

The Impact of Long QT Syndrome (LQTS) on First Nations People of Northern British Columbia: Update to the Research Participants May 2014

This is the fifth of a series of update notices sharing the progress and results of the LQTS study with participants and their families. Please contact us if you would like copies of the previous update notices.

Thank you for your ongoing participation in the Long QT Syndrome research study. With your support, the research has come a long way. We are also introducing a new study for the prevention of chronic diseases like other heart diseases, cancer, stroke, and dementia. Please see the information on page 6 of this newsletter about the Canadian Alliance Study for Healthy Hearts and Minds.

Background Information: "The Impact of Long QT Syndrome in Northern BC" study

This research study was started in 2005, when the Gitksan Health Society and other concerned community members asked doctors and researchers at the University of British Columbia to study why there seemed to be a high rate of Long QT Syndrome (LQTS) in people with First Nations ancestry from Northern BC. Since that time, Dr. Laura Arbour from the University of British Columbia has been the most common cause of LQTS in the Gitksan.

The normal job of the not not gene is to help the heart (http://www.heart.org) Tj / TT7 1 Tf 3.978hy-.001 1564D 0 Tc <0

down through the generations. Hundreds of years ago, a common ancestor must have carried this gene change, and over time it became common in the community.

Since 2005, we have been inviting anyone with First Nations ancestry from Northern BC who has a diagnosis of LQTS or who has a blood relative with LQTS to join this study.

Joining the study involves giving a blood or saliva sample for testing of the

gene also works in the heart to help electrical currents pass through heart cells. This flow of electricity is what causes our heart to beat. Certain changes in the ANK2 gene are known to interfere with the flow of electricity in the heart and can cause LQTS or other arrhythmias, as well as other heart problems. However, the particular ANK2 'variation' found in some of our research participants is a rarer 'spelling mistake' that has not been studied before by other scientists, so its effect on the heart is unclear. Some of our research participants who carry this gene change have LQTS, so it is quite possible that this variation is having an effect on the heart.

To understand whether S646F is contributing to LQTS in the community:

- We are offering genetic testing for this ANK2 variant to any research participants who are related to someone who carries it. We will then be able to compare the health of those who

to determine whether having the V205M change in KCNQ1 influences one's chance of developing type 2 diabetes.

Fernando presented his preliminary results at an Elder's conference in Hazelton last Spring. His preliminary results suggest that those with the V205M change may have a higher chance of having pre diabetes. Pre diabetes means having blood glucose levels that are above normal, but not high enough to be diagnosed as type 2 diabetes (i.e. 'borderline' blood glucose). Those with pre diabetes have a higher chance of developing diabetes in the future, although many people never develop the disease. It is important to note that Fernando's preliminary results show 'borderline' no

We would like to take this opportunity to let you know about another research study coming to the Hazeltons, and to invite you to participate. Although this study is not focused on LQTS, we felt we should let everyone know about it, since it is about other health conditions that are of equal concern to the community. This "Alliance" study

If you have any questions or would like further information, please contact the research team:

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Dr. Laura Arbour's research website: <http://www.uvic.ca/medsci/faculty/arbour.php>

Your ongoing participation and support for this research study is much appreciated.

Sincerely,

Dr. Laura Arbour and the entire LQTS research