GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS TRUST

RENAL UNIT TWELFTH ANNUAL REPORT

April 2011 to April 2012

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1. INTRODUCTION

This renal unit annual report is the last from our old facilities in Victoria Ward prior to our move in April 2012 to our brand new Eagle Ward in the Morgan Stanley Building, which is being made possible by support from The GOSH Charity and generous sponsorship by the BKPA and the Tick Tock Club. In this, our twelfth report, 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 2011 and April 2012.

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.

1.1 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 318 beds are arranged in 20 wards and 3 day care units and include 32 intensive care beds in 3 ICU wards (PICU, NICU and CICU). There are ten operating theatres in use performing over 18,500 operations per year. There are over 192,828 patient visits to GOSH each year (inpatients admissions and outpatients).

The Trust employs a total of 3,729 staff. The Interim Chief Executive is Ms Fiona Dalton and the Co-Directors of Clinical Services are Mr. Martin Elliott and Dr. Barbara Buckley. The Nephrology Unit reports to the Division of Medicine and Therapeutic Services, led by Dr. Melanie Hiorns as Clinical Unit Chair and Ms. Anna Jebb 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 Head of Nursing, 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 332 admissions to Victoria, the renal ward, 100 admissions to outlying wards, 7506 outpatients, 31 new renal transplants, 40 patients on chronic haemodialysis and 31 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 (chronic kidney disease (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 four clinical nurse specialist posts (CNS) for CKD 5, peritoneal dialysis and transplant patients: 2 CNS posts responsible for co-coordinating the living and deceased donor program, 2 CNS in charge of the HD unit and 2 to run the home haemodialysis programme. 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 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.

1.3 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 Aoife Waters	6 PAs in Paediatric Nephrology
Dr Sarah Ledermann	Associate Specialist, 6 PAs in Paediatric Nephrology
Dr Paul Winyard	Reader, Full time academic appointment and ICH lead
Dr David Long	Senior Lecturer, academic appointment
Prof Robert Kleta	Potter Chair of Nephrology

There is a team of 5 Transplant Surgeons who share the care of our patients from their base at Guys Hospital: Mr John Taylor, Mr Nizam Mamode, Mr Francis Calder, Mr Martin Drage and Mr Jonathan Olsburgh, led by Mr Calder. Mr Geoff Koffmann also assists with the programme.
There are 4 Urology Consultants: Mr Peter Cuckow, Mr Imran Mushtaq, Mr Abraham Cherian and Ms Naima Smeulders.

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 Owens
Clinical Nurse Specialists	Sr. Suzanne Bradley Sr. Maria Scanes Sr. Liz Wright Sr Liane Pilgrim Sr. Michelle Cantwell Sr. Lynsey Stronach Sr. Katie Knapp Nurse Cecilia Mcneice Nurse Jenny Tanton
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

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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 Senior 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/Reader 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.

Dr. Detlef Böckenhauer and Professor Robert Kleta

Dr Böckenhauer is a clinician scientist, working as a paediatric nephrologist at GOSH and as a HEFCE Senior 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 as well as clinical and basic sciences 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, next generation sequencing 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 recessive mutations 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 two genes associated with membranous nephropathy. Again, this discovery provides a basis for the development of improved diagnostic tests and rational treatment.

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.

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.

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:

1. **Renal transplantation**

   - including collaborative research of urine, blood and MRI biomarker studies, innovative drug trials concerning new anti-rejection therapies and assessment of children post-renal transplantation, including development of allergies.

2. Systemic lupus erythematosus and vasculitis

- research into the aetiopathogenesis, management and outcome of childhood onset lupus nephritis at various levels:
    (i) Locally (currently co-supervising MD student into cardiovascular morbidity in children and young people with SLE)
    (ii) Nationally (cohort study and repository of UK JSLE study group)
    (iii) European (paediatric nephrology expert for the joint European League Against Rheumatism and European Renal Association - European Dialysis and Transplant Association (EULAR / ERA-EDTA) recommendations for the management of adult and paediatric lupus nephritis)
    (iv) Internationally (UK Chief Investigator for the international SMILEY (Simple Measure of the Impact of Lupus Erythematosus in Youngsters) study developing a novel, valid and reliable health-related quality of life tool for children with systemic lupus erythematosus.

3. Renovascular 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.

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 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 studying the part played by FGF23 in the evolution of bone disease. Previous studies in the area of bone metabolism in CKD 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 and the role of angiopoietins in blood vessel damage.

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

Dr Rukshana Shroff

Cardiovascular disease is the most common cause of death in children with chronic kidney disease (CKD) and on dialysis. Through translational research that includes major clinical and laboratory components, I have investigated the impact of modifiable risk factors on the vasculature in children with CKD.
Clinical studies: In a multi-centre study involving >65% of the paediatric dialysis population of the UK, using established surrogate measures of vascular damage, I have shown the effects of mineral dysregulation and vitamin D on the vessels. I have conducted an RCT of vitamin D supplementation in CKD patients. I am working with a dietician, pharmacist and clinical fellows on projects investigating FGF23, role of vitamin A in hypercalcaemia, clinical trial of a newer vitamin D analogue.
I co-chair the cardiac-renal consortium, a group of clinicians and scientists with a research interest in cardiovascular disease. I am on the steering committee of the 4C study that is investigating risk factors for cardiovascular disease progression in >750 children with CKD across Europe.

In the laboratory I have extensively studied changes in the vessels from children with CKD to understand the pathophysiology of ectopic vascular calcification. I have developed and validated a novel in vitro model of intact human arteries to study the effects of mineral imbalance and 'uraemic toxins' on the development and progression of vascular calcification. I now have 2 PhD students who are further exploring the effects of vitamin D on the vasculature and effects of endothelial damage on calcification. I also have an interest in a newer dialysis modality, hemodiafiltration, and am working with colleagues across Europe to run a multicentre study on the benefits of HDF for growth and cardiovascular disease in children.

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

Clinical Governance

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

Risk Management:

The renal Risk Action Group (RAG) team meet independently but are now also part of the new medical specialities RAG team. They review local critical incidents monthly, or immediately if any are deemed 'high risk' and where necessary undertake root cause analyses. Inter-speciality learning is now encouraged through the new RAG group and through the work of our own renal consultant, Dr Hothi, who is the Patient Safety Officer for the division. In addition our risk lead maintains our local risk register and discusses potential operational, financial and clinical mitigations to manage these risks at our monthly board meeting.

One of our greatest risks this year was ensuring safe, harm free relocation of our ward from Victoria ward in the Southwood building to Eagle ward in the new Morgan Stanley Building. This was carefully planned and managed by a designated project team that included a parent representative. The ward moved, with very few hiccups in April 2012 and the team will continue to meet monthly to discuss and manage any ongoing issues and risks.

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:* ***Ongoing***
  This is a rolling, continuous audit aimed to determine the rate and outcomes of delayed and refused admissions to inform capacity requirement in the renal unit. This was in response to a recognised operational and financial risk within our unit. It is envisaged that this audit will roll out across our division.
- *Blood Pressure Monitoring:* ***Ongoing***
  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. It is clear from our initial results that BP monitoring is variable within the trust.
- *Washed RBC:* ***Ongoing***
  The aim of this audit is to ascertain whether washed red blood cells reduce the incidence of HLA sensitisation in patients receiving blood transfusions pre transplant. If so, this would reduce the risk of sensitisation precluding transplantation. The results so far suggest that washed cells do reduce senstitisation but further analysis is necessary. This is being undertaken with NHSBT.
- *Eosinophilic peritonitis:* ***Completed***
  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. Our annual audit has demonstrated improved success in correctly identifying eosinophilic peritonitis that was previously diagnosed as infective peritonitis.
- *Deceased Donor Renal Transplantation:* ***Ongoing***
  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:* ***Ongoing***
  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:* ***Ongoing***
  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:* ***Ongoing***
  The aim of this clinical audit is 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:* ***Ongoing***
  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:* ***Ongoing***
  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:* ***Ongoing***
  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.

Clinical Effectiveness and 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. This year we updated the protocol describing antibiotic prophylaxis pre-operatively for transplant and non-transplant patients.

***Clinical trials include*:**
- Eculizumab in paediatric patients with atypical Haemolytic Uraemic Syndrome
- Transplant ureter stent

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 transitional projects in collaboration with a number of national and international groups which we have described along with our achievements separately. Furthermore Dr William Van't Hoff is the

Co-Director Medicines for Children Research Network and the Head of the Somers Clinical Research Facility at GOSH.

Staffing and 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. This year we have secured 2 external grants for next year from the BKPA, one for a nurse specialist in nephrotic syndrome and the other will fund an additional social worker. We have also secured internal funding for an additional band 7 to support CKD and pre-transplant assessments and a part-time consultant to support our transplant service and help develop renal care with the paediatric and urology departments at Chelsea & Westminster hospital.

Maintaining staffing levels within the unit remains a challenge especially within the dialysis unit. In an attempt to address this we have a 4 monthly Haemodialysis rotation for ward nurses to develop the necessary competencies to safely undertake haemodialysis.

Education and Training:

A) Nursing
Mandatory and Specific Training is required of all nurses on VictoriaWard and HD/Clinics and this responsibility is on the whole managed locally.

In addition we organise several structured courses which are available to renal nurses outside of GOSH and have access to a number of courses at GOSH

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

- 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).
- In 2011 the course underwent 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

As a result of a high volume of new recruitments on the ward we have re-designed and implemented a full 6 month Preceptorship Programme for newly qualified nurses. This is largely undertaken by the practice educator and comprises 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.

In-Charge Study Day (Scenarios and Clinical Competency Booklet)
This course is encouraged to ensure that the majority of renal staff 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. These simulation days have been very successful and have been 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. 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.

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 60-70 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:
Finally the unit has contributed to a number of book chapters and have successfully submitted another of publications to peer reviewed journals (see publications section).

In addition all of our consultants are reviewers for several medical journals. Lesley Rees is the editor for *Pediatric Nephrology*, and Rukshana Shroff and Detlef Bockenhauer are Associate editors.

Patient and Public Involvement:

Concerned about the burden we place on the parents of children with renal disease we are undertaking 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 annually send local data to the UK renal registry, NHSBT, the International Pediatric Peritoneal Dialysis Network with plans to start submitting data to the International Pediatric Hemodialysis Network.

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 and hypertensive patients before rolling it out to the remaining renal patients.

We have developed several local information leaflets for families and children:

- Rituximab
- Childhood Nephrotic Syndrome
- Renal Biopsy
- Medicines Used To Treat Nephrotic Syndrome

As part of our pilot Home HD programme we initially developed a video diary of our first patient as he transitioned to Home HD. This DVD has been very warmly received and is use by the company internationally as an information supplement. We also use it locally as an introduction to Home HD. Owing to the success and positive feedback from this DVD we have also developed a library of educational DVDs: DVD 1 is an introduction to renal failure and all forms of dialysis, DVD2&3 describes the set-up and emergency alarms for 2 HHD circuits and finally DVD 4 talks about dialysis access

Finally we are now recruiting a parent for many of our important projects on the renal unit. A parent representative formed part of the project team

overlooking the relocation of the ward from Victoria Ward to Eagle Ward. We also now have a parent representative on consultant interviews.

Quality and Improvement:

Ensuring high quality care that is cost effective and harm-free was the thinking behind one of the trust key strategies: no waste, no wait, zero harm. In an attempt to achieve a strong transformation and improvement focus started to evolve and develop within the trust.

Dr Daljit Hothi, is a renal consultant who is also the Patient Safety and Clinical Improvement Officer for the MDTS division. She is involved in several trust transformation projects and is the lead for '*SBARD: internal referral'* and *'Respecting the Medical Notes'* projects. Locally the renal unit are also actively leading on a number of improvement projects:

- Developing patient held medication records upon discharge from the unit
- Developing a Paediatric Safety Thermometer
- Patients and families self-reporting critical incidents and near misses
- Quality of Medical Notes
- Managing Medical Errors
- Safe prescribing on Eagle Ward
- Managing external referrals
- Improving the speed at which discharge summaries are completed without compromising their quality

Service Development:

- *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 and now continues to successfully recruit more patients
- *Increased renal donor pool*
  Availability of organs for transplantation is lower than the demand for organs. Internationally the renal community have been finding ways to increase the donor pool. The renal transplant team have adopted some of these strategies. We transplanted our first en-bloc kidneys this year with an excellent outcome. More families have been recruited into the paired exchange pool and many are opting for non-heart beating and heart-beating donors on the deceased donor list.
- *In-centre haemodiafiltration*
  In consideration of data reporting on improved clinical outcomes in patients receiving haemodiafiltration (HDF) compared with haemodialysis 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.

- *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. The home HD team led by Dr Daljit Hothi are working to establish the first mobile home haemodialysis programme in Europe. In 20 months they have recruited 8 patients, 6 from GOSH, one from Evelina Hospital, London and one from Southampton. The outcomes thus far have been very positive such that 2 patients presented their experiences at World Kidney Day at the Houses of Parliament in 2011. We are hoping to continue to expand the service and open the service to patients nationally.

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
WEDNESDAY P.M.	ABPM Hypertension outpatients	Ms Eileen Brennan

THURSDAY A.M.	Transplant clinic	Dr Marks Dr Waters 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 6414. 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**	**2011-12**	
Transplant	625	771	873	736	799	743	858	897	1034	1119	1080	
Nurse Led Transplant	443	506	734	542	518	467	524	1387	1328	1231	1212	
Low Clearance/ Dialysis	507	543	859	610	636	638	665	694	749	650	730	
PreTx & GKRLTX						93	71	84	119	84	123	
General and Specialist Nephrology	3243	2467	4065	3199	3444	3194	3382	3464	3113	2929	3509	
Nephrotic Syndrome	405	481	692	468	400	321	344	389	446	479	454	
Stone	69	50	88	53	40	40	23	36	79	153	190	
Blood Pressure Monitoring			23	51	65	78	94	109	193	195	208	
Total	**5292**	**4818**	**7334**	**5674**	**5902**	**5738**	**5962**	**7060**	**7061**	**7166**	**7506**	

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	Intra-operative	Total
2000-1	71	19	1	11	0	102
2001-2	77	36	0	11	0	124
2002-3	79	43	3	15	0	140
2003-4	67	67	4	6	0	144
2004-5	74	54	7	15	0	150
2005-6	74	55	1	15	0	145
2006-7	70	43	0	8	0	121
2007-8	55	83	0	13	0	151
2008-9	75	51	1	17	0	144
2009-10	68	54	1	22	0	145
2010-11	61	68	0	13	0	142
2011-12	49	59	1	17	1	127

Four transplant patients (7%) developed perigraft haematomas after biopsy. Two of these were re-explored (on day 1 and day 3 following biopsy). In one of these patients the relationship between the biopsy and the need for surgery was unclear, because there was a pre-existing collection. One of these patients also developed a small AV fistula following biopsy, but this did not

require treatment.
One patient who underwent biopsy of a native kidney (2%) developed a perinephric haematoma.
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
2011-12	8	29	37

These numbers exclude access for other indications (e.g. stem cell harvest). One (3%) of the children who had permanent (tunnelled) HD catheter insertion had early (<30 days) infection (requiring line removal).

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
2011-12	8	13	21

RVH = renovascular hypertension

One patient (5%) 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
2011-12	2	0	2	1	12	17

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**		**2011-2012**	
	Total No	**%**	**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	**72**	22
2- <5	**81**	13	**87**	16	**66**	11	**106**	17	**84**	16	**105**	19	**90**	16	**81**	14	**99**	18	**102**	20	**54**	16
5- <10	**143**	23	**119**	21	**116**	20	**146**	23	**110**	21	**120**	22	**101**	18	**134**	23	**109**	19	**93**	18	**66**	20
10- <15	**214**	35	**176**	31	**191**	33	**167**	27	**153**	30	**169**	30	**161**	29	**153**	27	**137**	24	**131**	25.5	**77**	23
15 +	**153**	25	**137**	24	**153**	26	**124**	20	**97**	19	**88**	16	**148**	26	**124**	21	**129**	23	**131**	25.5	**63**	19
Total	**618**	100	**563**	100	**585**	100	**622**	100	**517**	100	**554**	100	**561**	100	**577**	100	**561**	100	**513**	100	**332**	100

5.2 NEPHROLOGY ADMISSIONS (EXCLUDING HAEMODIALYSIS) TO EAGLE 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**	**2011-12**
Victoria	618	563	585	622	517	554	561	577	561	513	332
Other	343	307	316	317	317	349	249	261	118	93	100
Total	961	870	901	939	834	903	810	838	679	606	432

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)

6.1 NUMBER AND AGE RANGE OF PATIENTS ON RENAL REPLACEMENT THERPAY

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						
2011	0	0	1	2	1	4
2012	0	0	2	3	2	7
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
2012	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
2012	6	7	5	6	7	31
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
2012	0	19	34	52	53	158

6.2 CHRONIC PERITONEAL DIALYSIS

There were a total of 31 patients in 2011-2012. Their age ranges are shown.

Annual figures-age breakdown:

	2002-3		**2003-4**		**2004-5**		**2005-6**		**2006-7**		**2007-8**		**2008-9**		**2009-10**		**2010- 11**		**2011-12**	
Age, yrs	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	%	**total**	%	**total**	%	**total**	%
<2	**3**	7.5	**3**	6.5	3	8	**2**	5	**4 (3)**	10	**6**	18	**6**	18	**12**	30	**4**	14	**6**	19
2-5	**6**	15	**5**	10.8	6	16	**2**	5	**5**	12	**4**	12	**6**	18	**7**	18	**7**	24	**7**	23
5-10	**5**	12.5	**5**	10.8	7	19	**10**	25	**9(7)**	22	**4**	12	**4**	12	**8**	20	**4**	14	**5**	16
10-15	**14**	35	**16**	35	11	30	**10**	25	**12**	29	**13**	38	**11**	32	**10**	25	**7**	24	6	9
>15	**12**	30	**17**	37	10	27	**16**	40	**11(10)**	27	**7**	20	**7**	20	**3**	7	**7**	24	**7**	23
Total	**40**	100	**46**	100	37	100	**40**	100	**41(37)**	100	**34**	100	**34**	100	**40**	100	**29**	100	**31**	100

Annual figures from 1999 onwards:

PATIENTS	**99-00**	**00-01**	**01-02**	**02-03**	**03-04**	**04-05**	**05-06**	**06-07**	**07-08**	**08-09**	**09-10**	**10-11**	**11-12**

total *new*	44	40 14	37 17	45 20	45 18	40 14	41 17	37 18	34 15	34 15	40 20	29 11	31 16
At year end	28	17	24	29	23	23	18	20	17	19	17	16	10
Transferred to HD	3	5	7	2	5	5	6	2	5	4	8	6	7
Transplanted	10	16	7	7	15	11	12	14	8	6	13	6	13
Adult unit		4	2	3	1	2	3	0	0	2	0	0	0
Improved		0	0	0	0	0	1	1	2	0	0	0	0
Deaths	1	1	0	1	1	0	0	1	1	3	2	0	1

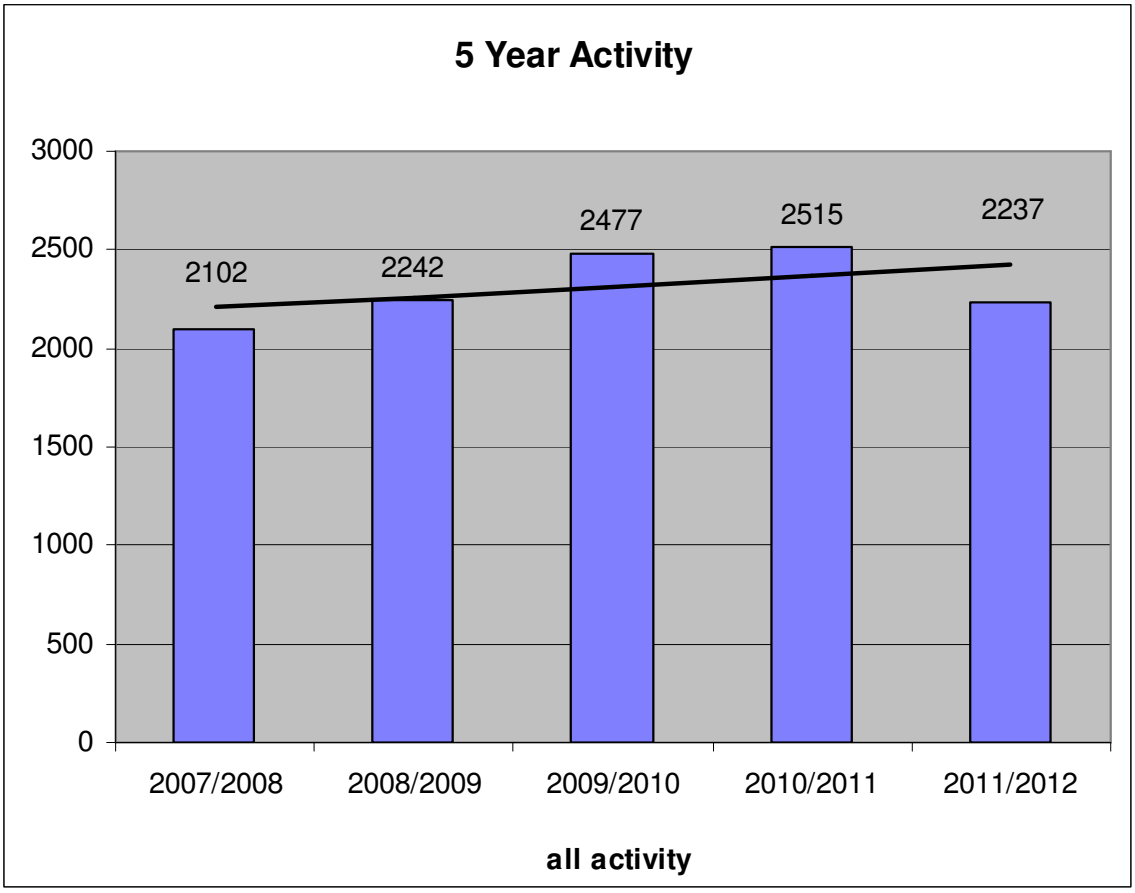
6.3CHRONIC HAEMODIALYSIS

During the year there were 2237 sessions in 47 children, 2212 sessions of HD (acute and chronic) and 25 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
01.04.11	17	
01.04.12	6	192

5 year activity



7. ACUTE RENAL FAILURE AND TREATMENT (INCLUDING PLASMAPHERESIS)

7.1 ACUTE HAEMODIALYSIS

4 children required acute haemodialysis. Their mean age was 8.57 years, range 1.01 to 16.62 years. These figures exclude children with acute kidney injury (AKI) in PICU and NICU.

Diagnosis	2005-6	2006-7	2007-8	2008-9	2009-10	2010-11	2011-12
HUS(D+)		2	1	1		2	
HUS (D-)		1		1			
MCGN/RPGN	1				1		
SLE	1		1		1		
Post heart Tx							
FSGS		1			1		1
RSV							1
Rhabdomyolosis						1	1
Acute on CRF			1	1			
Sepsis		1				1	
Post surgery		1					

Transplant rejection		1				1	1
Tumour lysis		1	1				
MMA							
Drug toxicity	1						
ATN	2	1	3	3	1		
Total Pts	**5**	**9**	**7**	**6**	**4**	**5**	**4**
Total number of sessions			**34**	**82**	**164**	**22**	**14**

7.2 PLASMA EXCHANGE

4 children were treated with plasma exchange (3 male; 1 female). The mean age was 11.7 years and range 5.9- 16.2 years.

Diagnosis	**2007/8**		**2008/9**		**2009/10**		**2010/11**		**2011/12**	
	No. Pts	**No. Sess**	**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									1	3
MPA										
Post tx FSGS			2	49			1	25	2	22
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								
Test									1	1
Total	**7**	**64**	**5**	**95**	**3**	**13**	**6**	**40**	**4**	**26**

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	2011-12
<1 year	1	3	1		1	3	2	0	0		2
1- <5 years	1	0	3		2	4	2	4	8		0
≥ 5 years	3	2	1		0	6	2	2	7		0
Total	**5**	**5**	**5**		**3**	**13**	**6**	**6**	**15**	**8**	**2**

8. RENAL TRANSPLANTATION

Details of patients undergoing renal transplantation 1998 – 2012

	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
01/04/2011 to 2012	21	1	8	1	31	19

Note – the on-call data is from 31/3/12 and does not include suspended patients.

9. RESEARCH

9.1 PAPERS :1 April 2011 – 31 March 2012 publications

1. Al-Khudairi, N., Riley, P., Desai, D. Y., Reid, C., & Mamode, N. Interventions for pre-existing bladder dysfunction in paediatric renal transplant recipients; when is best? Transplant International 24, 191. 2011.
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9.2 GRANTS
Awarded 2011-12
Active 2011-2012

R&D no.	Title	PI	Funder	Date awarded	Awarded
10NU30	MCRN107 (C10-003) - An open-label, multi-centre, clinical trial of Eculizumab in paediatric patients with atypical Haemolytic-Uraemic Syndrome (aHUS)	Dr Lesley Rees	Alexion Pharmaceuticals	02/06/2011	£46,276.06
10NU23	Planar cell polarity in glomerular development and disease	Dr David Long	Wellcome Trust	03/06/2011	£415,490.00
10NU25	MCRN108 (FER-CKD-251) - A randomized, open-label, active-controlled study of the safety, efficacy and pharmacokinetics of ferumoxytol compared with oral iron for the treatment of iron deficiency anaemia in paediatric subjects with dialysis-dependent chronic kidney disease	Dr Lesley Rees	AMAG Pharmaceuticals	08/08/2011	£12,500.00
10NU26	MCRN109 (FER-CKD-252) - A randomized, open-label, active-controlled study of the safety, efficacy and pharmacokinetics of ferumoxytol compared with oral iron for the treatment of iron deficiency anaemia in paediatric subjects with nondialysis-dependent chronic kidney disease	Dr Lesley Rees	AMAG Pharmaceuticals	30/08/2011	£15,000.00
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	01/09/2011	£15,000.00
10NU31	Restoring the angiopoietin balance as therapy for glomerular disease	Dr David Long	Kidney Research UK	22/09/2011	£112,272.00
10NU32	Genetics of renal disease	Dr Detlef Bockenhauer	Kids Kidney Research	15/12/2011	£99,451.00
11NU09	CCRN 675 (ADPKD): A Multi-center, Longitudinal, Observational Study of Patients with Autosomal Dominant Polycystic Kidney Disease (ADPKD) to Establish the Rate, Characteristics, and Determinants of Disease Progression (OVERTURE study)	Dr Detlef Bockenhauer	Otsuka Pharmaceuticals	19/01/2012	£41,068.00
				Total	**£757,057.06**

R&D no.	Title	PI	Funder	Sponsor	Start	End
04NU36	Identification of genes involved in renal and electrolyte disorders	Dr Detlef Bockenhauer	GOSH	Foundation for the Study of Infant Deaths (FSID)	01/12/2004	31/12/2015
04NU22	Retrospective review of post-mortem investigation of the cause of death in sudden unexpected death in infancy (excluding tissue review)	Dr Neil Sebire	GOSH	Kids Kidney Research	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	GOSH	British Heart Foundation (BHF) / GOSH Biomedical Research Centre (GOSH BRC) / Kidney Research UK / Kids Kidney Research	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 Rokshana Shroff	GOSH		01/01/2006	31/12/2012
06NU15	Understanding the molecular pathways involved in human kidney development	Dr Paul Winyard	GOSH	Kids Kidney Research	30/11/2006	31/12/2012
04NU03	Antenatal renal malformations - improved prognostic indicators	Dr Paul Winyard	Merck Sharp & Dohme	Merck Sharp & Dohme (MSD)	01/12/2006	31/05/2011
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	ICH		01/10/2007	31/03/2012
07NU23	Identifying molecules which orchestrate bladder development	Professor Adrian Woolf	GOSH		01/01/2008	

08NU02	Complement C1q auto-antibodies in glomerulonephritis	Dr Stephen Marks	ICH	European Molecular Biology Organisation	26/03/2008	05/11/2011
07NU20	Modelling fetal kidney programming ex vivo	Dr M Schreuder	ICH	Kidney Research UK	06/05/2008	
07NU25	Roles of angiopoietins in epithelial-endothelial interactions: using the renal glomerulus as a model system	Dr David Long	ICH	Kids Kidney Research	22/05/2008	06/04/2013
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	King's College London		20/10/2008	18/07/2015
08NU19	Role of angiopoietin growth factors in diabetic nephropathy	Dr David Long	GOSH	Foundation for the Study of Infant Deaths (FSID)	01/01/2009	31/12/2011
08NU10	Galectin-3, a novel therapy for autosomal recessive polycystic kidney disease	Dr Paul Winyard	ICH	Kidney Research UK	04/01/2009	30/06/2011
07NU27	Roles of Fras1, a basement membrane-associated protein, in normal differential of kidney collecting ducts and glomeruli	Professor Adrian Woolf	ICH	Wellcome Trust	01/03/2009	29/02/2012
08NU26	PhD Studentship: targeting blood vessels to prevent autosomal recessive polycystic kidney disease	Dr David Long	ICH	Kids Kidney Research	22/06/2009	30/09/2012
08NU18	Identification of genes involved in renal and electrolyte disorders	Dr Detlef Bockenhauer	ICH	GOSH Biomedical Research Centre (GOSH BRC) / Kids Kidney Research	09/09/2009	01/09/2014
07NU15	Identification of an X-linked gene conferring susceptibility to membranous nephropathy	Dr Detlef Bockenhauer	GOSH	Kids Kidney Research	01/11/2009	31/10/2011

10NU01	Audit of anaemia in paediatric transplant and dialysis patients	Dr Shazia Adalat			30/11/2009	30/06/2011
09NU15	Cardiovascular comorbidity in children with chronic kidney disease (4C) study	Dr Rokshana Shroff	University Childrens Hospital, University of Heidelberg, Germany		10/02/2010	30/11/2012
09NU04	Cross-cultural adaptation and validation of SMILEY	Dr Stephen Marks	University of Medicine and Dentistry of New Jersey		12/02/2010	04/01/2013
08NU16	European Network for the Study of Orphan Nephropathies (EUNEFRON)	Dr William van't Hoff	GOSH	European Union (EU)	16/02/2010	31/05/2012
09NU25	National Study of Steroid Resistant Nephrotic Syndrome in Childhood	Dr Stephen Marks	GOSH		02/03/2010	30/09/2014
09NU01	An investigation into the optimal reduction in dialysate temperature on systemic haemodynamics and myocardial stunning in paediatric haemodialysis	Dr Lesley Rees	ICH	British Association for Paediatric Nephrology	27/04/2010	30/09/2014
10NU08	TWIST Follow up study	Dr Stephen Marks	Central Manchester University Hospitals NHS Foundation Trust		28/04/2010	30/04/2015
10NU05	Investigating the role of Wnt signalling in podocyte differentiation	Dr David Long	ICH	St Peter's Trust for Kidney, Bladder and Prostate Research / Wellcome Trust	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	31/03/2013

10NU15	Complement susceptibility factors in aytpical Haemolytic Uraemic Syndrome (aHUS)	Dr U Kjell Tullus	Newcastle upon Tyne Hospitals NHS Foundation Trust		09/08/2010	31/12/2011
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	The University of Manchester		04/10/2010	24/07/2012
10NU18	Development of a measure of caregiver stress in carers of children and adolescents with chronic kidney disease	Dr Daljit Hothi	Canterbury Christ Church 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 Rokshana Shroff	Abbott Laboratories	Abbott Laboratories	10/12/2010	30/03/2012
10NU30	MCRN107 (C10-003) - An open-label, multi-centre, clinical trial of Eculizumab in paediatric patients with atypical Haemolytic-Uraemic Syndrome (aHUS)	Dr Lesley Rees	Alexion Pharmaceuticals	Alexion Pharmaceuticals	03/05/2011	31/07/2014
10NU25	MCRN108 (FER-CKD-251) - A randomized, open-label, active-controlled study of the safety, efficacy and pharmacokinetics of ferumoxytol compared with oral iron for the treatment of iron deficiency anaemia in paediatric subjects with dialysis-dependent chronic kidney disease	Dr Lesley Rees	AMAG Pharmaceuticals	AMAG Pharmaceuticals	16/08/2011	15/07/2013

10NU27	PREDnisolone in NephrOtic Syndrome: The PREDNOS study - Long-term tapering verses standard prednisolone (steroid) therapy for the treatment of the initial episode of childhood nephrotic syndrome: national multicentre randomised double blind trial	Dr Daljit Hothi	University of Birmingham		17/08/2011	01/05/2015
10NU28	Transplant ureteric stent trial. Version 1.0 - Transplant ureteric stent removal: Early versus standard removal. A Randomised Controlled Trial	Dr Stephen Marks	Guy's and St Thomas' NHS Foundation Trust		30/08/2011	01/01/2013
11NU05	Assessing validity and reliability of a caregiver stress measure in carers of children and adolescents with chronic kidney disease	Dr Daljit Hothi	Canterbury Christ Church University		07/09/2011	31/12/2012
10NU26	MCRN109 (FER-CKD-252) - A randomized, open-label, active-controlled study of the safety, efficacy and pharmacokinetics of ferumoxytol compared with oral iron for the treatment of iron deficiency anaemia in paediatric subjects with nondialysis-dependent chronic kidney disease	Dr Lesley Rees	AMAG Pharmaceuticals	AMAG Pharmaceuticals	19/09/2011	31/08/2014
10NU31	Restoring the angiopoietin balance as therapy for glomerular disease	Dr David Long	ICH	Kidney Research UK	26/09/2011	
10NU23	Planar cell polarity in glomerular development and disease	Dr David Long	ICH	Kids Kidney Research / Wellcome Trust	28/09/2011	

11NU07	Drug related problems in paediatric patients with chronic kidney disease	Dr Lesley Rees	School of Pharmacy		11/01/2012	10/01/2013
10NU32	Genetics of renal disease	Dr Detlef Bockenhauer	GOSH	Kids Kidney Research	26/01/2012	
11NU09	CCRN 675 (ADPKD): A Multi-center, Longitudinal, Observational Study of Patients with Autosomal Dominant Polycystic Kidney Disease (ADPKD) to Establish the Rate, Characteristics, and Determinants of Disease Progression (OVERTURE study)	Dr Detlef Bockenhauer	Otsuka Pharmaceuticals	Otsuka Pharmaceuticals	10/02/2012	10/01/2015
09NU10	The role of podocyte thymosin beta4 in kidney development and disease	Dr David Long	ICH		20/02/2012	20/02/2016
07NU19	Improving clinical and translational research at GOSH	Dr Detlef Bockenhauer	GOSH			
09NU12	A comparison of psychosocial aspects of living and deceased donor kidney donation in children and adolescents aged 6-18	Dr Lesley Rees	GOSH			

10 NEPHRO-UROLOGY ACADEMIC PROGRAMME

Nephro-Urology Academic Programme
Seminar Room, Renal Unit, Level 8, Southwood Building,

Great Ormond Street Hospital for Children

Summer term
(Tuesday afternoon 2.30pm – 4.30 pm)

Date	**Topic** *2.30 - 3.30 pm*	**Speaker**	**Topic** *3.30 – 4.30pm*	**Speaker**
3/5/11	Eculizumab site visit			
10/5/11	**Research meeting**	**Dr Paul Winyard**	Effect of temperature on the heart during dialysis	Dr Daljit Hothi
17/5/11	**Hyperoxaluria**	**Dr van't Hoff**	Audit of peritoneal dialysis	Nurse specialists Michelle Cantwell Cecelia MacNeice
26/5/11	Joint meeting with the Evelina Children's hospital at GOSH, Note Thursday, Roland Levinsky Room, ground floor, Philip Ullmann Wing, ICH.			
31/5/11	Half term, no meeting			
7/6/11	Renal biopsy meeting	Prof Neil Sebire	Audit of haemodialysis and plasmapheresis	Sisters Liz Wright and Lianne Pilgrim
14/6/11	Do washed cells prevent HLA sensitisation?	Anthony Aston	Vasculitis or fibromuscular hyperplasia?	Dr Kjell Tullus
21/6/11	Research meeting	Dr Paul Winyard	Audit of renal transplants	Clinical nurse specialists Suzanne Bradley and Jenni Tanton
30/6/11	Bipartite meeting at ICH **Note Thursday**			
5/7/11	Renal biopsy meeting	Prof Neil Sebire	Biologics in transplantation	Dr Steve marks
12/7/11	Research meeting	Dr Paul Winyard	Audit of living donation	Clinical nurse specialists Maria Scanes and Carol Jennings

Date	Topic	Speaker	Topic	Speaker
6/9/11	Practice session for ESPN Talks to be decided			
13/9/11	ESPN meeting, Croatia			
20/9/11	2.30 – 3.30 Renal biopsy meeting	**Prof Neil Sebire**	"Medicines Got Problem?"	**Norkasihan I**
27/9/11	2.30 – 3.30 **Trial of ureteric stent removal**	**Dr Steve Marks**	3.30 – 4.30 pm Renal Biomarkers in Lupus Nephritis	**Dr Louise W**
4/10/11	***2.30 – 3.30pm*** Audit of renal transplantation	CNS Suzanne Bradley	3.30 – 4.30 pm Audit of living and deceased donor programme	**CNS Maria S**
11/10/11	***2.30 – 3.30pm*** **Renal biopsy meeting**	**Prof Neil Sebire**	Audit of prescribing errors in the renal unit	Dr Hajera S Dr Manjari T Sue Pat
20/10/11	**Bipartite meeting at the Royal Free (note Thursday)**			
25/10/11	Half term, no meeting			
1/11/11	Difficult cases	**To be confirmed**	*3.30 – 4.30 pm* Audit of deaths	Nurse Cons Eileen Bre
8/11/11	***2.30 – 3.30pm*** **Renal biopsy meeting**	Prof Neil Sebire	Enteral feeding of the over 2s	Dr Helen J
17/11/11	Joint meeting with Evelina, at the Evelina Note thursday			
25/11/11	Nephrology Day for general paediatricians at the ICH (note Friday)			
29/11/11	***2.30 – 3.30pm*** A-V fistulae	Dr Alison Ma	Quality Improvement: how to get started on a project	**Dr Jane Rur**
8/12/11	Bipartite meeting at ICH (note thurs) Seminar Room 4, ground floor, Philip Ullmann Wing, ICH			
9/12/11	**BAPN meeting in Birmingham (all day)** Note Friday			
13/12/11	*2.30 – 3.30pm* Renal Biopsy Meeting	Dr Neil Sebire	*3.30-4.40pm* **The home haemodialysis programme**	Dr Daljit H

(Tuesday afternoon 2.30pm – 4.30 pm)

Date	Topic 2.30 - 3.30 pm	Speaker	Topic 3.30 – 4.30pm	Speaker
10/1/12	Renal biopsy meeting	Dr Neil Sebire	Clinical and genetic spectrum of polycystic kidney disease and other ciliopathies	Dr Carsten Ber
17/1/12	Audit of measurement of renal lengths: are our current methods adequate?	Susan Watts	Case presentation	Dr Faidra Vel
24/1/12	Vitamin D in CKD	Dr Rukshana Shroff	B cells and transplantation	Dr Jon Jim I
31/1/12	Renal biopsy meeting	Dr Neil Sebire	Case Presentation	**Dr Katherine S**
9/2/12	Joint meeting with the Evelina, Seminar Room 4, ground floor, Philip Ullmann Wing, ICH. **Note Thursday**			
14/2/12	Half term week, no meeting			
21/2/12	Renal biopsy meeting	**Dr Neil Sebire**	The Home Haemodialysis programme	Dr Daljit Ho
28/2/12	Level 3 safeguarding children module Jan Baker			
6/3/12	**Food allergy post-transplantation**	**Dr Steve marks**	Transplantation in the under 6s	Mr Geoff Koff
15/3/12	Bipartite at Royal free hospital **Note thursday**			
20/3/12	Course week at the ICH			
27/3/12	**Renal biopsy meeting**	**Dr Neil Sebire**	Feeding the over 2s	Dr Helen Jor
3/4/12	Easter holidays			
10/4/11	Easter holidays			

11. AUDIT

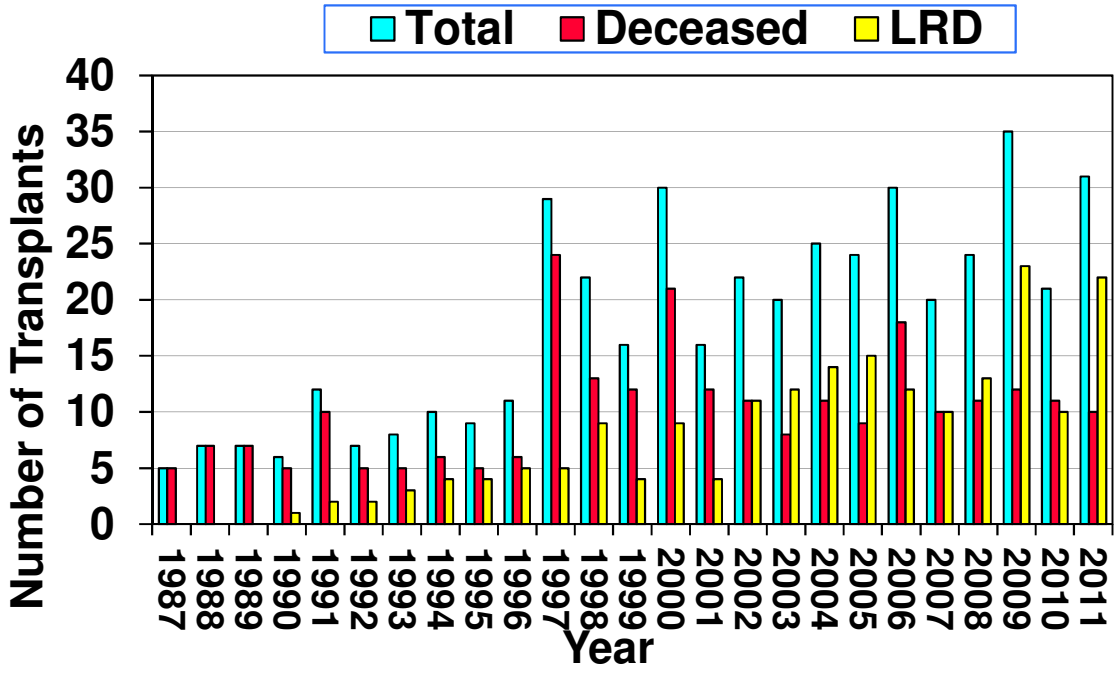
11.1 Pre Transplant Audit, Living and Deceased Donor, April 2010-March 2011

Maria Scanes and Katie Knapp Clinical Nurse Specialist

Transplant Numbers

- 31 transplants in 31 children
  Plus 1 Liver & kidney Tx in BCH22
- Lliving donor (69%)
  1 of which was an altruistic donor
- 10 deceased donor (31%)
  1 of which was en bloc

Transplant Numbers Since 1987



Recipient Demographics

- Male 18 (56%)
  Female 14 (44%)

- NHS 31
  1 IPP from Kuwait
  1 out of Centre – Belfast
- Mean age at TPX
  - 7.9 years (LRD Transplant)
  - 9.9 years (DD Transplant)
  - Range 1.3 – 16.8 yrs

- Median age at TPX
  - 9.08 years (LRD Transplant)
  - 9.6 years (DD Transplant)
  - Range 2.6 – 16.6 yrs

Modality at Time of Transplant

- HD 11 34%
- PD 12 37%

- Pre emptive 9 28%
- Of LDs 8 (36%) were pre-emptive

(will look at ↑ pre-emptive no's later)

Recipient Info

- There were 2 second grafts in 2 children
- 2 out of centre – From Belfast & Kuwait
- 1 combined liver & kidney performed in BCH
- 1 – ABOi
- 1- recipient retroviral disease
- 1- en bloc
- 1 - altruistic

Recipient Blood Groups

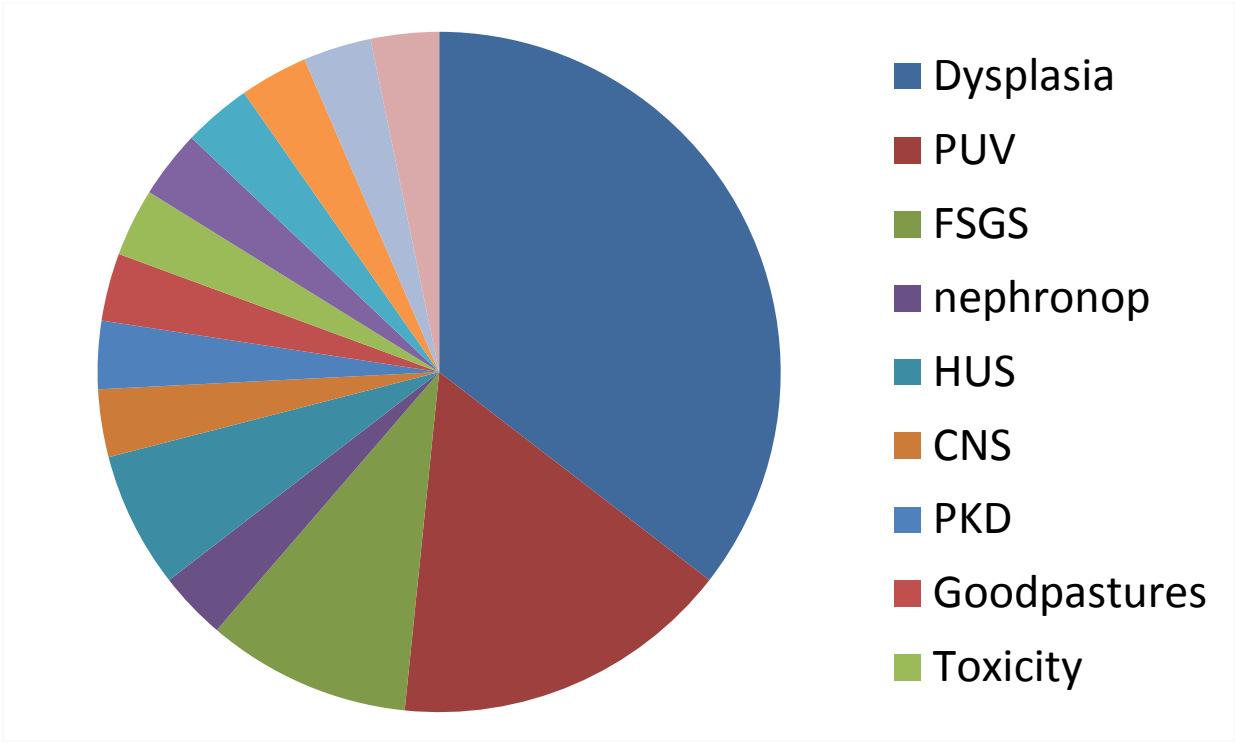
- O 19 (60%)
- A 8 (25%)
- B 3 (9%)
- AB 2 (6%)

Mismatches

- All the living donor mismatches were 3AM and above
- 1– 6 AM
- 3 – 5AM

- 7 – 4AM
- 11 – 3AM

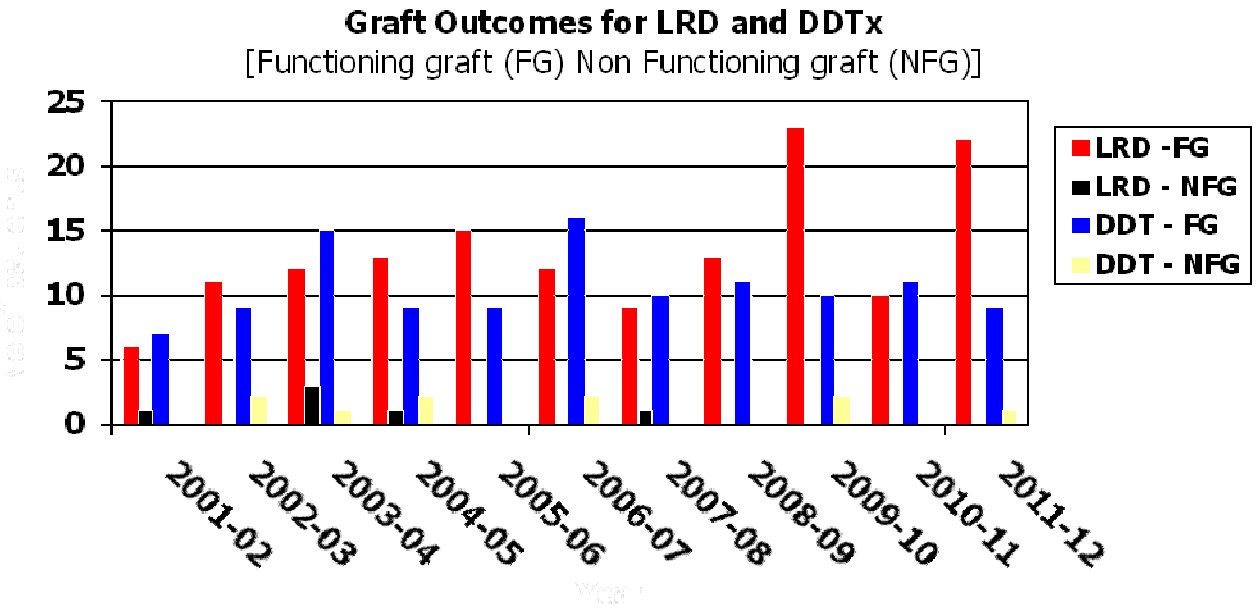
Recipient Diagnoses



Outcomes

- Of 32 transplants carried out during audit year 31 transplants functioning at year end.
- 97 % functioning LRD and Deceased Donor Transplants at the end of the audit year

End of Year Outcomes



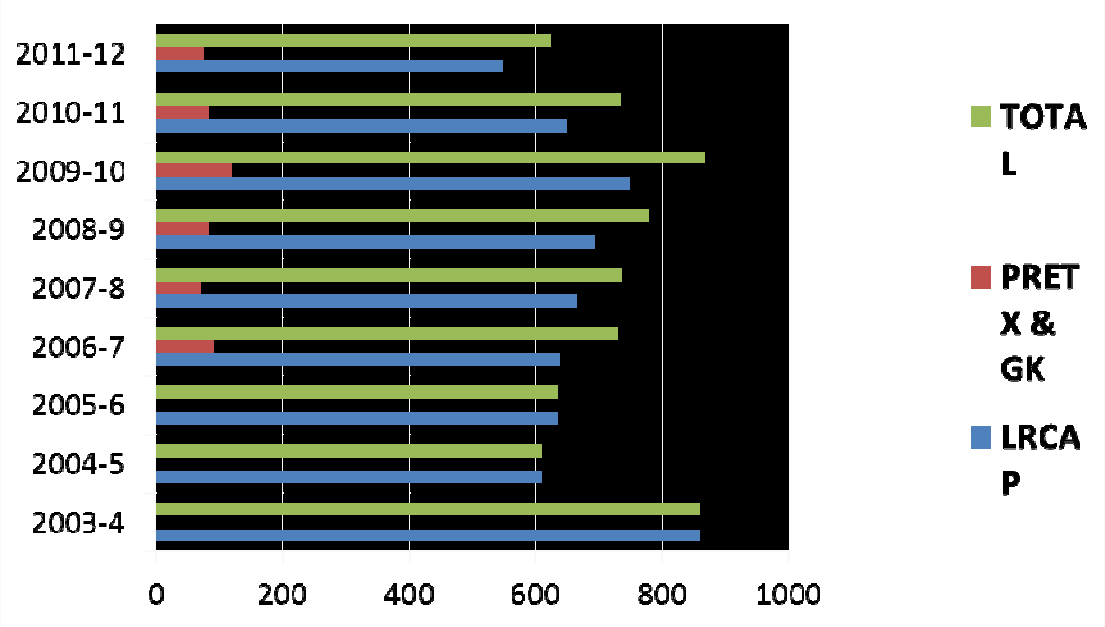
Cold Ischaemic Times

- LD - (data on 14 pts- 63%)
  - average 4hrs 20 minshrs (2 hrs- 5hr 50 mins hrs)
- DD - (data on 8 pts – 80 %)
  - average 12.5 hrs (9hrs – 14 hrs).

? Potential for increasing Pre-emptive numbers

- 9 (28%) pre-emptive
- 8 of these were Living Donor
- of other LRDs who were on Dx
- 4- babies
- 3 – anephric (CNS & FSGS)
- 1 – IPP
- 5 – crashlanders!
- 1 - altruistic

Clinic Activity



ABOi PX:

- Anti A &/B antibodies (sent to St Thomas')
- If titres < 1:512 can proceed
- Ritux given 1/12 prior to Tx
- 1/52 prior – daily titres
  DFPP
  Start immunosuppression
  Day of surgery titres sent v early prior to Tx

HIV Px:

PRE – Tac started 6/52 before
MMF started 1/52 before
Isoniazid started 1/52 before

POST – Basiliximab day 0 & 4
azithromycin & cotrimoxazole life long
Isoniazid for 6/12

Living Donor Information

- 14 fathers (63%)
- 4 mothers (18%)
- 2 Grandmothers (9%)
- 1 Uncle (5%)
- 1 Altruistic donor (5%)

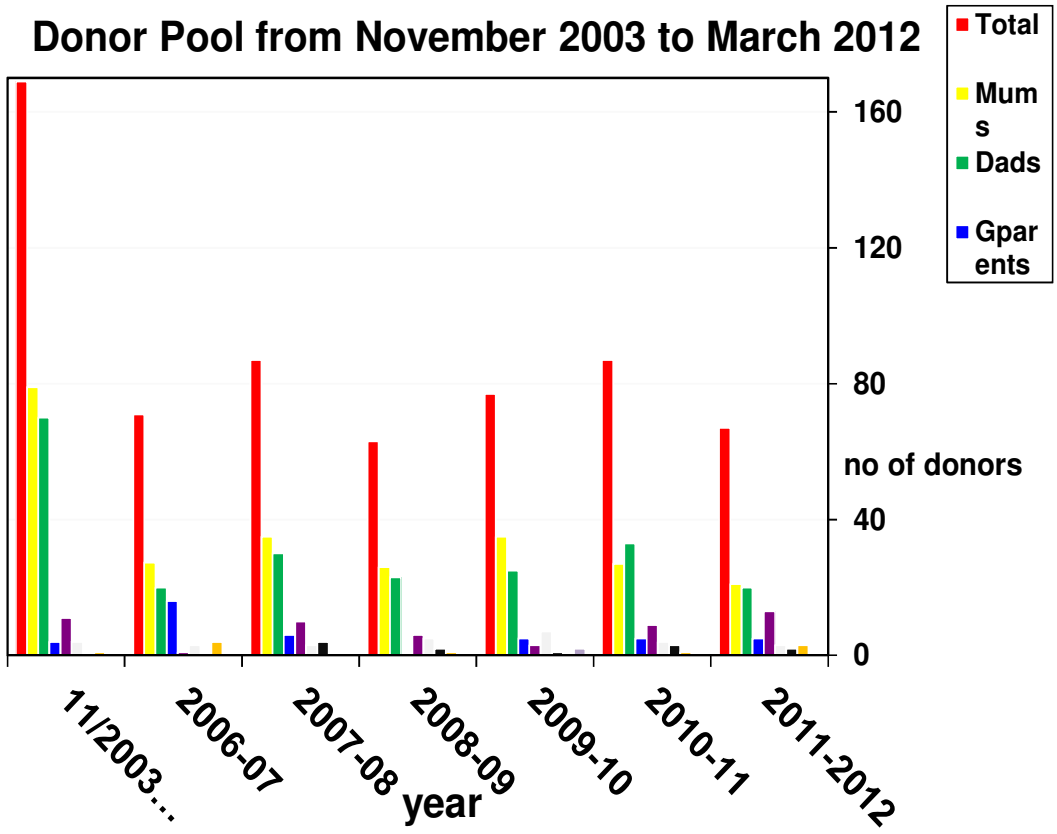
Mean age 40 yrs (23y – 60y)

- 1 at RFH
- 20 at Guys
- 1 altruistic donor
- All laparoscopic donations

Donor Pool (LRD)

67 potential donors came forward for 31 recipients.

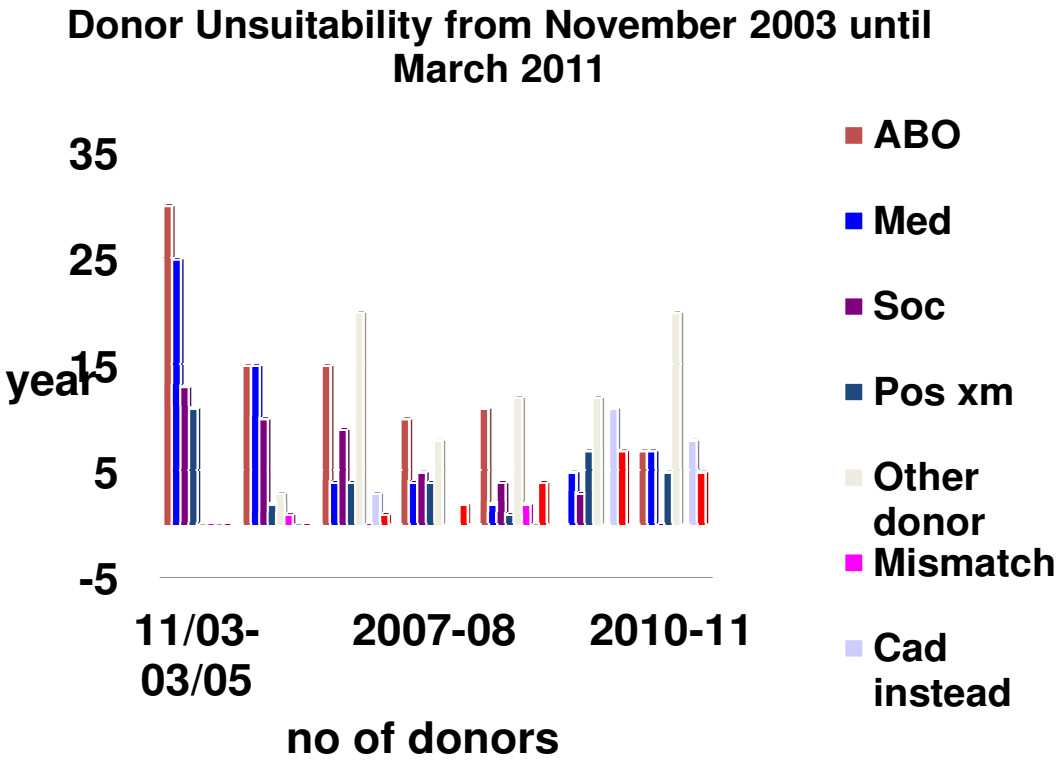
• Mothers	21	31%
• Fathers	20	30%
• Siblings	3	5%
• Aunts	4	6%
• Uncles	9	13%
• Cousins	2	3%
• Grandparents	5	7%
• Friends	3	5%



Donor Suitability:

From 67 potential donors within audit year

• DD Tx	5
• Ongoing Ref	19
• Other donor	16
• Med Unsuit	5
• Recipient unwell	1
• Pos Xmatch	10
• Enquiry only	1
• Social	3
• ABOi	4
• LRD	1
• Transition to adults	1


Donor Unsuitability from November 2003 until March 2011
35
25
15
5
-5
year
11/03-03/05
2007-08
2010-11
no of donors
ABO
Med
Soc
Pos xm
Other donor
Mismatch
Cad instead

Donor Attrition rates

- 41 donors from pot pool did not / will not proceed to Tx workup
- 61%
- This includes 16 where more than 1 donor came forward and another donor was used instead

LD Work in Progress (11/12)

- *72* children “on our books”
- 1 IPP/
- 6 out of centre / overseas (ROI, Denmark, Greece)
- 2 potential ABOi
- 1 currently listed for paired exchange
- 3 further potentials for paired exchange / ABOi

Deceased Donor Tx

Donor Pool

- *Complete data on 5 recipients (50%)*
- *Age 23/12 – 49 Y yrs (Mean 34 yrs)*
- *Donor COD – 6 ICH*
  1 meningitis
  3 not stated

Through out audit year:

- *26 children on call*
- *11 new activations*
- *Currently 19 children on call*

Achievements

- Recruited new Clinical Nurse Specialist
- Paired exchange / ABOi viable treatment option. (yet to Tx on paired exchange).
- 1 En bloc transplant
- 1 Recipient – retroviral disease
- 1 currently listed for Paired exchange, 2 more being worked up
- 1st Altruistic Tx
- 2nd ABOi Tx performed,2 pot ABOi
- Technically challenging (KB)
- O/seas / out of centre

- Court order – JW
- Liver & kid BCH
- IPP
- 1 RFH donor

Audit Points

- Expanding service to include ABOi, paired exchange, desensitisation
- All go for paired exchange prior to ABOi
- 1st – altruistic, en bloc, HIV recipient
- More technically challenging recipients (eg KB, LC)
- More referrals from over seas for tech difficult / paired exchange

Next audit

Use database to format audit
Calculate time from donor referral to Tx

With Thanks to
- Katie Knapp
- L 7 team
- Guys Team
- All

11.2 RENAL TRANSPLANT AUDIT

Renal Transplant Audit, April 2011 – March 2012

Suzanne Bradley and Jenny Tanton

Renal Transplants at GOSH

31 Patients received a Renal Transplant at GOSH in the 12 month period of 1st April 2011 – 31st March 2012

- 1 Patient received a Liver & Kidney Transplant at Birmingham but returned to GOSH for ongoing follow up at Day 25 post op
- 1 Patient received a kidney transplant at GOSH and returned to Belfast post discharge from ward
- 1 Patient received a kidney transplant at GOSH and returned to home country

Transplants

- 29 patients received their 1st renal graft
- 2 patients received their 2nd renal graft
- 1 patient received their 1st combined liver and kidney transplant
- 1 Patient had an Altruistic Renal Transplant
- 1 Patient had a NHB En Bloc Renal transplant
- 1 Patient had an ABOi Renal Transplant

Underlying Diagnoses

Dysplasia	11
FSGS	3
Posterior Urethral Valves	5
Nephronophthisis	1
Ecoli 0157	1
HUS	1

Polycystic Kidney Disease	1
Good Pastures Syndrome	1
Basement membrane Disorder	1
H & L Transplant	1
HIV Induced Nephropathy	1
Sclerosing Glomerulopathy	1
VACTERL	1
Renal Infarction	1

Donor Types

Live Related = 22 Patients
(Grandmothers x 2 / Uncle x 1/Altruistic Donor= 1 Patient)

Deceased Donor = 10 Patients
(1= En Bloc NHBD)

Patient Demographics

Female / Male= 14: 18
NHS / Private= 31:1

Pre-Transplantation Status

Modality	**No of Patients**
Pre-Emptive	9
Haemodialysis	9
Peritoneal Dialysis	14

HLA Mismatches

Mismatch	LRD	Deceased
0-0-0	1	1
0-1-0	1	
0-0-1	1	
0-1-1	2	
1-1-1	10	2
1-0-1		
1-1-0	6	4
1-0-0	1	
1-1-2		
1-2-1		
2-1-1		2
2-0-1		1

Renal Transplant Biopsies

Patients transplanted in 2011-2012

- 24/30 of the patients had a total of 45 biopsies in the audit year
- 15/30 patients had a time zero biopsy
- 4/30 patients had protocol biopsies
- 26/45 Biopsies done due to a rise in creatinine.

Time Zero Biopsies

	MD	FC	JO	NM	GK
	1	9	2	2	1

Time Zero Biopsies

No of Biopsies	Biopsy Results
1	Insufficient
5	NAD
3	Non Specific Changes
6	Chronic Vascular Changes (ranged from mild to severe)

Biopsy results in patients transplanted 2010-2011

Biopsy Result	Number of Biopsies made reference to:
Acute Tubular Necrosis /C4d Pos	1
No Acute Rejection	9
Acute 1B Rejection	2
Grade 2A Acute Rejection	2
Tubular Interstitial Inflammation	1
Chronic Allograft Nephropathy	2
Borderline Changes (BANFF)	3
C4d Antibody Mediated Rejection	1
Chronic Vascular changes	5

EBV Viraemia

- 5 Pos D to 5 Neg R became positive
- 1 ? P/N D to 1 Neg R became positive
- 3 Neg D to 3 Neg R became positive
- 4 Pos D to 4 Pos R became re-activated

CMV Viraemia

- 1 Pos D to 1 Neg R developed CMV
- 2 Pos D to 2 Pos R had reactivation of CMV
- CMV Prophlaxis =RK
- Tx Valgancyclovir Withdrawl of active treatment

Immunosuppression in New Renal Transplant Recipients 2011-2012

Start	End	No
Tac /Aza /Pred	Tac /Aza /Pred	9
Tac /Aza /Pred	Tac/Pred	11
Tac/MMF/Pred	Tac/MMF/Pred	3
Tac /Aza /Pred	Tac/MMF/Pred	4
Tac/MMF/Pred	Tac/Aza/Pred	1
Tac/Pred	Tac/Pred	1
Tac/MMF/Pred	Tac/Pred	1

Stent Removal – No of weeks into Transplant Journey

Weeks/Post Tx	No of Patients	Reason
Week 2	3	UTI Haematuria
Week 3	4	UTI/ Haematuria
Week 4	2	
Week 5	3	
Week 6	6	
Week 7	3	
Week 8	4	
Week 9	1	
At time of catheter	1	
Still in Situ 31/03/12	3	ROS April 2012

Anti-Hypertensive Treatment in New Renal Transplant Recipients 2011-2012

Start	End	No of Patients
0 agent	0 agent	14
1 agent	1 agent	10
1 agent	0 agents	3
1 agent	2 agents	2
2 agent	0 agent	1

Transplant Complications

- FSGS Recurrence
- Subcapsular Bleeds post Renal Biopsies x 2 resulting in graft dysfunction
- Loss of lower Pole (thrombosis)
- Perfusion Defect Upper Pole
- Delayed Graft Function
- Transplant Abd Wound &intra-abd wound bleeding
- Rejection
- DSA
- Diabetes

Transplant Complications

- Hypertension
- UTI's
- EBV/CMV/BK/JC
- Benign Intracranial Hypertension
- Seizures
- Aspergillus/Pseudomonas BAL
- Viral Bronchiolitis
- Metapneumovirus
- Staph Aureus Sepsis
- URTI's
- Graft Dysfunction-return to Haemodialysis
- Child Protection
- Depression/Suicidal Ideation

Transplant Biopsies

Existing transplant patients undergoing biopsy in audit year 2011-2012
15 patients had a total of 24 biopsies in the audit year

Biopsy Results –Existing Patients

Biopsy results	Number of Biopsies made reference to:
No rejection	4
Grade 1A Rejection	1
Grade 2A Rejection	1
Mild Chronic Interstitial Fibrosis & Tubular Atrophy	1
CAN with superimposed Grade 2a Rejection	1
Acute Pyelonephritis	1

CAN/Chronic vascular Changes	9
Chronic Vascular and Tubulointerstitial Change	1
CAN C4d Non Specific/ Pos	2
Acute 1B Rejection	1
Moderate Chronic Change Acute Inflammation-includes bacterial infection	1
CAN with features of acute rejection	1

Transplant Complications

- Rejection
- DSA's
- EBV/CMV/BK Viraemia
- UTI's
- Pneumonia
- CKD
- Anaemia
- Diabetes
- Pleural Effusion
- Return to Dialysis &Transplant Nephrectomy
- Ureteric Obstruction- r/o ureter
- MMF-Diarrhoea & Wt loss
- Acute Renal Failure
- Aspergillus-brain lesion
- Revision of keloid scar tissue

Return to Monday Clinic!!

4 patients monitored closely to avoid "crashlanding" and transition to LRCAP

Psychosocial

Body Image Concerns
Non Concordance / Non Attendance
Adolescent Care/ Transition
Child Protection
Family support
Family Bereavement
Emotional/ Psychological Support

Adolescent Transition

- 11 patients transitioned to 4 adult units in the audit year
- Joint Adolescent Transition Clinics continue with Guys/RLH/RFH and Oxford
- Monthly Adolescent Clinic
- Steering Group-SE London

Transition Units

Royal Free Hospital	4
Royal London Hospital	1
Guys Hospital	5
Sheffield	1

Total Transplant Patients

158 Transplant patients

Age Range

Under 5 years old	13
5 – 10 years old	40
10 – 15 years old	52
> 15 years	53

Transplant Clinic OPA'S 2011– 2012

	RENWAL	RSTCNS	RSTRTP
Total Appointments	**(675) 640**	**(689) 721**	**(1380) 1370**
Appointments Attended	**(639) 608**	**(592) 605**	**(1119) 1080**
DNA / Cancelled	**(36) 32**	**(97) 116**	**(261) 290**

Creatinine Trend-an overview in programme March 2012

Creatinine	**No of Pts**	**DD v LD**
Up to 100	22	7 v 15
100-200	7	2 v 5
500- 600	1	1

24hr Ambulatory BP Monitoring

14 tests performed, in 12 patients

- 11 post transplant, 1 PD
- 7 male, 5 female
- Ages: 5-11 years, 2 patients

- 11-15 years, 5 patients
- 15 years +, 5 patients

Reasons for performing test:

- Hypertensive in clinic - 11 patients
- Review of antihypertensive therapy – 1 patient
- Repeat test following treatment - 2 patients

Antihypertensive treatment at time of test:

- No agents – 6 patients (43%)
- 1 agent – 7 patients (50 %)
- 2 agents – 1 patient (7%)

14 test performed:

- 9 patients hypertensive (64%)
- 2 patients, started treatment
- 2 patients, dose increased
- 4 patients, second agent added
- 1 patient, no change

Where we are up to?

- Renal Transplant Protocol/Annual Scans/Annual DSA's/ABPM
- Documentation-Case Notes/Letters
- Transplant Database
- Research Studies—MRI/Protocol Biopsies/ Stent Study (Steve)
- NHSBT
- Fasting & Tacrolimus - Sanity v Insanity!
- Dietetic Input
- Psychosocial Input
- Consultant Input
- Surgeon Input
- Registrar Input
- Eileen-24 hour ABPM
- CNS Role

11.3 RENAL TRANSPLANT NATIONAL COMPARATIVE UNIT AUDIT

(Report and data from NHS Blood and Transplant)

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

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

DATA

Table 1 reports transplant activity by financial years 1986/87 to 2010/11, by donor type (DBD, DCD and living donor) and by transplant unit (Great Ormond Street Hospital, Royal Free Hospital and all other UK kidney transplant units). The numbers of multiple organ transplants are indicated within the table (50 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 DBD paediatric kidney-only transplants by transplant year (grouped: 1995/96 – 1998/99, 1999/00 – 2002/03, 2003/04 – 2006/07, 2007/08 – 2010/11) and by transplant unit (Great Ormond Street and Royal Free combined, and all other UK kidney transplant units). Transplants from DCDs 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: 1995/96 – 2002/03 and 2003/04 – 20010/11) and by transplant unit (Great Ormond Street and Royal Free combined, 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

	DBD			DCD			Living		
Transplant year	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units
1986/87	8	1	109	0	0	0	1	0	14
1987/88	15	7	106(1)	0	0	0	1	0	8
1988/89	10	5	102(2)	0	0	0	3	0	7
1989/90	12(2)	6	101	0	0	1	2	0	10
1990/91	17	5	55	1	1	0	2	0	5
1991/92	14(1)	8	88(1)	0	0	2	0	2	7
1992/93	12	8	104	2	0	2	3	3	9
1993/94	9	2	105(2)	0	0	0	3	4	8
1994/95	10	5	102(2)	1	0	0	5	2	11
1995/96	13(1)	6	114	0	0	1	2	5	14
1996/97	2	10	89(3)	0	0	0	4	4	18
1997/98	5(2)	21	80(3)	0	2	1	1	5	15
1998/99	1(1)	16	84(2)	0	0	0	0	7	16
1999/00	2	10	90(2)	0	0	1	1	5	30
2000/01	2(1)	23	77(2)	0	0	0	0	7	24
2001/02	0	7	83(1)	0	0	0	0	7	30
2002/03	1	10	66(1)	0	0	0	1	12	29
2003/04	0	16	78	0	0	0	0	15	32
2004/05	0	11	65(5)	0	0	0	0	14	34
2005/06	0	9	51(2)	0	0	0	1	15	32
2006/07	0	18	70(6)	0	0	1	0	12	36
2007/08	0	10	52(4)	0	0	1	0	10	41
2008/09	0	9	66(3)	0	0	2	0	11	53
2009/10	0	12	63(3)	0	0	1	0	23	47
2010/11	0	10	60(3)	0	1	1	0	9	57

( ) Number of which were multiple organ transplants

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

	DBD			DCD			Living		
Transplant year	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units	Royal Free	GOSH	Other UK paed units
1986/87	8	1	87	0	0	0	1	0	13
1987/88	14	5	88	0	0	0	1	0	7
1988/89	6	4	82	0	0	0	3	0	5
1989/90	10	3	66	0	0	0	2	0	9
1990/91	14	5	45	1	1	0	0	0	5
1991/92	12	3	73	0	0	2	0	2	5
1992/93	11	7	88	1	0	2	2	3	9
1993/94	9	2	90	0	0	0	3	4	8
1994/95	7	4	76	1	0	0	5	2	11
1995/96	10	6	97	0	0	1	2	5	13
1996/97	2	9	74	0	0	0	4	4	16
1997/98	2	18	58	0	2	0	1	5	13
1998/99	0	11	70	0	0	0	0	7	15
1999/00	2	8	74	0	0	1	1	5	26
2000/01	1	16	69	0	0	0	0	7	22
2001/02	0	5	73	0	0	0	0	6	29
2002/03	1	7	54	0	0	0	1	12	28
2003/04	0	15	66	0	0	0	0	14	28
2004/05	0	10	55	0	0	0	0	13	30
2005/06	0	9	47	0	0	0	1	15	29
2006/07	0	15	60	0	1	1	0	12	36
2007/08	0	9	43	0	0	0	0	10	41
2008/09	0	9	57	0	2	2	0	9	53
2009/10	0	10	59	0	1	1	0	22	47
2010/11	0	8	51	0	1	1	0	9	55

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 and Royal Free Hospital					
1995/96 – 1998/99	58	58	81	68 – 90	86
1999/00 – 2002/03	40	39	91	88 – 94	79
2003/04 – 2006/07	49	49	92	88 – 94	92
2007/08 – 2010/11	36	36	94	80 – 98	97
All other UK paediatric units					
1995/96 – 1998/99	299	299	87	82 – 90	88
1999/00 – 2002/03	270	270	91	88 – 94	91
2003/04 – 2006/07	228	228	92	88 – 94	95
2007/08 – 2010/11	210	207	97	94 – 98	91

Five year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1995/96 – 1998/99	58	58	68	54 – 78	72
1999/00 – 2002/03	40	39	67	50 – 80	67
2003/04 – 2006/07	49	49	84	70 – 92	78
2007/08 – 2010/11	36	-	-	-	1
All other UK paediatric units					
1995/96 – 1998/99	299	299	75	70 – 80	75
1999/00 – 2002/03	270	270	79	74 – 84	80
2003/04 – 2006/07	228	228	85	80 – 88	86
2007/08 – 2010/11	210	-	-	-	1

Ten year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Year group					
1995/96 – 1998/99	58	58	60	46 – 72	57
1999/00 – 2002/03	40	39	54	36 – 68	35
2003/04 – 2006/07	49	-	-	-	0
2007/08 – 2010/11	36	-	-	-	0
All other UK paediatric units					
1995/96 – 1998/99	299	299	59	54 – 64	54
1999/00 – 2002/03	270	270	70	64 – 74	50
2003/04 – 2006/07	228	-	-	-	0
2007/08 – 2010/11	210	-	-	-	0

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

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

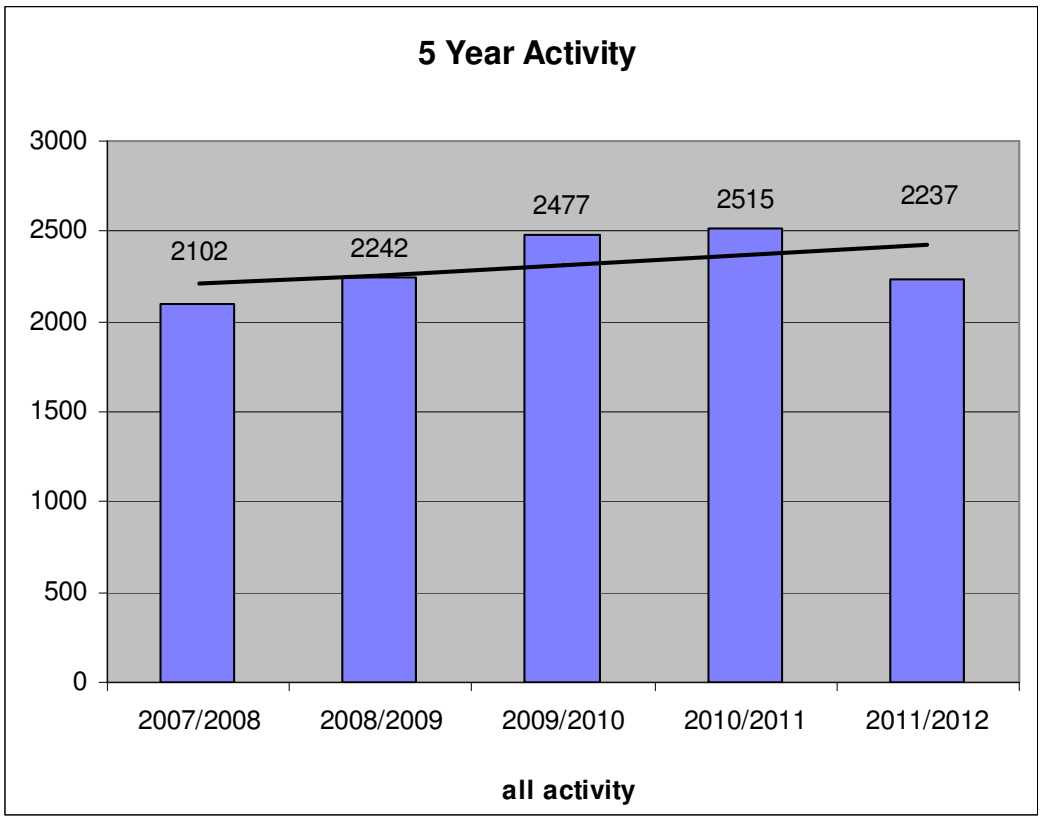
One year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1995/96 – 2002/03	60	57	95	84 – 98	83
2003/04 – 2010/11	105	105	97	94 – 98	94
All other UK paediatric units					
1995/96 – 2002/03	162	158	96	90 – 98	90
2003/04 – 2010/11	319	312	96	94 – 98	93

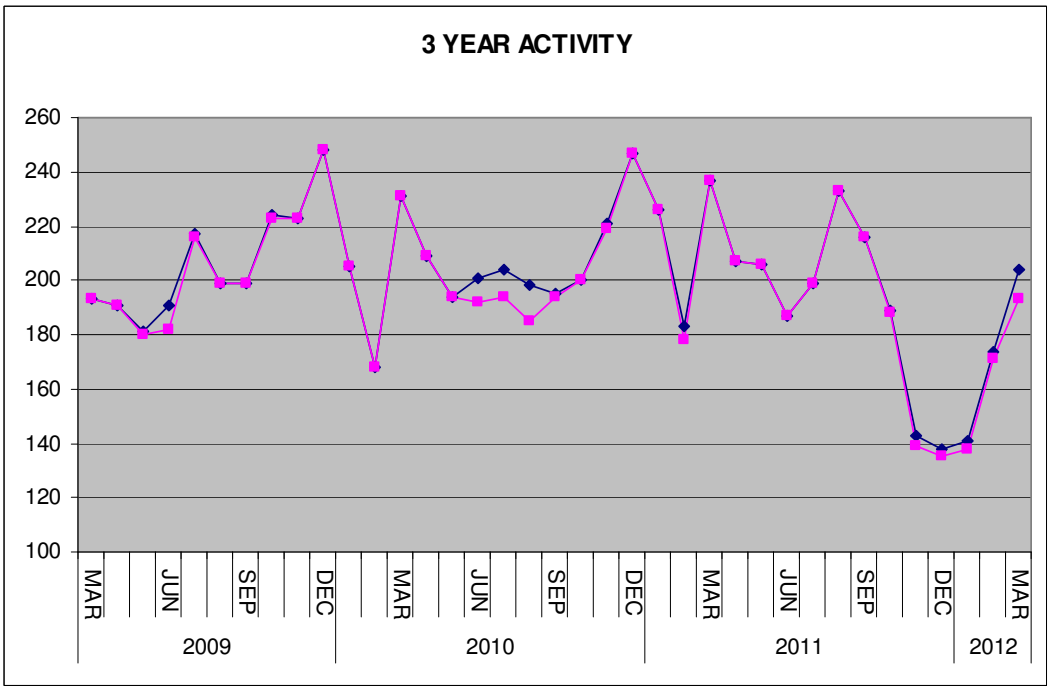
	Five year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1995/96 – 2002/03	60	57	85	72 – 92	69
2003/04 – 2010/11	105	-	-	-	43
All other UK paediatric units					
1995/96 – 2002/03	162	158	87	80 – 92	78
2003/04 – 2010/11	319	-	-	-	40

	Ten year transplant survival estimates				
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1995/96 – 2002/03	60	57	75	60 – 86	47
2003/04 – 2010/11	105	-	-	-	0
All other UK paediatric units					
1995/96 – 2002/03	162	158	74	66 – 80	52
2003/04 – 2010/11	319	-	-	-	0

11.4 HAEMODIALYSIS AUDIT 2011-2012

Liane Pilgrim, Liz Wright





Totals

Children receiving HD or PEX (GOS) only

Total = 47 (+ 2 never dialysed)

- Chronic HD = 40
- Acute HD = 4
- Plasma exchange = 4

Ages

- 49 children (26 male: 23 female)
  - 0 – 2 years = 7
  - 2 – 5 years = 8
  - 5 – 10 years = 9
  - 10 – 15 years = 8
  - 15+ years = 17

- Youngest – 0.03 years
- 32% of workload < 5 years

New HD Starters

Source	No.s of children
CRF	6
PD	7
Transplant	3
Visitors/ Pre transplant	4
Transfer in (HHD programme)	1
Acutes/PX	6
	27

Leavers

Reason	No.s of children
Transplant DD	7
Transplant LRT	4
PD	0
Transfer care	1
Transfer adult HD	4
HHD programme	4
Function recovered	6
Died	4
	30

Acute HD

- 2 children access in never required
- 14 sessions in 4 children
    - 1 = 6 sessions - RSV
    - 1 = 1 session - rhabdomyolosis
    - 1 = 2 sessions – renal tx
    - 1 = 5 sessions – FSGS post tx

Plasma Exchange

- 4 children had 26 sessions
- 1 - test plasma exchange
- 2 - FSGS recurrence post-transplant (x sessions)
- 1 – HSP nephritis (3 sessions)

Access Totals

- Total access = 50 catheters in 39 children
  - AVF – 17
  - Permanent – 45
  - Temporary – 5
- Accesses inserted over the year:
  - AVF – 8
  - Permanent - 29
  - Temporary - 5

Line Insertions

	Who	Permanent	Temporary	Total
IR (%)	DR	11		11
	AB	8	1	9
	SC	2	1	3
	LR (CNS)	4		4
Renal (%)	GK	0		0
	MD	4		4
	FC	0		0
	JT	0		0
	NM	0		0
Other		0	3	3
		29(85%)	**5**	**34**

Reason for Line Removal

Reason	Number
Infection	5
Poor flows	4
Cuff migration/damage	3
Transplant	5
Recovered/not needed	6
Died	4
AVF maturation	2
Conversion to permanent catheter	1
	30

Infection data

- 7 line infections
- 3726 catheter days
- 1.9 infections/ 1000 catheters days

Infection rates

	07/08	08/09	09/10	10/11	11/12
No of infections	10	7	5	7	7
Catheter days	1914	2434	3384	4076	3726
Infections/ 1000 catheter days	5.2	2.9	1.5	1.7	1.9

Line Infections

Patient	Time (days) from insertion	Microbiology	Outcome
1	221	CNS	Access replaced
	20	CNS	Access replaced
	18	Streptococcus	Cleared
2	8	CNS	Access removed
3	34	S. Aureus	Access replaced
4	55	Streptococcus	Cleared
5	143	S. Aureus	Access replaced

Exit Site Infections

- 0 exit site infection
- 1 tunnel infection – associated with line infection

AVF data

- 17 children had AVFs
- 8 created in this audit year

AVF

Age	Site	Surgeon	2nd Stage	Outcome
16.0	R brachio-cephalic	JT		Maturing
14.3	R radio-cephalic	FC		Primary non-function
17.9	L brachio-cephalic	JT		Maturing - adults
12.7	L radio-cephalic	GK		In use
16.2	R brachio-cephalic	GK		In use
11.3	L brachio-basilic	JT	yes	In use

17.0	L brachio-basilic	JT		Maturing
7.5	L brachio-basilic	NM	yes	Needs 2nd stage

AVF Infections

1 – Septicaemia (multi-organisms) associated with button-hole technique

11.6 PERITONEAL DIALYSIS AUDIT

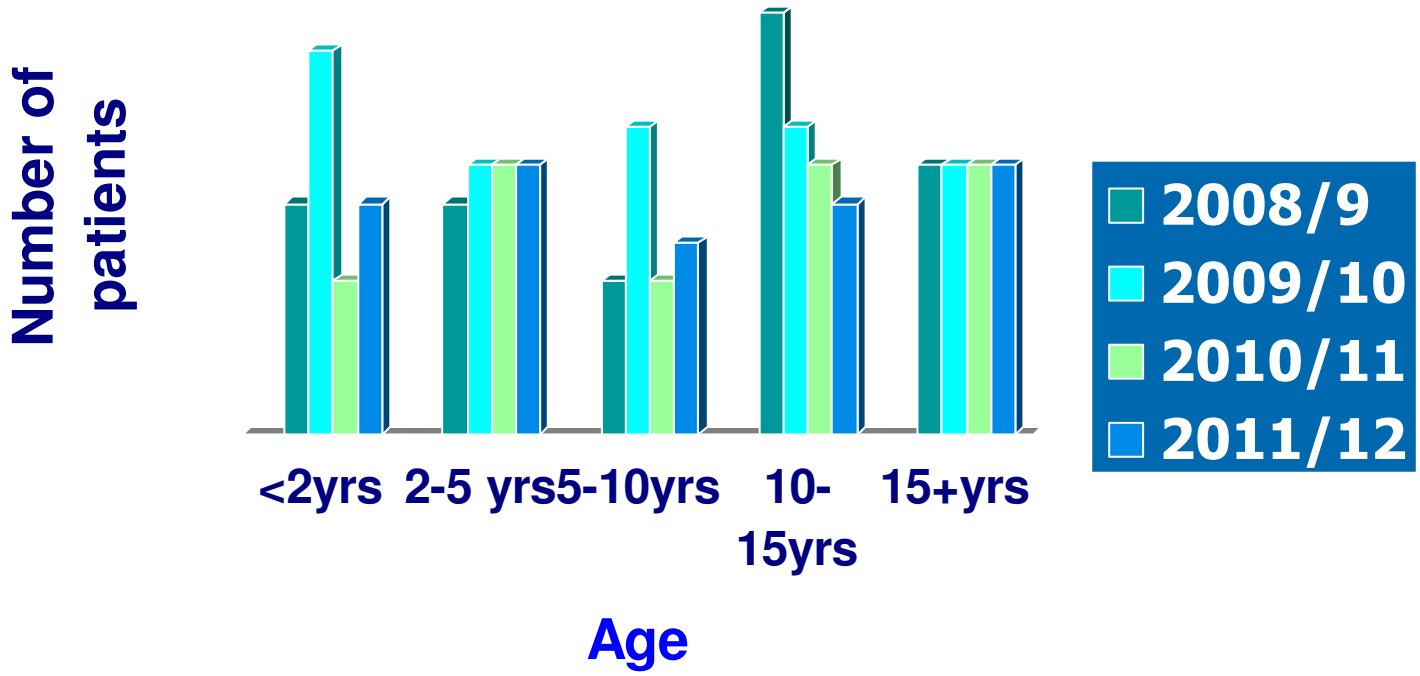
April 2011 – March 2012

Michelle Cantwell, Cecilia McNeice, Jenny Tanton, Eileen Brennen & Maria Rodrigues

Patient Demographics

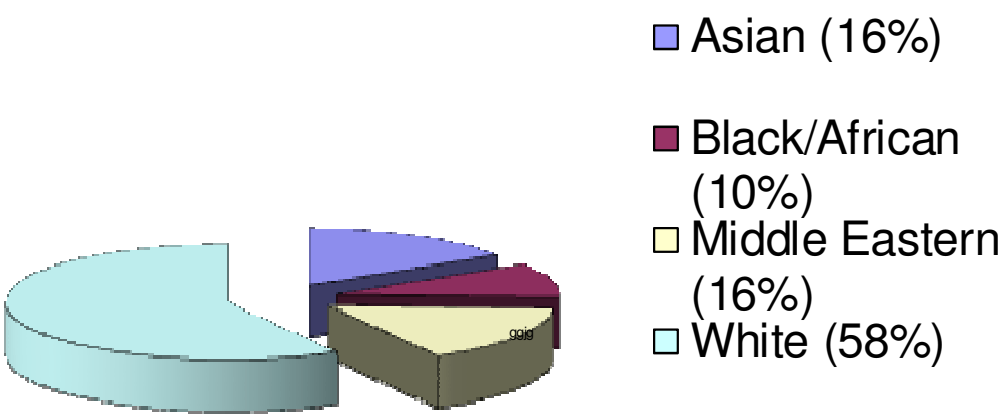
31 patients have been on the PD program:

- 61% (19) Male, 39% (12) Female
- Children's age on PD: between 0.4 - 17.5 years
- TOTAL PD MONTHS = 172.5 months



Patient Age Ranges 2008 to 2012

Ethnicity



Patients on PD – Primary Diagnosis

- Dysplasia (23%) 7
- FSGS (13%)4
- Nephronopthisis 4
- Posterior Uretheral Valves 4
- Congenital Nephrotic Syndrome 3
- ?MPGN 2
- Diffuse Mesangial Sclerosis 1
- Good pastures 1
- Alports Syndrome 1
- HUS 1
- Renal Vein Thrombosis 1
- Renal Calculi 1
- Unknown 1

New Patient Profile

16 new PD patients to PD:

- 1 returned to PD after failed transplant
- 7 families – English is not their first language

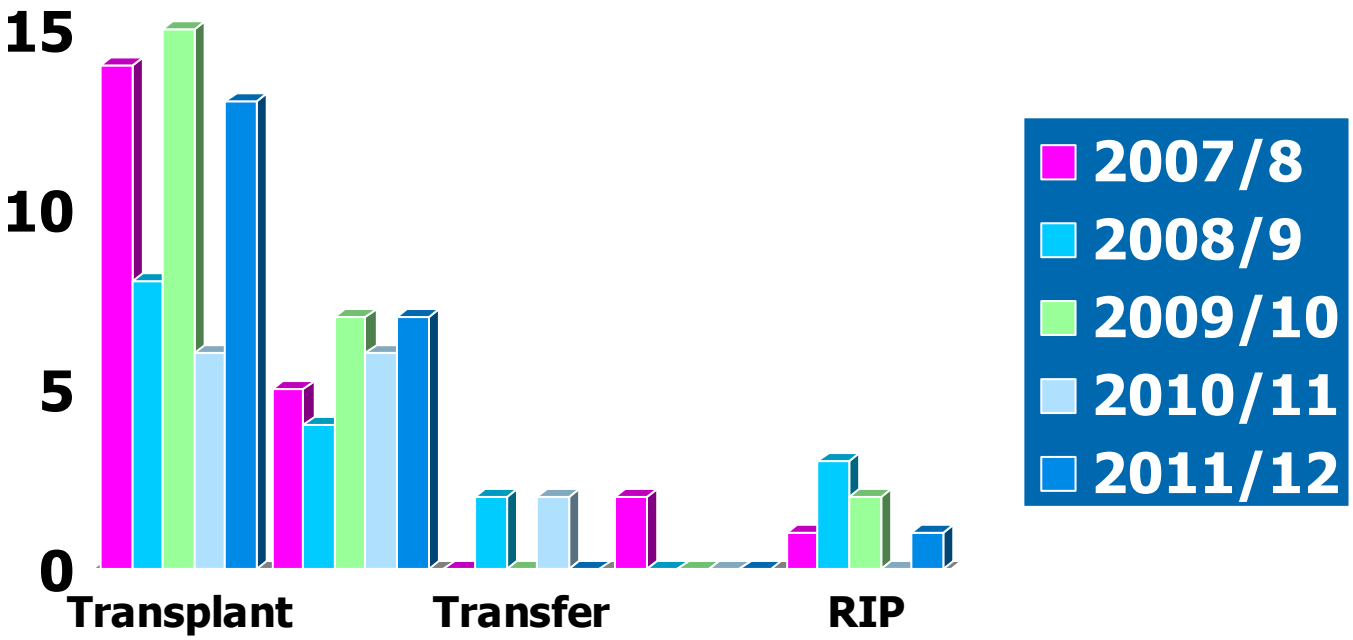
Patients Leaving PD

21 patients left PD in 2011 / 2012:

- 13 patients were transplanted
- 1 died
- 7 transferred to Haemodialysis:
- 2 – chronic eosinophilia / drain probs
- 1 - adhesions / drain probs
- 2 – peritonitis / not returned due to social concerns
- 2 –

Annual Figures 2004/5 – 11/12

	04-05	05-06	06-07	07-08	08-09	09-10	10-11	11
Patients	39	41	37	34	34	40	29	3
New Patient	14	17	18	15	15	20	11 (3PX)	1
No.at Year End	23	18	20	20	19	10	15 (1PX)	1
Transplants	11	12	14	8	6	15	6	1
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: 88 (66 last year)
- Number of Inpatient Days: 824 (1038 last year)
- 3 patients had no admissions in audit year

Inpatient Admissions

Reason for admission	No.	%
Diagnosis / Catheter insertion / Training	24	27
Peritonitis(true + eosin) / Exit Site Infect	15	17
Renal Surgical interventions	8	9
Catheter problems (no surg)	6	7
Renal Medical	10	11
Non Renal : Urology	3	3.5
Social	3	3.5
Other (non-renal infections)	19/15	22/17

PD Catheter Insertions (acute & chronic)

HIGH RISK: <1 year of age, Significant oedema, Significant gut problems, Extensive abdo surgery

22 catheters were inserted in 20 patients in 2011-2012 by 6 surgeons
- 41% of these insertions involved patients classified as 'high risk'

14% off all catheter insertions
FAILED within 3 months (3 caths)
- 22% of HIGH RISK catheters failed (2)
- 8% of LOW RISK catheters failed (1)

	09-10	10-11	11-12
Patients	42	23	20
First catheters ESRF	20	7 + 1 (returned post failed tx)	14 + 1 (returned post failed tx)
Replacement catheters ESRF	9 (at least)	6	5
New catheters ARF	14	9 (1 ARF had 2)	2
High risk	55%	50%	41%
Failed within 3 months	55%	24%	14% (? 1 true cath failure)
Surgeons	5	6	6

Annual Figures 2011 -2012

Total catheters of current ESRF caseload

Surgeon	No. of Insertions	% Failed	Leaked post op	% High Risk
A	3	33%	33% (chronic fibrin)	33%
B	7	28% (1 x adhesion)	14% (1 x adhesion)	43%
C	4	0%	25% (recovered)	50%
D	2	0%	0 %	0 %
E	2	0%	50%	50%
F	4	0 %	0 %	50 %

Peritonitis (chronic patients)

- 12 episodes of 'true' peritonitis
  - 8 Culture Positive episodes (70%)
  - 4 Culture Negative episodes (30%)
  - 4 catheters removed due to infection (1 secondary to leaking)
  - Eosinophilia seen in 10 patients (chronic / recurrent in some)

Culture Positive Peritonitis

- ORGANISM CLASSIFICATION

4 episodes of GRAM POSITIVE

- Staph aureus: 1 episode
- Coagulase negative Staph: 2 episodes
- Corynebacterium: 1 episode

4 episode of GRAM NEGATIVE

- E coli: 2 episodes
- Pseudomonas: 1 episode
- Klebsiella species: 1 episodePeritonitis

	07-08	08-09	09-10	10-11	11-
Culture -ve	13	10	5	7	4
Staph Epi	3	2	3	2	2
Staph Aureus	3	1	0	3	1
Candida	0	1	0	0	0
Enterococcus / coliform /E coli	2	3	3	0	2
Strep	0	0	2	2	0
Pseudomonas	3	0	3	0	1
Corynebacterium	0	0	0	1	1
klebsiella	0	0	0	1	1
Total episodes	**24**	**17**	**16**	**16**	**12**

Peritonitis Episode Breakdown

12 episodes of peritonitis in 172.5 patient months = 0.83 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	2011-2012
0.9	1.2	0.89	0.72	0.88	0.83

- Total of 12 episodes in 9 patients
- 7 of these episodes occurred in 3 patients under 3 years
- 3 episodes occurred in children with special needs
- 2 secondary to line breaks (Cult neg)
- Inpatients: 1 episode
- **THEREFORE 22 patients' peritonitis free**

Exit Site Infections (red / inflammed / exudate)

Organism	Infections	Treated with AB's	Catheter Removed
Staph aureus	2	2	0
Pseudomonas	3	3	0
No growth	1	1	0
Coag neg staph	1	1	0

	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-20
Staph aureus (SA)	14 (including colonised)	7	5	7	6	5	2
Pseud.	5	3	2	0	2	2	3
MRSA	1	1	0	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	0

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

Organism	Number	Treated with AB's
Coag neg staph	21	0
Staph aureus	5	5 (1 pt developed peritonitis & 1 pt developed ESI)

Coliform	4	0
Candida	3	3

Nasal Colonisation (outpt)

5 patients had nasal *Staph aureus* carriage:

- all received topical treatment
- 1 of these had MRSA aswell during year
- No patients had concurrent growth of Staph aureus at their exit site (ESI or colonised)
- No patients had SA nasal carriage leading up to / at time of SA peritonitis (?benefit of screening – second year running – shall we stop monitoring?)

PD Training

- 16 families underwent PD training in audit yr = approx 110days of CNS workload
- Additional carers trained for 2 high risk families (at GOSH) : 2 (4 days)

Clinical Nurse Specialist Community Activity

- Home Assessments: 13 (4 pts still in CRF)
- Home Visits at time of Discharge: 14
- Home Visits (social concerns, extra training): 3
- School visits (lower schools, special needs): 6
- Additional carers PD training: 3
- MDT external meetings: 3
- Hospice visit: 1

Aims for 2012 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
- Changed to Baxter Therapy Costing from April – should be a cost saving but involves extra CNS work
- Roll out upgraded 10.4 HomeChoice machines on Eagle (8th May) & in community

Thanks

All on the Renal Unit, Dr. Lesley Rees, Dr. Rukshana Shroff, Dr. Sarah Ledermann, Transplant surgeons, Maria Rodriguez and Eagle ward staff

12. NURSING REPORT

NURSING REPORT

The move to the Morgan Stanley is booked for the 3rd week in April 2012. During the last year the team has been working to achieve a safe and effective transition to the new unit. Haemodialysis with be joining the ward and in the next year we will be working towards functioning as one unit. The goal is to provide a seamless service for children and there families. We will continue for the Operational Group meets and a parent will continue to join us providing valuable insight from a parent's perspective. David fisher the Nurse Counsellor has now retired, the psychosocial team are covering this post at present.

12.1 STAFFING AND CLINICS

Nurse Consultant	Eileen Brennan
Ward Sister	Sr. Sarah Matthews Sr. Lucy Thomas
Clinical Nurse Specialists	Transplants Sr. Suzanne Bradley (1 WTE) LRD Transplant coordinators CNS Maria Scanes (0.64 WTE UKT 0.03 WTE GOSH) and CNS Katie Knapp (1 WTE). Senior Sr. Liz Wright (1 WTE) PD CNS. Michelle Cantwell (1 WTE) Transplants senior staff nurse (1.0 WTE) & PD Senior Staff nurse (0.88 WTE) Nephrotic nurse specialist Hazel Webb (1 WTE) Lynsey Stronach CNS Home Haemodialysis Sr. Liane Pilgrim, Haemodialysis Sister (1 WTE) Sr. Trish Evans, Practice Educator (WTE)

Clinics

Nurse Consultant Clinic

Nurse led	Transplantation	Daily reviews
	PD	Walk in clinic Phone clinics
	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	

12.2 PUBLICATIONS

12.3 GENERAL INFORMATION

Eagle 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 5 rotation posts
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 Eagle 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 Eagle
1 Band 3 HCA

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 2011/12

- GOSH assisted in the organization of the annual Paediatric Nurses Nephrology Conference Newcastle. It was attended by over 80 paediatric nephrology nurses representing every unit in England, Wales, Scotland, Northern and Southern Ireland, play specialists and dieticians.

12.5 EDUCATION

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

The role of the Nurse Independent prescribers continues to develop the nurse led service in this area We have 6 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
Lynsey Stronach

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.

12.6 PRESENTATIONS

Eileen Brennan:
Nephro/urology conference, ICH- GOSH
Ambulatory blood pressure monitoring in children, March 2012

Special interest group for Paediatric nephrology nurses Annual conference Newcastle Chair for Group

Lynsey Stronach:
Special interest group for Paediatric nephrology nurses Annual conference Newcastle – Presentation on Home Haemodialysis in Paediatrics. March 2012

Lynsey Stronach:
32nd Annual Dialysis Conference – San Antonia, Texas.
Poster presentation: Dialyser Induced Thrombocytopaenia in Children using the NxStage System. February 2012. Supported by the PNNG/BKPA

12.7 ACADEMIC ACHIEVEMENTS

Liz Wright – successfully completed 2 modules of MSc pathway:

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

Katie Knapp – undertook the diploma in higher education – nursing (child), BSC Honours. Awaiting official results but verbally has passed

Lynsey Stronach – 2nd year of MSs Children's Advance Nurse Practitioner completed. MSc to be completed in 2013.

12.8 OUTREACH COMMITMENTS

Eileen Brennan: Chair of the special interest group for paediatric nephrology
NICE guidelines for RCN
Workforce Planning
GOSH representative on the group The BKPA, the Royal College of Paediatrics and Child
Health (RCPCH) and the British Association of Paediatric Nephrology are working in partnership to produce a new and comprehensive set of information leaflets for children with kidney disease.

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)

Lynsey Stronach: Working closely with other paediatric renal units to increase patient choice by establishing pathways of care through service level agreements for referrals to the paediatric HHD service at GOSH. Working with Daljit Hothi, Christopher Reid and Carmen Barton.

Maria Scanes & Katie Knapp :

Was pupported by the BKPA to attend IPTA international paediatric transplant association in June 2011 Montreal.

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

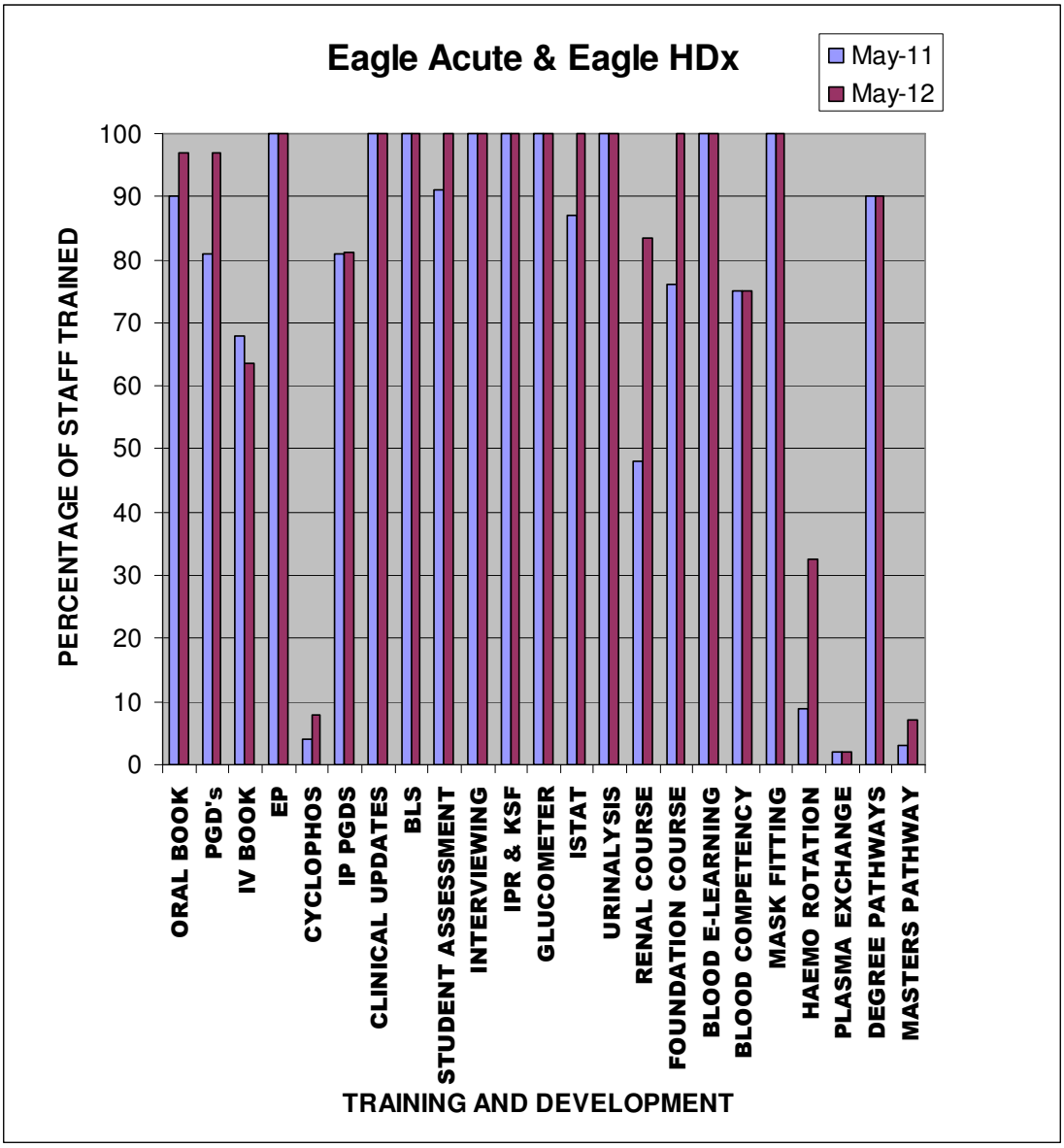
The Home Haemodialysis service has successfully over achieved the original expectations and there are currently 8 patients on HHD of varying ages. Nocturnal HHD has been established in the majority of these patients. We are in the process of trying to obtain a smaller circuit to allow lower weight children to have HHD. A training DVD for HHD has been produced and is being used successfully with the training package of care for families. We have also taken referrals from other regional paediatric renal units and are currently working together with the Evelina Children's Hospital.

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.

Education:

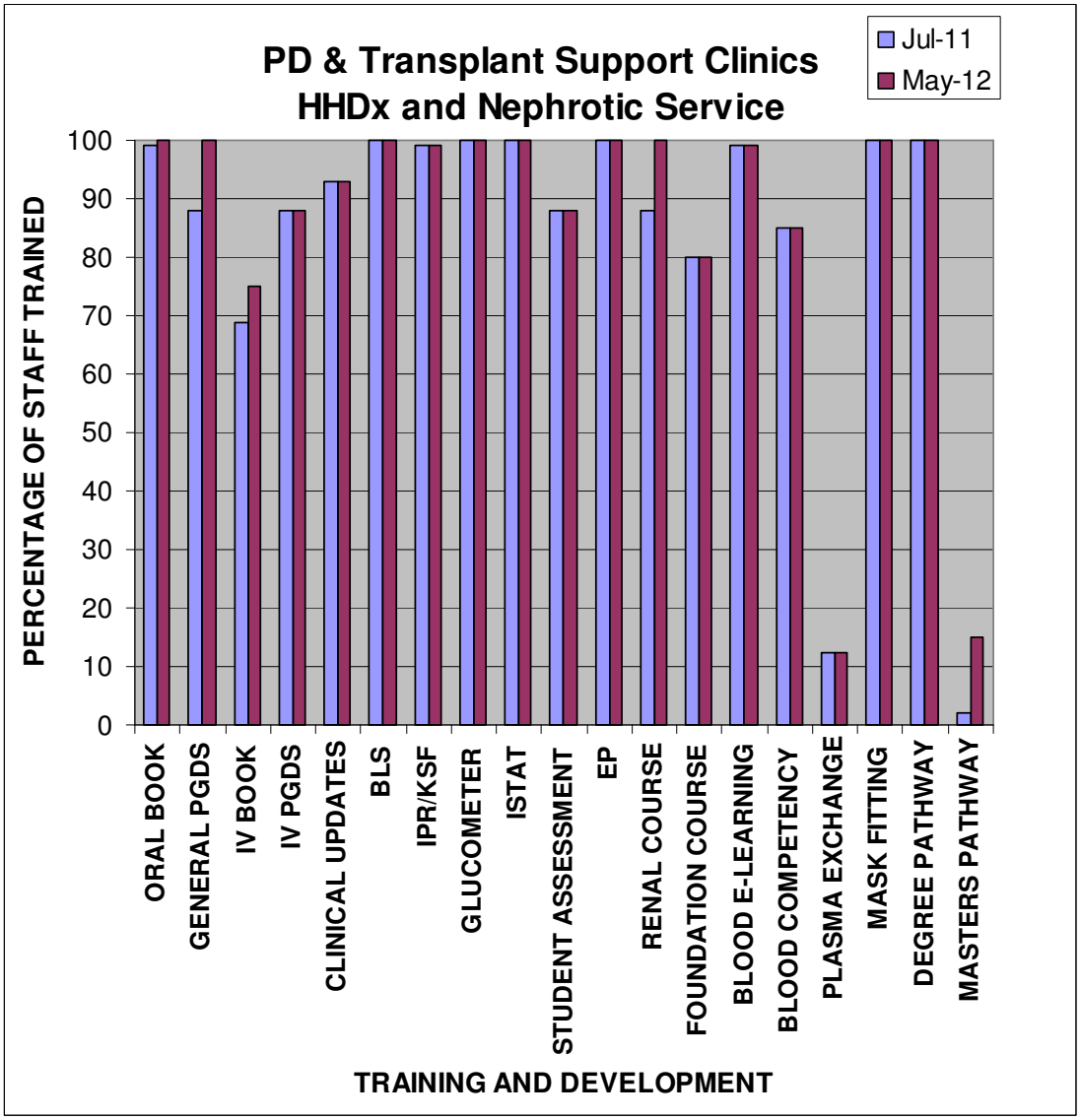
Mandatory and Specific Training required of all nurses on Eagle Acute and Eagle HDx



Analysis of Data:
Average % of Nursing Staff Trained in Core & Specific aspects: 95%
Eagle Ward and Hippo have merged together to form Eagle Acute and Eagle HDx

The number of IV competent nurses has decreased from last year and this reflects 11 new members of staff since March 2012 across both areas. These nurses are half way into their Preceptorship Period and therefore are not yet IV competent but working towards it.

Mandatory and Specific Training required of all nurses working in PD and Transplant Support Clinics, Home Haemodialysis and Nephrotic Service.



Average % of Nursing Staff Trained in Core & Specific aspects: 98%

Continuing Professional Development

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 (LSBU): 20 Credits

LSBU has increased this module 15 credits to 20 credits therefore much work has been done this year in re-developing the course and implementing Blended Learning within its content. Following on from the success of previous intakes 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 offered at both Level 6 (Degree) and Level 7 (Masters) and is the only Paediatric Renal course in the UK. October 2011 intake consisted of 9 Nurses, 8 Degree Level, 1 Masters Level representing renal units from GOSH, Manchester, Southampton and Liverpool. Eight students successfully completed their reflective logs, one student was referred and has chosen not to re-submit. Of the eight students who successfully completed their reflective logs, seven successfully pass their case presentations and one nurse referred. This nurse will re-sit in July 2012 following exam board. Therefore an overall pass rate of 98%. This academic years course is due to commence in autumn 2012 and will remain at 20 credits. The components of the course are: face to face teaching, problem based learning, blended learning, reflective logs and an oral case presentation. This course is co-run with Maire Horstman, Principal Lecturer at LSBU, Trish Evans, Practice Educator, Eagle Ward/Renal Unit at GOSH and Liane Pilgrim, Sister, Eagle HDx GOSH.

Foundations of Paediatric Renal Nursing:

This course remains an essential component to be undertaken shortly following nurses 6 month preceptorship period. This course enhances newly qualified nurses and those new to renal nursing by providing evidence based theory behind renal practice. The course consists of 6 renal study days with lectures, workshops; problem based learning, worksheets and competencies to complete. Each staff memebr 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. The next course commences in August 2012 and on completion 100% of staff in the renal unit have attended this course in varying formats.

In-Charge Study Day (Scenarios and Clinical Competency Booklet)

Once Band 5 Staff Nurses have attained their renal competencies and are working at a suitable level they are professionally developed to take on in-charge responsibilities. This includes attending an In-Charge study day, being clinically supervised by a Senior Staff Nurse and completing an In-Charge Competency Workbook. During the last year 3 members of staff have been worked up to being in charge and 2 have successfully completed this programme and no longer need supervising when 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

The Renal Unit continues to receive simulation ad-hoc sessions run by the CSP team. These evaluate extremely well and will be incorporated into the new Eagle Ward environment.

Eagle HDx Rotation

Rotating between the Eagle Acute and Eagle HDx continues to be carried out on a 4 monthly cycle to ensure a multi-skilled renal workforce. 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. Eagle HDx have employed a newly qualified Band 5 nurse who is progressing well with her core competencies.

Eagle HDx – Student Nurses

Haemodialysis is to become an Interface Placement for LSBU student nurses later this year. Student Nurses can expect to gain valuable insight into how renal patients live with their life limiting disease whilst receiving haemodialysis sessions three times a week. They can also expect to gain valuable essential nursing skills such as fluid balance, accurate weighting and heighting of patients and learning the art of taking manual blood pressures.

Move Preparation from Eagle and Hippo Wards to Eagle Ward

Fifteen months before Eagle Ward and Hippo Ward were to merge and become Eagle Ward senior staff in the unit set up 'Operation Eagle' to assist the smooth transition of this major change in working environment. Operation Eagle Meetings, comprising of key staff groups from within the unit, were introduced on a monthly (and nearer the move, fortnightly) basis and chaired by Sarah Matthews (Sister) and co-chaired by Lesley Rees (Lead Consultant). These meetings focused on strategic requirements such as operational policies and procedures, clinical space utilisation, non-clinical space utilisation and storage, equipment and procurement, medical workforce and nursing and health care assistant's organisation and multi-professional training.

It was recognised very early on that for the majority of staff merging of two wards and two teams was a new concept but by ensuring a robust training structure was established early enough this would help to embrace their enthusiasm, provide essential support and training to ensure a smoother, safer transition to Eagle Ward thereby ensuring patient safety (Zero Harm) at all times. Four staff away days from spring 2011 to spring 2012, bands 3, 4, 5, & 6 focused on gaining their reflections on the current wards and thoughts and idea on how to move forward to Eagle Ward. Part of this included a tour of the mock up cubicle to give them insight into their new working environment. As soon as tours could commence into the new building all staff were given the opportunity to view and again constructive ideas were discussed and taken forward following further away days and meetings. 'TOWIE training – 'The only way is Eagle!' dates were negotiated and incorporated all mandatory training as well as familiarisation and scenario training for the new building. In all, 4 tour dates during January and February 2012 were scheduled with 95% of staff uptake, 3 Familiarisation Training dates during February and March were scheduled with 92% of staff uptake (due to shift patterns), a Train the Trainer day followed by 4 multi-professional Scenario Training days allowed accurate planning and training was undertaken by 97% Nursing staff and 70% Medical Staff.

13. DIETETIC REPORT

April 2011 – March 2012

13.1 STAFFING

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

Shelley Cleghorn	Principal Dietitian and Team Leader
Jayne Holmes	Specialist Dietitian (from March 2012)
Bahee Manickavasagar	Specialist Dietitian
Louise McAlister	Specialist Dietitian
Vanessa Shaw	Head of Dietetics
Carolyn Southey	Specialist Dietitian

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.

Louise McAlister runs monthly journal updates for the dietetic department (renal and non-renal journals).

Shelley Cleghorn delivered a teaching session on renal nutrition for new renal nurses in April.

Carolyn Southey delivered an educational update session in May to Band 6 Victoria ward nurses on The Practical Aspects of Renal Nutrition in order to ensure consistent food advice and feeding practices on the ward

Bahee Manickavasagar delivered a nutrition education session to haemodialysis nursing staff in June.

Bahee Manickavasagar delivered a lecture to students as part of the MSc Paediatrics and Child Health course at ICH on "Feeding problems in the infant with reflux" in June.

Shelley Cleghorn carried out training for renal doctors on nutrition in renal disease in July.

Louise McAlister carried out a nutrition update teaching session for neurology nurses in September

13.3 PUBLICATIONS, PRESENTATIONS, AWARDS, APPOINTMENTS

Vanessa Shaw was made an Honorary Associate Professor at the University of Plymouth.

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.

Shelley Cleghorn was invited to be on the NICE Guideline Development Group for developing a short clinical guideline on the Management of Hyperphosphataemia in patients with stage 4-5 and 5D CKD which started in January.

Shelley Cleghorn chairs the national dietetic renal group PRING (Paediatric Renal Interest Nutrition Group).

Bahee Manickavasagar secured funding for 0.3 WTE dietetic time and consumables from the GOSH charity for her research project "Relationship of dietary vitamin A, hypervitaminosis A and hypercalcaemia in children with progressing stages of chronic kidney disease".

Shroff R, Wan M, Gullett A, Ledermann S, Shute R, Knott C, Wells D, Aitkenhead H, **Manickavasagar B**, van't Hoff W, Rees L. Ergocalciferol supplementation in children with CKD delays the onset of secondary hyperparathyroidism: a randomised trial. Clin J Am Soc Nephrol. 2012 Feb; 7(2):216-23

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 by Louise McAlister:
-Low oxalate dietsheet (June)
-Glycaemic Index for children with Bardet-Biedl Syndrome (May)

Louise McAlister and Shelley Cleghorn produced the Renal Dietetic Handbook in July which is a best practice reference guide for renal dietitians.

Journals
Renal journal club is incorporated into weekly team meetings.

Products
Shelley Cleghorn continues to been actively involved with Vitaflo in the formulation of a new renal sip/tube feed for children.

13.5 GUIDELINE/POLICY DEVELOPMENT

Carolyn is working on the British Association for Paediatric Nephrology clinical practice guidelines for CKD-MBD in children with CKD stages 2-5 and 5D together with Dr Rukshana Shroff, Dr Simon Waller and pharmacist, Mandy Wan.

Carolyn started working on a cleft gastro oesophageal reflux pathway with the cleft CNS in February 2012.

Louise McAlister and Vanessa Shaw were actively involved in the development of the Nutrition Policy and the Nutrition Screening Tool for GOSH in April 2011.

14. Renal Psychosocial team annual report 2011/2012

14.1 The psychosocial service

The primary aim of the renal psychosocial service is to address psychological and social difficulties experienced by children, adolescents and their families in the context of physical illness and treatment. It is known that 20% of children with a chronic illness are likely to have a diagnosable mental health problem. Disorders such as depression and anxiety, or family financial/practical stresses can interfere with adherence to medical treatment and affect medical outcomes.

As shown below, referrals to the psychosocial team have increased year on year alongside a substantial *decrease* in staffing. The complexity of psychosocial cases has also increased with more young people requiring intense support, both acutely and for long term psychosocial management.

Staffing

The renal psychosocial team currently has 1.6 WTE members of staff:

Dr Gwynneth Down (0.4 WTE) Consultant Family Psychotherapist,
Liz Nunn Social Worker 1.0 WTE (but 0.2 WTE allocated to pan hospital duty SW responsibilities)
Dr Fionna Bathgate (0.4 WTE).

In addition, Claire Dempster is a 0.5 WTE family psychotherapist specifically for the Home Haemodialysis service which is being developed within Great Ormond Street Hospital.

Until February 2012 the team also had 0.5 WTE of a counsellor post but this was not replaced when the post-holder retired in February 2012. This reduction in psychosocial provision, alongside a significant increase in referrals, affects the service that can be offered. Referral priorities and systems have had to change to accommodate this and unfortunately children and families are waiting longer for their first appointments with us following referral.

All referrals must also now be in written form in order to facilitate prioritisation and allocation to the most appropriate professional in the team. The new system and team awareness of the issues appear to have led to a reduction in total referrals this year.

Number of referrals to renal psychosocial team

	2006	**2007**	**2008**	**2009**	**2009/2010**	**2010-2011**	**2011-2012**
No of referrals to psychosocial team	86	109	123	120	161	186	128
Psychosocial Team WTE	**3.6 WTE** (2003 BAPN figures)					**2.3WTE** Excluding HHD	**1.6 WTE**

14.2 Clinical Services Offered

- *Involvement in multidisciplinary meetings* (regular and adhoc) to contribute to the understanding of children and adolescent's psychological, social and developmental needs alongside medical concerns in multidisciplinary team decision making. There is a weekly psychosocial meeting in which medical, nursing, play specialist and other staff can raise any concerns about children and families and make referrals when appropriate.
- *Assessment and treatment of emotional, behavioural or relational problems* - where issues have arisen from or impact upon medical and surgical care. Examples include poor adherence to treatment, depression, anxiety, procedural anxiety and distress, body image difficulties, trauma, and family conflict linked to treatment regimes. Also helping families to make decisions about treatment options.
- *Assessment and intervention for acute situations of risk* – these may include assessment of risk for self harm, psychotic behaviour or child in need/child protection issues.
- *Proactive pre-transplant assessment and intervention.* All children and families on the transplant programme are seen for psychosocial assessment and preparation for transplant. The aim is to ensure

psychological readiness for the transplant process including intervention around adjustment to illness, adherence and procedural anxiety. In over 40% of cases, psychosocial problems are identified by referrers at point of referral.

Home haemodialysis service

The renal unit at Great Ormond Street Hospital is developing a Home Haemodialysis service and is the first UK service to offer this. Home haemodialysis has many psychosocial advantages for children and families alongside medical improvements. It does however require a high level of family involvement and responsibility. All families meet with the family psychotherapist for routine assessment and preparations for the home based treatment, and are offered support after discharge home. Families are asked to complete measures to assess their wellbeing, quality of life and functioning, before commencing dialysis and at regular stages thereafter. These measures and proposed qualitative research focused on child and family experience of HHD will offer information to complement data about medical outcomes.

Other services

Staff support - Where appropriate, staff are supported to carry out psychosocial interventions with children and families. Staff may also feel supported by being able to share or hand over responsibility for psychosocial aspects of care, enabling them to carry out primary nursing/medical roles and tasks. The psychosocial team offer 'debriefs' or reflective meetings to discuss deaths or major incidents and meets with nurses on and ad hoc basis, to help them deal with the specific psychosocial stresses of the work.

Audit and research

Non direct clinical work within the nephrology service

Although limited by current staffing and clinical demand, the psychosocial team is currently developing a number of audit and research initiatives including a) patient experience survey, b) development of the patient pathway for psychosocial care when children are approaching or in end stage renal failure, c) research exploring child and family experience of home haemodialysis.