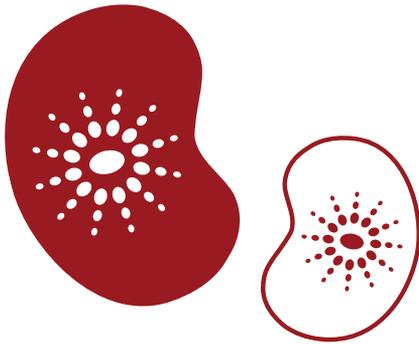


The new treatment model for aHUS

– a guide for patients on eculizumab
and ravulizumab from the National
aHUS Service



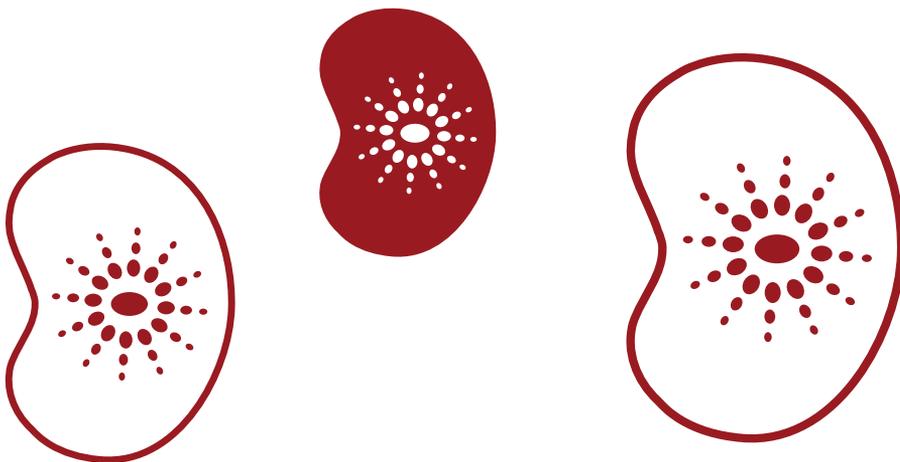


For people on treatment for atypical haemolytic uraemic syndrome (aHUS), it is now possible stop eculizumab or ravulizumab treatment.

This leaflet will tell you about:

-  **The new model of treatment for some aHUS patients**
-  **How the new model of care will work for patients**

You can read this alongside our leaflet on the “Stopping Eculizumab Treatment Safely in aHUS trial” (shortened to the “SETS aHUS trial”).



Why is there a new treatment model for aHUS?

In an international survey, patients on treatment told us they wanted to know whether or not they could stop treatment.

NICE (National Institute for Health and Care Excellence) recommended that a trial should look at whether patients could stop treatment safely after a time-limited course of treatment.

Treatment carries risks and is a burden for you and your family, so having the option to stop is important. The SETS aHUS trial was set up to look at this.

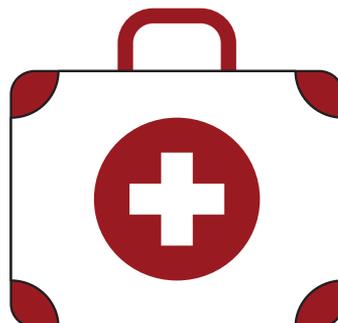
The findings of the SETS aHUS trial were published in August 2025. The trial showed that, for most patients, it is at least as safe to stop eculizumab and ravulizumab as it is to stay on treatment. But it should be done in a controlled way.

The safe way to stop treatment

The decision to stop treatment needs to be done with guidance from the specialist team at the National Centre

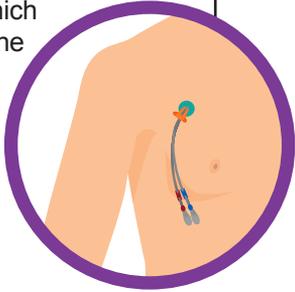
Most patients who have been on treatment can stop. They will need to be monitored - and know what to look out for and what to do if they think they are having an aHUS relapse (disease becomes active again).

Those who stop will be monitored with blood tests. They will be given a pathway to follow if they think they might be relapsing and will be able to re-start treatment quickly if needed.



Benefits of stopping treatment might include:

Reduced need for devices like portacaths and central lines – which reduces the risk of infection



Reduced treatment burden for patients, including children, allowing a greater sense of freedom



No need for regular cannulation or infusions



Advantages of stopping Eculizumab / Ravulizumab

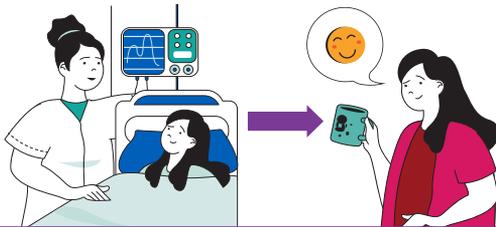
No longer having side-effects of treatment



Not needing to take regular antibiotics to reduce the risk of getting meningococcal infection



The risk of meningococcal infection reduces to the same as the general population

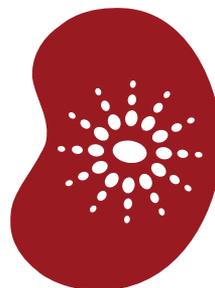
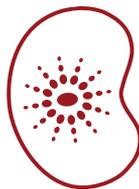
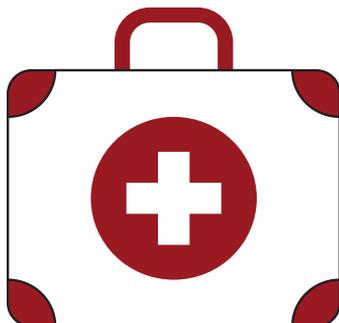


Having a sense of a more "normal" life

Patients and parents told us of their concerns about stopping treatment. These are the key concerns and how we address them:

Concern	How we address this
Risk of relapse	We can't remove the risk of relapse, but we can help you to understand what can trigger relapse, how to spot the signs of relapse, and empower you to seek help quickly if you think you might be relapsing so that it can be dealt with quickly.
Not spotting signs and symptoms of aHUS relapse.	We will give you information about what to look out for (signs/symptoms of aHUS relapse) during patient consultations and in this leaflet.
Not knowing what to do if worried you might be relapsing.	We will work with your local kidney team to provide a personal Emergency Healthcare Plan. This will have information about what to do if you are worried you might be relapsing. We will also provide an "at risk of relapse" card that you can show to the healthcare professional looking after you.
That a healthcare professional may not know what is wrong with you if you go to hospital with potential relapse.	We will give you an "Emergency Health Care Plan" (EHCP) to show a healthcare professional, telling them about your condition and action to take.

Concern	How we address this
That treatment may not work for a second time.	We are very confident that treatment will work well again, even if you have had a period off treatment.
Being in hospital for a long time if you relapsed.	If relapse is treated quickly, there is no reason why patients should be in hospital for a long time.
Being as ill as you were at the beginning	This is not likely as we know about your aHUS now, so if you relapse, you should re-start treatment and get better quickly.
Living with the uncertainty of relapse at any point	<p>In the trial patients said this got less over time, but did not go away fully.</p> <p>This is important though, as it makes people vigilant to look out for relapse and have blood tests if this happens.</p>

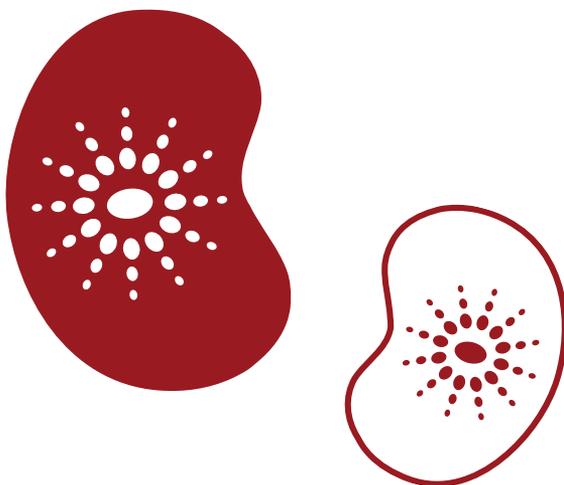


Monitoring after stopping treatment

After stopping treatment, it is important that you are monitored to look for aHUS relapse. If the doctors say you have a relapse, you will re-start treatment again. There are two aspects to this monitoring:

- **Routine blood tests** – these will happen regularly, but will lessen in frequency over time. These blood tests will measure kidney function and make sure there is no evidence of aHUS relapse.
- **Self-monitoring** – you need to know what things to look out for which might suggest you are having an aHUS relapse. You might relapse from aHUS between routine monitoring blood tests. If you feel unwell then you need to look out for signs and symptoms of possible aHUS relapse.

We know that half the people who relapsed during the SETS trial did so between their routine blood tests following an infection. This tells us that knowing what to look out for, and knowing what to do if worried, is very important.



Creating a personalised patient pathway

Before treatment is stopped, we will:

1.

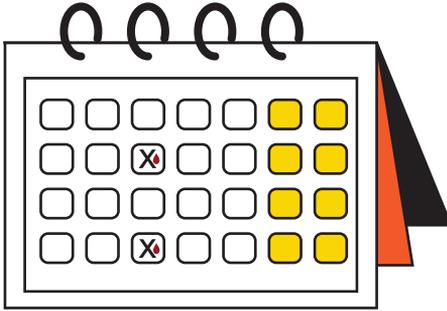
Talk to your local kidney doctors to seek their views about stopping treatment.



2.

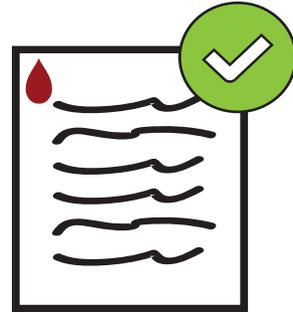
Talk to you in a patient consultation with your National aHUS consultant from the NRCTC, an aHUS Specialist nurse, and your local kidney consultant (if they can be there).



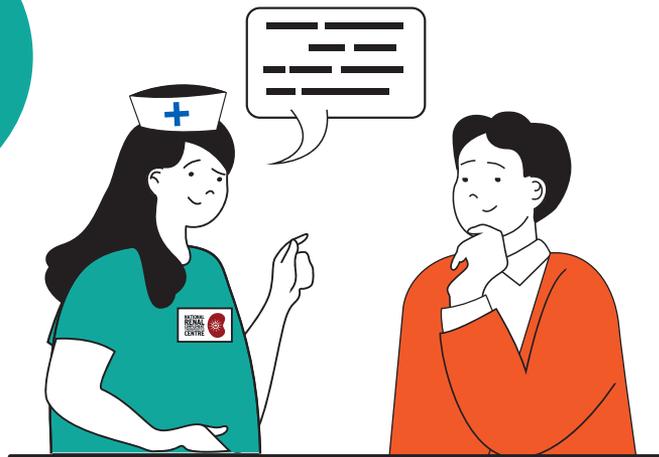


3.
Make a plan for your routine monitoring blood tests.

4.
Ask your local kidney doctors to check your routine blood test results. The NRCTC will also look at these blood results for the first 2 years after stopping.



5.
Offer you ongoing appointments with the aHUS Specialist Nurses



Emergency Health Care Plan (EHCP)

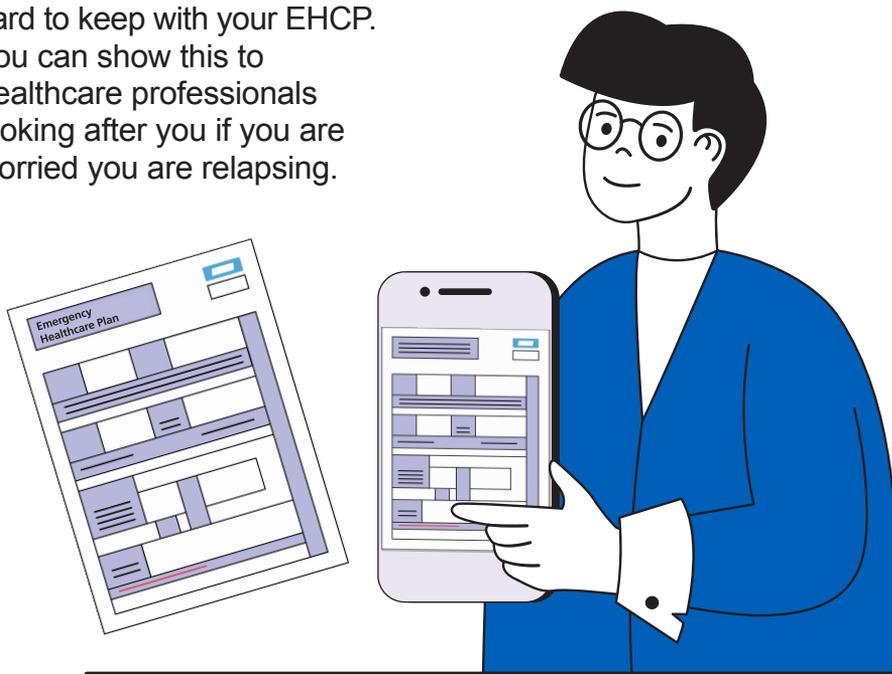
We will:

- Work with your local kidney team to develop a plan for you to follow if you are worried about relapse between routine blood tests.
- Give you an Emergency Health Care Plan telling you what to do if you are worried you are relapsing. We will give you a hard copy of this and a digital version that you can keep on your smart phone. This will be in place BEFORE you stop treatment.
- Give you an “at risk of relapse” card to keep with your EHCP. You can show this to healthcare professionals looking after you if you are worried you are relapsing.

The EHCP:

- Empowers you when you go to hospital because you are worried about relapse. It tells the healthcare professionals that you have aHUS and are at risk of having a relapse. It tells them what to do, and gives our contact details.

If you have problems following your EHCP, you should phone the NRCTC in Newcastle. We can then liaise with the staff looking after you in the hospital.

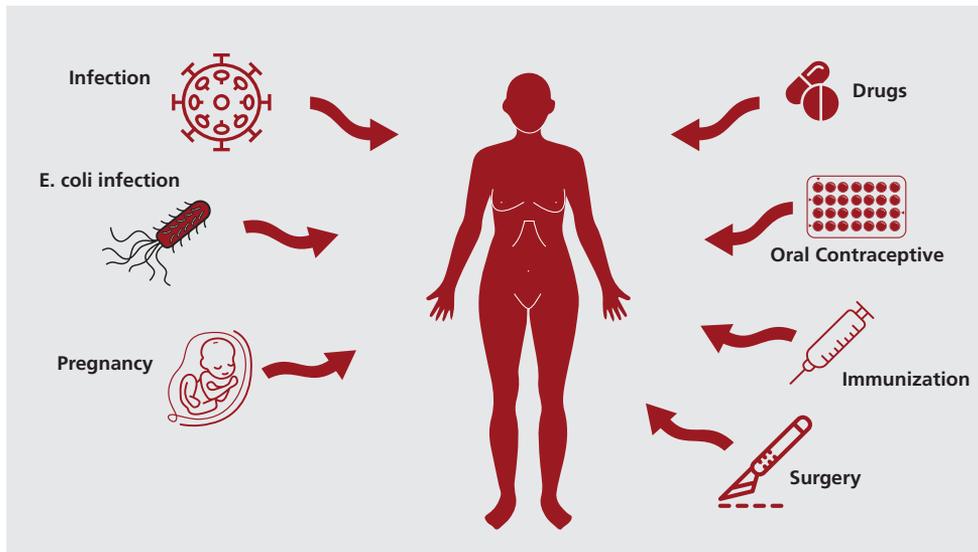


Triggers for aHUS relapse

We know that aHUS can be triggered by many things, but common triggers are:

- Infections
- Pregnancy. We recommend that you contact us if you are planning a pregnancy or become pregnant.
- Vaccinations. You can have vaccinations as recommended by your healthcare

professional. Be aware that while they can be a trigger for aHUS, so can the infection or disease you are being vaccinated against if you get it. For this reason, you should still have vaccines which are recommended to you.



Spotting aHUS relapse – signs and symptoms

It is important to know what to look out for as possible signs of aHUS relapse. Below are some possible signs and symptoms of aHUS relapse.

The list is not exhaustive. Sometimes relapse may not be obvious.

Signs	Symptoms		
 <p>Blood in urine or very dark urine (red flag)</p>	 <p>Nausea</p>	 <p>Unwell</p>	
 <p>Not peeing as much</p>	 <p>Feeling tired</p>	 <p>Feel more tired or breathless on exertion</p>	
 <p>Not peeing at all (red flag)</p>	 <p>Swelling (red flag)</p>	 <p>More than a “normal” cold or illness</p>	 <p>Feeling cold</p>
 <p>Rash (red flag)</p>	 <p>Bruising</p>	 <p>Not getting better in usual timescale</p>	

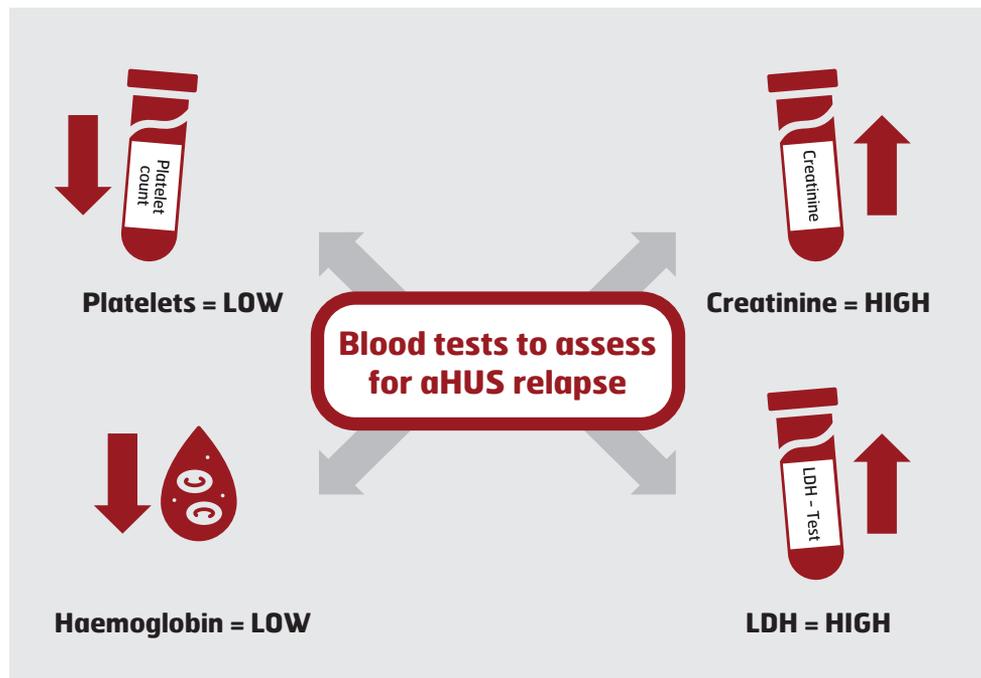
*** You might not get all of these ***

aHUS relapse – what to look out for in your blood tests if you stop treatment

Some patients like to keep an eye on their blood results. You may have access to see your own blood results, via platforms such as Patients Know Best or the NHS App.

Below is what we look at when assessing for aHUS relapse:

- Platelets (tiny blood cells needed to stop bleeding and form blood clots) – become low.
- Haemoglobin (red blood cells which carry oxygen around the body). Levels become low (sometimes called anaemia).
- Creatinine (waste product of the body filtered out by the kidneys and is marker of kidney function). Level increases.
- LDH is a protein that is released when red blood cells burst. The level goes up when aHUS is active.



What happens if you relapse

If a relapse is confirmed, we will recommend that you re-start treatment immediately.

We will then have a discussion with you about your longer-term care.

Travel

Kidney Care UK have a useful information leaflet about travel insurance for kidney patients. You can find this information on their website: www.kidneycareuk.org

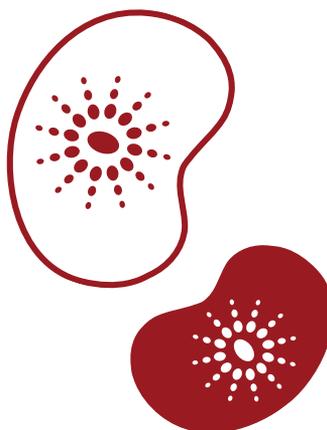
Patients in the SETS aHUS trial told us they valued being more flexible to arrange holidays without the strict ties of infusion dates. You should still consider the potential availability of eculizumab in any countries you are thinking of visiting.

Where to get more information

If you have any questions about information in this leaflet please contact us.

On our website:

- There is a short animation story of the SETS aHUS trial.
- You can also watch some videos of patients who stopped treatment, where they tell their stories and experiences.



www.atypicalhus.co.uk

Useful websites

You can find lots of information about atypical HUS on our website:

www.atypicalhus.co.uk

PALS (Patient Advice and Liaison Service) for help, advice and information about NHS services. You can contact them on freephone **0800 032 02 02**, email pals@nhct.nhs.uk

How to contact us:



Telephone:

0191 2820385
(aHUS National Service)



Email:

atypical.hus@nhs.net



Address:

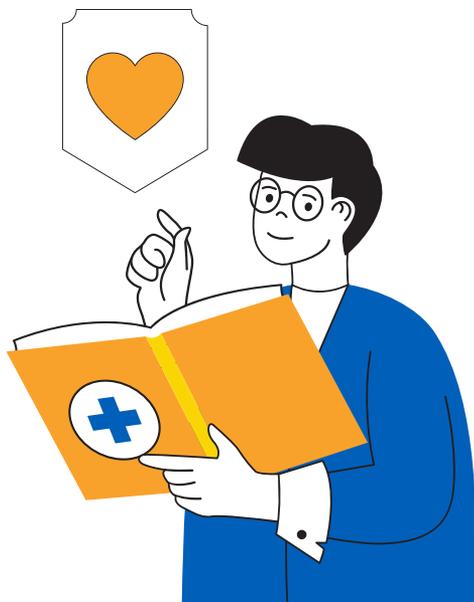
National Renal Complement
Therapeutics Service

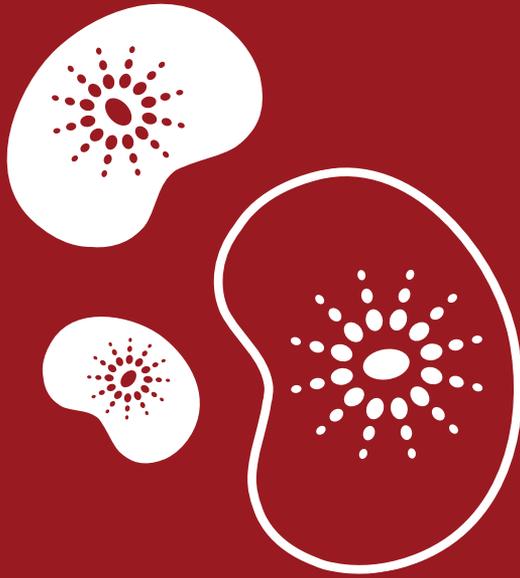
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Our Website



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