

A Family Affair: Sharing Information About Genetic Diseases

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I. Introduction

There is something about law and change (whether social or technological) that seems vaguely incompatible. Legal institutions are often accused of failing to “keep up” with change, and those accusations may sometimes be justified. At least in cases of technological change, the dilemma is generated by the interaction between existing law and new forms of conduct. Criticism tends to be levelled in circumstances where: (1) existing rules no longer achieve their purposes due to the changed nature of the world in which they operate, (2) there is ambiguity as to whether new forms of conduct fall within the scope of existing laws, (3) the inclusion or exclusion of new forms of conduct within the scope of existing rules is thought inappropriate, or (4) what law does apply may be inadequate to meet legitimate concerns arising out of the new conduct.

Much has been written about how the law ought to change in light of the technology of genetic testing. At first blush, the problems raised by the existence of genetic testing do not seem “new.” Prior to the use of genetic testing, people often knew vast amounts of information about their genetic heritage. Such information was derived from family histories as well as observable physical and psychological characteristics. However, prior to the use of genetic testing, one could withhold little genetic information from family members because they were able to derive similar information from family histories and observation. The use of genetic testing alters the information symmetry that previously existed within families. The results of a genetic test are not visible and may never manifest in observable features or symptoms. Thus, for the first time, people have control over their genetic information; they can decide how much to share with others.

Decisions as to whether to share information about susceptibility to genetic diseases with family members who might be affected are in that sense unique or “new.”

Information derived from a genetic test is deeply personal, yet also directly relevant to other people in the same family. For the person tested (hereinafter “proband”), the information might predict health problems far into the future and have a significant impact on identity. On the other hand, genetic information, unlike medical information pertaining to infections and injury, does not relate to only one person. If a person carries a particular gene, it is likely that at least one of that person’s parents carry the gene, and possible that the gene is carried by siblings, children, cousins, and even more distant relatives. The nature of genetic information generally, and information about genetic diseases in particular, is discussed in Section II below.

A person who discovers that he or she carries a gene associated with a genetic disease faces a new choice: the decision as to how much information to share with genetic relatives. The person making that decision will want to know what they ought to do, both in the moral and the legal sense. This Article considers the constraints affecting the decision to share information regarding genetic diseases with relatives. Section III focuses on the factors that a person faced with the decision might take into account and Section IV focuses on legal obligations, concluding that, while legal obligations ought to be imposed in extreme cases, this is unlikely on the current state of the law.

The questions considered in this Article are more relevant now than they ever were or will be. Previously, when few genetic tests were performed, the matters considered here did not affect a significant number of people. On the other hand if, as is likely, genetic testing becomes a routine part of health care, the problems of information

asymmetry within families will all but disappear.¹ In that sense, the problems posed by this Article are largely temporary. Nevertheless, at least at present, significant numbers of people are facing the decision as to how much genetic information to share with relatives with relatively little guidance.

II. Genetic Diseases

The basic nature of inheritance is generally well-known; what follows is a simplified account. A person's genome, which resides in the nucleus present in most human cells, consists of twenty-three pairs of chromosomes. One chromosome from each pair is inherited from each parent. Each chromosome is composed of double strands of deoxyribonucleic acid or DNA. DNA consists of strings of nucleotide bases, certain sequences code for particular proteins. Such sequences are referred to as genes.

Because different genes code for different proteins, many physical and psychological human characteristics are related to one or more genes, often in addition to environmental factors. Where proteins important for biological function are altered or absent due to one or more "defective" genes, a person may suffer severe physical consequences, resulting in illness or death. Although this simplifies matters somewhat, the term "genetic disease" will be used to describe illness whose primary cause is a defect

¹ See Allen Buchanan, *Ethical Responsibilities of Patients and Clinical Geneticists*, 1 J. HEALTH CARE L. & POL'Y 391, 399 (1998).

in one or more genes.² Genetic diseases are often classified into monogenic disorders, involving a single gene, and polygenic disorders, involving multiple genes.³

The extent of the relationship between a defective gene and the corresponding genetic disease varies significantly. An example of a monogenic disorder with a close relationship between the disease and a particular gene is Huntington disease. All cases of Huntington disease result from a defect in the associated gene, and certain defects will always lead to development of the condition, provided the person lives long enough.⁴ A weaker relationship exists in the case of breast cancer, only 5 to 10 breast cancers are genetically linked and not everyone with the relevant genes will develop the disease.⁵ In the case of sporadic Alzheimer disease, carrying the associated ApoE4 gene is one of many risk factors for developing the disease.⁶ Further, in some cases, a genetic disease may arise through mutation rather than inheritance.⁷

² Note that this definition does not include chromosomal disorders. Further, a proper definition would need to account for the fact that diseases rarely have a single cause. For example, skin cancer may be caused by both exposure to the sun (an environmental factor) and pale skin (a genetic factor). This Article will focus on situations where the genetic cause is invisible and relatively rare and the environmental causes are commonplace.

³ It should be noted that, because polygenic disorders involve the interaction of two or more genes as well as, in most cases, environmental factors, fewer predictions can be made on the basis of genetic testing or family history data. See Graeme T. Laurie, *Challenging Medical-Legal Norms: The Role of Autonomy, Confidentiality, and Privacy in Protecting Individual and Familial Group Rights in Genetic Information*, 22 J. LEGAL MED. 1, 5 (2001). In addition, information derived from polygenic disorders is likely to have less impact for the proband's family, because the probability of inheriting the same combination of genes decreases as the number of genes involved increases.

⁴ THE GALE ENCYCLOPEDIA OF GENETIC DISORDERS 569-71 (Stacey L. Bachford ed., 2002).

⁵ *Id.* at 173-78.

⁶ See *id.* at 65-70; John Bell, *The New Genetics in Clinical Practice*, 316 BRIT. MED. J. 618 (1998).

⁷ Genetic diseases that are primarily the result of mutation will not be considered further in this Article. Where a genetic disease could be the result of a mutation or inheritance, the calculations become somewhat complicated. Essentially, in the absence of other information, one would factor out the known incidence of mutations.

Until recently, information regarding one's propensity to develop a genetic disease was usually derived from family histories, consisting of descriptions of symptoms experienced by oneself or family members. Today, genes associated with particular diseases can be detected directly through genetic testing.⁸ People undergo genetic testing for a variety of reasons. A person may be tested as part of a research project, as an aid to diagnosis in the clinical context, as an aid to reproductive decision-making (before or after conception), as part of a compulsory or voluntary genetic screening program, or out of personal curiosity. Information derived from genetic testing rather than from family history is not only more accurate, it is also more specific. Learning about one's own genome can affect people differently than drawing inferences based on what has happened to others. Specific information can seem more reliable as a prediction of future ill health, whether or not that is statistically the case.⁹

As a matter of pure statistics, a genetic test reveals useful information about the proband (person being tested) and their relatives. The probability that a proband who tests positive for a particular gene or set of genes will develop symptoms of the associated disease will depend on the reliability of the laboratory where the test was performed, the accuracy of the test itself, and the penetrance of the gene or set of genes (being the probability that a person carrying the gene or genes will develop the disease). Throughout this Article, the term "genetic disease information" is used to describe information relating to the probability that that person will develop a particular genetic disease. Genetic disease information thus describes the chance that a person's health will be

⁸ The term "genetic testing" is used to refer to a range of procedures including linkage analysis, Southern blotting and DNA sequencing.

⁹ See Laurie, *supra* note 3, at 3-4.

negatively affected by one or more genes.¹⁰ Mathematically, the probability measured is the product of the probability that a person carries a particular gene and the penetrance of that gene.

Genetic disease information pertaining to one person can often be derived from genetic disease information pertaining to a member of that person's family. For example, if a man knows that his mother has or will develop Huntington disease, he also knows that he has 50% chance of developing the same condition. Because similar calculations are possible for many genetic diseases, genetic disease information never pertains to only one person. In other words, genetic disease information about one person is often also genetic disease information about his or her family, although the importance of the information diminishes as the extent of blood relationship is reduced and as the number of genes required for the expression of the trait increases.¹¹ Nevertheless, genetic disease information yielded by a genetic test has the greatest impact, statistically and psychologically for the proband.¹²

If people do not share genetic test results with close family members, the resulting asymmetry in information can potentially give rise to disputes. Family members who later develop the disease may claim that, had the information been shared with them, they could have taken precautions, reducing the probability of developing the disease. At the opposite extreme, a person who does not wish to know whether they carry a defective gene might complain of psychological harm if the information is shared. The ethical and

¹⁰ Note that only genetic diseases are being considered. In particular, this Article does not discuss health effects that are the result of a genetic propensity to engage in dangerous activities.

¹¹ See Laurie, *supra* note 3, at 3.

¹² See *supra* note 9 and accompanying text.

legal issues surrounding the decision to share genetic disease information with family members will be considered in Sections III and IV respectively.

III. The Diligent Proband

A person who discovers that he or she carries a gene or set of genes associated with a genetic disease must decide whether to share that knowledge with family members. The decision is rarely an easy one; if undertaken in good faith, it involves many conflicting considerations. This Section considers the factors that such a person, attempting to make the most appropriate decision in the circumstances, would likely take into account.

In the absence of other considerations, most people perceive an obligation not to inflict harm and a more limited obligation to prevent harm.¹³ The obligation to prevent harm cannot be treated as absolute; a single person does not have the resources to prevent all preventable harm to all people. One might suppose, therefore, that the obligation only arises where the costs of preventing harm are reasonable in light of the harm to be prevented and any special obligations owed to the person who would otherwise be harmed.¹⁴ In the circumstances under consideration, special obligations will usually arise out of a close personal relationship, such as that often found between friends or members of the same nuclear or extended family. Thus one might be more inclined to aid one's sibling than a third cousin one has never met.

As well as factors based on the potential for harm, issues of autonomy are involved. Respect for others' autonomy requires that one not compel another, who has

¹³ See Buchanan, *supra* note 1, at 400-01.

¹⁴ *Id.* at 401-02.

already expressed a preference to remain ignorant, to gain unwanted knowledge.¹⁵ This principle is of little use, however, unless the preferences of family members are known or deducible from past conduct.

Factors likely to be relevant to the decision to pass on genetic disease information to a specific family member (for convenience, X) include:

- A. the extent to which X would benefit from the knowledge;
- B. the extent to which X would be harmed by the knowledge;
- C. any knowledge the proband may have (or be able to deduce or obtain) as to the preferences of X in gaining such knowledge; and
- D. in situations where the first three factors point towards an obligation to pass on the information, the extent to which the proband would be harmed by disclosure and the extent to which the proband ought, in the circumstances, to bear that harm.¹⁶

These factors reflect a somewhat simplified model of the advantages and disadvantages of sharing genetic disease information. Other factors may arise in specific contexts. For example, sharing genetic disease information may stimulate intra-familial conflict or increase intra-familial emotional support for those carrying the “defective” gene or genes, and a conversation about genetic disease may affect the enjoyment of family celebrations if poorly timed. Such contextual factors will likely be relevant to the proband’s decision, but cannot be analyzed in the abstract.

¹⁵ See generally Laurie, *supra* note 3, at 19-23.

¹⁶ These categories are a variation of the factors affecting the decision to share genetic disease information with family members suggested in Buchanan, *supra* note 1, at 408 and Laurie, *supra* note 3.

A. Benefits to Person Informed

There are many different kinds of benefits in learning about one's propensity to genetic disease. The most obvious benefit is that one might be able to use advance knowledge to reduce either the probability that one will develop that disease or the severity of the symptoms that will eventually be experienced. Secondary benefits, including psychological benefits in having advance knowledge and the ability to make more "informed" decisions, may also be taken into account.

The primary benefit to X in receiving genetic disease information is that such knowledge might reduce the probability or extent to which the genetic disease will affect X. Assuming that advance knowledge would benefit X in this way, the extent of the benefit will depend on four factors: (1) the probability that genetic disease will in fact develop, taking into account the probability that X carries the relevant gene or genes (based on the genetic disease information)¹⁷ and the penetrance of the gene or genes, (2) the severity of the symptoms that would be experienced by X if the genetic disease manifested itself,¹⁸ (3) the extent to which the path of the disease can be altered by advance treatment or changes in lifestyle, and (4) the probability that X would choose to pursue such treatment or lifestyle changes.¹⁹

¹⁷ This factor would take account of the accuracy of the test, the reliability of the laboratory performing the test, and the nature of the genetic relationship between X and the proband.

¹⁸ Because the expressivity of a gene or set of genes, being the severity of the condition with which it is associated, can vary between individuals, this can only be estimated in advance. Some conditions have more variable etiologies than others; for example, neurofibromatosis can result in either severe or minor medical problems. THE GALE ENCYCLOPEDIA OF GENETIC DISORDERS, *supra note 4*, at 811-13.

¹⁹ The probability that X would choose to pursue treatment will depend on what is known about X's beliefs, psychology, and resources as well as on the nature of the available treatments.

Despite the promise of advance knowledge as creating opportunities for advance treatment or lifestyle changes, few genetic diseases are susceptible to advance interventions.²⁰ For example, there is no effective preventative treatment for one of the best known and most horrific genetic disorders, Huntington disease. There are at least some cases where effective treatment is available; for example, a phlebotomy is an effective treatment for hereditary hemochromatosis.²¹ There are many genetic diseases between these extremes, but most cannot be effectively treated. Thus in the majority of cases there is little primary benefit in having genetic disease information prior to the onset of symptoms of the disease.

Nevertheless, there may be some indirect benefits in genetic knowledge. It may give X an opportunity to prepare financially and psychologically in advance of the onset of symptoms, or enable more “informed” life decisions.²² One category of life decisions affected is reproductive decisions. A person who knows that their children may inherit a particular gene might choose to avoid conception of an affected child, to use assisted reproductive techniques to ensure no child inherits the gene, or to use prenatal testing, either to prepare psychologically and financially for the birth of an affected child, or to make a decision as to abortion. Generally speaking, the cases where reproductive decisions are affected are not those where the relative’s health is affected. The sorts of conditions that would have the most significant impact on reproductive decisions are those associated with severe symptoms commencing at birth or in early childhood. These

²⁰ TASK FORCE ON GENETIC TESTING, NIH-DOE WORKING GROUP ON ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS OF HUMAN GENOME RESEARCH, PROMOTING SAFE AND EFFECTIVE GENETIC TESTING IN THE UNITED STATES 3 (1997), available at <http://www.nhgri.nih.gov/elsi/tfgt_final/index.html>.

²¹ A phlebotomy is a simple procedure involving the removal of blood.

²² See the case studies referred to in Laurie, *supra* note 3, at 11-14. See also *infra* note 25

conditions are associated with recessive genes; a person may carry one copy of a recessive gene and remain unaffected, but a child inheriting the gene from both parents will be affected. Tay Sachs is an example. In such cases, knowledge of carrier status will not lead to treatment, lifestyle changes, or shortened life expectancy, but it might lead to greater caution in reproductive decision making. The focus in this Article, however, will be on situations where there are direct health or psychological consequences *to X* in learning of a genetic risk.

All benefits to X that are the result of receiving genetic disease information must be discounted by the probability that X would learn of his or her genetic status in any event. In fact, X is likely to be prompted to seek genetic testing for many of the same reasons that led the proband to be tested, including known family history and detectable symptoms. The probability that X will become aware of the genetic disease information in any event depends largely on the accessibility and pervasiveness of genetic testing, both of which can be expected to increase over time.

B. Harm to Person Informed

Most of the harms that X is likely to suffer if informed of his or her genetic status are the converse of benefits discussed in Section III(A) above. The converse of the primary benefit, being avoidance or reduction of symptoms, is the cost of pursuing treatment or life-style changes, evaluated in financial, physical, and psychological terms. At the extreme, where treatment is extremely painful and difficult to come by, it no longer provides a strong justification for disclosure.²³ The converse of the indirect

²³ See T. Takala & H. A. Gylling, *Who Should Know About Our Genetic Makeup and Why?*, 175 WEST J. MED. 260 (2001).

psychological benefit in knowing one's propensity to be affected genetic disease is the more significant psychological harm such knowledge may cause.²⁴ The negative psychological effects of learning that one carries the gene associated with a late-onset fatal disease such as Huntington Disease are well-documented.²⁵

In addition to harms associated with treatment, life-style changes and psychological distress, a person who is aware of a genetic risk may face insurance and employment discrimination.²⁶ Obviously, such harm will only result if the person informed is required to disclose such information to their insurer or employer, which will depend on the law of the relevant state. The potential for the genetic disease information to harm X, like the benefits, must be discounted by the probability that X would gain similar knowledge in any event.

C. Considerations of Autonomy

The principle of autonomy suggests that each person with capacity for reasoning, deciding and willing have a right to self-determination. In particular, people owe obligations to autonomous agents not to interfere with their decisions, including decisions

²⁴ See generally the case studies referred to in Laurie, *supra* note 3, at 11-14.

²⁵ See, e.g., Elisabeth W. Almqvist et al., *A Worldwide Assessment of the Frequency of Suicide, Suicide Attempts, or Psychiatric Hospitalization after Predictive Testing for Huntington Disease*, 64 AM. J. HUM. GENETICS 1293 (1999); Thomas D. Bird, *Outrageous Fortune: The Risk of Suicide in Genetic Testing for Huntington Disease*, 64 AM. J. HUM. GENETICS 1289 (1999); Maurice Bloch et al., *Predictive Testing for Huntington Disease in Canada: The Experience of Those Receiving an Increased Risk*, 42 AM. J. MED. GENETICS 499 (1992); Marguerite A. Chapman, *Canadian Experience with Predictive Testing for Huntington Disease: Lessons for Genetic Testing Centers and Policy Makers*, 42 AM. J. MED. GENETICS 491 (1992); Lindsay A. Farrer, *Suicide and Attempted Suicide in Huntington Disease: Implications for Preclinical Testing of Persons at Risk*, 24 AM. J. MED. GENETICS 305 (1986). See also Marlene Huggins et al., *Predictive Testing for Huntington Disease in Canada: Adverse and Unexpected Results in Those Receiving a Decreased Risk*, 42 AM. J. MED. GENETICS 508 (1992).

²⁶ Although the Health Insurance Accountability Act of 1996, 29 U.S.C. § 1181 (2000), prevents some uses of genetic information in group insurance plans, it does not assist purchasers of individual insurance policies or prevent insurers raising policy rates for people with some genetic conditions. State anti-discrimination and privacy legislation will be relevant in evaluating the risk of discrimination.

as to whether to undergo genetic testing and learn the results of those tests. In most cases, the situation cannot be fully analyzed by performing a utilitarian calculation as to the benefits and harms of disclosure; the proband would usually take account of any choice made by X, being the person most affected by disclosure. If X has already made an informed choice to remain ignorant, respect for autonomy would require that they be entitled to do so.²⁷ This factor will come into play where, for example, X was already aware of a family history of a particular genetic disease and has made a conscious decision not to be tested (of which the proband is aware).

Such situations are rare. If, as is more likely, the proband is not aware of X's preferences, the principle of autonomy has little to say. While sharing genetic disease information with X might enhance X's autonomy by providing him or her with information affecting other decisions,²⁸ the decision whether to know, which itself has important consequences,²⁹ will already have been made.³⁰ One might try to elucidate information as to X's preferences by asking an appropriately framed question. For example, one might say to X, "I have some information about my own future health that may affect yours; would you like to know it?"³¹ However, it is difficult to avoid making the question too vague, in which case X's response is uninformed and thus less credible, or too precise, thus providing X with some information he or she may not wish to know.³²

²⁷ See Laurie, *supra* note 3, at 14.

²⁸ Such as, for example, whether to seek treatment, whether to alter major life decisions, and whether to have children.

²⁹ In addition to consequences raised in Section III(B), *supra*, knowledge of genetic information can affect X's self-perception. See Laurie, *supra* note 3, at 21.

³⁰ See generally *id.* at 21-23.

³¹ See Buchanan, *supra* note 1, at 405-06.

³² See Laurie, *supra* note 3, at 21.

The only way out of this difficulty is to notify relevant family members before undergoing genetic testing, and gauge their reactions at that stage. However, where genetic testing is routine or undertaken in the context of an emergency, this possibility will rarely be taken up. Even where this possibility exists and is taken up by the proband, X may still be harmed because even discussing the fact that one will undergo genetic testing may convey some genetic information,³³ and may force X to address issues he or she would prefer not to consider.

D. Harm to Informer and Principle of Reasonable Costs

If the three factors discussed above point towards disclosure, the proband will likely take into account harms he or she may experience as a result of disclosure. As noted above, few would act unless the costs of doing so are reasonable.

There are many harms that the proband may face as a result of disclosing genetic disease information to X, from minor hassles, such as the time and cost involved in contacting affected relatives, to the more serious concerns of stigmatization³⁴ and loss of privacy. There is also a slight but potent risk that the information might be spread further to employers or insurance organizations, resulting in potential discrimination.³⁵ There may, on the other hand, be benefits to the proband of sharing genetic test results; for example, X may offer the proband emotional support.³⁶

³³ A person would usually seek genetic testing because they had some genetic disease information, whether based on family history, symptoms pertaining to a genetic disease, or knowledge of the result of a genetic test undertaken by a family member.

³⁴ The risk is that one might be stigmatized by X and by anyone with whom X shares the information.

³⁵ See *supra* note 26.

³⁶ At least one study indicates that informing a sister that one carries one of the breast cancer genes, BRCA1 or BRCA2, may decrease psychological distress. See Caryn Lerman et al., *Family Disclosure in*

Assuming the proband feels likely to suffer as a result of disclosure, there may nevertheless be circumstances where he or she would be prepared to bear those costs. Generally speaking, the closer the familial or friendship ties between X and the proband, the greater the costs the proband is likely to be prepared to bear and the greater the costs X would likely expect the proband to bear.³⁷ Such increased expectations of mutual protection can arise out of different types of family relationships, depending on cultural context as well as the way in which the particular family has defined itself.³⁸ Usually, a person will feel a stronger inclination to share information with siblings and nuclear family members than to share the information with more distant relatives.³⁹

E. Weighing the factors

As can be seen from the above discussion, the factors involved in the proband's decision are complex. Even a conscientious person, with time to examine and weigh the various factors, will ultimately face a difficult decision. One might imagine different situations falling in different positions on a continuous spectrum. At the left end of the spectrum are cases pointing strongly towards disclosure, and at the right end of the spectrum are those cases where disclosure would clearly be inappropriate. Much will lie in the middle, and in most situations neither a choice to share the information or a choice to remain silent would be "wrong," although one might argue that in such in between

Genetic Testing for Cancer Susceptibility: Determinants and Consequences, 1 J. HEALTH CARE L. & POL'Y 353, 363-64 (1998).

³⁷ See Buchanan, *supra* note 1, at 402-03.

³⁸ See *id.*; Sumner B. Twiss, Jr., *Ethical Issues in Genetic Screening: Models of Genetic Responsibility*, in ETHICAL, SOCIAL AND LEGAL DIMENSIONS OF SCREENING FOR HUMAN GENETIC DISEASE 225, 236-38 (Daniel Bergsma ed., 1974).

³⁹ Of course, the information is likely more pertinent for close relatives than for more distant relatives. See *supra* note 11 and accompanying text.

situations, the appropriate response is non-interference.⁴⁰ The following Section analyses the legal consequences might follow from a failure to warn in cases at the left end of the spectrum, and a failure to remain silent in cases at the right end.

IV. Legal issues in sharing genetic disease information

The existence of moral arguments pointing towards or away from disclosure does not necessarily make it appropriate to impose a legal duty. It may nevertheless be appropriate to impose a legal duty in cases at the extreme ends of the spectrum, where a decision to give or not to give a warning can have significant negative consequences. For example, assume that a person discovers that they have hereditary hemochromatosis, a potentially fatal disease where the simple procedure of phlebotomies is a largely effective treatment. There is little cost in warning those most likely to be affected (in this case, siblings) as there is negligible risk of discrimination or stigmatization in a close family member knowing about a controllable genetic condition. On the other hand, if the proband declines to do so, those affected by the same gene may face significant health consequences, such as liver cirrhosis, diabetes mellitus, and congestive heart failure.⁴¹ A close family member at risk for the same condition might expect to be warned of such dangers. In addition to the normal expectations of mutual protection existing between family members, the availability of genetic information increases the reliance and dependence members of a family have on one another.

⁴⁰ Laurie, *supra* note 3, uses the principle of spatial privacy to justify a preference for nondisclosure of genetic disease information where disclosure could result in substantial harm. *See generally infra* Section IV(C)(1).

⁴¹ THE GALE ENCYCLOPEDIA OF GENETIC DISORDERS, *supra* note 4, at 518-21.

The concern that a legal obligation to disclose genetic disease information would encourage disclosure in situations where such disclosure might cause harm is not justified. The fact that the decision to share the information may involve complex considerations does not justify refusing to impose legal obligations where all the factors point the same way. It does, however, justify caution. Duties should not be imposed in situations where the information might have caused as much harm as good, or in situations where disclosure might cause significant harm to the proband. However, such considerations ought not prevent a court imposing legal obligations where such harms are insignificant.

A. Duty to warn

Most commentators agree that, despite any moral obligation to share genetic information, there is no legal requirement to do so.⁴² Any legal duty to warn one's relatives that they may be at risk for a genetic disease would require positive conduct on the part of the proband. Thus the main obstacle for a disappointed relative wishing to assert the existence of a duty to warn is the traditional rule that there is generally no duty to rescue. If a person can watch silently as a blind man walks in front of a truck, or smoke a cigarette while a man drowns, then surely the proband can decline to share genetic information, even in circumstances where that information might save the life or health of another.⁴³ The general principle that there is no duty to rescue is set out in the Second Restatement of Torts:

⁴² See Ellen Wright Clayton, *What Should the Law Say About Disclosure of Genetic Information to Relatives?*, 1 J. HEALTH CARE L. & POL'Y 373, 389 (1998); Sonia M. Suter, *Whose Genes Are These Anyway? Familial Conflicts Over Access to Genetic Information*, 91 MICH. L. REV. 1854, 1887 (1993).

⁴³ See examples given in RESTATEMENT (SECOND) OF TORTS § 314 (1965).

The fact that the actor realizes or should realize that action on his part is necessary for another's aid or protection does not of itself impose upon him a duty to take such action.⁴⁴

The origin of the no duty to rescue rule is usually assumed to be the common law distinction between responsibility for actions and responsibility for omissions, or between “misfeasance” and “nonfeasance,”⁴⁵ although this historical explanation has been criticized.⁴⁶ Despite the fact that the rule has been frequently criticized on moral⁴⁷ and logical⁴⁸ grounds and theoretical bases for the existence of a duty to rescue have been suggested,⁴⁹ most jurisdictions refuse to impose liability for a failure to rescue unless a recognized exception applies.⁵⁰

⁴⁴ RESTATEMENT (SECOND) OF TORTS § 314 (1965). *See generally* Francis H. Bohlen, *The Moral Duty to Aid Others As a Basis of Tort Liability*, 56 U. PA. L. REV. 217 (1908) (explaining the distinction between misfeasance and nonfeasance).

⁴⁵ *See, e.g.*, RESTATEMENT (SECOND) OF TORTS § 314 cmt. c (1965); W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 56, at 373 (5th ed., 1984).

⁴⁶ Peter F. Lake, *Boys, Bad Men, and Bad Case Law: Re-Examining the Historical Foundations of No-Duty-To-Rescue Rules*, 43 N.Y.L. SCH. L. REV. 385 (1999) (suggesting that “no duty to rescue” rules arose largely in the context of socially unproductive behavior on the part of young males); Jean Elting Rowe & Theodore Silver, *The Jurisprudence of Action and Inaction in the Law of Tort: Solving the Puzzle of Nonfeasance and Misfeasance from the Fifteenth Through the Twentieth Centuries*, 33 DUQ. L. REV. 807 (1995) (arguing that there is no logical distinction between action and inaction and that the legal distinction between nonfeasance and misfeasance originates from a poor choice of words by the judge in *Watkins’ Case*, Y.B. Hil. 3 Hen. VI, fo. 36, pl. 33 (1425)). *See also* James P. Murphy, *Evolution of the Duty of Care: Some Thoughts*, 30 DEPAUL L. REV. 147 (1981) (suggesting that distinctions between misfeasance and nonfeasance are not part of the original conception of duty of care).

⁴⁷ *See, e.g.*, James Barr Ames, *Law and Morals*, 22 HARV. L. REV. 97, 112-113 (1908); Jay Silver, *The Duty to Rescue: A Reexamination and Proposal*, 26 WM. & MARY L. REV. 423, 428-34 (1985); Ernest J. Weinrib, *The Case for a Duty to Rescue*, 90 YALE L.J. 247 (1980); Robert Justin Lipkin, Comment, *Beyond Good Samaritans and Moral Monsters: An Individualistic Justification of the General Legal Duty to Rescue*, 31 UCLA L. REV. 252 (1983). *But see* Joshua Dressler, *Some Brief Thoughts (Mostly Negative) About “Bad Samaritan” Laws*, 40 SANTA CLARA L. REV. 971 (2000); Richard A. Epstein, *A Theory of Strict Liability*, 2 J. LEGAL STUD. 151 (1973); James A. Henderson, Jr., *Process Constraints in Tort*, 67 CORNELL L. REV. 901, 928-43 (1982).

⁴⁸ *See* John M. Adler, *Relying upon the Reasonableness of Strangers: Some Observations About the Current State of Common Law Affirmative Duties to Aid or Protect Others*, 1991 WIS. L. REV. 867; Rowe & Silver, *supra* note 46.

⁴⁹ *See, e.g.*, Steven J. Heyman, *Foundations of the Duty to Rescue*, 47 VAND. L. REV. 673 (1994).

⁵⁰ Vermont is an exception, having passed the Duty to Aid the Endangered Act, VT. STAT. ANN. tit. 12, § 519(a) (2002) (imposing a fine on persons who decline to give reasonable assistance knowing that someone is exposed to grave physical harm, at least where the assistance could be provided without danger

This is not to say that there is never negligence liability for omissions; a defendant who has a duty to act will be liable for the failure to do so.⁵¹ Affirmative duties are recognized, *inter alia*, in cases involving special relationships and in cases where the defendant's omission was preceded by a positive act that harmed the plaintiff or created a risk to the plaintiff. Special relationships will oblige a person to take reasonable action where either:

- SR1. that person is in a special relation with another person, who is at unreasonable risk of physical harm;⁵² or
- SR2. that person is aware that someone (X) will cause harm to another (Y) and has either a special relationship with X that creates a duty to control X or a special relationship with Y that gives Y a right to protection.⁵³

A person also has a positive obligation to take reasonable care to prevent harm where:

or peril and would not interfere with other important duties). Louisiana and Wisconsin are also possible exceptions. *See* *Wicker v. Harmony Corp.*, 784 So. 2d 660, 665-66 (La. Ct. App. 2001), *cert. denied*, 798 So.2d 115 (La. 2001) (although the case was decided on other grounds, the Court referred to the principle that a person has no duty to rescue another as an “uncivilized common law concept” and stated that Louisiana ought to follow civil law regimes that impose an obligation to rescue in some circumstances); *Schuster v. Altenberg*, 424 N.W.2d 159, 166 n.3 (stating that, under Wisconsin law, the court need not engage in the “analytical gymnastics” required by adherence to the no duty to rescue rule and its exceptions). Californian courts oscillate on this issue. *Compare* *Adams v. City of Fremont*, 80 Cal. Rptr. 2d 196, 222-24 (1998) (describing the distinction between nonfeasance and misfeasance as “artificial semantics”) *with* *Eric J. v. Betty M.*, 90 Cal. Rptr. 2d 549 (Cal. Ct. App. 1999), *appeal denied*, No. S084937, 2000 Cal. LEXIS 2015 (Cal. 2000) (affirming the no duty to rescue rule) *and* *Merrill v. Navegar, Inc.*, 28 P.3d 116, 144 (Cal. 2001) (Werdegar, J., dissenting) (“[M]isfeasance and nonfeasance do mark a significant conceptual border.”) Other states have passed laws creating exceptions to the no-duty-to-rescue rule but none are sufficiently broad to cover the situation discussed here. *See, e.g.*, MINN. STAT. ANN. § 604A.01(1) (West Supp. 2003); R.I. GEN. LAWS § 11-56-1 (2002) (obligation to assist only arises at “the scene of an emergency”).

⁵¹ RESTATEMENT (SECOND) OF TORTS §§ 314 cmt. a, 284(b) (1965).

⁵² RESTATEMENT (SECOND) OF TORTS § 314A (1965) (especially the Caveat and comment b).

⁵³ RESTATEMENT (SECOND) OF TORTS §§ 315-320 (1965).

PA1. that person realizes or should realize that his or her previous conduct has created an unreasonable risk of causing physical harm to another,⁵⁴ or

PA2. that person knows or has reason to know that, by his or her tortious or innocent conduct, he or she has caused such bodily harm to another as to make that other helpless and in danger of further harm.⁵⁵

Thus there are at least four categories of exceptions to the no duty to rescue rule. While these are neither universally recognized or comprehensive, and each state will have its own formulation of the rule and its exceptions, these categories, derived from the Restatement, provide a useful starting point for analysis. Before examining the obligations of the proband, it is worth taking a brief look at the obligations owed by the proband's physician to the proband's relatives.

1. Physician's duty to warn

In professional,⁵⁶ academic⁵⁷ and government⁵⁸ circles, as well as in the courts,⁵⁹ obligations of physicians have been the focus of the debate as to whether and how relatives of a person receiving a positive genetic test result ought to be informed.⁶⁰

⁵⁴ RESTATEMENT (SECOND) OF TORTS § 321 (1965).

⁵⁵ RESTATEMENT (SECOND) OF TORTS § 322 (1965).

⁵⁶ See John C. Fletcher & Dorothy C. Wertz, *Ethics, Law, and Medical Genetics: After the Human Genome Is Mapped*, 39 EMORY L.J. 747, 763-64 (1990).

⁵⁷ See, e.g., Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149 (1992); L.J. Deflos, *Genomic Torts: The Law of the Future – The Duty of Physicians to Disclose the Presence of a Genetic Disease to the Relatives of Their Patients with the Disease*, 32 U.S.F. L. REV. 105 (1997); Judith Hall, *The Concerns of Doctors and Patients*, in ETHICAL ISSUES IN HUMAN GENETICS: GENETIC COUNSELING AND THE USE OF GENETIC KNOWLEDGE 23, 27 (Bruce Hilton et al. eds., 1973); Michelle R. King, *Physician's Duty to Warn a Patient's Offspring of Hereditary Genetic Defects: Balancing the Patient's Right to Confidentiality Against the Family Member's Right to Know – Can or Should Tarasoff Apply?*, 4 QUINNIAC HEALTH L.J. 1 (2000); Ruth Macklin, *Privacy and Control of Genetic Information*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES 157, 162-64 (George J. Annas & Sherman Elias, eds. 1992); Alissa Brownrigg, Note, *Mother Still Knows Best: Cancer-*

In the search for authority regarding a physician's liability to non-relatives, two categories of cases are usually referred to: the psychotherapist cases and the contagious diseases cases. The basis for liability in the psychotherapist cases is an application of the exception labeled SR2 above.⁶¹ The special relationship between therapist and patient can in some circumstances create an obligation on the therapist to control the patient or warn the potential victim. The contagious disease cases typically involve one of the following situations: (1) a physician failed to diagnose a patient, who then unwittingly passed on the disease, (2) a physician failed to give proper advice to the patient regarding necessary means to avoid spread of the disease, or (3) a physician failed to directly warn third parties in close contact with the patient as to means of avoiding infection.⁶² In imposing positive obligations on physicians in these circumstances, the cases rely on duties owed by a physician directly to his or her patient, the existence of public health statutes or the SR2 exception to the no duty to rescue rule. Upon consideration of the principles underlying the psychotherapist and contagious disease cases, it is clear that neither

Related Gene Mutations, Familial Privacy, and a Physician's Duty to Warn, 26 FORDHAM URB. L.J. 247 (1999); Jeffrey W. Burnett, Comment, *A Physician's Duty to Warn a Patient's Relatives of a Patient's Genetically Inheritable Disease*, 36 HOUS. L. REV. 559 (1999); Angela Liang, Note, *The Argument Against a Physician's Duty to Warn for Genetic Diseases: The Conflicts Created by Safer v. Estate of Pack*, 1 J. HEALTH CARE L. & POL'Y 437 (1998); Andrea Suddell, Comment, *To Tell or Not to Tell: The Scope of Physician-Patient Confidentiality When Relatives Are At Risk of Genetic Disease*, 18 CONTEMP. HEALTH L. & POL'Y 273 (2001).

⁵⁸ See, e.g., PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS 43-45 (1983) (discussing the possibility of a physician's duty to warn relatives following a clinical diagnosis of an inheritable disease where efforts to elicit the voluntary consent of the patient to disclosure have failed).

⁵⁹ See *Pate v. Threlkel*, 661 So. 2d 278 (Fla. 1995); *Schroeder v. Perkel*, 432 A.2d 834 (N.J. 1981); *Safer v. Estate of Pack*, 677 A.2d 1188 (N.J. Super. Ct. App. Div. 1996), *cert. denied*, 683 A.2d 1163 (N.J. 1996).

⁶⁰ There is also commentary concerning the obligations of genetic counselors, but that issue will not be considered separately.

⁶¹ See *supra* note 53 and accompanying text.

⁶² See *infra* notes 65 and 69.

provides a useful analogy to the situation where a physician fails to warn his patient's relatives of a genetic risk.

Psychotherapists have been held liable for failure to take reasonable care to protect a non-patient from the danger posed by a patient who threatens to harm the non-patient where there is a serious danger of violence.⁶³ The basis of liability in these circumstances is SR2; the therapist's relationship with the patient is the source of the obligation to prevent harm. The psychotherapist cases are distinguishable from situations involving genetic diseases. Even leaving aside the absence of threatened violence in the genetic context, the source of danger is not the relative, but the "victim's" own genome. Although the patient may be in a position to ameliorate the danger, the failure to do so does not thereby become the source of danger.⁶⁴ Thus, any obligation on physicians to warn a patient's relatives of genetic risk would involve recognition of a new duty, unless it could be based on the contagious diseases cases.

⁶³ See *Tarasoff v. Regents of Univ. of Cal.*, 551 P.2d 334, 345 (Cal. 1976) ("[O]nce a therapist does in fact determine, or under applicable professional standards reasonably should have determined, that a patient poses a serious danger of violence to others, he bears a duty to exercise reasonable care to protect the foreseeable victim of that danger"); *Thompson v. County of Alameda*, 614 P.2d 728, 734 (Cal. 1980) (limiting *Tarasoff* to situations where the victim is readily identifiable). See also *McIntosh v. Milano*, 403 A.2d 500, 511-12 (N.J. Super. Ct. Law Div. 1979); *Estates of Morgan v. Fairfield Family Counseling Ctr.*, 673 N.E.2d 1311, 1328-31 (Ohio 1997). The *Tarasoff* principle and its variants have been widely, although not universally, accepted throughout the United States; see, e.g., *Bradley v. Ray*, 904 S.W.2d 302, 306 (Mo. Ct. App. 1995) ("[T]he vast majority of other courts to address the issue ... hold that when a psychologist or other professional knows or pursuant to the standards of the profession should have known that a patient presents a serious danger of violence to a readily identifiable victim, the psychologist has a common law duty to take such protective actions as may be reasonable under the circumstances to warn the intended victim or to communicate the existence of such danger to those likely to warn the victim, which may include notifying appropriate law enforcement authorities." (emphasis in original)). Although not relevant for present purposes, note that some jurisdictions have codified the *Tarasoff* principle for warnings in the mental health context. See, e.g., ARIZ. REV. STAT. § 36-517.02 (1993); CAL. CIV. CODE § 43.92 (West 1982); KY. REV. STAT. ANN. § 202A.400 (Mitchie Supp. 2002); LA. REV. STAT. ANN. § 9:2800.2 (West 1997); MINN. STAT. ANN. § 148.975 (1998); MONT. CODE ANN. §§ 27-1-1102, 1103 (2001), N.H. REV. STAT. ANN. § 330-A:35 (Supp. 2002); N.J. STAT. ANN. § 2A:62A-16 (West 2000); UTAH CODE ANN. § 78-14a-102 (2002).

⁶⁴ Note, this Article does not address the obligations that might be owed to a spouse or sexual partner to share genetic disease information so as to prevent harm to future children.

There are two bases on which physicians have been held liable to non-patients in the contagious diseases context. First, a failure to inform the *patient* of the genetic disease information, may breach a duty to the *patient*, with liability extending to foreseeable third parties.⁶⁵ This principle could only give rise to an obligation on a physician to properly explain the inheritable nature of a patient's condition *to the patient*. In fact, the Florida Supreme Court has limited a physician's duties in the context of genetic disease information to that obligation.⁶⁶ In *Pate v. Threlkel*, a physician's duty of care to his patient was assumed to include a requirement to discuss the genetically transferable nature of the patient's condition with the patient.⁶⁷ The court held that, because the intended beneficiaries of such a standard of care would be the family of the patient, members of the patient's family who were known to the physician would be able to recover for breach of that standard of care.⁶⁸

⁶⁵ *See, e.g.*, *Reisner v. Regents of Univ. of Cal.*, 37 Cal. Rptr. 2d 518, 523 (Cal. Ct. App. 1995) (stating that a claim arises where failure to warn a minor patient and her parents about dangers of HIV infection resulted in infection of the patient's subsequent sexual partner); *DiMarco v. Lynch Homes-Chester County, Inc.*, 583 A.2d 422, 424-25 (Pa. 1990) (holding that physicians have a duty to advise patients as to how to prevent the spread of a communicable disease and that liability extends to persons whose health was threatened); *Estate of Amos v. Vanderbilt Univ.*, 62 S.W.3d 133, 138 (Tenn. 2001) (holding a physician who failed to identify and warn a patient who had received blood transfusions at defendant hospital that she was at risk for HIV infection liable to her future husband and child).

⁶⁶ *Pate v. Threlkel*, 661 So. 2d 278, 282 (Fla. 1995) ("Our holding should not be read to require the physician to warn the patient's children of the disease. In most instances the physician is prohibited from disclosing the patient's medical condition to others except with the patient's permission. . . . Moreover, the patient ordinarily can be expected to pass on the warning. To require the physician to seek out and warn various members of the patient's family would often be difficult or impractical and would place too heavy a burden upon the physician. Thus, we emphasize that in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient.").

⁶⁷ *Id.* at 281. By virtue of the relevant Florida statute, this would be determined by expert testimony.

⁶⁸ *Id.* at 282.

Second, a failure to warn non-patients affected by the genetic disease information may breach a duty owed separately to them.⁶⁹ The rationales generally offered for the second type of duty are the existence of physician's obligations under public health laws⁷⁰ and the "special relationship" between the physician and the patient,⁷¹ creating liability pursuant to the SR2 exception to the no duty to rescue rule.⁷² The first rationale simply does not apply to genetic diseases; sterilization laws and other means of promoting a community's "genetic health" are generally considered abhorrent.⁷³ In the contagious disease cases, as in the psychotherapist cases, the logic of SR2 assumes that the patient poses an *active* threat (namely the risk of infection) arising out of a failure to prevent harm. There is thus no justification for relying on either the psychotherapist or the contagious diseases cases in considering whether the physician owes a duty to warn non-patients of genetic risk.

⁶⁹ See, e.g., *Davis v. Rodman*, 227 S.W. 612, 614 (Ark. 1921) (stating that physicians have a duty "to exercise reasonable care to advise members of the family and others, who are liable to be exposed [to the patient's contagious disease], of the nature of the disease and the danger of exposure"); *Hofmann v. Blackmon*, 241 So.2d 752 (Fla. Dist. Ct. App. 1970) (holding that physician's assumed negligent failure to diagnose patient with tuberculosis resulting in his failure to warn those responsible for his patient's minor child of the nature of the disease and means of avoiding infection would result in liability); *Skillings v. Allen*, 173 N.W. 663, 664 (Minn. 1919) (holding that a physician who inaccurately advised the parents of his minor patient who had scarlet fever that they could safely visit their child in hospital and bring the child home liable to the parents); *Edwards v. Lamb*, 45 A. 480 (N.H. 1899) (holding physician who negligently directed his patient's spouse to assist in dressing an infectious wound liable to the spouse). Technically, *Skillings* and *Edwards* involved misfeasance.

⁷⁰ See, e.g., *Skillings*, 173 N.W. at 664 (discussing obligations to a patient's family as if such obligations were extensions of obligations under state public health laws); *DiMarco v. Lynch Homes-Chester County, Inc.*, 583 A.2d 422 at 425 (Pa. 1990) (public health statute referred to as additional reason for imposing liability).

⁷¹ See, e.g., *Davis*, 227 S.W. at 614 (noting that the position of physicians is analogous to a person "in custody" of the patient); *Shepard*, 390 N.W.2d. at 245-46.

⁷² See *supra* note 53 and accompanying text.

⁷³ See Lori B. Andrews, *A Conceptual Framework for Genetic Policy: Comparing the Medical, Public Health, and Fundamental Rights Models*, 79 WASH. U. L.Q. 221, 269-77; Catherine J. Damme, *Controlling Genetic Disease Through Law*, 15 U. CAL. DAVIS L. REV. 801, 807-08 (1982). *But see* Margery W. Shaw, *Conditional Prospective Rights of the Fetus*, 5 J. LEGAL MED. 63, 93-95, 110-11 (1984).

However, there is at least one case that could be used justify the imposition of a physician's duty to warn, namely *Bradshaw v. Daniel*.⁷⁴ In that case, the Tennessee Supreme Court relied on the reasoning in the psychotherapist and contagious disease cases to conclude that a physician owes a duty to warn those at risk from *non-contagious* diseases.⁷⁵ In *Bradshaw*, Elmer Johns was admitted to hospital under the care of the defendant physician.⁷⁶ Mr. Johns died in hospital, the cause of death being Rocky Mountain Spotted Fever, a non-contagious disease transmitted by ticks.⁷⁷ Despite the non-contagious nature of the disease, Mr. John's wife was at increased risk due to clustering, a phenomenon related to the activity of the infected ticks that transmit the disease.⁷⁸ However, the defendant physician failed to tell Mrs. Johns of the cause of her husband's death or warn her of the risk of exposure.⁷⁹ The court held the physician liable to Mrs. Johns, resting its conclusion on the proposition that a physician has an obligation to protect identifiable third parties (such as the patient's family) at foreseeable risk of harm, even where that risk is not posed, either deliberately or accidentally, by the patient.⁸⁰ However, the basis of the court's decision is difficult to discern. It cited no authority apart from the psychotherapist and contagious diseases cases, which, as explained above, are inapplicable where the patient poses no active threat. It is thus unclear whether the reasoning in *Bradshaw* will be taken up by other state courts.

⁷⁴ 854 S.W.2d 865 (Tenn. 1993).

⁷⁵ *Id.* at 872.

⁷⁶ *Id.* at 866-67.

⁷⁷ *Id.* at 867.

⁷⁸ *Id.* at 872.

⁷⁹ *Id.* at 867.

⁸⁰ *Id.* at 872-73.

Despite the dearth of relevant precedent, two New Jersey cases have imposed a duty on physicians to warn a patient's family of the risk of genetic disease. The first of these, *Schroeder v. Perkel*,⁸¹ can be explained on other grounds. In that case, a physician was held liable for failing to warn the parents of a minor patient that their child suffered from cystic fibrosis and the parents were able to claim damages for the medical costs incurred when their second child was born with the same condition.⁸² However, where the patient is a minor child, it is customary to discuss important information with the child's parents, rather than the child itself. The court, therefore, did not need to consider whether the obligation was to inform *the patient* or *the patient's family*. *Schroeder v. Perkel* is thus relatively uncontroversial and courts in other jurisdictions have imposed obligations to inform the parents of minor children of genetic abnormalities.⁸³

In *Safer v. Estate of Pack*,⁸⁴ however, the Appellate Division of the New Jersey Superior Court broke new ground. It held that a physician could be liable for failure to take reasonable steps to ensure that information regarding avertable risks from genetic causes reached family members likely to be affected.⁸⁵ The court specifically noted that this duty would *not* necessarily be fulfilled by informing the patient of the inheritable nature of the condition.⁸⁶ Like the Tennessee court in *Bradshaw*, the *Safer* court relied on

⁸¹ 432 A.2d 834 (N.J. 1981).

⁸² *Id.* at 839-42.

⁸³ *See, e.g.,* *Molloy v. Meier*, 660 N.W.2d 444 (Minn. Ct. App. 2003) (noting that while medical practitioners owe an obligation to warn the parents of a minor child of genetic risks, no duty is owed to family members where the patient is an adult).

⁸⁴ *Safer v. Estate of Pack*, 677 A.2d 1188 (N.J. Super. Ct. App. Div 1996), *cert. denied*, 683 A.2d 1163 (N.J. 1996).

⁸⁵ *Id.* at 1192.

⁸⁶ *Id.* at 1192 (“[I]t is appropriate that the duty [to warn of avertable risk from genetic causes] be seen as owed not only to the patient himself but that it also extends beyond the interests of a patient to members of

both the contagious disease and psychotherapist cases without discussing the distinction between cases involving situations where the risk of harm was due to the patient's condition or intended conduct and cases where the risk of harm is pre-existing. It is therefore unlikely that the reasoning *Safer* will be adopted by other state courts, especially since the requirement that physicians discuss genetic diseases with their patient's family has been abolished by statute, at least during the patient's life in the absence of consent.⁸⁷

In summary, it seems likely that, in circumstances where a physician's standard of care would require him or her to discuss the inheritability of the patient's condition with the patient, a failure to meet this standard may result in liability to family members. More controversial is the situation where it is alleged that the physician had a duty to inform the patient's relatives directly. Although such a duty was found to exist in *Safer v. Estate of Pack*,⁸⁸ and possibly in *Schroeder v. Perkel*,⁸⁹ and could be deduced from *Bradshaw v. Daniel*,⁹⁰ the foundation on which these cases rest is unclear.

In the event that, despite these difficulties, *Safer*⁹¹ is followed, the physician's obligation to warn will inevitably come into conflict with the duty of confidentiality. To the extent this would breach the physician's *ethical* duty,⁹² the President's Commission

the immediate family of the patient who may be adversely affected by a breach of that duty.") (citations omitted)

⁸⁷ N.J. STAT. ANN. § 10:5-47 (2002).

⁸⁸ *Id.*

⁸⁹ 432 A.2d 834.

⁹⁰ 854 S.W.2d 865 (Tenn. 1993).

⁹¹ 677 A.2d 1188.

⁹² *See*, American Medical Association, Principles of Medical Ethics § IV (2001), available at <<http://www.ama-assn.org/ama/pub/category/2512.html>>. The ethical obligation to maintain confidentiality

for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research has concluded that the duty can be overridden, but only where (1) reasonable efforts to elicit voluntary consent to disclosure have failed, (2) there is a high probability that harm will occur if the information is used to avert harm, (3) the harm that identifiable individuals are likely to suffer would be serious, and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed.⁹³ Similar requirements were suggested by the Institute of Medicine's Committee on Assessing Genetic Risks⁹⁴ and the Task Force on Genetic Testing created by the National Institutes of Health – Department of Energy Working Group on Ethical, Legal, and Social Implications of Human Genome Research.⁹⁵ Slightly different requirements were proposed by the American Society for Human Genetics' Social Issues Subcommittee on Familial Disclosure, which would permit disclosure where: (1) harm is likely to occur and is serious, imminent and foreseeable, (2) the at-risk relative is identifiable, (3) the disease is preventable, treatable, or medically accepted standards indicate that early monitoring will reduce the genetic risk, and (4) the harm from failing to disclose outweighs the harm from disclosure.⁹⁶ Although each proposal

in the physician-patient relationship originates with the Oath of Hippocrates: "Whatever, in connection with my professional service, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret", available at <[ftp://ftp.std.com/obi/Hippocrates/Hippocratic.Oath](http://ftp.std.com/obi/Hippocrates/Hippocratic.Oath)>. See generally Roberta M. Berry, *The Genetic Revolution and the Physician's Duty of Confidentiality: The Rule of the Old Hippocratic Virtues in the Regulation of the New Genetic Intimacy*, 18 J. LEGAL MED. 401 (1997).

⁹³ PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *supra* note 58, at 44.

⁹⁴ COMMITTEE ON ASSESSING GENETIC RISKS, DIVISION OF HEALTH POLICY, INSTITUTE OF MEDICINE, ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 22-23, 278 (1994).

⁹⁵ TASK FORCE ON GENETIC TESTING, *supra* note 20.

⁹⁶ Social Issues Subcommittee on Familial Disclosure, American Society of Human Genetics, *Professional Disclosure of Familial Genetic Information*, 62 AM. J. HUM. GENET. 474 (1998).

has a different focus, all are based on considerations similar to those set out in Section III above.

Although many organizations have assessed the limits of a physician's *ethical* duty of confidentiality, it is difficult to predict the circumstances in which the corresponding *legal* duty would be abrogated. Federal law currently protects the confidentiality of health information held by certain entities; health care providers who conduct certain financial and administrative transactions electronically will need to comply with those regulations.⁹⁷ Otherwise, the legal duty of confidentiality is governed by state law. Most states recognize a duty of confidentiality owed by physicians to their patients, with exceptions for circumstances in which there is an overriding need to avert harm.⁹⁸ The existence and basis of a duty of confidentiality as well as the nature of the

⁹⁷ See 45 C.F.R. Parts 160 and 164 (2002). See, in particular, 45 C.F.R. § 164.104 (2002) (specifying the entities to whom the regulations apply); 45 C.F.R. § 164.512(b)(iv) (2002) (regarding disclosure to a person who may have been exposed to a communicable disease or may otherwise be at risk of contracting or spreading a disease or condition) and 45 C.F.R. § 164.512(j) (2002) (regarding disclosure for the purposes of preventing or lessening a serious and imminent threat to the health or safety of a person or the public). Neither of these latter two provisions are directly applicable to the disclosure of genetic disease information. See also 45 C.F.R. § 164.510(b) (2002) (setting out circumstances in which an individual's family can generally be provided with health information). Physicians to whom the regulation applies must comply with the regime by April 14, 2003. 45 C.F.R. § 164.534(a) (2002).

⁹⁸ See, e.g., *Horne v. Patton*, 287 So. 2d 824, 829-30 (Ala. 1973) (duty of confidentiality applies except where disclosure is prompted by a supervening societal interest or is in the patient's private interest); *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 346-47 (Cal. App. 1976) (duty of confidentiality must be weighed against the public interest in safety from violent assault); *Alberts v. Devine*, 479 N.E.2d 113, 119 (Mass. 1985) (duty of confidentiality applies except where there is a serious danger to the patient or to others); *Simonsen v. Swenson*, 177 N.W. 831, 832-33 (Neb. 1920) (duty of confidentiality is not breached where physician acts in good faith to prevent the spread of a contagious disease); *Hague v. Williams*, 181 A.2d 345, 349 (N.J. 1962) (duty of confidentiality applies except where disclosure is prompted by a supervening societal interest or is in the patient's private interest; physician can disclose health information to those with a legitimate interest in the patient's health); *Humphers v. First Interstate Bank of Or.*, 696 P.2d 527, 534-35 (Or. 1985) (duty of confidentiality applies except where disclosure is required by law, is necessary for safety of individuals, or is in the public interest); *McCormick v. England*, 494 S.E.2d 431, 437-38 (S.C. Ct. App. 1997) (duty of confidentiality applies except where it is necessary to disclose information in order to protect the interests of the patient or others); *Berry v. Moench*, 331 P.2d 814, 817-18 (Utah 1958) (duty of confidentiality applies except where there is a sufficiently important interest to protect, such as life, safety, or well-being). See generally Judy E. Zelin, Annotation, *Physician's Tort Liability for Unauthorized Disclosure of Confidential Information About Patient*, 48 A.L.R.4th 668 (1986 & Supp. 2002). For a description of the application of confidentiality principles after a patient's

exceptions need to be assessed on a state by state basis.⁹⁹ *Safer v. Estate of Pack*,¹⁰⁰ being the only case involving a physician's duty to share genetic disease information with a non-minor patient's family, did not address the issue of confidentiality. The issue has, at least for New Jersey, been resolved by legislation; a physician can only inform family members at risk where the proband consents or has died.¹⁰¹

There are several reasons why imposing the obligation to inform relatives on *physicians* is, from a normative perspective, less desirable than imposing the same obligation on *patients*. First, the physician will generally be caught between two potential sources of liability, liability to the patient for breach of the duty of confidentiality and liability to the patient's family for failure to warn. While there have been some suggestions, by ethical bodies and in state law, as to the physician's appropriate conduct in different situations, the advice is not always clear. Second, if the information is to be disclosed, most patients would rather retain control over the timing and context of the disclosure.¹⁰² In particular, having relatives informed by one's physician may cause additional harm to the patient, who may feel betrayed by their doctor and avoid trusting medical practitioners in the future. Third, in situations where disclosure is essential, the

death, see Jessica Berg, *Grave Secrets: Legal and Ethical Analysis of Postmortem Confidentiality*, 24 CONN. L. REV. 81 (2001).

⁹⁹ See cases referred to in *infra* note 98. In addition to common law rules, many states have general statutes governing a physician's duty of confidentiality and its exceptions. The Health Privacy Project maintains a website database of state health privacy laws, <http://www.healthprivacy.org/info-url_nocat2304/info-url_nocat.htm> (last visited Mar. 20, 2003). The National Conference of State Legislatures maintains website database of state laws specific to genetic privacy, <<http://www.ncsl.org/programs/health/genetics/ndislife.html>> (last modified Apr. 15, 2002).

¹⁰⁰ 677 A.2d at 1193.

¹⁰¹ N.J. STAT. ANN. § 10:5-47 (2002).

¹⁰² Caryn Lerman et al., *Family Disclosure in Genetic Testing for Cancer Susceptibility: Determinants and Consequences*, 1 J. HEALTH CARE L. & POL'Y 353, 358, 368 (1998).

moral obligation to share the information sits more heavily on the patient than on his or her physician.¹⁰³ Fourth, the patient is more likely to have the information necessary to make an assessment as to the benefits and harms of disclosure set out in Section III. Although a physician can easily communicate factors with which he or she is familiar, such as medical prognosis and treatment, it is more difficult for a patient to explain factors relating to a family member's desire to know. Finally, as a practical matter, the patient is more likely to have contact information for those who may be affected than his or her physician. A duty to warn is thus less of an imposition if placed on the patient. However, despite these considerations, there is even less legal basis for imposing a legal obligation to warn on the patient than for imposing the obligation on his or her physician.

2. Patient's duty to warn – special relationships

The most likely candidate for imposing positive obligations on the patient to warn his or her own relatives is the first special relationships exception to the no duty to rescue rule, SR1.¹⁰⁴ The special relationships rule relied on in the context of physician's duties, SR2, is not relevant here because it involves three parties: the perpetrator, the victim, and the person in a special relationship with either of them. The SR1 exception is based on section 314A of the Second Restatement Second of Torts, which states that positive obligations can arise out of the following special relationships: common carriers, innkeepers, possessors of land, and those who voluntarily take custody of another owe

¹⁰³ See COMMITTEE ON ASSESSING GENETIC RISKS, *supra* note 94 at 23, 278; GEORGE J. ANNAS, LEONARD H. GLANTZ, & PATRICIA A. ROCHE, THE GENETIC PRIVACY ACT AND COMMENTARY, Appendix (1995), available at <<http://www.bumc.bu.edu/www/sph/lw/pvl/act.html>>.

¹⁰⁴ See *supra* note 52 and accompanying text.

positive obligations.¹⁰⁵ The positive obligations owed to passengers, guests, invitees, or persons in custody are: (1) to protect them against unreasonable risk of physical harm, and (2) to render first aid after knowing or having reason to know that they are ill or injured, and to care for them until they can be cared for by others.¹⁰⁶ Such obligations are owed even if the risk, illness or injury is a result of natural causes or the plaintiff's own negligence.¹⁰⁷ If a special relationship could be established, the requirement to protect against unreasonable risk of physical harm would require a person to share genetic disease information with relatives in at least some circumstances. It is therefore necessary to consider what types of relationships are special for the purposes of imposition of affirmative obligations and, in particular, whether certain family relationships are special.

Although section 314A of the Restatement only provides for a finite list of special relationships, the Caveat states, "The Institute expresses no opinion as to whether there may not be other relations which impose a similar duty."¹⁰⁸ This is clarified in a comment, which provides in part:

"The relations listed are not intended to be exclusive, and are not necessarily the only ones in which a duty of affirmative action for the aid or protection of another may be found. There may be other such relations, as for example that of husband and wife, where the duty is recognized by the criminal law, but there have as yet

¹⁰⁵ RESTATEMENT (SECOND) OF TORTS § 314A (1965). There are other recognized categories, not set out in the Restatement and not relevant to the problem under consideration here, such as employees and employers, *e.g.*, *Bessemer Land & Improvement Co. v. Campbell*, 25 So. 793 (Ala. 1899), companions engaged in a common undertaking, *e.g.*, *Farwell v. Keaton*, 240 N.W.2d 217, 222 (Mich. 1976), and social hosts and guests, *e.g.*, *Hutchinson v. Dickie*, 162 F.2d 103, 106 (6th Cir. 1947).

¹⁰⁶ RESTATEMENT (SECOND) OF TORTS § 314A (1965).

¹⁰⁷ *Id.* cmt. d.

¹⁰⁸ *Id.* caveat. *See also supra* note 105.

been no decisions allowing recovery in tort in jurisdictions where negligence actions between husband and wife for personal injuries are permitted. The question is therefore left open by the Caveat...The law appears, however, to be working slowly toward a recognition of the duty to aid or protect in any relation of dependence or mutual dependence.”¹⁰⁹

Two bases have been suggested for extending the categories of special relationships; both are based on features shared by the recognized categories. The first suggested commonality is that the relationships recognized as special often involve situations where the defendant has received an economic benefit from the relationship.¹¹⁰ Obviously, family or genetic relationships could not be recognized as a new category on this basis. The second suggested common feature is that the recognized categories involve situations where a plaintiff was dependent on the defendant.¹¹¹ It is at least arguable that family members are dependent on one another, either generally or in the context of genetic disease information.

A plaintiff seeking to make such an argument would need to contend with the fact that family relationships have not to date been recognized as “special” for the purposes of SR1. For example, despite the fact that spouses may have affirmative obligations to avoid

¹⁰⁹ *Id.* cmt. b.

¹¹⁰ *See Stangle v. Fireman’s Fund Ins. Co.*, 244 Cal. Rptr. 103, 104-05 (Cal. App. 1988) (“Special relationships, which remove bystander status and invoke a duty to rescue or protect, are often based on economic considerations.”) This factor is also mentioned in *KEETON ET AL. supra* note 45, at 374.

¹¹¹ *See supra* text accompanying note 109. *See also Donaldson v. Young Women’s Christian Ass’n of Duluth*, 539 N.W.2d 789, 792 (Minn. 1995) (“Typically, the plaintiff [in a special relationship] is in some respect particularly vulnerable and dependent on the defendant, who in turn holds considerable power over the plaintiff’s welfare”). *See also Lundman v. McKown*, 530 N.W.2d 807, 820 (Minn. Ct. App. 1984); *M.H. v Barber*, 1999 WL 343806, at *4 (Minn. Ct. App. 1999). This factor is also mentioned in *KEETON ET AL. supra* note 45, at 374. *But see Williams v. State of California*, 664 P.2d 137, 143 (Cal. 1983) (stating that a relationship of dependence does not establish special relationship unless the dependence was brought about by conduct of the defendant).

criminal liability,¹¹² few cases have held that a marital relationship is “special” for the purposes of owing affirmative duties.¹¹³ In fact, cases considering whether a marital relationship is “special” for the purpose of creating a duty to control the conduct of one’s spouse pursuant to SR2 have reached divergent conclusions.¹¹⁴ It is possible that these cases could be distinguished on the grounds that a person may be in a better position to *assist* his or her spouse than to *control* his or her spouse. In fact, either the inability of spouses to control one another’s conduct or the undesirability of requiring such control is cited in the cases declining to treat marital relationships as special.¹¹⁵ Nevertheless, because spousal relationships generally carry the most mutual obligations, the mixed results in those cases might lead to pessimism as to the “specialness” of other family relationships. In fact, cases considering other family relationships have consistently held that those relationships are not special for the purpose of creating affirmative duties. Thus parents owe no special obligations to their son’s girlfriend,¹¹⁶ adult children owe no special obligations to their parents,¹¹⁷ a woman does not owe special obligations to her

¹¹² *E.g.*, *Territory v. Manton*, 19 P. 387, 392 (Mont. 1888) (duty owed by husband to wife).

¹¹³ *But see* *Maharam v. Maharam*, 123 A.D.2d 165, 170 (N.Y. App. Div. 1986) (long term marital relationship is special relationship giving rise to affirmative duties).

¹¹⁴ *Compare* *Wise v. Superior Court*, 272 Cal. Rptr. 222, 224-25 (Cal. Ct. App. 1990) *and* *Touchette v. Ganal*, 922 P.2d 347, 355 (Haw. 1996) *with* *J.S. v. R.T.H.*, 714 A.2d 924, 935 (N.J. 1998) (imposing positive duties on a woman to protect adolescent girls against sexual abuse by her husband; the decision was based in part on the failure to comply with obligations imposed by legislation). *See also* *Hermosillo v. Leadingham* 13 P.3d 79, 83 (N.M. App. 2000) (although the court did not need to decide the issue, it stated, “The general trend...appears to be that the marital relationship, without more, does not trigger an independent duty to control the behavior of one’s spouse.”); *T.A. v Allen*, 669 A.2d 360, 364 (Pa. Super. Ct. 1995) (declining to consider whether a spousal relationship created an obligation on the wife to control her husband’s conduct, despite the fact that this would have been relevant on the facts of the case).

¹¹⁵ *Wise v. Superior Court*, 272 Cal.Rptr. at 225 (citing lack of actual control in marital relationship); *Touchette v. Ganal*, 922 P.2d at 354-55 (citing lack of ability to control or actual control in marital relationship).

¹¹⁶ *Eric J. v. Betty M.*, 90 Cal. Rptr. 2d 549 (Cal. Ct. App. 1999), *appeal denied*, No. S084937, 2000 Cal. LEXIS 2015 (Cal. 2000).

¹¹⁷ *Marhoefer v. Nacozy*, 2 Cal. Rptr. 2d 466, 469-70 (Cal. Ct. App. 1991).

husband's grandchildren,¹¹⁸ and there are no special fiduciary-type obligations between siblings.¹¹⁹ On the other hand, a person who assumes responsibility for a minor child will have positive duties, even though there may be no family relationship.¹²⁰ Thus it seems that the existence of a family relationship will not alone give rise to positive obligations.

It is possible but unlikely that increased understanding of the nature of genetic relationships will encourage courts to recognize genetic family relationships as special.¹²¹ One might argue that none of the cases rejecting family relationships as special considered the situation where family members were dependent on each other for genetic information. However, it has been held that mere knowledge of genetic disease information pertaining to another does not create a special relationship. In *Olson v. Children's Home Society of California*,¹²² the California Court of Appeal held that there was no special relationship between the plaintiff and the defendant adoption agency requiring the agency to inform the plaintiff of the genetic condition affecting the child she had given up for adoption. Thus neither the existence of a family relationship, nor reliance on another for genetic disease information, will likely be sufficient to impose affirmative duties on the proband to share genetic information with family members.

¹¹⁸ *T.A. v. Allen*, 669 A.2d 360 (implicit in decision, which instead focused on the question of duties allegedly owed by the defendant to her step-grandchildren due to her status as co-owner of the building where the assaults took place).

¹¹⁹ *Holt Schneider v. Stratman*, 655 S.W.2d 47, 49 (Mo. Ct. App. 1983).

¹²⁰ *E.g. State v. Miranda*, 715 A.2d 680, 689 (Conn. 1998). *See also Doe v. Franklin*, 930 S.W.2d 921, 927-29 (Tex. App. 1996) (grandmother's positive obligations to grandchild based on the fact that she had assumed the care of her grandchild, not on the fact that she was in a special relationship with her grandchild nor on the fact that she had the obligation to control her spouse).

¹²¹ For an argument against the adoption of genetic relationships as the focus of a conception of family, see Janet L. Dolgin, *Choice, Tradition, and the New Genetics: The Fragmentation of the Ideology of Family*, 32 CONN. L. REV. 523 (2000).

¹²² 252 Cal. Rptr. 11, 13 (Cal. Ct. App. 1988).

Nevertheless, it is at least possible (if unlikely) that courts will recognize a special relationship where both of these elements are present.

3. Patient's duty to warn – responsibility for harm

As noted above, the Second Restatement of Torts recognizes two circumstances in which responsibility for the plaintiff's circumstances creates a positive duty to act. To recap, a person has an obligation to take reasonable action where:

PA1. that person realizes or should realize that his or her act, whether tortious or innocent, has created an unreasonable risk of causing physical harm to another;¹²³ or

PA2. that person knows or has reason to know that, by his or her tortious or innocent conduct, he or she has caused such bodily harm to another as to make that other helpless and in danger of further harm.¹²⁴

These provisions raise an issue as to whether people might have a duty to warn direct descendants of genetic risks, given their involvement in the creation of such risks. Generally speaking, one's genetic makeup is inherent; the fact that one has a genetic disease is not caused or created by the act of an individual. Thus the use of "causation" language in both PA1 and PA2 argues against imposing liability based on responsibility for harm. However, Rowe and Silver have hypothesized that PA1 and PA2 are in fact based on a broader principle that a person is responsible for omissions where action

¹²³ RESTATEMENT (SECOND) OF TORTS § 321 (1965).

¹²⁴ RESTATEMENT (SECOND) OF TORTS § 322 (1965).

would reduce a risk attributable to one's existence.¹²⁵ Expressed in this manner, a person might owe affirmative duties to his or her direct descendants to prevent harm from genetic causes. Note that the action here would not be wrongful life (the parents should not have conceived a child) but failure to warn (having conceived a child, the parents have an obligation to minimize the harm resulting from genetic factors). A claim expressed on this basis seems doubtful, primarily because there is no reason in principle for imposing a duty to warn only in situations where the plaintiff is a direct descendent of the defendant.

The discussion above focuses on the duty to warn a direct descendent of genetic risks, but separate questions arise while the descendent is still a minor. There is no duty to "warn" a child during its minority, although there may be positive obligations to ensure that the child obtains any necessary medical care. State laws often provide for criminal penalties where parents fail to provide necessary medical care to their minor children.¹²⁶ The ability for children to bring civil actions in negligence for failure to provide proper medical care depends upon the existence and extent of parental immunity doctrines, which vary by state.¹²⁷ It is important to note that any obligation towards a minor child is an obligation to ensure the child obtains necessary treatment, not an obligation to provide explanations. The amount of genetic information that a parent

¹²⁵ Rowe & Silver, *supra* note 46, at 851-52.

¹²⁶ See, e.g., MO. REV. STAT. § 210.166 (1996); NEV. REV. STAT. § 432B.140 (2002); N.D. CENT. CODE § 14-07-15(1) (2001); OKLA. STAT. tit. 21, § 852 (2002).

¹²⁷ Compare *Renko v. McLean*, 697 A.2d 468, 468 (Md. 1997) (providing for parental immunity for conduct occurring during a child's minority with an exception for "cruel or unusually malicious conduct") with *Goller v. White*, 122 N.W.2d 193, 198 (Wis. 1963) (prospectively abolishing parental tort immunity in negligence actions except (1) where the alleged negligent act involves an exercise of parental authority over the child; or (2) where the alleged negligent act involves an exercise of ordinary parental discretion with respect to the provision of food, clothing, housing, medical and dental services, and other care) and *Gibson v. Gibson*, 479 P.2d 648, 653 (Cal. 1971) (abolishing parental tort immunity).

chooses to share with their minor child is likely to be considered a matter of ordinary parental discretion.¹²⁸ Public policy reinforces this state of affairs; a requirement that parents share genetic disease information with minor children would be particularly unattractive given the potential psychological consequences for those too immature to cope.

4. Patient's duty to warn – analogy with contagious disease cases

From a simplistic outlook, the cases with the most similarity to a possible duty to warn of genetic disease are the cases establishing a duty to warn of contagious disease. Physician's obligations in relation to contagious disease have already been discussed in Section IV(A)(1) above, but patients also have an independent obligation to warn those who may be exposed to their infection.¹²⁹

Of course, in the genetic context, the only people who "expose" others to genetic disease are parents who pass on their genes to their children. The contagious diseases cases are unlikely to be helpful to people wishing to sue a parent for passing on a genetic disease to them in a wrongful life suit.¹³⁰ Nevertheless, it is at least worth exploring the possibility that the contagious disease cases could provide a basis for imposing a general duty to warn those at risk of genetic disease. To do this, it is necessary to re-examine the rationales offered for liability in the contagious disease context.

¹²⁸ Clayton, *supra* note 42, at 381.

¹²⁹ See *infra* notes 131, 133-138.

¹³⁰ This question has been subject to significant debate on its own, and will not be discussed here. See generally, Lois Shepard, *Protecting Parents' Freedom to Have Children with Genetic Diseases*, 1995 U. ILL. L. REV. 761; Margery W. Shaw, *supra* note 73, at 93-95, 110-11 (1984). Note also that many states do not permit wrongful life suits against parents. See, e.g., CAL. CIV. CODE § 43.6(a) (West 1982).

Many of the communicable disease cases rest on reasoning that could not be imported into the genetic disease context. Cases based directly or indirectly on public health statutes regulating the conduct of contagious persons cannot be carried over to the genetic context unless similar statutes were enacted controlling the behavior of persons carrying certain genes, an unlikely scenario.¹³¹ To date, states have understandably shown a far greater concern for patient privacy than for public health in the genetic disease context.¹³² Battery actions based on the fact that consent to sexual intercourse is vitiated by one partner's fraudulent concealment of the risk of infection with venereal disease are also specific to their context.¹³³ In particular, it would be a stretch to argue that consent to sexual intercourse was vitiated because of a lack of knowledge as to the possibility that one's sexual partner might carry a gene that, if transmitted to a child conceived of that sexual relationship, would result in that child having a genetic disease. Another category of contagious disease cases that are specific to their context are the cases alleging intentional infliction of emotional distress.¹³⁴

In most contagious disease cases, the plaintiff's action is based on either negligence, fraud, or both. Depending on their facts, the plaintiff alleges either

¹³¹ Cases whose outcome was based at least in part on the existence of public health statutes include *Berner v. Caldwell*, 543 So. 2d 686, 689 (Ala. 1989); *Gabriel v. Tripp*, 576 So. 2d 404, 405 (Fla. Dist. Ct. App. 1991); *Long v. Adams*, 333 S.E.2d 852, 856 (Ga. Ct. App. 1985); *Meany v. Meany*, 639 So.2d 229, 235 (La. 1994); *Maharam v. Maharam*, 123 A.D.2d 165, 170-71 (N.Y. App. Div. 1986); *Mussivand v. David*, 544 N.E.2d 265, 271-272 (Ohio 1989). For a case relying on public health policies promulgated by the courts, see *R.A.P. v. B.J.P.*, 428 N.W.2d 103, 106-08 (Minn. Ct. App. 1988).

¹³² See *supra* note 73 and accompanying text.

¹³³ Cases where battery actions were recognized in these circumstances include *Doe v. Johnson*, 817 F. Supp. 1382, 1396-1398 (W.D. Mich. 1993); *Kathleen K. v. Robert B.*, 198 Cal. Rptr. 273, 276-77 (Cal. Ct. App. 1984); *State v. Lankford*, 102 A. 63, 64 (Del. Ct. Gen. Sessions 1917). See generally RESTATEMENT (SECOND) OF TORTS § 892B cmt. e, illus. 5 (1979) ("A consents to sexual intercourse with B, who knows that A is ignorant of the fact that B has a venereal disease. B is subject to liability to A for battery.")

¹³⁴ See, e.g., *B.N. v. K.K.*, 538 A.2d 1175, 1179-82 (Md. 1988). See generally RESTATEMENT (SECOND) OF TORTS § 46 (1965).

misfeasance (the allegation being that the defendant negligently exposed the plaintiff to the disease¹³⁵ or fraudulently misrepresented the truth¹³⁶) or nonfeasance (failure to warn). Of the misfeasance cases, those alleging fraudulent misrepresentation might transfer to the genetic disease context if a person actually lies about their genetic test result, lulling relatives into a false sense of security. However, only cases involving nonfeasance could provide a more general basis for analogy.

The cases involving nonfeasance, or failure to warn, allege that the defendant had a duty to warn the plaintiff of the risk of exposure to a communicable disease and failed to do so, resulting in liability in fraud or negligence. Although this is phrased in the language of nonfeasance, there is little difference in substance from allegations of misfeasance (based on the negligent act of transmitting a disease). It is therefore not clear that these are true nonfeasance cases.¹³⁷ Nevertheless, even assuming these cases are in fact duty-to-rescue cases, they do not go any further than the cases discussed in Section IV(A)(2) (involving special relationships) and IV(A)(3) (involving responsibility for

¹³⁵ See, e.g., *B.N. v. K.K.*, 538 A.2d 1175, 1178-79 (Md. 1988); *M.M.D. v. B.L.G.*, 467 N.W.2d 645, 646-47 (Minn. Ct. App. 1991); *Franklin v. Butcher*, 129 S.W. 428, 430 (1910); *Earle v. Kuklo*, 98 A.2d 107, 109 (N.J. Super. Ct. App. Div. 1953); *Hamblen v. Davidson*, 50 S.W.3d 433, 438-39 (Tenn. Ct. App. 2000). These cases have even been extended to allow the spouse of the person infected with a venereal disease to claim damages. E.g., *Cerniglia v. Levasseur*, No. CV-95-0548181, 1995 WL 500673 (Conn. Super. Ct. Aug. 15, 1995); *Mussivand v. David*, 544 N.E.2d 265 (Ohio 1989); *Lockhart v. Loosen*, 943 P.2d 1074, 1079-82 (Okla. 1997).

¹³⁶ See, e.g., *Kathleen K. v. Robert B.*, 198 Cal. Rptr. 273, 276-77 (Cal. Ct. App. 1984) (although the judge's opinion uses language that does not clearly differentiate between affirmative misrepresentation and fraudulent concealment, the former is what the plaintiff alleged).

¹³⁷ The fact that either language can be used serves to highlight the absurdity of the distinction between misfeasance and nonfeasance.

harm).¹³⁸ The difficulties in relying on such bases for imposing affirmative duties are the same as those already discussed.

5. Conclusion

Many commentators have suggested that having a general rule that there is no duty to rescue is problematic.¹³⁹ There seems little reason in principle to limit recovery in failure-to-rescue cases to pre-defined categories while positive-action cases rest on more general principles.¹⁴⁰ While one might be more reluctant to impose positive duties than negative duties, there seems no reason to categorically refuse to impose liability in situations where a person declines to share important genetic disease information with those most affected where there are no significant negative consequences in doing so. Any such obligation would be owed only to those in a limited and easily identifiable class (close genetic relatives who share a significant risk) so there is no risk that the duty would involve a requirement to help everyone. In such circumstances, there is no normative basis for declining to recognize liability using the same general principles that determine liability for misfeasance.

Currently, however, it would seem that liability would not be imposed on a person who declines to share genetic disease information with family members no matter how

¹³⁸ See *Maharam v. Maharam*, 123 A.D.2d 165, 170 (N.Y. App. Div. 1986) (affirmative duty based on special relationship, being a 31 year marriage); *B.N. v. K.K.*, 538 A.2d 1175, 1184 (Md. 1988) (court noted in *obiter dicta* that an intimate boyfriend-girlfriend relationship might constitute a special relationship); *c.f.* *Doe v. Johnson*, 817 F. Supp. 1382, 1393 (W.D. Mich. 1993) (a single consensual sexual encounter does not create a special relationship).

¹³⁹ See *supra* notes 46, 47-49.

¹⁴⁰ See, e.g., *Lee v. Corregedore*, 925 P.2d 324, 336 (Haw. 1996) (“In considering whether to impose a duty of reasonable care on a defendant, we recognize that duty is not sacrosanct in itself, but only an expression of the sum total of those considerations of policy which lead the law to say that the particular plaintiff is entitled to protection.”). See also KEETON ET AL. *supra* note 45, at 373-74.

extreme the circumstances. A relatively new form of conduct, the refusal to share genetic disease information with those also affected, fits oddly with the existing legal framework. The poor fit is primarily the result of recognizing liability only in circumstances corresponding with judicially formulated categories in the case of nonfeasance, a habit largely left behind where negligence is based on misfeasance. New technology and new forms of conduct rarely fit into categories designed prior to their existence.

B. The Duty to Warn and the Constitutional Right to Privacy

Despite the fact that there is little chance that a court would conclude that a person has a legal obligation to share genetic disease information with family members, it is worth commenting briefly on the possibility that the creation of such a legal obligation would infringe upon the constitutional right to privacy.¹⁴¹

The right to privacy pursuant to the Fourteenth Amendment involves two branches: the right to make private decisions, such as the decision to marry or abort a fetus, and the somewhat more questionable right to informational privacy. In *Whalen v. Roe*,¹⁴² Justice Stevens explained this dual nature of privacy as follows, “The cases sometimes characterized as protecting ‘privacy’ have in fact involved at least two different kinds of interests. One is the individual interest in avoiding disclosure of personal matters, and another is the interest in independence in making certain kinds of

¹⁴¹ Recognition of a private cause of action by a court can constitute state action for the purposes of the Constitution. *See* *Cohen v. Cowles Media Co.*, 501 U.S. 663, 668 (1991) (“[T]he application of state rules of law in state courts in a manner alleged to restrict First Amendment freedoms constitutes ‘state action’ under the Fourteenth Amendment.”); *New York Times Co. v. Sullivan*, 376 U.S. 254, 264 (1964) (“The test is not the form in which state power has been applied but, whatever the form, whether such power has in fact been exercised.”)

¹⁴² 429 U.S. 589 (1977).

important decisions.”¹⁴³ Justice Stevens refused to consider whether the statute the subject of *Whalen* would be unconstitutional if the data collected pursuant to that statute were disclosed.¹⁴⁴ Thus the right of privacy in information, mentioned briefly, was not the subject of further discussion, rendering *Whalen* almost useless in determining the scope of a privacy right in information. The constitutional interest in avoiding disclosure of personal matters was again raised by the Supreme Court in *Nixon v. Administrator of General Services*,¹⁴⁵ although, in that case, privacy rights were only alleged in the context of the First, Fourth, and Fifth Amendments.¹⁴⁶

Both *Whalen* and *Nixon* are a somewhat vague as to the basis and existence of a right to informational privacy. At least at the Supreme Court level, the vagueness remains; the Supreme Court has never used the confidentiality branch of the Fourteenth Amendment privacy right as the basis for a finding of unconstitutionality. Nevertheless, the right has received a generally warm reception in the Circuit Courts of Appeal, being accepted in the second,¹⁴⁷ third,¹⁴⁸ fourth,¹⁴⁹ fifth,¹⁵⁰ seventh,¹⁵¹ ninth,¹⁵² tenth,¹⁵³ and

¹⁴³ *Id.* at 598-600.

¹⁴⁴ *Id.* at 605-06.

¹⁴⁵ 433 U.S. 425, 457-58 (1977).

¹⁴⁶ *Id.* at 455.

¹⁴⁷ *See Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994) (“[T]he right to confidentiality includes the right to protection regarding information about the state of one’s health...Clearly, an individual’s choice to inform others that she has contracted what is at this point invariably and sadly a fatal, incurable disease [HIV] is one that she should normally be allowed to make for herself.”)

¹⁴⁸ *See United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 577 (3d Cir. 1980) (“There can be no question that an employee’s medical records, which may contain intimate facts of a personal nature, are well within the ambit of materials entitled to privacy protection. ...This difference in treatment reflects a recognition that information concerning one’s body has a special character.”)

¹⁴⁹ *See Taylor v. Best*, 746 F.2d 220 (4th Cir. 1984) (“The right to privacy...includes an ‘individual interest in avoiding disclosure of personal matters.’”) However, the fourth circuit has been less enthusiastic about the right to confidentiality than other circuits. *See, e.g., Watson v. Lowcountry Red Cross*, 974 F.2d 482, 487-88 (4th Cir. 1992) (holding that disclosure of an anonymous blood donor’s identity to the court and counsel would not violate the privacy rights of the donor).

eleventh¹⁵⁴ circuits but rejected in the sixth¹⁵⁵ circuit. Although non-committal, the D.C. circuit seems reluctant to embrace the notion that the right to privacy includes a right to confidentiality.¹⁵⁶ The first circuit has also adopted a cautious attitude towards the alleged right.¹⁵⁷

If the Fourteenth Amendment right of privacy does have a confidentiality branch, then personal genetic disease information is likely protected. Courts have recognized the uniquely private nature of genetic information,¹⁵⁸ which falls within the category of health information, the most commonly cited example of information protected by the

¹⁵⁰ See *Zaffuto v. City of Hammond*, 308 F.3d 485, 489-91 (5th Cir. 2002) and cases cited therein, including *Fadjo v. Coon*, 633 F.2d 1172 (5th Cir. 1981).

¹⁵¹ See *Pesce v. J. Sterling Morton High Sch.*, 830 F.2d 789, 795 (7th Cir. 1987) (“The Federal Constitution does, of course, protect certain rights of privacy including a right of confidentiality in certain types of information.”). See also *Schail v. Tippecanoe County Sch. Corp.*, 864 F.2d 1309, 1322 n.19 (7th Cir. 1989) (recognizing “a substantial privacy interest in the confidentiality of medical information”).

¹⁵² See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1998) (“The constitutionally protected privacy interest in avoiding disclosure of personal matters clearly encompasses medical information and its confidentiality.”); *Doe v. Attorney General of the United States*, 941 F.2d 780, 796 (9th Cir. 1991) (“information regarding an individual’s HIV status or AIDS diagnosis would fall within the ambit of the privacy protection afforded medical information”).

¹⁵³ See *A.L.A. v. West Valley City*, 26 F.3d 989, 990 (10th Cir. 1994) (“[T]here is no dispute that confidential medical information is entitled to constitutional protection.”)

¹⁵⁴ The eleventh circuit follows the fifth circuit on this issue. See *James v. Douglas*, 941 F.2d 1539, 1543-44 (11th Cir. 1991).

¹⁵⁵ *Doe v. Wigginton*, 21 F.3d 733 (6th Cir. 1994); *J.P. v. DeSanti*, 653 F.2d 1080, 1089-90 (6th Cir. 1981) (holding that the right to privacy does not include a general right to nondisclosure of personal information but only protects personal rights deemed fundamental or implicit in the concept of ordered liberty). The sixth circuit’s position was more recently reaffirmed in *Overstreet v. Lexington-Fayette Urban County Gov’t*, 305 F.3d 566, 574 (6th Cir. 2002) (“Since *DeSanti*, this Court has not strayed from its holding, and continues to evaluate privacy claims based on whether the interest sought to be protected is a fundamental interest or an interest implicit in the concept of ordered liberty.”)

¹⁵⁶ See *American Fed’n of Gov’t Employees v. Dep’t of Hous. & Urban Dev.*, 118 F.3d 786 (D.C. Cir. 1997). Although the court in that case refused to decide the question, it expressed “grave doubts” as to the existence of a constitutional right of privacy in the nondisclosure of personal information.

¹⁵⁷ *Borucki v. Ryan*, 827 F.2d 836, 839-48 (1st Cir. 1987) (suggesting that the right of confidentiality might protect only information relating to matters within the scope of the right to autonomy). See also *Vega-Rodriguez v. Puerto Rico Tel. Co.*, 110 F.3d 174, 183 (1st Cir. 1997).

¹⁵⁸ See, e.g., *Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1269 (9th Cir. 1998) (“One can think of few subject areas more personal and more likely to implicate privacy interests than that of one’s health or genetic make-up.”)

right to confidentiality.¹⁵⁹ Further, the second circuit has recognized that information as to HIV seropositive status is protected due to the risks of discrimination and stigmatization; protection for genetic information could be justified on the same basis.¹⁶⁰ Thus, at least to the extent that most federal courts continue to recognize the confidentiality branch of the constitutional privacy right, genetic disease information will receive constitutional protection.

The autonomy branch of the constitutional right to privacy may also be implicated if citizens were required to share genetic disease information with family members. The right to make private decisions has been protected under both the rubric of privacy and of liberty; the distinction is not important here. It was described by the Supreme Court in *Planned Parenthood v. Casey*¹⁶¹ as follows,

[M]atters involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.¹⁶²

The Supreme Court has indicated that the autonomy right is limited to matters which are fundamental or implicit in the concept of ordered liberty.¹⁶³ The types of matters referred to by the Supreme Court as falling into this category are matters relating to marriage, procreation, contraception, family relationships, and child rearing and education.¹⁶⁴ A

¹⁵⁹ See *supra* notes 147-154.

¹⁶⁰ See *Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994).

¹⁶¹ 505 U.S. 833 (1992).

¹⁶² *Id.* at 851 (citations omitted).

¹⁶³ *Washington v. Glucksberg*, 521 U.S. 702, 720-22 (1997); *Palko v. Conn.*, 302 U.S. 319, 325 (1937).

¹⁶⁴ *Paul v. Davis*, 424 U.S. 693, 713 (1976); *Roe v. Wade*, 410 U.S. 113, 152-53 (1973).

decision as to what personal information will be shared with family members arguably falls within the protected category of “family relationships.”¹⁶⁵ Although most family relationships cases, including *Prince v. Massachusetts*,¹⁶⁶ the case originally cited for the inclusion of the category of family relationships in the above list,¹⁶⁷ involve the right to make fundamental decisions as to the care, custody, and control of one’s children,¹⁶⁸ the category is not limited to such cases. For example, in *Moore v. East Cleveland*,¹⁶⁹ the Supreme Court recognized the right of an extended family to live together under the Fourteenth Amendment.¹⁷⁰ Thus the freedom to make important decisions affecting a family’s self-definition are protected by the Fourteenth Amendment. On that basis, it is possible to argue that the decision to share or keep secret genetic disease information is subject to constitutional protection.

Assuming, as seems likely, that genetic disease information is protected under at least one branch of the constitutional right to privacy, that protection is not absolute.¹⁷¹ A court or legislature would not be prevented from imposing a duty to warn, despite the

¹⁶⁵ 424 U.S. at 713.

¹⁶⁶ 321 U.S. 158, 166 (1944).

¹⁶⁷ *See, e.g., Roe v. Wade*, 410 U.S. 113, 153 (1973).

¹⁶⁸ *See Troxel v. Granville*, 530 U.S. 57, 66 (2000) (“it cannot now be doubted that the Due Process Clause of the Fourteenth Amendment protects the fundamental right of parents to make decisions concerning the care, custody, and control of their children”) and cases cited therein.

¹⁶⁹ 431 U.S. 494 (1977).

¹⁷⁰ *Id.* at 506.

¹⁷¹ *See, e.g., Doe v. Attorney General of the United States*, 941 F.2d 780, 796 (9th Cir. 1991) (describing the right to privacy as “a conditional right which may be infringed upon showing of proper governmental interest.”); *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 578 (3d Cir. 1980) (“the right of an individual to control access to her or his medical history is not absolute...courts and legislatures have determined that public health or other public concerns may support access to facts an individual might otherwise choose to withhold.”)

privacy implications, if there is a strong interest in disclosure.¹⁷² Thus any institution imposing a legal obligation to share genetic disease information with family members would need to be careful to tailor any requirements to the legitimate state interest in the health of its citizens. This would not be difficult to do; the constitutional right to privacy implicated in the requirement that sexual partners warn one another about venereal disease has been held to be outweighed the state's interest in the prevention and control of contagious and dangerous diseases.¹⁷³ Provided disclosure was limited to circumstances involving significant benefit to life or health, there is no constitutional barrier to imposing a duty to warn.

C. Duty not to warn

Thus far, this Article has discussed potential liability for failure to warn family members that they may be at risk of genetic disease. For this purpose, the focus has been on situations at the left end of the spectrum, where the benefits of disclosure clearly outweighed the harms. This Section considers whether, in cases at the opposite, right end of the spectrum, a legal duty to remain silent, protecting the right “not to know,” might be imposed

1. The law of privacy

While it has been suggested that the tort of invasion of privacy would be an attractive means of protecting those who prefer not to know genetic information, an

¹⁷² *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 578 (3d Cir. 1980) (“In all cases in which a court has allowed some intrusion into the zone of privacy surrounding medical records, it has usually done so only after finding that the societal interest in disclosure outweighs the privacy interest on the specific facts of the case.”)

¹⁷³ *Doe v. Roe*, 267 Cal. Rptr. 564, 568 (Cal. Ct. App. 1990); *Kathleen K. v. Robert B.*, 198 Cal. Rptr. 273, 276 (Cal. Ct. App. 1984); *Doe v. Roe*, 598 N.Y.S.2d 678, 680 (N.Y. J. Ct. 1993). *See also* *R.A.P. v. B.J.P.*, 428 N.W.2d 103, 108 (Minn. Ct. App. 1988).

action on that basis would likely not be successful.¹⁷⁴ By far the most thorough analysis of the possibility of using privacy law in circumstances where a person is harmed by genetic disease information has been by Laurie;¹⁷⁵ there is little benefit in supplementing his analysis here. Laurie analyzes privacy from two perspectives: informational privacy and spatial privacy.¹⁷⁶ Informational privacy protects against unauthorized use and disclosure of information; it is of no assistance where the conduct complained of is the provision of unwanted information.¹⁷⁷ Spatial privacy protects personal or private space from unwanted intrusion. Laurie argues that spatial privacy would provide a useful guide in regulating the sharing of personal information. A person ought not approach someone and impart potentially damaging information without considering the consequences.¹⁷⁸

While Laurie suggests that this notion of privacy would provide a useful model for protecting against unwanted disclosure of genetic disease information, he agrees that the current law of privacy is insufficient for this purpose. The four privacy rights commonly recognized are: (1) unreasonable intrusion upon the seclusion of another; (2) appropriation of an individual's name or likeness, (3) unreasonable publicity given to a person's private life, and (4) subjecting an individual to publicity that casts them in a false light in the public's eye.¹⁷⁹ Of these, the second and fourth are irrelevant. The third,

¹⁷⁴ See generally Laurie, *supra* note 3.

¹⁷⁵ *Id.*; GRAEME LAURIE, *GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS* (2002).

¹⁷⁶ Laurie, *supra* note 3, at 29.

¹⁷⁷ *Id.* at 30.

¹⁷⁸ *Id.* at 40.

¹⁷⁹ RESTATEMENT (SECOND) OF TORTS § 652A (1977); Dean Prosser, *Privacy*, 48 CAL. L. REV. 383, 389 (1960).

like informational privacy referred to above,¹⁸⁰ only protects against disclosure of private information to third parties, it does not protect against receipt of unwanted news. The first is most analogous to the spatial privacy right suggested above, but does not go as far as Laurie suggests it should.¹⁸¹ The only conduct that has been recognized as unreasonable intrusion is conduct where personal information is acquired or removed from someone's personal or private space.¹⁸² Thus, cases typically involve illegal searches, physical invasion of a person's home, or eavesdropping.¹⁸³ No case, according to Laurie, has successfully alleged unreasonable intrusion where personal information has been added to someone's personal or private space.¹⁸⁴ Thus, the current law of privacy provides no basis for suit by a person who is harmed by receipt of genetic disease information.

¹⁸⁰ See *supra* text accompanying note 177.

¹⁸¹ The description in the RESTATEMENT (SECOND) OF TORTS § 652B (1977) is as follows: "One who intentionally intrudes, physically or otherwise, upon the solitude or seclusion of another or his private affairs or concerns, is subject to liability to the other for invasion of his privacy, if the intrusion would be highly offensive to a reasonable person."

¹⁸² See, e.g., *Beaumont v. Brown*, 237 N.W.2d 501, 505 (Mich. Ct. App. 1975), *rev'd*, 257 N.W.2d 522 (Mich. 1977) ("Intrusion as a branch of the right to privacy has three elements: (1) the existence of a secret and private subject matter; (2) a right possessed by plaintiff to keep that subject matter private; and (3) the obtaining of information about that subject matter by defendant through some method objectionable to the reasonable man.")

¹⁸³ Laurie, *supra* note 3, at 38. See also RESTATEMENT (SECOND) OF TORTS § 652B cmt. b (1977) ("The invasion may be by physical intrusion into a place in which the plaintiff has secluded himself, as when the defendant forces his way into the plaintiff's room in a hotel or insists over the plaintiff's objection in entering his home. It may also be by the use of the defendant's senses, with or without mechanical aids, to oversee or overhear the plaintiff's private affairs, as by looking into his upstairs windows with binoculars or tapping his telephone wires. It may be by some other form of investigation or examination into his private concerns, as by opening his private and personal mail, searching his safe or his wallet, examining his private bank account, or compelling him by a forged court order to permit an inspection of his personal documents. The intrusion itself makes the defendant subject to liability, even though there is no publication or other use of any kind of the photograph or information outlined.")

¹⁸⁴ *Id.*

2. The tort of intentional infliction of emotional distress

The tort of intentional infliction of emotional distress will only aid a person to whom genetic disease information has been disclosed in extreme cases. In order for such claim to be successful, the court would need to find that there was an intention to cause harm through conduct that the reasonable person would consider to be extreme and outrageous.¹⁸⁵ It is possible to imagine a situation in which this might apply. Suppose that a father and son are both in a family known to carry the gene for Huntington disease and that the son knows that the father prefers to remain ignorant of his genetic status. The son is tested and discovers that he carries the gene. If the son informs his father of the result of this test, the father can be almost certain that he, too, carries the gene and will develop Huntington disease. Because of the severe consequences that learning of Huntington disease can have,¹⁸⁶ the son's conduct, if intended to cause harm, might be classified as extreme and outrageous. Despite such examples, the tort of intentional infliction of emotional distress cannot provide a generalizable means of protecting the hypothesized right not to know genetic disease information.

V. Conclusion

As noted at the outset, the decision whether to share genetic disease information with relatives is a difficult one. Public policy, often the basis of imposing legal duties, would point towards a duty to warn in cases where failure to warn might have severe health consequences, and the costs of fulfilling the duty are insignificant. Nevertheless,

¹⁸⁵ See RESTATEMENT (SECOND) OF TORTS § 46 (1965) (“One who by extreme and outrageous conduct intentionally or recklessly causes severe emotional distress to another is subject to liability for such emotional distress...”)

¹⁸⁶ See *supra* note 25.

the artificial distinction maintained between liability for misfeasance and nonfeasance forces a plaintiff contemplating a negligence action to characterize the case in terms of one of the exceptions to the no duty to rescue rule. A plaintiff would have great difficulty arguing that the conduct involved fits into any recognized category. On the other hand, while disclosure of genetic disease information can cause significant harm, there are few cases where compensation is available. Thus neither “the right to know” nor “the right not to know” genetic disease information pertaining to oneself is likely to receive legal protection through obligations on family members who are in possession of such information.

Not everyone will share the view that such rights should be legally recognized. However, the new context of secret genetic disease information does at least pose new questions. A refusal to impose liability for silence cannot rest on the traditional rationales for the no-duty-to-rescue rule and yet is not covered by previously recognized categories of exceptions to the rule. At least some might think that the tort of privacy should be extended to protect against receipt of unwanted information. If rationales are offered for refusing to change the legal status quo, these will be new rationales, not those used to formulate the rule initially. Until new rationales are offered, there is a tension between existing rules and new forms of conduct that commentators will discuss, perhaps observing that the law has not yet “caught up” with the genetic revolution. The tension will only be resolved when an institution, whether a legislature or a court, is forced to consider the consequences of applying old rules in this new context.