1. Welcome.
   EJT welcomed everyone to the 2013 Winter Meeting.

2. Apologies
   These were received from Stephen Marks, Lyda Jadresic and Mohan Shenoy.

3. Minutes of the AGM (14 March 2013)
   These were agreed as a true record.

4. Matters arising (not otherwise on the agenda)
   No additional matters.

2. President’s Report – EJT
   EJT expressed thanks to the executive committee, particularly those who had recently stood down from a term of office: David Milford, Standards and Guidelines, Judith van der Voort, Treasurer, Sheetal Bhojani and Sally Feather, Secretary; and to those who had joined in those respective roles: Jan Dudley, Arvind Nagra, Jelena Stojanovic and Martin Christian.

   Links with the RA are now quite embedded. UK Kidney Week 2014 has significant paediatric representation, including a session on Alports, paediatric input into a registry session (Kitty Jager from The Netherlands), a session on complement disorders and paediatric input into a joint guidelines session.

   The new website now means the BAPN is an integral part of the RA.

   It is likely that there will be closer ties with the BRS. We should consider allowing MDT members to be part of the BAPN (non-medics can already join the RA). We should all encourage our MDT members to come to UK Kidney Week.
The issue of MDT membership opened to general discussion. DM asked if there had been any correspondence with the paediatric renal nurses' group to seek their views (none yet). He also pointed out that the historic British Paediatric Renal Society fizzled out through lack of support. A straw poll was taken of the membership present on their views of MDT members attending the Winter Meeting. Just over 50% were in favour. Some members questioned whether MDT members would want to come to the meeting in its present form and whether the nature of the meeting might change. RC pointed out that much good research takes place amongst the MDT and that it would be good to access that. It was agreed that the issue will be taken to the next exec meeting.

Commissioning will evolve with time. EJT is keen to hear feedback from around the country about local problems with commissioning. All specialist service specifications will have a generic general paediatric and generic transition section. AN is involved with the transition working group. All specialist groups are being asked to develop dashboards. EJT is keen to encourage BAPN involvement. Views on co-dependency have recently been submitted which are more comprehensive than the RCPCH document of a few years ago and again this will need BAPN feedback before agreeing. We are also being asked to develop a 5-year strategy which includes areas for improvement, particularly national developments – both those easily achievable and those more aspirational.

6. Secretary’s report (MC)
The process membership applications remains that each application requires two supporters. The exception is that new grid trainees will require a single nominee. Applications received by MCI are automatically accepted. The exec will review new members from the previous year and they will be formally welcomed into membership at the AGM each year.

New members during this calendar year are: Corinne Langstaff, Asheeta Gupta, Emma O’Hagan and Lucy Plumb.

The current exec post-holders and their dates of demitting are now on the website. The only vacancy during 2014 will be the CSAC chair.

7. Treasurer’s report (AN)
Ring-fenced funds now stand at £25,925 (previously £34,249). Forthcoming expenditure includes infoKID (£2,000). There is also £10,000 available for guideline development. MCI top up an expenses fund to £4,000 each year. Prior to the Winter Meeting there was £1,511 remaining for this financial year. £2,033 remains of £5,000 for an AKI project

8. Clinical standards and guidelines report (JD)
CS&G have several workplans ongoing:
• Co-ordinate BAPN involvement in/response to national guidance. Pathway attached as appendix.
• Info-KID (see below)
• Development of national standards and guidelines. There are named paediatric nephrology representatives to contribute to all RA guidelines which are overdue for revision and discussion is on-going as to how paediatric guidance maps to adult guidelines. The paediatric leads for the 8 priority areas are: PD (Chris Reid), PD access (Carol Inward), haemodialysis (Dal Hothi), bone metabolism (Rukshana Shroff), transplant – pre-op assessment (Jan Dudley), transplant – post-op care (Heather Maxwell) and anaemia (Jonathan Evans).
• Explore the development of patient/carer decision aids. This is new and will require separate funding.

9. Registry and audit report (MaS)
Two chapters describing 2012 Paediatric RRT data are now available online. 11 of 13 centres submitted returns electronically; 92% of ERF cohort representing 791 of 861 children which is similar to last year. Within the demography report are new analyses on pre-emptive transplantation, transfer to adult colleagues and survival on RRT during childhood. Within the biochemistry report are new analyses on BMI and data on bicarbonate levels. There is overall improved data as a result of improvement in internal registry data processes and opportunity to review submitted data by each centre. From next year, all registry returns will be paperless which presents several challenging practicalities. Several centres will have new software and will not necessarily be collecting RR data. Members of the RR team will be visiting centres to meet leads/ICT team to facilitate this. There is also to be a survey of bioinformatics support at each centre. SurveyMonkey survey about involvement in collecting and checking data for each centre showed 45% and 56% respectively were clinical staff.

There is enthusiasm for RR work in all centres. All have lead consultant for RR work and most have electronic platforms (though still trying to integrate new paediatric renal dataset). On the whole service is consultant-delivered but with limited administrative/infrastructure resources.

For reporting period 1/1/13 to 31/12/13, cohort incident and prevalent details are required by 31/1/14 and data returns need to be submitted by 31/3/14.

Output from the Paediatric Registry in 2013 included: ‘Longitudinal changes in BMI following renal transplantation in UK children’ published in NDT on behalf of the BAPN; 3 poster presentations at the Renal Association meeting 2013; 2 projects being written up (‘late presenters’ and infant dialysis project); on-going collaborations with ERA-EDTA; re-audit of renal biopsy.

Audits planned for next year include: retrospective audit of Paediatric AKI (David Milford); prospective audit of complications of chronic dialysis access. EJT congratulated MaS in getting this year’s data out so promptly. She also confirmed that electronic returns is now the paediatric nephrology service specification and should be used to take to commissioner discussions if it is not yet happening in individual regions.
10. Research report (RC)

RCPCH meeting 2014 (10 April): joint session with rheumatology - 3 invited speakers on lupus nephritis (Steve Marks/ Mike Beresford/ Louise Watson); HSP nephritis (Jan Dudley) and biologicals (Mark Frisswell).

UK Kidney Week (see president’s report above).

Travel bursary (£500) given to Lynsey Stronach (home haemo nurse at GOSH) towards Atlanta meeting for acceptance of abstracts for 1 oral presentation and 6 posters. This was well-deserved but there were in fact no other applicants. Last RCPCH meeting prize (£100) awarded to Dr Eleanor Hay for “A prospective questionnaire assessment of knowledge and application of estimated Glomerular Filtration Rates amongst Paediatric trainees”. This will be running again in 2014.

Nephrology CSG in the past has been accepted as being highly rated and successful, particularly with flagship studies (PREDNOS 1 and 2, HOT-KID and RaDaR). Present restructuring of NIHR means paediatrics will sit with genetics, reproductive health and haematology. It is likely to get similar resourcing. KDIGO glomerulonephritis guidelines (2012) illustrate need for renal research: of 167 recommendations, only 4 were supported by level 1A evidence and 87 had only level D evidence to support.

At the start of December there was an NIHR call for research into chronic disease in childhood. All the following funding programmes will participate: Efficacy and Mechanism Evaluation (EME); Health technology assessment (HTA); Health Services and Delivery Research (HS&DR); Innovation for intervention (i4i); NIHR Fellowship Programme; Programme grants for Applied Research (PGfAR); Research for Patient benefit (RfPB); Public Health Research (PHR). There is a launch meeting in London on February 5th 2014 and the BAPN need to be represented. CSG focus groups need to identify important questions and develop appropriate research projects.

In the future we need to continue to be a leading group in the research community; we need new members in the CSG so please consider coming forward; we also intend to involve trainees. On-going support of flagship studies is crucial.

SH referred to time needed for trainees to do research and time needed for preparation for NIHR fellowships. It was also pointed out that time to NIHR chronic illness launch in February is short and we do need to be constantly responsive to supply research projects. RC will send round email for expressions of interest.

NW gave an update presentation of PREDNOS and PREDNOS 2. PREDNOS currently has 173 out of 225 patients recruited (since August 2011). A funding extension has been granted until the summer of 2014. A huge effort is needed to deliver target recruitment by this date. 117 sites are now set up to recruit. PREDNOS 2 recruited its first patient on 19 March 2013 and has now recruited
55 out of 300 patients. Recruitment will continue until March 2015 but is now beginning to lag behind target. It was suggested that grid trainees should be encouraged to help with recruitment. NW confirmed he is happy to speak at regional meetings if that is required. Heather Lambert suggested a flyer which NW confirmed he can send out. PREDNOS 1 and 2 newsletters to be included regularly now with eNews.

MaS gave a brief update of HOT-KID. The trial commenced at Evelina in August 2013 but there will be a long period before first collaborating centre is open to recruitment. There are unique research governance related issues. There are 8 centres recruiting. Three further centres are to open soon. Visits to three external centres commenced in November 2013 (GOS, Glasgow and Liverpool). Study visits to 2 further centres are booked (Nottingham and Bristol); awaiting confirmation of dates to visit other centres. 16 months following commencement of study; 12 of 13 UK centres are participating; 41% of study patients have been recruited; 20% of children to be randomised have been recruited.

RS presented the background and proposal for this multi-centre study which has had MREC approval and is about to be circulated to individual centres.

12. ESPN 2017: proposed bid for Glasgow (HM)
2017 is the 50th anniversary of the first ESPN meeting and this bid is about bringing the meeting home. “The intention is to make a bid for the next ESPN council meeting in February 2014. A small group has begun to prepare a bid, meeting with Glasgow City Council marketing. HM asked for photos, stories from ESPN 1967 to include in the bid. Flap Tours now take on much of the organising but finance still needs to be sorted. St Petersburg is likely to be the rival bid. Scientific content is still to be decided. A scientific committee would be needed but it is not clear what role ESPN have with this. Glasgow has a good conference centre with lost of experience in hosting large conferences and offers some financial support. There is a reduce rate travel pass and marketing support. There is also lots of affordable accommodation within easy access. EJT encouraged all BAPN members to get behind this bid and support HM.

13. Clinical services committee report (DH)
Workforce 2013 document now completed. Individual doctors job-plans and retirement dates are held centrally by exec. A summary of projected retirement numbers and locations is on the website. Service specification was agreed last year. It will need to incorporate standards of care and outcomes (into revised service specifications in 2015 and including generic and nephrology-specific measures). There will be a requirement for a dashboard in the near future.
Peer review discussed separately below.
Draft paediatric generic transition service specification is currently with Dr Jackie Cornish (NCD for CYP/transition) who will be taking it to the CRG’s and then to the specialist commissioning route.

Service developments: Renal networks (MC) – currently applying for funding; strong foundation for peer review process; National Home HD (DH) - training; home centre model. Both applied for SSCIF funding but this has currently been withdrawn.

Coding. Checks and validation model (GOSH) discussed. A copy is available from DH for anyone wanting to look further at it.

HRG paediatric chapter. EWG recommendations have been submitted. There is alignment with the renal chapter; subdivision of PA into a number of specialised clinical areas; interactive CCs instead of binary system. CJ asked if others were aware that funding per HRG code in paediatric nephrology dropped last year. DH replied that there has not been resolution of regional differences yet.

14. Peer review of paediatric nephrology networks (MC)
National peer review is being rolled out from cancer services to other specialities and paediatric renal services has been spotted as a highly suitable service for peer review because it is a high-cost, low volume service which is not readily amendable to auditing by other means. Three centres and their associated networks (GOSH, Southampton and Nottingham) have put themselves forward to be part of a pilot project to take place over the next year. If successful it is anticipated that this would then roll out to other centres.

The process includes a self-appraisal against a previously agreed set of measures. This is followed by an external validation (by the peer review team) and then a peer review visit to interview the team, initiate the written report and provide face to face feedback. It is likely to be more successful that previous attempts at peer review within the paediatric renal community because of NHS support providing an accountability structure and administrative support.

The agreed measures document will be a moving target for future peer reviews so that it achieves a constantly improving service. The process provides paediatric renal services an opportunity for investment, particularly in network-delivered services, if the process proves to be effective.

15. CSAC report (MF)
In line with the RCPCH restructuring CSAC will now meet x3/year from 2014. The 2013/4 grid process is now completed; there were 9 applicants shortlisted and 5 were interviewed; 3 were appointable and offers were made. There have been 4 programme submissions from London (Evelina/GOSH), Newcastle, Manchester and Birmingham. The total number of trainees in the grid system is 12 (8 currently in clinical posts; 2 completing research; 1 on maternity leave; 1 doing an out of grid placement). There were 3 substantive consultant appointments 2012/3 (Glasgow, Bristol, Evelina). Three trainees completed CCT and are not yet in substantive posts (1 locum post/research; 1 ongoing research;
The CSAC Chair and a Training Advisor now attend trainees’ meetings and formally meet up with grid trainees to assess progress against the curriculum and to provide support and mentoring. These meetings are now documented/written up on the e-portfolio system for trainees and their supervisors to access and can be used as part of the trainee’s ARCP. The curriculum section in ‘The Framework for Competencies for Level 3 Training in Paediatric Nephrology’ has been updated by the CSAC and approved by the RCPCH Training Committee. The Framework of competencies for level 3 training SSM in Paediatric Nephrology directed at potential SPIN doctors is also on RCPCH website. START has been ratified by the GMC. There have been 3 sessions since Nov 2012; the next is March 2014. All trainees entering level 3 training from August 2011 are required to undertake START before applying for CCT. A working group for nephrology is convened by Larissa Kerecuk. CSAC has now submitted a comprehensive number of scenarios.

NW asked whether CSAC can intervene with workforce planning in individual Trusts. MF confirmed that CSAC can confirm job descriptions but Foundation Trusts are not obliged to take their advice.

MF comes to the end of her tenure in the summer of 2014 and encouraged BAPN members to consider taking on this interesting and enjoyable role.

16. Trainees’ report (JS)
There are 2 grid trainee educational meetings per year. These are well attended with good feedback and open to trainees, potential trainees and trainees interested in SPIN. 2013 meetings were held in Birmingham and London (GOS/ECH). The next trainee educational meeting is in Liverpool on 30th and 31st January 2014 to be organised by Dr Louise Watson. It is hoped that training days will visit all centres. A proposed US trainee exchange programme would be discussed. Centres in Chicago and Cincinnati have expressed an interest in participating. The exchanges would utilise study leave and annual leave for UK trainees, aiming for a US visit of around 3-4 weeks.

JS represented the BAPN at the French Paediatric Nephrology Society’s annual meeting in November. She was warmly welcomed and able to present in English although most of the meeting took place in French. There was some discussion about the future potential for similar joint meetings. EJT thanked JS for representing the BAPN at this meeting.

Trainees are not currently represented on the CSG and it is hoped to re-institute the trainee rep. There was also some discussion about how to incorporate the concept of quality improvement into training programmes.
17. SPIN report (MA)
There are currently 29 SPIN members of the BAPN. There are 12 paediatric trainees who wish to qualify with a special interest in nephrology. Advice about opportunities in paediatric nephrology as a special interest was given to 4 trainees in 2013.
A SPIN survey was done to assess the current combined outreach nephrology clinics. The results have been fed into the nephrology network group who met in Nottingham and are published on BAPN website.
There has been only one SPIN consultant post advertised in 2013 which encourages SPIN as a special interest. There was some general discussion about this and it is felt that this number will grow as more trainees exit with a special interest in nephrology.

18. Communication officer's report (AL)
AL gave a preview of the new website linked in with the new RA website. He will be contacting individual centre leads in the near future to update centre-specific information.
The SurveyMonkey survey on proposed changes to the constitution was mentioned but has had a poor response to date. Opportunity was taken of the WiFi available at the meeting to allow members present to vote.

19. Any other business
HL mentioned a 6 month consultant locum available in Newcastle. The post will be advertised in December’s eNews.
Appendix: algorithm for NICE Clinical Guideline pathway