



# Huntington's Disease Society of America

**Family is** *everything.*

## About HDSA

The Huntington's Disease Society of America is the premier nonprofit 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.

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

## Mission Statement

To improve the lives of everyone affected by Huntington's disease and their families.

## Vision

A world free of Huntington's disease.

## What is Huntington's Disease?

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

Every child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes HD. Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

In approximately 10% of cases, Juvenile Huntington's disease (JHD) affects children or adolescents and JHD typically progresses more rapidly than adult onset HD.

The symptoms of HD are described as having ALS, Parkinson's and Alzheimer's diseases – ***simultaneously***.

## HDSA History

The Huntington's Disease Society of America (formerly known as the Committee to Combat Huntington's Disease) was founded on September 18, 1967 by Marjorie Guthrie, the wife of legendary folk singer Woody Guthrie. Woody died from HD complications on October 3, 1967 when he was only 55 years old, but the Guthrie family legacy lives on at HDSA to this day.

## HDSA Chapters & Affiliates

HDSA currently has 53 volunteer-led Chapters and Affiliates across the United States with its headquarters in New York City. Chapters and Affiliates support HDSA's mission by bringing community-based services, awareness and grassroots fundraising to strengthen resources to families affected by HD.

HDSA's signature fundraising campaign is the *Team Hope* walk program. Since its inception in 2007, *Team Hope* walks have occurred in more than 100 different cities and have raised more than \$10 million to improve the lives of people affected by HD. Additionally, nearly 300 annual fundraising and educational events raise millions of dollars across the country.

## HDSA Centers of Excellence

HDSA currently has 43 Centers of Excellence across the United States. The Centers of Excellence provide the team approach to Huntington's disease care and research. There you will find HD-experienced neurologists, psychiatrists, speech and swallowing specialists, occupational therapists, physical therapists, genetic counselors and other professionals to help you plan the best care program.



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## **HD Research**

In 1993, after a ten year search that involved collaboration among top HD researchers worldwide, the gene that causes HD was identified. Since 1999, the HDSA has committed more than \$20 million to fund research with the goal of finding effective treatments to slow Huntington's disease. Our past research efforts have also helped increase the number of scientists working on HD and have shed light on many of the complex biological mechanisms involved in HD.

HDSA's research strategy is a patient-centric approach. Our largest research program, called the HD Human Biology Project, was launched in 2013 with the goal to foster innovative research at clinical centers like the HDSA Centers of Excellence to better understand the biology of Huntington's disease as it occurs in humans. We know that the most relevant scientific observations that will guide the research community in the hunt for effective therapies for HD will be those involving HD patients.

## **HDSA Social Workers & Support Groups**

HDSA currently has 68 Social Workers & more than 160 support groups across the United States working to provide vital support to HD families. HDSA Social Workers assist families with navigating HD by providing information, referrals and helping to start and maintain support groups.

## **HDSA Education**

HDSA takes pride in being the premier organization dedicated to providing the most up-to-date and accurate information about Huntington's disease. Through HDSA produced publications, online news updates and family stories, HDSA is the world's leader in HD support and education.

## **HDSA Advocacy**

HDSA advocates have successfully advanced legislation and policy to improve the lives of HD families, including passage of GINA (Genetic Information Nondiscrimination Act) and the addition of Adult Onset HD and Juvenile Onset HD to the Social Security Administration's Compassionate Allowances List. These successes would not have been possible without the continued involvement of dedicated individuals in the HD community.

Today, HDSA is currently working to pass the Huntington's Disease Parity Act (H.R. 842/S. 968) which will improve access to Social Security Disability benefits and Medicare coverage for individuals with Huntington's disease.

## **HDSA National Youth Alliance**

The HDSA National Youth Alliance (NYA) provides a support network for youth coping with Huntington's disease in their lives. This youth empowered community educates, engages and inspires young people and their families to face HD and Juvenile HD with strength and hope.

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

**HDSA.org**

**(800)345-HDSA**