

Use of Donor Information, Blood, and Blood Samples in Research

A copy of this information sheet is available at <http://www.bloodsystems.org/health.aspx> for reference.

Research studies may be conducted to improve overall blood safety, further the advancements made in transfusion medicine, and for other purposes.

Participation in research is voluntary. By agreeing to donate, you are agreeing to the potential use of your donor information, blood, and blood samples in research.

Research participation will not involve any cost, time, or additional procedures beyond the normal donation process. Risks of donation are uncommon and include anxiety, discomfort, injury, and loss of privacy or confidentiality. You will receive a separate document fully describing the normal donation process, its risks and hazards.

How will my donor information, blood, and blood samples be used in research?

- Your donor information, blood, and blood samples may be used in research to learn more about blood transfusion, human disease, and important public health issues.
- Your donor information, blood, and blood samples may be stored and made available for use by researchers indefinitely.

Who may use my donor information, blood, and blood samples for research?

- Research staff from blood centers, universities, government agencies, and drug or health companies from the U.S. and around the world may conduct studies using your donor information, blood, and blood samples.

How is my privacy protected when my donor information, blood, and blood samples are used in research?

- Strict security measures are in place to protect your privacy.
- Researchers will not be given any information that would allow them to identify you.
- Only select, authorized blood center personnel will have access to your personally identifiable health information, or identifiable blood, and blood samples.
- Unless required by law, your personally identifiable health information will not be shared with others.

What are the benefits of my participation?

- You will not receive financial or other benefits from any research; however, the results may lead to a better understanding of health and disease in the future as well as new treatments.

- It is possible that commercial researchers or companies may benefit financially from the use of your unidentifiable donor information, blood, and blood samples in research.

Will I be informed about the purpose and details of specific studies?

- You will not be informed of the purpose or details of specific studies that might be conducted, to which you may or may not have chosen to otherwise consent.

Will I be informed of any results?

- If we are made aware of any important personal results that may impact your health, we will attempt to contact you.
- You may not receive personal results from any research that does not identify you or is not known to be important to your health.

Will my blood be used in genetic research?

- Some researchers may examine short pieces of your genes, like your DNA, in some studies on blood and blood samples. It is extremely unlikely that results could be used to identify you.
- Without your specific additional consent, we will not allow research involving whole genome sequencing, which examines the entire length of a person's genetic code.

What else may happen if my donor information, blood, and blood samples are used for research?

- We may contact you to see if you want to participate in other research, ask for more samples, or gather more health information.
- If you are interested in participating in additional research, you will be given specific study details and a separate informed consent.

What are my rights?

- Your participation in research is voluntary.
- If you decide not to participate, you will not be able to donate blood today.
- You can discontinue participation at any time up until the start of blood collection.
- Your decision to not participate will not change your future relationship with the blood center. There is no penalty or loss of benefits to you.

Who should I contact if I have more questions?

If you have additional questions at any time about your rights, the storage and use of your donor information, blood and blood samples, or if you need to report potential harm related to research, you may contact our _____ at _____, Monday-Friday, _____. If you have questions about your rights as a research participant, call the Advarra Institutional Review Board administrator at _____.

By signing your Blood Donation Record, you are giving consent to allow us to use your information, blood, and blood samples for research purposes.