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April 2011

SHOULD GENETIC TEST RESULTS BE A FAMILY SECRET?

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SHOULD GENETIC TEST RESULTS BE A FAMILY SECRET?

I. INTRODUCTION

When individuals receive the devastating diagnosis that they either have a genetic condition or are a carrier of one, they may also learn that other family members could share the same fate. Patients¹ must then decide if they should tell their relatives about their genetic test results and how their results could affect their relatives. A modern trend in the law has found that this information must be shared in certain instances. Some jurisdictions have established that there is already a duty on doctors to warn a patient's relatives about possible genetic effects.¹ The next logical step would be to implement a duty on the patients, themselves, to inform their immediate family members about the results of their genetic tests. But should there be a duty imposed on these patients to share their genetic information with immediate family members²?

A. LEGAL BACKGROUND

Any creation of a legal duty that requires patients to share their genetic test results with relatives must be considered in light of how patients' medical information is treated. On one end of the spectrum is doctor-patient confidentiality; on the other, an emerging trend that sometimes finds doctors liable when they fail to share their patients' genetic test results with their patients' relatives. Doctor-patient confidentiality is a fundamental principle of American law that prohibits

¹ The term patient is used throughout this paper as shorthand for a recipient of genetic test results. The term patient is not meant to foreclose the possibility that a person learned genetic information from a direct to consumer test, such as 23andme, instead of a doctor.

² This paper will focus on whether immediate family members should have a duty to disclose genetic test results. Included in the definition of immediate family members are spouses, parents, children, and sibling. The term relative may be used interchangeably to mean immediate family member.

doctors from revealing to third parties any information that a patient reveals to them. Nearly every state has recognized that a patient's confidentiality must be protected.ⁱⁱ In some instances, modern law has allowed doctors to break their patients' confidentiality.

This chipping away at doctor-patient confidentiality began in 1976 with the case *Tarasoff v. Regents of the University of California*.ⁱⁱⁱ In *Tarasoff*, the Supreme Court of California held that doctors should break doctor-patient confidentiality to warn third parties who were at risk of a serious, violent, and foreseeable threat.^{iv} Courts have expanded on *Tarasoff* by finding that the duty to warn articulated by *Tarasoff* extends to genetically transmittable diseases. Two cases lead this trend, *Pate v. Therkel*^v and *Safer v. Pack*.^{vi}

In 1990, Heidi Pate filed a suit against Dr. Therkel, her mother's former doctor, for breaching the duty to warn.^{vii} Pate's mother was treated by Dr. Therkel for medullary thyroid carcinoma, a genetic cancer.^{viii} Pate later developed the same cancer, and argued that Dr. Therkel should have warned her of her genetic predisposition so that she could have taken preventative action.^{ix} The Florida Supreme Court found that physicians did have a duty to warn their patient's relatives of genetic risks, but that they could satisfy this duty by warning the patient and expecting them to convey the warning to their relatives.^x

Similarly, in 1996 Donna Safer filed a claim against the estate of her father's former doctor for failing to warn her of a genetic predisposition.^{xi} Dr. Pack treated Safer's father for multiple polyposis, a hereditary condition that if untreated can lead to metastatic colorectal cancer.^{xii} Nearly twenty years later, Safer developed the same condition.^{xiii} She sued alleging that Dr. Pack should have known that her father's cancer was hereditary and warned her so she could have sought preventative monitoring.^{xiv} The Superior Court of New Jersey, relying largely on *Tarasoff*, found that doctors had a legal duty to warn their patients' relatives of genetic

disorders.^{xv} According to medical knowledge at the time, Dr. Pack should have known that Safer's father's cancer was genetic.^{xvi} The court reasoned that the duty to warn applied in that case because there was no difference between a genetic disease and other contagious diseases or physical harm.^{xvii} Unlike the court in *Pate*, the Superior Court of New Jersey found in *Safer* that the duty to warn a patient's relative could not be satisfied by merely warning patients and expecting them to transmit the information.^{xviii} Instead, the warning should come directly from the doctor to the relative.^{xix}

II. POTENTIAL WAYS TO CREATE A DUTY THAT REQUIRES PATIENTS TO SHARE THEIR GENETIC TEST RESULTS.

Because courts have held in *Pate* and *Safer* that physicians have a duty to warn their patients' relatives about potential genetic predispositions, the next logical step would be to require the patients themselves to disclose their genetic results to family members. Although it may be a logical expansion of the duty to warn, the law should not impose a duty on patients to inform their relatives about the results of their genetic testing. A duty to require patients to share their genetic test results with relatives could be created either through tort law, an Equal Protection claim, or a statute enacted by a state legislature. However, any of these avenues for creating such a duty have limitations. A duty to warn relatives of their genetic results does not fare any better under policy rationales. Undoubtedly, the sharing of genetic test results could benefit the health and psychological well-being of relatives because the relatives could take steps to be tested or improve their health. However, these potential benefits are outweighed by negative psychological effects, family discord, a patient's loss of control over health information, and the inaccuracies that could be transmitted by the patient who lacks the competence to explain complicated genetic test results.

1. Tort Liability

The most obvious basis for creating a duty that requires patients to inform their relatives of the results of their genetic tests would be through tort liability. Specifically, a patient's relatives would be permitted to allege that their relatives breached a duty by failing to warn them that they could have a genetic disease. Duties are created in tort law based on the standard of conduct that society expects of a reasonable person.^{xx} A negligent act is one that falls below the standard of how society expects its members to behave and creates an unreasonable risk.^{xxi} A determination of what is an unreasonable risk requires balancing the probability that harm will occur, the extent of that harm, and the value in protecting against the harm.^{xxii} Arguably, because relatives share genes there is a strong possibility that family members could suffer from or be carriers of the same condition as the afflicted patient. The probability that they will acquire the disease will depend on the disease^{xxiii}, and their relation to the patient.^{xxiv} These relatives also have an interest in learning their relatives' results because earlier warnings could lead them to get tested to learn about their health or take preventative measures to treat the condition.

However, it seems that forcing relatives to disclose their genetic test results are best analogized to rescue cases.^{xxv} The majority rule in American law is that people do not have a duty to rescue others.^{xxvi} A person could walk by a child drowning in a river, do nothing, and escape any liability. Similarly, informing a relative that he or she may be predisposed to a genetic disease based on a patient's results can be viewed as a rescue.^{xxvii} Just as a person who happened upon the drowning child would be under no legal liability to rescue the child, patients should not be forced to rescue their relatives by sharing the results of their genetic tests. A person does not acquire a condition once his or her relative gets tested. A person with a genetic

predisposition to a genetic disorder will have the predisposition to the condition regardless of whether he or she learns about a relative's medical information. It is true that if relatives are made aware of potential disorders that they may share with relatives that they could take preventative action. For example, a woman who learns that her sister has the BRCA1 or BRCA2 mutation can get tested for the mutation and undergo a mastectomy to avoid breast cancer. A man who learns that he has a genetic predisposition to heart disease can begin exercising and change his diet. However, the mere possibility that the relative could take preventative measures should not justify creating a duty that requires patients to disclose the results of their medical test results to family members. Just as the drowning child is no worse off when the person does nothing to help them, a patient's relatives are no worse off if the patient refuses to disclose the results of his or her genetic test results.

It is true that American law does, in a few limited instances, impose a duty to rescue. The duty to rescue occurs when the rescuer created the risk or has a special relationship with the endangered person.^{xxviii} As previously discussed, patients have nothing to do with the risk that a relative may have for genetic conditions.^{xxix} The potential argument that there is a special relationship between patients and their relatives is more persuasive. Special relationships exist within a family between parents and children and husbands and wives. Therefore, the existing definition of special relationships should not be expanded to require disclosure of genetic information to siblings, cousins, or greater degree relatives.^{xxx}

The rationale for special relationships in tort law between husbands and wives and parents and children is based upon dependency. Children are dependent upon their parents for care, and husband and wives are assumed to be dependent on each other for monetary resources and care. Siblings are not assumed to be dependent on each other for care, which is why tort law does not

recognize a special relationship between them. Expanding the definition of special relationships to require siblings to warn each other about their genetic test results would be inconsistent with the rest of tort law. This expansion is problematic. Changing the definition of special relationships for one tort could lead to siblings being forced to act in other circumstances despite centuries of law that concluded otherwise.

Children have a better claim against their parents for failing to disclose their genetic test results. Children could argue that a special relationship exists because most states have statutes that require parents to care for their children, and if parents fail to meet reasonable standards they can be found guilty of neglect. In most instances parents are only required to provide a minimum amount of medical care to avoid being found guilty of negligence.^{xxxii} While parents are required to provide medical treatment for their children, they are found guilty only when they grossly breach this duty.^{xxxiii} Examples of medical neglect include not seeking treatment for a malnourished child who continually vomits formula,^{xxxiii} when a child is forced to seek emergency medical treatment for dehydration,^{xxxiv} or a mother who failed to seek treatment for her seriously ill child because she believes that prayer would cure him.^{xxxv} This sample of cases makes it apparent that when parents found guilty of medical neglect it was an extreme deprivation of care that almost resulted in death. This is fundamentally different from not disclosing the results of a genetic test to a child. The death of a patient's child is rarely imminent at the moment the patient learns his or her genetic results. Given these considerations, children will be unable to claim their parents had a duty to rescue them from a predetermined disease by virtue of a special relationship.

The only way that a child could avoid having a genetic mutation for a disease would be if they were never born. Some commentators have argued that this moves into the territory of

wrongful birth.^{xxxvi} Wrongful birth claims are tort actions brought by a child's parents whereas a wrongful life claim is brought on the behalf of the child.^{xxxvii} Wrongful birth or wrongful life causes of action can be compared to a duty that would require parents to disclose their genetic test results to their children. The essence of a child's claim would be that his or her parents are responsible for the genetic predisposition that afflicts the child. It is unlikely that a child would be unable to successfully argue that they should never have been born. The Supreme Court has recognized that the right to procreate is a fundamental right.^{xxxviii} Therefore, parents have a fundamental right to conceive and give birth to children even if their children have genetic disorders.

Despite the right of parents to make reproductive choices, at least one court has recognized that a child might have a cause of action for the pain and suffering that resulted from the genetic condition.^{xxxix} Because pain and suffering includes emotional harm, a child could bring a suit against its parents alleging that the parent failing to disclose that the child is predisposed to a genetic condition lead the child to make uninformed reproductive choices. It is true that passing on a genetic condition to the next generation can be psychologically damaging.^{xi} In cases where parents fail to disclose their genetic test results and their children cannot use that information to make reproductive choices, the parents' reproductive choices may be at odds with their children's desire to use this information to make their own reproductive choices. For example, if both parents are unaffected carriers of cystic fibrosis, a recessive disease, the probability is that one in four children will be affected with cystic fibrosis; one in four will be unaffected and not carriers; and two in four children will be carriers.^{xii} A child who knows that they could be a carrier could be tested to discover their status before conceiving his or her own child. A child may seek to expand upon existing law where some courts have found doctors owe a duty of

disclosure to non-patient parents so the parents can use this information to make subsequent reproductive choices. The case *Molloy v. Meier*^{xlii} illustrates this duty. The plaintiff, Kimberly Molloy was the mother of a daughter who suffered from developmental disabilities.^{xliii} She and her former husband, the child's father, met with Dr. Meier to discuss possible causes of the daughter's developmental difficulties.^{xliv} During their meeting, the parents and the doctor discussed the possibility that the daughter's developmental delays could be caused by Fragile X Syndrome.^{xlv} The parents and the doctor agreed that if they were caused by Fragile X syndrome, or another genetic disorder, that Molloy should be tested.^{xlvi} Dr. Meier never tested Molloy's daughter for Fragile X syndrome.^{xlvii} She later called Molloy to inform her that the results of the other genetic tests indicated that her daughter developmental delays were not caused by any genetic condition.^{xlviii} Molloy later remarried and conceived a son with her new husband who suffered from the same developmental difficulties.^{xlix} Another doctor determined that both children had Fragile X syndrome.¹ Molloy sued Dr. Meier for her failure to test for Fragile X syndrome.^{li} She argued that it was foreseeable that she would have used the test results in making future reproductive choices.^{lii} In other words, it was reasonably foreseeable that she would have used the results of her daughter's positive Fragile X Syndrome results to test herself to see if she was a carrier of the condition and used her carrier status to decide whether to have other children. The court accepted this foreseeability argument and found in favor of Molloy.^{liii}

A child could argue that the court's decision in *Molloy* should be expanded upon to require his or her parents to inform them that they may be carriers of a genetic condition. If their parent knows that they are a carrier of a genetic condition it can be compared to the foreseeability argument from *Molloy* that it is foreseeable that carriers will use their status to make reproductive choices based on this information. But expanding the duty to disclose in this way is

unwise because it assumes that a child's parent acts as a learned intermediary. In general the learned intermediary doctrine insulates a manufacturer for failing to give a warning directly to the user of the manufacturer's product if the warning was given or should have been given by a learned intermediary.^{liv} A classic example is prescriptive drug warnings are disseminated to patients by their doctors instead of directly from the manufacturer to the patient.^{lv} Applying the learned intermediary doctrine to a parent child relationship, can be compared to the court's decision in Pate where the doctor's duty to warn a patient's family is satisfied by warning the patient and expecting them to inform their family.^{lvi} But extending the learned intermediary doctrine to parents is unsound. In some jurisdictions, an important factor in determining if a doctor qualifies as a learned intermediary is whether he or she made an individualized medical decision.^{lvii}

The warnings which must accompany prescription drugs are directed to the physician rather than to the patient because it is for the prescribing physician to use his or her independent medical judgment, taking into account the data supplied by the manufacturer, other medical literature, and any other source available, and weighing that knowledge against the personal medical history of the patient, to determine whether to prescribe a given drug. The decision of weighing the benefits of a medication against potential dangers that are associated with it requires an individualized medical judgment; this individualized treatment is available in the context of a physician/patient relationship which has the benefits of medical history and extensive medical examinations.^{lviii}

There is a profound difference between the medical knowledge parents and doctors are expected to have. In some cases it is true that the parents may do extensive research into the condition that they have or are a carrier for, but this extensive research may not be present in every case. While some parents may spend hours researching a genetic condition, others may limit their knowledge to information that their doctor has told them. The gross discrepancy between the information that different parents might have disfavors creating a duty to warn based on a parent acting as a learned intermediary. While all doctors can be assumed to be

knowledgeable about side effects from the drugs that they prescribe, we cannot assume that all parents are equipped to deliver an adequate warning about a genetic condition that their children might have or be carriers based on the results of their genetic test results.

The last argument that children would be able to advance against their parents in tort law is that their parent should be held to a reasonable parent standard, and that reasonable parents would have disclosed their genetic test results to their children. Some courts have held parents to a reasonable parent standard when their actions harm their child.^{lix} One example of when a reasonable parent standard is used includes when a mother takes drugs during pregnancy that cause the child to be born with discolored teeth.^{lx} The presumption is that a reasonable parent would not behave this way because of the known risks that are associated with their behavior. A child could argue that a reasonable parent would have told the child about their predisposition. However, especially when considered in light of the policy rationales for not requiring such a duty, discussed in the second half of the paper, it becomes apparent that a reasonable parent standard is not useful. It has been argued by some that a reasonable parent standard is the same as a reasonable person standard.^{lxi} But even assessing what a reasonable person should tell their child becomes problematic in this area where the complexity of family relationships is concerned. The reasonable person or a reasonable parent standard would be based on objectivity. While most of us can agree that a reasonable person would not smoke or take drugs while pregnant because of the likelihood that these behaviors would harm the fetus, a determination into what a reasonable parent would tell their child about their predisposition to a genetic condition or being a carrier of one requires a more subjective determination. This subjective determination should be made by the parent assessing their situation and not by a jury made up of people not related to the child and not in a position to assess the unique situation.

This is especially important because disclosure can lead to negative consequences such as negative psychological effects, family discord, loss of control over information, and dissemination of inaccurate information.

The final special relationship that imposes a duty to rescue is the relationship between husbands and wives. While husbands and wives may have a duty to rescue each other from drowning, they should not have a duty to disclose their genetic test results. Incestuous marriages between siblings are prohibited in all states.^{lxii} Half of states prohibit marriages between first cousins.^{lxiii}

Of course one of the most often cited rationales for prohibiting consensual incest is that negative genetic effects can occur from inbreeding.^{lxiv} With this consideration, it could be argued that spouses have a duty to share their genetic test results, specifically if they are a carrier of a genetic condition, because reproduction is an important function of marriage. It is recognized that the choice of whether to conceive a child is constitutionally protected.^{lxv} Some commentators, including Rabbi Elliot N. Dorff, have advanced this position. Dorff has said that “women with the defective BRCA have a duty to inform their prospective mates of the fact.”^{lxvi} Studies indicate that some people would alter their marriage plans if they or their fiancé was a carrier for a genetic disorder.^{lxvii} However, in other studies the majority of participants in the studies decided that they would not alter their marriage plans.^{lxviii} Moreover, it was the carriers that were more likely to say that they would alter their marriage plans than their spouses.^{lxix} These studies provide evidence that the afflicted person cares more about using the information to make reproductive choices than their spouse does. The lack of a legal duty does not foreclose the possibility that spouses will be unable to jointly make reproductive choices based on their

known genetic information. All that not implementing a legal duty on spouses to share their genetic test results does is make that disclosure voluntary.

2. Equal Protection

Another potential legal way to create a duty to warn relatives would be through the Equal Protection Clause of the Fourteenth Amendment. In all states, statutes permit adopted children or their adoptive parents to non-identifying medical information about their birth parents at the time of adoption. About half of states require that the biological parents disclose known medical information before finalizing the adoption. In all states adopted children are allowed to access to any non-identifying information on file.^{lxx} Because adoptive children have access in most cases to some genetic health information, biological children could argue that they should have a right to their parents' health information. The Equal Protection Clause of the Fourteenth Amendment provides that "No state shall. . . deny to any person within its jurisdiction the equal protection of the law."^{lxxi} The children who were raised in their biological family could assert that laws allowing adopted children to access health information amounts to differential suspect class treatment.

However, this claim should fail. Neither children raised by adopted parents nor their biological parents belong to a suspect class that would trigger strict scrutiny.^{lxxii} Therefore, any statute that provides adopted children with the right to learn of genetic disorders that afflict their biological parents will only have to survive rational basis review.^{lxxiii}

Several rationale bases for the law can be identified. First, these statutes specify that children of adoptive parents have a right to their biological parents' health information so long as it does not identify their birth parents. This places an emphasis on both the privacy of the biological parents to not have their identity revealed and their biological parents' right to not

have private medical information revealed. The specification that the information revealed be non-identifying shows that the legislature who viewed protection of the birth parents' privacy as a compelling interest. Of course, it can be argued that biological parents who place a child up for adoption could have a multitude of reasons for not wanting their identity exposed in addition to privacy.^{lxxiv} However, as will soon become apparent, American society places an emphasis on ensuring that medical information remains private.

The second compelling interest that an Equal Protection Clause claim should fail is because of fundamental fairness. Most of the information available at adoption will be limited.^{lxxv} Most biological parents who place children up for adoption are teens^{lxxvi} and many disorders manifest later in life. For example, Huntington's disease is acquired in middle age and Alzheimer's disease typically emerges around age sixty.^{lxxvii} Further, other disorders many not be known at the time of adoption because they require that both biological parents are carriers of a recessive gene before they manifest, such as cystic fibrosis, Tay-Sachs, and sickle cell anemia.^{lxxviii}

It is debatable how much more information an adopted child would receive from his or her biological parents given these considerations. Additionally, children raised by their biological parents will have an advantage of watching their parents and other relatives age and witnessing what conditions manifest. Moreover, their parents and relatives potentially have the knowledge to provide them with a family history of diseases that relatives suffered from, and which the child could develop or be a carrier.

It is true that one state, Texas, requires biological parents to update health information as it becomes available.^{lxxix} However, the Texas statute still places an emphasis on protecting the biological parents' privacy. Texas law provides that the identity of birth parents can be disclosed only if a member of the adopted child's biological family and the adopted child mutually register

that they are attempting to locate each other.^{lxxx} Even then the Texas statute requires that both the biological parent and child sign a consent waiver and participate in counseling.^{lxxxii} This consideration is important because one reason why many want to ensure that their health information remains confidential is to avoid stigma and discrimination.

3. State Statutes

The final way that patients could be required to warn their relatives of their genetic test results would be through statutes enacted by state legislatures. These statutes would face an obvious Constitutional challenge based on substantive due process that they violate a person's fundamental right to privacy. Laws that limit fundamental rights, such as privacy, are analyzed under the heightened burden of strict scrutiny. To survive a challenge, the law must be necessary to achieve a compelling interest.

The Supreme Court has recognized that privacy is a fundamental right.^{lxxxii} The legislature would likely attempt to establish that warning relatives that they might face harm a predisposition to a genetic condition is a compelling interest. The Supreme Court has recognized that in certain cases there are compelling interests that justify limiting the right of privacy that is usually extended to medical information. In *Whalen v. Roe*, the Supreme Court found that personal medical information could be disclosed to hospital staff, insurance companies, and public health agencies.^{lxxxiii} The Court found that this disclosure was permitted even if others could learn damaging information about a patient.^{lxxxiv} But a duty to warn relatives is not the same as disclosure of medical information to hospital staff, insurance companies, and public health agencies. Therefore, the facts of *Whalen* readily distinguish themselves from a statute that would require patients to disclose their personal medical information to family members. First, *Whalen* permitted disclosure of this personal information to other doctors, insurance companies,

and public health agencies. All of these people and institutions have an apparent interest in this information because they can use it to treat the patient, which is a direct benefit to the patient. Even in the case of public health agencies, a patient's health information is most likely being used to gather health data.

These disclosures are different than ones to a patient's relatives because physicians and other agencies are only interested in the information to the extent that it aids in the patient's treatment. A patient's relative would be personally affected by learning health information. Most likely, the patient's and his or her condition is of little interest to doctors, insurance companies, and public health information once treatment is completed. Knowing a person suffers from certain diseases can be embarrassing or stigmatizing. A person's relatives could use information about a patient's condition in ways that would embarrass a patient or stigmatize them. Allowing doctors, insurance companies, and public health agencies to have this knowledge is fundamentally different. In most cases, they do not know the patient intimately like relatives would and would have little interest in a patients' condition after treatment is completed. Moreover, since doctors and other medical providers are bound by ethical duties to do no harm and keep information private in all but a few limited instances, it is unlikely that they would use this information to embarrass or stigmatize the patient in a way that a relative could.

The extent of a person's right to medical privacy can be implied from the Supreme Court's decision in *Planned Parenthood of S.E. Penn. v. Casey*.^{lxxxv} In this case, the Court overturned a state law that required a woman to obtain her husband's consent before having an abortion.^{lxxxvi} Implicit in this decision was a woman's right to keep a medical procedure a secret even from her husband. This implies that within privacy right there is a right to keep medical information secret, even within families. A husband has a stronger interest in learning about his wife's

abortion than a relative's interest in learning about a family member's genetic test results. The general presumption is that a husband is the father of any children conceived during his marriage.^{lxxxvii} The fact that a husband would be interested in a child conceived during his marriage is obvious. Therefore, the Supreme Court's prohibition on statutes that require a wife to obtain her husband's consent before seeking an abortion shows that, in some instances, a patient's right to medical privacy is more important, and that it outweighs even the right of a father to know about offspring he may have conceived. It is true that the Court's primary justification in *Planned Parenthood* for not requiring husbands to consent before married women receive an abortion was the threat that these women may be victims of domestic violence,^{lxxxviii} but women who are forced to share their genetic test results may be exposing themselves to domestic violence. One commentator argued that forcing women to share their genetic test results with their husband may expose them to domestic violence.^{lxxxix} The threat of women being exposed to violence brings the Supreme Court's reasoning in *Planned Parenthood* full circle. Both having an abortion and disclosing genetic test results can expose a patient to spousal violence. Thus, the same reasoning from *Planned Parenthood* can be applied to forced disclosure. A patient's right to medical privacy, especially if there is any threat that exposure of medical test results could lead to violence outweighs the spouses' and other family member's interest in the medical information.

Even Congress has recognized the importance of keeping medical information private. In 2003, it enacted the Privacy Rule to the Health Insurance Portability and Accountability Act (HIPAA).^{xc} The privacy rule prohibits the disclosure of a patient's health information.^{xcii} There is an exception for a "serious and imminent threat to the health or safety of a person or the public."^{xciii} With the possible exception for a few limited circumstances, the threat to the health of

relatives will not be imminent because the mutations that exist in a person may never produce the disease or may not produce the disease for several decades.

For these reasons, statutes that require patients to share their health information with their relatives would be unable to survive a strict scrutiny review. Past Supreme Court decisions have shown that a person's right to medical privacy needs the fullest protection possible.

B. AN EXPLORATION OF THE POLICY SURROUNDING THE CREATION OF A DUTY TO WARN RELATIVES

In addition to there being no legal basis for expanding the duty to require patients to disclose their genetic test results, an exploration of policy rationales opposes its creation. The two main arguments in support of a duty are health and psychological rationales. But even these reasons are insufficient to impose a duty of patients to share the results of their genetic test results.

While sharing health information might be beneficial in some cases, in others it can be harmful and cause negative psychological effects and family discord. Compelling disclosure forces a patient to lose control of his or her private health information. Finally, a patient may be too incompetent to explain complicated health information to relatives.

1. Health

The main argument that supports creating a duty to disclose genetic test results to family members is that family members can use this information to improve their health. Knowledge that a person may suffer from a condition or acquire it later in life can lead to earlier treatment and prevention.^{xciii} For example, a woman who has a mutation for the BCRA1 or BCRA2 mutations may choose to undergo a mastectomy to prevent the cancer from developing later in life. A person with a genetic predisposition to colon cancer can have routine colonoscopies, which could lead to earlier treatment and prevention. While earlier prevention and treatment of

diseases would be beneficial in many instances, there is no guarantee that the creation of a duty would result in a patient's relatives using the information to improve their health. Some diseases may not be treatable, and thus disclosure has no practicable effect other than stress and worry. Huntington's is untreatable and does not emerge until middle age and there is no preventative action that a person can take. Even if relatives receive knowledge that they might have a condition they may not know how to apply it. Disclosing information may also have a negative effect on the health of relatives who might learn that they do not have a condition and are not the carriers for it. After learning that they are spared from a genetic mutation, they might feel as though they have a free license to engage in unhealthy habits that could affect their health in other negative ways.

Arguably, a second benefit of learning about one's genetic risk through relatives is that it could lead people to make better choices about the future considering the genetic risk's effect on reproduction, career choices, and estate planning.^{xciv} A person who learns that he or she is a carrier for a disorder like cystic fibrosis or Tay-Sachs can make reproductive choices. This includes: not having children, screening embryos, or ensuring that his or her mate is also not a carrier before conception occurs to avoid passing a disorder onto a future generation. This assumes that relatives would become tested after learning about the patient's test results. There is no guarantee that they would use this information to discover their own risk or apply it to future decisions affecting their career, reproduction, or estate planning. Even if a majority of relatives would use the patient's genetic test results to make these future decisions a legal duty should not be imposed. Forced disclosure of genetic test results presumes that otherwise family members of the patient would have no access to this information. This presumption is mistaken. Family members concerned about their health can test themselves without waiting for someone

else in the family to do so as well. The two major problems with this approach are that they may not be aware of what disease they should have a doctor test for and the cost of testing. However, with the rise of direct to consumer genetic tests, such as 23andMe, both of these burdens are lessened. As of November 2010, 23andMe tests for carrier status for twenty-four diseases, eighteen drug responses, and forty-two traits for the price of 429 dollars.^{xcv} Included in the carrier status traits that 23andMe test for are the BRCA mutations, cystic fibrosis, phenylketonuria, sickle cell anemia and Tay-Sachs.^{xcvi} At the very least this and other direct to consumer test results offer some broad information that can narrow what else the relatives should receive more specific testing for.

2. Psychological

The second policy rationale for requiring disclosure is that it could be beneficial psychologically. One psychological benefit of requiring people to tell their relatives their results would be that it could reduce uncertainty. A person who was informed of a family member's test results could get tested to learn if he or she was at risk for developing the same disease or a carrier of it. These test results could reveal that the relative was neither afflicted nor a carrier of a devastating disease, which is emotionally beneficial.^{xcvii} Even if family members learn they are carriers, there might be a psychological benefit because he or she could use this information to make reproductive decisions. This notice would allow them to avoid later negative psychological effects that could occur if they passed a devastating condition on to their children.

Another potential benefit is that family members can provide emotional support to each other.^{xcviii} This can take the form of afflicted members bonding together with other afflicted members or carriers.^{xcix} Alternatively, unaffected members can group together to support those with the disease.^c In an empirical study of how one family dealt with learning that two of the

four siblings were affected with ataxia shows the benefit of unaffected family members extending their support to the affected ones. In that family, the mother, with the support of her unaffected children, decided to leave her estate to the affected children who would need money to support themselves once the condition manifested.^{ci}

Despite these potential psychological benefits from relatives sharing their test results with each other, sharing can also produce negative psychological effects and family discord. When a person learns that they suffer from an untreatable condition this can lead to stress within the family and to feelings of

loss of self-esteem, loss of privacy, survivor's guilt, and vulnerable child syndrome, along with the inadvertent provision of predictive information to uninterested family members.^{cii}

These negative psychological effects can be profound when a child is diagnosed with a condition even before he or she begins showing symptoms it can profoundly alter the relationships within the family.

A child known to have a deleterious gene may be overindulged, rejected, or treated as a scapegoat. The 'vulnerable child' syndrome occurs when the perception of serious illness causes parents to become overprotective and to restrict a child's participation in childhood activities, responses that can occur even when test results reveal a normal genotype. Unaffected sibling may also experience altered relationships with their parents, particularly in the case of children who feel disenfranchised if they see that an affected sibling is receiving a disproportionate amount of care and attention^{ciii}

The effects of learning that one has a particular disease or is a carrier can be devastating, and forced disclosure would require relations to confront these feelings. In particular, learning that one might have a pre-disposition to Huntington's can be devastating because "the disease is a virtual certainty."^{civ} Anyone who tests positive for Huntington's will develop it if he or she lives long enough.^{cv} Learning that a person will get Huntington's can lead to suicide.^{cvi} Similarly, in

an empirical study looking at the effects of diagnosis on a family, the two siblings that were diagnosed with ataxia reported suicidal ideation.^{cvi}

Even those who learn that they do not have a predisposition to a disease can suffer devastating effects. One effect is survivor's guilt, which is a condition suffered by family members who learn they do not carry a particular gene,^{cvi} while other family members are affected. One participant of a breast cancer study reported that she felt guilty when she tested negative for the BCRA1 or BRCA2 mutation while her sister suffered from cancer.^{cix} If relatives were required to disclose their medical results to each other, then it would be known within the family who was affected and who was spared.

Differences in status can create rifts within a family. A participant of the breast cancer study explained how her cousin's positive result caused a rift within her family. Her cousin felt that she was alone because she was the only one within the family that tested positive for the condition and often wished that someone else would be afflicted.^{cx} In a family study where two of four children tested positive for ataxia, the affected children found that they felt the negative members of the family could not understand their pain. Despite attempts from mutation-negative family members to reach out to the two children who tested positive for the mutation, the positive children reported feeling that the negative members could not understand their anger and despair.^{cx} Other participants of a breast cancer study reported that disclosures were met with anger and blame by relatives with inadequate coping skills.^{cxii}

Even telling family members that they may have a predisposition to a disease can produce stress. Those who told their relatives about their BRCA1 or BRCA2 mutation reported that sharing the bad news with relatives reported feelings of stress at "having to be the bearer of bad news."^{cxiii} Forcing people to disclose their medical test results can also lead to disclosure of

emotionally devastating "family secrets" such as a child was adopted, or misattributed paternity. Undoubtedly, these revelations can strain relationships and may alter the family dynamic.

There is also the risk that a person who is told does not want to know about the results and how they could affect his or her own health. Having this sort of information be revealed might also prevent a person from living up to his or her full potential or engage in risky behavior. If a person feels that they have been given a death sentence, he or she might run up debt and engage in other risky behavior since it is only a matter of time before debilitating symptoms emerge.

One man who merely suspected that he would die early from Huntington's because one of his parents had had the disease engaged in risky activities like skydiving, took out loans, and took on credit card debt because he believed he would have a short life.^{cxiv} His behavior was based on a mistaken belief, but it is foreseeable that others who have received their genetic test results and know of their positive status would do the same. Forcing people to confront health information when they do not want to can be psychologically damaging. People who learn that they will experience debilitating symptoms from a disease like Huntington's may forgo relationships, education, and career opportunities because it is only a matter of time before the disease emerges. Limiting a person's potential can come from the patient or relatives who know their genetic status. One mother requested that her sons be tested for Huntington's because she only had enough money to send them to college.^{cxv} These considerations, specifically the threat that a person's potential led to the policy to not test adolescence for Huntington's out of fear that if the adolescents know that the disease is inevitable it will limit their potential.^{cxvi}

Patients may want to shield relatives from the negative psychological effects of learning that a person passed on a mutation. Children who test positive for a mutation may wish to shield elderly parents from the guilt of knowing that they passed a mutation onto their children.^{cxvii} It

can also be speculated that a patient may not want to disclose to his or her offspring to protect themselves from having to deal with the guilt of knowing he or she passed a mutation on to their children.^{cxviii}

Additionally, sharing test results can produce family discord if one sibling chooses to terminate pregnancy based on a genetic disease that his or her sibling has. The affected sibling may perceive this as a rejection, which can damage the siblings' relationships.^{cxix}

The problem with imposing a duty that requires patients to reveal the results of their genetic tests results to family members is that it does not take into account the unique family dynamics that are present in every case. This rule would force patients to tell or potentially face liability without considering whether their relatives want to know that they too might be at risk for the same condition or if the relative was psychologically prepared to handle it. These disclosures would likely take place away from a doctor or genetic counselor who is trained to deal with the psychological ramifications that learning about genetic test results can reveal.

3. Loss of Control of Information

Another reason to not require patients to share their genetic test results is that forced sharing would also force patients to lose control over their health information. The control a person has over his or her information is a function of privacy.^{cxx} The disclosure of private health information, and the lack of control that stems from the disclosure, can have disastrous consequences. Susan B. Apel argues that health information disclosed by a physician to family members, even to a single person, represents a loss of control for the patient over that information.^{cxxi} This is because,

"[o]ne family member may tell others, who may repeat the information to yet other relatives. Nor is the expansion in the number of secret-holders limited to family members. Particularly in small communities, the lines between family, friend, neighbor and outside employer are tenuous."^{cxxii}

Apel's vision of how forced disclosure of health information can result in third parties, even though people outside the family who have a limited health interest in the information, can be applied to the effect that forcing patients to reveal their genetic test results to a family members could have. The patients are no longer in control of the information and instead have the details of their medical condition open for discussion by family, friends, and potentially even strangers. This loss of control can have devastating consequences to employment or insurance coverage. In fact, fear of health information being used to deny employment or insurance is one reason why some may be motivated to keep their genetic test results secret from even relatives. In one study detailing patients' experiences with testing for BRCA1 and BRCA2 mutations, one subject mentioned that she and other relatives made a pact that they would not discuss their statuses for fear that the information would be used to discriminate against them. Given how genetic information has been used in the past, it is apparent how it could negatively affect them. These fears that disclosing genetic information will have negative consequences are valid.

Health insurance companies can use this information to deny coverage to beneficiaries based on pre-existing conditions. In recent years, insurance companies have used these loopholes to deny coverage. A woman who was a carrier for cystic fibrosis as told by her insurance company that it would not pay for costs relating to her child if she chose not to abort.^{cxxiii} Another insurance company told a woman whose mother had breast cancer that it would not pay for her costs if she developed the cancer.^{cxxiv} Yet another insurance company refused to cover a healthy eight-year-old girl with phenylketonia^{cxxv} when her father changed jobs.^{cxxvi} Health insurance companies have even gone as far as to deny coverage to family members whose relatives have a genetic disorder. One insurance company denied coverage to a New Hampshire family whose son had Fragile X syndrome. The entire family, including the parents and the boy's three

siblings, were denied coverage even though none of the other family members had the condition.^{cxxvii} The insurance company learned of the boy's condition from a doctor's annotation on an insurance form.^{cxxviii}

The Genetic Information Nondiscrimination Act (GINA) does prevent insurers from denying health coverage based on genetic conditions,^{cxxix} but that does not guarantee that this information would not be used in other discriminatory ways. In the 1970s, when it was found that African-Americans had a higher rate of sickle cell anemia, airlines prevented African-American employees from flying based on a mistaken belief that the condition might be exacerbated in a depressurized cabin.^{cxxx} Women with a family history of Huntington's were prevented from adopting, even though it was uncertain that they would develop the condition.^{cxxxi} These fears have guided many people to guard their health information for fear that it would be used to discriminate against themselves or family members. Given how genetic information has been used in the past and people's perceptions of how others would use it, Susan Apel's fear that a person's test results would fuel small-town gossip and would be used to discriminate becomes real. It is easy to imagine that in these small towns that if people became aware that a certain person or family had a predisposition to a genetic disorder that employers may avoid hiring them. It is easier to protect this information than to deal with the consequences of its exposure.

4. Patients may lack competence to explain test results.

Lastly, patients may lack competence to explain information to their relatives. Some genetic tests produce ambiguous results or may require a detailed explanation. An ordinary patient may lack the capacity to explain and deliver an accurate warning.^{cxxxii} In 1999, researchers who conducted a study of women with breast or ovarian cancer found that 60 percent overestimated their chance of having a BRCA1 or BRCA2 mutation.^{cxxxiii} Another study found that even after

attending a genetic counseling session, patients' understanding about their results were limited.^{cxxxiv} Moreover, even doctors were not immune from misinterpreting genetic test results. One study concerning heritable colon cancer found that one third of doctors misinterpreted results and told at-risk patients that they were not at risk, which led patients to avoid life-saving colonoscopy exams.^{cxxxv} If medical professionals can misinterpret the results of genetic studies, then how can patients be expected to explain these results to their relatives adequately? An ordinary patient will not have the benefit of attending medical school where physicians are taught how to interpret and advise patients of their genetic test results. If the law is to impose any duty that permits the sharing of confidential patient information, then the law should also take precautions to ensure that the information is distributed in a way that produces the most benefit. Although the current laws created by *Safer* and *Pate* that requires physicians to disclose their patients' information to relatives can lead to the same negative effects as disclosure by the patient, at least when physicians disclose the information it is being conveyed by someone who is arguably competent to explain the implications of such information.

5. On balance the overall policy does not support the expansion of a legal duty.

After balancing policy advantages and disadvantages of imposing a duty on patients to reveal their genetic test results to family members, it becomes apparent that the disadvantages of imposing the duty are outweighed by the advantages. This information might benefit relatives because they could take steps to improve their health and could inspire the relatives to get tested themselves, which could reduce their uncertainty about whether they are afflicted with the same mutation. But these potential advantages are outweighed by the negative psychological effects and family discord that the same sharing can produce. Additionally, imposing a duty would result in patients losing control over their private test results, which could expose them to

discrimination. Finally, it is impractical to have the patients explain their genetic test results to relatives because they may not understand them. Forcing patients to explain their test results may result in inaccurate information being provided to their relatives.

III. CONCLUSION

While there is the potential for a legal duty to be created, through tort law, an Equal Protection Claim or state statute, these claims should fail. An Equal Protection Claim based on differential treatment of children raised in biological families and children raised in adopted families, who may have knowledge about the genetic health of their biological families, will not reach the level of strict scrutiny. Under a lesser rational basis standard of analysis the state will be able to assert that forcing biological parents to provide health information before adoption is fundamentally different because this disclosure still keeps information private. Moreover biological children raised by their biological families will most likely be exposed to more health information than adopted children would. Using tort law to impose such a duty would also fail. Because a predisposition exists since birth, disclosure can be analogized to rescue cases. The general rule is that a duty is only imposed when a person acts, not when he or she omits to act. A duty created under this regime would be inconsistent with the general position taken by American law. Special relationships, such as those that exist between parents and children and husbands and wives cannot overcome the presumption that there is no duty to rescue. Any statute aimed at forced disclosure of medical information to relatives will not withstand a challenge that it violates the fundamental right of privacy as it extends to a person's right to keep medical information privacy.

In addition to a weak legal basis, the policy rationales result in more disadvantages than advantages. There are benefits to disclosure in that the relatives can base their health choices

off of the experience of the patient. However, if the law were to impose a duty then the negative effects are forced on patients. These negative effects include negative psychological effects, family discord, a loss of control by patients to choose who learns about their conditions, and false information being disseminated by patients who lack competence to explain results. By not imposing a legal duty to share genetic test results, it accounts for the real concerns that need to be considered in every case before disclosure. Patients should remain in control of their information. The disastrous psychological effects can be limited because patients will have more ownership over how and to whom the information is presented. That is not to say that patients should never disclose their test results to relatives. They can and should, but their disclosure needs to be voluntary. A model of voluntary disclosure benefits all involved because it allows for individuals to assess the unique situation before warning relatives of the potential dangers lurking in their genes. This is an area where difficult decisions need to be made about who to tell and what to tell them. It is best for all involved if the law does not get involved in the personal and complicated family relations that are different in every case.

ⁱ *Safer v. Pack*, 715 A 2d (N.J. 1996); *Pate v. Threlkel*, 661 So. 2d 278 (Fla. 1995)

ⁱⁱ Ala. Code § 34-24-504 (Lexis 2010); Ariz. Rev. Stat. Ann. § 12-2291 (Lexis 2010); Ark. Code Ann. §§ 16-46-401-16-46-404 (Lexis 2010); Colo. Rev. Stat. §§ 25-1-1201-1203 (Lexis 2010); Ga. Code Ann. §290-9-7-.18 (Lexis 2010); Haw. Rev. Stat Ann. §622-57 (Lexis 2010); 210 Ill. Comp. Stat. Ann. 85/6.17 (Lexis 2010); Iowa Code Ann. 622.10 (Lexis 2010); Md. Health-General Code Ann. § 4-302 (2010); Mo. Rev. Stat. § 192.067 (2010); Tex. Health & Safety Code §§ 181.001-181.254.(2010)

ⁱⁱⁱ *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334 (Cal. 1976)

^{iv} *Id.* at 345.

^v *Pate v. Threlkel*, 661 So. 2d 278

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- vi *Safer v. Pack*, 715 A 2d (N.J. 1996)
- vii *Pate*, 661 So. 2d at 278.
- viii *Id.* at 279.
- ix *Id.*;
- x *Id.* at 282.
- xi *Safer*, 715 A 2d at 1189.
- xii *Id.*
- xiii *Id.* at 1190.
- xiv *Id.*
- xv *Id.* at 1192.
- xvi *Id.* at 1191.
- xvii *Id.* at 1192.
- xviii *Id.* at 1192-93.
- xix *Id.*
- xx W. Page Keeton et al., *Prosser and Keeton on Torts* § 31, 170. (5th ed. West 1984)
- xxi *Id.*
- xxii *Id.* at 173.
- xxiii For example, Huntington's is caused by a single defective gene inherited from a parent. If one of a child's parents has Huntington's then there is a 50 percent chance that the child inherited the disorder. Mayo Clinic Staff, Mayo Clinic, *Huntington's disease: Causes* <http://www.mayoclinic.com/health/huntingtons-disease/DS00401/DSECTION=causes> (last updated May 8, 2009).; A positive test for the BRCA1 or BRCA2 mutations does not mean that someone will acquire the disease, it only increases their chances. Mayo Clinic Staff, Mayo Clinic, *BRCA gene test for breast cancer*, <http://www.mayoclinic.com/health/brca-gene-test/MY00322/DSECTION=results> (last updated July 3, 2008).
- xxiv A child inherits 50 percent of its genes from each parents. The result is that a person shares 50 percent of its genes with each parent and siblings. Cousins share 25 percent of their genes.
- xxv Symposium: "*Testing and Telling?: Implications for Genetic Privacy, Family Disclosure and the Law.*" Article: *What should the Law say about Disclosure of Genetic Information to Relatives*, 1J. Health Care L. & Pol'y, 373, 377 (1998)
- xxvi W. Page Keeton et al., *Prosser and Keeton on Torts* § 56, 376. (5th ed. West 1984)
- xxvii Symposium: "*Testing and Telling?: Implications for Genetic Privacy, Family Disclosure and the Law.*" Article: *What should the Law say about Disclosure of Genetic Information to Relatives*, 1J. Health Care L. & Pol'y, 373, 377 (1998)
- xxviii W. Page Keeton et al., *Prosser and Keeton on Torts* § 56, 377. (5th ed. West 1984)
- xxix *Id.*
- xxx Symposium: "*Testing and Telling?: Implications for Genetic Privacy, Family Disclosure and the Law.*" Article: *What should the Law say about Disclosure of Genetic Information to Relatives*, 1J. Health Care L. & Pol'y, 373, 378 (1998)
- xxxi Symposium: "*Testing and Telling?: Implications for Genetic Privacy, Family Disclosure and the Law.*" Article: *What should the Law say about Disclosure of Genetic Information to Relatives*, 1J. Health Care L. & Pol'y, 373, 380-381. (1998)
- xxxii *Id.* at 380.
- xxxiii *St. of Tenn. v. Goodman*, 2003 Crim. App. LEXIS 288 (Tenn. Crim. App. 2003)

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- xxxiv *In the interest of M.W.*, 275 Ga. App. 849, 850 (Ga. App. 2005)
- xxxv *Mitchell v. Davis*, 205 S.W. 2d 812, 815 (Tex. App. 1947)
- xxxvi *Id.* at 380.
- xxxvii W. Page Keeton et al., *Prosser and Keeton on Torts* § 55, 370. (5th ed. West 1984)
- xxxviii *Skinner v. Ok.*, 316 U.S. 535, 541 (U.S. 1942)
- xxxix Justice Jefferson wrote in *Curlender v. Bio-Science Laboratories* that “‘The wrongful-life’ cause of action with which we are concerned is based upon negligently caused failure by someone under a duty to do so to inform the prospective parents of facts needed by them to make a conscious choice not to become parents. If a case arose where, despite due care by the medical profession in transmitting the necessary warnings, parents made a conscious choice to proceed with a pregnancy, with full knowledge that a seriously impaired infant would be born, that conscious choice would provide an intervening act of proximate cause to preclude liability insofar as defendants other than the parents were concerned. Under such circumstances, we see no sound public policy which should protect those parents from being answerable for the pain, suffering and misery which they have wrought upon their offspring.” *Curlender v. Bio-Science Laboratories*, 106 Cal. App. 811, 829 (Cal. 2 Dist. 1980)
- xl Loud et al, *Deliberate Deceit of Family Members: A Challenge to Providers of Clinical Genetics Services*, *Art of Oncology*
- xli WebMd, *Cystic Fibrosis Cause*, <http://children.webmd.com/tc/cystic-fibrosis-cause> (last updated June 23, 2009)
- xlii *Molloy v. Meier*, 679 N.W. 2d 711 (Minn. 2004)
- xliii *Id.* at 713-714.
- xliv *Id.* at 714.
- xlvi *Id.*
- xlvii *Id.*
- xlviii *Id.*
- xlix *Id.* at 715.
- l *Id.*
- li *Id.* at 713.
- lii *Id.* at 719.
- liii *Id.* at 720.
- liv 63A Am. Jur. 2d Products Liability §1097 (2010).
- lv *Id.*
- lvi *Pate*, 661 So. 2d at 282.
- lvii 63A Am. Jur. 2d Products Liability §1098 (2010).
- lviii *Id.*
- lix *Grodin v. Grodin*, 301 N.W.2d 869, 871 (Mich. App. 1980)
- lx *Id.*
- lxi Geoffrey A. Vance, *Rock-A-Bye Lawsuit: Can a Baby Sue the Hand that Rocked the Cradle*, 28 J. Marshall L. Rev. 429, 459 (1995)
- lxii Ala. Code §13A-13-3 (Lexis 2010); Alaska Stat. § 25.05.021 (Lexis 2010); Ariz. Rev. Stat. § 25-101 (Lexis 2010); Ark. Code Ann. §9-11-106 (Lexis 2010); Cal. FAMILY.CODE Code . §2200-2201 (Lexis 2010); Colo. Rev. Stat. §14-10-11 (Lexis 2010); Conn. Gen. Stat. §46b-21 (West 2010); Del. Code Ann. Tit. 13§101 (Lexis 2010); Fla. Stat. Ann. §741.21 (West

2010); Ga. Code Ann. §19-3-3 G (West 2010); Haw. Rev. Stat. Ann. §572-1 (Lexis 2010); Idaho Code Ann. §32-205 (Lexis 2010); 750 Ill. Comp. Stat. Ann. 212 (Lexis 2010); Ind. Code Ann. §31-11-1-2 (Lexis 2010); Iowa Code § 595.19 (West 2010); Kan. Domestic Relations § 23-102 (West 2010); Ky. Rev. Stat. Ann. §402.010 (Lexis 2010); La. Stat. Ann. §78 (2010); 19 Me. Rev. Stat. Ann. §701 (2010); Md. Family Law Code Ann. § 2-202 (2010); Mass. Gen. Laws ch. 207 §1 (Lexis 2010); Mich. Comp. Laws Serv § 3 (Lexis 2010); Minn. Stat. § 609.365 (2010); Miss. Code Ann. §93-1-1 (Lexis 2010); Mo. Rev. Stat. §451.020 (West 2010); Mont. Code Ann. § 40-1-401 (2010); Neb. Rev. Stat. §42-103 (Lexis 2010); Nev. Rev. Stat. 112.020 (Lexis 2010); N.H. Rev. Stat. Ann. §457:1-2 (Lexis 2010); N.J. Stat. Ann. 37:1-1 (West 2010); N. M. Stat §40-1-7 (Lexis 2010); N.C. Gen. Stat. § 51-3 (Lexis 2010); N.D. Cent. Code. §14-03-03 (2010); Ohio Rev. Code Ann. §3101.01 (Lexis 2010); Okla. Stat. Ann. Tit 43 § 3 (West 2010); Or. Rev. Stat. Ann. § 106.020 (West 2010); 23 P. Consol. Stat. Ann. § 1703 (West 2010); R.I. Gen. Laws § 15-1-1 (2010); S.C. Code Ann. § 20-1-10 (2010); S.D. Codified Laws §25-1-6 (2010); Tenn. Code Ann. §36-3-101 (Lexis 2010); Tex. Family Code §6.201 (West 2010); Utah Code Ann. §30-1-1 (Lexis 2010); Vt. Stat. Ann. Tit. 15, § 001 (2010); Va. Code Ann. §20-38.1 (Lexis 2010); Wash. Rev. Code §RCW 26.04.020 (Lexis 2010); W.Va. Code Ann. §48-1-2 (Lexis 2010); Wis. Stat. § 944.06 (West 2010); Wyo. Stat. Ann. 20-2-101 (2010).

^{lxiii} Ark. Code Ann. § 9-11-106 (Lexis 2010); Del. Code Ann. Tit. 13§101 (Lexis 2010); Idaho Code Ann. §32-206 (Lexis 2010); Iowa Code § 595.19 (West 2010); Kan. Domestic Relations § 23-102 (West 2010); La. Stat. Ann. §78 (2010); Mich. Comp. Laws Serv § 3 (Lexis 2010); Minn. Stat. § 609.365 (2010); Miss. Code Ann. §93-1-1 (Lexis 2010); Mo. Rev. Stat. §451.020 (West 2010); Neb. Rev. Stat. §42-103 (Lexis 2010); Nev. Rev. Stat. 112.020 (Lexis 2010); N.H. Rev. Stat. Ann. §457:1-2 (Lexis 2010); N.D. Cent. Code. §14-03-03 (2010); Ohio Rev. Code Ann. §3101.01 (Lexis 2010); Okla. Stat. Ann. Tit 43 § 3 (West 2010); Or. Rev. Stat. Ann. § 106.020 (West 2010); 23 P. Consol. Stat. Ann. § 1703 (West 2010); S.D. Codified Laws §25-1-6 (2010); Tex. Family Code §6.201 (West 2010); Wash. Rev. Code §RCW 26.04.020 (Lexis 2010); W.Va. Code Ann. §48-1-2 (Lexis 2010); Wyo. Stat. Ann. 20-2-101 (2010).;

^{lxiv} *Inbred Obscurity: Improving Incest Laws in the Shadow of the “Sexual Family,”* 119 Harv. L. Rev. 2464, (2006).

^{lxv} *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1376 (N.D. Ill. 1990) quoting *Carey v. Population Services Intl.* 431 U.S.678, 685 (U.S. 1977) "The decision whether or not to beget or bear a child is at the very heart of this cluster of constitutionally protected choices. That decision holds a particularly important place in the history of the right of privacy, a right first explicitly recognized in an opinion holding unconstitutional a statute prohibiting the use of contraceptives . . . and most prominently vindicated in recent years in the contexts of contraception . . . and abortion."

^{lxvi} Lori Andrews, *Future Perfect: Confronting Decisions about Genetics* 85 (Columbia Univ. Press 2001)

^{lxvii} *Id.* at 52. Nine percent of Ohio women in OB/GYN clinics believed cystic fibrosis carrier status was a good reason to avoid marriage

^{lxviii} *Id.* at 53. Eight years after testing ninety-five percent of female carriers and sixty-nine percent of male carriers for Tay-Sachs said that they would not alter marriage plans based on carrier status.

^{lxix} *Id.* Twenty-five percent of Tay-Sachs carriers would have altered their marriage plans while only six percent of the carrier's spouses would have.

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- lxx Dan Tilly, *Confidentiality of Adoption Records in Texas: A Good Case for Defining Good Cause*, 57 Baylor L. Rev. 531, 555 (2005).
- lxxi U.S. Const. amend. XIV.
- lxxii The only court to consider whether adopted persons were a suspect class was the Delaware Chancery Court in *Schlaepi v. Del. Trust Co.* It found that plaintiffs could not allege that adopted persons were a suspect class under the Equal Protection Clause because the Equal Protection Clause was traditionally limited suspect classes to race and national origin. *Schlaepi v. Del. Trust Co.*, 525 A.2d 562, 568 (Del. Ch. 1986)
- lxxiii Erwin Chemerinsky, *Constitutional Laws* § 9.2 p. 680-682 (3d.ed.Aspen 2006).
- lxxiv The American Pregnancy Association lists that in addition to protecting the privacy of the birth parents other benefits of closed adoptions are that it provides birth parents with closure, and prevents them from having to explain to their biological child why they chose adoption.
- lxxv American Pregnancy Association, *Closed Adoptions: Advantages*, <http://www.americanpregnancy.org/adoption/closedadvantages.htm> (last updated June 2007)
- lxxvi R. Scott Smith, *Disclosure of Post-Adoption Family Medical Information: A Continuing Birth Parent Duty*, 35 Fam. L.Q. 533, 554.
- lxxvii WebMd., *Huntington's Disease*, <http://www.webmd.com/brain/huntingtons-disease-11119> (last updated February 21, 2010); WebMd., *Alzheimer's Disease Guide*, <http://www.webmd.com/alzheimers/guide/alzheimers-disease-overview-facts>
- lxxviii WebMd., *Cystic Fibrosis Topic Overview*, <http://children.webmd.com/tc/cystic-fibrosis-topic-overview/> (last updated June 23, 2009) WebMd., *Tay-Sachs-Topic Overview*; <http://children.webmd.com/tc/tay-sachs-disease-topic-overview> (last updated April 4, 2008); WebMd. *Pain Management: Sickle Cell Disease*, <http://www.webmd.com/pain-management/pain-management-sickle-cell-disease> (last updated January 27, 2010)
- lxxix Tex. Fam. Code § 162.005 (b), (d), (f) (2010).
- lxxx *Id.* Tex. Fam. Code §§ 162.407; 162.413; 162.414; 162.416 (2010).
- lxxxi *Id.*
- lxxxii Justice Douglass wrote in *Griswold v. Connecticut* that "The foregoing cases suggest that specific guarantees in the Bill of Rights have penumbras, formed by the emanation from those guarantees that help give them life and substance. Various guarantees create zones of privacy... We have had many controversies over these penumbral rights of privacy and repose. These cases bear witness that the right of privacy which presses for recognition here is a legitimate one." *Griswold v. Connecticut*, 381 U.S. 479, 488 (U.S.1965)
- lxxxiii *Whalen v. Roe*, 429 U.S. 589, 602 (U.S. 1977)
- lxxxiv *Id.*
- lxxxv *Planned Parenthood v. Casey*, 505 U.S.833, (U.S. 1992).
- lxxxvi *Id.*at 895.
- lxxxvii *Michael H. v. Gerald D.* 491 U.S. 110 (U.S. 1989)
- lxxxviii *Planned Parenthood v. Casey*, 505 U.S.at 867.
- lxxxix Susan B. Apel, *Privacy in Genetic Testing: Why Women are Different.*, So. Cal. Interdis. L. J. 1, 17 (2001). Apel compares disclosing a genetic condition to a spouse with disclosing pregnancy and HIV status. Both of these disclosures correlate with increased domestic violence.
- xc 45 C.F.R §§ 160, 162, 164 (2010)
- lxxci *Id.*
- lxxcii *Id.*

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- xciii The American Society of Human Genetics Board of Directors and the American College of Medical Genetics Board of Directors, *Points to Consider: Ethical, Legal, and Psychological Implications of Genetic Testing in Children and Adolescence.*, Am. J. Hum. Genet. 57:1235, (1995)
- xciv *Id.* at 1233.
- xcv 23andMe, *23andMe:Health* <https://www.23andme.com/health/carrier/> (November 2010)
- xcvi *Id.*
- xcvii Symposium, *Twenty-First Annual Health Law Symposium, Human Genetics: Legal, Medical and Ethical Perspectives*”: *Magnetic Testing and Human Subjects in Research*. 24 Whittier L. Rev. 459 (2002)
- xcviii *Id.*
- xcix *Id.*
- c *Id.*
- ci Susan Sholtes and Howard F. Taswell, *Predictive Genetic Testing: A Story of One Family*. Families, Systems & Health, Vol. 17, No. 1 111, 114 (1999).
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