The Honourable William C. Winegard
Minister for Science
House of Commons
Ottawa, Ontario

Dear Dr Winegard:

In accordance with Section 13 of the Science Council of Canada Act, I take pleasure in forwarding to you the Council's Report No. 42, *Genetics in Canadian Health Care*.

This report explores the implications of applying genetic knowledge to improve the health of Canadians. It has been carried out in the framework of the Science Council's mandate:

> To assess the scientific and technological resources, requirements, and potentialities of Canada;
>
> To increase public awareness of
> - scientific and technological problems and opportunities;
> - the interdependence of the public, governments, industries, and universities in the development and use of science and technology.

Many of the issues dealt with in this report go well beyond the technological, as a matter of necessity. The complex ethical and legal issues associated with development and use of genetic technologies raise fundamental questions about our values and attitudes regarding human health.

This report raises profound public policy questions, but it does not pretend to have all the answers. There must be further public debate on the controversial questions surrounding the integration of genetics into the health care system. This report aims to catalyse that debate.

Yours sincerely,

Janet E. Halliwell
Chairman
Science Council of Canada

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PREFACE

Advances in science and technology are improving our understanding of the many factors affecting health and constantly generating new ways to prevent and treat disease. A major challenge is to ensure these advances are used in a way that maximizes their benefits and minimizes any potential harm.

In 1986 the Science Council of Canada launched a project to review the current and potential role of genetic knowledge and technologies in Canadian health care. The goal was to examine the related policy issues and to stimulate progress in addressing them.

The project's findings, presented in this report, are based on a comprehensive program of policy research and consultation. More than 200 people participated in the project: experts in law, education, medical ethics, health care economics, and science policy, as well as in medicine and medical research. Also consulted were 47 associations representing Canadians with diseases with possible genetic causes.

Genetics in Canadian Health Care focuses on the issues surrounding the development and application of genetic health services. However, the Science Council recognizes that genetic make-up is only one of many factors — biological, environmental, and social — that contribute to disease. Moreover, there are a number of approaches to preventing and treating disease. They include, for example, reducing poverty and improving the work environment as well as new surgical techniques and medications.

The Science Council acknowledges, too, that there is enormous competition for resources in the health care field. Genetics issues merit attention on several counts:

- the importance of genes as a causal factor in disease is increasing as other factors are better controlled;
- genes are being implicated in an increasingly wide range of disorders;
- genetic knowledge and technologies have the potential to profoundly affect the health of Canadians;
- genetic knowledge and technologies also raise complex ethical and technical questions that need to be addressed.

The goals and initiatives presented here provide a framework upon which effective and ethical development of genetic services can proceed. It is up to each reader — policy maker, planner, educator, health provider, or patient — to take the next steps to ensure that health care in Canada continues to evolve as a reflection of a caring society.