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# Executive Committee Officers & Trustees

## Trustees

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<tr>
<td>President</td>
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<td>Honorary Secretary</td>
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<td>Academic Vice-President</td>
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<td>Clinical Vice-President</td>
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<td>British Association of Paediatric Nephrology (BAPN) President (from May 2015)</td>
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<tr>
<td>Prof Bruce Hendry</td>
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<td>Prof David Wheeler</td>
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<td>Prof Donal O’Donoghue</td>
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<td>Dr Alison Brown</td>
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<td>Prof Neil Sheerin</td>
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<td>Prof Fiona Karet</td>
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<td>Dr Graham Lipkin</td>
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<td>Dr David Hughes</td>
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## Ex Officio

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<tr>
<td>National Clinical Director for Renal Services England</td>
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<td>Specialty Advisory Committee (SAC Renal Medicine Chair)</td>
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<tr>
<td>British Association of Paediatric Nephrology (BAPN) Honorary Secretary</td>
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<td>Associate Specialist Rep</td>
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<td>Specialist Registrar SpR Club Rep</td>
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<td>Society for District General Hospitals (DGH) Rep</td>
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<td>British Renal Society President</td>
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<td>Renal Patient View Chair</td>
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<td>Renal Scientists Working Party Chair</td>
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<td>Representative for Wales</td>
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<td>Representative for Scotland</td>
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<td>Green Nephrology</td>
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<td>Chairman of the National Institute for Health Research (NIHR) Speciality Group</td>
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<td>Dr Richard Fluck</td>
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## Executive Committee (Appointed)

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<td>Education &amp; Training Committee Chair</td>
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<td>Rare Disease Committee Chair</td>
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<td>Terminology Committee Chair</td>
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<td>Communications Officer</td>
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<td>Renal Patient View</td>
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<td>Medical Director, UK Renal Registry</td>
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<td>Chief Executive, UK Renal Registry</td>
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<td>Dr Jeremy Levy</td>
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<td>Prof David Goldsmith</td>
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## Executive Committee (Elected)

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<td>Elected Renal Scientist</td>
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<td>Dr Mark Dockrell</td>
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<td>Prof Moin Saleem</td>
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<td>Dr Indranil Dasgupta</td>
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<td>Dr Andy Stein</td>
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<td>Dr Rebecca Suckling</td>
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<td>Dr Richard Haynes</td>
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<td>Prof Sunil Bhandari</td>
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<td>Mark Brady</td>
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<td>Dr Michael Robson</td>
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A highlight of 2015 for the Renal Association was the opportunity to host the EDTA-ERA Congress in London and to integrate this with our Annual Meeting. This joint meeting was a great success. It was well attended with over 8,000 delegates; there was an excellent and well-received programme and the contributions from the UK in general and RA members in particular were highlights of the meeting. Our RA-badged sessions and the RA-named lectures were of very high quality. I thank all the RA team who worked so hard to deliver our contribution and who worked seamlessly with the ERA-EDTA officials and secretariat. The meeting resulted in a small financial surplus for the RA. I believe that this meeting puts the RA in a strong position to work again in the future with international organisations as partners in high quality clinical, academic and educational meetings.

The RA has further enhanced engagement with European nephrology in the forum of the European Kidney Health Alliance (EKHA) and in the Renal Section of the Union of European Medical Specialists (UEMS). Plans are well advanced for the presentation of a European Specialty Certificate Examination in Nephrology led by the RA in partnership with the UEMS and Royal Colleges.

The Renal Association has continued to play a major role in the leadership and delivery of training and education in nephrology and related areas. The 2015 Advanced Nephrology Course was a great success and over-subscribed. CPD sessions were delivered at the London ERA-EDTA Congress and in other boutique meetings through the year. The Renal Registry has become more sophisticated in its reporting and has developed further in the areas of Acute Kidney Injury and non-Dialysis CKD. The RA Rare Disease Initiative (RaDaR) has moved from concept to reality with the development of 22 functional rare disease registries with clinical and academic potential.

Further recent RA work has led to the initiation of the UK Kidney Disease Quality Initiative Partnership (KQuIP) under the leadership of the RA Clinical VP Graham Lipkin. The RA Academic VP Fiona Karet has led the development of the UK Renal Research Strategy to be launched in April 2016. The RA works very closely in partnership with Kidney Research UK on these and related projects. Renal Association officers, executive and members continue to have wide international impact, for example David Wheeler as co-chair of KDIGO and Fiona Karet as a member of the KDIGO “Controversies in Gitelman Syndrome” team. The Renal Association works closely with patients and patient organisations and in 2015 we have been delighted to welcome representatives of the National Kidney Federation and BKPA to the RA executive.

During 2015 we signed an agreement with the BRS to co-host UK Kidney Week 2016. This will be held at the ICC Birmingham June 7-10. I am confident that we will present an excellent meeting for all the renal community.

The RA continues to play a leading role in all matters relating to the care of kidney patients, including governance, quality, guidelines, education and research. In the light of the scope and depth of the work undertaken by the Association, our membership fees remain very good value indeed. Leadership is delivered by our trustees, officers, committee chairs and members of the executive. You will see detail of this work in the other sections of this 2015 annual report. I thank all those who contribute so much in this way.

Bruce Hendry
President
The Renal Association
Review of the Year
- DR ALISON BROWN

It has been another busy year, with the Renal Association working hard to lead and contribute in many areas, as times get even harder for us all!

At the end of 2015, there were 1059 members of the RA - I hope you agree membership remains very good value for money. Our Communications Officer Jim Moriarty @RenalAssoc tweets regularly to 1,714 followers.

Donal O’Donoghue was elected as our next President and is already working hard as President-Elect to investigate if we are providing everything the membership wants from us, and ensuring that all renal trainees want to join the RA.

The winners of the Renal Association awards in 2015 were as follows:
- The Raine Award winner was James Fotheringham, who gave an outstanding Raine Lecture entitled “Long breaks and disappearing PD catheters: lessons from linking UK Renal Registry data” at the 2015 RA-EDTA-ERA conference
- Adrian Woolf was the winner of the Lockwood award
- The Walls award (non-clinical) went to Amy Jayne McKnight
- The Walls award (clinical) went to Neeraj Dhaun

The 52nd ERA-EDTA Congress was held in partnership with the RA at the ExCel Conference Centre London May 28th-31st 2015; this was the first time the Congress had been in London since 1983. Over 8,200 people attended, 800 from the UK; the UK also had the most abstracts submitted, the most abstracts presented, and the most speakers in sessions. David Goldsmith, Chair of the RA International Committee, did a wonderful job as Congress President.

Preparation then got underway for UK Kidney Week 2016! Organising committee co-chairs Bruce Hendry, Donal O’Donoghue, Neil Sheerin and me (RA), David Hughes (BAPN) and Edwina Brown, Sharlene Greenwood, Helen Hurst, Louise Wells, and Maarten Taal (BRS) have put together a programme that we hope will appeal to everyone. 518 abstracts have been submitted.

We are delighted that these leading nephrologists have agreed to give the Renal Association named lectures at UK Kidney Week 2016:
- Chandos Lecturer is Liz Lightstone, Professor of Renal Medicine, Imperial College London
- De Wardener Lecturer is Adrian Woolf, Professor of Paediatric Science, University of Manchester
- Osman Lecturer is Claire Sharpe, Clinical Senior Lecturer and Honorary Consultant in Renal Medicine, King’s College London and King’s College Hospital, London

The Renal Association continues to work to promote renal medicine as a career, with support for renal-related elective projects for medical students - we hope the reports they write of their experiences (which are posted on the RA website) will provide inspiration for the next generation of students!!

Successful applicants are:
- Deborah Aldridge, St Georges
- Jennifer McNeill, Edinburgh
- Louis Evans, Cardiff
- Michael Adair, Edinburgh
- Patrick McMullan, Birmingham
- Rebecca Hardman, Birmingham
- Sugeeta Sukumar, Manchester
- Nicholas Cereceda-Moneolivia, Imperial

Finally, thanks again to all who have responded to my pleas for help for the RA over the past year. The “Consultations” page on the website shows just how many consultations the RA has responded to on your behalf, with details of the individuals who have done lots of work almost always at very short notice, and the details of their contributions plus the final outcomes. Please do contact me with any suggestions you have as to how we can improve communication and make sure we are tackling the issues that are important to you.

Alison Brown
Honorary Secretary
The Renal Association
Academic Affairs Report 2015
- PROF FIONA KARET

It has been a productive year on the Academic side. Much of my time has been spent on continuing to Chair the National Renal Research Strategy Steering Group as the Renal Association’s representative. Other steering group members represented the BAPN, BRS, Kidney Research UK, BKPA, NKF and the original Kidney Health: Delivering Excellence Writing Group. With multiple consultations across the whole renal community, the Strategy has come to life and as I write I am delighted that it has just been launched.

It is inherent in all of our individual activities as renal professionals that without research, there can be no improvement in health. It was therefore a bonus that George Freeman, minister for Life Sciences, wrote the Strategy’s foreword in which he acknowledges the challenges that lie ahead in ensuring the UK is attractive to researchers and in transforming the patient experience. “That is why I am so encouraged to see the kidney community come together, reflect on these challenges and set out clear research themes, research priorities and enablers,” he commented.

In the Strategy, we were careful to be fully inclusive of all forms of renal research, from molecular to population-based, and quantitative to qualitative. This mirrors the Renal Association’s own approach to its membership, and so I hope you will be able to attend the Strategy Implementation session in Birmingham.

The Strategy was produced under the UKKRC umbrella. UKKRC Chairmanship rotates biennially between the RA, Kidney Research UK and the BRS, and currently sits with Paula Ormandy (research chair of BRS). This year a new Clinical Trials network has been set up, led by Dr. Tom Hiemstra (Cambridge). Information about the UKKRC is now available on both RA and KRUK websites, as is a PDF of the Strategy.

The Renal Association’s Research Committee has been chaired by Moin Saleem, with Jill Norman as deputy. Moin is completing his term at the AGM, and will be succeeded as Chair by Jill, with Claire Sharpe as the new deputy. Thanks go to the committee and to Moin and Jill in particular. Moin writes: “the Research Committee is currently focusing on two areas:
- Better alignment with the Renal Scientists’ Working Party (RSWP), currently chaired by Amy-Jayne McKnight such that there is always a RSWP member as chair or deputy chair of the Committee and at least two non-clinical scientists as members; the working party and the committee always each have a representative helping develop the RA annual meeting; communications between the two groupings are more frequent. - Work is still continuing to revive and promote the development of a Renal Researchers’ Database - potentials include addition of key industry links, and information about current multi-centre clinical trials”. Following a Kidney Research UK industry day in November, it is clear that both industry and the charity are keen to help set up and shape the database to make it fit for purpose. Richard Phelps (Edinburgh) has been approached to advise on IT requirements. The Renal Association will be contributing financially, and discussions are under way with Kidney Research UK to help finance the first stage.

Under the Training and Education umbrella (chaired by Jeremy Levy), the Advanced Nephrology Course in Oxford in January was as successful as ever, and continuing thanks go to the course organizers, Sunil Bhandari and Paul Harden. RA members get a 10% discount on course fees – next year’s course is Jan 3-7, 2017, and registration will open as of May 1st 2016. Effective CPD sessions were delivered at last year’s Kidney Week/ERA meeting, and look very exciting for Kidney Week 2016. And the RA continues to lead and support a wide range of educational meetings across the specialty, including close links with the Royal Society of Medicine.

The SpR club is an active educational group, and meets regularly. Its current chair is Weng Oh, and a survey of trainees is currently open www.renal.org/news-item/2016/04/07/

During his chairmanship of the International committee (IC), David Goldsmith was local organizer for the very successful 2015 ERA/EDTA meeting in London. He now writes: “There are new members of the IC - Debasish Banerjee, Ibi Erekosima and Aimun Ahmed. Indranil Dasgupta and John Feehally have produced a superb guide to hosting overseas visitors and fellows (‘ISN Fellow UK advice.pdf’) which is available on the RA website; I would urge everyone with an interest in fostering these overseas links to read this, and use it where needed. The annual arrangements of KRUK/ISN and RA/ISN fellowships is continuing - the current visitor under this scheme is Dr A Qasem from Egypt, who is based at King’s”. David would also like to remind RA members that ISN membership is free to our trainees under 37y old.
The Rare Diseases Committee, led by Detlef Böckenhauer, has had a great year. RaDaR, the national rare renal disorders registry held within the Renal Registry has, as I write, 4,653 UK patients enrolled from 66 Renal Units. 2,565 of these were added in the last year. There has been expansion to now 23 Rare Disease Groups (RDGs) - IgA nephropathy, calciphylaxis, ADPKD and retroperitoneal fibrosis were all approved over the past year. New financial support from the PKD Charity and Kidney Research UK will ensure further NIHR portfolio status, and sustainability will be achieved through capitation fees. Since 80% of recruits are adults, the project (and associated funding to recruiters) has been moved across from paediatrics to nephrology. In February, RaDaR was re-launched with access to many additional data fields - condition-specific fields are currently available for 6 RDGs.

The NIHR’s Translational Research Collaboration includes a renal theme, on which I lead. To qualify for funding, researchers must be based in, or allied to, a Biomedical Research Centre or Unit or a Clinical Research Facility. To date, three projects and a Fellowship (on pregnancy and renal disease) have been funded through this scheme, and four rare RDGs have just been given funds to run patient information events.

The BAPN has had a successful year in developing and delivering a number of important clinical studies for children. Research lead Prof. Richard Coward lists five: HOT-KID - a randomised trial to compare effects of aggressive versus standard targets in blood pressure on target organ damage in children with CKD; T-INF Infant Kidney Dialysis and ultrafiltration study (aka NIDUS) examining efficacy, outcomes and safety of infant haemodialysis and ultrafiltration. ECUCilizumab in Shiga-Toxin producing E. Coli Haemolytic Uraemic Syndrome (ECUSTEC); Prednos, assessing steroids for nephrotic syndrome; and Prednos 2, examining the role of short-term steroids in viral infections associated with nephrotic syndrome. The BAPN is also working in close partnership with Kidney Research UK to develop new paediatric studies for the future through the new establishment of paediatric nephrology speciality study sub groups that will feed into and add value to UKKRC.

A big thank you to all involved in leading and working on these various areas of RA activity, and congratulations to Prof. Phil Kalra who will take over the AVP role in September.

Fiona Karet
Academic Vice President
The Renal Association
Clinical Affairs Board Report

- DR GRAHAM LIPKIN

The NHS continues to experience major changes in structure and function which impact substantially on renal services at a time with ‘no new money’ and focus on implementation of Simon Stevens 5 year forward strategy which sees other areas, not renal as key priorities. This makes it particularly challenging for CDs and renal services. The changes of particular concern are:

- **Loss of the Renal NCD from 1st April** - Both dialysis and transplant NCDs, Richard Fluck and Keith Rigg have served the Renal community extremely well. We will no longer have someone helping us in the corridors of power. The RA wrote to Sir Bruce Keogh stressing the importance of NCD role. A reply indicates that the NCD role will be lost but that NHS England will seek clinical advice from the revised CRG and professional societies. This makes the role of the RA even more vital. The Clinical VP sits on the Renal CRG, KQuIP and CEO Registry which will remain to support and advise the Responsible Commissioner, Jon Gulliver. The RA will advise on professional issues wherever possible and will be available to advise when asked. The service specification for 2016/17 have been published.

- **The Renal CRG** - The Renal Dialysis and Transplant CRGs will be amalgamated and reviewed. This may have some advantages in coordination of these 2 interlinked areas of practice. The RA will maintain a seat at the CRG and be an important route of clinical advice. The combined CRG will have fewer members than each previous CRG alone: 2 clinicians from each of 4 Regions, 4 professional society members and Chairman. Application to CRG is currently open to recruitment.

- **Renal Networks** - Most regions have functional Renal Expert Advisory Groups within the Strategic Clinical Networks (SCNs). Resource is being pulled from the SCNs. This is a risk to coordination of quality and service development. The Renal community has always been innovative and engaged. The Clinical Networks in many ways can function with little direct support. The clinical aspect can remain stable even if the SCNs disappear. The Professional societies & patients are leading an innovative QI initiative and rely on the Regions for delivery. KQuIP is working hard to assess what support Networks require and to coordinate resource. This could include project management for Regional QI and the development of a combined Registry/KQuIP annual meeting in each Region. Key to success is to follow the reorganised NHSE QI resource: Right Care and Commissioning for Value in NHS England.

I have no doubt that if we work together we will be able to overcome many of these challenges.

The Kidney Quality Improvement Partnership (KQuIP)

KQuIP is an important collaborative venture aimed at supporting the embedding of QI in our daily practice. I attach the Operational plan and TOR and outline of the Design Meeting event in May. KQuIP welcomes clinicians as faculty members.


The RA is grateful to the many members who have been actively involved in reviewing NICE guidance which is no small task.
There is a need to embed quality and safety within Renal Services. KQuIP is co-chaired by RA and BRS. We have developed an active Programme Board, Operational Group with project management. This is progressing well: KQuIP has:

• Buy in from all professional groups including BTS, patient organisations, the Registry which sees QI as a core function, NHSeng via CRG, patient organisations and KRUK and BKPA.
• Development of active Programme Board & Operational Group (KOG)
• Clear strategy based on:
  • Strategic influence by advising the new CRG using unwarranted variation identified in the Registry as evidence for choice and development of national QI projects. It allows NHSe to influence in the opposite direction.
  • Regional delivery; an annual day meeting in each region of England reviewing. This role is developing and will be guided by the KQuIP Design event. Registry outcomes, supporting and education of QI clinicians in developing QI projects. Providing leadership training in QI for Renal physicians and MPT.
  • Plans to embed QI methodology and leadership training for Renal trainees via the SAC.
  • Peer assist model for Renal units i.e. pair units with best outcomes in an area of practice with a unit with less good results.
  • KQuIP launch and session at Renal week and possibly at UKRR Annual meetings.
  • Seed funding from constituent bodies and from the Health Foundation.
  • Plans for ongoing funding.
  • Education web based platform.
• Meeting has with Q fellows from Health Foundation has taken place and will be central to role out of KQuIP.
• 6 work streams (Supporting Networks, Projects, Comms, Leadership, Education, Infrastructure).
• KQuIP aims to help coordinate, but not to interfere with existing projects. It is inclusive and facilitative and seeks to further develop its faculty.
• KQuIP aims to work with NHS Right Care and Commissioning for Value.

There are important links with the RA/BRS patient safety initiative led by Paul Rylance and Katie Jones.

KQuIP seeks engagement and support from the Renal Association Members
The design event in May aims to modify direction in light of input with launch during Renal Week 2016.

NICE Guidance Challenge to Transplantation

The RA is grateful to the many members who have been actively involved in reviewing NICE guidance which is no small task.

The NICE guidelines FAD for adult and paediatric post transplant immunosuppression have been a source of work and concern. It recommends use of basilixumab, immediate release tacrolimus and mycophenolate mofetil each with the lowest acquisition cost. It does not recommend any other immunosuppression. No suitable mechanism is in place to allow other drug use where clinically appropriate. The RA worked with BTS and BRS and patient groups. The consultation response was rebuffed by NICE. We, together with the BTS, BRS and BAPN appealed-in person on 30th March, the outcome of which is awaited.

Renal Tariff Development

The RA, together with NCD, BRS and patient organisations successfully argued for reversal of proposed dialysis tariffs for 2016/17 by Monitor which was granted. Monitor asked for engagement with the Renal Community to devise accurate tariffs. The RA has significant existing involvement already. James Medcalf sits on the EWG of HSCIC and John Bradley advises.

The RA has sought and been granted active co-working with Monitor to build accurate reference costs and to develop clinically relevant tariffs including BPT.

Clinical Services Committee
(Chair Alastair Hutchison)

The CSC continues to:

• Hold the Annual CD Forum. A very well evaluated CD Forum was held on 1st March in Manchester.
• Respond to CPG as reviewers.
• Circulate issues related to clinical practice and respond to requests for advice.
• Oversee the joint BRS/RA Patient Safety Group led by Paul Rylance.

Equal Opportunities Committee
(Claire Sharpe)

The EON continues to meet 2-3 times a year via teleconference. Ongoing projects:
1. EON and SpR club joint session during Kidney Week 2016
The EON ran a joint session with the SpR club during Kidney Week 2016. This focused on social media and digital learning and mentoring for new consultants. Following on from the new consultant survey last year, EON have recognised that there is a need for a more robust way of matching mentees and mentors. It has been suggested that we could seek out potential mentors via the Renal Association newsletter and match them to mentees during Kidney Week. EON asks the Executive for their thoughts on whether the Renal Association could offer a short training course for potential mentors.

2. New Consultant letters
EON continues to write to all new consultants to invite them to find a mentor locally. In total, 121 new consultants have been appointed in England in the 3.5 years up to 2016.

3. Identification of non-career grade doctors
EON continues to struggle to get an up to date list of non-career grade doctors employed in renal units across the country.

Clinical Practice Guidelines
(Andy Lewington)
This is a core group within the RA and receives largest number of hits on the RA Website. The Guidelines under Andy’s dynamic leadership have NICE evidence accreditation. There are 15 core CPG and a number of joint guidelines, most recently on diabetes care on dialysis, operative management of hypokalaemic alkalosis and water quality. All authors are working very hard. Trustees working with Andy recognise need for greater support from the RA. Measures being put in place include:
• Project Management (reminding authors, submissions, review dates, meeting arrangements, supporting the Chair, coordinating patient group input…). This is now provided by the Registry.
• Greater recognition from RA-authors highlighted on RA website during guideline development and review. Recognition from President (current).
• Splitting large guidelines into smaller sections and bringing in more authors.
• Exploring using evidence base review using EBPG, Cochrane and KDIGO.
• Exploring support with searches where needed.
• Presentation at sessions in Renal Week and perhaps the Registry Annual Meeting.
• Formal patient group input (BKPA/NKF).
• Links to the Patient Information Group-NICE (writing patient facing guidelines summary).
• Reducing core guideline numbers and consider commentaries on some e.g. ADPKD current from NICE will be discussed at Renal Week.
• Maintenance of NICE accreditation.

Terminology Group (Afzal Choudhury)
Afzal now moves to lead Patient View. We thank him for his hard work and major achievements.

Patient Information Group
(Rebecca Suckling)
Andy Stein has single handedly developed excellent patient information for the BKPA. Another Nephrologist also based in Coventry has worked on the NKF patient information. The BKPA approached the RA to develop guidelines. Rebecca Suckling has taken this on. The BAPN produced excellent INFO Kids leaflets according to Information Governance Standards. Rebecca is currently scoping the project (option appraisal) to determine resource requirements to work with BKPA.

The Future Direction of the RA
THE RA must maintain its strong focus on supporting academic research. I have a strong feeling that now is the time to review the role of the RA and use this time to ensure that it is delivering the needs of the Renal trainees and the newer consultants. These groups differ from those clinicians who were historically members: more clinically based, greater team workers, some less lab research based. The Registry, Patient View, QI development and Patient Information development are key.
The Renal Association - Structure

RA Trustees

RIGB

RA Exec

Academic affairs board

Clinical affairs board

Guidelines

EON

Terminology

Clinical services

Research

Rare diseases

International

Education and training

BAPN representation on all committees
The Registry continues to evolve from collecting routine health data from electronic health records for patients being treated in secondary care for end-stage renal disease, to receiving files direct from laboratories for patients in primary and secondary care with acute kidney injury and receiving patient reported outcomes direct from patients. These data flows should maintain and hopefully increase the relevance of the Registry to the wider range of stakeholders and put the Registry at the heart of quality improvement initiatives in the UK. Underpinning all of this is an evolution of the information technology that is essential to collect data from a range of computer systems in a timely fashion.

The UK Renal Data Collaboration
The UK Renal Data Collaboration aims to transform the way data is collected on people with kidney disease. It brings together eight major organisations with an interest in collecting routine renal health data – The UK Renal Registry, The Scottish Renal Registry, Patient View, The UK Registry for Rare Diseases, The British Association for Paediatric Nephrologists, The Northern Ireland Nephrology Forum, The Welsh Renal Clinical Network and the Renal Information Exchange Group. It has been in development for several years, but is now beginning pilot work in one or two renal units before wider roll out.

For renal units, commissioners and patients, this is likely to lead to a number of noticeable benefits:
- Data will be collected from renal units daily (rather than at the end of a quarter) and so the Registry will have a dataset that (1) contains all laboratory results from the quarter not just the latest one and (2) is a real-time copy of the local renal IT system
- It will be possible to improve and standardise data extractions and transfers with the ultimate aim of being able to transfer a patient's electronic health record between renal units, with the patient's permission, as required for continuity of clinical care
- Only one data extraction routine will be required (rather than one for each of the partner organisations) making it easier to maintain mapping and therefore data completeness
- 2-way data communication will become possible between renal units, the Registry and patients.

The technical “schema” for transferring data to the UKRDC was sent out for consultation in 2015 and published early in 2016. It is likely that a range of solutions will be required to meet the needs of all renal units in the UK. If anyone is interested in finding out more, and certainly if they are considering making changes to their renal IT system or extraction rules, they should contact the Registry at an early stage.

“The UK Renal Data Collaboration aims to transform the way data is collected on people with kidney disease.”
The Registry’s Dataset

There have been two major changes to the Registry data set over the last 12 months. These have been somewhat complicated by the slightly different timing of adoption across the four home countries.

- January 2015 – Adults in England – a requirement from the Clinical Reference Group for reporting of activity related to dialysis or plasma exchange for acute kidney injury.
- January 2016 – Adults and children in England, Wales and Northern Ireland – adoption of version 4 of the UK Renal Registry data set, which includes the requirement to report dialysis and plasma exchange for acute kidney injury and the requirement to submit data on pre-dialysis patients with an eGFR of less than 30 mL/min.1.73m2.

Due to the delays inherent in the Registry’s current (pre-UKRDC) model for data collection, the English acute dialysis data did not start being collected until October 2015 and should be reported for the first time in the 2016 Annual Report. It is anticipated that the new version 4 data set will start being extracted via the UKRDC in September 2016, with first reporting in the 2017 Annual Report. This will include the secondary care CKD G4&5 data. An expert Task and Finish group is developing the analysis plan for this novel set of data.

The Acute Kidney Injury National Programme – with NHS England

Data on cases of acute kidney injury in primary and secondary care are now flowing in from 65 of the estimated 125 laboratories in England. At the end of January 2016, this represented more than 145,000 patients with acute kidney injury, which is more than twice the number of patients currently receiving renal replacement therapy in the UK. To see if your local laboratory is yet sending in data see www.thinkkidneys.nhs.uk/aki/aki-data.

Analysis of this data is just beginning, with linkage to other data sets (such as Hospital Episode Statistics, The Office for National Statistics and the Intensive Care National Audit and Research Centre) providing the full picture of the impact of acute kidney injury.

The Patient Participation National Programme – with NHS England

The collection of patient reported outcomes – quality of life and patient activation – began in 10 sites in early 2016. 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

A patient reported experience measure has also been developed and will be administered to patients attending renal units with chronic kidney disease or on renal replacement therapy on an annual basis. The patient experience work is separate from the NHS England-funded work and is being funded by the British Kidney Patient Association.

Research

While Registry data has been used for research for many years, these analyses have always been observational in nature and therefore limited in how they can be used to inform the evidence base for changing clinical practice. It is therefore exciting for the Registry to be increasingly involved in interventional studies, providing efficient follow up for individual patient-level randomised controlled trials or more complex interventions delivered at the organisational level – cluster randomised trials.

A number of requests for data sharing have been approved in the past 12 months and a number of projects previously approved remain open. For details see Table 3 of the Introduction to the UK Renal Registry Eighteenth Annual Report (December 2015) www.renalreg.org/reports/2015-eleventeenth-anual-report. This number is considerably lower than it might have been because the use of Registry data for research has been restricted for a number of months while the new information governance permissions for research and linkage were obtained. Once these permissions are in place there will be many exciting opportunities for health professionals, researchers, patients and commissioners to use the Registry data to continue to improve care for people with kidney disease.

Dr Fergus Caskey
Medical Director
The UK Renal Registry
BAPN Report
- DR DAVID HUGHES

Since taking over the role of BAPN President in May 2015 from Jane Tizard I am increasingly aware of her considerable work in that role and I am immensely grateful for her leadership as President over the last 3 years. I have also learnt on her for support and advice during my steep learning curve, particularly as I grapple with the complexities of the continuing evolution and reorganisation of structures in NHS England. The welcome and support evident from colleagues on the Renal Association Board of Trustees, Executive Committees and Renal Information Governance Board has been invaluable.

Clinical Services
The paediatric nephrology voice needs to be well represented and heard on the various groups in NHS England that influence health service policy decisions, in drafting reference costs for services and in setting tariff costs if we are to ensure our Paediatric Nephrology Service is adequately resourced for the complex work it does there. Dal Hothi, our Chair of the Clinical Service Committee, continues to press this case with the challenge of gaining recognition of the service needs of our highly complex but relatively small volume specialty. I am also mindful of the learning and sharing we can achieve from our varying experiences across the health care systems in the devolved nations.

We have responded to the consultation processes on proposals to revisions to Clinical Reference Groups and Specialised Commissioning in NHSE, noting our concerns that some proposals could diminish our opportunity to inform and shape improvements in our patient services there. We are keen to see continued development of managed clinical network models of care, already well established in Scotland, supporting and improving region wide delivery of specialist paediatric renal care. We have been well supported in our submissions by the Renal Association and the patient support groups. I value greatly and recognise the importance of these supportive partnerships.

Research
Richard Coward has chaired both our Research Committee and Clinical Studies Group. He has been closely involved with the development of the National Renal Research strategy with its launch in March. Working with KRUK, progress has been made in identifying interested groups for future research priorities. KRUK have also supported opportunities to build research links with Industry. Having completed recruitment to the PREDNOS study on duration of steroid treatment in Nephrotic Syndrome, led by Nick Webb, the follow up phase will complete in the next year. Ongoing national studies include PREDNOS 2 and the HOT-KIDS study. Funding has been secured for the I-KID (previously NIDUS) study assessing a new infant dialysis machine that will commence in the next year. The ECUSTEC study, examining early use of Eculizumab in diarrhoea-associated haemolytic uraemic syndrome, has secured NIHR funding and is due to start recruitment. I am grateful for Richard’s major contributions as our research chair and now, having completed his tenure, he has handed the baton to Rachel Lennon, with whom I now look forward to working.

Clinical Standards and Guidelines
Jan Dudley continues to chair this group, together with Andy Lewington, in the ongoing development of Renal Association national guidelines. Current accredited standards in the development of robust guidelines provide a challenge to deliver. Resource to support this remained a key factor. A similar situation is seen in the exploration of how best to develop high quality information. Jan is also working closely with Rebecca Suckling as part of the Renal Association Patient Information Group exploring this with her experience developing the Infokid project. This has achieved considerable international recognition and is now due for a formal evaluation including reapplication for information standards accreditation.

Quality Improvement
Jan Dudley and Dal Hothi represent the BAPN on the Kidney Quality Improvement Partnership led by the Renal Association Clinical Vice President, Dr Graham Lipkin. This will aim to identify support and enable quality improvement projects and disseminate best practice.

AKI and WKD
The Paediatric Acute Kidney Injury Project continues, led by Dr David Milford. A snapshot of AKI incidence, co-ordinated by Richard Holt, has been taken across all hospitals in the UK with a paediatric renal unit on World Kidney Day. The initiative was able to take advantage of this year’s World Kidney Day focus on children’s kidney disease.

With BAPN support co-ordinated by Mordi Muorah, and with support from the Kidney Charities Together Group, many activities took place across the country. Many local, national and social media links were successfully used to help raise the profile of many aspects of kidney disease.
Training and trainees

Kay Tyerman, as Chair of CSAC, has led work with the Royal College of Paediatrics and Child Health revamping the training curriculum both for general paediatric trainees, including those with a special interest in nephrology (SPIN trainees), and the curriculum for higher speciality nephrology grid trainees. Across the UK currently there are 17 grid trainees either in post or about to commence training.

Hitesh Prajapati, as Trainee Representative, has been a valuable contributor to the Association. Training days again have been successfully delivered. Feedback from the trainees on the RCPCH Speciality Trainee Assessment of Readiness for Tenure (START) will help inform refinements to this process, making it a more effective assessment tool for nephrology trainees. The development of the SPIN Trainee curriculum will be timely with an increasing number of Paediatric Trainees declaring a specialty interest in nephrology as general paediatricians. Hitesh passes on the role of Trainee Representative to Louise Oni.

Paediatric Renal Registry

With the fuller integration and embedding of the Paediatric Renal Registry within the UK Renal Registry structures there will be increasing opportunity to explore the expanding information database that, in turn, can better inform our clinical practice. Manish Sinha has completed a successful tenure as Chairman of the Registry, with information now being reported on all patients up to age 18 years old, merging data reported both through the Paediatric and Adult Centres. Heather Maxwell, as the new Chairperson, will build on these developments.

Other colleagues who are moving on from their roles in the BAPN include Arvind Nagra, our Treasurer, succeeded by Shuman Haq; Andy Lunn, who has taken forward website and media developments as Communications Officer and is handing this over to Vincent Tse; and Munir Ahmed, representing SPIN Paediatricians in Nephrology, with that role taken on by Mona Aslam. They have all provided great support and commitment in their roles for which I am truly grateful.

I remain hugely indebted to the support of Martin Christian, as Honorary Secretary, whose tireless work ensures the smooth running of the Association. Martin had a major role in co-ordinating our first 2 day Winter Meeting, achieving this with industry support. He has also been integral in successful discussions with colleagues in the Société de Néphrologie Pédiatrique leading in 2016 to the first Franco-British Paediatric Nephrology Meeting with our French colleagues in Paris.

Other meetings continue to be successfully delivered including the ever popular Surgical Challenges meeting. Our session at this year’s Annual Meeting of the RCPCH sees us share in a joint session with colleagues in metabolic medicine. Preparations are also proceeding well for the 2017 ESPN meeting, hosted by the BAPN in Glasgow, as the 50th Anniversary celebration of the first ESPN meeting there in 1967.

With all this and more to look forward to, the time ahead for my period of office is both challenging and exciting. I am encouraged by the excellent support provided by my colleagues on our Committees and look forward to working closely with them over the next 2 years.

Dr David Hughes
President
British Association for Paediatric Nephrology

We are keen to see continued development of managed clinical network models of care, already well established in Scotland, supporting and improving region wide delivery of specialist paediatric renal care. We have been well supported in our submissions by the Renal Association and the patient support groups
Treasurer’s Report

- PROF NEIL SHEERIN

In 2015 the Renal Association again had an overall surplus of £59,686. Income during this period was £296,000 and expenditure was £236,314. The success of the ERA-EDTA meeting, jointly hosted by the Association in London was a major contribution to the Association’s income during this period and was largely responsible for the higher than predicted surplus.

Income from individual subscriptions remains a significant source of income and accounts for almost one third of our income (£89,585). This is a slight increase compared with income from subscriptions in 2014, returning to the level seen in 2013. This stability is despite changes in the membership charges over the last 2 years to reflect changes in working practices with an increasing number of members working less than full time. The Association has also seen an increase in income from corporate partners, rising from £25,000 in 2014 to £48,000 in 2015. This is the result of increased engagement between the Association and industry.

The Association’s partnership with the ERA-EDTA as part of the 2015 London meeting generated over £70,000 of income and, as a non-recurring event, is responsible for the higher than normal level of surplus made by the Association in 2015. The Specialist Certificate Examination continues to be a source of income although it is expected that this will fall after 2015 because of a reduction in the registration fee, an initiative that was supported by the Association.

The UK Renal Registry’s income in 2015 was £1,750,970. The UKRR has two significant income streams, capitation which funds the ‘core’ UKRR work and ‘other’ income, primarily grants, which fund the programmes work. The Renal Registry’s expenditure in 2015 was £2,167,551. In 2015, capitation fee income increased whilst grant income decreased. This resulted in the UKRR showing a deficit of £416,580 for the year. However, grant money brought forward from previous years for the programmes work covered this deficit, with the intention to embed much of this into core UKRR work in the future. Core UKRR work continued to be funded by the capitation fee, which will be increased in 2016.

The incomes and expenditures of both the Association and the UKRR are summarised in the pie charts on the following pages, which break down the income and expenditure into their component parts. Further details can be found in the full financial statement for 2015 at www.renal.org.

The Association continues to hold a restricted fund on behalf of the British Association of Paediatric Nephrology (£22,855) and the SpR Club (£1,400). The Association is currently discussing further financial management support for the SpR Club in the future.

At the end of 2014 the Association held a reserve of £219,243. By the end of 2015 this had increased to £278,929, reflecting the operating profit during 2015. This would cover expenditure for 15 months of operations. The UKRR saw an overall reduction of retained funds carried forward, from £2,566,809 in December 2014 to £2,150,074 in December 2015. Despite the reduction, the UKRR retained funds at year end continue to meet the stated policy of being able to cover 100% of 12 months core UKRR costs.

Overall the Renal Association and UKRR are financially secure. They hold funds to allow the organisations to operate for 12 months. The budget has been set for 2016 and the Association should maintain its reserves at this level. There are challenges ahead with pressures on corporate sponsorship and changes to the SCE registration. However I feel the Association and Registry are in a strong position and has the potential to support ongoing projects and to invest in new initiatives, for example Quality Improvement.

Prof Neil Sheerin
Honorary Treasurer
The Renal Association
Treasurer’s Report

Renal Association Income 2015

- Bank Interest Received: 0.57%
- Bursary Income: 1.69%
- Meet Income - Registration: 23.54%
- Consultancy and Other Income: 25.78%
- Subscriptions - Corporate: 16.16%
- Subscriptions - Members Current Year: 30.28%
- Total: £296,000,00

Renal Registry Income 2015

- Other Income: 1.44%
- Bank Interest: 0.59%
- Project Fees: 0.17%
- Capitation Fee: 78.76%
- Grants: 21.26%
- Total: £1,750,970

Renal Association Expenditure 2015

- Bank Charges & Interest: 0.55%
- Other Expenses: 8.73%
- Electronic Communications: 7.43%
- Secretariat Fees: 44.75%
- Awards and Bursaries: 6.86%
- Trustee and Committee Expenses: 2.06%
- Meetings: 59.22%
- Coalition Membership Fees: 0.00%
- Total: £236,314.32

Renal Registry Expenditure 2015

- Grant Allocations: 0.92%
- Depreciation: 0.45%
- Meeting Room Costs: 3.77%
- Office Overheads: 2.31%
- Postage/Sundries: 0.94%
- Staff Training and Development: 0.85%
- IT Costs: 14.29%
- Staff Salaries: 6.21%
- Legal and Professional Fees: 11.82%
- Staff Salary Costs: 58.44%
- Total: £2,167,551
Awards and Bursary Winners 2015

Renal Association awards and bursaries are annually available to all members.

Award and Bursary Winners 2015
Renal Association awards and bursaries are annually available to all members.

AEG Raine Award
The Raine Award was established in memory of Tony Raine, Professor of Renal Medicine at St Barts, following his tragically early death in 1995. This prestigious annual award is made to a relatively junior investigator (usually 35 years of age or less) who has made a significant contribution to renal research, especially through presentations made at the Renal Association annual meeting. In 2015 the AEG Raine Award was awarded to James Fotheringham - Long breaks and disappearing PD catheters: lessons from linking UK Renal Registry data.

Lockwood Award
These were established in memory of the late Dr Martin Lockwood, a distinguished investigator and active member of the Renal Association, who died in 1999. They are the successor to the Milne-Muehrcke award. Its aim is to help Association members present work at the American Society of Nephrology and combine this with a visit to a collaborating laboratory or clinical nephrology unit in the USA. In 2015 the Lockwood Award was presented to Adrian Woolf.

AMGEN Bursaries
In 2015, 10 Amgen Bursaries were awarded to the higher scoring Renal Association member abstract applicants.
- Edwin Wong
- Andrew Streets
- Vishal Nangalia
- Emma Watson
- Nadia Sarween
- Ingi Elsayed
- Emily McQuarrie
- Emma Montgomery
- Sokratis Stoumpos
- Roslyn Simms

Walls Bursaries
These bursaries were established in memory of the late Professor John Walls, President of the Renal Association 1995-1998, who died in 2001. Their aim is to help Renal Association members to spend short periods (e.g. weeks or months) at other centres, generally outside the UK, to learn new laboratory techniques or gain new clinical skills. In 2015 the Walls Bursaries were awarded to Amy Jayne McKnight and Neeraj Dhaun.

Medical Student Elective Bursaries
The Renal Association awards bursaries each year to medical students undertaking electives which include a significant renal component, either clinical or research. Awarded in 2015 for the following year:
- Deborah Aldridge
- Jennifer McNeill
- Louis Evans
- Michael Adair
- Patrick McMullan
- Rebecca Hardman
- Sugeeta Sukumar
- Nicholas Cereceda

Please visit www.renal.org for more information.
Corporate Members

Amgen is committed to unlocking the potential of biology for patients suffering from serious illness by discovering, developing and delivering innovative human therapeutics. This approach begins by using tools like advanced human genetics to unravel the complexities of disease and understand the fundamentals of human biology. Amgen focuses on areas of high unmet medical need, leveraging its expertise in biologics manufacturing to strive for solutions that dramatically improve people's lives. A biotechnology pioneer since 1980, Amgen has grown to be one of the world's leading independent biotechnology companies, reaching millions of patients around the world. For more information visit www.amgen.co.uk

Janssen is part of Johnson & Johnson, the biggest diversified healthcare company in the world and the largest single investor in life sciences in the UK. We are driven by our J&J Credo, which inspires us to go to extraordinary efforts to achieve the best possible outcomes for patients. Put simply, our ambition is to make a meaningful difference.
New Members

Dr Hassan Al – Zaved
Dr Tariq Aljemmali
Dr Inji Alshaer
Mr Amel Ahmed
Mr Imran Amwar
Dr Yasser Al-Mula Abed
Dr Usha Appalsawmy
Dr Terrina Abd Rahim
Dr Wendy Baird
Dr Matthew Butler
Dr Katherine Bull
Miss Danielle Creme
Dr Jonathan Campbell
Dr Jiehan Chong
Dr Mark Davies
Mrs Harriet Douthwaite
Miss Rebecca Evans

Miss Giulia Furini
Dr Natalie Finch
Dr Alessia Florentino
Dr Jordina Gorro Caelles
Dr Wesley Hayes
Dr Eadaoin Hannon
Dr Aileen Helps
Ms Barnaby Hole
Mr Rishab Kapoor
Dr Declan Keenan
Dr Ajaya Kumar Dhakal
Dr Simon Lines
Dr Ian Logan
Dr Rupert Major
Dr Kiruthikka Murugan
Dr Aesha Mohammedi
Dr Joseph Newton

Dr Vishal Nangalia
Dr Chrysoula Pipili
Dr Venkata Rukmini Latha Gullapudi
Dr Ravindra Rajakariar
Dr Ben Reynolds
Dr Alastair Rankin
Dr Sujit Saha
Dr Tina Thekkekkara
Dr Pratima Verma
Dr Wing Wan Winnie Chan
Mrs Harriet Williams
Dr Nicholas Ware
Dr Victoria Weir
Mr Stories Xenophontos
Dr Norica Zimmer
Dates for your Diaries

Advanced Nephrology Course
Corpus Christi College, Oxford
Tuesday 3rd to Saturday 7th January 2017

UK Kidney Week
ACC, Liverpool
Monday 19th to Wednesday 21st June 2017
Notes