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## BAPN BUSINESS MEETING MINUTES

**Thursday 9<sup>th</sup> June 2005, 1030 - 1330**  
**The Boardroom, Royal Manchester Children's Hospital**  
**Pendlebury from 10.30-13.30**

**Members Present:** Maurice Savage (President)    Nick Webb    Heather Maxwell (Secretary)  
 Detlef Bockenbauer    Caroline Jones    Kay Tyerman

**Apologies:**

Mary McGraw	Heather Lambert	Steve Marks
Jane Deal	Nadeem Moghal	Sue Rigden
Jane Tizard	Martin Christian	Chris Reid
Alan Watson	Jean Smellie	Colin Normand
Fareda Hussain	Dick Trompeter	Lesley Rees
Jon Evans	David Hughes	Mike Dillon
Ian Ramage	Jim Beattie	Anna Murphy
Carol Inward	Jan Dudley	Dennis Gill
Mary O'Connor	Judy Taylor	Sally Hulton
Adrian Woolf	Kate Verrier-Jones	Milos Ognjanovic
Malcolm Coulthard		

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

These were accepted as a true record.

## 2. Future Meetings

The first Clinico-pathological Meeting is due to be held in October and Paediatric Nephrology has agreed to publish the proceedings with one of the presenting juniors of the lead author.

It is proposed to change the timing of the BAPN Business and Research Meetings. Nick Webb has written to the Academic Secretary of the RCPCH to ask that the Nephrology Day at York can be expanded to allow more presentations and to allow a 2hr business meeting. A response is awaited from the college. An expanded Business Meeting in York would then allow us to have just one further Business Meeting each year, which we would propose would be in December as usual. Again it is hoped to have this as an expanded meeting with a meal to be held the night before to allow an early start. There will be a Business Meeting and a Research Meeting on this day.

<b>Dates of future meetings:-</b>	<b>[BAPN Executive Meeting</b>	<b>07.10.05. RCPCH, London]</b>
	<b>Surgical Challenges Meeting</b>	<b>11.11.05. Nottingham</b>
	<b>BAPN Business Meeting</b>	<b>09.12.05. ICH, London</b>

## 3. BAPN Executive Office Bearers

To allow continuity, it is proposed that the next BAPN President should be decided 1yr in advance to allow overlap with the outgoing President. This is also proposed for the Secretary's post. The term for the next President runs from May 2006 – May 2009 so nominations are requested prior to the Business Meeting in London in December.

The President, Secretary and Research Secretary all serve for 3yrs. The next Research Secretary will take up post in April 2006 and the next Secretary in April 2007. Nominations for BAPN President should be sent to the Secretary by the end of November 2005.

## 4. Levamisole

Levamisole is now available through Durbin, who are a generics importer, and who are obtaining the drug from Belgium. The Import Manager for Durbin is Tim Harrington who can be contacted on 0208 869 6500. This has been approved by the MHRA and is available now. It was noted that the Dutch are planning to hold a randomised controlled trial of the use of Levamisole which will be discussed at the general meeting at ESPN in Istanbul.

## 5. Renal Association

a) **Standards Committee** - No report was available from this Renal Association Committee. Leads have been appointed for each of the 5 clinical practice guidelines and members wishing to contribute to these should contact the Leads as per the minutes of the Business Meeting (19.04.05.). Sally Feather, who sits on the Standards Committee, will be asked to update us about its activities.

- b) **Renal Unit Directory** - Units are reminded that their details can be lodged on the Renal Association website.

## 6. NSF

Further to the discussions held at the Business Meeting in April, Maurice Savage and Heather Maxwell will write to Jane Verrity and Donal O'Donahugh in regard to developing a paediatric element to Part II of the NSF.

## 7. Information Strategy

- a) Kate Verrier-Jones provided a report on IT issues for paediatric nephrology (previously circulated).
- b) The Renal Information Exchange (RIX) Group continue to meet and work on renal patient view. A development is taking place in Leicester called "Do Once & Share" which is looking at information requirements for nephrology. This is part of an information implementation programme for the National Programme for IT (NpFIT). It is uncertain as to whether this covers paediatric nephrology and the executive will write to Jane Verrity to clarify this issue.
- c) Kate will be the RCPCH Rep on the Choose & Book programme.

Kate is starting a part-time secondment with the NpFIT working on the PSIS (National Spine) as of the beginning of August.

## 8. Registry Committee Report

No report was available. We will ask Chris Reid to update us as to progress to date of submission for the 2004 Registry Report. We are unsure as to how many units are in a position to submit data electronically, but we are aware that not all Proton units have the necessary screens for this e.g for Virology. We will ask Chris Reid to contact Vital Pulse as presumably many units have the same requirements for these new screens.

## 9. EDTA Registry Report

An official paediatric sub-group of the European Registry is being set up and Malcolm Lewis will be invited onto this group. There are currently 11 countries submitting basic paediatric data and an additional 4 units are submitting more comprehensive data (UK, Italy, France and Turkey). Another two countries may start submitting more comprehensive data soon.

There is a new adult initiative called The Quest Project (Quality Improvement in Renal Care) for which an application form has been submitted. This study collects clinical performance indicators, which is more detailed than the data collected by the European Registry, but similar to that collected by the UK Adult & Paediatric Registries. If this application is successful it could support development of the infrastructure for collecting this data in some other European

countries where this is lacking at present. It is hoped that other paediatric renal units in Europe will be included in this. This would allow a seamless transition between the paediatric and adult registries.

## **10. BRS**

### **a) *Patient DVD***

Jan Dudley has agreed to represent the BAPN on this project.

### **b) *Criteria for Success***

Part 1 of this project has now been published and Part 2 is in progress.

It is noted that next year the BRS annual meeting will be held jointly with the Renal Association. It is hoped that paediatric abstracts submitted to the RCPCH meeting in York will also be submitted to this meeting, which is to be held in Harrogate.

## **11. UK Transplant**

A copy of the new proposed allocation of deceased donor organs will be forwarded. For younger patients (including paediatric patients) the emphasis is on matching with a view to avoiding sensitisation, whereas for older patients the emphasis is on reducing waiting time. The proposed allocation system would allow considerably better matching for paediatric recipients with up to 95% of patients receiving a 000 mismatch or favourably matched organ (Current scheme = 71%). The cost of this would be an increase in median waiting time of approximately 1-2mth. To a certain extent this increased waiting time could be offset by prompt listing of paediatric recipients.

## **12. Kidney Alliance**

Nick Webb attends the Kidney Alliance meetings on behalf of the BAPN. The major issue discussed was that of payment by results. This is currently being piloted by First Wave Foundation Trusts. From 1<sup>st</sup> April 2005 only elective work is covered by this scheme. There are supposed to be supplements for specialist paediatric activity and an up-lift for other paediatric activity. Despite this, the tariff for an adult renal transplant is £4,500 greater than that for a child. It is unclear as to how these figures were generated but clearly they do not take into account the increased work needed in looking after children receiving renal transplants. Nick Webb will investigate this issue further.

In relation to this, speciality codes have been developed to allow payment by results. A code for paediatric nephrology has been developed but is at a "Treatment Function Code". Inpatient and Outpatient HRG's have been developed for renal disease in children <18yrs and payment by results will fix a tariff for them, which will probably vary between secondary and tertiary units. Jane Tizard has been involved with this within her own trust and is also taking this forward on behalf of the BAPN.



The Research Secretary is keen to receive new proposals, which can then be discussed at the Business Meeting on 9<sup>th</sup> December.

**17. Treasurer's Report**                      None received

**18. ESPN Report**

Trainees are encouraged to attend the ESPN Meeting in Istanbul and it is noted that there is a Fundamentals of Renal Replacement Therapy course being held on Saturday 10<sup>th</sup> September prior to the meeting.

ESPN Membership is now open to those committed to a career in Paediatric Nephrology and the criteria for presenting a paper at the ESPN meeting has now been dropped. Potential applicants are asked to visit the website and apply to the Council prior to the ESPN meeting in Istanbul. ESPN members have a reduced registration fee for meetings.

Kate Verrier-Jones has informed members that the Cardiff Account for ESPN members has now been closed and that future membership fees should be paid direct to ESPN.

The recent ESPN newsletter advertised an upcoming Levamisole trial being run by Jean-Claude Davin and further information can be obtained from him (Email: [j.c.davin@amc.uva.nl](mailto:j.c.davin@amc.uva.nl)).

Standards and training are being actively discussed at ESPN Council but there is nothing firm to report at this stage.

It is noted that applications for ESPN 2008 and 2009 will be discussed at the Istanbul meeting. BAPN members are encouraged to attend the General Assembly Meeting on 12<sup>th</sup> September in order to support the British proposal for the ESPN to be held in Birmingham in 2008/2009.

**19. Nominations for RCPCH Fellows** – this was not discussed as the deadline had passed.

**20. Transplantation in Atypical HUS**

Mark Taylor informed the BAPN that Tim Goodship has approached UK Transplant to suggest that all Atypical HUS cases are genotyped before grafting so that those with Factor H or Factor I mutations can be identified, as there is a high risk of graft loss or reactivation of HUS in this subset. He is proposing that LRD should also be genotyped. He proposes a standardised protocol for grafting of those with Factor H or Factor I mutation. A response is awaited from UK Transplant, the Renal Association and others. The BAPN are happy to go along with this, although it is noted that in the past it has taken a long time to obtain results from Tim Goodship's lab and that if this is to be a clinical service then a faster turnaround time would be required.

**21. Any Other Business**                      There was no other business

**22. Date of next meeting**                      *Friday 9<sup>th</sup> December, Institute of Child Health, London*

It is hoped to hold a meal on the evening before to allow an early start for this meeting.

### **ACTION POINTS**

<b>3.</b>	<b>Nominations for BAPN President</b>	<b>Membership</b>
<b>5a.</b>	<b>Update from RA Standards Committee</b>	<b>Sally Feather</b>
<b>6.</b>	<b>Letter to Jane Verity re NSF</b>	<b>H Maxwell &amp; M Savage</b>
<b>8.</b>	<b>Registry Committee Update Report</b>	<b>Chris Reid</b>
<b>8.</b>	<b>Contact VitalPulse re Paed Screens for Registry</b>	<b>Chris Reid</b>
<b>12.</b>	<b>Obtain more Information on Payment By Results</b>	<b>Nick Webb</b>
<b>13.</b>	<b>Dates for CSAC visits</b>	<b>Sally Hulton</b>