



# Huntington's Disease Society of America

## WHAT IS HUNTINGTON'S DISEASE?

Huntington's disease (HD) is a 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 is ultimately fatal. HD manifests as a triad of motor, cognitive, and psychiatric symptoms, which progressively get worse over time.

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

Every child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes the disease. Today, there are approximately 41,000 symptomatic Americans, or those that show signs of having HD. 200,000 people in the United States are at-risk of inheriting HD. In less than 10% of cases, juvenile Huntington's disease (JHD) affects children & adolescents.

There is no cure for HD.

## 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!*

HDSA 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. For more info visit [www.HDSA.org](http://www.HDSA.org)

## 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 2007, *Team Hope* walks have been held in more than 100 cities, raising more than \$22 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. To learn more, visit: [www.HDSA.org/inmycommunity](http://www.HDSA.org/inmycommunity).

## HDSA CENTERS OF EXCELLENCE

There are 54 HDSA Centers of Excellence across the United States with 8 satellite sites. The Centers of Excellence provide the team approach to HD care and research. At HDSA Centers of Excellence 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. To learn more, visit: [www.HDSA.org/COE](http://www.HDSA.org/COE)



## **HDSA 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, HDSA has committed more than \$25 million to fund research with the goal of finding effective treatments to slow HD. Our 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.

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 and their families. To learn more, visit: [www.HDSA.org/research](http://www.HDSA.org/research)

## **SOCIAL WORKERS & SUPPORT GROUPS**

HDSA currently has more than 70 social workers & more than 100 support groups across the United States working to provide vital support to HD families. HDSA Social Workers help families by providing information, referrals and the creation of support groups. HDSA offers FREE programs such as online support groups and telehealth services. To learn more, visit: [www.HDSA.org/support](http://www.HDSA.org/support)

## **HDSA EDUCATION**

HDSA is dedicated to providing the most up-to-date and accurate information about HD to the community and general public. Through print publications, online news updates and family stories, HDSA raises awareness of HD and keeps the community informed. Through in-person educational sessions at local chapter events and annual convention, HDSA provides quality educational programming. HDSA is a leader in HD support and education. To learn more, visit: [www.HDSA.org/support](http://www.HDSA.org/support)

## **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 working to pass the Huntington's Disease Parity Act which would waive the two-year Medicare waiting period for those with HD. To learn more, visit: [www.HDSA.org/takeaction](http://www.HDSA.org/takeaction)

## **HDSA NATIONAL YOUTH ALLIANCE**

HDSA's National Youth Alliance (NYA) is a network of children, teens and young adults between the ages of 9-29 who are impacted by HD from across the United States. NYA's mission is to improve the lives of young people affected by HD. Whether you are at-risk, gene positive, gene negative, impacted by JHD or you love someone who has HD, the NYA is here to be your *Ohana* (family). Year after year, NYA continues to support youth impacted by HD through local services, year-round programming and building life-changing relationships for the better, forever. To learn more, visit: [www.HDSA.org/NYA](http://www.HDSA.org/NYA)