GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS TRUST

RENAL UNIT TENTH ANNUAL REPORT

April 2009 to April 2010

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1. INTRODUCTION

The tenth annual report describes the staffing, facilities, workload, clinical audit results and teaching undertaken by the renal unit in the year between April 2009 and April 2010.

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 General Manager. The Unit has monthly multidisciplinary board meetings, with a team composed of a modern matron, dietician, pharmacist, nurse specialists, service manager and ward sister, with support from finance and contracts.

1.2 THE RENAL UNIT

Clinical Unit website:
http://www.gosh.nhs.uk/gosh/clinicalservices/Nephrology/Homepage

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 561 admissions to the Renal ward (excludes day case admissions to programmed investigation unit), 7061 outpatients, 35 new renal transplants, 34 patients on chronic haemodialysis and 40 patients on chronic peritoneal dialysis. These numbers represent a very high level of activity with 35 being the largest number of transplants undertaken by the Unit in any year to date. Having obtaining clinical ethical approval, we commenced the ABO incompatible renal transplantation programme with first successful renal

transplantation in August 2010. It was also the busiest year ever for the Haemodialysis Unit (number of sessions).

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 closely located. Day cases are also seen on the Medical Day Care and Programmed Investigations Unit. As well as renal replacement therapy (RRT), 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 patients approaching the need for RRT (CKD stage 5) 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 CKD 5 and transplant 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 counsellor, 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 (%)								
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 (%).								
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 Lesley Rees	12 PAs in Paediatric Nephrology (Lead clinician)
Dr Rukshana Shroff	12 PAs in Paediatric Nephrology
Dr Kjell Tullus	12 PAs in Paediatric Nephrology
Dr William van't Hoff	8 PAs in Paediatric Nephrology, and 4PAs for lead for the Medicine for Children's Research Network
Dr Detlef Bockenhauer	7 PAs in Paediatric Nephrology, 5PAs for research
Dr Steven Marks	12 PAs in Paediatric Nephrology
Dr Daljit Hothi	7 PAs in Paediatric Nephrology
Dr Sarah Ledermann	Associate Specialist, 6 PAs in Paediatric Nephrology
Prof Adrian Woolf	Full time academic appointment, moved from ICH in Jan 2010
Dr Paul Winyard	Reader, Full time academic appointment and now ICH lead
Dr David Long	Senior Lecturer, academic appointment
Prof Robert Kleta	Potter Professor of Paediatric Nephrology
Dr Aoife Waters	Full time academic appointment

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 2 ST2 and 5 ST4 posts
Nurse Consultant	Eileen Brennan
Ward Sisters	Sister Lucy Thomas 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

Academic Unit website:
http://www.gosh.nhs.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 outcome 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 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, headed by Professor Adrian Woolf and 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.

Professor Woolf left for Manchester in January 2010 and the Unit is now lead by Dr Paul Winyard, with able support from Dr David Long (Kidney Research UK Senior Fellow). Our aims are to build upon scientific excellence with a broader range of translational projects across ICH-GOS and partnership/collaborations with other local renal units including the Evelina Children's Hospital and Royal Free Centre for Nephrology. We are also keen to develop clinical academics (both Paediatric or Adult-focussed) and encourage potential applicants to contact us to discuss possible projects.

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, with the Fetal Medicine Unit at University College Hospital and the Centre for Nephrology at the Royal Free Hospital.

Projects within the Unit included 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 2009-2010 our research program was supported by 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 UCL Institute of Child Health Nephro-Urology Unit (2009-10)?

Senior Staff:

- Adrian S Woolf (Professor of Nephrology and Head of Unit; moved to Manchester in January 2010)
- Paul JD Winyard (Reader in Paediatric Nephrology and Head of Nephro-Urology Unit from January 2010)
- Lesley Rees (Reader in Paediatric Nephrology)
- David A Long (Kidney Research UK Senior Fellow)

Other Postdoctoral Scientists:

- Jolanta E Pitera (Moved to Molecular Medicine Unit, January 2010)
- Karen L Price
- Maria Kolatsi-Joannou

Scientists Doing PhD Theses:

- Shun-Kai Chan (KRUK Studentship)
- Jennifer Huang (KKR Studentship)

Clinicians Doing PhD or MD Theses:

- Shazia Adalat

Research Nurse:

- Ambrose Gullett

Visiting Lecturer:

- Jenny Papakrivopoulou

Unit Administrator:

- Jazz Dinza

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. OUTPATIENTS

2.1 WEEKLY OUTPATIENT CLINICS

	CLINIC	CONSULTANT
MONDAY P.M.	Low Clearance/Dialysis	Dr Rees Dr Shroff Dr Ledermann
TUESDAY A.M.	Generalised and specialised Nephrology (Tubular)	Dr van't Hoff Dr Bockenhauer
	Generalised and specialised Nephrology (hypertension/vasculitis)	Dr Tullus
	Transplant Clinic (Weekly)	Dr Marks
	Pre-Transplant Clinic (Monthly)*	Dr Marks
	Transplant Surgeon's Clinic Nephrotic Syndrome	On-call surgeon Dr Hothi, Dr Waters, Dr Bockenhauer, Dr Tullus
WEDNESDAY A.M.	General Nephrology	Dr Rees Prof Kleta Dr Marks Dr Shroff Dr Hothi
	Infant CKD	Dr Ledermann
	Renal Genetics	Professor Woolf**
THURSDAY A.M.	Transplant clinic	Dr Marks Dr Shroff Dr Bockenhauer
	Haemodialysis clinic (monthly)	Dr Rees Dr Shroff
	Hypertension/vasculitis/lupus	Dr Tullus
FRIDAY A.M.	Joint clinic with Rheumatology (monthly)	Dr Tullus

* Adolescent transition clinics are held monthly – see Section 10.2 for details
** This clinic came to an end in December 2009 when Professor Woolf left to take up a post at Manchester University.

2.2 NUMBER OF OUT PATIENT ATTENDANCES

The total number of out-patient attendances to the renal unit was 7061. 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**	**2009-10**
Transplant	625	771	873	736	799	743	858	897	1034
Nurse Led Transplant	443	506	734	542	518	467	524	1387	1328
Low Clearance/ Dialysis	507	543	859	610	636	638	665	694	749
PreTx & GKRLTX						93	71	84	119
General and Specialist Nephrology	3243	2467	4065	3199	3444	3194	3382	3464	3113
Nephrotic Syndrome	405	481	692	468	400	321	344	389	446
Stone	69	50	88	53	40	40	23	36	79
Blood Pressure Monitoring			23	51	65	78	94	109	193
Total	**5292**	**4818**	**7334**	**5674**	**5902**	**5738**	**5962**	**7060**	**7061**

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	DH	3	12	Approx 50-60
Whittington	LR	4	1	10
QE II, Welwyn Gdn City	DB	28	3	30
Lister	KT	35	2	Approx 30
Colchester*	KT	50	-	-
Oxford	WvH	56	6	70-80
Malta**	-	-	-	-
Reading	WvH	40	3	30
Royal Free***	RST			

* The Outreach Clinic at Colchester did not run in the last year though it is hoped that it will be re-established.
** This has not run since Dick Trompeter's retirement from NHS practice at GOSH. The plan is to re-establish this service in the coming year.
*** An adolescent transition clinic run by Dick Trompeter has been established for nephrotic syndrome patients at the Royal Free Hospital.

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
2009-10	68	54	1	22	145

One transplant patient (1.9%) suffered a significant complication. She became hypotensive and underwent surgical exploration for presumed intra-abdominal haemorrhage, although this may well not have been biopsy-related bleeding. This patient subsequently had uneventful embolization for post-biopsy arteriovenous fistula. Another transplant patient had an inadequate biopsy specimen.
One patient who underwent biopsy of a native kidney (1.5%) developed haematuria requiring catheterisation.
There were no other major complications of renal biopsy in 2009-10.

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
2009-10	5	55	60

There were 19 complications (32%) of permanent haemodialysis catheter insertion procedures in 2009-10.

- eight lines had poor flows at dialysis (and another clotted during dialysis)

- two patients had early (<30 days) infection (requiring line removal)
- three lines were accidentally removed or partly pulled
- there were three instances of malposition
- one catheter developed a late intravascular kink, which hindered dialysis and required correction
- in one coagulopathic patient, persistent oozing from the neck wound required transfusion of blood and fresh frozen plasma

3.3 ARTERIAL INTERVENTIONS

Angiographic procedures are performed for patients with suspected or confirmed renovascular hypertension and associated arterial disease.

Year	Diagnostic (RVH)	Interventional (RVH) incl. angioplasty and/or stenting	Total
2000-1	9	0	9
2001-2	5	6	11
2002-3	17	9	26
2003-4	16	4	20
2004-5	7	5	12
2005-6	11	9	20
2006-7	7	11	18
2007-8	10	13	23
2008-9	8	19	27
2009-10	11	12	23

RVH = renovascular hypertension

In one patient a stent used to treat a complex renal artery aneurysm thrombosed, and nephrectomy was performed. One patient 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
2009-10	5	3	3	0	17	28

There were no complications of venous interventional procedures in 2009-10.

4. INPATIENTS

4.1 ADMISSIONS TO VICTORIA WARD

Age (yrs)	2001-2002		2002-2003		2003-2004		2004-2005		2005-2006		2006-2007		2007-2008		2008-2009		2009-2010	
	Total No	**%**	**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	**87**	16
2- <5	**81**	13	**87**	16	**66**	11	**106**	17	**84**	16	**105**	19	**90**	16	**81**	14	**99**	18
5- <10	**143**	23	**119**	21	**116**	20	**146**	23	**110**	21	**120**	22	**101**	18	**134**	23	**109**	19
10- <15	**214**	35	**176**	31	**191**	33	**167**	27	**153**	30	**169**	30	**161**	29	**153**	27	**137**	24
15 +	**153**	25	**137**	24	**153**	26	**124**	20	**97**	19	**88**	16	**148**	26	**124**	21	**129**	23
Total	**618**	100	**563**	100	**585**	100	**622**	100	**517**	100	**554**	100	**561**	100	**577**	100	**561**	100

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**	**2009-10**
Victoria	618	563	585	622	517	554	561	577	561
Other	343	307	316	317	317	349	249	261	118
Total	961	870	901	939	834	903	810	838	679

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)

There were 261 attendances at the low clearance clinic. 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 of 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 on 1/4/10 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
2010	1	5	2	1	7	16
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
2010	0	0	1	0	0	1
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
2010	4	2	1	3	4	14
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
2010						

5.3 CHRONIC PERITONEAL DIALYSIS

There were a total of 40 patients in 2009-2010. 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**		**2009-10**	
Age, yrs	**total**	**%**	**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	**12**	30
2-5	**3**	8	**6**	15	**5**	10.8	6	16	**2**	5	**5**	12	**4**	12	**6**	18	**7**	18
5-10	**7**	20	**5**	12.5	**5**	10.8	7	19	**10**	25	**9(7)**	22	**4**	12	**4**	12	**8**	20
10-15	**14**	38	**14**	35	**16**	35	11	30	**10**	25	**12**	29	**13**	38	**11**	32	**10**	25
>15	**12**	32	**12**	30	**17**	37	10	27	**16**	40	**11(10)**	27	**7**	20	**7**	20	**3**	7
Total	**37**	100	**40**	100	**46**	100	37	100	**40**	100	**41(37)**	100	**34**	100	**34**	100	**40**	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**	**09-10**
total *new*	37	44	40 14	37 17	45 20	45 18	40 14	41 17	37 18	34 15	34 15	40 20
At year end	28	28	17	24	29	23	23	18	20	17	19	17
Transferred to HD	0	3	5	7	2	5	5	6	2	5	4	8
Transplanted	9	10	16	7	7	15	11	12	14	8	6	13
Adult unit			4	2	3	1	2	3	0	0	2	0
Improved			0	0	0	0	0	1	1	2	0	0
Deaths	1	1	1	0	1	1	0	0	1	1	3	2

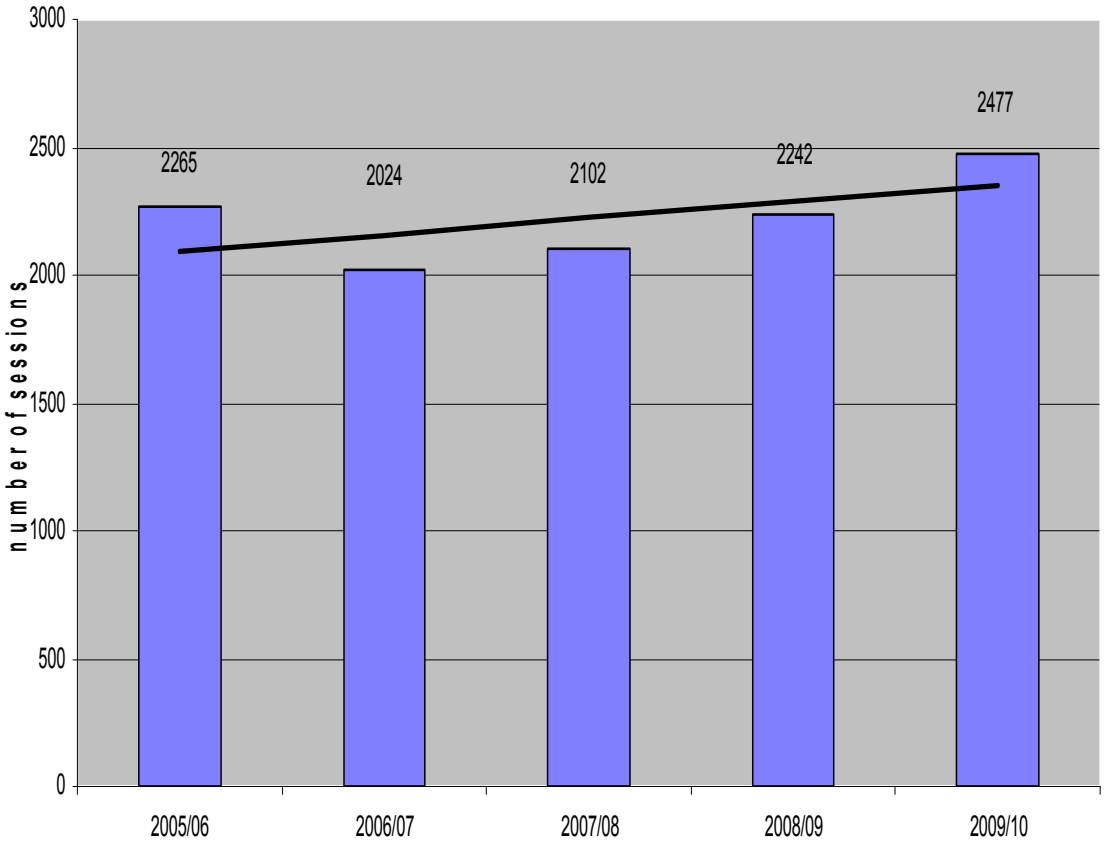
5.4 CHRONIC HAEMODIALYSIS

During the year there were 2477 sessions in 39 children, 2464 sessions of HD (acute and chronic) and 13 sessions of PE.

5.5 Number with a fistula

Date	No of patients with fistula in use	No of hours of dialysis for the week
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	
01.04.09	10	180

5.6 5 year activity



5.7 Water Quality

Water Quality
The Renal Association Clinical Practise Guidelines set limits for the quality of dialysate fluid; these limits are listed in sections 3.3 - 3.6 of the Guidelines. Tests carried out in April 2010 indicate that for both bacterial and endotoxin, all the machines were producing dialysate that meets the guideline for Ultrapure Dialysate.
The soft water supply system was cleaned twice over the period of the year. Chemical levels were within the Renal Association guideline limits.

6. ACUTE RENAL FAILURE AND TREATMENT (INCLUDING PLASMAPHERESIS)

6.1 ACUTE HAEMODIALYSIS

4 children required acute haemodialysis. Their mean age was 7.9 years, range 2.3 – 18.0 years. These figures exclude children with ARF in PICU and NICU.

Diagnosis	2003-4	2004-5	2005-6	2006-7	2007-8	2008-9	2009/10
HUS(D+)				2	1	1	
HUS (D-)	1	1		1		1	
MCGN/RPGN			1				1
SLE		1	1		1		1
Post heart Tx							
FSGS		2		1			1
Wegeners							
MPA							
NS							
HLH							
Acute on CRF	2				1	1	
Sepsis		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	1
Total Pts	13	10	5		7	6	
Total number of sessions	160	54			34	82	164

6.2 PLASMA EXCHANGE

3 children were treated with plasma exchange (1 male; 2 female). The mean age was 13.0 years and range 4.0 – 17.5 years

Diagnosis	**2005/6**		**2006/7**		**2007/8**		**2008/9**		**2009/10**	
	No. Pts	**No. Sess**	**No. Pts**	**No. Sess**	**No. Pts**	**No. Sess**	**No. Pts**	**No. Sess**	**No. Pts**	**No. Sess**
SLE	1	9			1	10	2	9		
HSP	1	5								
MPA	1	3								
Post tx FSGS	1	8					2	49		
MPGN	1	5								
RPGN									1	11
Vasculitis	1	5								
HUS D+			2							
HUS D-			1				1	37		
GvH			1						1	1
Anti-GBM			1							
Tx Rej					1	11				
Goodpastures					2	19				
Wegener's					1	5				
FSGS					1	16				
CNS					1	5			1	1
ABOi heart					1	8				
Total	**6**	**35**	**6**		**7**	**64**	**5**	**95**	**3**	**13**

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**	**2009-10**
<1 year	1	3	1		1	3	2	0	0
1- <5 years	1	0	3		2	4	2	4	8
≥ 5 years	3	2	1		0	6	2	2	7
Total	**5**	**5**	**5**		**3**	**13**	**6**	**6**	**15**

7. RENAL TRANSPLANTATION

Details of patients undergoing renal transplantation 1998 – 2010

	Live donor 1st graft	Subsequent graft	Cadaveric 1st graft	Subsequent graft	Total	Waiting
1/4/1998 to 1999	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
1/4/2006 to 2007	12	0	15	3	30	21
1/4/2007 to 2008	10	0	12	0	22	37
1/4/2008 to 2009	11	2	9	0	22	36
1/4/2009 to 2010	22	1	11	1	35	38

Note – the on-call data is from 31/3/10 and does not include suspended patients.

8. RESEARCH

8.1 PAPERS

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8.2 GRANTS

Awarded 2009-10

R&D No	PI	Research Title	Funder Organisation	Total Funding	Funder Start Date	Funder End Date	Funding Type
07NU15	Dr Detlef Bockenhauer	Identification of an X-linked gene conferring susceptibility to membranous nephropathy	Kids Kidney Research	£99,669	01/11/2009	31/10/2011	UK-based charity
08NU11	Dr Lesley Rees	Vitamin D levels in paediatric renal transplant recipients - a cross sectional study	ICH/GOSH Biomedical Research Centre	£3,000	01/06/2009	31/05/2010	UK central government
08NU18	Dr Detlef Bockenhauer	The genetics of human non-syndromic renal tract malformations	Kids Kidney Research	£70,100	01/09/2009	31/08/2010	UK-based charity
08NU18	Dr Detlef Bockenhauer	The genetics of human non-syndromic renal tract malformations	ICH/GOSH Biomedical Research Centre	£9,000	01/10/2009	30/09/2012	UK central government
08NU26	Dr David A Long	PhD Studentship: targeting blood vessels to prevent autosomal recessive polycystic kidney disease	Kids Kidney Research	£99,150	01/10/2009	30/09/2012	UK-based charity
09NU01	Dr Lesley Rees	An investigation into the optimal reduction in dialysate temperature on systemic haemodynamics and myocardial stunning in paediatric haemodialysis	British Association for Paediatric Nephrology	£100,000	01/04/2010	31/03/2012	UK-based charity
09NU03	Dr Stephen Marks	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	£33,565	22/06/2009	31/03/2011	Commercial/ industrial
09NU03	Dr Nick Webb	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					
10NU05	Dr David A Long	Wnt signalling and podocyte differentiation	Wellcome Trust	£1,520	01/07/2010	26/08/2010	UK-based charity
10NU06	Dr. William van't Hoff	A comparative single-dose pharmacokinetic and safety study of TAK-491 between infants, children and adolescents with hypertension and healthy adults	Takeda Global Research & Development Centre Ltd	£22,334	27/05/2010	30/06/2011	Commercial/ industrial

Active 2009-10

R&D No	PI	Research Title	Funder Organisation	Funder Start Date	Funder End Date	Funding Type	Total Funding
04NU33	Dr Stephen Marks	Childhood renal artery stenosis: a familial study and establishment of a DNA bank from affected individuals assessed at GOSH	Kids Kidney Research	01/10/2006	31/05/2011	UK-based charity	£54,144
07NU15	Dr Detlef Bockenhauer	Identification of an X-linked gene conferring susceptibility to membranous nephropathy	Kids Kidney Research	01/11/2009	31/10/2011	UK-based charity	£99,669
07NU18	Dr. William van't Hoff	A randomised double, parallel, placebo or amlodipine controlled study of the effects of losartan on proteinuria in pediatric patients with or without hypertension	Merck Sharp & Dohme	01/10/2007	30/05/2010	Commercial/ industrial	£13,339
07NU21	Dr Paul Winyard	Understanding expression of critical molecules in maldevelopment of the kidneys and urinary tract to identify factors that are abnormally expressed in kidney diseases, which may be targets for future therapies.	Kids Kidney Research	19/01/2009	18/07/2010	UK-based charity	£99,096
07NU25	Dr David A Long	Roles of angiopoietins in epithelial-endothelial interactions: using the renal glomerulus as a model system	Kidney Research UK	07/04/2008	06/04/2013	UK-based charity	£319,578
07NU27	Prof Adrian S Woolf	Roles of Fras1, a basement membrane-associated protein, in normal differential of kidney collecting ducts and glomeruli	Wellcome Trust	01/03/2009	29/02/2012	UK-based charity	£301,577
08NU01	Dr Lesley Rees	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	01/04/2008	31/03/2011	GOS special trustees	£954,202
08NU08	Dr Lesley Rees	Is it possible to optimise cardiovascular health in children with chronic kidney disease stage 5 by normalisation of vitamin D levels?-a pilot study	Kidney Research UK	01/09/2008	31/08/2010	UK-based charity	£39,969
08NU10	Dr Paul Winyard	Galectin-3, a novel therapy for autosomal recessive polycystic kidney disease	Kidney Research UK	06/01/2009	05/07/2011	UK-based charity	£132,466
08NU11	Dr Lesley Rees	Vitamin D levels in paediatric renal transplant recipients - a cross sectional study	ICH/GOSH Biomedical Research Centre	01/06/2009	31/05/2010	UK central government	£3,000
08NU16	Dr. William van't Hoff	European Network for the Study of Orphan Nephropathies (EUNEFRON)	European Union	01/05/2008	30/04/2013	European Community	£58,400
08NU18	Dr Detlef Bockenhauer	The genetics of human non-syndromic renal tract malformations	Kids Kidney Research	01/09/2009	31/08/2010	UK-based charity	£70,100

08NU18	Dr Detlef Bockenhauer	The genetics of human non-syndromic renal tract malformations	ICH/GOSH Biomedical Research Centre	01/10/2009	30/09/2012	UK central government	£9,000
08NU26	Dr David A Long	PhD Studentship: targeting blood vessels to prevent autosomal recessive polycystic kidney disease	Kids Kidney Research	01/10/2009	30/09/2012	UK-based charity	£99,150
09NU03	Dr Stephen Marks	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	22/06/2009	31/03/2011	Commercial/ industrial	£33,565

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
21/4/09	Renal Association, no meeting			
28/4/09	Renal biopsy meeting	Dr Martin Weber	Case discussion atypical HUS	Dr Aoife waters
5/5/09	Joint meeting with PICU-neonatal ARF	Dr Sophie Skellet Dr Steven Marks	US and scintigraphy of the parathyroid glands: a 5 year experience	Dr Vikas Shah
14/5/09	Joint meeting with the Evelina Children's hospital at ICH, Seminar room A, 2nd floor, note thursday			
19/5/09	Renal biopsy meeting	Dr Martin Weber	Psychosocial aspects of living kidney donation	Jenny Prufe
26/5/09	**Half term break**			
2/6/09	Summary of the family renal malformation clinic	Prof Adrian Woolf	Audit of peritoneal dialysis	Nurse specialist Michelle Cantwell
9/6/09	Renal biopsy meeting	Dr Neil Sebire	Video of information for patients in the haemodialysis unit	Dr Dal Hothi
18/6/09	Bipartite meeting at ICH Note thursday			
23/6/09	Sirolimus post transplant	Dr Steve Marks	Audit of haemodialysis and plasmapheresis	Sisters Liz Wright and Lianne Pilgrim
7/7/09	Renal biopsy meeting	Dr Neil Sebire	Screening for coagulation abnormalities pretransplant	Dr Mary Mathias
14/7/09	MMF in SLE	Dr Kjell Tullus	Audit of living donation	Clinical nurse specialists Maria Scanes and Carol Jennings
21/7/09	Renal biopsy meeting	Dr Neil Sebire	Audit of renal transplants	Clinical nurse specialists Suzanne Bradley and Cecelia MacNeice

Date	Topic *2.30 - 3.30 pm*	Speaker	Topic *3.30 – 4.30pm*	Speaker
1/9/09	ESPN week			
8/9/09	Renal Biopsy Meeting	Dr Neil Sebire	Basics of PD	Dr Rukshana Shroff
15/9/09	Practical aspects of PD	Michelle Cantwell	Talks on PD	Dr Dal Hothi
24/9/09	Bipartite meeting at the Royal Free Note Thursday			
29/9/09	Audit of deaths	Nurse Consultant Eileen Brennan	Sirolimus post transplant	Dr Steve Marks
6/10/09	Renal biopsy meeting	Dr Neil Sebire	Tales from the tubular clinic	Drs Bockenhauer and van't Hoff
13/10/09	2.30- 4.30pm You are the difference(Abigail Hopewell)			
20/10/09	Half term week. No meeting			
27/10/09	ASN week. No meeting			
3/11/09	Renal biopsy meeting	Dr Neil Sebire	Audit of renal transplantation	CNS Suzanne Bradley CNS Maria scanes
12/11/09	Joint meeting with Evelina, at the Evelina hospital Note thursday			
17/11/09	Expert Patient Programme Staying Healthy Workshop	Anna Gregorowski	Renal rickets	Dr Aoife Waters
27/11/09	Nephrology Day for general paediatricians at the ICH (note Friday)			
1/12/09	Renal Biopsy Meeting	Dr Neil Sebire	Congenital nephrotic syndrome	Dr Aoife Waters
8/12/09	Renal Fanconi syndromes	Prof Robert Kleta	Video of information for patients on HD	Dr Daljit Hothi
17/12/09	Bipartitie meeting at ICH (note thurs) Leolin Price lecture theatre			

Date	Topic 2.30 - 3.30 pm	Speaker	Topic 3.30 – 4.30pm	Speaker
12/1/10	Renal biopsy meeting	Dr Neil Sebire	Recent case of transplant loss	Mr Geoff Koffman
19/1/10	Renal rickets	Dr Aoife Waters	CMV	Dr Steve Marks
26/1/10	Video of information for patients on HD	Dr Daljit Hothi	Optimising dialysis	Dr Lesley Rees
4/2/10	Joint meeting with the Evelina, at the ICH Note Thursday			
9/2/10	Renal biopsy meeting	Dr Neil Sebire	Epidemiology of paediatric dialysis	Dr Rukshana Shroff
16/2/10	Half term break			
23/2/10	Course week at the ICH			

2/3/10	Renal biopsy meeting	Dr Neil Sebire	Difficult cases for discussion	Dr Daljit Hothi , second case to be decided
11/3/10	Bipartite at Royal free hospital Note thursday			
16/3/10	Vascular Access in young infants	Mr Francis Calder	Vitamin D in renal transplant patients	Dr Craig Knott
23/3/10	Renal biopsy meeting	Dr Neil Sebire	Transplantation in the under 6s	Mr Geoff Koffman
30/3/10	Easter holidays			
6/4/10	Easter holidays			
13/4/10	Practise session for RCPCH			
20-22/4/10	RCPCH week			

10. AUDIT

10.1 PRE TRANSPLANT AUDIT 2009-10): LIVING AND DECEASED DONOR

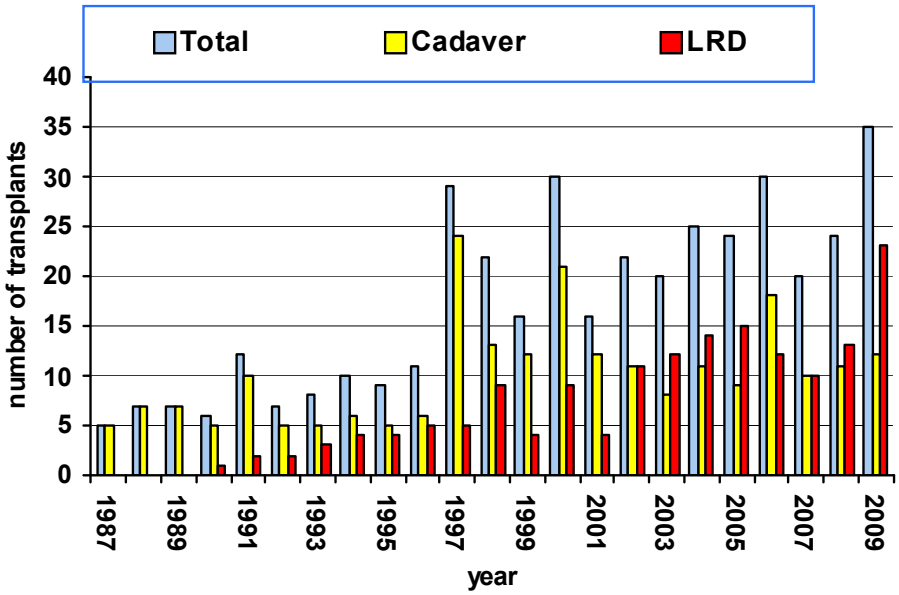
Transplant Numbers

- 35 transplants in 35 children
- 23 living donor (64%)
- 12 deceased donor (36%)

No included in these numbers

- 1 patient had a transplant in USA, but work-up started here and follow-up care here too
- 1 patient had Liver Tx at Kings

Transplant Numbers Since 1987



Recipient Demographics

- Male 20 (57%)
- Female 15 (43%)
- NHS 35 (including 1 Maltese)

Mean age at TPX

- 7.86yrs (LRT); 12.4yrs (DDTx)

Median age at TPX

- 8yrs (LRTx); 13yrs (DDTx)

Modality at Time of Transplant

- HD x 8 (23%)
- PD x 16 (46%)
- Pre emptive x 11 (31%)

[1 patient had PD catheter inserted to start dialysis, but got kidney instead)

- Of LDs 40% were pre-emptive (17% of DD were pre-emptive).
    - (Will look at ↑ pre-emptive no's later).
- 3 of the 35 children received their 2nd graft
- 35 – kidney
- 2 out of centre – 1 from Malta, 1 from Birmingham
- 1 – ABOi
- 1 – combined liver & kidney (Kings; RIP; not included in numbers)
- 1 – LRD in USA from Uncle (not incl in numbers)

Recipient Blood Groups

- O 16 (46%)
- A 12 (34%)
- B 5 (14%)
- AB 2 (6%)

- ABOi transplant

Mismatches

- 6 am 3 (9 %)
- 5 am 3 (9 %)
- 4 am 16 (46%)
- 3 am 10 (28%)

- Below -3 (9 %)

- 222 x 1, 211 x 2 (both deceased donor)

Living Donor Mismatches

- 22 of living donor mismatches were 3AM and above
- 2 – 6 AM
- 2 – 5AM
- 10 – 4AM
- 8 – 3AM
- 1 – 222 mm

Diagnoses

- Dysplasia - 8
- FSGS – 5
- PUV - 5
- Nephronopthisis - 4
- Bil Nx (Wilms) – 2
- Jouberts - 2
- 1 each of VUR, CNS ,HUS, Vacterl,cortical necrosis, Lebers Amorosis, Bardet Biedel, RVT, PUJ

Outcomes

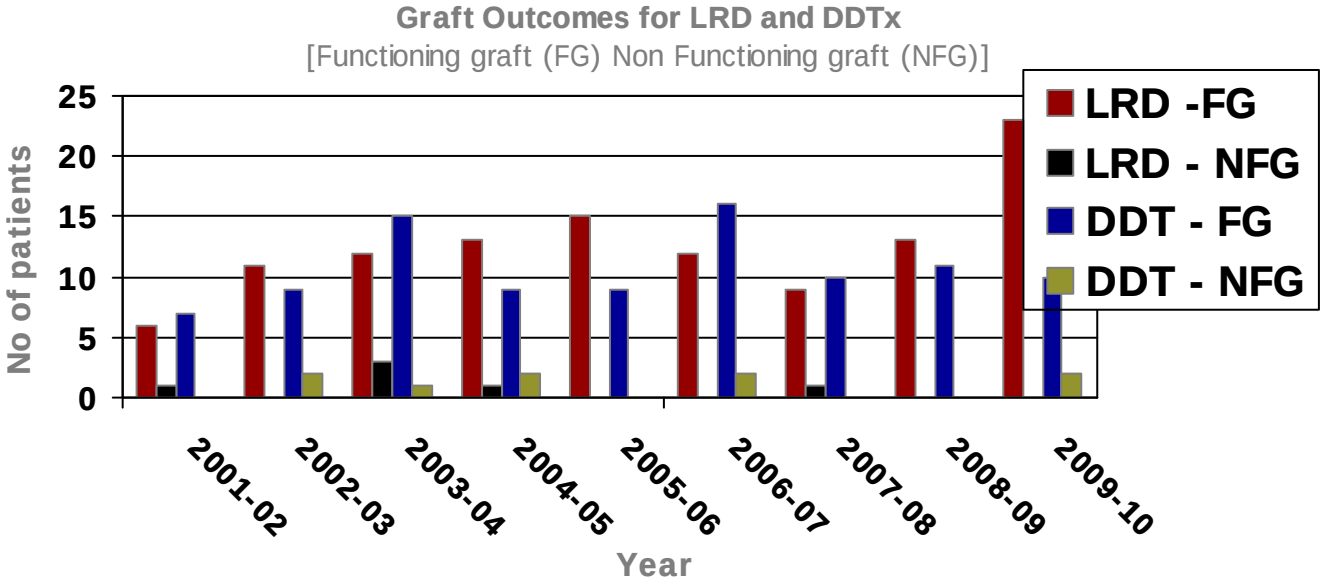
- Of 35 transplants carried out during audit year 33 transplants functioning at year end.
- 2 lost grafts [NKM, 2nd Tx, JR 1st Tx]
- 100% functioning LRD tx at year end
- 10 out of 12 DD Tx functioning at year end (83%)

Failed DD Tx (2)

1. Graft thrombosis at 1/52. Bx showed RVT & severe hypertensive vasculopathy.

2. Upper GI bleed, grade 2 rejection, bleed from Tx

End of Year Outcomes



Cold Ischaemic Times

LD (data on 9 pts- 40%)
- average 4.2 hrs (3 hrs- 6.1 hrs)

DD (data on 11 pts – 92 %)
- average 15 hrs (12hrs – 19 hrs).

Could we ↑ No. of Pre-emptive Tx
- LRDs – 60% on dialysis (7 HD, 7 PD)
- 5 bil Nx
- 3 late presentations
- 2 out of centre (AS, MNB)
- 1 started dx as a baby
- 1 previously failed tx
- 1 donor came forward after Dx started (KCW)
- 1 awaiting donor workup when Dx started (EB)
- DD - 17 % were pre-emptive (2)
- 1 – Tenckhoff inserted , PD not started
- 4 – HD. 3 – previously failed Tx, 1 late presentation
- 6 – PD. 1 out of centre, 1 bilateral nephrectomies, 4 – been on call for some time

Activity 2009-2010

Clinic Code	Total Appointments	Marked Attended	Marked As DNA or Cancelled	Marked As Not Specified
GKRLTX	**91**	**57**	**13**	**21**
LRCAP	**887**	**625**	**185**	**77**
PRETX	**49**	**37**	**8**	**4**
RENWAL	**773**	**361**	**47**	**365**

Living Donor Information
- 9 fathers (38%)
- 9 mothers (38%)
- 5 other (24%)

[1 step father; 1 grandmother; 1 step brother; 2 uncles)

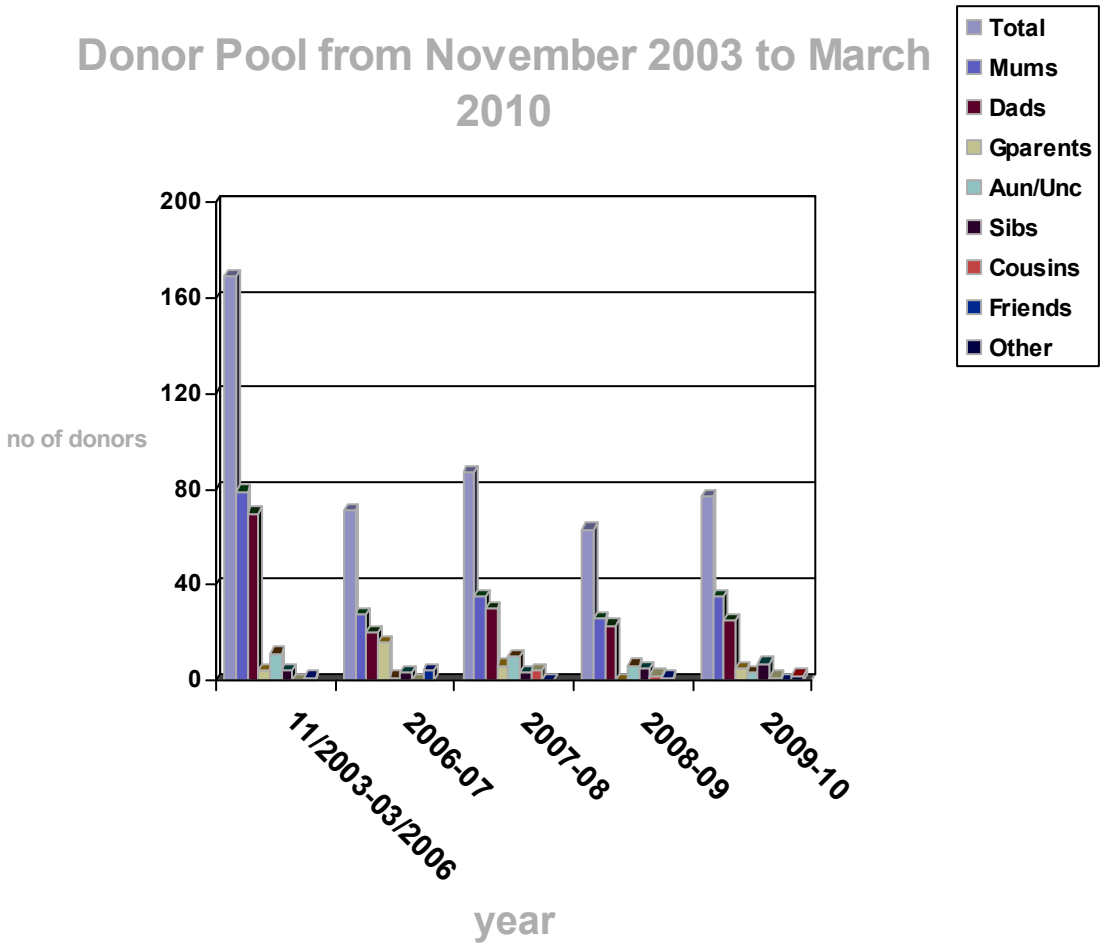
Mean age 37 yrs [DDTx – LRD]
- 23 – Retrieval at Guys
- (1 – USA – not included)

- All laparoscopic donations

Donor Pool (LRD)

77 potential donors came forward for 47 recipients.

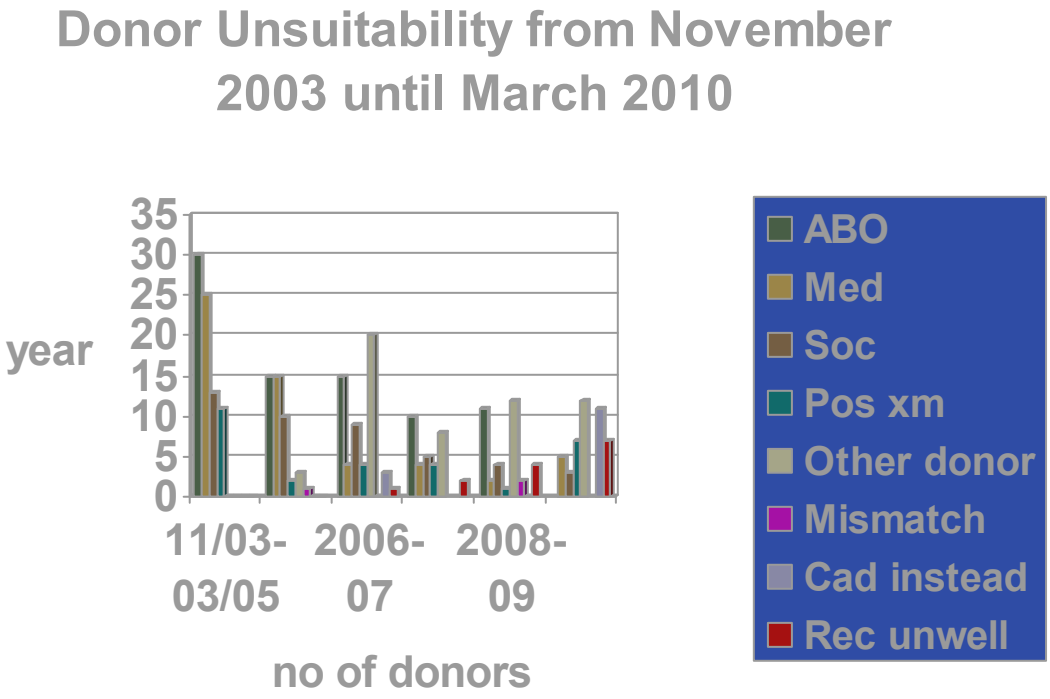
• Mothers	35	
• Fathers	25	
• Sisters	2	
• Brothers	4	
• Aunts		1
• Uncles	2	
• Cousins	1	
• Grandparents	5	
• Stepfathers		2



Donor Suitability

From 77 potential donors within audit year

- DD Tx 11
- LD Tx 3
- Ongoing Ref 12
- Early Ref 15
- Other donor 12
- Med Unsuit 5
- Recipient unwell / RIP 7
- Pos Xmatch 7
- Enquiry only 2
- Social 3



Work in Progress (06/10)

112 children "on our books"

- 44 on A list
- *21* on call
- Pot LRDs '10- '11- 16. (incl 4 tx to date)
- Potential for a further 3 IPP Tx

Deceased Donor Tx

Donor Pool
- *Data on 8 recipients (66%)*
- Age 17Y – 47 Y yrs (Mean *35* yrs)
  - Donor COD:
    - 3 SAH
    - 2 ICH
    - 1 Hypoxic brain injury
    - 1 Sub Dural haematoma
    - 1 Head injury
    - 1 asphyxiation, cardiac arrest
    - 1 pneumoccocal meningitis
    - 2 Unknown (1 diabetic)

Activations "On Call"

- 14 new registrations during audit year (4 transplanted within audit year)
- Between 24-31 children on call at some point during audit year (including new registrations),
- Average waiting time for 12 chidren who received DD Tx – 431 days (range 92 – 1309 days on call)

ABOi, HLAi, Paired Exchange

- See handout

Achievements

- UKT Consent for storage and use of information
- IA implemented successfully
- First ABOi transplant
- 2 pairs registered for paired exchange (unmatched)
- Regular meetings / clinics set up to look at potential for ABOi & paired exchange

Audit Points

- Poor collation of CIT
- ABO incompatibility
- Desensitisation
- Paired exchange
- ↑ referrals of children from other centres
- Pre Tx Echo as part of Protocol
- When to activate / Transplant?
- Education sessions, OTIS

With Thanks to

- Suzie Doyle. Guys Team

10.2 RENAL TRANSPLANT AUDIT

April 2009 – March 2010
Suzanne Bradley

Renal Transplants at GOSH

- 36 Transplant Patients to the programme in the 12 month period of 1st April 2009 – 31st March 2010
- 35 out of 36 children received Renal Transplants at GOSH
- 1 additional transplant was carried out on GOSH patient -Deceased Donor Liver Transplant at Kings College Hospital –RIP post transplant (LO)
- 1 patient returned to Birmingham Children's Hospital post living related transplant (MNB)
- 1 patient returned to Malta post living related transplant
- 2 of the 35 patients had a transplant graft nephrectomy & returned to dialysis
- 1 patient had LRD in USA

Transplants

- 33 patients received their 1st graft
- 2 patients received their 2nd graft

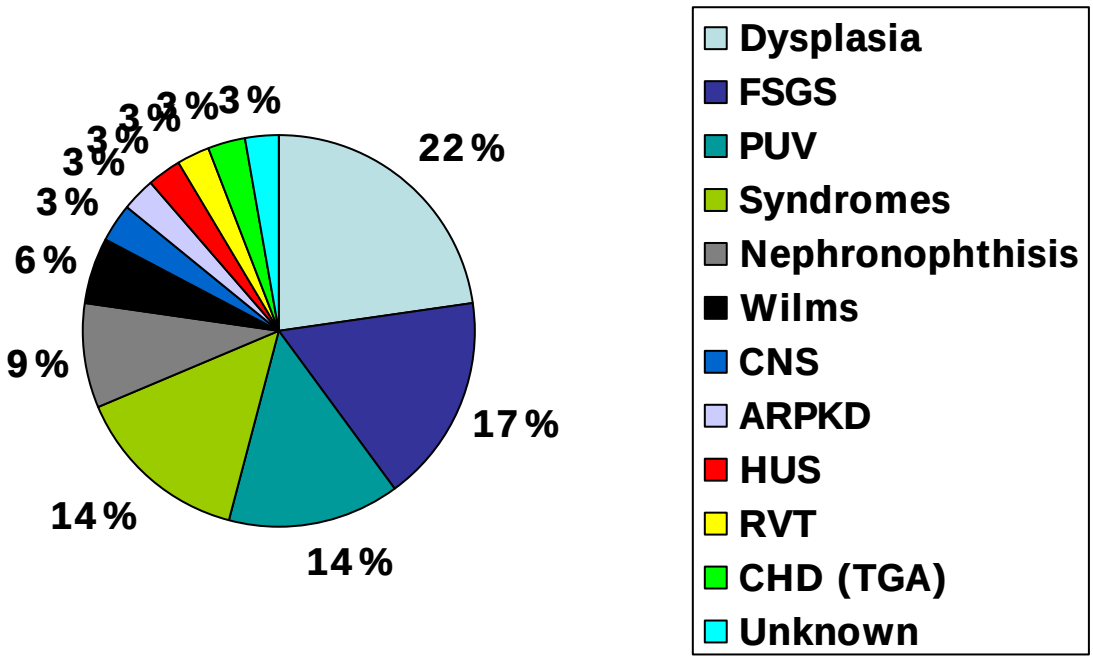
(Information based on 35 patients transplanted at GOSH)

Patient Demographics

- Female / Male= 15:20
- NHS / Private= 35:0
- Birmingham=1/35 patients
- Malta=1/35 patients

(Information based on 35 patients transplanted at GOSH)

Aetiology of ESRF



Dysplasia	7
FSGS	6
Posterior Urethral Valves	5
Nephronophthisis	3
Bilateral Wilm Tumours	2
Jouberts Syndrome	1
Bardet Biedl Syndrome	1
Congenital Nephrotic Syndrome	1
Lebers Amaurosis	1
APRKD	1
Metaphyseal Chondrodysplasia	1
HUS (E Coli not isolated)	1
Bilateral Hydronephrosis	1
VACTERL	1
Bilateral Renal Vein Thrombosis	1
Cardiac Transposition of vessels	1
Unknown	1

Pre-Transplantation Status
(Information based on 35 patients transplanted at GOSH)

Modality	No of Patients
Pre-Emptive	10
Haemodialysis	9
Peritoneal Dialysis	16

Donor Types
(Information based on 35 patients transplanted at GOSH)

Live Related =23 Patients

- (5/23=Uncle's x2/Grandmother/Stepfather/Step-brother)
- LRT X1= "ABOi" Transplant (1st on GOSH programme)

Deceased Donor =12 Patients

HLA Mismatches
(From this slide on-**Information based on 34/35 patients transplanted at GOSH)**

Mismatch	LRD	Deceased
0-0-0	2	1
0-1-0	0	2
0-0-1	1	0
0-1-1	5	0
1-0-0	0	0
1-0-1	1	1
1-1-0	4	5
1-1-1	9	1
2-1-1	0	1
2-1-0	0	1

Donor – Recipient CMV status

	Recipient CMV +ve	Recipient CMV -ve
Donor CMV +ve	9	7
Donor CMV –ve	1	16
Donor CMV status unknown	0	1

Donor – Recipient EBV status

	Recipient EBV +ve	Recipient EBV –ve
Donor EBV +ve	11	11
Donor EBV –ve		
Donor EBV status unknown	9	2
Donor EBV status unknown	0	Recipient non specific=1

Immunosuppression in New Renal Transplant Recipients 2009-2010

Start	**End**	**No**
Tac /Aza /Pred	Tac /Aza /Pred	15
Tac /Aza /Pred	Tac/Pred	10
Tac/MMF/Pred	Tac/MMF/Pred	3
Tac/Aza/Pred	Tac/MMF/Pred	2
MMF/Tac/Pred	Tac/Pred	1
Tac/Pred(Cycl)	Tac/Pred	1 (FSGS Recurrence)
Tac/Aza/Pred	-(JR)	1
Tac/MMF/Pred	-(NKM)	1

Renal Transplant Biopsies

34 Patients transplanted in 2009-2010

- 29 of the patients had a total of 47 biopsies in audit year
- 15 had biopsy at the time of transplant
- 32 Remaining biopsies done due to rise in creatinine

Time Zero Biopsies

Surgeon	A (FC)	B (Vas)	C (JT)	D (NM)	E (GK)
Time Zero: Yes	3	8	0	5	0
Time Zero: No	2	1	9	3	3

No of Biopsies	Biopsy Results
1	Arteriolar Hyalinosis
5	No abnormality noted
1	Mod Hypertensive Vasculopathy
8	Chronic changes/Vascular Changes/Tubular changes
1	Acute Ischaemic Changes

Biopsy results in patients transplanted 2009-2010

Biopsy Result	Number of Biopsies made reference to:
Acute Tubular Abnormalities	3
No Acute Rejection	14
Borderline Acute Rejection	3
Grade 1a rejection	1
Acute Vascular Rejection (DSA's)	1
Grade 2A Acute Rejection	4 (2 with DSA's)
Chronic Changes	5
Renal Infarction	1
Disease Recurrence - FSGS	1

BK Virus Post Transplant

BK Virus	+ve	-ve	Not checked
Blood	1	26	4
Renal Biopsy		3	

Stent Removal – No of weeks into Transplant Journey

Weeks/Post Tx	No of Patients	Reason
Week 1	2	Graft neph(1)/with cath(1)
Week 2	4	Haematuria
Week 3	4	c/o SPC/Routine/Haem
Week 4	3	Haematuria/Routine UTI
Week 5	7	Routine/Graft neph(1)
Week 6	2	Routine
Week 7	9	Routine
Week 8	1	Routine
Week 9	1	Routine
Week 10	1	Routine

Anti-Hypertensive Treatment in New Renal Transplant Recipients 2009-2010

Start	End	No of Patients
0 agent	0 agent	14
0 agent	1 agent	3
0 agent	2 agents	2
1 agent	0 agents	4
1 agent	1 agent	4
1 agent	2 agents	2
2 agents	1 agent	2
2 agents	2 agents	1
3 agents	3 agents	2

Transplant Complications

- 4=patients with New Onset of Diabetes mellitus After Transplantation (1=Diabetic Donor & remains on insulin)
- 5=patients needed treatment for CMV (Donor Pos/Recip Neg)
- 1=CMV re-activation
- 1=Pulmonary Oedema
- 3=patients required plasma exchange post transplant for FSGS re-occurrence but remained off dialysis in audit year
- 5=Haematuria
- 5=Primary EBV

Transplant Complications

- 2=Donor Specific Antibodies
- 2=GI Bleed
- 1=Revision of transplant ureter
- 1=Bleeding post renal biopsy
- 1=AV fistula
- 2=Graft Nephrectomies (RVTx1/elective x1)
- 1=Perinephric urine leak
- 2=Neutropaenia
- 3=UTI
- 1=Epididymitis
- 1= wound drain fell out Day 0
- 1=Oesophagitis

Transplant Biopsies
- Existing transplant patients undergoing biopsy in audit year 2009-2010

- 11 patients had a total of 17 biopsies in the audit year

Biopsy Results –Existing Patients

Biopsy results	**Biopsy report made reference to:**
No rejection	1
Borderline Acute Rejection	2
Grade 2A Rejection	2
CAN/Chronic vascular Changes	14 (2 with DSA'S)

Transplant complications in existing transplant patients

- Respiratory symptoms & bronchiectasis
- PTLD (2 patients)
- Return to Haemodialysis x 3
- Donor Specific Antibody formation

Creatinine trend-an overview in programme March 2010

Creatinine	No of Pts	Years out	DD v LD
Up to 100	104	1 Mth-14YRS	47 V 57
100-200	33	6 Mths- 13Yrs	19 V 14
200-300	5	7Yrs-14 Yrs	2 V 3
300-400	1	6 Yrs	1

Adolescent Transition

- Monthly Adolescent Transition clinic in addition to 16 joint clinics/year with Guys/RLH/RFH/Oxford

- Revision of patient information and transition for parents

- Project to upgrade adolescent room Level 4 with ongoing involvement of adolescent client group

Transition

24 adolescent patients transitioned to adult units.

- RFH=1
- Addenbookes=1
- RLH=2
- Ipswich/UCH=2
- Lister=1
- Guys=7
- Southend=1
- Oxford=6
- Bournemouth=1
- Hammersmith=1
- Cardiff=1

Total Transplant Patients

Transplant patients-Age Range March 2010

Under 5 years old	10
5 – 10 years old	34
10 – 15 years old	65
> 15 years	27

Based on patients age on 31/03/2010

Transplant Clinics 2009 – 2010

	RENWAL	RSTCNS	RSTRTP
Total Appointments	773	740	1270
Appointments Attended	726	604	1034
DNA/Cancelled	47	136	236

In Conclusion…the year ahead

- Revision of renal transplant protocol (SM)
- Adolescent Programme Development
- Renal Transplant Service Provision
- Continue Weekly Friday Transplant Review Meetings
- Fundraising for British Transplant Games Belfast 2011—all support/efforts welcomed!!

Thanks to……

Steve Marks, Detlef Bockenhauer, Rukshana Shroff & transplant surgeons for transplant team support throughout the audit year

Steve- for review, guidance & presentation of audit

Michelle Cantwell, Tanya Baldwin & Cecilia Mcneice for rotation to transplant service throughout the audit year.

Suzie Doyle-data support throughout audit year

10.3 RENAL TRANSPLANT NATIONAL COMPARATIVE UNIT AUDIT
(Report and data from NHS Blood and Tissues)

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 2009, 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 (46 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: 1993 - 1996, 1997 - 2000, 2001 - 2004, 2005 - 2008) 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: 1993 - 2000 and 2001 - 2008) 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	**23**
2005	0	12	60 (1)	0	0	0	1	13	32	**18**
2006	0	13	64 (6)	0	0	1	0	16	35	**29**
2007	0	13	54 (4)	0	0	1	0	7	43	**18**
2008	0	10	67 (3)	0	0	2	0	14	50	**143**
2009	0	12	53 (3)	0	0	1	0	17	48	**131**

( ) Number of which were multiple organ transplants

Table 2 First paediatric kidney-only 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	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**
2009	0	10	48	0	0	1	0	16	48	**123**

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					
1993 – 1996	51	51	78	64 – 87	100
1997 – 2000	56	55	73	59 – 83	98
2001 – 2004	38	37	92	77 – 97	97
2005 – 2008	44	44	93	80 – 98	100
All other UK paediatric units					
1993 – 1996	344	344	81	76 – 84	100
1997 – 2000	269	268	89	85 – 92	100
2001 – 2004	255	255	92	88 – 95	100
2005 – 2008	213	211	94	90 – 97	99

Five year transplant survival estimates					
	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1993 – 1996	51	51	67	52 – 78	100
1997 – 2000	56	55	62	48 – 73	98
2001 – 2004	38	37	78	61 – 89	97
2005 – 2008	44	44	-	-	25
All other UK paediatric units					
1993 – 1996	344	342	69	63 – 73	99
1997 – 2000	269	262	77	71 – 81	97
2001 – 2004	255	246	81	76 – 86	96
2005 – 2008	213	213	-	-	14

Ten year transplant survival estimates					
	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1993 – 1996	51	51	57	42 – 69	100
1997 – 2000	56	48	51	37 – 63	86
2001 – 2004	38	38	-	-	26
2005 – 2008	44	44	-	-	14
All other UK paediatric units					
1993 – 1996	344	332	53	48 – 59	97

1997 – 2000	269	224	53	48 – 58	83
2001 – 2004	255	255	-	-	23
2005 – 2008	213	213	-	-	9

- Insufficient follow-up for meaningful survival estimates
- [1] Percent with complete follow-up for the survival time period

One, five and 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					
1993 – 2000	55	48	94	82 – 98	87
2001 – 2008	93	84	94	87 – 98	90
All other UK paediatric units					
1993 – 2000	119	113	95	89 – 98	95
2001 – 2008	268	264	96	93 – 98	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					
1993 – 2000	55	41	83	69 – 91	75
2001 – 2008	93	93	-	-	43
All other UK paediatric units					
1993 – 2000	119	104	85	77 – 91	87
2001 – 2008	268	268	-	-	43

	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					
1993 – 2000	55	36	69	52 – 81	65
2001 – 2008	93	93	-	-	12
All other UK paediatric units					
1993 – 2000	119	90	69	59 – 77	76
2001 – 2008	268	268	-	-	8

10.4 HAEMODIALYSIS AUDIT 2009 - 2010

Totals

- No. of children receiving HD or PEX (GOS only)
    - 39 (19 boys and 20 girls)
    -
- HD = 38
    - 4 acute HD (JG)
    - 34 chronic HD

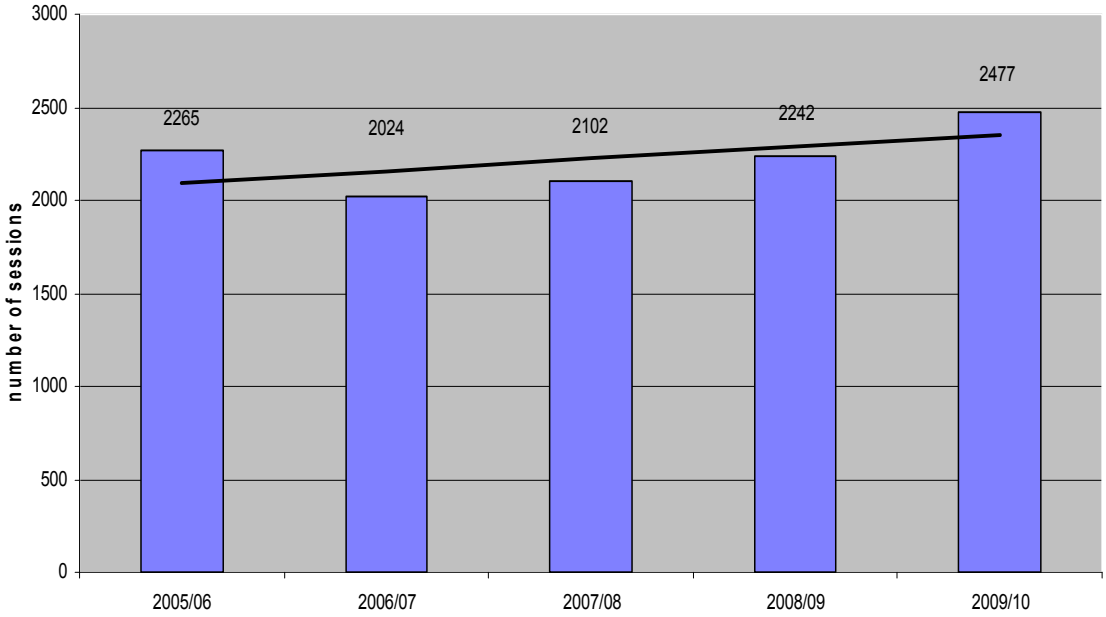
- PEX = 3
    - 2 children received HD + PEX
    - 1 child PEX only

Overview

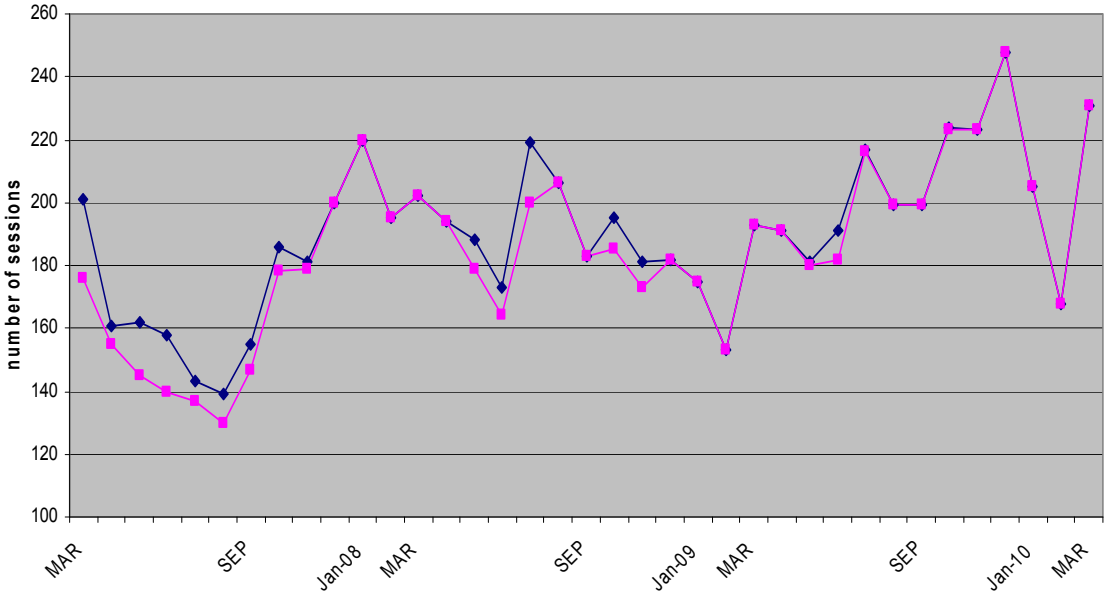
April 2009
- HD = 15 (6 lines; 9 fistulae)
- HHD = 1

March 2010
- HD = 15 (8 lines; 7 fistulae)
- HHD = 1

5 Year Activity



3 Year – monthly figures



Ages

Median age: 9.4 yrs (range 0.7 – 18.0 yrs)

- <2 yrs = 6
- 2-5 yrs = 6
- 5-10 yrs = 5
- 10-15 yrs = 8
- > 15 yrs = 9

Starters

Source	Reason	No.s of children
PD	Peritonitis PD rest – Surgery Leaking Tunnel infection	5 (1 child twice) 1 1 1
New ESRF		3
Transplant fail	Deceased donor LRT	1 2
Visitors	Work-up Line replacement Review	3 2 1
		20

Leavers (18)

Transfer adult HD	Luton Whipps Cross	1 1
Transplant	DD LRT	2 5
Died	Chronic HD Acute Pex	1 1
Function recovered	Acute HD Acute HD/PX	1 2
PD	Return New starter	3 1

Visitors

- LRT work –up = 2
- Line replacement – 2
- Malta - 1

Acute HD

4 children

- ARF (AML) 1
- ARF (SLE nephritis) 1
- ARF (RPGN) 1
- ATN (FGSG recurrence post-transplant) 1

Plasma Exchange

- 3 children had 13 sessions
    - 1 RPGN - 11 sessions
    - 1 CNS – 1 session as transplant assessment
    - 1 post lung transplant – 1 session

- 15 children treated by UCLH

Central Venous Catheters

Total number of lines: 74

- 68 lines actually inserted in 2009/10
- 6 already in situ

Permanent = 62 catheters in 17 children

- 2 inserted but never used

Temporary = 12 catheters in 9 children

CVCs inserted 09/10

	Who	Permanent	Temporary	Total
IR (%)	DR	17	2	19
	AB	15	1	16
	SC	12	1	13
Renal (%)	GK	3	0	3
	FC	3	0	3
	NM	1	1	2
	JT	0	0	0
	VH	5	2	7
Other	St. Mary's	0	1	1
	CICU/PICU	0	4	4
		56	12	68

Line Position

	Permanent	Temporary	Total
R IJV	32(57%)	4	41 (60%)
L IJV	21 (37%)	1	23 (33%)
R femoral	0	4	4
L femoral	0	3	3
Other	2	0	2
Unknown	1	0	1

Numbers of Lines in Children

Number of Children	Line Number
8	1
8	2
3	3
2	4
2	5
2	6
1	7

Infection Data

- 5 infections
- 3384 catheter days
- = 1.5 infections/1000 catheter days

Infections

Infection Number	Time (days) from insertion	Microbiology	Outcome
1	13	S. aureus	Cleared. Line still in.
2	127	S. aureus	Line pulled, abscess.
3	8	Coag. neg .Staph	Cleared. Line removed, leaking.
4	7	Coag. neg .Staph	Cleared. Line still in.
5	13	Coag. neg .Staph	Treated. Regrowth.

Infection Data

	05/06	06/07	07/08	08/09	09/10
No. of infections	20	12	10	7	5
Catheter days	2180	1309	1914	2434	3384
Infections/ 1000 catheter days	9.17	9.16	5.2	2.9	1.5
Infection frequency	1:3.6	1:3.6	1:6.3	1:11.4	1:22.2

CVL removal

No longer required - 15

- AVF 2
- Function recovered 4
- PD 3
- Tx 4
- Died 2

Mechanical - 31

- Poor flow 21
- Cuff extrusion 5
- Leaking 3
- Pulled out 2

Infection – 4

- 1 abscess
- 3 general sepsis

Replaced for permanent access - 8

Comparison of CVLs (n = 74)

Lines removed for mechanical reasons			'Splitcaths' n = 22 (30% of all lines)	'Permcath' n = 40 (54% of all lines)	'Vascaths' n = 12 (16% of all lines)
	Poor flow		2 (9%)	18 (45%)	1
	Cuff extrusion		1	4	n/a
	Leak		3	0	0
			6 (27%)	22 (30%)	1

Outcome Splitcaths

22 (35%) inserted of 62 total
- 3 – leaked
- 1 – cuff out
- 1 – poor flow
- 1 - revised, then removed poor flow
- 1 – pulled out
- 1 - removed for general sepsis
- 1 – returned to other unit
- 1 – renal function recovered
- 2 – avf in use
- 2 – LRT
  - 8 – still in situ

Exit Site Infections

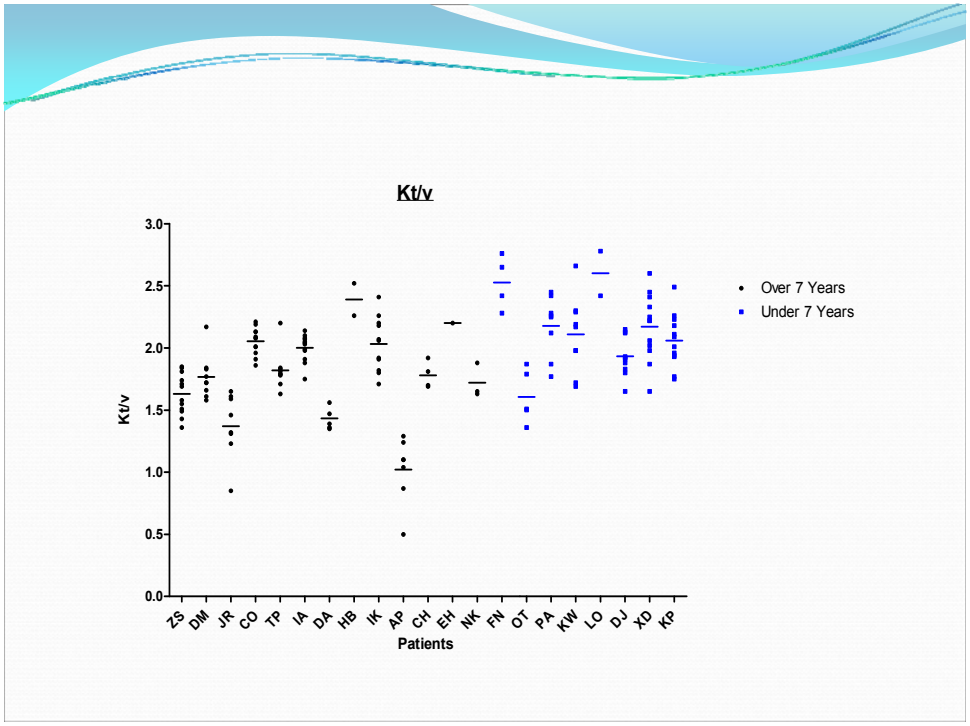
Number	Growth	Ass. with line sepsis
1	CNS	
2	S aureus	
3	S aureus	
4	S aureus	
5	CNS	
6	CNS	yes

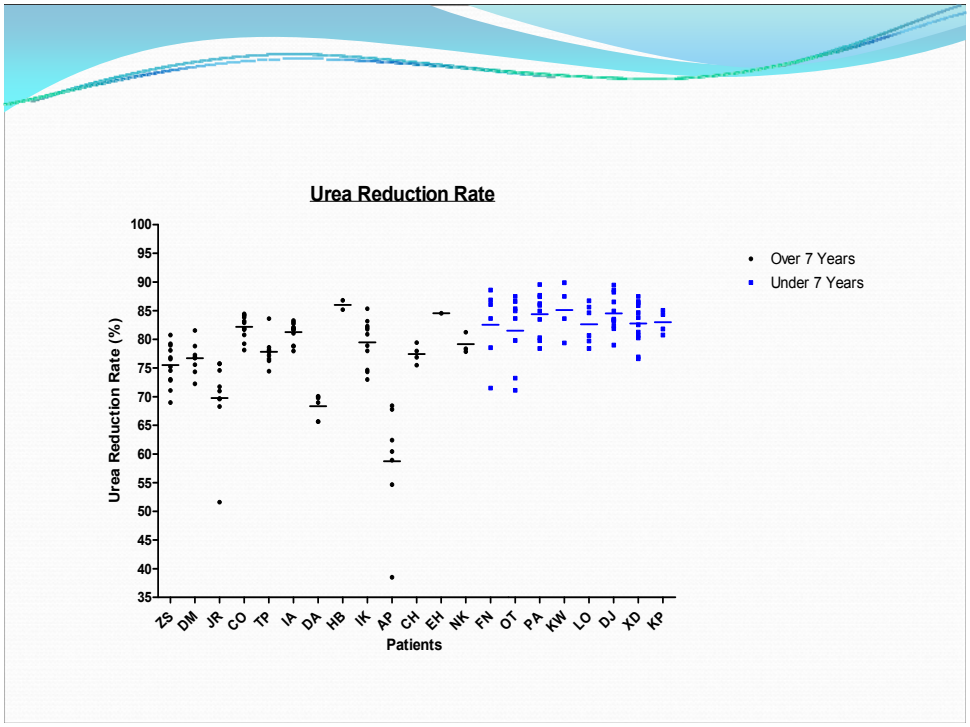
AVF overview

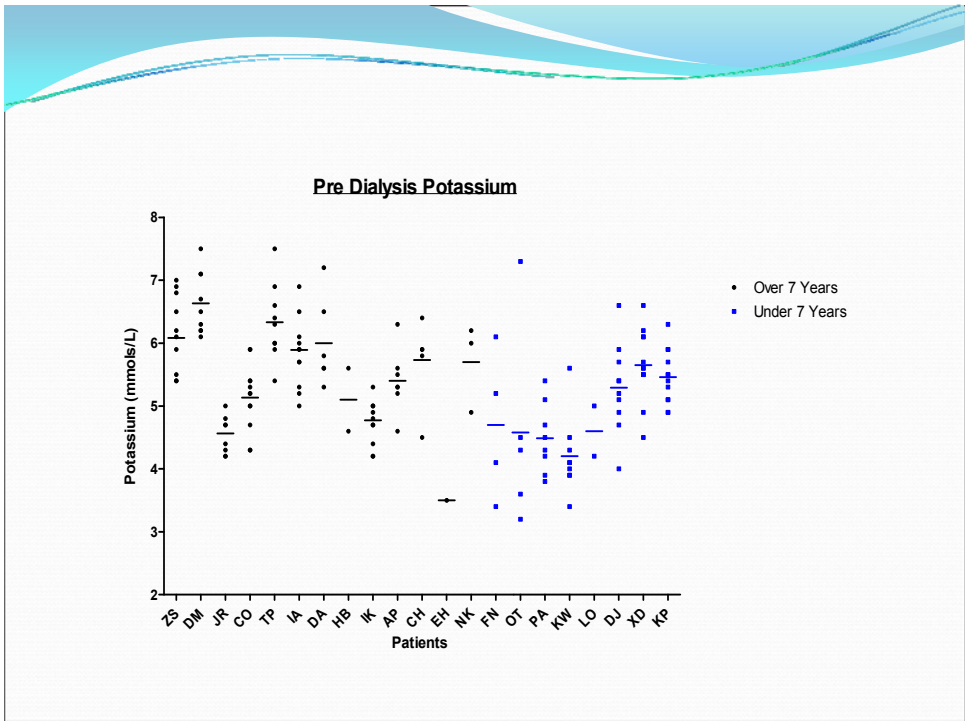
- 14 children were dialysed by fistula
- 8 new fistulae were created in 6 children
  - 1 failed immediately
  - 1 failed to mature
- 1 failed post transplant collapse

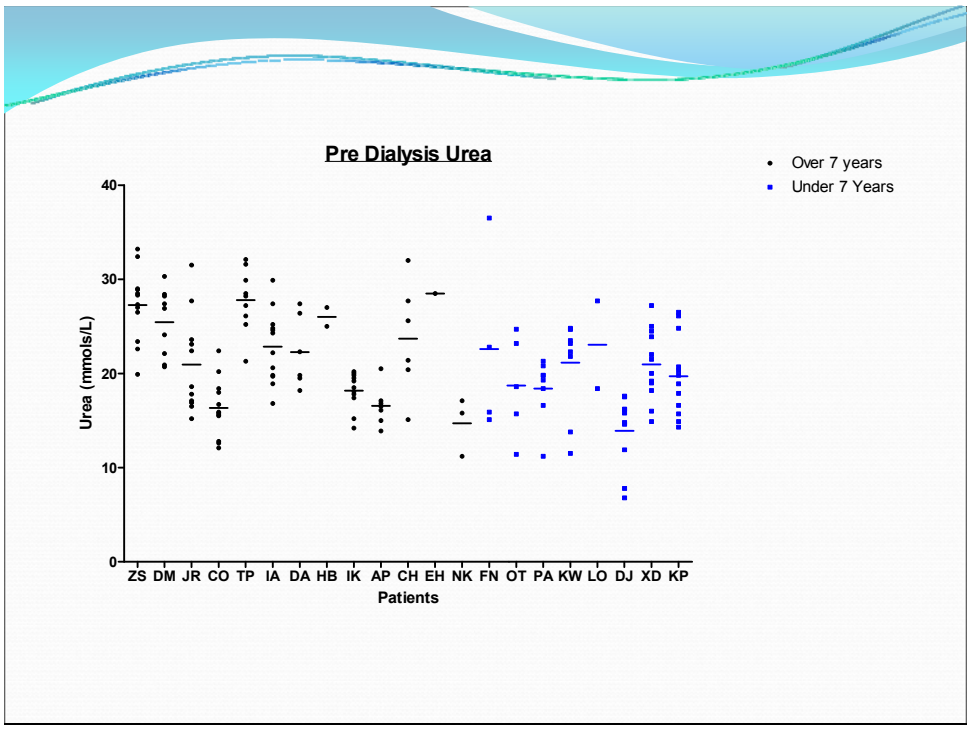
New AVFs

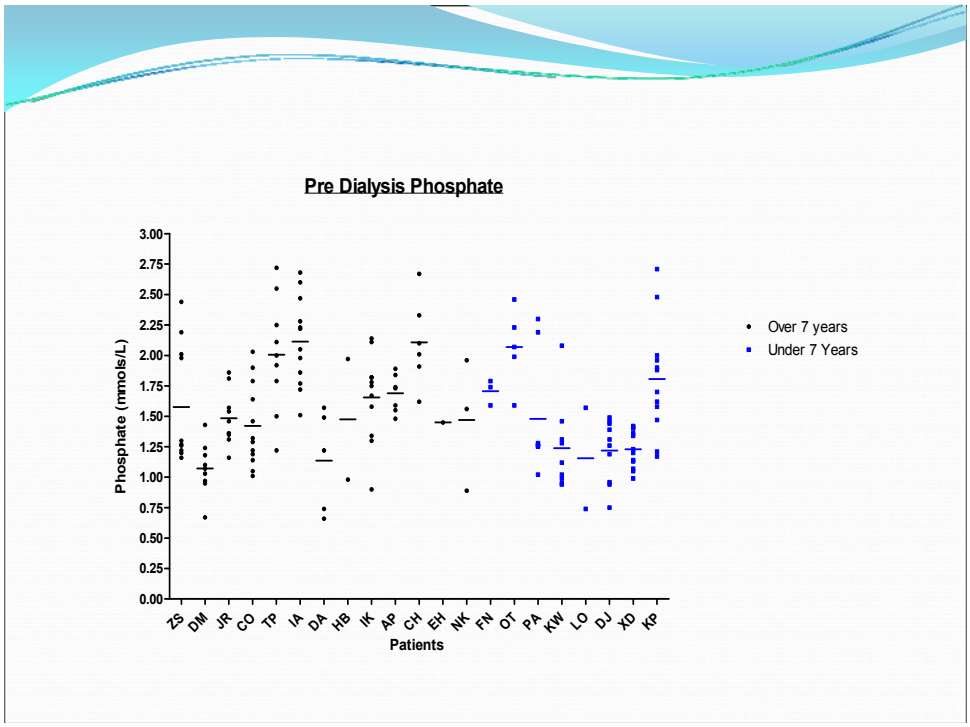
	Age	Site	Surgeon	2nd Stage	Outcome
DJM	2.93	R brachio-basilic	GK	Yes	Maturing
AP	15.6	L radio-cephalic L brachio-cephalic	NM JT		Failed In use
JR	15.1	R radio-cephalic R brachio-cephalic	FC VH		Failed imm. In use
CH	12.7	L brachio-cephalic	GK		In use
NKM	17.0	L brachio-cephalic	JT		Maturing
PR	9.4	L brachio-cephalic	GK	Yes	PD still

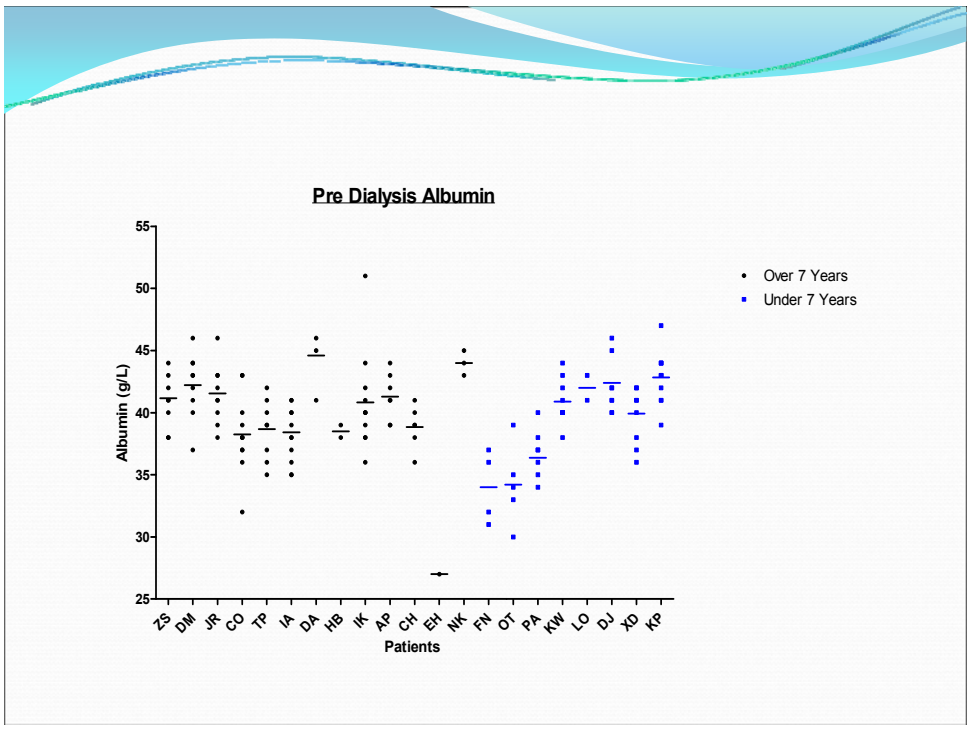

Kt/v
Kt/v
3.0
2.5
2.0
1.5
1.0
0.5
0.0
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 Years
Under 7 Years

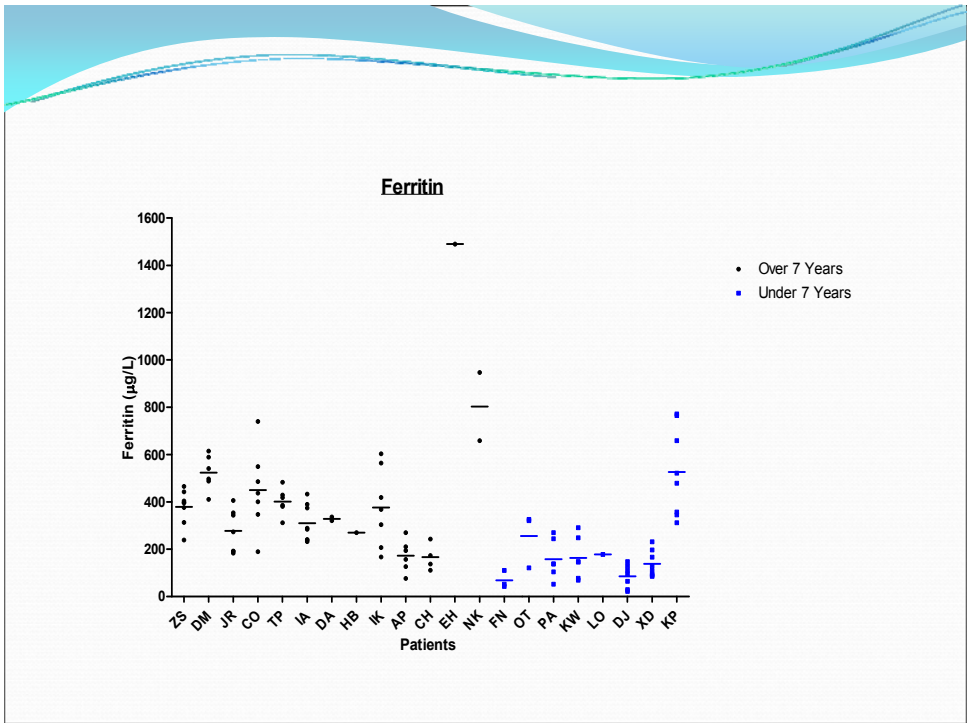

Urea Reduction Rate
Urea Reduction Rate (%)
100
95
90
85
80
75
70
65
60
55
50
45
40
35
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 Years
Under 7 Years

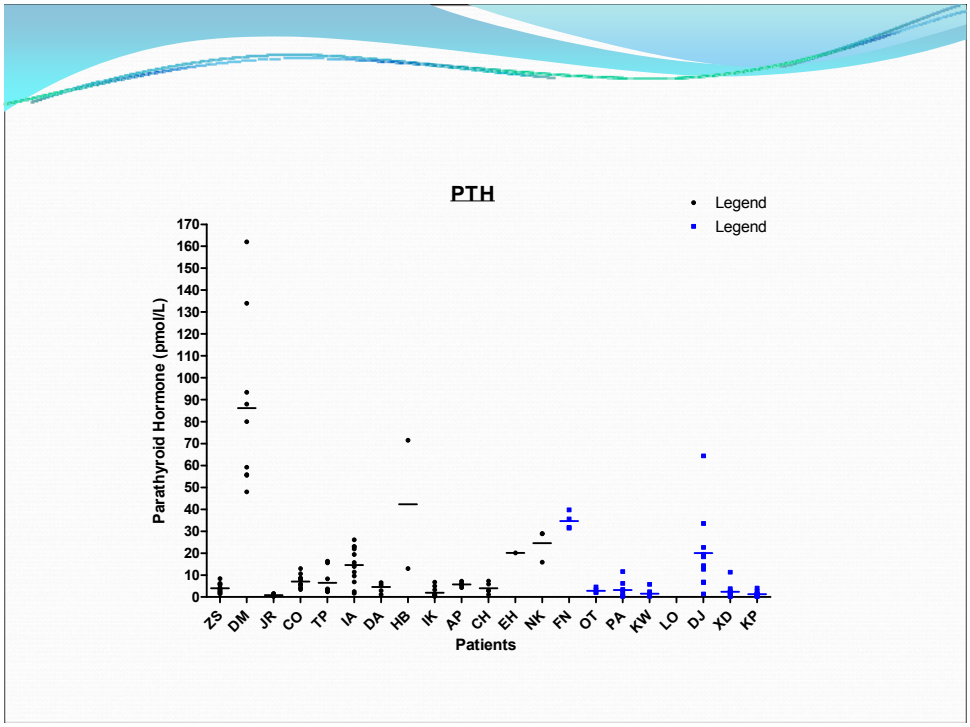

Pre Dialysis Potassium
Potassium (mmols/L)
8
7
6
5
4
3
2
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 Years
Under 7 Years

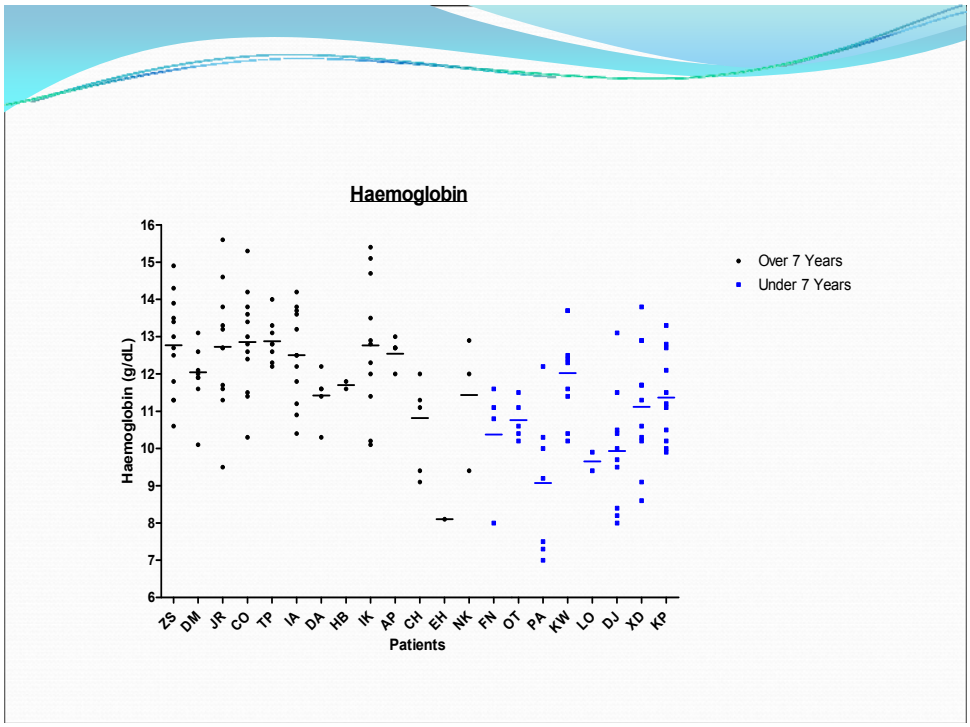

Pre Dialysis Urea
Urea (mmols/L)
40
30
20
10
0
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 years
Under 7 Years

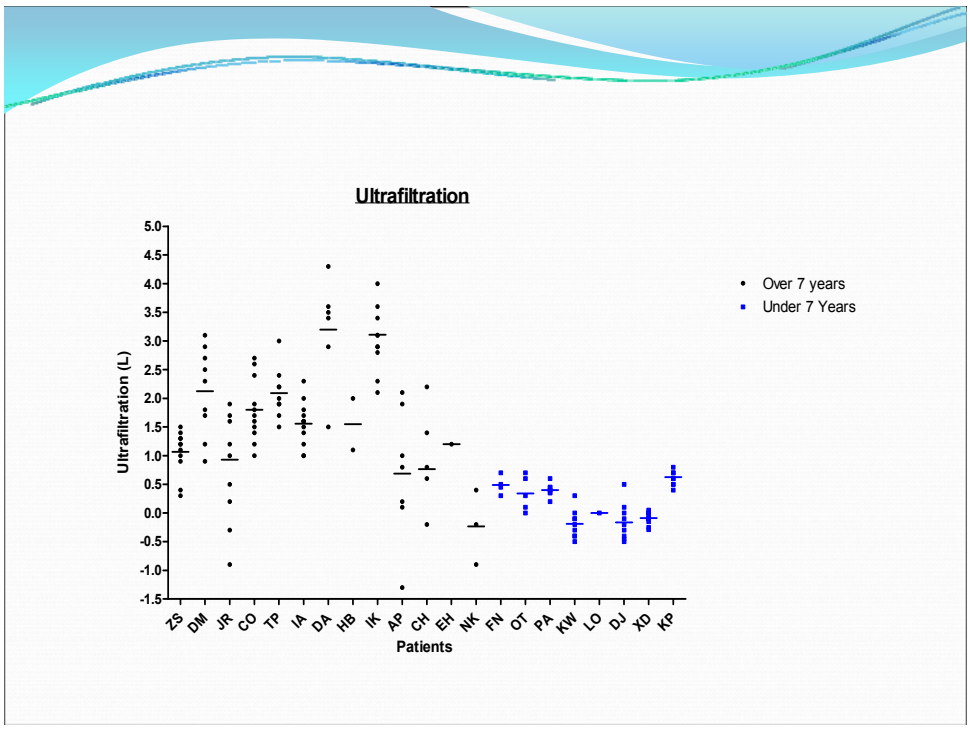

Pre Dialysis Phosphate
Phosphate (mmols/L)
3.00
2.75
2.50
2.25
2.00
1.75
1.50
1.25
1.00
0.75
0.50
0.25
0.00
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 years
Under 7 Years

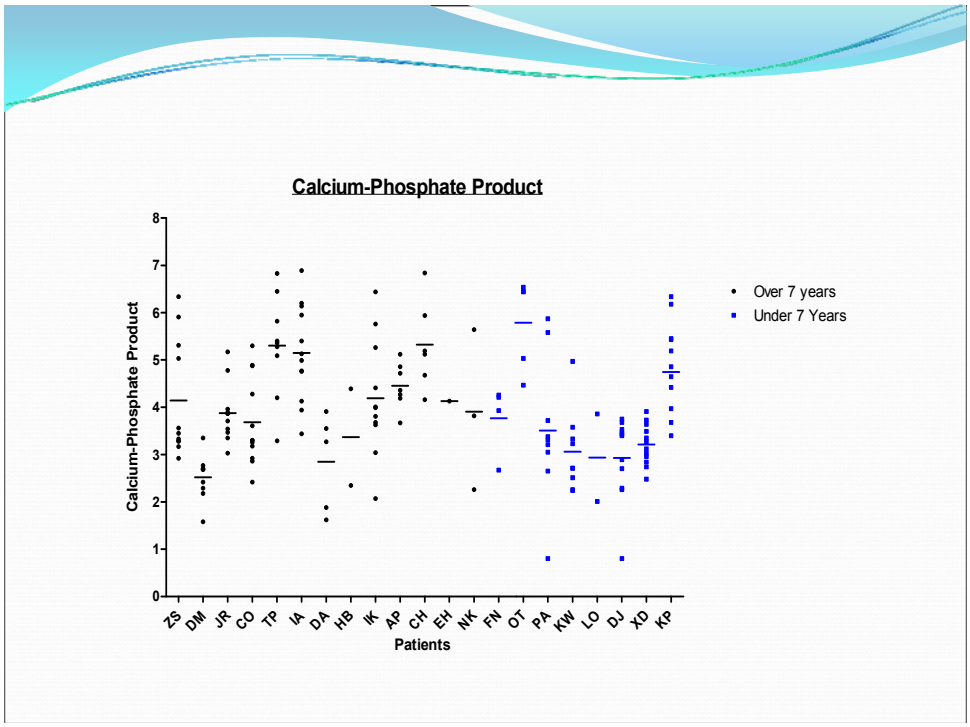

Pre Dialysis Albumin
Albumin (g/L)
55
50
45
40
35
30
25
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 Years
Under 7 Years

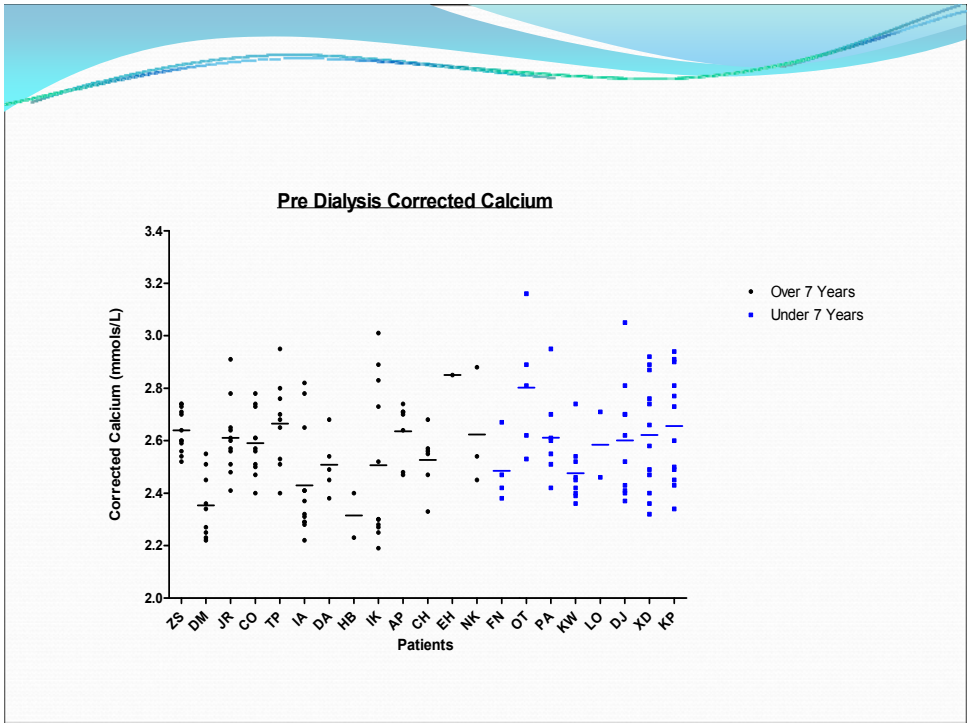

Ferritin
Ferritin (µg/L)
1600
1400
1200
1000
800
600
400
200
0
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 Years
Under 7 Years


PTH
Parathyroid Hormone (pmol/L)
170
160
150
140
130
120
110
100
90
80
70
60
50
40
30
20
10
0
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Legend
Legend


Haemoglobin
Haemoglobin (g/dL)
16
15
14
13
12
11
10
9
8
7
6
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 Years
Under 7 Years


Ultrafiltration
Ultrafiltration (L)
5.0
4.5
4.0
3.5
3.0
2.5
2.0
1.5
1.0
0.5
0.0
-0.5
-1.0
-1.5
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP
Patients
Over 7 years
Under 7 Years

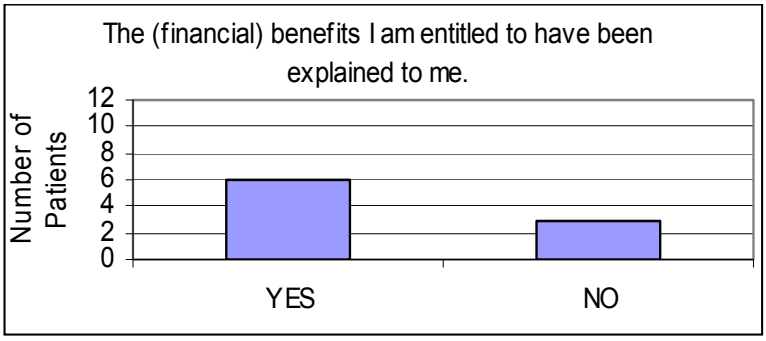
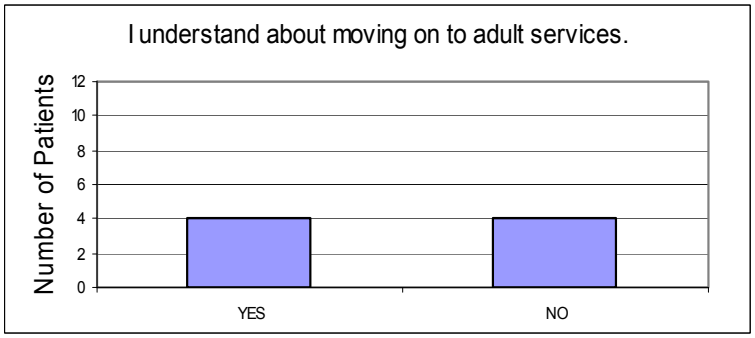
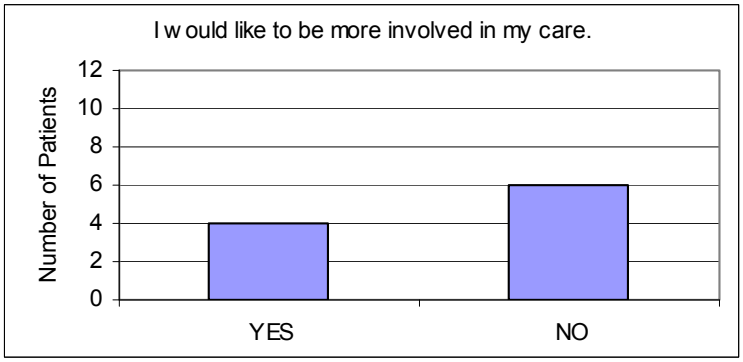

Calcium-Phosphate Product
Calcium-Phosphate Product
Patients
Over 7 years
Under 7 Years
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP


Pre Dialysis Corrected Calcium
Corrected Calcium (mmols/L)
Patients
Over 7 Years
Under 7 Years
ZS DM JR CO TP IA DA HB IK AP CH EH NK FN OT PA KW LO DJ XD KP

10.5 PATIENT REPORT OUTCOME MEASURES (PROM)

Haemodialysis Patient Survey

We recently conducted a patient survey.
Here's what we're doing to solve problems you raised

You Told Us	We're going to…	Target
	Work with the Social services department and with Citizen's advice to write a patient information leaflet on this issue	Six months
	Kate McSweeney, senior staff nurse, will lead on this and develop a better transition process	Six months
	Liz Wright, HD Sister, and Dr Rees will devise a questionnaire to ascertain the ways the patients would like to be more involved. We will ask Lee Robinson from 'Staying Positive' to come to talk to patients during a dialysis session	To start as soon as possible

10.6 Peritoneal Dialysis Audit

April 2009 – March 2010

Eileen Brennan Nurse Consultant, Cecilia McNeice CNS & Tanya Baldwin, Renal Team

Patient Demographics

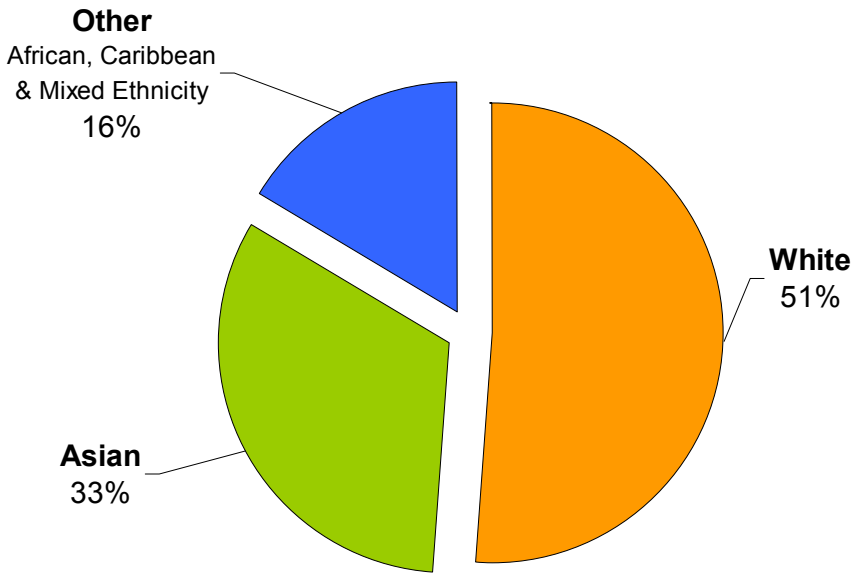
40 patients have been on the PD program

65% Male 35% Female

<u>20 new patients in ESRF</u>

- 17 new packages of care in community
- 3 patients are yet to be discharged
- 3 returned to PD after previous discontinuation
  - 1 – Failed Transplant
  - 1 – CRF Atypical HUS
  - 1 – CRF HUS
- 1 catheter not used as transplanted
- 2 patients deceased

Ethnicity of Patients on PD

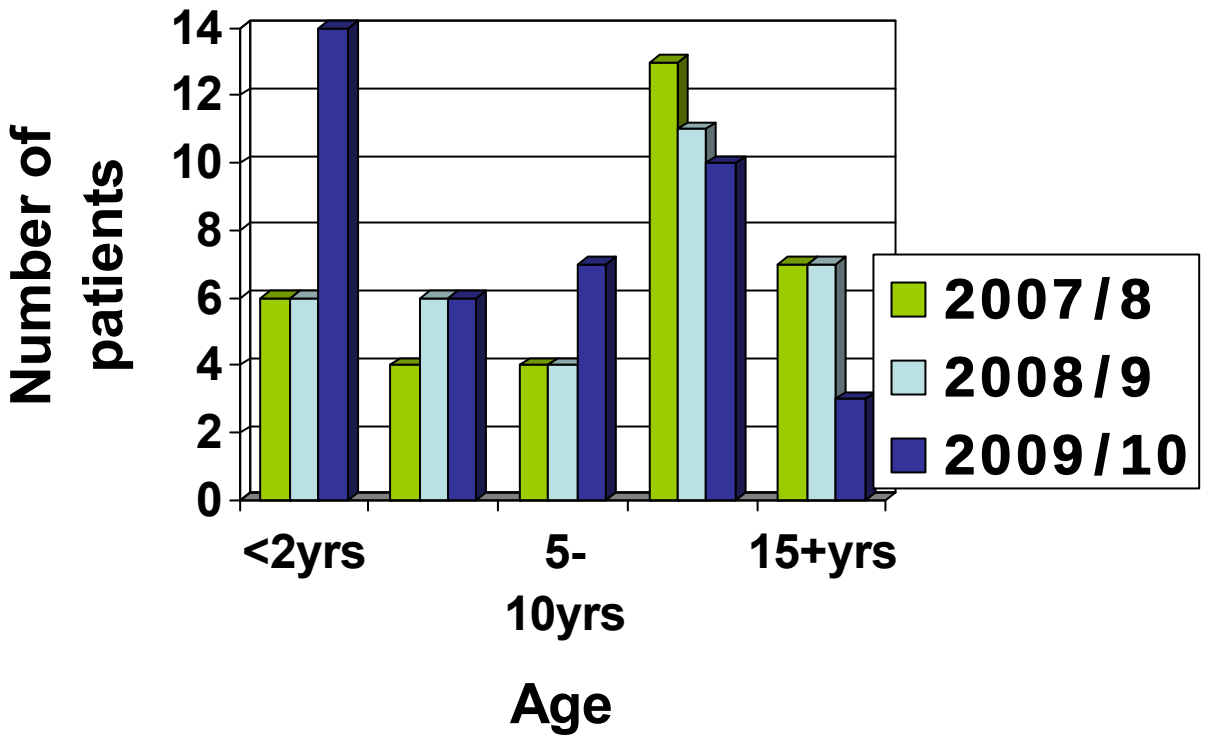


Patient Age

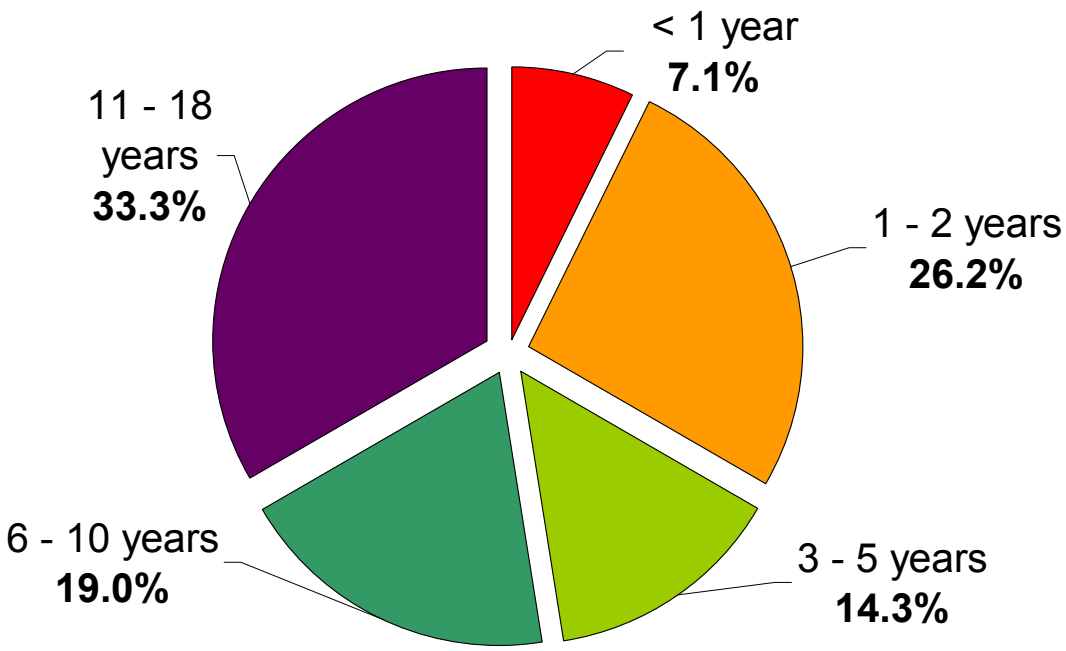
- Children on POC in the community
  Range: 1.06 – 15.86 years (mean 8.4)
- Age of children on ward
  1 – 42 days old
  2 – 27 days old
  3 – 11 months (housing)
- Youngest starting PD – 4 days
- Youngest discharged on PD – 3 months

TOTAL PD MONTHS = 264.25 months

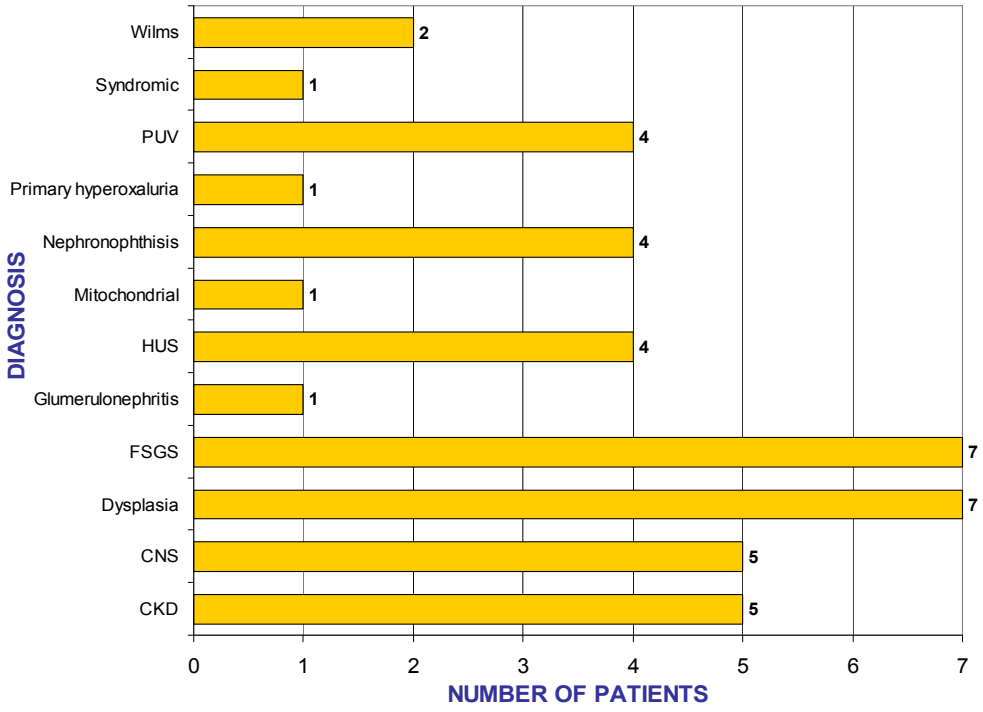
Patient Age Ranges 2007 to 2010



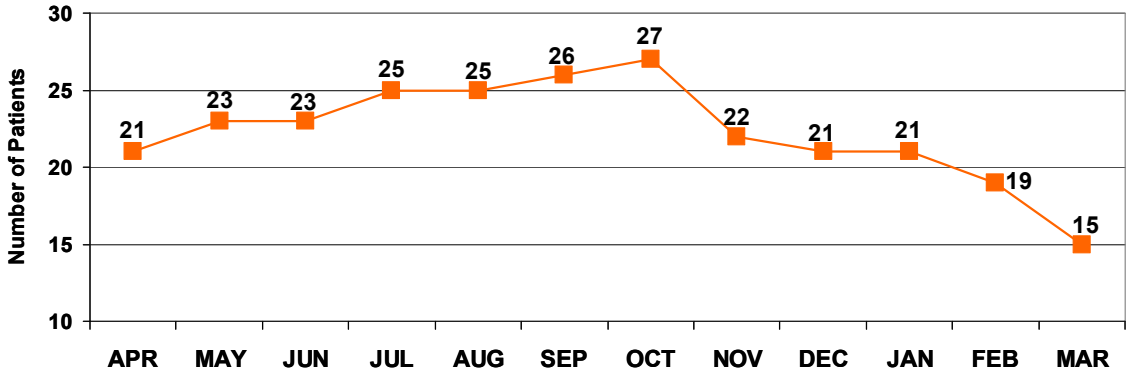
Current PD Patient - AGE



Patients on PD – Primary Diagnosis



PD patient number / month



Discharged Home	2	3	2	2	2	1	2	1	1	1	0	0	17
Off PD	0	1	3	1	1	3	1	3	3	1	4	3	24
Moved to HD	0	0	1	0	1	1	0	2	0	0	2	2	9
Transplant	0	1	2	1	0	2	1	1	3	1	2	1	15

Clinical Nurse Specialist Activity

- **Home visits: 31**
- New families: 19
  - 17 discharged
- Additional training: 13
  - Hospice, nurses, extended families
- Retrained: 4
- School visits: 5
- MDT external meetings: 5
- Brec utilisation: 3 carers, hospice

Peritonitis

40 treated **episodes of peritonitis**

- Eosinophilic: 37.5%
- Culture Positive: 40.0% (25% recurrence)
- Culture Negative: 22.5%

46.7% **of 1st peritonitis episodes after insertion were eosinophilic**

All except 1 of the 13 episodes of this eosinophilic peritonitis occurred in the initial 24 days after catheter insertion

- **Average time to presentation:** 11.5 days after insertion

Peritonitis Definition

ISPD Guidelines: Brandley et al, 2000 **Peritoneal Dialysis International** v20 p610-624.

- Cloudy effluent fluid

- WCC > 100mm and > 50% polymorphonuclear leukocytes (++ Neutrophils)
  - +/- pain
  - +/- pyrexia
  - +/- vomiting
  - +/- abdominal pain

- Relapsing = A recurrence of peritonitis with the same organism within 4 weeks of completion of treatment

Culture Positive Peritonitis

- ORGANISM CLASSIFICATION

10 episodes of GRAM POSITIVE (4 recurrences)
- Coagulase negative Staphylococci: 6 episodes (3 recurrences)
- Streptococcus species: 2 episodes
- Enterococcus species: 2 episodes (1 recurrence)

5 episodes of GRAM NEGATIVE
- Escherichia coli: 2 episodes
- Pseudomonas aeruginosa: 2 episodes
- Other Pseudomonas species: 1 episode

Peritonitis Episode Breakdown

- After removing relapsing episodes
  - 5 gram negative cultures
  - 6 gram positive cultures
  - 5 culture negative (sterile)

- 16 episodes of peritonitis in 264.25 patient months
  = 0.72 episodes per 12 patient months

Current BAPN Guidelines (2007)

Peritonitis rates should be < 1 episode per 12 patient months

Total of 15 episodes in 13 patients

– Outpatients - 11 episodes
  - 2nd to Exit site: 5 episodes
  - Line break:

– Inpatients - 5 episodes
  - 2nd to Exit site: 2
  - Post insertion of catheters: 3

THEREFORE
26 patients peritonitis free
(Plus 2 went straight to HD)

Peritonitis Details – per patient

Patient	Catheters	Eosinophils	Culture Positive	Recurrence	Culture Negative	Recurrence
EW	3	1	Coag Neg Staph	x3	-	-
ER	4	-	Enterococcus	x1	-	-
			Coag Neg Staph	x0		
LA	3	2	E.coli	x0	1	x0
EM	3	-	Pseudo aeruginosa	x0	-	-
			E.coli	x0		
MIM	1	-	Strep	x0	-	-
			Coag Neg Staph	x0		
GO	3	1	Strep	x0	-	-
AS	1	MALTA	? Pseudo aeruginosa	x0	-	-
KT	1	-	Other Pseudo	x0	-	-
SC	1	-	-	-	1	x0
SC	3	-	-	-	1	x3
RS	1	-	-	-	1	x0
AM	4	3	-	-	1	x0
BW	3	1	-	-	-	-
ZM	1	1	-	-	-	-
FN	1	1	-	-	-	-
AFM	1	1	-	-	-	-
PAE	3	1	-	-	-	-
JAR	1	1	-	-	-	-
SD	1	1	-	-	-	-
MM	1	1	-	-	-	-

Exit Site Infections
(red / inflammed / exudate)

Organism	Infections	Treated with AB's	Catheter Removed
Staph aureus	6	6	1
Pseudomonas	2	2	1
No growth Cultured	1	1	0
corynebacter	1	1	0

Exit Site Infections

(red/inflammed/exudate)

	2004 2005	2005 2006	2006 2007	2007 2008	2008 2009	2009 2010
Staph aureus (SA)	8	14 (including colonised)	7	5	7	6
Pseud.	5	5	3	2	0	2
MRSA	0	1	1	0	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	2 1 x SA 1 x pseud*

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

Organism	Number	Treated with AB's
Staph aureus	**4**	**Yes** **2 of 4 became colonised post treatment for ESI**
Coliform	**1**	**No**
Candida	**1**	**Yes**
Pseudomonas	**1**	**Yes** **2 of 4 became colonised post treatment for ESI**

Nasal Colonisation

7 patients had nasal *Staph aureus* carriage:

– **ALL** received topical treatment

– 5 patients had concurrent *Staph aureus* infections at their exit sites

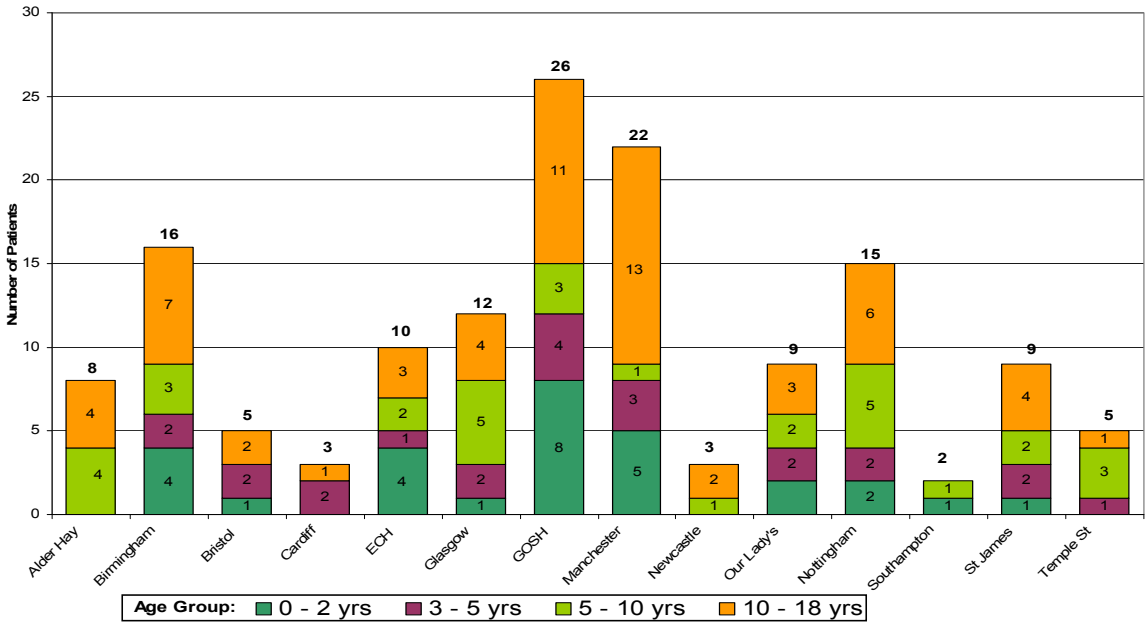
– 2 of 7 showed repeated *Staph aureus* growth.
  • **1 now is mupirocin resistant**

PD Questionnaire

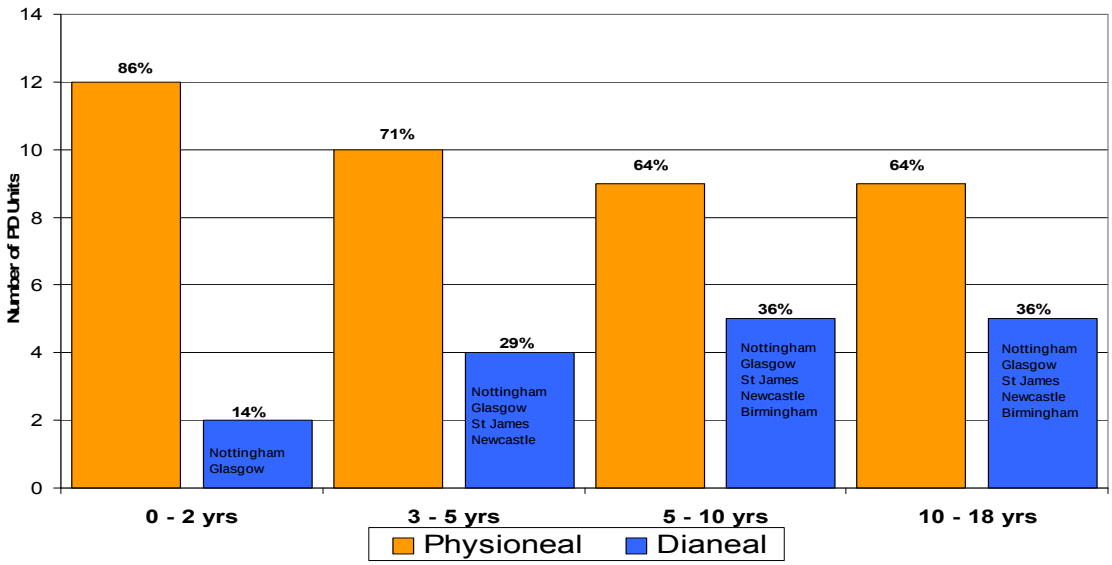
14 Paediatric PD units in UK & Ireland participated in a survey

- Snapshot of:
  - Current PD protocols
  - PD patient numbers and age groups
  - Insight into awareness of eosinophilic peritonitis

Paediatric Hospital PD Patient Number Snapshot & Age Group



What is your dialysate choice in different age groups?



PD Catheter Types & Procedures

- What type of PD catheter do you use?
  - 50% BOTH
  - 36% Kendall Quinton only
  - 7% Flex-neck only
  - 7% Other (Cool UK)
- Do you routinely use heparin to flush new catheters?
  - 79% Yes
  - 21% No
- Do you cycle children when they return following PD catheter insertion?
  - 71% Yes
  - 29% No
- Do you lock off new catheters with heparin?
  - 50% Yes
  - 50% No

Peritonitis Protocols

- What do you use as your standard WCC value for diagnosis of peritonitis?
  - 93% WCC >100
  - 7% WCC > 50
- Do you cycle children for 48hrs when they present with peritonitis?
  - 57% Yes
  - 43% No
- What's your policy for treating children found to be culture -ve with no organisms or growth?
  - 43% - 14 days ab
  - 43% - Stop ab
  - 7% - 7 days ab
  - 7% - 7-10 days ab

Eosinophilic Peritonitis

- Do you test PDF for differential WCC with manual eosinophil count?
  - 7% if WCC >100 routinely
  - 79% only if PD fluid is cloudy
  - 7% does not test
  - 7% unsure
- Have you seen eosinophilic peritonitis on your unit?
  - 57% Yes
  - 21.5% Infrequently / ?
  - 21.5% No
- If you have experience in treating eosinophilic peritonitis how do you treat?
  - 64% No answer
  - 36% use Hydrocortisone, Cetirizine, No treatment, Stop PD

PD Catheter Insertions

HIGH RISK: <1 year of age, Significant oedema, Significant gut problems, Extensive abdo surgery (Nissen, Mitrofanoff, Stoma)

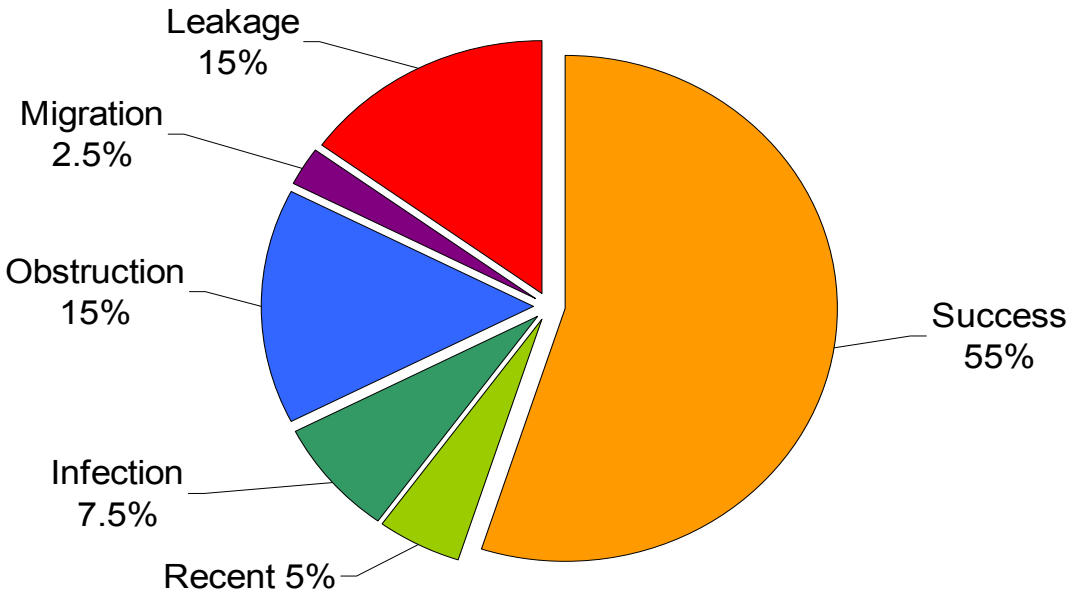
40 catheters were inserted in 2009-2010 by 5 surgeons

– 55% of these insertions involved patients classified as **'high risk'**

- Half of the insertions were on patients who had never before had a PD catheter

40% off all catheter insertions
FAILED within 3 months
- 45% of HIGH RISK catheters failed
- 33% of LOW RISK catheters failed

Reasons for failure within 1st 3 months



Total catheters of current ESRF caseload

Surgeon	Number of Insertions	% Failed	Leaked post op	% High Risk
A	**17**	41 %	29 %	53 %
B	**23**	22 %	9 %	61 %
C	**11**	45 %	36 %	82 %
D	**13**	46 %	15 %	54 %
E	**15**	47 %	53 %	54 %

Acute catheters

14 PD catheters inserted

- 2 were Acute / Chronic
  - *Received a period of PD but not discharged on PD*
- 1 leak - stopped PD
- 1 replaced after 1 week (obstruction)
- 2 transferred in from other hospitals with peritonitis/sepsis
- 1 developed peritonitis while waiting for removal (at home)
- 9 were problem free

Thanks

- Team
- Dr. Lesley Rees
- Dr. Ruckshana Shroff
- Dr. Sarah Ledermann
- Transplant surgeons Guys/Evelina
- Michelle Cantwell
- Tanya Walton
- Cecilia McNeice
- Lynsey Stronach
- Maria Rodriguez
- Anthea Bates
- Victoria ward staff

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 inter-professional framework.

11.1 STAFFING AND CLINICS

Nurse Consultant Eileen Brennan
Ward Sister Sr. Lucy Thomas
Ward Sister Sr. Sarah Matthews

Clinical Nurse Specialists Transplants Sr. Suzanne Bradley (1 WTE)
Sr. CRF Jo Pullen (0.64 WTE)
Sr. LRD Transplant coordinators Maria Scanes (0.64 WTE UKT 0.03 WTE GOSH) & Carol Jennings (0.64 WTE)
Senior Sr. Liz Wright (WTE)
Sr. Michelle Cantwell (WTE) Transplants Senior staff nurse (1 FTE) & Senior Staff nurse (0.74 WTE)

Sisters Sr. Liane Pilgrim, Haemodialysis (WTE)
Mr. David Fisher, Nurse Counsellor (21hrs)
Sr. Trish Evans, Practice Educator (WTE)

Clinics

Nurse Consultant Clinic

Nurse led	Transplantation	Daily reviews
	LRD	Weekly
	Adolescent transition	Monthly
Nurse Consultant	ABPM Hypertension outpatients 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

In progress

11.3 GENERAL 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)

Haemodialysis is currently fully established, however nurses rotating and on maternity leave occasionally stretch the service. Generally they service has been well supported and has delivered the care required including providing successful End-stage HD for our smallest infant to date.
The nursing team continues to attempt to deliver a service. 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 small increase in nursing establishment in the unit has been used to provide more resources to the haemodialysis unit and clinic areas.

With the increase of staff numbers the number of refuse admissions has reduced. 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. Talks are ongoing to possibly re-establish this service at GOSH

11.4 Events 2009/10

- GOSH assisted in the organization of the annual Paediatric Nurses Nephrology Conference in Bristol. It was attended by over 100 paediatric nephrology nurses representing every unit in England, Wales, Scotland, Northern and Southern Ireland, play specialists and dieticians.

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

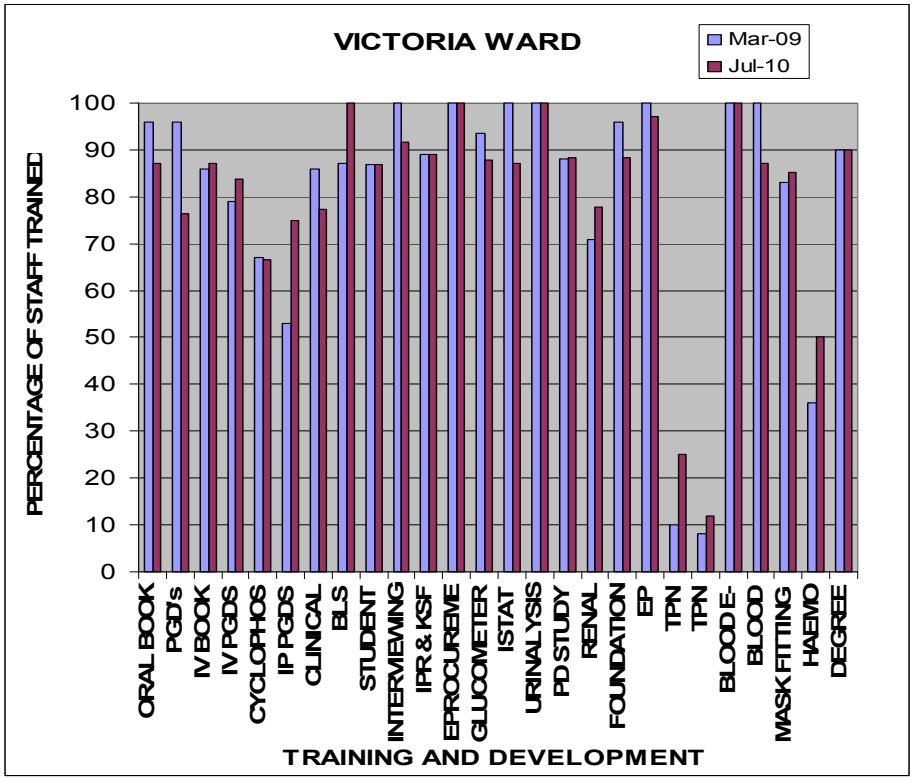
11.5 EDUCATION

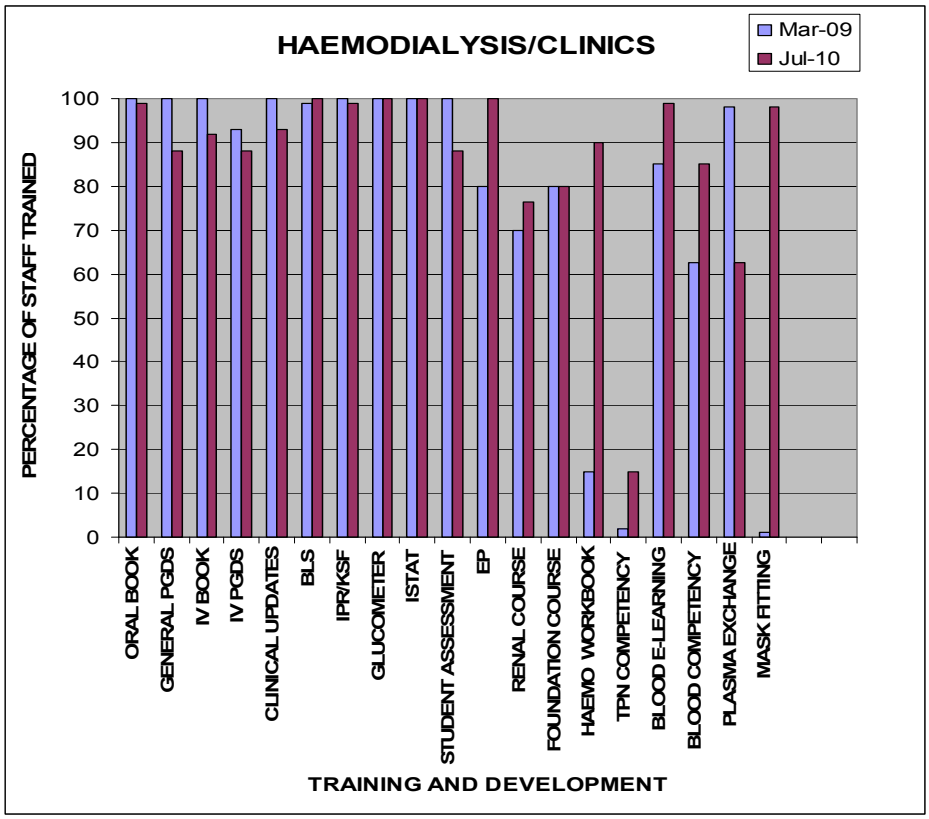
The Team continues to develop in new areas this year, phlebotomy and canulation and haemodialysis has been exemplary.

The role of the Nurse Independent prescribers continues to develop the nurse led service in this area We have 5 non medical prescribers within the Renal Unit and 1 due to commence the course next year.

Non medical prescribers
Eileen Brennan
Liz Wright
Michelle Cantwell
Liane Pilgrim
Lucy Thomas

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.





Average % of Nursing Staff Trained in Core aspects: 80% - Victoria
Average % of Nursing Staff Trained in Core aspects: 90% - Haemo

6 new members of staff between March and June on Victoria
2 new members of staff on Haemo

CPD

Renal WBL Degree and Masters Level Course with LSBU:
(Assessment Criteria: 4 Reflective Logs and Oral Viva)
11 Staff Nurses commenced in March: 6 Degree Level, 5 Masters Level,
3 referred in their reflective logs and will need to re-submit later in the year
8 progressed to Oral Viva's and all 8 successfully passed the module - provisional results August 2010

Foundations of Paediatric Renal Nursing:
Next course running in Sept 2010 – Assessment Criteria: Workbook, Presentation/Teaching Package and Clinical Competency booklet
8 staff members attending – HCA and Band 5's - on completion 100% of staff in renal unit will have attended this course.

Play Specialist offered place on this course but her manager refused to agree to let her attend.

Have also offered two places to IPP in preparation for Private Patient Transplants

In-Charge Study Day
(Scenarios and Clinical Competency Booklet)
Next day running in December – 5 SN attending – on completion 100% of staff eligible will have attended and working toward competencies

Simulation Training
Band 5 & 6 days replaced with a days Simulation Training in Sept – Paul Hunt (CSP) facilitating.

Haemodialysis Rotation
At present 2 staff members a year do rotation – workbook and competencies attached.
Plan to Divide workbook into Core and Advanced Skills (similar to PD workbook) and rotate staff for 3-4 months instead of 6 months – will gain by ensuring 3 – 4 nurses are trained a year instead of 2 – ready for Eagle Ward 2012.

11.6 Presentations

Eileen Brennan:
First line approach to hypertension. Diagnosis & Investigations
Nephrology for General Paediatricians November 09

Dialysis workshop, Paediatric Nephrology Course ICH 2010
ABPM in children Paediatric Nephrology Course ICH 2010

Hazel Webb:
Dialysis workshop Paediatric Nephrology Course ICH 2010

Eileen Brennan:
Chaired. Annual Conference Special Interest Group for Nursing:
Paediatric Nephrology. March 2010 Bristol

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!)

Maria Scanes:
Paediatric Nephrology Course ICH 2010
Presentation “Advances in Paediatric Renal Transplantation”

Carol Jennings:
Paediatric nephrology Course ICH 2010-09-07
Presentation – Living Donor Transplant, Gift or Burden

Maria Scanes:
British Transplant Society, London March 2010-09-07
Poster presentation – Blood Group Incompatible Transplants in Children

Liz Wright:
Haemodialysis workshop, Paediatric Nephrology Course ICH 2010

11.7 ACADEMIC ACHIEVEMENTS

Liz Wright – successfully completed 2 modules of MSc pathway: 'Underpinning physiological principles for nurses' and 'Assessment of the presenting child'.

11.8 Outreach commitments

Eileen Brennan:	Chair of the special interest group for paediatric nephrology NICE guidelines for RCN Workforce Planning
Michelle Cantwell:	Contribute to the International Pediatric PD Network (IPPN):
Anthea Bates	This year was the launch of our new Database for PD and Haemodialysis developed by Anthea Bates. We used this for the first time for the PD audit. We have also been able to audit PD catheter insertions which will be presented at GUY's hospital to the transplant team. This will be used to monitor practice with the aim of improve practice.
Maria Scanes Carol Jennings	Represent GOSH as the link with NHSBT (UKT), submit report re activity 3 monthly

12. DIETETIC REPORT

April 2009 – March 2010

12.1 Staffing

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

Shelley Cleghorn	Principal Dietitian and Team Leader
Bahee Manickavasagar	Specialist Dietitian
Louise McAlister	Specialist Dietitian
Graeme O'Connor	Specialist Dietitian
Vanessa Shaw	Head of Dietetics
Carolyn Southey	Specialist Dietitian

Due to CRES savings imposed this financial year posts have been held vacant so our establishment of 3.0wte has been reduced to 2.6wte. 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.

12.2 Teaching and Education

Vanessa Shaw is the Education Officer of the British Dietetic Association's Paediatric Group and is Professional Lead for the MSc in Paediatric Dietetics, hosted by the University of Plymouth from September 2009. This is the first MSc dedicated to paediatric dietitians and as such attracts international students. The renal dietitians teach on this MSc course.

The renal dietitians were also involved with in-house education and training events delivered to the multi-disciplinary team on nutrition and dietetic topics.

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

Vanessa Shaw and Bahee Manickavasagar lectured on Premature Infant Feeding and Feeding Difficulties in Children to Dietetic students (undergraduate and postgraduate) at Kings College London and London Metropolitan University.

Graeme O'Connor lectured on the MSc Nutritional Medicine at the University of Surrey on Anorexia Nervosa and at the International Eating Disorders Conference, ICH, London on Refeeding Syndrome.

Bahee Manickavasagar lectured on the Nutritional Management of Short Bowel: Dietetic Issues at the Intestinal Failure Symposium, La Plagne, France.

The team keeps active membership of the Paediatric Renal Nutrition Interest Group and Shelley Cleghorn chairs the Group.

12.3 Publications, Presentations, Awards, Appointments

Mekahli D, **Shaw, V**, Ledermann S, Rees, L (2010) Long-Term Outcome of Infants with Severe Chronic Kidney Disease. Clin J Am Nephrol 5: 10-17.

O'Connor G and Goldin J (2010) The Refeeding Syndrome and Glucose Load. Inter J Eating Disorders 2 Feb 2010 DOI: 10.1002/eat.20791.

Vanessa Shaw was awarded Manager of the Year at GOSH Staff Recognition Awards.

Vanessa Shaw is a co-opted member of the Advisory Committee on Borderline Substances which advises the Department of Health on special feeds and foods that can be prescribed as drugs.

Graeme O'Connor is a member of the Royal College of Psychiatrists' MARSIPAN Junior working group which is developing NICE Guidelines for the Management of very sick children with anorexia nervosa.

12.4 Improving patient care

Child protection
Bahee Manickavasager is a link member for Child Protection.

Resources
The following diet sheets/booklets have been produced or updated over the last 12 months:
High energy
Iron for children with kidney disease
Nutrition section of the Transplant booklet
Renal section of the ward nutrition folder

Journals
Monthly renal journal club sessions
Review of KDOQI Clinical Practice Guideline for Nutrition in Children with CKD: 2008 Update and impact on dietetic practice

Products
The team has been involved with Vitaflo in the formulation if 2 new renal feeds: Renastart, an infant formula; Renacal, a sip feed for older children