PAEDIATRIC REPORT

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Introduction

As has been pointed out in previous reports, the Registry has maintained a definition of "paediatric" to be <15 years of age. The current report will continue with this definition but with the inclusion of the "adolescent" subgroup (aged 15-19 years) which will also become a more regular feature of the Paediatric Report. It is quite clear that the adolescent age group provides a significant challenge for end stage renal failure care providers irrespective of whether these patients are being cared for in an adult or paediatric institution.

In this report, an attempt has been made to detail the history of end stage renal failure care in paediatric patients in Australia and New Zealand. Traditionally, the historical reviews have looked at the time periods 1963-82 (the pre-cyclosporin era) and post-1983 (the cyclosporin era). Whilst this is particularly relevant for children receiving transplants, there is perhaps sufficient data now to look at smaller time spans both for dialysis care and transplant care while still sub-totaling the data for the pre-1983 and post-1983 eras.

Incidence of End Stage Renal Failure

Table 102 shows the presentation of new patients (0-19 years of age) to end stage renal programs in Australia and New Zealand since such programs began in 1963. Progressively, there has clearly been wide acceptance for offering end stage renal failure care to children (<15 years of age) particularly younger children. For children <10 years of age, the acceptance rate has increased in Australia by 143% since 1982 and in New Zealand by 242%. For Australia and New Zealand combined, only 16 children (0 in New Zealand) <5 years of age were treated between 1963 and 1982. Since 1983 a further 88 have been treated (a 450% increase). Presentation rates of adolescent end stage renal failure (15-19 years of age) have been relatively constant.

Mode of First Treatment Related to Age

Tables 103 and 104 show the mode of first treatment for cohorts of five years between 1963-82 and 1983-96.

In Australia, the introduction of CAPD first occurred after 1977, was widely accepted in the period 1983-87 and during the rest of the 1980's, although automated forms of peritoneal dialysis remain the predominant form of dialysis therapy for children and particularly younger children (<4 years of age).

In transplantation, except for a few cases prior to 1982, preemptive transplantation was largely not attempted until the 1980's. Indeed in the period 1983-96, >10% of children entering into end stage renal failure programs, received a renal transplant preemptively rather than commencing dialysis as the first line of treatment.

For New Zealand (Table 104) there is a clear preference for CAPD over IPD in the years that CAPD has been widely available (1983-96). Preemptive transplantation has occurred in about 8% of paediatric patients in New Zealand.

In both Australia and New Zealand, there is a clear preference for haemodialysis as first line therapy for adolescents.

Mode of Current Treatment

Table 105 shows the mode of current treatment. Only 40 children in Australia and New Zealand are currently receiving dialysis.

Table 102 Australia and New Zealand

Incidence of End Stage Renal Failure by Year of Entry

Year of Entry	Age Groups				Total	Age Group
	0-2	3-4	5-9	10-14	0-14	15-19
AUSTRALIA						
1963-67	1	1	1	5	**8**	10
1968-72	1	1	5	23	**30**	59
1973-77	0	0	20	38	**58**	88
1978-82	4	8	27	59	**98**	111
Sub Total	6	10	53	125	**194**	268
1983-87	11	3	33	79	**126**	103
1988-92	20	7	29	46	**102**	109
1993-96	21	11	33	45	**110**	71
Sub Total	52	21	95	170	**338**	283
Total 1963-96	**58**	**31**	**148**	**295**	**532**	**551**
NEW ZEALAND						
1963-67	0	0	0	0	**0**	3
1968-72	0	0	0	3	**3**	14
1973-77	0	0	5	6	**11**	22
1978-82	0	0	7	16	**23**	37
Sub Total	0	0	12	25	**37**	76
1983-87	2	1	6	14	**23**	22
1988-92	1	2	8	15	**26**	24
1993-96	5	4	12	9	**30**	17
Sub Total	8	7	26	38	**79**	63
Total 1963-96	**8**	**7**	**38**	**63**	**116**	**139**

Table 103 Australia

Mode of First Treatment by Year, in Age Groups

Year of Entry	Mode of Treatment	Age Groups		Total	Age Group
		0-4	5-14	0-14	15-19
1963-67	CAPD	0	0	**0**	0
	IPD	2	5	**7**	6
	Haemodialysis	0	1	**1**	4
	Transplant	0	0	**0**	0
1968-72	CAPD	0	0	**0**	0
	IPD	2	11	**13**	24
	Haemodialysis	0	16	**16**	35
	Transplant	0	1	**1**	0
1973-76	CAPD	0	0	**0**	0
	IPD	0	25	**25**	22
	Haemodialysis	0	32	**32**	66
	Transplant	0	1	**1**	0
1977-82	CAPD	0	5	**5**	10
	IPD	9	37	**46**	27
	Haemodialysis	1	38	**39**	69
	Transplant	0	4	**4**	4
Total 1963-82		**14**	**176**	**190**	**264**
1983-87	CAPD	2	35	**37**	7
	IPD	11	50	**61**	31
	Haemodialysis	0	16	**16**	63
	Transplant	1	11	**12**	2
1988-92	CAPD	4	10	**14**	16
	IPD	18	45	**63**	16
	Haemodialysis	3	14	**17**	69
	Transplant	2	6	**8**	8
1993-96	CAPD	5	18	**23**	13
	IPD	24	27	**51**	8
	Haemodialysis	2	17	**19**	45
	Transplant	1	16	**17**	5
Total 1983-96		**73**	**265**	**338**	**283**

Table 104 New Zealand

Mode of First Treatment by Year, in Age Groups

Year of Entry	Mode of Treatment	Age Groups		Total 0-14	Age Group 15-19
		0-4	5-14		
1963-82	CAPD	0	3	**3**	3
	IPD	0	7	**7**	7
	Haemodialysis	0	27	**27**	63
	Transplant	0	0	**0**	3
Total 1963-82		**0**	**37**	**37**	**76**
1983-96	CAPD	10	32	**42**	21
	IPD	4	6	**10**	1
	Haemodialysis	0	12	**12**	38
	Transplant	1	14	**15**	3
Total 1983-96		**15**	**64**	**79**	**63**

Table 105 Australia and New Zealand

Mode of Current Treatment, in Age Groups 31-Mar-97

Country	Mode of Treatment	Age Group		Total 0-14	Age Group 15-19
		0-4	5-14		
AUSTRALIA	CAPD	1	2	**3**	10
	IPD	7	8	**15**	25
	Haemodialysis	1	9	**10**	10
	Transplant	9	84	**93**	81
Total		**18**	**103**	**121**	**126**
NEW ZEALAND	CAPD	0	0	**0**	10
	IPD	1	11	**12**	1
	Haemodialysis	0	0	**0**	2
	Transplant	1	21	**22**	15
Total		**2**	**32**	**34**	**28**

Renal Transplantation

Proportion of Patients Receiving Live Donor and Cadaveric Transplants

Table 106 shows the proportion of patients in various age groups receiving either cadaveric or live donor transplants. The data is set out in cohorts of five years and summarised for 1963-82 and from 1983-96.

The most striking finding is the clear acceptance of live donor transplantation as an appropriate therapy for children after 1977. Between 1983 and 1996, live donor transplantation appears to be the treatment of choice. More than 60% of transplants in children <15 years of age (1993-96) are from live donor sources. There has also been a trend towards live donor transplantation for adolescents with 11% or less receiving transplants from this source in the various cohorts of years between 1963 and 1982 but a steady increase in the proportions for the cohorts 1983-87 (22%), 1988-92 (26%) and 1993-96 (40.5%).

Outcome of Renal Transplantation

For this report, rather than presenting the traditional graft and patient survival data, graft outcome is shown as "median survival data". Thus, the outcome of renal transplantation is shown as the interval at which 50% of kidney transplants have been lost (or are still functioning). The data is shown in Table 107. Great care needs to be taken in interpretation of this data as some groups contain very few patients. Nonetheless there are some interesting observations.

In the cohorts of years prior to 1982, the median survival times were relatively poor for all age groups receiving cadaveric transplants. Indeed for the 0-14 year age group, of the 90 cadaveric transplants performed, the median survival was <2 years. The outcome for live donors was significantly better and surprisingly good for the 17 adolescent patients receiving live donor transplants (median survival = 15 years) until 1982.

As has been documented in the 1994-96 reports, from 1983-86, there was a clear improvement especially in the 0-14 year age group. The median survival had improved more than fourfold for the period 1983-96 compared to 1963-82 era for cadaveric renal transplants. The results for live donor transplants both for children <15 years of age and for adolescents are excellent (median >14 years for both groups). For the most part, the results in New Zealand children are similar to those seen in Australia. See Table 107.

For second grafts, the outcome prior to 1982 was also extremely poor both for children and adolescents. After 1983 there was a clear improvement. One interesting point is the relatively small numbers of second grafts performed after 1991. Presumably, this reflects in part the success of primary transplantation (both cadaveric and living related) thus reducing the numbers of patients actually requiring second grafts during childhood.

Proportion of Patients Receiving Live Donor and Cadaveric Transplants

Year of Entry	Age Groups	Donors				Total	
		Cadaver Donor		Living Donor			
		N	%	N	%	N	%
1963-67	0-4	3	100%	0	0%	**3**	**100%**
	5-14	2	67%	1	33%	**3**	**100%**
	15-19	8	89%	1	11%	**9**	**100%**
	20-55	90	92%	8	8%	**98**	**100%**
	>=56	0	0	0	0	**0**	**0**
1968-72	0-4	1	100%	0	0%	**1**	**100%**
	5-14	22	100%	0	0	**22**	**100%**
	15-19	38	95%	2	5%	**40**	**100%**
	20-55	790	99.9%	1	0.1%	**791**	**100%**
	>=56	24	96%	1	5%	**25**	**100%**
1973-76	0-4	0	0	0	0	**0**	**0**
	5-14	27	90%	3	10%	**30**	**100%**
	15-19	46	100%	0	0	**46**	**100%**
	20-55	894	97%	27	3%	**921**	**100%**
	>=56	82	100%	0	0	**82**	**100%**
1977-82	0-4	0	0	4	100%	**4**	**100%**
	5-14	51	63%	30	37%	**81**	**100%**
	15-19	118	89%	15	11%	**133**	**100%**
	20-55	1511	91.6%	138	8.4%	**1649**	**100%**
	>=56	234	98%	4	2%	**238**	**100%**
Sub Totals 1963-82	0-4	4	50%	4	50%	**8**	**100%**
	5-14	102	75%	34	25%	**136**	**100%**
	15-19	210	92%	18	8%	**228**	**100%**
	20-55	3285	95%	174	5%	**3459**	**100%**
	>=56	340	98.6%	5	1.4%	**345**	**100%**
Total 1963-82		**3941**	**94.4%**	**235**	**5.6%**	**4176**	**100%**
1983-87	0-4	3	43%	4	57%	**7**	**100%**
	5-14	68	63.5%	39	37%	**107**	**100%**
	15-19	74	78%	21	22%	**95**	**100%**
	20-55	1428	91.5%	133	8.5%	**1561**	**100%**
	>=56	260	98%	6	2%	**266**	**100%**
1988-92	0-4	8	61.5%	5	38.5%	**13**	**100%**
	5-14	34	57%	26	43%	**60**	**100%**
	15-19	64	74%	23	26%	**87**	**100%**
	20-55	1179	88%	164	12%	**1343**	**100%**
	>=56	354	96.7%	12	3.3%	**366**	**100%**
1992-96	0-4	12	41%	17	59%	**29**	**100%**
	5-14	30	38%	49	62%	**79**	**100%**
	15-19	47	59.5%	32	40.5%	**79**	**1005**
	20-55	3958	86.6%	611	13.4%	**4569**	**100%**
	>=56	405	93%	32	7%	**437**	**100%**
Sub Totals 1983-96	0-4	23	47%	26	53%	**49**	**100%**
	5-14	132	50.6%	114	15.4%	**246**	**100%**
	15-19	185	87%	76	13%	**261**	**100%**
	20-55	3958	86.6%	611	13.4%	**4569**	**100%**
	>=56	1019	96%	50	4%	**1069**	**100%**
Total 1983-96		**5317**	**85.8%**	**877**	**14.2%**	**6197**	**100%**
Total 1963-96		**9258**	**89.3%**	**1112**	**10.7%**	**10370**	**100%**

N = Number of Patients

Median Graft Survival for Renal Transplant Recipients (Children and Adolescents) by Age Group and Year of Transplant

Year of Transplant	Age Groups	Primary CD (Years)	N	Primary LD (Years)	N	Total Primary CD & LD (Years)	N	Total Secondary CD & LD (Years)	N
AUSTRALIA									
1963-67	0-4	0.5	2	0	0	0.5	2	0.5	1
	5-14	0.5	2	>20.0	1	0.8	3	0	0
	0-14	**0.5**	**4**	**>20.0**	**1**	**0.6**	**5**	**0.5**	**1**
	15-19	5.5	6	0	0	5.3	6	0.5	2
1968-72	0-4	0.5	1	0	0	0.5	1	0	0
	5-14	5.3	21	0	0	5.3	21	0.5	1
	0-14	**5.0**	**22**	**0**	**0**	**5.0**	**22**	**0.5**	**1**
	15-19	9.5	37	12.0	2	9.5	39	0.5	1
1973-77	0-4	0	0	0	0	0	0	0	0
	5-14	1.5	25	13.0	4	1.9	29	0.9	9
	0-14	**1.5**	**25**	**13.0**	**4**	**1.9**	**29**	**0.9**	**9**
	15-19	60	52	15.5	1	6.3	53	0.8	8
1978-82	0-4	0	0	5.0	4	5.0	4	0	0
	5-14	2.3	39	6.3	28	3.3	67	1.0	11
	0-14	**2.3**	**39**	**5.8**	**32**	**3.8**	**71**	**1.0**	**11**
	15-19	2.3	82	15.8	13	3.6	95	3.5	26
Sub Totals 1963-82	0-4	0.5	3	5.0	4	0.9	7	0.5	1
	5-14	2.1	87	7.5	33	3.0	120	0.9	16
	0-14	**1.9**	**90**	**6.8**	**37**	**2.9**	**127**	**0.9**	**17**
	15-19	4.9	177	15.0	17	5.3	194	0.9	34
1983-87	0-4	5.3	3	>12.0	4	>12.0	7	0	0
	5-14	6.3	55	11.6	36	9.3	91	>12.0	16
	0-14	**5.8**	**58**	**>14.0**	**40**	**9.5**	**98**	**>12.0**	**16**
	15-19	4.9	57	>14.0	17	7.7	74	2.6	21
1988-91	0-4	0.9	7	>8.0	4	>9.0	11	>9.0	2
	5-14	>9.0	24	>8.0	25	>9.0	49	4.5	11
	0-14	**>9.0**	**31**	**>8.0**	**29**	**>9.0**	**60**	**>9.0**	**13**
	15-19	9.0	52	8.0	21	>9.0	73	3.0	14
1992-96	0-4	>4.0	12	>4.0	17	>4.0	29	0	0
	5-14	>5.0	29	>5.0	45	>5.0	74	>3.0	5
	0-14	**>5.0**	**41**	**>5.0**	**62**	**>5.0**	**103**	**>3.0**	**5**
	15-19	>5.0	39	>5.0	31	>5.0	70	3.5	9
Sub Totals 1983-96	0-4	5.6	22	>12.0	25	>12.0	47	>9.0	2
	5-14	9.3	108	>14.0	106	10.6	214	>12.0	32
	0-14	**9.2**	**130**	**>14.0**	**131**	**10.9**	**261**	**>12.0**	**34**
	15-19	7.4	148	>14.0	69	9.6	217	3.0	44
NEW ZEALAND									
1963-82	0-4	0	0	0	0	0	0	0	0
	5-14	3.5	13	8.0	16	7.3	29	0.8	5
	0-14	**3.5**	**13**	**8.0**	**16**	**7.3**	**29**	**0.8**	**5**
	15-19	1.3	35	2.5	9	1.5	44	0.9	12
1983-96	0-4	>4.0	2	3.6	5	3.6	7	0	0
	5-14	3.9	9	>12.0	43	>12.0	52	1.3	3
	0-14	**3.9**	**11**	**>12.0**	**48**	**>12.0**	**59**	**1.3**	**3**
	15-19	2.8	28	>12.0	10	3.7	38	3.5	13

N = Number of Patients CD = Cadaver Donor LD = Living Donor

GROWTH

An analysis of growth in this report is limited to a review of the change in height standard deviation scores for children (2-18 years of age) either after commencing maintenance dialysis or after renal transplantation. The data is shown in Table 108. A fuller evaluation of growth appeared in the 1996 Registry Report.

SDS is calculated as follows :

$$\text{SDS} = \frac{\text{actual height – mean height for age}}{\text{standard deviation at that age}}$$

The "delta" or change in height standard deviation score is calculated for each of the intervals shown (0-6, 6-12, 12-18, 18-24, 24-30 and 30-36 months). In all instances, the change in height standard deviation score is calculated as the difference between the standard deviation score at the end of the interval compared to the beginning of that interval.

Again the data emphasises that when looking at the whole paediatric population, growth velocity appears to be maintained. At the extreme (maximum change in height standard deviation score) there are clearly some children achieving catch-up growth. However, the mean and median values for the whole group indicate that catch-up growth is not a major feature. Table 109 emphasises that the change in the median height standard deviation scores for the whole population (both dialysis and transplant) comparing the latest HtSDS with the earliest HtSDS is close to "zero" – i.e. normal growth velocity. Children on dialysis or with functioning renal transplants remain on average approximately two standard deviation scores for height below the mean for age and sex matched controls (see 1996 Report). An analysis related to bone age has not been done.

Table 108 **Australia and New Zealand**

Change in Height SDS for all Children

	Time of Observation in Months					
	0-6	**6-12**	**12-18**	**18-24**	**24-30**	**30-36**
All Children (2-18 years of age) after Commencing Maintenance Dialysis						
Mean	-0.08	-0.09	-0.04	0.01	-0.07	0.01
Median	-0.09	-0.7	-0.06	-0.02	-0.06	-0.04
Minimum	-1.03	-1.19	-0.52	-0.61	-0.89	-0.39
Maximum	1.32	0.98	0.63	0.71	1.62	0.49
No. of Patients	156	71	53	48	33	19
All Children (2-18 years of age) after Renal Transplantation						
Mean	0.03	0.09	0.05	0.05	0.00	0.01
Median	-0.02	0.02	-0.01	0.00	-0.04	-0.02
Minimum	-0.88	-0.82	-0.63	-1.45	-0.57	-0.57
Maximum	1.78	2.47	1.41	1.60	1.93	1.34
No. of Patients	104	115	113	102	96	84
Pre Pubertal Children after Renal Transplantation						
Mean	0.03	0.11	0.07	0.06	0.00	0.05
Median	-0.04	0.10	0.04	-0.03	-0.08	0.01
No. of Patients	68	77	65	58	51	45

Table 109 **Australia and New Zealand**

Change in Δ Median Height (range values) SDS
For all Children 2-18 Years of Age
After Commencement of Initial Dialysis and at Latest Followup
(Dialysis or Transplant)

	Δ Median Height SDS	**Range**	**No. of Patients**
Australia	-0.06	-3.4 - +4.5	185
New Zealand	-0.07	-3.4 - +2.4	39
All Patients	**-0.07**	**-3.4 - +4.5**	**224**

REHABILITATION

The Rehabilitation Status (and Quality of Life Status) for Australian and New Zealand children and adolescents either receiving dialysis and/or with a functioning transplant is shown in Table 110. The vast majority of children and school age adolescents remain in school at a class appropriate for age. Of school leavers (adolescents) only four of 48 in Australia and two of 15 in New Zealand are reported as being limited in achieving normal activity by symptoms.

Table 110 **Australia and New Zealand**

Rehabilitation Status of Paediatric and Adolescent Patients Alive 31-Mar-97

	Age Range in Years		Total
	0-14	15-19	
AUSTRALIA			
Pre school child	20	0	20
Attends school - full time - class appropriate for age	79	59	138
Attends school - class appropriate for age - limited by dialysis	6	5	11
Attends school - class lower than appropriate for age	13	10	23
Attends school - physically handicapped children	0	1	1
Attends school - developmentally handicapped children	3	2	5
Not at school - able to carry on normal activity; minor signs or symptoms	0	20	20
Not at school - care for self; unable to carry on normal activity	0	1	1
Not at school - disabled; requires special medical care and assistance	0	0	0
Not at school - normal activity with effort; some signs or symptoms	0	3	3
Not at school - normal; no complaints; no evidence of disease	0	25	25
Total	**121**	**126**	**247**
NEW ZEALAND			
Pre school child	2	0	2
Attends school - full time - class appropriate for age	27	12	39
Attends school - class appropriate for age - limited by dialysis	2	0	2
Attends school - class lower than appropriate for age	1	0	1
Attends school - physically handicapped children	2	0	2
Attends school - developmentally handicapped children	0	1	1
Not at school - able to carry on normal activity; minor signs or symptoms	0	5	0
Not at school - care for self; unable to carry on normal activity	0	0	0
Not at school - disabled; requires special medical care and assistance	0	1	1
Not at school - normal activity with effort; some signs or symptoms	0	1	1
Not at school - normal; no complaints; no evidence of disease	0	8	8
Total	**34**	**28**	**62**

CONCLUDING REMARKS

Whilst the number of young people on dialysis is gratifyingly small, there are still major challenges to be faced in renal transplantation where a high proportion of our patients will require at least two or three transplants over a lifetime despite our ability to achieve very good transplantation outcome results.

It is apparent that whilst we are able to achieve 'average' growth velocity for children with renal failure, 50% of the patient population fail to achieve HtSDS scores in the normal range.