6. EDUCATION AND AWARENESS

Until genetic knowledge and technologies are appropriately integrated into our health care systems, Canadians will not fully achieve the related benefits in disease prevention and treatment. To better realize the benefits of genetic technologies and to avoid their misuse, the Canadian public, health care professionals, and health policy makers need to become more aware of what the technologies and services can (and cannot) accomplish. This awareness should be anchored in solid scientific education and nurtured through full and open discussion of the issues.

Canadians need to become more aware of the potential of genetic technologies and services.

The education of most adult Canadians has not prepared us to deal with the issues that affect our health and our health care systems. Although Canadians generally have a high interest in health issues, most of us lack fundamental knowledge in biology and the health sciences, and we have little understanding of the biological mechanisms that affect personal health and the specific factors that place it at risk. Instead, we depend on information and direction from health care providers. Our ignorance does not confer bliss. On the one hand, we have an unrealistic expectation of what curative medical technologies can accomplish; on the other hand, we are resentful of surrendering control to high-technology health care that is seen as growing increasingly impersonal.

Most Canadians lack fundamental general knowledge in biology and the health sciences.

Individual Canadians need to acquire the basic knowledge necessary for them to play a greater role in understanding and managing their health and to participate in the debate on future directions for their health care systems. Only then can the users and the providers of health care become full partners. To achieve this, there is a critical need for better public education about health and health care. A knowledge of genetics and human diversity is increasingly a necessary part of understanding the determinants of health.

Individual Canadians should play a greater part in understanding and managing their health.

To address genetic issues adequately, the education process has to begin in elementary school and be carried on through our secondary schools, universities, and education programs for health care professionals. But education is a lifelong process and must also reach those in the general public and health care community who have already completed their formal schooling.

The education process must begin in the elementary grades and continue throughout life.

Elementary and Secondary Education

All Canadians should leave the public school system with a basic understanding of the important human biology (including genetic), environmental, lifestyle, and health care factors that affect health. This knowledge would serve as a framework to help individuals maintain their own health, and to understand the changes in health sciences and technologies that will occur during their lives. At present, most Canadians do not leave the school system with this knowledge. This is part of a larger problem: the inadequacy of science education in Canada, which was the subject of an earlier Science Council report.[139]

The climate for science and health education is improving. The current trend in science education is toward practical applications of science and the role of science in the lives of citizens. Attention is now being focused on the social context of science, as well as on scientific information and skills.[140] The health and social applications of genetic science and technologies are a logical component of this approach.

The climate for health education is improving, but some problems remain.

Science and the associated health issues are usually not well integrated in our schools.

Some problems still remain in providing genetic information to students. Although modern research is breaking down the barriers between formerly distinct disciplines, science and associated health issues are usually not well integrated in our schools; biology and health, for instance, are frequently taught in separate courses. Often the connections are not made between scientific facts and principles, human health, health care technologies and applications, and related social issues.

In addition, there are problems in developing and delivering an effective curriculum.[141] The teaching of genetics can be considered in terms of:

Genetics can be considered in terms of the intended, planned, taught, and learned curricula.

- the *intended* curriculum, defined by the curriculum outlines prescribed by the provincial ministries of education;
- the *planned* curriculum, consisting of programs and lesson plans created at the school board, school, and teacher level;
- the *taught* curriculum, which is what the students actually experience through classroom discussions and workbooks; and
- the *learned* curriculum, which is defined by the students' intellectual and practical achievements.

The health and science curricula up to Grade 9 provide little material on human genetics.

At present, the health and science curricula up to Grade 9 provide little material on human genetics or on the relationship between genes and health. In the upper grades, revised biology curricula are starting to reflect advances in genetic science. However, by Grade 10 many students have dropped out of school or have opted not to take biology; less than a quarter in the 15- to 19-year age group enrol in biology courses.[142] Therefore, the majority of students receive little instruction on the role genes play in health and disease.

Genetic knowledge and related health issues are developing rapidly and are not adequately represented in older curricula.

Significant findings on the role of human genetics in health have not been incorporated into most provincial curriculum objectives or school board outlines. In theory, curriculum reviews are to be conducted every five to eight years. In practice, intervals of 15 years are more common. The oldest existing biology curriculum, in Saskatchewan, was developed in 1971 (it is currently under revision); the most recent, in Ontario, dates from 1987. Genetic knowledge and related health care issues are developing rapidly and are therefore not adequately represented in the older curricula.

The current curriculum outlines for advanced biology courses generally cover theoretical aspects of genetics such as Mendel's laws, mitosis, meiosis, protein synthesis, and DNA replication. Curricula rarely cover the concept of genetic susceptibility to disease, or applications of genetic knowledge such as screening and counselling, or the associated ethical and social issues. There are exceptions. The advanced biology curricula in Ontario and Manitoba are excellent, not simply on the basis of their scientific content but also in their consideration of health implications and applications. In both provinces the medical genetics community assisted in the development of the curriculum.

The scarcity of textbooks and other teaching aids for genetics is particularly a problem.

Even when the health implications of genetics appear in the curriculum outline, the topics may not be included in the planned and taught curriculum. Course preparation is hampered by a lack of suitable textbooks (especially Canadian textbooks) and teaching aids. The Canadian market for textbooks is small and therefore publishers are generally slow to respond to changes in knowledge and perspectives. It is possible that the new Ontario and Manitoba biology curricula will result in the publication of Canadian biology texts that effectively cover genetic issues. The scarcity of textbooks and other teaching

aids is particularly a problem because genetic knowledge and issues are relatively new and teachers are unlikely to have received related formal training.

Biology teachers indicate that they generally do not teach health and social issues associated with genetics because they lack the information and resources necessary to cover the topic.[143] However, the teachers are interested in the issues and there is also evidence of student interest.[144] It is noteworthy that some excellent courses are being delivered in areas where local medical genetics centres have provided resource materials and professional development programs for teachers. More contact between teachers and the medical genetics community would assist in integrating genetics into the planned and taught curriculum.[145]

Teachers generally lack the information and resources to cover the topic.

More interaction between teachers and the medical genetics community would help integrate genetics into the curriculum.

To reach all students, the teaching of the fundamentals of human biology, genetics, and health should begin in elementary school and be a part of the core curriculum in junior high school. Courses should integrate the science and health aspects of genetics; students should also be introduced to the social and ethical choices that health applications raise.[146]

Although education is a provincial responsibility, in this era of rapid scientific advances it would be inefficient and time-consuming for each province to upgrade its curriculum on its own. Educators and students would both benefit if a national clearing house or agency, such as the National Association for School Health, were charged with providing up-to-date course outlines on biology and health that could be adapted by the individual provinces. Final responsibility for the curriculum would remain with the province, but the clearing house could serve as a resource, obtaining advice from the relevant health experts in developing the different units, producing teaching aids, and offering teaching clinics. The Canadian College of Medical Geneticists could provide ongoing curriculum advice to the clearing house.

A national clearing house or agency could provide provinces with course outlines and teaching aids.

University

Exposure to molecular biology and human genetics concepts at the undergraduate level could influence more science graduates to choose a related career or research specialty. Such exposure could also have direct applications for future health care workers, science teachers, and biotechnology entrepreneurs.

Exposure to human genetics at the undergraduate level would enhance the general knowledge of all science graduates.

General biology and molecular biology courses should provide information on the growing knowledge about, and technologies associated with, the mapping of the genome and the links between specific genes and diseases. Undergraduate biology programs should also introduce students both to the industrial and entrepreneurial opportunities associated with biology, and to the related social issues. To help achieve these goals, each biology department chairperson should undertake a curriculum review, and adjust the curriculum as needed.

Biology department chairpersons should review undergraduate curricula and make appropriate adjustments.

Public Education

Canadians would benefit from up-to-date information on health care issues relevant to their own personal well-being; they need information to improve their understanding of the social and technical issues surrounding Canadian

An informed public is necessary to ensure appropriate policies.

health care systems in general and genetic health care technologies and services in particular. In a democratic society, an informed public is essential for appropriate and effective decision making. The basic scientific literacy established through the formal education system must be supplemented and updated throughout life.

There are a number of ways to improve public awareness of health issues. These take advantage of the abilities and resources of government agencies, special interest groups, and the media.

For example, the *Ask Your Family Tree* readers' guide and workbook is a government-sponsored self-help health guide.[147] Its objective is to identify disorders for which family members (current and future) may be at risk. The guide helps in the construction of a three-generation family health tree, and provides basic information on the concepts of genetic disease and some common genetic disorders. The guide also identifies sources for additional information.

Federal and provincial health departments and non-governmental organizations could expand their role in public education.

In general, however, the federal and provincial health departments could expand their role in public education. The departments have the resources and experience to deliver excellent public education programs.

Professional and special interest groups such as the Canadian Medical Association, the Canadian College of Medical Geneticists, and various disease-specific associations also have important messages to deliver on the issues surrounding genetic knowledge and technologies. These organizations are making a valuable contribution by providing information needed for informed public debate.

Scientific literacy in Canada is poor.

There is still room to strengthen communications. Scientific literacy in Canada, as in Great Britain and the United States, is poor.[148] The Royal Society of Canada is addressing this problem by developing and promoting mechanisms for more effective communication of science and technology issues to the public.[149] Awareness of genetics-related issues would likely improve if provision of information to the public became a higher priority of the Canadian College of Medical Geneticists.

The public consistently expresses a strong interest in health care issues. The media provide coverage when information on genetic disease is packaged in an interesting and relevant manner, whether by government agencies, research institutes, scientists, or other experts in the field.

Health Care Professions

Until genetics is given a higher priority in the training of health care professionals, Canadians will not be able to reap all the benefits offered by the associated diagnostic and therapeutic techniques.

An understanding of the role of genetics in health is important to many health care fields.

An understanding of the importance of genetic predisposition to disease affects a range of health care fields including dentistry, dietetics, medicine, nursing, pharmacy, rehabilitation therapy, and social work. At present, genetics is poorly integrated into education in all these disciplines.[150] Provincial and national associations, accreditation bodies, and curriculum committees of the different health professions could address the problem by initiating a review of

the status of genetics education within their professional training with a view to modifying their training programs, objectives, and examinations as needed.

Education of Physicians

> We are now at a critical crossroads for the integration of human genetics teaching into medical school curricula.... Genetics is a core discipline in medicine that deals with human biological development and variation throughout the life cycle; hence, genetics is especially important in epidemiology and prevention of human disease. Molecular technology has provided human genetics with tools to begin to understand disease, within medical sub-specialties and across all age groups. As other fields begin to make use of this technology, human genetics can provide a central paradigm for the education of medical students.[151]

Genetics is not well integrated into medical education at all levels.

The applications of genetics to diagnosis, prevention, and treatment of a wide range of disorders are growing rapidly. However, many medical schools are not adequately preparing students to understand the revolution in human genetics that is affecting all areas of medicine. Although there are some promising signs of progress, genetic considerations are currently not well integrated into medical education at the undergraduate, specialty, or continuing education levels.[152]

A task force has identified a number of problems associated with teaching genetics in medical schools.

A 1985 survey of educators reported data from 119 of the 140 North American medical schools.[153] In 47 per cent of the schools, teaching of human genetics was assessed as nonexistent or poor. In 52 per cent of the schools, teaching of human genetics was the responsibility of the paediatrics department. The human genetics that was taught emphasized cytogenetics, Mendelian inheritance patterns, and clinical genetics. In many schools the basic science aspects of genetics were not covered at all; the gene was considered more as a heritable unit in a Mendelian sense than as a complex informational molecule. This perspective, although important, offers a limited view of genetics in health care and does not provide the necessary foundation for continuous, career-long learning.

A task force formed by the American Society of Human Genetics has examined and addressed the problems involved in teaching genetics in medical schools.[154] Some of their major findings appear in Box 24.

The challenge facing medical educators has not changed in more than a century — the overriding objective is still the preparation of competent and caring physicians. The central dilemma remains how to invest graduating physicians with a process for thinking about health and disease, instil a vast amount of factual knowledge, and prepare them for a lifetime of learning, all the while maintaining the humanity in medicine. The problem is aggravated today by tremendous growth in the factual material to be learned.

There are three components to incorporation of genetics into the curriculum.

Integration of medical genetics into the curriculum involves three approaches:

- as a basic science underlying all aspects of health and health care, with emphasis on the gene as a complex informational molecule;

Box 24
Teaching Genetics in North American Medical Schools

An American Society of Human Genetics task force found that the concepts of genetic disease and the benefits of genetic technologies have not been well integrated into undergraduate medical education. The task force noted:

- a lack of relevant teaching resources in many medical schools;
- a lack of vertical integration of human genetics teaching through all four years of medical school;
- a lack of a minimum core curriculum on human genetics;
- a need to teach students a genetic approach to thinking about clinical problems;
- a need for appropriate evaluation of the genetic knowledge of students;
- a need for an implementation strategy to improve teaching of human genetics.

There are several reasons why genetics has not been well integrated into medical education.

- The applications of genetic science are relatively new and still evolving.
- The importance of the new molecular biology knowledge and technologies in understanding and treating disease has not been adequately conveyed to the appropriate decision makers.
- Rapid advances in many other aspects of medical knowledge and technology are resulting in strong competition for curriculum content.
- In setting the curriculum and teaching, medical school faculty place priority on what they personally know to be important. Most faculty were educated before the current proliferation of genetic information.
- Health care educators with in-depth medical genetics training are rare.

- as a specific course on "medical genetics," with topics ranging from the basic science of genetics and the role of genetic variation in health and disease, to clinical medical genetics and ethical and legal issues;
- as an integral component of all other courses: biochemistry, cell biology, cardiology, neurology, and so forth.

In addition, the new medical technologies, including genetic technologies, are raising ethical dilemmas and concerns about misuse. The training in medical ethics that physicians receive should be designed to help them address the related issues in genetics.

Training in medical ethics should help physicians in addressing related issues in genetics.

The ultimate objective is to provide students with a broad conceptual framework regarding genetic mechanisms and applications and to instil a "genetic way of thinking." Medical education can involve different approaches including lectures, tutorials, formal courses, and training centred on case studies. The integration of genetics can be adapted to all these approaches.[155]

The objective is to instil a "genetic way of thinking."

Educators need help to keep up with progress in genetic knowledge. One development from which Canada may benefit is the program the American Society of Human Genetics (ASHG) has established, with Canadian input, to monitor and assist in improving the teaching of human genetics. The program will develop and provide educational resources, help to educate ASHG members in teaching methods, and encourage evaluation of human genetics education and learning.[156] The development of teaching aids is a priority: textbooks, monographs, slides, videos, and case studies for small group discussions are all required. Also considered a priority is a clearing house to provide information on the available resources.

The ASHG task force that reviewed medical education in North America concluded that the examination questions used to evaluate the genetic knowledge of medical students assessed a "primitive level of learning." The task force called for development of a bank of appropriate questions and answers.[157]

The growth in genetics knowledge also has implications for postgraduate medical education. Medical genetics has only recently been accepted as a freestanding specialty by the Royal College of Physicians and Surgeons of Canada. The new specialty training program should result in the availability of more providers of genetics-related health care and should heighten awareness of the importance of medical genetics among other health care professionals, resulting in a better integration of genetics into general health care delivery.

Medical genetics is now accepted as a freestanding specialty by the Royal College of Physicians and Surgeons.

As in undergraduate medical education, it is crucial that the role of genetics in medicine not be considered uniquely the territory of medical geneticists. A review of the Royal College's specialty objectives and examinations shows that genetic considerations are not well integrated into other relevant specialty programs.[158] Genetics questions on the specialty exams focus largely on the rare, classic disorders and their diagnosis. Generally, the exams do not reflect advances in genetic science and knowledge, or the relevance of genetics to common diseases and disease prevention. The integration of genetic considerations into the different specialty programs could be improved if each Royal College specialty committee consulted with a medical geneticist familiar with that specialty and then adjusted its objectives and examinations to reflect current genetic knowledge and relevant applications.

Integration of genetic considerations into other postgraduate specialty programs could be improved...

...family physicians in particular need to keep up to date.

It is also important that the College of Family Physicians of Canada integrate genetic knowledge and services into its objectives and examinations. Family physicians are the primary medical contact for most Canadians, and advances in genetics have significant clinical implications for their practices.

Genetics should be ranked as a higher priority in continuing medical education.

The rapid advances in medical knowledge and technologies are resulting in an ever-increasing need for continuing medical education. Maintaining physician competence is a growing priority to a variety of accreditation and licensing bodies. So far, medical genetics has not been identified as a primary area of interest by either the physicians seeking continuing education or the groups delivering the programs. This is probably because they do not fully appreciate the clinical relevance of genetic knowledge. Physicians are primarily interested in continuing education courses they see as having direct practical application to their practices.

Although awareness of the role of genes in disease is growing, our ability to use the related technologies as diagnostic or therapeutic tools is still limited. But the applications are increasing. The implications of the rapid growth in genetic information and technologies deserve to be made a higher priority in continuing medical education. As is the case at other levels of education, genetic knowledge and its applications should be included in the continuing education programs on different specialties and diseases rather than offered in separate genetics courses.

Strong liaison is needed between faculty members and the deans, chairs, and curriculum committees at Canadian medical schools.

Bringing about these changes and achieving full integration of human genetics into all aspects of medical education will require strong liaison between the medical genetics faculties and the deans, chairs, and curriculum committees of medical schools. The Canadian College of Medical Geneticists, the Association of Canadian Medical Colleges, and the American Society of Human Genetics also have valuable roles to play. They can help by identifying problems, recommending changes, and assisting in the development of curriculum objectives, teaching aids, and examination questions.

Genetics Associates

More training programs are needed to meet the demand for genetics associates.

Genetics associates are important members of the team required to deliver genetic health services efficiently. Although the need for trained genetics associates continues to grow, there is only one training program in Canada (at McGill University), and that program has fewer than 10 graduates each year. Canadian medical faculties and accredited genetic centres should consider offering additional training programs, and provincial governments should consider funding them.