



**Be FAIR and CARE: Operationalizing Responsible
Indigenous Data Sharing to Benefit Patients with Rare
Diseases**

March 26th-March 31st, 2023
Kaneohe, Hawaii

ACKNOWLEDGEMENT

We would like to thank the Canadian Institutes of Health Research, Silent Genomes, The Northern First Nations Biobank, and the Canadian Partnership Against Cancer for their contributions to this project. With their aid and contribution, this project was made possible.



CIHR
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**CANADIAN PARTNERSHIP
AGAINST CANCER**

**PARTENARIAT CANADIEN
CONTRE LE CANCER**

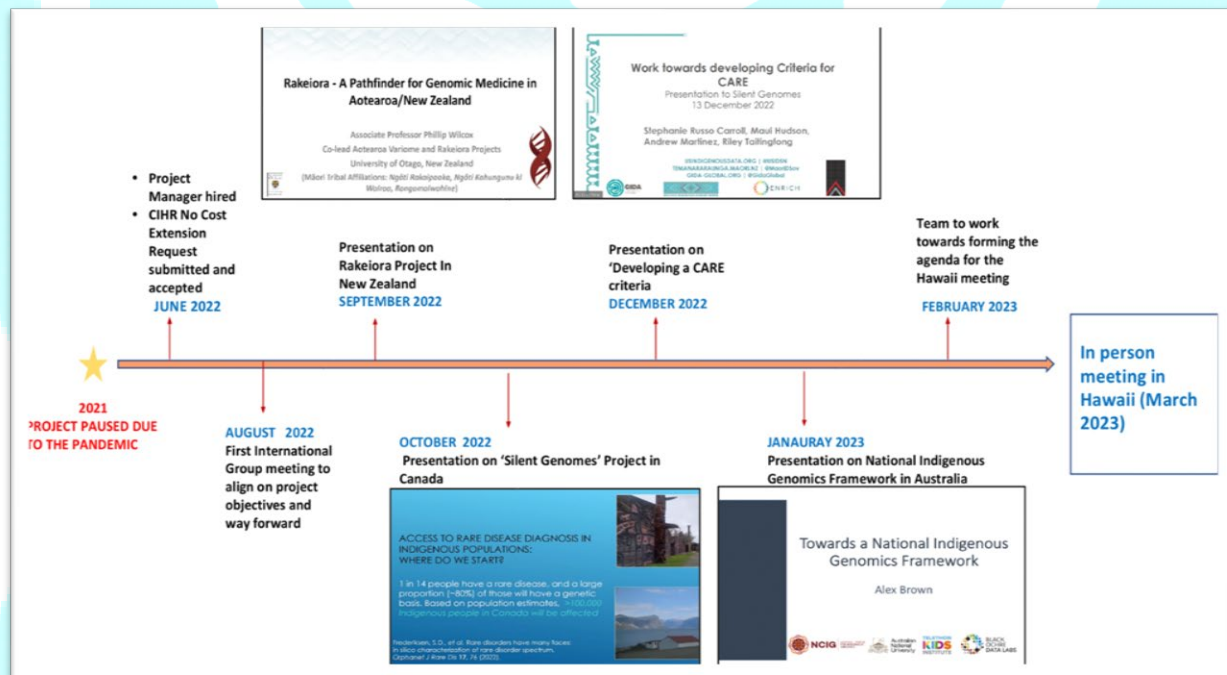
ABOUT THE PROJECT

Originally awarded pre-pandemic 2020 and initiated in 2022 after acquiring a no cost extension, this project aims to address the objectives below:

1. To explore how Indigenous genomic data can be shared internationally in a culturally safe manner to benefit patients with rare diseases, while respecting and integrating both the **FAIR** and **CARE** principles;
2. To discuss how national genomic Indigenous background variant databases are being established and how data access requests are culturally viewed through clinical and research lenses;
3. To explore establishment of new Indigenous data sharing partnerships between genomic background variant databases across borders;
4. To discuss development and operationalization of ethical frameworks, governance processes, and technical infrastructures and consider international genomic and phenotypic data sharing that is Indigenous led;
5. To discuss with partners and produce an overall report for how research granting agencies, research ethics boards and publishers of genomic research can exert processes to meet their accountability to Indigenous genomic data sovereignty.

PROJECT TIMELINE

From August 2022 to February 2023, virtual meetings have taken place to discuss data systems and sharing, agendas, and details of future meetings. The virtual meetings also served as preparation for the in-person meeting. Refer to image below for details:



IN-PERSON MEETING

Location

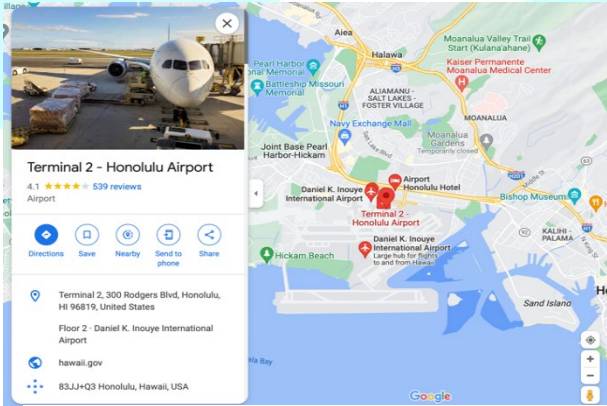


Figure 1: Honolulu Airport

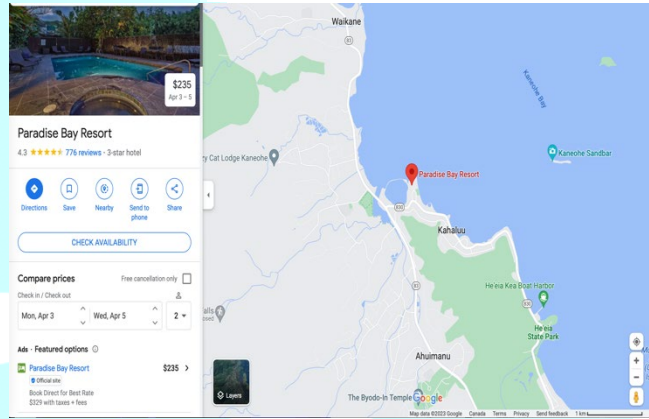


Figure 2: Paradise Bay Resort, Oahu

47-039 Lihikai Dr, Kaneohe, HI 96744, USA

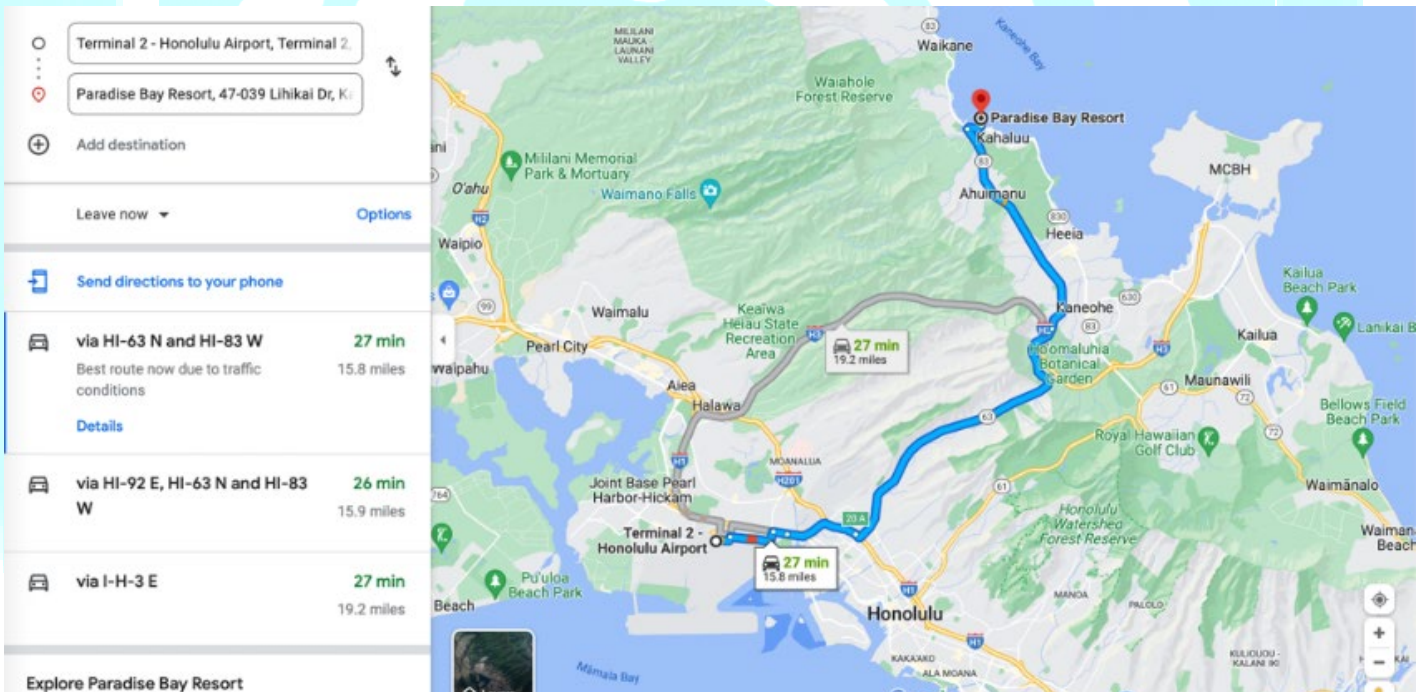


Figure 3 Distance

UBC Travel Policies

- **Meals per Diem and Mileage Rate:**

- <https://finance.ubc.ca/travel/pay/meals-diem-mileage-rates>
 - Per Diems will not be provided on days when meals are provided
 - Reimbursements for taxi claims will **ONLY** be made against a receipt
 - Mileage claims can be covered as per policy and would require a google maps image that provides an evidence of the KMs travelled, as well as complete addresses of origin to the final destination

*Please note that UBC policies stipulate the maximum amount of per diems per day, if receipts are submitted the reimbursement will be as per receipt. As this is a small research amount, we request for the team members to exercise discretion with per diem spending.

- **No reimbursements will be made for alcohol consumption.**

The event will not be offering alcoholic beverages. Expenses pertaining to alcohol consumption will be **out of pocket.**

AGENDA

Monday, March 27th 2023		
Program	Time	Led by
Rest and reset Light breakfast Lunch at 12:30 pm at the resort	9 am-12:30pm	Maile
Welcome reception-Maile's farmhouse: Tour and learn about traditional plants for hula and medicine	Pick up at 4pm	Maile
*Option to stay at the farm till 6pm		

*Scroll to next page for meeting Day 1 agenda

Tuesday, March 28th: Meeting Day 1

8 am-1pm-Papahana Kuala

2-5pm -meeting room

Objective 1: To explore how Indigenous genomic data can be shared internationally in a culturally safe manner to benefit patients with rare diseases, while respecting and integrating both the **FAIR** and **CARE** principles

Objective 2: To discuss how national genomic Indigenous background variant databases are being established and how data access requests are culturally viewed through clinical and research lenses;

Objective 4: To discuss development and operationalization of ethical frameworks, governance processes, and technical infrastructures and consider international genomic and phenotypic data sharing that is Indigenous led

Program	Time	Led by
Connecting to the land (venue: Papahana kuaola¹) Registration, Breakfast and Opening Remarks *Go to a Traditional farm in an educational program to connect to the land before initiating dialogue (TBC) https://papahanakuaola.org/about-us/	60 min	Nadine, Maile
RECAP: The Project at a glance About the project (Fair and Care principles; Project objectives and goals) - Share Back-What have we learnt from our conversations -Outcome of the in-person meeting (<i>How do we want to document the discussion- documentary?</i>) <i>*all presenters deliver a 5-7-minute summary of their presentations to the group</i>	120 min	Nadine, Laura
Objective 1: To explore how Indigenous genomic data can be shared internationally in a culturally safe manner to benefit patients with rare diseases, while respecting and integrating both the FAIR and CARE principles²		
Objective 1:	5 min	Nadine, Laura

¹ Subject to the resort's permission. If the resort confirms, there will be a welcoming ceremony. A volunteer is needed to participate in the ceremony.

Brief Introduction and background on presenter		
Working Group session on Objective 1 (Working tea session)	90 min	Facilitated by: Maile *Objective 4: Stephanie
Lessons learned	30 min	Maile
LUNCH BREAK (60 minutes)		
Objective 2: To discuss how national genomic Indigenous background variant databases are being established and how data access requests are culturally viewed through clinical and research lenses		
Objective 2: Brief Introduction and background on presenter	5 minutes	Nadine, Laura
Working Group session on Objective 2	90 min	Facilitated by: Wyeth and Phil *Objective 4 Stephanie
Lessons learned	30 min	Wyeth and Phil
Lessons Learned Objective 4's perspective	30 min	Stephanie
Concluding remarks	5 min	Nadine
END OF DAY 1		

*Scroll to next page for Day 2 agenda

**Time Keeping: Wardah Mirza and Danika Fiala

March 29th: Meeting Day 2
9 am-5pm

Objective 3: To explore establishment of new Indigenous data sharing partnerships between genomic background variant databases across borders

Objective 5: To discuss with partners and produce an overall report for how research granting agencies, research ethics boards and publishers of genomic research can exert processes to meet their accountability to Indigenous genomic data sovereignty.

Objective 4: To discuss development and operationalization of ethical frameworks, governance processes, and technical infrastructures and consider international genomic and phenotypic data sharing that is Indigenous led

Program	Time	Led by
Breakfast, registration and welcome	20 min	
RECAP: What was discussed in Day 1 (Objective 1 and 2) Lessons Learned	30 min	Nadine, Laura
Objective 3: To explore establishment of new Indigenous data sharing partnerships between genomic background variant databases across borders		
Objective 3: Brief Introduction and background on presenter	5 min	Nadine, Laura
Objective 3 Working Group session on Objective 3 (Working tea session)	90 min	Facilitated by: Alex and Stephen *Objective 4: Stephanie
Lessons Learned	30 min	Alex and Stephen
LUNCH BREAK		
Objective 5: To discuss with partners and produce an overall report for how research granting agencies, research ethics boards and publishers of genomic research can exert processes to meet their accountability to Indigenous genomic data sovereignty.		
Presentation on Objective 5 Brief Introduction and background on presenter	5 min	Laura
Working Group sessions	90 min	Facilitated by: Jeff and Keolu *Objective 4: Stephanie
Lessons learned	30 min	Jeff Reading and Keolu
Lessons Learned Objective 4's perspective	30 min	Stephanie
Concluding remarks	15 min	Nadine
END OF DAY 2		

*Scroll to next page for Day 3 agenda

**Time Keeping: Wardah Mirza and Danika Fiala

March 30th: Day 3
9 am-5pm

ACTION PLANNING: What comes next?

Registration, Breakfast and Welcome	20 min	Nadine, Laura
-RECAP What was discussed in Day 1 & 2 Lessons Learned	60 minutes	
How Does it all fit together? Action planning	60 min	All group discussion
Working Tea- Presentation on the Northern First Nations Biobank Initiative	60 minutes	Shannon Hall
LUNCH BREAK		
Way forward and Responsibility Assignment Matrix	TBD	All group discussion
Thank you and Concluding remarks	20	
END OF DAY 3 *Day 3 dinner sponsored by the Northern First Nations Biobank 's Team		

BIOGRAPHIES

Nadine Caron

*Attending in person meeting



Dr. Nadine Caron is a member of the Sagamok Anishnawbek First Nation. She is a practising surgical oncologist in northern British Columbia where she provides cancer screening, diagnosis, and surgical care for individuals in rural, remote, and northern BC - a large percentage of whom are Indigenous. Dr. Caron is the sole Indigenous physician within BC Cancer, the only Indigenous academic faculty member within the University of BC's School of Medicine, a Professor at UBC Northern Medical Program and Department of Surgery as well as a Senior Scientist at Canada's Michael Smith Genome Sciences Centre at BC Cancer. Dr. Caron is the inaugural First Nations Health Authority Chair in Cancer

and Wellness at the University of British Columbia. She is also a founding co-Director of the UBC Centre for Excellence in Indigenous Health and Consultant in development of BC's first-ever Indigenous Cancer Strategy to improve Indigenous cancer outcomes and experiences in BC. "Improving Indigenous Cancer Journeys: A Road Map". Dr. Caron currently leads the development of the Northern Biobank Initiative, including a First Nations-governed and controlled biobank in partnership with the FNHA that aims to provide safe access to cancer research for First Nations people in Northern BC. She is also co-Lead investigator on the Silent Genomes project which aims to address the genomic divide by reducing access barriers to diagnosis of genetic disease in Indigenous children and facilitating a governance framework to inform policy in fields of data sovereignty, genomic research, Indigenous research processes, among others.

Laura Arbour

*Attending in person meeting



Dr. Laura Arbour is a Professor in the Department of Medical Genetics situated at the UBC Island Medical Program, and an Affiliate Professor in the Division of Biomedical Sciences at the University of Victoria. Her clinical practice and research focuses on northern and Indigenous health issues as they pertain to genetics. Trained as both pediatrician and clinical geneticist (McGill University), her research integrates maternal-child health issues and the understanding of the genetic component of Indigenous health throughout the life course. Her research has been funded through the Canadian Institutes for Health Research since 2003. She leads the Community Genetics Research program situated at the University of Victoria and works with First Nations and Inuit partners on several projects. Current

research projects include: 1) *Silent Genomes: Reducing health-care disparities and improving diagnostic success for Indigenous children with genetic disease*, 2) Long QT Syndrome in Northern British Columbia, 3) The potential risk of CPT1A P479L for infant mortality in northern populations, 4) Primary Biliary Cholangitis in First Nations of the Pacific West Coast, and 5) a BC First Nations cohort of the Canadian Alliance for Healthy Heart and Minds. Other research interests include the genetics of inherited arrhythmias, the understanding and prevention of congenital anomalies and other adverse birth outcomes,

and etiology of rare diseases. Currently she is the Medical Genetics Lead for the British Columbia Inherited Arrhythmia Program (BCIAP)

Wyeth Wasserman

***Attending in person meeting**



Having worked in the biotechnology and pharmaceutical industry in both North America and Europe, Dr. Wasserman's research focuses on projects with applied biomedical impacts. His computational biology laboratory develops computer algorithms for the analysis of human DNA sequences. Originally established at Sweden's Karolinska Institute and since 2002 at the University of British Columbia, Dr. Wasserman's lab provides international leadership in the identification and engineered design of DNA sequences that control when and where in the body each gene is active – the On and Off switches. With the arrival of low cost DNA sequencing for patients, his team works closely with clinicians at BC Children's Hospital to discover the genetic

causes impacting patients and families. He has published over 150 peer-reviewed papers, participated in over \$25-million of funded research, and supervised more than 60 graduate and post-doctoral trainees.

Dean Regier

***Not attending in person meeting**



Dr. Dean Regier is a Scientist within Cancer Control Research, BC Cancer and the Canadian Centre for Applied Research in Cancer Control (ARCC), and an Assistant Professor, School of Population and Public Health, University of British Columbia. Dr. Regier's research focuses on understanding access to healthcare and improving methods to estimate the benefit of health care, with applications to genomic technologies and the 'value of genomic knowledge' i.e., how genes play a role in our personal lives and how publics value and trade between benefits and risks when making decisions to undergo testing. He incorporates this person-centred evidence into economic

models that answer questions of equity and value for money.

Maile Tauali'i



*Attending in person meeting

Maile Tauali'i, PhD, MPH, serves as an Assistant Clinical Investigator for Hawaii Permanente Medical Group. Dr. Tauali'i received her PhD in Health Services, with an emphasis in Public Health Informatics and Public Health Genetics, from the University of Washington. Dr. Tauali'i's advocacy work focuses on the utility and validity of health information for racial minorities. Her research focuses on eliminating health disparities, specifically for Indigenous Peoples. In 2015, Dr. Taualii established the world's first global Indigenous Master of Public Health degree program and was awarded the University of Hawai'i, Board of Regents

Excellence in Teaching Award. Prior work includes establishing the Urban Indian Health Institute, housed at the Seattle Indian Health Board. Her federal commitments include serving as a member of the National Advisory Committee on Racial, Ethnic, and Other Populations, U.S. Census Bureau (2013-2019) and a member of the National Institutes of Health and the PhenX Working Group on Social Determinants of Health. She and her husband, 6 children, and 3 dogs live on 20-acre food forest with their 'ohana, who aim to feed the community traditional, plant-based food from the land.

Alex Brown



*Attending in person meeting

Professor Alex Brown (BMed, MPH, PhD, FRACP (hon.), FCSANZ, FAHMS) is the Professor of Indigenous Genomics at the Telethon Kids Institute and The Australian National University (ANU) and the Director of the National Centre of Indigenous Genomics at the ANU. He is an internationally leading Aboriginal clinician/researcher who has worked his entire career in Aboriginal health. He is from the Yuin Nation, with family connections to Nowra, Wreck Bay and Wallaga Lake on the far south coast of NSW. Professor Brown leads a newly established Indigenous genomics research program, awarded a prestigious NHMRC Synergy grant in 2021 to drive

the establishment of Australia's first large scale efforts in Indigenous genomics. In 2022 Prof Brown and a significantly expanded consortium of investigators were awarded an MRRF grant to support the development of a National Indigenous Genomics Network. The Network will connect efforts in Indigenous Genomics from across the country, with clear plans to ensure that Indigenous communities can access the benefits of genomics on their terms. The Network will work and partner with Indigenous communities and stakeholders to establish Indigenous governance structures and Indigenous data governance and sovereignty models, local and national policies and will seek to build capacity across Indigenous health, genomic and research sectors. He has also established four highly regarded research groups over the past 18 years and much of his work has been at the difficult interface of geographical isolation, complex cultural context, severe socioeconomic disadvantage, inequitable access to and receipt of care and profound health disparities. He has built a research career spanning public health, quantitative

clinical epidemiology, mixed-method health service research, qualitative research, and implementation science, with an increasing focus on novel clinical trials in cardiometabolic disease within Indigenous communities.

Stephanie Carroll



***Attending in person meeting**

Dr. Stephanie Carroll is a citizen of the Native Village of Kluti-kaah in Alaska and of Sicilian-descent. At the University of Arizona, she is Assistant Professor of Public Health, Associate Director for the Native Nations Institute, and Acting Director/Assistant Research Professor at the Udall Center. Her research group, the Collaboratory for Indigenous Data Governance, develops research, policy, and practice innovations for Indigenous data sovereignty. Her research, teaching, and engagement seek to transform institutional governance and ethics for Indigenous control of Indigenous data, particularly within open science, open data, and big data

contexts. Stephanie co-edited the book *Indigenous Data Sovereignty and Policy* and led the publication of the CARE Principles for Indigenous Data Governance. Stephanie co-founded the US Indigenous Data Sovereignty Network and co-founded and chairs the Global Indigenous Data Alliance (GIDA), the International Indigenous Data Sovereignty Interest Group at the Research Data Alliance, and the Indigenous Data Working Group for the IEEE P2890 Recommended Practice for Provenance of Indigenous Peoples' Data. Stephanie is a founding board member for the Copper River Tribal College in Chitina, Alaska. She received her AB from Cornell University and MPH and DrPH from the University of Arizona.

Philip Wilcox



***Attending in person meeting**

Dr. Philip Wilcox is a professional geneticist and bioethicist based at the University of Otago in Aotearoa/New Zealand. He has worked at the interface of Māori bioethics and gene technologies, where he developed tikanga (Māori ethics)-based frameworks and guidelines for researchers. Dr. Wilcox also undertakes research on the genetics of inherited conditions in Māori, including development of genomic resources with Māori health applications. Previously, he has worked in the areas of genetics of tree species, statistical genetics methods development.

He also teaches Māori-related content in graduate and undergraduate science courses (particularly genetics and statistics), and run education programmes for Māori tauira (students) and pākeke (adults) on genomics and genetics that are taught in Māori learning environments such as SING-Aotearoa, which he

co-initiated with other Māori colleagues. Dr. Wilcox also runs quantitative genetics teaching programme, and supervised eight Māori and Pacific graduate students.

Maui Hudson

***Not attending in person meeting**



Maui Hudson affiliates to the Whakatōhea Nation in Aotearoa New Zealand and is a member of the Whakatohea Maori Trust Board. He is an Associate Professor and Director of Te Kotahi Research Institute at the University of Waikato. He is a founding member of Te Mana Raraunga Maori Data Sovereignty Network and Global Indigenous Data Alliance, and is a co-author of the CARE Principles for Indigenous Data Governance. Maui Hudson is a co-Director of ENRICH and Local Contexts and co-developer of the Biocultural Labels

Stephen Robertson

***Attending in person meeting**



Stephen Robertson has been the Curekids Professor of Paediatric Genetics at Otago University in Dunedin, New Zealand since 2002. He was educated at the University of Otago (graduating in Medicine, 1990) and Oxford (DPhil 2002). He is a Fellow of the Royal Australasian College of Physicians (Paediatrics and Clinical Genetics) and a Fellow of the Royal Society of New Zealand. Professor Robertson directs the Laboratory for Genomic Medicine within the Dunedin School of Medicine which has a world leading reputation for using genomic technologies to decipher the genetic basis of developmental disorders affecting children

and in the advancement of equitable genomic medicine with and for Māori. He collaborates widely with Clinical and Molecular Geneticists from around the globe and regularly presents at peak meetings in the field of Human Genetics. His laboratory has established a pipeline for the analysis of human exome and genome datasets (one of the first in NZ to do so). A major current body of work has been the assembly of a Variome dataset to enable genomic medicine for Māori. His work is supported primarily by Curekids but also the Marsden Fund, the Health Research Council of NZ and the Ministry of Business, Innovation and Employment. His work has led to the implication of several genes, in the generation of malformations in children including the characterization of the genetic basis of a broad group of disorders affecting the development of the skeleton and brain (the filaminopathies), studies that have implicated retinoic acid, a form of vitamin A, in skeletogenesis in humans and tumour suppressor genes in the morphogenesis of the skeleton and brain. This work has led to multiple publications in top journals in his field (Science, PNAS, Nature Genetics, Brain, Neurology, Human Mutation, American Journal of Human Genetics). He was

awarded the Liley Medal by the Health Research Council of NZ in 2010 for Distinguished Contributions to Medical Research and the Hercus Medal for excellent in medical research by the Royal Society of New Zealand in 2022. He has published in excess of 180 journal articles, and he sits on the Editorial Board of 5 international human genetics journals. Professor Robertson continues to be an active Clinical Geneticist, staffing clinics throughout the South and North Islands of NZ, in addition to teaching genetics to science and medical students in Dunedin. He was President of the Human Genetics Society of Australasia (NZ branch from 2007-2011). He Chairs the Medical and Scientific Advisory Committee for Curekids, NZ. His clinical work regularly involves the use of genomics technology for the purposes of diagnosis.

Jeffrey Reading

*Attending in person meeting



Professor Jeffrey Reading is an Indigenous researcher of Mohawk ancestry with more than two decades experience in enhancing knowledge in Indigenous health issues, both in Canada and globally. He obtained his MSc and PhD degrees in Community Health Sciences (now the Dalla Lana School of Public Health), University of Toronto and was the founding Director of the Centre for Aboriginal Health Research at the University of Victoria in British Columbia. As the inaugural Scientific Director of the Institute of Aboriginal Peoples' Health at the Canadian Institutes of Health Research (2000-2008), Jeff was part of a movement calling for a national advanced research agenda in the area of Aboriginal health. Jeff has played a pivotal role in the introduction of Canadian ethics guidelines for Aboriginal health research and

he also made key contributions to the Canadian Academy of Health Science's report and solutions that aim to have a particular impact on Indigenous Peoples' health globally. In 2015, Jeff took a one year leave of absence from the School of Public Health and Social Policy at the University of Victoria to join the Dalla Lana School of Public Health at the University of Toronto, as the first Interim Director of the Waakebiness-Bryce Institute for Indigenous Health. In 2016, Jeff began an appointment as Professor and Inaugural British Columbia First Nations Health Authority Chair in Heart Health and Wellness at St. Paul's Hospital, Vancouver, and Simon Fraser University.

Among his numerous distinctions Dr. Reading received the C.P. Shah Alumni Award of Excellence in Public Health (2015) from the Public Health Alumni Association of the Dalla Lana School of Public Health, University of Toronto; a National Aboriginal Achievement Award from the National Aboriginal Achievement Foundation, Canada – now known as Indspire (2008) and he was honored to be elected an inaugural Fellow of the Canadian Academy of Health Sciences (2005).



Nanibaa' Garrison

***Not attending in person meeting**

Nanibaa' Garrison (Navajo), Ph.D. is an Associate Professor at the University of California, Los Angeles. She has appointments in the Institute for Society and Genetics, the Institute for Precision Health, and the Division of General Internal Medicine & Health Services Research. She is a teaching faculty for the UCLA genetic counseling master's program. Dr. Garrison earned her Ph.D. in genetics at Stanford University and completed a postdoctoral fellowship in bioethics at the Stanford Center for Biomedical Ethics and the Center for Integration of Research on Genetics & Ethics at Stanford University. Prior to coming to

UCLA, Dr. Garrison was an Assistant Professor at Vanderbilt University, University of Washington, and Seattle Children's Research Institute. Dr. Garrison is the recipient of an NIH K01 career development award to explore perspectives of tribal leaders, physicians, scientists, and policy makers on genetic research with tribes. Her research focuses on the ethical, social, and cultural implications of genetic and genomic research in Indigenous communities. Using community-based research approaches, she engages with tribal communities to develop policies and guidance for tribes.



Ngiare Brown

***Not attending in person meeting**

Professor Ngiare Brown is a Yuin nation woman from the south coast of NSW. She is a senior Aboriginal medical practitioner with qualifications in medicine, public health, and primary care, and has studied bioethics, medical law and human rights. She was the first identified Aboriginal medical graduate from NSW, and is one of the first Aboriginal doctors in Australia. Over the past three decades she has developed extensive national and international networks in indigenous health and social justice, including engagement with the UN system. Ngiare is a clinician, researcher, and a chief investigator on multiple national and international grants. She works largely in the translation and implementation space, exploring how to utilise

'best evidence' to inform policy, resourcing, and service delivery. Ngiare is a founding member and was Foundation CEO of the Australian Indigenous Doctors' Association. She is a founding member of the Pacific Region Indigenous Doctors' Congress. Ngiare is also a member of the Prime Minister's Advisory Council. Ngiare is now the Founding Director of Ngaoara, a not-for-profit dedicated to Aboriginal child and adolescent wellbeing which supports communities to develop strength-based approaches to breaking intergenerational cycles of trauma and disparity.



Keolu Fox

***Attending in person meeting**

Keolu Fox Ph.D., Kānaka, Maoli (Native Hawaiian) is an assistant professor at University of California, San Diego, affiliated with the Department of Anthropology, the Global Health Program, the Halıcıoğlu Data Science Institute, the Climate Action Lab, and the Indigenous Futures Lab. He holds a Ph.D. in Genome Sciences from the University of Washington, Seattle (2016). Dr. Fox's multi-disciplinary research interests include genome sequencing, genome engineering, computational biology, evolutionary genetics, paleogenetics, and Indigenizing biomedical research. His

primary research focuses on questions of functionalizing genomics, testing theories of natural selection by editing genes and determining the functions of mutations. Dr. Fox has published numerous articles on human genetics, biomedicine, ancient genomics, and Indigenous data sovereignty, most recently in the New England Journal of Medicine, Nature, and the Proceedings of the Royal Society B. Dr. Fox is a recipient of grants from numerous organizations including the National Institutes of Health, the National Science Foundation, National Geographic, the American Association for Physical Anthropology, Emerson Collective, the Social Science Research Council and the Massachusetts Institutes of Technology, SOLVE Initiative.



Evan Adams

Attending in person meeting

Dr. Evan Adams is a member of, and grew up in the territories of, the Tla'amin First Nation in Powell River, British Columbia (BC). He completed his medical degree at the University of Calgary, an Indigenous Family Practice residency at Master St Paul's Hospital/ University of BC (as Chief Resident), and a of Public Health from John Hopkins University.

Dr. Adams has spent the past three years at Indigenous Service Canada as Deputy Chief Medical Officer of public Health, with a focus on National Covid-19 response and recovery. Prior to this, from 2014 to 2020, he was FNHA's inaugural Chief Medical Officer. His role at the FNHA included monitoring and reporting on the health of the First Nations Population, developing new ways to focus on wellness from a First Nations perspective, and advocating for cultural safety across the health system.

Dr. Adams will join Dr. Wieman and Dr. Louie in serving as the "face" of the FNHA's public health function, including being FNHA's representative/keynote speaker at health conferences and community events and social media. Together, they and the OCMO team will continue to develop and strengthen

partnerships and action plans with First Nations health governance partners, BC First Nations and to transforming the health care system to make it culturally safer for BC First Nations.

Before joining the FNHA, Dr. Adams served as BC's Deputy Provincial Health Officer from 2012 to 2014, where he provided direction on First Nations health issues to the Ministry of Health, reported to First Nations citizens on health issues affecting the general population, and set out a path for the improvement of First Nations health and Wellness.

ADDITIONAL GUESTS

Louise Lyons

*Attending in person meeting



Louise is a proud Jaadwa woman from western Victoria, Traditional Owner and a Director on the Barengi Gadjin Land Council. She's also a member of St Vincent's Hospital Melbourne, Human Research Ethics Committee. As the Senior Manager Strategy and Policy – Indigenous Genomics at the Telethon Kids Institute she works closely with Professor Alex Brown and a small team to develop and operationalise the National Indigenous Genomics Network as well as managing a number of Indigenous genomics research programs. The Network will see the development of 6 jurisdictional nodes and 5 Flagship themes (pharmacogenomics, genome biology, precision medicine, immunobiology and rare diseases) that will be developed over five years and clearly demonstrate pathways to benefit Aboriginal and Torres Strait Islander peoples. With a strong career in research, commercial and business management, she is passionate about identifying and translating research outcomes for the benefit of Aboriginal and Torres Strait Islander people. During her appointment as Senior Indigenous Project Manager at the CSIRO she developed a critical investment case for developing an Indigenous Science Program, so that the national science organisation could take significant leaps forward in research and industry partnerships with Indigenous peoples - with a greater understanding (and protection) of the knowledge systems that Indigenous people have held and practiced for >60,000 years. This investment case has now been implemented. Prior to that Louise worked at the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) for nearly 6 years as the Director of Public Health and Research, where she developed strong relationships with Aboriginal and Torres Strait Islander communities in Victoria and strong networks nationally with key ACCHOs and peaks. Her strengths and achievements include: managing large public health and research teams, developing research methodologies and projects, translating research knowledge into practice, policy & advocacy, Community engagement, strategic planning and developing culturally relevant evaluation and impact frameworks.

Rodney C. Haring

***Attending in person meeting**



Rodney C. Haring, PHD, MSW is the inaugural Director of the Roswell Park Center for Indigenous Cancer Research, Roswell Park Center for Indigenous Cancer Services, and Co-Director of the Health Communications Shared Resources. Dr. Haring serves as research faculty at Roswell Park Comprehensive Cancer Center's Office of Community Outreach and Engagement, Department of Cancer Prevention and Control and affiliate research faculty at the OU Health, Stephenson Cancer Center. He is also a past fellow at the National Congress of American Indians and Mayo Clinic. Dr. Haring is an enrolled member of the Seneca Nation of Indians (Beaver Clan) and

resides on the Cattaraugus Indian Reservation (NY). He holds a doctoral degree in social work, has more than 15 years of social work practice, and served as a former delegate on the US Department of Health and Human Services, American Indian and Alaska Native, Health Research Advisory Council. Dr. Haring is also the lead delegate for the historic MoU between Rowell Park and Indian Health Services with the common mission of addressing health burdens in Indigenous communities. In 2017 he was awarded an Impact Award by the National Indian Health Board and in 2021 he received the National Federation of Just Communities Hero Award. Dr. Haring's research interests intersect eliminating disparities and encouraging resiliencies within First Nations and Indigenous communities.

Paul Hage

***Attending in person meeting**



Paul Hage, MFA serves as Lead Project Manager and Co-Director of the Health Communications Shared Resource (HCR) since it was established in 2009. He has Master of Fine Arts degree in Documentary Film/Digital Media from at University at Buffalo, and a BSc degree in Television, Radio, Film production from Newhouse Communications School, Syracuse University, and has been a Roswell employee since 2008. He also holds an adjunct faculty position at the University at Buffalo Department of Community Health & Health Behavior, and SUNY Fredonia Department of Communications.

Shannon Hall

***Attending in person meeting**

Shannon Hall serves as the First Nations Biobank Research Manager for the FNHA Chair in Cancer and Wellness at UBC (Dr. Nadine Caron). Shannon lives and works in the true North. She is responsible for managing the community engagement arm of the Northern Biobank Initiative and brings a breath of experience in biobanking and Indigenous community engagement.



Administrative and Research Team

Wardah Mirza

***Attending in person meeting**

Wardah is a Project Manager, Indigenous Health, Engagement and Reconciliation at the Faculty of Medicine, UBC. She supports Dr. Nadine Caron - FNHA Chair in Cancer and Wellness at UBC- with research, administrative and finance tasks. She will also be providing administrative and research support for the CIHR funded 'Be Fair and Care' project led by Dr. Nadine Caron .



Tom Graham



***Attending in person meeting**

Dr. Tom Graham works with Dr. Caron on the cancer and wellness research agenda to address the genomic divide by reducing access barriers to diagnosis of genetic disease in Indigenous populations. Dr. Graham has completed a doctorate in health psychology with a concentration on the emotional experience of youth. He grew up in Comox, BC and is of First Nations extraction (Old Masset Village Council, Haida Gwaii). A member of the NBI team, he brings project management and grant writing experience to his position.

Kevin Linn



***Attending in person meeting**

Kevin has worked in strategic health policy and improving access to quality cancer care in Canada for over a decade in not-for-profit organizations and public health agencies. During this time, he was accountable for strategically managing relationships with diverse stakeholders and cancer control and health system partners to align quality improvement efforts. He is currently a Doctor of Public Health degree student at the Harvard T.H. Chan School of Public Health, with an interest in better understanding the development of health policy and governance structures within complex dynamic systems at the regional, national, and global levels. Kevin supported the development and FNHA's implementation of the

province's Indigenous Cancer Strategy and, has managed data linkage projects with BCC and the BCCDC. He provides strategic and research direction to the Caron group at UBC.

Danika Fiala

***Attending in person meeting**

Danika Fiala is a student volunteer for the 'Be Fair and Care' project and is currently an undergraduate student at UNBC.