

CANADIAN BLOOD SERVICES' CORD BLOOD BANK INFORMATION FOR CORD BLOOD DONATION FOR BIOMEDICAL RESEARCH

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This page contains information about donating cord blood to Canadian Blood Services' Cord Blood Bank ("Cord Blood Bank") research program.

Biomedical research using cord blood may increase knowledge about blood stem cell transplantation and the processes for collection, manufacturing and storage of cord blood. Some researchers are studying stem cells from cord blood to determine or develop new treatments for diseases, or to understand how stem cells work (e.g., gene expression). Other researchers may use cord blood for research (not related to stem cells) that might lead to improvements in future medical care.

When will cord blood donated to the Cord Blood Bank be used for research under the Cord Blood Bank's research program?

Cord blood may be found unsuitable for storage at various stages through the manufacturing process, if it does not meet the eligibility requirements of the Cord Blood Bank. If at any time, the Cord Blood Bank determines that the cord blood may not be stored or used for transplantation, it could still be distributed to researchers in Canada and worldwide, to be used for biomedical research under the Cord Blood Bank's research program rather than being discarded.

When preparing cord blood stem cells for storage, components are removed from the cord blood. These components, also known as by-products, include for example, red blood cells. The components that are not used during the preparation of the blood stem cells for storage could be distributed for biomedical research under the Cord Blood Bank's research program rather than being discarded.

Under the Cord Blood Bank's research program, donated cord blood will be distributed for use in biomedical research **only** if:

- You have given your consent for the cord blood to be used;
- The cord blood is found to be unsuitable for storage or for use in transplantation;
- The cord blood meets certain research criteria; and
- The research project that will use the cord blood has been ethically approved.

Canadian Blood Services may provide the cord blood or by-products to an approved research project on a cost recovery basis.

How do I consent to donate cord blood for biomedical research under the Cord Blood Bank's research program?

You must mark the Research Opt-In box if you want the cord blood to be distributed and used for biomedical research.

Will the care my baby and I receive be affected if I do not donate cord blood to the Cord Blood Bank's research program?

Your donation is completely voluntary. Your participation in the Cord Blood Bank's research program has no effect on the care you or your baby receive.

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Are there any risks if I donate cord blood for biomedical research under the Cord Blood Bank's research program?

There is no additional health risk to you or your baby if you donate cord blood for biomedical research under the Cord Blood Bank's research program. Canadian Blood Services will disclose only minimal information about you and your baby to researchers such as the date of collection of the cord blood, your baby's sex, and the criteria we used to determine that the cord blood was unsuitable for storage. Information that directly identifies you as an individual is replaced by a unique identifier. This way, the researchers will not know who donated the cord blood.

Are there any benefits if I choose to donate cord blood for biomedical research under the Cord Blood Bank's research program?

Though neither you nor your baby will directly benefit from donating cord blood, the cord blood is used in research related to human health and science that may benefit others. Cord blood may be useful for developing drugs, medical and/or commercial products to treat diseases. You will not own any rights in these products or receive any financial benefit from your donation.

What kind of biomedical research will the cord blood be used for under the Cord Blood Bank's research program?

Examples of cord blood biomedical research, that could be conducted by academia, not for profit or industry, include:

- Improvements to current clinical practices that use cord blood
- Improvements to cord blood collection, manufacturing and storage
- Study of stem cell biology (e.g. using gene expression)
- Discovery of other clinical and non-clinical uses of stem cells from cord blood
- Production of stem cell lines that could be maintained for many years and used for a variety of research purposes
- Development of drugs, medical and/or commercial products to treat human diseases

The Cord Blood Bank's biomedical research program will not provide cord blood for studies conducting genome sequencing.

Canadian Blood Services must approve all research projects under the Cord Blood Bank's research program. The Canadian Blood Services Research Ethics Board will also review all projects. In addition, researchers may require ethics approval from their own institutions and, if applicable, other advisory groups who supervise research.

If you donate cord blood, you cannot choose what kind of research or which research project the cord blood may be used for.

Find more information about research projects using donated cord blood under the Cord Blood Bank's research program on the Canadian Blood Services website at www.blood.ca/researchcordblood.

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How will the research results be disclosed?

The results of biomedical research using cord blood distributed under the Cord Blood Bank's research program may be presented at meetings or in publications, but your identity or that of your baby will not be disclosed. The cord blood distributed to researchers will not identify you or your baby and you will not receive results of any research conducted under the Cord Blood Bank's research program. While supported research projects are not designed to produce results that would impact you or your baby's health, in the rare case that a project reveals an unexpected finding that may be important to you, we may contact you. The Canadian Blood Services website has information about ongoing research projects and general results of completed research.

What if I want to withdraw my consent for biomedical research under the Cord Blood Bank's research program?

Donating cord blood is completely voluntary. You may request to withdraw consent at any time. Call 1 888 2 DONATE (1-888-236-6283) and we will send you a form titled *Canadian Blood Services' Cord Blood Bank Withdrawal of Consent*. Complete the form and return it to Canadian Blood Services.

Please note, most cord blood distributed to researchers under the Cord Blood Bank's research program will be shipped within 48 hours of collection. If you withdraw consent for biomedical research and the cord blood has not already been used for biomedical research it will be discarded or used for Other Uses (i.e., quality assurance (e.g. validation, training and quality control) or product improvement). If the cord blood has already been used for biomedical research under the Cord Blood Bank's research program, the cord blood and research results may not be withdrawn.

What if I have questions about the Cord Blood Bank's research program?

Call 1 888 2 DONATE (1-888-236-6283) or go to our website at www.blood.ca/researchcordblood for more information.

If you have any questions about research participant rights or the conduct of research projects under this research program, you may contact the Canadian Blood Services Research Ethics Board by emailing CBSREB@blood.ca. The Canadian Blood Services Research Ethics Board is an independent committee that operates at arm's length from Canadian Blood Services.