

Minutes - STEP-steering committee meeting 2022-04-22

Participants: Karin Skov, Per Lindner, Ilse Duus Weinreich, Ilkka Helanterä, Tommy Andersson, Poul Kruse-Hansen, Helle Bruunsgaard

Remotely: Külli Kõlvald, Mats Bengtsson, Lars Wennberg, Jouni Lauronen, Line Boulland, Margrét B. Andrésdóttir

1. Results

Per presented the results from the patients that have participated in the program, resulting in matching frequency close to almost 50 % and a total 50 patients transplanted including the first Swedish exchanges.

2. Publication of our program

We agreed that we think there is an interest to publish data. Per will make the first draft and share it with Helle, Ilse, Ilkka and Karin. There might be a need from the ethical committees to approve the study, one approval in Sweden and one in Denmark (Per's comment).

An add-on study could be a qoL-study utilizing RAND-36.

3. Discussion of issues that have occurred 2020-2021

4. Revision of the guidelines

Per, Karin and Ilse will make a suggestion for a revised version. Eventually include a suggested maximal age difference between 20-35 years, which has to be further discussed.

5. Revision of patient information

An update and revision needs to be made. Karin Skov will make the first draft.

6. Changes in the algorithm?

Simulations must be done before any changes can be made. The Scandiatransplant office will work on 3 different simulations that focus on

- Transplantability score
- Number of match runs
- Nested 2-ways

An online meeting will be held in October to look at and evaluate the results, so that any concrete suggestions can be brought forward at the NKG meeting 16th of November 2022.

7. Increase the population, can we do anything?

Working hard on getting Norway on board. It is important that we optimise within Scandiatransplant before we start to look for other possible cooperation.

8. Other items

- a. During the STS-meeting we should try to meet Frans Claas to discuss the Dutch experience
- b. It is possible to participate in both STAMP and STEP, but when the patient gets a match in STEP he will be temporarily withdrawn from the general waiting list including STAMP..

9. Split function

There is an interest from the Danish centers that all donors should undergo preoperative split function. From the Swedish centers it was argued that this is mainly done for the safety of the donor and therefore it is up to the donor center

itself to judge if this is necessary. As this is not done at any center in Sweden the Swedish centers were not sure that the method is available in Sweden.

Finally we thanked professor Tommy Andersson for his contribution to the program with a STEP-medal.

2022-07-28 Per Lindnér