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Rewriting Life

Baby Genome Sequencing for Sale in China

Chinese parents can now decode the genomes of their healthy newborns, revealing disease risks as well as the likelihood of physical traits like male-pattern baldness.

by Antonio Regalado June 15, 2017

Boston-based DNA sequencing company is offering to decode

A the complete genomes of newborns in China, leading some

to ask how much parents should know about their children's genes at birth.

Veritas Genetics says the test, ordered by a doctor, will report back on 950 serious early- and later-life disease risks, 200 genes connected to drug reactions, and more than 100 physical traits a child is likely to have.

Called myBabyGenome, the service costs $1,500 and could help identify serious hidden problems in newborns, the company says.

But some doctors say the plan is a huge overstep. "I think it's vastly premature to peddle a completely unproven set of data, especially to a vulnerable population like neonates," says Jim Evans, a professor of genetics at the University of North Carolina Chapel Hill.

The problem is that the risk posed by many disease genes remains uncertain. Even if a child has a mutation in a gene, he or she may never be affected, prompting debate among doctors about whether it's useful to inform parents.

The Veritas test also steps into uncharted territory by making predictions about how children will look and act: how wide their nose will be, whether they will overeat or have a "novelty seeking" personality, and even whether they are likely to go bald decades in the future.

Evans is sharply critical of any effort to predict traits. Especially with psychology, he says, genetic factors aren't well understood. "You run the risk of predestination based on bad science," he says. "Frankly, I think it's a little bit crazy to do genetic tests on your newborn to find out if 40 years from now they are going to be bald."

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Veritas, a spinoff of Harvard University's Personal Genome Project, specializes in inexpensive "whole genome" sequencing using the latest speedy DNA technology.

For $999, it has since last year offered adults in the U.S. the chance to learn the sequence of the six billion DNA letters in their cells. A doctor must order that test. Gene knowledge can be critically useful to anyone who's facing an undiagnosed disease or whose DNA harbors a cancer risk. But for most people the readout is little more than a novelty. Consumer demand for genome scans remains tepid.

Veritas, which already operates a sequencing lab in China, nevertheless appears to be betting that newborn sequencing could become a must-have product for ambitious parents there.

In an interview, Mirza Cifric, CEO of Veritas, declined to provide a timeline for launching a similar service in the U.S. While a few doctors here have begun sequencing newborns with unexplained illnesses, American medical bodies have opposed sequencing healthy babies because most of the data doesn't lead to clear actions doctors can take.

Robert Green, a genetics professor at Harvard University, co-leads a federally funded study called BabySeq that looks at the risks and

federally funded study called BabySeq that looks at the risks and benefits of sequencing newborns; it has sequenced the genomes of about 100 of them so far. Green reported in October than less than 10 percent of about 2,400 couples offered full-genome sequencing of their children were interested.

"Some families really don't want anything to do with this. The idea of finding a risk in their beautiful baby of something that might or might not happen is terrifying or repugnant," he says. "But other types of people are information seekers."

In a significant boost for Veritas, Green says he recently agreed to become a paid medical and scientific advisor to the company. He does not believe that the baby sequencing test will be accepted in the U.S. for the time being. But other companies are eyeing more limited DNA gene tests for babies as a way to expand on the neonatal screening routinely done in hospitals today.

In that process, a doctor pricks a newborn's heel and collects a drop of blood. The sample is then subjected to conventional tests to flag about six to 30 diseases, depending on the county or state, which can all be easily treated if caught early.

One U.S. company, BabyGenes, already offers a DNA panel that tests for about 100 genes and 70 conditions, including many rare ones not on government tests. "We're trying to get word out there that there is a better way," says the company's laboratory manager, Katie Morris.

By deciphering a baby's entire genome, the Veritas test will go still further. The selection of 950 disease risks it will tell parents about originates with a list assembled by Green's BabySeq project.

But Veritas will not reveal everything, in recognition that not all the information in the genome is appropriate to give parents right away. For

information in the genome is appropriate to give parents right away. For

instance, it won't tell them about a gene that can strongly predispose people to Alzheimer's in old age.

Instead, Veritas says, it will retain the rest of a newborn's genome data and let parents purchase further information at a later date.

That pay-as-you-go business concept was first introduced by a U.S. company called Helix, but it has yet to prove clearly successful (see "10 Breakthrough Technologies 2016: DNA App Store").

In the U.S., Veritas has received some poor reviews from customers who faced months-long delays in receiving their reports. Cifric says there were delays with some people's orders but that customers are now getting their genomes.

To catch the same high-risk conditions that newborn screening tests do, experts say, the Veritas genome reports will have to be delivered in just a few days.

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