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House of Representatives

IMPROVING ACCESS TO BENEFITS FOR PEOPLE WITH HUNTINGTON'S DISEASE!

HON. BOB FILNER

OF CALIFORNIA
IN THE HOUSE OF
REPRESENTATIVES

Mr. Speaker, I recently introduced H.R. 718, the Huntington's Disease Parity Act of 2011, which would direct the Social Security Administration (SSA) to revise outdated, medically inaccurate criteria for determining Social Security Disability and waive the Medicare two-year waiting period for people disabled by Huntington's Disease (HD).

HD is a devastating, hereditary degenerative brain disorder that causes total physical and mental deterioration. Eventually, every person affected by HD becomes completely dependent on others for care. Today, 30,000 Americans are known to have HD and an additional 200,000 have a fifty percent chance of inheriting the disease from an affected parent. The debilitating symptoms make it challenging, if not impossible, for the person with HD to remain employed, resulting in a loss of income and employer-sponsored health insurance benefits.

REVISE OUTDATED CRITERIA TO IMPROVE ACCESS TO DISABILITY BENEFITS

Due to the SSA's dependence on outdated medical guidelines, individuals experience long delays and multiple denials of critical Social Security benefits, forcing patients to wait years for benefits while HD's destructive cognitive, behavioral and physical symptoms rob the person of their ability to work and live independently. The HD Parity Act directs the Commissioner of SSA, in collaboration with the National Institutes of Health and HD experts, to update the agency's guidelines.

ELIMINATE MEDICARE WAITING PERIOD RATHER THAN ACCEPTING IMPASSE

Access to critical health care is often denied in the early stages of disease due to an individual's inability to work, thereby causing the loss of their employer-based insurance. During the required Medicare two year waiting period, individuals with HD see their physical and mental health deteriorate rapidly necessitating more costly care later.

Passing the Huntington's Disease Parity Act of 2011 will direct the SSA to revise the medically inaccurate criteria used to determine Social Security Disability and eliminate the Medicare two-year waiting period. These two critical reforms will directly impact the welfare and lives of individuals and their families impacted by this rare and devastating disease.