BAPN BUSINESS MEETING MINUTES

Friday 7th May 2004, 1100-1500

Giving for Living Centre, Royal Manchester Children’s Hospital

Members Present:  Maurice Savage (President), Chris Reid, William van’t Hoff, Janette Cansick, David Milford, Nadeem Moghal, Mark Bradbury, Jonathan Evans, Carol Inward, Bob Postlethwaite, Sue Rigden, Kate Verrier-Jones, Sally Feather, Nick Webb, Brian Judd, Eric Findlay, Nick Plant, Heather Maxwell (Secretary)

Apologies:  Jim Beattie, Ian Ramage, Anna Murphy, Jean Smellie, Alan Watson, Tim Chambers, Dick Trompeter, Manish Sinha, Jane Deal, Mark Taylor, Stephen Marks, Heather Lambert, Sepi Taheri, George Haycock, Martin Christian, Dick White, Denis Gill, Frank Willis, Mary McGraw, Graham Smith, Judy Taylor, Judith Van der Voort, Rodney Gilbert, Mike Dillon, Sally Hulton, Suzanne Stephens, Kaye Tyerman, Maggie Fitzpatrick, Lesley Rees, Kjell Tullis

1. Minutes of the Previous Meeting

These were agreed to be a true and accurate record and were signed.

2. Matters Arising

   a) Clashing of RCPCH and Renal Association meetings:
      These meetings often take place at the same time and have been booked for the next few years. Maurice Savage will write to both organisations to ask that they avoid clashes in the future.

   b) Paediatric Nephrology Committee Representatives
      There are a significant number of Committee’s and Meetings which the BAPN Executive members need to attend. A list of these will be sent as an appendix. Nick Webb will represent the BAPN on the Kidney Alliance. Maurice Savage will write to Rodger Greenwood in this regard.
3. **Research Matters (Dr Nick Webb)**

The Renal session at the RCPCH Meeting was discussed. There was poor attendance from Paediatric Nephrologists, Paediatric Nephrology Trainees and from General Paediatricians. This was felt to be as a result of the high cost of the meeting, the venue being at a distant location, the weather and increased security. The abstracts were of good quality. It was decided to keep invited speakers at the next nephrology session, but there was little support for poster sessions.

**a. Cystinosis Registry**

This is going well and an MREC application has been submitted through GOS. A local investigator is needed on each site and they will therefore have to fill in form C and send it on to their local LREC. The registry may be extended to include adult patients and possibly European patients in the future. Discussion took place regarding Data Protection in this regard. There was also discussion regarding patients who attend regional clinics. There is no need for a separate application to that hospital’s ethics committee as long as the patients have, at one time, been seen in the main hospital and have a main hospital number. The samples that are required for the registry can be collected locally.

The registry receives funding from both the BAPN and from Orphan Europe. The BAPN is keen to support the Cystinosis Registry, but limited funds will impact on the amount of support that can be offered. Chris Reid will find out if it is possible to obtain funds from the Renal Registry to support the Cystinosis Registry.

**b. VUR Study**

Sally Feather updated on the progress of the VUR study. All centres are now recruiting and approximately 150 sibling pairs have been identified. There will be a need in the future for discussion with the BAPN to consider models that will ensure full acknowledgement of the input of the BAPN members to this study in future publications. Further sibling pairs are required and centres are encouraged to contact General Paediatric Centres, through outreach clinics and personal links.

**c. The All Wales Birth Cohort Study**

Kate Verrier-Jones outlined this study, which aims to look at the incidence of antenatally diagnosed hydronephrosis, and other minor renal abnormalities, in a cohort of babies born in Wales. There will also be an analysis of routine investigations in these children and the utility of antibiotic prophylaxis in these patients. This study is very much in its infancy and Kate Verrier-Jones will discuss this further with Adrian Woolf and Nick Webb. The BAPN are supportive of the initiative, but recognise the need for general paediatric and obstetric support in such a study.

**d. European Registry for D – HUS in Children**

An abstract has been submitted to IPNA and adjudication is awaited. Mark Taylor also sent information that Dr Goodship offers a clinical service for DNA gene analysis of complement genes. This has to be purchased.

The UK follow-up study working group had a meeting in January. The BPSU were advised of the project, but did not wish to participate, so the study will be a BAPN and CDSC follow-up project. COREC application is currently being drafted and centres were reminded to submit patients to this study.

**e. Nephrotic syndrome Study**

This study now has sufficient funding (£50,000 from NKRF, £50,000 from KRAF) which will be used to employ a trial coordinator. The placebo and drug is being manufactured and an MREC application is in progress. Details are available on the BAPN Website. A flyer for this study was distributed at the RCPCH meeting, and centres were encouraged to make contact with general paediatricians and to use their local networks for distributing information about this study.
3. Research Matters contd…

f. C2 Monitoring Studies
These are now recruiting and, to date, six transplant and six nephrotic syndrome patients have been included in this study. A total of 200 patients are required and centres are again encouraged to recruit patients to this study. A BAPN Transplant Research Meeting will be held on 21st May in London, where this study will be discussed more fully.

g. Lipid Audit
Some centres are participating in a Lipid Audit.
There have been no recent updates regarding the EBV vaccine, the Rituximab, nor the PKD studies

4. Report from the Renal Registry

The renal registry sub-group (Chris Reid, Malcolm Lewis, Nick Webb, Rodney Gilbert, Kate Verrier-Jones, Jonathan Evans) met at the end of March. The Renal Registry report for 2003 (2002 data) is due to be published soon. The paediatric chapter contains sections on FSGS, Antenatally Diagnosed Renal Abnormalities, Graft function, Graft Rejection and Use of Immunosuppression. The 4th Department of Health survey of renal units took place last year and is the first to include paediatric unit data. An abstract from this survey appears in the Renal Registry 2003 report, but it is of concern that there was virtually no BAPN input into the drafting of this report. The Registry Sub-Committee have asked that a disclaimer be inserted to say that this report was not seen by the BAPN, and assurances have been sought that there will be paediatric input into the full report.

The 2004 report is being prepared. Unfortunately some data from April 2003 have not been returned. A deadline is to be set, and missing data will be left out of the report. It is important for this fact to be documented and the reason why data are lacking acknowledged. It is now a requirement of the NSF, the Renal Association and the Information Strategy, for data to be sent to the Registry and, if units are finding it impossible to do this, this needs to be highlighted.

Malcolm Lewis will be sending units cumulative data from the Paediatric Registry on CD.

Chris Reid gave an update on each centres progress on developing the ability to provide electronic submissions.

5. Report from ERA/EDTA Registry

Jane Tizard is one of two ESPN Reps on this registry. Malcolm Lewis has sent in data from the BAPN to this registry and Jane will represent this at the ERA/EDTA meeting in Lisbon in May.

6. Renal Unit Audit

Jane Tizard is part of the Peer Review Group, set up under the auspices of the British Renal Society. This group is due to meet shortly at the BRS Meeting in Harrogate in May.

An audit of renal biopsies has been proposed as a suggested project for a national grid trainee. Fareeda Hussain from Nottingham will supervise and Dr Malik could take on this work.
7. **Renal Information Strategy**

Kate Verrier-Jones sent round a detailed document outlining the renal information strategy. The information strategy will support the NSF through national comparative audit and provision of nationally available dates to help identify local priorities. There are to be 5 local area providers in England and the technology should interface with the renal registry. However, at the present time the implementation is uncertain and Kate Verrier-Jones finishes her work on the group towards the end of June this year.

8. **UK Transplant**

   a) **Centre Specific Data**
   
   It was discussed at the recent UKT Transplant Directors Meeting (March 2004) that centre specific data would be published. This has specific implications for paediatrics where the numbers are so small.

   b) **Inappropriate UKT Kidney Offers**
   
   Jane Tizard highlighted an incident of a less well-matched kidney than requested being offered to a patient in Bristol. This was found to be due to a computer problem, and hopefully has been rectified. If centres are offered less well matched kidneys than patients are listed for, then they should inform UKT through Heather Maxwell.

   c) **Waiting List Criteria**
   
   David Milford reported a fall-off in transplantation rate at his unit since adopting the UKT/BAPN recommendations for favourable matching. These apply only to easily matched patients and if the patient does not receive a kidney within 6-12mths then the matching criteria can be reduced. However UKT have set up an allocation sub-group to look at a new system for allocation of cadaveric kidneys, and Heather Maxwell represents the BAPN on this group. If members have views on allocation they should direct these to Heather Maxwell.

9. **Paediatric Nephrology Trainees**

Trainees main concern is the paucity of consultant posts at the moment and the high number of trainees who will complete CCST within the next 12-24mths. It is hoped that more consultant posts will become available, but it may be necessary to look at ways of extending the training period until such posts are available. This is to be discussed with Mark Taylor, CSAC Chair.

Lyda Jadresic is preparing a syllabus for paediatricians with an interest in paediatric Nephrologist.

10. **Treasurers Report**

At the present time outgoings seem to be greater than income and as of 1st October 2003 the balance was only £5,634. This is clearly an area of concern, but Rodney Gilbert was not present to discuss this further. It was suggested that a sub-group be set up to look at further issues of funding.

11. **Paediatric Guidelines for Management of Altered Conscious Level**

The group involved in this guideline have asked for paediatric nephrology representatives to work on this guideline. Martin Christian and Graham Smith were proposed to do this, and Heather Maxwell will write to them to ask them to take this on.
12. **NICE Health Technology Appraisals**

   a) **Immunosuppressive Therapy for Renal Transplantation**
   Nick Webb attended the appeal hearing for this HTA. The outcome was that as the guidance is based on adult data, paediatric patients would not be included. There will however be a statement in the HTA to support the need for further trials of immunosuppressant agents in paediatric patients.

   b) **HTA**
   The latest HTA is on the use of Prasterone for SLE. Kjell Tullis has agreed to take this on for the BAPN.

   c) **UTI in children**
   A guideline for the management of UTI in childhood is being proposed by NICE and Malcolm Coulthard and Heather Lambert will represent the BAPN.

   d) **Anaemia in Chronic Disease**
   Jonathan Evans will represent the BAPN on this guideline

13. **CSAC**
   Not discussed

14. **Response to NSF**

   Considerable discussion took place regarding the recently published NSF and the difficulties with commissioning for small volume specialties, such as paediatric nephrology. A related issue is the difficulty in manpower planning, both for medical consultants and for the multi-disciplinary team. Professor Savage will write on behalf of the BAPN to the Department of Health outlining our concerns.

15. **Any Other Business**
   There was no other competent business

16. **Date of Next Meeting**
   Friday 3rd December at the Institute of Child Health in London

**Action Points**

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<td>1</td>
<td>Maurice Savage to write to Renal Association and the RCPCH re annual meetings.</td>
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<td>2</td>
<td>Maurice Savage to write to Roger Greenwood re BAPN Representative on the Kidney Alliance.</td>
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<td>3</td>
<td>List of committee representatives to be sent as appendix.</td>
<td>Heather Maxwell</td>
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<td>4</td>
<td>All centres to consider how they can approach general paediatricians to recruit patients for the VUR study.</td>
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<td>5</td>
<td>Chris Reid to write to David Ansell at the Renal Registry re the Cystinosis Registry</td>
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<td>6</td>
<td>All members to send views on allocation of Cadaveric organs to Heather Maxwell.</td>
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<td>Options for paediatric nephrology trainees who complete CCST with no consultant job offer</td>
<td>Mark Taylor</td>
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<td>8</td>
<td>Treasury Sub-Group to be set up to look at BAPN finances</td>
<td>Rodney Gilbert</td>
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