GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST

RENAL UNIT THIRTEENTH ANNUAL REPORT

April 2012 to April 2013

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1. INTRODUCTION

This renal unit annual report is the first following the move from our old facilities in Victoria Ward to our brand new Eagle Ward in the Morgan Stanley Building in April 2012. This was made possible by support from The GOSH Charity and generous sponsorship by the BKPA and the Tick Tock Club. In this, our thirteenth 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 2012 and April 2013.

As well as safely and effectively achieving the move to our new unit, we have been able to co locate the haemodialysis day case area into the ward itself. This allows for better cross covering of the outpatient haemodialysis work and ward cover, allowing flexibility of staff according to patient demands. We have a system of rotation of nurses from the ward to the haemodialysis unit so that as many nurses as possible are trained in haemodialysis and can maintain their skills. Another success this year has been the full establishment into our service of our home haemodialysis programme, which is the first such service in the UK. The renovascular service continues to expand and is now attracting patients from all over the world.

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

GOSH NHS Foundation 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 361 beds are arranged in 27 wards and 4 day care units and include 35 intensive care beds in 3 ICU wards (PICU, NICU and CICU). There are 14 operating theatres in use performing over 18,880 operations per year. There are over 259,550 patient visits to GOSH each year (inpatients admissions and outpatients).

The Trust employs a total of 3,725 permanent staff and 412 Bank staff (excluding nursing). The Chief Executive is Mr Jan Filochowski 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.

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 paediatric renal unit in the UK. In the last year, there were 716 admissions to Eagle, the renal ward, 414 admissions to outlying wards, 7061 outpatients, 23 new renal transplants, 34 patients on chronic haemodialysis, 5 patients acute haemodialysis, 15 patients on home haemodialysis and 25 patients on chronic peritoneal dialysis.

The Unit comprises a 14-bedded ward, although currently nursing numbers have allowed us to open only 13. The Dialysis Day Care Unit is now incorporated into the ward and the Outpatient Renal Support Unit is 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 seven transplant surgeons (see below). The renal ward (Eagle) 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, 90% academic appointment and ICH lead
Dr David Long	Principal Research Associate, academic appointment
Prof Robert Kleta	Potter Chair of Nephrology

There is a team of 7 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, Mr Jonathan Olsburgh, Mr Chris Callaghan and Mr Nicos Kessaris, 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 Nurse Kate Sinnott
Renal Dietitians	At any time there is one Specialist dietician attached to the ward and there are rotations through Paediatric Nephrology by two further senior dieticians, giving total of 2 WTE renal dieticians

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

Academic Unit website:
http://www.ucl.ac.uk/ich/research-ich/nephro-urology

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

The Nephro-Urology Unit at ICH currently comprises a Unit Head (Dr Paul Winyard, Reader in Nephrology), a Reader in Paediatric Nephrology (Dr Lesley Rees), a HEFCE Reader (Dr Detlef Böckenhauer), one Principal Research Associate (Dr David Long, Kidney Research UK Senior Non-Clinical Fellow / MRC New Investigator), 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.

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 chronic kidney disease. In addition, the unit has been very successful in academic training of PhD, MD, MSc and both national and international visiting fellows. The unit organises and hosts the prestigious annual Paediatric Nephrology and Urology week,a day for paediatricians with an interest in nephrology and initiated the Kidney Development workshop, which has now expanded into the yearly European Nephrogenesis workshop. The Unit receives funding from Kidney Research UK, Action Medical Research, the Medical Research Council, the Wellcome Trust, 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. We are currently involved in a multicentre EU

Framework 7 Training grant with a PhD Student (Chiara Mari) funded to isolate kidney stem/progenitor cells for repair, regeneration and toxicology studies. Dr Price was recently awarded a GOS/ICH Biomedical Research Centre Fellowship to investigate whole kidney culture in vitro, and we have an Academic Clincal Fellow (Maanasa Polubothu) investigating molecular defects in dysplastic kidneys.
2) Polycystic kidney disease. We have ongoing studies of lectin and galectin-3 in normal and cystic kidney development, using experimental gene therapy *in-vivo* in the laboratory.With Dr David Long, funded by a Kids Kidney Research PhD award to Ms Jenifer Huang, we have also discovered dysregulation of blood and vascular vessels in two models of PKD. This led us to target the lymphatics using specific growth factors, which reduced PKD progression by around 50%. We have patented this invention and are currently investigating other fctors and seeking a commercial partner to exploit the discovery.
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. I am also hoping to set up a dedicated ADPKD clinic to ensure optimal early management for children with this lifelong condition.

Dr. Detlef Böckenhauer and Professor Robert Kleta
Dr Böckenhauer is a clinician scientist, working as a paediatric nephrologist at GOSH and as a HEFCE Clinical Reader 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 previously unrecognised multi-system disorders, including 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 has developed a zebrafish model to investigate potential treatments. Another recent success is the discovery of a gene associated with nephrocalcinosis, which reveals insight into the biology of calcium balance in the kidney tissue.

Dr Daljit K 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.

My research interest is exploring the effects of different dialysis prescriptions on acute and chronic cardiovascular outcomes. In the past we have tested the impact of sodium profiles, UF profiles, prophylactic mannitol, sequential dialysis and intradialytic midodrine on dialysis symptoms and outcomes

We are currently investigating the effects of quotidian dialysis versus conventional on cardiovascular and other health outcomes.

Dr. David Long
The overall aim of my research is determining the underlying causes of renal and vascular disease; and devising new therapeutic strategies to treat these conditions. Currently, over 47,000 people in the UK (1,000 of which are children) suffer from kidney disease; there is no cure and patients require dialysis and transplantation. My research areas include:

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. One recent discovery, was the demonstration that the angiopoietins, vascular growth factors involved in the formation of blood vessels play a key role in this process. Our recent work has demonstrated that modulation of angiopoietins prevents albuminuria and the progression of diabetic kidney disease. We have used a combination of genetic approaches to identify other novel molecules that may play a role in albuminuria and the functional role of these genes is currently being tested using zebrafish.

2) Podocyte cell shape and glomerular disease. We have been investigating 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 molecules which alter this process may impair glomerular development and function and contribute to the progression of kidney disease. Modulating these pathways may be a promising new therapy for renal disease in the future.

3) *Angiogenesis in renal health and disease.* A long-standing research interest is investigating endothelial damage and unsatisfactory vascular repair in chronic kidney disease and whether this is due to disturbance of vascular growth factors. 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, my group is working with colleagues at GOSH to examine vascular growth factors in children with CKD.

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. We are now developing a way of looking at calcium absorption using heavy isotopes of calcium. This is an area that has not been studied previously.

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 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 abnormalities of VEGF and angiopoietins on vascular smooth muscle cell damage and calcification.

Dr Kjell Tullus
Studies:

1. **Hypertension**
    a. We are continuing clinical studies into our large group of children with renovascular hypertension.
    b. We have collected DNA from a large group of children with RVH and together with Dr Bockenhauer and Prof Kleta we will now begin studies into any genetic causes for RVH.
2. **Lupus**
    a. We have in the JSLE consortium published a number of interesting clinical studies into different aspects of lupus.

    b. We are presently studying early vascular changes in children and adolescents with lupus.
3. **Nephrotic syndrome**
    a. We are studying early vascular changes in children with SRNS. They are an important and interesting group as they have chronically very elevated blood lipid levels.

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, and clinical trials of a newer vitamin D analogue and phosphate binder.
I also have an interest in a newer dialysis modality, hemodiafiltration, and have obtained a grant from Kidney Research UK to study the effects of HDF vs conventional hemodialysis on cardiovascular disease and growth in children. This is a multicentre study across all dialysis units in the UK and >20 European dialysis units.
I am on the KDIGO and NICE committees for the development of guidelines for CKD-MBD, as well as the ESPN working group for CKD-MBD. 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.
Translational research: 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 have a PhD student who is further exploring the effects of vitamin D on the vasculature. I also co-supervise a PhD student who is studying the effects of endothelial damage on vascular calcification.

Dr Aoife Waters
Research themes and current projects:

1.Ciliopathies: Understanding the Role of the Spindle Checkpoint Complex in the Pathogenesis of Ciliopathy Phenotypes.
Centrosomes are the major microtubule (MT)-nucleating organelles of mammalian cells and are critical for mitotic spindle formation, orientation and basal body assembly. Centrosomes act as signalling platforms in cell cycle transitions and checkpoints. The molecular intersection between proteins implicated in spindle checkpoint inactivation and ciliogenesis are beginning to unfold. We have recently identified mutations in a kinetochore protein previously implicated in spindle pole recruitment of the spindle checkpoint regulatory complex in a novel embryonic lethal ciliopathy syndrome. Biochemical assays and zebrafish knockdown experiments have suggested a novel pathway for regulators of mitotic spindle formation and the spindle checkpoint activation complex in the pathogenesis of severe ciliopathy-related phenotypes. The objective of future research is to elucidate further the molecular mechanisms underlying the organ phenotypes associated with centrosomal and cilia dysfunction.

2.Haemolytic Uraemic Syndrome: Studies of the Host Biological Determinants Of VTEC/STEC-Associated Hemolytic Uremic Syndrome (HUS).
Haemolytic uraemic syndrome (HUS) is the most common cause of childhood acutekidney injury. In 90% of cases, classical HUS occurs as a single event following infection with Shiga-toxin producing *E Coli*. Between 800 and 1,000 cases are reported each year in England and therefore, compared to other gastrointestinal tract infections, STEC are relatively rare but can be fatal, particularly in infants and young children. Our objective is try to understand why some family members develop HUS as a complication of STEC infection compared to other family members who do not develop HUS. In collaboration with international colleagues, our goal is to achieve a national and international comprehensive VTEC/STEC-Associated HUS disease portfolio that connects databases, registries, biobanks and clinical bioinformatics for the facilitation of studies of the host biological determinants of VTEC/STEC-associated HUS.

3. Proteinuria: Determining the Molecular Mechanisms of Nephrotic Syndrome.
Nephrotic syndrome (NS) is a rare childhood disease with an incidence of 2 per 100,000 children. Clinical manifestations include protein in the urine (proteinuria), resulting from podocyte malfunction. Our aim is to target those patients with NS for whom no further treatment options are available other than dialysis and renal transplantation. Given the critical role of Notch signalling in specifying podocyte cell fate and findings that aberrant podocyte Notch activation results in proteinuria, Notch pathway inhibition proposes to be a potential target for the development of anti-proteinuric therapies. Ongoing research proposes to investigate the role of temporal Notch activation in the development of GS in rodent models of human nephrotic syndrome and whether reversal of GS in these models could be achieved through pharmacological inhibition of Notch.

1.6 CONTACT NUMBERS

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 has a pro-active approach to the seven pillars of clinical governance within the department.

2.1 RISK MANAGEMENT

The renal Risk Action Group (RAG) team meet monthly to review local critical incidents monthly, or immediately if any are deemed 'high risk' and where necessary undertake root cause analyses. Dr Hothi 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. Inter-speciality learning is now encouraged through the new Divisional Quality & Safety Meeting and a monthly medical sisters meeting.

One of our greatest risks this year was ensuring safe integration of Eagle Haemodialysis with Eagle Acute on our new ward in the new Morgan Stanley Building. This is being carefully managed by a number of concurrent projects aimed at reducing variation in practice, developing haemodialysis and plasmapharesis expertise in a greater proportion of the renal nurses and improving situation awareness and the safety climate on the ward. Examples include the introduction of nurses huddles; developing a tool for measuring composite harm; facilitated debriefs in the haemodialysis unit and using SBARD formatted handover sheets to improve communication between doctors and nurses across shifts.

Finally we are hosting a Health Foundation Sponsored project aimed at developing a process for patients and their families to report harm and safety concerns on the ward.

2.2 AUDIT

We have registered 12 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:* ***Completed***
  The aim of this audit was 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 suggest that washed cells do not reduce senstitisation. Lab work with NHSBT has confirmed their lack of benefit.

- *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.
- *Home Haemodialysis clinical outcomes:* ***Ongoing***
  The aim of the audit is to determine the clinical outcomes of children on Home HD 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
- *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.

2.3 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.

***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 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.

2.5 STAFFING AND MANAGEMENT

The renal unit is managed by a multidisciplinary team. Sub speciality care is managed by teams of clinical nurse specialists working alongside renal consultants and we have a nurse consultant in hypertension. This year a part-time consultant was recruited 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. In addition there has a strategy to increase the number of renal nurses that are haemodialysis and plasmapheresis competent. To facilitate this we have recruited a practice educator for the Haemodialysis unit.

2.4 EDUCATION AND TRAINING

A) Nursing
Mandatory and Specific Training is required of all nurses on Eagle Ward 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 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 day of Simulation Training facilitated by the CSPs. These simulation days have been very successful and have been implemented on an ad-hoc system since 2011.

Haemodialysis Rotation

This rotation design has been re-developed to reflect the growing need to train more staff in Haemodialysis 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 include 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 offer 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.

2.5 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 are hosting an improvement project funded by the Shine Award from the Health Foundation. The project is called 'families reporting patient safety concerns in a children's hospital'. We are using a questionnaire called the 'Family Reporting System' on a laptop to record how frequent and how serious events are. We then deal with any problems quickly to ensure patient safety. We are currently testing the system on Eagle Ward and if it works it is hoped to expand it to all wards. We are also developing an app for mobiles so any episodes perceived as dangerous by families can be reported there and then.

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 tested and have now implemented email communication for the hypertensive, Home HD and nephrotic patients.

We have developed several local information leaflets for families and children. In addition Eileen Brennan, our nurse consultant is part of a national group developing information leaflets for renal conditions. This project is called '*Info Kids'* and is sponsored and supported by the Royal College of Paediatrics and Child Health.

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 describe the

set-up and emergency alarms for 2 HHD circuits and finally DVD 4 talks about dialysis access

Finally we also now have a parent representative on consultant interviews.

2.6 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 this 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 tool for measuring composite harm.
- 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
- Improving the admission to coding process

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 2 years they have recruited 12 patients, 10 from GOSH, 2 from Evelina Hospital, London. They are now successfully using a number of circuits and his has enabled them to lower the weight criteria from 20kg to 12kg.

3. OUTPATIENTS

3.1 WEEKLY OUTPATIENT CLINICS

	CLINIC	CONSULTANT
MONDAY A.M.	Low Clearance/Dialysis	Dr Rees Dr Shroff Dr Ledermann
	Home Haemodiaylsis Clinic	Dr Hothi
TUESDAY A.M.	Generalised and specialised Nephrology (Tubular)	Dr van't Hoff Dr Bockenhauer Prof Kleta
	Generalised and specialised Nephrology (hypertension/vasculitis)	Dr Tullus
	General Nephrology	Dr Hothi
	General Nephrology	Dr Waters
	Transplant Clinic	Dr Marks
	Pre-Transplant Clinic (Monthly)*	Dr Marks
	Transplant Surgeon's Clinic	On-call surgeon
	Joint Renal Stone Clinic (monthly)	Dr van't Hoff Ms Smeulders
	Antenatal diagnosis (Monthly)	Dr Winyard
	Haemodialysis Clinic (monthly)	Dr Rees Dr Shroff
	Vascular Access Clinic (monthly)	Dr Shroff and Mr Calder
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
	Renal genetic clinic (monthly)	Dr Barnicoat/Dr Bockenhauer
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
FRIDAY A.M.	Haemodialysis Clinic (monthly)	Dr Shroff

* 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 7061. The breakdown into clinics is shown in the table.

Clinic	**Patient Numbers**											
	2001-2	**2002-3**	**2003-4**	**2004-5**	**2005-6**	**2006-7**	**2007-8**	**2008-9**	**2009-10**	**2010-11**	**2011-12**	**2012-13**
Transplant	625	771	873	736	799	743	858	897	1034	1119	1080	1122
Nurse Led Transplant	443	506	734	542	518	467	524	1387	1328	1231	1212	1108
Low Clearance/ Dialysis	507	543	859	610	636	638	665	694	749	650	730	752
PreTx & GKRLTX						93	71	84	119	84	123	102
General and Specialist Nephrology	3243	2467	4065	3199	3444	3194	3382	3464	3113	2929	3509	3126
Nephrotic Syndrome	405	481	692	468	400	321	344	389	446	479	454	425
Stone	69	50	88	53	40	40	23	36	79	153	190	199
Blood Pressure Monitoring			23	51	65	78	94	109	193	195	208	227
Total	**5292**	**4818**	**7334**	**5674**	**5902**	**5738**	**5962**	**7060**	**7061**	**7166**	**7506**	**7061**

Due to the expansion of services, the use of telephone clinics has greatly increased:

Clinic	**2012-13**
Hypertension telephone clinic	135
Nephrotic telephone clinic	199
Total	**334**

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 80-100
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
Chelsea &Westminster	AW	5	24	Clinic just started
Malta**	RS	500	2 (on 2 consecutive days per year)	37 outpatients + 6 inpatients
Reading	WvH	40	3	30
UCLH	PW	1.3	12	Approx 120-144

**Work is underway to re-establish this service in the coming year – do we really need this sentence now? Clinic is established and running for 2 yrs!

4. INTERVENTIONAL RADIOLOGY

The interventional radiology team regularly performs procedures for renal patients.

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
2012-13	50	67	0	18	0	135

One transplant patient (1.5%) developed self-limiting clot retention (i.e. not requiring bladder catheterisation. One patient who underwent biopsy of a native kidney (2%) developed a perinephric haematoma, but this required no treatment.
There were no other major complications of renal biopsy in 2012-13.

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
2012-13	4	40	44

These numbers exclude access for other indications (e.g. stem cell harvest).
Permanent (tunnelled) HD catheter insertion: One procedure (2.5%) was abandoned after induction of anaesthesia but before starting the operation, due to bleeding from

previous venepuncture and incision sites. There were two catheters (5%) with poor flows in the first few days after insertion, and two (5%) cases of brachiocephalic vein obstruction.
Temporary (non-tunnelled) HD catheter insertion: One catheter (25%) had poor flows in the first few days after insertion.

4.3 ARTERIAL INTERVENTIONS

Angiographic procedures are performed for patients with suspected or confirmed renovascular hypertension and associated arterial disease. This activity appears to be increasing at Great Ormond Street Hospital. (We have already done 25 such procedures in the first 4 months of 2013-14.)

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
2012-13	11	24	35

RVH = renovascular hypertension

One patient (3%) had groin pain following an angioplasty (with no pseudoaneurysm), which persisted for several months before resolving spontaneously. One patient (3%) had self-limiting post-operative back pain after an angioplasty, which was treated with analgesia only. There was one instance (3%) of laryngospasm in the recovery area.

4.4 VENOUS INTERVENTIONS

Year	Diagnostic venograms for nephrology	Fistulagram and/or fistulaplasty	Recanalization, venoplasty and/or stenting	Thrombolysis or thrombectomy 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
2012-13	3	0	3	1	10	17

There were no complications of venous interventional procedures in nephrology patients in 2012-13. The most likely explanation for the decrease in the need for recanalization, venoplasty and/or stenting procedures over the last 10 years is that now almost all dialysis catheters are inserted in interventional radiology, using a percutaneous ultrasound-guided technique, which appears to minimise the risk of catheter-related venous occlusion.

5. Inpatients

5.1 Admissions to Victoria/Eagle Ward

Age (yrs)	2004-05		2005-06		2006-07		2007-08		2008-09		2009-10		2010-11		2011-12		2012-2013	
	Total No	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	**%**	**Total No**	%	**Total No**	%	**Total No**	%
<2	**79**	13	**73**	14	**72**	13	**61**	11	**85**	15	**87**	16	**56**	11	**72**	22	**141**	20
2-<5	**106**	17	**84**	16	**105**	19	**90**	16	**81**	14	**99**	18	**102**	20	**54**	16	**128**	18
5-<10	**146**	23	**110**	21	**120**	22	**101**	18	**134**	23	**109**	19	**93**	18	**66**	20	**154**	22
10-<15	**167**	27	**153**	30	**169**	30	**161**	29	**153**	27	**137**	24	**131**	25	**77**	23	**162**	23
15 +	**124**	20	**97**	19	**88**	16	**148**	26	**124**	21	**129**	23	**131**	25	**63**	19	**131**	18
Total	**622**	100	**517**	100	**554**	100	**561**	100	**577**	100	**561**	100	**513**	100	**332**	100	**716**	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	2012-13
Victoria/Eagle	618	563	585	622	517	554	561	577	561	513	332	716
Other	343	307	316	317	317	349	249	261	118	93	100	414
Total	961	870	901	939	834	903	810	838	679	606	432	1130

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 THERAPY

Total numbers of children on RRT was 204 on 1/4/13, The prevalence for the different modalities and age breakdown is shown below.

Age, yrs	<2	2-5	5-10	10-15	>15	total
Haemodialysis						
2002	0	0	2	5	6	13
2003	0	1	2	6	5	14
2004	1	2	1	5	5	14
2005	1	2	2	5	5	15
2006	3	1	2	7	4	17
2007	1	0	1	5	4	11
2008	1	0	2	4	6	13
2009	2	2	1	6	6	17
2010	1	5	2	1	7	16
2011	0	4	3	2	9	18
2012	3	1	2	4	6	16
2013	4	1	3	3	2	13
Home Haemodialysis						
2011	0	0	1	2	1	4
2012	0	0	2	3	2	7
2013	0	2	3	3	5	13
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
2013	0	0	0	0	2	2
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
2013	7	3	2	9	2	23
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
2013	1	15	35	51	50	153

6.2 CHRONIC PERITONEAL DIALYSIS

There were a total of 25 patients in 2012-2013. Their age ranges are shown.

Annual figures-age breakdown:

	2004-5		**2005-6**		**2006-7**		**2007-8**		**2008-9**		**2009-10**		**2010-11**		**2011-12**		**2012-13**	
Age, yrs	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	%	**total**	%	**total**	%	**total**	%
<2	**3**	8	2	5	**4**	10	**6**	18	**6**	18	**12**	30	**4**	14	**6**	14	**7**	28
2-5	**6**	16	2	5	**5**	12	**4**	12	**6**	18	**7**	18	**7**	24	**7**	24	**3**	12
5-10	**7**	19	10	25	**9**	22	**4**	12	**4**	12	**8**	20	**4**	14	**5**	14	**2**	8
10-15	**11**	30	10	25	**12**	29	**13**	38	**11**	32	**10**	25	**7**	24	**6**	24	9	36
>15	**10**	27	16	40	**11**	27	**7**	20	**7**	20	**3**	7	**7**	24	**7**	24	**4**	16
Total	**37**	100	40	100	**47**	100	**34**	100	**34**	100	**40**	100	**29**	100	**31**	100	**25**	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	12-13
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	25 14
At year end	28	17	24	29	23	23	18	20	17	19	17	16	10	14
Transferred to HD	3	5	7	2	5	5	6	2	5	4	8	6	7	3
Transplanted	10	16	7	7	15	11	12	14	8	6	13	6	13	5
Adult unit		4	2	3	1	2	3	0	0	2	0	0	0	1
Improved		0	0	0	0	0	1	1	2	0	0	0	0	0
Deaths	1	1	0	1	1	0	0	1	1	3	2	0	1	1

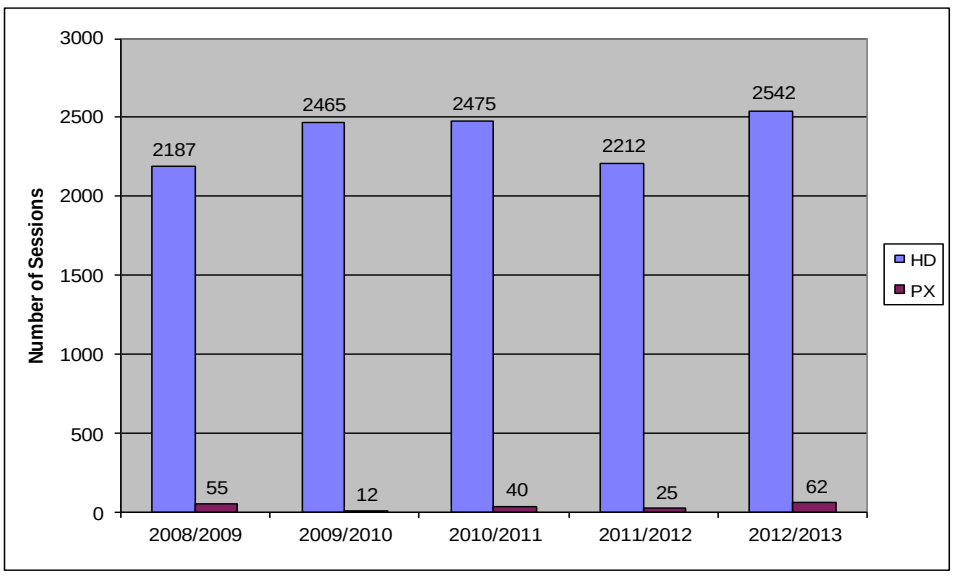
6.3 CHRONIC HAEMODIALYSIS

During the year 2012/2013 there were 2604 sessions in 44 children, 2542 sessions of HD (acute and chronic) and 62 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
01.04.13	2	168

5 year activity



ACUTE KIDNEY INJURY AND TREATMENT (INCLUDING PLASMAPHERESIS)

7.1 ACUTE HAEMODIALYSIS

5 children required acute haemodialysis (4 female: 1 male). Their mean age was 10.7 years, range 0.78 to 17.11 years. These figures exclude children with acute kidney injury in PICU and NICU.

Diagnosis	2005-6	2006-7	2007-8	2008-9	2009-10	2010-11	2011-12	2012-13
HUS(D+)		2	1	1		2		
HUS (D-)		1		1				
MCGN/RPGN	1				1			
SLE	1		1		1			1
Post heart Tx								
FSGS		1			1		1	
RSV							1	
Rhabdomyolosis						1	1	
Acute on CRF			1	1				
Sepsis		1				1		2
Post surgery		1						
Transplant rejection		1				1	1	
Tumour lysis		1	1					
MMA								
Drug toxicity	1							
ATN	2	1	3	3	1			2
Total Pts	**5**	**9**	**7**	**6**	**4**	**5**	**4**	**5**
Total number of sessions			**34**	**82**	**164**	**22**	**14**	**44**

7.2 PLASMA EXCHANGE

5 children were treated with plasma exchange (5 male; 0 female). The mean age was 8.9 years and range 1.9-15.7 years.

Diagnosis	2008/9		2009/10		2010/11		2011/12		2012/13	
	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	2	9			1	7				
HSP							1	3		
MPA										
Post tx FSGS	2	49			1	25	2	22	2	51
MPGN										
RPGN			1	11						
Vasculitis										
HUS D+										
HUS D-	1	37			1	5			1	6

GvH			1	1						
Anti-GBM										
Tx Rej									1	5
Goodpastures										
Wegener's										
FSGS										
CNS			1	1						
ABOi heart										
Test							1	1	1	1
Total	**5**	**95**	**3**	**13**	**6**	**40**	**4**	**26**	**5**	**62**

7.3 NUMBER AND AGES OF PATIENTS TREATED WITH PERITONEAL DIALYSIS FOR ACUTE KIDNEY INJURY

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**	**2012-13**
<1 year	1	3	1		1	3	2	0	0		2	2
1- <5 years	1	0	3		2	4	2	4	8		0	0
≥ 5 years	3	2	1		0	6	2	2	7		0	0
Total	**5**	**5**	**5**		**3**	**13**	**6**	**6**	**15**	**8**	**2**	**2**

8. RENAL TRANSPLANTATION

Details of patients undergoing renal transplantation 1998 – 2013

	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
01/04/2012 to 2013	13	0	8	2	23	17

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

9. RESEARCH

9.1 PAPERS :

1 April 2012 – 31 December 2012 publications

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Dr Aoife Waters
Publications 2012:

1. A founder missense mutation in *VPS37A* causes hereditary spastic paresis.
Yifat Zivony-Elboum,Wendy Westbroek, Nehama Kfir, David Savitzki,Yishay Shoval, Assnat Bloom, Raya Rod, Morad Khayat, Bella Gross, Walid Samri, Hector Cohen, Vadim Sonkin, Tatiana Freidman, Dan Geiger, Aviva Fattal-Valevski, Yair Anikster, **Aoife M. Waters,** Robert Kleta & Tzipora C. Falik-Zaccai. **J Med Genet 2012** Jul;49(7):462-72.

2. *Integrin α3* mutations cause kidney, lung and skin disease.
Has C, Sparta G, Kiritsi D, Weibel L, Moeller A, Vega-Warner V, **Waters, A**, He Y, Esser P, Straub B, Hausser I, Bockenhauer D, Dekel B, Hildebrandt F, Bruckner-Tuderman L, Laube G **N Engl J Med 2012** Apr 19;366(16):1508-14.

3. Comparison of 173 disease exomes to 1,000 Genome data suggests a role for private loss of function insertions and deletions in disease genetics. Francesco Lescai, Silvia Bonfiglio, Chiara Bacchelli, Estelle Chanudet, **Aoife Waters**, Sanjay M. Sisodiya, Dalia Kasperavičiūtė, Julie Williams, Denise Harold, John Hardy, Robert Kleta, Sebahattin Cirak, Richard Williams, John C. Achermann, John Anderson, David Kelsell, Tom Vulliamy, Henry Houlden, Nicholas Wood, Una Sheerin, Gian Paolo Tonini, Donna Mackay, Khalid Hussain, Jane Sowden, Veronica Kinsler, Justyna Osinska, Tony Brooks, Mike Hubank, Philip Beales and Elia Stupka. **PLoS One. 2012**;7(12):e51292. doi: 10.1371/journal.pone.0051292.

4. Growth in *PHEX*-associated X-linked hypophosphatemic rickets: the importance of early treatment. Quinlan C, Guegan K, Offiah A, Neill RO, Hiorns MP, Ellard S, Bockenhauer D, Hoff WV, **Waters AM**.
Pediatr Nephrol. 2012 Apr;27(4):581-8.

5. Is complement the culprit in infection-induced HUS?
Johnson SJ, **Waters AM**.
Immunobiology 2012 Feb;217(2):235-43.

6. Notch regulates nephrin endocytosis through dynamin-mediated endocytosis.
Waters AM, Wu Megan, Egan SE, Robinson L, Piscione TD. **J Am Soc Nephrol 2012** Jan;23(1):27-35.
7. An enzyme-linked immunosorbent assay (ELISA) for quantification of human collectin 11 (CL-11, CL-K1). Selman L, Henriksen ML, Brandt J, Palarasah Y, **Waters A**, Beales PL, Holmskov U, Jørgensen TJ, Nielsen C, Skjodt K, Hansen S. **J Immunol Methods. 2012** Jan 31;375(1-2):182-8.

Grants
Medical Research Council, UK Clinical Scientist Fellowship
Title: Determining the Role of Canonical Notch Signalling in the Regulation of the Glucocorticoid Receptor in SRNS
Award: £1,101,047
Year: 2013-2017

9.2 GRANTS

Research Title	Name
The role of the canonical notch effector, HES-1, in the regulation of the glucocorticoid receptor	Dr Aoife Waters
Biomarkers of clinical transplantation tolerance - Bringing markers of transplantation tolerance into the clinic	Dr Stephen Marks
Defining the role of the spindle checkpoint complex in the pathogenesis of ciliopathy phenotypes	Dr Aoife Waters
STEC-HUS Positive Rare Disease Working Group	Dr Aoife Waters
RITUXILUP - an open label randomised multicentre controlled trial of Rituximab and mycophenolate mofetil without oral steroids for the treatment of lupus nephritis	Dr Stephen Marks

Juvenile SLE Investigation - A Genetic Analysis of Systemic Lupus Erythematosus (SLE) in Children	Dr Stephen Marks
MCRN211 / CCRN 1101 (Atypical Hemolytic Uremic Syndrome) - An Observational, Multi-Center, Multi-National, Long Term Follow-Up Study of Atypical Hemolytic Uremic Syndrome (aHUS) Patients Treated with Eculizumab in a Prior Clinical Study	Dr Lesley Rees
Targeting the lymphatics as a therapy for polycystic kidney disease	Dr David Long
Diagnostic Modelling for Auditory Processing Disorder	Dr Tony Sirimanna
INVESTIGATION OF THE MOLECULAR MECHANISMS OF NEPHROTIC SYNDROME	Dr Aoife Waters
Identifying the molecular basis of polycystic kidneys associated with hyperinsulinaemic hypoglycaemia (HiPKD)	Dr Detlef Bockenhauer
Bladder Exstrophy and Epispadias Research Initiative	Mr Peter Cuckow
Transcutaneous very high resolution ultrasound to define vascular changes in children with Chronic Kidney Disease	Dr Rukshana Shroff
MCRN150: a 12-week randomized, open-label, active comparator period followed by a 12-week safety extension period to evaluate the safety and efficacy of fesoterodine in subjects aged 6 to 16 years and >25 kg with symptoms of detrusor overactivity associated with a neurological condition (neurogenic detrusor overactivity)	Dr Divyesh Desai
Cytomegalovirus disease Management in kidney transplant patients: role of the renal pharmacist	Dr Josie Solomon
Angiopoietin-2 as a biomarker and mediator for cardiovascular disease in children	Dr David Long
Renovascular hypertension 30 years review	Dr Kjell Tullus
Glomerular number and microalbuminuria	Dr David Long
MCRN230: A Long-Term Open-Label, Safety and Superior Effectiveness Study of Cysteamine Bitartrate Delayed release Capsules (RP103) in Patients with Cystinosis	Dr William van't Hoff
CCRN 1093 (aHUS) - An observational, non-interventional multicenter, multinational study of patients with Atypical HemolyticUremic Syndrome (aHUS	Dr Lesley Rees

Registry)	
Genetics of renovascular malformations	Dr Detlef Bockenhauer
Using zebrafish to examine novel genes implicated in albuminuria	Dr David Long
Targeting the lymphatics as a therapy for polycystic kidney disease	Dr Paul Winyard
Review of Hypospadias Literature	Mr Peter Cuckow
Normative Data collection for Parrot Test	Dr Tony Sirimanna
A Multi-centre, Randomised, Controlled, Parallel Group, Open-label Study Evaluating the Efficacy, Safety and Tolerability of Three Doses of Colestilan (MCI-196) Compared to Standard Therapy with a Calcium-based Phosphate Binder, in Paediatric Subjects with Chronic Kidney Disease Stage 5 on Dialysis and with Hyperphosphataemia	Dr Lesley Rees
Characteristics of Drug Related Problems (DRPs) and Effect of Medication Review in Resolving the DRPs at Paediatric Nephrology Clinics	Dr Lesley Rees
The effects of haemodiafiltration (HDF) vs conventional haemodialysis (HD) on growth and cardiovascular markers in children 3H (HDF, Hearts and Height) study	Dr Rukshana Shroff
MCRN221: A Multi-centre, Open-label study evaluating the safety and tolerability of Colestilan (MCI 196) in paediatric subjects with chronic kidney disease stages 3b to 5 and with Hyperphosphataemia not on dialysis	Dr Lesley Rees
MCRN223: A Multi-centre, Flexible Dose, Parallel Group, Open-Label, Active Control (Calcium based phosphate binder), Long-term Extension study evaluating the efficacy, safety and tolerability of Colestilan (MCI-196) in paediatric subjects with Hyperphosphataemia and with either chronic kidney disease stage 5 on dialysis or chronic kidney disease stage 3b to 5 not on dialysis.	Dr Lesley Rees
The PREDNOS 2 study - Short course daily prednisolone therapy at the time of upper respiratory tract infection in children with relapsing steroid sensitive nephrotic syndrome	Dr Detlef Bockenhauer
Endothelial dysfunction in children with SRNS	Dr Kjell Tullus
HARC - Exploring the Genetics of Renal Developmental Disease (version 1)	Dr Detlef Bockenhauer

Cardiovascular Disease in Chronic Kidney Disease - Version 1	Dr Rukshana Shroff
VEGF-C: a new therapy for polycystic kidney disease	Dr David Long
Growing 3-dimensional human kidneys	Dr Paul Winyard
A randomised trial to compare effects of lower versus higher levels of blood pressure control on target organ damage in children with chronic kidney disease	Dr Rukshana Shroff
Developing comprehensive genetic testing for renal diseases	Dr Detlef Bockenhauer
Imaging biomarker exploration for Prednisolone induced brain changes in children with idiopathic steroid sensitive nephrotic syndrome	Dr Detlef Bockenhauer
Secreted frizzled-related protein 2: a new therapeutic target for glomerular disease	Dr E Papakrivopoulou

10. NEPHRO-UROLOGY ACADEMIC PROGRAMME

Seminar Room, Renal Unit, Eagle Ward, Level 7, Morgan Stanley 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**
17/4/12	Preparations for move to eagle ward Eileen Brennan			
24/4/12	Renal biopsy meeting	Prof Neil Sebire	Home HD video	Dr Daljit Hothi Lyndsey Stronach
1/5/12	**Transplant Nephrectomy for the Failing Renal Allograft: predictors and outcomes**	**Dr Susie Minson**	Audit of peritoneal dialysis	Nurse specialists Michelle Cantwell Cecelia McNeice
8/5/11	Practise session for RCPCH and RA	Those presenting papers	Audit of haemodialysis and plasmapheresis	Sisters Liz Wright and Lianne Pilgrim
17/5/11	Joint meeting with the Evelina Children's hospital at the Evelina Note Thursday			
22/5/11	RCPCH meeting			
29/5/11	Renal biopsy meeting	Prof Neil Sebire	Renal transplant audit	Clinical nurse specialists Suzanne Bradley and
5/6/11	Bank holiday			
12/6/11	Renal Association, no meeting			
19/6/11	Renal biopsy meeting	Prof Neil Sebire	Audit of living donation	Clinical nurse specialists Maria Scanes and Katie Knapp
28/6/11	Bipartite meeting at ICH **Note Thursday**			
3/7/12	ATTOMIC	Dr Stephen Marks	Presentation of Renal Information database	Dr Steve Marks Mr David Bowen
10/7/12	Renal biopsy meeting	Prof Neil Sebire	Presentation of Renal Information database	Dr Steve Marks Mr David Bowen
17/7/12	Vitamin A in CKD	Bahee Manickavasagar	Presentation of Renal Information database	Dr Steve Marks Mr David Bowen

Seminar Room, Eagle ward, Level 7, Morgan Stanley Building,

Great Ormond Street Hospital for Children

(Tuesday or Thursday afternoon 2.30pm – 4.30 pm)

Date	**Topic** 2.30 – 3.30	**Speaker**	**Topic 3.30-4.30**	**Speaker**
4/9/12	ESPN meeting, Krakow			
11/9/12	Renal biopsy meeting	**Prof Neil Sebire**	Journal club	Dr Aoife waters
			Case report	Dr Ramnath Balasubramanium
18/9/12	Journal club	Dr William van't Hoff	Management of the failing renal allograft	**Dr Susie Minson**
	Case report	Dr Pallavi Yadav		
25/9/12	Journal club	**Dr Rukshana Shroff**	Overview of CVVH and citrate anticoagulation	Dr Dal Hothi
	Case report	**SHO**		
2/10/12	***2.30 – 3.30pm*** **Renal biopsy meeting**	**Prof Neil Sebire**	Lymphatics and PKD	**Dr David Long**
9/10/12	Journal club	**Dr Detlef Bockenhauer**	Vitamin A in CKD	Bahee Manickavasagar
	Case report	**SHO**		
18/10/12	**Bipartite meeting at the Royal Free (note Thursday)**			
23/10/12	Half term, no meeting			
30/10/12	Kidney information technology meeting Dr Steve Marks			
6/11/12	***2.30 – 3.30pm*** **Renal biopsy meeting**	Prof Neil Sebire	Enteral feeding of the over 2s	Dr Helen Jones
15/11/12	Joint meeting with Evelina, at ICH Note Thursday			
20/11/12	BAPN AGM, Birmingham			
30/11/12	Nephrology Day for general paediatricians at the ICH **(note Friday)**			
6/12/12	Bipartite meeting at ICH (note thurs) **Seminar Room 4, ground floor, Philip Ullmann Wing, ICH**			

11/12/12	***2.30 – 3.30pm*** **Renal biopsy meeting**	Prof Neil Sebire	**The KKR Teaching Parents Study**	Dr Veronica Swallow, University o Manchester
18/12/12	**BAPN meeting in Birmingham (all day)** Note Friday			

Outcome of non-heart beating donor transplantation Mr John Taylor
ASN 30th -4th nov

Nephro-Urology Academic Programme
Seminar Room, Renal Unit, Level 7, Morgan Stanley Building,
Great Ormond Street Hospital for Children

Date	Topic 2.30 - 3.30 pm	Speaker	Topic 3.30 – 4.30pm	Speaker
8/1/13	Journal club (2 papers)	Dr Bockenhauer Dr Rees	Case Report	Dr Caroline Maynes
15/1/13	Renal biopsy meeting	Dr Neil Sebire	HLA sensitisation by blood	Dr J J Kim
22/1/13	Planar Cell Polarity in kidney development and disease	Jenny Papakrivopoulou	Audit of deaths and complaints	Nurse Consultant Eileen brennan
31/1/13	Bipartite meeting with UCL ICH **Note Thursdays**			
5/2/13	Case Report	Dr Nur Ozyilmaz	Biopsy in Congenital nephrotic syndrome	Dr Jameela Kari
14/2/13	Joint meeting with the Evelina at the Evelina Note Thursday			
19/2/13	Renal biopsy meeting	Dr Neil Sebire	'Examining the Effects of Vitamin D Receptor Agonists on Vascular Smooth Muscle Cell Calcification'**.**	Dr Nicholas Ware
26/2/13	Journal club (2 papers)	Dr Rukshana Shroff Dr Stephen Marks	Immunosuppressive drugs in the pipeline	Catherine Clair Astellas Senior Medical and Scientific Liaison
5/3/13	**Food allergy post-transplantation**	**Dr Steve Marks**	Case Report	Dr Ramnath Balasubramanian
12/3/13	Audit of OPD clinic	Dr W van't Hoff to audit Dr Tullus nephrotic clinic	Angiopoietins and endothelial function	Alexandra Todd
19/3/13	Renal biopsy meeting	Dr Neil Sebire	Journal club (2 papers)	Dr Hothi Dr Kjell Tullus
26/3/13	Easter holidays			
2/4/13	Easter holidays			
8/4/13	Course week at the ICH			

11. AUDIT

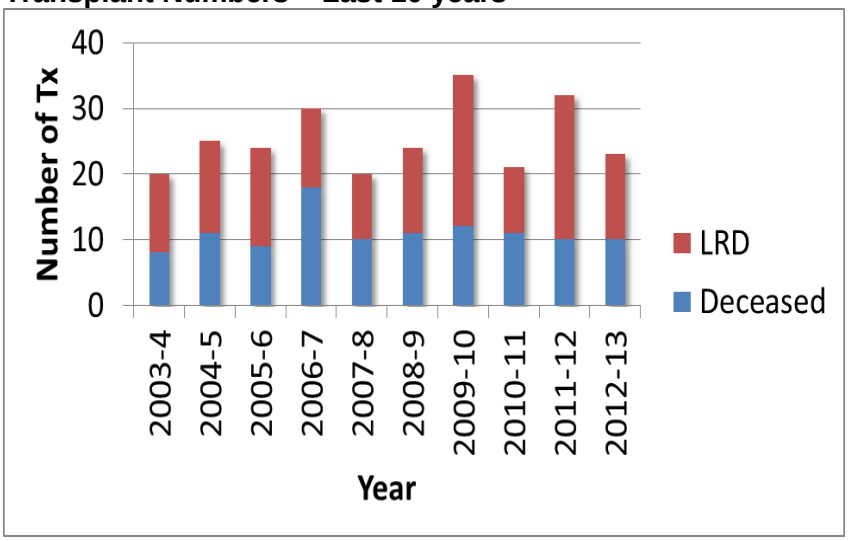
11.1 Pre Transplant Audit, Living and Deceased Donor, April 2012-March 2013

Maria Scanes and Katie Knapp Clinical Nurse Specialist

Transplant Numbers

- 23 transplants in 23 children
  - 13 Living donor (57%)
  - 10 Deceased donor (43%)
  - 3 patients NLKDSS runs (HF 3, MA 3, RC 2)
    RC = overseas patient

Transplant Numbers – Last 10 years



Recipient Demographics

- Male 16 (70%)
- Female 7 (30%)
- NHS 22
- 1 IPP from UAE

Recipient Age Demographics

- Mean age at Transplant = 9.2 years
  - 8.6 years (LD Transplant)
  - 10.7 (DD Transplant)
- Median Age at Transplant = 11.3 years
  - 9.0 years (LD Transplant)
  - 9.4 (DD Transplant)

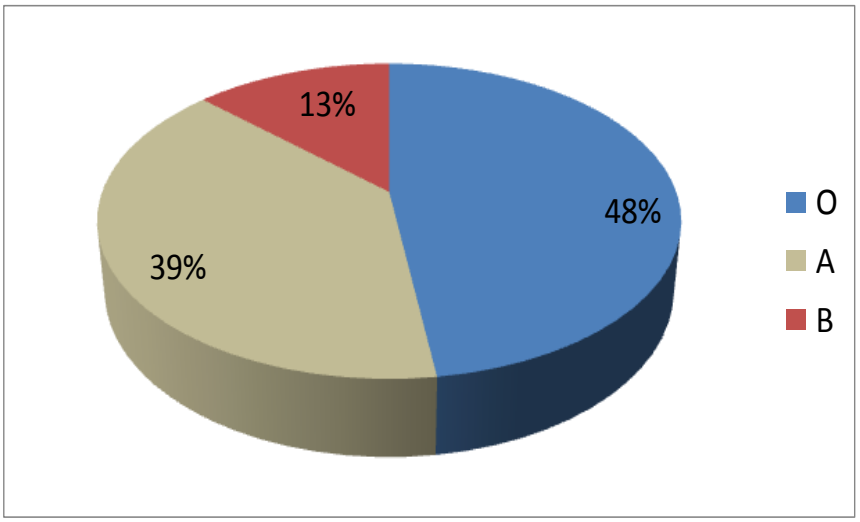
  (Range 1.5 – 15.9 years)

- 5 children under 3 years. 4 of which were LRD Tx

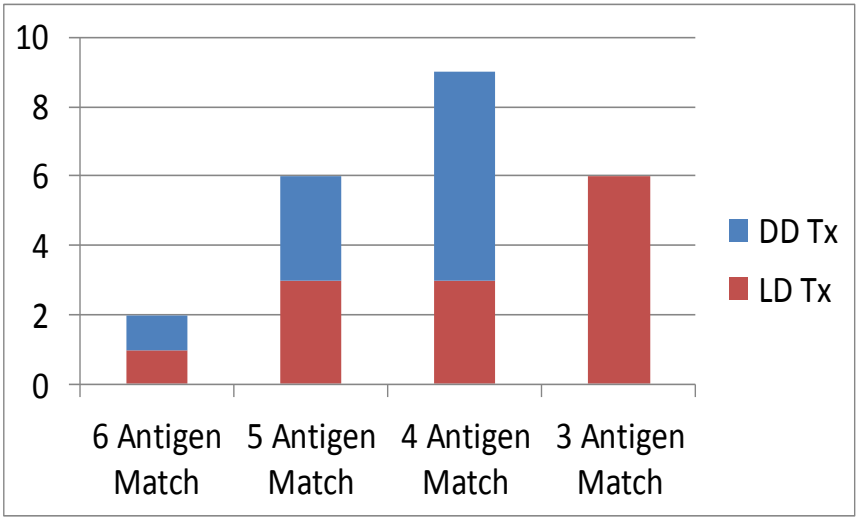
Modality at Time of Transplant

- HD 7 30% (5 LDTx)
- PD 5 22% (2 LDTx)
- Pre-emptive 11 48% (6 LDTx)
- Of 13 LDTxs 6 (46%) were pre-emptive

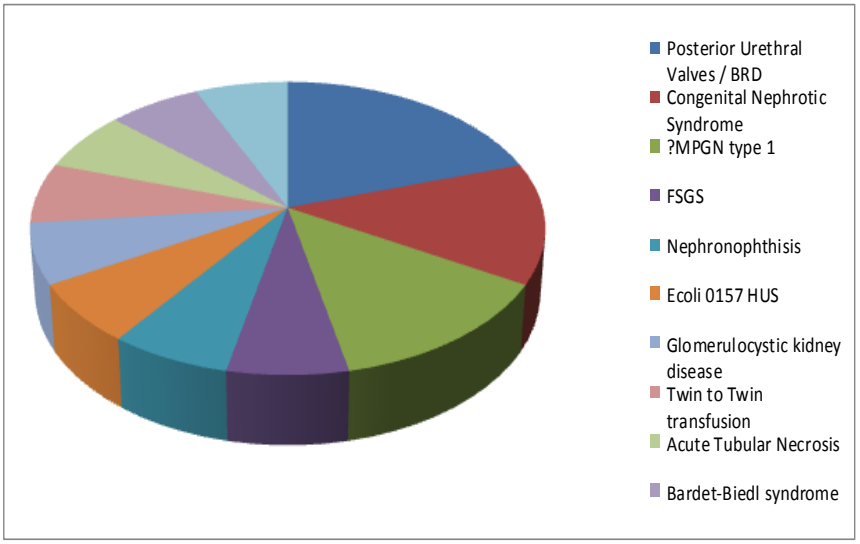
Recipient Blood Groups



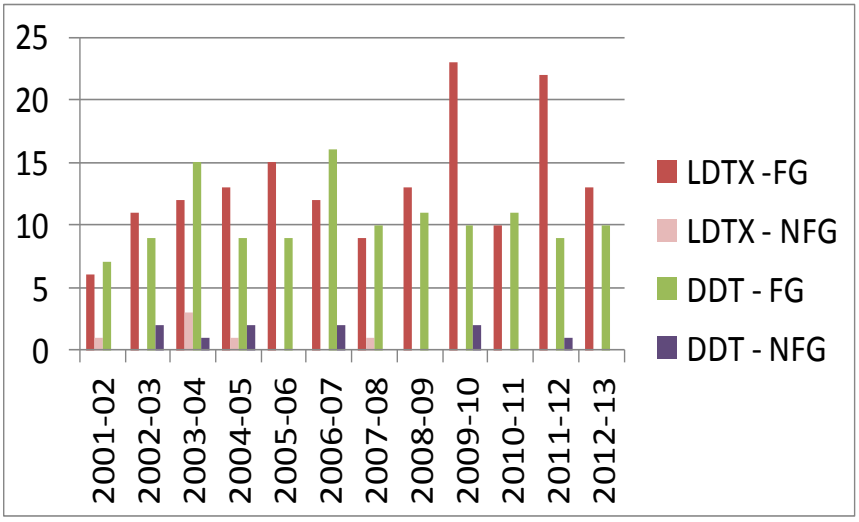
LD v DD Matching



Recipient Diagnoses



End of Year Outcomes



Cold Ischaemic Times

- Live Related Transplants
  - Mean = 4.5 hours

  (Range 3.5 - 5.5 hours) Data on 9 patients (70%)
- Deceased Donor Transplants
  - Mean = 11 hours

  (Range 7.5 - 23 hours) Data on 9 patients (90%)

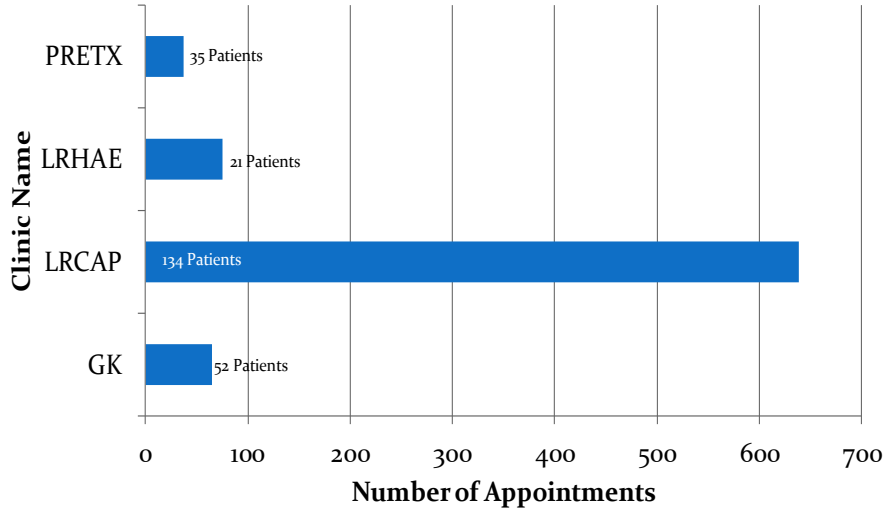
Pre-Emptive v Non Pre-Emptive

- Transplants were pre-emptive (48%)
- 6 of these were living donors

- Non pre-emptive transplants included:
  - babies

- 1 Private Patient (complicated work-up)
- Crash Landers
- 1 patient transferred from another centre

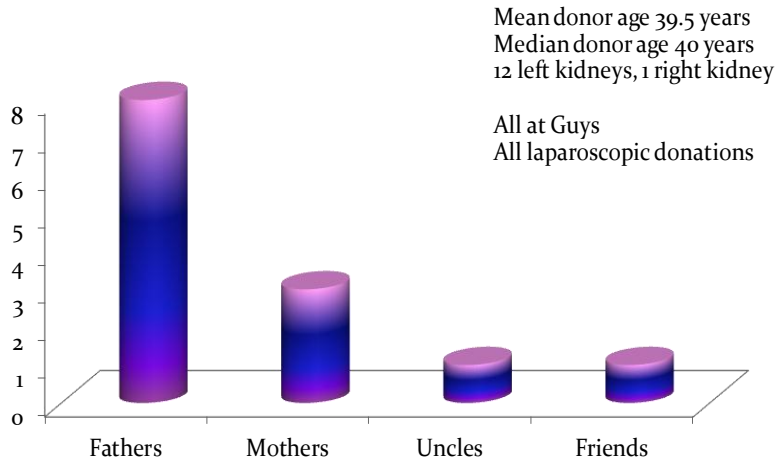
Clinic Activity



New Recipient Referrals

- LRCAP - (total patients seen 134, total appts 639)
- LRHAE – (total patients 25, total appts 75)
- HHD – 0 (transferred from LRHAE, total patients tx work up/on-call 6)
- Approx 70 new referal's for transplant work-up

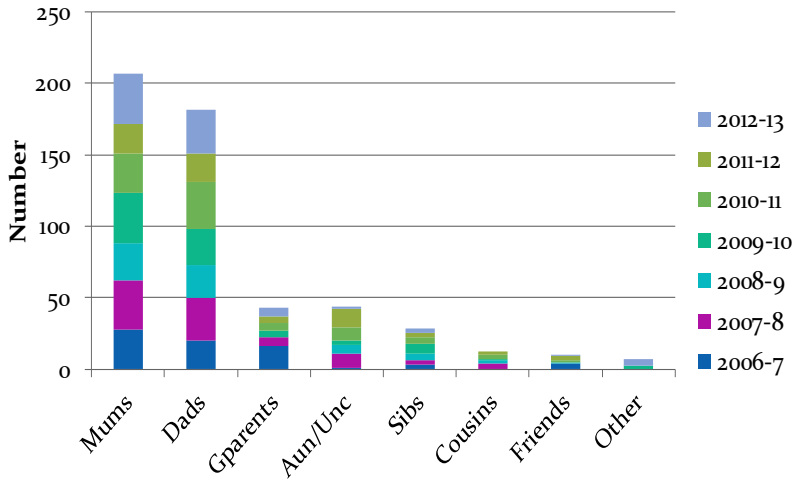
Living Donor Information



Deceased Donor Transplant

- Complete Data on 7 recipients (70%)
- Donor Cause of Death
  - 6 ICH
  - 1 Meningitis
  - 3 not stated

Donor Pool



Donor Suitability

Reason	Number
Ongoing Referral	31
Other Donor Used	11
Medically Unsuitable	8
Positive Cross Match	3
Enquiry Only	7
Social	11
ABOi	6
LDTx	4
25 Donors (20%) did not proceed to work up due to medical or social instability	

On Call Activity

- 12 patients activated on-call
- 4 of who received transplants within the same audit year.
- 18 patient's on-call at end of audit year + 1 patient suspended (social)
- Average waiting time 262.8 days

DD's v LRD's

- Inpatient stay Deceased Donor
  - 13.7 days (1 x relapse)
- Inpatient stay Living Donor
  - 14.6 days (1 x relapse + 1 x seizures + 1 x diabetes teaching)

- DD Average creatinine at end of year: 79
  - (Range 35-125)
- LD Average creatinine at end of year: 56
  - (Range 34-210)

Work in Progress

- 4 International Private Patients'
- 8 out of centre / overseas (ROI, Denmark, Greece, Holland)

- 2 potential ABOi (MA, FR)
- 1 currently listed for paired exchange (MA)
- 3 further potentials for paired exchange / ABOi

Achievements

- Paired exchange / ABOi viable treatment option (yet to Transplant on paired exchange)
- Utilised every paired exchange run
- One patient had 4th Kidney (94 crf)
- Transplanted two children with transplanted siblings
- IPP/Overseas
- HTA Pilot Study

Audit Points

- Length of stay similar for LDTx + DDTx
- Less transplants but increased workload – out of centre referrals take approx 3 times longer to plan
- All referrals to LRCAP this year made in good time
- Mean CIT for LDTx's unchanged from previous year
- DDTx cause of death not always documented
- Average LDTx creatinine approx 10% better than DDTx creatinine's at end of audit year.

Clinical Nurse Specialists

- Increased psychosocial input - Complex families
- Increased workload. No increased hours. (Patients from out of centre take approx 3 x longer to plan + more complex patients)
- Reduced administrative support
    - Improved since the end of the audit year
    - Improved with the reconfiguration of level 7 services

Next Year

- Capture ALL donors as RENWALS
- Revise and update Pre Transplant work up protocols
- Update Guys / GOSH protocols
- Continue to use NLKDSS + ABOI as viable option's
- Develop RRT pathways for LRCAP patients

With Thanks to

- The Guys Team
- The Level 7 Team
- Eagle Ward
- Suzanne Collin
- All!

11.2 RENAL TRANSPLANT AUDIT

Jenny Tanton, Kate Sinnot and Suzanne Bradley

Renal Transplants at GOSH

- 23 patients received a Renal Transplant at GOSH

- 1 Patient received a 2-2-2 mismatch DCD Kidney Transplant at Nottingham and his care transferred to GOSH Feb 2013. He will not be included in this audit.
- 1 Patient received a kidney transplant at GOSH and returned to home country Jan 2013.
- Data follow up based on 23/24 patients in the Audit Year

Transplants

- 21 patients received their first renal graft
- 1 patient received their second renal graft
- 1 patient recived their fourth renal graft

Underlying Diagnoses

Dysplasia	8
Posterior Urethral Valves / BRD	3
Congenital Nephrotic Syndrome	2
?MPGN type 1	2
FSGS	1
Nephronophthisis	1
Ecoli 0157 HUS	1
Glomerulocystic kidney disease	1
Twin to Twin transfusion	1
Acute Tubular Necrosis	1
Bardet-Biedl syndrome	1
?Systemic lupus erythematosus	1

Donor Types

Live Related = 13 Patients

Deceased Donor = 10 Patients

Patient Demographics

Female / Male = 16: 7
NHS / Private = 22:1

Pre-Transplantation Status

Modality	No of Patients
Pre-Emptive	11
Haemodialysis	7
Peritoneal Dialysis	5

HLA Mismatches

Mismatch	LRD	Deceased
0-0-0	1	1
0-1-0	2	2
0-2-1	1	
1-1-1	5	
1-1-0	3	6
1-0-0	1	1

Renal Transplant Biopsies

Patients transplanted in 2012-2013

- 78% (18/23) of patients had a total of 29 biopsies in the audit year
- 55% (16/29) biopsies performed for renal allograft dysfunction
- 10% (3/29) biopsies for ?disease recurrence
- 43% (10/23) patients had a time zero biopsy

Time Zero Biopsies

B	C	D	E
2	3	3	2

Time Zero Biopsies

No of Biopsies	Biopsy Results
1	Insufficient
2	NAD
3	Mild chronic changes
1	Moderate chronic vascular changes
2	Arteriolar Hyalinosis

1	Severe hypertensive changes

Biopsy results in patients transplanted 2012-2013

Biopsy Result	Number of Biopsies made reference to:
Chronic changes	8
No Acute Rejection	4
Grade 2A Acute rejection	2
Focal acute tubuar damage	1
Grade 1A Acute Rejection	1
Chronic Allograft Nephropathy	1
Boderline Changes	1
BK Nephropathy	1

EBV Viraemia

- 90% (9/10) D+ R- developed EBV viraemia
- 50% (3/6) D+ R+ developed reactivation
- 100% (1/1) D- R- developed EBV viraemia
- 75% (3/4) D unknown R+ developed reactivation

CMV Viraemia

- 80% (4/5) D+ R- developed CMV viraemia
- 100% (1/1) D+ R+ developed reactivation
- 80% (4/5) received oral treatment for CMV viraemia
- 20% (1/5) received intravenous + oral treatment for CMV viraemia
- 80% (4/5) received continuing oral prophylaxis

Immunosuppression in New Renal Transplant Recipients 2012-2013

Start	End	No
Tac /Aza /Pred	Tac /Aza /Pred	8
Tac /Aza /Pred	Tac/Pred	9
Tac/Aza/Pred	Tac/MMF/Pred	2
Tac /MMF/Pred Basiliximab	Tac/Aza/Pred	1

Tac/Aza/Pred Basiliximab	Tac/MMF /Pred	1
Tac/MMF/Pred Basiliximab	Tac/MMF/Pred	2

Stent Removal – No of weeks into Transplant Journey

Weeks/Post Tx	No of Patients	Reason
Day 5	4	With urethral catheter (NiHR TrUST study)
Week 2	2	With PD catheter / Macro haematuria
Week 3	2	Macro haematuria
Week 4	4	Pyrexia with PD catheter / UTI
Week 5	3	
Week 6	5	
Week 7	1	
Week 8	1	
Week 9	1	

Anti-Hypertensive Treatment in New Renal Transplant Recipients 2012-2013

Start	End	% of Patients
0 agent	0 agent	57%
0 agent	1 agent	4%
1 agent	0 agents	22%
1 agent	1 agents	4%
1 agent	2 agent	9%
2 agents	2 agent	4%

Transplant Complications (Audit year patients)

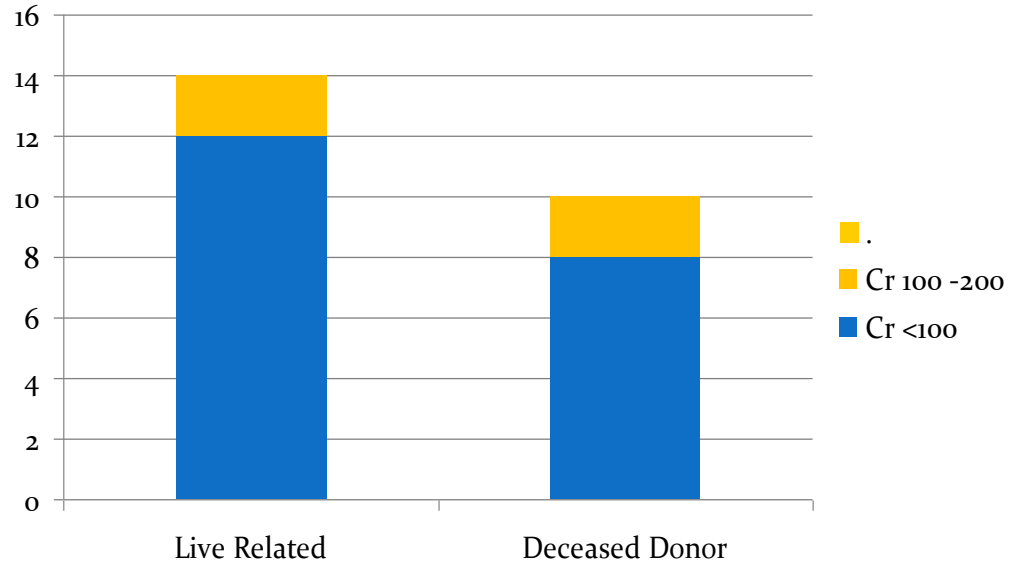
- CNS recurrence
    - First case ever of CNS recurrence at GOSH
    - Gastro viral illness / Malrotation- bowel resection
- FSGS recurrence

- Sub capsular haemorrhage post renal biopsy
    - resulting in renal allograft dysfunction which recovered
- Delayed Graft Function
    - R. leg claudication
    - Upper artery stenosis- angioplasty.
- Acute and humorally-mediated rejection (DSA positive)
- Ureteric stenosis
    - requiring nephrostomy and reimplantation
- Hypertension
- NODAT (New onset of diabetes after transplantation)
- UTI
- EBV/CMV/BK/JC viraemia
- Seizures
- URTI
- Safeguarding concerns (child protection / child in need)
- Depression

Transplant Complications – existing patients

- Rejection
- Ureteric stenosis
    - requiring nephrostomy and reimplantation
- DSA positivity
- EBV/CMV/BK viraemia
- UTI
- Benign Intracranial Hypertension
- CKD and ESRF / CKD-V(T)
    - return to dialysis
- Anaemia
- Revision of Keloid scar tissue
- FSGS reccurence
- Diabetes
- MMF
    - diarrhoea and weight loss

Transplant Creatinine Range



Biopsy Results –Existing Patients

- Existing transplant patients undergoing biopsy in audit year 2012-2013
- 30 patients had a total of 54 biopsies in the audit year

Biopsy results	Number of Biopsies made reference to:
Chronic changes	27
Grade 1B Rejection (celluar)	6
CAN	6
No rejection	3
CD4 postivity ? Humoral process	3
Grade 1A Rejection (celluar)	2
Grade 2A Recjection (celluar)	2
Chronic vascular changes	2
Grade 2A Rejection (Vascular)	1
Acute Pyelonephritis	1
Vascular rejection and ischemic changes	1

Transferred patients:

- 4 Patients returned to dialysis
- 3 Patient moved to low clearance clinic
- 1 Patient transferred care to another unit
- 21 Patients transferred to adult care.

Adolescent Transition

- 21 patients transitioned to adult units in audit year
- Fortnightly adolescent transition clinics
    - quarterly clinics joint with Guys/RLH/RFH and Oxford
    - 12 monthly adolescent clinics

Transition Units

Unit	Number of Patients
Royal Free	6
Royal London	4
Guys	2
Oxford	2
Leicester	2
Lister	1
Addenbrookes	1
Brighton	1
Broomfield	1
Hammersmith	1

Total Transplant Patients

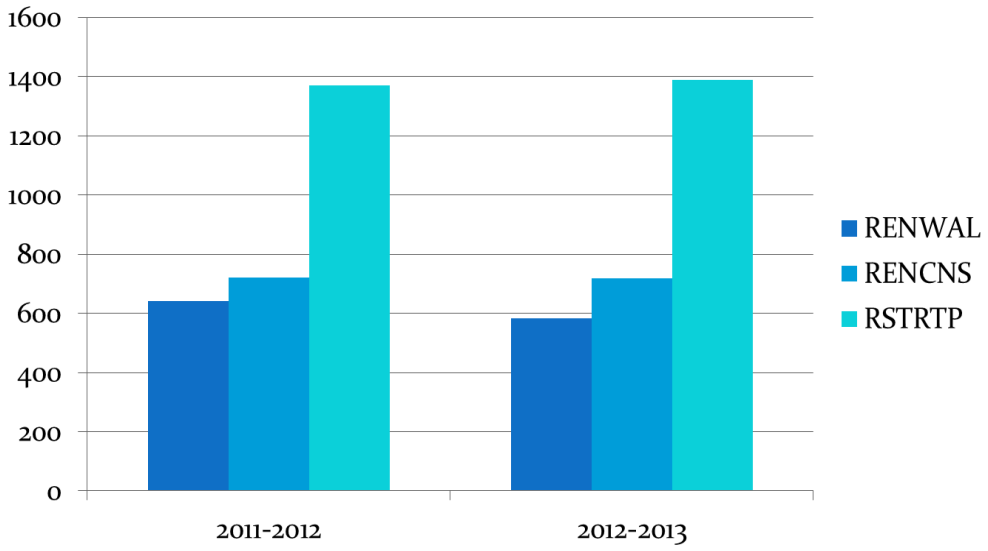
Total Transplant Patients = 149 on 31/03/2012

Transplant patients - Age Range:

Under 5 years old	23 (15%)
5 – 10 years old	39 (27%)
11 – 15 years old	56 (37%)
> 15 years	31 (21%)

Based on patients age on 31/03/2013

Transplant Clinic OPA'S 2012– 2013



	RENWAL	RSTCNS	RSTRTP
Total Appointments	(640) 583	(721) 717	(1370) 1389
Appointments Attended	(608) 172	(605) 460	(1080) 957
DNA/Cancelled	(32) 58	(116) 134	(290) 267
Not specified	353	123	165

24hr Ambulatory BP Monitoring

18 tests performed, in 18 patients

- All post transplant

- 9 male, 9 female
- Ages:
    - 6 x 5-11 years
    - 9 x 11-15 years
    - 3 X 15 years +

Reasons for performing test:

- Hypertensive in clinic - 11 patients
- Review of antihypertensive therapy – 4 patients
- Repeat test following treatment - 1 patient
- Headache – 1 patient
- ? RAS – 1 patient

Antihypertensive treatment at time of test:

- No agents – 5 patients (27%)
- 1 agent – 10 patients (56%)
- 2 agents – 2 patients (11%)
- 3 agents – 1 patient (6%)

18 tests performed:

- 12 patients hypertensive (67%)
    - 4 patients, started treatment
    - 5 patients, dose increased
    - 2 patients, second agent added
    - 1 patient referred for angio ? RAS
- 6 patients normotensive (33%)
    - 1 patient, white coat hypertension
    - 5 patients, remained on current regimen

Modigraf®

- Conversion of tacrolimus suspension to Modigraf®
    - 44 patients on suspension
    - 28 converted
    - 7 unable to convert (eg. lactose intolerant or low dose [HIV])
    - 1 converted to capsules
    - 7 families opted to stay on suspension
    - 1 converted back
- Pharmacy support and teaching

Of the 28 patients converted:

- 68% (19) patients
    - no change to dose.
- 18% (5) patients
    - dose increased
- 14% (4) patients
    - dose decreased

Tacrolimus and fasting

- Fasting optimal absorption
- Families given choice
- Reduce impact on daily life
- Consistent dosing

Where we are up to?

- Renal Transplant protocol completed

- Documentation and transplant database
    - KIT coming…. ?
- Research studies
    - NiHR studies (GAMBIT biomarkers and TrUST stent [SM])
    - MRI (SM)
- Meridian outpatient improvement project

CNS challenges

- Increased psychosocial input
    - complex families
    - more safeguarding concerns in last year
- Reduced nursing hours
    - 2 WTE's to 1.5 WTE's with more cover required for other ESRF services (eg. Eagle Acute and HD)
- Reduced administration support
    - improved since end of audit year
    - improved with configuration of Level 7 services

Improvements in renal support unit

- Relocation
    - integrated team
- Maintaining expertise and cross cover

HCA support and development

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 2011/12, 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 (54 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: 1996/97 – 1999/00, 2000/01 – 2003/04, 2004/05 – 2007/08, 2008/09 – 2011/12) 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: 1996/97 – 2003/04 and 2004/05 – 2011/12) 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	**TOTAL**
1986/87	8	1	109	0	0	0	1	0	14	**133**
1987/88	15	7	106(1)	0	0	0	1	0	8	**137**
1988/89	10	5	102(2)	0	0	0	3	0	7	**137**
1989/90	12(2)	6	101	0	0	1	2	0	10	**132**
1990/91	17	5	55	1	1	0	2	0	5	**86**
1991/92	14(1)	8	88(1)	0	0	2	0	2	7	**121**
1992/93	12	8	104	2	0	2	3	3	9	**143**
1993/94	9	2	105(2)	0	0	0	3	4	8	**131**
1994/95	10	5	102(2)	1	0	0	5	2	11	**136**
1995/96	13(1)	6	114	0	0	1	2	5	14	**155**
1996/97	2	10	89(3)	0	0	0	4	4	18	**127**
1997/98	5(2)	21	80(3)	0	2	1	1	5	15	**130**
1998/99	1(1)	16	84(2)	0	0	0	0	7	16	**124**
1999/00	2	10	90(2)	0	0	1	1	5	30	**139**
2000/01	2(1)	23	77(2)	0	0	0	0	7	24	**133**
2001/02	0	7	83(1)	0	0	0	0	7	30	**127**
2002/03	1	10	66(1)	0	0	0	1	12	29	**119**
2003/04	0	16	78	0	0	0	0	15	32	**141**
2004/05	0	11	65(5)	0	0	0	0	14	34	**124**
2005/06	0	9	51(2)	0	0	0	1	15	32	**108**
2006/07	0	18	70(6)	0	0	1	0	12	36	**137**
2007/08	0	10	52(4)	0	0	1	0	10	41	**114**

2008/09	0	9	66(3)	0	0	2	0	11	53	**141**
2009/10	0	12	63(3)	0	0	1	0	23	47	**146**
2010/11	0	10	60(3)	0	1	1	0	9	57	**138**
2011/12	0	8	61(4)	0	1	0	0	21	48	**139**

( ) 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	**TOTAL**
1986/87	8	1	87	0	0	0	1	0	13	**110**
1987/88	14	5	88	0	0	0	1	0	7	**115**
1988/89	6	4	82	0	0	0	3	0	5	**100**
1989/90	10	3	66	0	0	0	2	0	9	**90**
1990/91	14	5	45	1	1	0	0	0	5	**71**
1991/92	12	3	73	0	0	2	0	2	5	**97**
1992/93	11	7	88	1	0	2	2	3	9	**123**
1993/94	9	2	90	0	0	0	3	4	8	**116**
1994/95	7	4	76	1	0	0	5	2	11	**106**
1995/96	10	6	97	0	0	1	2	5	13	**134**
1996/97	2	9	74	0	0	0	4	4	16	**109**
1997/98	2	18	58	0	2	0	1	5	13	**99**
1998/99	0	11	70	0	0	0	0	7	15	**103**
1999/00	2	8	74	0	0	1	1	5	26	**117**
2000/01	1	16	69	0	0	0	0	7	22	**115**
2001/02	0	5	73	0	0	0	0	6	29	**113**
2002/03	1	7	54	0	0	0	1	12	28	**103**
2003/04	0	15	66	0	0	0	0	14	28	**123**
2004/05	0	10	55	0	0	0	0	13	30	**108**
2005/06	0	9	47	0	0	0	1	15	29	**101**
2006/07	0	15	60	0	1	1	0	12	36	**124**
2007/08	0	9	43	0	0	0	0	10	41	**103**
2008/09	0	9	57	0	2	2	0	9	53	**130**
2009/10	0	10	59	0	1	1	0	22	47	**139**
2010/11	0	8	51	0	1	1	0	9	55	**125**
2011/12	0	7	53	0	1	0	0	20	45	**126**

One, five and ten year graft 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					
1996/97 – 1999/00	52	52	79	(64-88)	79
2000/01 – 2003/04	45	44	89	(74-96)	93
2004/05 – 2007/08	43	43	88	(74-94)	100
2008/09 – 2011/12	34	34	91	(76-98)	94
All other UK paediatric units					
1996/97 – 1999/00	275	275	89	(86-92)	89
2000/01 – 2003/04	261	261	90	(86-94)	93
2004/05 – 2007/08	205	204	94	(90-96)	97
2008/09 – 2011/12	220	217	96	(92-98)	95

Five year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up1
Great Ormond Street Hospital and Royal Free Hospital					
1996/97 – 1999/00	52	52	66	(52-78)	69
2000/01 – 2003/04	45	44	75	(60-86)	79
2004/05 – 2007/08	43	43	86	(72-94)	85
2008/09 – 2011/12	34	-	-	-	3
All other UK paediatric units					
1996/97 – 1999/00	275	275	80	(74-84)	80
2000/01 – 2003/04	261	261	78	(72-82)	80
2004/05 – 2007/08	205	204	85	(80-90)	86
2008/09 – 2011/12	220	-	-	-	3

Ten year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence	% Follow up1

				interval	
Great Ormond Street Hospital and Royal Free Hospital					
1996/97 – 1999/00	52	52	56	(40-68)	48
2000/01 – 2003/04	45	44	63	(46-76)	37
2004/05 – 2007/08	43	-	-	-	0
2008/09 – 2011/12	34	-	-	-	0
All other UK paediatric units					
1996/97 – 1999/00	275	275	66	(60-70)	59
2000/01 – 2003/04	261	261	66	(60-72)	49
2004/05 – 2007/08	205	-	-	-	0
2008/09 – 2011/12	220	-	-	-	0

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

One, five and ten year graft 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					
1996/97 – 2003/04	67	64	95	(84-98)	88
2004/05 – 2011/12	111	110	98	(92-100)	95
All other UK paediatric units					
1996/97 – 2003/04	177	174	96	(92-98)	95
2004/05 – 2011/12	336	328	95	(92-96)	96

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					
1996/97 – 2003/04	67	64	85	(74-92)	70
2004/05 – 2011/12	111	110	93	(84-96)	38
All other UK paediatric units					
1996/97 – 2003/04	177	174	90	(84-94)	85
2004/05 – 2011/12	336	328	90	(86-94)	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					
1996/97 – 2003/04	67	64	75	(60-84)	47
2004/05 – 2011/12	111	-	-	-	0
All other UK paediatric units					
1996/97 – 2003/04	177	174	76	(68-82)	57
2004/05 – 2011/12	336	-	-	-	0

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					
1996/97 – 1999/00	52	52	77	(62-86)	79
2000/01 – 2003/04	45	44	89	(74-96)	93
2004/05 – 2007/08	43	43	88	(74-94)	100
2008/09 – 2011/12	34	34	91	(76-98)	94
All other UK paediatric units					
1996/97 – 1999/00	275	275	88	(84-92)	89
2000/01 – 2003/04	261	261	90	(86-92)	93
2004/05 – 2007/08	205	204	93	(88-96)	97
2008/09 – 2011/12	220	217	96	(92-98)	95

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					
1996/97 – 1999/00	52	52	63	(48-74)	69
2000/01 – 2003/04	45	44	75	(60-86)	79
2004/05 – 2007/08	43	43	86	(72-94)	85
2008/09 – 2011/12	34	-	-	-	3
All other UK paediatric units					
1996/97 – 1999/00	275	275	77	(72-82)	80
2000/01 – 2003/04	261	261	77	(72-82)	80

2004/05 – 2007/08	205	204	84	(78-88)	86
2008/09 – 2011/12	220	-	-	-	3

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					
1996/97 – 1999/00	52	52	53	(38-66)	48
2000/01 – 2003/04	45	44	61	(44-74)	37
2004/05 – 2007/08	43	-	-	-	0
2008/09 – 2011/12	34	-	-	-	0
All other UK paediatric units					
1996/97 – 1999/00	275	275	61	(56-66)	59
2000/01 – 2003/04	261	261	65	(60-70)	49
2004/05 – 2007/08	205	-	-	-	0
2008/09 – 2011/12	220	-	-	-	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					
1996/97 – 2003/04	67	64	92	(82-96)	88
2004/05 – 2011/12	111	110	98	(92-100)	95
All other UK paediatric units					

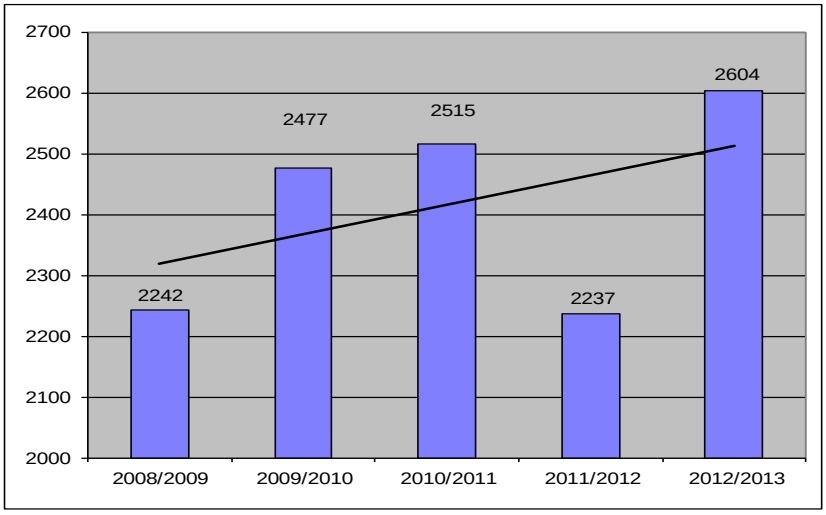
1996/97 – 2003/04	177	174	95	(90-98)	95
2004/05 – 2011/12	336	328	95	(92-96)	96

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					
1996/97 – 2003/04	67	64	81	(68-88)	70
2004/05 – 2011/12	111	110	93	(84-96)	38
All other UK paediatric units					
1996/97 – 2003/04	177	174	88	(82-92)	85
2004/05 – 2011/12	336	328	89	(84-92)	40

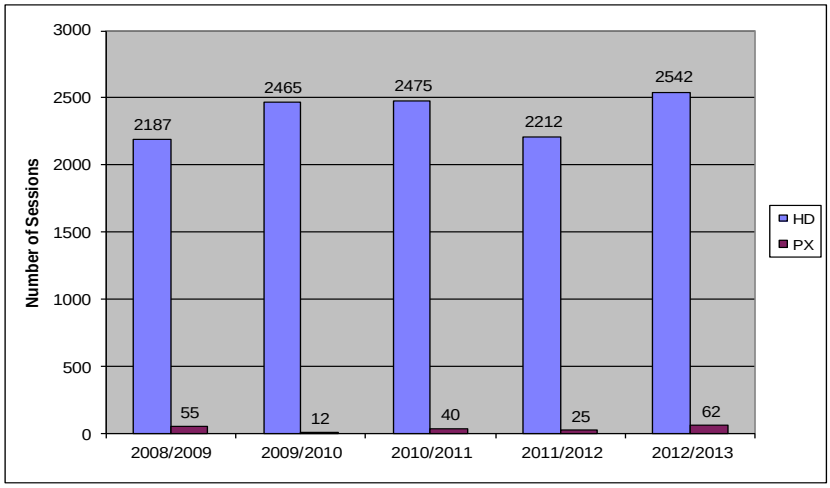
Ten year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
Great Ormond Street Hospital and Royal Free Hospital					
1996/97 – 2003/04	67	64	69	(56-80)	47
2004/05 – 2011/12	111	-	-	-	0
All other UK paediatric units					
1996/97 – 2003/04	177	174	73	(64-80)	57
2004/05 – 2011/12	336	-	-	-	0

11.4 HAEMODIALYSIS AUDIT 2012-2013
Liz Wright

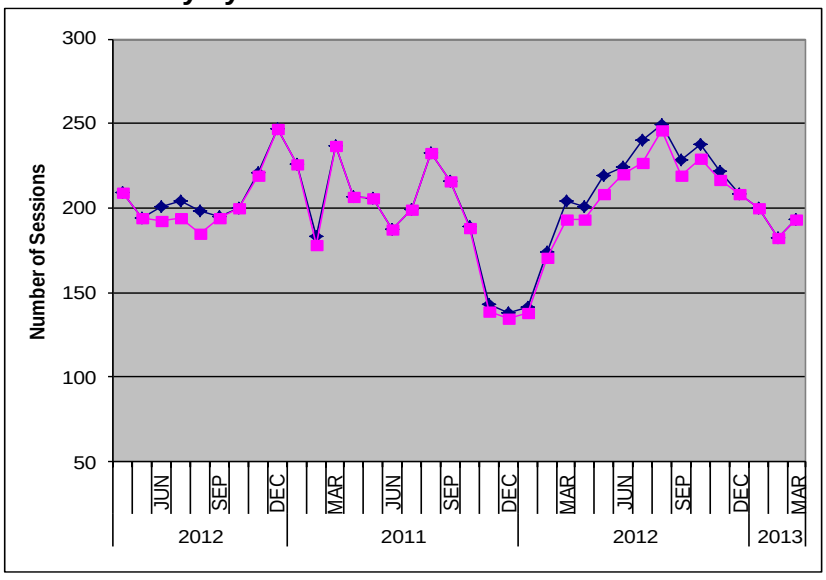
Eagle Haemodialysis Activity 2009-2013



5 Year Activity by Type



3 Year Activity by Month



Totals

- Children receiving haemodialysis or plasma exchange (GOS only)
  - Total = 44

- Chronic HD = 34
- Acute HD = 5
- PX = 5

Ages

- 44 children (25 male: 19 female)
  - 0 – 2 years = 9
  - 2 – 5 years = 3
  - 5 – 10 years = 10
  - 10 – 15 years = 11
  - 15+ years = 11

- Youngest – 0.14 years
  - 27 % of workload < 5 years

New HD Starters

Source	Number of Children
From CRF rogramme	4
From PD programme	2
From transplant programme	6
Transfer in	2
New patient	1
Acuutes/PX	10
	25

Leavers

Reason	Number of Children
Transplant DD	1
Transplant LRT	5
PD	1
Transfer adult HD	4
HHD programme	4
Function recovered	3
Died	2
	20

Non-movers

5 children remained on in-centre HD for the complete year

Visitors = 4

- For access insertion = 2
- Transplant work-up/assessment = 2
- Holiday HD = 0

Acute HD = 44 sessions

Patient	Diagnosis	No. of	Outcome

		sessions	
1	Acute on chronic, heart tx, osteosarcoma, tumour lysis	2	Function recovered
2	Autoimmune cytopenia, stem cell tx, TTP, adenoviraemia	18	Died
3	Meningococcal B septicaemia	2	Function recovered
4	SLE, EBV driven leiomyoma	20	Function recovered
5	Heart tx, ARDS, septic shock	2	Function recovered

Plasma Exchange = 62 sessions

Patient	Diagnosis	No. of sessions	Outcome
1	PUV	1	Test PEX
2	FSGS rec. post-tx	16+20	Function stable
3	Nephrotic post-tx	15	Function stable
4	Rejection	5	HD
5	aHUS	6 (+UCLH)	Recovered

Access Totals

- Total access = 61 catheters in children
  - AVF – 10
  - Permanent – 54 (3 in HHD children)
  - Temporary – 7

- Accesses inserted over the year:
  - AVF – 2
  - Permanent - 34
  - Temporary - 6

Line Insertions

	Who	Permanent	Temporary
IR%	DR	6	0
	SC	8	0
	AB	4	0
	Others	17	0
Renal %		0	
Other	PICU	0	6
	Other centre	0	
Total		**34**	**6**

Line Positions

Position	Permanent	Temporary	Total
R IJV	19	1	20
L IJV	11	2	13
R EJV	1	0	1
R brachiocephalic	2	0	2
R subcalvian	1	0	1

L subclavian	0	1	1
R femoral	0	0	0
L femoral	0	2	2
		6	**40**

Reason for Line Removal

Reason	Number
Infection	7
Poor flows	2
Cuff migration/damage	5
Pulled out	2
Transplant	6
Recovered/not needed	6
Died	2
AVF maturation	3
Conversion to permanent catheter	5
Move to PD	1
Total	**39**

Infections

- 7 line infections
- 4022 catheter days
- 1.7 infections/ 1000 catheters days

Infection rates

	08/09	09/10	10/11	11/12	12/13
No of infections	7	5	7	7	7
Catheter days	2434	3384	4076	3726	4022
Infections/1000 catheter days	2.9	1.5	1.7	1.9	1.7

Line Infections n = 7

Patient	Time (days) from insertion	Microbiology	Outcome
1	69	Mixed growth	Line replaced
2	33	S. aureus	Line replaced 1/12 later
3	32	S. aureus	Line removed; AVF
4	17	S. aureus	Line replaced
5	141	Enterocococcus	Line replaced
6	14 73	CNS CNS	Line replaced Line replaced

Exit Site Infections

- 4 exit site infections

- 3 in 1 child, staph aureus (RA)
    - 1 associated with line sepsis, line pulled
- 1 in 1 child, CNS (LG)

AVF data

- 10 children had AVFs
- 2 created in this audit year (and 1 HHD)

Approx 1339 sessions (51%)of total 2604 performed with AVF.

AVFs created

Age	Site	Surgeon	2nd Stage	Outcome
15.92	L brachiocephalic	N Mamode	Yes	Functioning
7.73	L brachiocephalic	J Taylor	No	Functioning

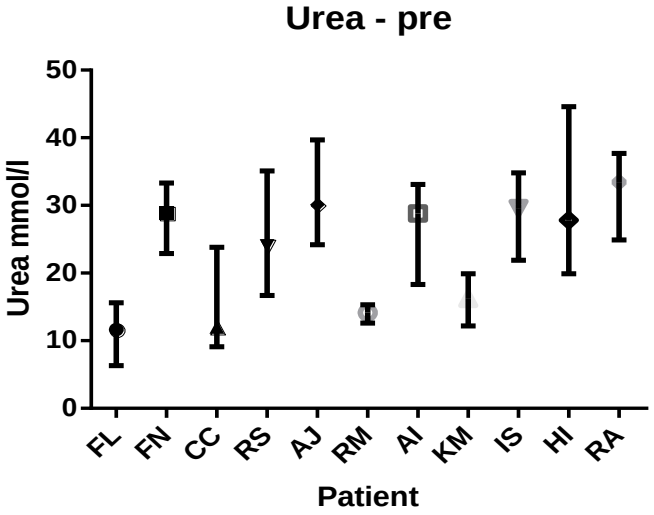
HDF

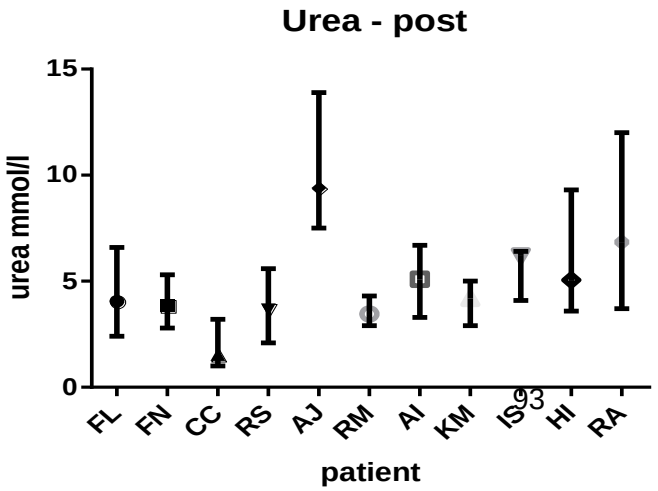
- Now have 5 machines capable of HDF

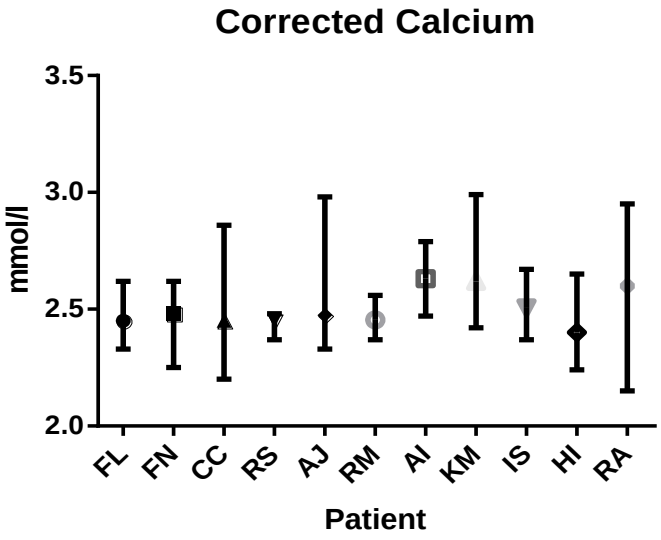
- 14 children have received post-dilution HDF
    - 9 have regularly had HDF
    - 5 have issues with access pressures/flows

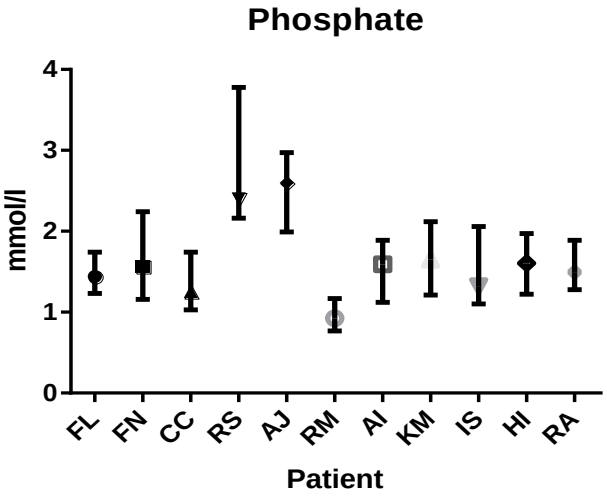
New for 2013

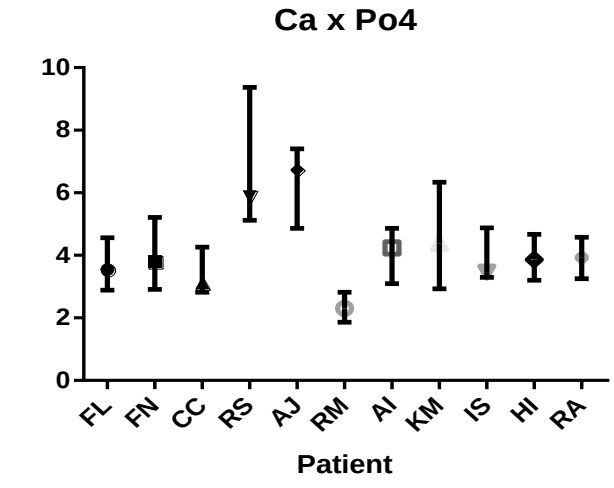
- Practice educator
- Parafilm started in March
- Tego caps
- Bolus iron administration?

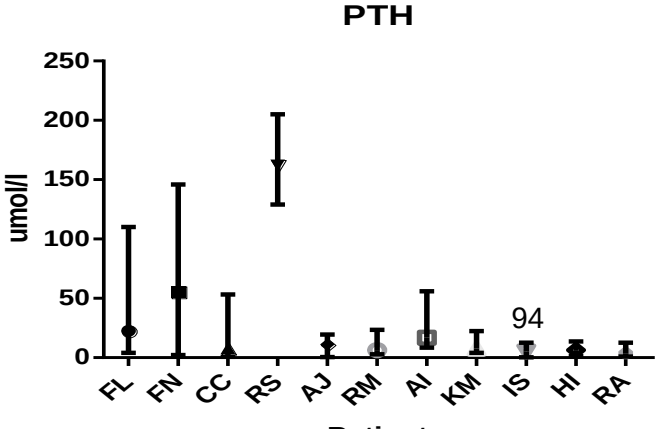


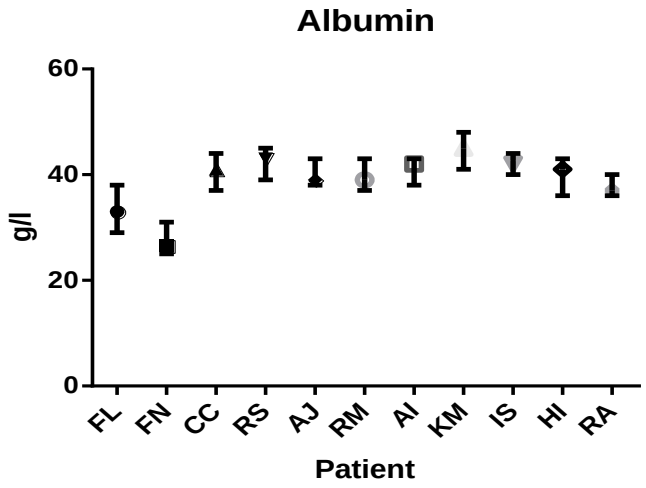


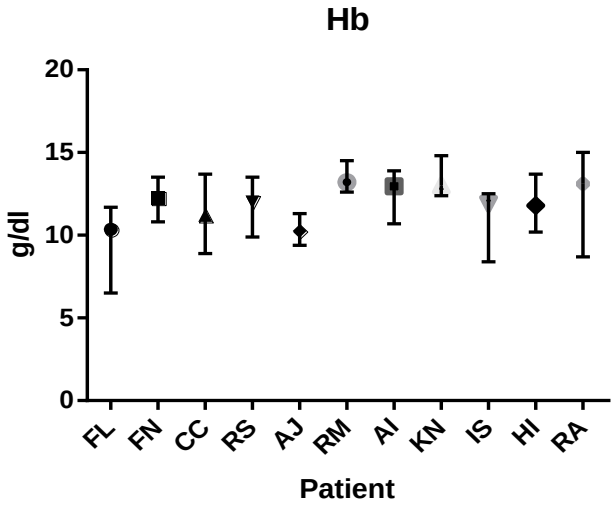

Corrected Calcium
3.5
3.0
2.5
2.0
mmol/l
FL
FN
CC
RS
AJ
RM
AI
KM
IS
HI
RA
Patient

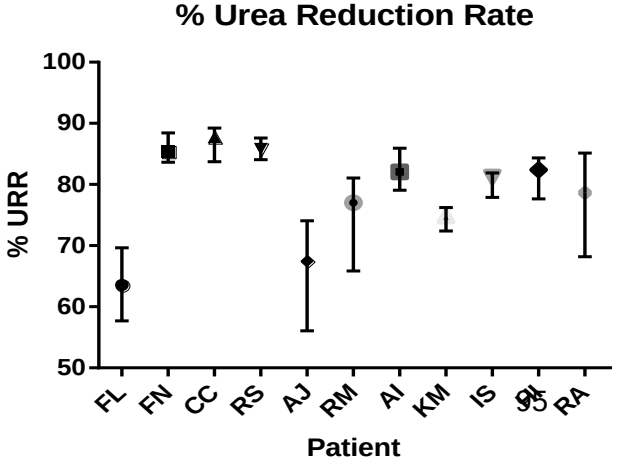

Phosphate
4
3
2
1
0
mmol/l
FL
FN
CC
RS
AJ
RM
AI
KM
IS
HI
RA
Patient

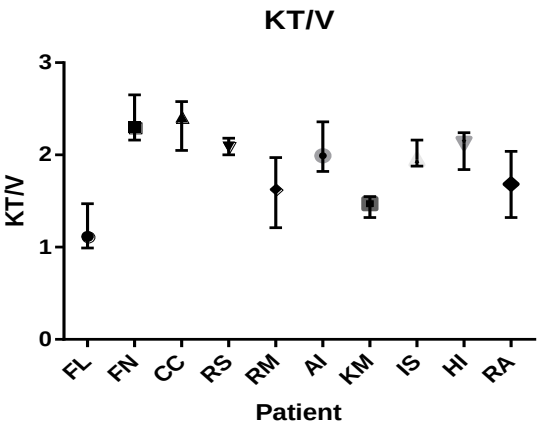

Ca x Po4
10
8
6
4
2
0
FL
FN
CC
RS
AJ
RM
AI
KM
IS
HI
RA
Patient

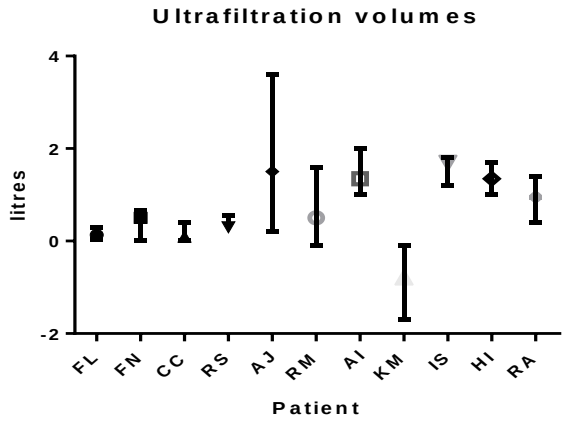

PTH
250
200
150
100
50
0
umol/l
FL
FN
CC
RS
AJ
RM
AI
KM
IS
HI
RA

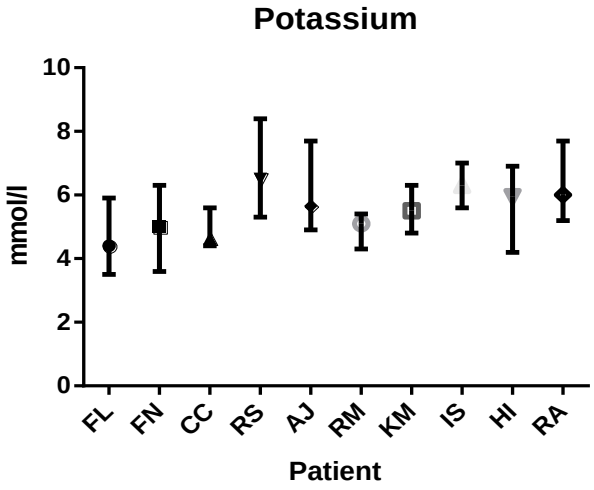

Albumin
60
40
20
0
g/l
FL
FN
CC
RS
AJ
RM
AI
KM
IS
HI
RA
Patient


Hb
20
15
10
5
0
g/dl
FL
FN
CC
RS
AJ
RM
AI
KN
IS
HI
RA
Patient


% Urea Reduction Rate
100
90
80
70
60
50
% URR
FL
FN
CC
RS
AJ
RM
AI
KM
IS
RA
Patient


KT/V
KT/V
3
2
1
0
FL
FN
CC
RS
RM
AI
KM
IS
HI
RA
Patient


Ultrafiltration volumes
litres
4
2
0
-2
FL
FN
CC
RS
AJ
RM
AI
KM
IS
HI
RA
Patient


Potassium
mmol/l
10
8
6
4
2
0
FL
FN
CC
RS
AJ
RM
KM
IS
HI
RA
Patient

11.5 HOME HAEMODIAYLSIS AUDIT

April 2012 – March 2013
Dr Dal Hothi, Lynsey Stronach and Cecilia Mcneice

Pilot Home HD Programme

- Proposal submitted 2013
- Trust approval for pilot programme Oct 2010

GOSH HHD programme Using the NxStage System
Multidisciplinary team

- Dal Hothi– Renal Consultant
- Lynsey Stronach – Band 7
- Band 6
- Family Therapist
- Play Specialist
- Social Worker
- Dietician
- Haemodialysis Unit
- Community teams

NxStage System & Standard CAR 172 circuit

- Freedom from home water conversion- uses sterile dialysis fluid in bags
- Single extracorporeal circuit cartridge with a polysulfone dialysis membrane
- Time efficiency (Conventional) vs. Water efficiency (NxStage) & HIGH DIALYSATE SATURATION

Dialysis Prescription

- Frequency
  - 5 hours, 4 days/week (min 20 hrs/week)
  - Nocturnal
- Anticoagulation
  - Dalteparin, single iv bolus 25-50u/kg

Criteria for HHD

- Established on HD
- Good functioning access, either CVC/fistula
- Housing
- Commitment from the family
- Psychosocial assessment
- Medically appropriate
- 12kg or above
- Carers – identify who will be trained?

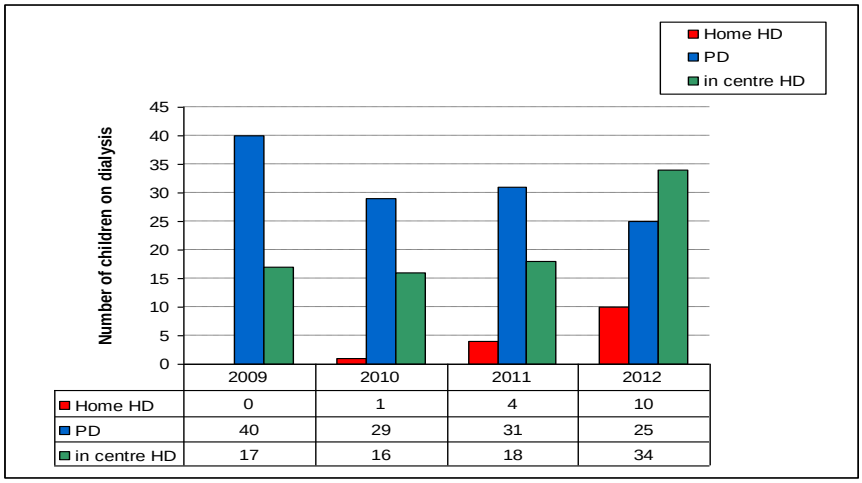
Training and discharge

- Approximately 4 to 6 weeks
- First 1 to 2 weeks on HD, then Patient Hotel: step down training facility
- Family have to be comfortable to dialysing independently, over the weekend before discharge
- Home visits for the first week
- Adherence contract

- Clinic appointments 4 to 6 weekly with local bloods in-between
- 6 monthly re-training

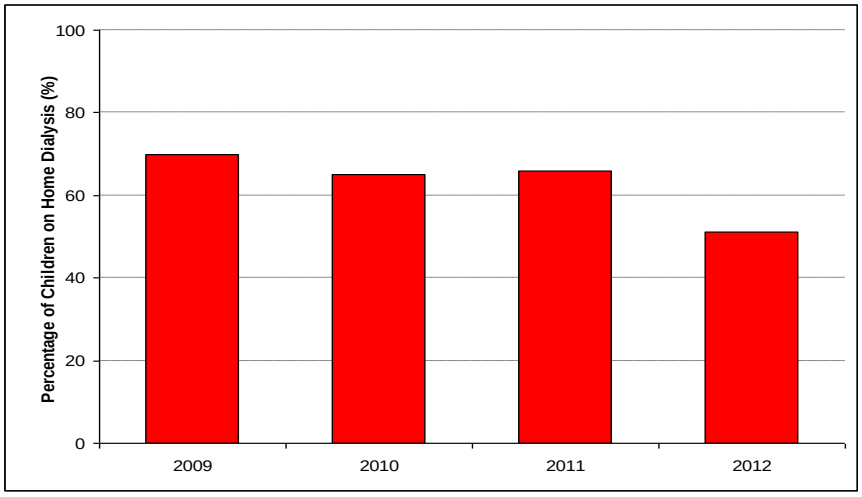
Outcomes

Of the paediatric patients, aged between 0-18 years, treated with dialysis we report the number of children on in-centre HD, PD & Home HD



	2009	2010	2011	2012
Home HD	0	1	4	10
PD	40	29	31	25
in centre HD	17	16	18	34

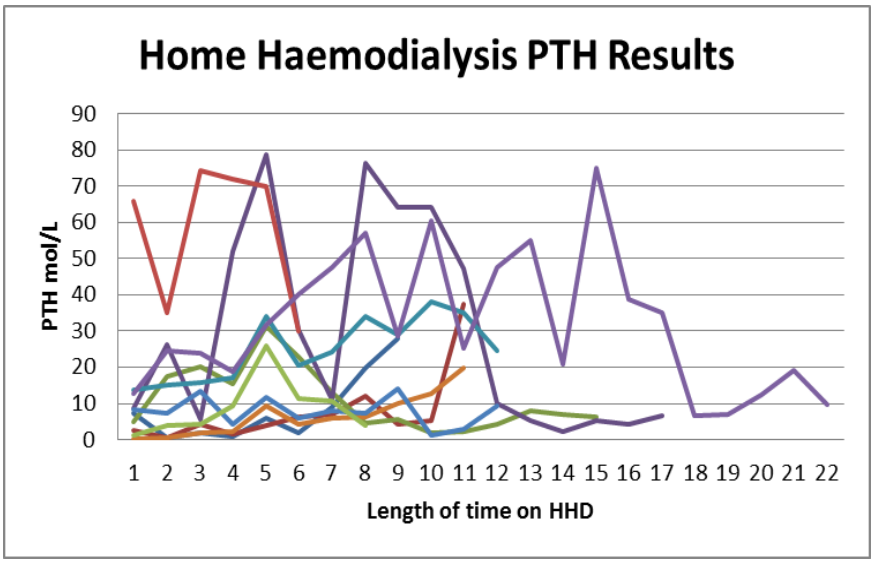
Of all the long-term paediatric dialysis patients, aged between 0-18 years, we report the percentage of children on home dialysis (PD & Home HD)

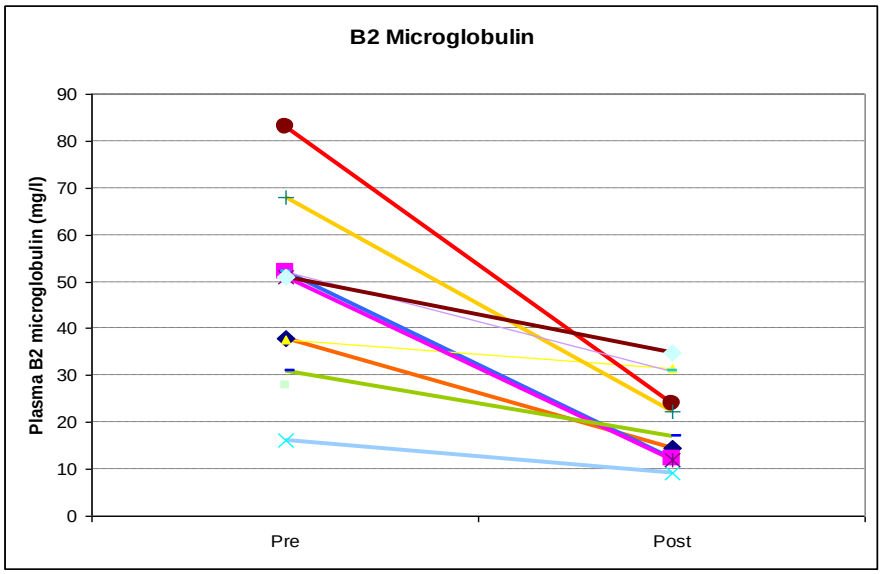


Patient	Age *[years]*	Weight *[kg]*	Time on HHD *[months]*	Primary Renal disorder	Vascular Access *[AVF/CVL]*	Dialysis Dose
1	17	72	22.0 (Adults)	Renal dysplasia	AVF	8hrs, alternate night
2	14	40.6	31.0	Posterior urethral valves	AVF	8hrs, 4 times/wk
3	16	67.5	26.0 (Adults)	Single dysplastic kidney Complex congenital heart	CVL-neck	5hours, 4 times/wk
4	8	22.2	27.0	Atypical HUS	AVF	3-4hrs, 4 times/wk
5	13	38	24.0	Bilateral Wilms tumours Cardiomyopathy	CVL-neck	8hrs, 5 times/wk
6	14	25.5	20.0	Cloacal anomaly, renal dysplasia	AVF	5hrs, 4 times/wk
7	12	36.5	15.0	Atypical MPGN	AVF	8hrs, 4 times/wk
8	18	30.9	12.0 (Adults)	Heart & lung transplant, progressive renal failure	AVF	3hrs, 3 times/wk
9	16	37	9.0	Steroid resistant Nephrotic Syndrome	AVF	5hrs, 4 times/wk
10	5	19.6	8.0	Bilateral renal dysplasia	CVL-neck	4hrs, 4 times/wk
11	3	15.5	8.0	Bilateral renal dysplasia	CVL-neck	3hrs, 5 times/wk
12	16	49.5	6.0	Congenital nephrotic syndrome	AVF	5hrs, 4 times/wk
13	16	68	3.0	Posterior urethral valves	CVL-neck	5hrs, 4 times/wk
14	8	21	2.0	FSGS	CVL- neck	3-4hrs, 5 times/wk

Patient	Age	Weight *[kg]*	Primary Renal disorder	Vascular Access	Blood flow rate *[mls/min]*	Aspirin?	Dalteparin dose	Post dialysis Factor Xa level
1	17	71	Renal dysplasia	AVF	280	Yes	24u/kg	0
2	14	40.6	Posterior urethral valves	AVF	250	Yes	37u/kg	0.01
3	16	67.5	Single dysplastic kidney	CVL-neck	300	Yes	30u/kg	0.11
4	8	22.2	Atypical HUS	AVF	180	Yes	90u/kg	0.02
5	13	38	Bilateral Wilms tumours	CVL-neck	200	Yes	53u/kg	0.23
6	14	25.5	Cloacal anomaly, renal dysplasia	AVF	200	Yes	39u/kg	0.06
7	12	36.5	Atypical MPGN	AVF	250	Alternate days	41u/kg	0.04
8	18	30.9	Heart & lung transplant, progressive renal failure	AVF	280	Yes	16u/kg	0.05
9	16	37	Steroid resistant Nephrotic Syndrome	AVF	280	Yes	14u/kg	0.02
10	5	19.6	Bilateral renal dysplasia	CVL-neck	150	Yes	51u/kg	0.04
11	3	15.5	Bilateral renal dysplasia	CVL-neck	120	No	45u/kg	0.05
12	16	49.5	Congenital nephrotic syndrome	AVF	340	Yes	20u/kg	0.03
13	16	68	Posterior urethral valves	CVL-neck	320	Yes	51u/kg	0.03
14	8	21	FSGS	CVL-femoral	160	No	57u/kg	0.24
15	12	41	FSGS	CVL-neck	220	Yes	36.5u/kg	0.01

Patient	Age *[years]*	Weight *[kg]*	Time on HHD *[months]*	Primary Renal disorder	Fluid Restrictions ?	Dietary Restrictions	Weight Gain *(kg)*	Height Gain (cm)
1	17	72	22.0 (Adults)	Renal dysplasia	No	No	4.5	0.6
2	14	40.6	31.0	Posterior urethral valves	No		11.5	16.8
3	16	67.5	26.0 (Adults)	Single dysplastic kidney Complex congenital heart	No	No	7.5	1.0
4	8	22.2	27.0	Atypical HUS	No	No	0	7.4
5	13	38	24.0	Bilateral Wilms tumours Cardiomyopathy	800mls	No	16.3	11.7
6	14	25.5	20.0	Cloacal anomaly, renal dysplasia	No	Careful with potassium	4.0	4.6
7	12	36.5	15.0	Atypical MPGN	No	No	3.5	6.8
8	18	30.9	12.0 (Adults)	Heart & lung transplant, progressive renal failure	No	No	2.0	0
9	16	37	9.0	Steroid resistant Nephrotic Syndrome	No	No	5.6	5.4
10	5	19.6	8.0	Bilateral renal dysplasia	No	tube feeds	0.5	4.6
11	3	15.5	8.0	Bilateral renal dysplasia	No	tube feeds	2.3	6.6
12	16	49.5	6.0	Congenital nephrotic syndrome	No	No	2.0	0.8
13	16	68	3.0	Posterior urethral valves	*No*	*No*	*4.3*	0.5
14	*8*	*21*	*2.0*	*FSGS*	*No*	*No*	*1.5*	1.6


Home Haemodialysis PTH Results
PTH mol/L
90
80
70
60
50
40
30
20
10
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22
Length of time on HHD


B2 Microglobulin
Plasma B2 microglobulin (mg/l)
90
80
70
60
50
40
30
20
10
0
Pre
Post

Patient	Age *[years]*	Weight *[kg]*	Time on HHD *[months]*	Primary Renal disorder	Cardiac Echo	Anti-hypertensive
1	17	72	22.0 (Adults)	Renal dysplasia	Normal	No
2	14	40.6	31.0	Posterior urethral valves	Mild concentric LVH	No
3	16	67.5	26.0 (Adults)	Single dysplastic kidney Complex congenital heart	No LVH	No
4	8	22.2	27.0	Atypical HUS	Normal	Enalapril 5mg
5	13	38	24.0	Bilateral Wilms tumours Cardiomyopathy	Normal	No
6	14	25.5	20.0	Cloacal anomaly, renal dysplasia	Normal	No
7	12	36.5	15.0	Atypical MPGN	Normal	No
8	18	30.9	12.0 (Adults)	Heart & lung transplant, progressive renal failure	Normal	No
9	16	37	9.0	Steroid resistant Nephrotic Syndrome	Normal	No
10	5	19.6	8.0	Bilateral renal dysplasia	Normal	No
11	3	15.5	8.0	Bilateral renal dysplasia	Normal	No
12	16	49.5	6.0	Congenital nephrotic syndrome	Normal	No
13	16	68	3.0	Posterior urethral valves	Normal	No
14	8	21	2.0	FSGS	Mild to moderate LVH	No

Changing Attitudes

- MDT
- Parents and patients
- Safe to dialyse at home
- Carer burden
- 'Inclusion criteria not exclusion criteria'
- Cost effective
- Avoding increasing in centre workload
- Recruitment of patients

Adherence

- Non compliance around 3-6 months
- Not wanting to go onto dialysis after school
- Feeling better so eating more (phosphate)
- Returning in centre
- Ncoturnal

Transition

- Package of Care cost
- Adult tariff
- Competency with NxStage in other units
- Confidence of family in non NxStage unit
- Consier transition before accepting on HHD programme

Out of hours support

- On call initially HHD consultant, HHD CNS AND Band 6
- Now part of HD on call
- Technical support – Air alarms
- Medical support
- Training and maintaining competence on HD

On call phone

- Blood pressure and fluid balance
- Access problems
- Temperature and rigor
- Saline clamp left open
- Vasovagal with neurological deterioration
- Fistula not clotting on removal of needles
- Fistula not buzzing
- Clotted circuit

Parental responses to HHD

- 'Really daunting'
- 'I was quite nervy in the beginning'
- 'Massive responsibility'
- 'We are parents not medical staff'

BUT…

- 'We can fit dialysis around our lives'
- 'The change in our child makes it worth it'
- 'The benefits outweigh the negatives'

Perception that child and family can develop confidence, sense of competence and increased resilience but need for continued support.

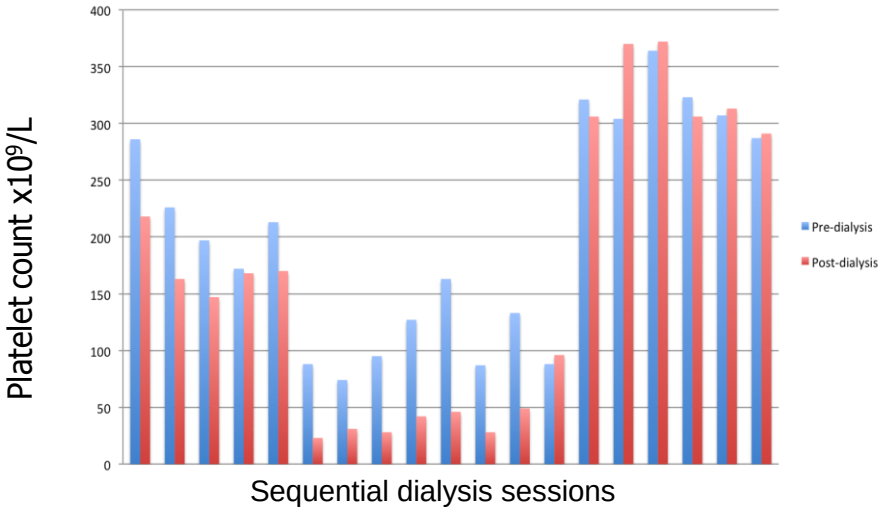
Developments

A) Nocturnal HHD

- Suitability both medically & psychosocially for 6mths on HHD
- Wake up for alarms
- Enuresis alarm for under fistula or CVC
- Cycler base fluid detection
- Programme 8 – 12 hours
- Increase dialysate and heparin
- Maintain blood flow
- Increased insensible losses on nocturnal

B) Dialysis Induced Thrombocytopenia

NxStage Gambro 140H dialyser with NxStage



Thrombocytopenia

Issues: Thrombocytopenia CAR 172

- Subsequently noted in 4/6 patients
- All stabilise after switching to CAR124 circuit with their original dialyser
- Not reported before
- Mechanism unknown

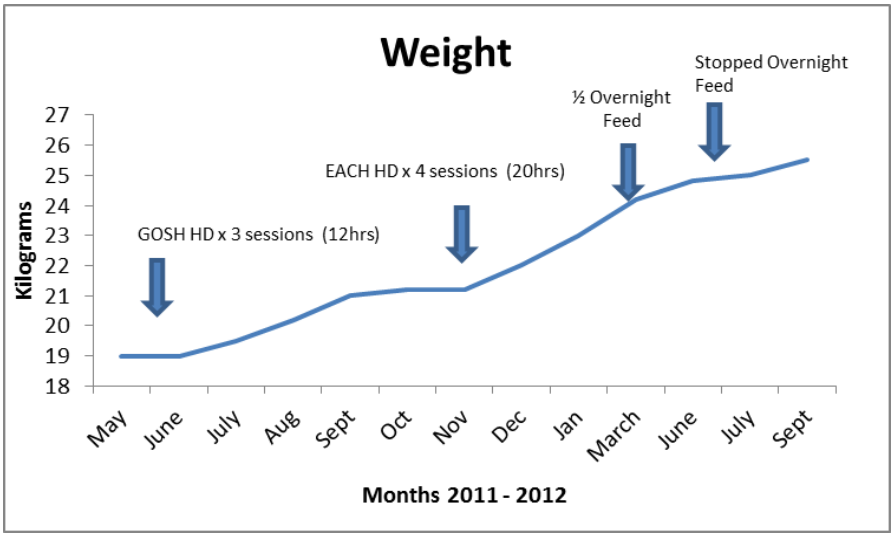
C) Innovative Care: Assisted Home HD in a Children's Hospice, Quidenham (Patient X)

- Free from fluid and dietary restrictions
- Improved blood results
- Quality of life for patient and their family
- Improved school report
- Improved social skills with children her own age
- Mum being able to start voluntary work
- Sibling support

Teaching Assistant:

“Since dialysis at Quidenham her work and effort that she has made at school has been excellent. She especially enjoys reading,maths and science. We are really pleased with how Kaychanel is doing and it is a joy for children and staff to have her back in school on a regular basis”

Nutrition



Patient X:

“The chef is really good to me and makes me all the meals I really like. My favourite is pizza topped with cheese and mushrooms and jacket potatoes. I get really hungry when I have dialysis’’

D) Managing A Hypotensive Child with Severe, Symptomatic Heart Failure
CASE PRESENTATION

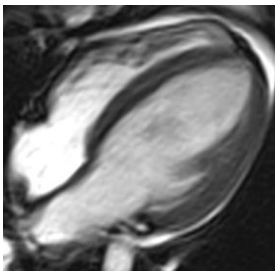
- Anuric, dialysis dependent, 11 year old girl
- Diagnosed with bilateral Wilms’ tumours at 3 years of age and was treated with anthracyclines and bilateral nephrectomies
- She commenced conventional dialysis in 2005 through a central venous catheter
- Immune thrombocytopenic purpura at 9 years of age
- From 2010 it became increasingly difficult to achieve good volume control. She became:
    - increasingly breathless with severely reduced exercise tolerance
    - struggled to climbs stairs and even attend a half day at school
    - lethargic with poor weight gain
    - she had developed several episodes of overt pulmonary oedema

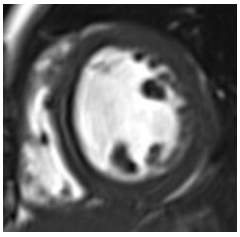
CASE PRESENTATION

- In 2011 exploring the possibility of a renal transplant she underwent a number of cardiac investigations that demonstrated frequent ventricular ectopics and severe cardiac dysfunction
- With a diagnosis of cardiomyopathy secondary to anthracycline cardiotoxicity and volume overload she was suspended of the transplant list
- We commenced 4 hours dialysis, 5 times per week in-centre on the NxStage™ in July 2012. One month later with both her parents she commenced home HD on the same dialysis schedule.
- Her pre-dialysis systolic BP ranged from 70-80mmHg falling to the 60s and

occasionally 50s during dialysis without her mounting a tachycardic response.

August 2011



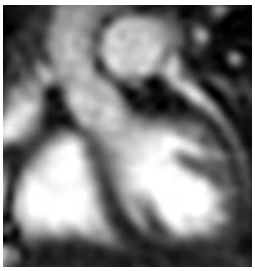


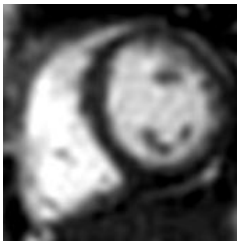
LV mildly dilated
Globally and severely impaired systolic function (LVEF 29%)

LV mass is upper limit of normal
Appearance of myocardial architecture within normal range

RV underfilled, with mildly impaired systolic contraction (RVEF 51%)

March 2012



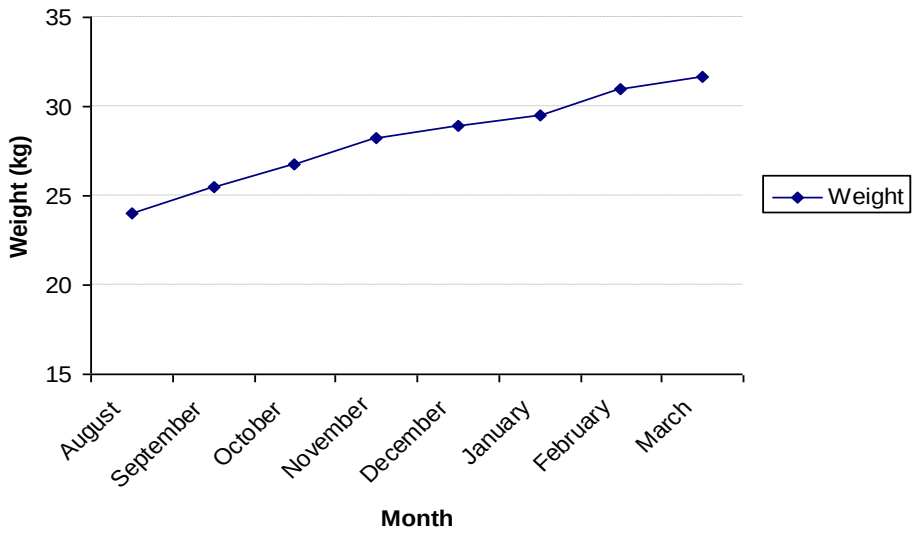


Normal sized LV without any LVH

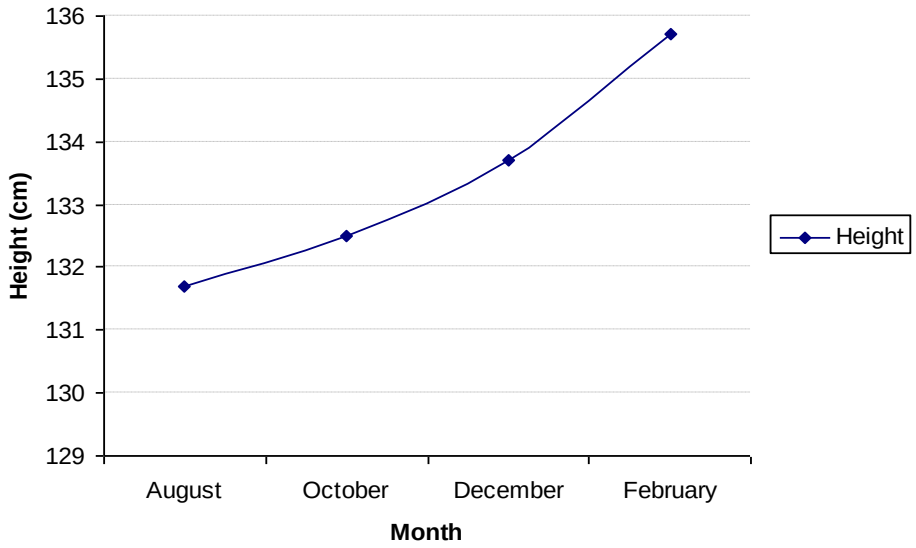
Normal left ventricular systolic function (LVEF 60%) (RVEF 58%)

In comparison to previous scan, this study shows significant improvement in biventricular systolic function and reduction in LV volumes

Patient Y: Weight



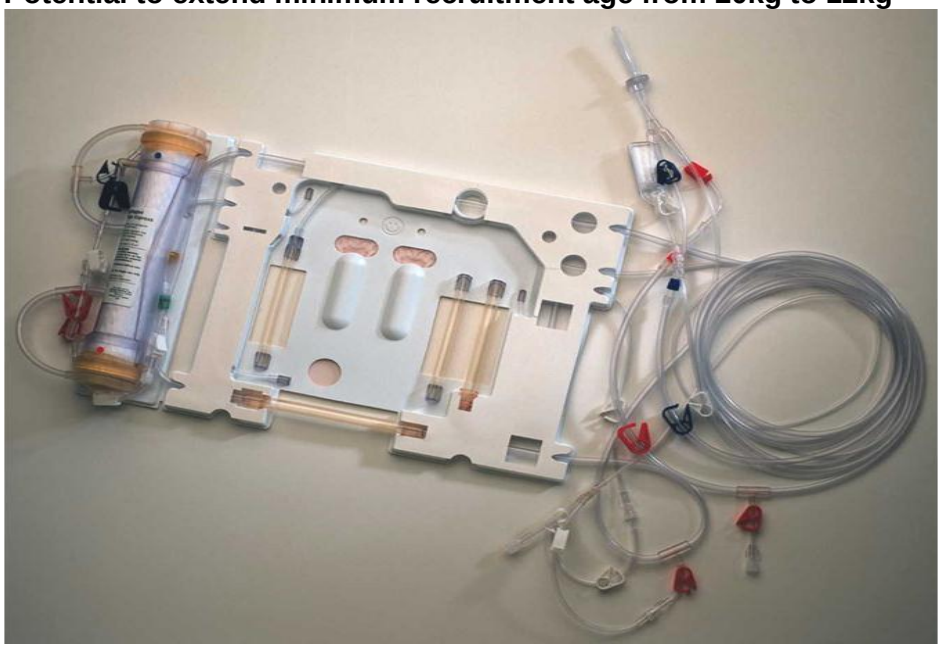
Patient Y: Height



E) CAR 125

- New Paediatric Circuit
- First to use internationally
- Circuit modified by Lynsey Stronach (CNS) for use

Potential to extend minimum recruitment age from 20kg to 12kg



Infant – 3 years old

- 5 times per week dialysis – family choice
- Home December 2012
- Starting weight 15.4 kg. Now 17.6 kg
- Continues gastrostomy feeds but eats small amounts.
- Height increased from 94.4cm - 100cm
- Not requiring UF

HHD Treatment Plan

Height (cm)	**94.4**
Surface Area (m²)	**0.66**
ECBV (mls)	**123**
Circuit (CAR-172/CAR-124)	**125**
Dialyser	**90 sureflux**
Dialyser Surface Area	**0.9**
Blood Flow Rate (ml/min)	**120**
Flow Fraction (%)	**50**
Dialysate (Litres)	**10**
Dialysate Bags	**205**
UF goal (Litres)	**0**
Estimated Treatment time	**3hrs**
Dalteparin (iu/treatment)	**900**

Infant – 4 years old

- 4 times per week dialysis
- Home December 2012
- Starting weight 19.2 kg. Now 19.7kg
- Continues gastrostomy feeds but eats small amounts.
- Height increased from 101cm to 105.6cm
- Not requiring UF

HHD Treatment Plan	
Height (cm)	**101cm**
Surface Area (m²)	**0.78**
ECBV (mls)	**1568**
ECBV: 8 – 10% (mls)	**156**
Circuit (CAR-172/CAR-124)	**CAR-125**
Dialyser	**90 surefl**

	ux
Dialyser Surface Area (m^2)	0.90
Cartridge + Dialyser Vol (mls)	110
Blood Flow Rate (ml/min)	150
Flow Fraction (%)	30
Dialysate (Litres)	10
Dialysate Bags	209
Estimated Treatment time	4 hrs
Dalteparin (iu/treatment)	1000iu

TIME LINE

July 2010	Application to GOSH Trust Board approved for a 4 Year Pilot Programme
Oct 2010	First Patient Trained and Discharged Home
Dec 2011	First Assisted HHD Patient: Hospice nurses trained to provide HD closer to home
March 2012	SLA Established with Evelina Children's Hospital
Aug 2012	GOSH Trust Board Approved request to change status from "Pilot" to "Substantive"
Dec 2012	First patient discharged home on the adapted CAR125 circuit

11.6 PERITONEAL DIALYSIS AUDIT

April 2012 – March 2013
Suzanne Bradley, Rachael Rogers & Eileen Brennan

Patient Demographics

25 patients have been on the ESRF PD programme
14 Male : 11 Female

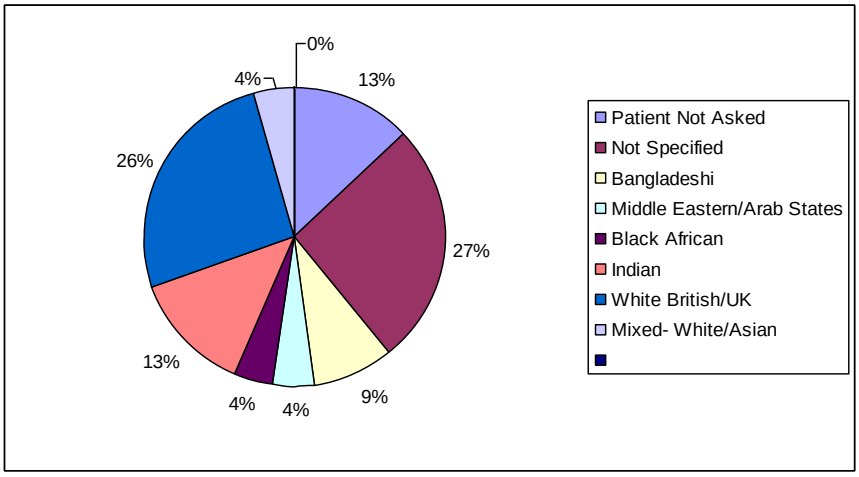
Dialysis Modality: APD = 23
CAPD= 2

14/25 = new patients

3 infants & 3 toddlers (1 patient is yet to be discharged)
1 patient with failed renal transplant graft-acute presentation
1st patient with MMA

Parental – Single parents =3

Ethnicity



Diagnosis

Diagnosis	Number
Posterior Urethral Valves	4
Dysplasia	4
Bilateral Hydronephrosis	3
FSGS	2
MMA	1
Congenital Nephrotic Syndrome	2
Alport Syndrome	1
MPGN	1 & ? 1
Nephronopthesis	2
Unknown (Stage 5 CKD presentation)	4

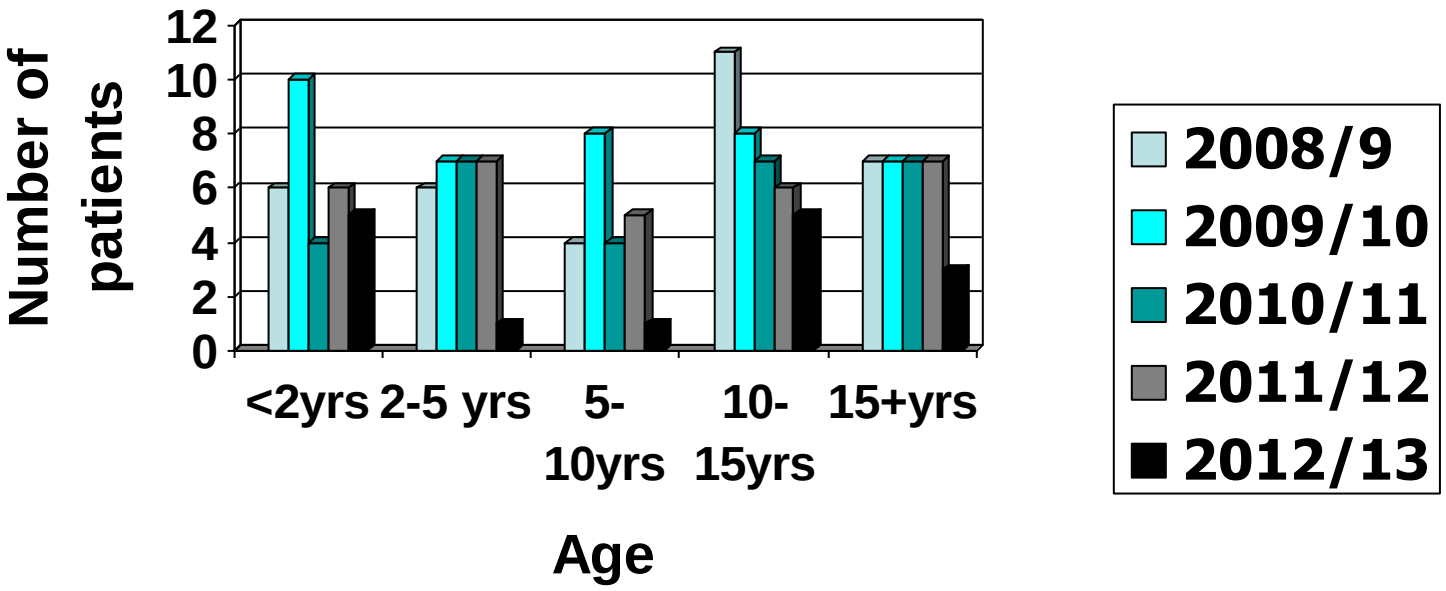
Patient Age range

- Children on POC in the community
  Age Range: 2 months to 13 years

Youngest starting PD – 3 days (RT)
Youngest discharged on PD – 2 months (LE)

ESRF TOTAL PD MONTHS = 168 months

Patient Age Ranges
2008 to 2012 (end of audit year)



Inpatient Admissions

Reason for admission	No.	
New Diagnosis	7	
Catheter insertion/Training	12	
Peritonitis (treated + eosin)	9	Eos 2
Surgical interventions/Catheter problems	4	HP VS FL ZO
Renal Transplant	LRD 2	DD3

Annual Figures 2005/6 – 12/13

	05-06	06-07	07-08	08-09	09-10	10-11	11-12	12-13
Patients	41	37	34	34	40	29	31	25 (1PX)
New Patient	17	18	15	15	20	**11** (3PX)	16	14
No. at year end	18	20	20	19	19	15 (1PX)	10	14
Transplants	12	14	8	6	15	6	13	5
Transfers	3	0	0	2	0	2 (PX)	0	1
To HD	6	2	5	4	7 + 1temp	6	7	3
To CRF	1	1	2	0	0	0	0	0
Deaths	0	1	1	3	2	0	1	1

Total catheters of current ESRF & AKI 29

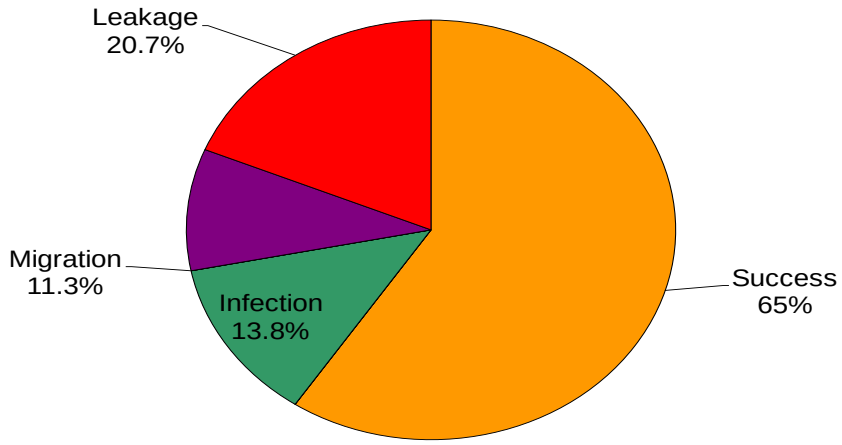
Surgeon	Cath Number	% Failed ESRF	% Failed AKI	Leaked post op	Migration
A	7	4	2	4	2
B	1	1	0	0	1
C	5	0	0	0	0
D	3	0	0	0	0
E	6	0	0	0	0
F	3	2	0	1	1
G	2	1	0	1	0
H	2	0	0	0	0

Catheter failure

- **7 AKI catheters inserted**
  - **1 leak - stopped PD**
  - **1 developed peritonitis while waiting for removal (in hospital)**

- **22 ESRF catheters inserted**
  - **5 leakage (All high risk)**
  - **3 migration**

Reasons for failure within 1st 3 months



Inpatient & LRCAP History

- Number of Inpt Episodes: 48 (88 last yr)
- Number of Inpt Days: 603 (824 last year)

CP-15days
JE-7days
FL- 48 days as PD patient pre converting to haemo

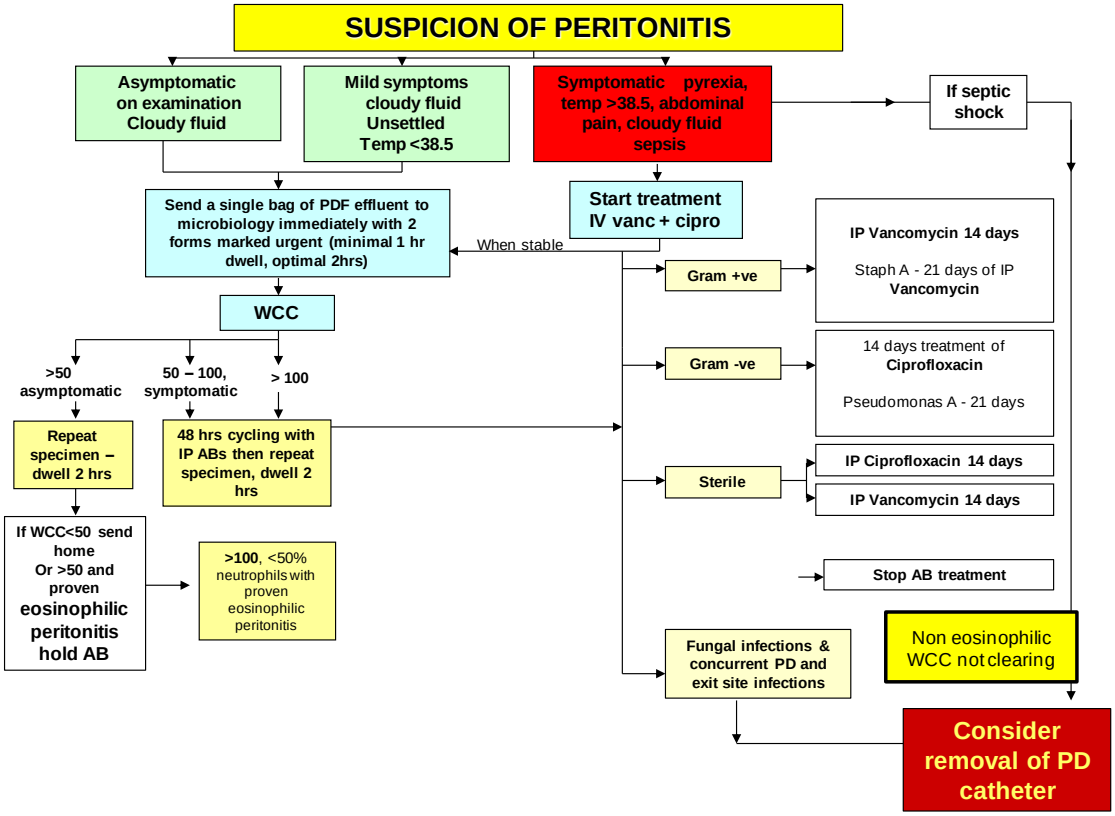
- Patients had no admissions in audit year

LRCAP OPA's
PD children attended=173
DNA/Cancelled= 21

`

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

- Cloudy effluent fluid
- WCC > 100mm and > 50% polymorphonuclear leukocytes (++ Neutrophils)
    - +/- pyrexia
    - +/- vomiting
    - +/- abdominal pain
- Relapsing = A recurrence of peritonitis with the same organism within 4 weeks of completion of treatment



Treated Peritonitis

- ORGANISM CLASSIFICATION
  - 4 Episodes of GRAM POSITIVE
    - Staph Aureus: 1 episode (RS)
    - Streptococcus species: 2 episodes (Viridans Strep) (ZO)
    - Enterococcus species: 1 episode (LE)
  - 1 Episodes of GRAM NEGATIVE
    - Coliform: 1 episode (NA)
  - 4 Culture Negative

Peritonitis (ESRF)

9 episodes of 'true' peritonitis
Culture Positive episodes= 5
Culture Negative episodes=4
Catheters removed due to infection= 4 (RS/LE/CW/FL)

2 patients had eosinophilia peritonitis (LE/VS) shortly after starting PD

Peritonitis Episode Breakdown

- 9 episodes of peritonitis in 168 patient months
- Eosinophilia x 2

= 0.64 episodes per 12 patient months
i.e. 1 episode in 18.75months
Peritonitis rates should be < 1 episode per 12 patient months (BAPN, 2007)

Current BAPN Guidelines (2007)
Peritonitis rates should be < 1 episode per 12 patient months

2008-2009	2009-2010	2011-2012	2012-2013
0.89	0.72	0.83	0.64

- **Total of episodes in patients**
  - **Outpatients - 8 episodes**
    - **2nd to Exit site/tunnell: 3 episodes**
    - **Line break: 0**
  - **Inpatients - 1 episodes**
    - **Post insertion of 3 catheters: over 2 weeks**

THEREFORE

- **16 patients peritonitis free**
- **(Plus 2 went straight to HD)**

Peritonitis						
	07-08	08-09	09-10	10-11	11-12	12-13
Total episodes	24	17	16	16	12	9
Culture -ve	13	10	5	7	4	4
Staph Epi	3	2	3	2	2	0
Staph Aureus	3	1	0	3	1	1
Candida	0	1	0	0	0	0
Enterococcus /coliform / E coli	2	3	3	0	2	2
Strep	0	0	2	2	0	2
Pseudomonas	3	0	3	0	1	0
Corynebacterium	0	0	0	1	1	0
Klebsiella	0	0	0	1	1	0

Exit Site Infections
(red/inflamed/exudate)

Organism	Infections	Treated with AB's	Catheter Removed
Staph aureus	3	3	1
Pseudomonas	3 (2=same patient)	3	1
Coag neg staph	2	2	2

Peritonitis episodes secondary to Exit Site Infections in the Audit Year

Exit Site Infections
(red / inflammed / exudate)

	2006 2007	2007 2008	2008 2009	2009 2010	2010 2011	2011 2012	2012 2013
Staph aureus (SA)	7	5	7	6	5	2	3
Coag Neg Staph							2
Pseud.	3	2	0	2	2	3	3
MRSA	1	0	0	0	0	0	0
Catheter removals * With peritonitis	**3 2 x pseud 1 x MRSA**	**2 1 x SA***	**0**	**2 1 x SA 1 x pseud***	**1 + 1 cuff shaved**	**0**	**4 RS CW LE FL**

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

Organism	Number	Treated with topical AB's
Coag neg staph	7	0
Stenotrophomonas Maltophilia	1	1
Staph Aureus	1	1

Nasal Colonisation

3 patients had nasal *Staph aureus* carriage:

- ALL received topical treatment
- 2 SA
- 1 with SA & MRSA

Patients Leaving PD programme 2012-2013

Reason		**Number**
Transplant	LRD =2 DD=3	5(JB/OEB/EZ/KF/TN)
Transfer		1
Transfer to Haemodialysis	Peritonitis Adhesions Catheter Failure	3 (RS/HP/FL)
Died		1

Clinical Nurse Specialist Activity

- PD training
- Home Assessments
- Home visits at Discharge on PD
- Home visits (social concerns/extra training)
- School visits

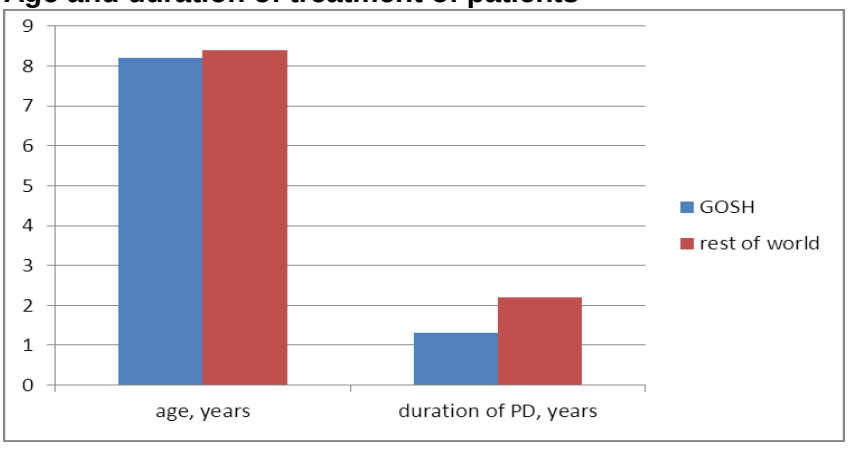
- MDT meetings/ Child Protection
- Clinical and emotional/practical support
- Advocate

2013 and onwards
- Revised protocol for Peritonitis end of Jan 2012
- Treatment for Eosinophil Peritonitis
- Inpatient training
- Burden of Care on families
- Alternative home dialysis therapy HHD
- Working in partnership with families
- CNS Adolescent Care in PD clinics/Transition/Adolescent friendly paperwork
- Audit tool re criteria for insertion of PD catheter for ESRF

Thanks
- Renal Consultant Team
- Dr. Lesley Rees
- Dr. Ruckshana Shroff
- Dr. Sarah Ledermann
- Transplant surgeons Guys/Evelina
- Michelle Cantwell
- Nora Tahir
- Maria Rodriguez
- Eagle ward staff
- Renal support unit team

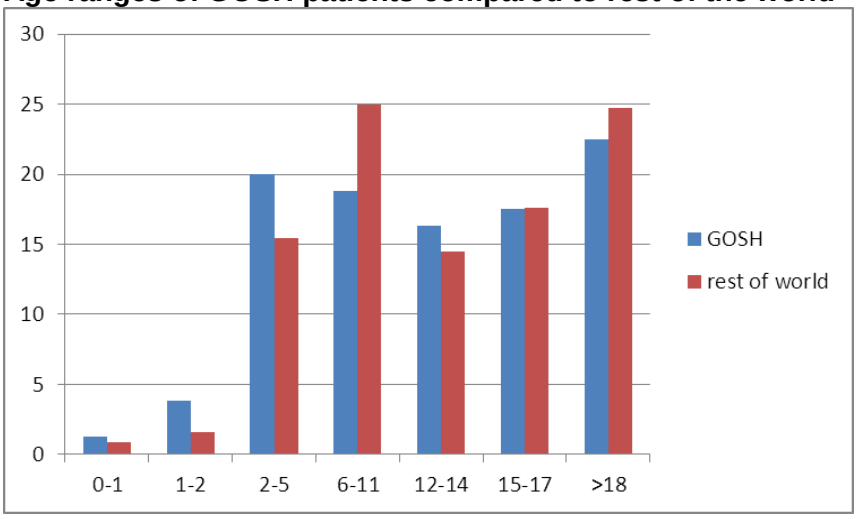
11.7 GOSH PD PATIENTS IN COMPARISON TO IPP PD NETWORK DATA

Age and duration of treatment of patients



Patients in registry, GOSH 80, rest of world 2146

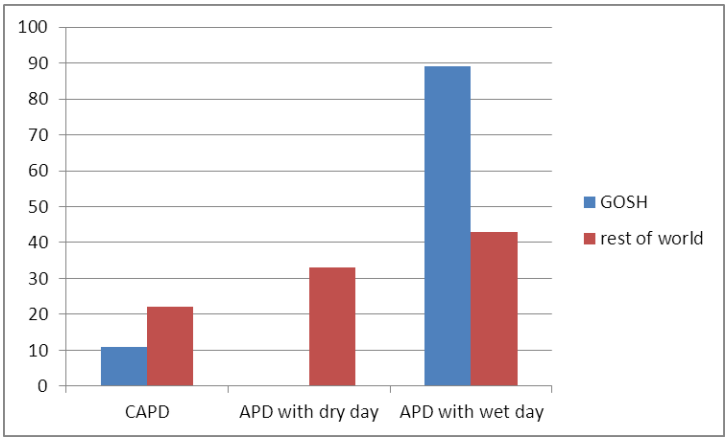
Age ranges of GOSH patients compared to rest of the world



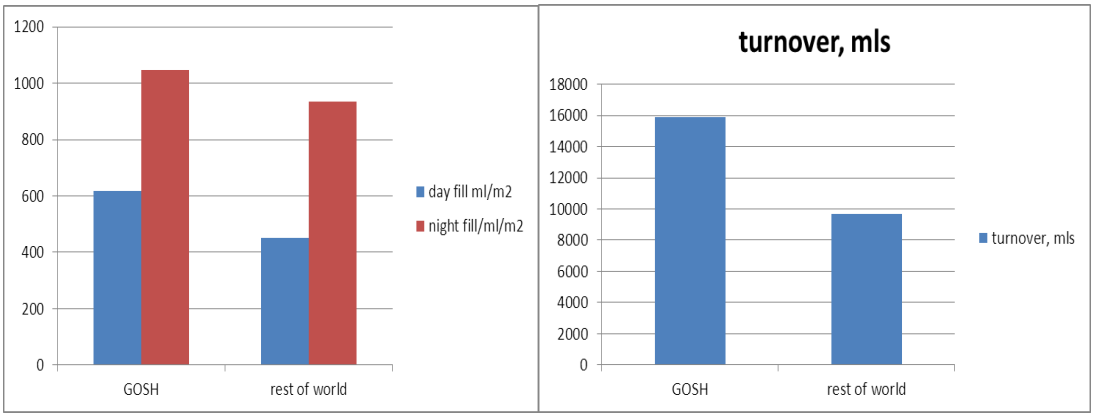
Peritonitis and exit site infection rates, hospitalisation and GFR at start of PD

	GOSH	Rest of world
Peritonitis per treatment months	7.3	6.7
Exit/tunnel infections per treatment months	8.6	8.2
Hospitalisation days per year	19	37
GFR at start	12	13

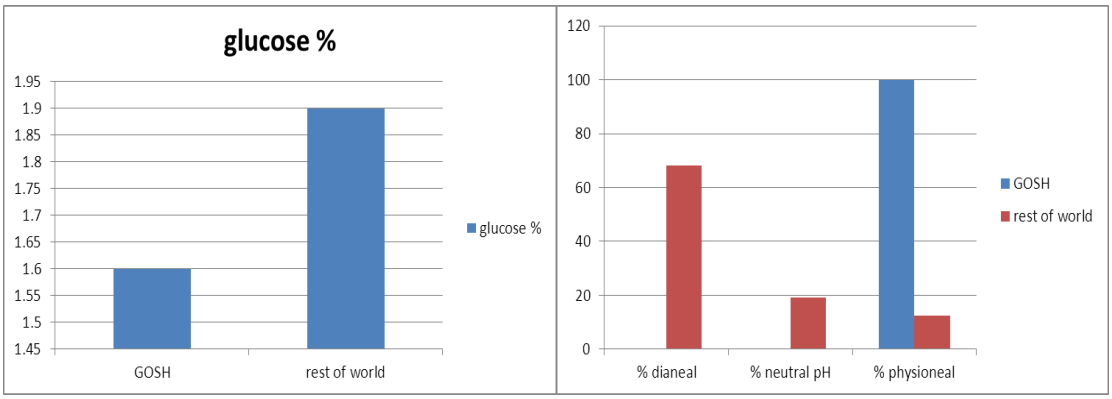
Types of PD (%)



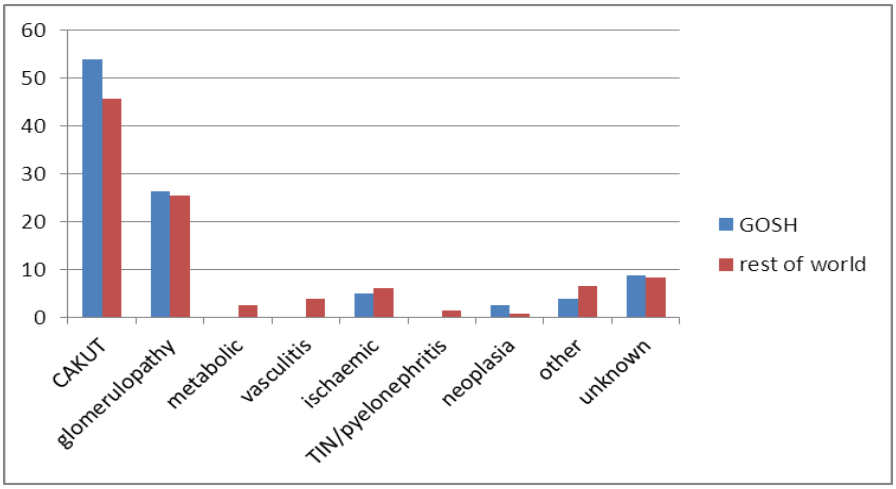
Fill volumes and daily PD turnover (mls)



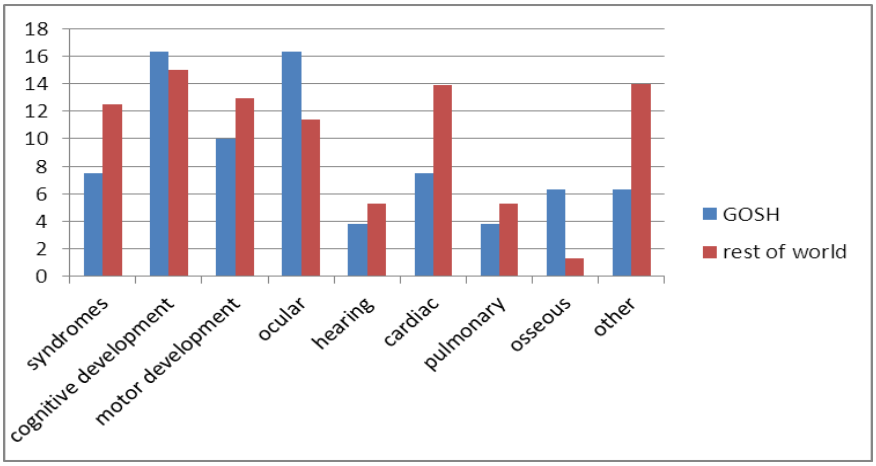
Dialysate glucose concentration and type of dialysate



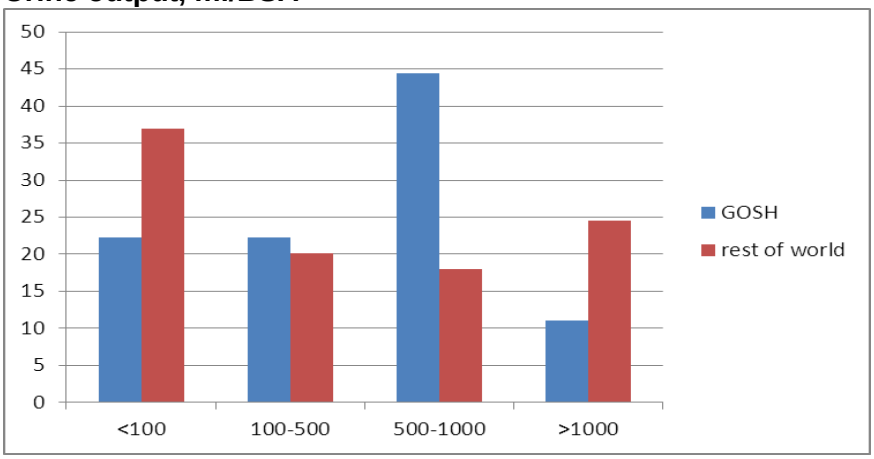
Diagnoses



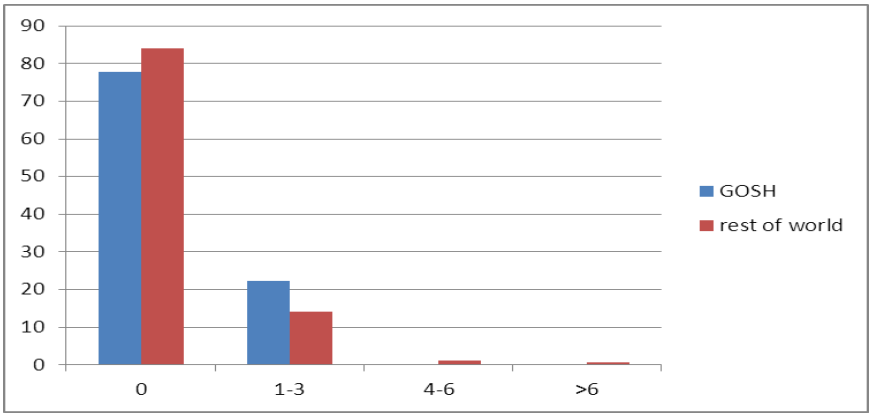
Co morbidities



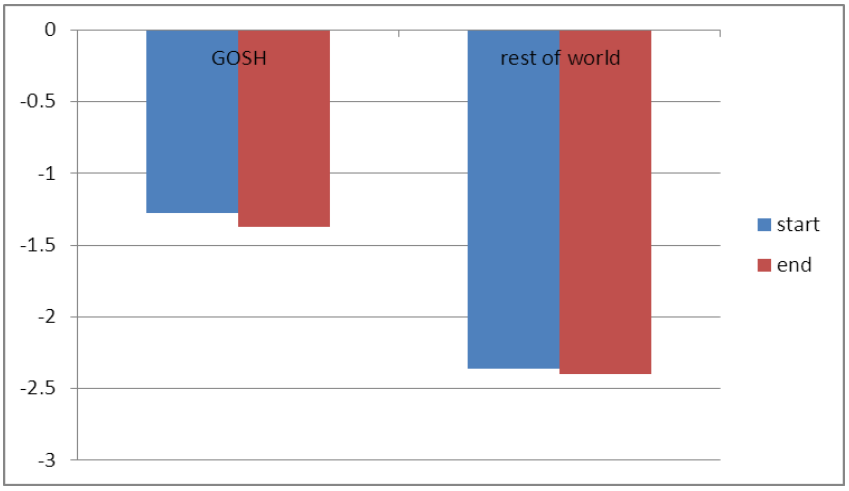
Urine output, ml/BSA



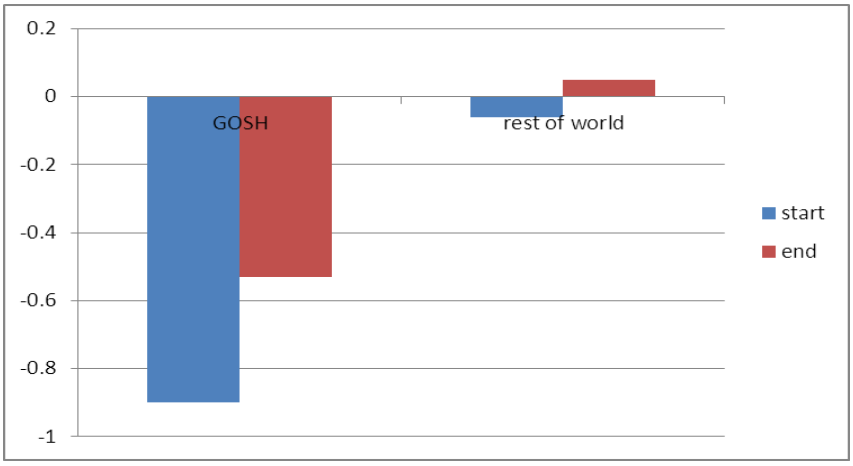
Exit site score



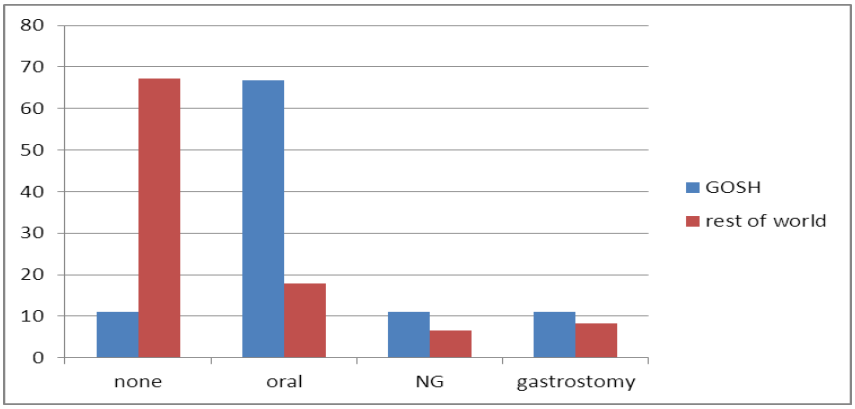
Ht SDS at first and last assessment



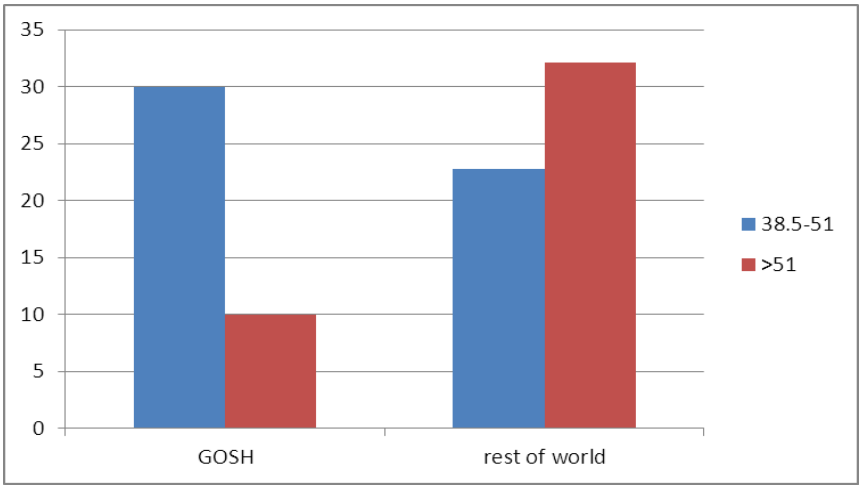
BMI SDS at first and last assessment



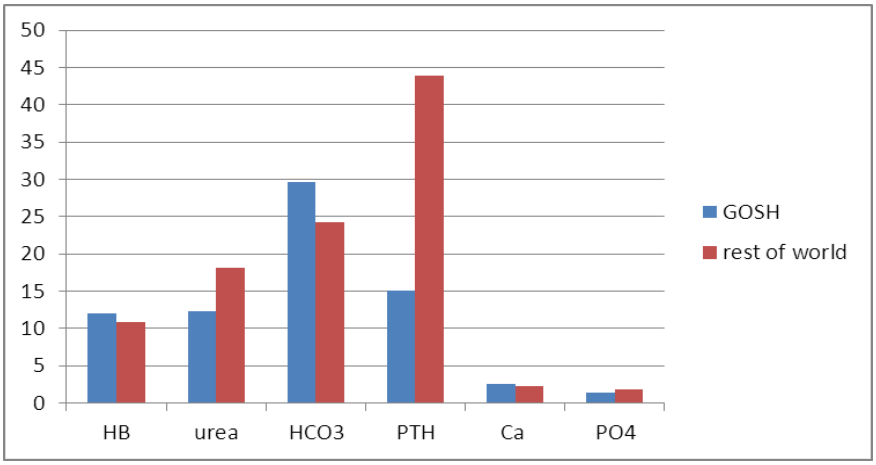
Feed supplementation



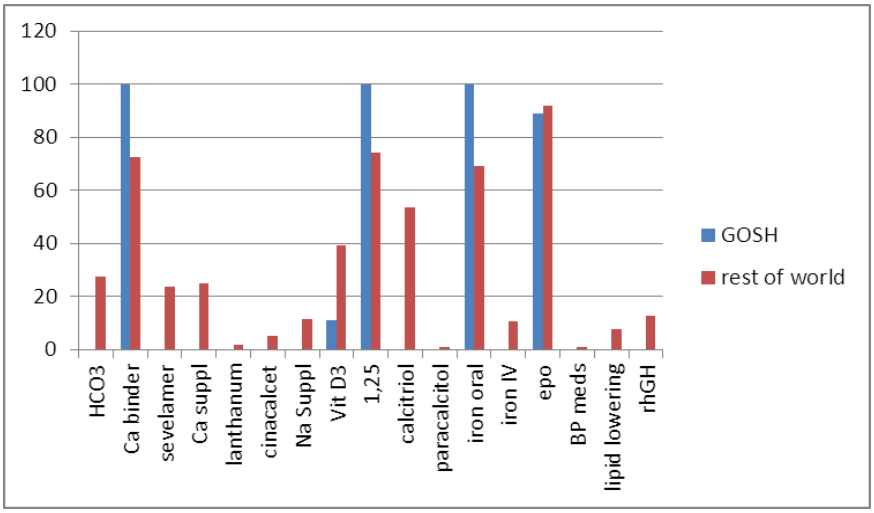
LVMI, g/m2



Haematology and biochemistry



Medications



12. NURSING REPORT

The move to the Morgan Stanley was completed successfully in April 2012. The team work and resilience achieved a safe and seamless transition to the new unit. The integration of the Haemodialysis unit and the ward is a work in progress as the newly appointed practice educator works tirelessly to bring consistency and continuity to both areas. The units goal is to continue to deliver a world class renal service for children and there families. The exceptional contribution to the move lead by the ward sisters Sarah Owen and Lucy Thomas was in part recognised by the hospital when they were awarded the Team leaders of the year at GOSH. The evaluation of the first year in Eagle ward is underway.

12.1 STAFFING AND CLINICS

Nurse Consultant	Eileen Brennan
Ward Sister	Sr. Sarah Owen Sr. Lucy Thomas
Practice Educator	Trish Evans, Renal unit (WTE) Clare Solomons HD (WTE)
Clinical Nurse Specialists	PD Suzanne Bradley (1 WTE) Transplant coordinators Maria Scanes (0.64 WTE UKT 0.03 WTE GOSH) and Katie Knapp (1 WTE). Senior Sr. Liz Wright (1 WTE) PD Michelle Cantwell (1 WTE) Mat leave Transplants senior staff nurse Jenny Tanton (0.88 & Kate Sinnot (1.0 WTE) PD Senior Staff nurse Rachel Rogers(1WTE) Nephrotic nurse specialist Hazel Webb (1 WTE) Lynsey Stronach CNS Home Haemodialysis Cecilia Mcneice (.88WTE)

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	

	& review of children in the community	

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
5 Band 3 Health Care Assistants
1 Band 4 Health Care Assistants
2 Housekeeper

Haemodialysis Unit establishment comprises:
1 Haemodialysis /Plasma Exchange CNS Band 8
1 Band 6 Practice Educator
3 Band 6 Senior Staff Nurses
3 Band 5 Staff Nurses (rotates to Eagle ward for one week per month)
2 Band 3 HCA & 1 band 4 HCA

Haemodialysis has lost a number of senior staff this year due to decisions not to return following Mat leave and a change and the ward sister leaving to take up health visiting. The 2 established sisters on Eagle ward have taken over some of the roles of management with the senior nurse Liz Wright following the amalgamation of the two areas. The first year of radical changes has proved a challenge for all concerned and we continue to work on this area to provide a high quality service. The further development of home HD has relieved some spaces for in-service dialysis resulting in smaller more dependent babies being cared for on HD.
All the areas provide a very high standard of nurse led services guiding and teaching junior doctors to care for children with renal conditions.

New initiative

This year we have been awarded additional posts to further develop the private patient initiative. This includes 2x band 6, 5x band 5, 2x band 3 and 1x band 7
Once the staff are recruited an additional 1.5 bed will be opened on the ward

UCH have provided a service of Plasma Exchange for a number of sessions for the unit and other areas at GOSH. The plan is to work towards taking this service in house if possible

12.4 EVENTS 2012/13

- GOSH assisted in the organization of the annual Paediatric Nurses Nephrology Conference Birmingham. It was attended by over 100 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

12.6 PRESENTATIONS

Eileen Brennan:
Southbank University non medical prescribing for children & adolescences

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

The investigation & treatment for hypertension in children
Cardiac study day at the Lister hospital medical trainees

Measurement of blood pressure in young children
Medical trainees
Royal college of Physicians London

ICH Nephrology for general paediatricians
The investigations and treatment for children with hypertension

ICH international paediatric nephrology week
Work shop on ambulatory blood pressure monitoring
Workshop on peritoneal dialysis

Lynsey Stronach:

The sixteenth congress of the International Pediatric Nephrology Association
7 poster presentations with Daljit Hothi - see below
Using The NxStage System To Deliver Evening and Nocturnal Paediatric Home Haemodialysis
Use of Low Molecular Weight Heparin during Paediatric Home Haemodialysis
Intradialytic Thrombocytopenia During Home Haemodialysis
A Weight Criteria for Home Haemodialysis: How Low Can We Go?'
Home Haemodialysis Education Package
Managing a hypotensive child with severe, symptomatic heart failure on home haemodialysis
Assisted home haemodialysis in a children's hospice

5th Annual Home Dialysis Conference, Manchester
Innovative Care : East Anglia Children's Hospice Quidenham

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

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:

Lynsey Stronach – Completed MSs Children's Advance Nurse Practitioner September 2013

Jo Newton successfully completed 2 modules of MSc in ANP pathway

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.

12.8 Publications

Rapid head growth in a baby with ADPKD Question
Shute R, Jeelani O, Lee L, Brennan E, Bockenhauer D, Barnicoat A, Shroff R. Pediatr Nephrol. 2013 Jun 4. [Epub ahead of print] No abstract available.

Rapid head growth in a baby with ADPKD Answer
Shute R, Jeelani O, Lee L, Brennan E, Bockenhauer D, Barnicoat A, Shroff R. Pediatr Nephrol. 2013 Jun 6. [Epub ahead of print] PMID:23740034

An action research study to explore the nature of the Nurse consultants role in the care of children and young people. Gregorowski A, Brennan E, Chapman S, Gibson F, Khair K, May L, Lindsay-Waters A.J Clin Nurs. 2013 Jan;22(1-2):201-10. doi: 10.1111/j.1365-2702.2012.04140.x. Epub 2012 Jul 27.

Renal artery revascularisation can restore kidney function with the absenct radiotracer uptake. Tse Y, Marks SD, Brennan E, Hamilton G, McLaren CA, Roebuck DJ, Tullus K.Pediatr Nephrol. 2012 Nov;27(11):2153-7. doi: 10.1007/s00467-012-2235-4. Epub 2012 Jun 29.PMID: 22744769 [PubMed - indexed for MEDLINE]

12.9 RESEARCH

Eileen Brennan
PI GOSH Supporting parents to care for children's kidney conditions

Evaluating a tool kit for nurse consultants and advance nurse practitioners.

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

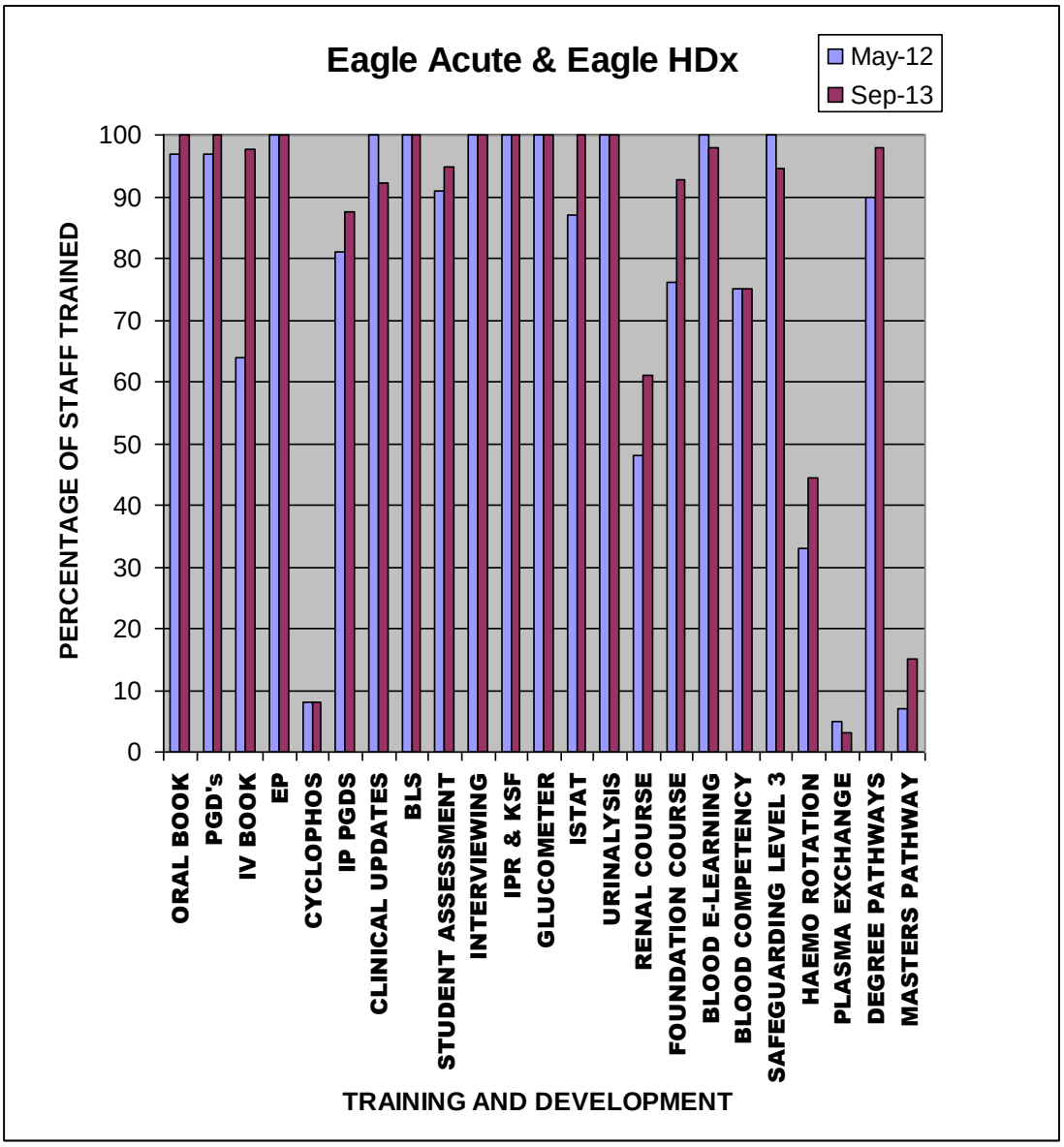
Home Haemodialysis
This service offers home haemodialysis to children. Originally this service was offered to children of 20kg and above. The lead nurse and nephrology consultant has stretched the boundaries of this service with skill and expertise to younger and smaller children (12kg) by devising different systems enabling smaller and younger children to take advantage of home haemodialysis using NxStage portable haemodialysis machine. The number of children established on Home haemodialysis is currently 12, 4 are on Nocturnal HHD. Since establishing the program 15 children have been established on home HD, 3 have now been transitioned to adult services. 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 with them to establish a national HHD network.

Living donation program
Additional resources have been made available to the unit to expand the international private patient programme for living donation renal transplantation.

Play Specialist
This year we have had our long awaited play specialist replaced by Lynsey Steele and play worker Victoria Tomkins. This additional support had made a considerable difference to the preparation of children for transplantation, needle phobia and accessing fistulae. We are delighted to see these services re-established within the unit, putting the children and families first.

Education – Trish Evans:

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

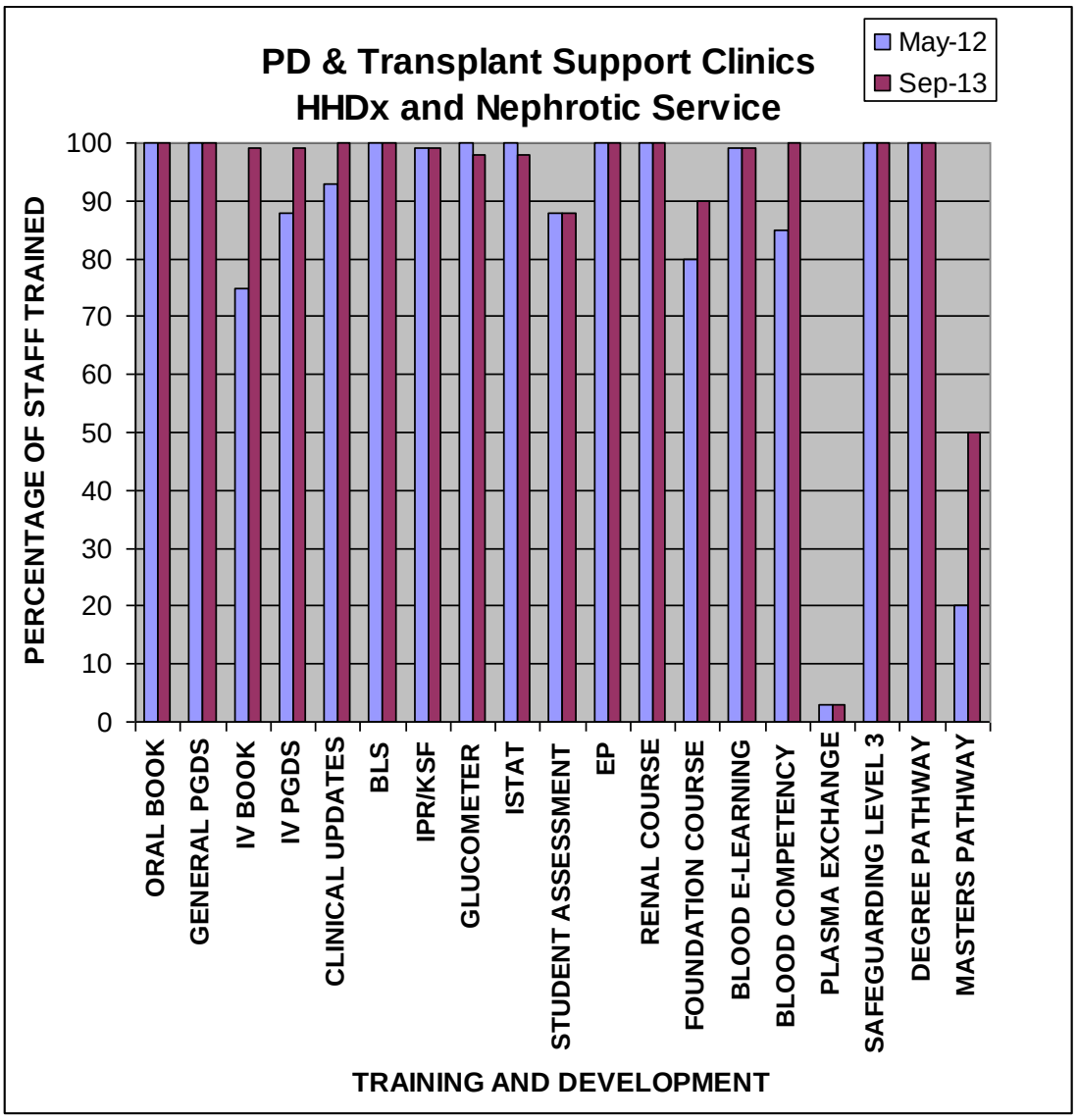


Analysis of Data:
Average % of Nursing Staff Trained in Core & Specific aspects: 90%
All staff have completed their Safeguarding Level 3 e-learning module but in order to be fully competent this needs to be followed up with a Face to Face 1.5hr update

session. In practice this is difficult to achieve due to availability of training, clinical commitments and releasing staff to attend. Bookings have been made for the remaining staff to achieve competence by December 2013.

The number of IV competent nurses has increased from last year which reflects their stage of development. This will decrease in the immediate coming months to reflect unfilled vacancies and new starters. It is anticipated that our newly qualified nurses due to start will take 6 months to become IV competent.

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: 99%

<u>Continuing Professional Development</u>

Developing Skills and Competence in Professional Practice, Work Based Learning Module: 20 Credits - Caring for a Child or Young Person with Renal Disease:

This work based module is now led by Great Ormond Street Hospital with an accreditation package purchased through London South Bank University. This

module consists of a choice of two components; Cardiac or Renal Disease. 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 2012 intake consisted of 8 Nurses, 7 Degree Level, 1 Masters Level representing renal units from GOSH, Southampton and Nottingham. Seven students successfully completed their reflective logs, one student was referred but passed their log on re-submission. Of the seven students who successfully completed their reflective logs, six successfully passed their case presentations and one nurse referred. This nurse went on to refer again at re-sit, thereby failing the course overall. October 2011 saw one nurse with extenuating circumstances re-submitting with the October 2012 group and went on to successfully pass the case presentation. Therefore October 2011 achieved a 100% pass rate overall and October 2012 saw an overall pass rate of 99%. This academic year module is due to commence in November 2013 and currently has 8 applicants. The components of the course are: face to face teaching, problem based learning, blended learning, reflective logs and an oral case presentation. The course lead at GOSH is Elizabeth Leonard, Lead Practice Educator, Cardiorespiratory and the renal element is led by Trish Evans, Practice Educator, Eagle Ward/Renal Unit.

Foundations of Paediatric Renal Nursing:

This course remains an essential component to be undertaken by all new starters following their 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 clinical competencies to complete. Each staff member 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 Knowledge and Skills Framework. The next course commences in April 2014 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 nurse 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

This year we have incorporated simulation training into all team away days. This took place in the simulation suite and feedback from nurses' state this training is essential to provide them with the clinical skill required for early recognition and prompt management of the child in Cardiac Arrest. A natural progression was to

bring a CET SIM (Mock 2222) to the ward to consolidate the simulation sessions and for nurses to apply their skills to a 'real event'. This took place at 11.30 on a Wednesday morning with only the senior nursing ward team aware. This ensured the ward could accommodate this training safely and to alert families that training would be taking place with the aim of improving patient care and outcomes. All multidisciplinary team members who were on the ward at the time attended and following feedback recommendations were given and auctioned. Simulation training, both in the suite and ward based, will continue as a priority for nursing and medical staff on Eagle.

Eagle HDx Rotation

Following the employment of an Assistant Practice Educator the rotation between 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. Since last year two Band 5 nurses have become competent in their core skills and a further two are commencing on their rotation imminently. The Band 6 senior staff nurses are also rotating to increase their Advanced Haemodialysis clinical skills. An in-charge checklist has been adapted from Eagle Acute and to date 18 Protocols/Guidelines have been written and implemented.

Eagle HDx – Student Nurses

Following the introduction of Haemodialysis becoming an Interface Placement for LSBU student nurses last year, the unit has seen two students successfully complete this placement and feedback is due to be gained from the university. These student nurses gained valuable insight into how renal patients live with their life limiting disease whilst receiving haemodialysis sessions three times a week, as well as gaining essential nursing skills such as fluid balance, measuring accurate weight and height's of patients and learning the art of taking manual blood pressures.

Eagle Ward:

Following the merging of Victoria and Hippo to become Eagle Ward and the move into the Morgan Stanley Clinical Building an evaluation report is being compiled of all wards experiences during this process. This will be reported on in next years annual report.

13. DIETETIC REPORT

April 2012 – March 2013

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
Bahee Manickavasagar	Specialist Dietitian (until July 2012)
Louise McAlister	Specialist Dietitian
Vanessa Shaw	Head of Dietetics
Carolyn Southey	Specialist Dieititan (until December 2012)

13.2 TEACHING AND EDUCATION

Vanessa Shaw is the Education Officer of the British Dietetic Association's Paediatric Group and is an Honorary Associate Professor at Plymouth University, running the clinical modules in the MSc in Paediatric Dietetics. 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) and has presented to the renal dietetic team on the management of various renal conditions.

Jayne Holmes carried out nutrition education for Eagle ward renal nurses in April, June and December 2012.

Jayne Holmes carried out nutrition education for doctors working on Eagle ward in March 2013.

Shelley Cleghorn and Jayne Holmes taught 'Nutrition Bites' as part of hospital induction in 2012.

Jayne Holmes is a dietetic student lead for students undertaking their Placement 1 at GOSH.

13.3 PUBLICATIONS, PRESENTATIONS, AWARDS, APPOINTMENTS

Vanessa Shaw was appointed a 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 chairs the national dietetic renal group, PRING (Paediatric Renal Interest Nutrition Group).

Jayne Holmes presented 'Feeding Issues for the BMT Child' at the Bone Marrow Transplant MDT study day in April 2013.

Bahee's research project, "Relationship of dietary vitamin A, hypervitaminosis A and hypercalcaemia in children with progressing stages of chronic kidney disease" was

presented as a poster at BTS & RA Congress in March 2013 and was awarded 'Best Poster Prize'.

13.4 IMPROVING PATIENT CARE

Child protection

Bahee Manickavasager is a link member for Child Protection.

Resources

Louise McAlister is involved in a rolling programme for continually updating the Renal Dietetics Handbook (a best practice reference guide for renal dietitians) and the Dietitian's Handbook (a GOSH specific guide for day-to-day dietetic management).

Louise McAlister has been the lead in developing educational resources for further improving the care of renal patients – including low potassium and phosphate dietsheets. She has also assisted in the development of teaching material and other resources for use throughout the dietetic department.

Feed Products and Food

Shelley Cleghorn is actively involved with Vitaflo in the formulation of a new renal sip/tube feed and renal specific vitamin for children.

Surveys

The dietetic department collected patient data for the Children's Nutrition Survey, April 2012, an audit conducted by the University of Ulster to establish the prevalence of malnutrition risk in children admitted to hospitals in the UK.

13.5 GUIDELINE/POLICY DEVELOPMENT

Shelley Cleghorn was on the NICE Guideline Development Group. A short clinical guideline on the Management of Hyperphosphataemia in patients with stage 4-5 and 5D CKD was developed and published in March 2013.

Shelley Cleghorn and Jayne Holmes updated the Bone Marrow Transplant Special Operating Procedures (SOP's) which are available on the GOSH intranet

- Dietetic management of gut GvHD
- Nutrition support of HPC transplant
- Policy for pasteurising feeds in the Special Feeds Unit
- BMT patient Diet Kitchen meal policy
- BMT meals – frequently asked questions

Carolyn was 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 until she left on maternity leave.

13.6 RESEARCH

Bahee Manickavasagar is completing her research project, "Relationship of dietary vitamin A, hypervitaminosis A and hypercalcaemia in children with progressing stages of chronic kidney disease".

14. Renal Psychosocial team annual report 2013/2014

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.

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 including fabricated or induced illness, abuse and neglect, non-adherence and other complex family 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 and practical readiness for the transplant process including intervention around adjustment to illness, adherence and procedural anxiety. In over 40% of pre-transplant cases, psychosocial problems are identified by referrers at point of referral. 45 of the 116 referrals during the year were for pre-transplant assessment and preparation.

14.3 Non direct clinical work within the nephrology service: audit and research

Although limited by current staffing and clinical demand, the psychosocial team has been involved in the development of a patient experience survey, and are about to begin qualitative research exploring child and family experience of home haemodialysis.

14.4 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.

Training - Social workers are available and have delivered bespoke Level 3 safeguarding training to the unit.

14.5 Home haemodialysis psychosocial service
The renal unit at Great Ormond Street Hospital has developed a successful 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. In the first year all families met with a family psychotherapist for routine assessment and preparation for the home based treatment. They were also offered support after discharge home. As the service has become more integrated with the overall renal service, the formal requirement for this has changed and other psychosocial team members may meet with children and families to help them in this process. Families are asked to complete measures to assess their wellbeing, quality of life and functioning, before commencing dialysis and at regular stages thereafter. Alongside these quantitive measures, qualitative research is about to begin, focused on the child and family experience of HHD. We hope these measures will offer valuable information to complement data about medical outcomes.

14.6 Staffing
Lissil Averill, Social Worker (0.4 WTE)
Dr Fionna Bathgate, Clinical Psychologist (0.4 WTE)
Claire Dempster, Family Psychotherapist (0.5 WTE)
Dr Gwynneth Down, Consultant Family Psychotherapist (0.4 WTE),
Liz Nunn, Social Worker (0.5 WTE)
Indira Rajendran, Social Worker (0.5 WTE)

There has been an increase in social work service by 0.54 WTE in November 2012 and the work of the family psychotherapist for the Home Haemodialysis service has been integrated with the overall psychosocial provision for children and families.

14.4 Number of referrals to renal psychosocial team

	2006	**2007**	**2008**	**2009**	**2009/2010**	**2010-2011**	**2011-2012**	**2012-2013**
No of referrals to psychosocial team	86	109	123	120	161	186	128	116
Psychosocial Team WTE	**3.6 WTE** (2003 BAPN figures)					**2.3WTE** Excluding HHD	**1.6 WTE**	2.7 WTE from November 2012. including FT previously for HHD only

All referrals must 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 further reduction in total

referrals this year.The complexity of psychosocial issues has however continued to increase with more young people requiring intense support, both acutely and for long term psychosocial management. In many cases two psychosocial team members will be required as they bring their different skill sets to the management of different issues (e.g. social work and family therapy or psychology).

Clinical involvement

Psychosocial Services have recently been developing a data collection system to more accurately inform delivery and development of services. The data collected in between April 2012 and March 2013 was not yet valid so data below is from a 6 month period within the current financial year which we feel will give a representative overview.

Social work had recorded activity in relation to 175 named children
Family psychotherapy had recorded activity in relation to 54 children
Psychology had recorded activity in relation to 29 children.

This activity does not include attendance at regular multidisciplinary meetings in which multiple children will be discussed or service development meetings. A minimum of 18 person hours per week are spent in this important aspect of renal care pathways.

The psychosocial team has aimed to meet all newly diagnosed end-stage patients in order to provide families with an overview of the psychosocial service and to identify and address psychosocial challenges in the early stages of presentation.