Minutes of Paediatric Nephrology Network Business Meeting
Eastwood Hall, 5th October 2012, 4.30 pm

Present:
Meeta Mallik, Consultant Paediatric Nephrologist, Nottingham
Viktoria Dixon, Consultant Paediatrician, Hinchingbrooke
James Donnelly, Paediatric SpR, Leeds
Simon Rhodes, Consultant Paediatrician, Kings Mill
Shelley Jepson, Renal Nurse, Nottingham
Emma Kelly, Renal Dietitian, Nottingham
Judith Hayes, Medical PA, Nottingham
Corrine Langstaff, Nottingham
Kunle Ayonrinde, Consultant Paediatrician, Chesterfield
Andrew Lunn, Consultant Paediatric Nephrologist, Nottingham
Birgit Ulbrich, Staff Grade Paediatrician, Addenbrookes,
Martin Christian, Consultant Paediatric Nephrologist, Nottingham (chair)
Raman Lakshman, Consultant Paediatrician, West Suffolk
Mona Aslam, Consultant Paediatrician, Peterborough
Peter Houtman, Consultant Paediatrician, Leicester
Amol Chingale, Consultant Paediatrician, Lincoln
Gail Moss, Consultant Paediatrician, Sheffield
Peter Macfarlane, Consultant Paediatrician, Rotherham
Ese Bentsi-Enchell, Consultant Paediatrician, James Paget
Richard Bowker, Consultant Paediatrician, Derby
Mark Howells, Manager, MCRN East

1. Review of notes from 2011
We hope to be reviewing the guideline for HSP in a year's time across the Network

2. Annual Report 2011
Martin apologised for being late in getting this out this year. He suggested that perhaps in future years this should be more of a report of renal services over the Network. He did a brief overview of outpatient numbers both in Nottingham and at the outreach clinics and also the number of day case patients for tests such as renal biopsies.
Richard Bowker suggested that the renal leads in each centre could provide the number of renal patients seen in their own clinics outside of the joint clinics.

3. Outreach Clinics
- Overall the total number has increased by 50% over 4 years. Addenbrookes has expanded to monthly clinics over the past year and most clinics in the region are getting too big. A Kettering clinic was started up in the last year. Six centres still have no outreach clinics and we are working to try and sort this out.
- There was a discussion on what is the best practice for reviewing results and writing clinic letters from the outreach clinics and who should be responsible for doing what and when. It was agreed that we should

concentrate on joint standards and guidelines. The 5 day turnaround for letters is being rolled out across the NHS and we should look at writing a Network standards document. It was suggested that perhaps once a year the visiting nephrologist and the local link paediatrician should review how the clinics are running.

- The use of nhs.net or encryption was also discussed.
- Dietetic support. We do not have the capacity for dietitians from Nottingham to visit the outreach clinics regularly and it would be better if the Nottingham dietitians could liaise with the local dietetic services. They will approach the local paediatric dietetic leads. It was also agreed that we need to share our resources.
- Lab issues.
  - Tacrolimus levels. It was suggested that patients newly starting tacrolimus might be seen in Nottingham and results processed in the lab there if the distance wasn't too great due to the need for quick availability of results.
  - Rituximab. This has to be received by the lab within 24 hours. What arrangements are in place in the local hospitals?
  - White cell cystine. There is now an assay in Nottingham for this but again it needs to be at the lab within 24 hours. This may cause problems if the clinic is on a Friday.
- Transplant patients. There is now a legal requirement for all the notes of children who have had a transplant to be stamped at the front and back. The wording should read "These records must be retained for 30 years from last episode. EU Organ Donation Directive." This needs to be in place in all hospitals where transplant patients are seen, hence it will be a requirement for every Trust. It will most likely need to be discussed at individual medical records committees.
- Paediatric Radiologists. The Nottingham radiologists have recently had a meeting involving local radiologists. They are endeavouring to have some regular updates for paediatric radiology. The contacts in Nottingham are Kath Halliday (kath.halliday@nuh.nhs.uk; ext 62449) and John Somers (john.somers@nuh.nhs.uk; ext 64229). They do provide (through a costed service) second opinions and first opinions when local colleagues are on leave. At present there are 3 radiologists in Nottingham and they are unable to provide 24 hour cover.

4. Research Issues

Mark Howells, Trent Paediatric Research Network manager attended for this part of the meeting.

- Mark explained that there are 6 research networks in the country.
- They offer the facility to conduct good research within paediatric medicine and are keen to work with clinical networks.
- All clinicians need to make patients aware of studies.
- MCRN and the non-medicines network are hoping to merge in the near future following a review and the NIHR redefining the boundaries of paediatric research.
- PREDNOS and PREDNOS 2.

  - PREDNOS. 85 patients have been recruited so far and this paediatric renal network is well-represented in national figures. The aim is to recruit 220 patients and the hope is that this will be achieved in another year.
  - PREDNOS 2. The pilot data from PREDNOS show that 72% of patients relapse within the first year. The aim of PREDNOS 2 is to evaluate in a cohort of British children the practice of giving a 6-day course of low-dose daily prednisolone during an URTI to prevent a nephrotic relapse. They hope to recruit 300 "all comers" over 2 years (i.e. children with frequently relapsing disease on alternate day steroid prophylaxis, other immunosuppression or none). Recruitment should start in the 1st quarter of 2013. Many Trusts have already expressed an interest. If you are interested, please ask Martin for more information.
- MCDK Registry. Martin and Alan are keen for this to continue because there are increasing concerns about living with a single kidney. This may possibly need registering in each participating centre. Hopefully the database may be on a secure website in the future.

5. Network Infrastructure

- The BKPA turned down our request for funding.
- However, Martin has secured a sizeable grant from the resilience fund from the East Midlands SHA to develop the network subject to approval of the plans. There are 2 options; a) the money to be spent by the end of the financial year and b) Martin hopes he may be able to negotiate a 12 month funding.
- Some of the money will pay for a secondment for Martin, Shelley and Judith for one day per week. They will look into the health needs of the entire network and what is required for a network infrastructure. The case of need will hopefully show cost savings for the network and we need to demonstrate good quality outcomes and value for money.
- There should also be some increased dietetic time to establish local links. Shelley will identify local lead paediatric nurses. A meeting of local nurses and paediatricians will be looked into with the long-term aim of making today's meeting multiprofessional.
- This needs to be "bottom up" and not "top down".
- Documents will need to be written outlining examples of good practice and the benefit to the paediatric renal service.
- Martin is open to suggestions as to how local paediatricians are involved and would like feedback in the near future.
- Potential patient benefits, preferably described by patients, should be sourced.
- A suggestion was raised that we may need access to a qualitative researcher.

6. Future education/business meetings

We would like to keep this education meeting going on an annual basis. It was agreed that Eastwood Hall is a good venue but that somewhere more

accessible to those from the East of England should be sought for next year, possibly in the Grantham area.
It was agreed that hypertension would be the main topic with a secondary topic of microscopic haematuria.

7. Any other business
One or two consultants have visited Nottingham and sat in on the chronic renal failure clinics. There is an open invitation to others if they would like the opportunity to do this.

Next meeting: following education day on Friday 4th October 2013