*The Ethical, Legal, and Social Issues component of the DOE Human Genome Program supports projects to help judges understand the scientific validity of the genetics-based claims that are poised to flood the nation's courtrooms. Robert F. Orr (left) of the North Carolina Supreme Court and Francis X. Spina of the Massachusetts Appeals Court at the New England Regional Conference on the Courts and Genetics (July 1997) participate in a hands-on laboratory session. As a prelude to learning the fundamentals of DNA science and genetic testing, the judges are precipitating DNA (seen as streaks on the glass rod in the tube) from a solution containing the bacterium* Escherichia coli. *[Courts and Science On-Line Magazine:* http://www.ornl.gov/courts*]*

# Ethical, Legal, and Social Issues (ELSI)

From the outset of the Human Genome Project, researchers recognized that the resulting increase in knowledge about human biology and personal genetic information would raise complex ethical and policy issues for individuals and society. Rapid worldwide progress in the project has heightened the urgency of this challenge.

Most observers agree that personal knowledge of genetic susceptibility can be expected to serve humankind well, opening the door to more accurate diagnoses, preventive intervention, intensified screening, lifestyle changes, and early and effective treatment. But such knowledge has another side, too: risk of anxiety, unwelcome changes in personal relationships, and the danger of stigmatization. Often, genetic tests can indicate possible future medical conditions far in advance of any symptoms or available therapies or treatments. If handled carelessly, genetic information could threaten an individual with discrimination by potential employers and insurers.

Other issues are perhaps less immediate than these personal concerns but no less challenging. How, for example, are products of the Human Genome Project to be patented and commercialized? How are the judicial, medical, and educational communities—not to mention the public at large—to be educated effectively about genetic research and its implications?

To confront these issues, the DOE and NIH ELSI programs jointly established an ELSI working group to coordinate policy and research between the two agencies. *[*An FY 1997 report evaluating the joint ELSI group is available on the Web (*http://www.ornl.gov/hgmis/archive/elsirept.html*).*]*

The DOE Human Genome Program has focused its ELSI efforts on education, privacy, and the fair use of genetic information (including ownership and commercialization); workplace issues, especially screening for susceptibilities to environmental agents; and implications of research findings regarding interactions among multiple genes and environmental influences.

A few highlights from the DOE ELSI portfolio for FY 1994 through FY 1997 are outlined below.

- Three high school curriculum modules developed by the Biological Sciences Curriculum Study (BSCS). *[http://www.bscs.org]*
- An educational program in Los Angeles to develop a culturally and linguistically appropriate genetics curriculum based on a BSCS module (see above) for Hispanic students and their families. *[http://vflylab.calstatela.edu/hgp]*
- A series of workshops to educate a core group of 1000 judges around the nation and a handbook with companion videotape to assist federal and state judges in understanding and assessing genetic evidence in an increasing number of civil and criminal cases (see photo above).