

Entering into this study takes about 1-2 hours. The study involves signing consent forms, answering some questions about your medical history, having a saliva or blood sample taken for LQTS genetic testing, and having an ECG.

What have we learned so far?

A specific gene change (known as V205M in the KCNQ1 gene) has been identified which is responsible for a large proportion of the LQTS occurring in the Gitksan people of Hazelton. We are continuing to learn more about how this specific gene change affects those who carry it. We are also exploring secondary genes that may cause LQTS or make it worse for those with the common change.

Where do we go from here?

There is still much to learn about LQTS in the Hazeltons. Research is currently being done to understand whether the common gene change might contribute to type II diabetes and hearing loss. We are also exploring whether lupus might cause a milder type of LQTS.

How do I learn more? How do I get involved?

For more information or to enroll in the study, please contact any person on the research team:

- **Dr. Laura Arbour**, a researcher at UBC looking at genetic causes of Long QT in the Gitksan, or **Sarah McIntosh** (genetic counsellor/research assistant) on our toll-free line: **1-888-853-8924**
- Community research assistants, **Gwen Weget-Simms** at **(250) 842-6295** or **Julia Sundell** at **(250) 842-5217**
- If you would like more information about Long QT syndrome but do not want to be a part of the research study you can contact **Samantha Lauson** (Genetic Counsellor) at Medical Genetics, Victoria General Hospital: **(250) 727-4461**

For more information, you can also call **The Gitksan Health Society: (250) 842-5165**

LQTS Logo of the Loon representing the family unit. This was created by a community member in an effort to inform the community about the condition.



Long QT Syndrome



Information pamphlet about Long QT syndrome in Northern British Columbia.



What is Long QT syndrome?

Long QT syndrome (LQTS) is a heart condition which may cause an abnormal heart rhythm that can lead to symptoms like dizziness, fainting, heart palpitations, seizures and in a very small number of people the heart may stop (cardiac arrest). About one third (1/3) of those with LQTS never experience symptoms, therefore

many people may never know they have LQTS.

There are hereditary forms of LQTS. Non-hereditary forms of LQTS exist, which can be caused by other medical problems.

How is Long QT syndrome diagnosed?

When someone has LQTS, a certain part of the heartbeat (known as the "QT interval") is typically longer than average. This can often, but not always, be seen on an electrocardiogram (ECG), a machine that measures the electrical pattern of the heartbeat. The diagnosis of LQTS may be made by a local physician or a cardiologist, after reviewing a patient's ECG results and medical history.

Genetic testing is another way that LQTS may be diagnosed. This involves a person giving a blood or saliva sample from which tests are done to look at certain genes known to cause LQTS.

How is Long QT syndrome treated?

Beta-blockers (a type of heart medication) are the most common treatment and are effective in about 90% of patients with the most common form of LQTS (called type 1). Beta-blockers work by preventing the heart from beating too fast, which could trigger an abnormal heartbeat. In some cases an implantable defibrillator (ICD) may be placed underneath the skin to reset the heartbeat if it becomes irregular.

People who have Long QT syndrome should also avoid certain medications which are known to prolong the QT interval including some over-the-counter medications. Please check with your pharmacist for further information.

What causes hereditary Long QT syndrome?

In most people of Northern BC First Nations ancestry, LQTS is a problem caused by two known specific gene changes. Genes determine traits, such as blood type and eye colour. Some genes play a role in controlling the way the heart beats. A change in a gene can prevent that gene from working properly. If there is a change in one of several specific genes, it can predispose individuals to LQTS.

How is Long QT syndrome passed down in families?

LQTS is usually inherited, meaning that the condition can be passed from parent to child. When one parent has LQTS, there is a 50% (1 in 2) chance that each child they have will be predisposed to LQTS and a 50% (1 in 2) chance that each child will not be predisposed to LQTS. Therefore, in one family, many generations of both men and women may be predisposed to LQTS.

The impact of LQTS on First Nations people of Northern BC

In 2005, concerned community members asked researchers at the University of British Columbia (UBC) to address the question of why there seemed to be a high rate of LQTS in the Hazelton area of Northern BC. This led to a joint effort between community members and health care providers in Hazelton, and the UBC to learn more about LQTS in the Hazeltons.

Who can enter this research study?

Anyone of First Nations ancestry who has LQTS, *OR* has a blood relative (a child, brother, sister, parent, aunt, uncle, cousin, etc) with LQTS can join this study. We will soon be opening the project to all who are interested.

