

Could prenatal DNA testing open Pandora's box?

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In this June 8, 2011 photo, Josephine Johnston poses for a portrait in New York. Johnston gave birth to a girl just two years ago. When offered a medical screening test for the fetus, she generally felt compelled to take it. Imagine being pregnant and taking a simple blood test that lays bare the DNA of your fetus. What if that DNA could reveal not just medical conditions but also things like eye color and height? So far that's still science fiction. But scientists have been taking some baby steps in that direction. And some ethics experts say it's now time to start talking about what that could mean for parents and society. (AP Photo/Mary Altaffer)

(AP) -- Imagine being pregnant and taking a simple blood test that lays bare the DNA of your fetus. And suppose that DNA could reveal not only medical conditions like Down syndrome, but also things like eye color and height. And the risk for developing depression or Alzheimer's disease. And the chances of being gay.

So far that's still science fiction. But scientists have been taking some baby steps in that direction. And some ethics experts say it's time to start talking now about what that could mean for parents and society.

This is the second story in a two-part series on fetal [DNA testing](#) and the [ethical issues](#) raised by it. The first part is [here](#).

Scanning fetal DNA from a blood test will be "without question a major medical advance that promises to greatly improve current [prenatal care](#)," says Jaime King, an associate professor at the UC Hastings College of Law in San Francisco who studies [genetic testing](#). But bringing it into practice "raises significant practical, legal, ethical and [social challenges](#)," she says.

"This really changes the experience of what it will be like to be pregnant and have a child," said Marcy Darnovsky of the Center for Genetics and Society in Berkeley, Calif. "I keep coming up with the word, game-changer."

She wonders if parents would withhold their commitment to a pregnancy until test results show a [fetus](#) is "good enough" to be born. And what, she asks, is good enough?

She and others worry about how well couples will be able to understand this flood of information, and just what should be revealed.

The issues have been discussed before. The DNA of a fetus has long

been recoverable through medical procedures, with a small risk of miscarriage. But a blood test would be free of that risk, which should make many more women interested in it and doctors willing to test for a wider range of conditions, some experts say. And the results could come early enough to allow for an abortion before the pregnancy is even obvious.

The trigger for the new round of discussion is a couple of papers published last December. In preliminary results, two research teams showed that they could essentially reconstruct a baby's genetic makeup by recovering fragments of fetal DNA from the mother's bloodstream. That ability, plus the rapidly falling cost of analyzing DNA, would open the door to inspecting individual genes.

That would go well beyond the more accurate prenatal blood test for Down syndrome that some companies hope to market within a year.

Within five to 10 years, doctors may be able to test for 100 or 200 diseases, albeit many of them rare, estimates Stanford University law professor Hank Greely, who studies the implications of biomedical technologies.

Prenatal testing "is going to put a lot more information about the genetics of a child into the hands of a lot more parents," said King.

That knowledge has a flip side. "How much responsibility are we expecting people to take for the genetic makeup of any child they might have?" asks Josephine Johnston, a research scholar at the Hastings Center, a bioethics think tank near New York City.

If a child is born with a condition that could have been detected, the presence of the test changes that outcome "from something that happened to you, to something that you participated in," she says.

"That's a very big burden to place on would-be parents," she said, adding that it's hard for a pregnant woman to refuse any test for a medical condition because it feels like the responsible thing to do.

Johnston has personal experience; she gave birth to a girl just two years ago. When offered a medical screening test for the fetus, she generally felt compelled to take it.

"At the moment these things happen, it's just you there by yourself," she said. Some people might like that level of control, but others "would be happier to leave things up to chance a little more."

She said if she were pregnant again and offered a wider range of tests, she'd restrict herself to "really, really serious disabilities and disorders."

King, who had a son 18 months ago, said she wouldn't have wanted to know about any risk for incurable diseases that show up in adulthood. Those are "things that would have caused us to spend a lot of time worrying about what his future would look like even though there's nothing we could do about it," she said.

In the future, such testing could also look for other genes - some of which aren't yet identified - that affect non-medical traits.

"If no limitations are put on, you can have a couple get a prenatal genetic test in the future saying their fetus has ... a 60 percent chance of having breast cancer at the age of 60 and a 30 percent chance of being gay," says Dr. Brian Skotko, a board member of the National [Down Syndrome Society](#).

Since such information would come early enough for an abortion, Skotko says, "The ultimate question for society is, What forms of human variation are valuable?"

Then there's the possibility of direct-to-consumer companies stepping in to fill demand, King said. Couples who go that route may miss out on getting help in understanding the nuances of what the test results really mean, said Dr. Mary Norton, a Stanford professor of obstetrics and gynecology.

Once the prenatal information is available, another question arises, King said: Should a woman be allowed to get an abortion for any reason, even a trivial one like test results about height or [eye color](#)? Some state governments have passed laws outlawing abortions on the basis of sex, she said. But it's not clear whether those are constitutional, and a woman might simply not reveal her true reasons for wanting the abortion, King said.

Skotko points out that people use their own personal perspective in deciding what they want for their children. Some couples who are deaf from a genetic condition already use current technology to avoid having children with normal hearing. "It's their lens by which they view the world, and they want a child who views the world through that same lens," he said.

Greely sees other concerns. Will the testing become so routine that women won't even realize they authorized it, and then be faced with information and an abortion decision they didn't necessarily want? How can they be helped to make an informed decision on whether to be tested? And if offered a choice of genes to be tested, or results to be told about, who will help them sort through the long list to decide what they want to know? Few doctors are informed enough, and there aren't enough genetic counselors go around, he said.

The same problem arises later when it comes time to help couples understand what the results really mean, he said. "How do you tell somebody about 100 different genetic things?" he asked. "Who's going

to do that? Who's going to listen to that? Who's going to pay for that?"

Results can be complex. For example, how is a woman supposed to balance a 25 percent increase in risk for one disease versus a 15 percent decrease in another, Darnovsky asks.

On a societal level, King said she's concerned that the prenatal diagnosis might become seen as a way of "curing" diseases by aborting fetuses that have them.

Greely recently spoke about prenatal diagnosis before the Presidential Commission for the Study of Bioethical issues, a federal advisory board. Valerie Bonham, executive director, said the commission may pursue the topic further as part of a project on DNA technology. "It's an important and emerging issue," she said.

Norton doesn't believe the arrival of a [blood test](#) for DNA analysis would raise all the issues some observers cite. But she thinks it's still a good idea to talk about what the new technology could mean.

"I think that it is always better and helpful and important to bring up all of these issues, whether they are likely to really become reality or not," she said.

"Once you've opened Pandora's box, it's harder to close it."

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