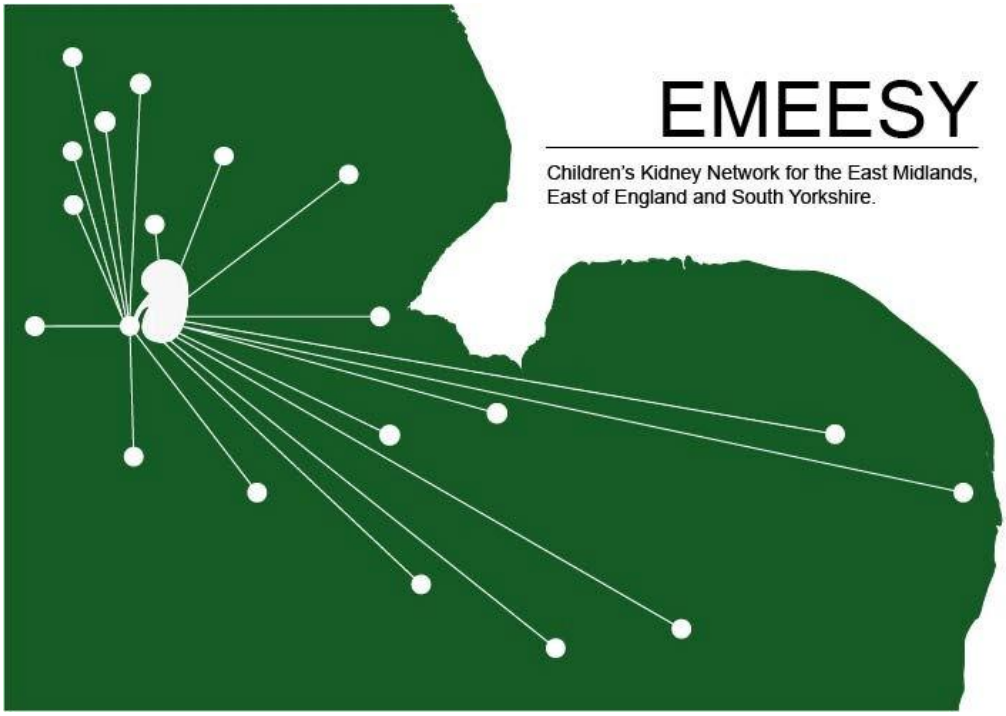
Nottingham Children's Hospital

Nottingham University Hospitals NHS
NHS Trust

Children's Kidney Network for the East Midlands, East of England and South Yorkshire



Annual Report 2013-14

www.emeesykidney.nhs.uk

Children's Kidney Network for the East Midlands, East of England and South Yorkshire

Annual Report 2013-14

Network base: Nottingham Children's Hospital

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1. INTRODUCTION

I am delighted to introduce the 2013-14 Annual Report for the EMEESY Children's Kidney Network. Strictly speaking, this is the first network annual report though it follows in the mould of the Nottingham Children's Hospital Kidney Unit annual report that has been published each year. Over the last year and a half we have focussed on developing locally-delivered services in partnership with local teams so that we cut down on the number of journeys to Nottingham our patients and their families have to make, a round-trip journey of up to six hours for some families.

We have recognised that this can only be done if we develop the local shared-care clinics into multi-professional clinics as happen in Nottingham. We have tried to develop contacts with local nurses and dietitians and at the same time, nurses and dietitians from Nottingham have been attending more shared-care clinics. If we want local nurses and dietitians to support care for children with chronic kidney disease we need to provide a supportive education structure and so we have developed a twice-yearly themed education day for various health professionals building on the medical education days that were already in place. With these changes in place and a network steering group meeting every 3-4 months to oversee governance, the EMEESY Children's Kidney Network was born.

For some time we have had the desire to overhaul the website that was originally developed for Nottingham Children's Renal Unit some years ago. We are delighted that the new EMEESY website has been developed as a resource for families affected by childhood chronic kidney disease and the professionals who support them. It has received positive feedback to date but to be truly effective it needs to be used regularly and developed in line with feedback. You can read more about all these network developments in chapters 15 and 17.

Other areas of development over the last year include the development of biofeedback for children with dysfunctional voiding (chapter 8) and the development of home-delivered intravenous eculizumab therapy for children with aHUS, a rare complex type of kidney disease. Nottingham has been one of the first children's renal and urology units to develop both these treatments.

We have been pleased to see the success of our attempts to engage with social media: the EMEESY Facebook page has active participation and the number of followers for the EMEESY twitter account is growing. Facebook seems to be popular to publicise fundraising events but we hope it will also provide the means for families to communicate and support one another.

Now that we have a basic network infrastructure in place, we hope to be able to justify the investment needed to co-ordinate all the clinic administration, the education events and the website. We also hope to be able to develop robust means of measuring outcomes for the network and recording patient/parent feedback. We have agreed that from this year onwards, the network steering group, the Nottingham annual time-out day and the network annual general meeting should be used to hold to account the workplan that is produced from the annual report and progress with the workplan will be reported in each annual report from here onwards.

In line with corporate thinking, we have moved to an April-March from a calendar year annual report. I hope you enjoy reading of the EMEESY activity over the last year and I would be very pleased to receive any feedback.

Martin Christian
Lead Consultant for Paediatric Nephrology
Network Lead for EMEESY Children's Kidney Network
martin.christian@nuh.nhs.uk
August 2014

Young people from the haemodialysis unit switching on the Nottingham Christmas lights in 2013

2. STAFFING

MEDICAL STAFF

CONSULTANT PAEDIATRIC NEPHROLOGISTS

Dr Jonathan Evans (Clinical Director for Family Health; 0.6 WTE clinical)
Dr Farida Hussain (on maternity leave until December 2014)
Dr Martin Christian (lead consultant and network lead)
Dr Meeta Mallik
Dr Andrew Lunn
Dr Corinne Langstaff (PT locum until October 2014)
Dr Sudarsana De (maternity locum until October 2014)

TRAINEES

National grid trainee: Dr Hitesh Prajapati (from August 2013)
Special interest in nephrology (SPIN) trainee: Dr David Broodbank (February to July 2013)
General paediatric trainee: Dr Asheeta Patel (August to October 2013)
Special interest in nephrology (SPIN) trainee: Dr Adamu Sambo (February to July 2014)

David Broodbank has recently been appointed to a consultant post at Pilgrim Hospital in Boston where he will be the link renal paediatrician; Asheeta Patel has been accepted onto the paediatric nephrology national grid to begin formal training in Birmingham in August.

There are two junior trainees attached to the ward at any one time for 4-6 months. A number of recent junior trainees have expressed an interest in careers in nephrology.

CONSULTANT PAEDIATRIC UROLOGISTS

Mr Manoj Shenoy (service lead for paediatric surgery)
Mr Alun Williams (transplantation and paediatric urology)
Mrs Nia Fraser (maternity leave until June 2014)
Mr Bharat More (locum consultant until April 2014)

TRAINEES

National grid paediatric trainee: Mr Paul Jackson
Paediatric surgical senior trainee rotates every 6-12 months
Surgical SHO rotates every 3 months

TRANSPLANT SURGEONS

Mr Keith Rigg, Mr Alun Williams, Mr Shantanu Bhattacharjya, Mrs Amanda Knight
Richard Bowen leads the team of seven recipient co-ordinators. Anne Theakstone and Karen Stopper are the live donor co-ordinators.

SUPPORTING SERVICES

Radiology: Dr Nigel Broderick, Dr John Somers and Dr Kath Halliday
Pathology: Dr Tom McCulloch and Dr Zsolt Hodi

NURSING STAFF

RENAL TEAM

Senior Paediatric Nephrology Nurse and Network Lead Nurse: Shelley Jepson
Clinical Nurse Specialist (Dialysis): Roy Connell
Clinical Nurse Specialist (Transplant): Kim Helm
Renal Nurse Educator: Diane Blyton
Renal Critical Care Educator: Molly McLaughlin
Renal Nurses: Kate Baker (Transplant), Sharon Mould (Dialysis), Monique Burgin (Nephrotic)

HAEMODIALYSIS TEAM

Junior Charge Nurses: David Cooper and Ian Buchan
Haemodialysis Nurses: Nichola Hughes, Angela Thomson and Helen Gregory

UROLOGY TEAM

Clinical Nurse Specialist: Christine Rhodes
Urology Nurses: Gill Young, Emma Gamble (maternity leave) and Caroline Ward

WARD E17

Ward Manager: Michelle Kirkland
Junior Sisters: Debbie Hiley, Frankie Wells and Amandip Kaur
Large team of staff nurses, clinical support workers and domestic staff

DIETETICS

Pearl Pugh and Emma Kelly. During the last year, Pearl has taken a part-time secondment to neonatology. Her nephrology hours have been backfilled by Ruth Prigg.

PSYCHOSOCIAL TEAM

SOCIAL WORK

Suzanne Batte and Heidi Steward. Heidi retired in January 2014. We hope to appoint a replacement full-time social worker later in 2014.
These posts are currently part-funded by the BKPA.

PSYCHOLOGIST

Dr Kathryn Bradley commenced work at the start of 2013 and provides 3 sessions of support per week. She was on maternity leave from June 2013 to June 2014.

PLAY

Play specialist: Claire Hardy
Nursery nurse: Rachel Niemand (from October 2013, charitably-funded for 12 months)

YOUTH WORK

Renal youth development worker: Dorro Hackett. This post is funded by the BKPA for 3 years until November 2014. She is supported by Donna Hilton who manages youth and play services for the children's hospital and the Nottingham Children's Hospital Youth Team and volunteers. Matt Tomlin, Young Adult Worker for Nottingham and Derby provides support for young people transitioning to local units.

ADMINISTRATIVE AND SECRETARIAL STAFF

Team leader and network administrator: Judith Hayes
Other secretaries: Sandie McLauchlan (urology) and Pauline Leivers (medical), Vicky Cancemi (urology) and Pam Greenbank (support). They are supported by a team of filing clerks.
Ward receptionist: Lynn Brand (until February 2014); Diane Walker (from June 2014)
Haemodialysis administrative assistant: Kate Frost (until April 2014); Kelly Gillingham (from July 2014)

PHARMACY

Paediatric renal pharmacist: Andrew Wignell, supported by Claire Fosbrook, Lorraine MacDonald and See Mun Wong (home delivery services).

EDUCATION

Teachers: Gary Mace and Karine Williams
Teaching assistant: Hannah Barbary

MANAGEMENT

General Manager for Family Health: Julia Scrine (until June 2014)
Assistant General Manager (Paediatrics): Jenni Twinn (to March 2014); Vicky Holden (from April 2014)
Clinical Lead for Children's Services: Angela Horsley (until June 2014)
Matron: Sally Shearer (until 2013); Jamie Crew (from 2014)

We wish Julia Scrine a happy retirement and Sally Shearer and Angela Horsley success in their new jobs as Senior Nurse for Paediatrics at Bart's and Lead Children's Nurse for NHS England respectively.

SUPPORT SERVICES

We acknowledge the help and support from various services essential to running a paediatric renal unit including the support from the renal unit technical staff for the running of the dialysis machines and support in supplies administration. We are also grateful for the housekeeping and domestic support provided on ward E17.

Families whose children are admitted to ward E17 benefit from the accommodation support team and have access to chaplaincy support from Rev Anne Ladd and a team of multi-faith chaplains from the main hospital chaplaincy.

VOLUNTEERS

Finally we are grateful for the voluntary support received from Pat Sands, Pauline Woods and Denise Hardy supporting clinic and ward day care. We are also grateful for the charitably-funded support from the Giggle Doctors and Opus Music who visit the ward and haemodialysis unit each week.

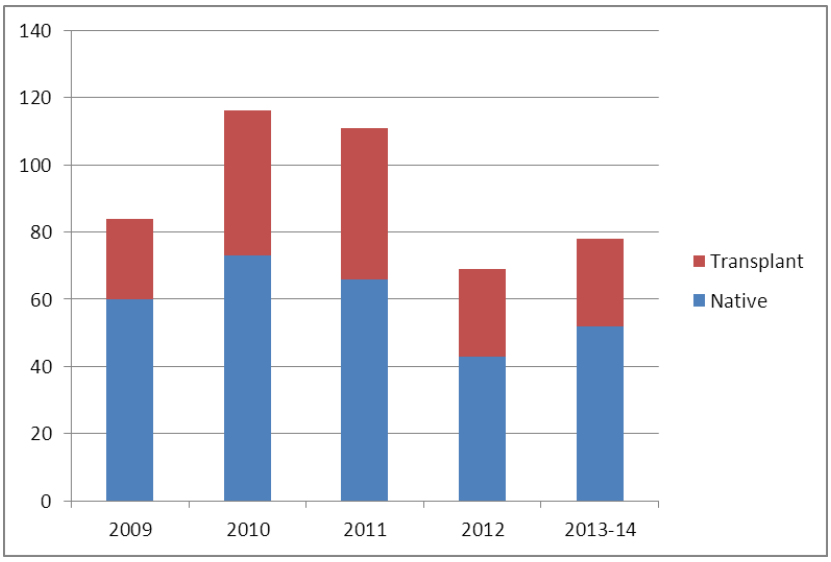
3. ACTIVITY AT NOTTINGHAM CHILDREN'S HOSPITAL

3A. WARD ACTIVITY

During 2013-14, there were 705 admissions, daycases or ward attendances for nephrology and 425 admissions, daycases or ward attendances for urology. Data in previous years has counted admissions to ward E17 indiscriminately of whether they were under the nephrourology team or one of the other paediatric teams. From next year, we hope to be able to differentiate between admitted patients, patients seen for daycase procedures and children attending the ward for clinical review.

3B. RENAL BIOPSIES

A total of 78 biopsies were done during the year, 52 native and 26 transplant. Numbers of biopsies have stay relatively steady in recent years with two busier years during 2010 and 2011 as shown in the figure.



3C. ACUTE KIDNEY INJURY

Ten children were admitted to ward E17 with acute kidney injury. Seven of those children had haemolytic uraemic syndrome related to E coli O157. The other children had AKI secondary to urological or other causes and none of these three children required acute dialysis.

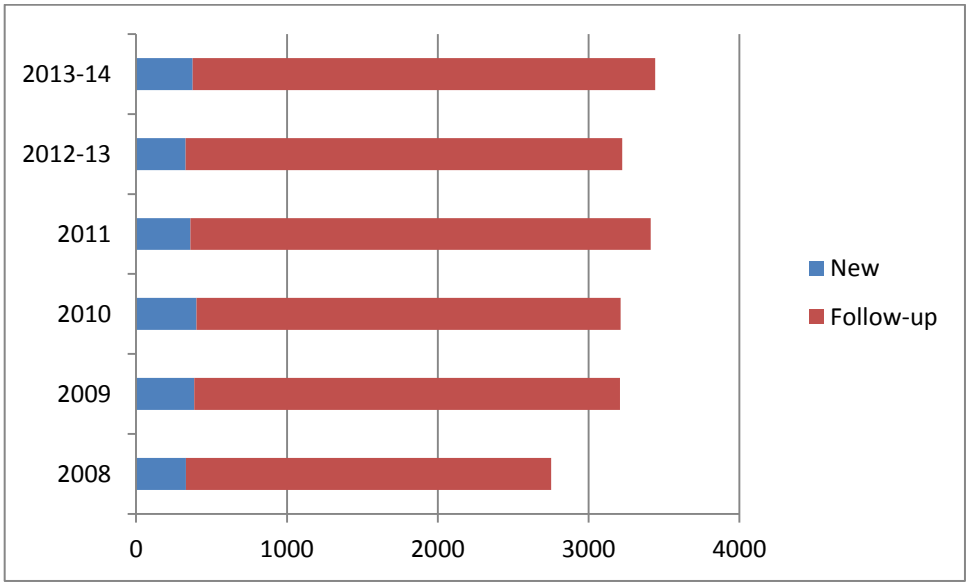
Of those children with HUS, all but one required dialysis which was needed for an average of 15 days. Two children were treated with peritoneal dialysis alone, one child received haemodialysis alone (due to severe colitis) and three children required a combination of peritoneal and haemodialysis due to complications with peritoneal dialysis.

3D. OUT-PATIENT ACTIVITY

For nephrology clinics in Nottingham during 2013-14, there were 374 new patients seen and 3067 follow-up patients. Overall there is a slight increase in numbers over the last 6 years but new patient numbers remain fairly constant.

The overall increase has occurred despite the large increase in numbers of patients seen in local shared-care clinics, particularly with new clinics starting over the last 12 months which has meant many patients being repatriated to follow-up at their local hospital shared-care clinic.

Figure showing new and follow-up clinic numbers each year from 2008 onwards. From 2012 the data has been captured from April to April but the graph represents a 12 month period each time.



4. CHRONIC DIALYSIS

Dialysis therapies are provided at Nottingham Children's Hospital for acute and chronic kidney failure. Peritoneal and haemodialysis are both used for both types of kidney disease. In addition, the haemodialysis unit staff provide apheresis therapies which are used to treat a variety of renal and non-renal diseases. This section deals with dialysis used for chronic diseases; information about dialysis used to treat acute kidney injury may be found in section 3 (Activity at Nottingham Children's Hospital) and section 17 (Critical Care Support).

Roy Connell, Clinical Nurse Specialist for Paediatric Dialysis

HAEMODIALYSIS

CURRENT WORKFORCE:

The haemodialysis unit is staffed by 3.2 WTE dedicated registered nurses. This consists of two band 6 nurses (1.6 WTE) and two band 5 nurses (1.6 WTE; 1.0 WTE currently on maternity leave) and is managed by a Clinical Nurse Specialist.

Staffing requirements fluctuate between 4.0 and 7.0 WTE according to the number and dependency of patients. The staffing gap is filled by regular input from all of the specialist renal nurses.

ACTIVITY 2013-14

Fifteen patients received haemodialysis as a chronic treatment, compared to 22 in 2012/13, 18 in 2011 and 29 in 2010). There were 1447 patient sessions during the year, compared to 1771 in 2012/13**,** 1684 in 2011, 2352 in 2010 and 2164 in 2009. Overall this represents a slight decrease in the haemodialysis numbers but workload has been challenging due to an increase in younger and more highly dependent children receiving dialysis.

The age range of children receiving haemodialysis was between 1 and 19 years.

Four patients were aged less than 5 years compared to seven in 2012/13 with one requiring dialysis 6 days per week.

Patient movement during the year has seen:

- 3 patients transfer to adult services
- 3 patients transplanted
- 1 patient converted to PD

WORK-PLAN FOR THE NEXT YEAR:

- Integration of the renal computer to allow 'real-time' electronic recording of dialysis sessions.
- Implementation of a home-haemodialysis service.

PERITONEAL DIALYSIS

CURRENT WORKFORCE:

The day-to-day management of the peritoneal dialysis programme is undertaken by Sharon Mould (pictured), a band 6 renal nurse (1.0 WTE) overseen by a Roy Connell, a clinical nurse specialist (1.0 WTE). Alongside the PD programme, the CNS and renal nurse have a regular haemodialysis commitment.

Roy Connell, the CNS is also responsible for:

- Management of the haemodialysis programme.
- Home therapies (including Albumin infusions)
- Shared Eculizumab service.
- Apheresis programme
- Ambulatory blood pressure monitoring

ACTIVITY DURING 2013-14

Fifteen patients received peritoneal dialysis over the last year (109 patient months). This is a similar workload to that seen in the previous two years (18 in 2012/13 and 19 in 2011) but still significantly down on the numbers seen in recent years prior to this (31 in 2010, 28 in 2009, 27 in 2008).

Five families were trained to undertake peritoneal dialysis at home. These annual numbers are variable: 12 families were trained in 2012/13, 2 in 2011, 17 in 2010 and 8 in 2009). The number of families trained compared to the numbers remaining on or transferring off PD is reflective of the ever-changing nature and needs of the PD population.

There were 6 episodes of peritonitis giving an incidence of 1 in 18 patient months (1:18 in 2012/13, 1:14 for 2011, 1:17 for 2010 and 1:16 for 2009). The unit's 5-year peritonitis rate is 1 in 16 patient months which meets the recommended Renal Association standard of 1 in 14 patient months. Almost half (47%) of the PD patients were aged less than 5 years during 2013/14 and therefore fall in the higher risk category for infections.

Patient movement during 2013/14 has seen:

- 1 patient transfer to adult services
- 5 patients transplanted
- 1 patient converted to haemodialysis.
- 8 patients remained on the PD programme.

WORK-PLAN FOR THE NEXT YEAR

- Audit and review the changes made to the peritonitis guidelines (implemented June 2014).

- Further development of the update programme for PD patients.

APHERESIS THERAPIES

Apheresis treatments which include plasmapheresis (or plasma exchange) and lipopheresis are treatments which involve removal of a part of the plasma to treat a diverse range of acute and chronic treatments. Treatments are mainly performed in the haemodialysis unit in addition to the regular patient workload. Therapies are carried out by the staff in the unit or the on-call nurse during out of hours periods.

CURRENT WORKFORCE

There is no dedicated apheresis nurse for the unit so it is important for all of the haemodialysis staff and specialist nurses to maintain their skills in the therapies we offer. The apheresis programme is managed by the Dialysis Clinical Nurse Specialist.

ACTIVITY DURING 2013-14

Overall, the overall number of patients (acute and chronic) requiring apheresis therapies was eight (compared to 13 in 2012/13, 13 in 2011, and 7 in 2010). However the number of delivered sessions has remained constant (200 sessions of acute and chronic apheresis performed during 2013/14 compared to 195 in 2012/13 and 174 in 2011).

Three patients received double filtration plasmapheresis (DFPP) as a chronic treatment – a total of 172 individual sessions.

Five patients were treated acutely using apheresis for a number of differing conditions. Therapeutic plasma exchange (TPE) was used to treat 2 patients (8 sessions) and DFPP to treat 3 (20 sessions).

Two chronic apheresis patients transferred to adult services during 2013/14. One of these was a long term patient with familial hypercholesterolemia who had been treated weekly in the unit for almost 9 years.

WORK-PLAN FOR THE NEXT YEAR

- Assess the need for a dedicated apheresis nurse to oversee the service, ensure skills are kept up-to-date and implement any changes or new technologies.
- Audit the therapies performed and complete the DFPP study

5. TRANSPLANTATION

Nottingham Children's Hospital is one of 10 paediatric transplant units in the UK. Both living donor and deceased donor transplants are carried out. We aim to transplant all children pre-emptively where possible.

Kim Helm, Clinical Nurse Specialist in Paediatric Transplantation

WORKFORCE

There is one (0.8 WTE) band 7 clinical nurse specialist, Kim Helm. She is supported by a renal nurse, Kate Baker (0.8 WTE) whose time is divided between transplantation and chronic kidney disease. All paediatric nephrologists look after children who have been transplanted. The surgical transplant team comprises four consultants, all of whom carry transplants in children. There is a living donor team at Nottingham City Hospital where parents who wish to be considered living donation can be referred.

ACTIVITY DURING 2013-14

The unit performed 13 transplants. At the end of the year there were just 4 patients active on the national list with a further three suspended. This is relatively small number active on the list for Nottingham. Many other children are currently being worked up for transplantation.

Source of donor	
Living donor	3
Deceased donor	9
Altruistic donor	1

Previous treatment	
Pre-emptive	4
Peritoneal dialysis	7
Haemodialysis	2

Transplant number	
First transplant	10
Second transplant	2
Third transplant	1

Post-transplant, patients are nursed either on the ward, PICU (if <15 kg) or PHDU (if 15-20 kg). There were six children nursed on the ward, five on PICU and two on PHDU. There were more children nursed in critical care areas than desired because of insufficient nursing on the ward to provide the 1:1 nursing required for the first 48 hours as a minimum.

A total of 101 transplant patients were being followed-up throughout the year. There was patient movement due to transferring to adult services, changing centres or deteriorating graft function requiring a return to dialysis. At the end of the year there were 90 patients under active follow-up. Most patients are followed in Nottingham clinics. There are some children who receive their follow-up in local shared-care clinics; most of these children return to Nottingham for an annual appointment.

Patients transition to adult centres within EMEESY. This year, five have transitioned to Nottingham, four to Sheffield and two to Derby. One patient has died and two patients returned to dialysis, both to peritoneal dialysis.

Transplant nurses liaise with other professionals throughout the network. Communication has improved since transplant nurses have begun to attend local shared-care clinics with the consultant on a regular basis. Kim Helm attended 5 such clinics this year. This can be combined with updates for the families which can be carried in the clinic, saving on several home visits.

Living donor transplant numbers in Nottingham are low compared to other paediatric transplant centres in the UK. In order to ensure that this is not due to a failure to share information about transplantation options at an early stage, a first transplant family information day took place in September 2013. The families of all children with CKD stage 4 and 5 were invited. The formal programme included talks from a paediatric nephrologist, a transplant co-ordinator, the transplant clinical nurse specialist and a member of the living donor team. The morning finished with a talk from a parent who was a living donor for his child several years ago. Several other families who had been through transplantation were also invited to be “expert” families and after the formal programme there was a lunch with time for invited families to talk with professionals or “expert” parents. The day was well attended (around 15 families) and excellent feedback was received. There is a plan to repeat the day in October this year.

Transition has been a major focus this year with improvements in the transition process with various adult units and the start of regular, successful multi disciplinary meetings. With some larger centres, transition clinics have been just that – an opportunity to meet the adult team alongside the paediatric team without the imperative to transfer care at the same clinic. In Nottingham, we try to ensure that young people have at least two visits to the transition clinic before transferring. Kim Helm attended 6 transition clinics.

Dorro Hackett, the youth worker and Kim arranged a coffee drop-in in Leicester in place of multiple home visits. This was also supported by the adult transplant nurse. Two young people and one carer attended.

Home visits are an essential part of our standard of care. This year, these included 18 home visits, 13 school visits and 11 Team Around the Child or multi professional meetings.

There are regular 3-monthly meetings with the whole transplant team, including the tissue typists from Sheffield. All children on or working towards the transplant list or preparing for living donor transplantation are discussed. This enables good communication about potential problems. The paediatric team has felt that a 3-month interval is too long for these discussions and an interim meeting has been established during this year.

Nottingham has been the first UK centre to take part in the international multi-centre CRADLE study, trialling an immunosuppressant drug called everolimus which has previously been used safely in adult transplantation and in a small number of children. Two other UK centres have since joined the study. Nottingham is one of the top recruiting sites for this study of all countries participating.

TRAINING, RESEARCH AND TEACHING

Conferences/courses attended:

- Transplantation Day, Freeman Hospital, Newcastle, October 2013 (KH)
- ITNS Chapter Birmingham 12th November 2013 (KH)
- Paediatric Nephrology Nurses conference March 2014 (both)
- Course : Motivational Interviewing workshop, Nottingham February 2014 (KH)
- Masters of Nursing degree modules (KB)
- Research time for RaDaR rare renal disease registry (KB)

Teaching to new starters: transplant on PICU, November 2013 (KH)

WORKPLAN FOR THE NEXT YEAR

We hope to continue to promote live donor transplantation, giving families an opportunity to consider their child's future treatment at a much earlier stage in the patients' journey than before.

We also plan to continue promoting living donor paired/pooled exchange where appropriate and also ABOi donation.

We plan to develop the concept of a transplant annual review to ensure that all patients and their families have a once a year overview of their transplant function and overall health.

Two of Nottingham's Transplant Games team for 2013, showing their medals.

6. ANTENATAL SERVICES

Antenatal counselling for pregnant women carrying babies with significant renal abnormalities is provided from Nottingham for patients from Nottinghamshire and Lincolnshire. This service is delivered by three consultant paediatric nephrologists in conjunction with the Fetomaternal Medicine Department. Arrangements for delivery and post-natal care are made as appropriate.

There were 32 infants referred post-natally in Nottingham but there are no data on the number of women counselled for 2013-14. Next year's report will contain information on numbers of women counselled and infants delivered in Nottingham due to significant renal tract abnormalities.

7. UROLOGY

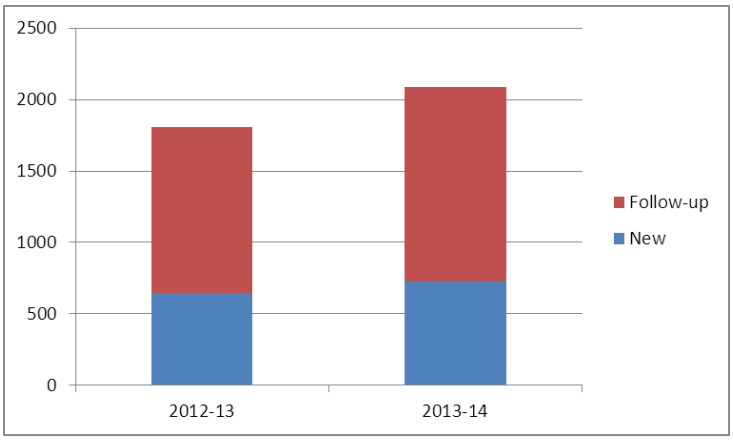
Urology surgical in-patients are nursed on ward E17. Other children who undergo day-case procedures are admitted through the Ambulatory Care Unit.

WORKFORCE

There are 3 consultant paediatric urologists: Mr Manoj Shenoy, Mr Alun Williams and Mrs Nia Fraser. Mr Williams also undertakes transplantation work for adults and children; his on-call is covering the transplant rota. Mrs Fraser returned from maternity leave in June 2014. During her leave, Mr Bharat More covered her clinical work during her leave.

There is one national grid paediatric urology trainee and one paediatric surgical registrar-level trainee.

2013-14 ACTIVITY



Clinics took place in Nottingham Children's Hospital at the QMC Campus. Numbers of children seen in Nottingham paediatric urology clinics are shown in the figure above. There has been a 16% increase overall in out-patient activity from the previous year.

As well as general urology clinics, there are monthly neuropathic bladder clinics and a regular clinic for children with disorders of sexual differentiation that is run jointly with paediatric endocrinologists.

Mr Williams does regular young persons' urology clinics at the City Hospital Campus. He also does operating sessions and clinics at Derbyshire Children's Hospital and Chesterfield Royal Hospital. Mrs Fraser does clinics at Kings Mill Hospital and Lincoln County Hospital.

8. UROLOGY NURSING

2013-14 was a year in which we made many changes that not only improve the quality of care we give but also to advance it. In January 2013 we became only the fourth hospital in the country to offer children with dysfunctional bladders the possibility of pelvic floor bio-feedback management/training.

Chris Rhodes, Clinical Nurse Specialist in Paediatric Urology

WORKFORCE

In June we were also granted an extra 14 hours of band 5 time from our ward team. This enabled us to increase Caroline Ward's hours up to 26 hours a week for Urology. The difference this makes will be demonstrated in our overall productivity.

ACTIVITY 2013-14

Our nocturnal enuresis service led by Caroline Ward continues to flourish and produces some excellent results as you will read, we were asked to take on the nursing care and overall management of children undergoing MRI urography and this has continued in 2013.

The number of children currently requiring our service is:

- 215 Children with a neuropathic bladder
- 211 Children with daytime enuresis
- 116 Young adults in the Young Persons' Clinic

CHILDREN'S OUTPATIENT DEPARTMENT

Total number of children seen in clinics by the urology nurses in 2013-14 was 408, a similar figure to that of 2012-13. This figure does not include the nocturnal enuresis clinic.

We continue to provide care and assessment within the out patient setting. During 2012-13 we had seen an increasing number of referrals from community paediatricians for our nurse led clinic, which at times were overwhelming in their number. A managerial joint decision was made that all new referrals have to be seen by doctor before they are referred into our service.

This year we came to the reluctant decision that we could no longer support the Nephro-Urology Young Person's clinic. Our decision was taken in light of the amount of referrals we were receiving for bladder assessments. Unfortunately as yet there is no adult urology nurse to whom to transfer the young person's care. This continues to causes some difficulties with families still contacting the paediatric service once in the adult care.

NOCTURNAL ENURESIS SERVICE

A structured approach to nocturnal enuresis is offered. Baseline information is obtained to enable ascertaining the child's/young person's problems and from this enuresis alarms are issued and/or medications commenced. Medication or treatment decisions are followed-up by phone, in consultant-led clinics and in the twice-monthly, nurse-led nocturnal enuresis.

There are have been 53 patients under the nurse-led enuresis clinic in the last year. 36 of these patients have been issued an alarm during this year. 44% of these are now dry having used the alarm only and a further 19% are dry with alarm and medication in combination. Of these children 14 (26%) have undergone bladder assessment to add their management

DAY CASE ASSESSMENTS

The total number of children requiring day case bladder assessment was 175 which is an increase of 15%. There are a large amount of referrals for this non invasive investigation through which quite detailed information can be obtained about how the child's bladder functions on a day-to-day basis.

URODYNAMICS

Last year 71 children underwent this investigation, an increase of 39% from the previous year. The service is supported by one radiologist and more recently two urologists, one of who is due to return from annual leave in June 2014.

Since 2011 Entonox has been used for urethral catheterisation in the x-ray department which has reduced the number of children requiring supra-pubic catheters to 12 in the last 3 years from over 20 per year. In turn, this has made a significant saving in the number of general anaesthetics required. More importantly positive feedback from our patients and their families has demonstrated an improved impact on our quality of care. These findings were presented at the 2013 ESPU congress with Christine Rhodes subsequently winning the Best Nurse Presentation at the conference.

CLEAN INTERMITTENT CATHETERISATION

40 children/parents, were taught clean intermittent catheterisation, plus a further 48 children were brought into hospital for their supra pubic catheter changes. As a result of improved network working through EMEESY, nurses in Peterborough are now happy to change supra pubic catheters locally which has reduced the number of families travelling to Nottingham.

COMMUNITY

We have carried out 31 homes and school visits which is similar to last year. We continue to follow the agreement set that only essential home/school visits should be carried out and when possible we have asked parents/carers and schools to travel in to hospital to see us for teaching, training and other advice.

The service made 1780 phone calls to parents, 291 phone calls to health-care workers and 143 phone calls to schools.

BIO FEEDBACK

In January 2013 we became only the fourth children's hospital in the country to offer pelvic floor rehabilitation through bio-feedback. Each child is offered a course of 6 consecutive weeks' therapy and each session lasts for approximately 1 hour. We commenced our service by seeing three children a week but more recently it has been necessary to increase this to six children a week due to the increase in demand.

The children who would benefit from this form of treatment are those with dysfunctional voiding (DV) which is a lack of co-ordination of sphincter and pelvic floor relaxation to enable the child to void to completion.

23 children have attended for bio-feedback and 130 sessions have been completed.

ACADEMIC ACTIVITY

Christine Rhodes remains the chairperson for the RCN Children's Urology Continence Community, and continues to work closely with the RCN. She was the secretary for the European Society for Paediatric Nurses (ESPUN) until May 2013.

All urology nurses have attended courses and meetings regularly through the year. Christine Rhodes and Gill Young have continued to teach on a wide variety of educational courses, study days and conferences:

May 2013. Chris Rhodes chaired the conference on children's continence run by Coloplast.

June 2013 Chris Rhodes chaired the British Association of Paediatric Urology Nurses meeting (as president) in Sheffield.

November 2013 Chris Rhodes and Gill Young taught on the bladder and bowel course in Nottingham.

March 2014. Chris Rhodes presented on The Wet Child at the EMEESY Spring Nephrouroradiology Symposium in Nottingham

April 2014 European Society of Paediatric Urology conference, Genoa, Italy. Chris Rhodes presented Entonox, a gasp of air.

WORKPLAN FOR 2014-15

- To continue to develop the urodynamics service with a full complement of medical staff supporting the service
- To continue to develop and evaluate the new biofeedback service
- To publish the experience of using Entonox to support urethral catheterisation for urodynamics.

9. PHARMACY

Pharmacy services are provided by Andrew Wignell, whose time is divided between the children's renal unit and PICU. He advises on prescribing for in-patients and out-patients. He also advises paediatric pharmacists throughout EMEESY on prescribing specialist renal drugs and gives advice about prescribing in renal impairment.

Children with renal transplants and children with chronic glomerular disease, like nephrotic syndrome may receive medication delivered to their homes through Healthcare at Home. Over the last year, there have been problems with this service through a distribution base move and the collapse of a competitor service leading to a significantly greater workload. This is a situation that we continue to monitor closely.

Four children have been commenced on eculizumab for atypical haemolytic uraemic syndrome and the drug is continuing in three children. This is an extremely high-cost drug and use of the drug for atypical HUS is currently being assessed by NICE. All three children now receive the drug at home, delivered by a paediatric nurse through a long-term port device. This is a service supported by BUPA Healthcare. Nottingham has been the first paediatric renal unit to use this service.

10. DIETETICS

Nutritional support for children with chronic kidney disease is a key aspect to management to support health and growth.

Pearl Pugh and Emma Kelly, Specialist Paediatric Renal Dietitians

WORKFORCE

The dietetic service is staffed by 1.6 WTE, Pearl Pugh (0.6 WTE) and Emma Kelly (1.0 WTE). Cover is provided for all in-patients and CKD clinics that take place on a Tuesday and Thursday morning. Only urgent referrals were seen in the Wednesday nephrology clinics. During periods of full staffing a dietitian attended an outreach clinic with the consultant in Leicester this has been identified as a priority for input. Both dietitians are members of the Paediatric Renal Special Interest Group (PRING). Pearl Pugh is a member of the EMEESY network steering group.

ACTIVITY DURING 2013-14

CONTACTS

	2009	2010	2011	2012	2013-14*
Total patients	225	224	187	188	242
New patients	87	71	76	70	74
Total dietetic activity	1732	1765	1540	1456	1745
Mean contacts	7.7	7.9	8.24	7.74	7.2

* Change to April-April analysis

BREAKDOWN OF NUMBER OF PATIENT CONTACTS

	2009	2010	2011	2012	2013-14
In-patients	764	768	628	622	690
Out patients	366	376	488	561	656
Dialysis unit				64	107
Home/school visits	1	1	0	1	0
Telephone	423	430	424	187	292
Total	**1554**	**1575**	**1540**	**1435**	**1745**

TYPES OF TREATMENT CONTACTS

Dietary assessment - computerised	35
Dietary assessment - other	13
Healthy eating advice	176
Simple/single dietary recommendation e.g. low Na/low fat	6
Complex/disease-specific dietary advice e.g. low K and PO_4	877
Controlled nutrient/portion	3
Oral supplements	386
Nasogastric tube feeding	327
Gastrostomy tube feeding	479
Central parenteral nutrition	39
Peripheral parenteral nutrition	3
Energy dense diet	128
Weaning advice	34
Nutrient-enriched infant formula	95
Total	**2601**

TRAINING, RESEARCH AND TEACHING

EMEESY network – developing dietetic links and providing training and education for paediatric deititians in regional shared care renal clinics (PP/EK)

Growth and nutrition audit update. To review the audit standards taking into account feedback from other renal units and UK/KDOQI guidelines (EK/PP Sept 2013)

CONFERENCE PRESENTATIONS/COURSES ATTENDED

Paediatric Renal Interest Group Meetings (EK)

First International Paediatric Renal Dietitians' Conference (EK)

Teaching methods course at Sutton Bonnington Campus (PP/EK)

East Midlands Leadership Academy Operational Leadership Series: Presenting with Excellence (PP)

International Congress on Renal Nutrition & Metabolism. Presentation: *What I tell my families about renal diets for children with CKD.* (PP, May 2014)

TEACHING

EMEESY multi-professional education meetings (PP/EK Oct 2013 and March 2014)

Teaching session for nurses, registrars and junior doctors on E17: dietary management of CKD and AKI (EK)

Organised dietetic student training programmes, work experience sessions and student mentor (EK)

Paediatric Registrar Training Day, Leicester (PP Sept 2013)

PLANS/ TARGETS FOR 2014-15

- To complete annual dietetic assessments involving analysis of 3-day food diary on all dialysis patients and complete annual dietary assessment report.
- Continued involvement in teaching of new staff and educating existing members of staff with regard to the renal diet.
- Continue to develop and review dietetic resources.
- Continue to work on a strategy to improve phosphate compliance in children and young people.
- To identify a student to undertake a detailed literature review to look at the use phosphate in preservatives.
- Investigate the feasibility of undertaking some micronutrient status analyses pre and post haemodialysis.
- Undertake a service evaluation of gastrostomy for nutritional support in chronic dialysis.

11. SOCIAL WORK

Social work support to children with chronic kidney disease and their families has been provided by Heidi Steward (full-time post) and Suzanne Batte (part-time post). The posts are part-funded by the British Kidney Patient Association (until 2014). Heidi retired in January 2014 after 13 years. This has been a significant event, as the social work provision in the team has been very stable for a long period of time. The full-time post is currently vacant but Suzanne Batte continues to work part-time. Heidi will be missed greatly by her friends and colleagues in the team, as well as the numerous children and families she has supported over many years.

Suzanne Batte, Specialist Paediatric Renal Social Worker

ROLE OF THE SPECIALIST PAEDIATRIC RENAL SOCIAL WORKER

Chronic kidney disease is a life-long condition which has complex psychosocial implications for the child and other family members which requires long term support. Heidi and Suzanne have continued to aim to provide a high standard of psychosocial care to children and their families through traditional social casework and counselling skills. This service is provided on the renal ward, outpatient clinic and dialysis unit. The support offered includes being available during ward admissions to discuss emotional, practical and financial implications. Home visits are also undertaken to follow up needs in the community.

Heidi and Suzanne have continued to visit families with specialist renal nurses at critical times during the treatment process including emotional trauma at the time of diagnosis, prior to transplant listing and at the commencement of dialysis. Particular practical issues that families face include storage and space when starting peritoneal dialysis at home or coping with long journeys and treatment three times a week for those on hospital haemodialysis. Sometimes a parent will have been forced to give up work too and so they will require help to look at their finances. The BKPA are a great source of support for lower income families and Suzanne continues to submit regular applications.

The broad range of backgrounds of families require individual responses. Suzanne is skilled at assessing the needs of children from a wide range of religious and cultural backgrounds. She also works with parents who have learning difficulties and mental health issues. Social workers work with children who have involvement from Social Care due to safeguarding issues. The impact of a specialist paediatric renal social worker is to ensure that local authority social workers, teachers and other professionals understand the impact of chronic kidney disease on families where there may already be substantial concerns. Being an advocate for families whilst monitoring concerns is a difficult task to balance but having experienced paediatric renal social workers who understand the thresholds for considering when children may be at risk of significant harm are an essential part of the team.

Advocacy work is an expectation of the renal social work role. Heidi and Suzanne have continued to represent the needs of children and their families with other agencies including housing departments, employers, the Benefits Agency, schools, nurseries and further

education establishments. We have sometimes been required to attend appeals tribunals in relation to Disability Living Allowance.

2013-14 ACTIVITY

Suzanne and Heidi made 45 home visits in the last year. They attended 20 Child in Need/Child Protection conferences/Core Group meetings, 13 Team around the Child (TAC) meetings and made 10 school visits.

Heidi and Suzanne receive regular supervision from an experienced social work team manager. This ensures that they can obtain advice about on-going work with families and discuss care plans. The supervision also focuses on training and developmental needs as this is a requirement for registration to practice as a social worker.

Both social workers are members of the BASW Special Interest Group which promotes the work of renal social workers nationally. This ensures that they keep informed about developments that impact on their daily work as indeed the group is a great source of information and advice. Heidi attended BASW meetings during the last year and Suzanne attended the Paediatric Special Interest Group meeting.

Heidi presented a paper at the 2013 EWOPA conference in Rotterdam regarding the Transition Workshop that the team organised the previous year.

CHALLENGES FOR THE YEAR AHEAD

At the current time, the social work provision is much reduced. However, effective planning and organisation has ensured that the service continues, with priority given to children subject to child protection plans, those receiving dialysis and children awaiting transplantation. Suzanne is currently based more in the hospital during this period so that ward patients and clinic patients continue to receive support. Weekly attendance at the chronic kidney disease out-patient clinics ensures that Suzanne can see families and be available to offer advice and support. For families attending infrequently, this provides an opportunity to assess how they are coping. She is also currently working with her colleagues to organise a second Transition Day in June 2014

It is clear that a comprehensive psychosocial service requires two social workers to ensure that families receive support throughout the whole treatment process. We hope to appoint a replacement full-time social worker later in the year.

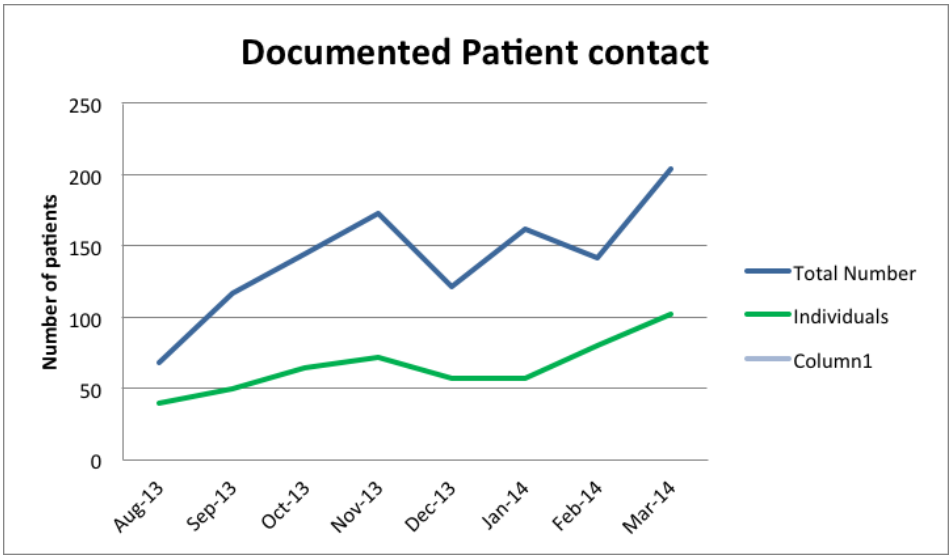
12. PLAY

CURRENT WORK FORCE:

In this last year we have been able to expand to one full time health play specialist, Claire Hardy (left) and, from October 2013, one 0.63 WTE nursery nurse, Rachel Niemand (right). This helps manage the increasing workload and allows Claire to spend more time in clinic, working with children to prepare for future treatments.

ACTIVITY DURING 2013-14

This graph shows the episodes of patient contact from August to March.



The types of intervention are broken down in the table below:

	AUG 2013	SEPT 2013	OCT 2013	NOV 2013	DEC 2013	JAN 2013	FEB 2013	MAR 2013
Psychology support	2							
Urology	1							
Transplant preparation	2	2		1				
Haemo	6	13	22	12	17	21	18	32
Prep, Distraction, Support	7	35	28	34	16	35	24	24
Renal Residential	9							
Biopsy Support	1	2	7	4	1	6	1	1
Referrals		3		1	1	2	2	2
Support other areas	4 other units				Xmas visits	PICU PICU	Adult ICU All wards	PICU
Play sessions						7		15
Sensory play							5	5
Renal Clinic							16	55
Home/School Visits					1			

SIGNIFICANT ACHIEVEMENTS:

- Appointment of nursery nurse.
- Development of new transplant preparation booklets
- New documentation
- More general play and play sessions carried out on the ward and in haemo due to nursery nurse appointment
- Now covering renal clinics so meeting more patients prior to needing specialist support

PUBLICATIONS AND PRESENTATIONS:

- Oxford Handbook of Clinical Skills
- Presentation at Nottingham Trent University on the role of health play specialists
- Organisation with the team of Nottingham Play Conference October 2014 (Chaired the event)
- Presentation to Japanese play staff visiting NCH

PLAN FOR 2014-2015:

- To increase PT Nursery nurse to FT if funding is secured
- To structure the way we work to ensure that all areas are covered (haemo, ward, clinic)
- To continue to do carry out home and school visits
- To link with other renal play specialists nationally, including visiting other areas to see how services are run.

13. YOUTH WORK

There is currently one Renal Youth Development Worker, Dorro Hackett, working full time with the Renal Team. This post is a three year post funded by the British Kidney Patient Association (BKPA) which is due to finish in November 2014. There are currently plans to extend the post.

ACTIVITY DURING 2013-14

Overall, 73 different young people and their siblings from the renal unit accessed youth services during the past year. This could mean advice and support from the youth workers; using the Youth Room during hospital stays; attending the weekly hospital youth club; activity and support programs for long-term patients; transition support; and/or becoming involved in long-term projects such as the Youth Forum, day trips and residential holidays. This number accounts for 13% of young people seen by the Youth Service as a whole and does not include young people admitted to E17 without renal conditions. 42 different young people were seen in a clinic setting; this accounts for 70% of young people seen in clinic by the Youth Service as a whole.

There were 55 episodes of young people from the renal unit accessing a day trip (23 different young people). This had increased from 21 contacts with 10 young people in 2012. Trips included Laser Quest, ten-pin bowling, Drayton Manor Park Theme Park, Legoland, Swadincote Ski and Snow Board Centre and a theatre trip – James and the Giant Peach. Four young people met the Lord Mayor of Nottingham at the switching-on of the festive lights in December.

27 young people from the renal unit accessed 38 residential activities. This was up from 15 contacts with 12 young people in 2012. Residentials included 5 days at the outdoor education centre Newgale in Wales, a 3-day Transition Residential at Center Parcs and a 3-day dialysis holiday to Center Parcs.

45 different young people were seen on ward E17 and in the Haemodialysis Unit. 16 different young people accessed support and/information through phone, email and Facebook contacts. This information was not previously recorded in this way and so this is the first opportunity to see the impact of this sort of work.

The impact of youth work is difficult define through numbers and statistics. Benefits of having a renal youth worker that cannot be easily measured include: increased peer support, 1-1 support for young people around bereavement, housing, sexual health, independent living, transition, driving and careers; opportunities to try new things; access to training and educational support; encouraging young people to join the Youth Forum to have their say in hospital services; and generally time away from the medical environment. Creating opportunities for young people to learn about themselves and others is a key aspect of youth work (NYA 2014). Over the last year, we have witnessed young people being able to push their comfort zones through various activities and workshops and developing stronger bonds with their peers.

INNOVATIONS

2013 saw the introduction of coffee drop-in sessions for transition in people's local community. Six young people and their parent/carers were able to access support and ask questions about transition. Alongside this, there were 39 contacts at a young adult clinic in 2013/14 and 4 1-1 visits to an adult unit. In March, three young people were asked to talk at a Transition conference. One of these young people was a renal patient and he was able to share his experiences of transition.

The Nottingham Children's Hospital Grand Round in September 2013 focussed on the Renal Unit's transition pathway and included contributions from Dorro and the medical staff.

WORKPLAN FOR THE YEAR

We need to secure on-going, long-term funding for youth work, developing an evidence-base for its effectiveness and sharing practice with other specialties within Nottingham Children's Hospital yet to take full advantage of the NUH Youth Service.

Waiting to climb at the Newgale Young People's Residential, July 2013

14. PSYCHOLOGY

There are 3 sessions per week of psychology time to support children and young people with kidney disease at Nottingham Children's Hospital. This falls well-short of the recommendations in the BAPN Multi-Professional Working document of 2003 which would recommend … WTE for a service covering a population of 6 million. The current post-holder, Dr Kat Bradley, has been on maternity leave for most of 2014-15 without locum cover.

Some psychological support is provided by other members of the psychosocial team including play specialists, youth worker and social workers. We also refer to the paediatric liaison psychiatry service at Nottingham Children's Hospital and have benefited significantly from the input of Mr Paul Fletcher, Systemic Psychotherapist with some of our patients and families.

Just prior to going on maternity leave, Kat led a review of the weekly psychosocial meeting which has been revised as a result. It is now chaired by a member of the psychosocial team rather than the consultant on-service Minutes are taken with an agreed plan. These minutes and plans are made available to the team through the confidential intranet shared-area. At the start of each meeting, the outstanding action points from the previous week are reviewed.

RESEARCH ACTIVITY

Jen Heath who was an assistant psychologist with the unit recently has completed a project as part of her doctoral thesis exploring further the question of why self-reported quality of life appears to be as high or higher in children and young people with CKD compared to their health peers. A presentation has been accepted for the 2014 EWOPA meeting in Porto and Jen is currently writing up the research for publication.

WORKPLAN FOR 2014-15

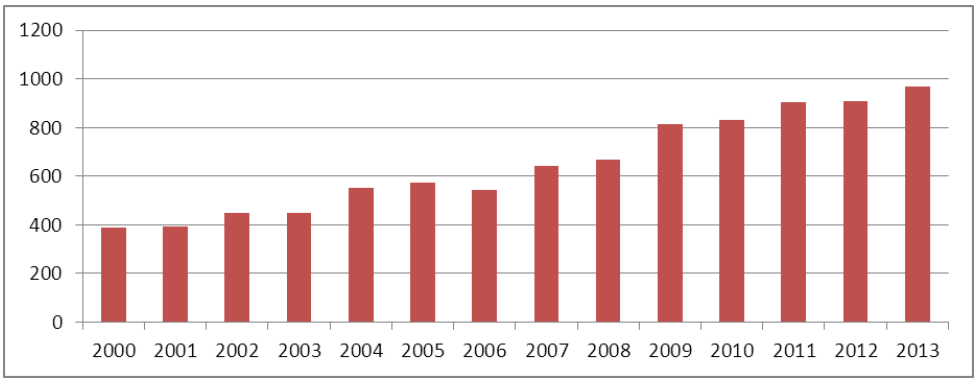
The prospect of securing additional hours is unlikely in the current financial climate. In the next year, we plan to continue to develop the training role of the psychologist and explore how some aspects of psychological assessment and treatment can be delivered by other members of the team.

15. ACTIVITY IN LOCAL CENTRES

With the network development secondments, 2013-14 has seen considerable growth in numbers of children seen in local shared-care clinics. We prefer to consider these clinics as shared-care rather than outreach or peripheral clinics to support our philosophy of delivering quality care as close to home as possible in partnership with local services.

During this second phase of network development, we have sought to make multi-professional links with local services. Nurses and dietitians from Nottingham have attended many local shared-care clinics.

ACTIVITY DURING 2013-14



Growth in overall shared-care clinic numbers since 2000 is shown in the above graph. Over the last year, new clinics in Doncaster, Bassetlaw (Worksop), West Suffolk Hospital, Grantham, Barnsley, Great Yarmouth and most recently Hinchingbrooke (Huntingdon) have started up. The predicted numbers for 2014 based on data for half the calendar year are almost 1200 patients, an increase of 30% from 2012 before the network development project began.

WORKPLAN FOR 2014-15

In the next financial year, we plan to revise all service-level agreements along the model of Nottingham Children's Hospital being responsible for activity in all centres, reimbursing each local centre for "hosting" the clinic. This allows all the activity to bundled as specialist commissioning and should result in smoother finance flows in future. We hope it will eventually result in an appropriate tariff for paediatric renal out-patient services to fund the large multi-disciplinary team that is required.

16. CRITICAL CARE SUPPORT

CURRENT WORKFORCE

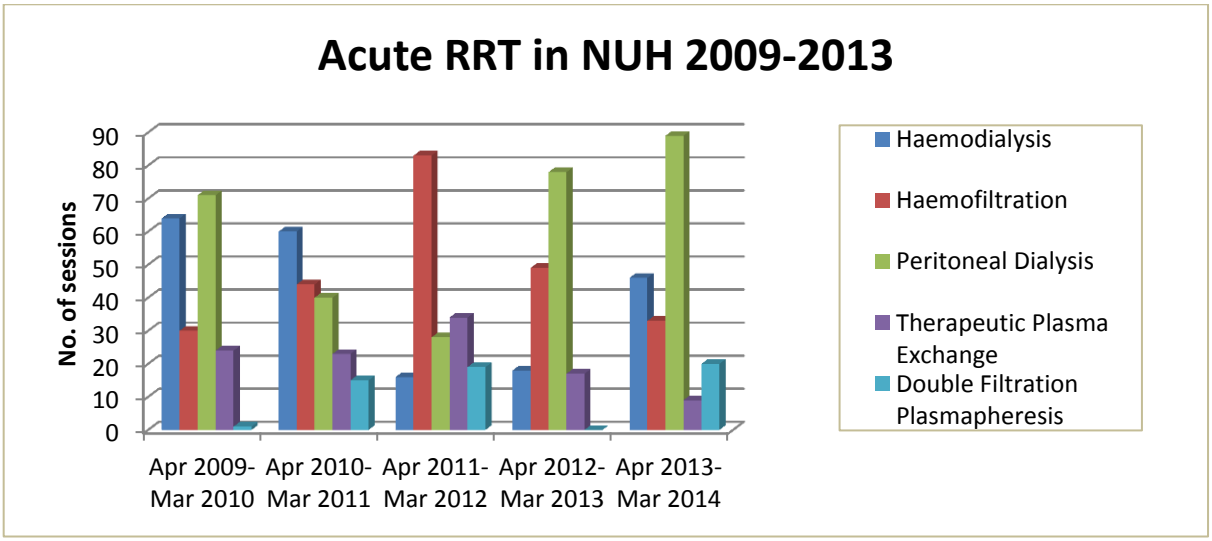
The Renal Critical Care Educator, Molly McLaughlin (0.8 WTE), provides specialist nursing support and education for staff caring for children within the regional PICUs covered by the EMEESY network. This includes Nottingham, Sheffield and Leicester (Glenfield and Leicester Royal Infirmary). Some support is also provided to Addenbrookes, but this is more as an in reach rather than outreach service.

Renal critical care education focuses mainly around Continuous Renal Replacement Therapies (CRRT). There are increasing numbers of children with acute kidney injury (AKI). requiring CRRT within PICU's, however the frequency and predictability of these treatments remains very varied. This means competence and confidence of PICU staff in delivering such specialised treatments can vary greatly. The renal critical care education support therefore aims to increase exposure to such treatments and improve their knowledge and practical skills through simulation, ad hoc bedside teaching, formal classroom teaching or study days and supervised practice when a patient is undergoing treatment.

ACTIVITY DURING 2013-14

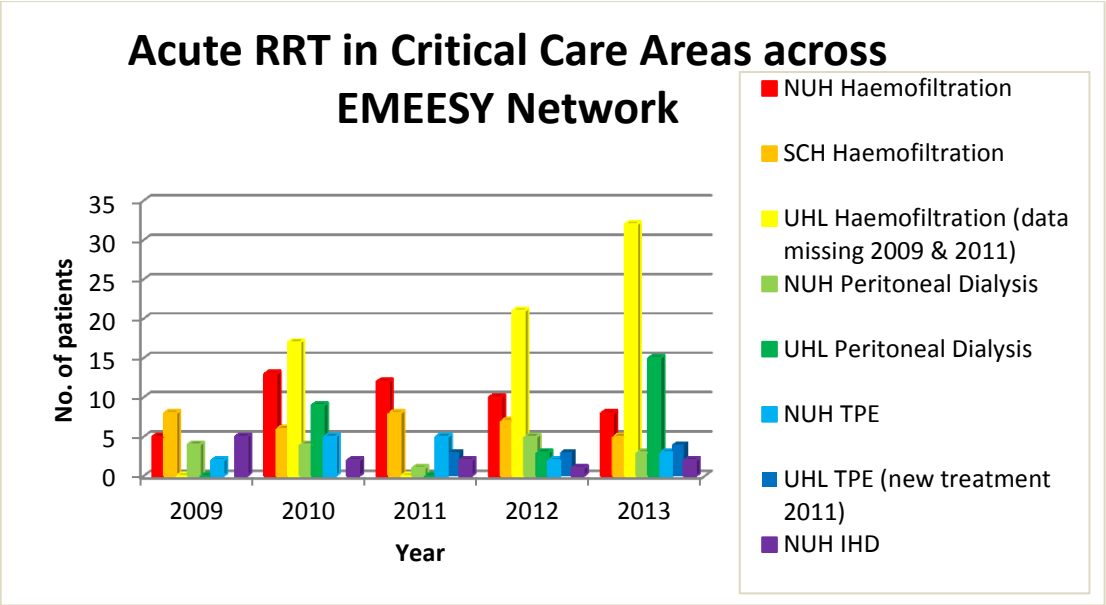
Seventeen patients received acute dialysis therapies within Nottingham Children's Hospital (8 had haemodialysis, 4 haemofiltration, 6 peritoneal dialysis, 2 plasma exchange and 3 double filtration plasmapheresis). These were either delivered on ward E17, PICU, PHDU or NICU.

The figure shows the number of sessions delivered in comparison with previous years (as haemofiltration is a continuous therapy 1 session is equal to 1 day of treatment).



Haemofiltration sessions have reduced whilst delivered sessions of peritoneal dialysis have increased over the last 2 years. In contrast, haemofiltration sessions have increased across

the EMEESY network as can be seen from the figure below. In particular haemofiltration in Leicester (solely at Glenfield Hospital) has increased markedly.



SIGNIFICANT ACHIEVEMENTS/INNOVATIONS

2013-14 has been a varied year across the network. Despite much work directed towards setting up a new service for continuous veno-venous haemofiltration (CVVH) at Leicester Royal Infirmary (LRI) PICU, the first patient was not treated until 2014. This has meant trying to ensure the skills and knowledge of nursing is maintained has proved quite demanding.

The demand for Therapeutic Plasma Exchange (TPE) for sepsis at Glenfield Hospital PICU continues to grow. Ensuring the core team of nurses were able to deliver this service at Glenfield Hospital was necessary to optimise service delivery, meaning an expansion of the initial team that had been set up in 2011. More work is planned for 2014 to consolidate the initial study day staff attended.

January 2014 saw the start of a new follow up pathway for all children who have received RRT for AKI within the regional PICU's. Now all children who fall within the EMEESY catchment area will be followed up for a minimum of 5 years following AKI within PICU.

More links with Addenbrookes Hospital were developed in 2013. The Renal Critical Care support extended to NICU to support the delivery of peritoneal dialysis, a treatment usually only delivered at NICU at NUH. Stronger links were also formed with PICU, with plans for 2014 to teach on their critical care course at Anglia Ruskin University and places on the Regional CVVH Simulation Day extended to staff here.

Sheffield PICU had a quieter year than usual from a CRRT perspective, but on the whole were a lot busier throughout the year. This meant maintaining skills, competence and confidence was even more challenging, as support to enable staff to attend formal study days was limited.

PUBLICATIONS/INVITED LECTURES

August 2013 – Taught on AKI and RRT, on Paediatric Critical Care Module at Sheffield Hallam University

September 2013 – Taught on AKI and RRT, on Paediatric Critical Care Module at De Montford University

24th September 2013 – Presented on 'Initiating TPE on PICU' at CRRT in PICU Conference at King's College Hospital London

November 2013 - Taught on Managing fluids in infants and children, AKI and RRT, on Paediatric Critical Care Module at University of Nottingham

Member of PICS Renal Sub Group

WORKPLAN FOR THE YEAR

LRI have just successfully treated their first patient on CVVH. This required a lot of renal critical care support and has highlighted some areas for future development through further education and training with plans to expand the initial team of nursing staff.

September 2014 – the first regional CVVH simulation study day in Nottingham.

Citrate anticoagulation will be explored further, with the possibility of developing guidelines/protocols and rolling this out at Nottingham Children's Hospital.

17. NETWORK MANAGEMENT

At the end of March 2013, we had completed a 5-month secondment project funded by a resilience grant from East Midlands Strategic Health Authority. During that time we demonstrated:

- That there were areas for quality development and cost savings with new shared care clinics
- That families paid a high price for regular travel to Nottingham in terms of the economic impact for them and the family disruption it caused
- That it is possible to develop local nursing and dietetic contacts

The organisational achievements of the secondment included:

- Organising a one-off multi-professional meeting
- Securing verbal agreements to establish 5 new shared-care clinics
- Establishing a network steering group, chaired by a specialist commissioner, to oversee governance of the network
- Setting up a Facebook site to be able to communicate with parents/patients

It was clear that more time was required to put into place many of the initial plans and we were grateful that Nottingham University Hospital Trust agreed to continue funding the secondments for a further 12 months through internal charitable funds.

In the last 12 months, we have built upon the achievements of the initial 5-month secondment to:

- Establish new shared-care clinics in six centres: Doncaster Royal Infirmary, Bassetlaw Hospital, Barnsley District General Hospital, Grantham District Hospital, West Suffolk Hospital (Bury St Edmonds) and James Paget University Hospital (Great Yarmouth).
- Develop multi-professional links with shared-care clinics with a Nottingham paediatric renal nurse accompanying the paediatric nephrologist for 2 clinics per year and a Nottingham dietitian attending yearly. These clinics are used to support local nurses/dietitians and encourage further links.
- Organise two further multi-professional education days, establishing a pattern of twice yearly events which are subsidised by pharmaceutical companies to provide low-cost education, particularly for non-medical staff.
- Launch a new website for the EMEESY children's kidney network which is aimed at staff, patients and parents to provide information on our services, guidelines for treatment of common conditions, dietetic, pharmacy and other resources for local professionals to download, and links to other sources of quality paediatric renal information.
- Engage with the national peer review department of NHS England to develop a peer review for paediatric renal services, sharing the experience of developing networks.
- Write an operational policy to describe the current services offered by the EMEESY children's kidney network, mapping this to the NHS England standard contract.

We recognise the need for a core central team to ensure that this network is sustainable. We have estimated that it will comprise: a full-time network administrator, 1-2 half-day sessions of lead consultant time, 2 days of central nurse time (including lead nurse time and

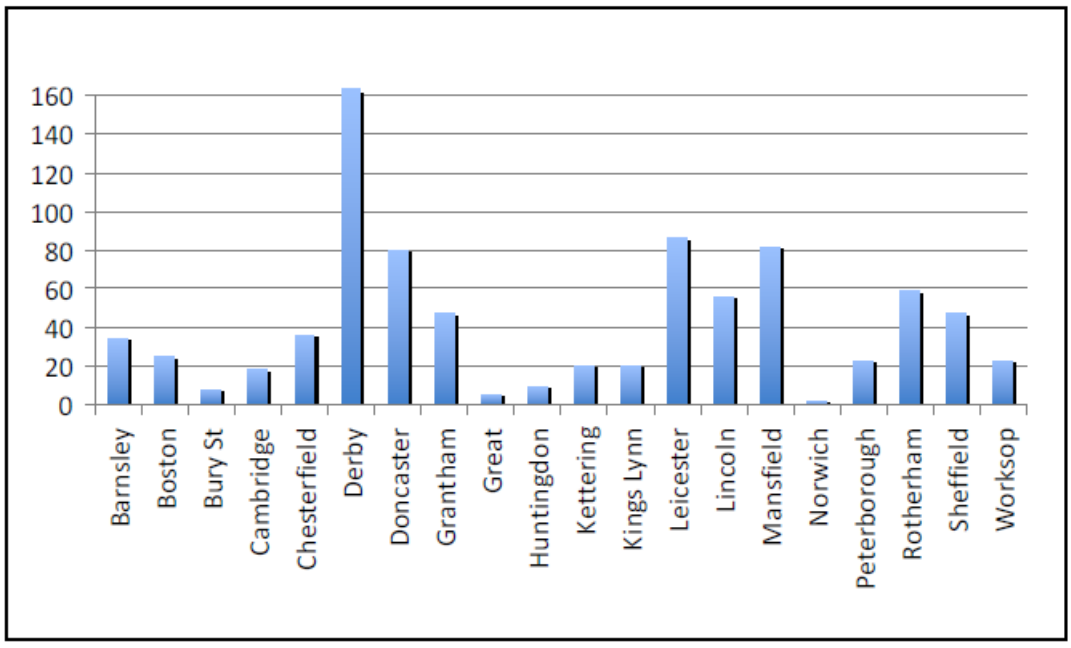
additional time for nurses to attend shared-care clinics) and around ½ day of additional dietetic time.

WORKPLAN FOR 2014-15

Over the next year, we aim to make robust business cases for long-term funding of this central infrastructure. The other elements of the network work plan for the next year include:

- Rolling out service level agreements for all new shared-care clinics and developing existing ones.
- Continuing to develop the work of the network steering group, particularly its role in governance of the network.
- Securing a shared-care clinic for Hinchingbrooke Hospital, the only local paediatric centre in the EMEESY region without one now.
- Developing the role of local paediatricians within the new and existing shared-care clinics, aiming to have a local paediatrician in attendance in each clinic.
- Aiming to increase the numbers of local nurses and dietitians attending educational events.
- Documenting patient pathways and agreeing these with commissioners.
- Working specifically with Sheffield and Leicester Children's Hospitals to develop paediatric nephrology services there.

In March, we learnt that NHS England support for new peer review projects had been withdrawn. We hope that work will resume at some point in the near future with a competitive application process for which paediatric nephrology has already made some preparation.



Data from the network secondment project showing numbers of children seen in Nottingham with a closer local hospital. We hope to use this as a crude metric towards continuing to work towards as many children as possible being seen in their local centres.

18. TRANSITION

Transition services have become a priority area for NHS England following the publication of the Quality Care Commission (CQC) report on transition services across the country. We have long-understood the consequences of poor transitioning of young people to adult services. We continue to champion transition with the appointment of a key worker for all young people with CKD who are approaching transition, specific transition clinics in the major centres and specific transition-focussed activities such as transition residentials or transition workshops.

ACTIVITY DURING 2013-14

Transition clinics took place twice yearly for Nottingham, Sheffield and Leicester patients with a multi-disciplinary team meeting prior to each clinic. For Sheffield and Leicester patients, one of these clinics took place in Nottingham and one in the unit to which the young people will transition.

19. EDUCATION AND TRAINING

Nursing Renal Education is supported by a part-time Paediatric Renal Nurse Educator, Diane Blyton, at 0.76 WTE, over three days per week.

On average one day (one third) per week is used to cover the haemodialysis unit. When the acute dialysis workload increases, this often increases. This can impact on available time to spend on educational activities.

EDUCATION DELIVERED

Two ward time out days were delivered in May-June 2013 with renal educational content. This enabled all nursing staff to attend one day for team building and updates in practice and EMEESY network.

All newly qualified nurses (9) commencing on E17 on their first rotation had a two-week supernumerary orientation period. This included a dedicated education day. This was not provided for every nurse rotating to the ward. These nurses will receive input on the Study days discussed below. Additional support provided as identified to staff on E17.

Two members of staff were trained to do Peritoneal Dialysis (PD) and most of the senior E17 nursing staff received a PD and central venous line update in 2013-14.

Teaching was provided for new staff on a Paediatric Critical Care study day.

Four Central Venous Access study days were provided, as planned for nursing staff across the Children's Hospital. Two additional sessions were provided for Paediatric Critical Care and the Children's Assessment unit. Ongoing support of assessment of practice is also provided.

The Paediatric Renal Nursing Team and Haemodialysis Unit officially became a spoke placement for nursing students. We received an excellent evaluation following this.

SIGNIFICANT ACHIEVEMENTS OF THE YEAR

The Proposed Paediatric Nephrology Distance learning module secured guaranteed funding of 10 places per year for 3 years from the Health Education East Midlands commissioners this year. This addresses a concern by the Education Provider involved, that there would not be sufficient students to make the module viable.

PUBLICATIONS/CONFERENCES

Diane Blyton and Shelley Jepson Renal Care in Infancy, Childhood and Early Adulthood

Chapter 12 in Renal Nursing. Fourth Edition (2014) Thomas, N. (Editor). Wiley Blackwell, Chichester.

The Paediatric Nephrology Nurses Annual Conference was hosted in Nottingham in March 2014. The nurse educator supported the development of the conference, assisted in the organisation on the day and chaired and facilitated discussion sessions on the day of the conference.

WORKPLAN 2014-15

Renal and Urology study days are planned for June 2014, to continue teaching away from the ward.
The aim is to provide teaching for staff away from the ward environment on an annual basis. These will be offered to other nurses within the Network if the programme is appropriate.

Complete work commenced on developing practice and education on ward E17 to enable patients requiring dopamine post transplantation to be nursed on E17.

Final work to be completed on the Paediatric Nephrology Module, to enable launch this academic year.

Develop e-learning options for on-going education of nurses within the renal service and EMEESY Network, at times when face-to-face education is challenging.

Continue to provide updates and training for extended roles for staff on E17.

20. AUDIT.

Audit is embedded as part of the clinical governance structures within Nottingham. It is being developed across our network as part of the evolving clinical governance of the network.

National audit data is submitted to the UK Renal Registry on all patients requiring dialysis or transplant. This has been reported and our results are comparable to other paediatric renal units in the UK. The reports may be viewed on the UK Renal Registry's website (www.renalreg.com).

Our outcome data regarding transplantation are also reported nationally as part of the NHSBT Kidney Advisory Group data. These data are presented in the form of one and five-year data on patient and graft survival. Although within the expected statistical variation our five year graft survival data is below the national average and will be the subject of an internal audit in 2014.

General audit of practice as part of the Nottingham Children's Hospital audit work plan including consent, medical records, infection control and prescribing are ongoing. These are regularly reported at the Children's Hospital audit and governance meetings.

Local audit is facilitated through regular audit and governance meetings. The focus of the audits includes growth and nutrition, anaemia, peritonitis rates, CVL infection rates and renal biopsy complications. Our aim this year is to develop an audit work plan.

21. PATIENT EXPERIENCE AND FEEDBACK

The EMEESY philosophy is to involve patients, parents and carers in the development, day-to-day delivery and evaluation of our service. A number of formal and informal communication methods have been used to ensure that patients and their families have access to information and opportunities to contribute to service delivery.

Shelley Jepson, Senior Paediatric Renal Nurse and PPI Lead

COMMUNICATION

Patients and families have access to the renal pager for 24 hour advice from the nursing staff. An average of 30 calls per week are managed. Patients are able to contact their consultant via secretarial staff and an appointment for call back can be arranged.

Renal Patient View is available to enable patients to view their blood results online from any computer. Many families currently use this facility.

The unit continues to link families of newly diagnosed patients with others to promote information sharing and peer support.

INFORMATION

The network website www.emeesykidney.nhs.uk was launched in March 2014. This was funded by the Kinder Appeal and is designed to provide information to young people, carers and parents as well as professional staff. Social networking has been successfully implemented. The EMEESY Facebook page has over 100 followers. Parents and carers regularly post news, comments and questions via this site. The network joined Twitter in January 2014 and has 10 followers to date.

INFORMATION EVENTS

"Nephrotic Natter": Information day for families with a child with nephrotic syndrome. 10 families attended.

Transplant information day: Event to raise awareness of issues around transplantation. 15 families attended.

PATIENT AND CARER INVOLVEMENT

Three parents have volunteered to join the EMEESY steering group as user representatives. None were able to attend the January meeting however feedback via meeting minutes and discussion was provided. A separate parent feedback meeting will be arranged after future steering group events.

WORK PLAN

- Quarterly review and update of EMEESY website
- Bi-annual steering group feedback for parents
- Information events for transplantation, nephrotic syndrome and transition
- Involve patients and carers in development of new information resources
- Support families to attend transplant games

22. RESEARCH

Research is considered a core part of the clinical care that is delivered in Nottingham and across the Network. At Nottingham and within EMEESY we have a good track record of involvement in multi-centre clinic research.

Dr Andy Lunn, Research Lead for Paediatric Nephrology at Nottingham Children's Hospital

WORKFORCE

Currently there is 1 WTE research nurse within the Clinical Research Network (CRN) who is employed to facilitate the research work in Nottingham and a second nurse working 0.5 WTE in research specifically within the department (appointed in January 2014). Other members of the clinical team in Nottingham are also involved in research according to the requirement of active studies at that time. There is 1 PA of consultant time, supported by the CRN, which is divided between the 5 consultants. This includes one consultant, Dr Andy Lunn, who is a member of the British Association for Paediatric Nephrology / CRN clinical studies group.

RESEARCH ACTIVITY

The research activity is divided between commercial studies and non-commercial studies supported by NIHR funding. All research is conducted ethically approved and performed according to Good Clinical Practice standards and guidelines. Details of current studies and numbers of recruited patients are shown in the tables below.

The intention of the British Association for Paediatric Nephrology / MCRN clinical studies group, and shared by our network, is to work towards being able to offer every patient the opportunity to be involved in research.

Paediatric nephrologists and the CRN team support multi-centre studies in other local centres, such as the PREDNOS and PREDNOS 2 studies of nephrotic syndrome, where patients need to be identified and recruited in general paediatric centres.

REGISTRY STUDIES

Study Name	Summary	Contact
aHUS Eculizumab Regsitry	Registry based study of aHUS NB –links with RaDaR aHUS registry	Jonathan Evans Olivia Silkstone
RaDaR	**Ra**re Renal **D**ise**a**se **R**egistry	Martin Christian Kate Baker

COMMERCIAL STUDIES

Study Name	Summary	Recruitment **actual (target)**	Contact
CRADLE	Unblinded RCT of Everolimus, low dose tac and steroid withdrawl vs standard pred, tac and MMF. Consent at transplant, randomise at 4-6 weeks after transplant.	6 (5)	Martin Christian Lindsay Crate
CONNECT MCI-196-E14	Unblinded, randomised dosing, safety and efficacy study of Colestilan (phosphate binder) in dialysis patients. Screening, washout then 17 weeks of fixed dose randomised to calcium carbonate (control), low, medium or high dose Colestilan.	0 (2)	Andy Lunn Olivia Silkstone
CONNECT MCI-196-E15	Variable Colestilan dose extension of above study.	0 (2)	Andy Lunn Olivia Silkstone
aHUS Eculizumab	Open label trial of eculizumab in aHUS	2 (1) Study complete	Jonathan Evans Olivia Silkstone

NON-COMMERCIAL STUDIES

Study Name	Summary	Recruitment **(target)**	Contact
Genetic basis of renal tract abnormalities	Genetic study – one blood test, clinical proforma recording medical history and data collection sheet. Study also recruiting parents of affected children.	20 (20)	Andy Lunn Olivia Silkstone
PREDNOS	Blinded placebo controlled RCT of short versus long course of steroids for initial treatment of nephrotic syndrome.	8 (6)	Andy Lunn Anna Frost
PREDNOS 2	Blinded placebo controlled RCT of 6 days of 15mg/m^2 prednisolone at time of URTI to prevent nephrotic relapses.	5 (6)	Martin Christian Olivia Silkstone
HOTKID	An unblinded randomised trial of standard (50-75th centile) vs aggressive (<40th centile) control of blood pressure in patients with CKD.	6 (5)	Andy Lunn Olivia Silkstone
RaDaR – SRNS	Genetic and steroid response study in patients with steroid resistant nephrotic syndrome. Requires one blood test.		Martin Christian Kate Baker
RaDaR - MPGN	Genetic and immune system testing in patients with MPGN. Requires one blood test every 6 – 12 months.		Martin Christian Kate Baker