

# Paediatric Haemophilia Service

**This leaflet explains the services available within the Paediatric Haemophilia and Haemostasis Service and what you can expect when you bring your child to clinic. If you have any further questions, please contact us on 020 8725 0763.**

## What is the Children's Haemophilia and Haemostasis clinic?

The Children's Haemophilia and Haemostasis clinic is part of the St George's University Hospitals NHS Foundation Trust Haemophilia Centre and is open to all children with haemophilia and other bleeding disorders (blood clotting problems).

## Who can attend / receive the service?

Children can be referred by their GP or other health care professional if they have previously been diagnosed with an inherited bleeding disorder or if a family member is affected. Children with symptoms of a bleeding disorder or with abnormal clotting test results may also be referred.

The purpose of the clinic is to provide specialist regular care for these children and to provide support for them and their families. The clinic is open to children from the time they are born until they are about 18 years old. When the children become teenagers we will prepare them to move to the appropriate adult clinic.

## Where is the Paediatric Haemophilia Clinic?

The clinic is held in the Children's Dragon Centre, which is on the Ground Floor of Lanesborough wing. The clinic is held every first, third and fifth Wednesday morning between 8.50am and 12.00pm.

The transition haemophilia clinic is held on the fourth Friday of alternate months.

## Who will I see in the Clinic?

We are dedicated to providing the best possible care for your child and we believe that your family benefits from having a whole team of experts involved in your child's care. The clinic is run by a multidisciplinary team which includes:

- Consultant Haematologists – Dr Rubina Malik or Dr Alison Thomas
- A Clinical Nurse Specialist in Paediatric Haemophilia and Haemostasis
- A Paediatric Physiotherapist – Clare Whistler
- Paediatric Phlebotomy
- Medical students
- Nursing students

## What can I expect from the clinic?

Upon arrival at the clinic you and your child should register at the reception desk.

The reception staff will check your child's name and address, contact details and the name and address of your GP.

A staff member will measure your child's weight and height. After this your child will be seen by a doctor and / or clinical nurse specialist.

During the first visit, the doctors will gather a lot of information about your child and your family. In addition to examining your child, the doctor will give you information about your child's condition and answer any questions you may have. Your child will also need to have a blood test by the paediatric phlebotomist.

During a follow up appointment the doctor and / or clinical nurse specialist will:

- Find out how your child has been since their last clinic appointment.
- Explain the results of blood tests that your child has had at previous clinic or follow up blood tests.
- Monitor any changes in weight and height.
- Answer any questions that you may have about your child's bleeding disorder.
- Ensure that you / your child understand any medication(s) that they need to take and when to take them.

At some follow up clinic appointments your child will need to have a blood test. This will usually take place on the same day as the clinic appointment and will take place in the paediatric phlebotomy room situated adjacent to the clinic waiting room.

If you would like your child to have cold spray (a local anaesthetic spray) that will help numb the area prior to the blood test, then please ask when you are called into the phlebotomy room. If you would prefer your child to have Ametop cream (a local anaesthetic cream) prior to their blood test, please speak to one of the nurses in the clinic.

After each clinic appointment your child's doctor / clinical nurse specialist will write a letter to your GP about your child's visit. You will receive a copy of this letter.

At the end of the clinic appointment your doctor will request an appointment for follow up.

## What if I need to cancel an appointment?

It is very important to attend all of your child's clinic appointments. Even if your child is doing well it is important to meet with the doctor to review his / her progress.

If you cannot attend an appointment, please call the clinic reception as soon as possible on **020 8725 5292 / 5291**. **Alternatively you could write an email to the [childrens.secretariesC@stgeorges.nhs.uk](mailto:childrens.secretariesC@stgeorges.nhs.uk)**. This will allow another child to use your original appointment slot.

## What other services are available?

- Paediatric Accident and Emergency department – where children will be reviewed by the emergency team (Doctors and Nurses) as well as by the Haemophilia team.
- Paediatric Day Care ward (Jungle ward) – where children may be asked to attend for specific tests related to their bleeding disorder and for follow up assessments.
- Specialist dentistry for children with inherited bleeding disorders.
- Physiotherapy.
- Clotting Factor Home Delivery service.
- School and nursery visits and providing schools with a Bleeding Disorder management plan.
- Travel information regarding haemophilia emergency care when travelling abroad.

## Inpatient Care

If your child needs to be admitted to hospital for treatment, s/he will be admitted to a paediatric ward. Your child will be reviewed by the paediatric team and paediatric haemophilia team.

The paediatric wards to which your child is likely to be admitted are: Nicholls ward, Frederick Hewitt ward or Pinckney ward. Parents are allowed to visit their children at all hours. Family and friends are not permitted during protected meal times from 12.30 to 1.30pm and 5 to 6pm.

## What to do if your child has a bleed or injury

Please contact the Haemophilia Centre on 020 8725 0763 if your child has a bleed. You can also contact us on the haemophilia nurse specialist's contact number on 07771 594 704 or 07393 249 628. We will need to assess the injury or bleed over the telephone and advise you appropriately. You will need to go to your nearest Emergency Department for assessment and treatment.

Out of hours, you must contact the Haematology Registrar on call via the hospital switchboard.

## How to access physiotherapy

You can contact physiotherapy by contacting the haemophilia team or via the clinical specialist nurse who will then contact the physiotherapist.

## How to access psychology

You can contact the haemophilia team or the clinical specialist nurse who will then refer to the paediatric psychologist.

## Contact us

If you have any questions or concerns, please contact the haemophilia team on 020 8725 0763 (Monday to Friday 8.00am to 5.00pm). Out of hours, please contact the on-call haematology registrar via the hospital switchboard on 020 8672 1255.

Clinical Nurse Specialists

Antoinette Brown – 07771 594 704

Charlotte Beeton – 07393 249 628

## Useful sources of information

The Haemophilia Society: [www.haemophilia.org.uk](http://www.haemophilia.org.uk) email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

The World Federation of Hemophilia: [www.wfh.org](http://www.wfh.org)

The Canadian Hemophilia society: [www.hemophilia.ca](http://www.hemophilia.ca)

**For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.stgeorges.nhs.uk](http://www.stgeorges.nhs.uk)**

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## Additional services

### Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:

Monday, Tuesday and Thursday between 10am and 4pm

Friday between 10am and 2pm.

Please contact PALS in advance to check if there are any changes to opening times.

The Walk-in and Advisory telephone services are closed on Wednesdays.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough wings.

**Tel:** 020 8725 2453 **Email:** [pals@stgeorges.nhs.uk](mailto:pals@stgeorges.nhs.uk)

### NHS UK

The NHS provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

**Web:** [www.nhs.uk](http://www.nhs.uk)

## NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

**Tel:** 111

## AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website ([www.accessable.co.uk](http://www.accessable.co.uk)).

The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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