



# GENETIC TESTING AND DISCRIMINATION

**T**he prospect of genetic testing that predicts an individual's likelihood of developing such illnesses as breast cancer or Alzheimer's disease raises serious public policy questions. Who should have access to genetic information? Who should not? Are there legitimate reasons for employers or insurers to have access? How can we best protect individual and family privacy?

Legislators and other policymakers struggle with these issues at the federal and state levels. Those who formulate public policy decisions try to balance individual rights and the common good, but must work under pressure from interest groups. Catholic health care organizations, like others, face such questions concerning their patients, plan members, and employees. Catholic organizations attempt to develop approaches that express their values and are consistent with their unique ethical commitments.

The current public debate on genetic privacy and discrimination forms a backdrop for the discussion of policies in Catholic health care institutions. In developing institutional policies, leaders need to be informed about both the factual realities and the legal context. In this article I offer tentative answers to four questions concerning genetic privacy and discrimination:

- What is the extent of the problem?
- Should we distinguish protecting privacy from preventing discrimination?

*How Can  
We Protect  
Job and  
Insurance  
Policy  
Applicants  
from  
Negative Test  
Consequences?*

**BY CAROL A.  
TAUER, PhD**

- Can we protect genetic information without also protecting the medical record as a whole?
- What are some problems regarding insurance and the linkage of employment with health insurance?

I will conclude with reflections on five values from the Catholic tradition that, I suggest, ought to guide the formulation of genetic information policies in Catholic institutions.

## **WHAT IS THE EXTENT OF THE PROBLEM?**

President Clinton frequently expressed concern about genetic discrimination and urged Congress to pass legislation that would protect people from adverse employment and insurance consequences of genetic testing. Hoping to spur Congress to act, he issued on February 8, 2000, an executive order prohibiting federal agencies from using genetic information in any decision to hire, promote, or dismiss workers. In announcing this order he said, "We must not allow advances in genetics to become the basis of discrimination against any individual or group. By signing this executive order, my goal is to set an example and pose a challenge for every employer in America."<sup>1</sup> Clinton made similar statements regarding discrimination by insurers.

The extent of the problem remains unclear, however. In conducting a public consultation on the oversight of genetic tests, the National Institutes of Health found "lingering and persistent concerns regarding the risks of inappropriate disclosure of genetic information about individuals and the potential that such disclosure would result in stigma and discrimination."<sup>2</sup> Philip Reilly, who has intensively studied the problem, notes a public perception that the risk of genetic discrimination is significant and that strong legislative measures are needed to prevent its misuse.<sup>3</sup> The public clearly worries a great deal about the privacy of genetic tests and test results.



*Dr. Tauer is senior scholar, Minnesota Center for Health Care Ethics, Minneapolis.*



Yet Reilly has also observed that the evidence for misuse of genetic test results is largely anecdotal, rather than based on systematic research.<sup>4</sup> After studying discrimination in health insurance, Mark Hall concluded that discrimination related to genetic testing is essentially nonexistent. He interviewed insurance agents, genetic counselors, medical geneticists, patient advocates, and executives at genetic testing firms. None could document a clear-cut case involving a currently healthy person denied coverage as a result of a genetic test.<sup>5</sup> Hall went so far as to hire a market research firm to inquire about group insurance for a fictitious small company in which one of three employees was positive for the BRCA1 gene mutation (predisposition to breast cancer) and another had diabetes. Approximately 85 percent of the insurance agents surveyed said they would have no problem writing group health insurance for the company; the other 15 percent said the coverage, although available, might come at higher rates. Hall concluded that the hypothetical employer could easily find an insurer who would issue the policy at standard rates.

The pressure of public opinion may have made

insurers hesitant to ask for, or to take account of, genetic tests. Or it may be that state laws prohibiting genetic discrimination by insurers—at least 34 states now have them—have been effective. Some state laws prohibit only the use of information from genetic testing; others protect all genetic information, including such traditional sources of information as family history. All these laws apply to health insurance, and some include life insurance as well.

However, whether these laws have had any direct effect is unclear. Several years ago I served on the Advisory Committee on Genetics for the Minnesota Department of Health. Attempting to measure the effectiveness of the state law prohibiting genetic discrimination in health insurance, we were unable to document so much as a single complaint filed under this law by an insurance applicant. Perhaps Minnesota citizens do not know their rights under the law. However, the legal scholar Mark Rothstein has concluded, after reviewing the impact of *all* such state laws, that “none of these well-intentioned laws is particularly effective.”<sup>6</sup>

## EMPLOYMENT DISCRIMINATION AND THE ADA

The Americans with Disabilities Act (ADA) has been useful in outlawing the pre-employment use of medical information indicating a disability. How might it apply to genetic test results?

According to the ADA, an employer may not seek medical information about a job applicant until after a conditional offer of employment has been made. In addition, the employer may not then withdraw the offer unless the medical information indicates that the applicant's health limitations are directly job related.

A 1995 ruling by the Equal Employment Opportunity Commission (EEOC) stated that genetic conditions were included under the ADA's protection. An employer could not refuse to hire an applicant just because genetic testing suggested that he or she might develop a disabling condition in the future, the EEOC said.

The first EEOC lawsuit challenging genetic testing by an employer was filed six years later, on February 9, 2001. The EEOC sued the Burlington Northern

Santa Fe Railroad for asking some employees who had claimed work-related carpal tunnel syndrome to provide blood samples for testing. Analysis of the samples might identify persons who were genetically predisposed to the syndrome, thus suggesting that their injuries were not work related. Several days after the lawsuit was filed, the company agreed to end the genetic testing (Associated Press, “Railroad's Genetic Test Prompts Lawsuit,” *Minneapolis Star Tribune*, February 10, 2001, p. A6; “Burlington Drops Genetic Test Policy,” *Star Tribune*, February 13, 2001, p. A4).

The fact that this case was the first of its kind to be filed by the EEOC may indicate that such use of genetic testing is rare. On the other hand, it may suggest that workers do not know their rights under the ADA.

Moreover, although the ADA apparently prohibits an employer from using genetic information gleaned from exams or medical records, it does not prohibit the employer from requiring an applicant to give his or her consent for

release of medical records as a condition of employment. Only one state, Minnesota, limits the employer's access to information that is directly job-related, a provision of a state Human Rights Law rather than a genetic discrimination statute. In other states, where the entire medical record may be requested, an employer can potentially obtain a great deal of genetic information, even if no positive test results are recorded. Physician-patient discussions of risk factors, tests recommended (even if not pursued), participation in genetic research—any of these items might raise “red flags” for a prospective employer. The applicant, even if currently healthy, might be presymptomatic for a serious genetic disease, such as Huntington's disease, or might be predicted to have a high probability of incurring unusual health care costs in the future, or might be at risk to have children with high health care costs (a possible concern to employers who provide health coverage for dependents).

—Carol Tauer



Health insurance companies today do not appear to be interested in using genetic tests as underwriting tools. Given the current cost of each genetic test, the possibility of false-negative or false-positive results, and the uncertainty inherent in presymptomatic and predictive tests, such use may be impractical. But this situation may change once it becomes possible to “multiplex” a large number of tests at a reasonable cost and once research demonstrates the health implications of a positive test result more precisely.

Extensive publicity given to the insurance and employment implications of genetic testing has increased public concern—perhaps to an exaggerated level. This concern persists even in states with comprehensive laws prohibiting genetic discrimination. Reilly worries that the public’s fear of genetic discrimination may, in fact, be so intense that enacting protective laws is not enough to reassure people.<sup>7</sup>

The Catholic tradition contributes a strong value commitment to this discussion: respect for the equal dignity of all human persons. In light of this commitment, the *perception* that people at genetic risk are being stigmatized is itself cause for moral concern. It is cause for concern even if neither misuse of test results nor stigmatization as a result of such misuse can, as yet, be documented. People act on the basis of perceptions. An ideal law would therefore, as Hall notes, both prevent discrimination and reassure the public.<sup>8</sup>

#### PROTECT PRIVACY OR PREVENT DISCRIMINATION?

If we are to determine what sorts of laws—if any—might achieve the goals Hall proposes, we must first examine some specific policy issues. One basic unresolved question is whether such laws should, on one hand, restrict *access* to genetic information, or, on the other, restrict only the *use* made of this information, thus permitting fairly broad access to data but outlawing its misuse.

Many proposals to curtail the misuse of genetic data are labeled *privacy protections*. These proposals are concerned with access. Those who support them argue that an employer or insurer who is denied access to this information will not be able to discriminate on the basis of it.

Unfortunately, as we have seen from the history of HIV infection, when organizations are prohibited from inquiring directly about an individual’s HIV status, they frequently look for clues to it—what we might call “proxy sources”: a T-cell count, for example, or signs indicating sexual preference, or membership in certain organizations or occupations. Policies protecting genetic privacy often define genetic information *solely* as

the results of genetic tests. Consequently, other sources of genetic information such as family history are not protected. Family history is certainly a proxy for genetic information, as are many other indicators, and is frequently not included under genetic privacy legislation.

And, of course, health insurance companies have, in addition to these legal loopholes, records of medical tests and treatments. Moreover, employers who provide health insurance routinely obtain benefits records, which, at a minimum, say whether a genetic test has been performed. Self-insuring employers (which today cover 55 to 65 percent of all persons with private coverage) either pay health benefit claims directly or require a plan administrator to report these claims.<sup>9</sup>

Restricting employer and insurer access to genetic information may thus be impossible. Perhaps privacy advocates should, instead, seek the passage of legislation that prohibits discrimination resulting from the information’s misuse.

Restricting  
employer and  
insurer access  
to genetic  
information  
may be  
impossible.

#### GENETIC INFORMATION AND MEDICAL RECORDS

The relative ease with which employers can gain access to medical information suggests that genetic information might be better protected if it were kept separate from other medical records. (See **Box**, p. 51.) Could there be a separate “shadow” record, as Fred Silva has suggested?<sup>10</sup> I believe not; attempts to keep genetic information in a separate, more protected record, would be unworkable and all but impossible.

We can anticipate that genetic information will become increasingly important for medical treatment in the future. It will be integrated into, not kept distinct from, medical information as a whole. The five-year plan for the Human Genome Project (1998-2003) sets as a major goal the study of “issues raised by the integration of genetic technologies and information into health care and public health activities.”<sup>11</sup>

Clinicians are aware that individual patients have differing responses to drug therapies. Some of these differences have already been identified as being due to genetic variation. For example, one genetic variant indicates patients likely to benefit from treatment with pravastatin for coronary artery disease; another indicates a dramatically increased risk of thrombosis in women taking oral contraceptives.<sup>12</sup> Knowledge of genetic factors predisposing patients to respond differently to pharmaceutical and other treatments is expected to explode in coming decades. Experts say a time is coming when patients will be expected to have genetic tests before physicians decide which prescriptions to write for them.<sup>13</sup>



The application of genetic information to medical treatment for nongenetic diseases has created a new field, "pharmacogenomics." Every sign points to the incorporation of more and more genetic information into the medical record, not its separation from that record. Thus it hardly makes sense to try to protect the privacy of genetic information unless we are able to protect medical information in its totality. Public concern should be directed toward *medical* discrimination, not just genetic discrimination.

#### HEALTH INSURANCE, LIFE INSURANCE, AND EMPLOYMENT

Most state laws concerning genetic discrimination focus on insurers, but some treat health insurance and life insurance differently. The basis for this distinction appears to be the belief, first, that health insurance is a necessity for everyone, and, second, that people predisposed to illness are in the greatest need of such insurance and should be able to get it. Life insurance, on the other hand, may be perceived as more of a luxury, or at least as elective.

When legislators in Minnesota began drafting genetic discrimination legislation, they treated health and life insurance alike; no genetic tests

could be required or used for underwriting in either case. However, while insurance industry lobbyists were willing to forgo genetic test information for health insurance underwriting, they would not accept this restriction for life insurance. As a result, the legislators decided to treat health and life differently.<sup>14</sup>

About half of the states currently have laws that refer specifically to life insurance, in many cases doing what Minnesota did—exempting life insurance from restrictions on the use of genetic tests. Some laws allow consideration of genetic tests only for policies issued above a certain dollar amount. Others allow genetic tests to be used provided that applicants are fully informed of the nature of the tests and give informed consent.<sup>15</sup>

Commentators disagree as to whether health and life insurance should be treated differently. Insurers argue that if an applicant were to know of (or suspect) a genetic condition likely to result in his or her premature death, and his or her insurer did *not* have the same information, then the applicant would have an economic advantage over the insurer in purchasing life insurance.

Strong arguments against differential treatment of health and life insurance have emerged in public policy contexts in Europe countries and

Some states  
treat health and  
life insurance  
differently.

## LOOPHOLES IN MEDICAL RECORDS PROTECTIONS

Once a company that provides health insurance has hired a job applicant, it usually has access to the new employee's insurance claims. Employers are not likely to discriminate overtly on the basis of these records, but they may do so in subtle ways. If, for example, two employees are candidates for promotion to the same position and one is at risk for serious health problems, the employer would have a difficult time ignoring that fact. If an employee incurs, or is expected to incur, high health care costs, the employer might be tempted to exert subtle pressures to persuade that employee to move to another company.

Mark Rothstein, who favors restricting access to medical information rather than controlling its use, acknowledges that the right of medical privacy has never been given adequate protection by the law. He believes, however, that the new era of genetic information in which

we now find ourselves makes such protection imperative (Mark A. Rothstein, "The Law of Medical and Genetic Privacy in the Workplace," in Mark A. Rothstein, ed., *Genetic Secrets*, Yale University Press, 1997, p. 296).

In an effort to give greater protection to health information, the federal government issued new privacy rules on December 20, 2000. These rules (which apply to providers and health plans but not to self-insuring employers) protect personal medical records in all forms, paper and electronic, cover all types of health information except psychotherapy notes (which have greater protection), and require patient consent for routine as well as non-routine disclosures (U.S. Department of Health and Human Services, "Protecting the Privacy of Patients' Health Information: Summary of the Final Regulations," December 20, 2000, available at <http://aspe.os.dhhs.gov/admsimp/pvc-fact1.htm>).

However, there are loopholes in these rules. They state that a person's health information may be used for health purposes only, "with few exceptions." One exception is submission of claims to an insurer. Another gives physicians, hospitals, and some associated businesses explicit permission to use personal health records for marketing and fundraising purposes. This exception, for which the health care industry lobbied heavily, undercuts the protections supposedly provided by the new rules. According to Thomas Murray, director of the Hastings Center, the provision in fact explodes traditional notions of medical confidentiality. The government has now approved use of your medical record as a marketing tool (Robert O'Harrow, Jr., "Patient Files Opened to Marketers, Fundraisers: Critics Decry Exemptions Won through Lobbying," *Washington Post*, January 16, 2001, p. E01).

—Carol Tauer



Canada. Because these societies all have national health plans and publicly provided health coverage, life insurance is the more crucial issue in relation to genetic discrimination. Some commentators in these societies argue that life insurance is *not a luxury but is as essential as health coverage*—needed to safeguard the security of one's family and to assure them of a home and other basic necessities in the case of a parent's death.<sup>16</sup>

British public policy, diverging from this view, has recently approved consideration of certain genetic tests by insurers, if the tests have proved to be reliable. As of October 2000, the British government's Human Genetics Commission had approved two tests for the Huntington's gene and was considering tests for six other genetic diseases.<sup>17</sup>

Insurance companies in the United States have generally been willing to accept prohibitions on the use of genetic information for underwriting health (but not life) insurance, for two reasons:

Insurers may become more interested in test results.

- Most Americans with health coverage are covered either by group employer-provided policies or by government plans. In these situations, the medical or genetic status of a particular individual is usually not significant. Only 10 percent to 15 percent of those with private health insurance are covered by policies involving individual underwriting.

- The current medical use of genetic testing is minimal. As a result, insurers do not have a strong incentive to request the results of presymptomatic or predictive tests, even when they are writing individual health insurance policies. However, as genetic testing becomes a more routine part of medical practice, insurers may become more interested in learning and using test results.

#### APPLICATION OF THE CATHOLIC TRADITION

As Catholic health care organizations struggle with the issues raised by the coming wave of

## THE LINK BETWEEN HEALTH INSURANCE AND EMPLOYMENT

Discrimination because of genetic test results, if and when it occurs, will be no more than a new twist on an old problem in health insurance. Discrimination *already* afflicts many people with serious health problems.

Some applicants are undeniably refused individual health insurance policies—or are charged higher rates, or have an exclusion in their contracts—because of their health status (Deborah A. Stone, "The Implications of the Human Genome Project for Access to Health Insurance," in Thomas H. Murray, Mark A. Rothstein, and Robert F. Murray, eds., *The Human Genome Project and the Future of Health Care*, Indiana University Press, Bloomington, IN, 1996, pp. 133-157). Insurers have largely replaced "community rating," in which they pool the risks of an entire geographic community, with "experience rating," for both groups and individuals. As a result, the sickest people often pay the most, are uninsurable, or must seek coverage from a public program.

Some states may be exceptions to this trend. New Jersey, for example, claims to have laws that effectively prevent health discrimination. Even so, most people try to avoid problems in

getting and keeping health insurance by finding a job that provides group coverage. However, as Adrienne Asch and other disability advocates note, finding such employment is particularly difficult for persons with disabilities—and, possibly, for persons with genetic conditions.

Although such people have a special need for jobs that provide health insurance benefits, they are at a disadvantage in securing such employment, according to Asch. "Remedying these problems depends upon once and for all ending the link between having a job and getting acceptable health care," she argues. "Until that link is severed, it is in an employer's self-interest—but not in the individual's or the nation's interest—to exclude people from the workforce" (Adrienne Asch, "Genetics and Employment: More Disability Discrimination," in Murray, Rothstein, and Murray, *The Human Genome and the Future of Health Care*, p. 159).

Some health care analysts believe that the connection between employment and health coverage will be severed within the next 20 years. They predict that once a large portion of the population is either retired, self-employed, or employed in jobs that do not offer

health benefits, public support for the tax exclusion for employer-provided health benefits will diminish. By 2020, a majority of Americans will no longer benefit from this tax exclusion and will therefore favor its modification or repeal. If the exclusion should be repealed or significantly changed, most employers will probably refuse to accept the role of payer of first resort (Sidney Taurel, "Health Care in the New Century," speech to the National Press Club, January 18, 2001; William Styring and Donald K. Jonas, *Health Care 2020: The Coming Collapse of Employer-Provided Health Care*, Hudson Institute, Indianapolis, 1999).

Severing health insurance from employment, thus removing one of the barriers to the hiring of disabled and genetically compromised people, would seem to respond to Asch's concern about employment discrimination vis-a-vis the disabled. But would such persons be able to purchase their own health insurance, even if a revised tax code offered a tax credit or subsidy? Removing a disadvantage in one area (employment) merely seems to shift it to another (insurance).

—Carol Tauer



genetic testing, what guidance can they find in the Catholic tradition? What values should inform the thinking of the leaders of such organizations as they develop policies regarding patient privacy, health plan fairness, and employee rights?

The late Rev. Richard McCormick, SJ, in an article called "Ethics and Genetic Research," warned against two extreme views: first, that the Catholic tradition has nothing to say on these ethical and policy issues; and, second, that the tradition provides concrete solutions for these problems.<sup>18</sup> What the Catholic tradition *does* offer is a set of values that can guide deliberations and serve as a standard against which proposed policies are measured.

Five value commitments of the Catholic faith tradition are directly applicable to decisions about genetic privacy, discrimination, and rights. Each of these values carries implications for policy development.

**Respect for the Dignity of Every Human Being** This value is central to Catholic theology. Respect for privacy—in particular medical privacy—is one of its concrete expressions. The value demands that each person's medical information be under his or her control. The patient must know how medical information is being shared and must consent to its release. In this regard, genetic information is no different from other medical information. However, genetic information may have greater implications for one's future than other medical data. And genetic data is also a source of information about family members, whose privacy must be considered as well.

**Fair Treatment That Is Administered with Honesty** This value is the opposite of discrimination. Discrimination, an unfair practice, means making decisions on the basis of factors that are either *irrelevant* or *inappropriate*. Excluding a person from a job she is capable of doing on grounds that she is deaf is one example of discrimination. Another is excluding a person from obtaining health coverage because her family has a history of breast cancer. In the first case, the deafness is not relevant to determining the applicant's qualifications for the position. In the second case, the potential future need for health care services is precisely the reason one obtains health insurance, hence not an appropriate reason for denial. Fair treatment requires that decisions not be based on discriminatory criteria. It also requires that criteria be stated honestly and be open for examination by those who are affected by them.

**Social Justice in the Distribution of Goods** This value requires that every member of society have the resources to meet basic needs, including compre-

Some commentators have viewed a complex rethinking of the American approach to health care as a direct outcome of advances in genetics.

hensive and preventive health care—not only emergency care. This goal obviously cannot be achieved by Catholic health care organizations independently; it must be one to which the entire society is committed. If the present system of employer-provided health benefits is, in fact, dismantled over the next 20 years, then this problem will require a complete rethinking of the American approach to providing health care. (See **Box**, p. 52.)

Some commentators have viewed such rethinking as a direct outcome of advances in genetics. Once a genetic profile of every individual becomes feasible, they argue, we each may be found to be genetically presymptomatic for or predisposed to a number of diseases. If employers and insurers have access to this information, a large proportion of the population could become uninsurable and perhaps unemployable. Expanded genetic testing, these commentators maintain, can thus be expected to lead to a system of health care coverage independent of employers, insurers, and the connection between them. In this view, a national health care program would be the inevitable outcome of the genetic revolution.<sup>19</sup>

**Particular Concern for Those Who Are Most Disadvantaged** This value is expressed in Catholic theology through the "preferential option for the poor" and the norms protecting vulnerable human life. It applies to those who have chronic illness and disability, mental as well as physical, and to those whose genetic makeup puts them at a disadvantage in pursuing their life goals.

The philosopher John Rawls has invoked this value in a test for the justness of a social system. According to him, a system that permits economic and social inequalities is ethically justifiable only if it is the arrangement that is most beneficial to the least advantaged group in society.<sup>20</sup> In his view, every proposed arrangement should be judged according to its impact on the situation of those who have the least.

In an adaptation of Rawls' criterion, Catholic teaching might argue that policies regarding genetic tests should be evaluated according to whether they improve the situation of those who are most at genetic risk. Society as a whole does not ordinarily focus on this criterion, but in the Catholic tradition preference for the needs of those who are most disadvantaged plays a central role.

**Solidarity in Pursuing the Common Good** In solidarity, the individual and the community recognize their responsibility for the good of each individual and the good of all. This value inclines persons and

*Continued on page 71*

## GENETICS TESTING AND DISCRIMINATION

Continued from page 53

institutions to foster the four values already mentioned and to develop policies and dedicate resources for carrying them out.

The Catholic tradition offers a rich menu of values to guide health care organizations struggling with issues raised by the expansion of genetic testing. In the development of specific policies, however, "the devil may be in the details." At the CHA colloquium on genetic testing and Catholic health care on March 24, 2000, discussants recommended a collaborative effort. They proposed that Catholic hospitals, systems, and health care plans develop model policies or become "demonstration leaders" in relation to genetic testing and services. The relationships Catholic health care organizations have with a variety of affected persons—employees, plan participants, and patients—provide them with an opportunity for grappling with specific issues and formulating concrete policies. A collaborative effort to develop policies that express the values of the Catholic tradition is apt to be most effective and to have the greatest impact on the decisions of society as a whole. □

### NOTES

1. Cited in Robert Pear, "Clinton Bans Use of Genetic Makeup in Federal Employment," *New York Times*, February 9, 2000.
2. National Institutes of Health, Secretary's Advisory Committee on Genetic Testing, "Enhancing the Oversight of Genetic Tests: Recommendations of the SACGT," June 2000, p. 13. Available at <http://www4.od.nih.gov/oba/sacgt.htm>
3. Cited in Dorothy Bonn, "Genetic Testing and Insurance: Fears Unfounded?" *Lancet*, vol. 355, 2000, p. 1,526.
4. Cited in Bonn, p. 1,526.
5. Karla Harby, "Genetic Discrimination in Health Insurance Called Rare," Reuters Health (online), September 26, 2000. (Accessed at [http://dailynews.yahoo.com/h/nm/20000926/hl/-insurance\\_2.html](http://dailynews.yahoo.com/h/nm/20000926/hl/-insurance_2.html), on October 4, 2000. No longer posted.)
6. Mark A. Rothstein, with Cheryl Erwin, "Genetic Testing and Discrimination in Health Insurance," April 16, 1998. Available at <http://www.law.uh.edu/healthlawperspectives/Genetics/980416Test.html>.
7. Cited in Bonn, p. 1,526.
8. Cited in Bonn, p. 1,526.
9. Nancy E. Kass, "The Implications of Genetic Testing for Health and Life Insurance," in Mark A. Rothstein, ed., *Genetic Secrets*, Yale University Press, New Haven, 1997, pp. 299-316.
10. Fred Silva, "Genetic Testing: Possibilities, Promises, and Limits," a lecture given at the CHA colloquium, "Meeting the Future: Genetic Testing and Catholic Healthcare," in San Antonio, TX, March 23, 2000.
11. Francis S. Collins, et al., "New Goals for the U.S. Human Genome Project: 1998-2003," *Science*, vol. 282, 1998, p. 688.
12. Francis S. Collins, "Medical and Societal Consequences of the Human Genome Project," *New England Journal of Medicine*, vol. 341, 1999, p. 33.
13. Rick Weiss, "The Promise of Precision Prescriptions," *Washington Post*, June 24, 2000, p. A01.
14. Minnesota Statute 72A.139 ("The Genetic Discrimination Act").
15. Elaine A. Lisko, "Genetics and Life Insurance," January 25, 1999. Available at <http://www.law.uh.edu/healthlawperspectives/Genetics/990125Life.html>
16. Mark A. Rothstein and Bartha Maria Knoppers, "Legal Aspects of Genetics, Work and Insurance in North America and Europe," *European Journal of Health Law*, vol. 3, 1996, pp. 143-161.
17. Emma Young, "Premium Genes: Britain Sanctions Genetic Tests for Insurance Purposes," *New Scientist*, no. 2,261, 2000, p. 7; "Share the Risk: Revealing the Secrets of Our Genes to Insurers Doesn't Add Up," *New Scientist*, no. 2,261, 2000, p. 3.
18. Richard A. McCormick, "Ethics and Genetic Research," in Todd A. Salzman, ed., *Method and Catholic Moral Theology*, Creighton University Press, Omaha, NE, 1999, p. 271.
19. Conference proceedings, "Legal and Ethical Issues Raised by the Human Genome Project," March 7-9, 1991, Houston.
20. John Rawls, *A Theory of Justice*, Harvard University Press, Cambridge, MA, 1971.

# next issue

## TIES THAT BIND: CULTURE IN TIMES OF MERGERS AND ACQUISITIONS

*The past several years have  
been witness to unprecedented  
consolidation in the health care  
arena, with Catholic and  
other-than-Catholic facilities  
forging new ties and bonds.  
The May/June issue of Health  
Progress will address how the  
Catholic health ministry is  
working to preserve identity and  
mission-based culture in an era  
of complex joint agreements and  
frequent mergers.*

chausa.org

have you been there today?



JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

[www.chausa.org](http://www.chausa.org)

# HEALTH PROGRESS®

---

Reprinted from *Health Progress*, March-April 2001  
Copyright © 2001 by The Catholic Health Association of the United States

---