

# Paediatric Haemophilia Service

**This leaflet explains more about 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 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 1<sup>st</sup>, 3<sup>rd</sup> and 5<sup>th</sup> Wednesday morning between 08.50am and 12.00pm and every Wednesday afternoon between 2.00pm and 5.00pm.

## Who will I see in the Clinic?

We are dedicated to providing the best possible care for your child and 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
- A Clinical Nurse Specialist in Paediatric Haemophilia and Haemostasis
- A Paediatric Physiotherapist
- 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 ask to see your child again, usually in a couple of months. It is important to make a follow up appointment before you leave the clinic. This can be done at the clinic reception desk before you leave.

## 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 1741**. This will allow another child to use your original appointment slot.

During the telephone call please make another appointment for a more convenient time.

## 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.

## Useful sources of information

The Haemophilia Society: [www.haemophilia.org.uk](http://www.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)

## 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.

**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 on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

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

### NHS Choices

NHS Choices 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 of 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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