

What to say to a parent who requests genetic testing

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Genetic testing can open the door to a wealth of information about an individual. Ethical guidance for physicians helps them know when to counsel parents that the wisest course is to hold off finding out what's there.

In genetic testing of children, the question is typically not one of "if", but "how much." Newborns routinely receive a few state-mandated genetic tests, but advances in science now allow for optional genetic tests that range well into the thousands. At the same time, access to testing has expanded greatly and home test kits can be ordered without going through a professional at all.

The AMA *Code of Medical Ethics* offers in-depth guidance for physicians on how to counsel parents in Opinion 2.2.5, "Genetic Testing of Children":

In genetics, the ability to diagnose disease or identify predisposition to disease often precedes the ability to prevent, treat or ameliorate the condition in question. Genetic diagnosis can carry both benefits and risks for the patient, as well as implications for others to whom the patient is biologically related. Thus, decisions to carry out genetic testing can be challenging for any patient.

Genetic testing of children implicates important concerns about the minor patient's present and future autonomy and best interests. Decisions to test must balance multiple considerations, including likely benefits, the risks of knowing genetic status (including abrogating the child's opportunity to make the choice about knowing genetic status him- or herself as an adult), features unique to the condition(s) being tested for (such as age of onset), and the availability of effective preventive, therapeutic, or palliative interventions.

With respect to genetic testing of a minor patient, including genetic testing of children being considered for adoption, physicians should:

(a) Offer diagnostic testing when the child is at risk for a condition for which effective measures to prevent, treat, or ameliorate it are available. As for any medical intervention, the physician should seek the informed consent of the minor patient's parents (or guardian) and engage the patient in decision making at a developmentally appropriate level, in keeping with ethics guidance.

(b) In general, respect the decision of the patient's parents/guardian about testing when the child is at risk for a condition with pediatric onset for which no effective measures to prevent, treat, or ameliorate the condition are available.

(c) Attempt to persuade reluctant parents/guardians to consent to testing when there are effective measures to prevent, treat, or ameliorate the condition and, in the physician's judgment, delaying testing would result in irreversible harm to the child.

(d) Regardless of the source of the testing, help the patient /parent/guardian access appropriate counseling.

(e) Refrain from offering, providing, or recommending a genetic test:

1. When parents/guardians request testing for a child who is at risk for a condition with adult onset for which no effective measures to prevent, treat or ameliorate the condition are available. Physicians should inform the parents/guardian about the test and why it is not recommended. When a minor patient seeks genetic testing for such a condition, physicians should condition testing on the patient's developmental status and ability to understand the implications of testing, in keeping with ethics guidance on decisions for minor patients.
2. When parents/guardians request testing to determine the child's carrier status for a recessive genetic condition and there are no other health implications for the child. Physicians may provide testing when reproductive decisions need to be made on behalf of or by a minor patient, in keeping with ethics guidance.
3. For the benefit of a family member, unless testing will prevent substantial harm to the individual.
4. When testing will not serve the child's health interests.

(f) Seek consultation from an ethics committee or other institutional resource when disagreements about genetic testing persist. If parents unreasonably request or refuse testing of their child, the physician should take steps to change or, if necessary, use legal means to override the parents' choice.

(g) Encourage parents to share genetic information with the child in a manner appropriate to the child's stage of development.

(h) Ensure that parents/guardians are aware of findings that are not immediately relevant but will need to be shared later so that the information can be conveyed to the child when it becomes relevant.

More go-to guidance

Explore other AMA *Code of Medical Ethics* opinions on genetics and reproductive medicine.

Parents might have heard that there are legal protections against genetic discrimination. The federal Genetic Information Nondiscrimination Act (GINA) was signed in 2008, and most states have their own laws regarding genetic discrimination.

Those state protections vary and are limited. GINA prevents genetic discrimination only in employment and health insurance. Most notably it does not cover life, disability or long-term care insurance, and it contains other loopholes or does not address other potential discrimination situations.

The AMA has policy ("Genetic Discrimination and the Genetic Information Nondiscrimination Act") that strongly opposes discrimination based on an individual's genetic information. The Association supports legislation intended to provide robust and comprehensive protections against genetic discrimination and misuse of genetic information, and supports education for health care providers and patients on the protections against genetic discrimination currently afforded by federal and state laws.