BAPN BUSINESS MEETING MINUTES

Friday 3rd December 2004, 1030 – 1315

Leolin Price Lecture Theatre, Institute of Child Health, London

Members Present: Alan Watson Martin Christian Nadeem Moghal
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 Kate Verrier-Jones

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. Minutes of the Previous Meeting

These were accepted as a true record.

2. Matters Arising from the Minutes
The Cystinosis Registry will not receive financial support from the BAPN.
3. **Manpower Planning**
   At the present time it is anticipated that there will be 18 trainees with CCST by the end of 2005. At the last CSAC meeting it was decided to restrict the number of national grid posts available for September 2005 to 2. There will be 2 retirements in 2008, but there are no retirements yet notified for 2007 and 2009. The decision to reduce the intake of trainees is for 2005 only and the intake will be re-evaluated each year.

Members expressed their concern at the reduction in intake of trainees in light of the difficulties in recruiting to consultant posts in the past. It is also appreciated that there may be geographic variations in the likelihood of recruiting to consultant posts. There has however been a great deal of anxiety expressed by trainees at the lack of consultant posts.

There was discussion that it may be appropriate to concentrate on training not only tertiary paediatric nephrology specialists, but also paediatricians with an interest in nephrology.

It is still possible, but not encouraged, to train outside the grid. For example trainees can do 1yr in a recognised paediatric nephrology training centre and 1yr in Toronto. This is not illegal but trainees may miss out on assessments and on national training days. Trainees are encouraged to train within the national grid system.

Cardiff has received funding for a total of 4 paediatric nephrology posts, so it is likely that 2 posts will be advertised there. There may also be posts in Dublin and Glasgow.

Discussion took place as to how to take manpower problems forward. Nationally the RCPCH are not taking on individual specialties, but are highlighting the difficulties of manpower planning in all paediatric specialties. Within the renal community it was felt that the National Renal Workforce Planning Group, the Kidney Alliance and the BRS might be appropriate routes to highlighting the difficulties in recruitment in paediatric nephrology. John Feehally, President of the Renal Association, is sympathetic to the difficulties in paediatric nephrology and has been in discussion with the Modernisation Agency.

4. **Report from CSAC**
   By the end of 2005 there will be 18 trainees with CCST. Assessments will take place at the end of January and National Grid interviews will take place during the week of 14th – 22nd March. Two consultants are needed for these interviews.

Again, the need to consider trainees going into posts for paediatricians with an interest in nephrology was discussed. There is a curriculum for paediatricians with an interest in nephrology being developed by Lyda Jadresic and this needs to be taken forward.

There is a flexible career scheme, which is available for up to 8 PA’s per week. Funding is available for 50% of this post in the first year, but less funding is available for the other 2yrs.
4. **Report from CSAC (contd)**
   The issue of the amount of time that paediatric nephrology trainees spend in general paediatrics was discussed. Up to 30% of their training time can be spent in general nephrology and surveys in Manchester and Birmingham have shown that trainees are spending only 52% and 56% of their time in paediatric nephrology respectively. This does decrease the exposure to paediatric nephrology and is something that will be discussed further by CSAC. This could result in trainees feeling they require further exposure to paediatric nephrology post-CCST and this would be possible through inter-deanery transfers or out-of-programme activity.

   Further discussion took place regarding the fact that the National Grid slots are for 2yrs, whereas European training in paediatric nephrology recommends 3yrs. Some other paediatric sub-specialties also recommend 3yrs.

   Training is competency based but experience is needed for confident performance. The college is not addressing this issue and it is expected that new consultants will develop confidence and experience within consultant posts, possible with a mentoring scheme.

   Assessment of trainees is becoming more time consuming. Trainees will have a 360° appraisal in year 4 and will also undergo DOPs, which is direct observation of practice. For paediatric nephrology this is really only for renal biopsies. There will also be a MiniCex, which is a 15min observation of clinic practice. Consultants performing assessments will require training, and adult nephrology trainer’s job plans include one session per week per nephrology trainee.

   There is a training committee working party that consists of a consultant (this post is vacant at the moment), two trainers (the CSAC chair and one other: Sally Hulton and Chris Reid) and 4 trainees.

5. **Report from the Renal Registry**
   The renal registry report for 2004 will be published towards the end of February 2005. The focus this year is on cardiovascular risk. The report is currently with Malcolm Lewis and will be submitted to the Registry Committee on 10.12.04. for review and then sent out to BAPN members by 17.12.04.

   Each unit will receive a CD with their own data, which can be used for internal audit. Anonymised UK data will also be available for comparison.

   Data for the 2005 report (data from April 2004) is to be submitted as soon as possible by those units who have not yet done so. Professor Savage has encouraged trusts which do not yet have adequate computer systems, for example Proton, to acquire these.

   For units in England and Wales this is a requirement of the NSF and these should be in place by the end of 2005. Clearly systems needs to be in operation soon to be able to comply with this. (Kate Verrier-Jones suggested that the key documents for units who are experiencing difficulty are the NSF and Output Based Specification Contract chapter 167). Funding may be an issue for those units who have not had the benefit of input from adult unit connections.
5. **Report from the Renal Registry** (contd)

Some units have data managers, but others don’t and are unlikely to acquire them because of funding issues.

A biopsy audit is going to take place. Documentation has been provided by Meeta Mallik and Farheeda Hussein from Nottingham for the audit which is due to start on 1st January 2005 and which will run for 12mths. These forms were available at the business meeting and will be forwarded to units electronically.

6. **Links with the Renal Association**

Professor Savage attended the Renal Association meeting recently. Professor Savage represents the BAPN on the Renal Association Executive, Chris Reid is our Representative on the Registry Committee, Rodney Gilbert on the Service Provision and Delivery Committee and Sally Feather on the Standards Committee. Nick Webb represents the BAPN on the Research Committee and Sally Halton on the Education Committee.

The Renal Association main meeting is now to be held in the spring. For the next 2yrs this will not clash with the RCPCH meeting.

In previous years there were “reserved” paediatric slots at the renal association autumn meeting, but now all papers will be selected on merit. There have been very few paediatric papers submitted to Renal Association meetings.

In addition to the main spring meeting there will be three peripheral meetings each year and one of these meetings will have a paediatric component.

On the Renal Association website there is information about individual renal units and paediatric renal units are encouraged to add their information. The format for this can be found on the renal association website under “Unit Identification”.

Professor Feehally has been active in communicating with the Children’s Care Group Workforce on our behalf in regard to the consultant staffing crisis.

The Renal Association is undertaking a review of the renal standards. Five topics will be reviewed in the next 12mths and these are:- Chronic Kidney Disease, Dialysis, Complications of Chronic Kidney Disease, Transplantation and Acute Renal Failure. Each of these areas will require an individual or individuals to take on this work in conjunction with Sally Feather who sits on the Standards Committee.

Clinical Directors of Renal Units are meeting in Guy’s Hospital, London, on 14th January for the Clinical Directors Forum. Professor Savage has asked that Directors of Paediatric Renal Units be invited to this meeting and Stuart Rodger is to be informed of who should be invited from each unit (stuart.rodger@northglasgow.scot.nhs.uk).
7. **Report from the European Registry**

Jane Tizard informed us that the UK and Italy have submitted paediatric data and that Spain will do so shortly. France may be able to contribute data in the future. It is recognised that some countries are submitting more detailed data sets (e.g. UK) than other countries.

It is hoped to perform paediatric projects using the data from this registry, but funding and personnel are needed for this. This is being investigated.

8. **Renal Information Exchange Group**

Kate Verrier-Jones represents the BAPN on this group. The renal information strategy is now on the Department of Health website and part 2 of this will be published when part 2 of the NSF is published next year. Part 1 of the NSF went to the Paediatric Renal Information Strategy website, which would appear not to have materialised. This will be discussed with Jane Verity.

There is local and national initiatives for IT. One of the national ones is Renal Patient View, where patients are able to obtain their blood results on a personalised website. It has been piloted in 1-2 adult centres and in some there is also a Word interface where patients are also able to see their clinic letters. Kate Verrier-Jones is hoping to run a paediatric pilot for renal patients in Wales which will have the Word interface and will also be for pre-end stage renal failure patients. Renal Patient View also contains a site with links to patient information leaflets and reliable sources of paediatric data and information. Members are encouraged to let Kate or Heather Maxwell know of useful sources of information.

9. **UK Transplant**

Heather Maxwell had attended the UK Transplant Kidney/Pancreas Advice Group meeting on 1\textsuperscript{st} December 2004. Items of interest on the agenda were a review of organ transport times and any members who are aware of instances of delays in organs being transported to transplant centres should let Heather Maxwell know. It is proposed to hold a cold ischaemia time audit to monitor all the different intervals between retrieval and transplantation. Proposals are being worked on.

UK Transplant is to merge with the National Blood Service to become NHSBT. This organisations will have one Chief Executive and one Medical Director and should be in operation by October 2005.

9. **UK Transplant (contd)**

A proposal was put forward for a guideline for management of patients on the cadaveric waiting list who are being worked-up for living related donor transplant. Patients should only be removed from the cadaveric list after discussion and only with their consent. Otherwise patients should remain on the cadaveric list until the living related transplant has gone ahead.

The main discussion at the KPAG meeting was of the work of three sub-groups:
a) **Allocation Sub-Group**
A group were meeting to review allocation of cadaveric organs. Kidneys are to be seen as a national resource, and the role of matching is to be reduced with increased reliance on waiting time and donor age. A review of paediatric centres has found that all units are keen to continue with matching as a priority for children and agreement has been reached that paediatric recipients should continue to receive priority in terms of well matched kidneys. The final proposals are to be reviewed at an Extraordinary KPAG meeting on 2nd February and then will form the bulk of the agenda at the renal unit directors meeting on Monday 7th March, which will be held at the Royal College of Physicians in London. Units are encouraged to attend.

b) **Equity of Access Sub-Group**
Much of the work of this sub-group relates to cardiovascular morbidity of adult patients and their suitability for transplantation. The issues for paediatrics are the time it takes to list patients, which may show significant geographical variation, and listing of patients with neurological deficit. Heather Maxwell will communicate with units for their views.

c) **Centre Specific Data**
Individual adult units are to have their data published. This is being done in the form of a funnel plot, which takes account of centre size. Work is being done looking at ways of presenting individual paediatric unit data, bearing in mind that the numbers of transplants in any one centre tend to be small.

10. **British Renal Society**
Jane Tizard represents the BAPN on the educational and training visit group (previously the “peer review” group). This group have drawn up standards (‘Criteria for Success’) based on the recommendations of the NSF and these are out for consultation at the moment. A “tool-kit” has been produced by the Kidney Alliance to give commissioners information on commissioning renal services. These two documents will be published jointly. None of the membership have yet had sight of the “tool-kit”. There would not appear to have been paediatric input into this, but as Nick Webb is now the BAPN representative on the Kidney Alliance we hope to have an input into future work. The renal advisory group are taking forward the work of the NSF and this group is chaired by Donal O’Donaghue.

11. **Training Issues**
This item was deferred as no trainees were present.

12. **Paediatrician with an Interest in Nephrology**
This item was deferred as Dr Jadresic was not present.
13. **Treasurer’s Report**

   A financial report for 2004 is attached. Not all consultants have paid their dues and this will be followed-up. The dues are £50 per year paid by standing order. Details can be obtained from Rodney Gilbert.

14. **NICE Health Technology Appraisals (HTAs)**

   a) **Immunosuppressive Therapy for Renal Transplantation**
   
   This HTA is now complete, but a separate one for children and young people has been commenced. It is important that we have as many paediatric representatives on this as possible. Heather Maxwell will represent the BAPN, and Nick Webb the RCPCH as per the previous HTA. The first meeting about this HTA will take place on 19\textsuperscript{th} January, at NICE in London.

   b) **Anaemia Management in Chronic Disease**

   Jonathan Evans and Nick Webb are representing the BAPN. The scope of the guideline has been revised to include children. Since then Jonathan Evans has attended the first of 12 guideline meetings. The guideline will be developed over the next 12mths followed by public consultation and publication is planned for June 2006. Jonathan Evans and Nick Webb will consult with the BAPN members over this guideline.

   c) **Prasterone for SLE  - Kjell Tulles**

   This item was not discussed.

   d) **UTI in Children  - Malcolm Coulthard**

   This item was not discussed.

15. **New Members**

   The following new members were welcomed to the BAPN:-

   - Larissa Kerecuk
   - John Schulga
   - Detlef Bockenhauer
   - Meeta Mallik
   - Nikki Gittins
   - Shivram Hegde
   - Raj Krishnan

16. **Any Other Competent Business**

   Mark Taylor spoke about Birmingham’s bid to host ESPN 2008. the Renal Association have agreed to a joint meeting were the ESPN to be held in Birmingham in 2008. No decision will be taken however until the ESPN meeting in Istanbul in 2005.
Nadeem Moghal spoke on the shortage of paediatric radiologists in Newcastle. There would appear to be a shortage of trainees in paediatric radiology. This may result in children having scans performed by adult radiologists or having to be referred to other paediatric nephrology centres for imaging.

17. **Date of Next Meeting**

To be decided.

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