

## AND FINALLY

On behalf of all at the National aHUS Service we would like to wish you all a very Merry Christmas and a peaceful and prosperous New Year.



### CONTACT INFORMATION

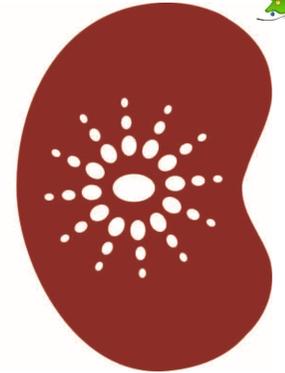
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# aHUS

ATYPICAL HAEMOLYTIC URAEMIC SYNDROME



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

Issue 4 November 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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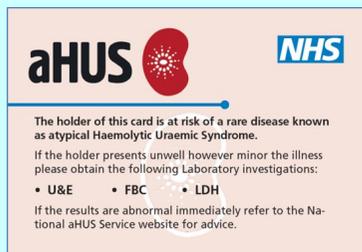
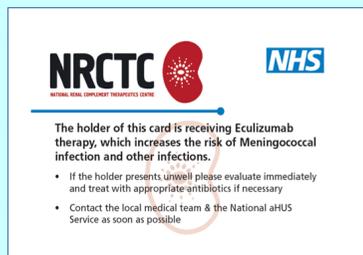


## WELCOME.....

....to the latest edition of the National aHUS Service Newsletter. We have had a busy few weeks at the service. Earlier this month we held our annual meeting with the specialist commissioners from NHS England and were delighted that some patient representatives were able to attend to provide feedback on our service. We also provided them with a draft copy of our annual report and hope to have the finalised version available in the near future for everyone to read.

On page 7 you will see the first of our patient stories—Hannah's aHUS story. We would like to hear more of your stories so if you would like to share them with others via this newsletter then please get in touch.

You may have seen that the service has designed its own patient alert cards. We have one card for patients already on Eculizumab and another for those at risk of developing aHUS. The cards are small enough to fit your wallet or purse and are waterproof and indestructible—we have tried! You can also write the contact details of your local team on them.



If you or any at risk members of your family would like the new cards then please contact the specialist nurses who will be happy to send them to you.

## HANNAH'S STORY

At 18 months I became ill with what my family were told was typical HUS. I had to have dialysis for around a month but my kidney function improved and I was able to come off dialysis but the paediatric nephrologists kept an eye on me throughout my childhood.

At the age of 18 I started my nurse training and around this time my kidney function started to decline. By the time I had finished my training 3 years later it was reaching the stage where I needed a transplant. My Mum had already begun the work up to donate a kidney to me and I had my transplant in December 2013.

My transplant worked really well for nearly 2 years but then my creatinine started to go up. A biopsy showed that I had lots of small clots in my kidney. My consultant spoke to the National aHUS Service and they agreed that they thought I had Atypical Haemolytic Uraemic Syndrome and should start on Eculizumab. I received the first dose 1 week later, in September 2015. My blood results returned to normal almost straight away but it was 4 months later before I began to feel better.

In September 2016 I discovered that I was pregnant. Because of the association between pregnancy and aHUS I had regular blood tests to monitor for any signs of a relapse and my dose of Eculizumab was gradually increased. Florence was born early at 29 weeks due to pre-eclampsia. She spent 54 days in the neonatal unit but is now home and has suffered no ill effects. I stayed on the increased dose of Eculizumab for another 4 months but have now returned to my usual dose.

Hannah has documented her journey on Youtube under the title 'Flossy and Me'. You can view it at

<https://m.youtube.com/watch?v=SVtyvIWa7Aq>

**Hannah, Jack and baby  
Florence**



## RESEARCH NEWS

The National aHUS Service is part of the National Renal Complement Therapeutics Centre—a fully integrated research, clinical, diagnostic and treatment centre for complement mediated renal diseases. It's an excellent example of the collaborative working that goes on between Newcastle University and the trust. The NRCTC opened in 2016 and the



team are already celebrating a number of key successes:



Dr Kevin Marchbank of the Institute of Cellular Medicine at Newcastle University has received funding from Kidney Research UK to investigate the trigger events that drive aHUS and also for a project entitled 'Testing the efficiency of new anti-complement therapies in a unique C3 gain of function model of kidney disease'.

Professor Claire Harris, also of the Institute, has also been awarded a grant from KRUK and the Northern Counties Kidney Research Fund to develop new blood tests that will be used to help assess suitability for clinical trials and monitor response to therapies.



## aHUS PATIENT SURVEY

Many of you will recall receiving a survey from the National Service at the end of 2016. The results were initially presented at the Renal Association's annual conference and at our recent patient focus group meeting. We have used them to guide development of the service in the first year. Here we summarise the main findings

- 55 responses received (46.2%)
- 81.8% of respondents were on Eculizumab
- 28.8% had a working kidney transplant and 7.6% were awaiting a transplant
- The majority of respondents had not been previously aware of the National Service and had not been offered the opportunity to meet with us
- Patients gained their information about aHUS from a variety of sources but the most popular were their local team or online
- Respondents typically wanted to know more about future developments and current research
- The most popular things that the service should provide were patient information packs (coming soon 😊) and newsletters

We hope you have already seen the difference in the service we have provided to our patients over the past year but we always welcome any further feedback. We would also like to thank those who took the time to return the survey at such a busy time of year.

## ASK THE EXPERT

In October we met with Professor Ray Borrow who is one of the country's leading experts on meningococcal disease. Prof Borrow kindly took the time to discuss some questions on the importance of meningitis prevention for patients on Eculizumab.

### **Why are patients on Eculizumab at an increased risk of meningitis?**

Eculizumab blocks a part of the body's normal immune response known as the complement system. Inhibiting its work can make you more prone to infection with some bugs. The most dangerous of these is the meningococcus which causes meningitis and/ or septicaemia.

### **What vaccinations are available to help prevent meningitis?**

Anyone who is treated with Eculizumab will receive either the Menveo© or Nimenrix© vaccinations. These protect against the A,C,W & Y strains of meningitis. In addition, we also recommend that all patients have the Bexsero© vaccination that protects against the group B strain.

### **What about children on Eculizumab?**

Children receive a vaccination against the group C strain at 12 months of age as part of their normal childhood immunisations. However, they should still have the ACWY 4 strain vaccination if they are started on Eculizumab. Some children may also have received Bexsero© as part of their vaccinations but it is still recommended for those who haven't.

### **How can I be sure that the vaccinations have worked?**

We recommend that you have a blood test taken about 4-6 weeks after your first vaccination to check that you have had a good immune response. Unfortunately we think that around 20% of patients will not have a full response to all of the strains. In those patients we would recommend that they have a booster dose of the vaccine.

We also know that response to the vaccine reduces over time so it is normal to need a repeat dose of the ACWY vaccination every few years.

## MENINGITIS PREVENTION

### **Why do I still need to take antibiotics?**

Although the vaccines are very effective they cannot guarantee that meningitis will occur and especially in a high risk group of patients. Therefore we recommend that all patients on Eculizumab should take antibiotics whilst they are receiving the drug and for 8 weeks after if the drug is stopped.

### **Have there been any cases of meningitis in aHUS patients?**

We are aware of 4 cases of meningococcal disease in the UK in patients on Eculizumab for aHUS. All the patients recovered from the illness. In 3 of those cases the patient was not on the recommended antibiotics. This is further evidence of the importance of taking the prescribed medications.

### **How would I know if I had meningitis?**

The most common symptoms of meningitis include a high temperature, feeling sick, irritability, headache and neck stiffness. Sufferers may have a blotchy rash that does not fade when a glass is pressed on it. However, it is important to note that not everyone will have all of these symptoms.

### **What should I or my family/friends do if we think I have meningitis?**

**YOU SHOULD SEEK MEDICAL ADVICE AS SOON AS POSSIBLE.** It is important to tell the doctors and nurses who are caring for you that you are on Eculizumab. The National Service produces a card that patients on the drug can carry which alerts healthcare professionals to the risks and tells them how to get advice.

### **Where can I find out more about meningitis?**

<http://www.atypicalhus.co.uk/ahus-2/useful-information/>

<https://www.nhs.uk/conditions/meningitis/>

<https://www.meningitis.org/>

