

Research Tissue Bank Fact Sheet

Thank you for participating in the Link My Heart initiative - Brugada Project. This fact sheet provides more information about the research tissue bank.

Page 1 lists definitions of some of the terms used in the consent form and fact sheet. This is followed by more details about what will happen to your samples and health information. Those sections correspond to the numbered sections in your consent form.

Definitions

Biorepository

- A “biorepository” is a collection or bank of biological samples, such as blood, urine, tissue, and DNA that are linked to health information, and are used for scientific research. We refer to the biorepository in the consent form as “the Bank” or “Repository”.
- In this study, you will not be asked to take any medication, receive treatment, or change your behaviors. We will just collect samples and health information for researchers to study.

DNA

- Your specimen consists of many cells. These cells contain genetic information called DNA that is inherited from your parents. DNA provides a code that instructs the cells in our bodies to do specific things. In some cases, abnormalities in the DNA can put us at risk for certain diseases

Genes

- Genes are parts of the DNA code that direct cells to perform certain functions. Genes contain the instructions that tell our bodies how to grow and work, and determine physical features such as hair and eye color.

Types of genetic tests - There are several types of tests that can be done; for example:

- Single or multiple DNA markers can be studied: this is called genotyping
- Many gene variants (mutations) can be studied to see if there is any relationship between specific genes and a particular disease: this is called genome wide association studies
- The entire DNA genome can be studied: this is called gene sequencing.
- Since many diseases are not just caused by one genetic variant, researchers may study many gene variants or the entire genome in order to understand the multiple genetic variants that contribute to disease. By providing a saliva sample, you are enabling researchers to do these complicated tests.

Genetic research

- Genetic research uses DNA, genes, and other health information to study the links to different types of health conditions.
- Genetic research may explore why some people are more likely than others to get certain diseases. This type of research may also show why some people respond to certain medicines or have side effects from other medicines.
- The long-term goals of genetic research are to learn how to better understand, prevent, diagnose or treat diseases.

Section 13. How will you protect my privacy? Do you share my identifiable health information?

- **Protecting your privacy.** All of your identifiable health information is private under federal law. However, there are certain cases where we may need to release your information to organizations such as federal and state agencies and audit committees that oversee research. We do not release any information stored in the repository to insurance companies.
- The main risk of your participation in this research is a loss of privacy. By sharing your information from your medical record with researchers, it is possible that someone could find out private information about you. However there are many safeguards in place to protect your privacy. These include assigning codes to your samples and information, requiring ethics board approval for researchers and staff, and an oversight committee.
- Research results that are provided to central banks also have many procedures to protect your privacy and confidentiality. While we think that there are only minimal risks associated with sharing research results, we cannot predict how this information might be used in the future.
- Your privacy is very important to us and we will use many safety measures to protect your privacy. However, in spite of all of the safety measures that we will use, we cannot guarantee that your identity will never become known. Although your genetic information is unique to you, you do share some genetic information with your children, parents, brothers, sisters, and other blood relatives. Therefore, it may be possible that genetic information from them could be used to help identify you. Also, it may be possible that genetic information from you could be used to help identify them.
- **Collaborating with researchers.** The Partners Institutional Review Board (IRB) is authorized to approve all researchers who will want to use samples and health information for their studies. The IRB ethics board independently reviews and watches over all research studies involving people. The board follows state and federal laws and codes of ethics to make sure that the rights and welfare of people taking part in research studies are protected.