

North England Sickle Cell and Thalassaemia Patient Event

Saturday 18th November 2023



Introduction

The North England Haemoglobinopathy Coordinating Centres (HCC) held their first joint sickle cell and thalassaemia patient event on Saturday 18th November 2023. The event was a collaboration between Manchester University NHS Foundation Trust and Sheffield Teaching Hospitals NHS Trust with support from Manchester Local Care Organisation.

Summary

The event was held at ETC Venue, 11 Portland Street, Manchester, M1 3HU. The aim of the event was to bring patients and their families together to meet with one another and engage with specialist clinicians and local / national voluntary organisations. The event provided free breakfast, refreshments throughout the day, lunch, and a raffle.

To cover a wide range of topics requested by patients, two rooms provided talks throughout the day. In room 1 the topics explored aspects that affect both sickle cell disease and thalassaemia such as gene therapy and new treatments, nutrition, and bone health, genotyping, patient perspectives and clinical research. In room 2, we created a space for social queries and collection of winter packs, and workshops run by local sickle cell and thalassaemia organisations (Appendix 1).

There was also a dedicated Kids Zone in room 3 that provided entertainment for children throughout the day. Afro cats provided African drums, dance, and creative writing. Spread a Smile org provided magicians who performed magic shows, and Whitworth Art Gallery provided a feel-good art workshop. The children also left the event with gifts, goodie bags and big smiles!



Above Images: Kids' Zone

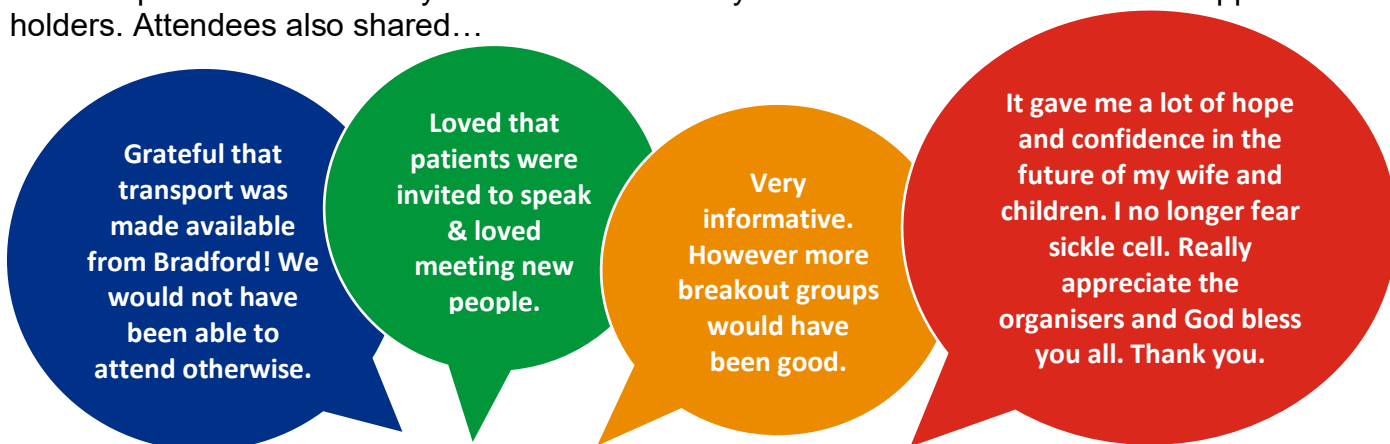
The HCC Network Manager invited organisations such as NHSBT, Citizens Advice (Manchester Branch), Black Health Agency, Medicare, Sickle Cell Care Manchester, UK Thalassaemia Society, Caribbean & African Mental Health Services & Liverpool Support Group to the event to engage with families throughout the day.

242 people attended the event. 179 patients (including 37 children under 16 years old) from across North England (appendix 2) and 63 members of staff participated and supported the event.

Patient Feedback

100% of the attendees* said that they would attend a future conference with the majority rating the venue as excellent and the length of the talks as satisfactory. The top four rated talks were: 1st place Gene Therapy and future treatments, 2nd place was sickle cell, memory loss and brain fog (Sickle Cell Care Manchester Workshop), 3. Patient Perspective (leg ulcer management and identity) and 4th place nutrition and diet. Topics that were requested by multiple attendees for future event were: Gene Therapy, fertility & pregnancy, management of sickle cell at work/school, preventative care, more time allocated to patient perspective talk, pain management at home and nutrition (inc. diet plans). Many patients also requested a talk on an aging sickle cell population as many patients are living longer due to improved care.

Patients shared that they would like to receive conference materials before the event and leaflets on the topics discussed. They also shared that they would have liked more time to approach stall holders. Attendees also shared...



Grateful that transport was made available from Bradford! We would not have been able to attend otherwise.

Loved that patients were invited to speak & loved meeting new people.

Very informative. However more breakout groups would have been good.

It gave me a lot of hope and confidence in the future of my wife and children. I no longer fear sickle cell. Really appreciate the organisers and God bless you all. Thank you.

A full list detailing patient feedback can be found in appendix 3.

Lessons Learnt

It is incredibly important to have a clear communication plan whilst implementing any event. Staff and attendee handouts (appendix 4) were provided prior to the event however communication regarding patient transport was not thorough enough and caused confusion between hospital providers.

The venue changed the terms and conditions of the contract two weeks prior to the event taking place. This resulted in the HCC Network Manager having to write a risk assessment (appendix 5) and create consent forms (appendix 6) as well as provide baby changing facilities and dispose of the nappy waste.











It is also vital to approach organisations for raffle donations (appendix 7) months prior to the event taking place.

Conclusion

The next event will address topics requested by patients above and will include longer breaks to allow attendees to approach stall holders and network. To receive requests for other topics and understand the interest in future events, HCC Network Manager has created a separate MS Teams Form (appendix 8). If the North HCCs decide to host a joint event again then the event will be held in a different city such as Sheffield, Leeds or Liverpool. As the Northwest HCC largely funded the event (appendix 9) the Northeast HCC would need to largely fund the next event.

This event was a huge success and a step in the right direction to improve patient care and experience across the North of England region. A special thanks to all the speakers, volunteers, stall organisations, and patients who were involved. And thank you to those who donated gifts to the raffle. Your contributions have really made a positive impact on our patients and their families.

Appendices

01 Patient Event Agenda	06 Consent Forms
 <p>2023-11-18_AGEND A_v2.docx</p>	  <p>2023-11-18_Event_P MFT consent form - arent-Guardian_Cor adult photos.docx</p>
02 Patient Geography	07 Raffle Donations
 <p>Appendix 2 - Pat Geography.docx</p>	 <p>7. Raffle Prize Inventory.xlsx</p>
03 Patient Feedback Results	08 MS Teams Form – interest for Future Events
 <p>Patient Conference Feedback Results.xls</p>	<p>https://forms.office.com/e/sqJbvb6SAG</p> 
04 Handout	09 Cost
 <p>2023-11-18_Staff_H andout_v3.0.pdf</p>	 <p>9. Cost of Event.xlsx</p>
05 Risk Assessment	
 <p>Risk Assessment Form .doc</p>	

Version 1

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