



Nordic Pancreas and Islet Transplant group

Date: April 7th 2016
Location: Clarion Hotel, Arlanda, Sweden



Participants: Bengt Gustafsson (Göteborg), Frank Pedersen (Scandiatriansplant), Kaj Anker Jørgensen (Scandiatriansplant), Olle Korsgren (Nordic Isletlab – paragraph 8-), Helene Malm (Uppsala – paragraph 7-), Bengt von Zur-Mühlen (Uppsala), Gunnar Tufveson (Uppsala), Maria Svenaeus Lundgren (Uppsala), Christina Andréasson (OFO Uppsala), Torbjörn Lundgren (Stockholm), Karin Fransson (Stockholm), Karin Linderståhl (Stockholm), Hanne Scholz (Oslo), Rune Horneland (Oslo), Gisle Kjøsen (Oslo), Kristina Rydenfelt (Oslo), Ehab Rafael (Malmö) and Helena Pollard (Malmö).

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 will update the e-mail list, information will not be separated concerning islets or pancreas.

6. Scandiatriansplant

- a. Frank Pedersen showed features of the Scandiatriansplant waiting lists.
- b. In the registry analyse shows that of total 648 donors 238 were < 51 years and 36 had BMI > 30 which leaves 199 potential pancreas donors. Of these 79 pancreas and 9 islets transplanted. 81 pancreases were not harvested, mainly due to poor organ or lack of consent for research.
- c. Also possible to retrieve exchange of organs between centers.

7. Scandiatriansplant board meeting

- a. Kaj Anker Jørgensen reported from the board of Scandiatriansplant. All the minutes are available on the homepage.
- b. Revision of the Scandiatriansplant articles is needed and the council decided in 2014 to form a revision working group composed by the board, representatives from the groups and medical directors and Scandiatriansplant office.
 - i. Today's articles do not reflect how Scandiatriansplant works today, e.g. groups or medical professional, no mention of the database or the office, Article 7 stipulates unanimously decisions, Article 10 stipulates that the associations capital is invested in a bank or invested in low-risk securities, ownership of the data, continue to be a "Danish" association etc.
 - ii. Drafts of revision have continuously been presented to the board.
 - iii. Major changes: Purpose, composition of council (DD=LD) every 75 tx gives a representative, medical issues placed in groups, article on office, article on groups, possibility of associate membership, ownership of the database in separate legal memorandum with agreements with each hospital, no possibility for sanctions etc.
 - iv. New model – the hospitals are responsible for the data which complies with each country's data legality
 - v. Final draft is presented in May 2016. The biggest issue concerns new members (e.g. new countries) and the structure groups.

- c. Discussion concerning representatives in Scandiatransplant. The number depends on last years number of transplants. The Hospital Directors of each center appoints the representatives. Bengt Gustafsson was elected to represent the **N TT TG** against Scandiatransplant and will participate in the meeting 11th May 2016.

8. Common Nordic follow up registry

Torbjörn Lundgren presented issues concerning a common follow up registry for all the Nordic centers and also common for both pancreas and islets organized by Scandiatransplant. Islets register today in MedSciNet – Nordic Islet Registry (NIR). Discussion of adherence to register data, problems with lack of data, possibility to report data to authorities required by law, the need of an alert system if data is missing, connections with international registries. Bengt Gustafsson, Maria Svenaeus-Lundgren, Torbjörn Lundgren and Rune Horneland represent **N TT TG** and will suggest the parameters for a common register.

9. Islet transplantation – what is going on?

- a. Sub study article from CIT-01 with PET to image remaining live islets in the liver is submitted and will be published in the autumn.
- b. The last patient in a study with IL-8 blockade (Reparixin manufactured by Dompé) has last visit in September 2016. The study evaluates efficacy and safety if IL-8 blockade is given intravenously 1w after Islet-Tx.
- c. In Sweden media and the public showed big interest after a recent fraud investigation with a researcher performing plastic transplanted trachea. This has put a damper on other research programs, especially research with stem-cells, human research subjects, transplantation and has opened the eyes concerning the lack of external investigations when fraud is suspected.
- d. Islet studies in pipe-line
 - i. Higher and repeated doses of LMW heparin
 - ii. Involving eculizumab
 - iii. Islets coated with Heparin
- e. Olle Korsgren has received a request from Estonia to establish an Estonian Islet laboratory but an alternative would be cooperation with membership/affiliation/association in the Scandiatransplant. There are already Scandiatransplant guidelines for non-nordic recipients. The Scandiatransplant council has turned Estonia down once. There is a big EU interest in facilitate collaborations, but to receive funding requires a considerable administrative effort.
- f. Simultaneous islet and kidney transplantation (SIK) – kidney first and islets from the same donor 2-7 days afterwards - could be done as a project but has not been done other than in research programs. Type-1 diabetes patients with renal failure not suitable for vascularized pancreas should be considered for SIK. The immunosuppression should be steroid free except induction. One advantage is that the kidney can signal rejection episodes. It is also possible to use otherwise considered suboptimal number of islets/marginal donors.

10. Do we agree on allocation and exchange criteria?

- a. Scandiatransplant has *Pancreas exchange and payback rules* from 11th December 2015 with headlines:
 - i. Pancreas and kidney-pancreas recipients (e.g. if no own recipient has to be offered etc.)
 - ii. Pancreas donor criteria (e.g. <50 years, BMI<30 etc.)
 - iii. Pay back after shipment of pancreas/kidney-pancreas (e.g. no mandatory pay back for pancreas but for kidney etc.)
 - iv. Reasons for no pancreas procurement shall be recorded (e.g. if neither pancreas or kidney is used etc.)
 - v. Pancreas rotation rules (e.g. respond within 30 min, rota list etc.)
- b. Identified problems: Islets are not mentioned in the document, choice of recipient: patient with longest waiting time own center, rota list or mutual Nordic waiting list, not mentioned non-diabetic in criteria, not mentioned recipient criteria e.g. PRA<20%, DSA >1500 MFI, even if pancreas is not used for transplantation islet isolation is important in diabetes research (the network has enabled more than 300 publications).

- c. The group decided:
 - i. The use of a rota list for surplus pancreases
 - ii. Rudbeck laboratory is removed from the rota list
 - iii. If pancreas is not used for vascularised transplantation it should be offered for islet isolation
 - iv. Supplement with islet transplantation
- d. The group decided that Torbjörn Lundgren and Olle Korsgren write the supplement regarding islet transplantation and Bengt Gustafsson writes the new draft.

11. Common immunosuppressive protocol – are we ready?

The group decided to aim for a common Nordic immunosuppressive protocol for pancreas as well as for islet transplantation. Fears with standardization are limiting the development of even better immunosuppression. It would be desirable to investigate if differences in present protocols show differences in outcome.

12. Can we perform research over the national boundaries?

Discussion was combined with the discussion of a common protocol for immunosuppression.

13. Micro dialysis after pancreas transplantation

- a. Håkon Haugga presented: In Oslo 30-35 pancreas transplantations are performed yearly (50 combined). Complications occur early. With the use of a semipermeable catheter and micro dialysis glycerol, glucose, pyruvate and lactate can be analysed bedside. In case of ischemia and rejection lactate and pyruvate, but in ischemia lactate increases more than pyruvate and for rejection *vice versa*. In liver transplantation IL-10 and C5a are selective markers for rejection and ischemia respectively.
- b. Gisle Kjøs presented micro dialysis in pancreas transplantation: 26 consecutive patients are included in a study, 6 venous thrombosis, 3 deep infections, 5 (20 %) re-laparotomies. Two catheters are used – one rostral and one ventral of the transplanted pancreas. Case reports were increase in lactate/glycerol enabled early detection of venous thrombosis or duodeno-duodenal anastomosis leakage.
- c. Discussion of a Nordic unified protocol –
 - i. Surgical differences in location of the anastomosis (duodenojejunal anastomosis does not require an elongation of the vein but it is more difficult to perform biopsy).
 - ii. Differences in thrombosis prophylaxis
 - iii. Common study with micro dialysis, adding coagulation parameters? A multi center study on Whipple patients is on going.

14. Are we happy with N TT TG?

The group is happy with a merged group - islets and pancreas.

15. Next meeting

The group decided to have meetings twice yearly. Next meeting October 20th 2016 in Stockholm, Arlanda 9.30-15.30h.

(Changed to October 27th 2016 in Stockholm, Arlanda 9.30-15.30h.)

16. The meeting ended

Bengt Gustafsson closed the meeting.

Stockholm Arlanda April 7th 2016

Bengt von Zur-Mühlen
Secretary

Bengt Gustafsson
chairman