

Minutes

Meeting No.: 65
Time: Jan.14-15, 2013
Place: Stockholm, Sweden

Participants: The board of Scandiatransplant:

CHAIRMAN: Krister Höckerstedt, Helsinki (KH)
SWEDEN: Lars Wennberg, Stockholm (LW)
FINLAND: Helena Isoniemi, Helsinki (HI)
NORWAY: Pål-Dag Line, Oslo (PDL)
ICELAND: Margrét B. Andrésdóttir, Reykjavik (MA)
DENMARK: Finn Gustafsson, Copenhagen (FG)
(only present on the 14th of Jan.)

Director of Scandiatransplant:

DENMARK: Kaj Anker Jørgensen, Aarhus (KAJ)

Leader of meeting: Krister Höckerstedt (KH)

Writer of minutes: Kaj Anker Jørgensen (KAJ)

The meeting was done in accordance with a revised agenda sent to the board approx. one week before the meeting.

1. Welcome:

KH welcomed everybody to the meeting stating that he was happy that everybody could take time off to come to the meeting.

2. Agenda and format of the meeting:

The revised agenda was approved. The format would be to follow the agenda, but we would try to get through things that had to be decided and discussed on Monday evening the 14th and leave issues which probably needed longer discussions to Tuesday the 15th. KH asked for a very short description of what was going on in each country.

Norway:

There has been no change. They are worried about the merging of hospitals. 2012 has been the best year ever in number of transplantations and donors. A proposal for definition of adverse events has been sent to the authorities but there has been no reply.

Sweden:

A registry for adverse events has been created at Socialstyrelsen. Donor numbers have gone up and down and there are big differences in neighbouring regions.

Finland:

There have been more donors. These donors have especially come from the Helsinki University Hospital. This is probably due to a new head of the huge emergency department and that a donor committee that has been formed.

Denmark:

Nothing new.

3. Approval of minutes from board meeting No. 64:

The minutes were approved with some comments. The data request form on the homepage: KAJ informed that the data request form had been set on the homepage again after communication with the chairman and after making some minor changes. The board still has problems with this data request form in that it looks like anybody can get any information from Scandiatransplant. KAJ commented that this was not the case and it was not the intention. After some discussion the conclusion was made, that there should be a link from the webpage to a page stating the rules for giving information from the Scandiatransplant database. Kaj Anker Jørgensen should also be added to the list of the people in the office that can be contacted.

The draft for an agreement between Scandiatransplant and Region Midt (Central Region Denmark) in relation to management of Scandiatransplant datasystem as designed by the data protection agency is still in the hands of the lawyer in Region Midt.

The physical place of Scandiatransplant: It is still at department of clinical immunology and the hospital is working on finding another location for the programmers since the department of clinical immunology needs the room that the programmers are in now.

The issues of salary for two of the personnel: We have managed to get a pay increase for Ilse Weinreich although not nearly the amount that was intended. This case is closed for the time being, but should be taken up again at a later time.

The case for Bo Hedemark Pedersen has been investigated. According to the AUH administration there is no possibility for giving extra bonus now as he has already a higher salary than persons in similar position at the AUH. Kaj and the Board should think about other possibilities (mail sent to the board after the meeting).

Possible new staff members: It is clear that the highest priority is to get one more programmer.

Thorax interface testing: The communication with coordinator Ulla Nystrøm has not been completely adequate. We are thinking of inviting her down to Scandiatransplant to see and talk with the personnel.

The liver conversion to web and cooperation with Helsinki: HI now suggests that data are exported from Finland in Excel format as the kidneys. HI and Bo Pedersen should get in contact on this matter.

Intestinal transplantation in Finland: Finland had just started doing intestinal transplantation in adults. They had previously done three in children. The meeting mentioned in the Minutes from the last board meeting has been held, and they have agreed to have a yearly meeting with nurses.

The issue about modernising the tables on transplantation and waiting lists, which come every quarter, is awaiting input from the board on how they want it modernised.

The function and job descriptions for all the personnel are now in place.

4. Status of Scandiatransplant as seen by the director:

a) Present tasks, organisation, legality: KAJ gave a short overview of the Scandiatransplant organisation and its tasks. The primary task is to run a database and application software so that the users can access and put in the data they need for allocation 24 hours a day. In general this is functioning very well.

Secondary task is to give service to the transplant association, the board, the committees, the council of representatives and all the registries we have.

The third task is to give information to researchers, the public, other OEOs and other databases and other interested parties.

A fourth emerging task that we are uncertain of is working for the Nordic governments and transplant centers implementing EU Directives.

Concerning our legality KAJ has been in contact with the national data protection authorities (Datatilsynet), a person Dana Safin. What has come out of these talks is that the responsibility for the data protection lies in Region Midt (Region Central Denmark) for Danish patients. On the other hand the legality of holding sensitive data from foreign patients must be clarified with each country's authorities. We have no written statement on this issue, but this should be clarified via our meetings in the Nordic Transplant Committee with the authorities. KAJ has sent a mail to the lawyer in Region Midt (Anette Sand), but has got no answers. We are still awaiting an answer from Anette Sand on the proposed agreement for cooperation and an answer to our inquiry if we have the correct permissions for Denmark.

Our present written agreements with the ten hospitals that own Scandiatransplant are put down in a so-called "Tegningsdokument" for each hospital. KAJ gave a copy of the Tegningsdokument for each participating hospital in a country to the country's board member. The opinion of the board is that we should have new documents written in English. This should be called membership agreement or certificate of approval. It was decided that KAJ should make a draft and send to the board. When the board members have given their comments, KH will contact a lawyer in Sweden, Tessi Alfthan. She has been representing the Swedish Health authorities in our previous Nordic Transplant Committee meetings during two years, before we ask the hospital directors to sign the documents.

KAJ then gave an overview of the present organisation of the work in the office and the problems that there may be there.

b) Servers – programming – new versus old system: KAJ presented an overview of the servers, the programming and the transforming of the old to the new system. The board was informed about an incidence on Monday Dec. 10th 2012 when there was no access from the internet to our main production server sc15 and also to sc35. The problem was from about 10 o'clock until 8 o'clock the next day, and was solved by a reboot of the system. This led to a meeting with the IT department of Region Midt, which revealed that the contract for service and surveillance we had with Skejby IT did not exist since IT Skejby stopped to exist when the hospitals were merged. Bo Hedemark Pedersen and Jacob Illum from Region Midt IT will negotiate a new agreement. The Region Midt have the principal, that they will not service servers, that are more than 10 years old and they do not accept the operating system Ubuntu, that is used on our virtual servers. They can agree if we have a plan for phasing out the old servers. We have not set a day for moving everything to the new system, but Bo Hedemark Pedersen still hopes that it can be by May 2014. There was made an agreement on a service to reboot the servers 24 hours a day.

c) Public/private; Locality (in or out side hospital): KAJ presented his view on the topic if Scandiatransplant should be a private or a public organisation. The board agreed with his view that we should be a public organisation because we are entirely funded by public institutions, we are owned by public institutions, we deal with health in countries where health matters are mostly public matters, and our function is to support public services. This led to a presentation of the arguments for the Scandiatransplant office staying at the hospital or aiming at some location outside the hospital. The pros are: much cheaper housing, the accounting system and documentation, the management of personnel with payment, tax, pensions, insurance, unions, negotiations etc., the legality and jurisdiction of the association, and that we work for patients and therefore should be in the hospital. The cons are: we cannot organise us as we want to with regard to space, room and facilities, we cannot pay personnel as we want to, and therefore we probably cannot compete with the

private sector for programmers. We have to obey the rules of Aarhus University Hospital, Skejby. The board accepts the present terms but emphasizes that we should work towards being able to decide how we pay our personnel.

Another related problem is, that we cannot get a credit card which gives big problems in reservation of hotel rooms, meeting rooms and facilities for meeting especially outside Denmark. The consequence is also that the director has to use his own Master Card for expenses abroad and must pay the interest rates from his private economy. This is in many ways an unacceptable situation.

KAJ has also been told by Niels Grunnet, that he has investigated many years ago if it was possible to give some compensation to the chairman of the board for the tasks he undertakes for the association, but this was not possible. KH has not asked for such a compensation or asked us to investigate the matter, but KAJ intends to investigate the matter again. KAJ will pursue the issue of being able to follow the board's wishes on payment of the personnel and to get a credit card for the use of the director and the office.

KAJ showed a map of the department of clinical immunology and presented locations we have now. "Teknisk afdeling" (the technical department which is responsible for allocating rooms) is seeking for new rooms at Skejby instead of the rooms where the programmers are sitting, since the clinical immunology department has an urgent need for this room. An architect is coming to visit the "big room" where Ilse Weinreich and Frank Pedersen are working. We want to transform this room into a working room for four people; Frank, Ilse, a student programmer and the director. The room where the secretary is sitting can only be a working place for one person. Niels Grunnet continues to have his office, which has always been owned by his present AUH Department.

d) Responsibility for "data export": Under the heading "who can sanction data export" KAJ took up the question of responsibility for data export from Scandiatransplant. As an example he presented a case where Jane Williamsen of the ISHLT registry asked Frank Pedersen for data for their annual report. The data in our database indicate that heart transplant patients have stopped dying for the last 1 to 1½ year in some hospitals. Frank Pedersen asked Ulla Nystrøm to confirm if the data are updated before export, but Ulla Nystrøm is unable to get this confirmation or the data from the doctors in charge. It was decided not to export the data and KAJ presented an e-mail from Jane Williamson to Frank Pedersen wishing us a happy New Year and asking if the ISHLT registry may expect to receive data from Scandiatransplant in 2013. The conclusion of the discussion in the board is that Scandiatransplant should continue to export data to the ISHLT and we should do what we can to be able to export the data in 2013. Scandiatransplant acted correct and should not export data that are obviously incorrect. In such cases KAJ should send an e-mail to the superior doctor involved with a copy to the board member from the same country.

We discussed who can sanction the export of data. It is accepted that everybody can get their own data. All data that will be published on the homepage and thus become public soon can be given. If we are asked for data from a whole country, the country's board member should be contacted and should sanction giving such data. Data regarding one of the reference groups is sanctioned by the group chairman or the group contact person. Data from all the Nordic countries should be sanctioned by the board or the chairman.

KAJ said that Susanne tries to keep a list of the centers, departments and contact persons, but this is difficult to keep updated. The Scandiatransplant office would like an updated list of all contact persons for the reference groups, but there were no suggestions to how this could be done. A problem concerning which uremic registry from Finland to import data from from 2013 and forward was touched. We are now importing data from Lauri's uremic

registry while we can see that there is another uremic registry which seems to report to EDTA. HI will look into this matter. The Uremic registry in Norway seems very dependent on one person, but they are working on solving this problem.

e) Meetings at the office November 2.: KAJ and KH reported on the meeting at the Scandiatriplant office on November 2nd 2012. The conclusion is that the personnel is engaged in their work and there is a high priority for one more programmer. KAJ reported on frustrations in the office from communication with some registries, but also within the office. He reported the results of the "APV" (Working Place Evaluation) stating that people are engaged in their own projects, but there is some lack of common strategy and common responsibility for priorities. It was stated that the director should learn the system, and this is the intention of KAJ.

f) The Frank Pedersen case - 25 years in the Scandiatriplant office: KAJ then presented the Frank Pedersen case which has been reported at earlier meetings. KAJ gave an overview of how the case had run according to the papers he had read. The case was now closed with the signatures of all involved persons, the last signature dated December 11, 2012. KAJ told the board that Frank Pedersen will have been employed at Scandiatriplant for 25 years on February 1, 2013. He will get some kind of recognition from the hospital and the office will recognize him in a manner which we have discussed at the office. The board approved of this.

g) How to thank Niels Grunnet for his work as MD of Sctp for 14 years. Niels Grunnet has told KAJ that the meeting on November 2., 2012 was his farewell to the office, and Scandia-plant gave him a wrist watch at this time. It was decided that Niels Grunnet will be invited to participate in the board and council meeting in May in Oslo, where he will be thanked by the chairman.

h) Descriptions of function: Are in place, signed, and have been sent to the board members.

i) Rules for economic support to reference groups: The rules for support from Scandiatriplant to meetings are not completely clear. KAJ suggested the following rules which were accepted by the board.

1. Council of representatives' meeting: Travel costs are paid for each spokesperson from each committee. This means 1 person per committee.
2. Committee meetings after application: A maximum of 15.000 DKK are given for meeting room and eating for a maximum of two times a year.
Travel costs for experts called by the committee are covered after application and judgement of the director.
3. First meeting in establishing new committees: max. 15.000 DKK for meeting room and eating. Travel costs for all participants.
4. Coordinators' meeting: this is as other committee meetings, but travel costs are covered for 1 coordinator from each country.

j) Term for working up of organ allocation: KAJ showed an overview of the organ transplantation accounts from each center which result in the invoices sent and the number of representatives. Some members of the board believe that this workup is made on number of organs transplanted. KAJ said that it was on transplantations, people receiving more than 1 organ were only counted once. The board wanted this clarified and KAJ will try and find out where the written rules are. KAJ was very certain that this is the way it has been done for the last years. The board agreed that protests for this workup should come no later than the annual meeting of the council of representatives, at which time the balance is final.

5. Since last meeting:

a) Agreement with Estonia: KAJ presented the agreement with Estonia and the cooperation is in effect from Monday the 7th of January 2013.

b) Newstickers : There has been no newsletter since the last meeting, but there are now newstickers on the homepage, and these were shown.

c) New projects: KAJ opened the discussion of priorities and presented 4 projects from the office that he had got at the meeting with the personnel one week ago as examples of priority. The board decided that the highest priority is getting everything on the new system without much delay. The new projects presented were:

1. The islet project. There is a problem here with the use of pool donors for one transplantation. This needs reprogramming and is now kept on an Excel sheet by Ilse. It is unclear how much Scandiatransplant should be involved in the islet network project. The same is the case with liver cells. For the time being the board accepts that these things are kept on Ilse's computer. LW will look into the issue and report to KAJ.
2. The NKG and possibly the liver group would like to have a facility in the Scandiatransplant program, where they could see exchange obligations balance. These are now kept by the coordinators on paper and problems are solved in the coordinators' group. The board thinks that such a program facility would be a good idea, and can be programmed if there is spare time, but this must not delay the transmission from the old to the new system.
4. The last project mentioned was the last fax issue we have, which is the "high urgent alert". It is the opinion of KAJ that there is not a great demand from the coordinators to change this to the SMS system. The priority is therefore low, but can change if there is a high demand from the coordinators.

If we are asked to make new projects and new registries from the groups, we must be sure that the groups have thoroughly discussed exactly what they want before we can accept the work of creating new registries.

6. Applications for transplantation of non-Nordic patients with non-Nordic organs in the Nordic centers:

This issue was discussed in the light of the heart transplant wish in Helsinki with Estonian recipients and donors, the wish to do a lung transplantation in Göteborg on a German patient, and the lung transplantation of Polish patients as an agreement between Rigshospitalet, Copenhagen and a Polish hospital. Scandiatransplant guidelines for this issue are somewhat unclear. There is no distinction between acute life-saving and planned operations. The board agrees that Scandiatransplant guidelines cannot override the laws in any country, and a country's laws have to be followed. It is suggested that the point 2 should be point 2a, and that there should be inserted a point 2b stating: "the only exception is people who fulfil the urgent criteria for liver". The board thinks that such transplantation should be done after they have been presented to and approved by the board according to point 3f in the guidelines. Such transplantation should also be discussed with the authorities. Scandiatransplant is against any commercial gain from transplantations. KH stated that the patient mobility directive excludes transplantation. KAJ was asked to try and find the exact formulation and wording on this in the patient mobility EU directive.

7. EU 2010/53 and 2012/25 directives – status in each country:

All three Nordic EU countries have passed the laws following the 2010/53 directive.

Finland: The office working with the adverse events issues of the EU Directive is the same that works with the tissues and cells Directive. Sweden now has an AE registry. Oslo has made a suggestion regarding AE and SAE registration. There has been no answer to the suggestion. The suggestion is mailed to the board members by PDL.

- 8. Estonia and expanding Scandiatransplant – present status:** PDL will have a meeting with a group selected to discuss this issue probably on February 25th. The group should provide the council with information at the council of representatives' meeting. PDL asked if there were other papers or guidelines than the articles which should be taken into
-

account. KAJ and the Board members do not think that such other guidelines exist, but will try to find out at the office. PDL will contact Arnt Jacobsen on this matter. Travel costs for people involved in this meeting will be covered by Scandiatransplant.

9. Descriptions of functions at the office (follow-up):

The description of functions for the director was approved.

10. Visions. How do we see Scandiatransplant in 3-5 years.

a) Alertness and communication: Owners/Users : Most board members think that the vision for Scandiatransplant is that it expands in relation to follow-up data and that these will be an increasing part of Scandiatransplant. Ideally the databases on transplant patients in the Nordic countries should be the same. The board members would like to see a database where the members easily can retrieve data and get statistics within the same operation. However, the board members see that the first thing is to get the new system working. KAJ brought up the subject of bringing the coordinators closer to Scandiatransplant. The board emphasizes that coordinators are employed at the hospital by the hospitals and should not be employed by Scandiatransplant.

b) Working environment at the office: KAJ made a proposal for making a strategy seminar for the Scandiatransplant office in order to increase togetherness and take mutual responsibility for working tasks and responsibilities. KAJ suggested that such a seminar could take place away outside the office and could take 1½ day. The conclusion was that the board approves such a seminar and that KH should and was willing to participate.

11. Any other business

The data request form on the webpage was again discussed, and it was concluded that this page must have a link to the rules of what data people can get and who can sanction what they get it. The danger of being dependent on a single person in our small organisation was discussed. We will always be dependent on expertise, but should strive to avoid being strongly dependent on one single person. The keywords seem to be open source programming and careful documentation.

KAJ reported on an interview of A. N. Costa in ISHLT Link, where the role of Scandiatransplant was described in manner that could be misunderstood. A correction will appear in the February issue of ISLHT Link and the wording of the correction has been sent to the board members.

KAJ has responded to an e-mail inquiry from “Die Zeit” on the possibility of the scandals like the ones occurring in Germany could occur in Scandiatransplant. Both issues were discussed with KH

12. Next meeting time and place

It was discussed if we needed an extra meeting before the Oslo meeting in May. The board think that issues regarding the economic workup for 2012 and budgets can be handled by e-mail and signed at the next board meeting which was to be held on May 6th, 2013 in Oslo.

Kaj Anker Jørgensen

Date: Feb. 1, 2013