



## **Minutes of Renal Association Annual General Meeting**

Thursday 14.3.13 0730-0830

Bayview Room, Bournemouth International Centre.

Attendance 56 members

**1. Welcome** to all present by Alison Brown

**2. Apologies** : Alan Bevington, Sunil Bhandari, Aine Burns, Catherine Byrne, Peter Drew, Sean Fenwick, Peter McClelland, Marianne Vennegor

**3. Minutes of last AGM** 14.6.12 accepted as a true record.

**4. President's Report:** David Wheeler presented his President's report. He thanked everyone for attending the AGM on World Kidney Day. On behalf of the renal Association, he thanked Donal O'Donoghue for his work and achievements as National Clinical Director as he prepares to stand down next month. DW highlighted Donal's role in increasing the national profile of CKD, achieving a reduction in crash landers and reduction in MRSA on renal units. DW then thanked all the Trustees for their help and support during his first year as President. He gave particular thanks to Martin Raftery who is due to step down as Clinical Vice President this September, having been a key contributor to the work of the RA. DW also thanked Bruce Hendry who is due to demit as Academic Vice President this September, and is now President-Elect; Fiona Karet who is due to demit as Chair of the Research Committee and who is now Academic Vice President- Elect: and Graham Lipkin who will demit as Chair of the Clinical Services Committee this September and is now Clinical Vice President-Elect.

DW reported the recent work by the RA Trustees at a Strategic Planning away day with MCI in November 2012, where they agreed a strategic plan for the next 5 years, and also agreed an updated RA mission statement: "Dedicated to research, education and service to patients for prevention and effective treatment of kidney disease".

The five main domains of RA activity for future efforts and promotion were agreed as

- Research
- quality in practice
- membership
- communication and networks
- education, teaching and careers

DW then reported on progress on closer collaboration with the British Renal Society (BRS), following a joint strategic meeting in April 2012, and a second planned for June 2013. A memorandum of understanding has been agreed, with 11 action points relating to combined

working and a commitment to joint meetings in future. DW explained that the plans for a default position of joint meetings in future arise not only from the wish for closer working, but also since pharma have told us they can no longer support two major meetings for the UK renal community. The next combined RA/BRS meeting will be badged as the "UK Kidney Week 2014", from April 29<sup>th</sup> to May 2<sup>nd</sup> at the Glasgow SECC. DW explained the concept of the multidisciplinary last day of the 4 days of meetings, to include other allied society meetings such as technicians, dieticians, pharmacists etc.

**5. Treasurer's report:** Jonathan Fox gave his report (attached)

a. RA membership is stable, with 1085 members (1067 at the end of 2011)

b. Corporate members are currently 5 (7 at the end of 2011) though we hope to recruit more in the next few months.

c. Overall funds are stable and better than expected, with a reduction in deficit; this is thanks to a reduction in membership debtors due to MCI's efforts in collecting these, a reduced loss on the 2012 Annual Meeting compared to 2011, a small surplus on SCE and a significant surplus on the ANC.

- Renal Association Fund: £370,059 (£374,018 at end 2011)  
deficit of £3,962 (deficit of £83,436 in 2011)

main income for 2012 is registration for Annual Conference and main expenditure is also on meetings, secretariat fee about 13%.

- Renal Registry Fund: £1,316,581 (£1,290,634 at end 2011)  
surplus of £25,948 (surplus of £27,377 in 2010)

Registry income is mainly capitation fees and expenditure mainly staff salaries and IT costs.

- Total reserves: £1,686,640 (approx. 11 months expenditure)
- RA account has separate funds for British Association of Paediatric Nephrology and Nephrology SpR Club
- Registry manages RPV

**6. Honorary Secretary's report:** Alison Brown gave her report

6.1 Requested that the Annual Report for 2012 be approved ; no objections.

6.2i AB thanked her predecessor as Honorary Secretary, Lorraine Harper, for all her efforts and achievements during her 4 year term of office. She also thanked all the Trustees and all RA members for their help and support in her first year as Secretary, particularly all those who have helped with the 2013 Congress. She thanked the BTS Congress Team (Chris Watson, Anthony Warrens, Richard Baker and Iain MacPhee) and all the RA Programme Committee, particularly the Scientific Programme Committee of Amy Jayne McNight, Mark Dockrell and Alan Salama.

6.2ii. AB asked the AGM formally to confirm the election of the President Elect Bruce Hendry, Academic Vice President Fiona Karet, and Clinical Vice President Graham Lipkin.

6.2iii. AB asked the AGM formally to confirm the election of three new elected members of the Executive Committee, Moin Saleem, Paul Warwicker and Rebecca Suckling.

6.3iv. AB asked the AGM to ratify the appointment of new members of the RA (list attached).

6.3i. AB asked the AGM to note the changes in the Rules which have been posted on the website. In accordance with the Articles, the Rule changes have been approved by the Trustees. The Rules have been amended to:

- Increase the duration of the term of elected Executive members to 4 years
- Remove details of the Renal Registry Management Board (RRMB) and replace with details of the new Renal Information Governance Board (RIGB) which replaces the RRMB and includes oversight of Renal PatientView and RADAR

6.3ii. AB discussed the new Renal Information Governance Board (RIGB) comprising the Trustees of the Association and attended by the accountable officers and general manager of Renal Patient View, RADAR and UK Renal Registry; this Board will now oversee all governance aspects of the three organisations. The role of Chair of the UKRR has gone following the planned change to a half-time equivalent Medical Director of the UKRR (to be appointed shortly) who will be a member of RIGB together with the UKRR Director.

The Chair of the Renal Information Governance Board will be the Past-President of the Association. The AGM was asked formally to approve the changes to the Articles -the only substantive change is that the UKRR Chair will no longer be a Trustee of the Association- and this was approved (show of hands).

6.3iii. Current membership categories of the current 1085 members:

- 365 trainees, NCGs
- 72 renal scientists and non-clinical
- 498 consultants
- 25 nurses/medical professionals
- 13 free memberships for trainees/PhD students

6.3iv. Awards and Bursaries: In 2012, the AEG Raine Award was awarded to Amy Jayne McKight and in 2013, to Andrew Hall for his work on the roles of metabolic and mitochondrial dysfunction in disorders of the kidney tubule. Walls Bursary winners are David Ferenbach and Lindsay Keir, and the Lockwood Travel Bursary has also been awarded to David Ferenbach. Eight medical students received travel bursaries to help towards electives which include some study of nephrology

6.4 Future meetings: 5th July 2013 Rare Disease Workshop RSM London

6-10 January 2014 Advanced Nephrology Course Corpus Christi College, Oxford

30-31st January 2014 Tripartite Renal Meeting (RA/RSM/Francophone Society) RSM London

29th April-2nd May 2014 UK Kidney Week, jointly hosted by BRS and RA, SECC Glasgow

**7. Clinical Vice President's report**, covering Clinical Affairs Board (CAB): Martin Raftery gave his last report as CVP. The CAB has had 2 meetings since the last AGM. The CAB receives regular reports from Guidelines Committee, UKRR, EON, Terminology Committee & Clinical services Committee and the UK Clinical Director for Kidney Care has usually attended. MR reported recent discussions regarding PbR tariffs and the work of the CAB in modifying these, for example the PD tariff. MR reported ongoing concerns about quality and access in a cash strapped climate. Mike Robson has been co-opted as Elected Member of Executive Committee, replacing Liz Lightstone. MR has

nominated RA members to sit on various NICE appraisals and has replied on behalf of RA to multiple consultations.

The Clinical Services Committee organised a successful CD Forum held in St Thomas Hospital on March 9<sup>th</sup> 2012; 57 registrants attended and presentations included topics such as quality, commissioning and service delivery. All presentations are posted on RA website. The CS Committee will have to be reorganised in 2013 due to abolition of SHAs (as previously composed of a representative from each SHA) and the plan is to reduce membership somewhat in future.

**8. Academic Vice President's report:** Bruce Hendry gave his report.

8i. The UK Kidney Research Consortium (UKKRC) has held two meetings in 2012 and has benefited from the reinvigorating effect of the multi-professional leadership (RA, BRS, KRUK). The Chair has now rotated from BH to Tim Goodship (KRUK). BH reported (as was evident in the Clinical Trials session at Congress the day before the AGM) that there is a definite stimulation of NIHR calls by nephrology community and rising renal presence in NIHR studies and all the Clinical Study Groups are currently very active. Rotation of leads of the Clinical Study Groups is planned since most leads have now been in place for 2 years. Next meeting of UKKRC 10.6.2013.

8ii. Rare Disease Committee: BH reported that Mark Taylor has led approval of 14+ rare Disease Groups (RDG) with active engagement of patients and professionals, and RD Registry Development ongoing with RR support. The UKRR is committed to IT and project management support. BH reminded the AGM of the Rare Disease Workshop RSM London 5<sup>th</sup> July 2013.

8iii. Education and Training Committee: Jeremy Levy has taken over as Chair. There has been a further very successful Advanced Nephrology Course. The E&T Committee are actively working on Curriculum and Examination projects, including scoping core medical undergraduate training, and also provide leadership for the Renal Specialty Exam (Renal CSE).

8iv. Research Committee led by Fiona Karet: BH reported that this Committee has expanded membership and scope of expertise. The National Research Database is near to live launch. Members of this Committee have provided leadership for Annual Meeting programme and there are plans to oversee an SpR clinical research network.

8v. International Committee: under Albert Ong's leadership, a second RA-ISN Fellow Dr Ahmad Nassary (Afghanistan) has been appointed, and will join Edwina Brown at the Hammersmith. New members of the International Committee are Indy Dasgupta (Exec) and Kjell Tullus (BAPN). Albert Ong has organised a joint session together with ISN at this meeting, but has also announced that he will shortly stand down as Chair of the International Committee ; BH asked for expressions of interest in succeeding Albert in this position.

**9. Report from the Chair of the UK Renal Registry, Damian Fogarty:**

9i. DF discussed in more detail the changes to the organization of the UKRR, as the UKRR Chairman will now become the Medical Director of the UKRR, working for 5 sessions per week, and so ceases to be a RA Trustee. DF reported that an advert and call for expressions of interest for this post will go out in next 4-6 weeks. This means that remaining RA Trustees will assume a greater corporate role in RIGB. DF remains the Acting Medical Director until he stands down next April.

9ii. DF discussed data, reports, study groups, finance and explained that timeliness has been a major focus of UKRR work along with governance.

In 2013 there will be two reports: June (2011 data), December (2012 data). In view of the 90 day rule for returns of data, UKRR reports are now as timely as is possible.

Current study groups include Dialysis Study Group (Martin Wilkie), Transplant Study Group (Iain McPhee), Paediatric Research & Study Group (Manish Sinha), PKD Study Group ( DF highlighted that the Chair of this group, Tess Harris, is the first patient chair of a study group), CKD Study Group (Nigel Brunskill), AKI soon, and Rare Disease Groups ( n=13 and growing).

The UKRR Capitation fee remains unchanged at £19/RRT patient (since 2008) – one of the most cost effective national registries.

9iii. DF reported that other work by the UK Renal Registry includes support for ATTOM, RaDaR and RPV; work on AKI and CKD is developing. The UKRR have been awarded the first Tony Wing award funding from the BKPA for a paediatric project. Funding has been secured from NHS institute to develop a tool to measure Shared Decision Making and there is a current application for funding from DH to measure PROMS and PREMS. The Vascular Access and Peritoneal Dialysis Audits have been repeated for a second year. The UK Renal Data Collaboration project is making headway and has moved from theory into detailed planning mode. DF reported the input from Keith Simpson to the data project, which Keith will present during the UKRR session at Congress today.

9iv. DF discussed the various collaborative projects in place:

- with patients involving support from individuals and groups
- with Renal units – there was a UKRR study day 09 Oct 2012
  
- Registries: UKRR, SRR and RaDaR Groups
- RPV: Amalgamating data sets underway
- Renal IT industries: there was a general meeting 19 Sept 2012 and further meetings with all major suppliers planned for 2013
- Data Governance: Section 251 application submitted
- NHS, DoH, ISD Presentations to EHI 07 Nov and NHS data standards 11 Dec 2012
- Ongoing teleconferences

DF concluded his report by thanking all UKRR staff and all contributing renal units and staff. DF particularly thanked Terry Feest and Keith Simpson for their valuable contributions to the Registry.

**10. AOB:** none

**11. Date of next RA AGM:** Thursday 1<sup>st</sup> May 2014, SECC Glasgow: room details and time TBC.

Minutes prepared by ALB 16.4.2013.