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## WHAT DO SCIENTISTS THINK OF THE ETHICAL ISSUES RAISED BY THEIR OWN RESEARCH IN HUMAN GENETICS? SUNY Empire State College Professor To Survey Scientists On Ethics Of Genetics Issues Project Endorsed by the American Society of Human Genetics

(New York, NY — November 22, 1999) They have proved you can clone mammals. They generally support the patenting of some genetically engineered plants and animals. But what about human genes, the very building blocks of life itself?

Now that a scientist in private industry has challenged the government-sponsored Human Genome Project, and may be the first to identify, patent and perhaps profit from mapping the entire human gene sequence, it becomes even more compelling to discover the thoughts and attitudes of research scientists themselves.

Although one hears the voices of outspoken critics of the new genetics, the thoughts and attitudes of the research scientists themselves are often shrouded in mystery.

To gauge the attitudes of the men and women forging this brave new frontier, Isaac Rabino, Ph.D., professor of biological and health sciences at the State University of New York's Empire State College has conducted several surveys of scientists in the field. He is now embarking upon his most exhaustive survey yet. The proposed research project, funded by the Richard Lounsbery Foundation, will survey the attitudes and perceptions of some of 3,000 scientists from the American Society of Human Genetics (ASHG) on such issues as the Human Genome Project, gene therapy, germ-line research, patenting, cloning, and other human genetics issues, as well as the ethical and legal issues pertaining to new information and rapid changes arising from innovative research in human genetics.

In endorsing the project, Uta Francke, president of ASHG, told members, "I am confident that results of this study will enlighten many people, including ourselves, about the attitudes of our colleagues... [T]he views of scientists working in the field are critical in developing an information basis for determining institutional and public policy."

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Rabino believes that genetic research allows scientists "to enter the ultimate intimacy of who we are." They must weigh the benefits of wiping out such dread genetic diseases as cystic fibrosis, Huntington's disease and sickle cell anemia — against the possibility of unknown consequences (do such genes have some unknown genetic benefit?) and possible abuse. For example, will it one day be routine to deny someone health or life insurance or employment if their genetic profile turns up evidence of eventual disease?

Dr. Rabino's last survey, undertaken in 1995, achieved an impressive 63 percent rate of return. In it, Dr. Rabino questioned 1,257 scientists working in the field of recombinant DNA, finding that in general they:

- approve of patenting living organisms that result from rDNA research but vary significantly on what should be patentable.
- oppose mandatory labeling of biologically engineered food products, but understand that the public has a right to know and advocate openness in this area.
- favor development of genetically modified crops but recognize potential threats to biodiversity and maintain that publicly funded researchers should be legally obligated to consider the potential environmental effects of their research.

Rabino's first survey, in 1988 and '89, investigated funding, patenting, freedom of inquiry and regulation. Dr. Rabino's second survey, conducted in 1991, compared American scientists' attitudes with those of European scientists, who tend to face greater opposition from the public for their work.

Dr. Rabino is the author of numerous academic articles published in such respected journals as *American Scientist*; *Science, Technology & Human Values; Nature Biotechnology; Politics and the Life Sciences;* and *Public Understanding of Science*. Results were also reported in national and international scientific meetings.

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