CANSSI ONTARIO **STAGE**

Laura Arbour

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University of British Columbia

Reducing Genetic and Genomic Health Disparities for Indigenous People of Canada: Insights from the Silent Genomes Project

Friday
Dec 5, 2025
2:30–3:30pm ET

Hybrid Event I Register Here
The Centre for Heart Lung Innovation, Room 166
1081 Burrard St. Vancouver, BC

Abstract: There are broad concerns that those with the greatest needs will benefit the least from advances in genetics and genomics. Furthermore, Indigenous patients and communities may hesitate to become involved in research and genetic healthcare that involves genetic/genomic sequencing because of concerns that resulting data will be misused. However, Indigenous involvement and on-going Indigenous governance of data has the potential to change the trajectory, improving access to diagnosis for Indigenous patients with genetic conditions. Dr. Arbour will present the challenges in achieving genetics and genomics health equity for Indigenous people in Canada and the solution focused Silent Genomes Project that assembled a diverse team to 1) Build an Indigenous led and operationalized governance model to support the principles of Indigenous Data Sovereignty 2) Address the paucity of Indigenous genomic reference data by building and launching an Indigenous Background Variant Library 3) Provide state of the art opportunities for genomic diagnosis for Indigenous patients with undiagnosed genetic disease, and 4) Support communities in addressing genetic conditions important to them. Insights revealing challenges, solutions, and lessons learned from the Silent Genome Project will be presented.

Profile: Dr. Laura Arbour is a Professor in the Department of Medical Genetics at the University of British Columbia, and an Affiliate Professor in the School of Medical Sciences at the University of Victoria. Trained as both pediatrician and clinical geneticist (McGill University) she has been addressing genetic conditions affecting Indigenous populations in partnership with them, for more than two decades. Through her UBC Community Genetics Research Program she has focused on addressing rare, single gene disorders and complex conditions in partnership with First Nations of BC and Inuit of Nunavut. Her research has been continuously funded through the Canadian Institutes of Health Research and others since 2004. She has received several awards for her work, with the most recent being the Life Sciences British Columbia-Genome BC Award for Scientific Excellence. Currently she is a project lead for The Silent Genomes Project (SGP), a nationwide Genome Canada, Genome BC, CIHR funded-Large Scale Applied Research Project-addressing inequity in genomic diagnosis for Indigenous patients of Canada. This multifaceted project, under Indigenous governance, has now launched an Indigenous Background Variant Library, a unique variant frequency database developed and launched in partnership with First Nations communities, to improve diagnostic accuracy for Indigenous patients with genetic conditions.

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