

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.

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## 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.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       This Act may be cited as the “Huntington’s Disease  
5       Parity Act of 2009”.

6       **SEC. 2. FINDINGS.**

7       Congress makes the following findings:

1           (1) Huntington’s Disease is a progressive de-  
2           generative neurological disease that causes total  
3           physical and mental deterioration over a 12 to 15  
4           year period. It affects 30,000 patients and 200,000  
5           individuals are genetically “at risk” in the United  
6           States.

7           (2) Huntington’s Disease has a triad of clinical  
8           features, including motor abnormalities, dementia,  
9           and disorders of mood and perception. While move-  
10          ment disorders are most commonly associated with  
11          Huntington’s Disease, early symptoms are often  
12          emotional and psychiatric. This may include person-  
13          ality changes, irritability, mood swings, depression,  
14          obsessive-compulsive behavior, inability to con-  
15          centrate, and decreased motivation.

16          (3) Because of its incapacitating nature, people  
17          with Huntington’s disease, including those in the  
18          early stages of the disease, are unable to retain em-  
19          ployment. As a result, many people with Hunting-  
20          ton’s Disease rely solely on Social Security Disability  
21          Income.

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

1       vised its rules for the medical evaluation of neuro-  
2       logical disabilities since 1985.

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

9           (6) In 2000, the Centers for Medicaid & Medi-  
10      care Services waived the 24-month waiting period re-  
11      quirement for people disabled by ALS (amyotropic  
12      lateral sclerosis), a degenerative neurological condi-  
13      tion similar to Huntington’s Disease.

14   **SEC. 3. REVISION OF THE MEDICAL CRITERIA FOR EVALU-**  
15                           **ATING DISABILITY CAUSED BY ADULT-ONSET**  
16                           **HUNTINGTON’S DISEASE.**

17       The Commissioner of Social Security shall revise the  
18      regulations prescribed by the Commissioner set forth as  
19      appendix 1 to subpart P of part 404 of title 20 of the  
20      Code of Federal Regulations (relating to the listing of im-  
21      pairments, published by the Social Security Administra-  
22      tion as “Disability Evaluation Under Social Security”,  
23      and commonly referred to as the “Blue Book”), as follows:

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

1 “H. Huntington’s Disease. Huntington’s Disease is an in-  
2 herited neuropsychiatric disorder that is progressive and  
3 terminates in death of the affected person. Recovery or  
4 remission never occurs. Treatment is ineffective in terms  
5 of halting or slowing the progression of the disease. The  
6 usual age of adult onset is between the ages of 30 and  
7 50, although the age of adult onset may be younger or  
8 older. Incapacitation occurs relatively early in the course  
9 of this debilitating illness with progression to total dis-  
10 ability and dependency for all activities of daily living.  
11 There are three characteristic clinical features: (1) loss of  
12 ability to control bodily movements; (2) loss of ability to  
13 think and act quickly, to learn new material and to re-  
14 member, and (3) apathy, personality changes, irritability,  
15 mood swings, depression, anxiety, inability to concentrate,  
16 decreased motivation, obsessive-compulsive disorder, and  
17 severe depression. Individuals with Huntington’s Disease  
18 also exhibit poor social judgment and may be irritable and  
19 aggressive. Inability to work is due to a combination of  
20 cognitive disturbance, behavioral or mood changes, poor  
21 coordination of voluntary movements, and the presence of  
22 involuntary movements. Individuals with Huntington’s  
23 Disease, even in the relatively early stages, have particular  
24 difficulty with decision-making, multi-tasking, and per-  
25 forming under time pressure or with the stress of inter-

1 personal interactions. The course of the disease varies  
 2 among individuals and families. The cognitive and behav-  
 3 ioral problems may become debilitating before disorganiza-  
 4 tion of motor functions. For other individuals, the motor  
 5 dysfunction may appear first.”.

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

8 “11.15 Huntington’s Disease. With:

9 “A. disorganization of motor function as de-  
 10 scribed in 11.04B; or

11 “B. chronic brain syndrome. Evaluate under  
 12 12.02, 12.04, and 12.06.”.

13 (3) The Commissioner shall remove the ref-  
 14 erence in 11.17 to “Huntington’s Chorea”.

15 **SEC. 4. REVISION OF THE MEDICAL CRITERIA FOR EVALU-**  
 16 **ATING DISABILITY CAUSED BY JUVENILE**  
 17 **HUNTINGTON’S DISEASE.**

18 The Commissioner of Social Security shall revise fur-  
 19 ther the regulations described in section 3 as follows:

20 (1) The Commissioner shall insert after  
 21 111.00E the following:

22 “F. Juvenile Huntington’s Disease. While there is no  
 23 symptom or group of symptoms that are absolutely re-  
 24 quired for the diagnosis of juvenile Huntington’s Disease,  
 25 most affected children offer several of the following fea-

1 tures at the time that the diagnosis is made: motor dys-  
 2 function, characterized by rigidity and dystonia, seizures,  
 3 declining cognitive function, behavioral or psychiatric  
 4 problems such as depression, aggressiveness and impul-  
 5 siveness, irritability, mood swings, and obsessions. Hun-  
 6 tington's Disease is a hereditary disorder and individuals  
 7 with very early onset of Huntington's Disease are far more  
 8 likely to have an affected father than an affected moth-  
 9 er.”.

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

12 “111.10. Juvenile Huntington's Disease. With:

13 “A. Motor dysfunction. Evaluate under 111.06;

14 or

15 “B. Behavioral or psychiatric problems. Evalu-

16 ate under 112.02, 112.06, and 112.08.”.

17 **SEC. 5. ELIMINATION OF 24-MONTH MEDICARE DISABILITY**

18 **WAITING PERIOD IN CASES OF INDIVIDUALS**

19 **WITH DISABLING HUNTINGTON'S DISEASE.**

20 (a) IN GENERAL.—Section 226(h) of the Social Secu-  
 21 rity Act (42 U.S.C. 426(h)) is amended, in the matter pre-  
 22 ceding paragraph (1), by inserting “or Huntington's Dis-  
 23 ease” after “amyotrophic lateral sclerosis (ALS)”.

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

- 1 the Social Security Act with respect to items and services
- 2 furnished in months beginning after the date of the enact-
- 3 ment of this Act.

