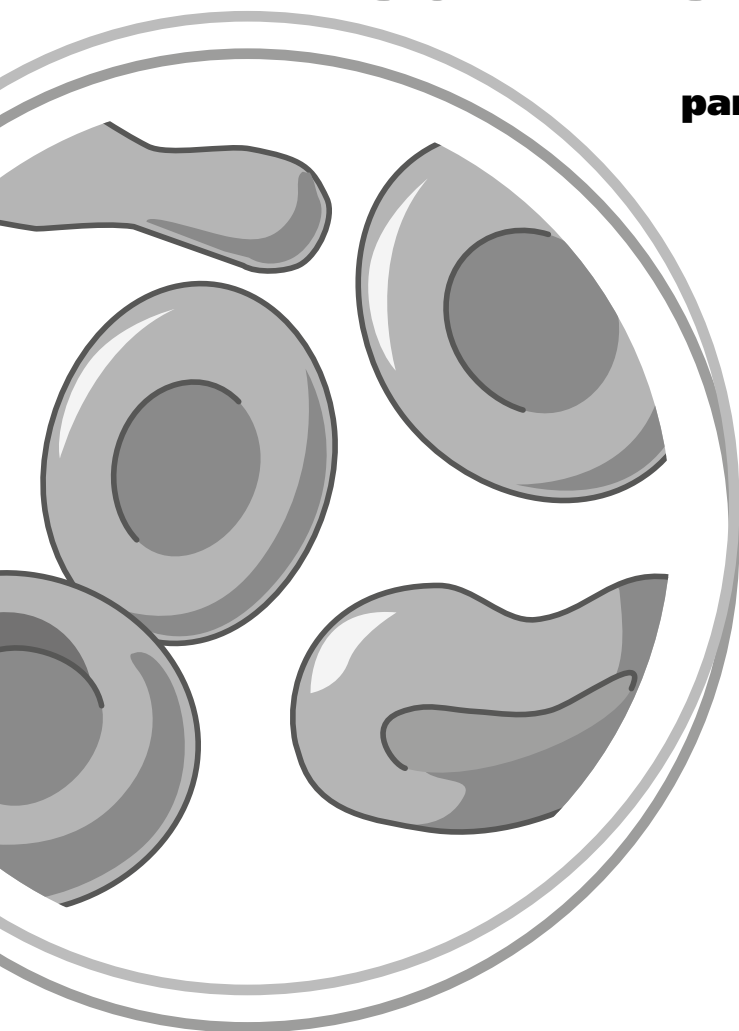


CHILDREN'S HAEMOGLOBINOPATHY AND RED CELL DISORDERS SERVICE

**Information for
parents and carers**



What are the haemoglobinopathies?

Haemoglobinopathies are a group of blood disorders including Sickle Cell Disease and Thalassaemia.

Other red cell disorders include Diamond Blackfan Anaemia (DBA).

This leaflet describes the services that are available for children with Haemoglobinopathies in Oxford and the surrounding areas, and include key contact details.

Our team

Dr Amrana Qureshi

Consultant Haematologist (Service Lead)

Lesley McCarthy

Roald Dahl Haemoglobinopathy Nurse Specialist

Dr Georgina Hall

Paediatric Haematology Consultant

Dr Neha Bhatnagar

Paediatric Haematology Consultant

We also have a Psychological Support Service, so please let us know if this might be useful for your child.

Outpatient Clinic

We will see your child in our Outpatient Clinic for regular reviews, and our Haematology Consultants will see them annually.

Our Outpatient Clinic is on Level LG1 of Oxford Children's Hospital. The Clinic is normally on Thursday afternoons, while annual reviews take place on Tuesday afternoons.

Transcranial Doppler (TCD) ultrasound scans also take place on Tuesday afternoons in Radiology.

If your child needs a blood test, we have a Phlebotomist (someone specially trained to take blood samples) and a Play Specialist to help.

Appointment enquiries

Outpatient Secretary: **01865 234 212**

Email: paediatrichaematology@ouh.nhs.uk

Kamran's Daycare

We carry out planned transfusions for children with Sickle Cell Disease, Diamond Blackfan Anaemia (DBA) and Thalassaemia in Kamran's Daycare on Kamran's Ward, Level 0, Oxford Children's Hospital. Our team arranges these.

Enquiries

Kamran's Daycare: **01865 234 062**

Monday to Friday 8.00am - 8.00pm

Inpatients

Urgent problems

If your child is unwell, we will assess them and admit them to Kamran's Ward.

If your child needs to be admitted to hospital for treatment, we will always try to find a bed on Kamran's Ward. If your child is admitted to another ward in the Children's Hospital, the Haematology team will still care for them.

If your child has a high temperature, uncontrolled pain or appears pale and unwell, please contact us on the number below.

Kamran's Ward: **01865 234 069**

01865 234 068

Nurse Specialist

Our Nurse Specialist provides advice and support and is present at clinic appointments, annual reviews and times of hospital admission.

They will also co-ordinate planned admissions for treatment and blood tests.

The Nurse Specialist also offers advice and support to your child's nursery or school and works with the adult team to enable smooth transitions to adult services.

Enquiries

Lesley McCarthy

Roald Dahl Haemoglobinopathy Nurse Specialist

Tel: **01865 226 487**

Mobile: 07775 543 174

Email: lesley.mccarthy@ouh.nhs.uk



(Roald Dahl is a children's charity which funds specialist nursing posts in the NHS and family grants to support children with chronic conditions.)

Coming to Oxford Children's Hospital

For information leaflets, videos and advice on transport, parking and hospital facilities, please visit:

www.ouh.nhs.uk/children

www.ouh.nhs.uk/hospitals/jr

Useful websites

NHS website

www.nhs.uk/conditions/sickle-cell-disease

Sickle Cell Society

sicklecellsociety.org

54 Station Road, London NW10 4UA

Tel: 020 8961 7795

Email: info@sicklecellsociet.org

UK Thalassaemia Society

ukts.org

Thalassaemia International

www.thalassaemia.org.cy

DBA UK Website

Diamondblackfan.org.uk

Social Services

www.oxfordshire.gov.uk

Benefits and Immigration Advice

Please contact Citizens Advice: www.citizensadvice.org.uk

Further support

Interpreter and advocacy services

Please let us know if you need an interpreter

Spiritual support

Please contact our Chaplaincy team

Tel: 01865 857921

Email: chaplaincy@ouh.nhs.uk

Feedback

We welcome your feedback, so if you have any comments or concerns please speak to a member of the Haematology team.

If they are unable to resolve your concerns, please contact our Patient Advice and Liaison Service.

Email: PALS@ouh.nhs.uk

Get involved in improving services

Congenital Anaemia Network

www.togetherwecan.co.uk

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.



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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

