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ELSI
BIBLIOGRAPHY:
Ethical Legal & Social Implications
of the Human Genome Project

May 1993

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INTRODUCTION

This second edition of the ELSI Bibliography provides a current and comprehensive resource for identifying publications on the major topics related to the ethical, legal and social issues (ELSI) of the Human Genome Project. Since the first edition of the ELSI Bibliography was printed last year, new publications and earlier ones identified by additional searching have doubled our computer database of ELSI publications to over 5600 entries. The second edition of the ELSI Bibliography reflects this growth of the underlying computer database. Researchers should note that an extensive collection of publications in the database is available for public use at the General Law Library of Los Alamos National Laboratory (LANL).

Books and articles in the academic and professional literatures comprise two-thirds of the entries in the computer database. The remaining entries are news articles, mostly from major newspapers and science journals. News articles have not been included in this printed ELSI Bibliography except under one topic, linkage, but can be searched in the database.

In addition to reflecting the growth of the database and generally excluding press entries, another major change in the second edition of the ELSI Bibliography has been to organize and select the entries by topic instead of providing a single, alphabetical list of all entries in the database. In the past year, the database was keyworded to enable topical computer searches and topical organization of the printed ELSI Bibliography. For this edition of the Bibliography, we compiled seventeen sections: fifteen lists by substantive topic, a list of publications supported by the ELSI programs of the National Center for Human Genome Research and the Department of Energy, and, as a sample of the news articles in the database, a list of press reports of linkages between genes and genetic conditions. The fifteen topical lists are:

- Behavior
- Cystic fibrosis *
- Counseling
- Discrimination
- Ethics
- Eugenics
- Forensic
- Huntington's disease *
- Law
- Patents
- Privacy
- Reproduction
- Screening and diagnosis
- Sickle cell anemia *
- Therapy

This is not a complete inventory of the keywords or topics that can be searched in the underlying database. We shall be happy to provide custom computer searches and sorts of the database to researchers interested in other topics. Also, the database will soon be made accessible on-line, enabling researchers to perform their own searches. Further information on these alternatives is provided below.

Since many of the topical lists overlap, some entries are included in more than one list. Conversely, the underlying database contains many entries that are not included in the topics selected for this edition of the ELSI Bibliography.

Most of the lists in this edition are sorted alphabetically by author. However, the topics marked above with an asterisk and the press reports on linkages are sorted chronologically to provide a sense of historical development in the particular areas. Of course, the results of any topical search on the underlying database can be sorted alphabetically or chronologically.

A few words about some of the topics in the ELSI Bibliography:

"Behavior" includes publications concerned with examining the extent to which behavior is genetically caused, identifying genes that affect behavior, or commenting on these efforts. The listings for three specific genetic disorders (cystic fibrosis, Huntington's disease, sickle cell anemia) include landmark science articles as well as publications about the social and ethical issues raised by the scientific discoveries. Many other genetic conditions and suspected genetic conditions can be searched in the database.

"Counseling" includes an extensive selection from the literature of this profession. Inevitably, many genetic counseling issues are ethical, legal and/or social issues as well. "Discrimination" includes the literature concerned with the impact of genetic knowledge on insurance and employment. "Ethics," a core topic of the Bibliography, is an extensive list that can be consulted at large in these pages or, upon request, broken into subtopics such as "religion," combined with other topics, limited to certain periods, etc.

"Forensic" includes publications on both the science and the public debate related to DNA identification. "Law," another core topic, includes relevant publications in jurisprudence but not statutes or appellate opinions, which are readily available through on-line legal databases.

"Privacy" includes the philosophical, legal and social science literature relevant to the protection of genetic data about individuals. "Reproduction" includes publications about the impact of genetics on reproductive decision making. "Screening and diagnosis" covers the introduction, utilization and impact of genetic testing and screening.

Most of the topics covered in the ELSI Bibliography are controversial. We have attempted to reflect all perspectives on the issues and to be inclusive rather than exclusive in listing relevant publications. Any omissions are inadvertent - please send us the missing citations (and text, if available) for addition to the database.

The computer database from which the ELSI Bibliography is drawn can be rapidly searched and sorted on a variety of parameters and combinations of parameters. For example, a search can be limited to any topic(s) and/or name(s), sorted chronologically or alphabetically by author, and/or limited to certain periods or publications. We will be happy to conduct searches upon request, which should be directed to Michael Roth or myself at MS A187, Los Alamos National Laboratory, Los Alamos, NM 87545. We can be reached by telephone: (505) 667-3766; by fax: (505) 665-4424; or by Internet:

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The results of custom searches can be e-mailed, faxed or U.S.-mailed to the requestors. Researchers are also invited to use our extensive collection of ELSI books and articles at the LANL General Law Library, located in Los Alamos, New Mexico, by appointment.

We plan to make the database directly accessible to researchers by Internet or modem in the near future. Two types of searches will probably be available: a simple-to-use word search with software commonly utilized on Internet, and a more powerful search engine that will duplicate the capabilities of our system at LANL described above. If you wish to be notified when the ELSI database goes on-line, please advise us and we will respond in the medium of your choice. Also, we would appreciate learning of your interest in an on-line ELSI bulletin board that might include announcements, debates, texts, etc.

The ELSI Bibliography could not have been prepared without the diligent efforts of Michael Roth, who has become skilled in genetics, computers, budgets and a host of other convoluted matters in the course of his work on the bibliography project. We are indebted to David Flaherty of the University of Western Ontario for his advice on reorganizing the Bibliography for greater usefulness. Robert Cook-Deegan of the Institute of Medicine and Robyn Nishimi of the Office of Technology Assessment generously shared their own bibliography materials.

The ELSI Bibliography, database and library collection were developed with the generous support of the Department of Energy's Office of Health and Environmental Research. Daniel Drell of that office has provided assistance of many kinds. It has been a pleasure to work with Daniel, Eric Juengst and the ELSI staff of the National Center for Human Genome Research, and the many participants in the ELSI programs. Finally, my own involvement in the ELSI program would not be possible without the support and encouragement of William R. Hughes, Laboratory Counsel, and James E. Mitchell, Senior Counsel, of LANL.

Michael S. Yesley
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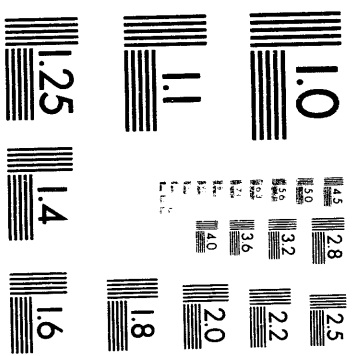
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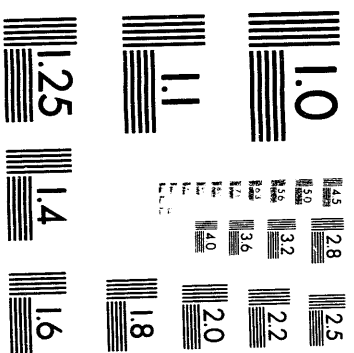
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