Welcome to November enews!

We are delighted to announce that James Fotheringham (Specialist Registrar at Sheffield Kidney Institute) is the winner of this year’s Raine Award, and the winner of the Lockwood Award is Jonathan Wong (Renal Research Fellow in Haemodialysis at the Lister Renal Research Unit). Very many congratulations to them both, and commiserations to unsuccessful applicants (no Walls Bursaries were awarded this year).

This month’s updates from the UK Renal Registry are below - please do read all the updates, but especially the update on planned timelines for the UK Renal Data Collaboration (UKRDC) - pilots of the new data warehouse should start for some units in January 2015, and the dataset should be embedded in systems for all units by January 2016 - and also the plans to collect data on all patients having acute dialysis or plasma exchange in a renal unit, from January 2015.

We are also pleased to announce that our new improved Guideline viewing system has been launched. The first guideline to be posted in the new format, which we hope you will find easier to search through, is the TREATMENT OF ACUTE HYPERKALAEMIA IN ADULTS. We are very grateful for the hard work of Annette Alfonzo, Consultant Nephrologist, and Jasmeet Soar, Consultant in Anaesthesia & Intensive Care Medicine, who led the guideline writing group.

We would like to remind you all that membership renewals will be due in January 2015. Further information regarding the membership renewal process will be distributed in the coming weeks.

And finally - abstract submission is now open for the 52nd congress of ERA-EDTA-RA meeting, 28th - 31st May 2015.

This is a great opportunity for everyone to attend this fantastic European meeting which will be held in the ExCeL Congress Centre to the East of London not far from London City Airport, the Olympic Site and Canary Wharf. Hotels will be available within the area and central London. ExCeL can be reached easily by public transport.

The Renal Association has been delighted to work with the ERA Scientific Programme Committee to put together a meeting that will showcase both UK and pan-European strengths in renal sciences and clinical research. We have a range of excellent invited lectures and it is a great pleasure to see the UK strongly represented in these. We have chosen to badge certain sessions with RA leadership to focus on certain areas of work in the UK; these include sessions on Acute Kidney Injury, Rare Renal Diseases, Haemolytic Uraemic Syndrome and T-cell targeted therapies in glomerulonephritis. The programme really does have something for everyone, so please get the dates in your diary and your abstracts ready for submission!!

For lots more information and updates below please do read on!

With best wishes
General Announcements

**UK Renal Registry Update**

UK Renal Registry - UK Renal Registry 2014 Informatics Meeting [click here] to read more.

UK Renal Registry - The UK Renal Registry’s Benefits Case Study of linkage between UK Renal Registry and the Health and Social Care Information Centre [click here] for more information

UK Renal Registry: Kidney Research UK Research Grants Committee (RCG) Members Required [click here] to read more

UK Renal Registry: Kidney Research UK Fellowship Grant Round Call For Applications [click here] for more information

**Overview of Development at the Renal Registry and Impact on Renal Units**

Dr Fergus Caskey, Medical Director of the UK Renal Registry, gives an overview of the current major developments at the Registry which will impact on all renal units. As well as the UK Renal Data Collaboration, which will completely change the way data are collected from renal units, he talks about the Clinical Reference Group and Renal Association requirements to report acute dialysis & plasma exchange and CKD4 & 5, plans to collect data on AKI direct from hospital laboratories and changes to research fellow posts at the Registry. Please see the attached report for further details.

**The New UK Renal Registry Website**

The UK Renal Registry (UKRR) has launched its new refreshed website designed by Virtual Pudding. The site includes up to date information on the UKRR, as well as news, forums and events features. We have also incorporated data and resources sections, which will allow users access to a wealth of information.

Please come and view the new website at [www.renalreg.org](http://www.renalreg.org). If you have any questions or comments then please direct them to Ms Stephanie Shearn, Stephanie.shearn@renalregistry.nhs.uk.

If we have sufficient interest we would like to run a virtual tour of the new website via WebEx. If you would like to attend please email Stephanie.Shearn@renalregistry.nhs.uk. Please note class sizes will be capped at 25 attendees per session.

**The call to apply for Kidney Research Fellowships is now open**

These grants are personal awards to researchers, both non-clinical and clinical, at key stages of their careers. The funding provides support for them to gain stronger expertise in renal research, developing their research careers in established UK institutions and, where relevant, to attain a higher degree. We are committed to supporting the future generation of renal research experts.

Further details are available at [http://www.kidneyresearchuk.org/file/August-2014-Fellowship-open-call.pdf](http://www.kidneyresearchuk.org/file/August-2014-Fellowship-open-call.pdf) and the closing date for applications is Friday 21st November, 2014.

**Kidney Research**

Kidney Research UK Fellowship Grant Round Call For Applications...

The Kidney Research UK Fellowship Grant Applications process is now open. If you or someone you know is looking for funding and falls within the eligibility criteria outlined below, please do not hesitate to contact us for more information.

Kidney Research UK; Funding research to save precious lives.
Kidney Research UK wishes to support research that is relevant to the understanding of the kidneys and urinary tract and the disease processes affecting them. There is a particular desire to support work leading to improved management, treatment and prevention of kidney disease and its complications.

**Senior Fellowships (non-clinical)**

This award supports non-clinical scientists who have conducted independent research in the renal field and wish to build on their history and reputation in this field, deepening their knowledge and experience. Ordinarily candidates will be expected to have a significant publication record in their chosen field. We regret that currently, Senior Clinical Fellowships are not offered by the charity.

**Training Fellowships (clinical)**

This award supports medical graduates to specialise in the renal field thereby expanding the levels of expertise in kidney research and treatment. Support is available for up to three years. It is expected that the candidate will register for a higher degree. The salary will be paid at the candidate’s current level, and allowance for consumables and higher degree fees at the ‘home’ rate is included.

**Post-Doctoral Fellowships (non-clinical)**

Supports experienced post-doctoral scientists to specialise in the renal field thereby expanding the levels of expertise in kidney research. Appropriate for non-clinical graduates who hold a PhD or equivalent degree and have at least two years’ post-doctoral experience. Awards are made for a period of up to three years. The salary will be based on the appropriate university scale with an allowance for consumables.

**Applications:**

All candidates must be resident in the United Kingdom and both the project and employment must also take place in a UK university. Applications must be submitted on the standard Kidney Research UK application forms, which are available here: www.kidneyresearchuk.org/research/application-forms

Closing date for all applications is 17:00hrs on 21st November 2014.

For further information, please contact: Tel: +44 (0) 1733 367835/6 or email grants@kidneyresearchuk.org

**Royal College of Physicians' survey of members and fellows on assisted dying**

The Royal College of Physicians London are currently surveying their members on the topic of assisted dying. If you are a member of the RCP you should have received a communication (either by email or by post) inviting you to respond to the survey. We would encourage you to respond to this survey as it is essential the result is informed by a broad range of physicians from across all specialties.

If you have not received details of the survey please contact RCP London on: enquiries@rcplondon.ac.uk or 020 3075 1539.

**NICE have issued draft guidance on the use of eculizumab for aHUS**


1.1 Eculizumab, within its marketing authorisation, is recommended for funding for the treatment of atypical haemolytic uraemic syndrome, only if all of the following arrangements are in place:

- coordination of the use of eculizumab through an expert centre;

- monitoring systems to record the number of people with a diagnosis of atypical haemolytic uraemic syndrome, the number of people who receive eculizumab, and the dose and duration of treatment for these people

- a national protocol for starting and stopping eculizumab for clinical reasons

- a research programme with robust methods to evaluate when stopping treatment or dose adjustment might occur.

1.2 The budget impact of eculizumab for treating atypical haemolytic uraemic syndrome is uncertain but will be considerable. NHS England and the company (Alexion Pharma UK) should consider what opportunities might exist to reduce the cost of eculizumab to the NHS.

NICE has not yet issued final guidance to the NHS; these decisions may change after consultation. Consultees, including the company, healthcare professionals, patient/carer organisations and members of the public are now able to comment on the preliminary recommendations which are available for public consultation until midday on Thursday, 25 September. Comments received during this consultation will be fully considered by the Committee at its next meeting in October and, following this meeting, the next draft guidance will be issued. Comments can be posted on the NICE website at https://www.nice.org.uk/guidance/indevelopment/GID-ATYPICALHAEMOLYTICURAEMICSYNDROMEAHUSECULIZUMAB/consultation.
In the meantime, the current interim commissioning arrangements by NHS England in line with the "Clinical Commissioning Policy Statement: Eculizumab for atypical haemolytic uraemic syndrome" will remain in place. Information about how to access the interim national aHUS service is available at [http://rarerenal.org/clinician-information/haemolytic-uraemic-syndrome-atypical-ahus-clinician-infor](http://rarerenal.org/clinician-information/haemolytic-uraemic-syndrome-atypical-ahus-clinician-infor)

**Royal College of Physicians' survey of members and fellows on assisted dying**

The survey consists of four short multiple choice questions and the option to write a more detailed response. All individual responses will be treated in strictest confidence and all comments will be anonymised before being published. Attached to this email are the substantive questions asked in the survey and the guidance document sent to all member and fellows setting out the background.

**Renal Specialist Certificate Examination - Question Writing Group**

As a consequence of natural turnover we are looking for a few additional persons to join the Question Writing Group. Members of the QWG need to be either consultant nephrologists or to have passed the Renal SCE. The commitment is one 2 day meeting per year, usually in September, and office/home time to draft questions. Participation provides excellent CME. Potential new question writers will need to attend a training session at RCP London on 9 February 2015.

If you are interested in joining the Question Writing Group please submit a brief CV to kate.beaumont@mrcpuk.org

**Call for grant applications**

As part of its aims, Vasculitis UK supports research into the causes and effects of vasculitis, into improvements in the diagnosis of vasculitis and into treatment of people suffering from different types of vasculitis. It now seeks to receive applications for projects lasting less than 3 years, with a strong patient focus and which will result in patient benefit in the medium term. Grants will only be awarded for funding up to a maximum of £50,000 over the period of the grant. Collaborative working for applications to this call is actively encouraged.

All applications for support received by Vasculitis UK are subject to peer review under the auspices of the Scientific Advisory Board (SAB). Relevance to the aims of the Vasculitis UK and medical/scientific excellence are the primary criteria by which all applications will be judged.

Full details of how to apply, guidelines for applicants and application forms can be downloaded from our website www.vasculitis.org.uk/research. Applications should be received no later than 5.00 p.m. on Friday 30th January 2015. Decisions on the successful applications are expected to be reached by the end of April 2015. For any queries related to an application for funding please email research@vasculitis.org.uk

**Kidney Research UK’s 2013 Patient Survey Results**

Preventing and curing kidney diseases should be research priority, patients tell us.

The results from the 1,000 patients responding, revealed that around half feel that future renal research should focus on finding cures for, and preventing kidney diseases. A further 27% feel that research into the causes of specific kidney diseases and early detection of kidney diseases should be prioritised.

37% of the patients who responded to the survey were kidney transplant recipients with the remainder being patients with early stage kidney disease, dialysis patients, patients diagnosed with chronic kidney disease (CKD) and patients diagnosed with a different type of kidney disease (not CKD).

To read about the results of our patient survey in full, visit www.kidneyresearchuk.org/patient-survey-2013-results. If you’d like to request a hard copy of the patient survey results booklet, please e-mail patients@kidneyresearchuk.org.

Kidney Research UK's 2013 patient survey, which builds on a similar survey in 2007, was conducted to set out research priorities for the charity over the next five years. Patients from across the UK were invited to take part and surveys were sent to all dialysis units in the UK, where staff then distributed materials.

**New educational resources for kidney patients**

When people are told their kidneys are failing and they need renal replacement treatment such as dialysis or a transplant, it can be a difficult and daunting time. Kidney Research UK has developed two different types of resource to provide information and support to help make an informed decision about which type of dialysis treatment is right for them.
This comprehensive booklet helps patients understand more about kidney disease, gives information on each different treatment option available, and enables them to think about which treatment might fit best into their lives. The booklet was developed through a Kidney Research UK-supported study, by the Yorkshire Dialysis Decision Aid (YoDA) research team (Hilary Bekker, University of Leeds, Andrew Mooney, Martin Wilkie et al) which included decision scientists and health service researchers from the University of Leeds, as well as nurses, doctors and patients from the NHS Hospital Trusts at Leeds, Sheffield, Doncaster, Bradford, York, Hull, and North Staffordshire. The team developed and validated this booklet with the involvement of patients, carers and healthcare professionals and the layout and content has been very carefully planned with various prompts guiding people through the booklet.

Research Networks Update

In this issue of the Renal Association eNews we would like to highlight a study that has been successful in recruiting a large number of patients over a relatively short period of time. Indeed, the ACQUATIK (Acute Care QUAliTy in chronic Kidney disease) Study is one of the highest recruiting studies on the NIHR portfolio. It uses a unique methodology that may form the blueprint for future studies conducted in the interface of primary and secondary care, both in nephrology and in other fields.

The ACQUATIK study is a prospective cohort study in the UK patients with and without CKD (eGFR <60 ml/min/1.73m2), as classified by their GP, which will compare death, hospital admissions, treatment received for chronic conditions, cardiovascular disease prevention measures, etc. It aims to minimize the resources and effort that are required to conduct good quality research at the interface of primary and secondary care. Furthermore, it also aims to greatly reduce the burden on patients who totally altruistically agree to participate in research. The study uses electronically held records (EHR) and combines them to form a dataset of joined-up patient journeys through primary and secondary care. The patients are approached when they are admitted to hospital and consented by a secondary care team and asked a handful of very basic demographic questions and information that is not usually routinely recorded. Pre-admission data is collected from primary care HER, admission data is collected from hospital HER and long-term follow-up data is prospectively collected from the Hospital Episodes Statistics database. Extraction of primary care data relies on insertion of a specially commissioned READ code, which will have been sent to along with a signed patient consent form.

ACQUATIK is the first phase in a process. It is an observational study in 4000 patients to be recruited over a 2-year period. So far recruitment is ahead of schedule with 2400 patients recruited in the first year from both the Queen Elizabeth and Birmingham Heartlands Hospitals. As the data are collated, the intention is to make sure that the processes and systems in place are robust enough and comply with all the necessary governance that would be needed for an interventional trial in the future. It is also the intention to ensure that the methodology is acceptable to all stakeholders. The response so far from patients has been phenomenal with the vast majority wondering why they had to give consent when they already assumed that this kind of data-sharing was already happening automatically. So far, most of the response from primary care has also been very positive.

Charlie Ferro, the CI of this study believes that the lessons learnt from this study and the feedback from patients and primary care physicians will help design future interventional studies that are not necessarily related to kidney disease. He says, 'We owe it to our patients and ourselves that meaningful and high-quality research be conducted in a resource efficient manner.'

The ACQUATIK (Acute Care QUAliTy in chronic Kidney disease) - NIHR CSP - Ref 132822. CI: Charlie Ferro - Charles.Ferro@uhb.nhs.uk.

- Indranil Dasgupta and Neil Sheerin, Communication Co-leads, Renal Specialty Group, NIHR CRN

ISN’s World Congress of Nephrology 2015

We would like to bring to your attention a very important deadlines not to miss for ISN’s World Congress of Nephrology 2015 (www.wcn2015.org).

Early Bird Registration Deadline: December 14, 2014

Take advantage of ISN’s special registration rates available only until December 14. You can save a lot of money and ensure yourself a pass to the Congress by registering at www.wcn2015.org/registration-home. All the registration information is available on the event website. You will also find information about the venue, accommodations, tours, satellite symposia, and the special social programs planned.
Developing a national Renal research Strategy (NRRS)

The Kidney Health: Delivering Excellence Report, published in October 2013, set out 16 ambitions for addressing the challenges in kidney healthcare. Ambition 15 is to establish a national strategy for kidney research. The renal community has now taken the lead on meeting this ambition with the formation of the National Renal Research Strategy Steering Group.

Your views are important!
There will be two phases of consultation, both before and following production of a first draft later this year, culminating in the final strategy document in 2015.

The NRRS Steering Group are asking individuals to consider the two questions below and E-mail their answers to: elainedavies@kidneyresearchuk.org

Q1. What is excellent about UK renal research?
Q2. What/how could we do better?

All responses will be presented to the NRRS Steering Group as part of this initial consultation process.

New educational resources for kidney patients

When people are told their kidneys are failing and they need renal replacement treatment such as dialysis or a transplant, it can be a difficult and daunting time. Kidney Research UK has developed two different types of resource to provide information and support to help make an informed decision about which type of dialysis treatment is right for them.

Please click here to read more about Dialysis: Making the right choices for you. The Dialysis Decision Aid Booklet and Dialysis Choices: What are the options?

Courses, Meetings & Events

Islet Transplantation Current Practice and Future Challenges
Friday 21 November 2014 Royal College of Physicians of Edinburgh -
Closing date for all bookings MONDAY 10 NOVEMBER 2014
Extended closing date to ensure everyone with an interest has an opportunity to attend.

Please click here for more information.

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 renalenews@mci-group.com.