

Myth vs. Fact: “The Huntington’s Disease Parity Act of 2009”

- Myth** *Congress does not favor ‘disease specific legislation.’ Eliminating the two year waiting period for a specific disease (HD) will open the door for requests for other diseases.*
- Fact** **Denying Social Security disability and Medicare benefits to people living with HD are particularly and patently unfair. Targeted legislation is necessary.**

There are only two disease specific bills in the 111th Congress that waive the Medicare two year waiting period. Huntington’s Disease (HD) is a rare and fatal disease with early onset cognitive impairments that often severely impact individuals in their working years, when disability is most important. The Social Security Administration’s (SSA’s) guidelines for defining HD are 30 years out of date resulting in wrongful denials to people with HD. To date only two waivers have been granted to disease specific groups with small populations like HD.

- Myth** *H.R. 1708/ S. 700 eliminates the two year waiting period for all diseases. Therefore, H.R. 678, “The Huntington’s Disease Parity Act” is not necessary.*

- Fact** **Rather than accepting a stalemate, Congress should start somewhere.**

HDSA supports H.R. 1708/S. 700, legislation to eliminate the two year waiting period for ALL diseases. However, this legislation was not included in health care reform or in any other moving legislation in Congress in the last 10 years. According to the Congressional Budget Office (CBO), eliminating the waiting period for all disease will cost the federal government \$104 billion over 10 years. Given this extremely high cost, it remains highly unlikely that this all encompassing legislation will become law this Congress. Congress should begin this movement with H.R. 678, “The HD Parity Act.”

- Myth** *H.R. 678, “The HD Parity Act,” costs too much.*

- Fact** **The cost to eliminate the two year waiting period for individuals living with HD is minimal, ranging from \$21 million to \$26 million annually. Not acting, costs more.**

Providing health insurance to those in the waiting period may actually *reduce* Medicare spending over the long term. People with HD often lose their jobs and employer-provided coverage forcing many to forego critical medical treatments, further compromising their health during the early stages of the disease. As a result, people with HD are often forced onto Medicaid and are sicker when they finally receive Medicare benefits.

- Myth** *Changes to SSA disability can be made through SSA regulations and Congress does not need to take action.*

- Fact** **People with HD cannot wait any longer for SSA to establish proper criteria or for Congress to remove the waiting period for all.**

SSA’s guidelines are 30 years out of date and HDSA has been working with SSA for more than 5 years to simply update the criteria, without success. H.R. 678 includes medically accurate criteria that people with HD need now. Without Congress’s support, those who are disabled and entitled to help will continue to wait unnecessarily. Further, while the President’s proposed 2010 budget includes \$12.5 billion in SSA funding, this is not nearly enough reduce SSA backlog and does not direct SSA to correct HD criteria.