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BAPN Executive Meeting Minutes

*Friday 4th February 2005
 10.00 am to 1.00 pm*

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

1. Members Present

Heather Maxwell (Secretary)	Chris Reid	Sally Feather
Maurice Savage (President)	Henry Morgan	Sally Hulton
Rodney Gilbert		

Apologies

Nick Webb	Alan Dickson
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Alan Dickson has written to Maurice Savage saying that the British Association of Paediatric Urologists feels that it is not particularly useful for a member to attend every BAPN Executive meeting, but that the President would be happy to attend Executive Meetings if there were a urology item on the agenda. As of October 2004 Patrick Duffy is the new President of BAPU

The meeting welcomed Henry Morgan as the new trainee representative.

2. Minutes of the Previous Meeting

The minutes of the previous meeting were accepted as a true record. Clarification was requested on item 9 in regard to the definition of a "Learning Set". The definition as given in the last minutes is that outlined in an email from the Department of Health.

3. Matters Arising

These are dealt with in subsequent items.

4. RCPCH Meeting 19th April

report from N Webb

The nephrology session is on Tuesday April 19th and will start at 10.00am. There are 12 free communications divided into three sessions each of 1hr. 1 ½ hrs has been given to lunch, during which time there will be a short BAPN Business Meeting. There will only be two agenda items. The first is to discuss the future of UK Paediatric Nephrology Meetings and the second will be manpower issues.

5. BAPN Business Meeting

H Maxwell

The next BAPN Business Meeting will be held on Thursday 9th June from 10.30am – 1.30pm in Manchester to coincide with the BRS meeting.

6. Committee Representation

H Maxwell

It is not clear if BAPN members are representatives on each of the renal association committees. Heather Maxwell will contact John Fairley to clarify this situation. BAPN representatives on other committees were discussed and a list is attached.

7. Renal Association Council

M Savage

a) Standards

There are to be separate paediatric sections for updated standards on chronic kidney disease, complications of chronic kidney disease, dialysis, transplantation and on acute renal failure. We will ask one individual to head up a working group for each standard and will ask them to approach other BAPN members to help with the work. The workgroups should include at least one trainee. Heather Maxwell will write to David Wheeler to ask for more information regarding the standards. We are aware that the joint speciality committee on kidney disease have produced guidelines for the management of chronic kidney disease in adults and we are unclear at the moment as to how these will fit in with the Renal Association standards.

7. Renal Association Council

(contd ...)

M Savage

a) *Standards*

Chris Reid suggested that Sue Rigden might head up the guideline on chronic kidney disease and possibly also that of complications of chronic kidney disease, Lesley Rees has offered to head up the section on dialysis, Heather Maxwell the section on transplantation and Sally Feather and Henry Morgan the section on acute renal failure.

b) *Renal Unit Directory*

The Renal Association is producing a directory of renal units in the UK. Paediatric units are encouraged to submit their details for this registry and a reminder will be sent to all paediatric unit clinical contacts.

8. Manpower Planning

M Taylor

Mark Taylor wrote to Professor Savage at the end of January on the subject of manpower planning. He felt that it was clear after the BAPN Business meeting in December 2004 that for many units, concern about consultant manpower was not foremost in their mind. Several consultant positions are to be advertised this year, but it is clear that some units are having more difficulty in expanding their consultant numbers than other units. This is a particular issue for those units where there is no backup from academic staff. Mark was also concerned at the lack of appointments for academic consultants.

Mark Taylor will send out a postal survey of staffing to get up-to-date data on manpower numbers.

9. Update on NSF / 'Learning Sets'

H Maxwell

Part 2 of the renal NSF has just been published. Not all members had received a copy at the time of the executive meeting.

10. BRS

H Maxwell

a) *Criteria for success*

The most up-to-date version of criteria for success is out for consultation at the present time. All members of the executive committee were asked for their comments on this document and for these to be sent to Jane Tizard by the end of February.

10. BRS (contd ...) **H Maxwell**

b) Renal Workforce survey

Jane MacDonald, Vice President of the BRS, has expanded the renal registry workforce survey and sent this round for comments. The survey refers to adult renal units but it was felt appropriate that paediatric units should be included. Chris Reid will liase with Jane MacDonald re this.

11. Registry Committee **C Reid**

The paediatric chapter for the 2004 report is now out. Chris Reid asked for comments from the Executive Committee as quickly as possible as it is hoped to have the chapter out to the membership to provide comments by the end of February.

Chris Reid asked that data for the 2005 report be provided by the end of February 2005.

It is hoped that 2-3 units with the Proton system already up and running will go on to provide automatic downloads to the renal registry within the next 12mths. Data will be sent in quarterly and will be an average of all of the data held in the system.

For those units who are having difficulty getting up the Proton system it is hoped that Jane Verrity will press commissioners to say that this is mandatory. Unfortunately trusts have many financial pressures on them at the present time.

The renal biopsy audit has been circulated and filled in by several units. Those who have not yet filled in the questionnaire are encouraged to do so. All units are asked to send in audit forms after each biopsy. Some units are batching these forms. A second audit is being planned and is thought to concentrate on anaemia management.

Malcolm Lewis is working on a CD to provide each unit with their own data and anonimised data for the whole of the UK. It is hoped that this may be ready by the end of February. It is hoped also that there will be publications from the BAPN registry. The Executive Committee will thank Malcolm Lewis for all of his hard work.

12. NICE Update

a) Immunosuppression

H Maxwell

Heather Maxwell and Nick Webb represented the BAPN and RCPCH at a meeting of the Health Technology Appraisal on Immunosuppression in Renal Transplantation in Children and Young People. As there is very little randomised controlled data for NICE to use for this HTA therefore, in addition to considering that information, NICE will also look at other data from paediatric studies to determine baseline risks and then apply treatment effects from the results of adult based RCT trials.

13. NICE Update (contd...)

a) Immunosuppression

H Maxwell

It is unclear whether this approach has been validated and is indeed appropriate in children. Similarly cost-effectiveness data will use adult utility scores and adjust them for children. This approach would seem to ignore the effects on parents and siblings, the effect on education and again does not seem a particularly valid approach for children and young people. Rodney Gilbert had been contacted by the BKPA to say that NICE had asked the BKPA to find families to be consultees. Southampton and Birmingham may have families who would be willing to take part.

b) Anaemia in Renal Failure

Not discussed

c) UTI in Childhood

Not discussed

13. UK Transplant

H Maxwell

a) Allocation Taskforce

A sub-group of KPAG have devised a new algorithm for allocation of cadaveric kidneys. This takes into account age, waiting time, matchability and cold ischaemic time. The proposed allocation scheme is out for consultation at the moment and will be discussed at the renal service users meeting at the Royal College of Surgeons on Monday 7th March. Heather Maxwell will distribute the allocation scheme to all clinical contacts.

b) Equity of Access to Transplantation

A separate KPAG working group looked at access to transplantation. For adult patients this was influenced mainly by cardiovascular status and cardiovascular investigations. Whilst much of this data does not apply to paediatrics, it is important for all units to show that patients have equity of access to transplantation. Units will therefore monitor:

- 1) The percentage of dialysis patients who are active on the cadaveric list
- 2) The time from starting dialysis to being listed
- 3) The percentage of transplants that are pre-emptive
- 4) The percentage of transplants that are LRD
- 5) Criteria for non-listing

Chris Reid has agreed to take on points 1-4 through the BAPN registry with the help of UKT.

13. UK Transplant (contd....)

H Maxwell

c) Centre-Specific Data

C Reid/H Maxwell

UKT already publish centre specific data for adult units. This will also happen for paediatric units, although competent intervals for such data are likely to be very large. The registry committee are working with UKT in this regard.

14. Research Update

report from N Webb

The C2 studies have recruited a total of 66 patients. Guys will shortly commence recruitment to boost numbers further.

The Nephrotic Syndrome Steroid RCT will commence recruitment in the near future. There have been some personnel changes and the study is now to be run from Great Ormond Street Hospital.

The national lipid audit is now complete and abstracts for this have been accepted for both the BTS meeting and the RCPCH meeting.

15. Renal Information Strategy

M Savage

Kate Verrier-Jones is trying to put together a list of high-quality information for children with renal disease and their parents, which can be available on the internet. Kate is approaching all units to collate information.

16. National Electronic Library for Child Health

H Maxwell

Lesley Rees attended a meeting on this electronic library on behalf of the BAPN. There is a site for nephrology within the library and gaps within this need to be identified. Similarly links to other sites need to be added, such as the NSF for nephrology, a link to the BAPN national registry, to the renal association standards document, BTF guidelines, living donor guidelines, "human bodies -human choices", Cochran and NICE reviews, the BAPN website, the ASPN website, UK transplant charities and other patient groups. Topics have to be nominated. Sally Feather has agreed to co-ordinate this process on behalf of the BAPN executive. She will liase with Lesley Rees in getting this information back to the national electronic library for child health.

17. Treasurers Report

R Gilbert

Balance at the start of financial year 2004/05	£5,713.95
Subscription income	£2,660
Other Income	£400
Expenses	£1986.84
Balance as of 30.09.04.	£6,784.11

17. Treasurers Report (contd ...)

R Gilbert

The need to formalise membership application and membership data was discussed. Heather Maxwell will distribute application forms to all current members and continuing members.

18. Trainee Issues

H Morgan

Henry Morgan reported that the European Working Time Directive is having an effect on the time trainees are spending in nephrology as opposed to general paediatrics and the trainees are doing a survey to document this.

Presentations from the training days need to be placed on the BAPN website.

19. UK Bid for ESPN 2008

M Taylor

Birmingham are keen to host the ESPN 2008, but are awaiting a decision on this to be made at the ESPN meeting in Istanbul this year. The renal association had been approached to have a joint meeting with the ESPN in Birmingham in 2008, but this is not possible.

20. Forthcoming Meetings

- a) RCPCH (19th April 2005) - Discussed previously
- b) The Renal Association and BTS are hosting a joint meeting in Belfast 5-8th April 2005.

21. Membership Lists

Discussed as part of the treasurers report

22. AOCB

There was no other competent business

23. Date of Next Meeting

6th May 2005

Action Points

			<i>Action</i>
1.	Item 6	Contact John Fairley to clarify committee representation situation	Heather Maxwell
2.	Item 7a	To write to David Freeler	Heather Maxwell
3.	Item 7b	Units to submit their details to the Renal Association Directory of Units	All
4.	Item 8	Postal survey of staffing	Mark Taylor
5.	Item 10b	Chris Reid to liase with Jane MacDonald re renal workforce survey	Chris Reid
6.	Item 13a	Distribute the allocation scheme to all clinical contacts.	Heather Maxwell
7.	Item 16	Liase with Lesley Reece in getting this information back to the national electronic library for child health	Sally Feather
8.	Item 17	Distribute application forms to all current members and continuing members.	Heather Maxwell
9.	Item 18	Distribute application forms to all current members and continuing members.	Henry Morgan