Annual report 2014

Scandiatransplant office
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Introduction
This annual report 2014 from the Scandiatransplant Office is intended to present a summary of the activities within the Association Scandiatransplant in 2014. It was a good year with an increase in number of donors and transplantations.

Organisation
Scandiatransplant is the Organ Exchange Organisation (OEO) of the five Nordic countries: Iceland, Norway, Sweden, Finland, and Denmark. It is an association and the members are the 10 hospitals performing organ transplantation in these countries. According to the articles the objectives of the association is to:

- to operate as an intermediary in the exchange of human organs and tissue for use by the Association's members in connection with transplantation,
- to develop European cooperation on organ donation and transplantation through maintenance of contacts with other European organ exchange organisations,
- to maintain dialogue with the health authorities in the Nordic countries concerning organ donation and transplantation,
- to operate a database on organ donation and transplantation and communicate optimum information from the database to the Association's members,
- to contribute to promoting the provision of human organs and tissue for use by the Association's members in connection with transplantation,
- to support scientific activities in accordance with the above-mentioned objectives subject to the guidelines laid down by the Council of Representatives.

The members elect representatives to the Council, which is the association’s supreme authority. It approves the members of the board, which represent all the countries, and is responsible for the day to day operations of the association. Suggestions for the activity and allocation rules are brought forward to the board from a number groups and committees.

During 2014 the council had 35 representatives. The chairman of the board was Krister Höckerstedt, Finland and the board members were: Lars Wennberg, Sweden; Helena Isoniemi, Finland; Pål-Dag Line, Norway; Finn Gustafsson, Denmark; and Runólfur Pálsson, Iceland until September when Margrét Andrésdóttir, Iceland again joined the board after her leave.
The Scandiatransplant Office is located at Aarhus University Hospital, Denmark. At the end of 2014 the staff consisted of 8 people in all, 4 full-time, 3 part-time and 1 student programmer. Our programmer through many years, the man who kept the “old system” running, Christian Mondrup, left the Office on August 31st for retirement. The primary task of the office is to maintain and develop the database holding data on all patients enlisted for organ transplantation in the Nordic countries. The database is accessible 24/7 for all health personnel at the member hospital performing organ retrieval and transplantation ensuring correct allocation of organs. In addition to this primary task the Scandiatransplant Office takes care many other tasks such as running follow-up registries, educate and support users, arranged meetings for council, board, groups and committees, comply with demands from owners, researchers, authorities and the public, participate in meetings with local health competent authorities, EU-commission and EU projects.

The total expenses (5.172 mill. DDK) were kept within the 2014 budget of 5.5 mill. DDK (737.000 EUROS) financed by the member hospitals.

The organisation of the Association Scandiatransplant.
Activities in the organisation in 2014

At the 2014 meeting of the Council of Representatives May 7th a mandate was given to form a working group to make a thorough revision of the Articles of the Association Scandiatransplant. The original Articles were adopted at the founding Assembly of Representatives in Copenhagen on 25 August 1993 and only minor revisions have been done since then. The working group was formed and consisted of the board, Lars Bäckman (Nordic Kidney Group), Allan Rasmussen (Nordic Transplant Liver Group), Martin Iversen (Nordic Thoracic Transplant Study Group), Bjarne Møller (Nordic Tissue Typer Group), Kaj Anker Jørgensen (group secretary, Medical Director, Scandiatransplant), Peder Christian Nørgaard (Scandiatransplant programmer) and two lawyers to assist with legal questions: Rasmus Grønbæk Jacobsen (Central Region Denmark) and Michael Sommer, who is an expert on legal matters regarding associations. The group had their first meeting on December 9th. The mandate is to come with suggestions for alterations of the articles to the council meeting in 2016, but a status of the groups work should be given and discussed at a council meeting May 2015.

The chairman of the board, the board, the Medical Director, and members of the staff at the office have all participated in meetings with the EU-commission, about EU-projects, and with the competent healthy authorities (CA) of the 5 Nordic countries. The board has made a proposal to CA to let Scandiatransplant be the place, where serious adverse events and adverse events related to organ donation and transplantation are registered and thereafter sent to the local competent authorities. The proposal has not yet been accepted by the CA.

The chairman, board and Medical Director have had meetings with the health competent authorities, the leadership of Aarhus University Hospital and EU to clarify their relationship to Scandiatransplant.

At the Office the top priority has been given developing the new Scandiatransplant user interface, which has been named “YASWA”. At the same time effort is still put into keeping everything functioning 24/7.
Transplantation and organ procurement activity
The year 2014 has been a good year for organ transplantation in the five Nordic countries due the increase in the number of utilized deceased donors. In this report we have chosen to present some key figures and compare some of them with data from 2005 and onwards showing the last ten year period.

First we looked at the total number of transplanted patients and compared with the number of patients on the waiting list at the end of the year. Although 2014 was the year with most transplantations, the demand has also increased so that at the end of 2014, there was also the highest number of patients on the waiting list.

In 2014 the number utilized donors was the highest in the 10-year period for the whole Scandiatransplant area and for all the Nordic countries except Iceland in actual numbers and PMP (per million population). The number organs used per donor, the age and demographics of the donors have not changed significantly during the ten year period. Thereafter we present data for the different organs.

Further presentation of Scandiatransplant data is available in the annual slideshow:

http://www.scandiatransplant.org/resources/dias2014_v2.pdf
Total transplanted and waiting patients\textsuperscript{1} within Scandiatransplant

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\textsuperscript{1} Including transplantation and waiting list figures for kidney, heart, liver, lung and pancreas.
Utilized deceased donors\(^2\) in numbers in Scandiatransplant

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<td>+36,21%</td>
<td>+26,32%</td>
<td>-25,00%</td>
<td>+4,50%</td>
<td>+9,93%</td>
<td>+15,75%</td>
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\(^2\)Definition of utilized donor: An actual donor from whom at least one solid organ was transplanted.  
Utilized deceased donors pmp in Scandiatransplant

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\[^{3}pmp: per million population\]
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<td><strong>AB0 blood type (%)</strong></td>
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\(^4\) Organs included Kidneys, Hearts, lungs (each single lung transplanted are counted), livers (each split liver transplanted are counted) and pancreas.
Kidneys 2014

- Total amount of patients waiting for a kidney as of 1st of January 2015: 1828
- Patients transplanted with kidneys from living donors during 2014: 347
- Patients transplanted with kidneys from deceased donors during 2014: 756
- Kidneys imported and transplanted from other European Organ Exchange Organisations (EOEO)/countries: 1379
- Kidneys exported to other EOEO/countries: 63
- Entries on kidney waiting list during 2014: 119
- Dead while waiting for kidney during 2014: 2
- Permanent withdrawn from the kidney waiting list during 2014: 0
Transplanted kidneys pmp\textsuperscript{5} from deceased donors per year

<table>
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\textsuperscript{5} pmp: per million population
Demographics of recipients transplanted with kidney from deceased donor

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\(^6\) Antibodies towards tissue types

\(^7\) Low immunized was introduced in 2011, before this date these were counted as ‘Not immunized’
Transplanted kidneys pmp\(^8\) from living donors per year

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<thead>
<tr>
<th>Year</th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
<th>Scandiatransplant</th>
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\(^8\) pmp: per million population
Demographics of recipients transplanted with kidney from living donors

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<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
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<td>67</td>
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Livers 2014

- Total amount of patients waiting for a liver as of 1st of January 2015: 459
- Patients transplanted with liver from living donors during 2014: 115
- Patients transplanted with liver from deceased donors during 2014: 377
- Livers imported and transplanted from other European Organ Exchange Organisations (EOEO)/countries: 26
- Livers exported to other EOEO/countries: 27
- Patients transplanted with high urgent status during 2014: 11
- Entries on liver waiting list during 2014: 0
- Dead while waiting for liver during 2014: 0
- Permanent withdrawn from the liver waiting list during 2014: 0
Transplanted livers (Deceased and living donors) pmp\(^9\) per year

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<td>19,5</td>
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<td>14,7</td>
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\(^9\) pmp: per million population
Demographics of recipients transplanted with liver

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<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
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<th>2014</th>
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<tr>
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<td>75</td>
<td>72</td>
<td>72</td>
<td>73</td>
<td>73</td>
</tr>
</tbody>
</table>

| AB0 blood group (%)           |      |      |      |      |      |      |      |      |      |      |
| A                             | 54   | 44   | 44   | 54   | 51   | 40   | 40   | 48   | 47   | 44   |
| B                             | 11   | 9    | 16   | 9    | 13   | 14   | 14   | 12   | 15   | 13   |
| AB                            | 5    | 8    | 6    | 4    | 6    | 7    | 6    | 7    | 6    | 3    |
| 0                             | 30   | 39   | 34   | 33   | 30   | 39   | 40   | 33   | 32   | 40   |

| Transplantation number (%)    |      |      |      |      |      |      |      |      |      |      |
| 1                             | 87,3 | 89,8 | 91,5 | 89,2 | 88,7 | 87,9 | 87,5 | 92,0 | 89,8 | 91,6 |
| 2                             | 12,3 | 7,9  | 6,1  | 9,2  | 9,0  | 9,8  | 10,2 | 7,2  | 9,1  | 7,1  |
| 3                             | 0,4  | 2,3  | 2,0  | 1,6  | 1,9  | 1,9  | 1,7  | 0,6  | 0,8  | 1,3  |
| 4                             | 0,0  | 0,0  | 0,3  | 0,0  | 0,3  | 0,3  | 0,6  | 0,6  | 0,3  | 0,0  |

| Donor type (%)                |      |      |      |      |      |      |      |      |      |      |
| Deceased                      | 95,5 | 96,2 | 97,3 | 95,7 | 96,8 | 95,3 | 97,9 | 96,9 | 96,9 | 97,1 |
| Living                        | 1,2  | 2,3  | 1,0  | 2,0  | 0,6  | 2,5  | 1,2  | 2,0  | 1,4  | 1,6  |
| Domino                        | 3,3  | 1,5  | 1,7  | 2,3  | 2,6  | 2,2  | 0,9  | 1,1  | 1,7  | 1,3  |

| Urgency (%)                   |      |      |      |      |      |      |      |      |      |      |
| High urgent                   | 8    | 14   | 10   | 10   | 9    | 10   | 9    | 9    | 8    | 7    |

| Gender (%)                    |      |      |      |      |      |      |      |      |      |      |
| Female                        | 44   | 41   | 37   | 45   | 44   | 42   | 36   | 44   | 34   | 39   |
| Male                          | 56   | 59   | 63   | 55   | 56   | 58   | 64   | 56   | 66   | 61   |

Hearts 2014

- **Total amount of patients waiting for a heart as of 1st of January 2015**: 191
- **Patients transplanted with heart from deceased donors during 2014**: 104
- **Hearts imported and transplanted from other EOEO/countries**: 157
- **Hearts exported to other EOEO/countries**: 6
- **Patients transplanted with high urgent status during 2014**: 5
- **Entries on heart waiting list during 2014**: 10
- **Dead while waiting for heart during 2014**: 6
- **Permanent withdrawn from the heart waiting list during 2014**: 13
### Transplanted hearts pmp\textsuperscript{11} per year

<table>
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<th>Year</th>
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<th>Finland</th>
<th>Norway</th>
<th>Sweden</th>
<th>Scandiatransplant</th>
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\textsuperscript{11} pmp: per million population
## Demographics of recipients transplanted with heart

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Lungs 2014

- Total amount of patients waiting for a lung as of 1st of January 2015: 108
- Patients transplanted with lung from deceased donors during 2014: 144
- Lungs imported and transplanted from other European Organ Exchange Organisations (EOEO)/countries: 157
- Lungs exported to other EOEO/countries: 15
- Patients transplanted with high urgent status during 2014: 8
- Entries on lung waiting list during 2014: 2
- Dead while waiting for lung during 2014: 11
- Permanent withdrawn from the lung waiting list during 2014: 8
Transplanted lungs (Double, single and heart-lung) pmp\textsuperscript{13} per year

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\textsuperscript{13} pmp: per million population
Demographics of recipients transplanted with lung

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14 The urgent lung list was introduced in 2009
Pancreas 2014

- Total amount of patients waiting for a pancreas as of 1st of January 2015: 27
- Patients transplanted with pancreas from deceased donors during 2014: 84
- Patients transplanted with combined kidney-pancreas: 65
- Pancreas imported and transplanted from European Organ Exchange Organisations (EOEO)/countries: 3
- Pancreas exported to other EOEO/countries: 0
- Entries on pancreas waiting list during 2014: 27
- Permanent withdrawn from the pancreas waiting list during 2014: 1
Transplanted pancreas pmp\textsuperscript{16} per year

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\textsuperscript{16} pmp: per million population
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Krister Höckerstedt  Kaj Anker Jørgensen  Ilse D. Weinreich
(Chairman)  (Medical Director)  (Clinical Data Manager)