

SERVICE UPDATES

- * Monthly aHUS clinics will begin at the RVI in February. If you would like to meet with a consultant from the National Service to discuss your diagnosis or treatment then please ask your local physician to send a referral
- * Joanne has been busy designing new patient cards for both those at risk of aHUS and those on Eculizumab—they should be available soon
- * Our new website is currently in development and we hope to have it 'live' very soon. The website will contain useful information for both patients and clinicians about aHUS and other related diseases

CONTACT INFORMATION

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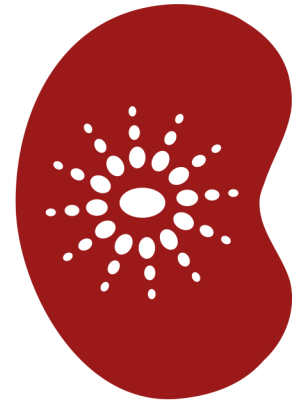
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aHUS



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WELCOME....

to the first patient newsletter from the National aHUS service.



The service is based at the Royal Victoria Infirmary in Newcastle upon Tyne and under a highly specialised service agreement with NHS England we share responsibility with local teams for the care of patients diagnosed with Atypical Haemolytic Uraemia Syndrome in England.

We plan to send out this newsletter on a regular basis to keep you up to date with what is happening at the National Service and in the wider world of aHUS.

Your feedback would be much appreciated—contact details for the National Service are on the back page.

ABOUT THE TEAM

Dr Sally Johnson—Consultant Paediatric Nephrologist

Professor David Kavanagh—Consultant Nephrologist

Professor Neil Sheerin—Consultant Nephrologist

Joanne Stout—Paediatric and Adult Specialist Nurse

Angela Watt—Adult Specialist Nurse

Jalibani Ndebele—Service Manager

Helen Nicholl—Senior Medical Secretary

URGENT—HELP REQUIRED!!!

Over the next few months we will be designing lots of new useful patient information including our website, patient cards and patient information packs. We would like to set up a focus group of patients who can look at these items before they are finalised and provide feedback. If you would be willing to help us with this then please get in touch using the contact details on the back page.



**We
Need
Your
Help
Please**

PATIENT SURVEYS

Thank you to everyone who took the time to respond to the patient surveys we recently sent out. Despite them arriving over the festive season we have already had a more than 50% response rate. Don't worry if you haven't yet returned your survey—there's still time!

Angela is currently putting together the data received from the results so far and we are looking to present the results to the great and the good of nephrology at UK Kidney Week in June. We'll also share the results here so keep an eye out.

**DO YOU HAVE AN
E-MAIL ADDRESS?**

**WOULD YOU BE
HAPPY TO RECEIVE
THIS NEWSLETTER
ELECTRONICALLY IN
THE FUTURE?**

**PLEASE LET US KNOW
AND WE'LL UPDATE
OUR E-MAIL LIST**

FUNDRAISING

As many of you will be aware, the patient charity aHUSUK has recently wound down following the successful campaign to get Eculizumab funded by NHS England. However, the good work does not stop there! The campaign has now joined up with Kidney Research UK under the banner 'Answers for aHUS'.

More information can be found at www.kidneyresearchuk.org/support-us/answers-for-ahus

