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BAPN Executive Minutes

Friday 3rd February 2006

Royal College of Paediatric & Child Health, London

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|---------------------------|---|---|
| 1. Members Present | Kate Verrier-Jones
Simon Waller
Mark Taylor
Heather Maxwell (secretary)
Sally Feather | Sally Hulton
Chris Reid
Maurice Savage (President)
Nick Webb
Rodney Gilbert |
|---------------------------|---|---|

No apologies were received; all members were present

2. Minutes of the Previous Meeting

Minutes of the previous meeting were accepted as a true record.

3. Matters Arising

RCPCH Spring Meeting

The Nephrology Day this year will be held on Tuesday 4th April between 1000-1700hrs. There are two invited sessions; there will be a debate in the morning entitled 'All Children with Bacterially Proven Urinary Tract Infections Should Undergo Radiological Investigations' with a proposer and opposer. The debate will be recorded and transcripts submitted to Archives of Disease in Childhood. There will be a talk in the afternoon; Sally Feather is going to present progress on the Oro Facial Digital Syndrome.

There will be a Business Meeting between 1215-1400hrs

4. Committee Representation

Joint Specialty Committee

Lesley Rees has previously represented the BAPN on this Committee. Professor Savage will take over and will attend the meeting on 15th February. The minutes of the last Joint Specialty Committee Meeting were reviewed and further information was requested on the Renal Workforce Review Team. Heather Maxwell will contact Patti Monkhouse at the BRS to obtain further information.

Action: **HM**

5. NSF for Renal Services

A Paediatric Renal Services event was held on 12th January. Jane Tizard, Jonathan Evans and Sally Feather attended this meeting and took part in workshops on palliative care, antenatal care and transition. The meeting was also attended by a number of other people who are not known to the Paediatric Nephrologists who attended. Unease was expressed that so much work is being done on the pathways of care for paediatric renal patients without a great deal of input from either the BAPN or individual paediatric nephrologists. Considerable discussion took place as to how much involvement the BAPN should have with a process such as this, to which the BAPN has had little contribution. The BAPN produced a document in 2003 entitled A Review of Multi-professional Paediatric Nephrology Services in the UK, to which there was little response. It was felt appropriate that Mark Taylor, as future President, Maurice Savage and Heather Maxwell should meet with John Feehally, President of the Renal Association, to discuss the best way forward for the BAPN. Should we align ourselves with the NSF or put further work into developing the previous report of 2003?

A further meeting relating to the NSF is to be held on 23rd March on Acute Renal Failure. Sally Feather and Nadeem Moghal will attend this meeting.

6. Warner Review of Specialist Services

Lord Warner is reviewing commissioning arrangements for specialised services and as such a questionnaire was produced at the end of last year asking for views on the commissioning arrangements for specialised services. This document came to the attention of the BAPN through Chris Rudge at UK Transplant, and Jane Tizard who has taken a lead in involvement in Payment by Results, responded on our behalf. The questionnaire merely asked for positive aspects, negative aspects and ways of improving commissioning arrangements by LSCG's, SCG's and national commissioning by NSCAG.

7. Adolescent Services

There are various initiatives taking place reviewing transition of paediatric patients to adult services and of adolescent services in general. This is one of the work streams of the recent NSF Paediatric Renal Services Meeting, there is a National Transitions Conference being run by the Department of Health at the Royal College of Physicians on 23rd March where there will be the launch of the guidance document "Good Transitions for Young People" and there is also a project being taken forward under the auspices of the Royal College of Physicians in Edinburgh.

8. Changing Face of Renal Medicine in the UK

Heather Maxwell presented evidence to this Committee in December 2005. This group are producing a document looking at the future of renal medicine and a draft of that document is due out shortly.

9. Renal Association Council

There have been no further meetings of the Renal Association Council since the BAPN Business Meeting. Rodney Gilbert is the BAPN Representative on the Clinical Standards Committee for producing patient information sheets. There is a need to produce paediatric patient information sheets and Rodney will circulate the membership for examples of patient information sheets. Further discussion took place as to the advantages of having patient information sheets which were agreed by the BAPN membership and which appeared with the BAPN logo. It was felt that this could be extended to guidelines but clearly would require a considerable amount of work.

One of the elected pieces of work that has been carried out is the reporting of creatinine as an estimated GFR. Discussion took place as to the best way of dealing with this in children and it was felt that it was appropriate for the CKD group under Sue Rigden to look at this issue as part of their Renal Association Clinical Practice Guidelines for the Management of Children with CKD.

10. Renal Association Standards Committee

Sally Feather updated us with this process. The adult groups have yet to finalise their guidelines and once this is done paediatric guidelines will be developed.

11. Registry Committee

Considerable discussion took place at the BAPN Business Meeting in December 2005 as to the way forward for the BAPN Registry. There has always been an assumption that the BAPN Registry would amalgamate with the UK Renal Registry once electronic downloads were available in each centre. In the meantime efforts were being made to work more closely with the adult renal registry and indeed to send them a copy of the Registry as it stands.

The BAPN and the BAPN Executive are aware that the Registry would not be where it is today without the considerable efforts of Malcolm Lewis and the Executive Committee are very grateful to Malcolm for all his efforts to date.

We are aware however of the increasing need to ensure patient confidentiality, to obtain patient consent and for management of databases that it would be more appropriate for the database to be held in Bristol. Chris Reid has discussed this with Malcolm Lewis, although to date no progress has been made. Chris Reid will discuss with David Ansell whether it is possible for returns to be submitted to the UK Adult Renal Registry in the meantime while we await electronic downloads.

Registry Committee Contd

The chapter for the UK further registry report is not yet available but we understand that Malcolm Lewis is in a position to submit this to the Registry Committee shortly.

12. Information Strategy

Kate Verrier-Jones discussed the work of the RIXG. Kate will circulate the minutes to the Executive members. Kate is working with "Communicating for Health". They are developing IT for several areas. The first relates to direct patient care and this involves the national spine of services provided by 5 local providers (LSP's) The LSP's will provide local assistance (which may or may not interface with current systems). It is hoped to have the national spine in place by 2007 such that it will be possible for patient's casenotes to be available wherever they are in the country. Also under direct patient care is development of renal patient view where patients can access their own data on the internet.

One of the other work streams is that of secondary purpose, which involves information for example for registries. The work of the dataset comes under this heading.

Another area of that is patient information and Rodney Gilbert will contribute to collate paediatric patient information from the various units. It is hoped to provide paediatric patient information in a web based form and we will consider asking the NKRF to host the paediatric information under the auspices of the BAPN with a link to the BAPN website. The National Electronic Library for Health also comes under this and there is going to be a renal specialist library and we understand that money is available for this. Sally Feather will contact David Goldsmith in this regard.

Action: SF

The 4th work-stream relates to that of training for personnel who will be involved in patient IT.

13. Payment by Results

Work continues on the development of payment by results. There are three codes involving renal problems. The 1st is that of renal disease, the 2nd renal disease associated with renal failure and the 3rd renal disease associated with renal failure where there are complications. There are also codes for length of stay and for patients who involve high dependency. A lot of the detail still requires to be worked out and at the present time thresholds have not been established. There is considerable anxiety that failure to determine appropriate thresholds will result in some units being unable to survive.

14. Manpower

Heather Maxwell again discussed the feasibility and the need to develop a generic job plan for paediatric nephrologists. There was little enthusiasm for this at the present time.

15. British Renal Society

There have been no further meetings since the last BAPN Executive. There was nothing new to discuss.

16. **Kidney Alliance**

Nick Webb attends the Kidney Alliance on behalf of the BAPN. There was nothing related to paediatric practice other than eGFR which was discussed above.

17. **NICE Update**

a) **Immunosuppression**

The Appraisal Committee for this HTA met on 25th January 2006. The Final Appraisal Determination will be released during the week commencing 6th March 2006. Heather Maxwell and Nick Webb have contributed to this on behalf of the BAPN and the RCPCH.

b) **Anaemia in Renal Failure**

Jonathan Evans has circulated the draft guidance for anaemia management in chronic kidney disease along with his draft comments to the guideline. Members are asked to respond to Jonathan by 20th February 2006.

c) **UTI in Childhood**

Kate Verrier-Jones is chairing this guideline development group. They have held 8 out of a total of 15 meetings so far, with a view to the guideline being developed by May 2007.

18. **UK Transplant**

The next renal transplant services meeting is to be held on Wednesday 8th February 2006. The new allocations system will be introduced as of 3rd April 2006 and an allocation review group is being brought together. This group will meet on Friday 3rd March 2006.

19. **Research Update**

Nick Webb gave an update of the Nephrotic Syndrome trial. Rachel Cook in Birmingham is helping centres to obtain ethics approval. Rachel can be contacted at r.a.cook@bham.ac.uk.

20. **ESPN Report**

Allan Watson has sent in a report. The ESPN meeting this year will be held in Palermo from 7th – 10th October. Abstracts require to be in by 14th April and there is a reduced fee for early registration. There is going to be a workshop on training issues and Mary McGraw, Sally Hulton and Nadeem Moghal will take part in this.

21. **Treasurers Report**

Total Income	£6,510
Expenditure	£3,447.53

Treasurers Report Contd

For the financial year 2005-2006 the account has increased from £6,265.07 to £9,327.54. Some members are still paying the reduced subscription fee and Rodney Gilbert will write to all members in this regard.

22. Trainee Issues

Simon Waller is the Trainee Representative for the next year. The trainee account requires to have the signatories changed and a decision has been taken to have younger members as signatories for the account in an effort to prevent so many changes.

The BAPN web page is being updated, the training days continue to be very valuable and a decision has been taken to invite some local trainees to attend to increase the interest in nephrology from pre-grid trainees. Considerable discussion took place in this regard as there was concern that this would increase the numbers considerably and reduce the specialist nephrology component of the days, but executive members were reassured that this would not happen. At the present time there are links to the old logbook and curriculum from the web page and as soon as the new curriculum has been released the web links will be updated.

Further to previous discussion on BAPN guidelines, it was felt that the website could be used as a resource and that trainees could contribute to guideline development.

At the ESPN this year there will be a trainee satellite symposium and it is hoped to continue this at future ESPN meetings.

23. Medicines for Children

The UK Medicines for Children Research Network has its national centre in Liverpool and 5 satellite centres throughout the country. This set-up is entirely for research, mostly for medicines but it may also cover other interventions. There are specialty sub-groups within the Medicines for Children's network and renal medicine is part of the rheumatology/allergy/nephrology/immunology/infectious diseases sub-group. A teleconference has been held and Nick Webb has participated on our behalf. The network has a substantial budget and infrastructure support system to allow research to take place. In the future it was felt that trials such as the current Nephrotic Syndrome trial could be carried out through the network.

24. Forthcoming Meetings

RCPCH Nephrology Day	-	Tuesday 4 th April 2006
Renal Association/BRS Meeting	-	3 rd -5 th May 2006

25. AOCB

The BPSU have written to the paediatric specialty groups asking if there are any projects that they would wish to have taken forward through the orange card reporting system.

26. Date of Next Meeting

To be held during the BRS/Renal Association Meeting on 3rd – 5th May 2006.

4	Contact Patti Monkhouse at BRS to obtain further information on the Renal Workforce Review Team	HM
5	MT, MS and HM to meet with John Feehally to decide on BAPN approach to the work of the NSF	MT
9	Collection of current patient information sheets and development of national 'BAPN' patient information sheets	RG
11	Discussions with UK RR on submitting paediatric data directly to the UK RR	CR
12.	Contact David Goldsmith re development of renal specialist library	SF