Trent and North Anglia Paediatric Nephrology Network

Annual Meeting

Tuesday 22nd April 2008
Papplewick Seminar Room, City Hospital Campus, Nottingham University Hospitals NHS Trust

Present:
Prof Alan Watson (Nottingham), Dr Farida Hussain (Nottingham), Dr Jonathan Evans (Nottingham), Dr Martin Christian (Nottingham), Dr Andy Lunn (Nottingham SpR), Dr Mona Aslam (Peterborough), Dr Peter MacFarlane (Rotherham), Dr Gail Moss (Sheffield), Dr Richard Bowker (Derby), Dr Alasdair Scammell (Lincoln), Dr Hani Ayyash (Doncaster)

In attendance: Ms Tina Howells, Network Research Group

Apologies:
Dr Peter Houtman, Dr Angela Hall, Dr Uma Ramaswami, Dr Kunle Ayonrinde, Dr Helena Clements, Dr Sue Rubin, Dr Chris Upton, Dr Mujeeb Pervez

Introduction
Following introductions, Alan Watson led some discussion around commissioning services, sharing anxieties over payment by results, foundation trusts and changing patterns of commissioning services. East Midlands SHA is about to conduct a review of the commissioning for specialist children's services with the BAPN pushing for more centralising for children's renal services.

Richard Bowker mentioned the Paediatric Critical Care Minimum Data Collection which requires compulsory data collection of HDU-type patients from October 2007. These include patients on any form of dialysis in hospital.

Move to QMC
Most of paediatrics has now moved to the QMC campus. Left at the City campus is just the renal unit, the respiratory unit and the burns unit. The burns unit will remain at the City but the renal and respiratory units will move to QMC on 8th June. There will be a slight change to the unit's name to reflect the fact that we are a nephro-urology unit. From the move to QMC, we will be known as The Children's Renal and Urology Unit, QMC Campus.

The new unit comprises 10 in-patient beds. Although this is a slight reduction from our current 11-bed unit, we will have 4 en-suite cubicles. There is also a 7-station haemodialysis bay which has been built out onto the roof. This has been financed by a generous grant from the British Kidney Patient Association and will be named the Elizabeth Ward Dialysis Unit after the founder president of the BKPA.

Out-patient facilities are not yet sorted. It is likely that we will take over the space currently occupied by dermatology out-patients when they vacate to move to the Diagnosis and Treatment Centre. For the first few weeks after the move however we are likely to have to continue to hold out-patient clinics at the City campus.

At the present time we are unsure of our new phone numbers for the unit. We will endeavour to send these out to everyone as soon as they are available. Alan reminded everyone that to contact the unit secretaries it was better to phone by 3pm each day as they often come in and leave early.

Some disadvantages to the move are that we will be separated from the adult renal unit and transplant surgeons. For the time being this means that living donor nephrectomies and transplants will be done on separate sites across Nottingham. Also the renal pathology services will remain at the City campus making the processing of paediatric renal biopsies more complicated to arrange.

Annual report

Alan Watson presented some highlights from the 2007 annual report:

- There were 400-500 day cases seen in 2007. Many of these were multiple scans co-ordinated into a single day visit
- There were 56 native renal biopsies and 21 transplant biopsies undertaken in the year. The number of native biopsies has increased from 2006 (48) and the number of transplant biopsies has remained stable. We continue to aim to do elective biopsies on Fridays which is a useful day both for the ward and the patient (to allow 48 hours resting before returning to school). We have a low complication rate. Indications for biopsies remain unchanged: unexplained chronic kidney disease, persistent haematuria, undiagnosed glomerulonephritis, heavy proteinuria
- In 2007 we undertook around 180 acute dialysis sessions. There were around 220 in 2006.
- The overall numbers of patients receiving chronic dialysis or with a functioning transplant remain stable. However we took on 19 new patients within the CKD stage 5 category (GFR<15 or needing dialysis) in 2007. This compares to 15 in 2006 and 12 in 2005. There has been an 80% increase in the number of chronic haemodialysis sessions delivered during 2007 and this has required significant support from senior renal nurses which in turn has had a major impact on our ability to carry out home visits and other aspects of psycho-social support.
- Nottingham's transplant survival figures are comparable to national figures. The biggest cause of graft loss remains thrombosis.
- There have been no deceased donor transplants within the last 6 months. It is now clear that living donor transplants have an improved graft survival and we aim to promote them where possible.
- Over the last year we have participated in an international immunosuppression study looking at early withdrawal of steroids (the TWIST study). There are also moves to try to minimise calcineurin inhibitor drugs (Tacrolimus and Ciclosporin) because of the harmful long-term effects they have on kidney function. Over the last year we have used a new drug – Rituximab, an anti-

CD20 monoclonal antibody which depletes B-cells – as a treatment for humoural transplant rejection.

- Alan Watson discussed some other current issues in transplantation such as the use of non-heart-beating donors.
- In 2007, three members of staff (Alan Watson, Pearl Pugh, dietitian and Shelley Jepson, senior nurse) visited the paediatric renal unit at Soba University Hospital in Khartoum, Sudan. We hope to continue an unofficial link with this unit.

Shared care clinic arrangements

From 9th June 2008 we will be joined by a new colleague, Dr Meeta Mallik who was our national grid SpR between 2004 and 2006. We have made some changes to the staffing of the outreach clinics as follows:

Centre	**Consultants to cover**
Sheffield	Alan Watson to continue
Leicester	Farida Hussain and Meeta Mallik
Cambridge	Alan Watson and Martin Christian to continue
Kings Lynn	Meeta Mallik
Norwich	Jonathan Evans to continue
Peterborough	Farida Hussain to continue
Kings Mill	Farida Hussain to continue
Chesterfield	Meeta Mallik
Rotherham	Martin Christian to continue
Boston	Martin Christian to continue
Lincoln	Jonathan Evans

Chris Nelson, consultant paediatrician with an interest in nephrology retired from Derby in 2007. We are in discussions with paediatricians and managers there over setting up a new clinic but as yet there are no plans.

During 2007 we have highlighted a large number of patients from the Doncaster area who are currently travelling to Nottingham for out-patient care. We hope we may be able to set up a new outreach clinic at Doncaster and deliver some of this care closer to home in line with the Children's NSF.

There was some discussion over local facilities for community nursing, options for respite care and access to paediatric dietitians. It was agreed a survey would be helpful to document this information centrally.

Alan Watson also highlighted some major issues we have encountered in 2007 over the provision of transport and escorts for children needing chronic haemodialysis. It has been very difficult to identify whether the PCTs or local social services are responsible for this aspect of healthcare.

Guidelines

Farida Hussain gave out a CD to all attendees with all the Nottingham renal guidelines. Local paediatricians are welcome to use and/or ratify these guidelines

within their own centres. Martin Christian has revised the nephrotic syndrome guideline to take into account second line treatments. However, the national BAPN study has suspended recruitment while the results of the pilot study are analysed and funding secured for the definitive study. The new guideline will be released after recruitment restarts. The new UTI guideline, based on NICE guidance has still to be ratified by Nottingham.

The multi-cystic dysplastic kidney guidelines and registry form were not included on the CD but will be sent out separately by email.

Education

Martin Christian discussed some suggestions for an annual or biennial education update meeting. There was some support for this as a meeting which would cover a different syllabus to the nephrouroradiology meeting. Gail Moss expressed and interest in hosting a first meeting this autumn. It was suggested that the meeting be a mixture of update lectures and cases brought along for discussion. It ought to be aimed at consultants but with the expectation that senior SpRs would also benefit.

Transition

We transfer two broad groups of patients: those with chronic renal failure (usually dialysis or transplanted patients) who transfer to the large centres: Nottingham, Leicester, Derby, Sheffield and Cambridge; and those with less significant renal pathology, many of whose care is transferred back to their GP at 18.

We now have a Transition Pack for use with young people from 14 onwards which aims to prepare them for this transition period and their ultimate transfer to an adult unit. Our criteria for the timing of that transfer is that the young person should have finished growing, should have finished their scholastic achievement and it should be done in the right social circumstances.

AOB

There was no other business to discuss.

The meeting finished around 5.30pm and was adjourned for dinner at the Banyan Tree restaurant.