

116TH CONGRESS
1ST SESSION

S. 1476

To waive the 24-month waiting period for Medicare eligibility for individuals disabled by Huntington’s disease.

IN THE SENATE OF THE UNITED STATES

MAY 15, 2019

Mrs. GILLIBRAND (for herself and Mr. CASSIDY) introduced the following bill;
which was read twice and referred to the Committee on Finance

A BILL

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 2019”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Huntington’s disease is a progressive degen-
9 erative neurological disease that causes total phys-
10 ical and mental deterioration. In the United States,

1 approximately 30,000 individuals are affected by
2 Huntington's disease, along with another 200,000
3 individuals who are genetically "at risk". There is no
4 effective treatment in terms of halting or slowing the
5 progression of the disease.

6 (2) Clinical indicators of Huntington's disease
7 include—

8 (A) loss of ability to control bodily move-
9 ments;

10 (B) loss of ability to think or act quickly,
11 inability to learn new material, and loss of
12 memory; and

13 (C) behavioral or psychological problems,
14 including personality changes, irritability, mood
15 swings, anxiety, obsessive-compulsive behavior,
16 inability to concentrate, decreased motivation,
17 and severe depression.

18 (3) Adult-onset Huntington's disease typically
19 results in the development of symptoms in individ-
20 uals between 30 and 50 years of age. Late-onset
21 Huntington's disease is characterized by develop-
22 ment of symptoms after 50 years of age and is usu-
23 ally associated with a milder course of the disease.
24 Juvenile Huntington's disease affects individuals

1 who have yet to attain 19 years of age and pro-
2 gresses at a more rapid rate.

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

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

16 (6) In 2000, the Centers for Medicare & Med-
17 icaid Services waived the 24-month waiting period
18 requirement for people disabled by amyotrophic lat-
19 eral sclerosis ("ALS"), a degenerative neurological
20 condition that is similar to Huntington's disease.

21 (7) In light of the significant cognitive, behav-
22 ioral, and physical incapacitation faced by individ-
23 uals with this disease, there is an urgent need for
24 the removal of the 24-month waiting period for cov-
25 erage under the Medicare program for such individ-

1 uals, similar to the existing exemption for individ-
2 uals who have been diagnosed with ALS.

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

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

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

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