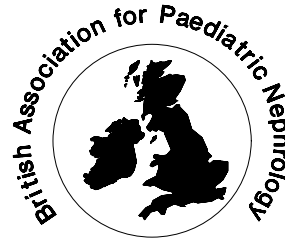


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www.uwcm.ac.uk/uwcm/ch/bapn

BAPN Business Meeting Minutes

Friday 8th December 2006

Queen Elizabeth Hospital, Birmingham

1. Members Present: Mark Taylor (President), Heather Maxwell (Secretary), Mary McGraw, Alan Watson, Farida Hussain, Martin Christian, Nick Webb, Catherine O'Brien, Caroline Jones, Sally Hulton, Sue Rigden, Chris Reid, Judy Taylor, Sally Johnson, Jan Dudley, Rukshana Shroff, Jane Deal, Mark Bradbury, Eric Finlay, Jane Tizard, Moin Saleem, Simon Waller, Dick White, Peter Houtman, Leather Lambert, William van't Hoff, Carol Inward, Nadeem Moghal, Dick Trompeter

2. Apologies: Manish Sinha, Lesley Rees, Kjell Tullus, Arvind Nagra, Maurice Savage, Kate Verrier-Jones, Rodney Gilbert, David Hughes, Jim Beattie, Ian Ramage, Sally Feather, Denis Gill, Shuman Haq, Sandra Iragorri, Robert Jones, Stephen Marks, Mary O'Connor, Judith van der Voort, Dr Adrian Woolf

3. Minutes of the last meeting were accepted as a true record.

4. Constitutional changes and structure

The structure of the executive has been changed to include new posts.

Treasurer

Rodney Gilbert has come to the end of his term as treasurer and the BAPN will write to him to thank him for his hard work since Feb 2002 and to wish him a swift recovery from his recent accident.

ACTION Mark Taylor

Dick Trompeter has taken over as BAPN treasurer, and has also recently taken up post as Treasurer and Secretary of the International Paediatric Transplant Association. He informed the membership that he has been in negotiation with a charity called Kids Kidney Research who have in the past supported research at GOS and the ICH and who are keen to increase their national profile. They have offered to support the BAPN to the tune of £300 000 with a further £100 000 or more over the next 2 years. The BAPN thanked Dick for his efforts.

Secretary

Jane Tizard will take over from Heather Maxwell as secretary in May 07 and is shadowing HM until that time.

Research

Moin Saleem has taken up the post of research secretary and, to ensure continuity, will work with Nick Webb over the next year to increase the profile of research within the BAPN.

Registry

Chris Reid will come to the end of his term as chair of the registry committee in March 07 and nominations for his replacement are requested. Please email Heather Maxwell with nominations for this post by the 20th of Jan 07.

ACTION ALL

Ordinary Member

Sally Feather will come to the end of her term as ordinary member in April 07. The ordinary member should be within 5 years of their first consultant post. Email nominations for a replacement are requested by the 20th of Jan 07.

ACTION ALL

Trainee Representative

Rukshana Shroff has come to the end of her term of office and was thanked for her work over this time. Sally Johnson has now taken over as trainee rep.

New Posts

Eric Finlay has taken up post as communications officer and Lesley Rees has taken up post as Chair of the Clinical Standards and Guidelines Committee. Nadeem Moghal has been co-opted to the Executive to lead a working party on service delivery.

5. Communications Strategy

Eric Finlay outlined proposals for a communications strategy for the BAPN. This centres around an updated BAPN website, which can be used for communicating with the membership, for displaying guidelines and standards, for paying subscriptions and possibly for a discussion forum. The BAPN will pay for the website to be designed by Leeds University with an ongoing charge for hiring ISP space. The total cost will be between £2600 and £3000 depending on whether a forum is included. The website will be eye catching and easy to use. Each centre will have a page and information for this has already been requested. It is proposed to have pages for the secretary/treasurer, for research, for the trainees, for the registry and for the clinical standards committee, as well as a calendar of events and the history of the BAPN. There will be a useful renal links page and if thought useful links to train times, route finders etc. Some links can generate a small amount of income and may be looked at.

Discussion took place regarding the amount of work needed to maintain the website and whether this was possible with the limited amount of time available to us. The RA have recently outsourced the upkeep of their website, which was previously maintained by one member. Whilst some of the work would fall to the communications officer, editing would also be done by other executive members and by a representative from each of the centres. This will require purchase of software and some training. It is hoped to have the website started by mid January 2007.

Suggestions which followed from the discussion of the website were to look at the possibility of buying administrator time, to have a public element to the website and of having links to patient and disease websites, and to have a private members forum which could include discussion of clinical governance issues. It was felt important to start 'small' and build on the basic elements.

6. Research

(A) *William van't Hoff*

UK Clinical Research Networks (UKCRN) have been set up for diabetes, cancer, mental health, stroke, dementia and Medicines for Children (MfC). WvH leads the London centre for MfC and Nick Webb is involved in the Manchester/Lancashire/Cumbria centre. MfC covers much but not all of England; Scotland and NI have affiliated networks. These networks will provide local assistance in the running of trials (but cannot be used to fund them directly). Assistance will take the form of help in trial design, set up, randomisation and running of trials etc. Trials that are endorsed through MfC will be 'fast-tracked' to the funding bodies associated with National Institute for Health Research (NIHR). These trials can be either industry or investigator led.

MfC has several Clinical Study Groups; RANII is the group that includes nephrology along with rheumatology, immunology and infectious diseases and allergy. One of the aims of MfC is to increase the number of licensed drugs for children. Twelve studies which are already in operation have been adopted by MfC during the first year of operation; the clinical study groups provide peer review. Three renal trials are making their way through the structure.

(B) *Moin Saleem*

MS spoke of the need to set up a BAPN research network, with a lead from each site. If the BAPN designs a trial, then applications for funding need to go through NIHR. There is no absolute requirement to go through UKCRNs, but it is advisable to do so, and trials that have followed this route are more likely to get funded.

At the present time, the major UK funding bodies including charities are looking for advice as to which areas are important, and are due to meet in February or March next year. The BAPN would be advised to consider its priorities for research in time to input into that meeting.

(C) *Nick Webb*

NW informed the group that the nephrotic syndrome trial has now recruited 9 patients. The trial process is working well with the pharmacy in Birmingham couriering medicines to the patients' homes. Please encourage recruitment with local paediatricians. If patients are to be managed fully by the local paediatrician, then that centre requires full ethical approval. However if a patient is seen by a paediatric nephrologist at the local hospital, then only R&D approval is required as long as the local paediatrician is made a co-investigator in the study.

7. Committee for Clinical Standards and Guidelines

Rukshana Shroff spoke on behalf of Lesley Rees who is in the process of setting up this committee. A paper was sent round to members prior to the Business Meeting. She has asked for representatives from the registry committee (Chris Reid), the Renal Association Clinical Practice Guideline group (Sally Feather) and the Trainees (Sally Johnson), as well as Nadeem Moghal as co-opted member on Service Delivery and Eric Finlay as Communications Officer. The membership felt it would be helpful to have two further 'ordinary members' who have past experience of guideline development. Nominations should be sent to the secretary by the end of December 2006.

The definitions of guidelines and standards and the structure and function of the subcommittee were accepted.

8. Registry report

Progress is being made toward amalgamating the BAPN registry with the UKRR. However progress is slower in establishing electronic links between centres and the UKRR. Birmingham is in the process of establishing laboratory links for their Proton system, but this is not yet functional. Liverpool is being set up as a satellite of Southmead and Southampton have a new 'Scorpio' system and links are being worked currently. Paper returns are still required for the coming year and an analysis comparing paper returns with electronic downloads from those centres with that capability.

9. National Renal Biopsy Audit

Farida Hussain presented data from the BAPN 2005 audit of renal biopsies in children in the UK. Eleven of the 13 centres responded. Data were anonymised, and agreement was reached that future audits and presentation of data should not be anonymised. Data from the audit will be circulated to all BAPN centres, but a few of the findings were interesting and provoked discussion. These included the use of play preparation in only one unit, the routine use of general anaesthetic in 6 centres, and the admission being daycase in 6 centres, but as inpatients in the other 5 centres. In 2 centres biopsies are exclusively performed by radiologist and in 4 exclusively by nephrologists. Standards for the performance of renal biopsies were as per the article by FH published in Pediatric Nephrology in 2003, although these are not entirely compatible with the Banff Criteria for transplant biopsies. Further points for discussion were the finding that 9.4% of native biopsies were classified as normal; this rate varied between 0-44% of biopsies in different centres. A total of 39 patients (7.3%) suffered major complications, mainly macroscopic haematuria, delay in discharge and pain. Four patients (0.8%) required blood transfusions.

The membership thanked Dr Hussain for her work in analysing the data and suggested some further analyses that could be undertaken.

Action F Hussain to send data to all units

10. Service Funding and Payment by Results (PbR)

Nadeem Moghal gave a comprehensive review of funding arrangements under PbR. He stressed the importance of accurate coding of activity for achieving appropriate remuneration and the need to have appropriate standards for care. HRG version 4 is now available and addresses some of the complexities around paying for specialised services, such as paediatric services. It is being tested at present and some work needs to be done to look at its usefulness for paediatric nephrology. Local commissioning for low volume high cost specialties is problematic and it would be ideal to have national commissioning for such services, although this seems unlikely to happen. National guidance or a national structure for commissioning with local involvement is perhaps more likely. NM suggested that it may be a good time to revisit the 2003 audit (and publication), but on this occasion to involve patients and carers as service users and to perform this piece of work with input from commissioners themselves.

It was agreed that data were required from all centres and that agreed standards of care/service were needed.

Psychology Services in Paediatric Nephrology Units

On a related matter, Dr Moghal spoke of the need for better access to psychology services for children with chronic renal conditions. We are aware of a high incidence of non-adherence and of the stresses faced by patients and their families, but there are few data relating to psychology input

and outcome. The MCRN has mental health as one of its priorities and perhaps this could be taken up by the research network. The BAPN will make contact with Sheila Shribman, in her role as paediatric advisor to the DH and possibly also Prof Ainsley-Green, as Children's Commissioner, to take this issue forward.

Action Executive

11. Training

Sally Hulton gave an update on training issues. Units will no longer receive a training visit. PMETB will visit deaneries on a 5 yearly basis, and for new training posts, the deanery will write to PMETB for approval. There should also be RCPCH approval, but it is uncertain how this will work in practice. The Colleges and Deaneries will continue to have local quality control and quality assurance. There is some concern about how to formalise visits with trainees. The adult renal SAC ensures one SAC visit in the penultimate year of training. There was some discussion as to whether the most appropriate timing for interview with a trainee would take place in the penultimate year of training or at the end of the first year of training.

- The visiting programme and questions are at present untested
- It is unclear how recommendations are to be implemented and maintained
- The measures of success or failure are unknown

The trainees reported positively regarding the current system where the CSAC Chair and Research Secretary have an informal interview with all good trainees on an annual basis. This interview takes place on a training day and allows trainees the opportunity to feedback regarding their training as well as to discuss future research proposals or potential. It was the opinion of the CSAC that this process should continue.

There was discussion regarding the proposal that there is a named Educational Supervisor for the NTN Grid trainees in each centre. The Educational Supervisor will be required to have undergone training in educational methods such as Teaching the Teacher courses.

The updated paediatric nephrology curriculum has been forwarded by the College to PMETB. Further outcome is awaited. Formal guidance from the College regarding competency assessment is also awaited. It is possible that assessment may include not only competency based assessment but also knowledge based assessment.

As a result of the implementation of modernising medical career programme, all paediatric NTN Grid posts will now commence in August. Thus, current trainees will have their training time shortened by one month. The College has advised that CSAC Chairs must sign off current trainees as having completed their training in order to synchronise dates. The interview date for nephrology grid training is Wednesday 21st February 2007.

Individual Trusts will have made applications for academic clinical fellow posts of which 25% of the funding is provided centrally, as well as the academic clinical lecturer post of which 50% of the funding is provided centrally. The Chair of the Academic CSAC panel is Professor Andrew Wilkinson from the Department of Paediatrics, John Radcliffe Hospital, Oxford. The Nephrology CSAC representative regarding clinical academic training will be Moin Saleem.

There is currently difficulty arranging multi centre training as the NTN Grid posts involve a 2 year training programme set up through a Deanery. In the current climate it is unlikely that trainees will be able to move during their first 2 years of training because of funding issues. The CSAC supports the movement of trainees in their final year of training and will assist in whatever way possible to

allow trainees experience in a second centre. The pairing of centres with regard to training has not been easy to achieve. In particular attempts to link Newcastle and Great Ormond Street in rotation have not been fulfilled. The CSAC remains concerned that excellent teaching centres such as Newcastle are currently not considered a stand alone training centre, despite the College direction favouring competency based training.

The CSAC Chair has been in correspondence with Dr David Pilling, a paediatric radiologist from Liverpool. Draft guidelines regarding ultrasound training for the purposes of conducting a renal biopsy have been circulated to the CSAC. Further comments regarding this will be directed to Dr Pilling and a final document will be produced.

Mark Taylor and Sally Hulton will produce an updated list regarding consultant manpower and forward this to the trainees. This will also relate to the request by Dr David Shortland, the RCPCCH Officer for Workforce Planning, regarding the number of consultants required for an on-call rota in paediatric nephrology. The views of the BAPN will be collected via survey.

Action Sally Hulton and Mark Taylor

12. Trainees

At present there are 16 grid trainees in post, including 7 who were appointed this year. The training days are working well. There are 3 sets of 2 days per year. One is held jointly with the adult trainees and another is linked to a meeting. For 2007 it is hoped to have the training days in association with the Renal Association meeting, usually from pharmaceutical companies. Previously the funding for the training days has been obtained by the host centre, but this can result in high charges from the host trust. It is hoped to revisit the BAPN training account to try and avoid incurring too many charges. Trainees with an interest in paediatric nephrology are welcome to the training days, but it is not possible to cover their accommodation costs.

The trainees views on multi-centre training was obtained from 13 individuals, of whom approximately half had trained in more than 2 centres and of whom 10 were grid trainees and 3 non grid trainees. The majority of trainees would prefer to train in more than one centre. Those who had trained in more than one centre all recommended this approach. The majority of trainees would like to be given the opportunity to move to a different training centre in the final year of training and would accept training at another UK centre or abroad.

It has been agreed that all grid trainees should automatically become members of the BAPN.

Guidance is still awaited from PMETB on assessment, but the trainees are keen to have a penultimate year assessment, as happens in adult nephrology.

13. Membership and Finances

This item was not discussed in Dr Gilbert's absence.

14. UK Transplant

Heather Maxwell discussed a paper she had circulated earlier relating to matters raised at the recent KPAG meeting.

- The new allocation system has been underway since 3/4/06; no units reported any difficulties with this.
- The new system continues to promote the use of favourable matches for easy to match recipients. Whilst this will reduce the overall likelihood of sensitisation, a 100 mismatch can

result in patients becoming sensitised to very common antigens eg. A2. The Standards and Guidelines Committee may wish to draw up further guidance in this regard. UKT have suggested that all patients be discussed with local tissue typist at the time of listing. Matchability scores are not always available at the time of listing.

- One unit has written to UKT to ask for their age limits for deceased donors to be changed. UKT will only do so if the BAPN as a whole wishes to do so. There was no support for a change at the Business Meeting.
- EBV testing of deceased donors is not routine and a serum sample continues to be sent for local testing of the donor EBV status if required.

15. Diary 2007

- **RCPCH Annual Meeting** Tuesday 27th March (to include Business Meeting)
- **BTS 2007** 28-30th March in Manchester
- **IPNA 2007** 31st August – 4th Sept Budapest
- Clinico-Pathology Day – To be held in July 07 and yearly thereafter.
- Young Consultants Day – Jan 07. (see AOCB)
- **ESPN 2009** 2-5th Sept in Birmingham This is a joint meeting with the Renal Association.

16. Nice Guideline for the Management of UTI in Childhood

The BAPN membership responded actively to the consultation on the above guideline. Members were grateful to Peter Houtman for compiling the responses received on the Stakeholder Comments Form. This was circulated to members prior to the Business meeting and was debated at the end of the session. Members felt strongly that there were significant methodological flaws in the selection and interpretation of the, albeit considerable, literature on UTIs in children. There was also a lack of clarity and usefulness in the terminology used. As there was such concern regarding the underlying methodology, it was felt inappropriate to respond on a point by point basis to the recommendations in the guideline. Several general statements were added to the response eg. that members supported a reduction in imaging, that it was important that the strategy for imaging ensured that infants and children with underlying structural and bladder problems were picked up and that it seemed premature to dispense with prophylaxis whilst trials of its use were still underway. A copy of the response to NICE has already been circulated to members.

AOCB

- Young Consultants Day. Martin Christian is organising a meeting for consultants within 5 years of their first consultant post, to be held in Nottingham. Accommodation will be provided the evening before. The morning session will focus on 'lessons learnt' during their time as consultants, to be followed by a talk from Mary McGraw on the future prospects for training in paediatric nephrology. The afternoon will focus on future services and George Haycock will talk about the early attempts to establish paediatric nephrology services, followed by Mark Taylor who will outline the short to medium term plans for the BAPN.
- Judy Taylor asked for members to pull their experience of the use of Rituximab for patients with nephrotic syndrome. She will develop a questionnaire for the membership.
- Nick Webb has taken from Alan Watson on ESPN Council. Members are encouraged to join the ESPN if they have not already done so.
- Richard Coward has been awarded an MRC Clinical Fellowship. Members congratulated him on this achievement.