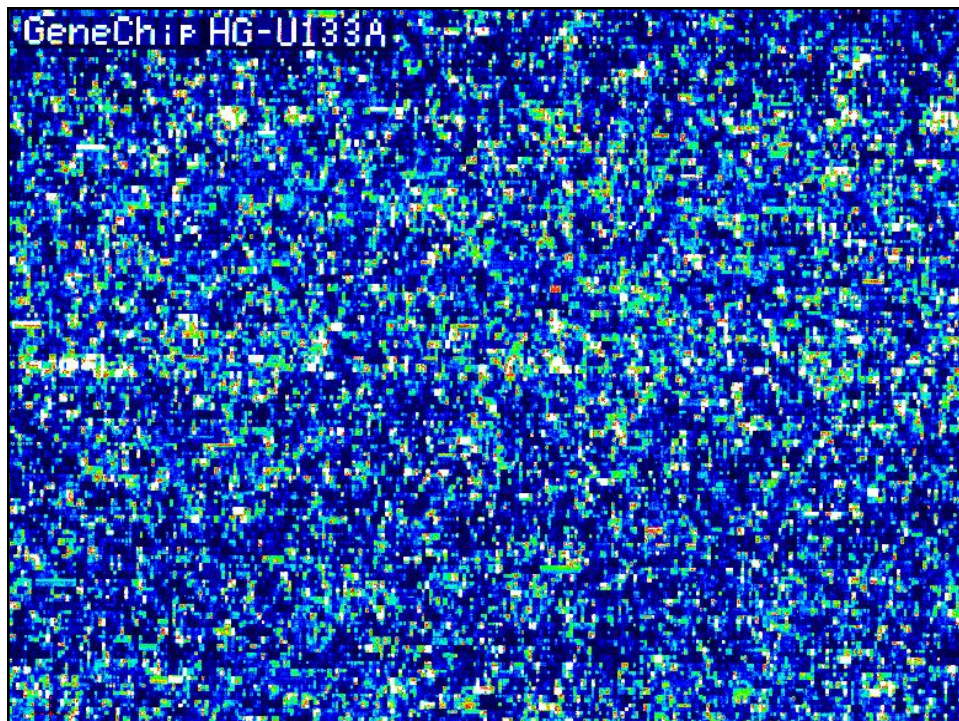
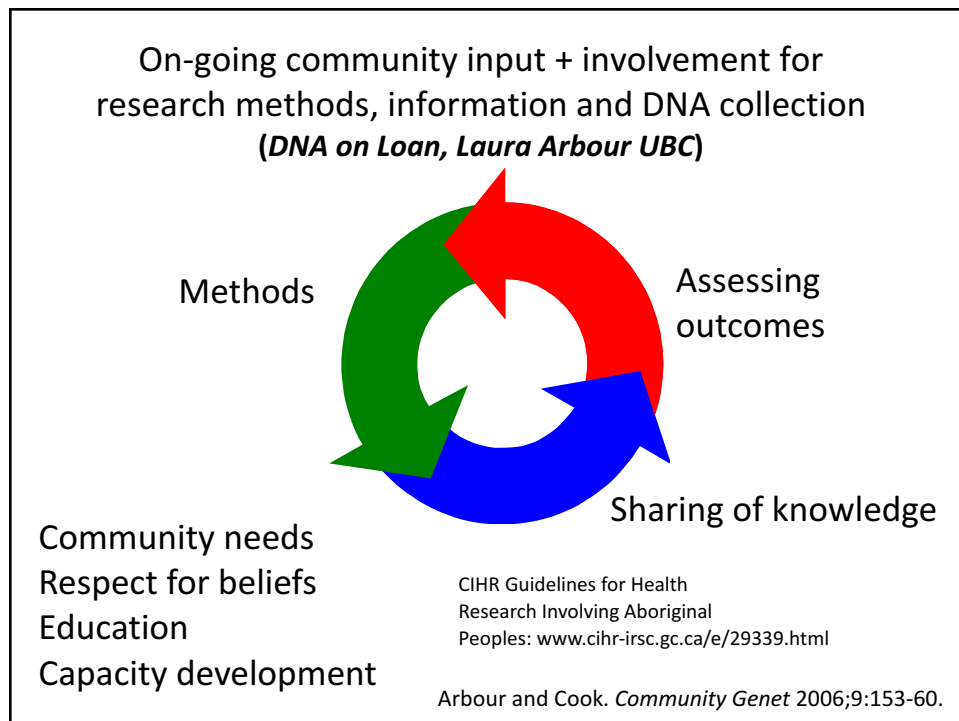


Respectful genetics research with indigenous communities

*2016 CAHS Forum, Montreal
Sep 15 1330-1430 h*

Robert A. Hegele MD FRCPC FACP FAHA FCCS FCAHS
Schulich School of Medicine & Robarts Research Institute
University of Western Ontario
London, Ontario, Canada





- CIHR guidelines for health research involving aboriginal peoples
- **Article 13: Biological samples should be considered “on loan”** to the researcher unless otherwise specified in the research agreement.

Tri-council policy statement
Chapter 9.40 section 9.19

“As part of community engagement, researchers shall address and specify in the research agreement the rights and proprietary interests of individuals and communities, to the extent such exist, in human biological materials and associated data to be collected, stored and used in the course of the research.”

Indigenous peoples’ concerns with genetic research

- Displaced research monies (priorities not addressed)
- Issues of trust: ‘helicopter research’
- Genetic study might violate a particular group’s cultural beliefs
- Secondary use of DNA and cell lines for research for which consent was not given, including research that traces ancestry
- General concerns of vulnerability to exploitation of the Aboriginal communities for the ***benefit of mainstream science and economics.***

The impact of genetic study

“To us, any part of ourselves is sacred.

Scientists say it’s just DNA.

For an Indian, it’s not just DNA, it’s part of a person, it is sacred, with deep religious significance.

It is part of the essence of a person.”

Frank Dukepoo, Interview, *San Francisco Chronicle*, 1998

Why would a community be in favor of genetic research?

Value to the community (priority based)

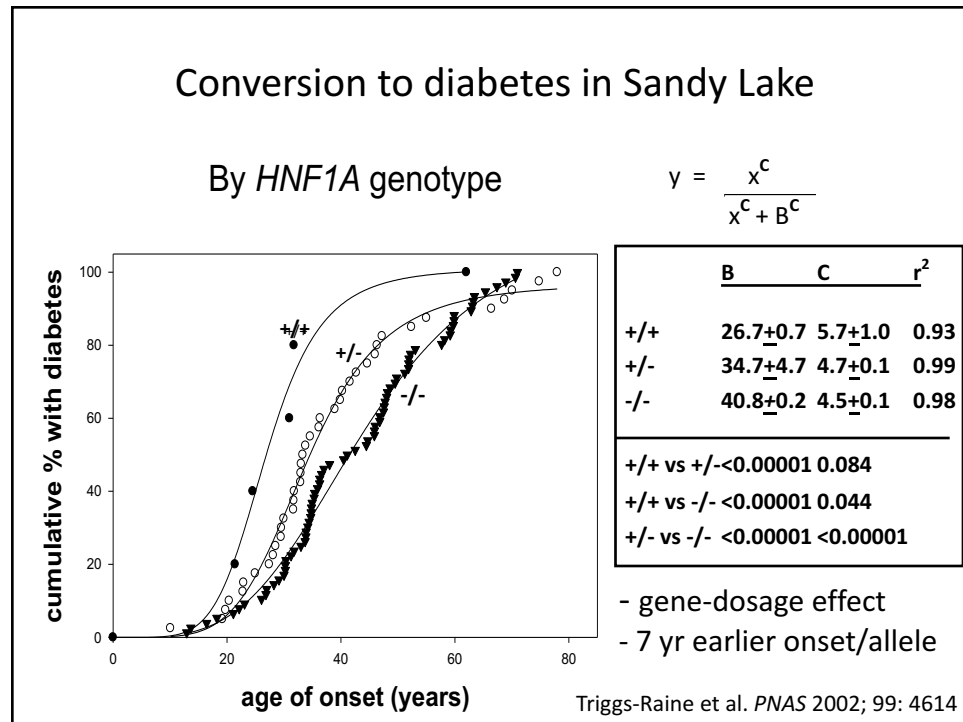
- Genetic disease has a significant impact on the community, and prevention is possible (e.g. inherited arrhythmias, cardiomyopathies, cancer, inherited metabolic disease)
- Genetic component of disease may be important to the final understanding (e.g. SLE, arthritis, diabetes, CVD)
- To study the genetic component of a disease may be de-stigmatizing (e.g. congenital anomalies, autoimmune liver disease)

SANDY LAKE HEALTH AND DIABETES PROJECT

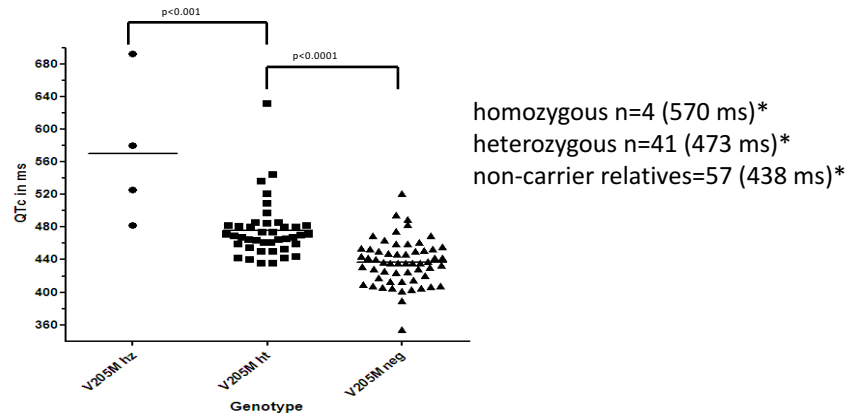


- isolated community
- small founder group
- 1000 Oji-Cree
- subarctic boreal forest
- 55th parallel of latitude
- 500 km N of highway's end
- air access only
- lifestyle unΔ for centuries
- 40% have diabetes





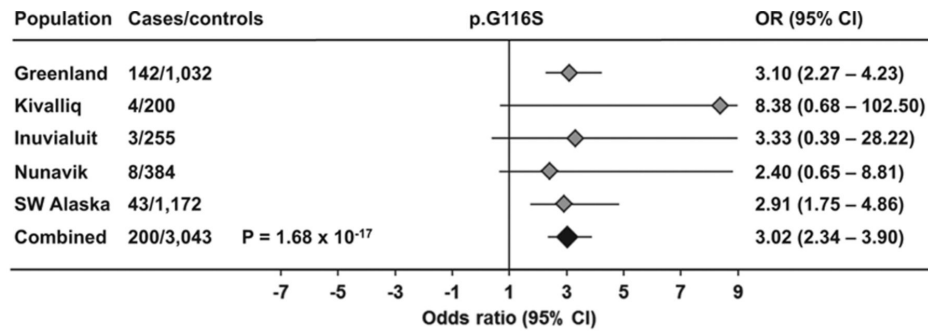
QTc V205M positive *adults* vs. 1-3rd degree relatives



Jackson *et al. Clin Genet* 2014; 86:85-90



Association between Inuit *LDLR* variant and elevated LDL cholesterol

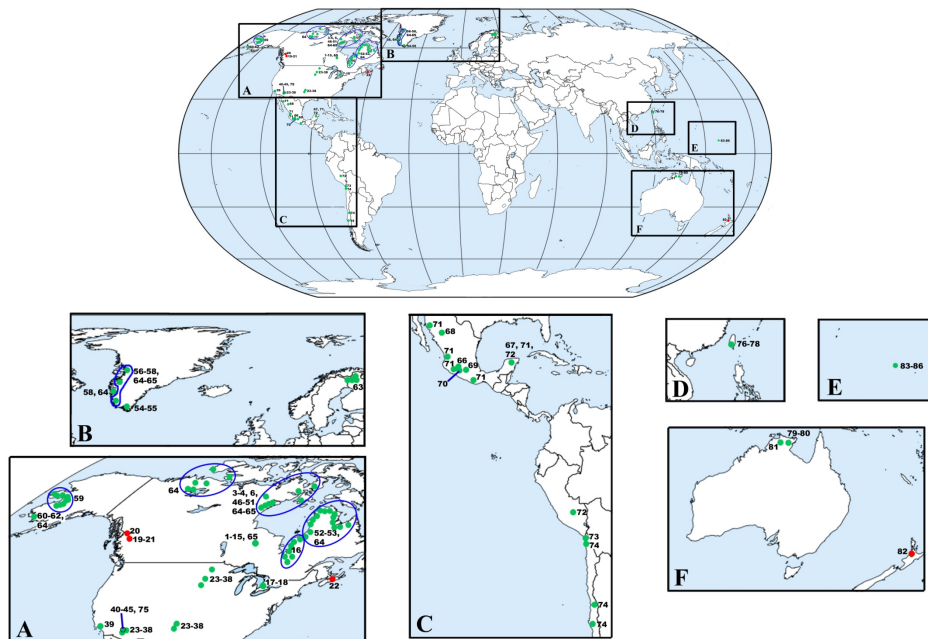


**American
Heart
Association®**

Dubé et al. *Circ Cardiovasc Genet*. 2015;8:100-105

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The Genetics of Cardiovascular Disease in Indigenous Populations



Arbour *et al.* *Can J Cardiol* 2015; 31:1094.

Community role

- Initiation of the research
- Development of protocol
- On-going advisory
- Local research assistants
- Review of results
- Review of manuscripts before submission
- New applications
- *Continuous conversation* (updates, results, research challenges)



**Harry Meekis
Jonas Fiddler
Stewart Harris
Bernie Zinman
Tony Hanley
Mary Mamakeesick
Kue Young
Laura Arbour**

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