Would you test your newborn for a disease that might strike years later?

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Advances in medicine, from genomics to biomarkers to artificial intelligence, have provided us with predictive tools that allow us to peer into our medical future in ways that once seemed inconceivable.

Today, we can find out whether we are predisposed to an array of diseases. Almost every baby in America gets their heels pricked shortly after birth, a blood sample is collected that screens them for serious treatable conditions like cystic fibrosis, sickle cell anemia and the rare metabolic disorder phenylketonuria, or PKU.

But today, through genomic screening, parents can choose to learn about hundreds of other conditions that might strike their babies one day, including learning about a disease that could otherwise go undetected.

Dr. Robert C. Green is one of the world's leading experts of genomic screening, saying it is key to preventing millions of deaths from preventable disease. He is a physician-scientist and professor at Harvard Medical School who studies and treats inherited and genetic disorders.

"Preventive genomics," as Green calls it, essentially provides a heads up about serious health conditions that a person might have long before symptoms appear.

"I really do think genomics is the tip of the spear for moving our entire society and our entire worldview from a sick-care system to a healthcare system that predicts and prevents disease and keeps people healthy," he tells CNN.

"This isn't future stuff," Green added. "This is here."

A skeptical public

But with the technology comes an array of serious ethical questions, ranging from patients' rights to how much information is too much. Parents — and doctors alike — must ask: Would you want to know? What do you do with the information? And how do you process it if the results bring devastating news?

Dr. Arthur Caplan, a renowned bioethicist and professor emeritus at New York University's Grossman School of Medicine, said the debate is more relevant than ever — and comes at a time when a post-Covid-19 world has brought a rise in skepticism of public health and a mistrust of the medical community.

"We've had a cultural shift in newborn testing in America away from the beneficence of the newborn to respect for autonomy of the parents," Caplan said.

Even the longstanding heel prick, Caplan said, has come under scrutiny in some states over constitutional and genetic privacy concerns.

"People don't like hearing that somebody's got their data stored without permission anywhere for any reason," he told CNN.

Caplan acknowledged it's noble to use genomic screening for the best of intentions — a newborn's health — but to him, the rise in testing opens a Pandora's box of other complex issues.

"I get the enthusiasm within the clinical genetics community for trying to use the information that's being discovered to help people," Caplan said. "That's not a bad thing, but it takes place in the US against a very broken healthcare system where costs are too high and access is not sufficient."

He added: How is a parent supposed to use the news that their baby has a 30% chance of catching a rare disease that may or may not occur 30 years later?

At the very least, he said, counselors should be available to any parent who undergoes a test for their newborn.

‘The message that’s been lost’

Green has emerged as one of the leaders in genomic screening over the last two decades, heading groundbreaking research in adults and newborns about risks for potential diseases, including dealing with the complex medical ethics involved in such issues.

“The message that’s been lost in all this is how many lives could be saved both in children and adults by genomic screening,” he said.

Green directs the Genomes2People Research Group, an initiative with Brigham and Women’s Hospital, the Broad Institute, and Harvard aimed at accelerating the implementation of genomic medicine and the promise of precision health.

In his years of research, Green said he and his team have exhaustively studied the negative what-ifs, from worries over depression, anxiety and distress among participants.

“We discovered that it simply was not as distressing as people had anticipated. It just wasn’t there,” Green said. “You never want to be cavalier about this, but people had over-indexed on that concern. At the same time, as the science progressed, more and more benefit was coming out around cancer predisposition and cardiac predisposition — all these things which we could truly intervene medically.”

Green delivered a similar message during a TED Talk last year, telling the audience that society needs to “embrace the knowledge of risk in order to preserve our health, rather than waiting for us and our children to get sick.”

He is currently helping lead one of his most ambitious projects: the nation’s first ever multi-state effort to integrate whole genome sequencing into existing newborn screening systems. Green hopes to enroll as many as 30,000 newborns and test for more than 750 conditions.

Known as the BRIDGES-NBS initiative, the program is funded by the National Institutes of Health and seeks to provide families the option of genomic screening “for childhood conditions where early detection can lead to treatment, proactive management or closer monitoring.” The study includes six participating states — Iowa, Minnesota, New York, Oregon, South Carolina and Texas — as well as Puerto Rico.

Green stressed that parents willingly sign up: “Nobody is talking about unconsented genomics.” He’s helping to lead an international conference in October where he says “the world is gathering in Boston and online to discuss the evidence and ethics” of genomic screening.

Pushing on amid pushback

For Green, the stakes are too high not to use genomics for the greater good of humankind. A child’s DNA doesn’t change over time, he said, but the science to treat disease improves. “What that means is we should sequence your child’s DNA,” he said, “and we should revisit and reanalyze that DNA over and over again to truly create the dream of genome-informed medicine.”

But for medical ethicists like Caplan, the debate is broader.

“You can save lives,” he added, “but if the lives that are saved have impairments and disabilities, don’t we then need to expand programs to help them?”

And, Caplan said, what if health insurers and life insurance companies won’t provide coverage if you might one day have a disease?

With technology comes great responsibility: What if, Caplan pondered, genomics was used for the worst impulses of human nature — in countries with “distaste for people with genetic diseases and anomalies?”

“They’re not out to spend money to fix them,” Caplan said. “They’re out to spend money to make sure they don’t happen.”

The debate will continue to rage.