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**Minutes of BAPN Executive meeting
Friday 30th September 10.00-13.00
Royal College of Paediatrics and Child Health**

Present

Mary McGraw (MMG)
Sally Feather (SF)
Wesley Hayes (WH)
Peter Houtman (PH)
Carol Inward (CI)
Simon Waller (SW)
Maggie Fitzpatrick (MMF)
Judith Van der Voort (JV)
Leah Krischock (LK)
Moin Saleem (MS) (present for research items only)

Apologies

David Milford (DM)

1. Welcome

MMG welcomed WH as new trainee representative to BAPN executive and thanked Helen Jones for her hard work as previous trainee representative.

2. Minutes

Minutes of last meeting were accepted as a true record.

3. Matters arising

- a) Nephrology networks document is now available (both electronic and hard copy) and has been advertised on eNews. The committee congratulated MMG and PH on their hard work on the document. MMG has been invited to write an article about the document in British Journal of Renal Medicine.
- b) Atypical HUS national commissioning bid. MMG has worked with Newcastle group and liaised with Renal Association on some aspects of the national commissioning bid. As a result, changes have been made to the national commissioning bid allowing the BAPN and Renal Association to fully support the bid which is now submitted. The outcome of the submission is due next year. **(Action; MMG to circulate final application to BAPN executive committee members)**
- c) Advisory group for National Specialised Commissioning services. MMG has written to Terence Stephenson (President RCPCH) and he has replied (copies of letters circulated with agenda) ensuring recognition of paediatric nephrology as the debate for national commissioning of services develops. Concern was raised about the process for setting up national services (usually initiated by an individual consultant enthusiast or a patient lobby group). In addition, national services are more applicable to technical procedures (eg surgical) not holistic medical packages of care as provided by paediatric nephrologists.
- d) Proposal for ethics and law specialist advisory group. Sally Hulton has decided not to proceed with developing this group.
- e) Steve Marks has been accepted as BAPN representative to KAG **(Action SF to contact Steve Marks)**

4. Work plan.

The BAPN executive committee work plan had been circulated to executive committee and amended by SF prior to committee meeting. A few minor amendments were suggested and work plan will be kept under review at future committee meetings **(Action SF)**.

5. Items requiring discussion/decision

- a) Winter meeting planning. The BAPN winter meeting will take place on Friday 9th December at Birmingham Children's Hospital from 10.00-16.00:
 - 10.00-12.00 BAPN AGM
 - 12.00-13.00 State of the art presentation; Mignon McCulloch: International Aspects of Paediatric Nephrology (proposed at last meeting, invitation accepted)
 - 13.00-14.00 Lunch
 - 14.00- 15.00 Trainee presentations (three)
 - 15.00-16.00 State of the art presentation: HUS management including Eculizumab Sally Johnson was proposed **(Action SF to invite Sally Johnson)**

WH has identified three trainees to present.

b) Honorary membership

eNews has included invitation to propose honorary membership for recently retired colleagues. No proposals have been received. It was thought this may in part be due to people not knowing who already had honorary membership **(Action SF to ask MCI for list of BAPN honorary members, forward to LK to be placed on BAPN website)**. Different categories of retired membership were clarified:

Ordinary retired member (Renal Association and BAPN; pays retired members fee)

Honorary member of Renal Association (no fee paid: includes no fee paid to BAPN)

Honorary member of BAPN (will pay retired members fee to Renal Association if they wish to remain members of the Renal Association. They may remain members of the BAPN free of charge.).

Plan to advertise again for honorary membership, with closing date on eNews. BAPN EC will then decide upon those to whom honorary membership will be offered and announce this at the BAPN Winter meeting agenda **(Action SF)**

c) Constitution: absence of Chair of Clinical Services committee

The BAPN Constitution currently does not mention Chair of Clinical Services Committee on list of officers although this post has been in place since 2010. A decision was made for the Constitution to be modified to include this post **(Action SF)**. Also for the amended Constitution to be placed on BAPN website **(Action SF to forward to LK)**

d) Terms of office of EC members

A document had been produced and circulated by MMG. It was noted that the Research secretary and Chair of MCRN (nephrology) are currently the same individual (MS) but that the Chair of MCRN is Ex officio member of BAPN executive. Posts due to be renewed in 2012 should be advertised in eNews and at the Winter meeting **(action SF)**. The formal call for nominations will take place early in 2012

e) Baxter dialysis machine changes

Lesley Rees had contacted MMG with concerns that the Baxter dialysis machine programme had been changed so that the fill volume range has been changed to a maximum of 50mls/kg (inadequate for children with dialysis prescription based on mls/m²) and that the new software was not compatible with renal procard (useful for checking concordance).

CI had recently received training in the new software from Baxter and fed back that it was possible to increase the maximum fill volume over 50mls/kg by introducing an incorrect higher weight for the patient into the programme. However, this did raise safety concerns for the software.

(Action MMG to write to MHRA, cc Baxter)

f) Withdrawal of Kimal 8 and 10F double lumen lines

Meeta Malik had raised concerns about withdrawal of Kimal lines with no notification. Although it was noted that alternative lines were available, Kimal had failed to provide appropriate notification of withdrawal of lines and MHRA should be notified when we have more details **(Action MMG)**.

h) Future of Webex for BAPN EC meetings

Renal Association has a licence for Webex to be used for committee meetings and MMG queried whether there was a role to use this for some future EC meetings. However Webex is different from the teleconference links used by RCPCH.

(Action MMG to explore the use of Webex for one of meetings in 2012)

6. Treasurers report (JV)

No updated financial statement had been received since AGM. BAPN is operating within expenses agreed by Renal Association. No suggestions had been made for spending of excess BAPN funds. A decision was made for this to be advertised in October eNews

(Action JV to liaise with SF)

7. Secretary's report (SF)

a) Annual paediatric nephrology clinicopathology meeting

SF had received communication from William Van't Hoff regarding charging for the annual paediatric nephrology clinicopathology meeting held annually at GOS, most recently held on the day before the GOS/ICH nephrology course. EC felt it was appropriate for a charge to be made for the day and it could be held as a satellite meeting of the GOS/ICH nephrology course. Although the meeting should not be badged as a BAPN meeting, a suggestion was made that the meeting could be called 'clinicopathological meeting supported by the BAPN'

(Action SF to inform William Van't Hoff of EC view)

b) BRS update

SF attends BRS council meetings. BRS is embarking on a piece of work on clinical services in adult nephrology and SF had forwarded document on networks in paediatric nephrology so a link could be provided. BRS had asked for advice about a paediatric session at the next BRS conference (1st - 3rd May, Manchester). A decision was made to suggest Nephrology networks as a session with MMG as invited speaker. In addition, liaison with other paediatric renal multidisciplinary organisations was required.

(Action SF)

c) Choice of date for BAPN AGM at Renal Association

A decision was taken that this year the AGM would take place on Tuesday so that it would be advertised early and in all programme information to ensure good attendance.

(Action SF)

d) Executive committee dates for 2012

Four dates to be set. SF to liaise with colleagues in Leeds and MMG to suggest dates.

(Action SF)

8. Registry and Audit Committee (CI)

A new Director for the Renal Registry has been appointed (Ron Cullen). The Renal Registry 2009 data is now accessible; this has been advertised in eNews. They are due to finalise plans for analysis of 2010 data. 19th October 2011 is the latest date for data submission.

Work is ongoing with current audit projects.

A funding application submission has been made for a PhD student to work in the Renal registry.

9. Clinical Standards and Guidelines committee (DM)

No report was received.

The patient information leaflet project has been funded by BKPA and Kirsten Olsen has been appointed; she will be based at RCPCH. The first meeting of the group will be November 2011.

Paediatric nephrology will now be represented on NICE AKI guidelines group. Quality outcome indicators for renal transplantation were requested and Nadeem Moghal has submitted indicators regarding pre-emptive renal transplantation to RAG.

10. Research (MS)

MS attended for part of meeting as present at CSG Chairs meeting at RCPCH. The research report was not circulated and is summarised: The RCPCH meeting will be held in Glasgow in 2012 and the nephrology section will be joint with the Genetics group. The programme for the Renal Association 2012 in Gateshead has been finalised.

Five groups have been funded by Rare Disease committee: HNF1b (Coralie Bingham), Cystinosis (John Feehally), Gitelman's, Bartters (Fiona Karet), Alports (Neil Turner), aHUS (Tim Goodship). A further announcement for new groups is planned for early 2012.

Over 160 patients have been recruited for SRSN on RADAR.

2/3 BAPN members are signed up for access to RADAR.

The PREDNOS study is actively recruiting.

BAPN travel bursaries: the deadline is due to expire and results will be announced shortly.

Kjell Tullus has been appointed deputy chair of CSG. 2 new patient representatives have been appointed to CSG.

11. Clinical Services Committee (MO)

No report received and no apologies received.

12. Communication (LK)

The website is running well and is a useful resource

13. CSAC report (MMF)

CSAC is due to meet this afternoon. The NTN grid process for paediatric nephrology is due to start and it was agreed that a maximum of three trainees should be appointed.

14. Trainees report (WH)

Currently there are 13 trainees in paediatric nephrology (8 in clinical training, 4 in research and 1 with honorary contract). Fifteen paediatric trainees are hoping to apply to national grid for paediatric nephrology training.

16. Consultations responded to

A list of consultations responded to by BAPN was reviewed and should be updated regularly on website (**Action SF to forward to LK**).

17. Items for information

- a) No report was received from Donal O'Donoghue
- b) Metolazone has been discontinued; however the EC considered alternatives are available. This should be noted in eNews when we have confirmation of the details (**Action SF**)
- c) BPSU update. A bid for surveillance on HUS has been accepted. A letter had been sent to Jane Tizard inviting any suggestions for BPSU projects from BAPN members. This should be advertised in eNews and suggestions forwarded to Alan Emond BPSU chair (**Action SF**).

18. External committee updates

SF to establish whether Malcolm Lewis attending RIXG or whether a different BAPN representative should be put forward (**Action SF**).

19. Meetings 2011

Surgical challenges in paediatric renal transplantation Friday 18th November 2011

BAPN winter meeting Friday 9th December (Birmingham)

British Renal Society meeting 1-3 May 2012 (Manchester)

Renal Association meeting 12-14 June 2012 (Gateshead)

RCPCH conference 22-24 May 2012 (Glasgow)

20. AOB

Jane Tizard was awarded the Golden Kidney award by ESPN for outstanding services to the ESPN registry. BAPN will be contacting Jane to offer congratulations. (Action SF).

21. Date of next Executive meeting Friday 18th November 2011