

British Association for Paediatric Nephrology

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Minutes of BAPN Executive Meeting

Friday 10th October 2008

Education Centre Birmingham Children's Hospital

Present: Mark Taylor (President)

Kay Tyerman
Moin Saleem
Leah Krischock
Sally Hulton
Chris Reid
Eric Finlay
Carol Inward
Jane Tizard(Secretary)

Apologies: Dick Trompeter
Nadeem Moghal
Lesley Rees

1. Minutes of the last meeting June 13th 2008 were agreed as a true record of the meeting
2. Matters Arising(not otherwise on the agenda)-none
3. RA/BAPN interaction
 - a. MT put forward a proposal to strengthen links with RA. It was suggested that the BAPN needs more formal support with for example keeping records of membership and to have a base which would remain the repository for all documents and a constant contact address. Currently the RA is managed by the MCI group. MT suggested this group could be asked to support the BAPN. It would be essential to maintain the identity of the BAPN and not to submerge in the RA. There should be synergism between the Associations but clear identification of BAPN which should not be a subgroup of the RA. Would be advantages for children particularly as they will be patients of the adult nephrologists in the future. Currently there is great support for paediatrics but

it is possible that this will not be so clear in the future –therefore there is a need to strengthen this relationship. Must consider general paediatricians with an interest who are BAPN members –they would not be expected to be members of RA too. There was general support for the proposal and it was agreed that MT, JT and EF should meet with either PM or LH and MCI to explore the possibilities and cost to the BAPN. Plan initially meet and bring proposal to December BAPN AGM. (**Action MT and JT**)

4. BAPN link with Nephron

- a. Robert Kleta has asked whether there would be interest for BAPN to adopt Nephron as its journal. This is being discussed between the RA and Nephron. Nephron would then publish RA abstracts. For paediatrics it is slightly different as York abstracts published in ADC and ESPN abstracts in Paediatric Nephrology. Paediatric Nephrologists have more allegiance to this. Therefore the BAPN should support the discussions between the RA and Nephron but not appropriate to have separate link. To let R Kleta know of discussion (**Action MT?**)

5. Reports

- a. Treasurer –written report discussed in DTs absence

- i. 3 X £1000 bursaries given to trainees for abstracts to ESPN/ASN
 1. Shazia Adalat, Rajiv Sinha and Dal Hothi
- ii. ESPN registry –MT proposed that the ESPN registry should be given some pump priming but that there should be an identified registry fund. Ask DT to approach KKR to see if they would consider a grant to the ESPN for this purpose (**Action JT**). MT to write to D Haffner, treasurer of ESPN to see if identified account can be created.
- iii. KKR providing £100,000 for 2 more years (2nd donation already received). KRUK had agreed to give £50,000 to support paediatric studies. This year 3 studies submitted, 2 funded for total of £75,000. The remaining £25,000 will be available for next year's funds + £50,000 from KRUK –therefore £175,000 total. Next call in October – for February deadline-MS to announce when available(**Action MS**)

b. Registry and Audit

- i. CI reported that there was excellent support from the adult Registry team.
- ii. Data protection concerns are being addressed. All units have an info leaflet and have been asked to request written consent from all families. This is required for paper returns. This is the responsibility of each Trust. Malcolm Lewis' laptop has been encrypted.
- iii. MLs link with proton has been re-established
- iv. Deadline for returns is end of October (April 08 data). 3 units' missing- Glasgow, Cardiff, Southampton. Meeting next week to discuss chapter in RR report –needs to be submitted by end of November.
- v. From April 09 the data will be submitted directly to the registry if electronic link available. Matthew Brealey is developing a screen to identify missing data from registry returns. For those with no electronic link ? to send paper returns via ML or to Bristol. CI to enquire (**Action CI**)

- vi. Implementation of the National Renal data set-is mandatory-these will be data items for the registry. Each Unit will need a system in place to input data.
 - vii. In the future will aim for quarterly returns. Centre specific reports will be available.
 - viii. The cost for patients on the registry is to increase.
- c. Audit
- i. CI reported that the DoH is trying to reinvigorate audit. Therefore money is available for audit-particularly to inform patient choice and commissioners.
 - ii. The Colleges will be defining what role consultants need to have in audit for revalidation
 - iii. BP in Tx patients. This in an excellent audit-M Sinha to be asked to present at the December AGM.(**Action JT**)
 - iv. Future audits-there should be a consultation process which should include “users”. Following on from NICE guidelines there should be audit of anaemia in CRF-Shazia Adalat has agreed to do this. Need to seek help from HR re honorary contracts (NIHSR-for research don’t need honorary contracts). CI to investigate further as this would facilitate audit. (**Action CI**). There needs to be action plan for audit projects as programme will escalate. It was agreed that chair of Registry and Audit committee should be overall in charge but with close liaison with Standards and guidelines group (Chair of R&A sits of CG Committee). BAPN should apply for funding for audit. Renal registry possibly a resource. (**Action CI**)
- d. Research
- i. The MCRN has worked well over first 6 months. There are a small number of funded projects.
 - ii. The rare diseases registry will be recruiting patients in 3-6/12. Consider applying to other conditions but as infrastructure still not quite established-wait until end of year. Aim is to link with UK Renal Registry.
 - iii. York-the meeting will be different structure. More general paediatrics and CPD sessions. Joint sessions encouraged. This year nephrology will link with genetics. Next year possible link with endocrinology. Hot topics 5 x 5’ to be organised by MS. (**Action MS**)
 - iv. RA April 2009. Encourage members to attend. BAPN meeting wed 22nd April 12.00-JT to arrange(**Action JT**)
- e. Clinical services committee-written report as NM unable to attend
- i. Dialysis tariff-being evaluated. Concern that adult tariff with 90% top up will be recommended-which would be insufficient based on data available.
 - ii. BRS/Workforce-exploring with Workforce Review Team funding for paediatric MDT meeting to define quality metrics and to use to define the necessary workforce to deliver on quality outcome.
- f. Communication strategy
- i. Branding for BAPN being looked at.(**Action EF**)
 - ii. Website and forum not being used much. It will be possible to link with GOS website for patient information leaflets. RA(?) website links to other literature on topics-this would encourage use. Possibly link with

Map of medicine. Could link via BAPN. EF to join meeting with MCI re RA link.

- g. Clinical guidelines-written report as LR unable to attend
 - i. UTI-guidelines implemented with local modifications in most units.
 - ii. KDOQI guidelines-the committee has provided a response.
 - iii. HUS guidelines by S Johnson accepted by group.
 - iv. Trainees-all have chose topics. LK to write to BJRM to see if these could in principle be published in this journal. (**Action LK**)
 - v. Astellas have agreed to provide money to develop guidelines-these will be Tx related initially. The Exec agreed that the money could be used in this way but BAPN must have overall responsibility.
 - vi. Personal Care Plans-this is an NSF requirement for every patient. Ask DM to take forward proposal for nationally agreed Care Plans (**Action JT**).
- h. CSAC
 - i. National Grid requirements are for 24months clinical and variable 12 months research or clinical. It is not possible to formally change to 36 months compulsory clinical. However there is flexibility within the CSAC to agree to the last 12 months being clinical. However should consider on individual basis.
 - ii. Have been asked by RCPCH for method of work force planning. Plan to do repeat Survey Monkey-also to ask for DCC PAs. **Action EF**
- i. **RIXG**
 - i. Continuing difficulties reported with development of CfH project and data collection of renal dataset. At Guy's Cormac Brean has developed own system which is not only renal specific. This could be an alternative to Proton soon.
 - ii. ERA/EDTA codes-there has been a significant expansion. Diagnostic criteria defined where possible-eg biopsy/gene. Maps to SNOMED(renal subset of SNOMED)
 - iii. RPV-increasing use-131 in Bristol/ Cardiff, 10 Nottingham. Guys/Evelina will be using soon. RA association will take over the administration. Will cost £2.50 per patient.
- j. Secretary
 - i. SSNDS-this was reviewed and agreed with minor amendments.
 - ii. Officers :
 1. President –term ends May 09-agreed to ask for nominations before December AGM (**Action JT**)
 2. Other officers it was agreed could be put forward for 1 year extension-but would be elected by ballot if others nominated.
 3. Clinical Services Officer –term ends may 09-could be re-elected for one year
 4. Clinical Standards Chair and Communications Officer term ends September 09-could be re-elected one year (EF does not wish to be considered for re-election).
 5. Research secretary –this post needs to be aligned with CSG chair. For this occasion MS will be asked to continue to 2011
 6. CSAC chair –SH has contacted the RCPCH re new appointment
 7. Paediatrician with an interest-is not in our constitution-to change constitution at AGM in December (**Action JT**).
 - iii. Transition committee

1. D Milford is leading this committee. The aim is to produce a professional statement from both colleges.
6. World Kidney Day **12/03/09**
 - a. There are 3 messages –raising awareness of kidney disease, increase GP testing and encourage healthy life style. Use of the logo is encouraged. Press Officer to increase media coverage. There will be parliamentary reception.
Paediatric cases are still needed. Need to publicise (Action all).
 - b. Presumed consent
 - i. KT has produced a further statement which was agreed by the Exec. Distribute to BAPN before Dec AGM. **(Action JT)**
7. ESPN 2009 Birmingham
 - a. Programme well advanced
 - b. Finances remain a concern.
8. External committee updates
 - a. UKT –there is now a paediatric subgroup of the Kidney Advisory group First meeting will be on the 22nd October
 - b. NICE-it was agreed that responses to requests from NICE should go via the guidelines group
9. Meetings – 2008-9
 - a. AGM Dec 5th Birmingham
 - b. General meeting at RA/BTS meeting wed 22nd April 09 TBA
 - c. BRS 1-3rd June 2009 Birmingham
 - d. Exec June 09 Book with CSAC-arrange with new President
 - e. 5th IPTA congress April 18th-21st Istanbul
10. Date of next Executive Meeting – March 13th 2009 at RCPCH-SH to book room(**Action SH**)