

# PAEDIATRIC REPORT

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## INTRODUCTION

The present report provides further data analysis of the historical 'paediatric' age group (0-14 years) but continues with the precedent established in 1994 of presenting data and analysis of data for the 15-19 year old (adolescent) age group. Where appropriate comparisons are made between the two groups.

Amongst a number of previously reported evaluations, there are several features of this report which have not previously been presented. In particular, these include a limited evaluation of transplant outcome based on primary disease and a time-related review of immunosuppression dosages for transplant recipients stratified by age.

## INCIDENCE OF END STAGE RENAL FAILURE (ESRF)

The age related incidence of ESRF for New Zealand and Australian patients is shown in Figure 291.

The overall incidence of ESRF for Australian children is approximately 6.8 per million of population aged <15 years in 1997 but the incidence for 0-4 year olds has in recent years approached 9-10 per million of population aged 0-4 years.

The incidence of ESRF in the adolescent age group has remained relatively stable around 13 per million population aged 15-19 years, in Australia.

**Figure 291**

**Australia and New Zealand**

### Age Groups of New Paediatric Patients 1983 - 1997

Age Groups	Year														
	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997
<b>Australia</b>															
00-04	4	4	2	0	4	4	4	4	8	7	4	4	12	12	7
05-14	23	26	24	12	27	17	13	14	13	18	15	24	20	18	20
<b>Total</b>	<b>27</b>	<b>30</b>	<b>26</b>	<b>12</b>	<b>31</b>	<b>21</b>	<b>17</b>	<b>18</b>	<b>21</b>	<b>25</b>	<b>19</b>	<b>28</b>	<b>32</b>	<b>30</b>	<b>27</b>
15-19	16	23	21	21	22	22	16	25	18	29	21	19	16	14	21
<b>New Zealand</b>															
00-04	0	0	0	1	2	0	0	0	2	1	4	1	1	3	1
05-14	4	1	3	6	6	3	5	5	4	6	4	5	4	7	6
<b>Total</b>	<b>4</b>	<b>1</b>	<b>3</b>	<b>7</b>	<b>8</b>	<b>3</b>	<b>5</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>6</b>	<b>5</b>	<b>10</b>	<b>7</b>
15-19	3	7	6	3	3	9	1	4	3	7	2	3	7	5	3

## MODE OF CURRENT TREATMENT

Figure 292 shows the mode of current treatment related to age for Australian and New Zealand patients at 31 March 1998.

For all children with ESRF currently being treated and aged 0-14 years, 72% had a functioning transplant on 31 March 1998 (compared to 70% at an equivalent time in 1994) and a distinctly better proportion than the 65% of adolescents aged 15-19 years on 31 March 1998 (unchanged from 65% at the equivalent time in 1994).

For children on dialysis there is an obvious trend towards intermittent peritoneal dialysis (IPD) and to a lesser extent haemodialysis (HD) at the expense of continuous ambulatory peritoneal dialysis (CAPD).

For New Zealand ESRF patients, 60% of children (0-14 years) have a functioning transplant and 50% of adolescents (15-19 years) have a functioning transplant at 31 March 1998.

The number of patients in New Zealand is much smaller but the same trend towards IPD for dialysis treated children is apparent, but CAPD (not HD) seems to be preferred for the adolescents.

**Figure 292**

**Australia and New Zealand**

### Mode of Current Treatment Related to Age 31-Mar-98

Mode of Treatment	Age in Years					
	00-04	05-14	Total	(1994 Total)	15-19	(1994 Total)
<b>Australia</b>						
Home CAPD	1	2	3	(13)	8	(14)
Hospital HD	0	12	12	(6)	15	(14)
Home HD	0	0	0	(0)	4	(4)
Satellite HD	0	0	0	(1)	7	(10)
Hospital IPD	1	2	3	(3)	0	(1)
Home IPD	7	13	20	(7)	3	(4)
Transplant	11	85	96	(70)	89	(86)
<b>Total</b>	<b>20</b>	<b>114</b>	<b>134</b>	<b>(100)</b>	<b>136</b>	<b>(133)</b>
<b>New Zealand</b>						
Home CAPD	0	1	1	(8)	7	(3)
Hospital HD	0	1	1	(0)	1	(4)
Home HD	0	1	1	(0)	1	(1)
Satellite HD	0	0	0	(0)	1	(0)
Hospital IPD	0	0	0	(0)	0	(0)
Home IPD	1	9	10	(2)	1	(0)
Transplant	2	20	22	(15)	11	(17)
<b>Total</b>	<b>3</b>	<b>32</b>	<b>35</b>	<b>(25)</b>	<b>22</b>	<b>(25)</b>

## DIALYSIS TECHNIQUE SURVIVAL

Figure 293 shows the actuarial dialysis technique survival for Australian children and adolescents treated with CAPD and HD. The reasons for technique failure are not analyzed. Only patients "receiving" the technique for > 90 days are considered. Successful transplantation is treated as a "withdrawal" not a "failure" of the technique survival

Figure 294 tabulates and compares the median dialysis technique survival for Australian and New Zealand children and adolescents receiving CAPD and HD

Perhaps the most striking observation is that approximately 50% of children on CAPD "fail" the technique by two years. Haemodialysis appears to be the more durable technique.

**Figure 293**

**Australia**

### Dialysis Technique Survival 1983 - 1997

Age Groups		Survival											
		3 months			6 months			1 year			2 years		
<b>Continuous Ambulatory PD</b>													
00-04	n=23	96 ± 4.3	21	96 ± 4.3	17	70 ± 11.4	9	59 ± 13.8	3				
05-14	n=139	89 ± 2.8	102	83 ± 3.5	76	69 ± 4.8	44	56 ± 6.0	24				
<b>Total</b>	<b>n=162</b>	<b>90 ± 2.5</b>	<b>123</b>	<b>85 ± 3.0</b>	<b>93</b>	<b>69 ± 4.4</b>	<b>53</b>	<b>57 ± 5.4</b>	<b>27</b>				
15-19	n=87	94 ± 2.7	67	88 ± 3.9	51	78 ± 5.2	40	62 ± 6.8	21				
<b>Haemodialysis</b>													
00-04	n=5	100 ± 0.0	4	100 ± 0.0	4	50 ± 25.0	2	50 ± 25.0	2				
05-14	n=34	94 ± 4.4	26	86 ± 6.7	20	86 ± 6.7	13	77 ± 10.1	6				
<b>Total</b>	<b>n=39</b>	<b>94 ± 4.0</b>	<b>30</b>	<b>88 ± 5.8</b>	<b>24</b>	<b>79 ± 8.0</b>	<b>15</b>	<b>72 ± 9.5</b>	<b>8</b>				
15-19	n=156	97 ± 1.4	132	96 ± 1.6	103	93 ± 2.4	66	88 ± 3.7	37				

% Survival ± S.E. / Number at Risk

n = Number of Patients

**Figure 294**

**Australia and New Zealand**

### Median Survival of Dialysis Technique 1983 - 1997

Mode of Treatment	Age Groups	
	0-14	15-19
<b>Australia</b>		
Continuous Ambulatory PD	2.4 years (162)	3.4 years (87)
Haemodialysis	>6.0 years (39)	>9.0 years (156)
<b>New Zealand</b>		
Continuous Ambulatory PD	2.2 years (42)	3.6 years (29)
Haemodialysis	>3.0 years (4)	>7.0 years (28)

( ) = Number of Patients

## PATIENT OUTCOME

Figure 295 shows the outcome of all Australian and New Zealand patients from their initial treatment by age (0-14 years compared to 15-19 years) for the era 1963-82 and the same information for the era 1983 - 97 is shown in Figure 296.

Note the high proportion of 'deaths' by 15 years; 43% for Australian children and 31% for adolescents in the era 1963-82. Similar outcomes are observed in New Zealand patients; 43% for children and 45% of adolescents.

Similar to the data shown under the heading of 'Mode of Current Treatment', there is a pleasing increase in the ratio of functioning grafts to patients receiving dialysis. For example, at 5 years for 1963-82 for Australian patients the ratio was **3.3 : 1** for children and **2.3 : 1** for adolescents compared to the 1983-97 era where the same ratios at 5 years were **6.1 : 1** and **3.0 : 1** respectively. The data for New Zealand patients is comparable.

**Figure 295**

**Australia and New Zealand**

### Outcome of Patients from Initial Treatment by Age and Era 1963 - 1982

Age Groups	Mode of Treatment	Time in Years								
		0	1	5	10	15	20	25	30	35
<b>Australia</b>										
00-14 years n=194	Intermittent PD	91	29	1	1	0	0	0	0	0
	Haemodialysis	88	64	24	25	23	7	3	1	0
	Continuous Ambulatory PD	5	10	7	4	1	0	0	0	0
	Transplant	10	70	106	89	83	36	12	2	0
	Post Graft Dialysis	0	0	0	0	0	0	0	0	0
	Temporary Recovery	0	2	2	2	2	2	2	2	2
	Lost to Follow Up	0	0	1	2	2	4	4	4	4
	Death	0	19	53	71	83	84	86	87	87
15-19 years n=268	Intermittent PD	79	7	2	1	1	0	0	0	0
	Haemodialysis	174	118	60	48	44	19	8	0	0
	Continuous Ambulatory PD	10	12	5	3	2	0	1	0	0
	Transplant	5	113	156	148	134	64	19	2	0
	Post Graft Dialysis	0	1	0	0	0	0	0	0	0
	Temporary Recovery	0	0	1	1	0	0	0	0	0
	Lost to Follow Up	0	0	0	2	5	8	8	9	9
	Death	0	17	44	65	82	99	106	107	107
<b>New Zealand</b>										
00-14 years n=37	Intermittent PD	7	0	0	0	0	0	0	0	0
	Haemodialysis	27	9	5	3	3	1	0	0	0
	Continuous Ambulatory PD	3	5	3	3	2	0	0	0	0
	Transplant	0	20	22	18	16	5	0	0	0
	Post Graft Dialysis	0	0	0	0	0	0	0	0	0
	Temporary Recovery	0	1	1	1	0	0	0	0	0
	Lost to Follow Up	0	0	0	0	0	0	0	0	0
	Death	0	2	6	12	16	16	16	16	16
15-19 years n=76	Intermittent PD	7	0	0	0	0	0	0	0	0
	Haemodialysis	63	35	16	11	11	5	1	0	0
	Continuous Ambulatory PD	3	4	3	0	0	1	0	0	0
	Transplant	3	30	36	37	31	15	7	2	0
	Post Graft Dialysis	0	0	0	0	0	0	0	0	0
	Temporary Recovery	0	1	0	0	0	0	0	0	0
	Lost to Follow Up	0	0	0	0	0	0	0	0	0
	Death	0	6	21	28	34	35	36	37	37

**Figure 296**

**Australia and New Zealand**

**Outcome of Patients from Initial Treatment by Age and Era  
1983 - 1997**

Age Groups	Mode of Treatment	Time in Years								
		0	1	5	10	15	20	25	30	35
<b>Australia</b>										
00-14 Years n=363	Intermittent PD	192	40	6	0	0	0	0	0	0
	Haemodialysis	55	37	18	19	0	0	0	0	0
	Continuous Ambulatory PD	75	85	6	3	0	0	0	0	0
	Transplant	42	165	184	84	4	0	0	0	0
	Post Graft Dialysis	0	0	0	0	0	0	0	0	0
	Temporary Recovery	0	1	0	0	0	0	0	0	0
	Lost to Follow Up	0	1	1	1	1	1	1	1	1
	Death	0	15	30	44	48	48	48	48	48
15-19 years n=304	Intermittent PD	54	10	1	0	0	0	0	0	0
	Haemodialysis	192	102	39	18	1	0	0	0	0
	Continuous Ambulatory PD	38	44	9	4	0	0	0	0	0
	Transplant	20	119	149	67	4	0	0	0	0
	Post Graft Dialysis	0	0	0	0	0	0	0	0	0
	Temporary Recovery	0	3	1	1	1	1	1	1	1
	Lost to Follow Up	0	1	0	1	2	2	2	2	2
	Death	0	10	26	34	35	35	35	35	35
<b>New Zealand</b>										
00-14 years n=85	Intermittent PD	13	5	5	1	0	0	0	0	0
	Haemodialysis	12	7	4	3	0	0	0	0	0
	Continuous Ambulatory PD	42	25	5	2	1	0	0	0	0
	Transplant	18	40	31	11	0	0	0	0	0
	Post Graft Dialysis	0	0	0	0	0	0	0	0	0
	Temporary Recovery	0	0	1	1	1	1	1	1	1
	Lost to Follow Up	0	0	1	1	1	1	1	1	1
	Death	0	3	8	12	12	12	12	12	12
15-19 years n=76	Intermittent PD	1	1	0	0	0	0	0	0	0
	Haemodialysis	38	19	10	3	0	0	0	0	0
	Continuous Ambulatory PD	24	23	3	2	0	0	0	0	0
	Transplant	3	19	23	13	0	0	0	0	0
	Post Graft Dialysis	0	0	0	0	0	0	0	0	0
	Temporary Recovery	0	1	2	2	1	1	1	1	1
	Lost to Follow Up	0	0	0	0	0	0	0	0	0
	Death	0	1	9	10	12	12	12	12	12

## TRANSPLANTATION

### PRIMARY DISEASE

Figure 297 shows the tabulated actuarial patient and graft survival for children (<15 years) and adolescents (15-19 years) for primary cadaveric (CAD) and living related grafts (LRD). This data has been presented previously in various forms (1994–1997). The present data provides a basis for comparison of survivals based on primary disease.

Figures 298 and 299 show the actuarial survival data (patient and graft survival) stratified for primary disease. There are no differences in patient survivals. As has been observed in adult populations, a better graft outcome for reflux associated conditions is observed for children <15 years of age. Children with glomerulonephritis

(of all varieties) have a 20% worse graft survival between five and ten years than children with reflux associated conditions. This pattern is however not observed in 15-19 year olds where graft outcomes are generally poorer. The explanation for this difference is uncertain but amongst the possibilities one might include

- i) the nature of nephritic disease in younger children.
- ii) the accuracy of the diagnosis.
- iii) other factors influencing graft outcome (such as compliance, etc) not corrected for in this analysis.

Of these, perhaps the third option seems the most likely.

**Figure 297**

**Australia and New Zealand**

### Primary Cadaver Patient and Graft Survival 1983 - 1997 By Age and Donor Source

Age Groups			Survival									
			1 year		3 years		5 years		10 years			
<b>Patient Survival</b>												
00-14	CAD	n=146	96 ± 1.7	136	96 ± 1.7	115	93 ± 2.2	95	87 ± 3.3	56		
	LRD	n=208	99 ± 0.9	193	97 ± 1.3	145	96 ± 1.6	116	90 ± 2.9	53		
15-19	CAD	n=182	98 ± 1.0	173	93 ± 1.9	154	87 ± 2.5	131	81 ± 3.4	60		
	LRD	n=96	97 ± 1.8	86	92 ± 2.9	72	92 ± 2.9	54	90 ± 3.5	24		
<b>Graft Survival</b>												
00-14	CAD	n=146	82 ± 3.2	117	74 ± 3.7	88	63 ± 4.3	63	45 ± 5.2	25		
	LRD	n=208	92 ± 2.0	179	85 ± 2.6	128	78 ± 3.2	94	63 ± 4.6	35		
15-19	CAD	n=182	79 ± 3.0	139	66 ± 3.6	108	53 ± 3.9	78	40 ± 4.2	28		
	LRD	n=96	91 ± 2.9	81	83 ± 4.0	64	80 ± 4.3	47	61 ± 7.1	18		

% Survival ± S.E. / Number at Risk  
n = Number of Patients

**Figure 298**

**Australia and New Zealand**

**Patient Survival Related to Age and Primary Renal Disease  
1983 - 1997  
Children (00-14 years) and Adolescents (15-19 years)**

All Grafts		Survival								
		1 year		3 years		5 years		10 years		
<b>Patient 0-14 years</b>										
Reflux Nephropathy	n=124	98 ± 1.4	115	98 ± 1.4	96	94 ± 2.5	74	92 ± 3.1	46	
Glomerulonephritis	n=95	99 ± 1.1	90	95 ± 2.3	75	94 ± 2.7	65	90 ± 3.5	37	
Other	n=166	97 ± 1.4	152	96 ± 1.6	114	93 ± 2.2	94	85 ± 3.8	39	
<b>Patient 15-19 years</b>										
Reflux Nephropathy	n=106	97 ± 1.6	101	91 ± 2.8	86	88 ± 3.3	71	82 ± 4.1	31	
Glomerulonephritis	n=132	97 ± 1.5	120	91 ± 2.1	106	86 ± 3.2	88	81 ± 3.5	46	
Other	n=91	97 ± 1.9	84	94 ± 2.5	74	87 ± 3.4	60	80 ± 5.4	26	

% Survival ± S.E. / Number at Risk

n = Number of Patients

Reflux = Reflux + Hypoplasia + Dysplasia + Pyelonephritis + Other Urinary Tract Abnormalities

Glomerulonephritis = All forms of glomerulonephritis

Other = All other diseases

**Figure 299**

**Australia and New Zealand**

**Graft Survival for Children (00-14 years) and Adolescents (15-19 years)  
By Country and Primary Renal Disease 1983 - 1997**

Country		All Grafts		Survival							
				1 year		3 years		5 years		10 years	
<b>Patient 0-14 years</b>											
Australia and New Zealand	Reflux Nephropathy	n=124	89 ± 2.8	105	85 ± 3.4	102	79 ± 4.0	59	64 ± 5.4	29	
	Glomerulonephritis	n=95	84 ± 3.8	77	70 ± 4.9	56	59 ± 5.4	40	41 ± 6.2	15	
	Other	n=166	87 ± 2.7	136	80 ± 3.2	94	72 ± 3.9	72	57 ± 5.4	24	
Australia	Reflux Nephropathy	n=102	89 ± 3.2	85	84 ± 3.8	67	79 ± 4.4	51	65 ± 5.9	23	
	Glomerulonephritis	n=75	85 ± 4.1	62	72 ± 5.4	44	59 ± 6.0	33	45 ± 7.0	15	
	Other	n=141	85 ± 3.1	112	79 ± 3.5	84	72 ± 4.1	65	56 ± 5.7	21	
New Zealand	Reflux Nephropathy	n=22	91 ± 6.1	20	86 ± 7.4	15	80 ± 9.1	8	60 ± 14.0	6	
	Glomerulonephritis	n=20	79 ± 9.1	15	64 ± 11.0	12	46 ± 11.7	7	-	1	
	Other	n=25	100 ± 0.0	24	83 ± 9.3	10	66 ± 12.8	7	-	3	
<b>Patient 15-19 years</b>											
Australia and New Zealand	Reflux Nephropathy	n=106	78 ± 4.0	81	62 ± 4.9	59	53 ± 5.1	42	47 ± 5.3	18	
	Glomerulonephritis	n=132	84 ± 3.3	103	70 ± 4.1	80	58 ± 4.6	58	39 ± 5.3	22	
	Other	n=91	81 ± 4.2	70	74 ± 4.7	56	61 ± 5.5	39	48 ± 6.2	14	
Australia	Reflux Nephropathy	n=88	79 ± 4.3	68	63 ± 5.3	49	54 ± 5.6	34	48 ± 5.9	13	
	Glomerulonephritis	n=105	86 ± 3.4	83	72 ± 4.6	64	60 ± 5.1	37	41 ± 6.0	18	
	Other	n=85	82 ± 4.2	66	77 ± 4.7	54	65 ± 5.6	38	50 ± 6.5	14	
New Zealand	Reflux Nephropathy	n=18	72 ± 10.6	13	56 ± 11.7	10	50 ± 11.9	8	43 ± 12.0	5	
	Glomerulonephritis	n=27	74 ± 8.4	20	63 ± 9.4	16	50 ± 10.0	11	32 ± 10.7	4	
	Other	n=6	67 ± 19.3	4	-	2	-	1	-	-	

% Survival ± S.E. / Number at Risk

n = Number of Patients

Reflux = Reflux + Hypoplasia + Dysplasia + Pyelonephritis + Other Urinary Tract Abnormalities

Glomerulonephritis = All forms of glomerulonephritis

Other = All other diseases

## IMMUNOSUPPRESSION

The dosages of the three main immunosuppressants, Cyclosporin, Azathioprine and Prednisolone are shown for all paediatric and adolescent grafts since 1983. Predictable variations in dosage on a mg/kg basis are evident for infants and very young children particularly for cyclosporin. Dosages for Azathioprine are very similar across the age spectrum. A desirably low dose of Prednisolone (including some children and adolescents receiving “zero”) seems to be achieved by 12 months.

Any effect of using Cyclosporin sparing agents (such as Diltiazem) in reducing Cyclosporin dosage in very young children and 5-9 year olds is not

evident. The number of young children actually receiving Cyclosporin sparing agents (usually Diltiazem) is very small.

No attempt has been made to analyse data for Mycophenolate Mofetil or Tacrolimus where the overall usage of these agents in children (and adolescents) is as yet very limited.

See Figure 300 and 301.

**Figure 300**

**Australia and New Zealand**

**Cya Dose (mg/kg/24h) by Cya Sparing Drug Use 1983 - 1997**

Age Groups	Cya Sparing Drug			No Cya Sparing Drug			Unknown		
	Median Dose	Range	No.Pts	Median Dose	Range	No.Pts	Median Dose	Range	No.Pts
<b>1 month</b>									
00-04	13.3	[6.7-36.0]	13	12.5	[0.0-28.3]	45	1.8	[0.0-22.5]	3
05-09	8.9	[6.0-20.7]	9	9.4	[0.0-33.3]	184	10.0	[0.0-10.5]	9
10-14	7.1	[1.8-16.7]	25	7.7	[0.0-23.1]	150	7.4	[0.0-14.7]	27
<b>Total</b>	<b>8.3</b>	<b>[1.8-36.0]</b>	<b>47</b>	<b>8.8</b>	<b>[0.0-33.3]</b>	<b>279</b>	<b>8.3</b>	<b>[0.0-22.5]</b>	<b>39</b>
15-19	5.0	[0.0-10.6]	50	6.7	[0.0-17.0]	200	7.0	[0.0-13.2]	52
<b>3 months</b>									
00-04	10.6	[3.6-32.0]	13	10.4	[0.0-23.6]	42	0.0	[0.0-0.0]	1
05-09	7.8	[4.7-19.3]	9	7.8	[0.0-38.9]	80	8.3	[0.0-17.4]	9
10-14	5.7	[1.6-11.7]	25	6.0	[0.0-17.9]	143	6.9	[0.0-13.9]	24
<b>Total</b>	<b>7.1</b>	<b>[1.6-32.0]</b>	<b>47</b>	<b>7.0</b>	<b>[0.0-38.9]</b>	<b>265</b>	<b>7.1</b>	<b>[0.0-17.4]</b>	<b>34</b>
15-19	4.1	[1.7-8.3]	51	5.2	[0.0-11.5]	182	5.7	[0.0-11.1]	48
<b>12 months</b>									
00-04	8.9	[5.8-17.3]	9	9.3	[0.0-17.5]	36	0.0	[0.0-0.0]	1
05-09	6.3	[3.9-8.6]	9	6.7	[0.0-28.6]	74	6.2	[0.0-13.9]	8
10-14	4.5	[1.7-9.4]	24	5.3	[0.0-16.7]	131	4.3	[0.0-13.6]	24
<b>Total</b>	<b>5.7</b>	<b>[1.7-17.3]</b>	<b>42</b>	<b>6.0</b>	<b>[0.0-28.6]</b>	<b>241</b>	<b>5.0</b>	<b>[0.0-5.0]</b>	<b>33</b>
15-19	3.8	[1.3-7.7]	43	3.8	[0.0-14.0]	173	4.4	[0.0-9.8]	36

**Figure 301**

**Australia and New Zealand**

**Azathioprine and Prednisolone Doses (mg/kg/24h)  
1983 - 1997**

Age Groups	Azathioprine			Prednisolone		
	Median Dose	Range	No.Pts	Median Dose	Range	No.Pts
<b>1 month</b>						
00-04	2.0	[0.0-4.2]	61	0.9	[0.0-2.3]	61
05-09	1.9	[0.0-5.0]	102	0.7	[0.0-2.9]	101
10-14	2.0	[0.0-4.3]	201	0.5	[0.0-20.8]	201
<b>Total</b>	<b>1.9</b>	<b>[0.0-5.0]</b>	<b>364</b>	<b>0.6</b>	<b>[0.0-20.8]</b>	<b>363</b>
15-19	1.7	[0.0-3.4]	301	0.4	[0.0-7.9]	301
<b>3 months</b>						
00-04	1.8	[0.0-3.6]	56	0.5	[0.0-1.5]	56
05-09	1.7	[0.0-5.0]	98	0.4	[0.0-2.2]	98
10-14	1.7	[0.0-5.3]	192	0.3	[0.0-1.1]	186
<b>Total</b>	<b>1.7</b>	<b>[0.0-5.3]</b>	<b>346</b>	<b>0.3</b>	<b>[0.0-2.2]</b>	<b>340</b>
15-19	1.5	[0.0-3.4]	280	0.3	[0.0-1.1]	273
<b>12 months</b>						
00-04	1.8	[0.0-4.6]	46	0.3	[0.0-1.0]	46
05-09	1.6	[0.0-6.0]	91	0.2	[0.0-0.6]	91
10-14	1.6	[0.0-5.2]	179	0.2	[0.0-0.5]	175
<b>Total</b>	<b>1.6</b>	<b>[0.0-6.0]</b>	<b>316</b>	<b>0.2</b>	<b>[0.0-1.0]</b>	<b>312</b>
15-19	1.6	[0.0-3.3]	252	0.2	[0.0-0.9]	249

**GROWTH**

Figure 302 shows the simplest analysis of growth in all ESRF patients in whom data is recorded. The Figure shows the earliest and latest median (range) height SDS scores for all children 2-18 years of age irrespective of mode of treatment, pubertal status and/or the use of recombinant human growth hormone.

Undoubtedly the most important observation is the lack of improvement in HtSDS seen over time. ‘Catch-up’ growth is not being observed. On average, children and (adolescents) with ESRF might expect to obtain an average final adult height of -2 SD. This observation is obviously consistent with data presented in the 1996 and 1997 ANZDATA Registry reports.

**Figure 302**

**Australia and New Zealand**

**Paediatric ESRF Patient's Height Standard Deviation Scores  
Age Range 2-18 years from First to Last Observation  
1-Jan-83 to 31-Mar-98**

Earliest Recorded	Latest Recorded
Median (Range)	Median (Range)
-1.7 (-12.1 to 4.6)	-1.7 (-12.0 to 3.3)

## QUALITY OF LIFE

Quality of Life data has historically been collected for all patients with ESRF. Figure 303 shows the quality of life code scale recorded for all ESRF patients including children and adolescents. Some interpretation is required in the application of the scale to younger age groups.

The assessment of "quality of life" has been notoriously difficult. In fact the Registry will no longer be collecting the data in the current format. The collection of data has been at six month time points and this makes the analysis and interpretation difficult. As a consequence of this method of collection of data, there are potentially multiple records for each patient and a single patient can appear across a number of codes (e.g. 100, 90, 80) depending on the assessment time.

Figure 304 shows the number and proportion of patients recorded at any "score" through the period 1983-1997. Figure 305 shows the proportion (%) of total patient records at various 'scores' on the

scale. In the latter analysis the percentages should total 100% whereas in the former, the percentages only give an indication of the proportion (%) of patients achieving that particular score (at any time over the whole period of observation)

Bearing in mind the limitations of this analysis as cited above, children <2 years of age were approximately twice as likely as other children (2-14 years) and adolescents to have scores of <70 recorded in their quality of life assessments. This point would potentially be an area of continuing interest given the increasing proportion of very young children being offered ESRF care. Further longitudinal data of a different type would be needed to adequately address the issues of the long term neurological and intellectual outcome of infants developing ESRF before the age of two years - this subject is a matter of ongoing concern amongst paediatric nephrologists. The rehabilitation status of children and adolescents was summarized in the 1997 report.

**Figure 303**

**Australia and New Zealand**

### Quality of Life Coding

Code	Explanation
10	Moribund. Fatal process progressing.
20	Very sick: hospital care needed.
30	Severely disabled: hospital care indicated: death not imminent.
40	Disabled: requires special medical care and assistance.
50	Requires considerable assistance and frequent medical care.
60	Requires occasional assistance but able to care for most needs.
70	Care for self: unable to carry on normal activity or do active work.
80	Normal activity with effort: some signs or symptoms of disease.
90	Able to carry on normal activity: minor signs or symptoms of disease.
100	Normal: no complaints: no evidence of disease.

**Figure 304**

**Australia and New Zealand**

**Number and Proportion (%) of Patients Recording a Particular Code for Quality of Life Assessment at any Time Between 1983 and 1997 Analysed by Age**

Age Groups	No. of Pts.	Not Assessed	Code									
			10	20	30	40	50	60	70	80	90	100
< 2	47	0 (0%)	5 (11%)	5 (11%)	0 (0%)	1 (2%)	11 (23%)	4 (9%)	1 (2%)	14 (30%)	31 (66%)	24 (51%)
2-14	407	6 (1%)	12 (3%)	19 (5%)	4 (1%)	15 (4%)	46 (11%)	22 (5%)	36 (9%)	142 (35%)	313 (78%)	295 (73%)
15-19	370	13 (3%)	7 (2%)	14 (4%)	4 (1%)	14 (4%)	29 (8%)	31 (8%)	61 (16%)	160 (43%)	304 (82%)	287 (78%)

**Figure 305**

**Australia and New Zealand**

**Proportion (%) of Patient Records Recording a Particular Quality of Life Code Between 1983 and 1997**

Age Groups	No. of Patient Records	Not Assessed	Codes			
			10-70	80	90	100
< 2	456	0%	12%	6%	30%	52%
2-14	5781	<1%	6%	8%	35%	51%
15-19	5501	<1%	5%	9%	35%	51%