



Huntington's Disease Society of America

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.

For more info visit www.HDSA.org.

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 Huntington's disease. Today, there are approximately 30,000 symptomatic Americans and 200,000 at-risk of inheriting the disease. In less than 10% of cases, juvenile Huntington's disease (JHD) affects children & adolescents.

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

HDSA History

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.

HDSA Chapters & Affiliates

HDSA currently has 54 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 \$18 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

The HDSA Centers of Excellence provide an elite team approach to Huntington's disease care and research. The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to bringing comprehensive care. Patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have extensive experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease. Applications to become an HDSA Center of Excellence are open to all HD clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research.

The 2019 HDSA Centers of Excellence program expanded to 47 Centers from 43 last year. Since 2015, the program has more than doubled! With the continued growth of the program, HDSA is bringing more 'boots on the ground' to support HD affected families across the United States with care locations in 31 States plus the District of Columbia. In addition, six Centers have partner sites to expand care in Oregon, California, Tennessee, Mississippi and Alabama.

For more info visit www.HDSA.org/COE.



HDSA Social Workers & Support Groups

HDSA currently has more than 70 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 offers FREE programs such as online support groups sponsored by Genentech and telehealth sponsored by Teva. For more info visit www.HDSA.org/support.

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 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, the HD Human Biology Project, was launched in 2013 with the goal to foster innovative research at clinical centers, like HDSA's 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. For more info visit HDSA.org/research.

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, comprehensive network, 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. 2770/S. 1476) which will improve access to Social Security Disability benefits and Medicare coverage for individuals with Huntington's disease. For more info visit www.HDSA.org/takeaction.

HDSA National Youth Alliance

HDSA's National Youth Alliance is a network of children, teens and young adults between the ages of 9-29 who are impacted by Huntington's disease from across the United States founded on the vision of becoming the last generation with 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).

The NYA motivates members to become a part of their local HDSA Chapters, Affiliates and support groups in an effort to integrate youth into the fight against HD. The NYA strives to make sure youth have information, education and support they need to manage their lives with HD. The NYA prides itself on their ability to meet the ever changing needs of the youth community. Year after year, they continue their mission to support youth impacted by HD through local services, year-round programming, and building life-changing relationships for the better, forever.

The NYA has built programs to support young people impacted by HD year-round. The NYA ensures that young people can find support in-person and virtually. Our stable of programs continues becomes stronger every year, making sure young people have the support and resources they need. For more info visit www.HDSA.org/NYA.