

<p><b>President: Prof Maurice Savage</b>          Royal Belfast Hospital for Sick Children          Tel: 028 90 272183          Fax: 02890 330571          Email: m.savage@qub.ac.uk</p> <p><b>Secretary: Dr Heather Maxwell</b>          Royal Hospital for Sick Children, Glasgow          Tel: 0141 201 0123          Fax: 0141 201 0859          Email: heather.maxwell@yorkhill.scot.nhs.uk</p> <p><b>Treasurer: Dr Rodney Gilbert</b>          Southampton General Hospital          Tel: 02380 798809          Fax: 02380 794750          E-mail: rodney.gilbert@suht.swest.nhs.uk</p>	 <p><a href="http://www.uwcm.ac.uk/uwcm/ch/bapn">www.uwcm.ac.uk/uwcm/ch/bapn</a></p>
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## **BAPN Executive Meeting**

Friday 7<sup>th</sup> October 2005

**10.30 am to 1.00 pm**

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

### 1. Members Present

Heather Maxwell (Secretary)	Maurice Savage (President)	Nick Webb
Kate Verrier Jones	Chris Reid	Sally Feather
Rodney Gilbert		

### Apologies

Sally Hulton	Henry Morgan
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### 2. Minutes of the Previous Meeting

These were accepted as a true record.

### 3. Matters Arising

#### a) RCPCH Meeting

Nick Webb has been negotiating with the Royal College to have an extended nephrology session at the next RCPCH meeting, which will be on Tuesday 4<sup>th</sup> April and will run from 1000 – 1700 hrs. Discussion took place as to whether

there should be a Guest Lecture and the issue of plenary abstracts of relevance to general paediatricians. These abstracts would be scheduled for before 1500hrs.

b) National Electronic Library for Child Health

No further information has been received regarding this and the process seems to have ground to a halt. Kate Verrier Jones will contact Muir Gray to find out what is happening and Sally Feather, who is our NELH Representative will contact David Goldsmith to find out more information.

**4. Committee Representation**

A list of BAPN representatives on various committees is attached. Rodney Gilbert has not yet been able to attend any of the Clinical Services Committee meetings but hopes to be able to attend the next one.

The Royal College of Physicians have a Committee on the Future of Renal Medicine to which Professor Savage has been invited.

**5. Proposals for Future Executive Members**

A few nominations have been received and a further reminder will be sent to BAPN members.

**6. Renal Association Council**

There is nothing further to report since the last meeting.

**7. Renal Association Standards Committee**

Sally Feather has been in touch with David Wheeler to discuss the development of Renal Association Standards. Work is progressing within the adult groups and Sally Feather was advised to wait until their work had progressed. The Executive Committee felt that it was important that there was paediatric involvement from the beginning and Sally Feather will contact David Wheeler to try and take this forward.

**8. Registry Committee**

All of the 2004 data has been received except for a few patients from Belfast. The report will focus on posterior urethral valves, co morbidity, dialysis access and those children who have been on dialysis for more than 3yrs.

Chris Reid will discuss with the Renal Registry when it may be possible to commence electronic submissions from paediatric units. There is an issue in terms of validating submitted data. It would appear that at the present time approximately 6 of the units could possibly download data electronically. It was noted that the Renal Registry has received £30,000 of funding to assist progress in amalgamating the adult and paediatric registries.

It would seem that different units have different screens and that the BAPN screens that have recently been added to assist with submission of data to the Registry may not encompass all of the fields required. Chris Reid will contact Vital Pulse to discuss which screens are necessary to ensure that all data required can be downloaded to the Registry.

Considerable discussion took place regarding the running of the BAPN Registry at present. Malcolm Lewis's input into the Registry has been vital and the Executive Committee appreciate and are very grateful to Malcolm for his contribution to the Registry.

Discussion took place regarding the need for statistical advice/validation, of the need for units to have access to their data and to be able to perform a comparison with UK data and the need for more regular publications over and above the registry report. The plan was that each unit would receive a CD with their own data and the UK average data but this has not yet happened.

This years audit project has been of Renal Biopsies and next years project is going to be Blood Pressure in Transplant Patients. Larissa Kerecuk and Manish Sinha have agreed to develop an audit protocol for this.

Discussion also took place regarding the diagnostic codes, which are used in the BAPN Registry. These have been developed from EDTA codes and a list was made available to the Executive Committee. Jane Tizard and Malcolm Lewis will take this forward with the European Registry to see if it is possible to develop European agreement over diagnostic codes.

We will ask other BAPN registries for an update from the Cystinosis and Hyperoxaluria.

## **9. Information Strategy**

Renal Information Strategy Parts I and II have been developed in parallel with Parts I and II of the NSF. Kate Verrier Jones updated us on the Information Strategy and this information has already been summarised by Kate and will be appended.

Previously we have dealt with Jane Verity at the Department of Health but she has been replaced by Joe Lynch as she is taking a career break. The best point of contact in the department is Tina Lee.

There are many aspects to the Information Strategy including sections for patient information and the national electronic library for health. There is some paediatric information available but work is required in this area.

Diane Stafford who is a journalist has been asked by the Department of Health to write an update of children's issues for the Renal NSF. She has been in touch with Kate Verrier Jones and Heather Maxwell. It was felt that with the change in the staff at the

Department of Health that it would be appropriate for Maurice Savage to contact Joe Lynch through Tina Lee. A further area within the Information Strategy is the Renal Data-set Development Group. There has been some confusion as to who represents the BAPN on this group but Chris Reid is our Representative. The next meeting is on 14.10.05. but Chris Reid is unable to attend this meeting. It is hoped that Jane Tizard will be able to attend the meeting, which is in Bristol on behalf of the BAPN.

## 10. Specialty Codes

Funding for services including paediatric nephrology services is going to be based on a national tariff. There are few codes available at present and funding for these do not appear to reflect the required activity. Clearly this is something that needs to be addressed. The new system will not be operational for paediatrics until 2008. Jane Tizard will update the BAPN at the December Business Meeting.

## 11. Manpower

Heather Maxwell suggested that it would be helpful to have a “typical” job plan for a Paediatric Nephrologist in terms of the number of patients seen in clinics and therefore the number of clinics required for the size of the service, then the average amount of time spent on admin. There was little support for this but it was felt appropriate to discuss it further at the next BAPN Business Meeting.

## 12. BRS

### a. Patient DVD

Jan Dudley is involved with the group developing the patient DVD and we will ask for an update at the BAPN Business Meeting.

### b. Criteria for Success

This is due to be discussed at the BRS Council Meeting next week and an update will be given at the BAPN Business Meeting.

### c. BRS / RA Meeting Harrogate 2006

The British Renal Society Meeting will be held jointly with the Renal Association in Harrogate between 3<sup>rd</sup>-5<sup>th</sup> May 2006. Trainees who submit abstracts for the RCPCH meeting in York will be encouraged to submit them for the BRS/RA Meeting.

## 13. Kidney Alliance

Nick Webb attends the Kidney Alliance meetings on behalf of the BAPN. Payment by results (which is linked to specialty codes) appears to be on hold at the moment. Initially it had been hoped to introduce this for elective procedures but there are some hospitals who appear to have withdrawn from this completely. We await further information.

## 14. NICE Update

### a. Immunosuppression

The assessment report has now been produced and Heather Maxwell and Nick Webb have replied to this slightly on behalf of the BAPN and RCPCH. The report is restrictive in terms of its recommendations for immunosuppression in children and appears to rely greatly on economic models which we are uncertain have been validated for paediatric use.

An addendum has been produced and a response is required to this shortly. Within the addendum the issue of side effects has been addressed and there appears to have been an error in the original economic analysis which has changed the results. The recommendations from this are slightly less restricted than the last report but do shed further concern as to the usefulness of these economic analyses for children.

### b. Anaemia in Renal Failure

Jonathan Evans provided an update. All of the evidence has been agreed by the Guideline Development Group and evidence statements developed and agreed and the draft is being written, which will be discussed at the next Guidelines Development Group meeting at the end of October. Following this a further literature search will be performed to pick up any new publications. The advice will then be put out to stakeholders at the beginning of next year. The hope is to have a separate paediatric introduction but to incorporate paediatric and adult guidelines together with separate points for children where necessary. A further report will be requested for the BAPN Business Meeting.

### c. UTI in Childhood

The Guideline Group are continuing to meet. The first meeting was held in May and the group has met monthly since that time and will do so until August of next year. Kate Verrier Jones chairs this group and will keep us updated with its progress. It is thought that the guideline will eventually be published in April 2007.

## 15. UK Transplant

### a. New Allocation System

Heather Maxwell discussed the new allocation system, a copy of which is appended. Further work is required and the new allocation system will not be operational for several months.

### b. Centre-Specific Data

This is now available for all paediatric units on the UKT Website where individual units data are compared to the national average.

The BAPN also chose to look at access to transplantation as well as transplant outcome. Chris Reid asked Phil Pocock at UKT to provide data relating to the time from the start of dialysis to the time of listing for transplantation. There is clearly considerable variation between the units. There was concern that this data did not take account of children who for valid reasons could not be listed for some time, but there is preliminary data which requires further work. It was felt that it was appropriate to do further work on this data. Heather Maxwell will discuss with Phil Pocock as we are keen for each of the units to be identified.

#### **16. Research Update**

Nick Webb provided an update on research. There has been progress with the nephrotic syndrome trial and a research nurse has been appointed in Birmingham. It is hoped to have all units up and running shortly. The research nurse will help with LREC applications.

A project is starting looking at renal failure in patients on ECMO.

An expanded Research Meeting will be held along with the Business Meeting in December and there are spare slots for proposals at the present time.

#### **17. ESPN Report**

Allan Watson provided an update. He has encouraged BAPN members to join the ESPN, particularly all new consultant appointments. ESPN fees are to be paid directly to Peter Hoyer in Germany.

The next ESPN meeting will be held in Palermo between 7<sup>th</sup>-10<sup>th</sup> October. The ESPN members will have a reduced registration fee. Mark Taylor's bid for the ESPN to be held in Birmingham was successful for 2009.

The ESPN are focussing on training this year, and it is important for CSAC to be aware of that.

#### **18. Treasurers Report**

The balance for 2005/06 is £9,105.07. Income is exceeding expenditure and the balance is therefore healthier. The income however is still not as great as expected and there are some members who are not paying the increased membership fee.

#### **19. Trainee Issues**

These were not discussed in detail as Henry Morgan was absent. Sally Hulton informed us that the training syllabus now has to be altered to meet with the College format and this will take place at a meeting on 18<sup>th</sup> October. The trainees page on the BAPN website is out of date and requires to be updated. The trainees also owe the BAPN main account £222.

#### **20. Medicines for Children Network**

Liverpool won the opportunity to be the main hub for the above network. There will be 5 satellite centres and Nick Webb will find out more about this from Roz Smith in Liverpool who was involved in the successful bid for the main hub. William van't Hoff has asked to put in a bid for nephrology, but we are unsure as to how this would sit with the role of the BAPN Research Secretary. Nick Webb will report back to us.

#### **21. Adolescent Health**

The RCPCH have asked us to keep this on the agenda. There is information relating to care of adolescents with renal disease in the Welsh NSF and the recent UKT data showing pro-transplant outcome for adolescents highlights this as an important issue for us. It will be kept on the agenda.

#### **22. Membership Lists**

This has not yet been updated but requires to be done. The membership will be sent a letter checking contact details and also checking that they are paying the correct membership fee.

#### **23. AOCB**

Merit Awards were discussed. BAPN nominations for 2006 require to be in by November.

#### **24. Dates of Next Meetings**

03.02.06.	RCPCH London
05.05.06.	Harrogate
13.10.06.	RCPCH London

## Action Points

			<i>Action</i>
1.	3b	Update on national electronic library for health	Kate Verrier Jones
2.	3b	Contact David Goldsmith to find out more information on the national electronic library for health	Sally Feather
3.	7	Contact David Wheeler regarding paediatric involvement with the Renal Association Standards Committee	Sally Feather
4.	8	Contact Vital Pulse to find out which screens are necessary for downloading information to the Registry	Chris Reid
5.	8	Discuss with European Registry re possibility of developing European agreement over diagnostic codes	Jane Tizard Malcolm Lewis
6.	15b	Provide data relating to time from the start of dialysis to the time of listing for transplantation.	Chris Reid
7.	15b	Discussion with Phil Pocock re identification of individual units data.	Heather Maxwell