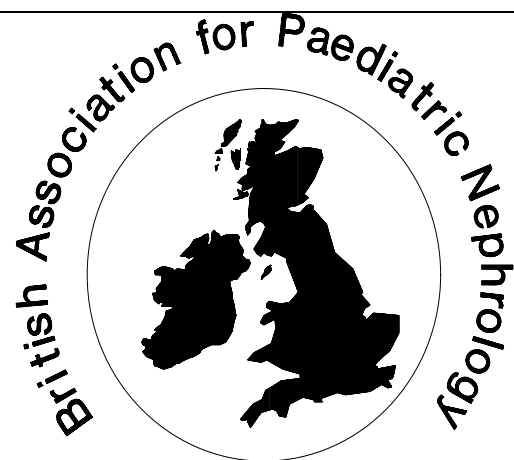


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www.uwcm.ac.uk/uwcm/ch/bapn

BAPN BUSINESS MEETING MINUTES

Tuesday 19th April 2005, 1230 – 1400
Langwith College, York University

Present:

Heather Maxwell	Dick Trompeter	Mark Taylor	Jane Deal
Judy Taylor	William van't Hoff	Malcolm Coulthard	Milos Ognjanovic
Heather Lambert	Theodore Anbu	Raj Krishnan	Sally Hulton
Maggie Fitzpatrick	Sepi Taheri	Stephen Marks	Fadwa Intriceg
I Anochie	R Pegden	Rachel Lennon	Carol Inward
Jan Dudley	Mark Bradbury	Mordikai Beeker (guest)	
Mike Dillon	Chris Reid	George Haycock	Paul Brogan
Moin Saleem	Graham Smith	Richard Coward	Martin Christian
Meeta Mallik	Nick Webb	Maurice Savage	

Apologies:

Mary McGraw	Nick Plant	Adrian Woolf	Nadeem Moghal
Manish Sinha	Rodney Gilbert	Sue Rigden	Peter Houtman
David Milford	Kay Tyerman	Jean Smellie	Jonathan Evans

1. Minutes of the Previous Meeting

These were accepted as a true record.

2. Levamisole

Nick Webb has been acting on behalf of the BAPN. He approached the ESPN but they felt it was not an issue for them to deal with. Janssen Cilag are still producing Levamisole in Mexico and

2. **Levamisole (contd..)**

and discussions are ongoing with the MHRA in regard to importing Levamisole from these countries. At the present time a response is awaited from the MHRA. Should this prove unsuccessful it would be helpful to have an idea of the number of children who are receiving Levamisole as second-line treatment for nephrotic syndrome. Members will be surveyed.

3. **Renal Biopsy Audit**

Meeta Malik reported that data have been sent in from Cardiff and Great Ormond Street, but are still awaited from all other centres. They would appreciate data being sent 1-2mthly and it was suggested that a contact be nominated at each centre for the survey.

4. **NSF Part 2**

There is little mention of children in the newly published renal NSF part 2. Lesley Rees has brought this up with Donal O'Donaghue and Jane Verrity in a letter dated 9th February 2005. She points out that there are inaccuracies relating to interpretation of renal function in children, that there are missed opportunities for children, and that some points in the NSF do not apply for children. These points are outlined below:-

1. Need for referral of all children with CKD to a paediatric nephrologist
2. The benefits of early detection of CKD are obviously in children, and paediatric nephrology input offers the opportunity to optimise growth and development as well as delaying the need for dialysis and transplantation.
3. Prevention also involves optimum antenatal management and planning for postnatal management, which can be provided by expert radiology, obstetric nephrology and urology combined antenatal clinics.
Other methods of prevention are screening of families with recognised renal problems at genetic clinics.
4. Children are not primarily looked after by their General Practitioner; care is undertaken principally by a district General Paediatrician liaising with a tertiary Paediatric Nephrologist.
5. Follow-up of children after episodes of acute renal failure is also important as many children do not make a complete renal recovery.
6. The need for expert pathology services is essential in post-mortem examinations for children who died of renal failure, particularly those who die in infancy, as there are implications for future offspring.
7. The role of structured transfer to adult services is not discussed.
8. There is nothing in the NSF on the management of a neonate with acute renal failure, which can be difficult if there are no tertiary paediatric nephrology services on site.
9. There is very little on the support services required for paediatrics such as dietary input, teaching play therapy etc.

Much of this had been discussed in previous versions and seems to have been removed from the final version.

Donal O'Donaghue and Jane Verrity have acknowledged the need for providing more detailed paediatric advice in the NSF and in one Email Jane Verrity has said

4. **NSF Part 2 (contd..)**

“As you know the minister has already given a commitment to a document for children’s renal services based on the NSF and we will be taking this forward shortly”

Clearly this is something that we need to look out for and Heather Maxwell and Maurice Savage will also respond to the NSF on behalf of the BAPN. The BAPN recognise Lesley Rees’ considerable input into the NSF.

5. **Renal Association Standards**

The Renal Association standards document published in 2002 is undergoing an update. The next edition will be produced in a modular format making maximum use of web-based technologies to facilitate cross-referencing and searching. There will be a facility to download and print copies of each module.

There will be 5 modules:-

1. Chronic Kidney Disease
2. Complications of Chronic Kidney Disease
3. Dialysis
4. Transplantation
5. Acute Renal Failure

The updates will be written in conjunction with representatives from relevant stakeholder organisations and will be available for public consultation before being finalised. The Transplantation module will focus on transplant medicine and is being written in conjunction with the British Transplant Society. Separate paediatric guidelines will be produced and incorporated.

The term “Standards” has been dropped in favour of “Clinical Practice Guidelines”. The new modules will contain a series of guideline statements accompanied by a brief justification, with references to supporting evidence where available. As in previous versions of the standards document, the modules will include audit measures which will be developed in conjunction with the Renal Registry.

David Wheeler, who is chair of the Standards Committee, has asked for a Paediatric Nephrologist to lead each module. This was discussed at the BAPN Executive Meeting in February 2005 where it was decided that there would be a lead for each module, with other consultants and trainees contributing. BAPN members who wish to be involved in any of the modules are asked to get in touch with the Secretary. Sue Rigdon has been asked (and agreed) to lead on Chronic Kidney Disease and Complications (modules 1-2), Lesley Rees on Dialysis, Heather Maxwell on Transplantation and Sally Feather on Acute Renal Failure. It was mentioned that some of the work has already been done for the Welsh Renal NSF under the leadership of Kate Verrier-Jones.

6. **EDTNA / ERCA Dialysis Survey**

Several paediatric dialysis units have received this comprehensive survey. Some of the information may be available from the renal registry and Chris Reid will look into this. Mark Bradbury has details of the complete survey and will forward this to the Executive Committee.

7. **Patient DVD**

The BRS and NKRF are involved in producing a DVD for patients with renal disease. This is a very detailed and well-funded project with a timeframe of October 2005 – 2007. The NKRF and BRS are lead partners and the BAPN have been asked to become a member of the group.

Discussion took place as to the BAPN's involvement and how the project will deal with children, for example, whether there will be a separate DVD for paediatric patients. Jan Dudley informed the meeting that the Bristol group are already involved in producing a patient DVD and Jan has agreed to be our representative on this project.

8. **Treasurer**

As of February 2005, Rodney Gilbert has completed 3yrs as Treasurer. The position is open for a further 2yrs and the BAPN supported Rodney to continue with this post for a further 2yrs as long as he felt able to do so. He is agreeable and will continue as Treasurer until February 2007.

9. **Future BAPN Meetings**

Discussion took place as to further meetings. There was considerable support for a paediatric renal clinico-pathological meeting to be held once yearly. Any unit could contribute and it was envisaged that there would be 8 or so cases discussed, which would have been submitted in advance. This would be a good training opportunity for both nephrologists and histopathologists.

Surgical Challenges in Paediatric Renal Transplantation meetings are also well attended and occur once yearly in October/November.

Discussion took place regarding the nephrology day at the RCPCH meeting in York. It is disappointing that this year there was only time for 3hrs of presentations. The college insists that sessions finish before the plenary session, which starts at 1500hrs. Sixteen of the 35 members present were agreeable to the RCPCH meeting continuing in its present format. There was however unanimous support for asking for a change in the meeting so that the specialist session could be longer, allowing more presentations.

There was support for a greater research component to the December Business Meeting, and there will be one other Business Meeting per year.

10. **Manpower**

There are several consultant posts being advertised at the present time. Two posts have been advertised in Cardiff, one in Southampton, one in Belfast and an academic post is also planned in Dublin. There will be two posts advertised in Liverpool, two at Guy's and one post in Leeds.

10. Manpower (contd..)

A change in the “rules” means that trainees can apply for consultant posts if they are within 6mths (rather than 3mths) of obtaining their CCST.

11. Any Other Business

Renal Registry Users Meeting:- Kate Verrier-Jones advised that the Renal Registry Users Meeting, which is organised by David Ansill and Hillary Doxford, is to be held on May 25th. Most adult renal units and other interested parties will be represented at the meeting.

TEALE Lecture:- Bob Postlethwaite is giving the TEALE Lecture at a renal meeting on 14th June at the Royal College of Physicians. The subject of the meeting is “Improving the care of children with Chronic Kidney Disease” and Bob is keen to hear from members as to their views on important outstanding issues in paediatric nephrology.

UK bid for ESPN 2008:- Mark Taylor was able to update the meeting on the UK bid for ESPN 2008. This would be in association with a Renal Association, to be held in Birmingham, and would include a scientific day on diseases and cell biology of primary epithelial cells organised by Caroline Savage. Should the UK bid for ESPN 2008 be unsuccessful the same meeting could be re-run for 2009, but this would only be possible if a decision could be made at the ESPN in Istanbul this year, for ESPN 2009.

17. Date of Next Meeting

Thursday 9th June 2005 1030 – 1330 at the BRS meeting in Manchester
Friday 9th December 2005 1030 – 1600 at the Institute of Child Health in London

Action Points

Item		Action
2	Survey units for numbers of patients on Levamisole	Heather Maxwell
3	Each unit to nominate a contact person for renal biopsy audit	All Members
4	Respond to the NSF on behalf of the BAPN	Heather Maxwell Maurice Savage
5	Members to help with modules 1-5 for the clinical practice guidelines	All Members
5	Ask Kate Verrier-Jones for information on the Welsh NSF	Heather Maxwell
6	Forward details of the dialysis survey to the Executive Committee	Mark Bradbury