WHO WE ARE

Hereditary Disease Foundation
The Hereditary Disease Foundation (HDF) funds innovative research to cure Huntington’s disease (HD) and impact other brain disorders. Huntington’s disease is an inherited, neurodegenerative disease causing irreversible declines in control of mood, memory, and movement. Currently there is no cure. Since HD is caused by a single gene, it serves as a model to potentially unlock cures for other brain disorders such as Parkinson’s, Alzheimer’s and Lou Gehrig’s (ALS) diseases.

Our unique approach to searching for a cure began in 1968 when Dr. Milton Wexler established the Hereditary Disease Foundation after his wife Leonore was diagnosed with Huntington’s disease, which meant their daughters Alice and Nancy were also at risk.

From 1979 to 2002, Dr. Nancy Wexler, President of the Hereditary Disease Foundation, led an international medical team to Venezuela, which has the world’s highest prevalence of HD. These researchers worked with thousands of Huntington’s disease patients and their families collecting blood samples and gathering clinical data.

The Hereditary Disease Foundation creates a culture of creativity, excellence, collaboration, and a sense of community and shared purpose, which helps to attract generations of scientists to join and stay in the field.

Looking back at my 19 years of independent scientific career, it all started with my very first grant from the Foundation.

—X. William Yang, MD, PhD
David Geffen School of Medicine at UCLA
Their efforts ultimately created one of the largest family trees for any genetic disorder, comprised of more than 18,000 individuals over ten generations. In 1993, the Gene Hunters, a decade-long collaboration of over 100 international scientists formed and led by the Hereditary Disease Foundation, discovered the Huntington’s disease gene, a breakthrough that laid the foundation for all research on Huntington’s disease. Today, techniques such as gene silencing and gene editing are being studied and developed and several clinical trials in humans are currently underway.

Huntington’s Disease

Each child of a parent affected with Huntington’s disease has a 50% risk of inheriting the same lethal affliction. HD usually appears in the prime of life—age 30-50—but it can strike as early as 2 or as old as 80. It is invariably fatal over a 10-20 year, unremitting course. Individuals in the late stages of illness lose the ability to walk, talk and feed themselves, but are still aware of themselves and their families.
FUNDING GROUNDBREAKING RESEARCH

The Hereditary Disease Foundation provides funding for Postdoctoral Fellowships and Grants to researchers to advance the discovery and development of treatments for Huntington’s disease and other brain disorders. We are passionate about finding and funding the most promising, creative and paradigm-changing research.

Our **Scientific Advisory Board** is composed of over 30 distinguished scientists from around the world who set the scientific priorities for the Foundation. Each year the Board reviews over 100 grant and postdoctoral fellowship applications and selects the most groundbreaking research projects for funding.

**HDF Postdoctoral Fellowships** fund the work of young, promising scientists. These fellowships are intended to cultivate interest in Huntington’s disease research by encouraging scientists early in their careers. The Hereditary Disease Foundation awards two-year fellowships for up to $75,000 per year.

**HDF Grants** provide more experienced researchers with the seed funding to enable them to collect the preliminary data needed to obtain major, long-term funding from other organizations, including the National Institutes of Health. The Hereditary Disease Foundation awards one-year grants for $75,000.

FOSTERING INNOVATION AT WORKSHOPS AND SYMPOSIA

**Hereditary Disease Foundation Workshops** bring together small groups of scientists from different disciplines to brainstorm and explore new directions for research. Participants are urged to collaborate and share unpublished data and often come away from our Workshops with new ideas and the impetus to apply for HDF funding. Our Workshops have critically changed the paths of many scientific careers, capturing imaginations to study genes and the brain.

Every two years, the **Hereditary Disease Foundation’s Milton Wexler Symposium** brings together some 300 of the world’s foremost experts in HD and other neurological diseases. For three days, scientists share their latest discoveries and explore cutting-edge approaches to research, sparking discussions of new ways to design and create therapies. Our Symposia often lead to the formation of extraordinary partnerships in the quest to find treatments and cures for Huntington’s disease.

> Everything I know about genomics I learned first at Hereditary Disease Foundation workshops!

> —Francis Collins, MD, PhD
> Director, National Institutes of Health
Each year the Hereditary Disease Foundation presents a Huntington’s disease researcher with the prestigious **Leslie Gehry Brenner Prize for Innovation in Science**. This award was created by HDF Founding Director and world-renowned architect Frank Gehry and his family to honor the memory of his late daughter and her many talents – originality, spontaneity, precision and rigor – all critical attributes in a scientist.

**The Nancy S. Wexler Young Investigator Prize** is awarded annually to a Huntington’s disease researcher whose work reflects the highest caliber of excellence, diligence and creative thinking. This prize, established in 2020, honors the pioneering spirit, relentless dedication and enduring optimism of Nancy Wexler, Hereditary Disease Foundation President since 1983.

We are very excited that our lab recently received a $1,766,800 five-year grant from the National Institute of Neurological Disorders and Stroke, NIH. The goal of our grant is to investigate a new way to potentially treat Huntington’s disease.

We are especially grateful to the HDF for realizing the importance of our work. It was their funding that enabled us to collect the preliminary data necessary to obtain this multi-million dollar NIH grant.

—Matthew Scaglione, PhD
Duke University School of Medicine
INNOVATING RESEARCH
DISCOVERING CURES

The future of Huntington’s disease research is exciting, promising and hopeful. The cure for HD is on the horizon. Your support NOW will make a difference. Together we will conquer this disease.

WAYS TO DONATE

Online
www.hdfoundation.org

By check payable to
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601 West 168th Street, Suite 54
New York, NY 10032

Call
212.928.2121

Email
cures@hdfoundation.org

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