

114TH CONGRESS
1ST SESSION

H. R. 842

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

FEBRUARY 10, 2015

Mr. KINZINGER of Illinois (for himself, Mr. PASCRELL, Mr. SESSIONS, Ms. SLAUGHTER, Mr. ROGERS of Kentucky, Mrs. LOWEY, Ms. JENKINS of Kansas, Mr. VAN HOLLEN, Ms. DELAURO, Mr. KELLY of Pennsylvania, Mr. BLUMENAUER, Mr. KIND, Mr. THOMPSON of California, Mr. LARSON of Connecticut, Mr. CROWLEY, Mr. LEWIS, Mr. RANGEL, Ms. LINDA T. SÁNCHEZ of California, Mrs. BLACKBURN, Mr. LANCE, Mrs. ELLMERS, Mr. MCKINLEY, Mr. HARPER, Mr. BUTTERFIELD, Mr. CÁRDENAS, Mr. BEN RAY LUJÁN of New Mexico, Ms. MATSUI, Mr. KENNEDY, Mr. LOEBSACK, Mr. MCNERNEY, Mr. TONKO, Mr. YARMUTH, Mr. AMODEI, Mr. FRELINGHUYSEN, Ms. HERRERA BEUTLER, Mr. JOYCE, Mr. STEWART, Mr. HONDA, Ms. LEE, Ms. ROYBAL-ALLARD, Ms. KAPTUR, Ms. MCCOLLUM, Mr. FATTAH, Mr. ISRAEL, Ms. PINGREE, Mr. RUPPERSBERGER, Mr. RYAN of Ohio, Mr. WITTMAN, Mr. KING of New York, Mr. SENSENBRENNER, Mr. DUNCAN of Tennessee, Mr. HUNTER, Mr. PETERSON, Mr. HIGGINS, Mr. PAYNE, Mrs. CAROLYN B. MALONEY of New York, Mr. CONYERS, Mr. DEFazio, Ms. BROWN of Florida, Mr. CARSON of Indiana, Ms. CLARK of Massachusetts, Mr. DELANEY, Ms. ESTY, Mr. FOSTER, Mr. POE of Texas, Mr. HECK of Washington, Mr. HINOJOSA, Mr. JOHNSON of Georgia, Mr. KILDEE, Mr. LARSEN of Washington, Mr. RIBBLE, Mr. THOMPSON of Pennsylvania, Mr. LIPINSKI, Mr. LYNCH, Mr. MCGOVERN, Mr. POCAN, Mr. POLIS, Mr. SIRES, Mr. FARENTHOLD, Mr. MASSIE, Ms. BROWNLEY of California, Mrs. BUSTOS, Mr. CARTWRIGHT, Mr. POSEY, Mr. COHEN, Ms. DELBENE, Mr. GRAYSON, Mr. YOUNG of Alaska, Mr. SMITH of New Jersey, Ms. BONAMICI, Mr. SWALWELL of California, Ms. TSONGAS, Mr. AUSTIN SCOTT of Georgia, Mr. AL GREEN of Texas, Mr. HASTINGS, Mr. LANGEVIN, Mr. LOWENTHAL, Mrs. NAPOLITANO, Ms. NORTON, Mr. SCHIFF, Mr. DAVID SCOTT of Georgia, Mr. TAKANO, Mr. HUIZENGA of Michigan, and Mr. HUFFMAN) 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 2015”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Huntington’s Disease is a progressive de-
9 generative neurological disease that causes total
10 physical and mental deterioration. In the United
11 States, approximately 30,000 individuals are af-
12 fected by Huntington’s Disease, along with another
13 200,000 individuals who are genetically “at risk”.
14 There is no effective treatment in terms of halting
15 or slowing the progression of the disease.

16 (2) Clinical indicators of Huntington’s Disease
17 include—

18 (A) loss of ability to control bodily move-
19 ments;

1 (B) loss of ability to think or act quickly,
2 inability to learn new material, and loss of
3 memory; and

4 (C) behavioral or psychological problems,
5 including personality changes, irritability, mood
6 swings, anxiety, obsessive-compulsive behavior,
7 inability to concentrate, decreased motivation,
8 and severe depression.

9 (3) Adult-onset Huntington's Disease typically
10 results in the development of symptoms in individ-
11 uals between 30 and 50 years of age. Late-onset
12 Huntington's Disease is characterized by develop-
13 ment of symptoms after 50 years of age and is usu-
14 ally associated with a milder course of the disease.
15 Juvenile Huntington's Disease affects individuals
16 who have yet to attain 19 years of age and pro-
17 gresses at a more rapid rate.

18 (4) Because of the incapacitating nature of
19 Huntington's Disease, individuals living with this ill-
20 ness, including those in the early stages of the dis-
21 ease, are unable to retain employment. As a result,
22 many such individuals rely solely on Social Security
23 Disability Insurance.

24 (5) Despite significant advances in medicine
25 and a greater understanding of Huntington's Dis-

1 ease, the Social Security Administration has not
2 comprehensively revised its rules for the medical
3 evaluation of neurological disabilities since 1985.
4 The designation of this disease by the Social Secu-
5 rity Administration as “Huntington’s Chorea” is
6 both outdated and medically inaccurate, as this term
7 fails to recognize the behavioral and cognitive impact
8 of Huntington’s Disease, while also providing an in-
9 complete characterization of the full spectrum of
10 Huntington’s Disease for purposes of Social Security
11 Disability Insurance and the Medicare program.

12 (6) After qualifying for Social Security Dis-
13 ability Insurance, individuals with Huntington’s Dis-
14 ease must wait another 24 months before receiving
15 benefits under the Medicare program, despite the
16 fact that such individuals often become incapacitated
17 before reaching the age-eligibility requirement under
18 the Medicare program of 65 years of age.

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

24 (8) In light of the outdated Social Security Dis-
25 ability Insurance guidelines for Huntington’s Dis-

1 ease and the significant cognitive, behavioral, and
2 physical incapacitation faced by individuals with this
3 disease, there is an urgent need for a revision of the
4 medical and evaluation criteria used by the Social
5 Security Administration in determining whether
6 such individuals are disabled, as well as removal of
7 the 24-month waiting period for coverage under the
8 Medicare program for such individuals, similar to
9 the existing exemption for individuals who have been
10 diagnosed with ALS.

11 **SEC. 3. REVISION OF MEDICAL AND EVALUATION CRITERIA**
12 **FOR EVALUATING DISABILITY CAUSED BY**
13 **ADULT-ONSET AND JUVENILE HUNTINGTON'S**
14 **DISEASE.**

15 (a) IN GENERAL.—For purposes of determinations of
16 cognitive, behavioral, and physical disability under titles
17 II and XVI of the Social Security Act, the Commissioner
18 of Social Security, in consultation with the National Insti-
19 tute of Neurological Disorders and Stroke, the National
20 Institutes of Health, and other relevant organizations with
21 medical expertise relating to Adult-Onset and Juvenile
22 Huntington's Disease, shall, not later than 180 days after
23 the date of the enactment of this Act—

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

4 (A) providing medical and evaluation cri-
5 teria for Huntington’s Disease; and

6 (B) striking “Huntington’s Chorea” each
7 place it appears;

8 (2) amend section 12.00 of part A of the List-
9 ing of Impairments (relating to mental disorders of
10 adults) by providing medical and evaluation criteria
11 for Huntington’s Disease;

12 (3) amend section 111.00 of part B of the List-
13 ing of Impairments (relating to neurological impair-
14 ments of children) by providing medical and evalua-
15 tion criteria for Juvenile Huntington’s Disease; and

16 (4) amend section 112.00 of part B of the List-
17 ing of Impairments (relating to mental disorders of
18 children) by providing medical and evaluation cri-
19 teria for Juvenile Huntington’s Disease.

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

1 **SEC. 4. WAIVER OF 24-MONTH WAITING PERIOD FOR COV-**
2 **ERAGE UNDER MEDICARE PROGRAM FOR IN-**
3 **DIVIDUALS DIAGNOSED WITH HUNTINGTON'S**
4 **DISEASE.**

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

9 (b) **EFFECTIVE DATE.**—The amendment made by
10 subsection (a) shall apply to benefits under title XVIII of
11 the Social Security Act with respect to items and services
12 furnished in months beginning after the date of the enact-
13 ment of this Act.

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