

## Nordic Pancreas and Islet Transplant group



Date:April 10th 2018Location:Clarion Hotel, Arlanda, Sweden

1. Opening of the meeting

Bengt Gustafsson welcomed all to Arlanda.

2. Election of chairman for the meeting

Bengt Gustafsson was elected chairman.

3. Election of secretary for the meeting

Bengt von Zur-Mühlen was elected secretary.

4. Approval of the agenda

The agenda was approved.

5. Update of the e-mail list

Frank Pedersen updated the e-mail list. Any further additions can be e-mailed to Frank Pedersen.

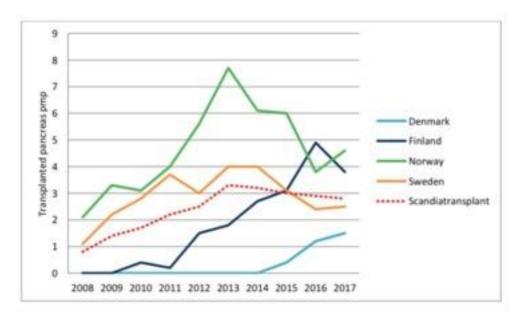
6. Minutes from last meeting 10<sup>th</sup> October 2017.

All minutes are available on Scandiatransplant's homepage. http://www.scandiatransplant.org/members/nordic-pancreas-group/minutes



## 7. Update of activities

In total 80 pancreas and 20 islets transplantations were done in 2017, figure pmp below.



#### Stockholm:

- *Pancreas:* In 2017 6 SPK + 4 single pancreas and during 2018 1.
- *Islets:* 2017 1 islet, 2018 1 islet. The last recipient with rare complication bleeding to the gall bladder

#### Uppsala:

- Pancreas: 2017 5 SPK + 2 single pancreas. three recipients with early arterial thrombosis (first month) now ASA is given earlier. 2018 one single pancreas.
- o *Islets:* 2017 7 islets, 2018 until now 5 islets.

Oslo:

- Pancreas: 2017 11 SPK + 13 single pancreas. Noticed lower rate of thrombosis after earlier introduction of ASA and Rheomacrodex day 0 and 1. Anasthomosis still to the duodenum, discussion ongoing. 2018 2 SPK and 1 PTA.
- *Islets:* 2017 11 islet transplantations, 2018 3 islet transplantations (2 patients) whereof 1 islet alone (IA) and one islet after kidney (IAK).

#### Copenhagen:

• **Pancreas:** 2017 9 SPK. 2018 until now 1. No thrombotic complications in the total of 19 cases.

#### Helsinki:

*Pancreas:* 2017 in total 21 pancreases (all SPK), one was re-operated due to pancreatitis. 2018 until now 9 SPK.

#### **Gothenburg:**

- *Pancreas:* 2017 6 SPK, 2 multivisceral transplantations including pancreas. No major complications. Discussion of a patient from Iceland transplanted 2015 and now appearing with fistula.
- o *Islets:* No islets.

#### Tartu:

 Pancreas: 2017 3 SPK with no major complications, 2018 5 patients on the waiting list.

#### Malmö:

- **Pancreas:** 2017 no program but will start in 2018.
- o Islets: New coordinator Anders was presented. In 2017 2 islets.

#### 8. Discussion

#### a. Pancreas donor potential

Frank Pedersen reported that there were more than 500 deceased donors in 2017 but only 80 pancreas and 20 islets transplanted. At least 21 were registered *"suitable recipient not found"* and even more with *"no information"*. There should be one common protocol for the coordinators. Torbjörn and Christina will come up with a suggestion for a definition list for 'not usage' causes and this will be brought up at the next NTCG meeting in May.

Even if not transplanted Olle Korsgren reported how islets contribute to the field of diabetes research and for example T2DM donors can be used for T2DM research. In Denmark the pancreas cannot be used for only research, but in Norway and Sweden if there is a consent.

#### b. Pancreas/islet procurement with no usage stated

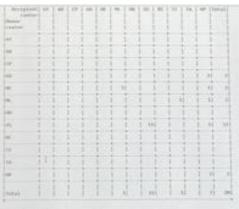
Around 1150 pancreas/islets in the Scandiatransplant database with procurement in 2011 and earlier are lacking registration of usage. Earlier organs for islets were not registered. Olle can supply data from the registry, the rest can be stated as used for research.

## c. Waiting list and allocation/exchange 2017 Figures from Scandiatransplant:

Pancreas

Islets

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Only 9 (6 SPK + 3 single pancreas) and 3 pancreas for islet transplantation crossed country borders in 2017. **Pancreas Exchange rules** 

d.



Discussion of changes in the exchange rules and a reminder that the rules of today for pancreas are recommendations (kidneys have rules). The purpose is to increase the number of pancreas for beta cell replacement. Today we have in total 28 active on SPK waiting list, and 21 waiting for single. Today there is almost no exchange between centers and complience is scarce.

Allan Rasmusen showed a new written suggestion with approximately 95 % agrrement with the present recommendations, but a change to rules and a rota-list with rota by country.

It was decided that each country should only have one entry on the rota-list.

There are some local priority rules and the kidney group has to be involved if the kidney is involved (SPK). Finland still preferes recommendations mainly due to delay of the payback kidney, for example the rare young B donor. If a center accept the organ they are obliged to retrieve the pancreas. Another problem is sending sera for cross-matches.

The group decided that Marko Lempinen, Bengt Gustafsson and Allan Rasmusen will write a new document with rules and local exceptions, distribute the document to all centers for agreement and then finalized by Ilse.

#### e. Simultaneous islet-kidney transplant and islet after kidney transplant



Ehab Rafael from Malmö reported on a protocol for SIK – simultaneous islet and kidney. Induction with ATG+SM, maintenance with Tac and MMF, minimum 2000-4000 IEQ/kg, <72h post kidney, infusion via mesenteric vein during kidney tx or to the portal vein. Islet and pancreas should complete not compete. All patients with T1DM and CRF, not suitable for SPK should have a decision in advance for the option of SIK in their records when they are actualized for the kidney

waiting list. Steroids in the protocol?

# f. Reimbursement cost for pancreas harvesting and transport for solid organ and islet

Olle Korsgren clarified that part of the costs for islet isolation are covered by national strategic research resources and the Swedish centers receive 330 000 SEK annually.

## g. Rudbeck laboratory

The Rudbeck laboratory will be closed 7<sup>th</sup> May 2018 for one week during renovation of ventilation. Pancreas can be shipped to Oslo, but the sera bank is still in Uppsala. Logistical solutions will be discussed between the laboratories.

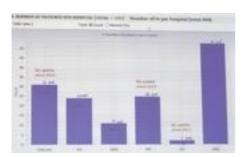
## h. Reporting of Serious Adverse Event or Serious Adverse Reaction



Ilse Duus: According to EU53/2010 directive there has to be systems to report SAE/SARs in relation with organ transplantation. Scandiatransplant has investigated if it is possible to report these events in their system. In December the system was implemented in YASWA. Reports can be sent out to all coordinators by e-mail or

SMS. Mainly donor process related complications such as infections/malignancies/wrong X-match...

## 9. Status from NIR - Nordic Islet Registry



Maria Svenaeus-Lundgren reported the registration situation in NIR. Bengt Gustafsson told us that Gothenburg will resume their islet program.

#### **10.** Suggested variables in a common pancreas follow-up registry

- Within the Scandiatransplant it-system YASWA
- Could start in autumn 2018 adding all data for 2018
- Yearly follow up updates
- Suggested parameters: Age, Tx type, diabetes duration, indication on top of T1DM, RRT, BMI, CM, Donor age, BMI, CIT, reoperation intervention, HbA1c, Cpeptide, Insulin need, rejection, GFR, reason for graft loss, Cause of death, antibodies, vascular reconstruction
- QoL SF36?, hypoglycemic events (Clark/HYPO score), CGM parameters

## 11. Present and future studies (Torbjörn Lundgren)

## a. Autologuous T-reg

Ready to go in Stockholm, the protocol might be extended to Uppsala. Harvested earlier, transplanted at the same time but transplanted in separate bags.

## b. Grafalon (previous ATG-Fresenius)

At the moment only, Helsinki is using Grafalon, the rest use Thymoglobulin. The company wants to sample and analyse different indicators for T-cells. There is a very basic synopsis – 15 patients in every group. Decision to go on to discuss a study.

## 12. Election of chairman for the $N\pi TG$

Suggestions should be ready before the next meeting, when a chairman is elected.

## 13. Next meeting

The N $\pi$ TG has decided having meetings twice yearly. The next meeting is on Monday 8<sup>th</sup> October 2018. The meeting will be in COPENHAGEN, Clarion (Old Hilton).

Bengt von Zur-Mühlen Secretary Bengt Gustafsson chairman

## **Participants:**

Allan Rasmussen, Copenhagen Paul Krohn, Copenhagen Bengt Gustafsson, Gothenburg Marko Lempinen, Helsinki Ehab Rafael, Malmö Anders Knutsson, Malmö Einar Martin Aandahl, Oslo Hanne B. Scholz, Oslo Ingebjørg Kvangarsnes, Oslo Johan Nordström, Stockholm Torbjörn Lundgren, Stockholm Malin Aram, Stockholm Irodotos Nikas, Stockholm Marko Murruste, Tartu Aksel Espen Foss, Uppsala Bengt von Zur-Mühlen, Uppsala Maria Svenaeus Lundgren, Uppsala Olle Korsgren, Uppsala Christina Andreasson, Uppsala Ilse D. Weinreich, Scandiatransplant Frank Pedersen, Scandiatransplant