



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 2: Testimonials

Author: Lee-Anna Huisman, MSc
with community members

Long QT Syndrome - A Family's Perspective, Part 2: Testimonials

What will be the impact on my family?

'I think my parents were my backbone in this right from the beginning. I've seen their strength. And I was able to stand up strong too for my kids. So, that's what I reinforced with my kids. Is to be thankful that the Creator allowed us to find this so that we could live a long happy life'

Will this change anything?

'It's been a very interesting journey. Going from now knowing to knowing and how it has changed my outlook on life and how valuable each and every life is and that you can't take things for granted, where as a young child you just don't know. You just go and you do it. You just have to find it'

'I know for a fact that I can't have over the counter cough medicine. I used to take it years ago, when I was um a young mom. And my heart used to just about jump out of my chest'

What will it be like waiting for the result?

'My daughter is hoping her diagnosis is wrong, that another test might be done. She's still hoping that she doesn't have it'



What will it be like to hear the results?

'I wish I could take the Long QT away from you and I had it instead of you'

'In the hospital, I made a choice. I actually just talked to God and I thanked God for allowing the doctors to find the Long QT, so that I could live longer. And so that I could be around to raise my children and watch my grandchildren grow up. So I was very, very thankful. I was very appreciative'

How can I cope with the results?

'Every night I go to bed, I think about it. Am I going to wake up?'

'Right after when we have our gathering and we share a meal, we say our prayers, we sing our songs, and we also have gratitude for all the blessings that we've had. We feel like there's a sense of relief, a bit of peace. And we also have hope'

"I'd say family is a big support to me. I think it's my kids too. They keep me going, because they're always busy with hockey, soccer, and basketball. I would say they're the light in my life. That keeps me going"

'It helped know that other people have it. Like my cousin for example, she talked about feeling light headed, even to the point of feeling nauseous. And then I realized that happens to me too, the feeling dizzy, not the nausea. It helped me to know there are more people in this category, and I feel less isolated than I did at first'

