



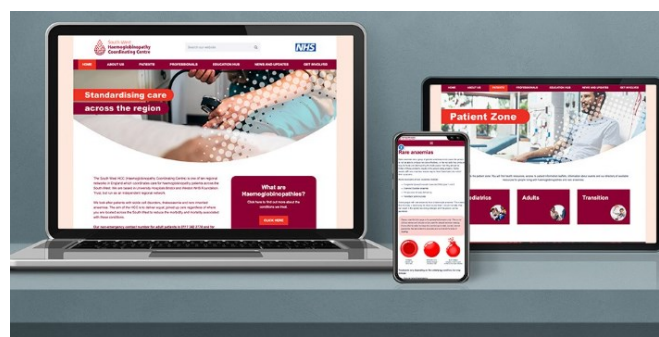
## Welcome to our summer edition

We are so excited to share our brand new regional website with you. Please visit:  
<http://www.southwesthcc.nhs.uk/>



The website is designed to provide support and information for patients, parents/carers, professionals, and education providers. There are also options for you to provide feedback on the website and our service. As always, we value your input.

From now on, the newsletter will be uploaded to our new website instead of being posted to homes. Please check our website every three months for newsletter updates.



### Inside this issue:

<i>Joke for spring</i>	2
<i>Black Mothers Matter</i>	2
<i>Sickle Cell Retreat</i>	3
<i>Cianna's Smile</i>	4
<i>Support group</i>	5
<i>Survey</i>	6-7
<i>Over the Wall Camps</i>	8
<i>Crescent Kids</i>	8
<i>Gene therapy</i>	9
<i>Family Support</i>	10

## Joke for the summer.....

### Newsflash!!

**A man is in hospital after eating a bag of daffodil bulbs.....Doctors say he will be out in the spring!!**



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**Black  
Mothers  
Matter**

Have you heard of Black Mothers Matter?  
Black Mothers Matter are committed to supporting and celebrating Black pregnancies across the UK.  
Please visit [www.blackmothersmatter.org](http://www.blackmothersmatter.org) for more information.



**29th to 31st August 2025**  
**@ Whitemoor Lakes, nr. Birmingham**

**Join the Sickle Cell Society for a FREE holistic weekend away full of education, adventures, learning and fun for all the family**

From 29th to 31st August 2025 the Sickle Cell Society are running the third Family Retreat for 30 families who have one or more children aged between 6-15 years old with sickle cell. The family retreat will be at Whitemoor Lakes in South Staffordshire (30 mins from Birmingham).

### **WHAT HAPPENS AT THE FAMILY RETREAT?**

Supported by a team of enthusiastic volunteers and experienced staff members, the families will embark on a programme which includes educational seminars, adventure activities such as climbing, zipwire and archery, peer-to-peer support, relaxation-based activities - and, of course, a Saturday evening party and Friday night stories around the campfire! All of this will be delivered in a medically safe environment which has been specifically designed with children with sickle cell in mind. There will also be a creche available for those aged 6 and under.

Please let Hayley know on 01173420658 or 07423743483 if you would like her to refer your family.

# CIANNA'S SMILE YOUTH



CIANNA'S  
Smile

## ENTREPRENEUR CLUB



MONDAY EVENINGS  
DURING TERM TIME,  
FROM 5:45 PM TO 7:00 PM

The Youth Entrepreneur Club is designed to empower young people aged 8-16 year olds, impacted by Sickle cell to be independent and earn a living, regardless of their circumstances. Through engaging workshops, participants will develop practical skills that can lead to exciting opportunities.

### Workshops Include:

- AI Art with Akanji Studios
- Creative Writing
- Podcasting
- Excel and Accounting
- Digital Illustration /Animation
- Web Design!



REGISTER NOW



COME JOIN US  
IT'S ONLINE!



We successfully started our young person's group in October half term. If you are interested in attending please scan the QR code or call Hayley on the telephone number below



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

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 other young people 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 will have a separate room available for parents/carers to sit and have a drink whilst waiting.

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



Sarah Muddle  
Psychologist



Amy Caswell  
Psychologist



Hayley Wiles  
Support Worker



Mel Marsh  
Support Worker



**Sign up here**

# WE WANT TO HEAR FROM YOU

## WE NEED YOUR VOICE

Take just 10 minutes to complete our survey and help shape the top 10 research priorities for sickle cell and genomics.

Your answers will directly influence the future of research, ensuring it reflects the needs and concerns of the sickle cell community.

That is why we are inviting people living with sickle cell, carriers, carers, family members, and healthcare professionals to share their thoughts on what needs to be prioritised for future research

## WHY TAKE PART?



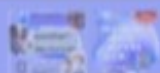
- ✓ MAKE A REAL IMPACT ON SICKLE CELL RESEARCH
- ✓ ENSURE YOUR VOICE IS HEARD
- ✓ ENTER A PRIZE DRAW TO WIN A £150 AMAZON VOUCHER!



James  
Lind  
Alliance  
Priority Setting Partnerships



Genomics  
England

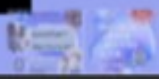




The Priority  
Setting  
Partnership

# The Sickle Cell and Genomics Survey

HAVE YOUR  
SAY



# OVER THE WALL CAMP

UK Children's Charity

a seriousfun camp

Would your child like to attend a camp?

Over The Wall is a UK based charity for children with serious illness and disabilities, and their families, to discover a world of mischief and magic. A place where they can be brave and have fun with others. These amazing places are physical – in residential camps and also available online – with Camp in the Cloud. And what's more, it's all free!

For more information please visit [www.otw.org.uk](http://www.otw.org.uk).

If you would like a referral to be made on behalf of your child please call Hayley on 01173420658.



Crescent Kids

Sickle Cell Research • Healthy Kids • Happy Lives

Have you heard of Crescent Kids? They support children and young people with sickle cell. They are also in the process of setting up an app called 'Eli'. If you would like guidance on how to use this app please contact Hayley and she can arrange for Crescent Kids to provide virtual training. Please visit [www.crescentkids.org](http://www.crescentkids.org) for more information





## **Exciting news!!!!**

**You may have heard in the news that gene therapy has been approved by the NHS for eligible patients that meet the criteria for sickle cell (HbSS) and thalassaemia patients (Beta Thalassaemia Major) in the UK.**

**Dr Cummins would like to offer a virtual questions and answers session to discuss this new treatment with parents and carers.**

**Please contact Hayley on 01173420658 or 07423743483 to add your name to the list. Hayley will then contact you with a date and time once arranged.**

## 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. We also recommend families keep a supply of paracetamol and ibuprofen at home. This can be purchased at most supermarkets and pharmacies.

Thank you

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Sadly, we've had a number of families not attending their appointments. Non-attendance to clinic appointments can be a significant issue in healthcare settings. It is essential to your child's health that we review them when required. We ask that you please give us as much notice as possible if you are unable to attend. This will enable us to add another patient into that slot.

Would you or your child like to give feedback on the service we provide? All comments will be anonymous. Please scan the QR codes below if you would like to do this. Thank you.

Child's Survey



Parent's Survey



Young Person's Survey

