

ETHICAL AND LEGAL STUDIES RELATING TO THE PROGRAM TO MAP AND SEQUENCE THE HUMAN GENOME

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Office of Human Genome Research
National Institute of General Medical Sciences

INTRODUCTION

The National Institutes of Health (NIH), under the auspices of the Human Genome Project, is interested in receiving applications for research grants or conference grants addressing the ethical, social, and legal issues that may arise from the application of knowledge gained as a result of the Human Genome initiative.

BACKGROUND

The plan to map and sequence the entire human genome is predicated on belief in the immense potential benefit to humankind of the information to be gained through advances in medicine, biological research and the biotechnology industry. While the prospect of benefits is clear, many questions arise regarding the best way to ensure that the information is used in the most beneficial and responsible manner. The NIH is interested in examining these questions and stimulating public discussion in order to facilitate an understanding of the issues and the development of public policy and education, regarding the use of knowledge gained from the Human Genome initiative.

RESEARCH SCOPE

Applications may be for support of conferences or workshops, for scholarly research and writing projects, or for the development of materials to educate the public about the underlying genetic principles and the ethical, legal, and social issues arising from the Human Genome Program. Projects should address questions such as'

- o What are the concerns to society and to individuals arising from the Human Genome Project?
- o What specific questions in the broad area of ethics and law need to be addressed?
- o What can we learn from precedents?
- o What are possible policy alternatives and the pros and cons of each?
- o How can we inform and involve the public and stimulate broad discussion?

It is essential that applicants address the full range of views on each issue covered in a responsible, scholarly, and balanced manner, with the goal of advancing scholarship, achieving better understanding, or working towards consensus or useful recommendations. While these questions are not intended to be limiting, projects should be relevant to issues raised by the scientific developments entailed in acquiring the complete DNA sequences of the human and other organisms.

MECHANISMS OF SUPPORT

Support for this program will be through research grants (R01) or conference grants (R13). Collaborative projects between biomedical scientists and ethicists, legal scholars, educators, and social scientists are encouraged.

APPLICATION AND REVIEW PROCEDURE

Applications received in response to this announcement will be reviewed by a special study section selected for expertise in the appropriate areas of ethics, law, medicine, biology, social science, and public education. Criteria for evaluating the applications will include:

- o Potential for producing new knowledge or new understanding.
- o Balance and breadth of approach.
- o Potential impact of the proposed project in terms of scholarly or lay audience reached.
- o Experience and expertise of the applicants.
- o Novelty of the project (i.e. does not duplicate other efforts).

We are interested in attracting individuals with varied backgrounds to consider the prospects of the Human Genome Project. However, individuals must show that they either have or will obtain a sound working knowledge of the underlying biology so that relevance to the Human Genome Project can be assured. Applicants are strongly urged to contact NIH staff to discuss their plans before submitting an application.

Although there is no set-aside of funds for this area of research, the Human Genome Project is prepared to spend 1 to 3 percent of its resources in the area, provided a sufficient number of high quality applications is received.

METHOD OF APPLYING

Applications should be submitted on the new form PHS 398 (rev. 9/86). Application kits are available at most institutional business offices and from:

Office of Grants Inquiries
Division of Research Grants
Westwood Building, Room 449
National Institutes of Health
Bethesda, Maryland 20892

Applications will be accepted in accordance with the usual NIH receipt dates for new applications-- October 1, February 1, and June 1. It is essential that applicants type "Ethical and Legal studies relating to the program to map and sequence the human genome" in item 2 on the face page of the application form. The original and six copies of the application should be submitted to the following office.

Application Receipt Office
Division of Research Grants
Westwood Building, Room 240
National Institutes of Health
Bethesda, Maryland 20892**

The conventional presentation for grant applications should be utilized (see instructions in application).

Applications will be assigned to the most appropriate NIH Institute, depending on subject matter. Funding decisions will be based on recommendations of the initial review groups and the respective Institute's Advisory Council regarding scientific merit and program relevance and on the availability of funds.

INQUIRIES

Depending on the nature of the application, applications may be assigned to one of several NIH Institutes. Applicants are advised to call prior to submitting an application. Calls will be referred to staff of one of the NIH Institutes when appropriate. Please contact:

Dr. Elke Jordan or Dr. Mark Guyer
Office of Human Genome Research
Shannon Building, Room 203
National Institutes of Health
Bethesda, Maryland 20892
Telephone: (301) 496-0844