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FROM THE EDITOR
Examining the Benefits and Harms of Genetic Information

This issue of *Virtual Mentor* is filled with questions about what kind of genetic information should be available to patients and their families. What conditions should we screen for in newborns? Is it too easy for patients to gain access to misleading information through Internet-based testing? Do doctors share too little with patients about the prospects of people with inherited disease and disability? Definitive answers to such questions, if there are any, may prescribe a course of action for physicians, but those actions will focus on the management of and access to genetic information more than the selection of medical therapy.

One fascinating aspect of the discussions in this month's *Virtual Mentor* is the role that patient autonomy plays in commentators' analyses of the desirability of genetic testing. This is most evident in the difference between commentators' opinions on genetic testing of minors and adults. In the case of minors, there is a suggestion that genetic information—the actual knowledge generated by genetic tests—has the potential to limit the child's future autonomy. In commenting on a clinical case of a toddler, Josh, whose parents want him tested for Huntington's disease, Robert Klitzman, Roberto Andorno, and Leon Dure come to the same conclusion—testing Josh now deprives him of his future right not to know about his risk (a choice made by 80 percent of adults at risk for Huntington's disease). Josh's father has inherited the gene for this degenerative neurologic disease, so Josh has a 50 percent chance of having it also. Klitzman, Andorno, and Dure also argue against the test because nothing can be done to stave off or cure the disease, so the information will not benefit Josh who, after all, is the patient. Moreover, positive test results could lead to parental decisions, about investing in education, for example, that would discriminate against Josh.

These reservations about the impact of genetic information reflect the policy of the American Medical Association, which states in its *Code of Medical Ethics*,

> When a child is at risk for a genetic condition with adult onset for which preventive or other therapeutic measures are not available, genetic testing of children should not be undertaken" [1].

Anne-Marie Laberge and Wylie Burke, in their commentary on a case about a woman with the BRCA1 gene, believe that physicians' legal and professional duty to warn does not cover genetic risk. In the health law article Kristin E. Schleiter continues to touch on physicians' legal duty to warn both a patient and the patient's blood relatives who may be at risk from a genetically transmissible condition. Court cases have agreed that physicians have a duty to warn patients' at-risk relatives but

have disagreed on whether or not telling the patient of the familial risk satisfies that duty.

The thinking about genetic-testing practices changes when the discussion shifts from children to adults. The right of adults to seek genetic testing places an increased demand for information sharing on the counselor or physician supervising the test. In this context, respect for patient autonomy demands that physicians provide patients with a relatively sophisticated understanding of the implications of possible results of the test obtained. Kelly E. Ormond, a genetic counselor, points out ways in which physicians can become better prepared to help their patients achieve that understanding. In their commentary on a case about prenatal genetic testing, Anam Pal and Lubna Pal place similar emphasis on ensuring that physicians understand the risks and benefits of in vitro fertilization and preimplantation genetic diagnosis when discussing the topics with patients. Tali Geva and Ora Gordon describe how a thorough family history can invert this dynamic, making the patient the source of crucial information. Their thoughts on effective ways to take a family history are an important reminder that good medicine requires effective listening just as much as talking on the part of physicians.

In her policy forum article, Emily E. Anderson addresses the significant gaps in the regulation of direct-to-consumer (DTC) genetic tests, testing laboratories, and advertising that pose threats to consumers who are inadequately prepared to understand the meaning of and limitations to the information they receive. Oversight and restrictions can be imposed on each of these areas—and probably should be—because the DTC market for genetic testing is growing rapidly. Shane K. Green and Mike Spear also examine DTC genomic testing, suggesting the ways in which even genomic testing obtained without the assistance of a physician has the ability to empower patients, making them, perhaps, more responsible in their approach to health care decisions. Of course, they warn, the knowledge that one has increased risk of developing a gene-mediated illness may lead some people to give up and accept what they mistakenly think is their genetic fate.

Bernard M. Dickens and Ariel Williams examine conscientious objection and describe a form of professional obligation that prohibits physicians from placing their own values above their respect for patient autonomy when the standard of care in a given field conflicts with the physician's personal moral code.

The link between patient education and patient autonomy is central to Adrienne Asch and David Wasserman's position on the ethics of prenatal testing. In general, they support recent federal legislation that requires sharing different sorts of information with parents about the social and psychological prospects for children with diagnoses of genetic impairment. The heart of their argument is that patients should understand the broad implications of the diagnosis in order to make a rational, autonomous decisions. Don B. Bailey and his policy forum coauthors discuss emerging dilemmas in newborn screening, urging policy makers to think in terms of benefits rather than unsubstantiated possible harms when considering whether or not to test for a specific

condition.

Because genetic testing and the specific information it yields are relative newcomers to clinical practice, this issue of *Virtual Mentor* contains many well-examined—but ultimately unanswered—questions. There is some consensus about not testing children for adult-onset diseases for which there are no preventions or cures. But there are many more areas that have yet to be settled—by law, regulatory policy, and professional consensus. I hope we have succeeded in laying a solid and accurate foundation for your future consideration of these topics that are gaining in clinical importance each day.

References

1. American Medical Association. Opinion 2.138 Genetic testing of children. *Code of Medical Ethics*, 2008-2009 ed. Chicago, IL: American Medical Association; 2008:57-58.

Bennett William Clark
MS-4
Stanford University School of Medicine