

Clinical haematology

Haemoglobinopathies services for children at St. Mary's Hospital

Information for patients, relatives and carers

Introduction

Haemoglobinopathies are a group of blood disorders including sickle cell disease (SCD) and thalassemia. This leaflet provides information about the haemoglobinopathies service at St Mary's Hospital. If you have any further questions during your visit here, please don't hesitate to ask a member of staff.

The children's haemoglobinopathies team consists of:

- Nurses
- Doctors
- Healthcare assistants
- Student nurses
- Administrative team
- Clinical nurse specialists (CNS)
- Community haemoglobinopathies nurse
- Clinical psychologists
- Pharmacist
- Phlebotomist
- Play specialists
- Teachers
- Social worker
- Volunteers
- Clinical trials team
- Cleaning and catering services staff

The haemoglobinopathies service is led by a consultant paediatric haematologist, with the support of a matron and a CNS. If your child is admitted to the wards, a specialist paediatric haematology consultant will oversee their care. The paediatric haematology doctors will also visit them every day.

Outpatient service

The children's haemoglobinopathies service includes the following clinics:

Monday clinics

Clinics are on Mondays in the paediatric haematology day unit (PHDU) between 13.30 and 17.00 (with the last appointment at 16.50). During this visit we:

- Monitor your child's general health
- Record their weight and height
- Monitor oxygen saturations and blood pressure (for older children we will also ask for a urine sample)

Once we have taken a baseline blood test (results we can compare future blood tests to), we will try to limit tests to once a year only. We might have to do more tests if your child is on specialist medication or having blood transfusions.

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

Appointments for **Trans-Cranial Doppler** studies (TCD – 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, Tuesday and Wednesday afternoons. Ask your CNS for more information.

Adolescent clinics

These clinics are held in Children's Main Outpatients every second Tuesday of the month between 16.00 and 19.00 (with the last appointment at 18.30).

If you cannot attend your appointment, please ring outpatients on **020 3312 6315** or the haematology secretary on **020 3312 6157**.

What you can expect at your clinic appointment

You will be seen by a haematology doctor when you attend your clinic appointment. There may be another member of the haemoglobinopathies clinical team at your appointment .

At your first outpatient appointment with the haemoglobinopathies service, we'll talk to you about your medical history and do an examination (such as height, weight, listening to your heart and chest as well as an abdominal examination). We might ask you about vaccinations you have received and any medication you are currently taking. We'll talk to you about your diagnosis; any related complications and give you advice on how you should take care of

yourself at home. You will also be given written information on sickle cell disease or thalassemia and information on support groups and how you can access more advice.

On the day of the appointment, we might ask you to take a blood test and the doctor will explain what this is for. A member of the team will inform you about the National Haemoglobinopathies Registry (NHR) and talk to you about consent to share some of your clinical information with the NHR.

At routine appointments, the doctor will ask you how you have been feeling since your last clinic appointment and about any concerns you have. You will usually have a repeat blood test and physical examination. You will normally be sent a record of your consultation shortly after your appointment.

Paediatric haematology day unit (PHDU)

The day care unit is open between **09.00 and 17.00 Monday to Friday**. It includes:

- outpatient clinics
- transfusion service and phlebotomy (where blood tests are taken)
- follow-up review clinics for after a hospital stay
- assessment clinics before surgery.

The day care unit is on the sixth floor of the Queen Elizabeth Queen Mother building. The service treats patients with cancer and non-cancer conditions who have planned procedures and treatments such as transfusions. It is run by nurses and supported by doctors.

Exchange transfusion is carried out at Grand Union Ward, which is on the seventh floor of the Queen Elizabeth Queen Mother building. We will give you a leaflet about the red cell exchange – let us know if you don't have it.

Phlebotomy service (blood sampling)

The phlebotomy service runs between **09.00 and 16.00 Monday to Friday**, on the 6th floor of the Queen Elizabeth Queen Mother building.

Other services and support available

- Bone marrow transplants
- Dietitians – offering specialist advice
- Pain management

We can make referrals to respiratory, neurology, dental, cardiology ophthalmology, audiology, ENT, orthopaedics and surgical consultants when needed.

Clinical nurse specialist

The CNS can give you clinical and inpatient advice over the telephone on **07795 651153** 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 contact your GP, phone NHS Direct on **111** or visit the children's A&E department.

Psychology services

The psychologist is a core member of the haemoglobinopathies team and can support to inpatients and outpatients with red cell disorders. The psychologist can help address any concerns you might have about your treatment or about pain, depression, stress or anxiety, relationships, communication and more. They will work with you to give you the skills to manage your condition.

Social services

We have a specialist haemoglobinopathies social worker, employed by Imperial College Healthcare NHS Trust. The social worker can give practical information, advice and support to patients, relatives and carers about:

- Finances
- Welfare benefits including universal credit, housing benefit, council tax support, disability living allowance and personal independence payment (PIP)
- Housing
- Education/employment
- Immigration
- Local support/charity services
- Local authority social services
- General support

Patients can either be referred by a professional to the specialist social worker or can contact them directly.

Local authority social services

Patients who need additional support can be referred to the children's social services team. Hospital staff can make a referral to their local authority children's social care services, who will do an assessment.

Immigration Advice

The specialist social worker can provide haemoglobinopathies patients with information and support on immigration. Please tell a member of the haemoglobinopathies team if you need more information on immigration.

Other useful sources of support and advice can come from: www.lawcentres.org.uk/other-sources-of-advice

Changing or cancelling your appointment

You should check your appointment letter or email for details of how to change or cancel your appointment. If unsure, contact our central booking team on **020 3313 5000** or

Email: appointments@imperial.nhs.uk. Please remember to include your hospital or NHS number (which can be found on your appointment letter), your full name and your date of birth in your email. Our central booking office is open **08.00 to 20.00, Monday to Friday**.

If your first appointment with us was made through the NHS e-Referral Service (previously known as Choose and Book) call the NHS e-Referral Service appointments line on **034 5608 8888** to reschedule your appointment.

If you can't make your appointment or want to change your appointment, please contact us on **020 3313 5000** as soon as possible. We will do our best to reschedule your appointment as well as offer your existing appointment to another patient. Missed appointments significantly impact on the way we provide our outpatient services, so it is very important that you contact us if you are unable to attend.

Inpatient wards

If admitted, children will stay on either the great western or grand union ward, where visiting for parents is unrestricted.

One parent or carer 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 (PHDU) is based on the sixth floor and cares for children who need regular blood transfusions. The paediatrics service also has a paediatric intensive care unit (PICU) providing specialist care and advice for children when needed.

Great Western Ward: Located on the 7th floor of the Queen Elizabeth Queen Mother

- Telephone: 020 3312 1987, 020 3312 6464
- Visiting Hours: 09.00 to 20.00 – for family and friends, parents anytime

Grand Union Ward: Located on the 7th floor of the Queen Elizabeth Queen Mother

- Telephone: 020 3312 6465, 020 3312 6405
- Visiting Hours: 09.00 to 20.00 – for family and friends, parents anytime

Interpretation service

Interpretation services, on call interpreters and translators are now able to take new bookings for face-to-face interpreters. This is in addition to the telephone interpretation service.

For telephone interpreting, please call **020 3434 3460**, tell them the name of our Trust (Imperial College Healthcare NHS Trust) and the language you need. You do not need to book in advance for this service.

If you need face-to-face interpretation services, you should also ring **02034343460**.

Chaplaincy and faith services

We understand that coming to hospital can be a difficult and emotional time for lots of people. If you are facing a time of illness, uncertainty or change, you can meet with a member of our friendly chaplaincy team who can provide emotional, pastoral and spiritual support, as well as a listening ear when you need it most. The team is available from **Monday to Friday, 09.00 to 17.00**. If you would like to speak with a chaplain, please ask a member of staff to contact the team and arrange a time for you.

The chaplaincy team also provide a 24/7 emergency service for people who are experiencing extreme distress. If you think your need is urgent, please talk to a member of staff and they will contact the on-call chaplain.

National Haemoglobinopathy Registry (NHR)

The NHR is a database of patients living in the UK who have red cell disorders (mainly SCD and thalassaemia). This database collects data from haemoglobinopathy centres, which is required by the Department of Health and Social Care. The aim of the registry is to improve patient care for these conditions. Your child's team will speak to you about this in detail and offer you an information leaflet.

Contact details

St. Mary's Hospital switchboard 020 3313 1000

Children's Outpatient Clinic reception 020 3312 5146

Paediatric Haematology Day Care Unit reception 020 3312 5080

Clinical Nurse Specialists for Children's Haemoglobinopathies (Sickle Cell Thalassemia etc.) 020 3312 3346 / 07795 651153

Grand Western Ward (including out of hours) 020 3312 1987 or 020 3312 6464

Grand Union Ward (including out of hours) 020 3312 6465 or 020 3312 6405

Paediatric Site Practitioner 07824625419

Clinical Psychologist via children's Haematology secretary (Sickle Cell /Thalassemia) 020 3312 6157

Social worker 020 3313 7136

Outpatient Pharmacy 020 3312 5625

Community CNS Information

- **Hounslow and Richmond:** Sonia Ambo (specialist nurse)
sonia.ambo@nhs.net
0203 7716092
07500 920558
- **Central London Community Healthcare NHS Trust (CLCH) (Hammersmith, Fulham, Kensington, Chelsea and Westminster):** Emma Savie-Disu (specialist haemoglobinopathy nurse/genetic nurse counsellor)
emma.savie-disu1@nhs.net
clcht.sicklethal@nhs.net
07876843443
Tuesday, Wednesday and Thursday only
- **Brent (Brent and Harrow):** Elizabeth Olukoga (specialist nurse)
elizabeth.olukoga@nhs.net
0208 453 2050/2054
- **Camden and Islington:** Grace Adjei-Clinton (paediatric community nurse)
grace.adjei-clinton@nhs.net
020 3316 8860

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 8967 5643
- **Hammersmith, Fulham and Westminster:** 020 7266 8892

Sickle Cell Society

020 8961 7795

info@sicklecellsociety.org

www.sicklecellsociety.org

Sickle Cell Information Centre

www.scinfo.org

Thalassaemia Society

thalassaemia@cytanet.com.cy

www.thalassaemia.org.cy

The Care Information Exchange (CIE)

CIE gives secure online access to information from the hospital such as test results, appointments and letters. Young people and their parents can also add things like symptoms the young person is experiencing to give a more complete record. To register and access the record QR code below to download the application.

Everyone registering will need to complete a form, show proof of identification, and have an email address. The email address will be the login name, and the address for notifications when something new is added to the record. Go to www.careinformationexchange-nwl.nhs.uk/ or scan this QR code with your phone camera to find out more and register:



How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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