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Roger B. Dworkin

*Indiana University Maurer School of Law*

Gilbert S. Omenn

*University of Washington - Seattle Campus*

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# LEGAL ASPECTS OF HUMAN GENETICS

*Roger B. Dworkin*

Indiana University School of Law, Bloomington, Indiana 47405

*Gilbert S. Omenn*

School of Public Health and Community Medicine, University of Washington, Seattle,  
Washington 98195

## INTRODUCTION

Knowledge of human genetics, the relative prevalence of genetic disease, and clinical genetic services have increased dramatically in recent years. Many of the 3–5% of newborns with significant congenital anomalies have conditions that are genetic. The proportion of infant deaths from genetic causes is estimated to have risen from 7% in 1915 to about 20% today, largely because of the reduction of infant deaths from other causes. Genetic disorders are major causes of death in the 1–4 year age group. Twenty-five to 30% of under 18-year-old and perhaps 13% of adult acute care hospital admissions are for genetic or genetically influenced conditions (53, 78, pp. 803–4).

As genetic disease has increased in importance, so too have methods for dealing with it. Genetic screening, genetic counseling, prenatal diagnosis, new reproductive technologies, conventional therapies, and potentially even gene therapy offer hope and information to an ever-increasing number of families. With increased knowledge and increased hope, however, come increased responsibilities, occasional disappointments, and ethical dilemmas (52a, 57). Disappointed persons may seek to use the law to establish responsibilities and to obtain compensation. Similarly, disputes over ethical and moral values may be transformed into legal actions.

In this chapter we examine some of the legal issues posed by new developments in human genetics and make some tentative observations about where the law may be headed. The law of human genetics is very new and largely

undeveloped. Therefore, any conclusions expressed here are highly speculative. Also, the law varies from state to state. Persons with specific questions should consult an attorney in their own jurisdiction.

## ADVANCES IN GENETIC SERVICES

Clinical genetics has blossomed as a field of medicine during the past 20 years as a result of remarkable scientific progress and numerous practical applications of genetic principles in diagnosis, treatment, and counseling of patients and their families (75a, 80). More than any other field except perhaps infectious diseases and traumatic injury, genetics bridges clinical medicine and public health (16a, 57, 60a). The individual patient is almost always considered part of the larger unit of the family or broader community. Genetic disorders are no longer viewed as rare and exotic, untreatable and inevitable. A much more activist approach to at least some of these diseases is feasible now, and treatments drawn from the full array of the medical and surgical armamentarium have been applied. Many treatments depend on knowledge of the biochemistry or enzymology of the disease; others involve surgery in circumstances of early diagnosis; still others utilize manipulation of the diet or manipulation of the immune response (53a).

Against this background, the relatively simple procedure of amniocentesis has revolutionized the practice of clinical genetics and genetic counseling and enhanced interest in genetic screening (53b). With this procedure to sample fetal cells from the amniotic fluid, specific tests of chromosomes, DNA, enzymes, and other proteins can be applied to pregnant women at "high risk" of delivering infants with certain birth defects or other genetic disorders. Previously, the physician could offer only statistical estimates of the likelihood of occurrence or recurrence of these disorders; now prospective parents can learn whether the fetus is affected or not affected. It must always be emphasized, however, that these tests cannot guarantee a "normal" baby, since there are many disorders for which no tests are available.

Amniocentesis should be performed by a skilled obstetrician only after the patient (couple) has received appropriate genetic counseling and has given informed consent. The safety and efficacy of this procedure were studied intensively as the technique was being introduced, a model of technology assessment in medicine. The timing, at 14–17 weeks of pregnancy, is determined by the time of appearance and accumulation of sufficient amniotic fluid. Chromosomal or biochemical studies generally require about 3 weeks to complete in the laboratory, so the couple must wait until the seventeenth to twentieth week of pregnancy to learn the results. Major indications for mid-trimester amniocentesis are listed in Table 1.

**Table 1** Indications for midtrimester amniocentesisCytogenetic studies on cultured amniotic fluid cells

- Mother's age > 35
- Previous child with Down syndrome
- Family history or carrier status for chromosomal disorder
- Determination of sex in X-linked disorders

Biochemical studies on amniotic fluid

- Previous child with neural tube closure defect
- Linkage study for myotonic dystrophy

Enzymatic analyses on cultured amniotic fluid cells

- Previous child with testable inborn error of metabolism
- Couple at risk for Tay-Sachs disease, detected by population screening

Gene studies on cultured amniotic fluid cells

- Couple at risk for  $\alpha$ -thalassemia

The complexities that arise with new tests can be illustrated with the alpha-fetoprotein (AFP) test for detection of neural tube closure defects (open spine, spina bifida, anencephaly). AFP is a normal plasma protein that is thought to "leak" into the amniotic fluid through neural tube defects. Some crosses into the maternal circulation. Instead of a qualitative change in chromosome pattern (such as trisomy 21 in Down syndrome), this disorder presents with a quantitative increase in measurable AFP in amniotic fluid and in maternal serum. Testing for increased AFP was rapidly accepted for prenatal diagnosis of fetuses in families with a previous, severely affected child (recurrence risk about 4%). However, there was a question of whether to do this test when amniocentesis was indicated to rule out Down syndrome or some other specific testable disorder. The fluid was already available, so it seemed desirable to add this inexpensive test. Since the general population incidence is only 0.2%, there is a problem with false positives and false negatives, as in most quantitative assays, and the normal range is influenced by gestational age and several other factors. Should a test be performed that the parents did not seek?

It was soon recognized that the appearance of AFP in maternal serum could be monitored as a means of screening to detect high-risk pregnancies before the couple ever had experienced the birth of an affected child. From a public health point of view, this screening approach is far more effective in reducing the incidence of neural tube defects than is waiting until a case has occurred in a family before beginning to test. Like all other screening tests, the population incidence, the specificity and sensitivity of the test, and the scheme for confirmation and management of the cases become crucial; these matters have been discussed in a previous volume of the *Annual Review of Public Health* by Holtzman et al (39b). Maternal serum screening for AFP has been introduced as

a routine part of obstetric care in the United Kingdom, but its introduction in the United States was delayed and has been rejected because of the lower population incidence and attendant higher proportion of false positives and because of the lack of organized public health service networks in this country. An additional twist in this case was the tortuous path for FDA approval of a test kit for AFP. Obstetricians opposed approval for fear of liability should the tests not be done or should tests be interpreted inappropriately; pediatricians and clinical geneticists insisted that approval should be tied to requirements for genetic counseling and follow-up; but organized medicine (the AMA) objected to the FDA's efforts to respond to these positions by placing certain constraints on this aspect of the practice of medicine! A test kit was finally approved, with instructions that testing be closely tied to genetic services.

Another eye-catching indication for amniocentesis in Table 1 is the determination of sex. This is a simple matter, since male and female fetal cells differ in their chromosome complement (46,XY for males; 46,XX for females). At present, amniocentesis followed by chromosome analysis for sex is used only in the very specific circumstances of X-linked recessive disorders of which the mother is known or thought to be a carrier and for which no biochemical test is available. The parents seek such testing in order to learn whether the fetus is female, indicating a daughter who will be unaffected (either genotypically normal or a carrier, like the mother), or a male. They will have already decided to consider terminating the pregnancy of a male fetus, despite the fact that they cannot know whether that fetus is affected or entirely normal. Examples of diseases for which this indication applies are Duchenne muscular dystrophy, hemophilia, and Lesch-Nyhan disease. Obviously the same testing could be applied to pregnancies by couples simply wanting to know the sex of the baby or wanting to terminate a pregnancy of undesired sex, either male or female. A few such requests have been experienced at most genetic counseling centers around the country, but most inquirers desist when they are informed that the test cannot be performed until well after the mother experiences "kicking" by the baby and that results would not be available until 18–20 weeks of pregnancy. The use of ultrasound visualization of the fetus, essential for fetoscopy and helpful in amniocentesis, vividly demonstrates the viability of the fetus and may well accelerate maternal/fetal bonding.

Thus, the late timing of amniocentesis helps assure that only serious problems will be addressed with this procedure, even though it would be desirable in many cases to be able to help the couple with information as early as possible in the pregnancy, whether they go ahead with the pregnancy (the vast majority, given the high odds of reassuring test results) or not. There is no question that the overriding social and political issue facing prenatal diagnosis is the controversy over abortion. Some parents who find abortion unacceptable in other circumstances choose to terminate a pregnancy in which the fetus is proved to

have a severe birth defect. Some couples are willing to have additional children only with the assurance that such testing is available. Others seek prenatal diagnosis, even though their personal and religious views preclude termination of the pregnancy, in order to prepare for the birth of an affected child with special needs.

First trimester testing is now becoming feasible with a procedure known as chorionic villus biopsy. A variety of techniques for chorionic villus sampling (CVS) has been reported from China, USSR, France, UK, Italy, and the US (8a, 59a, 64a). A *CVS Newsletter* in conjunction with the Hereditary Diseases Section of the World Health Organization (WHO) shows a high level of international interest, since this procedure can be carried out on unanesthetized outpatients, offers information early in the first trimester, may be applicable for major disorders in developing countries (such as thalassemias and sickle cell disease), and may find greater social and legal acceptance than has amniocentesis in certain European countries (64a). Ironically, development of these techniques was delayed a decade when systematic studies demonstrated the safety and efficacy of amniocentesis.

In brief, chorionic villus sampling involves insertion of an endoscope through the vagina and uterine cervix to permit needle aspiration of villi from either the implantation site (chorion frondosum) or the extraplacental chorion (which will degenerate). A successful biopsy yields fetal tissue uncontaminated with maternal cells and with minimal risks. The expensive aspect of the technique is the use of real-time ultrasound to identify the implantation site and to guide the endoscope. The risk of damage to the placenta can be avoided by sampling the degenerating extraplacental chorion, but that tissue may give unreliable results. The risk of increasing the "normal" rate of spontaneous miscarriage must be considered and investigated; preliminary results are quite encouraging, though there are sometimes technical difficulties in negotiating the cervical canal and reaching the chorion frondosum. Great care must be exercised to rule out maternal contamination from the passage through the endocervical canal. The optimal time for sampling appears to be 9–10 weeks of pregnancy (from the last menstrual period). Extensive investigation will be necessary to demonstrate for which enzymes these biopsy specimens reflect the characteristics of cells tested in midtrimester or after birth. Some diagnoses will be feasible by detecting mutations of polymorphic markers in the DNA itself. Chorionic villus biopsy offers the advantages of direct biochemical chromosomal analyses without the time-consuming cell culture step required for amniotic fluid.

As this technique comes into wide use (about 1000 pregnancies tested worldwide as of April 1984), public demand for this service may grow rapidly, far exceeding amniocentesis demand. The likelihood of use for determination of fetal sex will be greater. The diffusion of the technique to obstetricians

unassociated with counseling centers may increase the risk of misunderstandings and subsequent litigation.

These techniques for prenatal diagnosis will be essential for intrauterine therapies that are being developed. Rare vitamin-responsive inborn errors of metabolism may be treated by administration of large doses of vitamin to the mother; oral cyanocobalamin (B<sub>12</sub>) was used to treat methylmalonic aciduria in this way (53b). Surgery on the fetus is becoming frequent, especially for congenital defects affecting the urinary tract. The direct tie to first trimester genetic diagnoses, however, may come with further advances in the introduction of specific genes. Candidates are those for adenosine deaminase and purine nucleoside phosphorylase (deficiencies cause immune deficiency), hypoxanthine-guanine phosphoribosyl transferase (deficiency causes the Lesch-Nyhan syndrome of mental retardation, self-destructive behavior, and gout), and citrullinemia and other blocks in ammonia metabolism (which cause mental retardation). These genes have been cloned; they may function without the precise intracellular regulation that should be required for the globin genes (sickle cell disease, thalassemia) or immunoglobulin genes; and retroviruses may be useful carriers (46a). The problems lie in finding suitable means of introducing the genes to target tissues, means of assuring their expression at adequate levels, and criteria for determining when and how to begin such experiments with human beings (1a, 58).

## GENETIC MALPRACTICE

Persons disappointed with the outcome of genetic screening or genetic counseling may seek compensation by bringing a malpractice suit against those they believe are responsible.

The law of malpractice, including genetic malpractice, is part of the law of torts. Stated oversimply, tort law has two primary goals: the reduction of the likelihood of harm in society and minimization of the impact of those harms that do occur. Behaviorally, the law assumes that the risk of liability will encourage safe behavior. Economically, it assumes that losses are less devastating if distributed, for example, from the patient who is injured, through a doctor and an insurance company, to the company's policy holders (other doctors), and eventually to all patients in the form of increased health care costs, than if left to be borne entirely by the injured patient.

Since avoidance and allocation of losses are the primary goals, the first legal questions to ask in a medical genetic context are: what are losses, who may suffer them, and how much are they worth.

### *Claimants and Injuries*

Six types of persons may plausibly be expected to assert claims in the genetic disease context:

1. A patient whose own care could have been improved by a correct diagnosis or provision of adequate, accurate information. Such a patient's injuries give rise only to the same kinds of evaluation questions that arise in any case of misdiagnosis or misinformation. They are not affected by the genetic nature of the disease and will not be discussed further here.

2. Parents who abort a healthy child because they received erroneous or no genetic information or prenatal diagnosis. These claimants have obviously been injured. They are unlikely to receive substantial compensation, because the law has taken a very restrictive position on compensation for the death of unborn children (1, 48); however, the law is becoming less restrictive in this regard. If a practitioner were consciously to adopt a policy of erring on the side of encouraging abortion by overstating risks, substantial liability, including punitive damages, likely would be imposed.

3. Parents who bear an affected child because they received erroneous or no genetic information or prenatal diagnosis. These are the most likely claimants. Liability to them may be substantial. These parents will claim both economic and emotional loss from the preventable birth of an affected child. Economic loss includes the full range of special medical, custodial, and training costs the child may require over a lifetime (4, 62, 66, 67).

Emotional distress damages raise a harder question. Some courts allow recovery because of the clear legitimacy of the parents' claim and the foreseeability of the emotional suffering that negligent genetic counseling that leads to the birth of an affected child will cause (5). Others deny compensation because of the difficulty of measuring emotional loss in financial terms and a fear of faking (41). The view that results in compensation seems likely ultimately to prevail. The opposite approach is rooted in old doctrine that developed in nonmedical contexts. It is out of step with modern tendencies to provide fuller compensation to injured persons and to recognize the legitimacy of protecting interests beyond the merely physical.

A fair prediction seems to be that parents who would have refrained from conceiving or who would have aborted an affected fetus if given correct information, but who conceived or did not abort because of negligent failure to provide information or the negligent provision of incorrect information, will be permitted to recover both their economic losses and compensation for their emotional distress.

4. Siblings of an affected child. Siblings may claim that the birth of an affected child into the family deprived them of their fair share of parental attention and money. Such claims are probably not compensable (17), except perhaps in California (22).

5. The affected child. Acting through a guardian, an affected child may sue for "wrongful life," alleging that he would have been better off never to have been born than to have been born in his actual condition (63a). Until 1982, this claim was rejected every place it was litigated (4, 25, 27, 30). Courts generally



reject the claim because damages are too difficult to measure, as they cannot compare the monetary value of an injured life with the void of nonexistence, and because of the view that life is always better than nonlife. Neither of these arguments seems persuasive. Courts have long awarded damages for unmeasurable injuries, such as pain and suffering; nothing prevents them from doing so here. And a preference for life at any cost is hardly consistent with recent developments favoring a patient's "right to die" in some circumstances, which has been gaining considerable judicial (50, 56, 68) and legislative (10, 56) support nationwide.

Nonetheless, in at least one type of case a good reason to deny recovery to the child may exist. If the child's condition is one that will cause him to die early in life, the practical effect of compensating the child is to compensate his estate, which, of course, will be his parents. Since the parents have their own claim to compensation for their injuries, such a result would constitute a windfall to them. Moreover, by requiring compensation when no independent loss exists to compensate, this result would unnaturally inflate the costs of medical care. The system strives to make each activity pay its true costs, not to distort the market by imposing additional ones.

Three states, California (71), Washington (37), and New Jersey (58a), have now recognized a child's claim for wrongful life, but each state has been careful to avoid multiple recoveries and to limit the size of awards. The courts only awarded the children actual economic losses for care and training. They denied claims for so-called "general damages" to compensate a child for pain, suffering, loss of dignity, etc; and they specifically limited out-of-pocket awards to either the child or the parents, not both. Thus, the California, Washington, and New Jersey cases have only a slight practical impact. They provide financial care for the child regardless of the availability of the parents, and go no farther. Logically, however, no sound basis exists to deny general damages once the legitimacy of the child's claim has been recognized. Therefore, a future court is likely to permit such an award, dramatically increasing potential liability.

However circumscribed the damage award may be, if the wrongful life cause of action is recognized, many questions about it remain unresolved. First, how severe must the child's defect be to permit compensation? The three cases to date have involved hereditary deafness, fetal hydantoin syndrome, and congenital rubella syndrome. What else will qualify? Four possible answers, none of which is acceptable, present themselves:

- (a) The child will only be compensated if its condition is so bad that life is worse than no life. Courts will be loathe to make such assessments, and the cases already decided show that some other standard is being applied. Few would consider deafness a fate worse than death.
- (b) The child will only be compensated if its condition is so bad that its mother would have obtained an abortion had she been properly informed. This test is unacceptable because it gives mothers an incentive to lie and allows a

- child's claim to be determined by his mother's religious and moral views and her perception of a particular anomaly.
- (c) The child will only be compensated if its condition is so bad that a reasonable mother would have obtained an abortion if she had been properly informed. This is really only the first approach stated differently. No court can say which conditions require a reasonable mother to abort.
  - (d) Any child will be compensated for any unusual medical or educational expense that proper genetic counseling and prenatal diagnosis could have avoided. This approach will lead to uncontrollable, unpredictable recoveries for countless trivial imperfections. It is unworkable.

The courts have not yet begun to grapple with this question of how severe a child's condition must be before the child can be compensated.

A second question posed by the recognition of a claim for wrongful life is whether the child has such a claim against anyone other than the involved medical personnel. Specifically, may the child recover from his parents for being born with a defect (51, 63)? An intermediate appellate court in California answered that question in the affirmative (21). That case involved alleged negligence by a medical laboratory, which performed Tay Sachs testing. The court went out of its way to observe that if a case should arise in which all medical personnel performed properly, but the parents nonetheless chose to bear an affected child, the parents should have to compensate the child for the injury they caused it. This suggestion was rejected promptly by the California legislature (9). It seems inconsistent with notions of free choice in reproductive decision making (59), implies an obligation to obtain an abortion, and raises the spectre of extraordinary involvement in women's lifestyle decisions. No other court seems likely to adopt such an extreme position.

Nevertheless, some courts have imposed obligations on mothers to their unborn children (34, 45, 51, 63), and in some circumstances such obligations may be appropriate. For example, some persons may think it appropriate to impose liability on a mother with PKU who causes brain damage to her child by refusing to follow the low-phenylalanine diet during pregnancy. Thus, the question of parental obligations to unborn children is not yet fully resolved.

6. Relatives (and potential relatives) of patients. These persons may seek compensation for the failure of someone in the genetic counseling process to inform them of risks the counselor learned about from evaluating a patient. These claims raise questions about sharing information, and we discuss them in that context below.

### *Negligence*

Whoever the claimant is, the genetic counselor or other defendant will only be liable to him if the defendant was negligent. What constitutes negligence in the genetic disease context is by no means clear.

Negligence means unreasonably dangerous conduct. What is reasonable for

doctors practicing medicine is usually, but not always, measured by the ordinary behavior of other members of the same specialty, traditionally in the same or a similar community as the defendant (28, 65), but increasingly in the nation as a whole (64). Different standards are applied to different specialists (8). In the genetic disease area one would expect the highest standards to be imposed upon persons who claim expertise in medical genetics. Obstetricians, pediatricians, family practitioners, and others who deal often with genetic disease are also likely to be held to high standards of performance.

Unfortunately, specific answers to questions about what may constitute genetic negligence cannot be provided in advance. Case law to date provides no answers. Some cases, such as failure to take care properly to label laboratory samples, are clear examples of negligence. Most cases are not so easy.

Perhaps the most relevant questions are, how much genetic information must one know, and how forthcoming with that information must one be. As to the former, one clearly must know what others in the field know, so that as knowledge of genetic diseases increases, more and more physicians will be responsible for knowing more and more about them. One must also know what one claims to know. If a patient asks a question and the doctor answers it, the doctor is responsible for the accuracy of the answer (4). Finally, sometimes a doctor will be expected to know that he lacks sufficient expertise properly to handle the patient's case. In such a situation the doctor must seek consultation or refer the patient to an appropriate person.

The law does not reveal when a physician must raise a genetic issue with a family and when he may wait to be asked. Physicians probably have a duty to inform pregnant women over 35 of the increased risk of Down syndrome and of the availability of prenatal diagnosis for it. As to other conditions and techniques, all that can be said is that the law increasingly emphasizes full patient information and freedom of choice (11, 14, 79); this suggests that the prudent course for a doctor to follow is to overinform rather than underinform his patients.

Negligence law in general and malpractice law in particular are moving toward ever easier imposition of liability. This trend toward easier tort recovery coupled with the rapid expansion of medical genetic knowledge and techniques suggest that substantial liability for genetic malpractice is likely. Maximizing one's own education and taking care to engage in serious genetic history taking, screening, diagnosis, and referral will reduce the risk of liability by reducing the risk of error. As long as the courts continue to pursue loss distribution policies, however, no amount of care can guarantee immunity from liability.

## SHARING GENETIC INFORMATION

Some of the most difficult problems posed by genetic medicine involve the sharing of genetic information with the patient and others. Genetic diagnostic

techniques often reveal sensitive information that the counselor may prefer to keep from the patient. For example, diagnostic procedures may reveal that a married woman's husband is not the father of her child, that a male fetus or baby has an XYY chromosome configuration, or that a healthy fetus is of a sex the parents do not prefer. Must the counselor disclose this information to the patient (57)?

Surprisingly little law exists about patients' access to their own medical records. The usual view is that the physician owns the records themselves, but that the patient will be granted access to the information in the records, at least if he has a medical reason for wanting it (32, 52). These standard rules are of little help in the genetic counseling context.

For diagnosis to reveal nonpaternity the husband and wife must both have been evaluated, and both may have sought counseling services. Which one is the patient? To whom does access to information belong? Answers to these questions can only be sought through analysis of the probable consequences of different courses of action.

If the counselor withholds the information, lies, or makes up an implausible story (for example, that the baby carries a new mutation), and the husband eventually learns the truth, he may have a valid claim against the counselor for the costs of raising the child, emotional distress, and punitive damages. In some states, however, an irrefutable legal presumption that a child born to a married woman is legitimate may preclude recovery. Conversely, if the counselor does reveal the information, the mother's claims for invasion of privacy or intentional infliction of emotional distress will be weak because legal requirements of publicity in the privacy case and extreme and outrageous conduct in the emotional distress case cannot be met. Thus, telling the husband the truth is probably safer than withholding the information. This is consistent with conventional ethical norms about truth telling and with judicial preferences both for honesty and for full disclosure of information.

The XYY and fetal sex problems are also difficult. In the XYY setting a counselor may be reluctant to disclose information of ambiguous significance, which might lead either to an abortion or to a self-fulfilling prophecy of criminality. In the fetal sex case the counselor may not wish to facilitate abortion for sex choice. It seems clear that the XYY information must be disclosed. Its very ambiguity is what makes it essential to allow the patient to choose her course of action. The pregnant patient has a medical choice about abortion to make; the mother has choices about education and care for her son. The doctor may not make the choices for her by denying her the information she needs to make them.

The same seems true with regard to fetal sex. A woman's reason for seeking an abortion is irrelevant to her constitutional rights (59). No doctor or hospital has to perform amniocentesis for sex choice or to make its facilities available for abortions (55). However, if an amniocentesis has been performed, the

doctor's preference cannot deprive a woman of her full range of legal choices. Moreover, a legal rule that permitted fetal sex information to be withheld from women who revealed their desire to abort a child of the undesired sex would simply put a premium on lying, a position the law will surely try to avoid.

Genetic information may be relevant to persons in addition to patients, spouses, and their offspring. For example, consider a diagnosis of hemophilia, an X-linked disease, that reveals the patient's mother to be a carrier of the gene for hemophilia. This means that each of the mother's sisters may have a 50% change of being a carrier, too. If a woman is a carrier, each of her sons has a 50% chance of having hemophilia. May or must a genetic counselor attempt to locate and inform the sisters so that they may decide whether to seek amniocentesis and to abort male fetuses? If the counselor does not know the carrier status of his patient's mother's sisters, may or must the counselor seek out and inform their daughters (the patient's cousins, the patient's mother's nieces) that they have a 25% chance of being a hemophilia carrier, and that if they are a carrier each of their sons has a 50% chance of being affected (18, 57)?

Obviously, the ideal way to deal with these issues is to obtain consent to contact and inform relatives. Sometimes, however, a person may be unwilling to give such consent. In these cases, conventional legal rules seem to suggest that the information should be retained in confidence. Fuller analysis, however, suggests that courts will probably require reasonable efforts to disclose.

American law ordinarily imposes no obligation on a person to help a stranger, no obligation to be a Good Samaritan (31). The law does impose an obligation to maintain in confidence confidential information learned from a patient (40). Thus, at first blush, the law would appear to place liability on a genetic counselor who disclosed confidential information to a relative, and not to impose liability on such a counselor for failing to do so. However, unless one is governed by a specific statute that requires confidentiality (38, 44), this result seems unlikely.

The rule that one need not become a Good Samaritan is an unattractive rule, retained primarily for practical reasons. When the practical reasons are not present, courts often create exceptions to the rule. Thus, the rule avoids line-drawing problems in cases where many bystanders fail to come to an accident victim's aid; it prevents us from stigmatizing persons whose failure to rescue represents panic rather than amorality; and it recognizes the futility of attempting to make sound actuarial judgements in order to provide failure-to-rescue insurance. None of these problems exists in the genetic counseling context. One counselor or team is the obvious target for liability; time to think and plan how to do one's job, not panic-stricken response to an emergency, is involved; and the defendant's malpractice insurance is available to shift the loss. Thus, the reasons for not imposing duties to aid strangers are not present here.

Moreover, courts impose obligations to breach confidentiality when a supervening public interest requires the breach (40). An interest in promoting informed decision-making, reducing genetic disease, or reducing the impact of disease may be thought sufficiently more important than confidentiality to "supervene."

A notable California case suggests that the obligation in the genetic disease context will be to inform relatives rather than to protect confidences. In *Tarasoff v. Regents of University of California* (70), a patient told his psychotherapist that he intended to kill his girlfriend. After the patient made good his threat, the psychotherapist was held liable for not taking adequate steps to warn the victim. The court held the public interest in avoiding homicide more important than the interest in maintaining a patient's confidences and rejected as speculative the argument that requiring disclosure would actually increase violence by discouraging people from seeking and cooperating in psychiatric care.

The *Tarasoff* result seems even more likely in the genetic disease context, where fears of overpredicting violence (here genetic disease) are not present. Moreover, one can argue that genetic counseling is by its very nature a family-based rather than an individually-based branch of medicine. Therefore, obligations ought to be to family members rather than only to individual patients.

If this analysis is correct, counselors will sometimes be obligated to seek out patients' relatives and warn them of their genetic risks. How great an effort to locate such persons must they make?

In accordance with traditional negligence principles, physicians and other counselors will have to make reasonable efforts to locate and warn relatives. In the absence of previous decisions or well-established professional practices, it is difficult to say what reasonableness requires. Obviously, searching one's own telephone book for an unusual ethnic name is little enough to ask; combing the four corners of the world for relatives is too much. Courts will determine reasonableness on a case-by-case basis. The reasonableness standard also suggests that only potentially useful information has to be conveyed. Thus, for example, it seems unlikely that one would have to disclose the existence of an incurable disease in a family to a patient's asymptomatic sibling who is childless and past child-bearing age.

All of this suggests that a counselor's legal position in our hemophilia examples, while unclear, is probably improved by making reasonable efforts to locate relatives and inform them of their risks. The same principles are likely to apply to providing information to prospective spouses. Again reasonableness is the critical concept. In applying it courts will surely be able to distinguish between imposing an obligation to an acknowledged fiancé (likely) and seeking out everyone the patient dates and might conceivably marry (unlikely).

Additional problems of sharing genetic information arise from the practice of adoption (3, 35, 36). An adopted child or his adoptive parents may seek access to information about the child's genetic heritage in order to make medical decisions about the child or to permit the child to make informed reproductive decisions. Similarly, counselors may learn that a patient had a child whom the patient surrendered for adoption. The counselors may wish to locate the child in order to inform him of his genetic risks. Finally, a person may embark on a search for biological relatives in an attempt to locate potential bone marrow or other organ donors (2, 38).

Traditionally, adoption records have been sealed in order to protect the privacy of biological parents, adoptive parents, and children. As Hansen & Omenn (35) have noted, all applicable statutes permit the records to be opened under certain circumstances. The usual requirement, whether articulated in the statute or not, is a showing of good cause. A serious medical need for the information would usually qualify as good cause unless revealing the information seemed likely to do substantial harm. The likelihood of benefit from contacting the adoptive parents of a child newly found to be at risk for inheriting a gene for a particular disorder depends upon the clinical features of that disorder, especially the feasibility of presymptomatic diagnosis, the severity of the disease, and the effectiveness of treatment. The cases that have been described involved Huntington disease, myotonic dystrophy, Fabry disease, von Willebrand disease, and Waardenburg syndrome. In all cases, the biological mothers requested that the genetic counseling provided for them and their children be shared with the adoptive family. Informal contacts through intermediaries in social agencies led to some misunderstandings and complications and stimulated recommendations for better procedures under the aegis of the King County (Washington) Superior Court, Family Court Division (53c).

Conscientious courts may work very hard to structure a remedy that will permit a person to learn relevant information while protecting others' identities. For example, In *Application of George* (2), an adopted child sought to open the adoption record to learn his biological mother's identity for the purpose of exploring the possibility of her becoming a bone marrow donor for him. The appellate court in Missouri ordered the trial court to seek the biological father and mother, to act as an intermediary, and to try to work the situation out. It refrained from ordering disclosure of the biological parents' identities and expressed its preference for avoiding disclosure. Cases like *George* suggest that, while resort to cumbersome legal procedures is still required to provide good genetic medical care in situations involving adoption, room for optimism about the outcome of those procedures exists. Courts seem sensitive to the need to protect both physical health and the psychological and social well-being to which privacy is so important.

## ALTERNATIVE CONCEPTION TECHNOLOGIES

Genetic counseling provides patients with information about reproductive and treatment options as well as about genetic disease and their own genetic situations. For many married couples information about reproductive options is especially important. Technology has now provided such couples with choices beyond the traditional ones of (a) bearing or risking the birth of an affected child, (b) refraining from conception, (c) sterilization, (d) abortion, and (e) adoption. The most practical technological ways to permit low-risk reproduction for couples at risk for transmitting genetic disorders are artificial insemination and surrogate motherhood. The range of reproductive options includes in vitro fertilization and embryo transfer (7a). In Israel, where use of donor sperm and surrogate mothers is prohibited, in vitro fertilization and embryo transfer are favored approaches for patients with mechanical causes of infertility (61a). At the time of this writing, legal ramifications of the technical uncertainties and ethical dilemmas arising from these developments were still speculative (7a, 41a, 47a).

### *Artificial Insemination*

Artificial insemination is a widely used and well-established reproductive technology. Various estimates suggest that between 1000 and 20,000 babies are born annually in the United States as a result of artificial insemination, with current estimates running at about 6000 to 10,000 (20, 76, 77). A legal case about artificial insemination was decided as long ago as 1921 (54).

While traditionally artificial insemination using sperm from someone other than the husband (often called artificial insemination by donor or AID) has been used primarily as a way to deal with male infertility, the technique is increasingly seen as a useful response to genetic disease as well. If a husband and wife both carry the gene for an autosomal recessive disease, they can reduce the risk of having an affected child from 25% in each pregnancy to virtually zero by using AID with sperm from a noncarrier male. Similarly, a man with an autosomal dominant disease can spare his wife's child the 50% risk of being affected by consenting to AID using sperm from an unaffected man.

To date, legal issues posed by AID have involved status relationships. The earliest cases explored the question of whether a wife who consented to AID had committed adultery (24, 49, 54, 76). This problem is no longer of much practical significance because of the nearly universal adoption of no-fault divorce in the United States.

Much more important are the cases exploring the relationship between the husband and the child. The law in this regard is summarized through 1973 by Wadlington (77) and in a New York case, *In re Adoption of Anonymous* (42). It is brought up to date in Wadlington's newer work (76) and in recent New Jersey



(47) and Kansas (61) cases. Almost all of the cases involve married couples in which both the husband and wife consented to AID. In these cases, courts have been reluctant squarely to hold that the children born as a result of AID are legitimate. However, every reported case has reached the same result in the dispute before the court that it would have reached in a case involving the clearly legitimate offspring of the husband and wife. Thus, the husband is obligated to pay child support, is entitled to visitation after divorce, may prevent another man from adopting the child, etc.

These results give effect to the parties' plain intentions at the time they agreed to AID. They treat parenthood as a social, rather than a biological phenomenon. They serve the state's goals of providing two sources of support and nurture for children. They protect husbands, wives, and children. And they refrain from imposing any burden on doctors, donors, or donors' wives. They seem so eminently sensible that one should be able to assume that they will be followed in other states without regard to whether AID is used for genetic or infertility reasons.

Nonetheless, uncertainty generated by the courts' reluctance to pronounce the children legitimate and by the vagaries of case-by-case development have led 24 legislatures to enact statutes dealing with AID (39a, 76). In addition, the Commissioners on Uniform State Laws have offered a proposed uniform act on the subject (72). All the statutes reflect the same policy goals the courts have been pursuing. They attempt to have the husband-child relationship treated as legitimate.

Unfortunately, the statutes are badly drafted and create more problems than they solve. They fail to accomplish their goals, and they force courts either to avoid their apparent implications or to violate their obvious policies (61). In short, they fail to provide and may actually retard the search for comprehensiveness and clarity.

Comprehensiveness and clarity are widely prized. One may wonder, then, why the courts that have treated the husband-child relationship as legitimate have been reluctant to declare it always to be so. The most probable explanation is the courts' recognition of their own limited prescience and their desire to retain flexibility. This self-restraint has already served them well once in the artificial insemination context, and seems likely to be useful in at least two additional areas.

In the New Jersey case of *C.M. v. C.C.* (13), a couple decided to have a child, but not sexual intercourse(!) before they were married. As no physician was willing to perform artificial insemination for them under these circumstances, the couple did it themselves. During the ensuing pregnancy the romance went out of their relationship, and the marriage did not occur. The lawsuit was an effort by the man to gain visitation rights to the child. He succeeded, a result which again seems sensible when viewed from the perspectives of social policy and honoring expectations. The court's job in awarding

him visitation would have been much more difficult if earlier cases had decreed, for example, that a sperm donor can never be the father of the resulting child.

Such a statement, whether by case or statute (72), would also cause chaos in any surrogate mother case, where it would raise the spectre of the intended father having no rights or obligations and the husband of a married surrogate enjoying "blessings" roughly akin to those involved in raising his wife's illegitimate child.

Self-restraint has also left the courts free to deal creatively with another use of AID. In California a man opened a sperm bank to collect semen from Nobel laureates for the insemination of highly intelligent women (6). If a court disapproves of this use of AID as a speculative tool of positive eugenics, the easiest way to deal with it is to find on the facts of one case that a particular Nobel laureate donor must support the resulting child. The pool of Nobel donors will quickly dry up. Again this efficient, but moderate way to deal with a social problem would be precluded by a clear statement that AID children are always the legitimate children of their mother and her husband.

The remaining questions about AID that seem likely to arise in the genetic disease context involve an additional form of genetic malpractice. Curie-Cohen et al (20) report that potential sperm donors are subjected to very little screening for genetic disorders. Are doctors who practice AID likely to be held liable when, ironically, a technique used to avoid a genetic disease causes one (57, pp. 68-70)? The responsibility for untoward outcomes in children of AID has not yet been clarified. Licensing of sperm banks and research on the long-term storage and later use of sperm have been neglected, despite attention to the potential problems (52a). Finally, the "rights" of widows or others to sperm "stored" or donated years earlier by a deceased man are likely to be contested.

As noted earlier, a physician's behavior is often evaluated by comparing it to the behavior of other physicians engaged in the same type of practice. This is not always the case, however. Occasionally courts simply dictate an acceptable level of practice and hold doctors to it (39). Artificial insemination may be practiced by so few physicians that judicial standard setting will appear attractive. This seems especially likely with regard to a practice that primarily requires history taking and testing for genetic characteristics, because courts may be able to understand the technical information involved well enough to feel equipped to deal with it, and because the new and rapidly changing nature of the field makes reliance on professional custom less fruitful than it usually is.

As courts confront the question of negligence in the AID setting, they will be attempting to balance the need to maintain a supply of donors with the need to use only healthy men as donors. The balance will be struck with an eye toward two social policy questions: To what extent should AID to avoid genetic disease be encouraged; and who should bear the costs of children conceived through

AID and born with genetic disease? We predict that courts will move in the direction of requiring at least some screening of potential donors, perhaps limited to known family history, known exposure to mutagens, testing for ethnically related conditions of fairly high incidence, and age. Whether more will be required cannot yet be determined.

### *Surrogate Motherhood*

Surrogate motherhood employs the same technology as artificial insemination to overcome female instead of male infertility or to reduce the risk of genetic disease by eliminating the wife rather than the husband from the genetic chain. In the typical surrogate motherhood situation, a woman is artificially inseminated with semen provided by a married man. If the woman becomes pregnant, she carries the baby to term and then surrenders all rights in it to the man and his wife.

Typically, the married couple and the surrogate enter into a contract spelling out the rights and obligations of each (7, 49a, 54a, 76). A well-drafted contract may cover almost every eventuality from the surrogate's desire to keep the baby to the couple's refusal to accept it, and may include provisions about the surrogate's obligations to obtain prenatal care, eat properly, refrain from using alcohol, tobacco, drugs, caffeine, etc, and to avoid dangerous work. Problems may arise if the contract is oral or poorly drafted or if it fails to consider some eventuality. Even more basic problems arise about whether a court will enforce a surrogate motherhood contract or will find it unenforceable as against public policy.

Very little law exists on the subject of surrogate motherhood. Kentucky trial courts have considered some questions, but only in Michigan have cases reached the appellate level.

The Kentucky trial court cases point in different directions. *In re Baby Girl* (43) applied the presumption that a child born during marriage is the legitimate child of its mother and her husband and refused to allow a married woman who had served as a surrogate mother under a contract to terminate her parental rights. On the other hand, in *Kentucky v. Surrogate Parenting Associates, Inc.* (46), the court found no prohibition in Kentucky law of the payment of a fee for adoption or termination of parental rights. However, the court observed that, in accordance with a Kentucky statute, any agreement by the surrogate to terminate her parental rights is not binding unless made at least five days after the child's birth. Thus, a promise to surrender rights in the child made at the time of the original surrogate motherhood agreement would not be enforceable.

Trial court decisions are not binding on courts deciding later cases. Only appellate decisions are authoritative in that sense. Michigan is the only state whose appellate courts have considered surrogate motherhood issues. In *Doe v. Attorney General* (23) and *Syrkowski v. Appleyard* (69), Michigan courts have

refused to allow the adoption code, the Paternity Act, and the artificial insemination statute to be used to effect the transfer of parental rights from a surrogate mother to the child's biological father and his wife.

Thus, the legal picture for persons contemplating surrogate parenthood is unclear at best, discouraging at worst. As the Michigan cases make clear, old statutes designed to deal with other subjects cannot comfortably be applied in the surrogate motherhood context. Even the artificial insemination statutes are not helpful. Indeed, to the extent that those statutes try to make AID children the legitimate offspring of their mother and her husband, they seem to impose obligations on the surrogate's husband, which obviously is not what the parties had in mind. If legislatures want to deal with surrogate parenting, they will need to draft new statutes. Should they do so?

If one believes that surrogate parenting poses problems similar to those posed by AID, then no legislation is necessary. Courts have a great deal of experience dealing with status relationships, they have done a good job in the AID area, and no reason exists to think they will do less well here. Legislative approaches have been less successful. Uncertainty is a small price to pay for the flexibility that judicial resolution provides.

On the other hand, if one believes that surrogate motherhood is significantly different from AID and should be regulated, then legislation is necessary because courts deciding cases after the fact cannot control behavior nearly as well as legislatures, which act prospectively, can.

Is surrogate motherhood significantly different from AID? One might argue that it is because it poses two kinds of dangers that AID does not pose and that require controlling behavior. First, unlike AID, surrogate motherhood poses the risk of baby selling, a universally condemned practice, which, among other things, suggests profiteering at the expense of desperate couples. In addition, surrogate motherhood involves the surrogate for at least nine months. During that time her behavior regarding diet, prenatal care, abortion, etc must be controlled.

On the other hand, one might argue that surrogate motherhood is not significantly different from AID. Semen is sold for AID use, and the difference between selling semen and selling babies may be more rhetorical than real. In any event, the sperm donor husband is not buying a baby; as its biological father he already has rights and obligations to it (46). The technology used in surrogate motherhood is the same as in AID. In surrogate motherhood, however, the technology benefits women, while in AID it benefits men. Insisting that the technology be controlled more strictly in surrogate motherhood than in AID may be viewed as discrimination against women. And the asserted need to control the surrogate's behavior during pregnancy is outrageously intrusive and probably unconstitutional (59).

Obviously, what the right answer to these questions may be is unclear. Until

the legislatures act, however, we suggest that courts should enforce surrogate motherhood agreements. Doing so will support the honest intentions of the parties at the time they entered into the agreement; it will assure at least healthy children of placement in a home where they are wanted and will be cared for; it reduces the chance for fraud and blackmail by the surrogate; it makes as little law (and, therefore, as few mistakes) as possible; and it alerts the legislature to what will happen if it does not act, thereby inviting the legislature to change the situation if it wishes to do so.

## APPLICATIONS OF GENETIC INFORMATION

### *Gene Therapy*

At the present time developments in genetics are useful primarily to help families in their reproductive decision making and to promote accurate diagnosis in order to provide optimal treatment and training for persons with genetic disorders. However, other applications of genetic knowledge are possible, or may reasonably be expected to be developed.

Recently, some attention has been focused on the possibility of gene therapy, that is, intervention to alter genes in order to cure genetic diseases in particular patients or even in entire families (1a, 29, 33, 58). While gene therapy is not yet a reality, a few observations about potential legal questions may be made.

Two types of gene therapy are envisioned. Somatic gene therapy is designed to correct a specific genetic defect in an individual without affecting the patient's germ line. Gametic therapy, on the other hand, is designed to alter the sperm or ova, thereby preventing the passing of a particular disease and eliminating the disease from an entire family line.

Somatic gene therapy poses problems that do not differ qualitatively from those posed by other experimental medical techniques. Regulations for the protection of human subjects (15), including those requiring informed consent, must be complied with and careful technology assessment should be carried out. Persons using the new techniques will run typical risks of malpractice liability, but the genetic nature of the therapy ought not to require any special legal responses.

Gametic therapy is more problematic. The possibility of altering germ lines to eliminate genetic characteristics calls to mind the discredited eugenics movement and the subtler dangers of trying to modify humanness by designing persons of specific physical or mental types. Technologically we are very far from having such capability. Nonetheless, some may feel that the potential for abuse requires regulation or even prohibition of germ line experimentation. A more moderate response would be to rely on traditional approaches to the protection of human subjects, including fetuses (16), while recognizing that special risks to current subjects require careful scrutiny and conservatism about authorizing particular experiments.

### *Genetic Testing in the Workplace*

More realistic present issues are raised by efforts to perform genetic screening on workers or job applicants. Of course, if a test has poor predictive value, it should be rejected by the same criteria that should be applied to many current, nongenetic tests, such as low back x-ray exams (58b). However, if a screening test were available that would reveal persons who are hypersusceptible to certain specific work hazards, such as oxidizing chemicals, numerous questions would arise. May or must employers use screening procedures to warn persons who are at risk? May or must they take steps to protect hypersusceptible individuals from risks? Specifically, may they refrain from hiring or promoting, reassign, or fire such persons? At the present time none of these questions has been answered, although a major government study (19), Congressional hearings, and legal (60), medical (53d), and policy (53e) analyses have been devoted to them.

The Occupational Safety and Health Act (73) is designed to assure safe working conditions and to protect the health of workers, even the most susceptible (29a). However, neither the Act nor the Agency acting under it has addressed the questions of employer use of medical surveillance information or of criteria for dealing with high risk employees. As Rothstein has noted, this silence "leaves everyone in the dark" (60, p. 1429). Systematic studies should be carried out with full cooperation of labor and management to demonstrate the value of a test and the attributable risk of a trait before any such testing could be justified (53d).

The Rehabilitation Act of 1973 (74) and Title VII of the Civil Rights Act of 1964 (75) may provide some protection to persons whose employability or employment is adversely affected by genetic screening. The Rehabilitation Act is designed to protect otherwise qualified handicapped persons from discrimination in employment by federally assisted employers. At least one case has suggested that screening out qualified handicapped persons to avoid possible future injury may be permissible (26, 60). Whether a person with a genetic predisposition to an occupational disease is handicapped is unclear. Because the Rehabilitation Act is designed to prevent discrimination against the severely handicapped, it may not protect persons with only slight genetic "imperfections" from discrimination (60).

An additional avenue for protection may be available under the 1964 Civil Rights Act. That act is designed to prevent employment discrimination based on race, color, religion, sex, or national origin. Many genetic diseases have a significantly different prevalence in different racial groups. Therefore, genetic testing may have the effect of reducing employment options on the basis of race. Unintentional discrimination or discrimination against an individual might be prohibited, even if the result of using the genetic screening test is offset by other devices that result in proportional representation for the affected racial group (12, 60).

## CONCLUSION

The law of medical genetics is new and unformed. It provides little in the way of guidance or predictability. However, its freshness, lack of form, and lack of clarity provide a significant opportunity for health professionals, lawyers, and policy makers to work together to move the law in sound directions.

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