# Minutes
# Nordic Pancreas and Islet Transplant Group (NπTG) meeting at Clarion Hotel, Arlanda Airport October 7th 2019, 09.30 - 15.30

1. **Welcome and introduction**
Niclas Kvarnström started as chair.

2. **Further matters to the agenda** –
None

3. **Election of chairman and secretary for the meeting** –
Niclas Kvarnström started as a chair. Bengt Gustafsson arrived at 10.30 and continued as chair and Hanne Scholz as secretary for the meeting

4. **Minutes from last meeting April 8th 2019** (*Niclas Kvarnström*)
Approved

5. **Update of activities (*all centres 2019*):**

***Copenhagen*** *– 3 SPK and 1 PAK since last meeting.*
**Helsinki** - 28 PTX (27 SPK) (one problem with a pancreas (SPK) turn into blue/black immediately, hyperacute rejection according to pathologist (? from Marco as the duodenum was ok). Olle suggested to stain for complement.
**Oslo** – 7 PTX. For islet isolation 19 pancreases harvested but this also includes many research pancreas (2 Islet Tx from Uppsala Lab and 3 Islet Tx from Oslo Lab). Oslo has two PhD dissertationsthis week (Simen W. Schive, MD, on islet transplantation and Rune Hornland, MD, on pancreas transplantation).
**Stockholm** – 6 SPK and 3 ITx
**Uppsala** – 2 SPK and 1 PTA. 7 ITx
***Göteborg*** *- 1 SPK. None on waiting list for islets and few for pancreas Tx. Malmö previously sent their patients on the waiting list to Gothenburg which can be one of the explanations for the low number along with few referrals.*
***Malmö*** *- 2 PTA and 2 SPK*
**Tartu -** *1 SPK*
**Discussion:** *Problem with few referrals from the diabetologists. Patients are doing well with the new technologies (pumps and sensors. Alan: SPK with lost pancreas but functional kidney. Could islets be suitable for that? What is the best choice for each patient? Age limit for SPK? (most centers don't have absolute limits but generally accept good donors 50-55 years old, whereas Helsinki accepts up to 60 years).*

6. **Discussion - proposed topics:**

- Pancreas/islet procurement potential usage. Pancreas donor potential 2019: DBD (total 394) Total pancreas potential 127 (32% for PTx and 35% for ITx). See attached document (*Ilse Weinreich*)

- Waiting list and allocation/exchange 2019 (*Ilse Weinreich*)

All centers agree that a virtual X match should be enough for exchange and that a flow X match can be done at the receiving site to confirm absence of HLA antibodies. Follow on the previous discussion about low number of patients on waiting list. Both for PTx and ITx the waiting list is decreasing. Alan pointed out that it seems that both pancreas and islets tx are going down, a trend observed in Europe and the US. Drop may be due to fear of side effects of immunosuppressants for both procedures. The islet after kidney (or SIK) are almost not done anymore. Most of these patients are referred to SPK and PAK. The threshold for the diabetologists for offering beta cell replacement seems to be very high. Kidney failure due to T1D is decreasing which also contribute to this. Bengt intends to contact all nephrologists in his region to figure out how many T1D patients with functioning kidney grafts that could be offered

Itx. Discussion around highly immunized patients and graft outcome.

- Pancreas follow-up registry 2019 (*Ilse Weinreich*)
  Access granted so far to Helsinki, Uppsala, Copenhagen, Oslo, Malmö.
  -Pancreas pre tx, automatically inserted when patient is listed.
  -Pancreas tx, automatically inserted when patient is transplanted
  -Pancreas follow up, manually inserted by users
  **ACTION: All centers entering retrospective follow up data for the last 6 years and all new follow up into the registry.**

- Ongoing and planned islet studies. Olle: How to share data into registry? Data agreement is needed if you have key/code. Recipients on waiting list is ok but what about on the follow up data of that patients? Which registry is the recipients signing? The group need to work on this to find a way to answer these questions. E.g detailed information how to withdraw the data needed to be included in the signed consent. We are in this context probably somewhere in-between the Personal Act and the Transplantation law.

  **ACTION: Alan will bring it up on the next Scandia Transplant board meeting in March 2020. We need to prepare document(s) to be sent to the Scandia Transplant Board upfront. Ilse is contributing.**
  Uppsala/Stockholm: (1) NNCIT2: Low Molecular Dextran Sulphate (high dose) is ready to start. Total of 18 transplantations planned. Edmonton, Oxford, and centers in Sweden are participating. (2) Simultaneous autologous Tregs and allogenic islet transplantation study. First patient transplanted in Stockholm. Total of 6-10 planned.

- Oslo: (1) Development of renal function over time in patients after islet or single pancreas transplantation. (2) Validity and concordance between pancreas and duodenum transplant biopsies.

  Ongoing/new study in Goteborg: Potential treatment for T1D? Cooperation with the 'diabetes community' (Prof. Marcus Lind, NÄL Hospital). QoL, cGCM in recipient before and after transplantation. All centers agree to support. The protocol will be shared and maybe open up for more centers.
  Bengt will review 5 years' retrospective data on PTx (SPK).
  **ACTION: Bengt will send out email to all centers with invitation and how to contribute**

- Torbjörn Lundgren has the intention of gathering an islet scientific meeting in January/February 2020. A date will be set in December 2019.

**7. When to elect next chairman?**
**ACTION: Start the process of election of new chairman at the spring meeting. Suggestion of a candidate should be done done at least one week before the meeting.**

**8. Any other business**

Discussion: *Everyone happy with the present common IS protocol?*
Discussion of bleeding after intensified/earlier anticoagulation. Uppsala has followed the Oslo protocol but has experienced some bleeding.

**Next meeting**
March 31th 2020 10.00 am Arlanda Airport, Stockholm.