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THE DNA AGE

Taking a Peek at the Experts' Genetic Secrets

By [AMY HARMON](#)

BOSTON — Is [Esther Dyson](#), the technology venture capitalist who is training to be an astronaut, genetically predisposed to a major heart attack?

Does [Steven Pinker](#), the prominent psychologist and author, have a gene variant that raises his risk of Alzheimer's, which his grandmother suffered from, to greater than 50 percent?

Did Misha Angrist, an assistant professor at [Duke University](#), inherit a high risk of breast cancer, which he may have passed on to his young daughters?

On Monday, they may learn the answers to these and other questions — and, if all goes according to plan, so will everyone else who cares to visit a public Web site, www.personalgenomes.org. The three are among the first 10 volunteers in the Personal Genome Project, a study at [Harvard University](#) Medical School aimed at challenging the conventional wisdom that the secrets of our genes are best kept to ourselves.

The goal of the project, which hopes to expand to 100,000 participants, is to speed medical research by dispensing with the elaborate precautions traditionally taken to protect the privacy of human subjects. The more genetic information can be made open and publicly available, nearly everyone agrees, the faster research will progress.

In exchange for the decoding of their DNA, participants agree to make it available to all — along with photographs, their disease histories, allergies, medications, ethnic backgrounds and a trove of other traits, called phenotypes, from food preferences to television viewing habits.

Including phenotypes, which most other public genetic databases have avoided in deference to privacy concerns, should allow researchers to more easily discover how genes and traits are linked. Because the “PGP 10,” as they call themselves, agreed to forfeit their privacy, any researcher will have a chance to mine the data, rather than just a small group with clearance.

The project is as much a social experiment as a scientific one. “We don't yet know the consequences of having one's genome out in the open,” said George M. Church, a human geneticist at Harvard who is the project's leader and one of its subjects. “But it's worth exploring.”

A new federal law prohibits health insurers and employers from discriminating against individuals on the basis of their genetic profile. But any one of the PGP 10 could be denied life insurance, long-term care insurance or disability insurance, with no legal penalty. And no law can bar colleagues from raising an annoyed eyebrow at a PGP participant who, say, indulges in a brownie after disclosing on the Internet that she is genetically predisposed to diabetes.

Then there is the matter of potential recrimination — from siblings, parents and children who share half of the participants' genes and did not necessarily agree to display them in public. Prospective participants are advised to consult with first-degree relatives, but except for identical twins, their consent is not required. Some volunteers are worried about their hurting their teenagers' dating prospects.

“A potential boyfriend could look at my genome and say, ‘I don’t know if this relationship is meant to be,’ ” said John Halamka, a participant and the chief information officer of Harvard Medical School, who has a 15-year-old daughter. (His daughter, he said, told him that if a suitor did that, “I wouldn’t want them as a boyfriend anyway.”)

Because of the known and unknown risks, Dr. Church required the first 10 participants to demonstrate the equivalent of a master’s degree in genetics. Most are either investors or executives in the biomedical industry, or else teach or write about it, so they may have a financial interest in encouraging people to part with their genetic privacy.

The project has drawn criticism from scientists and bioethicists who caution that even its highly educated volunteers cannot understand the practical and psychological risks of disclosing information long regarded as quintessentially private.

“I’m concerned that this could make it seem easy and cool to put your information out there when there is still a lot of stigma associated with certain genetic traits,” said Kathy Hudson, director of the Genetics and Public Policy Center at [Johns Hopkins University](#). “There will be new uses of this data that people can’t anticipate — and they can’t do anything to get it back.”

For now, the PGP, which is privately funded, is sequencing only the fraction of participants’ genomes thought to have the most influence over disease, behavior and physical traits. But the question of how much value to place on genetic privacy has taken on more urgency as the technology for sequencing an entire human genome accelerated and the price has plummeted to as low as \$5,000, so that it may soon be possible for everyone to possess their own genetic readout.

Sequencing a human genome — the six billion letters of genetic code containing the complete inventory of the traits we inherited from our parents — cost over \$1 million just two years ago.

The two scientists whose full genomes were sequenced in the name of research both made them public. But they differ on whether the practice should be widely recommended.

“I put mine out there, but I’m 80,” said [James D. Watson](#), the chancellor emeritus of Cold Spring Harbor Laboratory and co-discoverer of the structure of DNA. “Randomly putting up young people’s genomes could cause individual harm, simply because there will be so many mistakes. We don’t know enough yet to interpret them.”

[J. Craig Venter](#), a pioneer in human genome sequencing, said his nonprofit institute planned to sequence several dozen human genomes by the end of next year and to deposit the information in the public domain along with phenotype information in a model similar to that of the PGP. He said he had already heard from thousands of volunteers.

“If they want privacy we tell them to go somewhere else,” Dr. Venter said. “To truly understand humans we need a huge data set of 10,000 complete genomes, and the data needs to be open to everyone for interpretation.”

Besides, promises of privacy may be impossible to keep, given the extraordinary identifying properties of DNA. Over the last three years, more than a half-million people who participated in over 100 publicly financed genetic studies on traits like schizophrenia and drug addiction were promised that their anonymity would be protected. But last month, after a paper in a scientific journal described how an individual's profile could be identified even when it was aggregated with hundreds of others, the [National Institutes of Health](#) abruptly restricted access to the data.

There are some signs that the reflex to protect genetic privacy may be shifting. On the Web site of 23 and Me, a company that markets a \$400 minisnapshot of traits from risk of heart disease to ear wax type, some customers use pseudonyms to discuss their results, while others include links with their contact information.

And [Sergey Brin](#), the co-founder of Google, recently revealed on his blog that he learned he has a considerably higher than average risk of developing Parkinson's disease, which was diagnosed in his mother several years ago. (Mr. Brin is the husband of Anne Wojcicki, a co-founder of 23 and Me.)

“There are costs to keeping things secret,” Mr. Brin said in an interview. “There's a much better chance that you will learn something useful if you are not trying to hide it.”

Still, it may depend on what “it” is.

As the PGP 10 gathered Sunday at Harvard Medical School in Boston to receive the first batch of their genetic data, many said they were motivated by a desire to demystify genetics, which is often wrongly viewed as determining a person's fate.

As the hour approached when they would be asked to reveal their data to the world, Dr. Pinker said he was still considering whether he wanted to learn of his Alzheimer's risk, or if he would ask the researchers to withhold the data from himself and the public. Everyone, Dr. Church said, is given a chance to change their mind about going public up until the last minute, “but we try very hard in our screening process to choose the people who understand that it is better to have it all out there.”

Only about 1,300 of the 20,000 human genes have been so far linked to a particular trait, PGP researchers said.

Thus, even if Dr. Pinker chooses to remove from public view the chunk of DNA currently associated with Alzheimer's risk, he is not necessarily protecting himself from future associations scientists may make about genetic data that may now seem innocuous enough to put on the Web.

Dr. Halamka, a PGP volunteer who found out Sunday afternoon that he has a gene variant that has been associated with childhood blindness, said he had no qualms about putting that, and all of his other information, online. Since he is not blind, and neither is his 15-year-old daughter, the project's researchers told him it seemed likely that something in his genetic makeup was compensating for the defect.

Still, he asked whether it was associated with multiple sclerosis, which his father has. "My daughter," Dr. Halamka said, "will be asking questions."

What happens to the PGP, Dr. Church said, may serve as a litmus test for the fears of sharing genetic data, in an era when everyone's inborn imperfections are becoming more identifiable. If this group is tracked "like major league baseball players, everyone will want to be like them," he said. "If it runs into social hassles and financial hassles, then no one will."

The volunteers will be given more information as the data is analyzed, and they may be asked to answer questions that might help researchers. But the only requirement is that they notify the project if they suffer any adverse effects from their participation.

Dr. Church said that information, too, will be made public.

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