BAPN Executive meeting

Friday 22 November 2013, 10.00-13.00
Royal College of Paediatrics and Child Health, London

Present: Jane Tizard (EJT), Richard Coward (RC), Andy Lunn (AL), Mohan Shenoy (MoS), Dal Hothi (DH), Martin Christian (MC), Jan Dudley (JD), Maggie Fitzpatrick (MF)

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<td><strong>1</strong></td>
<td><strong>Welcome</strong></td>
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<td><strong>2</strong></td>
<td><strong>Apologies</strong> received from Arvind Nagra (AN), Jelena Stojanovic (JS), Manish Sinha (MaS) and Munir Ahmed (MA).</td>
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<td><strong>3</strong></td>
<td><strong>Minutes of last executive meeting</strong> The minutes were accepted as a true record of the BAPN executive committee meeting on 20 September 2013. Future minutes to be paginated and distributed as a PDF document.</td>
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<td><strong>4</strong></td>
<td><strong>Matters arising</strong> (not otherwise on the agenda) 3. BAPN RIXG representative. (Post meeting note: Malcolm Lewis is still the current BAPN rep but has been unable to attend recent meetings and would like to pass on this responsibility.) 4. On-line survey of membership about constitution change. Now live and advertised in November’s eNews. Response deadline of 10 December to feedback results at Winter Meeting. 9. Links with French Paediatric Nephrology Society. Joint meeting between UK and French renal associations noted. To await feedback from Jelena after her presentation and discuss at Winter Meeting. 13. New DWGs update and Birmingham’s successful bid for NIHR rare diseases translational research collaboration. Not yet published in eNews. To go into December’s edition. 16. Updating centre-specific information on new website. Changes happened too quickly. AL to send round template to each unit for updating on new website. 21. Duration of clinical services committee tenure. Updated information now on website</td>
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<td><strong>5</strong></td>
<td><strong>Winter meeting</strong> Agenda for business meeting to be written soon. Default slot of 10 minutes with longer session for research. MC to email to service leads as a prompt to confirm attendance. MC to email Heather Maxwell to offer a slot to discuss 2017 ESPN bid for Glasgow. MC to email trainees to confirm timing of 10 minutes for presentation with 5 minutes for discussion.</td>
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|   | **UK Kidney Week 2014**  
Draft programme circulated. Interesting programme for paediatrics. Sally Johnson and Daniel Gale to chair session on complement-mediated disease; EJT and David Wheeler to chair paediatric session on Alport’s with David Milford, expert parent, Susie Gear and Neil Turner speaking. All exec members to encourage colleagues to attend. |   |
|---|---|
|   | **Glasgow bid for ESPN 2017**  
Small group formed comprising Heather Maxwell, EJT, AN, RC and MC to support development of bid. Recent teleconference with Glasgow team who have subsequently sent round outline bid. More information awaited from ESPN about financial liability and also the role of Flap Tours group. For further discussion at Winter Meeting. |   |
|   | **Deflux advert in Archives**  
Letter has been drafted by Kjell Tullus and amended by exec. Paediatric Urologists have responded separately so response to be sent in will be signed by Kjell, Ian Ramage, Jonathan Evans and EJT on behalf of the BAPN. AL has individually contacted Advertising Standards Agency who are unable to act as this is not within their remit because of publication within a scientific journal. EJT has taken advice from MHRA but this counts as a device rather than a drug and is not covering by MHRA licensing.  
Action: MC/EJT |   |
|   | **Commissioning (EJT)**  
EJT at CRG meeting this week. Paediatric nephrology service specification was agreed last year but will need to incorporate outcome standards (to be revised in 2015). Some of these will be generic but others need to be nephrology-specific. Discussion of dashboards. EJT to circulate rheumatology template to exec for future discussion. GOSH have produced patient-focussed dashboard which DH will circulate to exec.  
DH and MC submitted applications for Innovation Fund which has since been withdrawn. EJT shared news of new national source of innovation funding. Any other applicants with potential innovations should notify Jacqui Kemp.  
Rheumatology have experienced problems in funding biologics (pre-NICE approval); once 15 individual funding requests (IFTs) are received nationally, this becomes a cohort and is dealt with via a different route. Subsequent discussion took place on funding of rituximab for nephrotic syndrome; around the table several funding agreements are in place.  
Genetic testing funding. Genetics departments pay for 10% of testing, primarily diagnostic testing. EJT has raised this issue of funding with commissioners and it is to be taken to the Programme of Care Board.  
NHS England developing 5 year strategies for directly commissioned specialised services. This is to be aspirational in goals and achievable in objectives, driving forward promotion of equity and excellence. CRG will complete this on behalf of paediatric renal services.  
Transition service specification is a generic document which will be incorporated into every specialised service specification but can be adapted to include some nephrology-specific aspects. The document does not address the issue of mutual consent between... |   |
| Action: EJT | Action: DH |
Paediatric and adult services over the age of transition and does not support the children’s renal NSF in this regard. This also presents an issue in regard to where newly-presenting patients with CKD aged 16-18 should be managed. This issue might be better addressed in the general paediatric service specification rather than in the transition one but does need clarification. EJT to take this issue back to the CRG.

**Action:** EJT

| 10 | **Peer review of paediatric renal networks**  
The first steering group for the pilot project took place yesterday. It was chaired by Ruth Bridgeman (National Director for Peer Review) and attended by DH, EJT, MC, Rodney Gilbert and various MDT colleagues. Two representatives from the SPRUN Scottish network also attended. A timetable for peer review has been set out. Documents that BAPN representatives have submitted have been used to draw up an initial draft of an outcome measures document. This document is to be commented upon by delegates yesterday and then distributed to the wider BAPN membership for consultation. For further discussion at Winter Meeting. |

**Action:** EJT

| 11 | **President’s report (EJT)**  
All issues discussed elsewhere in minutes. |

| 12 | **Secretary’s report (MC)**  
MC represented BAPN at Kidney Health’s launch of “Ambitions” document which was circulated with November’s eNews. Paediatric chapter written by MC (delivery of care as close to home as possible) and AN (transition). Clarification of process for new members received from MCI. MC can receive details of new applications from MCI. These are approved at the point of application (each requires 2 proposers unless a grid trainee who requires a single proposer). New applications since 26 February this year received from: Asheeta Gupta, Emma O’Hagan, Lucy Plumb (all applying for NTN posts this time) and Corinne Langstaff (née Nevard, returning to practice after a career break). MC to request updated list for next exec meeting (prior to AGM) and re-request to pick up any additional applications before AGM so that they can be ratified there. Discussion about applications for BAPN membership from non-medical professionals. All supported but this would require change of BAPN constitution so for further discussion at Winter Meeting ahead of proposed constitution amendment for AGM. |

**Action:** MC

| 13 | **Treasurer’s report**  
Ring fenced account: no new income and £100 expenditure leaving a balance of £25,924.35. Renal Association float: expenditure of £200 leaving approximately £2500 pounds. We will receive an annual top-up to £4000 in January as expenditure may increase for 2014. Renal Association funds for the AKI meeting in 2013: income was £5000 from the Snyiveson project fund; expenditure to date is £2033.38 leaving £2966.62. We will put this toward the audit which we hope to undertake. AN to discuss with David Milford. |

**Action:** AN

| 14 | **Clinical standards and guidelines report (JD)**  
Discussion about clarification of BAPN involvement in NICE processes following confusion about Jonathan Evans’ query. Invitations to scoping workshops are sent out to registered |

| 90 | **Action:** EJT

**Peer review of paediatric renal networks**  
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**Action:** EJT
stakeholders who can then propose representatives. This may be both BAPN and RCPCH. JD noted that applications for guideline development groups are done on an individual basis rather than via specialist groups or Colleges (participants from scoping workshops are notified of the call for applications). If there are no applications received from a, specialist area, the relevant group is usually approached by NICE, either directly or via the College. Different processes exist for different types of guidance. JD to devise algorithm.

CSGG not yet met under JD’s leadership. May meet during UK Kidney Week next year. JD planning to discuss on-going guideline development options with Andrew Lewington.

Eculizumab NICE guidance: Moin Saleem and Carol Inward have been co-opted as experts. MC has not received an invitation to apply for GDG following scoping workshop in July. MC to chase this up with NICE.

MC has received notification of technology appraisal for tolvaptan in ADPKD (via a local paediatric colleague rather than NICE) but this has not been received by JD. JD to clarify this with NICE.

Development of national paediatric AKI audit. JD to contact David Milford to find out progress here and offer slot to update membership at Winter Meeting if appropriate.

15 **Registry and Audit Committee report**

Two chapters of 2012 paediatric RRT data completed and will be available electronically soon. Plans for 2013: registry returns to be paperless from 2013 all centres aware data will only be accepted via electronic submission: change format of report - consider themed sub-section in the second chapter – teleconference planned in December; nhs.net accounts at each centre - discussions with Belfast regarding this ongoing.

Two projects being written up: infant dialysis project and late presenters manuscript. ERA-EDTA - annual data submitted with ongoing collaborations. Re-audit of renal biopsy – report completed

Tony Wing Award – awaiting University of Bristol agreeing contracts prior to advertising.

16 **National Renal Dataset**

Letter received from Richard Fluck sent to all stakeholders of the NRD to ask whether it should be discontinued in the light of projects he feels have superseded it such as the renal data collaborative and the terminology committee of the Renal Association. The NRD forms part of the renal registry returns which has been successful purely because of the mandatory nature of the NRD. The exec felt the renal data collaborative was concerned with data sharing rather than gathering and was concerned that its work would not supersede the NRD as was claimed. MaS and EJT to discuss BAPN response to Richard Fluck. Post meeting comment: EJT discussed on Trustees teleconference and the issue will be discussed at the RIGB on 9th December.

17 **Research (RC)**

Agreed to give Lynsey Stronach (GOSH home haemo nurse) £500 travel bursary towards Atlanta meeting for acceptance of abstracts for 1 oral presentation and 6 posters. To consider

| Action: JD |
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| Action: EJT/MaS |
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inviting non-medic member to present at future Winter Meetings.  

 Speakers for RCPCH meeting confirmed in joint session with 
rheumatologists: Jan Dudley on HSP; Steve Marks and Michael 
Berestford on lupus nephritis; and Mark Friswell from Newcastle 
doing biological talk. Plan to give prize for best renal presentation. 
UK Kidney Week talks discussed above.  
Agreed to ask Nick Webb for update on PREDNOS 1 & 2 and 
MaS for update on HotKID at Winter Meeting.  
Nephrology currently well thought-of amongst CSGs, particularly 
with regard to PREDNOS studies and RaDaR. There is a need 
for more nephrology support on CSGs.  
Restructuring of research networks discussed. Paediatrics will sit 
within group that includes O&G, genetics, neonates, child health 
and haematology, and within this group we sit well. However there 
is likely to be an amalgamation of resources with this new 
structure  
Within the nephrology CSG are informal subgroups such as 
tubular, transplantation etc. Plans to discuss how this will develop 
within new structure at the Winter Meeting.  
NIHR have made an early announcement of a call for proposals 
for research into chronic disease in childhood. They are 
particcularly encouraging collaborative research which sits well with 
nephrology. DH felt that projects that demonstrate improving 
quality and cost-savings would be welcomed. RC will ask for 
information about which projects were successful in a recent 
similar call for surgical projects as a guide to how projects should 
be developed. This will be discussed at the Winter Meeting with a 
view to the establishment of working group(s). BAPN might 
commit funding towards bringing such groups together.  

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<th>18</th>
<th><strong>UK Kidney Research Consortium</strong></th>
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<td>Paediatrics currently represented on this group by RC/SAH as CSG chair and Moin Saleem as RA academic vice-president. There is one BAPN representative the Chair of the CSG (currently RC) and Tim Goodship has asked if there should be another one. Agreed that the president will be the nominated second representative.</td>
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<th><strong>SPIN report</strong></th>
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<td>No update - MA unable to attend.</td>
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<th><strong>Clinical services committee report (DH)</strong></th>
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<td>Workforce/workplan document is now available on the website and was discussed. Concern expressed about manpower planning: by 2016, there are 5 retirement posts but will be 13 trainees with CCTs. The issue of revalidation for trainees who are post-CCT was raised and how these individuals might continue to be supported. DH to discuss issue of coding at Winter Meeting.</td>
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<th><strong>Communications officer (AL)</strong></th>
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<td>Exec viewed the new RA website (not yet live). One of the home page tiles is for the BAPN. This should ideally read British Association for Paediatric Nephrology in full as many may not know what the BAPN is.  Exec agreed that the BAPN page should mirror the main RA site for subsections/terminology. The BAPN page should also contain the BAPN logo. Currently it is the old logo that is in use and there is not thought to be a high-quality</td>
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 Action: RC

 Action: DH

 Action: AL
graphics file of this available. All felt that a new logo would be good and that there might be a competition with a small prize for paediatric patients to design a new logo. InfoKID (JD – in future to map to CSGG report). Currently running behind and only ~25 leaflets will be ready for original launch date of 13 December. Options are to continue with limited launch on that day or to delay. There is a BKPA grant of £28k for evaluation of the project. InfoKID currently has the information standards kitemark and this is due for review in March. DH asked whether there should be a patient reported experience measure (PREM) carried out. Following a successful evaluation, the plan would be to intertwine the project with RaDaR. There will be stalls for infoKID at the RCPCH and UK Kidney Week meetings.

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22 **CSAC report (MF)**
Applicants for NTN posts have now been shortlisted and there are 5 shortlisted for up to 4 posts - London (Evelina/GOSH, Northern (Newcastle), North Western (Manchester) and West Midlands (Birmingham).
12 trainees currently in grid system (8 in clinical posts; 2 in research; 1 on maternity leave; 1 doing an out of grid placement - educational course/teaching UCL).
3 substantive consultant appointments in 2013 (Glasgow, Evelina, Bristol); 3 trainees completed CCT and not yet in substantive posts (1 locum post, 1 ongoing research, 1 working in India).
START has been ratified by the GMC. There have been 3 sessions - November 2012, March and October 2013; next is March 2014.
All trainees entering level 3 training from August 2011 are required to undertake START before applying for their CCT. A working group for nephrology has been convened by Larissa Kerecuk - Assessment Advisor - working with the CSAC which has now submitted a comprehensive number of scenarios. The RCPCH has suggested the following areas that assessments should cover - maintaining trust, safety and quality, communication, teacher and scholar, leader of the clinical team, logistics and organisation, collaboration and service management.
CSAC needs to continue to update the bank of scenarios for nephrology.

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<th>23 <strong>Trainees report</strong></th>
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| Next grid training days Liverpool, 30-31 January 2014. Programme includes: AKI in different scenarios, research, tips for being a consultant, primers in histopathology and radiology. Mordi Mourah will be closing trainees' account on 9 December to transfer funds to budget line within BAPN account.
Alexion pharmaceuticals have offered regular funding for training days for the next two years. Exec felt the decision to accept should be left to trainees but cautioned about close ties with a single pharmaceutical company. Trainees will discuss this when they meet in Liverpool. |

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<th>24 <strong>Ordinary member’s report (MoS)</strong></th>
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<td>Kidney Alliance no longer in existence. MoS will continue to be BAPN link to World Kidney Day which is now separately organised.</td>
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| 25 **Annual workplan for 2014** |
Has been partly updated. Each committee member to incorporate pertinent workplan issues into their reports for next exec meeting. EJT also called for individual annual reports to be sent to her for February (to incorporate into BAPN section of Renal Association annual report). The same reports can be used for the BAPN annual report.

| Action: All |

26 Review of external committees
Not discussed

| Action: All |

27 Any other business

| Action: AN |
| Action: JD |
| Action: MC |

a) Supporting Young Adults with CKD Special Interest Group. AN representing BAPN. DH also willing to participate. EJT to check this is acceptable with Rachel Gair (post meeting discussion – agreed for DH to take EJT’s place). Questions asked about transparency in filling other posts. To ask AN for update.

b) RCPCH educational courses. BAPN have been asked to consider renal input into courses on the themes: how to manage series; evening of evidence; and progressing paediatric series. To discuss setting up a nephrology group at Winter Meeting.

c) Lay representative. Post meeting identified that SM term of office ends March 2014. Will need to seek new lay representative.

Dates of future meetings
Winter Meeting: 13 December
2014 exec meetings:
• 7 February 2014
• 6 June 2014
• 3 October 2014
EJT asked all exec members to try to ensure cover for meetings, particularly as there are only 3 meetings per year from hereon.

Two minor amendments made to Item 13. Minutes then accepted as a true record of the BAPN executive committee meeting on 22 November 2013.

Martin Christian
BAPN secretary
7 February 2014