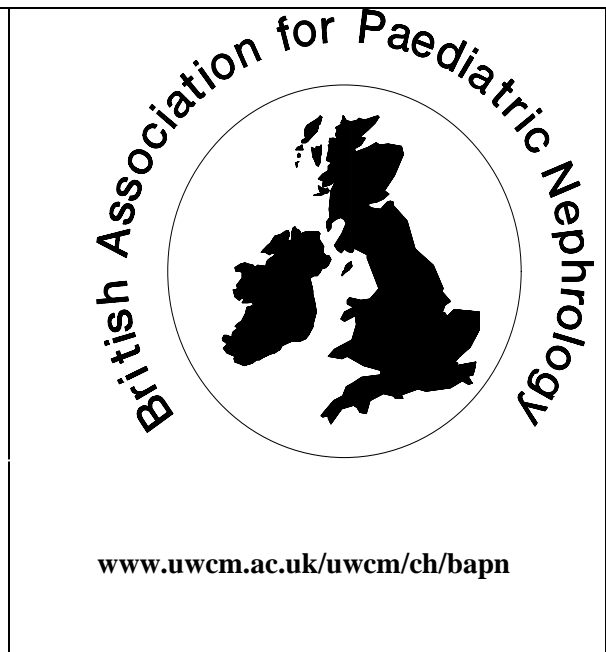


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BAPN Business Meeting Minutes

Friday 9th December 2005

Roland Levinsky Room, Institute for Child Health, London

Members Present:	Maurice Savage (President)	Heather Maxwell (Secretary)
	Milos Ognjanovic	Farida Hussain
	Alan Watson	Lesley Rees
	Jane Deal	Sally Feather
	Judith van der Voort	Sally Hulton
	Jan Dudley	Chris Reid
	Nick Webb	Jane Tizard
	Nadeem Moghal	Steve Marks
	Mark Taylor	Adrian Woolfe
	Mike Dillon	Detlef Bockenbauer
	Judy Taylor	Caroline Booth
	Kjell Tullus	Dick Trompeter
	Rodney Gilbert	Kate Verrier-Jones

Apologies:	Jean Smellie	Jonathan Evans
	Kay Tyerman	Martin Christian
	Sir Cyril Chantler	Sue Rigden
	David Milford	Carol Inward
	George Haycock	Richard Holt
	Brian Judd	Caroline Jones
	Lyda Jadresic	Mary McGraw
	Simon Waller	David Hughes
	Jim Beattie	Anna Murphy
	Ian Ramage	

1. Minutes of the Previous Meeting

These minutes were accepted as an accurate record

2. Matters Arising from the Minutes

All matters arising from the minutes were dealt with in the Agenda.

3. Report from Renal Association Council (Maurice Savage)

Professor Savage gave an update on Renal Association activities. Professor Feehally who has visited all of the Adult Renal Units in the UK is intending to visit all Paediatric Renal Units within the next 6 months. The Clinical Affairs Board of the Renal Association oversees three committees; the Registry Committee, Standards Committee and Clinical Services Committee. The first two will be dealt with separately on the Agenda and the Clinical Service Committee, on which Rodney Gilbert is the BAPN representative, is developing patient information sheets, although these are primarily for adults, and is also involved in proposals to report creatinine as an estimated GFR.

The other main Board reporting to Council is the Education and Research Board where Sally Hulton represents us on the Training and Education committee, and Nick Webb represents us on the Clinical Trials and Research Committee. It is proposed that a Renal Research Network will be formed within the UK to promote renal research.

Progress with the NSF has been discussed at the Renal Association and it would appear that the Renal Policy Team, in conjunction with the Children's NSF, are linking in with the Paediatric Renal Community in progressing a document on paediatric aspects of the NSF. It is understood that Diane Stafford, a Medical Journalist, is drawing up this document and has done so in conjunction with Lesley Rees. She is hoped to hold a paediatric summit at the beginning of next year with Dr Sheila Shribman, the new National Clinical Director for Children, to focus on paediatric renal care pathways and implementation of the renal NSF. Some members of the BAPN appear to have been invited to this, although there has been no communication with the BAPN as an organisation. Heather Maxwell will write to Gerry Lynch to ask that the BAPN are kept up to date with the progress.

Action: HM

The renal association have been involved with the Royal College of Physicians, London, in a piece of work entitled The Future of Renal Services in the UK, where representatives from different areas of the renal community have been interviewed with a view to planning and looking at the difficulties ahead for renal services in the next decade. Heather Maxwell represented the BAPN at this. A draft document will be produced shortly.

Other pieces of work include Renal Patient View (discussed later under IT, the Renal Workforce Group meeting early next year, and the Patient DVD Project on which Jan Dudley represents the BAPN.

The Renal Association is joining with the ESPN to hold a joint meeting in Birmingham in 2009

4. Renal Association Clinical Practice Guidelines (Sally Feather)

Sally Feather has been working with the Renal Association producing Clinical Practice guidelines. The 5 adult modules are well underway and once these have been developed we will add paediatric practice guidelines. These will be Web based and it was decided that the paediatric guidelines should sit on the Renal Association website, with a link to and from the BAPN website.

5. Report from CSAC (Sally Hulton)

PMETB have taken over the education, training and inspection duties from the RCPCH. There is a 6 month transition period (which may be extended) and it is recognised that PMETB will be more prescriptive with regard to inspections, and that the reports of such inspections will be published and therefore freely available. Trusts can appeal against the inspection reports if they so wish.

The National Training Scheme Working Group under the leadership of Nadeem Moghal has developed an updated curriculum, which includes associated competencies. Word is awaited from PMETB as to how assessment will be taken forward.

There have been several consultant appointments so far this year.

Glasgow	Dr David Hughes
Cardiff	Dr Judith van der Voort
	Dr Shivram Hegde
Guys	Dr Manish Sinha
	Dr Anne Durkan
Southampton	Dr Arvind Nagra
	Dr Shuman Haq
Liverpool	Dr Henry Morgan
	Dr Richard Holt
Leeds	Dr Eric Findlay

There is a vacant post in Belfast and a further post will become available in Glasgow at the end of March 2006. Four trainees will obtain their CCST in 2006 (Aoife Waters, Simon Waller, Jeanette Cansick, Rukshana Shroff), a further seven will obtain their CCST by the end of 2007.

Several centres are planning to submit training posts to the national grid this year. These need to be done shortly. Interviews will take place at the end of March 2006.

For those paediatricians who wish to develop a special responsibility for paediatric nephrology, they are expected to undertake 1yr of training in Paediatric Nephrology.

6. Renal IT Matters (Kate Verrier-Jones)

Kate Verrier-Jones updated the meeting on various IT projects that are underway.

- a) **Renal Patient View** – this is an electronic care plan where patients can obtain a password and view their own results on the computer. Within each unit an administrator will be trained who in turn will train the patients in the use of this system. Information leaflets about Renal Patient view are available and have been sent round to centres. Within Renal Patient View there is information on diagnosis, medical information for GPs and password protected information for patients on their results, medications and clinic letters. At the present time Renal Patient View is only available for those centres which use Proton, but it is hoped to roll it out to the centres which use different systems. There is a joining fee of £2,000 per unit. For paediatric units who are part of the adult system this is waved.

Kate Verrier-Jones has piloted this for paediatric patients in Cardiff and has been pleasantly surprised by the uptake. The information is available only in English; non-English speaking patients will require interpreters.

6. Renal IT Matters contd...

a) Renal Patient View

Information on paediatric illnesses is scarce and it would be helpful for somebody within the BAPN to work with the Renal Information Exchange Group to improve paediatric information sites. Steve Marks told the meeting that a considerable amount of information is available on the Great Ormond Street site at www.gosh.nhs.uk under clinical services, nephrology then medical services.

b) **DVD Project** - This is at the foundation and budget stage and it is hoped that the NKF will join in with this.

c) **NHS Direct Online** - Paediatric nephrology input is required for this to make sure that the information available is appropriate. Sally Feather has agreed to take this on. **Action: SF**

d) **Renal Data Set** – A group under Es Wills has met to look at developing a renal Data Set that will capture all necessary information. Paediatrics was only added to this at a late stage and our representatives therefore missed the first two meetings. However Kate Verrier Jones and Chris Reid have since met with the project manager and will go to the next meeting. The Data Set includes not only hard data, such as results, but also recording choice, for example choice regarding vascular access or type of renal replacement therapy, and action in terms for example, of slowing down progression of renal failure. The development of the Data Set has been partly driven by the NSF, and partly by existing Data Sets such as the UK Renal Registry, and UKT.

e) **National Electronic Library for Health** – Development of this seems to have slowed down, but hopefully will be resumed.

f) **“Do Once and Share” Project** – This project is to develop care pathways for conditions and to monitor exactly what information is required to do so.

g) **Map of Medicine**

h) **Proton Systems** - There is an undertaking that the Proton systems will be maintained and developed at the present time, although it is expected that in the future with the development of electronic patient records and the National Spine that newer systems may be introduced.

7. Report from the Renal Registry (Chris Reid)

Chris Reid reported on the activities of the Registry Committee. The 2005 report (based on April 2004 data) will hopefully be published in January 2006. The paediatric chapter will have a focus on posterior urethral valves, core morbidity data and on patients who have been on long-term (greater than 3yrs) dialysis. The chapter is at the draft stage and was discussed at the last registry meeting in November 2005.

The data for the 2006 report (April 2005 data) have been coming in, and complete data have been received from Birmingham, Bristol, Glasgow, Manchester, Newcastle and Nottingham. Partial data have been sent in from Southampton, Belfast and Liverpool and as yet no data are available from Cardiff, GOSH, Guys or Leeds.

The 2005 audit was on renal biopsies. Ten units have sent in preliminary surveys but audit forms have only been received from eight units and for most of these units, the data are incomplete. It is hoped to capture data from all biopsies performed in 2005 and forms can still be sent in. All units are encouraged to do so.

7. Report from the Renal Registry contd....

It is hoped to have an audit for 2006 on blood pressure management in transplant patients (to be discussed at the research meeting)

Links With Renal Registry

Chris Reid met with David Ansell at the Renal Registry in Bristol last week. It is hoped that eventually all paediatric units will download data electronically to the Renal Registry and a £30,000 grant has been obtained from the Department of Health to help with this. Some centres are able to download data automatically at the moment; it is the last set of patient data for each quarter, which will be downloaded to the Registry. So far data are being downloaded from Nottingham, Bristol, Leeds and Newcastle as part of the adult unit data download. Chris Reid presented the data that are available for the last two quarters of 2004 and it was very encouraging to see that such data are becoming available within the renal registry. To help other centres, money from the DOH grant will go to Birmingham to develop lab links, and discussions have taken place with Liverpool to set it up as a "Satellite" of Bristol. It is recognised that the Bristol Paediatric Renal Unit have the most comprehensive set of paediatric screens and David Ansell is working with Andy Webb of Vitalpulse to see if it is possible to share these screens with other paediatric units.

The meeting was encouraged to see the progress that has been made in developing links with the Renal Registry and the meeting appreciated that this will have implications for the workings of the BAPN registry, which at the present time is being held by Malcolm Lewis in Manchester. The BAPN are extremely grateful to Malcolm for all his hard work over the years in maintaining the BAPN Registry, but with the move to electronic downloads the paediatric registry will have far stronger links with the adult Renal Registry in Bristol. Glasgow will continue to submit data to the UK Renal Registry via the Scottish Renal Registry.

The Renal Registry Committee are now going to meet at the UK Renal Registry offices in Bristol. A UK Renal Registry Patient Information Leaflet is available which outlines the workings of the UK renal registry. A poster copy of this leaflet should be displayed in all units as a way of obtaining "consent".

8. European Registry (Jane Tizard)

The European Registry wish to employ a half time person to work with the data from paediatric patients. The anticipated cost is €30,000 per year and the ESPN have already promised €10,000. Individual member organisations are expected to provide the other €20,000. Following considerable discussion the BAPN agreed to contribute €1,000 for the next 3yrs and will also look for pharma sponsorship. Maurice Savage will speak to John Feeley, President of the Renal Association, with a view to contacting Jane Fishwick who is the Renal Association contact with Industry.

9. Report from ESPN (Alan Watson)

The next ESPN meeting is to be held in Palermo between 7th – 10th October 2006. There is a reduced registration fee for ESPN members. All BAPN members are encouraged to join the ESPN. ESPN fees are now due to be paid directly to Peter Hoyer.

The ESPN are going to focus on training this year and it was agreed that the CSAC training requirements should be compatible with ESPN training.

10. UK Transplant Update (Heather Maxwell)

Heather Maxwell updated the meeting on changes at UK Transplant. UKT is now part of NHS BT, which incorporates UKT, the Blood Service and PBL (the blood fractionating service). There are 6 non-executive members on the board, two of whom have transplant experience, and the Chair, Bill Fullager,

10. UK Transplant Update contd...

previously worked for Sandoz. There had been concern that UKT might be lost within this much larger service but it is encouraging to see so many board members with an interest in transplantation. Chris Rudge is now the Managing Director of UKT.

The next Renal Transplant Services meeting will be held at the Royal College of Surgeons in London on February 8th 2006.

The new allocation scheme is to be introduced from 1st April 2006. Documentation relating to this has been circulated; children will still have priority for well-matched grafts with 97 % of children having a 000 or well matched graft. The cost of improved matching will be an increase in the median waiting time of approximately 1month.

An allocation review group is being set up which will report to KPAG. This group will meet 6 monthly to monitor changes in activity as a result to the new allocation system. There will be 3-4 representatives from each region, so more renal units will be represented on this group than are represented on KPAG at present. The constitution of KPAG may therefore change in the future.

Centre specific data is available on the UKT website for donor, list and transplant activity. Proposed additions to this are cold ischaemic time, waiting time to transplantation and possible also time to activation on the transplant list (i.e. percentage of dialysis patients listed within specific time periods of starting dialysis).

The Human Tissue Authority (www.hta.gov.uk) is training independent assessors to oversee the donation process. There will be increasing degrees of involvement of these assessors from the perceived "low-risk" situation of living related donation, with more involvement to those "high-risk" situations of paired donation or altruistic donation.

Chris Rudge has asked that we think again about clinically urgent patients. Two years ago the kidney and pancreas advisory group had a working group looking at this and the issue was discussed with the BAPN. At that time it was felt that it was difficult to justify a clinically urgent list, that it would be unworkable and that in the past such a system had been subject to abuse. He has asked us to revisit this in the light of the new allocation system where the emphasis is on matching and where it may be more difficult to get urgent (and presumably less well matched) kidneys. For adult recipients it is anticipated that such kidneys will be obtained locally or from non heart beating donor programmes. The same will hopefully be possible for paediatric patients and the situation will be monitored closely.

The issue of non-favourably matched grafts being placed in easy to match patients was discussed again. There have been 13 such episodes over the last year, however many of these patients have waited a long time and therefore fall outwith this rule. Additionally some patients were treated in adult centres. Of note, most of the donors were paediatric donors and in some of the cases there mismatches against very common antigens. In the past such a situation has led to a letter being received from Chris Rudge with an explanation as to why the transplant went ahead. Often there are very good and clear reasons for doing so.

During discussion it became clear that centres were more concerned about sensitisation to common antigens and that intelligent mismatching (avoiding common antigens) is acceptable. It was felt that this could be taken forward within the sub-group looking at transplant clinical practice guidelines and Heather Maxwell will write to Chris Rudge to let him know how we are taking this forward.

Action: HM

11. Kidney Alliance (Nick Webb)

Nick Webb has attended the Kidney Alliance meetings. There is little to report other than work on Payment by Results (see agenda item 13).

12. British Renal Society (Heather Maxwell)

Heather Maxwell is the paediatric representative on the BRS. Any issues discussed at the BRS have been brought up in other agenda items. There is nothing new to report.

13. Payment by Results

Jane Tizard gave an update on Payment by Results. Considerable discussion took place regarding the payment for care as determined by health related groups (HRG's). There are two non-elective HRG's for renal; Renal Disease and Renal Disease with Renal Failure. For the first diagnosis the payment for inpatients is £560 for two days plus £266 per day thereafter, and for renal disease with renal failure the payment is £1,396 for 11 days. Only one diagnosis counts and it is clear that coding is key to this process. Considerable discussion took place regarding how best this could be take forward and who would be good sources of information and advice on this subject. Jane Tizard agreed to head up a BAPN working group on this subject and it was felt appropriate that there be a representative from each unit on this group. Nadeem Moghal and Alan Watson expressed an interest. Amy Potts who works for Baxter has talked on this subject previously and Es Well has been involved on the adult side.

Action JT

14. Trainee Issues

There were no trainee issues intimated and no trainees were available for comment.

15. Treasurers Report

For the 2004/2005 financial year the opening balance was £5,713.95 and after income and expenditure the end of year balance was £6,265.07.

For the current financial year income to date has been £2,840 and expenditure has yet to be deducted. It is clear that not all members are paying the full BAPN subscription and members are asked to check that their standing order is for the correct amount. Rodney Gilbert will circulate the membership.

Action: HM

16. NICE Update

a) Immunosuppressive therapy for renal transplantation

The committee have sent a document for consultation which is available on the NICE website. Heather Maxwell and Nick Webb will reply on behalf of the BAPN and RCPCH.

Action: HM, NW

b) Anaemia Management in Chronic Disease

Jonathan Evans sits on this guideline group which has met monthly for the last 12mths. Evidence has been gathered and reviewed and recommendations drafted. Jonathan has previously circulated the membership to canvas opinion on what in reality is the only contentious issue, namely that of target haemoglobin. It is likely that for children over 2yrs a target level of 11-12 g/d will be set, with one of 10-11 g/dl for those under 2yrs. The guideline should be out for formal consultation in the new year and released in the summer. Jonathan has asked that members look at the draft when it is released and send comments to him.

c) **UTI in children**

Kate Verrier-Jones chairs the guideline committee and Kjell Tullus is a representative on it. To date there have been 6 meetings and work is still in progress.

17. President Elections

There have been two nominations for President. Mary McGraw and Jonathon Evans have proposed Alan Watson and Lesley Rees and William Vant Hoff have proposed Mark Taylor. We will hold an email ballot shortly.

18. New Members

Two new members were proposed, Karl McKeever and Mohan Shenoy. It has previously been agreed that National Grid SpR's should have automatic entry to the BAPN.

19. AOCB

Kay Tyerman announced that the next Surgical Challenges meeting will be held in Leeds in November 2006.

20. Date of Next Meeting

The next BAPN Business Meeting will be a 2hr meeting at lunch during the nephrology session of the RCPCH annual meeting in York on 4th April 2006.

3	Write letter to Gerry Lynch to as that BAPN are kept up to date with progress of Paediatric Summit	HM
6c	Paediatric nephrology input for NHS Direct Online	SF
8	Payment by Results Group to be convened	JT
10	Update to Chris Rudge on progress with discussion on intelligent mismatching	HM
15	Send up to date membership list to Rodney Gilbert	HM
16a	Reply to NICE re consultation document	HM NW