

Nancy Wexler led the research to identify the gene responsible for Huntington's disease. Gina Kolata tells her singular story

She Didn't Want To Know

On my second visit to Nancy Wexler at her Manhattan apartment, she had a gift for me — a copy of her newly published memoir, *My Life, My Science: Pursuing a Cure for Huntington's Disease*. It had been signed with a stamp of her signature — she isn't able to sign it herself. Nor could she rise from her brown faux-leather recliner to greet me — she can't get up unassisted. Speaking requires effort.

Nancy and her sister Alice Wexler sat side by side in recliners, their backs to windows that offered a stunning view of the Hudson River far below. Alice lives in California but she visits Nancy every other month.

At age 80, Nancy has Huntington's disease, which destroys a person's ability to control movements. There is no treatment. There is no cure. The disease is inherited: Nancy's grandfather, three uncles and mother had it. Alice, however, does not.

For decades, Nancy led a research effort in a remote area of Venezuela that found the gene responsible for Huntington's. That work yielded a blood test that enables at-risk people to find out if they are destined to get the disease. Nancy has garnered numerous accolades and prizes, including a Lasker award, among the most prestigious in science. She devoted her life to understanding what it's like to be at risk for Huntington's, what it's like to have it. What she did not know, though, was that she would get it herself.

Huntington's disease was first described in a paper published in 1872 by American doctor George Huntington. Symptoms start slowly, with clumsiness or a stumbling walk; patients are often thought to be drunk as they stagger down a street. As years go by, patients become plagued by constant involuntary movements.

After graduating from Radcliffe College, Nancy was in Europe on Fulbright fellowship when she was called home to learn her mother had the disease.

She had grown up in luxury in Pacific Palisades, California — her father Milton Wexler was a psychoanalyst to Hollywood stars. Her

mother Leonore had a master's degree in zoology from Columbia University and a teaching certificate but did not work. She did, however, have a secret: Leonore's father had Huntington's.

Nancy made Huntington's the focus of her life, getting a PhD in clinical psychology from the University of Michigan. Her thesis subject: the experiences of people with Huntington's, and of those at risk for getting it.

Nancy's father started a chapter of the Committee to Combat Huntington's Disease, which later became the Huntington's Disease Foundation. Its express goal was to find the Huntington's gene

and search for a cure. Nancy started a chapter in Michigan and also worked with her father in California.

Her first job, at age 29, was at the New School for Social Research in New York where she continued her studies of Huntington's sufferers and those at risk. But she never told her colleagues about her own risk.

On frequent trips to California, Nancy was also helping her father lead the Huntington Disease Foundation. The group's gatherings couldn't be further from the staid scientific meetings that are the staple of academic life. There were no traditional talks, no slides. Instead,

INHERITANCE: Neurobiologist Nancy Wexler as she used to be and as seen on the cover of her book *My Life, My Science*; (below) as she is now, wheelchair-bound

Nancy and her father invited creative scientists — who may or may not have ever thought about Huntington's before — to brainstorm about ways to find the gene. The meetings always included a Huntington's patient, or the family member of a patient, so the scientists could understand what was at stake.

Back in New York, as part of her social science work, Nancy held hearings with Huntington's families and people who worked with them. She asked people who had Huntington's in their families whether they would take a test for the gene if one were developed. Two-thirds said yes. Nancy thought she'd want to be tested too.

The search for the gene began in earnest in 1980, focusing on three communities around Lake Maracaibo, Venezuela, that had the greatest prevalence of Huntington's disease in the world. Three years later, the researchers found a marker, like a flag on DNA, that was

present only when someone had the Huntington's gene. It wasn't the actual gene — that would come later — but it could be used to tell people if they had the gene.

In Nancy's doctoral thesis, she had cautioned that when a test became available, many who thought they'd want it would change their minds. She hadn't realized she would be one of them.

In 1996, Alice began noticing little abnormal movements in her sister. Nancy was just 51. She denied anything was wrong. By 2015 she had lost a lot of weight. And she was unsteady when she walked. Finally, in 2019, there was a clinical trial of an experimental drug. Nancy wanted to participate — but she would have to have a Huntington's diagnosis.

She asked neurologist Linda Lewis to tell her the truth. Did she have Huntington's? "Yes, Nancy, you do," Lewis said.

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