Scandiatransplant

Annual Meeting 2023

November 21th,

Arlanda, Stockholm 10:30-15.30

Minutes

Host:

Lars Wennberg

1.Welcome

Lars Wennberg opened the meeting.

2. Election of the writer of the minutes

Anna Bjerre was approved to write the minutes of the meeting

3. Approval of previous meeting's minutes

The minutes from the last meeting (Helsinki (online) October 13, 2021) were approved.

4. Presentation of participants:

Denmark: Søren Sørensen-Schwartz, Ida Maria Schmidt, Line Mortensen

Estonia: Inga Vainumäe

Finland: Timo Jahnukainen

Norway: Anna Bjerre, Ann Christin Gjerstad

Sweden: Zivile Bekassy, Helena Genberg, Mia Herthelius, Peter Barany, Åsa Norén, Tobias Axelsson, Mia Dursun, Marie Tranäng, Lars Wennberg, Marita Blad, Amir Sedigh, Charlotte Dahlberg

5. Election of National Key Persons

Ann Christin Gjerstad replaces Anna Bjerre as key person in Norway.

National key persons 2023-2024

Denmark - Helle Thiesson
Estonia - Inga Vainumäe
Finland - Timo Jahnukainen
Iceland - Vidar Edvardsson
Norway – Ann Christin Gjerstad
Sweden - Lars Wennberg

NKG- represented by Søren Schwartz Sørensen

6. Annual Registry report – Søren Schwartz, Copenhagen and Anders Åsberg, Oslo.

Søren S, Copenhagen and Anders Å, Oslo, have gone through the data from the registry (1995 - 2020 and 2011 - 2020). The data are quite stable.

There was a discussion concerning and rules for exchange and allocations: Helena Genberg , Åsa Norén and Amir Sedigh wil form a working group on this.

7. Status of ERN Transplant Child and PETER Registry - Lars Wennberg, Marie Tranäng

The number of Transplant Child centers is still increasing. There is now a formal division in different regional groups and the Scandinavian group (Group 1) is the same as the area covering Scandiatransplant and as a consequence NPRTSG. Lars Wennberg is the leader of Group 1.

The PETER registry is quite extensive with basal data and FU data at 3-6-12 months. This is also time consuming and with no local technical support.

There are many overlaps with the NPRTSG registry data.

PedsQoL data will also be collected which is much welcomed.

8. Infections after pediatric RTx - Helena Genberg, (Felicia Kjærnet)

During the work with the ABOitx study, with a total data on 392 patients, data on infections were also retrieved. Overall, 61% had any kind of infection with an equal amount of bacterial vs viral infections.

GI infections were most common, followed by pneumonia and UTI in 26%.

Young age was a risk factor.

At 1 year: Bacterial infections, often as UTIs (E. coli as the most common cause) was seen in 24%, and viral infections in 20%.

Concerning CMV, EBv and BK virus was seen in 3.1,3.6 and 1.8% and at 92, 97 and 107 days, resp.

9. EBV infection after rituximab treatment - Helena Genberg, (Felicia Kjærnet)

In ABOitx a single dose of rituximab is given. In these patients, no EBv infections were seen. There was a discussion on the general preemptive use of Rituximab. The retrospective study though, documented an increase in CMV infections, overall 26%. Most centers have a protocol with Valcyte prophylaxis in CMV D+/R- patients. In Norway, the prophylaxis will now be removed. The reason for this, significant increase in severe CMV infections.
A discussion was also on this and the length on any prophylaxis. Perhaps a prospective study on this?

10. Re-transplantation in patients with BK-and/or EBV-infections
Was not debated

11. Update on NPRSTG study on changes in immunosuppression - Timo Jahnukainen
Henna Kaijansinkko is working on the project "Changes in immunosuppressive medication after kidney transplantation - preliminary results" – project. The data was presented as an oral poster at the ESPN meeting in Amsterdam September 2021. More data has now emerged: There is an increase in the use of both tacrolimus and MMF. Of patients on CyA, 50% of them have now changed to tacrolimus. The effect were less cosmetic side effects and a slower decline in GFR. No statistical data to see any effect on PTLD. The results are prepared to be published.

12. MMF vs AZA in pediatric RTx - Helena Genberg
Overtime, MMF has replaced AZA as one of the cornerstones in IS. The consequences registered are an increase in urosepsis and Gi side effects. Most agreed on that MMF have several side effects and affects both on the GI system and the bone marrow.
A concern of AZA are the dermatological side effects

13. Surgical complications after pediatric RTx - Helena Genberg, (Felicia Kjærnet)
Concerning surgical complications they were divided in < 3 months post tx and at 1 year posttx.
The smallest children were the most vulnerable to complications at a risk of 33% vs 13% when > 40 kg.
There were surgical complications early on of 18.7%.
In general, when surgical complications occurred, there were no difference in GS.
Though, if vascular complications, GS was reduced.
At most centers, a recipient age of 12 kg was required.
A discussion on looking more thoroughly into this was proposed.

14. RTx in highly immunized pediatric patients in SCTP - Lars Wennberg

a. waiting lists: very few patients on the waiting lists; 1-2 per center

b. few centers had formal protocols on highly sensitized children. Some have tried PE , Riuxiamb and IvIG. Overall few children have this problem

c. STEP in pediatric RTx including altruistic donation

Lars Wennberg informed about this option, which is not, so far, extensively used in children. With the STEP program also introduced in pediatrics, more recipients can be transplanted. A win-win situation for all.

d. Desensitization with imlifidase in pediatric RTX

15. New study proposals -

Ann Christin Gjerstad had a short presentation of an ongoing Norwegian retrospective study on PTLD in all SOT recipients. A proposal on extending this to the rest of the Nordic country was raised. This was met with enthusiasm and all member countries attending wished to participate.

16. How to use the NPRTSG registry

No formal discussion this, though many suggestions for more studies as mentioned in this report.

17. Any other business?

A discussion was on increasing the age limit from 16 to 18 years in the NPRTSG Registry as most pediatric department now have patients up to 18 years (and even more). The general agreement was that this is a good idea. A suggestion of this should be proposed to Ilse.

18. Next meeting

The next meeting will be organized by Denmark; November 19, 2024. Helle Thiesson (national key person) and Ida Maria Schmidt will announce place and program.

Thank you all for an excellent meeting and interesting discussions!