Minutes from the inaugural meeting of The Nordic Pancreas and Islet Transplantation Group ($N\pi TG$)

Clarion Hotel, Arlanda Airport, Stockholm, Sweden 2015-12-08

Attending

Bengt Gustafsson, Surgeon, <u>Göteborg</u> Niclas Kvarnström, Surgeon, Göteborg (1 PM-) Torbjörn Lundgren, Surgeon, Stockholm Mikael Rydén, Endocrinologist, Stockholm (-1PM) Johan Nordström, Surgeon, Stockholm Carl Jorns, Surgeon, Stockholm Karin Fransson, Research Nurse, Stockholm Birgitta Nässén, Research Nurse Stockholm Gunnar Tufveson, Surgeon, Uppsala Per Ola Carlsson, Endocrinologist, Uppsala Olle Korsgren, Immunologist, Uppsala Bengt von Zur Muhlen, Nephrologist, Uppsala Maria Svenaeus Lundgren, Research Nurse, Uppsala Anna Högvall, Research Nurse, Uppsala Karin Lindh, Transplant Coordinator, Uppsala Ehab Rafael, Surgeon, Malmö Helena Pollard, Research Nurse, Malmö Marko Lempinen, Surgeon, Helsinki Trond Jensen, Nephrologist/Endocrinologist, Oslo Rune Horneland, Surgeon, Oslo Hanne Scholz, Head Islet Lab, Oslo Simen Schive, PhD student, Oslo Ilse Duus Weinreich, Clinical Data and Office Manager, Scandiatransplant

- a/ Welcome and Introduction / Bengt Gustafsson
- b/ Approval of agenda (attached (1)), Dr Biglarnia not present for presentation.
- c/ Election of chairman (Gustafsson) and secretary (Lundgren) for the meeting
- d/ Current status of pancreas transplantation / Rune Horneland (att 2).
- e/ Current status of islet transplantation / Olle Korsgren (att 3)
- f/ Current status of islet transplantation / Hanne Scholz (att 4)
- g/ The diabetologist's perspective / Trond Jenssen (att 5)

Indication for pancreas or islets primarily depending on level of need of exogenous insulin.

High demand -> whole pancreas. General previous reasoning that all "good" pancreases

should be used for whole organ transplantation led to an unacceptable long waiting time for

islets in Norway. Recent decision on one waiting list for both planned islet and pancreas transplantations in Norway.

Lunch

h/ Pancreas transplantation in the Nordic countries 2000-2015/ Bengt Gustafsson (att 6)

i/ Islet transplantation in the Nordic countries 2000-2015/ Torbjörn Lundgren (att 7)

j/ Scandiatransplant (by-laws, groups, registry) / Ilse Duus Weinreich (<u>att 8</u>), <u>Current</u> <u>Guidelines for the Pancreas Transplantation Group</u>

k/ Future organization

-On the basis of both groups treating the same illness (primarily type 1 diabetes) with tissue from the same organ, using the same medications and trying to achieve the same goals a decision was taken to merge.

-A common goal is to make use of all available pancreases in the best sake of current and future patients.

-Suggested chairman of the new combined group is Bengt Gustafsson

-The name of the new group will be Nordic Pancreas and Islet Transplantation Group with the acronym $\ensuremath{\mathsf{N}\pi\mathsf{T}\mathsf{G}}$

-Chairman will together with Scandiatransplant look through present guidelines for the former pancreas group and see if these can be adapted to the new situation

I/ Donor operation

-The donor operation and dedication to the task is of huge importance for the result both in pancreas and islet transplantation.

-Harvesting surgeons should be registered within the islet isolation registry (NICS, Magnus Ståhle, <u>magnus.stahle@igp.uu.se</u>) to receive feedback after islet isolation.

m/

Allocation and exchange. If a pancreas is not used at donor center it should be offered to other centers for whole organ transplantation or islet isolation. A "Rota list" (including islet labs) was discussed and also possible pay back systems. It was pointed out that these decisions should primarily be patient centred and not necessarily be left to the surgeons. There are still pancreases that are not used. Ilse has recently looked at the figures for Sweden Jan-Sep 2015 (att 9) and one can among other things see that in a total of 127

donors, 21 pancreases in donors under 60 years of age were not used for pancreas transplantation or islet isolation. Waiting lists should be (and are through Scandiatransplant) transparent.

Discussion will continue until next meeting

n/ The Nordic Network for Clinical Islet Transplantation have had common SOPs and harmonized the use of immunosuppression etc. They are currently found in the log in protected part of <u>www.nordicislets.org</u>. Intentions to make these public have not been fulfilled. The pancreas group has had discussions regarding standardized protocols (current found in <u>att 10</u>) without any decisions being made yet.

o/ The islet group has a common registry in Nordic Islet Registry (NIR). The pancreas group has planned a basic common follow up registry. Gustafsson, Lundgren and Oyen were planned to put together a suggestion. Oyen will be replaced by Horneland and Maria Svenaeus Lundgren will be added to the group. Possibilities to combine islet and pancreas registration and keeping it under Scandiatransplant will be explored.

p/Next meeting – Arlanda April 7, 2016

Minutes/ Torbjörn Lundgren Checked by/ Bengt Gustafsson