



2020

ANNUAL REPORT

IMPROVING LIVES BY SUPPORTING PROFESSIONALS
IN THE DELIVERY OF KIDNEY CARE AND RESEARCH



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PRESIDENT'S REPORT

This is my final annual report after three years of having the privilege of being President of the Renal Association. The RA has never been stronger or more effective and rests on a bedrock of strong governance structures. It can be rightly proud of its substantial delivery, and continues to grow, having merged with the UK Renal Pharmacy Group in December. We continue to achieve our Mission through initiatives to serve our membership and the broader kidney community, and despite COVID-19, have delivered an ambitious three-year strategy.

Following due diligence, three years of careful negotiation, and an overwhelmingly positive membership vote, the British Renal Society merged with the RA in June to create the UK Kidney Association (UKKA). This new national, democratic multi-professional membership organisation is fit for future delivery, whilst protecting the UK Renal Registry functions. I warmly welcome my friend, colleague, successor, the hugely capable Paul Cockwell as our next President. We are in very secure hands.

It could hardly have been a worse year for our patients and professional community. Patients paid a very high price with the death of 1 in 25 of those on dialysis, high mortality with CKD and transplant recipients. Transplant services had to be suspended. Two RA surveys identified that Renal Unit staff have been left with psychological challenges, which the UKKA will position itself to support on. I am hugely proud of the RA's response to COVID-19. We came together as a professional community, producing guidance, data, research and advice to healthcare commissioners and the system, to maximise care and minimise harm.



DR GRAHAM LIPKIN
PRESIDENT

***"I AM
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THE RA'S
RESPONSE
TO COVID"***





**PROFESSOR DONAL
O'DONOGHUE OBE
1956-2021**

Donal O'Donoghue

Tragically, several RA members succumbed to the pandemic. In January we lost Donal O'Donoghue to this cruel disease; our 'father of modern nephrology', an outstanding Past President and a dear friend. It was a tragic loss, individually and to the UK Medical community. He is deeply missed. Together with the RCP, the RA created a permanent record presented to Donal's wife Marie and his family. We continue to honour Donal with an annual O'Donoghue Lecture at UK Kidney Week, focused on excellence in clinical service delivery and inequities in service access, all subjects dear to Donal's heart. The inaugural lecture this year will be delivered by Professor Chris Whitty, Chief Medical Officer of England. In due course, we hope to develop an annual O'Donoghue Trainee Fellowship with Kidney Care UK.

Thank You.

As President, I am very proud of the role of the RA membership in standing together, and with hard work and care, selflessly addressing key issues. The response to the COVID-19 emergency has been nothing short of stunning. The RA linked the UK kidney community, creating guidelines, policy, patient information and professional development. The Registry has collected superbly useful data with its ongoing analysis informing upon policy. Thank you to Paul Cockwell and Katie Vinen for leading and delivering on this.

I also thank the tireless great work of our CEO Ron Cullen, the Secretariat and Executive who have delivered in spades. Ron's contribution has been truly outstanding; a dedicated, innovative, wise head in difficult seas. None of what we have, or will achieve, would be possible without the brilliant, selfless and tireless work of my fellow Trustee colleagues who have supported us all in negotiations with the BRS, set strategies and delivered during difficult times. We shouldn't underestimate the out of hours voluntary work that Trustees invest with good grace and humour. We have a robust financial position due to the work of RA Treasurer Claire Sharpe and Head of Finance Stephanie Lock. Thank you for your support, and for achieving this position despite COVID and its impact on income from UKKW 20/21.

"THERE ARE MAJOR OPPORTUNITIES AHEAD FOR SERVICE IMPROVEMENT AND RESEARCH"

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[illegible]

The UK Renal Registry have delivered above and beyond. Work continues on audit and assurance, delivery of the national report, new AKI report and data portal. The excellence of the COVID-19 infection and vaccination registries have enabled us to protect our patients and influence national policy. There are opportunities ahead for service improvement and research through linked data analysis. The Registry has recently joined the UK Health Data Research Alliance, engaged with the national Goldacre review, and works closely with NHS Digital and Kidney Research UK.



**"WE ARE TRULY
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The UK Kidney Association

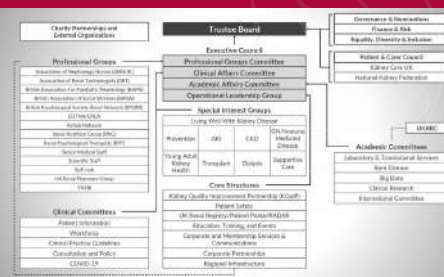
The UK Kidney Association (UKKA) will support the whole multi-professional team in the delivery of kidney care, education and research - enabling people to live well with kidney disease.

We are truly delighted to announce the creation of the UKKA, a unique opportunity created by the merger of the BRS and its Affiliates into the Renal Association. After prolonged negotiations, at which principles were agreed, Heads of Terms confirmed, due diligence, RA and BRS member votes and asset transfer, the UKKA has been created and will launch fully in July. It fundamentally changes the UK renal medical/MPT landscape. The new Board has been appointed, pending approval at the RA AGM, and a new structure, new logo, branding and website are in progress.

The opportunities are huge for the community and include:

- Improved collaboration and communication
- Economies of scale and increased income
- National structures reflecting how we work as a team at renal unit level
- Additional influence with national healthcare commissioners and research funding bodies
- Greater CPD support across the community
- Improved QI support
- Improved workforce planning
- Supporting research
- Greater attractiveness to Industry partners

The UKKA is focused on delivery around a series of Special Interest Groups. The Trustee board includes an MPT Clinical Vice President (CVP) and Academic Vice President (AVP), BRS President (in 1st year) and two non-member trustees. Day-to-day delivery will be coordinated by the Operational Leadership Group comprising Presidents, AVPs, CVPs and UKKA executive. The Trustees are supported by the Governance and Nominations, Finance and Risk and Equality, Diversity and Inclusion Committees and advised by an Executive Council and Patient Council. A series of Core structures will support including KQuIP, Education, Corporate partners and UK Kidney Week. All committees and SIGs will be co-chaired by joint MPT and medical leadership.



The Renal Pharmacy Group

It is a great pleasure to welcome Clare Morlidge and the UK Renal Pharmacy Group (UK RPG) as members who have joined the Renal Association. There are great opportunities for integrated working on workforce, guidelines, information and CPD/research whilst maintaining the unique identity of the UK RPG within the UKKA. Advanced Pharmacist roles are crucial to improving quality renal care as highlighted in the Renal GIRFT National Report and BRS Workforce document.

Supporting Service Recovery and beyond; Commissioning, GIRFT and RSTP

There is real room for optimism in recovery as we enter probably the most exciting opportunities for renal services and research in a decade:

1. Expedited COVID-19 vaccination roll out to our patients is complete (low vaccine hesitancy)
2. GIRFT National Report is about to be published and RSTP implementation has launched in June to implement improved renal services
3. Joint planning with the MPT through the creation of the UK Kidney Association
4. Renal Research strategy refresh in combination with Kidney Research UK


COVID-19 has caused substantial renal patient mortality and a considerable backlog of activity, exacerbating existing inequities in access to and delivery of care. Major changes in NHSE commissioning are in progress with a move to local Integrated Care Systems which will impact all renal services. Close linkage with new UKKA-supported regional renal networks is important to ensuring care quality ahead.

After extensive data development, visits to all 52 adult renal units, and bespoke reports, the National Renal GIRFT report has been published in an embargoed format. It has 18 stem and nearly 100 recommendations for improving equity and high-quality renal care. It focuses on the importance of regional renal networks, embedding QI, MPT input to service planning and improvements in data collection and reporting, and improved access to transplantation, home dialysis, vascular access and the care of patients with AKI.



***"A FOCUS ON THE
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NHSE Renal Services Transformation Programme (RSTP) has truly high-calibre clinicians who will support implementation through regional networks. This is led by Neil Ashman with sub-group leads Smeeta Sinha (systems), Albert Power (dialysis) and Nick Torpey (transplant). An AKI lead is being appointed.

The RA/UKKA, through KQulP and clinical leadership, has an essential role in delivering change and sits on the RSTP Board. KQulP has established a superb charity-funded engaged QI structure with regional project managers covering 80% of England and the devolved nations. This, in addition to the Clinical Directors Network, will be crucial in supporting service improvements. We will seek to develop integrated working of KQulP and the Regional Networks. The creation of the UKKA allows for coordinated, comprehensive clinical engagement with the planned developments.

UK Kidney Week

UKKW 2020 virtual was a great success with over 2,500 registrants, 85 units attended from 23 countries and the event was delivered in financial balance. We are learning how best to engage with Industry. UKKW 2021 is led by Beccy Suckling and Neil Sheerin and will again be virtual, opening in the 1st week of October. It will include a joint session with an RCP session dedicated to Donal, opened by CMO Professor Chris Whitty, and a plenary session led by the Nobel Laureate, Professor Sir Peter Ratcliffe. UKKW 2022 is now in planning and we will seek members' opinions on how best to deliver this in a hybrid format.

UK Renal Registry

The Registry remains the jewel in the RA Crown, with James Medcalf and Dorothea Nitsch as Medical and Research Directors. Registry staff have delivered above and beyond with new COVID-19 Registries, the first national AKI report, PREMS and data portals. There are recommendations pertinent to the UKRR in the GIRFT report including the collection of CKD Stage 4-5 data and contemporary dashboard data supporting QI.

The Registry is also moving its innovative patient portal, for reasons of governance and quality, from Patient View to Patients Know Best.

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Supporting Professional Development

Despite the pandemic, the Academic Vice President, Neil Sheerin and Debasish Banerjee, Education and Training Committee Chair, have developed and led a series of high-quality, monthly Webinars in collaboration with the BRS across major areas of practice which are ongoing. The eLearning platform will soon be used for learning modules, created in collaboration with industry partners. These are major opportunities for the UKKA to develop a strong educational base for all UK kidney health professional members.

Rare Renal and RaDaR continue to grow in strength, delivery and increasing research, realising the opportunities available.

Renal Trainees

Support for renal trainees remains a core focus of the RA and will continue in the UKKA. We are privileged to have Hannah Beckwith as chair of the SpR Club, arranging highly valued twice-yearly meetings. Hannah also attends every Trustees session.

Renal Research

Renal Scientists remain a key constituency in the RA and will continue to be in the UKKA. We are keen to liaise further with Kidney Research UK through the UK Kidney Research Consortium to further enhance research opportunities and support. The UK Renal Research Strategy requires a refresh and the UKKA will work with stakeholders to update this.

External Stakeholders

Delivery of improved services to patients, research, Registry delivery, and patient engagement are all enhanced by close collaboration with our stakeholder charity organisations. The RA has worked jointly with Kidney Care UK to deliver KQulP and extensive patient information. We are grateful to Beccy Suckling for the delivery of a suite of high-quality patient information leaflets and for supporting NKF in its materials. UKKW is delivered with input from BTS.



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The RA has been very effective in its corporate strategy, led by Neil Sheerin. Increasing the number and enhancing effective corporate partnerships is a key strategic objective of UKKA.

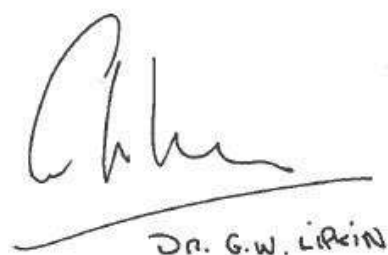
UKKA Strategic Priorities for the coming year

The priority areas for UKKA delivery are:

- Embedding agreed rules and structures to ensure optimal delivery of UKKA going forward
- Developing a three-year strategy for UKKA members
- Realising the opportunities of Big Data Renal Research Informatics and supporting renal scientists
- Embedding a marketing and communications strategy
- Delivering a virtual UKKW 2021 and planning UKKW 2022
- Ensuring KQulP is put on a secure future footing
- Building effective Corporate Partnerships
- Working with GIRFT/RSTP at national and regional Professional (QI) Networks level
- Seeking mutually beneficial co-working with KRUK

I offer heartfelt thanks to all Committee Chairs and members for your support and hard work.

I wish to end by offering my complete support to my successor Paul Cockwell. Paul is a fantastically capable and effective leader. I look forward to my role as Past President and Trustee of the UKKA over the next year. I am truly confident that the Association with its exciting future is in very strong hands with Paul Cockwell as President and Sharlene Greenwood as President (BRS) at the helm and with a highly talented and dedicated expanded Trustee Board. These are exciting times for all kidney health professionals and represents huge opportunities for the improved care of patients with kidney disease.



Dr. G.W. Lipkin

Dr Graham Lipkin

President, the Renal Association

GOVERNANCE AND STRUCTURE

The board of trustees is the Renal Association's governing body as a charity. It is responsible for the management of the Renal Association's business, for which purpose they may exercise all the powers of the Renal 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 Renal Association and delegates the operational aspects of its affairs to its CEO and committees. It works closely and liaises with the Renal 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

Dr Graham Lipkin
*Queen Elizabeth
Hospital Birmingham*



PAST PRESIDENT

Prof Donal O'Donaghue
Salford Royal Hospital



VICE PRESIDENT BAPN PRESIDENT

Dr Sally-Anne Hulton
*Birmingham Children's
Hospital*



CLINICAL VICE PRESIDENT INCOMING PRESIDENT

Prof Paul Cockwell
*Queen Elizabeth
Hospital Birmingham*



ACADEMIC VICE PRESIDENT

Prof Neil Sheerin
*Institute of Cellular
Medicine, Newcastle
University*



HONORARY SECRETARY

Dr Indranil Dasgupta
*Heartlands Hospital,
Birmingham*



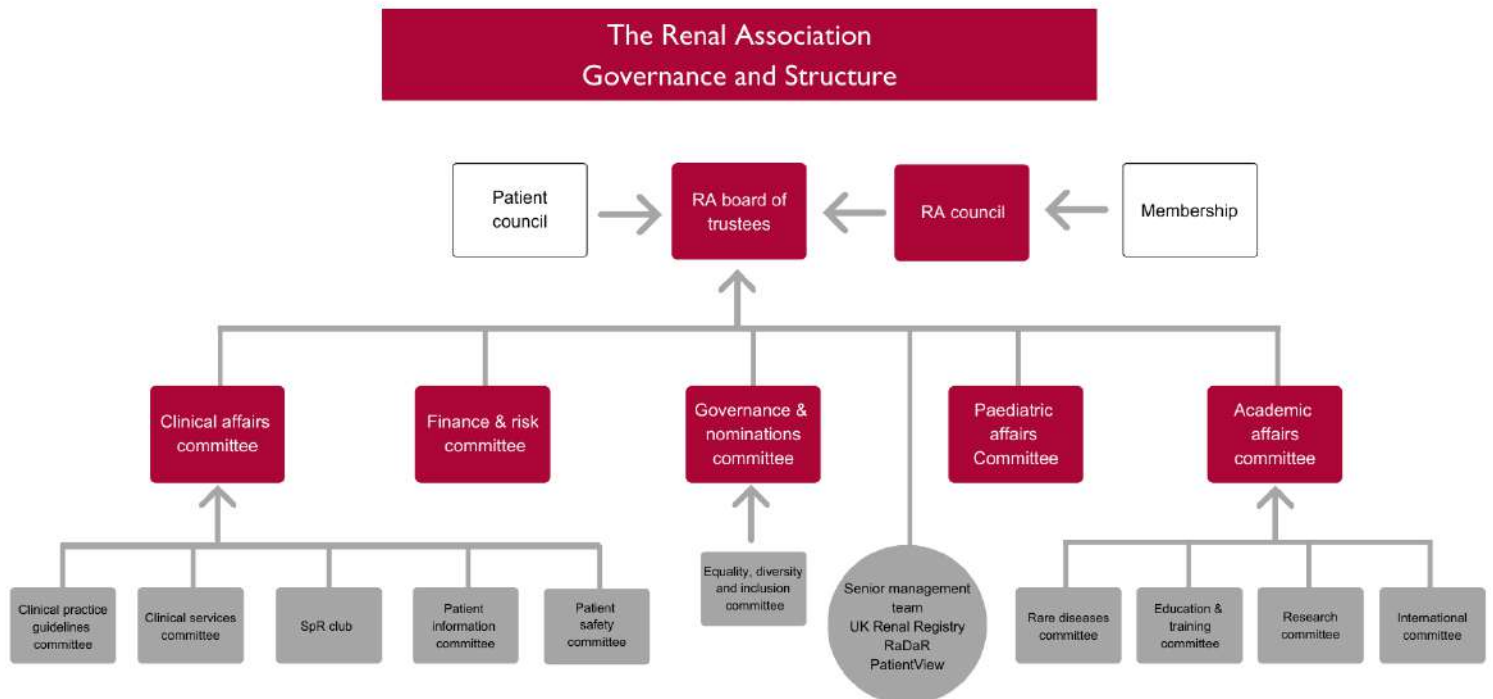
TREASURER

Prof Claire Sharpe
King's College London



NON-MEMBER TRUSTEE

David Silver



Revised September 2019

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

Council and committees

The Renal Association Council meets at least three times a year and develops policy. It considers and acts on current issues affecting the renal community and reports to the RA Board of Trustees. The RA Council includes elected members who represent the views and opinions of the membership of the RA. Day to day affairs are conducted with advice from committees.

Elected

Dr Victoria Ingham (2019 – 2022)

Dr Colin Geddes (2020 - 2023)

Dr Richard Hull - Consultant less than 5 years (2018 – 2021)

Dr Edwin Wong (2020 - 2023)

Dr Debasish Banerjee (2018 – 2021)

Dr Peter Hewins (2017 – 2021)

Dr Marie Condon - Consultant less than 5 years (2017 – 2021)

Committee chairs

Dr Mike Robson (Clinical practice guidelines committee 2017 - 2021)

Professor Alan Salama (International committee 2019 - 2022)

Dr Katie Vinen (Clinical services committee 2017 - 2021)

Dr Debasish Banerjee (Education and training committee 2020 - 2023)

Dr Danny Gale (Rare diseases committee 2018 - 2021)

Dr Afzal Chaudhry (Renal PatientView)

Dr Rebecca Suckling (Patient information committee)

Dr Katrin Jones (Patient safety committee)

Dr Tim Bowen (Renal scientists committee 2020 - 2023)

Ex-officio

Dr Yook Mun Woo (representative for non-consultant grades)

Dr Hannah Beckwith (SpR club representative)

Professor Peter Maxwell (representative for Northern Ireland)

Dr Mark Andrews (Chairman, SAC Renal Medicine)

Dr Mick Kumwenda (Society of DGH Nephrologists)

Dr Sharlene Greenwood (President, British Renal Society)

Professor Phil Kalra (Chair, National Institute for Health Research (NIHR) Speciality Group)

Dr Andrew Lunn (Honorary Secretary, BAPN)

Dr Aled Philips (representative for Wales)

Dr Paddy Mark (representative for Scotland)

Dr Mark Dockrell and Dr Gavin Welsh (Co-chairs, Renal Scientists Working Party)

Dr Andrew Connor (Green Nephrology)

Dr Jim Moriarty (Renal Association Communications Consultant)

Mr Ron Cullen (Renal Association CEO)

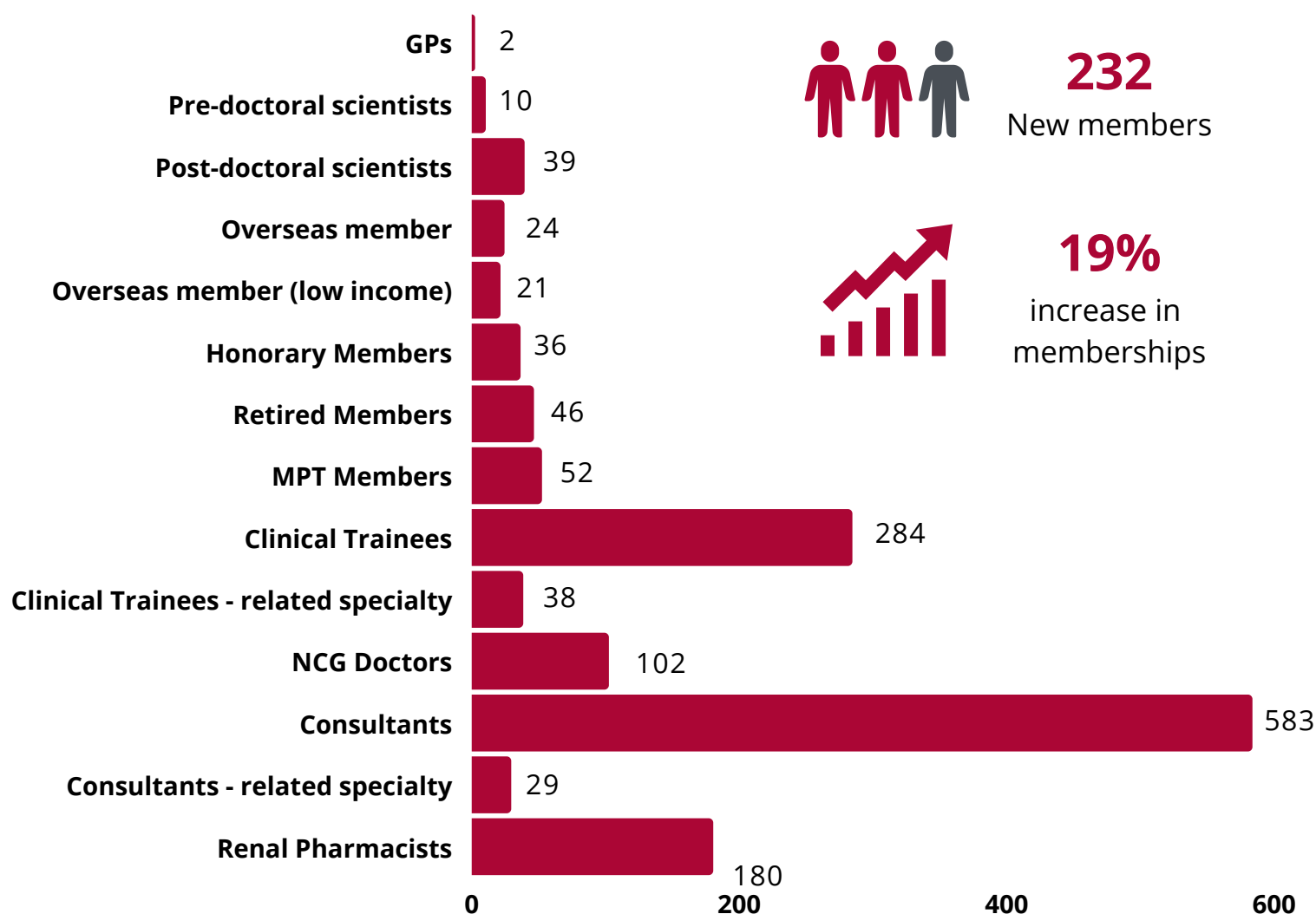
Dr James Medcalf (Medical director, UK Renal Registry)

Fiona Loud (Policy director, Kidney Care UK)

Kirit Modi (National Kidney Federation)

OUR MEMBERS

The members of the RA comprise over **1,446** doctors, scientists and MPT members.



Awards and bursaries

Raine Award

This prestigious award is made to a relatively junior member who has made a significant contribution to research. In 2020 the Raine Award was closed to applicants, it re-opens in September 2021.

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 2020 the Lockwood Award was closed to applicants.

Walls bursaries

These bursaries enable a clinician and non-clinician to spend short periods at other centres, generally outside the UK. In 2020 no bursaries were awarded, applications re-open in July 2021.

Medical student elective bursaries

The Renal Association awards 8 bursaries to medical students who are planning to undertake electives which include a significant renal component, either clinical or research. In 2020 no bursaries were awarded, applications re-open in July 2021.

Consultations

The Renal 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 on behalf of Samira Bell, Peter Thompson
- 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
- 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
- NICE Distal renal tubular acidosis - potassium bicarbonate and potassium citrate [ID3787] – Jan Dudley, Sarit Shah and Detlef Bockenhauer
- NICE Medical Technologies Evaluation Programme – ClearGuard HD Antimicrobial Barrier Cap for preventing haemodialysis catheter-related bloodstream infections: Draft scope – Jyoti Baharani
- NICE IP1540 Robot-assisted kidney transplant – Elham Asgari
- 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 – Jenny Pinney
- NICE Scoping Workshop and Consultation Invitation (Professional): Cytomegalovirus infection (refractory, resistant) - maribavir (after transplant) [ID3900] – Sunil Daga
- NICE Scoping Consultation Invitation (All C&C): Pruritus (haemodialysis) - difelikefalin [ID3890] – Indranil Dasgupta
- NICE Managing the long-term effects of COVID-19 - Scoping workshop invite – Chris Laing

FINANCIAL REPORT

Professor Claire Sharpe, Treasurer

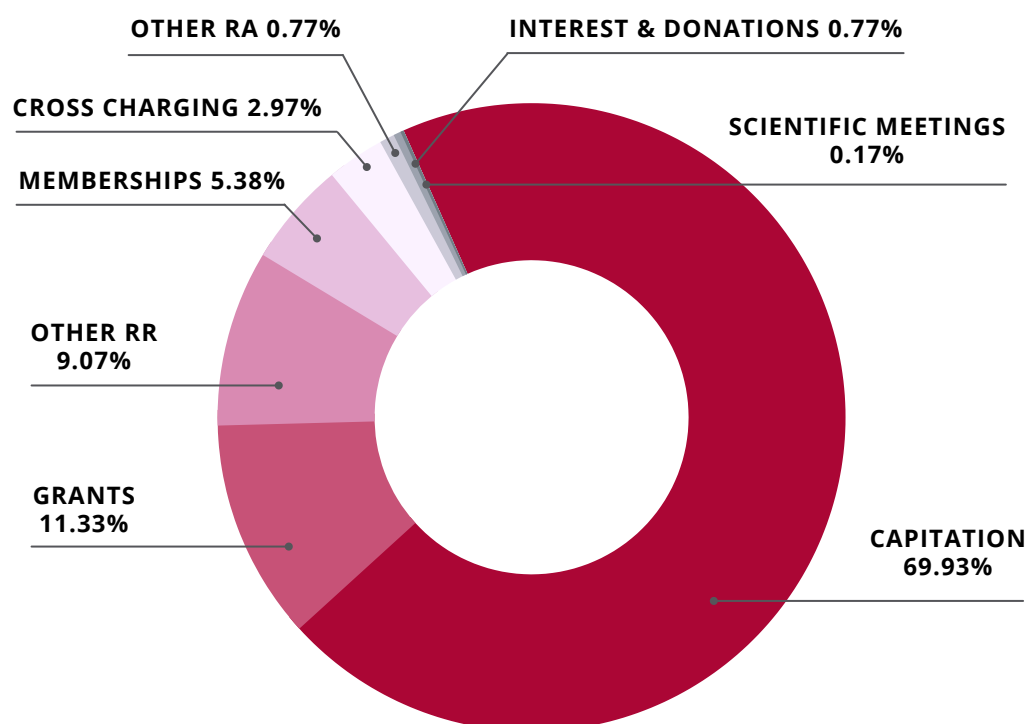
The Renal Association had an overall surplus for 2020 of £203,507 (2019: £25,679).

2020 was a difficult year for many charities; however, with the support of our membership and the commitment of our staff, we have come through this period in a strong financial position.

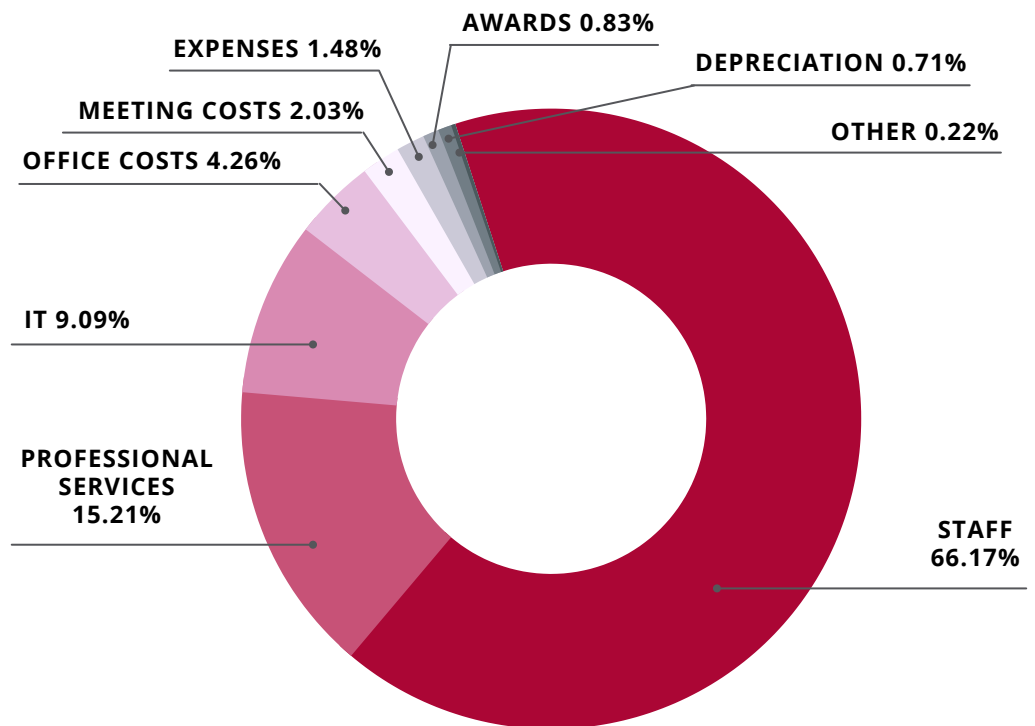
Overall the RA is financially very secure. The minimum agreed reserve for 2020 was £2.2 million to be held either as immediately available funds or in short to medium term investments. **The reserves at the end of 2020 were £2,424,482 (2019: £2,220,975).**

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 RA remains financially stable during this period of extreme uncertainty.

The Renal Association has become increasingly aware of the importance of healthcare delivery by a multidisciplinary team and is affiliated with the British Renal Society and in 2020 explored the possibility of merging with the British Renal Society in 2021. There has been much work around the financial implications of this merger.



INCOME £3,081,027



EXPENDITURE £2,877,520

In 2020 we undertook many new projects:

- Helping to support the fight against the pandemic, a programme manager was supported by NHS England
- We explored the opportunities of collaboration with industry for the Rare Disease Registry (RaDaR), employing a dedicated statistician.
- We participated in the GIRFT report, with two staff members funded.
- As quality improvement becomes increasingly important we have worked collaboratively with two regions (the North West and Yorkshire and Humber) to start developing regional networks, funded through a trust level capitation. Further regions are in discussions to adopt a similar model.

We adapted to the challenge of no physical meetings and ran a successful virtual conference in its place for UK Kidney Week 2020, which was coordinated by an external secretariat in conjunction with the British Renal Society.

We generated £11,532 of interest income compared to £8,831 in 2019. For further details please see the annual accounts which are available at www.renal.org from October 2021.

Disclaimer

The data reported here have been supplied by the Renal Association however the interpretation and reporting of the data are the responsibility of the author. This information is subject to amendments deemed necessary following the audit in 2021.

Equality and diversity

The Renal 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 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](#).



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