



# PERSONAL PRIVACY AND THE COMMON GOOD

**W**ith the announcement on June 26, 2000, that the sequencing of the human genome had essentially been completed, the medical, ethical, and social implications of this project took on new urgency. Experts predicted that genetic advances would revolutionize the way medical care was provided. Genetic tests would be available for more common diseases, such as Alzheimer's disease, cancer, mental illness, and heart disease. Genetic predisposition to such diseases would be identifiable before any symptoms appeared.

The potential availability of a wide range of genetic tests poses personal, familial, and societal dilemmas. This article will deal primarily with the personal and familial dimensions. How should individuals and families make decisions regarding genetic testing? Who should assist them in these decisions? What is the appropriate balance between an individual's privacy and the needs of others, especially family members, for genetic information about hereditary conditions?

## GENETIC COUNSELING VALUES

The profession of genetic counseling exists to supplement the advice of primary care providers when patients need genetic information and resources. Genetic counselors are committed to three dominant values:

- The central focus of counseling is the individual self-determination of the client or the client



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*Genetic  
Testing  
Raises  
Ethical  
Considerations for  
both  
Patients and  
Clinicians*

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couple; the counselor's role is to enhance client autonomy.

- The counselor is to be nondirective. The counselor provides information that the clients want and describes options to them.

- Strict confidentiality is expected regarding the client's genetic information. The position statement of the National Society of Genetic Counselors states: "It is the right and responsibility of the individual to determine who shall have access to medical information, particularly results of testing for genetic conditions."<sup>1</sup>

These three principles were developed primarily within the context of prenatal genetic testing. Within this context, genetic counselors wanted to avoid giving advice that would suggest a bias toward eugenics, an attempt to influence reproductive decisions, or a pro-abortion attitude toward the pregnancy. As a result, genetic counselors historically have subscribed to the morality of informed client choice.

## ALTERNATIVE MORAL VALUES

With current advances in genetics and the increasing use of genetic information for a wide variety of purposes beyond prenatal testing, the landscape has changed. Genetic testing may now be used as part of a preventive strategy or as an aid in determining the appropriate treatment for an individual who has a particular genetic makeup. The broadened applications of genetic testing raise new questions in relation to the three dominant values of genetic counseling. Perhaps the principles that were considered appropriate in the context of prenatal testing need to be revisited in this new landscape.

Catholic theology also suggests that the prevailing values of genetic counseling are not adequate guides for moral decisions. Three principles in particular offer a response to the three genetic counseling values:



- Catholic teaching has never held that any decision is morally acceptable just because the choice is informed and autonomous.

- Patients have duties and responsibilities as well as rights.

- Morality is not solely an individual matter. The individual is also responsible for the common good, a duty expressed through principles such as solidarity in Catholic social teaching. In the words of Pope John Paul II, solidarity is a "firm and persevering determination to commit oneself to the common good, that is to say to the good of all and of each individual, for we are all really responsible for all."<sup>2</sup>

These three principles are also gaining prominence in secular bioethics. There is a decreasing emphasis on the principle of autonomy, an exploration of patient responsibilities as well as patient rights, and a rich consideration of what is often called communitarian ethics. In his discussion of the "Ethical Responsibilities of Patients and Clinical Geneticists," Allen Buchanan emphasizes the duties of patients regarding genetic information and the responsibilities individuals may have in relation to the welfare of other persons. He says:

But from the fact (if it is a fact) that clinicians should not tell patients what their ethical responsibilities are, it does not follow that patients have no ethical responsibilities, and that whatever they do is acceptable as long as it reflects their own values and is freely chosen. Ethical responsibilities, in general, are not reducible to acting consistently on whatever values one happens to have. . . . A person's action may be authentic in the sense that it is an expression of his deepest, stable values, yet it may be a wrongful action.<sup>3</sup>

### KNOWLEDGE AND IGNORANCE

What responsibilities might an individual have regarding genetic information? Current discussions of genetic ethics debate whether an individual has any obligation to obtain genetic information through testing, or whether one has a right to

choose "not to know." Catholic theology has traditionally regarded knowledge and ignorance as morally relevant factors and has made a moral distinction between vincible and invincible ignorance.

*Vincible ignorance* means that you could have removed your ignorance. You could have known the facts or the truth, and thus you are morally responsible for acting out of ignorance. *Invincible ignorance* means that you could not reasonably have known, or could not have known that you should have sought information. Thus you are not responsible for acting in ignorance.<sup>4</sup>

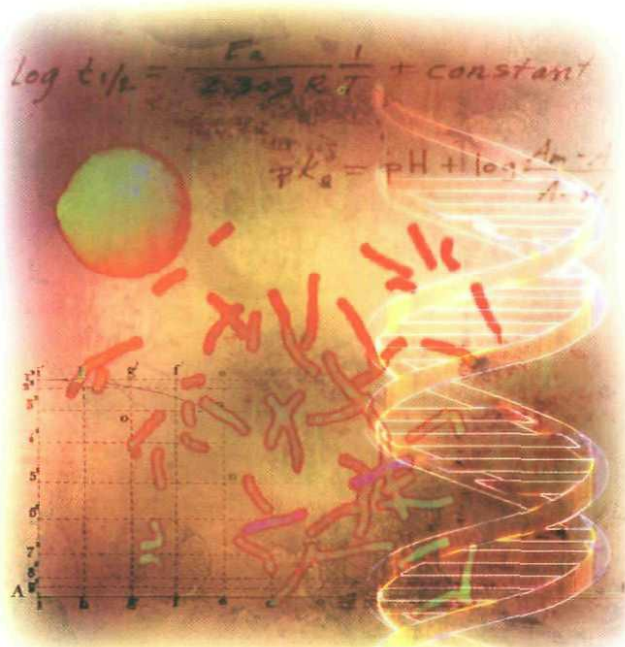
These concepts of personal responsibility stem back to Aristotle and are expressed in our legal and ethical systems by the adage, "Ignorance (of the law) is no excuse."

Some bioethicists take a strong position regarding one's responsibility to seek genetic information. They argue that you ought to find out whether you are at genetic risk and what the consequences may be, both to yourself and to others who could be affected. They claim that autonomy does not give you a right to choose ignorance. In fact, true autonomy or autonomous choice *requires* adequate information. Medical practice recognizes this fact in its requirement of informed consent, which is not possible without adequate information.

In her article on genetic knowledge, Rosamund Rhodes argues that failure to seek genetic information frequently represents vincible ignorance and is blameworthy. She says, "When I choose to remain ignorant of relevant information, I am choosing to leave whatever happens to chance." But according to Rhodes, I may still be responsible for the consequences.<sup>5</sup>

### FACTORS AFFECTING RESPONSIBILITY

In the area of genetic knowledge, one's responsibility "to know" depends significantly on two variables. The first is whether anything effective can be done as a result of having the knowledge. Can one really make any choices once one "knows" a genetic predisposition, for example? This question needs to be asked about all medical testing: What will you do after you get the results of the test? If you





can do nothing and make no choices, having the test is probably pointless. However, you may need to make nonmedical decisions (for example, choice of occupation or whether to have children), or you may have psychological benefits from knowing a test result.

The second variable is whether the genetic information affects only the individual or whether it also affects others. Ordinarily one has more leeway morally if no one else is affected. When others are affected (such as one's children or siblings), when family members may suffer harm, or when the common good is at stake, one's responsibility is ordinarily more weighty.

The analysis of moral responsibility applies differently to every genetic test, depending on such

factors as whether the test is diagnostic, predictive, or presymptomatic and whether the genetic condition is treatable or not. Buchanan illustrates the moral analysis by means of two examples in which the application is quite clear. For the condition of hereditary hemochromatosis, he believes that one has a responsibility to know one's genetic status and to inform family members if they are at risk. This genetic condition is easily treatable but is highly lethal if untreated, and the damage may be done before any symptoms appear.<sup>6</sup>

At the opposite extreme, Buchanan cites Alzheimer's disease. For this condition, one is under no obligation either to find out or to inform others that one has the APOE4 gene that is predictive of an increased risk of developing Alzheimer's.<sup>7</sup> At present no treatment or preventive strategy exists, the prediction is highly uncertain, and the genetic information itself may be stigmatizing. In fact, professional genetics organizations recommend that the gene test for Alzheimer's not be used for predictive testing at this time.<sup>8</sup>

Between these two rather clear cases, Buchanan notes a continuum of genetic conditions in which one's responsibility to know and to inform others requires careful balancing of all factors involved. Predictive tests for an increased risk of developing certain types of cancer fall between the two extremes on the continuum.

Tests for BRCA1 and BRCA2, mutations of genes that indicate a predisposition to breast and ovarian cancer, are being offered to women whose family history indicates a high risk of breast and/or ovarian cancer. Does a woman identified as high risk have any obligation to be tested in order to take preventive measures if she has the mutation? Possible preventive measures include increased monitoring, such as earlier and more frequent mammography, or highly aggressive approaches such as removal of both breasts and/or both ovaries. If a woman chooses not to know her own status, she might still have an obligation to participate in family linkage studies for the sake of other family members who want the information. And if a woman does know her own genetic status, she might be obligated to share this information with close relatives. Anecdotal information indicates that some relatives benefit from receiving the information, whereas others truly may not want to know.<sup>9</sup>

Testing for the gene that indicates a predisposition to colon cancer (hereditary nonpolyposis type) presents similar dilemmas. However, the preventive strategies are somewhat less controversial than those for breast cancer and are highly effective. Frequent colonoscopies enable the removal of polyps before they become cancerous

## BENEFITS AND RISKS OF TESTING

Every type of genetic testing carries benefits and risks related to the results of testing. The following summary was prepared by the Secretary's Advisory Committee on Genetic Testing, established at the National Institutes of Health to conduct a public consultation (request for public views) and to make recommendations on the oversight of genetic testing. The committee's recommendations were issued in June 2000.<sup>29</sup>

### CONSEQUENCES OF A POSITIVE TEST

#### Potential Benefits:

- May provide knowledge of diagnosis or risk status
- May allow preventive steps or treatment interventions to be taken
- May identify information about risk status in other family members (also a potential harm)
- May facilitate reproductive decisions [added by author]

#### Potential Risks:

- May expose individuals to unproven treatments
- May cause social, psychological, and economic harms, including stigmatization and potential exclusion from insurance and employment
- May identify information about risk status in other family members (also a potential benefit)
- For false-positive test results, may expose individuals to unnecessary screening and treatment

### CONSEQUENCES OF A NEGATIVE TEST

#### Potential Benefits:

- May rule out specific genetic diagnosis or risk
- May eliminate the need for unnecessary screening or treatment
- May facilitate reproductive decisions [added by author]

#### Potential Risks:

- May give false reassurance regarding risk due to nongenetic causes
- May have psychological effects, such as "survivor guilt"
- For false-negative test results, may delay diagnosis, screening, and treatment



without requiring removal of part of the colon itself. These facts may reinforce one's responsibility to know one's own status and to inform others who are affected.

### CASE SCENARIOS

The analysis of an individual moral decision regarding genetic testing incorporates three elements:

- Assessment of whether an effective response is available if the test result is positive
- Consideration of the interests of family members who may be affected by test results
- Examination of the overall benefits and risks of knowing a test result

Case scenarios help illustrate the complexity of the individual decision process. The following scenarios are abbreviated versions of cases proposed by Rhodes.<sup>10</sup> They feature four characters: Tom, Dick, Harry, and Harriette.

**Case 1** In families with a history of Huntington's disease, a particular genetic pattern identifies persons who will develop the disease. However, population-based studies of Huntington's have not been done, and whether this same genetic pattern is an indicator of the disease when no family history exists is not known. If Tom's family has no history of Huntington's disease, but he is invited to be part of such a population study, should he volunteer? Does he have any obligation to volunteer?

**Case 2** Dick has been diagnosed with Marfan syndrome, an inherited disorder of the connective tissue. Dick's cousin Martha wants to know (presymptomatically) whether she has the gene for Marfan syndrome. The best way for her to find out would be through family linkage studies that would identify a familial pattern associated with the genetic defect. For this linkage study, Martha needs a blood sample from Dick. Does Dick have a moral responsibility to provide this sample? Suppose Martha wants the results mainly so she can use prenatal testing to avoid having children with the disease; does her intention affect Dick's responsibility?

**Case 3** Harry's father died of Huntington's disease at age 49 years. When tested for the genetic marker, Harry's brother was found to be unaffected, but Harry has refused the test because he does not want to know. Now Harry is planning to marry Sally, who does not know about his genetic risk. In this situation, does Harry continue to have a right not to know his genetic status? What is his obligation with regard to informing Sally and including her in future decisions?

**Case 4** Harriette's sister's child died of Tay-Sachs disease after a brief life of suffering. Both Harriette and her husband are part of an ethnic community known to have a high percentage of

A scientist  
who discovers  
the gene for  
any disease  
knows that it  
may eventually  
be used for  
prenatal testing  
for abortion.  
This possibility  
is not an  
adequate  
argument for  
opposing all  
genetic  
research.

Tay-Sachs carriers. Although Harriette and her husband could be tested for carrier status, they refuse, saying they have decided to have children and to take whatever happens. Is it morally acceptable for them to choose to be ignorant of their status? In Rhodes' words, "Is it ethically permissible. . . to take this chance for [their] child?"<sup>11</sup>

Rhodes argues that all four of these cases carry an obligation. Tom should contribute to the common good by participating in research; Dick should help his cousin Martha; Harry needs to know his genetic status because of decisions he has to make about marrying and having children; and Harriette needs to know because of potential harm to future children. Rhodes believes that one is acting irresponsibly whenever one chooses to remain ignorant and to rely on chance.<sup>12</sup>

### ANALYSIS OF CASE SCENARIOS

Is Rhodes correct in attributing such responsibilities to these four people? For the moment, let us put aside Tom's involvement in research and turn to the other three cases. In these three cases, specific decisions depend on the outcome of testing, and these decisions affect the welfare of other individuals besides Dick, Harry, and Harriette. The criteria suggested earlier—whether other persons are affected and whether effective responses to knowledge of increased genetic risk even exist—incline one to agree with Rhodes' conclusion that each of these individuals has a responsibility to obtain genetic information and/or to share information with others who are affected and who have choices to make. Is this the correct conclusion in these three cases?

**Case 2** Because Dick already knows that he has Marfan syndrome, the blood sample he could provide Martha will not lead to new information about his own medical condition. He will neither benefit nor suffer harm as a result of responding to Martha's request. The risk and inconvenience of giving a blood sample are minimal when weighed against what Martha perceives to be a great benefit to herself, and thus Dick appears to have little justification for refusing her request.

What about her intent to use the results for future prenatal testing? Martha may find she does not have the genetic marker that indicates Marfan syndrome, which would mean she could have children without concern. Even if she does have the marker, her plan to have prenatal testing is purely hypothetical at this point. She may well choose other alternatives, such as not to have children or to find out more about Marfan syndrome in order to be prepared for the possible birth of an affected child.

Because morally acceptable ways for her to



make use of the genetic information do exist, and because prenatal testing and selective abortion are not her immediate plan, I believe Dick would not be morally responsible if she should eventually use the information for this purpose. Consider the following analogy: A scientist who discovers the gene for any disease knows that it may eventually be used for prenatal testing leading to abortion. This possibility is not an adequate argument for opposing all genetic research. Jerome Lejeune, an abortion opponent, discovered the chromosomal anomaly for Down syndrome and many other birth defects. He published these results but consistently opposed the use of his discoveries for selective abortion. He would not be considered morally responsible if prenatal chromosomal testing results led some parents to choose abortion.

**Case 3** The majority of persons who have Huntington's disease in their families choose not to be tested. Thus, Harry's wish not to know whether he carries the Huntington gene is very understandable. If he does carry the gene, however, there is a 50 percent probability that each one of his children will have the gene and, therefore, the disease. Knowledge of his genetic risk is a factor in his decisions whether to marry and whether to have children. In making these decisions, he may not choose to act out of ignorance; the genetic facts available to him must be included in a responsible decision-making process.

Even stronger arguments obligate him to inform Sally of his risk status, whether he takes the test or not. Entering into a marriage covenant with Sally while withholding information that is central to their union and to Sally's ability to give a free consent to the marriage would be deeply dishonest.<sup>13</sup> Harry's deliberate withholding of such important information could possibly contribute to grounds for annulment if Sally found out after they married.<sup>14</sup>

**Case 4** In my article, "Preventing the Transmission of Genetic Diseases," I argued that some genetic diseases are so severe that couples are morally obligated to avoid knowingly transmitting them to their children.<sup>15</sup> Tay-Sachs, which causes physical and mental deterioration in infancy and results in death within two to four years, is one such disease. Because Harriette's sister is known to be a carrier of Tay-Sachs, a high probability exists that Harriette is also a carrier. If both she and her husband are carriers, each of their children will have a 25 percent probability of having the disease.

Morally, Harriette and her husband may not choose to be ignorant when such a serious harm is at stake. They are probably not both carriers, which would mean they could have children with-

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out concern. If they are both carriers, they can avoid the high risk of having children with the disease by not procreating. For Catholics, preventing the conception of severely diseased offspring is a morally acceptable justification for long-term use of natural family planning. Pope Pius XII stated that "Serious reasons . . . put forward on medical [or] eugenic grounds" permit a couple to avoid the woman's fertile period "even for the entire duration of the marriage."<sup>16</sup>

The fact that three of Rhodes' four cases incorporate reproductive decisions suggests that avoiding these issues in a discussion of genetic testing is difficult. For example, the possibility exists that women carrying the BRCA1 or BRCA2 gene mutations that predispose to breast cancer might consider prenatal testing for sex, with the intention of aborting a female fetus. Tests recommended for preventive or diagnostic purposes may also have implications for reproductive decisions.

#### GENETIC RESEARCH

The first case, regarding Tom's opportunity to participate in genetic research, is of a very different type. Rhodes claims that Tom has a moral obligation to accept an invitation to participate in population-based genetic research. Most ethicists would disagree with this conclusion, however. Although Tom would be altruistic to participate in research, this action would not be obligatory.

Each of us has many opportunities to contribute to the good of the community, and participation in medical research is one such opportunity. Catholic teaching requires each of us to contribute to the welfare of others through acts of charity, traditionally called "works of mercy." Medical practice, including medical research, is a work of mercy, an aspect of assisting the sick and the suffering. Volunteering to participate in medical research is a response to the obligation to contribute to the community through performing works of mercy.

But there are many other ways of fulfilling this obligation, and one is permitted to choose among them. No one can do every good work that presents itself. Tom cannot be required to respond to every invitation to participate in research, although he might have a particular obligation to accept the invitation from the Huntington project if his genetic makeup is of special value in relation to the goals of this study.

As a result of progress in the sequencing of the human genome, numerous opportunities have been created for each of us to respond to requests for health history and genetic data to be used in population-based genetic research. One of the most highly publicized efforts is the DNA Sciences



Gene Trust Project, which gathers personal information from volunteers on its website and then requests blood samples from selected respondents for DNA collection.<sup>17</sup> The development of such databases raises questions about the adequacy of informed consent procedures and privacy protections. For example, respondents provide information that may impinge on their family members, but these relatives have not been asked for consent. The unresolved ethical questions related to such large-scale genetic research projects suggest additional reasons why an individual could not have a moral obligation to participate in this research, although one may voluntarily choose to do so.

### DUTIES OF CLINICIANS

What responsibility does a clinician have when a patient's genetic information affects others? Genetic counselors agree that a patient must be informed about risks to relatives and encouraged to share pertinent information with them. Buchanan believes that, in some cases, the clinician should go further.

Where the prevention of serious harm is at stake, one should not assume that clinicians must abstain from communicating to the patient any ethical judgment whatsoever. . . . There are instances in which a patient's ethical obligation to inform relatives is clear and uncontroverted, in the light of the widely accepted principle that we ought to prevent serious harm. Informing the patient that this is so need not involve "imposing values."<sup>18</sup>

In some cases the clinician may believe sharing genetic information with family members is important, but the client chooses not to do so. Is the clinician ever permitted, or perhaps required, to *communicate with family members without consent of the client*?

The position statement of the American Society of Genetic Counselors (cited earlier) implies that confidentiality must take priority and be inviolate. However, in discussing this obligation genetic counselors recognize some exceptions in rare situations.<sup>19</sup> Buchanan argues that although informing a client's relative(s) is not obligatory, disclosure is permissible under these four conditions:

- The risk or harm to the relative(s) is a serious one
- The harm is likely to occur if the relative is not informed
- The harm is preventable through medical means or personal choices
- The information provided is likely to be acted

on (difficult for the clinician to assess in most cases)

The British Royal College of Physicians suggests that the clinician may have an *obligation* to inform relatives. In the college's view, genetic information is *not* particularly personal, but is the common property of those who share particular genes:

Because of the nature of genes, it may be argued that genetic information about any individual should not be regarded as personal to that individual, but as the common property of other people who may share those genes and who need the information in order to find out their own genetic constitution. . . . If so, an individual's *prima facie* right to confidentiality and privacy might be regarded as overridden by the rights of others to have access to information *about themselves* [emphasis added].<sup>20</sup>

Of course, if a clinician decides that confidentiality must be broken, then the client involved should be forewarned.

The positions of the American Society of Genetic Counselors, Allen Buchanan, and the British Royal College of Physicians present a range of views on what clinicians ought to do or are permitted to do. Buchanan's view represents a widely accepted set of general conditions under which one is permitted to violate a client or patient's confidentiality to prevent harm to others. However, the genetic sphere may be somewhat unique, and further discussion is warranted.

### LEGAL DUTIES

From a legal perspective, to date only one appellate level case has recognized a legal duty on the part of physicians to inform family members of genetic risks. In 1996 an appellate court in New Jersey ruled that a physician was obligated to inform the children of a man who died of colon cancer that they were at increased risk of developing this disease.<sup>21</sup> The court did not specify how information is to be conveyed, but says that "reasonable steps" must be taken "to assure that the information reaches those likely to be affected or is made available for their benefit."<sup>22</sup>

In this particular case no evidence was presented that the patient had any objection to his children's having the information. The patient was probably not adequately informed by his physician that the children needed to know. Violating confidentiality to see that the information was provided to the children would probably not have been necessary.

A highly respected commentator on this case

What  
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maintains that the legal opinion is badly reasoned and should not be viewed as a legal precedent on the clinician's duty to inform.<sup>23</sup> Undoubtedly we will see more cases of this type before the legal duty of the clinician is clarified.

#### **ETHICAL CONSIDERATIONS FOR PATIENTS AND FAMILIES**

A decision whether to pursue genetic testing is often a difficult one, requiring consideration of many factors. The decision whether to inform family members and relatives about their genetic risk raises an additional problem.

The crucial ethical concept for genetic decision making is *responsibility*. What course of action would a responsible individual pursue? Responsibility requires thoughtfulness and reflection, concern for the interests of all who are affected, and the courage to take difficult or unpleasant decisions and actions. Regarding genetic testing and genetic options, the person(s) directly involved bears responsibility for the choice of a morally good option. No authority, religious or secular, can tell a person or family what is the right thing to do.<sup>24</sup> This choice is their moral responsibility, and they will live with the consequences of any decision, including a decision to do nothing.

Making responsible decisions requires seeking pertinent information. One may be morally blameworthy for acting out of ignorance if one is aware that information is available but chooses to ignore it. A person at genetic risk is not necessarily required to undergo genetic testing. In some situations testing may be obligatory. But in other situations, simply acquiring information about the genetic condition, one's options, and the likely consequences would be adequate to enable one to make a responsible decision not to be tested.

In assessing the moral obligation to seek genetic information or to undergo testing, the question of what one would do with test results is crucial. As noted earlier, if nothing can be done as a response to a positive test result, then little point exists to having a test; not pursuing testing may therefore be advisable. Some currently available genetic tests offer the opportunity for treatment (hemochromatosis) or preventive strategies (breast and colon cancer) if a test is positive. Many tests, whether for carrier status or for a genetic disease, provide information to consider in making marital and reproductive decisions. For some members of families at high risk for a particular condition, distress at not knowing their genetic status may be so great that the prospect of simply finding out may be enough for them to choose to be tested.

According to Catholic teaching, a person is

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obligated to care for his or her health and to take suitable measures to protect and preserve health. Thus, if one is at high risk for a treatable condition, or in a situation in which effective preventive strategies exist, then one is required to take reasonable measures to obtain information to pursue these health measures. Genetic test results may form part of the critical information base.

A person is also obligated to protect the health of those under his or her care. Within families this obligation applies mainly to one's children. Thus an obligation exists to share with one's children (at an appropriately mature age) the genetic risks associated with their family membership. Family health history should be shared with offspring, and genetic information is a specific part of this history.

Responsibility for protecting the health of one's children, it could be argued, includes avoiding the conception of offspring when the risk is high of transmitting a severe or lethal genetic disease. Prospective parents who face this decision need to recognize the moral seriousness of the decision and the fact that Catholic teaching, explicitly enunciated by Pope Pius XII, supports the choice to avoid conception in such cases. Nevertheless, the decision remains the moral responsibility of each individual couple, and no one else can make it for them.<sup>25</sup>

A person at genetic risk, or someone who has had a positive genetic test result, may also have a responsibility toward a wider circle of persons. A potential marriage partner is crucially affected, and to conceal such information is deceptive and a violation of the commitment and mutual giving required by the marriage covenant.<sup>26</sup> One's siblings may need genetic information to protect their own health and to make marital and reproductive decisions. The obligation to share such information with relatives is stronger depending on the degree of relationship, and are likely to want the information and whether they are apt to pay heed to it. One would not be obligated to inform relatives who clearly do not want to know or who are estranged. A test of whether information should be communicated is whether conveying it would serve any useful purpose. The question of how far one's responsibility extends in the web of relatives depends on a variety of factors. Generally one is less responsible for those at greater distance (cousins, second cousins), partly because their genetic connection, hence risk, is presumed to be weaker.<sup>27</sup>

Although one has an obligation toward the common good, or the good of all in society, this obligation is fulfilled mainly by being responsible regarding one's own genetic health, that of one's offspring, and that of one's more immediate relatives.

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## JURISPRUDENCE AND GENETICS

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### NOTES

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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.<sup>28</sup>

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

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