

Sickle cell and thalassaemia service for babies, children and young people

About our service

The paediatric (children's) sickle cell and thalassaemia team runs a specialist and comprehensive care service for children and adolescents in south east London who are born with these inherited disorders.

The service we provide begins at birth and continues until patients are transferred to the adult team.

We are based at the Evelina London Children's Hospital on St Thomas' Hospital site (Westminster Bridge Road). If St Thomas' is not your local hospital, we will work closely with your local NHS trust to help you receive the specialised care that you need, both in hospital and in the community.

Within the service, our specialist adolescent team will ensure a smooth transfer from paediatric to adult care when your child moves into adolescence.

Clinics

We hold clinics every Friday, from 9am to 1.30pm, at Evelina London Children's Hospital on the ground floor (Ocean). Please arrive for your appointment on time, as this will help us run the clinic smoothly and avoid delays.

What will happen in the clinic?

Please check in with the receptionist when you arrive and let them know if any of your contact details have changed.

Your child will be weighed and measured by a member of the nursing team before you see the doctors. They will also measure your child's blood pressure and oxygen saturation. At some appointments your child may need to provide a urine sample, or have a blood test or immunisation.

You will then be called to see one of the doctors who will talk to you and your child and examine them. The doctor will discuss any concerns you have regarding managing your child's medical condition and compliance with medications.

If your child needs a blood test, the doctor will order these on the computer system. After you leave the doctor's room you should go to the waiting area where your child's name will be displayed on the monitor informing you where to go.

Any other tests that may be necessary such as X-ray, ultrasound or transcranial Doppler scan (TCD) will be explained and arranged by the doctor you see in clinic.

Who else may your child see in clinic?

Your child may also see one of the following members of our team:

- clinical nurse specialist
- senior research nurse
- adolescent nurse practitioner
- community nurse specialist
- psychologist.

Joint specialist clinics

We work closely with other specialists to provide joint care for your child. If your child needs to be seen in one of these clinics, we will explain why.

In these clinics, Dr Inusa or Dr Pelidis and a second specialist consultant will see you together.

Joint respiratory clinic: every third Wednesday of the month, 9am to 1pm, 2pm to 5pm.

Joint neurology clinic: every second Thursday of the month, 9am to 1pm.

Joint nephrology clinic: every third Tuesday of the month.

Transition service

The transition service is a service involved in planning your child's care and supporting you and your child to move from the children's hospital to the adult hospital. As your child has a chronic condition that will require ongoing treatment, it is important that you and your child understand and prepare for the changes that your child will go through as they grow, and what they mean for their care.

The transition team will discuss a number of issues with you and your child. Their aim is to help you and your child understand the condition better and to prepare them for the changeover to adult services.

Cancelling appointments

If you cannot make an appointment please telephone the outpatient appointment department on 020 7188 4000 as soon as possible and make another appointment that is convenient.

Admission to hospital

If your child is unwell, they may be admitted onto one of the following wards:

Mountain – medical/surgical

Forest – paediatric intensive care unit (PICU)

If your child requires a blood transfusion, an MRI under general anaesthetic, or a day review, they will be admitted onto **Snow Fox** ward, which is open from 7.30am to 8pm (excluding bank holidays).

Out of hours transfusions take place on **Mountain** ward.

Your child may be seen by other doctors from other teams if they are admitted over the weekend or out of hours Monday to Friday. They will liaise closely with the haematology consultant.

Phlebotomy service

Phlebotomy is located on the ground floor of St Thomas' Hospital, North Wing. Opening times are Monday to Friday, 8.30am to 5.30pm (excluding bank holidays).

Community services

We work closely with the community specialist sickle cell and thalassaemia nurses. Certain parts of your child's care are best provided by them rather than us. With your consent, we can refer you to them if you need support.

They can provide the following:

- home visits
- genetic counselling
- pre-conception screening
- support with housing and other social issues
- care plans for schools
- help with benefits applications
- patient support group details
- health promotion.

Research

The hospital is also a major research centre. During your visit you may be asked whether you are willing for your child to take part in a clinical research study. You are under no obligation to do so and this will not affect the care that you receive.

Help and advice will always be available if you have any questions or concerns.

Meet our team

Consultants:

Dr Baba Inusa – lead consultant for children with haemoglobin disorders

t: 020 7188 7774 (secretary – Mary Adeyoluwa)

e: mary.adeyoluwai@gstt.nhs.uk

Dr Maria Pelidis – consultant in paediatric haematology

t: 020 7188 7774 (secretary – Mary Adeyoluwa)

e: mary.adeyoluwai@gstt.nhs.uk

Dr Jay Alamelu – lead consultant for haemophilia and thrombosis

t: 0207 188 7545 (secretary – Janet Roads)

Therapy and psychology team:

Dr Hatel Bhatt – counselling psychologist. Dr Bhatt is trained to help children cope with the difficulties that can arise from having a chronic illness. She will meet you in clinic or arrange a visit if needed.

Dr Anna Hurley – neuropsychologist for assessment of children with haemoglobin disorders.

t: 020 7188 9125

Sickle cell nurse specialists:

Natalee Murray – sees children within the hospital, and also offers support and advice to all those caring for your child. She works with the sickle cell nurses, who are based in the community.

t: 020 7188 9432 or 07771 345 847

e: natalee.murray@gstt.nhs.uk

Sharon Ndoro – senior research nurse coordinator.
Sees children within the hospital and also offers support and advice to all those caring for your child. She works with children involved in research or who might be interested in taking part. She will explain what is involved and what the research is about.

t: 020 7188 6637 or 07918 338 730

e: sharon.ndoro@gstt.nhs.uk

Stephanie Quirk – research data assistant

She works with children involved in research or who might be interested in taking part.

Community nurses

Community nurses are based in the **South East London Sickle Cell and Thalassaemia Centre** at Wooden Spoon House. Although they are based in the community, they work closely with the hospital team.

The community nurses offer specialist services, including genetic counselling, pre-conception screening, health promotion and education, support and counselling for all those affected by haemoglobinopathies. They accept self-referral or referral from health professionals or others. Clients can be seen at the centre's drop-in clinics or at home. Visits may be requested by clients who live in the boroughs of Lambeth, Southwark and Lewisham.

Kemi Ajamufua – specialist nurse (community)

t: 020 3049 5993

e: olukemi.ajamufua@gstt.nhs.uk

Other team contacts:

Paediatric and haematology registrar for
haemoglobinopathies

t: 020 7188 7188 and ask for the bleep desk. Ask for bleep 1621 and wait for a response. This will connect you to the registrar directly. You can also ask for bleep 2918 Monday to Friday, 8am to 5pm.

Emergencies

If you need to come to the Emergency Department (A&E) at St Thomas' Hospital, please telephone the department before you arrive on **t:** 020 7188 2111 and let them know about your child's condition. This will help to improve your child's care when you arrive.

Where can I get further information?

Sickle Cell and Thalassaemia Conference

This annual international conference is held at the Guy's and St Thomas', with world experts in haemoglobinopathies. For more information visit the websites below. If you are interested in attending, please email Dr Baba Inusa.

w: www.scorecharity.com

w: www.ststn.co.uk

e: baba.inusa@gstt.nhs.uk

Sickle Cell Society

Provides help and support for people affected by sickle cell disorders and their carers.

t: 0800 001 5660

w: www.sicklecellsociety.org

The Sickle Cell & Thalassaemia Centre

Provides information about sickle cell disease.

Thalassaemia counsellors can also offer support and information. The centre can also direct you to local services.

t: 020 7414 1363

South Thames Sickle Cell and Thalassaemia Network (STSTN)

Produces a newsletter for patients three times a year.

This is a new collaboration led by doctors from Evelina London Children's Hospital, Guy's and St. Thomas' Hospitals and King's College Hospital. More information

can be found on their website.

w: www.ststn.co.uk

Notes

Contact us

Mountain ward t: 020 7188 8845 (medical reception) or 020 7188 8852 (surgical reception)

Forest ward t: 020 7188 4500 / 4501

Snow Fox ward t: 020 7188 4670, Monday to Friday, 7.30am to 8pm.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003, Monday to Friday, 10am to 5pm

e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:**

complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

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