The Centre of Genomics and Policy (CGP) applies a multidisciplinary perspective, while collaborating with national and international partners, in several research areas including: stem cell research and therapies, personalized medicine, prevention and treatment of cancer, data sharing, pediatrics, genetic counseling, digital health and AI, intellectual property and open science, epigenetics, intersex and diversity in health, gene editing, genetic discrimination and biobanking (population genetics).

RESEARCH AWARDS

Canadian Research Chair in Law and Medicine
(Prof. Bartha Maria Knoppers)

FRQS Chercheurs boursier
Junior 1 & 2
(Prof. Yann Joly)

FRQS Chercheurs boursier
Junior 1
(Prof. Ma’n H. Zawati)
The Centre of Genomics and Policy has been actively engaged in rare disease research, policy and tool development for more than ten years. This summary will provide an overview of the breath and depth of our engagement and expertise in this domain.

**2023**

**RARE DISEASE PROJECTS**

**THE LAST 10 YEARS**

- **APR 2022**
  - ALL FOR ONE HEALTH DATA ECOSYSTEM (HDE)

- **OCT 2020**
  - DEVELOPMENT OF AN ETHICAL AND LEGAL FRAMEWORK FOR THE DEPLOYMENT OF RÉSEAU QUÉBEC DIAGNOSTIQUE MOLÉCULAIRE (MSSS) ACTIVITIES AND THE HARMONIZATION OF PATIENT CONSENT

- **MAR 2019**
  - CANADIAN GENOMICS PARTNERSHIP FOR RARE DISEASE (ALL FOR ONE): POLICY TOOLKIT

- **MAR 2018**
  - CARE4RARE CANADA: HARNESSING MULTI-OMICS TO DELIVER INNOVATIVE DIAGNOSTIC CARE FOR RARE GENETIC DISEASES IN CANADA (C4R-SOLVE)

- **MAR 2016**
  - PROGRAMME DE RECHERCHE ET D’INNOVATION SUR LES MALADIES RARES (PRISMES)
ENHANCED CARE FOR RARE GENETIC DISEASES IN CANADA

RECHERCHE SUR LES MALADIES RARES: VIE PRIVÉE «BON GRÉ MAL GRÉ»? (PRISMES)

FRAMEWORK FOR DECISION-MAKING FOR RARE DISEASES

DEVELOPING A CANADIAN FRAMEWORK FOR EVALUATION AND DECISION-MAKING FOR EXPENSIVE DRUGS FOR RARE DISEASES THROUGH INNOVATION, VALUE, AND PRIORITY SETTING

RADICAL - RARE DISEASE CONSORTIUM FOR AUTOSOMAL LOCI

FINDING OF RARE DISEASE GENES IN CANADA (FORGE)

CIHR EMERGING TEAM IN GENOMICS SCREENING
ARTICLES

JOURNAL ARTICLE

JOURNAL ARTICLE

JOURNAL ARTICLE
Puscas, Maria, Martineau, Gabrielle, Bhella, Gurjot, Bonnen, Penelope E., Carr, Phil, Lim, Robyn, Mitchell, John, Osmond, Matthew, Urquieta, Emmanuel, Flamenbaum, Jaime, Iaria, Giuseppe, Joly, Yann, Richer, Étienne, Saary, Joan, Saint-Jacques, David, Buckley, Nicole, Low-Decarie, Etienne. Rare diseases and space health: optimizing synergies from scientific questions to care. npj Microgravity. 2022;8(1):1-10. Available from: https://www.nature.com/articles/s41526-022-00224-5.

JOURNAL ARTICLE

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JOURNAL ARTICLE
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 over 23 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 existing normative models work best and develop new ones.

- AI
- LAW
- GENETICS
- BIOETHICS
- SOCIOLOGY
- HEALTH POLICY
- PATIENT GROUPS
From January to November 2022, the GDO website reached 164,000 VISITORS (an average of 13,700 visits/month)

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).

approved by GA4GH/GDO in January 2022

GDO INTERNATIONAL COLLABORATIONS

26 COUNTRIES  27 JURISDICTIONS

CANADA  UNITED STATES  SOUTH AFRICA
MEXICO  COLUMBIA  UGANDA
CHILE  ICELAND  UKRAINE
IRELAND  KAZAKHSTAN  LEBANON
UNITED KINGDOM  INDIA  ISRAEL
DENMARK  CHINA  TAIWAN
BELGIUM  HONG KONG  SOUTH KOREA
FRANCE  SOUTH AFRICA  JAPAN
GERMANY  KAZAKHSTAN  AUSTRALIA
SPAIN

GDO PUBLICATIONS


The GDO is funded by Genome Canada