Huntington’s Disease Parity Act Of 2015 (H.R. 842)
Fact Sheet

What is Huntington’s disease?
Huntington’s disease (HD) is a rare, fatal, genetic neurodegenerative disease that progressively causes total physical and mental deterioration during an individual’s prime working years. Every individual with HD will ultimately lose the ability to live independently and become totally dependent on others. Today, 30,000 Americans are known to have HD, and another 200,000-250,000 children of an affected parent are at risk of inheriting the deadly disease.

The Safety Net is Broken for Individuals with HD
The Social Security Disability and Medicare systems continue to fail individuals with HD, causing delays in access to care and significant hardship on individuals with HD and their families.

SSA’s Use of Outdated Disability Guidelines
- People with HD applying for Social Security Disability (SSD) are routinely denied and experience long delays due to the Social Security Administration’s use of outdated, medically inaccurate guidelines which were written over 30-years ago and only take into account the physical impairments of HD.
- The SSD guidelines ignore the debilitating cognitive and behavioral effects of HD – which occur years before the physical manifestations of the disease – often leading to loss of employment, healthcare benefits, and the financial resources to access necessary care.
- As a result, SSA’s outdated guidelines cause individuals with HD who are legitimately unable to work to experience long delays and multiple denials of critical SSD benefits until years after HD has cause them to be disabled.

Lack of Access to Necessary Health Care
- Even after they finally qualify for SSD, individuals with HD must then wait two years to qualify for Medicare coverage, further delaying the care they require.
- We know that access to early medical intervention is imperative in the treatment of individuals with HD. While we cannot stop or slow the disease down, access to consistent care beginning in the early stages of the disease helps control the individual's progressive decline – providing dignity and independence for a much greater period of time.
- Left untreated, an individual with HD is likely to develop additional complex medical conditions, necessitate more expensive medical interventions, and ultimately spend a significantly longer time in a full-time nursing facility.

Pass the HD Parity Act (H.R. 842)
- Direct the Commissioner of SSA to revise its outdated medical and evaluation criteria for determining disability, thus enabling individuals with HD to receive the essential disability benefits that they are often denied.
- Waive the Medicare two-year waiting period, thereby ensuring individuals receive critical health benefits and care in the early stages of the disease – ensuring dignity and independence to individuals with HD, their families, and providing long-term financial security to our health care safety net.

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