2013 ANNUAL REPORT

CGP

Centre of Genomics and Policy
Centre de génomique et politiques

2013 ANNUAL REPORT

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A MESSAGE FROM THE DIRECTOR

Welcome to the Centre of Genomics and Policy's (**CGP**) 2013 Annual Report.

This year's Annual Report aims to showcase the work of the CGP, its people, and values. We hope the Report informs readers, introduces them to the CGP's scholars and their projects, and illustrates the commitment they have for their work.

The 2013 Annual Report invites both the general reader and the specialist to learn about the Centre's projects and activities. Through features and our reader-friendly format, we hope our work is accessible to the lay reader, yet relevant to researchers, professionals, policy-makers, and students.

The CGP has had some big changes this year with the retirement of our beloved Research Director, Professor Denise Avard. The position of Research Director has been filled by Professor Yann Joly. We also welcomed Dr. Nicole Palmour as our Executive Director.

Several features of this year's Annual Report highlight the CGP's innovative research program, as well as the people who make it happen. The Report provides details about the CGP: its ongoing research projects, awards and recognition received by its members, and the team's publications. We are also proud to announce a new internship program in collaboration with McGill's Department of Human Genetics. Finally, both the HumGen and CGP websites have undergone a makeover, making it is easier to search for and mobilize our international policy database and our outreach. We hope you will enjoy getting to know the CGP, its people, and our work.

Bartha Maria Knoppers

ABOUT THE CENTRE OF GENOMICS AND POLICY

Located within the Genome Quebec Innovation Centre at McGill University, the CGP works at the crossroads of law, medicine, and public policy. Applying a multidisciplinary perspective and collaborating with national and international partners, the CGP analyzes the socio-ethical and legal norms influencing the promotion, prevention and protection of human health.

Currently, the CGP's research covers six areas of genomics and policy: stem cell research and therapies, pediatrics, privacy, cancer, intellectual property, and biobanks (population genetics). These domains are approached using three guiding foundations: internationalization, policy development and knowledge transfer. First, CGP promotes internationalization by undertaking comparative analyses of policies and guidelines around the world. Secondly, CGP actively participates in the creation of international consortia with a view to promoting multidisciplinary policymaking. Finally, via the HumGen law and policy database (**www.humgen.org**), the CGP promotes knowledge transfer.

Don't forget to follow us on Twitter @GenomicsPolicy.

CENTRE OF GENOMICS AND POLICY

CGP TEAM 2013

PROFESSOR
KNOPPERS Bartha Maria

ASSOCIATE PROFESSOR
AVARD Denise

ASSISTANT PROFESSOR
JOLY Yann

EXECUTIVE DIRECTOR
PALMOUR Nicole

ACADEMIC COORDINATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATES
ALLEN Clarissa
DOVE Edward
ISASI Rosario
LÉVESQUE Emmanuelle
MILIUS Djims
NGUENG-FEZE Ida
NGUYEN Minh Thu
SÉNÉCAL Karine
TASSÉ Anne-Marie

ASSOCIATE MEMBER
GOLD Richard

SCIENTIFIC CONSULTANT
LABERGE Claude

RESEARCH ASSISTANTS
ALI-KHAN Sarah
BEAK Carla
BESSO Annyck
BIRKO Stanislav
BLACK Lee
CHARLEBOIS Kathleen
COHEN Eliza
CRIMI Laura
DAINOW Susannah
DALPÉ Gratien
DAM Amy
DWIVEDI Supriya
DUPUIS Marie-Andrée
ESQUIVEL SADA Daphne
GAGNON Johannie
GRANADOS Palmira
HAGAN Julie
HÉTU Martin
KIM Rosel
KLEIDERMAN Erika
LIU Anita
MALLETTE Ariane
OSIEN Gladys
PARRY David
RAHIMZADEH Vasiliki
SALMAN Shahad
SHUANG Shuang
SO Derek
THOROGOOD Adrian
VARDATSIKOS George

INVITED SCHOLARS
BORRY Pascal
LYND Larry
SECKO David

GRAPHIC DESIGNER
OLVERA Elena

ADMINISTRATORS
HOZYAN Rose-Marie
ROSSI Marisa
THORSEN Nadine

COMPLETED RESEARCH PROJECTS

Integrated Research Network in Perinatalogy of Quebec and Eastern Ontario (IRNPQEO)

Canadian Institutes of Health Research (CIHR)
September 2008 – March 2013

PRINCIPAL INVESTIGATOR
FRASER William

CO-INVESTIGATORS
AVARD Denise
DUBOIS Lise
LUO Zhong-Cheng
MICHAUD Jacques
MOUTQUIN Jean-Marie
MUCKEL Gina
SEQUIN Jean
SOMERVILLE Margaret
TRASLER Jacquetta
TREMBLAY Richard E.

ACADEMIC ASSOCIATES
LÉVESQUE Emmanuelle
SÉNÉCAL Karine

The mission of this multi-institutional network and its transdisciplinary research programme is to serve as a catalyst:

- To enhance the quality and impact of perinatal research in Quebec and in Canada;
- To train the next generation of researchers in an environment that reflects CIHR's four pillars (clinical, biomedical, health services, and population health);
- To create an innovative regional/provincial clinical research model ensuring evidence-based care; and
- To address important knowledge gaps, concerning the long-term impact of various adverse exposures (environmental or genetic) during pregnancy on the health of future generations.

Maternal, Infant, Child & Youth Research Network (MICYRN)
Promoting Health Research Involving Children and Adolescents

MICYRN
March 2011-March 2013

PRINCIPAL INVESTIGATOR
JUNKER Anne

CO-INVESTIGATORS
AVARD Denise
KNOPPERS Bartha Maria
O'DOHERTY Kieran

ACADEMIC ASSOCIATES
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RESEARCH ASSISTANTS
BLACK Lee
KLEIDERMAN Erika

MICYRN brings together the 17 Canadian academic child/child-maternal health centres and research institutes in a multi-disciplinary national initiative committed to removing barriers and building capacity for the conduct of safe and high quality health research.

The CGP is involved in several projects with MICYRN, including:

- Research harmonization, newborn screening programs (e.g., public engagement in the elaboration of policies; storage issues; and genomic sequencing), and creating policy tools for the P^{3}G International Paediatrics Platform.
- Evaluating a novel model for Canadian National Federated Ethics Review: Expert review of 5 new research protocols in order to test new ways of doing ethics review for pediatric research.
- P^{3}G International Paediatric Platform: The Paediatric Platform has developed an online platform, hosted by P^{3}G, providing research tools for researchers and REBs concerned with pediatric issues. Using model documents in informed consent, data sharing, and biobank governance, the platform facilitates harmonization, provides practical value for researchers, works to improve ELSI management in paediatric biobanking, and facilitates REB review.

Optimizing Public Cord Banking and Research in Canada Phase II

Stem Cell Network
August 2012-July 2013

PRINCIPAL INVESTIGATOR
KNOPPERS Bartha Maria

CO-INVESTIGATORS
ALLAN David
EAVES Connie J.
HESLEGRAVE Ron J.
WALKER Mark
ZANDSTRA Peter

ACADEMIC ASSOCIATE
ISASI Rosario

RESEARCH ASSISTANTS
BEAK Carla
DWIVEDI Supriya
DALPÉ Gratien

The main objective of this project is to develop tools for optimizing access to ethically sourced umbilical cord blood (UCB) for research. UCB is considered a valuable source of stem cells for research and clinical applications. Furthermore, UCB transplantation is standard practice for the treatment of blood disorders and studies suggest their potential use for the development of novel blood and immune-based therapies. Canadian Blood Services (CBS) will establish and operate the national OneMatch Public Cord Blood Bank (OMPCBB) that will be accessible to Canadian and international patients. The OMPCBB will promote efforts that contribute to research and improved clinical care by making non-bankable units available for research. In this context, the development of harmonized tools for UCB collection and uses that meet the needs of all stakeholders is critical. In partnership with CBS and other stakeholders, we will develop practical tools to enable ethical provenance of UCB stem cells as well as policy recommendations for UCB research (e.g. informed consent protocols, information pamphlets for donors and ethics review boards) to facilitate the interpretation of ethical guidelines and ensure research is performed within a strong ethical and legal framework.

Emerging Team in Development of Strategies for Uptake and Analysis of Nanosequencing-Derived Data Sets and Linking to Disease

Canadian Institutes of Health Research (CIHR)
October 2008 – September 2013

PRINCIPAL INVESTIGATOR
ROULEAU Guy

CO-INVESTIGATORS
AWADALLA Philip
BOUVIER Michel
CHOUINARD Sylvain
DRAPEAU Pierre
DUBÉ Marie-Pierre
KNOPPERS Bartha Maria
L'ESPERANCE Paul
MICHAUD Jacques
SAMUELS Mark

The goal of this project is to create a multidisciplinary team to develop strategies for uptake of nanotechnology derived data sets. The scientific interest of this project is the identification and validation of genes that cause or predispose to brain diseases. Our team is developing approaches for interpretation and follow-up of the genetic information arising from nanosequencing in human patients. Tourette Syndrome (TS) is used as the major model of a brain disease disorder for implementation of these goals.

Returning Research Results of Paediatric Genomic Research to Participants

National Institutes of Health (NIH)
September 2011 – September 2013

PRINCIPAL INVESTIGATOR
WRIGHT CLAYTON Ellen

CO-INVESTIGATORS
KNOPPERS Bartha Maria
MCGUIRE Amy

ACADEMIC ASSOCIATE
ZAWATI Ma'n H.

RESEARCH ASSISTANTS
COHEN Eliza
MALLETTE Ariane
PARRY David

This project, in partnership with research groups in the United States, aims to determine what criteria should govern return of individual results in paediatric genomic research, using analysis of US law and international guidelines regarding decision making for and by minors as the foundation. This issue, which has received remarkably little attention, must be resolved if this research, which is vital to understanding the contributions of genetic variation to the health of children, is to proceed. In order to develop these criteria, the project will draw upon a host of ethical, legal, and sociocultural sources, as well as empirical data. The Centre of Genomics and Policy is analyzing international (including Canadian) policies and guidelines on the return of paediatric research results, and the US PI's are analyzing US legislation and case law that may impact on the return of paediatric research results.

Susceptibilité génétique au cancer du sein: échange international de données et discrimination génétique

Ministère du Développement Économique, Innovation et Exportation, Québec
June 2010 – September 2013

PRINCIPAL INVESTIGATOR
SIMARD Jacques

CO-INVESTIGATORS
AMARA Nabil
AVARD Denise
DORVAL Michel
DROIT Arnaud
LAKHAL-CHAIEB M'hamed Lajmi
LANDRY Réjean
JBILOU Jalila
JOLY Yann
KNOPPERS Bartha Maria
SINNETT Daniel

ACADEMIC ASSOCIATE
NGUENG-FEZE Ida

RESEARCH ASSISTANTS
DALPÉ Gratien
GRANADOS Palmira
KLEIDERMAN Erika
MALLETTE Ariane
OSIEN Gladys
SALMAN Shahad
SO Derek

The rules and policies of collaborative oncological gene-environment studies (COGS) as well as the laws and public policies applicable to the international exchange of genetic samples in the United Kingdom, Australia, Canada, Europe (confidentiality), and France (material transfer agreements and broad consent) will be systematically identified and analyzed by this project. Findings will be validated by consultation (teleconference or email) with experts from each of the selected countries or regions. Our analysis, complemented by a critical literature review, will allow us to outline the central similarities and differences between norms and produce recommendations aiming to harmonize current rules with those of COGS. Our second objective concerns the communication of information to third parties. We will carry out a review of the relevant law, regulations, and guidelines concerning medical liability and genetic discrimination in Quebec. This review is necessary to identify the actual practices of insurance companies in Quebec and to compare them to legal and ethical norms. We will analyze the forms available on the websites of personal insurance companies in Quebec (Desjardins, La Capitale, Groupe Promutuel, etc.). Norms will be organized according to the emergent issues, such as confidentiality, access, and discrimination. The contextual legal analysis of these issues will serve to identify those elements that would benefit from the issuance of recommendations addressing medical liability and genetic discrimination in Quebec.

Returning Research Results of Paediatric Genomic Research to Participants

National Institutes of Health (NIH)
September 2011 – September 2013

PRINCIPAL INVESTIGATOR
WRIGHT CLAYTON Ellen

CO-INVESTIGATORS
KNOPPERS Bartha Maria
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ACADEMIC ASSOCIATE
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RESEARCH ASSISTANTS
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PARRY David

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CIHR Team of Prediction and Communication of Familial Risks of Breast Cancer (INHERIT)

Canadian Institutes of Health Research (CIHR)
October 2008 – October 2013

PRINCIPAL INVESTIGATOR
SIMARD Jacques

CO-INVESTIGATORS
AMARA Nabil
ANDRULIS Irene
ANTONIOU Antonis
AVARD Denise
BRIDGE Peter
CHIQUETTE Jocelyn
DORVAL Michel
DUROCHER Francine
EASTON Douglas
GLENDON Greg
GOLDGAR David Elliot
GOLDGERG Mark
JOLY Yann
KIM-SING Charmine
KNOPPERS Bartha Maria
LAFRAMBOISE Rachel
LANDRY Réjean
LESPÉRANCE Bernard
MAUGARD Christine M.
OUIMET Mathieu
PLANTE Marie
SINILNIKOVA Olga
SINNETT Daniel
TAVTIGIAN Sean

ACADEMIC ASSOCIATES
LÉVESQUE Emmanuelle
NGUENG-FEZE Ida

RESEARCH ASSISTANT
GAGNON Johannie

The overarching goal of this project is to thoroughly evaluate the prediction of breast cancer risk and its communication to individuals with a family history of breast cancer. The 4 components of the program are designed:

- To determine the contribution of uncommon or rare intermediate-risk variants in selected candidate genes to the genetic population attributable fraction and the familial relative risk of breast cancer, and to assess the robustness of their risk in women ascertained through clinic-based and population-based studies.
- To improve estimation of breast and ovarian cancer risks associated with mutations in BRCA1 and BRCA2 genes by identifying the genetic and environmental modifiers that may influence these risks.
- To integrate the knowledge on newly identified genetic an environmental factors, as well as biologic markers, in breast cancer risk prediction models providing individual risk estimates.
- To assess communication of risk prediction information by health professionals and the impact of such information on women at moderate to high risk of the disease.
- This program is identifying specific genetic factors contributing to breast cancer susceptibility, in particular, yet poorly explored, uncommon or rare intermediate-risk variants that potentially explain a significant proportion of missing familial risk of breast cancer. Some of these could enter clinical cancer genetics practice in the foreseeable future.

Cultured Epithelial Autografts for the Treatment of Corneal Limbal Stem Cell

Stem Cell Network
January 2013 – December 2013

PRINCIPAL INVESTIGATOR
GERMAIN Lucie

CO-INVESTIGATORS
AUGER François
BAZIN Richard
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE
NGUYEN Minh Thu

This research will develop cell therapies for the treatment of corneal limbal stem cell deficiency ("LSCD"); a severe disease caused by damage or depletion of the corneal stem cells in the limbus region of the eye following trauma or disease. To treat LSCD patients, we have developed a tissue engineering technique involving massive expansion of epithelial cells in vitro to produce epithelial sheets for autologous transplantation (cultured epithelial corneal autografts – "CECA"). Our team of scientific researchers, clinicians and ethical/legal experts, with extra funding support from CHA hospital foundation, FRSQ ThéCell Network, we will be the first in Canada to offer treatment for unilaterally blind or vision impaired patients suffering from LSCD. At first, our approach has been to finalize the production of documents essential to the conduct of the clinical trial, such as SOPs. This process is facilitated by the close collaboration between scientists and experts at Université Laval LOEX with the Centre Genomics and Policy at McGill University.

Optimizing Public Cord Banking and Research in Canada Phase I

Stem Cell Network

August 2012-December 2013

PRINCIPAL INVESTIGATOR
KNOPPERS Bartha Maria

CO-INVESTIGATORS
ALLAN David
EAVES Connie J.
HESLEGRAVE Ron J.
WALKER Mark
ZANDSTRA Peter

ACADEMIC ASSOCIATE
ISASI Rosario

RESEARCH ASSISTANTS
BEAK Carla
DWIVEDI Supriya
DALPÉ Gratien

The main objective of this project is to develop tools for optimizing access to ethically sourced umbilical cord blood (UCB) for research. UCB is considered a valuable source of stem cells for research and clinical applications. Furthermore, UCB transplantation is standard practice for the treatment of blood disorders and studies suggest their potential use for the development of novel blood and immune-based therapies. Phase I involves the review of consent protocols developed by the Canadian Blood Services (CBS) to ensure that they adhere to national standards, and the development of an informed consent process for cord blood donation for the OneMatch Public Cord Blood Bank (OMPCBB) that adheres to national and international standards. Phase I also focuses on the development of an information pamphlet for potential UCB donors, focusing on donations for the purposes of research, and complementing the OMPCBB brochure. Finally, Phase I facilitates stakeholder involvement by coordinating workshops to develop the above consent protocols and a proposed national guideline.

The Terry Fox New Frontiers Program Project in Genomic Determinants of Childhood Leukemia

Canadian Institutes of Health Research (CIHR), Terry Fox Foundation

June 2010 – June 2014

PRINCIPAL INVESTIGATORS
AVARD Denise
AWADALLA Philip
KRAJINOVIC Maja
PASTINEN Tomi
SINNETT Daniel

CO-INVESTIGATORS
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ACADEMIC ASSOCIATE
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RESEARCH ASSISTANTS
DAM Amy
ESQUIVEL SADA Daphne
HAGAN Julie
RAHIMZADEH Vasiliki

This project aims to examine whole-genome sequence variations from a sample of childhood acute lymphoblastic leukemia (ALL) patients with the following aims:
1) to identify novel sequence and structural variants in childhood ALL genomes; 2) to explore changes in gene expression associated with ALL by examining the transcriptome and allelic expression; 3) to assess the impact of selected genes on disease susceptibility and disease outcomes and investigate the functional significance of these genes in vitro; and 4) to translate the genetic discoveries into appropriate health care policy and services. These findings will ultimately lead to the development of powerful research and clinical tools that could improve detection, diagnosis and treatment of childhood leukemia.

The CGP aims to identify ethical, legal and social issues in the return of paediatrics research results. More specifically, our Centre is reviewing the ELSI implications of Genome-wide re-sequencing results on children and parents. This involves an analysis of international and national policy statements, the obligations and needs of researchers and health professionals regarding the return of research results, and the needs of families and their children. This analysis will culminate in the production of a comprehensive discussion document. The development of the discussion document also involves literature and policy review, interviews with healthcare providers and families, and collaboration with various stakeholders.

ONGOING RESEARCH PROJECTS

The Leucegene Project: Transcriptome Sequencing to Identify Novel Prognostic Markers and Therapeutic Targets in Acute Myeloid Leukemia

Genome Quebec
January 2011 – January 2014

PRINCIPAL INVESTIGATORS
SAUVAGEAU Guy

CO-INVESTIGATORS
AVARD Denise
BARABÉ Frédéric
BOUVIER Michel
HÉBERT Josée
LEMIEUX Sébastien
WILHELM Brian

ACADEMIC ASSOCIATE
PALMOUR Nicole

RESEARCH ASSISTANTS
ALI-KHAN Sarah
BESSO Annyck
BLACK Lee
KLEIDERMAN Erika

The project proposes to identify novel prognostic markers and therapeutic targets in acute myeloid leukemia. The ELSI portion of this project, for which the Centre of Genomics and Policy has primary responsibility, analyzes the 2010 Tri-Council Policy Statement requirement that material incidental findings be disclosed to research participants. Of particular interest are how diligent must researchers be in looking for 'incidental findings', how should they be disclosed, and how is this obligation funded (or not). We will also be pursuing a qualitative study that will ask researchers about difficulties they have had with this obligation, whether it be known what to disclose, how to disclose it, or how to fund the staff to assist in the disclosure if the researcher is not qualified to do so.

Next Generation Predictive Signatures for Breast Cancer

Genome Quebec
January 2011 – January 2014

PRINCIPAL INVESTIGATOR
HALLETT Michael

CO-INVESTIGATORS
AVARD Denise
BASIK Mark
BATIST Gerald
GABOURY Louis
MULLER William
NEPVEU Alain
PARK Morag
SIEGEL Peter
URSINI-SIEGEL Josie

ACADEMIC ASSOCIATE
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RESEARCH ASSISTANTS
ALI-KHAN Sarah
BESSO Annyck
BLACK Lee

The project proposes to develop a prognostic gene signature and validate a "made in Quebec" clinical test for ER-positive breast cancer patients. The ELSI portion of this project, for which the Centre of Genomics and Policy has primary responsibility, revolves around the barriers to the adoption of new technologies into clinical practice. We are focusing first on the educational factors that might limit uptake or understanding of these tests. That is, does the education received by physicians and nurses as part of primary or continuing education curricula adequately take into account the growth of genetic medicine in everyday medical practice? We will also be pursuing a qualitative study. For this, we will be interviewing or sending questionnaires to clinical care providers to obtain their input on what barriers exist for them, if any, for the use of genetic testing in their practice. From this we hope to develop a discussion paper on barriers to uptake of new genetic technologies, including educational and any other barriers that arise from the qualitative study.

ThéCell
(Réseau de thérapie cellulaire et tissulaire)

Fonds de la recherche en santé du Québec (FRSQ)
April 2009 – March 2014

PRINCIPAL INVESTIGATOR
GERMAIN Lucie

CO-INVESTIGATORS
AUGER François
BERTHOD François
KNOPPERS Bartha Maria
LAVERTY Sheila
ROUTY Jean-Pierre
ROY Denis-Claude
TANGUAY Jean-François

ACADEMIC ASSOCIATES
ISASI Rosario
NGUYEN Minh Thu

Created in 2009, the Cell and Tissue Therapy Network (ThéCell) brings together some 50 researchers in order to facilitate Phase 1 and 2 clinical studies aimed at making advanced cell therapy publicly accessible by enhancing and developing technological platforms established through Québec universities and their partners. ThéCell is a lever and catalyst in mobilizing and coordinating use of and access to infrastructure and highly qualified personnel in the field of cell and tissue therapy.

Enjeux socio-ethiques et juridiques des therapies cellulaires et tissulaires

ThéCell
January 2013 – March 2014

PRINCIPAL INVESTIGATOR
GERMAIN Lucie

CO-INVESTIGATOR
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE
NGUYEN Minh Thu

Created in 2009, ThéCell brings together some 50 researchers in order to facilitate Phase 1 and 2 clinical studies aimed at making advanced cell therapy publicly accessible by enhancing and developing technological platforms established through Québec universities and their partners. ThéCell is a lever and catalyst in mobilizing and coordinating use of and access to infrastructure and highly qualified personnel in the field of cell and tissue therapy. As the Socio-Ethical and Legal Platform, our role is to provide ad hoc consultation to researchers and clinicians on ethical and regulatory issues related to cell and tissue therapies. We provide assistance with drafting consent forms and research protocols for research ethics approval and Health Canada clinical trial applications.

Recherche sur les maladies rares : Vie privée « bon gré mal gré »?

Fonds de recherche du Québec-Santé / Réseau de médicine génétique appliquée du Québec
April 2013 – March 2014

PRINCIPAL INVESTIGATOR
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE
SÉNÉCAL, Karine

RESEARCH ASSISTANTS
SHUANG Shuang
HÉTU Martin

Research on rare diseases raises special issues regarding the privacy and confidentiality, notably due to the low number of people affected by each of these rare diseases that makes that indirect identification of participants often remains possible despite the usual measures of protection of privacy and confidentiality. Moreover, research on rare diseases requires concerted action and transnational (and even international) data sharing. This fact may exacerbate concerns relating to the protection of privacy and confidentiality. The goal of this pilot-project is to examine whether the legal and ethical rules on protection of privacy and confidentiality can be a barrier to research on rare diseases and to provide, if needed, practical solutions to rectify the situation. This involves an analysis of provincial laws, and national and international policy and guidelines on the protection of privacy and confidentiality of human research participants, as well as a review of the literature. These analyses will culminate in the production of a green paper, i.e. a prospective report containing a set of proposals to be discussed for the development of a policy. This green paper will inform policymakers, researchers and REB on the specific issues of research on rare diseases and outline the strategic measures (legislative, normative or administrative) that could be implemented to not impede research in this area.

Centre for Commercialization of Regenerative Medicine ("CCRM") Ethics and Policy Unit

Centres of Excellence for Commercialization and Research (CECR)
May 2012 - April 2014

PRINCIPAL INVESTIGATOR
MAY Michael

CO-INVESTIGATORS
BATHIA Mick
ELLIS James
JOLY Yann
KNOPPERS Bartha Maria
KELLER Gordon
SHOICHET Molly
STANFORD Bill
TIMMINS Nick
ZANDSTRA Peter

ACADEMIC ASSOCIATE
ISASI Rosario

RESEARCH ASSISTANT
GRANADOS Palmira

CCRM is a Canadian, not-for-profit organization supporting the development of foundational technologies that accelerate the commercialization of stem cell- and biomaterials-based products and therapies. CCRM is supported by the Centres of Excellence for Commercialization and Research (CECR) Program.

The CCRM Ethics and Policy Unit is housed at the Center of Genomics and Policy, McGill University. The overall objective of the Ethics and Policy Unit is to provide gold standard policies on Socio-Ethical and Legal Issues (ELSI) related to commercialization for CCRM core activities as well as on communication strategies.

From the Lab to the Clinic: ELS Issues in Cancer Stem Cell Research

Cancer Stem Cell Consortium (CSCC)
May 2010-April 2014

PRINCIPAL INVESTIGATOR
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CO-INVESTIGATORS
KAYE Jane
KNOPPERS Bartha Maria
LEMMENS Trudo
LOMAX Geoff
McCORMICK Jennifer B.
McDONALD Micahel
SCHIMMER Aaron
SCOTT Christopher Thomas
SIPP Douglas
WANG Jean
WILLISON Donald
WOLF Susan

RESEARCH ASSOCIATE
ISASI Rosario

RESEARCH ASSISTANT
BEAK Carla

From the Lab to the Clinic: ELS Issues in Cancer Stem Cell Research is a project key to a larger Cancer Stem Cell Consortium (CSCC) funded initiative that aims to identify, characterize and develop methods of destroying leukemia stem cells (LSC). This latter research project involves three key phases of the innovation process: the use of a large tissue bank (basic research), the engagement of industry partners (commercialization) and the development of valuable therapeutics (translation) for patients with intractable leukemia. The ELS initiative led by HeaLS Research Director Timothy Caulfield explores the ethical, legal, social and policy issues affiliated with each realm of research associated with the innovative process. The team will be investigating ELS challenges that characterize tissue banking and the commercialization process, in addition to those associated with the marketing of therapies. This latter component is being done through the lens of medical tourism.

Réseau de médecine génétique appliquée (RMGA) Infrastructure

Fonds de recherche du Québec-Santé
June 2010 - May 2014

PRINCIPAL INVESTIGATOR
ROULEAU Guy

CO-INVESTIGATORS
AVARD Denise
BOUCHARD Gérard
BRAIS Bernard
KNOPPERS Bartha Maria
MICHAUD Jacques
PHILLIPS Michael
PUYMIRAT Jack
ROUSSEAU François
SIMARD Jacques
VÉZINA Hélène

ACADEMIC ASSOCIATES
LÉVESQUE Emmanuelle
SÉNÉCAL Karine
TASSÉ Anne-Marie

The RMGA is a network of multi- and trans-disciplinary researchers. Its objective is to support and develop basic and applied human genetic research by creating, managing, and promoting scientific infrastructures and knowledge transfer through health services and interventions, for the benefit of the Quebec population. The Network has close to 350 members, representing the majority of human genetics researchers in Quebec. The RMGA includes a Legal and Socio-Ethical Issues Infrastructure at the CGP that considers issues arising from the research activities of the RMGA members and provides ELSI guidance on emerging issues.

Applied Metagenomics of the Watershed Microbiome

Genome British Columbia, Genome Canada
July 2011 - June 2014

PRINCIPAL INVESTIGATORS
ISAAC-RENTON Judith
TANG Patrick

CO-INVESTIGATORS
BAKKER Karen
BRINKMAN Fiona
BRUNHAM Robert
GARDY Jennifer
HEMMINGSEN Sean
HENRICH Natalie
HILL Janet
HOLMES Bev
HOLT Robert
JOLY Yann
KNOPPERS Bartha Maria
MARZIALI Andre
OZDEMIR Vural
PRYSTAJECKY Natalie
SUTTLE Curtis

ACADEMIC ASSOCIATES
DOVE Edward
NGUENG-FEZE Ida
PALMOUR Nicole

RESEARCH ASSISTANT
BIRKO Stanislav

Water quality is primarily assessed at the tap using coliform bacterial species as indicators of microbial pollution, a paradigm which reflects an anthropocentric focus on drinking water and human health. Metagenomics is a "culture-independent" method for analysis of multiple microbial genomes, for example, in the drinking water. Importantly, water safety and genomics together create a highly volatile postgenomics innovation trajectory for metagenomics applications in public health and ecosystem health.
This study comprises three stages. First, we will identify the metagenomics stakeholders for water safety in consultation with the water and metagenomics experts and through metagenomics and water safety document analyses and interviews. Second, the issues associated with a new watershed test that may impact each stakeholder group will be identified through complementary social science methodologies including document analyses, literature reviews, surveys, focus groups and interviews. Third, we will hold a multi-stakeholder workshop to present, negotiate and validate the identified social, legal, ethical and policy issues in the form of a "points-to-consider" document to inform prospective policy.

Design and Evaluation of Electronic Consent and Governance Processes for Clinical Research

Canadian Institutes of Health Research
February 2011-July 2014

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The objective of this study is to create Canadian recommendations and other resources for electronic consent for future research use of data and biological materials. Informed consent signals the primary duty to inform and protect research participants. Providing consent is based on the right of research participants to exercise full autonomy in decisions affecting their health and personal privacy. As technologies in medical research improve and research questions become increasingly complex, there is a need to recruit new participants, as well as use previously-collected data and biological materials to increase statistical power and minimize the burden on research populations. This application addresses the need for guidance in the use of research data and biological materials to answer questions that were not planned or known at the time of collection. This guidance will provide recommendations for the use of data and biological materials that have already been collected and provide recommendations and a model electronic consent process for data and biological materials that will be collected in the future.
Specifically we will: 1) Evaluate the feasibility of creating a digital governance system in Canada by identifying the legal and ethical issues relating to the use of an electronic approach to consent for future research use of data and biological materials; 2) Draft an Electronic Consent Technical Report with actionable recommendations, and validate it with pertinent stakeholders (ethics boards, patient organizations, etc).

The Terry Fox New Frontiers Program Project in Genomic Determinants of Childhood Leukemia

Canadian Institutes of Health Research (CIHR), Terry Fox Foundation
June 2010 – September 2014

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The scientific objectives of this project are to evaluate in a nonhuman primate (NHP; vervet monkey) model differences in the microbiome of the gastro-intestinal tract at different locations, determine whether stool is a relevant material for microbiome studies, and assess how age, sex, genetics and diet influence the diversity of the microbiome at points along the gastrointestinal tract. Microbiome based therapies, namely fecal transplantation (FT) therapeutics, are thought to hold great potential for treatment of a number of disorders. However, potential FT based therapeutics raise GE3LS issues that are unique to microbiome research and implementation. The project aims to investigate the regulatory hurdles of FT based therapies, namely: 1) How would FT based therapeutics, as they are currently prepared and administered, be treated under Canadian and International legislative and regulatory regimes? 2) What are the legislative, regulatory, and/ or local administrative hurdles that both current, and anticipated FT based therapeutics face in Canada and Internationally?

Translation Challenges, Science Policy and Stem Cell Research

Stem Cell Network
October 2011 – March 2015

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Intellectual property (IP) is perceived as playing an important role in the commercialization process, and the role of patents in particular has received a considerable amount of attention in the literature (Golden 2010). Our focus in this phase will be on the relationship between translation and commercialization pressure (including IP policies), and data access policies. We will investigate current restrictions to access, as reflected in (for example) international stem cell banking policies, including restrictions to future IP claims, and compare them with existing open access policies (e.g., UK Stem Cell Initiative and the CIRM iPS biobank). This work will include an analysis of whether certain commercialization policies, and concomitant IP approaches (such as restrictive patenting practices) do in fact conflict with emerging open access approaches and policies, as reflected, for example, in the UK Stem Cell Bank.

Canadian Partnership for Tomorrow Project (CPTP)

Canadian Partnership Against Cancer
April 2009 – March 2015

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The Canadian Partnership for Tomorrow Project (CPTP) enrols 300,000 Canadians between the ages of 35 and 69 years, who agree to be followed for their adult lifetime, to explore how genetics, environment, lifestyle and behavior interact and contribute to the development of cancer and other chronic diseases. This pan-Canadian Project has five participating Cohorts (Atlantic PATH, CARTaGENE, Ontario Health Study, Alberta Tomorrow Project, BC Generations Project).
Hosted at The Public Population Project in Genomics and Society (P^3G), the ELSI Standing Committee builds the ELSI infrastructure of the CPTP platform. The goals are to bring together ELSI experts from each cohort and develop relevant policies, documents, and procedures that are needed either by the CPTP or by a specific cohort and to ensure the conformity of the platform with legislation and ethics guidelines so as to prospectively guide the cohorts. The ELSI Standing Committee mandate is broad. It ranges from developing interoperable recruitment and access policies and procedures to dealing with ethical issues surrounding consent, privacy and data sharing, and proposing governance structures for the CPTP and supporting the cohorts.

From Banking to International Governance: Fostering Innovation in Stem Cell Research

Stem Cell Network - Networks of Centres of Excellence (NCE)
October 2011 – March 2015

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International initiatives are emerging to address harmonization and standardization processes for Stem Cell Research and banking (e.g. International Society for Stem Cell Research (ISSCR) and the International Stem Cell Banking Initiative (ISCBI)). Until recently however, these efforts adopted an 'embryo-centric' approach, leaving behind other timely and promising sources (e.g. induced pluripotent stem (iPS) cells, cells derived from placentas, etc.).
While certain socio-ethical and legal (ELSI) concerns are specific to the nature of Stem Cells Banks, can they thrive by applying the lessons learned in biobanking generally? To answer this, we will examine the current national and international SC banking landscape against the biobanking models for human tissues generally, with a view to evaluating existing governance, commercialization and regulatory frameworks and to proposing policy recommendations to increase the upstream understanding of the factors which encourage or hinder SC translation. We will develop "international governance models" and a "Points to Consider" thereby providing a wide range of stakeholders and receptors (e.g. researchers, SC bankers, policy-makers and the general public), with analyses, strategies and solutions for moving towards translational SCR within Canada and on the global stage. Furthermore, we will build capacity by training and mentoring future ELSI researchers.

A Research and Knowledge Network on Genetic Health Services and Policy: Building on the APOGEE-Net and CanGeneTest Experiences

Canada Institutes of Health Research (CIHR)
November 2008 – March 2015

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Consent has long been considered as the crystallization of the researcher's duty to inform research participants. Indeed, providing consent is based on the right of participants to exercise full autonomy in decisions affecting their personal privacy. That being said, as the number of participants recruited in large-scale longitudinal studies – for example – grows, obtaining and maintaining consents will become increasingly onerous and complex. Hence, research studies are gradually using interactive, electronic media for consent procedures – which are seen as more accurate, dynamic and cost-effective. It is unclear, however, how and under what conditions such an approach will satisfy the legal and ethical requirements related to consent. Outcomes from this research will interest various stakeholders, including clinical researchers, health policy advisors, lawyers as well as technology and computer specialists, as it will promote the research-to-practice transition and provide preliminary data and guidelines for the legal and ethical design, implementation and approval of projects using e-consent procedures. More generally, the future use of e-consent will likely require that decision-makers provide guidelines and rules specifically addressing the role of new technologies in this field, thereby impacting the research, ethical and legal fields.

International Cancer Genome Consortium/Data Access Compliance Office (DACO)

Ontario Institute for Cancer Research (OICR)
July 2009 – May 2015

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The International Cancer Genome Consortium (ICGC) has been organized to launch and coordinate a large number of national cancer research projects that have the common aim of elucidating the genomic changes present in many forms of cancers that contribute to the burden of disease in people throughout the world.
Hosted at The Public Population Project in Genomics and Society (P^3G), the DACO is responsible for the handling of requests for access to controlled data collected by the ICGC. It reports to both the Data Coordination Centre and the International Data Access Committee. Its objectives are to facilitate ethical, efficient, and responsible transfer of controlled data to members of the scientific community who agree to the Consortium terms and objectives.

Quebec Training Network in Perinatal Research (QTNPR)

Canadian Institutes of Health Research (CIHR)
April 2009 – May 2015

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The QTNPR network is creating a multidisciplinary curriculum on the impact of environmental exposures on maternal and child health. The objectives of QTNPR are to 1) provide trainees the knowledge, skills, and values that will allow them to address the complex interdisciplinary challenges of the current reproductive and perinatal health environment; 2) integrate into a single training network several research groups with complementary expertise in reproductive, perinatal, and infant health research; 3) link state-of-the-art, discipline specific teaching to crosscutting core competencies in the form of a transdisciplinary training grid; and 4) establish and maintain national and international partnerships with relevant complementary training programs.

International Stem Cell Forum Ethics Working Party (EWP)

International Stem Cell Forum, Medical Research Council (UK),
Canadian Institutes of Health Research (CIHR)
April 2004 – May 2015

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Scientific collaboration is a key aspect of the globalization of research. It is essential for the feasibility of any international collaborative project such as the International Stem Cell Forum (ISCF). The ISCF is composed of twenty-one partners and research funding institutions from around the world. It faces the challenge of conflicting regulatory and policy approaches regarding the exchange of materials and data adopted by its various health ministries. The divergent policy frameworks and governing regulations affect the permissibility of conducting stem cell research, (i.e. procurement, derivation, banking, distribution and use of stem cell lines) affecting collaboration at the national and international levels.

The Ethics Working Party (EWP) initiative was set up on behalf of the International Stem Cell Forum by its Canadian member organization, the CIHR, and is now supported by the Canadian Stem Cell Network. The EWP is comprised of independent experts in the area, appointed by each of the Forum's member organizations. It is chaired by Dr. Bartha Maria Knoppers and its Secretariat is housed at the CGP in the Genome Quebec / McGill University Innovation Centre. The primary purpose of the Ethics Working Party is to assist member countries to undertake stem cell research within a transparent and well-considered ethical framework. The EWP seeks to identify prospective strategies to foster the scientific and ethical integrity of research in a global context.

Biobank Standardisation and Harmonisation for Research Excellence in the European Union (BioSHaRE-EU)

The European Commission
December 2010 – June 2015

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BioSHaRE-EU has assembled a consortium of leading international researchers from all domains of biobanking science. These experts are working to develop and apply methods and tools that will provide a foundation for an ambitious program of harmonization and standardization in European biobanks and major biomedical studies. This facilitates the full participation of European bioscience in the next phase of international aetiological research that demands access to studies that have 3 complementary characteristics: 1) participants must be comprehensively assessed not only for genotype, but also for phenotype; 2) measurement quality must be high; and 3) because no single study will provide adequate numbers of subjects for certain questions, biobanks must therefore be harmonized and standardized so that studies can pool biobank data in valid and effective ways. The CGP is involved in the development of ethical, legal and social guidance in order to harmonize the treatment of environmental risk and personal life-style data in and from different European biobanks. The CGP also offers BioSHaRE its ethical expertise on issues of privacy and retrospective access to samples and data.

Reconciling Law and Ethics with Open Science in Biotechnology Research

Fonds de recherche du Québec-Santé
July 2011 – June 2015

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Do the current ethical and legal policies applicable to research with genomic databases sufficiently account for the new reality of open biotechnology? How could the current policy framework be improved to facilitate the transition to a more transparent, collaborative research context? Our research will investigate the impact of open biotechnology on research ethics and legal policies with a particular focus placed on informed consent (scope of consent, privacy, data ownership) to large open database projects. We will use a combination of quantitative and qualitative research strategies that will offer complementary applied legal and ethical data on the impact of open biotechnology on the governance of genomic research. The use of a common research methodology in all streams of the project will facilitate comparisons and integration of our results. Our methods will include comparative legal and ethical research (policy review, legal research), questionnaire analysis and focus group interviews. To validate our findings, we will engage stakeholders at the annual meetings of two major organizations involved in research with open databases: The Public Population Project in Genomics and Society (P^3G) and the International Cancer Genome Consortium (ICGC).

Towards Systems Medicine for Fatty Liver Disease

Fonds de recherche du Québec-Santé
September 2011 – September 2015

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This project focuses on three questions relating to a disease-specific biobank:
1)Given its current ethical framework, can the liver biobank re-contact research participants for updates to enrich the quality of the bank? If so, what measures will need to be taken to meet Canadian and international ethical standards?
2)How can a policy to return incidental findings be developed that takes advantage of a double-coding system of privacy protection but is streamlined and efficient?
3)What is the scientific, ethical, legal and policy framework applicable to the return of results in the context of a personalized medicine biobank project?

Cell-based Regenerative Medicine: new challenges for EU legislation and governance (EUCellLex)

European Commission/INSERM
October 2013 – September 2016

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The aim of this project is to collect and analyze facts and figures to assess the current legislation on the therapeutic use of somatic cells, and to bridge it with the research infrastructure capacity building. The project is based on a coherent consortium of experts in the fields of cells therapies, cells banks and translational biomedicine, having strong expertise in law and/ or in governance issues to provide evidence about the contemporary practices around cells and design a picture of the "market" and its distribution between the public and private sector. The CGP's role in the project is to examine and enhance the understanding and interpretation of national, regional and international legal and ethical issues surrounding umbilical cord blood (UCB) research and provide recommendations. This is a critical and logical step towards building a robust implementation process for the ethical and legal frameworks governing UCB research, banking and clinical applications in Europe, so as to harness its potential for novel therapeutic applications. The project will thus help the Commission in the regulatory choices covering the use of human cells for therapeutic purposes and to foster the innovation potential of related research activities.

Risk Stratification for Prevention and Early Detection of Breast Cancer: Development and Implementation of Communication Tools

La fondation du cancer du sein du Québec
September 2012 – September 2016

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The goal of this project is to develop an integrated information campaign that aims to sensitize the population to the importance of considering family history to fight effectively against breast cancer. The campaign also aims to better equip health professionals to evaluate the risk of breast cancer on the basis of family history. This campaign will be realized through a rigourous process that will partner diverse professional and community associations. Information and sensitization tools will be developed and compiled into information toolkits. These toolkits will respond to three needs: to effectively collect, use, and share information on family history of breast cancer. The tools will allow users, for example, to answer the following questions: From whom should I obtain information? What kind of medical information do I need? How can I obtain this information from my family? With whom should I share the information I gather on breast cancer risk?
The team includes experts in genetics, epidemiology, public health, psychosocial evaluation, ethics, and public law (CGP).

Multidimensional Epigenomics Mapping Centre (EMC) at McGill

Canadian Institutes of Health Research (CIHR)
March 2012-February 2017

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To join global efforts (The International Human Epigenome Consortium), we will establish an Epigenome Mapping Centre (EMC) at McGill University that builds upon a high-throughput sequencing infrastructure with a critical mass of expertise and technology available to contribute significantly in deciphering the functional code of the human genome. Our work is internationally coordinated and will support research initiatives across the Canadian research community. We apply epigenome mapping to understand interactions between environment and genome in human blood cells, to interpret diseases impacting metabolism using tissue samples and to study how epigenetic changes can alter function of the brain. EMC McGill is a national hub housing a critical mass of epigenomics expertise supported by state-of-the-art genomics infrastructure. Our integrated operation also includes a legal and ethics component. It will contribute to Canadian leadership in epigenome research in biomedicine.

Integrative Epigenomic Data Coordination Centre (EDCC) at McGill

Canadian Institutes of Health Research
March 2012-February 2017

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This project proposes an integrative Epigenomic Data Coordination Centre (EDCC) at McGill, which will be a national hub to support data collection, processing, storage and dissemination for projects funded under the CEEHRC initiative and facilitate integration with the IHEC. The outcome will include data pipelines and tools using standardized formats and vocabularies for verification, validation, and analyses across the CEEHRC network. The EDCC McGill will also develop a framework that leverages Compute Canada national resources to support large-scale processing, sharing and visualization of epigenomics data. The platform will enable epigenetic researchers on a national level to query and exploit this valuable resource.

Framework for Decision-Making for Rare Diseases

Canadian Institutes of Health Research (CIHR)
March 2012-February 2017

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As our understanding of diseases and how to treat them evolves, so too must our decision-making procedures for providing fair and cost effective treatments for those living with an illness. Today, one area of policy and decision-making in particular lags behind, that for treating rare diseases. At present there is no policy framework to help decision makers navigate the complex factors involved when making decisions about paying for orphan drugs. This project brings together a multidisciplinary team of experts in matters relating to treatment for rare diseases, and will incorporate input from the public and key stakeholders to develop such a framework. It will facilitate priority setting for orphan treatment decisions constrained by a limited budget, that considers the relevant developmental, clinical and economic factors and ethical principles, as well as being consistent with the values of society at large.

The Canadian Alliance for Healthy Hearts and Minds

Canadian Partnership Against Cancer and Heart and Stroke Foundation
April 2013 – March 2017

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The Canadian Alliance for Healthy Hearts and Minds is a project that aims to build on the Canadian Partnership for Tomorrow Project (CPTP), a pan-Canadian research platform, by expanding efforts to identify the early root causes that lead to chronic diseases of the brain, the heart and the cardiovascular system. To do so, the Alliance will gather detailed information from about 10,000 Canadian participants on their environments, lifestyle and behaviors that could affect their cardiovascular health. Participants will also be assessed by magnetic resonance imaging (MRI) of the brain, blood vessels, heart and liver. Adding this to the health and biological information assembled over many years within CPTP will allow researchers to explore how these factors contribute to the development of chronic disease leading to heart failure and dementia. In partnership with the Public Population Project in Genomics and Society (P^3G), the Centre of Genomics and Policy will support the project in its development of consent forms and policies.

Enhanced CARE for RARE Genetic Diseases in Canada

Genome Canada
April 2013 – March 2017

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CARE for RARE is a collaborative pan-Canadian project configured to improve the diagnosis and treatment of rare diseases. Powerful new DNA sequencing methods such as whole-genome (WGS) and whole-exome sequencing (WES), will be used to discover 60 new genes, each of which causes a rare disease. The identification of new genes provides useful biological information, giving us insight into cellular pathways significant in human health. It is hoped that the research will lead to the implementation of WES as an effective and reliable diagnostic tool for clinical use. However, in order to facilitate the integration of WES into the clinical setting, the GE3LS component of this study, which will be conducted at the Centre of Genomics and Policy, will include: 1) the drafting of clinical exome trial consent forms; 2) a qualitative analysis of the clinical utility of WES as a diagnostic tool for patients with rare diseases (from the patients' and clinicians' point of view); 3) the drafting of a national position statement and best practices outlining professional and ethical standards for the reporting of incidental findings found using WES; and 4) the development of clinical integration tools for use by clinics offering exome sequencing to patients with rare diseases.

Personalized Risk Stratification for the Prevention and Early Detection of Breast Cancer

Québec Fondation for Breast Cancer, Genome Canada, Genome Québec, Canadian Institutes of Health Research (CIHR), Ministère de l'enseignement supérieur, de la recherche, de la science et de la technologie du Québec
April 2013 – March 2017

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The project is designed to significantly extend the benefits of the current high-quality population screening program, particularly for younger women (35 to 49), by implementing a risk stratification approach targeting screening at an identifiable subset of women with relatively high risk of breast cancer (BC) who are missed by the current standard age-based screening program. This personalized risk-based approach to breast cancer screening will detect cancers at an earlier stage. Significant socio-economic and health benefits will be achieved since a woman's survival prospects will be increased and the burden of disease and costs of treatment will be reduced.

Knowledge of the genetic basis of BC and its risk factors will allow stratification of individuals into different risk groups for screening, and personalized follow-up with appropriate preventive and clinical measures. However, a strategic approach is needed to facilitate the acceptance and adoption of risk-based stratification BC screening models in clinical settings, healthcare services and policies. At the end of our project we will deliver a web-based risk stratification and communication toolbox for use by health professionals and women to facilitate the implementation of a personalized risk-based approach in BC screening and management.

Innovative Chemogenomic Tools to Improve Outcome in Acute Myeloid Leukemia

Genome Canada
April 2013 – April 2017

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This project intends to implement two novel tests in the healthcare system: 1) a chemogenomic model for the development of a prognostic test in Acute Myeloid Leukemia (AML); and 2) an integrated detection kit for Minimal Residual Disease (MRD). Our first objective is to highlight the strengths and weaknesses of Canadian federal and provincial regulatory test approval models. To this end, we will undertake a comparative analysis of US and EU models. Our second objective is to develop recommendations based on an ethical and legal analysis of the duty to inform in the context of lab directors (i.e., whether these directors are under an obligation to inform treating physicians of clinically-valuable information resulting from AML research).

COURSES

HGEN-660B - GENETICS, ETHICS AND LAW

Instructor: Prof. Yann Joly, PhD (DCL), 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 will be 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 will be asked to reflect on the complex relationships between science, law and ethics. Each member of the class will participate in and contribute to the learning that occurs. Such collaborative learning experience will be reflected in the way that the course is structured and the student's work is evaluated.

HGEN-674 -RESEARCH INTERNSHIP IN GENOMICS AND POLICY

Instructor: Me. Ma'n H. Zawati, LL.B., LL.M.

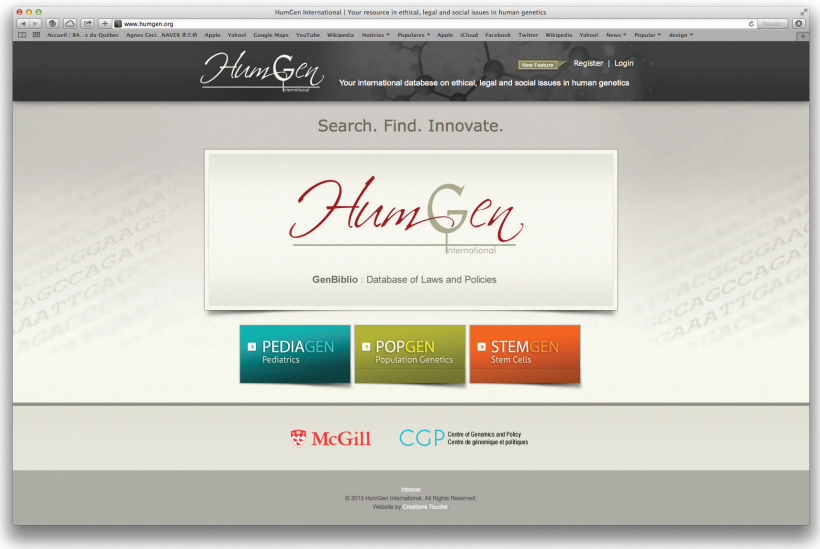
The *Research Internship in Genomics and Policy* course aims at providing 1 to 2 graduate students in the Human Genetics program with an opportunity to do research on the ethico-legal and policy issues in human genetics. More specifically, graduate students will be 1) introduced to the ethical, legal 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 will be 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 include but are not limited to: population genomics, biobanks, stem cells, reproductive technologies, pediatric 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.

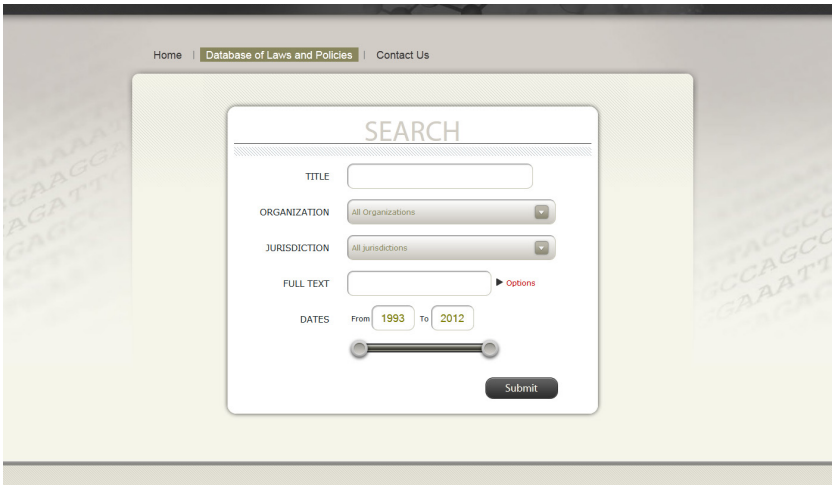
Undertaking an internship at the Centre of Genomics and Policy will allow students to benefit from a close collaboration with experts at the crossroads of the ethico-legal, medical and policy fields.

HUMGEN – DATABASE

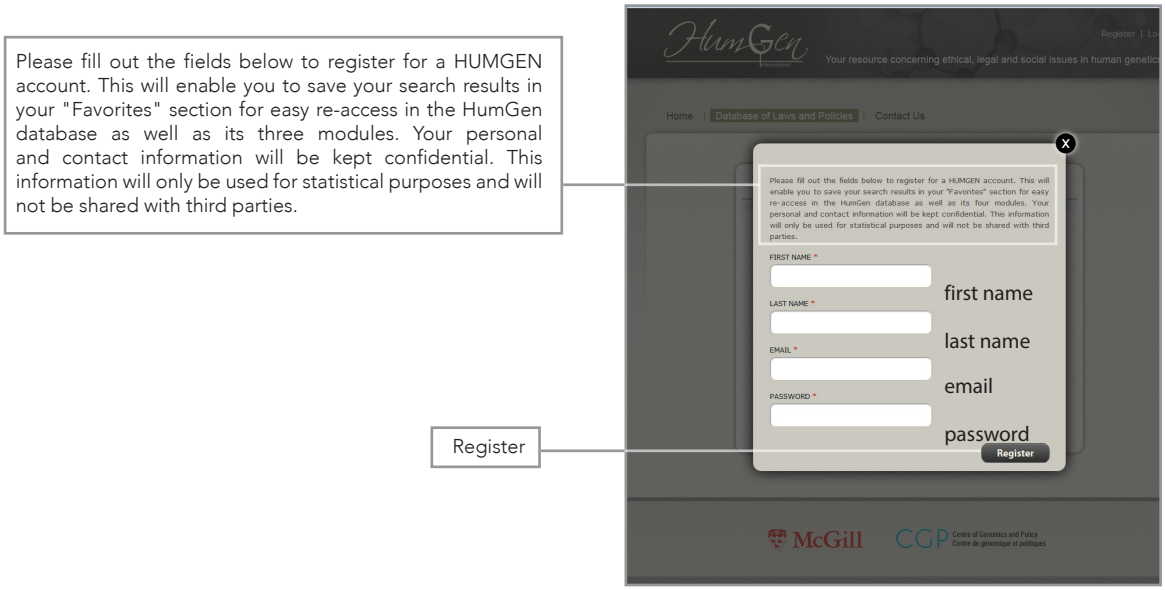
In 2012, the Centre for Genomics and Policy revamped its HumGen international database search engine to promote online access to information on laws, policies, and guidelines in human genetics research. Now, the HumGen can optimize searches through three modules in order to make it easier for users to conduct research into ethical, legal and social issues in human genetics, and to personalize the user's experience at the same time. The three modules are:



The new search engine has been redesigned to improve access to normative documents (laws, policies and guidelines), and word and phrase searches. Search results are displayed in subsections of international, regional, national, and provincial documents, giving a sense of socio geographical context to the findings. HumGen's new search functions make research easier to conduct and organize and allows researchers to better track international developments.



Registration is open. It enables users, to create and save a personalized favourites list. This function is useful for when users want to bookmark especially interesting results, or when you want to return to certain documents at a later date. The list is your creation within the site; indeed, the HumGen experience for the registered user has been personalized in several respects.



It is also easy to personalize the HumGen experience by sharing findings with colleagues and friends. Click the "share" button at the bottom of a search result to send a link to the document. A useful tool for study as well as for informal reading, the share feature is another aspect of HumGen's evolving role in ELSI research.

HumGen has been built to serve multiple audiences. The search engine is a streamlined research tool for researchers, professionals, policymakers, and students alike. We hope the new HumGen search engine will assist researchers in exploring the world of legislation and policy in human genetics research.

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