

Paediatrics

Sickle Cell and Thalassaemia services

About our service

The haemoglobinopathy service at University Hospital Coventry cares for around 150 children and young people with a haemoglobinopathy disorder. Most have sickle cell disease or thalassaemia, but we also look after children with rare inherited anaemias.

Our aim is to provide high-quality, evidence-based care while considering the individual physical, social, psychological, and spiritual needs of our patients and their families. Our staff are committed to ongoing training to make sure we provide the specialist care these children require.

Haemoglobinopathies

Haemoglobinopathies are inherited blood disorders that affect the production of haemoglobin. Haemoglobin is the substance in red blood cells that carries oxygen around the body. Sickle cell disease and thalassaemia are the most common conditions in this group.

Our patients

Most of our patients live in Coventry, but UHCW also provides specialist care for patients across Warwickshire.

Our location

Children's Outpatients
1st floor reception, West Wing



Patient Information

University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

For directions, please visit: <http://www.uhcw.nhs.uk/find-us/university-hospital>

Parking and transport

- Parking is available near the Women's and Children's entrance. Additional car parks are near the Accident and Emergency department and the main hospital entrance.
- Drop-off zones are located outside the main entrance and Women's and Children's department.
- Public transport stops outside the main entrance.

Children's Haemoglobinopathy team at UHCW NHS Trust

Paediatric consultants

Dr Muhammad Farooqi and Dr Kim Neuling

Secretary: 024 7696 7234

Paediatric ANP for Haematology and Oncology

Kate Norton

Tel: 024 7696 7291

Paediatric Haemoglobinopathy clinical nurse specialists

Vicki Hagger and Elle Lakhani

Service hours: 8am - 5pm, (Monday - Friday)

Secretary: 024 7696 7234

Office: 024 7696 7225

Mobile: 07876681069

Patient Information

Please note: the nursing team is available for advice and guidance only. This is not an emergency contact number. Please allow up to 2 working days for a response.

Emergency service and out of hours

If your child is unwell or experiencing a painful sickle cell crisis that you cannot manage at home, please go to the Children's Emergency department. On arrival, tell staff that your child has sickle cell disease or thalassaemia and present your sickle cell alert card, if you have one.

The emergency department staff are trained to care for children with these conditions and will seek support from the specialist team if needed. Please bring your personalised care plan, if you have one, to help with your child's treatment.

Our services

- Follow-up after neonatal screening.
- Specialist consultants and nurses.
- Co-ordination of care for children with haemoglobinopathy disorders.
- Specialist clinics on the second and fourth Wednesday of the month, between 9am – 12pm.
- Hydroxycarbamide clinics.
- Joint clinics with a haematology specialist from Birmingham Children's Hospital every 3-6 months.
- Transition clinics for patients moving to adult care.
- Transcranial Doppler screening clinics.
- Link nurses on the wards.
- Training and education for patients, parents, and health professionals.
- Education for nurseries and schools, including school care plans.
- Home visits.
- Phlebotomy services via mainstream services or the Paediatric Medical Day Unit.
- Auditing and research.

Patient Information

- Links with the Children's Emergency Department.
- Referrals and links with specialist services, including endocrinology, heart specialists (cardiology), kidney specialists (renal), urology, orthopaedic, and maternity.
- Signposting to welfare and other social services.

The West Midlands Paediatric Haemoglobinopathy Network (WMPHN) was launched on 23 May 2016. Its aim is to improve and standardise care for patients with cell disease and thalassaemia living in the West Midlands. More information is available at: <https://www.westmidstn.nhs.uk/>

Haemoglobinopathy service Padlet

Use the QR code below to access our Padlet. It provides up-to-date information and links about the support and services available.



Other departments

Children's Medical Day Unit, Ward 16, Children Unit

- Mainly for blood transfusions and blood tests.
- Tel: 024 7696 7271
- Open: 07.30am to 6pm, Monday, Wednesday, Thursday, Friday.

Children's Wards

- Age 0 - 2 years old: Ward 15, Tel: 024 7696 6595
- Age 3 -12 years old: Ward 16, Tel: 024 7696 7224
- Age 13 -16 years old: Ward 14, Tel: 024 7696 7432

Children's outpatients department:

For appointment queries or cancellations, please contact 024 7696 7216.

Patient Information

Other useful services

The Sickle Cell Society

54 Station Road, London, NW10 4UA

Tel: 020 8961 7795

Website: www.sicklecellsociety.org

The UK Thalassaemia Society

19 The Broadway, Southgate Circus, London, N14 6PH

Tel: 020 8882 0011

Website: www.ukts.org

NHS Sickle & Thalassaemia Screening Programme

www.gov.uk/topic/population-screening-programmes/newborn-blood-spot

Benefit support

Coventry City Council - Benefits

- Tel: 024 7683 2000
- Website: www.coventry.gov.uk/benefits
- Address: Customer Service Centre, Floor 1, Broadgate House, Coventry, CV1 2FS

WMSTN Citizens Advice - Welfare Advisor

- Tel: 07841023120
- Website: www.bcabs.org.uk/page/view/wmstn

Your views

If you are unhappy about any aspect of care, please tell a member of staff as soon as possible. They may be able to resolve the problem straight away.

If you prefer to speak to someone independent from your care team, contact our Patient Advice and Liaison Service (PALS). To make a formal complaint, you must write a letter or email to the Trust's complaints manager.

Patient Information

PALS:

- Tel: 0800 028 4203
- Email: feedback@uhcw.nhs.uk
- Address: Patient Advice & Liaison Service (PALS) University Hospital, Clifford Bridge Road, Coventry, CV2 2DX

ICAS for Coventry (provided by Healthwatch Coventry)

- Tel: 024 7625 2011
- Email: ICAS@healthwatchcoventry.co.uk

The Trust has access to interpreting and translation services. If you need this information in another language or format, please contact us and we will do our best to meet your needs.

If you need assistance for an appointment, please call: 024 7646 7234.

The Trust operates a smoke free policy.

Did we get it right?

We would like you to tell us what you think about our services. This helps us make further improvements and recognise members of staff who provide a good service.

Have your say. Scan the QR code or visit:

www.uhcw.nhs.uk/feedback



Document History

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