



# ETHICAL ISSUES IN GENETICS

**F**our major developments in genetics in the past 75 years have established the context for our understanding of contemporary genetics. The first was the eugenics movement of the early part of this century, which found a receptive home in England and the United States and, in Germany, found horrifying application in the Holocaust. The second development was the discovery in 1953 of the DNA molecule's double-helix structure, which was key to an understanding of the working of the gene. Third, the discovery in the 1970s of recombinant DNA (rDNA) enabled scientists to use chemical "scissors" to snip apart a chromosome and reinsert material from another chromosome, not necessarily from the same species. The fourth development was the inception in 1990 of the Human Genome Project, a multibillion-dollar project to map the entire human genetic sequence. Such a map will be the basis for learning genes' function, as well as how to alter them.

With these discoveries we have made, and will make, tremendous advances in genetics and biotechnology. But the application of now-possible gene therapies poses serious ethical questions that can be particularly thorny for those in Catholic healthcare.



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*Genetic  
Advances  
Force Us to  
Evaluate  
How We  
Practice  
Medicine*

**BY THOMAS A.  
SHANNON, PhD**

## CURRENT APPLICATIONS

**Prenatal Diagnosis** In prenatal diagnosis, fetal cells are analyzed to determine their genetic content. There are several ways to obtain fetal cells for this analysis. The most common is amniocentesis, in which needle aspiration is used to collect fetal cells from the amniotic fluid in the uterus. Chorionic villi sampling entails taking biopsies of some of the chorionic villi that protrude from the placenta. It is also possible to extract fetal cells from a maternal blood sample, or take a cell from an embryo conceived through in vitro fertilization (preimplantation diagnosis). All these techniques enable the screening of the fetal genotype for genetic diseases or abnormalities.

**Genetic Testing** Genetic testing can tell an adult if he or she is a carrier for a particular genetic abnormality, has a genetic condition that will cause a particular disease, or has a gene for a disease or a predisposition for a disease that might show up later in life, such as Huntington's disease or breast cancer. Insurance companies and employers are increasingly interested in genetic testing. Insurance companies want such information to help them eliminate high-risk clients from their risk pool; employers want such information to avoid hiring individuals with a genetic predisposition to a condition that might be set off by the workplace environment or might be expensive to treat.

**Gene Therapy** Gene therapy attempts to cure a disease by altering the gene that causes it. Though highly experimental, more than 100 research protocols have been approved to test various forms of gene therapy.

Two different types of gene therapy exist: somatic and germ line. There are three forms of somatic gene therapy: *ex vivo*, in which cells are removed from the body, corrected, and replaced to correct the disease; *in situ*, in which the new





gene is placed directly into the locus of the disease; and *in vivo*, in which the corrected gene is put in the bloodstream to travel to the appropriate tissue. Germ-line therapy remedies a genetic problem by placing corrected cells in the germ cells of the embryo, thus correcting the condition for the individual and ensuring that the correction passes to his or her descendants.

Although there is some disagreement on this point, in my opinion, in general, the Catholic tradition, which places primacy on the dignity of the individual, would view such forms of therapy as it would other forms of medical experimentation. The key ethical issues are informed consent and the risk-benefit ratio. Thus Catholic healthcare providers would have no general objection in principle to gene therapy, but would resolve the issue on a case-by-case basis.

#### PROBLEMS POSED BY PRENATAL DIAGNOSIS

Prenatal diagnosis poses several problems. Although we can identify a multitude of genetic abnormalities and diseases related to them, we understand the health implications of only a few of these abnormalities. That is, we simply do not know what impact, if any, a particular genetic variation has. Also, even if we know that a particular variation is associated with a disease, we cannot cure that disease. Thus, while genetic information might allow prospective parents to prepare for what is to come or choose some interventions to alleviate some symptoms, the underlying genetic disease will remain. Their choices consequently are limited: avoid reproduction, use donor sperm or eggs, abort, or continue the pregnancy and let the disease run its natural course.

Abortion is prohibited by the Catholic Church, as is the use of donor sperm or eggs. Since prenatal diagnosis usually raises the possibility of abortion, Catholic facilities must decide what genetic services to offer, if any. If a merger occurs between a Catholic facility and an other-than-Catholic facility that has a genetic counseling service, the facilities involved must make a decision about the service's status in the new entity. Prenatal diagnosis is viewed as morally acceptable in the Catholic tradition when it is used in view of early treatment of the fetus or newborn or to allow the parents to prepare for the birth of a genetically affected child.

But continuing the pregnancy is difficult because of rapidly diminishing insurance and

social resources that would help the parents care for the child. Catholic teaching on the intrinsic value of human life can provide a foundation for ensuring the availability of support services for those who give birth to children with genetic diseases or other anomalies. Public funds to help such families are rapidly dwindling, and parents who knowingly give birth to such children are sometimes regarded as morally deficient. Catholic genetic counseling services can make an important social contribution by carrying on the Catholic prolife tradition.

#### ISSUES IN GENETIC TESTING

Another issue for any genetics test—prenatal or later in life—is its accuracy, as well as the number of false positives and false negatives it produces. These technical questions raise important ethical questions: When should a test be made available? How expensive will the test be, and how shall it be paid for? Will the number of false positives or false negatives cause more harm than not making the test available at all?

Genetic testing of children raises another set of questions. For example, should any genetic tests be administered to minors? On one hand, the issue is who decides on behalf of minors, particularly older teenagers. But a more important question is the value of such information for the child, particularly when either no interventions can be made or the disease is a late-onset disease such as breast cancer or Huntington's disease. One Huntington's researcher reported that a woman with two children at risk for the disease asked to have them tested because she could send only one of them to Harvard. While this example is extreme, it suggests that genetic information could be used to determine how to interact with a child and how to utilize resources.

Yet another issue is privacy and confidentiality. We accept that information about one's health and well-being is private and is to be shared only with those the patient explicitly designates. Physicians and hospitals must protect confidential information. But all forms of genetic testing complicate this picture considerably.

To trace possible genetic components to an individual's disease, elaborate family pedigrees must be constructed. This helps identify the specific gene or genes responsible for the problem, but may raise questions of privacy and confidentiality. Instances of extramarital paternity may come to light, or the fact that many family mem-

Catholic  
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diagnosis as  
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to treat the  
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allow the  
parents to  
prepare for  
the birth of a  
genetically  
affected child.





bers are at risk for a genetic disease. If one family member has a genetic predisposition for a disease, this has implications for other members. Can one family member even be tested without implicitly forcing the issue on others? Genetic information is essentially *social* information, and we need to reconsider our understanding of privacy in this area.

Genetic technology also could affect eligibility for healthcare insurance. Private insurance companies have the right to accept or reject customers for their policies, typically based on the results of a physical examination or family history. But many fear that genetic testing, or the results of previous genetic tests, will be required to obtain insurance. This is particularly problematic in two cases: when genetic testing reveals a predisposition for a disease, and when it reveals the presence of a late-onset disease. In the former case, the danger lies in confusing the predisposition with the actual disease; in the latter, it lies in assuming that since the gene is there, the person is actually symptomatic. In both cases, the information might be used to disqualify an individual from insurance because of a preexisting condition, even though the person is not ill and may not become ill for several decades.

Increased availability of genetic information will complicate, while at the same time revealing the shortcomings of, our current system of private healthcare insurance. Because insurance is frequently a function of one's employment, employers as well as insurance companies have a strong interest in learning individuals' genetic status. Although our current system has been assailed by many, we must consider how genetic testing will affect it or any future system.

### CONCERNS ABOUT GENE THERAPY

Gene therapy also raises some ethical concerns. While only about 100 protocols for gene therapy have been approved, greater emphasis on it will occur as a consequence of the Human Genome Project, which will identify all our genes and thus make specific genetic interventions much more likely. But one key question is, How quickly should gene therapy move from research to clinical practice? To answer this, we have to consider how long the effects of the therapy should be tracked in order to determine that it inflicts no long-term harm. This question is particularly important for companies making capital investments in genetic tests and therapies.

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Another key question has to do with allocation. While the consequences of genetic diseases are severe, relatively few people are affected by them. Can we justify the costs of research and clinical trials for these diseases? Genetic cures will come at a high cost at a time when other health needs of the nation are increasing.

Germ-line gene therapy presents several ethical issues because the genetic correction is passed on to descendants. Some have argued that a germ-line intervention violates the rights of succeeding generations to inherit genes that have not been modified. But this position raises several questions. Is there such a right, and what is its basis? Since the human genome continues to be modified through evolution, why is the present form privileged? How is human dignity harmed if one can intervene to prevent a disease in an individual and his or her descendants?

Our perception of human nature is also important in this discussion, for if our bodily dimension is not of critical importance to who we are, then modifying it would not cause harm to our person. That is, if the essence of who we are lies in our souls, then no bodily alteration could substantially modify us. This position assumes a Platonic/Cartesian dualism in which the body is purely a *res extensa* with no relation to the self. Others argue that such a position misunderstands the nature of personhood by neglecting the subjectivity of the body. The body-person dichotomy is at the center of the self, and to change the body is to change the person. While by no means univocal, the Hebrew and Christian traditions tend to view human beings as a body-spirit unity.

### GENETICS AND THE PRACTICE OF MEDICINE

A final question must be asked: How does modern genetics fit into the system of medicine as practiced in the United States? The dominant styles of medicine in the United States are rescue medicine, which focuses on high-tech interventions, and curative medicine, which is supported by major research programs. These medical approaches give priority to the individual, which until recently healthcare spared no expense in trying to cure.

Preventive medicine, on the other hand, focuses on the community, rather than the individual, and on efforts to prevent disease. Preventive medicine looks to the environment and people's lifestyles as places for intervention. Frequently

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## GENETIC MEDICINE IN THE NEXT FIVE YEARS

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We've already seen results like this in the study of breast cancer. Some genes have been identified that affect a relatively small proportion of women—maybe 5 to 15 percent—who develop the illness. But by coming to understand the genetic mechanisms involved in that small number, we are coming to understand the way *all* breast cancers occur. Actually, this is something scientists have known for centuries: Studying unusual phenomena can lead to a fuller understanding of the more usual ones.

**How can a faith-based organization like the Catholic Health Association help prepare its members for what lies ahead? How, especially, can we contribute constructively to discussion of the ethical issues involved?**

In our society, individuals historically look to faith-based organizations for discussions of ethical issues. The ELSI program has sponsored a number of meetings on ethical issues. I organized one in Vermont, in which leaders of various religious faiths came together for several days to talk about the ethical implications of the new genetics.

Maybe the most important thing faith-based organizations can do right now is to let people know that this is a group of issues *they* should have some real impact on. We read in news magazines about things like cloning and Dolly, for example, but many other issues are much more pertinent to the average person's daily life. It would be wonderful to have faith-based organizations involved in—perhaps even *leading*—those conversations.

—Gordon Burnside

 For further discussion of these issues, contact Ron Hamel, CHA senior associate, ethics, 314-253-3563. More information can be found at Web sites of the National Human Genome Research Institute ([www.nhgri.nih.gov](http://www.nhgri.nih.gov)) and the National Coalition for Health Professional Education in Genetics ([www.nchpeg.org](http://www.nchpeg.org)).

## ETHICAL ISSUES IN GENETICS


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**G**enetic tests and therapies raise a social justice issue.

this approach to medicine will also emphasize some sort of national health insurance so that all receive important, preventive interventions early in life.

The growing possibility of practical application of genetic tests and therapies raises a key issue of social justice: Should we continue to emphasize forms of medical intervention—for example, gene therapy—that are very expensive and that will benefit a very few, or should we begin to shift our resources toward interventions that will benefit the majority—for example, the immunization of all children, or nursing care for the elderly? Such a shift will require prolonged national discussion. But the path we are going down, in my judgment, can no longer be sustained. More and more money is being spent on the care of a smaller number of people, and on research for diseases that affect relatively few. While no one should be denied reasonable healthcare, we need to consider carefully how modern genetics fits into the definition of reasonable healthcare and how such a resolution will affect the healthcare needs of all. □

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