

Nordic Pancreas and Islet Transplant group

Date: October 27th 2016

Location: Clarion Hotel, Arlanda, Sweden



Participants:

Bengt Gustafsson (Göteborg), Frank Pedersen (Scandiatransplant), Bengt von Zur-Mühlen (Uppsala), Einar Martin Aandahl (Oslo), Morten Hagness (Oslo), Torbjörn Lundgren (Stockholm), Anna Högvall (Uppsala), Maria Svenaeus Lundgren (Uppsala), Gunnar Tufveson (Uppsala), Christina Andréasson (Tx coordinator), Helene Malm (Uppsala), Ehab Rafael (Malmö), Helena Pollard (Malmö), Hanne Bjørnson Scholz (Oslo Islet laboratory), Gisle Kjøsen (Oslo), Karin Fransson (Stockholm), Carl Jorns (Stockholm), Johan Nordström (Stockholm), Allan Rasmusen (Copenhagen), Marko Lempinen (Helsinki), Trond Geir Jensen (Oslo), Niclas Kvarnström (Göteborg) and Paul Krohn (Copenhagen).

1. Opening of the meeting

Frank Pedersen 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 has updated the e-mail list, information will not be separated concerning islets or pancreas. Ehab Rafael will replace Ragnar Källén. Information concerning function (surgeon, nephrology/research nurse). After corrections 37 persons are on the list.

Name	Center	Meeting 27. Oct. 2016	Role	Mail
Henrik Birn	AR	Absent		henrbirn@rm.dk
Mads Hornum	СР	Absent		mads.hornum@gmail.com
Søren Schwartz Sørensen	СР	Absent		soeren.schwartz.soerensen@rh.regionh.dk
Vibeke Rømming	СР	Absent		vr@dadlnet.dk
Marie Felldin	GO	Absent		marie.felldin@surgery.gu.se
Helena Isoniemi	HE	Absent		helena.isoniemi@hus.fi
Alireza Biglarnia	ML	Absent		alireza.biglarnia@skane.se
Jan Carstens	OD	Absent		Jan.Carstens@ouh.regionsyddanmark.dk
Rune Horneland	os	Absent	Pancreas FU	runhor@ous-hf.no
Håkon Haugaa	OS	Absent		hhaugaa@ous-hf.no
Tor Inge Tønessen	os	Absent		t.i.tonnessen@medisin.uio.no

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Kaj Anker Jørgensen	SCTP	Absent		Kaj.Joergensen@skejby.rm.dk
Mikael Rydén	ST	Absent		mikael.ryden@ki.se
Karin Linderstål	ST	Absent		karin.linderstahl@karolinska.se
Per Ola Carlsson	UP	Absent		Per-Ola.Carlsson@mcb.uu.se
Olle Korsgren	UP	Absent	Roules for rotation	olle.korsgren@igp.uu.se
Allan Rasmussen	СР	Present		allan.rasmussen@dadlnet.dk
Paul Krohn	СР	Present		paulskrohn@dadlnet.dk
Niclas Kvarnström	GO	Present		niclas.kvarnstrom@vgregion.se
Bengt Gustafsson	GO	Present	Chair / Pancreas FU	bengt.gustafsson@surgery.gu.se
Marko Lempinen	HE	Present		marko.lempinen@hus.fi
Ehab Rafael	ML	Present		Ehab.Rafael@skane.se
Helena Pollard	ML	Present		helena.pollard@skane.se
Christina Andréasson	NTCG	Present		christina.andreasson@akademiska.se
Gisle Kjøsen	OS	Present		giskjo@ous-hf.no
Hanne Bjørnson Scholz	OS	Present		hanne.scholz@medisin.uio.no
Trond Geir Jenssen	OS	Present		trond.jenssen@ous-hf.no
Morten Hagness	OS	Present		mhagness@ous-hf.no
Einar Martin Aandahl	OS	Present		einaan@ous-hf.no
Frank Pedersen	SCTP	Present		help@scandiatransplant.org
Karin Fransson	ST	Present		karin.fransson@karolinska.se
Torbjörn Lundgren	ST	Present		torbjorn.lundgren@karolinska.se
Johan Nordström	ST	Present		johan.nordstrom@karolinska.se
Carl Jorns	ST	Present		carl.jorns@karolinska.se
Helene Malm	UP	Present		helene.malm@akademiska.se
Maria Svenaeus Lundgren	UP	Present	Pancreas FU	maria.svenaeus.lundgren@akademiska.se
Anna Högvall	UP	Present		anna.hedvig.lovisa.hogvall@akademiska.se
Bengt von Zur-Mühlen	UP	Present	Pancreas FU	bengt.muhlen@medsci.uu.se
Gunnar Tufveson	UP	Present		gunnar.tufveson@akademiska.se

6. Minutes from last meeting 7th April 2016

Late corrections:

Paragraph 6 – numbers do not add regarding possible pancreas donors and transplanted organs/islets

Paragraph 7 – The articles of Scandiatransplant are rewritten since the last meeting

Paragraph 8 – Torbjörn Lundgren replaced by Bengt von Zur-Mühlen in the informal group for follow up registry

Paragraph 9 – Islet study with eculizumab has started, islet study with heparin slowly in progress and not started

Paragraph 10 –the rules from 11th December 2015 are only a suggestion. There are still no decided rules.

7. Update of activities

In total 64 pancreas and 13 islets. Occasionally there are problems with coordinating vessels for procurement of the pancreas. Most obvious trend in Scandinavia is the increasing volume in Helsinki. No change in age limits (recipient or donor). Norway started antifungal prophylaxis. There are differences in the use of Sandostatin. Only Uppsala uses basiliximab for SPK but all use ATG for single pancreas.

Oslo: This year 4 single pancreas, 14 combined and 5 islets. 7 thrombotic events leading to 3 graft loss. Due to this fewer surgeons are involved and changes have been in

- Anticoagulation (Rheomacrodex also day 2, aspirin day 3 and change in dose of Fragmin).
- Only two surgeons are doing the procurements.
- More frequent CT scan (ultrasound suboptimal for thrombosis)

Stockholm: 1 single pancreas, 6 combined, kidney, 1 paediatric combined with liver and 1 islet.

Denmark: 3 combined with kidney

Helsinki: No islets performed in last 6 years. Helsinki 19 combined with kidney and 1 pancreas after kidney. Two main surgeons are doing both retrieval and transplantation. Cold ischemia time is in median 8 hours. Anticoagulation is 2500 U Fragmin twice daily and aspirin from day 1. One late thrombosis two months after Tx. Four trans abdominal indication biopsies have been performed without complications. For the moment there are 13 patients on the waiting list.

Gothenburg: 6 combined with kidney, no reoperations, no thrombosis, 1 complicated infection with drainage. Earlier use of aspirin and almost stopped sandostatin. In total two deaths since 2009 due to infections why immunosuppression has been lowered earlier. Median cold ischemia time is 8 hours.

Uppsala: Five combined, four single, and 5 islets. Earlier usage of aspirin.

Malmö: One islet. Might start with pancreas next year.

8. Scandiatransplant

Frank Pedersen showed features of the Scandiatransplant waiting lists. Discussion and limitations of accepting organs outside of Scandiatransplant due to differences in retrieval traditions.

- 44 patients on the waiting list for SPK (9 temporarily withdrawn)
- 64 pancreas, and 13 islets have been transplanted in 2016 until now
- In the registry there is a discrepancy for islets caused by change from report of patient to number of transplantations.
- In total 782 pancreas transplantations.
- 52 SPK, 20 single pancreas and 41 islets on the Nordic waiting list.

Torbjörn Lundgren showed data first 9 Months of 2016 from Scandiatransplant with deceased donors, procured pancreases, transplanted pancreases, pancreas sent to islet lab, transplanted islets, not procured with or without cause for the Nordic countries.

Scandiatransplant pancreas and islet status - first 9 Months of 2016

Denmark -									
Age	0-9	10-	20-	30-	40-	50-	60-	70-	80-
		19	29	39	49	59	69	79	
Deceased donors	1	2	5	4	9	17	13	10	3
Procured pancreases	0	2	0	1	1	4	0	0	0
Transplanted pancreases	0	2	0	1	0	1	0	0	0
Sent to islet lab.	0	0	0	0	0	3	0	0	0
Transplanted islet	0	0	0	0	0	1	0	0	0
Not procured with cause	1	0	5	1	7	11	10	9	3
Not procured without	0	0	0	2	1	2	3	1	0
cause									

Norway -									
Age	0-9	10-	20-	30-	40-	50-	60-	70-	80-
		19	29	39	49	59	69	79	
Deceased donors	1	4	10	8	11	10	12	13	9
Procured pancreases	1	3	6	2	9	5	5	0	0
Transplanted pancreases	1	3	6	1	6	1	0	0	0
Sent to islet lab.	0	0	0	1	3	4	5	0	0
Transplanted islet	0	0	0	1	1	3	0	0	0
Not procured with cause	0	1	4	5	2	5	7	13	7
Not procured without	0	0	0	1	0	0	0	0	2
cause									

Sweden (incl. donors from Iceland)									
Age	0-9	10-	20-	30-	40-	50-	60-	70-	80-
		19	29	39	49	59	69	79	
Deceased donors	1	3	10	12	18	29	34	29	8
Procured pancreases	1	3	5	10	11	17	21	8	2
Transplanted pancreases	1	1	4	4	7	2	0	0	0
Sent to islet lab.	0	1	0	6	4	11	18	7	2
Transplanted islet	0	0	0	0	2	3	0	0	0
Not procured with cause	0	1	5	2	6	12	13	17	4
Not procured without	0	0	0	0	1	0	0	4	2
cause									

Finland -									
Age	0-9	10-	20-	30-	40-	50-	60-	70-	80-
		19	29	39	49	59	69	79	
Deceased donors	0	3	6	5	16	21	31	20	0
Procured pancreases	0	1	3	3	8	5	2	0	0
Transplanted pancreases	0	1	2	3	7	4	0	0	0
Sent to islet lab.	0	0	1	0	1	0	2	0	0
Transplanted islet	0	0	1	0	0	0	?	0	0
Not procured with cause	0	2	1	2	5	13	22	17	0
Not procured without	0	0	2	0	3	3	7	3	0
cause									

9. Guidelines of the Nordic Pancreas Transplant group in Scandiatransplant.

Frank Pedersen will add islets where only pancreas is mentioned. The guidelines before these corrections are:

Guidelines of the Nordic Pancreas Transplant Group (NPTG) in Scandiatransplant (These Guidelines were approved at the Nordic Pancreas Transplant Group Meeting September 2, 2014)

ARTICLE I - Name and main objectives

Section 1: The name of the organisation is the Nordic Pancreas Transplant Group (NPTG), founded in 2013.

Section 2: The main objectives for NPTG are to:

- Create a forum for discussion on questions relevant to cooperation and exchange of information between the Nordic transplant centres and the Scandiatransplant organisation.
- To support and increase the pancreas transplant activity within Scandiatransplant
- Prepare issues and matters relevant to pancreas transplantation coming up for discussion and decision at the Scandiatransplant Representatives' meeting.
- Plan and agree on studies using the Scandiatransplant transplant database.
- Agree on data to be presented in the annual report at the Scandiatransplant Representatives' meeting.
- Yearly evaluation of the exchange of pancreases for transplantation.

ARTICLE II - Organisation

Section 1: At least one member shall be appointed to the Group from each hospital involved in pancreas transplantation.

In addition one member of the Scandiatransplant staff and one transplant coordinator are appointed to be part of the group.

One person is appointed as chairman. A new chairman should be appointed every 2 year, however it's allowed to be re-elected one time (total 2 x 2 years). Chairman candidates should be announced to all present NPTG members at least one week before the annual meeting.

ARTICLE III - Tasks and responsibility

Section 1: NPTG defines at the annual meeting each year what tasks should be looked into the next year.

Members make use of electronic devices such as phone/fax/mail for taking decisions between the "face to face" meetings.

ARTICLE IV - Meetings

Section 1: The date, time and place of the next annual meeting shall be set by the NPTG at the annual meeting.

Section 2: Extra meetings may be called by the members of the group.

Section 3: Notice of each meeting shall be given to each member, by e-mail, not less than one month before the meeting.

Section 4: The agenda for the meeting should be sent out by e-mail at least two weeks ahead of the meeting.

ARTICLE V - Committees

Section 1: When needed the group may form ad hoc working groups with a specific interest or task. The NPTG appoints and agrees upon the members of the ad hoc group and decides on overall policy and principles governing the activities.

ARTICLE VI - Publications and Scandiatransplant database

Section 1: Any member of the NPTG can make a suggestion on a topic for an article using data from the common database.

Section 2: The group must be consulted and give its acceptance on the relevance of each publication.

Section 3: Authors shall be those who significantly contribute to produce the publication. Section 4: All publications and reports using other country or centre data must be presented to and accepted by all involved centres.

10. Pancreas exchange and payback rules

Bengt Gustafsson has prepared the following suggestion with the main objective being maximum usage of organs:

- Any pancreas from a donor <50 years old and with a BMI <30 should be considered for pancreas/pancreas-kidney recipients.
- A pancreas can be used without any limitation in own centre.
- If there is no suitable recipient in own centre, the pancreas (and kidney if SPK) has to be offered to ABO compatible recipients in other centres. The centre at the highest position on the rota list accepting the pancreas will receive it and be put last.
- Shipment of a kidney is only obligatory if no other kidney exchange obligation with higher priority (as defined by Scandiatransplant) exists.
- The receiving centre has the responsibility for the pancreas procurement.
- The receiving centre has to pay back, as soon as possible, with an ABO identical kidney of a quality acceptable to the recipient centre.
- There is no mandatory payback for the pancreas.
- If a pancreas is not used for transplantation or islet isolation, the reason for not using it shall be recorded in Scandiatransplant.

Discussion if the Rudbeck islet laboratory should be on the rota list or not, that islets should be mentioned in a more positive manner and coordination of exchange rules with the Nordic kidney group. You are entitled to payback with an ABO identical kidney (no payback for the pancreas but for the kidney) but have the possibility to accept not ABO identical.

Additional suggestions from the group:

- Rules are replaced by recommendations
- Has to be offered is replaced by strongly recommended
- The reason why a perfect organ is not used for transplantation or isolation has to be registered.
- A yearly audit at the $N\pi TG$ meetings.
- Any pancreas from a donor 50 to 70 years old and with a BMI <35 should be considered for islet isolation.
- Rudbeck laboratory is last on the rota-list and if no centre has a pancreas recipient the pancreas can be utilized for islet isolation.

Bengt Gustafsson will write a new draft with exchange and payback rules.

Torbjörn Lundgren will review the Scandiatransplant registry and report the reasons why organs (pancreas) are not used from donors.

11. Common immunosuppressive protocol

The group has already decided to aim for a common Nordic immunosuppressive protocol for pancreas as well as for islet transplantation. If all **N\piTG** could agree on a common immunosuppressive protocol the possibilities for scientific evaluation would be much better. The largest difference is Uppsala not using ATG in SPK. UK use Campath.

All centres send their actual protocols to Bengt Gustafsson who together with Torbjörn Lundgren will prepare suggestions for a new common protocol for immunosuppression and adjuvant therapy.

12. Follow up registry

Also follow up should be as common as possible to increase the possibilities for evaluation. The group with Bengt Gustafsson, Bengt von Zur-Mühlen, Maria Svenaeus Lundgren and Rune Horneland continue their work.

13. Next meeting

The **N\piTG** has decided having meetings twice yearly. The next meeting is on Tuesday 28th March 2017 in Stockholm, Arlanda 9.30-15.30h. The scientific *Islet meeting* will be on the 11th of January 2017. The combined IPITA/EPITA meeting in IgIs will be 28th to 31st of January 2017.

14. The meeting ended

Bengt Gustafsson closed the meeting.

Stockholm Arlanda October 27th 2016

Bengt von Zur-Mühlen Secretary Bengt Gustafsson chairman