

How do the CBDR and MyCBDR protect my privacy?

MyCBDR and the CBDR are overseen by the CBDR Committee of the Association of Hemophilia Clinic Directors of Canada.

Safeguarding your privacy is a top priority for the CBDR. Strict security rules are in place to guarantee patient privacy is maintained at all times. Only authorised staff from your own treatment centre or McMaster University can access your data.

Your information is kept on the CBDR database which is physically located in a secure data centre at McMaster University with bank-grade physical, administrative and technical safeguards in place. These procedures protect your information from misuse, unauthorised access, interference, alteration, loss and/or disclosure.

Important note

MyCBDR is a tool to record information on your bleeds and treatments. Always contact the health care team at your treatment centre for medical advice.

More information and support

Go to mycbdr.ca/MyCBDR/Info/Help or call 905-525-9140 ext. 27595 or

e-mail help@mycbdr.ca or

talk to the nurse coordinator at your treatment centre, or

call or e-mail the CHS at 1-800-668-2686 | chs@hemophilia.ca

CBDR/MyCBDR is a collaboration among the Association of Hemophilia Clinic Directors of Canada (AHCDC), McMaster University and the Australian National Blood Authority (NBA) with support from the Canadian Hemophilia Society (CHS). The AHCDC owns the CBDR and MyCBDR. McMaster manages the system on behalf of the AHCDC. It is developed jointly by the NBA, the AHCDC and McMaster University with input from the CHS and Canadian health care providers.



The best way

to report treatments and bleeds
to your health care team

- Fast
- Easy
- Accurate
- Secure
- Private

Find out more at
www.cbdrr.ca/Info

What is the CBDR?

The Canadian Bleeding Disorders Registry (CBDR) is a national registry and database of patients with inherited bleeding disorders. It is used by treatment centres to support patient care, approved research and monitoring of factor concentrate utilization.

What information does MyCBDR help you record?

- Your treatment plan
- Your factor concentrate inventory
- A record of all bleeds
- A record of all treatments
- Contact information for you and your family members

What special features does MyCBDR have?

MyCBDR allows you to:

- view and print reports about your history of bleeds;
- view and print reports about your product use;
- send messages, photos and documents to your health care team.

What is MyCBDR?

MyCBDR is the system used by patients and/or their caregivers who are on home treatment. It is linked directly to the CBDR at your treatment centre.

MyCBDR is Internet-based. It offers a computer application and a mobile app (Android, iPhone).

MyCBDR is a fast, easy and secure way to:

- record bleeds and home treatments;
- share this information with your health care team;
- manage your home inventory of factor concentrates;
- keep an easy-to-see record of your own health care.

Is use of MyCBDR obligatory?

No, it is optional. You can still use paper logs. However, MyCBDR is the fastest, easiest and most accurate way to record and report bleeds and home treatments.

What are the benefits of using MyCBDR?

1. **No more paper bleed logs!**
2. Fast and easy transmission of your bleed and treatment information via computer interface or mobile device. **Most infusion reports take less than one minute to complete and send!**
3. Information at your fingertips on the locations of all bleeds and factor concentrate use that you can view and print. **You'll be able to better manage your own care.**
4. Accurate and timely information about your bleeds and your treatments for your health care team. **They will be better able to guide you in your personalized care.**
5. More complete information on health outcomes for all patients on home treatment. **This will help clinicians and researchers improve care for all.**

How do I register?

Via computer

1. Go to www.mycbdr.ca/MyCBDR/Account/Login
2. Click on "New user"
3. Complete the information in the "My details" section
4. View the "Terms and Conditions" and then accept
5. Click on "Submit"

Via mobile device

1. Download the MyCBDR app from the Apple Store or from the Google Play Store
2. Click on "Create an account"
3. Complete the information in the "My details" section
4. View the "Terms and Conditions" and then accept
5. Click on "Submit"

To be sure the computer application and mobile app are synchronized, so you can use both seamlessly, always use MyCBDR in online mode.