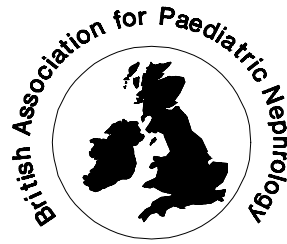


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www.uwcm.ac.uk/uwcm/ch/bapn

BAPN Business Meeting Minutes
Tuesday 27th March 2007
Langwith College, University of York

- Members Present:** Mark Taylor (President), Heather Maxwell (Secretary), Jane Tizard, Moin Saleem, Dick Trompeter, Sally Johnson, Chris Reid, Kay Tyerman, Eric Finlay, Nadeem Moghal, Sally Feather, Michael Riordan, Caroline Jones, Stephen Marks, Simon Waller, Rukshana Shroff, Zahida Ahmed, Mark Bradbury, Mary O'Connor, Jane Deal, Richard Coward, Rachel Lennon, Mordi Muorah, Ihab Shaheen, Mohan Shenoy, Shivram Hegde, Milos Ognjanovic, George Haycock, William Van't Hoff, Robert Kleta, Alan Watson,

Apologies: David Hughes, Ian Ramage, Martin Christian, Lesley Rees, Jonathan Evans, Sally Hulton, Shuman Haq, Maurice Savage, Adrian Woolf, Jean Smellie, Colin Normand, Heather Lambert, Peter Houtman, Henry Morgan, Judy Taylor, Catherine O'Brien, David Milford, Mike Dillon, Jim Beattie, Malcolm Coulthard

- Minutes of the Previous Meeting**

These minutes were accepted as a true record of the meeting.

- Presidents Report**

Mark Taylor outlined the structural changes to the BAPN Executive that had taken place over the preceding months. Several new sub-committees have been formed and Mark stressed the importance of the Executive drawing together the work of the sub-committees and the research group to allow improvements in service provision. As an example, an audit by the registry might inform guideline development, will identify areas of strength and weakness in service provision, and could feed into research plans. The communication strategy and the BAPN website brings all of this together. Details of executive personnel and sub-committee members are available on the website. (www.bapn.org)

A sub-committee for clinical services has been proposed to deal with issues of service provision. To date Nadeem Moghal has been co-opted to the Exec to deal with these issues. However Mark Taylor has proposed that Nadeem should chair this new sub-committee, which would be composed of a CD or clinical lead from each paediatric nephrology centre. He further proposed that Nadeem would serve as chair for three years following which the sub-committee would elect a chair from within its membership. Alan Watson gave his support for this proposal and suggested that this sub-committee could be opened up to other members of the multi-disciplinary team. It was agreed that others could be co-opted on to this sub-committee as and when required. The proposal was carried unanimously.

Mark Taylor reminded the membership that much of the work of the BAPN had focussed on tertiary nephrology and that the Association needed to be aware of the needs of the members who are general paediatricians with special responsibility for nephrology. This issue would be debated at the Executive and members with suggestions for taking this forward were encouraged to get in touch. Alan Watson suggested that contact could be made with the group which represents DGH paediatricians.

The executive has agreed that membership income from trainees will be used directly for their training program and has also agreed to seek funding to promote and support academic development. To date the trainee representative has not been a full member of the Executive and the President proposed that the trainee representative should become a full member of the Executive; this proposal was carried unanimously.

Heather Maxwell, Nick Webb and Chris Reid are due to demit office and special thanks were given to them for their services to the Executive over the past years. Jane Tizard, Moin Saleem and Jonathan Evans have taken over as Secretary, Research Secretary and Registry Chair respectively.

George Haycock, Kate Verrier-Jones and Anna Murphy were all awarded honorary BAPN membership and tribute was paid to the outstanding contribution that they had made to the development of paediatric nephrology services in the UK.

New members Michael Riordan, Robert Kleta and Beena Padmukumar were welcomed.

4. Website Demonstration

Eric Finlay

Eric Finlay gave a tour of the newly developed website (www.bapn.org) to the membership. Congratulations were offered to Eric for overseeing the work of developing the website which all agreed was excellent. Eric Finlay will continue to upkeep the site himself which he estimated would take approximately 2 hours per week. The Executive and the sub-committee will keep him updated with current business issues. The secretary and research secretary will also have access to update the website.

The forum is not yet operational but should be up and running in about 2 weeks. It will be possible shortly to pay the BAPN membership dues (currently £50) through the website via Paypal. Completion of payment will then allow access to the forum on the website.

The colour and the font (optima) of the BAPN title are now owned by the BAPN.

Members should contact Eric Finlay if they require information to be placed on the website.

5. Research

Moin Saleem

The research group, which has a representative from each centre, is keen to promote high quality multi-centre research and to collect robust data in an ongoing fashion for patients with complex and rare disorders. Clearly there are overlaps with audit and the BAPN registry.

Members who have proposals for research should submit them to the research group, which plans to hold periodic strategy meetings. If a piece of research or trial is taken forward by the research group, then the research secretary will set up a small working group of 3-4 interested parties, which will hopefully include a trainee, to oversee the running of the trial.

A meeting of the research group was held in Manchester in January 2007. This meeting went well and four trials were selected to be taken forward, and will be discussed further below.

There are several 'partners' that the BAPN are keen to work with. The first is the Medicines for Children Research Network (MCRN), which will adopt trials that have already been granted funding. Nephrology is part of the RANNI subgroup of MCRN and the list of supported trials has been sent to RANNI. The other partner is the Renal Association. Caroline Savage has proposed a renal subgroup within the NIHR, and the BAPN are included on the proposal.

Funding could be available from a number of sources. NIHR have several funding streams; the Research for Patient Benefit is the most appropriate one for the BAPN. For this a University partnership is required. There are also sources such as MRC/Wellcome, Kidney Research UK and Kids' Kidney Research. The latter group previously raised funds locally, but are now keen to support paediatric nephrology nationally. They have agreed to administer an open grant to match funding that is gained through other sources.

BAPN Proposed Trials

William Van't Hoff gave an outline of a suggested trial of the addition of ARB to an ACE inhibitor in CKD. Details of this study has been circulated to the membership prior to the Business meeting. The length of the study will depend on the end point: if GFR is used this would require a long study period; if degree of proteinuria were used, then a shorter trial could be contemplated. An estimate of the numbers involved is approximately 200 patients, but the exact numbers will depend on the end point and study design. Further discussion is required and members who are particularly interested are asked to contact William Van't Hoff. Further details of this and all of the studies mentioned will be available on the website.

Eric Finlay spoke briefly about a study of the use of Turolock in children on Haemodialysis. He has already surveyed centres and 10 are willing to be involved. The study would involve the use of Turolock vs Standard Heparin for locking HD lines. This does raise issues in terms of blinding of treatment and would require all centres involved to stick to a standard protocol for HD line handling. Nursing colleagues have already been involved in discussions. Details of the study are on the website.

Sally Feather had circulated details of a study of the genetic pre-determinants of and the use of antibiotic prophylaxis in vesico-ureteric reflux in children under 1 year who are found to have VUR. The protocol for this study is well developed and a study group is already in place. The outcomes are either number of UTIs or changes on DMSA. The numbers needed are likely to be several hundred, but this might be possible if a number of DGHs were involved in the study.

The fourth study that the BAPN are supporting is the Nephrotic Syndrome Trial; the pilot study for this trial is underway at present. This study was not discussed further in view of time constraints.

6. Standards and Guidelines

This agenda item was not discussed in view of Dr Rees' absence.

7. A Sub-committee for Clinical Services

Nadeem Moghal

Mark Taylor had sent a letter to all clinical leads outlining the need for a clinical services sub-committee of the BAPN Executive. This proposal was accepted earlier in the meeting and Nadeem Moghal gave a presentation on progress to date and the future direction of this sub-committee.

Since the last Business Meeting in December, Nadeem has produced two briefing papers; one on the potential of the NSF to provoke change, but this is unlikely to happen in the short term but may have effects in the longer term, and the other on informed commissioning which seems to be the way forward. Details are on the BAPN website. A new structure of specialist

commissioning groups (SCGs) has been developed, which approximates to the regions served by BAPN centres in England. This does not include Wales or Scotland. Each SCG has two commissioners. These groups will feed into a national Childrens SCG and then to the Head of specialist commissioning who is Julia Stalabrass. It is suggested that paediatric nephrology centres liase with their local SCG, and that the BAPN, through the work of the clinical services sub-committee, should liase with the Childrens SCG, the renal and childrens Tsars and the RCPCH to influence specialty commissioning. Discussion has already taken place between Nadeem, Mark Taylor and Donal O'Donaghue, the renal Tsar. He has suggested that service provision at a regional level requires a more flexible approach. We need urgently to identify the pressures on all aspects of our service. Development of agreed standard care pathways and involvement of patient representation are seen as crucial. Nadeem is proposing that we obtain very complete and detailed service provision data as part of a larger mapping exercise that is being undertaken on behalf of the DoH.

Implementation of payment by results (PbR) has been delayed to 2009. Ihab Shaheen, a paediatric nephrology grid trainee is undertaking a coding exercise in preparation for PbR.

Donal O'Donahue has also raised transitional care as an issue and is keen to look at models of care and evidence of outcomes.

12. AOCB

No items were discussed.

13. Date of next meeting

The next Business Meeting will be held in Birmingham on Friday the 7th December 2007.