Paediatric Nephrourology Network Meeting
Thursday 19th April, 1430h
MedChi Room, PGEC, City Hospital, Nottingham

Present:
Dr Peter Houtman, Leicester Royal Infirmary
Dr Angela Hall, Leicester Royal Infirmary
Dr Kunle Ayonrinde, Chesterfield and North Derbyshire Royal Infirmary
Ms Shelley Jepson, Senior Nurse, Paediatric Nephrology, City Hospital Nottingham
Dr Mujeeb Pervez, Pilgrim Hospital, Boston
Dr Chris Nelson, Derby Children's Hospital
Dr Mona Alsam, Peterborough District Hospital
Dr Jonathan Evans, Nottingham University Hospitals
Dr Helena Clements, Kings Mill Hospital, Mansfield
Dr Gail Moss, Sheffield Children's Hospital
Prof Alan Watson, Nottingham University Hospitals (chair)
Dr Farida Hussain, Nottingham University Hospitals
Dr Martin Christian, Nottingham University Hospitals

In attendance:
Dr Tina Howells, University of Nottingham (Paediatric Networks Researcher)

Apologies
Dr Martin Becker, Hinchingbrooke Hospital, Huntingdon
Dr Alastair Scammell, Lincoln County Hospital
Dr Uma Ramaswami, Addenbrooke's Hospital, Cambridge

Outreach clinic provision

After introductions, the meeting started with some discussion of the current service provision for paediatric nephrology across the network. There are currently outreach clinics in the following hospitals: Sheffield Children's (7 per year), King's Lynn (3 per year), Addenbrooke's (8 per year), Leicester Royal Infirmary (12 per year), Norfolk and Norwich Hospital (4 per year), Peterborough District (4 per year), King's Mill (4 per year), Lincoln County (4 per year), Chesterfield and North Derbyshire Royal Infirmary (4 per year), Rotherham General (4 per year) and Pilgrim Hospital Boston (3 per year).

Derby Children's Hospital has a paediatrician with a special interest in nephrology (CN) who is due to retire this year. There is currently no plan for future paediatric nephrology service provision in Derby. There are no outreach clinics at present in Barnsley, Doncaster, Kettering, Hinchingbrooke or Bassetlaw.

Role of local paediatrician with an interest

PH highlighted that there is no national acknowledgement of a renal special interest so that a lot of locally delivered care is poorly accounted for. MA endorsed this, emphasising that as a paediatrician with a special interest (PSI), there is no clear cut-off between PSI and general paediatrician as she is seeking to establish a local renal clinic.

Different systems are operating in different centres: in some centres all renal work is directed towards one consultant whereas in other centres the work is shared out. This second model applies usually in centres where there is no local lead for nephrology. Several people mentioned the dilution of experience in nephrology amongst general paediatricians, partly as a result of spreading out of workload, partly as a result of new consultants being less "pluripotent" than before. PH, as someone with formal training in nephrology, commented that this did not prepare him well for managing day-to-day renal issues such as complex UTIs. He has found this sort of work easy to pick up "on the job" as a consultant with regional shared-care clinic support and that a lack of paediatric nephrology training did not need to exclude one from taking a local lead in nephrology.

Administration of outreach clinics

JE and MC said that outreach clinics are easier to manage when there is one nominated lead with whom to do all liaising. AW raised the issue of a lack of uniformity over honorary contracts with local hospitals and the governance issues that that raises. He questioned whether we should set standards in terms of turnaround time for letters, actioning results etc. JE said that in the near future all outreach clinics will be charged for. This is happening on a national level and will lead to questioning by business managers over the arrangements and frequency of outreach clinics.

Multi-disciplinary outreach

AW is anxious that it is the paediatric nephrology *service*, not just a doctor that is outreaching and how this is in line with the local delivery of care mentioned in the National Service Framework for Renal Services for Children. SJ mentioned examples of existing liaison with local community nursing and examples of dietetic liaison (Norfolk and Norwich) were cited. There is a lack of uniformity of community paediatric nursing coverage. JE said how access to these services have occasionally been restricted if a local paediatrician is not seeing the child regularly. SJ highlighted how many children with chronic renal failure have significant other morbidity and the importance of a local general paediatric lead in these circumstances. HC thought that local leads for nursing and dietetics could be developed.

Specialist commissioning of regional paediatric nephrology services

AW shared plans of our desire to expand to 5 consultants so that the outreach service might be extended to those hospitals where there are currently no clinics and to develop the educational service provided by Nottingham. In terms of all the above issues such as adequate dietetic support, we all within the network need to be signed up to the need for these developments.

Aspects from annual report

AW discussed the annual report of the Nottingham Children and Young People's Kidney Unit, highlighting several areas:

Antenatal diagnoses. Different services have been established and range between referral to Nottingham, and local neonatologists/paediatricians/surgeons taking this on. This is an area we hope to discuss more at future network meetings.

Acute renal failure. There is a degree of standardisation where ARF is managed in the critical care setting. This is through Ben Harvey, the Critical Care Educator who works between the Paediatric Intensive Care Units in Leicester, Nottingham and Sheffield. There was some discussion over standardising follow-up for children with dialysis-dependent ARF to be that of children who have had haemolytic uraemic syndrome, namely blood pressure, urinalysis and formal GFR at one year.

Chronic renal failure. Now that CRF has been redefined as Chronic Kidney Disease (CKD) with stages 1 to 5 dependent upon GFR, there is the potential for identifying many more children with mild chronic kidney disease. We have previously published on the importance of early dietetic intervention and the need for children even with CKD stage 2 (GFR 60 – 90 ml/min/1.73m^2) to be seen annually in outreach clinics was emphasised. There was some discussion over blood pressure control for these patients.

Transition. Generally across the region there is little provision for adolescent patients.

Children's Network Services

Tina Howells gave a short presentation on the study of a comparative evaluation of paediatric networks of which our nephrology network is one of three being studied. She hopes to liaise with 2 centres more closely (Sheffield and Peterborough).

Nephrotic Syndrome Trial

MC presented on the BAPN-sponsored trial of the initial treatment of nephrotic syndrome. Nationally there are 23 patients enrolled. In Nottingham we have enrolled 6 and had a further patient who had to be withdrawn. Of these 6, most are Nottingham-based, but there is one from Mansfield who is being jointly managed. The Medicines for Children Network (MfCN) have now taken on the trial which also provisionally has sufficient funding to recruit 200

patients. We have been advised that if children are seen at local hospitals, they should also get R&D approval unless the frequency of clinic visits is not different to what would be considered usual clinical practice. This can be interpreted to be the case for the second six months but probably not the first 6 months of monthly follow-up and for this patients would need to be seen in Nottingham. The lack of transport expenses and inconvenience of travel to Nottingham was raised by MA. Both MA (Peterborough) and GM (Sheffield) will look into their own R&D application. Leicester is registered separately and has also already recruited several patients. Other centres agreed to discuss potential patients shortly after diagnosis.

Nephrotic Syndrome Pathway of Care

MC continued the nephrotic theme using the condition as an example of a typical pathway of care to illustrate how the network can work and areas for development. Some specific issues were highlighted:

- Should Nottingham's guidelines be followed in all local centres and should Nottingham's information booklet be available in each local centre? Leicester have their own booklet which is a simplified version of the Nottingham one. HC pointed out that other Trusts are not able to simply use another hospital's guideline but may adopt them as their own. It was also suggested that immunisation advice be part of the guideline.
- Dietetic advice. It was suggested that a similar leaflet could be produced to give simple advice about restricted salt intake.
- Management of hypovolaemia. JE said how difficult it can be to give advice over the telephone on the management of hypovolaemia, particularly with increasingly inexperienced juniors. It was controversially suggested in the presentation that all children outside large centres who need 20% albumin should come to Nottingham for that.
- All children with nephrotic syndrome to be seen at least once by a paediatric nephrologist? This suggestion was made in the presentation for which there was general agreement.

Following discussions it was agreed that the Nottingham guidelines should be reviewed in the light of comments made as above and in light of the BAPN trial, and then circulated around the Network for adoption by local centres.

NICE guidelines on UTI management

PH presented briefly on the proposed NICE-guidance on the management of UTIs which is expected later this year. It will make a major impact on the investigation of UTIs as advice differs significantly from current practice.

Education Meetings

AW mentioned the twice yearly nephrourology meetings that take place in Nottingham and encouraged all to attend. These are meetings organised jointly by paediatric nephrologists, paediatric urologists and paediatric radiologists. In November the meeting is based mostly around case presentations. Over the last 2 years the March meeting has been organised around a theme with national and international speakers invited to give talks and lead discussion in the morning session. The afternoon session is given over to relevant high-quality case presentations. The themes for the last 2 meetings have been posterior urethral valves and antenatal diagnosis. The proposed theme for March 2008 is UTIs.

The meeting finished around 6.15pm and was adjourned to Mr Man's in Wollaton for an evening meal.

Notes taken by Martin Christian, 27/04/07