**TEXT Excerpt: *Facing Life With a Lethal Gene***

Top of Form

Bottom of Form

The test, the counselor said, had come back positive. Katharine Moser inhaled sharply. She thought she was as ready as anyone could be to face her genetic destiny. She had attended a genetic counseling session and visited a psychiatrist, as required by the clinic. She had undergone the recommended neurological exam. And yet, she realized in that moment, she had never expected to hear those words.

 “What do I do now?” Ms. Moser asked.

 “What do you want to do?” the counselor replied.

 “Cry,” she said quietly. Her best friend, Colleen Elio, seated next to her, had already begun.

Ms. Moser was 23. It had taken her months to convince the clinic at NewYork-Presbyterian Hospital/Columbia University Medical Center in Manhattan that she wanted, at such a young age, to find out whether she carried the gene for [Huntington’s disease.](http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/huntingtonsdisease/index.html?inline=nyt-classifier) Huntington’s, the incurable brain disorder that possessed her grandfather’s body and ravaged his mind for three decades, typically strikes in middle age. But most young adults who know the disease runs in their family have avoided the [DNA](http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/geneticsandheredity/index.html?inline=nyt-classifier) test that can tell whether they will get it, preferring the torture — and hope — of not knowing. Ms. Moser is part of a vanguard of people at risk for Huntington’s who are choosing to learn early what their future holds. Facing their genetic heritage, they say, will help them decide how to live their lives.

Yet even as a raft of new DNA tests are revealing predispositions to all kinds of conditions, including [breast cancer](http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/breastcancer/index.html?inline=nyt-classifier), depression and dementia, little is known about what it is like to live with such knowledge. “What runs in your own family, and would you want to know?” said Nancy Wexler, a neuropsychologist at Columbia and the president of the [Hereditary Disease Foundation](http://www.hdfoundation.org/), which has pioneered Huntington’s research. “Soon everyone is going to have an option like this. You make the decision to test, you have to live with the consequences.”

On that drizzly spring morning two years ago, Ms. Moser was feeling her way, with perhaps the most definitive and disturbing verdict genetic testing has to offer. Anyone who carries the gene will inevitably develop Huntington’s. She fought her tears. She tried for humor. Don’t let yourself get too thin, said the clinic’s social worker. Not a problem, Ms. Moser responded, gesturing to her curvy frame. No more than two drinks at a time. Perhaps, Ms. Moser suggested to Ms. Elio, she meant one in each hand. Then came anger. “Why me?” she remembers thinking, in a refrain she found hard to shake in the coming months. “I’m the good one. It’s not like I’m sick because I have [emphysema](http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/emphysema/index.html?inline=nyt-classifier) from [smoking](http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/smoking/index.html?inline=nyt-classifier) or I did something dangerous.”

The gene that will kill Ms. Moser sits on the short arm of everyone’s fourth chromosome, where the letters of the genetic alphabet normally repeat C-A-G as many as 35 times in a row. In people who develop Huntington’s, however, there are more than 35 repeats.

No one quite knows why this DNA hiccup causes cell death in the brain, leading Huntington’s patients to jerk and twitch uncontrollably and rendering them progressively unable to walk, talk, think and swallow. But the greater the number of repeats, the earlier symptoms tend to appear and the faster they progress. Ms. Moser’s “CAG number” was 45, the counselor said. She had more repeats than her grandfather, whose first symptoms — loss of short-term memory, mood swings and a constant ticking noise he made with his mouth — surfaced when he turned 50. But it was another year before Ms. Moser would realize that she could have less than 12 years until she showed symptoms.

Immediately after getting her results, Ms. Moser was too busy making plans. “I’m going to become super-strong and super-balanced,” she vowed over lunch with Ms. Elio, her straight brown hair pulled into a determined bun. “So when I start to lose it I’ll be a little closer to normal.” In the tumultuous months that followed, Ms. Moser often found herself unable to remember what normal had once been. She forced herself to renounce the crush she had long nursed on a certain firefighter, sure that marriage was no longer an option for her. She threw herself into fund-raising in the hopes that someone would find a cure. Sometimes, she raged. She never, she said, regretted being tested. But at night, crying herself to sleep in the dark of her lavender bedroom, she would go over and over it. She was the same, but she was also different. And there was nothing she could do.

Ms. Moser grew up in Connecticut, part of a large Irish Catholic family. Like many families affected by Huntington’s, Ms. Moser’s regarded the disease as a curse, not to be mentioned even as it dominated their lives in the form of her grandfather’s writhing body and unpredictable rages. Once, staying in Ms. Moser’s room on a visit, he broke her trundle bed with his violent, involuntary jerking. Another time, he came into the kitchen naked, his underpants on his head. When the children giggled, Ms. Moser’s mother defended her father: “If you don’t like it, get out of my house and go.”

But no one explained what had happened to their grandfather, Thomas Dowd, a former New York City police officer who once had dreams of retiring to Florida. In 1990, Mr. Dowd’s older brother, living in a veteran’s hospital in an advanced stage of the disease, was strangled in his own restraints. But a year or so later, when Ms. Moser wanted to do her sixth-grade science project on Huntington’s, her mother recoiled. “Why,” she demanded, “would you want to do it on this disease that is killing your grandfather?”

Ms. Moser was left to confirm for herself, through library books and a CD-ROM encyclopedia, that she and her brothers, her mother, her aunts, an uncle and cousins could all face the same fate. Any child who has a parent with Huntington’s has a 50 percent chance of having inherited the gene that causes it, Ms. Moser learned. Her mother, who asked not to be identified by name for fear of discrimination, had not always been so guarded. At one point, she drove around with a “Cure HD” sign in the window of her van. She told people that her father had “[Woody Guthrie](http://topics.nytimes.com/top/reference/timestopics/people/g/woody_guthrie/index.html?inline=nyt-per)’s disease,” invoking the folk icon who died of Huntington’s in 1967. But her efforts to raise awareness soon foundered. Huntington’s is a rare genetic disease, affecting about 30,000 people in the United States, with about 250,000 more at risk. Few people know what it is. Strangers assumed her father’s unsteady walk, a frequent early symptom, meant he was drunk. “Nobody has compassion,” Ms. Moser’s mother concluded. “People look at you like you’re strange, and ‘What’s wrong with you?’ ”

Shortly after a simple DNA test became available for Huntington’s in 1993, one of Ms. Moser’s aunts tested positive. Another, driven to find out if her own medical problems were related to Huntington’s, tested negative. But when Ms. Moser announced as a teenager that she wanted to get tested one day, her mother insisted that she should not. If her daughter carried the gene, that meant she did, too. And she did not want to know. “You don’t want to know stuff like that,” Ms. Moser’s mother said in an interview. “You want to enjoy life.”

Ms. Moser’s father, who met and married his wife six years before Ms. Moser’s grandfather received his Huntington’s diagnosis, said he had managed not to think much about her at-risk status. “So she was at risk,” he said. “Everyone’s at risk for everything.”

When Ms. Moser graduated in 2003 with a degree in occupational therapy, their relationship, never peaceful, was getting worse. She moved to Queens without giving her mother her new address. Out of school, Ms. Moser soon spotted a listing for a job at Terence Cardinal Cooke Health Care Center, a nursing home on the Upper East Side of Manhattan. She knew it was meant for her. Her grandfather had died there in 2002 after living for a decade at the home, one of only a handful in the country with a unit devoted entirely to Huntington’s. “I hated visiting him growing up,” Ms. Moser said. “It was scary.”

Now, though, she was drawn to see the disease up close. On breaks from her duties elsewhere, she visited her cousin James Dowd, the son of her grandfather’s brother who had come to live in the Huntington’s unit several years earlier. It was there, in a conversation with another staff member, that she learned she could be tested for only a few hundred dollars at the Columbia clinic across town. She scheduled an appointment for the next week. The staff at Columbia urged Ms. Moser to consider the downside of genetic testing. Some people battle depression after they test positive. And the information, she was cautioned, could make it harder for her to get a job or health insurance. But Ms. Moser bristled at the idea that she should have to remain ignorant about her genetic status to avoid discrimination. “I didn’t do anything wrong,” she said. “It’s not like telling people I’m a drug addict.”

Before the test, Ms. Moser made two lists of life goals. Under “if negative,” she wrote married, children and Ireland. Under “if positive” was exercise, [vitamins](http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/vitamins/index.html?inline=nyt-classifier) and ballroom dancing. Balance, in that case, would be important. Opening a bed-and-breakfast, a goal since childhood, made both lists.

Last May 6, a year to the day after she had received her test results, the subject line “CAG Count” caught Ms. Moser’s attention as she was scrolling through the online discussion forums of the [Huntington’s Disease Advocacy Center](http://www.hdac.org/). She knew she had 45 CAG repeats, but she had never investigated it further. She clicked on the message.

“My mother’s CAG was 43,” it read. “She started forgetting the punch line to jokes at 39/40.” Another woman whose husband’s CAG count was 47 had just sold his car. “He’s 39 years old,” she wrote. “It was time for him to quit driving.” Quickly, Ms. Moser scanned a chart that accompanied the messages for her number, 45. The median age of onset to which it corresponded was 37. “That’s 12 years away,” Ms. Moser said.

Harmon, Amy. "Facing Life with a Lethal Gene." *Health*. New York Times, 18 Mar. 2007. Web. 16 Mar. 2014. <http://www.nytimes.com/2007/03/18/health/18huntington.html?pagewanted=all&_r=0>