CGP
Annual Report
2024 - 2025

CGP Centre of Genomics and Policy
Centre de génomique et politiques

McGill Faculty of Medicine and Health Sciences

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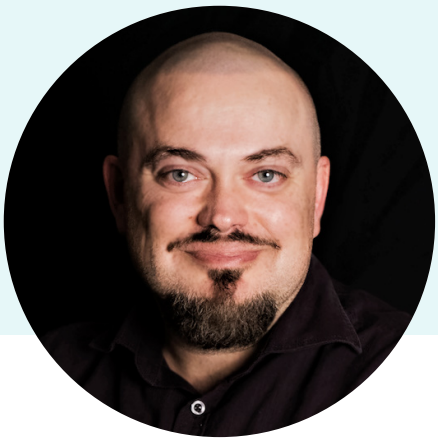


Message from the Director

« On ne peut oublier le temps qu'en s'en servant »
– Charles Baudelaire

In this aphorism, the poet reminds us that the surest way to forget the ceaseless passing of time is to use it fully: to create, to work, to live intensely, and to dedicate ourselves to the common good. With this thought in mind, I can say without hesitation that many of us at the Centre of Genomics and Policy (CGP) all but lost sight of the clock during the 2024–2025 academic year.

It was a year marked by extraordinary vitality. The CGP was busier than ever, welcoming fifteen new regular and associate members into its expanding ranks. The CGP is now firmly embedded in the scientific landscape, recognized as one of the four core Centres of the Victor Dahdaleh Institute of Genomic Medicine at McGill. At the same time, it has solidified its role on the international stage as a training hub for the Regulatory and Ethics Work Stream (REWS) of the Global Alliance for Genomics and Health.

But beyond these structural achievements, there were moments of genuine joy. I was especially delighted to see our Research Director and my long-standing collaborator, Prof. Ma'n H. Zawati, transition from a research contract to a tenure-track position in the Faculty of Medicine—just in time for the Fall 2025 semester. And as if one honour were not enough, he was also elected to the College of New Scholars, Artists, and Scientists of the Royal Society of Canada. To witness Ma'n's exemplary contributions to research and teaching at McGill finally acknowledged at their full value filled me with pride.

For my own part, I accepted an additional appointment as Adjunct Professor in the Department of Medical Humanities and Social Medicine, Division of Medical Law and Ethics, at Yonsei University, South Korea. This new role opens opportunities to deepen our collaborations across East Asia. I was also invited to join the Board on Life Sciences of the U.S. National Academies of Sciences, Engineering, and Medicine (NASEM)—an honour, and a challenge, I could not decline at such a decisive moment in American history.

Our team grew in remarkable ways as well. We welcomed two seasoned researchers, Dr. Maelenn Corfmat and Dr. Lingqiao Song, along with a new doctoral candidate and three new master's students. The year culminated in two unforgettable highlights: Prof. Calvin Ho's brilliant contribution to the 2025 Annual Bartha Knoppers Lecture, and a dynamic workshop on the future of public health, co-organized with the PHG Foundation of Cambridge and funded, in part, by the WYNG foundation.

And so, as we look back on this intense, fruitful year, we are reminded again of Baudelaire's wisdom: time, once filled with meaning, can slip away almost unnoticed. If only he had also given us instructions on how to slow its passage while forgetting it.

Yann Joly
James McGill Professor

Message from the Research Director

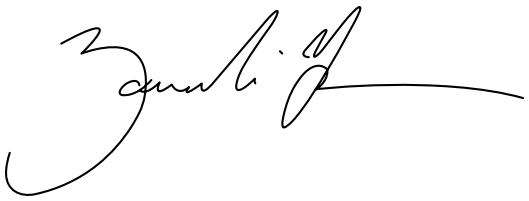
2024–2025 has been an exceptional year of growth and achievement for the Centre of Genomics and Policy (CGP). Our researchers, students, and collaborators have produced a remarkable body of scholarship, with more than 35 peer-reviewed articles, book chapters, and reports published in leading journals across law, medicine, ethics, and genomics, such as BMJ, Science, and Nature Genetics. These contributions addressed pressing issues at the intersection of science, technology, and society—from the governance of genomic data to the development of genetic non-discrimination policies.

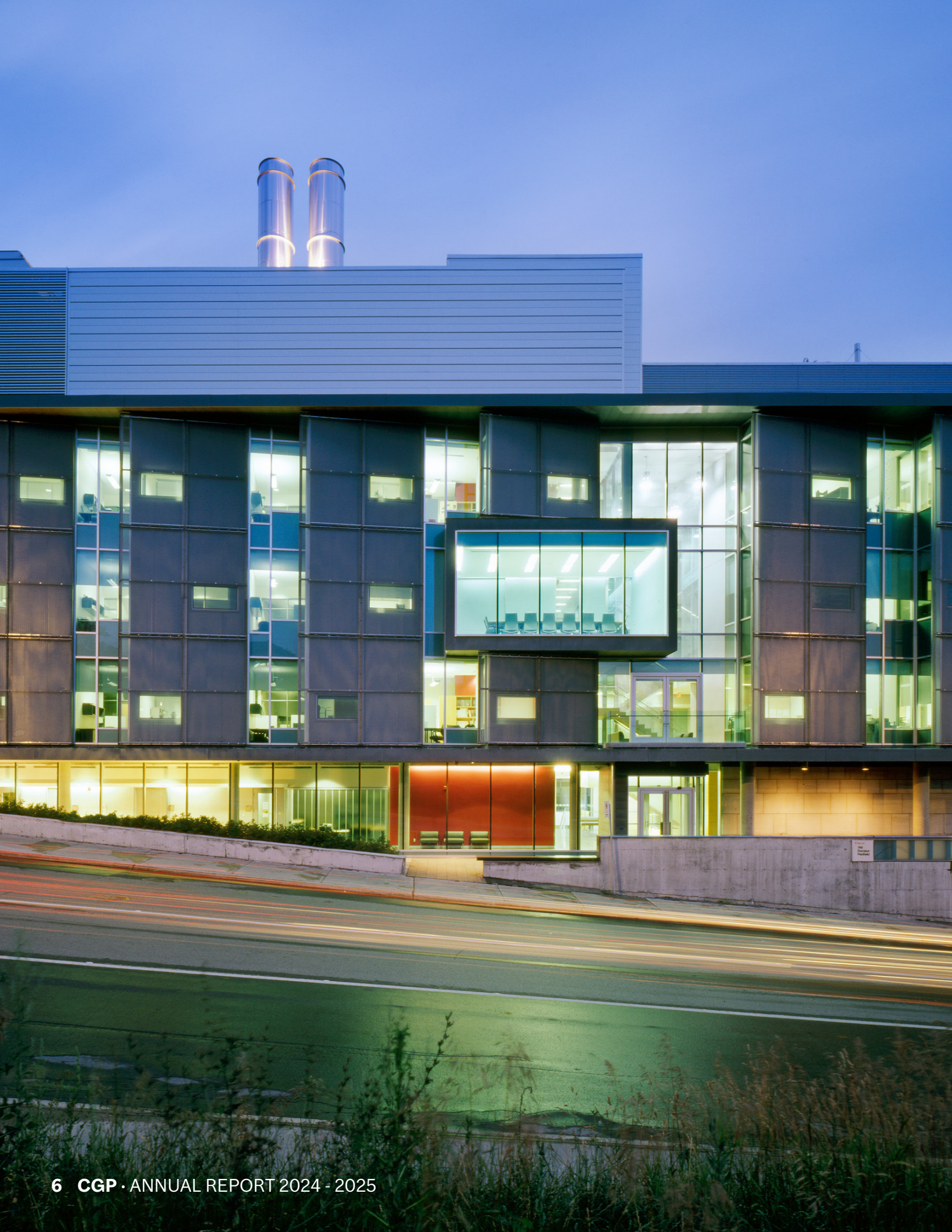
Equally important, the CGP secured significant new funding that will sustain our research leadership for years to come. In 2024–2025 alone, our team was awarded support for more than a dozen major projects, covering topics as diverse as pediatric oncology, RNA therapeutics, rare disease registries, forensic genetics, and the governance of AI in biomarker discovery. Among these are flagship initiatives such as the Canadian Precision Health Initiative, the DNA to RNA (D2R) program, the ACCESS initiative, and the Human Cell Atlas—multi-year, multi-partner projects that reinforce CGP's central role in shaping the future of genomic research infrastructures in Canada and globally.

This momentum reflects the extraordinary dedication of our researchers, staff, and students, whose efforts continue to position the CGP as a world-leading hub for interdisciplinary, impact-driven research. Seeing these collective achievements reminds me of why I chose to pursue a career in research and academia: the opportunity to work alongside brilliant minds, to ask meaningful questions, and to help translate knowledge into positive change for society.

Looking ahead, we remain committed to producing scholarship that not only informs academic debates but also provides concrete tools for policymakers, researchers, and clinicians locally and internationally. If the pace and quality of this year's work are any indication, the CGP will continue to push boundaries, advance knowledge, and contribute meaningfully to a more equitable and innovative future for genomics and health.

Ma'n H. Zawati
Associate Professor





ABOUT US

CGP

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.

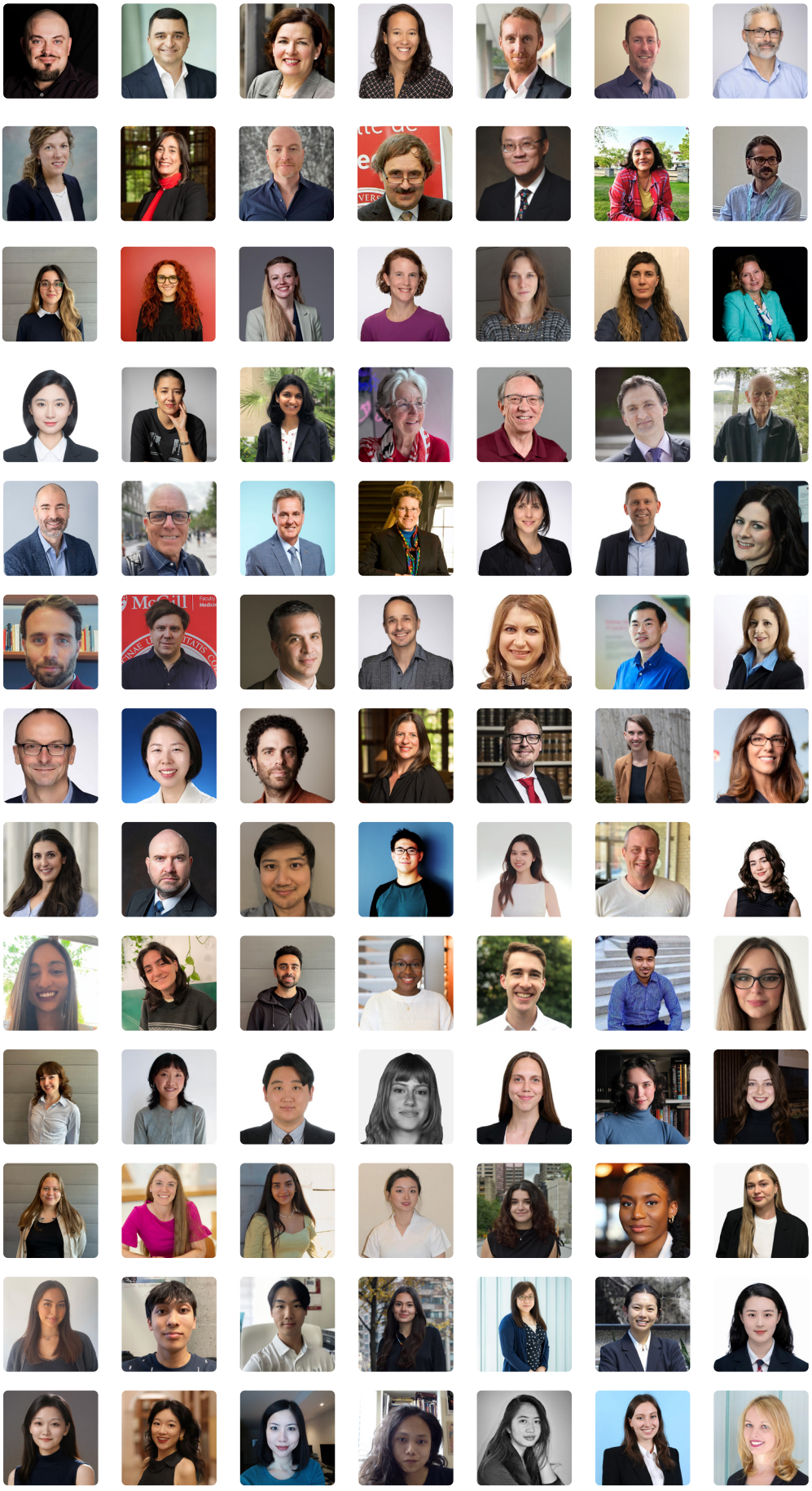
The CGP pursues a unique, integrated and innovative research program founded on three universal human rights: 1) right to science; 2) right to non-discrimination and 3) right to health. These rights span numerous population and research contexts, including pediatrics, (preimplantation / cell / gene therapies),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

Follow Us to Learn More:

- **Website: www.genomicsandpolicy.org/**
- **LinkedIn: Centre of Genomics and Policy**
- **X: @genomics_policy**
- **BlueSky: @genomicsandpolicy.bsky.social**
- **YouTube: @genomics_policy**

INTRODUCING THE CGP TEAM



REGULAR MEMBERS

Yann **JOLY** – *Director*
Ma'n H. **ZAWATI** – *Research Director*
Laurence **BARET**
Guillaume **BOURQUE**
David **BUCKERIDGE**
Thomas **DUCHAINE**
Catherine **GOUDIE**
Lara **KHOURY**
Nicholas B. **KING**
Mark **LATHROP**
Seang **LIN TAN**

ACADEMIC ASSOCIATES

Maushumi **BHATTACHARJEE**
Stanislav **BIRKO**
Sarah **BOUHOUITA-GUERMECH**
Mathilde **CASSOU**
Maelenn **CORFMAT**
Lindsay **DAYTON** – *Executive Director*
Emily **KIRBY**
Terese **KNOPPERS**
Nicole **PALMOUR** – *Coordinator*
Lingqiao **SONG**
Yuan **STEVENS**
Diya **UBEROI**

ADVISORY COMMITTEE MEMBERS

Denise **AVARD**
Robert **COOK-DEEGAN**
Vincent **GAUTRAIS**
Bartha Maria **KNOPPERS** – *Founding Director*
Claude **LABERGE**
Martin **LETENDRE**
Eric **MESLIN**
Jacques **SIMARD**
Ellen **WRIGHT CLAYTON**

ASSOCIATE MEMBERS

Claude **BHÉRER**
Pascal **BORRY**
Aisling **DE PAOR**
Charles **DUPRAS**
Jorg **FRITZ**
Richard **GOLD**
Simon **GRAVEL**
Hazar **HAIDAR**
Calvin **HO**
Amalia **ISSA**
David **JUNCKER**
Hannah **KIM**
Jonathan **KIMMELMAN**
Alana **KLEIN**
Timo **MINSSEN**
Anya **PRINCE**
Amélie **QUESNEL-VALLÉE**
Vaso **RAHIMZADEH**
Donrich **THALDAR**

PHD STUDENTS

Zoulikha **REZOUG**
Keanu (Dhaam) **SAKUNTABHAI**
Derek **SO**
Lingqiao **SONG**

MASTER'S STUDENTS

Ally **HUANG**
Antonio **PINHEIRO**
Rose-Marie **SÉGUIN**

RESEARCH ASSISTANTS

Priya **AYYAPPASWAMY**
Jessica **BAPTISTA**
Michael **BENLOLO**
Fatoumata **BINTA DIALLO**
Maxwell **BRODIE**
Sasha **FARAJI**
Sonia **HAJO**
Paige **HANIC**
Jessica **HUANG**
Aaron (Zhaoping) **JU**
Emma **KONDRUP**
Alycia **NOË**
Erin **PORTER**
Ariella **RUBY**
Abby **RUD**
Nadine **RUTLEDGE**
Angelica **VOUTSINAS**
Ariel (Yunhe) **XUE**

INTERNS

Farah **ABOASALI**
Annaëlle **BARREAU**
Kate (Kathleen) **BORNAIS**
Naomi **JOLY**
Nathan **JOLY**
Leon **LI**
Olivia **MARACLE-HILL**

INVITED SCHOLARS

Mayumi **KUSUNOSE**
Anjie **NI**
Rachel (Jinyi) **TIAN**
Meng **WANG**
Gloria (Guangzu) **XU**

ADMINISTRATIVE ASSISTANTS

Mei-Chen **CHANG**
Kathryn **GAMBOA**
Kacey Miranda **SAN DIEGO**
Chiara **SPINO**
Nadine **THORSEN**

COMPLETED RESEARCH PROJECTS

APRIL 2024 - MARCH 2025

FEB 2017 – MAR 2025	Multidimensional Epigenomics Mapping Centre (EMC) at McGill
OCT 2018 – MAR 2025	euCanSHare: An Eu-Canada Joint Infrastructure for Next-Generation Multi-Study Heart Research
OCT 2018 – MAR 2025	EUCANCan: A Federated Network of Aligned and Interoperable Infrastructures for the Homogeneous Analysis, Management and Sharing of Genomic Oncology Data for Personalized Medicine
JAN 2021 – DEC 2024	Smartphone crowdsourced medical data for biomedical research: Addressing the ethical, legal and health policy concerns
APR 2021 – MAR 2025	CanDIG: Canadian Distributed Cyber-Infrastructure for Genomics data sharing and analysis
JUL 2021 – JUL 2024	International Good Practices for Genomic Data Sharing
JUL 2021 – DEC 2024	The Québec SmartCare Consortium

JAN 2022 – DEC 2024	Personnel Hautement Qualifié Intelligence Artificielle et Santé Numérique
APR 2022 – JAN 2025	Engineered hematopoietic stem cells (eHSCs) as vehicles for next generation therapies
APR 2022 – JAN 2025	Tissue Engineering to Treat Canadian Burn Patients: The Self-Assembled Skin Substitutes (SASS)
APR 2022 – MAR 2025	Psilocybin to relieve existential distress at the end of life: Audace, acceptability and access
MAR 2023 – MAR 2025	Élaboration d'un cadre réglementaire international en matière de technologie nanomédicale
APR 2023 – JAN 2025	Allogeneic dermis to accelerate the production of a tissue-engineered skin substitute to treat Canadian burn patients
DEC 2023 – MAR 2025	Analyse comparative des documents de gouvernance de la recherche en situation de crise

ONGOING RESEARCH PROJECTS

Large Scale GE3LS Project: GenCOUNSEL: Optimization of Genetic Counseling for Clinical Implementation of Genome-wide sequencing

JUL 2018
JUN 2025

Genome British Columbia

Genome Canada

Genome Quebec

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 costs decrease, 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
Jehannine AUSTIN
Alison ELLIOTT
Bartha Maria KNOPPERS
Larry LYND

CO-INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Terese KNOPPERS

RESEARCH ASSISTANT
Alycia NOË

MSSNG Project Data Access Compliance Office (DACO)

JUL 2018
DEC 2026

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.

PRINCIPAL INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATES
Maushumi BHATTACHARJEE
Maelenn CORFMAT
Emily KIRBY

RESEARCH ASSISTANT
Alycia NOË

ADMIN
Chiara SPINO

Q1K_1000 Families

APR 2019
MAR 2026

Fondation Marcelle et Jean Coutu

The Québec 1000 Families (Q1K) is an initiative that draws on research expertise in neurodevelopment combined with lived experiences to accelerate discovery and transform care and services. Q1K will create an Open Science database that researchers can access from around the world. CGP's role within the project is to support the ethics, policy and governance aspects.

PRINCIPAL INVESTIGATOR
Guy ROULEAU

CO-INVESTIGATORS
P. ABADIE
Mayada ELSABABAGH
Carl ERNST
Alan C. EVANS
Baudouin FORGEOT D'ARC
Sébastien JACQUEMONT
Ridha JOOBER
Sarah LIPPE
Jacques MICHAUD
Laurent MOTTRON
Julie SCORAH
Jean-Claude TARDIF
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Maushumi BHATTACHARJEE

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
Guillaume BOURQUE
Vincent FERRETTI

CO-INVESTIGATORS
Michael BRUDNO
Anne-Claude GINGRAS
Anna GOLDENBERG
Benjamin HAIBE-KAINS
Julie HUSSIN
Pierre-Etienne JACQUES
Yann JOLY
Bartha Maria KNOPPERS
Jacques SIMARD

ACADEMIC ASSOCIATE
Nicole PALMOUR

MASTER'S STUDENT
Antonio PINHEIRO

RESEARCH ASSISTANTS
Maxwell BRODIE
Sasha FARAJI

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

APR 2022
SEP 2025

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

ACADEMIC ASSOCIATE
Maelenn CORFMAT

Responsible Pathways for Pediatric Cell Therapies

APR 2022
JAN 2026

Stem Cell Network (SCN)

This project will address the lack of guidance for researchers designing cell therapy clinical trials, particularly at the first-in-human stage. It will also consider the limited educational resources and guidance to research participants, especially minors and families, REBs and regulatory bodies (who assess such trials), regarding the risk-benefits and the ethical, legal and social implications of such trials. 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
Vardit RAVITSKY
Ma'n H. ZAWATI
(PI as of September 2024)

CO-INVESTIGATORS
Jonathan KIMMELMAN

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

ACADEMIC ASSOCIATES
Stanislav BIRKO
Mathilde CASSOU

RESEARCH ASSISTANT
Paige HANIC

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

JUL 2022
JUN 2025

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

International observatory on the societal impacts of AI and digital technology (OBVIA)

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
Ma'n H. ZAWATI

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

ACADEMIC ASSOCIATES
Maushumi BHATTACHARJEE
Sarah BOUHOUITA-GUERMECH
Yuan STEVENS

RESEARCH ASSISTANT
Michael BENLOLO

CGP / WYNG Visiting Scholars Program

JAN 2023
JUN 2026

The WYNG Foundation

The CGP/WYNG Visiting Scholars Program strengthens international collaboration between McGill University and Hong Kong University's (HKU) Centre for Medical Ethics and Law. Funding supports visiting scholars, research internships, faculty exchanges, and participation in international conferences, including the Ayers Cliff 2025 meeting, creating opportunities for interdisciplinary collaboration in genomics, medical law, and bioethics. Through these initiatives, the program advances research, informs policy, and cultivates a global network of scholars. The CGP and WYNG Foundation will continue to foster meaningful dialogue, promote academic excellence, and address emerging challenges at the intersection of genomics, law, and bioethics in the years ahead.

PRINCIPAL INVESTIGATOR
Yann JOLY
(PI as of Sept 2025)

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.

The CGP will utilize its experience to implement a Delphi with expert stakeholders to identify elements of a viable normative framework. This co-construction of knowledge will result in the development of a bilingual guide tailored towards pharmaceutical companies, which could be adapted to other industries.

PRINCIPAL INVESTIGATOR
Melanie BOURASSA-FOURCIER

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

ACADEMIC ASSOCIATES
Nicole PALMOUR
Diya UBEROI

RESEARCH ASSISTANT
Jessica HUANG

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

APR 2023
MAR 2027

Canadian Institutes of Health Research (CIHR)

The Canadian Pediatric Cancer Consortium (CPCC) is the largest-ever Canadian pediatric cancer research project. It performs 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
David MALKIN
Jim WHITLOCK

CO-INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATES
Emily KIRBY
Terese KNOPPERS

RESEARCH ASSISTANT
Paige HANIC

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, 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. The CGP will be responsible for developing and overseeing the implementation of the project's ethical-legal framework.

PRINCIPAL INVESTIGATORS
Kristian FILION
Emily MCDONALD
Robyn TAMBLYN

COLLABORATORS
Patricia PLOUFFE
Rosalba PUPA
Joseph YANG

CO-APPLICANTS
Susan BARTLETT
Sasha BERNATSKY
David BUCKERIDGE
Michael CHASSE
Louise PILOTTE
Robert PLATT
Doina PRECUP
Samy SUISSA
Kednapa THAVORN
Lora TOTINO
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Maelenn CORFMAT

RESEARCH ASSISTANT
Alycia NOË

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. 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, 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: 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
David BUCKERIDGE

CO-INVESTIGATOR
Yann JOLY

ACADEMIC ASSOCIATE
Nicole PALMOUR

RESEARCH ASSISTANTS
Maxwell BRODIE
Sasha FARAJI

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

JUN 2023
JUN 2028

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.

The CGP will provide data governance and bioethics expertise to develop a comprehensive data governance framework aligned with technical, ethical, and security standards and conduct ethical assessments of datasets for potential inclusion in DESIIR. The CGP will also design standard consent forms and validation tools, evaluate legal and ethical requirements for data consolidation, and support secure data integration and access protocols throughout the project's lifecycle.

PRINCIPAL INVESTIGATORS
Yann JOLY
Catherine LA PRISE

ACADEMIC ASSOCIATE
Nicole PALMOUR

RESEARCH ASSISTANT
Sasha FARAJI

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

JUL 2023
JUN 2025

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, along with guidance to the Work Stream and Clinical Projects Manager.

PRINCIPAL INVESTIGATOR
Peter GOODHAND

CO-INVESTIGATOR
Yann JOLY

ACADEMIC ASSOCIATE
Diya UBEROI

RESEARCH ASSISTANTS
Ariel (Yunhe) XUE
Aaron (Zhaoping) JU
Abby RUD

INTERN
Nathan JOLY

The Pan-Canadian Genome Library (PCGL)

JUL 2023
MAR 2030

Canadian Institutes of Health Research (CIHR)

Genome Canada (funding from March 2025-29)

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 leading to more efficient and cost-effective healthcare delivery for all members of Canadian society.

The 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; 2) identifying and prioritizing new partnership opportunities to support the implementation of the PCGL strategy and its sustainability.

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

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

ACADEMIC ASSOCIATES
Maelenn CORFMAT
Nicole PALMOUR
Lingqiao SONG

RESEARCH ASSISTANTS
Ariella RUBY
Sasha FARAJI

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). 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
Catherine GOUDIE

COLLABORATOR
Federico ARROYAVE OSSA

CO-APPLICANTS
Yvonne BOMBARD
Nandini DENDUKURI
Petros PECHLIVANOGLOU
Lara REICHMAN
Raoul SANTIAGO
Argerie TSIMICALIS
Stephanie VAIRY
Leora WITKOWSKI
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Sarah BOUHOUITA-GUERMECH

RESEARCH ASSISTANT
Alycia NOË

La Réponse immunitaire aux peaux reconstruites avec des cellules allogeniques (ThéCell)

APR 2024
MAR 2028

Fonds de recherche du Québec - Santé (FRQS)

Created in 2009, the Québec Cell, Tissue and Gene Therapy Network (ThéCell) focuses on the development of novel cell, tissue and gene therapies to improve patient care in an innovative and sustainable manner. It brings together researchers with diverse expertise in the field of regenerative medicine within Québec to build a multi-disciplinary team. The Network aimed to promote and structure translational research and advance knowledge, technological tools and treatments in regenerative medicine. CGP members will support researchers with the socio-ethical and legal issues surrounding regenerative medicine.

PRINCIPAL INVESTIGATOR
Jean-Sébastien DELISLE

CO-INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Stanislav BIRKO

Data Governance Resource - Human Cell Atlas

AUG 2024
JUL 2027

The Leona M. and Harry B. Helmsley Charitable Trust

There is a growing aim to share genomic and health data, particularly "omics" data, at national and international levels; however, data sharing consortia or projects often must contend with heterogeneous data landscapes. Current ethical and legal governance resources propose tools that are often specific to a single project, jurisdiction (e.g., one country), population (adult, pediatric, etc.), or disease. In this context, it becomes increasingly important to devise clear, simple, streamlined, and interoperable data governance arrangements while co-constructing policies with researchers from low-and-middle-income countries. The CGP will continue to support the work of the Ethics Working Group of HCA and develop a modular and adaptable portal that provides easily accessible biomedical and genomic governance tools for researchers and members of the public. It will also continue the study of emerging ethical and legal issues related to the Helmsley funded Gut Cell Atlas (GCA) consortium.

PRINCIPAL INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATES
Maushumi BHATTACHARJEE
Emily KIRBY

RESEARCH ASSISTANT
Michael Benlolo

ADMIN
Chiara SPINO

Data Production and Operations for the Human Cell Atlas Data Ecosystem

SEP 2024
OCT 2025

Human Cell Atlas

The CGP at McGill University hosts the Data Access Office (DAO) for the Human Cell Atlas and plays a key role in overseeing data governance and access. Under the leadership of Prof. Ma'n H. Zawati, who chairs the independent Data Access Committee (DAC), the CGP is responsible for the administrative management and adjudication of data access requests. This includes coordinating the submission, review, approval, and reporting processes for researchers requesting access to controlled data. The DAO ensures that only qualified researchers are granted access and that all research projects comply with ethical, legal, and privacy standards. It also monitors ongoing projects to validate appropriate data use and manage any changes in research teams or protocols. The DAC comprises experts in IT, genomic research ethics, data sharing, and data protection.

PRINCIPAL INVESTIGATOR
Ma'n H. ZAWATI

ADMIN
Chiara SPINO

Development of Responsible AI for Genomic Biomarker Identification in the Context of the D2R Initiative

SEP 2024
AUG 2026

DNA to RNA (D2R)

This project examines the ethical and social impacts of using AI to identify genomic biomarkers—biological indicators that help develop personalized therapies for diseases like rare disorders and cancer. While AI offers exciting opportunities to analyze large datasets and find new biomarkers, it also poses risks of exacerbating existing inequalities and ethical concerns in healthcare. We will review current AI uses in biomarker identification, analyze relevant policies and laws, interview experts, and conduct focus group with people from diverse backgrounds. We will produce ethico-legal guidance to inform the responsible use of AI for biomarker selection and identification by D2R researchers.

PRINCIPAL INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Maelenn CORFMAT

RESEARCH ASSISTANTS
Michael BENLOLO
Ariella RUBY

INTERNS
Kate (Kathleen) BORNAIS
Leon LI

A first inclusive study on the ELSI aspects of RNA technologies and therapeutics

SEP 2024
AUG 2026

DNA to RNA (D2R)

Our project will be the first to identify ethical, legal, and social issues raised by research and medical practice involving RNA technologies. We will use a "Delphi study" method, in which experts share their views, respond to each other's perspectives, and revise their own opinions until the group reaches consensus about the most important issues raised by RNA technology. The Delphi study will include scientists, clinicians, policymakers, bioethicists, legal scholars, and social scientists. We will also conduct a series of interviews to gather the perspectives of people representing vulnerable and marginalized groups who may be affected by these technologies.

PRINCIPAL INVESTIGATOR
Yann JOLY

COLLABORATORS
Thomas DUCHAINE
Charles DUPRAS
Silvia VIDAL

ACADEMIC ASSOCIATES
Terese KNOPPERS
Nicole PALMOUR

RESEARCH ASSISTANTS
Jessica BAPTISTA
Fatoumata BINTA DIALLO

INTERNS
Farah ABOASALI
Olivia MARACLE-HILL

Genetic discrimination in the era of artificial intelligence and advancing technologies

OCT 2024
SEP 2026

Social Sciences and Humanities Research Council (SSHRC)

Genetic Discrimination (GD) has become a multifaceted, international concern, that can infringe upon human rights, and hinder public trust in genetic services. Broadly defined, GD occurs when an individual or a group is negatively treated, unfairly profiled, or harmed, relative to the rest of the population, on the basis of their actual or presumed genetic characteristics. If not adequately regulated, GD can discourage individuals from accessing clinical genetic services, undergoing genetic testing or participating in research out of concern for how their information may be used. Addressing GD has become more crucial in today's postgenomic era, where AI and other technological advances make it easier for individuals and machines to access, process and misuse sensitive data. To help untangle the ethical and legal implications of AI, devise multidisciplinary solutions that address GD, and ensure more trustworthy use of novel technologies, the Genetic Discrimination Observatory (GDO) will be convening a conference of international experts. This conference will allow the GDO's expert members to collaborate on matters of GD and devise a model GND clause and other policy tools that can be adopted globally.

PRINCIPAL INVESTIGATOR
Yann JOLY

ACADEMIC ASSOCIATE
Diya UBEROI

RESEARCH ASSISTANTS
Fatoumata BINTA DIALLO
Abby RUD
Ariel (Yunhe) XUE

INTERN
Naomi JOLY

Legal framework and impact analyses: Groundwork for a Diabetes Prevention and Remission Program in Quebec

NOV 2024
MAR 2026

Canadian Institutes of Health Research (CIHR)

We believe that Canadians deserve access to publicly funded type 2 diabetes prevention and remission programs. There is abundant evidence to support the utility of such programs. The key case example relevant to Canada is the England-wide National Health Service (NHS) Program. To convince the Treasury Board of the merits of such a program, the NHS assembled (i) the clinical trial evidence for the effectiveness of such programs; (ii) estimated the number of diabetes cases that would be prevented and the number that would go into remission if programs were implemented based on the evidence; and (iii) performed an impact analysis to estimate costs and to determine the time points at which the programs would become cost neutral and then cost saving.

We will apply this approach to demonstrate to the Quebec Health Ministry that a Quebec-wide diabetes prevention and remission program is warranted. We will conduct an analysis of existing legislation and policies to determine a pathway whereby blood tests and medication information on individual persons can be used to determine their prediabetes/early diabetes status and alert them to the possibility of enrolling in a program. Using available epidemiological and demographic information, we will estimate diabetes incidence within regions, by sex-at-birth, and by social position (INSPQ deprivation index) in the absence and presence of a diabetes prevention and remission program and estimate the Quebec costs of diabetes. We will determine the time horizon over which the program would become cost neutral and then cost saving.

The CGP team will work to build a legal and ethical analysis, with a particular focus on prediabetes and early diabetes detection using health data and linkage of individuals to an eventual provincial diabetes prevention and remission program. We will address issues of consent, data governance, and confidentiality, among other considerations.

PRINCIPAL INVESTIGATOR
Kaberi DASGUPTA

CO-INVESTIGATORS
Anne-Sophie BRAZEAU
Jonathan CAMPBELL
Yann JOLY

ACADEMIC ASSOCIATE
Nicole PALMOUR

RESEARCH ASSISTANT
Sasha FARAJI

Leveraging human rights to clarify the risk of genetic discrimination in pediatric oncology

DEC 2024
MAR 2027

Canadian Institutes of Health Research (CIHR)

It is 2024, but several Canadian children affected with rare genetic cancer are still prevented from participating in genomics research due to unwarranted concerns around Genetic Discrimination (GD). Broadly understood, GD occurs when an individual or group is negatively treated or harmed, relative to the rest of the population, on the basis of actual or presumed genetic characteristics. To protect people from GD, the Canadian Parliament passed the Genetic Non-Discrimination Act in 2017. Yet, children are still perceived as being at risk of GD by many ethics committees, and parents and researchers fear including them in cancer genomics research projects. Under the pretense of " better protecting children" from GD, Canadian ethics boards have adopted overly protectionist informal practices that require researchers to include clauses in their consent forms that overemphasize the concerns associated with GD and privacy risks. While these consent clauses are intended to protect children, they create unwarranted worries amongst families and risk limiting the diversity of datasets, by making it difficult to recruit children to participate in research.

Without sufficient data specific to children, children with rare genetic cancer, or those who have pharmacogenomic profiles distinct from the norm, may not be able to access the most innovative research protocols that may be the last hope for their wellness, an outcome that we contend constitutes a type of GD. This project leverages human rights to support the creation of updated consent clauses and demonstrates how a human rights-based approach can protect against GD and thereby address a barrier that unnecessarily inhibits the participation of children in research.

We expect that our project will generate valuable data on the perspectives of parents and researchers regarding GD in pediatric research and will provide the ACCESS network with policies, evidence, and information on how they can use human rights to support ethics policies and formulate more nuanced consent clauses that promote inclusion in the context of pediatric oncology. The values of reciprocity, equity and human rights lie at the core of ACCESS' mission and by reducing systemic barriers to research, this project also ensures that all children can access personalized cancer research that could hopefully benefit their health.

PRINCIPAL INVESTIGATOR
Yann JOLY

CO-APPLICANT
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Diya UBEROI

RESEARCH ASSISTANTS
Fatoumata BINTA DIALLO
Erin PORTER

Forensic Genetics Frequency Databases: Between Science and Law Enforcement

JAN 2025
DEC 2026

Swiss National Science Foundation (SNSF)

This project highlights the need for reliable population data in DNA profiling to ensure the probative value of matches in court. Forensic Genetics Frequency Databases (FGFDs) to provide essential statistical data for evaluating DNA evidence and conducting kinship testing. The study aims to enhance the understanding and application of FGFDs, particularly concerning potentially re-identifiable data. The CGP will contribute its expertise in bioethics, research ethics, and public health law, ensuring that ethical considerations are integrated into the project's framework.

PRINCIPAL INVESTIGATOR
Martin ZIEGER

CO-INVESTIGATORS
Fruzsina MOLNÁR-GÁBOR
Yann JOLY

ACADEMIC ASSOCIATE
Nicole PALMOUR

D2R Centre Support: Centre of Genomics and Policy

JAN 2025
DEC 2027

DNA to RNA (D2R)

With the support from the D2R Centre and Institute program, the CGP will significantly enhance its administration and capacity to fully support the D2R program (for e.g. by contributing to the data governance framework). Our Centre will continue tackling complex legal, ethical, and policy challenges in omics and modern medicine through comprehensive research, knowledge mobilization, education, and practice through collaborating with local, national, and international partners.

PRINCIPAL INVESTIGATOR
Yann JOLY

ADMIN
Mei-Chen CHANG

Health Data Science (D2R-HeDS) platform

FEB 2025
JAN 2028

DNA to RNA (D2R)

Data science is essential in biomedical research, particularly in genomics and RNA studies. To achieve D2R's objectives, we must effectively collect, organize, and analyze data across the program. As noted in the CFREF proposal, "novel computational methods, including big data technologies, analytics, and AI, will support analysis and interpretation of large datasets and drug design." D2R-HeDS's mission is to integrate data science into RNA-based research to fulfill D2R's objectives. Objectives: Bioinformatics, machine learning (ML), and artificial intelligence (AI) are crucial for understanding DNA and RNA sequences, predicting genetic variations' impacts, and developing precision medicine approaches. Multi-omics analysis and integration of multi-modal data are key to identifying biomarkers and therapeutic targets, especially for rare diseases and precision oncology. The COVID-19 pandemic has also underscored the importance of future responses that will rely on AI models that integrate genetic and phenotypic data to predict clinical outcomes. D2R-HeDS objectives are to increase the overall D2R expertise in data science, which is essential to achieving high-standard research outcomes. Goals: The D2R-HeDS platform will respond to the growing demand for advanced data science tools, supporting AI-driven biomarker discovery for disease diagnosis and therapeutic decision-making. The platform will provide data science services, tools, and resources to support D2R researchers, bridging the gap between data generation and actionable insights. Key objectives include improving data accessibility, promoting reuse, and accelerating research productivity through advanced analytics. The CGP will tackle specific consent-related ethical challenges around genomics data and its use in AI applications.

PRINCIPAL INVESTIGATOR
Guillaume BOURQUE

CO-INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Maelenn CORFMAT

Investigating the Impacts of Generative AI in Pediatric Oncology: Identifying Ethico-Legal Best Practices and Addressing Patient Community Concerns

APR 2025
MAR 2027

Canadian Institutes of Health Research (CIHR)

This project explores the use of generative AI in pediatric oncology. It will examine the ethical and legal issues associated with the use of generative AI in pediatric oncology through a scoping review of literature. This project will also explore patient perception and levels of trust in this technology through focus groups. In terms of outputs, we will provide an information guide for patients, researchers, and clinicians in the ACCESS community on generative AI works and its use in pediatric oncology. We will draft an ethico-legal guidance points document with the support of People with Lived Experience for the benefit of ACCESS stakeholders and the pediatric oncology research, clinician, and patient community in Canada and beyond. We will also publish an academic article based on this research and present our findings at a scientific conference.

PRINCIPAL INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Maelenn CORFMAT

RESEARCH ASSISTANT
Paige HANIC

Toward a combined gene therapy and tissue engineering novel treatment for junctional epidermolysis bullosa

APR 2025
MAR 2027

Stem Cell Network (SCN)

Junctional epidermolysis bullosa (JEB) is a rare genetic disease characterized by the presence of large blisters on the skin filled with clear fluid (bullae) at birth, lack of scarring of the lesions, and early death. It is caused by genetic changes in several genes (LAMB3, COL17A1, LAMC2, LAMA3, integrin a6ß4 or integrin a3) that leads to epidermal loss and cause the skin to blister easily. There is no established cure for JEB and the treatment is palliative, mainly with bandages to protect epithelial wounds. We aim to regenerate a fully functional epidermis for JEB patients by gene correcting their epidermal cells in the lab and use them to produce an artificial skin substitute. The patient's own transduced cells will be used to produce sheets of skin implementing the autologous self-assembly method invented in the LOEX. The functionality and the mechanical properties of the produced gene corrected skin equivalents will be assessed longterm, in mice, to determine if it is safe to trial in JEB patients. If successful, this approach would provide a therapeutic option for the skin lesions of JEB patients. The CGP provides ethical and governance consultation.

PRINCIPAL INVESTIGATOR
Lucie GERMAIN

CO-INVESTIGATOR
Ma'n H. ZAWATI

ACADEMIC ASSOCIATE
Stanislav BIRKO

Courses

Courses offered at McGill University instructed by our CGP members.

Genetics and Bioethics

Instructors: Prof. Yann Joly, Ph.D. (DCL), Ad.E. & Prof. Ma'n H. Zawati, Ph.D. (DCL)

HGEN 660 **Fall 2024 - 2025**

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.

Research Internship in Genomics and Policy

Instructors: Prof. Yann Joly, Ph.D. (DCL), Ad.E. & Prof. Ma'n H. Zawati, Ph.D. (DCL)

HGEN 674 **Winter 2024 - 25**

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 CGP 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 CGP allows students to benefit from a close collaboration with experts at the crossroads of the ethico-legal, medical, and policy fields.

Global Health Law

Instructors: Prof. Yann Joly, Ph.D. (DCL), Ad.E. & Diya Uberoi, Ph.D.

McGill Summer Institutes in Global Health **Summer 2024 - 25**

This course, led by the Centre of Genomics & Policy at McGill, offers an introduction to the fundamentals of global health law and policy. It considered the form and function of global health and provided an introduction to how laws and policies interact with emerging issues in global health today. While many faculties approach this subject with a focus on the present and the foundations of the "eld, this course also endeavours to consider its future. Key topics included: the role of the WHO in global health governance, global health and human rights, international frameworks for pandemic preparedness, the ethical implications of mobile health-care applications, and the role of law and governance in matters of genomics. The course was taught in a seminar style, complemented by thematic class discussions and case studies. Through class lectures, case studies, and discussions, students were asked to reflect on the complex relationship between law and emerging health concerns.

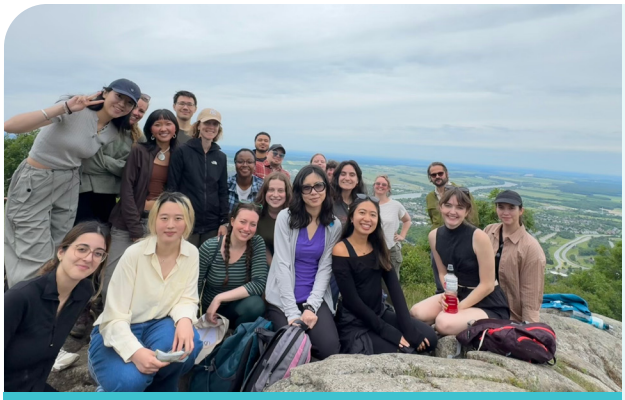
WYNG
FOUNDATION

The CGP continues to foster valuable collaborations with ongoing support from the WYNG Foundation. Notable past events include the WYNG-Hatton Lecture and Conference on Medical Ethics and Law in Cambridge (April 17–18, 2024), attended by CGP Professors Knoppers, Joly, and Zawati. The lecture addressed ethical considerations for implementing AI and data-driven technologies in healthcare, focusing on risk management challenges. Professors Knoppers, Joly and Zawati also presented on their respective areas of expertise. In June 2025, the CGP welcomed the first cohort of LLM graduate students, Rachel (Jinyi) Tian and Gloria (Guangzu) Xu, from the University of Hong Kong medical ethics and law program for a 1-month research placement.

In parallel with these efforts, we have expanded our global network of scholars and academics through the creation of the International Exchange Group on Medical Law, Bioethics & Society. Initiated by CGP Professor Yann Joly, the group fosters collaboration with leading institutions such as the Centre for Medical Ethics and Law (CMEL) at HKU, the Centre of Law, Medicine and Life Sciences (LML) at Cambridge, and the PHG Foundation. The group meets online every two months and brings together 12-20 graduate students and research professionals to share insights and exchange ideas on topics related to medicine, health laws, policies, and bioethics. Recent presentations included topics on regenerative medicine, international humanitarian law, and medical law mandates.

In September 2025, the Ayers Cliff Meeting in Quebec convened 30 interdisciplinary scholars from genomics, bioethics, law, medicine, and public policy to explore the long-term implications of genomics and computational intelligence for health over the next 25 years. On September 5, the CGP hosted Professor Calvin Ho's (Monash University) seminar on polygenic risk scores and human rights. Later, in October, Dr. Zohar Lederman (University of Hong Kong) led discussions on the intersection of AI, genomics, and One Health approaches.

Through these initiatives, CGP and the WYNG Foundation continue to advance interdisciplinary research and dialogue in genomics, law, and bioethics, with plans to host the WYNG-Hatton Lecture in 2026.



WYNG Visiting Scholars Rachel Tian and Gloria Xu with CGP colleagues during the June 26 2025 hiking retreat at the Gault Nature Reserve, Mont-Saint-Hilaire, QC.

Members of the PHG Foundation with the speakers of the 2024 WYNG-Hatton conference.

Members at the Ayer's Cliff Meeting on September 2025.

Visiting Scholar Programs

Visiting scholars Meng Wang and Mayumi Kusunose at the Centre of Genomics and Policy during Senior French magistrate Gwenola Joly-Coz' visit.

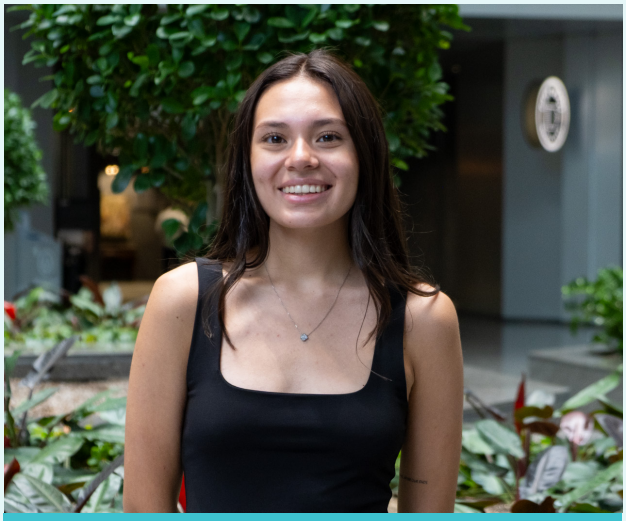


Image Credit: Emily Hackett. In the summer of 2025, Olivia Maracle-Hill worked at the CGP on a D2R-funded project, as part of her IMPRESS Internship.

The CGP continues to strengthen its international collaborations through several visiting scholar initiatives. A key highlight is the McGill–RIKEN Partnership, which fosters world-class research between McGill's Faculty of Medicine and Health Sciences and Japan's RIKEN Centre for Integrative Medical Sciences (IMS). In the fall 2024, CGP welcomed Dr. Mayumi Kusunose from RIKEN's Laboratory for Biomedical Ethics and Co-Design, whose research focused on the ethical, social, and legal implications of genomic research and medicine, including data sharing and the return of research results. Her presentation, "Exploring Benefit-Sharing in Japan: Public Attitudes and a Pilot Framework," provided valuable international insights into bioethics and data governance. Meng Wang, a visiting scholar from the University of Macau's Faculty of Law, also joined the CGP in fall 2024 to advance research on health law, regulatory science, and human rights. Her work on the protection of intersex individuals' rights and her talk, "Innovative Biotherapies and Patient Rights: Exploring China's Regulatory Landscape," reflected CGP's expanding engagement in global discussions on ethics and biotechnology governance.

The CGP further advanced its commitment to equity and mentorship through the IMPRESS (Indigenous Mentorship and Paid Research Experience for Summer Students) program. In summer 2025, Olivia Maracle-Hill, a psychology student from Six Nations of the Grand River Territory, joined Professor Yann Joly's team for the D2R-funded project "A First Inclusive Study on the ELSI Aspects of RNA Technologies and Therapeutics." Her contributions brought essential Indigenous perspectives to the ethical, legal, and social dimensions of emerging RNA technologies, underscoring CGP's dedication to inclusive and interdisciplinary research.

Together, these initiatives highlight CGP's leadership in fostering international collaboration, training, and discussion at the intersection of genomics, law, and bioethics.

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
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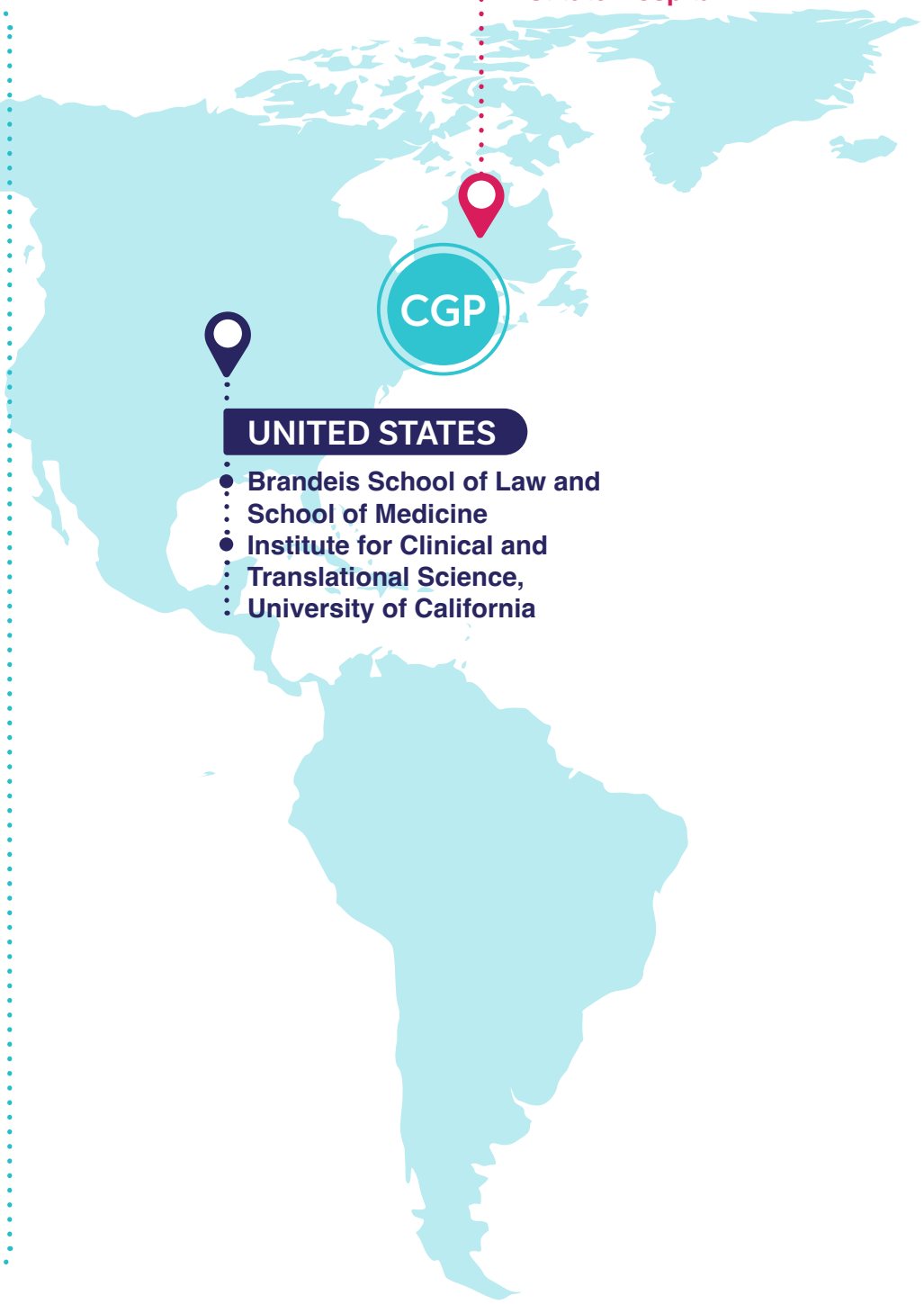

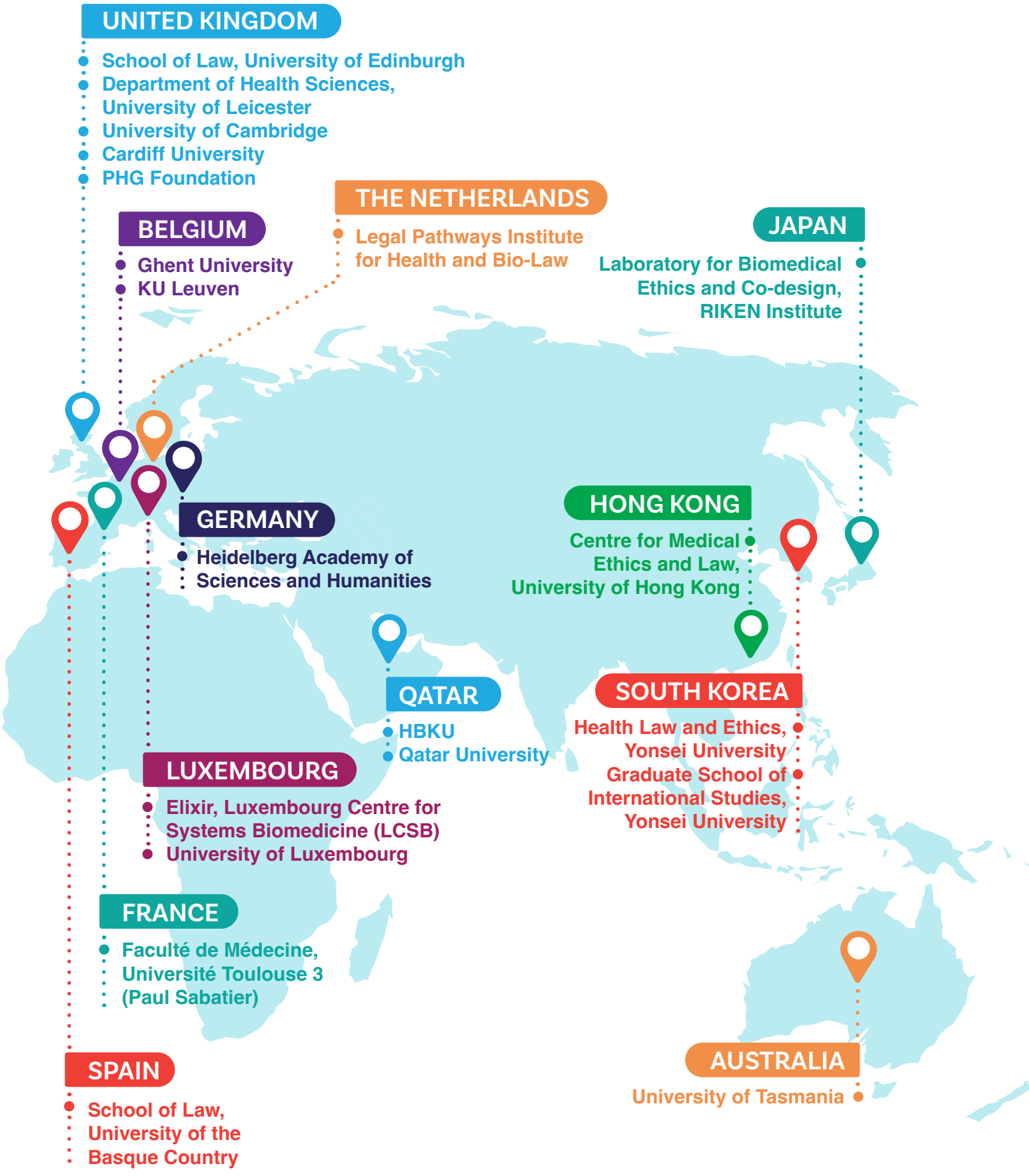
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GENETIC DISCRIMINATION OBSERVATORY
OBSERVATOIRE DE LA DISCRIMINATION GENETIQUE

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 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.**

Collaborative Research

The GDO's current study examines the interplay between regulations and practices in pharmacogenomic data use by insurers, with the aim to develop recommendations that promote personalized medicine while preserving rights to privacy and non-discrimination of individuals.

GDO's Impact Throughout the Globe

In 2024-2025, the GDO website reached 286,885 visitors
(average of 13,040 visits per month)

NEW countries represented in the GDO in 2024-25:

- Singapore
- Switzerland
- Macao
- Malaysia

On December 17th & 18th, 2024, the GDO held its 5th Annual Scientific Meeting in Istanbul, Turkey.

GDO is funded by

CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

SSHRC CRSH Social Sciences and Humanities Research Council of Canada / Conseil de recherches en sciences humaines du Canada

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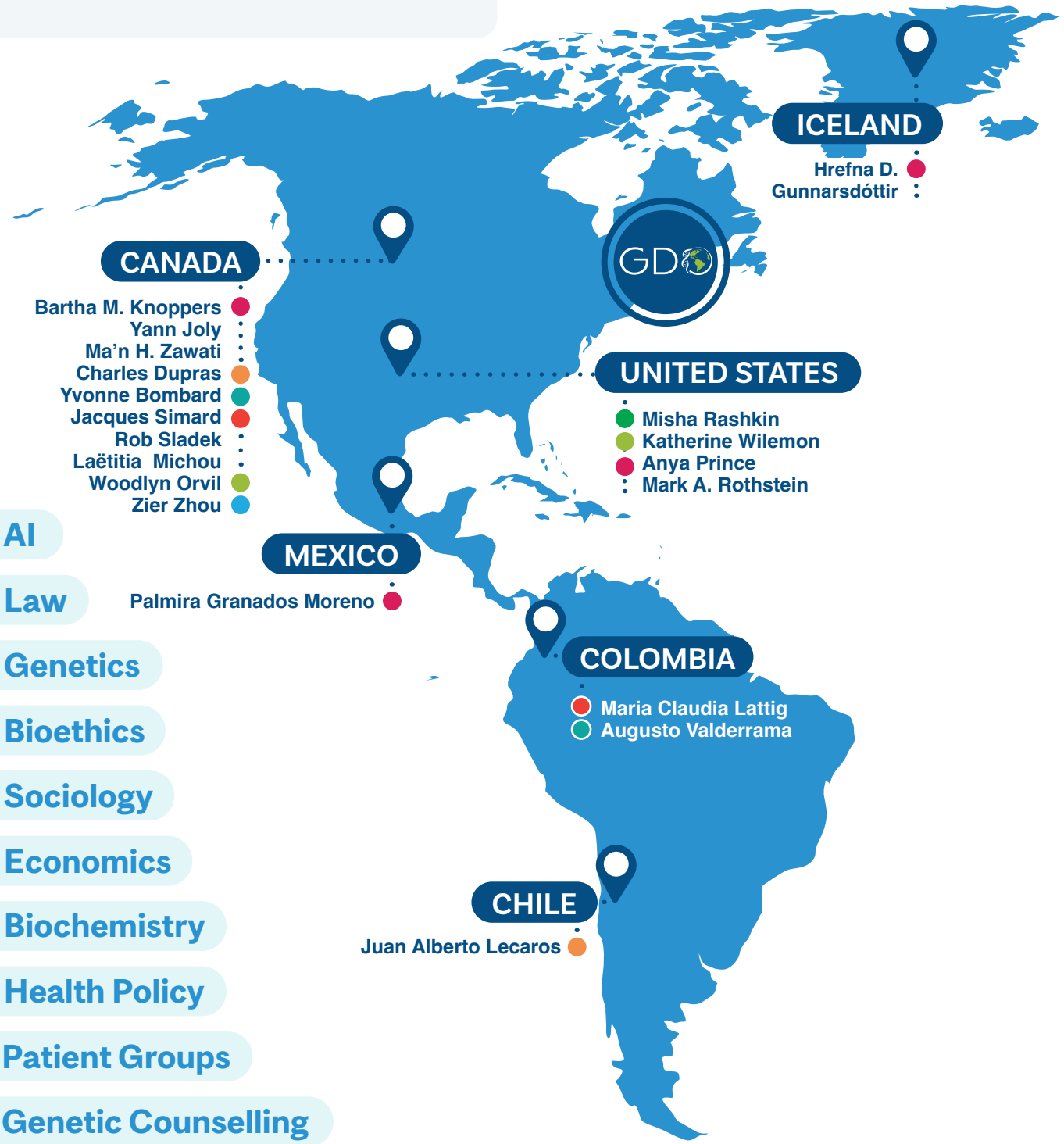

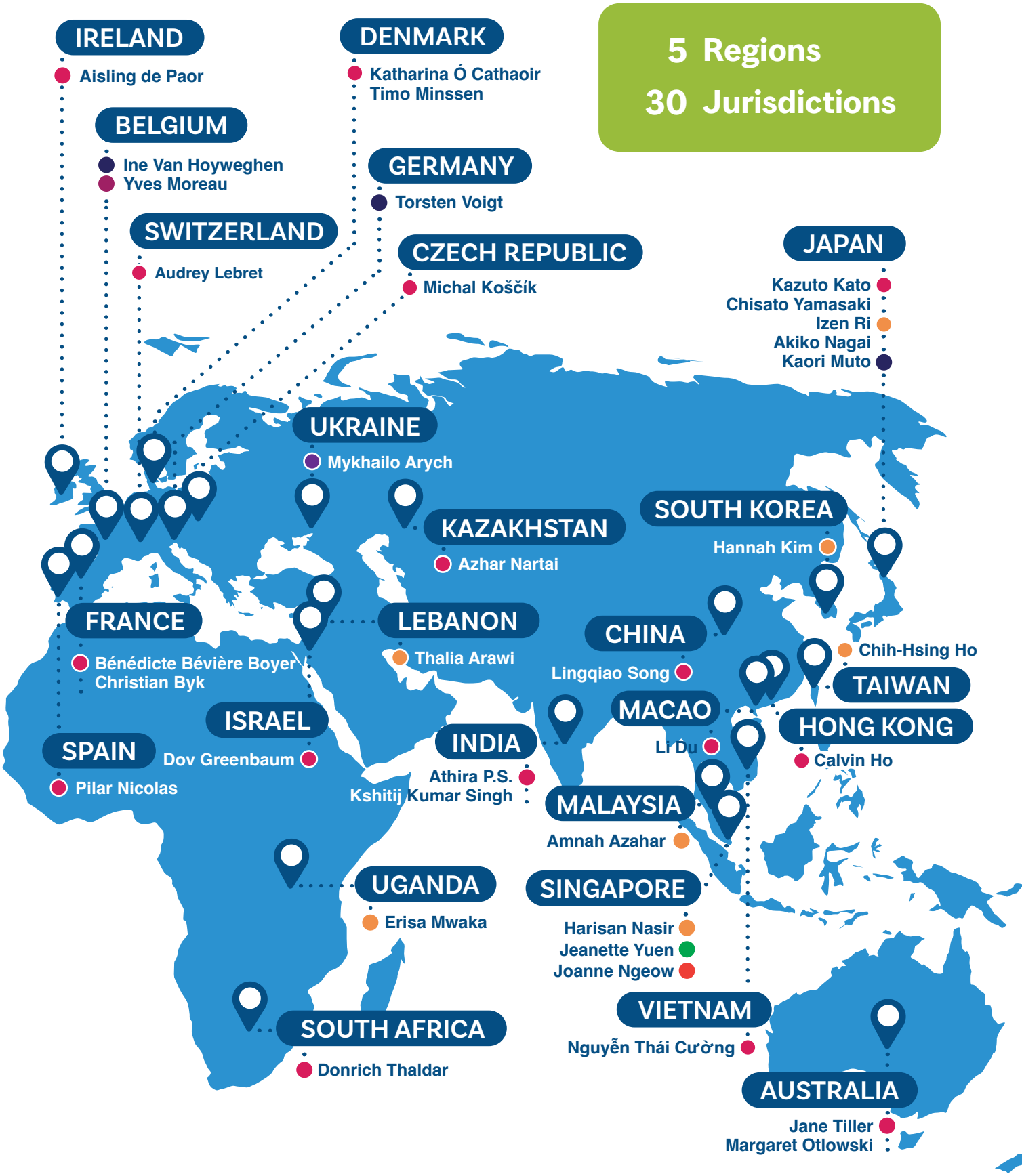
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