

17th Annual Report

2007

**Children & Young People's Kidney Unit
Nottingham**

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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

Our Mission Statement “We will strive for excellence in the care of all children with acute and chronic renal and urological problems” has been tested in a major way in 2007. The strength of a multiprofessional team is how it copes with adversity. Financial pressures and staffing levels have sapped morale this year. The figures will show how we have had to cope with a **38%** increase in ward admissions and over the past 2 years an increasing number of patients entering chronic kidney disease category 5 (dialysis and transplantation) from 10 in 2005 to 15 in 2006 and now to 19 in 2007. Many of those 19 patients were less than 5 years of age and others have handicapping conditions which has made for a considerable workload. Medical and social issues have meant that more younger children have been treated on haemodialysis with an **80%** increase in individual dialysis sessions compared to 2006. This has meant that many of our specialist nurses have been drawn into providing dialysis care and hence the significant fall in home visits, community support and respite care. The outreach arm of our programme has always valued by the children and families we support and goes a long way to delivering the efficient and holistic care for families from within our catchment area of 6 million.

At the time of writing we are still hopeful that our delayed move to the QMC will take place in the early summer of 2008. We are looking forward to our refurbished ward and dialysis unit with facilities which were enhanced by a grant of £378,000 from Mrs Elizabeth Ward, President of the British Kidney Patient Association which we gratefully acknowledge. We look forward, also, to the appointment of another Consultant Paediatric Nephrologist and expansion of our shared care renal clinics throughout the region to deliver care nearer to the patient’s home as well as education and support for our paediatric colleagues.

Summary points of our report include:

- Activity in our 11-bedded nephrourology ward and combined ward with Papplewick since October 2007 has recorded a **38%** increase in admissions, **34%** increase in ward outpatients and a **21%** decrease in day cases.
- Outpatient referrals to the City Campus showed an **8%** reduction in new patients but a small increase in follow up attendees. There was an **9%** increase in patients seen at regional shared care clinics
- We continue to offer an antenatal counselling service in liaison with the fetal medicine specialists and others for antenatally detected urinary tract abnormalities.
- The paediatric renal unit is never closed to admissions and jointly manages many patients with acute renal failure from throughout the region in conjunction with the paediatric intensive care unit. The Renal Critical Care Educator and acute renal failure nurse provide liaison support for the 3 paediatric intensive care units in our region.
- **19** patients were entirely new to the dialysis and transplant programme (CKD 5) in 2007 compared to 15 in 2006 and 10 in 2005. Many of the 19 patients were less than 5 and 7 of the 19 were entirely new to the renal unit and required intensive education about chronic renal failure treatments.
- Our stock of patients on dialysis and transplantation increased slightly this year but we continue to have an active transition programme and we refer patients to adult units at the appropriate time.
- Our patient survival is excellent with only **5** deaths in the past 3 years and patient survival is **98%** 5 years post renal transplant.
- The national downturn in deceased donor offers means that we carried **11** transplants in 10 children in 2007 with **33%** receiving parental donor kidneys. Our **33%** pre-emptive transplantation rate remains one of the highest in Europe.

- In Nottingham we have the ability to undertake laparoscopic live donor nephrectomies for transplantation with great benefits for the donor. This should be the standard for LRD transplantation for all children.
- We continue to audit outcomes using Renal Association standards for our kidney transplant patient graft survival, episodes of peritonitis and central venous infection rates are all comparable or better than published standards.

Innovations

- We continue to reduce the time needed for intravenous iron infusions to 5 minutes hence making it feasible as an outpatient procedure
- Access for patients to Renal Patient View so that they can have up-to-date results and information
- Recruitment of 2 families whose child is on chronic dialysis to the Expert Patient Advice Panel
- Sibling residential organised by Senior Youth Worker involving siblings of children with chronic renal failure

Teaching and Education

Education commitments have been carried out by a large number of team members.

- Several team members contributed to the paediatric modules run for the Masters/Diploma Course in Nephrology run by the Sheffield Kidney Institute (University of Sheffield)
- 3 members visited our sister unit at Soba University Hospital, Khartoum, Sudan and in 2007 we also trained one transplant nurse and one nephrology fellow in Nottingham with sponsorship from the International Paediatric Nephrology Association and our own unit funds
- 731 copies of the booklets and leaflets produced by our unit were requested by other units in 2007. Many of these have been adopted by the National Kidney Federation.

Clinical Research

- **14** projects were active, 3 in collaboration with the BAPN and 2 with international collaboration
- **12** publications including 3 chapters
- **14** conference presentations (5 at international conferences)
- **24** invited lectures (13 abroad)
- **3** meetings and conferences were organised
- Prof Alan Watson remains Chair of the UK Clinical Ethics Network Trustee Board and Vice-President of the ESPN meeting to be held in Birmingham in 2009

On behalf of our team, I am proud to present our 17th Annual Report.

Never doubt that a small group of thoughtful, committed citizens can change the world: indeed it's the only thing that ever has.

Margaret Mead

Prof Alan R Watson
March 2008

STAFF AND FACILITIES

Medical Staff

<i>Consultant Paediatric Nephrologists</i>	Prof Alan R Watson (Unit Director) Dr Jonathan Evans (Divisional Director, Family Health) Dr Farida Hussain Dr Martin Christian
<i>Year 4/5 SpR</i>	Dr Andy Lunn (National Grid Trainee)
<i>Year 2/3 Trainee</i>	Dr Kiran Damera
<i>SHO</i>	Rotates every 3 months
<i>Paediatric Urologists</i>	Mr Manoj Shenoy Mr Alun Williams
<i>Surgical Trainee</i>	Rotates every 6 months
<i>Surgical SHO</i>	Rotates every 3 months
<i>Transplant Surgeons</i>	Mr Keith Rigg, Mr Magdi Shehata, Mr Mohamed El-Sheikh and Mr O Cole (urologist)
<i>Radiologists</i>	Dr Nigel Broderick, Dr John Somers, Dr Kath Halliday, Dr Don Rose (Nuclear Medicine) – retired 2007
<i>Pathologists</i>	Dr Tom McCulloch and Dr Zsolt Hodie

The nephrology service remains a **CONSULTANT DELIVERED SERVICE** as only one of the on-call middle grade staff is training specifically in paediatric nephrology and all SpRs participate in general paediatric on call rotas.

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 (0.5 WTE)
Sharon Mould	Respite Care Nurse (0.8 WTE)
Gillian Elwood	Nephrology Liaison Nurse (0.7 WTE)
Diane Blyton	Renal Nurse Educator (currently on extended leave)
Chris Rhodes	Urology Nurse Specialist (0.6 WTE)
Gill Young	Urology Nurse (currently on maternity leave)
Ben Harvey	Critical Care Educator
Ian Buchan	Acute Renal Failure Nurse
David Cooper	Junior Charge Nurse – Haemodialysis
Sue Marsden	Ward Manager
Michelle Kirkland	Practice Development Nurse (0.8 WTE)

The Children's Clinic

The clinic is run by Pip Waddington. She and her staff continue to provide an excellent working environment.

Dietetics

Pearl Pugh, Renal Dietitian, is currently on maternity leave. Lara Morrison joined us on 16th July 2007 and Alison Tooke on 1st October 2007.

Social Work

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

Psychologist

Dorothy MacKinlay provides part time support to the unit
Assistant Psychologists – Emily Talbot (left September 2007) and Hilary Maxwell

School Teachers

Hazel Coalwood has now been appointed as the Education Centre Manager and Julie Overend is the City Campus Education Base Coordinator. She is supported by Sally Eminson who acts as the Renal Team liaison, Elaine Boon and Carol Laverick. They continue to provide valuable teaching support to inpatients and children on haemodialysis as well as liaison with pupil's schools for children with chronic problems.

Play Leader

Claire Hardy

Youth Worker

Donna Hilton continues to develop youth work support for all young people in the paediatric unit with part-time assistance

Family Care Coordinator

Excellent facilities for resident parents are provided on Papplewick Ward and Denise Martin continues to provide support to our families.

Administrative and Secretarial Staff

Ann Johnson, Barbara Wiklo, Rosie Allen, Joy Lees and Sandie McLauchlan continue to provide their invaluable support at the City Hospital. Judith Hayes gives excellent support in her post as part-time data manager/research assistant (funded by the KINDER APPEAL/Research Fund).

Andrea Christodoulou provides secretarial support at the QMC.

Linda Benson helps in data collection as the ward receptionist.

Housekeeping

Della Langham and others 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

Deirdre Cunningham, Richard Bowen, Louise Hubner and Jackie Brannon.

Renal Pharmacist

Sue Clarke provides pharmacy support with advice from Judith Palmer, Adult Unit Pharmacist

Volunteers

Fred provides support for our small garden area. Pat and Pauline provide invaluable support on the ward and Evelyn and Mary in the clinic.

Management

Carol Arme provides leadership in her role as Matron, Children's Services on the City Campus.

The Multidisciplinary Team in 2007 (not all members present)

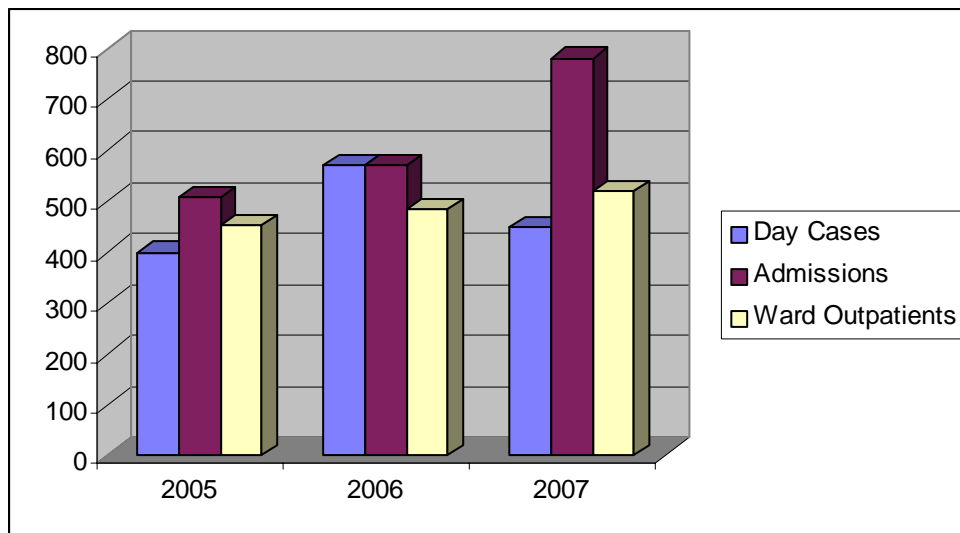


WARD ACTIVITY

The Children & Young People's Kidney Unit has been housed on Lambley Ward in an 11-bedded unit (3 cubicles) which are used flexibly to accommodate renal and urology patients along with medical admissions of children requiring access for radiotherapy. Later in the year the inpatient beds from Lambley moved to Papplewick Ward to consolidate services in the face of increasing nursing shortages.

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 now 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.

The sense of business on the ward has been confirmed by a **38%** increase in admissions compared to 2006 with a **37%** increase in ward outpatients and a **21%** reduction in daycases. Nephrology patients accounted for **55%** of activity overall with **39%** of the admissions, **69%** of daycases and **67%** of ward outpatients.



Lambley Ward houses a 6-bedded haemodialysis unit and all 6 stations have been in use during the year. There is also a home peritoneal dialysis training room which doubles as a haemodialysis isolation cubicle.

Two of the consultants and their secretaries (ARW and JE) have offices on Lambley Ward which also houses a treatment room with ultrasound facilities, renal office, senior sisters office, urology office, youth workers office, schoolroom, playroom and youth room. The juxtaposition of many team members facilitates ease of communication and problem-solving.

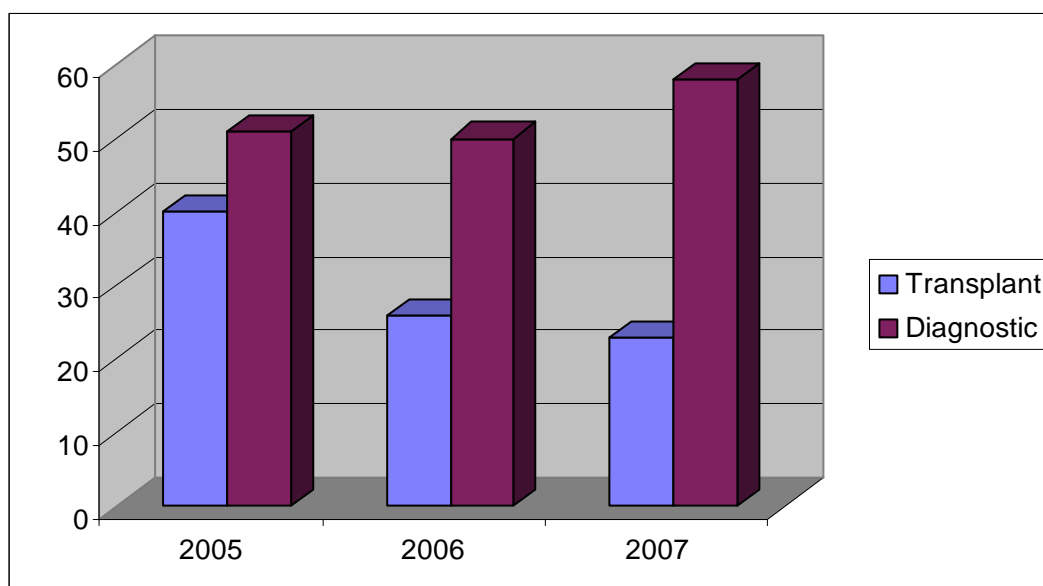
RENAL BIOPSIES

Children are admitted from throughout our catchment area for renal biopsies which we attempt to do as a daycase procedure whenever possible. A total of **78** biopsies were performed in 2007 which is a **16%** increase in number of diagnostic biopsies compared to 2006.

We perform more biopsies on a daycase basis than any other unit in the country and rely heavily on the excellent play preparation and support during the procedure provided by our play leaders. 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.

Regular clinical pathological meetings are held monthly with Dr Tom McCulloch. Dr Zsolt Hodie provides additional help in the acute situation.

Number of Biopsies 2005-2007



Referral Centres for Diagnostic Biopsies in 2007 (n = 58)

Nottingham	13	Derby	3	Leicester	8
Cambridge	1	Norwich	3	Doncaster	8
Peterborough	5	Rotherham	5	Sheffield	2
Lincoln	5	Bassetlaw	2	Barnsley	1
Hinchingbrooke	1	Herts	1		

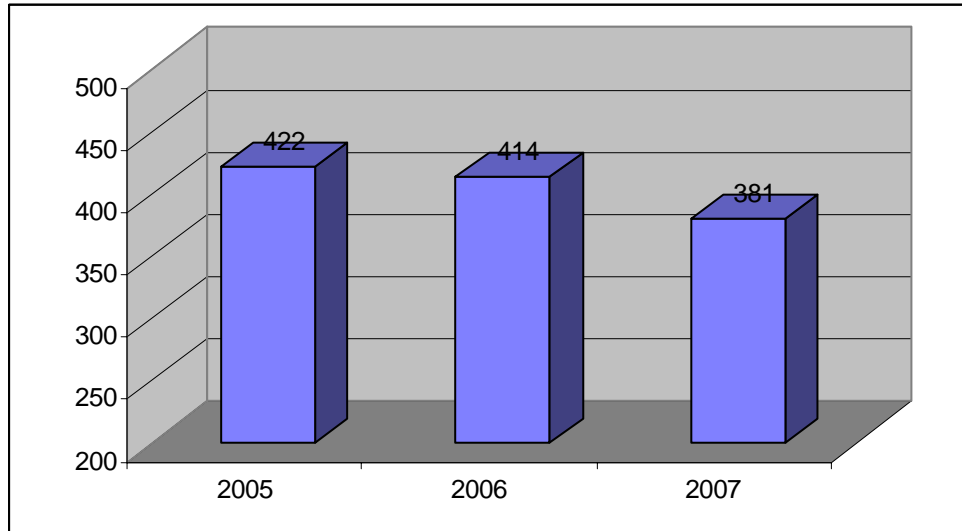
An **annual audit** is undertaken of renal biopsies with standards that we have set locally. These have been published [1,2] and are standards for a national audit which commenced in 2005 with Nottingham as the data collection centre. Standards for adequate material for diagnosis (>95%) and complications 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

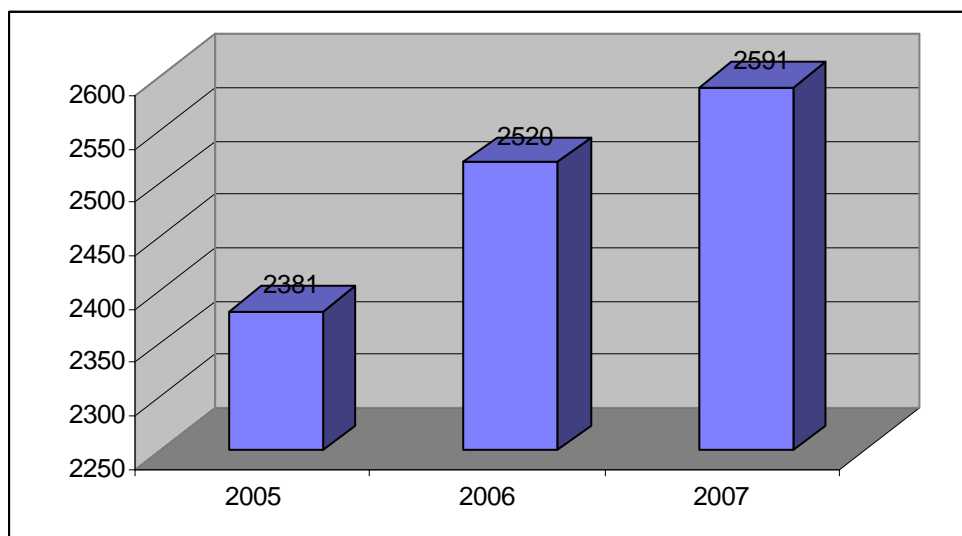
2. Hussain F, Watson AR, Mallik M, Evans J, Christian M. Standards for renal biopsies: an 8-year prospective audit. *Pediatr Nephrol* 2005;20:C103

OUTPATIENT ACTIVITY AT CITY CAMPUS (Nephrology Only)

(a) New Patients (total 381 + 39 DNA)



(b) Consultant Initiated (total 2591 + 570 DNA)



- There was an **8%** reduction in new patients seen in 2007 (381 compared to 414 in 2006) with a **3%** increase in follow up attendees
- General nephrology clinics are held on Mondays (Dr Hussain along with Mr Shenoy, Paediatric Urologist) and Wednesdays (Prof Watson, Dr Evans and Dr Christian) when there is a joint clinic with Mr Williams, Paediatric Urologist.
- 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
- The enuresis clinic and the nurse led diurnal enuresis clinic are held on Wednesdays

- Mr Williams has a monthly neurogenic bladder clinic with the urology nurses in attendance.
- Mr Hunter, Consultant Paediatric Orthopaedic Surgeon, joins us for a twice yearly joint renal and orthopaedic clinic at the City Hospital
- A young adult urology clinic is held 3-monthly

We are grateful for the support of Pip Waddington and the nursing team in the Children & Young People's Clinic where a great deal of activity takes place assisted by Evelyn Evans and Mary Westwood, volunteer staff.

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 leaders 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.

Antenatal Urinary Tract Abnormalities

28 couples were counselled antenatally by Prof Watson either in the Pregnancy Assessment Centre at QMC or in the Children and Young People's Clinic at the City Hospital after referral from fetal medicine specialists.

Children with antenatally detected urinary tract abnormalities are referred from the neonatal service to the paediatric renal unit for postnatal investigation. In 2007 **14** 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).

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. **767** patients were either seen or discussed in 2007. 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. Further regional clinics could be developed but will require investment by the Trusts concerned and a fifth paediatric nephrologist.

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*). Unfortunately, staffing issues have curtailed this aspect of support and also nursing support cannot yet be given at regional clinics.

	2005	2006	2007	Discussed
QMC (monthly)	99	145	57	
Pilgrim Hospital, Boston (4 monthly)	47	32	54	6
County Hospital, Lincoln (3 monthly)	46	45	46	
King's Mill Hospital, Mansfield (3 monthly)	38	39	43	13
Leicester Royal Infirmary (monthly)	109	103	106	
Sheffield Children's Hospital (2 monthly)	19	23	32	10
Queen Elizabeth Hospital, King's Lynn (4 monthly)	26	35	30	4
Norfolk & Norwich Hospital (3 monthly)	52	45	59	
Addenbrooke's Hospital, Cambridge (3 monthly) Nephrology (am) + Nephrourology (pm)	114	110	120	20
Peterborough District Hospital (3 monthly)	47	61	58	15
Rotherham District Hospital (3 monthly)	31	28	56	
Chesterfield Royal Hospital (3 monthly)	42	21	38	

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), Mona Aslam (Peterborough General Hospital) and Chris Nelson, who retired during 2007 (Derbyshire Children's 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.

Two nephrourology meetings are held in Nottingham each year to which nephrologists, urologists, radiologists and paediatricians are invited from throughout the Trent & Anglia region. The Spring meeting is usually organised as a national symposium.

In 2007 we commenced a project in collaboration with Professors Graeme Currie and Robert Dingwall from the University of Nottingham on Clinical Networks for the Care of Children & Young People. Paediatric Nephrology, Cleft Lip & Palate and Safeguarding Children will be studied.

Acute Renal Failure

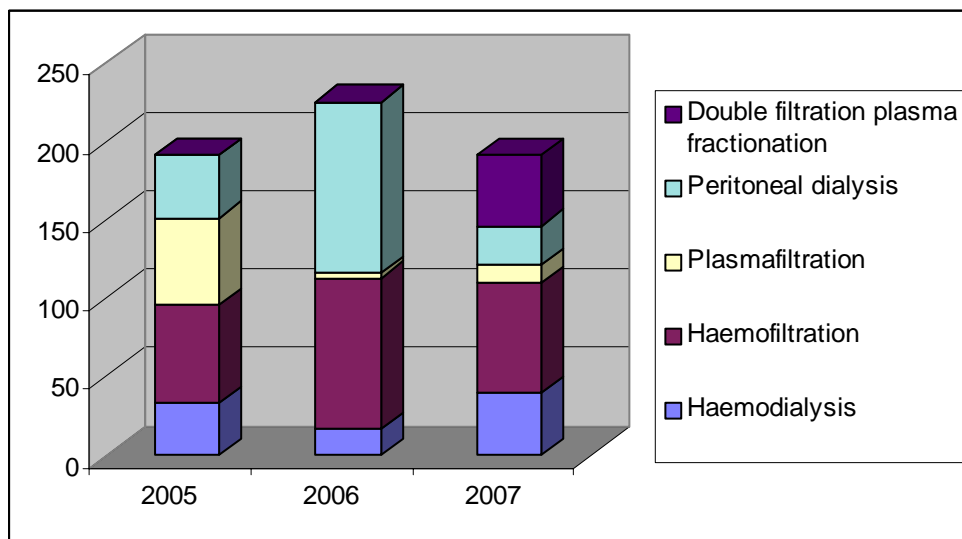
2007 has been a very difficult year to provide acute services and has seen an increase in acute patients treated at City hospital, often with the added difficulties generated by their age and dependency. These difficulties have been compounded by key staff being off on long term sick leave. The problems were further compounded by the times there was more than one acute patient being treated at the same time. The whole nursing team has worked extremely hard to provide acute services often neglecting their own roles to cover the needs of acute patients.

The use of Double Filtration Plasma Fractionation (DFPP) has developed over the course of 2007 in the children's unit. It has now become the standard treatment for children requiring acute antibody and toxin removal. This has replaced Plasmafiltration and therefore almost eliminated the need for human blood products and stopped the use of Fresh Frozen plasma, Octoplas and cyroprecipitate in these patients.

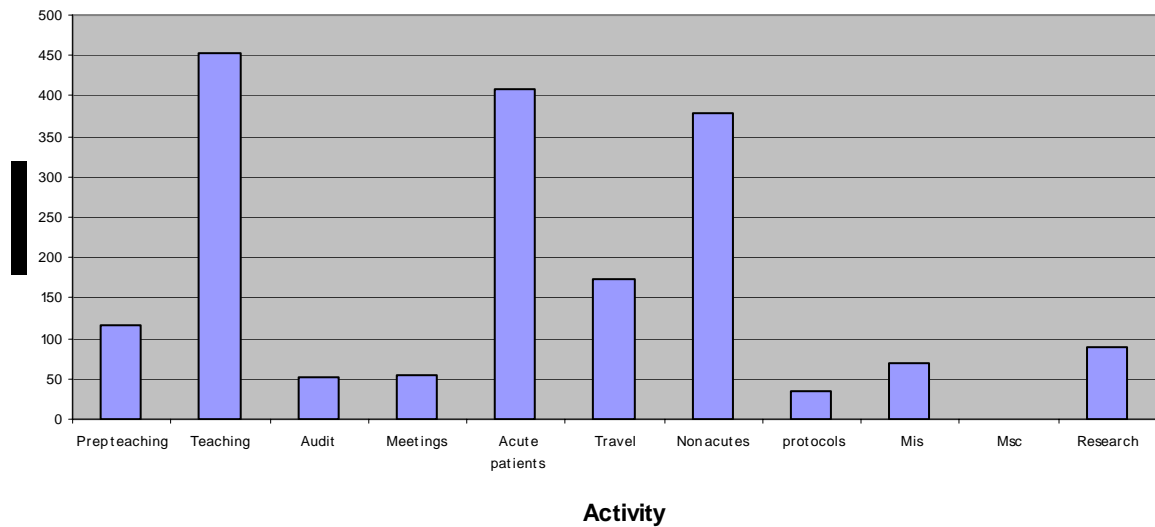
Patients and Treatment

In 2007 **32** patients received acute dialysis therapies (11 haemodialysis, 12 continuous haemofiltration, 2 intermittent peritoneal dialysis, 2 plasmafiltration and 10 double plasmafiltration).

Acute Dialysis Treatment Sessions Delivered in Hospital 2005 – 2007



Renal Critical Educater Use of Time 2007



Despite the challenges of 2007, 450 hours education have been undertaken at Nottingham University Hospital, Sheffield Children's Hospital, Glenfield Hospital and Leicester Royal Infirmary. This has been in all aspects of treatment Haemofiltration (HF) and Peritoneal dialysis. Trials of the Aquarius, Infomed and Prismaflex on PICU at Sheffield Children's Hospital have taken place in 2007. The ability to now perform more advanced forms of HF in children because of improvements in technology is making the educational strategy more complex, with a three times as many key concepts to cover to understand the therapy. Formal education has taken place at Sheffield University and Nottingham University.

Acute renal replacement therapy has been support across the region with over 400 hours of work directly with acute renal patients. The RCCE has been needed to provide acute renal replacement therapy on a number of occasions at QMC, without this input no treatment could have been provided. While every effort is being made to improve this situation, time resources at QMC remain limited.

Prevision of extracorporeal services for patients with chronic kidney disease has proved difficult, with number and dependence of patients casing difficulties with staffing in 2007. The RCCE has been involved in providing this service on a weekly and bi-weekly basis providing 375 hours of treatment.

The RCCE has also been trained to set up and initiate treatment with the Molecular Adsorption recirculation system (M.A.R.S.)

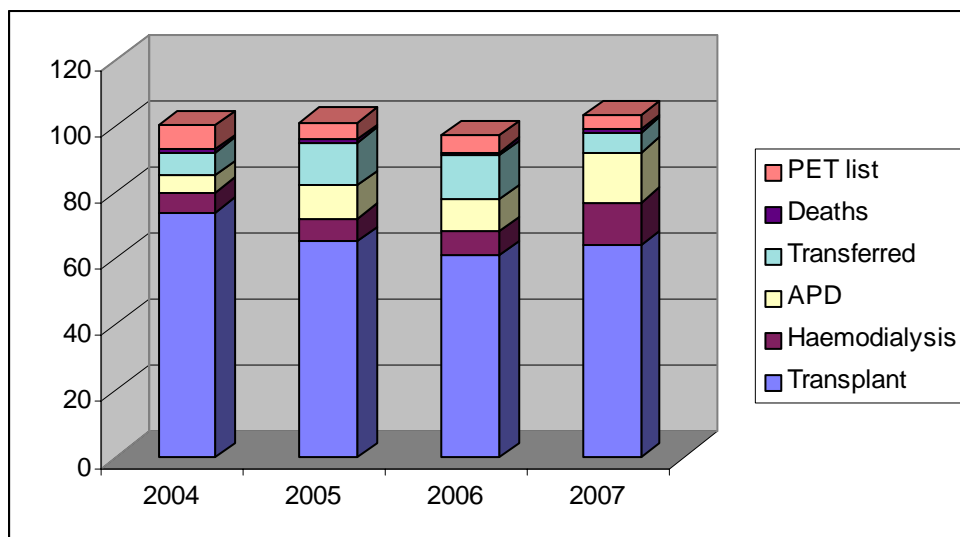
The RCCE has been the lead investigator for an in-vitro drug removal study in CVVH. The study team was Dr Anton Mayer at Sheffield Children's Hospital, Dr Hussain Mulla at Glenfield General Hospital and Dr Trevor Johnson at Sheffield Children's Hospital. He continues also with his Masters Degree in Health Care Education.

Ben Harvey, RCCE
03/08

CHRONIC DIALYSIS & TRANSPLANT PROGRAMME

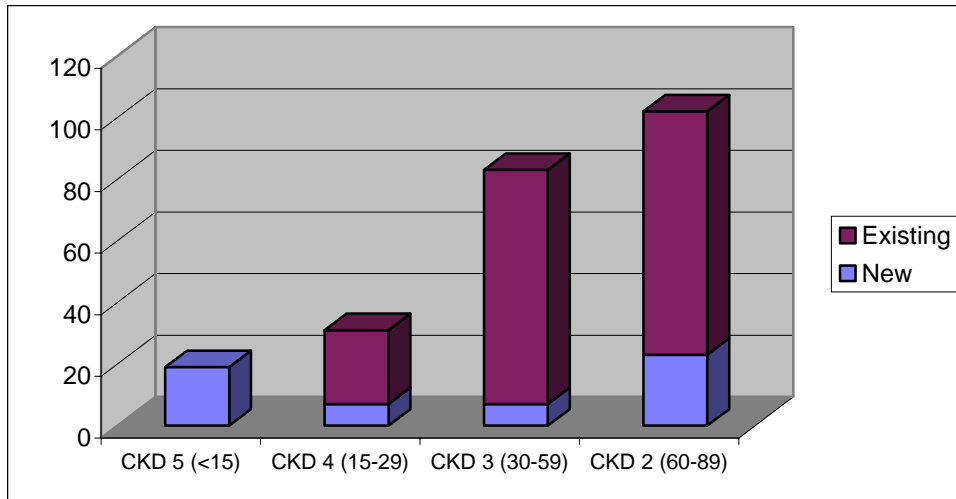
- **19** patients were added to the dialysis and transplant programme (CKD5) in 2007 (compared to 15 in 2006 and 10 in 2005). 9 of the 19 were < 5 years of age.
- **11** commenced treatment on automated peritoneal dialysis (APD), **5** were listed for pre-emptive transplants and **3** commenced on haemodialysis.
- **7** of the patients were entirely new to the renal unit and required intensive education about chronic renal failure treatments
- **11** transplants were performed in 10 children in 2007 (13 in 2006, 9 in 2005). **3** of the 11 were from parental kidney donors. One transplant failed because of thrombosis but the child was successfully retransplanted 7 months later.
- **15** patients were on APD at the end of 2007 and **13** were on haemodialysis.
- **1** baby died on APD. Patient survival remains at **98%**
- **64** transplant patients were being followed at the end of 2007
- **6** transplant patients were transferred to adult units in 2007 (13 in 2006, 13 in 2005)

Current Status of Dialysis and Transplantation 2007



Chronic Kidney Disease (CKD) Patients

The number of patients in CKD categories 4 remains relatively stable as we actively pursue pre-emptive transplantation and early dialysis. There is a steady acquisition of patients in CKD categories 3 and 2. Many of these patients are followed in regional shared care clinics and every effort is being made to slow the progression of renal failure with dietary advice (hampered by lack of personnel), treatment of hypertension and proteinuria and prevention of osteodystrophy and recurrent infections.



Chronic Peritoneal Dialysis

A total of **23** patients received peritoneal dialysis in 2007. This is the same number of patients as the previous year (2006) giving us two very busy years back to back.

12 new families were trained to do peritoneal dialysis at home during 2007. This is slightly down from the 15 families trained in 2006, and indicates that we have had some longer term patients throughout last year.

The caseload was managed by one full time Clinical Nurse Specialist.

PD patient movement:

<u>Remain on PD</u>	<u>Changed to Haemo</u>	<u>Transplanted</u>	<u>Recovered Function</u>	<u>Deceased</u>
13	3	5	1	1

One patient was commenced on the PD program at home as a short term measure and has managed to regain enough kidney function to have her catheter removed.

Inpatient admissions.

There was a fall in inpatient admissions in 2007 with 143 days. This is compared to 252 days in 2006 and 170 days in 2005.

Peritonitis

8 episodes of peritonitis in **144** patient months were identified in 2007, giving an incidence of **1 in 18** patient months. This is compared to 1 in 12 for 2006 and 1 in 10 for 2005.

This is better than the recommended Renal Association standard of 1 in 14 patient months (*Renal Association Standards Document 3rd ed 2002*).

For the second year in a row, 30% of the PD patients were aged less than 5 years and therefore fall in the higher risk category for infections.

The unit's **5-year** peritonitis rate now works out to be **1 in 18** patient months. This a more accurate reflection of peritonitis rates, which shows that overall we are keeping above the standard in this area.

Exit site infections.

Exit site infections have continued to decline in number. No changes have been made in the cleaning technique but more diligence in this area has been encouraged.

Catheter loss

A total of **4** catheters were removed in 2007 compared to **7** in 2006.

All of these catheters were removed due to infection with all the patients requiring transfer to haemodialysis. Three of these patients remain on haemo and one has started back on PD.

Community visits.

A total of **15** community visits were made throughout 2007, compared to **39** in 2006. This dramatic drop in visits can be directly attributed to the staffing levels in the unit and the need to cover an increasing haemodialysis workload.

Aims and Objectives.

Although the peritonitis rates have decreased slightly over the past twelve months, the main objective for 2008 would still be to make improvements in this area. This would involve increasing the number of community visits and revising the update program of the PD patients.

Roy Connell
Clinical Nurse Specialist

Chronic Haemodialysis

- A total of **23** patients received haemodialysis as a chronic treatment in 2007 (compared to 17 in 2006).
- There was again an increase in the number of haemodialysis sessions totalling **313** (305 in 2006 and 299 in 2005) with the dialysis unit being open 6 days a week every week.
- Many of the children were young and had a high dependency and because of the age or high cytotoxic antibodies the number of urgent dialysis sessions increased by **80%** to **1618** compared to 894 in 2006.
- Again we had 5 patients under 5 years of age in 2007 with 2 other children having major learning difficulties. This adds greatly to the workload in the unit.
- There was an average of 10.2 patients having haemodialysis treatment per month in 2007 (compared to 6.6 in 2006).

Double Filtration

2 children continued to have chronic lipid apheresis in 2007 and combined with those who needed double plasmapheresis for vasculitic illness a total of **77** sessions were completed with **116** treatments.

Complications

The number of central venous line infections is being studied in a current project with the majority being treated by leaving the line in situ and treatment with intravenous antibiotics through the line. We continue to use Vancomycin, Gentamicin and heparin locks and are exploring the more regular use of Taurolock.

AV Fistula

Two patients with rejected transplants due to non-adherence and high cytotoxic antibodies continued to dialyse using AV fistula but the majority of children remain on internal jugular venous catheters.

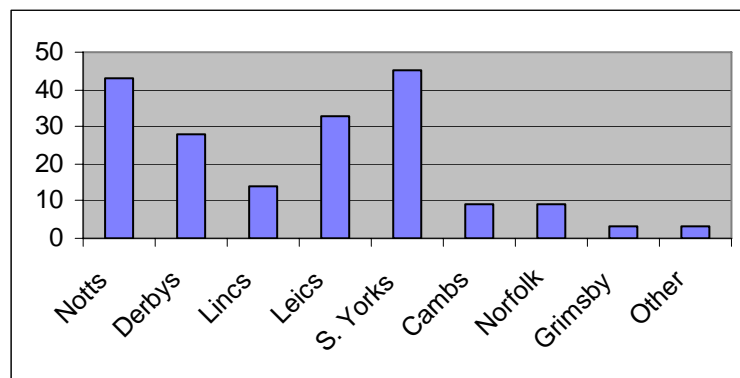
Summary of Haemodialysis Patients in 2007

<i>Month</i>	<i>Number of haemo sessions</i>	<i>Number of patients dialysed</i>	<i>Number of patient sessions</i>
January	27	9	124
February	24	9	125
March	27	11	128
April	25	11	132
May	27	12	133
June	26	12	130
July	26	11	130
August	27	10	125
September	25	11	115
October	27	12	156
November	26	14	153
December	26	14	167
Total	313		1618 (894 in 2006)

Transplantation

10 children (11 transplants) were transplanted in 2007 (**3** from parental donors) and **4** pre-emptively.

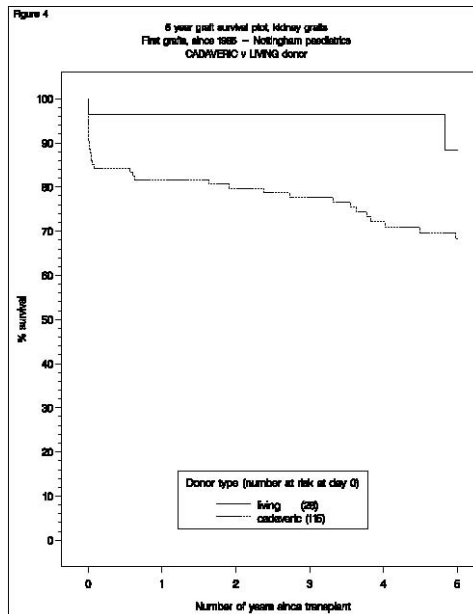
Paediatric Transplants Nottingham 1985-2007 – Area of Origin of Recipients



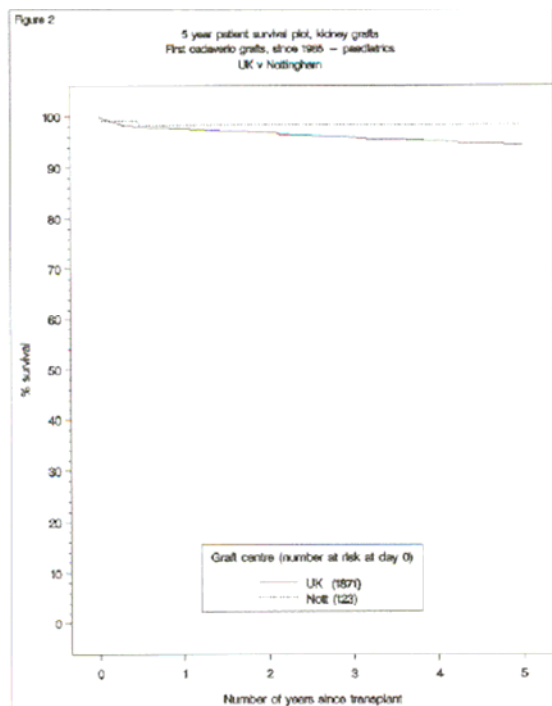
Our 12 month and 5 year cadaveric graft survival rates from 1985 onwards are **83%** (national standard 80%) and **70%** (national standard 68%) respectively (Data supplied by UK Transplant, Feb 2008).

We remained one of the major contributors to the third European multicentre trial of immunosuppressive drugs in transplantation (TWIST trial) during 2007.

The corresponding graft survival figures in living related donor transplants are **95%** and **89%** respectively.



5 year patient survival is **98%** compared to **95%** UK (excluding Nottingham).



Paediatric Renal Transplant Nurses

- **11** transplants were performed in 2007 and **10** are working well at present, one patient had a transplant that failed early in the year and was re-transplanted in the latter part of 2007. **4** of the **11** transplants were performed pre-emptively before dialysis was required. **1** patient required haemodialysis before transplant and **5** patients had required peritoneal dialysis. **2** required short-term peritoneal dialysis before their 2nd transplant. **3** transplants were from live donors, **3** of these from parents. There are a total of **60** transplant patients at present.
- **24** potential living related donors commenced workup in 2007. **15** donors were revisited who had started workup in 2005 and 2006. **3** donors revisited from 2005 were transplanted in 2007 and **3** others continue updated work up for transplants in 2008. **3** donors from 2006 are on hold, **3** are being worked up, **1** planned for 2008 and **1** recipient had a cadaveric transplant and **1** withdrew. **9** donors worked up in 2007. **2** of these were non-compatible and **2** withdrew. We have **1** donor from Birmingham waiting donation in early 2008.
- The unit continues to promote good pain control for all our transplant patients. Pain management is usually maintained by Diamorphine infusion. Regular liaison with the specialist pain team and regular meetings with theatre staff helps maintain communication regarding pain relief.
Live donor pain management is usually maintained with an epidural. Regular liaison with the adult pain team and the live donor coordinator ensures that the donors have adequate pain management. Continuous feedback from previous donors helps us keep informed of the pain relief required.
- The unit aims to try to pre-emptively transplant our patients. It is a role of the Transplant Clinical Nurse Specialist (CNS) to coordinate the pre-emptive transplant workup prior to transplant. To maintain the units workup standard the Transplant CNS ensure that patients attend the unit for a Renal assessment day, to have tests and meet members of staff prior to dialysis and Transplant. **5** renal assessments were carried out in 2007. There were **30** pre-emptive patients either on or waiting to go on the cadaveric list or having conservative treatment in 2007, but **4** patients were transplanted (**2** Live donor and **2** cadaveric) **3** went on to Peritoneal dialysis, **1** on to haemodialysis and **1** moved away.
- Liaison work by the Transplant CNS continues, both with the adult unit and other health care professionals such as GPs and practice nurses and local hospitals, enabling transplant patients to have bloods checked locally. Communication remains an important element in managing patients and families throughout the hospital and community. In 2007 approximately **500** phone calls were made to patients and parents and health care professionals. Approximately **350** calls were received from patients, parents and health care professionals.
- To ensure that the child or young person's needs are met throughout all disciplines, the Transplant CNS carried out **3** school visits and **no** GP visits and **3** multi professional review meetings were attended. No GP visits were carried out but after transplant, a curtsey telephone call was made to the patients GP, followed by written information.
- Transplant patients were seen regularly in clinic or reviewed on Lambley Ward. For patients and families who are going to be placed on the transplant list, clinic is not the ideal place to discuss in detail any issues or problems, therefore a home visit is felt to be beneficial. Only **8** home visits were carried out.
- A number of young adult transplant patients transfer to various adults units in the Trent region - **1** to Sheffield and **4** to Nottingham. **1** patient to Grimsby
- Compliance remains a concern amongst the transplant patients. This is an area which, we in our unit like to address by doing updates once yearly with all our patients

and carers. Unfortunately due to high demand of haemodialysis patients, the transplant sister as only carried out 8 updates. This is an area that needs prioritising in 2008.

- The Transplant CNS continues to carry out procedures such as venepuncture and cannulation. Along with patient group directives to prescribe and give iron infusions, this improves the service we provide for our patients; cutting down the time a patient is waiting for treatment.
- The transplant nurse continues to support the Transplant CNS but due to the increasing number of haemodialysis patients, this support has been unavailable towards the latter part of the year.
- The Transplant CNS continues to carry out other renal therapies along with other members of the renal team, by providing a 24hr on call service.
- The Transplant CNS attended two conferences in 2007
The British Transplant Society - Live Donor meeting held a conference at Manchester
International Transplant Nurse Society UK and Ireland Chapter held in London
- The transplant CNS continues to be involved with many groups within the City Hospital Trust:
 - Child Protection Link Nurse for the renal team.
 - Transition Group.

This annual report shows below average number of visits but an increase in new patients. Unfortunately due to the high demand haemodialysis required, the Transplant CNS was required to support haemodialysis staff, therefore all visits were put on hold unless urgent. The hours worked in haemodialysis were equivalent to 40 working days. Transitional care is an area where there is working progress. It is hoped that next year, the unit develops a much-improved process, due to the high number of patients requiring transfer to adult units in 2008; this will coincide with the merger with the Queens Medical centre.

To promote good health following transplant it is necessary to prioritise updates for our post transplant patients and continue to carry out home visits for new patients.

Kim Helm
Transplant Clinical Nurse Specialist

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 consultants and specialist renal nurses with a direct telephone line to the renal office
- **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, dietitian and sometimes 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)
- **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 leaders 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

Respite Care Support

- **Babysitting scheme** funded from unit charity funds
- **Respite renal nurse**
- Annual **Children's Renal Holiday** to Center Parcs is organised and run by our unit which raises all the sponsorship involved. Villas for patients on their own with staff and 2 villas also for families
- **Holiday caravan** in Hunstanton. This came to the end of its 'site life' in October this year and we are unlikely to replace it at present
- **Haemodialysis** for young patient with family and nursing support in Notts Family Fund House in Skegness
- **Annual young people's holiday** at Fairthorne Manor (BKPA supported) for adolescents
- See other activities under Youth Work report.

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
- 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

- **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
- **Nephrotic Parents Evening** is held annually. We also support the **Childhood Nephrotic Support Group** which has a national membership

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) standard [3,4]
- 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

Postgraduate Meetings

- Joint meeting weekly with adult renal unit, Friday 1300hrs
- Joint meeting with paediatric urologists, radiologists and adult urologists, Wednesday 0800hrs
- Paediatric renal meeting Monday 1200hrs
- Monthly paediatric biopsy meeting with pathologists
- Paediatric renal journal club alternate Fridays 0800hrs
- 3-monthly meeting with transplant surgeons and coordinators
- General paediatric radiology meeting Monday 1300hrs
- Paediatric postgraduate meeting Thursday 1600hrs

3. Treatment of adults and children with renal failure. Standards and audit measures. (3rd edition). The Renal Association, London 2002

4. Review of multiprofessional paediatric nephrology services in the UK – Towards standards and equity of care. Report of a Working Party of the British Association for Paediatric Nephrology 2003

TEACHING

- a) Medical undergraduates – regular tutorials were held on both general paediatric and renal topics. Students at QMC currently have the opportunity to attend the general and specialist nephrology clinics at the City Campus
- b) Postgraduates –
 - Participation in organised **teaching programme for SHOs and specialist registrars**
 - Specialist Registrar teaching sessions have been 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
- c) Nursing staff are involved in lectures to nursing undergraduates and paediatric renal, intensive and neonatal care.
- d) We continue to develop the “sister unit” link with Dr Mohamed Abdelraheem and Dr El-Tijani M Ali at Soba University Hospital, Khartoum providing journals and textbooks to the unit. Prof Watson, Shelley Jepson and Pearl Pugh visited the unit in February 2007 and we also trained a nurse and junior consultant in Nottingham later in the year from Soba University Hospital.
- e) We continue to provide e-mail support clinical advice to units in Egypt, Jordan, Saudi Arabia and Iraq
- f) Prof Alan Watson acts as Medical Adviser to Kidney Research UK and the National Kidney Foundation
- g) Prof Alan Watson is the BAPN paediatric representative on the International Committee of the Renal Association (UK)



Dr Reem Mirghani (visiting fellow to UK in 2007), Dr Mohamed Abdelraheem, Amira (visiting nurse 2007), Prof Alan Watson, Shelley Jepson, Pearl Pugh and Dr El-Tijani M Ali during UK group's visit to Soba University, Sudan February 2007

RESEARCH

Judith Hayes, Data Manager and Research Secretary is funded by KINDER (Children's Kidney Appeal) and maintains unit databases and liaison with the **National Paediatric Renal Registry** for collaborative demographic research

Research & Development Approved Projects

Active

- Long-term tapering or standard steroids for nephrotic syndrome. (BAPN collaborative study with Dick Trompeter (GOS), Nick Webb (Manchester) and Birmingham Children's Hospital, MREC approved). Commenced 2006 (N)05PA11
- FG-02-43 3rd 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) (MREC approved) 2005-2008
- International Pediatric Peritoneal Dialysis Registry 2007 –
- Prospective registry of antenatally detected urinary tract abnormalities (N)880A01
- Clinical Networks for the care of children and young people (CN)147 in collaboration with Profs Graeme Currie and Robert Dingwall, University of Nottingham 2007-
- Complement C1q autoantibody in glomerulonephritis (R&D O8CS001) in collaboration with Mark Taylor, Birmingham Children's Hospital (awaiting approval)

Completed

- Transition from paediatric to adult care (N Anderton, D MacKinlay, AR Watson) 2005-2007
- The pathobiology of the podocyte in congenital and acquired nephrotic syndrome (N)02PA02 in collaboration with M Saleem, Bristol Children's Hospital

Other Projects include:

Urinary tract infection and malformations

- 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**
- **Quality of Life** for children with chronic renal failure (service evaluation) in collaboration with Hilary Maxwell and Dot Mackinlay

Chronic renal failure

- Growth and dietary intakes post-renal transplant
- Does high folic acid reduce hyperhomocysteine levels in CRF patients?
- Prospective monitoring of complications of internal jugular venous access in children on haemodialysis
- Long-term follow-up of renal function in children following haemolytic uraemic syndrome
- Registry of D- HUS patients (in collaboration with Dr Mark Taylor, Birmingham)
- The development of guidelines for paediatric dialysis (A Watson is convenor of the European Paediatric Dialysis Working Group)
- Transition from gastrostomy to oral feeding following successful renal transplantation
- The toxicity of aminoglycosides in cystic fibrosis patients

Registries

- Maintenance of a UK Cystinosis Registry (in collaboration with William Van't Hoff, GOS)
- Regular updating of National Paediatric Renal Registry (and hence Renal Registry and redeveloped EDTA Registry) by Judith Hayes

Prof Alan Watson acts as research lead for BAPN collaborative studies

PUBLICATIONS IN 2007

Webb NJA, Coulthard MG, Trompeter RS, Fitzpatrick MM, Stevens S, Dudley J, Maxwell H, Waller S, Watson AR, Hughes DA, Keevil BG, Ellis JS. Correlation between finger-prick and venous ciclosporin levels: association with gingival overgrowth and hypertrichosis. *Pediatr Nephrol* 2007;22:2111-2118

Watson AR. Aminoglycosides, toxicity and cystic fibrosis. *J R Soc Med* 2007;100(Suppl 47):24-28

Shaheen I, Harvey B, Watson AR, Pandya HC, Mayer A, Thomas D. Continuous veno-venous haemofiltration with or without extracorporeal membrane oxygenation in children. *Pediatr Crit Care Med* 2007;8(4):362-365

Shroff RC, Donald AE, Hiorns M, Watson AR et al. Mineral metabolism and vascular damage in children on dialysis. *JASN* 2007;18:2996-3003

Bertenshaw C, Watson A, Lewis S, Smyth A. A survey of acute renal failure in cystic fibrosis patients in the United Kingdom. *Thorax* 2007;62:541-545

Hiley D, Watson AR. Preparation of children undergoing nuclear medicine procedures. *Paediatr Nurs* 2007;19(10):26-28

Schaefer F, Feneberg R, Aksu N, Donmez O, Sadikoglu B, Alexander SR, Mir S, Ha IS, Fischbach M, Simkova E, Watson AR, Moller K, von Baum H, Waraday BA. Worldwide variation of dialysis-associated peritonitis in children. *Kidney Int* 2007;11:1374-1379

Mallik M, Watson AR. Antenatally detected urinary tract abnormalities: more detection but less action. *Pediatr Nephrol* (in press)

Watson AR. Management of urinary tract infection in children. *BMJ* 2007;335:356-357

Articles Reviewed for Medical Journals

During 2007 Prof Watson has reviewed 21 articles for a total of 11 different journals.

Christian M. Book review: Pediatric Nephrology (2nd ed). *Paediatrics & Child Health* 2007;17:423

Chapters

Watson AR. Chronic renal failure in children. In: Barratt J, Topham P, Harris K (eds). Oxford Desk Reference: Nephrology (in press)

Watson AR. Urinary tract infection in infancy and childhood. In: Barratt J, Topham P, Harris K (eds). Oxford Desk Reference: Nephrology (in press)

Blyton D, Jepson S. Renal care in infancy, childhood and early adulthood. In: Thomas N (ed). Renal Nursing (3rd ed). Edinburgh, Bailliere Tindall 2007. pp295-315

CONFERENCES AND PRESENTATIONS

Conferences

Ali E, Abdelraheem M, Mohamed R, Watson A. Chronic renal failure in Sudanese children; aetiology and outcome. 14th Congress of the International Pediatric Nephrology Association, Budapest 31/8/07 – 4/9/07. *Pediatr Nephrol* 2007;22:1558

Blyton D. Double filtration plasmapheresis. Paediatric Nephrology Nurses Conference. Southampton, March 2007

Elwood G. Nephrotic syndrome 10 years on. Paediatric Nephrology Nurses Conference. Southampton, March 2007

Hussain F. BAPN audit of renal biopsies. BAPN Clinico-Pathology Meeting, June 2007.

Hussain F, Mallik M, Watson AR. Practice and outcomes of pediatric renal biopsies in UK centres. 14th Congress of the International Pediatric Nephrology Association, Budapest 31/8/07 – 4/9/07. *Pediatr Nephrol* 2007;22:1458

Lunn A, Holden S, Watson AR. A comparison of flow cytometry, urine dipstick and culture in the diagnosis of urinary tract infection in children. Trent Regional Paediatric Society Meeting, QMC, Nottingham, 15 October 2007

Prayle A, Lunn A, Watson AR. Karyomegalic nephropathy, Ewings sarcoma and renal insufficiency. Trent Regional Paediatric Society Meeting, QMC, Nottingham, 15 October 2007

Rhodes S, Watson AR. Unilateral renal agenesis: what investigations and who to follow up? Royal College of Paediatrics and Child Health. 11th Spring Meeting, York, March 2007.

Rhodes S, Watson AR. Unilateral renal agenesis: what investigations and who to follow up? 14th Congress of the International Pediatric Nephrology Association, Budapest 31/8/07 – 4/9/07. *Pediatr Nephrol* 2007;22:1444

Shroff R, Donald A, Hiorns M, Watson AR et al. Preventing secondary hyperparathyroidism reduces vascular damage and calcification in children on dialysis. RCPC Spring Meeting, 26—29 March 2007. *Arch Dis Child* 2007;92(Suppl 1):A5

Watson AR. More detection – less action. 2nd Annual Paediatric Nephrourology Conference, Nottingham March 2007.

Webb N, Prokurat S, Vondrak K, Watson A, Hughes D, Hamer C, Rhodes S. Multicentre randomised prospective trial of Tacrolimus, Azathioprine and Prednisolone with or without Basiliximab: two year follow up data. 14th Congress of the International Pediatric Nephrology Association, Budapest 31/8/07 – 4/9/07. *Pediatr Nephrol* 2007;22:1446

Williams A. Is the laparoscopic approach to pyeloplasty the future? 2nd Annual Paediatric Nephrourology Conference, Nottingham March 2007.

Wood D, Watson A, Christian M. Renal dysplasia due to twin to twin transfusion syndrome is a poorly recognised cause of chronic renal failure. 14th Congress of the International Pediatric Nephrology Association, Budapest 31/8/07 – 4/9/07. *Pediatr*

Nephrol 2007;22:1556 (poster selected for “blue ribbon award” for excellent poster presentation)

Invited Lectures

Christian M. Cystinosis and oxalosis. Mid Trent SpR Training in (Adult) Nephrology. 1st March 2007. Sheffield

Christian M. Childhood nephrotic syndrome. Pilgrim Hospital, Boston. 15 May 2007.

Christian M. Renal physiology for the paediatric intensivist. Paediatric Intensive Care Society. 19th September 2007. University of Nottingham.

Watson AR. Bridging the Paediatric/Adult Divide. Renal Association Advanced Nephrology Course. 18th January 2007. London

Watson AR. Pre-emptive transplantation in children. AFRAN 9th Congress & SSKDT 2nd Congress in collaboration with the ISN. Khartoum, Sudan. 2-5 February 2007.

Watson AR. Acute renal failure in children. AFRAN 9th Congress & SSKDT 2nd Congress in collaboration with the ISN. Khartoum, Sudan. 2-5 February 2007.

Jepson S. The challenges of dialysis in Children. AFRAN 9th Congress & SSKDT 2nd Congress in collaboration with the ISN. Khartoum, Sudan. 2-5 February 2007.

Pugh P. Principles of renal dietetics in children. AFRAN 9th Congress & SSKDT 2nd Congress in collaboration with the ISN. Khartoum, Sudan. 2-5 February 2007.

Watson AR. Update on nephrotic syndrome. Khartoum Teaching Hospital, Khartoum, Sudan. 7th February 2007.

Watson AR. Adherence to therapy. Paediatric Nephrology and Urology Week 2007. Institute of Child Health, London. 28 February 2007.

Watson AR. Psychosocial imbalance in children with CKD. Survival is Not Enough: Quality of Life in CKD. 1st International Conference, Naples 7-8 March 2007.

Watson AR. Ethical dilemmas 2007. 27 April 2007. Queen Elizabeth Hospital, Kings Lynn.

Watson AR, Hilton D. Supporting the transition to adult care. Grand Rounds. Sheffield Children’s Hospital, 2nd May 2007.

Watson AR. Starting and sustaining chronic peritoneal dialysis: European guidelines. Polish Paediatric Nephrology Association, Warsaw. May 2007

Watson AR. The natural history of antenatally detected urinary tract abnormalities: more detection but less intervention. Polish Paediatric Nephrology Association, Warsaw. May 2007

Watson AR. Improving entry into adult care. British Renal Society Annual Conference, Birmingham. June 2007

Watson AR. Ethical support in clinical practice. Ethical Issues in the Management of Older People, City Hospital Campus, Nottingham. 29 June 2007.

Watson AR. The Nottingham experience. Transitional care in renal medicine. Northern General Hospital, Sheffield 24 July 2007.

Watson AR. Adequate dialysis includes adequate nutrition. 14th Congress of the International Pediatric Nephrology Association, Budapest 31/8/07 – 4/9/07. *Pediatr Nephrol* 2007;22:1434 (symposium organiser: Chronic peritoneal dialysis – an update)

Watson AR. The non-adherent adolescent awaiting transplant. Pediatric Dialysis Day of IPNA in conjunction with the 14th Budapest Nephrology Summer School 31 August 2007.

Watson AR, Fischbach M. Overviews of principles of dialysis. 14th Congress of the International Pediatric Nephrology Association, Budapest 31/8/07 – 4/9/07.

Watson AR. Successful dialysis requires social support as well as science. Symposium on chronic renal disease in children. A tribute to Ulla Berg. Karolinska University Hospital, Stockholm, Sweden September 20th 2007.

Watson AR. Transition of paediatric patients to adult care. Cairo-Sheffield 2007 Workshop. In-EI-Sokhna, December 2007

Watson AR. Clinical ethic support: not just another hospital quango. Grand Rounds. Royal Hospital for Sick Children, Glasgow. 4 December 2007.

Conferences & Meetings Organised

2nd Annual Paediatric Nephrourology Conference, 30th March 2007, City Hospital Campus, Nottingham University Hospitals

Trent Paediatric Nephrourology meeting October 2007, City Hospital Campus, Nottingham University Hospitals

Trent & Anglia Clinical Ethics Group. 14th November 2007, QMC Campus, Nottingham University Hospitals

BOOKLETS AND LEAFLETS

Booklets (distributed nationally and abroad)

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

Leaflets:

Chronic Renal Failure: Tests
Urinary Tract Infection in Children
Kidney and Bladder Problems Detected Before Birth by Ultrasound
Multicystic Dysplastic Kidney (MCDK) Explained
A Guide to the Management of Childhood Nephritis
Haemolytic Uraemic Syndrome

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

731 copies of the above booklets were requested by other units in 2007.

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

Paediatric Renal Dietetic Service

(FULL REPORT AVAILABLE)

The dietetic service provided to the paediatric renal unit during 2007 was staffed by one full-time Paediatric Renal Dietitian, Pearl Pugh until August 2007. After this date maternity cover (0.45 wte) was provided by Lara Morrison. From October 2007, Alison Tooke joined the team and provided an additional 0.5 wte. Consequently the paediatric renal dietetic service was understaffed during 2007 compared with past years.

Overall paediatric activity by the renal dietitians cannot be compared to 2006 data because of the part-time nature of Alison Tooke's position. However, the total paediatric renal dietetic activity amounted to **1436** contacts during 2007 compared to 1636 in 2006. This decrease reflects the reduction in the service due to a combination of factors including reduced staffing, maternity cover and training of new staff.

Paediatric Renal Dietetic Activity

Total renal dietetic activity = **1436 contacts**

Total number of new renal patients = **76**

The mean number of contacts per renal patient per year was **7.1** compared with 7.8 for 2006.

Outpatient Activity at NUH City Hospital Campus

Outpatient work continued with a weekly chronic renal failure clinic (Thursday am). The dietetic service to the nephrology clinic (Wednesday am) remained suspended with only urgent referrals being seen due to reduced staffing. Dietitians did not attend clinics on the QMC Campus but did remain in contact with dietetic colleagues at the QMC by telephone.

Regional Shared Care Clinics

Regional shared care service remained suspended due to reduced staffing in 2007. Telephone contact was available for shared care clinics where necessary.

Clinical Renal Patient Contacts at NCH

Direct and indirect clinical contacts in 2007 are compared to 2004-2006, distributed as depicted in the following table.

	No of Contacts			
	2004	2005	2006	2007
Inpatients	703	1051	678	661
Outpatients	644	468	411	333
Day cases	82	170	119	111
Home/school visits	3	6	3	1
Telephone	218	309	470	330

(Inpatients include indirect contact with health care professionals)

(Day cases include contact with patients attending for haemodialysis)

In/Outpatient Activity

Inpatient and outpatient total dietetic contacts were down. The decrease in outpatients is probably a reflection of generally reduced staffing at clinics and continued suspension of the Wednesday nephrology clinic. Telephone contacts were also down but remained **23%** of total contacts, which is the same as 2006.

Combined inpatient and outpatient work continued to represent **77%** of paediatric renal contacts, as it had in 2006.

Nutritional Support

Enteral supplements administered either orally via a tube and parenteral nutrition (PN) accounted for **57%** of all dietetic contacts during 2007 compared with 63% in 2006. The decreased numbers of contacts overall again reflect reduced staffing levels in 2007.

	Np of Contacts			
	2004	2005	2006	2007
Oral calorie supplements	511	306	544	285
Gastrostomy button feeding	237	426	512	357
NG/NJ tube feeding	171	157	180	175
PN	16	2	14	7

(OCS includes oral supplements and nutrient enriched infant formula codes)

Ongoing Research 2004

- Does high folic acid reduce hyperhomocysteine levels in CRF patients? (PP)
- TWIST study – assessment of dietary intake 6 and 12 months post renal transplant (PP)

Conference Presentations/Attendance

Invited to visit Soba University Hospital in Sudan. Presented at a pre-congress nursing conference on ‘The dietetic management of a child with chronic kidney disease’.

Teaching

- Medical student tutorial (PP)
- Teaching sessions to paediatric renal ward nurses and medical staff (PP)
- Teaching sessions on the haemodialysis bay to patients (PP)
- Involved in dietetic student training (PP/LM/AT)
- Teaching to Research Fellow with clinical attachment in paediatric nephrology (PP)
- Research and audit tutorial to dietetic students (PP)

Lara Morrison
Alison Tooke

Paediatric Urology Nursing Service 2007

The number of children currently requiring our service is:

150 children with a neuropathic bladder (14.5% increase in 2007, 29.5% in 2 yrs)

97 children with daytime enuresis

76 young adults in the young persons clinic (25% increase in 2007, 47% in 2ys)

Children's Outpatient Department

Total number of children seen in clinics by the urology nurses in 2007 was 340; a fall of 22 patients from last year.

Day Case Assessments

Total number of children requiring day case bladder assessment was 118, which is a 28% increase from that of last year, a 50% increase in 2 years.

It has only been possible to achieve this figure by compromising other aspects of our service such as home & school visits, research, in house training and audit work, none of which have been undertaken. In October due to the phenomenal amount of referrals we were receiving from not only our own consultants but also many others we had to implement referral guidelines that stated we would only take referrals from the Paediatric nephrologist and urologists.

It appears that there is additional demand for this service which we are currently unable to meet, within our current staffing levels, and as a consequence, this suggests that the Trust is not currently achieving the maximum revenues that are potentially available from this procedure.

Urodynamics

Total number of children undergoing this investigation was 54 an increase of 64% since 2006. This increase has been achieved only by adding in additional days for the investigation, which had to be done because the waiting list was exceeding the department of health requirements. However, the focus on this area, has again contributed to our inability to devote time to other elements of the service. We very much hope that with the long awaited move to the Queens Medical Centre in June 08 that we will implement either a weekly urodynamics session, or twice monthly sessions, however, this will very much depend on the availability of nursing staff to support this.

Clean Intermittent Catheterisation

20 Children / parents were taught clean intermittent catheterisation, however, in previous years we have been able to offer home and school support/ education, prior to the teaching of this procedure. In 2007, this preparatory work was not possible with any of these patients.

Community

We have carried out 23 home and school visits, this figure remains static from 2006. It has been agreed that whilst nursing hours have fallen 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

940 calls to parent's	785 calls were received from parents
196 calls to health care workers	150 calls received from health care workers
82 calls to schools	79 calls received from schools

Overall total 2232 calls made/received by this service

Other Areas of development

Christine Rhodes has continued to teach on a wide variety of educational courses, study days and conferences.

Feb 07 Taught 6hrs on the Bladder and Bowel Dysfunction course.

March 07 Chaired the RCN Paediatric Urology/Continence Special Interest Group (PUCSIG) study day in Manchester.

April 07 European Society of Paediatric Urology conference (Bruges- Belgium) Spoke on an expert panel debate.

May 07 Spoke for Enuresis Research and Information Centre (ERIC) in Sterling Scotland

May 07 Teaching MSc Students at QMC

June 07 Chaired PUCSIG meeting in Sheffield.

July 07 RCN meeting re PUCSIG

September 07 Spoke at the British Association of Paediatric Urology meeting in Cambridge.

September 07 Taught on Bladder and bowel course here in Nottingham.

November 07 Continence UK conference attended as part of there editorial group.

Christine remains the chairperson for the RCN Paediatric Urology Nurses Group, and continues to work closely with the R.C.N, she also lectures for the Enuresis Resource and Information Centre (ERIC) several times throughout the year. Christine sits on the Editorial Panel of Continence UK a nursing journal. All of this work is carried out in Christine's own time.

Christine Rhodes
Senior CNS Paediatric Urology

Nephrology Liaison Nurse

Introduction

The Nephrology Liaison Nurse is responsible for overseeing transition from hospital to community to promote continuity in care, coordinating outreach support for children and families with a variety of nephro-urological conditions including (but not limited to) chronic kidney disease, nephrotic syndrome and cystinosis. Working outwards from the hospital base as part of the multidisciplinary team the Nephrology Liaison Nurse acts as a specialist resource, communicating with the primary healthcare team and other community based professionals, many of whom will have had little experience of renal conditions in children.

Providing patients and families with the intervention and support to achieve maximum independence and control over their health needs, the Nephrology Liaison Nurse in response to discussions with families and other professionals and in collaboration with others continues to develop information and resource materials.

Development of this role continues to enhance communication between the hospital, family and community and contributes to early discharge reducing time in hospital and disruption to family life.

Activity 2007

- 170 families supported
- 22 new patients
- 10 patients transferred to other treatment modalities
- 30 home/community visits
- 1763 miles travelled
- 30 % of time (estimate) spent on telephone liaison

The Nephrology Liaison Nurse provides support and advice to families at point of diagnosis, during the initial discharge period and acts as a point of contact to provide support and advice in the longer term.

Time spent on community visits continues at a reduced rate this year due to the continuing demands of the haemodialysis workload. Effective communication continues via telephone and written means.

Nephrotic syndrome

- 72 families received support.
- 12 new nephrotic patients in 2007

The Nephrology Liaison Nurse, where possible will meet the child and family during the acute admission and supporting the ward nurses to develop a discharge plan. Communicating with the primary health care team, school and nursery, providing information about nephrotic syndrome and providing feedback and acting as a point of contact to provide support and advice if the child relapses or if there are any concerns.

- The development of "Nephrotic Natter", an internet based support group is still in progress, it should be up and running within a short while after funding has been secured.

Cystinosis

- 8 patients receive support
- 0 new patients in 2006
- National Cystinosis conference in July 2007 was cancelled

- Some of our families have made contacts with others through the cystinosis foundation and are interested in attending future conference events

Children with Gastrostomy Feeding

- Review of gastrostomy devices used: Use of non – balloon devices has led to longevity, reduction in cost and improved patient experience.
- Co-ordinating out patient visits for replacement and review
- Responsible for stock and costing supplies
- Continuing coordination of community support for gastrostomy provision. Majority of supplies continue to be provided by local services. This has resulted in financial saving for the Trust
- Working in collaboration with Gastrostomy Nurse Specialist to review and standardise information provided to patients, families and community support

Ambulatory Blood Pressure monitoring (ABPM)

- Monitoring devices are applied at the hospital and returned by post when patients live a long distance from the unit. This is a change to the traditional home visit to retrieve the equipment. This has resulted in cost savings with no change in outcome

Haemodialysis

- The post holder has worked 25 % of available time in haemodialysis unit and has completed haemodialysis training programme. This is required of all specialist nurses, however time spent in haemodialysis is greater than average due to volume of work and staff sickness.

Achievements 2007

- Presentation of Nephrotic Support Programme and web site at Nephrology Nurses Conference (March '07)
- Organised and led Cannulation by Nurses study day (March '07)
- Collaborated on updating policy for use of oral and enteral syringes in response to BAPN
- Co author of 'Care of Child with Gastrostomy'
- Continuing self development through BSc Hons Clinical Nursing Studies

Aims for 2008

- Continued development of Nephrotic Syndrome web site
- Development of Nephrotic Syndrome Care Pathway
- Review of information booklets and DVD for Nephrotic Syndrome
- Develop comprehensive teaching programme for nursing staff re Nephrotic Syndrome
- Development of information DVD for patients and families prior to insertion of gastrostomy device
- Participation in audit of services provided to children with gastrostomy devices
- Continued participation in renal nurse on call service – covering 1 night per week
- Continuing review of communication and support for patients and families at home

Gillian Elwood
Paediatric Nephrology Liaison Nurse

EDUCATION

Nottingham City's Hospital and Home Education Pupil Referral Unit (HHEPRU) is comprised of The City Hospital Education Base, The Queen's Medical Centre Education Base, Home Education and Thorneywood Education Base.

The City and Queen's Bases are now working in tandem in preparation for merger in May and Hazel Coalwood has been appointed as Education Centre Manager to oversee this process and develop the new merged unit.

Seventeen chronic patients were taught whilst on haemodialysis.

KEY STAGE	CHRONIC HAEMODIALYSIS
1	4
1 then 2	2
2	3
3	2
3 then 4	2
4	1
4 then 16+	2
16+	1

- The number of teaching sessions per chronic haemodialysis pupil varied from 13 to 203 sessions with an average of 80 sessions per pupil. (A session being either morning or afternoon school).
- GCSE's – 2 pupils took exams whilst having haemodialysis
- SAT's – 2 pupils took exams whilst having haemodialysis
- Dependent upon dialysis schedules pupils attend the Hospital School either on Mondays, Wednesdays and Fridays or on Tuesdays and Thursdays. The intervening days are spent at their home school.
- We now have a modern foreign language specialist on the staff who is available to teach this specialised subject.
- We have regular visits from our Connexions Link Officer who has developed links with 6 of our dialysis students.

The teachers working with these pupils are:

Mrs Elaine Boon: Mondays and Tuesdays
 Ms Sally Eminson: Wednesdays, Thursdays and Fridays
 Ms Carol Laverick: Thursdays and Fridays

Extra teaching support is provided in the dialysis bay when required in recognition of the importance of maintaining educational progress and continuity.

Liaison

This 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. This liaison is achieved by:

- Regular telephone contact with the schools of our long-stay pupils requesting curriculum work thus ensuring continuity of education across both sites.

- Termly reports are sent to schools and parents of haemodialysis patients to inform them of work carried out in hospital.
- Short reports are sent to schools when a pupils 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 school feedback forms allow use to evaluate our input ensuring that we provide appropriate child-centred support which builds on best practice.
- Telephone calls are regularly made to a variety of agencies who provide support for our pupils. Connexions, LEO's, Home Education, examination boards, Education Welfare Officers and FE Colleges are contacted as and when appropriate.
- Weekly multi-disciplinary meetings are attended.
- Whenever possible a teacher will attend the weekly outpatients' clinic in order to ensure that any educational concerns are appropriately addressed.
- The Renal Time-Out day is attended by one of the teachers.

Other Educational Activities and Information

- Educational sessions have been provided for children and young people admitted to the renal unit and for accompanying siblings.
- Home Education has been arranged as and when necessary in order to supplement education or ease reintegration into the home school.
- A peripatetic music teacher attends weekly to enrich the curriculum.
- Beauty students offer free therapies to pupils and parents once a week.

This has been an extremely busy year for the School. In February 2007 we had an Ofsted Inspection which although stressful proved highly successful. We were awarded a 'good' which is the next to top grade. As this was our first inspection we were all delighted.

In December one of our staff members emigrated to Australia and is now enjoying the sunshine in the Blue Mountains. Kate Lawes has taken over this post and is working in either the dialysis bay or with the renal children on Papplewick.

Preparations are well underway towards the merger of the City and Queen's Education Bases in May. Various activities have been undertaken over the year both as training days and social events. We are currently negotiating a new working area over at Queen's so both Bases will be packing up and moving during 2008. A hectic time but also very exciting.

We are all looking forward to another year of promoting and enhancing the educational opportunities of our hospitalised children and young people.

Hazel Coalwood
Education Centre Manager

SOCIAL WORK REPORT 2007

Social work support to children with Chronic Renal Failure and their families continues to be provided by Heidi Steward (full-time post) and Suzanne Batte (part-time post). Although the social workers are employed by the Local Authority, funding for their posts comes through health. This arrangement means that the social workers are able to work exclusively with children who are attached to the unit and their families.

The psychosocial issues arising from having a child with chronic renal failure are complex and wide-ranging. The amount and type of support needed varies from family to family and may also be linked to the stage of the illness the child is currently at. For example, the time of diagnosis and the time at which a child begins dialysis or has a transplant can be particularly difficult.

We aim to provide a high standard of social care to children who attend the unit, and their families, through traditional social casework/counselling skills. In addition to emotional support, we also offer practical and financial assistance of various kinds.

In the last few years, there has been a reduction in the number of home visits made by the social workers. This may be due in part to increased activity within the hospital, both in terms of the numbers of inpatients and also the numbers of children receiving haemodialysis. This trend continued during 2007. Despite this, the importance of home visits is acknowledged and such visits are made whenever possible. Parents who are treating children at home on peritoneal dialysis can feel particularly isolated and under stress as the burden of care in this situation is enormous. Regular home visits to these families at home are very important.

Home visits are also made to families of children who are about to go onto the transplant list. Similarly, the medical work-up for Living Related Donor transplants is complemented by home visits made by the social worker to discuss practical, financial and emotional issues raised by LRD transplants.

The social workers also see children who have been admitted to the ward with acute illness. Parents who find themselves in these situations are often in a state of shock at the sudden onset of serious illness in their child. Difficulties may be compounded by the distance of this hospital from their homes, problems with employment, care of other children in the family and financial worries. The social workers again provide both practical and emotional help in such situations.

The following is a list of social work activity carried out in the previous year:

Visits

- 54 home visits were made in total. Some of these visits were made jointly with other team members.
- 3 School visits were made.

Acute Patients

44 acute patients were seen on the ward. Some of these patients moved from acute to chronic renal failure, requiring further social work support.

National Links

The social workers continue to maintain close links with other renal social workers across the country through the BASW Renal Special Interest Group, attending various meetings and training events specific to renal social work. Heidi is the Secretary of this group.

Holiday Caravan

2007 saw the final year of provision of holidays for families in the renal caravan at Hunstanton. The caravan was originally set up, in the main, to provide holidays for children on home dialysis. As dialysis machines have become more compact and other types of holiday more accessible, the need for the caravan has reduced. This, combined with the age of the caravan, led to the decision to give the caravan up. We will be considering alternative holiday provision in the coming year.

Heidi Steward
Paediatric Renal Social Worker

Play Specialist Report

2007 has been a year of many changes within Children's Services, these changes have had an impact on many members of the team and the play team is no exception.

At the beginning of 2007 Lambley Ward had 2 play specialists, Kerrie Waby and Claire Hardy. With Claire being full time ward based and Kerrie working as the play coordinator across QMC and City campus as well as having ward hours. The end of March saw the departure of Kerrie leaving Claire as the only play specialist on the Renal and Urology Unit, (2 down on the recommended number of play specialists for a Regional Centre covering a population of its size). This meant that although the children and young people were receiving play input the standard was not being achieved.

Areas that Children's Renal and Urology require play input:

- Ward inpatients
- Haemodialysis
- Ward Attendees and Day Cases
- Bladder Pressure Studies
- Home visits
- Renal Assessment days / Transplant work up
- Renal Clinic

As well as carrying out general play, specialised play preparation, distraction and support, and developmental play programmes.

In order to improve the amount of play input offered it was necessary for other members of the play team (Lisa Wright, Sam Ward) to help cover, e.g. on theatre days while Claire was taking patients to theatre Lisa would cover Haemodialysis and Sam would cover the other Children's ward. On a positive note this has developed our skills as a team as now both Lisa and Sam are confident in preparing and supporting patients for renal procedures.

Since the summer Lambley ward has been closed except for Haemodialysis and urology patients. With all ward inpatients, ward attendees and day cases now based on Papplewick ward. This has meant that as a small team we work closely together to ensure as much as possible that all patients have some play input each day. Allocating areas to be covered by each member of the team. Although we are now all based on one ward we still cover all of the above areas as well as carrying out specialist procedures for Papplewick and Linby patients.

This has meant that all round we have each developed skills in other areas. Since November our numbers have further dwindled with one member of the team being off on long term sickness. This has meant that the number of areas the remaining 3 members have had to cover has increased, as we now have to provide daily cover for children's outpatients. Added to this was the fact that QMC no longer provides cover for Day surgery, which takes place once a week. Meaning that on occasions there will only be 2/3 play specialists covering 6 areas on a particular day, resulting in some areas receiving little or no input.

The service we provide

At present we provide ward cover Monday to Friday 8am - 4pm

One member of the team works Thursday 7am – 3pm (Day Surgery)

One member of the team works Tuesday 9am – 5pm (Theatre Day)

We also cover bank holidays including Christmas Day and New Years Day on a rota.

Work with Teachers

Where possible and depending on staffing we work alongside the teaching staff in the haemodialysis bay. However as there are a number of children on dialysis who are under school age these are the children that we allocate our time to primarily. Hopefully in the future if play staff numbers increase we will be able to offer more support for the younger school age children in the dialysis bay.

Teaching about our role

We have continued to share our knowledge and experience with members of the multi professional team, including:

- Visiting doctors / nurses
- Student nurses
- New rotating F1's
- Health and social care and nursery nurse students
- Members of outside agencies e.g. Barbados

Home Visits

Unfortunately Home visits for renal transplant preparation have been limited over the last year due to staffing. Where possible home visits have been provided to support the patients and siblings in the run up to transplantation. For those who have not had home visits follow up sessions have been carried out within the hospital setting

Residential

Once again this years residential to Fairthorne Manor in Southampton was lead by Claire, taking ten young people aged 8-12 years on an activity and adventure holiday for five days, along with a Staff nurse, Youth work volunteer and a work experience/ student volunteer. During the week the young people participated in many activities including canoeing, kayaking, sailing, zip wires, climbing to name a few.

All of the children, and staff had yet another fantastic time away and all made new friends within the group and with those attending from Great Ormond Street Hospital.

Christmas Party

This year our Christmas party went back to its original format of entertainment, face painter and disco after feedback from last year's event. Our party was held on Sunday 9th December 2007 in Sherwood Hall, City Campus. The party was attended by approximately 65 children (patients and siblings), as well as parents and staff.

The Starlight Foundation again supported our party and provided funding for the entertainer, party food, face painter, and party bags for each child to take home.

Presents from Santa were purchased from a donation made by the Lambley Village fete/ summer fair, with support from Fred the WRVS gardener.

Visitors

During 2007 we had a number of visitors to the unit including Firemen, Nottingham Panthers, Debra Stephenson and the Starlight panto.

Future

2008 will see many changes within the play services team to provide a better service for the patients and their families.

Claire Hardy
Play Specialist

CLINICAL PSYCHOLOGY REPORT

This has been another busy year both clinically and in terms of carrying out clinically relevant audits and research.

As usual, we have worked as an integral part of the service which the renal team provides. By attending the CRF clinics in Children's OPD, we are able to see patients when they attend for their appointments with other members of the multidisciplinary team. By providing timely interventions in this way it is possible to provide the necessary psychological support in the most cost-effective fashion.

Although home visits do take place, these are generally restricted to local patients because of the additional pressures of time which such visits represent. However, these visits are usually extremely useful and it is to be hoped that the same service can be expected for all of the patients who need it.

We have been fortunate in obtaining further funding from the BKPA for an Assistant Psychologist's post. This support has enabled us to carry out the audits and research which help ensure that good psychological practice is incorporated into various aspects of care. Hilary Maxwell has been appointed to the post and we are pleased to welcome her into the team.

Previously, this support has allowed us to conduct investigations into the following areas:

Transition to Adult Services

This piece of research into action has now been completed and is currently being written up for publication. It was also the key information which was used by the Hospital Paediatric Working Group to develop a common policy for children in all departments moving to adult services.

Our thanks go to Nicola Anderton and Emily Talbot who completed this study and drew up the Transition Plan template.

Quality of Life Audit

People are becoming increasingly interested in how children perceive their Quality of Life, and thus we have begun an audit of this with children as they attend for their outpatient appointments. This audit was started by Emily Talbot last year and is now being carried on by Hilary. This audit will enable us to look at this dimension over time and thus better understand the impact of treatment on the children's lives.

Painful procedures DVD

Funding has been obtained to update the video and teaching package on this very important topic. Much distress is caused to children who have to undergo various painful/invasive procedures. It is hoped that by developing this teaching package further, we can help ensure that where such distress occurs, it is kept to a minimum and further distress is reduced by teaching children appropriate coping skills.

Dot Mackinlay

Youth Work Report

Mission Statement

Nottingham University Hospitals Youth Service recognises young people for who they are and not by their illness.

NUH Youth Service will support and encourage young people in helping them become whatever it is in them to be.

NUH Youth Service will offer support to enable a smooth transition into adult services.

Aims

- ❖ *To support young people enabling them to achieve and progress.*
- ❖ To provide a diverse range of personal and social development opportunities.
- ❖ To help prevent disengagement and social exclusion.
- ❖ To enable young people to have their voices heard and influence decision making at various levels.

Staffing

- ❖ **Donna Hilton** – Senior Youth Worker.
- ❖ **Renal Youth Development Worker** - TBC
- ❖ **Stacey Curzon** - Part-time Youth Worker (Youth Club) funded by Nottingham City Council.
- ❖ **Daniel Pickup** - Part-time Youth Worker (Youth Club) funded by Nottingham City Council.
- ❖ **Volunteers** – a team of 10 dedicated volunteers help out at the weekly youth club sessions.

Young People Involved

Over 300 different young people, in the 10-25 year age bracket, have been involved with the Youth Service at some point during 2007. This could mean advice and support work from the youth workers, using the Youth Room during hospital stays, attending the weekly hospital youth club, activity and support programmes on dialysis, transition support, and/or becoming involved in long-term projects such as the Youth Achievement Awards, day trips and residential holidays.

Hospital Youth Club

The youth club is held at The Children's Centre two evenings a week: Mondays for 10-14 year olds and Wednesdays for 15-20+ year olds.

Young people can come along and take part in activities such as pool, table tennis, Playstation games, computers, art & craft, board games and group games; educational projects such as the Youth Achievement Awards; drama; outdoor events and trips out; or just a coffee and a chat.

We have two part-time youth workers, funded by the City Council, that helps run the club as well as a small team of dedicated volunteers.

Many young people who attend value the peer support they receive as well as opportunities to build confidence and learn new skills.

Activities and Events

Several activities and events have been organised throughout the year, away from the hospital wards, to increase peer support and offer fun opportunities for patients and their siblings.

These have included:

- ❖ Ice Skating
- ❖ Laser Quest
- ❖ Drayton Manor Park
- ❖ Alton Towers
- ❖ Narrow Boat Trips
- ❖ Theatre Trips
- ❖ Mountain Biking
- ❖ Quad Biking
- ❖ Laser Clay Pigeon Shooting
- ❖ West Midlands Safari Park
- ❖ Camping
- ❖ Skegness
- ❖ Shopping
- ❖ The Young People's own Pantomime production at the Lace Market Theatre

Over 80 different young people attended these events, which were based on their needs and interests, and had a fantastic time!

Residentials

Residential holidays for young people provide the opportunities to explore issues, deepen relationships, gain new experiences and learn new skills. They are therefore a vital part of youth work provision.

The Youth Service provides many opportunities for residential experiences. There were three during 2007 that renal patients were able to get involved with:

Young Movers Residential

Back in February the new hospital Youth Committee was formed. HYPE (Hearing Young People Everywhere) got together to discuss and comment on ideas for merging Children's Services and the move across to the QMC.

A three-day residential was organised to help build relationships and develop the young people's skills in discussion, team-building and decision-making.

Youth Club Camp

In July members of the hospital Youth Club went away for a three-day camping experience in Scarborough. Young people were able to learn about the outdoors and aspects of camping as well as develop confidence and peer relationships. All young people involved received an accreditation certificate in outdoor education and camping skills.

United Kingdom Sailing Academy

In August the BKPA provided funding for 6 renal patients to experience a week away sailing and taking part in other water sports at the centre on the Isle of Wight. The young people were able to take part in new activities, build confidence and peer relationships, learn new skills and share their experiences around Chronic Kidney Disease.

One-to-One Support

The Youth Work Team has supported many young people surrounding various needs and issues throughout 2007. This has included:

School...Family...Youth Offending...Illness...Medical Conditions...Sexual
Health...Careers...Alcohol advice...Bullying...Bereavement
Support...Housing...Transition...Volunteering...Developing Interests...Increasing self-
confidence...References...Advocacy work...Listening to young people.

Fundraising

The Youth Service has generated over £20,000 during 2007 to help support the projects that we run.

Many thanks to:

- V Project Grants
- NCF Local Network Fund
- NCF Neighbourhood Renewal Fund
- Nottingham City Council
- Round Table Fund
- Owen Meese & Family
- The Crampton Family
- The Lace Market Theatre
- Young people who completed the sponsored 24-hour Stay Awake Challenge
- Young people, families and members of the public who supported our Pantomime.

Teaching and Training

The Senior Youth Worker has been involved in various teaching, training and steering groups throughout 2007. These have included:

- Teaching on the Youth & Community degree course at Derby University
- Presenting at the 2nd Annual Transition Conference, London, March 07
- Presenting at the Hard To Reach Seminar, Nottingham, June 07
- Co-chairing the Transition Working Group
- Member of the Children's Transition Champions Group for the DH
- Supporting professionals and other hospitals around adolescent issues

- Training young people as volunteers
- Youth Work Staff Training Programmes
- Supporting student youth work placements

“Youth work starts where young people are – with their own view 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

Donna Hilton
Senior Youth Worker