

# Customers Handed Over Their DNA. The Company Let the FBI Take a Look. Millions of consumers have bought home-test kits, including 1.5 million from FamilyTreeDNA. How that data is used is largely left up to the companies

Brandon Thibodeaux for The Wall Street Journal . Wall Street Journal (Online) ; New York, N.Y. [New York, N.Y.]22 Aug 2019.

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## FULL TEXT

The trouble started when the Federal Bureau of Investigation attorney made a personal appeal to Bennett Greenspan.

Mr. Greenspan, president of FamilyTreeDNA, was used to fielding requests from genealogists, customers, even friends of friends, seeking help with DNA testing . The FBI's Steve Kramer wasn't among them.

The company's database of over 1.5 million customers could help solve heinous crimes, the attorney said. He wanted to upload DNA data in two cases to see if there were genetic links to other users. Turning up matches to even distant relatives might generate leads.

This wasn't what his customers signed up for, Mr. Greenspan knew. People typically took DNA tests to find long-lost relatives or learn more about their ancestry. They didn't expect their genetic data might become part of a criminal investigation.

But one case involved a dead child whose body had never been claimed. The other was from a rape crime scene. Mr. Greenspan was horrified by the details.

He didn't tell the FBI attorney to come back with a court order. He didn't stop to ponder the moral quandaries. He said yes on the spot.

"I have been a CEO for a long time," said Mr. Greenspan, 67 years old, who founded the Houston-based company in 1999. "I have made decisions on my own for a long time. In this case, it was easy. We were talking about horrendous crimes. So I made the decision."

Increasing numbers of people are taking DNA tests. As the databases expand, so do uses of the information. Decisions on what uses are permissible largely rest with the controllers of the DNA databases—sometimes a single individual at a company.

Millions of consumers use genetic data to gain insight into family roots or learn about health risks. The boom has also revealed information test takers never expected, such as the identities of biological parents in adoptions or partners involved in secret relationships.

DNA databases have drawn interest from outsiders too—drug companies eager to mine them for information, researchers studying population migration and law enforcement seeking leads to crime suspects.

"Taking a DNA test does not just tell a story about me. DNA tests inevitably reveal information about many other people too, without their consent," says Natalie Ram, an associate professor of law at the University of Maryland Francis King Carey School of Law, who studies genetic privacy. "Should genetic databases be allowed to make up

the rules as they go along?"

Companies make the call over what to sell or share with varying levels of disclosure. Whether a company issues a press release detailing a policy or flags it on a website, consumers don't always pay attention or fully understand the way their DNA will be used, say researchers studying genetic privacy.

When the FBI's Mr. Kramer called FamilyTreeDNA in late 2017 and then again in early 2018, he framed the requests as appeals for help from a good citizen, Mr. Greenspan said. So in both instances, he agreed to help.

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The FBI declined to make Mr. Kramer available for comment. "It is important to note that investigative genealogy is for lead purposes only. All arrests should be based upon independent criminal forensic DNA testing," an FBI spokeswoman said.

When there is a genetic match in the FamilyTreeDNA database, the FBI sees what a regular customer sees: the name of the person if the customer has provided it, the amount of DNA that is shared in common, and contact information if the customer lists it.

The dead child's identity wasn't revealed through matching in the FamilyTreeDNA database. But the rape case did generate leads, according to Mr. Greenspan. He said he learned much later the suspect was the man police alleged was the Golden State Killer, who was arrested in April 2018, and has been charged with multiple crimes. Police suspect him of murders and rapes over the course of decades.

The announcement of the Golden State Killer's arrest electrified the public. It also drew attention to the notion genealogy databases could help solve crimes. The suspect's DNA file had been uploaded to an open database run by the genealogy website GEDmatch.

GEDmatch, a free site, allows individuals to upload their DNA files from consumer testing companies to help them find relatives.

In May, GEDmatch changed its rules regarding law enforcement use of the database. Individuals who upload DNA data to the site must now choose to opt in to allow law enforcement to use their profiles in investigations.

GEDmatch also announced a change that would enable law enforcement to use the site to investigate a wider number of crimes, including robbery and aggravated assault.

In the wake of the Golden State case, Mr. Greenspan said the FBI attorney pressed him to cooperate with the agency on a regular basis. This time, Mr. Greenspan felt uncomfortable. It was one thing to perform a civic duty with an urgent case. It was another to routinely do forensic testing, which he considered outside the realm of genealogy.

Mr. Greenspan describes himself first and foremost a genealogist, his passion since age 12, when his grandmother died and he spent the hours after her burial asking elderly relatives the names of their grandparents and filling out a family tree.

The FBI attorney let him know that "if I didn't find a way to work with him, I would perpetually be dealing with a subpoena," Mr. Greenspan said.

Other consumer DNA testing companies, such as 23andMe, Ancestry, and MyHeritage, say they won't share genetic data with law enforcement unless required to do so by law, such as with a warrant or a subpoena.

FamilyTreeDNA is privately owned and doesn't have a board. There is no in-house counsel; the company uses outside attorneys when needed. Mr. Greenspan discussed the FBI calls with the co-owner of the company, Max Blankfeld, FamilyTreeDNA's vice president and chief operating officer. Regarding the decision about the FBI, Mr. Blankfeld said, "This was not a case where we argued." Mr. Blankfeld said there was no reason to block the FBI from taking the same actions as a paying customer.

DNA companies differ in how they share their data in other arenas, too. In 2018, 23andMe announced a \$300 million deal allowing the pharmaceutical company GlaxoSmithKline to use the company's genetic data to develop drugs.

Kathy Hibbs, chief legal and regulatory officer of 23andMe, said the company emailed customers and told them of

the deal. Those who had previously given consent for their data to be used for research were reminded they could withdraw consent. "Very few people do," she said.

FamilyTreeDNA launched a marketing campaign in 2017, called "Can the Other Guys Say That?," promising consumers it would never sell their genetic data. It contrasted itself in a press release with competitors that were "selling consumers' genetic data to pharmaceutical companies for a profit."

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DNA-testing companies offer customers an opportunity to see if there are others in their databases who share common segments of DNA. In general, individuals share more DNA with people to whom they are more closely related, such as parents or siblings.

The FBI maintains a national forensic DNA database that includes genetic information from felons and others, and allows federal, state, and local forensic labs to compare DNA profiles. DNA files generated from crime scenes can be run through the system to see if there are any matches.

Law enforcement is interested in consumer DNA databases because they offer an opportunity to generate new leads with a wider pool of people.

Using the leads, investigators and genealogists can build family trees and home in on a person's identity, even though they often need to gather additional information.

In August 2018, Mr. Greenspan agreed to run a pilot test. The FBI sent DNA from three cold cases to the company's lab, he said. Mr. Greenspan went into the office of lab director Connie Bormans to explain. He said she was the first person he told.

"It was proof of concept. We were going to see if it worked," Dr. Bormans said. She wanted to make sure the lab could create the DNA data files that are then uploaded into the database for matching.

It worked, and one case eventually led to an arrest, according to Mr. Greenspan.

As the months went on, Mr. Greenspan says his relationship with Mr. Kramer deepened. In November, the FBI attorney invited Mr. Greenspan to an FBI meeting in Houston to discuss the use of genetic genealogy to help solve crimes. It was the first time the two met in person. "I had never seen so many people with guns in one place," Mr. Greenspan said.

His son, Elliott, who is director of IT and engineering for FamilyTreeDNA, gave a presentation on the basic science of DNA, genetics, and genealogy, Mr. Greenspan said.

The company still hadn't informed customers that the FBI was searching for genetic matches in the FamilyTreeDNA database.

In December, Mr. Greenspan decided to meet with his marketing director, Clayton Conder, about the company's relationship with the FBI.

She suggested he review the company's terms-of-service, which stated the company would allow law enforcement to use its services only with "legal documentation and written permission of FamilyTreeDNA."

Mr. Greenspan didn't feel the FBI DNA data uploads so far had violated the terms of the agreement.

Ms. Conder said she told him some customers would be surprised to learn about an arrangement with the FBI and would ask what limits investigators would be under. "People get scared," she says.

Mr. Greenspan wrote new language regarding the company's policy, stating law enforcement could use its services only in cases involving homicide or sexual assault, or identifying deceased individuals.

The change was posted online around the time Mr. Greenspan left for a long-planned vacation to India in mid-December.

Ms. Conder recommended the company send an email to customers and issue a press release.

He didn't take that advice. He wanted to film videos and offer a personal explanation to customers.

On Jan. 22, while the videos were in the works, Mr. Greenspan sent Mr. Kramer and the FBI a draft press release,

letting them know the kinds of cases where the company would permit DNA uploads.

Mr. Kramer called with a different suggestion, Mr. Greenspan said. He wanted a definition of violent crime that allowed the FBI to upload DNA profiles from any case where physical force was used in an attempt to commit a crime against an individual or property.

Ms. Conder, who was on the call, felt Mr. Kramer's suggestion would make customers uncomfortable. She had immersed herself in the debate about genetic privacy that heightened in the wake of the Golden State Killer announcement.

Privacy advocates argued that when consumers submitted their DNA to a company, they didn't expect it could be used by law enforcement without a warrant. Some are concerned about the government potentially having access to the genetic data of large numbers of people, many of whom never agreed to its use, and without wider public debate. Innocent people could get caught up in an investigation.

Ultimately Mr. Greenspan agreed to a different suggestion by Mr. Kramer, which included cases involving physical force.

FamilyTreeDNA knew it was running out of time to get the word out to customers. The news site BuzzFeed had contacted FamilyTreeDNA to ask about the company working with law enforcement.

The company posted another term of service on its website Jan. 30 with the new language, but didn't make an announcement. The next day, BuzzFeed ran an article revealing that FamilyTreeDNA was working with the FBI. A few hours after the BuzzFeed story, FamilyTreeDNA issued a press release explaining its new policy and stating Mr. Greenspan had acted "in good conscience and without violating consumers' trust" to help the FBI save lives. The decision was controversial, and some greeted the news with outrage.

Customers, irate or confused, called or emailed the company with questions. Academics spoke out about the limits of genetic privacy. Genealogists were bitterly divided.

"I don't think there are a bunch of people saying it is normal for a commercial entity to take my unique identifiers and data and share that with no legal process with the FBI," said John Verdi, vice president of policy at Future of Privacy Forum, a Washington, D.C., think tank that has published guidelines on privacy best practices for consumer DNA testing. "That is a vanishingly rare view among consumers."

Katherine Borges, director of the International Society of Genetic Genealogy, said she decided to bar any discussion about law enforcement in the online forum she moderates because conversation about the topic quickly turned vitriolic; people made personal comments rather than discussing the broader privacy issues, she said.

"It is frustrating," she said. "I want them to be able to talk about it, but they can't talk about it without fighting." Roberta Estes, a genetic genealogist who supports law-enforcement matching, said some genealogists worried consumers would be scared off from DNA testing completely if they thought law enforcement might have access to their information. "I am concerned the divisiveness will damage the genetic genealogy industry as a whole." Judy G. Russell, a genealogist who has a law degree, pointed out in her blog "The Legal Genealogist," that FamilyTreeDNA's press release didn't explain that the definition of violent crime cited left open the possibility of the FBI uploading DNA in cases of juvenile delinquency "involving use or carrying of a gun or knife even if no one was harmed."

The decision to work with the FBI, she wrote, left her "flummoxed—downright gobsmacked."

Mr. Greenspan gave a pep talk to the company's customer-service department, saying everyone would receive a bonus that week, which he referred to as "combat pay."

He said he felt vilified by many of the initial reactions. One close friend, he said, told him he understood the higher good involved with helping solve brutal crimes, but still wasn't comfortable with Mr. Greenspan's decision.

Mr. Greenspan said he also received emails from longtime customers, some of whom agreed with him. Others worried his stance might cause genealogists or other customers to stop using FamilyTreeDNA and that the company was moving away from its purpose to help people research ancestry.

The company tried to respond to the criticism.

In an email to customers in February, Mr. Greenspan wrote, "I am genuinely sorry for not having handled our communications with you as we should have." The company set up a panel of advisers, including a bioethicist and genealogists, to help the sort through future issues.

In March, FamilyTreeDNA said it figured out a way to allow customers to opt out of law-enforcement matching but still see if they matched with regular customers. Under the current rules, law enforcement can upload DNA profiles in cases involving homicide, sexual assault, child abduction, or identification of deceased individuals.

As of now, the company said approximately 50 law-enforcement agencies or their representatives have submitted DNA samples and requested matching. DNA profiles from close to 150 cases have been loaded into the database.

Mr. Greenspan said the company charges less than \$1,000 for the law-enforcement work, and while it isn't a major part of the company's business, he expects it to grow.

"I am not trying to put myself out there as anything but a small man confronted with an extraordinary problem," Mr. Greenspan said. "I still believe I made the right decision for me as a person and for our community as Americans." He said less than 2% of customers have requested opting out of law-enforcement searches.

Ms. Ram, of the University of Maryland, thinks consumers should be required to take affirmative steps to opt in to law-enforcement matching, rather than having to decide to take steps to opt out.

One recent morning, Mr. Greenspan arrived to give a tour of the lab to a group of local genealogists. No one asked any questions about the law-enforcement debate.

Stefani Elkort Twyford, president of the Greater Houston Jewish Genealogical Society, who took the tour, later said she personally favors law-enforcement matching—but opted out of law-enforcement searches, not only for herself but all 22 relatives whose kits she manages and paid for.

"The last thing I want is to get lambasted by a relative who says, 'I told you that you could use my DNA to find relatives, not get me in a dragnet,'" she said.

At the company's annual genealogy conference in March, a representative from the FBI office in Houston gave a talk about the role of genetic genealogy in law enforcement. FamilyTreeDNA convened the advisory panel for the first time. In a sign of the lingering tensions, those in the group agreed to keep their discussions private, said Ms. Borges, who is a member of the panel.

When controversial issues next arise, Mr. Greenspan says he will seek the panel members' views. He still intends to have the final word, but these days, he says, "I am tired of making decisions alone."

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Credit: By Amy Dockser Marcus | Photographs by Brandon Thibodeaux for The Wall Street Journal

## DETAILS

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