

## HD Research

HDSA supports the goals of clinical, translational and basic research aimed at developing treatments and, ultimately, a cure for HD by supporting leading research facilities globally. HDSA has committed tens of millions of dollars to fund research with the goal of finding effective treatments to pave the way to a world free of HD.

Each year, HDSA supports a wide range of research programs & services:

- Berman/Topper HD Career Development Fellowship
- HD Human Biology Project
- Donald A. King HD Research Fellowships
- HDSA Monthly Webinars
- HD News Mobile App
- HD TrialFinder Call Center & clinical trial search tool

The most critical component of HD research is clinical trial involvement. Without clinical trials there will be no treatments for HD. Please visit [www.HDTrialFinder.org](http://www.HDTrialFinder.org) for more info on HD clinical trials in your area.

## Advocacy

Through the work of our Advocacy program, HDSA has seen the passage of the Genetic Information Nondiscrimination Act (GINA) and added HD & JHD to the Social Security Administration's Compassionate Allowances List. The work of our ever-growing network of dedicated advocates includes supporting the Huntington's Disease Parity Act, a bill that will help people with HD access crucial Disability, Social Security & Medicare benefits.



**In the battle against Huntington's disease, no one fights alone. At HDSA, family is everything.**

### **Volunteer. Educate. Advocate. Donate.**

Your generous donation and your time will directly impact the lives of HD families. Join the fight against Huntington's disease in your community by visiting [www.hdsa.org](http://www.hdsa.org) or call (800) 345-HDSA.



505 Eighth Avenue, Suite 902, New York, NY 10018  
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## About HDSA

The Huntington's Disease Society of America is the premier not-for-profit organization dedicated to improving the lives of everyone affected by Huntington's disease.

From community services and education to advocacy and research, HDSA is the world's leader in providing *help for today, hope for tomorrow* for people with Huntington's disease and their families.

Across the United States, HDSA currently supports:

- 50+ Volunteer-led Chapters & Affiliates
- HD Research
- HDSA Centers of Excellence
- Social Workers
- Support Groups
- Education Programs
- Advocacy Efforts
- Extensive Community Education & Awareness through Team Hope Walks and more than 200 Special Events

HDSA was founded in 1967 by Marjorie Guthrie, the wife of legendary folk singer Woody Guthrie. Woody died from HD complications when he was only 55 years old, but the Guthrie family legacy lives on at HDSA to this day.



## What is Huntington's Disease?

Huntington's disease (HD) is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. HD deteriorates a person's physical and mental abilities during their prime working years and currently has no cure.

Many describe the symptoms of HD as having ALS, Parkinson's and Alzheimer's disease – **simultaneously**. Over time, HD affects the individual's ability to reason, walk and speak. Symptoms usually appear between the ages of 30 to 50, and worsen over a 10 to 25 year period. Ultimately, the weakened individual succumbs to pneumonia, heart failure or other complications.

The gene that leads to HD was identified by researchers in 1993. Every person who inherits the expanded HD gene will eventually develop the disease.

### Symptoms include:

- **Personality changes, mood swings & depression**
- **Forgetfulness & impaired judgment**
- **Unsteady gait & involuntary movements (chorea)**
- **Slurred speech, difficulty in swallowing & significant weight loss**

Nearly 10% of individuals with HD develop symptoms before the age of 20. Juvenile HD (JHD) typically progresses more rapidly than adult HD.

## The Quintessential Family Disease

Every child of a parent with HD has a 50/50 chance of carrying the faulty gene that causes HD. If the child has not inherited this expanded gene, he or she will never develop the disease and cannot pass it on to their children.

Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

## HD Care

Within a family, multiple generations may have inherited the disease. Those at-risk may experience tremendous stress from the uncertainty and sense of responsibility. Lack of knowledge about HD in a community may keep friends and neighbors from offering social and emotional support to the family, fostering unnecessary isolation.

HDSA has a nationwide network that provides support and referrals for individuals with HD and their families through support groups, educational programs and the signature HDSA Centers of Excellence which provide multidisciplinary HD care.

*Example of a family affected by Huntington's disease.*

