

**ACCESSIBLE GENETICS RESEARCH ETHICS EDUCATION (AGREE): A
WEB-BASED PROGRAM FOR IRBS AND INVESTIGATORS**

Grant No. DE-FG02-02ER63433

FINAL REPORT (7/13/04)

With funding from the Department of Energy, AGREE now provides a web-based educational program for members of institutional review boards and investigators concerning the ethical issues associated with genetics. Funding through the end of the project period (12/31/03) made possible the development of the publicly available web site [<http://agree.mc.duke.edu>]. The site currently features two modules ("Ethics and Genetics Research in Populations", "Ethics in Behavioral Genetics Research"). Each module is available for free and can be viewed in one of three ways: audio streaming, HTML, and as a PDF file. A knowledge quiz and evaluation can be completed on-line following each module. For a fee of \$25, CME credits are available for interested users. The AGREE site also provides audio streaming of three talks regarding ethics and genetics from a national conference, *Working at the Frontiers of Law and Science: Applications of the Human Genome* held October 2-3, 2003 at the University of North Carolina at Chapel Hill. Finally, the AGREE site has a listing of General Resources in ethics and genetics as well as information about the AGREE team and the Expert Advisory Panel.

The decisions regarding the topics to include in the modules were based on a needs assessment with experts and non-experts. The development of each module involves a series of steps: (1) background research by the AGREE team; (2) production of a draft presentation that is circulated to the expert advisory committee and some users; (3) initial production of a web-based version that includes graphics; (4) review by the AGREE team; (5) revision of the web-based version; (6) final expert review, pilot testing by users, and CME review; (7) final revisions; and (8) posting. In addition, the background papers for the first two educational modules have been published (attached) in the peer-reviewed literature:

DeCamp M, Sugarman J. Ethics in population-based genetic research. *Accountability in Research* 2004; 11: 1-26. - COPYRIGHTED

DeCamp M, Sugarman J. Ethics in behavioral genetics research. *Accountability in Research* 2004; 11: 27-47. - COPYRIGHTED

Work on AGREE will continue under a separate grant to the Johns Hopkins University. Plans for this project include the development of three additional modules, program evaluation, and dissemination.

DOE Patent Clearance Granted

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Office of Intellectual Property Law

DOE Chicago Operations Office

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Date

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