

26. Oct. 2020

MINUTES OF MEETING

Meeting No: 25th virtual Zoom meeting of the Nordic Transplant Committee

Time: Oct. 6, 2020 at 13:00-15:00

Participants:

National Health Authority representatives:

Norway: Jorunn Svendsen, Øystein Flesland, Norwegian Directorate for Health
Tone Blørstad, Investigation Unit for Serious Adverse Events, Norwegian Board of Health Supervision

Finland: Arno Nordin

Sweden: Linda Savolainen, Socialstyrelsen
Pia Oscarsson, Health and Social Care Inspectorate (IVO)

Denmark: Maria Herlev Ahrenfeldt, Danish Health Authority
Ole Boye Fjord Terkelsen, Danish Patient Safety Authority

Iceland: Jóhann Jónsson

Estonia: Siim Suutre, State Agency of Medicines

Scandiatransplant board:

CHAIRMAN: Bo-Göran Ericzon, Stockholm

SWEDEN: Johan Nilsson, Lund

FINLAND: Arno Nordin

NORWAY: Morten Hagness, Oslo

ICELAND: Jóhann Jónsson, Reykjavik

DENMARK: Allan Rasmussen, Copenhagen

Invited associate member:

ESTONIA: Virge Pall, Tartu

Director of Scandiatransplant:

DENMARK: Kaj Anker Jørgensen, Aarhus (Kaj)

Agenda for NTC meeting (virtual) on 06.10.2020 at 13.00-15.00:

1. Welcome and presentation of each participant:

Bo-Göran bid everybody welcome and explained that the meeting should have been in Stockholm and it should have been the competent authority host who should bid welcome. However, since it was a virtual meeting, he bid welcome and said that it was the intention to have the next NTC meeting in Stockholm where we would continue the tradition. After that each participant in the meeting presented him/herself.

2. Election of leader of meeting and writer of minutes:

Bo-Göran suggested Kaj as leader of the meeting because he was the host of the Zoom and also the writer of minutes since Kaj was recording the whole meeting.

3. Minutes of last meeting (24th; 03.10.2019 Oslo):

http://www.scandiatransplant.org/members/ntc/MINUTES_NordicTransplantCommitteemeeting_2019Oct3_Oslo.pdf

Kaj then showed and went through the minutes of the last meeting which was in Oslo on 3rd of Oct. 2019. The minutes were accepted.

4. Additional issues for the agenda:

Bo-Göran had an issue of transplanting foreigners who were not accepted as refugees in a country. Kaj had an issue on using the Scandiatransplant IT-system for registries.

5. Presentation: Scandiatransplant and COVID-19:

Kaj then showed a presentation he had prepared and which had been sent out beforehand of what Scandiatransplant had done in relation to the Covid-19 and efforts to try to see what impact Covid-19 had had on transplantation and organ donation. The conclusion was that the total impact on organ donation and transplantation in the Scandiatransplant countries had been small. There seems to have been a small decrease in deceased donor donation and transplantation in April, but in most cases the total effect this year compared to previous years has been very small. Some transplanted patients had been diagnosed with Covid-19 and a few of these patients have died mainly in Sweden until now. This was followed by a discussion of why the impact of Covid in Scandiatransplant had been so little while it has been so great in many of the other European countries.

6. What has happened in the last 12 months in each country:

a. Competent authorities: Main transplantation and administrative issues:

Norway: Jorunn Svendsen told that the DCD project in Norway is still paused after the high level expert group had published their evaluation. The deadline for consultation input to this was delayed by Covid-19 to September 15th. The regional health authorities have now ordered a compilation of the many consultation inputs, then this will go back to the regional authorities for further decision. She told that the Norwegian directorate of health is following the process closely, and ready to contribute to further standardization for the method of review. Then Tone Blørstad showed a PowerPoint presentation where she showed how Norway is divided into regions and that each region has its regional health authority. The issue of organ donation lies within the regional health authorities who must ensure that all potential donors can be evaluated and given the opportunity for donation. Due to Covid-19 there had not been inspections in the regions, but there had been desk-based reviews to verify that regional health authorities are compliant with EU and national legislation for their activities. They are looking to the material they have received to ensure that the regional authorities fulfill their obligations.

Finland: Arno Nordin told us that the new law passed last year is working well and they now have both altruistic donors and have living donors that are now closely related so they can go into for example the STEP programme. He also told us that the national coordinator has been working very well and has been a big success. He also asked if it was a problem that after the Covid-19 many small air fields were closed in Finland. The discussion revealed that this is happening in some countries, but that the transplant centers until now are successful in working around this problem.

Sweden: Linda Savolainen, who participated in the NTC-meeting for the first time, had prepared a presentation, but we could not get it to work on the Zoom, so the presentation was given orally. She told about the

NDC which is the center that she is working at in Socialstyrelsen. They have the responsibility to support national donation and transplantation questions, and also for information to the public. They have the responsibility for the donation registry and they must facilitate the public so they can make their wishes to donation known. The goal in Sweden for organ and tissue donation is to match the need. They want to have a national follow-up of the known donation process. They also want to have a continuous high will to donate in the Swedish population. They have a cooperation with many national and international organisations. They have a lot of projects which she had listed in the presentation which we could not see, but she told us that they are producing guidelines which are based a lot on advice from ECDC. They can be seen on their website. There is a project of increased donation in children, and a project on living donation. A new communication strategy will be launched very soon where they hope it will be seen by a lot of people. It is mostly directed to the age group 25-40 because this is the age group that is willing to donate but really haven't told their relatives or registered in the donation registry. They are also working on making it legal to give treatment directed against donation before and after death. And a veto of next of kin is to be removed. They believe it will be in effect by July 1st 2021. The DCD project has finished. It was successful. It is now up to the hospitals to start doing DCD.

Pia Oscarsson then told us that the planned inspections on organ donation centers this year have not been possible due to Covid. They have inspected the blood and tissue via video conferences. They hope to have the inspections next year.

Denmark: Maria Ahrenfeldt told us that the working group to make specific recommendations for DCD has had two meetings, they have of course been delayed by the Covid-19 situation. She hopes that the working group will finalise their work in November this year, so that it can go to the public hearing. The hope is that the big university hospitals can perform DCD in 2021. At the same time as the public hearing, they are planning to make a public information campaign on donation in general but with special focus on DCD.

Ole Terkelsen told us that the Covid-situation had made it impossible to make inspections during the lockdown and after the lockdown, the Danish Patient Safety Authority has been fully employed in contact tracing and advising other authorities.

Iceland: Jóhann Jónsson told us that the opt out law that had been passed in Iceland on January 1st 2019 has until now not had an effect on donation. They hope that in the long run it will make a change. The preparation for DCD has been slowed down by Covid and really nothing has changed the last year. While they had been doing living donor kidney transplantation in Iceland since 2003, it was not until this year that they have done their first deceased donor kidney transplantation in cooperation with the donor retrieval team from Gothenburg.

Estonia: Siim Suutre told us that inspections had been postponed due to Covid-19, but they are starting again. He explained the way inspections are organised in Estonia and they are trying to map their responsibilities so the different authorities do not overlap too much when doing

inspections. He feels the SAE/SAR reporting is working OK for the initial reports and they are contacting the hospitals when they need follow up information.

Virge Pall told us that closing of airports especially in the evening and very few commercial flights have been a big problem for organ sharing. She also told us that in the beginning of the year before the Covid situation they had a campaign aimed at everybody and all the country to increase donation, and this has already been a success.

b. Board members: supplementary information:

No further comments.

7. Data Processor Agreements:

Oslo has now signed a data processor agreement, and we now have a data processor agreement with all centers.

8. SAE/SAR reports:

Kaj then went through the four reports that have come before September 1st. There was a report on packing routines for kidneys not being followed, but Kaj has learned that another procedure was followed because the kidney was too large to be put into the normal containers. Kaj also said that he feels the reporting is working well so he will not put it on the agenda next year.

Pia Oscarsson said that she has got reports from Malmö which have not been reported through the Scandiatransplant system, so she asked if we have discussed in the transplant community to use other ways of reporting. Kaj responded that the reporting system in the Scandiatransplant IT-system is a help and a tool for the doctors to report, but they can of course report any way they want. Bo-Göran Ericzon told us that this whole reporting system was started because the clinicians wanted us to do it.

Arno also told us that the organ groups really are going through what happens in other centers and they discuss this, especially in the liver group.

Pia Oscarsson also said that there had been a report which was reported a couple of months after the event. Kaj could not give any answer to this question, it is up to the reporting doctor to send the report. Maybe they just found out that it was an SAE two months later, or there may be another cause, but otherwise Kaj could not answer that question.

9. Any other business:

1. Bo-Göran brought up the question about transplanting refugees who have not got a permanent permission to stay in the country. He asked if there could be some guidelines that were the same in all the centers or else it could affect organ sharing if some centers were more liberal than other centers.

Allan Rasmussen commented that in Denmark we had asked the authorities and ministry about this. The answer was very clear that if you need a life saving procedure you will get it in Denmark even if this will influence the decision of giving them a permanent stay. The grey zone is people with chronic disease where you can postpone the transplantation.

Arno Nordin commented that basically you cannot transplant a patient if you are not sure that they can get the services needed for the rest of their life time.

Bo-Göran also commented that this has also a lot to do with transplant tourism.

Jóhan Nilsson told that they have discussed this over two years and have made a document with ten points on this. This should be published within two weeks. They are translating this document to English and he would send it to the participants of this meeting. This problem has been discussed in the EU and the European Council but there is no consensus. It has also been discussed in Sweden, and Linda Savolainen asks people to e-mail her if they know of good lawyers at the other competent authorities with whom you can discuss this question. Bo-Göran suggested that we bring this up and have it as a point on the agenda to the next NTC meeting.

Then Kaj pointed out that we have the Scandiatransplant IT-system registering data regarding

transplantation. Kaj just pointed out that he wanted people to know that the system is there and it can be a registry for any country or center that they want. He asks people to think about this when they are planning a working on new registries.

10. Next meeting (Stockholm Oct. 5th 2021?):

It was decided that the next meeting would be September 28th 2021 at 13:00 in Stockholm.