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**Minutes of the BAPN executive meeting
Friday 10th June
Royal College of Paediatrics and Child Health, London**

Present: Mary McGraw (MMG), Sally Feather (SF), Milos Ogagnovic (MO), Peter Houtman (PH), David Milford (DM), Leah Krischock (LK), Simon Waller (SW), Moin Saleem (MS), Judith van der Voort (JV), Carol Inward (CI), Maggie Fitzpatrick (MMF), Helen Jones (HJ)

Apologies: Shahid Muhammed (SM)

1. Minutes of last meeting/matters arising

These were taken to be a true record of meeting. Apologies that Leah Krischock was present (not Larissa Kerecuk as recorded).

2. Agenda items

2a. Nephrology networks document (MMG)

The document is at the proof reading stage. The meetings are all finished. Of note the document has been used and modified by RCPCH as generic document for paediatric subspecialities. Hence the guidelines will be shared which adds power to the nephrology document. The nephrology networks document will be published by RCPCH as PDF which will also appear on BAPN website. RCPCH are planning a launch for their document, paediatric nephrology will be part of the launch.

2b. Atypical HUS national commissioning proposal (MMG)

The outline application has been accepted. The data used is UK data, however the application will only be for national commissioning for England. The process whereby devolved countries may or may not choose to purchase Eculizumab is unclear at present.

MMG became aware that the Renal Association were not aware of the detail of the National commissioning bid, hence it is not clear that there is adult nephrology endorsement for the adult component of the proposal. MMG has

requested the Renal Association executive to produce a named representative for the proposal.

In principle the BAPN is supportive of ensuring that Eculizumab treatment and investigations for atypical HUS are available in an equitable manner across the UK. However, there is concern that if plasma exchange therapy is not mentioned in the proposal, Eculizumab will become the default treatment for atypical HUS. MMG is aware of patients successfully managed and maintained on plasma exchange. It is not clear whether some patients will do better on plasma exchange treatment and others will do better on Eculizumab. In addition, transplantation is also a treatment option for atypical HUS although this is not mentioned in the proposal.

The clinical model in the proposal was also discussed: although Eculizumab would be provided locally, clinical responsibility would be held in the lead centre and patients would be reviewed in their local tertiary centre every 3 months by the lead clinician. The bid includes 1 WTE paediatric nephrologist based in Newcastle (with a plan to split the role between 2 0.5WTE consultants).

Concerns were raised regarding the proposed model of clinical care. Although there is a need to collate data and produce a registry it may not be necessary for clinical responsibility to be held by the lead centre clinician plus patients should really be seen in the most suitable place which might not be their tertiary centre.

Action: SF to circulate memo to all BAPN centres who provided data with letter from MMG detailing concerns together with current proposal. MMG to collate BAPN centre comments and contact Newcastle team with feedback. MMG to share comments with named representative from Renal Association.

2c. Honorary membership

The BAPN has a different mechanism for honorary membership compared with Renal Association. BAPN has offered honorary membership to all retired members. The Renal Association has no objective criteria but honorary membership is offered to a smaller number of individuals and confers some financial benefits.

Action: SF to determine the current list of honorary membership of the BAPN. SF to put out a call in eNews for honorary membership of BAPN. A list of suggested individuals could be raised at BAPN Winter meeting.

2d. Membership application process

The membership application form is on the BAPN website and requires 2 proposers. The completed form plus CV should then be sent to MCI who will then forward to secretary (SF) in order to have membership ratified at executive meeting. After the membership is ratified the secretary will contact the new member and MCI in order to have membership progressed.

All nephrology grid trainees will automatically become members (the appointing committee includes 2 BAPN members who will act as proposer and seconder for the trainee). Other trainees should be proposed. In the case of SPIN trainees the executive considered that they should be proposed by 2 members and should pay the same fee as SPIN doctors.

A new SPIN member was ratified at the committee: Catherine Derry (proposed by Jan Dudley and MMG).

2e. Proposal for ethics and law special advisory group.

MMG had received a letter from Sally Hulton asking for the BAPN executive committee for their view on a proposal to form a special interest group as a subdivision of the BAPN. The committee noted that the RCPCH also has a specialist ethics and law advisory group and wondered if nephrology might link in with this group.

Action: SF to contact Sally Hulton to offer her a slot at the BAPN Winter meeting to present ethics and law aspects of paediatric nephrology.

Kidney Advisory group (KAG) representation

Jane Tizard is currently chair of paediatric KAG (PKAG) and also the BAPN representative to KAG. She is coming to the end of her term of office and needs to be replaced by new BAPN representative to KAG. Each of the paediatric units in the UK has a representative on PKAG.

Action: SF to advertise in eNews for a current member of PKAG to become the BAPN representative to KAG. If there is more than one application, the BAPN executive will choose the representative.

2f. Winter meeting 9th December (Birmingham Children's Hospital)

The format of the meeting was discussed. The timing will be 10.00-16.00. A BAPN business meeting (2 hours) will be followed by state of the art presentations and trainee slot for 3 trainees (one hour) to present. Sally Hulton (law and ethics) and Mignon McCulloch (international aspects of paediatric nephrology) to be invited to give state of the art presentations (**action SF**).

2g. EWOPA meeting (financial shortfall)

Martin Christian had contacted BAPN to request a contribution to £8.5K shortfall in funding of EWOPA meeting based in Nottingham this year. The short fall was due to an unexpectedly low number of attending delegates. The executive agreed on this occasion to contribute £1K towards the shortfall but would not necessarily be in a position to help any other meetings with shortfall of funding. A suggestion was also made to Martin Christian to contact other European organisations to ask for financial assistance with shortfall and also to ask the delegates to do the same.

Action: MMG to inform Martin Christian of decision

3. Treasurers report (JV)

Concern was raised that the BAPN treasurer was not receiving accurate information from MCI re BAPN funding. Current funding in BAPN ring fenced account is £31K. It was agreed that funding could be provided for three £500 bursaries for trainee BAPN members to present abstracts at international meetings. An advertisement was to be placed in eNews (**action SF**). In addition JV to request eNews item in October asking for calls for suggestions for spending £31K. (**action JV and SF**). A request had been received from Mignon McCulloch for BAPN to fund a joint ISN/BAPN fellowship.

Unfortunately the BAPN did not have sufficient funds for a fellowship. Members of the BAPN executive were reminded to claim reimbursement of funds for committee meetings from the MCI (form is on the Renal Association website).

Action all members

4. Secretary's report (SF)

The BRS is holding a separate conference in 2012. SF will suggest a paediatric session on transition and encourage multidisciplinary members of paediatric nephrology units to attend.

5. Registry and audit report (CI)

There was no new update since report at BAPN AGM. Gradually paper returns are diminishing. Some centres are using different systems to input laboratory and patient demographics.

The anaemia audit project is progressing. A suggestion has been made to re-audit the biopsy standards.

6. Standards and guidelines report (DM)

The hypertension guidelines have been approved and hopefully should be put on the BAPN website. These could be linked to a comment in eNews.

The chairman of the NICE Acute Kidney Injury guidelines committee has unfortunately decided to exclude under 16 year olds from guidelines. A suggestion was made to ask RCPCH to produce a guideline on acute kidney injury in children. MMG offered to contact Jan Dudley regarding this. **(action MMG)**.

Other NICE guidelines in progress include Immunosuppressant therapy, CKD and Peritoneal Dialysis.

A template for how guidelines in speciality should be developed is required **(action DM)**.

Patient Information leaflet: DM has asked Jan Dudley for information. MMG to contact JD for update, probably the request for individual supported by BKPA to be located at RCPCH is still with RCPCH executive **(Action MMG)**.

7. Research report (MS)

A request was made to consider ideas for the Renal Association meeting in Newcastle (joint meeting with Mayo clinic).

8. Clinical services committee (MO)

The committee has not yet met. The group is involved in Kidney Care project on clinical coding by providing a paediatric addendum to a larger document. Paediatric co-morbidities are different from adult.

NHS Kidney care has asked if paediatric nephrology is signed up to You are Welcome criteria and MO is checking with units which units are registered

Action MO

The group is trying to work on acute re-admissions criteria to see if this can be useful to paediatric nephrology.

9. Communications Officer report (LK)

The annual report is available on the BAPN website and LK was thanked for ensuring all documents are uploaded to BAPN website.

10. CSAC report (MMG)

Currently CSAC is focussing on a complete update of paediatric nephrology curriculum. Concerns were raised about the naming and monitoring of special studies module for general paediatricians with an interest in nephrology. The grid trainee application process is due to start again.

11. Trainees report (HJ)

The current trainee representative HJ is coming to the end of her tenure. She will raise this to ask for a replacement at the trainees day in Nottingham on 7/8 July. It was suggested that SPIN doctors could attend the trainee day and pay a fee.

12. External committees

Kidney Alliance (SW) Kidney Alliance are in financial difficulties and will no longer be able to run World Kidney day.

International Committee of Renal Association. Mignon McCulloch had completed a survey of international links with BAPN centres together with Alan Watson.

Date for 2011: Executive meetings Friday 18th November (RCPCH). BAPN Winter meeting Friday 9th December (Birmingham)

Date of next executive meeting: Friday 30th September RCPCH