Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

# Institute of Genetics

## STRATEGIC PLAN
2004-2009

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

Canada

Institute of Genetics
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# Profile of the Institute of Genetics

The Canadian Institutes for Health Research (CIHR) was established in June 2000 to "excel in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system". Most notably, CIHR has a broader mandate than its predecessor, the Medical Research Council of Canada (MRC). This mandate embraces all forms of health research, from the study of molecules, to research on health policy and populations. In addition, CIHR has been charged with the responsibility of examining social, ethical and legal issues related to health, a responsibility that is particularly acute with the technical possibilities of modern biology (including genomics, cell biology, stem cell research and cloning). Knowledge translation is also a major component of the mandate of CIHR, a component that will assure that the Canadian population receives the benefit from its investment in health research.

CIHR's mandate and structure are unique in the world. CIHR is structured around 13 Institutes that each support research in biomedical, clinical, health systems and services and population health. The Institutes are based in universities or teaching hospitals across the country, but may also have staff located in a variety of other venues. The Institutes are part of a larger national research network that links researchers and other stakeholders across the country.

Established in December 2000, the Institute of Genetics (IG) is one of 13 Institutes of CIHR. The Institute is based at The Hospital for Sick Children in Toronto, the home institution of the inaugural Scientific Director, Dr. Roderick R. McInnes.

***OUR VISION*** *is to become the leading Canadian organization for the advocacy, development and support of all fields of genetic, basic biochemistry and cell biology research, maximizing the health opportunities offered by this knowledge to the benefit of Canadians and the global community.*

***OUR MANDATE*** *is to support research on the human and model genomes and on all aspects of genetics, basic biochemistry and cell biology related to health and disease, including the translation of knowledge into health policy and practice, and the societal implications of genetic discoveries (Figure 1).*

The Institute's Advisory Board (IAB) consists of 17 individuals with exceptional qualifications and demonstrated leadership - from Canada and abroad - under the guidance of the inaugural Chair, Dr. Joel Weiner, and the inaugural Vice-Chair, Dr. François Rousseau.

In the complex funding landscape of Canada, the IG has a special responsibility to support research in fundamental biomedical science. The increasing importance to health research of the basic disciplines of genetics, biochemistry, proteomics, cell biology and bioinformatics derives partly from the following forces:

- The unrelenting 'molecularization' of biology and medicine, a trend that is nevertheless complemented by the increasing power of integrative approaches, such as systems biology, to understanding cell function. These approaches have made biomedical research a holistic rather than just a reductionist or a "black box" science.
- The emergence of biology as an information science that is due largely to the Human Genome Project
- The potential, due to the genome project, to identify the genes and the genetic environmental interactions associated with common diseases.

## Emerging disciplines

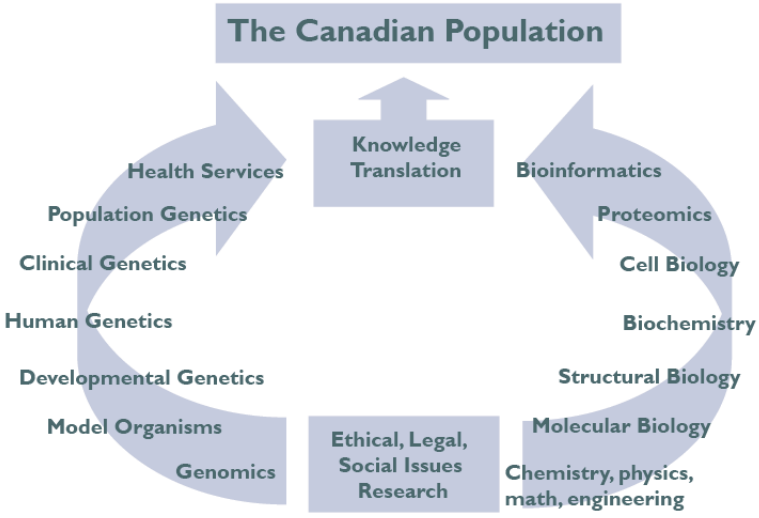
In addition to supporting established areas, the Institute recognizes that new fields of health research are continually emerging. Investigators working in these nascent, leading-edge fields will require the support of the Institute of Genetics in developing their programs and in bringing the significance of their work to the attention of other disciplines. The rapidly expanding science of bioinformatics, for example, has a central role in integrating the massive amount of new information flowing from the genome project into more established fields.

Research in mathematics, physics, chemistry and engineering is also of increasing relevance to biology and medicine, and the Institute will foster the integration of these scientists into health research. Finally, the ethical, legal and social issues that emanate from the science and medicine of genetics are of great importance to policy makers and to the public, as well as to the research community. These issues require special consideration in all of the activities supported by the Institute of Genetics.

## The importance of the Institute of Genetics to other CIHR Institutes

There is increasing recognition of the genetic contribution to virtually all disease processes, and therefore to health. Consequently, the study of genes and genetics is central to the well-being of all Canadians. The importance of genetics to all branches of health research therefore requires that the Institute facilitate and support the genetic, biochemical and cell biology research of the 12 other CIHR Institutes. In these diverse roles, the activities of the IG are of significance to the entire health research community.

**Figure 1.**
The major research communities aligned with the IG




*This figure highlights the importance of translating research knowledge to the Canadian population*

***OUR VALUES:***

- Research excellence
- Investigator-initiated and innovative research
- Partnership and collaboration
- Grassroots involvement and inclusiveness
- Public engagement and responsiveness to diverse communities
- Recognition and leveraging of Canadian research strengths

# The Consultative Process: A Grassroots Approach

A variety of approaches were used to define the strategic directions of the IG for its initial 5-8 years. Most importantly, the Institute consulted nationally with researchers, academics, clinicians, policy makers, voluntary health organizations, government bodies, the private sector and other stakeholders with an interest in basic biochemistry, basic cell biology and genetics, including their societal implications. This process has led to the recognition that the IG is a "bottom-up" organization (Figure 2). By responding to the needs of individual investigators and other stakeholders, the Institute can ensure that its strategic goals and research priorities are consistent with the requirements of those who generate new knowledge and those who use it.

## Strategic Directions: Consulting with our Community

At its first meeting in March 2001, the Institute Advisory Board (IAB) gave the Institute initial direction by identifying several number of research areas of particular importance. In response, the IG organized five consultation workshops during 2001 that provided Institute stakeholders with forums in which they could collectively identify the research needs and opportunities in their areas of research.

The Scientific Director's extensive national consultations during the first year, including visits to over 15 universities and research institutions, also provided guidance for the priority-setting process, and forged essential links with the research community.

Through an iterative process of consultation, this national dialogue informed and refined the Institute's Draft Strategic Plan "Strategic Directions: Consulting with our Community", released in September 2002. This draft was then subject to further modifications at a

**Figure 2.**
Grassroots consultation process


Strategic Planning Retreat held in September 2002 (Aylmer, Quebec), and attended by approximately 60 leading researchers, academics, government and scientific policy makers in the genetics, biochemistry, cell biology and social science research communities. The following six research priority themes have emerged from the grassroots consultation process and have been adopted by the IAB:

- Integrating the Physical and Applied Sciences into Health Research
- Proteomics and Bioinformatics
- From Genes to Genomic Medicine (including Clinical Genetics Research)
- Population Genetics, Genetic Epidemiology, and Complex Diseases
- Health Services for Genetic Diseases
- Genetics and Ethical, Legal and Social Issues

These Research Priority Themes were selected because each of these areas of research is considered to be of fundamental and increasing national importance, and because strategic funding is considered likely to have a significant impact in building on Canadian research strength, or in addressing a critical weakness. The designation of these Research Priorities will direct greater resources for training and research to these fields of investigation.

The Research Priority Themes *From Genes to Genomic Medicine* and *Proteomics* build on the established strengths in Canada in human molecular genetics and proteomics research. Others, such as *Clinical Genetics Research* and *Health Services for Genetic Diseases*, exemplify areas where there is a great need to enhance Canadian research in the discipline. In these nascent fields of research, where the existing community is often small and inexperienced, it will be the goal of the Institute to support the research community to the point where they can be successful in the CIHR Open Competition. The choice of other Research Priorities, including *Population Genetics, Genetic Epidemiology, and Complex Diseases,* and of both *Genetics and Ethical, Legal and Social Issues*, as well as *Bioinformatics*, recognizes the presence in Canada of relatively small but internationally respected cohorts of Canadian researchers in each of these fields. The efforts and expertise of these leaders will provide the foundation for increasing Canada's capacity and impact in these critically important disciplines.

By definition, the Research Priority Themes are not permanent. Rather, the Institute will continue to evaluate these Themes, and the scope of strategic initiatives within them, in consultation with the research community, partners (particularly other CIHR Institutes and national funding agencies), and other stakeholders. The Institute will change or modify its strategic directions over the years, in response to the ever-changing international research landscape.

Each Research Priority Theme is examined at greater length in subsequent sections of this Strategic Plan.

## Strengths, Opportunities & Challenges

During the strategic planning process, the research community identified strengths, opportunities and challenges that will influence the strategic directions of the Institute:

*Strengths*

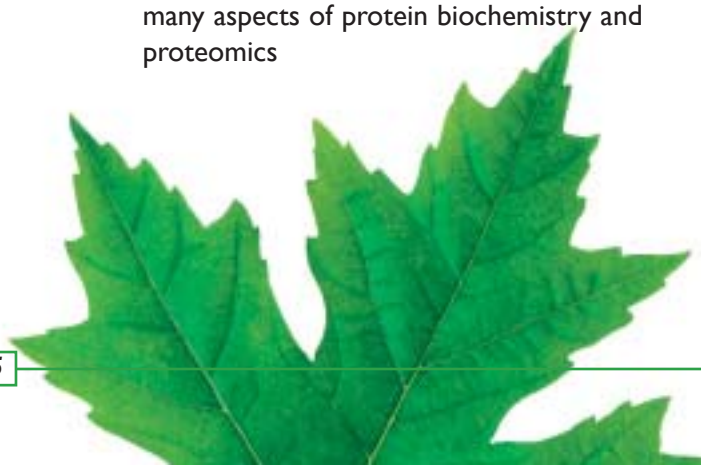
- International recognition in basic genetics, disease gene research and developmental biology
- Highly committed and accomplished biochemistry and cell biology research communities
- Leading research in proteomics, particularly in structural biology, protein function discovery, protein-protein interactions and the analysis of protein complexes
- A health care system conducive to collaboration, and to clinical and population research
- A small but internationally influential community of researchers concerned with the ethical, legal and social implications of genetics research

*Opportunities*

- The potential for partnerships with Voluntary Health Organizations and other agencies
- The ability to form partnerships with other CIHR Institutes
- A national mandate that will facilitate the development of national and international collaborations
- The potential to capitalize on areas of research where Canada is strong, including disease gene discovery and many aspects of protein biochemistry and proteomics

*Challenges*

- Managing the expectations of the research community that were generated by the founding of CIHR
- Winning the confidence of the research community aligned with the Institute by facilitating investigator-initiated research, while also sponsoring strategic research in the priority areas identified by the community and the IAB
- Developing strong, long-term relationships with partners, such as the National Research Council (NRC), the Natural Sciences and Engineering Research Council (NSERC) and Genome Canada, whose mandates overlap with the IG
- Expediting the work both of large health charities (such as the Heart and Stroke Foundation) and of smaller organizations focused on a single disease or group of disorders (such as the Cystic Fibrosis Foundation of Canada)
- Balancing the agenda of the Institute with the need to support the genetics, biochemistry and cell biology research activities of the other CIHR Institutes
- Effectively translating discoveries in the research areas of the IG into improved health services, and ultimately into better health for Canadians
- Advancing the knowledge and treatment of both single gene as well as genetically complex diseases
- Addressing the array of ethical, legal and social issues associated with genetics (GELS issues)



# Strategic Goals

Four strategic goals will guide the activities of the Institute of Genetics in the coming years, as indicated:

- Supporting individual investigators and strengthening the IG research community
- Advancing research and building capacity in areas of strategic priority
- Establishing Strategic Partnerships
- Facilitating the knowledge transfer of genetic and biochemistry discoveries, and the examination of their ethical, legal and social implications

## 1 Supporting individual investigators and strengthening the IG research community

The IG bears a special responsibility to support the work of individual investigators and research communities in the fundamental biological and biomedical sciences, and of researchers investigating social, legal and ethical issues related to genetics.

*Supporting individual investigators*

Throughout the consultation process, there was a consistent request that the Institute provide clear and unwavering support for investigator-initiated research. The IG research community is looking for the Institute's support of their work through the CIHR Open Operating Grants Program. The expected support includes advocacy for adequate funding, access to essential infrastructure and a range of funding programs to seed and strengthen the CIHR Open Competition.

In addition, the IG has developed a suite of **Regular Funding Programs** (continuous launch cycle) that are a constant feature in the IG research funding landscape (Figure 3).

**Figure 3.**
Our Regular Funding Programs:

- Career Transition Awards
- Clinical Investigatorship Awards
- Drs. Walter and Jessie Boyd & Charles Scriver MD/PhD Studentship Awards
- Invention and Technology Application Grants: Tools, Techniques and Devices for Research and Medicine
- New Discoveries: High-Risk, High-Benefit Grants
- One-Year Bridging Operating Grants
- Short-Term Research Visit Grants
- Workshop Support Grants

*Subject to an annual review by the Institute Advisory Board, these programs are designed to facilitate training and/or research within the IG Research Community.*

*Actions*

- Advocate increased funding for investigator initiated research
- Improve the effectiveness of the peer review process
- Facilitate efforts to improve the access of researchers to critical core facilities
- Where appropriate, fund excellent operating grants that were not funded through the CIHR Open Competition
- Promote and ensure access to critical national research infrastructures

*Strengthening the IG research community*

To fulfill its mandate, the Institute must work with its constituent communities to facilitate the development of their areas of research.

*Actions*

- Sponsor workshops and meetings that facilitate peer networking and mentorship
- Support initiatives that involve mentorship of new researchers and establish networks of collaborations and support

- Facilitate and support the establishment of national networks of researchers
- Increase the Canadian contribution and visibility in international initiatives in health research
- Improve opportunities for Canadian researchers to participate in international research collaborations, including providing support for establishing collaboration and developing proposals
- Develop, support and sustain new national platforms and initiatives for health researchers.

## 2 Advancing research and building capacity in areas of strategic priority

The Institute must facilitate the research of all members of its research community, and continue to support our strong research communities in the basic sciences of genetics, biochemistry and cell biology. In addition, however, the Institute must also maintain its strategic focus and concentrate funding in its areas of research priority. An essential part of this process is to build researcher capacity in those Research Priority Areas in which the training of additional investigators is deemed to be critical.

*Actions*

- Formulate strategies to increase the number of investigators in the identified areas of need
- Increase and retain the number of outstanding new investigators in Canada
- Facilitate the recruitment of outstanding researchers to Canada from abroad
- Support existing and new training and career development programs
- Develop effective mechanisms to attract researchers from diverse disciplines to health research

## 3 Establishing Strategic Partnerships

The broad research mandate of the Institute, together with the importance of disseminating new knowledge that emanates from this research, underscores the requirement for the Institute to build multiple and effective partnerships. The Institute will identify and facilitate partnership opportunities with health research stakeholders whose interests align with the vision, mandate and strategic goals of the Institute, to the mutual benefit of all parties.

While partnerships provide additional financial resources for research, they are also critical to the Institute for other reasons. A key tenet of creating partnerships is to engage stakeholders at early stages of our activities, to allow the Institute to develop research programs that align with the interests of the stakeholder as well as the Institute. Early engagement facilitates more effective knowledge transfer and exchange - including the sharing of best practices. Partnership activities create synergies, eliminate redundancies in research activities and funding, and lead to a more effective use of resources. At the international level, the Institute will collaborate with international colleagues to build on the strengths of Canadian researchers, thereby complementing our expertise with that of other countries.

*Actions*

- Identify and facilitate collaborative opportunities between the Institute and key health research stakeholders at the national and international level, in accordance with the research priorities of the Institute
- Build on synergies with other CIHR Institutes, related Networks of Centres of Excellence, Genome Canada, Natural Sciences and Engineering Research Council (NSERC), The National Research Council (NRC) and international partners to further basic, translational and social science and legal studies related to genetics, world-wide

*Voluntary Health Organizations*

The IG Voluntary Health Organizations (VHO) Working Group is a critical link between the Institute and the VHO community in Canada. The members of the working group inform and advance the IG research agenda and advise the Institute, and through it, CIHR, of their own research objectives. This Working Group is essential in assuring that CIHR facilitates the work of these national organizations.

*Actions*

- Explore collaborative models and stimulate shared initiatives with VHO partners
- Promote public engagement in the work of CIHR through this influential group of stakeholders

## 4 Facilitating the knowledge transfer of genetic and biochemistry discoveries, and the examination of their ethical, legal and social implications

One of CIHR's principal obligations is to accelerate "the discovery of cures and treatments and improvements to health care, prevention and wellness strategies." The ever-accelerating generation of new genetic and basic biomedical knowledge, which is relevant to virtually all areas of medicine, has created a remarkable challenge in knowledge translation. In addition, the appetite for information on molecular medicine and genetics has exploded in both the public and scientific communities. The Institute of Genetics recognizes the enormous disparity between extant and expanding knowledge in genetics and the biomedical sciences, and the highly imperfect level of awareness of this knowledge and its applications.

Accordingly, a primary objective of the Institute is to promote knowledge translation and exchange that will help the public and health services providers to fully appreciate the benefits of a strong national investment in health research. The Institute of Genetics and its research community must facilitate the transfer of new knowledge to researchers in other disciplines, to physicians and other health care givers, and to policy makers, governments and the public.

For the public sector, knowledge transfer of the findings of health research constitutes the foundation for the fair allocation of financial and human resources for health care. Without a full appreciation of the substance and significance of this new knowledge, no government can make informed decisions on the future of health care.

The scope and breadth of the Institute mandate, and the need to reach out to a diverse group of stakeholders, including the public as well as policy makers, requires a multifaceted knowledge translation strategy for the Institute and for the CIHR.

*Actions*

- Promote knowledge translation and exchange between researchers, physicians, health services providers, policy makers, governments and the public
- Increase public awareness and education of genetic issues and address the gap between the growing knowledge in the field of human genetics and public understanding of genetics
- Communicate the benefits of genetic and health research to Canadian society
- Where applicable, incorporate knowledge translation activities as a core criterion for strategic research initiatives
- Collaborate with the CIHR Knowledge Translation Portfolio to develop knowledge translation of genetic and basic biomedical information
- Engage youth in health research

# Research Priority Themes

The identification, confirmation and constant reassessment of its six Research Priority Themes are major responsibilities of the Institute. They are:

- Integrating the Physical and Applied Sciences into Health Research
- Proteomics and Bioinformatics
- From Genes to Genomic Medicine (including Clinical Genetics Research)
- Population Genetics, Genetic Epidemiology, and Complex Diseases
- Health Services for Genetic Diseases
- Genetics and Ethical, Legal and Social Issues

## 1 Integrating the Physical and Applied Sciences into Health Research

It is becoming quite evident that many of the significant findings in health research have been - and continue to be - greatly influenced by advances in the physical and applied sciences. For example, advances in proteomics and genomics have benefited greatly from engineering initiatives in nanotechnology, robotics, imaging technologies and surface chemistry. Similarly, there is ample evidence that many of the new directions in the physical and applied sciences had their start in the biological and biomedical fields. Examples of the latter can be found in recent research initiatives in biomaterials ranging from new adhesives through new peptide-based gel materials for drug delivery.

*Actions*

- Facilitate collaboration and integration of health research with the physical and applied sciences
- Foster research at the interface of health research, physics, chemistry and engineering
- Encourage the public and private sectors to increase their support of this research priority
- Actively promote interdisciplinary research

## 2 Proteomics and Bioinformatics

Two Priority and Planning (P&P) Committees, one for Proteomics and the other for Bioinformatics, will guide the Institute in defining the strategic goals of this important theme.

*Proteomics*

The IG recognizes that medical research is increasingly shifting from the process of gene discovery to an emphasis on the molecular nature of protein structure and function on the genomic scale. This field, called "proteomics", studies the proteome (the complete protein complement of a given genome). Presently, the research community is in a position to capitalize on applications of existing proteomics technology where Canada has strength: structural proteomics, protein function discovery, protein-protein interactions and analysis of protein complexes. The emerging area of proteomics research is the integration of proteomics into a "global view" of cell structure and function (e.g., sub-cellular localization of individual proteins, on the proteome scale). Integration with other disciplines, including bioinformatics, chemistry, physics and engineering, is crucial to the success of proteomics research. We can also anticipate an increasing use of proteomics tools in clinical laboratory medicine.

*Actions*

- Increase the capacity of the Canadian proteomics research community
- Support and facilitate community building and networking activities for the Canadian proteomics community
- Support the development of novel enabling technologies and integrative, collaborative approaches in proteomics
- Coordinate major proteomics efforts nationally and internationally, with partners and stakeholders

*Bioinformatics*

In its broadest sense, bioinformatics is concerned with the application of computational approaches to the solution of biological problems. This field includes DNA and RNA protein sequence analysis, data mining, molecular evolution, *in silico* simulations of cellular signaling and metabolic networks, computational molecular and structural biology, and the analysis of high throughput data arising from DNA and protein large scale analysis. A multidisciplinary science, bioinformatics lies at the intersection of computational, molecular and structural biology. It is therefore concerned with the development of methods for the acquisition, manipulation and analysis of biological data, as well as for testing research hypotheses that will ultimately result in biological and medical discoveries. Canada, with its strengths in mathematics, computer sciences and biological and health sciences is well positioned to be a leader in this new and emerging discipline. The Human Genome Project and other recent discoveries have transformed biology into an information science. This transformation has created a tremendous international demand for bioinformaticians.

*Actions*

- Increase the capacity of the Canadian bioinformatics research community
- Support the Canadian Bioinformatics Workshops
- Promote integrative programs linking diverse disciplines with bioinformatics and health research
- Support and facilitate community-building and networking activities

## 3 From Genes to Genomic Medicine (including Clinical Genetics Research)

The overall goal of this Research Priority Theme is to foster research leading to the clinical application of genetic discoveries. It will be directly aligned with CIHR's strategic objective of "stimulating research activities that accelerate the translation of research into action". The challenging, complex, multi-step process leading from basic research discoveries to their ultimate integration into clinical practice will require the active participation and collaboration of many research disciplines and partners. To facilitate this process, the Institute will support research that bridges clinical and more basic research expertise. Canadian clinical investigators work within a publicly-funded health care system that confers important advantages compared to researchers in many other countries. The prevalent culture favors collaboration, as well as clinical and population research. In addition, the community of GELS researchers will enable clinical investigators to observe and address ethical issues related to clinical research.

*Actions*

- Establish research priorities related to the burden of disease in the Canadian population
- Support research leading to better understanding of the pathogenesis of disease, including research on model organisms
- Support research on development of new genetic approaches to therapies, including novel methodological advancements
- Strengthen support for intervention research and clinical trials with potential to directly affect quality of care and the effectiveness of the health care system

*Clinical Genetics Research*

The support of clinical genetics research is an integral component of this research theme. Apart from a small number of outstanding individuals, clinical genetics research is an underdeveloped area in Canada - a weak link in the translation of new discoveries to the clinic.

The demand for clinical genetics researchers is substantial and increasing. This demand is driven by a number of factors, including the identification of the genes associated with single gene diseases, the development of treatment for these individually rare disorders, and the increasing relevance of genetics to the diagnosis and management of patients in all areas of medicine, particularly the genetically complex common diseases. Moreover, the increasing importance of novel molecular therapies requires their evaluation in well-designed clinical trials.

Despite the exciting potential of laboratory research for clinical applications, several major factors impair the translation of knowledge from the lab to the clinical population. These factors include the limited number of clinical investigators, the failure to provide them with mentors and defined career paths, the weakness or absence of local peer groups, and the near-absence of adequate and stable platforms and infrastructures for their research. Moreover, the research interests of many clinical geneticists become overwhelmed by the ever-present demands of the clinic. One major goal of this Theme, therefore, is to identify remedies for these rate-limiting factors, and to enact strategies and provide platforms that will introduce the structural changes required to make Canada a leader in clinical genetics research.

*Actions*

- Increase the capacity of the Canadian clinical genetics research community, by formulating training, cross-training and career development opportunities for clinical investigators as well as investigators from non-clinical disciplines
- Facilitate collaborative research and networking activities among the clinical genetics and developmental biology communities in Canada and abroad
- Enhance collaboration and partnerships with Voluntary Health Organizations, professional associations and government organizations
- Facilitate knowledge transfer to the public and among clinical genetics disciplines

## 4 Population Genetics, Genetic Epidemiology, and Complex Diseases

The Human Genome Project, together with advances in other fields such as population genetics and genetic epidemiology, has made it feasible for researchers to begin to elucidate the genetic contribution to common diseases, which are genetically complex. Consequently, this priority will remain a predominant long-term research theme of the Institute of Genetics. The impact of genetics on most diseases is due to variant forms of genes (predisposing alleles) that confer on the carrier an increased risk of acquiring the disorder. Whether the condition actually develops depends on the presence of other factors, particularly environmental exposures. Consequently, identification of the risk alleles of complex diseases requires both the genetic analysis of populations and of their environments. Since the identification of the causes of the common diseases is of great importance to the core objectives of all CIHR Institutes, this strategic priority is of interest to the entire CIHR community. The opportunities and challenges in this area for the next 5 to 10 years include the development of conceptual and methodological foundations, the design and methodology for large scale population-based approaches, and the integration of diverse research communities. Further challenges relate to building investigator capacity and addressing the shortage of practitioners and methodologists with knowledge and experience in more

*Actions*

- Increase the number of genetic epidemiologists, population geneticists and researchers in allied fields
- Foster research on genetically complex diseases, including the development of the conceptual and methodological foundations for large scale population-based studies
- Develop ethical and legal guidelines for research involving population groups
- Establish partnerships and alliances with Canadian and international agencies to facilitate research within this theme

## 5 Health Services for Genetic Diseases

The explosion in our understanding of the genetic contribution to both monogenic and genetically complex diseases requires a corresponding increase in our efforts to deliver this new knowledge to the Canadian population. For example, we must determine how new knowledge about disease genes is best transferred to health care givers, to patients and to their families. Our increased knowledge of genetics requires that we determine which genetic tests should be offered, given economic realities. We must also learn how to evaluate the efficacy and impact of the transfer of knowledge about genetic disease, so that policy makers and governments can make informed decisions about the delivery of health services for genetic diseases.

*Actions*

- Build collaborations between researchers in genetics and health services at the national and international level
- Foster interactions between stakeholders, particularly between policy makers, voluntary health organizations, researchers, clinicians and genetic counselors, to enable them to collectively develop common strategies to address issues arising from the generation and translation of new knowledge
- Fund research that will develop - and evaluate the utility of - decision frameworks and tools that can be used by policy-makers (in the absence of rigorous assessments of evidence on costs and outcomes) to make decisions on issues such as which genetic health services should be provided, by whom, in what settings, and how they should be financed.
- Strengthen the health care system and promote health by fostering mechanisms that will integrate information regarding effective genetic products and services into clinical practice

## 6 Genetics and Ethical, Legal and Social Issues

The impact of genetics is evident at many levels of our society.The ethical, legal and social issues related to genetics will play a critical role in the way humanity perceives itself and will influence the way in which research is performed. Although Canada has many internationally respected leaders in GELS research, the rapid emergence of numerous, novel GELS issues requires that the number of researchers working in this area be greatly expanded; thus, research training in this area is a constant focus of our Institute.

*Actions:*

- Increase the number of researchers interested in the ethical, legal and societal impacts of genetics
- Facilitate the training and development of Canadians conducting research into the ethical, legal and social issues associated with genetics
- Foster interedisciplinary communication through workshops and conferences, and research partnership among the GELS and biomedical research communities
- Explore and develop knowledge transfer strategies customized for the dissemination of GELS research findings to target audiences in other professional disciplines and to the public at large

# Organizational Structure

The development and the constant re-evaluation of the Institute's national health research agenda are processes carried out by the Scientific Director, the Institute Advisory Board, the 12 Planning and Priority Committees and the Voluntary Health Organizations Working Group of the Institute, and the IG Staff.

*Institute Advisory Board (IAB)* members provide critical advice on the development and implementation of the research priorities of the Institute. In addition, on behalf of the research community and CIHR, the IAB exercises a fiduciary responsibility with respect to the affairs of the Institute. IAB members also often participate in the activities of P&P and other Committees. The IAB meets at least twice a year to discuss and review all the activities of the Institute.

*Priority and Planning (P&P) Committees* provide a mechanism through which members of the extended research community can advise the Scientific Director and the IAB on strategic initiatives - in their specific domain of research - that should be undertaken by the Institute. The P&P Committees (Figure 3) foster the development of their research communities; provide a forum for the identification of critical issues and opportunities; and facilitate input from and dialogue with their research communities and the users of their research, including, in some instances, patient groups.

Through the P&P committees, over 100 leading researchers and other committed stakeholders are engaged on a regular basis in informing and advancing the strategic research agenda of the Institute. Each P&P Committee is led or co-led by a distinguished Canadian scientist(s) with experience and strong commitment to advancing research in a specific area. The membership of the P&P Committees is diverse and multidisciplinary, and includes basic science researchers, clinicians, investigators in population and public health, and researchers from the humanities who focus on ethical, legal and social issues.

**Figure 4.**
Priority & Planning Committees and Working Group of the IG


*The leadership of the Institute of Genetics is widely distributed across Canada. The blue circles indicate P&P Committees that support the IG Research Priority Themes. The white circles indicate P&P Committees that support the IG Enabling Strategies.*

# Management and Evaluation

The staff of the Institute is responsible for the implementation of the Strategic Plan under the guidance and direction of the Scientific Director and Institute Advisory Board. The Strategic Plan and the Research Priority Themes will be reevaluated on a regular basis, to best reflect changing research needs and emerging priorities.

The Institute will be evaluated in accordance with the CIHR document - "A Performance Measurement Framework for the Canadian Institutes of Health Research". The Institute of Genetics will measure and report on the effectiveness and impact of all programs that it has developed, and on other activities undertaken by the Institute, based on the outcomes indicated in this document. These outcomes include:

- Outstanding Research
- Outstanding Researchers in Innovative Research Environments
- Partnerships and Public Engagement
- Translation and Use of Knowledge
- Organizational Excellence


# Financial Resources

CIHR is funded entirely through federal government appropriations. The CIHR Governing Council delegates financial authority to each Institute for managing a portion of these funds, described below:

### Funds for Institute Strategic Initiatives

These funds comprise the great majority of Institute funds, and are used to support strategic research initiatives, through peer-reviewed grants and personnel awards.

### Institute Support Grant

Each Institute receives $1 million annually to operate and to develop the research communities that it represents, through an array of collaborative activities including workshops and national meetings.

# Conclusions and Next Steps

The development of the IG Strategic Plan has been a comprehensive and national process, involving extensive consultation with members of the IG-related scientific community and key stakeholders with a shared interest and passion for genetic, biochemistry and cell biology research, and research on the social, legal and ethical issues related to genetics.

The Strategic Plan provides a framework to advance the mandate of the Institute. It has been designed to provide a clear vision and sufficient direction for its highly dispersed and independent community, while being flexible enough to respond effectively to the many opportunities and challenges that may present themselves to the Institute over the next five years.

# ACKNOWLEDGEMENTS

I would like to thank the many Canadian research leaders who have contributed so much time and effort to the development of this Strategic Plan, in particular the Institute Advisory Board members, the Chairs of the 12 Priority and Planning Committees of the Institute of Genetics, and the Voluntary Health Organizations Working Group. In addition, I am greatly indebted to the staff of the Institute for bringing this document to life. Stephanie Robertson, the Institute Assistant Director in Ottawa, and Amanda Devost, the Institute Project Officer, were responsible for the coordination of this document, and together with Milka Popov, the Assistant Director in Toronto, and Jennifer Jennings, the Executive Assistant and Project Manager, they have produced what I believe to be an excellent road map for the Institute for the next few years.

# CONTACT

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