Clinical Genetic Service leaflet reference: 088

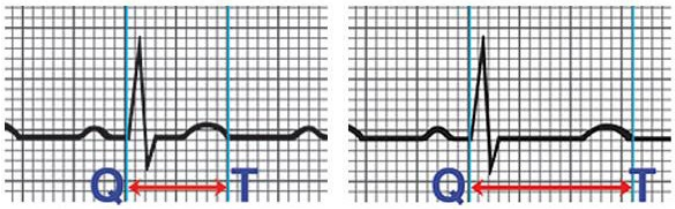
South East Of Scotland Genetic Service
Western General Hospital, Crewe Road, Edinburgh, EH4 2XU
Tel: 0131 537 1116

Patient Label

Genetic Testing – Long QT syndrome (LQTS)

Information for patients

Long QT syndrome (LQTS) can cause disturbances in the electrical system of your heart, leading to an abnormal heart rhythm called an arrhythmia. This can sometimes be seen on an electrocardiogram (ECG) recording as a lengthening of the time period of a particular part of the heartbeat cycle, known as the 'QT interval'.



Normal Q-T Interval *Long Q-T Interval*

Symptoms can include unexplained fainting, seizures or in some cases can lead to a sudden cardiac arrest.

Long QT syndrome can be inherited (due to an altered gene) or acquired (usually due to QT prolonging medication).

It is common for individuals in the same family with inherited LQTS to have different experiences of the syndrome. Some may have a normal QT interval and not have any symptoms; some may have a very abnormal QT interval but no symptoms; and some may have a very abnormal QT interval and episodes of abnormal heart rhythm that put them at risk. It is therefore important to identify those at risk so individualised care can be provided.

Several investigations may be required before a diagnosis of LQTS is confirmed. The most common test is an ECG which provides a recording of electrical signals in your heart. As signs of LQT can be infrequent, sometimes additional investigations are required e.g. repeated ECGs, exercise stress test and holter monitoring over a period of time. Genetic testing can also be utilised to help confirm a diagnosis of LQTS and to provide clarification of familial risk.

There are a number of genes that when altered cause LQTS. We are able to offer you a genetic test to determine if you have alterations in these genes.

Possible outcomes of gene panel testing:

- ***If a genetic change is identified in your sample,*** it means we can offer a genetic test to your blood relatives. In most cases, your children, siblings and parents would each have a 50:50 chance of having this gene change. The outcome of their genetic test would ensure their cardiac screening recommendations are appropriate.

- ***If a genetic change is not identified in your sample,*** we will not have a blood test to offer your relatives. Individual advice would be provided about whether family members should have cardiac screening as not finding a genetic change does not necessarily mean you do not have the condition.

- **Occasionally we find an unclassified variant**. This is a change in a gene where it is not known if it was significant in causing you to have LQTS or if it is just a natural variation that does not cause the syndrome. We will not have a blood test to offer your relatives; however, personal and familial screening advice would be based on your clinical presentation of the syndrome and family history.

Please tick as appropriate	Plan of action going forward	Enter details
	You have decided to proceed with testing and we have made the following arrangements for you to receive the results:	Letter / phone call /appointment
	You have decided to get back in touch when you feel ready to proceed with testing.	

Following testing, **results are usually available within 3 months**. Results are confirmed in writing to you and copied to your referring clinician/GP.

You were seen by:	Genetic Counsellor (0131 537 1116)	Date:

For more information and links to support organisations you can look at the website: Network for Inherited Cardiac Conditions Scotland (NICCS) at **www.niccs.scot.nhs.uk/**

SCAN ME

You may also find the following website useful for information regarding up to date advice on medications to avoid with LQTS: www.crediblemeds.org

SCAN ME

A limitation of the genetic test *is that just like much of medical science, we cannot yet know with certainty all the factors that influence health. There is very small chance that current classification of a gene variant may change as more information becomes available. This may change the clinical diagnosis, prognosis or treatment you receive.*