



# TABLE OF CONTENTS

President's report	3
Governance and structure	7
Committees and SIGs	10
Our members	11
Financial report	15
Equality and diversity Legal status Articles and rules	18



The UK Kidney Association Brandon House, Building 20A1 Southmead Road Bristol BS34 7RR



renal@renal.org



0117 414 8152

## PRESIDENT'S REPORT 2021 - 2022

Thank you to the Trustees, CEO and executive team, all UKKA leaders, and all UKKA members for their time and efforts as we continue to grow as a new organisation. The breadth of work that is going on across the UKKA continues to grow and we are in a process of embedding new leadership into our various workstreams, as well as growing our membership.

### **Professional groups**

Most professional groups have come in as members of the UKKA. The Association of Nephrology Nurses UK (ANN UK) and the UKKA are in final discussions about a pathway to full membership for ANN UK; and discussions are in progress with VASBI, with co-working on an Interventional Nephrology Special Interest Group and consideration for a pathway into the UKKA.

We have developed a partnership with the International Society of Nephrology (ISN), an excellent membership offer will go out shortly, and we are planning a combined education offer at UKKW 2023. We are also supporting the African Association of Nephrology through a pre-meeting symposium at their meeting in February 2023, and the Sustainable Kidney Care Committee and SpR club are working with the ISN. The ISN is predominantly a medical-led organisation, we are working hard within the ISN to encourage its development towards a true multi-professional organisation.

## Leadership and Mentorship

We have committed significant funding to support the development and delivery of a leadership course for UKKA members. This course is being designed with the Royal College of Physicians and will be for medical doctors and multi-professional team members. We are particularly focused on supporting UKKA members who have roles within the association and want to develop these to take on more senior positions in UKKA and in the broader healthcare system.

We will also be running a UKKA mentorship training programme. This will be focused on colleagues who are more senior leaders, be that clinical, academic, or operational to support the development of a UKKA mentorship programme.

#### Workforce

Members of the UKKA and their colleagues are under intense pressure. The travails of the NHS and academic partners in respect of staffing and skill mix are clear to all. We are currently updating the existing Renal Workforce document and we are hoping to run a workforce summit in 2023 with the NHS and other partners.





We continue to work closely with NHSE/I on a range of areas including the renal services transformation programme (RSTP) and the Renal clinical reference group (CRG). We await the re-establishment of the Transform CRG. A national clinical director has been appointed and we anticipate an announcement about this shortly. The RSTP work is reaching a conclusion with aims to develop the Renal Toolkit and final recommendations being presented in joint weekly UKKA/NHSE webinars.

This remains a crucial time for the establishment of Integrated Care Systems in England. There is no underestimating the potential impact of the change that will be enacted in the Health and Social Care Act 2022, with the move to single locality-held budgets (across providers) and local commissioning, including dialysis and kidney transplantation. Regional renal networks are well established now and are supporting this transition. We have good links with the Welsh Renal Network and working to ensure that there is balanced support from the UKKA to the other devolved nations.

#### **Devolved nations**

We have set up regular meetings with professional renal leadership in the devolved nations and will be working to ensure that clinicians and scientists in the devolved nations have a full voice in the UKKA.

#### COVID-19

There are major uncertainties around the direction of the pandemic, including the virulence of the dominant variance, vaccination schedules, prophylactic and treatment responses. We are currently evolving the COVID-19 leadership group to an Infection Prevention and Control Committee which will also have responsibility for other areas within UKKA. We have indicated to patient partner organisations that we may need to find funding for protected time for the leadership of this group to ensure that we can continue to deal with the pressures of COVID-19

## **Equality Diversity and Inclusion**

We recognise this as a key area of work, with individual workstreams and the UKKW continuing to focus on EDI and putting in place a formalised EDI structure.

### **Kidney Beam**

Kidney Beam, the emotional and physical wellbeing digital health intervention which has been supported and nurtured by the UKKA, together with the other UK kidney charities, continues its implementation phase across some of the UK kidney networks. Contracting remains an issue for some regions, but we are pleased to report that we have two regions underway already. A huge thank you to the trustees for supporting this initiative and to our CEO Ron Cullen who has helped to steer this.

#### **UK Kidney Week**

UKKW 2021 and 2022 were great successes, with UKKW 2022 being the first face-to-face meeting in three years. We thank the Programme Committee Co-Chairs, the wider Programme Committee, and the Secretariat team. The feedback for 2022 was excellent. An indication of the growth and aspiration of the UKKA is that the meeting was the first in-house UKKW, so we now have our own events team. The Co-Chairs, Programme Committee, and Secretariat team are now working hard on UK Kidney Week 2023, which will be held at the Welsh International Convention Centre from 5-7 June 2023. This will be the most ambitious UKKW yet. The venue is fantastic, and the programme will be outstanding. The invitation for proposals for sessions at UKKW has just been announced and we are expecting some exciting and novel submissions.

#### Kidney Quality Improvement Partnership (KQuIP)

Most regions have indicated that they will fund KQuIP Programme Manager time with their Network and those relationships are now being formalised. We are in detailed discussions with Kidney Care UK about partnership funding, and Fresenius has committed to a partnership in the DAYLife project. Two UKKA KQuIP leads have been appointed, Dr Rosie Donne and Dr Udaya Udayaraj. The Programme Managers are working through a time of great change and are doing an outstanding job in developing formal links in the programme. Thank you to Rachel Gair and the KQuIP team.

#### **Executive team and Trustee roles**

Several of the current leadership team will be demitting between now and the next annual general meeting. We would like to express particular thanks to Graham Lipkin who is stepping down as a Trustee at this AGM. Graham has been an outstanding leader for the professional community, initially as Clinical Services Committee Chair of the Renal Association (RA), then as Clinical Vice President and subsequently as President of the RA. Graham led the RA and worked with Sharlene and Maarten Taal and other BRS leaders to establish the UKKA and has been the first Past-President of the UKKA. Graham had a central role in setting up KQuIP. As if he has not had enough to do, Graham has also (with Will McKane) been medical lead for Renal Getting It Right First Time (GIRFT) during this period. Thank you, Graham.

#### **New MPT President**

We would like to welcome Clare Morlidge to the position of UKKA co-President. Clare is known to many in the UKKA and beyond through her leadership roles across a range of areas including in the Renal Pharmacy Group. Clare has outstanding skills and we are blessed that she is coming into the UKKA Co-President role.







As I step into the Past-President position, I look forward to supporting Clare Morlidge in her new role. I would like to thank the Trustees. Ron Cullen and the executive team, all the UKKA leaders, and the membership for their support during my time as President of the UKKA. A special thank you to Paul Cockwell who has been a trusted Co-President, colleague, and friend. I know I leave the UKKA in safe hands with Paul and Clare at the helm.

Saludup

**Dr Sharlene Greenwood** 

President, the UKKA



Sharlene Greenwood is a transformational leader and I feel blessed to have worked with Sharlene closely, both since the launch of UKKA and from 2017 in joint leadership roles for KQuIP and beyond. I would like to thank her very much both for her close collegiate working and her friendship and personal support. I know that I speak for all UKKA leadership and members in thanking Sharlene for her outstanding contribution.

Ene Cortwer

**Prof Paul Cockwell** President, the UKKA

## **GOVERNANCE AND STRUCTURE**

The board of trustees is the UK Kidney Association's governing body as a charity. It is responsible for the management of the UK Kidney Association's business, for which purpose they may exercise all the powers of the UK Kidney Association. The board meets face to face at least three times a year to:

- Manage risk
- · Oversee strategy, define policy, agree the business plan and monitor progress
- Ensure the proper management of the assets of the Renal Association for the benefit of the objects.

It has the authority to carry out the charitable responsibilities of the UK Kidney Association and delegates the operational aspects of its affairs to its CEO and committees. It works closely and liaises with the UK Kidney Association Council but ultimately, all decisions (apart from changes to the Articles of Association) are either taken by, or on behalf of, the Board of Trustees and reported to the membership at the annual general meeting.

## **TRUSTEES**



PRESIDENT
Prof Paul Cockwell
Queen Elizabeth
Hospital Birmingham



PRESIDENT

Dr Sharlene
Greenwood

King's College Hospital



PAST-PRESIDENT

Dr Graham Lipkin

Queen Elizabeth
Hospital Birmingham



BAPN PRESIDENT

Dr Jan Dudley

Bristol Royal Hospital for Children



HONORARY SECRETARY Prof Alan Salama Royal Free Hospital London



TREASURER

Prof Claire Sharpe

King's College London



CLINICAL VICE PRESIDENT

Dr Katie Vinen

King's College Hospital



PRESIDENT

Karen Jenkins

East Kent Hospitals

**CLINICAL VICE** 



ACADEMIC VICE PRESIDENT Prof Neil Sheerin Institute of Cellular Medicine, Newcastle University



ACADEMIC VICE PRESIDENT Helen Hurst Manchester University Hospitals



NON-MEMBER TRUSTEE

Heather Lawrence



NON-MEMBER TRUSTEE

David Silver

## SENIOR MANAGEMENT TEAM



**CEO**Ron Cullen



DIRECTOR OF INFORMATICS RESEARCH Professor Dorothea Nitsch



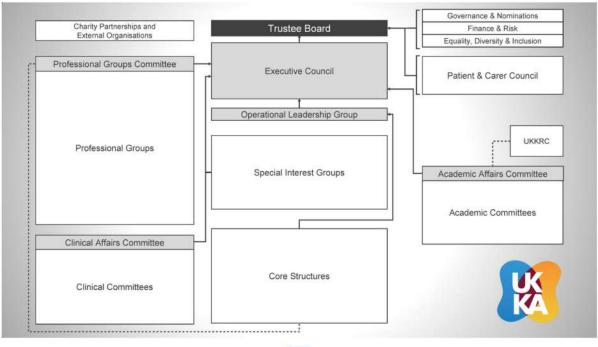
UKRR MEDICAL DIRECTOR

Dr James Medcalf

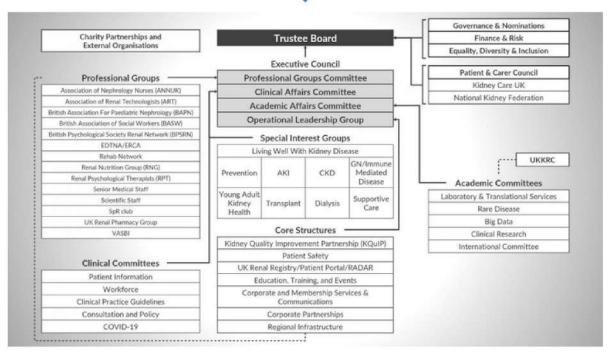


UKRR HEAD OF OPERATIONS Dr Retha Steenkamp

## **STRUCTURE**







## THE SIX PILLARS OF THE UKKA



## COMMITTEES & SPECIAL INTEREST GROUPS

Clinical and Academic committees continue to meet the needs of UK Kidney Association members. Central to delivery, the UKKA is focused on the creation of a series of multiprofessional Special Interest Groups (SIGs) supported and enabled through core UKKA corporate structures.













#### Committees & chairs

- Clinical practice guidelines committee Dr James Burton & Dr Katie Fielding
- International committee Dr Sunil Bhandari
- Clinical services committee Dr Clara Day
- Education and training committee Dr Debasish Banerjee
- Patient safety committee Dr Katrin Jones & Karen Jenkins
- Patient information committee Dr Rebecca Suckling
- Renal scientists committee Dr Tim Bowen
- Sustainable kidney care committee Dr Suren Kanagasundaram
- Rare diseases committee Dr Danny Gale
- Renal PatientView Dr Afzal Chaudhry









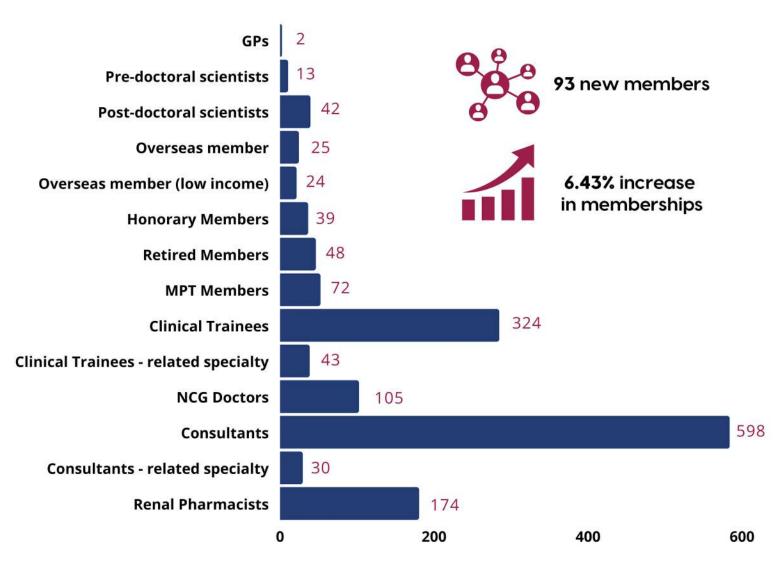
## Special Interest Groups & chairs

- Acute Kidney Injury Dr Jon Murray & Clare Morlidge
- Chronic Kidney Disease Prof Paul Cockwell
- Dialysis Dr Mark Lambie and Gail Williams
- Living Well With Kidney Disease Juliet Mayes & Dr Matt Graham-Brown
- Supportive Care Karen Jenkins & Dr Katie Vinen



## **OUR MEMBERS**

The members of the UKKA comprise over 1,539 doctors, scientists and MPT members.





## **OUR MEMBERS**

## **AWARDS, BURSARIES & LECTURES**

#### **Raine Award**

This prestigious award is made to a relatively junior member who has made a significant contribution to research. Due to the COVID-19 pandemic, this rolled over from 2020 and was awarded to **Dr Matthew Graham-Brown**.

#### **Lockwood Award**

The Lockwood Award is awarded to help RA members present work, combined with a visit to a collaborating laboratory or clinical nephrology unit overseas. In 2021 this was not awarded.

#### Walls bursaries

These bursaries enable a clinician and non-clinician to spend short periods at other centres, generally outside the UK. In 2021 no bursaries were awarded.

#### Medical student elective bursaries

The UK Kidney Association awards 8 bursaries to medical students who are planning to undertake electives which include a significant renal component, either clinical or research. In 2021 no bursaries were awarded.

### O'Donoghue Lecture

This lecture is named in honour of the UKKA's former President Professor Donal O'Donoghue OBE. The inaugural lecture was delivered in 2021 by **Prof Chris Whitty**, Chief Medical Officer for England, at UK Kidney Week.

#### **Chandos Lecture**

This lecture honours the Chandos family who have given great support to the kidney community over many years. In 2021 this Lecture was delivered by **Prof Megan Griffith** at UK Kidney Week.

#### de Wardener Lecture

The de Wardener lecture was established in 2004 in honour of Professor Hugh de Wardener (1915-2014), one of the UK's most distinguished nephrologists and clinical scientists. In 2021 this Lecture was given by **Prof Rachel Lennon** at UK Kidney Week.

#### Osman Lecture

The Osman Lecture was endowed by Mrs Ruth Osman, widow of Dr Arnold Osman, a founding member and the first President of the Renal Association who died in 1972. In 2021 this Lecture was given by **Professor Sir Peter Ratcliffe.** 

### Jane Macdonald Leadership Award

For outstanding leadership in the renal community. In 2021 this was awarded to **Clair Main**.

#### **Donna Lamping Researcher Award**

For outstanding research in Kidney Care. In 2021 this was awarded to **Lina Johansson**.

#### Mallick Lecture Award

For lifetime services to the renal community. In 2021 this was awarded to **Gill Manning**.

## CONSULTATIONS

The UK Kidney Association has been involved in a number of NICE, NHSE and HEE consultations in the last year. Thank you to all members who contributed.

- NICE Review Consultation: TA164; Febuxostat for the management of hyperuricaemia in people with gout - Paddy Mark
- NICE/SIGN/RCGP draft scope consultation management of post-COVID-19 syndrome Paul Cockwell, Indranil Dasgupta
- NHSE/I Genomics: Consultation on Updating and Managing the National Genomic Test Directory - Albert Ong
- NICE appraisal invitation consultees: Systemic lupus erythematosus (active, autoantibody positive) - belimumab (review of TA397) [ID1591] - Liz Lightstone
- Technical engagement (C&C's): Kidney transplant (rejection prevention, chronic kidney disease) imlifidase [ID1672] **Michelle Willicombe**
- NICE Technical engagement(C&C's): Atypical haemolytic uraemic syndrome ravulizumab [ID1530] - Edwin Wong
- NICE process of health technology evaluation consultation Edwin Wong
- Scoping Consultation Invitation (All C&C): Chronic kidney disease dapagliflozin ID3866 Andrew Frankel
- NICE draft guideline consultation chronic kidney disease: assessment and management -Maarten Taal on behalf of Sian Griffin, Andrew Mooney, Kate Bramham and ABCD RA group
- Technical engagement (stakeholders): Systemic lupus erythematosus (active, autoantibody positive) - belimumab (review of TA397) [ID1591] - Liz Lightstone
- Scoping Workshop for slow-release potassium bicarbonate and potassium citrate for distal RTA - Detlef Bockenhauer, Sarit Shah
- Distal renal tubular acidosis potassium bicarbonate and potassium citrate ID3787 Jan Dudley
- NICE Medical Technologies Evaluation Programme ClearGuard HD Antimicrobial Barrier Cap for preventing haemodialysis catheter-related bloodstream infections: Draft scope for comments - Jyoti Baharani
- NICE appraisal invitation consultees: Chronic kidney disease dapagliflozin [ID3866] Debasish Banerjee, Rosa Montero
- NICE appraisal invitation consultees: Chronic kidney disease dapagliflozin [ID3866] Andrew Frankel
- IP1540 Robot-assisted kidney transplant Ellie Asgari

## CONSULTATIONS

- NICE draft guideline consultation Type 1 diabetes in adults: diagnosis and management (update) - Robert Lewis
- NICE appraisal invitation consultees: Amyloidosis (systemic, amyloid light-chain, untreated) - daratumumab (in combination) [ID3748] - workshop attendance - Jenny Pinney
- NICE appraisal invitation consultees: Amyloidosis (systemic, amyloid light-chain, untreated) - daratumumab (in combination) [ID3748] - comments - Jenny Pinney
- Scoping Consultation Invitation (All C&C): Pruritus (haemodialysis) difelikefalin ID3890 - Indranil Dasgupta
- NICE appraisal invitation consultees: Distal renal tubular acidosis potassium bicarbonate and potassium citrate [ID3787] - workshop - Matko Marlais
- NICE appraisal invitation consultees: Distal renal tubular acidosis potassium bicarbonate and potassium citrate [ID3787] - comments - Detlef Bockenhauer
- Scoping Workshop and Consultation Invitation (Professional): Cytomegalovirus infection (refractory, resistant) maribavir (after transplant) ID3900 Sunil Daga
- Managing the long-term effects of COVID-19 Scoping workshop invite 10 June -Chris Laing
- Scoping Workshop and Consultation Invitation (Professional): Lupus nephritis (active, uncontrolled) - belimumab [ID2722] - Liz Lightstone
- Anifrolumab for treating active autoantibody-positive systemic lupus erythematosus [ID3804] - Liz Lightstone
- NICE appraisal invitation consultees: Chronic kidney disease (diabetes type 2) finerenone [ID3773] - Indranil Dasgupta and Debasish Banerjee on behalf of ABCD/UKKA

## FINANCIAL REPORT

## **Professor Claire Sharpe, Treasurer**

The UK Kidney Association (UKKA) had an overall surplus for 2021 of £1,047,985 (2020: £288,470).

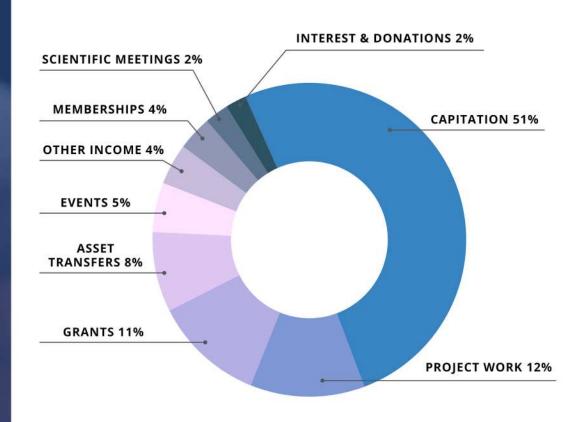
2021 was a year of great change within the organisation. Significantly, the British Renal Society (BRS) and the Renal Association merged to form the UK Kidney Association. The Renal Association retained its legal status and is now trading under the new name. Assets from the BRS totalling £285,000 were transferred and this amount is included in the surplus.

The new organisation was created to support the whole multi-professional team (MPT) in the delivery of kidney care, education and research and the Renal Pharmacy Group (RPG) was the first allied health professional (AHP) group to join. The. Assets from the RPG, totalling £65,000, were transferred and this amount is included in the surplus.

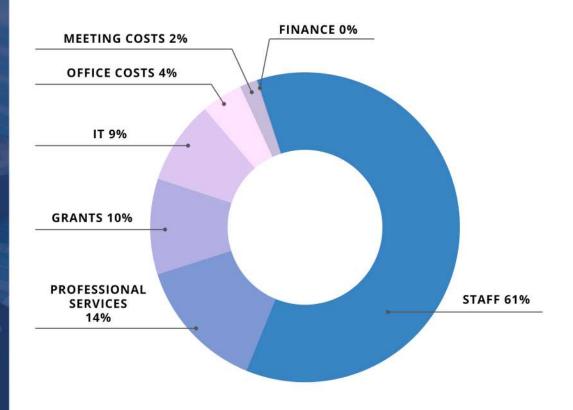
UK Kidney Week took place virtually due to the pandemic and was organised by an external secretariat. The finances for this meeting were managed internally for the first time, accounting for £231,000 of income previously not recognised in the accounts, as this was historically managed by the BRS.

Overall, the UKKA is financially very secure. The agreed reserve level for 2021 was £3.0 million to be held either as immediately available funds or in short to medium-term investments. The reserves at the end of 2021 were £3,557,430 (2020: £2,509,445). The reserves held are sufficient to cover 12 months' operating costs and this should be maintained at this level. The strength of our reserves policy and the quick response of our staff to new demands and risks have ensured that the UKKA remains financially stable during this period of economic uncertainty.









EXPENDITURE £3,185,391

### In 2021 we undertook many new projects:

- Many AHP groups voted to join the UKKA. These
  integrations will be finalised in 2022 but we took the
  decision to offer a special introductory membership
  rate to these members. This resulted in individual
  membership income decreasing by 2% although the
  actual number of members grew by 4%.
- We continued to explore the opportunities of collaboration with industry for the Rare Disease Registry (RaDaR), employing new staff and building this team further.
- We decided to organise UK Kidney Week 2022 in-house, developing the skills of our own staff to build improved relationships with industry and to offer exceptional service to our delegates.
- As quality improvement becomes increasingly important, we have worked collaboratively with regions to continue to develop local networks. Further regions are in discussions to adopt similar models.

Income from investments decreased to £7,772 (2020: £11,531), we are addressing this in a new investment policy for 2022.

For further details please see the annual accounts which are available at <a href="https://ukkidney.org">https://ukkidney.org</a> from October 2022.

#### Disclaimer

The data reported here have been supplied by the UKKA however the interpretation and reporting of the data are the responsibility of the author.

## **Equality and diversity**

The UK Kidney Association continues to be committed to creating and sustaining a positive, fair and mutually supportive environment. We accept, respect and value people with diverse identities and backgrounds and believe our differences make us stronger and more effective in achieving our goals. We ensure appointments are made on the recommendation of a transparent, balanced and appropriate panel, are made on the basis of merit, and encourage applications from all suitably qualified and eligible candidates.

## Legal status

The Renal Association (trading as the UK Kidney Association) is registered in England and Wales as Company 2229663, limited by guarantee and registered as charity number 800733.

#### **Articles and rules**

You can read the articles and rules here.



The UK Kidney Association
Brandon House, Building 20A1
Southmead Road
Bristol
BS34 7RR



renal@renal.org



0117 414 8152



ukkidney.org

