

HD Advocate Talking Points

About Huntington's Disease

- HD is a degenerative brain disorder caused by a defective gene that slowly diminishes the affected individual's ability to walk, talk and reason. Everyone who carries the gene will develop the disease.
- One in every 10,000 Americans has HD and another 200,000 are at risk of inheriting the deadly gene.
- Each child born to a person who carries the defective gene has a 50/50 chance of inheriting the gene.
- HD typically begins in mid-life between the ages of 30-50, although onset may occur as early as infancy.
- Early symptoms include depression, mood swings, forgetfulness, clumsiness, involuntary twitching and lack of coordination, while in later stages independent living becomes impossible for the affected person.
- At present there is no effective treatment or cure. However, HDSA-funded researchers have made significant strides in understanding the disease.

About HDSA

- HDSA was founded in 1967 by Marjorie Guthrie, widow of legendary folksinger Woody Guthrie who succumbed to complications associated with HD at the age of 55.
- HDSA funds both basic and clinical research while providing education and support services to those affected by HD and their families.
- HDSA provides a national network of medical and social services that are provided through HDSA Centers of Excellence, HDSA chapters, affiliates and support groups.

Huntington's Disease and Disability

- People with HD applying for Social Security benefits often experience multiple delays and unnecessary denials due to a general unfamiliarity with HD on the part of Social Security case workers and physicians.
- The Social Security Administration (SSA) has not comprehensively revised the neurological disease listings used by these SSA officials to determine disability since 1985.
- The current listing for HD does not accurately reflect the complexity of the disease, most notably HD's triad of cognitive, psychiatric and physical impairments.
- Because of its incapacitating nature, and given the relatively young age of onset, people with HD are frequently unable to stay employed, including those in the early stages of the disease. As a result, many people with HD must rely solely on Social Security Disability Income.
- By the time many people with HD navigate their way through the disability application process, they, as well as their families in many cases, have lost their employer-provided health insurance benefits. Due to the age of onset, people with HD do not qualify for Medicare and often receive insufficient treatment during the early stages of the disease.
- Eliminating the 24 month Medicare Disability waiting period would allow HD patients access to crucial care early on.
- In 2000, the Centers for Medicaid and Medicare Services waived the 24 month waiting period requirement for people disabled by ALS (amyotrophic lateral sclerosis), a degenerative neurological condition similar to HD.

Summary

- Legislative Goals: HDSA and its many advocates in every state actively support **H.R. 678**, *The Huntington's Disease Parity Act of 2009*, which would revise the medical criteria used by the SSA for evaluating disability caused by HD and eliminate the 2 year waiting period for Medicare benefits once HD applicants are approved for disability benefits.
- We would appreciate the support of this Congress Member in co-sponsoring this legislation.