

The UK Kidney Association

Annual General Meeting

Date: Wednesday 1st November 2023

Location: Virtual

Time: 16:30-17:30

Chair: Alan Salama (AS)

Minutes by: UKKA Secretariat

1. Welcome- Alan Salama, Honorary Secretary

AS welcomed members to the AGM.

Approval of minutes of last meeting

AS asked members to approve the minutes from the last AGM meeting.
19/21 approved the minutes.

2. Treasurer's Report- Tim Bowen

There was an overall surplus in 2022 of just over £65,000. Reserves at the end of last year were approximately £3.6 million which was marginally up from the previous year. Breakdown of income exceeds expenditure. A significant input from donations, scientific meetings and membership. Predictably the majority of expenditure is for staff, meeting costs and professional services. Overall, in surplus and reserves are in good shape.

Approval of the annual report of the year ending December 2022

24/26 approved the annual report.

3. Honorary Secretary Report- Alan Salama

Has been a focus on trying to boost membership numbers. In the past 12 months membership numbers have increased by 6% with 102 members. Have had other specialties who have joined that have increased the numbers but there are still specialties where impact can be made. Going to be a focus on diversity going forward to ensure everyone who is a part of renal services in the UK is being adequately represented. Need to consider how to gather this data going forward.

Confirmation of the new appointments of the honorary members

Claire Sharpe
Karen Jenkins
Neil Sheerin
Helen Hurst

22/24 confirmed the new appointments of the honorary members.

Confirmation of the new appointments of the trustees

Katie Vinen- President
Tim Bowen-Trustee with financial governance responsibility
John Sayer- Academic Vice President
Kathrine Parker- Academic Vice President

Lisa Ancliffe- Clinical Vice President

Jim Burton- Clinical Vice President

21/22 confirmed the new appointments of the trustees.

4. Presidents' Report- Paul Cockwell and Clare Morlidge

Have had growth in many parts of the organisation. The UKKA's Secretariat has grown which has provided the UKKA with structure and support to all groups, committees and SIGS as well as enabled the organisation of UK Kidney Week to take place in house. Going to be a focus on membership going forward to ensure that the UKKA is representing all healthcare professionals that work with people with kidney disease. Continuing to develop membership offers, currently have a membership offer with the ISN. Has been a real focus on developing leadership across the UK renal space, had a leadership programme where 40 people went through a highly evaluated, expert leadership development programme for those who are going to be taking on leadership positions within the UKKA. Workforce is also going to be a priority going forward. Will be developing the Workforce Planning Document and looking at how to manage, protect and support the workforce. Other priorities are education and equality, diversity and inclusion, have an EDI group that has been set up and meets regularly.

5. Academic Vice Presidents' Report- Kathrine Parker and John Sayer

Have been developing and updating the rare renal disease strategy as it has been over 5 years since it was last updated. Have started to implement the strategy, phase one has involved looking at the rare disease groups, membership and output of those groups. Had a promising meeting where all the great work done by the rare disease groups was shared. Phase 2 and 3 will be linking in the rare disease groups with some of the UKKA activities and will include some short educational packages. A new Education Project Manager position at the UKKA has been filled. They are currently in the process of finding a new platform for educational materials and looking at developing short educational modules which all members will be able to access.

The Scientists now have their own professional group within the UKKA, a Scientist Research Group has been set up by Tim Bowen. A new terms of reference has been developed for the Education Committee, currently looking for new members that represent all of the professional groups. Have reviewed the UKKW named lectures and written some text, nominations are currently out. Have been developing a process of endorsement for courses and educational materials, particularly ones that are sponsored by Pharma. The Clinical Research Committee has been disbanded, now just have the Science Research Committee. Need to do a piece of work with members around what is needed from the committee. Also had discussions about trusted research environments, expensive to maintain but good for gathering data so worth seeing if the UKKA will be able to manage this.

6. Clinical Vice Presidents' Report- Lisa Ancliffe and Jim Burton

An interactive website has been established for guidelines. Recently had joint funding agreed between UKKA and KCUK for a three year project that is looking at unmet needs in the advanced kidney care clinics. What was previously the Covid 19 Committee is now being reestablished as the Infection Committee. Going to be working on a review of the specialist Interest Groups, will be creating an operational framework, which will ensure that all the chairs of the different SIGs are linked in with each other. Will provide the SIGs with support

from the registry and the guideline and education groups within the UKKA. Also looking at the development of leadership and the Clinical Director Forum. Looking at developing a regional model as want to ensure there is good multiprofessional representation and equity across all of the devolved nations.

7. UK Renal Registry Report- James Medcalf

The annual report is being published in time for UK Kidney Week. There will be a further annual report on the AKI and master patient index. Have put together four factual reports on disparities which describe the difference in care and outcomes for four characteristics that are routinely measured (sex, age, deprivation and ethnicity). Worked in collaboration with the Patient Council on this. Also have an improved date completeness measure. Have been working on the national data opt out where patients are allowed to opt out of their data being collected and used for improvement and research. Can still process people's information without their direct consent providing that other means to opt out are given.

PatientView has now moved over to Patients Know Best, had some issues to begin with but have now been successful overall in implementing. Have had some issues in Scotland and Northern Ireland with governance. The UKKA has now moved from North Bristol Trust to an independent provider for their IT and the Registry has a series of ongoing research collaborations. Many kidney centres are now deploying electronic health records which incorporate kidney care, collecting this data has come with many issues as centres struggle to support existing data reporting and moving to new systems. There has been slow progress on implementing daily feeds of information. Haven't really seen any improvement since NHS Digital and NHS England merged and Public Health England became the Health Security Agency. Currently looking for a suitable solution, the Registry and UKKA still have linkage directly with NHS Digital. Exploring gathering the data more frequently and in house. OpenSAFELY for example, offers an opportunity for linkage just in a different model.

8. BAPN Report- Jan Dudley

Roy Connell and the Paediatric Nephrology Nursing group have managed to get funding for developing a UK renal standard of competencies. Have currently got an expression of interest out for a life arc grant which is an opportunity to develop programmes for a continuum across the field of nephrology from small children to the elderly. Got a QI project running looking at and reducing unwarranted variation in declined offers between centres. Got grant funding for shared decision making. InfoKID is a paediatric nephrology information portal for parents and carers, sits alongside patient leaflets run by KCUK. There is a newly formed paediatric nephrology clinical reference group, first two meetings have been held. Service specifications are being developed, looking at developing a risk register to address some of the key issues.

Steve Marks has been appointed as the president elect of BAPN, will take over next June. There have been ongoing issues with medication and medical equipment supplies for a small population in both numbers and size. Has recently become more challenging, would like to have this on the risk register going forward. Have also been having issues with the workforce and the numbers of available consultant posts. The CSAC group which is a college based certification of accreditation may look to limit number of paediatric nephrologist GRID training posts. Currently working with colleagues in adult practices as there has been a year

on year decline in the number of clinical academics. Pulling together an academic strategy to try to future proof the academics across Nephrology. Need to recognise the clinical academics to ensure the work is included in the job plans.

NHS England are currently doing data mapping for centres in England to look at haemodialysis capacity in particular. Dialysis numbers have improved slightly, still functioning at 25% above the 2019 base line. Some units are very stretched, looking at buddy services. Still have recommendations in place from the 2021 task and finish group to prioritise access to theatre for children and young people to get them transplanted sooner. Some units are struggling with the new kidney allocation system as it hasn't caught up after COVID. Deceased donor offers are highly variable, has only been two offers this year for kidney replacement therapy and a dialysis population of 25 or so. Don't have many listed currently. For 20 children listed, only getting two offers is challenging. Challenge hasn't gone away but has settled slightly.

9. Q and A

No questions were asked.

10. AOB

No other business was raised so the meeting was concluded.