**BAPN Executive Committee**

**Friday 19 June 2015, 1000-1300**  
Royal College of Paediatrics and Child Health, London

Present: David Hughes (DHu), Manish Sinha (MaS), Dal Hothi (DHo), Arvind Nagra (AN), Kay Tyerman (KT), Martin Christian (MC), Andrew Lunn (AL), Hitesh Prajapati (HP), Jan Dudley (JD), Mordi Muorah (MM), Michelle Rossiter (MR), Richard Coward (RC).

In attendance: Detlef Bockenhauer (DB)

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<td><strong>1</strong></td>
<td>Welcome (EJТ). DHu welcomed MM and MR to their first exec meeting.</td>
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<td><strong>2</strong></td>
<td>Apologies received from Jane Tizard (EJT) Munir Ahmed (MA)</td>
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| **3** | Minutes of last executive meeting  
Approved as an accurate record. |
| **4** | Matters arising (not otherwise on the agenda)  
Action point belonging to EJT to be added to next agenda. |
| **5** | **2015 winter meeting**  
10-11 December. Suggested programme for 1½ day meeting shared with exec. It would commence with 2 hour business meeting 4-6pm on 10 December followed by dinner. Full-day academic programme the following day to include the following sessions: trainee presentations (x6), flagship research study update, quality improvement and innovation session, invited speaker. The importance of a representative from each unit was stressed. MC to contact centre leads to encourage this but to gauge likelihood of participation. Pharma sponsorship approved. Companies to contact include: Alexion, Amgen, Fresenius, Astellas, Baxter, Link medical, NxStage. MC to approach pharma reps before committing to 1½ day programme because introducing cost to the meeting may influence decision to attend. No suggestions for an invited speaker were made. RC suggested this would be a good forum to seek members' suggestions for the ESPN 2017 programme.  
Action: MC |
| **6** | **Franco-British meeting**  
Venue will be Necker Hospital, Paris. No date yet but will be late November/early December. Some concern expressed about multiple meetings though it was stressed that this meeting would take the place of the Winter Meeting for 2016. A teleconference is due to take place in the near future. Rachel Lennon and MM have offered to  
Action: MC |
help MC with the UK-side organisation. RC agreed to join initial teleconference to plan programme. Suggestions for topics included service delivery models and population-based research (including RaDaR). It is proposed to seek pharma sponsorship but MC to ask about format of French meeting at teleconference.

### 7 ESPN 2017

DHu outlined plans to date. Initial LOC meeting took place during ERA-EDTA. Rosanna Coppo (ESPN secretary general) and Elena Letvchenko (Congress co-president 2017) were able to join. Plans for low-key publicity at this year's ESPN but unable to move forward with more concrete plans until ESPN’s new PCO is appointed (September). Teleconference to take place next week. RC suggested members attending Brussels congress make note of programme/organisation. DHo asked that the option of virtual attendance (through webinars) be considered. EWOPA are keen have satellite meeting but there needs to be confidence in the financial arrangements. Chris Reid to email MC with summary of how this was achieved for Porto. AN suggested allowing a patient/parent voice through a satellite support group meeting as happened with the NKF conference attached to the ERA-EDTA.

### 8 President’s report (DHu)

From RA Trustees. The 2016 Renal Association meeting will be a joint meeting with the BRS in Birmingham ICC on 7-10 June 2016. On-going negotiations about conference funding before confirmation of any further collaborations.

BAPN have missed out nominating Malcolm Lewis for Terry Feest Award a second year because of being unaware of deadlines. He should be automatically nominated for 2016. MS to keep watching brief.

BMC Nephrology have offered to publish 3 guidelines per year from Renal Guidelines Project Group. The journal has also offered a discounted publication fee for RA members and financial support to the Tony Raine Award recipient in return for publishing rights. RIGB. There has been no progress on RA guidelines for core data requirements for RIGB. Renal data warehouse is now up and running. It will offer the possibility for patients to upload their own data. DHo raised difficulties with transferring of consent for young people as they reach their 18th birthday when the communication aspects are involved. DHu to take this back to RIGB.

The AKI capitation fee resourced out of the AKI national (English) tariff applies to adults only. Paediatric registry supported by these adult capitation fees. From paediatric AKI audit, 666 cases of AKI have been identified with only 4/6 hospitals’ data analysed so far. It is not clear which class of AKI will pay the capitation fee.

Patient View has received £75k funding from KRUK. Feedback on non-recruiting units will be available and it was questioned whether this should be a standard. The growth/success of PV has been acknowledged and also the vulnerability of investing in a single unpaid individual (Neil Turner). A medical director post (2 PAs) has been approved and will be advertised in September.

UKRR. 3 units are struggling with data returns. The paediatric year-end deficit is £27k. Adult capitation fees continue to subsidise this. The separation of paediatric and adult accounts is proposed to remain to make use of paediatric-specific information on commissioning children’s renal services.

Action: MC

Action: MS

Action: DHu
9. **Secretary’s report (MC)**

There are currently 129 BAPN members. 59 current UK consultant paediatric nephrologists are members but 11 are not. Two individuals have expressly decided to remain outside of the BAPN, others are probably members who have allowed their membership to lapse. MC to provide names to DHu who will contact individuals personally.

MC encouraged members to read eNews regularly, at least the digest part for important pieces of BAPN news. Digest part to include BAPN news such as new consultant appointments. MC to ask MCI for feedback about readership.

Several committee members coming to end of tenure in 2016. Importance of early planning emphasised. RC suggested using Winter Meeting to indentify potential successors. MC to provide a list of exec posts and dates of demittance.

Peer review steering group to meeting in 2 weeks. Measures document should be finalised and will then be circulated to BAPN and other stakeholders for consultation. KT asked about inclusion of training and will comment on circulated document.

**Action:** MC/DHu

**Action:** MC

**Action:** MC

10. **Treasurer’s report (AN)**

Ring-fenced account static at £23,924. Suggestion to renegotiate expenses fund was discussed. DHu’s expenses will be mainly from external sources (RCPCH for exec meetings; RA itself when representing Trustees). Exec agreed to review this later in 2015.

Decision made to set level of support for trainee grants/prizes at £1,500. This should come from ring-fenced fund but terms and conditions of expenses fund not clear. AN to clarify from EJT’s original email whether this can be used for trainee travel grants and support for members attending Winter Meeting. Ring-fenced fund to be invested with RA main funds in high-interest account with instant access which will pay 1.1% interest (not sufficient to finance trainee prizes annually).

**Action:** AN/EJT

11. **Clinical standards and guidelines (JD)**

Joint guidelines. Little progress on national guidance because of the need to maintain NICE accreditation. RA guidelines project group recognise need for project management. Administrative support has been agreed but project management requires analytical skills.

KRUK are unable to fund this role. JD awaiting response from BKPA. MR will discuss with Paddy Tabor. New paediatric representatives within joint paediatric/adult groups: David Milford with AKI, DHo with haemodialysis.

InfoKID. MR endorsed how helpful she has found this resource as a parent. There is 6 months (full-time) or 12 months (part-time) funding available for project management for evaluation. Part-time funding over 12 months is the preferred option. There will be a questionnaire for parents/carers’ feedback. Centre leads are asked to become involved in evaluation of the use of InfoKID during a consultation. DHo asked if evaluation can recommend an outcome measure. Patient stories and webinars are included amongst several developments planned for phase 2 and 3. Amongst an IPNA survey of international patient information, InfoKID was the clear leader. JD is to put together a proposal for translation/development for an international audience. A similar information resource is planned for adult nephrology in the UK. Graham Lipkin is leading and an adaptation of InfoKID is planned. DHo asked about geographical

**Action:** MR
usage and JD confirmed that only 45% hits are from the UK. MC suggested it should be possible to identify usage inside and outside hospitals. Promotion amongst general paediatricians and other health professionals was discussed. AL suggested approaching the BMJ.

Consensus ADPKD pathway will involve 4 statements to try to achieve UK consistency. Two trainees are reviewing literature and will then formulate questions for a Delphi process. The anticipated timeframe is one year. AN asked about an adult nephrology representative. Paul Winyard will identify one.

NICE guidance in process. JD to discuss paediatric representative on transition guidance with AN.

Use of eculizumab in dense deposit disease (DDD). The BAPN have been asked to consider a response to a recent case which has attracted considerable publicity. National Clinical Directors for both children’s services (Jacqui Cornish) and renal services (Richard Fluck) have been asked for comments and NICE are to review the medical evidence this month. Exec members were wary of the significant consequences of producing a consensus statement. Note was taken of individual cases in England and Scotland and the dangers of each health service taking a different approach. It was noted that medical evidence supporting a role for eculizumab in treating DDD is mixed. JD asked whether the BAPN might define “exceptional circumstances” in which the drug might be used. RC suggested using the Winter Meeting to debate the issue with the medical evidence presented; DHu suggested guidance when eculizumab should not be used might be easier to formulate; DHo suggested asking individuals to be part of a group to write a consensus statement. No conclusions were reached and JD to consider these suggestions further.

UTI paper. Due to confusion about the original terms of the commission from Archives of Disease in Childhood (ADC), the paper on UTI diagnosis has been rejected after ADC editorial review. This has caused considerable upset to those leading the project. Options for progressing from here were discussed, which include rewriting the paper or sending the paper elsewhere. The BAPN need to be happy with the content of the paper in its submitted form. DHu suggested seeking the views of each centre lead for the paper on how to take things forward. DHu/MC/JD to collaborate on communication. AN to ask Rodney Gilbert to speak to Mark Beattie (ADC editor, fellow Southampton consultant) for his view.

Registry and audit committee report (MS)

Last year 7-8 centres moved platforms but only 3 centres had problems. Returns this year received from 10 units; 2 centres with new platforms have returned data but have experienced problems with downloading new dataset due to contracts; 1 centre (Belfast) has returned no data and will have to be removed from the report if not submitted by the end of June. A proposal for a 2-tier capitation fee was discussed: those centres needing support with extracting data would pay £40 per patient. DHu suggested an exceptional circumstance package that would be appropriately costed. MS to produce summary and options appraisal to send to centre leads for them rather than BAPN exec to decide.

Paediatric renal registry day planned for spring 2016 with focus on inviting IT personnel from each unit.
A prospective dialysis access audit is to be launched soon. Three members of the registry and audit committee are due to demit next year in addition to MS demitting as chair. Catherine O'Brien has already stepped down. To avoid a wholesale committee change at the same time Carol Inward will step down following next Registry meeting in October and Vincent Tse in summer next year.

Two Chapters describing 2013 Paediatric RRT data are completed and available electronically including new analyses on cardiovascular risk factors and growth.

Publications and presentations from the Registry include: ‘late presentation report’ (submitted); ‘infant dialysis report’ (write-up). Two abstracts submitted to ESPN from the UKRR – both accepted as oral presentations. ERA-EDTA - annual data submitted with additional data collaborations.

Audit report: re-audit of renal biopsy (manuscript submitted); audit of paediatric AKI (data analyses ongoing).

13. **Quality improvement and innovation proposal**

Proposal for QII team that CSGG forms part of were discussed at AGM. This would be to support grant writing, research with QI aspects and consider developments in delivery of care leading to cost-improvement. RA KQIP group have proposed 3 projects, asking for members to vote on their top priority: reducing avoidable AKI, improving geographical variations in pre-emptive/LRD rates; and improving geographical variation in update of home dialysis therapies. RA are looking for QI champions for each academic health science network. JD and DHo to collaborate on content for QII session on Winter Meeting programme.

**Action:** JD/DHo

14. **CRG report**

EJT not present and no recent update.

15. **RaDaR**

DB attended exec to present RaDaR update. There are currently around 2,500 patients recruited with around 100 being recruited each month. Initial 5-year grant expires in March 2016. KRUK/BKPA/KKR are all positive about on-going funding. RaDaR is trying to reduce operating costs – there is now just one part-time person (Melanie Dillon) instead of 1.5 previously. There is a plan to out-source operating costs for RDGs to seek their own funding via charities. Each RDG may approach the BKPA for this funding who have funded patient information days for some RDGs.

RC asked about “second page” of website database. DB confirmed that this is going forward and the renal data warehouse will mean that most data will be downloaded directly. Each RDG will be asked to identify around 4-5 key fields that cannot be populated automatically. MC raised the issue of “double-consenting” that was previous discussed at exec. DB confirmed that this was not within RaDaR but to do with separate research studies/databases. MS flagged up that CRN nurse support for registries is being curtailed. DB confirmed that there is a £50 incentive for each patient recruited. KT asked about patients recruited from outreach centres. DB confirmed that the visiting consultant paediatric nephrologist should have authority to consent these patients to be part of the tertiary centre’s recruitment (meaning that the tertiary centre would receive the £50 funding). AL mentioned that there may be issues with IT support in local hospitals.
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| **16.** | **UK strategy for rare disease**  
BAPN response to Edmund Jessup circulated with agenda. This response had not been discussed yet by NHSE. DB has not been contacted by Edmund Jessup. |
| **17.** | **Research report (RC)**  
Meetings. RCPCH meeting for 2016 paired with gastro/nutrition. ESPN 2017 will be in Glasgow. We are planning the academic programme for this: ideas and suggestions gratefully received. Academic committee will be formed in near future.  
**National renal research strategy (NRRS)** on-going and has input from the BAPN. Draft document to be generated imminently. This will then be circulated to all stakeholders.  
**Research priorities.** We are currently establishing a number of key study groups in paediatric nephrology to consider these and to decide on the research priorities for paediatric nephrology in the future.  
**Current Research studies.** PREDNOS: last recruit on September 2014; PREDNOS2 on-going, but recruitment has declined again. Please continue to promote in local and outreach centres; HOTKID study recruiting. 3H study (HD vs HDF) is looking to involved other centres to boost recruitment. Update will appear in eNews.  
Recently submitted to EME: Nidus is funded; ECUSTEC has progressed to a full application and is now going to be a full study with stop-go element. Awaiting outcome.  
CSGs funding reduced and groups encouraged to find their own funding. No plans for face-to-face meetings at present. Suggestions for taking forward including combining with generic paediatric groups, approaching KKR for funding or considering matched funding from BAPN. MC suggested satellite meeting at Winter Meeting. |
| **18.** | **SPIN report (MA)**  
MA not present. Report submitted. SPIN members include 29 consultants and 7 trainees. SPIN curriculum under review at CSAC meeting and comments will be sought from all SPIN members once draft agreed. There are some potential consultant vacancies coming up with SPIN interest and should be SPIN trainees ready to fill them. |
| **19.** | **Clinical services committee report (DHo)**  
DHo part of EWG paediatrics chapter and has had 3 meetings with Monitor. A breakdown of HRG costings has shown discrepancies about processes. For example, daycase incentives in paediatrics are not relevant when paediatricians try to avoid prolonging in-patient stay for children anyway. With much change at Monitor currently and in the near future, DHo is keen to remain in post beyond her term of office to straddle this transition. There has been a poor response to request for one representative from each unit to be part of a group to look at tariffs and service-level costing. MC to email service leads again.  
Workforce document has been sent out to centre leads this week for updating. DHo will collate responses and share with exec/CSAC. |
| **20.** | **Communication officer’s report (AL)**  
Website update is on-going with content needing to be revised. Awaiting response from RA to align BAPN pages with RA headings. On-going work to combine two sections of website which contain |
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| **Information about BAPN centres and need to determine measure of dialysis/transplant activity for this database.** Annual report requires final reports. | Action: AL  
Action: AL |
| **21. CSAC report (KT)** Recruitment process for 2016 is about to start. Number of trainees needs to be decided. 11 trainees in post; 4 due to commence in Sept 2015. 1 trainee switching to SPIN; 1 trainee appointed within 6 months of CCT to consultant post; further 2 post CCT trainees have gained substantive appointments. 1 post CCT is in a locum post and another in research. 2 trainees will gain CCT in 2016 but likely to be surge in trainees gaining CCT in 2017 due to OOPE/maternity leave. 3 trainees are sitting START in October 2015 and following this date nephrology trainees will move to April sitting. RCPCH revising GRID curriculum and will integrate with portfolio assessments. CSACs have been set target to complete over next 6 - 12 months. Current SPIN curriculum also needs review to ensure it is fit for purpose. KT also now involved in approving job plans for SPIN consultants and reviewing portfolios for those applying for SPIN posts. |   |
| **22. Trainees’ report (HP)** Next trainee meeting is scheduled for 25-26 June in Southampton with first meeting of 2016 to be held at Evelina. No concerns raised by trainees. |   |
| **23. Ordinary member’s report (MM)** This was MM’s first exec meeting with no report to present. |   |
| **24. Lay member’s report (MR)** This was MR’s first exec meeting with no report to present. |   |
| **25. Excellence awards** There was insufficient time to review MC’s document in detail. Brief explanation of the reason for writing BAPN guidance for supporting excellence awards. All members asked to feed back comments within the next month and document to be ratified at October exec. | Action: all |
| **26. Review of external committees** AKI national programme. BAPN have been asked by David Milford to approve AKI algorithm guideline and then allow BAPN branding on the document and publication on the BAPN and Think Kidneys websites. RA’s NICE accreditation means that it can only publish guidelines which have been through the NICE accreditation process. However, if the algorithm is simply a distillation of the NICE guidance it should be possible to publish it so long as this is made clear. JD felt that the algorithm would have an important role being signposted from Paediatric Care On-line. MC/JD to communicate this to David Milford. Plans for plenary session on AKI at next year’s RCPCH meeting were presented. RC asked that RCPCH ensure this takes place on the same day as the nephrology subspeciality session. For information only and not discussed: Paediatric subgroup of KAG (Steve Marks). Latest data show reduction in 1-year graft survival for paediatric LRD transplants but internal review has concluded there are no clinical governance concerns. Kidney offer decline rate audit for 2014 is currently being analysed and has oral presentation at ESPN. ESPN (Rukshana Shroff - RS). The 8 working groups, organised by | Action: MC  
Action: MC/JD |
Rosanna Copp will organise all the pre-course CME sessions. RS has introduced more CME events, especially web-based and more young nephrologist forums. RS is happy to represent ESPN 2017 on ESPN council.

27. **Any other business**
AN mentioned NHSE organised Transforming Participation in CKD workstream. She has already organised for one parent and one young person (from Southampton) to take part and hopes to organise another user-rep from the north. AN also mentioned that *Ready, Steady, Go* has been presented to IPNA council who have agreed to signpost the resource.

28. **Dates of future meetings**
Exec meeting 2015: 2 October
Winter Meeting 10-11 December 2015
Exec meetings 2016: 5 February, 24 June, 7 October.

Minutes accepted as a true record of the BAPN executive committee meeting on 19 June 2015

2 October 2015

Martin Christian
BAPN secretary