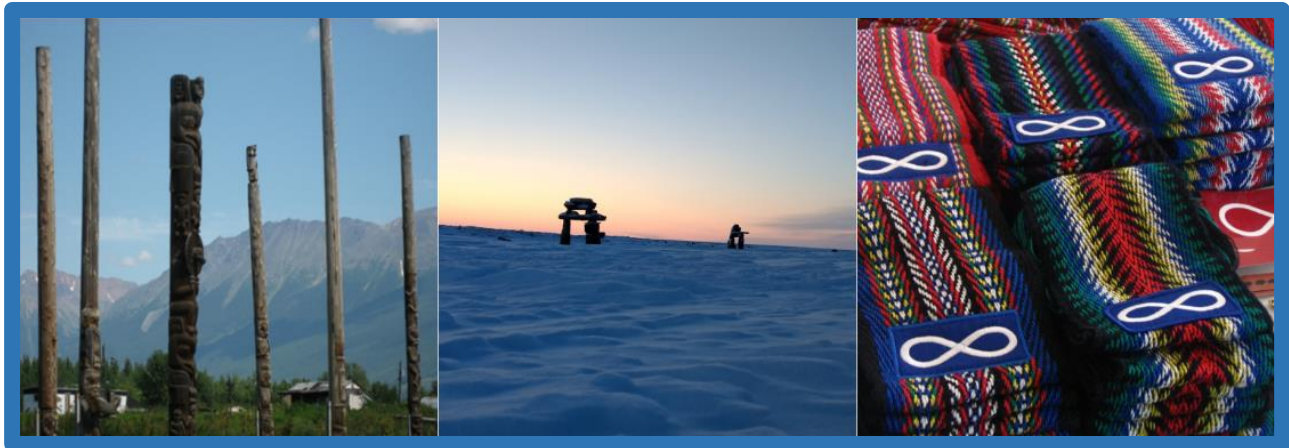


THE SILENT GENOMES PROJECT – PRECISION DIAGNOSIS STUDY (ACTIVITY 2) NEWSLETTER



- ✚ Thank you to all the families who participated in [Silent Genomes – Precision Diagnosis](#)! Through this project, we worked to make the best possible genetic testing both easier to access, and more effective, for Indigenous (First Nation, Inuit and Métis) families in Canada.
- ✚ We are happy to report that we were able to provide genetic testing to a total of 89 Indigenous patients and their families.
- ✚ Families have participated at 10 sites across the country through our “National Clinical Network” (Victoria, Vancouver, Calgary, Edmonton, Winnipeg, London, Toronto, Kingston, Ottawa, and Montréal).
- ✚ So far, about 25% of those who participated received a test result that helped their doctor make a diagnosis for their health condition.

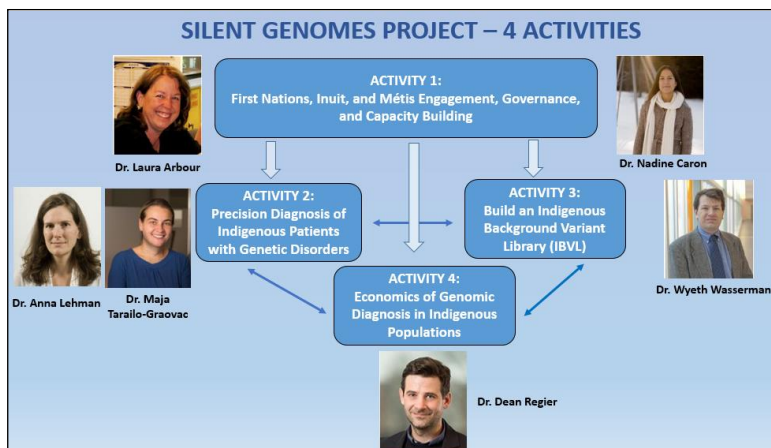


We wish we could have provided a clear answer to all the families who participated – there remains much work to do in this field of medicine and work is still ongoing.

For more information about Silent Genomes, please read on below or visit our website:

<https://www.bcchr.ca/silent-genomes-project>

THE SILENT GENOMES PROJECT – PRECISION DIAGNOSIS STUDY (ACTIVITY 2) NEWSLETTER



Silent Genomes – Precision Diagnosis, is part of the larger Silent Genomes Project, which has 4 different related “Activities.”

WHY THIS PROJECT STARTED

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- ✚ In Canada, genetic testing (genomic sequencing) for diagnoses for genetic conditions is becoming standard.
 - ✚ Although genetic testing can be done for Indigenous patients, and will result in a diagnosis in some cases, what is missing is important background information about genetic variation in Indigenous populations. Background, or ‘reference information’ is needed to make a ‘precise’ diagnoses for many Indigenous patients.
 - ✚ This barrier, along with other barriers to healthcare means that Indigenous patients may not have the same chances to receive a genetic diagnosis (when they have a genetic condition) and therefore less of a chance of receiving specialized care that comes from having a precise diagnosis.
 - ✚ The Silent Genomes Project, developed with Indigenous scholars, community members, and organizations such as the Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK) and the Métis National Council (MNC), is designed to address these barriers.
 - ✚ The Silent Genomes Project has of a team of doctors, genetic counsellors, scientists and Indigenous advisors working towards improving the chance of genetic diagnosis for Indigenous patients and their families.



Silent Genomes Project team and our partners at the Gathering Ceremony, July 2018