

British Association for Paediatric Nephrology

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BAPN GENERAL MEETING

Friday December 5th 2008
Birmingham Children's Hospital

Minutes

Present: Mark Taylor (MT) (President) Jane Tizard (Secretary), Nick Webb, Dick Trompeter, Mark Bradbury, Manish Sinha, Eric Finlay, Kay Tyerman, Eva Simkova, Jane Deal, Lesley Rees, Judy Taylor, Sandra Irragori, Larissa Kerecuk, Kjell Tullus, V Ganesan, Carol Inward, Brian Judd, Peter Houtman, Martin Christian, Jane Dudley, Alan Watson, Mordi Muorah, Catherine O'Brien, David Milford, Sally Hulton, Moin Saleem, Nadeem Moghal.

Apologies: Henry Morgan, Chris Reid, Steven Marks, Andrew Lunn, Leah Krischock, Mary McGraw, Shuman Haq, Jonathan Evans, Javed Iqbal, Arvind Nagra, Maggie Fitzpatrick, Rachel Lennon, Maurice Savage, Jean Smellie, Mike Dillon.

1. Minutes of last meeting (Glasgow May 2008)
 - a. These were agreed and signed as a true record.
2. Matters arising (not otherwise on agenda)
 - a. None other than on the agenda
3. New President
 - a. Mark Taylor was delighted to announce that Mary McGraw will take up office as the new President of the BAPN from May 2009.
4. Professional organisation, quote from MCI group
 - a. MT gave a brief outline of his proposal to develop the corporate infrastructure of the BAPN. (This had been circulated prior to the AGM). The rationale is to provide a permanent base for the BAPN, support for the infrastructure and financial aspects of the Association and to facilitate corporate sponsorship. MT met with Peter Mathieson, President of the RA, Stuart Rogers (Treasurer) and the MCI group which currently manage the RA to discuss integration of the BAPN within the RA. It was suggested that the BAPN should become a Division of the RA but would have access to all the infrastructural services. The BAPN would retain its own

identity. Members would be members of both organisations for the RA fee. The website would need to be replicated within the RA website. The perceived disadvantage would be for the paediatricians with an interest in nephrology and it would be important to address the needs of this group particularly with regard to educational meetings. Strong paediatric links would still remain: Training would still be managed via the RCPCH CSAC and paediatric nephrology research is now organised via the MCRN (Medicines for Children Research Network) CSG.

- b. There was a lively debate about this proposal. Mary McGraw has previously circulated a letter with her concerns. The main concerns of the audience were related to maintaining the identity of the BAPN. AW stressed the different focus on children and while it was accepted that there has been strong support from the RA for the Transition work it was thought that this might not be so strong for areas that did not impinge on adult nephrology. VG thought that lobbying for patients would be supported by the RA but professional issues would link via the RCPCH. This could cause some conflict. PH was concerned about the paediatricians with an interest in nephrology as the BAPN is already more of a tertiary Association compared with other paediatric specialties and the general paediatricians should be encouraged to join. MS was very positive about the possible financial support for the BAPN from the RA due to their ability to secure pharmaceutical sponsorship. On the political aspects it was suggested that the BAPN should consult Donal O'Donoghue. LR was very positive about the Research and audit links with the RA. EF stressed the benefit of alleviating the administrative work for the website to allow time for more productive work which could be of benefit to all including the general paediatricians. JT had explored the current position for those specialties currently using the RCPCH as their secretariat. The BAPM and BACCH currently have support from the RCPCH. However, these are bigger Associations with approx 1000 members each and therefore they pay for the personnel but are supported by employment via the RCPCH. The BAPN membership fee would not be sufficient to do this. MM has informed us that support for smaller specialties will be discussed at the RCPCH in January.
- c. Although many people had some mixed views the general impression was of support for the proposed link with the RA. However, it was agreed that it was very important to explore both options of links with the RA and to set up a working party to do this ASAP. **Action: Mark Taylor & Jane Tizard.**

5. Research and development

- a. The CSG is meeting 6/12ly –Minutes to be circulated soon
- b. York 2009 –
 - i. Joint meeting with genetics.
 - ii. Hot topics 5x5 –each specialty will do every 3 years –nephrology this year.
- c. Rare diseases registry
 - i. This is a web based registry. There are currently 2 cohorts-FSGS and MCGN included in the project. Potential to expand to other diseases. Website being designed –will collect data 6/12ly. Aim to link to pathology systems and RR in the future. There will be Histopathological review. May identify patients from the pathologists. System will go live in 6/12.

6. Clinical services committee

- a. PbR-the assessment of cost of HD has almost been completed via, Newcastle, Birmingham and Leeds. Cost of paediatric HD is £550 v £150 in adult. The current advice is to use a day case tariff. Report due to be circulated in January.
- b. The Newcastle whole service PbR work has been useful for Newcastle-the outcome has been the financial desegregation of the service from all other services. This has allowed Newcastle to reach a service level accounting position. All units are encouraged to seek this degree of service level economic understanding-whether net profit or loss positions, the information can be used to service advantage in terms of local cost base etc.

- c. Benchmarking-
 - i. Benchmarking can be used to advantage or disadvantage depending on who generates the data and for what purpose. It requires engagement as starting position with managers.
 - ii. The Quality Agenda
 - 1. The Darzi agenda is beginning to be structured. The NHS Medical Director. Chris Keogh has established a survey as way of consultation on approximately 331 indicators that look at input and output aspects of service delivery. Of these only 4 involve children
 - 2. Need to develop quality metrics-this is challenging in a low procedure/low mortality chronic disease specialty.
 - 3. NM has been awarded a Fellowship by the NHS Institute of Innovations and Improvement at the University of Warwick. He will spend one year working on a project to define the quality issues in the context of delivering a service from all perspectives. Internal metrics include pathways structured to reveal value. Need to apply metrics across all perspectives including patient reported outcomes. This needs a national perspective.

7. Registry Update

- a. Data Protection
 - i. Consent now being obtained for all patients. Birmingham, Bristol, Cardiff, Glasgow, Guys, Liverpool, Nottingham confirmed in process. 1 family refused. Consent only needed once. For electronic returns next year –no consent required but need to ensure families have information so that they can opt out. Newly registered patients need give consent for paper returns.**(Action all)**
- b. Data collection-
 - i. for 2008 completed 31.10.08. Only one unit did not contribute. Chapter for 11th report being submitted.
 - ii. Database transfer to UKRR 2009-advantage of registry expertise and continuity to adult services. Enable linkage to HES data base, HPA data base, collaboration with OPCS data via public health observatory.
 - iii. 2009 data collection
 - 1. via Proton/similar to registry direct
 - 2. paper to Manchester and to RR via proton
 - 3. **The 2009 deadline for data submission is 30/06/08.(Action all)**
 - iv. **Submission of data will be mandatory for Trusts from May 2009.**
 - v. This should assist in getting resources.
 - vi. Current systems:
 - 1. Bespoke Guys/Southampton (C Reid happy to share info in Guys system)
 - 2. Clinical vision –Manchester/Newcastle
 - 3. Cybernius-Liverpool
 - 4. Mediqa-Belfast
 - 5. Proton-Birmingham, Bristol, Cardiff, Glasgow, Leeds, Liverpool, Manchester, Nottingham
 - 6. Unknown-GOSH
 - 7. Screens being produced by registry to identify data required.
 - vii. CfH estimate for EPR is 4-5 years
- c. Publications planned: young adults and transition-this will be the subject of a PhD study. UKRR will be published in Nephron so that results are citable. There was encouragement to publish the raw data from the registry.
- d. ML was thanked for his continuing efforts in the Registry.

8. Audit

- a. Renal biopsy audit to be submitted for publication soon
- b. BP in transplanted patients will also be submitted
- c. Audit of anaemia in children on RRT-to be led by Shazia Adalat
- d. 3 proposals for national audit were submitted by the BAPN to HQIP on subjects of anaemia, growth and BP-none of these were accepted. Three of the proposals reaching the next stage were 1) A Quality improvement programme relating to pain, 2) Audit of Multi- agency care pathway for children with life threatening/life limiting conditions and 3) management of stage 4 or 5 CKD. CI to investigate if the latter will include children. **(Action CI)**
- e. Manish Sinha presented the audit of BP post transplantation. Overall prevalence of hypertension was 25% in these patients. Presentation was previously circulated-in the presentation the Units were identified (please contact MS for updated version). This audit will be submitted for publication in due course.

9. Standards and Guidelines

- a. UTI NICE guideline response posted on website in October. Little response. JD to write closing statement. Review in 4 years. **(Action JD)**
- b. KDOQI nutritional guidelines were commented on by the group. They will be published soon
- c. HUS guidelines by Sally Johnston should be adopted onto website –however, need to get permission from P Nephrology due to copyright. EF could create link.
- d. Trainees-all have topic and supervisor. BJRM have been approached to publish
- e. It was suggested that guidelines could be presented at the RCPCH meetings-this was supported.
- f. Alternative to audit for trainees is national review of unit practice-eg management of peri-operative pain
- g. RA guidelines –some still awaited LR to ask leaders of groups again NW agreed to produce the Tx guidance by Jan 2009 **(Action LR and NW)**
- h. Patient information-it was agreed that the Astellas money that JD had obtained should be used for developing patient information. The GOS patient information is being altered to make suitable for BAPN labelled information but with due recognition of LR/GOS.**(Action EF/JT and others)**
- i. Personalised care plans-DM is leading on integrated care pathways and care plans. Some have been developed in Newcastle. Plan for BAPN template that could be modified locally. NM to discuss with guideline group**(Action NM and DM)**

10. Home HD service proposal.

- a. LR presented the previously circulated proposal which is being submitted to NHS Kidney care to set up a pilot project to develop home HD. The aim of the project is to develop educational material including videos and to facilitate training staff from other units to provide Home HD across the UK. The proposal is not to provide Home HD from GOS for the UK. This proposal meets the NHS priorities and DO'D is positive about it. There was discussion about the merits of a broader agenda of home dialysis support for both HD and PD.

11. Renovascular disease service

- a. KT presented the amended application (original previously circulated) to develop National Commissioning and designation for the management of Renovascular hypertension. This is now planned to be a 2 centre proposal from GOS and Manchester. It is planned that angiography may be performed in the local hospital unless the local hospital wished to refer. The cases would be discussed and management instituted at GOS/Manchester.

- b. There was concern about this proposal. Nephrologists from Guys consider that they can provide an excellent service for these patients and that there is considerable benefit from having the experienced adult service which they and have access to. Currently some cases are referred to other centres where particular expertise is required but it was questioned as to whether a formal arrangement was necessary and compulsory referral would not be beneficial to the patient. It appeared that the proposal related to native kidneys only and therefore the local expertise would be diluted for management of the transplant cases. The vascular surgeons had not been asked their opinions.
- c. It was agreed that there should be a survey of the number of patients that would be involved. Audit number of patients over last 5 years who required angiographies and vascular procedures, including transplants. **(Action KT /EF)**
- d. Currently the application is not supported by the BAPN.

12. Patient Information

- a. The GOS patient information is being altered to make suitable for BAPN labelled information but with due recognition of LR/GOS. **(Action EF/JD and others)**
- b. It was agreed that the Astellas money that JD had obtained should be used for developing patient information. **(Action JD)**

13. RIXG

- a. The report sent by Chris Reid was not discussed in his absence

14. Treasurer

- a. Details of account previously circulated.
- b. £100,000 from KKR was not fully allocated (£75,000 allocated) therefore paediatric projects did not get the benefit of the extra £50,000 from KRUK. Need to submit more applications in 2009 to benefit from this.
- c. The N/S project was not funded. Resubmitted to HTA-awaiting decision this month. Discussion as to whether £100,000 for next year should be retained by BAPN to consider for use to support N/S study if HTA bid unsuccessful. This was not supported by the Association.
- d. Funding of MCRN CSG. To date no funds have been requested. MS to investigate whether the BAPN needs to pay. **(Action MS)**
- e. Need to consider where to invest current KKR donation. RT to investigate. **(Action RT)**
- f. ESPN registry. KKR have agreed to support ESPN registry with one-off payment of 10,000E. This will come via the BAPN and will be given to the registry on the understanding that an identification of Registry funds are clarified within the ESPN accounts. **(Action MT /RT)**

15. Training and trainees

- a. The curriculum is on the website
- b. The Assessment of the curriculum is being undertaken via the RCPCH-this is still in progress.
- c. PMETB has produced assessment forms for use in nephrology as a pilot scheme – further information still awaited.
- d. Curriculum for Paediatricians with Special Responsibility for Nephrology -P Houtman chaired the SPIN group (R Jones, H Cottis, L Jadresic, K Tyerman). The curriculum for SPIN will go onto the RCPCH website. Includes 18/12 training of which 6/12 Paed nephrology centre, 6/12 outside tertiary centre but doing paediatric nephrology and 6/12 in specialty allied to nephrology. Assessment still being devised.
- e. Paediatric Nephrology trainees
 - i. CSAC agreed that all new trainees should complete 36/12 clinical training (research to be done outside this time)

- ii. Need to clarify with deanery re last year and whether this can be done in another centre.
 - iii. Ideal to work in different Unit for 3rd year to maximise exposure to different units.
- f. Academic trainees
 - i. MS, PW and SH assessed academic records of all centres. Bristol, Birmingham and GOS identified as main academic training centres. MS to liaise with T Stephenson re RCPCH support for academic posts. Should require backing from RCPCH and BAPN for academic nephrology training posts.
- g. Trainees:
 - i. 6 will have CCT in 6/12
 - ii. 7 more in 12 months
 - iii. Posts available in Glasgow, Newcastle, Birmingham and GOS in 2009
- h. There will be 3 Grid posts offered in 2009
- i. Young Nephrologists symposium –planned for day prior to the ESPN in September.

16. Communication and the website

- a. Forum now redundant- 3 visits in 3 months-therefore will be closed
- b. Overall hit rate has decreased
- c. Vacancies page-sent to EF information on vacancies.
- d. Paypal closed.
- e. Patient information leaflets-being processed as above.
- f. Branding for BAPN in progress.

17. Presumed consent

- a. KT had reviewed the 38 returned from the questionnaire on presumed consent. The previously circulated statement was approved as a BAPN consensus statement.

18. World kidney day

- a. 12/03/09. Key message is “keep the pressure down”. World wide march “on the move for kidney health”. Please advertise.

19. Secretary

- a. Constitution
 - i. The previously circulated proposals for amendment to the BAPN constitution were approved. As not sufficient membership present this will be circulated for approval. In addition it was suggested that the general paediatrician with an interest should be invited onto the CSAC.
- b. Officers
 - i. Officers that will become vacant in 2009 are
 - 1. Chair of Clinical services sub- committee May 2009
 - 2. Treasurer-April 2009
 - 3. Clinical standards and guideline group September 2009
 - 4. Communications Officer September 2009
 - ii. All these officers are eligible for re-election for further year except Dick Trompeter who is retiring and therefore leaving office.
- c. New members-none

20. AOB

- a. IPNA has money for fellowships for Advanced nephrology training-please disseminate this information.

21. Date of next business meetings :

- a. RCPCH York March 30th to April 2nd

- b. Renal Association April 20th -24th Liverpool
- c. **Business meeting April 22nd 2009 Liverpool RA**
- d. AGM Dec 4th 2009 Birmingham TBC
- e. Other meetings;
 - i. BRS 2009 June 1st -3rd
 - ii. ESPN 2009 Sept 2-5th