

Angela Watt, Specialist Nurse spoke about the work that has already been undertaken at the service with regard to patient involvement.

This stemmed from the survey sent out to patients in December 2016. Developments to date include

- Quarterly newsletter
- New patient cards
- Patient information on the website
- aHUS clinics
- Patient information packs –due to be sent out in the near future



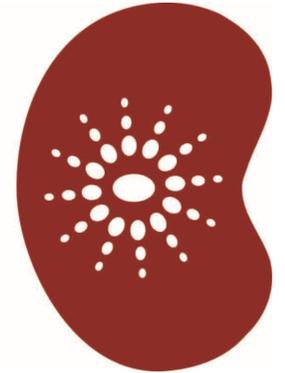
Joanne Stout, Paediatric Specialist Nurse, spoke to the group about the team's upcoming visit from NHS England. As a specially commissioned service, the team meets with the commissioners on an annual basis. We also have to produce an annual report. Once reviewed by NHS England this report will be available to view online.

We are very grateful that a number of those people attending the meeting agreed to come and represent the patient population at this meeting.



aHUS

ATYPICAL HAEMOLYTIC URAEMIC SYNDROME



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

Special Edition October 2017

FEEDBACK FROM PATIENT FOCUS GROUP MEETING

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

CONTACT INFORMATION

National aHUS Service
Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Tel 0191 2820385
www.atypicalhus.co.uk

Nurse Specialists
ahus.nurses@nhs.net
Tel 0191 2825098



The core value of the National Renal Complement Therapeutic Centre is to put the patients at the heart of everything we do. We wish to empower our patients to be knowledgeable about the care they receive and our aspiration is to encourage our patients to influence the care we deliver in enabling personalised management.

Because of this we held our first aHUS patient focus group on 7th October 2017. Regional patient representatives were requested and we had a great mixture of attendees that included those on Eculizumab, those at risk of aHUS and transplanted patients and family members. The aim of the meeting was to provide a forum for you to tell us what you wanted to see from your national service.

Sandra Currie, chief executive of Kidney Research UK spoke about the role the charity has played and will continue to play in the aHUS cause.



KRUK has helped to fund much of the seminal research into aHUS and will continue to do so in the future. Following the dissolution of aHUSUK, its successor—Answers for aHUS—now comes under the KRUK banner. Thanks to previous fundraising efforts, a significant amount of money is available that will help to fund future research and to enhance patient experience.

Sandra reminded us of 2 ways in which anyone can continue to raise money directly for Answers for aHUS

- **Set up a Just Giving page to raise money for the charity. More details at**

<https://www.kidneyresearchuk.org/support-us/answers-for-ahus>

- **Register with Easy Fundraising to allow donations from your online shopping to go directly to the charity.**

<https://www.easyfundraising.org.uk/>



Patient advocate Len Woodward spoke movingly about the difficulties patients faced a mere 10 years ago with this disease. He told us how there was no good treatment for patients and they often ended up on dialysis. Transplantation was

not an option because this disease came back rapidly and the kidneys failed. Len told us about the work of aHUS UK in advocating for Eculizumab and a national specialist centre in the UK. Following the government's decision to fund Eculizumab, aHUS UK has morphed into Answers for aHUS, merging with Kidney Research UK. Len then announced his decision to step back from his role in aHUS. Professor Kavanagh then spoke in glowing terms of Len's contribution to the introduction of Eculizumab in the UK. Len was then presented with a token of our appreciation for all of his hard work over the years. I am sure everyone would like to join with us in thanking Len and his family for the outstanding work they have done for the cause of aHUS patients both in the UK and internationally.



Professor David Kavanagh, clinical lead at the National aHUS Service, opened the proceedings with a brief overview of the service from the initial discovery of the role of complement in aHUS in Newcastle almost 20 years ago until the present day. Professor Kavanagh then went on to outline the goals of the meeting. He discussed our vision to have you at the heart of everything we do, continuing our engagement culture and asked what was the correct media and technology platforms to get our message through to you. He discussed the importance of empowering you to drive patient care and how we want things to evolve. In one year's time we hope that the steering group will reconvene to review progress and to come up with new ideas.

YOU ASKED US

There was lively debate and many wonderful ideas came out of the discussions at this meeting. Much feedback focused on the isolation experienced by those with aHUS and how we could get around this. You suggested a number of ideas.....

Regional roadshows—you suggested that staff could hold patient information meetings around the UK. All interested patients and family members would be invited to attend and have the opportunity to hear more about aHUS, ask questions directly and to make contact with

Introductory telephone call from the National aHUS Service nurses to newly diagnosed patients to provide them with more information.

Please e-mail us with your ideas for developing your aHUS service on
ahus.nurses@nhs.net

Patient contacts—a number of people expressed a willingness to be contacted by patients newly diagnosed with aHUS. The National Service could co-ordinate this so contact details were not made public

Social media—a desire for a closed Facebook group moderated by the national service would be useful for patients to get in touch and share experiences.

Publicising relevant research studies or papers relevant to aHUS through the aHUS service website.

We are already working towards introducing these ideas into the national service.