

# THE NORDIC LIVER TRANSPLANT REGISTRY ANNUAL REPORT 2001

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## **Nordic liver transplant registry - 2001**

As of December 31<sup>st</sup> 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 Fifteen were permanently withdrawn from the waiting list without receiving a liver allograft.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 31<sup>st</sup>, 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 0 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	Krister 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 Bjøro

### **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

	Total tx	First liver tx		ReTx	DEA	PW
		CDT	LDT			
København	32	26	0	6	3	3
Göteborg	54	46	4	4	4	8
Helsinki	38	37	0	1	4	6
Oslo	37	31	1	5	5	2
Stockholm	47	43	3	1	1	1
Uppsala	1	1	0	0	0	0
<b>Total</b>	<b>209</b>	<b>184</b>	<b>8</b>	<b>17</b>	<b>17*</b>	<b>20</b>

\* 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:

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

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):**

	2001	2000	1999	1998	1997	1996
Acute hepatic failure	43	24	28	26	28	19
Primary sclerosing cholangitis	36	38	27	25	32	25
Malignant diseases	20	18	21	23	10	7
Primary biliary cirrhosis	10	16	20	17	17	16
Hepatitis C cirrhosis	14	20	20	20	11	10
Alcoholic cirrhosis	27	25	18	30	23	15
Metabolic diseases	9	11	16	16	5	6
Biliary atresia	11	11	11	10	4	7
Autoimmune cirrhosis	7	7	9	3	4	11
Cryptogenic cirrhosis	6	8	8	3	7	7
Hepatitis B cirrhosis	8	6	7	6	7	3
Budd Chiari syndrome*	6	0	3	5	2	6
Other cholestatic diseases	5	2	2	7	6	8
Other	23	14	23	11	20	24
<b>Total</b>	<b>225</b>	<b>202</b>	<b>213</b>	<b>202</b>	<b>176</b>	<b>164</b>

\*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)**

	2001	2000	1999	1998	1997	1996
median (days)	42	43	30	21	23	27
mean (days)	85	75	55	53	63	64

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

	2001	2000	1999	1998	1997	1996
Tx no 1	192	169	164	175	161	141
Tx no 2	15	19	16	28	17	20
Tx no 3	2	3	3	1	0	5
Tx no 4	0	0	0	0	0	2
	<b>209</b>	<b>191</b>	<b>183</b>	<b>204</b>	<b>178</b>	<b>168</b>

**Number of liver transplantations per centre, 1996-2001**

	1.liver transplantations						Retransplantations*					
	2001	2000	1999	1998	1997	1996	2001	2000	1999	1998	1997	1996
Copenhagen	26	20	26	28	37	35	6	4	5	6	2	9
Gothenburg	50	40	41	54	46	39	4	8	5	5	3	4
Helsinki	37	28	28	33	23	23	1	3	2	6	5	6
Oslo	32	25	23	19	16	15	5	5	5	6	2	6
Stockholm	46	56	46	41	39	29	1	2	1	6	5	3
Uppsala	1											
<b>Total</b>	<b>192</b>	<b>169</b>	<b>164</b>	<b>175</b>	<b>161</b>	<b>141</b>	<b>17</b>	<b>22</b>	<b>18</b>	<b>29</b>	<b>17</b>	<b>26</b>

\* includes all retransplants - second, third and fourth

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

	2001	2000	1999	1998	1997	1996
Primary sclerosing cholangitis	37	28	21	24	31	25
Acute hepatic failure	33	16	20	18	24	15
Hepatitis C cirrhosis	10	16	17	17	11	5
Primary biliary cirrhosis	10	18	16	16	14	13
Metabolic diseases	9	11	14	15	6	6
Alcoholic cirrhosis	21	21	13	28	21	14
Malignant diseases	15	17	12	19	9	5
Autoimmune cirrhosis	5	6	10	1	5	9
Biliary atresia	11	7	9	8	3	9
Hepatitis B cirrhosis	4	6	7	5	5	4
Cryptogenic cirrhosis	5	9	4	4	9	6
Budd Chiari syndrome*	5	0	3	5	6	6
Other cholestatic diseases	4	0	1	6	9	9
Other	23	14	17	7	8	19
<b>Totalt</b>	<b>192</b>	<b>169</b>	<b>164</b>	<b>175</b>	<b>161</b>	<b>141</b>

\*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)**

age - year	2001	2000	1999	1998	1997	1996
<1	10	2	7	6	2	4
1-2	1	4	2	2	6	3
2-10	5	2	10	8	4	6
11-20	6	5	7	4	8	4
21-30	19	19	7	6	12	12
31-40	21	14	18	23	17	14
41-50	40	50	38	48	44	33
51-60	50	56	50	53	42	47
>60	40	26	23	23	24	18

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

	Mean age	Median age	Per cent of recipients being > 60 years
Copenhagen	46.5	51.2	12%
Gothenburg	49.7	51.5	21%
Helsinki	46.7	48.5	16%
Oslo	44.1	44.8	8%
Stockholm	46.4	49.4	15%

\*excluding patients <5 years of age

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

	No of recipients < 5 years	Per cent recipients being < 5 years
Copenhagen	7	5%
Gothenburg	12	5%
Helsinki	10	6%
Oslo	17	14%
Stockholm	9	4%

**Donor age\* (years) – centrewise (1996-2001)  
(first liver allografts)**

	Mean	Median	Per cent donors being > 60 years
Copenhagen	40.7	45	7%
Gothenburg	44.5	47	14%
Helsinki	37.2	40	3%
Oslo	38.5	43	6%
Stockholm	46.1	50	22%

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

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

	Copenhagen	Gothenburg	Helsinki	Oslo	Stockholm
AHF	29	21	53	14	25
ALCI	51	49	17	10	18
AUCI	7	21	4	6	7
BIAT	13	11	8	15	16
BCDI	4	6	6	5	5
CRCI/OCCI	22	22	16	10	9
MEDI	8	10	6	7	44
PBCI	16	27	36	15	19
PCYS	6	7	0	2	0
PHCC	9	27	3	9	38
PHCB	4	17	0	3	14
SCCH	20	49	29	42	49
HCCA	2	10	14	2	33
OTCA	3	18	2	3	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 including cholangiocarcinoma, other primary hepatic cancers and secondary cancers



**Activity 1982-2001**

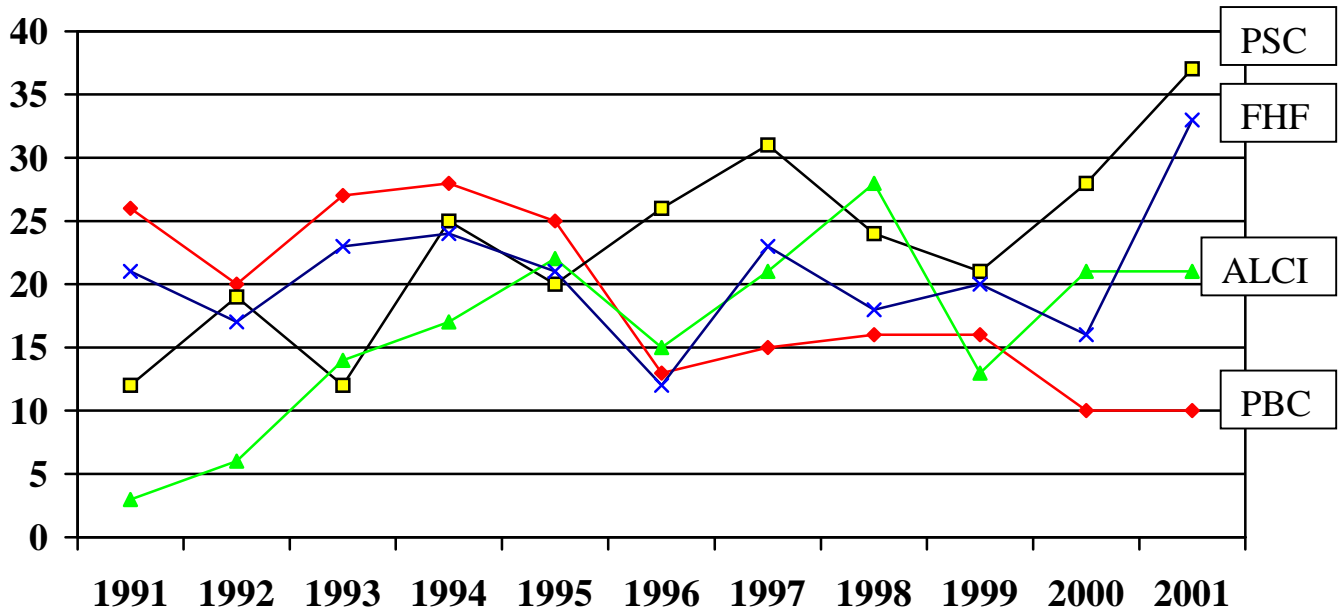
A total of 2005 first liver transplantations and 236 retransplantations have been performed since 1982, the distribution among the centres is given below.

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

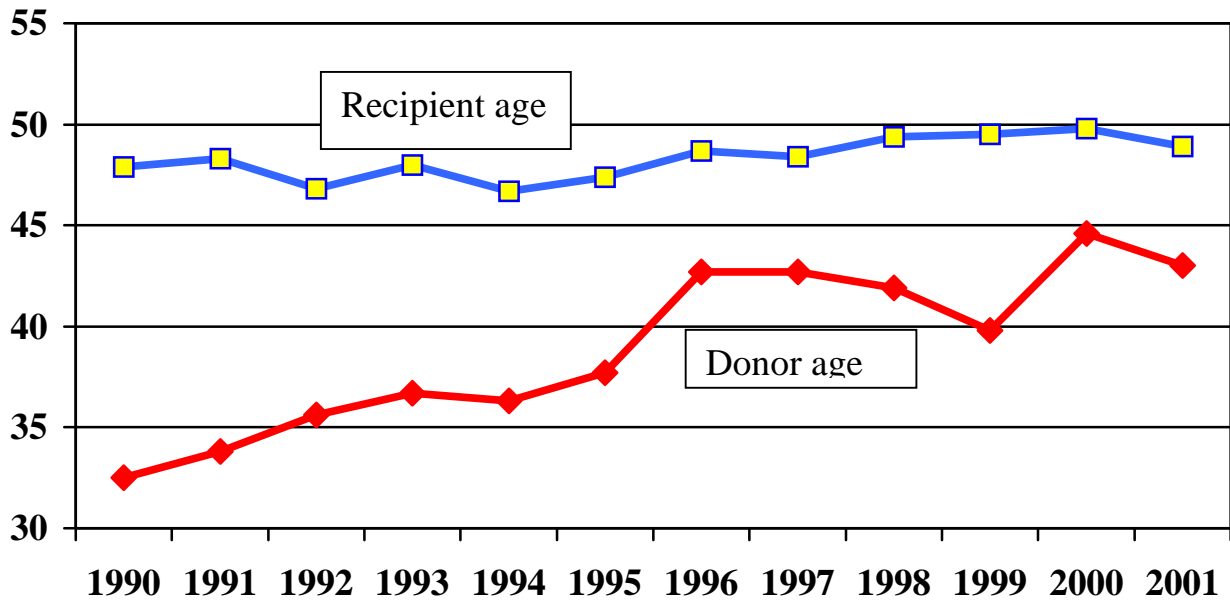
	1.liver transplants	Retransplants	Total number
Helsinki	363	43	406
Stockholm	520	50	570
Gothenburg	515	56	571
Copenhagen	332	48	380
Oslo	254	36	290
Aarhus	20	3	23
<b>total</b>	<b>2004*</b>	<b>236</b>	<b>2241</b>

\* One additional patient recorded with a first transplant in Uppsala 2001.

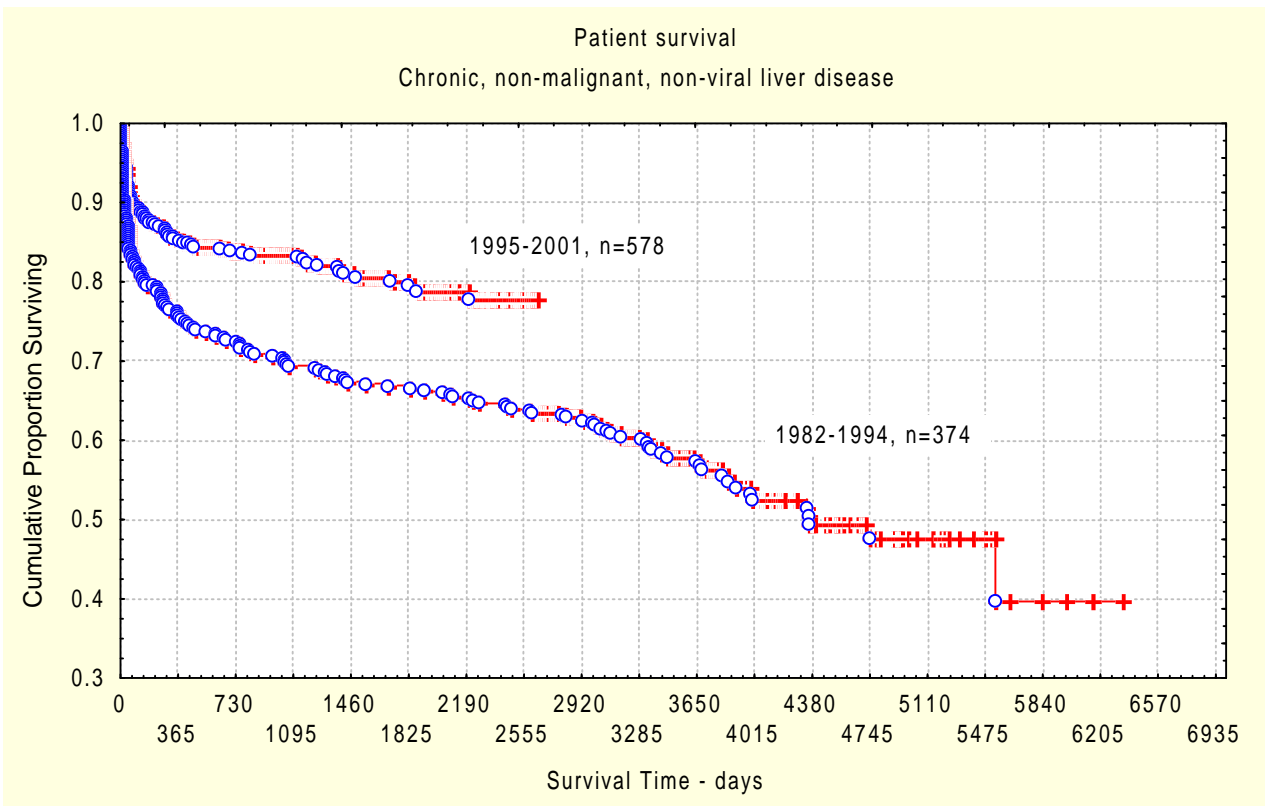
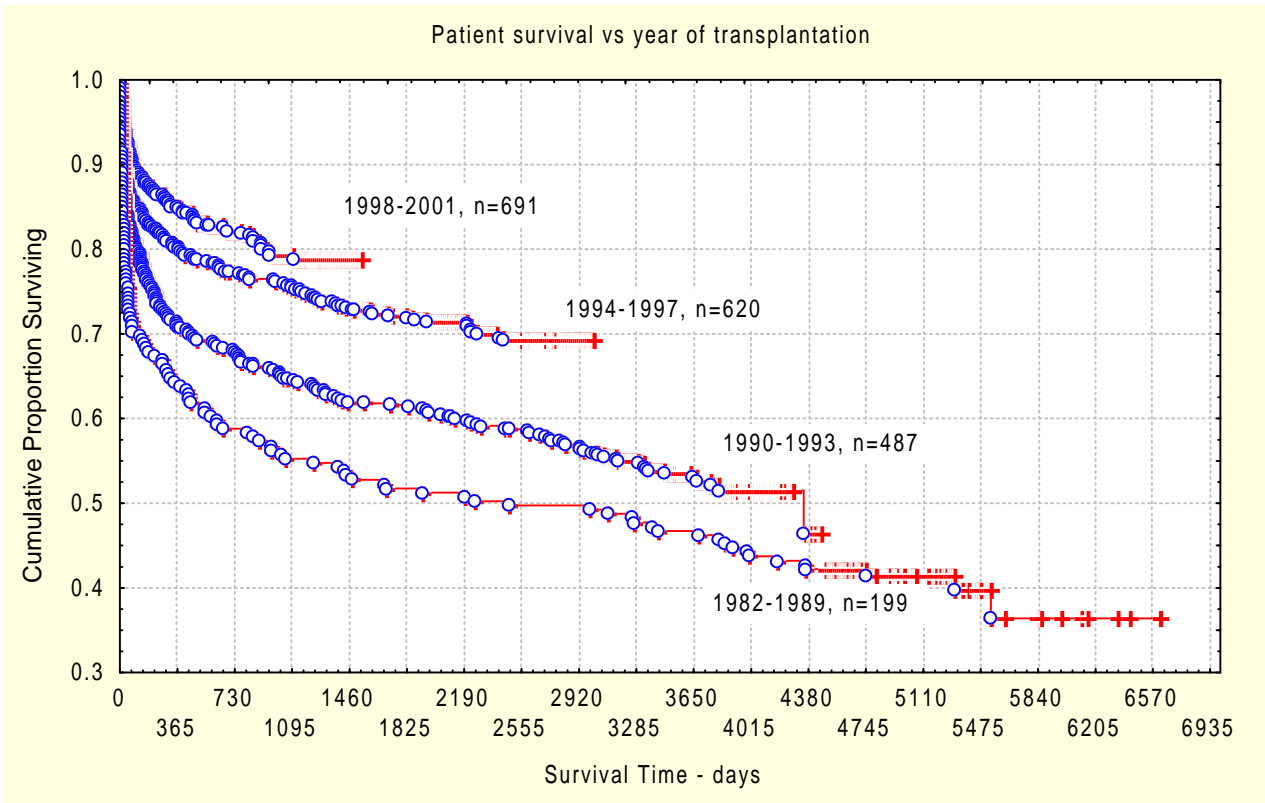
Annual number of first liver transplantations according to diagnosis (PSC-primary sclerosing cholangitis, FHF-fulminant hepatic failure, ALCI-alcoholic cirrhosis, PBC-primary biliary cirrhosis)



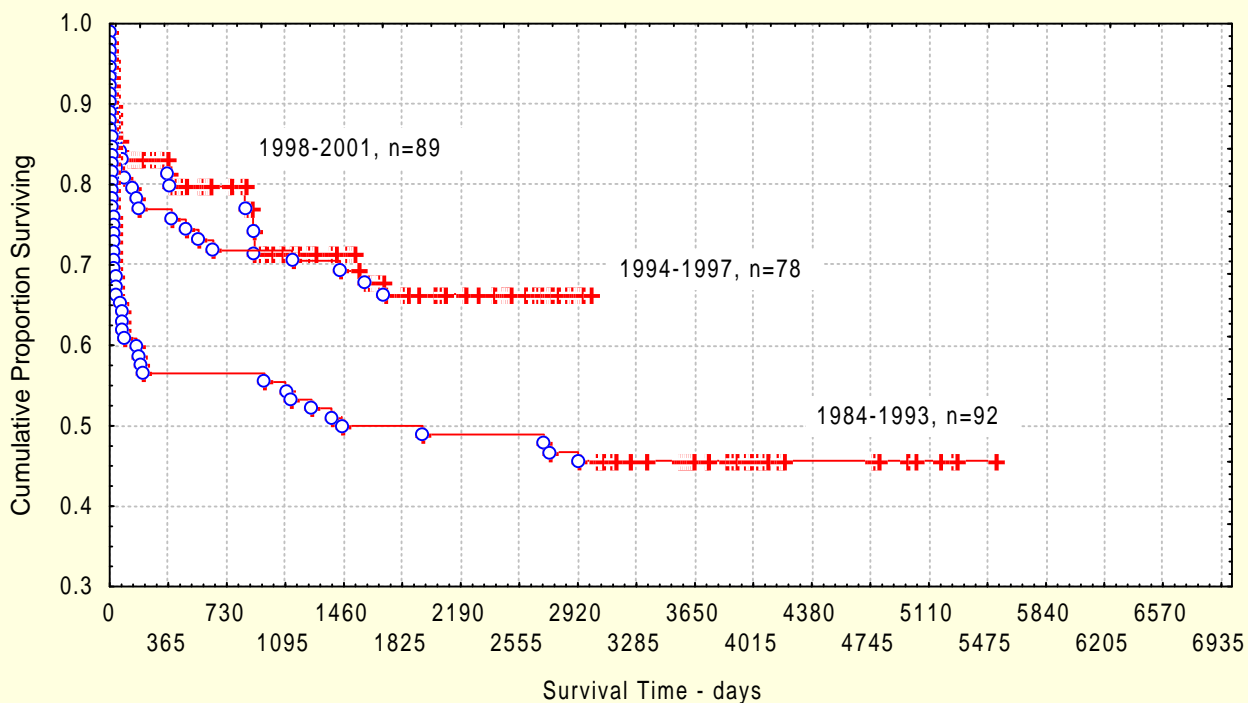
Mean donor and recipient age during 1990-2001



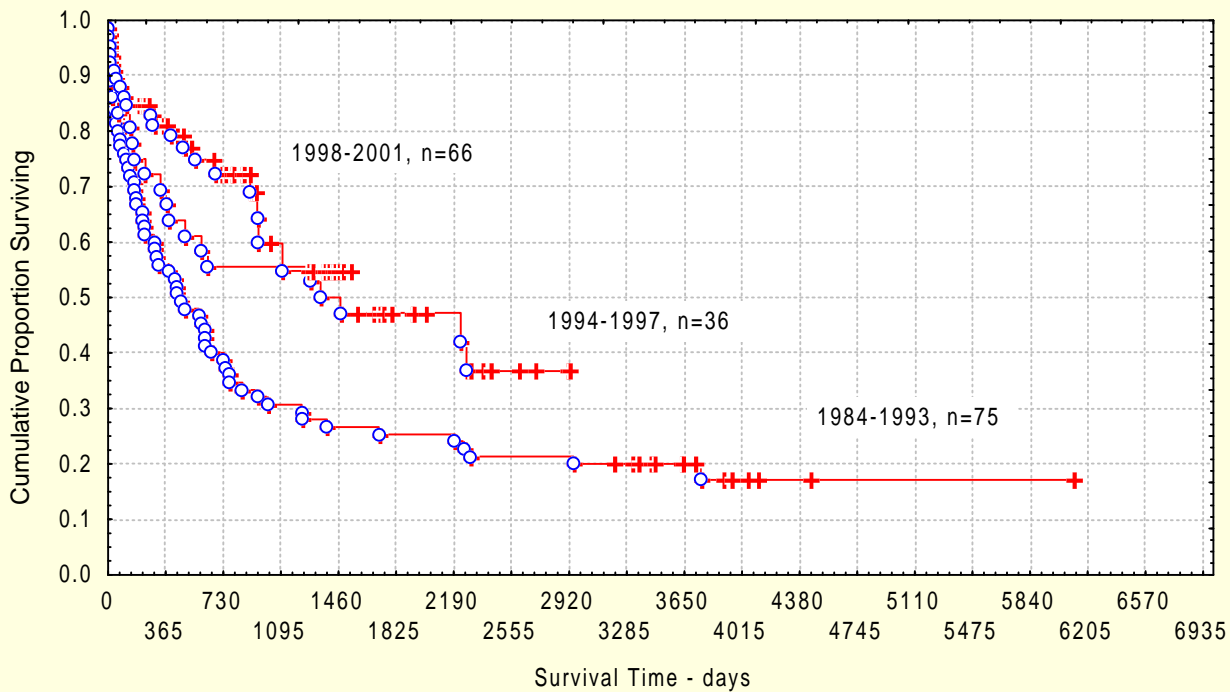
# Survival curves



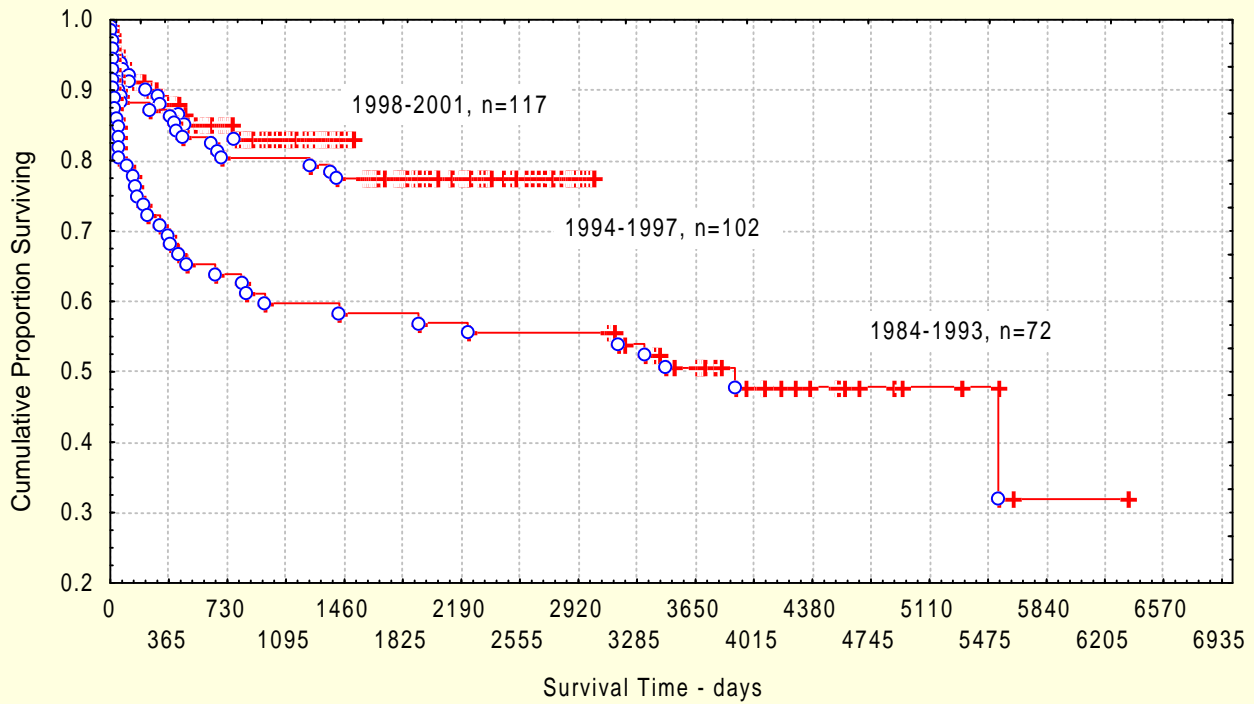
Patient survival  
Fulminant hepatic failure



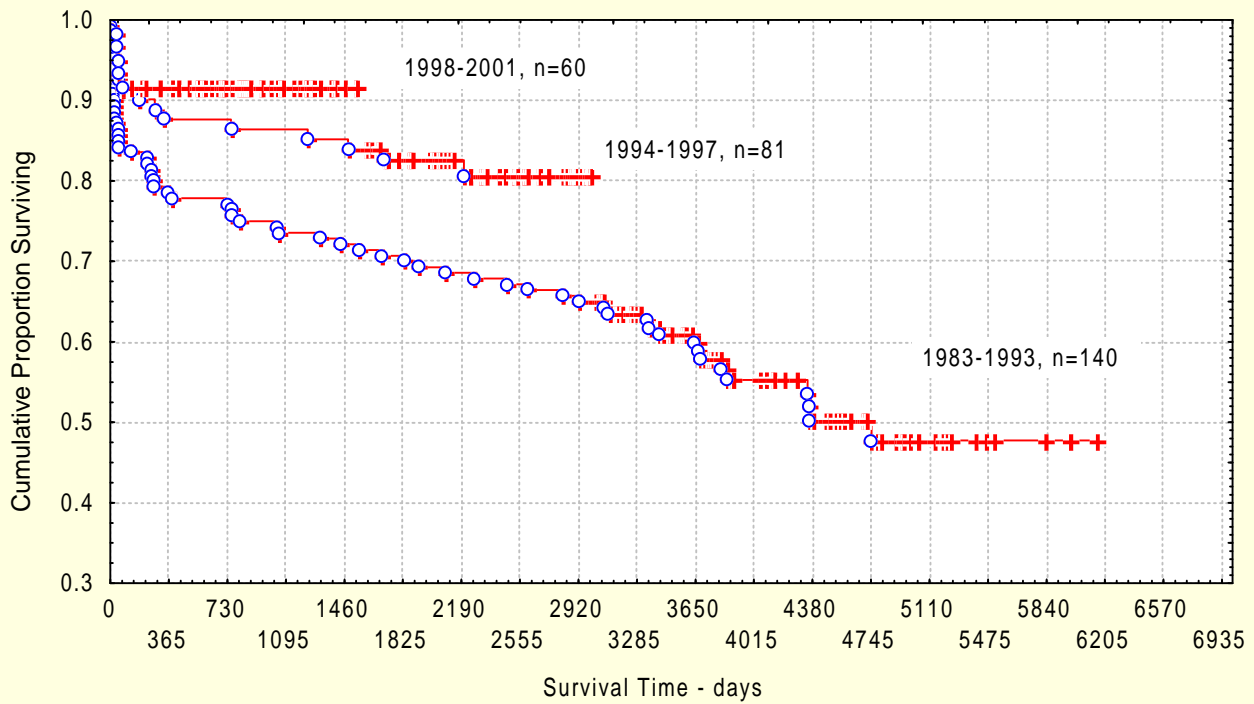
Patient survival  
Malignant liver disease



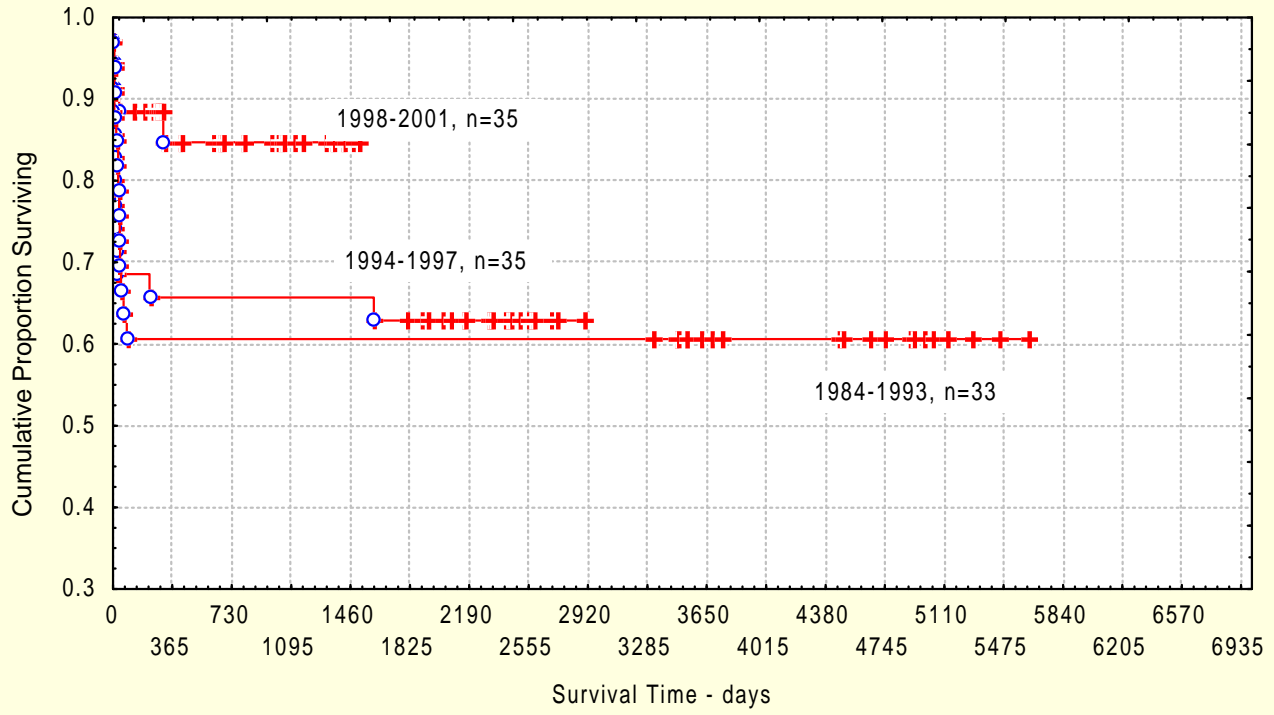
Patient survival  
Primary sclerosing cholangitis



Patient survival  
Primary biliary cirrhosis



Patient survival  
Biliary atresia



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## **abstracts**

11. Bjøro K, Keiding S, Ericzon BG, Friman S, Olausson M, Kirkegaard P, Hjortrup A, Höckerstedt K, Isoniemi H, Bergan A, Schrupf E. The Nordic liver transplant registry. Organisation and outcome of 1160 patients accepted for liver transplantation 1990-1996. *Scandinavian Congres for Organ transplantation, Oslo 1997, abstract*
12. Bjøro K, Keiding S, Ericzon BG, Friman S, Olausson M, Kirkegaard P, Hjortrup A, Höckerstedt K, Isoniemi H, Bergan A, Schrupf E. Indication for liver transplantation in

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  20. Bjørø K, Höckerstedt K, Friman S, Kirkegaard BG, Ericzon BG. Outcome after listing for highly urgent liver transplantation – impact of ABO blood type. Joint Meeting of International Liver Transplantation Society and European Liver Transplantation Association. Berlin 2001, abstract no 91
  21. Ericzon BG, Bjørø K, Höckerstedt K, Hansen B, Olausson M, Isoniemi H, Kirkegaard P, Söderdahl G, Foss A, Friman S. Time to request ABO-identity when transplanting for fulminant hepatic failure? Transpl odysse, Istanbul, August 2001
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