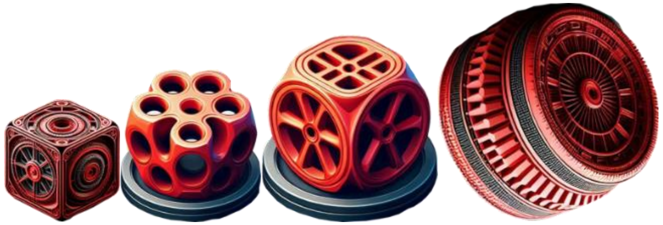
National Haemoglobinopathy Panel

https://www.nationalhaempanel-nhs.net

DON’T TRY TO REINVENT THE WHEEL!



Much smarter to jump on the solid foundation and work others have been doing and make it stronger. Below are just a few pointers

LEARN	**GIVE BLOOD**	**VOLUNTEER**	**DONATE/FUNDRAISE**	**JOIN A SUUPPORT GROUP**	**BECOME A CHAMPION/ADVOCATE**	**GROUP/ORGANISATION**	LINK
√						**The National Haemoglobinopathy Panel (NHP)** The NHP coordinates and supports development of Haemoglobinopathy (Sickle Cell Disease (SCD) & Thalassaemia) as well as Rare Inherited Anaemia services in England. The website provides clinical, professional and operational information and guidelines, notably for clinicians	https://www.nationalhaempanel-nhs.net

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						and service developers. Sign up to join the Monthly MDTs for exciting learning and service-impacting cases and discussions. (Site currently in transition but accessible)	
√						**Academy for Sickle Cell and Thalassaemia (ASCAT)** ASCAT is an international body of professionals and patient groups that operates on every facet of the Sickle Cell and Thalassaemia realm from research and service modelling, to patient feedback and exercise. The annual conference is full of impactful sessions that are one of the most valued for this sector. The next conference is 2-5 October 2024.	https://ascatconferences.com

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√				√	√	**Haemoglobinopathies Coordinating Centres (HCCs)** HCCs are regional bodies which oversee and coordinate all the Haemoglobinopathy and Rare Inherited Anaemia services within their region. Their websites are full of valuable training and patient support information as well as service updates and communication links. There are 10 Sickle Cell Disease (SCD) HCCs and 4 Thalassaemia HCCs	**North West SCD HCC/North Thalassaemia HCC:** https://mft.nhs.uk/hcc/ **North East and Yorkshire HCC:** https://www.ney-hcc.co.uk **East Midlands HCC:** https://emstn.org/about/ **West Midlands SCD HCC/ Midlands Thalassaemia HCC** https://www.westmidsstn.nhs.uk **East London and Essex SCD HCC/London & South East Thalassaemia HCC:** https://www.bartshealth.nhs.uk/hcc **South East London and South East SCD HCC:** http://www.ststn.co.uk

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							West London SCD HCC: https://www.westlondonhcc.nhs.uk
							North Central London and East Anglia SCD HCC/London South Central & South West Thalassaemia HCC: https://www.uclh.nhs.uk/theredcellnetwork
							Wessex and Thames Valley SCD HCC: https://www.ouh.nhs.uk/services/departments/other/hcc/
							South West SCD HCC: https://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/treatments/haemoglobinopathy

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	√					**NHS Blood and Transplant** Learn about the value, use and ways that blood and cellular donations afford and get yourself registered to save a life.	https://www.blood.co.uk
√		√	√	√	√	**Sickle Cell Society** The Sickle Cell Society supports and represents people affected by sickle Cell Disorder to improve their overall quality of life. Their reach is broad, ranging from support group to policy advocacy in the halls of power. They can also signpost to testing.	https://www.sicklecellsociety.org
√		√	√	√	√	**United Kingdom Thalassaemia Society (UKTS)** The UKTS is a on-stop-shop for support, patient and public empowerment, advocacy for service improvement and patient representation for Thalassaemia patients. They can also signpost to testing.	https://ukts.org

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√		√	√	√	√	**UK's Diamond Blackfan Anaemia Syndrome Charity (DBAS UK)** DBAS UK Are the UK's Charity providing support, networking, information on this Rare Inherited Anaemia.	https://diamondblackfan.org.uk
√						**UK Forum For Haemoglobin Disorders** This is a great place to learn scientific and professional issues and developments within he haemoglobinopathy sector. They run periodic educational events. Well recommended particularly for clinicians.	https://haemoglobin.org.uk