

---

## Introduction

This leaflet provides information about St Mary's Hospital's haemoglobinopathy services. If you have any further questions during your visit here please don't hesitate to ask a member of staff.

## The team

The haemoglobinopathy service is led by a consultant paediatric haematologist, with the support of a clinical nurse specialist (CNS). If your child is admitted to the wards, a specialist paediatric haematology consultant will oversee their care. They will also be seen daily by the paediatric haematology doctors.

## Accident & emergency

St Mary's Hospital has a 24-hour paediatric A&E department where guidelines for the management of children with sickle cell disease and thalassaemia are in place. Please help the staff by bringing your red book and patient-held record book.

## Wards

If admitted, children will stay on either the **great western** or **grand union ward**, where visiting for parents is unrestricted. One parent is welcome to stay overnight and we can provide a folding bed.

For family and friends, visiting is allowed until 20.00. Staff will explain visiting restrictions when your child is admitted.

The **paediatric haematology day care unit** is based on the sixth floor and cares for children who need regular blood transfusions. The centre also has a **paediatric intensive care unit** providing specialist care and advice for children when needed.

## Monday clinics

Clinics are held on Mondays between 13.30 and 17.00 (with the last appointment at 16.00). During this visit we will:

- monitor your child's general health
- record their weight and height
- monitor oxygen saturations and blood pressure (for older children urinalysis will also be performed)

Once we have taken a baseline blood test, we will try to limit further tests to once a year only, unless your child is on specialist medication or having blood transfusions.

Additionally, a specialist **endocrine clinic** (monitoring of growth and hormones) is held every three months and a specialist **respiratory clinic** is held every two months.

Appointments for **trans-cranial doppler** studies (ultrasound test of cerebral arteries to detect children who may be at increased risk of stroke) for children aged two and above are also held on Monday afternoons. Ask a nurse for more information.

## Adolescent clinics

These clinics are held once a month on Tuesdays between 15.00 and 19.00 (with the last appointment at 18.15).

If you are unable to attend your appointment please ring outpatients on **020 3312 6315** or the haematology secretary on **020 3312 6157**.

## Other services and support available

- Bone marrow transplants
- Dietitian – offering specialist advice
- Psychological support
- Specialist social work support - referrals can be made via our CNS
- Play specialist support
- Pain management

Referrals can also be made to respiratory, neurology, dental, cardiology, ophthalmology, audiology, ENT, orthopaedics and surgical consultants when needed.

## Support group

Meetings are held every 12 weeks on a Friday evening. Contact our CNS for the dates of the meetings on **020 3312 3346** or **07795 651 153**.

Children are welcome to attend and a play specialist will be available.

## Clinical nurse specialist

The CNS can offer clinical and inpatient advice over the telephone from 09.00 to 17.00, Monday to Friday. However, if the CNS is not available or you are worried about your child, you should either contact your GP, phone NHS Direct on **111** or visit the children's A&E department.

## Further information and support

If you live in the following areas, further support is available via your local Sickle Cell & Thalassaemia Centre:

**Brent:** 020 8453 2050 / 2052

**Ealing:** 020 8825 8241

**Hammersmith & Fulham:** 020 3315 2980

### Sickle Cell Society

Telephone: 020 8961 7795

Email: [info@sicklecellsociety.org](mailto:info@sicklecellsociety.org).

Website: [www.sicklecellsociety.org](http://www.sicklecellsociety.org)

### Sickle Cell Information Centre

[www.scinfo.org](http://www.scinfo.org)

### Thalassaemia Society

Telephone: 020 8882 0011

Website: [www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)

## How do I make a comment about my treatment?

Please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777**. You can also email PALS at [pals@imperial.nhs.uk](mailto:pals@imperial.nhs.uk). Alternatively, you may wish to express your concerns in **writing** to: Chief executive – complaints, Imperial College Healthcare NHS Trust, Trust Headquarters, The Bays, South Wharf Road, London W2 1NY.

## Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on 020 3312 5592.

Haemoglobinopathy services

Published: June 2015

Review date: June 2018

Reference no: 2425v3

© Imperial College Healthcare NHS Trust

# Haemoglobinopathy services at St Mary's Hospital

## Information for patients, relatives and carers



THALASSAEMIA

