



Long QT Study

Do you have Long QT syndrome? Do you have a relative with Long QT syndrome? Do you know someone with Long QT syndrome? If so, please read ahead.

Long QT syndrome is found in people from all over the world. It also affects many Gitksan people in the Hazeltons. Long QT is a hereditary condition that affects the control of normal heart beats.

What happens with Long QT syndrome?

A portion of the normal heartbeat (“the QT interval”) is longer than it should be, putting people of all ages at risk for an irregular heart rhythm. This can lead to sudden fainting, or the heart stopping (cardiac arrest). Most people with Long QT remain healthy throughout their lifetime, especially if they have good medical care. They may need to take a medication that keeps the heart beating regularly, and they will need to avoid many medications (even some that are bought over-the-counter in stores).

What is being done about this?

People in Hazelton (some with the condition), doctors, and others at the Wrinch Memorial Hospital are working with health care providers and researchers from the University of British Columbia and BC Children’s and Women’s Health Centre to learn more about the condition in Hazelton.

There is much to learn about Long QT syndrome in the Hazeltons. As a start, a community research project has been initiated to explore which genes are involved in Long QT syndrome in the Gitksan people of Hazelton, and which medications and activities make the condition worse.

Who can enter this research study?

Anyone of Gitxsan ancestry who has Long QT syndrome, *OR* has a blood relative (a child, brother, sister, parent, aunt, uncle, cousin, etc) with Long QT syndrome can join this study.

If a person enters the study, what will happen?

Entering into this study takes about 1-2 hours. The study involves signing consent forms, answering some questions about your medical history, having a blood sample taken for Long QT genetic testing, and having a test of your heart rhythm (called an ECG).

Who can help?

If you have Long QT, or have a relative with Long QT you can help by being a part of this study, and helping to plan future studies. If you know someone with Long QT, please tell them about the study.

How do I learn more?

Please call any person on the research team. They can tell you more about the study and help you decide whether you want to be part of it:

- **Gwen Weget-Simms** (Community member, Research Liaison): **(250)842-6295**
- **Julia Sundell** (Wrinch Memorial Hospital, Research Assistant): **(250)842-5217**
- **Dr. Laura Arbour** (Doctor at UBC/BC Children's and Women's Health Centre); **Sarah McIntosh** (Genetic Counsellor, Research Assistant);
Samantha Lauson (Genetic Counsellor, Research Assistant):
Toll-free: 1-888-853-8924

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

Long QT Logo of the Loon and her children, displaying their hearts, was created and donated by a community member in an effort to inform the community about the condition.

