

## Welcome to our autumn edition



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We would like to introduce our new Clinical Nurse Specialist Katrina, some of you may recognise her from being a nurse on Ocean Unit. We are so excited to have her as part of our team. Please join us in welcoming her to the Benign Haematology Service

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## A warm welcome from our new Clinical Nurse Specialist

Hi! My name is Katrina and I am so proud to have joined the Benign Haematology team alongside Helen, Sophie and Hayley. I have been a nurse for over 10 Years, previously working on Ocean Unit. I have a lot of experience in working with patients and families with a variety of conditions and have a passion for Benign Haematology. I am looking forward to meeting and speaking to those of you who I have not previously met. It is an exciting time to be joining the service and I hope you feel supported and able to approach me with any questions or concerns.

Take care, Katrina





## Joke for the autumn:

How do you fix a broken pumpkin?.....

With a pumpkin patch!!!!



Would your child like the opportunity to attend a camp? To meet other children with health challenges? Or would you like to attend a camp as a family?

Applications for the 2025 camps will be taken soon, please visit [www.otw.org.uk](http://www.otw.org.uk) for more information and to register your interest. We can also refer your child with your consent, please let us know if you would like us to do this.

**NHS**

University Hospitals  
Bristol and Weston  
NHS Foundation Trust



Bristol Royal Hospital  
For Children

# Support group for young people living with Sickle Cell or Thalassaemia

We are inviting you to attend a support group with other young people with a focus on transition and transferring to adult services.

The group will be for young people between the ages of **14-18 years old**. It will give you the opportunity to meet and chat with others experiencing the same health condition as you.

The venue will be confirmed once we have an idea of how many people would like to attend. We do promote independence however if you would like to bring a parent/carer we can provide refreshments and a waiting area.



Sarah Muddle  
Psychologist



Amy Caswell  
Psychologist



Hayley Wiles  
Support Worker



Mel Marsh  
Support Worker

Please sign up via QR code or  
<https://forms.office.com/e/DNAPCT2XJh> or  
let Hayley know via call or text on  
07423743483 or 01173420658



**Sign up here**

## Does your child have a diagnosis of Thalassaemia?

## Would you like to join the Thalassaemia Society?



**Please visit: [www.ukts.org](http://www.ukts.org) for more information on how they can support you and membership details. Please see information below regarding a survey they are offering for Thalassaemia patients**

Dear All, We invite you to participate in a research study conducted by QC Medica and sponsored by a pharmaceutical company. As part of this research study, a survey has been developed:

- Aims to understand how people with transfusion-dependent  $\beta$ -thalassaemia (TDT), and members of the general public (without TDT), value different aspects of quality of life.
- Will take approximately 30 minutes to complete.

Individuals who are eligible to participate and complete the full survey will receive a £50 Amazon Electronic Gift Card Voucher as compensation for participation.

If you are interested in participating, we first ask that you respond to some questions to assess your eligibility to take part in our study. These questions should take less than 5 minutes to complete.

Copy and paste the URL below into your internet browser:

[https://qcmedica.qualtrics.com/jfe/form/SV\\_5zqe5XEprzlMS3A](https://qcmedica.qualtrics.com/jfe/form/SV_5zqe5XEprzlMS3A)

Please contact QC Medica if you have any questions about this study at: Tel: +44 (0)151 4402 647 or Email: [tdt@qcmedica.com](mailto:tdt@qcmedica.com)

Kind Regards, Antony

Antony P. Martin BSc (Hons) MSc PhD

Director, Health Economics & Real World Evidence

## Please Remember

Bristol Children's Hospital  
Upper Maudlin Street  
Ocean Unit, Level 6  
Bristol BS2 8BJ

Call Helen, Sophie or  
Katrina CNS's on  
01173428721 or  
07747004996 or  
07920545620

Or Hayley Benign  
Haematology Family  
Support Worker on  
01173420658

If your child is running low on medication that we normally prescribe please give us at least 3-4 weeks notice. This will enable us to ensure you receive your child's medication in a timely manner. Thank you

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As we know living with a long term health condition can have a huge impact on the whole family.

Would you like to meet and talk with other parents? Or would you like to be a parent supporter?

We would like to facilitate parent/carer meetings. These can be held face to face or virtually. If you would be interested in this please call Hayley to discuss

We have found parent to parent support to be very beneficial. If you would like to volunteer to be a parent supporter please give Hayley a call to discuss.

**S U P P O R T**

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Is your child starting a new school or nursery in Sept? Please ask Hayley if you would like her to deliver some training around your child's condition.