NORD Issues Gene Patenting Statement

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GENETIC SCREENING FOR ABNORMAL EMBRYOS
The Human Fertilisation and Embryology Authority (HFEA), the body that regulates in vitro fertilization (IVF) in the UK, has agreed in principle to allow embryos to be screened for an abnormal number of chromosomes. The technique called aneuploidy can screen out embryos that are aneuploid (contain more or less than 46 chromosomes). Embryos that contain an abnormal number of chromosomes usually result in a failure to implant in the womb that can lead to miscarriage. For such reasons, HFEA contends that aneuploidy screening would be of particular benefit to women who have suffered repeated miscarriages or unsuccessful IVF. Additionally, the screening would also likely increase the success rate of IVF by eliminating embryos that have little chance of implanting in the womb.

A fertilization clinic in London and another in Nottingham have applied for licenses to conduct aneuploidy screening. A spokesman for HFEA stated that "any such license would be subject to satisfactory inspection of the intended laboratories; approval of clinic staff; the provision of detailed technical and patient information; and ongoing monitoring." HFEA recognizes that although the technique is used in a number of fertilization clinics around the world, it is still in its early stages of utilization and needs to be overseen.

Paul Scriven, a principal scientist at Guy’s and St. Thomas’s Hospitals NHS Trust in London, said that with present aneuploidy testing methods, “it is too easy to misdiagnose a normal embryo as abnormal and therefore not attempt to transfer it into the womb.” Other opponents of the screening are concerned that it is another step toward designing a “perfect” baby. Richard Nicholson, editor of the Bulletin of Medical Ethics, said that, “it is important to realize that the same technique has be used to screen out other abnormalities like Down’s and Turner’s syndrome.” Until now, fertility specialists in the UK have only been permitted to screen for specific genetic disorders. However, aneuploidy screening can detect a whole range of genetic abnormalities, leading some to worry about in-discriminate screening that could “eliminate” an embryo for what most would now consider a minor genetic flaw.

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.

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.