

The Chairman's Report for the period from May the 15th 2008 until April the 14th 2009

On behalf of myself, as Chairman of the Board of Scandiatransplant, I have the pleasure of presenting this report for the above mentioned period to the Council of Representatives. The transplant activity data and financial aspects refer to the year 2008.

The Board and I would like to honour our former colleague Hans Brynger who passed away after a long illness in February this year. Michael Olausson has said memorial words.

The Board has consisted of:

Arnt Jakobsen – chairman
Magnus Bodvarsson – Iceland
Lauri Kyllonen – Finland
Michael Olausson – Sweden
Per Pfeffer – Norway
Søren Schwartz Sørensen – Denmark

The Board has had 2 meetings; in Copenhagen on the 22nd and the 23rd of September 2008 and in Copenhagen on the 2nd of March 2009. In conjunction with the September meeting in Copenhagen, I visited the transplant centre in Odense and I spent a few hours with Claus Bistrup who gave me an introduction into the transplant activity in Odense. A third Board meeting is planned in Malmø on the 14th-15th of April 2009 in conjunction with the Council meeting on the 15th of April. The Medical Director of Scandiatransplant, dr. Niels Grunnet has attended both Board meetings and has written the minutes from each meeting. The minutes of the 2 meetings have been sent to the members of the Council of Representatives and those employed by Scandiatransplant. In conjunction with the first Board meeting in Copenhagen, the Board met with representatives of the health authorities in the Nordic countries (Nordisk Transplantasjonskomite). The minutes from the meeting, on the 23rd of September, has been sent to the Council of the representatives. At the meeting of the Council of Representatives in June 2004 in Århus, the chairman announced his intention to visit all the transplant centres within Scandiatransplant. A visit to Gothenburgh still remains, but will hopefully take place in May this year.

Organ transplant activity in 2008

The organ transplant activity in the Nordic countries (25.1 mill inhabitants) has in 2008 been higher than ever. Within Scandiatransplant there were 398 deceased donors (DD 15.9 / mil). (390 in 2007) (The DD rate varies from 6.3 in Reykjavik to 20.5 in Oslo, with averages for Iceland 6.3, Denmark 11.8, Finland 15.2, Norway 20.5 and Sweden 16.5 pmp. DD organs have been transplanted into 1268 recipients which is an all time high (1259 in 2007). The distribution of organs were as follows: (2007 figures in brackets)

DD kidneys: 691 (679)
DD kidneys and pancreas: 24 (24)
DD liver: 295 (286)
DD liver and kidney: 8 (8)
DD hearts: 119 (125)
DD heart and lungs: 4 (4)
DD lung (single and double): 107 (115)

DD heart and kidney: 2 (2)
 DD double lung and kidney: 1 (0)
 Whole organ pancreas only: 1 (0)
 DD islets: 12 (13)
 DD multivisceral: 4 (2)

In addition 322 (277) were kidneys transplanted from living donors. (12.8 pmp versus 11.1 pmp in 2007)) plus 13 (8) living domino livers.

The numbers of transplanted recipients (irrespective of the numbers of organs transplanted into the recipient) is the basis for the cost of Scandiarttransplant to each centre. For each recipient of organs(s) from DD the fee is DKK 3.100 and for each living donor transplant the fee is DKK 800.

Scandiarttransplant cooperates with national and supranational organ allocation organisations. In 2007/2008 the import from outside Scandiarttransplant into Scandiarttransplant countries was 5/2 organs and the export from Scandiarttransplant area to outside countries 4/3 organs.

Waiting list statistics end of 2008 (end of 2007 in brackets) were:

Kidneys : 1168 (active) – 46/ pmp -(1170). 1567 (active+inactive) (1623)
 Kidney – pancreas; 40 (27)
 Liver: 92 - 3.8 pmp - (76).
 Heart: 50 - 2.0 pmp - (46)
 Heart-lung: 3 (2 patients)
 Single/double lungs: 101 (96).
 Islets: 12 (11) patients
 Liver-kidney: 4 (4)

Economy

The financial situation of Scandiarttransplant is acceptable. At the beginning of 2008 Scandiarttransplant had DKK 2.954.243 in an account at Aarhus University Hospital, Skejby. The accounts for the fiscal year 2008 are not available at the time of writing and will be presented at the Council meeting in Malmø. (The Council meeting is a month earlier than usual). A total of DKK 4.198.800 has to be paid by the owners for the year 2008. Scandiarttransplant received in 2008 the remaining DKK 60.000 from Nordic Council of Ministers. Scandiarttransplant has been informed by the Secretariat of the Nordic Council that there is no money available for health related projects for 2009.

Personnel

Scandiarttransplant employs at the end of 2008, 5 persons. Dr. Niels Grunnet as Medical Director, is engaged for 7 hours/week (his main job is as Head of the Blood Transfusion Service), one person is employed full time; Frank Pedersen who is in charge of the day-to-day running of the computer system as well as being the person who has almost daily contact with the users of the system and Christian Mondrup has during 2007 worked in about a ¾ to a full position and has been partly responsible for construction of the database and is in charge of programming. Susanne Sønder is working 25 hours/week as secretary. It has long been a wish of the Board to employ another IT person (and it has been in the budget for 2007 and for

2008), but it has proved difficult to attract the right person. In the fall of 2008 a fifth person, Bo Hedemark Pedersen was employed. It was the intention that he would focus on the IT development project. He has a university degree in computer science and worked previously for UNI-C (the firm that in fact designed the present Scandiatransplant IT database in the early 90'ties). In UNI-C he was also responsible for the Danish Uremic Register. He has also designed a register for follow up of Danish leucemic patients. He is at present employed for 3-4 days a week (see more below).

The computer system – the present day situation (the 8th of March 2009)

The main object of Scandiatransplant is to run a waiting list based on histocompatibility data, waiting time and the presence of antibodies in patients waiting for a transplant from a deceased donor, and to act as a clearing house for organs from deceased donors based on the above principles. The existence of a well designed and well functioning system is the sole basis for Scandiatransplant's existence. It is the opinion of the users that so far these objectives have been met, but that the inter-phase of the system is not sufficiently user friendly. As a result it was decided by the Council in 2004 that a more updated system, including a redesign of the data-model was absolutely necessary.

Defining the design ("kravspesifikasjon"), was carried out by the firm Oracle. Oracle was chosen because our present system uses Oracle technology. The design for the new system was ready by the beginning of April 2006 and a tender went out on April the 8th 2006. The firm Oracle was chosen to carry out the job. The project management would be carried out by Skejby -IT for which Scandiatransplant paid a monthly fee. The Council was given a thorough orientation at its meeting in Gothenborg in May 2006. The project-offer from Oracle consists of 3 different phases, each can be divided into many "steps". For Scandiatransplant it was of importance that the new system could exist side by side with the new system. Tests, during the autumn 2006 confirmed that they could. Oracle hired its Indian partner to start the work.

At the council meeting in Oslo in May 2008, I reported that work has progressed, but rather slowly. There had at the time of the Oslo meeting been a change of personnel 4 times over in Oracle and the 3 times over in Skejby-IT since the start of the project. The system delivered by Oracle in the end of October 2007 was full of mistakes, and irregularities. Of approximately 500 fields tested, about 250 contained minor or more major faults. Since the meeting in Oslo in May 2008 the project does not seem to have progressed at all. Our dissatisfaction with the progress and management of the project was expressed to Skejby IT and Oracle throughout the spring 2008. Not only had deliverance not happened on the agreed time, the quality of what has been presented was far below acceptance. Documentation of the new system was also missing.

Following a letter in May 2008 from the then acting IT director at Skejby, the IT steering group of Scandiatransplant (the Skejby IT director, Søren, Niels and myself) meet with 2 persons from DK Oracle (one salesman and one computer man) on the 1st of July 2008 at RH in Copenhagen. The Oracle people presented a slick slide show and about 1 m of documents (all of which turned out to be of no value to our project). In no uncertain words they were told that what they had delivered were not what one could expect. The Oracle persons promised to get back to Scandiatransplant ("we were very important customers"). So far nothing apart from a bill has appeared.

Bo Hedemark Pedersen started work in November of 2008. His first job was to analyze the project and its development and work carried out by Oracle including the licences that had been part of the project. As part of the project management financial transactions between Scandiatransplant and Oracle have been handled by Skejby-IT. For this and being project manager Skejby-IT charged Scandiatransplant a management fee. From autumn 2008, due to internal reorganisation at Skejby, the IT department could no longer function as project manager. Bo Hedemark Pedersen has thus been appointed Scandiatransplant's IT project manager.

Oracle sells licences bunched together in packages. The price for such a package depends on content and thereafter a yearly fee of 20% of the initial cost. Many of Oracles programmes exist in different versions. Packages with tools for development purposes are more expensive than those without. Oracle's policy is that one cannot just buy a package and then not pay for the parts not being used, but one has to terminate all licences and then re-buy what you really need. If the development of a new programme is Oracle dependent, a buyer like Scandiatransplant easily becomes dependent on Oracle also in a financial manner.

Our present system and the development of the new system use programmes for two servers. Both of these are of the type enterprise and the total price for transfer from Skejby-IT to Scandiatransplant is DKK 600.000 + the yearly fee of 20%. Analysis carried out by Bo Hedemark Pedersen with assistance of persons from the computer firm Miracle show that the functionality necessary for running our present system, upkeep and further development of our present system could be managed by ordinary licences for the price of DKK 60.000 and a yearly fee of DKK 6.000. These packages have been bought and installed, a process that took 8 hours and was the reason that the Scandiatransplant system was non-functional for some hours on the 12th of January this year. The system has since performed perfectly and certain functions are even quicker than before.

Our former programme packages had in addition to programmes for running the system also programmes for development of new forms in our new system. It would cost DKK 100.000 + a yearly 20 % fee of the original cost to transfer this part of the packages from Skejby - IT to Scandiatransplant. Developing new forms can, however, be done with the use of open source programmes. Using such programmes reduces our dependency on suppliers like Oracle in further development work. The steering group decided that it would be cheaper to scrap the work Oracle had been done.

Oracle has delivered the database-part of the new system. It has been tested and found to function well. Forms delivered for phase 1 have been tested and found not useable. The coding is valued to be of a poor standard and difficult to further develop and support. Many of the forms are direct copies of the present system and do not seem to be a product of a new development. The programme delivered by Oracle does not contain so-called "versioning" which means that when developing the product, if unstable, one can retreat to a former, stable version. Oracle has invoiced for all this work, unsatisfactory as much of it is, 2222 hours. (for comparison; a similar clinical database relating to follow up on leucemia patients, an other firm invoiced 240 hours.)

Oracle have reported that they have coded and unit-tested their product. This is work that Scandiatransplant presumably have paid for. In spite of various e-mails to the representatives of Oracle that we met on the 1st of July 2008 in Copenhagen, Oracle has forwarded no documentation that such work has been carried out. For Scandiatransplant it is of importance

to have such documentation in our future work. Bo Hedemark Pedersen has contacted Oracle in order to get this material.

Oracle planned to develop a 2 layer strategy with a database and a user-inter-phase. The analysis carried out by Bo Hedemark Pedersen has pointed out the possibility for a 3 layer strategy, a database, an application/web-server and a client/internet browser. Such a design will make development and transfer to the new system more fluent and make it possible to access new parts of the system as they come along. It will also make it possible to integrate earlier in the process an XML part, necessary for communication with other systems like the Finnish system. Necessary programmes for this are freely accessible.

After years of work and money spent, Scandiatransplant does not have a new system that is ready for use. It is completely unacceptable that much of what Oracle has delivered is not up to expected standard. A continuation of the present strategy binding ourselves to Oracle, both on short and long term, will be expensive.

Bo Hedemark Pedersen has in collaboration with Frank Pedersen and Christian Mondrup suggested to the Board that our development strategy should change direction. Scandiatransplant should adapt a 3 layer architecture in our database, with the use of open standards and development taken care of Scandiatransplant itself with the additional help from hired student programmers (on an hourly basis). The use of open standards will secure documentation of the system. The steering group has decided that the first development project should be the "Nordic Registry for follow up in Living Donors". The plan is to have this in production around the time of the Council meeting in Malmø. End-users should therefore within a short time have the possibility to use the system daily.

This new strategy implicating a break from the previous Oracle based development model were discussed at a steering group meeting on the 21st of January and confirmed at the Board meeting on the 2nd of March. Some of the elements have already been implicated and certain contracts with Oracle terminated.

I and the Board have wanted to elucidate as properly as we are able to about the status of the IT project. It has taken many, many years, a lot of extra work for our 2 IT people and Scandiatransplant has spent a lot of money. The project was ambitious and technically difficult. As neither I nor the Board has any IT expertise and even our 2 IT persons do not possess the kind of IT knowledge needed to manage such a project, the Board sought this in Skejby- IT. Obviously, neither they had enough knowledge to understand and to ask the right questions. Scandiatransplant has been taken for a ride. Scandiatransplant had been offered and paid for a chromed Bentley, which was difficult to start nor was able to do a right or left hand turn when the driver wanted to. A standard, off the roller band, Volvo or Saab would have sufficed. At the Board meeting on March the 2nd the Medical director was instructed to contact the regional county lawyer for advice.

Scandiatransplant –VAT (moms) exemption.

Scandiatransplant has in period not had to pay VAT on the invoices from outside firms concerning the IT-projects while these were handled by Skejby IT. With the reorganisation meaning separation from Skejby-IT for development and operations apart from an agreement on some technical issues this system will no longer exist. One possibility, in order to keep such an arrangement is to become a department of Skejby Sygehus. Skejby would handle our

accounts and bank accounts. Said in other words, Scandiatransplants money would become part of Skejby Hospital's finances and not appear as Scandiatransplants "own" money. In case of financial crisis, Scandiatransplant may have to execute cuts ordered by Skejby Sygehus. The Board discussed this on its meeting in March 2009 and decided not to enter into such an arrangement with Skejby Sygehus. Scandiatransplant will continue as a legal unity that has to pay VAT because we are an association according to Danish law.

Scandiatransplant's Acceptable Mismatch Programme (STAMP)

Last year the Council of Scandiatransplant decided to launch an acceptable mismatch programme. Governing rules and a committee for accepting candidates have been set up (Mats Bengtson, Thorbjørn Leivestad, Jussi Merenmies and Bjarne Møller (coordinator of the group)). In the steering committee they are supplemented with two from the Nordic Kidney Group (Nils H. Persson and Lauri Kyllönen). All centres performing DD transplants have wanted to join the project. Centres with new candidates should contact one of the committee. The project became operable by the 1st of March 2009 after adjustments of the Scandiatransplant datasystem. Several candidates are under "clearance". The committee will report annually to the Council. "The Rules for exchange of kidneys from DD within the Scandiatransplant cooperation" has been amended as of 1st of March, adding STAMP patients as priority no. 5. (see: http://www.scandiatransplant.org/Manual_STAMP_26jan2009.pdf)

Follow up on living renal donors from outside Europe/North –America.

Up to recently there has, within Scandiatransplant, existed different models for follow up of living kidney donors. Following "The consensus statement of the Amsterdam Forum on the care of the living donor" (Transplantation 2005; 79; 53-66), The Council of Europe's resolution (CM/RES 2008) 6 "On transplantation of kidneys from living donors who are not genetically related to the recipient" and more recently "The Declaration of Istanbul" (Lancet vol 372, July 5, 2008 ; 5-6) all centres have enacted a policy for follow up of living kidney donors in line with the recommendations in these publications.

During the years a small number of recipients living in the Scandiatransplant area have received a transplant from a living donor of a non Scandiatransplant country. Most of these donors have been a relative and an inhabitant of a 3rd world country in Africa, Asia or South-America. Post donation follow up of these living kidney donors, will necessarily be cumbersome, if at all possible. The leading nephrologists of the 4 Danish transplant centres saw this as a problem and thus wrote to Sundhedsstyrelsen in August 2008. They presented the problem and suggested certain measures. They stated that life long follow up was difficult to arrange and that flying the donor from its home place to Denmark every 2- 5 year would be impossible. Furthermore they suggested a "cooling off period" (after acceptance of the donor, the donor had to return to its native country to think the situation over for a 3 month period before a final say). Finally they asked advice relating to possible claims in case of serious complications.

The Board discussed this matter in September 2008 and conducted in October 2008 a survey to find out about the size of the problem. During the last 5 years Herlev had performed 4 such transplants, RH Copenhagen 5, Odense 1, Århus 2, Helsinki 0, Oslo 2, Gothenburgh 4, Malmö 0, Stockholm 3 and Uppsala 1, totalling 22 transplants over a 5 year period, in other

words about 4 transplants a year. The centres had a varied policy regarding follow up. One centre had a follow up visit to referring nephrologists at one year, but all the others had no scheduled visit. Some centres had internal rules relating to content of the discharge note as to “whom it may concern”.

Sundhedsstyrelsen replied that as “life long follow up” in Denmark seemed impossible, a pragmatic solution could be to make it clear to the potential donor that if a donation took place, the donors would have to organise follow up for themselves. Regarding how to handle possible claims Sundhedsstyrelsen passed the question to another Ministry. Sundhedsstyrelsen concluded that if there should be special risks related to donation, in particular with the view that the donor lived in an area where medical follow up would be difficult to arrange, it would be in the donors best interest not to become a donor.

The Board discussed this at the meeting in March 2009 and what recommendations the Board should suggest to the transplant centres. There seems 2 options; (1) as a medical follow up is not possible at the centre of donation, such a follow up had to be arranged by the donor in his/her country. The donor would not become a participant in the Scandiatransplant LD Registry. A cooling off period might in itself reduce the number of potential donors. (2) as the number of donors who cannot be ascertained a medical follow up in their own country, the Board would recommend centres not to accept donors from a 3rd. world country unless one can establish, prior to the donation, a medical follow up system in line with the recommendations of the Amsterdam Forum.

The Board decided to recommend to the Scandiatransplant centres to follow the second alternative. In case of a potential donation the Board recommended the centre to practice a cooling off period.

Suggestion from Riga transplant centre to collaborate with Karolinska Sjukhuset regarding a liver transplant programme and Eurotransplant’s twinning programmes

The transplant centre in Riga does not perform liver transplants. Livers are thus not procured. The Riga centre and the authorities want to start a liver programme. In October/November 2008 surgeons from the Riga transplant centre visited Karolinska with the intention to train Latvian surgeons in liver procurement. One discussed the possibility of liver procurement in Latvia and liver transplantation of a Latvian patient by Swedish surgeons in Riga or at Karolinska. In case of a non Latvian recipient, procured, surplus organs could be “given” to Karolinska.

There are, however, rules within Europe for such activities. Organs from another country cannot be offered to a specific transplant centre within another country, they have to be offered to the allocation organisation to which that country belong (in casu Scandiatransplant/ Eurotransplant, or national allocation organisations) who then decides on that organisation’s normal criteria where the organ should be transferred to. The reason for this is quite clear, it avoids favourism and it prevents selling and buying of procured organs.

A Scandiatransplant centre can of course send surgeons to non Scandiatransplant country to perform transplantations, if the country’s authorities accept these doctor’s medical status. Similarly a transplant centre in Scandiatransplant centre can transplant a foreign national who “brings” an organ with him/her (in casu a Latvian patient with a liver procured in Latvia.)

Eurotransplant (ET) has formal arrangements relating to such activity on a regular basis. They are referred to as **twinning agreements**, and there are 3 different models. To each of these models there are some rights and obligations and something about finances. Model A concerns itself with cooperation between a ET and a non-ET centre to promote donation and transplantation. Model B is a transplantation support programme where the ET centre on behalf of the non ET transplant certain patients. This can only take place over a short period. These patients have to be approved by ET and the patients can then be put on the ET waiting list. Again there are certain specific rights and obligations (among others "payback" if an organ comes from another ET country). Organs from the non-ET centre have to be offered to ET who decides where that organ is to be transferred. Model C deals with delegated responsibility for a specific transplantation programme.

The Board has discussed this by e-mail and at the meeting in March. The advice to Karolinska, if they want to proceed with a cooperation and helping the Riga transplant centre to establish a liver transplant programme (which the Board endorses as a good project) it should be in line with one of the 3 ET models of twinning. Preferably the Board would like to see an agreement between Scandiarttransplant and Balt-transplant. However, Balt-transplant is not very functional at the moment. The Board decided that Michael Olausson should bring the matter forward on the liver group meeting in Scandiarttransplant due to take place in the middle of March.

EU Directive on tissues and cells.

This directive also concerns Islets of Langerhans. However at a meeting of experts within the Council of Europe, there were some suggestions that Islets should belong to the Organ Directive.

EU Directive on Organ Transplantation

A Directive on “Standards of quality and safety of human organs intended for transplantation together with the Action Plan on organ donation and transplantation (2009 -2015): Strengthened cooperation between Member States” were adopted by the Commission on the 8th of December 2008. The Directive is now a proposal to the European Parliament. Scandiarttransplant has presented its comments on the Proposal to the Commission in February 2009. Prior to writing Scandiarttransplants comments I had contact with Eurotransplant so as to coordinate our comments. Scandiarttransplant’s comments – a general and a more detailed are attached to this document. The Directive can be found on http://ec.europa.eu/health/ph_threats/human_substance/oc-organs/oc_organs_en.htm

The work prior to the presentation of the proposal has taken into account the positions of various experts in the field of transplantation. From July 2007 to January 2008 there have been 3 one-day meetings with experts where Scandiarttransplant have, as have Eurotransplant been allowed as observers with full status. Representatives from the Scandiarttransplant area have been Bo-Göran Ericson, Niels Grunnet and myself. In December 2008 some of the same experts attended a meeting in Brussels where the object was to plan a meeting of experts and others in March 2008. This will be full 2 days meeting with representatives of all member states and associates through EFTA/EEA. Various experts have been asked to speak on given subjects. I have been asked to speak about living kidney donation in Norway. As Sweden was not present at that meeting in December, I was asked to speak about “The perspective of heavy media investment yielding poor results” with reference to the Swedish media campaign

in 2002-2005. In collaboration with Håkan Gabel, I prepared a presentation, but I have been approached by Åsa Welin, executive of the Swedish Donation Council who thought it more appropriate that she should speak on that matter. I thus withdrew my presentation.

The Commission plan to arrange 2 such meetings a year over a 2 year period.

Further activity within the transplant community with Scandiatransplant

Reports will be given by

The Living Kidney Donor Registry
 The Nordic Kidney Group
 The Tissue-typer Group
 The Nordic Liver Study group
 The Nordic Thoracic Study Group
 The Infectious Disease Group.
 The Transplant Coordinators Group
 The Islets Cell Group

Nordisk Transplantasjonskomite

The yearly meeting with representatives of the Health Authorities in the Nordic countries took place in Copenhagen on the 23rd of September 2008. All the 5 Nordic countries were present. The minutes have been sent the representatives of last years Council
 The following issues were discussed:

1. The Board underlined the importance of regular contact with the Nordic Health authorities on matters relating to organ transplantation and the need for the Nordic countries to seek to speak with one voice when meeting the authorities of other countries.
2. Comments were given on donation-rates in the various countries. There is a decrease in Finland and a raise in Norway and Sweden. There is an increased pressure to increase LD in Finland. In Norway a reimbursement system for payment to donor hospitals (NOK 70.000) have been in place since 1.1.09
3. Comments were given on the islets cell work carried out in Uppsala.
4. The Danish representative commented on the function of the Danish Centre for Organ Donation. The Council will focus on education (EDHEP), data collection and organisation. The Council receives DKK 9 mill /year. They are also discussing various models of organ donation teams.
5. The Swedish representative reported on a national survey on the potential heart-beating solid organ donors in Sweden. Only 59 % of potential donors became actual organ donors. The goal is to increase this to 90%
6. Scandiatransplant informed about the IT situation (per September 2008)
7. Scandiatransplant informed about the present work within the Council of Europe now within the framework of EDQM. A new edition of the Quality Assurance and Safety book is under way. Per Pfeffer is acting chairman of the group.
8. The EU Directive on Organ Donation was discussed.
9. Problems relating to organ trafficking was discussed and the Declaration of Istanbul was distributed to the authorities.

10. The issue of living kidney donors from 3rd. world countries was discussed. The Board of Scandiatransplant will give the various transplantation centres within Scandiatransplant some advice.

11. The next meeting with the authorities will be in Stockholm on the 22nd of September 2009

International contacts

As Chairman of Scandiatransplant I have since the start of my tenure made a point of fostering international contacts. I believe it is in the interest of Scandiatransplant to have close cooperation with similar organisations in Europe, in particular Eurotransplant. I have thus attended their Annual General meeting in Leiden in the fall of 2008 and their winter meeting in Austria in January. Our conversations over the Directive (we have both been members of the special expert group that EU formed when preparing the Directive, and we are both members of the group organising the meeting for all Member States.) have lead to a common understanding and we have used similar arguments to favour our views on certain issues. We have seen that some of the issues we have raised have found their way into the Directive.

A number of European projects have been finalised. Alliance O (lead by France), EURO CET – IT portal for organ information-(lead by Italy) and DOPKI (Improving the Practises and Knowledge in Organ Donation (lead by Spain) are all finished (or about to be). EULID is a Spanish lead project looking at living donation. Scandiatransplant has been asked to participate in an Eurotransplant lead project EFRETOS (European Framework for Evaluation of Organ Transplants) together with representatives from ESOT, Spain, Italy and France, UK. This project is EU financed over 2 years. The project is about to start. One may wonder about all these projects. So far it is difficult to see how useful or important the results or advice is going to be, but my feeling is that Scandiatransplant should try to participate so we at least know what is happening. But as a colleague said: “there is no more to think”. I have written reports from the meetings to the Board. There has been no contact with group ”Global Alliance for Transplantation Registry and Statistical Reporting”, an organization under the auspices of The Transplantation Society which works in close collaboration with WHO.

Subjects on the European agenda

At meetings with representatives of organ allocation systems in Europe, there are 3 issues that keep cropping up; organ allocation systems, transplant tourism and how to deal with non-residents.

- **Organ allocation.** Organ allocation is said to be the art of sophistication. There are various methods for organ allocation. Firstly a more or less stringent “point system” Such systems give fairness to all recipients and is transparent. Eurotransplant, UK-transplant and many national organisations use such an approach. Such systems leads to exchange of a large numbers of organs often resulting in long cold ischemia times. Pre-dialytic transplantation is often difficult to achieve as “time on dialysis” is a factor in the algorithm. The other option, chosen by Scandiatransplant and some national organisations (Spain) is a system of few absolute obligations for exchange of organs, followed by a transplant centred allocation system with emphasis on the need of the individual patient. Such systems allow for pre-dialytic transplant. As more organs are transplanted locally it leads to shorter ischaemia times. But such systems are not fully transparent and may thus be open to criticism by health authorities and patient organisations. The Board decided last year to produce a document with more details

- on the policy of the various centres within Scandiatransplant, but this work is just starting and will be finished for the next Council meeting.
- **Transplant tourism/frank trafficking** does occur and it is in the interest of organ allocation and transplant organisations to get an understanding of the mechanisms and find a way of controlling such activity. Under the auspices of the Ethics committee of the Transplantation Society more than 100 participants; transplanters, ethics people, lawyers and lay people discussed organ trafficking and transplant tourism at a meeting in Istanbul in April/May 2008. A steering committee with Annika Tibell prepared a declaration that was unanimously passed. (reference given above) The Board of Scandiatransplant wants Scandiatransplant to endorse this document
 - Many countries in the south of Europe have a large problem with **non residents** seeking access to the transplant waiting-lists. At the moment there is no uniform attitude to the problem.

Scholarships.

The Board has distributed guidelines for scholarships. Financial support will not be given for attending congresses or for partial financing of post-doc studies. This year there were 8 applicants. Six of these were honoured partly or in full. The Board wants to stress that the reports from site visits are written in such a manner that they have an educational function for members of the transplant community within Scandiatransplant.

Scandiatransplant was founded in 1969

It is 40 years since Scandiatransplant was founded. The Board has discussed how to collect bits and pieces of the history. Obviously it is important to start collecting data now. The Board will, shortly, get back to senior members of the Scandiatransplant community.

Acknowledgments

The Chairman and the Board of Councillors are very grateful to Niels Grunnet, Christian Mondrup, Frank Pedersen and Susanne Sønder for the excellent work they have performed during this year. The Board specially wishes to welcome Bo Hedemark Pedersen to our organisation. Within very short time he has proven himself as a very valuable contributor to the future work of Scandiatransplant. The support of the Board has been invaluable for the function of Scandiatransplant for their support relating to the IT- and other projects. The Chairman will also this year thank Søren Schwartz Sørensen specially, for the extremely valuable work he has done on behalf of the Board in relation to the IT project. The Chairman and the Board would also like to express their gratitude to all those working at the various transplant centres and to the work of the various study groups.

Oslo, the 7th of March 2009

Arnt Jakobsen