

Nordic Kidney Group
Constitution meeting
20-Nov-2003, 10.00 am at Amtssygehuset i Herlev

Present:

Nordic transplantation/nephrologic departments:

James Heaf	- Amtssygehuset i Herlev
Bente Jespersen	- Odense Universitetshospital
Lauri Kyllönen	- Helsingin Yliopistollinen Keskussairaala
Melvin Madsen	- Skejby Sygehus
Lars Mjörnstedt	- Sahlgrenska Universitetssjukhuset
Nils H. Persson	- Universitetssjukhuset MAS
Anna Varberg Reisæter	- Rikshospitalet
Søren Swarts Sørensen	- Rigshospitalet
Gunnar Tufveson	- Akademiska sjukhuset

Nordic uremic registries:

Páll Asmundson	- Mr. Island
Torbjørn Leivestad	- Norsk Nefrologiregister
Hans Løkkegaard	- Dansk Uremi register
Staffan Schön	- Svenskt Register för Aktiv Uremivård

Scandiatransplant:

[Christian Mondrup](#)
[Frank Pedersen](#)

Absent:

[Gunnar Tydén](#) - [Karolinska Universitetssjukhuset](#)
[Niels Grunnet](#) - [Scandiatransplant](#)

- I. Meeting called to order at 10.05 am by Hans Løkkegaard.
Nils H. Persson described the long run from the first agreement to include uremic follow up back in 1993 up to today, where all five involved countries for several years have donate their yearly follow up into Scandiatransplant's database. Also the importance of transparency towards the public, authorities, the press, science and related uremic organisations was emphasised

II. **DECISIONS**

A. Constituting NKG. One member shall be appointed from each hospital involved in kidney transplantation and one from each national uremic registry. Torbjørn Leivestad was elected as chairman of the group for one year.

Until further notice Finland and Island are only structured to one member each, the people present at the meeting (except Scandiatransplant) are members of the group.

All members agreed to make use of electronically devices such as phone/fax/mail for taking binding decisions between the yearly “face to face” meetings.

A “chairman group” was founded with one member from each country - James Heaf (DK), Lauri Kyllönen (FI), Lars Mjörnstedt (SE) and Torbjørn Leivestad (NO).

Additionally a group for code evaluation was founded consisting of - Lauri Kyllönen, Hans Løkkegaard, Melvin Madsen, Torbjørn Leivestad and Staffan Schön.

NKG decides on overall policy and principles governing the activities of working groups.

B. Publication rules. A very elaborate discussion with all aspects from the NKG to everybody involved, who should be credited, but a decision was reached.

- Homepage:

All units and persons involved in NKG will be mentioned in appropriate pages.
All publications showing country or center data must be presented and accepted by all members of the NKG first.

The homepage shall be written in plain words to be easy understandable by all visitors.

- Annual report:

The name of the unit of the representative will be acknowledged.
NKG decides on the content of annual reports.

- Publications:

- Any member of the NKG can make a suggestion on a topic for an article using data from the common database.

- The group must be consulted and give it's acceptance on the relevance of each article.

-Authors shall be those who significantly contribute to produce the article.

- When the article is ready for publication, the group must be presented the content before publishing. If the conclusion is harmful to the group or a single center, the group has the right to ask that to be rewritten.

- People contributing to an article in the line of their daily work shall not be in the publisher list, but they can be acknowledged.

C. Data exchanges. The data that is been exchanged today between Scandiatransplant and National registries is legal and uncontroversial.

Extended import into Scandiatransplant must be sanctioned by NKG.

The National representatives must sanction extended import to National registries.

III. ONGOING ACTIVITIES

A. Presentation of NKG.

- Torbjørn Leivestad's slide-show from 2001 was discussed and a subset of them was selected to be the start of an Internet presentation and a future annual report.
- The "chairman group" will discuss on further presentation to be presented to NKG.

B. Code evaluation.

- The "code group" will investigate the possibility of replacing the present [EDTA](#) codes with [ICD-10](#) codes in Scandiatransplant. It must be noted that SRAU and Norsk nefrologiregister still is using EDTA in their national registry.
- The definition of "Date of graft loss" used in each registry must be clarified.

C. Upcoming publications.

- It was decided that Melvin Madsen may start collecting data from the individual centres for a case study on Kidney exchange.
- A case study on the outcome of donations from donors older than 65 and older than 70 will be initiated by Nils H. Persson and Melvin Madsen.

D. Present and future data exchange.

- The possibility of importing patient diagnosis from National registries was discussed. Today 57% of the Cadaveric and 60% of the Living transplanted patients have an identified diagnosis.
- Ischemic time can be extracted from Scandiatransplant, however it's only usable if both "Preservation started" as well as " Transplantation Date" is entered correctly with date and time.
- Data presentations for ones own center compared with total Scandiatransplant figures can be requested from Torbjørn Leivestad.

IV. NEXT MEETING

Nils H. Persson will be hosting the next meeting at [Universitetssjukhuset MAS](#) November 18 2004.

Respectfully submitted,

Frank Pedersen, Scandiatransplant