GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST

RENAL UNIT FOURTEENTH ANNUAL REPORT

April 2013 to April 2014

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1. INTRODUCTION

This renal unit annual report is now in its fourteenth year. 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 2013 and April 2014.

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 305 beds are arranged in 40 wards and 4 day care units and include 51 intensive care beds in 3 ICU wards (PICU, NICU and CICU). There are 10 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 3,889 permanent staff and 366 Bank staff (excluding nursing). The Chief Executives during this year were Edward Jan Filochowski (until 31 Dec 2013), Julian Philip Nettel (from 01 Jan 2014) and the Co-Directors of Clinical Services are Professor Martin Elliott and Dr. Cathy Cale (Interim). 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 722 admissions to Eagle, the renal ward, 145 admissions to outlying wards, 7401 outpatients, 28 new renal transplants, 27 patients on chronic haemodialysis, 13 patients on home haemodialysis and 26 patients on chronic peritoneal dialysis.

The Unit comprises a 14-bedded ward. We have one bed that is funded entirely by International Private Patients for use by overseas patients. The Haemodialysis Day Care Unit has 10 stations and is now incorporated into the ward. 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	6 PAs in Paediatric Nephrology, and 6PAs 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	9.3PAs in Paediatric Nephrology
Dr Aoife Waters	6 PAs in Paediatric Nephrology (1 for Chelsea and Westminster)
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 6 Transplant Surgeons who share the care of our patients from their base at Guys Hospital: 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 Nurse Clare Solomons 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 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. Our 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. Vascular calcification is one of the most significant causes of cardiovascular mortality in CKD. Our 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.
My PhD and current research focus on cardiovascular disease in children with chronic kidney disease, with particular emphasis on mineral and bone disorders, in order to identify and reduce the burden of modifiable risk factors in CKD patients.
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 have worked 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 binders.
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 have represented paediatrics 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 >700 children with CKD across Europe. I am an Associate Editor for Pediatric Nephrology.

Translational research: I have extensively studied changes in the vessels from children with CKD to understand the pathophysiology of ectopic vascular calcification. In the course of my PhD, we have developed and validated a novel *in vitro* model of intact human arteries to study the effects of mineral imbalance and 'uraemic toxins' on the development and progression of vascular calcification. I now supervise a PhD student who is further exploring the effects of vitamin D on the vasculature. I also co-supervise a PhD student and post-doc who are 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; Eagle 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 so that they are no longer prescribed in our unit.
- *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

-Study of a new phosphate binder

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. Initial data indicate reduced intradialytic symptoms and hypotension and improved middle molecule clearance. A study comparing growth and cardiovascular outocmes of HDF vs conventional HD is currently running across the EU.
- *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 Rees 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 7398. The breakdown into clinics is shown in the table.

Clinic	**Patient Numbers**											
	2002-3	**2003-4**	**2004-5**	**2005-6**	**2006-7**	**2007-8**	**2008-9**	**2009-10**	**2010-11**	**2011-12**	**2012-13**	**2013-14**
Transplant	771	873	736	799	743	858	897	1034	1119	1080	1122	1074
Nurse Led Transplant	506	734	542	518	467	524	1387	1328	1231	1212	1108	1293
Low Clearance/ Dialysis	543	859	610	636	638	665	694	749	650	730	752	869
PreTx & GKRLTX					93	71	84	119	84	123	102	127
General and Specialist Nephrology	2467	4065	3199	3444	3194	3382	3464	3113	2929	3509	3126	3145
Nephrotic Syndrome	481	692	468	400	321	344	389	446	479	454	425	475
Stone	50	88	53	40	40	23	36	79	153	190	199	169
Blood Pressure Monitoring		23	51	65	78	94	109	193	195	208	227	246
Total	**4818**	**7334**	**5674**	**5902**	**5738**	**5962**	**7060**	**7061**	**7166**	**7506**	**7061**	**7398**

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

Clinic	**2012-13**	**2013-2014**
Hypertension telephone clinic	135	241
Nephrotic telephone clinic	199	145
Total	**334**	**386**

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
Reading	WvH	40	3	30
UCLH	PW	1.3	12	Approx 120-144

4. INTERVENTIONAL RADIOLOGY

The interventional radiology team performs various procedures for or in collaboration with the renal unit. These include renal biopsy, central venous access (usually for haemodialysis), other venous intervention (venous reconstruction procedures, fistula work and diagnostic venography) and angiography (mostly in patients with hypertension).

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
2013-14	57	82	0	13	0	152

Complications
Transplant biopsy: One transplant patient developed clot retention and AKI with a creatinine of 350 µmol l^{-1}. Two asymptomatic arteriovenous fistulae were identified at ultrasound performed for other reasons. One biopsy sample contained some liver tissue.
Native kidney biopsy: One patient (with thrombocytopenia) developed loin pain and fever on day 5, and was found to have a perinephric haematoma. One biopsy sample contained only 6 glomeruli and was not fully adequate for diagnosis.

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
2013-14	10	37	47

These numbers exclude access for other indications (e.g. stem cell harvest).

Complications of permanent (tunnelled) HD catheter insertion
Bleeding: One patient had severe bleeding requiring transfusion and catheter removal. Another patient who was being treated with aspirin had exit site bleeding which was controlled with tranexamic acid. Two patients had relatively minor external bleeding or haematoma requiring only local treatment (pressure dressings).
Early infection: Two catheters were removed within 30 days for infection.
Accidental removal: Four catheters were accidentally (partly) removed and needed replacement.
Poor flows: Two catheters were removed because of inadequate flow rates.

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 (see below).

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
2013-14	14	37	51

RVH = renovascular hypertension

Complications
Six patients who underwent angioplasty developed complications.
Three developed arterial thrombosis involving renal arteries and/or the aorta. One of these was small and resolved spontaneously, but two patients required intra-arterial thrombolysis, one of whom had a significant renal injury as a result of this complication.
There was one flow-limiting dissection that necessitated the deployment of a renal artery stent.
One patient developed macroscopic haematuria and another a femoral artery pseudoaneurysm, but both were self-limiting.

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
2013-14	15	0	10	1	11	37

5. Inpatients

5.1 Admissions to Victoria/Eagle Ward

Age (yrs)	2006-07		2007-08		2008-09		2009-10		2010-11		2011-12		2012-13		2013-2014	
	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%	Total No	%
<2	72	13	61	11	85	15	87	16	56	11	72	22	141	20	84	12
2- <5	105	19	90	16	81	14	99	18	102	20	54	16	128	18	107	15
5-<10	120	22	101	18	134	23	109	19	93	18	66	20	154	22	211	29
10-<15	169	30	161	29	153	27	137	24	131	25	77	23	162	23	202	28
15 +	88	16	148	26	124	21	129	23	131	25	63	19	131	18	118	16
Total	554	100	561	100	577	100	561	100	513	100	332	100	716	100	722	100

5.2 NEPHROLOGY ADMISSIONS (EXCLUDING HAEMODIALYSIS) TO EAGLE WARD, TO OTHER WARDS AND IN TOTAL

Year	2002-03	2003-04	2004-05	2005-06	2006-07	2007-08	2008-09	2009-10	2010 - 11	2011-12	2012 -13	2013 -14
Victoria/ Eagle	563	585	622	517	554	561	577	561	513	332	716	722
Other	307	316	317	317	349	249	261	118	93	100	414	145
Total	870	901	939	834	903	810	838	679	606	432	1130	867

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 212 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
2014	4	2	1	3	3	13
Home Haemodialysis						
2011	0	0	1	2	1	4
2012	0	0	2	3	2	7
2013	0	2	3	3	5	13
2014	0	1	5	3	5	14
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	1	1
2014	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
2014	4	2	6	8	4	24
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
2014	0	12	35	64	48	159

6.2 CHRONIC PERITONEAL DIALYSIS

There were a total of 26 patients in 2013-2014. Their age ranges are shown.

Annual figures-age breakdown:

	2005-6		**2006-7**		**2007-8**		**2008-9**		**2009-10**		**2010-11**		**2011- 12**		**2012-13**		**2013-14**	
Age, yrs	**total**	**%**	**total**	**%**	**total**	**%**	**total**	**%**	**total**	%	**total**	%	**total**	%	**total**	%	**total**	%
<2	2	5	**4**	10	**6**	18	**6**	18	**12**	30	**4**	14	**6**	14	**7**	28	**4**	15
2-5	2	5	**5**	12	**4**	12	**6**	18	**7**	18	**7**	24	**7**	24	**3**	12	**2**	8
5-10	10	25	**9**	22	**4**	12	**4**	12	**8**	20	**4**	14	**5**	14	**2**	8	**6**	23
10-15	10	25	**12**	29	**13**	38	**11**	32	**10**	25	**7**	24	**6**	24	9	36	**8**	31
>15	16	40	**11**	27	**7**	20	**7**	20	**3**	7	**7**	24	**7**	24	**4**	16	**6**	23
Total	40	100	**47**	100	**34**	100	**34**	100	**40**	100	**29**	100	**31**	100	**25**	100	**26**	100

Annual figures from 2002 onwards:

PATIENTS	02-03	03-04	04-05	05-06	06-07	07-08	08-09	09-10	10-11	11-12	12-13	13-14
total *new*	45 20	45 18	40 14	41 17	37 18	34 15	34 15	40 20	29 11	31 16	25 14	26 11
At year end	29	23	23	18	20	17	19	17	16	10	14	12
Transferred to HD	2	5	5	6	2	5	4	8	6	7	3	3
Transplanted	7	15	11	12	14	8	6	13	6	13	5	10
Adult unit	3	1	2	3	0	0	2	0	0	0	1	1
Improved	0	0	0	1	1	2	0	0	0	0	0	0
Deaths	1	1	0	0	1	1	3	2	0	1	1	0

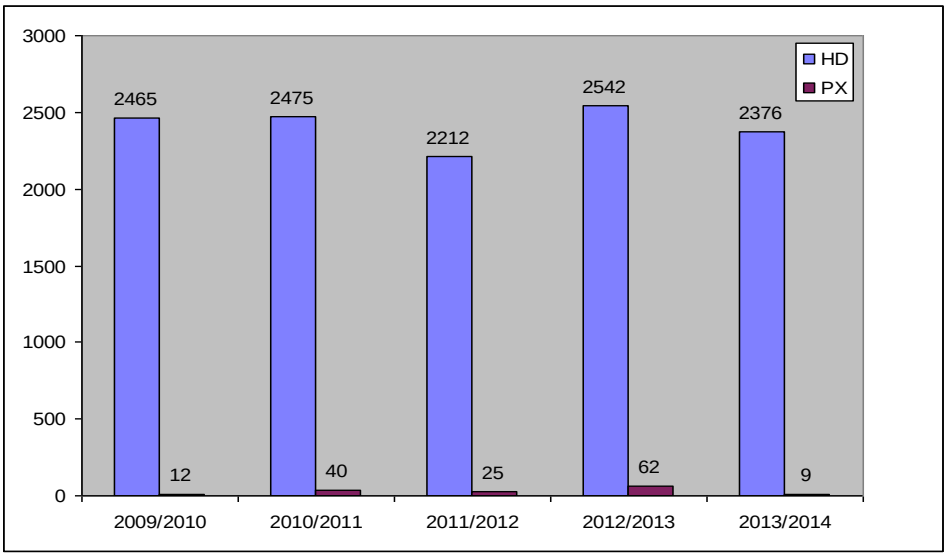
6.3 CHRONIC HAEMODIALYSIS

During the year 2013/2014 there were 2385 sessions in 30 children, 2376 sessions of HD (acute and chronic) and 2 sessions of PE. For the first time 3 sessions of DFPP (double filtration plasma exchange) and 4 sessions of IA (immunoadsorption) were carried out to facilitate blood group incompatible transplantation.

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
01.04.14	3	148

6.4 5 year activity



ACUTE KIDNEY INJURY AND TREATMENT (INCLUDING PLASMAPHERESIS)

7.1 ACUTE HAEMODIALYSIS

No children required acute haemodialysis during the audit year. These figures exclude children with acute kidney injury in PICU and NICU.

Diagnosis	2007-8	2008-9	2009-10	2010-11	2011-12	2012-13	2013-14
HUS(D+)	1	1		2			
HUS (D-)		1					
MCGN/RPGN			1				
SLE	1		1			1	
FSGS			1		1		
RSV					1		
Rhabdomyolosis				1	1		
Acute on CRF	1	1					
Sepsis				1		2	
Transplant rejection				1	1		
Tumour lysis	1						
ATN	3	3	1			2	
Total Pts	**7**	**6**	**4**	**5**	**4**	**5**	**0**
Total number of sessions	**34**	**82**	**164**	**22**	**14**	**44**	**0**

7.2 PLASMA EXCHANGE

3 children were treated with plasma exchange type therapies (0 male; 3 female).

Diagnosis	2009/10		2010/11		2011/12		2012/13		2013/14	
	No. Pts	No. Sess	No. Pts	No. Sess	No. Pts	No. Sess	No. Pts	No. Sess	No. Pts	No. sess
AB reduction			3	3						
SLE			1	7						
HSP					1	3				
Post tx FSGS			1	25	2	22	2	51		
RPGN	1	11								
HUS D+										
HUS D-			1	5			1	6		
GvH	1	1								
Tx Rej							1	5		
CNS	1	1								
Test PX					1	1	1	1		
ABOi									3	9
Total	**3**	**13**	**6**	**40**	**4**	**26**	**5**	**62**	**3**	**9**

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

Age on admission	2005-6	2006-7	2007-8	2008-9	2009-10	2011-12	2012-13	2013-14
<1 year	1	3	2	0	0	2	2	0
1- <5 years	2	4	2	4	8	0	0	4
≥ 5 years	0	6	2	2	7	0	0	2
Total	**3**	**13**	**6**	**6**	**15**	**2**	**2**	**6**

8. RENAL TRANSPLANTATION

Details of patients undergoing renal transplantation 1998 – 2014

	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
01/04/2013 to 2014	15	2	11	0	28	28

RESEARCH

9.1 PAPERS :

1 April 2013 – 31 March 2014 publications

1. Evidence update on Urinary tract infections in Children,.
   Verrier Jones K, Jadresic L, Larcombe J, **Tullus K,** Vernon S.
   NICE Oct 2013 http://www.evidence.nhs.uk/about-evidence-services/bulletins-and-alerts/evidence-updates

2. Urine biomarkers for monitoring juvenile lupus nephritis: a prospective longitudinal study. Watson L, **Tullus K**, Pilkington C, Chesters C, Marks SD, Newland P, Jones CA, Beresford MW.
   Pediatric Nephrology 2014;29:397-405, Epub 2013 Nov 16

3. Skattning av njurfunktionen hos barn – använd gärna Schwarz formel
   Tullus K
   Läkartidningen 2013;110:2125

4. Mucocutaneous manifestations in a UK National Cohort of Juvenile-Onset Systemic Lupus Erythematosus Patients
   Chiewchengchol D, Murphy R, Morgan T, Edwards SW, Leone V, Friswell M, Pilkington C, **Tullus K,** Rangaraj S, McDonagh JE, Gardner-Medwin J, Wilkinson N, Riley P, Tizard J, Armon K, Sinha MD, Ioannou Y, Mann R, Bailey K, Davidson J, Baildam EM, Pain CE, Cleary G, McCann LJ and Beresford MW on behalf of the UK JSLE Study Group
   Rheumatology (Oxford) 2014; Epub Marcch 2014

5. Indications for use and safety of rituximab in childhood renal diseases
   K Tullus, SD Marks
   Pediatric Nephrology 2013;28:1001-1009

6. A review of guidelines for urinary tracts in children younger than 2 years
   K Tullus
   Pediatric Annals 2013; 42:52-56

7. Pitfalls in diagnosing and treating children with renal artery stenosis
   K Tullus, D Roebuck
   Pediatric Nephrology 2013;28:1321-1322

8. Does the ureteric jet Doppler waveform have a role in detecting vesicoureteric reflux?
   K Tullus
   Pediatric Nephrology 2013;28:1719-1721

9. Systemic polyarteritis nodosa in the young: a single-centre experience over thirty-two years
   D Elefteriou, MJ Dillon, **K Tullus,** SD Marks, CA Pilkington, DJ Roebuck, NJ Klein, PA Brogan
   Arthritis and Rheumatism 2013;65:2476-2485

10. Controversy in urinary tract infection management in children: a review of new data and subsequent changes in guidelines
    J Kari, **K Tullus**

Journal Tropical Pediatrics 2013;59:465-469

11. Comment on: fifteen management consultation: a structured approach to the management of facial paralysis in a child
    D Roebuck, **K Tullus**
    Archives of Disease in Childhood Education Practice Edition 2013;98:196

12. Is there an obesity-related epidemic of CKD starting already in childhood?
    K Tullus
    Nephrology Transplantation Dialysis 2013;28: Suppl iv114-116

13. Variability in the CIITA gene interacts with HLA in multiple sclerosis
    A Gyllenberg, F Piehl, L Alfredsson, J Hillert, IL Bomfim, L Padyukov, M Orho-Melander, E Lindholm, M Landin-Olsson, A Lernmark, **K Tullus** in the Swedish Childhood Diabetes Study Group, T Olsson, I Kockum
    Genes Immunity 2014;15:162-167

14. C1q nephropathy in children: clinical characteristics and outcome
    VN Guanasekara, NJ Sebire, **K Tullus**
    Pediatric Nephrology 2014;29:407-413

15. Systemic Lupus Erythematosus complicated by Neuromyelitis Optica (Devic's Syndrome): case series from a single paediatric rheumatology centre
    D Maritsi, M Al-Obadi, S Melo-Gomes, **K Tullus,** CA Pilkington
    Pediatric Rheumatology 2014;9:1-2

16. The indications, efficacy and adverse reactions to rituximab in a large cohort of patients with Juvenile-onset SLE
    L Watson, MW Beresford, C Maynes, C Pilkington, SD Marks, Y Glackin, **K Tullus**Lupus 2014;

17. Lupus Nephritis
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19. Infants and children need prompt testing and treatment for UTI
    K Tullus
    Guidelines in Practice 2014;17:39-42

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115. Marks SD, Hudson A, Pankhurst L, Fuggle S. "Is a good HLA match more important than donor type ?" Pediatr Nephrol 2013; 28(8): 1350. *Oral Presentation at the 16th Congress of the IPNA (International Pediatric Nephrology Association), Shanghai, China, August 2013.*

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Congress of the IPNA (International Pediatric Nephrology Association), Shanghai, China, August 2013.

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126. Ma AL, Mohamed I, Sebire NJ, Marks SD. "Can pre-implantation biopsies predict renal allograft function in paediatric renal transplant recipients ?" Pediatr Transplant 2013; 17 (Suppl 1): 64. *Oral Presentation at 7th Congress of the IPTA (International Pediatric Transplant Association), Warsaw, Poland, July 2013.*

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129. Marks SD, McCulloch M, Novelli V, Shingadia D, Clapson M, Jagani M, Patey S, Mamode N, Sebire NJ, Bradley S, Shroff R. "Successful outcome of first paediatric renal transplant for HIV associated nephropathy." Pediatr Transplant 2013; 17 (Suppl 1): 93. *Poster Presentation at 7th Congress of the IPTA (International Pediatric Transplant Association), Warsaw, Poland, July 2013.*

130. Moorthy LN, International SMILEY collaborative group. "Age of onset of systemic lupus erythematosus in children in an international cohort." *Poster Presentation at the 10th International Congress on Systemic Lupus Erythematosus, Buenos Aires, Argentina, April 2013.*

131. Watson L, Tullus K, Pilkington C, Chesters C, Marks SD, Newland P, Jones CA, Beresford MW. "Novel urine biomarkers for monitoring disease activity in juvenile lupus nephritis: A prospective longitudinal validation study." *Poster Presentation at the 10th International Congress on Systemic Lupus Erythematosus, Buenos Aires, Argentina, April 2013.*

132. Marks SD. "The adolescent with renal disease." In *Oxford Textbook of Clinical Nephrology, 4th edition.* Edited by Turner N, Goldsmith D, Winearls C, Lameire N, Himmelfarb J, Remuzzi G. Oxford University Press; 2014 (in press).

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9.2 GRANTS

Research Title	Name
GOSH and ICH Biomedical research centre £27,000 2011-2014 Vascular growth factors in children with chronic kidney disease	Dr Rees, Dr Shroff and Dr Long
KKR, £92,021, 2011-2014 The role of vascular endothelial growth factors (VEGF) and angiopoietins (Ang) in endothelial dysfunction in children with chronic kidney disease (CKD) stage 5.	Principal applicant L Rees with Dr Long and Dr Shroff
Grants from Industry £73,776, 2011-2014 PI for the UK study of eculizumab in aHUS, both acute treatment and long term follow up. PI for trial of a new phosphate binder	Dr Rees
GOSH charity £15,000, 2013-2015 Calcium balance in children on dialysis: a pilot study of a new measurement technique using heavy isotopes of calcium.	Dr Rees
The effects of haemodiafiltration (HDF) vs conventional haemodialysis (HD) on growth and cardiovascular markers in children Kidney Research UK (KRUK) Amount £199,938 over 3 years	R Shroff and F Schaefer
Angiopoietin-2 as a biomarker and mediator of cardiovascular disease in children. GOSH Charities Amount £195,000 over 2 years	D Long, R Shroff and J Deanfield
Examining the effects of vitamin D receptor activators on vascular smooth muscle calcification using a model of intact vessels from children with chronic kidney disease. Kids Kidney Research Amount - £91,220 over 3 years	R Shroff, D Long and C Shanahan
March 2014:Kids Kidney Research grant of £24,300 for project “Complement fixing donor specific HLA antibodies in paediatric renal transplant patients”. (PI).	Dr Shroff
May 2013: Kids Kidney Research grant of £87,000 for project “Genetics of renovascular malformations”.	Dr Shroff – co applicant
April 2013: BRC industrial collaboration diagnostics grant of £70k for “The development of next generation sequencing for EBV diagnostics.” (Collaborative work with Professors Judith Breuer and Persis Amrolia, UCL).	Dr Shroff
Kids Kidney Research: Genetics of renovascular malformation; £87.000; 01/09/2013- 30/08/2014; Principal Investigator	Dr Bockenhauer
Great Ormond Street Hospital Charity: Identifying the	Dr Bockenhauer

molecular basis of polycystic kidneys associated with hyperinsulinaemic hypoglycaemia.; £93,414; 01/09/2013-31/03/2015; Principal Investigator	
European Union, Framework 7: EuRONOMICS; £215,000; Co-Investigator (PI: F. Schafer)	Dr Bockenhauer
King AbdulAziz University Jeddah, Collaborative renal research grant; £300.000; 1/1/2012-31/12/2014, Principal Investigator (Co-I: J. Kari and R. Kleta)	Dr Bockenhauer
Kids Kidney Research: Genetics of Renal Disease; £99.451; 01/09/2011- 30/08/2014; Principal Investigator	Dr Bockenhauer
Higher Education Funding Council of England (HEFCE): Clinical Senior Lecturership; £250,000; 2010-2015; Principal Investigator	Dr Bockenhauer
2008-2014 Roles of angiopoietins in epithelial-endothelial interactions: using the renal glomerulus as a model system. Kidney Research UK Senior Non-Clinical Fellowship. £319,578	Dr Long
2011-2013 Restoring the angiopoietin balance as a therapy for glomerular disease. Kidney Research UK. PI: Dr. £112,272	Dr Long
2011-2015 Planar cell polarity in glomerular development and disease. Wellcome Trust Postdoctoral Fellowship for MB/PhD graduates., £415,490	PI: Dr. Eugenia Papakrivopoulou, Supervisors: Dr David Long, Dr. Alan Salama
2012-2015 The role of podocyte thymosin-beta4 in the healthy and diseased glomerulus. MRC New Investigator Award, £483,507	Dr Long
2012-2015 A novel role for the transmembrane protein Nogo-B in protection against cardio-renal vascular disease, Heart Research UK, £75,000	PI: Dr. Luigi Gnudi, Co-I: Dr. David Long
2012-2015 Understanding the role of planar cell polarity in the kidney filtration barrier, Kids Kidney Research, £99,720	PI: Dr. Eugenia Papakrivopoulou, Co-I: Dr David Long, Professor Andrew Copp
2013-2015 Targeting the lymphatics as a therapy for polycystic kidney disease, Kids Kidney Research, £99,527	PI Dr Paul Winyard Co-I Dr David Long
2013-2016 VEGF-C as a new therapy for polycystic kidney disease, Kidney Research UK Project Grant, £153,475	PI: Dr David Long, Co-I Dr Paul Winyard
2014-2016 Using zebrafish to implicate novel genes in the early stages of diabetic kidney disease, Diabetes UK, £195,094	PI: Dr David Long, Co-I Professor Steve Wilson, Professor Adrian Woolf
2014 Secreted frizzled-related protein 2: a new therapeutic target for glomerular disease?, Kidney Research UK Innovation Grant, £39,775	PI: Dr Eugenia Papakrivopoulou, Co-I Dr David Long

10. NEPHRO-UROLOGY ACADEMIC PROGRAMME

Seminar Room, Renal Unit, Eagle Ward, Level 6, Morgan Stanley Building,

Great Ormond Street Hospital for Children

(Tuesday or Thursday afternoons 2.30pm – 4.30 pm)

Date	**Topic** ***2.30 - 3.30 pm***	**Speaker**	**Topic** *3.30 – 4.30pm*	**Speaker**
16/4/13	Journal Club	Dr Shroff Dr Bokenhauer	Review of renal unit protocols	All
23/4/13	Renal biopsy meeting	Prof Neil Sebire	improvement project updates	Dr Daljit Hothi
30/4/13	UTI – a few things that you might not have thought about	**Dr Tullus**	D+ HUS and eculizumab- a new study for discussion	Dr Kjell Tullus
9/5/13 Thurs	Surgical Approaches to PD catheter insertion	Pankaj Chandak	Audit of peritoneal dialysis	Consultant Eileen Brennan, Nurse specialists Rachael Rogers Suzanne Bradley
14/5/13	Assessment of Dr Rees' general clinic	Dr William van't Hoff	Genetic research; what is up and coming?	Dr Detlef Bockenhauer
21/5/13	Renal biopsy meeting	Prof Neil Sebire		
28/5/13	The role of n-3 fatty acids on cachectic inflammatory cytokines, muscle wasting and lipid profile in CKD	Graeme O'Connor		
6/6/13 Thurs	**Joint meeting with** Marginal organs and DCDs for children	**The Evelina** Ramesh Batra	**Children's** Renal transplant audit	**Hospital** Clinical nurse specialists Kate Sinnott Suzanne Bradley, Jenny Tanton
13/6/13	Haemodialysis study day **Note thursday**			
18/6/13	Renal biopsy meeting	Prof Neil Sebire	Rituximab use in nephrotic syndrome: Single or double dosing?	Hazel Webb
27/6/13	Bipartite meeting at the Royal Free Hospital **Note Thursday**			
4/7/13 Thurs	Perioperative outcomes after transplantation in children under 20kg	Rajesh	Audit of living donation	Clinical Nurse Specialists Maria Scanes and Katie Knapp

9/7/13	Renal biopsy meeting	Prof Neil Sebire	• 'Examining the Effects of Vitamin D Receptor Agonists on Vascular Smooth Muscle Cell Calcification'	Nick Ware
16/7/13	Audit of home HD	Lynsey stronach Dal hothi	Audit of inpatient extracorporeal treatments	Liz Wright

Date	**Topic** 2.30 – 3.30	**Speaker**	**Topic 3.30-4.30**	**Speaker**
3/9/13	IPNA meeting, shanghai			
10/9/13	Renal biopsy meeting	**Prof Neil Sebire**	IPNA meeting report Best papers	Best paper report from Drs Rees, Hothi, Shroff, Tullus, Bockenhauer, Marks
17/9/13	HHD audit	Lynsey Stronach and Dal Hothi	New biomarkers of renal function from MRI – what role in clinical practice?	Prof Isky Gordon
24/9/13	KIT	Dr Steve Marks		
26/9/13	**Joint meeting with the transplant surgical team Note Thursday**			
	Tx surgical slot		Encapsulating peritonitis	Dr Shroff
3/10/13	Bipartite meeting at ICH (note Thurs) **Roland Levinsky Room, Philip Ullmann Wing, ICH**			
8/10/13	Renal biopsy meeting	**Prof Neil Sebire**	Journal club	Dr Bockenhauer Dr Waters
15/10/13	HLA typing in transplantation	Dr Olivia Shaw		
24/10/13	Joint meeting with the transplant surgical team Note Thursday			
	Tx surgical slot		GOSH presentations and report from the IPTA meeting	Dr Steven Marks
29/10/13	**Half term, no meeting**			
5/11/13	**Renal biopsy meeting**	Prof Neil Sebire	Journal club	Drs van't hoff Dr Tullus
12/11/13	**Research Update**	**Dr Waters**	Insulin receptor and nephrocalcinosis	Dr Bockenhauer
21/11/13	Joint meeting with Evelina, at the Evelina **Note Thursday**			

22/11/13	Nephrology Day for general paediatricians at the ICH **(note Friday)**			
28/11/13	Joint meeting with the transplant surgical team **Note Thursday**			
	Immunosuppression post transplant Dr Stephen Marks Mr Nizam Mamode			
3/12/13	**Renal biopsy meeting**	Prof Neil Sebire	**HDF study**	**Dr Shroff**
10/12/13	**Vascular effects of vitamin D**	Jo Laycock	**Results of the SHINE project**	Dr Hothi Ms Charlotte Magness
13/12/13	BAPN AGM, Birmingham Note Friday			
19/12/13	Bipartite meeting at RFH (note Thurs)			

Date	Topic 2.30 - 3.30 pm	Speaker	Topic 3.30 – 4.30pm	Speaker
7/1/14	A case from the tubular clinic	Dr Detlef Bockenhauer	Anti-micropeptides	Dr Milan Chromek
14/1/14	Renal biopsy meeting	Dr Neil Sebire	n-3 fatty acids and the proinflammatory response in CKD	Graeme o'Connor
21/1/14	Do we need so much steroids for paediatric lupus nephritis?	Dr Stephen Marks	Audit of deaths and complaints	Nurse Consultant Eileen Brennan
30/1/14	**Bipartite meeting, ICH** Note Thursday			
6/2/14	Joint meeting with the Evelina **Note Thursday**			
13/2/14	Meeting with transplant surgical team **Note Thursday**			
18/2/14	Renal biopsy meeting	Dr Neil Sebire	HDL in CKD: toxic or non toxic?	Dr Rukshana Shroff
25/2/14	STEC HUS data from the last 2 years	Dr Kajal Soni	Graft versus host renal disease	Dr Pallavi Yadav
4/3/14	**Feeding the over 2s**	**Dr Jelena Stovanovic**	UTI; new insights	Dr Kjell Tullus
11/3/14	Information Governance	Clare Reed	Topic to be decided	Dr William van't Hoff
18/3/14	Renal biopsy meeting	Dr Neil Sebire	Journal club	Dr Maitrayee Thoppat-Kumarasamy Dr Nabil Melhem
27/3/14	**Meeting with transplant surgical team** Note Thursday			
31/3-4/4/14	Course week at ICH			

8-10/4/14	RCPCH meeting, Birmingham
15/4/14	Easter holidays
22/4/14	Easter holidays
29/4/14	Renal Assoc, BAPN and BRs Renal week, Glasgow

11. AUDIT

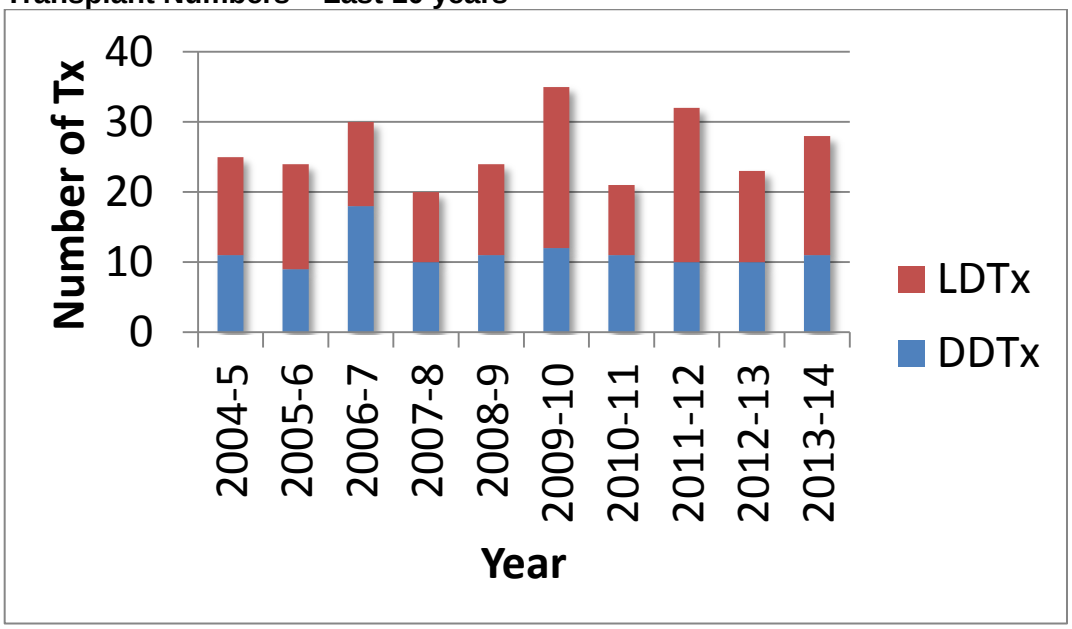
11.1 Pre Transplant Audit, Living and Deceased Donor, April 2013-March 2014

Katie Knapp, Jenny Tanton, Maria Scanes
Clinical Nurse Specialists

Transplant Numbers

- 28 transplants in 27 children
    - 17 Living donor (61%)
        - 1 directed altruistic donor
        - 2 ABOI
    - 11 Deceased donor (39%)
        - 2 En Bloc
    - 0 NLKDSS runs

Transplant Numbers – Last 10 years



Recipient Demographics

- Male 11 (40%)
- Female 16 (60%)

- NHS (all GOSH patients) 26
- IPP from UAE 1 (SI)

Recipient Age Demographics

- Mean age at Transplant = 10.6 years
    - 9.7 years (LD Transplant)
    - 12.1 (DD Transplant)
- Median Age at Transplant = 12 years
    - 12.0 years (LD Transplant)
    - 13.0 (DD Transplant)

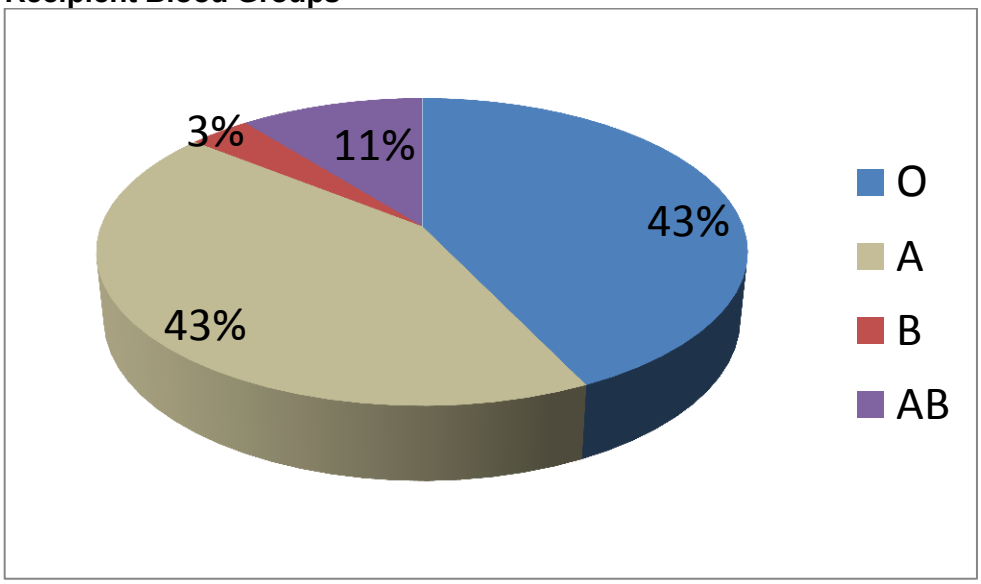
(Range 1 – 17 years)

- 3 children under 3 years, all of which were LDTx

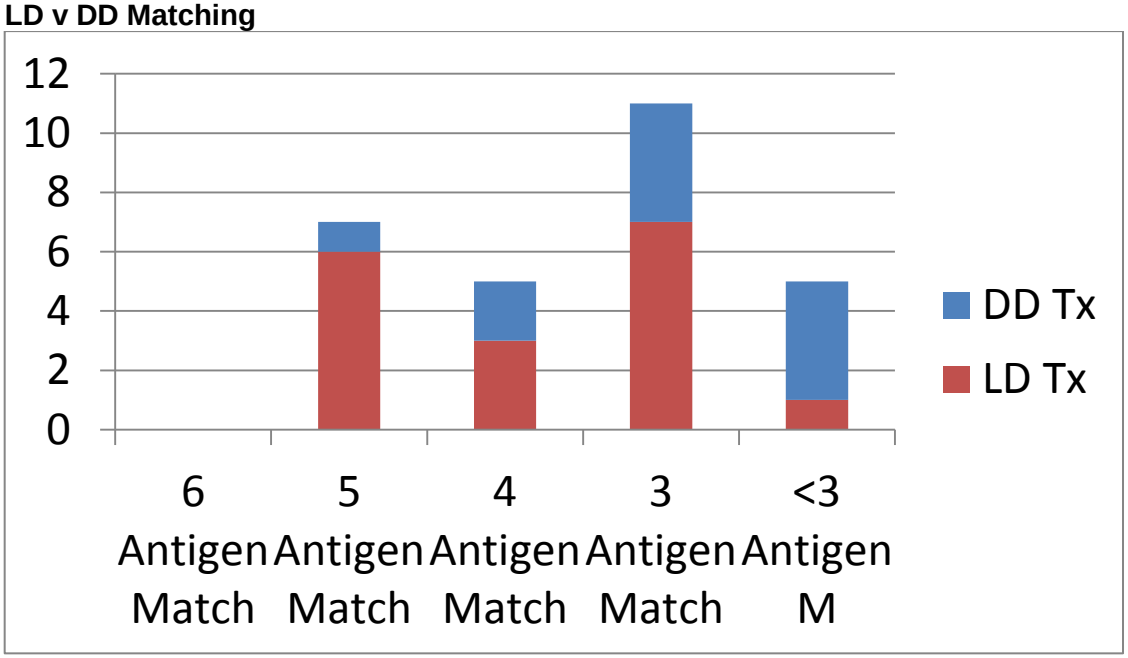
Modality at Time of Transplant

- HD 7 25% (4 LDTx)
- HHD 2 7% (1 LDtx)
- PD 9 32% (5 LDTx)
- Pre-emptive 10 36% (7 LDTx)
- 41% of LDTx pre-emptive

Recipient Blood Groups



LD v DD Matching



Cold Ischaemic Times

- Live Donor Transplants
  - Mean = 4.4 hours

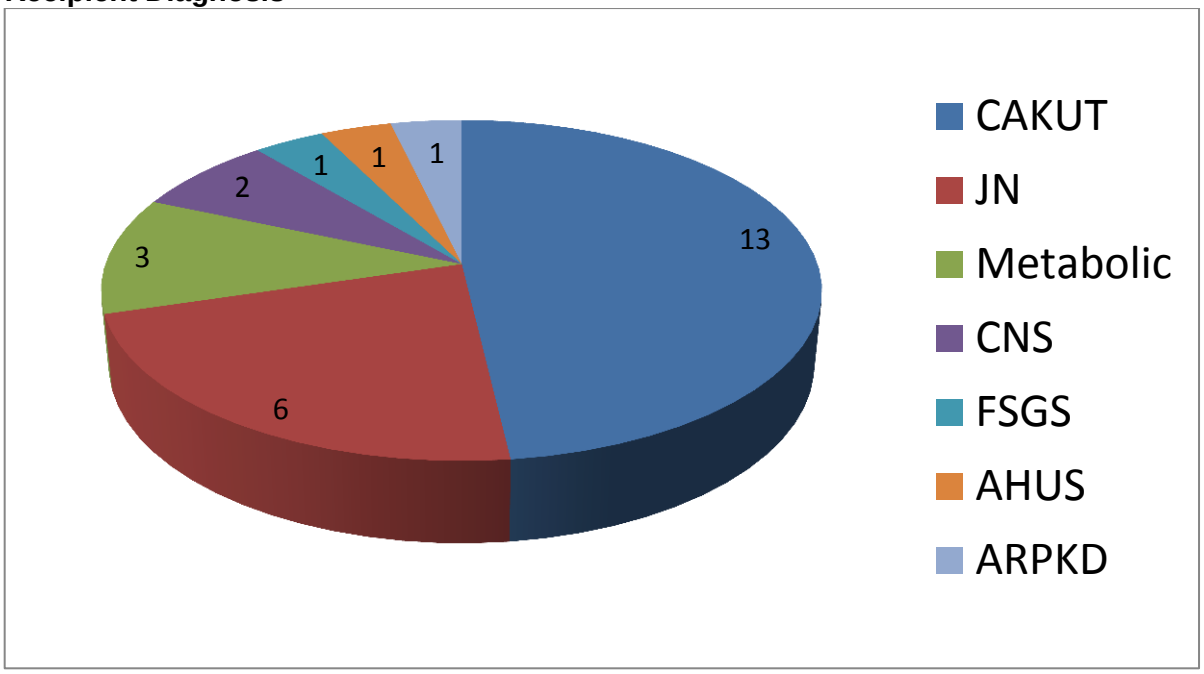
(Range 3.0 – 6.0 hours) Data on 11 patients (65%)

- Deceased Donor Transplants

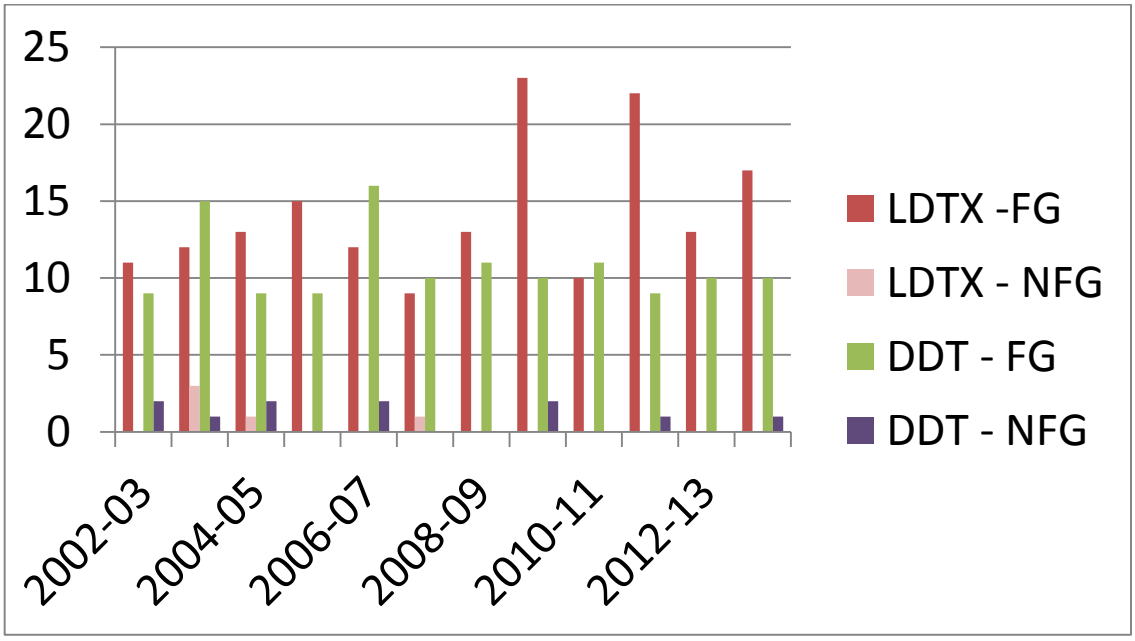
- Mean = 8.5 hours

(Range 4.8 – 12.1 hours) Data on 11 patients (100%)

Recipient Diagnosis



End of Year Outcomes

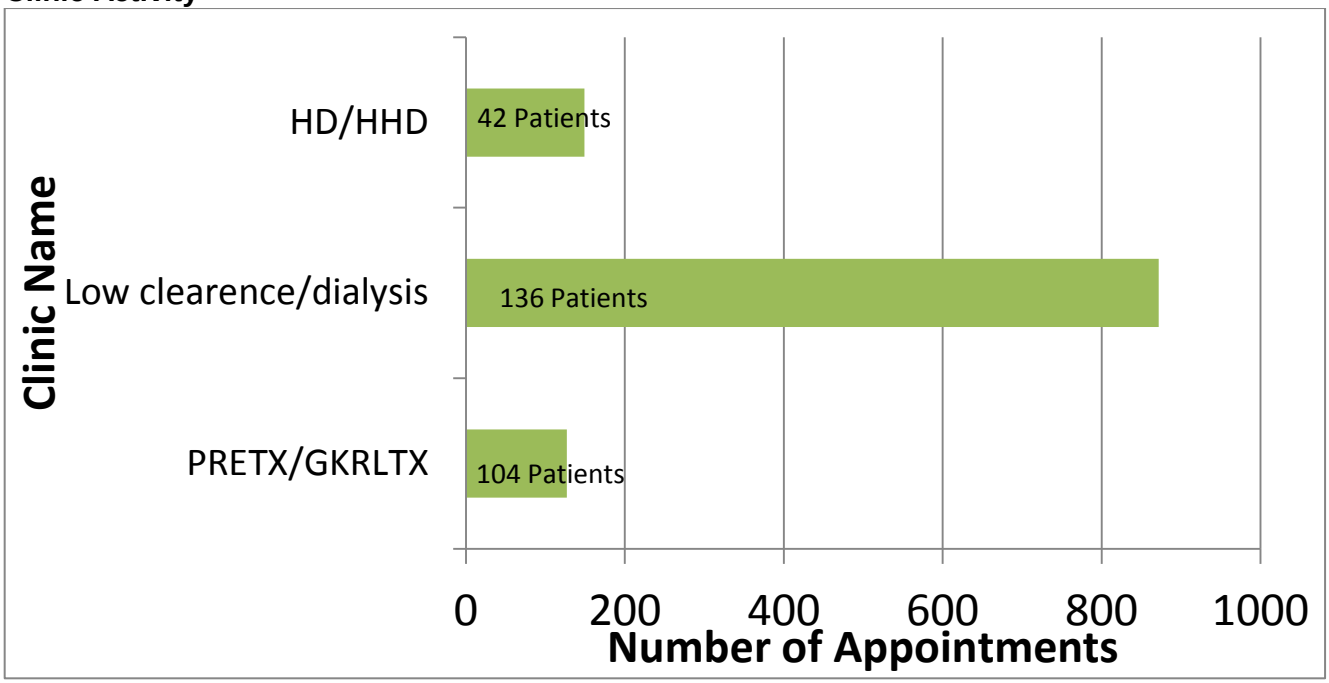


Pre-Emptive v Non Pre-Emptive

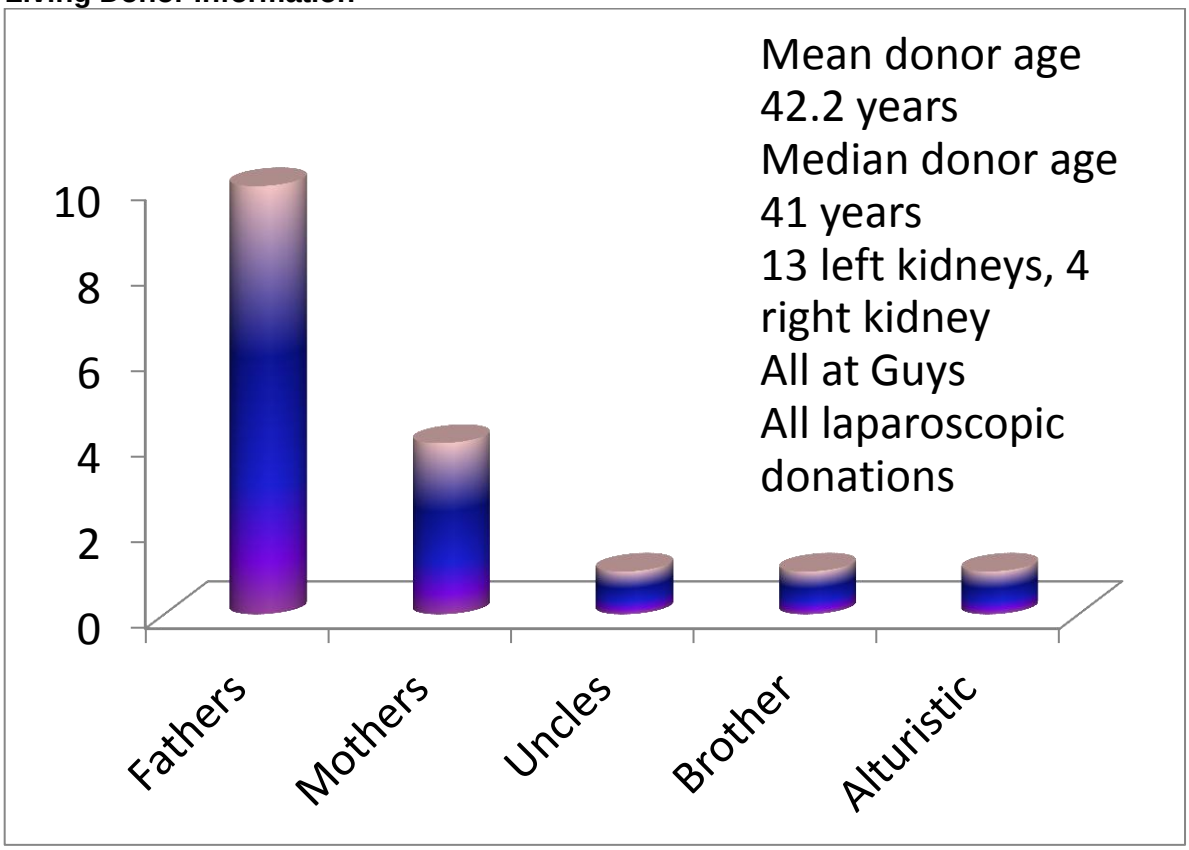
- 10 Transplants were pre-emptive (36%)
- 7 of these were from living donors
- Non pre-emptive transplants included;
  - 3 Babies
  - 8 Crash Landers
  - 3 nephrectomies/oxylosis

- 1 Sudden deterioration UTI
- 2 Waiting on-call

Clinic Activity



42 new referrals for transplant work-up
Living Donor Information



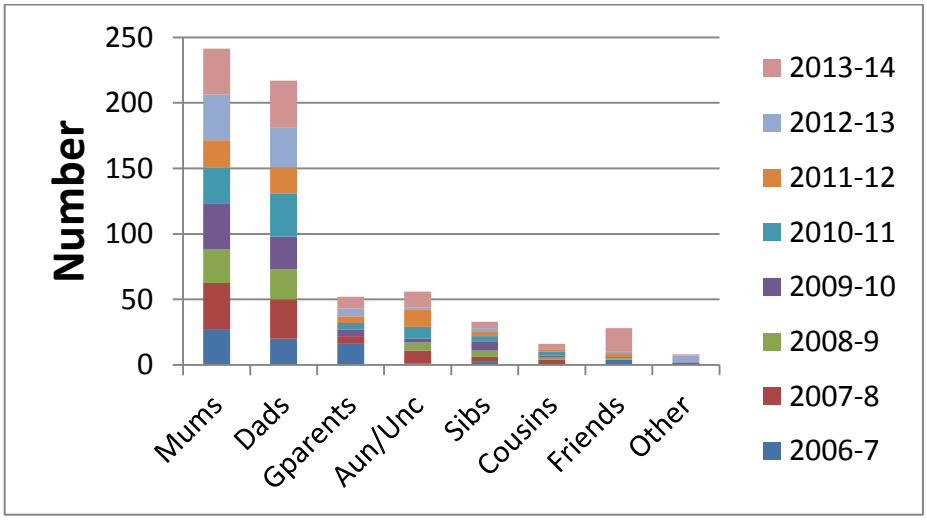
Deceased Donor Transplant

- Complete Data on 11 recipients (100%)

- Donor Cause of Death
  - 6 Cerebral hemorrhage
  - 2 Cerebral hemorrhage (Trauma)
  - 2 Hypoxic Brain injury
  - 1 Respiratory failure

Donor Pool

120 potential donors came forward for 43 recipients



Donor Suitability

Reason	Number
Ongoing Referral	26
Other Donor Used	17
Medically Unsuitable	14
Positive Cross Match/unsuitable mm	8
Enquiry Only	27
Social	8
ABOi	13
LDTx	5
Other	2
22 Donors (18%) did not proceed to work up due to medical or social instability	

On Call Activity

- 11 patients activated on-call
- 2 of who received transplants within the same audit year (KS, SB).
- 13 patient's on-call at end of audit year
- Average waiting time 387 days.
  - Range 62-757 days

DD's v LD's

- Inpatient stay Deceased Donor
  - 12.2 days
- Inpatient stay Living Donor
  - 14.7 days (1 x relapse + 1 x infant + 1 x delayed function + IPP-diabetes training)
- DD Average creatinine at end of year: 91.7

  - (Range 27-171)
- LD Average creatinine at end of year: 68.3
  - (Range 21-148)

Work in Progress
- 4 International Private Patients'
- 9 out of centre / overseas (ROI, Denmark, Greece, Holland)
- 7 potential ABOi/HLAi
- 4 complex vascular patients (1 is ABOI)
- 1 currently listed for paired exchange
- 2 further potentials for paired exchange

Achievements
- Paired exchange / ABOi/HLAi growing treatment option (yet to Transplant on paired exchange)
- IPP/Overseas numbers increasing
- Passed HTA audit
- Online ODT patient registration
- Extra CNS post + pre transplant service coordinator
- Implemented surgical op note – improved documentations + timely NHSBT returns
- Monthly MDM's with all surgeons

Audit Points
- More transplants and increasing workload – out of centre referrals take approx. 3 times longer to plan + IPP's.
- Average LDTx creatinine approx 35% less than DDTx creatinine at end of audit year.
- No 6 antigen matches.
- All transplants that could have been pre-emptive were.
- 1st Directed altruistic donation

Next Year
- Employ new CNS
- Revise and update pre transplant work up protocols
- Databases for audit purposes (recipients and donors)
- Monthly meetings face to face with Guy's LD coordinator
- Develop pathways for IPP and LRCAP patients
- Joint pre + post transplant audit

11.2 RENAL TRANSPLANT AUDIT

1 April 2013 - 31 March 2014
Jenny Tanton / Kate Sinnott / Suzanne Bradley / Stephen Marks

GOSH renal transplants

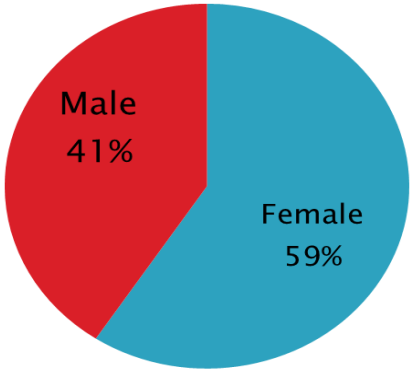
- 27 patients received 28 renal transplants at GOSH
  - 12 month period of 1 April 2013 - 31 March 2014
  - 1 IPP patient returned home in February 2014

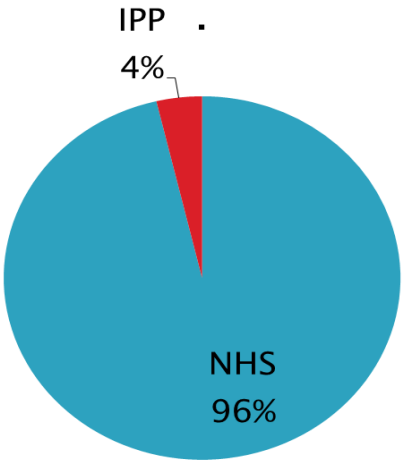
Transplants

- 24 patients received their first renal allograft
- 3 patients received their second renal graft

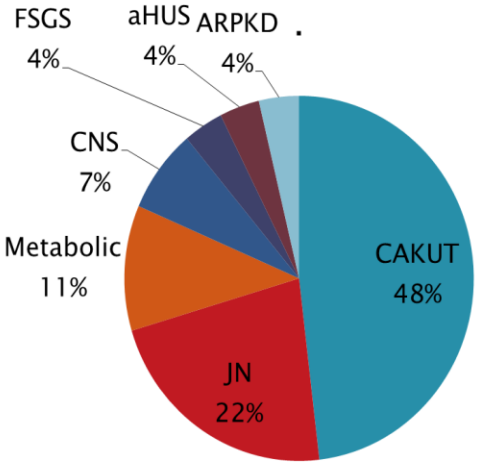
- 1 patient received two renal allografts in same audit year
  - first failed en bloc DCD renal transplant
  - 2nd ABOi LRD transplant with aHUS recurrence

Patient demographics

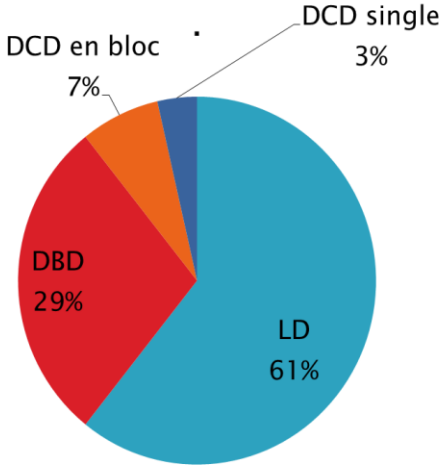




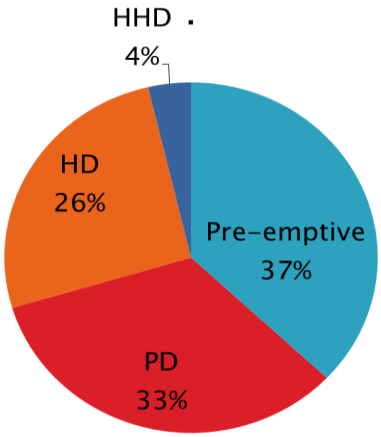
Underlying diagnoses



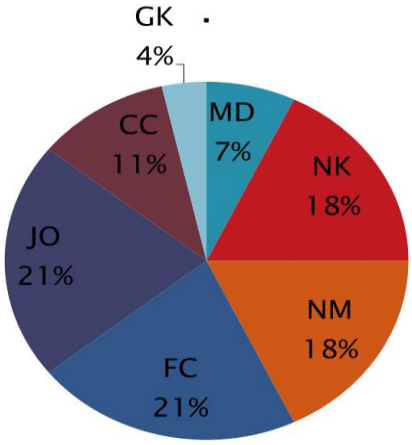
Donor types



Pre-transplantation status



Surgeon



HLA Mismatches

Mismatch	LD	DD
1-0-0	2 (7%)	
0-0-1	2 (7%)	
0-1-1	1 (4%)	
1-0-1	2 (7%)	
0-1-0	1 (4%)	1 (4%)
0-2-1	1 (4%)	
1-1-1	6 (2%)	3 (11%)
1-1-0	1 (4%)	2 (7%)
1-2-1		2 (7%)
2-2-1	1 (4%)	
2-1-1		2 (7%)

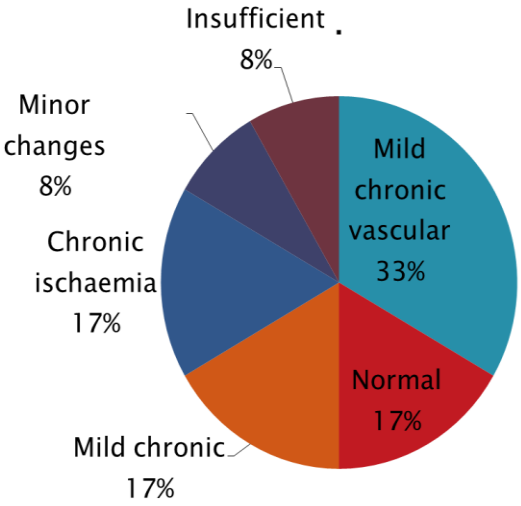
Transplant in-patient stay

Transplant inpatient stay (days)	LD	DD
At end of audit year		
6-14 days	10 (37%)	7 (26%)
15-21 days	3 (11%)	2 (7%)
22-28 days	4 (15%)	
> 28 days	1 (4%)	

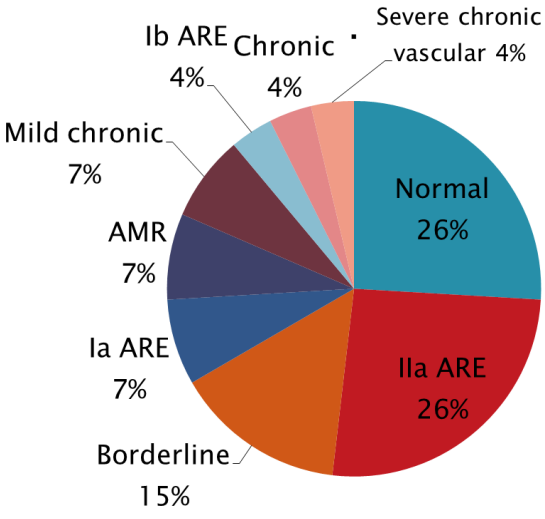
Time zero biopsies

A	B	C	D	E	F	G
0	4	1	5	2	1	0

Time zero biopsies (44%)



Renal transplant biopsy results in patients transplanted 2013-4



EBV Viraemia

D+R- developed EBV viraemia = (RH/TH/ME/CW/CP/CB) = 6 (22%)
D+R+ developed reactivation = (HF/FN/EW/JM) = 4 (15%)
D-R- developed EBV viraemia + (RH/RW) = 2 (7%)

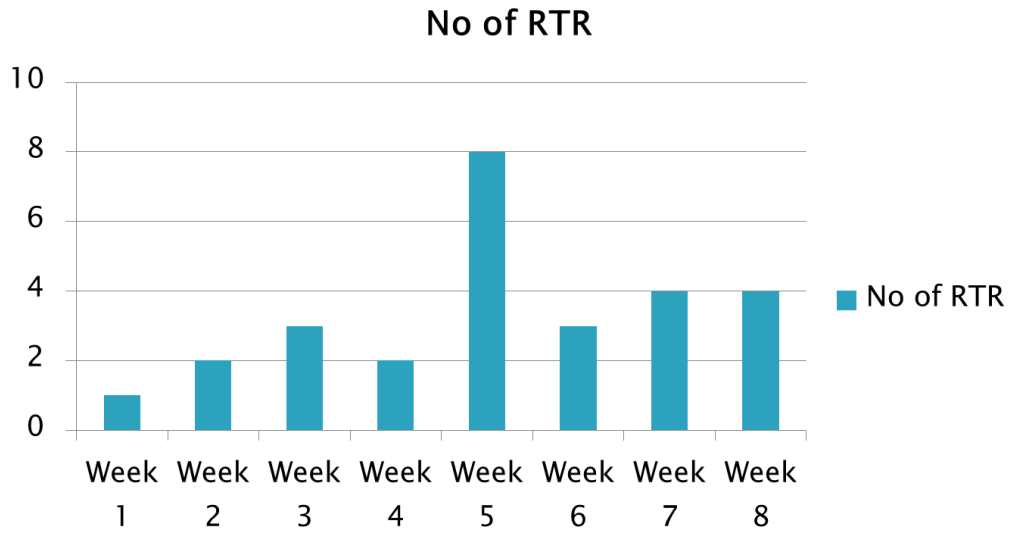
CMV Viraemia

D+R+ developed reactivation = 4 (15%) (EV/AI/SR/SI)
D-R+ developed reactivation = 3 (11%) (AS/CB/ZO)
D-R- developed CMV viraemia = 3 (11%) (KA/HI/TB)
D+R- developed CMV viraemia = 1 (4%) (ME)
D+R- prophylaxis = 1 (4%) (MA)
Recevied oral treamtnet for CMV viraemia = 9 (33%) (AS/CB/ZO/EV/AI/SR/KA/ME/HI)

Immunosuppression in new RTR 2013-2014

Start	End	No (%)
Tac / Aza / Pred	Tac / Aza / Pred	8 (30%)
Tac / Aza / Pred	Tac/ Pred	7 (26%)
Tac / Aza / Pred	Tac / MMF/ Pred	5 (19%)
Tac / MMF/ Pred	Tac / MMF/ Pred	5 (19%)
Tac / MMF/ Pred Basiliximab	Tac / Aza / Pred	1 (4%)
Tac / MMF/ Pred	Tac	1 (4%)

Timing of stent removal



Anti-hypertensive treatment in new renal transplant recipients

Start	End	% of patients
0 agents	0 agents	9 (33%)
0 agents	2 agents	1 (4%)
1 agent	0 agents	3 (11%)

1 agent	1 agent	6 (22%)
1 agent	2 agents	3 (11%)
2 agents	1 agent	2 (7%)
2 agents	2 agents	2 (7%)
3 agents	4 agents	1 (4%)

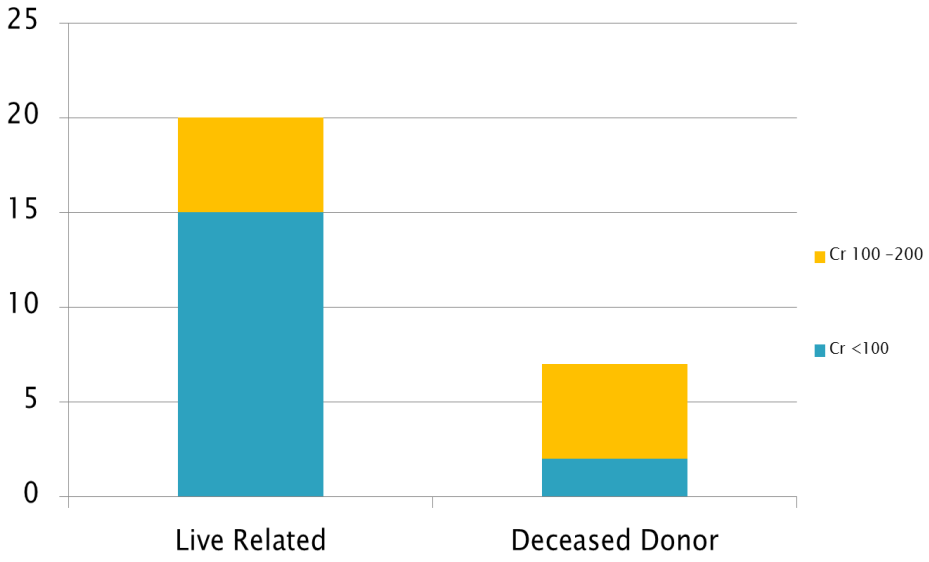
Surgical transplant complications

- Post-biopsy haemorrhage
- Hydronephrosis
- Re-anastamosis and removal of clot
- Kink in renal transplant artery
- Ureteric obstruction
- Wound dehiscence
- Difficult anastomosis
- Stenosis at anastomosis site
- Av fistula post biopsy
- Ivc thrombus

Medical transplant complications

- Hypertension
- Nodat (new onset of diabetes after transplantation)
- Uti
- Ebv/cmv/bk/jc viraemia/herpes
- Proteinuria
- Diarrhoea
- Neutropenia
- Atypical hus recurrence –on eculizumab fortnightly
- Pneumonia
- Fsgs recurrence
- Acute and humoral-mediated rejection (dsa positive)
- Acute kidney injury
- Delayed graft function
- Parovirus B19 PCR pos

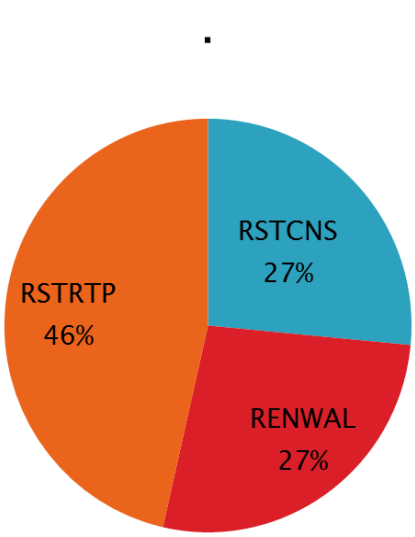
Renal function at end of audit year

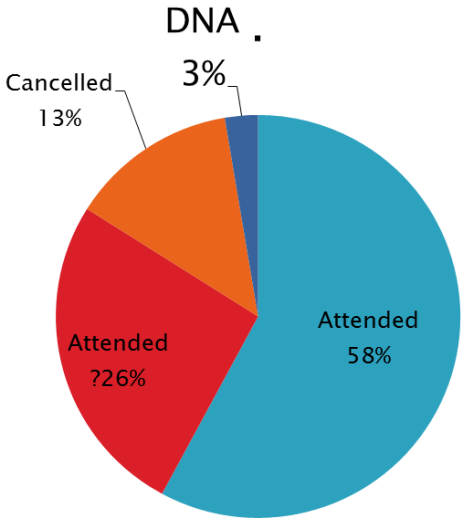


Outcome of RTR in audit year

- 0 patients returned to dialysis
- 2 patients moved to low clearance clinic
- 14 patients transferred to adult care

2,799 renal transplant outpatient clinic appointments in audit year

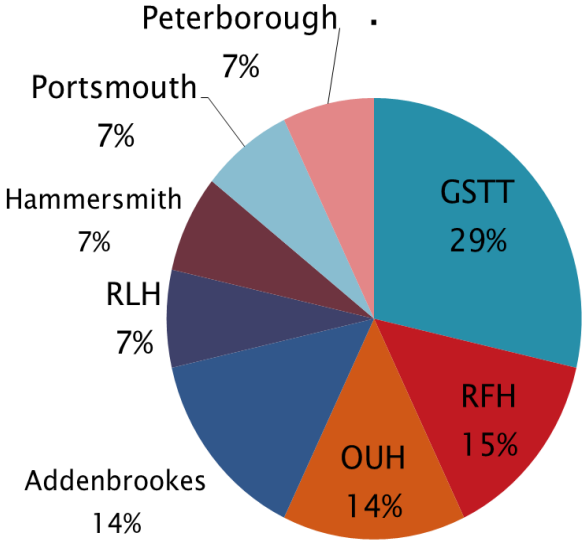




Adolescent transition

- 14 patients transferred to adult units in year
- 28 adolescent transition clinics per audit year
  - Quarterly joint adolescent clinics with 4 adult centres
  - Guys, RLH, RFH and Oxford continue
  - Monthly adolescent transition clinic
- First adolescent education day
  - For 16-18year olds
  - 13 February 2014

Patients transferred units



VZV - update

- Re-test VZV IgG once after two vaccine doses and give a third if there is no antibody detected
- After that it is important to test VZV IgG at the time of exposure

    - Give Zig if VCV IgG negative
    - For both vaccinated and natural infection
    - No other testing

Updates

- Studies planned for April 2014 to March 2015 (SM)
- Renal transplant protocol updated November 2013 (SM)
- KIT (SM)
- Transplant antibiotic prophylaxis (SM)
- Post transplant family and team agreement
- Post transplant surgical operation sheet

11.3 RENAL TRANSPLANT NATIONAL COMPARATIVE UNIT AUDIT

(Report and data from NHS Blood and Transplant)

NHSBT

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 2012/13, 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 (55 kidney/liver transplants, 5 kidney/pancreas transplants,1 kidney/heart transplant, 1 IF multivisceral and 1 double kidney) 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: 1997/98 – 2000/01, 2001/02 – 2004/05, 2005/06 – 2008/09, 2009/10 – 2012/13) 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: 1997/98 – 2004/05 and 2005/06 – 2012/13) 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	**127**
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**
2012/13	0	10	39 (2)	0	0	6	0	13	53	**121**

( ) 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**
2012/13	0	8	34	0	0	6	0	13	53	**114**

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**					
1997/98 – 2000/01	58	58	77	(64-86)	79
2001/02 – 2004/05	38	37	92	(76-98)	100
2005/06 – 2008/09	42	42	93	(80-98)	100
2009/10 – 2012/13	33	33	91	(74-96)	94
• **All other UK paediatric units**					
1997/98 – 2000/01	270	270	91	(88-94)	91
2001/02 – 2004/05	247	247	91	(86-94)	94
2005/06 – 2008/09	207	206	96	(92-98)	98
2009/10 – 2012/13	197	195	96	(92-98)	96

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					
1997/98 – 2000/01	58	58	63	(48-74)	68
2001/02 – 2004/05	38	37	81	(64-90)	83
2005/06 – 2008/09	42	42	76	(60-86)	76
2009/10 – 2012/13	33	-	-	-	0
All other UK paediatric units					
1997/98 – 2000/01	270	270	80	(74-84)	81
2001/02 – 2004/05	247	247	80	(74-84)	83
2005/06 – 2008/09	207	206	86	(80-90)	85
2009/10 – 2012/13	197	-	-	-	1

Ten year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up1
Great Ormond Street Hospital and Royal Free Hospital					
1997/98 – 2000/01	58	58	51	(38-64)	44
2001/02 – 2004/05	38	37	76	(58-86)	50
2005/06 – 2008/09	42	-	-	-	0
2009/10 – 2012/13	33	-	-	-	0
All other UK paediatric units					
1997/98 – 2000/01	270	270	66	(60-72)	63
2001/02 – 2004/05	247	247	67	(60-72)	50
2005/06 – 2008/09	207	-	-	-	0
2009/10 – 2012/13	197	-	-	-	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**					
1997/98 – 2004/05	72	69	94	(84-98)	87
2005/06 – 2012/13	111	110	99	(94-100)	95
• **All other UK paediatric units**					
1997/98 – 2004/05	191	189	96	(92-98)	95
2005/06 – 2012/13	359	350	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**					
1997/98 – 2004/05	72	69	83	(70-90)	67
2005/06 – 2012/13	111	110	95	(88-98)	36
• **All other UK paediatric units**					
1997/98 – 2004/05	191	189	89	(84-92)	84
2005/06 – 2012/13	359	350	91	(86-94)	41

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**					
1997/98 – 2004/05	72	69	71	(58-82)	43
2005/06 – 2012/13	111	-	-	-	0
• **All other UK paediatric units**					
1997/98 – 2004/05	191	189	77	(70-82)	59
2005/06 – 2012/13	359	-	-	-	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**					
1997/98 – 2000/01	58	58	76	(62-84)	79
2001/02 – 2004/05	38	37	92	(76-98)	100
2005/06 – 2008/09	42	42	93	(80-98)	100
2009/10 – 2012/13	33	33	91	(74-96)	94
• **All other UK paediatric units**					
1997/98 – 2000/01	270	270	90	(86-94)	91
2001/02 – 2004/05	247	247	91	(86-94)	94
2005/06 – 2008/09	207	206	95	(92-98)	98
2009/10 – 2012/13	197	195	96	(92-98)	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**					
1997/98 – 2000/01	58	58	60	(46-72)	68
2001/02 – 2004/05	38	37	81	(64-90)	83
2005/06 – 2008/09	42	42	76	(60-86)	76
2009/10 – 2012/13	33	-	-	-	0
• **All other UK paediatric units**					
1997/98 – 2000/01	270	270	78	(72-82)	81
2001/02 – 2004/05	247	247	80	(74-84)	83
2005/06 – 2008/09	207	206	85	(80-90)	85
2009/10 – 2012/13	197	-	-	-	1

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					
1997/98 – 2000/01	58	58	47	(34-60)	44
2001/02 – 2004/05	38	37	76	(58-86)	50
2005/06 – 2008/09	42	-	-	-	0
2009/10 – 2012/13	33	-	-	-	0
• **All other UK paediatric units**					
1997/98 – 2000/01	270	270	63	(58-68)	63
2001/02 – 2004/05	247	247	66	(60-72)	50
2005/06 – 2008/09	207	-	-	-	0
2009/10 – 2012/13	197	-	-	-	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**					
1997/98 – 2004/05	72	69	91	(80-96)	87
2005/06 – 2012/13	111	110	99	(94-100)	95
• **All other UK paediatric units**					
1997/98 – 2004/05	191	189	95	(90-98)	95
2005/06 – 2012/13	359	350	95	(92-96)	96

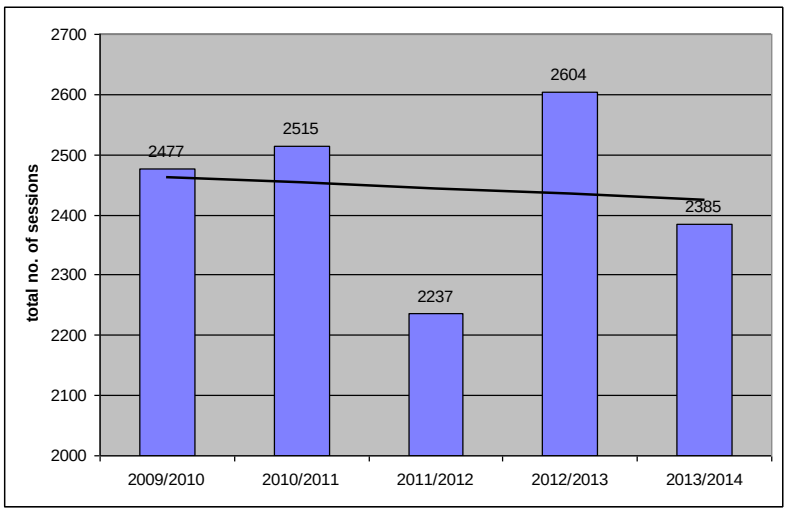
Five year transplant survival estimates					
Year group	N	No. analysed	Survival estimate (%)	95% confidence interval	% Follow up[1]
• **Great Ormond Street Hospital and Royal Free Hospital**					
1997/98 – 2004/05	72	69	79	(66-88)	67
2005/06 – 2012/13	111	110	93	(84-98)	36
• **All other UK paediatric units**					
1997/98 – 2004/05	191	189	87	(82-92)	84
2005/06 – 2012/13	359	350	90	(86-94)	41

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**					
1997/98 – 2004/05	72	69	66	(52-76)	43
2005/06 – 2012/13	111	-	-	-	0
• **All other UK paediatric units**					
1997/98 – 2004/05	191	189	74	(66-80)	59
2005/06 – 2012/13	359	-	-	-	0

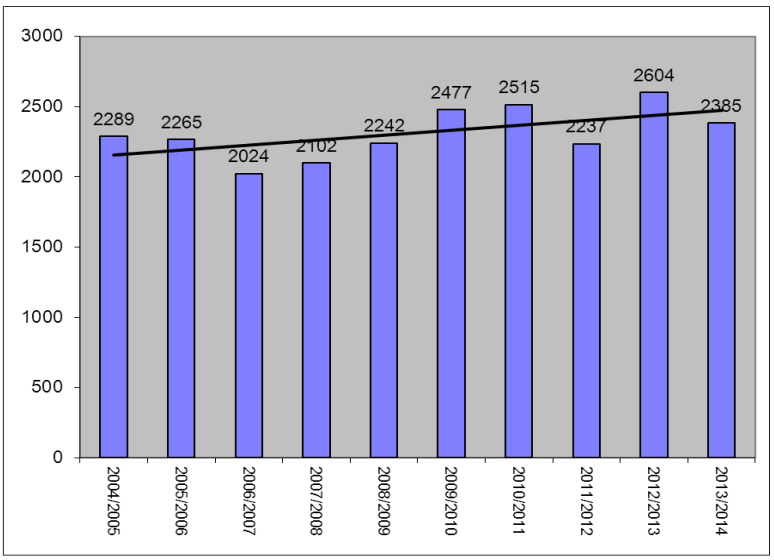
11.4 EAGLE HAEMODIALYSIS AUDIT 2013-2014

Liz Wright

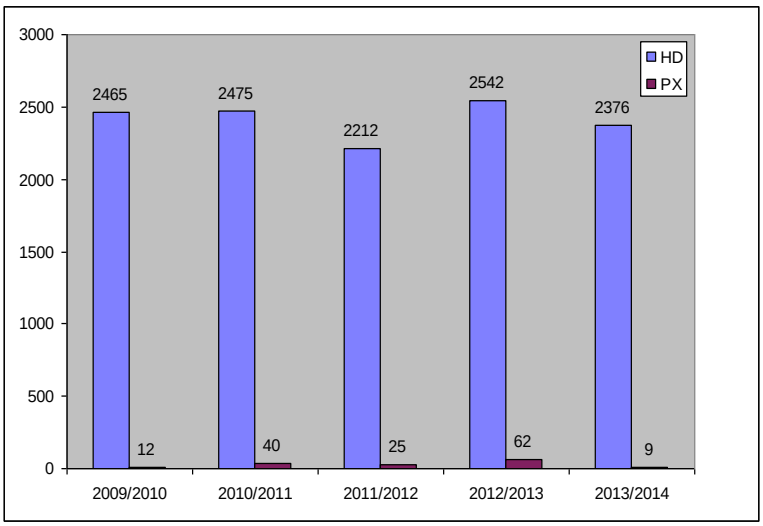
Eagle Haemodialysis Activity 2009-2014



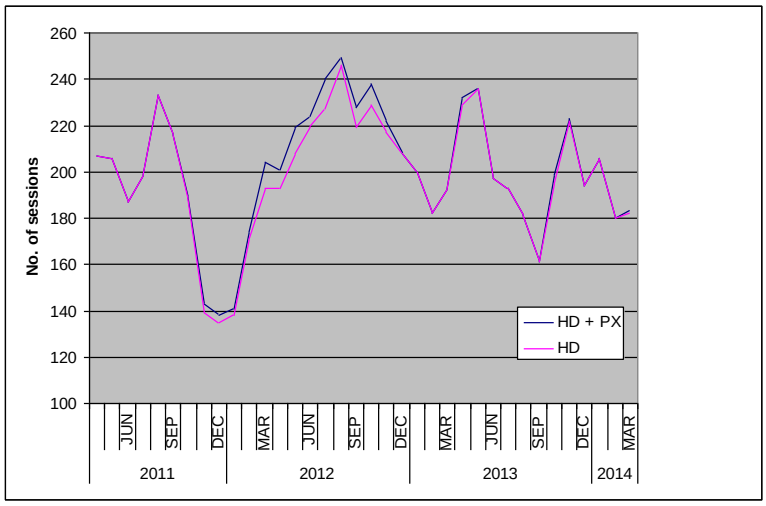
10 Year Total Activity



5 Year Activity by Type



3 Year Activity by Month



Totals

Children receiving haemodialysis or plasma exchange (previous year)

- Total = 30 (44)
- Chronic HD = 27
- Acute HD = 0
- PX = 3

Ages

- 30 children, 14 male: 16 female
    - 0 – 2 years = 7 (9)
    - 2 – 5 years = 2 (3)
    - 5 – 10 years = 9 (10)
    - 10 – 15 years = 7 (11)
    - 15+ years = 5 (11)
    - Youngest –0.1 years

- 30 % of workload < 5 years (27%)

New Patients

Source	No.s of children
From CRF programme	3
From PD programme	1
From transplant programme	1
Transfer from abroad	1
New patients – first RRT	3
PX	2
Total	**11**

Leavers

Reason	No.s of children
Transplant DD	3
Transplant LRT	4
PD	1
Transfer adult HD	1
HHD programme	2
Died	0
Total	**11**

Non-movers

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

Visitors

- Visitors = 6
- For access insertion = 0
- Transplant work-up/assessment = 5
- Holiday HD = 1

Acute sessions & TPE

- 0 acute HD sessions
- 0 therapeutic plasma exchanges

Access Totals

- Total access = 48 catheters in 27 children
    - AVF – 8
    - Permanent – 47 (4 in HHD children)
    - Temporary – 1

- Accesses inserted over the year:
    - AVF – 5 (and 3 in HHD children)
    - Permanent – 30
    - Temporary – 1

Line Removals

Reason	Number
Infection	4
Poor flows	9
Cuff migration	3
Malposition	1
Trabsplant	6
Upgrade to dual lumen	1
Thrombus	1
AVF maturation	2
Conversion to permanent catheter	1
PUO	1
Total	**11**

Infections

- 11 line infections in 7 children
- 4003 catheter days

- 2.75 infections/ 1000 catheters days
- Tego bungs used since Feb 2014, following accidental disconnection.

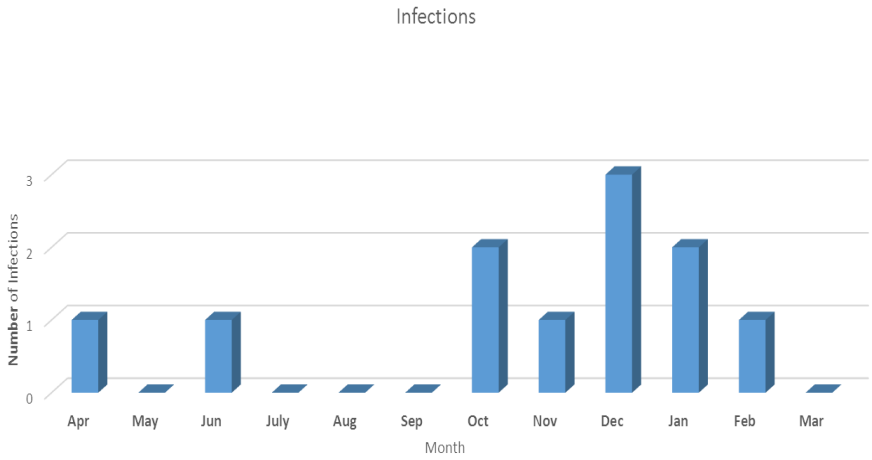
Infection Rates

	08/09	09/10	10/11	11/12	12/13	13/14
No of infections	7	5	7	7	7	11
Catheter days	2434	3384	4076	3726	4022	4003
Infections/1000 catheter days	2.9	1.5	1.7	1.9	1.7	2.75

Line Infections n = 11

Patient	Time (days) from insertion	Microbiology	Outcome
CB	61 289	CNS Enterococcus	Cleared Line replaced
MS	54 188	Staph aureus CNS	Cleared Line removed/AVF
LO	11 104	CNS CNS	Cleared Cleared
JB	247 345	Gp B strep CNS	Cleared Cleared
WC	31	Klebsiella	Cleared
TT	5	Micrococcus	Line replaced
CC	23	CNS	Cleared

Infections by Month



Exit site infection

8 children had 11 exit site infections.
Of which 9 were CNS, 1 was staph aureus, and one beta haem strep gp A.

One fistula swab grew staph aureus.

AVF Data

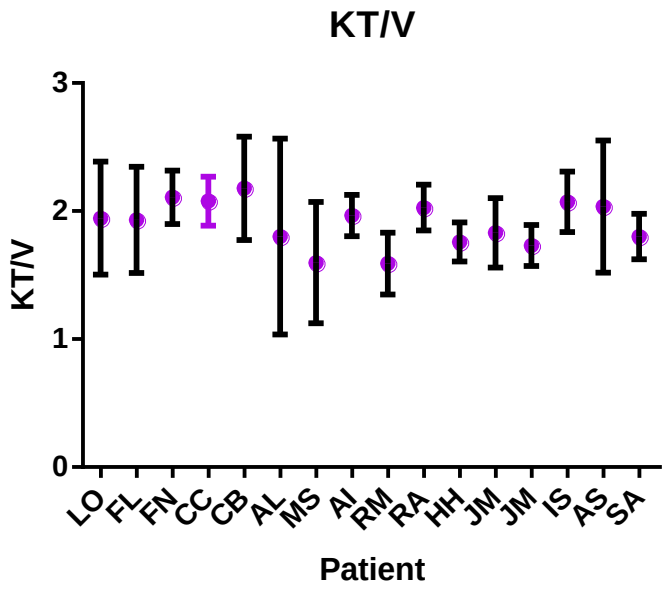
- 8 children had AVFs
- 5 created in this audit year (and 3 HHD)

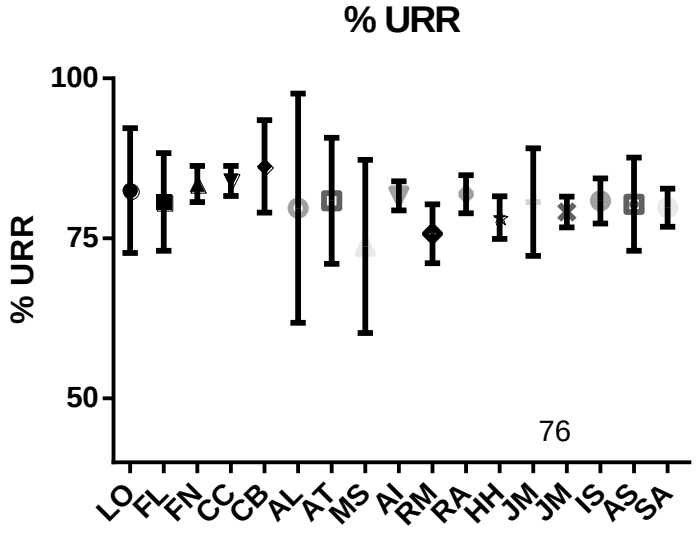
AVFs created in Audit Year

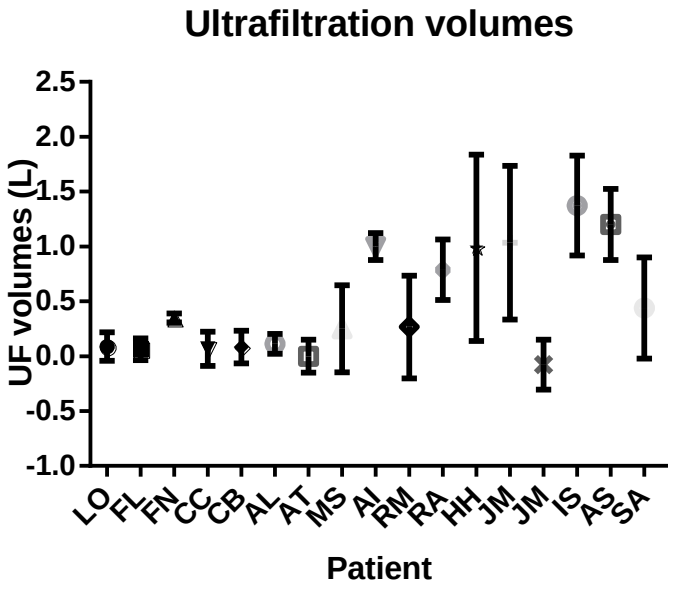
Patient	Age	Site	Surgeon	2nd Stage	Outcome
IS	9.5	L basilica vein transposition	FC	Yes	In use
SA	15.5	R brachio-cephalic	FC	Yes	Waiting 2nd stage
MS	7.5	L brachio-cephalic	FC	No	In use
HH	15.1	L basicic vein transposition	FC	Yes	In use
HI	10.4	R brachio-cephalic	FC	No	Never used – DD tx

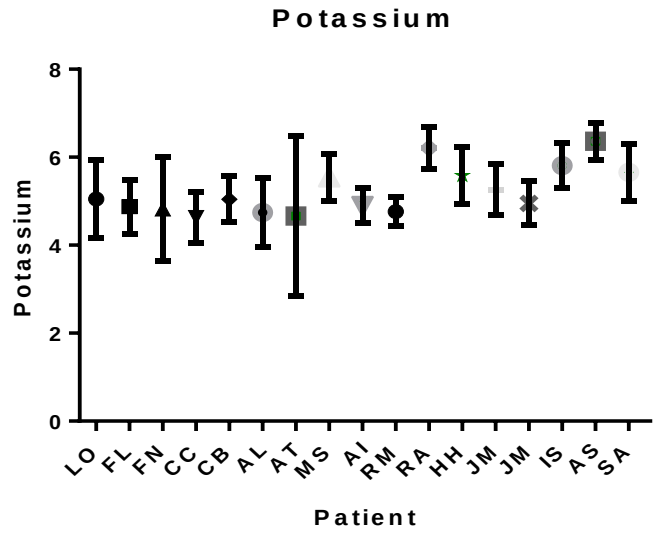
Septicaemia

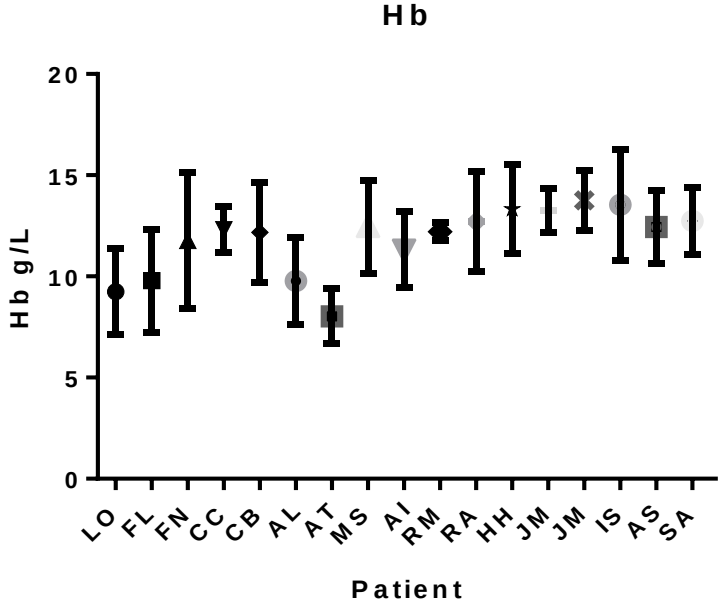
- One child developed a Staph aureus septicaemia with an AVF.
- Concurrent with AVF complications.

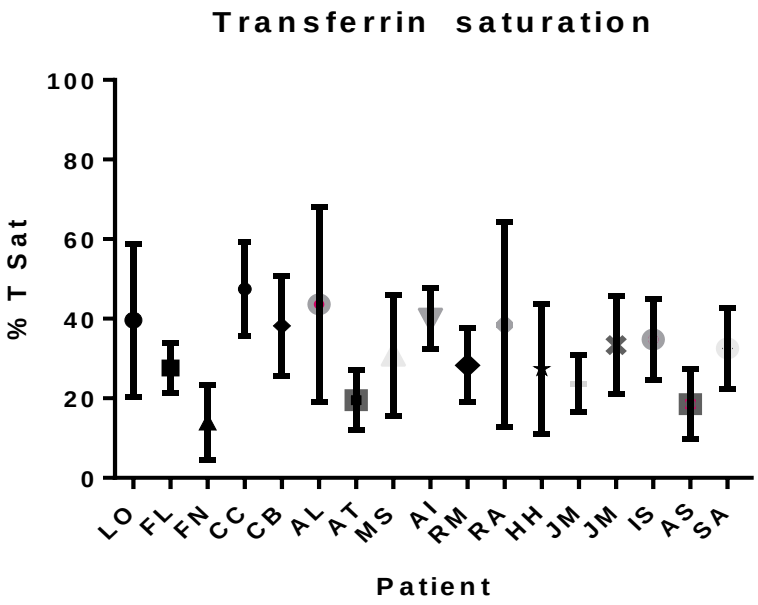


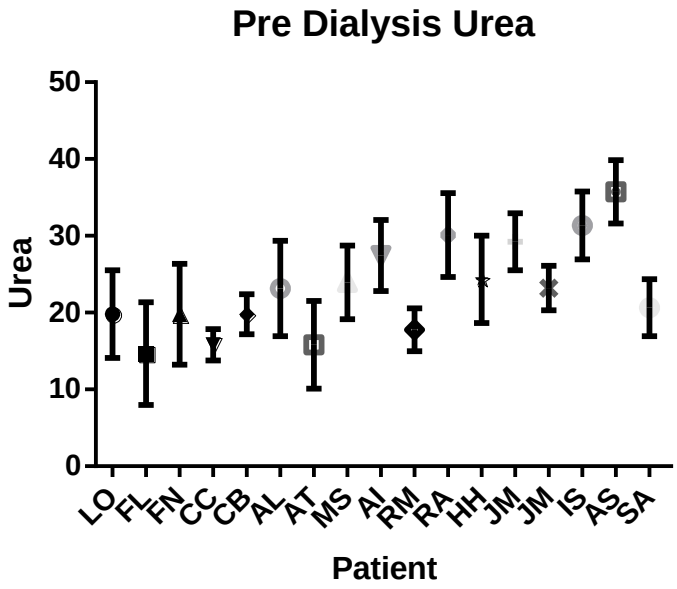


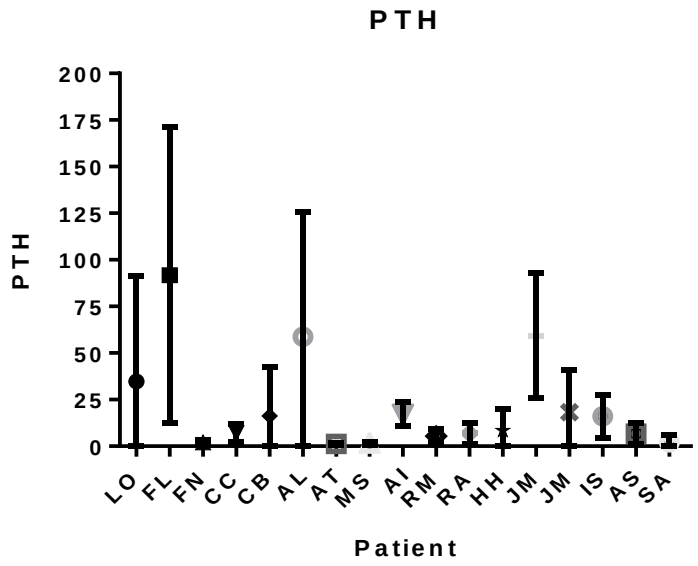

Ultrafiltration volumes
UF volumes (L)
2.5
2.0
1.5
1.0
0.5
0.0
-0.5
-1.0
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient

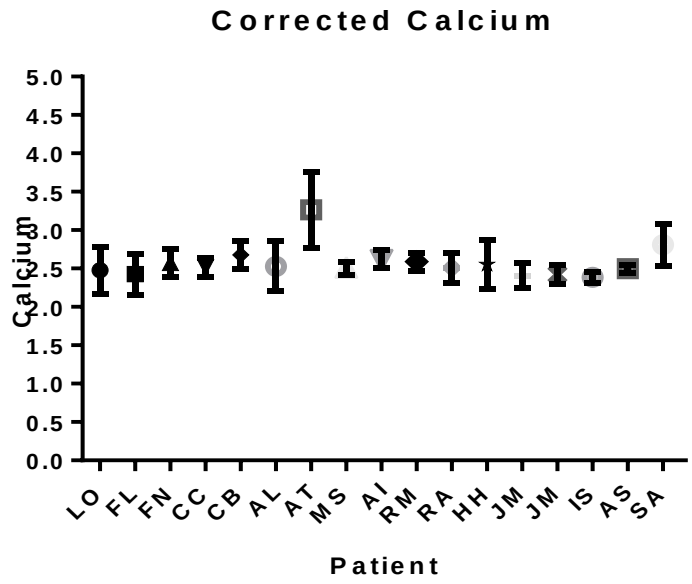

Potassium
Potassium
8
6
4
2
0
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient

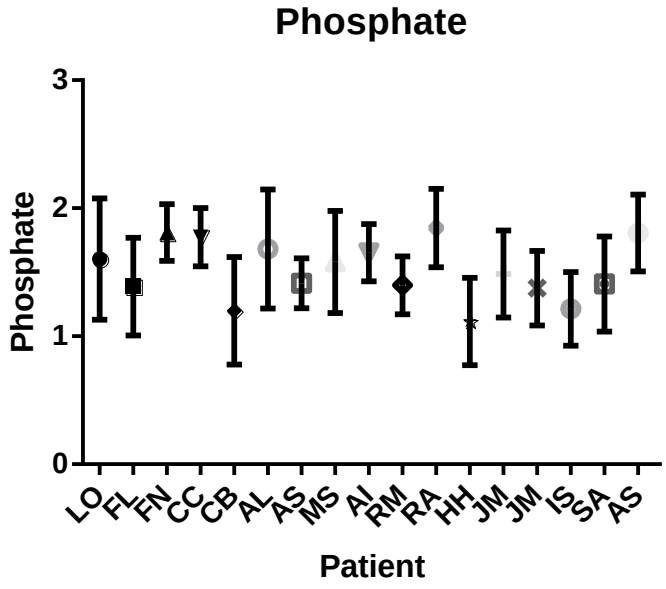

Hb
Hb g/L
20
15
10
5
0
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient

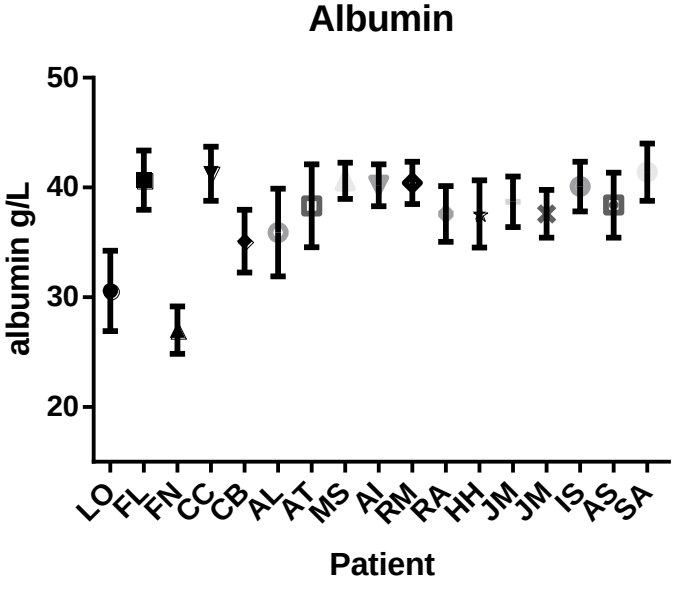

Transferrin saturation
% T Sat
100
80
60
40
20
0
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient


Pre Dialysis Urea
Urea
50
40
30
20
10
0
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient


PTH
PTH
200
175
150
125
100
75
50
25
0
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient


Corrected Calcium
Calcium
5.0
4.5
4.0
3.5
3.0
2.5
2.0
1.5
1.0
0.5
0.0
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient

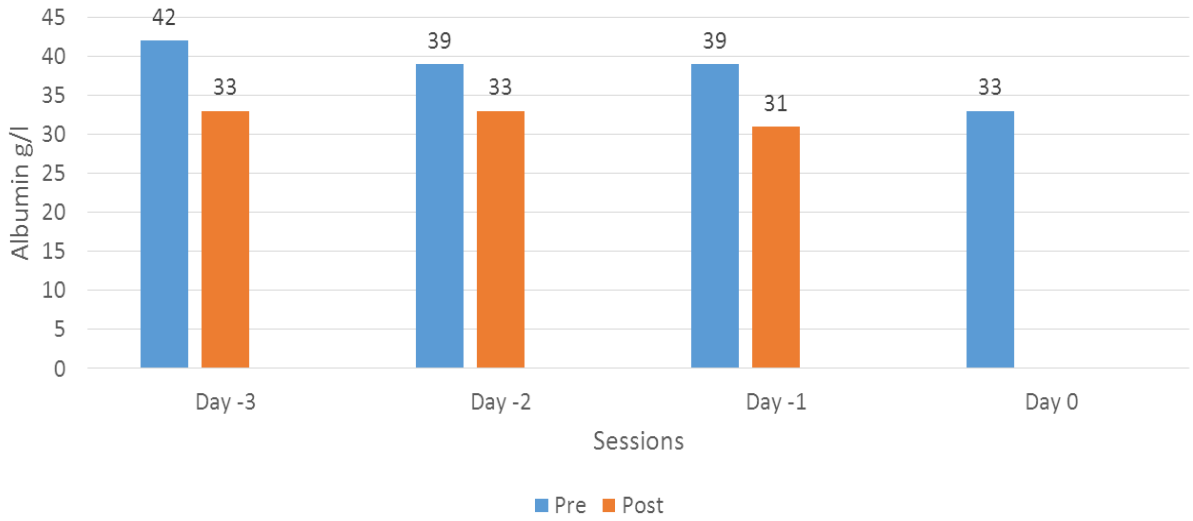

Phosphate
Phosphate
3
2
1
0
LO FL FN CC CB AL AS MS AI RM RA HH JM JM IS SA AS
Patient


Albumin
albumin g/L
50
40
30
20
LO FL FN CC CB AL AT MS AI RM RA HH JM JM IS AS SA
Patient

DFPP Plasma Volumes

- 1.5-2 plasma volumes processed:
- Day 1 - 1.5; 164 mins
- Day 2 - 2.0; 194 mins
- Day 3 - 1.5; 130 mins

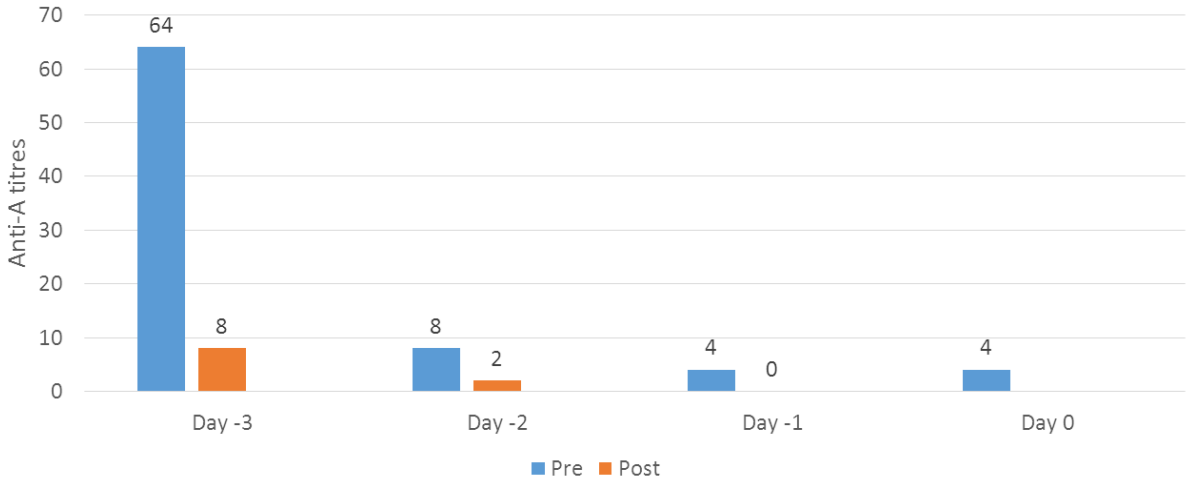
DFPP - Serum Albumin levels



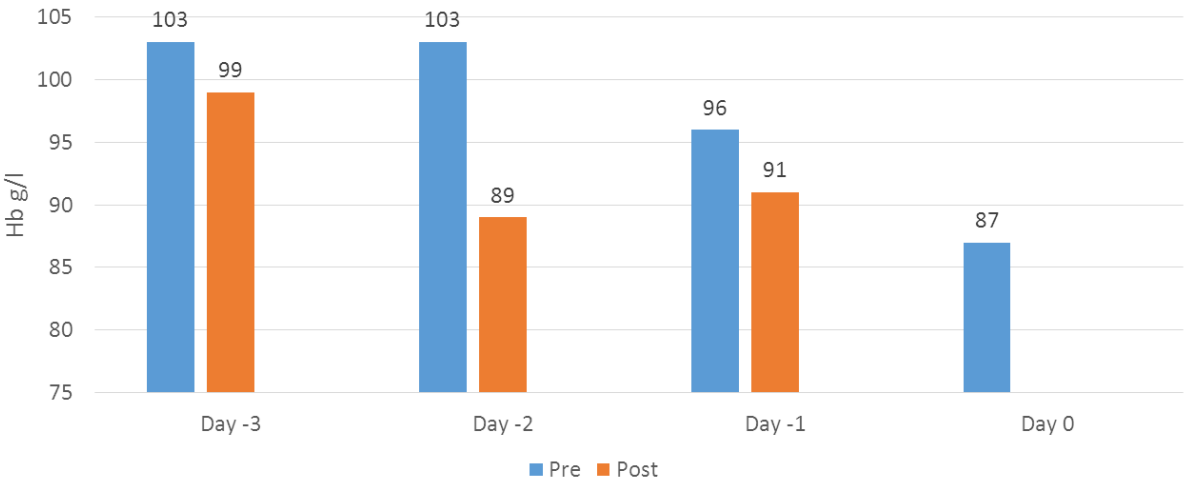
Case Study DFPP - Fluid Balance

DFPP Session	Weight Pre-DFPP (kg)	Weight Post DFPP (kg)	End Procedure Balance	Actual Gain (kg)
1	34.1	34.6	645mls	0.5kg
2	34.0	34.7	754mls	0.7kg
3	34.9	35.1	577mls	0.2kg

DFPP Anti-A Titres



DFPP - Hb Levels

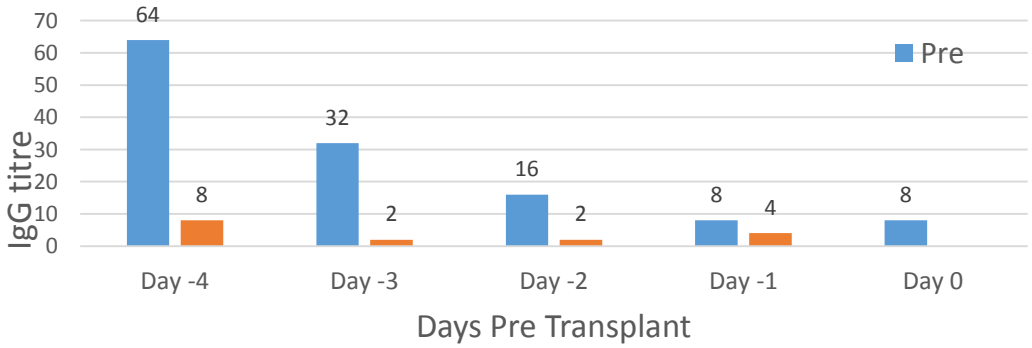


Immunoadsorption

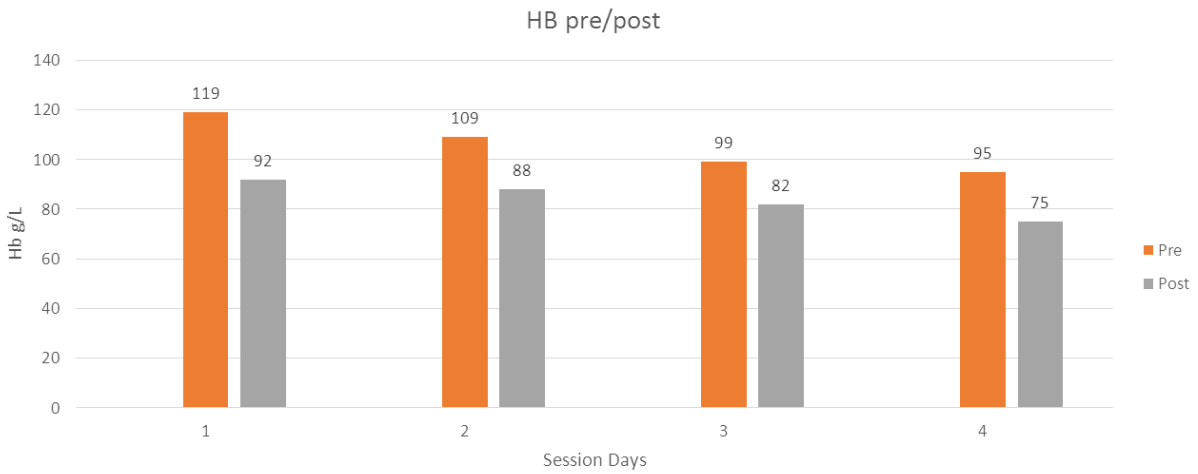
IA procedure

- ACD-A anticoagulant
- Calcium gluconate 10% infused IV via 3-way tap into distal end of circuit
    - 0.04 mmol/kg/hour; made up to 50-100mls.
- Ionised calcium checked pre and post-procedure
- 2.5 plasma volumes treated each day
- 4 hours per session

Titres – pre/post IA



Hb - pre/post IA



Fluid Balance

IA Session	Weight Pre-IA (kg)	Weight Post IA (kg)	End Procedure Balance	Actual Gain (kg)
1	21.5	22.15	491ml	0.65
2	21.4	22.1	381ml	0.7
3	21.6	22.2	404ml	0.6
4	21.5	22.25	554ml	0.75

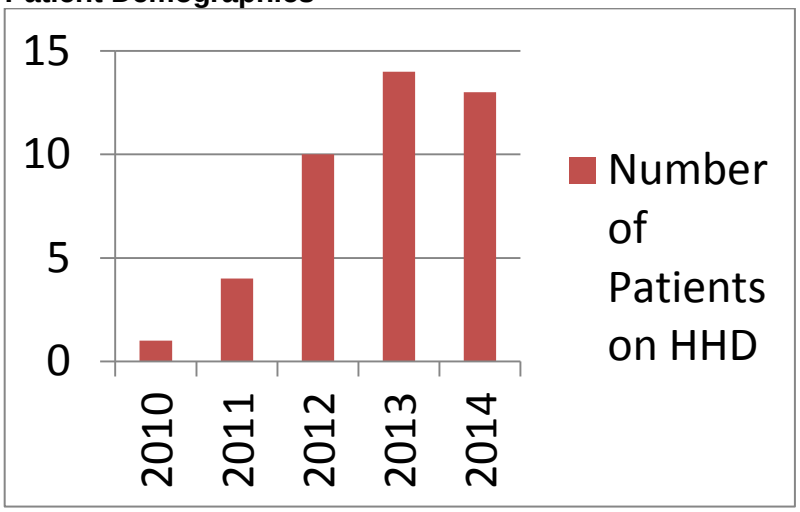
11.5 HOME HAEMODIAYLSIS AUDIT

April 2013 – March 2014
Dr Daljit Hothi, Lynsey Stronach, Cecilia McNeice and Kate Sinnott

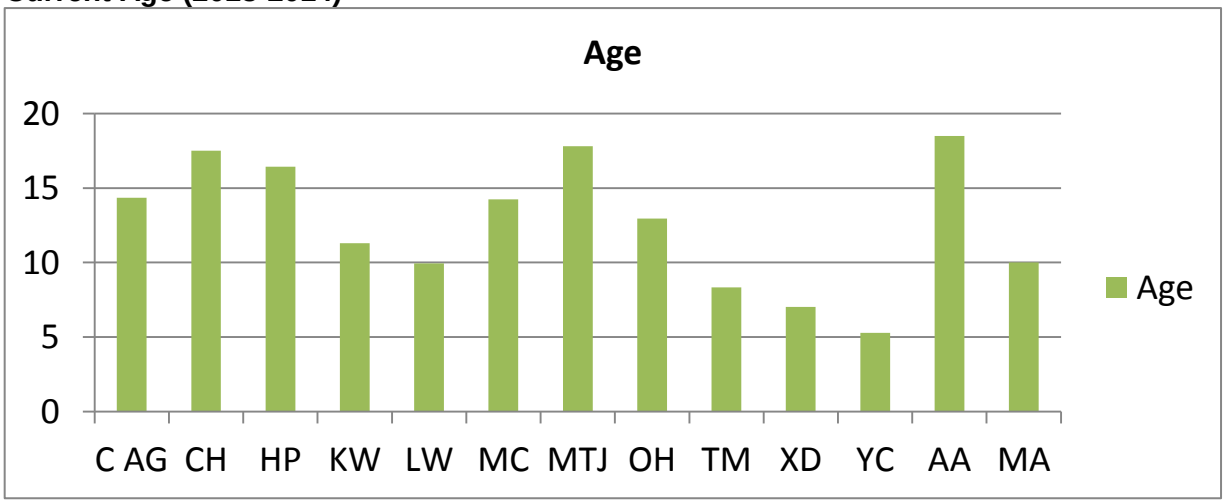
Patient Demographics

- 17 HHD Patients since 2010
- 13 Patients this Audit Year
- Currently 12 HHD patients (1 patient managed by Southampton Nephrology Team)
- Total of 315.60 Months of Patients on HHD

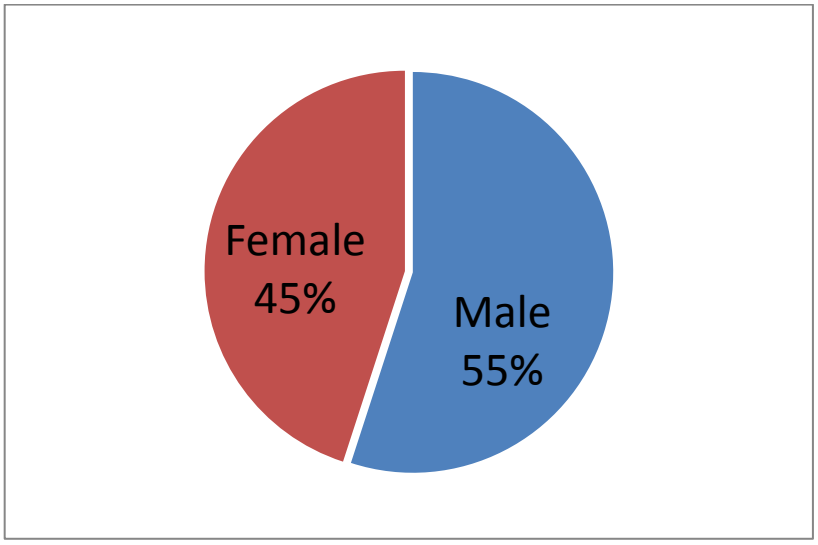
Patient Demographics



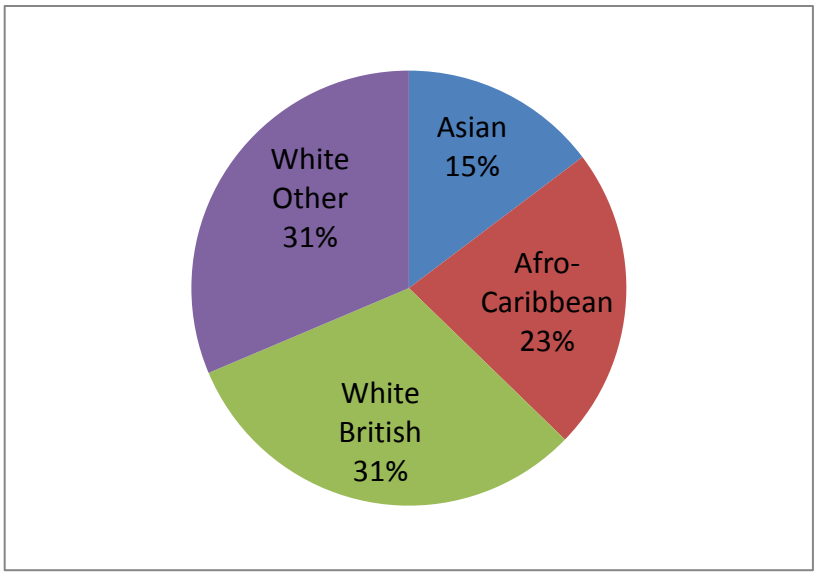
Current Age (2013-2014)



Gender
2013-2014



Ethnicity
2013-2014



Number of Patients
2013-2014

- 6 Patients Successfully Trained and Discharged
- 3 Discharged from HHD Service

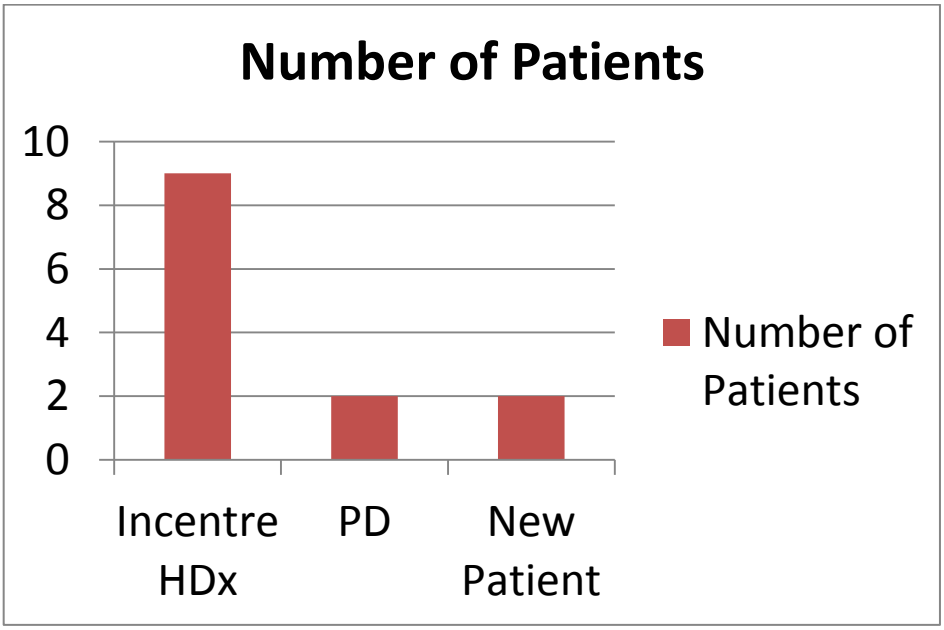
<u>Reason For Discharge</u>

- 2 Patients Transferred to Adult Services
- 1 Successful ABOi Transplant

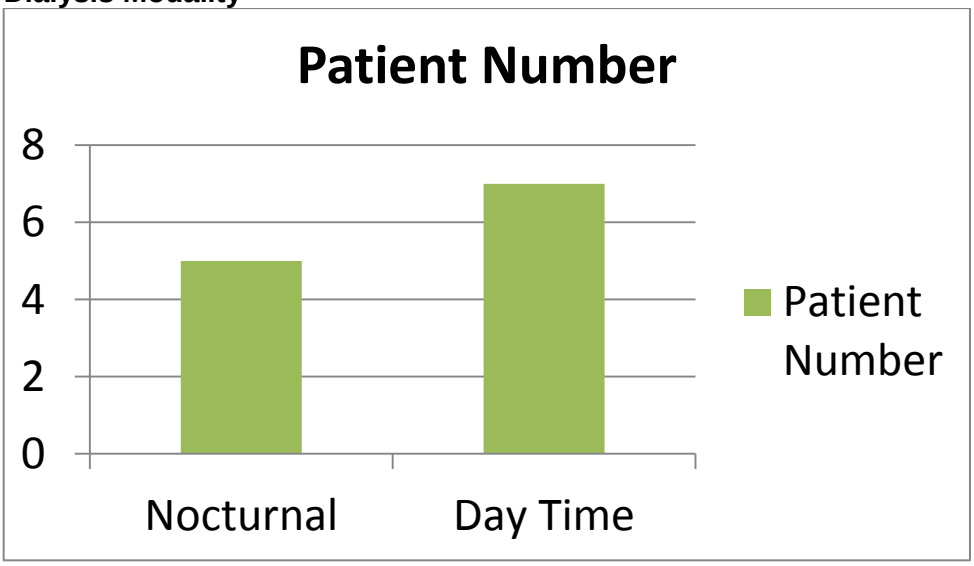
Primary Diagnosis

Number of patients	Primary Diagnosis
2	Steroid-Resistant Nephrotic Syndrome
2	Posterior Urethral Valves
2	Renal Dysplasia
2	Bilateral Renal Dysplasia
1	FSGS
1	Bilateral Wilms Tumours & Cardiomyopathy
1	Congenital Nephrotic Syndrome
1	Atypical MPGN
1	Atypical HUS

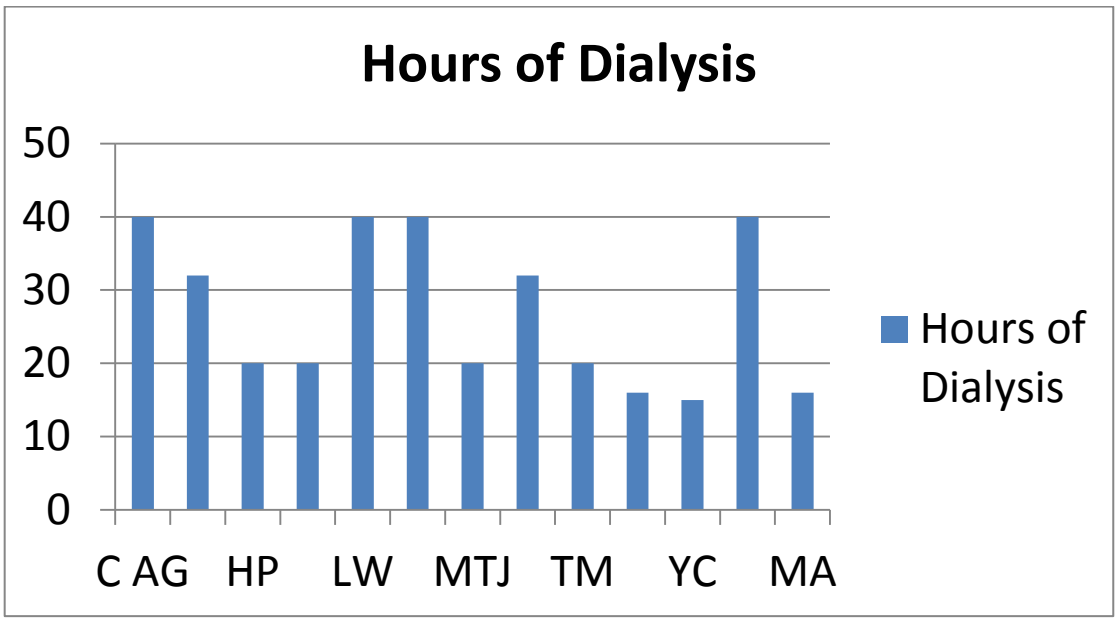
Previous Renal Replacement



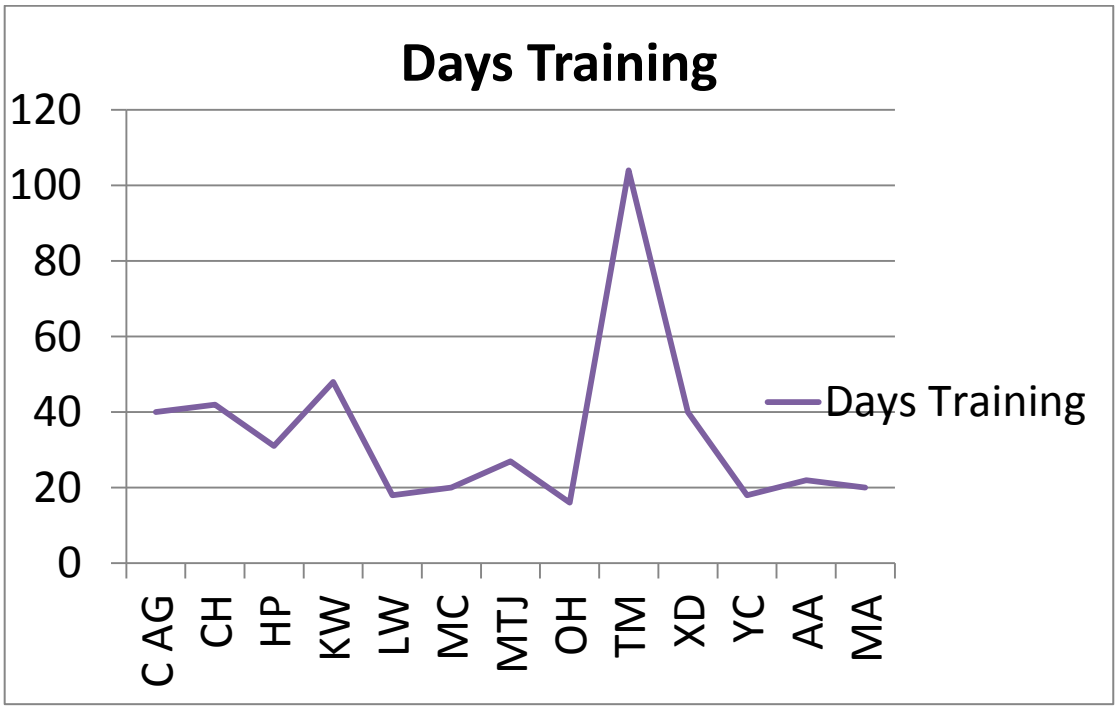
Dialysis Modality



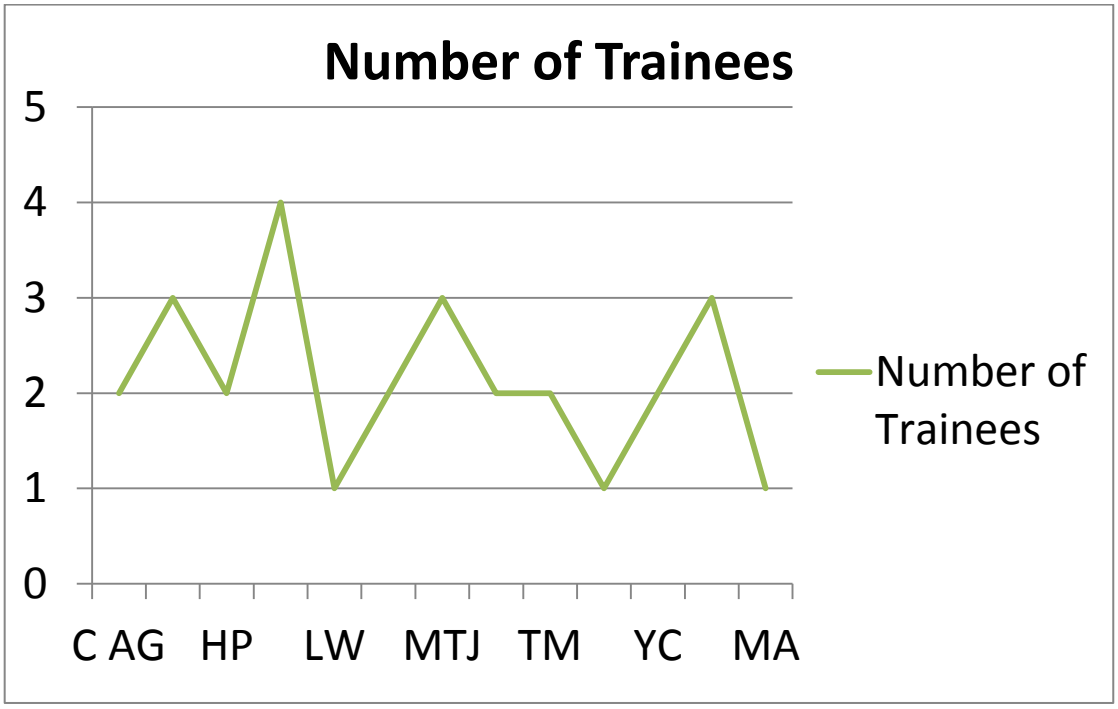
Dialysis Dose



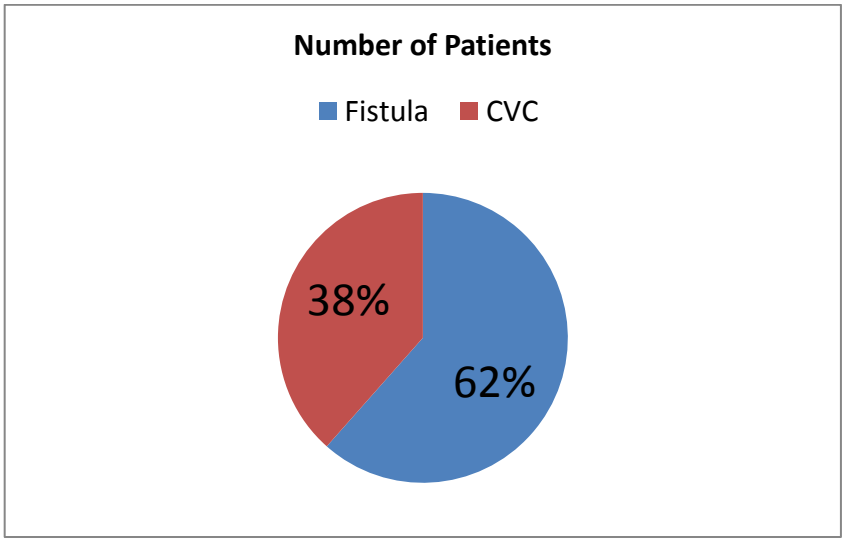
Training Time Required (Total 436 Working Days)



Number of Trainees



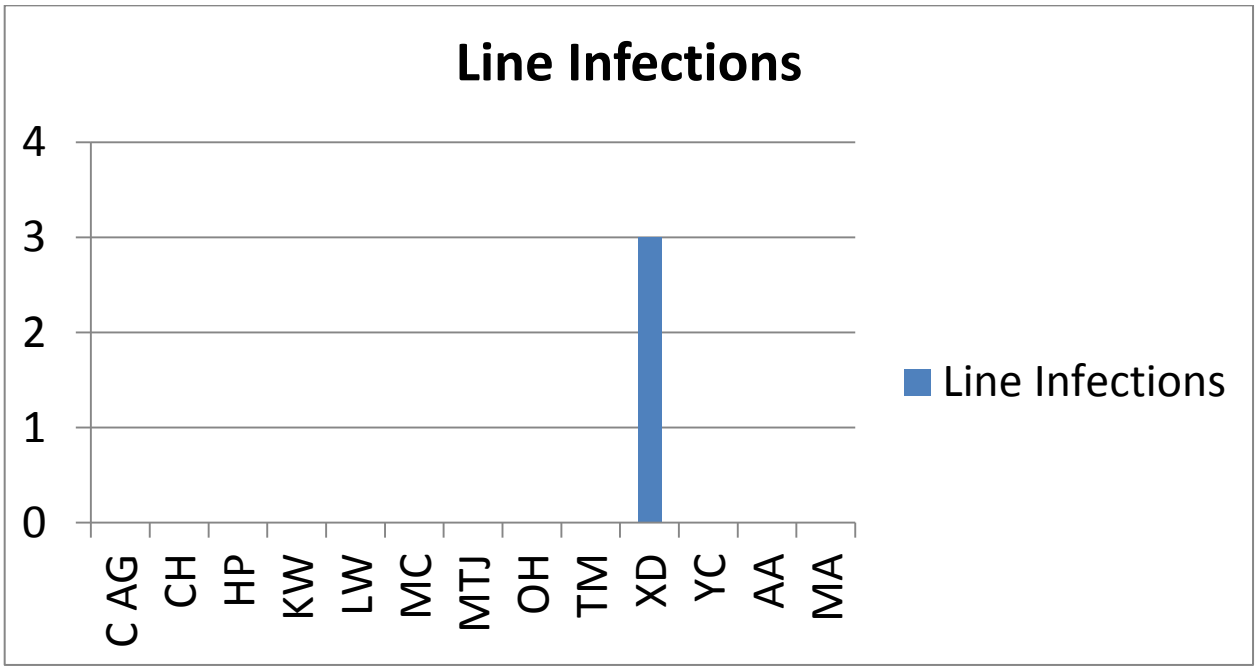
Dialysis Access



Dalteparin Doses

Patient	Blood Flow	Aspirin	Dalteparin Dose	Anti Xa
C AG	250	Yes	30 iu/kg	0.06
CH	250	Yes	37 iu/kg	0.01
HP	320	Yes	51 in/kg	0.03
KW	200	Yes	39 iu/kg	0.06
LW	140	No	57 iu/kg	0.24
MC	200	Yes	53 in/kg	0.23
MTJ	340	Yes	20 iu/kg	0.03
OH	250	Alt Days	41 iu/kg	0.04
TM	150	Yes	50 iu/kg	0.31
XD	150	Yes	51 iu/kg	0.03
YC	120	No	45 iu/kg	0.05
MA	180	Yes	90 iu/kg	0.02
AA	280	Yes	14 iu/kg	0.02

Number of CVC Infections



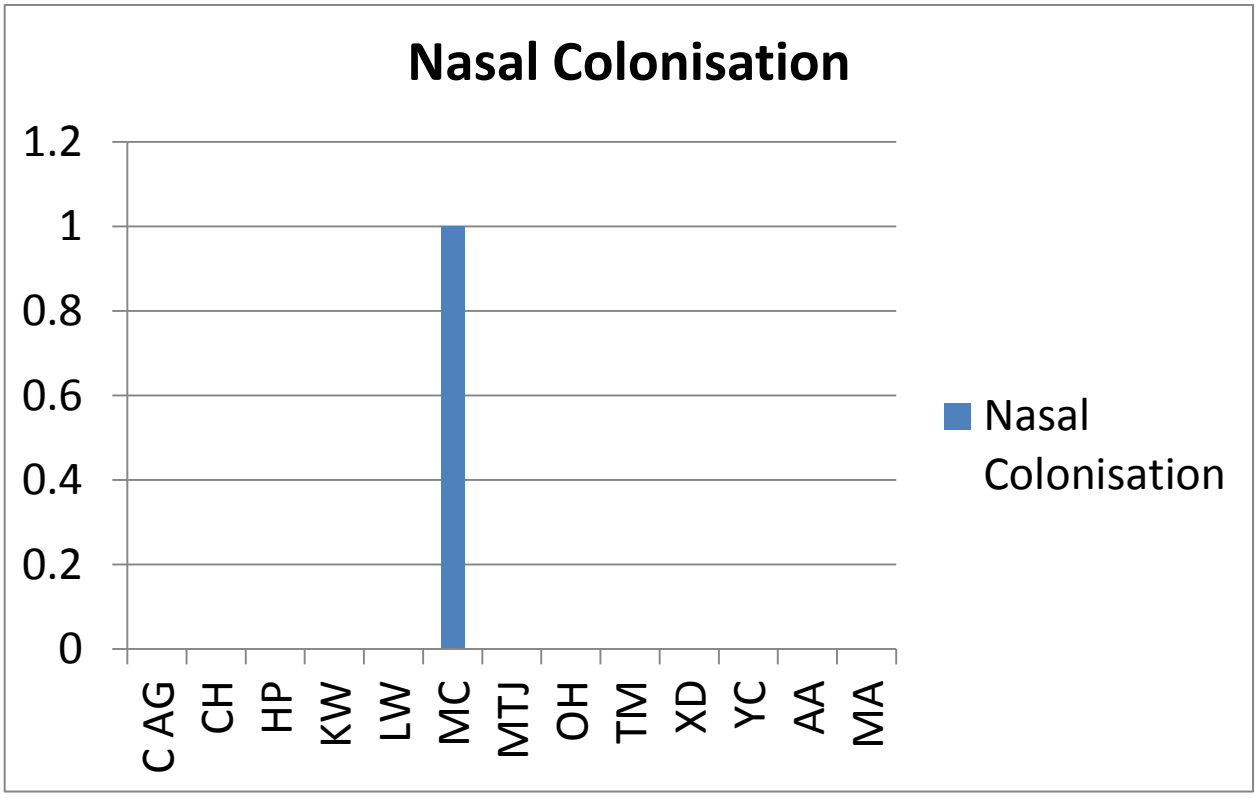
Outcome
August 2013
Line replaced- Suspected line infection
Vanc and Cipro
Negative Cultures (Positive locally) , Exit Site – Grew Coag Neg Staph

Sept 2013
Line Replaced- Suspected line infection
Vanc and Cipro
Negative Cultures (Positive locally)

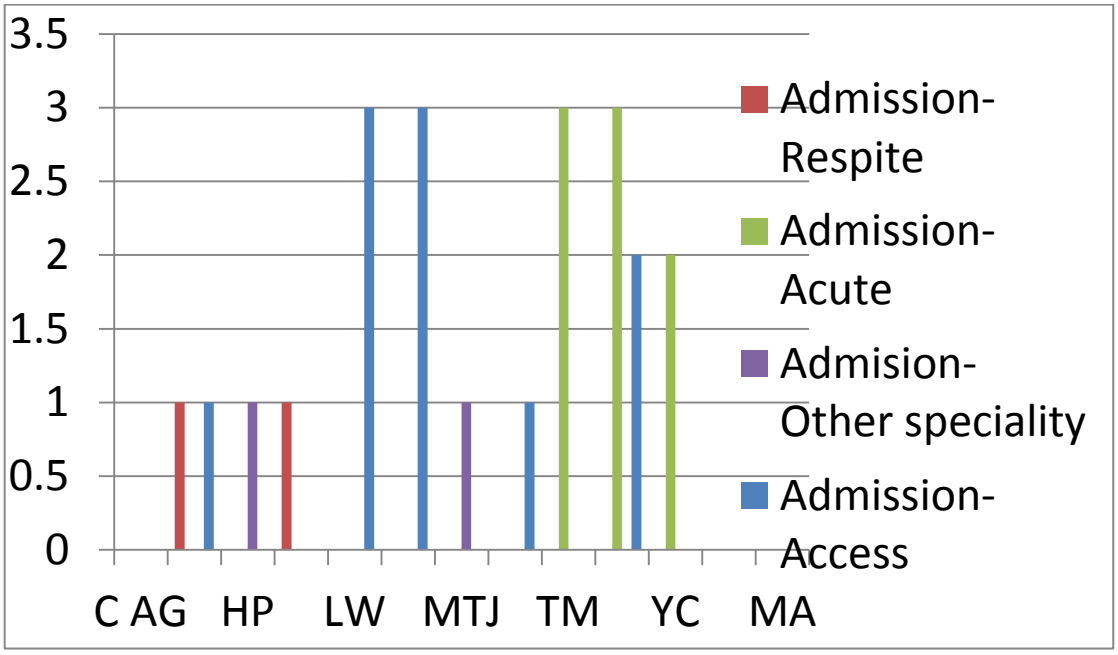
November 2013
Positive Blood Cultures (Coag Neg Staph, Entrocococcus, Diptheroids)
Contaminant?
Vanc and Cipro

Total length of stay 21 days

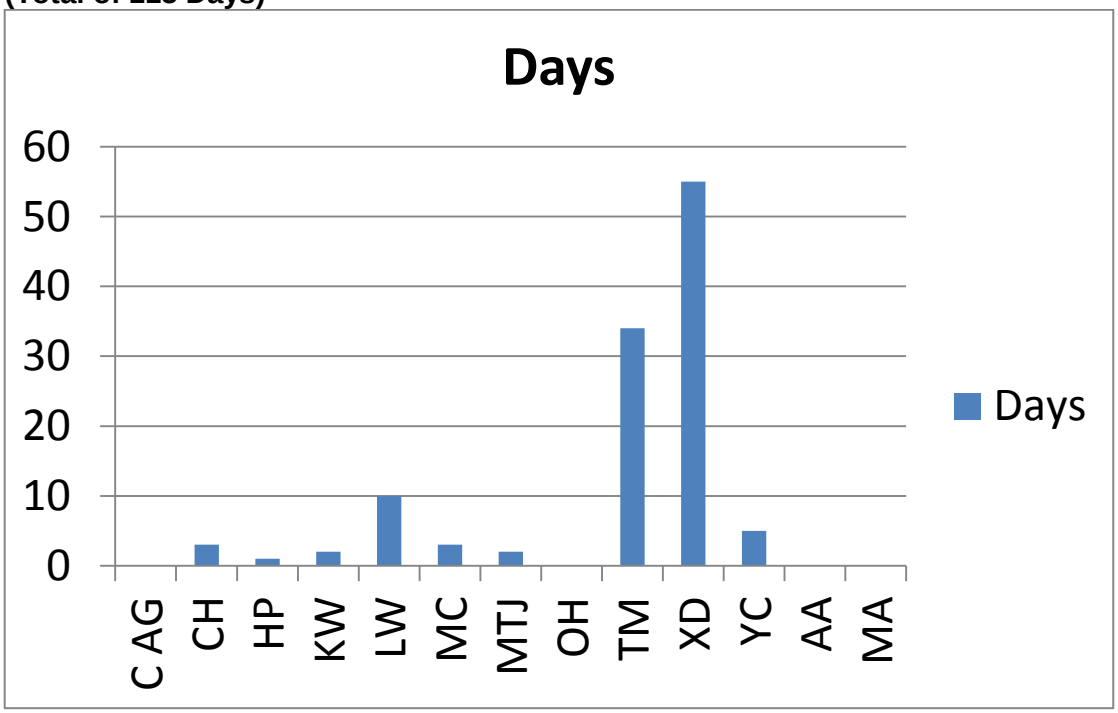
Nasal Colonisation



Number of Hospital Admissions
2013-2014

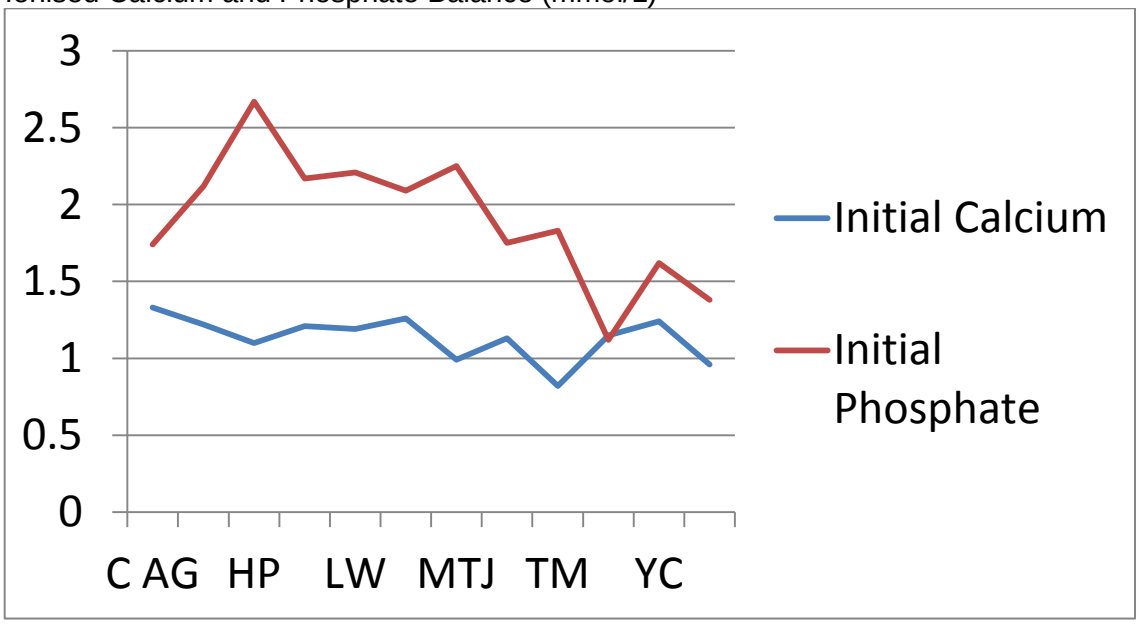


Hospital Admissions in Days
(Total of 115 Days)

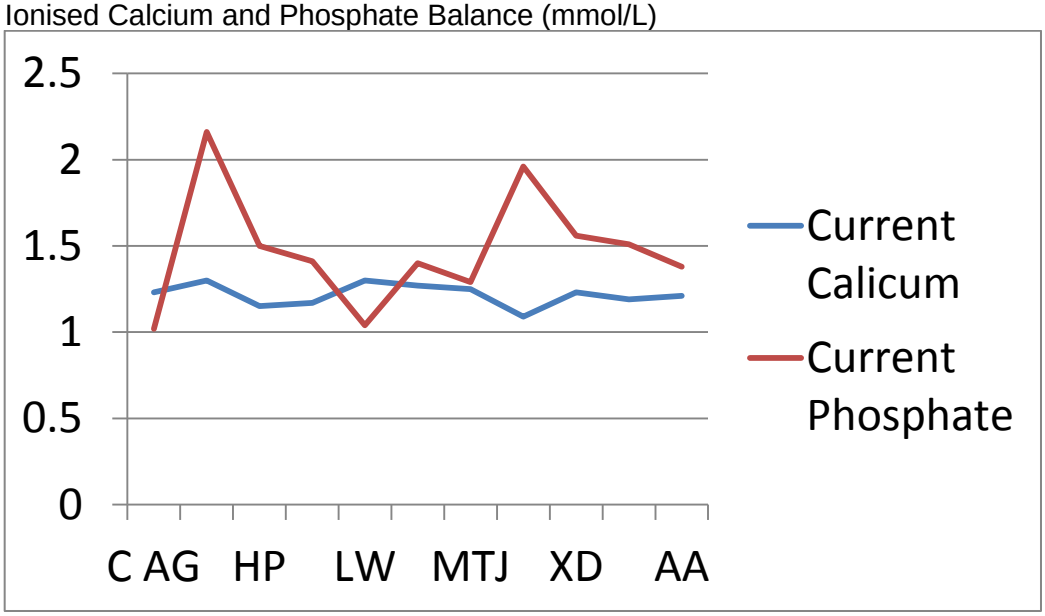


Clinical Outcomes

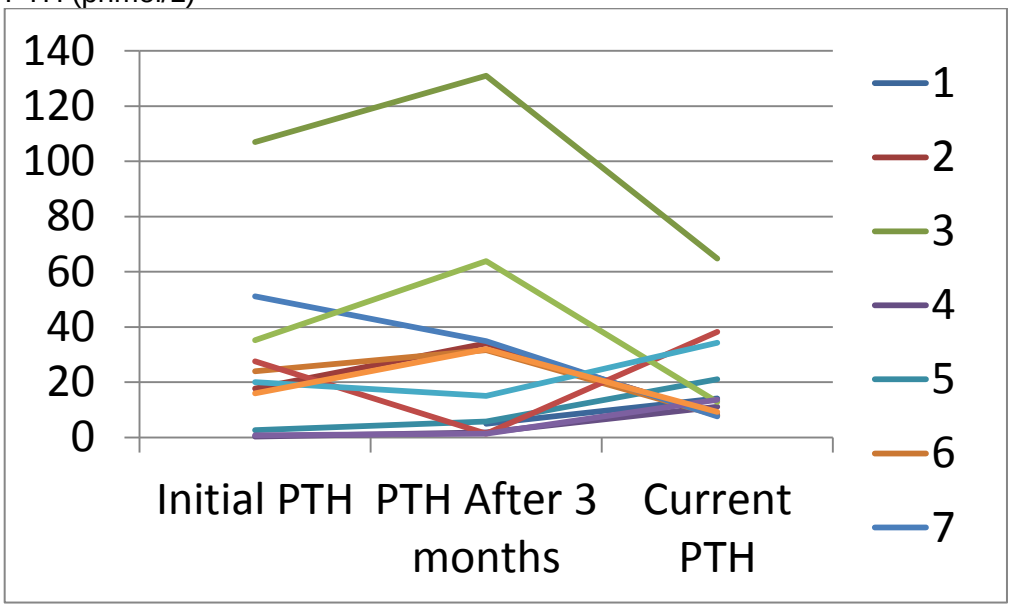
Ionised Calcium and Phosphate Balance (mmol/L)



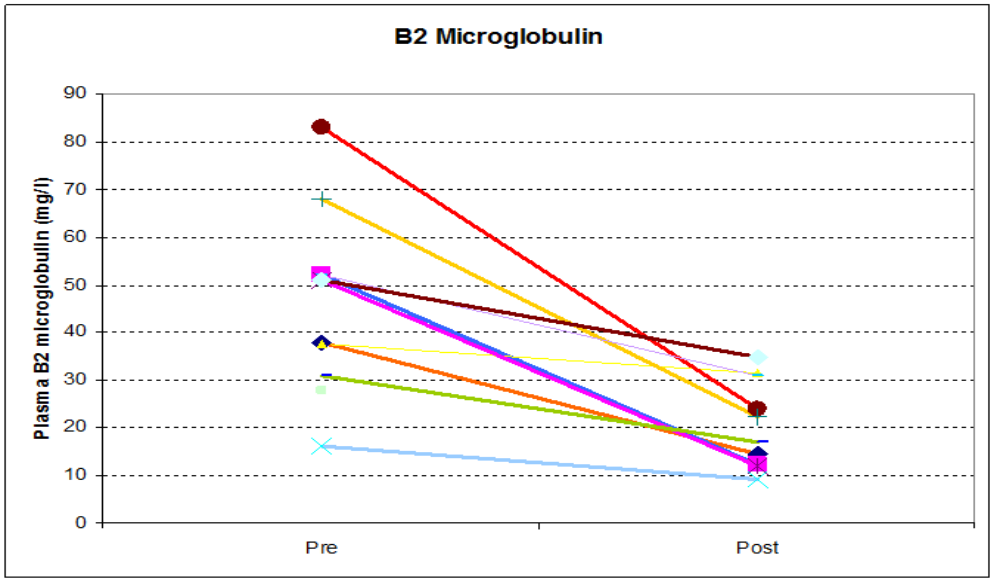
Ionised Calcium and Phosphate Balance (mmol/L)



PTH (pnmol/L)



B2 Microglobulin



Cardiac Parameters

Patient	Cardiac Echo	Anti-Hypertensive
CAG	Normal	No
CH	Mild Concentric LVH	No
HP	Normal	No
KW	Normal	No
LW	Mild to Moderate LVH	No
MC	Normal	No
MTJ	Normal	No
OH	Normal	5mg Enalapril OD
TM	Normal	No
XD	Normal	No

YC	Normal	No
AA	Normal	No
MA	Normal	No

Cardiac Function

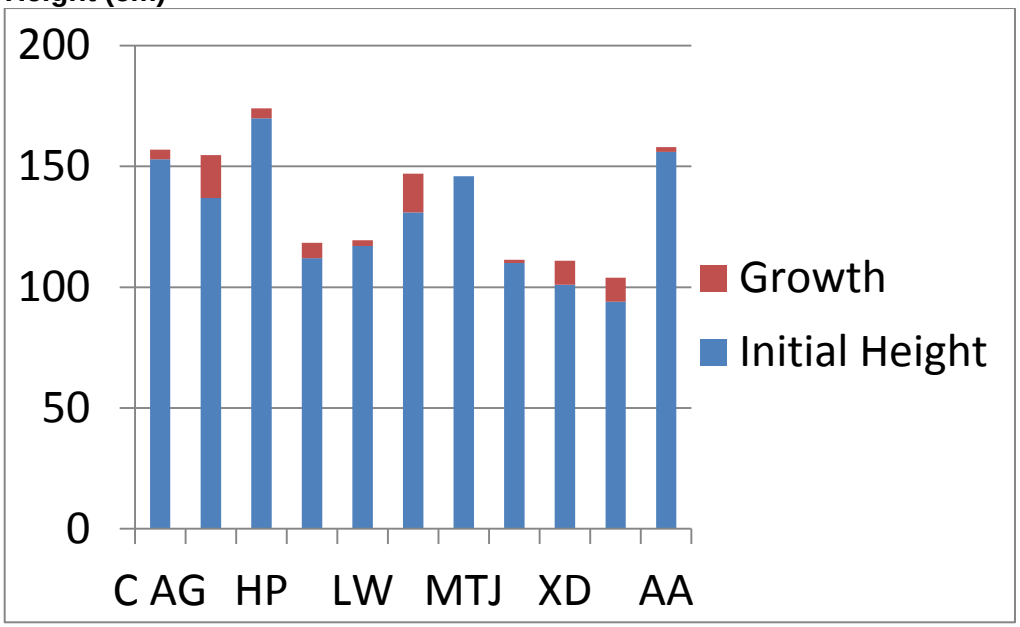
August 2011
LV mildly dilated
Globally and severely impaired systolic function (LVEF 29%)
LV mass is upper limit of normal Appearance of myocardial architecture within normal range
RV underfilled, with mildly impaired systolic contraction (RVEF 51%)

March 2012
Normal sized LV without any LVH
Normal left ventricular systolic function (LVEF 60%) (RVEF 58%)
This study shows significant improvement in biventricular systolic function and reduction in LV volumes

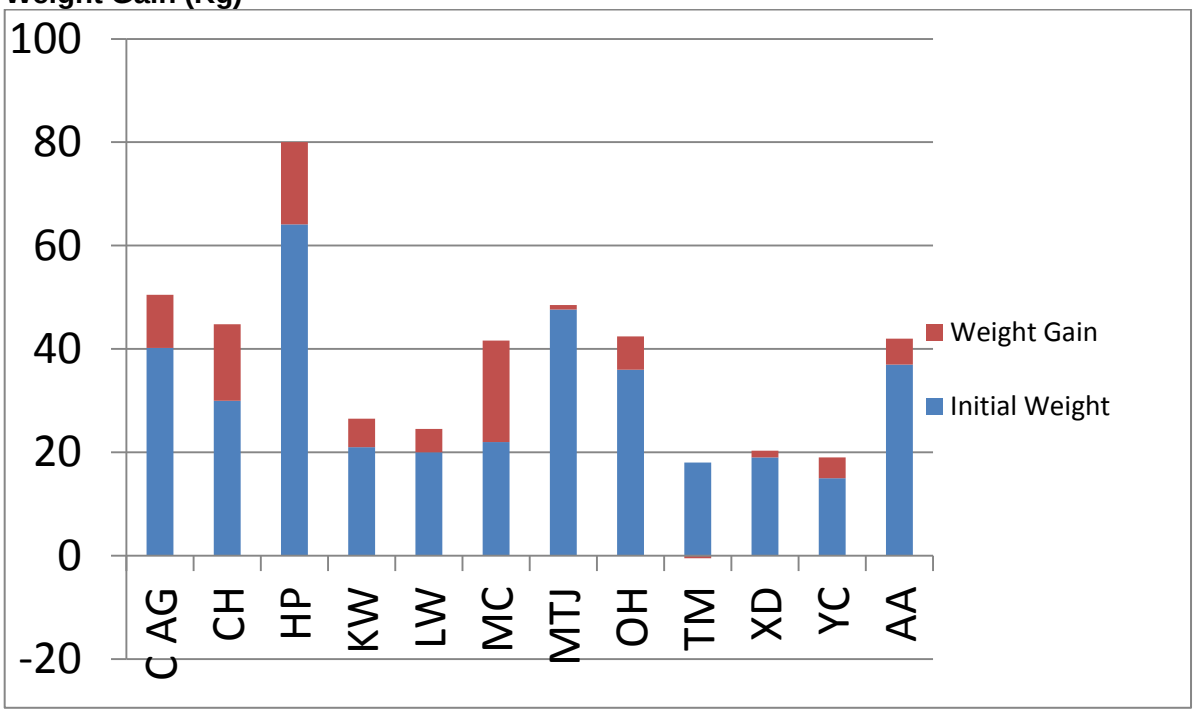
Diet & Fluid Allowance

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

Height (cm)



Weight Gain (Kg)



Well-being

- Increased energy
- Minimal post dialysis recovery time: minutes rather than hours
- Minimal diet and fluid restrictions
- Schooling
- Social life

Carer Burden……

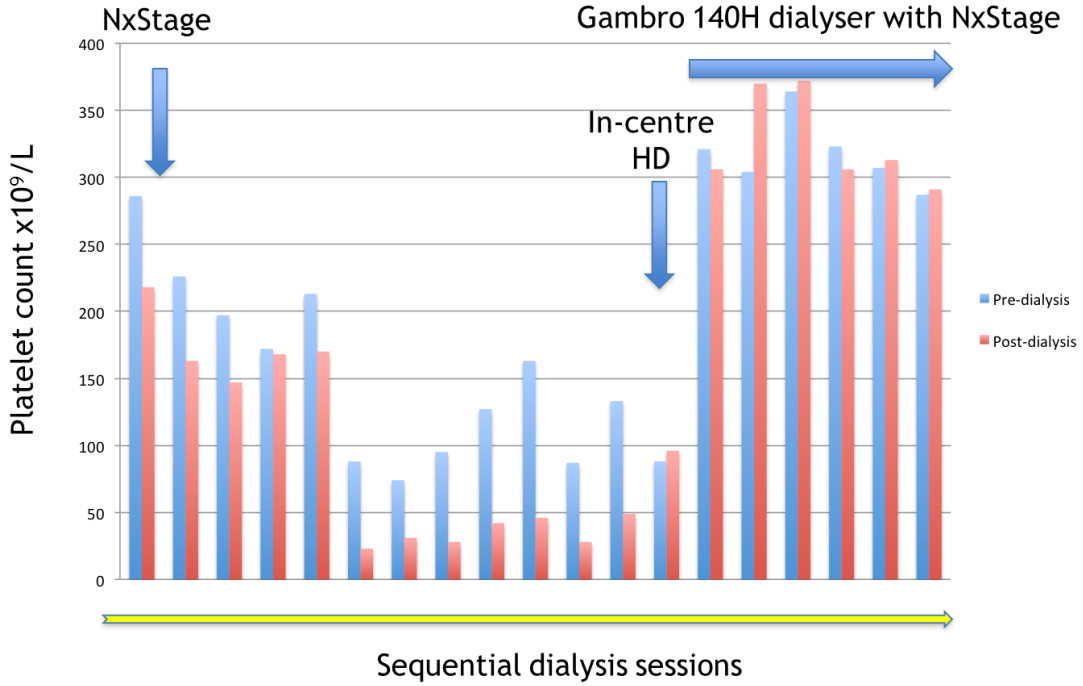
Parental feedback

- ‘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.

Dialysis Induced Thrombocytopenia



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

Future Developments

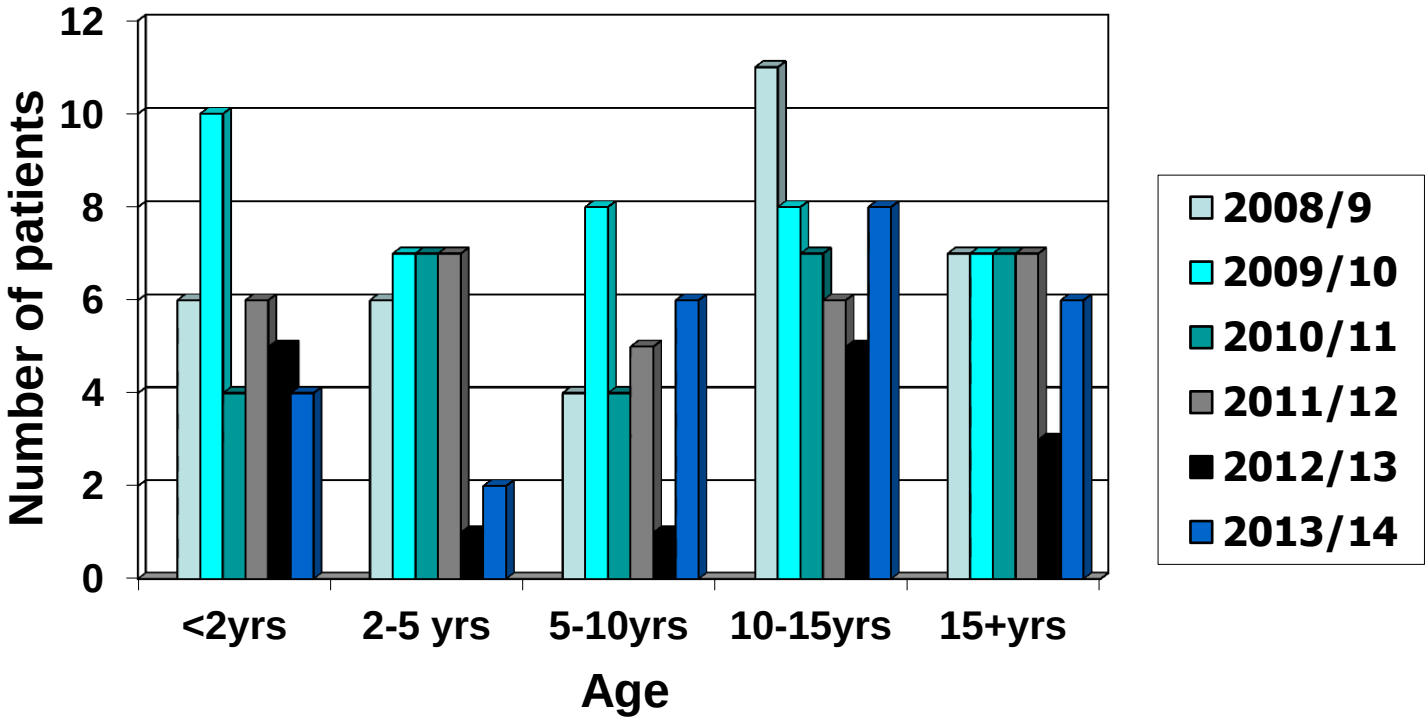
- Placing pressure for higher dialyse calcium bag
- IV Alfacalcidol achieved higher ionised calcium for the same dose and helped to lower PTH
- Regional network: GOSH training centre for Southampton and Evelina. Once patients trained they return to home centre and managed by them with our continued support 24/7 helpline by NxStage

11.6 PERITONEAL DIALYSIS AUDIT

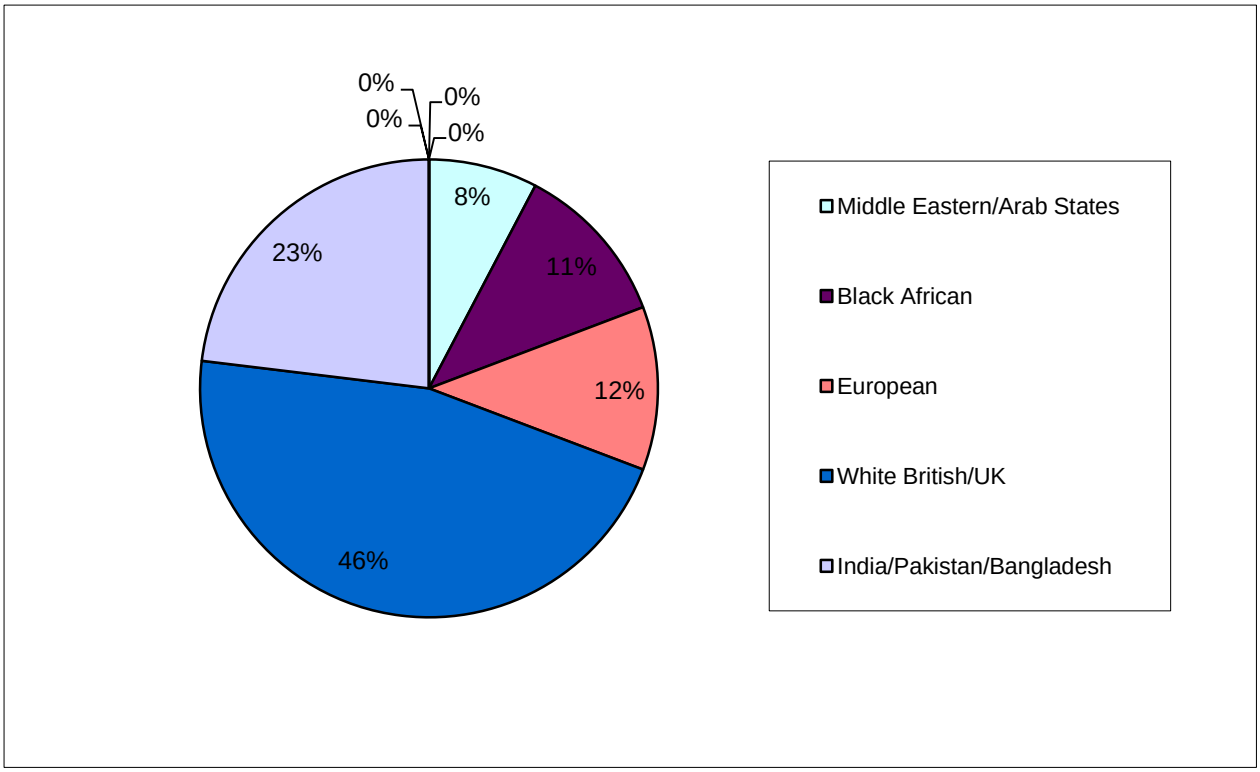
1st April 2013 – 31st March 2014
Michelle Blaauw, Cecilia McNeice, Maria Rodriguez, Suzanne Bradley, Rachael Rogers & Eileen Brennan

Patient Demographics
26 patients have been on the ESRF PD programme
12 Male (46%) : 14 Female (54%)
Dialysis Modality: APD = 22
CAPD= 2
2 pts - PD never started (catheters inserted)
Children's age on PD: between 5 months - 17 years 11 months
ESRF TOTAL PD MONTHS = 183.5 months

Patient Age Ranges
(end of audit year or date left PD)



Ethnicity

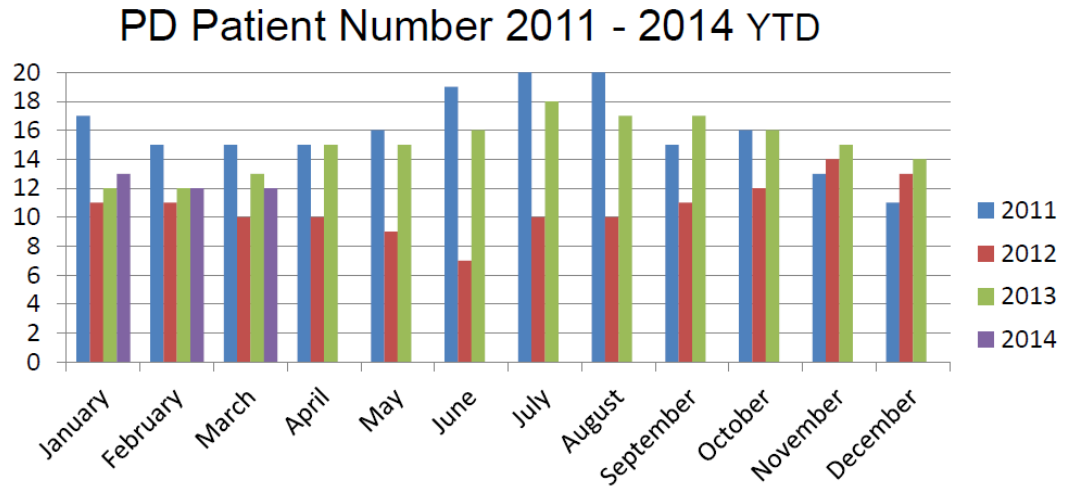


Diagnosis

Diagnosis	Number (%)
Dysplasia	7 (27%)
Posterior Urethral Valves	5 (19%)
Nephronopthesis	3 (11%)
Berdet Biedl	1
Ciliopathy	1
Congenital Nephrotic Syndrome	1
Glomerulonephritis	1
Hydronephrosis	1
MMA	1
?MPGN	1
Acute on chronic	1
Reflux/horsehow	1
Renal calculi	1
Drug induced nephrotoxicity	1

Review Meeting

Baxter

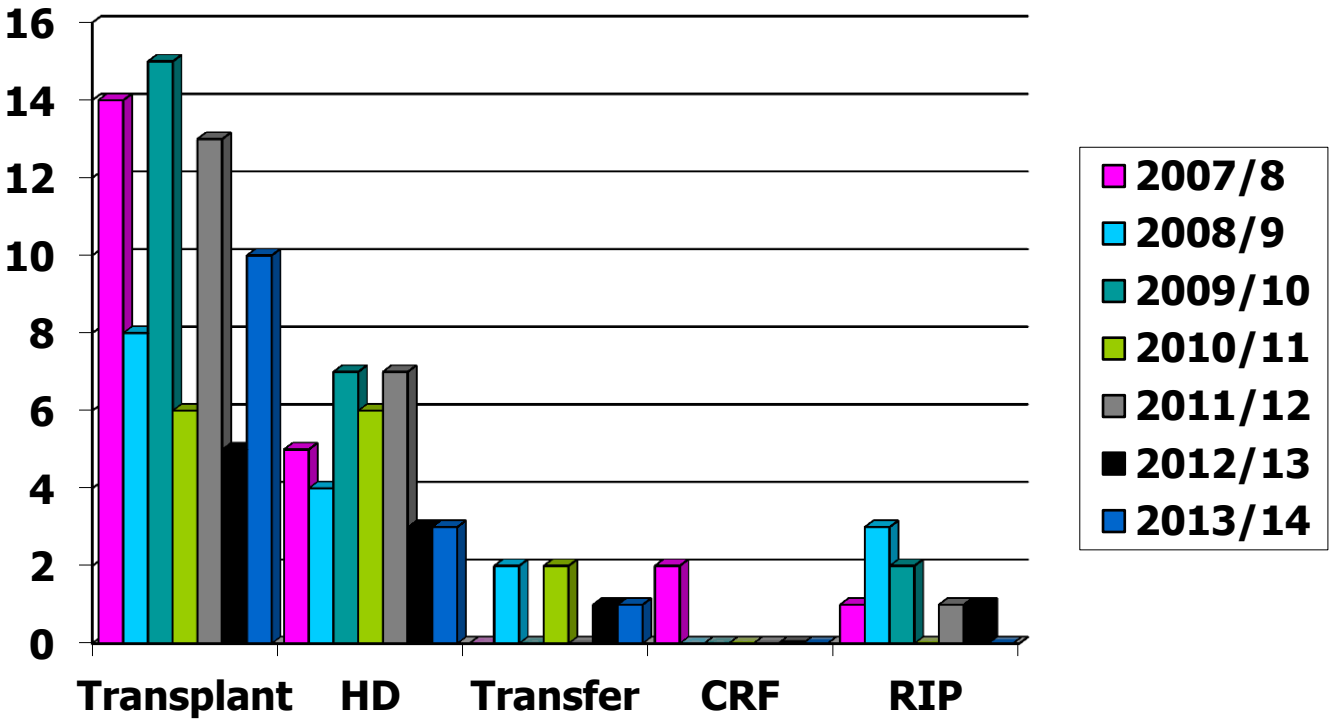


Average PD Patient Number 2011 = 16
Average PD Patient Number 2012 = 10
Average PD Patient Number 2013 = 15
Average PD Patient Number 2014 = 12

Annual Figures 2006/7 - 13/14

	06-07	07-08	08-09	09-10	10-11	11-12	12-13	13-14
Patients	37	34	34	40	29	31	25 (1PX)	26
New Patient	18	15	15	20	11 (3PX)	16	14	11
No. at Year End	20	20	19	19	15 (1PX)	10	14	12
Transplants	14	8	6	15	6	13	5	10
Transfers	0	0	2	0	2 (PX)	0	1	1
To HD	2	5	4	7 +1temp	6	7	3	3 (1 of these out of centre)
To CRF	1	2	0	0	0	0	0	0
Deaths	1	1	3	2	0	1	1	0

Reasons for leaving PD

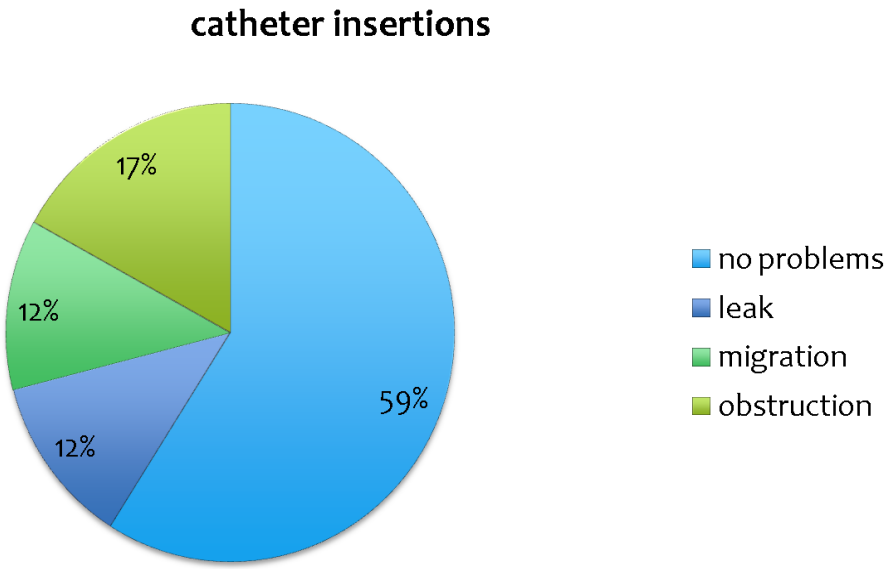


Catheter insertions & problems

17 (+2 acute) new catheters inserted in 12 ESRF patients.

- 3 patients had 3 catheter procedures
    - 2 catheters wrapped with omentum (1 revised then later replaced) ie. 3 catheter procedures
    - 2 tunnelled catheters + 2 acute cook catheters leaked
    - 2 catheter migrations (constipation)
        - 1 + leaked – immediate post insertion
        - 1 chronic constipation – no surgical involvement
    - 1 catheter removed as improving function (infected)

Chronic catheter outcomes



Acute PD Catheters

- 5 AKI catheters inserted in 6 acute patients
- 1 arrived with a PD catheter from Europe

Total catheters of current ESRF & AKI

Surgeon	Catheter Number	% Failed ESRFT	% Failed AKI	Leaked	Migration	Obstruction
FC	1A	0	0	0	0	0
MD	6 + R	28.5	0	0	0	1 + R
NK	2 + 3A	0	0	0	0	0
CC	3 + 1A	33	0	1	0	0
JO	4	50	0	0	1	1
NT	1	100	0	1	0	0
NM	1	0	0	0	0	0

Peritonitis (ESRF)
14 episodes of 'true' peritonitis
Culture Positive episodes = 8 (57%)
1 episode of relapsing culture positive peritonitis

'We recommend that a diagnosis of relapsing peritonitis be made if peritonitis recurs with the same organism as in the preceding episode, according to antibiotic susceptibilities, within 4 weeks of completion of antibiotic treatment (1A)' (ISPD 2012)

Culture Negative episodes = 6 (43%)
4 of these patients symptomatic / unwell
1 line break, 1 cloudy (not eosin)

Peritonitis
Catheters removed due to infection = 2
(1 x CNS, 1 cult neg)

2 patients had eosinophilia peritonitis

14 peritonitis episodes in 183.5 patient months
= 0.91 episodes per 12 patient months

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

2008-2009	2009-2010	2011-2012	2012-2013	2013-2014
0.89	**0.72**	**0.83**	**0.64**	**0.91**

14 episodes seen in 10 patients.
8 episodes (57%) between 3 pts:

- SA – 2 cult neg, 1 positive
- RT – 1 cult neg, 2 CNS (+ 1 relapsing)
- LM – immunosuppressed – 2 cult positive

Therefore, 16 (62%) patients peritonitis free

Peritonitis						
	08-09	**09-10**	**10-11**	**11-12**	**12-13**	**13-14**
TOTAL EPISODES	17	16	16	12	9	14 + 1 relapse
Culture –ve	10	5	7	4	4	6
Staph Epi	2	3	2	2	0	3 + R
Staph Aureus	1	0	3	1	1	0
Candida	1	0	0	0	0	0
Enterococ/coliform/Ecoli	3	3	0	2	2	2
Strep	0	2	2	0	2	0
Pseudomonas	0	3	0	1	0	0
Corynebacterium	0	0	1	1	0	0
Klebsiella	0	0	1	1	0	0
Serratia	0	0	0	0	0	1
Acinetobacter	0	0	0	0	0	1
Haemophilus influenza	0	0	0	0	0	1

Exit Site Infections
(red / inflammed / exudate)

Organism	**Infections**	**Treated with AB's**	**Catheter Removed**
Staph aureus	1	1	0
Pseudomonas	0	0	0
Strept	1	1	0

No Peritonitis episodes secondary to Exit Site Infections this Year

Exit Site Infections
(red / inflammed / exudate)

	2007 2008	**2008 2009**	**2009 2010**	**2010 2011**	**2011 2012**	**2012 2013**	**2013 2014**
Staph aureus (SA)	5	7	6	5	2	3	1
Coag Neg Staph						2	0
Pseud.	2	0	2	2	3	3	0
MRSA	0	0	0	0	0	0	0
Catheter removals *with peritonitis	2 1 x SA*	0	2 1 x SA* 1 x pseud*	1 + 1 cuff shaved	0	2* 1 x SA*	0

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

Organism	**Number**	**Topical Treatment**
Candida	2	2
Staph Aureus	3	3

2014 and onwards…

- Assisted PD
- Further develop home therapies service
- ?New PD machines later this year
- 5L physioneal bags
- Working Together Agreements

Impact on PD service:

- HX support
- Activity tool recording
- Monthly clinical shifts

Thanks

- Dr. Lesley Rees
- Dr. Rukshana Shroff
- Dr. Sarah Ledermann
- Suzanne Bradley
- Rachael Rogers
- Eileen Brennan
- Maria Rodriguez
- Eagle ward staff
- Renal support unit team
- Transplant surgeons Guys/Evelina

11.7 Current practice of removal of PD catheter post renal transplant at GOSH Eileen Brennan, Nurse Consultant

Name	Age at Tx	DDT date	PD catheter in	PD catheter out	Cit hrs	Outcome
IT	14yrs	2009	in		13	?peritonitis 3 ws post Tx
DK	5YRS	2009	-	OUT	15	Hd FOR ? PE PLACED
BS	5yrs	2009	in		19	
MC	13yrs	2009	in		16	Removed 8wks with stent
AF	11yrs	2009	in		17	Stent & catheter removed 4wks
AM	14yrs	2009	in		14	PD post T heart failure
FJ	16	2010			28	
OA	15	2010	in		28	Removed at 16days? infection

Name	Age at Tx	DDT date 2009	PD catheter in	PD catheter out	Cit hrs	Outcome
IT	14yrs		√		13	peritonitis 3 wks post Tx
DK	5YRS		-	√	15	HD FSGS
ABS	5yrs		-	√	19	Not recorded
MC	13yrs		√		16	St & PD removed 8wks
AF	11yrs		√		23	St & PD removed 4wks

AM	14yrs		√		14	PD post T heart failure

Name	Age at Tx	DDT date 2010	PD catheter in	Cit hrs	Outcome
FJ	16		√	28	St & PD removed 6wks
OA	15		√	18	Removed at 16days peritonitis

Name	Age at Tx	DDT date 2011	PD cath Removed	cit	Outcome
ZM	5yrs		√	22	Functioning kidney
GO	15yrs		√	18	Functioning kidney
AG	16		√	20	Functioning kidney

Name	Age at Tx	DDT date 2012	PD catheter in	CIT	Outcome
KF	6		√	30	HD FSGS pd cath removed with stent 6 WKS
TN	14		√	?12	St & PD removed 6wks

Name	Age at Tx	DDT date 2013	PD catheter in	CIT	Outcome

OEB	12		√	22	St & PD removed wk 5
EV	13		√	17	PD for 1 day DGF 3 d PD & ST 3 wks ? infection
ZO	16		√	22	St & PD removed wk 6
SB	12		√	7	St & PD removed wk 6

Year	DDtx	PD cath used	Outcome
2009	6	1catheter used PICU days HF	Recovered some function HD
2010	2	nil	1 infection/1 rem 6wks
2011	3	nil	All removed good kidney function
2012	2	nil	Rem 5wks
2013	4	1 catheter used 1 day	2 sch rem, 1 used, 1 infection

Conclusion

- 17 DD transplants
- Age range 5-16
- Cold ischemic time 7-30hrs
- 2 children had PD
    - 1 heart failure post Tx
    - 1 at d 3 for 1 day (high K)
- 2 had HD lines for recurrence of FSGS
- 3 infections ? peritonitis

Should peritoneal dialysis catheters be removed at the time of kidney transplantation? 2012

Jeff Warren, MD,[*] Emily Jones,[*] Alp Sener, MD,[*] Martin Drage, MD,[*†] Ali Taqi, MD,[*] Sian Griffin, MD,[†] Christopher Watson, MD,[†] and Patrick P. W. Luke, MD, FRCSC[*]

- 137 patients over 4yrs

Conclusions:

PD catheter removal should be considered at the time of renal transplantation, as postoperative PD-related failure/complication rates are high

Complications linked to chronic peritoneal dialysis in children after kidney transplantation: experience of the Italian Registry of Pediatric Chronic Peritoneal Dialysis. 2001

Andreetta B, Verrina E, Sorino P, Edefonti A, Perfumo F, Bassi S, Ghio L, Cattarelli D, Coppo R, Rinaldi S, Capasso G, Zanon GF, Zacchello G.

- 86 pediatric renal transplants The mean time of catheter removal was 80.3 days
- Two of 80 children returned to CPD (at four and at 12 months, respectively) because of persistent allograft failure.
- 12 patients were on CPD because of temporary graft failure

Peritoneal dialysis catheter infections in children after renal transplantation: choosing the time of removal.1994

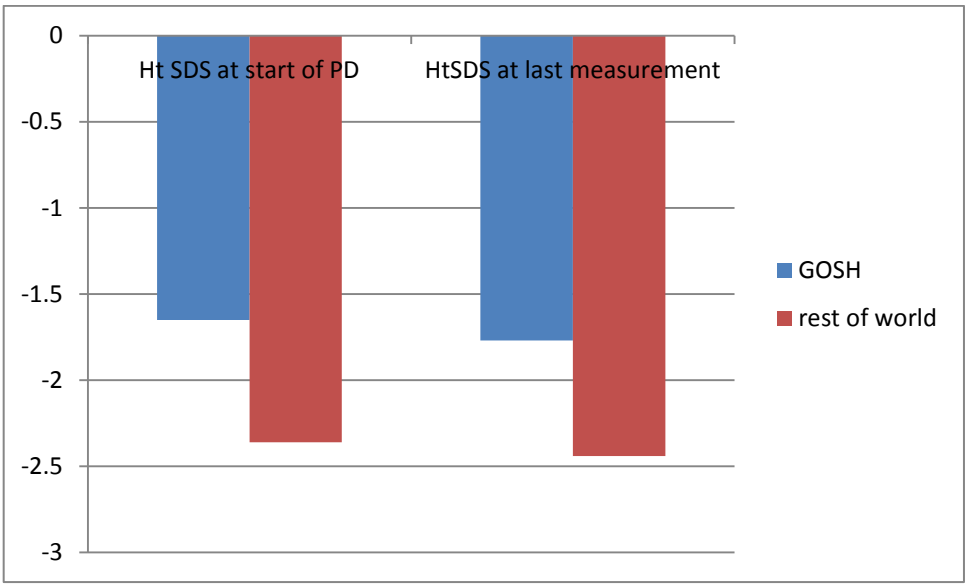
Palmer JA, Kaiser BA, Polinsky MS, Dunn SP, Braas C, Waltz R, Baluarte HJ.

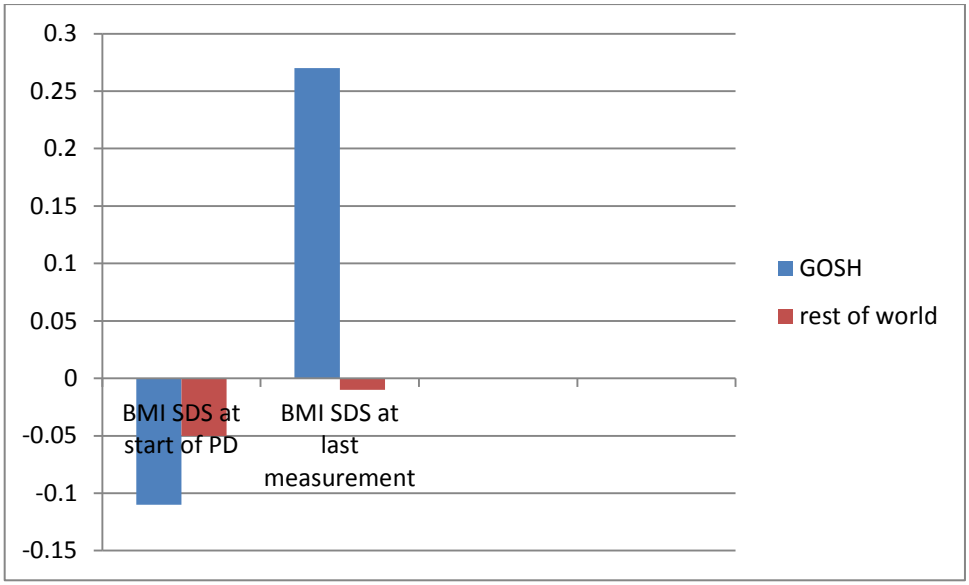
- 6yrs -35 children
- During the 1st month post transplantation, the PD catheter was used in 25 patients (58%) because of acute rejection or primary allograft non-function. Thirty-one patients were eventually discharged with functioning allografts and a PD catheter in place.
- Of them, 43% developed a catheter-related infection within the next 2 months, a period during which PD was not performed.
- PD catheters represent an additional source of infection following transplantation and should be removed at the time of hospital discharge, after which the likelihood of use is low.

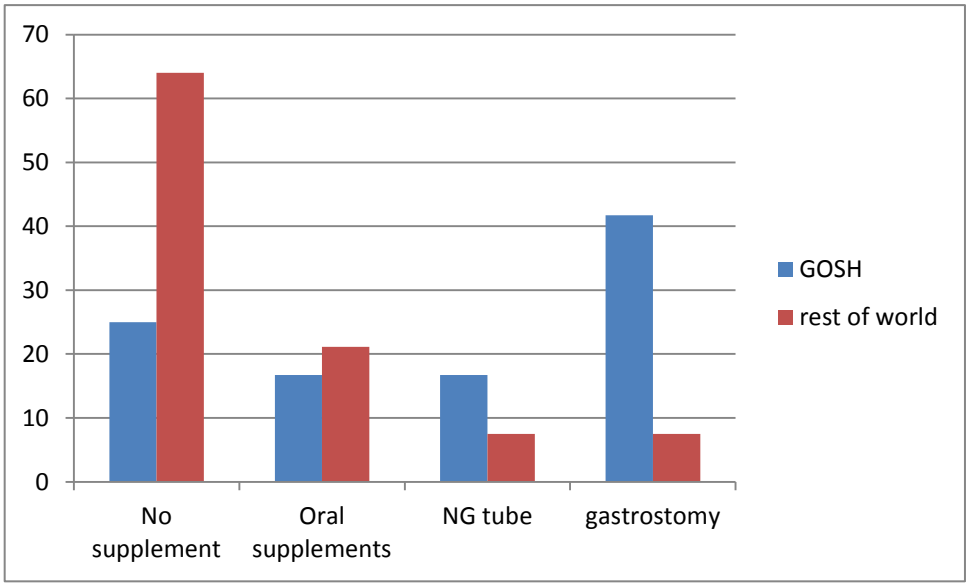
Recommended change of practice

- ?Change current practice to removal of PD catheters at the time of transplant with the exception of high risk DD/risk of ATN/high risk patients, on the discretion of the transplant consultant
- Insertion of HD line for FSGS as required, pre/during/post Tx

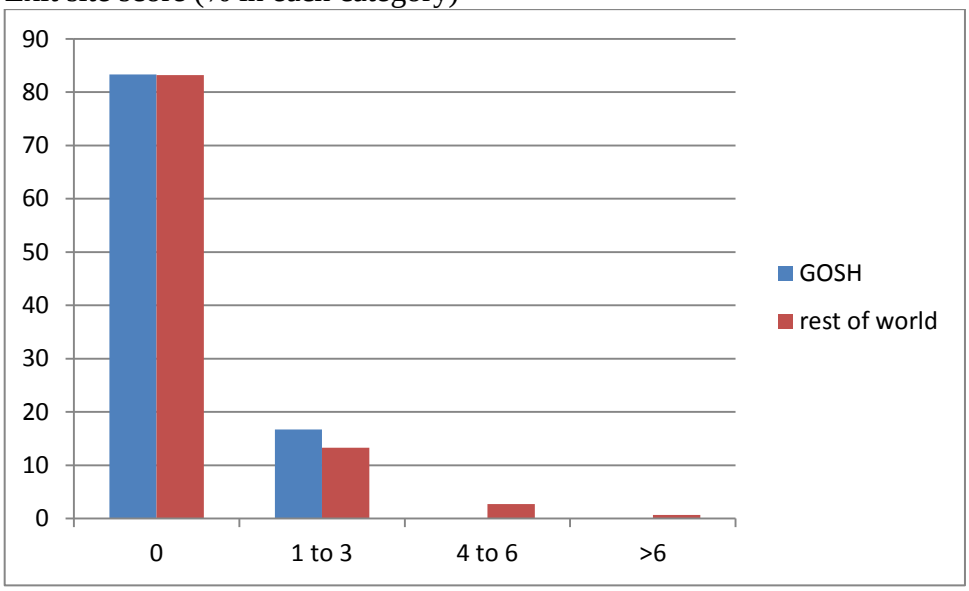
11.8 GOSH PD PATIENTS IN COMPARISON TO INTERNATIONAL PAEDIATRIC DIAYLSIS NETWORK DATA

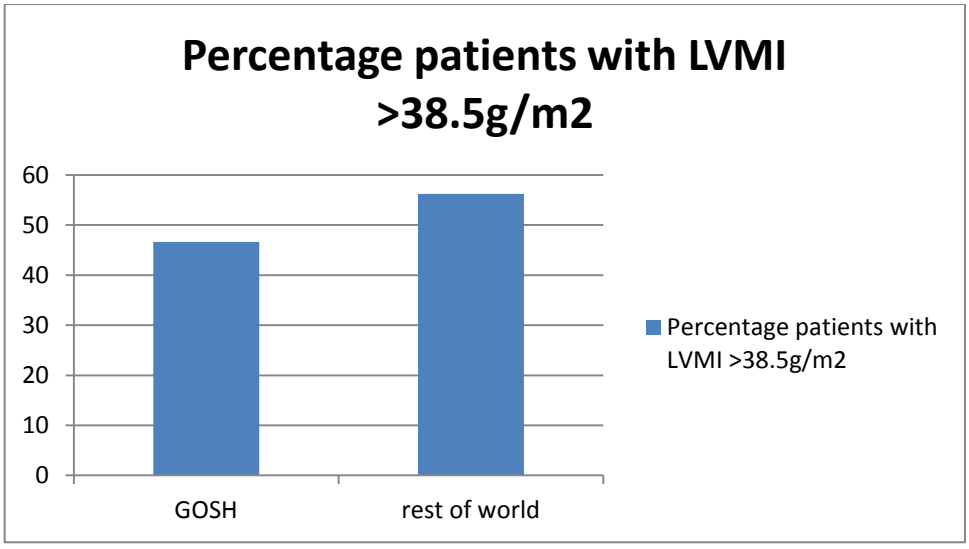




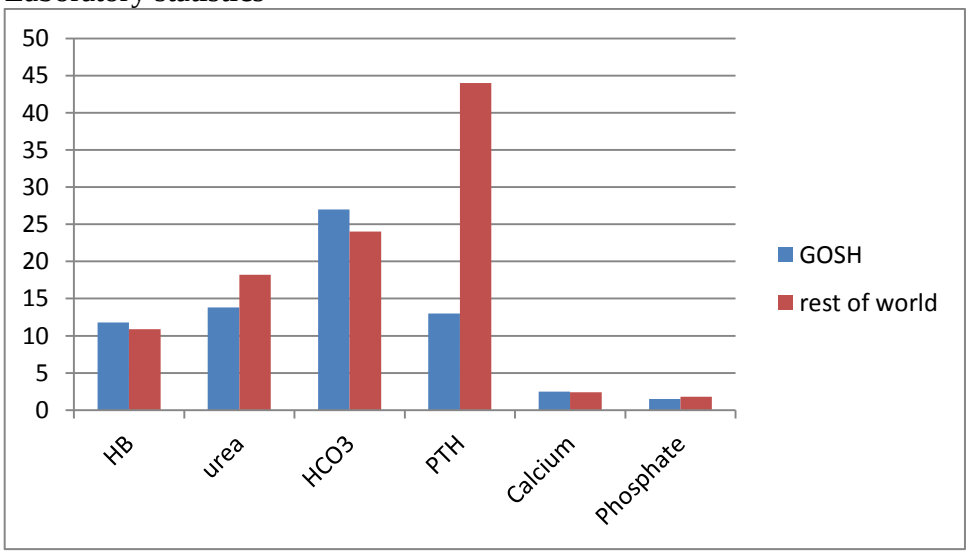


Exit site score (% in each category)

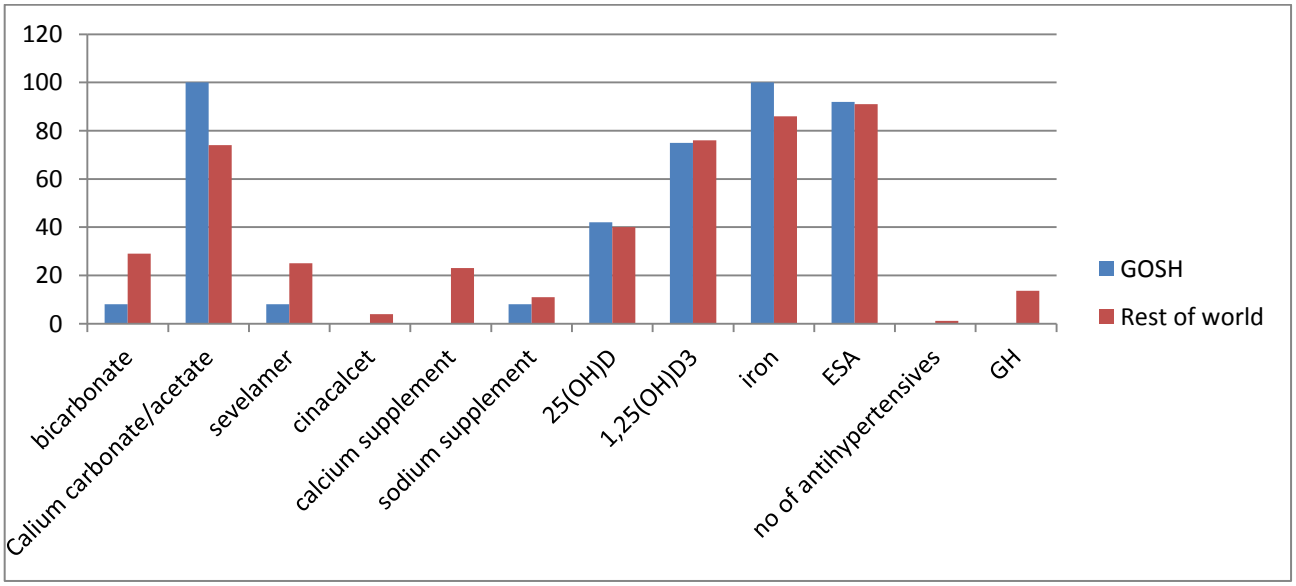




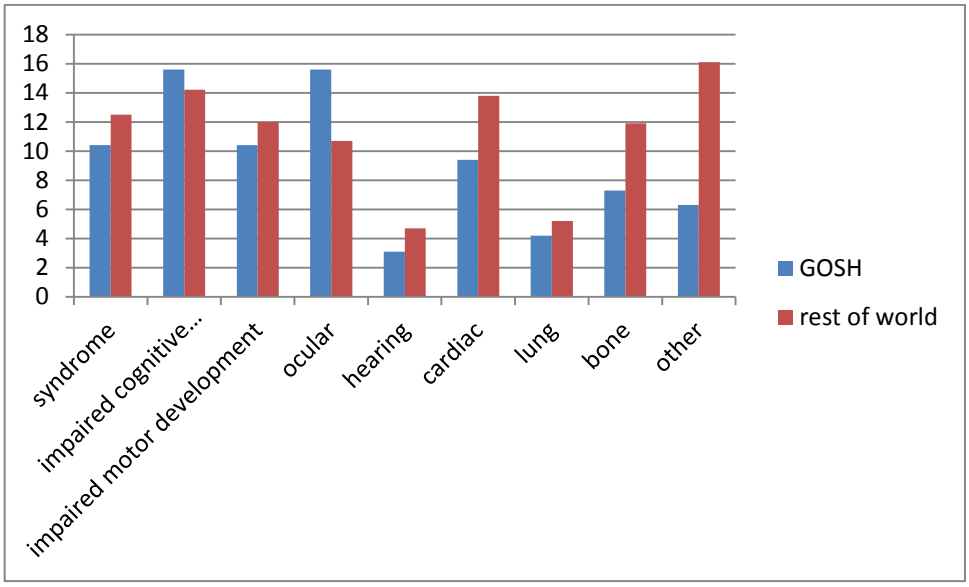
Laboratory statistics



Medications



Comorbid conditions



12. NURSING REPORT

Since the move to the Morgan Stanley building the team work continues to focus on a seamless integration of the ward and haemodialysis staff. The appointed practice educator Clare Solomons has managed to bring consistency and continuity to both areas. The units goal remains committed to deliver a world class renal service for children and their families. This year has brought new challenges of delivering brand new extracorporeal treatments to children pre transplant. Liz Wright continues to lead the way in the UK on adapting treatments for use in paediatrics; she has been recognised by the trust receiving an award for education by GOSH along with outstanding work By Sue Spiteri (HCA) for her contribution to both the hospital and renal unit.

12.1 STAFFING AND CLINICS

Nurse Consultant Eileen Brennan

Ward Sister Acting Sister Jo Van Ree
Sr. Lucy Thomas

Practice Educator Trish Evans, Renal unit
Clare Solomons HD

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).
CNS. Liz Wright (1 WTE)
PD Michelle Cantwell (1 WTE) Mat leave
Transplants senior staff nurse Jenny Tanton (0.88 & Kate Sinnott (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 Led 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	
Nurse Consultant	New infant hypertension clinic Investigation and treatment clinic including ABPM service	Tuesday morning weekly Wednesday afternoon weekly

Eagle ward establishment (new integration of posts)

1 Haemodialysis /Plasma Exchange CNS Band 8
2 Band 7 Ward Sisters
1 Band 7 Practice educator
1 Band 6 Assistant Practice Educator
13 Band 6 Senior Staff Nurses
25 Band 5 Staff Nurses
8 Band 3 Health Care Assistants
2 Band 4 Health Care Assistants
2 Housekeeper

The Hemodialysis service has now been totally integrated onto Eagle ward. The sisters have taken over the nursing off duty to amalgamation the two areas, releasing Liz Wright to concentrate on the delivery of new treatments for children. Home HD has relieved pressure on the PD service however the HD numbers continue to be at maximum capacity. All the areas provide a very high standard of nurse led services, guiding and teaching junior doctors to care for children with renal conditions.

12.2 Publications

Fabio Paglialonga, Claus Peter Schmitt, Rukshana Shroff, Karel Vondrak, Christoph Aufricht, Alan Rees Watson, Gema Ariceta, Michael Fischbach, Gunter Klaus, Tuula Holtta, Sevcan A. Bakkaloglu, Alexandra Zurowska, Augustina Jankauskiene, Johan Vande Walle, Betti Schaefer, Elizabeth Wright, Roy Connell, Alberto Edefonti (2014), Indications, technique, and outcome of therapeutic apheresis in European pediatric nephrology units, *Pediatric Nephrology*, epub Aug 20.

12.3 EVENTS 2013/14

GOSH assisted in the organization of the annual Paediatric Nurses Nephrology Conference Nottingham. It was attended by over 90 paediatric nephrology nurses representing every unit in England, Wales, Scotland, Northern and Southern Ireland, play specialists and dieticians.

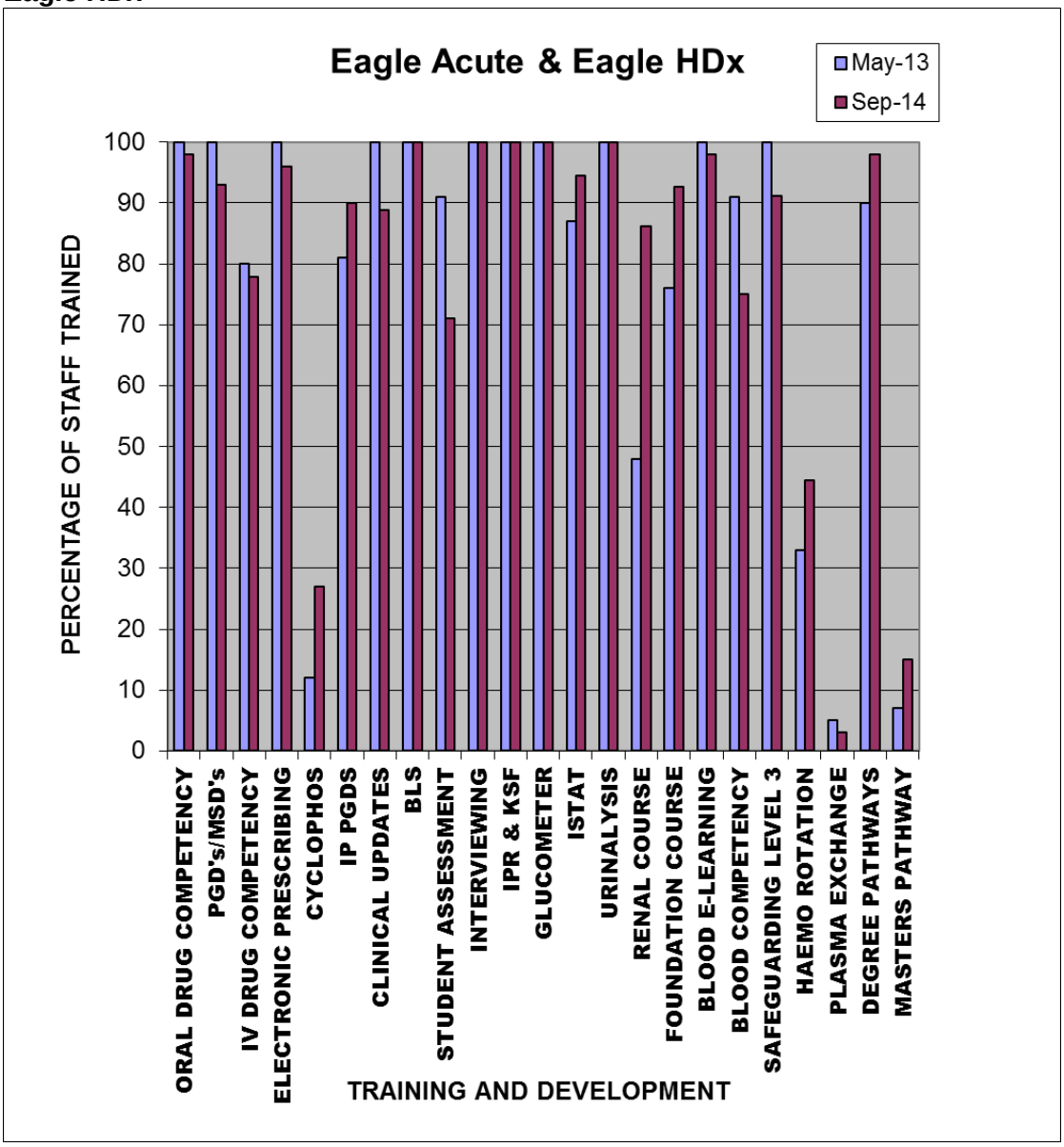
12.4 EDUCATION

The Team continues to develop in new areas this year, phlebotomy and cannulation and increased number of nurses gaining skills in hemodialysis

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

Education – Trish Evans:

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



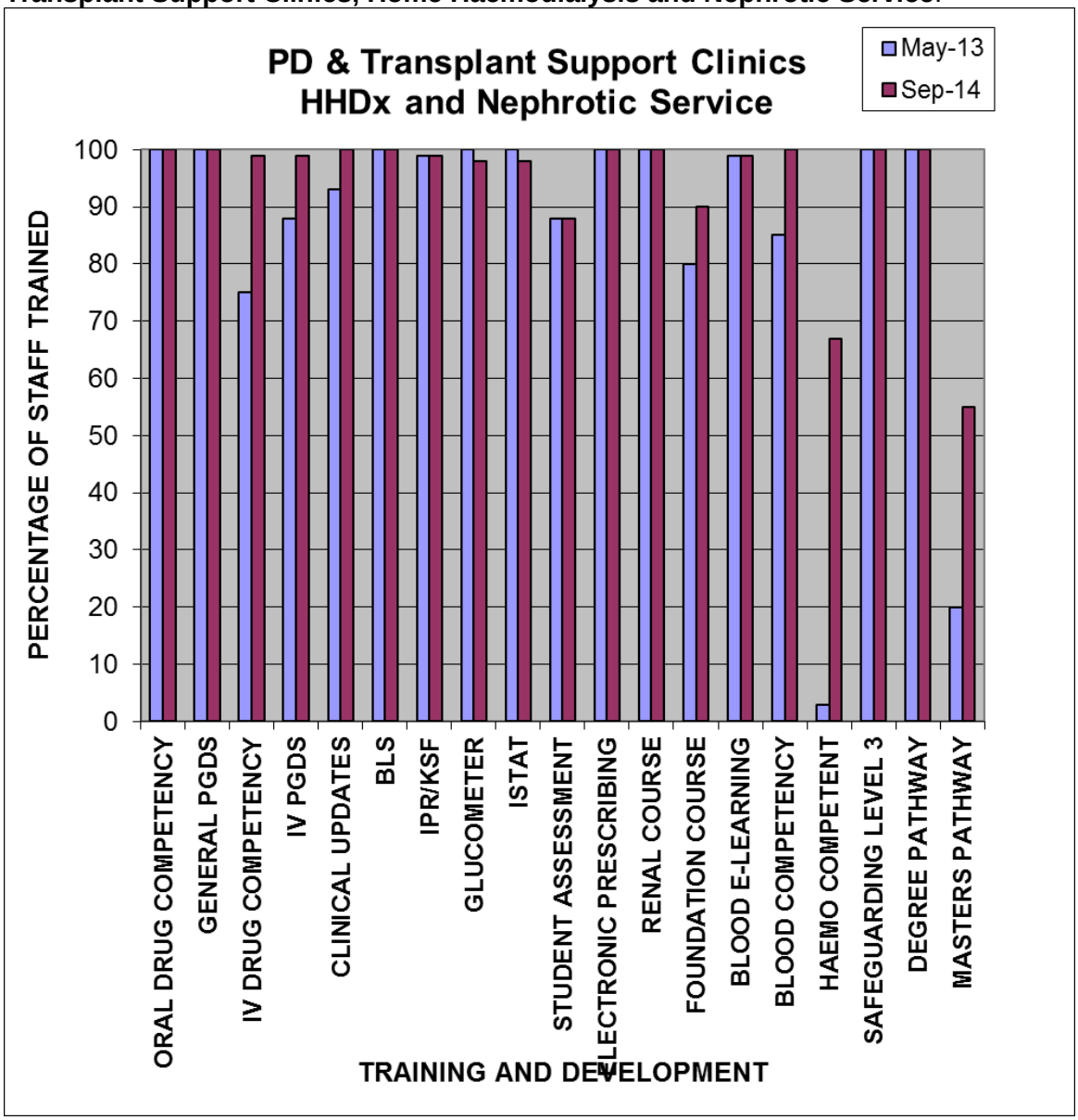
Analysis of Data:

Average % of Nursing Staff Trained in Core & Specific aspects: 85% - this figure reflects the changing workforce over the last year.

All qualified staff trained >1 year 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 2014. All newly qualified nurses who joined Eagle last year have until October 2014 to complete their Level 3 Safeguarding, it is anticipated this will be achievable.

The number of IV competent nurses has decreased from last year, this reflects the number of junior newly qualified nurses on the unit, however this will increase by October when these nurses achieve their competency. The unit will experience more newly qualified nurse's in September and March where it is anticipated they 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: 97%
This reflects 3 new team members who are working towards gaining these skills.

<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 'face to face' course in the UK.

November 2013 cohort comprised of 8 students, all students successfully completed and passed their reflective logs and all progressed to present their case studies. Following exam board 100% achieved a Pass rate. This academic year module is due to commence in the second semester, February 2015, and is currently being recruited to. 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/Lead Nurse, Eagle Ward/Renal Unit/MDTS.

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 2015 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 updated and improved In-Charge Competency Workbook. During the last year 2 members of staff have been worked up to being in charge and both have successfully completed this programme and no longer need supervising when in-charge. 100% of staff eligible will have attended and become proficient at being in charge on the Renal Unit.

Simulation Training
Following last year's successful simulation training being built into the team away days, these were included again this year. Full use of the new simulation suite was made 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. We have not had a CET SIM (Mock 2222) on the ward this year thus far but 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 train all IV competent staff in HDx. The re-designed Workbook reflects 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. The Band 6 senior staff nurses continue to rotate to increase their Advanced Haemodialysis clinical skills. Eagle Acute and Eagle Haemodialysis is gradually becoming one unit and all staff rotates to maintain skills and ensure a multi-skilled renal workforce. Due to staff changes this rotation is commencing again in October 2014.

Eagle HDx – Student Nurses

Following the introduction of Haemodialysis becoming an Interface Placement for LSBU student nurses last year, the unit has seen four 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.

Non-medical prescribers

Eileen Brennan
Liz Wright
Michelle Cantwell
Lucy Thomas
Lynsey Stronach

Liz Wright

Feb 2014 - MSc (Distinction): Children's Advanced Nurse Practitioner
Dissertation - *'What is the optimal dose of apheresis in children undergoing blood group incompatible renal transplantation?'*

12.5 PRESENTATIONS

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

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

Case study sympathetic denervation in an adolescent with treatment resistant hypertension
Special interest group for Paediatric nephrology nurses Annual conference
Nottingham Chair for Group

The investigation & treatment for hypertension in children
Ireland national study day 2013

Lynsey Stronach:

Special interest group for Paediatric nephrology nurses Annual conference Nottingham Oral Presentation: Home Haemodialysis: Managed Clinical Network

6th Annual Conference on Home Dialysis 2013*(Manchester)* Clinical horizon- Treatment of heart failure – Joint presentation with a patient on HHD

Joint poster presentations with Daljit Hothi at IPNA Congress 2013 (Shanghai) and ADC
(Atlanta) 2014 Use of Low Molecular Weight Heparin During Pediatric Home HD, Infant
home Hemodialysis,Home Hemodialysis Education Package,Assisted Home Hemodialysis,
Managing a Hypotensive Child with Severe, Symptomatic Heart Failure on Home HD, Using
The NxStage™ System To Deliver Evening and Nocturnal Home Haemodialysis In Childre
Dialyser Induced Thrombocytopaenia In Children Using The NxStage System

Liz Wright
Blood Group Incompatible Renal Transplantation and Apheresis, RCN Special Interest Group Paediatric Renal Conference, Nottingham, March, 22/3/2014
Haemodialysis Workshop, co-presenter with Dr R Shroff, Nephrology Course, Institute of Child Health, London, 3/4/2014.
Dissertation: The Systematic Review, MSc CANP Development Day, London South Bank University, London, 9/9/2014.

12.6 ACADEMIC ACHIEVEMENTS

Liz Wright – successfully completed MSc in advanced practice
Katie Knapp successfully completed 2 modules in advanced practice
Jo Newton successfully completed MSc in advanced practice
Hazel Webb successfully completed 2 modules of her Msc in advanced practice

Award

Liz Wright

Staff Recognition Award: the Vanessa Garside Award for Outstanding Academic Achievement and Clinical Excellence in Nursing, Great Ormond Street, June 2014.

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 has not been resolved.

12.7 OUTREACH COMMITMENTS

Eileen Brennan: Chair of the special interest group for paediatric nephrology
NICE guidelines for RCN
Education & 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 is working in partnership to produce a new and comprehensive set of information leaflets for children with kidney disease.
Nurse lead London children's Nephrology Strategic Clinical Network Group Working party

Michelle Cantwell: Contribute to the International Paediatric 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 Paediatric Patients Receiving Peritoneal Dialysis', on behalf of the International Society of Peritoneal Dialysis (ISPD)

Lynsey Stronach: Lead nurse on the National Home Hameodialysis Network working group

12.8 RESEARCH

Eileen Brennan
PI for the PIAnT national study Supporting parents to care for children's kidney conditions

12.9 NEW SERVICE

Blood Group Incompatible (ABOi) and HLA Incompatible Renal (HLAi) Transplantation
Since April 2013 to date, the Renal Unit has successfully performed 5 renal transplants (4 ABOi, 1 HLAi), using a combination of B cell ablation by monoclonal antibody therapy and selective or non-selective apheresis techniques, such as plasma exchange, double filtration plasmapheresis or immunoadsorption.
The apheresis service is provided by the CNS for haemodialysis, working closely with the living donor co-ordinators. This services enables the child to receive a kidney from a family member who was previously declared unsuitable to donate.

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

I am delighted to report that the work of the play team Lynsey Steele and play worker Victoria Tomkins has made a noticeable improvement to the delivery of care on the unit. This additional support had made a considerable difference to the preparation of children for transplantation, needle phobia and accessing fistulae. We not have a team of play specialists and volunteers that has been working to an excellent standard putting the children and families first.

13. DIETETIC REPORT

April 2013 – March 2014

The dietetic team continues to be an integral part of the renal team. We aim to provide the optimum and most appropriate nutrition for specific renal diseases and dialysis modalities to ensure that our children grow to their full potential while keeping biochemistry stable. We moved to our new office based on level 2, Nurses Home in April 2013 and rolled out our new electronic dietetic record system in November 2013. The system can also be accessed on IPADs across the hospital. This has helped us become more efficient with patient care and with all levels of communication.

13.1 STAFFING

There are currently 3.25wte dietitians working with the renal unit:

Shelley Cleghorn	Principal Dietitian and Team Leader
Jayne Holmes	Specialist Dietitian (until February 2014)
Victoria Kearns	Specialist Dietitian
Louise McAlister	Specialist Dietitian
Danielle Petersen	Specialist Dietitian (from February 2014)
Vanessa Shaw	Head of Dietetics

13.2 TEACHING AND EDUCATION

Vanessa Shaw is the Education Officer of the British Dietetic Association's Paediatric Group and is Professional Lead for the MSc Advanced Professional Practice in Paediatric Dietetics, hosted by the University of Plymouth, and is an Honorary Associate Professor at Plymouth.

Vanessa Shaw was module host for Clinical Dietetics for Infants and Children, MSc Advanced Professional Practice in Paediatric Dietetics, London, UK, September 2013.

Louise McAlister taught on the MSc module Clinical Dietetics for Infants and Children on the Nutritional Management of Renal Disease and ran a workshop in September 2013. Jayne Holmes ran a renal workshop at this module.

Shelley Cleghorn ran a workshop at the International Nephrology Course held at ICH, London, UK in April 2013.

Vanessa Shaw chaired the 1st International Paediatric Renal Dietitians Meeting in Windsor, UK, October 2013. Shelley Cleghorn presented a case study and facilitated additional case study discussions at this meeting. Bahee Manickavasagar presented her vitamin A research work: Hypervitaminosis A is prevalent in children with chronic kidney disease and contributes to hypercalcaemia.

Victoria Kearns developed and delivered a presentation to Paediatricians, Registrars and SHOs on Nutritional Requirements as a part of the Nutrition, Growth and Physical Activity module of UCL MSc Paediatrics and Child Health, London, UK, June 2013.

Victoria Kearns developed and delivered a presentation to Koala ward nurses to update them on nutrition and enteral feeding in September 2013.

Victoria Kearns spoke at a GOSH Volunteers Forum about dietetics at GOSH in June 2013.

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

Louise McAlister co-ordinates and teaches on 'Nutrition Bites' as part of hospital induction. Danielle Petersen, Victoria Kearns and Jayne Holmes were involved with the teaching this year.

Victoria Kearns developed resources and co-organised a public information event in the Lagoon for Nutrition and Hydration Week in March 2014.

The dietetic renal team have all been actively involved in teaching visiting dietitians on clinical attachments from Melbourne 21-25th October 2013 and Costa Rica 20th January- 14th February 2014.

The dietetic department is involved in Placement 1 dietetic student training for Kings College London and London Metropolitan University throughout the year. Victoria Kearns and Jaynes Holmes are student supervisors.

Shelley Cleghorn organises weekly team meetings where all team members discuss individual cases, review journals and provide powerpoint CPD updates.

13.3 PUBLICATIONS, PRESENTATIONS, AWARDS, APPOINTMENTS

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

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 chaired the national dietetic renal group, PRING (Paediatric Renal Interest Nutrition Group) until October 2013 (4 year term).

Danielle Petersen completed her MSc Advanced Professional Practice in Paediatric Dietetics in September 2013. Her research project was: Current practices across the United Kingdom regarding the monitoring and supplementation of sodium in surgical infants and children.

13.4 IMPROVING PATIENT CARE

Resources

Louise McAlister with the help of her renal dietetic colleagues 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. She has also assisted in the development of teaching material and other resources for use throughout the dietetic department.

Vanessa Shaw and Louise McAlister have helped develop a paperless electronic record system for dietetics. This was successfully rolled out in November 2013 and can be accessed from iPads.

Victoria Kearns is one of the leads for updating the dietetic department intranet and Internet websites.

Products

Shelley Cleghorn continues to be actively involved with Vitaflo in the formulation of a new renal specific sip/tube feed for children and is now working on a new renal specific vitamin and mineral powder.

13.5 GUIDELINE/POLICY DEVELOPMENT

Louise McAlister and Vanessa Shaw have been involved in updating the Nutrition Policy which is available on the GOSH intranet.

13.6 RESEARCH

Shelley Cleghorn is the Paediatric Nephrology Dietitian involved in the Colestilan (MCI-196) paediatric study which is an international study trialling a calcium free phosphate binder.

The dietetic department was involved in collecting data for the national Children's Nutrition Survey in April 2013.

14. Renal Psychosocial team annual report 2014/2015

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. We also aim to support families throughout their journey through renal replacement therapy, transplantation and during the stressful post transplant period.

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.

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 written agreements setting out expectations for home based dialysis between parents and staff. The views of parents and staff are being formally evaluated within an audit process for both peritoneal dialysis and we hope for the post-transplant process.

A recent survey of patient/family experience of social work within the unit showed a high level of patient satisfaction.

A member of the psychosocial team is also contributing to European wide study comparing the experience of dialysis approaches. This means that alongside information about growth and cardiac function, we will also have information from young people and their parents/carers about what works for them and the place of any therapeutic / mental health concerns that may relate to this.

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 safeguarding training to nursing staff.

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 quantitative measures, we are hoping to use qualitative research approaches to focus 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

Vacant post 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) Post supported by BKPA grant
Indira Rajendran, Social Worker (0.5 WTE) Post supported by BKPA grant

14.7 Number of referrals to Renal Psychosocial (PS) team

	2006	**2007**	**2008**	**2009**	**2009 - 2010**	**2010 - 2011**	**2011 - 2012**	**2012 - 2013**	**2013 - 2014**
No of referrals to PS team	86	109	123	120	161	186	128	116	**166**
PS Team WTE	**3.6 WTE** (2003 BAPN figures)					2.3WTE Excluding HHD	1.6 WTE	2.7 WTE from Nov 2012. inc FT previously for HHD only	**2.7 WTE**

There have been 166 new referrals over the period April 2013 to end of March 2014. All referrals must now be in written form in order to facilitate prioritisation and allocation to the most appropriate professional in the team. We are also examining this data to understand further the needs of this patient group e.g. what are children most typically referred for.

The complexity of psychosocial issues of those children and families seen has 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). Extensive liaison is frequently needed for children with complex social and psychological difficulties and/or adverse living conditions.

Clinical involvement

Alongside the new referrals this year, the psychosocial team continue to work with longer term issues with families referred prior to this year. The following therefore reflects more accurately the number of children and families who have been offered intervention/support during the year:

Social work had recorded activity in relation to 192 named children
Family psychotherapy had recorded activity in relation to 113 children
Psychology had recorded activity in relation to 49 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.

Continuing professional and service development

Dr Gwynneth Down is a member of the London Children's Strategic Clinical Network Nephrology Pathway group which aims to provide strategic direction advice for the improvement of children's nephrology services.

The social workers attend Renal special interest groups facilitated by British Association of Social Workers (and supported by the BKPA) and an annual renal social work conference.

Dr Claire Dempster completed her Doctorate in Family & Systemic Psychotherapy at the start of this year; an ethnographic study of whiteness in clinical practice.

Liz Nunn (Social Worker) and Dr Claire Dempster (Family Therapist) presented renal clinical dilemmas at The Association of Child and Adolescent Mental Health conference in February.

Unfilled 0.5 WTE social work post
Dr Gwynneth Down, Consultant Family Psychotherapist
Liz Nunn, Social Worker
Dr Fionna Bathgate, Clinical Psychologist
Dr Claire Dempster, Family Psychotherapist
Indira Rajendran, Social Worker