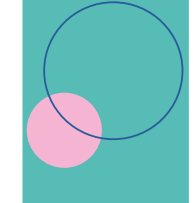


A source of information on thalassaemia, sickle cell and rare inherited anaemias (RIA).
Catering for patients and clinical staff in the North of England.



NEWS

- △ The Manchester Sickle Cell & Thalassaemia Centre is being extensively refurbished between 16th January – 31st March 2023. Even though there will be some disruption it is hoped it will be minimal. Staff will continue to attend clinics and make domiciliary visits. The reception will remain open, and for appointments already booked, a space elsewhere will be used.
- △ Crizanlizumab, the new sickle cell treatment, has been getting a lot of coverage in the UK press recently. If you have missed the news articles we have collected some together into a mini feature later in this edition of the HCC newsletter.
- △ Newsletter news - starting this issue we have a new section listing updates from different hospitals and regions across the HCC Network.



STAFF EVENTS

Globe Interactive Live Webinar Series 2023.

This series, presented by Vertex Pharmaceuticals, explores key topics in the management of haemoglobinopathies. The dates for the sessions are listed below. For more information about the event, and how to register interest, please see this linked poster: bit.ly/3RqHfW1

- △ 31/01/23, 17:30 - 18:30, Spotlight on Sickle Cell (Part 1: Pathology and clinical complications)
- △ 21/03/23, 17:30 - 18:30, Spotlight on Sickle Cell (Part 2: The therapeutic landscape)
- △ 07/02/23, 17:30 - 18:30, Talking β -Thalassaemia (Part 1: Pathology and clinical complications)
- △ 28/03/23, 17:30 - 18:30, Talking β -Thalassaemia (Part 2: The therapeutic landscape)



HCC Online Education

More regional and national sessions have been announced for the next few months. Please see below for more details:

NW & North of England HCC Programme

- △ 15/02/2023, 12:00 - 13:00, 'Blood Transfusion, Antibodies & Hyperhaemolysis in Sickle Cell Patients', Andy Houghton, Lead Haemoglobinopathy CNS, Royal Liverpool University Hospital.
- △ 06/03/2023, 12:00 – 13:00, 'Endocrinopathies and bone disease in Thalassaemia', Dr Laxmi Balmuri, Endocrinology and Metabolic Consultant, Manchester Royal Infirmary.

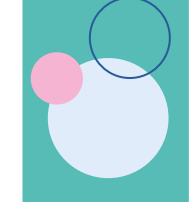
National HCC Programme

- △ 13/02/2023, 16:00 – 18:00, 'Chronic Complications in Adult Thalassaemia Patients', presented by West Midlands HCC.
- △ 15/03/2023, 16:00 – 17:00, 'Rare Inherited Anaemias', presented by Wessex and Thames Valley HCC

All take place on MS Teams and registration is via Eventbrite, for more info please contact HCC Network Manager, Eva Clarke, or a member of the HCC team in Manchester.

HCC Training

If your staff need some training related to sickle cell, thalassaemia or RIA in the North West region you will need to make a formal request. This can be done by completing a North West HCC education booking form. This can be found via the following link: bit.ly/3Dfhlyv
Please note details of where to return the completed form are found at the bottom of the document.





PATIENT EVENTS & SUPPORT

The Caribbean & African Health Network (CAHN) wanted us to let you know they provide regular health related sessions on a number of subjects and even have a health podcast. More details about services can be found at this link: bit.ly/3WM887A and www.cahn.org.uk

Sickle Cell Care Manchester (SCCM), in partnership with North Manchester Inclusion Partnership, will be delivering 4 cafe style events in North Manchester. The aim is to raise awareness of services available to individuals living with sickle cell, give tips around nutrition and keeping well. Communications regarding these events will be shared on their website: www.sicklecellcaremanchester.co.uk

The Liverpool Sickle Cell & Thalassaemia Support Group is an organisation that offers information, advice and moral support to those in the Merseyside area. For details about meetings and contact details please see their promotional poster: bit.ly/408ULS4



NHS BLOOD AND TRANSPLANT (NHSBT)

The NHSBT and Therapeutic Apheresis Services (TAS) provide lifesaving and life enhancing treatments to adults and children, operating from 8 units across England. More detailed information can be found at: <https://www.nhsbt.nhs.uk/what-we-do/diagnostic-and-therapeutic-services/therapeutic-apheresis/therapeutic-apheresis-treatments/>

We wanted to highlight the great work they do in this issue and let you know that TAS has recently joined forces with the Manchester Royal Infirmary (MRI). Since mid-October 2022 they have commenced a collaborative adult emergency red cell exchange service for patients with sickle cell disease who present to hospitals served by the MRI Specialist Haemoglobinopathy Team (SHT).

This new pathway delivers the emergency provision of automated red cell exchange as an outreach service, providing equality in healthcare and improving access to emergency apheresis in the region.

The first patient to be treated on the new emergency red cell exchange pathway was referred from the Royal Bolton Hospital on 25th October after presenting with a sickle chest crisis. NHSBT subsequently travelled to treat a patient at Leighton Hospital on 28th November who presented in chest crisis also.



CRIZANLIZUMAB IN THE NATIONAL NEWS

As mentioned in the news section there has been substantial press coverage about the drug crizanlizumab. Below are a few links to articles, featuring patients from the North, that may be of interest to readers. Please note to read the full article in The Independent you do have to register but this is free.

The Independent Newspaper: www.independent.co.uk/news/health/sickle-cell-disease-treatment-patients-b2228231.html#comments-area

ITV News: <https://www.itv.com/news/granada/2022-03-11/life-changing-drug-to-tackle-sickle-cell-disease-rolled-out-to-first-patients>

Eastern Eye: <https://www.easterneye.biz/breakthrough-nhs-treatment-transforms-the-life-of-sanah-shaikh-who-has-sickle-cell-condition-i-feel-like-ive-wings/>





Some of the speakers on the day:

Marilyn Burton



Dr Sharif



The NHSBT Team



Sanah Shaikh



Patient Rep

NORTH WEST SICKLE CELL PATIENT EVENT 2022

The global pandemic severely hampered the opportunity for the Haemoglobinopathy Coordinating Centres across the country to hold patient events. However, with the easing of restrictions, and the country returning to some sort of normality, the North West HCC was able to hold its first sickle cell engagement event. This collaboration between MRI, RMCH, MLCO, NHSBT and patient representatives across the region took place on Saturday 12th November at Citylabs 1.0, Manchester.



The event explored health care roles, new treatments, transition of care, patient experiences of living with sickle cell, introduction to the community team, support with bills management, red cell exchange and what to expect, education, career and sickle cell's impact on holistic wellbeing.

As well as the presentations and education it was also a time for people to come together. It was a fantastic opportunity for people to share experiences and benefit from the community spirit. Additionally, there were fun activities for all ages including a kids dancing competition and a raffle where almost everyone won a prize. If you weren't able to attend, we have peppered a few photos around this page, although unfortunately no one is dancing or winning big on the raffle!

More than 80 people attended and many asked if more events like this could take place, which we definitely have planned. The next event will address topics requested by patients and careers such as diet and nutrition, men's health, managing pain, bone marrow transplant and the latest information regarding A&E practice. This event is a step in the right direction to improve patient care and experience and allow region wide services to work together.

The organisers would like to give a big thank you to all those who helped on the day and for local businesses who kindly donated snacks and a few of the raffle prizes. Last, but not least, thank you to all the patients who attended in person and online who made it such a great experience. Unfortunately, there were some technical issues outside of our control that hampered the online attendee experience. Apologies if this affected you. Thankfully this shouldn't happen for future events.

We gave the opportunity for attendees to give feedback throughout the day. Below is a selection of some of the feedback received. As feedback was anonymous, we'd like to thank our patient picture stand ins – Rishi and Beyoncé.

"I really appreciated all your effort and help"



"Me and my family have had a wonderful time, I can't thank you enough, all the people who made this event possible, from doctors, nurses and patients for their personal experience. The questions answered put me at ease."

"Personal stories have given me some sort of hope"



"Please can we come again next year mum"



UPDATES FROM ACROSS THE NORTH

Teams around the region have provided sickle cell, thalassaemia and RIA related updates.

Alder Hey, Liverpool

The team at Alder Hey are pleased to announce they have registered 6 patients for voxelotor. Those that have already started the treatment are doing well. Hydroxycarbamide has been offered to 100% of eligible sickle cell patients. 97.3% of patients are on hydroxycarbamide and are monitored by a well-established nurse led clinic. This winter, working closely with the immunisation team, flu jabs have been coordinated at the same time as routine clinic appointments so it can be offered to as many patients as possible.

Bradford

Plans for the new and dedicated transfusion unit are moving forward. Posters on the ward and at The Meadows have information on how to send ideas and suggestions online regards the design and decor of the unit. The next Listening Event on 01/03/23 will be an opportunity to update the progress and plans, and to receive feedback on these.

A new clinical psychologist has been appointed and is due to join the team in February. Dr Kiran Kauser is experienced in supporting people with chronic health conditions using a range of therapeutic approaches and will be a welcome addition to our team.

Sheffield

Sophie Basford has joined Lisa Kirk in the CNS team and is working closely with in-patient and day ward teams to deliver support and education. Additionally, funding has been confirmed for a benefits advisor to be in place to support HBO/RIA patients. An appointment announcement will be made in the next HCC newsletter.

Royal Manchester Children's Hospital (RMCH)

RMCH have let us know the exciting news that their first patient started crizanlizumab recently. It is still early days but things are progressing well for the patient.

Thank you to Dr Sandham (Alder Hey), Dr Samuelson (Sheffield & Bradford), and Dr Kausar (RMCH) for providing this information.



ANNOUNCEMENTS

- △ As some of you may know one of the clinical nurse specialists in Manchester recently left her role in haemoglobinopathy. Rachel De Fazio remains within the haematology department but will no longer be treating those with thalassaemia, sickle cell and rare inherited anaemias. Good luck with the new job and thank you for all your hard work over the years.
- △ The HCC Newsletter team are always looking for input and contributions from clinical staff and patients. If you have any news, information or have a feature idea please contact the HCC Network Manager, Eva Clarke, or a member of the HCC team in Manchester. If you receive the newsletter via an HCC email address please simply reply to the sender.

Other Useful Organisations

National Bodies

- △ National Haemoglobinopathy Panel (NHP) - www.nationalhaempanel-nhs.net
- △ UK Thalassaemia Society (UKTS) - www.ukts.org
- △ Sickle Cell Society (SCS) - www.sicklecellsociety.org
- △ Diamond Blackfan Anaemia UK (DBAUK) - www.diamondblackfan.org.uk

Local Patient Support Groups

- △ Manchester Sickle Cell & Thalassaemia Centre (MSCTC)
- △ Sickle Cell Care Manchester (SCCM) - www.sicklecellcaremanchester.co.uk
- △ North of England Bone Marrow & Thalassaemia Association (NEBATA)
- △ Caribbean & African Health Network (CAHN) - www.cahn.org.uk

