Interview: Joann Boughman and Professor Lori Andrews discuss the benefits and drawbacks of genetic testing

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BRYANT GUMBEL, co-host:

Genetic testing has become increasingly routine among obstetricians, internists and even dentists screening for the presence of certain genes. Proponents see a lot of potential benefits to such testing, but there are many who feel that the costs outweigh those benefits. **Joann Boughman** is the executive vice president of the American Society of Human Genetics. She's in Washington. Ms. Boughman, good morning.

Ms. **JOANN BOUGHMAN** (Executive Vice President, American Society of Human Genetics): Good morning.

GUMBEL: Let's start with a working definition. What is genetic testing, and why is it being used with increasing frequency?

Ms. BOUGHMAN: Genetic testing actually covers a wide variety of laboratory tests, either for disease, or to screen an individual to see if they have a single copy of a gene. And it's becoming more and more frequent now, as we learn more about the human genome and genes that are related to or actually cause diseases. And now we're even moving into the area of pharmacogenetic testing, where we might do genetic tests to determine which patients are more susceptible or would metabolize drugs better or worse.

GUMBEL: If--if I have a gene that often proves fatal, or shows I'm predisposed to a fatal disease, why would I want to know?

Ms. BOUGHMAN: In many cases, the disease that might be fatal also might have an intervention or a treatment available. And, in fact, if we could figure out those individuals at higher risk for developing that disease by doing genetic testing, then we might also intervene, as in the case of some of the families with cancer where we might start doing colonoscopies, or screening tests much more early and more consistently.

GUMBEL: Uh-huh. But as a rule, how reliable are these tests? I mean, how often do you come up with false positives?

Ms. BOUGHMAN: Reliability is--becomes a difficult concept in some of these tests because there are not so many of the complex or common disorders that have one gene that actually causes the disease. What we are testing for is a higher risk for that disease. In that respect, to interpret a test as positive or negative is actually pretty complicated, and we urge that the physicians and those that are doing the tests carefully interpret the test and explain to the families exactly what those results mean.

GUMBEL: Let me come back to you in just a second. I want to bring in Lori Andrews. She's a law professor and the author of a book called "Future Perfect: Confronting Choices About Genetics." Ms. Andrews, good morning.

Professor LORI ANDREWS (Author, "Future Perfect: Confronting Decisions About Genetics"): Good morning.

GUMBEL: Would it be fair to say that the--that the ethics and legal aspects of genetic testing at this point are trailing behind the science?

Prof. ANDREWS: Yeah, they haven't caught up with it, in large measure because many genetic diseases cannot be treated. We can diagnose them. And so, for example, insurers want to know whether you, as a healthy person now, 10 years from now will get cancer, and so many people are being stigmatized, discriminated against based on their genes. Courts are getting into the act as well. In one South Carolina case, a court actually ordered genetic testing on a wife in a divorce case to see if she would die young, and then was going to give the children to the husband. And so we may be unfairly treated based on our genes.

GUMBEL: And in an awful lot of cases is it true that people don't know they're being screened, they're being--they're being screened without their consent?

Prof. ANDREWS: Yes. In some cases, employees who have gone through routine physicals at work find out that genetic testing was done by their employer, who might want to put them in a job based on their genotype. But genetics is entering into society more broadly.

GUMBEL: How is it possible that we only have six states with laws on the books that require informed consent for genetic testing? How's that possible?

Prof. ANDREWS: I think that people haven't been aware about the many ways that their genetic makeup can be used against them by employers, insurers. It may turn out that your mortgage company wants to know what your genotype is before underwriting your mortgage. And there are many instances in which people are making profoundly important ethical decisions based on genetics. Now 12 percent of parents say they would abort a fetus with a genetic propensity to be fat. So do we really want to be a society that is measured on the value of our genes. All of us have between eight and 12 genetic defects.

GUMBEL: Miss Boughman are--are--are there people who you say should or should not be genetically tested?

Ms. BOUGHMAN: It's not so much a matter of who should or should not be tested, but in what situations testing should be offered and explained to the individuals and then they would be able to choose whether they would be tested and how they would use that information. Professor Andrews is absolutely correct that there have been inappropriate uses of the information that is gleaned from genetic testing, but there are many situations where a genetic test might help us plan for the health care of an individual or a family.

GUMBEL: How real is the possibility, or even the probability, that the psychological and emotional damage you're getting from genetic testing is worse than the--than the physical benefits?

Prof. ANDREWS: I think for some diseases genetic test results are what's called toxic knowledge. Most people, for example, who are at risk for Huntington's disease, an untreatable genetic disease that is often fatal when you're young, in your 50s, don't want to know. And so, to allow an insurer or employer to give that information to them, without their consent, is profoundly psychologically troubling.

GUMBEL: Yeah. Real quick, Miss Boughman, what new types of genetic testing are on the horizon? What's our future?

Ms. BOUGHMAN: Well, it's ex--genetic testing is expanding very rapidly as the human genome is more clearly understood, and we are learning more and more about the complex common disorders where specific genes may lead to a much higher risk of those disorders.

GUMBEL: All right.

Ms. BOUGHMAN: And I think that's really where we are--are moving now along with the pharmacogenetic testing in--in determining which drugs are most effective.

GUMBEL: OK. All right. **Joann Boughman** in Washington, Lori Andrews here in New York, thank you both, ladies. I appreciate it.

Prof. ANDREWS: Thank you.

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