THE NORDIC LIVER TRANSPLANT REGISTRY ANNUAL REPORT 2001

This complete report is distributed to a limited number of persons through the responsible contact persons at each centre. Additional copies can be obtained from K. Bjøro, Oslo

Responsible contact persons:

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Report prepared by Kristian Bjøro

March 2002
Nordic liver transplant registry - 2001

As of December 31st 2001 the registry comprised data on 2392 patients of whom 2004 had received a first liver allograft. The registry comprises complete data on all patients listed for liver transplantation during the period 1990-2001; 2173 patients. The remaining 219 patients received a liver allograft prior to 1990, waiting list data are not available for these patients.

Transplantation activity 2001

A total of 225 patients were listed for a first liver transplantation in 2001. Of these 159 received a first liver allograft. Eleven of the 225 patients died while being active on the waiting list – two of these while awaiting a second transplantation. Fifteen were permanently withdrawn from the waiting list without receiving a liver allograft. Forty patients were active on the waiting list as of December 31st, a higher number as compared to previous years.

The total number of patients receiving a first liver allograft during 2001 was 192 (31 patients were listed prior to January 1st 2001), in addition 17 retransplants (15 second and 2 third) were performed. The number of first liver transplantations increased by more than 10% as compared to the period 1996-2000.

Fulminant hepatic failure (n=43) was the most frequent indication for being listed for a liver transplantation, followed by primary sclerosing cholangitis (n=36).

Older recipients (above 60 years of age) increased in number. During 2001, 40 patients above 60 years of age received a first liver allograft, comprising 21% of the total population of patients.

Median and mean waiting times (electively listed patients) have increased to 42 and 85 days respectively. Median waiting time for blood type O recipients in 2001 was 85 days. The number of deaths on the waiting list is unchanged. A total of 17 patients died while waiting for a liver allograft during 2001.

Donor age has increased steadily during the nineties, approximately 10% of the donors were above 60 years of age.

Survival rates following liver transplantation are still increasing and for the last 3-year period the 1-year patient survival is above 85%. Survival data will strongly depend on patient selection. As this most probably differs between the various centres, comparison between the five participating centres is not performed.

Maintenance of the registry

Most centres are as of today relatively up-to-date as concerns the completeness of data. Very few data on number of patients, dates of transplantation, diagnosis and status dead/alive are lacking. In some patients, detailed data on acceptance and transplantation are missing. C-forms, comprising data on follow-up, are still incomplete in many patients.

The results presented in this report are based on the data in the registry as of March 5th. 2002.
Acknowledgements - financial support

The maintenance of the software has been performed by Scandiatransplant. We greatly acknowledge the help and support from Niels Grunnet, Melvin Madsen, Christian Mondrup and Frank Pedersen in Aarhus. Without their help and support it would not have been possible to maintain the registry. Without the day-to-day assistance we have received from Christian Mondrup and Frank Pedersen it would have been impossible to tie up a large number of loose ends and develop the registry further.

Transplant nurses and transplant coordinators at the individual centres have made an enormous effort in updating and maintaining the registry. The existence of the registry depends completely on their work and dedication.

The registry received financial support from Fujisawa and Novartis during 2001. This support has been of great help. All financial support has been given without any obligations and the registry has no commitments to any pharmaceutical company.

Organisation and data ownership

It should be emphasised that the registry (software) is the property of Scandiatransplant while the data in the registry is the property of the Nordic Liver Transplantation Group. Utilisation of data should be censored by the latter. The data presented here should not be used without permission from the Nordic Liver Transplantation Group. The contact persons from each centre are the following:

- Copenhagen: Preben Kirkegaard
- Gothenburg: Styrbjörn Friman
- Helsinki: Krista Höckerstedt
- Oslo: Inge Bjørn Brekke
- Stockholm: Bo-Göran Ericzon

This complete report is distributed to a limited number of persons at each centre, further copies can be delivered on request. A preliminary report has been sent to the contact persons for comments.

A slightly condensed version is available on http://www.scandiatransplant.org

Copies of the report can be supplied on request as a Word-97 file (text and tables) or Power-Point files (survival curves).

Oslo March 2002 Kristian Bjoro

NB Patients listed and receiving liver allografts in Uppsala prior to 2000 are recorded as Stockholm-patients.
**ACTIVITY 2001**

Activity during 2001 – total number of transplantations, first transplantations, retransplantations, deaths on waiting list and permanent withdrawals – irrespective of when the patients were listed

<table>
<thead>
<tr>
<th></th>
<th>Total tx</th>
<th>First liver tx</th>
<th>ReTx</th>
<th>DEA</th>
<th>PW</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>CDT</td>
<td>LDT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>København</td>
<td>32</td>
<td>26</td>
<td>0</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Göteborg</td>
<td>54</td>
<td>46</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Helsinki</td>
<td>38</td>
<td>37</td>
<td>0</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Oslo</td>
<td>37</td>
<td>31</td>
<td>1</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Stockholm</td>
<td>47</td>
<td>43</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Uppsala</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>209</td>
<td>184</td>
<td>8</td>
<td>17</td>
<td>17*</td>
</tr>
</tbody>
</table>

* 2 of these patients died while waiting for a retransplantation

**Total number of patients accepted on liver tx waiting list (1. acceptance): 225**

Outcome of patients *listed* during 2001:

<table>
<thead>
<tr>
<th></th>
<th>total</th>
<th>DEA</th>
<th>PW</th>
<th>CDT</th>
<th>LDT</th>
<th>Active</th>
</tr>
</thead>
<tbody>
<tr>
<td>København</td>
<td>30</td>
<td>3</td>
<td>2</td>
<td>22</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Göteborg</td>
<td>57</td>
<td>3</td>
<td>4</td>
<td>42</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Helsinki</td>
<td>51</td>
<td>0</td>
<td>6</td>
<td>37</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Oslo</td>
<td>41</td>
<td>4</td>
<td>1</td>
<td>26</td>
<td>1</td>
<td>9</td>
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<tr>
<td>Stockholm</td>
<td>43</td>
<td>1</td>
<td>1</td>
<td>25</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Uppsala</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total 2001</strong></td>
<td>225</td>
<td>11</td>
<td>15</td>
<td>153</td>
<td>6</td>
<td>40</td>
</tr>
</tbody>
</table>

DEA - dead while active on waiting list
PW - permanently withdrawn
CDT - cadaveric donor transplants
LDT - living donor transplants (includes domino liver)
Active - active on waiting list as of Dec.31. 2001
**Diagnoses of patients accepted on waiting list 1996-2001 (1. acceptance):**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute hepatic failure</td>
<td>43</td>
<td>24</td>
<td>28</td>
<td>26</td>
<td>28</td>
<td>19</td>
</tr>
<tr>
<td>Primary sclerosing cholangitis</td>
<td>36</td>
<td>38</td>
<td>27</td>
<td>25</td>
<td>32</td>
<td>25</td>
</tr>
<tr>
<td>Malignant diseases</td>
<td>20</td>
<td>18</td>
<td>21</td>
<td>23</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Primary biliary cirrhosis</td>
<td>10</td>
<td>16</td>
<td>20</td>
<td>17</td>
<td>17</td>
<td>16</td>
</tr>
<tr>
<td>Hepatitis C cirrhosis</td>
<td>14</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Alcoholic cirrhosis</td>
<td>27</td>
<td>25</td>
<td>18</td>
<td>30</td>
<td>23</td>
<td>15</td>
</tr>
<tr>
<td>Metabolic diseases</td>
<td>9</td>
<td>11</td>
<td>16</td>
<td>16</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Biliary atresia</td>
<td>11</td>
<td>11</td>
<td>11</td>
<td>10</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Autoimmune cirrhosis</td>
<td>7</td>
<td>7</td>
<td>9</td>
<td>3</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Cryptogenic cirrhosis</td>
<td>6</td>
<td>8</td>
<td>8</td>
<td>3</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Hepatitis B cirrhosis</td>
<td>8</td>
<td>6</td>
<td>7</td>
<td>6</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Budd Chiari syndrome*</td>
<td>6</td>
<td>0</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Other cholestatic diseases</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>7</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>14</td>
<td>23</td>
<td>11</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>225</td>
<td>202</td>
<td>213</td>
<td>202</td>
<td>176</td>
<td>164</td>
</tr>
</tbody>
</table>

*Patients with Budd Chiari may be recorded as acute hepatic failure if listed as urgent, the figures given for Budd Chiari in this table exclude patients listed as acute hepatic failure.

**Duration of time on waiting list, patients receiving 1. liver allograft 1996-2001 (excluding urgent listings)**

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>median (days)</td>
<td>42</td>
<td>43</td>
<td>30</td>
<td>21</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>mean (days)</td>
<td>85</td>
<td>75</td>
<td>55</td>
<td>53</td>
<td>63</td>
<td>64</td>
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</tbody>
</table>

**Annual total number of liver transplantations, 1996-2001**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Tx no 1</td>
<td>192</td>
<td>169</td>
<td>164</td>
<td>175</td>
<td>161</td>
<td>141</td>
</tr>
<tr>
<td>Tx no 2</td>
<td>15</td>
<td>19</td>
<td>16</td>
<td>28</td>
<td>17</td>
<td>20</td>
</tr>
<tr>
<td>Tx no 3</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Tx no 4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>209</td>
<td>191</td>
<td>183</td>
<td>204</td>
<td>178</td>
<td>168</td>
</tr>
</tbody>
</table>
**Number of liver transplantations per centre, 1996-2001**

<table>
<thead>
<tr>
<th></th>
<th>1. liver transplantations</th>
<th>Retransplantations*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copenhagen</td>
<td>26</td>
<td>20</td>
</tr>
<tr>
<td>Gothenburg</td>
<td>50</td>
<td>40</td>
</tr>
<tr>
<td>Helsinki</td>
<td>37</td>
<td>28</td>
</tr>
<tr>
<td>Oslo</td>
<td>32</td>
<td>25</td>
</tr>
<tr>
<td>Stockholm</td>
<td>46</td>
<td>56</td>
</tr>
<tr>
<td>Uppsala</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>192</td>
<td>169</td>
</tr>
</tbody>
</table>

* includes all retransplants - second, third and fourth

**Diagnoses of patients receiving a first liver transplant 1996-2001**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary sclerosing cholangitis</td>
<td>37</td>
<td>28</td>
<td>21</td>
<td>24</td>
<td>31</td>
<td>25</td>
</tr>
<tr>
<td>Acute hepatic failure</td>
<td>33</td>
<td>16</td>
<td>20</td>
<td>18</td>
<td>24</td>
<td>15</td>
</tr>
<tr>
<td>Hepatitis C cirrhosis</td>
<td>10</td>
<td>16</td>
<td>17</td>
<td>17</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Primary biliary cirrhosis</td>
<td>10</td>
<td>18</td>
<td>16</td>
<td>16</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td>Metabolic diseases</td>
<td>9</td>
<td>11</td>
<td>14</td>
<td>15</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Alcoholic cirrhosis</td>
<td>21</td>
<td>21</td>
<td>13</td>
<td>28</td>
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<td>14</td>
</tr>
<tr>
<td>Malignant diseases</td>
<td>15</td>
<td>17</td>
<td>12</td>
<td>19</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Autoimmune cirrhosis</td>
<td>5</td>
<td>6</td>
<td>10</td>
<td>1</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Biliary atresia</td>
<td>11</td>
<td>7</td>
<td>9</td>
<td>8</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Hepatitis B cirrhosis</td>
<td>4</td>
<td>6</td>
<td>7</td>
<td>5</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Cryptogenic cirrhosis</td>
<td>5</td>
<td>9</td>
<td>4</td>
<td>4</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Budd Chiari syndrome*</td>
<td>5</td>
<td>0</td>
<td>3</td>
<td>5</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Other cholestatic diseases</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>14</td>
<td>17</td>
<td>7</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>192</td>
<td>169</td>
<td>164</td>
<td>175</td>
<td>161</td>
<td>141</td>
</tr>
</tbody>
</table>

* Patients with Budd Chiari syndrome may be recorded as acute hepatic failure if listed as urgent, the figures given for Budd Chiari in this table exclude patients listed as acute hepatic failure
### Age distribution of patients receiving a first liver transplant in 1996-2001 (age at transplantation)

<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 year</td>
<td>10</td>
<td>2</td>
<td>7</td>
<td>6</td>
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<tr>
<td>1-2</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>2-10</td>
<td>5</td>
<td>2</td>
<td>10</td>
<td>8</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>11-20</td>
<td>6</td>
<td>5</td>
<td>7</td>
<td>4</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>21-30</td>
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<td>19</td>
<td>7</td>
<td>6</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>31-40</td>
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<td>14</td>
<td>18</td>
<td>23</td>
<td>17</td>
<td>14</td>
</tr>
<tr>
<td>41-50</td>
<td>40</td>
<td>50</td>
<td>38</td>
<td>48</td>
<td>44</td>
<td>33</td>
</tr>
<tr>
<td>51-60</td>
<td>50</td>
<td>56</td>
<td>50</td>
<td>53</td>
<td>42</td>
<td>47</td>
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<tr>
<td>&gt;60</td>
<td>40</td>
<td>26</td>
<td>23</td>
<td>23</td>
<td>24</td>
<td>18</td>
</tr>
</tbody>
</table>

### Recipient age – centrewise 1996-2001 (6-year period)*
(first liver allografts)

<table>
<thead>
<tr>
<th></th>
<th>Mean age</th>
<th>Median age</th>
<th>Per cent of recipients being &gt; 60 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copenhagen</td>
<td>46.5</td>
<td>51.2</td>
<td>12%</td>
</tr>
<tr>
<td>Gothenburg</td>
<td>49.7</td>
<td>51.5</td>
<td>21%</td>
</tr>
<tr>
<td>Helsinki</td>
<td>46.7</td>
<td>48.5</td>
<td>16%</td>
</tr>
<tr>
<td>Oslo</td>
<td>44.1</td>
<td>44.8</td>
<td>8%</td>
</tr>
<tr>
<td>Stockholm</td>
<td>46.4</td>
<td>49.4</td>
<td>15%</td>
</tr>
</tbody>
</table>

*excluding patients <5 years of age

### Total number of small children receiving a liver allograft (1996-2001) (first liver allografts)

<table>
<thead>
<tr>
<th></th>
<th>No of recipients</th>
<th>Per cent recipients being &lt; 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copenhagen</td>
<td>7</td>
<td>5%</td>
</tr>
<tr>
<td>Gothenburg</td>
<td>12</td>
<td>5%</td>
</tr>
<tr>
<td>Helsinki</td>
<td>10</td>
<td>6%</td>
</tr>
<tr>
<td>Oslo</td>
<td>17</td>
<td>14%</td>
</tr>
<tr>
<td>Stockholm</td>
<td>9</td>
<td>4%</td>
</tr>
</tbody>
</table>
**Donor age* (years) – centrewise (1996-2001)  
(first liver allografts)**

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Median</th>
<th>Per cent donors being &gt; 60 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copenhagen</td>
<td>40.7</td>
<td>45</td>
<td>7%</td>
</tr>
<tr>
<td>Gothenburg</td>
<td>44.5</td>
<td>47</td>
<td>14%</td>
</tr>
<tr>
<td>Helsinki</td>
<td>37.2</td>
<td>40</td>
<td>3%</td>
</tr>
<tr>
<td>Oslo</td>
<td>38.5</td>
<td>43</td>
<td>6%</td>
</tr>
<tr>
<td>Stockholm</td>
<td>46.1</td>
<td>50</td>
<td>22%</td>
</tr>
</tbody>
</table>

*donor age is missing in approximately 3-5% of cases

**Distribution of some of the major diagnoses (patients receiving a 1.liver allograft) – centrewise – 1995-2001**

<table>
<thead>
<tr>
<th>Diagnosis</th>
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AHF - acute hepatic failure  
ALCI - alcoholic cirrhosis  
AUCI - autoimmune hepatitis-cirrhosis  
BCDI - Budd Chiari (only chronic cases)  
BIAT - biliary atresia  
CRCI/OCCI – cryptogenic cirrhosis and cirrhosis other causes  
MEDI - metabolic diseases  
PBCI - primary biliary cirrhosis  
PCYS - polycystic liver disease  
PHCC - HCV cirrhosis  
PHCB - HBV cirrhosis  
SCCH – primary sclerosing cholangitis  
HCCA - hepatocellular carcinoma  
OTCA - all other cancers including cholangiocarcinoma, other primary hepatic cancers and secondary cancers
**Activity 1982-2001**

A total of 2005 first liver transplantations and 236 retransplantations have been performed since 1982, the distribution among the centres is given below.

Survival curves for the total material, for different time periods and for major diagnostic groups are given. In addition survival curves for a limited number of diagnoses – primary sclerosing cholangitis, primary biliary cirrhosis, HCV and HBV are presented. The survival curves comprise data for all patients who have received a liver allograft as of March 1. 2002

<table>
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<tr>
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<th>1.liver transplants</th>
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<td><strong>2004</strong>*</td>
<td><strong>236</strong></td>
<td><strong>2241</strong></td>
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</table>

* One additional patient recorded with a first transplant in Uppsala 2001.
Annual number of first liver transplantations according to diagnosis (PSC-primary sclerosing cholangitis, FHF-fulminant hepatic failure, ALCI-alcoholic cirrhosis, PBC-primary biliary cirrhosis)

Mean donor and recipient age during 1990-2001
Survival curves

Patient survival vs year of transplantation

Survival Time - days

Cumulative Proportion Surviving

0.0
0.1
0.2
0.3
0.4
0.5
0.6
0.7
0.8
0.9
1.0

0
365
730
1095
1460
1825
2190
2555
2920
3285
3650
4015
4380
4745
5110
5475
5840
6205
6570
6935

1982-1989, n=199
1990-1993, n=487
1994-1997, n=620
1998-2001, n=691

Patient survival
Chronic, non-malignant, non-viral liver disease

Survival Time - days

Cumulative Proportion Surviving

0.0
0.1
0.2
0.3
0.4
0.5
0.6
0.7
0.8
0.9
1.0

0
365
730
1095
1460
1825
2190
2555
2920
3285
3650
4015
4380
4745
5110
5475
5840
6205
6570
6935

1982-1989, n=199
1982-1994, n=374
1995-2001, n=578
1990-1993, n=487
1994-1997, n=620
1998-2001, n=691
Patient survival
Primary sclerosing cholangitis

Survival Time - days

Cumulative Proportion Surviving

1984-1993, n=72
1994-1997, n=102
1998-2001, n=117

Patient survival
Primary biliary cirrhosis

Survival Time - days

Cumulative Proportion Surviving

1983-1993, n=140
1994-1997, n=81
1998-2001, n=60
Patient survival
Biliary atresia

Survival Time - days
Cumulative Proportion Surviving

1984-1993, n=33
1994-1997, n=35
1998-2001, n=35
Publications NLTR 1990-2001


abstracts


24. Brandsæter B, …… Primary sclerosing cholangitis in the Nordic countries – survival after liver transplantation. The XXIV Nordic Meeting of Gastroenterology, Aarhus May 2002
