Stockholm DENMARK: Allan Rasmussen, Copenhagen

NORWAY: Morten Hagness, Oslo

DIRECTOR:

Kaj Anker Jørgensen, Aarhus

Present online: The BOARD of Scandiatransplant:

SWEDEN: Johan Nilsson, Lund
FINLAND: Arno Nordin, Helsinki
ICELAND: Johann Jonsson, Reykjavik

ESTONIA: Virge Pall, Tartu

Leader of meeting: Bo-Göran Ericzon

Writer of minutes: Kaj Anker Jørgensen

Board meeting (Hybrid): Sept. 27th 16.00-18.00 and Sept. 28th 9.30-11.30 at Huddinge

1. Welcome:

Bo-Göran bid everybody welcome to this hybrid board meeting from Huddinge Hospital.

2. Issues for any other business:

Arno Nordin had a question if there should be a group for national transplant coordinators.

3. Minutes of last Board meeting (link):

Kaj went quickly through the minutes of the last board meeting including how the last council meeting went.

4. Status at the Office:

Kaj said that Covid-19 from Sept. 10th 2021 was not any longer considered a critical disease for society in Denmark and almost all internal restrictions have been relieved. The Scandiatransplant office is now back to work at the office, but people work from home on Tuesday and Thursday, because this has worked very fine. He told the board that Lorraine Mortensen has left the office, and we are thinking about how we can get a person to relieve llse of some of her work. Annie Susanne Sønder has gone down to work three days a week. Poul must submit his master thesis to the university this year. Then Kaj gave a short presentation of the status of incorporating more donor functionalities in YASWA (iSMaRT project). The conclusion was that we are approximately half way through and that the work will be done within the estimated time of one to one and a half year. Kaj then told the board about the challenge we have with Oslo. He started with pointing out how the legal situation was in 2012 when he became director and where the central region Denmark was the owner and the controller of the data. In 2014 a lawyer,

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Rasmus Grønborg Jakobsen, made a legal memorandum describing how transplant work and how it would function legally. Since then Kaj has been working on getting data processor agreements with all the hospitals, but this was difficult in Oslo, so on May 11th 2019 Kaj, Ilse and Bo went and discussed the problems with the IT-people and the technicians in Oslo. On Oct. 25th 2019, Morten T. Eriksen signed the data processor agreement for Oslo and we thought we had a plan on how to solve the problems. However, it turned out that Oslo could not participate in the STEP, because installation of a script to transfer FUSION results to YASWA was prohibited by somebody in Oslo. Since then we have had many questions from many different people which the Scandiatransplant office has tried to answer. The Scandiatransplant office wants these issues solved and wants Oslo to be able to participate in STEP, but Kaj is afraid that it is becoming a "never ending" story. It was decided to wait and see what happens with the last 60 questions that has been answered by the Scandiatransplant office. Morten told us that on October 8th the result of the evaluation will go from Sykehus Partner to the hospital IT-department and he really thinks that things will be solved before the next board meeting. It was decided that if things are not solved before the next board meeting, Scandiatransplant will request another meeting asking whoever is responsible for Oslo not being able to participate, to tell Scandiatransplant exactly why. We can then decide if we can meet the demands, or if Oslo cannot participate in STEP. Kaj then showed a short presentation of the results of transplantation and donation in the Scandiatransplant area for first six months from 2017 until 2021 to sort of see the impact of Covid-19 on transplantation in Scanddiatransplant as a whole. It seems like the living kidney donors did go down in 2020, but otherwise the diseased donors seem to be the same these six months for the last five years. In heart and lung transplantation there was a decrease in 2020 and it still persists in 2021. The liver and kidney transplantations seem quite unaffected through these five years. Kaj then went through the Covid registration and updates on the homepage and there are now 886 patients registered as Covid positive in Scandiatransplant and 100 have died. It seems that about 11% of the patients who have been infected die. Looking overall there was a great wave from April to July 2020 and then from November 2020 to May 2021, but then the number of new registrations have fallen. Kaj is of the opinion that only Sweden and Estonia have updated consequently, and we have learned that Sweden has stopped to register Covid in the Uremic register by July 1st this year. All the data are still in the database and updates can be retrieved at any time. Kaj therefore felt that these updates on the homepage do not have a great interest and it would be better to use the time on something else, and the board completely agreed on this. So we will stop updating the Covid figures on the homepage.

Donors and cancer:

A group under the Danish Transplantation Society had produced a document about evaluation of donors with cancer, and Kaj had been asked if Scandiatransplant was interested in this document. Allan Rasmussen told us about how the document came about and it was intended for Danish centers to be more alike when evaluating these donors. The document has not been put on the homepage of the Danish Transplantation Society yet. Scandiatransplant has on its homepage a link to the European Council's "Guide to Quality and Safety of Organs for Transplantation". There is a lot of work put into these quidelines and they can be downloaded so the board thinks we do not need one document more for the time being.

6. Board after 2022:

Kaj showed which board members and alternates are on election in 2022 and which ones can be reelected so that the people on the board can start looking for the ones to replace them. Bo-Göran Ericzon has to leave as chairman of Scandiatransplant in 2022, and he had at the last meeting asked people to contact him if there were candidates. A

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candidate who would be willing to take the job of chairman if there was support from the board was mentioned. Bo-Göran will look further into this matter. The replacement of the medical director was also discussed. This issue was also discussed on the board two to three years ago, and the board confirmed the formal conclusion that the medical director must be a person working in Aarhus. Kaj had had some talks with some people in Aarhus about this two years ago, and it was decided that he should talk to these people again and hear if the situation still is the same.

7. Status on STS 2022:

Jóhann Jónsson told us that they are working on arranging the meeting, it will be in the big congress center in Reykjavik from August 31st to September 2nd in 2022. A preliminary agenda for the meeting will be sent out within the next few weeks.

8. Status on WG Latvia/Lithuania:

Nobody in the board had heard from this group except from the very first mail from Are Martin Holm. It was decided that Kaj should ask Are if there was a need for any practical help from Scandiatransplant to move this issue forward.

9. NTC meeting (go through the agenda):

The board went through the agenda for the NTC meeting and went through a document on the subject of performing transplantations of refugees who do not have a permanent permission to stay in the country made by the Swedish Transplantation Society and which can be seen on their homepage. This document would be presented to health authorities next day.

10. Any Other Business:

Arno Nordin asked if there should be a group in Scandiatransplant for national donor coordinators. The board is of the opinion that this would be outside the scope of Scandiatransplant. It was suggested that they could be invited to NTC meeting.

11. Next Board Meeting (January 27th, 2022, Kastrup?):

It was decided that we should have a short online Zoom meeting on January 27th 2022 at 17:00 hrs. The board then agreed to really try to commit themselves to come to a face-to-face meeting 17th of March 2022 in Kastrup. This should be a whole day meeting. Another short board meeting in May just before the short online Council meeting was discussed, but we will wait to decide on this later.