

THE RENAL
ASSOCIATION

founded 1950



ANNUAL REPORT

2019



www.renal.org

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President's report



Dr Graham Lipkin

Improving lives by supporting professionals in the delivery of kidney care and research.

Who could have anticipated the fundamental destruction wrought on our patients, health system and working lives by the arrival of the COVID-19 Pandemic when I last reported to the AGM? I am hugely proud of the RA and grateful to the RA members for the magnificent, selfless response of the Association in support of our patients, members, health care providers and the broader community. The RA continues to lead from the front in the recovery phase, including rapid integration of remote consultation and service review.

We are in exciting times, at the gateway of major opportunities created through the [Renal GIRFT](#) and Renal Services Transformation Programme. The RA has worked hard with the British Renal Society and its Affiliates and has a clear strategy for closer working which we hope will lead to the creation of a merged organisation, the UK Kidney Association. The opportunities for the community here are substantial and we will present Articles to the AGM seeking support to enable this. Once the detail is agreed, we will put the proposal to a vote of our members.

The Renal Association continues to grow in membership and initiatives to serve its members and the broader kidney community. We continue to achieve our mission and have effective plans to deliver the ambitious RA strategy launched last year by embedding strategic aims led by the RA committee chairs. RA finances remain healthy due to enlarging membership, the success of the corporate strategy and a successful UK Kidney Week 2019. I am truly grateful to my fellow trustees, executive and committee chairs for their tireless work. The focus of the last year has been to embed greater support for hard pressed RA volunteers. I am delighted to announce that the RA has employed a project support officer to support committees, industry partners and eLearning, a communications officer and extra administrative support in the Secretariat. **There have been major developments in the RA Registry which, together with the Kidney Quality improvement Partnership, has had remarkable impact in supporting the community.**



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President's report

RA Response to COVID-19

RA input has been immense; as highlights - substantial contribution to four NICE COVID-19 clinical guidelines, 2 NHSE emergency guidelines, several clinical guidance papers - Paul Cockwell and others; a whole new COVID-19 outcome Registry guiding practice - James Medcalf and UKRR; weekly detailed community clinical support calls - Paul; crisis management of AKI in ITU; extensive patient information; a webinar attended by over 300 members - Indy Dasgupta and Claire Sharpe; great communications -Indy; development of research and data analysis - Neil Sheerin and James in the most arduous of times; superb collaboration making good relations with other stakeholders and across the UK... the list is endless . Ron Cullen as CEO and our secretariat have been front and centre in all these effects, a big thank you to all.

Ron and Claire have managed a really tricky financial commitment with the collapse of UKKW2020 in Birmingham. There are many positive lessons which we now need to collate and embed in practice. It is important to recognise that the community is tired, vacation starved and actually quite traumatised from the experience. We need to remember to be kind to ourselves and to our colleagues and each other encouraging talk, not forgetting our trainee colleagues who have suffered the most, to debrief and where needed offer more professional support.

Recovery and the Opportunities Ahead: GIRFT and RSTP

After a refresh we have major opportunities ahead. The Renal Service Transformation Programme and GIRFT are on the verge of publishing their reports setting the direction led by clinicians. The RA clinical committees, Registry and KQIP are in a strong position to support and lead much needed clinical change to deliver our strategy.

RA Finances

Under the expert stewardship of our Treasurer, Claire Sharpe and Head of Finance, Stephanie Lock, RA finances remain healthy. This is due to enlarging membership, the success of the RA corporate strategy and a successful UKKW19, despite the collapse of UKKW2020. We must be aware of the risks of UKKW2021 in Edinburgh, the potential impact of a merger with the BRS and taking on the Renal Pharmacy Group (RPG) and a possible conversion of the Advanced Nephrology Course to a virtual meeting.

President's report

Adoption of the Renal Pharmacy Group (RPG) and merger with BRS

Trustees continue to work on a unique opportunity with the BRS trustees and affiliate chairs to change the UK renal medical/multi-professional team (MPT) landscape long term. We are mandated by the RA membership on survey and unanimously by RA council to seek closer integrated working with MPT colleagues, including the option of scoping a merger with the BRS and its affiliates.

There are many well-rehearsed major operational delivery and financial efficiencies opportunities of a merger (in papers already approved).

The aim is to create a joint democratic membership organisation for all kidney professionals supported by a CEO and Executive to enable all volunteers to deliver. It is based upon the RA entity, encompassing the UK Renal Registry, PatientView, RaDaR and secretariat services. This will achieve financial benefits to invest in the whole community and achieve improved collaborations, integrated working and increased outputs.

Trustees of both the RA and BRS have met and worked hard including on work streams developed to explore in detail how this might best address the concerns of RA members and better deliver our mission and charitable objectives. The Trustees met formally in June to discuss the options to join with unanimous agreement to progress further with the aim of seeking approval from members in 2020 for merger, if due diligence and further talks progress satisfactorily.

The role of RA President demands significant time and dedication. After review by the Charities Commission, we propose payment of up to 8 hours per week for the employer of future Presidents. This should expand diversity in applicants for this post going forward, a key aim of the RA.

A merger comes with a small risk, including the time devoted by volunteers to develop and deliver the merger, a potential loss of decision making control and strategic direction, as there are risks to remaining as we are. Significant Governance issues need to be overcome. Each affiliate will be required to approve as separate organisations to the BRS.

Alternatively the RA and BRS/Affiliates could remain separate, with the RPG joining the RA in December and seek closer collaboration with other affiliates; we remain much as we are but look to engage affiliate groups. The expectation of the community will not be delivered and the opportunities and financial benefits used to support volunteers diminished.

President's report

Registry

The Registry moved to new premises near to North Bristol NHS Trust just prior to the COVID-19 outbreak. This year has seen the development of the Registry Patient Portal, allowing each unit to view individual benchmarked results. The Registry has published the 3rd Renal PREM report, an exemplar to other specialties. In addition the first landmark national AKI report has been published comparing incidence and outcomes of AKI across England. Further work will allow comparison of provider outcomes. The Registry continues to oversee project managers who are the bedrock of KQIP, which now covers 80% of the UK population with three active national QI projects, regional clinical QI Networks and a repository of resources.

PatientView (PV)

PatientView has been another exemplar innovative project of the RA supporting patients to see their results and records over a considerable time. It has been in need of technical review and the requirements of Information Governance now require us to review the delivery of this service in order to maintain and expand functionality. The Renal Association has therefore performed a carefully considered option appraisal and due diligence with a view to transferring PV functionality to a highly credited provider, PatientsKnowBest (PKB). PKB offers the opportunity to develop further services expected by patients with kidney disease.

Annual Conferences: UKKW 2020/21 & Renal Association CPD offer

Sadly UKKW2020 which was due to be held in Birmingham has been a casualty of the COVID-19 pandemic. The UKKW programme committee, led by Neil Sheerin and Paul Cockwell, has instead developed a superb agenda for UKKW2020 Virtual, an entirely online offering delivered with the BRS over a 2 week period in 6 sessions. EBS, our conference provider has agreed a contract to cover UKKW2020 Virtual and Edinburgh UKKW21. The COVID-19 pandemic has changed conference delivery for the foreseeable future. The composition of UKKW 2021 is likely to be a hybrid model comprising a smaller onsite presence in Edinburgh with a virtual component.

RA Webinar Series

One exciting and positive development this year has been the creation of a series of high quality webinar CPD offerings by the RA. Two highly successful deliveries have taken place and we intend to continue monthly sessions as the centre-piece of our delivery going forward.

President's report

The Priority Areas for RA delivery are:



Supporting RA volunteers to deliver. Operationalise the Secretariat role supporting committee chairs.



Delivering the RA strategy focused on areas of membership support; CPD webinars and eLearning portal.



Registry move to new premises completed allows continued development: data portal, Director of Informatics Research, COVID-19 research, data linkages just agreed with major opportunities for audit and research in a transparent manner.



Optimising joint working with the renal MPT.



Young Persons Care.



Embedding the communications strategy with the appointment of a communications officer and unveiling of a new modern website and Customer Relations Software.



Delivering virtual UKKW in 2020 and planning Edinburgh 2021.



Realising the opportunities of Big Data Renal Research Informatics and supporting renal scientists.



Building further effective corporate partnerships.



Supporting the delivery of Regional Professional (QI) networks.



Supporting trainees by enabling CPD and the NephWork.

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President's report

RA Strategic Priorities for Coming Year

Corporate strategy. The corporate strategy led by Neil Sheerin and supported by Gill Manning has led to seven corporate partners in a mature mutually beneficial relationship which we will build on.

'Big Data' opportunities. The Registry is ideally positioned and tooled to deliver Big Data research for and with the UK renal community. Dorothea Nitsch, Director of Informatics Research has produced a strategy focused on transparent access and opportunity. opportunities for collaborative working with Industry will be discussed.

The Kidney Quality Improvement Partnership (KQIP). This continues to go from strength to strength in QI support to the community. Funding support has been achieved from industry, Kidney Care UK and the UK Renal Registry for a further two years. End of programme funding support must focus on NHSE.

Regional networks. The RA is piloting a semi autonomous regional network focus for its members based upon the success of the KQIP Regional QI approach led by Clinical Vice President Paul Cockwell.

The Renal Association intends to develop and support a series of clinical **sub-speciality special clinical interest groups**. Areas highlighted in the first phase include:

1. **Acute kidney injury.** This aims to re-focus clinical and research development in this area in an inclusive but supported manner.
2. **End of life - palliative care.** There is huge national variation in access to this vital aspect of care serving our most vulnerable patients.
3. **Virtual/remote renal outpatient CKD support** - a key focus of the NHS Long Term Plan. The group intends to develop a joint conference for those interested in 2021.

These interest groups will be developed in a transparent, inclusive and outward looking manner including engaging MPT and patient involvement.

President's report

RA Strategic Priorities for Coming Year Cont'd

Support for Renal Scientists. Increasing support for the renal scientists who are a small but key RA constituency is a major strategy aim. The terms of reference of the research committee have been revised and include developing an annual meeting together with educational support and links to the UK Kidney Research Consortium.

Seeking a new mutually beneficial relationship with Kidney Research UK

Support for Trainees, the future of our speciality. This is a prime area of the RA strategy including:

1. Support for the now integrated SpR trainee committee
2. NephWork delivery (an audit project)
3. Involvement with KQuIP and enabling supportive links to the Specialist Advisory Committee
4. Research, leadership and training opportunities

A key aim is to be outward looking, working with our stakeholders and most importantly seeking agreement from our members for development of a more effective and financially secure organisation reflecting the joint skills of all UK kidney clinicians and researchers.

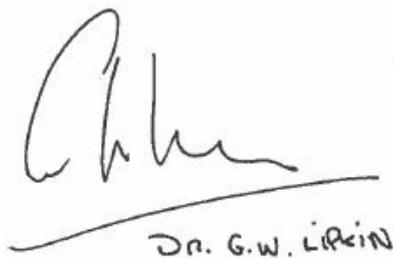
President's report

The Association

The level of work that goes on behind the scenes to deliver for the community should not be underestimated. I am blessed to have and sincerely thank my fellow trustees Indy Dasgupta, Claire Sharpe, Neil Sheerin, Sally Hulton, Donal O'Donoghue and Paul Cockwell for their enormous dedication and delivery. I am particularly grateful to David Silver, non-member trustee, who has devoted considerable work to support the RA particularly in relation to merger and commercial contracts. James Medcalf, as Medical Director, is the architect of substantial changes in the delivery offer of the Registry, working together with our fantastic CEO, Ron Cullen and Director of Operations Retha Steenkamp. Dorothea Nitsch, appointed last year as Director of Research Informatics, is already developing outputs and future opportunities by the Registry in the area of linked data research. Finally I thank our excellent Secretariat, Sarah, Jodie and Amy without whom none of the outputs would happen.

I offer sincere thanks for the hard work of Aine Burns, Alan Salama and Tim Bowen who stand down from elected council member posts. Aine has provided strong leadership in the Education & Training committee and Alan has taken over Chair of the International Committee whilst Tim takes up a new position.

It is with great pleasure that I congratulate Debu Banerjee who takes over as Chair of the Education and Training Committee, Tim Bowen for his election as Chair of the Renal Scientists Committee, Paul Cockwell as RA President Elect and Jan Dudley as President Elect of BAPN. The Association is in safe hands going forward.



Dr. G.W. LIPKIN

Dr Graham Lipkin
President, The Renal Association

Governance and structure

The board of trustees is the RA's governing body as a charity. It is responsible for the management of the RA's business, for which purpose they may exercise all the powers of the RA. 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 RA for the benefit of the objects.

It has the authority to carry out the RA's charitable responsibilities 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 AGM held at the annual conference of the association, UK Kidney Week (UKKW).



President

Dr Graham Lipkin
Queen Elizabeth Hospital, Birmingham



Vice President and BAPN President

Dr Sally-Anne Hulton
Birmingham Children's Hospital



Past President

Professor Donal O'Donoghue
Salford Royal Hospital



Clinical Vice President

Professor Paul Cockwell
Queen Elizabeth Hospital, Birmingham



Academic Vice President

Professor Neil Sheerin
Institute of Cellular Medicine,
Newcastle University



Honorary Secretary

Dr Indranil Dasgupta
Heartlands Hospital, Birmingham



Treasurer

Professor Claire Sharpe
King's College London

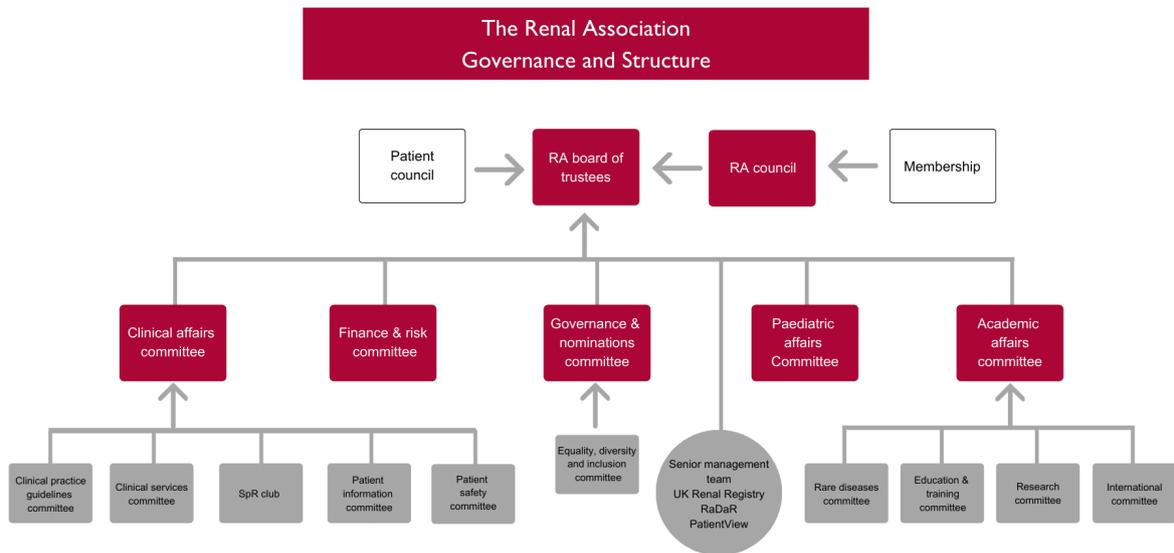


Non Member Trustee

David Silver

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Governance and structure



Revised February 2020

Senior management team



CEO
Ron Cullen



RA Director of Audit and Informatics and UKRR Medical Director
Professor James Medcalf



Head of Operations
Dr Retha Steenkamp



Director of Informatics Research
Dr Dorethea Nitsch

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Council and committees

The RA 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.

Council members

Elected

Dr Debasish Banerjee
Dr Tim Bowen - Renal Scientist
Prof Aine Burns
Dr Marie Condon - Consultant Less than five years
Dr Peter Hewins
Dr Richard Hull - Consultant Less than five years
Dr Victoria Ingham
Prof Alan Salama

Committee chairs (appointed)

Prof Aine Burns (Education and Training Committee)
Dr Afzal Chaudhry (Renal PatientView)
Dr Danny Gale (Rare Diseases Committee)
Dr Katrin Jones (Patient Safety Committee)
Prof Alan Salama (International Committee)
Dr Rebecca Suckling (Equality, Diversity and Inclusion Committee and Patient Information Committee)
Dr Mike Robson (Clinical Practice Guidelines)
Dr Katie Vinen (Clinical Services Committee)

Ex-officio

Dr Mark Andrews	Chairman, SAC Renal Medicine
Dr Andrew Connor	Green Nephrology
Mr Ron Cullen	RA CEO
Dr Mark Dockrell	Co-Chair, Renal Scientists Working Party
Dr Matt Graham-Brown	SpR Club Rep
Dr Mick Kumwenda	Society of DGH Nephrologists
Fiona Loud	Kidney Care UK
Dr Paddy Mark	Representative for Scotland
David Marshall	National Kidney Federation
Prof Peter Maxwell	Representative for Northern Ireland
Dr James Medcalf	RA Director of Audit and Clinical Informatics and UKRR Medical Director
Dr Jim Moriarty	RA Communications Officer
Dr Aled Philips	Representative for Wales
Dr Sharlene Greenwood	President BRS
Dr Vincent Tse	Honorary Secretary, BAPN
Dr Gavin Welsh	Co-Chair, Renal Scientists Working Party
Dr Yook Mun Woo	Rep for non-consultant grades

Our members

The members of the RA comprise over 1,214 doctors, scientists and MPT members.

Clinical trainee	264
Clinical trainee in related speciality	33
Consultant	568
Consultant in related speciality	28
GP with renal interest	2
Honorary member	27
MPT member	53
Non consultant grade doctor	103
Overseas member	28
Overseas member (low income)	9
Post doctoral scientist	41
Pre doctoral scientist	9
Retired	49

**TOTAL MEMBERSHIP
IS 1,214, UP 1.3% YEAR
ON YEAR**



**183 NEW MEMBERS
JOINED THE RA IN 2019**

**14% INCREASE IN
TRAINEE MEMBERSHIPS**



Raine Award

The Raine Award is made annually to a relatively junior member who has made a significant contribution to research. In 2019 this was awarded to Dr Matthew Graham-Brown for his work, 'Phenotyping cardiovascular disease in patients with chronic kidney disease – the problems, the solutions and the future'

Lockwood Award

The Lockwood Award is awarded to help RA members present work and combine this with a visit to a collaborating laboratory or clinical nephrology unit overseas. In 2018 this was awarded to Dr Elisa Molinari.

Walls bursaries

The Walls bursaries enable a clinician and non clinician to spend short periods at other centres, generally outside the UK. In 2019, the Walls bursaries were not awarded.

Medical student elective bursaries

In 2018 eight medical student elective bursaries were awarded to Catherine Beeby, Calum Cardle, Keya Jethwa, Ronan Lyne, Eleanor Manners, Amber Pankhurst, Stewart Rodney, Ayonija Sundararajan.

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Our members

Consultations

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

- NICE Guideline on hypertension in adults: diagnosis and management - Dr Indranil Dasgupta on behalf of Dr Laura Ratcliffe, Dr Richard Fish, Dr Tim Doulton, Dr Adam Macdiarmaid-Gordon, Prof Paddy Mark and Dr Charlie Tomson
- NICE Scoping Workshop - The NephroCheck Test System (and alternative technologies identified during scoping) to help assess the risk of acute kidney injury in people who are critically ill - Dr Marlies Ostermann
- NHSE - A new policy statement is being developed for: Rituximab for the treatment of Focal Segmental Glomerulosclerosis in Adults - Dr Ruth Pepper
- NHSE - Draft Service Specification for Adult Critical Care (NHS England) – Dr John Prowle
- NICE Guidelines for the Provision of Intensive Care Services (GPICS V2, The Faculty of Intensive Care Medicine) - Dr John Prowle
- NICE Draft guideline consultation – hypertension in pregnancy: diagnosis and management (update) - Dr Matt Hall
- NICE Avacopan for inducing remission in anti-neutrophil cytoplasmic antibody-associated vasculitis - Prof Alan Salama
- NICE Stakeholder testing: Medical abortions when the pregnant women has co-morbidities - Dr Matt Hall
- NICE Stakeholder testing for Cystinosis Service Specification - Dr Graham Lipkin

Our members

Consultations

The RA has been involved in a number of consultations in the last year. Thank you all members who contributed.

- GOV.UK opt-out organ donation: organs and tissues excluded from the new system
 - - Dr Adnan Sharif
- FICM care at end of Life endorsement request - Dr Katie Vinen
- NICE code of practice F: donation of solid organs and tissue for transplantation - Dr Alison Brown
- NICE acute kidney injury: prevention, detection and management - Dr Nick Selby
- NICE SEEK SA – IP1795 laparoscopic renal denervation - Professor Indranil Dasgupta
- NICE final appraisal document: consultee: hyperkalaemia - patiromer [ID877] - Professor Sunil Bhandari
- HSJ round table to discuss access to home HD - Dr Natalie Borman
- NICE Acutely ill adults in hospital: recognising and responding to deterioration (2007) NICE guideline CG50 - Dr Mark Thomas
- NICE kidney transplant (rejection prevention, chronic kidney disease) – imlifidase ID1672 - Dr Sian Griffin
- NICE renal and ureteric stones quality standard - Professor John Sayer
- GIRFT national report draft for radiology - Dr Anijeet Hameed

Our members

- NICE atypical haemolytic uraemic syndrome - ravulizumab ID1530 - Dr Edwin Wong
- NICE guidance review proposal – PIGF based testing to help diagnose suspected pre-eclampsia (Triage PIGF test, Elecsys immunoassay sFlt-1/PIGF ratio, DELFIA Xpress PIGF 1-2-3 test, and BRAHMS sFlt-1 Kryptor/BRAHMS PIGF plus Kryptor PE ratio - Dr Kate Bramham
- NICE canagliflozin for treating chronic kidney disease in people with type 2 diabetes ID1653 - Professor Indranil Dasgupta (with Association of British Clinical Diabetologists and British Renal Society)
- NICE diagnostics consultation document: tests to help assess risk of acute kidney injury for people being considered for critical care admission (ARCHITECT and Alinity Urine NGAL assays, BioPorto NGAL test and NephroCheck test) - Dr Marlies Ostermann
- NICE draft scope consultation – management of gout – Dr Paddy Mark on behalf of Dr Samira Bell and Dr Peter Thompson
- NICE venous thromboembolic diseases quality standard - quality standards advisory committee - Dr Albert Power
- NICE consultation on cystinosis services - Dr Graham Lipkin
- NICE / NHSE COVID-19 guidance - renal transplantation - Dr Graham Lipkin and Professor Neil Sheerin
- NICE Lumasiran for treating primary hyperoxaluria type 1 ID3765 - Dr Shabbir Moochhala
- NICE Roxudustat Technology Appraisal - Dr Mark Thomas

Financial report

Prof Claire Sharpe, Honorary Treasurer

The RA had an overall surplus for 2019 of £25,679 (2018: £457,944).



This is my first report as Honorary Treasurer of the Renal Association. I would like to take this opportunity to thank my predecessor, Professor Neil Sheerin, for all his hard work as Treasurer and for leaving the Renal Association finances in such good shape.

In 2019 the RA was in the process of moving our registered office. As our headcount grew, we had planned to make a loss within the UK Renal Registry to invest in this relocation, renovation and IT infrastructure.

UK Kidney Week 2019, which was run by an external secretariat in conjunction with the British Renal Society, was a great success and contributed to the Association's improved financial position.

We achieved our goal of engaging with new corporate partners; income from all memberships increased in 2019 to a total of £185,102 (2018: £123,717) including a growth in individual memberships by a respectable 8%. I would like to thank our membership (old and new) for their support for the Association which has enabled us to expand our work and go from strength to strength.

The review of our investments was successful in generating £8,831 of interest income compared to £3,262 in 2018.

We are very excited that autumn 2020 will see a complete website relaunch which was fully accounted for financially in 2019.

Overall the RA is financially very secure. The minimum agreed reserve for 2019 was £1.72 million to be held either as immediately available funds or in short to medium term investments. The reserves at the end of 2019 were £2,220,975 (2018: £2,195,295). This exceeds the benchmark because of an expected increase in expenditure for 2020 as the Renal Association relocates. The reserves held are sufficient to cover 12 months operating costs and this should be maintained at this level.

The start to 2020 has been a difficult year for all charitable organisations but the RA has taken the following steps to mitigate the threats that the COVID-19 pandemic poses to the organisation:

Action 1 - A review of any risk of income due to the possibility of work not being completed



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Action 2 - To reduce costs as much as possible

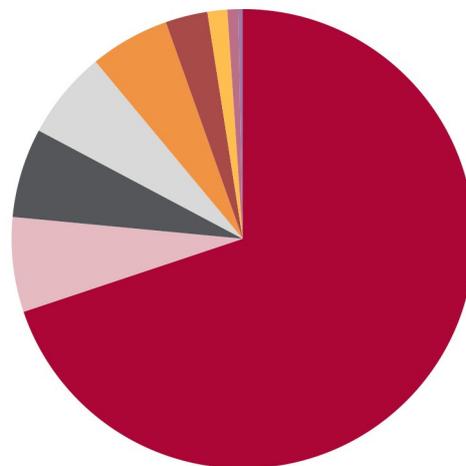
Action 3 - Recovered all possible expense from the cancellation of UK Kidney Week

Action 4 - To plan for a contingency should the Advanced Nephrology Course not be viable in January 2021.

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.

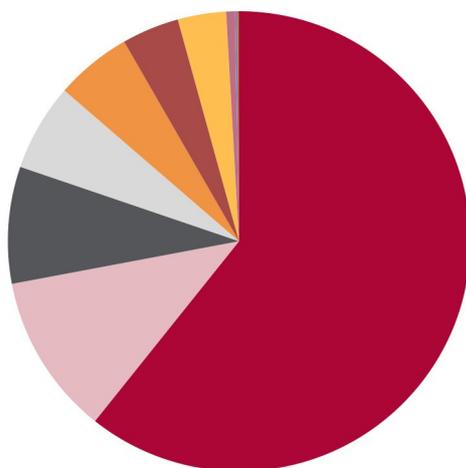
The pie charts* give an overview of streams of income received by the RA and how it is spent. For further details please see the annual accounts which are available at renal.org from October 2020.

Income £2,941,431



- Capitation 69.8%
- Memberships 6.3%
- Scientific Meetings 5.6%
- Events 1.4%
- Interest and donations 0.3%
- Grants 6.7%
- Other RR 6.2%
- Cross charging 2.9%
- Other RA 0.7%

Expenditure £2,915,412



- Staff 60.7%
- IT 8.2%
- Office costs 5.3%
- Secretariat 3.4%
- Awards 0.2%
- Professional services 11.3%
- Meeting costs 6.1%
- Expenses 4.0%
- Depreciation 0.6%
- Other 0.1%

*The data has been supplied by the Renal Association, its interpretation and reporting is the responsibility of the author.

Equality & diversity

The RA is 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 RA 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](#).