Consent to share health info (accessible version)

Your data may save lives

Unlock cures for lymphoma, leukemia, sickle cell disease and more



If you have received a blood or marrow transplant (BMT), CAR-T cells, or another cell therapy, **your data could be life-saving**. You may help future patients fight lymphoma, leukemia, sickle cell and other diseases by **sharing some of your health information for research**.

Your health care provider may ask you to consider joining the Center for International Blood and Marrow Transplant Research (CIBMTR) **Research Database**.

This allows your medical center to share information about **your health and your treatments**. Also, you may take online surveys about **your quality of life**.

How info from volunteers has helped so far



The CIBMTR is a **nonprofit** group that analyzes health data to help people live longer. By looking for patterns in how well treatments work for thousands of people like you, our researchers show:

- Which treatments help people live longer
- When to use BMT or CAR-T cells
- How closely donors need to match patients

This evidence helps justify Medicare coverage of BMT and CAR-T cells for certain diseases.

Joining is free and optional



The CIBMTR database is paid for by grants and contracts, not by patients. There are no costs and no payments to you. You do not need to travel, and you may opt out at any time.

We protect your privacy



The CIBMTR database is secure. The CIBMTR obeys US and international privacy laws. We cannot share your name or information about your identity.

Sharing knowledge, sharing hope



The CIBMTR publicly shares the results about the best treatments through scientific journals, professional conferences and cibmtr.org.

Thinking of joining?



- Consider signing the Informed Consent Form for the CIBMTR Research Database, allowing your medical center to share certain health info with the CIBMTR.
- 2. If you would like to be directly involved, you may also give permission for the CIBMTR to contact you for studies about how you are feeling and your **quality of life**.

Thank you for sharing your experience.

Learn more about



- Data privacy and protection: email <u>CIBMTR-DataProtection@mcw.edu</u>
- ClinicalTrials.gov Identifier: NCT01166009
- **Your rights or risks:** NMDP Institutional Review Board Administrator, 1-800-526-7809.
- Financial aid and emotional support: NMDP Patient Support Center, 1-888-999-6743 or patientinfo@nmdp.org
- Plain-language summaries of research: cibmtr.org

