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BAPN Executive Meeting Minutes

*Friday 6th May 2005
 10.00 am to 1.00 pm*

Royal College of Paediatrics and Child Health, Hallam St, London

1. Members Present

Heather Maxwell (Secretary)	Nick Webb	Sally Hulton
Maurice Savage (President)		

Apologies

Sally Feather	Chris Reid	Rodney Gilbert
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2. Minutes of the Previous Meeting

The minutes of the previous meeting were accepted as a true record.

3. Matters Arising

All matters arising were dealt with in the agenda.

4. a) RCPCH Meeting 19th April

The College meeting was well attended with between 40-60 delegates at each session. Attendees were mostly Nephrologists; there were a few general paediatricians. The quality of presentations was very good, however the venue was less than ideal and breakfast had to be cleared from the room before the start of the session. The venue was also far from the lunch venue. Unfortunately this room was locked on arrival and despite ordering lunch to be available there, this did not happen.

In total there were only 3hrs of presentations and it would have been preferable to have had longer. Feedback is being requested by the academic board and the research secretary will respond on behalf of the BAPN.

Action: NW

4. b) RCPCH Nominations

There has been a call from the RCPCH for nominations for honorary fellowship for 2006. This is for either UK Paediatricians, International Paediatricians, Non-Paediatric Scientists here or abroad or Non-Scientists, which can include pioneers from the voluntary sector, sociologists, philosophers, politicians from both here and internationally. The college is particularly interested in nominations from honorary fellows in the international categories. Members who have nominations should advise the Secretary.

Action: Membership

5. BAPN Business and Exec Meetings

Following discussion at the Business Meeting there has been a request for an increased research component to BAPN meetings. Proposals for future BAPN meetings are as follows.

A research meeting will be held at the RCPCH Spring meeting. We will request more time for presentations and this meeting will include a 2hr Business Meeting. There will no longer be a meeting in June, but there will be a longer meeting in December. It is planned to have an overnight stay on the Thursday with an early start on the Friday for a meeting that will be part Business and part Research Proposals and Updates. We will look for sponsorship for a meal for the Thursday evening. These meetings are all medical with no multi-disciplinary input. Approaches have been made to the renal nurses special interest group, but they have not been enthusiastic about joining together for meetings.

The renal association have a 3-day meeting in the spring (3-5 May 2006). The meeting is being held jointly with the BRS who have requested paediatric input into the programme. Nick Webb will be the paediatric representative for this. Trainees who submit abstracts to the York meeting will be encouraged to submit these abstracts to the Renal Association also.

Action: HM / NW

6. Committee Representation

Following discussion with John Feeley we have finalised paediatric nephrology representation at the Renal Association committees. The Education & Training Committees have now joined together and Sally Hulton will represent the BAPN at this committee.

7. Renal Association

a. Standards

Three Consultant Paediatric Nephrologists have been appointed for each of the modules of the new Renal Association standards. Sue Rigden has agreed to lead modules 1&2 on Chronic Renal Failure and Complications, Dr Lesley Rees - module 3 on Dialysis, Heather Maxwell – module 4 on Transplantation and Sally Feather – module 5 on Acute Renal Failure. The leads have been asked to form working groups.

Action: HM

b. Renal Unit Directory

We are not aware of any units who have as yet put their details in the directory on the Renal Association website. Units will be reminded at the next BAPN Business Meeting.

8. Manpower Planning

(see CSAC minutes)

9. NSF

Discussion has taken place already between Lesley Rees, who was involved with the NSF, and Jane Verrity at the Department of Health and Donal O'Donahue who is the Chairman of the Renal Advisory Group. The BAPN will write to Jane Verrity to ask her to expand on the contents of an email dated 9th February 2005, which refers to a Childrens' Renal NSF. We will ask for details as to how this will be taken forward. We will also write to Donal O'Donahue asking how we can take the situation forward.

We are aware that Part 2 of Criteria for Success (mapping to Part 2 of the NSF) is being contemplated.

Kate Verrier-Jones has been involved with the Welsh Renal NSF and has done much of the work relating to children. Kate will be asked to become a co-opted member of the executive for matters relating to the NSF.

Action: HM / MS

10. Specialty Codes

The Department of Health / NHSIA are undertaking a review of specialty codes. At the present time there are only codes for a minority of paediatric specialities, whereas a specific code would be useful for commissioning tertiary paediatric services. Heather Maxwell will write to Dr Nick Griffin who is leading on the review of specialty codes to find out if it would be possible to have a specific code for paediatric nephrology.

Action: HM

11. Criteria for Success

Criteria for Success for Part 1 of the NSF have been submitted to the BRS and will be available on the website. An outline has now been developed for Part 2 of the NSF and the process will begin again to develop standards to try to achieve the targets expressed in the NSF. Jane Tizard is progressing this work on behalf of the BAPN.

12. BRS

a. Patient DVD

The BRS in conjunction with the NKRF are involved in producing a DVD for patients with renal disease. This was discussed at the BAPN Business Meeting and the BAPN are agreeable to becoming a member of the group involved in producing the DVD. Jan Dudley will be our representative on this group.

Action: HM

b. BRS / RA Meeting Harrogate 2006

This item was discussed earlier. Members submitting abstracts to the RCPCH meeting in 2006 will be encouraged to submit the abstract to the joint Renal Association Meeting in Harrogate. We were asked to provide paediatric input into the programme for the joint conference and Nick Webb as Research Secretary has agreed to do this.

Action: HM

13. NICE Update

a. *Immunosuppression*

The appraisal committee report is due on 1st August 2005. The timeline for this HTA may be delayed slightly following the Department of Health's review of its Arms Length Bodies. The National Institute for Clinical Excellence has now taken on the functions of the Health Development Agency to become the National Institute for Health and Clinical Excellence (NICE). A decision has been taken to reduce the number of appraisal committees from 3 down to 2, which will impact on the timeline for the HTA.

b. *Anaemia in Renal Failure*

Jonathan Evans and Nick Webb are attending the guideline meetings on behalf of the BAPN.

c. *UTI in Childhood*

Kate Verrier-Jones is chairing this guideline committee and Kjell Tullis is the paediatric nephrology representative. The paediatrician on the group is Vaughn Lewis.

14. UK Transplant

a. *New Allocation System*

This was discussed at the Renal Transplant Services Meeting earlier this year. Objections were raised regarding the affect on Blood Group O patients and on the transplant activity of certain units. Adjustments have therefore been made to the proposed allocation system and where the simulations are being run.

b. *Centre-Specific Data*

Not discussed

15. Registry Committee

A report for 2004 has not yet been compiled and therefore 2004 data will be accepted up until the end of May 2005.

Chris Reid has looked through the EDTNA dialysis survey and feels that it is not appropriate for the BAPN to be involved in it.

16. Other BAPN Registries

The Cystinosis, Atypical HUS and Hyperoxaluria registries are "endorsed" by the BAPN. They fall under the remit of the Registry Committee and should be standing sub-items of the registry committee report at business and executive meetings.

Action: HM/CR

17. Research Update

Nephrotic Syndrome Primary Therapy Trial

Initially this was being undertaken by the Clinical Trials Unit at Birmingham Children's Hospital but work has not progressed at the anticipated pace and targets have not been met. Nick Webb and Dick Trompeter are meeting to decide how to proceed with the trial and will report to the BAPN at the Business Meeting in June.

C2 Trial

Guy's Hospital are due to come on board shortly and hopefully this will allow the numbers to reach 100 when the data will be analysed.

Lipid Audit

This was reported at York and was well received.

VUR Study and EBV Vaccine Studies are progressing.

Proposals for research will be requested at the business meeting in June and will be submitted to the research secretary before the research meeting in December.

18. Transplantation in patients with atypical HUS

Mark Taylor forwarded information regarding genetic testing in patients with atypical HUS undergoing transplantation. This will be taken to the Business Meeting in June.

19. Renal Information Strategy

Kate Verrier-Jones has kindly forwarded minutes from the RIXG Group along with an outline of the group's work. The Group is involved with Renal Patient View, the patient information DVD and contact with NHS Direct on-line. They are also involved with the National Programme for IT where it relates to renal matters. This includes the renal information strategy (NSF) the Renal Data-Set Development Project, the definitions and categorisations of disease and Health Care Episodes, the National Electronic Library for Health – Renal Specialist Library and the Do Once and Share Project. Reading through the minutes of the meeting, in Item 6 John Feehaly has mentioned that the majority of paediatric units are still not returning data to the Renal Registry. We were unsure as to whether this was electronic or manual data and will ask Chris Reid to contact Kate Verrier-Jones to clarify this.

Action: CR

20. National Electronic Library for Child Health

This issue was not discussed.

21. Treasurers Report

There has been no movement in the BAPN account since the last meeting, apart from a payment of £222.04 for expenses incurred by the trainees. This will be repaid to the main account from the trainees account in due course.

22. Trainee Issues

No trainee representative was available and this was not discussed.

23. UK Bid for ESPN 2008

We are awaiting discussions at the ESPN meeting this year as to the bids for ESPN 2008. A decision may be taken in Istanbul this summer.

24. Adolescent Health

The Royal College are keen to highlight the needs of adolescents in hospital and the need for appropriate transition between paediatric and adult care. Documents relating to these were discussed at the meeting. We will keep this item on the agenda.

25. Forthcoming Meetings

BRS Meeting 9-11th June 2005 - The next BAPN Business Meeting will take place prior to this meeting.

26. Membership Lists

The BAPN Membership List needs updating.

Action: HM

27. AOCB

Levamisole

Nick Webb informed the meeting that a source for Levamisole has been found and the drug should be available in due course.

Kidney Alliance

Nick Webb attended this meeting. Payment by results is currently being piloted by the First Wave Foundation Trust. There have been numerous teething problems and PCT's have needed a £637 million top-up to cover their costs. From 1st April 2005 it was agreed that only elective work would be covered by this scheme. There are supposed to be supplements for specialist paediatric activity and an uplift for other paediatric activity, however despite this the tariffs for renal transplantation for an adult are £17,649, but only £13,154 for a child. Nick Webb will look further at the source of these figures and see if the BAPN can have input into this process.

28. Date of Next Meeting – Friday 7th October 2005

Action Points

			<i>Action</i>
1.	Item 4A	Feedback from RCPCH York – 2005	Nick Webb
2.	Item 4B	Proposals for RCPCH Honorary Fellows - 2006	Membership
3.	Item 5	Reply to Steve Smith (President of BRS)	Heather Maxwell
4.	Item 5	Join RA/BRS Programme Committee	Nick Webb
5.	Item 7A	Write to each module leader inviting them to form a working group	Heather Maxwell
6.	Item 9	Letter to Jane Verrity re Children's Renal NSF	Heather Maxwell / Maurice Savage
7.	Item 10	Letter to Nick Griffon regarding Speciality Codes	Heather Maxwell
8.	Item 12A	Letter to Steve Smith re Patient DVD	Heather Maxwell
9.	Item 16	Write to Chris Reid re BAPN Registries	Heather Maxwell
10.	Item 19	Contact Kate Verrier-Jones to clarify what information is not being returned.	Chris Reid
11.	Item 26	Update BAPN Membership List	Heather Maxwell