United States government grows a family health tree, helping people trace hand-me-down genetic risks

Family trees are no longer just a display of crazy aunts, cousins thrice removed and great-grandfathers in stiff collars. They are also a rich picture of hereditary health risks that genetic testing and traditional consultations between patients and doctors often miss. That's why the US government is encouraging Americans to assemble family health histories in a free computer program they can pass from relative to relative, share with medical professionals and make part of the front line of defence against hand-me-down diseases carried through generations.

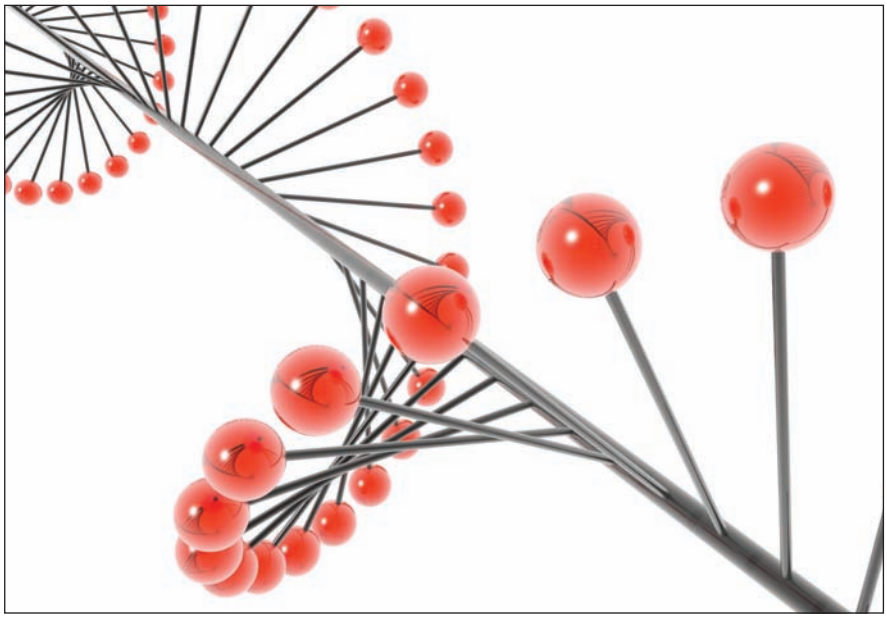
The online program from the US surgeon general, called My Family Health Portrait, is rooted in the time-honoured habit of keeping up with relatives — a habit that appears to be fading. The government estimates that more than two-thirds of Americans don't keep records of family health. That means missing clues at the intersection of genealogy and genetic medicine, like an uncle's heart attack or a grandmother's ovarian cancer, which may foretell health problems in descendants many years later.

Acting Surgeon General Steven K. Galson released an updated version of the software program (https://familyhistory.hhs.gov) in January. About 2500 people download it daily, a 10-fold increase since the first nonstandards-based version was released in 2004. Galson says a simple family health portrait can achieve what the leading edge of science may not.

"You ask some people about the age of personalized medicine and they think, take a drop of blood and put it in a machine and it's going to tell me everything," he says. "That's really science fiction. Today, in 2009, and for the foreseeable future, the best way to inform your health care practitioners about your genetic predisposition is through old-fashioned family history."

That point was echoed by Dr. Tom Hudson, president of the Ontario Institute for Cancer Research and one of the top genome scientists in North America, who says that genetic testing can only do so much at the clinical level.

"Family history gives more predictive information," he says. "If your father has type 2 diabetes, that information is more predictive than all the new gene tests we've identified."



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Much information about your health lies in your genes, but the best way to inform doctors about your genetic predisposition to particular health conditions may still be through maintaining an old-fashioned family history.

Similarly, despite the recent identification of 10 or so new genes for colon cancer, the knowledge that colon cancer runs in the family counts for more, Hudson adds.

Since Galson released the new program, US President Barack Obama has acted to supercharge America's lagging transition to electronic record-keeping in health care with a US$19-billion investment. The family health tree, introduced 5 years ago in rudimentary form, is now ready for use in electronic health records, the government says. It takes about 15 minutes to fill out the program, once the user has collected information on birthdates, disease history and other basics. The result: a family tree starring the first person to use it.

After a woman, for instance, adds what she knows, she can turn the program over to her husband. When he fills it out, the tree is reindexed to make him the centre of attention and his side of the extended family becomes part of the history, too. The more hands on the tree, the more verdant it becomes. To guard privacy, no information is stored online. Users download the information to share with family members and doctors.

The program's code is free to all takers, meaning any organization can adopt it or adapt it. Among those using it: Mexico's National Institute of Genomic Medicine, the US Indian Health Service and the cancer-focused Lance Armstrong Foundation.

Other personal health information services are also popping up online, including one run by Google and another called Medem run by a consortium of medical societies, while many studies are looking into the benefits of people being more knowledgeable of their health histories. The US Agency for Healthcare Research and Quality is financing several projects to see whether patients using personal health records fare better than those who don't. The studies look at chronic disease, medication use, cancer screenings and immunizations. — Cal Woodward, Washington, DC

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