

## WHY HAVE I BEEN OFFERED A GENETIC TEST?

Cardiac conditions can have lots of different causes but some are known to be due to genetic changes and can be inherited in families.

You have been offered a genetic test as the cardiac condition you have is one that **can** have an inherited cause.

Finding out if you have a genetic change that has caused your cardiac condition can sometimes help you and your doctor **make the best choices for your current and future treatments**. It can also mean there is a test that will tell your family members about their risk and if there is any screening or prevention they might need.

## THE TEST

The test is carried out on a DNA sample, usually from a blood sample, and looks for changes in several different genes known to be associated with inherited cardiac conditions.

## THE RESULTS

Possible results of genetic testing:

- **No gene change identified:** This result does not change your cardiac diagnosis. This result reduces the chance an inherited gene change is responsible for your condition but cannot completely rule out the possibility there is some inherited risk in your family.
- **“Pathogenic” or “Likely Pathogenic” (disease-causing) gene change identified:** This result confirms an inherited gene change is the cause for your cardiac condition. Because we share genes with our families, there is a chance other people in your family will have the same genetic change. It would be possible for them to have a genetic test that will tell them about their risk of a cardiac condition.
- **“Variant of unknown clinical significance”:** This result means a genetic change has been found but it is not clear if it is a change that causes a problem or if it is one that is part of the natural variation that we all have. If the test finds a variant which requires further assessment, this will be discussed with you.

## WHAT WILL HAPPEN NEXT IF I AGREE TO TESTING?

If you decide to have the test, you will be asked to sign a consent form. A blood sample will be taken for the test and sent to the laboratory.

## WHAT IF I WANT MORE INFORMATION ABOUT HAVING THE TEST?

Genetic testing is an **important test in cardiac care**. It can help your specialist decide the best treatment and advice for you. It can also provide information about risk in the family. People who have an increased risk can be advised about what to avoid and can access heart checks and preventative treatments.

You have the right not to have genetic testing. Please speak with your cardiac clinician if you have questions or you can contact the duty genetic counsellor (contact details below).

## HOW WILL I RECEIVE MY RESULT?

The results can take around 10 weeks to be ready but may be available sooner. Your genetic test result will be sent to your Cardiologist. **If the test finds a genetic change the genetic clinic will also send you an appointment.** At the genetic clinic you will meet with a genetic clinician who will discuss your result with you and what it might mean for you and your relatives. There will be time to think about the best way forward for you and they can spend time answering any questions you might have. If appropriate, they will also provide you with information that you can share with relatives.

## WHAT IF I STILL HAVE MORE QUESTIONS?

**If your genetic test does not find any genetic changes it DOES NOT MEAN YOU DO NOT HAVE THE CONDITION and it is still possible that your first-degree relatives may have an increased risk of developing a similar cardiac problem to you. They can request a baseline cardiology assessment from their GP. If you are concerned about your family history, ask your GP or cardiologist to refer you to genetics.**

*A limitation of any genetic test is that like much of medical science, we do not know all the factors that influence health. Very occasionally the current understanding of a gene change may alter over time. You will be tested for changes in several genes all linked to inherited heart problems. Some of these genes are also linked to a risk of other health problems. If you have any questions about which genes you are being tested for, either now or in the future, please contact the genetics clinic below.*

## CONTACT DETAILS FOR THE GENETIC SERVICES

Duty Genetic Counsellor  
South East of Scotland Clinical Genetics Service, Institute of Genetics and Cancer  
Western General Hospital  
Crewe Road South  
Edinburgh, EH4 2XU

Tel: 0131 537 1116 Email: WGHClinicalGenetics@nhs.scot