

Minutes NπTG

Zoom meeting February 4th, 2021

1. Welcome to all (see list of participants below) (BG).
2. Approval of agenda.
 - a. Minor corrections have been made to [Guidelines for the Nordic Pancreas and Islet group](#)
 - b. The agenda was then approved
3. Election of chairman and secretary for the meeting
 - a. Bengt G as chairman for the meeting
 - b. Hanne S as secretary for the meeting
4. Last minutes [NπTG meeting 7th of October 2019](#)
 - a. Approved
5. Update of activities (all centers)
 - a. Oslo (Kristine F): 1 PTA (intervention with stent of the artery and vein due to rejection?), 5 SPK (one reoperation due to bleeding, two thrombosis in the splenic vein but treated with anti-coagulation), 2IA (blood transfusion).
Waiting list: 1 IA, 10 Pancreas (5 SPK+ 5 re-transplant PTA)
 - b. Stockholm (Johan): No TX in spring. From July: 6 SPK, 1 PTA, 1 ITA.
 - c. Helsinki (Marco L): No TX in spring. 26 SPK (one failure due to pancreatitis/infection), changed the protocol to start using somatostatin analog.
 - d. Estland (Marko M): 6 SPK, 1 PAK. One serious venous thrombosis led to loss of graft.
 - e. Copenhagen (Paul): 7 SPK (two loss of grafts due to venous thrombosis, and one due to leak of duodenum).
 - f. Gothenburg (Bengt): 2 SPK, 1 re-transplant of previously SPK with a new PTA, working on getting IAK on waiting list.
 - g. Uppsala (Amir): No pancreas last year, 4 ITA (re-transplant)
6. Waiting list and allocation/exchange 2019-2020 (Ilse D)
 - a. Presentation is attached. Briefly, Ilse presented the annual entries on pancreas waiting list (incl kidney-pancreas), activities, import/export of pancreas. Helsinki impress with 39 pancreas transplants in 2019. Entrance of the patients on waiting list for islets is decreasing followed by decreasing islet transplantation.
7. Experiences of Covid-19 (all) briefly presented
 - a. Sweden transplant experience: Mortality rate on 9.6 (lower than expected), risk factors seems to be the same in the transplant cohort compare to general population. Dialysis patients is worse than transplant patients.
 - b. Norway experience: 18 cases in kidney transplant-4 died, 9 cases on dialysis-3 died.
 - c. Denmark experience: Three Rituximab related dead (LD kidney recipients. One shortly after transplantation, two more than a year after)
 - d. Helsinki experience: 17 HD, 1 PD 17 kidney tx. 3 have died, I do not know if they were tx or dialysis patients
8. Spinal problems in relation to pancreas tx (Johan N, Stockholm)

- a. UK has shown 6 cases the last 10 years at the EPITA (Igl) winter meeting (risk 1: 400). Second case has appeared in Stockholm. Johan presented the case. Torbjörn can share the presentation with details for those who is interested. The case is still under investigation but it seems to be related to the epidural. Due this they have stopped using EDA per/per-op. Only EDA post-op if needed. Helsinki (Marko) do not normally use EDA. Olle: Read the UK paper (attached), and we can have discussion later how to inform the risk to the patients.
9. Video pancreas/islets (BvZM)
 - a. Uppsala have recorded patients' story (one islet transplant and one pancreas transplant) who has been very effective in communicate the beta cell, replacement procedure and what to expect (both for possible patients and endocrinologists).
 - b. Oslo have made a pool of transplanted patients that volunteers to be contacted by patients that are recruited on the waiting list.

ACTION: Contact Uppsala (Amir, Tim, Anna) if members of your group wants to use these videos to present at meetings (to ensure informed consent)

10. Follow-up registry (Ilse D, TL)- Yearly update
 - a. Pancreas pre tx data entry 2018-2020. Good data entry by Helsinki (87%) and Malmö (94%). Oslo, Gothenb., Stockh., Tartu and Uppsala have not entered data.
 - b. Tx data entry 2018-2020. Good data entry by Helsinki (99%), Copenh. (89%) and Malmö (100%). Oslo, Gothenb., Stockh. and Tartu have not entered data.
 - c. Data entry for pancreas follow up (manually inserted by user). A lot of follow up entries by Helsinki and some by Tartu and Copenh.
It is suggested that follow up data is entered yearly

ACTION: All centers need to add in their data.

11. Databases - Scandia, NIR, NICS (TL)

ACTION: Ilse will together with Torbjörn look into the possibility of incorporating the NIR (islet registry) into the Scandiatransplant database. If so, it would make ownership of the data clearer and solve some ongoing regulatory discussions. The group approved this action.

12. Agreement between Scandiatransplant and islets labs in Uppsala and Oslo (OK, HS)
 - a. Regulatory bodies will need a written support document for the donor procurement-isolation-distribution islet activity in this group.

ACTION: The group discussed how to move forward with the task and agree that Olle Torbjörn, and Hanne will write a suggestion for such agreement and discuss with Scandiatransplant.

13. Projects/studies

- a. Uppsala/Stockholm: Autologous T-regs in allo ITA is done, 5 patients in total transplanted. No severe side effects. Good function of the grafts. Plan to publish this spring
- b. LMW-DS (IBSolvMIR) NNCIT_02 study. Participating centers: Stockholm/Uppsala/Gothenburg/Oslo
All good to start in Uppsala and Stockholm. Gothenburg and Oslo later this spring

14. Election of new chair

Torbjörn Lundgren, Stockholm as new chairman and Hanne Scholz, Oslo as co-chair.
We thank Bengt G for his excellent service as chairman for the group.

15. Please send updates to the e-mail/group list on e-mail to Torbjörn, Hanne and Ilse.

Next meeting

ACTION: Islet-specific meeting in March/April (Zoom meeting 25.03.21- invitation will come). Next NπTG October 19th 2021 (Face to Face at Arlanda) (dates were set after the meeting)

Meeting participants:

Paul Krohn, Copenhagen
Carina Lund Sørensen, Copenhagen
Bengt Gustafsson, Gothenburg
John Söfteland, Gothenburg
Marcus Lind, Gothenburg
Marko Lempinen, Helsinki
Hanne Bjørnson Scholz, Oslo
Kristine Lyck Fasting, Oslo
Monika Olofsson Storrø, Oslo
Trond Geir Jenssen, Oslo
Johan Nordström, Stockholm
Torbjörn Lundgren, Stockholm
Øystein Jynge, Stockholm (NTCG)
Bo-Göran Ericzon, Stockholm
Marko Murruste, Tartu
Amir Sedigh, Uppsala
Anna Högvall, Uppsala
Olle Korsgren, Uppsala
Shinji Yamamoto, Uppsala
Christina Andreasson, Uppsala
Lydia Junebjørk, Uppsala
Ilse D. Weinreich, Scandiatriplant