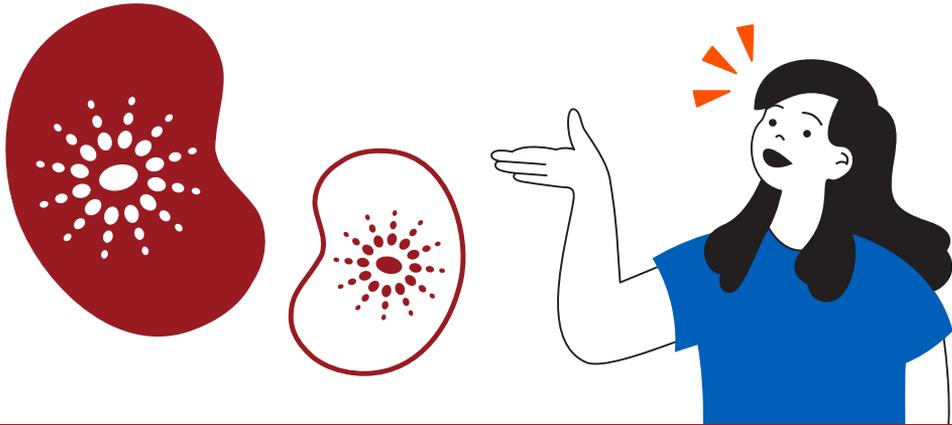


# Stopping Eculizumab Treatment Safely in aHUS

- a summary of the trial results from the  
National aHUS Service





**This leaflet will tell you about:**

-  **The “Stopping Eculizumab Treatment Safely in aHUS trial” (shortened to the “SETS aHUS trial”)**
-  **Why the SETS aHUS trial was done and what the results showed**

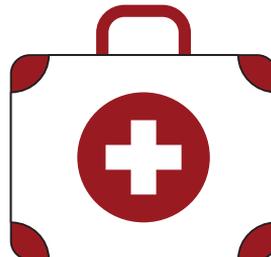
## **The SETS aHUS trial**

**In an international survey, aHUS patients on Eculizumab 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 eculizumab safely after a short course of treatment.

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

The SETS aHUS trial ran between 2018 to 2024. The findings of this study were published in August 2025.



## Summary conclusion from the trial

The results of the trial suggest that:

The majority of patients are able to stay off treatment long-term with precautions in place.

Some people will relapse and need to start back on treatment.

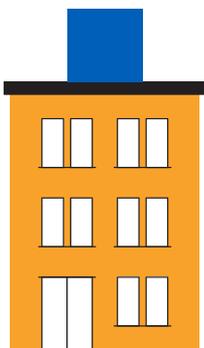


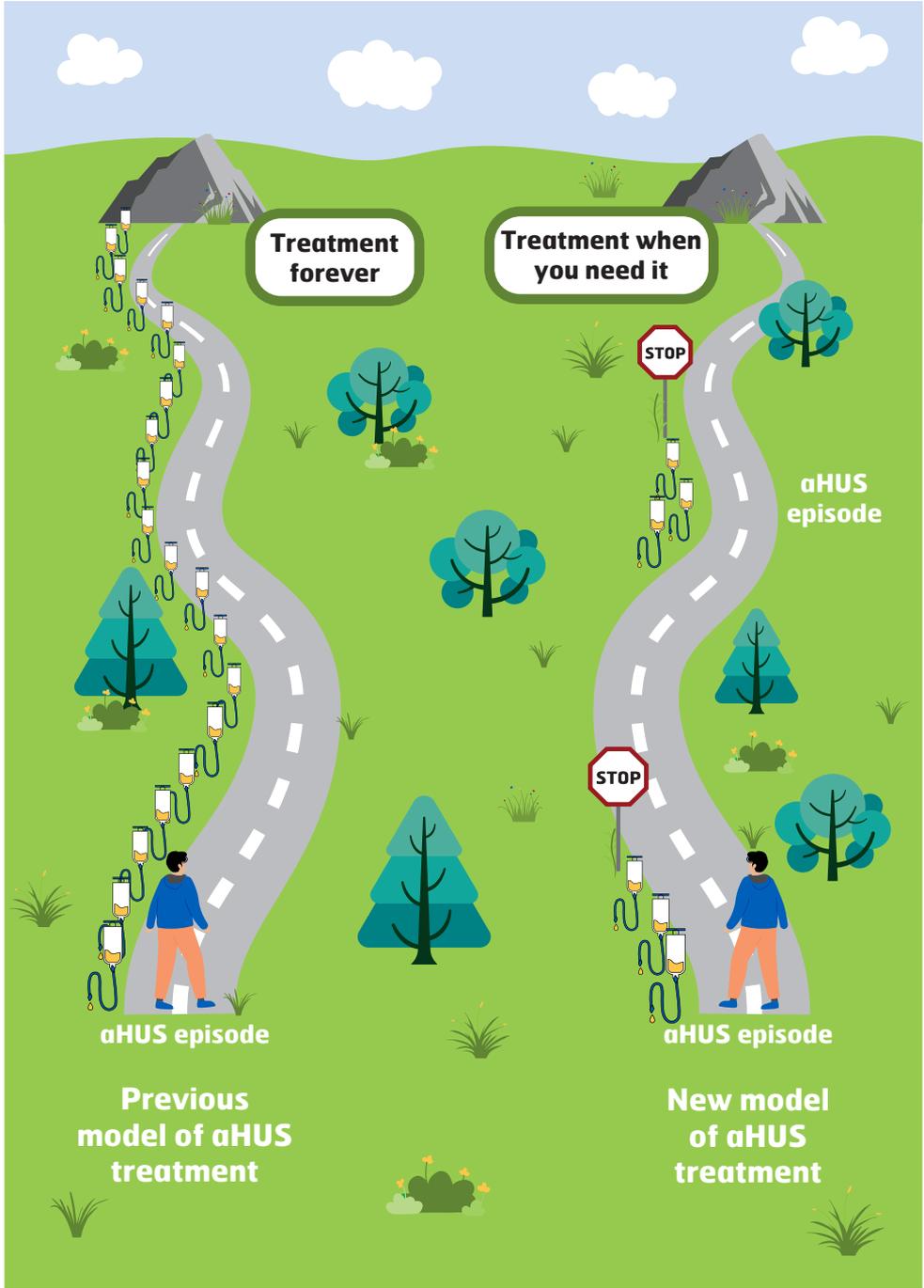
Treatment can be replaced by monitoring. It is safe to stop treatment in most patients as long as patients:



In most patients, we can treat for a short time and then stop treatment.

- Are adequately monitored with blood tests.
- Know what to look out for to spot symptoms of relapse.
- Seek help if worried they are relapsing.
- Have a pathway that allows the re-starting of treatment quickly if they do relapse.





**The rest of this leaflet tells you about the trial and its results in more detail if you want to know more about it.**



## **Why was the SETS aHUS trial carried out?**

### **Eculizumab is a highly effective treatment for aHUS.**

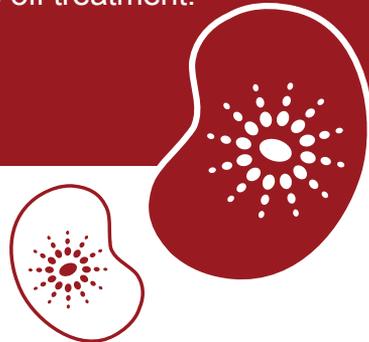
When Eculizumab was introduced for aHUS in the UK, lifelong use was recommended once treatment was started because the best way to use it had not yet been established.

However treatment can carry risks:

- Patients are at a 550 times increased risk of getting meningococcal infection which can be life-threatening.

- Regular intravenous infusions can be a significant treatment burden for patients.
- Some patients on treatment experience side-effects.

It was hoped that the trial could show if patients could safely come off treatment.



## What did the trial look at?

- Is it safe to stop treatment in some patients with aHUS, and replace with monitoring to detect aHUS relapse?
- Is it possible to pick up relapse early and successfully re-introduce treatment?

Patients in the trial stopped treatment.

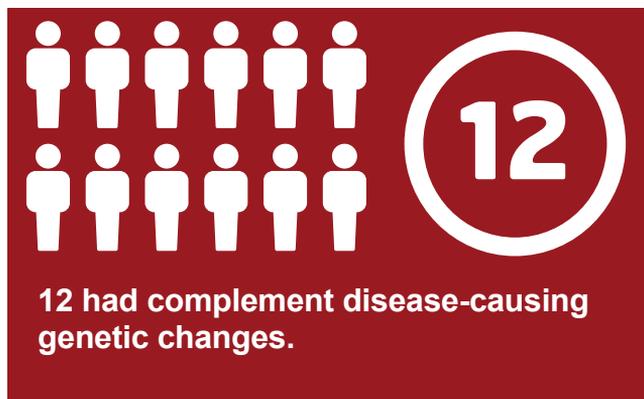
They were followed up for 2 years with regular blood tests.

A plan was put in place in case they became unwell in between these regular scheduled blood tests.

If they relapsed, they were re-started on Eculizumab very quickly.

## Who was in the trial?

28 patients (18 children, 10 adults) stopped treatment and were followed up for 2 years after stopping.



## Who was NOT included?

Some “higher risk” patients were not able to join the trial – this included patients:

- ⊖ Who had received a kidney transplant with a higher risk complement genetic change.
- ⊖ With chronic kidney disease (CKD) stage 4–5.
- ⊖ With uncontrolled high blood pressure.
- ⊖ With unstable kidney function.
- ⊖ Under 2 years of age.

## Summary of Trial results

### Relapses

#### *How many? / Who?*

- The 4 patients who relapsed all had a disease-causing complement genetic change.
- There were no relapses in those with no identified disease-causing complement genetic change.
- Whilst no patients in the SETS aHUS trial with Factor H autoantibodies relapsed, we know from international studies that this is possible.

#### *How did people relapse?*

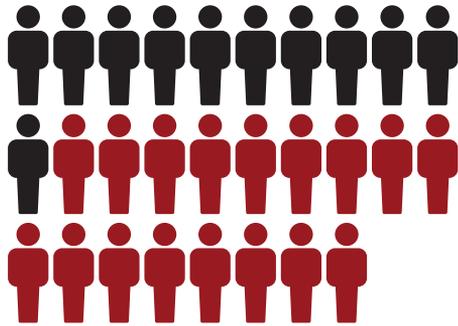
- Half of those who relapsed did so after a mild infection and went to their kidney doctor who confirmed the relapse on a blood test.

#### *Relapse rate*

- The relapse rate was 24% in patients with disease-causing complement genetics changes or Factor H autoantibodies, equalling one relapse for every 8.5 years follow up.
- In patients without a disease-causing complement genetic change or Factor H autoantibodies nobody relapsed.

Home urine testing was not found to be useful in detecting relapse.



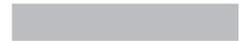


11 patients - no mutations (in black)  
 17 patients with either genetic changes  
 or factor H autoantibodies (in red)

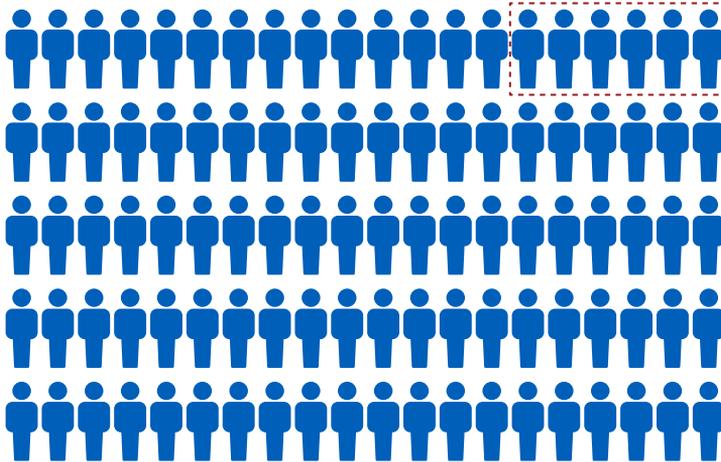
**SETS aHUS Trial Group**

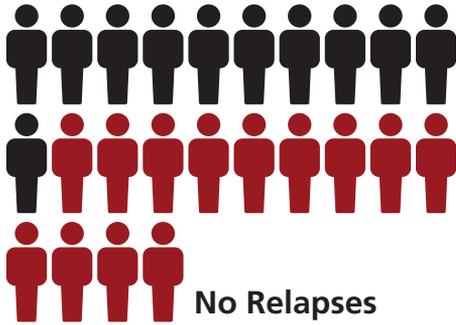


**4 Relapses**

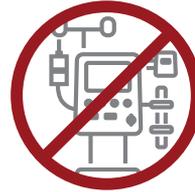


**Comparison group - 1st 100 aHUS patients  
 treated with Eculizumab in the UK**





No patient needed dialysis



Restart Eculizumab

At least as safe to stop eculizumab as to continue with treatment



Long term Eculizumab treatment



6% of patients had serious adverse event

## Conclusions

### The results of the trial suggest that:

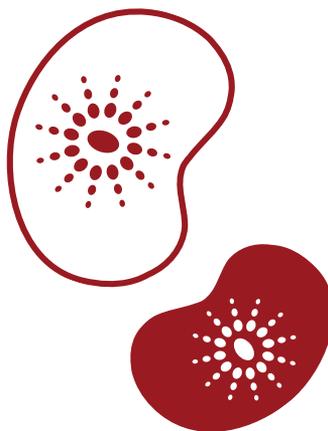
- The majority of patients are able to stay off treatment long-term.
- Some people will relapse and need reintroduction of treatment.
- We can treat for a limited time and then stop treatment in most patients.
- Treatment can be replaced by monitoring. It is safe to stop treatment in most patients as long as patients:
  - Are adequately monitored with blood tests.
  - Know what to look out for to spot symptoms of relapse.
  - Seek help if worried they are relapsing.
  - Have a pathway that allows the re-starting of treatment quickly if they do relapse.

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

## Useful websites

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

[www.atypicalhus.co.uk](http://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](mailto:pals@nhct.nhs.uk)

## How to contact us:



### Telephone:

0191 2820385  
(aHUS National Service)



### Email:

[atypical.hus@nhs.net](mailto:atypical.hus@nhs.net)



### Address:

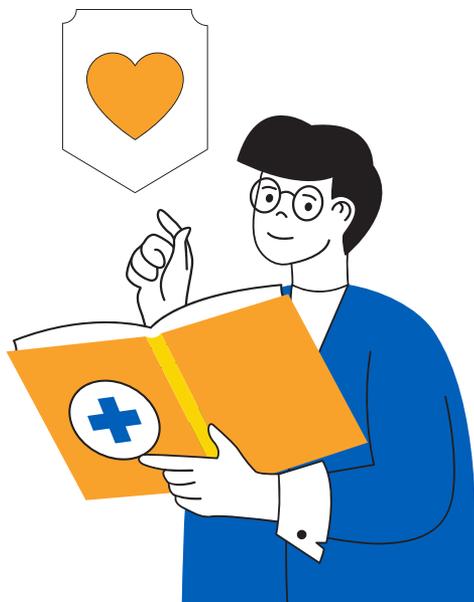
National Renal Complement  
Therapeutics Service

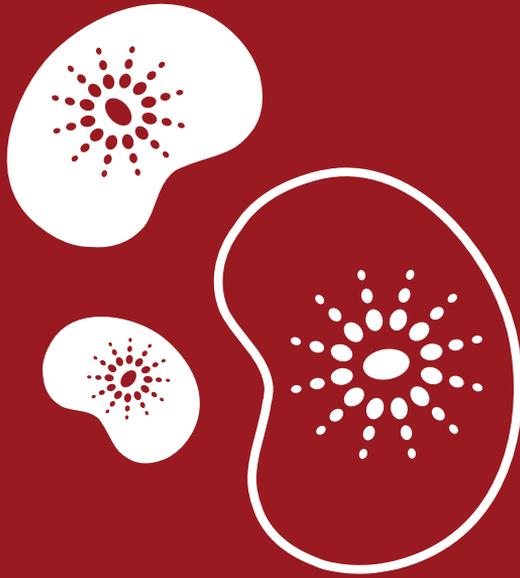
Royal Victoria Infirmary  
Building 26 (Old Children's  
Outpatients)

Queen Victoria Road  
Newcastle upon Tyne  
NE1 4LP

X [@aHUSnurses](#)

X [@NationalaHUS](#)





## **National Renal Complement Therapeutics Centre**

**Building 26,  
Royal Victoria Infirmary,  
Queen Victoria Road,  
Newcastle upon Tyne  
NE1 4LP**

**Tel: 0191 28 20385**

## **Our Website**



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