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Boston University
STUDY LOOKS AT ETHICAL DILEMMAS IN GENETICS

Boston, Mass.—Geneticists in 19 countries including the United States are struggling with new ethical dilemmas as the field of genetics evolves, and they disagree about how some of these issues should be handled. Results of an international study conducted by researchers at Boston University School of Public Health and the University of Virginia are reported in the July issue of the Hastings Center Report.

The researchers surveyed 682 geneticists to determine their views about some of the issues raised by new knowledge and technology in genetics. "We expected to find more of a consensus among geneticists," says Dorothy Wertz, Ph.D., associate research professor at Boston University School of Public Health. "Instead, we found a widespread difference in opinion about some very sensitive issues, such as prenatal sex selection and disclosure of information."

Those surveyed were given theoretical cases that represented typical problems faced by geneticists, including patient confidentiality, mandatory versus voluntary genetic screening and third party access to screening results. They were then asked how they would respond in each of the situations. For example, they were asked what they would do if a patient diagnosed with Huntington disease refused to tell his or her siblings or children about the diagnosis. Thirty-two percent indicated they would preserve the patient's confidentiality, 34 percent would tell relatives if asked, 24 percent would tell relatives even if they were not asked, and 10 percent would refer the matter to a family physician.

Another case—one that geneticists in Greece, India, Switzerland and Turkey said gave them the greatest conflict—involved a situation in which...
testing revealed that a husband was not the biological father of a child with a genetic disorder. Geneticists overwhelmingly said they would protect the mother's confidentiality (96 percent); most (81 percent) said they would tell her privately so that she could decide how to handle the situation.

In terms of genetic screening, 72 percent thought screening in the workplace should be voluntary (geneticists from several countries supported mandatory screening as a means of protecting the worker); there was a strong consensus (81-89 percent) that employers and insurers should not have access to the results without worker consent; 40 percent thought insurers should not have access even with consent.

Wertz and John Fletcher, Ph.D., of the University of Virginia, conclude by suggesting that one of the most difficult future issues involves disclosure. "In genetics, the patient is the entire genetic family rather than the individual," says Wertz. "We think in some cases that the duty to prevent harm to the family takes precedence over the individual right to privacy."

According to Wertz, this survey provides a starting point for ethical discussion about the many sensitive issues confronting geneticists.