

Fast Facts About HD

These pages are intended as a helpful and brief reference guide to introduce HD to people who may never have heard of the disease and who want information about the disease. You can print out Fast Facts About HD and use it when you are asked to describe what HD is about and what HDSA is doing to "Make this the Last Generation with HD."

Disclaimer

The Huntington's Disease Society of America, does not promote, endorse, or recommend any treatment or therapy that may be mentioned herein. The reader should consult a physician or other appropriate healthcare professional for appropriate advice, treatment or therapy.

What is Huntington's Disease?

Huntington's Disease (HD) is an inherited, progressively degenerative brain disorder that results in a loss of both mental faculties and physical control. Symptoms usually appear in an individual between 30 to 50 years of age and progress over a 10 to 25 year period. HD affects the individual's ability to think, speak and walk. Ultimately, the weakened individual succumbs to pneumonia, heart failure or other complications. Presently, there is no effective treatment or cure. Although medications can relieve some symptoms in certain individuals, research has yet to find a means of conquering or even slowing the deadly progression of HD.

Every person who inherits the HD gene will eventually develop the disease.

Symptoms

- Depression, personality changes, and mood swings
- Forgetfulness, and impaired judgment
- Unsteady gait and involuntary movements
- Slurred speech or intoxicated demeanor
- Difficulty in swallowing

Who is At-Risk?

Approximately 30,000 Americans have HD and over 200,000 more are at-risk of inheriting it from a parent. Once thought of as a rare disease, HD is now considered to be one of the more common hereditary diseases.

*HD does not skip generations;
if one does not inherit the gene,
one cannot pass it on.*

The Scope of HD

Current estimates are that 1 in every 10,000 people in the U.S. have HD, but the devastating effects of this disease touch many more. Huntington's Disease creates a ripple effect throughout families and their communities. Within the family, multiple generations may have inherited the disease, thus overwhelming family resources. Within

the community, lack of information about the disease can isolate members of HD families and/or impact their medical care.

The presence of Huntington's Disease affects decisions about careers, marriage and having children.

The emotional, social and economic challenge to everyone involved, whether they have the disease or not, cannot be underestimated.

Effective support and services can improve the quality of life for all those touched by HD. The Huntington's Disease Society of America (HDSA) provides family services and regional referrals through its nationwide network of volunteer-based chapters and through its HDSA Centers of Excellence that assist families in managing the challenges of HD, as well as providing vital information about care, financial planning and legal issues.

Each child of a parent with HD has a 50/50 chance of inheriting the gene.

An End to HD?

The outlook for solving the puzzle of Huntington's Disease is promising. In 1993, researchers were finally able to identify the gene that causes HD. Momentum in HD research continues to increase our understanding about the Huntington's gene and how it functions. Current research projects or those in development could provide the next major discovery at any time.

The Huntington's Disease Society of America (HDSA) funds both clinical and basic research at leading hospitals and research facilities through the HDSA Coalition for the Cure, the HDSA Grants and Fellowships program and through our HDSA Centers of Excellence for Family Services. With your help, our continued commitment to research funding *will* solve the puzzle of HD.

Genetic Testing for HD

The 1993 discovery of the gene that causes Huntington's made possible a new predictive test. Those "at-risk" for HD can now find out whether they carry the gene before symptoms arise. Decisions can be made about careers, childbearing and other long-term issues. But because there are few therapeutic options that are effective in combating HD, not every "at-risk" individual for this disease will choose to have the test performed.

The Test

A predictive genetic test allows those "at-risk" to learn whether they carry the HD gene. If the gene is not present, the person will not develop HD and cannot pass it on to any of their children.

The new test requires only a blood sample from the individual being tested. Some testing centers may request a parent's blood sample for confirmation.

Pre-test and post-test counseling is part of the procedure.
Testing should take place at specialized HD testing centers.

HD affects both sexes and all races and ethnic groups around the world.

Where to Find Help

The Huntington's Disease Society of America has a nationwide network of chapters, affiliates, support groups and the HDSA Centers of Excellence for Family Services that provide support and referrals as well as state of the art regional care for individuals with HD and their families. To locate an HDSA chapter, affiliate or Center of Excellence near you, please contact HDSA by calling (800) 345-HDSA or visit our web site at <http://www.hdsa.org/>

What is the Huntington's Disease Society of America?

The Huntington's Disease Society of America (HDSA) is a national voluntary non-profit organization dedicated to finding a cure for Huntington's Disease while providing support and services for those patients and families, caregivers and medical professionals who are living with HD. Founded in 1967, HDSA promotes and supports both basic and clinical HD research, aids families throughout the continuum of HD and educates families, the public and healthcare professionals about this devastating disease.

HDSA's Programs

Research - Funding of both basic and clinical research into the causes and treatment of HD and ultimately, a cure.

Patient and Family Services - A national network of services and referrals for HD families through local HDSA chapters, affiliates, support groups, social workers and the HDSA Centers of Excellence.

Education - Dissemination of information and ways and materials to educate the public, HD families and allied healthcare professionals.

How You Can Help...

Be a part of HDSA's mission. Help us work towards ending HD by our funding research, providing support systems, care and treatment options for those who must face the disease daily and enabling us to spread information about HD. Both funds and volunteers are needed. Contact HDSA's National Office for ways you can make a difference in the fight against HD. Call us at (800) 345-HDSA (4372) or by visit our web site at <http://www.hdsa.org/>.