

Nordic Transplant Committee

Nordic Transplant Committee / Minutes meeting No. 27 Sept. 31st 2022 Hybrid meeting

19th Sept. 2022

Minutes of meeting

Meeting No: 27th – Hybrid meeting of the Nordic Transplant Committee

Time: August 31st, 2022 at 10:00-12:00

Participants:

National Health Authority representatives:

Norway: Online - Jorunn Svendsen & Sigrid Beitland, Norwegian Directorate for Health
Tone Blørstad, Norwegian Board of Health Supervision

Sweden: Online - Helena Almen, The National Board of Health and Welfare

Denmark: Present - Maria Herlev Ahrenfeldt & Marie-Louise Kirkegaard Mikkelsen, Danish
Health Authority
Online - Helle Haubro Andersen, Danish Center for Organ Donation

Estonia: Online - Siim Suutre, State Agency of Medicines

Iceland: Present - Thorgunnur Hjaltadottir, Directorate of Health

The board of Scandiatransplant

Present - Bo-Göran Ericzon, Stockholm
Present - Arno Nordin, Helsinki
Present - Johan Nilsson, Lund
Present - Morten Hagness, Oslo
Present - Jóhann Jónsson, Reykjavik
Present - Virge Pall, Tartu, Estonia
Excused - Allan Rasmussen, Copenhagen

Present - Medical Director Kaj Anker Jørgensen

Minutes of the Nordic Transplant Committee meeting 31.08.2022 at 10:00-12:00

Hybrid meeting at the Directorate of Health, Katrínartún 2, 105 Reykjavík, Iceland.

AGENDA:

1. Welcome – presentation of participants:

Alma Möller, Director of Health in Iceland, gave us a warm welcome to the meeting followed by a welcome from Thorgunnur Hjaltadottir. All participants then presented themselves.

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

Bo-Göran Ericzon was elected as leader of the meeting, and Kaj Jørgensen as writer of minutes.

3. Minutes of last meeting:

Kaj then quickly scrolled the minutes of the last meeting and the minutes were accepted.

4. Issues for “any other business”:

No other issues

5. What has happened in each country:

Iceland:

Thorgunnur Hjaltadóttir: The first of January 2019 we changed the Icelandic legislation on organ donation by which informed consent was replaced by presumed consent. Now we have had three full years of experience with the new law. In general, the new legislation has been well received. Around 1% of the population has registered a refusal of organ donation. Our legislation demands that hospital staff obtain permission from the next of kin when the wish of the deceased person regarding donation is unknown. This means that we must confer with the family in all cases, and it is difficult to see us donate organs from a deceased person against the will of the family.

The pandemic appears to have had a negative impact on the organ donation rate in 2020 as there were unusually few potential donors, resulting in a drop in the donation rate to 11 per million population. But COVID-19 did not influence our transplant activities very much in 2021. Although large waves of the pandemic did certainly place a heavy burden on our health care workers, including the members of the transplant team, a significant disruption of our services did not occur. In 2021 Iceland had 11 utilized donors, it is a donation rate of 29,35 which is the second-best year since the agreement was signed. A total of 35 organs could be collected for transplantation from Icelandic donors, which corresponds to 3,18 organs per donor. This is an increase from the previous year when 3 organs per donor were utilized. All three hospitals in Iceland which participate in the program, identified and enabled donation in 2021 (Fossvogur (8), Hringbraut (2) and Akureyri (1)). The collaboration on kidney transplantation with a deceased donor in Iceland has continued to develop, which is positive for patients in Iceland who can be cared for closer to home. According to Runólfur Pálsson in the National hospital of Iceland, sustaining our successful organ transplant services will be a challenge in the coming years. We must find a way to secure the future of our kidney transplantation program, where staffing will continue to be a challenge, just as elsewhere in the health service, and another important aim is to establish a donation after cardiac death program at Landspítali–The National University Hospital, in collaboration with the Sahlgrenska University Hospital.

Johann Jonsson described the excellent cooperation with Gothenburg, where they leave one or 2 kidneys behind for transplantation in Iceland. This is a huge benefit for the patient and for the economy.

Norway:

Jorunn Svendsen gave brief information on the Circular on the donation of organs, cells and tissues from a deceased donor.

Due to the introduction and use of the cDCD method in Norway, The Directorate of Health has prepared a new Circular on the donation of organs, cells and tissues from a deceased donor. The circular is published at www.helsedirektoratet.no.

The background for this elaboration was to provide clearer guidance on whether it is in line with current regulations to use the cDCD method.

The circular provides summarized information on the donation of organs, cells and tissues from a deceased donor, and specifically mentions the donation process, approval of donor hospitals and general requirements for the organization of donor hospitals. The circular complements and also provides comments on laws and regulations.

It does not provide new professional or legal guidance, but:

- Clarifies the legal basis for organ donation from a deceased donor
- It complements and provides comments on the Transplantation Act and regulations on the definition of death.
- Several issues are mentioned about DBD and cDCD and it is made clear that both donation processes are legal.

Morten Hagness was worried about a tendency to a declined donor rate in Norway and they were trying to find the reason for this. The DCD is up and running, but he does not think this has any relation to the declining donor rate. Norway is now participating in STEP.

Denmark:

Marie-Louise Kirkegaard Mikkelsen: Ole Terkelsen from the Danish Patient Safety Authority was not able to attend the meeting. Regarding the inspections, the situation is the same as he said at the last meeting, that they are not doing any ordinary routine inspections at this moment.

At the last meeting, Maria informed that we were primarily working on two things - DCD and the differences in waiting times for kidney transplantation across the Danish regions.

On the last meeting we said that we expected DCD to be implemented in 2022. We have been further delayed, but the DCD report seems to finally be almost finished. This means that we can hopefully publish the report for review and public hearing this autumn and start implementing in 2023.

The work on the waiting times for kidney transplantation has been delayed due to other tasks, but we expect to finish it this year. It will basically just be a report describing the situation thoroughly. We don't know yet if we need to do anything about the situation, but as Kaj said last year, the region that previously had low donation, rates are going up and vice versa, so we don't expect that we will do anything right now, but just wait and see. A lot of things have already been implemented at the hospitals so we would rather support those things.

Currently there are some political discussions happening about consent forms. Two new models have been proposed - one is an opt-out or presumed consent model and the other is a mandated choice model, meaning that people will have to register in the organ donor register when for example getting their driver's license or a new passport.

The political negotiations will be happening this fall. However, there is a possibility that there will be a governmental election soon. If the prime minister calls for an election, everything will be paused until a new government is formed.

Helle Haubro Andersen: She is looking forward to DCD and the model for consent. The increase in the donation rate in Denmark is probably because of the work in the hospitals.

Sweden: Helena Almen told us that Covid had not decreased the donation, it had actually increased. DCD had increased fast and 25% were donors this year and it seems like this has not had any impact of the DBD donors. They were promoting pediatric donation with knowledge support and national guidelines. There were government amendments to the Transplantation Act in July 2022 giving clearer rules concerning how continued intensive care may be provided to make more donations possible. – The relatives' veto has been removed. Instead, it is the individual's position on donation that will be decisive. The relatives remain an important source of information. – Incapacitated adults are exempted as they have not been able to make their own decisions concerning the issue of donation. – If it emerges during the investigation of willingness to donate that the patient does not want to donate organs, the intensive care interventions will be stopped. If the patient does want to donate organs, the organ-preserving treatment may continue for up to 72 hours. If there is a willingness to donate, investigations are also conducted to determine if the patient is medically suitable for a donation. – It is only intensive care interventions that cannot wait until after death that may be given, and these may not cause more than negligible pain or negligible injury. And care for the patient's own sake always comes before the organ-preserving treatment. By September 1st there was a new regulation on death by neurological criteria. From December 2022 they had got an assignment to investigate obstacles for organ donation in Sweden.

Finland:

Arno Nordin: CA's from FIMEA have been auditing the donor hospitals during the previous years so that all university hospitals have been audited 3 times, and other hospitals at least once, the second round is going. The transplantation unit has also been audited last winter, and passed with minor changes in recording rules, and some guidelines and reports.

Last year 2021 was the second best in transplantation figures, altogether 420 transplantations of which 24 were for children. The number of donors (DBD) were 119, 72% were multiorgan donors, mean age was 59 yrs (10 – 84).

DCDD pilot program started in autumn and the number of these donations reached ten in the beginning of 2022, we have the license to continue, so now 11 DCDD's have been done.

Seventy five liver transplantations were performed 2021, pancreas transplantations 31, hearts 22 and lungs 24. The year 2022 started almost at similar rate or speed, but quite soon the donation

rate decreased slightly, perhaps because of still ongoing pandemic, the nurse strike and decreasing resources in many intensive care units due to the resigning nurses. At the end of August, the donor number was 76, some 172 kidneys were transplanted, which may end in less total numbers than in year 2021. There is a trend that the proportion of DCDD and living donation may become high, almost 20 – 30% of all donations. This should end in much higher total number of donations, but that does not seem to be the situation. On the contrary, proportion of DBD donations may be less than in former years, and that is a prediction which should be addressed during the end of the year. So far DCDD donors are only kidney donors. In the future we will be prepared to include also other organs, but so far for example liver transplantation program is running well without DCDD donated livers. We are with the STEP program now.

Estonia,:

Siim Suutre:

- Inspection to a procurement hospital – North-Estonia Medical Centre in February 2022. North-Estonia Medical Centre has a close cooperation with Helsinki University Hospital on heart transplantations.
- We continue to follow the ECDC, professional societies and Scandiatransplant COVID-19 guidelines of donor selection. There have been talks about ECDC updating their guide “Coronavirus disease 2019 (COVID-19) and supply of substances of human origin in the EU/EEA”, but this has not happened yet.
- In February European Commission sent a survey on the implementation of the Organs Directive (Directive 2010/53/EU), covering the period 2015-2021. That was completed by State Agency of Medicines with the help of Tartu University Hospital. The main changes for Estonia were related to new legislation and joining Scandiatransplant.
- In April there was an urgent request for information on liver transplants in children of 16 years or under from ECDC. Tartu University Hospital answered to that.
- ECDC is in the process of establishing a new public health expert network, SoHONet (Network for the Microbial Safety of Substances of Human Origin). National Focal Points established for blood, tissues and cells, medically assisted reproduction, and organs. Estonia’s national focal point for organs is Tartu University Hospital.

6. Ukraine refugees:

Kaj informed that the Scandiatransplant Board has discussed the issue of transplanting Ukraine refugees. It was agreed that these would be treated like other citizens of the scandiatransplant countries if the legal issues were clarified. We would not consider that as transplant tourism.

7. SAE/SAR questionnaire to EU-COM

Kaj offered to help the CAs with these questionnaires.

8. ESOT registries from EU

Scandiatransplant will still prioritize getting our registries to be better and hesitate to get involved in these projects.

9. Update on STEP

Kaj gave a short update on the STEP program in which 47 patients have been transplanted since it became a Scandiatransplant project. It is much work to prepare the patient and donors for the STEP and about a great deal of the cycles/chains are broken.

10. Any other business: None

11. Next NTC meeting October 4th 2023 in Copenhagen.