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[www.uwcm.ac.uk/uwcm/ch/bapn](http://www.uwcm.ac.uk/uwcm/ch/bapn)

## **BAPN Executive Meeting Minutes**

**Friday 20<sup>th</sup> October 2006**

### **Birmingham Children's Hospital**

- 1. Members Present:**
- |                 |                 |
|-----------------|-----------------|
| Sally Hulton    | Mark Taylor     |
| Nadeem Moghal   | Nick Webb       |
| Rukshana Shroff | Heather Maxwell |
| Jane Tizard     | Moin Saleem     |
| Sally Feather   | Eric Finlay     |
- Apologies:**
- |                |                    |
|----------------|--------------------|
| Chris Reid     | Kate Verrier-Jones |
| Dick Trompeter |                    |

Mark Taylor welcomed the new members to the Executive Meeting.

### **2. Minutes of the Previous Meeting**

These minutes were accepted as an accurate record

### **3. Matters Arising from the Minutes**

*a) Renal Association Meeting in Brighton – 21-23 May 2007*

The Paediatric session has been arranged on the 3<sup>rd</sup> day. This will be a metabolic session looking at hyperoxaluria, cystinosis and mitochondrial diseases and the membership are encouraged to attend this session. Unfortunately the session coincides with the annual general meeting of the Renal Association and another free communications session. There are also 6 slots for Paediatric free communications on the 2<sup>nd</sup> day of the conference and this session will be chaired by Lesley Rees. This session coincides with another session where Agnes Fogo will speak. The deadline for submissions to the Renal Association is 4<sup>th</sup> January 2007.

Note added in proof: order of Brighton meeting changed to given less conflict with the paediatric/metabolic session (CMT)

a) *Renal Association Meeting in Brighton – 21-23 May 2007 (contd...)*

The trainees may substitute one of their training days for attending the Paediatric Sessions at the Renal Association, however there are both time and financial constraints. Of their 3 training days one of the other has been substituted for a meeting along with adult trainees, leaving only 1 full day for Paediatric training.

**Action: Membership to be emailed regarding deadline for submissions and advertising the meeting.**

b) *Joint Specialties Committee*

Mark Taylor will attend this on behalf of the BAPN Executive.

c) *The National Service Framework for Renal Services - Working for Children and Young People*

This document and the document criteria for success which relate to Parts I and II of the Renal NSF have been recently circulated. We need a mechanism for working with these and the most likely way forward is to take this through the new Standards Committee.

**Action: Criteria for Success document to be emailed to the executive.**

d) *Review of Specialist Services*

This document has been produced by Andrew Cant and has been circulated. Mark Taylor has responded on behalf of the BAPN.

e) *Adolescent Services*

This issue has been discussed with John Feehaly and the Renal Association for a future topic for one of the meetings.

f) *Changing Face of Renal Medicine in the UK*

A report from this committee is still awaited.

g) *Patient Information Sheets*

This issue will be handed on to the Standards Committee.

h) *Renal Association Guidelines*

The Paediatric Haemodialysis Module has been written and has been circulated for comments. These should be sent to Sally Feather by the end of November 2006. Again this issue will be dealt with by the Standards Committee, but also needs to be part of the communication strategy.

i) *BAPN Executive Posts*

Dick Trompeter will take over as BAPN Treasurer from December 2006 and Jane Tizard will take over as BAPN Secretary from May 2007. The constitution will be further adjusted to allow Grid Trainees to become full members of the BAPN.

j) *ERA European Registry*

A meeting was held at the ESPN Meeting in Palermo of the Chairs of National Groups to look at funding for the Epidemiologist who will deal with paediatric data. Some funds have been received from the ERA, but other funding is required. The BAPN had agreed to fund € 1000/yr and this needs to be confirmed with Rodney Gilbert, Treasurer.

**4. ESPN Birmingham - 2-5 September 2009**

This will be held at the ICC in Birmingham. A governance committee, made up of the ESPN President (Pierre Cochat), ESPN Treasurer (Peter Hoyer), Renal Association President (John Feehally), Renal Association Treasurer and the BAPN President and Treasurer is being set up. The contact with the ICC is a commercial arrangement and there needs to be some cover of risk. This needs further discussion and the MIC Group, who are the secretariat for the Renal Association, will take this work forward.

The philosophy for the meeting will be one of a good academic meeting, structured to promote learning. Fernando Santos will head the scientific programme. Albert Ong is in charge of the Renal Association scientific programme. The ESPN meeting will be a 3-day meeting, of which the first day is shared with the Renal Association. This day will have the theme of the Primary Cilium and will look at cystic diseases and renal development from cell biology to modern concepts of treatment. A local organising committee drawn from BAPN members has been set up, chaired by Alan Watson.

**5. Reports**

*Treasurers Report*

In Rodney Gilbert's absence this was not discussed.

*Registry Report*

Chris Reid had circulated a Registry Report to BAPN members.

1. 2006 Registry Report – Paediatric Chapter  
We are waiting to hear from Malcolm Lewis as to progress with the chapter.
2. Chris Reid met at the Renal Registry in May 2006 with Registry staff, including David Ansell and Charlie Thomson, and it was decided that data returns would be sent to Manchester who would enter the data manually into a Proton based system set up as a subset of the Bristol Proton Database, which will be used to transfer all paediatric data to the UKRR. Malcolm will also work on electronically transferring the existing data in the Manchester Paediatric Registry into this Proton Database, allowing longitudinal follow-up of all patients.
3. 2005 Biopsy Audit  
An update has been requested from Farida Hussain.
4. 2006 Audit  
Manish Sinha and Larissa Kerecuk are making progress in collecting data for the audit of Blood Pressure Control in Transplant Patients. It is hoped that it will be possible to use the Renal Registry Statisticians to work with this data.
5. Patient Consent Forms  
Chris Reid emailed draft consent forms for patients, asking for their data to be submitted to the Registry.

Chris Reid will meet with David Ansell and Charlie Thomson again on November 10<sup>th</sup>. It is hoped to discuss uploading the Bristol screens for other Proton users. Unfortunately it will not be possible for those people using Clinical Vision to use the Proton screens.

Heather Maxwell expressed her disappointment that the Paediatric Proton screens were not yet available to individual units. Units who use Proton, but do not have all of requisite fields, are not able to progress with electronic submissions.

### *Research Reports*

NIHR - The BAPN put in a bid for money from NIHR but were unsuccessful. Further funding is available for Research for Patients. Up to £250,000 is available and bids need to be submitted in partnership with patient organisations. The Research Officers are in the process of putting together a bid.

Medicines for Children is developing alongside this and is a mechanism to aid the carrying out of research projects which have already received funding. It covers approximately 60% of England, has its centre in Liverpool with 5 coordinating centres, and has several sub-committees'. Nephrology lies within the RAANI sub-group.

**Action: Moin Saleem and Nick Webb to produce a briefing paper for the Business Meeting for December 2006**

At the present time Nick Webb is the BAPN Rep on the RAANI. He has been on this committee for 3yrs. The subsequent representatives however need to be officially appointed and elected by the bodies they represent. The BAPN would wish that this representative is also the Research Secretary of the BAPN.

There was a recent meeting of English children's hospitals to discuss difficulties with research at the present time. The Department of Health was present at the meeting and Nick Webb and Mark Taylor attended. The meeting was set up by Deirdre Kelly from Birmingham and she will set up a small working party to meet with Patricia Hamilton (President of the RCPCH) to work out how to lobby the Department of Health on research in children via the RCPCH.

## **6. Communication Strategy**

Eric Finlay surveyed the membership on their views on the current BAPN website and how they would wish to see this redeveloped. The outcome of the survey was discussed. At the present time members only use the BAPN website infrequently, but would approve the new website having both a professional and a public element. A majority of 84% would use a professional forum were it created. The membership provided suggestions for links to other websites. Again a majority of members were keen to share guidelines on patient information and other programme's via the website. There was a 50:50 split on the use of advertising. Eric Finlay has looked at the costs for professional website designers and the costs for maintaining a website. It was decided that the BAPN would pay up to £3,000 for the website to be developed professionally and Eric Finlay would look into who could do this for us most efficiently. The Committee was keen that the BAPN logo be updated and the website be simple but striking.

**Action: Eric Finlay will take this forward and Mark Taylor will write to Rodney Gilbert re the finances**

## **7. Clinical Standards and Guidelines**

Lesley Rees joined the Executive by telephone. She will chair this committee which will have a Renal Association Guideline Subcommittee liaison post (Sally Feather), the chair of the Registry Committee Chris Reid), a Trainee Representative (Rukshana Shroff), and Service Delivery expertise (Nadeem Moghal). The Committee will have the power to co-opt members from outwith the BAPN,

for example Haemodialysis Nursing Specialists, and also to take external advice on guideline development. Lesley Rees discussed how she would see the committee working and felt that the first area to develop was the work that is being done at present on the Paediatric Modules of the Renal Association Guidelines. The Executive expressed the view that all guidelines must be auditable.

**Action:** Lesley Rees will email all of the Renal Association Standards contacts

## **8. Payment By Result**

Nadeem Moghal did a short presentation on Payment by Result. A new version of HRG (HRG4) has recently been produced. This is more flexible than previous versions and is age sensitive in that there is a recognition that children cost more than adults, and it also takes more account of the complex nature of many illnesses. Adequate funding of service activity relies on accurate coding. At the present time there is a lack of accurate data on the actual cost of providing services and a lack of benchmarking data. Nadeem Moghal will present further information about Payment by Result at the December business meeting.

## **9. External Committee Update**

There was nothing new to report.

## **10. Meetings for 2007**

BAPN Executive meetings (revised after email correspondence) on:

- 23<sup>rd</sup> February 2007 in Bristol
- 8<sup>th</sup> June at RCPCH in London
- 28<sup>th</sup> September in Birmingham
  
- The next BAPN Business/Research meeting will be held on 7<sup>th</sup> December 2007 in Birmingham.

The format of the Business Meetings will be discussed further at the Business Meeting to be held in December 2006.

## **11. AOCB**

A new member, Beena Padmakumar, has been proposed by Nick Webb and Shaila Sukthankar.

The NICE UTI guideline is out for consultation and comments from the membership will be compiled and sent to NICE on behalf of the BAPN.

Kate Verrier-Jones continues to attend the RIX Group meetings on behalf of the BAPN. She has also been involved in work on the National Renal Dataset and requires information from the Registry for this. She is continuing to work with CFH and feels that she will be less able to attend the BAPN Executive. Mark Taylor will write to thank her for all her work over the preceding months.

Heather Maxwell received a letter from Dr Tessa Lewis, a General Practitioner in Wales, who sits on the All Vales Prescribing Advisory Group. This group are concerned about the increased use of Ibuprofen in children as an anti-pyretic. She enquired whether the BAPN had concerns about the use of non-steroidal in children. The response to this is Yes, the BAPN do have a concern, and it is such that we are considering approaching the BPSU to do a survey on non-steroidal associated acute renal failure.

## 12. Date of Next Meeting

The BAPN Business Meeting will be held on 8<sup>th</sup> December in Birmingham at the Queen Elizabeth Hospital. Further details will follow.

### Action

3a	Membership to be emailed regarding deadline for submissions and advertising the meeting	
3c	Criteria for Success document to be emailed to the executive	
5	Moin Saleem and Nick Webb to produce a briefing paper for the Business Meeting for December 2006	MS / NW
6	Eric Finlay will take this forward and Mark Taylor will write to Rodney Gilbert re the finances	EF / MT
7	Lesley Rees will email all of the Renal Association Standards contacts	LR