

British Association for Paediatric Nephrology

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www.bapn.org

BAPN Executive Meeting

Friday 5th March
RCPCH London
Minutes

Present: Peter Houtman, Maggie Fitzpatrick, Leah Krischock, Moin Saleem, Judith van der Voort, David Milford, Sally Feather, Simon Waller, Hugh McCarthy, Mary McGraw (President) Jane Tizard (Secretary)

Apologies: Carol Inward, Kay Tyerman, Milos Ognjanovic, Nadeem Moghal

1. New members of the Executive committee were welcomed
 - a. David Milford-Chair of the CS&G Committee
 - b. Sally Feather as Secretary elect
 - c. Simon Waller as ordinary member elect
2. Minutes of last Exec meeting
 - a. These were agreed as a true record of the meeting in September 2009
3. Matters Arising(not otherwise on the agenda)
 - a. Quality initiative
 - i. JT explained that the NM had tried to get RCPCH support for a meeting for this but it was not forthcoming. The BRS had hosted a meeting which NM had led the paediatric component. However the report from this meeting is being compiled by Paul Stevens from the BRS and JT had agreed to input the workforce data for paediatrics. This is now becoming more of a numbers report. The quality issues may become part of the networking document.
 - b. AGM 2009
 - i. A report of feed back showed that this was well received. The business meeting was appropriate length and other talks enjoyed. (Post meeting PH stated that the minutes of the AGM did not include the rest of the day and therefore no documentation of the service /network discussion. It was agreed by JT/MEM to put slides onto the website)
 - c. 2010 meeting
 - i. The plan for the RCPCH meeting to be devolved to the regions has been abandoned. This would have worked well for nephrology. There will be a clash of the RA (at which the AGM will be held) with the RCPCH meeting every year and the future of the renal day at the

RCPCH is uncertain. It was agreed that the 2nd business meeting in the year was good opportunity for networking and to involve the SPIN doctors more than at the RA meeting at which the AGM will be held. Similar format to 2009 welcomed. It may be necessary to self fund. Birmingham a good venue, DM to see if available on Friday Dec 3rd.
(Action DM)

4. Work plan
 - a. This has been updated recently-there were no new comments
5. Paediatric Nephrology Networks
 - a. MEM has produced an outline proposal for this piece of work. The BAPN proposal is for guidance to commissioners and others on the service specification for a paediatric nephrology service/network. This has followed the work of Peter Houtman which has identified an inequity of services available across the UK. The plan is to produce standards of care but acknowledging that there will be different processes in each region.
 - b. It was suggested
 - i. That there should be increased presence of commissioners in the group. If commissioners involved then this may help financial impact of the report's recommendations
 - ii. There could be 2 separate parts –standard setting and commissioning
 - iii. Other examples to consider-
 1. model of cardiology services
 2. Welsh document covering same issues **(Action JVV to send to Exec)**
 3. Scottish networks are well developed. Need to ask D Hughes re experience**(Action LK)**
 - iv. Financial support
 1. RCPCH shown some interest re link with general paediatricians but unlikely to give financial support apart from venue
 2. NHS kidney has been approached and has indicated some support but awaiting responses to formal request to Beverly Matthews.
6. Reports from NHSBT
 - a. This was a request by S Marks to discuss the issue of transplanting small children and whether there should be rationalisation into fewer units for these patients. It arose from analyses of waiting times to Tx by NHSBT which identified that patients in Birmingham and Belfast were waiting longer than other regions for Tx. There were a large number of refusals of kidneys due to kidney size. In Birmingham this has probably been addressed by the appointment of a new surgeon. In Belfast this information was available to them to be discussed locally. It was agreed that JT should write to MOC to suggest that in the event of children being disadvantaged by waiting until reaching 20-25Kg before listing for adult kidneys, families should be offered the option of travelling elsewhere in the UK. **(Action JT)**
 - b. It was also reported that at the KAGPaed subgroup the surgeons had suggested that a transplant workshop would be useful –this was agreed but thought that it should be BTS driven. Therefore JT to contact BTS link.
 - c. Further discussion re the reasons for refusal of kidneys. Apparent that in some centres the surgeons take initial call and many kidneys refused before the nephrologists even aware. For Email survey of centres to establish local practice. **(Action JT)**
 - d. Guidelines for accepting kidneys were discussed. JT explained that this had been discussed at the KAG paed subgroup and it is quite difficult to do but is being considered.
7. European directive on organ transplantation

- a. There is a planned amendment to the EU that will make live donor transplantation a second option and will make LRD Tx much more difficult. The reason is that there is concern about exploitation of donors. Various organisations have responded to this as if passed by the EU will have a significant impact on Tx in children. JT has written a draft letter from the BAPN and it was agreed to send this to the MEPS involved in this group. Letter will be sent prior to meeting of this group on 16th March **(Action JT)**
8. Education and Renal transplantation
- a. This article from JCHC had been brought to the attention of the Executive on behalf of patient representative from the Paed KAG. It highlights the need for improved liaison with education for children with Tx. It was agreed that this should include all patients with ESRF and this area should be included in the network project.
9. Atypical HUS
- a. This document was sent by NHS kidney care to MEM for comment. It was agreed that it is a good summary and guideline and well written but not clear why it was developed, who it is aimed at and the authority of it. As it is a specification for commissioning it was questioned as to whether this was pre-empting an NCG bid. There was concern at the statement on page 13 " the aHUS group would make recommendations to PCTs on the individual appropriateness of these drugs on a case by case basis"
 - b. MEM to contact Mark Taylor for further information and respond by 31st March **(Action MEM)**
10. Committees
- a. New appointments-
 - i. As above in 1
 - ii. Milos Ognjanovic Chair of the Clinical services subcommittee
 - iii. Lyda Jadresic-member of the Clinical Standards and Guidelines group
 - iv. Agreed that LJ would deputise for PH on Executive when necessary.
 - b. New appointments
 - i. RA international committee
 - 1. If no other applicants via MCI then Mignon McCulloch is the only applicant –strongly supported
 - ii. Link with ISN-appropriate for International committee link
 - iii. Member of clinical guideline group- if no applications JT to contact Meeta Malik **(Action JT)**
 - iv. Link with RA Clinical guideline group should be Chair of BAPN CSG group i.e. DM. Contact RA **(Action JT)**
 - v. CSAC-STA. Need for new STA was requested by MF but not advertised yet. Contact RCPCH. **(Action MF)**
 - c. Lay representative
 - i. Person Specification and Terms of reference were agreed. To be sent to NKF to advertise. Request short personal statement. **(Action JT)**
 - d. ACCEA committee-composition of panel to be recorded for SF for 2010
11. Constitution
- a. Needs to be altered to reflect that BAPN is now a Division of the RA
 - b. Will need to be agreed at the AGM in May.
 - c. JT had submitted changes. All agreed except for paragraph on financial aspects. JVV to discuss with S Roger, RA treasurer ASAP. **(Action JVV)**
 - d. Circulate to Exec for final approval **(Action JT)**
12. Reports
- a. Treasurer
 - i. Report noted

- ii. Expenses will now be sent direct to MCI. Form to be put on to website and circulated to Exec **(Action JVV and LK)**
 - iii. With change to subscription payments some have paid earlier than planned-therefore paid extra this year. It was agreed that repayments not possible.
 - iv. Balance of £ 24,254 is from KKR money-this will need to be put into restricted funds within RA account. Report on this part of account will be made to BAPN AGM annually.
 - v. Payment for the Nephrology CSG had been agreed from the KKR funds. CSG requesting £10,000pa. Future of this funding will be discussed at meeting between MS, MM and KKR in March. **(Action MM &MS)**
- b. Audit and Registry
- i. Report noted
 - ii. Renal Biopsy standards had been discussed at CCG group. Modifications being made and will be sent to Exec to ratify. Standards will be put on the website and reaudit undertaken.
 - iii. There was support for the Paediatric renal registry committee to have the same status as the Tx and dialysis committee within the UKRR structure.
- c. Research
- i. RDUK report noted
 - ii. Meeting with KKR on 24/03/10 to discuss funding and grant applications. **(Action MM and MS)**
 - iii. Rare Kidney Disease Strategy document.
 - 1. The BAPN was invited to endorse this. Initiated from Rare disease Strategy working group.
 - 2. It was considered a well written document although with some lack of clarity of relationship with RaDaR, the purpose of the document and who it was aimed at.
 - 3. Overall the Executive agreed to endorse with some minor changes. MM will feed back to John Feehally/Mark Taylor. **(Action MM)**
- d. Clinical Services Committee
- i. Paediatric Pathology services
 - 1. Highlighted the differences across UK. However need pathologists to action. No further action from BAPN
 - 2. Paediatric dialysis costs. JT had had reassurance from Donal O'Donoghue that there are no plans to bring paediatric dialysis into tariff in the near future. Also PbR would not be considered without full clinical engagement
 - 3. Newcastle PbR-NFA
 - 4. Benchmarking-need to consider quality outcomes.
 - ii. It was agreed that MO should discuss with NM re any further work that results from these pieces of work.**(Action MO)**
- e. Communication Strategy
- i. Report noted
 - ii. Patient information leaflets
 - 1. LK will hold Word versions for adaptation by local units. There will be list of available PILs which can be requested from LK. This is to overcome issue of quality control of National PILs.
 - 2. Consider application for funding from BKPA for national resource. Previous possible funding not available.**(Action DM & Jan Dudley)**
 - iii. Website development-aim to ask MCI to take this on. LK will discuss at meeting with RA/MCI in March**(Action LK)**
 - iv. Advertising meetings-it was agreed that the same processes as used by the RA should be used, which is via endorsement by the Education committee. For paediatric meetings agreed to use the CSAC for

endorsement. Main meetings should be on calendar on BAPN website and these will be advertised on e news too.

- f. Clinical Standards and Guidelines
 - i. Report noted
 - ii. Kidney Care plans
 - 1. DM has word version. He will check with Beverly Matthews that these can be adapted but it is thought that they can be. Will then put on website. **(Action DM & LK)**
 - iii. Patient reported outcome surveys will be placed on the website for local use. **(Action DM & LK)**
 - iv. Birmingham standards document used for local peer review will be made available on website as self assessment tool for units. **(Action DM & LK)**
 - v. Guidelines for trainees
 - 1. A list of suggested guidelines will be made available for trainees by Standards and Guidelines group and CSAC. **(Action DM & MF)**
 - vi. RA standards
 - 1. The paediatric additions to these could be made available via a tab on the RA webpage. These additions would have to be approved by the RA Standards and guidelines group. It was agreed this was appropriate. BAPN guidelines that are only accessible on BAPN website do not need approval by RA.
- g. CSAC and trainee issues
 - i. 17 trainees, 9 will have CCT by end of 2010.
 - ii. Considerable anxiety re job availability. 2 jobs, 1 in Nottingham and 1 in Birmingham for 2010. Also 0.6WTE Cardiff and 1 year locum in Leeds.
 - iii. Need to be clear with trainees that cannot guarantee tertiary post but are likely to be more SPIN posts in the future. Need to keep up general paediatrics so that still appointable as general paediatricians.
 - iv. JT is collecting retirement dates-not all available yet.
 - v. 2 Grid posts appointed for September-will need to keep restricting posts for the foreseeable time.
- h. SPIN
 - i. Report noted
 - ii. PH will email those who responded to survey to encourage joining BAPN. **(Action PH)**
- i. Secretary
 - i. NICE representation
 - 1. Hypertension update-Kjell Tullus represented BAPN but did not think it appropriate to extend to children.
 - 2. Peritoneal dialysis-D Milford will be the BAPN representative
 - ii. Workforce
 - 1. The document being produced by the BRS has changed direction from quality to quantity. The paediatric data collected is much more limited than from the previous report. This will be analysed and discussed as to whether appropriate for report. JT may ask for support from SF.

13. World kidney day

- a. Report noted
- b. There will be paediatric representation at the parliamentary reception specifically for research attended by M Saleem, D Hothi and P Winyard.

14. NeoRecormon

- a. The BAPN and KA have expressed their concern over the withdrawal of the EPO pen option of delivering erythropoietin. This concern has been also been expressed by the MHRA and EMA. It is not known whether Roche will reverse the decision in the light of this pressure.
- b. Darbeapoetin is the alternative licensed preparation for children but no suitable preparation for young children to use with pen device.
- c. JT has been approached by link with (Jansenn-Cilag). They may consider trying to extend licence and produce pen device.

15. Transition/adolescent nephrology

- a. MM is now on the project board for the Transition project to take forward the issues from the RA/BAPN transition document. This document is on the RA website.

16. Ira Greifer award

- a. MM has received a request for Executive Committee support for a nomination for the Ira Greifer award. The Executive gave their full support to this nomination.

17. Meetings –2010-11

- a. RCPCH Warwick wed 21st April 2010
 - i. Invited speakers are: Dr T Chambers –Salt poisoning and Dr M Sinha - Hypertension
- b. RA/BRS Manchester May 17-20th 2010 (plus BAPN business meeting Tues 18th May
- c. Exec meetings 28th May, 10th Sept, 26th November RCPCH
- d. Histopathology meeting GOSH Friday 4th June

18. Date of next Executive Meeting – May 28th RCPCH 10.00-13.30