

## Patient information

# National Haemophilia Database, and the Bleeding Disorder Alert Card

Haematology Liverpool

### How do I register with the Haemophilia Centre?

It is recommended that all patients with a bleeding disorder such as haemophilia are registered with a Comprehensive Care Centre. Once a diagnosis has been confirmed, you will be registered with the Comprehensive Care Centre at the Royal Liverpool University Hospital.

### What is the National Haemophilia Database?

For us to be able to register you we need to use the National Haemophilia Database. This is a register of UK patients (both adults and children) with all kinds of bleeding disorders. The database is managed by the UK Haemophilia Centre Doctors' Organisation (UKHCDO). It collects information about you, which is needed by the NHS to help plan haemophilia services, inform purchasing decisions, and learn more about the treatment and complications of these conditions.

More information is available on the UKHCDO website [www.ukhcdo.org](http://www.ukhcdo.org)

### What is the Bleeding Disorder Alert Card?

Once registered, you will be issued with a Bleeding Disorder Alert Card. This card will hold information about your bleeding disorder, the treatment needed, and your baseline factor levels (the level of the clotting factor when we diagnosed your bleeding disorder). The card will have the details on how to contact the Haemophilia Centre in and out of normal working hours.

### Please carry this card with you at all times.

If you are going to the dentist, doctor, or have an admission to hospital, please show staff your card. Ask them to contact the Haemophilia Centre or the out of hours on-call Consultant for Haemophilia on the numbers provided on the card.

### The card will also have the following warnings:

- **No aspirin or non-steroidal anti-inflammatory drugs**

This is because anti-inflammatory drugs such as aspirin or ibuprofen can increase the risk of bleeding.

- **No intramuscular injections**

Intramuscular injections are avoided because of the risk of bleeding into muscle. The majority of medications can be given as an injection just under the skin, which would be safer and prevent bleeding into the muscle. If a medicine can only be given as an intramuscular injection, then some treatment to minimise the risk of bleeding may be needed.

### **What happens if I lose or damage my card?**

If you lose or damage your Bleeding Disorder Alert Card or any of your details change, please contact the Haemophilia Centre for a replacement. A new card will be issued to you as soon as possible.

### **Feedback**

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

### **Further information**

**If you have any further questions, please ask a member of our medical / nursing team. Please contact the Haemophilia Team**

**Available Monday – Friday**

**9am - 5pm**

**Tel: 0151 706 3397**

### **Useful Websites**

**The Haemophilia Society:**

**<https://haemophilia.org.uk/>**

**World Federation of Haemophilia:**

**[www.wfh.org](http://www.wfh.org)**

**Author: Haematology Liverpool**

**Review date: December 2026**

All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل انتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والكترونياً.

所有經信托基金批准的患者資訊均可以其它格式提供，包括其它語言、易讀閱讀軟件、大字體、音頻、盲文、穆恩體 ( Moon ) 盲文和電子格式，敬請索取。

در صورت تمایل میتوانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانباریی پیوهندیدار بهو نهخوشانهی له لایمن تراستهوه پهسهند کراون، نهگهر داوا بکریت له فورماتهکانی تردا بریتی له زمانهکانی تر، نیزی رید (هاسان خویندنهوه)، چاپی گهوره، شریتی دهنک، هیلای موون و نهلیکترونیکی همیه.

所有经信托基金批准的患者信息均可以其它格式提供，包括其它语言、易读阅读软件、大字体、音频、盲文、穆恩体 (Moon) 盲文和电子格式，敬请索取。

Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhado kale, sida luqado kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.