AFTERWORD

This report documents the significance of genes to the health and ill health of Canadians and outlines some of the major issues, opportunities, and problems associated with the use of genetic knowledge and technology. The Science Council believes that existing genetic knowledge can and should be used to improve delivery of health care, and that the growing understanding of the role of genes in health and disease will profoundly affect disease prevention and treatment in the future.

Effective planning and action are required immediately to integrate genetics more thoroughly into current health care delivery. Planning is also needed to lead to future beneficial applications of genetic knowledge and technologies, and to avoid potential problems. The goals and initiatives presented in the first chapter of this report provide a framework upon which effective and ethical development and delivery of genetic services can proceed. It is up to each reader — as policy maker, planner, health provider, patient — to take the next steps. We must all take appropriate action to ensure that the Canadian health care system continues to evolve as a reflection of our caring society.

APPENDIX 1
Basic Genetic Facts: DNA, Genes, and Chromosomes

- The organization, structure, and function of cells are controlled by genetic material in the nucleus of cells. The genetic material consists of molecules of deoxyribonucleic acid (DNA), which serve as an encyclopedia of genetic information.

- The DNA molecules are made up of chains of nucleotides bound together in a double helix. The chains are made up of sequences of four nitrogen bases. The two strands of the DNA molecules are held together by weak bonds between the bases.

- In human beings DNA is organized into 23 pairs of chromosomes. One chromosome of each pair comes from the father and one from the mother. With the exception of the pair of sex chromosomes, the members of a chromosome pair are similar to each other in appearance and possess the same sequence of genes along their length.

- A gene is a specific stretch of the DNA molecule that codes information to translate into a specific protein. In human beings it is estimated that there are 50 000 to 100 000 genes located along the chromosomes.

- It is the specific linear sequence of nucleotides that provides the code of instructions for protein production. The number of nucleotide pairs in a gene can vary from 2000 to two million.

- Only 1 to 3 per cent of the DNA codes for proteins. The purpose of the remaining DNA is not well known, but other DNA functions include copying and transcribing genetic information, and turning genes on and off.

- The genetic message in the DNA is transferred from the nucleus to the cell protoplasm, where the protein is constructed. When the protein is formed, the gene message has been "expressed."

- An individual's full complement of DNA is referred to as his or her genome and is normally identical in the nucleus of every cell in the human body.

- In the process of sexual reproduction, the DNA divides and each parent contributes one-half the genetic complement of the offspring via the egg or sperm. The process of cell division provides ample opportunities for exchanges in the nucleotide sequences. These exchanges are one cause of mutations.

APPENDIX 2
Recombinant DNA Technologies

Recombinant DNA technologies are based on: cleavage of DNA into specific fragments; construction of recombinant DNA molecules; multiplication (cloning) of DNA; and separation and "visualization" of DNA fragments.

- Cleavage of DNA into specific fragments became possible with the discovery of restriction endonucleases, naturally occurring enzymes found in bacteria. The enzymes have the function of recognizing specific nucleotide sequences in the DNA molecule and cutting DNA at particular sites, resulting in fragments of different lengths. Each restriction enzyme, and over 400 have been identified to date, produces characteristic fragments. In addition, as a consequence of natural variations in DNA, specific fragments may vary in length between individuals. These different forms of the same fragment are called restriction fragment length polymorphisms (RFLPs).

- Different methods are available to separate an individual's DNA fragments prior to analysis. For example, because the fragments are of different lengths, a gel matrix and an electrical field (electrophoresis) can be used to generate characteristic patterns.

- Single-stranded DNA fragments, produced by cleaving DNA, can recombine when complementary fragment ends anneal through the process of base-pairing.

- Thousands (even millions) of copies of a specific fragment can be produced by inserting it into the DNA of unicellular organisms such as bacteria, viruses, or yeast, and then culturing the organism. An unlimited number of copies of specific small segments of DNA can also be made by polymerase chain reaction.

Recombinant DNA technologies have numerous applications in diagnosis of disease and carrier detection. The technologies can be used to analyse the DNA of an individual to determine whether a specific known mutation is present, or to locate and identify genes responsible for specific single-gene or multifactorial disorders. The technologies can also be used to develop libraries of cloned DNA fragments, and to aid in gene mapping and sequencing.

To analyse DNA for the presence of a known mutation involves the use of a probe. A probe is the specific DNA sequence of a known mutation that has been cloned, denatured (made single stranded), and labelled using radioactive material or biotin. Using the Southern Blotting method, single-stranded DNA fragments from the individual are separated by electrophoresis and transferred onto a nitrocellulose filter. Probe material is added and will hybridize (bind) with complementary DNA sequences on the filter. Probe DNA that does not bind can be washed away. The probe material permits "visualization" of the

probe-fragment hybrids. For example, an x-ray film placed over the filter will show darkened bands where DNA has hybridized with radioactively labelled probe material.

When the precise mutation causing a disease is not known, RFLP patterns can be used to compare the DNA of the individuals with the disease to that of individuals without disease. The gene causing the disease may be linked with a specific polymorphism. Finding such linkages will help localize the genes for specific diseases and can provide markers.

More detailed descriptions of the recombinant technologies and their applications can be found in the source documents provided below.

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APPENDIX 3
Genetic Screening Programs in Canada

Genetic screening programs are in place in all provinces and territories; they demonstrate that genetic knowledge and technology can be used, within Canadian health care systems, to prevent and treat disease.

Canada has been a pioneer in the development, evaluation, and delivery of genetic screening programs. For example, the Quebec health care system was the first in the world to offer screening for congenital hypothyroidism as a universal service.

Genetic screening serves three purposes:

1. early detection, diagnosis, and treatment of disease (the primary goal);
2. provision of reproductive options to individuals at risk for having children with serious genetic disorders;
3. clinical and epidemiological research.

Screening programs should be appropriately evaluated. Decisions to offer specific screening programs should be based on consideration of the incidence and health implications of the disorder, and the cost and effectiveness of both the screening program and follow-up treatments. All screening programs that become routine health care services in Canada are preceded by pilot studies to evaluate their effectiveness. Screening programs should be offered as part of a continuum of genetic services that includes diagnosis, counselling, and treatment.

The number of disorders for which screening programs are available is still small, but will likely grow in response to improvements both in the technology to screen for and diagnose genetic disorders, and in the options for effectively preventing and treating genetic disease.

The majority of screening programs currently offered in Canada are for newborns. In addition, there are a few programs targeted to specific populations at risk for certain serious recessive disorders to help identify adolescent or adult carriers.

At present there are no programs in Canada to screen for individuals with, or susceptible to, multifactorial diseases. Similarly, there are no workplace programs in place to screen potential employees for genetic susceptibility to disease, or to monitor employees for mutations or disease onset resulting from workplace exposures.

Neonatal Screening and Related Services

Neonatal screening programs are used primarily to assist in early diagnosis to enable early medical intervention and improved prognosis. The programs vary among provinces. The tables indicate neonatal screening programs in Canada, and the location of screening laboratories and follow-up centres. Tests for a number of other disorders are available but are not offered on a widespread basis because of doubts as to their benefits and cost effectiveness.

Adult/Adolescent Carrier Screening

These programs screen for carriers of single genes that when present in a double dose cause fatal diseases for which no successful treatments are currently available. The programs are often targeted to a specific community or population in response to high incidence of a disorder. Few such programs are in place in Canada. Well-established programs include screening for Tay-Sachs disease carriers in Toronto and Montreal, and for carriers of thalassaemia in Montreal.

Table 1
Neonatal Screening Programs by Province

Neonatal screening services are provided by the health ministries of the provinces and territories. Screening and follow-up for newborns in the Northwest Territories and Yukon is done in British Columbia, Alberta, Manitoba, and Quebec on the basis of proximity; the specific tests undertaken depend on which province does the screening. Participation in neonatal screening is voluntary; in all provinces and territories parents have an option to refuse.

	BC	Alta	Sask	Man	Ont	Que	NB	NS	PEI	Nfld
Blood Tests										
Phenylketonuria	■	■	■	■	■	■	■	■	■	■
Congenital hypothyroidism	■	■	■	■	■	■	■	■	■	■
Aminocidopathies[1]		■		■		■[2]				■
Galactosaemia	■			■						
Congenital adrenal hyperplasia				■						
Biotinidase deficiency	■[p]			■[p]						■[p]
Duchenne muscular dystrophy				■[p]						
Urine Tests										
Aminocidopathies (other than PKU)				■[3]		■[3]				
Neuroblastoma						■[p]				

1. Alberta, Manitoba, and Newfoundland do general screening based on blood amino acid chromatography. Amino acid disorders that can be detected include maple syrup urine disease, tyrosinaemias, and hypermethionaemias.
2. Quebec has developed and offers a screening program for tyrosinaemia 1, because of the relatively high incidence of the disorder, particularly in the Chicoutimi region.
3. Screening for methylmalonic aciduria is available to parents in Quebec and Manitoba. Parents are asked to send dried urine samples on filter paper when the infant is two to three weeks of age. In Quebec, 94 per cent of families with newborns have chosen to participate; in Manitoba the figure is 85 per cent.

p. pilot project

Table 2
Organization of Neonatal Screening Programs in Canada: Laboratories and Follow-up Centres

SCREENING LABORATORIES	FOLLOW-UP CENTRES
B.C. C.H. Wills Laboratory, B.C. Children's Hospital, Vancouver	VANCOUVER - B.C. Children's Hospital
ALBERTA University of Alberta Hospital, Edmonton	EDMONTON - University of Alberta Hospital CALGARY - Alberta Children's Hospital
SASKATCHEWAN Provincial Laboratory, Regina	SASKATOON - Alvin Buckwald Centre
MANITOBA Cadham Provincial Laboratory, Winnipeg	WINNIPEG - Health Sciences Centre, Children's Hospital
ONTARIO Special Laboratory Services Branch, Ministry of Health, Toronto	TORONTO - Hospital for Sick Children LONDON - War Memorial Children's Hospital KINGSTON - Queen's University HAMILTON - McMaster University Medical Centre OTTAWA - Children's Hospital of Eastern Ontario
QUEBEC Centre Hospitalier de l'Université Laval (Blood screening) Centre Hospitalier de l'Université de Sherbrooke (Urine screening)	QUEBEC - Centre Hospitalier de l'Université Laval SHERBROOKE - Centre Hospitalier de l'Université de Sherbrooke MONTREAL - McGill University & Montreal Children's Hospital MONTREAL - Hôpital Ste-Justine CHICOUTIMI - Hôpital de Chicoutimi
NEW BRUNSWICK St. John Regional Hospital, St. John	ST. JOHN - St. John Regional Hospital Not centralized in other areas
NOVA SCOTIA Biochem Labs, Izaak Walton Killam Hospital, Halifax (PKU) D.J. MacKenzie Labs, Victoria General Hospital, Halifax (CH)	HALIFAX - Izaak Walton Killam Hospital for Children
P.E.I. Izaak Walton Killam Hospital, Nova Scotia (PKU) Queen Elizabeth Hospital, Charlottetown (CH)	Follow-up is done in Nova Scotia.
NEWFOUNDLAND Janeway Child Health Centre, St. John's (PKU) Health Science Centre, St. John's (CH)	ST. JOHN'S - Janeway Child Health Centre
N.W.T. AND YUKON Screening and follow-up are done in nearest province (B.C., Alberta, Manitoba, or Quebec).	

CH = congenital hypothyroidism
PKU = phenylketonuria

Sources: P. Ferreira, "Current Canadian Newborn Screening Practices," *Paediatric Medicine Quarterly* 3, no. 4 (September 1989): 111-120;
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Table 1 was adapted, with minor variations, from the article by P. Ferreira.

APPENDIX 4

Recommendations on Prenatal Diagnosis and Genetic Screening, The Royal College of Physicians of London

1. Genetic screening and prenatal diagnosis services should be equally available to the whole community. They should be recognised as an intrinsic component of maternal and child health services.

Equity in health care

2. A policy advisory structure should be set up to facilitate decision making in the future.

Policy advisory structure

3. Although there is clear majority support for the principles of prenatal diagnosis, some serious ethical issues are involved. A professional code of practice governing genetic screening should be developed. It should be widely publicised to reassure the public that:

Code of practice

   a prenatal diagnosis will not be used for a positive eugenic policy;

   b prevention programmes will not detract from the appreciation of, and provision for, people with disabilities.

4. Resources should be made available:

Resources

   a to ensure equitable delivery of existing services;

   b to support the development, evaluation and early application of new approaches.

5. Professional training in medical genetics and the principles of genetic counselling should be provided for all maternal and child health workers (GPs, obstetricians, paediatricians, family planners, health visitors and midwives). Official contact should be made with the relevant professional bodies to develop the genetic component of the training curriculum and to organise updating courses for existing practitioners.

Professional training

6. Because of the large numbers involved, and the relative simplicity of some issues in large-scale screening programmes, genetic information and counselling must be provided at the community level. The ideal professionals to provide information and counselling would be specially trained health visitors and midwives, who are already the point of first and most frequent contact with mother and child. The suggestion is consistent with current proposals to train nurse specialists, who in this case would act as reference and training resources for MCH [maternal and child health care] workers in general.

Information and counselling

Specialist genetic counsellors

7. Specialist genetic counsellors already work with clinical geneticists and with specialists in particular disorders. Equivalent specialist counsellors should be attached to each obstetric unit practising prenatal diagnosis. It is urgent to define a career structure for such specialist counsellors, who may have differing professional backgrounds, and carry out a wide range of activities.

National organisation

8. a Policy formulation, defining a career structure for genetic counsellors, development and distribution of educational materials and service monitoring, should be organised at the national level.

Regional organisation

b Each region needs to develop an organisation for ensuring delivery of genetic screening and prenatal diagnosis. This organisation should include clinical genetics and fetal medicine centres, neonatologists and paediatric pathologists, obstetric and paediatric consultants, primary care physicians, community physicians, health workers involved in family-planning, health visitors, midwives, nurses, and experts in health education and community medicine.

District organisation

c For the service to be delivered effectively, the regional organisation must have roots at the district level, in the antenatal clinics and among general practitioners and other maternal and child health workers.

District and regional co-ordinators

9. Because of their multidisciplinary nature, prenatal diagnosis services should be under the overall supervision of designated district and regional co-ordinators who may often, but not always, be clinical geneticists. The co-ordinator's responsibility should be to ensure that the services are provided to the recommended standard and co-ordinated and monitored throughout each region.

National audit

10. Though monitoring should be organised on a regional basis, a national centre is needed to develop appropriate methods, co-ordinate information nationally, and stimulate equal service delivery throughout the country.

Genetic health education

11. Face-to-face counselling and written information are complementary rather than alternative sources of information for an educated population; one should not be given without the other. Information packages need to be directed to schools, young couples and pregnant women, and individuals with defined genetic risks. Because of the wide range and different levels of educational resources needed to cover the spectrum of potential abnormalities, a National Genetic Health Education Unit is needed to generate, store and disseminate information.

Implementation

12. These proposals should be implemented through working groups and supported by the DoH [Department of Health].

Source: *Prenatal Diagnosis and Genetic Screening: Community and Service Implications*, The Royal College of Physicians of London, September 1989.

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BOX NOTES

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The Science Council and project steering committee thank all those who contributed for their valuable assistance and advice, including Joan Watson and Paul Tisdall for their contributions to the writing of the report and summary documents.

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Notes:
1. In the course of the project, genetics education was discussed with geneticists at all Canadian medical schools.
2. Because an extensive survey of genetics education in North American medical schools was conducted recently by the American Society of Human Genetics, a separate survey was not conducted.

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Note:
Committee and subcommittee members provided information on specific diseases: Charles Scriver (thalassaemia, Tay-Sachs disease, phenylketonuria); Ronald Worton (muscular dystrophy).

Associations Representing Individuals with or at Risk for Diseases with Possible Genetic Causes

Patricia Guyda, Canadians for Health Research, Montreal

In addition, the following 47 societies participated through a survey conducted for the Science Council by Canadians for Health Research.

Alberta Heritage Foundation for Medical Research
Allergy Foundation of Canada
Alzheimer Society of Canada
Association canadienne de l'ataxie de Friedreich
Autism Society of Canada
British Columbia Lung Association
Canadian Association for Narcolepsy
Canadian Celiac Association
Canadian Cerebral Palsy Association
Canadian Cystic Fibrosis Foundation
Canadian Foundation for Ileitis and Colitis
Canadian Foundation for the Study of Infant Deaths
Canadian Friends of Schizophrenics
Canadian Geriatrics Research Society
Canadian Hemochromatosis Society
Canadian Institute of Child Health
Canadian Liver Foundation
Canadian Lung Association
Canadian Mental Health Association
Canadian Neurological Coalition
Canadian Sickle Cell Society of Quebec
Cancer Research Society Inc.
Charcot-Marie-Tooth Disease International Association, Inc.
Dystonia Medical Research Foundation (Canada)
Huntington Society of Canada
Juvenile Diabetes Foundation Canada
Kidney Foundation of Canada
Kidney Foundation of Canada (Manitoba Branch)
Learning Disabilities Association of Canada
Manic Depressive Association of Metro Toronto
Manitoba Cancer Treatment and Research Foundation
Manitoba Mental Health Research Foundation
Multiple Sclerosis Society of Canada
Muscular Dystrophy Association of Canada
National Cancer Institute of Canada
National Eating Disorder Information Centre
Neurofibromatosis Association of Saskatchewan
Neurofibromatosis Society of Ontario
Ontario Mental Health Foundation
Osteoporosis Society of Canada
Quebec Rette Syndrome Foundation
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The following 30 firms participated in a survey conducted for the Science Council by Ying Gravel of the HSC Research Development Corporation.

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Synphar Labs

British Columbia

Helix Biotech Corporation
Quadra Logic Technologies Inc.
Syndel Laboratories Ltd.
Vancouver Island Antibodies Ltd.

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ABI Biotechnology Inc.

Nova Scotia

Dominion Biologicals Ltd.

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Cangene Corp.
Cedarlane Lab Ltd.
Ciba-Geigy Canada Ltd.
Connaught Labs Ltd.
Cyberfluor Inc.
Eli Lilly Inc.
HSC Research Development Corporation
Hybrisens Ltd.
Joldon Diagnostics
Mann Testing Laboratories
Meiogenic Research Corp.
Ortho Pharmaceutical (Canada) Ltd.
Syntex Inc.
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REPORT 42

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