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U.S. NEWS

Obama Announces \$215 Million Precision-Medicine Genetic Plan

Effort Seeks to Take Advantage of Technological Advances to Analyze People's Full Genetic Makeups

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President Barack Obama on Friday laid out an ambitious effort to amass genetic data on one million or more Americans, a plan aimed at discovering genetic causes of disease and finding new drugs that will target dangerous mutations.

Speaking at the White House, Mr. Obama called the \$215 million Precision Medicine Initiative “one of the biggest opportunities for breakthroughs in medicine that we have ever seen.”

The gathering included genetics experts, patients, academics and government officials. Towering over everyone was basketball legend Kareem Abdul-Jabbar, who as a cancer patient was treated using precision medicine.

The initiative, which envisions accumulating genetic data on one million or more volunteers, would greatly expand the knowledge of people's genetic makeups, known as their genomes. It would seek to decipher clues from genetic patterns across the broad population. Many details have yet to be ironed out—such as who will have access to the data under what conditions—but leading federal scientists said they expect researchers

from academia, industry and government all to play crucial roles.

The \$215 million in additional funding, included in the president's budget for fiscal 2016, would go toward research by the National Institutes of Health, the NIH's National Cancer Institute and the Food and Drug Administration. The NIH would get \$130 million for the genetic mapping project, which would take advantage of technological advances that have made it possible—and relatively affordable—to analyze people's full genetic makeups.



President Obama is introduced by Harvard University student Elana Simon at the White House on Friday before he announced a genetic-mapping plan intended to improve the treatment of diseases. Ms. Simon was the subject of a Wall Street Journal profile last year. *PHOTO: REUTERS*

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- Teen Elana Simon Helped Research Her Own Disease (<http://www.wsj.com/articles/SB10001424052702304071004579409260544992476>) (Feb. 27, 2014)

Funding is subject to congressional approval. Bipartisan support has been growing for

expanded research at the National Institutes of Health. Underscoring that, Mr. Obama met before Friday's announcement with congressional leaders including Sen. Lamar Alexander (R., Tenn.), the new chairman of the Senate committee that will oversee the NIH, FDA and related medical initiatives.

"The way you know the moment is right," the president said, "is you get bipartisan support for the idea."

In a statement, Mr. Alexander said, "We have a real opportunity to work together and get a result so that cutting-edge medicine begins reaching patients more quickly." He said he looked forward to hearing the plan's specifics.

Rep. Fred Upton (R., Mich.), chairman of the House Energy & Commerce Committee, which plays a similar role in the House, said he and House Republicans hope "to get a bill to the president's desk by the end of this year" that would incorporate GOP ideas. These would likely include faster approvals for new drugs and medical devices by the FDA, supported by the pharmaceutical and device industries.

In addition to the NIH funding, the National Cancer Institute would get \$70 million to study genetic causes of cancer; the FDA would get \$10 million to evaluate new diagnostic devices and drugs; and \$5 million would be devoted to building the computing and privacy components of the genetic-data network.

At a Thursday briefing, NIH Director Francis Collins called the initiative "an exciting, but somewhat general plan."

In an interview, he estimated that full genetic information now is known for 10,000 to 20,000 people. "A million [people] would be an enormous advance, particularly if it could be done in a coordinated fashion," he said.

A human genome can be sequenced by machine for as little as \$1,000, down from \$400 million 15 years ago. Increased computing power means researchers can sort through reams of sequencing data and health records to find patterns linking specific genes to diseases.

Drugs that would attack these new genetic targets promise to modify the course of diseases, if not cure them, researchers say. But there would still be years of work to develop the drugs and prove they are safe and effective.

"This is a very important and necessary first step, but it is not sufficient," said Jeffrey

Leiden, chief executive of Vertex Pharmaceuticals Inc. After the cystic-fibrosis gene was discovered in 1989, it took Vertex until 2012 to get approval for the first drug treating one genetic mutation involved in the disease. About 1,650 patients in the U.S. with this mutation are candidates for the drug Kalydeco.

Some companies have already been undertaking genomic-data research efforts. In Iceland, deCODE Genetics is helping parent company Amgen Inc. to find genetic risk factors for diseases and fuel its early drug research. Regeneron Pharmaceuticals Inc. is collaborating with Geisinger Health System and other health networks to sequence 50,000 patients a year for its research.

Precision medicine already is transforming cancer treatment with drugs such as Roche Holding AG 's Zelboraf. If a patient with melanoma, for instance, is found to have a mutation in a gene called BRAF, he may be prescribed Zelboraf, which targets the mutation. If the tumor doesn't have that gene variant, doctors are likely to try something else rather than expose a patient to the cost and side effects of a drug that is unlikely to work. This is one of the tenets of precision medicine.

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