HEALTH INC.

< Search For Parkinson's Genes Turns To Online Social Networking

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STEVE INSKEEP, HOST:

There's a huge amount of interest in what our genes, our genetic material, can tell us about our health. Over the last several years, a number of emerging companies have offered personalized DNA analysis. For a few hundred dollars and a vial of spit, these companies will search your DNA for sequences that predict your physical traits, your response to certain medications and your risk for any number of diseases.

DAVID GREENE, HOST:

One company, California-based 23andMe, is attempting to use the data to do something different - search for new genes linked to Parkinson's disease. Reporter Gretchen Cuda-Kroen has the story.

GRETCHEN CUDA-KROEN, BYLINE: 23andMe calls itself the world's first genetics-based social network. The company says they've collected over 125,000 DNA samples from customers. Most of them likely joined to find out more about their personal genetic risks, not to contribute to medical science. But in 2009, the company decided to do something new - genetic research - and they invited anyone diagnosed with Parkinson's disease to donate their DNA sample.

UNIDENTIFIED WOMAN: I'm thinking that we're going to store your sample. That means they're going to keep your DNA and if they find further use for it they'll continue to use it in the future. And now, your email and your birthday, please.

CUDA-KROEN: They recruited people online using social media and at Parkinson's research conferences. And in exchange, they offered up their personalized genetics services for free. Participants provided a DNA sample and answered questions about their diagnosis, symptoms and lifestyle habits in online surveys.

The goal is to collect data on 10,000 individuals, many more than any other research study to date. And that could be an enormous asset, explains Hank Greely, a Stanford Law professor who follows genetics companies.

HANK GREELY: They may in theory be able to enroll 10,000 people with Parkinson's disease, and do it cheaply and easily. Now, that's something that academic researchers would love to be able to do.

CUDA-KROEN: In the past, researchers specifically looked at families where many members had the disease. This allowed them to zero in on single genes that would dramatically increase a person's risk of getting Parkinson's. But out of the million or so people in the United States with Parkinson's disease, less than 10 percent have any of the genes discovered so far.

Researchers think that's because there are lots of genes involved in Parkinson's - but that their effects are too small to be seen in just a few hundred to a few thousand people. Emily Drabant, research director at 23andMe, hopes that by looking at many thousands of people, they may be able to find them.

EMILY DRABANT: We know that there are many genes, so the idea is when you aggregate across many thousands of people, you can start to see genes that have perhaps a small effect on risk for Parkinson's. So perhaps, you have three or four risk variants and the combination increases your risk for Parkinson's quite significantly.

CUDA-KROEN: Talking to Drabant, it's hard not to become a believer in the power of internet-based medical research. Empowering everyday people that cure diseases like Parkinson's by sharing a little DNA is a noble goal - and is infectious.

But outside observers like Greely say a dose of skepticism is in order. He wonders if 23andMe's customers will truly be representative of the population, and if the subjects can be trusted to accurately report their diagnosis and symptoms.

GREELY: We know for example that if you ask people how much they weigh, you will get a systemic bias; they will always say they weigh less than they actually do. Will that be true of some of the symptoms they're seeking to have people report? We don't know, and at this point I don't think they know either.

CUDA-KROEN: Criticism of direct-to-consumer genetics companies is nothing new. Many have questioned the ethics of delivering genetic information directly to the consumer, as well as the value and the accuracy of the genetic risks they report.

And when it comes to research, many wonder if these companies will have incentives to report positive findings too soon. But Robert Green of Harvard Medical school says that companies with large profit incentives have been doing medical research for years - and while skepticism is in order, the controversial nature of these companies is not a reason to entirely discredit their approach to research.

ROBERT GREEN: You know, social media has changed the rest of our lives. There's no reason why social media and the Internet can't revolutionize some aspects of medical research as well. So I see this as part of a larger trend, not something that's really restricted to genetic testing companies.

CUDA-KROEN: And to be fair, in just a short time, 23andMe has had considerable success. Even though they're still short of their goal, they've discovered two new genes. And what's more, Drabant says they have also been able to uncover rare combinations of mutated genes that are associated with Parkinson's no one has ever been able to find before.

Drabant says she recognizes an Internet-based approach to genetics research makes many scientists uncomfortable. It's something new. But she also says she truly believes that companies like 23andMe have the power to make important genetic discoveries faster, and cheaper than has been done in the past. And given enough time and research subjects, she hopes to prove it.

For NPR News, I'm Gretchen Cuda-Kroen.

(SOUNDBITE OF MUSIC)

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(SOUNDBITE OF MUSIC)