



How do I learn more about Long QT? How do I get involved?

For more information or to enroll in the Long QT research 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) 842-5234**
- 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**

Long QT Syndrome



A Family's Perspective

Part 1: A Story

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Long QT Syndrome - A Family's Perspective, Part 1: A Story

One typical afternoon, a young boy was doing homework at his grandmother's kitchen table. Grandmother was making tea for the both of them. The young boy was studying science, and asked his grandmother 'What makes your heart grow healthy?'

'Well, I'm not sure. Would you like some milk in your tea?'

Grandmother replied. The boy nodded yes. As grandmother poured a little milk into the boy's tea cup he shared some of what he learned that day in science class 'My teacher says our fish have strong heart, with two chambers. And she says that frogs have three chambers'

'Really? Three chambers?'

'Teacher says that all reptiles have three chambers in their hearts', the boy shares. Grandmother points to the many pieces of art that display the Frog Clan that decorate her cozy home. She laughs as she tells the young boy 'That's news to me. I inherited my Clan from my Mom, just like you did.'

'Ya', said the young boy, 'I'm Gibuu, wolf clan, from Mom's side of our family. But Grandma, you don't have three chambers in your heart like a frog. You have four chambers, because people are like wolves, coyotes, and even whales. They are all mammals and have four chambered hearts.'

Grandmother scans the frog design pieces, and the young boy returns to doing his homework. Grandmother's gaze brings her to a photo of her deceased husband, and her eyes remain on the photo as she begins to tell the young boy about life with Grandfather. The young boy is curious, and Grandmother answers all the questions he has. She tells him about fishing trips in Prince Rupert, and summers spent working in the canneries. Then his sudden death, unexplained, an arrhythmia of unknown origin.

Grandmother and the young boy shed tears.

Grandmother continued, 'Investigation by doctors got them to find Long QT syndrome in some of our family members'

The young boy replied, 'Is that what Auntie has? I think I remember when Auntie fainted and collapsed'

Inspired to learn more about his family, the young boy went to the computer and searched online for more information about Long QT Syndrome and heart health in general. He found a website that highlighted the physical appearance of different foods to their health benefits for the body. 'Grandma, did you know that tomatoes have chambers inside of them, kind of like the chambers in your heart? And that they have lots of good nutrients in them? Oh and that bunches of grapes and saskatoon berries look clusters of cells, almost the same shape as a heart?'

Grandmother smiled at the young boy, encouraged him to always ask questions and happily noted the young boy's scientific curiosity. 'We have good medical care now. Just like our sockeye fish with adaptations that got them strong hearts, our hearts can be strengthened. If our doctor checks us out, and we take our medications, and we eat our proper foods, and like Auntie, sometimes get an implantable device if needed, then our hearts will be strong and healthy too', Grandmother said.

Grandmother's heartfelt hope is that the young boy's curiosity will keep him interested in learning new subjects at school. The boy tells his Grandmother that he plans to keep asking questions, especially in science class.

