MEHORANDUM OF UNDERSTANDING

BETWEEN THE

UNITED STATES DEPARTMENT OF ENERGY

AND THE

NATIONAL INSTITUTES OF HEALTH

TO COORDINATE RESEARCH AND TECHNICAL ACTIVITIES

RELATED TO THE HUMAN GENOME

I. Introduction

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The National Institutes of Health (NIH), Department of Health and Human Services, and the United States Department of Energy (DOE) agree to foster interagency cooperation that will enhance the human genome research capabilities of both agencies.

DOE and NIH are the Federal Agencies primarily responsible for supporting research relating to the human genome. There has been considerable discussion in the scientific community over the past two years about the need for a coordinated long-term project to map and sequence the human genome. While NIH and DOE have informally coordinated such research efforts, the increasing complexity and scope of the project require a more formal mechanism. The purpose of this Memorandum of Understanding (MOU) is to provide for the formal coordination of the activities of DOE and NIH, and to provide for interfaces with relevant activities both within and outside the United States. The MOU also provides a mechanism by which NIH and DOE can jointly obtain outside advice regarding the human genome project.

II. <u>Definition</u>

For the purposes of this MOU, human genome research encompasses efforts to develop and apply technologies for the large-scale mapping, sequencing and analysis of the human genome. It includes the development of shared centralized facilities such as repositories for cloned DNA fragments, databases, and data centers to collect and distribute the large amounts of information generated on the project.

III. Goals

The goals of the project include: completion of a high-resolution genetic map of the human genome; completion of a series of complementary physical maps of increasing resolution; acquisition of a collection of ordered DNA clones encompassing the entire genome; determination of the complete nucleotide sequence of a reference genome; location of all the genes; and development of the tools to use the above information for a variety of biological and medical applications. Parallel studies in model organisms will be required in order to achieve a full understanding of the human genome.

IV. Management and Program Guidelines

A. Establishment of a joint advisory subcommittee chosen from the members of the DOE Health and Environmental Research Advisory Committee and the NIH Program Advisory Committee on the Human Genome.

The joint subcommittee will receive charges jointly prepared by NIH and DOE and communicated to their appropriate parent advisory committees. The joint subcommittee shall be co-chaired by representatives from the DOE and NIH committees. The joint subcommittee shall meet quarterly in order to advise and review the relevant activities of the two agencies. Subcommittee reports will be delivered through the two parent advisory committees to appropriate senior officials of NIH and DOE.

- B. Establishment of an Interagency Working Group (IAWG) on genome research between DOE and NIH. The IAWG will be co-chaired by NIH and DOE and will meet at least on a quarterly basis to explore the need for and the feasibility of initiating a variety of cooperative and complementary programs and projects in order to advance knowledge in human genome research. The IAWG will also provide oversight of activities carried out under this MOU. In addition to the chairpersons, the IAWG will consist of an equal number of full members from DOE and NIH. Additional ad hoc members may be added for temporary assignments by either agency with prior concurrence of the chairpersons.
- C. Continued coordination with other Federal agencies, with outside scientific groups, both national and international, and with private organizations involved in the genome project.

- D. Continued joint participation and sponsorship of meetings and workshops for the purposes of planning and review of technical progress including an annual symposium to review progress in the science, to identify areas of need, and to address general policy questions.
- E. Development of synchronous calendars for the agencies' research award cycles.
- F. Concurrent funding and management of selected programs in human genome research that require utilization of unique NIH or DOE facilities.
- G. Maintenance of regularly scheduled joint program staff meetings to exchange program information and plans.
- H. Promotion of the sharing of technological advances and relevant biological materials (probes, cell lines, etc.) among investigators supported by both agencies. Assurance that relevant data are rapidly placed in appropriate databases and that relevant biological materials are rapidly placed in appropriate repositories.
- I. Promotion of coordination and exchange of data with other countries.
- J. Advance sharing of public policy statements relevant to human genome research.

V. Administration

- A. Public Information Coordination: Subject to the Freedom of Information Act (5 U.S.C. 552), decisions on disclosure of information to the public regarding projects and programs implemented under the Memorandum of Understanding will be made following consultation between DOE and NIH respresentatives.
- B. Intellectual Property: Specific provisions concerning the disposition of rights in intellectual property will be included in any interagency agreement under this Memorandum of Understanding.
- C. Amendment and Termination: This Memorandum of Understanding may be modified or amended by written agreement between NIH and DOE and terminated by mutual agreement of DOE and NIH or by either party upon 90-day written notice to the other.

D. Effective Date: This Memorandum of Understanding is effective when signed by both parties.

James B. Wyngaarden Director National Institutes of Health

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Robert O. Hunter, Director Office of Energy Research U. S. Department of Energy