

**ANNUAL REPORT 1997**

**The**

**Norwegian Renal Registry**

**(Norsk Nefrologiregister)**

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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), the latter being the formal owner. National data on renal replacement therapy (RRT) had been collected within The Renal Association since 1980 in a less formalized manner, and the transplant center 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 have been distributed earlier (in Norwegian only).

## National organization and policy

Norway has 4.4 mill. inhabitants (1997) and 19 counties with populations ranging from 75000 to 449000. 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 center (two in 1963-83). Pretransplant 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 1997, 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 1997

During 1997 a total of 363 new patients (in 1996: 309) entered renal replacement therapy (RRT), i.e. 82.5 pr mill. inhabitants.

A majority of 63.9% were males and 36.1% females. Median age at start was 64 years, mean 60.2 years, with a range from 11 months to 87 years.

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

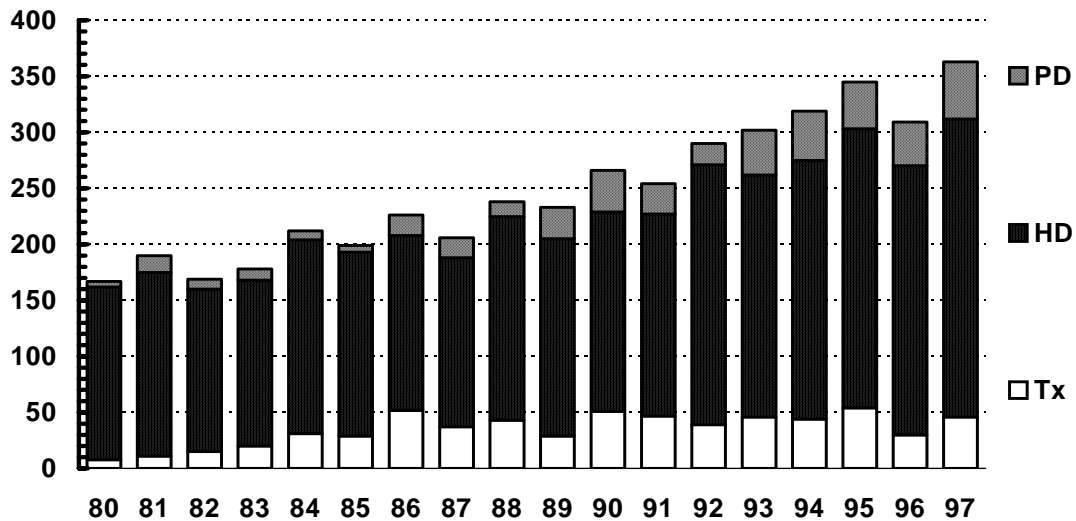
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	2	4	13	17	44	38	82	66	266	73.3
PD	0	0	5	7	11	8	12	8	51	14.0
Tx	1	3	5	9	12	11	4	1	46	12.7
Total	3	7	23	33	67	57	98	75	363	100
in %	0.8	1.9	6.3	9.1	18.5	15.7	27.0	20.6	100	

Among the PD-patients, 34 were registered with CAPD as first mode of treatment and 17 with CCPD/APD as first treatment.

At start of treatment, 257 (70.8%) were considered by their nephrologist to be potential candidates for transplantation, while 106 (29.2%) were accepted for life-long dialysis (constituting 36% of those starting with HD and 20% of those starting PD).

## Incidence data: Changes 1980-1997

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

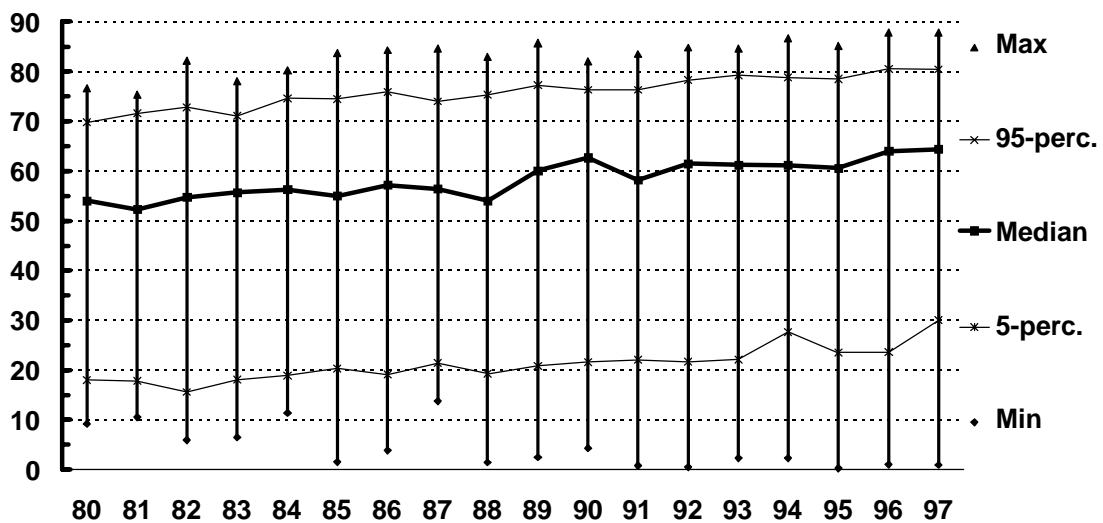


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As appears from the figure the incidence is still rising, during the nineties with a mean of 6% per year.

## 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	1997
Glomerulonephritis	34%	36%	31%	24%
Pyelo/interstitial nephr.	16%	14%	11%	11%
Polycystic diseases	10%	9%	9%	9%
Diabetic nephropathy	13%	12%	12%	11%
Amyloidosis	7%	6%	6%	5%
Vascular/hypertensive	5%	8%	18%	24%
Immunological	4%	5%	4%	7%
Kidney tumour	1%	1%	1%	1%
Myelomatosis	3%	2%	1%	2%
Other defined	4%	4%	4%	2%
Unknown	3%	3%	3%	4%
N:	912	1106	1419	363

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 1997, 19 were registered as having Type I and 21 as Type II diabetes. In addition 28 patients with other types of primary renal disease were recorded having diabetes as a co-morbid factor (all Type II), thus 19% of new patients were diabetics.

## **Prevalence data: Status by 31.dec. 1997**

By the end of 1997, 2162 patients in Norway received renal replacement therapy, i.e. 491.4 per million inhabitants. This represents an increase of 107 patients, or 5.2% since 1996.

Gender: 64% males and 36% females.

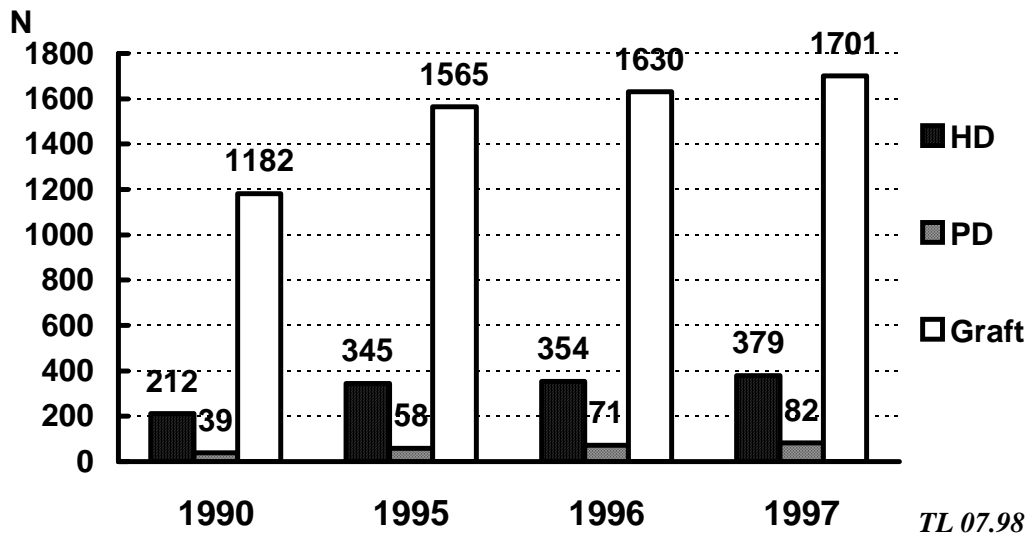
Median age by the end of the year was 52 years, mean 52.5 years and range 1-87 years.

Tabulated by last mode of treatment, and age by end of 1997:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	1	11	18	31	68	53	106	91	379	17.5
PD	0	2	5	11	15	13	18	18	82	3.8
Tx	26	70	218	308	429	328	242	80	1701	78.7
Total	27	83	241	350	512	394	366	189	2162	100
in %	1.2	3.8	11.1	16.2	23.7	18.2	16.9	8.7	100	

# Renal replacement therapy in Norway

Prevalence of treatment modes in 1990, -95, -96 and -97.



## Death in RRT in 1997:

A total of 249 patients in renal replacement therapy died during 1997, i.e. 10.3% out of the 2418 persons at risk. Among these, 65% were males and 35% females. Median age at death was 70 years, mean 67.2 years and the range 25-89 years. Median time from start of RRT until death was 20 months, with a range spanning from one day to 26 years.

The final mode of treatment was HD for 167 patients and PD for 17, while 65 died with a more or less well-functioning graft. Two died within two months after graft loss, thus 67 deaths were termed 'tx-related'.

As in previous years, cardiac (34%) and vascular (21%) complications were the most frequent causes of death, followed by infections (16%) and malignant tumours (12%).

## Transplantation and waiting lists:

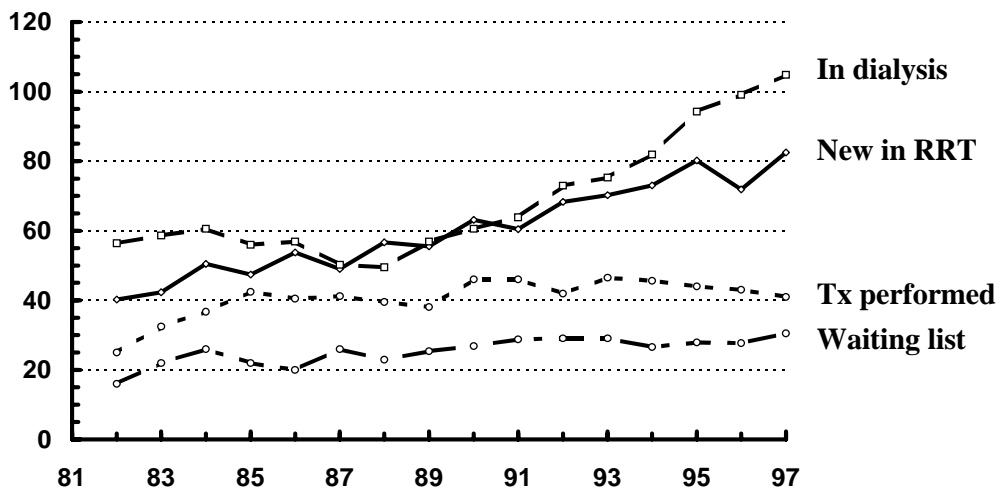
A total of 180 renal transplants were performed at The National Hospital (Rikshospitalet) in 1997- i.e. 41 per million inhabitants. In 68 (38%) the graft came from a living related or spouse donor. 147 (82%) were first grafts.

By end 1997, 134 patients (30.5 per mill.) were on the active waiting list for a necro-kidney. This represented an increase of 15 patients (13%) - the first appreciable increase since 1991. Among those waiting by Dec.31, median time on the list was 10 months. 43% had waited less than 6 months, 68% less than one year and 91% less than two years. The 112 recipients given a necro-kidney in 1997 had a median waiting time of 7 months and a maximum of 41 months at the time of grafting..

One third of the patients in dialysis treatment by Dec.31 were for various reasons not considered candidates for a new renal graft.

# Renal replacement therapy in Norway

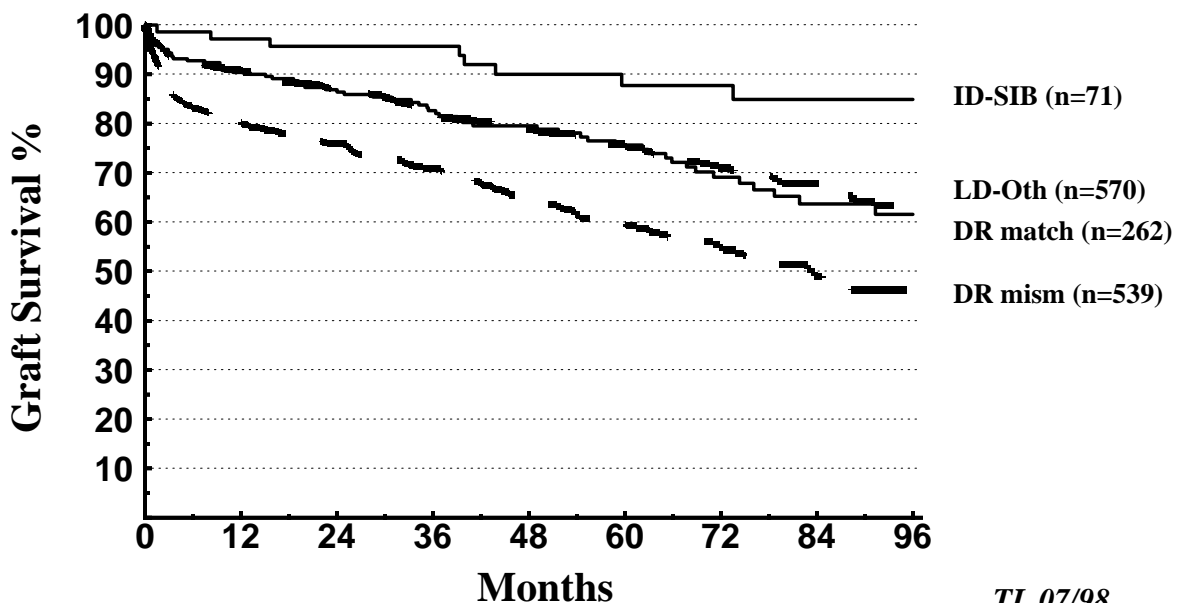
## Status by end of year - pats. pr mill. inhabitants



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# Survival of first renal grafts

## Norway 1989-1997



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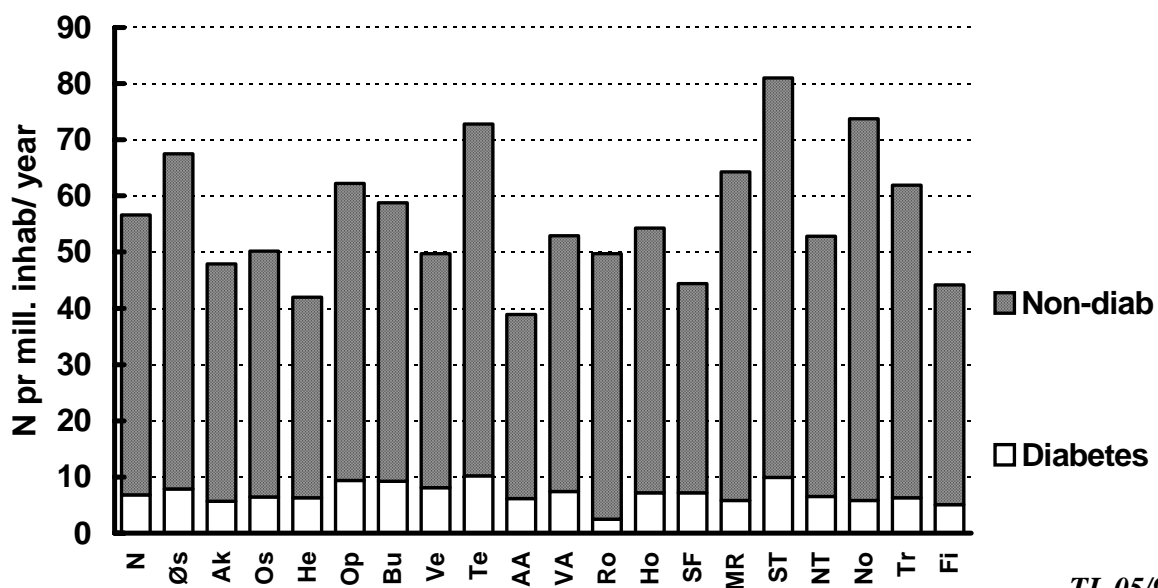
The best graft survival (G.S.) is seen when the donor is an HLA-identical sibling (n=71, mean recipient age at tx.: 44.1 year). Among the 'LD-Oth' (n=570, mean age 42.1) are recipients of a one HLA-haplotype mismatched graft (n=419, mean age 38.9), of a graft from a relative mismatched for both HLA-haplotypes (n=43, mean age 41.4) and recipients of a spouse graft (n=108, mean age 53.1 years), all with similar G.S rates and poorer than 'ID-SIB' (p < .0001). Among recipients of a first graft from a necro-donor, HLA-DR matched grafts (n=262, mean age 56 years) did better than the HLA-DR mismatched (n=539, mean age 53.6) grafts - p<.0001.

(Plot: Kaplan-Meier. Comparisons: Mantel-Haenszel log-rank)

## 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 1997) for calculations of incidences and prevalences. 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 period 1980-97.

### **RRT in Norway 1980-97** Mean yearly incidence, by county



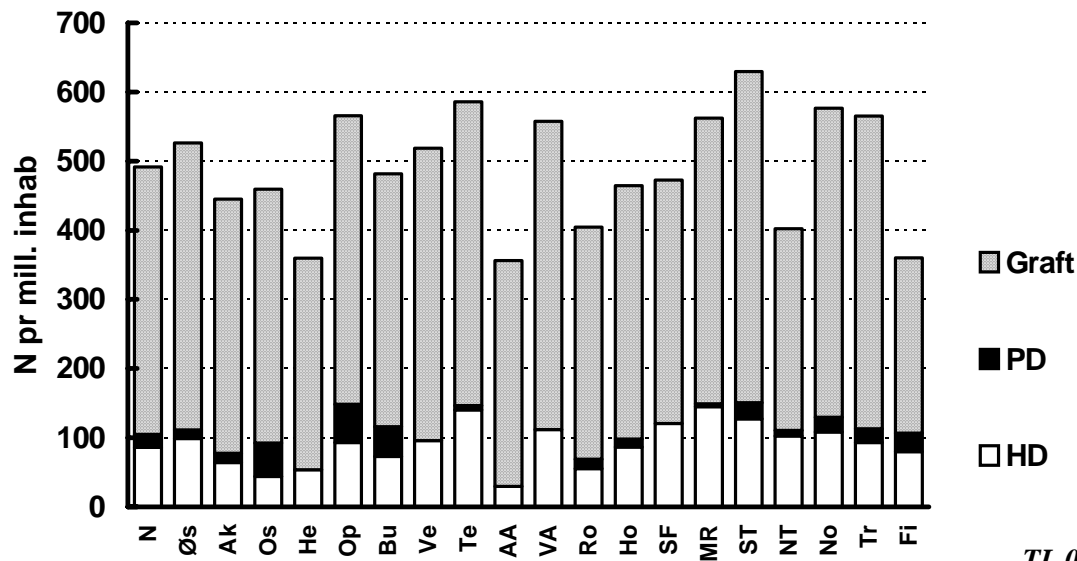
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**Incidence:** As appears from the figure above, the mean incidence differs considerably between the counties. E.g., the incidence of RRT-start in Sør-Trøndelag (ST) has been twice that in Aust-Agder (AA). While the incidence of renal failure due to diabetic nephropathy in Rogaland (Ro) is markedly lower than in all the other counties. (N=National mean values).

In general, identification and evaluation of transplant candidates in pre-terminal phase could facilitate preemptive transplantation, thereby reducing the need for dialysis. In the period 1980-97, approx. 18% of those considered potential candidates for transplantation at start of RRT were grafted without preceding dialysis ('preemptive'). 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 1997

## 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 70% to 92% of the total RRT-population. The dialysis prevalence ranges from 30 to 150 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 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.

Comparing to the Swedish RRT-incidence (118 per million in 1997) and prevalence (643 per million), Norwegian numbers still are low. As long as there are no clear reasons for this difference between the two nations which are so similar in most respects, the Norwegian health service should prepare for accommodating a significantly increased number of RRT-patients in the near future.

*Report completed 25.08.1998  
Torbjørn Leivestad M.D.*