

The Inherited Bleeding Disorder Centre

Information for patients & families



leeds children's
hospital

caring about children

The Combined Adult and Paediatric Leeds Inherited Bleeding Disorder (Haemophilia) Centre is a Comprehensive Care Centre (CCC) providing outpatient and inpatient care for over 500 patients with inherited bleeding disorders.

The Leeds Children's Hospital Centre manages Children and Young Adults up to the age of 18 years. Paediatric and adult services are located at different sites within Leeds Teaching Hospitals NHS Trust but many of the team work with both groups and thus we consider ourselves as one Comprehensive Care Centre. We are able to provide diagnostic services; 24 hour access for the assessment and treatment of bleeds; home treatment training programmes; home delivery services and counselling and support for patients and their families.

Additional services include - a combined Haematology Obstetric Clinic, a combined Haemophilia Orthopaedic Clinic, Specialist Podiatry and Physiotherapy services, a combined Children's Haemophilia / Rheumatology Clinic, venous access workshops and a Paediatric Social Worker.

The outpatient facilities

The outpatient facilities for Children and Young Adults with bleeding disorders are located on C Floor in Clarendon wing at the Leeds General Infirmary (LGI) site. It is based within the designated outpatient suite for children and young adults with haematology and oncology disorders. This is a purpose built facility with a child friendly play area staffed by Play Therapists and a separate waiting area for adolescent patients.

Day case beds and individual consultation rooms are available of which one is designated as the Haemophilia Centre.

Clinics for children and young adults with haemophilia and other heritable bleeding disorders are held on Monday mornings. The contact telephone number to enquire about or change appointment times is 0113 392 7179.

The inpatient facilities

The inpatient facilities are age based with one ward designated for children under the age of 13 (**Ward L31**) (**Tel: 0113 392 7431**) and another ward designated for teenagers and young adults (**Ward L33**) (**Tel: 0113 392 7433**). There are teaching assistants who provide ongoing education for children whilst an inpatient. The teenage facilities include entertainment and distraction areas relevant to this age group. There is unrestricted visiting for family members.

9am to 5pm Monday to Friday

Haematology Clinic, C Floor, Clarendon Wing

Tel: 0113 392 7379

All other times

Ward 31, A Floor, Clarendon Wing

Tel: 0113 392 7431

Ward 33, A Floor, Clarendon Wing

Tel: 0113 392 7433

Website: www.leedsth.nhs.uk/a-z-of-services/haemophilia-comprehensive-care-centre

Paediatric team members

| | Name | Contact number |
|----------------------------|------------------|--------------------------------|
| Paediatric Centre Director | Dr Mike Richards | 0113 392 8776 |
| Lead Nurse | Sarah Garside | 0113 392 6863 0771 730 3306 |
| Clinical Nurse Specialists | Ruth Hughes | 0113 392 6863 0787 659 7097 |
| | Liz Smith | 0113 392 2724 0787 620 7903 |
| Physiotherapists | Anne Penn | 0113 206 8373 |
| | Thuvia Flannery | |
| Paediatric Social Worker | Musrat Pinnu | 0113 535 1503 0770 371 5460 |

If you feel **social work** support would be of benefit to your family referrals can be made directly to the number above or through any member of the Haemophilia Team. Support can be offered at the time of diagnosis or at any point thereafter. Support can be given with a wide range of issues and an individual assessment is offered to help identify areas of work.

We have a **dedicated physiotherapy team**, to provide assessment, treatment and advice for those children affected by bleeding disorders. Physiotherapy has a role in reducing any complications following a bleed. We complete detailed assessments to monitor joint health and function. These assessments highlight any problems with joints or muscles, but the results can also assist in onward referral for imaging.

We provide support / education to school and nurseries regarding the importance of appropriate exercise, as well as assessing gross motor skills i.e. rolling, crawling and walking in our younger children.

If you require physiotherapy, please do not hesitate to contact us on the number on page 4 of this leaflet.

If you need an **interpreter** please ask your GP at the time of referral or speak to our administrators. There is a **local support group** with its own Facebook page, please ask us for contacts. There is a local haemophilia society group, please ask us for contacts. See our website for details of national organisations.

Please complete a form at reception to give **feedback** and provide us ideas to improve our service. Our Trust **Patient Advice and Liaison Service** is available to ask general questions, give feedback or help you with advocacy services. They can be contacted via email:

- patientexperience.leedsth@nhs.net

or The PALS intranet link is:

- <http://lthweb.leedsth.nhs.uk/sites/complaints/patient-experience/pals-homepage>

Useful links

World Federation of Hemophilia

An international resource with information on bleeding disorders in a number of languages and also a locator of haemophilia centres around the world for travel information.

www.wfh.org

Haemophilia Society

A UK support group with useful information on bleeding disorders.

www.haemophilia.org.uk

National Haemophilia Database

The National Haemophilia Database (NHD) is a register of UK patients (adults and children) with all kinds of bleeding disorders, which was established in 1969. The database is managed by the UK Haemophilia Centre Doctors' Organisation (UKHCDO) - the doctors who treat bleeding disorders in the UK. This leaflet describes the data and how the information is used.

www.ukhcd.org/nhd

Haemtrack

A secure haemophilia factor treatment recording system connecting patients and clinicians through a phone app and website.

<http://haemtrack.mdsas.com>

The United Kingdom Haemophilia Centre Doctors' Organisation

An association of medical practitioners who work within the Haemophilia Centres of England, Scotland, Northern Ireland or Wales and have an interest in the care of people with Haemophilia or other inherited bleeding disorders.

www.ukhcdo.org

The Leeds Teaching Hospitals

This is the Leeds Teaching Hospital Website to find out about our general and specialist services.

www.leedsth.nhs.uk

The Leeds Teaching Hospitals

This is the Leeds Teaching Hospitals PALS intranet link to obtain information about feedback and how to make a complaint. You are welcome to discuss any issues regarding the service with any team member. We greatly value your feedback.

<http://lthweb.leedsth.nhs.uk/sites/complaints/patient-experience/pals-homepage>



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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