Huntington’s Disease Society of America

HDSA Legislation Fact Sheet: 119th Congress

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. It deteriorates a person’s physical and mental abilities, usually during their prime working years. HD is characterized by a triad of symptoms, including progressive motor dysfunction, behavioral disturbance, and cognitive decline. No therapies exist to slow or stop the progression of HD, or to extend expected lifespan. If one parent has HD, their children have a 50 percent chance of inheriting HD. If both parents have HD, that chance is 100 percent.

HD usually strikes during an individual’s 30s or 40s, an age that is typically characterized by high productivity in the workplace and at home. Persons with HD lose the ability to work and drive relatively early in the disease course. They become unable to perform domestic and childcare activities, and their normal roles must be assumed by other family members. The generational impact of HD means families experience an outsized financial burden as they care for their loved one living with HD.

About Huntington’s Disease Society of America

The **Huntington’s Disease Society of America (HDSA)** is a leading national organization dedicated to the care and cure of Huntington’s disease. HDSA supports continued research to better understand HD, as well as improve access to quality treatment by financially supporting **57 HDSA Centers of Excellence and 11 Clinical Partner Sites covering 36 states plus the District of Columbia.** HDSA has a long history of supporting people living with HD and family members through a network of **50 Chapters** and **Affiliates** that provide access to locally-based social workers and support group meetings.

Legislation That Will Make a Difference

Lawmakers should consider that HD burdens not only the patient in mid-life, but generations of families who are robbed of their ability to work, parent, and function due to complex symptoms or the challenges of caregiving. The legislation listed below supports equitable access to health care and generational wealth to patients and families affected by this incurable multigenerational disease.

Innovation in Development of Therapies	• **Ensuring Pathways to Innovative Cures EPIC Act (S.832/H.R. 1492)**
Access to Quality Healthcare	• **Alleviating Barriers for Caregivers Act (S. 1227/H.R. 2491)** • **Telehealth Coverage Act (H.R. 2263)** • **Expanded Telehealth Access Act (H.R. 1614)**
Access to Medication and Medical Devices	• **Providing Realistic Opportunity to Equal and Comparable Treatment for RARE Act** • **HELP Copays Act (S. 864)** • **Safe Step Act**
Support Families Financial Health	• **SSI Savings Penalty Elimination Act (S. 1234/H.R. 2540)** • **Credit for Caring Act (S. 925/H.R. 2036)**