

June 2016

Dear Colleagues,

I hope to see you all next week at the **UK KIDNEY WEEK CONFERENCE 2016, 7th-10th June 2016 in the ICC, Birmingham** - the conference theme is "Innovation for better care: improving kidney care through quality research and team working" and I hope that everyone will enjoy the excellent programme and the fantastic speakers lined up - look them up here at <http://www.ukkw.org.uk/programme/>

The **Kidney Quality Improvement Partnership (KQuIP)** will formally launch at UK Kidney Week on **Wednesday June 8 at 11.45am in room 11, at the ICC in Birmingham** - please come along and get involved in this dynamic network which aims to improve the lives of people affected by kidney disease by improving the quality of care service across the UK - reducing unwarranted variation, improving patient outcomes and sharing good practice- the more people get involved, the more successful this will be.

Don't forget to come along to **Hall 1 on Thursday 9th at 14.15** to participate in the **UK National Renal Research Strategy Implementation Session** - your voice, your ideas and your priorities need to be heard! Copies of the UKRRS are available at the UKKRC exhibition on stand D12 and can also be accessed by clicking [here](#).

Please don't stay out too late on Wednesday so you can get up early on **Thursday 9th** to take part in the **Kidney Research UK 5K Fun Run** - registration opens at 6am with a prompt 6:30am start time. I'm very sorry it is such an early start, but with such a packed programme any other time takes delegates away from the industry sponsored symposia (on which we depend for sponsorship and support to help to keep registration fees down) or from the conference itself - also the traffic is better then!! Don't be shy- I guarantee everyone can run faster than I can so you won't be the slowest- it's not about **WINNING** or being **VERY FAST** it's about **TAKING PART** !! Entry is only £10 and you will receive your very own Kidney Research UK t-shirt to run in on the day. Register now at www.kidneyresearchuk.org/kidney-week-fun-run

Programme highlights include these Renal Association named lectures:

- **Liz Lightstone, Professor of Renal Medicine, Imperial College London**, will give the Chandos Lecture "Pregnancy and kidney disease: the 3 Ps" at 1645 in Hall 1, Wednesday 9th June
- **Eoin McKinney** will give this year's Raine Lecture entitled "Better off sick and tired: T cell exhaustion and outcome in autoimmune disease" at 0845 in Hall 1, Thursday 9th June
- **Adrian Woolf, Professor of Paediatric Science, University of**

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Manchester will give the De Warden Lecture "Kidney and urinary tract malformations: from the clinic to understanding molecular mechanisms and envisioning novel therapies" at 1615 in Hall 1, Thursday 9th June

- Claire Sharpe, Clinical Senior Lecturer and Honorary Consultant in Renal Medicine, King's College London and King's College Hospital, London, will give the Osman Lecture "New therapeutic targets in renal fibrosis, how do we jump the barrier to clinical translation?" at 1400 in Hall1, Friday 10th June

Other news - NHS England announced last week that the Newcastle upon Tyne Hospitals NHS Foundation Trust is to be the specialist provider of a national service

for **Atypical Haemolytic Uraemic Syndrome (aHUS)**, which affects around 200 people in the UK with 20 to 30 new diagnoses every year. The use of Eculizumab in aHUS was pioneered at the Institute of Genetic Medicine in Newcastle, as the result of research led by Professor Tim Goodship, and you can read the press release from NHS England here <https://www.england.nhs.uk/2016/05/kidney-condition-a-hus/>

The Newcastle team will be writing to individual units to provide further information about the Expert Centre in due course. The referral process for new aHUS patients remains unchanged.

<http://rarerenal.org/clinician-information/haemolytic-uraemic-syndrome-atypical-a-hus-clinician-information/>

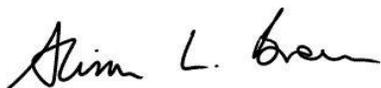
We are delighted to hear that the appeal against the **proposed NICE Kidney transplantation (adults) - immunosuppressive therapy Guideline-(Review of TA 85) [ID456]** has been successful :thanks to CVP Graham Lipkin who coordinated the RA input to the appeal with other kidney stakeholders, societies & patient groups to give a robust response to this - read the message from Graham below.

Next, many of you will already know about the BiCARB Study - Does oral sodium bicarbonate therapy improve function and quality of life in older patients with chronic kidney disease and low-grade acidosis? (<http://www.bicarb.org.uk/how-get-involved>)

The trial organisers want to survey current practice amongst UK nephrologists around bicarbonate prescribing, knowledge of the trial, willingness to randomise etc, so they have put together a very short on-line survey - please read their message below and click on this link to complete the BiCARB survey! <https://www.surveymonkey.co.uk/r/NTBYBRR>

And finally please read on below for other news - updates from Think Kidneys and from RaDaR, plus a link to a very useful letter for an update on the advice for male patients taking MMF who want to start a family.

See you all next week!



Alison Brown
Honorary Secretary

General Announcements

UK Renal Registry Update

- Think Kidneys AKI programme keeps on delivering - please [click here](#) to read the news
- Please [click here](#) to read the RaDaR Rare Disease

Mycophenolate and fathers to be letter

Please [click here](#) to read the letter regarding recommendations for men taking mycophenolate derivatives and

pregnancy following MHRA recommendations.

Expert Centre for aHUS

NHS England have announced that Newcastle will provide the Expert Centre for aHUS (<https://www.england.nhs.uk/2016/05/kidney-condition-ahus/>) from the 1st June 2016. The Newcastle team will be writing to individual units to provide further information about the Expert Centre in due course. The referral process for new aHUS patients remains unchanged.

<http://rarerenal.org/clinician-information/haemolytic-uraemic-syndrome-a-typical-ahus-clinician-information/>

Clinical practice guideline update

Please note that there is now 3 draft guidelines for review and can be found on the following [link](#).

1. Protein Energy Wasting in Chronic Kidney Disease Clinical Practice Guideline
2. Peritoneal Dialysis Clinical Practice Guideline
3. Post-Operative Care of the Kidney Transplant Patient Clinical Practice Guideline

Additionally the final version for Renal Association Commentary on NICE Guidelines on Tolvaptan for treating autosomal dominant polycystic kidney disease has been published and can be found at the following [link](#).

Successful appeal against proposed NICE Kidney transplantation (adults) - immunosuppressive therapy Guideline-(Review of TA 85) [ID456]

This final appraisal determination caused serious concerns amongst the renal community recommending an overly restrictive use of post transplant immune based on limited evidence. This would have required a substantial change in current practice.

The Renal Association in a coordinated an appeal with other kidney stakeholders, societies & patient groups and presented a considered response to the Appeal Panel who met on 30 March 2016 to consider the appeals lodged against the Final Appraisal Determination (FAD) for this appraisal. **The appeal was upheld based mainly on the lack in clarity of the scope of the guidance.** Unusually the outcome was that the appraisal should be 'remitted back to the Appraisal Committee to reconsider. The Committee must take all reasonable steps to address.

ISN Fellowship Program - Advice for Applicants and Hosts in the United Kingdom

Please [click here](#) to read the advice.

Five must-dos at UK Kidney Week

If you are attending UK Kidney Week 2016 from 7-9 June at the ICC in Birmingham, Kidney Research UK has five must-do activities for you to get your teeth into:

1. Visit us at our stand (E10), where you can find out more about our grants programme, including the newly relaunched [Allied Health Professional Fellowship](#) and take away armfuls of literature for you and your patients.
2. On Thursday 9 June you can meet our Birmingham-based Peer Educators at our stand (E10) and find out about the Acceptance, Choice and Empowerment (ACE) project in which our Peer Educators enable patient to make choices about their dialysis treatment options.
3. Join the panel discussion on the Implementation of the [UK Renal Research Strategy](#), launched by the UK Kidney Research Consortium. This takes place in the Hall 1 Auditorium, 14:15-15:45 on Thursday 9 June. Hear about the new strategy and pose your questions from the floor.
4. Put on your running shoes and kick start your Thursday morning with a 5K morning fun run outside the ICC, and help raise more funds to support vital kidney research. Registration opens at 06:00 for a prompt 06:30 start! Avoid the queues and register now through the [Kidney Research UK website](#).

5. Join us on our stand (E10), late morning and over lunch on Friday 10 June and 'Meet the PIVOTAL' team. Come along and chat to Professor Iain Macdougall, Trial Manager, Claire White and some of the PIs and research nurses from the 50 participating sites to hear firsthand about running a renal clinical trial.

Bicarb survey

As part of our ongoing NIHR-funded work, we are conducting a UK-wide survey of nephrologists to gauge current practice on treating metabolic acidosis in advanced chronic kidney disease. This work complements the ongoing BiCARB trial, and will help to place the results of the BiCARB trial in context, as well as helping us to understand current drivers and barriers to recruitment.

I would be very grateful if you could spare two minutes of your time to complete our (very short!) online survey; the link to the survey is: <https://www.surveymonkey.co.uk/r/NTBYBRR>

With thanks for your help

Dr Miles D Witham

Lead Investigator, BiCARB trial (www.bicarb.org.uk)

KQuIP counts down to launch

Kidney Quality Improvement Partnership - KQuIP is a dynamic network which aims to improve the lives of people affected by kidney disease by improving the quality of care service across the UK - reducing unwarranted variation, improving patient outcomes and sharing good practice.

This week saw 100 people meet to develop the scope and scale of KQuIP, looking at the barriers to change and quality improvement, the priorities for KQuIP and the outputs of the six workstreams. This was a design day, in readiness for formal launch at UK Kidney Week on Wednesday June 8 at 11.45am in room 11, at the ICC in Birmingham. On this day the website will also go live. Come and find us if you're at the event or visit the website soon after to find out more and get involved.

Management of adults with diabetes on the haemodialysis unit

Diabetic nephropathy remains the principal cause of end-stage renal failure (ESRF) in the UK, as elsewhere in the developed world, and patients with diabetes are forming a greater proportion of patients on maintenance hospital haemodialysis. These are a vulnerable group at high risk of adverse cardiovascular outcomes, which is the leading cause of mortality on this population.

Accordingly, people with diabetes and ESRF require improved delivery of care, in particular to overcome the organisational difficulties they face with their care split across a variety of organisations in primary and secondary care.

These national guidelines, the first in this area, are intended to support the practice of all healthcare professionals who care for this vulnerable group of patients, based on the best available evidence or on expert opinion where there is no clear evidence to inform practice. We aim to provide clear advice to clinicians caring for people with diabetes on maintenance haemodialysis and to encourage and improve education for clinicians and patients to promote patient empowerment and self-management.

Please [click here](#) to view the Joint guideline.

Transforming participation in CKD continues to work co-productively

A peer review event was held on May 10 bringing together teams of patients and staff in equal numbers from the 10 renal units in cohort 1. The aim of the event was to share the challenges and successes of implementing 'Your Health Surveys' across different patient groups and discuss ways in which teams could use this learning and experience to spread and embed further.

It was really exciting to see co-production in action throughout the day with patients and clinical staff working in ways to promote this. The event was planned by staff and patients from units in cohort 1 and patients introduced and facilitated each of the sessions on the day.

Overall the event was a great success with learning captured to share with units in cohort 2 as they come on board in the autumn.

Acute Kidney Injury Programme

Warning Stage Test Results for Acute Kidney Injury - measuring results one year on

It's now one year since implementation of the algorithm for warning stage test results for AKI was required in pathology lab information systems by NHS England in its [Patient Safety Alert of June 2014](#) - on standardising the early identification of an acute kidney injury.

Since then 90% of Trusts are reporting compliance with the safety alert, although only 54% are sending the relevant data through to the UK Renal Registry. The data are published monthly on the Think Kidneys website [here](#), and we will be taking steps to make contact with those who are not yet sending data to find out why and if there are specific problems we can help address. Best practice guidance on transmitting data to the UK Renal Registry is published on the Think Kidneys website along with other helpful resources for clinical biochemists [here](#).

Transforming Participation in CKD Programme

Patient Reported Experience Measures for Renal Services - PREM

The UK Renal Registry (UKRR) and British Kidney Patient Association (BKPA) have developed a national strategy for an annual PREM Survey for all renal units to take part in. The survey comprises 43 questions and is currently a hard copy survey for renal patients. The plan is that this will be an online survey by next year.

The survey has been developed by members of the Measurement Workstream for the Think Kidneys - Transforming Participation in Chronic Kidney Disease Programme and has had input from patients from the kidney charities such as the National Kidney Federation, BKPA and the UKRR Patients Council.

Recognising the patient voice should be at the heart of quality improvement, the pilot is the first stage in making sure renal patients' views and experiences have an impact on how services can change to bring about better experiences and outcomes, improve a patient's quality of life, and improve value and reduce unwarranted variation in service.

The national PREM strategy and data collection aims to:

1. Facilitate benchmarking of kidney patient experience
2. Inform service improvement for individual renal units

This first annual survey will start in June 2016 and we are currently pulling all the resources together that units will need to enable them to take part. Unit results will be available mid-October and a national report will be published on the UKRR website in November 2016. In subsequent years PREM will be run in April with results available in October.

PDI Subscription Special Rates: Save 25%

Established in 1980, [Peritoneal Dialysis International \(PDI\)](#), the official journal of the [International Society for Peritoneal Dialysis \(ISPD\)](#), is the premier resource for nephrologists, nurses and fellows practicing PD throughout the world. [PDI](#) is published bi-monthly, plus special supplemental issues, in Print and Online format.

To subscribe to PDI for 2016, at our special discounted rate, please [download our subscription form](#).

E-mail: subscription@multi-med.com

Allied Health Professional Fellowships 2016

Kidney Research UK is pleased to re-introduce a career development award that supports allied health professionals and nurses to undertake a renal research study and obtain a higher degree (Masters, DPhil or PhD). The closing date is 5pm on 29 July 2016 and funding decisions will be communicated in December 2016. Visit the [website](#) for more information.

Fellows Day

An impressive line-up has been confirmed for Kidney Research UK's 16th annual Fellows Day taking place on 8-9 September at Murray Edwards College, University of Cambridge. Distinguished guest speakers include:

- Ms Lorna Marson Reader in Transplant Surgery and Hon. Consultant Transplant Surgeon, University of Edinburgh, speaking on "Factors affecting cold ischaemic time, the impact of the virtual cross match and the management of antibody mediated rejection"

- Dr Marcello Tonelli Associate Vice Principal (research) and Senior Associate Dean (Health Research) University of Calgary, Canada, speaking on "Patient-centred kidney care"
- Friedo Dekker, Professor of Clinical Epidemiology, Leiden University Medical Center, The Netherlands, speaking on "Clinical Research in Nephrology - ins and outs"

Free to attend, the event is a fabulous opportunity to hear about Kidney Research UK researchers' findings and to network with some of the best minds in renal research. Those who hold or have held a Kidney Research UK career award are requested to attend, and those involved in our other grants and programmes are also invited. There may be the opportunity for health and research professionals involved or interested in renal research to attend, subject to availability.

To view the full programme and to book your place, visit our [website](#).

State of the art microscopy brings BK virus into focus

The work of a Kidney Research UK funded scientist has made some vital advances in helping to understand a virus which can cause kidney transplants to fail. A paper written by Dr Andrew Macdonald, Associated Professor in Virology, and his colleagues at the University of Leeds, on their discoveries concerning the BK polyomavirus has been published in the prestigious academic journal *Structure*. Read more [here](#).

ISN and UK RA International Committee initiative

The ISN is now offering free ISN membership to all trainees under the age of 37. This is a generous offer, and comes with no strings attached. The ISN of course is responsible for Kidney International (so access to the journal will be available through the ISN Membership) as well as discounted registration for future ISN conferences. It would be good to see a full house UK trainee turnout if we can.

Please see (from the [ISN webpages](#)) :
Member in Training (FREE)

Trainees in nephrology are encouraged to apply for ISN Member in Training. Members receive all member benefits except print copies of Kidney International. All other benefits apply. Eligible individuals must submit an online application.

Advisors/Instructors/Professors/Supervisors of trainees in nephrology wishing to apply for In-Training Membership for their trainees can submit their applications using a dedicated application form. If submitting multiple applications, please fill in separate forms for each applicant, [click here](#) to download the application form.

Professor David Goldsmith and Dr Weng Oh

Courses, Meetings & Events

Masterclass for Nephrologists on how to develop as a renal clinical researcher (with an initial focus on renal commercial NIHR portfolio studies)

7 June 2016, 11:15- 12:45

Room 101 1st Floor, Library of Birmingham, Centenary Square, Birmingham, B1 2ND

Under the auspices of the NIHR and Kidney Research UK, we would like to draw your attention to a new and somewhat experimental event at the start of UK Kidney Week. This will take the form of a Masterclass, targeted at young (as well as not so young!) budding clinical researchers, who would like to develop a clinical research portfolio, using recruitment to commercial studies as an initial means to achieve this.

Nationally, there is increasing interest in commercial NIHR portfolio studies, and our aim is to make the UK an attractive stage for companies to come to with innovative therapeutic agents and clinical trials. There is already considerable experience from various researchers up and down the country on delivery of commercial studies, and the Masterclass will take the form of a workshop investigating various strategies for becoming an investigator in a renal commercial portfolio study, as well as providing a toolkit to ensure successful delivery. Strategies that will be discussed include how to overcome the various bureaucratic processes involved in study set-up, how to make this work for you financially, recruitment to studies, retention of patients in studies,

which responsibilities are for the investigator and which are for the research nurse, common problems and pitfalls, etc.

For more details, please feel free to e-mail Professor Iain Macdougall (ia.in.macdougall@nhs.net) or Professor Phil Kalra (philip.kalra@srft.nhs.uk), and to register for this meeting, please e-mail Hilary Prais (Hilary.Prais@srft.nhs.uk).

Please also spread the word around anyone in your department who you feel might be interested in this event, which is free-of-charge and does not require registration for UK Kidney Week.

UK Kidney Week

07-10 June, 2016

ICC, Birmingham

"Innovation for better care - improving Kidney Care through quality research and team working"

Jointly hosted with the Renal Association and British Renal Society. Early Registration Deadline is the 15th April [click here](#) to register.

Details of the event can be found [here](#).

Frontiers in Transplantation Clinical Excellence through Innovation 2016

08-09 September 2016

Kings College London

Details of the event can be found [here](#).

Renal Pathology Society Symposium Cologne 2016

25 September 2016

Cologne Germany

Details of the event can be found [here](#).

Advanced Nephrology Course

03-07 January 2017

Corpus Christi College, Oxford

Details of the event can be found [here](#).

Further Events for Your Diary

Please [click here](#) to view the calendar of events on the RA website.

If you have any ideas or would like to include an article or event in eNews, please contact The Renal Association Secretariat on 0870 458 4155 or renaleneeds@mci-group.com.