


20th Annual Report 2010

CHILDRENS
**RENAL &
UROLOGY
UNIT**
QMC • NOTTINGHAM

25th Anniversary
1985 • 2010

25th Anniversary

Party



Monty Hind Youth Centre
Leengate, Nottingham NG7 2LX.
(on QMC Goods Entrance Road)
Sunday 4th July 2010 • 12.00am - 5.00pm

**Children's Renal & Urology Unit
Nottingham**

CHILDREN'S RENAL & UROLOGY UNIT

ANNUAL REPORT 2010

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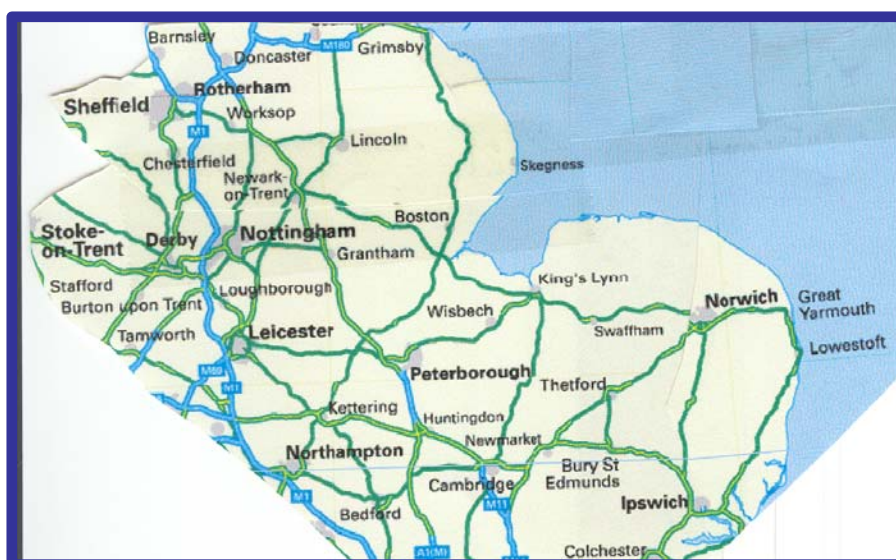
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MISSION STATEMENT

We will

- a) Strive for excellence in the care of all children with acute and chronic renal and urological problems**
- b) Embrace a partnership ideal with the families and be sensitive to multiculturalism**
- c) Improve and develop all means of communication with children and their carers and ensure meaningful patient and family involvement**
- d) Educate all staff and professionals in contact with children with renal problems, including those outside the hospital such as general practitioners, school and nursery staff**
- f) Seek to carry out research on clinical care and implement new scientific knowledge to maintain the unit at the leading edge of paediatric renal and urology care**

Adopted in 1991 for First Annual Report



SUMMARY

The release of the 2010 annual report for the Children's Renal and Urology Unit is later than usual this year. And it is no coincidence that it is the first report I have compiled as lead consultant, yet another reminder of the enormous energy and drive that my predecessor, Professor Alan Watson, had that he managed to undertake this task so efficiently each year!

2010 was an eventful year. It saw the 25th anniversary of the unit (more on that below). It also saw the retiral of Professor Alan Watson as consultant and unit director. Alan was appointed as the first consultant paediatric nephrologist in Nottingham in 1985. He was a single-handed consultant until 1993 when Jonathan Evans was appointed. Alan was acutely conscious that care for children with chronic renal failure could only be delivered effectively through a multi-disciplinary team and he set about building up this team using all his creativity and charm as well as the conventional writing of business cases! The team I have inherited today and which has been the envy of other paediatric renal units through the years is listed below.

Alan's huge national and international contribution to paediatric nephrology was celebrated with a retiral festschrift in September. A number of renowned speakers gave lectures about specific areas where Alan has made notable contributions. There was not sufficient time in the day to cover all of Alan's interests but those that were included:

- Dr Lesley Rees (Consultant Paediatric Nephrologist at Great Ormond Street Hospital, London) on nutrition and chronic renal failure. Alan has written extensively about the importance of nutrition if children with chronic kidney disease are to grow normally. He also pioneered the use of gastrostomy feeding for children with chronic kidney disease.
- Dr Meeta Mallik on follow-up of antenatally detected urinary tract abnormalities. Alan has been responsible for maintaining one of the largest databases of children followed up for antenatally detected urinary tract abnormalities and continues to help guide the follow-up imaging and care of these children.
- Dr Vic Larcher (Consultant Paediatrician and Clinical Ethicist at Great Ormond Street Hospital, London) on clinical ethics. Outside of paediatric nephrology Alan has used his interest in clinical ethics to found a National Clinical Ethics Network. He has recently stepped down as the network's first chairman.
- Dr Nicholas Webb (Consultant Paediatric Nephrologist, Manchester) on transplantation. Alan has been an active promoter of transplantation and a keen supporter of multi-centre studies of paediatric renal transplantation.
- Dr Donal O'Donoghue (Clinical Director for National Kidney Care) on renal services for young people. Alan was one of the first paediatricians to appreciate the vulnerability of adolescents with chronic illness transferring to adult units. He has encouraged a large body of research into transition. One of his on-going projects is chairing a report on transitioning of renal patients from paediatric to adult services for the International Society of Nephrology.
- Dr Mike Shooter (retired Consultant Psychiatrist and former president of the Royal College of Psychiatrists) on psycho-social care for children with chronic renal failure. Throughout his consultant career, Alan has been one of the most vocal proponents of the necessity for adequate psycho-social care to support children with chronic renal failure and their families. He has written and spoken extensively on the subject.
- Dr Mary McGraw (Consultant Paediatric Nephrologist from Bristol and current president of the British Association for Paediatric Nephrology) gave an introduction to Alan just before he gave his valedictory lecture at the end of the afternoon. She spoke very fondly of Alan as a former colleague in Toronto and of his enthusiasm as a national colleague. In what she said, she was able to encapsulate all we know of Alan's warmth and support as a senior colleague.

In his 25 year consultant career Alan published over 300 peer-reviewed papers, wrote over 30 book chapters and continues to be a regular invited speaker at international conferences. I am acutely conscious that the enormous shoes he has left behind are not fillable by one person. I have taken on responsibility for the consultant lead in the unit but we plan a team approach to cover all the

areas that Alan oversaw. We were delighted in June to be able to appoint Dr Andrew Lunn, previously national grid paediatric trainee in Nottingham, to the consultant vacancy on Alan's retirement. Thankfully Alan has not disappeared completely. He continues in research and is a very welcome regular visitor to the hospital.

2010 also saw the 25th anniversary of the founding of the unit. At the annual time-out in April, we specifically focussed on the developments in paediatric renal care over 25 years to guide vision over what we might achieve in the next quarter century. In June a civic reception was held at the Council House in Nottingham, the seat of the City Council in the centre of the city. Current and former staff as well as several patients and their families were invited to the mayoral reception and enjoyed an evening reminiscing together as we celebrated all that the unit has been able to achieve in 25 years.

A party specifically for children, young people and their families who are current or former patients was held on Sunday 4th July last year at the Monty Hind Youth Centre adjacent to the Queen's Medical Centre. There was children's entertainment, indoor games and a cold buffet to facilitate many old friends meeting up and sharing memories. As professionals, these events are good to remind ourselves that kidney failure is just a part, not the total or even the biggest part of the lives of the young people we care for. Although we strive to offer psycho-social care to families, the support that comes through friendship with other families is impossible to quantify but it was very clear to see again on that day.

2010 was also a year in which we had record numbers of transplants: the adult unit carried out a record 100 transplants and we did a record 20 transplants. Although the overall number was our highest by a large margin (16 transplants was the previously highest number in 1999), the number of living donor and pre-emptive transplants have slipped from previous years as other paediatric renal units have increased their numbers of living donor transplants so there is work to be done.

By 2016, Nottingham University Hospitals NHS Trust, of which the Nottingham Children's Hospital is a part, is aiming to be the leading acute hospital trust in the country. To be the leading children's kidney unit means facing up to these national statistics, ensuring that we are giving parents appropriate information about transplant choices and supporting those who wish to be considered as living donors. If necessary, we need to be about to make careful and appropriate changes to our service. In all areas of service, we are currently reviewing our practice and determining our priorities over the next few years as we strive for that same excellence in clinical outcomes and patient experience. The challenge is a great one in these times of financial uncertainty. Gone are the days of service development built on making business cases for new staff. We have to rely on more creative ways of improving without additional resources. But I have inherited a great legacy and I am fortunate to lead a committed and dedicated team and in those near-immortal words of Alan we will strive "ever onward"!

Martin Christian
Lead Consultant, May 2011



Assembled voices of the children's renal unit valley choir in a moving rendition of "Ever Onward" (the theme tune of Cwm Rhondda)



Jonathan Evans pays tribute to his ex-colleague in work and play, before presenting him with a special memento of former glory days of Welsh rugby



Alan Watson hands over the reins of the lead for the children's renal unit to Martin Christian



Dress code for the evening reception was formal; optional handle-bar moustaches were available at each place setting

STAFF AND FACILITIES

Medical Staff

<i>Consultant Paediatric Nephrologists</i>	Prof Alan Watson (until August 2010) Dr Jonathan Evans (Clinical Director, Family Health & 0.6 WTE clinical) Dr Farida Hussain Dr Martin Christian Dr Meeta Mallik Dr Andrew Lunn (appointed September 2010)
<i>National grid trainee</i>	Dr Wesley Hayes (from August 2010)
<i>ST 2/3 Trainee</i>	Rotates every 6 months
<i>F2 Trainee</i>	Rotates every 4 months
<i>Paediatric Urologists</i>	Mr Manoj Shenoy Mr Alun Williams Mrs Nia Fraser (appointed 2010)
<i>Surgical Trainee</i>	Rotates every 6 months
<i>Surgical SHO</i>	Rotates every 3 months
<i>Transplant Surgeons</i>	Mr Keith Rigg, Mr Alun Williams, Mr Shantanu Bhattacharjya (appointed 2010), Mrs Amanda Knight (appointed 2010), Mr Owen Cole (urologist)
<i>Radiologists</i>	Dr Nigel Broderick, Dr John Somers, Dr Kath Halliday and Dr Laura Fender
<i>Pathologists</i>	Dr Tom McCulloch and Dr Zsolt Hodi

The nephrology service remains a **CONSULTANT DELIVERED SERVICE** as all middle grade and junior staff participate in general paediatric on call rota.

Nursing Team

Shelley Jepson	Senior Paediatric Nephrology Nurse
Roy Connell	Clinical Nurse Specialist – Dialysis
Kim Helm	Clinical Nurse Specialist – Transplant
Kate Baker	Renal Nurse – Transplant (0.7 WTE)
Sharon Mould	Dialysis Nurse (0.8 WTE)
Gillian Elwood	Nephrology Liaison Nurse (0.9 WTE)
Diane Blyton	Renal Nurse Educator
Chris Rhodes	Urology Nurse Specialist (0.6 WTE)
Gill Young	Urology Nurse
Emma Stockdale	Urology Nurse
Caroline Ward	Urology Nurse
Molly McLaughlin	Renal Critical Care Nurse
Ian Buchan	Junior Charge Nurse
David Cooper	Junior Charge Nurse – Haemodialysis
Michelle Kirkland	Ward Manager (0.8 WTE)

The Children's Clinic

The clinic is run by June Nicholson and Pip Waddington.

Dietetics

Pearl Pugh (0.6 WTE) and Alison Tooke (0.8 WTE) are our paediatric renal dietitians

Social Work

Paediatric Renal Social Workers are Heidi Steward (FT) and Suzanne Batte (PT)

Psychologist

Dorothy MacKinlay provides part time support to the unit

School Teachers

Elaine Boon, Kate Lawes and John Young are the schoolteachers on the Dialysis Unit and Ward E17. They are greatly assisted on the Dialysis Unit by 2 Teaching Assistants, Jonathan Gray and Denise Cross. They are also helped once a week by a volunteer, Janet Wilson.

Play Specialist

Claire Hardy

Youth Worker

Donna Hilton continues to develop youth work support for all young people in the paediatric unit with part-time assistance. Dorro Hackett supports her on a part-time basis and is funded by the BKPA.

Family Care Coordinator

Denise Martin continues to provide support to our families.

Administrative and Secretarial Staff

Ann Johnson, Barbara Wiklo, Judith Hayes and Sandie McLauchlan continue to provide their invaluable senior administrative support. They are supported by a team of band 3 secretaries and filing clerks. Lynn Brand helps in data collection as the ward receptionist.

Housekeeping

Ann, Janet and Val endeavour to maintain high standards on the ward.

Technical Support

The excellent support from the renal unit technical staff for the running of the dialysis machines is very much appreciated and Paula Conway for administration of supplies.

Transplant Coordinators

Richard Bowen, Louise Hubner and Jackie Brannon. Anne Theakstone and Karen Stopper are the live donor co-ordinators.

Renal Pharmacist

Andrew Wignell provides pharmacy support

Volunteers

Pat, Pauline and Denise provide invaluable support on the ward and in clinic.

Chaplaincy Support

No specific paediatric cover at present.

Management

Duncan Hanslow and Sandra Minich are Business and Assistant Business Managers respectively. Angela Horsley is Clinical Lead for Children's Services and Sally Shearer is Matron for Children's Services.

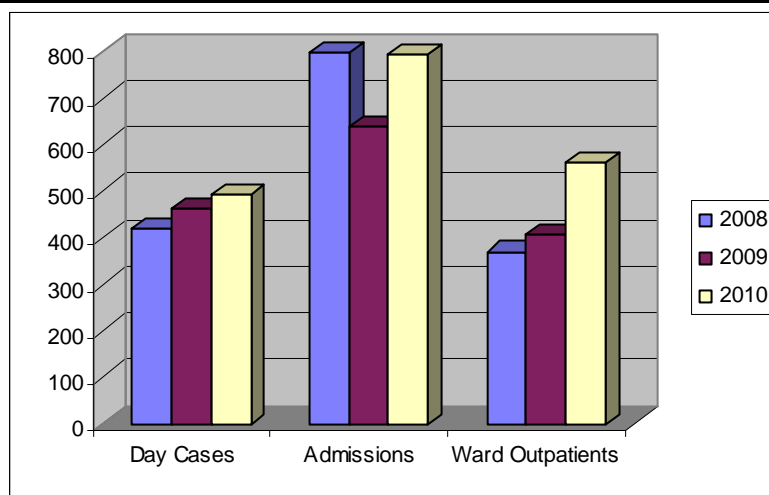
WARD ACTIVITY

The Children's Renal & Urology Unit is housed on Ward E17 in a 10-bedded unit (4 cubicles) which are used flexibly to accommodate renal and urology patients along with medical admissions of children.

Our strong tradition of maintaining patients out of hospital with daycase investigations and community support is reflected in the continued activity of daycases and ward outpatients. We classify ward attenders as ward outpatients as the patients are being assessed by nursing and medical staff on the ward, often at times convenient to the family.

Over the past year activity on the ward has shown an increase in admissions along with increases in ward outpatients and daycases (Figure 1). Nephrology patients accounted for **55%** of activity overall. The number of ward outpatients and day cases continues to increase. The establishment of a Day Case Unit has proved more complex than when first conceived but we continue to work towards that aim in conjunction with the general development of Day Care facilities with the Children's Hospital.

Day Case, Admission and Ward Outpatient numbers from 2008 to 2010



Ward E17 houses the enhanced Elizabeth Ward Dialysis Unit which is a spacious 7-bedded haemodialysis unit with one isolation cubicle. Additional haemodialysis facilities are available in ward cubicles, PICU and HDU and are linked to a water plant expertly maintained by the technical staff.

Ward E17 also houses a treatment room with ultrasound facilities, office accommodation for senior renal nurses, senior sisters office, schoolroom/youth room and playroom. A multipurpose room provides privacy for interviewing families, training for home peritoneal dialysis and small meetings. The juxtaposition of many team members facilitates ease of communication and problem-solving.

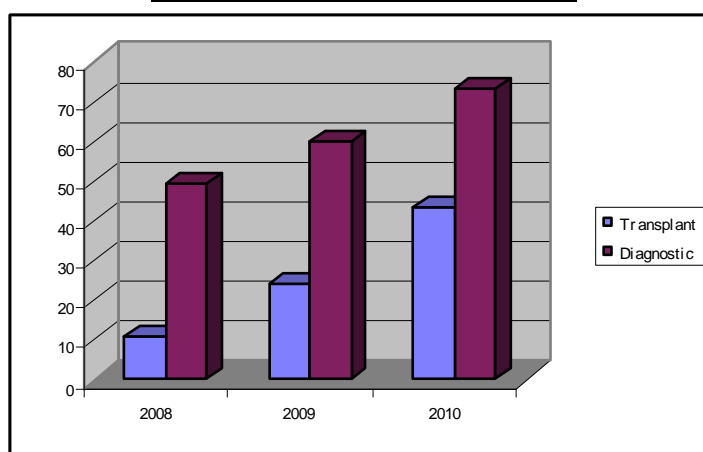
RENAL BIOPSIES

We attempt to do renal biopsies as a daycase procedure whenever possible. A total of **116** biopsies were performed in 2010, an increase of 38% on **84** in 2009. The number of both transplant and native (diagnostic) biopsies increased last year (Figure 2). We rely heavily on the excellent play preparation and support during the procedure provided by our play specialists. Parents are given the option to stay with their child during the procedure which is performed in the treatment room on the ward with ultrasound localisation of the kidneys.

We have responded to the NICE guidelines about sedation in children by discussion with our anaesthetic colleagues. We value the control that ward-based biopsies under sedation gives us and the benefits in terms of ease of a provisional result in urgent cases within 24 hours which is not replicated across all centres, especially where there is insistence that all renal biopsies in children should be performed under general anaesthesia in theatre. We can also report an excellent safety record of managing children under sedation. Changes ahead are likely to include better documentation of observations during the procedure and a formal training package on the delivery of sedation for our junior doctors.

Clinical pathological meetings to review renal biopsies are held monthly with Dr Tom McCulloch and Dr Zsolt Hodi, Consultant Histopathologists. The renal histopathology service remains located at the City Hospital Campus but we are in negotiation about the development of telepathology facilities in the near future which would enable clinico-pathology discussion of acute renal biopsies.

Number of Biopsies 2008-2010



Referral Centres for Native Diagnostic Biopsies in 2010 (n = 73)

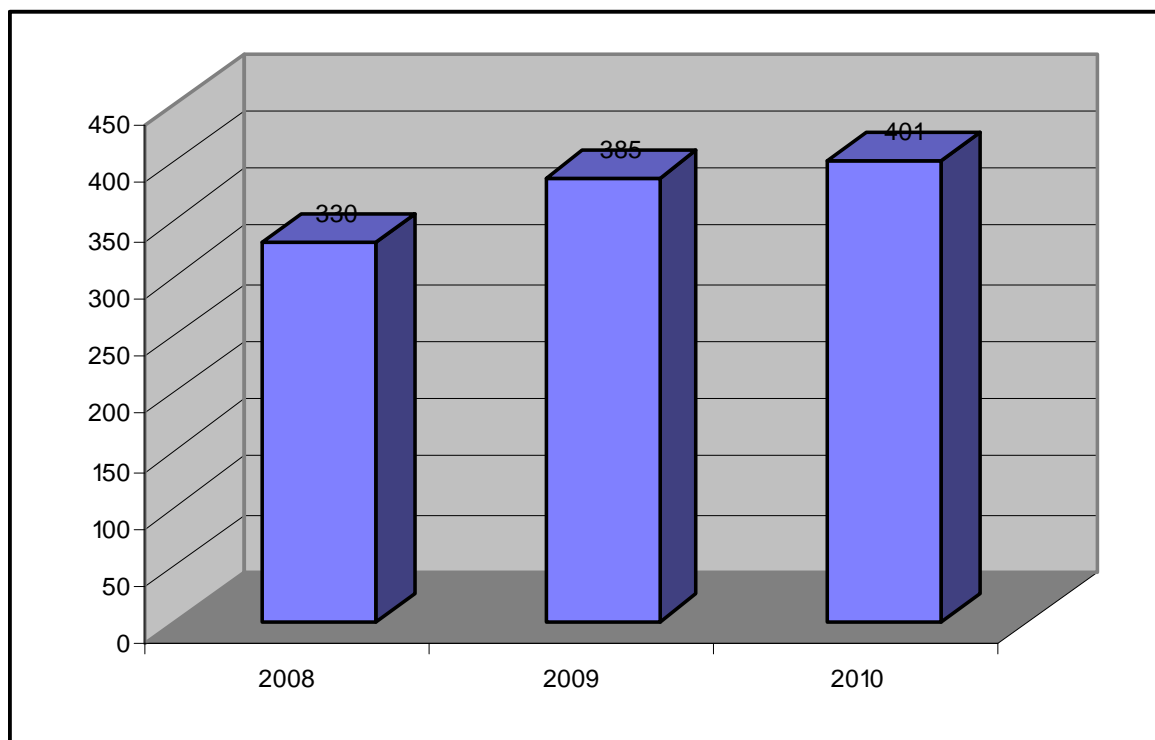
Nottingham	9	Derby	7	Leicester	5
Cambridge	4	Norwich	6	Chesterfield	3
Doncaster	2	Kings Mill	4	Peterborough	6
Rotherham	4	Barnsley	3	Sheffield	7
Lincoln	4	Northants	2	West Suffolk	2
Grimsby	1	Bassetlaw	1		

An ongoing **annual audit** is undertaken of renal biopsies with standards that we have set locally. These have been published [1,2] and were the basis of a national audit which has been published with Nottingham as the data collection centre [3]. Standards for adequate material for diagnosis (>95%) and complications resulting in delayed discharge (<5%) have been met in our local audit.

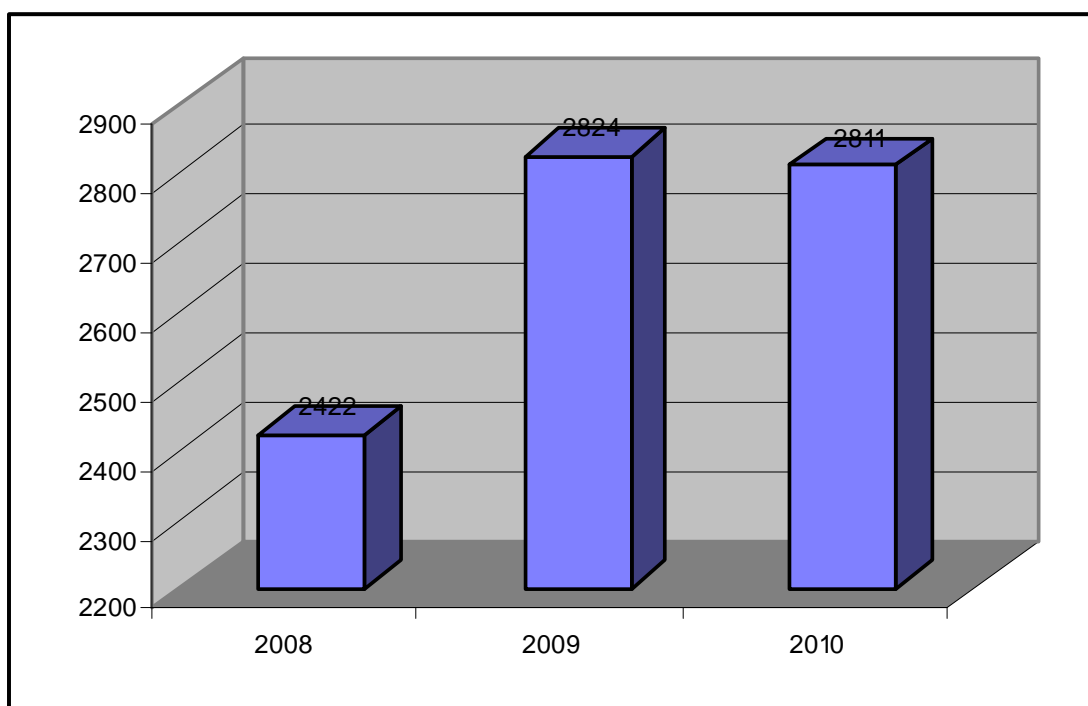
1. Hussain F, Watson AR, Hayes J, Evans JHE. Standards for renal biopsy comparison of inpatient and daycase procedures. *Pediatr Nephrol* 2003;18:53-56
2. Hussain F, Watson AR, Mallik M, Evans J, Christian M. Standards for renal biopsies: an 8-year prospective audit. *Pediatr Nephrol* 2005;20:C103
3. Hussain F, Mallik M, Marks S, Watson AR on behalf of the BAPN. Current practice and audit of renal biopsies in UK paediatric renal centres. *Nephrol Dial Transpl* 2009; DOI: 10.1093/ndt/gfp434

OUTPATIENT ACTIVITY IN NOTTINGHAM (Nephrology Only)

(a) New Patients (total 401 + 48 DNA)



(b) Consultant Initiated (total 2811 + 519 DNA)



- There was an **4%** increase on new patients seen in 2009 (401 compared to 385) along with a **4%** decrease in follow up attendees
- General nephrology clinics are held on Mondays (Dr Hussain along with Mr Shenoy, Paediatric Urologist), Tuesdays (Dr Mallik) and Wednesdays (Dr Lunn, Dr Christian and Dr Evans) when there is a joint clinic with Mr Williams and Mrs Fraser, Paediatric Urologists.
- The major chronic renal failure and transplant clinic takes place on Thursday mornings with members of the multiprofessional team including nursing staff, dietitians, social workers, psychologist, teacher and youth worker in attendance. Numbers for this clinic are becoming excessive and in 2011 we will review the organisation of this clinic to improve the patient experience.
- The nurse-led diurnal enuresis clinic is held on Wednesdays
- Mr Williams has a monthly neurogenic bladder clinic with the urology nurses in attendance.
- A young adult urology clinic is held 3-monthly

We are grateful for the support of Pip Waddington, June Nicholson and the nursing team in the Children's Outpatient Clinic where a great deal of activity takes place.

Unfortunately a number of children require blood tests and this role is largely carried out by nursing staff as there is no dedicated phlebotomy team available for children. Play specialists also help with procedures and children who are needle phobic or who have other problems can benefit from consultations with Dot MacKinlay, Consultant Clinical Psychologist, in the clinic. Dr MacKinlay has produced a DVD on the psychological trauma of painful procedures and how to prepare children for such procedures to minimise the trauma. This is now available to buy through the departmental office.

Antenatal Urinary Tract Abnormalities

29 couples were counselled antenatally either in the Pregnancy Assessment Centre at QMC or in the clinic after referral from fetal medicine specialists. The ante-natal service is led by Dr Meeta Mallik and Dr Farida Hussain in conjunction with the Fetal Medicine Consultants.

Children with antenatally detected urinary tract abnormalities are referred from the neonatal service to the paediatric renal unit for postnatal investigation. In 2010 **9** babies with a mild abnormality antenatally were not seen in the outpatient clinic (with communication to the GP and parents) as the decision was taken not to investigate further on the basis of the postnatal ultrasound.

Transition and Transfer Clinics

Transfer from paediatric to adult renal units only occurs at the end of a process of transition. We continue to refine the transition support that we are providing and transfer clinics to adult services are held each year with Drs Simon Roe, Charlotte Bebb and Catherine Byrne (Nottingham renal physicians), Dr Sarah Jenkins (Sheffield Kidney Institute) and Prof John Feehally (Leicester General Hospital).

Every potential transition patient is given a Transition Plan and transfer is supported by the specialist nurses and the Youth Work Service.

REGIONAL SHARED CARE CLINICS

Regional shared care clinics provide an opportunity not only to see patients locally, but also as a means of discussing problems and protocols with local paediatricians. 841 patients were either seen or discussed in 2010 compared to 812 in 2009 (4% increase). Surveys have emphasised the value of such clinics and the National Service Framework for Children and Renal Services has emphasised the need in taking the service as close to the patients' home as possible.

However, maintaining the regional clinics does place demands upon the service, especially with the travelling time and subsequent follow up correspondence that is required. Previously we have had the benefit of paediatric renal dietetic advice at the larger regional clinics which was commended previously as good practice (*Postlethwaite R. Problems in the commissioning and provision of services for children and young adults. The way forward in renal care for the UK. National Kidney Research Fund, November 2002*). There was some ad hoc nursing support to selected outreach clinics in 2010 but we are not yet in a position to offer this routinely. The concept of outreaching with the multidisciplinary team, however, is a vision to which we aspire.

In 2010, discussions took place surrounding the establishment of a new outreach clinic at Kettering General Hospital and this is now due to commence in 2011. We also negotiated increasing the frequency of an outreach clinic to Addenbrookes Hospital in Cambridge. From the beginning of 2011, there will be a monthly renal clinic at Addenbrookes. The clinic will last for 1.5 sessions: for six clinics per year the afternoon part of clinic will be nephrourology and ante-natal follow-up; on other months the whole clinic will be medical nephrology. We remain concerned that we are not able to offer an outreach clinic to all local hospitals within the catchment area we cover. Discussions are on-going with paediatricians in Doncaster, Hinchingsbrooke and West Suffolk about outreach services in those hospitals.

Numbers of children attending paediatric renal outreach clinics by centre between 2008 and 2010

	2008	2009	2010
Pilgrim Hospital, Boston (3 monthly)	73	76	88
County Hospital, Lincoln (3 monthly)	57	63	48
King's Mill Hospital, Mansfield (3 monthly)	55	62	56
Leicester Royal Infirmary (monthly)	121	113	122
Sheffield Children's Hospital (2 monthly)	38	42	36
Queen Elizabeth Hospital, King's Lynn (4 monthly)	35	45	59
Norfolk & Norwich Hospital (3 monthly)	58	81	82
Addenbrooke's Hospital, Cambridge (3 monthly) Nephrology (am) + Nephrourology (pm)	105	131	113
Peterborough District Hospital (3 monthly)	41	51	58
Rotherham District Hospital (3 monthly)	51	63	67
Chesterfield Royal Hospital (3 monthly)	32	68	58
Derbyshire Childrens Hospital (2 monthly)		17	54
Total	666	812	841

TRENT PAEDIATRIC NEPHROLOGY NETWORK

We meet annually for a general service review with paediatricians with an interest in paediatric nephrology, viz Gail Moss (Sheffield Children's Hospital), Peter Houtman (Leicester Royal Infirmary) and Mona Aslam (Peterborough General Hospital) along with invitations to other regional paediatricians. In most DGHs we have a link paediatrician who is kept informed of any potential developments, meetings or other educational opportunities and an annual report is provided each year.

An annual nephrourology meeting on a themed topic is held in Nottingham to which nephrologists, urologists, radiologists and paediatricians are invited from throughout the Trent & Anglia region. 2010 saw the fifth of these themed symposia. The topic was urinary incontinence and guest speakers included Dr Johan Van Der Walle, Paediatric Nephrologist from Ghent, Belgium and Dr Anne Wright, Neurodevelopmental Paediatrician from the Evelina Children's Hospital in London as well as an annual visit from Dr Marty Koyle, Paediatric Urologist from Denver, USA.

In 2011 there are plans to establish an annual nephrology meeting for paediatricians around the region which would aim to cover the major general nephrology topics in a rolling programme.

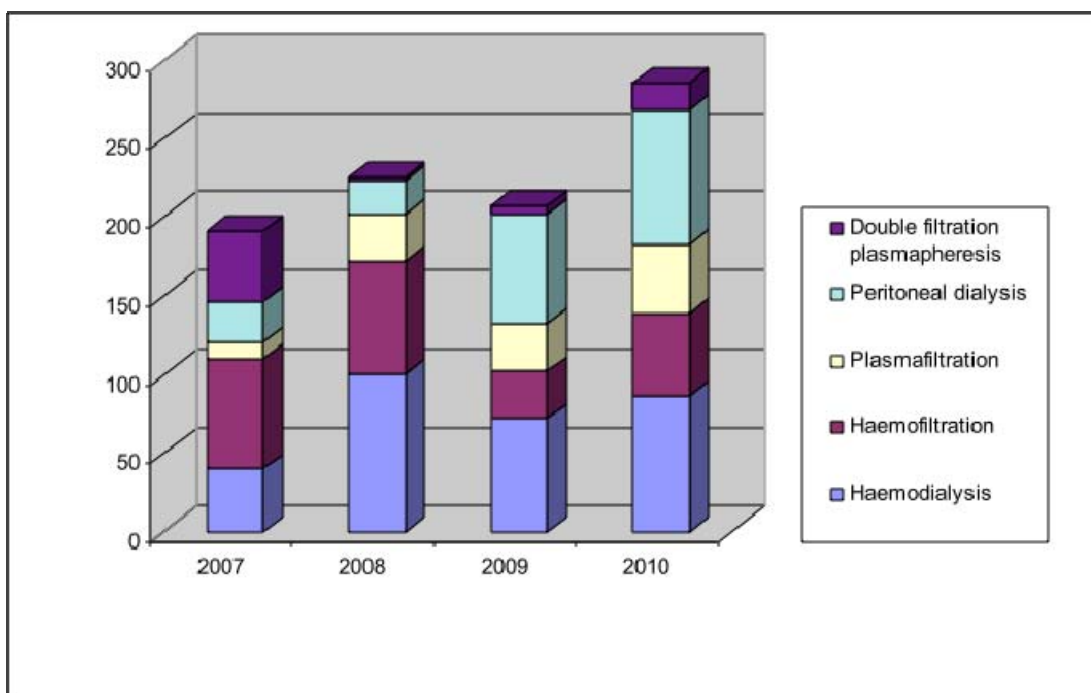


ACUTE RENAL FAILURE

Patients and Treatment

The unit provides all modalities of acute renal replacement therapy on an intermittent or continuous basis and works closely with PICU and PHDU to deliver these treatments. In 2010 36 patients received acute dialysis therapies (14 haemodialysis, 15 continuous haemofiltration, 9 peritoneal dialysis, 7 plasmfiltration and 5 double plasmfiltration). These were either delivered on E17, PICU or PHDU.

Acute dialysis treatment sessions delivered in hospital 2007-2010



CHRONIC DIALYSIS & TRANSPLANT PROGRAMME

Chronic Haemodialysis

A total of **29** patients received haemodialysis as a chronic treatment in 2010 (compared to 23 in 2009 and 24 in 2008).

The number of patient sessions in 2010 was **2352** compared to 2164 in 2009 and 1855 in 2008, representing a 27% overall increase in the haemodialysis workload over the last two years.

The age range of children receiving haemodialysis in 2010 was between 17 months and 19 years.

We had 7 patients aged less than 5 years in 2010, only 1 of whom spent the whole 12 months receiving haemodialysis and the remaining 6 spent between 3 and 11 months attending the unit. Children under 5 years require more intensive nursing care whilst dialysing and this can add greatly to the workload in the unit.

There was an average of 16 patients having haemodialysis treatment per month in 2010 (compared to 14 in 2009). The increased haemodialysis workload increases the number of haemodialysis shifts the senior renal nurses are required to do and consequently impacts on the amount of time within their job plans for their main area of service (chronic kidney disease, peritoneal dialysis or transplantation).

Summary of haemodialysis patients in 2010 (2009 in brackets)

<i>Month</i>	<i>Number of haemo sessions.</i>	<i>Number of patients dialysed</i>
January	203 (154)	17 (13)
February	213 (179)	17 (13)
March	202 (202)	19 (15)
April	201 (191)	19 (16)
May	202 (175)	17 (13)
June	214 (187)	17 (15)
July	213 (178)	17 (14)
August	189 (201)	16 (16)
September	195 (196)	18 (15)
October	178 (192)	12 (15)
November	188 (164)	13 (12)
December	154 (165)	10 (12)
Total	2352 (2164)	29 (23)

Chronic haemodialysis patients received treatment for between 4 weeks and 12 months. Only 5 of the 29 patients remained on haemodialysis for the whole 12 months, indicating the regular turnover of renal replacement modality in children with established renal failure and the input required from staff to commence new patients onto the programme. Table 3 illustrates that the number of haemodialysis patients and sessions remains high despite a large number of children on haemodialysis who were successfully transplanted in 2010.

Haemodialysis patient movement (figures for 2009 in brackets)

<i>New Patients</i>	<i>Haemo for full 12 months.</i>	<i>From PD</i>	<i>To PD</i>	<i>From failed transplant</i>	<i>Successful Transplant</i>	<i>To Adult Unit</i>
20 (10)	5 (7)	5 (4)	7 (6)	1 (1)	7 (2)	2 (3)

Holiday and acute Patients: The Elizabeth Ward Haemodialysis unit still offers a reciprocal arrangement to dialyse children from other centres if holidaying within our region. One patient visited the unit for this purpose in 2010.

Other therapies: Apheresis treatments increased in 2010 with 4 patients being treated regularly in the haemodialysis unit for different conditions. These treatments are in addition to the regular haemodialysis workload.

Double filtration plasmapheresis (DFPP): is a therapy which can be used to treat children with a variety of complex conditions. The Children's Renal and Urology Unit was the first in the UK to use this treatment in children, and we have now have over 5 years' experience with the treatment modality.

Currently 2 patients with familial hypercholesterolemia receive lipopheresis using this technique on a weekly basis to maintain their lipid profiles. Recently we altered the therapy to 'Thermo' DFPP and have seen a significant improvement in maintaining cholesterol levels within the normal range.

DFPP has also been used in the acute setting for the treatment of immunological conditions including, humoral rejection and disease recurrence in renal transplants. As predicted in last year's annual report, the use of DFPP in the treatment of transplant rejection has increased in 2010.

Number of lipopheresis treatments: **88** (51 in 2009)

Number of treatments for other conditions: **56**

Plasma exchange: is used in the treatment of acute conditions such as haemolytic uraemic syndrome (HUS) and meningococcal sepsis. Again these treatments are carried out by the specialist nursing team in any area they are needed including PICU, PHDU and E17 as well as the haemodialysis unit. Often, this therapy needs to be instigated quickly and those circumstances, the on-call renal nurse may be called upon to deliver the treatment at any time of day or night.

The therapy can also be used for the long term treatment of some chronic conditions such as recurrence of primary disease in transplantation.

No. of treatments: **44** (acute and chronic)

Central Venous Lines

We continue to use the Kimal central venous lines for chronic haemodialysis patients. During 2010 we continued to use Alteplase as our standard lock for all long term CVLs. Our on-going audit of the central venous lines shows that we are having less problems with occlusion and infections; and the machine flow rates we achieve has risen since the change from heparin or Taurolock to Alteplase.

We continued to have a low number of central venous line infections throughout 2010: only 3 infections despite the large number of patients and treatments which is an improvement on previous years (4 in 2009 and 6 in 2008).

AV Fistula

Three patients had an arteriovenous fistula surgically created in 2010. One patient with an existing fistula was transferred to the adult unit. No infections or problems were encountered.

Aims and Objectives

As in 2009, we made very good progress with our objectives set for 2010. These were, to complete the audit for Alteplase and demonstrate the benefits for dialysis adequacy and to introduce a new audit tool to aid data collection. Our objective to increase the number of dialysis stations in the main unit was reconsidered and put on hold due to staffing issues. We also put our use of haemodiafiltration (HDF) on hold until we had confirmation of the enhanced water quality required for this treatment. We have now restarted HDF treatments and plan to further expand its use.

In 2011, we plan to:

- further develop audit tools to allow analysis of all areas including the benefits of haemodiafiltration
- further use of haemodiafiltration
- increase the use of AV fistulae
- develop the use of dialysis-specific information for patients and parents
- establish a haemodialysis parents support group

Roy Connell
Clinical Nurse Specialist – Dialysis



Chronic Peritoneal Dialysis

A total of **31** patients received chronic peritoneal dialysis for all or part of 2010. From 2008 when there were a record number of 27 patients who received PD, the figures have increased for the second year sequentially.

A total of **17** families were trained to undertake peritoneal dialysis at home during 2010 (13 new patients and 4 families retraining). This has also increased from previous years with 8 trained in 2009 and 14 in 2008. These numbers highlight the changing needs of the PD caseload, with high numbers of patients entering and leaving the program, alongside those who remained on PD for throughout the year. We recognise that those families with children on PD for over a year have an increased risk of increased infection risk and psychological burn out.

The caseload was managed by:

One full time Clinical Nurse Specialist (with 20% haemodialysis commitment)

One Band 6 Renal Nurse (0.8 WTE with 40% haemodialysis commitment).

PD Patient movement (figures for 2009 in brackets).

<i>Remain on PD</i>	Changed to haemo	Transplanted	Transferred to adult services
19 (16)	3 (2)	11 (7)	0 (1)

Inpatient admissions

There was an increase in inpatient admissions of children on chronic PD in 2010 with 212 days. This compares to 170 days in 2009 and 225 days in 2008

Peritonitis

16 episodes of peritonitis in 271 patient months were identified in 2010, giving an incidence of **1 in 17** patient months. This is a slight improvement on previous years results (1 in 16 patient months during 2009 and 1 in 15 patient months during 2008). This meets the Renal Association standard of 1 in 14 patient months (*Renal Association Standards Document 3rd ed 2002*). 30% of the PD patients were aged less than 5 years and therefore fall in the higher risk category for infections. This age group contributed to 50% of the peritonitis episodes.

The unit's **5-year** peritonitis rate remains at **1 in 16** patient months. This is a more accurate reflection of peritonitis rates, which shows that overall we are keeping within the standard in this area.

Exit site infections

Exit site infections have again continued to affect only small numbers of patients. No changes have been made in this area but again, diligence in this area is encouraged.

Catheter loss

A total of 9 catheters were removed or replaced during 2010 compared to 4 in 2009:

- 4 due to infection
- 2 due to dysfunction
- 2 due to damage (split)
- 1 due to leakage

Community visits

A total of 24 community visits were made throughout 2010, compared to 32 in 2009. The community/outreach side of the service has been severely stretched with increased pressure from haemodialysis numbers. This represents the lowest number of visits carried out in any one year.

This remains a major area of concern and in order for us to maintain nationally-agreed standards in the PD program and adequately support patients/families at home, it is imperative that the frequency of community visits increases.

Update program

The locality based update visits, commenced in 2009, have unfortunately not continued in 2010. The increased workload in PD and haemodialysis has led to these visits being put on hold. It is hoped that they can be re-introduced in 2011, as they are seen as an important part of the support and continuing education process.

Aims and Objectives

Further progress in reducing the rates of peritonitis and hospital admissions remain one of the priorities for the chronic PD program. The re-introduction and increased frequency of the update visits is seen as the first move towards improvement.

Other aims include:

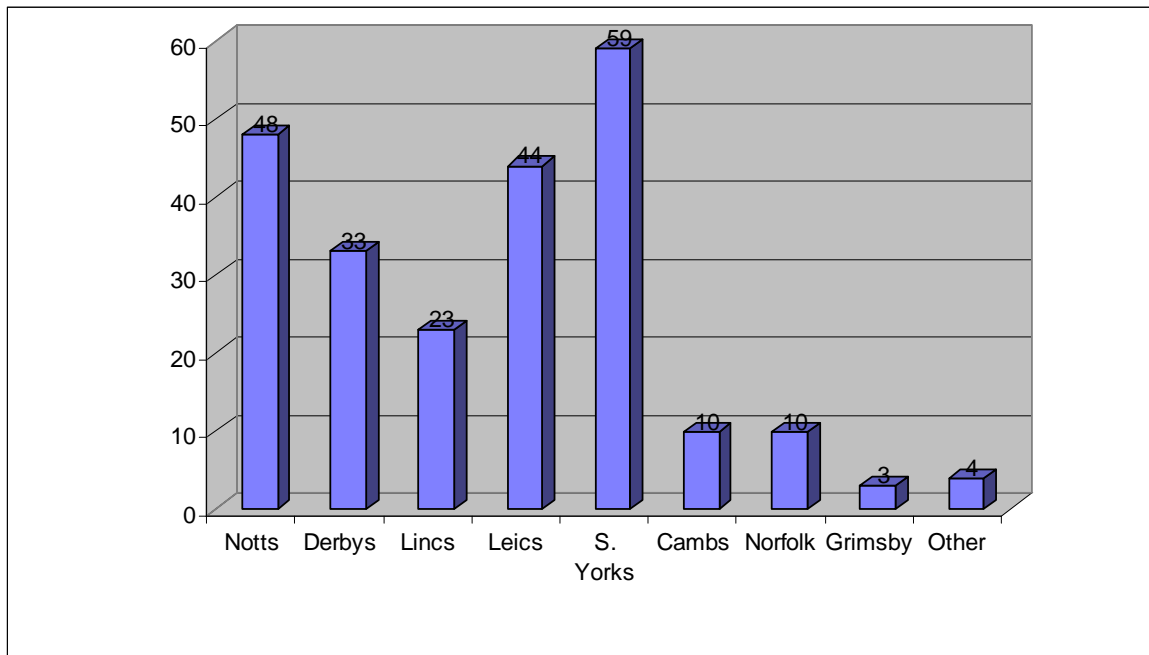
- The development of peritoneal dialysis specific information for patients and parents
- A review of the peritonitis treatment pathway.

Roy Connell
Clinical Nurse Specialist

Sharon Mould
Renal Nurse

Transplantation

Paediatric Transplants Nottingham 1985-2010 – Area of Origin of Recipients



- One year graft survival from living donor transplants for children transplanted between 2005 and 2009 inclusive is 90% (national average: 97%; confidence interval (94 – 98%))
- Five year graft survival from living donor transplants for children transplanted between 2001 and 2005 inclusive is 94% (national average: 91%; confidence interval (96 – 94%))
- One year graft survival from deceased donor transplants for children transplanted between 2005 and 2009 inclusive is 82% (national average: 94%; confidence interval (90 – 96%))
- Five year graft survival from deceased donor transplants for children transplanted between 2001 and 2005 inclusive is 67% (national average: 81%; confidence interval (77 – 85%))

UK Transplant

In some areas our results are at the lower end of the national range. All paediatric centres transplant small numbers of children and are subject to large variations in survival rates. We suspect that our figures are low because in this time period a small number of transplants failed immediately or soon after transplant. We are, however, reviewing the 7 out of 77 cases which failed in this time period to ensure that any improvements we can make are being made. In the 43 transplants carried out in children in Nottingham since January 2009 we have had only two early transplant failures (95% graft survival) which is comparable to the national average.

In 2010 the Unit performed 20 transplants, compared to 13 in 2009. All the transplants were successful. The highest previous number was 16 in 1999. The transplant team also performed 100 transplants in the adult unit in 2010 which represents an increase of 50% on 2009.

In part these large increases are due to a widening of the donor pool. In 2010 we performed our first altruistic donor transplants. Altruistic donors, who volunteer to donate a kidney without specifying the recipient have increased in number across the country although still represent a relatively small number of transplants. The details of donor and recipient are kept anonymous from each other although, as with deceased donors, the recipient family are encouraged to write a non-identifying letter of thanks which is then passed onto the donor via transplant co-ordinators.

Another paediatric patient received a successful *en bloc* kidney transplant which was another first for the unit. This is the use of two small kidneys with the adjoining aorta where each kidney would

be considered too small to use individually. The patient in question benefited from the *en bloc* transplant and now is off dialysis and progressing well. Within the adult unit, there has been an increase in the use of circulatory death (DCD) as opposed to brain death (DBD) donors. Nationally this has increased the donor pool considerably. As yet we have not carried out any in children in Nottingham but we discuss each kidney offer on its merits and this source of donor does have the potential to increase the number of transplants in children.

Three patients received a kidney from a living related donor, either from a father or mother. All three of these patients are doing well at present. The remaining 15 children or young people received deceased donor transplants and at the present time all are working successfully.

Of children transplanted in 2010, their pre-transplant treatments were:

- Peritoneal dialysis: 11
- Haemodialysis: 6
- Conservative (pre-emptive transplants): 3

During 2010 there were 82 children with renal transplants under follow-up in the unit. These included 2 patients whose care was shared: one with Birmingham Children's Hospital and one with Great Ormond Street Hospital. At the end of 2010 there were a total of 69 transplant patients. Two patients' graft function deteriorated and they returned to dialysis (one to peritoneal dialysis and one to haemodialysis). The care of 11 patients was transferred as follows:

- 10 patients transferred to adult renal units (2 to Norwich, 2 to Nottingham, 4 to Sheffield, 1 to Leicester and 1 to Lincoln)
- 1 patient transferred care to Great Ormond Street Hospital

At the end of 2010 there were 23 patients active on the transplant list and 18 patients waiting to go on the transplant list.

The transplant nursing team comprises a (1.0 WTE) clinical nurse specialist (CNS) and a staff nurse (0.6 WTE). With the high number of transplant this year, there has been a high turnover of ward attenders. The transplant CNS saw 105 ward attenders. In-patient ward activity has also been high and has regularly required the support of specialist nurses. At least 140 hours of such additional ward support work have been carried out by transplant specialist nurses in 2010.

The transplant nurses remain active in attendance at renal clinic, with over 850 patients seen during 2010. The role of the specialist nurses in clinic includes administration of iron infusions and 27 children received iron infusions in clinic, preventing them from having to attend the ward for an infusion. Alongside their roles in transplantation, the transplant nurse, the staff nurse and CNS cover haemodialysis. The staff nurse worked 412 hours and the CNS worked 218 hours, which includes some on call work.

Patients that reach chronic kidney disease (CKD) stage 3 to 4 are asked to attend a CKD day at the hospital. This day consists of various tests and meeting staff in preparation for either dialysis or transplant. The transplant staff nurse carried out 12 CKD days in 2010.

During 2010 27 patients and their families received home visits. The purpose of these visits was: for follow-up of a CKD day; a general transplant update; before live donor transplant to plan around the date of operation; and young people transitioning before transfer to adult services. Along with home visits the transplant clinical nurse specialist visited 6 schools and attended 1 multi-professional team meeting in 2010. Total mileage was 2700 miles.

Communication remains a large part of the transplants nurses' role. Approximately 850 phone calls were made to patients, health care professionals or schools. In addition there were approximately 400 calls received from parents, patients and professionals.

This is a surprising number due to the introduction of a pager system in March. The pager system enables the patient or parents to contact a nurse 24/7. Renal specialist nurses hold the pager during the day and the ward staff during the night and weekend. There has been a separate audit on the pager use and it is proven to be the quickest turn around to patients/parents calls.

The transplant CNS liaises closely with the adult transplant coordinators. There is a quarterly paediatric transplant meeting with co-ordinators, tissue typing specialists and transplant surgeons. These meetings discuss all children/young people on the transplant waiting list or working towards it. The meeting also discusses future live donor transplants. The CNS and live donor coordinator work in conjunction with each other. The CNS discusses with family members about live donation, giving out a health questionnaire to interested parties. The questionnaire is reviewed by the coordinators when the donor has their first appointment. Of 20 potential donors considered from 2009:

- 3 live donors were performed in 2010
- 6 were not required as the recipients received deceased donor transplants
- 1 live donor transplant was carried out at Great Ormond Street Hospital
- 7 donors were not suitable for various reasons
- 1 donor continues work up for 2011

Separately to these donors 28 more questionnaires were sent out to potential donors in 2010. Two potential donors were not compatible; four are being followed up for 2011; 8 were not required because the recipients received deceased donor transplants; and one donor did not progress because a partner progressed with their work-up instead.

Transition is important to our unit, making every effort to work with adult services within the region to improve the transition for young people. The CNS works very closely with the youth worker and other health care professionals. Clinics at Nottingham and Sheffield have developed. Contacts at Norwich and Leicester have also improved. Developments for 2011 include the involvement of young people. Meetings have been set up in three cities (Nottingham, Leicester and Sheffield) to plan a generic residential, to improve documentation for transition process and to develop leaflets about the effect of drugs, smoking and alcohol on the transplanted kidney.

The transplant nurses attended the Nephrology Nurses Conference in Bristol. Whilst in Bristol they visited the headquarters of UK Transplant. The transplant nurse attended ITNS study day. The CNS attended two study days for Renal Patient View and Renal Education Network.

Recent developments in transplantation that are already underway in the adult unit in Nottingham may enable the Children's Renal and Urology Unit to carry out more transplants. The techniques include: paired/pooled exchange of living donors; ABO incompatible donation; and transplantation in highly sensitised individuals.

Kim Helm
Transplant Clinical Nurse Specialist

Kate Baker
Transplant Staff Nurse

QUALITY ASSURANCE AND AUDIT

Quality Assurance

- Consultant delivered service. The most invasive procedures such as renal biopsies, placement of acute dialysis catheters and immediate transplant supervision are carried out by the consultant or specialist registrars under close supervision.
- All new outpatient referrals are screened by the consultant and if new patient referrals are seen by the specialist registrar they are also discussed with the consultant.
- A 24 hour on-call service is provided by consultant and specialist renal nurses with a direct telephone line to the renal pager.
- Consultants are available 24 hours a day for advice calls to other paediatric units throughout the East Midlands, South Yorkshire, East Anglia and the East of England.
- Specialist renal nurses have the ENB 136/147 course or appropriate training modules and provide continuity of patient care between hospital and home.
- Close support post renal transplant by a transplant nursing sister who coordinates blood samples locally wherever possible.
- Joint visits made to the home, nursery or school and general practitioner by named nurse, social worker, and sometimes dietitian and school teacher.
- Further support for families with a child at home on home peritoneal dialysis by the respite care renal nurse with an evening babysitting service (funded by charitable donations and suspended at present but planning to restart in 2011)
- Specialist urology nurses supervise children undergoing intermittent catheterisation and bladder training and also attend specialist clinics for neuropathic bladder.
- Investigation of children requiring radiological investigations of the urinary tract and/or renal biopsies are coordinated by a named nurse on the ward.
- Play preparation packages developed by play specialists and support given during potentially distressing procedures.
- Extensive literature and audiovisual materials available to families, most of which has been produced by our team.
- Newsletter twice a year distributed to all established renal failure patients.
- Access to families to Renal Patient View for direct confirmation of their blood results on computer.

Multidisciplinary Team Working

- Patient review meeting held at the end of ward round, Monday and Friday, with the use of the data contained on the renal computer
- Nephrourology x-ray meetings held weekly to discuss the surgical care and medical follow-up of children with complex urinary tracts.
- Monthly paediatric biopsy meeting with pathologists to review histology together and discuss complex cases amongst consultants.
- Paediatric transplant meetings held quarterly with transplant surgeons, tissue typists and transplant coordinators to discuss children on the UK transplant waiting list or preparing to be listed.
- A regular multidisciplinary meeting to discuss psychosocial aspects of care is held after the Thursday chronic renal failure clinic.
- Team meetings held monthly with an open agenda to discuss general and specific issues such as risk assessment.
- Time out meetings held annually to discuss unit philosophy and policies.
- Regular meetings with laboratory colleagues to discuss problems with samples and test results
- Parents Group organised by senior nurse, social workers and psychologist is planned to meet annually and is a valuable means of parents discussing issues which directly affect the quality of care offered by the unit.
- Feeding Support Group organised by dietitians and psychologists meeting twice yearly to support parents of children with difficult feeding.

- Nephrotic support day organised every 2-3 years with the aspiration of more regular meetings around the region.

Protocols

There is an extensive manual of procedures and protocols which are regularly revised.

Audit

- Multidisciplinary audit programme initiated in 1996 involving assessment of daycase work, procedures, nutrition and growth and psychosocial care (with reference to Renal Association standards).
- Audit of acute renal failure, biopsies, renal transplants, growth and nutrition is part of a rolling programme of annual audit. We are grateful for the support of the Clinical Effectiveness Department for help with the audit.
- Monthly audit meetings are held with the general paediatricians.
- All paediatric nephrologists participate in national and regional audit meetings for the British Association for Paediatric Nephrology.
- Data collection for the National Paediatric Renal Registry is coordinated by Judith Hayes.

Additional Postgraduate Meetings

- Joint half-day meeting with the adult renal unit to discuss cases and important common topics.
- Educational departmental meeting Monday 1200 hrs
- 3-monthly academic transplant meeting with adult renal unit and transplant surgical team, organised by Dr Christian.
- Paediatric postgraduate meeting Thursday 1600 hrs

TEACHING

Medical Undergraduates

- Regular tutorials were held on both general paediatric and renal topics. Students are attached to the renal unit for 8 weeks at a time during which time they have the opportunity to attend the general and specialist nephrology clinics.
- Special study module students on a regular basis (twice yearly from 2011) for specific study of paediatric nephrology during which time they undertake a small audit or research project.

Postgraduates

- Participation in organised teaching programme for paediatric trainees in Nottingham
- Specialist registrar teaching sessions also organised for the Eastern Deanery in Cambridge by Dr Christian and Prof Watson
- Prof Watson organises the paediatric module of the Masters/Diploma in Nephrology course run by Sheffield Kidney Institute. A number of team members lecture on the module.
- Consultants participate in MRCPCH teaching and Prof Watson is an MRCPCH examiner.

Multidisciplinary Team

- Nursing staff are involved in lectures to nursing undergraduates and paediatric renal, intensive and neonatal care.
- We continue to provide e-mail support clinical advice to units in Egypt, Jordan, Saudi Arabia, Iraq, Poland and Trinidad

NATIONAL AND INTERNATIONAL POSITIONS HELD

- Dr Farida Hussain is on the audit committee of the BAPN
- Dr Meeta Mallik is on the clinical standards committee of the BAPN
- Prof Alan Watson acts as Medical Adviser to Kidney Research UK and the National Kidney Federation
- Prof Alan Watson is the BAPN paediatric representative on the International Committee of the Renal Association (UK) and a member of the International Paediatric Nephrology Council
- Chris Rhodes is the chair of the RCN Childrens and Young Persons Continence Community, Secretary to the European Society of Paediatric Urology Nurses Group and Board member for the Paediatric Continence Forum
- Heidi Steward is the chair of the UK Renal Social Workers Special Interest Group

Awards

- Prof Alan Watson awarded WellChild Doctor of the Year

Innovations

- Introduction of the use of Entonox for urethral catheterisation of children
- Introduction of Rituximab to treat steroid dependent and steroid resistant nephrotic syndrome

Charity Funding

- We are grateful to the British Kidney Patient Association (BKPA) for their continued support of many families and projects
- Much of the financial support for holidays, literature production and research is provided by the Kinder Appeal



SISTER RENAL CENTRE LINK

- In January 2010 Prof Watson, Shelley Jepson and Pearl Pugh made a second visit to Soba University Hospital in Khartoum, three years after the first visit. There had been significant developments in that time. A new 4-bedded paediatric intensive care unit had been built in preparation for paediatric transplant patients. The number of haemodialysis patients had grown considerably from 21 to 43. There has been a further senior doctor appointed and senior nursing posts remain well covered. However, there are still challenges establishing other members of the multidisciplinary team including dietetics, social work and teachers.
- In June 2010 we welcomed three visitors from Soba University Hospital: Dr Rashid Ellidir (senior doctor), Salima Yahia Abdel Gadir (transplant coordinator nurse) and Wigdan Alamin (renal dietitian). They spent 3 weeks observing delivery of care with their relevant specialty colleagues. All felt the visit was very beneficial. Their reflection of future priorities from the learning experience was to try to improve documentation and case note organisation, to establish dietetic support for renal patients and to establish multidisciplinary meetings (such as radiology meetings with urologists and clinico-pathology meetings surrounding renal biopsies).
- In 2011 Prof Watson hopes to visit Sudan once again and we anticipate further visits in each direction in the future.



RESEARCH ACTIVITY

Research & Development Approved Projects

- International Pediatric Peritoneal Dialysis Network 2007
- Prospective registry of antenatally detected urinary tract abnormalities (N)880A01
- Long-term follow up of European Multicentre Trial – An open, randomised, multicentre clinical study to investigate the safety and efficacy of steroid withdrawal with tacrolimus, mycophenolate mofetil and dacluzimab against tacrolimus, mycophenolate mofetil and steroids in children after kidney transplantation (TWIST Study) 2010-

In Partnership with the Medicines for Children Research Network

- MYCYC. A comparison of mycophenolate mofetil with cyclophosphamide in children with systemic ANCA-associated vasculitis. Principal investigator: Dr Christian
- TAKEDA. A pharmacokinetic study of a new angiotensin 2 receptor blocker for children with hypertension. Principal investigator: Prof Watson
- RaDaR (Rare renal disease registry) and associated studies of children with steroid-resistant nephrotic syndrome (SRNS) and membranoproliferative glomerulonephritis (MPGN). SRNS study commenced 2010; MPGN study awaiting national amendments. Principle investigator: Dr Christian
- PREDNOS. Long-term tapering or standard steroids for nephrotic syndrome (BAPN collaborative study with Dr Nick Webb [Manchester]). Commencing 2011
- Pharmacokinetic study of Cinacalcet in young children. To commence in 2011. Principal investigator: Dr Lunn

Other Projects Include:

- A prospective study of the outcome of multicystic dysplastic kidney (in conjunction with members of the Trent & Anglia Nephrourology Group)
- The management of urinary tract infection in children <5 years of age (CUTIS)
- Quality of Life for children with chronic renal failure (service evaluation) in collaboration with Dot Mackinlay, Consultant Clinical Psychologist

PUBLICATIONS IN 2010

Chapters

Hussain FK, Castledine C, van Schalkwyk D, Sinha MD, Lewis M, Inward C. UK Renal Registry – the Twelfth Annual Report – December 2009, Chapter15 – Clinical, Haematological and Biochemical Parameters in patients receiving renal replacement therapy in paediatric centres in the UK in 2008: national and centre-specific analysis

Watson AR. Hematuria and proteinuria. In: Godbole P, Koyle M, Wilcox D (eds). Paediatric Urology in Clinical Practice (in press)

Papers

NICE clinical guideline 111: Nocturnal enuresis: the management of bedwetting in children and young people. October 2010. (Jonathan Evans was Chair of Guideline Development Group) <http://www.nice.org.uk/guidance/CG111>

Neveus T, Eggert P, Evans J et al, 2010. Evaluation of and Treatment for Monosymptomatic Enuresis: A Standardisation Document From the International Children's Continence Society. *J Urol* 183: 441-447

Delgado Nunes V, O'Flynn N, Evans J, Sawyer L, 2010. Management of bedwetting in children and young people: summary of NICE guidance. *BMJ* 341:c5399

Lunn A, Ravenscroft J, Watson AR (2010). Cutaneous warts in children before and after renal transplantation. *Pediatr Nephrol* 25(5): 941-6.

Lunn A, Holden S, Boswell T, Watson AR (2010). Automated microscopy, dipsticks and the diagnosis of urinary tract infection. *Arch Dis Child* 95(3):193-7.

Lunn A, Watson AR, Suri M (2010). Extreme hypernatraemia, breast-feeding and red skin. *Pediatr Nephrol* 25(2):379-80.

Strazdins V, Watson AR, Schroder C, Edefonti A, Fischbach M, Stefanidis CJ on behalf of the European Paediatric Dialysis Working Group. Prevention and treatment of cardiovascular risk factors in children with chronic kidney disease. (submitted)

Maxwell H, Mackinlay D, Watson AR. Quality of life or health status in children with chronic kidney disease. *Pediatr Nephrol* 2010;25:1191-1192

Watson AR, Abdelraheem M, Ali EI-T, Jepson S, Razig SA. Developing paediatric nephrology in a low income country using a sister centre link: The Sudan Experience. *Pediatr Nephrol* 2010;25:1569-1571. DOI 10.1007/S00467-009-1421-5

O'Grady JGM, Asderakis A, Bradley R, Burnapp L, McPake DM, Perrin M, Russell S, Watson AR, Watson CJ, Wray J, Wilson LC. Multidisciplinary insights into optimising adherence following solid organ transplantation. *Transplantation* (in press)

Larcher V, Slowther A-M, Watson AR on behalf of the UK Clinical Ethics Network. Core competencies for clinical ethics committees. *Clin Med* 2010;10:30-33

Grenda R, Watson AR, Trompeter R, Tonshoff B, Jaray J, Fitzpatrick M, Murer L, Vondrak K, Maxwell H, van Damme-Lombaerts R, Loirat C, Mor E, Cochat P, Milford DV, Brown M, Webb NJA. A randomized trial to assess the impact of early steroid withdrawal on growth in pediatric renal transplantation: the TWIST* study. *Am J Transpl* 2010;10:828-836

Lane JC, Warady BA, Feneberg R, Majkowski NL, Watson AR, Fischbach M, Kang HG, Bonzel KE, Simkova E, Stefanidis CJ, Klaus G, Alexander SR, Ekim M, Bilge I, Schaefer F, for the IPPR. Relapsing peritonitis in children who undergo chronic peritoneal dialysis: a prospective study of the International Pediatric Peritonitis Registry. *C J Am Soc Nephrol*. Epub. April 2010

Abdelraheem MB, El-Tigani MA Ali, Mohamed RM, Abdalla OA, Mekki SO, Yousif BM, Watson AR. Pattern of glomerular diseases in Sudanese children: a clinicopathological study. *Saudi J Kidney Dis Transplant* 2010;21:778-783

Prayle A, Watson AR, Fortnum H, Smyth A. Side effects of aminoglycosides on the kidney, ear and balance in cystic fibrosis. *Thorax* 2010;65:654-658

Webb N, Harden P, Lewis C, Tizzard S, Walsh G, Wray J, Watson A. Building consensus on transition of transplant patients from paediatric to adult healthcare. *Arch Dis Child* 2010;95:606-611

Watson AR. Urinary tract abnormalities detected antenatally: Investigations and management. *Paediatr Child Health* 2010;20:286-290

Rees L, Azocar M, Borzych D, Watson AR, Buscher A, Edefonti A, Askenazi D, Leozappa G, Gonzales C, van Hoeck K, Secker D, Zurowska A, Ronnholm K, Bouts A, Stewart H, Ariceta G, Ranchin B, Warady BA, Schaefer F. Factors affecting growth in children younger than two years undergoing chronic peritoneal dialysis: a prospective study from the International Pediatric Peritoneal Dialysis Network.

Watson AR. The continuum of transition from paediatric to adult renal care. *J Ren Nurs* 2010

CONFERENCES AND PRESENTATIONS

Conference Presentations

Batte S, Steward H, Watson AR. Social work support for children and families with acute kidney injury. 21st European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure. Helsinki, Finland. 6-8 May 2010

Hayes W, Watson AR. Unilateral multicystic dysplastic kidney: does size matter? Trent Paediatric Society Meeting, Barnsley 28.6.2010

Hayes W, Watson AR. How long should we follow children with unilateral multicystic dysplastic kidneys (MCDK)? 15th Congress of the International Pediatric Nephrology Association, New York, USA. 2010. *Ped Nephrol* 2010;25:1970

Heath J, Mackinlay D, Watson AR. Does chronic renal failure affect the quality of life of children and young people? Trent Paediatric Society Meeting, Barnsley 28.6.2010

Hussain FK. Alteplase in pediatric hemodialysis patients. Does it reduce catheter dysfunction, infections and the need for revisions? A prospective study. International Pediatric Nephrology Association, New York, September 2010

Hussain F, Connell R, Lunn A. Alteplase (tPA) in pediatric hemodialysis (HD) patients – does it reduce catheter dysfunction, infections and the need for revisions? 15th Congress of the International Pediatric Nephrology Association, New York, USA. 2010. *Ped Nephrol* 2010;25:1941

Lunn AJ. The incidence, outcome and risk factors for recurrent FSGS following renal transplantation. International Paediatric Nephrology Association, New York, September 2010

Lunn AJ. Membranoproliferative glomerulonephritis (MPGN) type 1 - A case for complement therapy? International Paediatric Nephrology Association, New York, September 2010

Lunn AJF, Watson AR. Should reflux nephropathy be reclassified as reflux associated damage (RAD)? 15th Congress of the International Pediatric Nephrology Association, New York, USA. 2010. *Ped Nephrol* 2010;25:1848

Lunn A, Langlois V, Licht C. Membranoproliferative glomerulonephritis (MPGN) Type 1 – a case for complement therapy? 15th Congress of the International Pediatric Nephrology Association, New York, USA. 2010. *Ped Nephrol* 2010;25:1876

Lunn A, Langois V, Hebert D. The incidence, outcome and risk factors for recurrent FSGS following renal transplantation. 15th Congress of the International Pediatric Nephrology Association, New York, USA. 2010. *Ped Nephrol* 2010;25:1891

Mackinlay D, Heath J, Watson AR. Does chronic renal failure affect quality of life for children and young people? 21st European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure. Helsinki, Finland. 6-8 May 2010

Watson AR, Currie G, Starr T. Integrating clinical and psychosocial knowledge through knowledge brokering (KB) in a paediatric nephrology multiprofessional team. 15th Congress of the International Pediatric Nephrology Association, New York, USA. 2010. *Ped Nephrol* 2010;25:1933

Invited Lectures

Evans JH. Introducing the NICE Guidelines – Nocturnal Enuresis. ERIC National Conference. Birmingham, 2 December 2010.

Evans JH. Development of Renal Function. British Association of Paediatric Urologists Annual Course. Cambridge, 17 September 2010.

Evans JH. Management of Monosymptomatic Nocturnal Enuresis. International Children's Continence Society Course, Rio de Janeiro Brazil, March 2010.

Evans JH. Successes & challenges for Paediatrics in Nottingham. Trent Paediatric Society & Trent Local Children's Research Network 3rd Annual Conference. Nottingham, 11 February 2010.

Lunn AJ. Managing nephritis in a DGH. Barnsley District General Hospital, October 2010.

Mallik, M. Follow-up of antenatally-detected urinary tract abnormalities. Festschrift for the retirement of Prof Alan Watson, September 2010.

Watson AR. Nephrology for General Practitioners. Manchester Royal Infirmary 12 Jan 2010.

Watson AR. Can we make them grow? Health Research Seminar, Feb 2010

Watson AR, Hackett D. Smaller gaps and bigger bridges. East Midlands Renal Education Course, Loughborough 3 Mar 2010.

Watson AR. UTI – Know the protocols. International CME on Pediatric Nephrology, Surat, India. March 2010

Watson AR. Nephrourolithiasis – evaluation and management – medical perspective. International CME on Pediatric Nephrology, Surat, India. March 2010

Watson AR. Antenatally diagnosed urinary tract abnormalities. International CME on Pediatric Nephrology, Surat, India. March 2010

Watson AR. Adolescent transition. The Northern Postgraduate Nephrology Course, St James's University Hospital, Leeds. March 2010

Watson AR. Ethical considerations in CAD and transplantation. 21st European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure. Helsinki, Finland. 6-8 May 2010

Watson AR. Why are we so slow to introduce enteral feeding? BRS/Renal Association Conference, Manchester. May 2010

Watson AR. Transition into adult care. 15th Congress of the International Pediatric Nephrology Association, New York, USA. 2010

Watson AR. Perspectives on renal transplantation in children. Conference of Lithuanian Nephrology, Dialysis and Transplantation Association dedicated to 40 years of renal transplantation in Lithuania. Kaunas, Lithuania. 17 September 2010.

Watson AR. Viruses and renal transplantation. Conference of Lithuanian Nephrology, Dialysis and Transplantation Association dedicated to 40 years of renal transplantation in Lithuania. Kaunas, Lithuania. 17 September 2010.

Watson AR. Transition: building stronger bridges between paediatric and adult renal care. 10th Baltic Nephrology Conference. Latvia, Oct 14-16 2010.

Watson AR. Stones in children: changing aetiology in children and current management. 10th Baltic Nephrology Conference. Latvia, Oct 14-16 2010.

Conferences and Meetings Organised

Trent Paediatric Nephrourology Symposium. March 2010. East Midlands Conference Centre, Nottingham

Trent & Anglia Paediatric Nephrology Network meeting. Tuesday 25 May 2010. Nottingham.

BOOKLETS AND LEAFLETS

Booklets (distributed nationally and abroad)

Childhood Nephrotic Syndrome, 1988. Revised 1993, Revised 2008
Your Child and Chronic Renal Failure, 1990. Revised 1998, Revised 2008
Kidney Transplantation in Childhood. 1993, Revised 2007
Sharon Has a Very Important Test, 1994
Darren Has a Very Important Test, 1994
Mary Has a Mag 3 Scan, 1994, Revised 2008
Arnold Goes for a DMSA Scan, 1994
Why Annie Needs a Blood Test, 1994, Revised 2010
Arnold Has an Ultrasound, 1994. Revised 2006
Graham Has a GFR Test, 1994, Revised 2010
Rebecca Has a Renal Biopsy, 1994
Bertie Button: A Children's Story About Gastrostomy Button Feeding, 1998
Children With Recurrent Urinary Tract Infection, 1996, Revised 2008
Brian Has Bladder Pressure Studies, 1999, Revised 2008
Dietary Advice for Children on Dialysis, 1997, Revised 2010

Leaflets:

Chronic Renal Failure: Tests
Urinary Tract Infection in Children
Kidney and Bladder Problems Detected Before Birth by Ultrasound, Revised 2008
Multicystic Dysplastic Kidney (MCDK) Explained Revised 2010
A Guide to Childhood Nephritis 2010
Haemolytic Uraemic Syndrome
Daytime Wetting: Advice for Children and Parents/Carers 2008
Posterior Urethral Valves 2010
Warts and Kidney Disease 2010

Patient Information (published in British Journal of Renal Medicine)

Watson AR. What I tell parents about childhood nephrotic syndrome, 1998
Watson AR. What I tell parents about UTIs and reflux in children, 1999
Nevard C. What I tell parents about HUS syndrome, 2000
Watson A. What I tell families about a kidney biopsy in children, 2002
Watson A. What I tell families about kidney and bladder problems detected before birth 2003
Hewson D. What I tell families about haemodialysis in children. 2003

Videos

Supplementary Feeding by Tube
Feeding by Gastrostomy
Haemodialysis
Continuous Cycling Peritoneal Dialysis
Painful Procedures: Helping Children to Cope, 1995
Nephrotic Syndrome in Children, 1995

CDRom

Boss of my Bladder

DVD

Moving On (transition issues), 2006

Several of these booklets have been made accessible on the National Kidney Federation website (www.nkf.org.uk) with our permission and also on our own website (www.childrenskidneynottingham.nhs.uk)

Paediatric Renal Dietetic Service

The dietetic service provided to the paediatric renal unit during 2010 was staffed by Alison Tooke working 1.0 WTE (band 6) and Pearl Pugh working 0.7 WTE (band 7) (Total 1.7 WTE).

During the year paediatric activity by the renal dietitians amounted to **1765 contacts** compared to **1732** contacts in 2009.

Paediatric Dietetic Activity

Total number of renal patients requiring dietetic input = **224**

Total number of dietetic consultations = **1765**

Total number of new renal patients = **71**

Mean number of contacts per renal patient was **7.9** (7.7 in 2009)

Number of acute and chronic renal failure patients receiving dietetic support from 2005 to 2010 by treatment group

Treatment	Number of patients				
	2010	2009	2008	2007	2005
Transplant	20	13	13	13	7
CCPD	31 (13)*	23	27	23	8
HD	29	23	15	15	7
AKI	40	37	21	25	23
Total	120	96	76	76	45

*The number in brackets represents the number of new patients starting PD.

Outpatient Activity at Nottingham University Hospital

The CKD clinic takes place on a Thursday morning. Only urgent referrals were seen in the Tuesday and Wednesday general nephrology clinics.

Regional Shared Care Clinics

A dietitian attends outreach clinics with the consultant at both Leicester and Cambridge; these have been identified as a priority for input. Telephone contact was available for all shared care clinics throughout the year.

Data reflecting exact contacts is not available for 2010 due to a change in the way data is recorded on Clinical Manager. Activity remains constant at these clinics with 5-10 patients seen per clinic.

A review of dietetic input at shared care clinics is currently taking place to reassess the priority clinics. Kettering, Sheffield and Derby have been identified as possible priorities for 2011. Recent training has been undertaken with a dietetic colleague in Cambridge, this will provide local follow up and improved liaison for the renal service.

Clinical renal patient contacts at NUH

Direct and indirect clinical contacts from 2000 to 2010

	2000	2001	2002	2004	2005	2006	2007	2008	2009	2010
Inpatients	680	706	638	703	1051	678	661	771	764	768
Out-patients	737	817	628	644	468	411	333	447	366	376
Day cases	111	45	25	82	170	119	111	61	178	190
Home/school visits	6	4	5	3	6	3	1	2	1	1
Telephone	195	224	229	218	309	470	330	394	423	430
Total	1729	1796	1525	1650	32004	1681	1436	1675	1732	1765

(Inpatients includes indirect contact with health care professionals)

(Day cases includes contact with patients attending for haemodialysis)

Inpatient and outpatient total dietetic contacts (including day case patient contacts) is constant at 76%. The total number of day case contacts has increased, which reflects a significant rise in haemodialysis patients. Telephone contacts continued to account for 24% of total patient contacts similar to 2009.

Nutritional Support

Contacts for nutritional support either orally, via a tube or parenteral nutrition (PN) accounted for 69% of all dietetic contacts during 2010, compared with 65% in 2009. The number of contacts for PN has increased dramatically, which reflects a few complex patients with post surgical complications. The number of new gastrostomies inserted during 2010 was 3. We currently have a total of 30 patients with a gastrostomy in situ and 4 patients who receive nasogastric tube feeds. The number of contacts for patients with gastrostomies has increased, which may reflect a large number of patients under 5 years old who require regular review and monitoring. The number of referrals from HDU/PICU was 50, which has increased from 33 in 2009, which reflects the increased number of renal transplants. These patients generally transfer to PHDU and PICU immediately post transplant.

Number of contacts by dietetic support required

	2005	2006	2007	2008	2009	2010
Oral calorie supplements (OCS)*	306	544	285	390	415	435
Gastrostomy button feeding	426	512	357	375	460	569
NG/NJ tube feeding	157	180	175	225	246	184
PN	2	14	7	38	7	29

*OCS - includes Oral Supplements and Nutrient Enriched Infant Formula codes

Abstract/ Publications 2010

No new publications during this period.

Ongoing research 2010

TWIST study- assessment of dietary intake 6 and 12 months post renal transplant (PP/AT)

Texting study. A novel study to improve phosphate compliance in young people on HD. To be written up as abstract (PP/AT)

Conference Presentations/Attendance/ Course attendance

Attended Soba University Children's Hospital to undertake teaching regarding nutrition and CKD, diet post renal transplantation.

Presented at Baxter dialysis conference, Khartoum, Sudan

Teaching

Teaching newly qualified renal nurses on E17 (PP/AT)

Teaching Registrar Training Day (PP/AT)

Teaching to visiting Sudanese Dietitian (PP/AT)

Teaching to visiting health care professionals from Qatar (PP/AT)

Teaching sessions on the haemodialysis bay to patients (PP/AT)

Involved in dietetic student training (PP/AT/LM)

Set up feeding support group for parents of children with CKD (PP/AT). To run 3 times per year

Information stand at nephrotic study day (AT)

Memberships

Members of the British Dietetic Association (BDA) (AT/PP)

Members of the BDA Paediatric Group (AT/PP)

Members of PRING (2 meetings per year) (AT/PP)

Innovations/working groups/courses

Designed phosphate information sheet and moderate phosphate information (AT/PP)

Designed steroid induced information sheet (AT/PP)

Updated diet and dialysis booklet (PP/AT)

Ongoing work with catering regarding children's renal menus at QMC (PP/AT)

Update Paediatric Dialyvit information sheet (PP)

Time out and unit holiday

Attended Renal 'Time Out' day (May) at the Martins Arms (PP/AT).

Plans/ Targets for 2011

- To complete annual dietetic assessments involving analysis of 3 day food diary on all dialysis patients.
- Continue to measure zinc, copper, red cell folate on all new dialysis patients or those changing modality
- For all new and existing infants requiring renal specific formula a switch will be made from Kindergen to Renastart due to LCP content.
- Continued involvement in teaching of new staff and educating existing members of staff with regard to the renal diet.
- Continue feeding group in collaboration with Clinical Psychologist for infants and children with feeding problems
- Continue to improve menu choices for patients on E17.
- Review of post transplant dietetic education
- Continue to develop and review dietetic resources
- Complete abstract for texting study
- Write up transplant study
- Continue to work on a strategy to improve phosphate compliance in children and young people

Pearl Pugh/Alison Tooke
Paediatric Renal Dietitians

Paediatric Urology Nursing Service

2010 was a challenging year: we identified very early in the year that we had insufficient nursing resources to meet the constant and increasing demand of this service. In March I wrote a case of need for further nursing support but unfortunately due to many different reasons this was not successful. However we have endeavoured to maintain a well organised, professional and caring team even when our resources have been stretched to the limit and through it all we have still been able to implement new methods of management which improve our patient care.

The number of children currently requiring our service is:

- 194** children with a neuropathic bladder (6% increase)
- 180** children with daytime enuresis
- 94** young adults in the Young Persons Clinic (5% increase)

Children's Outpatient Department

Total number of children seen in clinics by the urology nurses in 2010 was **398**.

Urology nursing support continues to provide care and assessment within the out patient setting. Within our nurse led enuresis clinic we have seen an increasing number of referrals from community paediatricians who have little to no paediatric continence nursing cover within Nottingham County PCT and as such refer into our service for advice and ultrasound screening for these children.

Due to lack of experience within the out-patient department, we have also increasingly been asked to support children with nocturnal enuresis, a role that has not previously been one for the urology nursing service. There are currently insufficient resources within the service but this remains an area for future discussion.

Day Case Assessments

Total number of children requiring day case bladder assessment was 128 which is almost identical to last year. This nurse-led and delivered investigation generates a large revenue and continues to be well-utilised. With an increasing number of consultants making referrals, consideration will need to be given to the development of the service in order that the patients continue to receive a detailed assessment. With current resourcing, it may be necessary for us to accept referrals only from within our nephrourology team which would be regrettable.

Urodynamics

Total number of children undergoing this investigation was 60, an increase of 39% from last year, as we now carry out this investigation three times a month. This has greatly improved our flexibility and allows us to add urgent cases to the lists without the need to cancel other children already booked.

Following a paper presented at the ESPUN meeting in Turkey, Christine has introduced the use of Entonox when having urethral catheters inserted in the x-ray department. Our aim is to reduce the number of children requiring supra-pubic catheter insertion in theatre prior to this investigation, thus reducing the level of intervention required, the need for a general anaesthetic and the overall cost. This improvement has been well accepted by both the children, parents and staff.

In 2011 we hope to begin to carry out our first ambulatory urodynamics which have been unfortunately delayed due to lengthy debates between our Infection Control Department and the manufacturers over adequate sterilising between uses.

Clean Intermittent Catheterisation

35 children/parents, were taught clean intermittent catheterisation, an increase of 9% from 2009 plus a further 30 children were brought into hospital for their suprapubic catheter changes, an increase of 50% from 2009.

In previous years we have been able to offer home and school support/ education, but as I have mentioned in previous reports this support is increasingly difficult to continue with increasing inpatient care required and cost implications of our time being spent out in the community.

Community

We carried out **25** home and school visits in 2010, a figure which remains consistent with last year's numbers. 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.

Telephone Calls

The service made:	We received:
934 calls to parents	879 calls from parents
167 calls to health care workers	189 calls from health care workers
89 calls to schools	77 calls from schools

Overall total **2335** calls made or received by this service in 2010.

Other areas of development

Two out of the three of our urology nurses are now qualified to administer Entonox and we hope very shortly to have another nurse trained also. This over the last 12 months has proved to be extremely useful to our service when carrying out difficult and painful procedures.

Christine Rhodes remains the chairperson for the RCN Children's Urology Continence Community, and continues to work closely with the RCN. This year she was voted to be the secretary for the European Society for Paediatric Urology Nurses (ESPUN). Christine also works with the Paediatric Continence Forum led by Penny Dobson, all of this work being carried out in Christine's own time.

Christine and Gill Young have continued to teach on a wide variety of educational courses, study days and conferences

Conclusion

2010 was a very busy year, during which our overall patient numbers have increased for the third year running. We will continue to strive to maintain the highest possible standards of care for our urological patients at all times.

Christine Rhodes
CNS Paediatric Urology

Renal Nurse Educator

The role of the renal nurse educator remained challenging in 2010, with turnover of staff and the need to maintain knowledge and skill level.

In House Training/Study days

- 2010 has seen **7** new nursing staff joining the team, some permanent and some on the rotational programme.
- The formal orientation programme for all staff new to Renal and Urology continues and gets very good feedback.
- This includes a one to one study day covering basic renal principles for all staff new to the speciality.
- For the Children's Hospital, four Central Venous Access Study days have been provided by the renal educator, and ongoing support and verification of skills and knowledge. Staff from E17 have been accessing this training.
- Goal: All new nursing staff to the renal speciality will receive introductory teaching. There is a need for ongoing development of staff in an equitable format.

A Renal and Urology Foundation competency document has been introduced to guide training and support in 2011. Several study days are planned to build on initial knowledge and for the development of other staff in the unit.

University of Nottingham School of Nursing/Pre-registration Students

The nurse educator continues to be the practice representative for the Paediatric Practice Learning Team, collaboration between lecturers in the School of Nursing and nurses in practice supporting students. Lectures have been provided for pre registration nursing students, on the basics of renal nursing. Teaching has also been provided on a Post Registration module on fluid and electrolyte management.

Learning Beyond Registration (LBR) Nephrourology education

There continues to be a problem in providing a higher education provision in Paediatric Renal Nursing. Several options have been considered, including accessing the adult renal module. A proposal has been approved by the Strategic Health Authority to run a single module in Paediatric Nephrology. This module will be provided on a distance learning basis, and will be promoted to our outreach centres as well as other renal units across the country. The date for launching this module is not yet confirmed.

Goal: The target is to achieve 70% of staff with a specialist module, current actual level for E17 in patient area is 23%.

Working in New Ways (expanded) Procedures

All permanently placed nurses require training in these procedures (for example, peritoneal dialysis) as appropriate to their role. This year the need for training junior nurses has increased, due to changes in staffing on E17. However obtaining time for training has proven difficult with reduced staffing levels overall. Updates for previously trained staff have been impossible to achieve away from the ward and support has been offered on an ad hoc basis.

Clinical

The educator post has clinical responsibilities including:

- The on call renal nursing service support to E17, PICU and PHDU out of hours, for advice and therapies.
- During 2010 **68** shifts were worked in the dialysis unit, on average of 1.5 days per working week. This number does not include educational shifts and cover for lunch relief and staff development. This commitment of course reduces the time available for educational activities.
- Supporting/supervising clinical skills of nurses on the unit, including working with nurses during clinical shifts.

Other groups/special interests/roles

- Family Health representative on the Nursing and Midwifery Education Steering Group.
- Coordinating teaching of Central Venous Access Devices across Children's Services.
- Working with a Trust-wide group to redesign the IV and CVL Working in New Ways Package.
- Member of Children's Services Clinical Educator Group, meetings monthly.
- Nottingham Committee Member of Paediatric Nephrology Nurses Special Interest Group.
- Coordinating Medical Devices Training for staff working on E17.

Achievements

In 2010 the first patients were successfully treated with Haemodiafiltration. The Renal Nurse Educator was one of the leads in establishing this therapy, including staff support and training.

General education aims for 2010

- To continue to provide education and information to all areas with which children with renal disorders have contact.
- To raise the profile of the Children's Renal and Urology Unit, and therefore contribute to the recruitment of staff to the service.
- To continue to develop the formal basic teaching programme for new staff, and dedicated time for staff to attend.

Diane Blyton
Renal Nurse Educator

NEPHROLOGY LIAISON NURSE

Working as an integral member of the specialist team supporting the Childrens Renal & Urology Unit, my role is specifically to work with children with Chronic Kidney Disease and their families. Support begins at diagnosis and continues until the child or young person transitions to adult services. The age range of the patient is from neonate to adult.

Covering the East Midlands region involves providing support through outreach and education and through effective multi-disciplinary working to minimise the disruption to child and family caused by frequent travel to Nottingham. Support is also given to staff, patients and families on Ward E17, and in the Out Patients Departments at Nottingham Children's Hospital.

The caseload can vary from children requiring coordination of community support and information, to the long-term complex issues surrounding all aspects of chronic kidney disease. This can require ongoing management and family support through education, and information in conjunction with the development of patient-centred multi professional care, including issues associated with growth and development, and with supplementary feeding via gastrostomy.

Also included is the support provided to children and families with nephrotic syndrome, and to those receiving conservative treatment for chronic kidney disease.

Education and the updating of protocols, and information leaflets are also part of the role of the Nephrology Liaison Nurse.

Activity in 2010 for chronic kidney disease stage 1 - 4

- 125 patients
- 15 new patients
- 37 home / school / community visits
- 2050 miles travelled

Home and community visits continue to provide a key element to holistic, patient centred care and are often made in conjunction with the paediatric renal social worker, youth worker or play specialist, contributing to the support which is available to the family which combine as protective influences in coping with childhood chronic illness and influence family functioning. This is in line with the *National Service Framework for Renal Services: Working for Children and Young People*. It is during these visits that relationships of trust and support are developed which continue through the childhood and adolescent years and transition to adult services.

Activity in 2010 for nephrotic syndrome

- 128 patients
- 19 new patients

Continuing support is provided through face to face opportunity within the hospital ward or clinic setting and by telephone. Telephone liaison is particularly effective when supported by the tools developed to guide the child and family through management of a relapse.

Development of the web based support group in conjunction with one of our young people with nephrotic syndrome is ongoing.

Our second nephrotic family day was held in October and was well attended. Family feedback indicated the event and format were beneficial to developing contacts within the patient group (*National Service Framework for Children, October 2004*).

Ambulatory Blood Pressure Monitoring

Monitoring continues at the request of consultants and the availability of machines has proved effective in prompt delivery of results.

Enteral Feeding Support

Changes to policy are being made in response to National Patient Safety Alerts and in conjunction with Ali Wright (Gastrostomy Nurse Specialist) new guidelines are being developed. Support continues to be provided to families at home and through education to nurseries, schools and local health care providers.

Cystinosis

- 9 patients received ongoing support including home and community liaison
- Continued involvement with Cystinosis Foundation

Haemodialysis

20% of available hours spent in support of patients receiving haemodialysis

Research

- Completed GCP study course
- Participated in research project working in collaboration with MCRN
- Further involvement planned

Courses attended / extended roles undertaken

- Risk assessment
- Ethics and Disability Conference, Cardiff (self funded)
- GCP study day
- Investigating Incidents
- ECPC
- Mandatory study sessions
- Resuscitation link, training and support
- Immunisation up-date and provision
- Cannulation study day, planned and delivered
- Gastrostomy updates and support provided
- Co-ordinated and managed Nephrotic Family Day
- Participated in interview process for staff recruitment
- Contributed to development of revised gastrostomy / enteral feeding information
- Chairing uniform review for Children's Hospital

Plans in place for 2011

- NSCB Study session – Assessment skills
- NSCB Study session – Working with non-compliant families
- Advanced Communication Skills Training
- Further research development
- Possible audit of gastrostomy devices
- Planned attendance at outreach clinics throughout the area served
- Attendance at National renal nurses conference

Gillian Elwood
Paediatric Nephrology Liaison Nurse

Renal Critical Care Education

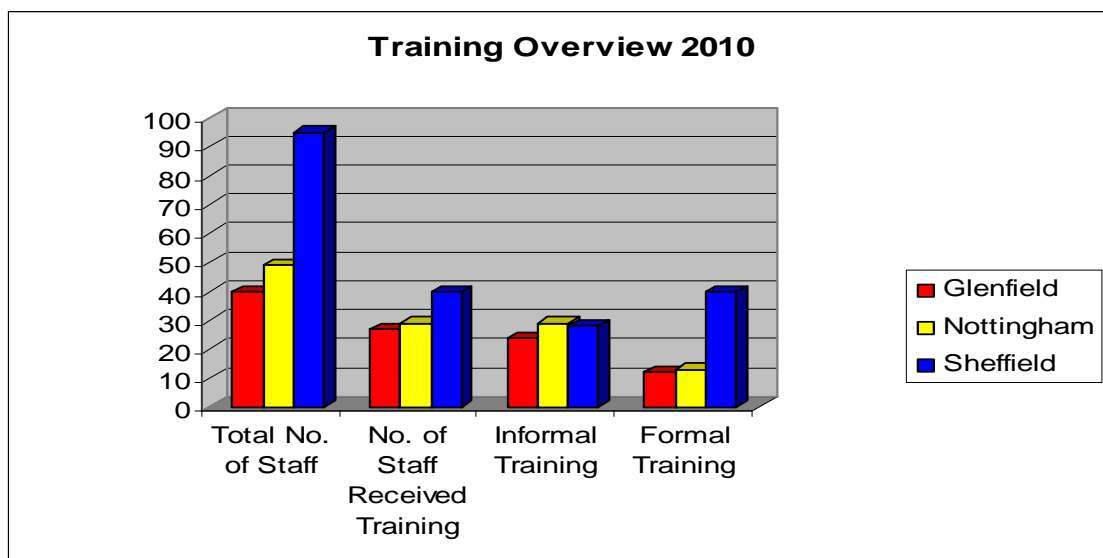
2010 has brought a diverse range of educational challenges within all three of the Critical Care areas (Nottingham, Glenfield and Sheffield PICU). Attempting to provide a standardised educational training programme for all PICUs presented quite a challenge with differing availability of study time and resources across the regional units.

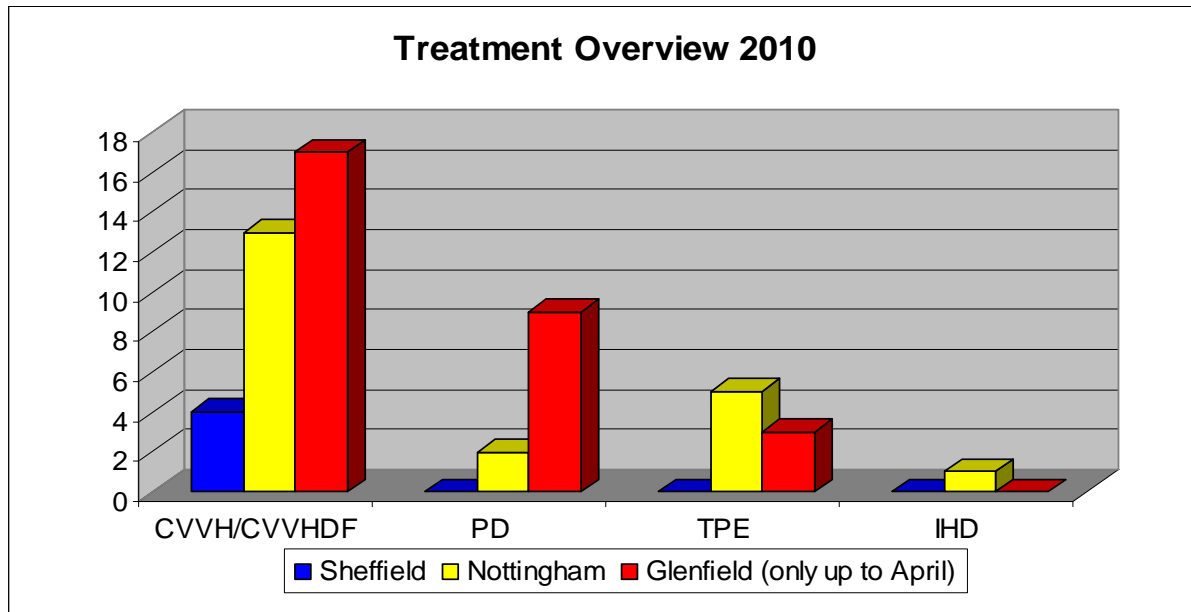
The standardising of all equipment for delivering continuous renal replacement therapies (CRRT) did aid this goal and enabled the first regional CRRT simulation study days to be delivered. Nursing staff from all three units attended the study day which incorporated a mix of theoretical seminars and simulated scenarios. Sheffield Children's Hospital hosted the first of these days, but there are plans for further days to be delivered in 2011 with the goal of rotating the host.



Other formal teaching has been delivered on development days, simulation sessions in conjunction with mandatory training days and taught sessions at academic institutions. Other opportunities for education and support have been working alongside staff for supervised practice, bedside teaching and informal ad hoc sessions. E-Learning has been implemented at Glenfield with mixed success and I am currently exploring ways of implementing some kind electronic resource across all three sites.

All three PICUs offer slight variations in the modalities of acute renal replacement therapies delivered and have had differing demands for treatment throughout the year. This is partly due to the different patient groups cared for within in each unit (e.g. Glenfield being a cardiac unit often results in greater need for acute renal replacement therapies). My role aims to support the optimum delivery of the variety of treatments delivered.





Other areas of development

March 2010 - Nottingham PICU purchased and introduced the Prismaflex machine. Intense period of training implemented.

April 2010 - Attended International Continuous Renal Replacement Therapy conference in Rome, Italy

May 2010 - CVVHDF approved and implemented at Sheffield PICU.

September 2010 - Presented at the annual Paediatric Intensive Care Society (PICS) conference in Manchester on Renal Replacement Therapy and Simulation.

September 2010 - First Regional CRRT Simulation Training days delivered.

September 2010 - Work commenced on setting up PICS Renal Group to provide a national forum for information sharing and best practice.

October 2010 – Taught on Critical Care Course at Sheffield Hallam University.

November 2010 - Taught on Critical Care Module at Nottingham University.

November 2010 - Asked to look at some collaborative work with the Boston Childrens Simulator Programme with regard to CRRT and simulation.

Molly McLaughlin
Paediatric Renal Critical Care Nurse

Social Work Report

Social Work support to children with chronic kidney disease and their families continues to be provided by Heidi Steward (full-time post) and Suzanne Batte (part-time post).

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. The social workers are an integral part of the renal team but are professionally apart from health service colleagues and this allows them to provide this unique type of support. We are committed to providing a high standard of psychosocial care to children with chronic kidney disease and their families through traditional social casework and counseling skills. We aim to provide emotional support as well as offering practical and financial assistance such as advice regarding benefit entitlements and also by applying to charities.

An important part of our role is to visit families at home as this allows time and space away from a clinical setting to discuss worries and concerns. In particular, parents who are caring for children on peritoneal dialysis at home can feel isolated and they can become exhausted due to the daily demands of this treatment.

Home visits are also important for all families and we try to visit at critical stages from diagnosis through to when active treatment is required. It is particularly important that children and their families understand what is involved with starting dialysis or going on the transplant list. Parents expressing an interest in live donation also require home visits to discuss the practical, emotional and financial implications associated with this procedure.

A social work service is also provided to acute patients attending the unit. The sudden onset of a very serious illness can be very worrying for a child and their family particularly if the child requires acute dialysis. These families are often some considerable distance from home which can cause problems with employment and childcare for other children in the family. We try to alleviate some of this stress by giving appropriate advice and sometimes applications are made to charitable organisations for financial assistance. We also advise families to contact us after the admission as sometimes there is delayed shock and anxiety following these acute episodes.

The following provides some information regarding social work activity during the last year:

- 56 home visits were made in total and some of these were joint visits with other team members.
- 32 multidisciplinary meetings were attended.
- 33 acute patients were seen and some of these required longer term support as they developed chronic kidney disease.

National Links

We continue to maintain close links with other renal social workers across the country through the BASW Renal Special Interest Group. Heidi also attended the annual training day and provided a presentation to the group. This annual training day encourages renal social workers to share good practice via presentations and outside speakers are also invited to provide relevant training.

Teaching

Suzanne was involved in a training session for students undertaking the Masters in Nephrology Course. This teaching is important in terms of educating medical professionals about the importance of psychosocial support for children with chronic kidney disease.

Conferences

Suzanne attended the annual EWOPA conference in May which was held in Helsinki. She presented a paper on the social work service provided to children with acute renal failure at our unit.

Suzanne Batte
Paediatric Renal Social Worker

EDUCATION

2010 has been a very busy year for us, catering for a changing population in the Dialysis Unit and on E17.

The teachers working on E17 and the Dialysis Unit are Elaine Boon, Kate Lawes and John Young. Two teaching assistants, Jonathan Gray and Denise Cross also provide support in the Dialysis Unit. We have a volunteer, Janet Wilson, once a week and are helped from time to time by other volunteers and students. Sally Eminson, who taught at QMC and before that at the City Hospital for seven 7 years, was successful in applying for a post at the Beckhampton Centre. Sally took up her exciting new post in September. Carol Laverick's work here to develop staff to provide Modern Foreign Language teaching came to a successful conclusion. Both members of staff left the Hospital School in July 2010.

Education is provided for all school-age children on the ward, either by the bedside or in the small classroom, or whilst receiving haemodialysis. In the very busy Dialysis Unit 19 children with chronic kidney disease were taught whilst having treatment.

Educational stages of children on chronic haemodialysis

KEY STAGE	NUMBER
Foundation	2
1	1
2	2
3	2
4	6
16+	6

- The number of teaching sessions per chronic haemodialysis pupil varied from 5 to 143 sessions with an average of 77 sessions per pupil. (A session being either morning or afternoon school).
- GCSE's – pupils have been able to undertake exams whilst having haemodialysis
- Depending upon dialysis schedules, pupils attend the Hospital School on either two or three days per school week. The intervening days are spent at their home school. This means that for many pupils the majority of their schooling is with us.
- We continue to have regular visits from our Connexions Career Officer who has developed links with some of our students.
- Liaison continues to be a key area of the Hospital School's work. Every attempt is made to ensure that there is close liaison between the Hospital School and the home school in order to minimise the disruption to education that could be experienced by our renal pupils. The liaison is achieved by:
 - Regular telephone contact with the schools of our long-stay pupils, requesting curriculum work, thus ensuring continuity of education.
 - Termly reports are sent to schools and parents of haemodialysis patients to inform them of work carried out and progress made whilst in hospital.
 - Short reports are sent to schools when a pupil has been with us for two weeks or more.
 - Requests for curriculum information from the home school are made for our haemodialysis pupils.
 - For our chronic renal pupils who have received regular education input from the Hospital School throughout the academic year we request SATs and GCSE results. These, along with the school feedback forms, allow us to evaluate our input ensuring that we provide appropriate child-centred support which builds on best practice.
 - Review meetings are attended as necessary.

- Telephone contact is maintained with a range of partners who provide support for our pupils. Connexions, Home Education, Examination Boards, Education Welfare Officers and FE Colleges are involved as and when appropriate.
- Weekly, multi-disciplinary, psycho-social meetings are attended where the wider needs and issues of patients are discussed by the Renal team.
- The Renal Time-Out day was attended by two of the teachers.
- One teacher attends the weekly renal outpatient clinic, making contact with children and young people and helping with school or college issues or problems.

Educational and other activities include:

- Arranging home tuition for supplementary education or to support reintegration on return to school.
- Languages Day, when children and staff joined in a day of activities, food and fun with a language theme.
- Weekly music sessions for pupils who are able to leave the ward.
- We recognise the paramount importance of the children keeping up with their schoolwork but we also try to make their time in school enjoyable and therefore fit in organised “fun” activities such as cooking, murder mysteries, plays and art. We have also held Transplant Mastermind sessions which helped to increase awareness of issues relating to transplants in a fun way.

Recognising the importance of keeping to a renal diet we regularly focus work on healthy eating and are collaborating with the Renal Youth Worker in arranging cooking sessions in the Dialysis Unit. This will contribute towards a Youth Achievement Award, for our older students.

On 11 and 12 May 2010 our OFSTED inspection took place, resulting in the Hospital and Home Education Learning Centre being awarded an “Outstanding” grade. This was a fantastic success and a testament to the hard work of all QMC Hospital School staff, together with our colleagues at the Thorneywood Education Base and Home Education. We were also awarded Healthy Schools accreditation and a Silver Gilt Award for the Hospital School garden held by Nottingham in Bloom. A Garden Party was held in the School in July to celebrate these successes and was extremely well attended by both hospital colleagues and patients who were able to leave their wards.

This year, within the Renal Team, we have been involved in negotiating dialysis times of the secondary pupils to fit in with lesson and exam timetables in mainstream schools, thus helping to maximise the quality time there.

We continue to look forward to promoting and enhancing the educational opportunities of our hospitalised children and young people in 2011.

Kate Lawes
Hospital School Teacher



Play Specialist Report

2010 has been another year for change on the Children's Renal and Urology Unit, and with still only one play specialist covering the ward and the dialysis unit my time has been spread pretty thinly, trying to cover both ward activity, dialysis patients and trying to fit in a few home visits. Still with the number of patients attending for haemodialysis plus the amount of ward activity with inpatients, day cases and ward attenders I have found it extremely difficult to spend significant amounts of time with patients. As a member of the play team I also have link roles which I have to take on which at times can also take me away from the unit, such as co-ordinating visitors, and being the second link for PPI.

2010 also saw a change in management of the play team with Donna Hilton now managing Play and Youth Services.

Contact with patients

Due to the changes in our documentation there are not specific numbers for patient contact in 2010. However areas in which I have had contact with patients include:

- General play on the ward and Dialysis Unit
- Preparation for procedures, including, blood pressure measurement, dialysis, transplantation, needling of AV fistulas, cannulation and renal biopsy.
- Distraction during painful and invasive procedures, in theatre, on the ward, and in the x-ray/ultrasound department.
- Specialised play, working with a child to encourage them to have blood pressure taken and for child and sibling preparation for transplantation.

Hours of cover

My hours on the unit are currently Monday to Friday, usually working 8:30am – 4:30pm (after trialling various shifts, working one late shift a week, or doing 8-4, 9-5, 10-6.) However this is flexible and depending on home visits etc I do occasionally change my shift.

We continue to cover bank holidays as a team with 2/3 play staff covering the unit each day (except Boxing Day and New Year's Day).

Areas of cover

As the only play specialist working on the Children's Renal and Urology Unit it is still very difficult to cover all areas where our patients are being treated and require play input. This is still a large concern as patients do not receive continuity and the standard of play input is not being met for a supra-regional unit.

The areas where cover is required by the renal play specialist include:

- Ward in-patients
- Theatre patients
- Haemodialysis
- Ward attenders and day cases
- Bladder pressure studies
- Home visits
- CKD assessments
- Renal clinics
- Residentials
- X-ray, ultrasound, MRI
- Echo, ECG

Occasionally some patients may be called at the same time to be in different departments so I have to assess which patient requires the most input from me and ask for assistance from other members of the team to help support others.

Haemodialysis

During 2010 there were times when there were mostly school age children which meant that during school hours they had input from the teachers. However at times with the children that were pre school age, it was still a problem to spend quality time at an activity without being called away to go to support another child. This is a particular problem during school holiday as providing activities and changing games for the 6/7 patients in dialysis can take up a considerable amount of time on top of the ward activity.

I have therefore tried to allocate certain times to dialysis, for instance on a Monday, Wednesday and Friday I would try and spend most of the mornings in the dialysis bay with the pre school aged children, (but still be available for distraction etc to the ward) and then wherever possible try to spend time interacting with the other children and young people in dialysis.

Bladder Pressure Studies

The number of patients I supported for this has considerably decreased over the last year for a number of reasons. Due to Thursday being busy on the ward with day case patients, dialysis patients as well as ward attenders, plus team meeting or psychosocial meetings, bladder pressure study patients are now supported depending on the child's needs. The nurses inform me prior to the investigations which patients will need my support as some patients are used to being catheterised or have had supra-pubic catheters inserted the day before. Also due to the lack of space in the x-ray room the role of parents in distracting and supporting has taken priority over my role.

Home Visits

These had been restricted due to pressure on hospital-based work but from late 2010 it has again been possible for me to attend home visits with other members of the renal team. At present there is a need for clearer identification of visits that would especially benefit from the presence of the play specialist.

Renal Clinics

Unfortunately I am still unable to cover renal clinic sessions with the rest of the multi professional team. This remains a concern in terms of the continuity of care with a group of patients with a chronic illness who are regularly hospitalised and who regularly have to undertake traumatic and/or painful procedures in hospital. There is much that could be initiated in clinic such as making contact with those children who have hitherto had most of their care delivered as out-patients but who are planning towards pre-emptive transplantation. There is also the need for on-going post-transplant care and this issue in particular has been raised by a number of parents who have had support from me up to and during transplantation for this support not to continue in clinic. Over the last year I have tried to make patients aware that if they would like input from me I can still be called down to support them.

Renal Residentials

Fairthorne Manor

In August 2010, along with another member of staff, I took a group of 9 - 12 year old renal patients to the YMCA Fairthorne Manor near Southampton, along with two youth service volunteers.

The residential is funded by the BKPA (British Kidney Patient Association). This funding allows for us to take up to 10 children on an activity week where they can build relationships with other children with chronic kidney disease.

From the moment we arrive on the Monday it is straight into team building activities and the challenges don't stop until we leave at lunchtime on Friday. With Kayaking, canoeing, and sailing, to

archery, climbing and abseiling there is no end to the range of activities that the children get to take part in.

All in all the week in 2010 was a fantastic experience for the children with some great friendships made, as well as concurring fears and achieving goals. It was again a very successful residential and received positive feedback from patients, parents and staff.

Centre Parcs

In 2010 the trip to Centre Parcs was over a weekend. I was involved briefly, escorting a patient there for the day who was unable to stay for the whole weekend. Again we had fun in the pool area, and had some informal education through the ready steady cook challenge.

Visitors

During 2010 we had another great year of visitors to the unit, including Nottingham Forest Football Club, Nottingham Panthers and people making Christmas Donations. Starlight Foundation this year staged a pantomime of Sleeping Beauty in the hospital chapel and we were fortunate enough to be part of the Channel 5 documentary about Starlight.

Donations

The children's Renal and Urology Unit have also received some fantastic donations this year including:

- Diane & Pete and everyone at The Arnold & Daybrook Conservative Club
- Arnold Fire Station (gifts for the Christmas raffle and Christmas gifts)
- Mike & Sure Hares (arts and crafts, and toys for the ward)
- David Trickett (Christmas gifts and raffle prizes)
- Unity Football Club

Future

In 2011 I would like to see:

- An increase in play specialist cover on the renal unit.
- An increase in home visits
- Professional development
- To provide a better more consistent play service for renal patients

Claire Hardy
Play Specialist, Ward E17



CLINICAL PSYCHOLOGY REPORT

We have now settled in to our accommodation at QMC although many challenges remain as it is still cramped and it is not easy finding rooms to see people in when they need it. This is a problem which is faced by a number of people in the team and is currently the subject of some deliberation.

Activity

70 separate referrals were made to the Psychology department from the Renal/Urology team. These people were seen in the OPD or on the ward as required.

Although these referrals were for a variety of problems, for the majority, procedural anxiety was a significant issue, coupled with other issues such as compliance. In many instances, coping strategies were able to be taught in a few sessions thus giving the child/young person some element of control in their treatment and removing some of their possible distress. Other problems often require longer term involvement.

Quality of Life Audit

Quality of life is still a huge interest of the Renal team and we were fortunate to secure the help of Jennifer Heath as an Assistant Psychologist, thanks to funding from Kinder, to enable us to complete our own audit of Quality of Life in children with Chronic Renal Disease. Thanks to Jennifer, the audit data from the other 6 participating paediatric renal units in the UK was analysed and these results were presented at the EWOPA Conference in Helsinki.

In addition a paper was prepared for publication (subsequently published in the journal *Pediatric Nephrology* in 2011).

Painful procedures DVD

At last the DVD is completed and we now face the task of taking this round the various clinical teams to help promote discussion on this important topic and help ensure that painful procedures are undertaken as sensitively as possible. A further part of the DVD is in preparation. This features comments from parents and young people about their experiences especially when things do not go well. This should be a helpful aid to teaching.

Transition to Adult Services

Currently work is proceeding on shortening the Transition Plan to make it easier to complete.

Dr Dorothy MacKinlay
Consultant Clinical Psychologist

Youth Work Report

'The purpose of youth work is to work with young people to facilitate their personal, social and educational development, and enable them to gain a voice, influence and place in society in a period of their transition from dependence to independence' (National Youth Agency 2007)

The NUH Youth Service will recognise young people for who they are and not by their illness or condition, support and encourage young people in helping them become whatever it is in them to be and offer support to enable a smooth transition to adult services.

NUH Youth Service support young people (11-24 years) in both Children's and Adult Services from a wide range of long-term medical conditions and disabilities, along with their siblings.

This could mean advice and support from the youth workers; using the Youth Room during hospital stays; attending the weekly hospital youth club; activity and support programs for long-term patients; transition support; and/or becoming involved in long-term projects such as the Youth Achievement Awards, Youth Forum, day trips and residential holidays.

The Youth Development Worker is part of the wider youth service team made up of a Youth Service Manager, a Senior Youth Workers, 2 Youth Support Workers and a large Volunteer Team.

Young People Involved:

From January 2010 to December 2010, The NUH Youth Service has worked with 509 different young people. Of these, 72 have been renal patients aged between 12 and 24.

Activities and Events:

Dialysis Unit:

Providing activities for young people on haemo dialysis is important for many different reasons; it allows the young people to interact with each other; develop different and new skills; be distracted from the hospital environment and have fun. Throughout the year different activities such as games, art sessions, quizzes, cooking sessions and Youth Achievement Award have been provided for the young people on dialysis.

Drop-In Sessions:



The youth service provides daily drop-in sessions for young people to come and use the facilities. I have been able to encourage young people from the renal unit to access this service which has enabled them to have time away from the ward in a non-medical environment. It also allows them to meet other young people in hospital and access support from staff.

'I love the Youth Room so much! I can get away from it all when I feel swamped by medical stuff and I can just come and chill out.' (Young Person)

Youth Club:

City Youth Club (CYC) is open to young people 2 nights a week. Available for young people in the Nottingham area it is also open to inpatients. They can take part in different activities such as arts and crafts, group games, team-building activities and lots more!

'The youth club is really good for young people. It helps pass the time and the staff always welcome you with open arms!' (Young Person)

Young People for Change:



2010 saw the re-launch of our youth forum, Young People for Change. This gives young people the opportunity to have their say in hospital services and make them more young people friendly. At the moment we have one renal patient involved but are always looking to recruit more.

Trips to places of interest:



Young people have been involved in trips run by the youth service. Through 2010 we went to Water World, Drayton Alton Towers, Sherwood Pines, London's West End, Arches Adventure Base, Trip, Quad Biking and Go



involved in service. Laser Quest, Manor Park,

Narrow Boat Karting, Harry

Potter Film, Mother Goose Panto and the Clothes Show Live. Over 30 young people with CKD and their siblings have been involved in trips over the year.

Residentials:



Throughout 2010, there have been three renal residentials; one dialysis holiday to Center Parcs; the annual sailing holiday to the Isle of White, supported by the BKPA and; this year we able to offer a new experience to young adults working jointly with Sheffield to go on a young adult residential to Center Parcs.

The young adult residential provided new support for a particular group who were able to share their experience of the adult unit, get advice and support from staff, reconnect with friends and have fun.



Each residential provides young people with the opportunity to experience new things, challenge themselves, learn more about themselves and others and have fun. Young people from the renal unit have also taken part in residentials to Wales and Nottingham run through the youth service also involving other young people accessing the youth service. This has given them the opportunity to meet other young people with long term health conditions, try new activities and

raise their self esteem.

'Some of the young people in my group really pushed themselves and were doing activities they would never normally have the opportunity to even try!' (Young Volunteer). 'This week I learned about friendship. Before, we didn't know each other and now we all really get on!' (Young Person). 'I learned that I am more independent with my dialysis' (Young Person).

Youth Achievement Award:



Informal Education is an important part of youth work and through out 2010, young people have been taking part in the Youth Achievement Award scheme. This nationally recognised accreditation allows young people to develop their confidence and group work skills whilst learning something new and having fun! In finishing this course, the young people will not only have an accreditation but an increased knowledge base and skills that they can use in their own lives. This year, a young person was able to plan a cake sale to raise money for the renal unit. He raised £130 to go towards the trip to the Clothes How Live and will also use this experience as part of his Youth Achievement Award.

Support:

Through residential, clinics and ward visits, I have been able to support young people in many different aspects of their lives, through one-to-one and group work settings.

Transition:

The support of young people transferring to the adult unit is an important part of the youth development role. Through the use of transition folders, home visits and transfer clinics, young people have been able to access comprehensive support for different concerns or queries that they have in regards to their transfer to the adult unit.

General:

Day trips, residential, clinic, drop-in sessions, ward work in the dialysis bay have all provided different young people to access support. Whether it is work or informal discussions young people have experience new things, meet new people and have



based work and opportunities for through group been able to fun.

'I have learned that we all have different experiences of CKD but we think the same and can share our experiences with each other' (Young Person)

Outcomes:

The youth service as a whole provides vital support for young people in hospitals. As the renal youth development worker, the numbers of young people with renal conditions accessing the youth services are the highest throughout the service. This evidence shows that having a dedicated youth worker for Renal Services ensures that these young people have the appropriate support and sign posting to relevant services. My role has meant that more renal patients have attended the day trips and residential held by the youth service as a whole. The impact of youth work on young people are many; they can access peer support; they can get advice and guidance; they can raise their self esteem; gain accreditations; develop new skills; have the opportunity to try new things and have fun.

'Youth work starts where young people are – with their own views of their lives, the world and their interests. But it does not end there – youth work is about encouraging young people to think critically about their lives and values, about offering new experiences and challenges, about increasing young people's abilities and aspirations'

(National Youth Agency, 2007)

Dorro Hackett
Youth Worker

Nottingham Children's Hospital

