GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS TRUST

RENAL UNIT ELEVENTH ANNUAL REPORT

April 2010 to April 2011

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1. INTRODUCTION

The renal unit annual report now moves into its second decade. We continue to describe the cumulative changes in staffing, facilities, workload, clinical audit results and teaching undertaken by the renal unit, focussing on the year between April 2010 and April 2011.

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 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 323 beds are arranged in 31 wards and day care units and include 32 intensive care beds (PICU, NICU and CICU). There are ten operating theatres in use performing over 17,500 operations per year. There are over 175,000 patient visits to GOSH each year (inpatients admissions and outpatients).

The Trust employs a total of 3,600 staff. The Chief Executive is Dr Jane Collins and the Co-Directors of Clinical Services are Mr. Martin Elliott and Dr. Barbara Buckley. The Nephrology Unit reports to the Division of Medicine, led by Dr. Melanie Hiorns as Clinical Unit Chair and Ms. Jacqui Allan as General Manager. The Nephrology Unit is led by Dr. Lesley Rees. 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 513 admissions to the Renal ward, 93 admissions to outlying wards, 7166 outpatients, 21 new renal transplants, 40 patients on chronic haemodialysis and 29 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 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 a play therapist.

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	7.3PAs in Paediatric Nephrology
Dr Sarah Ledermann	Associate Specialist, 6 PAs in Paediatric Nephrology
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 Martin Drage, led by Mr Geoff Koffman.
There are 4 Urology Consultants: Mr Peter Cuckow, Mr Imran Mushtaq, Mr Abraham Cherian and Ms Naima Smeulders (locum appointment).

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 Sr. Lynsey Stronach 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.ucl.ac.uk/ich/research-ich/nephro-urology

The UCL Institute of Child Health (ICH) together with its clinical partner Great Ormond Street Hospital for Children (GOSH), forms the largest concentration of children's health research outside North America.

The Nephro-Urology Unit at ICH was formed in 1997 under the supervision of Professor Adrian Woolf and moved into its extensively refurbished laboratory in 1998. The Unit currently comprises a Unit Head (Dr Paul Winyard, Reader in Nephrology), a Reader in Paediatric Nephrology (Dr Lesley Rees), a HEFCE Clinical Lecturer (Dr Detlef Böckenhauer), one Senior Non-Clinical Researcher (Dr David Long, Kidney Research UK Senior Non-Clinical Fellow), as well as post-doctoral research fellows, clinical research fellows and graduate students. There are strong clinical links with GOSH, with all of the Consultants in Nephro-Urology afforded Honorary Senior Lecturer status to facilitate research collaborations and the unit has two Academic Clinical Fellows in Nephrology.

Our overall mission is to improve the diagnosis, treatment and prognosis of children with kidney and urinary tract diseases by high quality basic science and clinical research. 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 and with the Fetal Medicine Unit at University College Hospital.

Current active projects include: the genetics and cell biology of normal and abnormal development of the kidney and urinary tract; functional restoration of abnormal genitourinary tracts; the renal vasculature and hypertension; nephrotic syndrome and vasculitis; the clinical consequences and treatment of kidney failure in children; control of differentiation of epithelial and endothelial cell lineages; genetics and cell biology of renal tubular disease; nutrition, growth and bone turnover in children with renal failure. In addition, the unit has been very successful in academic training of PhD, MD, MSc and both national and international visiting fellows. The unit also organises and hosts the prestigious annual Paediatric Nephrology and Urology week and initiated the Kidney Development workshop, which has now expanded into the yearly European Nephrogenesis workshop. The Unit receives funding from the Kidney Research UK, Action Medical Research, the Medical Research Council, the Wellcome Trust, the Kids Kidney Research and several other sources.

Individual research interests

Dr. Paul Winyard

My research follows three major strands:
1) Normal and dysplastic human renal precursor cells. Working with Dr. Karen Price we have generated a panel of normal and abnormal human cell lines from human fetal and postnatal dysplastic kidneys with which to investigate key processes *in-vitro*. These stem-like cells are unique, and no-one else in the world has been able to generate comparable human lines and we are now generating more with amniotic-fluid derived cells. Capacity to promote normal differentiation *in-vitro*, raises the possibility of using these cells as therapies *in-vivo*.
2) Galectin-3 in normal and cystic kidney development. I am investigating roles of galectin-3 in cystic renal disease. Our earlier work suggested this lectin may be a natural brake on cyst formation. I am currently investigating galectin-3 gene therapy *in-vivo* in the *cpk* model. Novel therapies arising from this study may be applicable to humans with PKD in future.
3) My clinical research (and practice) centres on children with kidney malformations, particularly those that present before birth. I work with Dr Lyn Chitty (Fetal Medicine and Genetics) and Mr Divyesh Desai (Paediatric Urology) in a dedicated Fetal Nephro-Urology clinic at UCLH to investigate kidney/urinary tract malformations. Proteomic analysis of amniotic fluid has identified several markers that look promising for use in routine clinical practice.

- Kolatsi-Joannou M., et al. Modified citrus pectin reduces galectin-3 expression and disease severity in experimental acute kidney injury. *PLoS One.* 2011 ;6: e18683.
- Price KL., et al. Microarray interrogation of human metanephric mesenchymal cells highlights potentially important molecules in vivo. *Physiol Genomics*. 2007 28:193-202.
- Winyard P., Jenkins D. Putative roles of cilia in polycystic kidney disease. *Biochim Biophys Acta* 2011 (May 8, e-pub ahead of print).

Dr. Detlef Böckenhauer and Professor Robert Kleta

Dr Böckenhauer is a clinician scientist, working as a paediatric nephrologist at GOSH and as a HEFCE Clinical Lecturer at ICH. The aim of his research is to define the precise molecular pathways which are broken in patients with kidney disease. Where the root cause of kidney disease is unknown, exposure to various treatments is a “hit-or miss” approach. Understanding the molecular basis, in contrast, allows a more rational approach. Since the majority of kidney diseases in childhood are congenital, genetics is an obvious tool to unravel the pathophysiology. To this end, Dr Böckenhauer works closely with Professor Robert Kleta. Both lead a multidisciplinary team linking paediatric and adult nephrology based at GOSH and Royal Free Hospital within the academic setting of the ICH and UCL. They utilise up to date genetic technology including linkage analysis and whole genome association studies. Recent successes include the description of a previously

unrecognised multi-system disorder, which they named EAST syndrome, an acronym for the cardinal symptoms of epilepsy, ataxia, sensorineural deafness and tubulopathy. The underlying genetic basis is mutation in a potassium channel, called KCNJ10 and the team is now working to develop models to investigate potential treatments. Another recent success is the discovery of 2 genes associated with membranous nephropathy. Again, this discovery provides a basis for the development of improved diagnostic tests and rational treatment.

- Bockenhauer D., et al. Epilepsy, ataxia, sensorineural deafness, tubulopathy, and KCNJ10 mutations. *N Engl J Med*, 2009, 360: 1960-70.
- Stanescu, HC., et al. Risk HLA-DQA1 and PLA(2)R1 alleles in idiopathic membranous nephropathy. *N Engl J Med*, 2011, 364: 616-626.

Dr Daljit Hothi

The relationship between hypertension and cardiovascular morbidity has long been recognised. However evidence is mounting implicating hypotension and not hypertension as the predominant risk factor for mortality in haemodialysis patients. I demonstrated a 20-30% prevalence of intradialytic symptoms and hypotension in children during conventional, 4 hour haemodialysis (HD) sessions. The declining blood pressure (BP) was originally believed to be caused by ultrafiltration (UF) and priming of the HD circuit due to loss of fluid from the intravascular space. However data, largely in adults, challenged this hypothesis leading to a new consensus that intradialytic hypotension has a multifactorial aetiology. The uraemic milieu triggers a series of events that alters the cardiovascular compensatory responses to haemodynamic stresses, however the extent to which these physiological responses are impaired and their consequences are unknown and poorly understood. We corroborated adult findings that a poor correlation existed between relative blood volume changes and intradialytic hypotension in children, supporting the theory that fluid removal alone was not responsible for cardiovascular decompensation during HD. Using a traditional method (endocardial wall motion) and a novel method (Speckle tracking 2-dimensional strain) we then demonstrated acute dialysis induced regional myocardial dysfunction. The level of dysfunction significantly correlated with actual BP, the degree of intradialytic BP fall and UF volumes. Pursuing this trail we are planning a longitudinal study to determine the long-term consequences of acute HD induced myocardial injury. Finally we are investigating how alterations in the conventional dialysis prescription abrogate intradialytic morbidy in children. We have tested sodium profiles, UF profiles, prophylactic mannitol, sequential dialysis and intradialytic midodrine. Our next objective is to examine the effects of cooling during HD, haemodiafiltration and quotidian dialysis.

- Hothi DK., et al. Pediatric myocardial stunning underscores the cardiac toxicity of conventional hemodialysis treatments. *Clin J Am Soc Nephrol.* 2009 4 :790-797.

Dr. David Long

1) Identifying new biomarkers and therapeutic targets in early kidney disease. Defects in the glomerular filtration apparatus lead to albuminuria; an early warning sign for several chronic glomerular diseases including diabetic nephropathy. Therefore, the discovery of molecules deregulated in "leaky" glomeruli may suggest novel biomarkers and therapeutic targets in early kidney disease which is the focus of my work. One recent discovery, in collaboration with Professor Adrian Woolf and Professor Luigi Gnudi (King's College London) was the demonstration that the angiopoietins, vascular growth factors involved in the formation of blood vessels play a key role in this process. My on-going studies funded by a Kidney Research UK Senior Non-Clinical Fellowship involve understanding how angiopoietins influence glomerular biology and how this contributes to albuminuria using a combination of genetic and proteomic approaches. These studies have enabled the identification of other potential genes that may play a role in albuminuria.

2) Planar cell polarity and the glomerulus In studies with Dr Jenny Papakrivopoulou we have investigated planar cell polarity genes which control cell shape, movement and division through cytoskeletal organisation in the glomerular podocytes. Our hypothesis is that podocyte shape is essential to maintain the structure and function of the glomerular filtration barrier; hence alterations in planar cell polarity genes could impair glomerular development and function. We have been using the Loop-tail model with a loss of function mutation of Vangl2, a core planar cell polarity gen and showed Vangl2 is required for kidney branching morphogenesis.

3) Angiogenesis in renal health and disease. A long-standing research interest is investigating endothelial damage and unsatisfactory vascular repair in chronic kidney disease (CKD) and whether this is due to disturbance of vascular growth factors. In collaboration with Professor Adrian Woolf and Professor Rick Johnson at the University of Denver, we have performed several studies using gene delivery of pro-angiogenic compounds as a potential novel therapy for kidney disease. At a more translational level, I am working with Rukshana Shroff and Lesley Rees to examine vascular growth factors in their population of children with CKD. In related studies, Jennifer Huang, a PhD student is investigating the balance between angiogenesis and lymphangiogenesisis in polycystic kidney disease.

- Davis B., et al. Podocyte-specific expression of angiopoietin-2 causes proteinuria and apoptosis of glomerular endothelia. *J Am Soc Nephrol*. 2007, 18: 2320-2329.
- Long DA., et al. Angiopoietin-1 therapy enhances fibrosis and inflammation following folic acid-induced acute renal injury. *Kidney Int*. 2008 74: 300-309
- Yates LL,. et al. The planar cell polarity gene Vangl2 is required for mammalian kidney-branching morphogenesis and glomerular maturation. *Hum Mol Genet.* 2010 19:4663-4676.

Dr Stephen Marks

Dr Stephen Marks is a consultant paediatric nephrologist and clinical lead for renal transplantation at GOSH. His research continues to date in the fields of renal transplantation (including innovative drug trials concerning new anti-rejection therapies and assessment of children post-renal transplantation), systemic lupus erythematosus and vasculitis (including studies of the aetiopathogenesis, management and outcome of childhood onset SLE and lupus nephritis) and hypertension (including genetic linkage and familial studies of renovascular hypertension and clinical studies on the management and long-term prognosis of children with renovascular hypertension).

- Marks SD., et al. Renal FMD may not confer a familial hypertensive risk nor is it caused by *ACTA2* mutations." *Ped Nephrol* 2011; in press.

Dr. Lesley Rees

Major complications of CKD in childhood: identification of the causes and investigation of possible therapeutic strategies

It is estimated that 10% of the world's population has CKD leading to early mortality. In the UK >30,000 people are dialysed or transplanted and many more have less severe CKD. In a significant subset CKD originates in childhood; it is likely that these children will develop the same complications as adults at a proportionately earlier age. Medical advances have led to the ability to treat even the youngest children with CKD with dialysis and transplantation. However, many children suffer from handicaps due to poor growth and renal bone disease. In addition, young adults have a risk of death from cardiovascular disease equivalent to an 85 year old. The main focus of my research has been to investigate these 3 most significant, and inter-related, complications. My key objectives are to reduce morbidity by improving understanding of the causes and to identify preventative measures or treatments, aiming to reduce the burden of CKD morbidity and mortality in adult life, allowing the best use of NHS resources. This work has been conducted using clinical, basic science and translational research.

1) Growth in CKD **(with Dr. Sarah Ledermann) -** Nutrition is the most important factor in the prevention of growth failure in CKD, and can influence final height. We are part of an international study, evaluating the benefits of enteral feeding in infancy and, in our unit, its benefits in older children. We are recognised worldwide for our feeding programmes and our work is quoted in international nutritional guidelines.

2) Renal bone disease (**with Dr. Rukshana Shroff**)**-** Renal bone disease is a cause of poor growth, pain and deformity. We are analysing the results of a recently completed randomised, controlled trial of nutritional vitamin D in the prevention of hyperparathyroidism in early CKD and also studying the part played by FGF23 in the evolution of bone disease. Previous studies in this area have gained our unit an international reputation, and helped to provide an evidence base for treatment protocols for children.

3) Cardiovascular disease (CVD, **with Rukshana Shroff*) -*** Perhaps the most important complication of CKD in childhood is the 700-fold increase in mortality from CVD in young adult life. Recently, vascular calcification has emerged as one of the most significant causes of cardiovascular mortality in

CKD. Our current research is focusing on its relationship with the biochemical abnormalities of renal bone disease. We are looking to see if normalisation of activated vitamin D blood levels can influence the progression of markers of vascular disease in a cohort of children who were first studied on dialysis 2 years ago. We have developed the first in-vitro model of intact human (paediatric) arteries and have shown a significantly increased tendency to calcification in vessels from children on dialysis, due to apoptosis of vascular smooth muscle cells and conversion to a bone generating phenotype. We are now studying the effects of Vitamin D receptor activators on vessel calcium uptake, vascular smooth muscle cell damage and calcification.

- Borzych D., et al. The bone and mineral disorder of children undergoing chronic peritoneal dialysis. *Kidney Int*. 2010, 78:1295-304.
- Mekhali D., et al. Long term outcome of infants with severe CKD. *Clin J Am Soc Nephrol* 2010 5: 10-17
- Shroff RC., et al. Dialysis accelerates medial vascular calcification in part by triggering smooth muscle cell apoptosis. *Circulation.*2008 118: 1748-1757

Dr Rukshana Shroff

I am a Consultant Paediatric Nephrologist involved in the care of children with chronic kidney disease and dialysis at Great Ormond Street Hospital. I have a PhD from University College London investigating cardiovascular risk factors in children with kidney disease. Through multicentre studies and translational research that includes major clinical and laboratory components, I have investigated the impact of modifiable risk factors on the vasculature in children on dialysis and have explored the role of vitamin D on vascular health. I plan to continue my research exploring the role of different vitamin D analogues in vascular calcification through clinical and in vitro studies. I have formed successful collaborations with basic scientists and clinicians across Europe and am involved in a longitudinal study of long-term outcome of cardiovascular risks of childhood CKD. I am co-supervising a PhD student who is working on endothelial dysfunction in CKD

Professor Pete Scambler, Professor Adrian Woolf and Dr. Jolanta Pitera.

Fraser Syndrome is a multisystem human birth defect characterised by a skin fold over the eyes, webbed digits and/or toes together with renal defects. A strikingly similar set of features occur in mouse “blebbed” mutants. We have used human and mouse genetics to identify the genes mutated in these disorders. The genes encode three large extracellular matrix proteins (Fras1, Frem1, Frem2) and an intracellular adapter protein (Grip1) which are required for normal skin adhesion early in development, and formation of the kidney. Loss of any one of these proteins appears to affect the stability of the entire complex, disrupting the basement membrane of epithelia and signalling during renal induction (and subsequently). Our current work centres upon examining the signalling pathways affected by loss of the Fraser complex. We have been able to achieve rescue of the defect by up-regulating a signalling pathway involving the ligands Gdf11 and Gdnf in ex vivo kidney culture. In vivo, up-regulating receptor tyrosine kinase signalling using a loss of function sprouty 1 allele can rescue the lethality observed in Fras1 mutants. In other

words, whereas mice lacking Fras1 die, a few “rescued” animals may survive to birth. We are currently examining post-natal requirements for Fras1 using conditional mutagenesis. All together, our work aims to identify pathways that could allow us to rescue defective renal development.
- Pitera,JE., et al. 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*. 2008 17, 3953-3964.

Dr Kjell Tullus
I do studies in several areas including:

1) **Hypertension,** mainly in our very large group of children with renovascular hypertension. We are studying the aetiology for renovascular hypertension and also our long-term results of angioplasty, stenting and surgery. We have also described results in the group that has got Mid Aortic Syndrome.
2) **Lupus and other vasculitides.** We have published on our experience with novel treatments of rituximab and MMF. We are starting a study on cardiovascular problems among these children where we will measure a number of different markers for cardiovascular disease and also several physiological studies of their vasculature.

- Kazyra I., et al. Mycophenolate mofetil treatment in children and adolescents with lupus. *Arch Dis Child.* 2010 95: 1059-1061.
- Stadermann MB., et al. Results of surgical treatment for renovascular hypertension in children: 30 year single centre experience. *Nephrol Dial Transplant.* 2010 25: 807-813.

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. CLINICAL GOVERNANCE

The renal unit is committed to achieving excellence in patient care and has a pro-active approach to the seven pillars of clinical governance.

2.1 RISK MANAGEMENT

The renal risk group comprises of the HD sister, ward sister and renal team patient safety lead. The team reviews local critical incidents monthly, or immediately if any are deemed 'high risk' and where necessary undertake root cause analyses. In addition the risk management lead holds a meeting with the trust risk management team monthly to inform of local objectives, and update the risk register. We have also implemented a number of controls locally in response to our operational, financial and clinical risks.

- We have initiated a number of audits after identifying recurring risks within the unit
- Owing to repeated steroid prescription errors we developed a protocol for steroid prescribing locally and this has reduced the number of errors.
- Having identified that patients with Joubert syndrome present unacceptably late to the renal team we reviewed the patient journey and referral process of these patients and have made several recommendations for improvement.
- Children on haemodialysis are dependent on their treatment to sustain life. With this in mind we have identified a 'never event'- a situation where the haemodialysis unit, for whatever reason, is not operational and children cannot be dialysed. We are developing a contingency plan both for staffing and activity with the objective to meet the dialysis needs of patients during emergencies.
- Owing to the perceived high number of refused and delayed admissions to the unit in order to appropriately plan for renal capacity in the future we developed an audit of delayed and refused admissions. Owing to the success of this project this audit has been developed further to a database that will capture data on activity, missed activity and readmissions. We hope this database will identify and subsequently reduce the financial risk from inaccurate from data used for coding, costing and activity.
- because GOSH dialysis are managed by the liver team at Kings College Hospital following liver transplantation, we actioned a service level agreement with the Evelina Hospital for their renal team to manage and supervise these patients renal care while they as inpatients at Kings Hospital. This has been agreed and is now implemented.
- A number of service development initiatives have been implemented to address clinical, operational and financial risks and improve efficiency within the unit.

2.2 AUDIT

We have registered 11 local projects with the trust audit team. Projects are selected in-keeping with trust audit objectives, to monitor practice within high risk activity and to benchmark against national standards of practice.

- *Audit of delayed and refused admissions to Victoria Ward*
  The aim of this audit was to determine the rate and outcomes of delayed and refused admissions to Victoria Ward to inform capacity requirement in the renal unit. This was in response to a recognised operational risk within our unit
- *Blood Pressure Monitoring*
  The aim of this audit was to determine the accuracy of blood pressure monitoring within the Trust and thus ascertain the rate of appropriate referrals to the renal team for the management of genuine hypertension. This was in response to operational risk and perceived process failure within the trust.
- *Washed RBC*
  The aim of this audit is to , and evaluate the benefits of washed cells compared to standard red cells to prevent HLA sensitisation,
- *Eosinophilic peritonitis*
  The aim of this audit was to determine the incidence of eosinophilic peritonitis within our unit and describe our success in managing it, in children on PD. This was performed in response to a clinical risk that was identified within the unit.
- *Deceased Donor Renal Transplantation*
  The aim of the audit is to evaluate GOSH deceased donation rates and barriers to donation. This was in response to a national directive and to benchmark against practices achieved nationally.
- *Audit of EBV disease and PTLD post renal transplantation*
  The aim of this audit was to determine laboratory EBV surveillance practice after changing from a qualitative to a quantitative test. The secondary aims were to identify the risk factors and prevalence of EBV disease post transplantation. Through using the data collected we hope to be able to improve our practice in reducing the risk of EBV and PTLD in our renal transplant patients.
- *Gastrostomy feeds for children 2 yrs and above with CKD*
  The aim of this audit is to evaluate referral of children older than 2 years for a gastrostomy if growth is being compromised. This was in done in recognition of the fact that our local standard of care exceeds international practices and developing measures to ensure that this high standard of care is being maintained.
- *Haemodialysis clinical outcomes*
  To determine the clinical outcomes of children on conventional HD and HDF within the dialysis unit. This is being done to benchmark local practice against national standards of care.
- *Peritoneal dialysis clinical outcomes*
  The aim of the audit is to determine the clinical outcomes of children on peritoneal dialysis at GOSH. The rationale for the audit is to compare practice to national standards and to benchmark our practice against other units nationally and internationally.
- *Renal Transplant clinical outcomes*
  The aim of this audit is to determine the clinical outcomes of children who have received renal transplants at GOSH. The rationale for the audit is to benchmark our practice against other units nationally and internationally.

- *PD access and associated complications*
  The aim of this audit was to determine the prevalence, nature, and treatment of PD catheter complications within our unit and compare this to local and national standards of care. This audit was done in recognition of the perception that complication rates in our PD patients was rising and thus determine at risk patients, potential confounders and a review of the care pathway.

2.3 CLINICAL EFFECTIVENESS & RESEARCH

Monitoring the safety and efficacy of the medicines we use in the renal unit is especially important as so many are used either off-label, unlicensed or as unlicensed 'specials'.

Protocols are reviewed in line with NICE guidelines (eg constipation guideline) and the Immunisation guidelines prior to transplantation are frequently reviewed in line with Department of Health recommendations. Within the unit protocols are regularly reviewed and updated (e.g.Nephrotic syndrome, Anaemia management in CKD)

Clinical trials include:
- Vitamin D supplementation in children with early chronic kidney disease (Completed)
- Losartan liquid in chronic kidney disease
- Eculizumab in paediatric patients with atypical Haemolytic Uraemic Syndrome.

Research is a strong and well established theme that runs through our unit. We firmly believe that contributions to research are essential for maintaining the highest standard of care for our patients and thus collectively we place great emphasis on our research efforts. Our current research programme comprises of molecular, genetic and translational projects in collaboration with a number of national and international groups which we have described along with our achievements separately.

2.4 STAFFING & STAFF MANAGEMENT

The renal unit is managed by a multidisciplinary team. Speciality care within renal is managed by teams of clinical nurse specialists working along renal consultants and we have a nurse consultant in hypertension.

Maintaining staffing levels within the unit has been a great challenge over the past year especially within the dialysis unit. In addition we have had a number of nurses on maternity leave and others leaving for jobs in other trusts.

Following an active advertising and recruitment campaign we are finally back to full complement. In addition we secured four year funding for a pilot home HD project. The team consists of a renal consultant, full-time band 7 clinical nurse specialist, part-time band 6 nurse specialist, part-time play therapist,

part-time pharmacy technician, part-time social worker and part-time family therapist.

2.5 EDUCATION & TRAINING

A) Nursing
Mandatory and Specific Training is required of all nurses on Victoria Ward and HD/Clinics. This is covered in full in the Nursing section of the annual report.

B) Medical
Our junior staff comprise of general paediatric trainees, nephrology grid trainees and international fellows. In addition we mentor a number of visitors/observers from Europe, Asia and the UK. We have developed a structured training programme for our junior staff that consists of regular radiology meetings, interactive ward rounds, tutorials and lectures. On average we have 5 hours of programmed teaching activity per week.

In addition we run regular external meetings:

- Annual 'Nephrology Day for General Paediatricians' that recruits on average 60 attendees and has been very well received.
- Annual continuing education programme in Paediatric Nephrology and Urology that runs over 4 days with a rolling programme. This is usually attended by national and European nephrologists.
- Annual clinical pathology meeting that offers trainees the opportunity to present difficult and interesting cases to colleagues from the UK.

C) Publications:
All publications covered in Section 9

2.6 PATIENT AND PUBLIC INVOLVEMENT

Concerned about the burden we place on the parents of children with renal disease we are undertaking a research project to develop a tool that measures carer burden. We are hoping this facilitate and expedite support for these families.

We developed and completed a PROM on the transition process amongst our renal transplant patients. As a result of the PROM and general dissatisfaction with the number of adult units patients were being transferred to and the perceived lack of specialist care within smaller adult centres we instigated and have completed a transition pathway to 2 tertiary level adult transplant centres (John Radcliffe Oxford and Guys Hospital). This is supported by a transition clinic at GOSH years prior to transfer of care to adult units. This has been a success and has certainly improved the quality of the transition pathway. In addition Dr Stephen Marks and Suzanne Bradley are involved in a working group in London looking at transition of transplant patients.

We have developed a PROM in the HD unit to assess the patient experience of the facilities and service provided by the HD unit. This was very well

received by the families on the unit and has been adopted by the British Paediatric Nephrology Association (BAPN).
USING INFORMATION & IT
We have recruited a database manager to develop local databases for dialysis patients that will support audit, research and clinical care.

We also annually send local data to the UK renal registry.

Finally in consideration of the data protection act and Trust Information Governance policy we have developed a consent form for patients and their parents that permits email as a communication strategy. After obtaining approval from the management board and Dr Robert Evans we have decided to test the uptake, applicability and workload generated by this initiative in a pilot in nephrotic patients before rolling it out to the remaining renal patients.

2.7 SERVICE IMPROVEMENT / TRANSFORMATION

- *ABO incompatible transplants*
  Renal transplantation is associated with the best health and survival outcomes compared with all renal replacement therapies. However transplant efforts are thwarted by a small and limited pool of kidneys suitable for donation. ABO incompatible transplantation increases the odds of finding a suitable living donor. Dr Stephen Marks has led the first paediatric ABO incompatible renal transplant in the UK with the support of Guys Hospital.
- *Home haemodialysis program*
  Quotidian dialysis for the first time is generating health and survival outcomes that are approaching transplantation. Accessing such treatments in paediatrics has been difficult and almost limited to isolated cases. Dr Daljit Hothi and Dr Lesley Rees are working to establish the first mobile home haemodialysis programme in Europe.
- *In-centre haemodiafiltration*
  In consideration of data reporting on improved clinical outcomes in patients receiving haemodiafiltration (HDF) compared with haemdialysis Dr Rukshana Shroff and Dr Lesley Rees have introduced HDF within our dialysis unit. Initial data indicate reduced intradialytic symptoms and hypotension and improved middle molecule clearance.
- *Renal transplant transition clinic*
  Transition can be a stressful time and result in poor patient outcomes as patients transfer to unfamiliar adult environments. For transplant patients this is a recognised period of accelerated graft impairment or even failure. With an intention to facilitate and improve existing transiton Dr Stephen Marks and Suzanne Bradley have worked with colleagues in John Radcliffe in Oxford and Guys Hospital to develop a regular transition clinic for renal transplant patients at GOSH.

3. OUTPATIENTS

3.1 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
	General Nephrology	Dr Hothi
	Transplant Clinic (Weekly)	Dr Marks
	Pre-Transplant Clinic (Monthly)*	Dr Marks
	Transplant Surgeon's Clinic	On-call surgeon
WEDNESDAY A.M.	General Nephrology	Dr Rees Prof Kleta Dr Marks Dr Shroff
	Infant CKD	Dr Ledermann
	Nephrotic Syndrome	Dr Hothi, Dr Waters, Dr Bockenhauer, Dr Tullus
	Antenatal diagnosis (Monthly)	Dr Winyard
THURSDAY A.M.	Transplant clinic	Dr Marks Dr Shroff Dr Bockenhauer
	Haemodialysis clinic (monthly)	Dr Rees Dr Shroff
	Hypertension/vasculitis/lupus	Dr Tullus

* Adolescent transition clinics are held monthly – see Section 10.2 for details

3.2 NUMBER OF OUT PATIENT ATTENDANCES

The total number of out-patient attendances to the renal unit was 7166. 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**	**2010-11**
Transplant	625	771	873	736	799	743	858	897	1034	1119
Nurse Led Transplant	443	506	734	542	518	467	524	1387	1328	1231
Low Clearance/ Dialysis	507	543	859	610	636	638	665	694	749	650
PreTx & GKRLTX						93	71	84	119	84
General and Specialist Nephrology	3243	2467	4065	3199	3444	3194	3382	3464	3113	2929
Nephrotic Syndrome	405	481	692	468	400	321	344	389	446	479
Stone	69	50	88	53	40	40	23	36	79	153
Blood Pressure Monitoring			23	51	65	78	94	109	193	195
Total	**5292**	**4818**	**7334**	**5674**	**5902**	**5738**	**5962**	**7060**	**7061**	**7166**

3.3 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	3	Approx 40-45
Colchester	KT	50	2	Approx 40-50
Oxford	WvH	56	6	70-80
Malta**	-	-	-	-
Reading	WvH	40	3	30
Royal Free***	RST			

**Work is underway to re-establish this service in the coming year

4. INTERVENTIONAL RADIOLOGY

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

4.1 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
2010-11	61	68	0	13	142

One transplant patient (1.5%) suffered significant cbleeding, requiring two surgical explorations. One patient who underwent biopsy of a native kidney (1.6%) developed fever and a perinephric collection, and was treated with antibiotics.
There were no other major complications of renal biopsy in 2010-11.

4.2 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
2010-11	3	29	32

There were complications after 5 (17%) permanent haemodialysis catheter insertion procedures in 2010-11 (one patient had two complications):

- one patient developed an infected subcutaneous collection that did not require line removal
- one patient had early (<30 days) infection (requiring line removal)

- two lines were accidentally removed or partly pulled
- there were two instances of minor blood oozing from exit site after insertion

4.3 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
2010-11	17	17	34

RVH = renovascular hypertension

In one patient angioplasty caused a renal artery dissection which was treated by stent insertion. Another patient had a small groin haematoma, which required no specific treatment. There were no other significant complications.

4.4 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
2010-11	0	4	0	0	14	18

There were no complications of venous interventional procedures in 2010-11.

5. INPATIENTS

5.1 Admissions to Victoria Ward

Age (yrs)	2001-2002		2002-2003		2003-2004		2004-2005		2005-2006		2006-2007		2007-2008		2008-2009		2009-2010		2010-2011	
	Total No	**%**	**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	**56**	11
2- <5	**81**	13	**87**	16	**66**	11	**106**	17	**84**	16	**105**	19	**90**	16	**81**	14	**99**	18	**102**	20
5- <10	**143**	23	**119**	21	**116**	20	**146**	23	**110**	21	**120**	22	**101**	18	**134**	23	**109**	19	**93**	18
10- <15	**214**	35	**176**	31	**191**	33	**167**	27	**153**	30	**169**	30	**161**	29	**153**	27	**137**	24	**131**	25.5
15 +	**153**	25	**137**	24	**153**	26	**124**	20	**97**	19	**88**	16	**148**	26	**124**	21	**129**	23	**131**	25.5
Total	**618**	100	**563**	100	**585**	100	**622**	100	**517**	100	**554**	100	**561**	100	**577**	100	**561**	100	**513**	100

5.2 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**	**2009-10**	**2010 - 11**
Victoria	618	563	585	622	517	554	561	577	561	513
Other	343	307	316	317	317	349	249	261	118	93
Total	961	870	901	939	834	903	810	838	679	606

5.3 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.

6. CHRONIC KIDNEY DISEASE (CKD) (2010 DATA)

6.1 CKD (PRE TRANSPLANT)

There were 228 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.

6.2 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, 205 on 1/4/09, and 179 on 1/4/10. The prevalence for the different modalities and age breakdown on 1/4/11 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
2011	0	4	3	2	9	18
Home Haemodialysis						
	0	0	0	1	3	4
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
2011	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
2010	4	2	1	3	4	14
2011	2	4	3	2	4	15
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	1	10	31	58	48	148
2011	0	13	28	55	49	145

6.3 CHRONIC PERITONEAL DIALYSIS

There were a total of 29 patients in 2010-2011. 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**		**2010- 11**	
Age, yrs	**total**	**%**	**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	**4**	14
2-5	**3**	8	**6**	15	**5**	10.8	6	16	**2**	5	**5**	12	**4**	12	**6**	18	**7**	18	**7**	24
5-10	**7**	20	**5**	12.5	**5**	10.8	7	19	**10**	25	**9(7)**	22	**4**	12	**4**	12	**8**	20	**4**	14
10-15	**14**	38	**14**	35	**16**	35	11	30	**10**	25	**12**	29	**13**	38	**11**	32	**10**	25	**7**	24
>15	**12**	32	**12**	30	**17**	37	10	27	**16**	40	**11(10)**	27	**7**	20	**7**	20	**3**	7	**7**	24
Total	**37**	100	**40**	100	**46**	100	37	100	**40**	100	**41(37)**	100	**34**	100	**34**	100	**40**	100	**29**	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**	**10-11**
total *new*	37	44	40 14	37 17	45 20	45 18	40 14	41 17	37 18	34 15	34 15	40 20	29 11
At year end	28	28	17	24	29	23	23	18	20	17	19	17	16
Transferred to HD	0	3	5	7	2	5	5	6	2	5	4	8	6
Transplanted	9	10	16	7	7	15	11	12	14	8	6	13	6
Adult unit			4	2	3	1	2	3	0	0	2	0	0
Improved			0	0	0	0	0	1	1	2	0	0	0
Deaths	1	1	1	0	1	1	0	0	1	1	3	2	0

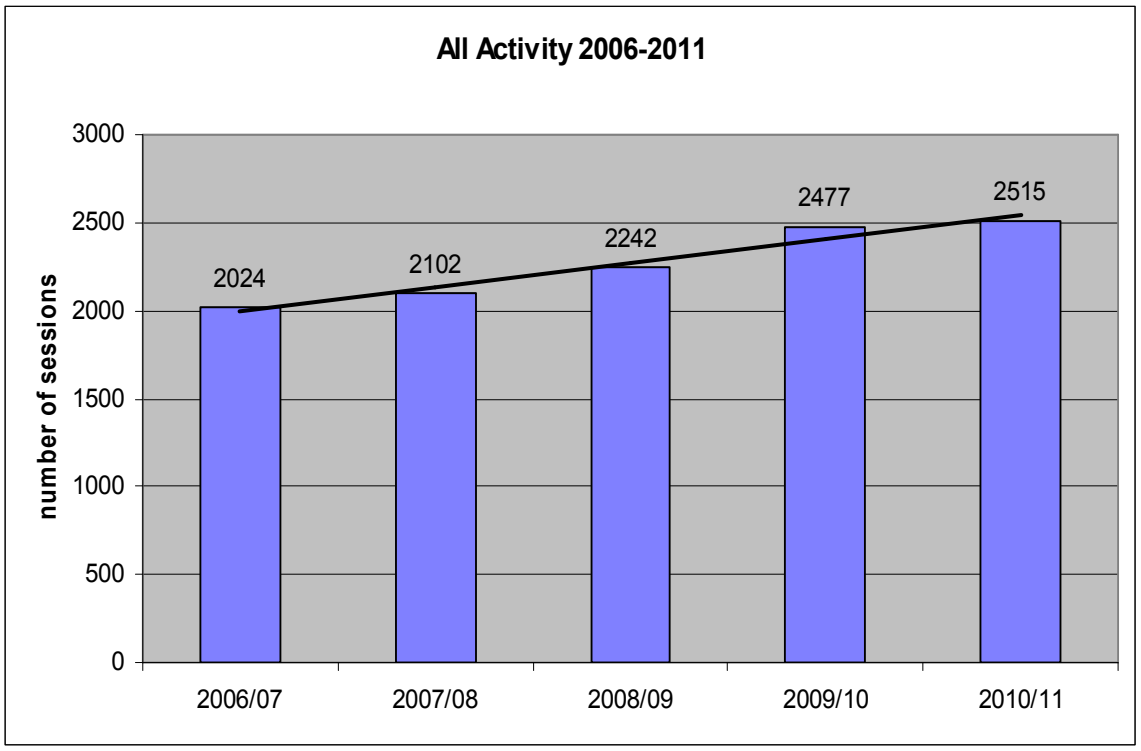
6.4 CHRONIC HAEMODIALYSIS

During the year there were 2515 sessions in 45 children, 2475 sessions of HD (acute and chronic) and 40 sessions of PE.

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
01.04.10	6	207

5 year activity



7. ACUTE RENAL FAILURE AND TREATMENT (INCLUDING PLASMAPHERESIS)

7.1 ACUTE HAEMODIALYSIS

5 children required acute haemodialysis. Their mean age was 11.5 years, range 4.5 – 15.6 years. These figures exclude children with ARF in PICU and NICU.

Diagnosis	2005-6	2006-7	2007-8	2008-9	2009/10	2010/11
HUS(D+)		2	1	1		2
HUS (D-)		1		1		
MCGN/RPGN	1				1	
SLE	1		1		1	
Post heart Tx						
FSGS		1			1	
Rhabdomyolosis						1
Acute on CRF			1	1		
Sepsis		1				1
Post surgery		1				
Transplant rejection		1				1
Tumour lysis		1	1			
MMA						
Drug toxicity	1					
ATN	2	1	3	3	1	
Total Pts	**5**	**9**	**7**	**6**	**4**	**5**
Total number of sessions			**34**	**82**	**164**	**22**

7.2 PLASMA EXCHANGE

6 children were treated with plasma exchange (3 male; 3 female). The mean age was 13.2 years and range 7.69 – 17.0 years.

Diagnosis	**2007/8**		**2008/9**		**2009/10**		**2010/11**	
	No. Pts	**No. Sess**	**No. Pts**	**No. Sess**	**No. Pts**	**No. Sess**	**No. Pts**	**No. Sess**
AB reduction							3	3
SLE	1	10	2	9			1	7
HSP								
MPA								
Post tx FSGS			2	49			1	25
MPGN								
RPGN					1	11		
Vasculitis								
HUS D+								
HUS D-			1	37			1	5
GvH					1	1		
Anti-GBM								
Tx Rej	1	11						
Goodpastures	2	19						
Wegener's	1	5						
FSGS	1	16						
CNS	1	5			1	1		
ABOi heart	1	8						
Total	**7**	**64**	**5**	**95**	**3**	**13**	**6**	**40**

7.3 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**	**2010-11**
<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**	**8**

8. 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
1/4/2010 to 2011	10	0	9	2	21	30

Note – the on-call data is from 31/3/11 and does not include suspended patients.

9. RESEARCH

9.1 PAPERS

1. Adalat, S., Taylor, J., Booth, C., McCullough, M., Waller, S., Rigden, S., Sinha, M., & Kozicll, A. Efficacy of rituximab in childhood nephrotic syndrome. Pediatric Nephrology 25[9], 1795. 2010.
   Ref Type: Abstract

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   Ref Type: Abstract

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   Ref Type: Abstract

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9.2 GRANTS

Awarded 2010-11

R&D no.	Title	PI	Funder	Date awarded	Awarded
10NU05	Investigating the role of Wnt signalling in podocyte differentiation	Dr David Long	Wellcome Trust	17/05/2010	£ 1,520.00
10NU06	A comparative single-dose pharmacokinetic and safety study of TAK-491 between infants, children and adolescents with hypertension and healthy adults	Dr William van't Hoff	Takeda Global Research & Development Centre Ltd	27/05/2010	£ 22,334.00
09NU24	Renal differentiation of human amniotic fluid stem cells	Dr Paul Winyard	Kids Kidney Research	14/07/2010	£ 99,517.00
08NU09	Vitamin D (ergocalciferol) supplementation in children with early chronic kidney disease - a multicentre, randomised, double-blinded, placebo-controlled study	Dr Lesley Rees	Kidney Research UK	31/08/2010	£ 4,800.00
			Kids Kidney Research	31/08/2010	£ 4,800.00
10NU22	Phase 3, prospective, randomized, double blind, placebo controlled multicenter study to evaluate the pharmacokinetics, safety and efficacy of paricalcitol capsules in decreasing serum intact parathyroid hormone levels in paediatric subjects ages 10 to 16 years with moderate to severe chronic kidney disease	Dr Rukshana Shroff	Abbott Laboratories	10/12/2010	£ 45,730.00
				Total	**£178,701.00**

Active 2010-11

R&D no.	Title	PI	Funder	Sponsor	Start	End
04NU03	Antenatal renal malformations - improved prognostic indicators	Dr Paul Winyard	Kids Kidney Research	GOSH	01/12/2006	31/05/2011
04NU22	Retrospective review of post-mortem investigation of the cause of death in sudden unexpected death in infancy (excluding tissue review)	Dr Neil Sebire	Foundation for the Study of Infant Deaths	GOSH	01/02/2005	18/01/2015
04NU33	Childhood renal artery stenosis: a familial study and establishment of a DNA bank from affected individuals assessed at GOSH	Dr Stephen Marks	Kids Kidney Research	GOSH	01/10/2005	31/05/2011
05NU04	Examining the effects of vitamin D receptor activators on vascular smooth muscle cell calcification using a model of intact vessels from children with chronic kidney disease	Dr David Long	British Heart Foundation ICH/GOSH Biomedical Research Centre	GOSH	01/01/2006	31/12/2012
07NU15	Identification of an X-linked gene conferring susceptibility to membranous nephropathy	Dr Detlef Bockenhauer	Kids Kidney Research	GOSH	01/11/2009	31/10/2011
07NU18	A randomised double, parallel, placebo or amlodipine controlled study of the effects of losartan on proteinuria in pediatric patients with or without hypertension	Dr William van't Hoff	Merck Sharp & Dohme	Merck Sharp & Dohme	01/10/2007	31/03/2012
07NU21	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	Dr Paul Winyard	Kids Kidney Research	ICH	20/10/2008	18/07/2015
07NU25	Roles of angiopoietins in epithelial-endothelial interactions: using the renal glomerulus as a model system	Dr David Long	Kidney Research UK	ICH	22/05/2008	06/04/2013
07NU27	Roles of Fras1, a basement membrane-associated protein, in normal differential of kidney collecting ducts and glomeruli	Professor Adrian Woolf	Wellcome Trust	ICH	01/03/2009	29/02/2012
08NU01	Chronic kidney disease (CKD) from childhood to adult life; optimising diagnosis and identifying interventions to improve lifelong outcome	Dr Lesley Rees	Great Ormond Street Hospital Children's Charity	GOSH	16/02/2009	31/03/2011

08NU02	Complement C1q auto-antibodies in glomerulonephritis	Dr Stephen Marks		GOSH	26/03/2008	05/11/2011
08NU08	Is it possible to optimise cardiovascular health in children with chronic kidney disease stage 5 by normalisation of vitamin D levels?-a pilot study	Dr Lesley Rees	Kidney Research UK	ICH	01/10/2008	01/10/2010
08NU09	Vitamin D (ergocalciferol) supplementation in children with early chronic kidney disease - a multicentre, randomised, double-blinded, placebo-controlled study	Dr Lesley Rees	Kids Kidney Research	GOSH	26/01/2009	31/01/2011
08NU10	Galectin-3, a novel therapy for autosomal recessive polycystic kidney disease	Dr Paul Winyard	Kidney Research UK	ICH	04/01/2009	30/06/2011
08NU16	European Network for the Study of Orphan Nephropathies (EUNEFRON)	Dr William van't Hoff	European Union	GOSH	16/02/2010	31/05/2012
08NU18	Identification of genes involved in renal and electrolyte disorders	Dr Detlef Bockenhauer	ICH/GOSH Biomedical Research Centre	ICH	09/09/2009	01/09/2014
08NU19	Role of angiopoietin growth factors in diabetic nephropathy	Dr David Long	Diabetes UK	King's College London	01/01/2009	31/12/2011
08NU20	Insights into endothelial-epithelial interactions using proteomic analysis	Dr David Long	Central Research Fund (University of London)	ICH	20/01/2009	31/08/2010
08NU26	PhD Studentship: targeting blood vessels to prevent autosomal recessive polycystic kidney disease	Dr David Long	Kids Kidney Research	ICH	22/06/2009	30/09/2012
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	Dr Stephen Marks	Merck & Co Inc	Merck & Co Inc	22/06/2009	31/03/2011
09NU25	National Study of Steroid Resistant Nephrotic Syndrome in Childhood	Dr Stephen Marks	Medical Research Council	GOSH	02/03/2010	30/09/2014
10NU05	Investigating the role of Wnt signalling in podocyte differentiation	Dr David Long	St Peter's Trust Wellcome Trust Child Health Research Appeal Trust	ICH	11/05/2010	30/09/2011

10NU06	A comparative single-dose pharmacokinetic and safety study of TAK-491 between infants, children and adolescents with hypertension and healthy adults	Dr William van't Hoff	Takeda Global Research & Development Centre Ltd	Takeda Global Research & Development Centre Ltd	27/05/2010	30/06/2011
10NU12	Teaching parents to become home-based care-givers of children's long term kidney conditions: a mixed methods study in all UK Children's Kidney Units	Ms Eileen Brennan	Kids Kidney Research	University of Manchester	04/10/2010	31/03/2012
10NU15	Complement susceptibility factors in aytpical Haemolytic Uraemic Syndrome (aHUS)	Dr Kjell Tullus	Medical Research Council	Newcastle upon Tyne Hospitals NHS Foundation Trust	09/08/2010	31/12/2011
10NU18	Development of a measure of caregiver stress in carers of children and adolescents with chronic kidney disease	Dr Daljit Hothi		Canterbury Christchurch University	07/10/2010	31/10/2011
10NU22	Phase 3, prospective, randomized, double blind, placebo controlled multicenter study to evaluate the pharmacokinetics, safety and efficacy of paricalcitol capsules in decreasing serum intact parathyroid hormone levels in paediatric subjects ages 10 to 16 years with moderate to severe chronic kidney disease	Dr Rukshana Shroff	Abbott Laboratories	Abbott Laboratories	10/12/2010	30/03/2012

10 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
20/4/10	RCPCH week, no meeting			
27/4/10	Renal biopsy meeting	Prof Neil Sebire	Video of information for patients in the haemodialysis unit	Dr Dal Hothi
4/5/10	Peritoneal dialysis masterclass	Rukshana shroff	The RADAR study; outline and discussion	Prof Moin Saleem
11/5/10	Renal biopsy meeting	Prof Neil Sebire	Improving health care systems… science or snake oil	Dr Nadeem Moghal
18/5/10	Haemodiafiltration	Dr Rukshana Shroff	Home HD	Dr Daljit Hothi
25/5/10	Renal biopsy meeting	Prof Neil Sebire	Audit of peritoneal dialysis	Nurse specialists Cecelia MacNeice, Tanya Baldwin and Michelle Cantwell
4/6/10	BAPN Clinico-Pathology Meeting, Weston House, Great Ormond Street Great Ormond Street Hospital Note Friday			
10/6/10	Joint meeting with the Evelina Children's hospital at the Evelina, Note thursday			
17/6/10	Bipartite meeting at ICH Note thursday			
22/6/10	Renal biopsy meeting	Prof Neil Sebire	Audit of renal transplants	Clinical nurse specialists Suzanne Bradley and Michelle Cantwell
29/6/10	Audit of haemodialysis and plasmapheresis	Sisters Liz Wright and Lianne Pilgrim	An overview of research at ICH	Dr Paul Winyard
6/7/10	Vascular Access in young infants	Mr Francis Calder	Ureteric stents in transplant patients	Dr Steve Marks
13/7/10	Psychosocial aspects of living donation	Carol Jennings and Gwynneth down	Audit of living donation	Clinical nurse specialists Maria Scanes and Carol Jennings
20/7/10	Renal biopsy meeting	Prof Neil Sebire	Challenging renovascular cases	Dr Kjell Tullus

Date	Topic	Speaker	Topic	Speaker
31/8/10	IPNA week			
7/9/10	2.30 – 3.30 Basics of PD.1	Dr Rukshana Shroff	3.30 – 4.30 pm Audit of renal transplantation	CNS Suzanne Bradley
14/9/10	2.30 – 3.30pm Renal Biopsy Meeting	Dr Neil Sebire	3.30 – 4.30pm Basics of PD.2	Dr Rukshana Shroff
21/9/10	2.30 – 3.30pm SBARD and CEWS	Dr Peter Lachmann	Audit of AKI in NICU	Dr Sophie Skellett
30/9/10	Bipartite meeting at the Royal Free Seminar Room 2, Sheila Sherlock Education Centre, RFH; Note Thursday			
5/10/09	*2.30 – 3.30pm* Renal biopsy meeting	Dr Neil Sebire	SUPPORTING PARENTS TO CARE FOR CHILDREN'S KIDNEY CONDITIONS	Veronica Swallow Senior Lecturer in Children's Nursing University of Manchester
15/10/10	Nephrology Day for general paediatricians at the ICH (note Friday)			
19/10/10	Half term week, no meeting			
26/10/10	*2.30 – 3.00pm* Explosive Information: Tissue Typing as Paternity Test.	Liz Nunn	The highlights of the meeting on SLE	Dr Kjell Tullus
2/11/10	*2.30 – 3.30pm* Renal biopsy meeting	Dr Neil Sebire	*3.30 – 4.30 pm* Accelerated calcification in dialysis patients	Dr Rukshana Shroff
11/11/10	Joint meeting with Evelina, at the ICH Note thursday			
16/11/10	ASN week, no meeting			
23/11/10	*2.30 – 3.30pm* Audit of deaths	Nurse Consultant Eileen Brennan	Complement research in MPGN	Dr Steve Marks
3/12/10	BAPN meeting in Birmingham (all day) Note Friday			
9/12/10	Bipartitie meeting at ICH (note thurs) Leolin Price lecture theatre			
14/12/10	*2.30 – 3.30pm* Renal Biopsy Meeting	Dr Neil Sebire	*3.30-4.40pm* Difficult cases	To be confirmed

Date	Topic 2.30 - 3.30 pm	Speaker	Topic 3.30 – 4.30pm	Speaker
11/1/11	Renal biopsy meeting	Dr Neil Sebire	Home HD videos	Dr Daljit Hothi
18/1/11	Research update from ICH	Dr Paul Winyard	Eculizumab study	Dr Lesley Rees Beth Leach
25/1/11	Difficult cases for discussion	Dr Daljit Hothi , second case to be decided	Training Patients and Families for Prevention and Home Treatment of Peritonitis	Michelle Cantwell
3/2/11	Joint meeting with the Evelina, at the Evelina Note Thursday			
8/2/11	Renal biopsy meeting	Dr Neil Sebire	Infant dialysis	Helen Jones
15/2/11	What happens in the renovascular meetings?	Kjell Tullus	Research update from ICH	Dr Paul Winyard
22/2/11	Half term week, no meeting			
1/3/11	Update on Medicines for Children	Dr van't Hoff	Transplantation in the under 2s	Mr Geoff Koffman
8/3/11	Renal biopsy meeting	Dr Neil Sebire	Outcome of non-heart beating donor transplantation	Mr John Taylor
15/3/11	Teaching on PD for PICU and Renal SPRs Dr Rukshana Shroff			
17/3/11	Bipartite at Royal free hospital Note thursday			
22/3/11	Course week at the ICH			
29/3/11	RCPCH practise session			
5/4/11	RCPCH meeting			
12/4/11	Renal biopsy meeting	Dr Neil Sebire	Research update from ICH	Dr Paul Winyard
19/4/11	Easter holidays			
26/4/11	Easter holidays			

11. AUDIT

11.1 Pre Transplant Audit, Living and Deceased Donor, April 2010-March 2011

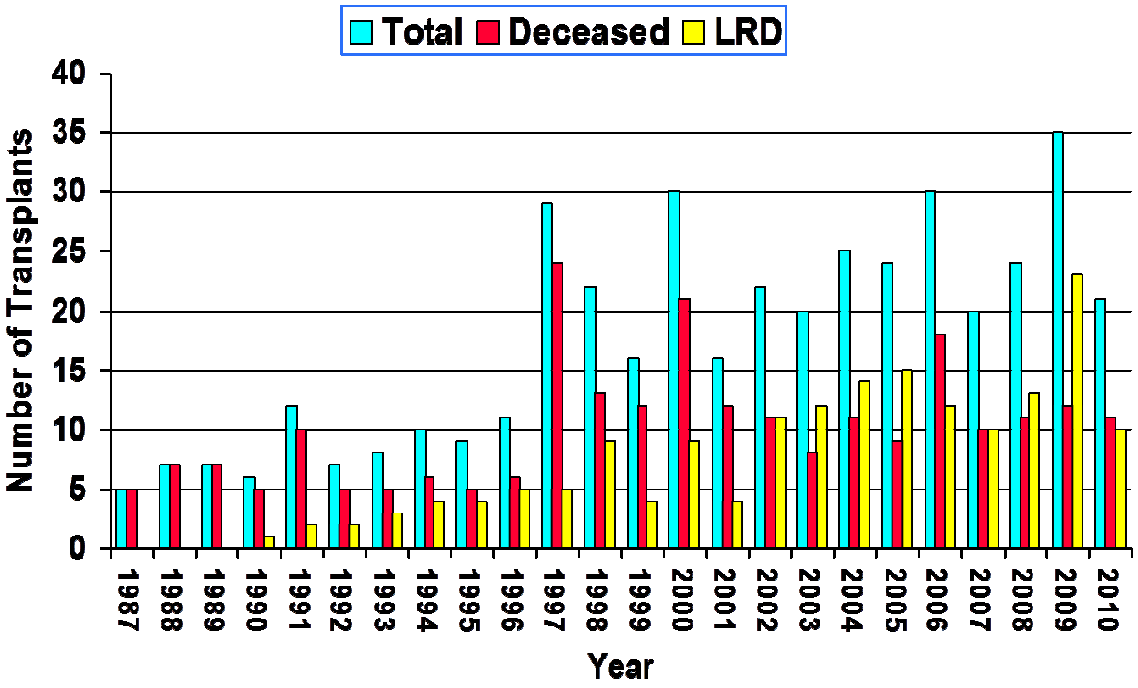
Maria Scanes, Clinical Nurse Specialist

Transplant Numbers

21 Transplants in 21 children

10 Living donor (48%)
11 Deceased donor (52%)

Transplant Numbers Since 1987



Recipient Demographics

Male	13	(62%)
Female	8	(38%)

NHS 20
One patient from British Virgin Islands referred under terms of bilateral agreement

Mean age at TPX
7.9 years (LRD Transplant)
9.6 years (DD Transplant)

Median age at TPX
8.2 years (LRD Transplant)
7.5 years (DD Transplant)

(Range 1.5 – 16.3)

Modality at Time of Transplant

HD	7	(33%)
PD	6	(28%)
Pre emptive	8	(38%)

Of LDs 6 (60%) were pre-emptive, 2 (18%) of DD were pre-emptive.
(will look at ↑ pre-emptive no's later)

Recipient Info (cont.)
There were 2 second grafts in 21 Transplants
21 kidney transplants

3 out of centre – 1 from NI, 1 from BVI, 1 from Nottingham
0 - ABOi
0 – combined liver & kidney

Recipient Blood Groups

O	11	(52.4%)
A	7	(33.4%)
B	3	(14.3%)

Mismatches

6 am	2	(9 %)
5 am	1	(5 %)
4 am	13	(62%)
3 am	2	(9 %)
Below	3	(14 %)

112, 211, 121 all DD

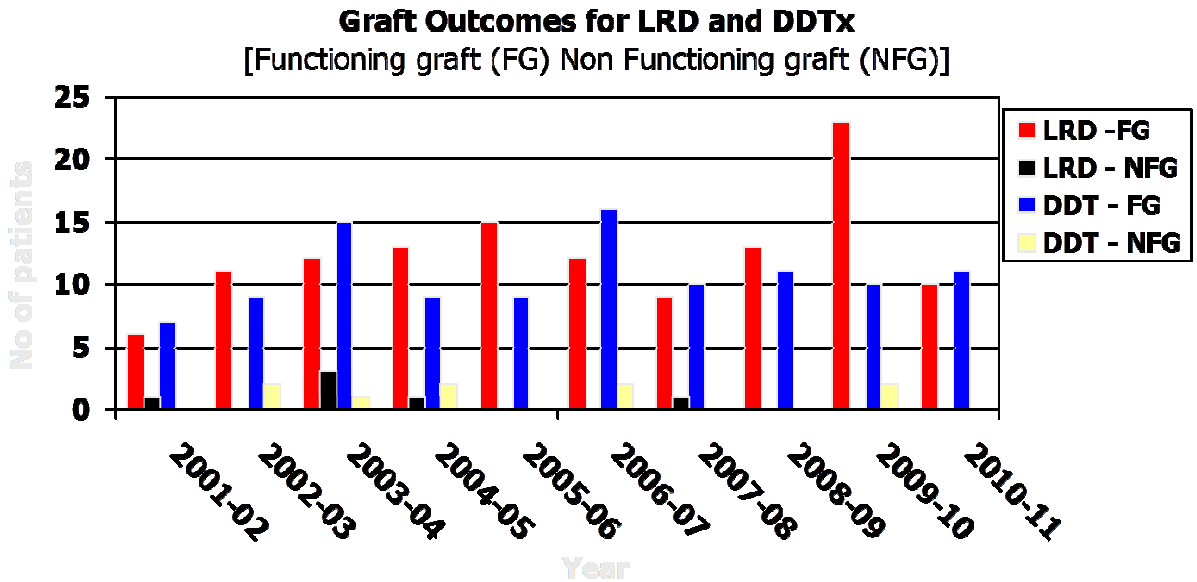
Living Donor Mismatches
All of living donor mismatches were 3AM and above

1 – 6 AM
1 – 5AM
5 – 4AM
3 – 3AM

Diagnoses.
Nephronopthesis - 4
PUV – 4
CKD – 3
Dysplasia – 3
FSGS - 2
ESRD - 1
Cloacal Anomoly – 1
Congenital Nephrotic Syndrome – 1
Nephrotic Type Presentation - 1
Solitary Dysplastic Kidney – 1

Outcomes
Of 21 transplants carried out during audit year 21 transplants functioning at year end.
100% functioning LRD and Deceased Donor Transplants at the end of the audit year

End of Year Outcomes



Cold Ischaemic Times

LD

- data on 8 pts (80%)
- average 3.5 hrs (3 hrs - 4.5 hrs)

DD

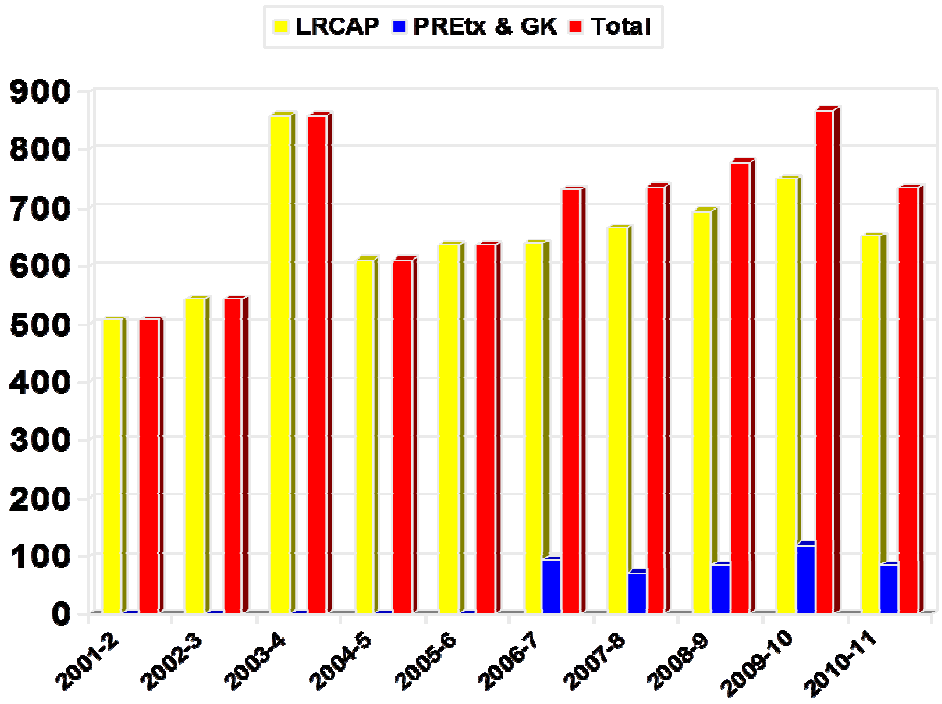
- data on 11 pts (100 %)
- average 15 hrs (8hrs - 21 hrs)

Could we ↑ No. of Pre-emptive Tx

LRDs

4 (40%) on dialysis (2 HD, 2 PD)

- 1 out of centre (TSF)
- 1 started dx as a baby
- 2 awaiting donor workup when Dx started ((1- BW – Mum had to wait 1 yr after birth of baby, Dad med unsuit.
- 1 – JL – donor problems identified late on in work up process)



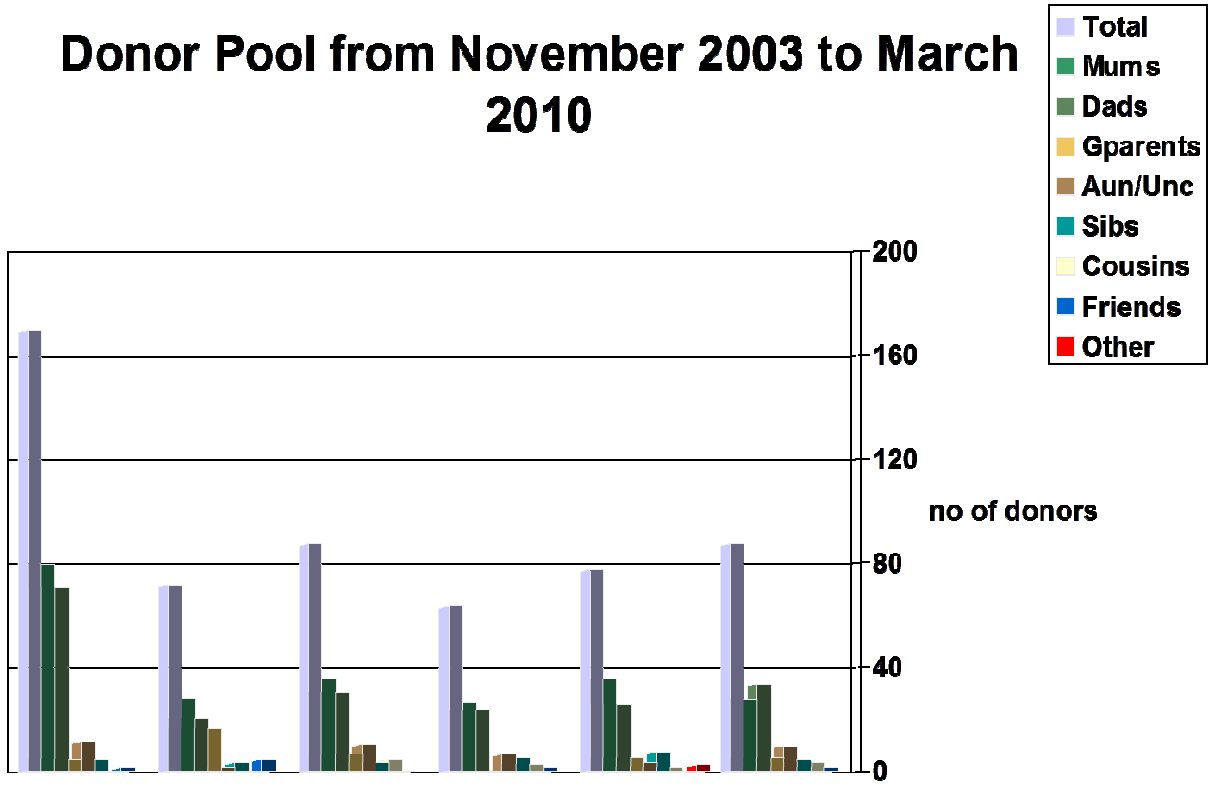
Living Donor Information

- 4 fathers (40%), 6 mothers (60%)
- Mean age 39 yrs (28 – 58y)
- All at Guys
- All laparoscopic donations

Donor Pool (LRD)

87 potential donors came forward for 48 recipients.

Mothers	27	(31%)
Fathers	33	(38%)
Siblings	4	(4%)
Aunts	9	(10%)
Uncles	5	(6%)
Cousins	3	(3%)
Grandparents	5	(6%)
Friends	1	(1%)

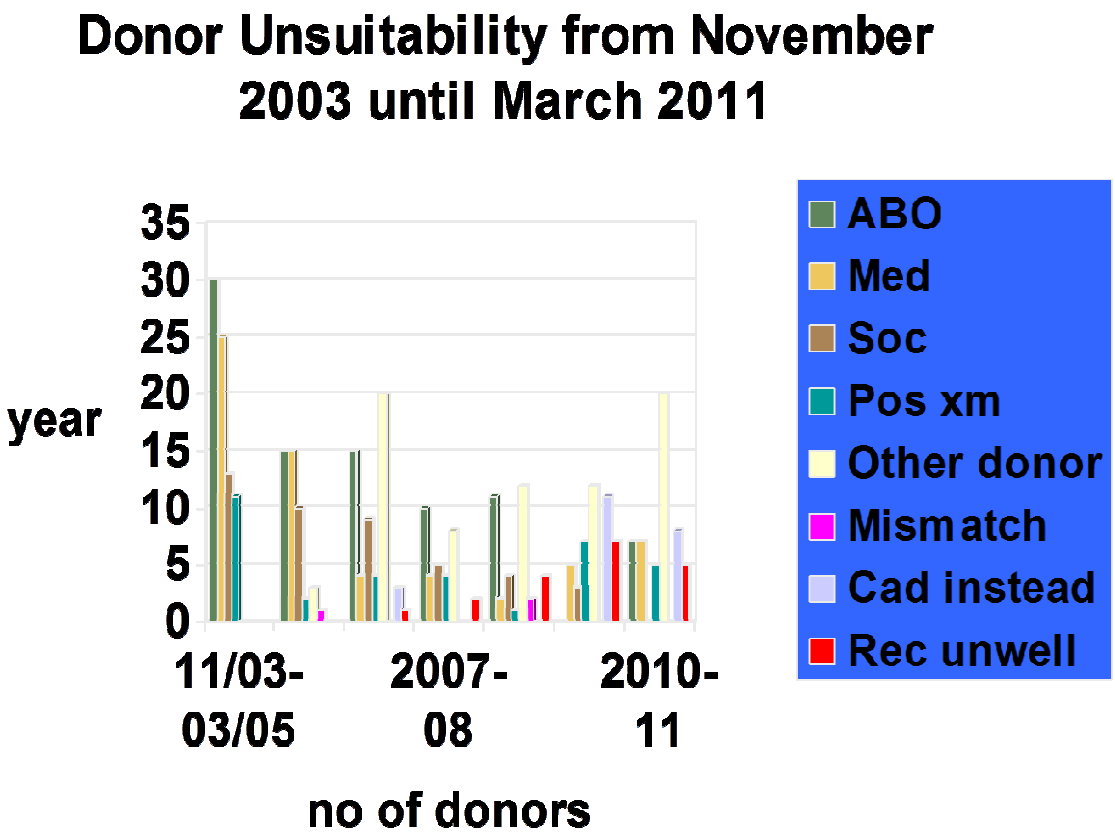


Donor Suitability

From 87 potential donors within audit year

DD Tx	8
Ongoing Referral	19
Early Ref	10
Other donor	20
Med Unsuitable	7
Recipient unwell	5
Pos X-match	5

Enquiry only	8
Social	1
ABOi	4



Donor Attrition Rates

45 potential donors did not / will not proceed to Tx workup (52%)

This includes 20 where more than 1 donor came forward and another donor was used instead

Work in Progress (10/11)

133 children "on our books"

- 66 on A list
- 7 IPP
- 15 on call
- Pot LRDs '11- '12- 22. (incl 11 tx to date)

- Potential for a further 1 IPP Tx

Deceased Donor Tx

Donor Pool
Complete data on 9 recipients (81%)
Age 9Y – 50 Y yrs (Mean *35* yrs)

Donor COD
- 2 cerebral anoxia SAH
- 5 ICH
- 2 meningitis
- 2 not stated

Achievements

- Paired exchange / ABOi viable treatment option (yet to Tx on paired exchange)

- 1st non heart beating donor

Audit Points

Next audit
- Use database to format audit
- Calculate time from donor referral to Tx
- Compare previous donor attrition rates

Service
- Improve ++ with increased staffing levels particularly transplant preparation including education forms.

With Thanks to
- Guys Team
- Suzanne Collin
- L 7 team
- Welcome to Katie!!

11.2 RENAL TRANSPLANT AUDIT (2010 DATA)

Renal Transplant Audit, April 2010 – March 2011

Suzanne Bradley

Renal Transplants at GOSH

21 Patients received a Renal Transplant at GOSH in the 12 month period of 1st April 2010 – 31st March 2011

- 1 patient returned to Belfast post living related transplant
- 1 patient returned to Nottingham post living related transplant
- 1 patient resident in UK at time of audit but with plan to return to British Virgin Islands 3 months post transplant
- 1 patient = NHBT

Transplants

19 patients received their 1st graft

2 patients received their 2nd graft

Underlying Diagnoses

Dysplasia	2
FSGS	2
Posterior Urethral Valves	4
Nephronophthisis	4
HUS	1
Congenital Nephrotic Syndrome	1
Hydronephrosis	1
Nephrotic Type Presentation	1
CRF post Cardiac Transplant	1
Cloacal Anomoly	1
Cardiac Transposition of vessels	1
Single Cystic Kidney & Urology Involvement (LFM)	1
Unknown	1

Donor Types

Live Related =10 Patients

Deceased Donor =11 Patients

Patient Demographics

Female / Male= 8/13
NHS / Private= 21:0
Nottingham=1/21 patients
Belfast= 1/21 patients
British Virgin Islands=1/21 patients

Pre-Transplantation Status

(Information based on 21 patients transplanted at GOSH)

Modality	No of Patients
Pre-Emptive	8
Haemodialysis	7
Peritoneal Dialysis	6

HLA Mismatches

Mismatch	LRD	Deceased
0-0-0	1	1
0-1-0	1	
0-1-1	1	
1-1-1	2	
1-0-1	1	
1-1-0	4	7
1-1-2		1
1-2-1		1
2-1-1		1

Renal Transplant Biopsies

21 Patients transplanted in 2010-2011

- 12 of the patients had a total of 18 biopsies in the audit year
- 5 had a time zero biopsy
- Remaining biopsies done due to a rise in creatinine
- Protocol biopsies

Biopsy results in patients transplanted 2010-2011

Biopsy Result	Number of Biopsies made reference to:
Acute Tubular Necrosis	1
No Acute Rejection	8
Grade 1b Rejection	1
Grade 2b rejection	1
Acute Vascular Rejection	1
Grade 2A Acute Rejection	3
Chronic Allograft Nephropathy	1
Borderline Changes (BANFF)	1
Pre-existing chronic changes	1

Time Zero Biopsies

	JT	MD	FC	VH	NM	GK
Yes			2	1	1	1
No	5	1		1	2	7

Time Zero Biopsies

No of Biopsies	Biopsy Results
4	Normal
1	Arteriosclerosis

Donor – Recipient EBV status at time of transplant

	Recipient EBV +ve	Recipient EBV –ve
Donor EBV +ve	5	6
Donor EBV –ve	1	0
Donor EBV status unknown	4	5

Donor – Recipient CMV status

	Recipient CMV +ve	Recipient CMV -ve
Donor CMV +ve	3	7
Donor CMV –ve	4	7
Donor CMV status unknown	0	0

Immunosuppression in New Renal Transplant Recipients 2010-2011- based on 19/21 patients

Start	End	No
Tac /Aza /Pred	Tac /Aza /Pred	8
Tac /Aza /Pred	Tac/Pred	5
Tac/MMF/Pred	Tac/MMF/Pred	2
Tac /Aza /Pred	Tac/MMF/Pred	3
Tac/MMF/Pred	Tac/Pred	1

Stent Removal – No of weeks into Transplant Journey
(Does not include 2 patients as r/o stent April 2011)

Weeks/Post Tx	No of Patients	Reason
Week 1	0	
Week 2	1	Haematuria
Week 3	2	Haematuria
Week 4	2	Haematuria Routine
Week 5	5	Routine / Blocked stent / Haematuria
Week 6	7	Routine
Week 7	2	Routine

Anti-Hypertensive Treatment in New Renal Transplant Recipients 2010-2011 based on 19/21 patients

Start	End	No of Patients
0 agent	0 agent	10
0 agent	1 agent	3
0 agent	2 agents	1
1 agent	0 agents	1
1 agent	1 agent	2
2 agents	1 agent	1
2 agents	2 agents	1

Transplant Complications

- FSGS Recurrence
- Donor Toxoplasmosis
- Hypomanic response to steroid therapy
- EBV viraemia
- CMV viraemia
- Dysaesthesia
- Chickenpox-April 2011
- Donor Specific A/B's
- BK Viraemia

Transplant Complications

- Kinking of donor renal artery
- Elevated Blood sugars-managed with diet
- Hypertension
- Haemodialysis for ATN
- Post –Operative Bleeding
- Acute Tubular Necrosis
- Acute Rejection
- Chronic Rejection

Transplant Complications

- Wound Dehiscence
- Seizures
- Renal Artery Stenosis
- Pyleonephritis
- Haematuria secondary to stent
- Donor-renal calculi
- Aspiration Pneumonia

Transplant Biopsies

Existing transplant patients undergoing biopsy in audit year 2010-2011

- 21 patients had a total of 28 biopsies in the audit year

Biopsy Results –Existing Patients

Biopsy results	Biopsy Report made reference to:
No rejection	10
Borderline Rejection	2
Acute Tubular Necrosis	1
Borderline T Cell Rejection	1
Acute Rejection	1
Grade 2A Rejection	3
Grade 2B Rejection	1
CAN/DSA's CAN/C4d pos	2 1
CAN/Chronic vascular Changes	6

In addition

- Rituximab
- EBV Viraemia
- MMF - Wt loss & Anaemia
- Cellulitis of foot
- Necrotic bowel
- Seizures
- UTI'S
- Clot Retention post Bx
- R Cervical Lymphadenopathy
- NODAT
- Hematosalphinx
- DSA'S

In addition…..

- Pneumococcal Pneumonia -IVIG
- Wound breakdown post revision of keloid scar tissue
- Gastroenteritis
- C2-C6 Cervical Cord Injury ? Ischemia post surgery
- Metapneumovirus Respiratory Infection
- Seizure post PRES
- Appendicectomy
- Graft Nephrectomy
- Return to Haemodialysis
- Withdrawl of active treatment

Return to Monday Clinic!!

… 5 patients returned to LRCAP

…3 patients monitored closely to avoid “crashlanding” but may require transition to LRCAP

Ambulatory BP Measurement

10 patients had AMBP testing in the audit year

…..3 patients had anti-hypertensive treatment amended and 1 patient recommenced treatment based on results

Psychosocial

Body Image Concerns
Non Concordance
Non Attendance
Dietary Issues- Patients Requiring Ongoing dietary Input
AA Aged 15 “ Never taken anything by mouth”
Family support
Family Illness

Adolescent Transition

- Revision of patient information and transition for parents
- Project to upgrade adolescent room Level 4 with ongoing involvement of adolescent client group
- Young Adolescent Project ~Steering Group-Kidney Care

Transition

15 adolescent patients transitioned to adult units.

Monthly young persons clinic

14 Joint Adolescent Clinics (Guys / Royal London / Royal Free/ Oxford)

31 Patients involved in these joint clinics

Transition Units

Royal Free Hospital	2
Royal London Hospital	3
John Radcliffe Oxford	2
Guys Hospital	1
Lister Hospital	1
Addenbrookes Hospital	2
Ipswich Hospital	1
Bournemouth	1
Kent & Canterbury	1
Australia	1

Total Transplant Patients

144 Transplant patients

Age Range

Under 5 years old	16
5 – 10 years old	37
10 – 15 years old	57
> 15 years	34

Transplant Clinic OPA'S 2010 – 2011

	RENWAL	RSTCNS	RSTRTP
Total Appointments	**675 (773)**	**689 (740)**	**1380 (1270)**
Appointments Attended	**639 (726)**	**592 (604)**	**1119 (1034)**
DNA / Cancelled	**36 (47)**	**97 (136)**	**261 (236)**

Creatinine Trend-an overview in programme March 2011

Creatinine	**No of Pts**	**Years out**	**DD v LD**	
Up to 100	104	1 month - 15 yrs	47	57
100-200	34	1 month- 14 yrs	20	14
200-300	5	3 yrs – 15 yrs	2	3
300-400	1	13 yrs	1	

In Conclusion…the year ahead

- Renal Transplant Protocol
- Documentation
- Transplant Database

Thanks to all….For their teamwork!!!

11.3 RENAL TRANSPLANT NATIONAL COMPARATIVE UNIT AUDIT
(Report and data from NHS Blood and Transplant)

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 2010, by donor type (donor after brain death, donor after circulatory death and living donor) and by transplant unit (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: 1994 - 1997, 1998 - 2001, 2002 - 2005, 2006 - 2009) and by transplant unit (Great Ormond Street Hospital and all other UK kidney transplant units). Transplants from donors after circulatory death 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: 1994 - 2001 and 2002 - 2009) and by transplant unit (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	GOSH	Other UK paed units	GOSH	Other UK paed units	GOSH	Other UK paed units	**TOTAL**
1987	5	104	0	0	0	9	**118**
1988	6	122(2)	0	0	0	11	**139**
1989	7	116(3)	0	0	0	10	**133**
1990	4	80	1	3	0	10	**98**
1991	10	101(2)	0	0	2	8	**121**
1992	5	96	0	5	2	12	**120**
1993	4	136(1)	0	1	3	9	**153**
1994	6	107(3)	0	1	4	19	**137**
1995	5	124(1)	0	1	4	17	**151**
1996	6	93(3)	0	0	4	22	**125**
1997	23	94(3)	1	1	5	14	**138**
1998	13	75(3)	1	0	8	18	**115**
1999	12	96(4)	0	1	4	27	**140**
2000	21	74(2)	0	0	8	25	**128**
2001	12	90(2)	0	0	4	30	**136**
2002	9	73(1)	0	0	13	31	**126**
2003	11	72	0	0	16	30	**129**
2004	14	65(5)	0	0	14	30	**123**
2005	12	60(1)	0	0	13	33	**118**
2006	13	64(6)	0	1	16	35	**129**
2007	13	54(4)	0	1	7	43	**118**
2008	10	67(3)	0	2	14	50	**143**
2009	12	53(3)	0	1	17	47	**130**
2010	8	64(3)	1	1	14	54	**142**

( ) 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	GOSH	Other UK paed units	GOSH	Other UK paed units	GOSH	Other UK paed units	**TOTAL**
1987	5	90	0	0	0	9	**104**
1988	3	98	0	0	0	8	**109**
1989	5	79	0	0	0	10	**94**
1990	3	61	1	2	0	7	**74**
1991	5	87	0	0	2	6	**100**
1992	5	82	0	4	2	11	**104**
1993	3	116	0	1	3	9	**132**
1994	5	79	0	1	4	19	**108**
1995	5	101	0	1	4	17	**128**
1996	6	80	0	0	4	19	**109**
1997	20	69	1	0	5	14	**109**
1998	9	64	1	0	8	16	**98**
1999	9	74	0	1	4	22	**110**
2000	15	65	0	0	8	23	**111**
2001	9	80	0	0	4	30	**123**
2002	5	60	0	0	12	29	**106**
2003	11	63	0	0	15	27	**116**
2004	12	53	0	0	13	26	**104**
2005	12	56	0	0	13	29	**110**
2006	10	55	0	1	16	35	**117**
2007	12	45	0	0	7	43	**107**
2008	10	58	0	2	12	50	**132**
2009	10	48	0	1	16	47	**122**
2010	6	56	1	1	14	52	**130**

One, five and ten year transplant survival estimates for first paediatric kidney-only transplants from donors after brain death 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					
1994 – 1997	36	36	81	64 – 90	97
1998 – 2001	42	42	74	58 – 85	100
2002 – 2005	40	39	92	78 – 98	97
2006 – 2009	42	42	88	74 – 95	88
All other UK paediatric units					
1994 – 1997	359	358	81	77 – 85	99
1998 – 2001	303	303	89	85 – 92	99
2002 – 2005	250	250	92	88 – 95	100
2006 – 2009	230	228	95	91 – 97	82

Five year transplant survival estimates					
	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital					
1994 – 1997	36	36	72	54 – 84	97
1998 – 2001	42	42	62	46 – 75	100
2002 – 2005	40	39	79	63 – 89	79
2006 – 2009	42	42	-	-	17
All other UK paediatric units					
1994 – 1997	359	358	67	62 – 72	98
1998 – 2001	303	303	78	72 – 82	97
2002 – 2005	250	250	80	74 - 84	88
2006 – 2009	230	228	-	-	8

Ten year transplant survival estimates					
	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital					
1994 – 1997	36	36	63	45 – 77	94
1998 – 2001	42	42	49	33 – 64	71
2002 – 2005	40	39	-	-	23
2006 – 2009	42	42	-	-	17
All other UK paediatric units					
1994 – 1997	359	358	53	48 – 59	96
1998 – 2001	303	303	63	57 – 69	72
2002 – 2005	250	250	-	-	23
2006 – 2009	230	228	-	-	8

- 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

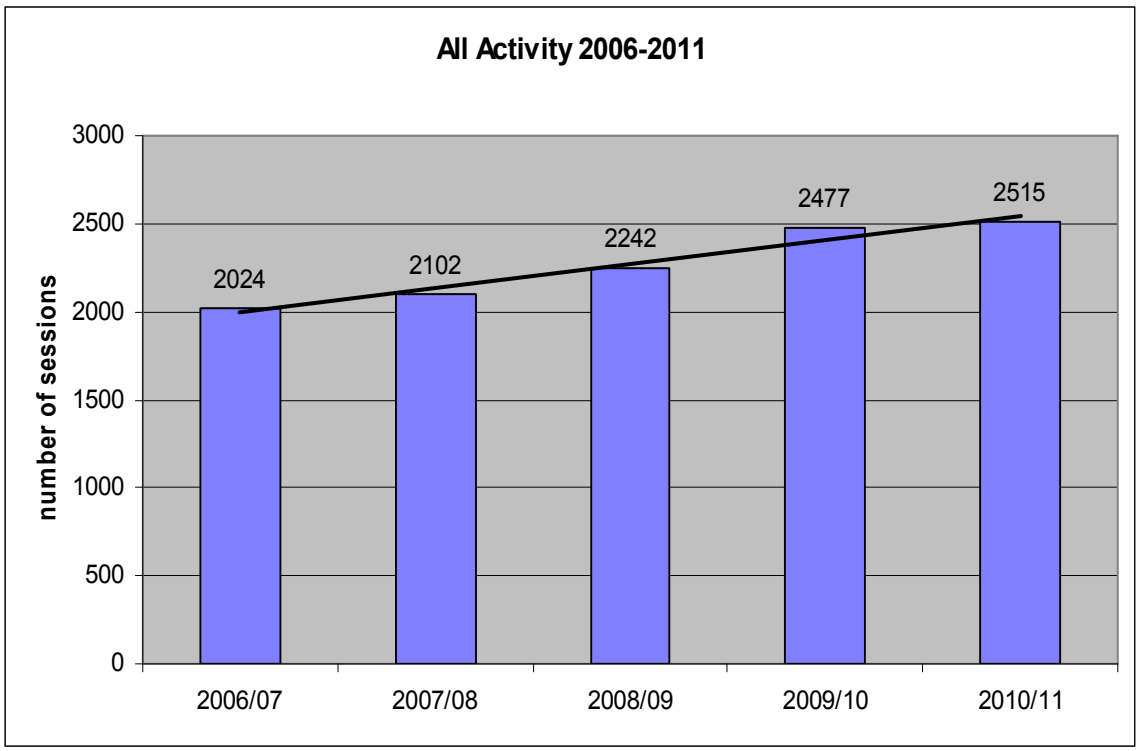
	One year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital					
1994 – 2001	41	37	92	77 – 97	95
2002 – 2009	105	105	95	89 – 98	81
All other UK paediatric units					
1994 – 2001	190	183	95	90 – 97	98
2002 – 2009	327	325	96	94 – 98	89

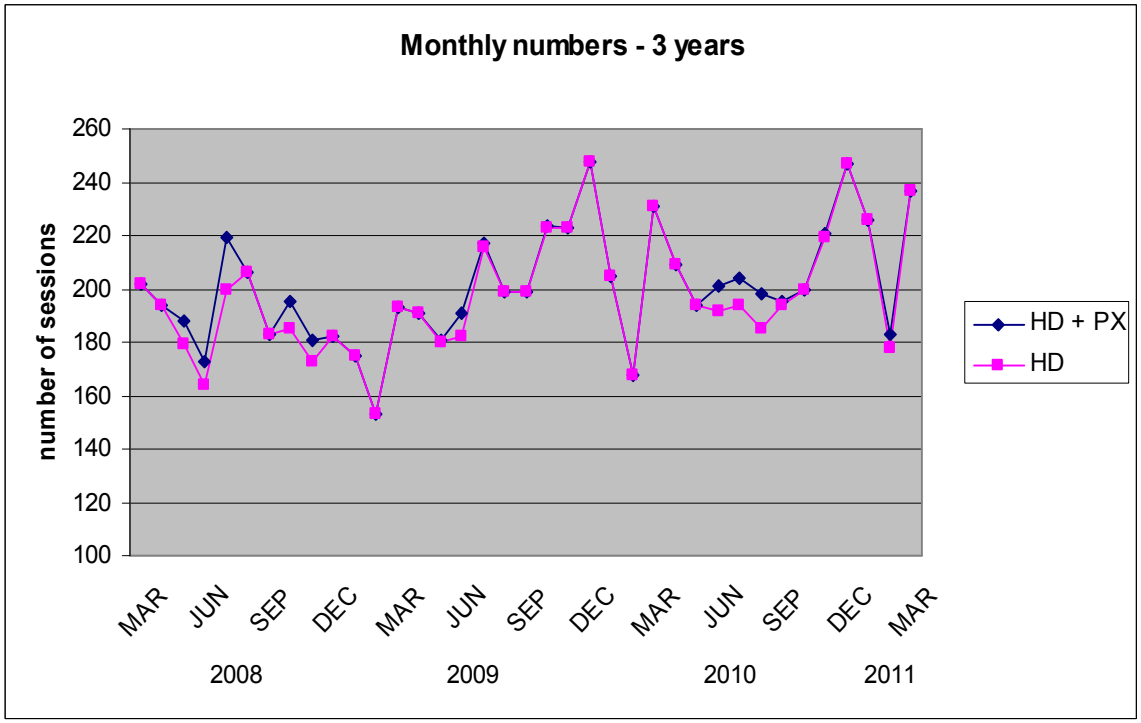
	Five year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital					
1994 – 2001	41	37	86	69 – 94	78
2002 – 2009	105	105	-	-	36
All other UK paediatric units					
1994 – 2001	190	183	84	77 – 88	98
2002 – 2009	327	325	-	-	89

	Ten year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital					
1994 – 2001	41	37	75	55 – 87	59
2002 – 2009	105	105	-	-	11
All other UK paediatric units					
1994 – 2001	190	183	69	61 – 75	69
2002 – 2009	327	325	-	-	8

11.4 HAEMODIALYSIS AUDIT 2010-2011

Liane Pilgrim, Liz Wright





Totals

Children receiving HD or PEX (GOS) only

Total = 45

- Chronic HD = 38
- Acute HD = 4
- Plasma exchange = 2
- HD + PX = 4

Ages

Under 2yrs = 7

- Youngest 0.24 & 0.28

2yrs -5 yrs = 6
5yrs -10 yrs = 8
10yrs -15 yrs = 6
Over 15 yrs = 18

New HD Starters

Source	Reason	No.s of children
PD	Peritonitis	5
CRF	New ESRF	3
Transplant fail	Deceased donor	2
Visitors	Line replacement/insertion	2
		12

Leavers

Reason for leaving	No.s of children
Transfer adult HD	2
Transplant - DD - LRT	4 2
Died	1
Function recovered	10
PD - Return	2

Acute HD

4 children
- 2 – HUS
- 1 – ARF sec. to rhabdomyolosis
- 1 – ARF sec. EBV/Hantavirus

2 had access inserted but renal function stable, and never dialysed

Plasma Exchange

6 children
- 2 had trial exchange to assess antibody response
- 1 pre-transplant session
- 1 cerebral vasculitis SLE (7)
- 1 post-tx FSGS recurrence (25)
- 1 HUS (5)

40 sessions in total

Access Totals

Total access = 75 in 44 children

- AVF – 20
- Permcath – 49
- Vascath – 6

Access inserted over the audit year

- AVF – 8
- Permcath – 36
- Vascath – 6 (of which 2 inserted KCH)

Line Insertions

	Who	Permanent	Temporary	Total
IR (%)	**DR**	12		12
	NT	5	1	6
	AB	5	2	7
	SC	7		7
Renal (%)	**GK**	2		2
	FC	1		1
	NM	0		0
	JT	1		1
	MD	1		1
	VH	1		1
Other	**KCH**		2	2
	CICU/PICU		1	1
		35 + 1?	**6**	

Line Positions

Position	Permanent	Temporary	Total
Right IJV	29		29
Left IJV	6		6
Right femoral		5	5
Left femoral		1	1
Other	1		1
Total	36	6	42

Reason for Line Removal

Of 55 lines (permcath and vascath) 40 were removed:

- No longer required (38%)
  - AVF - 5
  - Function recovered - 8
  - PD - 2
  - Tx - 5
  - Died - 1

- Mechanical (18%)
  - Poor flow - 5
  - Cuff extrusion -3
  - Leaking - 0
  - Pulled out - 1
  - Obstruction -1

- Infection (10%) – 6 (2 for line colonisation 4%)

- Replaced for permanent access (5%) – 3

Infection data

- 7 infections
- 4076 catheter days
- 1.7 infections/1000 catheter days

Infection rates

	06/07	07/08	08/09	09/10	10/11
No. of infections	12	10	7	5	7
Catheter days	1309	1914	2434	3384	4076
Infections/ 1000 catheter days	9.16	5.2	2.9	1.5	1.7

Line Infections

Patient	Infection Number	Time (days) from insertion	Microbiology	Outcome
1	1	14	CNS	Cleared
2	2	7	Mixed growth	Cleared
3	3	67	Staph aureus	Cleared
	4	145	CNS	Access replaced
	5	52	Staph aureus	Access replaced
4	6	37	CNS	Cleared
	7	80	CNS	Cleared

Exit Site Infections

Patient	Number	Growth	Local	IVs	Ass. with line sepsis?
1	1	CNS	y		No
2	2	Staph Aureus	y		No
3	3	CNS	y	y	Yes – presented first
4	4	CNS	y		No
	5	Mixed		y	Yes
	6	CNS	y		No

AVF data

20 children had fistulae
- 16 children were dialysed by fistula

8 new fistulae were created in 7 children
- 3 failed within a few weeks of creation

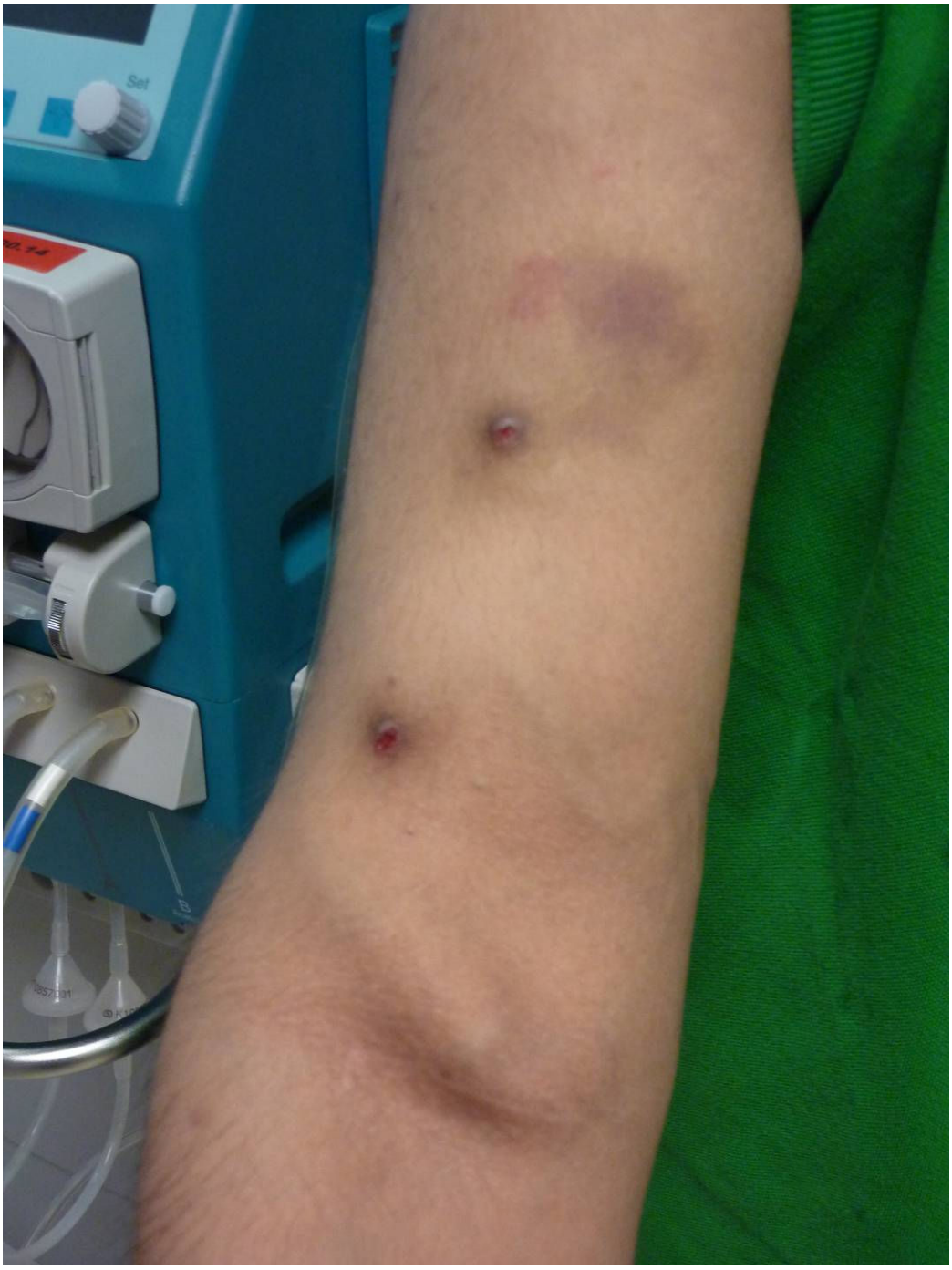
AVF

	Age	Site	Surgeon	2nd Stage	Outcome
TS	7.0	L brachiobasilic	GK		Functioning
MIM	9.6	R brachiobasilic	FC	Yes	Further revision required
SC	16.3	L brachiocephalic	FC		Thrombosed
KT	16.5	R brachiocephalic	FC		Functioning
KMcT	15.7	L brachiobasilic	VH		Failed
KMcT	15.7	L brachiocephalic	MD		Failed
IS	16.0	L radiocephalic	MD		Poor flows
MA	6.4	L brachiocephalic	NM		Phobic!

AVF Infections

Septicaemia associated with fistula and buttonhole needling method = 2

1 - Streptococcus
1 - Staph aureus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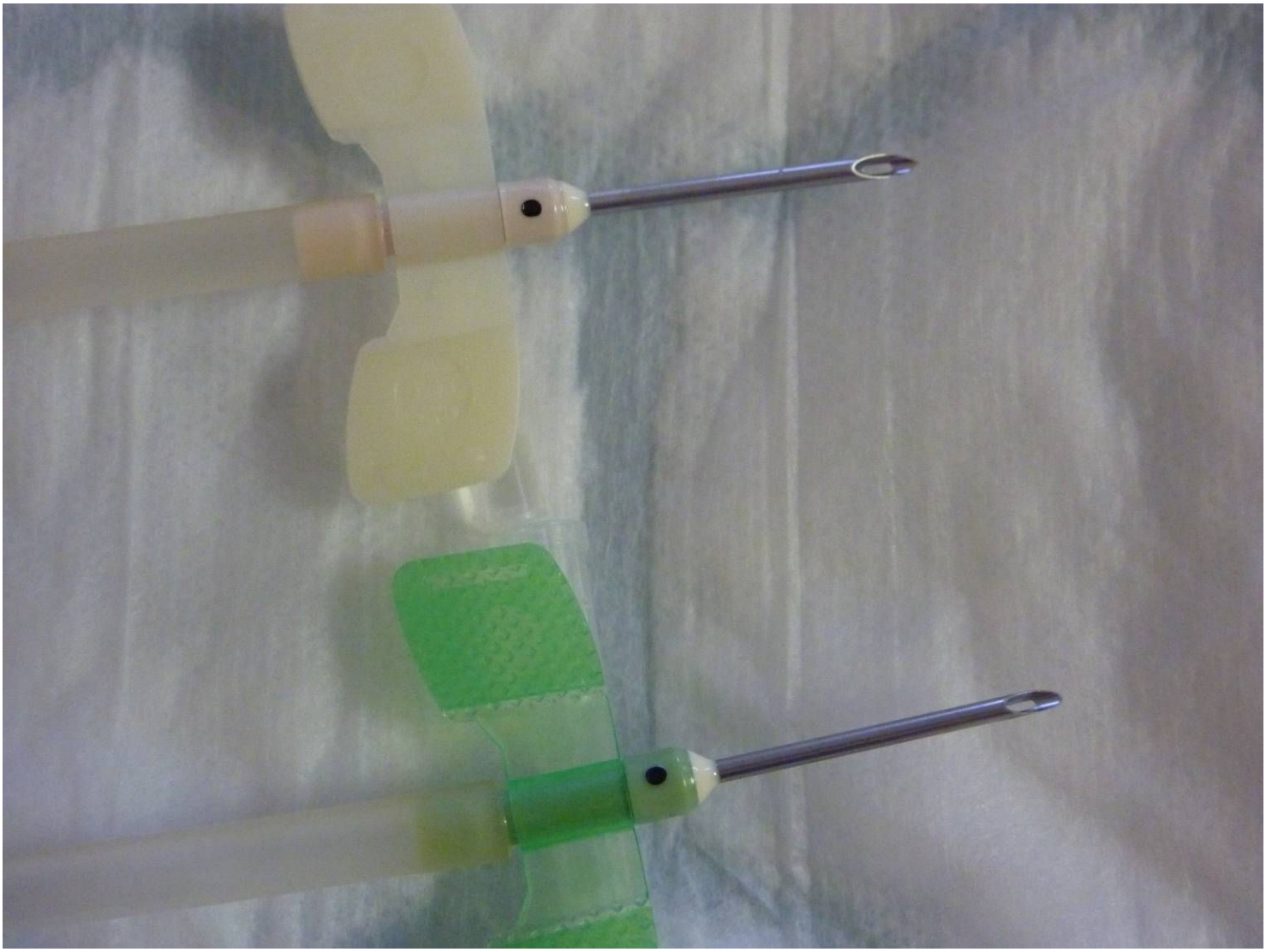
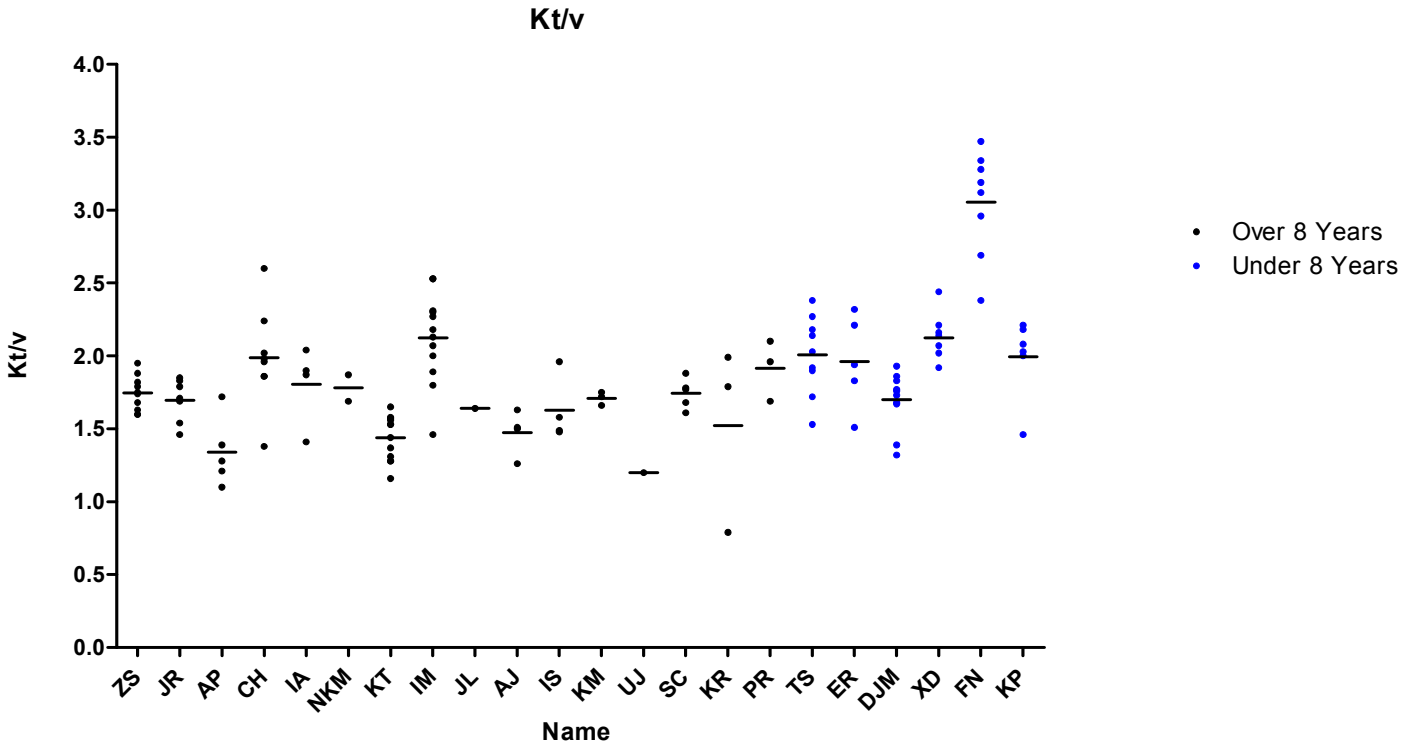


HDF

- Started May 2010
- 3 machines capable on-line HDF
- Post-dilution, high volume
- Paediatric or adult lines only
- Good arterial flows required! 5 line; 1 avf
- Well tolerated
- Youngest 14kgs


Kt/v
Kt/v
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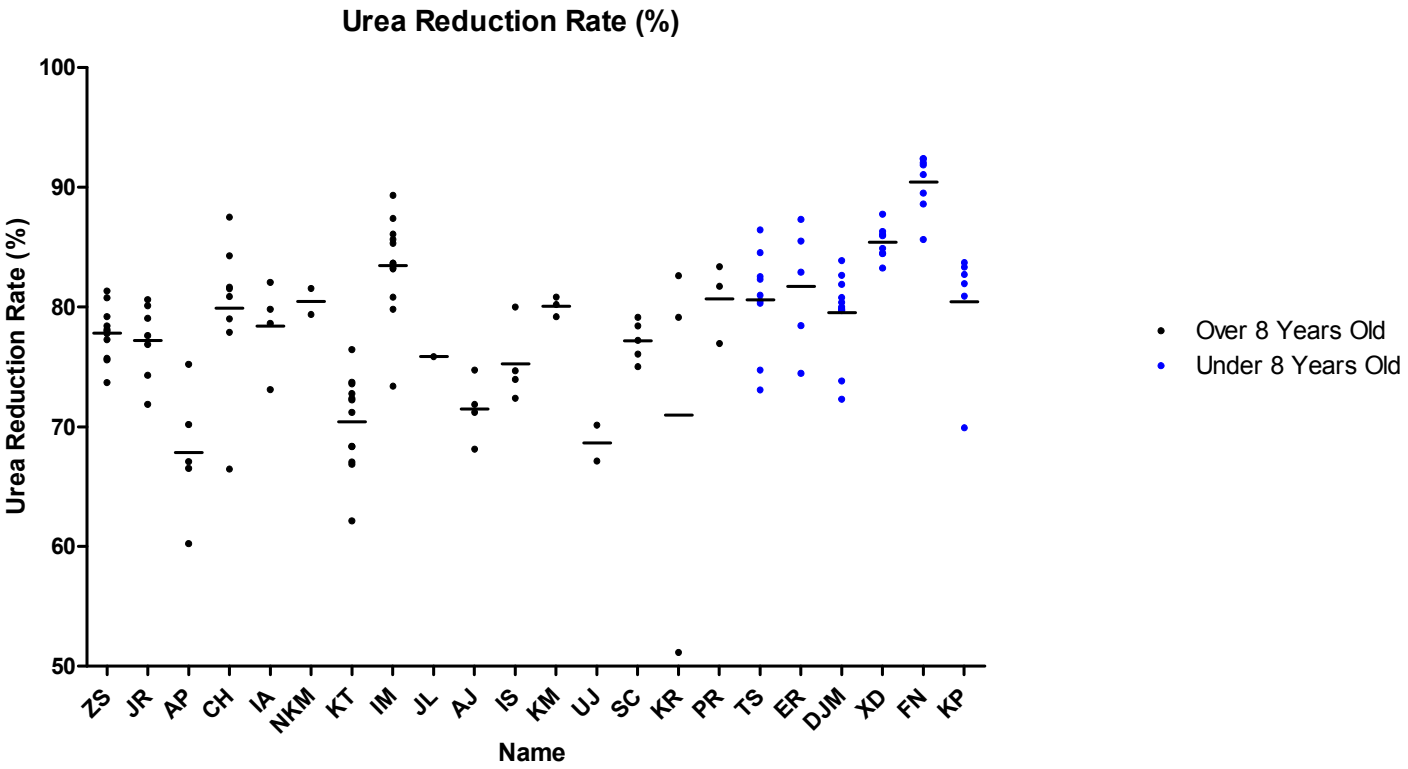
3.5
3.0
2.5
2.0
1.5
1.0
0.5
0.0
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years
Under 8 Years


Urea Reduction Rate (%)
Urea Reduction Rate (%)
100
90
80
70
60
50
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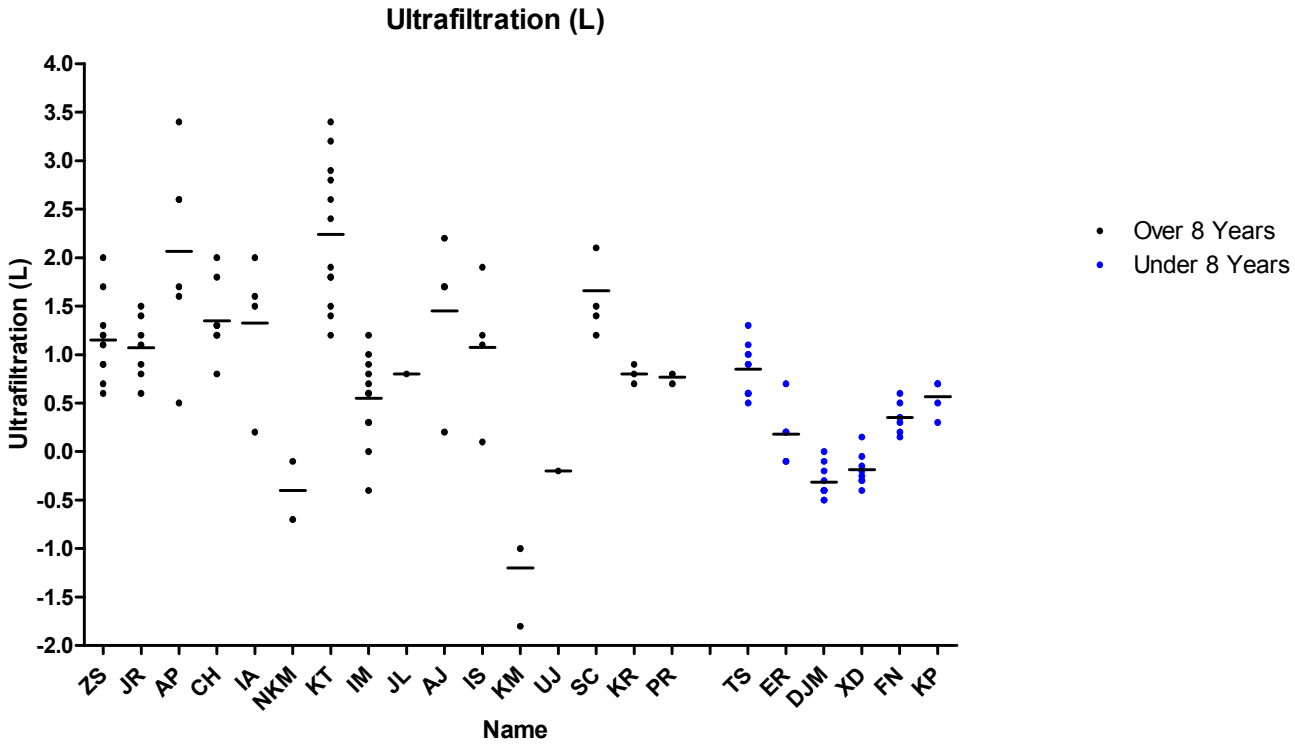
Name
Over 8 Years Old
Under 8 Years Old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Ultrafiltration (L)
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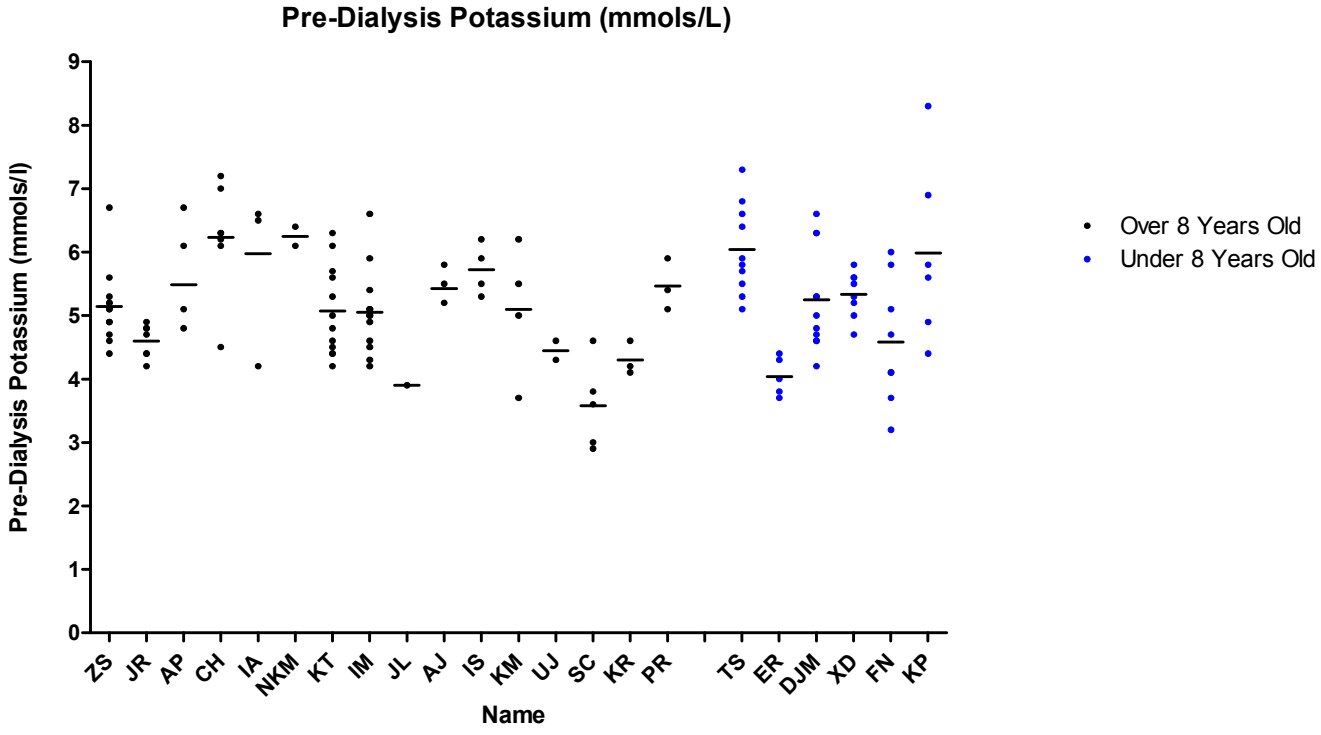
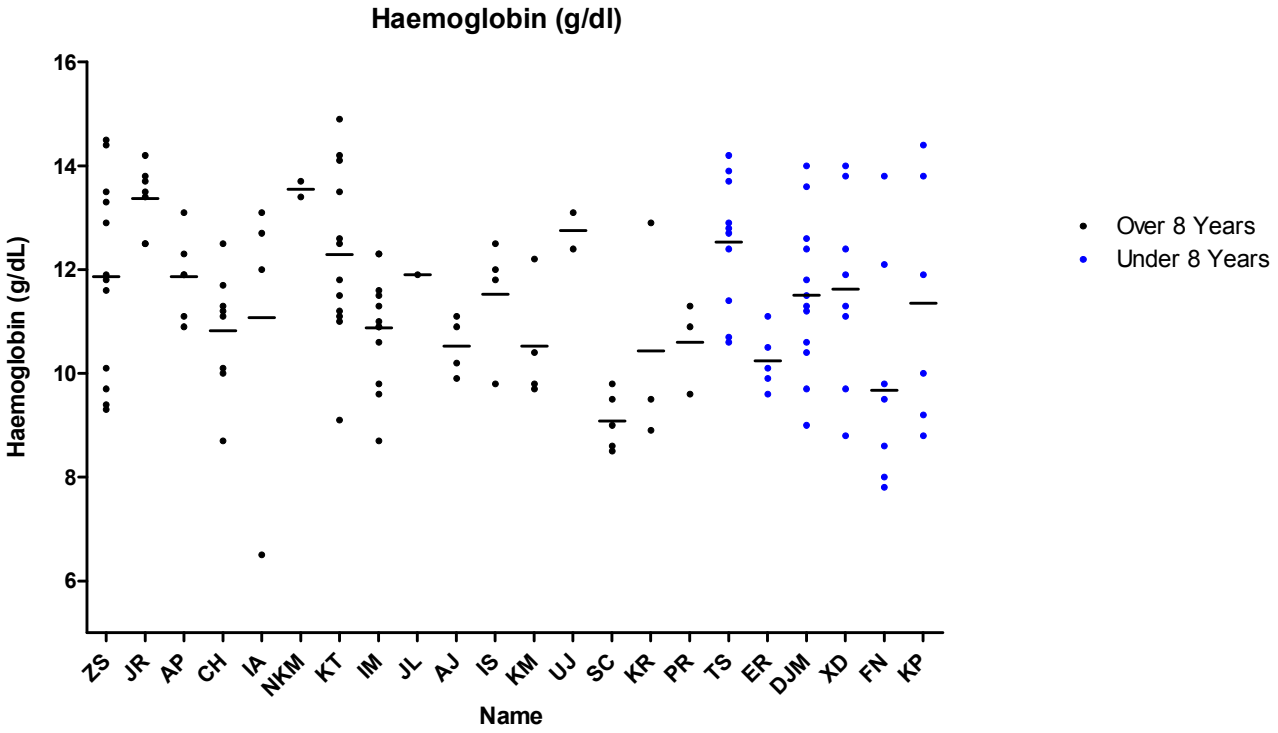
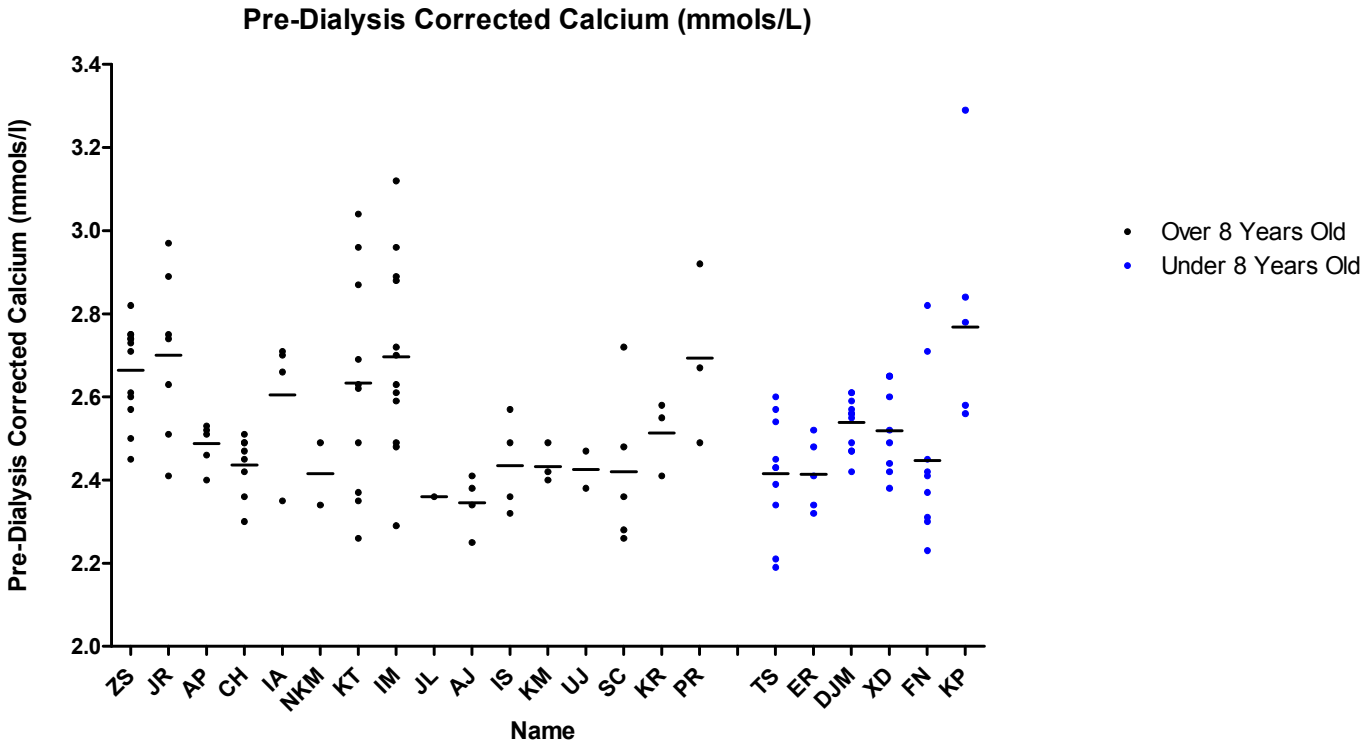
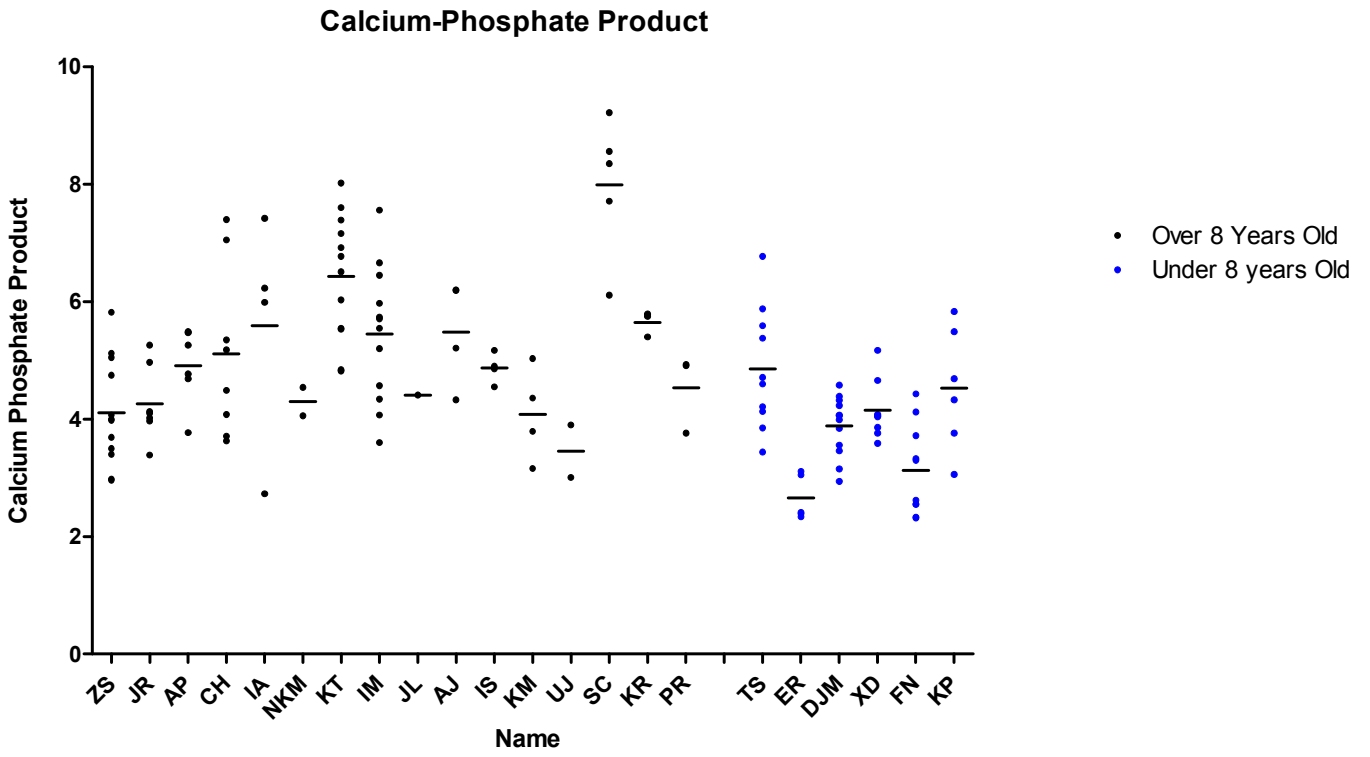
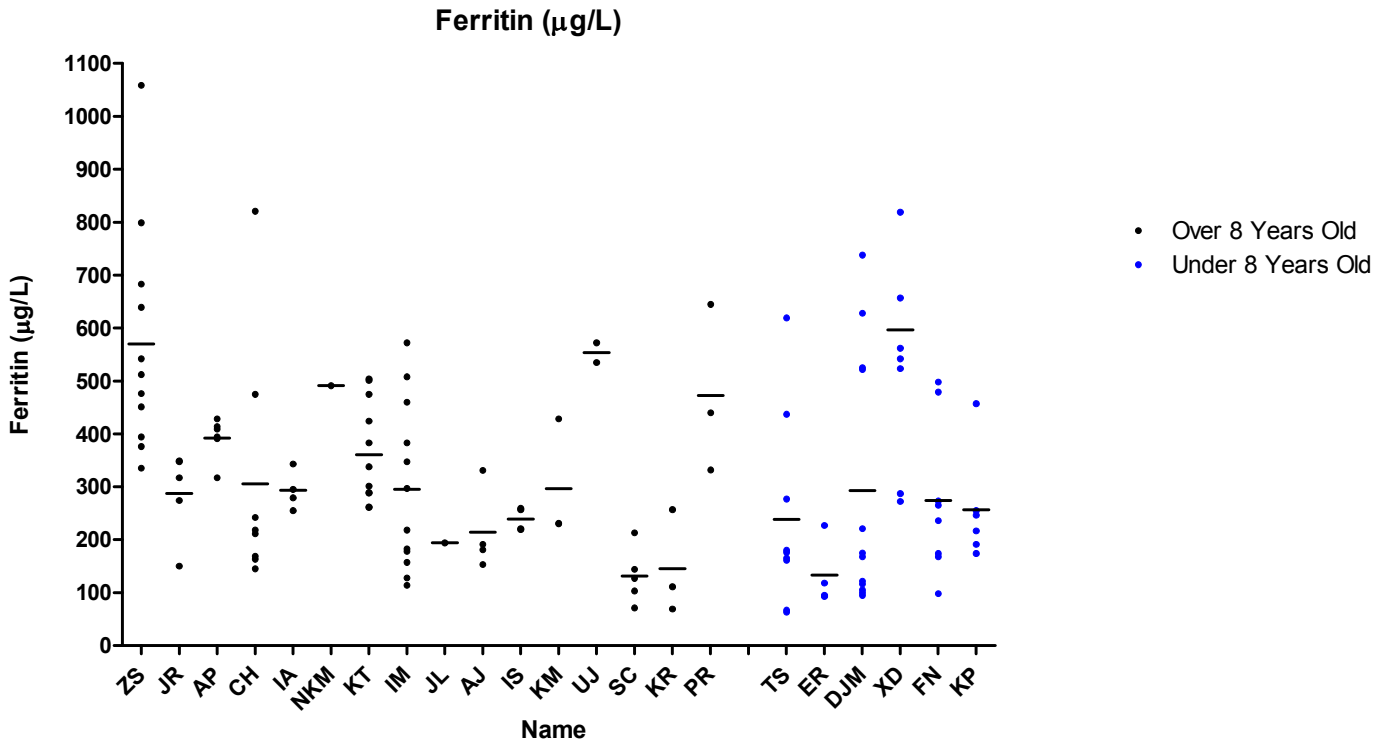
3.5
3.0
2.5
2.0
1.5
1.0
0.5
0.0
-0.5
-1.0
-1.5
-2.0
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years
Under 8 Years

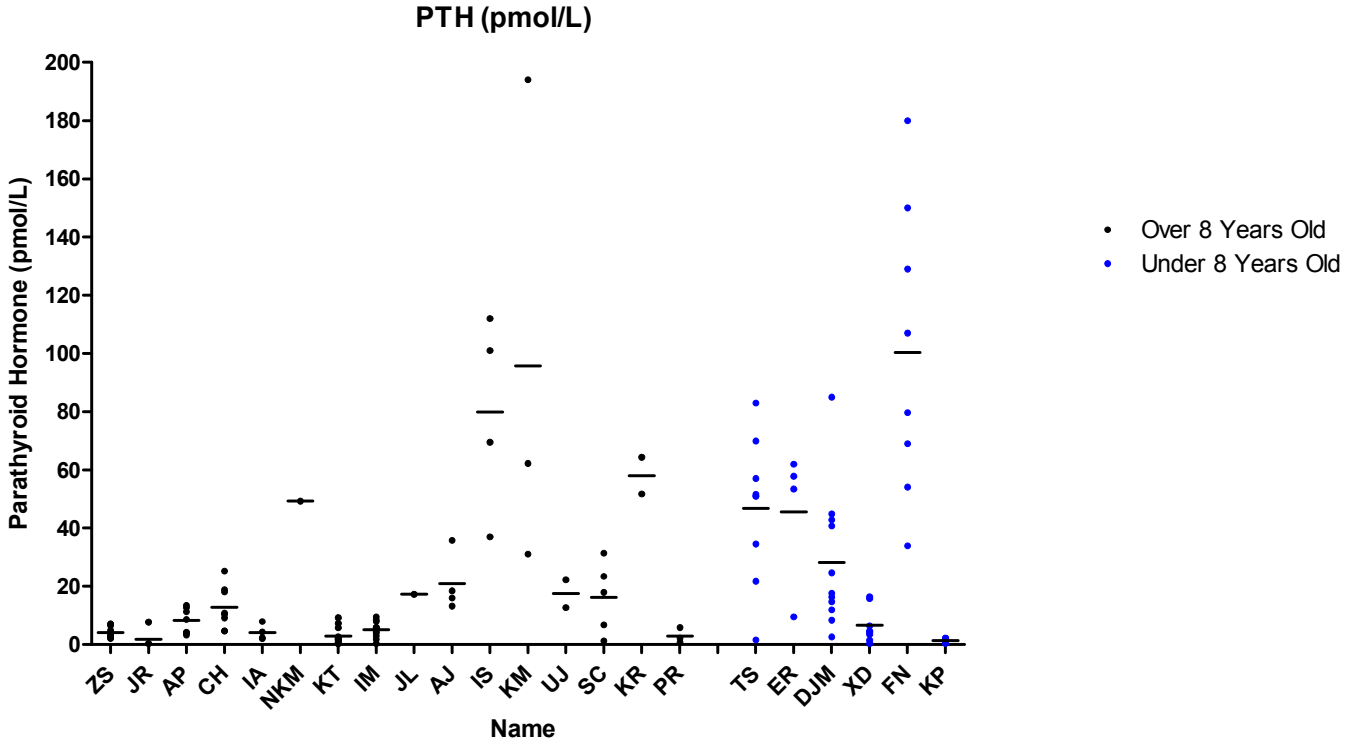

Pre-Dialysis Potassium (mmols/L)
Pre-Dialysis Potassium (mmols/l)
9
8
7
6
5
4
3
2
1
0
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years Old
Under 8 Years Old

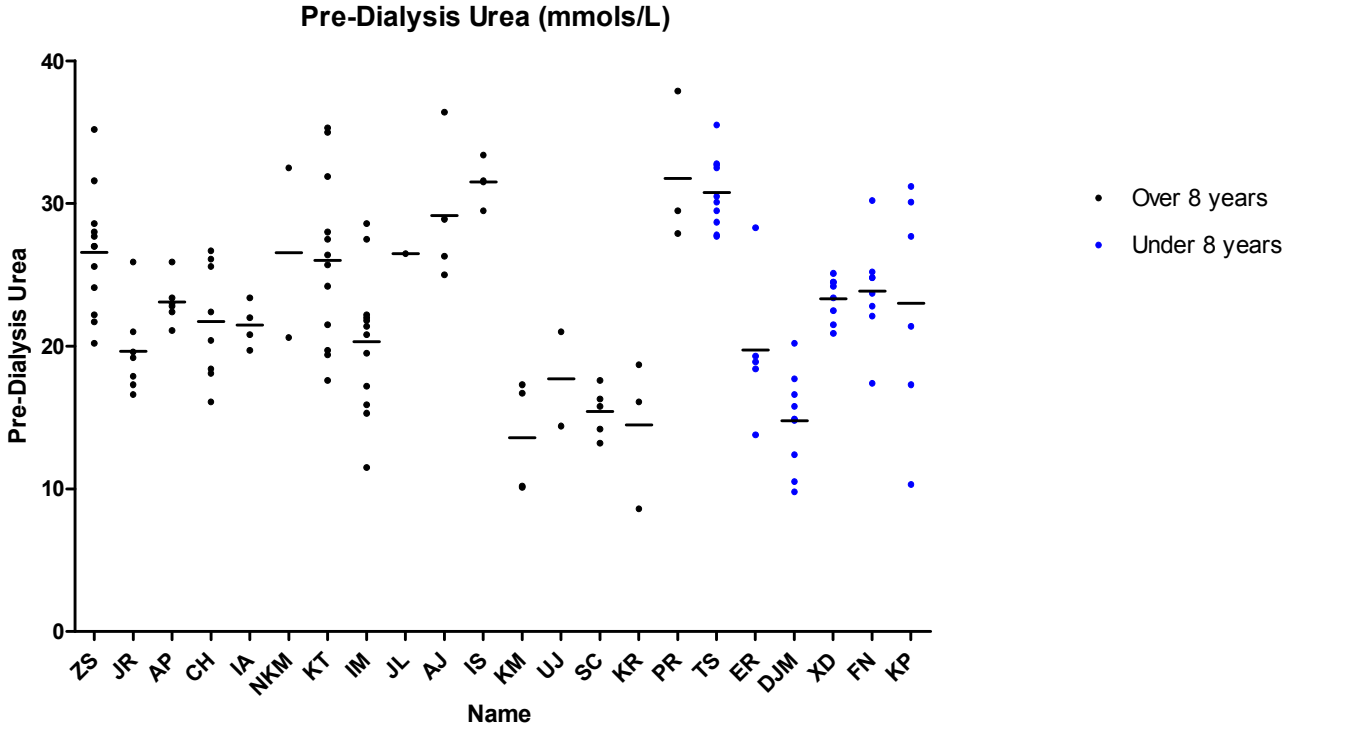

Haemoglobin (g/dl)
Haemoglobin (g/dL)
16
14
12
10
8
6
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years
Under 8 Years

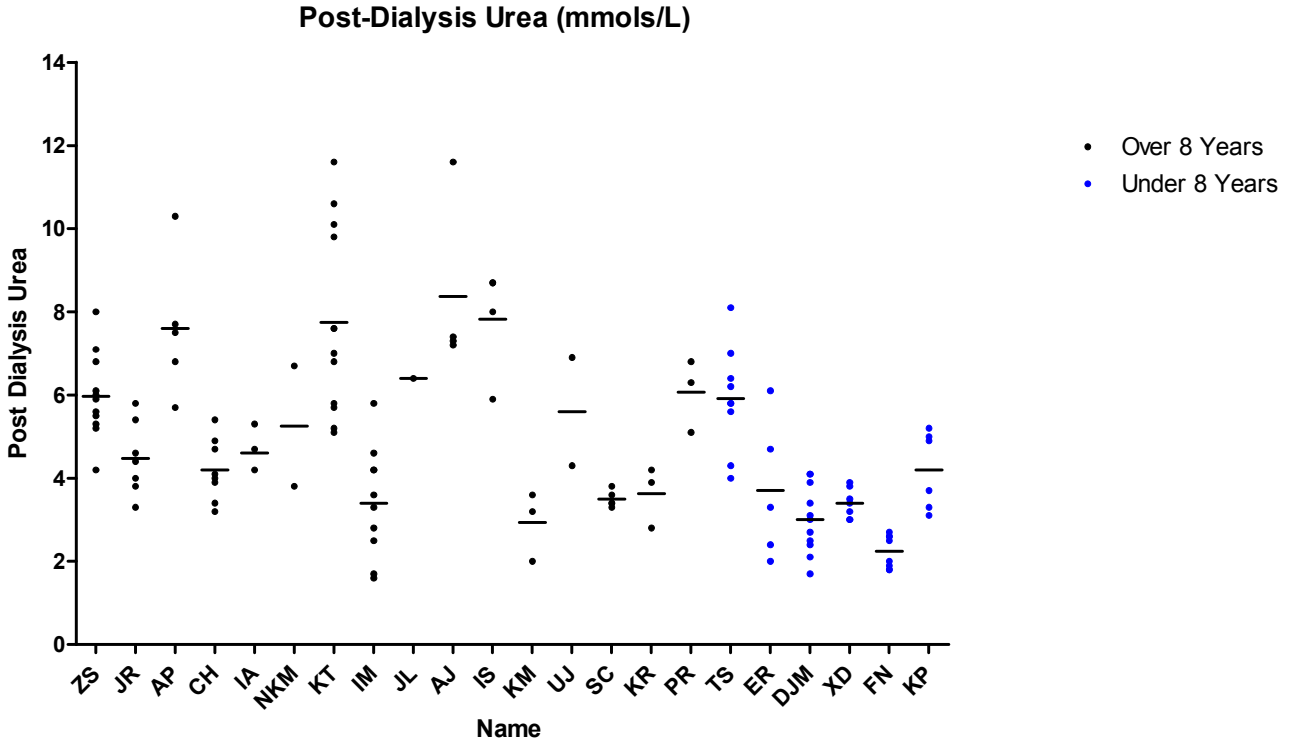

Pre-Dialysis Corrected Calcium (mmols/L)
Pre-Dialysis Corrected Calcium (mmols/l)
3.4
3.2
3.0
2.8
2.6
2.4
2.2
2.0
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years Old
Under 8 Years Old

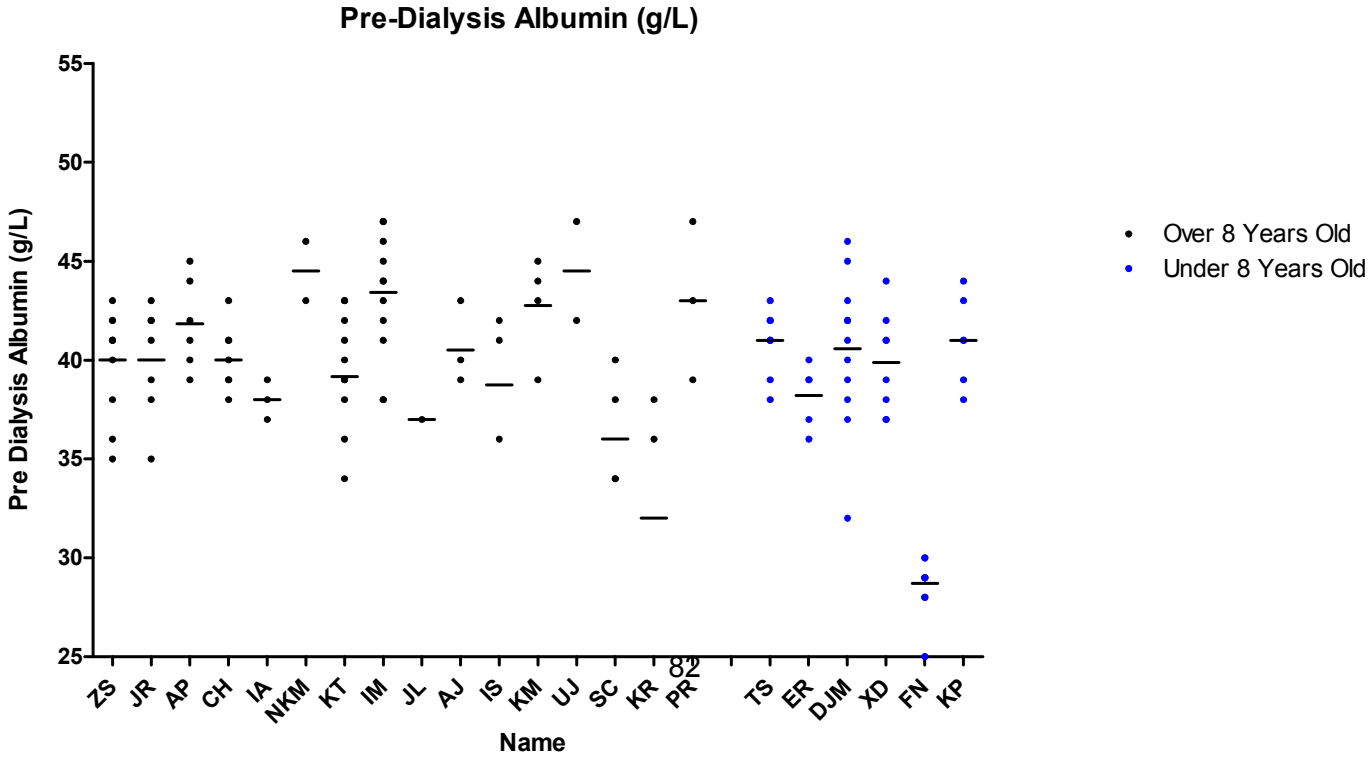

Calcium-Phosphate Product
Calcium Phosphate Product
10
8
6
4
2
0
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years Old
Under 8 years Old


Ferritin (µg/L)
Ferritin (µg/L)
1100
1000
900
800
700
600
500
400
300
200
100
0
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years Old
Under 8 Years Old


PTH (pmol/L)
Parathyroid Hormone (pmol/L)
200
180
160
140
120
100
80
60
40
20
0
ZS
JR
AP
CH
IA
NKM
KT
IM
JL
AJ
IS
KM
UJ
SC
KR
PR
TS
ER
DJM
XD
FN
KP
Name
Over 8 Years Old
Under 8 Years Old


Pre-Dialysis Urea (mmols/L)
Pre-Dialysis Urea
40
30
20
10
0
ZS
JR
AP
CH
IA
NKM
KT
IM
JL
AJ
IS
KM
UJ
SC
KR
PR
TS
ER
DJM
XD
FN
KP
Name
Over 8 years
Under 8 years


Post-Dialysis Urea (mmols/L)
Post Dialysis Urea
0
2
4
6
8
10
12
14
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years
Under 8 Years


Pre-Dialysis Albumin (g/L)
Pre Dialysis Albumin (g/L)
25
30
35
40
45
50
55
ZS JR AP CH IA NKM KT IM JL AJ IS KM UJ SC KR PR TS ER DJM XD FN KP
Name
Over 8 Years Old
Under 8 Years Old

Successes

- HDF
- Buttonholing/blunt needles
- Single-needle, neonatal circuit
- Chlorprepp skin preparation
- Biopatch?

Failures?

- Needle phobia in one patient

Future Challenges

- Eagle Ward
- Plasma exchange service
- Replacement plasma exchange machines and training
- Immunoabsorption
- In-centre training/usage of NX stage

11.6 PERITONEAL DIALYSIS AUDIT

April 2010 – March 2011

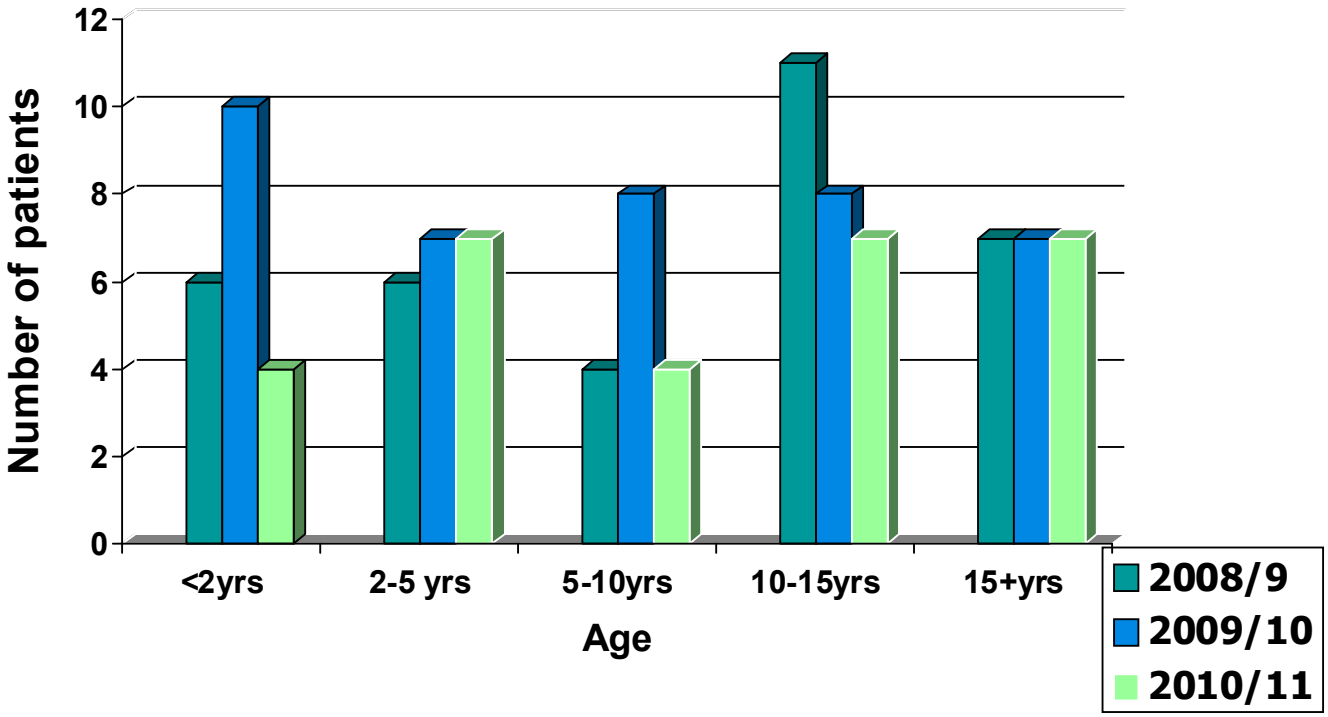
Michelle Cantwell, Cecilia McNeice, Eileen Brennen & Rob Uscroft

Patient Demographics

29 patients have been on the PD program. 55 % (16) Male, 45 % (13) Female

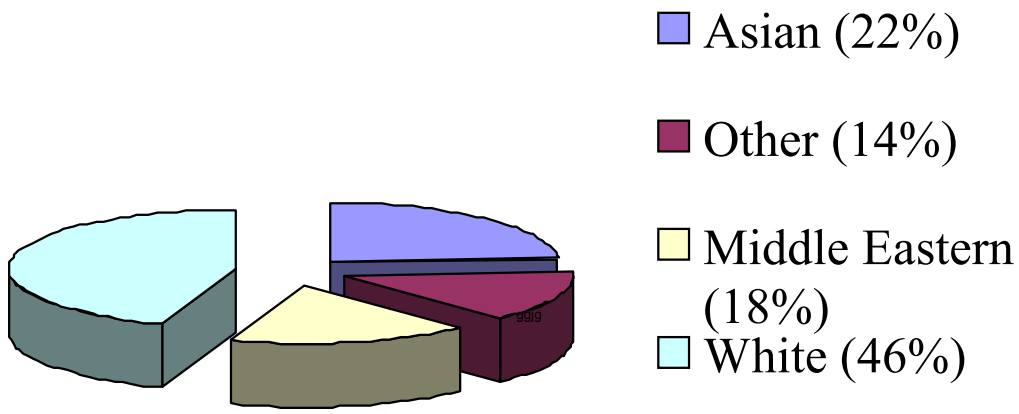
- Children currently on PD in the community: between 1.11 – 16.53 years

TOTAL PD MONTHS = 218.3 months



Patient Age Ranges 2008 to 2011 (End of Year)

Ethnicity



Patients on PD – Primary Diagnosis

➢ Dysplasia	(24%)	7
➢ FSGS	(14%)	4
➢ Nephronopthisis		4
➢ HUS		3
➢ Posterior Uretheral Valves		3
➢ Congenital Nephrotic Syndrome		3
➢ ?Basement membrane disorder		1
➢ Good pastures		1
➢ Mitochondial Cytopathy		1
➢ Renal Vein Thrombosis		1
➢ Unknown		1

New Patient Profile

12 new PD patients to PD in 2010 – 2011:

- New packages of care in community
- 1 returned to PD after temp hx
- 1 returned to PD after failed transplant
- Overseas patients converted to Baxter / GOS trained

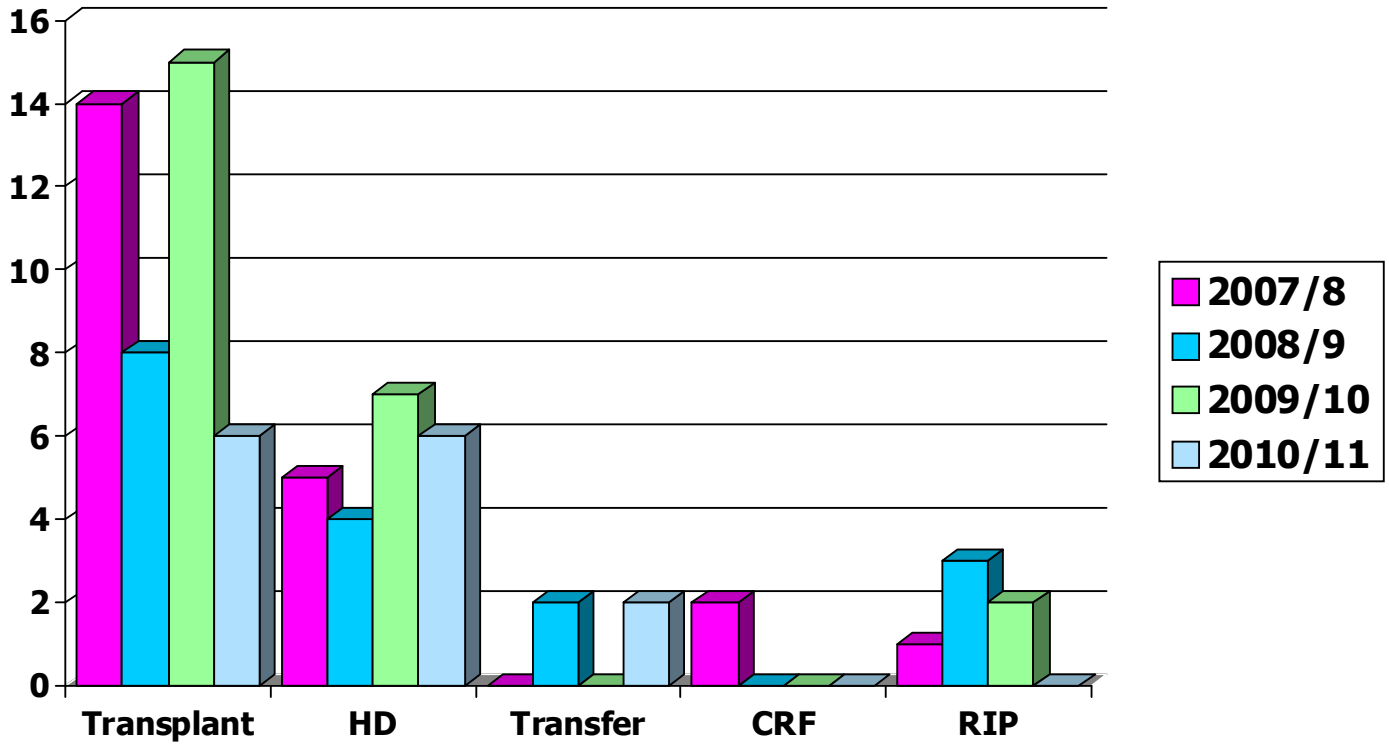
Patients Leaving PD

14 patients left PD in 2010/2011:

- Patients were transplanted
- Transferred to Haemodialysis due to infection. They did not return to PD because:
  3 - PD failing / catheter problems
  1 - social concerns
  1 – for planned home hx
  1 – died shortly after transfer to hx
  2 patients transferred back to Kuwait

Annual Figures 2004/5 - 10/11

	04-05	05-06	06-07	07-08	08-09	09-10	10-11
Patients	39	41	37	34	34	40	29
New Patient	14	17	18	15	15	20	11 (3PX)
No.at Year End	23	18	20	20	19	1	15 (1PX)
Transplants	11	12	14	8	6	15	6
Transfers	2	3	0	0	2	0	2 (PX)
To HD	5	6	2	5	4	7+1temp	6
To CRF		1	1	2	0	0	0
Deaths	0	0	1	1	3	2	0



Reasons for Leaving

Inpatient History

- Number of Inpatient Episodes: 66
- Number of Inpatient Days: 1038
- 602 inpatient days if 5 long term admissions removed (2 babies, 3 PX)
- 4 patients had no admissions in audit year.
- 2 of these patients were on PD for the 12 months

Inpatient Admissions

Reason for admission		No.	%
Diagnosis / Catheter insertion / Training		18	27
Peritonitis / Exit Site Infections		16	24
Renal	Surgical interventions	3	5
	Catheter changes	5	7.5
	Catheter problems (no surg)	5	7.5
Renal Medical		6	9
Non Renal		13	20

PD Catheter Insertions (acute & chronic)

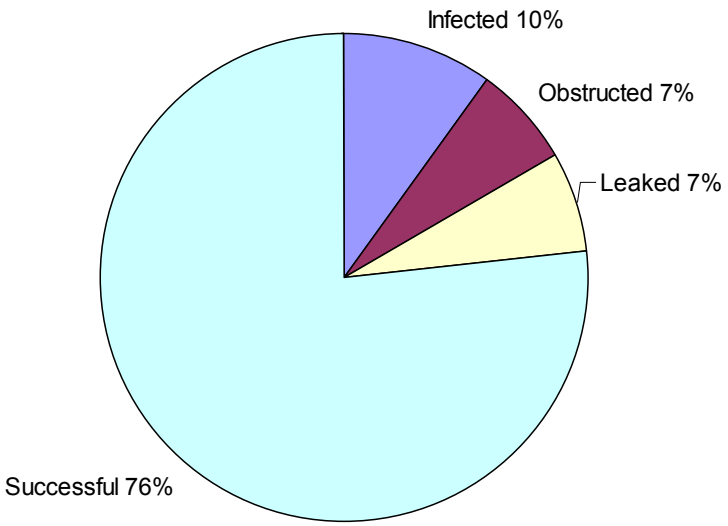
HIGH RISK: <1 year of age, Significant oedema, Significant gut problems, Extensive abdo surgery (Nissen, Mitrofanoff, Stoma)

- **30 catheters were inserted in 23 patients in 2010-2011 by 6 surgeons**
  - 50% of these insertions involved patients classified as **'high risk'**

24% of all catheter insertions FAILED within 3 months

- 78% of HIGH RISK catheters failed
- 22% of LOW RISK catheters failed

Catheter failures within 3 months



Annual Figures 2009 - 2011

	09-10	10-11
Patients	42	23
First catheters ESRF	20	7 + 1 (returned post failed tx)
Replacement catheters ESRF	9 (at least)	6
New catheters ARF	14	9 (1 ARF had 2)
High risk	55%	50%
Failed within 3 months	55%	24%
Surgeons	5	6

Total catheters of current ESRF caseload

Surgeon	No. of Insertions	% Failed	Leaked post op	% High Risk
A	4	25 %	75 %	25 %
B	6	17%	17 %	50 %
C	12	17 %	8%	%
D	1	100%	100 %	100 %
E	5	40%	0%	25%
F	2	0 %	0 %	100 %

Acute catheters

- **9 PD catheters inserted in 8 patients:**
  - 6 catheters were problem free
  - 3 problematic:1x exit site ooze/loose cuff
    2x leak / poor drainage
  - 1 catheter needed replacing (1 pt – second period of ARF, 3 PD caths)
  - 1 patient developed peritonitis, 3 days post catheter insertion (CNS on subculture)

Peritonitis (chronic patients)

- 16 episodes of 'true' peritonitis
  - Culture Positive episodes (56%)
  - Culture Negative episodes (44%)
  - Eosinophilia seen in 6 patients (chronic / recurrent in some)

Culture Positive Peritonitis

- ORGANISM CLASSIFICATION

  - **8 episodes of GRAM POSITIVE**
    - Staph aureus: 3 episodes
    - *Coagulase negative Staph:* 2 episodes
    - *Streptococcus* species: 2 episodes
    - Corynebacterium: 1 episode

  - **1 episode of GRAM NEGATIVE**
    - Klebsiella species: 1 episode

Peritonitis

	07-08	08-09	09-10	10-11
Culture -ve	13	10	5	7
Staph Epi	3	2	3	2
Staph Aureus	3	1	0	3
Candida	0	1	0	0
Enterococcus / coliform /E coli	2	3	3	0
Strep	0	0	2	2
Pseudomonas	3	0	3	0
Corynebacterium	0	0	0	1
klebsiella	0	0	0	1
Total episodes	**24**	**17**	**16**	**16**

Peritonitis Episode Breakdown

16 episodes of peritonitis in 218.3 patient months = 0.88 episodes per 12 patient months
(Peritonitis rates should be < 1 episode per 12 patient months (BAPN, 2007))

Peritonitis Episodes / 12 patient months

2006-2007	2007-2008	2008-2009	2009-2010	2010-2011
0.9	1.2	0.89	0.72	0.88

- Total of 16 episodes in 8 patients
- 7 of these episodes occurred in 3 patients under 2 years
- Outpatients: 13 episodes
- Inpatients: 3 episodes
- Only 1 episode while 'care by parent'

THEREFORE 21 patients' peritonitis free

Patient Breakdown- Peritonitis Hx

- Patient 1:1 x cult neg; 1 x strept. (2 CATH REMOV)
- Patient 2: 1 x cult neg; 1 x corynebacterium (1 CATH REMOV)
- Patient 3: 1 x cult neg; 1 x strept; 1 x SA (1 CATH REMOV)
- Patient 4: 2 x CNS; 1 x SA (2 CATH REMOV)
- Patient 5: 3 x cult neg

Patient 5 – Culture Neg Peritonitis Hx

WC	SYMPTOMS	Neut %	Eos %	Mono%
1100	CRP 39, PYREXIA, WELL IN HIMSELF	55	18	26
132	PAIN, TENSE ABDO,PYREXIACARE BY PARENT	0	0	100
310	VOMITING, APYREXIAL, SA ESI	56	13	31

Exit Site Infections (red / inflammed / exudate)

Organism	Infections	Treated with AB's	Catheter Removed
Staph aureus	5 (2 in same pt)	5	0 (1 cuff shaved)
Pseudomonas	2	2	both still on treatment
Mycobacterium	1	1	1

	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011
Staph aureus (SA)	14 (including colonised)	7	5	7	6	5
Pseud.	5	3	2	0	2	2
MRSA	1	1	0	0	0	0
Catheter removals *With peritonitis	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*	1 + 1 cuff shaved

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

Organism	Number	Treated with AB's
Coag neg staph	14	0
Staph aureus	8 (in 7 pts)	8 (2 pts developed peritonitis)
Coliform	3	0
Candida	1	1
Pseudomonas	1	1

Nasal Colonisation (outpt)

8 patients had nasal *Staph aureus* carriage:

- all received topical treatment
- 1 of these had MRSA
- only 1 patient had a concurrent *Staph aureus* ESI
- only 1 patient had concurrent *SA* colonisation at site.
- **No** patients had SA nasal carriage leading up to / at time of SA peritonitis (?benefit of screening)

PD Training

- 10 families underwent PD training in audit yr = approx 125 days of CNS workload
- 4 families required training with an interpreter (40%)

Clinical Nurse Specialist Community Activity

- Home Assessments: 10
- Home Visits at time of Discharge: 9
- Additional training: 1 (2 at GOSH)
  - Carers / HCAs, extended families
- Retraining in home setting: 4
  - further 5 sessions performed in hospital
- School visits: 3
- MDT external meetings: 2

Aims for 2011 and onwards

- Review / revise Peritonitis and Exit Site protocols, in conjunction with new International Paediatric Recommendations (to be published later this year)
- Retraining to be offered to all PD families on at least yearly basis OR after a peritonitis episode if concerns
- Launch PD Respite Service to all families (small pilot already complete)

Catheter replacements secondary to infection - discussion

GOSH PERITONITIS PROTOCOL (07/09):

- A new catheter can be inserted at a **minimum of one week after all clinical evidence of peritonitis has subsided**, providing Staphylococcus aureus carriage has been eliminated and any infection in the Tenckhoff tunnel has resolved.
- **NB. Ideally, the peritoneum should be rested for 4 weeks**

Consensus Guidelines for the Prevention and Treatment of Catheter Related Infections and Peritonitis in Pediatric Patients Receiving Peritoneal Dialysis: 2011 Update (IN PRESS)

Bradley A. Warady1, Sevcan Bakkaloglu2, Jason Newland1, Michelle Cantwell3,
Enrico Verrina4, Alicia Neu5, Vimal Chadha1, Hui-Kim Yap6, Franz Schaefer7

Catheter removal		Reinsertion (minimum time)
	Refractory bacterial peritonitis	After 2-3 wks
	Fungal peritonitis	After >3 wks
	ESI/TI in conjunct with peritonitis with same organism (except CNS)	After 2-3 wks
Simultaneous removal and replacement of catheter	Repeatedly relapsing or refractory ESI/TI Relapsing peritonitis	
	Repeat peritonitis	After 2-3 wks
	Mycobacterial peritonitis	After 6 wks

Case History 1

- C2. 27/5/08 – 11/12/09. Pulled due to **pseud peritonitis and ESI**
- C3. **inserted 18 days later**, 29/12/09, as Hx cath pulled out – used **immediately. Drain probs, Leaked ++, led to Ecoli peritonitis**. Removed 12/2/10

SURGEON ADVICE – REST PERITONEUM for 8 weeks

- C4. 13/4/10 (best catheter in his 3 years on PD). Removed on 27/12/10 as **SA peritonitis**.
- C5. **inserted 16 days later**, 11/1/11 as hx cath pulled out – leaked post op. Rested but **leaked again**. Removed 25/1/11
- **C6.new catheter inserted on same day**. Rested. UF probs. **CNS peritonitis and tunnel changes** (while inpt). Removed 15/2/11

Case History 2

- C1. 29/5/07 – 15/4/08. Removed as chronic tunnel infection. NO peritonitis
- C2. 18/4/08 – 2/08/09. Removed as chronic tunnel infection. NO peritonitis
- C3. 18/2/09 – 02/02/10 Removed as enterococcus peritonitis ?secondary to orchiditis
- C4. Inserted 4 days after. Used immediately. Leaked +++, CNS peritonitis / drain probs. Removed 1/03/10

Thanks

All on the Renal Unit, Dr. Lesley Rees, Dr. Rukshana Shroff, Dr. Sarah Ledermann, Transplant surgeons, Tanya Walton, Lynsey Stronach, Maria Rodriguez, Victoria ward staff

12. NURSING REPORT

During the last year the team has been working on the final plans for the move out of the Southwood building into the new Morgan Stanley building. We are now in the final stages of planning and are working towards a seamless move. One of the big challengers for the forthcoming ward will be to merge Victoria Ward and Hippo to become one unit. An Operational Group meets monthly to oversee the planning required. Several subgroups have been set up to bring the unit together. A Core Group of members of staff will ensure the patients, families and staff are supported through this process and that the delivery of high quality patient care is continued. Sarah Matthews is leading this group.

12.1 STAFFING AND CLINICS

Nurse Consultant	Eileen Brennan
Ward Sister	Joanna van Ree Acting Ward Sister
Ward Sister	Sr. Sarah Matthews Sr. Lucy Thomas mat leave
Clinical Nurse Specialists	Transplants Sr. Suzanne Bradley (1 WTE) Sr. CRF vacant (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) PD Sr. Michelle Cantwell (1 WTE) Transplants Senior staff nurse (0.7 WTE) & PD Senior Staff nurse (0.74 WTE)
Sisters	Sr. Liane Pilgrim, Haemodialysis (WTE) Mr. David Fisher, Nurse Counsellor (21hrs) Sr. Trish Evans, Practice Educator (WTE)

New Post
Lynsey Stronach Band 7 CNS Home Haemo

Clinics

Nurse Consultant Clinic

Nurse led	Transplantation	Daily reviews
	PD	Walk in clinic
	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

12.2 PUBLICATIONS

Quinlan C, **Cantwell M**, **Rees L** (2010) Eosinophilic peritonitis in children on chronic peritoneal dialysis. .**Pediatric Nephrology.** Mar;25(3):517-22.

12.3 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

12.4 EVENTS 2009/10

- GOSH assisted in the organization of the annual Paediatric Nurses Nephrology Conference Manchester. 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 support the Electronic prescribing and be involved in the hospital pilot schemes for Novell delivery applications.

12.5 EDUCATION

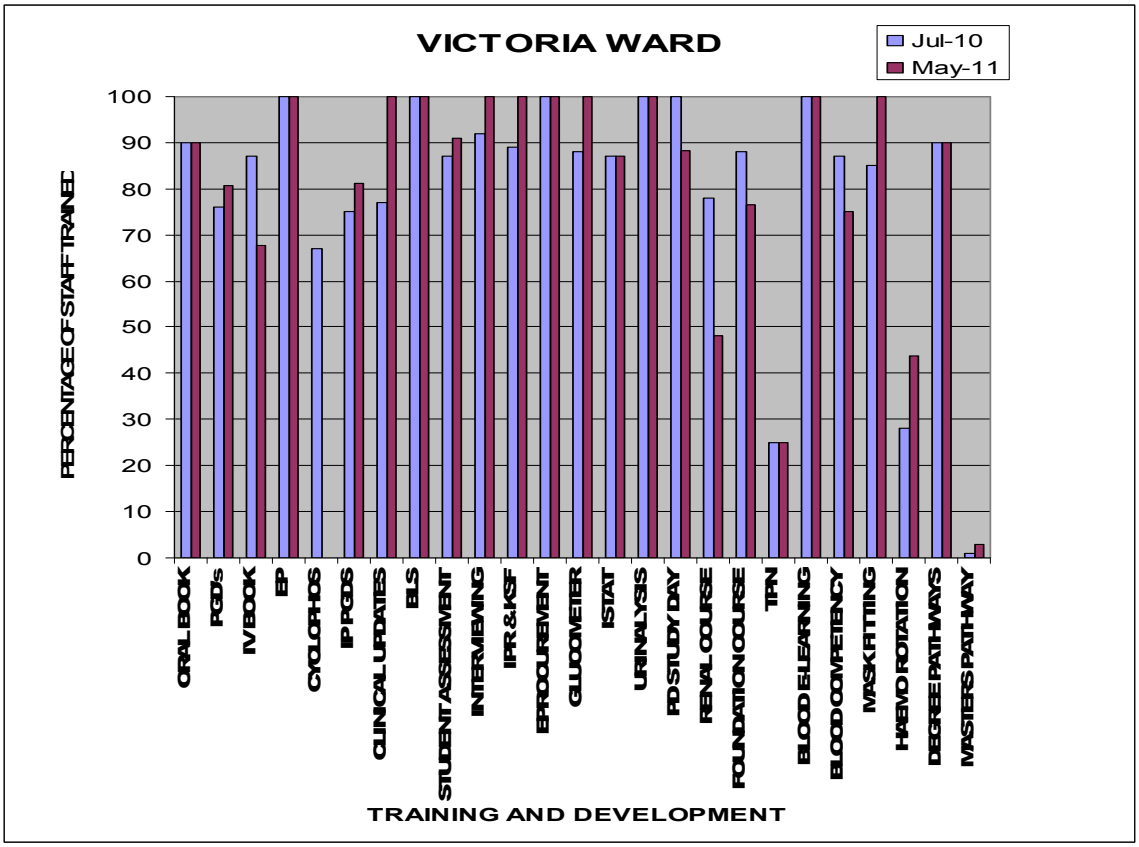
The Team continues to develop in new areas this year, phlebotomy and canulation and haemodialysis has been exemplary.

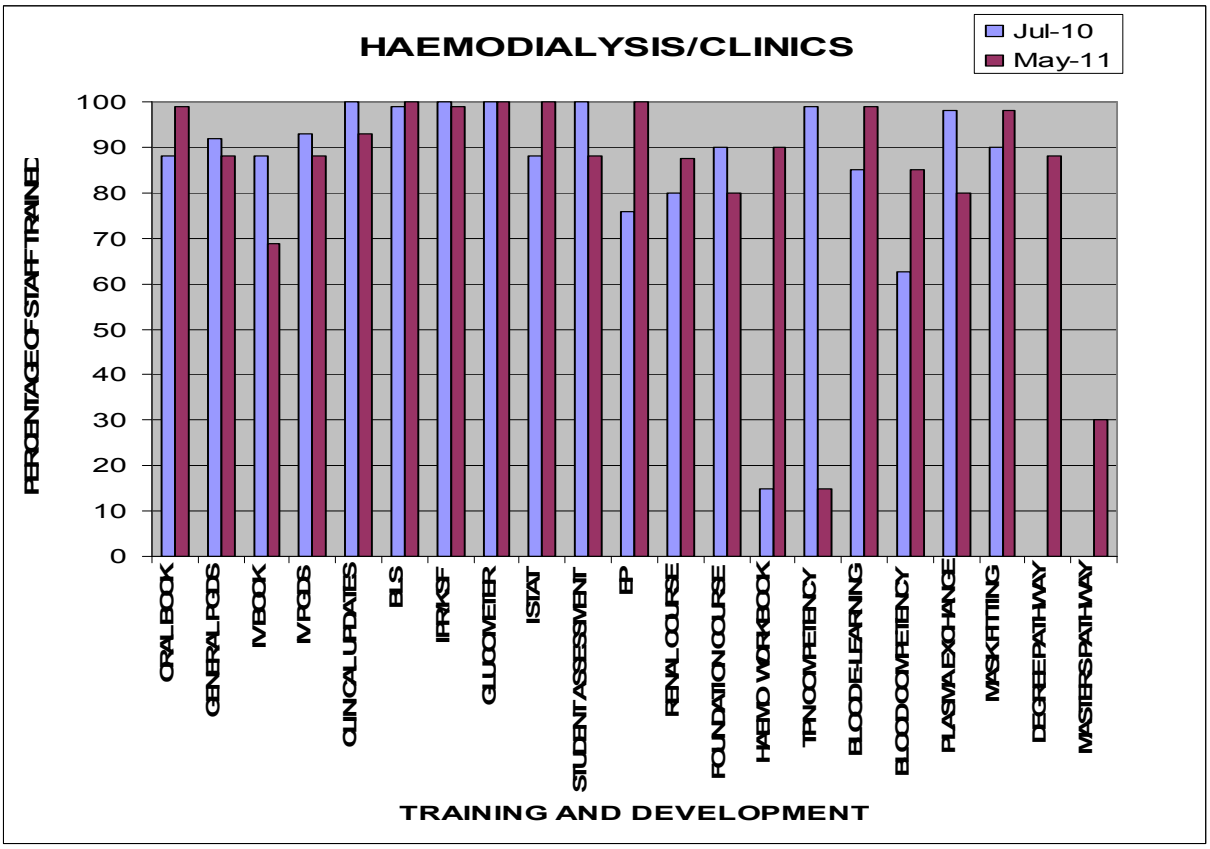
The role of the Nurse Independent prescribers continues to develop the nurse led service in this area We have 5 non medical prescribers within the Renal Unit and 1 due to commence the course next year.

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.

Mandatory and Specific Training required of all nurses on Victoria Ward and Haemodialysis/Clinics





Average % of Nursing Staff Trained in Core & Specific aspects: 92% - Victoria
Average % of Nursing Staff Trained in Core & Specific aspects: 98% - Haemo/Clinics
These figures reflect:
9 new members of staff between November 2010 and March 2011 on Victoria
2 new members of staff on Haemo since April 2011

CPD

Caring for a Child or Young Person with Renal Disease: Developing Skills and Competence in Professional Practice, Work Based Learning Module affiliated with London South Bank University: 15 Credits

Following on from the success of 2009 intake this module continues to provide the student with essential knowledge that underpins an accurate systematic renal assessment of an infant, child or adolescent using an appropriate tool. To promote understanding of the principles and underpinning theory of the management of renal disease in childhood using a problem solving approach in partnership with the multi-professional team and to facilitate the student's development of clinical skills which enables them to provide optimum level care which is based on the evidence thus promoting best practice. This course is now offered at both Level 6 (Degree) and Level 7 (Masters).
March 2010 intake consisted of 11 Nurses, 6 Degree Level, 5 Masters Level representing renal units from GOSH, Ireland, Leeds and Westminster Community Team. Ten students successfully completed their reflective logs and Oral Viva giving an overall pass rate of 99%.
Following changes in accreditation at LSBU, this years course will commence in October 2011 and is currently undergoing elements of re-design; blended learning, reflective logs and oral viva, to account for the accredited 20 credits.
This course was presented by Trish Evans (Practice Educator & GOSH Course Lead) at the Annual Conference Special Interest Group for Nursing: Paediatric Nephrology, March 2011 Manchester. Interest from Southampton, Ireland and Manchester has been received so far.

Foundations of Paediatric Renal Nursing:
Following 8 new starters on Victoria Ward this course has been re-designed and implemented by the practice educator to act as a full 6 month Preceptorship Programme for newly qualified nurses. The course consists of 6 renal study days with lectures, workshops; problem based learning, worksheets and competencies to complete. Each Staff Nurse will present a case presentation of a patient they have cared for over the last 6 months as form of assessment together with achieving basic competencies to enable them to fulfil their Band 5 KSF. On completion in July 100% of staff in the renal unit have attended this course in varying formats.

In-Charge Study Day (Scenarios and Clinical Competency Booklet)
5 Staff Nurses attend the study day in December 2010, 4 have been signed off as no longer needing supervision to be in charge, 1 continues to work towards achieving her competencies. On completion 100% of staff eligible will have attended and become proficient at being in charge on the Renal Unit.

Simulation Training
September 2010 Band 5 & 6 days were replaced with a days Simulation Training facilitated by the CSPs. The days went very well with more being implemented on an ad-hoc system throughout 2011.

Haemodialysis Rotation
This rotation design has been re-developed to reflect the growing need to train more staff at becoming competent in Haemodialysis in preparation for the move to Eagle Ward in April 2012. The Workbook has been re-designed to reflect Core and Advanced Skills to enable staff to become competent during a 4 month rotation and proficient during their protected rotation weeks in order to keep their skills up to date and to aid further professional development. Due to staff shortage there has been an interruption in the rotation but this is now back on track with the recruitment of Victoria Wards new staff. Future plans are for a senior and junior member of staff to rotate once the new starters have gained their core competencies on the ward.

12.6 PRESENTATIONS

Michelle Cantwell:
Training Patients and Families for Prevention and Home Treatment of Peritonitis. The 31st Annual Dialysis Conference, Phoenix, USA, Feb 2011

Eileen Brennan:
Nephro/urology conference, ICH- GOSH
Workshop on peritoneal dialysis in paediatrics, March 2011
Ambulatory blood pressure monitoring in children, March 2011

Special interest group for Paediatric nephrology nurses Annual conference Manchester
Is Eosinophilic Peritonitis on the increase? Presenting Feedback from the multi centered audit, March 2011

Suzanne Bradley
Building Blocks Programme at GOSH- Presented on Transition within the Renal Transplant Service

Presentation--Bronchiectasis & Renal Transplantation--our experience
Special interest group for Paediatric nephrology nurses, Bristol, March 2010

12.7 ACADEMIC ACHIEVEMENTS

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

Joanna van Ree - completed Bsc (hons)

Lynsey Stronach - currently undertaking the first year of MSc Children's Advanced Nurse Practitioner. Due to complete the nurse prescribing in July

12.8 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)
Nurse representative on the working party updating the 'Consensus Guidelines for the Prevention and Treatment of Catheter-Related Infections and Peritonitis in Pediatric Patients Receiving Peritoneal Dialysis', on behalf of the International Society of Peritoneal Dialysis (ISPD)

Maria Scanes & Carol Jennings :

Working with the HTA on the development of the Independent Assessment process. (Independent Assessment is an integral part of live donation and was established to protect the live donor from any possible duress or coercion.)

Two major changes include:
Assessors now are to be provided with written data citing the readiness of the child recipient, both physiologically and psychologically, for live donation from a specific adult donor and
Child recipients must now be represented during the IA process by a parent, or other delegated adult, who is not the donor.
Adult recipients may voice any concerns they may have to the Assessor. Hitherto a child accompanied by their potential donor, should they wish to do so, may have found this impossible. Assessors now will have background information from both donor and recipient and the opportunity to view the potential transplant from the perspective not only of the adult concerned but that of the child.
A Trial is currently underway using new paperwork in UK Units. Evaluated (by the HTA) is due later this year. The overall aim is to improve the quality and equity of the IA process and for the voice of the young and vulnerable to be heard.

Suzanne Bradley: Working party for the revision of transplant information making information 'young person friendly' and addressing issues pertinent to this age-group. Working with Nigel Mills, Beki Moult, Sue Patey & Steve Marks. A new booklet on transition specifically for parents is now in use and accompanies the booklet on transition for young people.

12.9 RESEARCH

Eileen Brennan
PI GOSH Supporting parents to care for children's kidney conditions.
May 2010-2011

Maria Scanes
Working on the 4c study- cardiovascular comorbidity in children with chronic kidney disease study. Multicentre study for at least 3 years, maybe up to 8 years, across Europe.

12.10 NEW SERVICE

Home Haemodialysis
The Paediatric Home Haemodialysis Pilot Study commenced in September 2010. The nursing team consists of one full time band 7 and 0.64 of a band 6 who provide a high standard of quality nurse led care in the development of this service.
This service offers home haemodialysis to children who are 20kg and above using the NxStage portable haemodialysis machine. There are currently four children receiving a home based haemodialysis therapy on the Nxstage machine with positive feedback from the families. Currently one adolescent has now switched to nocturnal HHD.
The home haemodialysis team have filmed a patient perspective DVD of the first patients' experience of switching from in centre dialysis to a home haemodialysis therapy. An education DVD is planned to be filmed later in the year.

Living donation program
Introduction of international private patient programme for assessment for living donation.

13. DIETETIC REPORT

April 2010 – March 2011

13.1 STAFFING

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

Shelley Cleghorn	Principal Dietitian and Team Leader (from December 2010)
Graeme O'Connor	Specialist Dietitian (to January 2011)
Bahee Manickavasagar	Specialist Dietitian
Louise McAlister	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 2.7wte. 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.

13.2 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. The renal dietitians teach on this MSc course on a variety of subjects.

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 and Bahee Manickavasagar lectured on the undergraduate and postgraduate Dietetics degree courses at Kings College London and London Metropolitan University.

Shelley Cleghorn and Bahee Manickavasagar held two workshops at the International Nephrology Course held at ICH in March 2011.

The team keeps active membership of the Paediatric Renal Nutrition Interest Group. Graeme O'Connor and Bahee Manickavasagar chaired this Group while Shelley Cleghorn was on leave.

13.3 PUBLICATIONS, PRESENTATIONS, AWARDS, APPOINTMENTS

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 (in press).

Graeme O'Connor was awarded a GOSH Charity Research Grant and a British Dietetic Association Education Grant to undertake a PhD project to investigate total energy intake on the physiological recovery rate of critically ill children with anorexia nervosa.

13.4 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:
First weaning foods for babies with kidney disease
Progressing with weaning for babies with kidney disease
Dietary treatment of nephrogenic diabetes insipidus

Journals

Monthly renal journal club sessions.

Products

The team has been involved with Vitaflo in the formulation of a new renal sip feed for children: Renajoule