

CGP ANNUAL REPORT 2023-2024

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MESSAGE FROM THE DIRECTOR

2024 was my first year in my new functions as Director of the Centre of Genomics and Policy (CGP). I embraced this leadership role with a mixture of pride, enthusiasm and, some apprehensions about stepping in the very big shoes of my predecessor Bartha Maria Knoppers.

Overall, the year saw many positive developments for the CGP. After a period of employment uncertainty post-COVID, we are now back to full capacity and working in person with an amazing team of 20 students and research professionals! Additionally, we have started an official registration process at McGill for our Centre which has allowed us to invite some of our closest colleagues to join the CGP as Associate Members. It is thus my pleasure to welcome Professors Laurence Baret, Guillaume Bourque, Thomas Duchaine, Phoebe Friesen, Jorg Fritz, Richard Gold, Catherine Goudie, Simon Gravel, David Juncker, Lara Khoury and Johnathan Kimmelman to the CGP.

Our continued collaborations with members of the scientific communities on large scale genomics initiatives such as the Global Alliance for Genomics and Health (GA4GH), the Pan-Canadian Genome Library (PCGL) and, DNA to RNA (D2R) bode extremely well for our sustainability in the coming years. Finally, we continued to actively expand on our existing regional ties in East Asia (Yonsei University, RIKEN, WYNG Foundation- Hong Kong University), Europe (KU Leuven, Toulouse Paul Sabatier, PHG Foundation), North America and the Middle East (Qatar Precision Health Institute, Jordan's King Hussein Cancer Centre, the American University of Beirut).

I strongly believe that in 2024 more than ever, the CGP is the best positioned Centre in the world to carry out first class comparative law and public policy research in genomics and health!

A stylized, handwritten signature in black ink, consisting of a series of loops and a long horizontal stroke.

Yann Joly
PROFESSOR



MESSAGE FROM THE RESEARCH DIRECTOR

2023-2024 has been a very successful year at the Centre of Genomics and Policy. Our team has produced outstanding scholarship with more than 30 peer-reviewed articles and reports published in high impact publications, including, but not limited to: Annual Reviews of Genomics and Human Genetics, AJOB, BMJ and Human Genetics. We were also funded on 11 projects reflecting a diversity of timely topics, such as nanotechnology, gender affirming care for youth, regenerative medicine, digital health & AI and genetic discrimination. The CGP was also a pillar of two major successful funding initiatives: DNA to RNA (D2R) and the Pan-Canadian Genome Library (CIHR), both spanning until 2030.

The CGP continues to host the international Genetic Discrimination Observatory. It is one of our Centre's flagship projects, which has now expanded to include more than 50 multidisciplinary experts and collaborators from 30 jurisdictions dedicated to researching and preventing genetic discrimination.

Our Centre continues to attract high calibre researchers to its team. This year was no different. We have welcomed experts in human rights law, artificial intelligence and empirical research methodologies in our ranks. We have also enrolled more than 12 graduate students and interns who saw the CGP as an ideal research Centre offering interdisciplinary and innovative programs of study at the interface of law, medicine and public policy.

This year has also been significant to me, marking my appointment as the CGP's new Research Director, following on the trailblazing footsteps of my colleague Prof. Yann Joly. I would also like to take this opportunity to extend a very warm welcome to Lindsay Dayton who has taken over the role of Executive Director of the CGP from me. Ms. Dayton comes to the CGP with a rich experience in the private sector as well as in the Academic setting, having played instrumental roles in research teams and in our University's grants and agreements office. After having been in this role for almost 9 years, I am confident of Ms. Dayton's ability to support our team and innovate.

If the trend of this year persists, the CGP can anticipate ongoing successes and groundbreaking advancements in our domain, propelled by the diligent efforts of our esteemed researchers, staff and students!

Ma'n H. Zawati

ASSOCIATE PROFESSOR



THANK YOU PROF. BARTHA MARIA KNOPPERS

After more than 15 years at the Centre of Genomics and Policy, it is with a heavy heart yet profound gratitude that we bid Bartha Maria Knoppers farewell at the end of April 2024 as she transitions to her role as Professor Emeritus. Her retirement marks the end of an era, one that has been defined by her unwavering dedication and exceptional leadership spanning more than 35 years (at Université de Montréal and McGill University).

Since her 1985 Sorbonne doctorate on the ethical and legal implications of new reproductive technologies, Professor Bartha Maria Knoppers has been an international pioneer for the building of prospective policy frameworks for emerging biotechnologies. Full Professor, Canada Research Chair in Law and Medicine and Founding Director of the Centre of Genomics and Policy of the Faculty of Medicine and Health Sciences at McGill University, Prof. Knoppers has contributed to policymaking of scientific and governmental bodies for over 35 years. Her approach was not one of erudite distance, however. Indeed, conscious of the need to understand the nature of genomic “progress”, she immersed herself in the Human Genome Organization and other scientific societies before helping to draft UNESCO’s *Universal Declaration on the Human Genome and Human Rights* (1997) and then in 2017, OECD’s *Recommendation on Health Data Governance*. She led the Policy Committee of the Canadian Stem Cell Network (2005-2018), and chaired the Ethics Working Party of the International Stem Cell Forum (2005-2015). Additionally, she was the founder of the Public Population Project in Genomics (P3G) and CARTaGENE Quebec’s population biobank (2007-2019). She gave the Galton Lecture in November 2017 and the Baron de Lancey Lecture in 2022 (UK). She served on the International Commission on the Clinical Use of Human Germline Genome Editing in 2020, and currently co-chairs the Ethics Working Group of the Human Cell Atlas.

Prof. Knoppers holds five Doctorates Honoris Causa: Doctor of Laws, University of Waterloo (2001); Doctor of Medicine, University of Paris – René Descartes, France (2002); Doctor of Laws, McMaster University (2007); Doctor of Laws, University of Alberta (2008), and Doctor of Laws, University of British Columbia (2024). She is a Fellow of the American Association for the Advancement of Science (AAAS), the Hastings Center (bioethics), the Canadian Academy Health Sciences (CAHS), and the Royal Society of Canada (RSC). She is also an Officer of the Order of Canada, and of the Province of Quebec, and was awarded the Henry G. Friesen International Prize in Health Research (2019), the Till and McCulloch Award for science policy (2020) and the Lifetime Achievement Award, Canadian Bioethics Society Lifetime Achievement award (2021).

The last decade has been dedicated to building the Global Alliance for Genomics and Health (GA4GH) and drafting its *Framework for the Responsible Sharing of Genomic and Health-Related Data*, a living instrument that was translated into 16 languages. Based on the right of everyone to benefit from scientific advances, GA4GH is the first international organization to provide both the policy and IT data sharing tools for international implementation and interoperability within and across different national systems. Her current challenge is to anticipate the governance needed for the nascent Human Cell Atlas and to develop a Code of Conduct for the international sharing of genomic and health data across health technologies industries.

On behalf of the CGP team, we want to express our deepest gratitude for Bartha Maria Knoppers’ years of service. Her impact at CGP is immeasurable, and we are grateful for the privilege of having worked under her leadership and guidance.

Wishing her many more years of great achievements!

The CGP team



ABOUT US

Located within the Victor Phillip Dahdaleh Institute of Genomic Medicine at McGill University, **the Centre of Genomics and Policy (CGP)** is an interdisciplinary and international research Centre with a distinct focus on how universal human rights can both frame -omics and other health innovations while supporting the promotion and protection of human health. As precision medicine increasingly relies on data-intensive novel technologies, there's a notable risk that the resulting health benefits, both current and future, may not be fully realized or equitably distributed without concurrent research into ethico-legal and policy issues.

The CGP pursues a unique, integrated and innovative research program founded on three universal human rights: 1) right to science; 2) right to non-discrimination and 3) right to health. These rights span numerous population and research contexts, including pediatrics, (preimplantation / cell / gene therapies), RNA-based precision medicine, rare diseases, cancer, clinical / research, -omics generally, and artificial intelligence.

The CGP is dedicated to anticipating and addressing complex legal, ethical and policy issues in the fields of omics and modern medicine through research, education, and practice in collaboration with local, national and international partners.

Learn more at www.genomicsandpolicy.org/





MEET THE CGP TEAM



FOUNDING DIRECTOR

KNOPPERS Bartha Maria
Professor

DIRECTOR

JOLY Yann
Professor

RESEARCH DIRECTOR

ZAWATI Ma'n H.
Associate Professor

ACADEMIC ASSOCIATES

BERNIER Alexander
BIRKO Stanislav
BOUHOUITA-GUERMECH Sarah
DALPÉ Gratien
DAYTON Lindsay – *Executive Director*
UBEROI Diya
KIRBY Emily
KNOPPERS Terese
PALMOUR Nicole – *Coordinator*
PATRINOS Dimitri
SONG Lingqiao
STEVENS Yuan

RESEARCH ASSISTANTS

AYYAPPASWAMY Priya
BHATTACHARJEE Maushumi
BRODIE Maxwell
CHEUNG Katherine
DAUGE Aurélie
EXIUS Rutherford
FARAG Nada
FARAJI Sasha
HOTTER YISHAY Amir
HUERNE Katherine
KAISER Beatrice
KONDRUP Emma
MEHTA Preksha
NOË Alycia
REVEIZ Manuela
RUTLEDGE Nadine
SAN DIEGO Kacey Miranda
VOUSINAS Angelica
XUE Ariel (Yunhe)

SCHOLARLY CONTRIBUTORS

ASSOCIATE MEMBERS

BARET Laurence
BOURQUE Guillaume
DUCHAINÉ Thomas
FRIESEN Phoebe
FRITZ Jorg
GOLD Richard
GOUDIE Catherine
GRAVEL Simon
JUNCKER David
KHOURY Lara
KIMMELMAN Jonathan

SCIENTIFIC CONSULTANTS

AVARD Denise
LABERGE Claude

INVITED SCHOLARS

BORRY Pascal
DOVE Edward
HO Calvin
MESLIN Eric
RAHIMZADEH Vasiliki N.
SATO Momoko

PhD STUDENT

SO Derek

MASTER'S STUDENTS

BONILHA Ana Eliza
BRADBURY-JOST Jacqueline
DOERKSEN Emily
HALEY Cassandra
LIU Hanshi

INTERNS

BARREAU Annaëlle
FETTOUS Ines
HANSEN Sayaka
LEMYRE Simon
NI Anjie
SENTELL Zachary
VAILLANCOURT Emilie

ADMINISTRATIVE ASSISTANTS

CHANG Mei-Chen
GAMBOA Kathryn
HOZAN Rose-Marie
THORSEN Nadine

COMPLETED PROJECTS

APR 2016

MAR 2024

Sino-Canada HeLTI: A Multifaceted Community-Family-Mother-Child Intervention Study for the Prevention of Childhood Obesity (SCHeLTI)

MAR 2018

MAR 2024

Toward effective health communication with intersex Canadians: A study of ethical and legal challenges

APR 2018

MAR 2023

Precision Oncology for Young People (PROFYLE 2)

APR 2018

MAR 2024

Care4Rare Canada: Harnessing Multi-Omics to Deliver Innovative Diagnostic Care for Rare Genetic Diseases in Canada (C4R-SOLVE)

APR 2018

MAR 2024

Interrogating and Implementing Omics for Precision Medicine in Acute Myeloid Leukemia

APR 2018

MAR 2024

Personalized Risk Assessments for Prevention and Early Detection of Breast Cancer: Integration and Implementation (Perspective II)

APR 2018

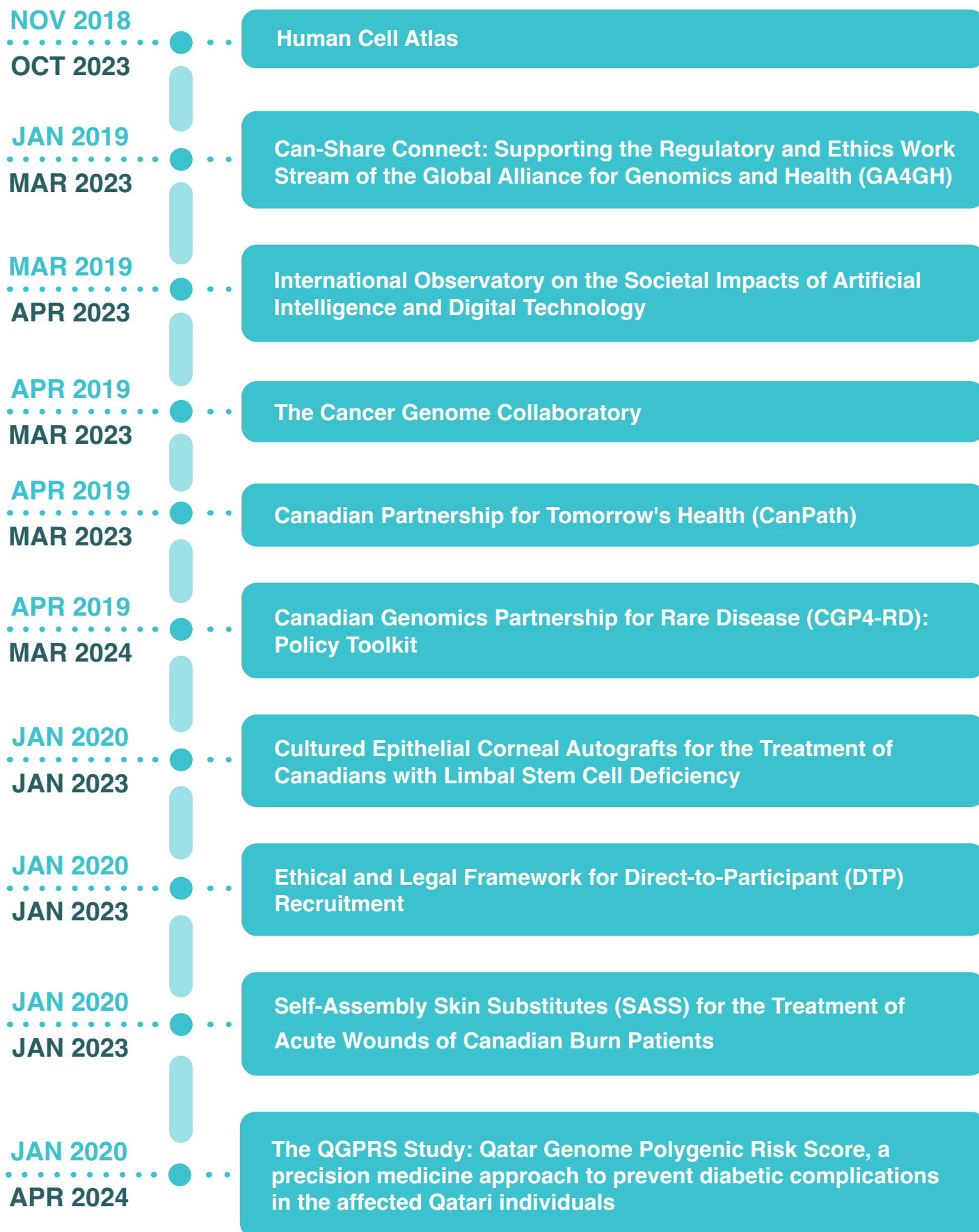
MAR 2024

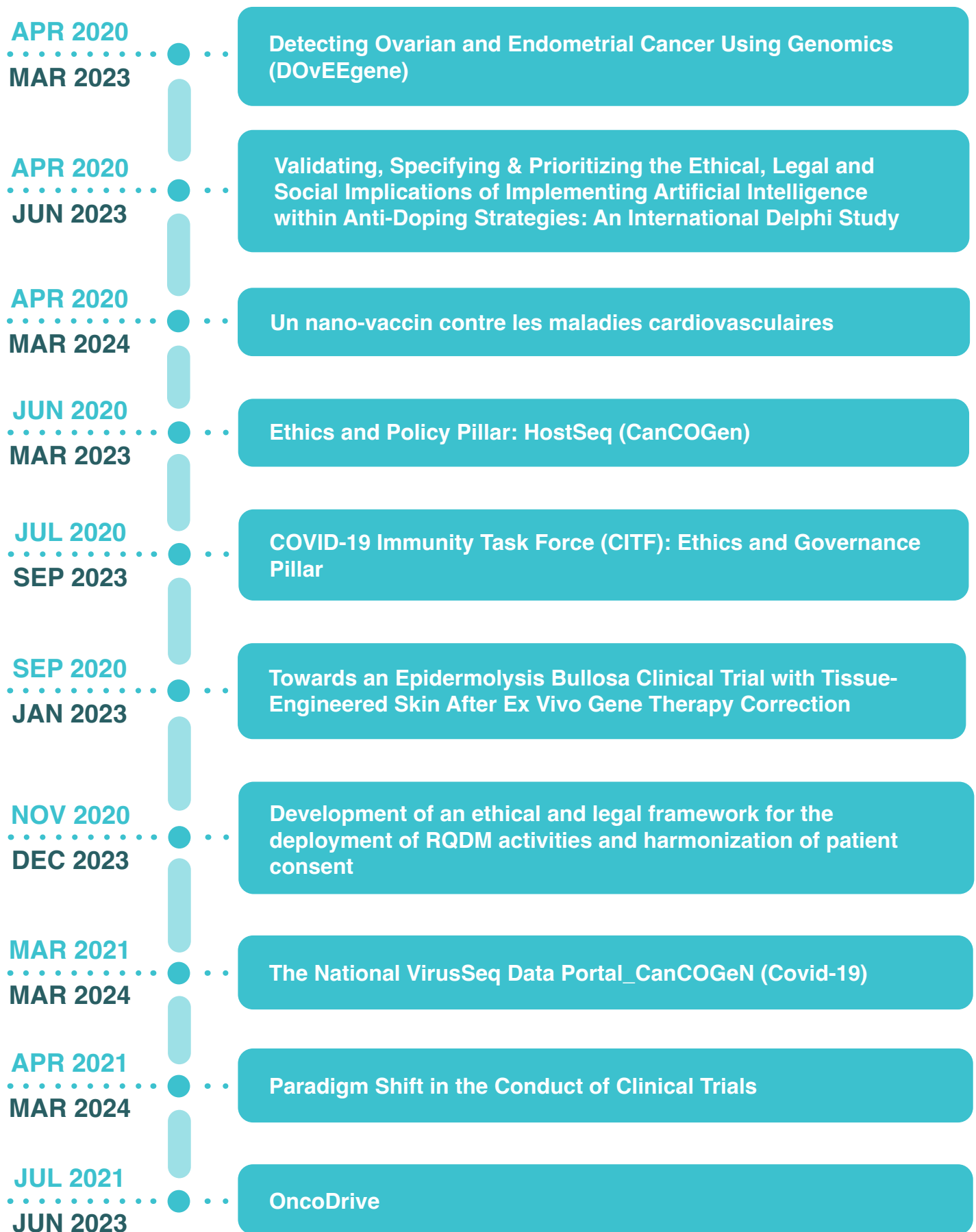
Personalized Therapy for Individuals with Cystic Fibrosis

APR 2018

MAR 2024

QUEBEC 1000 FAMILIES (Q1K) PROJECT (Transforming Autism Care Consortium)





JUL 2021 MAR 2024	● ..	GA4GH Genomic Data Sharing Tools Against COVID-19
JAN 2022 DEC 2023	● ..	The Canadian Open Neuroscience Platform (CONP)
MAR 2022 MAR 2024	● ..	Federated Data Access Committees for Harmonised Pan-Canadian Cancer Data Management (CanFed)
MAR 2022 MAR 2024	● ..	The 2022 Genetic Discrimination Observatory Conference
APR 2022 MAR 2024	● ..	Combining tissue-engineered skin with ex vivo gene therapy correction to develop a treatment for epidermolysis bullosa
APR 2022 MAR 2024	● ..	Canadian Platform for Precision Health
DEC 2022 NOV 2023	● ..	Setting up the conditions for the biobanking of tissues and cells from hypertrophic scars
JAN 2023 MAR 2024	● ..	Authentic Lives and the Right to Gender Affirming Care for Youth: Actors, Values, and Legislative Approaches in the U.S. and Canada
MAY 2023 APR 2024	● ..	Opportunity and Misuse of Genetic Ancestry Data in Biomedical Research: A Systematic Review of the Literature
NOV 2023 MAR 2024	● ..	Tests épigénétiques de l'âge et du vieillissement offerts directement aux consommateurs: opportunités et enjeux éthiques en promotion commerciale de la jeunesse biologique



**Multidimensional
Epigenomics
Mapping Centre
(EMC) at McGill**

FEB 2017 - MAR 2025

**Canadian Institutes
of Health Research
(CIHR)**

To join global efforts, the International Human Epigenome Consortium (IHEC) has established an Epigenome Mapping Centre (EMC) at McGill University that applies epigenome mapping in order to understand interactions between environment and genome in human blood cells, interprets diseases impacting metabolism using tissue samples, and studies how epigenetic changes can alter function of the brain. The large-scale generation and sharing of human epigenome data present challenges to the informed consent process that are managed first through the integration of existing cohort data with EMC McGill, using a special template developed in conjunction with the Policy Partnership Project for Genomic Governance,* and subsequently by prospectively developing a model consent template that ensures all IHEC consent, policy, and ethics requirements are met. The CGP will continue to actively participate in discussions on the development of a more comprehensive ethical policy framework at the IHEC level. Both the EMC and Epigenomic Data Coordination Centre (EDCC) projects also involve the development of and support for a bioethics workgroup for the IHEC.

PRINCIPAL INVESTIGATOR

BOURQUE Guillaume

CO-INVESTIGATORS

BARREIRO Luis

JOLY Yann

LATHROP Mark

PASTINEN Tomi

COLLABORATORS

BAGLOLE Carolyn

BERNATSKY Sasha

GREENWOOD Celia

GRUNBERG Elin

HUDSON Marie

MEANEY Michael

ROSENBLATT David

SHOUBRIDGE Eric

SLIM Rima

STIFANI Stefano

TRASLER Jaquetta

WHITE John

ACADEMIC ASSOCIATE

PALMOUR Nicole

RESEARCH ASSISTANT

HUERNE Katherine

* P3G2 – Was a non-profit international consortium, associated with the CGP, to optimize cross-border data access and use via ethical and governance frameworks, policy and tool development.

**Large Scale
GE3LS Project:
GenCOUNSEL:
Optimization of
Genetic Counseling
for Clinical
Implementation
of Genome-Wide
Sequencing**

JUL 2018 - JUN 2025

**Genome British
Columbia
Génome Québec
Genome Canada**

Genome-wide sequencing (GWS; whole genome or exome sequencing) is a powerful new tool that analyzes a person's entire genetic make-up. However, the information garnered from this type of testing can be overwhelming and may be misinterpreted by non-experts. Genetic counsellors are health professionals that aid patients and families in making informed decisions for this type of testing. However, due to the small number of genetic counsellors in Canada and lack of legal recognition, access to their services is extremely limited. As access to GWS improves and cost decreases, the use of this technology will increase along with the need for genetic counselling. As a result, further exploration of the possible legal recognition of genetic counsellors and key related strategies is necessary. The CGP oversees policy development for the future legal recognition of genetic counsellors in Canada. Specifically, the CGP 1) researched models of legal recognition available to genetic counsellors; 2) categorized the main tasks performed by genetic counsellors and assessed how they translate into legal duties; and 3) convened a pan-Canadian working group comprised of key stakeholders to discuss the feasibility of and potential pathways toward legal recognition.

PRINCIPAL INVESTIGATORS

AUSTIN Jehannine

ELLIOTT Alison

KNOPPERS Bartha Maria

LYND Larry

CO-INVESTIGATOR

ZAWATI Ma'n H.

ACADEMIC ASSOCIATES

KNOPPERS Terese

PATRINOS Dimitri

RESEARCH ASSISTANT

NOË Alycia

MASTER'S STUDENT

BONILHA Ana Eliza

**MSSNG Project Data
Access Compliance
Office (DACO)**

JUL 2018 - DEC 2025

Autism Speaks

MSSNG and Autism Genetic Resource Exchange (AGRE) are the world's largest databases of genomic information collected from individuals with autism spectrum disorder (ASD) and their families. MSSNG in particular advances the goal of sequencing 10,000 families affected by ASD to answer significant remaining questions about autism, its causes, and effects. Scientists from around the world may access trillions of data points in a single database. The CGP hosts the Data Access Committee for MSSNG and AGRE, adjudicating access on the part of external researchers to these valuable resources. CGP manages the review of data access applications and grants access to qualified researchers. In 2023, the Data Access Committee approved 7 new applications.

PRINCIPAL INVESTIGATOR

ZAWATI Ma'n H.

ACADEMIC ASSOCIATES

KIRBY Emily

PATRINOS Dimitri

RESEARCH ASSISTANT

NOË Alycia

MASTER'S STUDENT

BONILHA Ana Eliza

**euCanSHare: An
Eu-Canada Joint
Infrastructure for
Next-Generation
Multi-Study Heart
Research**

OCT 2018 - MAR 2025

**Canadian Institutes
of Health Research
(CIHR)
Fonds de recherche
du Québec - Santé
(FRQS)**

The euCanShare platform is a data discovery tool that brings together summary statistics, metadata, and other information from 27 cardiovascular health studies and cohort studies across Canada and the European Union. Participating cohort studies include the Canadian Alliance for Healthy Hearts and Minds, and the European Biomar Care project. The CGP leads the ethical-legal work-package of euCanSHare, including the development of ethical-legal metadata describing the data governance conditions and data stewardship conditions applicable to each participating study. This enables researchers to find, and obtain access to, data that is useful for their anticipated research purposes, considering both the scientific features and the governance conditions of the data. The euCanSHare project is launching a follow-up effort to enable downstream access to data from multiple retrospective studies and cohorts through a single centralized Data Access Portal.

PRINCIPAL INVESTIGATORS

ANAND Sonia
FERRETTI Vincent
FORTIER Isabel
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE

BERNIER Alexander

**EUCANCan: A
Federated Network
of Aligned and
Interoperable
Infrastructures for
the Homogeneous
Analysis,
Management and
Sharing of Genomic
Oncology Data
for Personalized
Medicine**

OCT 2018 - MAR 2025

**Canadian Institute
for Health Research
(CIHR)**

The European-Canadian Cancer Network (EUCANCan) is a pilot project to develop and test a federated platform for the privacy-preserving, scalable analysis of clinical data across multiple healthcare organisations in Canada and the European Union. The CGP drafted a number of legal analyses assessing the data protection implications of proposed technical implementations thereof, and of federated data analysis more generally. Federated data analysis is a recent technological innovation that will help multiple clinical partners to pool and to analyze their data at scale without encountering the technical challenges and governance barriers of traditional efforts to centralize data for future use. The articulated policy proposals will be instrumental in formulating data governance and legal compliance strategies for future precision health initiatives.

PRINCIPAL INVESTIGATOR

STEIN Lincoln

CO-INVESTIGATORS

FERRETTI Vincent
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE

BERNIER Alexander

SecureData4Health

NOV 2020 - DEC 2025

**Canadian
Foundation for
Innovation (CFI)**

Data has the potential to dramatically transform biomedical research and health care. In particular, we are now in an era where genomes can be systematically sequenced and provide fundamental insights into our predisposition to diseases, our response to therapies and how our health can be affected by our environment. The SecureData4Health proposal creates the computational and software infrastructure needed to safely store, interpret and share the genomic and health information that is rapidly expanding within our centres and hospitals. It also facilitates access to the wealth of complementary information being made available across the world. The SecureData4Health infrastructure is deployed within the existing host sites of Compute Canada, allowing our team of scientists and users easy access to the technologies needed to reap the full benefits of their data, without the need to duplicate resources.

Finally, our project provides innovative data sharing modalities where the security and confidentiality of participants' data will be paramount. It enables Canada to play a leading role in the challenging but critically important movement towards international health data sharing. The CGP will contribute leadership, expertise, and coordination to develop a variety of policies, Good Practices, and standards on behalf of the SecureData4Health Initiative. Additionally, the CGP, will provide guidance on privacy, security, and data governance.

PRINCIPAL INVESTIGATORS

BOURQUE Guillaume
FERRETTI Vincent

CO-INVESTIGATORS

BRUDNO Michael
GINGRAS Anne-Claude

GOLDENBERG Anna
HAIBE-KAINS Benjamin
HUSSIN Julie
JACQUES Pierre-Etienne
JOLY Yann
KNOPPERS Bartha Maria
SIMARD Jacques

MASTER'S STUDENT

LIU Hanshi

RESEARCH ASSISTANT

BRODIE Maxwell

**Smartphone
crowdsourced
medical data for
biomedical research:
Addressing the
ethical, legal and
health policy
concerns**

JAN 2021 - DEC 2024

**Fonds de recherche
du Québec (FRQ)**

Smartphone applications for health are being increasingly used as a platform to collect and share large volumes of crowdsourced personal health data for biomedical research and algorithm training. Consumer genetics products are similarly allowing individuals to have direct access to their own genetic data and to share such data with researchers. Using smartphone and genetic data in these ways presents numerous opportunities to expand biomedical knowledge, though it also raises certain risks. Some of these include risks to personal privacy and risks associated with unclear ethical and legal obligations on the part of app developers and researchers. In this project, the CGP collaborates with Belgian partners to mitigate these risks. We do so by determining how smartphone applications and other mobile tools that collect health data work in practice and by addressing legal, ethical, and regulatory uncertainty in both Canada and the European Union. We will use this evidence to develop health policy guidelines that will enable smartphone data to be used safely, in a manner that protects users and the public. In doing so, we will assure that such data will contribute to improved health outcomes by expanding biomedical knowledge and making health more effective and efficient.

PRINCIPAL INVESTIGATORS

BORRY Pascal
GAUTRAIS Vincent
SHABANI Mahsa
ZAWATI Ma'n H.

ACADEMIC ASSOCIATES

BOUHOUITA-GUERMECH
Sarah
PATRINOS Dimitri

RESEARCH ASSISTANT

FARAG Nada

**CanDIG: Canadian
Distributed Cyber-
Infrastructure for
Genomics data
sharing and analysis**

APR 2021 - MAR 2025

**Canadian
Foundation for
Innovation (CFI)**

The Distributed Infrastructure for Genomics Data Sharing and Analysis project is divided into four activities. In Activity 1, the CGP will develop a broad Canadian data sharing framework, using the application programming interface definition developed under the auspices of the Global Alliance for Genomics and Health (GA4GH). Activity 2 continues the development of GenAP: a computational gateway for data analysis in life sciences that is configured to take advantage of Compute Canada infrastructure. Activity 3 builds a data-sharing platform to allow for the collection of standardized clinical data, dynamic cohorts, and the performance of genome analytics across datasets stored on various Compute Canada nodes, and to enable genome-guided clinical trials across Canada. Finally, Activity 4 will establish the Canadian Molecular Profiling in Cancer Trials Interchange. Together, the four activities will utilize Compute Canada infrastructure to build a distributed and secure computational framework for the analysis of genomic datasets relevant to human diseases and beyond. The CGP will also contribute to the implementation of the data sharing and privacy policy framework of the International Human Epigenome Consortium as well as that of the GA4GH.

PRINCIPAL INVESTIGATOR

BRUDNO Michael

CO-APPLICANTS

BASIK Mark
BOURQUE Guillaume
JACQUES Pierre-Etienne
JOLY Yann
JONES Steven

KARSAN Aly
LATHROP Mark
PUGH Trevor
SCERER Steven
VIRTANEN Carl

**International
Good Practices
for Genomic Data
Sharing**

JUL 2021 - JUL 2024

Illumina

As the secretariat and academic partner for the International Good Practices for Genomic Data Sharing project, the CGP drafted the International Good Practices for Genomic Data Sharing document, and sought, organized, and incorporated feedback on drafts from Industry Core Group members. The CGP synthesized pre-existing Global Alliance for Genomics and Health (GA4GH) guidance and assessed its applicability to the International Good Practices for Genomic Data Sharing. Discussions between Industry Core Group members and other relevant stakeholders regarding the International Good Practices for Genomic Data Sharing content were facilitated by the CGP which ensured needing administration.

Following completion of the Work Product, the CGP will introduce the International Good Practices for Genomic Data Sharing document to the GA4GH Regulatory & Ethics Workstream and facilitates its socialisation among the broader GA4GH membership.

PRINCIPAL INVESTIGATORS

JOLY Yann
KNOPPERS Bartha Maria
ZAWATI Ma'n H.

The Québec SmartCare Consortium

JUL 2021 - DEC 2024

Ministère de
l'Économie et de
l'Innovation (MEI)

The Québec SmartCare (Soins intelligents) Consortium (QSCC) is an innovative research project centred on the Opal patient portal (opalmedapps.com) at the Research Institute of the McGill University Health Centre that is designed to address the challenges caused by the siloing of data in the Québec healthcare system. It comprises a unique group of public and private partners with expertise and interest in patient-centered care, mHealth technology, and AI research. Working together, the consortium partners will strengthen the patient-centered technology of the existing Opal patient portal, enable secure data flow from wearable devices into Québec hospitals, and collect real-world data for artificial intelligence and real-world evidence research.

The CGP: 1) examined specific ethico-legal issues associated with access to data; 2) developed a governance framework for access and associated consent; 3) developed a "Collaboration with Industry" policy with industry partners and other stakeholders; 4) and advised the QSCC on selecting an access system to coordinate, review and adjudication of access requests by researchers.

The work established solid frameworks for data governance and commercialization / technology transfer that are expected to persist well beyond the lifetime of the QSCC and will help foster continued collaboration amongst the partners.

PRINCIPAL INVESTIGATORS

HIJAL Tarek
KILDEA John

CO-APPLICANTS

ALMEIDA Nisha
BESSISSOW Talat
DENDUKURI Nadini
JOLY Yann
LI Yue
MAZER Bruce
MCCUSKER Christine
ZAWATI Ma'n H.

COLLABORATORS

CUCCIA Luca
LAIZNER Andréa
MOTULSKY Aude

ACADEMIC ASSOCIATE

PALMOUR Nicole

Personnel Hautement Qualifié Intelligence Artificielle et Santé Numérique

JAN 2022 - DEC 2024

Fonds de
recherche du
Québec - Santé
(FRQS)

The CGP along with the McGill University Health Centre (MUHC) Data Governance Task force will develop an MUHC / MUHC-RI Data Governance Framework encompassing the use of clinical and administrative data from MUHC information systems and other sources by researchers at the RI-MUHC. The Framework will clearly define the ethical and legal foundations for, and limits on, the use of clinical and administrative data for research within and outside of the MUHC in the province of Québec. The Framework will facilitate legal and ethical conformity in domains including privacy, data access, research ethics and information systems. The Framework will also consider, when possible, the use of these data by clinicians and administrators for quality assurance of healthcare. The use of clinical and administrative data for research and quality assurance are well aligned under the concept of a learning healthcare system, in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation with new knowledge being captured as an integral by-product of care delivery.

PRINCIPAL INVESTIGATOR

BUCKERIDGE David

CO-INVESTIGATOR

JOLY Yann

ACADEMIC ASSOCIATE

PALMOUR Nicole

RESEARCH ASSISTANTS

BRODIE Maxwell
FARAJI Sasha
RUTLEDGE Nadine

Delineating a Canadian data solution that will deliver precision health for rare genetic disease

APR 2022 - SEP 2024

Genome Canada

Breakthroughs in precision health, which harnesses the power of genome sequencing for diagnosis and treatment of genetic conditions, are revolutionizing healthcare. But access to clinical genomic testing is inconsistent across Canada. The All for One Health Data Ecosystem (HDE) initiative aims to advance precision health across the country through the creation of a pan-Canadian variant database and promote access to precision health research for rare disease patients through the creation of a patient registry. Ultimately, the All for One HDE initiative aims to improve the health and wellness of Canadians by building regional genomics capacity, promoting the equitable and ethical uptake of precision health tools and addressing barriers to data sharing. The CGP is responsible for the development of governance tools for the database and registry, including frameworks and model consent clauses. The CGP also provides input on the ethical, legal and social implications of the sharing of health data in Canada.

PRINCIPAL INVESTIGATORS
 BERNIER Francois
 BOYCOTT Kym
 BULLMAN Denis
 FERRETTI Vincent
 LERNER-ELLIS Jordan
 MARSHALL Christian
 MICHAUD Jacques
ZAWATI Ma'n H.

ACADEMIC ASSOCIATE
 BERNIER Alexander

Engineered hematopoietic stem cells (eHSCs) as vehicles for next generation therapies

APR 2022 - JAN 2025

Stem Cell Network (SCN)

Modern cancer therapies increasingly rely on antibody-based drugs or genetically engineered immune cells that are programmed to recognize specific proteins on the surface of cancerous cells while not attacking their healthy counterparts. The goal of this project is to better target leukemia cells while sparing the normal blood cells by engineering blood stem cell grafts as a next-generation therapy for treating aggressive blood cancers. Further, establishing an improved delivery method for genetically engineered anti-leukemia immune cells into leukemia patients by completely modifying blood stem cells would allow for the regeneration of engineered immune cells for life. Overall, this research has the capability to vastly improve therapeutic prospects for leukemia patients.

The CGP's role is to investigate potential liability for race-associated precision medicine interventions. We will review and document how North American courts have considered medical liability when adjudicating claims of medical negligence for the race-disparate effects of clinical interventions. We will also engage in a systematic review of legal scholarship on race-based or race-influenced medical care and document the degree to which academic legal commenters predict that such interventions will affect the professional and clinical obligations of individuals engaged in providing care of this kind.

Furthermore, CGP will investigate the social-economical assessment to determine the viability of this approach in the Canadian context.

PRINCIPAL INVESTIGATOR
 SAUVAGEAU Guy

SHAKIBA Nika
ZANDSTRA Peter
ZAWATI Ma'n H.

LEHNERTZ Bernhard
NELSON Brad
TREMBLAY Gabriel

CO-INVESTIGATORS
 GAGNON Etienne
 HÉBERT Josée
 LAVALLÉE Vincent-Philippe
 ROUX Philippe

COLLABORATORS
 DELISLE Jean-Sébastien
 GENTNER Bernhard
 HUMPHRIES Keith

ACADEMIC ASSOCIATE
 BIRKO Stanislav

Responsible Pathways for Pediatric Cell Therapies

APR 2022 - JAN 2025

Stem Cell Network (SCN)

This project will address the lack of guidance for researchers designing cell therapy clinical trials, especially at the first-in-human stage. It will consider the lack of guidance and educational resources for REBs and regulatory bodies assessing such trials, and the lack of guidance for research participants considering the risks and benefits of their participation, as well as the ethical, legal and social issues associated with these gaps. To facilitate the ethical and responsible clinical translation of cell therapies, via ethically conducted clinical trials, with a specific focus on minors and their parents / families. Issues addressed by this project will include: criteria to be used by researchers / clinicians, REBs and regulatory bodies to select which potential therapies should move towards clinical trials; review criteria for REBs to assess such proposals; clarification of the legal and ethical duties and professional liabilities of researchers / clinicians; specific considerations regarding the participation of minors in clinical trials; and concerns perceived as important by minors, their parents / families, and their pediatricians, regarding cell therapies. Addressing these issues will allow us to better understand how to overcome challenges and barriers to clinical translation.

The CGP will analyze the legal roles and ethical responsibilities of researchers / clinicians in the context of clinical trials using cell therapies, with an emphasis on first-in-human trials in minors, and to understand the perspectives of clinicians and researchers on how to operationalize the high-level principles of the Charter for Regenerative Medicine relevant to their practice and their interactions with participants.

PRINCIPAL INVESTIGATORS

RAVITSKY Vardit
(until Aug 2023)
ZAWATI Ma'n H.
(since Sept 2023)

CO-INVESTIGATORS

KIMMELMAN Jonathan
ZAWATI Ma'n H.
(until Aug 2023)

COLLABORATORS

ADASHI Eli
BUBELA Tania
CAULFIELD Timothy
COHEN Glenn
KNOPPERS Bartha Maria
KOFLEK Natalie
MAKANI Julie
SNYDER Jeremy
WILLIAM-JONES Bryn

ACADEMIC ASSOCIATE

BIRKO Stanislav

RESEARCH ASSISTANTS

MEHTA Preksha
NOË Alycia

**Tissue Engineering
to Treat Canadian
Burn Patients: The
Self-Assembled Skin
Substitutes (SASS)**

APR 2022 - JAN 2025

**Stem Cell Network
(SCN)**

Skin autografts are used to treat burn wounds, but they take on a strategic role when the area that needs to be covered is greater than 50% of the total body surface area. Autologous Self-Assembly Skin Substitutes can be made from just a little skin biopsy using tissue engineering techniques established in Dr. Moulin's lab (Université Laval), and they might be used to permanently cover all the patient's wounds. Health Canada had approved this early-stage clinical trial, and only a small number of patients have received care in Quebec. By extending the study to burn units in other Canadian provinces, this project will serve as a model treatment approach. This trial's objective is to assess this cutting-edge therapeutic strategy for treating Canadian patients with extensive burns to promote skin regeneration. Preliminary findings have shown that treatment reduces morbidity brought on by current treatments and improves patients' quality of life, suggesting that treatment should have economic and societal benefits. Dr. Moulin's lab will be the first in Canada to routinely treat patients with autologous rebuilt skin after the clinical trial and approval by Health Canada.

The CGP will assist with the preparation of the requirements needed for research ethics coordination and approval (including preparing standardized recruitment procedures and protocols, consent forms and information pamphlets). Documentation for the clinical trial application meetings and for regulatory approval with Health Canada will be prepared by the CGP.

PRINCIPAL INVESTIGATOR

MOULIN Véronique

CO-INVESTIGATORS

GERMAIN Lucie
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE

BIRKO Stanislav

**Psilocybin to relieve
existential distress
at the end of life:
Audace, acceptability
and access**

APR 2022 - MAR 2025

**Fonds de la recherche
du Québec - Society
and Culture (FRQSC)**

Psilocybin is the psychoactive element found in hallucinogenic mushrooms or "magic mushrooms". Although the production, possession, and sale of these mushrooms are illegal in Canada, the potential therapeutic uses of psilocybin are attracting growing interest internationally. Randomized clinical trials have demonstrated that a moderate single dose of psilocybin combined with psychotherapy produces rapid, robust, and long-lasting anxiolytic and antidepressant effects in patients with advanced cancer and suffering from cancer-related psychological distress.

This project aimed to 1) assess the social and professional acceptability of psilocybin-assisted therapy to relieve existential distress at the end of life; 2) identify the issues to consider for access to this innovative therapy; 3) propose recommendations establishing guidelines for the use of psilocybin for therapeutic purposes in the Quebec forensic context. In addition to the recommendations that were presented to decision-makers in the form of a memorandum, this work laid the foundations of a community resource that, together with the care settings, will have the mission of informing and supporting patients considering using assisted therapy with psilocybin to alleviate their existential distress.

PRINCIPAL INVESTIGATORS

DORVAL Michel
FALLU Jean-Sébastien

CO-INVESTIGATORS

FARZIN Houman
GAGNON Pierre
HÉBERT Johanne
JOLY Yann

COLLABORATORS

BARRAULT-COUCOURON
Marion
CHANG Sue-Ling
DESCHAMPS Pierre
FOXMAN Robert

RESEARCH ASSISTANT

BRODIE Maxwell

Explaining the Right to Explanation: Data Protection Legislation and Clinical Automated Decision-Making

JUL 2022 - JUN 2025

Observatoire International sur les Impacts Sociétaux de l'IA et du Numérique (OBVIA)

Quebec's National Assembly adopted a right to explanation for automated decision-making in late 2021. This is the first such right implemented in Canada, with as yet unknown consequences for the practice of medicine. Automated decision-making tools for the diagnosis, management, and treatment of disease are being applied across the healthcare system, and these newly adopted rights might have significant legal consequences for clinicians. This project will address how statutory rights to explanation for automated decision-making adopted in Quebec and elsewhere are likely to affect the legal obligations of clinicians providing care that is facilitated by automated medical devices. The CGP is conducting a comparative legal analysis to understand the effects of rights to explanation adopted in other jurisdictions, with particular focus on European Union member states. We will also define the potential scope of rights to explanation by surveying automated decision-making tools presently being used in Canada, hold a virtual deliberative exercise with relevant stakeholders (including clinicians and patient representatives), and prepare policy tools outlining how rights to explanation will affect the use of clinical automated decision making.

PRINCIPAL INVESTIGATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATES
PATRINOS Dimitri
STEVENS Yuan

RESEARCH ASSISTANTS
BHATTACHARJEE Maushumi
EXIUS Rutherford
MEHTA Preksha

CO-INVESTIGATORS
CHAREST Anne-Sophie
DAVIDSON Ann-Lousie
HAIDAR Hazar

Élaboration d'un cadre réglementaire international en matière de technologie nanomédicale

MAR 2023 - DEC 2024

Ministère des Relations internationales et Francophonie (MRIF)

Previously unrelated emergent technologies like artificial intelligence, gene editing, nanotechnology, neurotechnology, and robotics are now deeply entwined. As a consequence of the globalization, the socio-technical novelty, the cross-disciplinary nature and the disruptive potential, of digital nanotechnologies necessitates the development of adapted policies harmonized with that of Canada's economic and research partners. In collaboration with our Korean colleagues at Yonsei University Bioethics Department we will research and develop the foundations for a more coherent international regulatory framework between our two countries. The project will solidify existing bonds through collaborative research and knowledge translation activities. Lastly, the regulatory framework should allay public fears towards the integration and societal impact of nanotechnologies and help to re-build public trust in science.

PRINCIPAL INVESTIGATOR
JOLY Yann

ACADEMIC ASSOCIATE
PALMOUR Nicole

Développement de la recherche et accès équitable aux médicaments et aux vaccins brevetés en contexte de pandémie

MAR 2023 - MAR 2028

Social Sciences and Humanities Research Council (SSHRC)

The COVID-19 pandemic has brought back to the forefront the inequities that exist in access to patented medicines and vaccines worldwide, while reaffirming the primordial role of research and development (R&D) and access to data for the international health community. The practices observed over the past two years testify to the shortcomings of the normative framework underlying patents, within which institutional and pharmaceutical players operate. Initiatives stemming from international efforts and aimed at equitable access worldwide have unfortunately proved insufficient to achieve this goal.

The project aims to identify and propose the elements (agreements, laws, policies, practices) of a normative patent framework that maximize R&D and access to patented medicines and vaccines, particularly in the context of a pandemic.

Two concepts in particular, namely the notion of technological non-discrimination, which underlies patents, and the notion of Corporate Social Responsibility applicable to the pharmaceutical sector will be utilized. More specifically, we want to assess the extent to which the use of these two concepts can or cannot maximize R&D and access to patented medicines and vaccines in the context of a pandemic. To achieve this, we will draw on neo-institutionalism and the stakeholder preference theory approach. A Delphi survey (iterative survey) will be used to identify elements of a normative framework (hard law, soft law, including contractual practices) relating to patents that are viable and realistic from an institutional and political point of view for all stakeholders.

Our work will also lead to the development of a bilingual guide, in the form of a tutorial, aimed at pharmaceutical companies, which could be adapted to other industries, such as the agri-food sector.

More specifically, the CGP will utilize the Delphi method, supported by his multidisciplinary team at the Centre de Génomique et Politique (CGP). In carrying out this method, as well as in analyzing the responses it generates, the CGP will accompany him and draw on its expertise in pharmaceutical policy, in taking preferences into account in policy-making, and its skills in the co-construction of knowledge.

PRINCIPAL INVESTIGATOR
BOURASSA-FOURCIER
Mélanie

CO-INVESTIGATORS
CORRIVEAU Anne-Marie
JEAN-BOUCHARD Evelyne
JOLY Yann

ACADEMIC ASSOCIATES
PALMOUR Nicole
UBEROI Diya

RESEARCH ASSISTANT
KONDRUP Emma

Allogeneic dermis to accelerate the production of a tissue-engineered skin substitute to treat Canadian burn patients

APR 2023 - JAN 2025

Stem Cell Network (SCN)

Expanding on tissue engineering techniques established in Dr. Moulin's lab (Université Laval) this project will continue to assess the use of Autologous Self-Assembly Skin Substitutes (SASS) to cover greater than 50% of the total body surface area of burn victims. Health Canada had approved this early-stage clinical trial, and this project will serve as a model treatment approach. This trial's objective is to assess this cutting-edge therapeutic strategy for treating Canadian patients with extensive burns to promote skin regeneration. Preliminary findings have shown that treatment reduces morbidity brought on by current treatments and improves patients' quality of life, suggesting that treatment should have economic and societal benefits. Dr. Moulin's lab will be the first in Canada to routinely treat patients with autologous rebuilt skin after the clinical trial and approval by Health Canada.

The CGP will help with the preparation of the requirements needed for research ethics coordination and approval (including preparing standardized recruitment procedures and protocols, consent forms and information pamphlets). Documentation for the clinical trial application meetings and for regulatory approval with Health Canada will also be provided.

PRINCIPAL INVESTIGATOR
MOULIN Véronique

CO-INVESTIGATORS
BEAUDOIN-CLOUTIER
Chanel
GERMAIN Lucie
ZAWATI Ma'n H.

RESEARCH ASSISTANT
NOË Alycia

Pan-Canadian approaches to sharing research data and fostering access by participants

APR 2023 - MAR 2026

Canadian Institutes of Health Research (CIHR)

The Canadian Pediatric Cancer Consortium (CPCC) is the largest-ever Canadian pediatric cancer research project. It is performing a broad array of distinct research activities, including both clinical data generation, and public policy work in areas such as health economics, law, and other fields. The CGP leads its ethical-legal and data governance work-package, which includes the development of policies and procedures to enable the stewardship of the data that the CPCC generates. The CPCC raises a plethora of public policy challenges that lie at the intersection of pediatric bioethics and data governance. Building on prior research in the PROFYLE project, governance proposals arising from this initiative could serve as a template for future Pan-Canadian efforts to generate and share pediatric oncology data.

PRINCIPAL INVESTIGATORS
MALKIN David
WHITLOCK Jim

CO-INVESTIGATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATE
KIRBY Emily

A.I. and Personalized Therapeutics

APR 2023 - MAR 2029

Canadian Institutes of Health Research (CIHR)

Prescription drugs play an expanding and essential role in preventing and treating chronic health problems. Despite the benefits of modern drug therapy, the full potential of medications to improve population health has not been realized due to limited capacity to assess real-world safety and effectiveness, personalized treatment, and influence use in practice. Drugs are often prescribed to populations in which they were not tested, with 5%-20% of patients experiencing potentially preventable adverse drug events, and 30%-50% not adhering to therapy due to side-effects, costs, or attitudes towards medication. To achieve high value pharmacare, we must optimize medication use in ways that address patient priorities, maximize benefits, and minimize risks. Digital advances in computerized prescribing and dispensing, electronic medical records, artificial intelligence (AI), computerized decision support, and patient-centered mobile apps and portals have created opportunities to catalyze the science of high value pharmacare. The purpose of this research program is to develop a new family of predictive algorithms for predicting benefit, risk, and adherence to a drug for a specific patient through AI-enabled analysis of real-world data, implement them as clinical decision-support tools in computerized prescribing systems, and determine if they improve patient outcomes.

PRINCIPAL INVESTIGATORS

FILION Kristian
MCDONALD Emily
TAMBLYN Robyn

COLLABORATORS

PLOUFFE Patricia
PUPA Rosalba
YANG Joseph

CO-APPLICANTS

BARTLETT Susan
BERNATSKY Sasha
BUCKERIDGE David
CHASSE Michael
PILOTTE Louise
PLATT Robert
PRECUP Doina
SUISSA Samy

THAVORN Kednapa
TOTINO Lora
ZAWATI Ma'n H.

RESEARCH ASSISTANT

NOË Alycia

Optimiser les soins et accélérer l'innovation en valorisant l'intégration des trajectoires de soins numériques des patients entre les établissements

JUN 2023 - MAY 2026

Ministry of the Economy, Innovation and Energy

The project goal is to develop and pilot data governance, data quality, and digital infrastructure methods and tools to enable the computational analysis of high-dimensional digital trajectories across establishments in Quebec. The developed methods and tools will directly address existing barriers to the secondary use of clinical data within the consortium which includes the Integrated Health and Social Services University Network for West-Central Montreal (CCOMTL), the McGill University Health Center (MUHC) and its Research Institute (RI-MUHC). This will enable a scaling-up in the sophistication and volume of data-driven research and innovation within the consortium and accelerate progress towards a Learning Health System. Moreover, we will translate knowledge and methods and tools generated through this project to other stakeholders in Quebec to enable similar advances in research and innovation throughout the province.

The CGP will assist with the Data Governance to: 1) develop a data governance framework to clarify the process for sharing trajectory data between establishments for research and innovation, including with and without patient consent; 2) adapt existing consent processes to facilitate clinical trial recruitment; 3) identify the requirements for implementing a consent registry to support the use of artificial intelligence to screen for patients eligible for clinical trials across the MUHC and the CCOMTL.

PRINCIPAL INVESTIGATOR

BUCKERIDGE David

CO-INVESTIGATOR

JOLY Yann

RESEARCH ASSISTANT

BRODIE Maxwell
RUTLEDGE Nadine

ACADEMIC ASSOCIATE

PALMOUR Nicole

Écosystème numérique DESIIR [Données Environnementales et de Santé Intégrées pour une Infrastructure de Recherche]

JUN 2023 - MAR 2029

Canadian Foundation for Innovation (CFI)

The COVID-19 pandemic has highlighted the dependence between living species and their environment. This means that researchers from all relevant disciplines must work together to achieve sustainable health goals. With this in mind, the DESIIR project aims to bring together in a digital infrastructure the health and environmental data collected or generated in the Saguenay-Lac-Saint-Jean (SLSJ) region over the past 50 years. The diversity of the data, UQAC's research approach (based on interdisciplinary collaborations), and the mobilization of the population make the SLSJ the ideal region for this project. To this end, the CGP will complete an ethical assessment of potential data contributors and will validate the possibility of integrating the data sets. The data will then be cleaned and described before being entered into DESIIR. A description of DESIIR data holdings will be publicly available to researchers and will help identify relevant data for new projects or collaborations. Thanks to DESIIR, it will be possible to identify data gaps and plan future initiatives. A DESIIR promotion and valorization strategy will be put in place to maximize project opportunities and spin-offs. This infrastructure will enable a global approach to the study of complex health issues, and ensure Canada's influence in sustainable health.

PRINCIPAL INVESTIGATORS

JOLY Yann
LA PRISE Catherine

ACADEMIC ASSOCIATE

PALMOUR Nicole

RESEARCH ASSISTANT

FARAJI Sasha

Supporting Canadian Leadership in International Genomic Data Sharing Through the Global Alliance for Genomics and Health (GA4GH)

JUL 2023 - DEC 2024

Genome Canada

In this project, the CGP will advance the deliverables of the Regulatory and Ethics Work Stream (REWS), including the development of consent registry standards, clinical data sharing Good Practices, integration of Equity, Diversity and Inclusion considerations in the Global Alliance for Genomic Health Work Streams, developing recommendations for diverse genomic dataset development, development of a genetic discrimination policy, and supporting the coordination of the Global Policy Forum. In addition, the CGP will provide REWS leadership, strategy, and oversight, and will provide guidance to the Work Stream and Clinical Projects Manager.

PRINCIPAL INVESTIGATOR
GOODHAND Peter

CO-INVESTIGATOR
JOLY Yann

RESEARCH ASSISTANTS
Ayyappaswamy Priya
Xue Ariel (Yunhe)

ACADEMIC ASSOCIATE
UBEROI Diya

The Pan-Canadian Genome Library (PCGL)

JUL 2023 - MAR 2030

Canadian Institutes of Health Research (CIHR)

Canada is in an ideal position to capitalize on the opportunities afforded by big genomic data - we boast world-leading expertise in genomics and in the development of data sharing policies and tools. However, we lack a national strategy to capture, store and access Canadian data in an equitable, secure and sustainable manner. At the same time, the size and complexity of human genomics datasets and their associated clinical data are growing rapidly. The Pan-Canadian Genome Library (PCGL) will establish the strategy for Canada's management and sharing of human genomic data. The PCGL will build upon Canadian-made foundational components and datasets, and utilize international standards to unify Canada's human genome sequencing efforts and set out a federated data management system that respects limitations on the jurisdictional movement of human genetic data. To respectfully support research relying on Indigenous data, we will also work with the Silent Genome Project and others to develop an Indigenous Genetics Circle. The PCGL will lay the groundwork for large-scale genomic data sharing and storage and raise the international visibility of Canadian research as well as lead to more effective and cost-effective healthcare delivery for all members of Canadian society.

CGP is responsible for 1) establishing the overall ethics and governance framework for the PCGL, aiming to promote broad data access, while remaining both compliant with Canadian legal and research ethics norms and interoperable with national and international initiatives and platforms and 2) for identifying and prioritizing new partnership opportunities to support the implementation of the PCGL strategy and its sustainability.

PRINCIPAL INVESTIGATORS
BHÉRER Claude
BOURQUE Guillaume
BOYCOTT Kym
BRAZAS Michelle D.
BRUDNO Michael
CARON Nadine R.
COURTOT Mélanie
FERRETTI Vincent
JOLY Yann
JONES Steven
LERNER-ELLIS Jordan
SCHERER Stephen W.
STEDMAN Ian
STEIN Lincoln
WASSERMAN Wyeth
ZAWATI Ma'n H.

CO-INVESTIGATORS
ARBOUR Laura T.
BEN AMOR Ibtihel M.
BERNIER François
BOMBARD Yvonne
HICKS Geoffrey G.
JABADO Nada
LETTRE Guillaume
LONGSTAFF Holly
MOOSER Vincent
MORRISSY Anca S.
NABI Hermann
OUELLETTE Francis
STRUG Lisa J.
TALIUN Daniel
WISHART David S.

ACADEMIC ASSOCIATE
PALMOUR Nicole

RESEARCH ASSISTANT
FARAJI Sasha

**Analyse comparative
des documents de
gouvernance de
la recherche en
situation de crise**

DEC 2023 - MAR 2025

**Réseau Québécois
COVID-Pandémie
/ Quebec COVID -
Pandemic Network
(RQCP / QCPN)**

In March 2020, the World Health Organization declared the outbreak of the new coronavirus 2019 (COVID-19) a global pandemic. Since then, the rapid spread of the virus and the resulting public health emergency required immediate action on the part of local, regional, national and international and international actors. The state of public health emergency resulting from the COVID-19 pandemic was exacerbated by the many unknown factors surrounding the virus including its origins, etiology, modes of transmission and infection. That said, the implementation of sound governance is one of the crucial elements of any research in times of crisis.

The CGP will: 1) identify research projects and the documents (governance framework, access policies, specifications, consent, etc.) supporting their governance; 2) analyze and compare these documents in order to identify the basic elements; 3) validate the basic elements based on a literature review and an analysis of the applicable framework (legislative, regulatory, jurisprudential, policy); 4) set up focus groups with patient partners to gain a better understanding of their perspective on different approaches to research in times of crisis; 5) develop an electronic resource in the form of a toolbox enabling researchers, patients, ethics committees, institutions and members of the public to better inform themselves about the components of good governance.

PRINCIPAL INVESTIGATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATE
STEVENS Yuan

RESEARCH ASSISTANT
NOË Alycia

**Leveraging precision
medicine and eHealth
to predict cancer
predisposition
syndromes in
children: A Canadian
initiative to redress
global health
disparities in cancer
genetics**

APR 2024 - MAR 2028

**Canadian Institutes
of Health Research
(CIHR)**

One child diagnosed with cancer out of ten has an underlying cancer predisposition syndrome. In the majority of children, the cancer arises before the cancer predisposition syndrome is recognised (i.e., the cancer predisposition syndrome goes unrecognised until a child develops a first cancer or worse, when the child develops a subsequent cancer or when their sibling or parent develops cancer). Cancer predisposition syndrome evaluation is now considered a necessary part of the holistic care in pediatric oncology, as such a diagnosis can lead to concrete actions in children and families. McGill Interactive Pediatric OncoGenetic Guidelines (MIPOGG) is a pediatric focused eHealth solution. Healthcare providers who evaluate and treat children and adolescents with cancer (any type of cancer, any type of setting, anywhere in the world) is MIPOGG's target population with direct impacts on patient and family care. The essence of this proposal aligns with the knowledge translation and mobilization mandates of the Canadian Pediatric Cancer Consortium (CPCC). The MIPOGG project deliverables are anticipated to be useful for various CPCC related activities.

The CGP will contribute to elucidating questions on the responsible development of eHealth technology and AI including topics of fairness, explainability and transparency in machine learning, as well as liability and responsibilities of clinicians and researchers who use these technologies in clinical care and research.

PRINCIPAL INVESTIGATOR
GOUDIE Catherine

COLLABORATOR
ARROYAVE OSSA Federico

CO-APPLICANTS
BOMBARD Yvonne
DENDUKURI Nandini
PECHLIVANOGLU Petros
REICHMAN Lara
SANTIAGO Raoul
TSIMICALIS Argerie

VAIRY Stephanie
WITKOWSKI Leora
ZAWATI Ma'n H.

RESEARCH ASSISTANT
NOË Alycia



COURSES

HGEN 660

GENETICS AND BIOETHICS

Instructor Prof. Yann Joly, D.C.L. (Ph.D.), Ad.E.

The objectives of this course are to: 1) introduce students to legal, ethical, and policy scholarship in genetics and related “omics” disciplines; 2) promote interdisciplinary collaboration and debate as a means of enriching scientific practices; 3) enable students to develop analytical research skills and to identify and critically evaluate the legal, ethical and policy issues that arise in genetic research and in clinical genetics.

The classes are taught in seminar style, complemented by thematic class discussions and case studies. Themes covered in this course include, but are not limited to: genetic testing, genetic counseling, personalized medicine, privacy and confidentiality, population genetics, regenerative medicine, commercialization and intellectual property, genetic discrimination, and genetic analysis of social and behavioral traits. Through class lectures, case studies and discussions on a series of selected readings, students are asked to reflect on the complex relationships between science, law, and ethics. Each member of the class participates and contributes to the learning experience. The collaborative learning experience is reflected in the way that the course is structured and the way in which the student’s work is evaluated.

HGEN 674

RESEARCH INTERNSHIP IN GENOMICS AND POLICY

Instructor Prof. Ma’n H. Zawati, D.C.L. (Ph.D.)

The Research Internship in Genomics and Policy course aims to provide graduate students in the Human Genetics program with an opportunity to do research on the ethico-legal and policy issues in human genetics. More specifically, graduate students are 1) introduced to the ethical, legal, and policy issues in human genetics in both the research and clinical settings; and 2) familiarized with social science research methodologies, especially international comparative analysis of normative policy and legal instruments. As an internship, these objectives are achieved through active research under the supervision of a mentor working in the student’s area of interest. Specific areas of research at the Centre of Genomics and Policy included but were not limited to: population genomics, biobanks, stem cells, reproductive technologies, paediatric genetic research, data protection, direct-to-consumer genetic testing, gene therapy, personalized medicine, and genetic counseling. Interested students are encouraged to explore the CGP website (www.genomicsandpolicy.org) to identify areas of interest. Undertaking an internship at the Centre of Genomics and Policy allows students to benefit from a close collaboration with experts at the crossroads of the ethico-legal, medical, and policy fields.



WYNG FOUNDATION

VISITING SCHOLAR PROGRAM

Thanks to a collaborative agreement with the Centre for Medical Ethics and Law of the University of Hong Kong (CMEL) and the WYNG Foundation, we are pleased to support the CGP / WYNG Trust Visiting Scholars Program.

The WYNG Foundation is making a difference at the Centre of Genomics and Policy by creating partnerships and fostering collaborations across disciplines. Despite pandemic travel restrictions, we have slowly, but surely restarted our activities. Most notably, our Centre welcomed on October 23rd, 2023 Prof. Calvin Ho, Associate Professor at the Faculty of Law and Co-Director at the Centre for Medical Ethics at the University of Hong Kong to discuss generative AI in health research. Additionally, CGP Professor Yann Joly attended the WYNG-Hatton Lecture and CMEL Anniversary Conference on December 4-6th, 2023 in Hong Kong to address smart regulation for innovations in technology.

Looking ahead, we will continue our partnership with the Centre for Medical Ethics and Law (CMEL) and resume our Visiting Scholars Program. This opportunity provides scholars with a chance to gain invaluable hands-on legal research experience. We also propose jumpstarting new activities such as a practicum project for scholars with a more clinical or bioethics background who wish to undertake a research paper (or equivalent writing project) under the joint supervision of a CGP and a CMEL Professor. Other activities include convening in relevant conferences, think tanks, meetings of common interest. CGP Professors Knoppers, Joly and Zawati recently attended the WYNG-Hatton Lecture on medical ethics and law on April 17-18th, 2024 in Cambridge to participate in the discussion on the careful considerations for implementing AI and other data-driven technologies to enhance and promote health. We will also host an international Conference in Quebec in the year 2025 that will address the future of genomics, medicine and public health in the next 25 years.

CGP

International Collaborations

HPRC

HUMAN PANGENOME
REFERENCE CONSORTIUM

GA4GH

GLOBAL ALLIANCE FOR
GENOMICS AND HEALTH

HCA

HUMAN CELL ATLAS

IHEC

INTERNATIONAL HUMAN
EPIGENOME CONSORTIUM

HeLTI

HEALTHY LIFE
TRAJECTORIES INITIATIVES

IRDiRC

INTERNATIONAL RARE DISEASES
RESEARCH CONSORTIUM

ICGC

INTERNATIONAL CANCER
GENOME CONSORTIUM

ICDA

INTERNATIONAL COMMON
DISEASES ALLIANCES

QUÉBEC

- Tanenbaum Open Science Institute
- Montreal Neurological Institute-Hospital

CGP

UNITED STATES

- Brandeis School of Law and School of Medicine
- Institute for Clinical and Translational Science, University of California

UNITED KINGDOM

- School of Law, University of Edinburgh
- Department of Health Sciences, University of Leicester
- University of Cambridge
- Cardiff University
- PHG Foundation

BELGIUM

- Ghent University
- KU Leuven

THE NETHERLANDS

- Legal Pathways Institute for Health and Bio-Law

JAPAN

- Laboratory for Biomedical Ethics and Co-design, RIKEN Institute

GERMANY

- Heidelberg Academy of Sciences and Humanities

HONG KONG

- Centre for Medical Ethics and Law, University of Hong Kong

QATAR

- HBKU
- Qatar University

LUXEMBOURG

- Elixir, Luxembourg Centre for Systems Biomedicine (LCSB)
- University of Luxembourg

FRANCE

- Faculté de Médecine, Université Toulouse 3 (Paul Sabatier)

SPAIN

- School of Law, University of the Basque Country

SOUTH KOREA

- Health Law and Ethics, Yonsei University
- Graduate School of International Studies, Yonsei University

AUSTRALIA

- University of Tasmania



GENETIC DISCRIMINATION OBSERVATORY

Genetic discrimination involves treating differently and negatively or unfairly profiling individuals or a group relative to the rest of the population based on actual or presumed genomic and other predictive data.

The Genetic Discrimination Observatory (GDO) is a network of international experts and collaborators from 30 jurisdictions dedicated to researching and preventing genetic discrimination.



GDO MAIN OBJECTIVES ● ● ● ● ● ● ● ● ● ●



1.

Document the issue of genetic discrimination in a scientific and evidence-based manner.



2.

Engage the public, policymakers and other stakeholders in a collective debate about genetic discrimination.



3.

Use this information to assess which existing normative models work best and develop new ones.

GDO
members
specialized in:
.....



AI



LAW



GENETICS



BIOETHICS



SOCIOLOGY



ECONOMICS



BIOCHEMISTRY



HEALTH POLICY



PATIENT GROUPS



GENETIC COUNSELLING



In 2023, the GDO website reached **84 788 visitors** (average of 7066 visits / month)



NEW countries represented in the GDO in 2023:



VIETNAM



CZECH REPUBLIC



**DECEMBER
11-12 2023**

The GDO held its **4th Annual Scientific Meeting** in a hybrid format in Panama.

Collaborative Research



GDO is now in collaboration with the Global Alliance for Genomic and Health (GA4GH) to develop tools and policies to address genetic discrimination. The first product of this collaboration is the information brief Genetic Discrimination: Implications for Data Sharing Projects (GeDI).

<https://www.ga4gh.org/document/genetic-discrimination/>

approved by GA4GH / GDO in January 2022

GDO 
is funded by



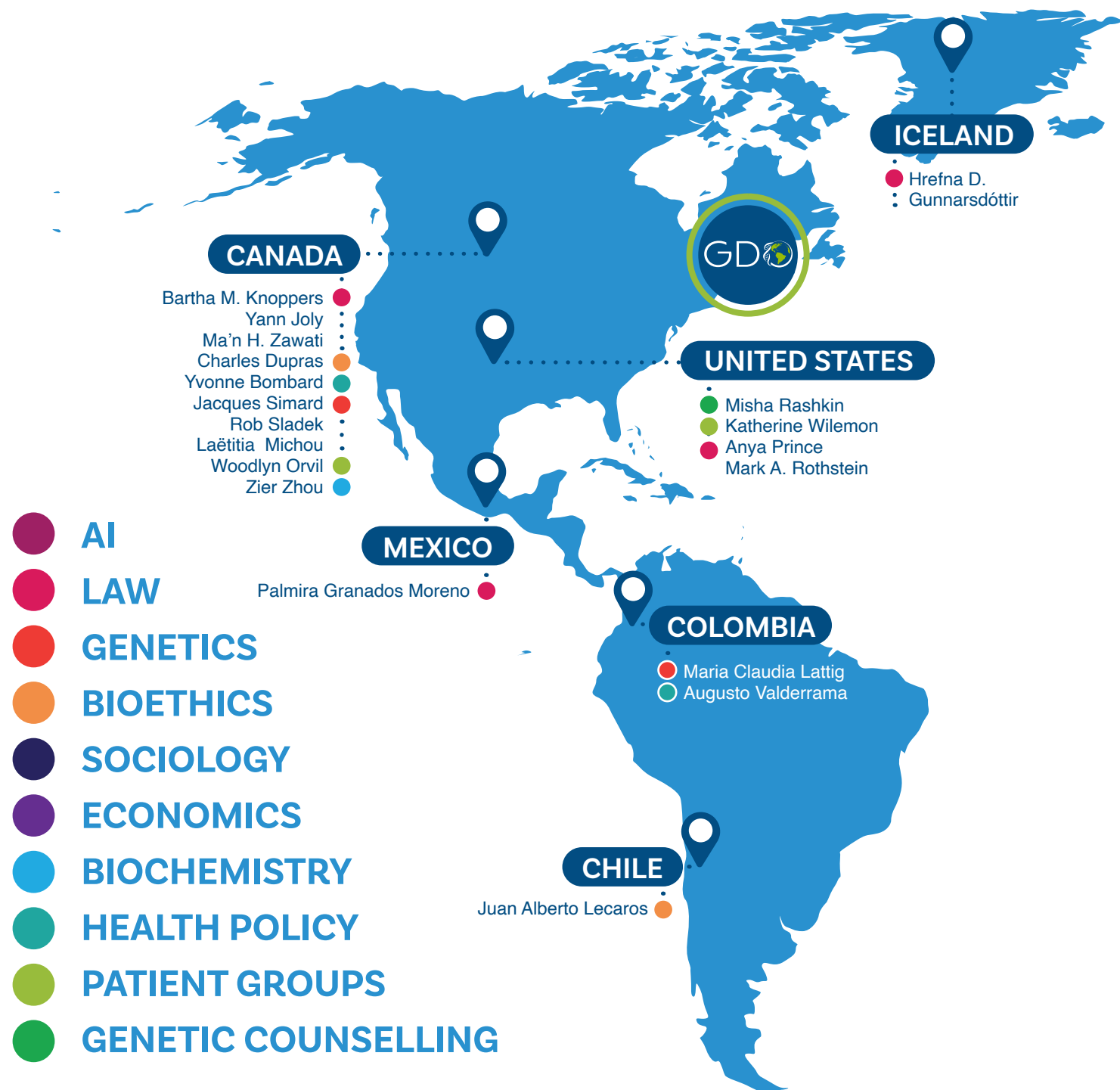
GenomeCanada



**Global Alliance
for Genomics & Health**



International Collaborations



5 REGIONS
30 JURISDICTIONS





2023-2024

Publications

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BOOK CHAPTER

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BLOG POST

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