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The Life-Saving Secrets in Your Family Tree

By [ANNA WILDE MATHEWS](#)

Each year, when Dale Kagan's cousins gather for the Rosh Hashana holiday, they catch her up on important family news like births and marriages -- and the results of their colonoscopies.

Ms. Kagan, of Glencoe, Ill., has been tracking her extended family's medical history for more than a decade. The 59-year-old began keeping the unusual health record after she and many of her relatives observed a tendency in the family to get colon polyps, which can sometimes lead to cancer. The pattern convinced family members to start getting tested more frequently and at younger ages. One cousin learned he had colon cancer at the age of 42.

Heredity plays a strong role in many health problems, ranging from Alzheimer's disease to macular degeneration and immune-system disorders like Crohn's disease. Though scientists have discovered genetic markers tied to many illnesses -- and tests have been developed to determine which patients have such markers -- these currently account for only a small portion of the risk for some diseases. That's the case with maladies such as stroke, most types of epilepsy and schizophrenia.

Many doctors say that keeping track of your family history can be a better way to gauge your risks than getting genetic tests. Family records might turn up correlations that tests can't yet fully explain.

"For most common diseases, it's more informative to work out your family history" than to get a genetic profile, says David B. Goldstein, a professor of genetics at Duke University. Among these are Type 2 diabetes and heart disease, he says.

Genetic-profiling companies say their services provide insights that a family history can't, including differences between siblings. Also, some people may learn things from their genetic profiles that aren't apparent, such as that they are carriers for certain diseases, says Linda Avey, co-founder of 23andMe Inc., a personal genome service that charges \$399 for its scans. "There's all this stuff hidden in our genome that we have no idea of," she says.

A family history can signal the need for proven genetic tests that pinpoint diseases closely linked to one or relatively few genes. A well-known example is the test that looks at BRCA1 and BRCA2 genes, certain mutations of which indicate a predisposition to early-onset breast cancer. Others include tests for Huntington's disease and cystic fibrosis.

In Ms. Kagan's case, after she brought her family history to the attention of two doctors, they recommended that she get genetically tested for familial adenomatous polyposis, a condition that

has a high risk for colon cancer. Ms. Kagan turned out not to have the condition, but a genetic counselor did confirm a genetic tendency to get polyps.

Researchers are paying close attention to the role of family medical history. The National Institutes of Health in August plans a research conference focused on the topic. There's also a family history initiative at the Centers for Disease Control and Prevention. And a growing number of institutions have launched free Web sites to help people create records and share them with doctors and relatives.

Three Generations

In putting together a family health history, it's helpful to gather information about at least three generations. Seek out older relatives, possibly at family gatherings. You should be asking about health problems, including conditions that may not seem serious such as benign colon polyps, and causes of death. Diagnostic information such as the date of onset or the type of cancer can be important.

"Really go back and probe family members," says Scott Weissman, a genetic counselor at NorthShore University HealthSystem in Evanston, Ill. You may also want to check death records, he says.

Looking for Clues

When gathering family health histories, stay alert for patterns that may signal undiagnosed conditions, such as a history of unexplained sudden deaths. Among other things, this can signal heart problems such as hypertrophic cardiomyopathy, a thickening of the heart muscle. Repeat miscarriages may be a sign of a chromosomal condition that, while not obvious in a parent, can result in a fetus that isn't viable.

Several Web sites can help people put together a family history. The Office of the Surgeon General recently relaunched its online family history tool, available at familyhistory.hhs.gov. The new version allows results to be emailed or integrated into digital health records. Eventually, the site will enable users to calculate the likelihood they'll get diseases such as colon cancer and diabetes.

NorthShore University HealthSystem also offers a family history tool at northshore.org/mygenerations. Researchers at Ohio State have a tool for assessing risk of heart disease and cancer at <https://familyhealthlink.osumc.edu>. For more background on creating your history, also check sites from the Genetic Alliance at geneticalliance.org/familyhealthhistory and the CDC at cdc.gov/genomics/fhix.htm.

To be sure, family health histories can be tough to gather. Often, relatives with important knowledge have passed away. Older kin who are still living may be reluctant to discuss health issues, or they may simply be hard to reach.

Sara Al-Saigh and her sister and father have long suffered certain symptoms, including recurring stomach pain, sore joints and rashes. But the 23-year-old Indianapolis college student didn't realize how many of her father's relatives in Saudi Arabia, whom she has never met, had similar problems.

A few months ago, a physician figured out that her father had Mediterranean fever, a hereditary disease. Ms. Al-Saigh found out she had the same condition. In the wake of the diagnosis, she says, her father called his family to ask about their health histories.

Ms. Al-Saigh says she now understands the importance of families' passing on their health histories, especially when relatives live far away. If she had known about the number of relatives with health issues similar to her father's, it might have provided an earlier clue about the genetic cause of their symptoms, she says. She now plans to relay this information to her young daughter and a soon-to-be-born son, and to get them genetically tested for Mediterranean fever. "From the time you're born, your parents should know everything about your family, both sides," she says.

Many doctors lack the time or knowledge to get a full family history or properly advise patients about its implications. A review published last year in *JAMA*, the journal of the American Medical Association, concluded that primary-care doctors "feel woefully underprepared" to integrate genomics into their practice.

Integrating Genomics

Patients often fill out questionnaires about their family history, especially the first time they see a new doctor, but the questions are often perfunctory. Without doing research in advance, patients might have little knowledge of medical conditions beyond their closest relatives.

Patients should bring a printout of a family history to a primary-care checkup and discuss with their doctor questions that seem important. Based on that information, a physician may decide to check a patient's blood sugar or do other tests that could pinpoint an undiagnosed condition. It also can be useful to talk about family health history with a genetic counselor, who can help identify patterns in the family records and suggest additional questions to ask to fill in blanks. Counselors can be found through the National Society of Genetic Counselors, at nsgc.org.

Anti-Discrimination Law

One thing to keep in mind is that a federal law passed last year is supposed to protect Americans against genetic discrimination. The law prohibits employers and health insurers from forcing people to answer questions about genetic-test results or family health history. It also blocks them from using such information in hiring or coverage decisions. Information about the law can be found online at genome.gov/24519851.

But Sharon Terry, chief executive of Genetic Alliance, a nonprofit patient-advocacy group, says the law didn't cover life insurance, long-term-care insurance or disability insurance. Companies that offer such coverage can use information about potentially inherited health risks in setting your rates, she says. Ms. Terry feels that the advantages of knowing your full family history almost always outweigh the possible danger of bigger premiums, but "it's a benefit and risk analysis" for each patient, she says.

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