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111TH CONGRESS
1ST SESSION

H. R. 678

To require the Commissioner of Social Security to revise the medical criteria for evaluating disability in a person diagnosed with Huntington's Disease and to waive the 24-month waiting period for Medicare eligibility for individuals disabled by Huntington's Disease.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 26, 2009

Mr. FILNER introduced the following bill; which was referred to the Committee on Ways and Means

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A BILL

To require the Commissioner of Social Security to revise the medical criteria for evaluating disability in a person diagnosed with Huntington's Disease and to waive the 24-month waiting period for Medicare eligibility for individuals disabled by Huntington's Disease.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Huntington's Disease Parity Act of 2009''.

SEC. 2. FINDINGS.

Congress makes the following findings:

(1) Huntington's Disease is a progressive degenerative neurological disease that causes total physical and mental deterioration over a 12 to 15 year period. It affects 30,000 patients and 200,000 individuals are genetically ''at risk'' in the United States.

(2) Huntington's Disease has a triad of clinical features, including motor abnormalities, dementia, and disorders of mood and perception. While movement disorders are most commonly associated with Huntington's Disease, early symptoms are often emotional and psychiatric. This may include personality changes, irritability, mood swings, depression, obsessive-compulsive behavior, inability to concentrate, and decreased motivation.

(3) Because of its incapacitating nature, people with Huntington's disease, including those in the early stages of the disease, are unable to retain employment. As a result, many people with Huntington's Disease rely solely on Social Security Disability Income.

(4) Despite significant advances in medicine and greater understanding of disability, the Social Security Administration has not comprehensively re-

vised its rules for the medical evaluation of neurological disabilities since 1985.

(5) Because people with Huntington's Disease are frequently not employed, many families have lost their employer-provided health insurance benefits. As a result, many people with Huntington's Disease do not receive necessary treatment during the early stages of the disease.

(6) In 2000, the Centers for Medicaid & Medicare Services waived the 24-month waiting period requirement for people disabled by ALS (amyotropic lateral sclerosis), a degenerative neurological condition similar to Huntington's Disease.

SEC. 3. REVISION OF THE MEDICAL CRITERIA FOR EVALUATING DISABILITY CAUSED BY ADULT-ONSET HUNTINGTON'S DISEASE.

The Commissioner of Social Security shall revise the regulations prescribed by the Commissioner set forth as appendix 1 to subpart P of part 404 of title 20 of the Code of Federal Regulations (relating to the listing of impairments, published by the Social Security Administration as ''Disability Evaluation Under Social Security'', and commonly referred to as the ''Blue Book''), as follows:

(1) The Commissioner shall insert after 11.00G the following:

''H. Huntington's Disease. Huntington's Disease is an inherited neuropsychiatric disorder that is progressive and terminates in death of the affected person. Recovery or remission never occurs. Treatment is ineffective in terms of halting or slowing the progression of the disease. The usual age of adult onset is between the ages of 30 and 50, although the age of adult onset may be younger or older. Incapacitation occurs relatively early in the course of this debilitating illness with progression to total disability and dependency for all activities of daily living. There are three characteristic clinical features: (1) loss of ability to control bodily movements; (2) loss of ability to think and act quickly, to learn new material and to remember, and (3) apathy, personality changes, irritability, mood swings, depression, anxiety, inability to concentrate, decreased motivation, obsessive-compulsive disorder, and severe depression. Individuals with Huntington's Disease also exhibit poor social judgment and may be irritable and aggressive. Inability to work is due to a combination of cognitive disturbance, behavioral or mood changes, poor coordination of voluntary movements, and the presence of involuntary movements. Individuals with Huntington's Disease, even in the relatively early stages, have particular difficulty with decision-making, multi-tasking, and performing under time pressure or with the stress of inter-

personal interactions. The course of the disease varies among individuals and families. The cognitive and behavioral problems may become debilitating before disorganization of motor functions. For other individuals, the motor dysfunction may appear first.''.

(2) The Commissioner shall insert after 11.14 the following:

''11.15 Huntington's Disease. With:

''A. disorganization of motor function as described in 11.04B; or

''B. chronic brain syndrome. Evaluate under 12.02, 12.04, and 12.06.''.

(3) The Commissioner shall remove the reference in 11.17 to ''Huntington's Chorea''.

SEC. 4. REVISION OF THE MEDICAL CRITERIA FOR EVALUATING DISABILITY CAUSED BY JUVENILE HUNTINGTON'S DISEASE.

The Commissioner of Social Security shall revise further the regulations described in section 3 as follows:

(1) The Commissioner shall insert after 111.00E the following:

''F. Juvenile Huntington's Disease. While there is no symptom or group of symptoms that are absolutely required for the diagnosis of juvenile Huntington's Disease, most affected children offer several of the following fea-

tures at the time that the diagnosis is made: motor dysfunction, characterized by rigidity and dystonia, seizures, declining cognitive function, behavioral or psychiatric problems such as depression, aggressiveness and impulsiveness, irritability, mood swings, and obsessions. Huntington's Disease is a hereditary disorder and individuals with very early onset of Huntington's Disease are far more likely to have an affected father than an affected mother.''.

(2) The Commissioner shall insert after 111.09 the following:

''111.10. Junvenile Huntington's Disease. With:

''A. Motor dysfunction. Evaluate under 111.06; or

''B. Behavioral or psychiatric problems. Evaluate under 112.02, 112.06, and 112.08.''.

SEC. 5. ELIMINATION OF 24-MONTH MEDICARE DISABILITY WAITING PERIOD IN CASES OF INDIVIDUALS WITH DISABLING HUNTINGTON'S DISEASE.

(a) IN GENERAL.—Section 226(h) of the Social Security Act (42 U.S.C. 426(h)) is amended, in the matter preceding paragraph (1), by inserting ''or Huntington's Disease'' after ''amyotrophic lateral sclerosis (ALS)''.

(b) EFFECTIVE DATE.—The amendment made by subsection (a) shall apply to benefits under title XVIII of

the Social Security Act with respect to items and services furnished in months beginning after the date of the enactment of this Act.

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