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House of Representatives

OBTAINING DISABILITY BENEFITS FOR THOSE WITH HUNTINGTON'S DISEASE!

HON. BOB FILNER

OF CALIFORNIA
IN THE HOUSE OF
REPRESENTATIVES

Mr. FILNER. Madam Speaker, I have introduced the Huntington's Disease Parity Act of 2009 (H.R. 678). The purpose of this bill is to improve Social Security Disability Benefits and Medicare coverage for people affected by Huntington's Disease.

Huntington's Disease (HD), is a genetic neurodegenerative disease (like Alzheimer's) that causes total physical and mental deterioration over a 10 to 25 year period. Eventually, every person diagnosed with HD will lose the ability to live independently. It is a rare disease, affecting 30,000 Americans, while another 200,000 are considered "at risk" of inheriting it from an affected parent.

Many people with HD who apply for Social Security disability benefits experience delays and denials due to the continued use of outdated and insufficient medical criteria. Often, by the time persons affected by HD are "under

review" for SSA disability, many have already lost their employer-provided health insurance benefits. This legislation would address this problem by directing the Social Security Administration to revise its medical criteria for determining disability for people with HD.

The legislation would also remove the two-year waiting period for people living with HD to receive Medicare benefits after receiving Social Security disability benefits. Eliminating this waiting period will ensure individuals will get crucial care they need in the early stages of the disease. In 2000, the Centers for Medicaid and Medicare Services waived this waiting period requirement for people disabled by ALS (Amyotrophic Lateral Sclerosis or Lou Gehrig's disease), another degenerative neurological condition similar to HD.