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# EXECUTIVE COMMITTEE OFFICERS & TRUSTEES

## TRUSTEES

<table>
<thead>
<tr>
<th>Position</th>
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</thead>
<tbody>
<tr>
<td>President</td>
<td>Prof Donal O’Donoghue</td>
</tr>
<tr>
<td>Past President</td>
<td>Prof Bruce Hendry</td>
</tr>
<tr>
<td>Academic Vice President</td>
<td>Prof Phil Kalra</td>
</tr>
<tr>
<td>Honorary Secretary</td>
<td>Dr Alison Brown</td>
</tr>
<tr>
<td>Honorary Treasurer</td>
<td>Prof Neil Sheerin</td>
</tr>
<tr>
<td>Clinical Vice President</td>
<td>Dr Graham Lipkin</td>
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<tr>
<td>BAPN President</td>
<td>Dr David Hughes</td>
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## EX OFFICIO

<table>
<thead>
<tr>
<th>Position</th>
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<tbody>
<tr>
<td>National Clinical Director for Renal Services England</td>
<td>Dr Richard Fluck</td>
</tr>
<tr>
<td>Special Advisory Committee (SAC Renal Medicine Chair)</td>
<td>Dr Mark Andrews</td>
</tr>
<tr>
<td>British Association of Paediatric Nephrology (BAPN) Honorary Secretary</td>
<td>Dr Martin Christian</td>
</tr>
<tr>
<td>Associate Specialist Rep</td>
<td>Dr Yook Mun Woo</td>
</tr>
<tr>
<td>Specialist Registrar SpR Club Rep</td>
<td>Dr Fiona Duthrie</td>
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<tr>
<td>Society of District General Hospitals (DGH) Rep</td>
<td>Dr Mick Kumwenda</td>
</tr>
<tr>
<td>British Renal Society President</td>
<td>Prof Maarten Taal</td>
</tr>
<tr>
<td>Patient View</td>
<td>Dr Afzal Chaudhry</td>
</tr>
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<td>Renal Scientists Working Party Co Chair</td>
<td>Dr Mark Dockrell</td>
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<td>Renal Services Working Party Co Chair</td>
<td>Dr Gavin Welsh</td>
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<tr>
<td>Representative for Wales</td>
<td>Prof Aled Phillips</td>
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<tr>
<td>Representative for Northern Ireland</td>
<td>Dr Peter Maxwell</td>
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<td>Representative for Scotland</td>
<td>Dr Mark MacGregor</td>
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<td>Green Nephrology</td>
<td>Dr Andrew Maxwell</td>
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<td>Chair of NIHR CRN Renal Disorders Group</td>
<td>Prof Phil Kalra</td>
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<tr>
<td>Chair of Renal Dialysis and Transplant Clinical Reference Group</td>
<td>Dr Richard Baker</td>
</tr>
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<td>Interventional Nephrology Group Co-Chair</td>
<td>Dr Paul Warwicker</td>
</tr>
<tr>
<td>Interventional Nephrology Group Co Chair</td>
<td>Dr Aine Burns</td>
</tr>
<tr>
<td>Chair Patient Information Group</td>
<td>Dr Rebecca Suckling</td>
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## EXECUTIVE COMMITTEE (APPOINTED)

<table>
<thead>
<tr>
<th>Committee Chair</th>
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<tbody>
<tr>
<td>Education &amp; Training Committee Chair</td>
<td>Dr Jeremy Levy</td>
</tr>
<tr>
<td>International Committee Chair</td>
<td>Prof David Goldsmith</td>
</tr>
<tr>
<td>Research Committee Chair</td>
<td>Dr Jill Norman</td>
</tr>
<tr>
<td>Clinical Services Committee Chair</td>
<td>Prof Alastair Hutchinson</td>
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<tr>
<td>Clinical Practice Guidelines Committee Chair</td>
<td>Dr Andrew Lewington</td>
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<tr>
<td>Equal Opportunities in Nephrology Committee Chair</td>
<td>Dr Bhavna Pandya</td>
</tr>
<tr>
<td>Rare Disease Committee Chair</td>
<td>Dr Detlef Bockenhauer</td>
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<tr>
<td>Clinical Data Standards Committee Chair</td>
<td>Dr Afzal Chaudhry</td>
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<td>Communications Officer</td>
<td>Dr Jim Moriarty</td>
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<tr>
<td>Medical Director, UK Renal Registry</td>
<td>Dr Fergus Caskey</td>
</tr>
<tr>
<td>Chief Executive, UK Renal Registry</td>
<td>Mr Ron Cullen</td>
</tr>
<tr>
<td>BAPN Research Committee Chair</td>
<td>Dr Rachel Lennon</td>
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## EXECUTIVE COMMITTEE (ELECTED)

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<tr>
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<tr>
<td>Dr Tim Bowen</td>
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<td>Dr Paul Warwicker</td>
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<tr>
<td>Prof Alan Salama</td>
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<tr>
<td>Dr Aine Burns</td>
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<tr>
<td>Dr Andy Stein</td>
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<tr>
<td>Dr Rebecca Suckling</td>
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<td>Dr Richard Haynes</td>
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<td>Dr Mark Brady</td>
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The triple aim of the Renal Association to promote and disseminate research, to provide education and development for renal healthcare professionals and scientists and to lead the delivery of reliable evidenced based care for patients and families affected by kidney disease remains as relevant today as it did when the Renal Association was formed in 1950. The Renal Association is it’s membership. The trustees have a legal duty of stewardship under charities law, while the executive and wider membership are the professional body and architects of the future. The Renal Association exists as a professional body to support our members building networks and partnerships to design and deliver the triple aim of the association. Judged against these ambitions 2016 has been a successful year on all fronts. The better our understanding of the kidney, mechanisms of disease, treatments and reasons for individual patient responses the better we are able to prevent, delay and mitigate the impact of kidney disease on patients, families and populations. 2016 saw a focus on this core objective of kidney knowledge generation. The UK Renal Research Strategy was launched with our partners in the UK Renal Consortium in April 2016. Our Renal Association academic vice president, Fiona Karet, played a leading role in writing this first UK renal research strategy which was developed through a series of consultations and collaborations across the renal sector including the Renal Association, British Association of Paediatric Nephrology, British Transplant society, British Renal Society, Kidney Research United Kingdom, National Kidney Federation, British Kidney Patient Association and representatives of the Kidney Health: Delivering Excellence group. The then minister for life sciences, George Freeman MP heralded it as “ambitious yet realistic”. The launch celebrated the end of the beginning and pre-staged ongoing work to deliver the four strategic research aims and thirteen detailed recommendations. In the words of Minister Freeman “kidney care is an area that historically has been somewhat neglected and the strategy provides an invaluable starting point from which we can ensure that the UK’s kidney health sector is now recognised as a global beacon of excellence”.

Trainees are the future workforce and the lifeblood of the Renal Association. We are fortunate to have a strong and thriving renal specialist registrar community that welcomes renal scientists in training and works closely with the Renal Association. The Royal College of Physicians draws on our membership to identify the local champions who fulfil the roles of Regional Specialist Advisors, who ensure that job descriptions and job plans are appropriate for the delivery of high quality renal care. Our Advanced Nephrology Course continues to be the must go to meeting for our SpR’s. It is rated as excellent by nearly 100% and over the 3 year cycle our members provide comprehensive coverage of the renal training curriculum. The speakers who give their time and energy freely love it. We are indebted to them and their organisations, Professor Sunil Bhandari and Dr Paul Harden. In 2016 we led the introduction of the European specialist examination in nephrology in partnership with the Union of European Medical Specialties and Royal Colleges. Thanks go to our specialty examination board and all the colleagues who help with drafting and editing the questions; and congratulations to all the successful candidates for the UK and European certificates. Education of course doesn’t end at certification. Rather that is the beginning of a lifelong career of learning and rewarding practice. The continuing professional education high point of the year was again UK Kidney Week, which we held in partnership with the BRS at the International Conference Centre in Birmingham in June. This joint meeting was a great academic and professional success. It was well attended with over 800 delegates; there was an excellent and well received programme and our named Renal Association lectures were again highlights of the meeting. Financially the meeting made a loss. Disappointingly our BRS colleagues opted not to partner for UK Kidney Week 2017.

The purpose of asking and answering research questions and then of disseminating resulting knowledge and understanding is to reduce the burden of kidney disease and to improve the experience of care and outcomes for people with kidney disease. To do this knowledge needs to be synthesised. Our Renal Association Clinical Guidelines group lead that process and articulate the basis of good clinical practice, many of the elements which are measured, analysed and reported by our Renal Association UK Renal Registry. Writing and disseminated guidelines and reporting key measures of renal unit performance have been core functions of the Renal Association for several decades. The excellence of our guidelines are recognised by NICE accreditation and the quality of our registry by the NHS which has mandated participation in the registry through the renal services specification. The Renal Registry is of course now a successful research engine in its own right with an impressive research programme track record and portfolio of projects. Increasingly we recognised that delivery of reliable high quality care requires quality improvement capability as well as evidenced based guidelines. The kidney quality improvement partnership the Renal Association has assembled with the other professional and patient organisations resulted from that understanding. The partnership has done a great deal in identifying national kidney care priorities and I am pleased to be able to report that the Renal Association has agreed funding and resources of nearly £500,000 over the next 3 years to help build the capacity and capability of our local and regional renal communities and networks to enhance quality improvement knowhow and drive improvements in care and outcomes for kidney patients.

In the past year we have seen a logarithmic growth in RADAR, our rare renal diseases registry, which now covers over 35 renal conditions. In 2016 over five thousand, five hundred previously unregistered people with rare kidney diseases joined the initiative which is open to all kidney units and rare disease patients. Similarly Patient View, allowing our patients access to their electronic patient record continues to thrive. The patient information committee continue to work closely with the British Kidney Patient Association to develop material that has been awarded the information standard and supports the National Kidney Federation in the maintenance of their large library of patient leaflets.

Great progress and much to celebrate in 2016 but the challenges over the next few years remain immense. The Renal Association stands ready to play it’s part supporting our NHS and research members, focusing on the needs of patients and continuing to contribute to our Renal Association triple aim of education, research and service excellence. UK Kidney Week 17 in partnership with International Society of Nephrology and the British Transplant Society will be the educational high point, solid progress with the UK kidney research strategy will underpin new knowledge generation and I am confident that our trainees, consultants and the wider multidisciplinary team will embrace the quality improvement programme we are beginning to put in place.

Prof Donal O’Donoghue
President The Renal Association
This will be my last report for the Renal Association, and I am delighted to be handing over to my illustrious successor Indy Dasgupta who will now take over as Honorary Secretary, and will do a fantastic job.

I’d like to thank the following Elected Members who are due to demit from office at the AGM this June for all their hard work:

- Rebecca Suckling has contributed to many aspects of RA work and took over as Chair of the new Patient Information Committee last year, and is really driving progress on this important project.
- Paul Warwicker has also worked on many issues, including updating (together with Clara Day) the renal section for the RCP’s latest iteration of ‘Medical Care’ (formerly known as ‘Physicians working with patients’), and Paul continues as co-chair of the RA interventional nephrology working party together with Aine Burns.
- Many thanks also to the retiring Chair of the Education and Training Committee, Jeremy Levy, who has provided fantastic input to conference programmes over recent years.
- Bhavna Pandya took over from Claire Sharpe as Chair of the Equal Opportunities in Nephrology (EON) Committee last year and has worked hard to improve communication and get the EON Facebook page up and running.

The Trustees of the Renal Association continue to think hard about how best to increase the attractiveness and relevance of RA membership for all member categories, and improve communication — current membership details are given below — so please do email in any suggestions you may have. All the tweeps already know that our Communications Officer Jim Moriarty @RenalAssoc tweets regularly to 2,775 followers, #UKKW2017 has 532 followers — the renal community is really lucky to have so many active nephrologists to keep the rest of us up to date via Twitter!

**UKKW2016** in Birmingham was a great success, with a total attendance of 1274, and 518 abstracts submitted. UKKW2017 is going to be fantastic and here are just some of the programme highlights:

- Edwin Wong is the winner of the Raine Award and will give the Raine Lecture at UKKW 2017 on his research in complement-mediated renal disease.
- De Wardener Lecturer is Professor David Wheeeler.
- Chandos Lecturer is Professor Simon Davies.
- Osman lecturer is Professor Paul Brenchley.

In 2016, one Walls Bursary was awarded to Dr Helen Noble, renal nurse and Lecturer at Queens University Belfast, and the second Walls Bursary to Dr Roslyn Simms, NIHR Clinical Lecturer in Nephrology at the University of Sheffield.

8 or 9 bursaries of £250 are awarded each year to support renal-themed electives for medical students, who are asked to submit a report within 3 months of their return, which is posted on the website, under “Prizes and Awards” — this is currently hard to find and we plan a “Student” page to promote this better. This year, bursaries were awarded to Anna Fairclough (Oxford), Emma Carter (Glasgow), Grace Pearson (Bristol), Holly Gillott (Birmingham), Jake Tobin (Cambridge), Jennifer Ng (Cambridge), Kevin Joyce (Cambridge), Martin Lee (Sheffield) and Roisin McCormack (Glasgow).

We hope these student bursaries help to encourage the next generation of nephrologists! We have come a long way since I was told by a very eminent professor of nephrology that I wasn’t suitable for a career in nephrology — (as a grammar school girl from Middlesbrough with only a 2:1 from Cambridge, and married with children - it was a long time ago!) — but we can see that we are not doing enough to make sure that nephrology is an attractive career for today’s graduates, who want an enjoyable and challenging career but also a reasonable work-life balance. All the renal community needs to consider what we can do to improve training and ways of working for the future. The more gaps there are in training, the more stressful life becomes for our trainees, and it is vital to find new ways of working to address this.

Finally, I will always be grateful to the many people who have responded to my pleas for help for the RA, always requiring lots of work at very short notice — thanks very much!

**Dr Alison Brown**
Honorary Secretary
The Renal Association

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**REVIEW OF THE YEAR**

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<td>Overseas</td>
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ACADEMIC AFFAIRS REPORT

Talk about ‘hitting the ground running’ – although I officially took over as Academic Vice President (AVP) from Fiona Karet in September 2016, I was already immersed in co-ordinating planning for the programme and wider organisation of UK Kidney Week 2017 within days of learning of my appointment in the early summer!

A primary role of the AVP is to chair the Academic Affairs Board, which, to recap, encompasses 5 committees (the International, Education and Training, Renal research, Rare Disease and BAPN research committees). A summary of activities within each of these areas is presented below. It was also the turn of the AVP to take over the chairmanship of the UK Kidney Research Consortium (UKKRC) from the end of 2016. I have been involved in this consortium since its inception in 2007/8 and have been delighted by the way that it has helped bring structure, vision and collaboration to the clinical research effort in UK nephrology over the last decade. The development of disease specific clinical study groups (CSGs) – eg in CKD, haemodialysis, peritoneal dialysis, anaemia and cardio-renal - has been very fruitful in terms of design of key studies, not only increasing UK nephrology’s visibility on the international map, but also being replicated by other specialities, such as cardiology and diabetology.

A key function of the UKKRC chair is to co-ordinate delivery of the UK Renal Research Strategy in liaison with key stakeholders such as KRUK, BRS, BKPA and the renal research committee, ensuring that the strategy maintains momentum gained after its launch in early 2016. Considerable progress has already been made in many areas, especially in improvement science (eg KQUIP), clinical trial development, involvement of patients and carers in planning research, development of a national kidney biobank (the NURT uRE CKD project is now underway) and in our important interactions with industry to create research partnerships.

Planning for UKKW 2017 at the Liverpool ACC (June 19-21st) is now complete. The 3 day meeting will consist of 25 academic symposia. There will be co-sponsorship by the ISN, who are providing 3 internationally recognised speakers, the BTS (Wednesday 21st), and we have interacted with the Paediatric nephrologists, UK Renal Pharmacist group, regenerative medicine experts, and veterinary scientists in formulation of an exciting programme. Our renal trainees (both specialist registrars and research fellows) have played a fundamental role in design of several sessions within the programme, and many of them will be actively participating in the meeting as speakers, session chairs and moderators of some of the 300 posters that will be presented. I would urge you to try to attend the meeting, and please bring along your colleagues! For the athletically accomplished there will be a 5 Km fun run on Monday 19th June at 6.30 pm, sponsored by KRUK, and the conference dinner will take place on the Tuesday in the iconic Royal Liver building.

The International committee, chaired by David Goldsmith, has been helping develop the overseas sister centre scheme, which is led by the ISN but supported by the RA. Several UK centres are already participating, with links in eg Malawi and Nigeria. There is a desire to encourage other centres to consider participating, so please do consider this for your own centre. The scheme not only raises the profile of UK renal centres in developing countries, but also aims to provide UK training opportunities for nephrologists and trainees from these countries. Discussions are also taking place with the ERA-EDTA President regarding involvement in similar schemes in European countries.

The Education and Training (E&T) committee has a wide remit, and has been chaired by Jeremy Levy for several years. Notable activities within in the last year have included another successful and acclaimed annual RA Advanced Nephrology course (in Oxford - January 2017) with ~ 100 participants, an increased number of whom were from overseas (including from Australia, as well as Europe). Feedback is excellent and the RA thanks Sunil Bhandari and Paul Harden for their hard work in its continuing success. In 2017 the Renal Specialty Certificate Exam was run across Europe as an accredited European renal exam and the exam board now includes representation from European Nephrologists. It was pleasing to see the cost for trainees to sit the exam being reduced in 2016 and 2017. The number of candidates sitting the exam continues to rise, with increasing numbers of overseas doctors in addition to all UK trainees; the standard of UK trainees remains excellent, with most passing the exam on their first attempt. The E+T committee contributes to the RCP specialty advisory committee (SAC) and the renal curriculum. Changes in medical training and workforce issues have taken centre stage recently. A worrying trend of fewer applicants for training places in nephrology programmes in some regions has been noted, and there are major discrepancies with applications for other specialities.

Our nephrology community needs to carefully consider how we can reverse this trend and stimulate young doctors into considering a career in renal medicine; a working group is being formed to develop a strategy. The baton for this important task will be passed to Aine Burns, the new chair of the E&T committee, who has just replaced Jeremy; no pressure there then, task will be passed to Aine Burns, the new chair of the E&T committee, who has just replaced Jeremy; no pressure there then, Aine – but welcome aboard!

The Renal Research committee has been chaired by Jill Norman. Only a relatively small number of renal basic scientists are RA members, and we would like to see a step change with greater collaborative opportunities between clinical and basic science research. Non-clinician renal scientists have strongly contributed to the development of the UKKW 2017 programme, and a focus has been on greater integration of basic science and clinical research. This has also been manifest in a UKKRC plan to encourage renal scientists to join CSGs relevant to their interests. In addition, the Renal Scientists Working Party has an organised structure that seeks to promote high quality laboratory and translational science and foster a supportive and collaborative environment for renal scientists within the Renal Association.
The Rare Diseases committee, led by Detlef Bockenhauer, has focused activity on the very successful RaDaR project, which currently includes 35 rare disease groups (recent additions have included calciphylaxis and fibromuscular disease). Almost 10,000 patients have now consented into RaDaR (6,000 of these in 2016) from 78 UK renal units and the target has now increased to an impressive 25,000 patients by 2019. Wearing another hat, Chair of the NIHR CRN Renal Disorders theme, I am delighted that RaDaR is contributing massively to recruitment of patients onto the NIHR portfolio; these patients are generously making themselves available for approach for research studies, and they are benefiting from the supportive community of their individual disease group. Each of the rare disease groups has/will have pages on the rarerenal.org website. The current list of approved Rare Disease groups is shown below, with details of key contacts. There is certainly scope for new groups to be added to RaDaR, and the criteria for inclusion of a new disease group are available on the website.

<table>
<thead>
<tr>
<th>RARE DISEASE GROUPS</th>
<th>ADPKD</th>
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<th>aHUS</th>
<th>Alport Syndrome</th>
<th>APRT-D</th>
<th>ARPKD</th>
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<th>Cystinosis</th>
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The British Association for Paediatric Nephrology research committee, chaired by Rachel Lennon, have been key contributors to the programme of UKKW 2017, and the Wednesday (21st June) of the meeting will have bespoke paediatric content. In fact, 2017 is a very busy year for paediatric nephrology conferences, as the European Society (ESPN) meeting will be hosted in Glasgow in September and the Royal College of Paediatrics and Child Health (RCPCH) conference will be in Birmingham during May 24-26. The paediatric nephrologists have an active research CSG, and there have been several notable successes with ongoing large HTA or BHF funded RCTs (eg PREDNOS and PREDNOS 2 – steroids and nephrotic syndrome; HOT-KID – blood pressure control in paediatric CKD).

Many thanks to all those colleagues who have been working in these different areas during the last 12 months, and also to Fiona for having left the ship in such a seaworthy condition at the beginning of my watch.

Prof Phil Kalra
Academic Vice President
This is my final annual report as Clinical Vice President. I have relished the opportunity to work for the benefit of the UK Renal Community and am immensely grateful for the support and hard work and of the President, Trustees, Executive and Committees.

I am humbled by the dedication of the Renal Association members in innovating & striving to improve the care of our patients. The Renal Association aims to further support Renal Community service delivery, with an increased focus on enabling quality improvement, patient safety & with partners, high quality patient information. The Clinical Practice Guidelines Committee continues to work tirelessly to update guidelines and successfully achieved NICE re-accreditation in January 2017 lasting until 2022. The Clinical Affairs Board offers clinical service advice to commissioners, NICE and NHS Improvement (ex-Monitor) who now set tariff. Increasing clinical activity, with year on year tariff reduction, austerity & increased expectation of quality is particularly challenging for CDs and renal services. The renal community continues to make best use of available resources supported by the RA.

The Renal Dialysis & Transplant CRG. The new combined CRG is chaired by Richard Baker, Consultant Nephrologist in Leeds & Jon Gulliver as responsible Commissioner. The RA is represented on CRG by the Clinical VP and CEO of the Registry. Two members of each of the 4 regions have been appointed and 4 partner clinical (RA, BTS, BRS and Registry) and patient organisations. The RA and RA/Renal Registry can both add expert professional advice & support quality improvement. The CRG is working on an enhanced dashboard to underpin quality assurance.

Renal Networks. Renal Expert Advisory Groups within the Strategic Clinical Networks (SCNs) are no longer funded in many English regions. The Kidney Quality Improvement Partnership (KQuIP) will support the critical QI role of these Networks.

New Committees in line with increasing focus of RA on enhancing Service Delivery.

- Interventional Nephrology Group (Aine Burns and Paul Warwicker)
- Patient Information Group (Rebecca Suckling and Andrew Stein))
- The Rheumatology CRG is seeking a member of the RA to join. This important role will report to the Clinical VP and the Executive. It has been awarded to Alan Salama.

Response to Renal Tariff proposal by NHS Improvement

https://improvement.nhs.uk/resources/national-tariff-1719/

This year Tariff proposals covered 2 years. Despite our objections in the consultation, these new tariffs have been adopted. There is continued downward pressure on dialysis tariffs & the MDT OP follow up tariff has been reduced by 40%. The tariffs are based on flawed Reference costs. https://improvement.nhs.uk/uploads/documents/NHSI_RCA_Sector_Report_-_final.pdf

We have offered engagement. James Medcalf continues to represent the renal community tirelessly on developing accurate tariff with NHSdigital (Ex HSCIC) and EWG and we thank him for this. John Bradley has a wealth of experience and support for RA. There is a real opportunity through engagement to achieve realistic tariffs for the future.
Kidney Quality Improvement Partnership
The Renal Association through leadership of KQuIP supports Improved quality and safety of Kidney Patient Care. KQuIP is supported to the value of £400k from the Registry/Renal Association over the next 3 years. In addition KQuIP is grateful to the BKPA which has funded 2 Regional QI Project Managers for a 2 year period.

Why is the Needed?
The renal community through the Renal Association have a proud history of innovative developments in renal service delivery: the Renal Registry, Patient View, Renal Association clinical practice guidelines & have worked together with patients to define our joint ambitions for future care, documented in The Kidney Health Delivering Excellence Document (currently being updated).
However, major unwarranted variation in key outcomes of care persists. KQuIP is the vehicle to support embedding QI in the day to day working of renal units.

What is KQuIP & who is involved?
KQuIP is a dynamic network of kidney health professionals, patients and carers who are committed to developing, supporting and sharing quality improvement in kidney services in order to enhance outcomes and quality of life for patients with kidney disease. It is led and co-chaired by the Clinical Vice Presidents of the Renal Association and British Renal society.

KQuIP is Project Managed centrally through the Renal Registry, overseen by the Renal Association Trustees. It has a representative Programme Board to set strategy and 3 active work streams.

What are the priorities for KQuIP?
• Improving access to transplantation
• Improving access to Home Dialysis therapies
• Increasing incident and prevalent haemodialysis vascular access rates

KQuIP is developing with Industry partners new relationship learning from each other and collaborating for the benefit of patients.

How is the Renal Association Supporting Delivery of Quality Improvement?
1. KQuIP Annual Registry/Regional Delivery days. The first day was a great success, held in the Wmid.
2. The KQuIP Online Hub (Opened April 2017). www.thinkkidneys.nhs.uk/kquip/hub/ The KQuIP Hub is a ‘go-to’ online repository of QI resources, project materials, SOPs, educational resources.
3. Renal Unit Peer Assist Programme. KQuIP will oversee the ‘buddying’ of Units to share learning and good practice.
4. National Conference: sessions at UK Kidney Week & BRS Conferences

Please visit www.thinkkidneys.nhs.uk/kquip/ to learn more and sign up. Contact KQuIP: thinkkidneys@renalregistry.nhs.uk

NICE Guidance Consultations. The RA continues to respond to all relevant NICE Consultations. I am grateful to all members who have contributed. This includes Guidance Renal Replacement Therapy (Jan Dudley & Andrew Mooney) & Transplant Immunosuppression in Adults. The RA with other professional groups and patients led a successful appeal against this ill advised guidance. NICE has now approached the community for advice and consultation in this area.

Clinical Services Committee
(Chair: Alastair Hutchison, 2013-17)
I am very grateful to Alastair who demits this year and the Clinical Services Committee (CSC) members for their hard work. The Committee runs the well attended and highly valued Annual Renal Clinical Directors Forum. This is an important RA-led meeting enabling communication, sharing of good practice and informs the Clinical affairs Board in guiding policy. The CSC provides an important role in reviewing draft RA guidelines.

Equal Opportunities Committee
(Chair: Bhavna Pandya, 2016-2019)
We welcome Bhavna who taken over from Claire Sharpe after her very successful term. Diversity is a key focus of the RA. The EON group write to all new appointees offering mentorship and keep a register of Non-career grade nephrology members to represent their views.

RA/BRS Patient Safety Initiative
(Chair Katy Jones 2017)
We wish to gratefully thank Paul Rylance who after many successful single handed years of leading on patient safety for the RA has now handed over the Katy Jones. The Committee runs jointly with the BRS. In addition to highlighting safety issues, the Committee is keen to develop projects which proactively focus on improving the safety of care of our patients. There is a clear overlap with QI, in which KQuIP will help support the PSI.
Clinical Practice Guidelines
(Andy Lewington 2013-217, Vice Chair Mike Robson)

This is a core group within the RA and the CPG page receives largest number of hits on the RA Website. Congratulations to Andy Lewington, Mike Robson, Jan Dudley and UKRR (Melanie Dillon) plus the guideline writers for achieving NICE Evidence re-accreditation valid until 2022. The Committee is now strongly supported by RA/Registry Project Management. The CPG have patient, registrar and MPT input into development. I wish to sincerely thank Andy Lewington for his energy and achievements over his time as Chair of the CPG Committee.

Patient View (Afzal Choudhury 2016)

I would wish to thank Afzal who now leads Patient View and continues its great success. There are over 55,000 renal patients registered most of whom actively use & benefit from the system. Afzal has been working on a ‘Vanilla’ version which could in future be adopted if supported by other specialities. Security testing, App development and work on developing Donor View, a portal to allow potential live kidney donors in work up to view their progress are some of the major activity of this group.

Patient Information Group (Rebecca Suckling 2016)

Rebecca Suckling has taken this on with initial focus on 10 areas with real delivery. Patient information is developed by the group to information standard level in combination and on behalf of the BKPA. Rebecca has developed the project further & has expand the writing group ensuring the Renal Association meets the evolving needs of its members and the patients it serves. The group also supports review of existing NKF patient information leaflets.

Ongoing Developments

- Sub-speciality Service Clinical Interest Group Development?

Renal Medicine continues to increase sub-specialisation. This includes focus on developing service models of care, standard operating procedures, and multi-professional team working. These areas of service development and innovation of practice have as yet only been peripherally addressed by the RA. Renal trainees and newly appointed consultants are keen to further assist in developing these areas. The RA wishes to discuss the development of such groups. The aim would be to develop these with the MPT in combination, where possible through collaboration with the specialist MPT groupings within the confederation that is the BRS. Examples of sub-speciality area Groups could include: dialysis, AKI, GN and CKD.

We would be interested to gauge interest in the potential development of these. There would be close collaboration and overlap with the CSGs.

I wish my successor, colleague and friend, Prof Paul Cockwell support and every success as incoming Clinical Vice President. I have no doubt that he will be highly effective and I wish him a term that has been as enjoyable as the one I have had.

Dr Graham Lipkin
Clinical Vice President
THE RENAL ASSOCIATION - STRUCTURE

RA Trustees

RIGB

RA Exec

Academic affairs board

Clinical affairs board

Research

International

Education and training

Rare diseases

Guidelines

EON

Terminology

Clinical services

BAPN representation on all committees
National Audit
A challenge for the Registry over the last 12 months has been the extension of the dataset to include acute dialysis and the changes to the way data are extracted and submitted. The work required to clean and validate the new data has been greater than expected and resulted in delays to the closure of the 2015 database and publication of the 2016 report. As a result, a lot of preparatory work has been done in anticipation for the further extension of the dataset to include people with pre-dialysis chronic kidney disease from 2016.

Research
Following the concerns raised by the Health and Social Care Information Centre’s Care.Data programme in England, there have been considerable challenges for organisations wanting to undertake audit and research that relies on routinely collected data. For the Registry this meant spending most of 2016 re-applying to the Health Research Authority for a legal basis for collecting individual patient-level data for audit and research without consent. The old audit permissions were initially extended to allow the core work to continue until the new audit permissions (which allow linkage to Hospital Episode Statistics and the Office for National Statistics) were obtained in December 2016. This allowed the separate research ethics and Section 251 applications to be approved in February and March 2017, enabling future use of the Registry’s database for a range of research purposes without applying for each analysis separately.

All research activity involving UK Renal Registry data had to cease during this period, including previously approved doctoral and postdoctoral fellowships involving Registry data and the inclusion of UK Renal Registry data in analyses by the ERA-EDTA Registry. We are very grateful to all researchers for their patience during this time and are delighted to have been able to open our first call for work proposals under the new permissions. If you are interested in finding out more, please visit www.renalreg.org/about-us/working-with-us.

During this period we have been pouring efforts into building a primary research programme, supporting successful grant applications for individual and cluster randomised controlled trials from other research groups and leading two successful NIHR HTA funded trials – one comparing preparation for conservative care with preparation for dialysis and the other comparing high-volume haemodiafiltration with high-flux haemodialysis. We see this as a new era for the Registry, as it uses its infrastructure to generate randomised interventional evidence that will inform clinical service delivery for people with kidney disease.

Acute kidney injury
Following a very successful closing event in February 2017, the acute kidney injury (AKI) National Programme has handed over responsibility for the AKI Master Patient Index to the Registry, with a Task and Finish Group established to manage the validation of the data and plans for analyses and publications. Data on cases of AKI in primary and secondary care are now being submitted to the Registry from 71% of the estimated 147 laboratories in England, with more than 390,000 patients reported to have acute kidney injury since March 2015 until January 2017. The real power of the data will come through linkage of the Master Patient Index to other data sets such as Hospital Episode Statistics, The Office for National Statistics and the Intensive Care National Audit and Research Centre.
Patient reported outcomes

As part of Think Kidneys' Transforming Participation in Chronic Kidney Disease National Programme, the collection of patient reported outcomes – quality of life and patient activation – began in 10 sites in early 2016 and is extending to a further 4 sites in 2017. This work has three aims:

- To establish whether it is possible to collect patient reported outcomes from broad range of patients
- To explore the association between patient activation and quality of life
- To test whether patient activation can be modified by the introduction of interventions

Separate from this NHS England-funded work, the UK Renal Registry and British Kidney Patient Association co-funded the first patient experience survey in 2016. Responses have been received from 40 renal units and a report containing all the results will be published in summer 2017.

Kidney Quality Improvement Partnership

Working with a wide range of stakeholders from across the renal community (Figure 1), the UK Renal Registry has been finding novel ways for its data to be used for patient benefit through quality improvement. From a practical perspective, this has led to the Registry’s annual Audit and Informatics Meetings being replaced by 3-4 joint UKRR-KQuIP regional meetings each year. The first of these was held in the West Midlands in March 2017 and the second is planned for Yorkshire and Humber in July.

For more information about the Think Kidneys work and to see if your local laboratory is yet sending in data visit www.thinkkidneys.nhs.uk.
In my second year as BAPN President I am increasingly aware of the amount of support given by BAPN colleagues, from our relatively small paediatric membership, to the many areas of interest that impact on developing best care for children with renal disease. I wish to record my personal thanks to those colleagues on the Executive Committee demitting office this year for that support and commitment: Dal Hothi (Clinical Services), Richard Coward (Research), Manish Sinha (Audit & Registry), Arvind Nagra (Treasurer), Andy Lunn (Communications), Munir Ahmed (SPIN), Louise Oni (Trainee), Jane Tizard (Clinical Reference Group), with 16 years on the executive committee including her tenure as President, and Martin Christian (Secretary) whose quiet efficient support has been immeasurably helpful. I am fortunate in welcoming Yincent Tse to fill Martin’s boots. Having seen Yincent’s whirlwind impact in his short tenure as Communications Officer, he takes on the secretarial role with the same enthusiasm, passing the Communication brief to Dean Wallace. Contributions come not only from the Association officers but from others across the clinical team, from parents, patients and support groups. We are indebted to all of them for that support.

A personal highlight was the Franco-British meeting in Paris in December exemplifying the diversity of our members’ contributions. Twelve trainees trail blazed the way: all presenting their research, supported by Association travel grants, one with a prize winning presentation; developing social links with French trainees; using the various social media tweeting as they went. The welcome from French colleagues created a genuine ‘entente cordiale’, including the Anglophone delivery of presentations, with special thanks to Mordi Muorah for simultaneous translation of the few made in French. The quality of research presented was high. Our committee’s parent representative received a standing ovation as she recounted the challenging journey of a young person and family living with chronic kidney disease.

Clinical Services

We were pleased to receive Dr Richard Baker’s invitation to have an observer on the Renal Dialysis and Transplant CRG. Carol Inward, new Chair of the Clinical Service Committee, will use that opportunity to better inform the paediatric nephrology position as we endeavour to ensure health service policy decisions do not disadvantage Paediatric Nephrology Services. As health service commissioning structures continue to develop in NHSE Carol represents the paediatric nephrology view at the EWG. Transition programmes continue to develop, often implementing the Ready, Steady, Go (and Hello) instruments.

Research

Our new Research Secretary Rachel Lennon chairs the Paediatric Clinical Studies Group (CSG) and represents CSG at UK Renal Research Consortium meetings. She is working closely with KRUK on a development plan for paediatric research. UK Paediatric nephrology research was showcased at national and international conferences this year; notably the UK Kidney Week, the Royal College of Paediatrics and Child Health annual meeting, the American Society of Nephrology Kidney Week in Chicago and the Franco-British meeting in Paris.

There have also been notable funding successes in 2016: Rukshana Shroff was awarded a Career Development Fellowship from NIHR, Rachel Lennon a Wellcome Trust Senior Research Fellowship in Clinical Science and Lucy Plumb a NIHR Clinical Research Training Fellowship.

The national PREDNOS study of initial steroid treatment in Nephrotic Syndrome completed the follow up phase and will report in 2017. PREDNOS 2 continues to recruit. Recruitment to the HOT-KIDS study led by Manish Sinha is complete. Two major multicentre studies will start in 2017: the I-KID study, led by Heather Lambert, examining a new infant dialysis machine and the ECUSTEC study led by Sally Johnson, to investigate the early use of Eculizumab in diarrhoea-associated haemolytic uraemic syndrome.

I now look forward to working with Rachel as she builds on Richard Coward’s major contributions.
Quality Improvement and Innovations

The infoKID website, providing information for parents and carers on kidney conditions, has undergone an evaluation of how it is accessed and how parents, carers and patients, and healthcare professionals use it. A report will be published in early 2017. Jan Dudley and Dal Hothi continue to represent the BAPN on the Kidney Quality Improvement Partnership. We will align paediatric workstreams in transplantation and home therapies with the development of the national KQuIP projects on fistula, transplantation and home dialysis in adult services.

Clinical Standards and Guidelines

With the NICE accreditation of the process used by The Renal Association to produce Clinical Practice Guidelines, we look forward to contributing to joint adult and paediatric guidelines where relevant. Jan Dudley, QII chair, leads the BAPN guideline process. She has also been appointed chair of the NICE guideline committee on Renal Replacement Therapy, working with a team of skilled professionals to deliver guidance in this key area.

We await the final outcome of our appeal on the NICE guidance on transplant immunosuppression in children and young people. At the annual ‘Challenges in Paediatric Renal Transplantation’ meeting in Birmingham information gathered for the NICE appeal process on our current practice for ‘de novo’ transplantation was discussed, and will aid centres following agreed immunosuppression paths.

AKI and WKD

The AKI project, led by David Milford, drew to a conclusion in 2016 with many achievements including AKI treatment guidance for paediatric patients in primary and secondary care, harmonisation of biochemistry reference ranges and increased awareness for families and the public.

A successful AKI incidence snapshot was taken on World Kidney Day. Led by Mordi Muorah many local, national and social media links were successfully used to take advantage of the focus on children’s kidney disease to raise awareness of kidney disease on WKD 2016.

Training and trainees

Kay Tyerman, CSAC Chair, working with the RCPCH has finalised the ‘capabilities based curriculum’ for higher specialty nephrology grid trainees for submission to the GMC in 2017. Currently there are 15 grid trainees with 3 appointees commencing training in 2017. A number of trainees went through Speciality Trainee Assessment of Readiness for Tenure (START) with feedback helping their professional development and reciprocal feedback to the College helping improve the START process. As part of that readiness for tenure increasing numbers of final year trainees are receiving an opportunity to ‘act up’.

Drew Maxted continues the work of his predecessor Louise Oni, including support of the active WhatsApp group and using social media presence for learning and raising the profile of the BAPN and #BAPNtrainees, as seen in their excellent contributions throughout the Franco-British meeting.

Grid days continue to be a success, with Newcastle and London Evelina hosting in 2016. Increasing specialist interest (SPIN) trainee attendance is improving learning and building relationships. With increasing numbers of general paediatricians completing SPIN training in paediatric nephrology, the development of the SPIN Trainee curriculum takes on an increasing relevance. Mona Aslam, as our SPIN representative, engaged with SPIN trainees attending GRID training days and I look forward to working with Mona developing training for both trainees and interested general paediatricians post appointment.

Paediatric Renal Registry

With regulatory issues affecting this year’s activity Heather Maxwell, as new Chair, used the opportunity to take stock on how we develop opportunities to better use the registry resource. These opportunities will include links with both Research and Quality Improvement developments and initiatives. The integration of the Paediatric Renal Registry into UK Renal Registry enabled greatly assisted Alex Hamilton’s work on the clinical epidemiology of young adults starting renal replacement therapy in the UK, leading to publication. Lucy Plumb’s NIHR Clinical Research Training Fellowship will be based at the UKRR. The opportunity for other trainees to participate in registry based research has been highlighted in a grid training day presentation.

Finally, in 2017, one event causes me particular excitement and some pride. The BAPN welcomes back to my home city, Glasgow, the European Society for Paediatric Nephrology for its 50th Anniversary celebration of the first meeting hosted here in 1967. Ceud Mile Fàilte - a hundred thousand welcomes!

Dr David Hughes
President
British Association for Paediatric Nephrology
The Renal Association had an overall loss of £23,751. Income during this period was £246,460 and expenditure of £270,211. This loss related to a loss made in relation to UK Kidney Week 2016 of £22,734 (inclusive of VAT).

Income from individual membership increased in 2016 to a total of £93,642. Individual subscriptions remains the Association’s largest source of income. Income from corporate sponsors fell despite initiatives to increase the number of sponsors. Surpluses from Conference, the Advanced Nephrology Course and the Speciality Certificate Examination made a significant contribution to the income of the Association.

The UK Renal Registry had a loss of £342,176 in 2016. This loss related to investment in the IT infrastructure of the UK Renal Registry and PatientView. The income to the UK Renal Registry was £2,131,274 with capitation fees providing the major source of income with a significant income from grants. The UK Renal Registry continues to manage the finances of PatientView which is funded by a capitation fee (except Scotland).

For further details, please see the full financial statement for 2016 which is available at www.renal.org.

The pie charts on the following pages give an overview of the income and expenditure for the Renal Association and UK Renal Registry in 2016. Income and expenditure are broken down into their component parts. Further details are in the full financial statement for 2016 which is available at www.renal.org. The Renal Association holds funds separately for the British Association of Paediatric Nephrology (£23,070) and for the Nephrology SpR club (£1,400).

At the end of 2016 the amount of funds held by the Renal Association was £245,927. The reserves equate to approximately 12 months expenditure for the Renal Association. The UK Renal Registry have reserves of £1,807,152 at the end of 2016, equating to 8 months of expenditure.

Overall the Renal Association and UK Renal Registry are secure. The reserves held are sufficient to cover 12 months operating costs and this should be maintained. There are opportunities to increase income from corporate engagement and membership. Future annual meetings remain the biggest financial risk.

Prof Neil Sheerin
Honorary Treasurer
The Renal Association
RENAL ASSOCIATION
INCOME 2016

- Donations and Grants Received: 2.84%
- Subscriptions - Members Current Year: 37.98%
- Subscriptions - Corporate: 1.83%
- Consultancy and Other Income: 46.09%
- Meet Income - Registration: 1.22%
- Sponsorship Income: 0.81%
- Bank Interest Received: 0.43%

Total: £246,460

RENAL REGISTRY
INCOME 2016

- Grants: 6.92%
- Capitation Fee: 82.05%
- Project Fees: 8.73%
- Bank Interests: 0.46%
- Other Income: 1.84%

Total: £2,131,274

RENAL ASSOCIATION
EXPENDITURE 2016

- Coalition Membership Fees: 1.20%
- Meetings: 37.93%
- Trustee and Committee Expenses: 1.56%
- Awards and Bursaries: 4.95%
- Secretary Fees: 37.44%
- Electronic Communications: 5.91%
- Other Expenses: 9.13%
- Bank Charges & Interest: 0.03%

Total: £270,211

RENAL REGISTRY
EXPENDITURE 2016

- Staff Salary Costs: 57.61%
- Staff Expenses: 4.55%
- IT Costs: 13.75%
- Staff Training and Development: 1.08%
- Postage/Sundries: 1.24%
- Office Overheads: 2.85%
- Meeting Room Costs: 2.85%
- Depreciation: 0.49%
- Grant Allocations: 1.01%

Total: £2,473,450
Medical Student Elective Bursaries

Eight Medical Student Elective Bursaries were awarded in 2016. The recipients were:

• Nicholas Monteoliva
• Louis Evans
• Patrick McMullan
• Jennifer McNeill
• Sugeeta Sukumar
• Rebeccas Hardman
• Deborah Aldridge
• Michael Adair

AEG Raine Award

The AEG Raine award is made annually to a relatively junior member who has made a significant contribution to research, especially through presentations made at the Renal Association Conference. In 2016 this was awarded to Eoin McKinny.

Walls Bursaries

The John Walls Bursary enables two members, a clinician and non-clinician, to spend short periods at other centres, generally outside the UK, to learn new laboratory techniques or gain new clinical skills. The recipients of this were Roslyn Simms and Helen Noble.
Sanofi Genzyme, the specialty care business unit of Sanofi, focuses on rare diseases, multiple sclerosis, oncology, and immunology. We help people with debilitating and complex conditions that are often difficult to diagnose and treat. Our approach is shaped by our experience developing highly specialised treatments and working collaboratively with healthcare providers and patient groups. We are dedicated to discovering and advancing new therapies, providing hope to patients and their families around the world.

Gilead Sciences, a research-based biopharmaceutical company, discovers, develops and commercializes innovative medicines in areas of unmet medical need. Gilead’s therapeutic areas of focus include HIV/AIDS, liver diseases, haematology and oncology, inflammatory and respiratory diseases, and cardiovascular conditions. Gilead has a rapidly expanding product portfolio, a growing pipeline of investigational drugs and over 8,900 employees in offices across six continents. Millions of people around the world are living healthier lives because of innovative therapies developed by Gilead.

Alexion is a global biopharmaceutical company focused on developing and delivering life-transforming therapies for patients with devastating and rare diseases. Patients with these life-threatening diseases often have no effective treatment options, and they and their families suffer with little hope. Our goal is to deliver medical breakthroughs where none currently exist. We are driven because we know people’s lives depend on our work.

Otsuka Pharmaceutical is a global healthcare company with the corporate philosophy: ‘Otsuka—people creating new products for better health worldwide.’ The Otsuka Group is comprised of 166 companies and employs approximately 44,000 people globally with products available in more than 80 countries worldwide. Otsuka is committed to focusing its research and development on innovative products and medical devices that address unmet medical needs, particularly in our specialist areas of renal, endocrine, gastrointestinal and central nervous system disorders.

Vifor Fresenius Medical Care Renal Pharma UK (VFMCRP UK), established in November 2015, is a pharmaceutical company specialising in Nephrology. The company is a joint operation between Vifor Pharma and Fresenius Medical Care. VFMCRP UK has been working in partnership with our customers and supplying our leading brands of intravenous iron and our latest product, a non-calcium, iron based phosphate binder to support renal patient needs.

Our vision is to be the customers’ partner of choice for renal pharmaceuticals and innovative patient-centric solutions. We have a strong pipeline focused on helping improve the lives of the growing numbers of patients around the world who suffer from chronic kidney disease
NEW MEMBERS

Dr Boavoujivie Oseya
Dr Michael Oliver
Dr Hithanadura Dilini De Silva
Dr Farah Latif
Dr Tani Abedin
Dr David Wandless
Dr Caroline Platt
Dr Helen Noble
Dr Grace McCall
Dr Sayyid M Ammar Raza
Dr Matko Marlais
Dr Pallavi Yadav
Dr Rachel Hung
Dr Andrew Peter Maxted
Dr Fawad Muhammad
Dr Bakhiet Osman
Dr Yu Kwong Wong
Dr Tharindra Navodhi
Dr Eileen Nolan
Dr Sarah Yoon Ai
Dr Ademola Olaitan
Dr Hannah Wilkinson
Dr Sarah Abbas
Dr Holly Mabillard
Mrs Rachel Gair
Dr Emily Bowen
Dr Pugazh Kandaswamy
Tania Gracia Bustos
Jennifer O’Brien
Ya Su
Zoe Golder
Yan Song
Heather Mackinnon
Patrick Highton
Prof Alex Woywodt
David Wimbury
Dr Ravi Varma
Dr Nasirul Ekbal
Dr Victoria Carnall
Dr Tarel Abdelaziz
Thomas Wilkinson
Dr Pritpal Virdee
Dr Sudha Priya
Soundara Pandi
Dr Dina Nilsari
Dr Eleanor Murray
Aruna Arjunan
Dr Jonathan Law
Dr Douglas Stewart
Dr Tim Scale
Dr Ines Held
Dr Manu Prkash