



## Welcome to our spring edition!



### Inside this issue:

Sadly, we need to announce that our lovely Laura will not be returning to our team following her maternity leave. She will be very much missed and I know you will join us in wishing her and her family well for the future

*New Sickle Cell Programme* 2

Sarah is a Clinical Psychologist. She works with children and young people looked after by our team, their siblings and/or parents, as needed. She helps people who are feeling distress related with their health condition or where people are struggling to live with elements of having a medical condition. It is normal and understandable to struggle with difficult feelings because of a medical conditions but sometimes it can be helpful to have some extra support.



*Make a Move* 3

*Pharmacy and Support* 4

Some of the things she commonly supports families with include:

- Understanding, and coping with a diagnosis
- Managing difficult feelings including anxiety, low mood, frustration and other emotions linked with living alongside a long term condition
- Managing specific fears related to procedures or experiences in hospital (e.g. of needles or blood transfusions)
- Non-medical help with symptoms such as pain and fatigue
- Keeping up with the things your child needs to do to keep themselves healthy (e.g. taking medications, drinking plenty of water)
- Some people with conditions like Sickle Cell Disease and Thalassaemia experience changes in their thinking and learning, either due to their condition or missing school due to difficult symptoms. Sarah runs a Cognitive Assessment Clinic where she invites children into hospital to complete certain games and tasks designed to assess their thinking and learning skills. She also talks to parents and schools as part of this and then writes a report to summarise things she thinks might help them with thinking or learning. If you would like a referral to Sarah or to discuss a referral to Sarah please call Hayley on 01173420658.

## New Sickle Cell Programme

NHS England has been working on a new national programme to better identify blood groups for all patients in England living with inherited anaemias including Sickle Cell Disorder, Thalassaemia and transfusion dependant rare anaemias. Through this programme it will, over time be possible to identify better matched blood for transfusions and so reduce antibody formation. You/your child may be asked if you would like to take part when routine blood tests are being taken.

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We have received a recommendation from a lovely patient of ours called Samuel that we should add a joke to our newsletter:

“Why were the doctors cross?..... Because they ran out of patients!!”



We hope you like this one Samuel

Don't forget Make a Move is back for 2024!! Please scan the QR code below for more information and how to register

# MAKE A MOVE!

with Bristol Royal Hospital for Children  
Together...through treatment and beyond.

SAT 31  
AUG  
2024

**SAVE THE DATE!**



**A DAY OF DIFFERENT SPORTING  
ACTIVITIES FOR PATIENTS PAST  
AND PRESENT.**

Patients up to and including  
16-year-olds under the care of  
the Oncology and Haematology  
Department.

TeamBath Sports Training Village,  
Claverton Down, Bath, BA2 7AY.

Family and friends  
**WELCOME.**



**LIMITED SPACES**  
so register now!

[make-a-move.org.uk](http://make-a-move.org.uk)



**NHS**

University Hospitals  
Bristol and Weston  
NHS Foundation Trust



Bristol Royal Hospital  
For Children

The Grand Appeal®. Registered charity 1043603. © &™  
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**Box4Kids**

## Nominate your child for a **VIP experience** they deserve

The Barrie Wells Trust Box4Kids initiative provides VIP experiences for seriously ill and disabled children aged 8-18. With access to executive boxes in over 100 major UK sports and entertainment venues, they help thousands of children to enjoy an exclusive day away from their hospital treatment.



*Elliot described his night in the box as the best night of his life! As a parent, to witness that joy on your child's face is irreplaceable.*

**Jackie Wild, mother of 9 year old Elliot**

 /BarrieWellsTrust  info@barriewellstrust.org  @barriewellstrust  01524 590 600  www.barriewellstrust.org  @BWellsTrust

Visit [barriewellstrust.org](http://barriewellstrust.org) to nominate your child for a Box4Kids event



SICKLE  
CELL  
SOCIETY

# Sickle Cell Family Retreat

For families with a child with Sickle Cell aged between 6-15yrs

## 30th Aug - 1st Sept 2024

@ 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

**APPLY NOW - [bit.ly/scs-family-retreat](https://bit.ly/scs-family-retreat)**



Questions? Email Jessica:  
[jessica.boatright@sicklecellsociety.org](mailto:jessica.boatright@sicklecellsociety.org)



If you would like Hayley to refer your child please contact her on the telephone number on the next page.

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

Call Helen and Morag  
CNS's on 01173428721

or  
07747004996 or  
07920545620

Or Hayley Benign  
Haematology Family  
Support Worker on  
01173420658

If you would rather receive this newsletter in another format, for example via email please let us know. Also if you wish not to receive a copy please let us know using the details provided.

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### **Change of pharmacy provider**

The pharmacy within the BRI in Bristol will no longer be run by Boots. Lloyds pharmacy will be taking over from April 2024. This will not effect you being able to collect your prescription in person. We may also have to arrange delivery of your medications directly to your home address.

We ask again for you to please give us 3-4 weeks notice if your medication is running low.

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Would you like to be a guest speaker at training awareness days? Or are you interested in befriending or offering support to other parents/carers that are living with a child with a long term condition? Please let us know if this is something you would like to do.

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

**S U P P O R T**