GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS TRUST

RENAL UNIT NINTH ANNUAL REPORT

April 2008 to April 2009

INDEX

1. INTRODUCTION

The ninth annual report describes the staffing, facilities, workload, clinical audit results and teaching undertaken by the renal unit in the year between April 2008 and April 2009.

Managerially we are now grouped with other specialties into a unit called ‘Medicine’. Dr Lesley Rees is Specialty Lead and Dr Melanie Hiorns Medical Unit Lead. Our main success for this year has been to successfully compete for a grant from the Special Trustees to further our already active unit research. We have appointed a research nurse, Ambrose Gullett, and have

been able to increase Dr Bockenhauer's research time with a view to developing a first class renal genetics research centre at GOSH. This year has seen the retirement of Dr Richard Trompeter, who has been a Consultant in the unit for over 25 years. He has been replaced by Dr Rukshana Shroff, who successfully completed her PhD in the unit this year.

1.1 GREAT ORMOND STREET HOSPITAL FOR CHILDREN TRUST

GOS Trust is a postgraduate teaching hospital, linked with the Institute of Child Health (ICH), the Postgraduate Medical School. ICH integrated with the United Medical and Dental School at University College London, in April 1996.

The Trust has 350 beds incorporating the Variety Club Building, which provides operating theatres and intensive care facilities as well as ward facilities. The hospital provides a comprehensive range of paediatric specialties for tertiary level care. In association with the Institute of Child Health it has responsibility for Research, Development, Teaching and Training in all aspects of health and disease in children.

The Trust's 350 beds are arranged in 26 wards including 33 intensive care beds (PICU, NICU and CICU), 8 high dependency and 5 transitional care beds. There are seven operating theatres in use performing over 9,000 operations per year. The patient population consists of 22,000 inpatients per annum including 7,500 day cases (35% of inpatient activity). Some 78,000 outpatients attend the hospital annually and in addition there are over 600 outreach clinics per year.

The Trust employs a total of 2,100 staff. The Chief Executive is Dr Jane Collins and the Director of Clinical Services Mr. Robert Evans. The Nephro-Urology Unit reports to the Division of Medicine. The Nephrology Unit is led by Dr. Lesley Rees and Ms. Jacqui Allan is Service Manager. The Unit has monthly multidisciplinary board meetings, with a team composed ofour modern matron, dietician, pharmacist, nurse specialists, service manager and ward sister, with support from finance and contracts.

1.2 THE RENAL UNIT

The Renal Unit provides a comprehensive diagnostic and treatment service for children with renal disorders. It is the largest renal unit in the UK. In the last year, there were 577 admissions to the Renal ward (excludes day case admissions to programmed investigation unit), 7060 outpatients, 24 new renal transplants, 36 patients on chronic haemodialysis and 34 patients on chronic peritoneal dialysis.

The Unit comprises a 16-bedded ward, although currently nursing numbers have allowed us to open only 13. The Renal Transplant and Dialysis Day Care Unit and the 18-bed Urology ward are adjacent. Day cases are also seen on the Medical Day Care and Programmed Investigations Unit. The unit also covers every other aspect of Paediatric Nephrology with special expertise in

congenital renal anomalies, nephrotic syndrome, hypertension, vasculitis, tubular, metabolic and stone disorders. Strong working links exist with Paediatric Urology, Radiology and Pathology. In addition, there are outreach links with a large number of teaching and district general paediatric departments. Surgical care of the end-stage renal failure (ESRF) patients is provided by a team of five transplant surgeons (see below). The renal ward (Victoria) is managed by a senior and a junior sister. There are five clinical nurse specialist posts (CNS) for ESRF patients: a CNS post responsible for co-coordinating the living and deceased donor program (currently a job share), 2 CNS in charge of the HD unit, one for PD and one for transplantation. We also have a senior and two other renal dieticians, a senior pharmacist, clinical psychologist, consultant family therapist, nurse counselor, social worker, teacher and two play therapists.

The report also describes the research overlap with the Institute of Child Health. It does not include clinical data from the Urology department. We hope this report provides information that is useful to the Trust, for clinical governance and audit, to bodies commissioning care for children with renal disease, and for patients and their families.

1.3 POPULATION SERVED

The table below gives estimate populations for the NHS English regions. The renal unit at GOSH draws its referrals from London, Eastern, South East, South West and West Midlands regions, a total population of 32.9m, of whom around 20% are age 15 and below. In addition there are a significant number of referrals from Wales.

Estimated population (thousands)	**Northern and Yorkshire**	**Trent**	**Eastern**	**London**	**South East**	**South West**	**North West**	**West Midlands**
1999	6,336	5,148	5,419	7,285	8,699	4,936	5,336	6,595
of which (percentages)								
0–4	5.9	5.9	6.1	6.9	6.0	5.6	6.2	6.0
5–15	14.4	14.2	14.1	13.6	14.1	13.7	14.7	14.9
Projection								
2021	6,464	5,371	5,941	7,736	9,594	5,452	5,411	6,515
of which (percentages).								
0–4	5.5	5.4	5.5	6.4	5.5	4.9	5.7	5.7
5–15	12.2	11.9	12.1	12.5	12.1	11.2	12.5	12.5

1.4 STAFFING

Senior Medical and Surgical Staff:

Dr Richard Trompeter	12 PAs in Paediatric Nephrology - retired and replaced by Dr Rukshana Shroff
Dr Kjell Tullus	12 PAs in Paediatric Nephrology
Dr Lesley Rees	12 PAs in Paediatric Nephrology (Lead clinician)
Dr William van't Hoff	8 PAs in Paediatric Nephrology (supported by 4 PAs from National Institute for Health Research)
Dr Detlef Bockenhauer	12 PAs in Paediatric Nephrology (5 identified for research)
Dr Steven Marks	12 PAs in Paediatric Nephrology
Prof Adrian Woolf	Full time academic appointment (2 clinics per month)
Dr Paul Winyard	Reader, Full time academic appointment
Prof Robert Kleta	Potter Professor of Paediatric Nephrology
Dr Sarah Ledermann	Associate Specialist, 6 sessions in Paediatric Nephrology

There is a team of 5 Transplant Surgeons who share the care of our patients from their base at Guys Hospital: Mr John Taylor, Mr Nizam Mamode, Mr Francis Calder and Mr Vass Hadjianastassiou, led by Mr Geoff Koffman.

There are 4 Urology Consultants: Mr Peter Cuckow, Mr Imran Mushtaq, Mr Abraham Cherian and Mr Patrick Duffy.

Junior Medical Staff:	The junior doctor establishment is currently 1 ST2 and 5 ST4 posts
Nurse Consultant	Eileen Brennan
Ward Sister	Senior Sister Lucy Thomas Junior Sister Sarah Matthews
Clinical Nurse Specialists	Sr. Suzanne Bradley Sr. Maria Scanes Sr. Liz Wright Sr Liane Pilgrim Sr. Michelle Cantwell Nurse Joe Pullen Nurse Carol Jennings Nurse Cecilia Mcneice
Nurse Counsellor	Mr David Fisher
Renal Dietitians	At any time there is one Specialist dietician attached to the ward and there are rotations through Paediatric Nephrology by two further senior dieticians, giving total of 2 WTE renal dieticians

1.5 THE NEPHRO-UROLOGY UNIT AT THE UCL INSTITUTE OF CHILD HEALTH

Unit website:

http://www.ich.ucl.ac.uk/ich/academicunits/Nephro_Urology/Homepage

The rationale for, and history of the academic Nephro-Urology Unit

Our mission is to improve the diagnosis, treatment and prognosis of children with kidney and urinary tract diseases by investigating the underlying causes and mechanisms of initiation and progression of these conditions with high quality basic science and clinical research.

Over 40,000 individuals in the UK have kidney failure severe enough to require transplantation or life-long dialysis. Of these, a little under 1000 are children. With advances in medical technology, a new cohort of youngsters, who would otherwise have died from kidney failure, are reaching adulthood.

In the mid-1990s, our vision was to create a research centre of potentially international standing, which would unite Nephrology, Urology, Genetics, Fetal Medicine and Histopathology clinical services with basic science perspectives drawn from Developmental and Cell Biology and Molecular Genetics. With this in mind, the Nephro-Urology ICH Unit was created in 1997, aided by refurbishment of laboratories on level 2 of the main ICH building. Since then, the Unit has expanded from a handful of individuals into a group of clinicians and scientists who are passionate of about their chosen field of study.

There are extensive laboratory facilities for molecular and cellular biology within the Unit with strong links to affiliated laboratories including the Clinical and Molecular Genetics and Molecular Medicine Units, as well as with clinical staff in the Nephrology and Urology Departments within Great Ormond Street Hospital and with the Fetal Medicine Unit at University College Hospital, and the Centre for Nephrology at the Royal Free Hospital.

Projects within the Unit include investigations into: the genetics and cell biology of normal and abnormal development of the kidney and urinary tract; the reconstruction and functional restoration of abnormal genitourinary tracts; the renal vasculature and hypertension; nephrotic syndrome; vasculitis; the clinical consequences and treatment of kidney failure in children; biology of renal tubular disease; nutrition, growth, vascular disease and bone turnover in children with renal failure.

The Unit also organises and hosts the prestigious annual Continuing Education Program in Paediatric Nephrology and Urology.

During 2008-2009 our research program was supported by the British Council, Diabetes UK, Kids Kidney Research, Kidney Research UK, Medical Research Council, Special Trustees of Great Ormond Street Hospital, Wellcome Trust and several others.

In addition the Unit continues to be very successful in academic training of PhD, MD, MSc and both national and international visiting Fellows.

Who is in the UCL Institute of Child Health Nephro-Urology Unit?

Staff and students in the period 2008-2009 were:

Senior Staff:
- Adrian S Woolf (Professor of Nephrology and Head of Unit)
- Paul JD Winyard (Reader in Paediatric Nephrology and Head of Learning and Teaching at the UCL Institute of Child Health)
- Lesley Rees (Reader in Paediatric Nephrology)

Kidney Research UK Senior Fellow:
- David A Long

Other Postdoctoral Scientists:
- Zahabia S Ali
- Maggie Godley
- Jolanta E Pitera
- Karen L Price
- Leila Romio

Scientists Doing PhD Theses:
- Shun-Kai Chan (KRUK Studentship)

Clinicians Doing PhD or MD Theses:
- Rukshana Shroff
- Larissa Kerecuk (MRC Clinical Training Fellow)
- Daljit Hothi
- Stephen Marks

Research Nurse:
- Ambrose Gullett

Visiting Research Fellows:
- Jenny Papakrivopoulou
- Michiel Schrueder (ERA-EDTA Fellow)

Unit Administrator:
- Jazz Dinza

Original research papers April 2008 to March 2009

Renal developmental biology

• Caubit X, Lye CM, Martin E, Core N, Long DA, Vola C, Jenkins D, Garratt AN, Skaer H, Woolf AS, Fasano L. Teashirt 3 is necessary for ureteral smooth muscle differentiation downstream of SHH and BMP4. *Development* 135:3301-3310, 2008.

• Pitera JE, Scambler PJ, Woolf AS**.** Fras1, a basement membrane-associated protein mutated in Fraser syndrome, mediates both the initiation of the mammalian kidney and the integrity of renal glomeruli. *Hum Mol Genet* 17:3953-3964, 2008.

• Ferrante MI, Romio L, Castro S, Collins JE, Goulding DA, Stemple DL, Woolf AS, Wilson SW. Convergent extension movements and ciliary function are mediated by *ofd1*, a zebrafish orthologue of the human oral-facial-digital type 1 syndrome gene. *Hum Mol Genet* 18:289-303, 2009.

• Pastorelli L, Wells S, Fray M, Smith A, Hough T, Harfe BD, McManus MT, Smith L, Woolf AS, Cheeseman M, Greenfield A. Genetic analyses reveal a requirement for Dicer1 in the mouse urogenital tract. *Mamm Genome* 20:140-151, 2009.

• Price KL, Woolf AS, Long DA. Unravelling the genetic landscape of urinary bladder development in mice. *J Urol* 181:2366-2374. 2009.

Congenital renal disease

• Hothi DK, Wade AS, Gilbert R, Winyard PJ. Mild fetal renal pelvis dilatation: much ado about nothing? *Clin J Am Soc Nephrol* 4:168-177, 2009.

• Weber S, Taylor JC, Winyard P, Baker KF, Sullivan-Brown J, Schild R, Knüppel T, Zurowska AM, Caldas-Alfonso A, Litwin M, Emre S, Ghiggeri GM, Bakkaloglu A, Mehls O, Antignac C, Network E, Schaefer F, Burdine RD. SIX2 and BMP4 mutations associate with anomalous kidney development. *J Am Soc Nephrol* 19:891-903, 2008.

Chronic renal failure

• Shroff RC, McNair R, Figg N, Skepper JN, Schurgers L, Gupta A, Hiorns M, Donald AE, Deanfield J, Rees L, Shanahan CM. Dialysis accelerates medial vascular calcification in part by triggering smooth muscle cell apoptosis. *Circulation* 118:1748-1757, 2008.

• Waller S, Shroff R, Freemont AJ, Rees L Bone histomorphometry in children prior to commencing renal replacement therapy. *Pediatr Nephrol* 23:1523-1529, 2008.

• Shroff RC, Shah V, Hiorns MP, Schoppet M, Hofbauer LC, Hawa G, Schurgers LJ, Singhal A, Merryweather I, Brogan P, Shanahan C, Deanfield J, Rees L. The circulating calcification inhibitors, fetuin-A and osteoprotegerin, but not matrix Gla protein, are associated with vascular stiffness and calcification in children on dialysis. *Nephrol Dial Transplant* 23:3263-3271, 2008.

• Shroff R, Egerton M, Bridel M, Shah V, Donald AE, Cole TJ, Hiorns MP, Deanfield JE, Rees L. A bimodal association of vitamin D levels and vascular disease in children on dialysis. *J Am Soc Nephrol* 19:1239-1246, 2008

Novel therapies

• Mu W, Long DA, Ouyang X, Agarwal A, Cruz PE, Roncal CA, Nakagawa T, Yu X, Hauswirth WW, Johnson RJ. Angiostatin overexpression is associated with an improvement in chronic kidney injury by an anti-inflammatory mechanism. *Am J Physiol Renal Physiol* 296:F145-F152, 2009.

• Long DA, Price KL, Ioffe E, Gannon CM, Gnudi L, White KE, Yancopoulos GD, Rudge JS, Woolf AS. Angiopoietin-1 therapy enhances fibrosis and inflammation following folic acid-induced acute renal injury. *Kidney Int* 74:300-309, 2009.

1.6 CONTACT NUMBERS

All medical staff carry pagers. There is always a renal SpR and a Consultant available to give advice. They can be contacted by the switchboard at Great Ormond Street Hospital, phone 020 7405 9200. Other numbers for parents to contact are: peritoneal dialysis and transplant, phone 020 7829 8172; haemodialysis 020 7829 8817; Victoria ward 020 7829 8815.

2.0 OUTPATIENTS

2.1 WEEKLY OUTPATIENT CLINICS

	CLINIC	**CONSULTANT**
MONDAY P.M.	Dialysis	Dr Rees Dr Shroff Dr Ledermann
TUESDAY A.M.	Generalised and specialised Nephrology (Tubular)	Dr van't Hoff Dr Bockenhauer
	Transplant Clinic	Dr Marks
	Transplant Surgeon's Clinic Hypertension/vasculitis Nephrotic	On-call surgeon Dr Tullus Dr Trompeter/Dr Iragorri
WEDNESDAY A.M.	General Nephrology Renal Genetics Renal Cysts**	Dr Rees Dr Ledermann Prof Kleta Dr Marks Dr Iragorri/Dr Shroff Professor Woolf Dr Winyard
THURSDAY A.M.	Transplant clinic Haemodialysis clinic (monthly) Hypertension/vasculitis	Dr Trompeter/Shroff Dr Marks Dr Bockenhauer Dr Rees Dr Shroff Dr Tullus
FRIDAY A.M.	Joint clinic with Rheumatology (monthly)	Dr Tullus

** This clinic came to an end in December when Dr Winyard gave up his clinical workload.

2.2 NUMBER OF OUT PATIENT ATTENDANCES

The total number of out-patient attendances to the renal unit was 7060 The breakdown into clinics is shown in the table.

Clinic	**Patient Numbers**							
	2001-2	**2002-3**	**2003-4**	**2004-5**	**2005-6**	**2006-7**	**2007-8**	**2008-9**
Transplant	625	771	873	736	799	743	858	897
Dialysis	507	543	859	610	636	638	665	694
General and Specialist Nephrology	3243	2467	4065	3199	3444	3194	3382	3464
Nephrotic	405	481	692	468	400	321	344	389
Nurse led Transplant Clinic	443	506	734	542	518	467	524	1387
Stone	69	50	88	53	40	40	23	36
Blood pressure monitoring			23	51	65	78	94	109
Pre Tx & GKRLTX						93	71	84
Total	**5292**	**4818**	**7334**	**5674**	**5902**	**5738**	**5962**	**7060**

2.3 OUTREACH CLINICS

Location of secondary paediatric unit	Consultant	Distance from base (miles)	No. clinics per year	No. patients seen (in last year)
Royal London	RST	3	12	Approx 50-60
Whittington	LR	4	1	10
QE II, Welwyn Gdn City	DB	28	2	20
Lister	KT	35	2	Approx 30
Colchester	KT	50	-	-
Oxford	WvH	56	6	70-80
Malta	RST	-	1	40-50
Reading	WvH	40	3	30

The Outreach Clinic at Colchester did not run in the last year though it is hoped that it will be re-established. The clinic at Lister will now run thrice yearly.

2.4 PROGRAMMED INVESTIGATION UNIT, KINGFISHER WARD

Kingfisher Ward continues to be able to offer the GFR test within 3 weeks. There is a named person in the administration office leading on this ensuring the GFR booking goes smoothly. The children and their family are given a choice of dates with a 3 weeks notice period to help fit in with family life. If the waiting list increases ad-hoc extra days during the week and at the weekend have been performed by the staff in conjunction with biochemistry. This has been achieved through continuous vigilant liaison and the dedication of all the team members.

- The Iohexol method implemented in July 2007 is now in bedded in clinical practice. The Clinical Procedure Guidelines are due to be revised again along with the teaching/training package and Inter-grated Care Pathway, data sheet, patient leaflet. The Patient Group Directions (PGD's) continues to be used through the electronic prescribing system.

- New Staff have been trained to perform the test leaving less reliance on a few staff and greater flexibility.

- Manual blood pressures continue to be an issue and the Practice Educator and Ward Sister have been asked to monitor accuracy and action as appropriate.

Zoe Wilks Modern Matron Medicine June 2009.

3. INTERVENTIONAL RADIOLOGY

The interventional radiology team performs certain types of procedure for the renal unit.

3.1 RENAL BIOPSIES

Year	Native	Transplant	Focal lesion	Tumour	Total
2000-1	71	19	1	11	102
2001-2	77	36	0	11	124
2002-3	79	43	3	15	140
2003-4	67	67	4	6	144
2004-5	74	54	7	15	150
2005-6	74	55	1	15	145
2006-7	70	43	0	8	121
2007-8	55	83	0	13	151
2008-9	75	51	1	17	144

There were no complications of biopsy of native kidneys. Two transplant patients (4%) suffered significant complications after biopsy. One developed a perinephric haematoma associated with a fall in haemoglobin concentration, and the other developed haematuria requiring insertion of a nephrostomy.

One patient with a renal tumour and respiratory failure was electively ventilated after a biopsy procedure.
There were no other major complications of renal biopsy in 2008-9.

3.2 CENTRAL VENOUS ACCESS FOR HAEMODIALYSIS AND/OR PLASMA EXCHANGE

Year	Temporary haemodialysis catheter insertion	Permanent haemodialysis catheter insertion	Total
2000-1	15	2	17
2001-2	18	12	30
2002-3	14	15	29
2003-4	20	9	29
2004-5	18	17	35
2005-6	6	9	15
2006-7	8	19	27
2007-8	2	14	16
2008-9	3	20	23

There were six complications (30%) of permanent haemodialysis catheter insertion procedures in 2007-8.

- five lines had poor flows at dialysis (in two this required revision of the catheter)
- one patient had early (<30 days) infection (requiring line removal)

3.3 ARTERIAL INTERVENTIONS

Various angiographic procedures are performed for the renal unit.

Year	Diagnostic (RVH)	Diagnostic (vasculitis)	Interventional (RVH) incl. angioplasty and/or stenting	Total
2000-1	9	15	0	24
2001-2	5	8	6	19
2002-3	17	11	9	37
2003-4	16	13	4	33
2004-5	7	15	5	27
2005-6	11	17	9	37
2006-7	7	24	11	42
2007-8	10	16	13	39
2008-9	8	19	19	46

RVH = renovascular hypertension

One patient (2%) had a small groin haematoma, which required no specific treatment. There were no other significant complications.

3.4 VENOUS INTERVENTIONS

Year	Diagnostic venograms for nephrology	Fistulagram and/or fistulaplasty	Recanalization, venoplasty and/or stenting	Thrombolysis for nephrology patients	Renal vein renin sampling	Total
2000-1	1	0	10	1	10	22
2001-2	2	1	9	0	9	21
2002-3	32	2	17	0	17	68
2003-4	9	3	11	0	11	34
2004-5	11	2	6	0	9	28
2005-6	5	4	1	0	6	16
2006-7	8	2	4	0	11	25
2007-8	3	1	3	2	9	18
2008-9	3	0	4	0	16	23

There were no complications of venous interventional procedures in 2007-8.

4.1 Admissions to Victoria Ward

We have revised the way that we present these figures, so that patients who transfer from Victoria Ward to other wards and then return are only counted as a single admission. We have also made clear the distinction between patients admitted to Victoria Ward and patients admitted under Nephrology to other wards.

Age (yrs)	**2001-2002**		**2002-2003**		**2003-2004**		**2004-2005**		**2005-2006**		**2006-2007**		**2007-2008**		**2008-2009**	
	Total No	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**
<2	**27**	4	**44**	8	**59**	10	**79**	13	**73**	14	**72**	13	**61**	11	**85**	15
2- <5	**81**	13	**87**	16	**66**	11	**106**	17	**84**	16	**105**	19	**90**	16	**81**	14
5- <10	**143**	23	**119**	21	**116**	20	**146**	23	**110**	21	**120**	22	**101**	18	**134**	23
10- <15	**214**	35	**176**	31	**191**	33	**167**	27	**153**	30	**169**	30	**161**	29	**153**	27
15 +	**153**	25	**137**	24	**153**	26	**124**	20	**97**	19	**88**	16	**148**	26	**124**	21
Total	**618**	100	**563**	100	**585**	100	**622**	100	**517**	100	**554**	100	**561**	100	**577**	100

4.2 Nephrology admissions (excluding haemodialysis) to Victoria Ward, to other wards and in total

Year	2001-02	2002-03	2003-04	2004-05	2005-06	2006-07	2007-08	2008-09
Victoria	618	563	585	622	517	554	561	577
Other	343	307	316	317	317	349	249	261
Total	961	870	901	939	834	903	810	838

4.3 CONSULTATIONS

Many patients within the hospital but in other units require the attention of the Nephrology Department. There are also phone calls for advice from District General Hospital Paediatric departments. On an average day there were 2 to 3 new referrals of in-patients in other wards, up to 20 in-patients in other wards needing regular review (on average, 8 seen each day) and up to 12 phone calls per day for advice from outside hospitals, GPs and parents.

5. CHRONIC KIDNEY DISEASE (CKD)

5.1 CKD (PRE TRANSPLANT)

Over the course of the year there were 210 patients aged <17 years attending with a GFR <40 ml/min/1.73mP^{2P} (excluding those on dialysis).

Age	2001-2002		2002-2003		2003-2004		2004-2005		2005-2006		2006-2007		2007-2008		2008 -2009	
	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%
<2	**13**	9	**27**	14	**48**	22	**63**	**29**	**44**	19	**62**	22	46	20	**31**	15
2-5	**28**	20	**37**	19	**33**	15	**42**	**20**	**49**	21	**-**	29	70	30	**39**	19
5-10	**41**	29	**52**	26	**53**	25	**45**	**20**	**61**	27	**58**	20	59	26	**62**	29
10-15	**38**	27	**58**	29	**54**	25	**46**	**22**	**54**	24	**56**	19	40	17	**55**	26
>15	**19**	14	**23**	12	**27**	13	**20**	**9**	**21**	9	**28**	10	15	7	**23**	11
total	**139**	100	**197**	100	**215**	100	**214**	**100**	**228**	100	**286**	100	**230**	100	**210**	100

The names of these children are kept on a database. The list of children is reviewed weekly at the renal unit multidisciplinary meeting, in order to discuss individual management problems and to plan in advance end-stage renal failure management.

5.2 NUMBER AND AGE RANGE OF PATIENTS WITH ESRF

Total numbers of children in ESRF was 155 on 1/4/02, 176 on 1/4/03, 174 on 1/4/04, 169 on 1/4/05,166 on 1/4/06, 139 on 01/04/07, 172 on 1/4/08 and 205 on 1/4/09. The prevalence for the different modalities and age breakdown is shown below.

Age, yrs	**<2**	**2-5**	**5-10**	**10-15**	**>15**	**total**
Haemodialysis						
2002	0	0	2	5	6	13
2003	0	1	2	6	5	14
2004	1	2	1	5	5	14
2005	1	2	2	5	5	15
2006	3	1	2	7	4	17
2007	1	0	1	5	4	11
2008	1	0	2	4	6	13
2009	2	2	1	6	6	17
CAPD						
2002	0	0	0	1	2	3
2003	0	0	0	1	2	3
2004	0	0	0	0	1	1
2005	0	0	0	0	0	0
2006	0	0	0	0	0	0
2007	0	0	0	0	0	0
2008	0	0	0	0	0	0
2009	0	0	0	0	0	0
CCPD						
2002	1	3	4	9	4	21
2003	3	3	4	9	6	28
2004	3	2	3	8	7	23
2005	2	1	8	7	5	23
2006	2	2	6	4	5	19
2007	3	2	4	6	5	20
2008	3	3	1	5	5	17
2009	6	6	4	11	7	34
Transplant						
2002	0	7	25	47	39	118
2003	0	7	27	46	54	134
2004	0	6	29	51	48	134
2005	0	5	27	49	50	131
2006	0	7	27	52	44	130
2007	1	11	30	49	48	139
2008	1	7	29	63	42	142
2009	-	7	28	60	59	154

5.3 CHRONIC PERITONEAL DIALYSIS

There were a total of 40 (1 Maltese) patients managed with chronic peritoneal dialysis during 2002-3, 40 in 2002-3, 46 in 2003-4, 40 in 2004-5, 41 in 2005-6, 37 in 2006-7, 34 in 2007-8 and 34 in 2008-9. Their age ranges are shown.

Annual figures-age breakdown:

	2001-2		**2002-3**		**2003-4**		**2004-5**		**2005-6**		**2006-7**		**2007-8**		**2008-9**	
Age, yrs	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	%
<2	**1**	3	**3**	7.5	**3**	6.5	3	8	**2**	5	**4 (3)**	10	**6**	18	**6**	18
2-5	**3**	8	**6**	15	**5**	10.8	6	16	**2**	5	**5**	12	**4**	12	**6**	18
5-10	**7**	20	**5**	12.5	**5**	10.8	7	19	**10**	25	**9(7)**	22	**4**	12	**4**	12
10-15	**14**	38	**14**	35	**16**	35	11	30	**10**	25	**12**	29	**13**	38	**11**	32
>15	**12**	32	**12**	30	**17**	37	10	27	**16**	40	**11(10)**	27	**7**	20	**7**	20
Total	**37**	100	**40**	100	**46**	100	37	100	**40**	100	**41(37)**	100	**34**	100	**34**	100

Annual figures from 1998 onwards:

PATIENTS	**98-99**	**99-00**	**00-01**	**01-02**	**02-03**	**03-04**	**04-05**	**05-06**	**06-07**	**07-08**	**08-09**
total	37	44	40	37	45	45	40	41	37	34	34
new			14	17	20	18	14	17	18	15	15
At year end	28	28	17	24	29	23	23	18	20	17	19
Transferred to HD	0	3	5	7	2	5	5	6	2	5	4
Transplanted	9	10	16	7	7	15	11	12	14	8	6
Adult unit			4	2	3	1	2	3	0	0	2
Improved			0	0	0	0	0	1	1	2	0
Deaths	1	1	1	0	1	1	0	0	1	1	3

CHRONIC HAEMODIALYSIS

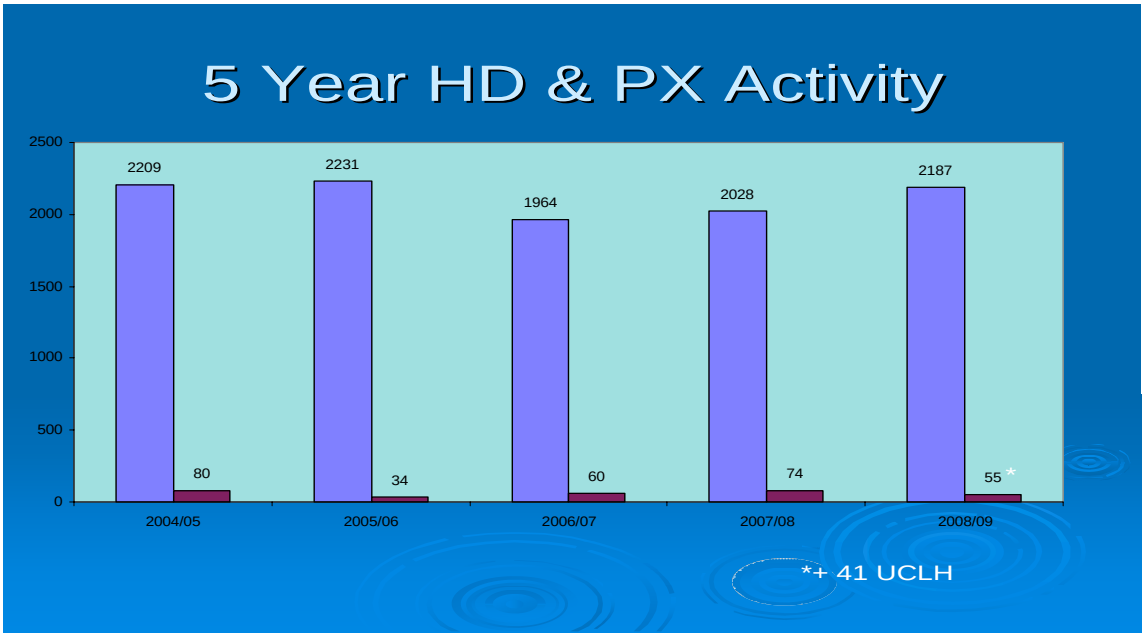
During the year there were 2042 sessions in 42 children (2187 sessions of HD, (acute and chronic) and 55 PE.

5.5 Number with a fistula

Date	No of patients with fistula in use week	No of hours of dialysis for the
01.04.01	4	147
01.10.02	4	154
01.04.02	6	180
01.04.03	9	168
01.04.04	6	161
01.04.05	8	180
01.04.06	11	204
01.04.07	7	148
01.04.08	11	168

Commitments

5.6 5 year activity



5.7 Water Quality

Dialysate quality

The latest analysis of dialysate shows all machines to be within the guidelines. Endotoxin levels are at worst 0.1Eu/ml with the best at 0.03Eu/ml. Bacterial levels remain good with all machines except two having a level of 0cfu/ml, the exceptions being 1cfu/ml and 58cfu/ml. The worst level is for the oldest machine, which has no Ultrafilter fitted.

Water quality

July saw the first disinfection of the soft water supply and the samples taken after show low levels of bacteria, at worst 10cfu/ml. Endotoxin levels remain high at > 10Eu/ml, the investigation into the cause of this continues.

The supply will be disinfected at least twice a year and more if the quality deteriorates.

All chemical levels are within guidelines; the unit is now fed from a mains water connection that bypasses the copper/silver ionisation plant.

ACUTE RENAL FAILURE AND TREATMENT (INCLUDING PLASMAPHERESIS)

6.1 ACUTE HAEMODIALYSIS

6 children required acute haemodialysis. Their mean age was 7.8 years, range 2.1 – 14.7 years. These figures exclude children with ARF in PICU and NICU.

Diagnosis	2002-3	2003-4	2004-5	2005-6	2006-7	2007-8	2008-9
HUS(D+)					2	1	1
HUS (D-)	1	1	1		1		1
MCGN				1			
SLE			1	1		1	
Post heart Tx							
FSGS	1		2		1		
Wegeners							
MPA	1						
NS	1						
HLH	1						
Acute on CRF	5	2				1	1
Sepsis	1		1		1		
Post surgery		4	1		1		
Transplant rejection		2	1		1		
Tumour lysis		1	2		1	AML	
MMA		1					
Drug toxicity		1		1			
Rhabdomyolysis		1					
PTLD			1				
ATN				2	1	3	3
Total Pts	11	13	10	5		7	6
Total number of sessions	73	160	54			34	82

6.2 PLASMA EXCHANGE

5 children were treated with plasma exchange (2 male; 3 female). The mean age was 13.0 years and range 4.0 – 17.5 years.

Diagnosis	2001-2		2002-3		2003-4		2004-5		2005-6	
	No. of patients	No. of sessions	No. of patients	No. of sessions	No. of patients	No. of sessions	No. of patients	No. of Sessions	No. of pts	No. sessions
D+ HUS	0	0	1	5	1	5	0	0		
D- HUS	3	46	2	30	1	5	1	19		
HUS T+	0	0	0	0	0	0	1	5		
TTP	0	0	1	9	2	14	0	0		
SLE	3	21	2	22	4	19	2	14	1	9
MS	0	0	0	0	1	5	0	0		
HSP	2	10	0	0	1	5	1	5	1	5
MPA	2	7	2	13	1	9	0	0	1	3
Post Tx FSGS	1	5	1	18	3	39	2	19	1	8
Post Tx MPGN	0	0	0	0	1	19	1	5		
Lung/heart Tx	1	5	0	0	1	5	0	0		
MPGN	1	32	0	0	0	0	1	1	1	5
Vasculitis									1	5
other	0	0	2	19	0	0	2	7		
Total	**13**	**126**	**11**	**111**	**19**	**136**	**11**	**80**	**6**	**35**

Diagnosis/no of sessions	D+ HUS	D- HUS	GvH disease	Post Tx rejection	Anti-GBM	Goodpasture	SLE	WG	FSGS	CGN	Post-tx FSGS	ABOi Heart Tx	total
2006-7	**2**	**1**	**1**	**1**	**1**								
2007-8				**1/11**		**2/19**	**1/10**	**1/5**	**1/16**	**1/5**		**1/8**	**8/74**
2008-9		**1/37**					**2/9**				**2/49**		**5/95**

6.3 NUMBER AND AGES OF PATIENTS TREATED WITH PERITONEAL DIALYSIS FOR ACUTE RENAL FAILURE

Age on admission	2001-2	2002-3	2003-4	2004-5	2005-6	2006-7	2007-8	2008-9
<1 year	1	3	1		1	3	2	0
1-5 years	1	0	3		2	4	2	4
>5 years	3	2	1		0	6	2	2
Total	**5**	**5**	**5**		**3**	**13**	**6**	**6**

7. RENAL TRANSPLANTATION

7.1 Details of patients undergoing renal transplantation between 1998 and 2006

	Live donor 1P^{stP} graft	**Subsequent graft**	**Cadaveric 1P^{stP} graft**	**Subsequent graft**	**Total**	**Waiting**
1/4/1998 to 99	7	0	11	4	22	27
1/4/1999 to 2000	6	0	8	2	16	27
1/4/2000 to 2001	7	0	16	7	30	16
1/4/2001 to 2002	6	2	5	1	14	27
1/4/2002 to 2003	17	0	10	3	30	20
1/4/2003 to 2004	14	1	15	1	31	20
1/4/2004 to 2005	13	1	10	1	25	26
1/4/2005 to 2006	15	0	8	1	24	26
01/04/06 to 2007	12	0	15	3	30	21
01/04/07 to 2008	10	0	12	0	22	37
01/04/2008 to 2009	11	2	9	0	22	36

2 patients who received combined liver-kidney transplant at Birmingham Children's Hospital are not included in the above data.

Note – the on-call data is from 31/3/09 and does not include suspended patients.

8. Research

8.1 Papers

1. Adalat, S., Woolf, A. S., Bingham, C., Edghill, E., Ellard, S., & Bockenhauer, D. Hepatocyte nuclear factor 1B mutations commonly cause hypomagnesemia. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
   Ref Type: Abstract

2. Ahmad, N., Ahmed, K., Khan, M. S., Calder, F., Mamode, N., Taylor, J., & Koffman, G. 2008, "Living-unrelated donor renal transplantation: an alternative to living-related donor transplantation?", *Annals of the Royal College of Surgeons of England*, vol. 90, no. 3, pp. 247-250.

3. Ahmad, N., Ahmed, K., & Mamode, N. 2009, "Does nephrectomy of failed allograft influence graft survival after re-transplantation?", *Nephrology Dialysis Transplantation*, vol. 24, no. 2, pp. 639-642.

4. Ahmed, K., Ahmad, N., Khan, M. S., Koffman, G., Calder, F., Taylor, J., & Mamode, N. 2008, "Influence of number of retransplants on renal graft outcome", *Transplantation Proceedings*, vol. 40, no. 5, pp. 1349-1352.

5. Benden, C., Kansra, S., Ridout, D. A., Shaw, N. L., Aurora, P., Elliott, M. J., & Marks, S. D. 2009, "Chronic kidney disease in children following lung and heart-lung transplantation", *Pediatric Transplantation*, vol. 13, no. 1, pp. 104-110.

6. Bockenhauer, D., Bokenkamp, A., van't, H. W., Levtchenko, E., Kist-van Holthe, J. E., Tasic, V., & Ludwig, M. 2008, "Renal phenotype in Lowe Syndrome: a selective proximal tubular dysfunction", *Clinical Journal of the American Society of Nephrology*, vol. 3, no. 5, pp. 1430-1436.

7. Bockenhauer, D., Rees, L., Neumann, H., & Foo, Y. 2008, "A sporadic case of paraganglioma undetected by urine metabolite screening", *Pediatric Nephrology*, vol. 23, no. 10, pp. 1889-1891.

8. Bockenhauer, D., Cruwys, M., Kleta, R., Halperin, L. F., Wildgoose, P., Souma, T., Nukiwa, N., Cheema-Dhadli, S., Chong, C. K., Kamel, K. S., Davids, M. R., & Halperin, M. L. 2008, "Antenatal Bartter's syndrome: why is this not a lethal condition?", *QJM*, vol. 101, no. 12, pp. 927-942.

9. Bockenhauer, D., Debiec, H., Sebire, N., Barratt, M., Warwicker, P., Ronco, P., & Kleta, R. 2008, "Familial membranous nephropathy: an X-linked genetic susceptibility?", *Nephron Clinical Practice*, vol. 108, no. 1, p. c10-c15.

10. Bockenhauer, D. 2008, "Diabetes insipidus," in *Comprehensive Pediatric Nephrology*, 1st edn, D. F. Geary & F. Schaefer, eds., Mosby Elsevier, Philadelphia, pp. 489-498.

11. Bockenhauer, D. & van't Hoff, W. G. 2008, "Fanconi syndrome," in *Comprehensive Pediatric Nephrology*, 1st edn, D. F. Geary & F. Schaefer, eds., Mosby Elsevier, Philadelphia, pp. 433-450.

12. Bredrup, C., Matejas, V., Barrow, M., Blahova, K., Bockenhauer, D., Fowler, D. J., Gregson, R. M., Maruniak-Chudek, I., Medeira, A., Mendonca, E. L., Kagan, M., Koenig, J., Krastel, H., Kroes, H. Y., Saggar, A., Sawyer, T., Schittkowski, M., Swietlinski, J., Thompson, D., VanDeVoorde, R. G., Wittebol-Post, D., Woodruff, G., Zurowska, A., Hennekam, R. C., Zenker, M., & Russell-Eggitt, I. 2008, "Ophthalmological aspects of Pierson syndrome", *American Journal of Ophthalmology*, vol. 146, no. 4, pp. 602-611.

13. Camargo, S. M., Bockenhauer, D., & Kleta, R. 2008, "Aminoacidurias: Clinical and molecular aspects", *Kidney International*, vol. 73, no. 8, pp. 918-925.

14. Camargo, S. M., Singer, D., Makrides, V., Huggel, K., Pos, K. M., Wagner, C. A., Kuba, K., Danilczyk, U., Skovby, F., Kleta, R., Penninger, J. M., & Verrey, F. 2009, "Tissue-specific amino acid transporter partners ACE2 and collectrin differentially interact with hartnup mutations", *Gastroenterology*, vol. 136, no. 3, pp. 872-882.

15. Camargo, S. M. R., Singer, D., Makrides, V., Huggel, K., Pos, K. M., Wagner, C. A., Kuba, K., Danilczyk, U., Skovby, F., Kleta, R., Penninger, J. M., & Verrey, F. ACE2 and collectrin are tissue-specifc associated protein of Hartnup amino acid transport B^0AT1. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
Ref Type: Abstract

16. Caubit, X., Lye, C. M., Martin, E., Core, N., Long, D. A., Vola, C., Jenkins, D., Garratt, A. N., Skaer, H., Woolf, A. S., & Fasano, L. 2008, "Teashirt 3 is necessary for ureteral smooth muscle differentiation downstream of SHH and BMP4", *Development*, vol. 135, no. 19, pp. 3301-3310.

17. Chandak, P., Kessaris, N., Challacombe, B., Olsburgh, J., Calder, F., & Mamode, N. 2009, "How safe is hand-assisted laparoscopic donor nephrectomy?--results of 200 live donor nephrectomies by two different techniques", *Nephrology Dialysis Transplantation*, vol. 24, no. 1, pp. 293-297.

18. Chitty, L. S. & Woolf, A. S. 2008, "Perinatal renal disease", *Seminars in Fetal and Neonatal Medicine*, vol. 13, no. 3, p. 117.

19. de Bruyn R. & Marks, S. D. 2008, "Postnatal investigation of fetal renal disease", *Seminars in Fetal and Neonatal Medicine*, vol. 13, no. 3, pp. 133-141.

20. de Bruyn, R., Feather, S. A., Goonasekera, C. G., Ledermann, S. E., Marks, S. D., Nash, M., Rees, L., Roy, S., Sebire, N. J., Trompeter, R. S., van't Hoff, W., & Winyard, P. J. D. 2008, "Renal diseases," in *Visual Handbook of Pediatrics and Child Health: The Core*, S. Ludwig et al., eds., Lippincott, Williams & Wilkins, Philadelphia, PA, USA, chap. 10, pp. 297-311.

21. Devuyst, O., Meij, I., Jeunemaitre, X., Ronco, P., Antignac, C., Christensen, E. I., Levtchenko, E. N., Knoers, N. V., Deen, P., Müller, D., Wagner, C. A., Rampoldi, L., van't Hoff, W., & on Behalf of the EUNEFRON Consortium. *EUNEFRON*, the European network for the study of orphan nephropathies. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
Ref Type: Abstract

22. Dhillon, H. K. 2008, "Prenatal diagnosis," in *Essentials of Paediatric Urology*, 2nd edn, D. F. M. Thomas, P. G. Duffy, & A. M. K. Rickwood, eds., Informa Healthcare, London, chap. 10, pp. 133-142.

23. Ferrante, M. I., Romio, L., Castro, S., Collins, J. E., Goulding, D. A., Stemple, D. L., Woolf, A. S., & Wilson, S. W. 2009, "Convergent extension movements and ciliary function are mediated by ofd1, a zebrafish orthologue of the human oral-facial-digital type 1 syndrome gene", *Human Molecular Genetics*, vol. 18, no. 2, pp. 289-303.

24. Gonzales, P. A., Pisitkun, T., Hoffert, J. D., Tchapyjnikov, D., Star, R. A., Kleta, R., Wang, N. S., & Knepper, M. A. 2009, "Large-scale proteomics and phosphoproteomics of urinary exosomes", *Journal of the American Society of Nephrology*, vol. 20, no. 2, pp. 363-379.

25. Guignard, J.-P. & Rees, L. 2008, "Recent advances in paediatric nephrology," in *Recent Advances in General Paediatrics*, R. Medeiros, ed., John Libbey Eurotext, Paris, pp. 131-148.

26. Heeringa, S. F., Vlangos, C. N., Chernin, G., Hinkes, B., Gbadegesin, R., Liu, J., Hoskins, B. E., Ozaltin, F., Hildebrandt, F., & Members of the APN Study Group 2008, "Thirteen novel NPHS1 mutations in a large cohort of children with congenital nephrotic syndrome", *Nephrology Dialysis Transplantation*, vol. 23, no. 11, pp. 3527-3533.

27. Hothi, D. K., Harvey, E., Goia, C. M., & Geary, D. 2008, "Blood-volume monitoring in paediatric haemodialysis", *Pediatric Nephrology*, vol. 23, no. 5, pp. 813-820.

28. Hothi, D. K., Harvey, E., Goia, C. M., & Geary, D. F. 2008, "Evaluating methods for improving ultrafiltration in pediatric hemodialysis", *Pediatric Nephrology*, vol. 23, no. 4, pp. 631-638.

29. Hothi, D. K., Rees, L., Marek, J., & McIntyre, C. Hemodialysis induced myocardial stunning is common in children and associated with dialysis induced hypotension. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
Ref Type: Abstract

30. Hothi, D. K., Rees, L., & McIntyre, C. The hemodynamic response to hemodialysis in children. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
Ref Type: Abstract

31. Hothi, D. K. & Geary, D. F. 2008, "Pediatric hemodialysis presciption, efficacy, and outcome," in *Comprehensive Pediatric Nephrology*, 1st edn, D. F. Geary & F. Schaefer, eds., Mosby Elsevier, Philadelphia, pp. 867-894.

32. Hothi, D. K., Wade, A. S., Gilbert, R., & Winyard, P. J. 2009, "Mild fetal renal pelvis dilatation: much ado about nothing?", *Clinical Journal of the American Society of Nephrology*, vol. 4, no. 1, pp. 168-177.

33. Howie, A. J., Agarwal, A., Sebire, N. J., & Trompeter, R. S. 2008, "Glomerular tip changes in childhood minimal change nephropathy", *Pediatric Nephrology*, vol. 23, no. 8, pp. 1281-1286.

34. Kausman, J. Y., Patel, B., & Marks, S. D. 2008, "Standard dosing of tacrolimus leads to overexposure in pediatric renal transplantation recipients", *Pediatric Transplantation*, vol. 12, no. 3, pp. 329-335.

35. Ledermann, S (Member of work group). KDOQI Work Group 2009, "KDOQI Clinical Practice Guideline for Nutrition in Children with CKD: 2008 Update", *American Journal of Kidney Diseases*, vol. 53, no. 3 Suppl 2, pp. S11-104.

36. Kerecuk, L., Schreuder, M. F., & Woolf, A. S. 2008, "Renal tract malformations: perspectives for nephrologists", *Nature Clinical Practice Nephrology*, vol. 4, no. 6, pp. 312-325.

37. Kessaris, N., Mukherjee, D., Chandak, P., & Mamode, N. 2008, "Renal transplantation in identical twins in United States and United Kingdom", *Transplantation*, vol. 86, no. 11, pp. 1572-1577.

38. Kleta, R. 2008, "Fanconi or not Fanconi? Lowe syndrome revisited", *Clinical Journal of the American Society of Nephrology*, vol. 3, no. 5, pp. 1244-1245.

39. Long, D., Price, K., & Woolf, A. 2008, "Unravelling the Genetic Landscape of Bladder Development", *Journal of Pediatric Urology*, vol. 4, no. Supplement 1, p. S37.

40. Long, D., Farrugia, M.-K., Thiruchelvam, N., & Woolf, A. 2008, "Urothelial Vascular Endothelial Growth Factor-a Expression in Fetal Bladder Outflow Obstruction", *Journal of Pediatric Urology*, vol. 4, no. Supplement 1, p. S67.

41. Long, D. A., Price, K. L., Ioffe, E., Gannon, C. M., Gnudi, L., White, K. E., Yancopoulos, G. D., Rudge, J. S., & Woolf, A. S. 2008, "Angiopoietin-1 therapy enhances fibrosis and inflammation following folic acid-induced acute renal injury", *Kidney International*, vol. 74, no. 3, pp. 300-309.

42. Ludwig, S., Strobel, S., Marks, S. D., Smith, P. K., El Habbal, M. H., & Spitz, L. 2008, *Visual Handbook of Pediatrics and Child Health: The Core* Philadelphia, PA, USA: Lippincott, Williams & Wilkins.

43. Marhaug, G., Shah, V., Shroff, R., Varsani, H., Wedderburn, L. R., Pilkington, C. A., & Brogan, P. A. 2008, "Age-dependent inhibition of ectopic calcification: a possible role for fetuin-A and osteopontin in patients with juvenile dermatomyositis with calcinosis", *Rheumatology*, vol. 47, no. 7, pp. 1031-1037.

44. Marks, S. D., Fisher, D., Hothi, D., Rees, L., Walsh, G., Lord, R., & Scoble, J. E. Transitioning adolescent renal transplant patients. Archives of Disease in Childhood 93[Suppl I], A28-A29. 2008.
Ref Type: Abstract

45. Marks, S. D., Gullett, A., Brennan, E., Tullus, K., & Woolf, A. S. A familial study of childhood renal artery stenosis. Archives of Disease in Childhood 93[Suppl I], A28. 2008.
Ref Type: Abstract

46. Marks, S. D., Fisher, D., Hothi, D., Rees, L., Walsh, G., Lord, R., & Scoble, J. E. Action learning set on transition of adolescent renal transplant recipients. O71 Abstract Book , 132. 2008.
Ref Type: Abstract

47. Marks, S. D., Shah, V., Hasson, N., Pilkington, C., & Tullus, K. Urinary monocyte chemoattractant protein-1 correlates with disease activity in paediatric lupus nephritis. P265 Abstract Book , 444. 2008.
Ref Type: Abstract

48. Marks, S. D., Williams, S. J., Tullus, K., & Sebire, N. J. 2008, "Glomerular expression of monocyte chemoattractant protein-1 is predictive of poor renal prognosis in paediatric lupus nephritis", *Nephrology Dialysis Transplantation*, vol. 23, no. 11, pp. 3521-3526.

49. Marks, S. D. & Tullus, K. 2008, "Lupus nephritis," in *Comprehensive Pediatric Nephrology*, 1st edn, D. F. Geary & F. Schaefer, eds., Mosby Elsevier, Philadelphia, chap. 22, pp. 329-342.

50. Marks, S. D. & Harden, P. N. 2008, "Transitioning from paediatric to adult service," in *Dilemmas in Renal Transplant Management*, Contract Medical Communications, chap. 15, pp. 100-107.

51. Marks, S. D. 2009, "Congenital abnormalities of the urinary tract (chap. 16 Structural and congenital abnormalities)," in *Oxford Desk Reference Nephrology*, J. Barratt, K. Harris, & P. Topham, eds., Oxford University Press, pp. 658-663.

52. Marks, S. D. 2009, "Medullary sponge kidney (chap. 16 Structural and congenital abnormalities)," in *Oxford Desk Reference Nephrology*, J. Barratt, K. Harris, & P. Topham, eds., Oxford University Press, pp. 664-666.

53. Meister, M. G., Olsen, O. E., de Bruyn R., McHugh, K., & Marks, S. D. 2008, "What is the value of magnetic resonance venography in children before renal transplantation?", *Pediatric Nephrology*, vol. 23, no. 7, pp. 1157-1162.

54. Mendichovszky, I. A., Marks, S. D., Simcock, C. M., & Olsen, O. E. 2008, "Gadolinium and nephrogenic systemic fibrosis: time to tighten practice", *Pediatric Radiology*, vol. 38, no. 5, pp. 489-496.

55. Milford, D. V., Fisher, D., & Marks, S. D. 2008, "Adolescent transfer to adult renal units", *British Journal of Renal Medicine*, vol. 13, no. 3, pp. 30-31.

56. Muorah, M. R., Brogan, P. A., Sebire, N. J., Trompeter, R. S., & Marks, S. D. 2009, "Dense B cell infiltrates in paediatric renal transplant biopsies are predictive of allograft loss", *Pediatric Transplantation*, vol. 13, no. 2, pp. 217-222.

57. Murphy, D., Challacombe, B., Olsburgh, J., Calder, F., Mamode, N., Khan, M. S., Mushtaq, I., & Dasgupta, P. 2008, "Ablative and reconstructive robotic-assisted laparoscopic renal surgery", *International Journal of Clinical Practice*, vol. 62, no. 11, pp. 1703-1708.

58. Norden, A. G., Gardner, S. C., van't Hoff W., & Unwin, R. J. 2008, "Lysosomal enzymuria is a feature of hereditary Fanconi syndrome and is related to elevated CI-mannose-6-P-receptor excretion", *Nephrology Dialysis Transplantation*, vol. 23, no. 9, pp. 2795-2803.

59. Oram, R. A., Edghill, E. L., Woolf, A. S., Hennekam, R. C., Ellard, S., Hattersley, A. T., & Bingham, C. *RET* gene mutations are not a common cause of congenital solitary functioning kidney in an adult cohort. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
Ref Type: Abstract

60. Pastorelli, L. M., Wells, S., Fray, M., Smith, A., Hough, T., Harfe, B. D., McManus, M. T., Smith, L., Woolf, A. S., Cheeseman, M., & Greenfield, A. 2009, "Genetic analyses reveal a requirement for Dicer1 in the mouse urogenital tract", *Mammalian Genome*, vol. 20, no. 3, pp. 140-151.

61. Pitera, J. E., Scambler, P. J., & Woolf, A. S. 2008, "Fras1, a basement membrane-associated protein mutated in Fraser syndrome, mediates both the initiation of the mammalian kidney and the integrity of renal glomeruli", *Human Molecular Genetics*, vol. 17, no. 24, pp. 3953-3964.

62. Podolskaya, A., Stadermann, M., Pilkington, C., Marks, S. D., & Tullus, K. 2008, "B cell depletion therapy for 19 patients with refractory systemic lupus erythematosus", *Archives of Disease in Childhood*, vol. 93, no. 5, pp. 401-406.

63. Rees, L. 2008, "Management of the neonate with chronic renal failure", *Seminars in Fetal and Neonatal Medicine*, vol. 13, no. 3, pp. 181-188.

64. Rees, L. 2008, "Nutritional management in children with renal disease," in *Paediatric Nutrition in Practice*, B. Koletzko, ed., S Karger, pp. 234-238.

65. Rees, L. 2009, "Long-term outcome after renal transplantation in childhood", *Pediatric Nephrology*, vol. 24, no. 3, pp. 475-484.

66. Rembratt, A., Jensen, J.-K., Tullus, K., Marild, S., & on behalf of the Renal Concentrating Capacity Test (RCCT) study group 2008, "Overnight testing of renal concentrating capacity in children using desmopressin tablets: Sensitivity, repeatability and non-inferiority versus intranasal spray", *Scandinavian Journal of Urology and Nephrology*, vol. 42, no. 3, pp. 274-277.

67. Resic-Lindehammer, S., Larsson, K., Ortqvist, E., Carlsson, A., Cederwall, E., Cilio, C. M., Ivarsson, S. A., Jonsson, B. A., Larsson, H. E., Lynch, K., Neiderud, J., Nilsson, A., Sjoblad, S., Lernmark, A., Aili, M., Baath, L. E., Carlsson, E., Edenwall, H., Forsander, G., Granstro, B. W., Gustavsson, I., Hanas, R., Hellenberg, L., Hellgren, H., Holmberg,

E., Hornell, H., Ivarsson, S. A., Johansson, C., Jonsell, G., Kockum, K., Lindblad, B., Lindh, A., Ludvigsson, J., Myrdal, U., Neiderud, J., Segnestam, K., Sjoblad, S., Skogsberg, L., Stromberg, L., Stahle, U., Thalme, B., Tullus, K., Tuvemo, T., Wallensteen, M., Westphal, O., & Aman, J. 2008, "Temporal trends of HLA genotype frequencies of type 1 diabetes patients in Sweden from 1986 to 2005 suggest altered risk", *Acta Diabetologica*, vol. 45, no. 4, pp. 231-235.

68. Rossetti, S., Kubly, V., van't Hoff, W. G., Niaudet, W. P., Torres, V. E., & Harris, P. C. Incompletely penetrant *PKD1* alleles associated with mild, homozygous or in utero onset PKD. Journal of the American Society of Nephrology [Abstracts Issue]. 2008. Ref Type: Abstract

69. Sadideen, H. M., Blaker, P., O'Donnell, P., Taylor, J., & Goldsmith, D. J. 2008, "Tuberculosis complicating tertiary hyperparathyroidism in a patient with end-stage renal disease: a case report", *Journal of Nephrology*, vol. 21, no. 3, pp. 438-441.

70. Sanjeevi, C. B., Sedimbi, S. K., Landin-Olsson, M., Kockum, I., Lernmark, A., & Swedish Childhood Diabetes and the Diabetes Incidence in Sweden Study Groups 2008, "Risk conferred by HLA-DR and DQ for type 1 diabetes in 0-35-year age group in Sweden", *Annals of the New York Academy of Sciences*, vol. 1150, pp. 106-111.

71. Shroff, R., Egerton, M., Bridel, M., Shah, V., Donald, A. E., Cole, T. J., Hiorns, M. P., Deanfield, J. E., & Rees, L. 2008, "A bimodal association of vitamin D levels and vascular disease in children on dialysis", *Journal of the American Society of Nephrology*, vol. 19, no. 6, pp. 1239-1246.

72. Shroff, R., McNair, R., Figg, N., Skepper, J., Deanfield, J., Rees, L., & Shanahan, C. Arteries from paediatric dialysis patients show an increased susceptibility to mineral ion induced apoptosis and oxidative stress leading to accelerated vesicle-mediated calcification. Journal of the American Society of Nephrology [Abstracts Issue]. 2008. Ref Type: Abstract

73. Shroff, R. & Ledermann, S. 2009, "Long-term outcome of chronic dialysis in children", *Pediatric Nephrology*, vol. 24, no. 3, pp. 463-474.

74. Shroff, R. 2009, "Monitoring cardiovascular risk factors in children on dialysis", *Peritoneal Dialysis International*, vol. 29 Suppl 2, p. S173-S175.

75. Shroff, R. C., McNair, R., Figg, N., Skepper, J. N., Schurgers, L., Gupta, A., Hiorns, M., Donald, A. E., Deanfield, J., Rees, L., & Shanahan, C. M. 2008, "Dialysis accelerates medial vascular calcification in part by triggering smooth muscle cell apoptosis", *Circulation*, vol. 118, no. 17, pp. 1748-1757.

76. Shroff, R. C., Shah, V., Hiorns, M. P., Schoppet, M., Hofbauer, L. C., Hawa, G., Schurgers, L. J., Singhal, A., Merryweather, I., Brogan, P., Shanahan, C., Deanfield, J., & Rees, L. 2008, "The circulating calcification inhibitors, fetuin-A and osteoprotegerin, but not Matrix Gla protein, are associated with vascular stiffness and calcification in children on dialysis", *Nephrology Dialysis Transplantation*, vol. 23, no. 10, pp. 3263-3271.

77. Sinha, R., Nandi, M., Tullus, K., Marks, S. D., & Taraphder, A. 2009, "Ten-year follow-up of children after acute renal failure from a developing country", *Nephrology Dialysis Transplantation*, vol. 24, no. 3, pp. 829-833.

78. Smith, J. B. & Calder, F. R. 2008, "Proximal radial artery ligation after distalization of a high flow brachio-cephalic fistula. A novel approach to inflow reduction", *Journal of Vascular Access*, vol. 9, no. 4, pp. 291-292.

79. Tullus, K., Brennan, E., Hamilton, G., Lord, R., McLaren, C. A., Marks, S. D., & Roebuck, D. J. 2008, "Renovascular hypertension in children", *Lancet*, vol. 371, no. 9622, pp. 1453-1463.

80. Tullus, K. 2008, "[Children with urinary tract infections. New scientific findings must change running routines]", *Läkartidningen*, vol. 105, no. 23, pp. 1757-1758.

81. Tullus, K., Lakhanpaul, M., & Mori, R. 2008, "A different view on imaging of UTI", *Acta Paediatrica*, vol. 97, no. 8, pp. 1016-1018.

82. Tullus, K. 2008, "[Swedish physician practicing in England: a risk that private pediatric hospital care will not be as good as public]", *Läkartidningen*, vol. 105, no. 30-31, pp. 2116-2117.

83. Tullus, K., Mori, R., & Lakhanpaul, R. 2008, "NICE guidelines on managing urinary tract infections in children", *Urology News*, vol. 12, pp. 8-9.

84. Waller, S., Shroff, R., Freemont, A. J., & Rees, L. 2008, "Bone histomorphometry in children prior to commencing renal replacement therapy", *Pediatric Nephrology*, vol. 23, no. 9, pp. 1523-1529.

85. Webb, N. J., Prokurat, S., Vondrak, K., Watson, A. R., Hughes, D. A., Marks, S. D., Moghal, N. E., Fitzpatrick, M. M., Milford, D. V., Saleem, M. A., Jones, C. A., Friman, S., Van Damme-Lombaerts, R., Janssen, F., Hamer, C., & Rhodes, S. 2009, "Multicentre prospective randomised trial of tacrolimus, azathioprine and prednisolone with or without basiliximab: two-year follow-up data", *Pediatric Nephrology*, vol. 24, no. 1, pp. 177-182.

86. Weber, S., Taylor, J. C., Winyard, P., Baker, K. F., Sullivan-Brown, J., Schild, R., Knuppel, T., Zurowska, A. M., Caldas-Alfonso, A., Litwin, M., Emre, S., Ghiggeri, G. M., Bakkaloglu, A., Mehls, O., Antignac, C., Network, E., Schaefer, F., & Burdine, R. D. 2008, "SIX2 and BMP4 mutations associate with anomalous kidney development", *Journal of the American Society of Nephrology*, vol. 19, no. 5, pp. 891-903.

87. Westbroek, W., Tuchman, M., Tinloy, B., De, W. O., Vilboux, T., Hertz, J. M., Hasle, H., Heilmann, C., Helip-Wooley, A., Kleta, R., & Gahl, W. A. 2008, "A novel missense mutation (G43S) in the switch I region of Rab27A causing Griscelli syndrome", *Molecular Genetics and Metabolism*, vol. 94, no. 2, pp. 248-254.

88. Willicombe, M., Harber, M., Jones, G., Juszczak, M., Lord, R., Sweny, P., & Dupont, P. Conversion from calcineurin inhibitors to sirolimus and MMF in renal transplant recipients with chronic allograft nephropathy. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
Ref Type: Abstract

89. Winyard, P. & Chitty, L. S. 2008, "Dysplastic kidneys", *Seminars in Fetal and Neonatal Medicine*, vol. 13, no. 3, pp. 142-151.

90. Winyard, P. Genetics and mechanisms of dysplastic kidneys. Journal of the American Society of Nephrology [Abstracts Issue]. 2008.
Ref Type: Abstract

91. Woolf, A. S. 2008, "Perspectives on human perinatal renal tract disease", *Seminars in Fetal and Neonatal Medicine* , vol. 13, no. 3, pp. 196-201.

92. Woolf, A. S., Gnudi, L., & Long, D. A. 2009, "Roles of angiopoietins in kidney development and disease", *Journal of the American Society of Nephrology*, vol. 20, no. 2, pp. 239-244.

8.2 Grants

R&D No	Research Title	Funder Organisation	Total Funding	PI
07NU15	Identification of an X-linked gene conferring susceptibility to membranous nephropathy	Kids Kidney Research	£99,669	Detlef Bockenhauer
07NU21	Developing unique human renal progenitor cell lines - towards novel therapies for congenital and acquired kidney diseases	Kidney Research Aid Fund	£99,096	Paul Winyard
07NU25	Roles of angiopoietins in epithelial-endothelial interactions: using the renal glomerulus as a model system	Kidney Research UK	£247,466	David Long
07NU27	Roles of Fras1, a basement membrane-associated protein, in normal differential of kidney collecting ducts and glomeruli	Wellcome Trust	£301,577	Adrian S Woolf
08NU01	Chronic kidney disease (CKD) from chidhood to adult life; optimising diagnosis and identifying interventions to improve lifelong outcome	Great Ormond Street Hospital Children's Charity	£954,202	Lesley Rees
08NU07	Gene profiling in renal agenesis	Kidney Research UK	£56,421	Adrian S Woolf
08NU08	Is it possible to optimise cardiovascular health in children with chronic kidney disease stage 5 by normalisation of vitamin D levels?-a point study	Kidney Research UK	£39,969	Lesley Rees
08NU10	Galectin-3, a novel therapy for autosomal recessive polycystic kidney disease	Kidney Research UK	£132,466	Paul Winyard
08NU20	Insights into endothelial-epithelial interactions using proteomic analysis	Central Research Fund (University of London)	£4,500	David Long
		Total	**£1,935,366**	

R&D No	Research Title	Funding	PI
03NU09	An investigation into the presence and extent of early markers of vascular calcification in children with chronic renal failure (CRF) and the role of management of hyperparathyroidism in these abnormalities	British Medical Association (£10000) Kidney Research Aid Fund (£57533)	Lesley Rees
04NU18	OFD1, a centrosomal protein mutated in human polycystic kidney disease: an investigation of its role in kidney growth and differentiation	Wellcome Trust (£226547)	Adrian S Woolf
04NU34	As study of candidate molecules which modulate dietary programming of early nephrogenesis	National Kidney Research Fund (£50084)	Adrian S Woolf
05NU04	The effects of phosphate and PTH regulation on vascular smooth muscle cal calcification in children with End Stage Renal Failure (ESRF) - clinical and laboratory correlation	National Kidney Research Fund (£65803)	Lesley Rees

05NU19	A randomised, open trial to compare the safety and efficacy of a combination therapy of Tacrolimus, Myophenolate Mofetil (MMF) and Daclizumab with early steroid withdrawal versus Tacrolimus, MMF and steroids in children after kidney transplantation	Astellas Pharma GmbH (£13898) Astellas Pharma GmbH (£68780)	Richard Trompeter
06NU05	Gene therapy for Polycystic Kidney Disease - testing novel therapies in animal models		Paul Winyard
06NU04	Audit of outcome in renal transplant recipients	Roche Products (£2000)	SD Marks
06NU06	Audit of outcome of typical and atypical SLE patients		SD Marks
06NU09	Hyperoxaluria and gene expression	National Institute of Health USA (Funded non ICH account)	Detlef Bockenhauer
06NU10	Exploring how vascular endothelial growth factor enhances the growth and differentiation of the embryonic urinary bladder	Kids Kidney Appeal (£85940) Great Ormond Street Hospital Children's Charity Awarded (£41597)	Adrian S Woolf
06NU18	AV-fistula use in paediatric hemodialysis- A change of culture		DK Hothi
07NU01	Investigating the roles of Teashirt (Tshz) transcription factors in the developing and injured/regenerating mouse renal system	British Council Awarded (£3800)	Adrian S Woolf
07NU07	Pre and Post DMSA and MAG3 as screening test for renovascular hypertension		Kjell Tullus
07NU08	Myocardial Stunning During Paediatric Dialysis	Kids Kidney Research Awarded (£80065)	Lesley Rees
07NU29	Five-year retrospective review of laparoscopic heminephrectomies performed at Great Ormond Street Hospital		Stanwell
08NU01	Chronic kidney disease (CKD) from chidhood to adult life; optimising diagnosis and identifying interventions to improve lifelong outcome	Great Ormond Street Hospital Children's Charity Awarded (£954202)	Lesley Rees
08NU02	Complement C1q auto-antibodies in glomerulonephritis		SD Marks
08NU12	Autosomal Dominant Polycystic Kidney Disease (ADPKD) in childhood: The future?		Detlef Bockenhauer
08NU15	Outcome of bladder augmentation in those under 5 years of age		S Griffin
08NU17	Case note review of patients assessed for mutations in HNF1 beta		Detlef Bockenhauer
08NU19	Role of angiopoietin growth factors in diabetic nephropathy	Diabetes UK (Funded non-ICH/GOSH A/c)	David Long
08NU21	Case note review of patients with Bartter and Gitelman syndrome		Detlef Bockenhauer
08NU24	National cohort study of adult cystinosis patients		William van't Hoff

08NU25	NPHS2 (podocin encoding gene) mutation analysis in steroid resistant nephrotic syndrome		Detlef Bockenhauer
03NU13	Long term tapering versus standard Prednisolone therapy for the treatment of the initial episode of childhood nephrotic syndrome: National multi-centre randomised double blind pilot study	Kidney Research Aid Fund (£50000) National Kidney Research Fund Awarded (£49664) National Kidney Research Fund Awarded (£49664)	Richard Trompeter
04NU03	Antenatal renal malformations - improved prognostic indicators	Kidney Research Aid Fund Awarded (£63947)	Paul Winyard
04NU33	Childhood renal artery stenosis: a familial study and establishment of a DNA bank from affected individuals assessed at GOSH	Kidney Research Aid Fund Awarded (£54144)	SD Marks
04NU36	Identification of genes involved in renal and electrolyte disorders		Detlef Bockenhauer
05NU10	SNP based sib-pair linkage study to identify loci contributing to Vesicoureteric Reflux	Medical Research Council Awarded (£23957)	Adrian S Woolf
05NU11	Modelling urinary tract pathophysiology of human fetal bladder outflow obstruction using fetal sheep		Adrian S Woolf
05NU17	Relationship of EBV load post transplant to post transplant lymphoproliferation disease (PTLD)		Lesley Rees
06NU07	Living with transplantation and dialysis through transition to adulthood, 16 - 30 years		SD Marks
06NU08	Quality of life measurement in children: development of methods tailored for child's stage of development		Richard Trompeter
06NU12	Exploring the expression and potential roles of Fras1 and Frem2 in models of kidney diseases affecting the collecting duct lineage	Medical Research Council Awarded (£147263)	L Kerecuk
07NU15	Identification of an X-linked gene conferring susceptibility to membranous nephropathy	Kids Kidney Research Awarded (£99669)	Detlef Bockenhauer
07NU18	A Randomised double, parallel, placebo or amiodipnie controlled study of the effects of losartan on proteinuria in pediatric patients with or without hypertension	Merck Sharp & Dohme Awarded (£13339)	William van't Hoff
07NU20	Modelling fetal kidney programming ex vivo	European Molecular Biology Organisation (Funded non-ICH/GOSH A/c)	M Schreuder
07NU21	Developing unique human renal progenitor cell lines - towards novel therapies for congenital and acquired kidney diseases	Kidney Research Aid Fund Awarded (£99096)	Paul Winyard
07NU23	Identifying molecules which orchestrate bladder development		Adrian S Woolf

07NU25	Roles of angiopoietins in epithelial-endothelial interactions: using the renal glomerulus as a model system	Kidney Research UK Awarded (£3247466)	David Long
07NU27	Roles of Fras1, a basement membrane-associated protein, in normal differential of kidney collecting ducts and glomeruli	Wellcome Trust Awarded (£301577)	Adrian S Woolf
08NU09	Vitamin D (ergocalciferol) supplementation in children with early chronic kidney disease - a multicentre, randomised, double-blinded, placebo-controlled study		Lesley Rees
08NU07	Gene profiling in renal agenesis	Kidney Research UK Awarded (£56421)	Adrian S Woolf
08NU08	Is it possible to optimise cardiovascular health in children with chronic kidney disease stage 5 by normalisation of vitamin D levels?-a point study	Kidney Research UK Awarded (£39969)	Lesley Rees
08NU10	Galectin-3, a novel therapy for autosomal recessive polycystic kidney disease	Kidney Research UK Awarded (£132466)	Paul Winyard
08NU11	Vitamin D levels in paediatric renal transplant recipients - a cross sectional study		Lesley Rees
08NU13	Assessment of kidney function: Non-invasive transdermal Iontophoresis as an alternative to blood sampling iohexol GFR test	Algerian Government (Funded non-ICH/GOSH A/c) National Institute of Health USA (Funded non-ICH/GOSH A/c)	William van't Hoff
	Insights into endothelial-epithelial interactions using proteomic analysis	Central Research Fund University of London (£4500	

R&D No	Research Title	Funding	Sponsor Organisation	PI
08NU11	Vitamin D levels in paediatric renal transplant recipients - a cross sectional study	ICH/GOSH Biomedical Research Centre (Submitted)	Great Ormond Street Hospital for Children NHS Trust	Lesley Rees
08NU13	Assessment of kidney function: Non-invasive transdermal Iontophoresis as an alternative to blood sampling iohexol GFR test	Algerian Government (Funded non-ICH/GOSH A/c), National Institute of Health USA (Funded non-ICH/GOSH A/c), National Institute for Health Research (Submitted)	University of Bath	William van't Hoff
08NU12	Autosomal Dominant Polycystic Kidney Disease (ADPKD) in childhood: The future?		Great Ormond Street Hospital for Children NHS Trust	Detlef Bockenhauer
08NU14	Fetal programming of inherited polycystic kidney disease	Child Health Research Appeal Trust (Submitted), Child Health Research Appeal Trust (Submitted), Kidney Research UK (Submitted)	UCL Institute of Child Health	Adrian S Woolf
08NU16	European Network for the Study of Orphan Nephropathies (EUNEFRON)	European Union (Submitted)	Great Ormond Street Hospital for Children NHS Trust	William van't Hoff

08NU15	Outcome of bladder augmentation in those under 5 years of age		Great Ormond Street Hospital for Children NHS Trust	S Griffin
08NU17	Case note review of patients assessed for mutations in HNF1 beta		UCL Institute of Child Health	Detlef Bockenhauer
08NU18	The genetics of human non-syndromic renal tract malformations	Medical Research Council (Unsuccessful), Wellcome Trust (Unsuccessful), Action Medical Research (Submitted), Kids Kidney Research (Submitted), ICH/GOSH Biomedical Research Centre (Submitted)	UCL Institute of Child Health	S Adalat
08NU20	Insights into endothelial-epithelial interactions using proteomic analysis	Central Research Fund University of London (Awarded ICH A/c)	UCL Institute of Child Health	David Long
08NU19	Role of angiopoietin growth factors in diabetic nephropathy	Diabetes UK (Funded non-ICH/GOSH A/c)	Kings College London	David Long
08NU22	Thymosin-beta4 in kidney development and disease	Wellcome Trust (Unsuccessful)	UCL Institute of Child Health	Paul Winyard
08NU21	Case note review of patients with Bartter and Gitelman syndrome			Detlef Bockenhauer
08NU23	Vascular growth factors in children with chronic kidney disease	ICH/GOSH Biomedical Research Centre Unsuccessful, , , , ,	UCL Institute of Child Health	David Long
08NU24	National cohort study of adult cystinosis patients		Great Ormond Street Hospital for Children NHS Trust	William van't Hoff
08NU26	PhD Studentship: targeting blood vessels to prevent autosomal recessive polycystic kidney disease	Kids Kidney Research (Submitted)	UCL Institute of Child Health	David Long
08NU25	NPHS2 (podocin encoding gene) mutation analysis in steroid resistant nephrotic syndrome			Detlef Bockenhauer
09NU02	Does treatment with an angiotensin receptor blocker to reduce proteinuria futher protect long-term renal function in children with Chronic Kidney Disease and strict blood pressure control	Health Technology Assessment Programme (Submitted)		Kjell Tullus
09NU01	An investigation into the optimal reduction in dialysate temperature on systemic haemodynamics and myocardial stunning in paediatric haemodialysis	British Heart Foundation (Submitted), Kids Kidney Research (Submitted)	UCL Institute of Child Health	Lesley Rees
09NU03	A phase III, randomised, open label, parallel-group, dose ranging clinical trial to study the safety and efficacy of MK 0954/Losartan potassium in paediatric patients with hypertension	Merck & Co Inc (Under Negotiation Industrial)	Merck & Co Inc	SD Marks
09NU04	Cross-cultural adaptation and validation of SMILEY		UCL Institute of Child Health	SD Marks
09NU05	What is the role of the microtubule cytoskeleton	Wellcome Trust (Submitted)	University College London	Adrian S Woolf

	during podocyte process formation and how is it regulated			
09NU06	The role of angiopoietin-1 and vascular endothelial growth factor in controlling glomerular capillary permeability	British Heart Foundation (Submitted)	Kings College London	David Long

9 Nephro-Urology Academic Programme (Tuesday or Thursday afternoon 2.30pm – 4.30 pm)

Date	Topic *2.30 - 3.30 pm*	Speaker	Topic *3.30 – 4.30pm*	Speaker
21/4/08	Renal Association, no meeting			
28/4/08	**Renal biopsy meeting**	**Dr Neil Sebire**	Sirolimus post transplant	Dr Steve Marks
5/5/08				
14/5/08	Joint meeting with the Evelina Children's hospital at ICH, Seminar room A, 2nd floor, note thursday			
13/5/08	Renal Association/BAPN meeting at Glasgow			
20/5/08			**CKD-MBD**	**Dr Rukshana Shroff**
27/5/08	Half term break			
5/6/08	Bipartite meeting at the ICH, Welcome Trust Building, level 2 room B Note Thursday			
12/6/08	BAPN histopathology meeting **Note thursday**			
17/6/08	Renal biopsy meeting	Dr Neil Sebire	Audit of peritoneal dialysis	Nurse specialists Michelle Cantwell
24/6/08	Review of recent case of transplant loss	Dr van't hoff	Myocardial stunning	Dr daljit hothi
1/7/08	Risk management and clinical governance	Dr Daljit Hothi	Audit of living donation	Clinical nurse specialists Maria Scanes and Carol Jennings
18/7/08	Renal biopsy meeting	Dr Neil Sebire	Audit of renal transplants	Clinical nurse specialists Suzanne Bradley and Cecelia MacNeice

Date	Topic	Speaker	Topic	Speaker
9/9/08	Practise session for ESPN			
16/9/08	***2.30 – 3.30pm*** Renal Biopsy Meeting	**Dr Neil Sebire**	*3.30 – 4.30 pm* Talks on PD	Michelle Cantwell
23/9/08	***2.30 – 3.30pm*** 20 year outcome of infants with severe CKD	**Dr Djalila Mekhali**	Talks on PD	Dr Dal Hothi
30/9/08	***2.30 – 3.30pm*** The use of captopril studies in the diagnosis of renal artery stenosis	**Dr Sameh Abdulsamea**	3.30-4.30 Does vitamin D play a part in nephrotic syndrome	Dr Sandra Iragorri
7/10/08	***2.30 – 3.30pm*** **Renal biopsy meeting**	**Dr Neil Sebire**	*3.30 – 4.30 pm* Transplanting ABO incompatible and HLA sensitised patients	Mr Nizam Mamode
16/10/08	**Bipartite meeting at the Royal Free** Note Thursday			
21/10/08	Half term week, no meeting			
28/10/08	Dr Detlef Bockenhauer	**EAST syndrome**	***3.30-4.30pm*** Audit of deaths and complaints	Nurse Consultant Eileen Brennan
6/11/08	**Joint meeting with Evelina, at the Evelina hospital** Note thursday			
11/11/08	***2.30 – 3.30pm*** **Renal biopsy meeting**	**Dr Neil Sebire**	**A history of renal failure management**	Dr Dick Trompeter
18/11/08	***2.30 – 3.30pm*** **Interesting cases for discussion**	**Prof Adrian Woolf**	Developmental genes in kidney disease	**Dr Larissa Kerekuk**
25/11/08	**Nephrology Day for general paediatricians at the ICH (note Friday)**			
2/12/08	*2.30 – 3.30pm* The Twist study	Company presentation, name to be announced	*3.30-4.40pm* **Translational research: CVD and CKD**	Dr Rukshana Shroff
9/12/08	***2.30 – 3.30pm*** Renal Biopsy Meeting	Dr Neil Sebire	*3.30 – 4.30 pm* MMF in SLE	**Dr Kjell Tullus**
11/12/08	**Bipartitie meeting at ICH (note thurs)**			
16/12/08	***2.30 – 3.30pm*** **CKD in transplant patients**	Dr Steve Marks	*3.30 – 4.30 pm*	

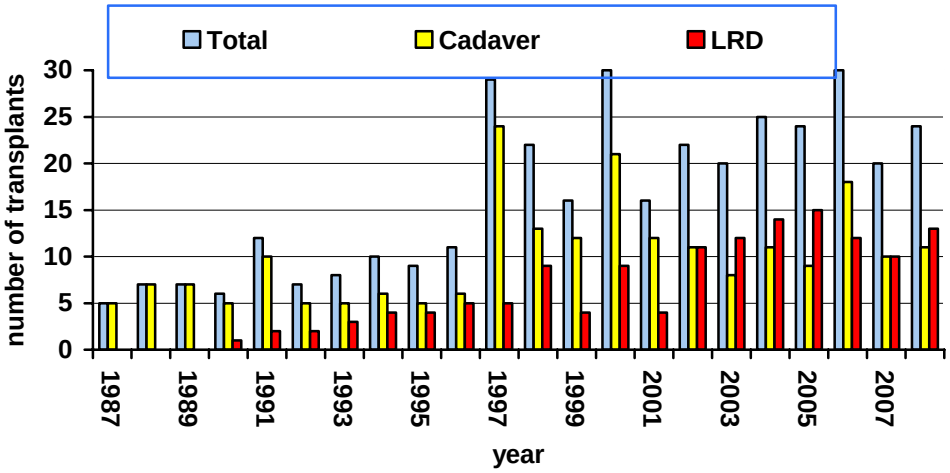
Date	Topic *2.30 - 3.30 pm*	Speaker	Topic *3.30 – 4.30pm*	Speaker
15/1/09	Joint meeting with the Evelina, at the Evelina Hospital **Note Thursday**			
20/1/09	**Renal biopsy meeting**	Dr Neil Sebire	COQ10 deficiency	Dr Giovanni Montini
27/1/09	A podocyte trapped in notch	Dr Aoife Waters	Developmental genes and the kidney	Dr Larissa Kerecuk
3/2/09	Renal biopsy meeting	**Dr Neil Sebire**	Twist study	**Malcolm Brown Astellas**
10/2/09	Eosinophilic peritonitis	Dr Cathy Quinlan	BK virus in renal transplants	Dr Niamh Dolan
17/2/09	**Half term break**			
24/2/09	The timing of ostomies in CKD	Dr Rukshana Shroff	20 years experience of enteral feeding in CKD	Dr Lesley Rees
3/3/09	**Renal biopsy meeting**	**Dr Neil Sebire**	Rituximab in idiopathic nephrotic sydrome	Dr Agnieska Prytula
12/3/09	Bipartite at Royal free hospital Note thursday			
16/3/09	**Course week at the ICH**			
23/3/09	**Practise session for RCPCH**			
30/3/09	**RCPCH week**			
6/4/09	**Easter holidays**			
13/4/09	**Easter holidays**			

10. AUDIT

10.1 PRE TRANSPLANT AUDIT
Living and Deceased Donor - April 2008 – March 2009

Transplant Numbers:

- 24 transplants in 24 children
- 13 living donor (54%)
- 11 deceased donor (46%)



Recipient Demographics:

- Male 14 (58%)
- Female 10 (42%)
- NHS 24 (2 Maltese)

Modality at the time of Transplant:

- HD x 9 (38%)
- PD x 7 (29%)
- Pre emptive x 8 (33%)

Recipient info continued:

- 2 of the 24 children received their 2nd graft
- 22 – kidney
- 2 – combined liver & kidney (Birmingham)
- 3 out of centre – 2 from Malta, 1 from N Ireland

Recipient Blood Groups:

- O 12 (50%)
- A 6 (25%)
- B 4 (17%)
- AB 2 (8%)

Mismatches:

- 6 AM 0 (0%)
- 5 AM 2 (8%)
- 4 AM 10 (42%)
- 3 AM 6 (25%)

DD Mismatches:

- 5 patients who had less than 3 AM were all deceased donor transplants
- 1 of these was combined liver & kidney

Living Donor Mismatches:

- All living donor mismatches were 3 AM and above
- 1 – 5 AM
- 9 – 4 AM
- 3 – 3A M

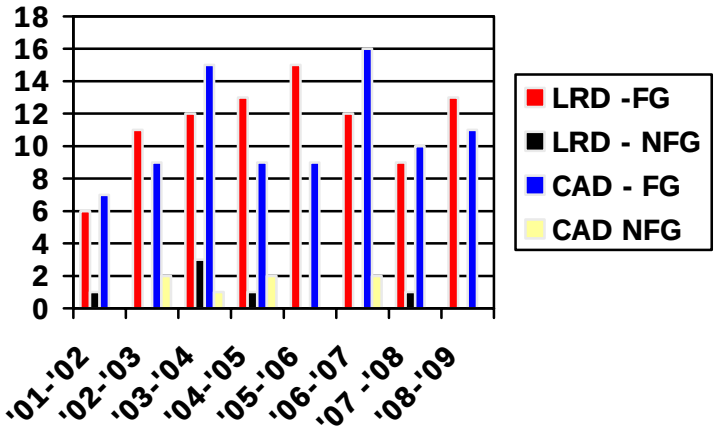
Diagnoses:

- Dysplasia 4
- FSGS 4
- ARPKD 4
- Nephronopthisis 2
- 1 each of PUV, Cystinosis, Cloacal anomaly, Goodpastures, Cortical Necrosis, Neuropathic bladder, Jouberts, Ivemark, Fanconi, GN, Unknown (KB)

Outcomes:

- Of 24 transplants carried out during audit year all transplant functioning at year end
- 1 CRF – (TA)

End of Year Outcomes



Cold Ischaemic Times:

- LD
  - data on 7 pts (50%)
  - average 4 hrs (2.30 hrs – 5 hrs)

- DD
  - data on 9 pts (82%)
  - average 12.7 hrs (9.57 hrs – 16.40 hrs)
  - missing data from 2 Birmingham tx

Could we ↑ Number of Pre-emptive Transplants:

- Possibly 3 out of 24 could have been avoided. Cr ↑ dramatically and donor initially elusive (DA)
- All were LRD pts
  - BD – initially post xmatch. Rushed through Mum's workup
  - CS – on HD in Malta. Could have been referred earlier
  - YP – deemed high risk due to cardiac complications

Activity:

- LRCAP clinic - 644 appts
- PRETX clinic - 26 appts
- GKRLTX clinic - 58 appts

Living Donor Information:

- 7 fathers (54%)
- 6 mothers (46%)

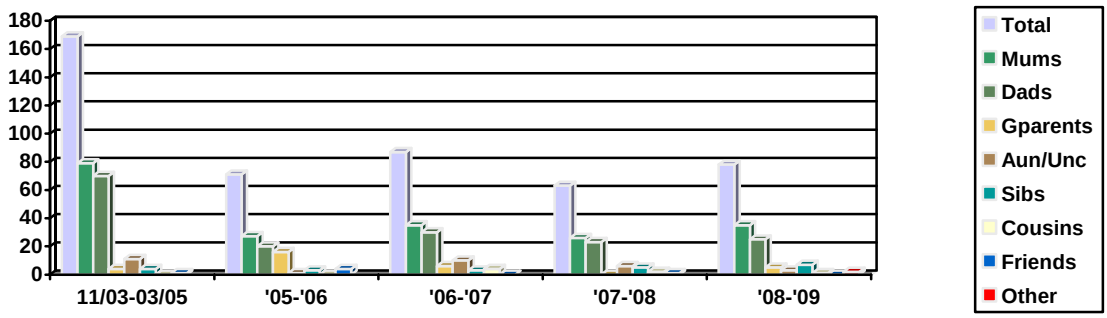
Mean age 38 yrs (25-51.3 yrs)

- 8 – Guys (57%)
- 6 – Royal Free (46%)

Donor Pool:

- 78 donors came forward for 47 potential recipients
  - Mothers 35
  - Fathers 25
  - Sisters 2
  - Brothers 4
  - Aunts 1
  - Uncles 2
  - Cousins 1
  - Grandparents 5
  - Stepfathers 2

Donor Pool from November 2003



Donor Suitability

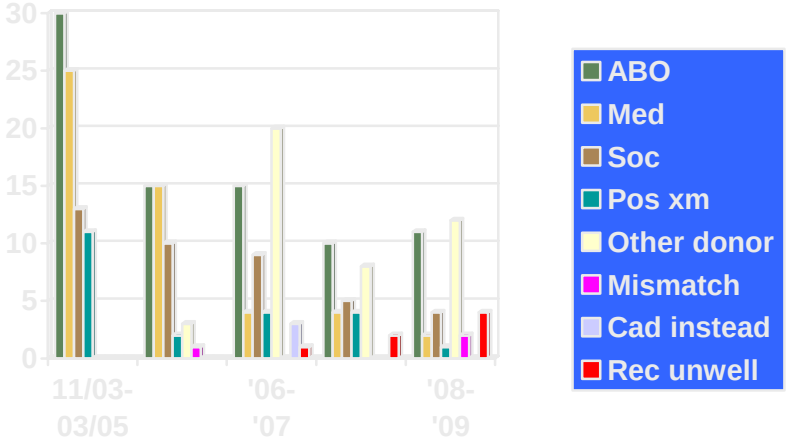
From 78 potential donors within audit year

- 3 transplanted within audit year
- 24 referred to adult units
- 21 awaiting referral to adult units
- 45 unsuitable (58% attrition rate)

Unsuitable Donors

- BGI 11 (24%)
- Medical reasons 2
- Social 4
- Other donors 12 (26%)
- Positive X match 1
- Recipients unsuitable 4
- Unsuitable HLA 2
- Ref adults 3
- Transfer out 4
- Young donor 2

Donor Suitability Since November 2003



Work in Progress (06/09)

- 118 children "on our books"
- 24 on-call
- For pot LRDs – by Dec 09 – 11
  - Tx Apr – June 4

Potential For ABO Incompatible Tx

	RBG	DBG	Titres	Time OC	Score	Points	Cl 1 abs %	Cl 2 abs %
HB	O+	B+	1:32	1278	4	10	90	90
AF	O+	B+	?	215	79	5	0	0
0		B+	?					
JR	O+	?	?	129	211	2	25	5
			?					
KR	A+	B	?	487	45	7	0	0
KT	O+	A+	1:64	68	8	10	10	90
		B+	1:16					
SH	O	B	?	241	23	8	0	0
KB	O	A	1:51	-	-	-	-	-
MC	O	A	[2]					
ZS	O	B+	1:32	409	5	10	55	45

Achievements

- UKT consent for storage and use of information
- IA implemented successfully

Audit Points

- ABO incompatibility
- Desensitisation
- Paired exchange
- ? no of children from other centers
- Pre Tx Echo as part of protocol
- When to activate/Transplant?
- Education sessions, OTIS.

10.2 Renal Transplant Audit

April 2008 – March 2009
Suzanne Bradley

Renal Transplants at GOSH

- 24 Transplant Patients to the programme in the 12 month period of 1st April 2008 – 31st March 2009
- 22 out of 24 children received Renal Transplants at GOSH
- 2 additional transplants were carried out on GOSH patients -These patients had Deceased Donor Liver & Kidney Transplants at Birmingham Children's Hospital
- (AI & KB)
- 2 patients returned to Malta and 1 to Belfast post living related transplants
- 22 patients received their 1st graft
- 2 patients received their 2nd graft
- JM had 1st graft (DD) for15yrs
- QL had 1st graft (LRT) for 8yrs

Patient Demographics

- Mean age at TPX = 11.3 years
- Median age at TPX = 13.2 years
- Female / Male= 10 (42%):14 (58%)
- NHS / Private= 24:0
- Malta= 2/24 patients
- Belfast=1/24 patients

Underlying Diagnosis

- Dysplasia= 4
- FSGS =4
- APRKD = 3
- Posterior Urethral Valves= 1
- Cystinosis=1
- Jouberts=1
- Goodpastures Syndrome= 1
- Fanconi Syndrome= 1
- Cortical Necrosis= 1
- ? Ivemark Syndrome= 1
- ? Alagille Syndrome=1
- Juvenile Nephronopthisis = 1 & ?1
- Neuropathic Bladder = 1
- Cloacal Anomaly = 1
- Chronic Glomerulonephritis ?cause =1

Pre-Transplantation Status

- Pre-Emptive = 9 x (37.5 %)
- Haemodialysis = 9 x (37.5%)
  Peritoneal Dialysis = 6 x (25 %)

Donor Types

- Live Related = 13 Patients (54%)
- Deceased Donor = 11 Patients (46%)
- [2 patients received a kidney from the same donor – TA; RB]

HLA Mismatches

0-1-1	5
1-0-0	1
1-0-1	3
1-1-0	3
1-1-1	6
2-1-0	1
2-1-1	3
2-2-1	1
Unknown	AI

Donor – Recipient CMV Status

	Recipient CMV +ve	Recipient CMV -ve
Donor CMV +ve	2	5
Donor CMV –ve	1	14
Donor CMV status unknown	-	2

Donor – Recipient EBV status

	Recipient EBV +ve	Recipient EBV -ve
Donor EBV +ve	6	3
Donor EBV –ve	3	1
Donor EBV status unknown	7	4

Immunosuppression in New Renal Transplant Recipients 2008-2009

Start	End	No. of Patients
Tac/Aza/Pred	Tac/Aza/Pred	6
Tac/MMF/Pred	Tac/Aza/Pred	10
Tac/Aza/Pred	Tac/MMF/Pred	5
Tac/Aza/Pred	Tac/Pred	3

Renal Transplant Biopsies

Patients transplanted in 2008-2009

- 19 of the 24 patients had a total of 33 biopsies in audit year
- 6 had biopsy at the time of transplant
- 27 Remaining biopsies done due to rise in creatinine

Biopsy results in patients transplanted 2008-2009

Biopsy Result	**Number of Biopsies made reference to:**
No Abnormalities Noted	2
Chronic Vascular Changes	8
No Acute Rejection	15
Borderline Acute Rejection	2
Grade 1a rejection	3
BK Nephropathy	5
Acute Tubular Abnormalities	2
Disease Recurrence - FSGS	3
Chronic Changes	6

BK Virus Post Transplant

BK Virus	**+ve**	**-ve**	**Not Checked**
Blood	2	14	7
Renal Biopsy	2	-	-

Stent Removal – No of weeks into Transplant Journey

Weeks Post Tx	No. of Patients	Reason
Week 1	0	-
Week 2	1	UTI
Week 3	4	Haematuria x 2/Migration to bladder x 1/Routine x1 (CN)
Week 4	1	Routine
Week 5	6	Routine
Week 6	2	Routine
Week 7	6	Routine
Week 8	1	Routine
Week 9	0	-
Week 10	1	Routine

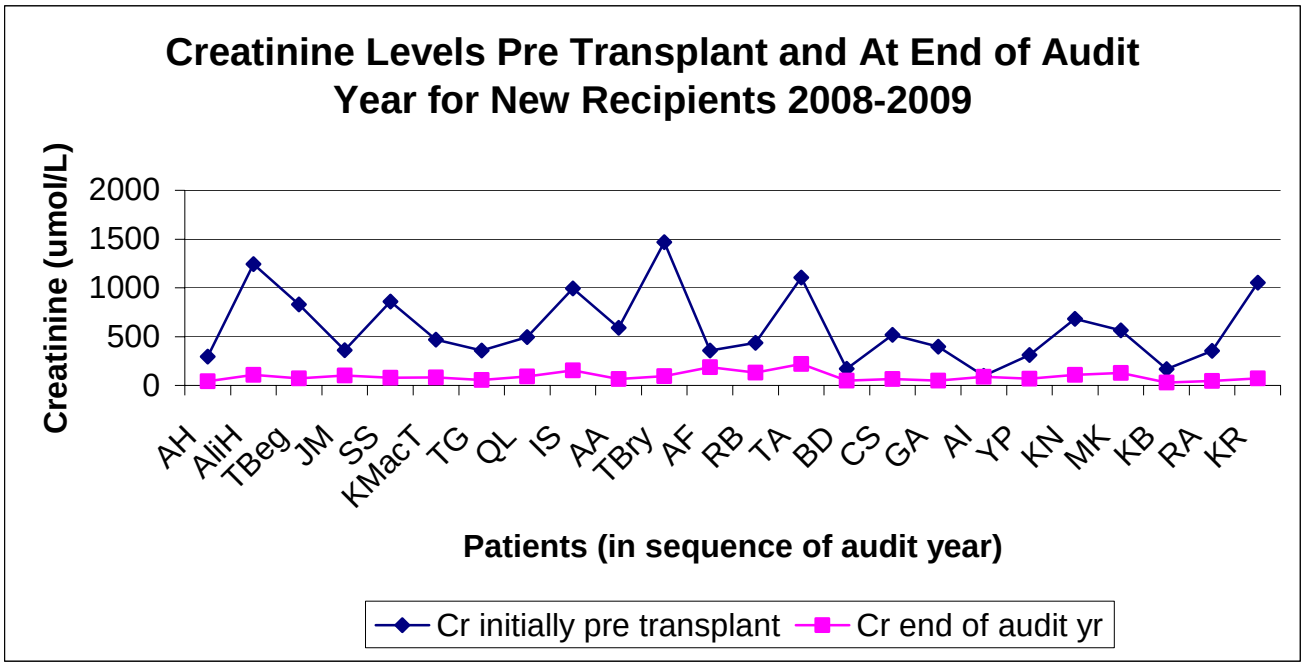
Anti-Hypertensive Treatment in New Renal Transplant Recipients 2008-2009

Start	End	No. of Patients
0	0 agent	8
0	1 agent	1
0	2 agents	1
0	4 agents	1
1	0 agents	2
1	1 agents	4
1	2 agents	1
1	3 agents	1
2	0 agents	1
2	2 agents	4

Major Transplant Complications

- 3 patients became Insulin Dependent Diabetics post transplant (Family Hx in 2 of the 3 patients but one Patient now off insulin)
- 2 patients needed treatment for CMV (Donor Pos/Recip Neg)
- 2 patient required plasma exchange post transplant for FSGS re-occurrence but remained off dialysis in audit year
- 3 patients =initial ATN (2=DD transplants/1=LRT transplant)
- Wound Infection
- Wound Dehiscence
- Febrile neutropenia
- Donor Specific Antibodies

Creatinine Levels Pre Transplant and At End of Audit Year for New Transplants 2008 – 2009



Transplant Biopsies

Existing transplant patients undergoing biopsy in audit year 2008-2009

- 19 patients had a total of 23 biopsies in the audit year

Biopsy Results

Biopsy Results	Biopsy Report made reference to:
No rejection	10
Acute Rejection	2
Grade 1A Rejection	2
Grade 2A Rejection	1
Chronic changes	8
CAN	6
FSGS Re-occurrence	1
BK Nephropathy	2

Transplant Complications in existing transplant patients

- Respiratory symptoms & bronchiectasis
- 1 existing patient required a graft nephrectomy for FSGS re-occurence & returned to peritoneal dialysis
- PS- RIP-PTLD
- JT- RIP-co-morbid factors
- Biochemistry & Low Tacrolimus levels-sent to Kings

Creatinine Trend-an overview in programme

Creatinine	No of Pts	Years out	DD v LRT
Up to 100	84	2/12-13yrs	45 v 39
100-200	53	6/12-15yrs	26 v 27
200-300	6	6/12- 13yrs	2 v 4
300-400	-	-	-
400-500	1	2 yrs 8/12	1
500-600	1	3yrs 6/12	1

Adolescent Transition

- February 2008 - Launch of joint Renal Adolescent Transition Clinic with the RFH and Guys Hospital. Aim 4 clinics each in the calendar year.
- Dec 2008- Launch of joint Renal Adolescent Transition Clinic with RLH
- Joint Renal Adolescent Transition Clinic with Oxford continues
- Nigel Mills (Adolescent CNS)

Transition

- 10 adolescent patients transitioned to 7 adult units.
- RFH=3
- Addenbookes=2
- RLH=1
- Ipswich/UCH=1
- Norwich & Norfolk=1
- Guys=1
- Northamptonshire=1

Total Transplant Patients

Transplant patients seen in outpatients by age (*Based on patients age on 31/03/2009*)

Under 5 years old	7
5 – 10 years old	28
10 – 15 years old	60
> 15 years	59

Transplant Clinics 2008 - 2009

- RSTRTP Clinic Attendance =897
- RENWAL Clinic Attendance = 772
- RSTCNS Clinic Attendance = 615

In Conclusion…the year ahead

- Revision of renal transplant protocol (SM)
- Adolescent Programme Development
- Renal Transplant Service Provision
- OTIS
- And finally….
- 6 GOSH Renal Transplant Patients on British Transplant Team-World Games Australia August 2009

Thanks to……

- *Cecelia McNeice*
- *Steve Marks, Detlef Bockenhauer & Rukshana Shroff*
- *Suzie Doyle*

10.2 Renal transplant national comparative unit audit (*Report and data from UK TRANSPLANT)*

ROYAL FREE HOSPITAL & GREAT ORMOND STREET HOSPITAL PAEDIATRIC KIDNEY TRANSPLANT SURVIVAL

This report summarises transplant activity and transplant survival for UK paediatric recipients only i.e. those aged less than 18 years at transplant.

DATA

Table 1 reports transplant activity by calendar years 1987 to 2008, by donor type (deceased heartbeating, deceased non-heartbeating and living) and by transplant unit (Royal Free Hospital, Great Ormond Street Hospital and all other UK kidney transplant units). The numbers of multiple organ transplants are indicated within the table (43 kidney/liver transplants, 5 kidney/pancreas transplants and 1 kidney/heart transplant) and figures include both first grafts and re-grafts.

Table 2 details the same activity as described in **Table 1** but includes only first grafts and kidney only grafts i.e. re-grafts and multiple organ transplants are excluded. The survival analysis reported in **Tables 3** and **4** is based on these transplants.

Table 3 **summarises one, five and ten year transplant survival estimates for first deceased heartbeating paediatric kidney-only transplants by transplant year (grouped: 1992 - 1995, 1996 - 1999, 2000 - 2003, 2004 - 2007) and by transplant unit (Royal Free Hospital, Great Ormond Street Hospital and all other UK kidney transplant units). Deceased non-heartbeating donor transplants are not included in this analysis. Some survival estimates have not been reported due to insufficient follow-up information being available at time of analysis.**

Table 4 **summarises one, five and ten year transplant survival estimates for first living paediatric kidney-only transplants by transplant year (grouped: 1992 - 1999 and 2000 - 2007) and by transplant unit (Royal Free Hospital, Great Ormond Street Hospital and all other UK kidney transplant units). For five and ten year survival, follow-up levels may appear low, but recipients lost to follow-up largely account for this.**

Note **Tables 3** and **4** quote the overall number of transplants (N) and the number of transplants that were included in the survival analysis (No. analysed) - the latter excludes transplants with no reported follow-up.

Table 1 Paediatric kidney transplants at UK paediatric units, by transplant year and donor type

	Deceased heartbeating			Deceased non-heartbeating			Living			
Transplant year	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units	**TOTAL**
1987	13	5	91	0	0	0	0	0	9	**118**
1988	10	6	112(2)	0	0	0	3	0	8	**139**
1989	13(2)	7	102(1)	0	0	0	2	0	8	**132**
1990	16	4	64	1	1	1	2	0	6	**95**
1991	14(1)	10	87(1)	0	0	0	0	2	8	**121**
1992	12	5	84	2	0	3	2	2	9	**119**
1993	13	4	123(1)	0	0	1	2	3	6	**152**
1994	8	6	99 (3)	1	0	0	5	4	13	**136**
1995	13 (1)	5	111	0	0	1	2	4	13	**149**
1996	4	6	89(3)	0	0	0	5	4	17	**125**
1997	2 (1)	23	92(2)	0	1	1	0	5	14	**138**
1998	1 (1)	13	74(2)	0	1	0	1	7	17	**114**
1999	3 (1)	12	93(3)	0	0	1	0	4	27	**140**
2000	2 (1)	21	72(1)	0	0	0	1	8	24	**128**
2001	0	12	90(2)	0	0	1	0	4	30	**137**
2002	0	9	73(1)	0	0	0	0	13	31	**126**
2003	1	11	71	0	0	0	0	16	30	**129**
2004	0	14	65(5)	0	0	0	0	14	30	**123**
2005	0	12	60 (1)	0	0	0	1	13	32	**118**
2006	0	13	64(6)	0	0	1	0	16	35	**129**
2007	0	13	54(4)	0	0	1	0	7	43	**118**
2008	0	10	67(3)	0	0	2	0	14	50	**143**

( ) Number of which were multiple organ transplants

Table 2 **First paediatric kidney-only transplants at UK paediatric units, by transplant year and donor type**

Tx year	Deceased heartbeating			Deceased non-heartbeating			Living			TOTAL
	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units	
1987	13	5	77	0	0	0	0	0	9	**103**
1988	7	3	91	0	0	0	3	0	5	**109**
1989	9	5	69	0	0	0	2	0	8	**93**
1990	14	3	47	1	1	0	0	0	5	**71**
1991	12	5	75	0	0	0	0	2	6	**100**
1992	10	5	72	1	0	3	1	2	9	**103**
1993	13	3	103	0	0	1	2	3	6	**131**
1994	5	5	74	1	0	0	5	4	13	**107**
1995	10	5	91	0	0	1	2	4	13	**126**
1996	4	6	76	0	0	0	5	4	14	**109**
1997	0	20	69	0	1	0	0	5	14	**109**
1998	0	9	64	0	1	0	1	7	15	**97**
1999	2	9	72	0	0	1	0	4	22	**110**
2000	1	15	64	0	0	0	1	8	22	**111**
2001	0	9	80	0	0	1	0	4	30	**124**
2002	0	5	60	0	0	0	0	12	29	**106**
2003	1	11	62	0	0	0	0	15	27	**116**
2004	0	12	53	0	0	0	0	13	26	**104**
2005	0	12	56	0	0	0	1	13	28	**110**
2006	0	10	55	0	0	1	0	16	35	**117**
2007	0	12	45	0	0	0	0	7	43	**107**
2008	0	10	58	0	0	2	0	12	50	**132**

Table 3. One, Five and ten year transplant survival estimates for first deceased heartbeating paediatric kidney-only transplants at UK paediatric units, by transplant year group

	One year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1992 - 1995	56	56	80	67 - 89	100
1996 - 1999	50	50	74	59 - 84	98
2000 - 2003	42	41	85	70 - 93	98
2004 - 2007	46	46	89	76 - 95	100
All other UK paediatric units					
1992 - 1995	340	340	81	76 - 84	100
1996 - 1999	281	281	88	83 - 91	100
2000 - 2003	266	266	90	86 - 93	100
2004 - 2007	209	209	93	89 - 96	99

	Five year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1992 - 1995	56	56	63	49 - 74	100
1996 - 1999	50	50	64	49 - 75	98
2000 - 2003	42	41	73	56 - 84	91
2004 - 2007	46	46	-	-	20
All other UK paediatric units					
1992 - 1995	340	340	68	62 - 72	100
1996 - 1999	281	281	76	70 - 81	98
2000 - 2003	266	266	78	72 - 82	94
2004 - 2007	209	209	-	-	13

	Ten year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1992 - 1995	56	56	53	39 - 65	98
1996 - 1999	50	50	53	38 - 66	90
2000 - 2003	42	41	-	-	31
2004 - 2007	46	46	-	-	13
All other UK paediatric units					
1992 - 1995	340	340	54	48 - 59	98
1996 - 1999	281	281	60	54 - 66	78
2000 - 2003	266	266	-	-	26
2004 - 2007	209	209	-	-	10

Table 4. One, five, ten year transplant survival estimates for first living-donor paediatric kidney-only transplants at UK paediatric units, by transplant year group.

	One year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1992 - 1999	49	44	95	83 - 99	88
2000 - 2007	90	88	94	86 - 97	87
All other UK paediatric units					
1992 - 1999	106	104	95	89 - 98	96
2000 - 2007	240	238	95	92 - 97	98

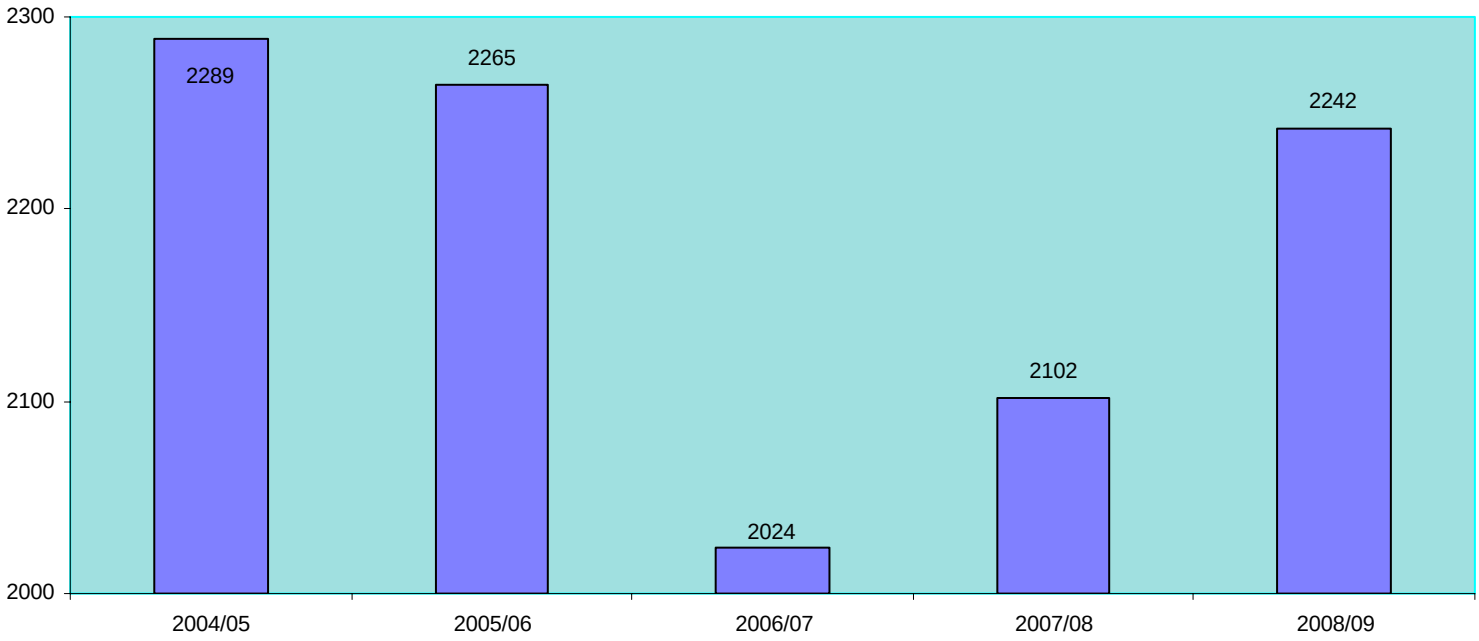
	Five year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1992 - 1999	49	44	86	71 - 93	74
2000 - 2007	90	88	-	-	38
All other UK paediatric units					
1992 - 1999	106	104	85	76 - 91	90
2000 - 2007	240	238	-	-	45

	Ten year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1992 - 1999	49	44	70	51 - 82	61
2000 - 2007	90	88	-	-	11
All other UK paediatric units					
1992 - 1999	106	104	68	58 - 77	71
2000 - 2007	240	238	-	-	9

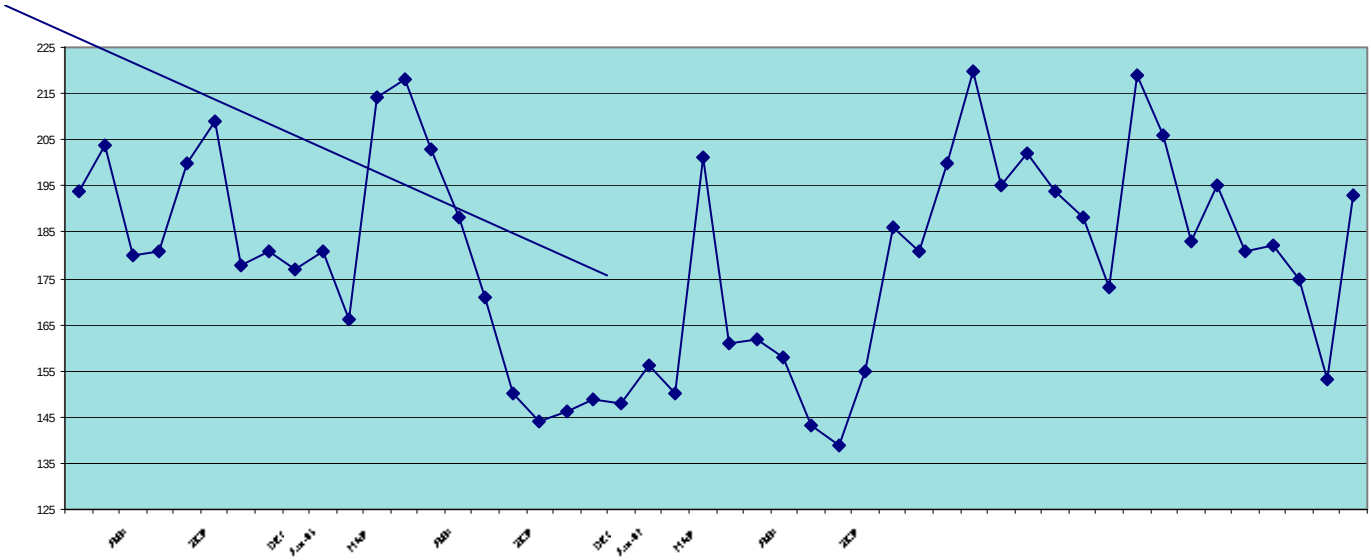
Haemodialysis Audit

2008-2009
Liz Wright

5 Year Total Activity

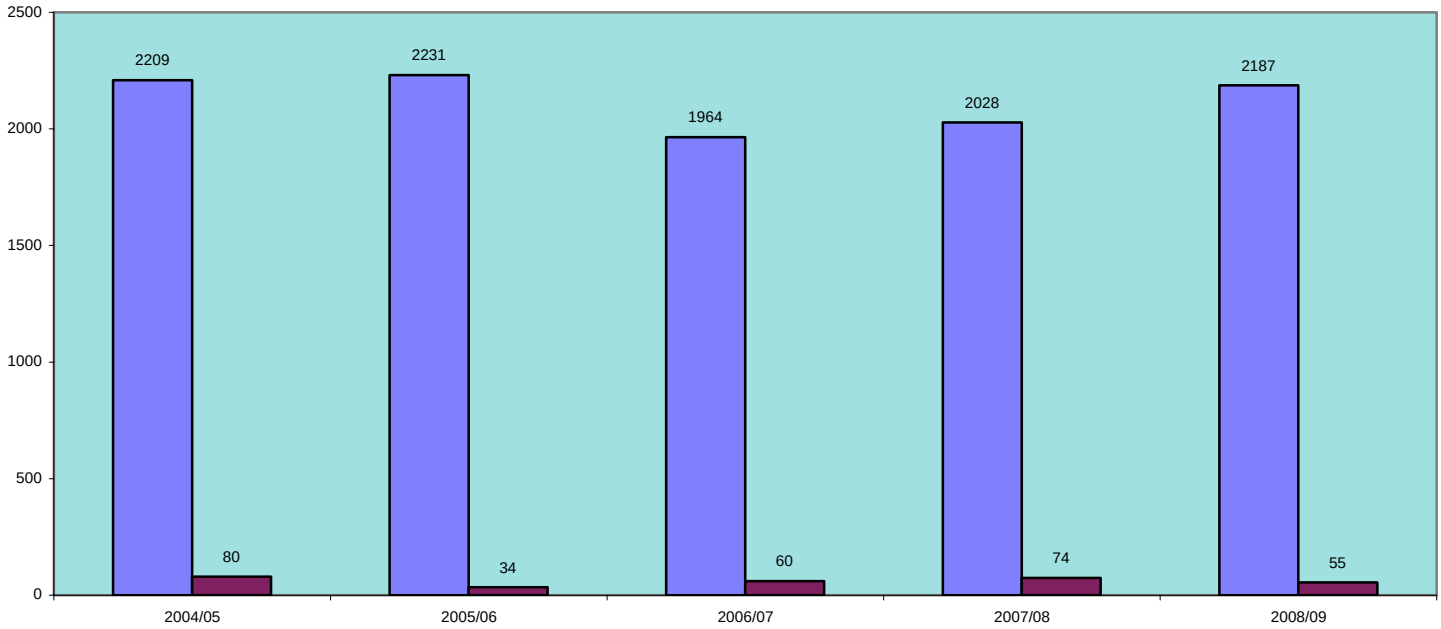


5 Year HD & PX Activity



*+ 41 UCLH

2005-2009 Breakdown HD activity



Overview

April 2008

- 14 chronic HD
- 1 HHD
- 4 lines
- 11 AVFs (73%)

March 2009

- 15 chronic HD
- 1 HHD
- 6 lines
- 10 AVFs (63%)

42 children treated

- 20 girls
- 22 boys
- 38 children had HD
- 5 children had PX (inc 3 by UCL

Age Ranges

- Under 2 yrs = 4
- yrs = 5
- 5–10 yrs = 8
- 10-15 yrs = 18
- 15 yrs + = 7

New Starters to HD (19)

- Peritonitis - 3
- PD social - 1
- PD fail - 1
- PD leak - 2
- PD medically not option - 5
- Acutes/esrf - 1
- PD waiting - 2
- Tx fail - 1
- Waiting for LRT - 3
- (Visitors 3)

Children out (19)

- Transfer to adults - 1
- Tx - 9
    - DD 6
    - LRT 3
- Pd start - 4
- PD return – 3
- Function recovered - 2

Acute HD

- 6 children, 3 boys, 3 girls

- 82 sessions (check on Olivia)

Acute HD

- HUS x 2
- ATN
- Post TX ATN
- ?ESRF
- ?ATN post sub-total nephrectomies
- 82 days HD

Plasma Exchange

5 children
- 2 – SLE
- 2 – FSGS recurrence post transplant
- 1- atypical HUS

95 sessions
- 41 of which by UCLH

Central Venous Lines
- 49 lines
- 6 uncuffed in 5 children
- 43 cuffed in 23 children
- 2434 catheter days (all lines)

CVL Position
49 lines inserted
- Permanent (43)
  - RIJ = 23 (54%)
  - LIJ = 18 (42%)
  - REJ = 1
  - Fem IVC = 1
- Temporary (6)
  - L fem = 1
  - R fem = 1
  - RIJ = 4

CVLs
- 1 child had 4 lines (YP)
- 4 children had 3 lines (KB, IS, BW, LO)
- 9 children had 2 lines
- 15 children had 1 line

CVLs - Insertion Details

	Dr	Permanent (43)	Temporary (6)	Total (49)
IR 45%	AB DR	13 8	0 1	13 9
Renal 47%	JT FC GK NM	9 4 3 3	2 1 0 1	11 5 3 4
Other 8%	AC Picu BCH Malta	1 0 1 1	0 1 0 0	1 1 0 1

CVLs – reasons for removal (37/43)

No longer required – 20 (47%)

- Therapy completed (4)
- Renal function recovered (3)
- LRT (3)
- Cad TX (1)
- PD (3)
- AVF (6)

Mechanical – 14 (33%)

- Cuff out (2)
- Pulled out (2)
- Poor flows (10)

Infection – 3 (7%)

- Abscess (1)
- Line infection (2)

Still in situ – 6 (14%)

CVLs Removed for Poor Flow (10)

Patient	Dr	Site	Days in situ
KOK	AB	RIJ	3
KW	AB	RIJ	15
DJM	JT	RIJ	7
DK	JT	RIJ	4
YP	GK NM	LIJ RIJ	22 14
LO	NM	LIJ	3
KP	AB	RIJ	113
KB	JT	RIJ	277

Manipulations for Poor Flow

Line inserted by	Line manipulated by	When	Outcome	
JT	NM	1 day	Fell out day 25	DK
AB	AB	Same day	Removed day 57 for PD	PAE
JT	JT	3 days	Replaced at day 7	DJM

CVL Removal – Other

What	Who	Dr	Where	Days in Situ
Line infection	PAE	GK	RIJ	15
	IA	JT	LIJ	700
Abscess	YP	JT	LIJ	56
Cuff - displaced	KB	FC	LIJ	3
	DJM	AB	LIJ	26
Cuff – fell out	MA	JT	RIJ	36
	DK	JT	LIJ	25*

Temporary Lines (6) – reasons for removal

- Replace with permanent access (2)
- Poor flows (1)
- Start PD (3)
- Complication: haemothorax

Infection Data

	05/06	**06/07**	**07/08**	**08/09**
No. Infections	20	12*	10	7
Catheter days	2180	1309	1914	2434
Infections/ 1000 catheter days	9.17	9.16	5.2	2.9
Infection frequency	1:3.6	1:3.3	1:6.3	1:11.4

Patient No	**Infection No.**	**Micro**	**Days line in**	**Outcome**
1	1	CNS	622	Continued using
	2	S Aureus	699	Removed (AVF)
2	3	S Aureus	11	Continued using
3	4	S Aureus	9	Removed & replaced
4	5	CNS	64	Continued Using
5	6	CNS	16	Continued Using
6	7	CNS	73	Continued using

Exit Site Infections

2 (4%) = S Aureus

- Treated with oral a/bs
  - 1 resolved but line removed as AVF 7 days later
  - 1 resolved

4 (8%) No Growth but mucky

- 3 treated oral a/bs + bactraban
  - 1 infection resolved
  - 1 line fell out 8 days later
  - 1 line fell out 21 days later

1 bactraban only; resolved

None associated with line infections

New AVFs in 2008-9

Pt	Site	Dr	Age at formation	Days to 1st needle	Fully in use, days
IA	L brachio-cephalic	NM	14.1	49	11
DA*	L brachio-Cephalic	GK	13.7	51	26
IK	R radio-Cephalic	FC	14.9	49	4
JR	L radio-Cephalic	GK	14.1	62	9
KR	L radio-Cephalic	GK	14.1	135	12
KW	L basilic Vein trans	FC	5.8	failed	

AVFs

18 children

- 17 successful and used (48%)
- 1 failed (no plans for further)
- 16 first creation
- 2 second creations (SS, DA)

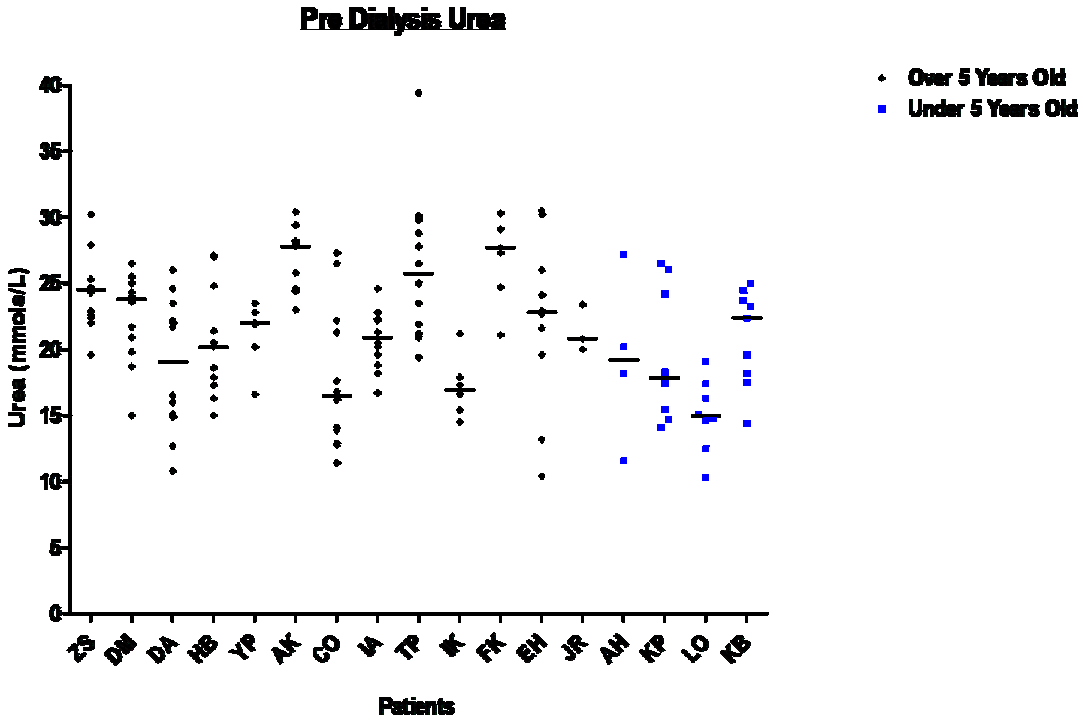
AVF formation

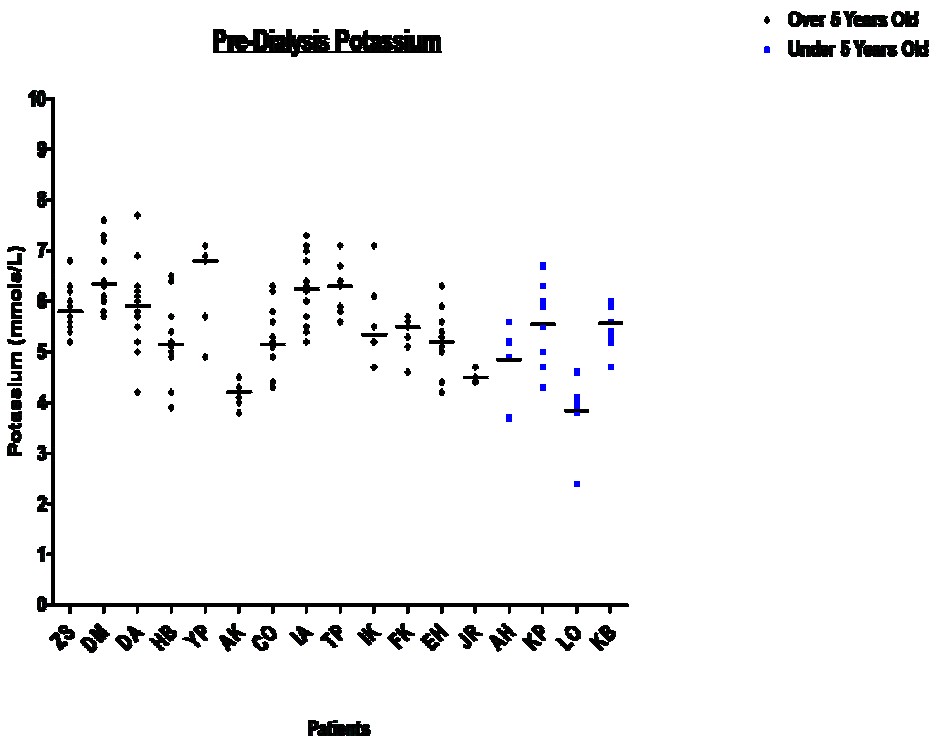
- 5 children had AVF prior to HD
- Of which 2 failed
- Range 43 to 135 days prior to HD start

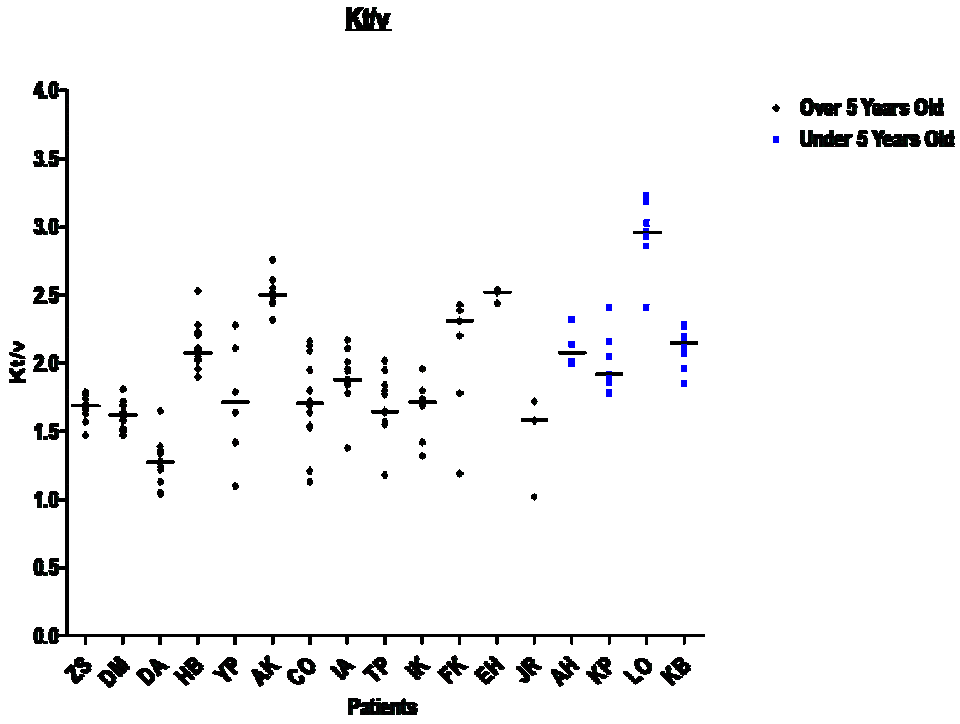
12 children had AVF formed after HD had started

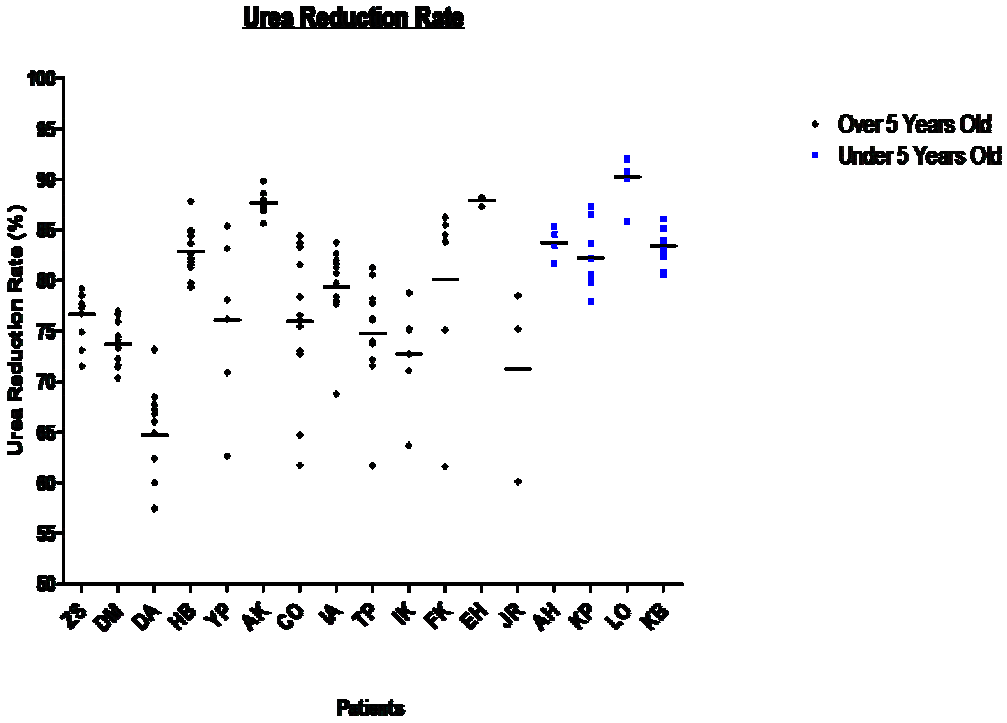
- All in use
- Median 106 days (Range 43-750 days)
- Of which 6 formed < 75 days

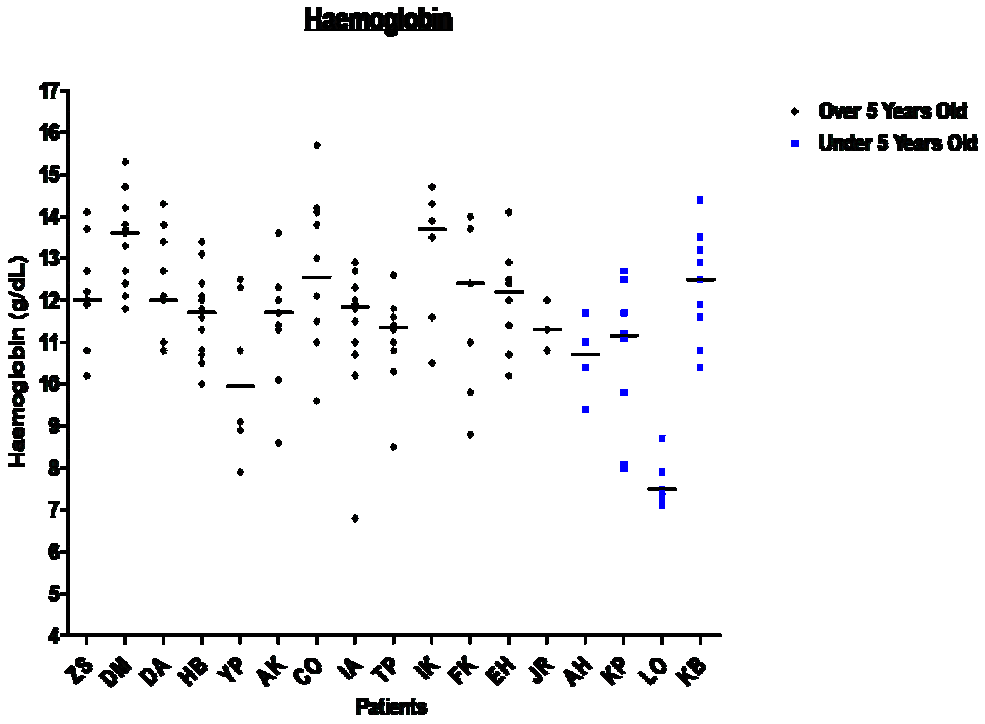
1 child had previous AVF formed 5 years previously

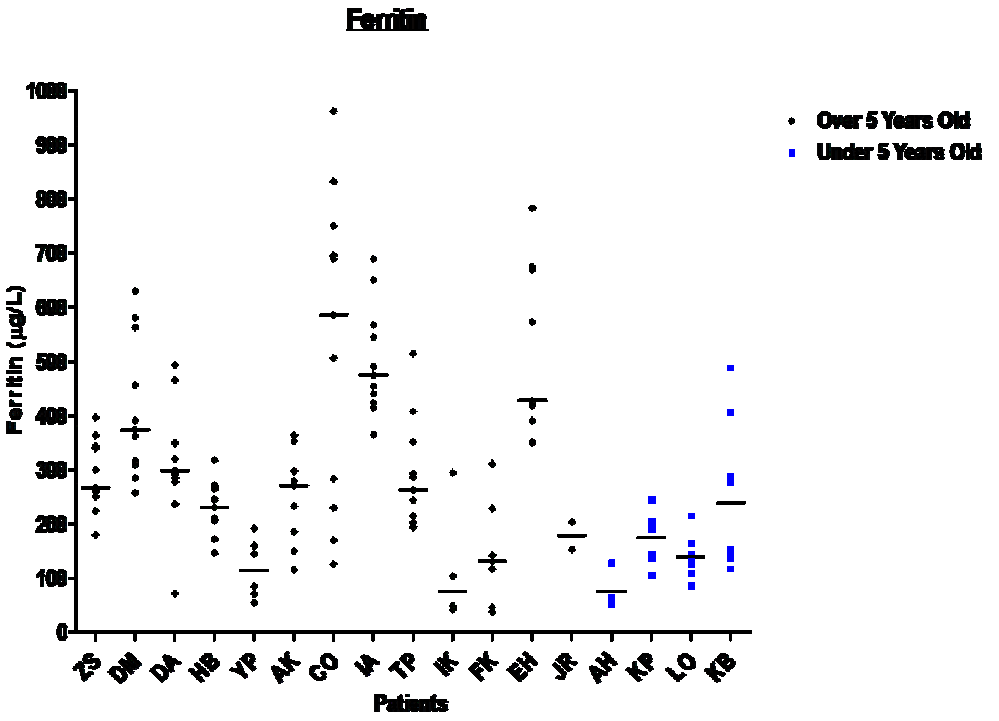


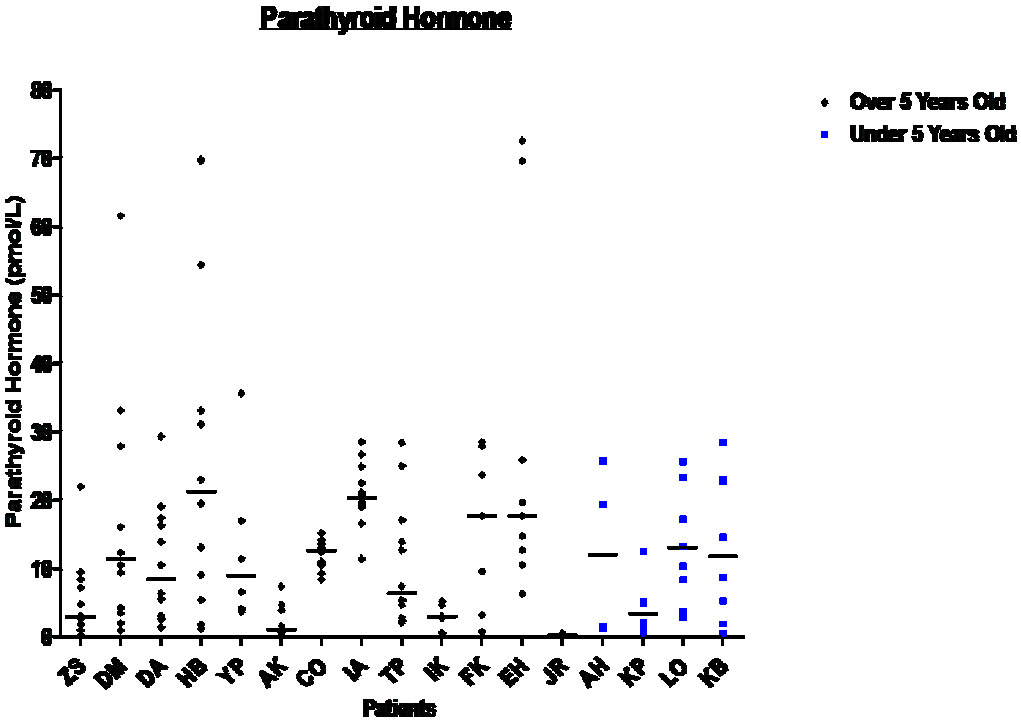

Pre-Dialysis Potassium
Over 5 Years Old
Under 5 Years Old
Potassium (mmole/L)
0
1
2
3
4
5
6
7
8
9
10
ZS
DM
DA
HB
YP
AK
CO
VA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Patients

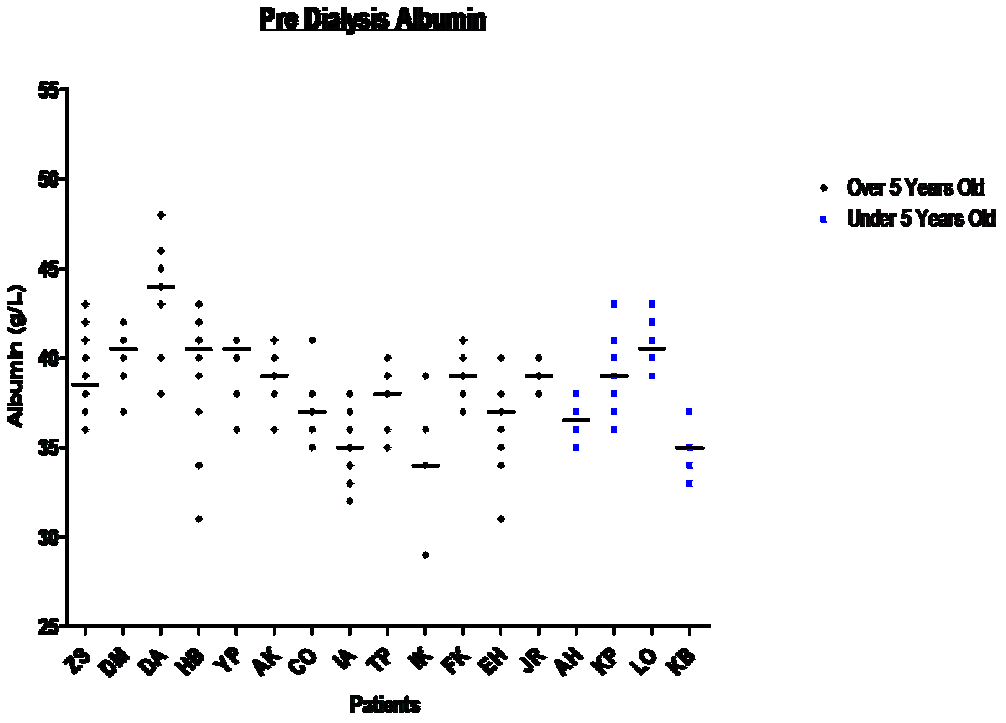

Kt/v
Over 5 Years Old
Under 5 Years Old
Kt/v
0.0
0.5
1.0
1.5
2.0
2.5
3.0
3.5
4.0
ZS
DM
DA
HB
YP
AK
CO
VA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Patients

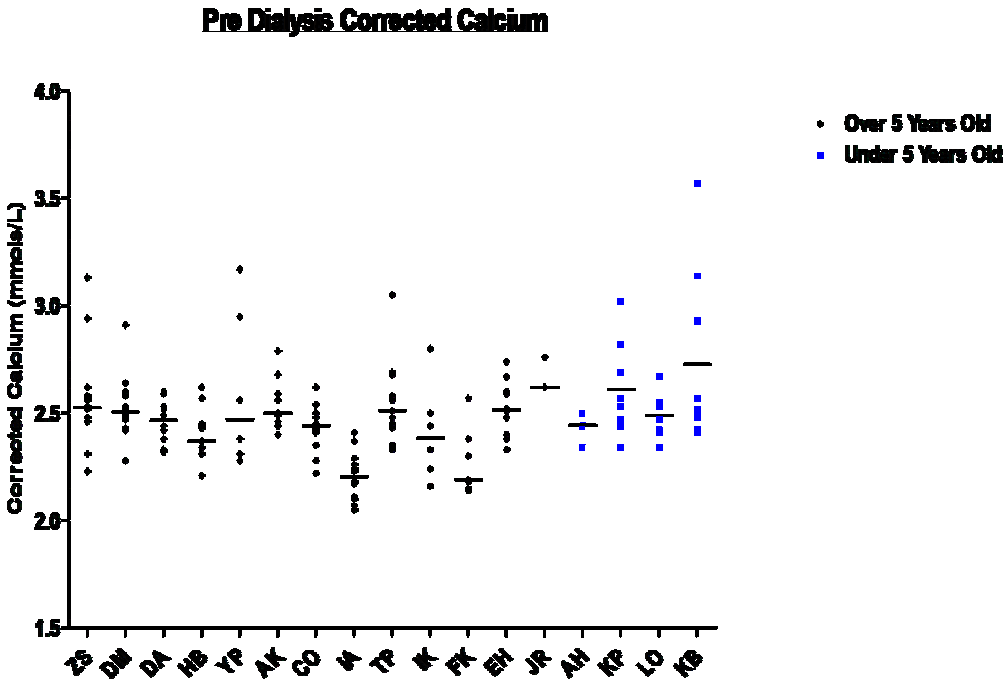

Urea Reduction Rate
Urea Reduction Rate (%)
100
95
90
85
80
75
70
65
60
55
50
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Patients
Over 5 Years Old
Under 5 Years Old

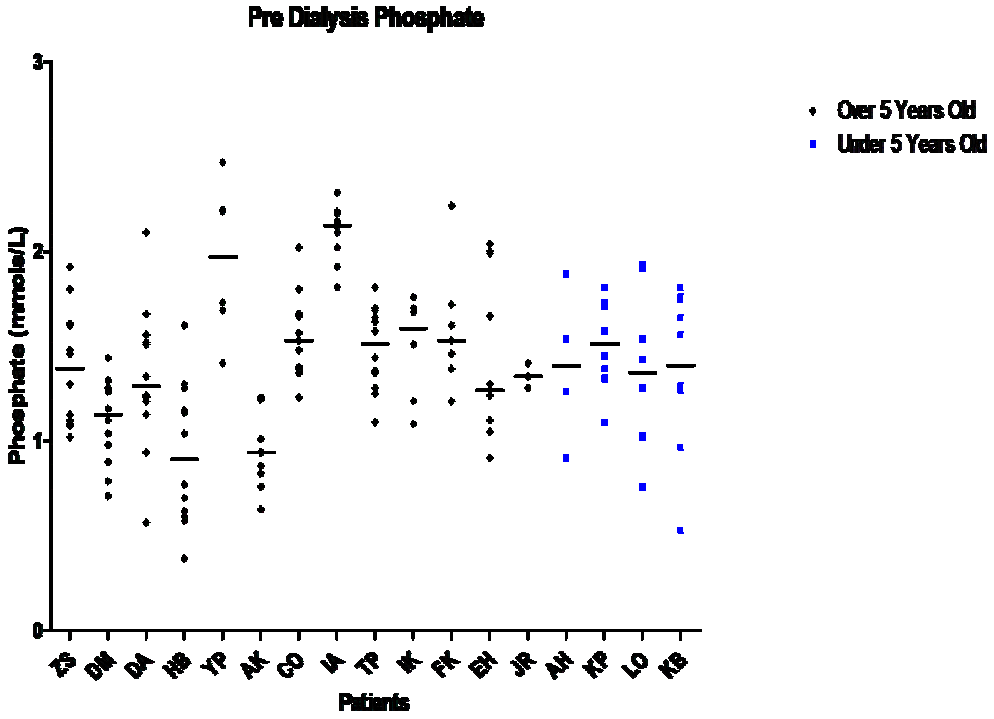

Haemoglobin
Haemoglobin (g/dL)
17
16
15
14
13
12
11
10
9
8
7
6
5
4
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Patients
Over 5 Years Old
Under 5 Years Old

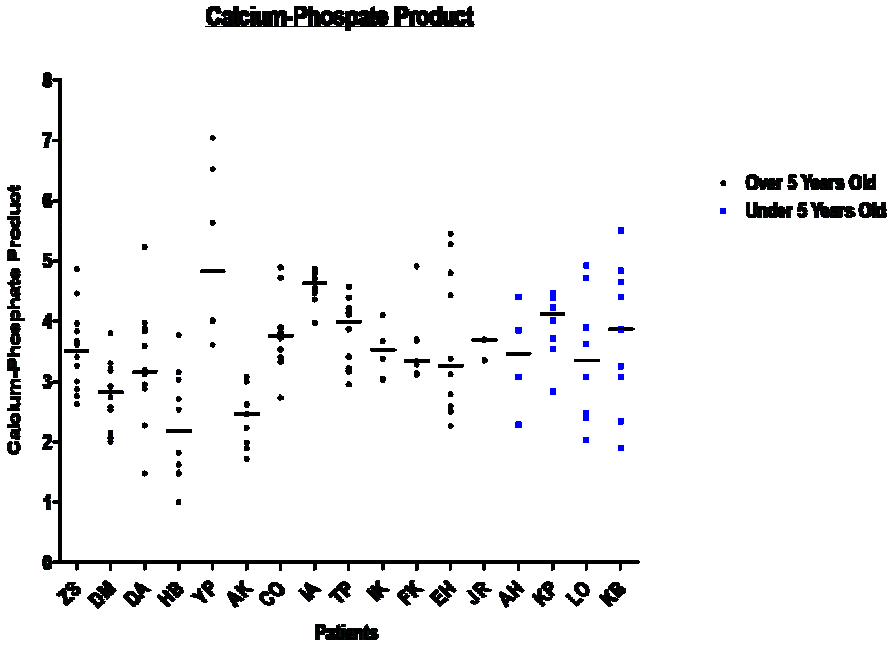

Ferritin
Ferritin (µg/L)
Patients
Over 5 Years Old
Under 5 Years Old
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB

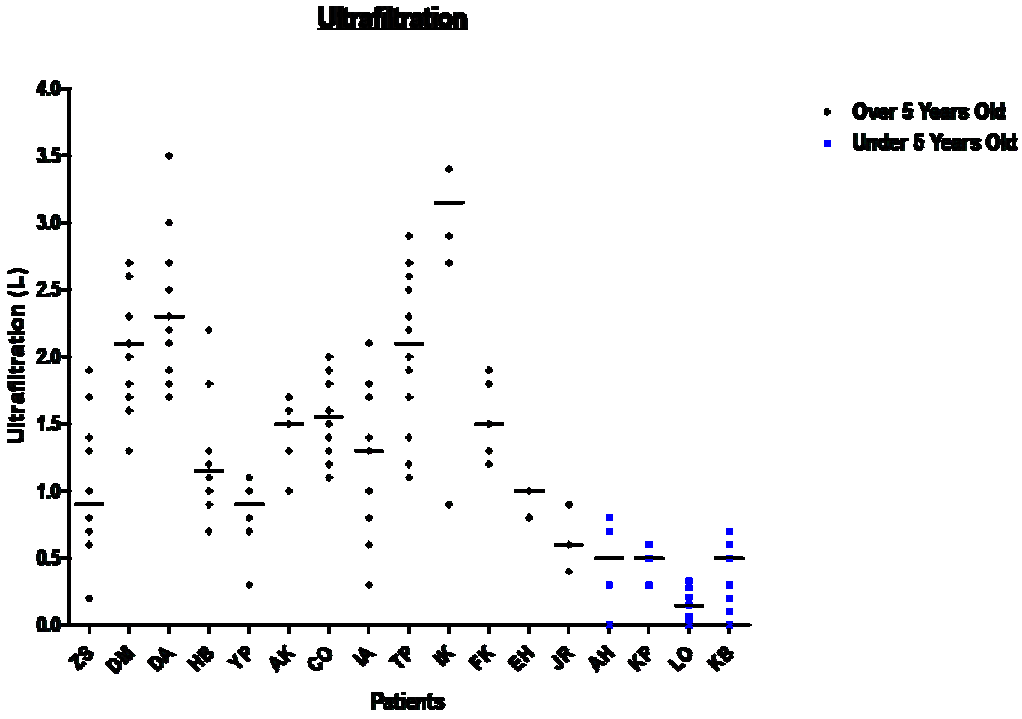

Parathyroid Hormone
Parathyroid Hormone (pmol/L)
Patients
Over 5 Years Old
Under 5 Years Old
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB


Pre Dialysis Albumin
Albumin (g/L)
55
50
45
40
35
30
25
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Patients
Over 5 Years Old
Under 5 Years Old


Pre Dialysis Corrected Calcium
Corrected Calcium (mmols/L)
4.0
3.5
3.0
2.5
2.0
1.5
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Over 5 Years Old
Under 5 Years Old


Pre Dialysis Phosphate
Phosphate (mmols/L)
0
1
2
3
Over 5 Years Old
Under 5 Years Old
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Patients


Calcium-Phospate Product
Calcium-Phosphate Product
0
1
2
3
4
5
6
7
8
Over 5 Years Old
Under 5 Years Old
ZS
DM
DA
HB
YP
AK
CO
IA
TP
IK
FK
EH
JR
AH
KP
LO
KB
Patients



2009…

- High flux dialysers
- Haemodiafiltration (HDF)
- Double filtration plasma exchange
- Immunoadsorption

Home haemodialysis…

Peritoneal Dialysis Audit

April 2008 – March 2009

Michelle Cantwell, Tanya Walton,
Cecilia McNeice, Maria Rodriguez, Suzy Doyle

Patient Demographics

34 patients on PD between Apr 08 – Mar 09

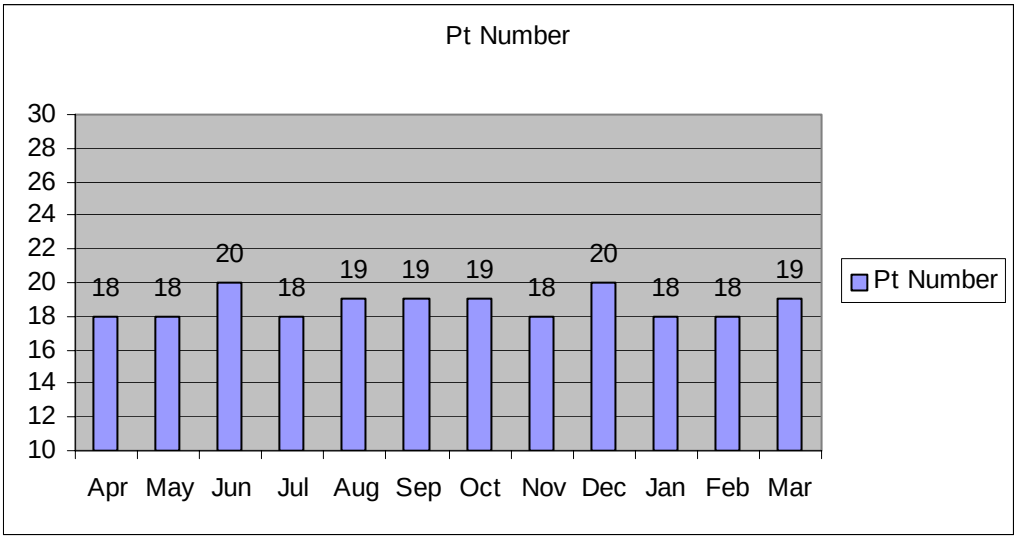
20 Male (59%), 14 Female

4 further patients have catheters insitu on 31/3 but PD not yet started – not included in total pt numbers

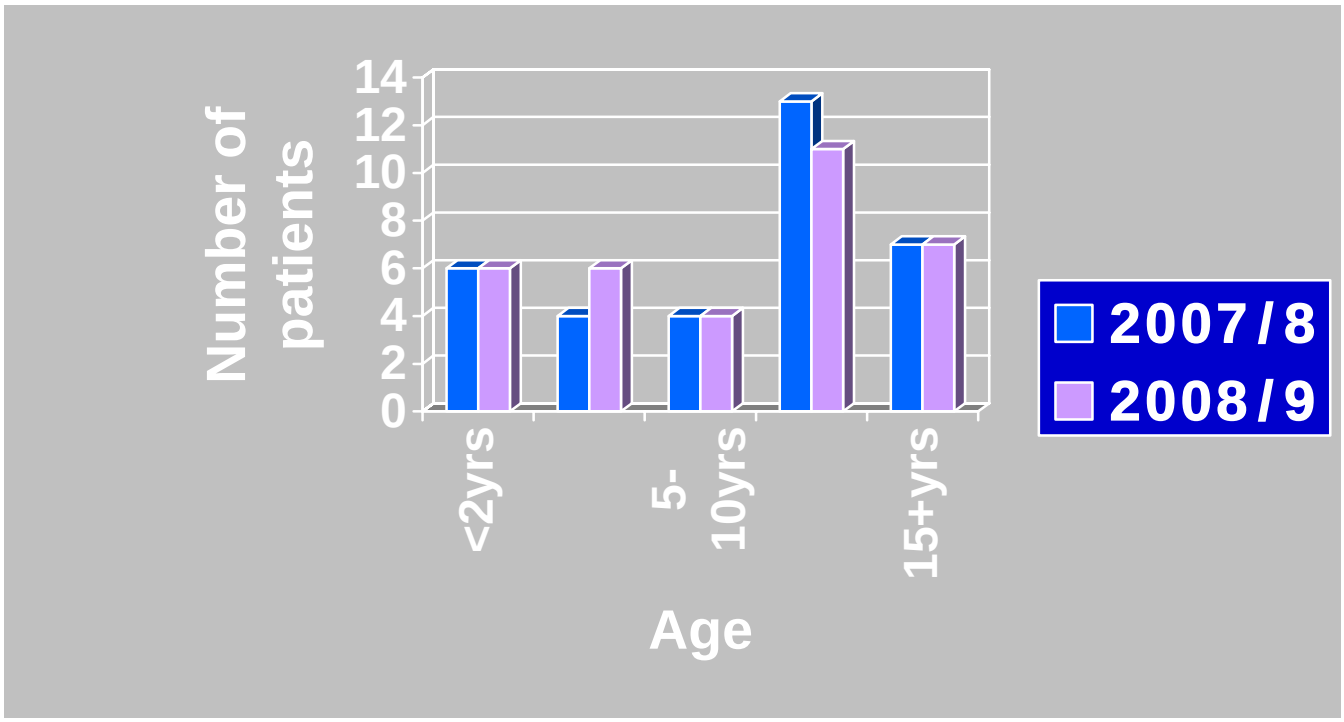
Mean age at 31/03/09 = 12 years 8 months
(range: 2 months – 17yrs 9 months)

Total of 229 PD months

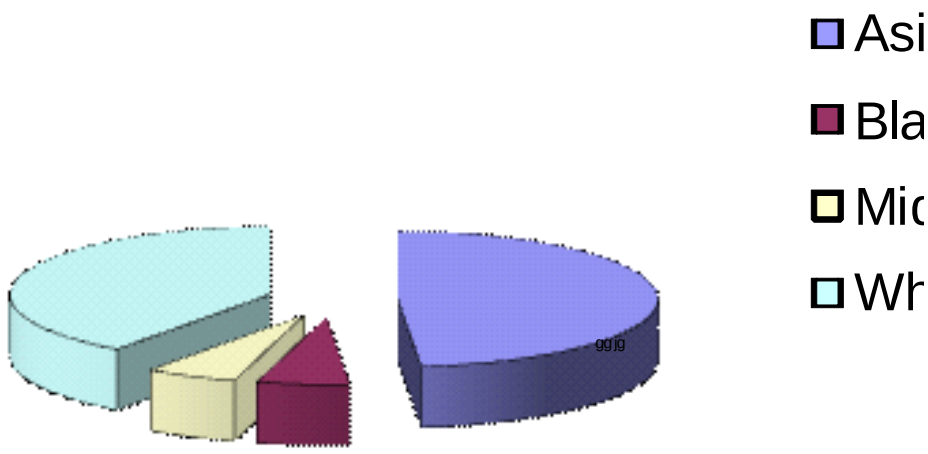
Outpatient PD Numbers



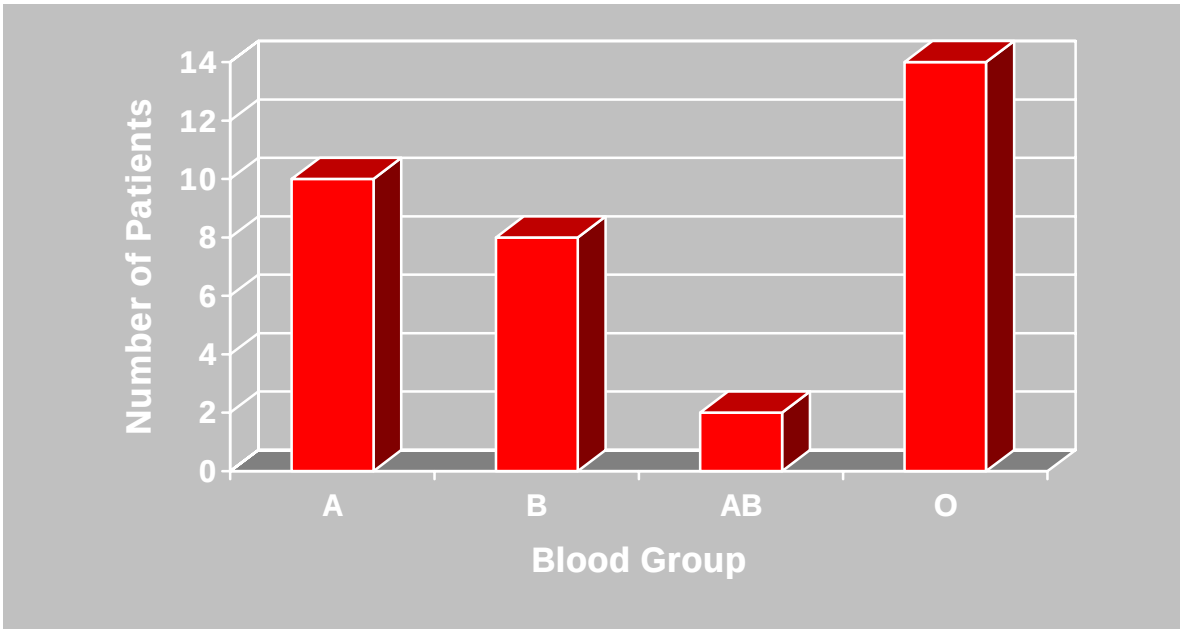
Patient Age Ranges (March '09)



Ethnicity



Blood Groups of Patients



PD fluids (on 31/3/09)

Current patients (19): All APD
19 patients Physioneal 40 (Ca 1.25)

- 0 patients Physioneal 35 (Ca 1.75)
- 11 patients (58%) Extraneal

3 patients changed between CAPD and APD

Diagnoses

• Acrodysostosis		1
• Atypical HUS		2
• Congenital Nephrotic Syndrome		3
• Dysplasia		2
• Fanconi		1
• FSGS	(20%)	7
• Jouberts		3
• Leber's Amaurosis		1
• Mitochondial Cytopathy		1
• Nephronopthisis	(18%)	6
• Posterior Uretheral Valves		2
• Pyelonephritis (chronic)		1
• Renal Vein Thrombosis		1
• Unknown		1
• Wilms Tumour		2

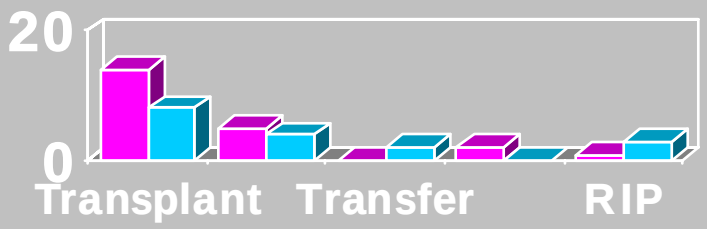
New Patient Profile

- **15 patients joined the GOSH PD programme in 08-09:**
  - 4 - returned to PD
  - 4 - presented acutely needing dialysis
  - 3 – received long term hospital PD (never
  - provided at home)

Patients Leaving PD

- **14 patients left PD in 2008/2009 (+1 temporarily)**
  - 5 patients transplanted
  - 5 transferred to Haemodialysis:
    - 3 due to PD failure / problems
    - 1 due to social reasons
    - 1 temporarily due to peritonitis
  - 3 patients died
  - 2 patients transferred to adult services

Reasons for Leaving



Chronic PD catheters

Inserted	Replaced	Removed
26 catheters:	11 catheters:	11 catheters:
15 new patients	6 catheter migration	6 transplant
11 replacements	1catheter blocked	1 social issues
	1 tunnel infection	3 peritonitis
	3 catheter leak	1 PD failure

Annual Figures 2002/3 - 08/09

	02-03	03-04	04-05	05-06	06-07	07-08	08-09
Patients	45	44	39	41	37	34	34
New Patients	20	17	14	17	18	15	15
No. Held Year End	29	23	23	18	20	20	19
Transplants	7	16	11	12	14	8	6
Transfers	3	1	2	3	0	0	2
To HD	2	5	5	6	2	5	4
To CRF				1	1	2	0
Deaths	1	1	0	0	1	1	3

Inpatient History

- Number of Inpatient Episodes: 71
- 3 patients had no admissions in audit year. Only 1 of these patients was on PD for the 12 months
- 19 families underwent PD training in audit yr = approx 130 days of CNS workload

Inpatient Admissions

Reason for admission	**No**	**%**
Diagnosis/ Catheter insertion / Training	28	39
Peritonitis / Exit Site Infections	11	16
Renal: Surgical Medical	8 7	11 10
Fluid Overload (x3 FK cath probs)	7	10
Non Renal Surgical	2	3
Other	8	11

Dialysis / Surgical Problems

- Hernias/hydroceles – 5 (repaired 3)
- Catheter probs/migration – 6
    - Associated constipation in 3
- Leaking at exit site – 8 catheters in 7 patients (3 replaced due to this)
- Subcutaneous leak – 1
- Nephrectomies 8

Acute PD catheters

- 7 patients had acute PD catheters
- 2 of these patients (28%) had catheter problems – both flipped / migrated – both needed replacing
- No leaking this year!

Peritonitis Rates by Organism

Organism	Number	%	Catheter removal
Culture neg (no eosinophils)	10	58	1
Coag negative staph	2	12	0
Staph aureus	1	6	1
Candida	1	6	1
E Coli	2	12	1
Enterococci	1	6	0

Peritonitis

	02- 03	03-04	04-05	05-06	06-07	07-08	08-09
Total episodes	?	17	17	21	19	24 + 5 eos	17 +8 eos
Culture –ve	74%	35%	59%	62%	68%	41%	58%
Staph Epi	0%	18%	0%	9.5%	16%	10.3%	12%
Staph Aureus	11%	24%	18%	0%	5.2%	10.3%	6%
Candida	4%	6%	0%	9.5%	0%	0%	6%
Enterococcus/ Coliform/ E coli	0%	0%	6% VRE	14.2%	5.2%	7%	18%
Strep	0%	0%	6%	0%	0%	0%	0%
Pseudomas	0%	6%	6%	4.8%	0%	10.3%	0%
Citrobacter					5.2%	0%	0%

Peritonitis

Current BAPN Guidelines (2007)

- Peritonitis rates should be less than 1 episode per 12 patient months
- 17 episodes of peritonitis (-eosin) in 12 / 33 patients (36% of patients)
- Total PD patient months = 229
  = 0.89 episodes per 12 patient months

Associated Factors leading to Peritonitis

- 6 episodes were in the under 2 yrs. 2 of these were secondary to line breaks
- 1 episode - child with severe special needs
- 1 episode secondary to Exit site col (SA)
- 2 episodes post op (septic)

- Congrats to CK, ER and JSF's families – high risk pts but peritonitis free

Culture Neg Episodes (eos–ve):

NAME	WC COUNT	SYMPTOMS	POLY %	EOSIN TEST	HX	2/52 AB?
EM	95-226	ASYMPTOM	30-80	YES	PD BREAK	YES
YSF	120	ASYMPTOM	0	NO	PD BREAK	YES
OT	325	PYREX, CRP, FLOPPY	60	NO		YES
	1700	APYREX, CRP, EPIGASTRIC PAIN	65	YES	? PANCREATITIS – NO LIPASE TAKEN	YES
FJ	85-110	APYREX, WELL, MILD ABDO PAIN	85	YES		6 DAYS

Culture Neg Episodes (eos–ve):

NAME	WC COUNT	SYMPTOMS	POLY %	EOSIN TEST	HX	2/52 AB?
EM	95-226	ASYMPTOM	30-80	YES	PD BREAK	YES
YSF	120	ASYMPTOM	0	NO	PD BREAK	YES
OT	325	PYREX, CRP, FLOPPY	60	NO		YES
	1700	APYREX, CRP, EPIGASTRIC PAIN	65	YES	? PANCREATITIS – NO LIPASE	YES

					TAKEN	
FJ	85-110	APYREX, WELL, MILD ABDO PAIN	85	YES		6 DAYS
AJ	130	PYREX, CRP	75	NO	UNKNOWN ORIGIN	DIED
TH	120	VOMIT, MILD ABDO PAIN ON PD	5	NO – MACHINE BROKEN	RELAPSE HUS	YES
FK	WC++ CLUMPS	APYREX, HYPOTENSIVE		YES	48 HOURS POST OP	CATH OUT
DK	12400	CRP, PYREX	85	NO	PD LEAKING	YES
	125	APYREX	78	YES		YES

Exit Site Infections (red/inflammed/exudate)

Organism	No. of Infections	**No.treated with AB's**	**Catheter Removed**
Staph aureus	7 (x 3 same pt)	7	0
Coag neg staph	1	1	0
E Coli	1	TOPICAL	0

Exit Site Infections (red/inflammed/exudates)

	04-05	**05-06**	**06-07**	**07-08**	**08-09**
Staph Aureus	8	14 (include col)	7	5	7
Pseudomonas	5	5	3	2	0
MRSA	0	1	1	0	0
Catheter removals * With peritonitis	4 3 x SA* 1x pseud*	2 1 X SA 1 X mrsa *	3 2 x pseud 1 x mrsa	2 1 x SA*	0

Exit site colonisations
(+ve swab, BUT dry and clean)

Organism	NUMBER	Treated with ABs
Staph	4	4 (2 – now long term)
AureusColiform	3	0
Candida	2	2
Pseudomonas	2	1 (PO)
Acinetobacter	1	0
Diptheroids	1	0

Nasal Colonisation

5 patients had nasal Staph Aureus carriage:

- All received topical treatment
- 1 patient had cocurrent staph aureus at exit site (colonised)
- 1 patient had cocurrent staph aureus at exit site (infected)

Community Visits

- Home Visits - 34 Total
  19 patients - PD families
  4 patients - PD not started

- School Visits - 9

- Multidisciplinary Team Meetings - 3
- Adult transition visit - 1
- Community PD Training - 2

Adequacy

- 6 patient Adequacy Tests performed so far:
- Kt/V ranged from 1.77-12 L/wk/1.73m^2
- All patients achieved K/DOQI (2006) and BAPN (2007) recommendations of 1.7 L/wk/1.73m^2

Conclusion

- Increase in eosinophilic peritonitis rates (OR an increase in screening)
- Increase in under 2s requiring PD
- More complex cases / teaching challenges – [a] demanding on CNS time
- Increase in mortality
- Increase in chronic PD catheter problems

Plans for 2009 and onwards

- Surgical audit of catheter problems
- Adapt ESI protocol to include gent cream
- Eosinophil study (continuing)
- Continue to contribute to International PD Registry / Publications
- To establish protocol for CNS team to order renal USSs / xrays for PD, pre tx workup and post tx needs

Thanks…….

- Tanya Walton
- Cecilia McNeice
- Maria Rodriguez
- Suzy Doyle

11. NURSING REPORT

The renal unit continues to lead in the development of all members of staff to reach their maximum potential. A higher level of practice is encouraged working within a model of a collaborative interprofessional framework.

11.1 STAFFING AND CLINICS

Nurse Consultant	*Eileen Brennan*
Ward Sister	Sr. Lucy Thomas
New ward sister	Sarah Matthews
Clinical Nurse Specialists	Transplants Sr. Suzanne Bradley
	Sr. CRF Jo Pullen
Sr. LRD Transplant coordinators	Maria Scanes & Carol Jennings
	Sr. Plasma Exchange Liz Wright
	Sr. PD Michelle Cantwell
Sisters	Sr. Liane Pilgrim, Haemodialysis
	Mr. David Fisher, Nurse Counsellor
	Sr. Trish Evans, Practice Educator

Clinics

Nurse Consultant Clinic

Nurse led	Transplantation	Daily reviews
	LRD	Weekly
	Adolescent transition	monthly
Nurse Consultant	ABPM Hypertension out patients clinic to include ward and hospital follow up following discharge Weekly outlier round at GOSH for hypertensive children Weekly Phone clinic for consultation of hypertensive children in the community	
Nurse Counsellor	Work up for transplantation	Weekly

11.2 Publications

Eileen Brennan: Contribution to NHS Nice guideline Diarrhoea and vomiting in children April 2009. Guideline 84

11.2GENERAL INFORMATION

Victoria ward establishment
1 Band 7 Practice educator
2 Band 7 Ward Sisters
9 Band 6 Senior Staff Nurses
19 band 5 Staff Nurses
2 Band 3 Health Care Assistants
1 Band 4 Health Care Assistants
1 Housekeeper

Haemodialysis Unit establishment comprises:
1 Haemodialysis /Plasma Exchange CNS Band 8
1 Band 7 Sister
2 Band 6 Senior Staff Nurses
2 Band 5 Staff Nurses (rotates to Victoria ward for one week per month)
Of whom1 further Band 5 post has become available this week with the amalgamation of vacant part time posts on Victoria
1 Band 3 HCA
0.5 Housekeeper (vacant for 9 months)

A rotation program continues to grow from Victoria ward to enable the training of nurses in haemodialysis. After spending 6 months on the unit they rotate back to dialysis for a week every two months to maintain their skills.

Haemodialysis is currently fully established, but the increased activity of the haemodialysis unit continues to put this area under pressure. 2 additional posts may have been found for this area. The haemodialysis unit has been relocated and refurbished on 8A with ten dialysis stations. New dialysis technologies have been integrated into the unit with the purchase of state of the art dialysis machines.

The nursing team continues to attempt to deliver a service which is chronically under funded. All the areas provide a very high standard of nurse led services guiding and teaching junior doctors to care for children with renal conditions. The service is often over stretched in all areas and at times the demands of the service especially in the haemodialysis unit are over stretched. This in itself results in the delivery of a sub standard level of care to other children. This at times compromised the safety of the unit where the risk of errors in treatment decisions is increased. This has been recorded as high risk to management board and is a priority area for an increase in staff.

We continue to refuse a number of admissions due to staff shortages. UCH have provided a service of Plasma Exchange for a number of sessions for the

unit and other areas at GOSH. This help comes at considerable cost to the trust however it has provided a life line to our service, we should not over look the fact that this is an adult service and is not best practice for children.

11.4 Events 2008/9

- GOSH assisted in the organization of the annual Paediatric Nurses Nephrology Conference in Dublin. It was attended by 110 nephrology nurses representing every unit in England, Wales, Scotland, Northern and Southern Ireland.

- The team in the unit continues to lead and support the Electronic prescribing.

11.5 EDUCATION

The Nephro/Urology course which previously ran yearly has been redeveloped into a work based learning module. This course was stopped in September 2007 as the Lecturer Practitioner moved on to be a modern matron in a different area of the hospital. Trish Evans, Practice Educator and Liane Pilgrim, Haemodialysis Sister, redeveloped this module into a New Paediatric Renal course titled: Caring for a Child or Young Person with Renal Disease: Developing Skills and Competence in Professional Practice through Work-Based Learning. The main focus of the unit is to enhance the student's ability to undertake a systematic assessment of a child/young person with renal disease and provide optimum evidence based care in conjunction with the inter-professional team. The module, which is an accredited component in the BSc (Hons) Professional Practice: Children's Nursing pathway at London South Bank University, runs over a period of three months and the theoretical assessment comprises of two components: A reflective log and an Oral Viva. The first course ran in November 2008 with 6 in house staff nurses being supported on it and 3 external applicants; 2 from Saint Mary's London, and 1 from Bristol Children's Hospital. The course had a 100% Pass rate and evaluated extremely well. Although students had difficulty with the Reflective Logs (not being succinct enough within word limits and challenging writing techniques) the Oral Viva increased overall marks noticeably thereby demonstrating good level of patient knowledge & care provided.
The next course is due to run in March 2010 and will link into the Cardiac work based learning module for core university sessions.

- Competencies based supervised 'In-Charge' Study Day for senior band 5's with competencies
- Foundations of Paediatric Renal Nursing – In house certificated course with workbook and competencies
- The ward has consistently high scores for nursing performance indicators (name bands, cleaning charts). Also have good results in recording of central lines and central line infections.

- Currently taking part in transforming care on your ward project with transformation team. Patient status at a glance board in final stages. About to start SBAR handover project.
- A competency framework for Peritoneal Dialysis has been fully implemented using workbook and Competency skills log developed by the sister Sarah Matthews as a result of a risk assessment plan.
- Staff development days for band 5 & 6 continue 6 monthly
- Clinical supervision provided to all band 6 grades and above
- NVQ training and assessment provided for HCA's
- High dependency nursing, we have had a very successful year with nurses rotation to haemo/clinics and PICU to gain further valuable experience and expertise
- 1 nurse currently studying for their Msc in Advanced Practice
- 90% of the ward nurses are being supported through degree pathway

The Team continues to develop in new areas this year, phlebotomy and canulation and haemodialysis has been exemplary. A further two senior band 5's have rotated from Victoria Ward to the Haemodialysis unit and completed their competency workbooks making a total of 2 band 5's rotating and 2 band 6's rotating to maintain their skills. A band 6 is currently on rotation for 6 months. Two Haemodialysis nurse rotates to Victoria to maintain current skills and gain nurse in charge skills.

The role of the Nurse Independent prescribers continues to develop the nurse led service in this area and Liane Pilgrim has qualified this year as a new prescriber. Lucy Thomas also qualified as a new prescriber this year and is currently applying to undertake her Masters dissertation.

We now have 5 non medical prescribers within the Renal Unit and 1 due to commence the course next year.

Non medical prescribers
Eileen Brennan (Lead in prescribing for GOSH)
Liz Wright
Michelle Cantwell
Liane Pilgrim
Lucy Thomas
Maria Scanes (to start the course 2010)

The following graphs demonstrate the mandatory training requirements set by the trust as well as the essential clinical components to enable individual members of the nursing team to fully function according to their KSF guideline. All the training is carried out by and/or supported by the Practice Educator.

11.6 Presentations

Eileen Brennan: Prescribing in practice. Special interest group Dublin March 09

Eileen Brennan: Chaired. Annual Conference RCN Special Interest Group for

Paediatric Nephrology. March 2009 Dublin

Carol Jennings: Best Interests; Small children Big decisions June 09 Presentation at 40th EWOPA Meeting in Leuven Belgium (European Working Group for Psychosocial Care of Children in Chronic Renal Failure!)

11.7 ACADEMIC ACHIEVEMENTS

Post Graduate Certificate in Non-Medical Prescribing:
Liane Pilgrim, Nurse Practitioner, BSc (Hons) and Lucy Thomas, Nurse Practitioner, BSc (Hons)

BSc (Honours) Professional Practice: Children's Nursing
Sarah Matthews, Ward Sister

BSc Professional Practice: Children's Nursing
Jenny Tanton, Senior Staff Nurse

.

11.8 Outreach commitments

Eileen Brennan: nephrology	Chair of the special interest group for paediatric
	Chair for ambulatory forum at the RCN NICE guidelines for RCN Workforce Planning
Michelle Cantwell:	Contribute to the International Pediatric PD Network (IPPN): 41 patients registered to date, with 6 monthly patient updates and all infection episodes entered.

12. Dietetic Report

April 2008 – March 2009

12.1 Staffing

There are currently 3.0 wte dietitians working with the renal unit:

Monica Adhikari	Specialist dietitian (April – August 2008)
Shelley Cleghorn	Specialist dietitian
Marcelle Glantz	Specialist dietitian (to December 2008)
Louise McAlister	Specialist dietitian
Priscilla Natalia	Specialist dietitian (to June 2008)
Graeme O'Connor	Specialist dietitian (from September 2008)
Vanessa Shaw	Head of Dietetics

Due to CRES savings imposed this financial year the Team Leader post was held vacant. Our establishment of 3.0wte was reduced to 2.4wte. This had an impact on the service we could provide. Whilst we could maintain a service to the wards and provide support for the families at home through regular telephone contact, the haemodialysis unit and outpatient clinics were often not covered when staff were absent.

We are still understaffed according to The British Association for Paediatric Nephrology review (2001) that suggested an ideal staffing level of 1 post per 2.5-3 million population, equivalent to 4.7 wte dietitians for the GOSH population.

12.2 Teaching and Education

Vanessa Shaw is the Education Officer of the British Dietetic Association's Paediatric Group and is Course Leader for the Paediatric Dietetics Modules, awarded Master's level accreditation with the University of Plymouth from January 2008

The Dietetic Renal Team was involved with in-house education and training events delivered to the multi-disciplinary team on nutrition and dietetic topics

Vanessa Shaw teaches at Dubai Hospital with Dr Kjell Tullus as part of the visiting consultant's programme

Vanessa Shaw, Priscilla Natalia and Shelley Cleghorn lectured on Premature Infant Feeding, Nutrition Support and Feeding Difficulties to Dietetic students (undergraduate and postgraduate) at Kings College London and London Metropolitan University

Vanessa Shaw presented at the Leeds Course in Clinical Nutrition September 2008

The team presented at the Paediatric study days for dietetic students at GOSH

The team keeps active membership of the Paediatric Renal Nutrition Interest Group

12.3 Publications, Presentations, Awards

Vanessa Shaw was made a Fellow of the British Dietetic Association in recognition of outstanding services to the profession

Vanessa Shaw was awarded an MBE in the Queen's birthday honours for services to children's healthcare

Vanessa Shaw contributed to the KDOQI Clinical practice guideline for nutrition in children with CKD: 2008 update

12.4 Improving patient care

Completed the competencies for prescription of Paediatric Dialyvit under Patient Group Directions (PGD)

Completed a renal transplant care guideline to provide consistency of care by the dietitians looking after these children

Completed guideline for usage of PO4 binders for dietitians

Updated renal section of ward nutrition folder

Vanessa Shaw is a member of the Renal Unit board

Development of resources for patients and carers

The following diet booklets have been produced or updated over the last 12 months

- Low protein and phosphate weaning
- Moderate protein and phosphate weaning
- Low sodium weaning
- High energy