## BAPN WINTER MEETING

12 December 2014, 10.00am, Education Centre, Birmingham Children’s Hospital

**Present:** Munir Ahmed (MA), Caroline Booth (CB), Mark Bradbury, Martin Christian (MC), Richard Coward (RC), Jan Dudley (JD), Angela Hall, Alexander Hamilton, Eleanor Hay, Wesley Hayes, Dal Hothi (DH), Peter Houtman, David Hughes (DH), Sally Hulton (SH), Sally Johnson, Larissa Kerecuk (LK), Heather Lambert, Andy Lunn (AL), Heather Maxwell (HM), David Milford (DM), Mordi Muorah, Arvind Nagra (AN), Amanda Newnham, Louise Oni, Hitesh Prajapati, Ben Reynolds, Manish Sinha (MaS), Mohan Shenoy (MoS), Suzanne Stephens, Jelena Stojanovic (JS), Jane Tizard (EJT), Kay Tyerman (KT), Dean Wallace, Nick Webb.

|   | **Welcome**  
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<tr>
<td>1</td>
<td>EJT welcomed everyone to the Winter Meeting.</td>
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|   | **Apologies**  
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<td>2</td>
<td>Received from Kjell Tullus, Steve Marks, Lesley Rees, Pallavi Yadav, Mary O’Connor, Mairead Convery, Carol Inward.</td>
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|   | **Minutes of AGM (2 May 2014)**  
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|   | **Matters arising (not otherwise on agenda)**  
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|   | **President’s report (EJT)**  
|---|-----------------------------|
| 5 | EJT congratulated David Hughes (DH) on his election as the next BAPN president. She thanked the exec for their support over the last year and in particular Maggie Fitzpatrick who is standing down after 5 years as CSAC chair and Jelena Stojanovic who is standing down after 1 year as trainee rep. New members were welcomed to the exec: Kay Tyerman as CSAC chair and Hitesh Prajapati as trainee rep.  
Commissioning issues. In view of increasing number of IFRs for rituximab for management of NS, Nick Webb and Moin Saleem have developed commissioning policies for rituximab use in SSNS and SRNS respectively. Policies have been put out for consultation and amendments made in response to feedback. Both policies were well supported at a prioritisation event on 28 October. We are awaiting the outcome of NHS England’s meeting in December. We have stated that these patients should be entered into a registry but funding for this not yet identified.  
Plans for national commissioning of cystinosis services were discussed later in the Winter Meeting programme, led by Stephen Waldek.  
Outcome measures. We were asked to develop paediatric nephrology outcome measures for national service contract (service specification). Feedback received from draft measures circulated but they are difficult to develop and will need further discussion. Currently there is less pressure to develop for national service contract but overlap with measures required for peer review which will be needed sooner. |
Meetings in 2015 and beyond. RA meeting will be combined with ERA-EDTA being held in London. All are encouraged to attend. BRS will be stand-alone meeting in 2015 in Leeds. AN is presenting on transition. All encouraged to come and support MDTs in submitting abstracts. Congratulations to Glasgow team for their winning bid to host ESPN in 2017. RA Trustees are very supportive of this and the BAPN will actively support the meeting organisation.

RIGB issues. DM to speak later on AKI update. Alexander Hamilton is the new Tony Wing Fellow and will present his plans for his tenure later in the programme. RaDaR now recruiting for 18 RDGs. 1307 patients recruited (328 SRNS). RaDaR facilitator has visited 46 renal units. Need to promote this in paediatric units. IT has been a problem but now working with IT system used by UKRDC (UK renal data collaboration project). Using InterSystems integration engine, which should move project forward. RPV undergoing PV2 rebuild to work on mobile devices and will enable data entry from /access from different sources/ authenticated applications. Now PV and not RPV as are branching out to include other diseases (diabetes and IBD). Devices for Dignity (D4D) is a project now applying for phase 2 funding to develop systems where patients can input and amend some data. Looking for renal units to participate in this (email sent to centre leads recently). Plan to increase capitation fees for UKRR patients to £22 per annum by 2017 but additional income expected from AKI/CKD patients from 2016. UKRR capitation fees currently support RaDaR.

Secretary’s report (MC)
For information. Changes proposed to exec which would introduce 4-year presidential term with first year as president-elect overlapping with outgoing president for leadership continuity. If approved, changes would take effect from 2017. New constitution to be circulated with eNews and voted upon at AGM. EJT has agreed to remain on exec in co-opted role as CRG rep. BKPA are identifying suitable candidate for lay rep. Peer review has restarted. Broader process is now proposed which would see all units participating with only certain ones selected for peer review visit. Draft measures document is almost ready for circulation for comments from members.

Issues for voting. No objections received for re-categorisation of members. One member did not receive eNews regularly. MC to follow-up with MCI. Some members felt that a Winter Meeting in Glasgow would be less accessible for a one-day meeting. MC to conduct on-line survey to take wider views.

Anglo-French meeting. Members of the Société Néphrologie Pédiatrique (SNP) are enthusiastic to try out a joint meeting. This is supported by the BAPN exec. The suggestion is for a 3-yearly meeting, held separately to the joint adult meeting (Entente Cordiale). The French have offered to host a first meeting in Lille in November/December 2016 and this might combine with the BAPN Winter Meeting that year. Members were broadly supportive but conscious of a further meeting. An initial trial meeting was suggested before committing to regular 3-yearly meetings. Lille as a venue was questioned about its convenience outside of London. MC to take these views back to the SNP exec.

Treasurer’s report (AN)
Funds currently stand a £23,924 which remains unchanged. RA expenses fund is at £616 once travel grants have been paid out and this is due to be topped up again in January. Only 2 travel grants paid out to members for Porto presentations. Trainees’ fund is now set-up. NW suggested using open access funds to pay for open access to UTI paper to promote readership and citing. Are BAPN funds in a high-interest account? AN to check with MCI. EJT clarified that £10k ring-fenced for guideline development can still be used.

Clinical standards and guidelines (JD)
CS&G committee met in February. Group comprises: JD, AL, MaS, DH, JS, Meeta Mallik and Lyda Jadresic.

Guidelines. Little progress on national guidance development. Current RA guidelines have
NICE accreditation. RA/BAPN to apply for funding to complete guidelines update. KRUK have been approached with a view to a project manager to co-ordinate. Need to consider other sources of funding if KRUK cannot support. Some discussion about how the paediatric guidelines will fit within plans to develop IPNA guidelines. There is to be a teleconference about this between JD, Andy Lewington and Brue Hendry as there is a suggestion that the UK should make more use of the KDIGO guidelines rather than doing new guidelines in some areas.

InfoKID. First phase completed in March 2014. Currently receiving 3000 hits/month with most from UK but significant hits from US, India, Canada and Australia. IPNA will link to the site. Evaluation in March 2015 is aiming to include development of clinical decision aids. JD encouraged all units to include the infoKID website on clinic letters.

Pediatric Care Online (PCO). This is an on-line diagnostic support aid. BAPN support is required for adapting US-based information for a UK audience. There are 10 guides, all 4-8 pages long. As yet no consultants have volunteered.

Quality and innovations group. Discussion recently about broadening the remit of the CS&G to become a forum for Q&I idea sharing. The outputs of the group would include grant applications and collaborations with other groups, e.g. RCPCH. JD and DH to work together to develop draft format for further discussion.

9 Registry and Audit Committee report (MaS)

Registry. 2013 report will contain 2 chapters on paediatric ESRD and data for this report should be on-line imminently. All returns have been electronic (891 children). Demography report contains analyses on pre-emptive transplantation, transfer to adult services and survival on RRT during childhood. Biochemistry chapter has been restructured to give more interesting read. New analyses on growth and CVRFs (35%, 27% and 12% had 1, 2 and 3 CVRFs respectively). Hypertension and increased BMI were most prevalent CVRF. Highlight areas to improve for all centres include: cholesterol (50%), ESA and IV iron usage, co-morbidity data, understanding in transition and transfer policies.

Future work to include: merger of paediatric and adult databases to allow reporting of data for 16-18 year olds (final height, longer term outcomes and graft lifespan); integration of the adult and paediatric dataset (paediatric specific items in New adult Dataset v4.0 at https://www.renalreg.org/datasets/the-uk-renal-registry-dataset/; 2 specific paediatric pages in the dataset; dataset being rolled out to renal IT software publishers; move towards quarterly reporting and will provide uniformity in data items collected). Formation of renal data warehouse should lead to tighter data.

Practicalities for 2013 data were challenging. Several centres had new IT systems and some centres were left with no data extraction support for 2012 data on ‘old’ systems. RR team member visited some centres to facilitate this process. From 2014 data returns will only be accepted via electronic submission.

All must ensure that their unit is on Patient View. There are new EDTA codes for new patients are available www.era-edta-reg.org/prd.jsp. There is a plan to arrange an education day in 2015 to meet the Registry team and explore registry capabilities.

For 2014 report timelines: numbers, new, prevalent and transferred patient details must be received by 31/1/15. Reminders of this process in your inbox 1-2 weeks’ time. There will be mid-January reminders to units that have not yet sent this. Quarterly returns will be requested for biochemistry. All data returns (annual/quarterly) need to be submitted by the 31/3/15. Submitting data on time is essential. Summary data returned to centres by 30/05/15. Analysis and write up will take place from July onwards.

The aim in 2015 is to improve output from the Paediatric Registry: annual returns process is exhausting and time consuming and this impacts on other projects. ERA-EDTA annual data has been submitted and there are plans to increase collaborative projects.

Audit. Output from the Paediatric Registry in 2014 has been limited as focus has been on
new datasets/databases. Two projects are being written up: ‘late presenters’ and ‘infant dialysis project’ manuscript. There are on-going collaborations with ERA-EDTA. Re-audit of renal biopsy in children has taken place. AKI audit taking place in early 2015 in 3 tertiary centres and 3 “DGHs” using shared electronic returns. Data are needed for March when the patient safety alert directive for standardising the early identification of AKI will need to be implemented in all English Trusts.

**Questions.** HM congratulated MS on the huge effort to achieve 100% electronic returns. She also commented that ERA codes are not particularly paediatric and anticipated some difficulties extracting paediatric data. MS stated that paediatricians were involved in the new coding and that any difficulties when using should be flagged up. DH asked about plans for including CKD3-5 data. EJT suggested that all these patients should be added to local renal IT systems now so that their data can be uploaded when asked for in the near future. DH stated that BAPU are now recording all new cases of posterior urethral valves.

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<th><strong>Research report (SH)</strong></th>
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<td><strong>Meetings.</strong> Next RCPCH meeting 10 April 2015 (Birmingham) will be joint with endocrinology Sally Hulton liaising with Paul Dimitri from endocrinology regarding the programme. Speakers arranged are: Nicola Crabtree (current use of bone densitometry); Nick Shaw (FGF23 in kidney disease). RCPCH meeting for 2016 paired with gastro/nutrition. ESPN 2017 will be in Glasgow. We are planning the academic programme for this: ideas and suggestions gratefully received. Suggestions to facilitate a paediatric/adult trainee meeting have been favourable, possibly link to the NTN grid training days with careful planning. <strong>NRRS.</strong> Established following Kidney Health Delivering Excellence document. Steering group co-ordinated by UKRR consortium. BAPN need to be identifying research priorities; each CSG sub-group to prioritise top 1-2 ideas with patient/parent input and link in with adult CSGs. Draft document planned to be generated by the end of the year, which will be circulated to all stakeholders. <strong>Current research studies.</strong> PREDNOS has closed with 237 recruits. Last patient visit will take place in September 2017. Retention has been &gt;90%. NW thanked all members for their support and encouraged them to continue to send in data returns. PREDNOS2 is behind target. The study has applied to the HTA for a funding extension. Current recruitment is steady at around 7/month. This will be the largest ever multi-centre study in nephrotic syndrome and it is important to be able to deliver on this. There followed some general discussion about the need to continue looking and re-looking for recruits. Regular newsletters are being sent out. eNews contains a link to the latest newsletter and will also carry up-to-date information on individual centre recruitment from now on. HOT-KID has recruited 194 patients and randomised 67. Another 5 centres will be taking part: Leeds, Southampton, Brighton, St. George’s and Medway Hospital. Inclusion criteria have been revised: now CKD stages 1-4 in the last 12 months; first line anti-hypertensive may be either ACEi or ARB. Newsletter to be sent out shortly. <strong>Challenges in paediatric transplantation.</strong> This is the group and annual meeting formally known as surgical challenges in paediatric transplantation. 2 multi-centre studies are proposed as an initial group output: indomethacin associated bladder dysfunction in congenital NS: retrospective national audit (led by Liam McCarthy, BCH) and CMV/EBV/BKV infection post renal transplant (MoS) – a prospective surveillance study using a BPSU-like approach of initial identification followed by more detailed questionnaire.</td>
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<td>HM updated members on progress with Glasgow’s bid to host the ESPN meeting in 2017, the 50th anniversary of the first meeting also held there. The proposed dates are 7th-9th September. The bid has had enormous support from Glasgow City Marketing and the SECC. The proposed local organising committee is HM (chair and congress president), EJT, MC, AN and DH. The proposed scientific committee will be chaired by RC and will include NW, Moin</td>
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Saleem and Detlef Bockenhauer. It is not yet clear how the ESPN committee will contribute to the scientific committee. Flaptours’ contract with ESPN goes out for re-tendering next year so the ESPN administrative support for the meeting is also not yet clear. The meeting plans to take advantage of various professional/scientific links in the UK, such as with RaDaR, UKRR and NHSBT. The SECC has purpose-built rooms that easily meet ESPN requirements. Glasgow city marketing will contribute £10k towards transport and a social programme. Possibilities for an opening ceremony and gala dinner were discussed. Feedback from Porto 2014 had been sought after the meeting. Some thoughts to address for Glasgow 2017 include: sufficient number of plenaries and high-profile keynote speakers (to begin and finish each day?), virtual speakers, organisation of industry-sponsored symposia (also, should they be pre-conference?), themed sessions, appropriate starting time for early morning CPD sessions, advance publicity for ESPN working group sessions, timing of poster sessions, availability of coffee through the day, consideration of breakfast with early morning sessions, availability of abstracts on-line, interactive site map, hotel booking from conference website. As part of a social programme a gold tournament and 10k run were discussed. The LOC will meet at the ERA conference. DM suggested an early search for industry-funding to reduce the cost for delegates. HM stated that the Glasgow conference organisation support had been tasked to bring the meeting in on budget.

12 Clinical services committee report (SH)

Tariffs. Changes to the proposed in-patient tariff were discussed. PA38D, the main in-patient code will attract a reduction of 13.6% from next year. This has been challenged by the adult renal community and the tariff change is now being reviewed. DH stressed the importance of accurately coding co-morbidities. Out-patient tariffs were reviewed. Most paediatric sub-specialties now have a national tariff but this is not yet the case for nephrology. Individual units were surveyed for their locally-agreed tariffs and these varied enormously. If a national tariff is implemented, this may well be the lowest of the individual centres. After discussion, it was agreed that this information would be shared with individual centres anonymised for use with further local negotiations but that we should take care with sharing it.

Quality improvement projects. Good ideas received from individual units were shared. There is now a need for closer collaborative working to develop some of these ideas, drive down cost and maintain/improve quality. DH and JD are leading on this.

13 CSAC report (KT)

General. CSAC meets 3 x/year, following the BAPN exec and oversees recruitment to nephrology NTN GRID, review the curriculum/assessments plus appraise trainees annually. Dr Maggie Fitzpatrick completed 4 year tenure as CSAC Chair in August 2014. KT appointed successor and CB appointed as STA in November 2014. Other committee members include EJT and MC (quality advisors), RC and SH (training advisors), LK (assessment advisor). Co-opted by RCPCH is MA as SPIN rep. A request for representation from the adult nephrology SAC has been made.

Trainees. Five applicants were short-listed for latest round of GRID applications. The CSAC cannot approve training in the UK for paediatric nephrology outside of GRID programme. There are currently 14 trainees (13 in clinical posts; 1 completing research). An additional two trainees are post-CCT in research or undertaking Darzi fellowship. One trainee is due CCT in 2014, 5 in 2015, and 4 in 2016. Two Grid Trainee Educational Meetings were held in 2014 - Liverpool (January), organised by Dr Louise Watson and Leeds (July) organised by Amanda Newnham. Both were excellent meetings, well attended by trainees and prospective GRID applicants. STA (KT) and research advisor (RC) attended both meetings and formally met up with grid trainees.

Consultant posts. In 2014, there was 1 substantive consultant appointment in Birmingham; 1 substantive in Glasgow (December); 1 locum consultant post in Leeds (October); and 1 locum
post advertised in Newcastle.

Curriculum. The curriculum section in ‘The Framework for competencies for level 3 training in Paediatric Nephrology’ is on the RCPCH website. The updated curriculum has been circulated to all current trainees. Paediatric Nephrology plans to stick to a topic-based rather than symptom-based curriculum. The curriculum will be expanded to include a Quality Improvement module. The Framework of competencies for level 3 training SSM in Paediatric Nephrology directed at potential SPIN doctors is also on RCPCH website. RCPCH are working with CSAC to develop a framework to manage and monitor SPIN training. RCPCH are also considering the development of post CCT SPIN modules.

START. This has now been ratified by GMC. All trainees entering level 3 training on or after August 2011 are required to undertake START before applying for CCT. Feedback from trainees is that they have found START a positive experience and feedback from the RCPCH indicates nephrology trainees have performed extremely well. LK is working with the CSAC and has submitted a comprehensive number of scenarios directed at paediatric nephrology trainees to be used as part of START. CSAC will need to continue to update the bank of scenarios for our subspecialty and ensure they are benchmarked. There is a scenario writing day to be held at the RCPCH on Friday 27 February 2015.

‘Acting up as a consultant’. ST trainees previously were only allowed to ‘act up’ as an out of programme experience. The RCPCH have changed this rule to now allow trainees to ‘act up’ during final year of training. Trainees must have prospective approval for these posts from RCPCH, CSAC and local deanery. They can act up for 3 months, and up to 6 months in exceptional cases. Ideally acting up posts should be in the same deanery as training post but in a small sub-speciality the RCPCH recognises that acting-up posts may be in another deanery. Trainees must have ongoing clinical and educational supervision during these posts. Advisory Appointment Committee. RCPCH hold a list of paediatric nephrology consultants who have previously represented the College and/or undertaken training to be part of consultant interview panels. Any consultant wishing to represent RCPCH on AAC is encouraged to contact RCPCH and attend a training day.

14 Trainees’ report (JS)
JS thanked the exec for their support over the last year. Hitesh Prajapati will be the new trainee rep on exec and Tamara Mallett will be the new trainee rep on the Renal Registry.

15 SPIN report (MA)
There were 7 applications for approval for trainee SPIN posts in 2014 but no consultant SPIN posts advertised. There are now 29 SPIN members of the BAPN. The curriculum for SPIN training needs to be reviewed. Retrospective training is no longer recognised. Application for approval for recognition of SPIN training can be done from ST4.

16 Ordinary member’s report (MoS)
MoS is the UK paediatric lead for World Kidney Day (12 March 2015). Resources available on the WKD website were flagged up. MoS is now also on the BPSU committee.

17 Communication officer’s report (AL)
The website has now merged with the RA website. There are two databases of paediatric renal units. AL will integrate both of these. A competition for a new BAPN logo was won by a Bristol patient. There was no whole-hearted supported for adoption of the winning design and it was agreed to stick with the current logo for standard use but to use the new logo for a single event such as World Kidney Day.

18 Any other business
Pallavi Yadav hoped to attend to discuss the UTI diagnosis/treatment consensus paper that she and Kjell Tullus have written with input from all units. Plans for the second paper on investigations are on-going. HL encouraged members to ensure their views were represented through their centre-reps.