

# Possible Use of Donor Information and Blood Samples in Medical Research

The American Red Cross mission is to provide a safe and effective blood supply. As part of this mission, the American Red Cross may conduct research. We conduct some research with other institutions, such as academic centers, government agencies, and biomedical companies. Research is an important aspect of our commitment to donor and recipient safety.

## How might your blood or information be used in medical research?

We may store and use a portion of your blood or information collected at the time of donation for research studies. Some examples of the types of research are studies related to

- Testing, storing, collecting, or processing blood
- Ways to recruit blood donors or evaluate donor eligibility or contributions to public health
- Analyzing short pieces of your genes, like your DNA, for research related to blood transfusion and safety. It is extremely unlikely that results could be used to identify you or result in discrimination by insurers or employers. We will not allow research involving whole genome sequencing, which is looking at the entire length of a donor's genetic code.

You will not receive any direct benefit from any research. It is possible that the research may benefit commercial interests. You will not be notified as to the use of your blood or donor information when it is used for research.

## How is your confidentiality protected when your blood or information is used in research?

- Research participation will not involve any cost, time, or additional procedures beyond the normal donation process. The risk of the research use of your sample or information is loss of confidentiality. Protections are in place to minimize this risk.
- Samples used by researchers are coded. Only authorized Red Cross personnel can link coded samples to a donor's identifying information.

The Red Cross does not share your identifying information with other entities, except as required by law and in limited circumstances with research partners who are bound by strict privacy and data protection requirements. An independent committee (the Institutional Review Board [IRB]) approves all American Red Cross research using donor samples or information. The IRB is government-regulated and is established to protect your rights and welfare.

## How might your sample be tested, and will you be informed of results?

- We may use samples linked to your identifying information for infectious disease testing to provide a safe blood supply.
- We will notify you in person, by phone, by letter, or electronically about any test results that are identified to you and that may impact your health, and we may invite you to participate in a follow-up study.

## What will happen if your sample or information is stored?

- Your donor information, blood, and blood sample may be stored and made available for future research use indefinitely.
- Your identified sample and information will not be used for research unrelated to donor safety, blood safety and/or blood product efficacy, and contributions to public health without your consent.
- If your sample is stored, only authorized Red Cross personnel can link it to your identifying information.

## What are your rights?

- If you decide that you do not want your donation to be used for research, you will not be able to donate today. It is very important to include blood donors and their donations in possible research studies to continue to provide a safe and effective blood supply.
- Participation in research is voluntary.
- 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.
- If you have questions about the storage and use of your sample or information or you decide that you do not want your sample or information to be stored for research, contact the Scientific Support Office at (866) 771-5534. However, test information collected before your withdrawal may still be used after your withdrawal.

## How to obtain more information

If you have questions about your rights as a research participant, or if you need to report potential harm related to research, call the American Red Cross Institutional Review Board administrator at (877) 738-0856.

