PAEDIATRIC NEPHROLOGY NETWORK MEETING
TUESDAY 25 MAY 2010, E37 SEMINAR ROOM – QMC

MINUTES

Present:	Alan R Watson	Martin Christian
	Jonathan Evans	Farida Hussain
	Meeta Mallik	Richard Bowker
	Simon Rhodes	Kunle Ayonrinde
	Peter Houtman	
Apologies:	Alastair Scammell	Gail Moss

1. Outreach clinics and Annual Report

Last year saw an increase in the number of patients seen in outreach clinics from 666 in 2008 to 812. This increase has been sustained each year and compared to 2002 there is an 81% increase in the number of patients seen in outreach clinics. Presently there are outreach clinics in 12 centres but there are plans for an outreach clinic to be set up in Kettering. We are in active negotiations over setting up a clinic in Doncaster where we are currently seeing many chronic patients and West Suffolk Hospital have also expressed interest in setting up a 6-monthly clinic.

Currently only 2 clinics (Addenbrookes and Leicester) have dietetic input through a dietitian attending clinic. We all recognise the need for greater dietetic input and have been trying to cost that and negotiate with our own dietetic department.

Over the last year King's Mill Hospital have seen a new development which has been a multidisciplinary x-ray meeting. This has been well received and many patients are discussed each time.

Richard Bowker gave some feedback about the most recently established outreach clinic in Derby. He felt that having a local consultant and visiting consultant in together provided good liaison and in particular increased efficiency in booking renal biopsies. There is also a potential for education. In Derby there are interested dietitians but none that have renal training. Alan Watson suggested identifying one dietitian who would be a link renal dietitian. In Derby, as in other outreach centres, we hope to be able to develop links with the adult renal unit for transitioning patients.

2. New consultant arrangements

Dr Andrew Lunn has been appointed to replace Alan Watson on his retirement at the end of August. Andy will start on 6 September. He will be responsible for the Sheffield outreach clinic. Other outreach clinic arrangements remain to be discussed and decided.

3. SPIN doctors

Peter Houtman reported back on the recent BAPN survey of network paediatric renal services. There has been huge variation in services around the UK. In some areas (Scotland) there are managed commissioned

networks. At the other end of the spectrum are poorly organised services. On the back of this a “Task and Finish” group has been organised by Mary McGraw, currently President of the BAPN to forward the issue of commissioning networks for paediatric renal services around the UK.

Peter pointed out that any paediatrician who is a lead for paediatric renal in their centre can now apply to be a BAPN member as a SPIN doctor. There is a reduced BAPN/Renal Association membership fee for this. They would be part of an e-mail group. Peter also discussed the training package now in place for paediatricians with an interest in nephrology. It is in the form of a special study module which is currently in the pilot stage. The competencies for this can be seen on the RCPCH and BAPN websites. It involves 6 months in a paediatric nephrology centre, 6 months in another centre working with a SPIN doctor in paediatric nephrology and a further 6 months doing a nephrology related sub-specialty such as neonates, PICU or oncology with particular focus on the renal aspects for that time.

4. Educational meetings

Prof Watson reviewed the meetings currently in place. The annual nephrouroradiology meeting in March has now become a regular feature and attracted a more national audience this year. We are continuing with an autumn meeting of nephrourology cases. In addition we provide individual talks or training days when requested. A nephrology meeting organised by Gail Moss in November last year was received very well. A suggestion was made to have an annual nephrology interest meeting that would be open to consultants and registrars. It was thought there were around 10 major topics in nephrology and the plan could be to rotate through 2 of these per meeting. All agreed that the focus of the meeting should include case presentations, discussions and interactive sessions. There was some resistance as to whether we could couple this on to the annual nephrology network meeting but we felt that an education meeting in the autumn would be best. We also discussed negotiating with deaneries to tie in with official training days.

5. Nephrotic trial and RaDaR

The tapering steroids in newly diagnosed nephrotic syndrome study has been revamped and funded. It has been adopted by MCRN and should be relaunched by this autumn. All centres will be asked to put this through R&D so that a maximum number of children can be recruited. Local MCRN staff should be able to facilitate this.

Also discussed was the Rare Renal Disease Registry (RaDaR). This is in the infrastructure for data to be collected nationally on children with a range of rare renal diseases. Piloting the infrastructure is the research study of children with steroid resistant nephrotic syndrome and FSGS. At the present time this has gone through R&D in Nottingham but it is our hope that it will be able to be approved in other centres too to maximise the number of children that can be recruited. There is also a membranoproliferative glomerulonephritis study which is in the early stages of going through Ethics and R&D at the present time.

6. Any Other Business

Nil

The meeting concluded at 5.30 pm and was followed by dinner at The Wollaton.