

Welcome to our summer edition!



Inside this issue:

Sadly, we need to announce that our marvelous Morag's secondment has sadly come to an end and she will be moving onto new adventures in Puzzlewood Ward. We thank her for all the hard work she has given the benign haematology service and I'm sure you will join me in wishing her all the best for the future.

| | |
|--------------------------------------|---|
| <i>Sickle Cell Survey</i> | 2 |
| <i>Make a Move</i> | 3 |
| <i>Internet safety</i> | 4 |
| <i>Summer holiday activity ideas</i> | 5 |
| <i>Bristol Oscar</i> | 6 |
| <i>Pharmacy and support</i> | |

A warm welcome from our new Clinical Nurse Specialist'

Hi, my name is Sophie and I am delighted to be joining the Paediatric Benign Haematology team alongside Helen and Hayley. I have been a nurse for 7 years, with a background in neurosciences and haematology. Most recently for the last 3 years I have been working as a Clinical Nurse Specialist in the Oncology & Haematology teams based on Ocean Unit and in the community. Hopefully I will be a familiar face to some.

My goal is to ensure that each patient is listened to and receives comprehensive, personalised and compassionate care tailored to their unique needs. In my role, I will be working closely with you to create individualised care plans, offering guidance, knowledge and support from diagnosis. I am here to answer your questions, provide emotional support and a seamless coordination of care among all healthcare professionals involved in your child's treatment.

I feel very privileged to be joining the team and am really looking forward to getting to know each of you. Please feel free to reach out to me with any questions or concerns - I am here to support you in any way I can.

See you soon, Sophie.





Joke for the summer:

**“Where do sheep go on vacation?.....
To the Baa –hamas”**



Haemoglobinopathy parent/carer and patient survey

The surveys below are about the healthcare your child receives and the results will be used to make improvements to the service. Taking part in this survey is entirely voluntary, your answers are kept confidential and will not affect the care your child receives. Please scan the QR codes below if you would like to give your feedback.

**[https://forms.office.com/e/
xsk5kHX5Ky](https://forms.office.com/e/xsk5kHX5Ky)**



**[https://forms.office.com/e/
YdJ2wtkQww](https://forms.office.com/e/YdJ2wtkQww)**



Don't forget to register for Make a Move! 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



NHS

University Hospitals
Bristol and Weston
NHS Foundation Trust



Bristol Royal Hospital
For Children

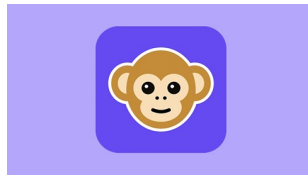
The Grand Appeal®. Registered charity 1043603. © &™
Aardman Animations, Ltd 2024. All rights reserved.

Online Safety

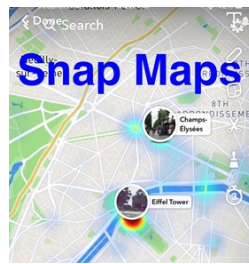
Are you aware of the potential dangers of apps on your child's phone or tablet?

Members of our team have recently received training around internet safety for children from Avon and Somerset Police. We were informed that the apps below can pose several risks to children and young people.

The monkey app allows users to talk with strangers. Rules state users should be 18+ however there is no verification process apart from a tick box



Snap maps allow your child to be tracked at every opportunity unless they select 'Ghost mode'



Discord is well known for inappropriate and harmful content



Yubo has been described as a dating app for young people. Enabling adults to talk with children and young people.



Apps can also be hidden behind tools such as calculators and alarms. If you have concerns please visit the Barnardos, NSPCC or Internet Watch Foundation sites for more information



Please see links below to summer holiday activities:

Bristol:

www.yourholidayhubbristol.co.uk

www.bristol.gov.uk/residents/people-and-communities/find-a-holiday-activity-in-your-area

Gloucester:

[Holiday activities and food programme \(HAF\) | Gloucestershire County Council](#)

[Holiday Activities | Young Gloucestershire \(youngglos.org.uk\)](#)

Bath

[Activate: Holiday Activities and Food | Live Well in Bath & North East Somerset \(bathnes.gov.uk\)](#)

[Family activities and events for primary school children | Primary Times](#)

Somerset

[About the HAF programme | North Somerset Council \(n-somerset.gov.uk\)](#)

Devon

[Holiday Activities and Food \(HAF\) programme – Education and Families \(devon.gov.uk\)](#)

Cornwall

[Parents and Carers – Active Cornwall](#)

The 19th June is World Sickle Cell Day, why not join Bristol Oscar on the 22nd June to celebrate their relaunch!



SICKLE CELL AWARENESS DAY

An event in aid of
World Sickle Cell Day 2024
being held to provide
information and support to
individuals and families
within our communities

Come and find out more
about Sickle Cell and
Thalassaemia and how you
can support the cause!

**SATURDAY
22ND JUNE
2024
12PM-3PM**

FREE TO ATTEND & LIGHT REFRESHMENTS AVAILABLE

**Bristol Sickle Cell & Thalassaemia Centre
256 Stapleton Rd Easton BS5 0NP
0117 951 2200**



Change of pharmacy provider

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

Call Helen and Sophie
CNS's on 01173428721

or

07747004996 or
07920545620

Or Hayley Benign
Haematology Family
Support Worker on
01173420658

Transition of Outpatient pharmacy services moved from Boots to Lloyds from 1st April. There were some teething problems early on which resulted in longer than anticipated delays in home deliveries. We are now expecting home deliveries to be 3-6 days following the team prescribing your medicine. For collection from BRI Lloyds - this should be ready 48 hours after the prescription has been received.

For home deliveries this is what you should expect:

Patients will receive their first text the day the parcel is collected from the outpatient dispensary (prior to the day the delivery is due), this will include their PIN, Message as below, however the patient will not be able to select an option as the package needs to be delivered to a patient and cannot be left in a safe place, porch etc due to the nature of the contents.

Example message below:

The patient will get a delivery window of 2 hours, remember your driver will need your delivery PIN

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

We're expecting your Lloyds Pharmacy parcel. We'll be in touch when we have it and it's out for delivery

Remember, your driver will need your delivery PIN 8153.

We won't ask you to sign for your parcel, we'll take a photo of it instead in your open doorway as proof it has been delivered.

[Show my options](#)

Your parcel: 1550 5745 673 330

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.