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STATE OF THE ART AND SCIENCE

Why Physicians Should Know the Legal and Ethical Issues Raised by Genetic Information and Technology

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As a basic science, genetics is fascinating, exposing for study life's oldest, indeed, life's *defining* secret--the ability of a molecule to replicate itself. When medical students and physicians turn to more pressing concerns, people with illnesses and injuries and clinical problem-solving--the heady stuff of DNA replication soon fades into the background, as, of course, it must. One can't walk around absorbed in the mysteries of amino acid synthesis and be an attentive, effective clinician at the same time. And yet...

Putting genetics and its role in disease transmission entirely aside can come at a cost. Headlines announce a new gene for anything from risk-taking behavior to sexual preference every other week; designer babies are the topic of daily talk shows. It's easy for the public to get the impression that complex physical and personality characteristics are simply a matter of one genome trait transmission. No wonder couples expect the doctor to be able to assure them that their child will be healthy. Not surprising that, upon receiving a diagnosis of serious illness, the patient wants to find a genetic answer to the question "why me?"

These desires for genetic answers and healthy babies--and the desire to blame someone if the answers or babies are less than satisfactory--can mean legal and ethical entanglements for physicians. Three areas with legal and ethical issues of note are recognizing when prenatal testing is prudent, deducing the possibility of genetically transferred illness from a patient's family health history, and knowing when a patient's diagnosis could imply risk to present or future offspring. (There are of course many other areas where genetics intersects clinical practice, but these 3 present much to consider for starters.)

Challenging Physician Advice on Genetic Testing

These problem areas are noteworthy because they represent instances in which physicians have been sued by parents or family members who claim they would have acted differently had the physician warned of the possibility of genetically transmitted disease.

The Munros had a child afflicted with Tay-Sachs. They sought damages from the university physician who had ordered some genetic tests but not the test for Tay-Sachs (*Munro v. Regents of the U. of Calif., 1989*). The family history had satisfied

the physician that the couple had no Jewish ancestry. The court ruled in the physician's favor; the plaintiffs appealed, and the appeals court affirmed the original judgment.

Perhaps to protect itself against wrongful birth cases such as this, the California Department of Health Services, Genetic Disease Branch has an expanded alpha-fetoprotein (AFP) screening program. In association with consumer education, clinicians present pregnant women with a booklet explaining the AFP test, the meaning of results, and the conditions for which the test *does and does not* screen. The booklet contains a consent/refusal form that the woman signs and the physician retains in her file. The AFP test, of course, does not screen for Tay-Sachs, but it does constitute a first screen for many abnormal conditions, including neural tube defects, Down syndrome, and trisomy 18. And it alerts women to the potential need for other types of testing such as amniocentesis.

Courts Disagree on the Physician's Duty to Warn

Heidi Pate's mother died of medullary thyroid cancer. Three years later, Heidi Pate was herself diagnosed with medullary thyroid cancer. She sued the physician, Dr. Threlkel, (*Pate v. Threlkel, Florida, 1995*) and other health care providers for not telling her that her mother's disease was genetically transmittable, arguing that had she been tested 3 years earlier, she would have taken preventive action. The jury decided that, in any circumstance in which the physician has a duty to warn of a genetically transferable disease, that duty is satisfied by warning the patient.

A New Jersey superior court came to the opposite conclusion in a case also involving the physician's duty to inform family members of a patient's genetically transmitted disease (*Safer v. Pack, New Jersey Superior Ct.,1996*). Donna Safer's father died of colon cancer when she was 10 years old. Her father's physician (Dr. Pack) did not tell his patient's wife (Safer's mother) of her husband's exact diagnosis or that it might have a hereditary component. Thirty-six years later, Donna Safer became ill with colon cancer. She obtained her father's medical records and, upon discovering that he had polyposis, sued the estate of the now-deceased Dr. Pack. Here, the court decided that the duty to warn may not be satisfied in all cases by informing the patient. It may be necessary at some stage to resolve a conflict between the physician's broader duty to warn and his fidelity to the expressed preference of the patient that nothing be said to family members about details of the disease.

As the decision in the Safer case indicates, recognizing that your patient has a disease that places offspring at risk is not the end of the problem. It can be the beginning, given the physician's confidential relationship with the patient. That quandary is the topic for another "Genethics" column.

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