

## COMING UP

- ◆ Our first patient focus group meeting will be taking place at the National aHUS service in October with patient representatives attending from all around the UK

**WE ARE STILL LOOKING FOR PATIENT REPRESENTATIVES FROM THE NORTH WEST OR THE MIDLANDS. IF YOU ARE INTERESTED PLEASE CONTACT US ON THE DETAILS BELOW. ALL TRAVEL AND ACCOMMODATION COSTS WILL BE MET**

- ◆ aHUS awareness day takes place on 24th September this year. Information on what is taking place can be found at

<http://www.ahusallianceaction.org/ahus-awareness-day-upcoming-24-september-2017/>

### CONTACT INFORMATION

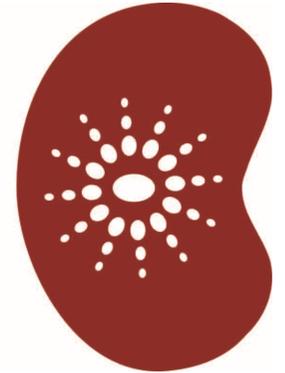
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# aHUS

ATYPICAL HAEMOLYTIC URAEMIC SYNDROME



Your quarterly newsletter from the National aHUS Service at the National Renal Complement Therapeutics Centre.

Issue 3 August 2017

Do you have access to e-mail?

If so would you consider receiving future newsletters electronically to assist us in reducing the costs of postage?

Let us know via our usual contact details

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Welcome to the latest edition of the newsletter of the National aHUS service.

Our biggest news is that our service website is now up and running



As well as information for clinicians about aHUS and C3G and how to refer patients for treatment with Eculizumab, there are dedicated pages of patient information and we would appreciate any feedback you have on them.

The all important web address is

[www.atypicalhus.co.uk](http://www.atypicalhus.co.uk)

## DO YOU USE THE HOMECARE INFUSION SERVICE FOR ECULIZUMAB?

HC Insight are currently undertaking a review of the service on behalf of Alexion Pharmaceuticals who fund this. They have designed a short online survey that they would like patients or carers of those who use the service to complete. The survey can be found at

<https://www.surveymonkey.co.uk/r/68QWQPQ>

## NURSING STUDY DAY

On 26th and 27th June, the National aHUS Service hosted its first study days for nursing staff with an interest in aHUS.

Over 20 nurses from across England attended the 2 day event. Speakers included staff from the National Service, colleagues with a wider interest in renal care and also an excellent patient representative.



Angela and Jo would like to thank Alexion pharmaceuticals who provided funding to enable the nurses to attend the study days. Hopefully this will be the first of many such events.



## NEWCASTLE BRIDGES WALK

On 11th June Newcastle's iconic quayside was a sea of purple as Kidney Research UK held its annual 7 mile walk across the bridges of the River Tyne. The event began in 2015 thanks to Keren Burdett, who's son, Jack, was diagnosed with aHUS (pictured).



Amongst the many adults and children who participated were those with kidney disease, transplant recipients and their donors and those walking in memory of loved ones. They were joined by a group from the National aHUS service and their 'willing' families (below).

If you would like to take part in next year's walk or similar events that take place in London and Glasgow then details can be found at



[https://  
www.kidneyresearchuk.org/  
get-involved/events](https://www.kidneyresearchuk.org/get-involved/events)

## MRC AWARDS

Two of our renal research fellows have recently been awarded prestigious Medical Research Council Training Fellowships that will allow them to undertake three years of funded research at the National Renal Complement Therapeutics Centre.

Dr Vicky Brocklebank is funded jointly with Kidney Research UK to investigate cases of aHUS that do not respond to Eculizumab.



Dr Kate Smith-Jackson will be undertaking work to probe the mechanism of disease using her world leading comparative model of aHUS.



## **RAINE AWARD 2017**

**We are delighted to announce that Dr Edwin Wong, Consultant Nephrologist at the National aHUS Service, is the recipient of this year's Raine Award.**

**The award is presented by the Renal Association, the professional body for nephrologists and renal scientists in the United Kingdom, and is given to the most outstanding junior investigator within this area.**



**Dr Wong's work centred around the complement mediated renal diseases aHUS and C3G. At the Renal Association's annual conference he delivered his Raine Award lecture 'Losing Control of Complement'.**

**Dr Wong is pictured receiving his award from Dr June Raine, the wife of Professor Tony Raine, in whose memory the award was established.**



**The Renal Association's annual conference, UK Kidney Week, took place from 19th—21st June in Liverpool. As well as Dr Wong's Raine Award lecture, other staff from the National aHUS Service gave poster presentations about their recent work.**

- ♦ **Dr Vicky Brocklebank presented her poster on rare genetic causes of non-response to Eculizumab treatment.**
- ♦ **Dr Patrick Walsh presented a case of a rare genetic disorder of red blood cells masquerading as aHUS.**
- ♦ **Specialist Nurse Angela Watt presented the results of our postal survey of aHUS patients in England (more information on this in the next newsletter).**