

113TH CONGRESS  
1ST SESSION

# H. R. 1015

To require the Commissioner of Social Security to revise the medical and evaluation criteria for determining 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

MARCH 6, 2013

Mr. PASCARELL (for himself and Mr. KINZINGER of Illinois) introduced the following bill; which was referred to the Committee on Ways and Means

---

## A BILL

To require the Commissioner of Social Security to revise the medical and evaluation criteria for determining 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 2013".

1 **SEC. 2. FINDINGS.**

2 Congress makes the following findings:

3 (1) Huntington's Disease is a progressive de-  
4 generative neurological disease that causes total  
5 physical and mental deterioration. In the United  
6 States, approximately 30,000 individuals are af-  
7 fected by Huntington's Disease, along with another  
8 200,000 individuals who are genetically "at risk".  
9 There is no effective treatment in terms of halting  
10 or slowing the progression of the disease.

11 (2) Clinical indicators of Huntington's Disease  
12 include—

13 (A) loss of ability to control bodily move-  
14 ments;

15 (B) loss of ability to think or act quickly,  
16 inability to learn new material, and loss of  
17 memory; and

18 (C) behavioral or psychological problems,  
19 including personality changes, irritability, mood  
20 swings, anxiety, obsessive-compulsive behavior,  
21 inability to concentrate, decreased motivation,  
22 and severe depression.

23 (3) Adult-onset Huntington's Disease typically  
24 results in the development of symptoms in individ-  
25 uals between 30 and 50 years of age. Late-onset  
26 Huntington's Disease is characterized by develop-

1       ment of symptoms after 50 years of age and is usu-  
2       ally associated with a milder course of the disease.  
3       Juvenile Huntington’s Disease affects individuals  
4       who have yet to attain 19 years of age and pro-  
5       gresses at a more rapid rate.

6           (4) Because of the incapacitating nature of  
7       Huntington’s Disease, individuals living with this ill-  
8       ness, including those in the early stages of the dis-  
9       ease, are unable to retain employment. As a result,  
10      many such individuals rely solely on Social Security  
11      Disability Insurance.

12          (5) Despite significant advances in medicine  
13      and a greater understanding of Huntington’s Dis-  
14      ease, the Social Security Administration has not  
15      comprehensively revised its rules for the medical  
16      evaluation of neurological disabilities since 1985.  
17      The designation of this disease by the Social Secu-  
18      rity Administration as “Huntington’s Chorea” is  
19      both outdated and medically inaccurate, as this term  
20      fails to recognize the behavioral and cognitive impact  
21      of Huntington’s Disease, while also providing an in-  
22      complete characterization of the full spectrum of  
23      Huntington’s Disease for purposes of Social Security  
24      Disability Insurance and the Medicare program.

1           (6) After qualifying for Social Security Dis-  
2           ability Insurance, individuals with Huntington’s Dis-  
3           ease must wait another 24 months before receiving  
4           benefits under the Medicare program, despite the  
5           fact that such individuals often become incapacitated  
6           before reaching the age-eligibility requirement under  
7           the Medicare program of 65 years of age.

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

13          (8) In light of the outdated Social Security Dis-  
14          ability Insurance guidelines for Huntington’s Dis-  
15          ease and the significant cognitive, behavioral, and  
16          physical incapacitation faced by individuals with this  
17          disease, there is an urgent need for a revision of the  
18          medical and evaluation criteria used by the Social  
19          Security Administration in determining whether  
20          such individuals are disabled, as well as removal of  
21          the 24-month waiting period for coverage under the  
22          Medicare program for such individuals, similar to  
23          the existing exemption for individuals who have been  
24          diagnosed with ALS.

1 **SEC. 3. REVISION OF MEDICAL AND EVALUATION CRITERIA**  
2 **FOR EVALUATING DISABILITY CAUSED BY**  
3 **ADULT-ONSET AND JUVENILE HUNTINGTON'S**  
4 **DISEASE.**

5 (a) IN GENERAL.—For purposes of determinations of  
6 cognitive, behavioral, and physical disability under titles  
7 II and XVI of the Social Security Act, the Commissioner  
8 of Social Security, in consultation with the National Insti-  
9 tute of Neurological Disorders and Stroke, the National  
10 Institutes of Health, and other relevant organizations with  
11 medical expertise relating to Adult-Onset and Juvenile  
12 Huntington's Disease, shall, not later than 180 days after  
13 the date of the enactment of this Act—

14 (1) amend section 11.00 of part A of the List-  
15 ing of Impairments (relating to neurological impair-  
16 ments of adults) by—

17 (A) providing medical and evaluation cri-  
18 teria for Huntington's Disease; and

19 (B) striking “Huntington's Chorea” each  
20 place it appears;

21 (2) amend section 12.00 of part A of the List-  
22 ing of Impairments (relating to mental disorders of  
23 adults) by providing medical and evaluation criteria  
24 for Huntington's Disease;

25 (3) amend section 111.00 of part B of the List-  
26 ing of Impairments (relating to neurological impair-

1       ments of children) by providing medical and evalua-  
 2       tion criteria for Juvenile Huntington’s Disease; and  
 3               (4) amend section 112.00 of part B of the List-  
 4       ing of Impairments (relating to mental disorders of  
 5       children) by providing medical and evaluation cri-  
 6       teria for Juvenile Huntington’s Disease.

7       (b) LISTING OF IMPAIRMENTS.—For purposes of this  
 8       section, the term “Listing of Impairments” means appen-  
 9       dix 1 to subpart P of part 404 of title 20 of the Code  
 10      of Federal Regulations.

11   **SEC. 4. WAIVER OF 24-MONTH WAITING PERIOD FOR COV-**  
 12                           **ERAGE UNDER MEDICARE PROGRAM FOR IN-**  
 13                           **DIVIDUALS DIAGNOSED WITH HUNTINGTON’S**  
 14                           **DISEASE.**

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

19       (b) EFFECTIVE DATE.—The amendment made by  
 20       subsection (a) shall apply to benefits under title XVIII of  
 21       the Social Security Act with respect to items and services  
 22       furnished in months beginning after the date of the enact-  
 23       ment of this Act.

○