BAPN RESEARCH MEETING MINUTES

Friday 3rd December 2004

Leolin Price Lecture Theatre, Institute Of Child Health, London

Members Present:  Alan Watson  Martin Christian  Kate Verrier-Jones
                 Adrian Woolf  Rodney Gilbert  Dick Trompeter
                 Mark Taylor  Jane Tizard  Kjell Tullis
                 Maggie Fitzpatrick  Heather Maxwell  Chris Reid
                 Sally Hulton  Stephen Marks  Maurice Savage
                 Nick Webb

Apologies:  Mary McGraw  Bob Postlethwaite  Lyda Jadresic
            Sally Feather  Jan Dudley  Sue Rigdon
            Paul Winward  Caroline Jones  David Hughes
            Dennis Gill  Jane Deal  David Milford
            Mike Dillon  Jonathan Evans  William van’t Hoff
            Anna Murphy  Jim Beattie  Ian Ramage
            Heather Lambert  Malcolm Coulthard

1. York Meeting - 2005

The nephrology day will be held on Tuesday 19th April. Abstracts are being reviewed at present. There is no invited speaker for the nephrology session, but Professor George Haycock will be delivery the plenary session at 1530hrs on the topic of “Salt Poisoning.”
2. Research Matters

**Nephrotic Syndrome Study (Carol Cummins)**
Carol Cummins from the Birmingham Paediatric Clinic Trials Centre-Unit spoke on the nephrotic syndrome trial. This has been passed by the MREC and it is hoped that drug manufacture will start by February 2005. Centres are asked to promote this study to associated district general paediatricians who can then either put the study through their own LREC Committee or carry out shared care of patients within regional paediatric nephrology centres.

The protocol is attached. If there is a relapse during treatment then the Prednisolone should be increased to 60mg/m\(^2\) as per the ISKDC protocol. Should this happen there is no need to break the code and patients can stay in the study for the 12 month follow-up period.

Information about the study is available in English, but has not been translated into other languages. This was felt to be too difficult and it would be preferable to have interpreters available.

**Cystinosis Registry**
This issue was not discussed

**VUR Study (Adrian Woolf)**
2yrs of this 3yr study have now been completed. This study is being funded by the Wellcome Trust, but the NKRF have a steering group, which meets to discuss the study. 113 families have been recruited and this includes 150 sib-pairs. Recruitment is still required and centres are encouraged to continue to contribute families and to encourage district general paediatricians to do likewise.

The funding for this study to date has been for collection of samples. The next step is a genome wide search for which a significant amount of funding is required. This is being sought at present. Judith Goodship will be the lead for the next stage and Sue Malcolm has retired from the study. A genetic statistician, Heather Cordell, from Cambridge has been recruited. It is hoped to complete the genome search between 2005-2006, with a view to this being written up by 2006.

**D- HUS Registry (Mark Taylor)**
This is up and running and a presentation given in Adelaide in September 2004 reported over 100 cases. German patients are yet to be recruited, but will bring up the numbers to between 140-150. A couple of UK centres have not yet obtained ELREC approval for this study. Revised paperwork is available for COREC.

**D+ HUS Registry (Mark Taylor)**
Ethics approval has been applied for, for this study. This is a follow-up of the cohorts who-were studied between 1985-1988 and includes 380 children. Tertiary centres will be approached to ask for the names of the General Practitioners of these patients. The patients will
then be invited via their General Practitioner to be involved in this study. There may be a biased response in that those who are more affected may be more likely to take part.

£15,000–£20,000 of funding is available at present and further funding is being sought.

**C2 Studies (Nick Webb)**

62 patients have now been recruited to these nephrotic syndrome and transplant trials. Further recruitment is requested and it is hoped that the inclusion of patients from Guy’s Hospital will increase the numbers significantly.

**Lipidaemia-Dyslipidaemia Audit (Nick Webb)**

7 centres were involved in this study, which represents 66% of the British paediatric renal transplant population. An audit nurse, funded by Fujisawa, visited each centre and extracted data from the casenotes. Further funding is available for a 1-day symposium on Dyslipidaemia. An abstract has been submitted to the RCPCH meeting.

**EBV Vaccine (Lesley Rees & Jane Tizard)**

Recruitment is continuing for this pilot study, which is taking place at Great Ormond Street and Bristol. The study is however proving a lot of work and recruitment has been slow to date. 5 patients will receive the vaccine at the low dose and 10 will receive a mid-range dose. There have been problems with the preparation of the higher dose so a further 5 patients will receive the mid-dose.

**Rituximab Study (Kjell Tullis)**

Dr Tullis spoke of the experience at UCH and GOS of using Rituximab in SLE, which has shown good results. Discussion took place as to whether it would be possible to look at a study-trial using Rituximab in SLE. It was felt that the number of patients was likely to be low and any study would need to either be multi-centre, include adult centres or include all patients with Lupus (not just those with renal involvement). Dr Tullis is going to bring this back to the BAPN at a future meeting.

**All Wales Birth Cohort Study (Kate Verrier-Jones)**

This study is still in the early stages and is looking for funding.

### 3. Any Other Competent Business

Mark Taylor suggested that as it is so difficult to perform trials in patients with rare diseases (because of low-small patient numbers), that it would be helpful to hold workshops on these conditions and to develop standardised protocols for centres to use. There was interest in this proposal.

### 4. Date of Next Meeting

To be arranged.