

# Virtual Mentor

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## Case in Health Law

### A Physician's Role in Informing Family Members of Genetic Risk

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Individuals whose illnesses have a genetic component—as certain cancers, neurologic diseases, and many other illnesses do—should be told about the inheritable characteristic of their diagnosed conditions. This knowledge allows patients to make informed reproductive decisions and enables those who already have biological children to take action to protect or preserve the health of those children. That action may be genetic testing of a child, if appropriate, informing an adult child of his or her potential risk, or doing nothing at all. The appropriate course of action depends not only on the probability of a child's inheriting the trait and the seriousness of the illness, but also on whether symptoms of the disease first develop in childhood, young adulthood, middle age, or beyond, and whether any lifestyle or medical intervention can protect the children from the disease or ameliorate its severity.

How great is the physician's ethical duty to insure that the patient informs his or her offspring? Certainly physicians cannot be expected to track down their patients' adult children, wherever they may be, to notify them of possible risk. But what about family medicine specialists who often care for parents and children in the same family? Does this physician have a greater duty to protect these children because they are also his patients? The more medical science learns about the genetic component of disease, the more prevalent this conflict will become; a conflict that pits the principle of respect for patient confidentiality against the principle of nonmaleficence—do no harm. In law, the medical injunction to “do no harm” has been interpreted to impose, under certain circumstances, a duty to warn those who are in immediate risk of serious harm [1].

### Duty to Warn About Potential Genetic Disease

The court system first faced claims against physicians for failure to perform genetic tests (and hence inform parents-to-be of potential risk) in the late 1980s [2]. Claims for failure to inform patients' children of their risk followed shortly after, in the mid 1990s. Two landmark cases (that reached the higher courts in their respective states within 1 year of each other) came to different conclusions on the question of the scope of a physician's responsibility to inform.

The earlier of these 2 cases, *Pate v Threlkel*, was decided by the Florida Supreme Court in 1995 [3]. Heidi Pate, after learning in 1990 that she had medullary thyroid carcinoma, discovered that her mother had been treated for the genetically transmittable disease 3 years before. Pate sued the physicians who had treated her mother and their employers, claiming that they had a duty to inform her mother of the genetic component of the disease so that she could have her children tested. Pate's suit

alleged that, had she been tested in 1987, her condition could have been prevented or cured. The Florida court agreed that Pate's mother's physician had a duty to inform his patient of the genetic component of her disease. But, the court said further, in any circumstances in which a physician has a duty to warn of genetically transferable disease, that duty is satisfied by warning the patient.

A year later, the New Jersey Superior Court reached a decision in *Safer v Estate of Pack* that implied a more extensive duty for physicians [4]. In this case, Donna Safer's father died from colorectal cancer that had metastasized to his liver. Donna was 10 years old at the time. Twenty-six years later she was diagnosed with colorectal cancer that had spread to one ovary. She retrieved her father's medical records and learned of her father's cause of death. Thereupon, Safer sued the estate of the late-Dr Pack who had treated her father, contending that the cancer was known 26 years earlier to be a hereditary condition and that Dr Pack was required, by medical standards of the time, to warn those at risk. She claimed that, given the opportunity for monitoring, early detection, and treatment, she would have been spared the severe consequences of her metastasized disease. The Safer court decided that a physician's duty to warn may not be satisfied in all cases by informing the patient. While not specifying how, exactly, the physician's duty to warn should be fulfilled—especially in the case of a young child, as Donna Safer had been when her father died—the court said that it might be necessary for a physician to weigh his or her broader duty to warn against his or her duty to respect patient confidentiality [4].

### **Implications for Physicians**

In the decade since these precedent opinions were issued, physicians have been asking which opinion they should follow. It must be emphasized that the New Jersey court did *not* go so far as to say that a physician who maintains confidentiality and does not warn a patient's children of their risk is negligent. Legal and bioethics scholars have, by and large, taken the conservative approach that favors preserving patient confidentiality, and no recent court cases against physicians for failure to warn about genetic disease have come to light.

The representative thinking of the medical community is expressed in the AMA's *Code of Medical Ethics*, Opinion 2.131 "Disclosure of Familial Risk in Genetic Testing," issued in December 2003 [5]. The overriding message of this guideline is that "physicians have a professional duty to protect the confidentiality of their patients' information, including genetic information" [5]. The opinion also advised that physicians should counsel patients before genetic testing, explaining that, if the illness or predisposition to the illness is found to be genetically transferable, the patient will be expected to share that information with at-risk, biological children. Physicians should also offer to participate in the communication to at-risk children in any way the patient desires. But that's as far as the guideline goes in establishing a physicians "duty" to warn; it does not—explicitly or implicitly—encourage physicians to breach patient confidentiality. The AMA's position on the primacy of patient confidentiality, demonstrated in this opinion, is shared by most physicians and ethicists in the field, all of whom acknowledge that, without assurance of confidentiality, patients will not feel

free to share the history and lifestyle information that physicians need to diagnose and treat them most effectively.

### **References**

1. The famous precedent case concerning duty to warn is *Tarasoff v Regents of University of Calif*, 551 P2d 334 (1976). Here a University of California psychologist failed to inform anyone that his student-patient had threatened to take the life of a young woman who had spurned him. The student carried out his threat, and the family of the murdered woman sued the psychologist and the University.
2. *Munro v Regents of the U. of Calif*, 215 Cal App 3d 977 (1989). A recent Minnesota case, *Malloy v Meier*, 629 NW2d 711 (Minn 2004), involved the failure to perform the genetic test specific for Fragile x syndrome on the Malloy's young daughter. More general genetic testing led Malloy to believe that her daughter's learning disability did not have a genetic cause. Six years later, Malloy had another child who had Fragile x and severe learning disabilities. Malloy alleged that a positive Fragile x test results on her older child would have prevented her from having a second child.
3. *Pate v Threlkel*, 661 So 2d 278 (Fla 1995).
4. *Safer v Estate of T. Pak*, 677 A 2d 1188 (NJ Supp 1996).
5. American Medical Association. Opinion 2.131 Disclosure of familial risk in genetic testing. *Code of Medical Ethics*. Available at [http://www.ama-assn.org/apps/pf\\_new/pf\\_online?f\\_n=browse&doc=policyfiles/HnE/E-2.131.HTM&&s\\_t=&st\\_p=&nth=1&prev\\_pol=policyfiles/HnE/E-1.02.HTM&nxt\\_pol=policyfiles/HnE/E-2.01.HTM](http://www.ama-assn.org/apps/pf_new/pf_online?f_n=browse&doc=policyfiles/HnE/E-2.131.HTM&&s_t=&st_p=&nth=1&prev_pol=policyfiles/HnE/E-1.02.HTM&nxt_pol=policyfiles/HnE/E-2.01.HTM). Accessed May 28, 2005.

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