

Foreword

It is with pleasure that we provide a Foreword to this Special Issue of *Cancer Epidemiology, Biomarkers & Prevention*, entitled "Psychosocial Aspects of Cancer Genetic Testing: Findings from the Cancer Genetics Studies Consortium." The CGSC¹ comprises a unique set of research projects designed to examine issues surrounding the use of genetic testing and counseling in the identification of individuals who have an increased hereditary risk of cancer. The development of this Consortium was sponsored and facilitated by the National Human Genome Research Institute's Ethical, Legal, and Social Implications Research Program at the National Institutes of Health.

Along with the Department of Energy, the NHGRI directs the U.S. Human Genome Project. Formally begun in 1990, the goals of the HGP are to map and sequence a reference human genome (containing an estimated 80,000 genes) by the year 2005. As the HGP progresses, the power of its tools and technologies is already being realized, particularly in the rapid acceleration of disease gene discoveries. These revelations are having a significant impact on how biomedical and behavioral research is being conducted and is also beginning to influence, in a major way, how medicine is being practiced and health care is being delivered.

The architects of the HGP recognized that the discovery of these technologies and this store of genetic information would likely have a significant impact on individuals, families, and society. To address these concerns, the planners proposed the development of a distinct but integrated program to examine the ethical, legal, and social implications surrounding the development and use of these new discoveries. As it has evolved, four high priority areas have emerged in the ELSI Program: *a*) issues surrounding genetics research; *b*) clinical integration of new genetic technologies; *c*) privacy and fairness in the use and interpretation of genetic information; and *d*) professional and public education. At this time, almost half of the ELSI budget is devoted to research on the clinical integration of new genetic technologies.

In order to examine issues surrounding the use of new cancer genetic testing technologies, the NHGRI developed a Request for Applications in 1994 to solicit research proposals

designed to study the use of predictive testing for cancer susceptibility. The goal of this effort, initiated just prior to the identification of the *BRCA1* and *BRCA2* genes, was to study the use of these technologies in a controlled research environment, before they made their way into mainstream medical practice. This initiative was co-sponsored by the National Cancer Institute, the National Institute of Mental Health, the National Institute of Nursing Research, and the NIH Office of Research on Women's Health. The purpose of this solicitation was to accumulate information regarding knowledge and attitudes about cancer genetic testing, as well as to assess interest and demand. In addition, empirical information about the true impact of using cancer genetic tests in individuals and families in which there appears to be an inherited form of cancer was sought.

Over the past three years, these projects have examined a wide range of issues. The investigators have studied informed consent and laboratory testing principles and have developed a mutually agreed upon set of recommendations for followup care for those individuals identified as having *BRCA1*, *BRCA2*, and *HNPCC* mutations. Ethical and health policy issues have been examined as well. Now, in this Special Issue of *Cancer Epidemiology, Biomarkers & Prevention*, an entirely new set of papers is presented, providing in one place a summary of some of the major findings from these research projects.

These investigators have developed productive multidisciplinary collaborations that demonstrate that the whole can be greater than the sum of the parts. We applaud their efforts and look forward to future collaborations of this type. On behalf of the NHGRI, we express our appreciation to the families with inherited cancer mutations who form the participant groups for many of these research projects.

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¹The abbreviations used are: CGSC, Cancer Genetics Studies Consortium; NHGRI, National Human Genome Research Institute; HGP, Human Genome Project; ELSI, Ethical, Legal, and Social Implications; NIH, National Institutes of Health.