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NORD Issues Gene Patenting Statement

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No licenses for aneuploidy screening have been issued yet. Further information on HFEA can be found on the WWW at: http://www.hfea.gov.uk.

NORD ISSUES GENE PATENTING STATEMENT
In May 2001, the National Organization for Rare Disorders (NORD) issued a statement condemning the U.S. Patent and Trademark Office’s (PTO) policy of allowing scientists and corporations to patent genes and gene sequences even before any applications of this knowledge are known.

NORD’s policy position regarding the patenting of genes states that the practice restricts scientific research, thereby limiting the development of therapies and pharmaceuticals that could benefit millions of people. It argues that preventing research on any illness, particularly those with a genetic basis, is “unethical.” The organization calls on PTO and the federal government to disallow future patenting of genes or gene sequences. According to the statement, Congress should enact a “compulsory licensing law” that requires free access to genes by researchers without having to pay fees or sign confidentiality agreements. Claiming that genes are not inventions (and thus protected by PTO as such), NORD calls for the federal government to monitor current gene patent holders so that the latter could not require royalty payments or secrecy agreements unless the gene or gene sequence has been changed or engineered in order to create a product for commercial use. According to NORD, until such time, free access to genes should be mandated in order to foster research. The full statement can be found at http://www.rarediseases.org.

IN THE SOCIETIES
AMA ADOPTS NEW PRINCIPLES OF MEDICAL ETHICS
For the first time in twenty-one years, the American Medical Association (AMA) adopted two new principles and revised existing principles as a part of its Medical Ethics. On June 17, 2001, the Revised Principles of Medical Ethics were adopted. The action represents a change toward emphasizing patient care and providing access to medical care for all people.

The most notable change to the document is the addition of Principles VIII and IX.