

FEATURE

Ethicist works to explain the best of genetic testing

By Nancy Frazier O'Brien
Catholic News Service

ATLANTA — Catholic understanding of the ethical issues involved in genetic testing is lagging because it is linked with abortion in the minds of many, a Minnesota ethicist told a workshop at the Catholic Health Association convention in Atlanta June 11.

"I go to churches all the time to talk about genetics," said Carol A. Tauer, senior scholar at the Minnesota Center for Health Care Ethics in Minneapolis. "I go to Lutheran churches, I go to Episcopalian churches, but I don't go to Catholic churches."

She said she thought Catholics avoided discussion of genetic issues because of the "bad connotations" raised by the fact that some couples who undergo prenatal genetic testing later decide on an abortion.

Noting that 90 percent of prenatal genetic testing shows no genetic problem in the unborn child, Tauer said such testing can "put people's minds at rest." And if the testing shows a problem, Catholic hospital personnel can help couples who want to keep the child "find resources" to deal with their decision, she said.

If Catholic hospitals send away couples in need of such testing, "you're saying, 'We're not going to be with you as you confront this problem,'" she added.

But genetic issues go well beyond prenatal testing, Tauer emphasized in her presentation. She listed the types of genetic testing:

- Diagnostic, to determine the nature of a presenting disease or unexplained

symptoms.

- Presymptomatic testing, to determine if a patient has a particular gene or gene mutation for an inheritable disease.

- Predictive or predispositional testing, to screen for certain genes that could lead to diseases.

- Carrier testing for diseases such as cystic fibrosis or Tay-Sachs before a couple decides to become pregnant.

- Pharmacogenetic testing, to determine the safest, most effective drugs according to the patient's genetic makeup.

Among the ethical concerns surrounding genetic testing are its potential for use in discriminatory hiring and insuring practices, the possibility that its cost will make certain tests or gene treatments available only to the very rich, and the implications for family members who may not wish to know the results.

For example, Tauer said, although there is a test to determine whether a person has the gene for Huntington's disease, which is incurable, few people actually take the test. "It's not unusual not to want to know," she said.

The biggest ethical concerns today relate to genetic privacy issues, especially at a time when 67 percent of Americans don't trust that their medical information is kept confidential, Tauer said.

"I don't agree with the view of some that genetic information should be kept separate from other medical records," she said, adding that the concern should be for better assuring the privacy of all medical information.

Health-care institutions also need to assure that no genetic testing takes place in their facilities without informed con-



Karin von Voigtlander/Photo intern

Healing hands

Massage therapy student Joelle Catalina lends her services to Donna Albert at the Sunshine Rotary Camp in Rush Sept. 15. People with MS were invited to the camp for a "Weekend Getaway" of activities and sharing sponsored by The National Multiple Sclerosis Society.

sent. "People have to know what the test is, and how it will be used," Tauer said.

In the only genetic-testing case to be decided at the federal level, the Equal Employment Opportunity Commission ruled against Burlington Northern Railroad for having had employees tested for a genetic predisposition to carpal tunnel syndrome without their knowledge.

That testing took place at a Catholic

hospital, a member of the workshop audience said.

Tauer suggested that Catholic institutions might want to start training "pastoral genetic counselors" to help patients deal with information from genetic testing.

"We need people to think of all the ramifications of these tests — the moral and religious implications as well as the social and economic ones," she said.

Study quashes alleged Vatican Radio link with leukemia

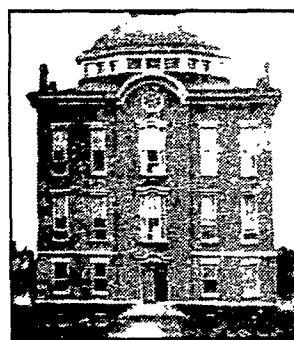
VATICAN CITY (CNS) — Vatican Radio welcomed study results from an international panel that found no connection between the broadcaster's antennae radiation and child leukemia rates.

Jesuit Father Federico Lombardi, the radio's program director, said Sept. 15 he hoped the study finally would give peace of mind to people living around the transmission center.

He said the radio would maintain measures adopted in recent months to lower radiation levels in residential areas to strict limits which have been established by Italian law.

The study, commissioned in April by Italy's health ministry, concluded that leukemia rates around the Santa Maria di Galeria transmission center outside Rome were no higher than in the nation's capital.

Earlier in the year, a study by a regional health agency had been widely misquoted in Italian media as concluding that children living near the radio's antennae were six times as likely to get leukemia as children in other parts of Rome. But the reports' authors said the evidence — one sick child in a 13-year period — was statistically insignificant.



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