

ANNUAL REPORT 1998

The Norwegian Renal Registry

(Norsk Nefrologiregister)

This report will also be available on:
<http://pc-33-85.his.no/Nyreforening/Uremiregisteret/1998.html>

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Preface

The Norwegian Renal Registry (Norsk Nefrologiregister) was formally constituted in 1994 as a collaboration between The Norwegian Renal Association (Norsk Nyremedisinsk Forening) and The National Hospital (Rikshospitalet), with the latter as the formal owner. National data on renal replacement therapy (RRT) had been collected within The Renal Association since 1980 in a less formalised manner, and the transplant centre had data on transplanted patients since the sixties. Further, Norwegian renal units had reported to the ERA/EDTA-registry since the late sixties.

According to its statutes, The Norwegian Renal Registry shall combine the handling of data for all these purposes. It shall present national statistical reports and form a basis for research. Reports for 1995 and 1996 (in Norwegian) and 1997 (in English) have been distributed, the latter has also been made available on Internet.

National organisation and policy

Norway has 4.4 mill. inhabitants (1998) and 19 counties with populations ranging from 74000 to 502000. Each county, except one, has a central renal unit and some have additional unit(s) run in close contact with the central unit. There is only one transplant centre (two in 1963-83). Pre-transplant work-up, as well as post-transplant follow-up beyond 3 months, is handled by the county-centres.

Transplantation has always been considered the treatment of choice, if possible with a living related donor. Since 1984, also spouse donors have been used. Acceptance criteria for transplantation have been wide, strict age limits have not been applied. Over time, an increasing number of non-transplantable patients have also been offered life-long dialysis.

Incidence and prevalence calculations in this report are based on the national population data from Oct.1 1998, although this in some instances may be slightly misleading since population changes have not been uniform in all counties during the period.

Incidence figures for 1998

During 1998 a total of 401 new patients (in 1996: 367) entered renal replacement therapy (RRT), i.e. 91.1 pr mill. inhabitants.

A majority of 66.1% were males and 33.9% females. Median age at start was 63 years, mean 59.1 years, ranging from one up to 85 years.

Tabulated by first mode of treatment, and age at start of treatment:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	6	10	12	21	33	63	86	69	300	74.8
PD	0	2	6	9	5	10	17	9	58	14.5
TX	2	3	5	12	6	10	5	0	43	10.7
Total	8	15	23	42	44	83	108	78	401	100
in %	2.0	3.7	5.7	10.5	11.0	20.7	26.9	19.5	100	

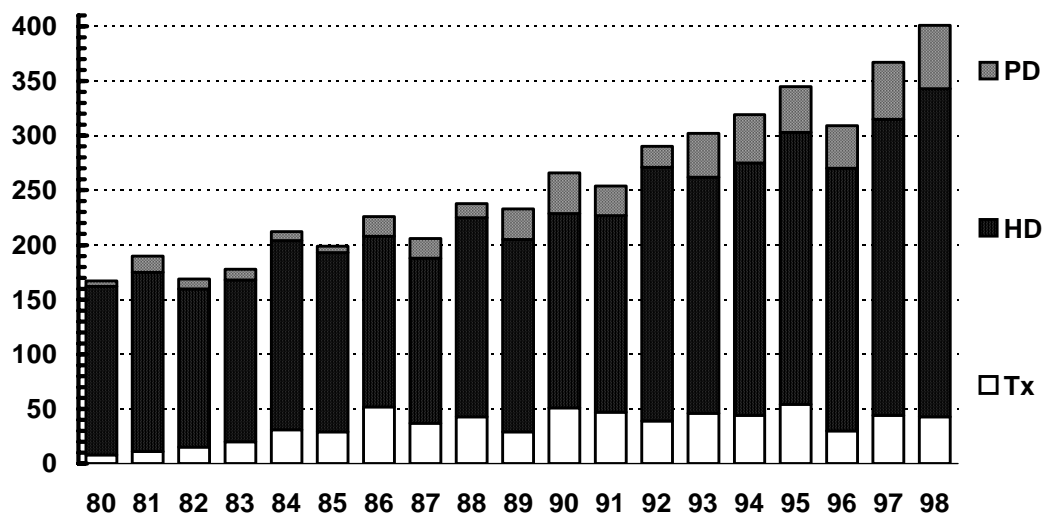
Among the PD-patients, 47 were registered with CAPD as first mode of treatment, 10 with CCPD/APD and one with IPD as first treatment.

At start of treatment, 289 (72.1%) were considered by their nephrologist to be a potential candidate for transplantation, while 112 (27.9%) were accepted for life-long dialysis (constituting 33% of those starting with HD and 21% of those starting PD).

Among patients starting dialysis in 1998, 21% were previously unknown to the renal unit when they presented with terminal renal failure, 48% were known and started RRT as planned, while 31% were known but had a hastened RRT-start.

Incidence data: Changes 1980-1998

New patients in RRT by year of start, and first mode of treatment

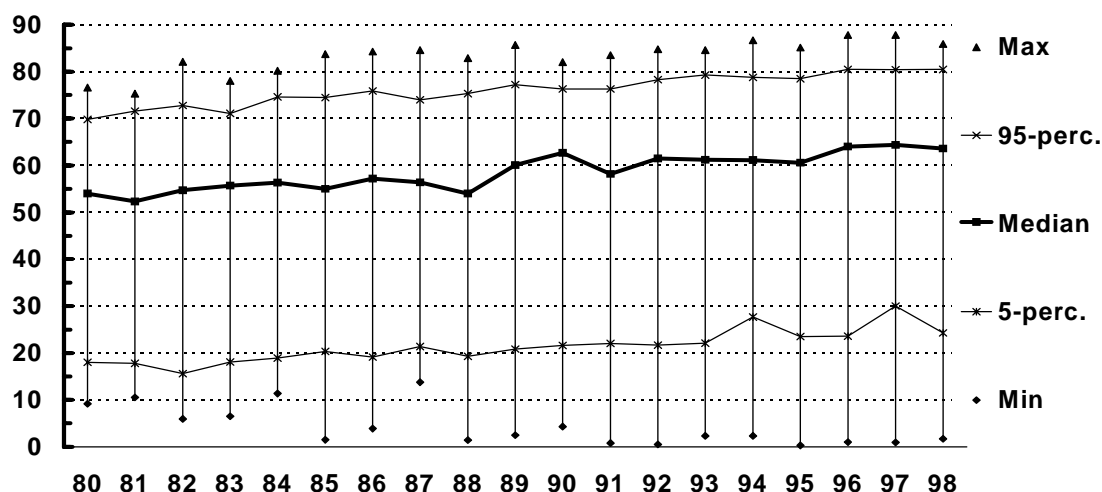


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As appears from the figure the incidence is still rising, during the nineties the mean yearly increase has been 6.8% per year.

Incidence data: Age at start

Age of new patients in RRT Percentiles and range, by year of start



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Since registration started in 1980 there has been a continuous shift in patient age. Both the maximum and the median age at start of RRT have increased. Also the 5-percentile and 95-percentile values (i.e. including the majority of patients) have increased with a similar number of years. At the same time, it appears that even younger children have been included. The number of children below 15 years has not changed during the period - it has ranged from two to eight per year.

Incidence data: Primary renal disease

	1980-84	1985-89	1990-94	1995-97	1998
Glomerulonephritis	34%	36%	31%	26%	22%
Pyelo/interstitial nephr.	16%	14%	11%	12%	11%
Polycystic diseases	10%	9%	9%	10%	11%
Diabetic nephropathy	13%	12%	12%	11%	10%
Amyloidosis	7%	6%	6%	4%	5%
Vascular/hypertensive	5%	8%	18%	22%	24%
Immunological	4%	5%	4%	6%	5%
Kidney tumour	1%	1%	1%	1%	2%
Myelomatosis	3%	2%	1%	2%	3%
Other defined	4%	4%	4%	3%	3%
Unknown	3%	3%	3%	4%	3%
N:	912	1106	1419	1020	401

The main change over time has been an increase of vascular/hypertensive nephropathy and a relative reduction of glomerulonephritis and pyelonephritis/interstitial nephritis. Whether this only reflects changed coding practice or a true shift is not known.

Diabetic nephropathy has contributed 10-14% per year. During most of the period no sub-classification has been registered. In 1998, 22 were registered as having Type I and 18 as Type II diabetes. In addition 27 patients with other types of primary renal disease were recorded having diabetes as a co-morbid factor (2 Type I and 25 Type II), thus 17% of new patients were diabetics.

Prevalence data: Status by 31.dec. 1998

By the end of 1998, 2318 patients in Norway received renal replacement therapy, i.e. 526.8 per million inhabitants. This represents an increase of 154 patients, or 7.1% since 1997.

Gender: 64% males and 36% females.

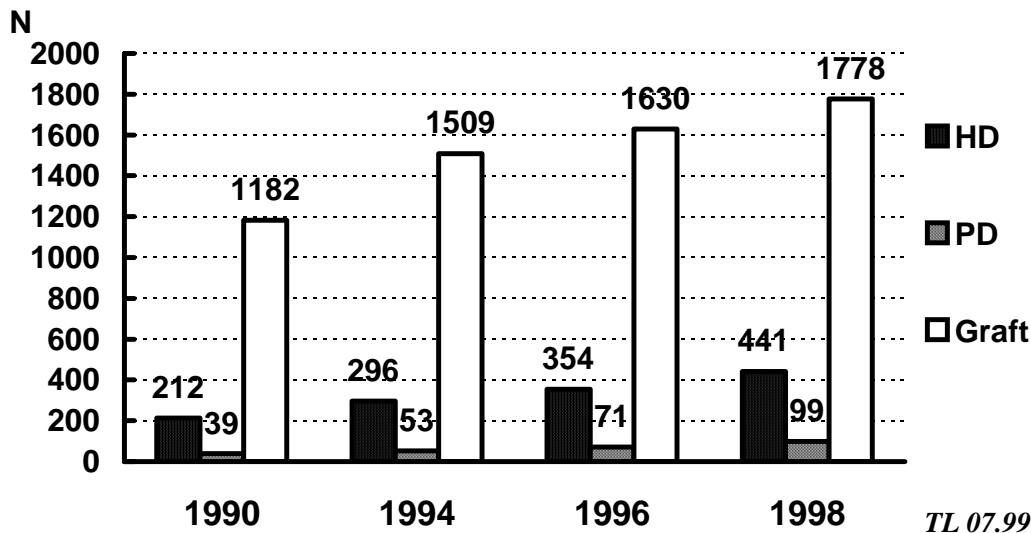
Median age by the end of the year was 53 years, mean 53.1 years and range 3-86 years.

Tabulated by last mode of treatment, and age by end of 1998:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	3	13	19	37	57	71	124	117	441	19.0
PD	0	4	7	13	18	18	22	17	99	4.3
TX	24	73	214	322	446	360	243	96	1778	76.7
Total	27	90	240	372	521	449	389	230	2318	100
in %	1.2	3.9	10.4	16.0	22.5	19.4	16.8	9.9	100	

Renal replacement therapy in Norway

Prevalence of treatment modes in 1990, -94, -96 and -98.



Death in RRT in 1998:

A total of 242 patients in renal replacement therapy died during 1998, i.e. 9.4% out of the 2565 persons at risk. Among these, 70% were males and 30% females. Median age at death was 70 years, mean 67.2 years and the range 1-87 years. Median time from start of RRT until death was 23 months, with a range spanning from one day to 28 years.

The final mode of treatment was HD for 137 patients and PD for 17, while 88 died with a more or less well-functioning graft. Three died within two months after graft loss, thus 91 deaths were termed 'TX-related'.

As in previous years, cardiac (43%) complications were the most frequent causes of death, followed by infections (17%), vascular complications (15%) and malignant tumours (8%).

Transplantation and waiting lists:

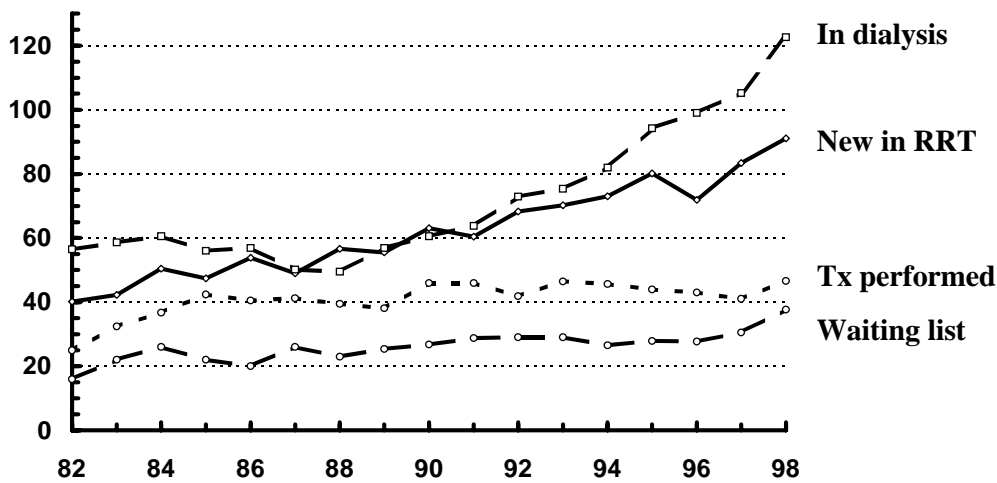
A total of 203 renal transplants were performed at The National Hospital (Rikshospitalet) in 1998- i.e. 46.6 per million inhabitants. In 78 (38%) the graft came from a living related or spouse donor. 175 (86%) were first grafts.

By end 1998, 166 patients (37.7 per mill.) were on the active waiting list for a necro-kidney. This represented an increase of 32 patients (24%). Among those waiting by Dec.31, median time on the list was 7 months. 45% had waited less than 6 months, 74% less than one year and 95% less than two years. The 125 recipients given a necro-kidney in 1998 had a median waiting time of 9 months and a maximum of 51 months at the time of grafting.

Among the 450 patients in dialysis treatment by Dec.31, 205 (38%) were for various reasons not considered candidates for a new renal graft.

Renal replacement therapy in Norway

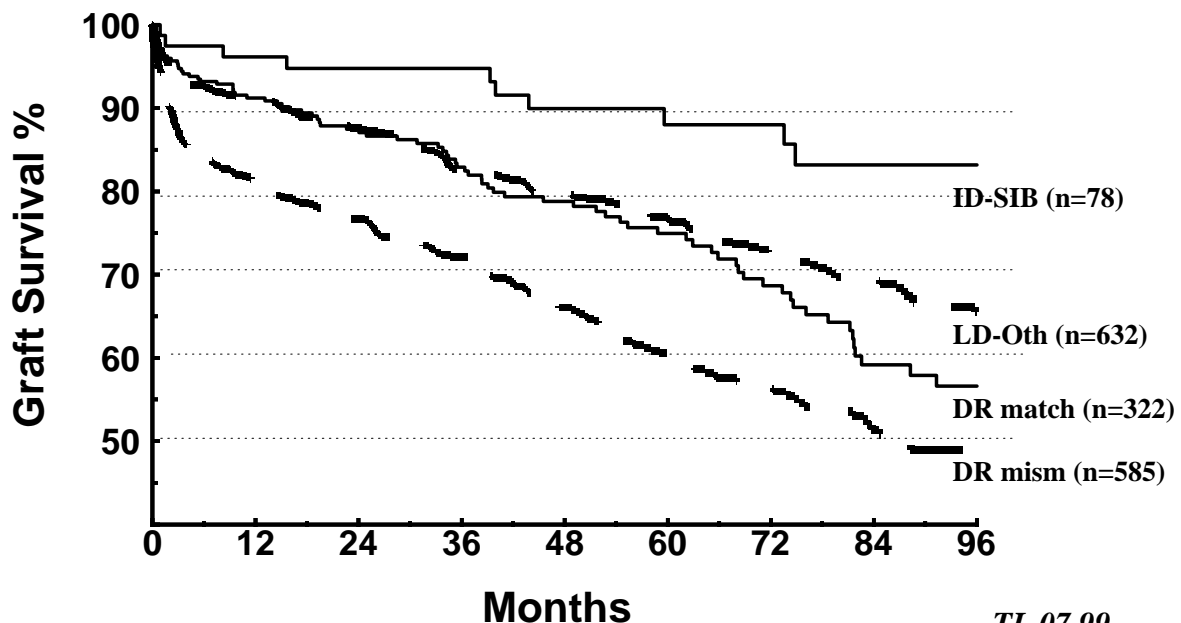
Status by end of year - pats. pr mill. inhabitants



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Survival of first renal grafts

Norway 1989-1998



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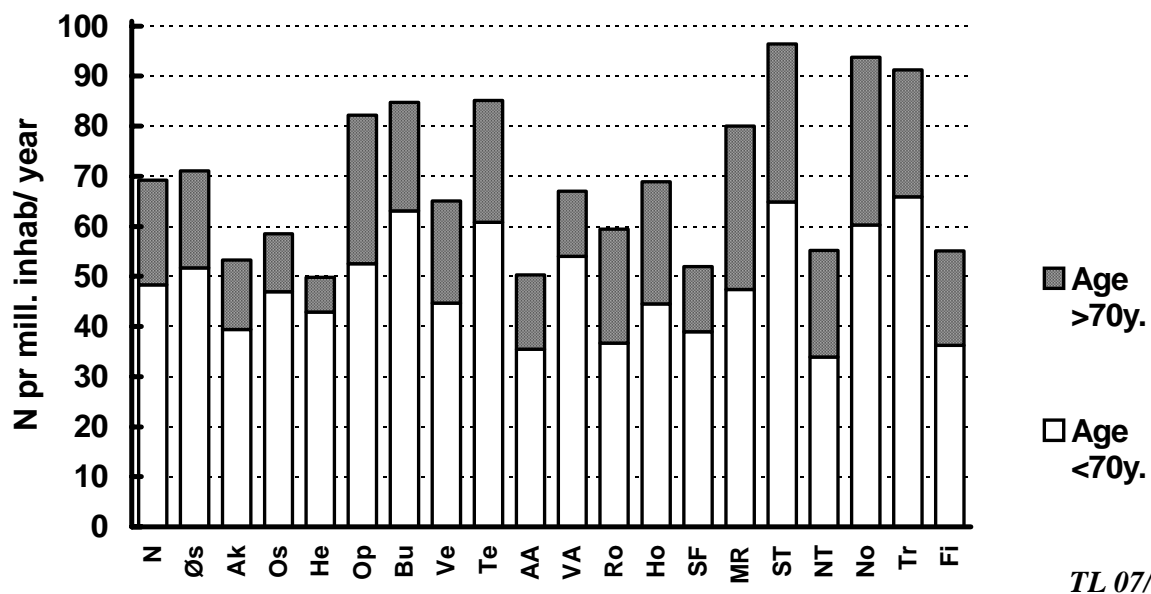
The best graft survival is seen when the donor is an HLA-identical sibling (n=78, mean recipient age at TX.: 45.1 year; p=0.0105 vs. other LD-recipients). Among the 'LD-Oth' (n=632, mean age 42.0) are recipients of a graft from a relative mismatched for one or both HLA-haplotypes and recipients of a spouse graft. Among recipients of a first graft from a necro-donor, HLA-DR matched grafts (n=322, mean age 56.0 years) did better than the HLA-DR mismatched (n=585, mean age 53.9) grafts. A detailed analysis of matching effects (first grafts and re-grafts) will appear in Reviews in Immunogenetics 1991:1 (Leivestad T & al. – in press).

Regional differences within Norway

During all the years since data collection was started, the number of patients reported has differed substantially between centres, also after correction for population size. Registry data have been tabulated by county of domicile (at start, and by end 1998) for calculations of incidences and prevalence. Since many counties are rather small and the number of new patients in each county may vary considerably from year to year, incidence data have been calculated as a mean for the ten-year period 1989-98.

RRT in Norway 1989-98

Mean yearly incidence, by county



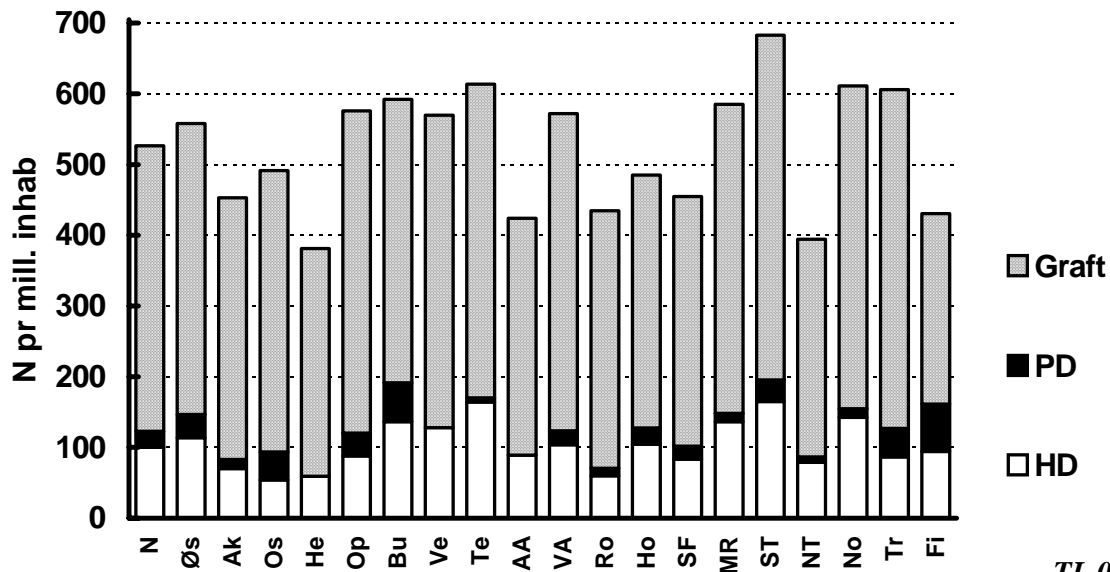
Incidence: As appears from the figure above, the mean incidence differs considerably between the counties. E.g., the incidence of RRT-start in Sør-Trøndelag (ST) has been close to twice that in Hedmark (He). Further, there are also considerable differences between counties as to the age distribution, the proportion of patients above 70 years at start varies from 14% to 41%. Whether this reflects different age distribution among the general population or different attitudes among the public or doctors is not clear. (N = National mean values).

The proportion of new patients who first presented in the renal unit with a terminal renal failure also varied considerably between counties – from less than 5% to more than 50%. This would indicate that there might be a need for improved co-operation within the health service.

In general, identification and evaluation of transplant candidates in pre-terminal phase could facilitate pre-emptive transplantation, thereby reducing the need for dialysis. In the period 1989-98, approx. 18% of those considered potential candidates for transplantation at start of RRT were grafted without preceding dialysis ('pre-emptive'). The corresponding figures for each county varied from a low 9% to a high 33%, indicating that there may be a considerable potential for improvements.

RRT in Norway by end of 1998

Prevalence, by treatment mode and county



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Prevalence: Again, the data demonstrate great differences between the counties. In all counties the majority of patients have a functioning graft, constituting from 66% to 83% of the total RRT-population. The dialysis prevalence ranges from 59 to 196 per mill. inhabitants in the counties, indicating great differences in workloads and costs. In some counties, two out of three dialysis patients are not considered candidates for a new graft, in others this applies only for 10-15%. But counties with a high dialysis prevalence do not necessarily have a high prevalence of ‘non-transplantables’.

Future development :

The data indicate a that the number of RRT-patients will continue to increase in the coming years. Unless a corresponding rise in kidney donation (living and necro-donors) is achieved, the number of patients in dialysis will rise and they will constitute an increasing proportion of the RRT-population.

Compared to the Swedish RRT-incidence (119 per million in 1998) and prevalence (668 per million), Norwegian numbers still are low. As long as there are no clear reasons for this difference between the two nations that are so similar in most respects, the Norwegian health service should prepare to accommodate a significantly increased number of RRT-patients in the near future.

*Report completed 12.07.1999
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