

Participating in research is a choice

Joining a research study is an important personal decision. Before you join, researchers will talk with you about the goals of the study and possible risks and benefits. They will also explain the rules they follow to protect your safety and privacy. Ask for help if you don't understand something or have questions.

You should never feel rushed or pressured to make a decision. Being part of a research study is completely voluntary - it's your choice.

After you understand the study, if you decide to take part you will be asked to sign a document called an "informed consent form." You can change your mind at any time, for any reason, even after you sign.

Questions to ask

You have a right to ask questions about genetic research before you decide whether to take part in a research study.

You may want to ask the following questions:

- > What is the purpose of the study?
- > How will you collect my genetic sample(s)?
- > Will I receive results from this study?
- > What happens if the tests reveal a medical issue?
- > Will the test results become part of my medical record?
- > Will the genetic testing impact my family?
- > Will test results impact my health insurance coverage in the future?
- > Will my samples or genetic information be used for future research? If so, will I need to give my consent?
- > Will my samples or genetic information be shared with any other researchers?

Cardiovascular Disease Study *HeartCare™ Panel*



Participating in research is your choice.
Be informed. Ask questions. Get answers.

The Baylor College of Medicine - Human Genome Sequencing Center Clinical Laboratory has developed a custom test targeting genes that influence risk for cardiovascular disease and related conditions.

What does HeartCare™ Test For?

Genetic risk of:

- > **Aortic aneurysms** - "ballooning" of the aorta which may require surgical repair to prevent rupture
- > **Cardiomyopathies** - diseases of the heart muscle which may lead to heart failure
- > **Arrhythmias** - a group of conditions in which the heartbeat is irregular, too fast, or too slow
- > **High Cholesterol** - condition characterized by very high levels of cholesterol in the blood which may lead to early heart disease
- > **Medication sensitivity** - to certain prescribed medications including clopidogrel (Plavix®), warfarin (Coumadin®), statins (Lipitor®, Crestor®)

Who Can Take Part?

- > **All adults** (18-85 years)
 - Ability to read and understand English
- > Your doctor may recommend the HeartCare™ test based on your medical history
- > Alternatively, you can ask your medical provider if you'd like to participate

Why Do Testing?

- > About **1 in 20** people have a risk for a hereditary cardiovascular disease with established management guidelines¹
- > Identifying genetic risks for cardiovascular diseases may lead to personalized treatment and better outcomes²
- > Because inherited heart conditions can run in families, your results can help your family members identify underlying conditions for proactive care
- > **No cost to you or your insurance!**

How Does Testing Work?

- > Simple blood or saliva collection
- > 158 genes are analyzed for any changes that could impact your health
- > Results are returned to your doctor and become part of your medical record
- > You and your doctor discuss if any management changes are needed

REFERENCES: (1) Haverfield, E. (2018). Multigene panel screening for hereditary disease risk in healthy individuals. ACMG Annual Meeting Charlotte, NC.; (2). Roberts, R. (2018). Genetic Risk Stratification: Tipping Point for Global Primary Prevention of Coronary Artery Disease. Circulation 137, 2554-2556.

Understanding Your Results

- > Your Physician will discuss your results with you
- > Genetic counseling services are available
- > Referral to adult genetics, if needed

Do I Have to Participate?

- > No, participating is **voluntary**.
- > Your decision whether or not to take part will have no effect on the quality of your medical care
- > You will be asked if your samples can be used for other studies

Are There Any Risks?

- > The Genetic Information Nondiscrimination Act (GINA) protects you from genetic discrimination by health insurers or employers
- > However, the law does not cover all types of insurance (for example life and disability)
- > Make sure you understand the risks outlined in the consent before you agree to take part

