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

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

Annual Report 2015-16
www.emeesykidney.nhs.uk
Children’s Kidney Network for the East Midlands, East of England and South Yorkshire

Annual Report 2015-16

Network base: Nottingham Children’s Hospital
            QMC Campus
            Nottingham University Hospitals NHS Trust
            Derby Road
            Nottingham
            NG7 2UH

Direct Line: 0115 970 9420
Renal nurse pager: 07659 598269
Fax: 0115 970 9419

www.emeesykidney.nhs.uk
## CONTENTS

1. Introduction .................................................................................................................. 4
2. Staffing .......................................................................................................................... 6
3. Activity at Nottingham Children’s Hospital ................................................................. 9
4. Network management .................................................................................................. 11
5. Activity in local centres .............................................................................................. 13
6. Chronic dialysis ........................................................................................................... 14
7. Transplantation ............................................................................................................ 17
8. Chronic kidney disease ............................................................................................... 20
9. Nephrotic syndrome .................................................................................................... 21
10. Antenatal services ....................................................................................................... 22
11. Urology ....................................................................................................................... 23
12. Urology nursing .......................................................................................................... 25
13. Pharmacy .................................................................................................................... 29
14. Dietetics ....................................................................................................................... 30
15. Social work .................................................................................................................. 33
16. Play ............................................................................................................................... 35
17. Youth work .................................................................................................................. 37
18. Psychology ................................................................................................................... 40
19. Critical care support .................................................................................................... 41
20. Transition .................................................................................................................... 43
21. Education and training ............................................................................................... 44
22. Clinical governance and audit ................................................................................... 47
23. Patient experience and feedback ............................................................................... 50
24. Research ...................................................................................................................... 53
25. Awards, selected publications and external activity .................................................... 55
26. Workplan ...................................................................................................................... 56
1. **INTRODUCTION**

In 2015-16, we have continued to develop structures for the EMEESY children’s kidney network. Numbers of children seen in local shared-care clinics increased significantly whilst numbers of children seen in Nottingham remained stable. We now see over a third of our patients in clinics close to their home.

Some notable achievements for 2015-16 include our first ABO incompatible transplant and purchase of equipment to start training parents for home haemodialysis. In this we have achieved two outstanding items within the national service contract.

We are also delighted with the success of the Transplant Games team, both the medals that come back each year but the growing size of the team too. The event is gathering momentum; we hope that an increasing number of children attending each year will give children a better self-esteem and impart a desire to succeed. We also hope that the event will lead to stronger peer support amongst families.

Changing the format of the transplant information day to a family fun day at Conkers in November last year was an attempt to help develop peer support. Great fun was had by all as you can read in the PPI section below and many links were established between “expert” parents and those at the start of their renal failure journeys. Information was shared in a relaxed environment and the day was related as a success by all who attended. I am very grateful to all my colleagues who gave up a Saturday to help organise the day and very grateful for the support from The Kinder Appeal, without whom such events would not be possible.

We have commenced working more closely with Leicester Children’s Hospital following the retirement of Peter Houtman in August last year. A new post to replace him has been approved as a network position so that more than one consultant from Nottingham can increase working in Leicester. Dr Sudarsana De, well known to us from covering maternity leave recently, commenced in May 2016. A challenge for the next year will be to secure a substantive business case for that post. We also want to develop multi-disciplinary working in Leicester, both with closer working with the paediatric urologists there and other paediatricians, but also by establishing closer links with the multi-professional team.

This year has seen long-term staff retire: Angela Thomson retired after many years as a ward staff nurse then haemodialysis nurse; Ian Buchan after 24 years of service on the haemodialysis unit; Denise Martin after 30 years as the family care co-ordinator and Debbie Hiley after 35 years on the ward. We are enormously grateful to the years of service these individuals have given. We have also had new members of staff join the team: we welcome Lyn Hopkinson as a new social work colleague and JJ Kim as a new consultant paediatric nephrologist. Terrence Green (youth worker) and Charlotte Evans (nursery nurse) have joined on 12 month contracts supported by charitable funds; Ruth Prigg has re-joined the team to support dietetics during Pearl Pugh’s sabbatical year.
Continuing the staff theme, we were very proud that our Transplant Clinical Nurse Specialist, Kim Helm, won the overall Nurse of the Year last year and had a tram named in her honour. In this year’s awards, Danielle Barnes, Healthcare Assistant on Ward E17 was nominated for her unfailing cheerfulness and helpfulness around the ward and Haemodialysis Unit. We’re very proud that she won the Healthcare Assistant of the Year!

EMEESY has been in the news several times through the year: as well as media coverage of Transplant Games and the Family Fun Day, Claire Hardy, our senior play specialist was interviewed on Radio Nottingham running up to Christmas and again on Christmas Day itself by Claire Balding on Radio 2. It was a surreal experience for me, arriving at work on Christmas Day as the on-call consultant to hear one of my team being interviewed on national radio!

Day case figures have been difficult to obtain this year but we recognise that day case and ward attender patients put a heavy demand on the in-patient ward at Nottingham Children’s Hospital. Discussions are on-going about a dedicated daycare unit.

That remains on the workplan for 2016-17. Our priority challenges for the year ahead are in establishing secure funding for posts where we have just temporary or charitable funding for now, including the youth worker, nursery nurse, network administrator and Leicester partnership consultant.

I would also like thank my colleagues for helping compile our annual report, particularly Judith Hayes in her new role as Network Administrator, who has helped assemble it all this year.

Martin Christian
Lead Consultant for Paediatric Nephrology
Network Lead for EMEESY Children’s Kidney Network
martin.christian@nuh.nhs.uk
July 2016
2. STAFFING

MEDICAL STAFF

CONSULTANT PAEDIATRIC NEPHROLOGISTS

Dr Jonathan Evans (Divisional Director for Family Health 0.5 WTE)
Dr Farida Hussain
Dr Martin Christian (lead consultant and network lead)
Dr Meeta Mallik (maternity leave from March 2016)
Dr Andrew Lunn
Dr Jon Jin Kim (From January 2016)

TRAINEES

National grid trainee: Dr Hitesh Prajapati (August 2013 – February 2016)
National grid trainee: Dr Drew Maxted (from August 2015)
Special interest in nephrology (SPIN) trainee: Tina Thekkekkara (February – July 2016)
There are 2 junior trainees attached to the ward at any one time for 4-6 months.

CONSULTANT PAEDIATRIC UROLOGISTS

Mr Manoj Shenoy (Clinical Service Unit Chair for surgery, nephrology, gastroenterology)
Mr Alun Williams (transplantation and paediatric urology)
Mrs Nia Fraser
Mr Bharat More

TRAINEES

National grid trainee: Mr Paul Jackson (until January 2016)
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
Transplant recipient coordinator: Kate Taylor
Anne Theakstone and Karen Stopper are the live donor coordinators.

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 (maternity leave from February 2016)
- Renal Nurses: Kate Baker (CKD), Sharon Mould (Dialysis), Monique Burgin (Nephrotic)
- Renal Nurse Assistant: Anisah Hussain

**HAEMODIALYSIS TEAM**
- Junior Charge Nurses: David Cooper (until Jan 2016). Nichola Hughes (from Jan 2016)
- Ian Buchan retired after 24 years with the haemodialysis team
- Staff Nurses: Angela Thomson, Helen Bolam and Frankie Wells
- Haemodialysis support worker: Danielle Barnes

**UROLOGY TEAM**
- Clinical Nurse Specialist: Christine Rhodes
- Urology Nurses: Gill Young, Emma Gamble and Caroline Ward

**WARD E17**
- Ward Manager: Michelle Kirkland

**DIETETICS**
- Pearl Pugh (university secondment from September 2015), Emma Kelly and Ruth Prigg.

**PSYCHOSOCIAL TEAM**

**SOCIAL WORK**
- Suzanne Batte (0.5 WTE). Lyn Hopkinson (0.5 WTE) joined the team in November 2015

**PSYCHOLOGIST**
- Dr Kathryn Bradley provides a referral-based support service.

**PLAY**
- Play specialist: Claire Hardy
- BKPA nursery nurse: Charlotte Evans joined in October 2015. This post is kindly supported by the BKPA for one year
YOUTH WORK

Terrence Green joined the team as Youth Development worker in August 2015. This post is funded by the Kinder Appeal. 1.0 WTE youth work support from the whole youth work team is now available.

ADMINISTRATIVE AND SECRETARIAL STAFF

Team leader and network administrator: Judith Hayes
Other secretaries: Sandie McLauchlan and Vicky Cancemi (both urology) and Jodie Claydon (nephrology; maternity leave from March 2016)
Ward receptionist: Sue Averill
Ward administrator: Diane Walker (0.5 WTE)

PHARMACY

Paediatric renal pharmacist: Peter Foxon, supported by See Mun Wong (home delivery services)

EDUCATION

Teachers: Karine Williams, Craig Matthews and Jenny Collins

MANAGEMENT

General Manager for Family Health: Fiona Lennon
Assistant General Manager: Jane Walker
Head Nurse for Children’s Services: Dorothy Bean
Deputy Clinical Lead: Jamie Crew
Matrons: Rachel Barker and Kerry Webb

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 bay each week.
3. ACTIVITY AT NOTTINGHAM CHILDREN’S HOSPITAL

3A. WARD ACTIVITY

During 2014-15, there were 419 admissions under nephrology and 351 admissions under urology. Day case and ward attender activity was recorded separately this year.

3B. RENAL BIOPSIES

A total of 49 biopsies were done during the year, 30 native and 19 transplant. This is down on last year’s number. 78% of these biopsies were done as a daycase procedure. The national standard of up to 3 cores in 80% of cases was met and this provided adequate material in 100% of cases. Three children (6%) had minor complications requiring a delay in discharge or return to the ward. The national standard for this is 5%.

In 2014-15, the national renal biopsy audit, which was led by Farida Hussain was repeated and has now been published.

3C. ACUTE KIDNEY INJURY

The Children’s Renal and Urology Unit provides all modalities of acute renal replacement therapy (RRT) on an intermittent or continuous basis and works closely with PICU, PHDU and NICU to deliver these treatments. From April 2015 to March 2016, 10 patients received acute dialysis therapies at Nottingham Children’s Hospital (3 had haemodialysis, 8 haemofiltration, 3 peritoneal dialysis, 2 plasma exchange). These were either delivered on E17, PICU, PHDU or NICU.

Patients with AKI who have not required renal replacement therapy are managed throughout the network: of these patients, 13 were recorded on Ward E17 at NUH, 9 patients throughout Nottingham Children’s Hospital and Neonatal Intensive Care and 16 patients throughout the EMEESY network. This is likely to be an under-estimate because of the lack of a robust system of data collection. With the introduction of mandatory AKI reporting nationally numbers are likely to increase further and we therefore have plans for a more formal network-wide reporting system next year.

3D. OUT-PATIENT ACTIVITY

For nephrology clinics in Nottingham during 2015-16, there were 377 new patients seen and 2371 follow-up patients.
Overall numbers are similar to last year: the number of new patients increased by 11% whilst there was a fall in follow-up appointments of 5%. Overall the difference was -3%. In the last year we recorded haemodialysis reviews for the first time and 14 of these were recorded within the CKD clinic figures. These take the place of an additional clinic for children on haemodialysis already attending at least three times weekly who would otherwise require an additional clinic appointment.

The breakdown into different types of clinic is as shown in the table below with last year’s figures in brackets:

<table>
<thead>
<tr>
<th></th>
<th>New</th>
<th>Follow-up</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All general clinics</td>
<td>285 (271)</td>
<td>766 (893)</td>
<td>1164 (1419)</td>
</tr>
<tr>
<td>All CKD clinics</td>
<td>64 (50)</td>
<td>1477 (1521)</td>
<td>1541 (1571)</td>
</tr>
<tr>
<td>Enuresis clinic</td>
<td>28 (19)</td>
<td>70 (57)</td>
<td>98 (76)</td>
</tr>
<tr>
<td>Renal-endocrine</td>
<td>0 (0)</td>
<td>23 (17)</td>
<td>23 (17)</td>
</tr>
<tr>
<td>Transition clinics</td>
<td>0 (0)</td>
<td>35 (10)</td>
<td>35 (10)</td>
</tr>
</tbody>
</table>

The overall non-attendance (DNA) rate for Nottingham remains unacceptably high at 20% and this has not changed from last year. We will investigate how text reminders are sent out.

Telephone clinics continue to be recorded in shadow form but the activity is not yet recognised by commissioners.
4. NETWORK MANAGEMENT

NETWORK STEERING GROUP

Management aspects to the network were quiet during 2015-16. The network steering group met by teleconference in September 2016. During this year, specialised commissioners agreed the funding for a 12-month network administrator post. Following a recruitment process and competitive interview, Judith Hayes was appointed to be seconded from her current position into this role with a plan to start in June 2016. Plans for the role include administration of the network steering group and we hope to be able to convene regular meetings from this point onwards.

NETWORK ADMINISTRATOR

The other aspects of the network administrator role include co-ordination of the shared-care clinics. This in turn includes liaising to book patients onto clinic, importing electronic clinic letters into Nottingham digital health record as well as booking the clinic dates. There is also a need for administrative support to co-ordinate consultant service delivery between on-call activity, local clinics and shared-care clinics.

Judith will be responsible for updating the EMEESY website regularly and organising the twice yearly educational meetings.

PARTNERSHIP WORKING WITH LEICESTER

Negotiations with Leicester Children’s Hospital for an EMEESY consultant appointment to replace Dr Peter Houtman following his retirement in August last year resulted in the agreement to a 12-month locum consultant post to allow partnership working between Leicester and Nottingham which would help develop specialised renal services at the Leicester site. This post was filled with an appointment in April 2016 with Dr Sudarsana De due to start in May 2016.

WEBSITE

The EMEESY website continues to attract a large number of hits each month. We have continued our relationship with Volute, the website designers with the Kinder charity funding an annual website budget that allows for a 4-monthly review meeting with Volute. This year has seen the addition of a glossary on the website. The adjacent figure shows how an underlined word – “dialysis” in this
case – brings up a lightbox to define it. The A-Z glossary can be accessed from the main left hand menu and we plan to encourage families to use this as they read medical letters.

The other main addition was an on-line booking form for the education meetings. On-line payments continue to prove problematic but we intend to relook at that during 2016-17.

WORKPLAN FOR 2016-17

There are a number of network posts for which we require long-term sustainable funding and these will be our top priority for 2016-17. The posts are:

- Network administrator
- Youth development worker
- Consultant paediatric nephrologist to support Leicester service
- Adequate dietetic support
- Nursery nurse

We will continue to work with specialised commissioners towards a coherent funding for the network, including appropriately costed tariffs and appropriately written service level agreements for shared-care clinics that allow the network to develop according to the health needs of the population.

With the support of a network administrator, we plan to support the development of IT links that allow visiting paediatric nephrologists to access Nottingham IT systems when they are in local centres and to access local results when back in Nottingham.

With a network steering group meeting more regularly, we plan to develop patient experience outcome measures for local clinics and look at useful clinical outcome measures. We also plan to trial network-based audit.

A word picture constructed from parents’ feedback about the renal clinic at James Paget University Hospital in Great Yarmouth
5. **ACTIVITY IN LOCAL CENTRES**

2015-16 has been a year of consolidation of newly-established clinics. We have continued to take specialist nurses to clinics, aiming for two visits per centre each year. Dietetic provision continues to be problematic, both in identifying local support available and in providing centralised care provision and support.

In local centres where there is a local nephrology-interest paediatrician (“SPIN”) in post, there have been more developments of arrangements for local clinics and shared-care working arrangements. A number of centres are now arranging blood tests ahead of clinic so that results can be discussed during the clinic rather than by letter or phone call afterwards.

**ACTIVITY DURING 2015-16**

Numbers of children seen in shared-care clinics continued to grow in 2015-16 as can be seen above. There was a 27% growth in numbers compared to 2014-15 and nearly 100% growth from 2010. This means that that over a third of out-patient consultations now take place outside Nottingham. The figure for 2013-14 was 22% so EMEESY is delivering on its aim to provide quality care close to home.

**WORKPLAN FOR 2016-17**

Plans for revising all service-level agreements have been difficult to realise but remain on the workplan for the forthcoming year. We continue to develop service in individual centres through sharing of best practice. Pre-clinic blood tests and IT links will be a particular focus of developments this year.
6. 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 acute kidney injury (AKI) and chronic kidney disease (CKD). In addition, the haemodialysis unit staff provide apheresis therapies which are used to treat a variety of renal and non-renal diseases in acute and chronic settings. 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 19 (Critical Care Support).

Roy Connell, Clinical Nurse Specialist for Paediatric Dialysis

HAEMODIALYSIS

CURRENT WORKFORCE:

Staffing in the haemodialysis unit has undergone a few changes over the last 12 months but overall remains at 3.4 WTE dedicated registered nurses (two band 6 nurses (1.4 WTE) reduced to one over the year (0.6 WTE) and four band 5 nurses (2.8 WTE). It is managed by the Clinical Nurse Specialist.

Staffing requirements fluctuate between 3.0 and 6.0 WTE. The staffing gap is filled by regular input from all of the specialist renal nurses. This enables staffing numbers to be efficiently managed, and the team to maintain their skills for on call purposes. However, this can impact on others roles if the requirement is ongoing.

ACTIVITY 2015-16

A total of 22 patients received haemodialysis as a chronic treatment over the last year (129 patient months). Overall the patient number is relatively high compared to previous years but the total number of sessions delivered has been more modest. Only 5 of the patients attended haemodialysis for the whole 12 months. The number of patient sessions during this period was 1488.

The age range of children receiving haemodialysis was between 2 and 20 years. Five patients were aged less than 5 years, with one requiring dialysis 5 days per week. Children aged less
than 5 require more intensive nursing care whilst dialysing and this can add greatly to the workload in the unit.

Activity compared to recent years is shown below:

<table>
<thead>
<tr>
<th>Year</th>
<th>Total patient number</th>
<th>Patients under 5</th>
<th>Number of sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015-16</td>
<td>22</td>
<td>5</td>
<td>1488</td>
</tr>
<tr>
<td>2014-15</td>
<td>15</td>
<td>6</td>
<td>1736</td>
</tr>
<tr>
<td>2013-14</td>
<td>15</td>
<td>4</td>
<td>1447</td>
</tr>
<tr>
<td>2012-13</td>
<td>22</td>
<td>7</td>
<td>1771</td>
</tr>
</tbody>
</table>

Patient movement during 2015/16 has seen:
- 5 patients transplanted
- 3 patients transferred to other units
- 3 patients converted to PD

**WORK-PLAN FOR THE NEXT YEAR:**

The launch of the new renal computer was delayed until February 2015 so plans to integrate ‘real-time’ electronic recording of dialysis sessions will remain on the workplan for 2016-17. We plan to develop the home haemodialysis service and training of the first patient (a charity funded machine has now been purchased to enable staff and family training)

**PERITONEAL DIALYSIS**

**CURRENT WORKFORCE:**

The day to day management of the peritoneal dialysis programme is undertaken by a Band 6 Renal Nurse (1.0 WTE), Sharon Mould (pictured) and overseen by a Clinical Nurse Specialist (1.0 WTE). Alongside the PD programme, the Renal Nurse has a regular haemodialysis commitment.

The CNS is also responsible for:
- Management of the haemodialysis programme.
- Setting up of the home haemodialysis service
- Apheresis programme
- Ambulatory blood pressure monitoring

**ACTIVITY 2015-16**

Fifteen patients received peritoneal dialysis over the last year (125 patient months) giving a similar workload to that seen in the previous three years. Seven families were trained to
undertake peritoneal dialysis at home. These annual numbers are variable. 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.

<table>
<thead>
<tr>
<th>Year</th>
<th>Total patient number</th>
<th>Number of families trained</th>
<th>Incidence of peritonitis</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015-16</td>
<td>15</td>
<td>7</td>
<td>1 in 18 months</td>
</tr>
<tr>
<td>2014-15</td>
<td>13</td>
<td>5</td>
<td>1 in 26 months</td>
</tr>
<tr>
<td>2013-14</td>
<td>15</td>
<td>5</td>
<td>1 in 18 months</td>
</tr>
<tr>
<td>2012-13</td>
<td>18</td>
<td>12</td>
<td>1 in 18 months</td>
</tr>
</tbody>
</table>

There were 7 episodes of peritonitis giving an incidence of 1 in 18 patient months. The unit’s 5-year peritonitis rate is 1 in 19 patient months which meets the recommended Renal Association standard of 1 in 14 patient months. Just under half (46%) of the PD patients were aged less than 5 years during 2015/16 and therefore fall in the higher risk category for infections.

Patient movement during 2013/14 has seen:
- 3 patients transplanted
- 1 patient converted to haemodialysis.
- 11 patients remained on the PD programme.

**WORK-PLAN FOR THE NEXT YEAR**
- Review the home therapies strategy and training
- Introduce the new *Homechoice Claria* to appropriate 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.

Apheresis is a service that may be quiet for long periods unless there are long-term patients as has occurred in recent years. There were no long-term patients during 2015-16. Only two sessions of acute double-filtration plasmapheresis were delivered in 2015 but these represented an important landmark for the unit as they were pre-treatment prior to subsequently successful ABO incompatible transplant.
7. 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
Nottingham Nurse of the Year (Children’s and Overall Winner) 2015

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) who is responsible for chronic kidney disease but within this includes work-up for transplantation. 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 2015-16

The unit performed 13 transplants, a substantial increase on last year’s activity. At the end of the year there were 8 patients active on the national list with a further 2 suspended. The lower number on the active waiting list for a year is because of increased numbers of patients having had live donor transplants that are not on the waiting list. We did an ABO blood group incompatible (ABOi) living donor transplant for the first time this year. These are more complex transplants with children often needing more involved preparation before the transplant and more intensive surveillance after. The patient continues to do well.

<table>
<thead>
<tr>
<th>Source of donor</th>
<th>2015-16</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living donor</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Deceased donor</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Altruistic donor</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

The number of living donors has remained the same. We recognise the need to present parents with the option of living donor transplantation at an early stage. Developments this year are discussed below.

<table>
<thead>
<tr>
<th>Previous treatment</th>
<th>2015-16</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-emptive</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Haemodialysis</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Pre-emptive transplantation is our aim where possible. In the last year only four patients (31%) were transplanted pre-emptively. Of the nine children who did not have a pre-emptive transplant, six children had absolute reasons why dialysis was needed first, such as a late presentation in advanced CKD or a need for dialysis before they were big enough to
receive a kidney transplant. We also share the care of two patients who in the last year have had combined liver and kidney transplants at Birmingham.

Post-transplant, patients are nursed either on the ward, PICU (if <15 kg) or PHDU (if 15-20 kg). However, due to staffing constraints on ward E17 to provide the 1:1 nursing required for the first 48 hours, most children go to PICU or PHDU. 11 were nursed on PICU and 2 on the ward.

A total of 91 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 78 patients under active follow-up (79 at the end of March 2015). Most patients are followed in Nottingham clinics. Those with stable graft function receive their follow-up in local shared-care clinics; most of these children return to Nottingham for an annual appointment.

One patient moved to a different centre and one patient returned to haemodialysis.

Patients transition to adult centres within EMEESY. This year, 4 have transitioned to Nottingham, 4 to Sheffield, 2 to Cambridge and 1 to Hull. In Nottingham, we try to ensure that young people have at least two visits to the transition clinic before transferring. This process has now been set up in Sheffield and Leicester. Kim Helm has attended transition clinics throughout EMEESY (total of 8 clinics) followed by transition clinics in Nottingham.

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 10 such clinics including transition clinics this year. This can be combined with updates for the families which can be carried in the clinic, saving on several home visits.

Following the success of transplant information day, we decided to combine an information day with a Christmas theme and promoting Transplant Games. This took place at Conkers in Leicestershire. The meeting was well attended and positive feedback was given by the families. The families had opportunity to meet with other families throughout the region, both pre and post-transplant.

Home visits are an essential part of our standard of care. This year, these included 8 home visits, 11 school visits and 5 Team Around the Child (TAC) 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 felt that a 3month interval was too long for these discussions so we set up interim meetings. This year we have now replaced this with the live donor coordinator attending a twice monthly clinic. We found that twice a month did not get many patients so it was then changed to monthly. We feel this has made a real difference to the number of live donors coming forward and an increase in numbers.
Kim Helm has attended regular meetings and conferences on nephrology, transplantation, transition and multi-cultural issues.

**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 patient’s journey than before. With new input monthly from the live donor coordinators we hope this will reflect in our live donor numbers next year.

We also plan to continue promoting living donor paired and pooled donation along with ABOi donation. Following on from the first ABOi there is a potential to do a further two patients next year.

Last year we planned to develop the concept of a transplant annual review to ensure all patients have a once a year overview of their transplant function and health. Unfortunately this was difficult to achieve with an increase in workload but it remains on the workforce plan.

**TRANSPLANT GAMES 2015**

Nottingham Children’s Team again fielded a team of nine competitors at the Transplant Games in Newcastle in 2015. Of the nine children and young people taking part we had a record 23 medals!

We are extremely proud of our athletes!

Once again Declan Bennett achieved five gold, one bronze and one silver. He also competed in the World transplant in Argentina and tallied up seven gold medals and three personal best times! Once again huge thanks to Kate Frost along with Kim Helm managing the team in Newcastle. Sadly Kate will be giving up the role of manager now she has left the trust.

Thanks also goes to the NUH Hospital Charity (Kinder Appeal) and British Kidney Patients’ Association for providing financial support for the Nottingham Children’s team – we could not do the games without their help.

We are hoping for an even bigger team in 2016 in Liverpool!
8. CHRONIC KIDNEY DISEASE

WORKFORCE

There is one (0.85 WTE) chronic kidney disease (CKD) specialist nurse who supports patients and families through all stages of CKD and works alongside the nephrologists and transplant nurse to complete the transplant work-up process so they can be activated on the national transplant list. She then cares for patients until the point of either transplant or the start of dialysis.

*CKD specialist nurse, Kate Baker*

**ACTIVITY 2015-16**

Home visits are a vital part of the CKD nurse role. A total of 23 (20) home visits were carried out: 5 (8) school visits, 2 (2) MDT meetings and 7 school reviews. Figures for 2014-15 are shown in brackets.

Part of the work up process for transplantation involves a CKD assessment day co-ordinated by the CKD specialist nurse. This involves the patient and family attending the hospital for a whole day to meet all the members of the multidisciplinary team to discuss dialysis and transplantation in detail. Seven CKD assessment days took place this year (3 in 2014-15).

The CKD nurse attends the majority of the 3-monthly transplant meetings at the City Hospital to discuss the paediatric patients on/awaiting activation on the national transplant list.

Many of the CKD patients are seen in Nottingham and in shared-care clinics at their local hospital as part of our growing EMEESY network. Part of the workforce plan for 2014-15 was to continue to attend as many of these clinics as possible. The CKD nurse has attended 5 of these outreach clinics.

**TRAINING, RESEARCH AND TEACHING**

Kate is now completing her Masters in Health Communication with her dissertation looking at the value of copy letters to patients.

**WORK PLAN FOR THE NEXT YEAR**

- Aim to get all the patients transplant work-ups onto the renal computer EMED so that they are more easily accessed and updated. So far this has not been achieved due to the introduction of DHR. Aiming to find a more effective way to record this information on the new systems.
- To continue attending shared care clinics especially Leicester as this is where many of our CKD patients are seen.
  To continue working on starting the vaccination process earlier in the patients’ treatment so this doesn’t delay their activation on the national transplant list.
9. Nephrotic Syndrome

Nephrotic syndrome is relatively rare in the general population but forms a large part of workload for a children’s renal unit. Parents often need to be able to phone someone at times of a relapse of the condition for advice about medication. Many of the calls we receive through the nurse pager are for children with nephrotic syndrome.

Monique Burgin, Paediatric Nephrology Specialist Nurse

WORKFORCE:

There is one 1 WTE, band 6 nephrotic nurse specialist, Monique Burgin. Monique provides education and support for patients and their families, alongside our nephrologists and local teams, to deliver safe care as close to the patients home as possible.

Monique also oversees and supports our patients with aHUS, all of which have now successfully stopped eculizumab in 2015 and are under the close monitoring of bloods with the help of community nurses.

ACTIVITY:

Nephrotic syndrome is a chronic condition, but in which the level of involvement varies greatly depending on each patient. We currently have around 150 nephrotic patients across the EMEESY network. Many of our patients are now seen at their local clinic, meaning a shift in how patients are reviewed and followed up. Monique continues to work closely with these families whilst in relapse, reviewing and monitoring them over the phone and referring to local hospitals if needed. Attending the EMEESY outreach clinics becomes ever more important not to lose contact with these families and meet local teams to help assess patients and increase confidence in our families when being reviewed, at times of a relapse.

This year we have had 5 newly diagnosed nephrotic patients, requiring a review in Nottingham. Monique has also overseen 65 patients during their relapses, many of which were frequently relapsing and some developed steroid resistance. One patient required a double is now on haemodialysis.

PREDNOS2 is a clinical trial, looking at the effectiveness of a 6 day course of low dose steroids to prevent relapses at the time of an upper respiratory tract infection (cough or cold). Monique regularly meets with the Nottingham research team to help identify potential patients for this study. She aims to work closely alongside consultants across EMEESY to do the same and improve recruitment figures across the network.

Monique recently attended a nephrotic information day at Manchester. This was a fantastic opportunity to meet and learn from other centres. She is now preparing for Nottingham’s second nephrotic family day, to be held in 2017. She hopes for this to be a multicentre approach, inviting speakers from the NeST charity and the Bristol research team, to discuss their work and create a platform for future projects.
10. ANTE NATAL SERVICES

Currently, our unit provides an antenatal counselling service in Nottingham, predominantly for patients from Nottinghamshire and Lincolnshire. Women carrying babies who are suspected to have significant renal abnormalities are referred for counselling by the two Nottingham fetomaternal centres (QMC and City Hospital).

Andrew Lunn, Interim Lead for Antenatal Services

ANTE NATAL COUNSELLING

Counselling is provided by three consultant paediatric nephrologists. The counselling service is individualised and dependent on the nature of the suspected problem. Expectant mothers are seen either in the paediatric nephrology clinic, or jointly with specialist colleagues at the fetomaternal centre. Patients receive detailed information regarding the potential diagnoses and a postnatal management plan tailored to each case is made with. We liaise regularly with our fetomaternal and neonatal colleagues to ensure that mechanisms are in place to undertake these plans.

From April 2015 – March 2016 we provided antenatal counselling for 27 women, an increase from 18 women in the previous year.

POSTNATAL MANAGEMENT

We receive between 2-4 referrals each month for babies delivered in Nottingham with an antenatally detected urinary tract abnormality (AUTA). In the last year, 34 post-natal referrals were received (41 in 2014-15). We have a comprehensive guideline in place for the management of such cases and postnatal investigations and management are arranged in line with this document. Advice is also offered for babies delivered across the EMEESY network.

For complex cases, management is discussed at our multidisciplinary nephrouroradiology meetings. Again, imaging for babies born across the network is also imported for review at these meetings.

Nottingham has well established research reputation in this field. The outcome data for several cohorts of babies delivered with AUTAs have been published. Our most recent study compares the incidence and outcome of babies born between 2011-2013 with those born between 2007-2009 and was presented as a poster at the 2015 ESPN meeting. This work has now been submitted and accepted for publication.

WORKPLAN FOR 2016-17

Our workplan for 2015-2016 focussed on counselling across the network. We have commenced a videoconference with local fetomaternal centres to discuss patients and determine the need for further investigation and counselling before birth. In 2016-17 we will look to increase the number of centres that have access to this across our region. We also plan to develop a pathway for referral for antenatal counselling.
11. UROLOGY

Urology surgical in-patients are nursed on ward E17. Other children who undergo day-case procedures are admitted through the Ambulatory Care Unit. Numbers for admissions (including day case procedures) are found in section 3a above.

Manoj Shenoy, Lead for Surgical Specialties
Nottingham Children’s Hospital

WORKFORCE

The consultant paediatric urologists are Mr Manoj Shenoy, Mr Alun Williams, Mrs Nia Fraser and Mr Bharat More (appointed 2015). Mr Williams also undertakes transplantation work for adults and children; his on-call is covering the transplant rota.

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

2014-15 ACTIVITY

All clinics took place in Nottingham Children’s Hospital at the QMC Campus apart from the Young Person’s Urology Clinic (Mr Williams) which takes place at the City Campus. Numbers of children seen in Nottingham paediatric urology clinics are shown in the figure above. There has been a small (5%) decrease in overall out-patient activity from the previous year though numbers over the last 4 years are steady.

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.

The last working days before retirement for long-service colleagues Debbie Hiley, Denise Martin and Ian Buchan.
2015 was a year in which many changes have been made that not only improve the quality of care we give but also advance it in the new services we are now able to offer.

Throughout the year we have endeavoured to maintain a well organised, professional and caring team.

*Christine Rhodes, Clinical Nurse Specialist in Paediatric Urology*

**WORKFORCE**

There are four paediatric urology nurses: Christine Rhodes (0.8 WTE), Gill Young (0.53 WTE), Emma Gamble (0.48 WTE) and Caroline Ward (full-time).

**ACTIVITY 2015/16**

The number of children currently requiring our service is:

- 288 children with a neuropathic bladder
- 477 children with daytime enuresis

**CHILDREN’S OUTPATIENT DEPARTMENT**

Total number of children seen in clinics by the urology nurses in 2014 was 354 (385 in 2014).

There remains no paediatric continence nursing service within Nottingham County PCT or within North Nottinghamshire covering the area of Mansfield although as NUH have now amalgamated with the Sherwood Hospitals NHS Trust and I hope that we may be able to have some influence with this development. However, until this is addressed these children continue to be referred into our service for advice and ultrasound screening.

**NOCTURNAL ENURESIS SERVICE**

77 patients were seen in 2015 compared to 75 the previous year.

We offer a personalised, dignified, patient-centred approach to nocturnal enuresis giving the child/young person the opportunity to tell us their patient story. We obtain vital baseline information using a structured approach and the supportive literature from the National Institute for Health and Clinical Excellence (NICE) for the management of bedwetting in children and young people. This enables Caroline to consider the treatment options available for use in treating nocturnal enuresis with the issue of an enuresis alarm as a first-line treatment option and/or the consideration of medicinal support if required. The decisions that are made are supported by a consultant nephrologist or urologists and additional specialist paediatric urology nurse support.
Telephone consultation support is offered. For families who live at a distance from Nottingham, this reduces the travel and financial pressures that travelling to clinic can incur. All patients are followed up by telephone 2-4 weeks after issue of an enuresis alarm or any medicine commencement/changes. Caroline is the named nurse contact for nocturnal enuresis which allows her to build a rapport with the patient and their family. She is in a position to offer a holistic approach to enuresis; often managing psychosocial or emotional concerns that occur from incontinence issues.

Of the children who have been under the care of the nocturnal enuresis service for greater than a year:
- 1 has relapsed after a period of dryness
- 1 is non-compliant but has experienced dryness when compliant
- 5 are medicine monitoring/consultant support but are currently dry

Of the children who have been seen for over 2 years:
- 3 relapsed after a period of dryness but are currently dry
- 5 are non-compliant but have/can experience dryness when compliant
- 7 medicine monitoring/consultant support and dry
- 3 have ongoing issues with other medical factors and are still wet; their care is shared with a consultant

17 new patients are now dry on the alarm since April 2014, 6 with medication/alarm, 18 with medication only. 43 alarms have been issues this year (60 in 2014).

**DAY CASE ASSESSMENTS**

Total number of children requiring day case bladder assessment was 225, an increase of 9%. This examination is popular as we can obtain quite detailed information about how the child’s bladder functions on a day to day basis which can be very valuable when deciding what the next method of treatment will be. It gives the urology nurses an opportunity to discuss at length the child’s wetting and toileting pattern, their fluid intake and how generally the family cope with this difficult and embarrassing problem.

**URODYNAMICS**

Total number of children undergoing this investigation was 54 (57 in 2014). We have moved our investigation day from a Thursday to a Tuesday and adjusted our nursing coverage of that day accordingly.

**CLEAN INTERMITTENT CATHETERISATION**

In 2014 the following activity took place with previous year’s figures in brackets: 33 (38) children/parents were taught clean intermittent catheterisation and 87 (74) suprapubic catheters were changed.
COMMUNITY

We have carried out 26 home and school visits (31 in 2014). 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 1902 (2429) phone calls to parents, 772 (208) phone calls to health-care workers and 318 (232) phone calls to schools. Greater support for health-care workers is reflected in increased engagement of local paediatric nurses in urology care.

BIO-FEEDBACK

32 children ranging in age from 6 – 16 years were seen for biofeedback training, compared to 28 children in 2014. These included 28 girls and 4 boys.

- 6 children had previous biofeedback sessions and had returned for top-ups
- 14 had previously undergone urodynamics
- 16 had a history of recurrent UTIs
- 10 were currently or previously taken medication for overactive bladders
- At 3 months results showed that 19 benefitted from the treatment, 3 abandoned the sessions before completion and 5 did not see any benefit
- At 6-12 months results showed that 7 had maintained their improvement, 3 had a partial relapse but were still much improved. We were unable to contact 9 patients.

TRANSCUTANEOUS NERVE STIMULATION (TENS) FOR THE TREATMENT OF OVERACTIVE BLadders

From January 2015 to March 2016 we have seen 19 children for TENS treatment of overactive bladders (15 girls and 4 boys, age range 7-18 years). Twelve children had had previous urinary tract infections, six had previously had biofeedback and eight had had urodynamics. Four had received both treatments. 18 patients were on, or had previously had, anticholinergic medications. Four have not yet completed treatment.

- Of those completed, 9 showed some degree of improvement:
  - 2 girls greatly improved whilst using the TENS but relapsed once discontinued
  - 1 boy reduced voiding from 11-15 times a day down to 4-6 times a day
  - 2 girls no longer wearing pads and frequency reduced
  - 1 girl completely dry and off all medication and TENS
  - 2 girls improved at night but still having odd accident during day
  - 1 girl no improvement but better on Solifenacin
- 6 showed no improvement:
  - 2 boys went on to have urodynamics and have been listed for Botox
  - 1 girl no improvement, urodynamics normal
  - 1 girl with neurological cause for wetting
  - 2 girls no improvement with TENS or biofeedback
ACADEMIC ACTIVITY

Christine Rhodes stood down as chairperson for the RCN Children’s Urology Continence Community in December 2015, but she will continue to work closely with the board.

Christine Rhodes accepted the role of Practitioner Health Lecturer for the children’s bladder and bowel course from Nottingham University. This course began last week with 16 students attending from all parts of the UK. It is the only degree/masters level course available within the UK for nurses requiring a qualification in the care of children with complex bladder and bowel dysfunction.

WORKPLAN FOR 2016-17

- To strive to maintain the highest possible standards of care for urological patients at all times

Patients, parents and staff on World Kidney Day 2016
Pharmacy services are provided a half-time equivalent post working with the children’s renal unit in a combined post with clinical trials. Advice is provided on prescribing for inpatients and outpatients. There is also advice given to paediatric pharmacists throughout EMEESY on prescribing specialist renal drugs and gives advice about prescribing in renal impairment and dialysis.

*Peter Foxon, Paediatric Renal Pharmacist*

**ACTIVITY DURING 2015-16**

The children’s renal unit have successfully completed their switch to a generic form of twice a day tacrolimus, Adoport® for renal transplant and nephrotic patients. This is currently making cost savings for the NHS, some of which are fed back into Nottingham Children’s Hospital. This was achieved with minimal disruption to the children and families involved and was helped by an improving homecare service from Healthcare at Home.

Pharmacy has a page on the EMEESY website which has been used to update professionals around the region on news about availability or other updates with commonly-used renal drugs. It is also the place where we have stored the high-risk monographs, drug guidelines that have been written in Nottingham for intravenous drugs that may have different clinical implications for patients with reduced kidney function. The list of these drugs is now complete and is available for professionals in other EMEESY centres to share.

**WORKPLAN FOR 2016-17**

- Development of a funded network position.
- Review clinical data from Adoport® switch project for publication
- Streamline and standardise availability of specials medicines across the network
- Streamline and standardise availability of unlicensed medicines across the network

Harley, one of our dialysis patients showing that nurses don’t have a monopoly on having public transport name after them!
14. DIETETICS

WORKFORCE

The dietetic service provided to the paediatric renal unit during 2015-16 was staffed for the throughout the whole year by 1.6 WTE paediatric renal dietitians. Emma Kelly works full time at Band 6/7; Pearl Pugh worked 0.6 WTE (Band 7) from April to September 2015, when she took a secondment to complete a Masters course; since September 2015 Ruth Prigg has been working 0.6 WTE (Band 6).

ACTIVITY DURING 2015-16

CONTACTS

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of renal patients</td>
<td>224</td>
<td>187</td>
<td>188</td>
<td>242</td>
<td>239</td>
<td>245</td>
</tr>
<tr>
<td>New patients</td>
<td>71</td>
<td>76</td>
<td>70</td>
<td>74</td>
<td>75</td>
<td>87</td>
</tr>
<tr>
<td>Total dietetic activity</td>
<td>1765</td>
<td>1540</td>
<td>1456</td>
<td>1745</td>
<td>1849</td>
<td>1777</td>
</tr>
<tr>
<td>Mean number of contacts</td>
<td>7.9</td>
<td>8.2</td>
<td>7.7</td>
<td>7.2</td>
<td>7.7</td>
<td>7.2</td>
</tr>
</tbody>
</table>

The mean number of contacts here refers to the average number of dietetic contacts each renal patient has had in one year. This figure has remained stable over the last 7 years and shows the intensity of dietetic support that may be required for renal patients.

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. A dietitian has attended CKD clinics in Leicester. Now that more regular clinics are taking place in Leicester, this clinic has been prioritised for input.

BREAKDOWN OF NUMBER OF PATIENT CONTACTS

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatients</td>
<td>661</td>
<td>771</td>
<td>764</td>
<td>768</td>
<td>628</td>
<td>622</td>
<td>690</td>
<td>613</td>
<td>682</td>
</tr>
<tr>
<td>Outpatients</td>
<td>333</td>
<td>447</td>
<td>366</td>
<td>376</td>
<td>488</td>
<td>561</td>
<td>656</td>
<td>667</td>
<td>596</td>
</tr>
<tr>
<td>Dialysis unit</td>
<td></td>
<td></td>
<td></td>
<td>64</td>
<td>107</td>
<td>169</td>
<td>131</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home/school visits</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Telephone</td>
<td>330</td>
<td>394</td>
<td>423</td>
<td>430</td>
<td>424</td>
<td>187</td>
<td>292</td>
<td>122</td>
<td>367</td>
</tr>
<tr>
<td>Total</td>
<td>1325</td>
<td>1614</td>
<td>1554</td>
<td>1575</td>
<td>1540</td>
<td>1435</td>
<td>1745</td>
<td>1574</td>
<td>1777</td>
</tr>
</tbody>
</table>

Patient contacts include the following:

- telephone conversations with health care professional
- writing social service reports
- dietary analysis
- calculating feed plans
- setting up home enteral feeding contracts
• writing to GP re supplements
• developing resources

Telephone consultations increased by 200% this year. This reflects an identified need for dietetic support in network clinics around the region and the paucity of dietetic support in many centres outside Nottingham. A specific meeting for dietitians, *Fundamentals in Paediatric Nephrology*, was organised by Pearl Pugh and Emma Kelly and formed a part of the Network Education Day in October 2015. Sponsorship was provided by the nutrition companies Vitaflo and Danone and this financial support enabled 20 (check) dietitians to attend free of charge.

We recognise that much further work is required to ensure transparency of funding for dietetic support for renal shared care clinics and we are in discussion with specialist commissioners about this.

### TYPES OF TREATMENT CONTACTS

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral calorie supplements</td>
<td>390</td>
<td>415</td>
<td>435</td>
<td>456</td>
<td>205</td>
<td>213</td>
<td>714</td>
<td>501</td>
</tr>
<tr>
<td>Gastrostomy feeding</td>
<td>375</td>
<td>460</td>
<td>569</td>
<td>387</td>
<td>221</td>
<td>437</td>
<td>433</td>
<td>464</td>
</tr>
<tr>
<td>NG/NJ tube feeding</td>
<td>225</td>
<td>246</td>
<td>184</td>
<td>319</td>
<td>171</td>
<td>265</td>
<td>259</td>
<td>312</td>
</tr>
<tr>
<td>PN</td>
<td>38</td>
<td>7</td>
<td>29</td>
<td>4</td>
<td>10</td>
<td>38</td>
<td>8</td>
<td>19</td>
</tr>
</tbody>
</table>

A more detailed breakdown of the composition of consultations is shown below. Each consultation may comprise of more than one element.

<table>
<thead>
<tr>
<th></th>
<th>2014/15</th>
<th>2015-16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary assessment - computerised</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietary assessment - other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthy eating advice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simple or single dietary recommendation e.g. low Na, low fat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complex or disease specific dietary advice e.g. diabetes, renal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlled nutrient/allergy</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Oral supplements</td>
<td>540</td>
<td>411</td>
</tr>
<tr>
<td>Nasogastric tube-feeding</td>
<td>257</td>
<td>312</td>
</tr>
<tr>
<td>Gastrostomy tube-feeding</td>
<td>433</td>
<td>464</td>
</tr>
<tr>
<td>Central parenteral nutrition</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>Peripheral parenteral nutrition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Energy dense diet</td>
<td>174</td>
<td>90</td>
</tr>
<tr>
<td>Weaning advice</td>
<td>31</td>
<td>17</td>
</tr>
<tr>
<td>Nutrient enriched infant formula</td>
<td>74</td>
<td>124</td>
</tr>
<tr>
<td></td>
<td>2664</td>
<td>2345</td>
</tr>
</tbody>
</table>
TRAINING, RESEARCH AND TEACHING

RESEARCH

Pearl Pugh undertaking Masters in Research Methods.

CONFERENCE PRESENTATIONS/TEACHING

- Attended PRING meeting (EK/PP April 2015)
- Paediatric Renal Interest Group and International Conference, facilitated group workshop (EK Nov 2015)
- Presented growth audit to renal team, October 2015 (EK)
- Nutrition teaching session for the nutrition link professional’s day, October 2015 (EK)
- Involved in dietetic student training (EK ongoing)

COURSES ATTENDED

- Psychology of feeding training day, November 2015 (EK)

INNOVATIONS/WORKING GROUPS/COURSES

- Organised dietetic placement students programmes and work experience sessions for dietetic student (EK)
- Student mentor (EK)
- Updated diet sheet (PP/EK/RP)

PLANS/TARGETS FOR 2015-16

- To complete annual dietetic assessments involving analysis of 3 day food diary on all dialysis patients
- 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
- Plan annual second year of Fundamentals in Paediatric Nephrology education day
15. SOCIAL WORK

Social work support to children with chronic kidney disease and their families is provided currently by 2 part-time social workers. Suzanne has been providing this service since 1998 and Lyn Hopkinson joined the team in October 2015 after a 20 month gap since the retirement of Heidi Steward in January 2014.

*Suzanne Batte, 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. Suzanne and Lyn 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.

Suzanne and Lyn visit families with specialist renal nurses at critical times during the treatment process including 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.

The broad range of families’ backgrounds requires individual responses. Suzanne and Lyn are both experienced social workers skilled at assessing the needs of children from a wide range of religious and cultural backgrounds. Suzanne and Lyn also liaise regularly with other agencies to ensure that other needs are met. We have a number of children subject to Child Protection and Child in Need plans as well as those requiring targeted early support. Having specialist renal social workers that understand the impact of chronic kidney disease on children and their families, as well as being knowledgeable about child protection procedures and social care provision is essential. The role of the paediatric renal social worker is also to provide information and support to other professionals such as teachers and health visitors in conjunction with nursing colleagues. Being an advocate for families whilst monitoring concerns is a difficult task to balance which calls for experienced social workers.

Advocacy work is an expectation of the renal social work role. Suzanne and Lyn continue 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.
2015-16 ACTIVITY

At the current time Suzanne and Lyn both work part-time and the posts equate to one full-time post, meaning the overall social work provision remains less than before 2014. Effective planning and organisation has ensured that the service continues requiring a degree of prioritisation. Home visits have always been an important part of the service, to give families time away from the ward and clinic to discuss their worries and concerns. Suzanne and Lyn will continue to provide this as much as possible. Telephone support and catching up with families at the weekly clinics provide other means of support.

In the last year, Suzanne has made 16 home visits, 6 school visits and attended 18 Child Protection/Child in Need meetings.

Suzanne and Lyn 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. Suzanne has continued to attend training courses provided by the Nottinghamshire Safeguarding Board to keep up to date with changes in legislation and practice in social work. Lyn is new in post but will also be able to access this training.

Suzanne is a member of the BASW Specialist Interest Group which promotes the work of renal social workers nationally and ensures that she keeps informed about developments that impact on her daily work.

Presentation at the annual EWOPA conference has not been possible this year due to pressures on meeting service requirements.

CHALLENGES FOR THE YEAR AHEAD

We now have two social workers in post which should hopefully improve the service provided. However, the provision is still 18.5 hours down on previous years yet the workload remains high. The challenge for Lyn and Suzanne is trying to manage and prioritise their work to ensure that the support offered to families is timely and effective.
There are many aspects to play in healthcare, including preparation, distraction and post procedural work which are all vital for working with long term patients. Play is a universal language so can support patients of all ages, abilities and backgrounds to understand and cope with their illness and treatment, through building relationships, helping them to process and explore what is happening to them. Working alongside the multi professional team is extremely important to the play specialist role, as this ensures that the child, young person and family as a whole are supported together through each step.

Claire Hardy, Senior Play Specialist

CURRENT WORK FORCE:

One full time health play specialist (Claire Hardy) and one full-time BKPA-funded nursery nurse from November (post funded for one year).

ACTIVITY DURING 2015-16

<table>
<thead>
<tr>
<th>Month</th>
<th>Urology</th>
<th>Transplant Preparation</th>
<th>Haemo Patient Interaction</th>
<th>Prep, Dist, Post Support</th>
<th>Sibling Support</th>
<th>Support other areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>April</td>
<td>19</td>
<td>26</td>
<td>11</td>
<td>4</td>
<td>PCU,COPD,E40</td>
<td>3</td>
</tr>
<tr>
<td>May</td>
<td>1</td>
<td>25</td>
<td>20</td>
<td>10</td>
<td>Xray,D35,PCU,E37</td>
<td>1</td>
</tr>
<tr>
<td>June</td>
<td>27</td>
<td>22</td>
<td>5</td>
<td>2</td>
<td>Eye Out patients</td>
<td>5</td>
</tr>
<tr>
<td>July</td>
<td>43</td>
<td>17</td>
<td>17</td>
<td>3</td>
<td>D33 PCU COPD</td>
<td>44</td>
</tr>
<tr>
<td>August</td>
<td>1</td>
<td>11</td>
<td>13</td>
<td>11</td>
<td>PCCU</td>
<td>5</td>
</tr>
<tr>
<td>September</td>
<td>24</td>
<td>14</td>
<td>5</td>
<td>2</td>
<td>E39</td>
<td>4</td>
</tr>
<tr>
<td>October</td>
<td>1</td>
<td>2</td>
<td>24</td>
<td>24</td>
<td>Xray,US5 PCCU</td>
<td>26</td>
</tr>
<tr>
<td>November</td>
<td>4</td>
<td>17</td>
<td>17</td>
<td>1</td>
<td>USS</td>
<td>5</td>
</tr>
<tr>
<td>December</td>
<td>1</td>
<td>27</td>
<td>9</td>
<td>3</td>
<td></td>
<td>53</td>
</tr>
<tr>
<td>January</td>
<td>1</td>
<td>34</td>
<td>15</td>
<td>1</td>
<td>Orthotics</td>
<td>5</td>
</tr>
<tr>
<td>February</td>
<td>1</td>
<td>2</td>
<td>29</td>
<td>8</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>March</td>
<td>3</td>
<td>17</td>
<td>34</td>
<td>4</td>
<td>Xray</td>
<td>4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>7 (5)</td>
<td>12 (8)</td>
<td>297 (589)</td>
<td>219 (101)</td>
<td>76 (98)</td>
<td>19 (56)</td>
</tr>
</tbody>
</table>

The number of patients having support for procedures, in 2015-2016 has increased as priority was given to patients for preparation, distraction and specialised play support.

The number of general play sessional and emotional and family support has increased towards the end of the year due to the additional member of play staff increasing.
As can be seen from the table and chart the number of haemodialysis patient interactions has dropped during this year due to only one member of play staff covering the ward and dialysis unit.

Claire has continued to organise the week long residential holiday for patients aged 9-13 years, and this year took 9 children (8 patients and 1 sibling) to Hilltop outdoor centre in Norfolk.

**SIGNIFICANT ACHIEVEMENTS:**

- Funding secured from the BKPA to appoint a band 3 nursery nurse to support the Hospital Play Service has helped with increasing play sessions within the dialysis unit for younger children missing out on nursery provision.
- Involvement with Family Fun Day at Conkers
- Involvement in development of Play and recreation cleaning guidance with the Trust infection control team.
- Funding from Sandoz to enable the development of preparation animation for biopsies
- Visitors from Japan working with play staff on the wards to develop skills to move the role forward in Japanese hospitals

**PUBLICATIONS AND PRESENTATIONS:**

- Student open days: presentations to prospective NTU students
- Teaching sessions to Japanese HPS students as part of their 3 day educational visit to NUH
- Teaching sessions on the role of the HPS to first year nursing students on E17

**PLAN FOR 2016-2017:**

- To secure funding to keep the nursery nurse post on E17
- To continue to do carry out home and school visits, and residential holidays for chronic, dialysis and transplanted patients.
- To link with other renal play specialists nationally, including visiting other areas to see how services are run.
- To develop and update more of our resources for transplant and dialysis preparation
17. YOUTH WORK

In August 2015 we said “Hello and welcome” to Terrence Green, our youth development worker funded by the Kinder Appeal.

ACTIVITY DURING 2015-16

We now have 1.0 WTE support from the youth service. The team provide young people with advice, information, and guidance allowing them to make an informed choice as to whether they would like to access the youth service. Meeting young people on ward E17 allows opportunities to discuss projects and activities that they may be of interest to them, eg participating in ‘Take over day,’ attending day trips that are of interest such as ‘The Brick Show’.

The Youth Work Team is based on E Floor, East Block in the ‘Youth Room’ and consists of:

- Donna Hilton (Youth Service Manager)
- Mark Howard (Senior Youth Worker)
- Lucy Rychwalska-Brown (Young People’s Emotional Health Worker)
- Terrence Green (Youth Development Worker)

We also have sessional staff to help run the Youth Club and other projects, along with a team of dedicated volunteers, including young adult renal patients. A few of the volunteers have accessed the youth service as young people. Over the years they have made the transition to establish themselves as part of the team. Often volunteers have influenced service delivery by informing other young people and their families of the support they have received from informal educational experiences provided by the NUH Youth Service. The Youth Service offers a variety of activities and resources for young people, aged 11 – 25 years) accessing hospital services; these include:

ONE-TO-ONE SUPPORT AND COUNSELLING

During difficult times, young people can offload informally and receive advice and support from one of the Youth Workers. There is also the opportunity to meet with Lucy, who is a trained counsellor and relates specifically to young people and can offer more in-depth support if needed.
**YOUTH ROOM DROP-IN SESSIONS**

For young people staying in hospital, there is an opportunity to visit the Youth Room daily and take part in a wide variety of activities with other young people and the youth work team. From Mario Kart to art and craft activities to a cup of tea and a chat, there is something for everyone.

**YOUTH CLUB**

For inpatients, and those living locally, Youth Club runs every Wednesday evening from 7-9pm at the Monty Hind Centre on Leen Gate (just behind the QMC). Young people come along and meet other young people, taking part in a wide variety of activities such as pool, table tennis, arts and crafts, cooking, drama, music, sports, games consoles and other projects. This different space gives young people the opportunity to explore and express their voice knowing they are physically away from a ward/clinical environment.

**MONDAY NIGHT ACTIVITY GROUPS**

For in-patients, and those living locally, Monday sessions run from 6:30-8:30pm in our Youth Room within the hospital. They consist of the following:

- 1st Monday of the month: Youth Achievement Awards – gain a nationally recognised accreditation for any activities and projects you are doing with the Youth Service
- 2nd Monday of the month – ‘Beyond the Brick’ – a Lego© based social group to have fun and express yourself!
- 3rd Monday of the Month: ‘Let’s Cook!’ – improve your cooking and baking skills, try new recipes and meet other young people.
- 4th Monday of the month: ‘Chat & Snap!’ – a photography group to learn new camera skills and take part in exciting media projects.

**YOUNG PEOPLE 4 CHANGE**

If any young people 11-19 years want to have their voices heard and represent young people’s views in hospital, then our Youth Forum is the ideal group. Meeting on the last Tuesday of every month in the Youth Room, young people can meet together to share ideas, comment on hospital policies and leaflets and engage in some exciting youth-led projects.

A project hoped to be completed this year is the implementation of a ‘welcome box’. 
INNOVATIONS

Our Young Adult Group ‘Prospect’ is for young adults 16-25 years who might need support around transition, independence, life skills, CV building and/or want to meet other young adults. The group meets every Friday morning in the Youth Room from 10am – 1pm and the 3rd Monday of the month from 6.30pm – 8.30pm. Trips and social outings are also organised for the group.

WORKPLAN FOR THE YEAR

We have managed to secure funding for a renal youth worker for one year. We are seeking other avenues of charitable support in the short-term in the hope of embedding this post within the funding structure for the whole EMEESY children’s kidney network.

CONTACT

For further information, see the youth service website: www.nuhyouthservice.org.uk

Telephone: 0115 970 9421

Email: nahyouthservice@nuh.nhs.uk

Find us on social media:

NUH YouthService

@NUHYS
Currently, due to an overall shortage of psychologists for Nottingham Children’s Hospital, psychology support for the children’s renal service is provided on a referral-only basis. Current waiting time to be seen is approximately 6 months. This falls well-short of the recommendations in the BAPN Multi-Professional Working document of 2003 which would recommend at least 2 WTE for a service covering a population of 6 million. This referral service is provided by Dr Kathryn (Kat) Bradley.

Absence of psychology support has been added to the Nottingham Children’s Hospital risk register and we continue to monitor this.

It remains part of the network business case to add in dedicated psychology support: ideally we would like a 0.5 WTE post with an additional 0.2 WTE hours for research development to allow us to continue the strong tradition we have had for psychosocial research in the field of childhood chronic kidney disease.

A group of Japanese play specialists make a return visit to Nottingham after Claire Hardy visited Japan last year.
19. CRITICAL CARE SUPPORT

CURRENT WORKFORCE

The Renal Critical Care Educator (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.

Molly McLaughlin, Renal Critical Care Educator

ACTIVITY DURING 2015-16

The renal critical care educator has been on maternity leave from February 2016. Although approval to cover maternity leave was granted we have unfortunately been unable to recruit into this post.

The Childrens Renal and Urology Unit provides all modalities of acute renal replacement therapy (RRT) on an intermittent or continuous basis and works closely with PICU, PHDU and NICU to deliver these treatments. For activity on AKI management, please see section 3 above.

SIGNIFICANT ACHIEVEMENTS/INNOVATIONS

The AKI follow up pathway for all children who have received RRT within the regional PICUs is continuing. Now all children who fall within the EMEESY catchment area will be followed up lifelong following AKI within PICU. To date 24 patients have been referred for follow up care. Processes have been tightened to ensure that follow up is arranged for all patients. This project was presented nationally at the International Paediatric Continuous Renal Replacement Therapy conference in London.

The Regional CVVH Simulation Days continue. The number of trusts invited to these days has also expanded to four, as nursing staff from Addenbrookes PICU are now able to attend the days. The four trusts now covered are Cambridge University NHS Foundation Trust, Nottingham University Hospitals NHS Trust, Sheffield Childrens NHS Foundation Trust and University Hospitals of Leicester, which incorporates all the PICU areas within EMEESY network. These days encourage working collaboratively to provide standardised care for children with AKI requiring CVVH across EMEESY.

PUBLICATIONS/INVITED LECTURES

Member of PICS Renal Sub Group

In July 2015 the International Paediatric Continuous Renal Replacement Therapy conference was hosted in the UK for the first time, at the Queen Elizabeth Conference Centre London.
Molly McLaughlin was part of the organising committee for this conference. This 3 day conference consisted of 1 day of workshops followed by 2 days conference. During the full day of workshops she delivered workshops on Plasmapheresis in the Paediatric Renal and Critical Care setting. The workshops generated a lot of discussion surrounding differing practices in relation to this treatment internationally.

During the 2 days of conference two posters were presented; one on the new AKI follow up pathway delivered across EMEESY and the other on the simulation training program offered to nursing and medical staff within the critical care units. There was a lot of interest in the AKI follow up pathway in particular in relation to the network between nephrology and critical care within EMEESY.

WORKPLAN FOR THE YEAR

- To continue to develop and consolidate the CVVH service at LRI.
- To continue to develop the Regional CVVH Simulation Days further to provide a more inter-professional approach.
- To continue to develop the referral of AKI patients for long term follow up.
- To improve network reporting of AKI

The annual residential holiday for children aged 9-13, taking place at Sherringham in Norfolk.
20. **TRANSITION**

Transition is an important area of focus for our unit. NICE guidance was published in Feb 2016 on transition from children’s to adult services for young people using health or social care services. This highlights key areas, including using a person-centred approach to transition planning and support, empowering the young person, and integrating services to ensure a smooth and gradual transition.

*Farida Hussain, Interim Lead for Transition*

**ACTIVITY DURING 2015-16**

We continue to provide strong support for transition by identifying a key worker for all young people with CKD who are approaching transition and we hold specific transition clinics in the major renal centres across our region.

Other transition-focused activities include home visits to aid in preparation for transition and joint home visits with colleagues from adult centres to prepare for transfer. We hold drop-in coffee sessions together with colleagues in adult units to give young people the opportunity to meet these teams in an informal setting.

Our youth work team offers a comprehensive service to support the transition process. The service offers drop-in session for patients and a regular youth club. Patients are also invited to attend an annual transition residential. Home visits together with our specialist nurses are offered in selected cases where the need for increased input is identified.

Young people are encouraged to come in to the first part of consultations on their own joined later by their parents from the age of 14 years (younger for some patients). Copies of clinic letters are sent directly to young people from the age of 16 years. We currently have a single page transition planning reminder in place as a tool for transition. We are currently using the nationally accredited *Ready-Steady-Go* tool for transition planning. Plans are in place for this tool to be accessible via digital health records in the future.

**TRANSITION CLINICS 2015-2016**

Over the last 12 months there has been a dramatic expansion in our transition clinics around the region, with new clinics being formalised in four of our centres.

In addition, in two centres (Norfolk & Norwich and Kettering), adult nephrologists attend the outreach clinics whenever there is an adolescent patient attending, providing a much more flexible and individualised approach for the patients.

We continue to have a well-established links with Sheffield Kidney Institute, Nottingham adult renal unit and the adult unit at Leicester General Hospital. Clinics alternate between the paediatric and adult centres, with MDT meetings being held either at the beginning of these clinics, or some time prior to, to allow members of the adult MDT to be involved in transition planning with joint home visits arranged for selected cases.
We also held twice yearly transition clinics with the Leicester team at Leicester Royal Infirmary for patients transitioning via the shared care clinics held there.

**WORKPLAN FOR 2016-2017**

We have a well-established transition process, but documentation of the pathway needs to be improved. We need to finalise our transition guideline and pathway incorporating the NICE guideline.

In addition to liaising with adult nephrology colleagues, we need to involve GPs in the transition process, particularly for those patients who will be transferring to primary care for follow-up; this will be reflected in our pathway.

To continue to use and expand the use of the ‘Ready Steady Go’ tool to aid our transition planning.

<table>
<thead>
<tr>
<th>Centre</th>
<th>Number of clinics per year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nottingham</td>
<td>4</td>
</tr>
<tr>
<td>Sheffield</td>
<td>2</td>
</tr>
<tr>
<td>Leicester Royal Infirmary</td>
<td>2</td>
</tr>
<tr>
<td>Kettering</td>
<td>Adult nephrologist attends each outreach clinic</td>
</tr>
<tr>
<td>Leicester General</td>
<td>3</td>
</tr>
<tr>
<td>Norfolk and Norwich</td>
<td>Adult nephrologist attends each clinic with patients from 15</td>
</tr>
<tr>
<td>Lincoln</td>
<td>2</td>
</tr>
<tr>
<td>Derby</td>
<td>2</td>
</tr>
<tr>
<td>Cambridge</td>
<td>2</td>
</tr>
<tr>
<td>Doncaster</td>
<td>2</td>
</tr>
<tr>
<td>Rotherham</td>
<td>2</td>
</tr>
<tr>
<td>West Suffolk</td>
<td>2</td>
</tr>
<tr>
<td>Boston</td>
<td>2</td>
</tr>
<tr>
<td>Bassetlaw</td>
<td>1</td>
</tr>
</tbody>
</table>

Staff from the Children’s Renal Unit at Nottingham Children’s Hospital taking part in the annual Dragon Boat Challenge as *The Breakfast Club*
21. EDUCATION AND TRAINING

Nursing Renal Education is supported by a part-time Paediatric Renal Nurse Educator at 0.76 WTE, over three days per week. Cover for the Haemodialysis unit is included in these hours; the need fluctuates dependent upon staffing and number of acute patients. The educator also supports the on call renal nursing service.

*Diane Blyton, Nurse Educator*

NURSING EDUCATION DELIVERED

Both newly qualified nurses commencing on E17 this year 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, as they may not be able to be released. Where possible the educator worked clinical shifts with new staff to offer support and learning.

Assessment of training needs is completed on a regular basis, but more formally through the annual Training Needs Analysis. This enabled nurses to attend learning beyond registration modules, conferences and other training.

Other in house training included two renal teaching days, which were delivered in June providing additional teaching and updates to the ward based nursing staff. This included the simulation training mentioned below, general updates and training on managing difficult conversations. An introductory education session was provided to new members of the multi-professional team, and also to new nurses on Paediatric Critical Care.

Two members of staff were trained to set up and manage Peritoneal Dialysis (PD), and PD updates were provided to 5 additional staff members. One new member of staff received training in Haemodialysis.

The renal module has had to be put on hold at present. We are exploring other ways of hosting this course for the future.

Additional roles of the nurse educator within the children’s Hospital and Trust:

- Five *Central Venous Access* study days were delivered for nursing staff across the Children’s Hospital. This also involves on-going support of assessment of practice. Updates in ANTT and CVL were also provided to staff.
- The educator sits on the Nursing and Midwifery Education Steering Group, and within this supported the Quality Management Visit by the Health Education East Midlands. The educator also participates in the CQC peer review process, and also the Matron Cleaning audit process.
- Work on managing difficult situations was undertaken with Organisation Development. This is on-going and part of wider work within the Children’s Hospital.
MULTI-PROFESSIONAL EDUCATION DELIVERED

The 2015 autumn Annual Education Day was held at Sedgebrook Hall in Northamptonshire. The main theme was renal genetics. Four consultant geneticists (Dr Richard Sandford from Cambridge, Dr Jackie Cook and Dr Michael Parker from Sheffield, and Dr Abhijit Dixit from Nottingham) from around the EMEESY network contributed to different sessions. Professor Moin Saleem from Bristol spoke about research into steroid resistant nephrotic syndrome. A total of 58 individuals attended, including 33 doctors and 6 nurses. A wholly separate programme for dietitians was organised. Free registration due to support from Vitaflo and Danone allowed 21 dietitians to attend. Nurses attended some of the dietetic sessions, some of the medical sessions and had some separate sessions.

The 2016 spring meeting was held in Nottingham at the East Midlands Conference Centre. Instead of a single theme this year, 4 “conundrums” were selected and speakers selected to bring their own contribution, a mix of evidence and personal experience, to these sessions. Feedback was highly positive and we plan to repeat this formula next year. A total of 50 individuals attended, mainly doctors on this occasion.

As before, with speakers’ permission, talks from both meetings are uploaded to the education section of the EMEESY website after the education days to be a resource available again as needed.

SIGNIFICANT ACHIEVEMENTS OF THE YEAR

A simulation training day was provided for ward based nurses, in peritoneal dialysis management. Scenario training was provided and also skills based skills stations.

WORKPLAN 2014-15

- Update competency documents in use in the children’s renal unit.
- Complete work commenced to enable Dopamine administration post transplantation on E17, ward staffing permitting.
- Continue to develop e-learning/blended options for on-going education of nurses within the renal service and EMEESY Network. Links have been made with the Learning@nuh team.
- Continue to provide updates and training for extended roles for staff on E17 and the specialist nursing team.
- Continue to develop multi-professional learning opportunities within the team.
- Multi-professional education days planned for October 2016 (renal biopsy, Stoke Rochford Hall, near Grantham) and March 2017 (theme and venue to be confirmed).
- October meeting to contain second whole day’s separate dietetic programme.
22. CLINICAL GOVERNANCE AND AUDIT

Clinical governance is a systematic approach to maintaining and improving the quality of patient care. An important part of this approach is to identify incidents which have or may have caused harm and to take measure to prevent future incidents.

*Andy Lunn, Departmental Lead for Governance*

**ACTIVITY DURING 2015-16**

We routinely collect information on incidents through the hospitals reporting system. In the financial year 2015-2016 we reported 77 incidents of which 52 did not cause harm, 19 were considered a low level of harm and 1 was considered a moderate degree of harm. The category of incidents followed a similar pattern to the trust. Categories with 5 or more incidents are shown in the table below and compared to previous years.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>11</td>
<td>28</td>
<td>26</td>
<td>21</td>
<td>27</td>
<td>23</td>
<td>19</td>
</tr>
<tr>
<td>Staffing</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>7</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Delay/failure to treatment or procedure</td>
<td>8</td>
<td>4</td>
<td>3</td>
<td>10</td>
<td>7</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>8</td>
<td>5</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Communication failure</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>0</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Aggression, violence and harassment</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>20</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

Learning outcomes were reviewed for each incident with areas for improvement most often noted in clinical practice and staff communication. More than one learning outcome can be derived from each incident. The learning outcomes occurring five or more times in 2015-16 are summarised in the table below and compared to previous years.

<table>
<thead>
<tr>
<th>Category</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication with staff</td>
<td>2</td>
<td>38</td>
<td>44</td>
</tr>
<tr>
<td>Clinical practice</td>
<td>2</td>
<td>35</td>
<td>30</td>
</tr>
<tr>
<td>Staffing levels</td>
<td>0</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Delivery of care</td>
<td>0</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Equipment use</td>
<td>0</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Staff education / Knowledge / Training</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
</tbody>
</table>
The number of incidents and learning outcomes related to staffing levels has increased in the past 12 months. There is a national shortage of nursing staff and this is being addressed by the Nottingham Children’s Hospital management team with our staff playing a lead role in recruitment. Ward E17 in particular in not at a full establishment of nursing staff. We are in discussion with the Nottingham Children’s Hospital management team to minimise the staff shortages and reviewing our working practices to minimise the impact of staff shortages. This includes an in-depth review of our frequently occurring incidents.

Following an in-depth review of two incidents, one of which caused a moderate degree of harm, we have modified our practice across the network to improve our network communication and pathways. This has included the appointment of an EMEESY Network Administrator.

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. Ward E17 was commended for a consistently high achievement in many areas.

**AUDIT 2015-16**

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 are submitted to the 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.

Our outcome data regarding transplantation are also reported nationally as part of the NHSBT Kidney Advisory Group data. These data are presented as one and five year outcomes for patient and graft survival. Although within the expected statistical variation our five year graft survival data was below the national average in 2014. The latest data show that this is improving but we are still reviewing our practice to consider how we can make further improvements.

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. Ward E17 was commended for a consistently high achievement in many areas.

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. An audit workplan is in place to ensure they are reviewed regularly.

**WORKPLAN 2014-15**

1. We are changing the Clinical Governance and Audit structure to become Quality Improvement. This includes governance and audit but has a wider remit to innovatively, systematically and measurably improve patient care. Suggestions on
how we can improve patient care are always welcome from patients, parents and staff alike.

2. We will continue to monitor incidents and work with management to address staffing shortages.

3. We will have an annual audit day to review our key performance indicators i.e. transplant outcomes, growth and nutrition, peritonitis rates, CVL infection rates, renal biopsy complications, renal registry data.

The haemodialysis parents’ support group taking part in a golf trip in July 2015. Thanks to DG Taxis for the provision of a free minibus.
23. 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. The use of social media has enhanced our ability to share information using minimal time and resources.

Shelley Jepson, Senior Paediatric Renal Nurse and PPI Lead

COMMUNICATION

Families are encouraged to contact the unit via the message pager (07659 598629) which is carried by a nurse 24 hours per day. The aim is to ensure calls are directed to the appropriate team member as soon as possible, an added benefit is to reduce telephone calls to the ward staff which can interrupt patient care. Approximately 30 calls per week are handled.

Families can also receive telephone advice from team members based on a telephone clinic system which is managed by the renal secretary.

INFORMATION

The EMEESY website www.emeesynh.nhs.uk continues to develop. 4-monthly meetings with the team at Volute ensure the website maintains its quality and security. Website update and development is largely undertaken by Dr Martin Christian in addition to his clinical and leadership roles. This year new software has been added to enable professionals to book education days electronically. Our patient information booklets are being added to the site in an easy to read format.

We continue to use our units own information booklets which are due for review in 2016. We also advise that families use InfoKID (www.infokid.org.uk)

The network continues to use social media to communicate with families and professionals. Our Facebook page www.facebook.com/emeesynuh has over 300 followers. Regular postings include news from the network, new information, and details of charitable fund raising. Facebook remains popular with families. No posts have been removed in 2015-16. We continue to use Twitter in addition to Facebook. Many colleagues use Twitter and we intend to use this more in 2016 to share information with health care professionals.
INFORMATION EVENTS

FAMILY FUN DAY

In November 2015 we held our first family fun day at Conkers theme park. This venue was chosen after a survey to families told us that they would like to meet other families and receive information in a relaxed environment which was fun for children.

22 families (100 people) joined us in Conkers Winter Wonderland and 10 members of staff and volunteers were present to support the day. The day was informal with an introduction by Dr Martin Christian, and the other team members present. Several expert parents were available to advise and support families who were new to the unit. A SurveyMonkey evaluation of the day was positive overall with parents’ comments reflecting the value of meeting families facing similar challenges.

“Experiencing common sympathy from someone who knows what that feels like was very empowering for me. I didn't feel so alone, and I felt like I could keep on going, as these other parents obviously have done, and are continuing to do”

“We really enjoy the get together, meeting new people in the same situation as yourselves. It is good to compare things with others but at the same time the children enjoy themselves and forget about things with their siblings included”

“Talking to other families really helped us. The kids had a great time, which they really deserve”

The feedback also suggested that a more structured programme for the day with supervised activities for children would enable parents to have better opportunities to meet other families. The weather was cold which limited outdoor activity. This feedback will be incorporated into an event in the summer months of 2016.

We are grateful to our charity, The Kinder Appeal for supporting the event.

TRANSPLANT GAMES

The Transplant Games 2015 took place in Newcastle. 10 families attended supported by staff and volunteers. Our team brought back the greatest medal haul so far. We intend to encourage even more transplant patients to enter in 2016. Please see the transplantation section above for more detailed information.
HAEMODIALYSIS PARENTS AND CARERS

It is recognised that the burden of care for families with children with renal disease can be overwhelming. Parents and carers with children on hospital haemodialysis have to spend long periods of time in hospital and we are aware that this can be frustrating.

A number of events, led by renal assistant Anisah Hussain have been organised over the last year.

We are grateful to The Kinder Appeal and DG Taxis for supporting these events.

WORLD KIDNEY DAY 2016

We always try to mark World Kidney Day in March each year but this year’s focus was kidney disease in children. Along with other children’s renal units, we organised special events. In Nottingham, staff manned a juicer exercise bike and sold cakes and organised other activities to raise money for The Kinder Appeal and to raise awareness of kidney disease amongst the general public.

Elsewhere around EMEESY children took promotional literature into school to raise awareness of kidney disease amongst their peers.

PATIENT AND CARER INVOLVEMENT

We were delighted that a parent was able to contribute to the interview and appointment of new consultant Dr JJ Kim.

WORK PLAN

- Quarterly review and update of EMEESY website including monthly blog
- Identify patient/carer advocate to attend EMEESY steering group
- Information events for transplantation, nephrotic syndrome and transition
- Support families to attend transplant games
- Involve families in EMEESY cycle fundraising events
24. **RESEARCH**

Research continues to be a core part of the clinical care that is delivered in Nottingham and across the EMEESY Network we cover.

*Andy Lunn, Research Lead*

**WORKFORCE**

Currently there is 1 WTE research nurse (Olivia Silkstone) within the Clinical Research Network (CRN) who is employed to facilitate the research work in Nottingham. We are grateful to the tireless effort she and other members of the CRN team have done to help achieve the successful delivery of the research studies we are involved. There will be some changes in the coming year to cover maternity leave. Last year we appointed a 1 WTE research administrator (Marriam Ghaffar) who has supported the breadth of research that the department is involved in. 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 6 consultants. This includes one consultant who is a member of the British Association for Paediatric Nephrology / CRN clinical studies group. Pearl Pugh, our dietitian, has also been undertaking a Masters in research methods looking to develop her own research skills.

**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.

We continue to build on our previous success as one of the largest recruiting centres for many studies. Having previously been a key recruiting centre to PREDNOS study we have recruited well to PREDNOS 2. We remain the second largest paediatric centre for RaDaR, the largest recruiting centre in the UK for CRADLE and the largest recruiting centre in the UK for the RaDaR MPGN study.

Details of current studies and numbers of recruited patients are below:

<table>
<thead>
<tr>
<th>COMMERCIAL STUDIES</th>
<th>Study Name</th>
<th>Summary</th>
<th>Recruitment actual (target)</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRADLE</td>
<td>Unblinded RCT of everolimus, low dose tac and steroid withdrawal vs standard pred, tac and MMF. Consent at transplant, randomise at 4-6 weeks after transplant. Recruitment now completed.</td>
<td>7(5)</td>
<td>Martin Christian Lindsay Crate</td>
<td></td>
</tr>
</tbody>
</table>
### Registry Studies

<table>
<thead>
<tr>
<th>Study Name</th>
<th>Summary</th>
<th>Contact</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>aHUS Eculizumab</td>
<td>Registry based study of aHUS</td>
<td>Jonathan Evans</td>
<td>Stopped recruitment – target exceeded (1)</td>
</tr>
<tr>
<td>RaDaR (10RE005)</td>
<td>Rare Renal Disease Registry</td>
<td>Andrew Lunn Marriam Ghaffar</td>
<td>312 patients recruited in total of whom 115 are paediatric. Recruitment ongoing.</td>
</tr>
</tbody>
</table>

### Non-Commercial Studies

<table>
<thead>
<tr>
<th>Study Name</th>
<th>Summary</th>
<th>Recruitment actual (target)</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic basis of renal tract</td>
<td>Genetic study – one blood test, clinical proforma recording medical history and data collection sheet. Study also recruiting parents of affected children.</td>
<td>36(20) Closing to recruitment</td>
<td>Andy Lunn Olivia Silkstone</td>
</tr>
<tr>
<td>PREDNOS (10CS017)</td>
<td>Blinded placebo controlled RCT of short versus long course of steroids for initial treatment of nephrotic syndrome. Recruitment complete nationally – in follow-up phase.</td>
<td>8 (6)</td>
<td>Andy Lunn Maria Saxton</td>
</tr>
<tr>
<td>PREDNOS 2 (12CS018)</td>
<td>Blinded placebo controlled RCT of 6 days of low dose prednisolone at time of URTI to prevent nephrotic relapses.</td>
<td>6 (6)</td>
<td>Martin Christian Maria Saxton Monique Burgin</td>
</tr>
<tr>
<td>HOTKID (12CS013)</td>
<td>An unblinded randomised trial of standard (50-75&lt;sup&gt;th&lt;/sup&gt; centile) vs aggressive (&lt;40&lt;sup&gt;th&lt;/sup&gt; centile) control of blood pressure in patients with CKD.</td>
<td>6 (5)</td>
<td>Andy Lunn Marriam Ghaffar</td>
</tr>
<tr>
<td>RaDaR – NephroS</td>
<td>Genetic and steroid response study in patients with nephrotic syndrome. Requires blood test.</td>
<td>48 (15)</td>
<td>Martin Christian Maria Saxton Marriam Ghaffar</td>
</tr>
<tr>
<td>RaDaR – MPGN</td>
<td>Genetic and immune system testing in patients with MPGN. Requires one blood test.</td>
<td>28 (20)</td>
<td>Martin Christian Marriam Ghaffar</td>
</tr>
</tbody>
</table>

We continue to work towards our goal of offering every patient the opportunity to be involved in research and supporting paediatric nephrology research in hospitals across the EMEESY network. There are many opportunities that we could be involved in going forwards. This is supported nationally by the publication of the UK Renal Research Strategy, our ongoing involvement in the British Association for Paediatric Nephrology clinical studies group and locally through appointment of our new consultant JJ Kim with his experience and interest in research. The challenge remains to secure funding and support to maintain this level of work and recruitment success whilst looking to build local projects so that in the future we can be leading on national studies.
AWARDS

Danielle Barnes, Support Worker of the Year 2016

PUBLICATIONS


EXTERNAL RESPONSIBILITIES

Martin Christian

- BAPN Honorary Secretary
- Paediatric representative on AKI National Programme (education stream, until January 2016)
- Member of Trial Steering Committee for PREDNOS2 study

Andrew Lunn

- BAPN Communications Officer (until February 2016)
- Paediatric representative on AKI National Programme (education stream from January 2016)
- Member of paediatric nephrology clinical studies group
Meeta Mallik
- Chair NUH Drugs and Therapeutics Committee (until December 2015)
- Member of BAPN Clinical Standards and Guidelines Sub-committee

Jonathan Evans
- NUH Clinical Director for Family Health
- Member of CQC inspection team

Hitesh Prajapati
- BAPN Trainee Representative on BAPN Executive Committee (until December 2015)

Manoj Shenoy
- Service Lead for Surgical Specialties, Nottingham Children’s Hospital
- BAPU representative on Specialty Advisory Committee for Royal College of Surgeons
- MCQ examiner group for the Inter-Collegiate Board

Alun Williams
- National Institute for Health and Care Excellence Fellow 2013-16
- MRCS examiner

Shelley Jepson
- Member of National Peer Review pilot steering group for paediatric renal services

Roy Connell
- Member of Specialist Interest Group for Paediatric Nephrology Nurses

Height-independent GFR reporting was introduced in Nottingham Children’s Hospital on World Kidney Day in 2016, thanks to work from Dr Andy Lunn. We are the first children’s hospital in the UK to do this and we believe it will make a difference to early referral for children with kidney impairment.
A year ago, we aimed to:

1. Re-tender the service with an appropriate outpatient tariff to fund the infrastructure and MDT posts required.
   *This work is on-going and has proved to be more difficult than first thought but discussions with specialised commissioners are on-going*

2. Sort a robust system to record all telephone consultation work
   *At present commissioners are not interested in recording telephone clinic work but we continue to aim to record it in preparation.*

3. Ensure that all new AKI patients are registered on EMED
   *This is on-going.*

4. Procure NxStage machine in preparation for developing a home haemodialysis service
   *This has been achieved.*

5. Update resources for biopsy and transplant preparation
   *We are in negotiation with a pharmaceutical company who have helped us produce a new video clip to be accessed on the internet. We plan to launch it in October at the Annual Network Meeting.*

6. Recruit two new consultants – one substantive post based in Nottingham; one locum post working half-time in Leicester
   *This has been achieved.*

7. Develop a business case for a substantive consultant post to cover Leicester service
   *A locum consultant took longer than expected to appoint but started work in May 2016 and the business case for a substantive consultant will form part of next year’s workplan.*

8. Pilot a network-wide audit
   *The Network Steering Group not meeting regularly did not help this. There are plans in place to use some internet-based software to enable individual centres to input data easily and we will add this to next year’s workplan.*

9. Pilot patient experience outcome measures in out-patient clinics throughout the network
   *Plans to trial patient experience measures will form part of next year’s workplan.*

10. Develop tutorial videos to be embedded in the website
    *We have taken advice about this from the media company involved in the biopsy preparation video above and hope to make progress on this in 2016-17.*
NEW PRIORITY WORKPLAN FOR 2016-17

In 2016-17, we will prioritise the following workplan items:

1. Secure funding for a substantive network administrator
2. Secure funding for a new Nottingham-Leicester consultant paediatric nephrologist
3. Reapply for charitable funding for a youth worker and work towards embedding the post in the unit establishment with secure long-term funding
4. Aim to unravel the complexities of network funding
5. Make progress towards the feasibility of a daycase unit
6. Develop an EMEESY policy on transition
7. Develop an antenatal and CKD pathway for EMEESY
8. Embed the use of the renal computer EMED into everyday practice
9. Develop IT links with each local centre
10. Find a host for the paediatric renal nurse e-learning module