

## 11 cousins give up stomachs after genetic testing

With 70 percent chance of heredity cancer, family takes action

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LOS ANGELES - Mike Slabaugh doesn't have a stomach. Neither do his 10 cousins.

Growing up, they watched helplessly as a rare hereditary stomach cancer killed their grandmother and some of their parents, aunts and uncles.

Determined to outsmart the cancer, they turned to genetic testing. Upon learning they had inherited Grandmother Golda Bradfield's flawed gene, these were their options:

Risk the odds that they might not develop cancer, with a 70 percent chance they would; or have their stomachs removed. The latter would mean a challenging life of eating very little, very often.

All the cousins chose the life-changing operation. Doctors say they're the largest family to have preventive surgery to protect themselves from hereditary stomach cancer.

"We're not only surviving, we're thriving," said Slabaugh 16 months after his operation at Stanford University Medical Center in Palo Alto.

Advances in genetic testing are increasingly giving families with bad genes a chance to see the future, sometimes with the hope of pre-emptive action. People have had stomachs, breasts, ovaries, colons or thyroid glands removed when genetic tests showed they carried a defective gene that gave them a high risk of cancer.

But what about people whose families don't have these rare, but powerful genetic defects? Experts say that someday, doctors may do DNA tests as routinely as they check cholesterol levels now, spotting disease risks that can be lowered. That day isn't here yet, but progress is being made.

"We do not yet have a general DNA test that fits into that category, but we're headed for it at a pretty good clip," said Dr. Francis Collins, head of the National Human Genome Research Institute.

### **Predicting your health**

By 2010, there might be several such tests, along with recommendations to help high-risk people avoid certain diseases, he said. (In fact, newborns are routinely tested now for some genetic conditions, but those tests generally focus on substances in the blood rather than DNA.)

To come up with a useful DNA mass-screening test, it's not enough to identify a particular gene variant that raises the risk of a disease, experts said. There are other questions:

- Are there enough potential cases in the general population to make mass screening worthwhile?
- Is there good evidence that screening would improve health?
- Is the risk of disease high enough to make the test result useful?
- How useful is the test in various ethnic groups?
- Is there a way to lower the disease risk?

For now, "mass screening with DNA testing isn't quite ready for prime time," said Dr. Ned Calonge, head of the U.S. Preventive Services Task Force, which recommends steps people can take to prevent disease.

### **Who to test**

The task force recently recommended against routinely testing women for harmful mutations in BRCA genes. Those mutations raise the risk of breast and ovarian cancer. But it endorsed such testing for women whose family histories show certain suggestive patterns of cancer — a situation like stomach cancer in the Bradfield family.

Slabaugh, who lives in Dallas, reunited with his many scattered cousins recently in Las Vegas just two months after the last in the group — Bill Bradfield of Farmington, N.M. — had his operation. Several hadn't seen each other for decades while others met for the first time.

They gambled, went to shows and dined in the City of Sin.

### **Tackling 'genetic destiny'**

"Rather than live in fear, they tackled their genetic destiny head-on," said Dr. David Huntsman, who found the gene mutation in the family. Huntsman is a genetic pathologist at the British Columbia Cancer Agency, which funded his work.

About 22,000 Americans will be diagnosed with stomach cancer this year and half will die, according to the American Cancer Society. But the form that runs in the Bradfield family called hereditary diffuse gastric cancer is extremely rare with about 100 families diagnosed worldwide.

The CDH1 gene mutation was first discovered in 1998 in a large New Zealand family with a history of stomach cancer. Those with the mutation have a 70 percent risk of stomach cancer.

It killed Golda Bradfield in 1960. She passed the faulty gene to seven of her children. Six died of the disease in their 40s and 50s.

The 18 grandchildren learned of the defective gene after one of them, David Allen, died of stomach cancer in 2003. His doctor had sent a blood sample to Huntsman's lab, which confirmed the genetic mutation.

Soon after, the remaining 18 got tested. Eleven who had the bad gene had surgery.

Slabaugh, haunted by his mother's death since his teen years, didn't hesitate to have the operation. He and five other cousins had it done at Stanford. The other family members had surgery closer to home.

"I wake up every morning and think, 'This is a free day. I get a bonus today,'" said the 52-year-old marketing executive.

During surgery, doctors removed the entire stomach and surrounding lymph nodes and attached the bottom of the esophagus to the intestine to create a pouch. Without a stomach, patients typically lose significant weight and must eat smaller meals more often. They can still digest food through the small intestine.

Insurance paid for part or all of the procedure, which cost between \$65,000 to \$85,000.

While the stomachs of all six Stanford patients looked normal before surgery, a study of the tissue revealed early tumor growths, said Dr. Jeff Norton, the surgeon.

The long-term effects of stomach removal surgery are still unclear. Researchers around the world are following families with hereditary stomach cancer to find out how the procedure affects quality of life.

### **'Life is pretty good without a stomach'**

It took about a year for Linda Bradfield, a 55-year-old merchandising coordinator from Irvine, Calif., to adjust to her missing stomach. Initially, she could only eat 800 calories a day and was on a strict bland diet. She gradually added vegetables such as cabbage and lettuce, but still avoids white bread, which she finds tough to digest.

"Life is pretty good without a stomach," she said.

Before Diane Sindt and her two older sisters had their stomachs taken out, they ate their "last supper" during Thanksgiving. True to their sisterly bond, they scheduled their operations at Stanford on consecutive days in December 2004.

The upside is that Sindt dropped eight dress sizes, from a 12 to a 2, since the surgery. But she has trouble keeping down certain foods like ice cream and tends to shed weight easily if she over-exercises. To overcome it, Sindt sticks with meat and has replaced running with "power walking."

"It's definitely a new normal for us," said the 51-year-old real estate broker from the Sacramento area.

Unlike his other cousins, Bill Bradfield of New Mexico wrestled over what to do. He wondered how his life would change without a stomach. Would he still have enough energy for his demanding job as a mechanic for a natural gas company?

But after watching his other cousins slowly regain parts of their former lives, Bradfield went ahead with the operation at the University of Texas M.D. Anderson Cancer Center in March, becoming the last in the family to give up his stomach.

"We're all going to die of something," he said, "but I know I won't die of stomach cancer."

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