

**Grant Number:** 5T15AI07545-02  
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**Project Title:** DISTANCE LEARNING FOR INSTITUTIONAL REVIEW BOARDS  
ON ETHICAL ISSUES IN GENETICS

**Description:**

This is an innovative proposal to use the Internet to connect institutional review board (IRB) administrators from five institutions for distant learning on ethical issues in genetics. In addition to the permanent impact of the Internet course, 4,000 training manuals will be made available based on the course. The program, however, depends critically on a trickle down concept that IRB administrators can influence and instruct IRB committee members, which would ultimately have a broad impact on research involving human subjects. The assumption that a course of this type will have this effect is questionable, but the course should have broad applicability to a wide audience.

This project on ethical issues in genetic research is directed primarily toward research administrators and the nation's 4000 IRBs who serve as "gatekeepers to genetic research." The authors point out that many IRB members are unfamiliar with both the techniques and research applications of the new genetics and with the ethical, legal, and social issues unique to these new developments. This program aims: 1) to develop a distance-learning curriculum for IRB members and research administrators, using the Internet as an efficient way of reaching a widely-scattered audience; 2) to produce a printed manual for research administrators to keep on file; 3) to place the manual on the Internet as a hypertext resource.

The course will be field-tested on approximately 35 IRB members at various sites, including a site serving primarily minority populations. Trainees will include physicians, nurses, social workers, psychologists, lawyers, community representatives, clergy, pharmacists and others who may serve on IRBs. The course will be fully interactive, with a scheduled chat box providing classroom-like discussion.

After field-testing, the course will be put on-line, with the capacity for training several hundred students per year. The course curriculum will include: Types of Genetic Research Protocols Expected in the Next Ten Years; Sharing Genetic Information with Relatives; Accidental Findings of Non-paternity; Predictive and Pre-symptomatic Testing: Uses and Misuses of Information; Participants' Right to Information; Dangers of "Genetic Discrimination"; Informed Consent: Elements of Informed Consent and Standards for Protecting Privacy; Uses of Stored DNA Samples; Ownership of Information; Compensation; Children's Assent; Duties to Re-contact; Collaboration with Other Institutions; Special Concerns of Women, People with Disabilities, Cross-cultural and Minority Groups; Use of Interpreters; Research Involving Products from Transgenic Animals and Xenotransplantation; Special Problems of Behavioral Genetics; and How IRBs Can Interact with Communities.

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**ICD:** NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

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