

NANCY WEXLER

Leonore Wexler's final years, like those of most people who suffer from Huntington's disease, were wretched. Her body writhed and jerked incessantly. When she sat in the chair beside her bed, her twitching legs and feet invariably worked her into the corner, where she repeatedly banged the back of her head against the wall. As the end approached, her slurred words became nearly impossible to make out.

"She had these huge, limpid brown eyes," Nancy Wexler recalls of her mother. "And they always looked so sad."

Nancy Wexler gazes out the window of her office in the New York State Psychiatric Institute on 168th Street in Manhattan, near Presbyterian Hospital. Her eyes, a soft blue, bespeak not sadness so much as a lifelong battle against it. Signs of that battle surround Wexler: high, white filing cabinets filled with 25 years of her genetic research; several white metal tables stacked with computer printouts and journal articles. On the floor, amid piles of paper, sit baskets of flowers and chocolates. They are gifts from friends and colleagues congratulating Wexler, who in October received an Albert Lasker Public Service Award — the highest honor in American medicine — for "her groundbreaking work ... toward finding a cure for Huntington's disease and for increasing awareness of all genetic disease."

"The Lasker Award is wonderful," Wexler says, smiling briefly. "But we still don't have a cure."

Huntington's disease, which afflicts some 30,000 Americans, is an inherited brain disorder that impairs nerve control and thinking. Victims suffer a quaking chorea that eventually leaves them unable to walk, stand or even speak intelligibly. The disease also brings disorientation, memory lapses (though sufferers maintain an excruciating awareness of their decline), severe depression and, after 10 to 20 years, death. Since 1872,

when a Long Island physician named George Huntington first described the disease, scientists have made enormous progress toward understanding it. Most of the advances have been made during the course of Wexler's career, and it is no exaggeration to say that she has played a part in all of them.

For 25 years, the clinical psychologist searched for the gene that causes Huntington's disease — and pondered the 50-50 odds that she has it herself.

BY MARY MURRAY

Notably, Wexler spearheaded the scientific effort that led, a year ago, to the discovery of the gene that causes Huntington's. In a style virtually unknown in the conduct of modern science, researchers at six laboratories in the

United States, England and Wales cooperated for 10 years to find the fatal culprit. Wexler, a clinical psychologist by training, organized the effort and aided it by collecting hundreds of blood samples from people with Huntington's in Venezuela, thereby providing the raw material the biologists needed for their search.

It is Wexler's personal familiarity with the disease, however, that has fostered her most lasting contributions. Because Huntington's is caused by a single, dominant gene, a child born to someone with Huntington's has a 50-50 chance of inheriting it; Wexler, now 48, is nearly the age her mother was when she was first told she had the disease. In response to her own uncertain fate, Wexler has become a leading expert on the traumas associated with genetic testing. Now that the location of the Huntington's gene is known, a blood test can accurately predict whether a member of an afflicted family — someone

