# THE NORDIC LIVER TRANSPLANT REGISTRY ANNUAL REPORT 2000

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#### Nordic liver transplant registry - 2000

As of December 31.2000 the registry comprised data on 2167 patients of whom 1813 had received a first liver allograft. The registry comprises complete data on all patients listed for liver transplantation during the period 1990-2000; 1948 patients. The remaining 219 patients received a liver allograft prior to 1990, waiting list data are not available for these patients.

# Transplantation activity 2000

The total number of patients receiving a first liver allograft during 2000 was 169 (29 patients were listed prior to January 1st 2000), in addition 21 retransplants (18 second and 3 third) were performed (see below). The number of retransplantations was relatively low and does not seem to be increasing when considering data from the last 6-year period (1995-2000).

A total of 25 patients died while waiting for a liver allograft, 3 of these while waiting for a retransplantation.

Primary sclerosing cholangitis was by far the most frequent indication for being listed for a first liver transplant in 2000, 38 such patients were listed. The number of patients with alcoholic liver cirrhosis and hepatitis C cirrhosis has not increased further.

Distribution as to age of recipients was unaltered as compared to previous years, there was thus no further increase in the number of older (>60 years of age) recipients. Older recipients (above 60 years of age) still comprise approximately 15% of the total patient population.

Median and mean waiting times have increased to 43 and 75 days respectively. Median waiting time for blood type 0 recpients is now 85 days. The number of deaths on the waiting list is unchanged.

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 improving and for the last 3-year period the 1-year patient survival is nearly 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 15. 2001.

#### 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 2000. 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 Krister Höckerstedt
Oslo Inge Bjørn Brekke
Stockholm Bo-Göran Ericzon

The 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 of the report will be made available on internet; 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 2001 Kristian Bjøro

### **ACTIVITY 2000**

# Duration of time on waiting list, patients receiving 1. liver allograft 1996-2000 (excluding urgent listings)

	2000	1999	1998	1997	1996
median (days)	43	30	21	23	27
mean (days)	75	55	53	63	64

# Number of liver transplantations per year, 1996-2000

	2000	1999	1998	1997	1996
Tx no 1	169	164	175	161	141
Tx no 2	19	16	28	17	20
Tx no 3	3	3	1	0	5
Tx no 4	0	0	0	0	2
	191	183	204	178	168

# Number of liver transplantations per centre, 1996-2000

	1.liver transplantations			Retransplantations*						
	2000	1999	1998	1997	1996	2000	1999	1998	1997	1996
Copenhagen	20	26	28	37	35	4	5	6	2	9
Gothenburg	40	41	54	46	39	8	5	5	3	4
Helsinki	28	28	33	23	23	3	2	6	5	6
Oslo	25	23	19	16	15	5	5	6	2	6
Stockholm	56	46	41	39	29	2	1	6	5	3
Total	169	164	175	161	141	22	18	29	17	26

<sup>\*</sup> includes all retransplants - second, third and fourth

# Diagnoses of patients receiving a first liver transplant in 1996-2000

	2000	1999	1998	1997	1996
Primary sclerosing cholangitis	28	21	24	31	25
Acute hepatic failure	16	20	18	24	15
Hepatitis C cirrhosis	16	17	17	11	5
Primary biliary cirrhosis	18	16	16	14	13
Metabolic diseases	11	14	15	6	6
Alcoholic cirrhosis	21	13	28	21	14
Malignant diseases	17	12	19	9	5
Autoimmune cirrhosis	6	10	1	5	9
Biliary atresia	7	9	8	3	9
Hepatitis B cirrhosis	6	7	5	5	4
Cryptogenic cirrhosis	9	4	4	9	6
Budd Chiari syndrome*	0	3	5	6	6
Other cholestatic diseases	0	1	6	9	9
Other	14	17	7	8	19
Total	169	164	175	161	141

<sup>\*</sup>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

# Age distribution of patients receiving a first liver transplant in 1996-2000 (age in years at transplantation)

age - year	2000	1999	1998	1997	1996
<1	2	7	6	2	4
1-2	4	2	2	6	3
2-10	2	10	8	4	6
11-20	5	7	4	8	4
21-30	19	7	6	12	12
31-40	14	18	23	17	14
41-50	50	38	48	44	33
51-60	56	50	53	42	47
>60	26	23	23	24	18

# Distribution of some of the major diagnosis (patients receiving a 1.liver allograft) – centerwise – 1995-2000

	Copenhagen	Gothenburg	Helsinki	Oslo	Stockholm
AHF	23	17	45	11	18
ALCI	46	40	12	8	14
AUCI	7	21	3	4	7
BIAT	12	9	5	13	15
BCDI	4	4	6	2	5
CRCI/OCCI	21	19	16	6	7
MEDI	6	11	6	6	36
PBCI	14	25	35	16	18
PCYS	6	7	0	1	1
PHCC	7	23	2	8	32
PHCB	4	16	0	2	8
SCCH	17	42	24	35	37
HCCA	1	7	13	2	26
OTCA	3	16	2	1	6

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 inlcuding cholangiocarcinoma, other primary hepatic

cancers and secondary cancers

### Activity 1982-2000

A total of 1813 first liver transplantations and 219 retransplantations have been performed since 1982, the distribution among the centres is given below.

Survival curves 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. Survival curves comprise data on all patients who have received a liver allograft as of March 1. 2001.

	1.liver transplants	Retransplants	Total number
Helsinki	326	42	368
Stockholm	474	49	523
Gothenburg	465	52	517
Copenhagen	306	42	348
Oslo	222	31	253
Aarhus	20	3	23
	1813	219	2032

### Survival curves













