# JURISPRUDENCE AND GENETICS

*Law Governing the New Technologies Should Be Grounded in a Moral Vision*

BY M. CATHLEEN KAVENY, JD, PhD

Some commentators have described the sequencing of the human genome as equal in importance to the 1969 Apollo moon landing. David Stipp has perceptively observed, however, that the comparison fails to do justice to the gene sequencing's momentous implications.[1] The moon landing was a nice novelty for most of us, but it had few, if any, practical effects on our day-to-day lives. In contrast, the sequencing of the human genome promises to revolutionize the way medicine is practiced. More importantly, it may alter the way we view ourselves and each other. It may shape the way that we understand illness and structure our responsibilities to those thus afflicted. It may change the way we think about the obligations of parents to their children.

How will we grapple with the newfound power that genetics is soon to give us? Law is one of the crucial tools we will use in answering this question. Most people think of legal rules simply as regulating behavior, as guiding us toward or away from the actions that a particular situation requires or forbids. Although this is certainly an important task, it is by no means law's only function. More fundamentally, law has a pedagogical role, influencing our thoughts as well as our behavior by supplying the key moral presuppositions with which we approach the important issues of our day.

In dealing with the legal implications of the genetic revolution, we must keep the pedagogical function of law squarely before us. Precisely because so many Americans do not know what to think about the challenges posed by the new genetics, we are likely to be greatly influenced by the underlying moral assumptions of the laws that our community passes. We must scrutinize not only the detailed content of proposed schemes to regulate the fruits of genetic advances, but also their more fundamental messages about human dignity and solidarity, both within families and in the community as a whole.

For many people, including many Catholics, advances in our understanding of the human genome raise the specter of abuses that violate basic human dignity, made all the more terrible because they are officially sanctioned by the legal system. But we should not forget that these advances may provide us with a catalyst to effect positive change in our nation's legal framework, with an opportunity to critique and reform some of its most deeply flawed assumptions. If the United States is to deal responsibly with recent advances in genetics, we Americans must first rethink the normative presuppositions of two crucial areas of our legal framework—those pertaining to health care and to reproductive freedom. In the long run, I believe, the challenges of dealing with the genetic revolution will confirm the wisdom of the Catholic Church's call for solidarity with those who are suffering and its proclamation of the importance of accepting one's children as a divine gift, rather than as a product of one's desires.

We American Catholics must do our best to ensure that these concerns are not mistaken for a narrow or sectarian political agenda, but are properly understood as corresponding to the deepest desires of all human beings to protect the dignity and well-being of those they love.

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## The Human Genome Project: What's Next?

Although last summer's announcement of the human genome's sequencing was a milestone, its import was largely symbolic. The geneticists involved—from the government's Human Genome Project and the private Celera Genomics company—had discovered a rough version of the alphabet of a complicated and exotic language. As important as that discovery was, however, the key task is yet to come. The new language's words and sentences must be identified, their meaning and use understood.

Having made their announcement, the geneticists went back to their laboratories to face a substantial amount of work. First, they must correct and proofread the sequence itself, which will require resequencing the genome 12 or more times. They must fill in tens of thousands of gaps and attend to the 7 percent or so of the genome they deliberately excluded from the initial sequencing. Second, the geneticists need to find the genes that make proteins. This task is complicated by the fact that there is as yet no agreement on the number of genes; estimates range from 26,588 to 31,000.[2] Geneticists need also to identify the genes that make RNA instead of protein, discover the regulatory sequences that activate a gene and govern how much of its product to generate, and untangle the genes' interaction with other molecules in the cell.[3]

What are the implications and possible benefits of genetic knowledge? First, we can hope to develop a more accurate knowledge of pathology within the human system. At present, scientists are still trying to identify mutations that cause disease. They still do not know very much about diseases caused by the interaction of genes and the environment or by the mutation of more than one gene. Even with monogenic diseases, such as Duchenne muscular dystrophy, hemophilia A, and cystic fibrosis, the mutation detection rate is only 60 to 90 percent. It is even lower for BRCA1 and BRCA2, the genes associated with breast cancer.[4] Ultimately researchers hope not only to discover the genetic causes of human illness but to provide a cure for it. They expect the first wave of gene-based drugs to become available in five years.[5] The Human Genome Scientists corporation hopes to market drugs that:

- Speed the healing of ulcers
- Produce proteins that show promise in curbing the uncomfortable side effects of chemotherapy
- Produce proteins that spur the growth of new blood vessels to feed the heart and other crucial muscles of the body[6]

Genetics will enable the development of "smart" drugs that target the precise disease afflicting a given patient. Physicians believe, for example, that "asthma" is a name that we give to a half dozen distinct clinical disorders. Eventually they will be able to pick a drug that corresponds exactly to the type of asthma a particular patient has.[7]

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## Genes, Privacy, and Solidarity

For the foreseeable future, however, our ability to identify genetic defects will far outstrip our ability to cure them. Geneticists have already identified and developed tests for genes associated with hundreds of diseases, including breast cancer, Alzheimer's disease, and Huntington's disease. In an increasing number of circumstances, people will be able to discover that they suffer from, or will suffer from, a particular ailment—but without the benefit of new medical tools that help them combat that ailment. Other people may discover that although they themselves are not susceptible to a disease, they have some chance of having a child who will be susceptible to it.

Needless to say, this information is of great interest not only to the individuals themselves but also to third parties such as employers and insurers. Thus many policy-makers have come to believe that the most immediate challenge is the control of genetic information. That is why they issue increasingly urgent calls for laws protecting "genetic privacy."

At this point, the privacy protection offered by the U.S. legal system is spotty at best. For example, the Health Insurance Portability and Accountability Act of 1996 prohibits group health plans from denying individuals coverage on the basis of genetic information or using such information to charge them higher rates.[8] It does not, however, prohibit them from charging higher rates to employers on the basis of that information, which may give employers an incentive to avoid the genetically "imperfect." The Americans with Disabilities Act has been interpreted as prohibiting employers from taking genetic information about asymptomatic applicants into account when making job offers.[9] It does not, however, prohibit them from obtaining such information from prospective employees after making an offer.

Some states have enacted fairly stringent genetic privacy laws. Massachusetts, for example, now prevents health insurers and employers from gaining access to genetic test results without a persons's written consent. It has added genetic information to the list of characteristics protected under the state antidiscrimination statute and prohibits any requirement that a consumer take or disclose results of genetic tests in order to

obtain health insurance. The law also limits the use of genetic tests in life, disability, and long-term care insurance.[10] Other states, however, have done little or nothing to protect persons from coerced disclosure of genetic information.

Why are people so concerned to protect their genetic privacy? In part, they fear disclosing secrets of their bodies that they themselves barely understand. They also fear that discrimination will ensue against them once these secrets are revealed, particularly on the part of employers and health insurers.

Jobs and health insurance are not entirely distinct entities because most Americans are covered by health insurance provided through their employers. Although I do not doubt the good intentions of those who advocate stringent genetic privacy laws, I do not believe the problems raised by the collection and possible dissemination of genetic information can be adequately addressed by keeping the genetic genie in the bottle.

Unfortunately, we cannot make the current conception of medical privacy safe for genetic data. Instead, we must grapple with the ways in which the nature of such data calls that conception into question. In so doing, I believe, we will need to move away from the notion of individualism characteristically embedded in the American concern for privacy and toward a notion of solidarity on both a familial and societal level. In sum, the new genetics both confirms the essential sociality of the human person and requires ethical and legal frameworks that take that sociality into full account.

For example, consider the presuppositions of the Genetic Privacy Act, proposed as model federal legislation by George Annas, Leonard Glantz, and Patricia Roche.[11] The act defines protected genetic information narrowly to include only information that is directly obtained by analysis of the DNA of a particular person or her relatives. In fact, a major concern of the act is safeguarding the DNA sample itself.

Two questions immediately arise concerning the act's scope:

**Is There a Justifiable Basis for Defining Genetic Information So Narrowly?** It seems illogical to exclude protection of information that is indirectly obtained by taking the medical history of family members or by performing tests for the proteins expressed by particular genes. However, as the act's authors themselves note, once the definition is broadened to include any information about a person's genome, no matter what the source, it becomes very difficult to segregate it from other information contained in a patient's record.

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**Who Should Have Access to Genetic Information?** With some exceptions, the law assumes that the information contained in a patient's medical record concerns only that particular patient. The law is individualistic in its focus. Consequently, it holds (again with exceptions) that only the patient can authorize release of her record. In relying almost exclusively on the prevailing individualistic consent model for release of medical information, however, the act affords it protection that is at once too broad and too narrow.

Consider, first, why its protection is too broad: The act attempts to bring genetic information under the prevailing model by defining it in terms of its source from the DNA of a particular person, who must consent to its release. But why should genetic information be defined in terms of its source, rather than its referent? Such information tells us not only about the patient herself but also about her parents, siblings, and even children not yet born. Do not they have a claim to know about it, at least under some circumstances? To account for the familial nature of genetic information, we may need to rethink our notion of the physician-patient relationship in a clan-based way, creating a new ethos of the "family physician." The new genetics may force bioethics and biolaw, which has thus far understood patients largely in an individualistic way, to pay more attention to the essential sociality of human beings.

From another perspective, however, the protection offered by the act is far too narrow. Family members are not the only persons who might seek information about a person's genetic makeup. Employers and health insurers are also interested in obtaining that information to control costs and maintain profits. At first glance, rendering genetic information invisible to such parties seems to be a good approach. But further reflection reveals that it contains serious flaws. First, consider the matter of basic equity. Is it fair to confer protection on persons who have genetic disorders, while denying it to those whose disorders are manifest by other types of tests? Second, any attempt to recreate a world untainted by genetic information must ultimately be futile because that information is not invisible to the persons who are its source. For example, insurance companies legitimately fear that genetically compromised persons will purchase added insurance and that those without known genetic defects will be more likely to go without it. Such narrowly self-interested behavior is likely to compromise the financial viability of the existing health insurance system.

In my view, to deal adequately with the genetic revolution, we must renounce the goal of genetic

invisibility and begin the hard task of rethinking fundamental elements of the U.S. health care financing and delivery system. Most important, we need to reinterpret our common task as providing health care, not as providing health insurance. A system of health insurance made sense in an era in which risk of illness was like risk of fire. In either case, although people could take some sensible measures to protect themselves, the identity of those stricken and those spared seemed by and large to be determined by unpredictable twists of fate. The unpredictable nature of, say, fire or serious illness made it rational for a wide range of persons to throw in their lot together. In the new era of genetics, however, that is no longer the case. If we are to deal adequately with the challenges of genetic information, we must move beyond the framework of rational protection of individual and familial self-interest presupposed by the idea of health insurance. We need to move toward social solidarity, by recognizing health care as a basic right of all persons, which should be provided to all, no matter what genetic status, no matter how likely or unlikely they are to be sick during the course of their lifetimes.

### Parenthood and the Limits of Individualism

A second major area in which the new genetics will claim our attention is the procreation of children. Although it is unlikely to occur soon, the knowledge gleaned from the HGP will eventually enable us to ensure that our offspring display—or refrain from displaying—certain physical or mental characteristics.

However, long before we are able to make extensive changes in the genetic makeup of our children, we will be able to produce them through cloning. In one sense, cloning is a more radical intervention in the reproductive process than is genetic enhancement. Cloning is by definition asexual reproduction, which does not involve the mixture of parental genetic material involved in sexual reproduction. In another sense, cloning is more conservative than genetic enhancement because it is simply "copying" a person who already exists, not designing one with its own innovative and hand-picked genetic makeup.

How should Americans approach the complicated questions of law and morality involved in these new possibilities in human reproduction? To grapple with them adequately, we need to seriously reconsider the expansive understanding of the right to have a child that is so pervasive in U.S. law and ethics. To date, the primary reproductive right recognized under the Constitution has been a negative one: the right, protected by legally available access to contraception and abortion, to be free of the burdens of bearing and raising a child. The Supreme Court has never found a positive right to reproduce, a right that would protect one's legally unimpeded access to reproductive technology. Even so, many legal scholars—and one federal district court—have argued that there is indeed a constitutionally protected right allowing one to reproduce without undue governmental interference. Not that state legislatures are rushing to criminalize emerging reproductive technologies. In fact, most states have been slow to prohibit or even regulate the use of such technologies as surrogate motherhood and in vitro fertilization with donor gametes. Few states regulate the practices of fertility clinics. Very few have systematically sorted through the complex familial relationships that can arise in such situations and then gone on to adopt some version of the Uniform Status of Children of Assisted Conception Act.[12]

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This understanding of reproductive liberty, already expansive, has been slowly but inexorably stretched to cover cloning as well. Few doubt that it will eventually include the emerging developments in genetic engineering. The legal scholar John Robertson, for example, has recently published a spirited defense of human cloning in which he suggests that parents should be able to clone a minor child despite the child's lack of legal capacity to consent.[13] Robertson also argues that parents of an adult child should not be able to prevent her from cloning herself, although, should such cloning succeed, they will stand in essentially the same genetic relationship to the clone as they do to their natural child. In fact, Robertson unequivocally supports only one absolute limit on cloning: He withholds the right to initiate the cloning process from a person who is not committed to rearing the cloned child.

One can seriously critique the dominant view of reproductive liberty in U.S. law and policy from a variety of different points of view. For example, the official teaching of the Catholic magisterium, like a number of theologians, raises powerful objections to many of the new reproductive technologies on the grounds that they may undermine the equal dignity of the children who are conceived through their use. The church fears that when we bring children into being in a manner separate from the act of marital lovemaking, we inevitably treat them as "products" made to parental specifications—and, therefore, as inferior to their parents.[14] Although it is more radical than many other approaches, the church's concern for the equal dignity of children and their parents, ultimately rooted in the theological

vision of the human person as made in the image and likeness of God, does not stand isolated and alone in the broader discussion of these matters. Instead, it resonates with some strong nonreligious reasons to be concerned about cloning and other new possibilities for human reproduction. We could, drawing on the best secular moral philosophy, argue that the basic problem with the American approach to reproductive liberty is that its one-sided concern for the freedom of the parents has blinded it to the need to protect and promote the legitimate freedom of the children involved.

In his important book, *The Morality of Freedom*, the liberal legal philosopher Joseph Raz powerfully argues that autonomy is not just an individual right but also a culture-dependent value requiring social support for its continued recognition. We are not born autonomous but grow to become so—if we get care, training, and more than a little luck. Raz suggests that human beings can and should provide each other with the conditions that are necessary for the exercise of autonomy. These include:

- The mental capacities necessary to exercise autonomy, both intellectual and psychological
- Independence, understood as the absence of coercion or manipulation
- A range of morally worthwhile options from which to choose[15]

Drawing upon Raz's work, we can evaluate cloning (and, by extension, some applications of the emerging techniques of genetic engineering) in terms of its likelihood to undermine or advance the conditions of autonomy for a child born of that procedure:

**Mental Capacity** Could a child be affected negatively by the realization that she has not the usual two biological parents but only one progenitor? Is it not likely that such knowledge would affect her sense of dignity and uniqueness in a way that interferes with her self-understanding as a person charged with responsibility for creating her own future?

**Independence** Might not cloning have manipulative effects on the psychology of the child who results from it? A child who happens to have the same genetic makeup as the template a year or two further down life's path might well believe that her calling is to follow in the template's footsteps—or, alternatively, to turn her back on them. Will she pursue some options, and rule out others, solely because of the choices made by her template?

**A Range of Options** Is there not reason to worry that children produced through the cloning process might lack the wide array of options possessed by children conceived naturally? The most crucial options available to children come from their parents; the successful pursuit of life plans usually requires a solid foundation in early childhood education. Children born as a result of conventional reproduction often discover their talents and interests at the same time their parents do. Moreover, although many parents hope their children will become doctors, scientists, musicians, or Olympic athletes, they have no real expectation that these hopes will be fulfilled. Consequently, it is easier for them to defer to their children's own assessment of their interests and talents. People who, in contrast, become parents as the result of cloning (or at least with the aid of genetic enhancement) may do so with specific expectations concerning their child's talents, expectations they believe justified by the child's genetic makeup. Consequently, they may be less willing to provide her with a range of options.

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Needless to say, these considerations drawn from the work of Joseph Raz do not rule out any and every genetic alteration of human offspring. For example, we will need to draw upon and greatly refine the rough distinction between therapeutic interventions designed to cure genetic defects (which may not raise as many concerns) and non-therapeutic interventions designed to enhance the capacities of a person who would otherwise be within the normal range (which are likely to be more problematic). However, Raz's considerations do give us a way to organize our deliberations about how our newfound knowledge of human genetics may affect our ability to transmit to the next generation our key values of equal dignity and autonomy of all persons.

## Needed: A Moral Vision

As the legal theorist James Boyd White has argued, law has a constitutive function as well as a regulatory one. Law not only tells people what they may or may not do with respect to a given issue, it also provides the conceptual and imaginative framework in which they consider the question in the first place.[16] Consequently, in framing a jurisprudence adequate to the new developments in genetics, we need to consider what moral vision of our common life we want to instantiate and inculcate in the next generation.

This is a task not just for lawyers and ethicists. Because it affects such fundamental aspects of our life together as the obligations of the stronger to the weaker and the moral meaning of parenthood, it calls for moral reflection on the part of each and every one of us.

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### NOTES

1. David Stipp, "Blessings from the Book of Life," *Fortune,* March 6, 2000, pp. F21-F28.
2. "On Human Nature," *Economist,* February 17, 2001, pp. 79-82.
3. Much of the material in this paragraph is taken from Tabitha M. Powledge, "Beyond the First Draft," *Scientific American,* September 2000.
4. G. j. B. Van Ommen, E. Bakker, and J. T. den Dunnen, "The Human Genome Project and the Future of Diagnostics, Treatment, and Prevention," *Lancet,* July 31, 1999, pp. SI5-SI11.
5. W. French Anderson, "A Cure That May Cost Us Ourselves," *Newsweek,* December 27, 1999-January 3, 2000, p. 74.
6. See, for example, William Haseltine, "What the Map Means to Your Health," *Washington Times,* June 28, 2000, p. A17.
7. Nicholas Wade, "Tailoring Drugs to Fit the Genes," *New York Times,* April 20, 1999, p. F9; Cinda Becker, "The DNA RX: Advances in Genetics Give Physicians Ability to Tailor Drugs to Patients Unique Makeup," *Modern Healthcare,* August 28, 2000, pp. 24-29.
8. Health Insurance Portability and Accountability Act of 1996, U.S. Code, vol. 42, secs. 201 et seq.
9. Americans with Disability Act of 1990, U.S. Code, vol. 42, secs. 12,101 et seq.
10. Mass. Ann. Laws, ch. 111, sec. 70G.
11. George J. Annas, Leonard H. Glantz, and Patricia A. Roche, "The Genetic Privacy Act and Commentary," available online at http://www.bumc.bu.edu/www/sphlw/gpa.
12. See, for example, the Uniform Status of Children of Assisted Conception Act, North Dakota Code, secs. 14-18-01 to 14-18-07, 1997.
13. John A. Robertson, "Liberty, Identity, and Human Cloning," *Texas Law Review,* 1998, pp. 1,371, 1,388-1,403.
14. See, for example, the Catechism of the Catholic Church, para. 2,376.
15. Joseph Raz, *The Morality of Freedom,* Oxford University Press, Oxford, England, 1986, pp. 369-378.
16. James Boyd White, *Heracles' Bow: Essays on the Rhetoric and Poetics of the Law,* University of Wisconsin Press, Madison, WI, 1985, pp. 28-48.

## PERSONAL PRIVACY AND THE COMMON GOOD

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It is commendable to contribute to the genetic well-being of society as a whole by volunteering to provide information for genetic research, but one may be selective regarding any such opportunities. A person who has an unusual genetic condition may have a greater responsibility to contribute to this research because few people could make a similar contribution. Solidarity with the community of those who share a particular genetic condition that is under study may motivate altruistic involvement that is not expected of those who do not have such a condition.[28]

Finally, any decision with regard to personal and family genetic information and testing must take into account the total range of risks and potential benefits involved. In this regard, health and medical consequences—as well as the role of genetic information in marital, reproductive, and perhaps occupational life decisions—is pertinent. In addition, the possibility that a genetic test might be stigmatizing or have negative employment or insurance consequences deserves consideration. Although moral decisions do not depend exclusively on weighing consequences, responsible decisions surely require taking into account the probable consequences of one's choices. □

### NOTES

1. National Society of Genetic counselors, "Position Statements," 1995. Available at http://www.nsgc.org/about_position.asp#accesstocare
2. Pope John Paul II, "On Social Concern," 1987, para. 38.
3. Allen Buchanan, "Ethical Responsibilities of Patients and Clinical Geneticists," *Journal of Health Care Law & Policy,* vol. 1, no. 2, 1998, p. 395.
4. Edwin F. Healy, *Moral Guidance,* Loyola University Press, Chicago, 1943, pp. 10-12.
5. Rosamund Rhodes, "Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge," *Journal of Medicine and Philosophy,* vol. 23, no. 1, 1998, p. 18.
6. Buchanan, pp. 396-397.
7. Buchanan, pp. 408-410.
8. American College of Medical Genetics/American Society of Human Genetics Working Group, "Statement on Use of Apolipoprotein E Testing for Alzheimer Disease," *Journal of the American Medical Association,* vol. 274, 1995, pp. 1,627-1,629.
9. Tamar Lewin, "Boom in Gene Testing Raises Questions on Sharing Results," *New York Times,* July 21, 2000.
10. Rhodes, pp. 12-14.
11. Rhodes, p. 14.
12. Rhodes, p. 18.
13. Gary M. Atkinson and Albert S. Moraczewski, *Genetic Counseling, The Church, & the Law,* St. Louis, Pope John XXIII Medical-Moral Research and Education Center, 1980, p. 130.
14. See discussions of deceit in Ralph Brown, *Marriage Annulment in the Catholic Church,* 3rd edition, Bury St. Edmunds UK, Kevin Mayhew Ltd., 1990, pp. 82-86; and Terence E. Tierney and Joseph J. Campo, *Annulment: Do You Have a Case?,* 2nd edition, New York, Alba House, 1993, pp. 91-93.
15. Carol A. Tauer, "Preventing the Transmission of Genetic Diseases," *Chicago Studies,* vol. 33, no. 3, November 1994, pp. 213-227.
16. Pope Pius XII, "Address to Midwives," October 29, 1951. In Odile M. Liebard, ed., *Official Catholic Teachings: Love & Sexuality,* Wilmington, NC, Consortium Books, 1978, p. 113.
17. See Andrew Pollack, "Company Seeking Donors of DNA for a 'Gene Trust,'" *New York Times,* August 1, 2000; "DNA Donation Site Draws a Crowd," *Science,* vol. 290, 2000, p. 7; and DNA Sciences web site at http://www.dna.com.
18. Buchanan, pp. 415-417.
19. Barbara Bowles Biesecker, "Privacy in Genetic Counseling," in Mark A. Rothstein, editor, *Genetic Secrets,* New Haven, CT, Yale University Press, 1997, pp. 108-125.
20. Cited in Ann Sommerville and Veronica English, "Genetic Privacy: Orthodoxy or Oxymoron?" *Journal of Medical Ethics,* vol. 25, 1999, p. 149.
21. *Safer v. Pack,* 677 A.2d 1188 (N.J. Super. Ct. App. Div. 1996).
22. Ellen Wright Clayton, "What Should the Law Say About Disclosure of Genetic Information to Relatives?" *Journal of Health Care Law & Policy,* vol. 1, no. 2, 1998, pp. 384-385.
23. Clayton, pp. 387-390.
24. Atkinson and Moraczewski, p. 121.
25. Tauer, pp. 214-219; Atkinson and Moraczewski, pp. 118-131.
26. Atkinson and Moraczewski, p. 130.
27. Buchanan, pp. 406-408.
28. See http://www.geneticalliance.org.
29. Secretary's Advisory Committee on Genetic Testing, "Enhancing the Oversight of Genetic Tests: Recommendations of the SACGT," June 2000. Available at http://www4.od.nih.gov/oba/sacgt.htm

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