

105TH CONGRESS
2D SESSION

S. 2265

To amend the Social Security Act to waive the 24-month waiting period for Medicare coverage of individuals disabled with amyotrophic lateral sclerosis (ALS), to provide Medicare coverage of drugs used for treatment of ALS, and to amend the Public Health Service Act to increase Federal funding for research on ALS.

IN THE SENATE OF THE UNITED STATES

JULY 7, 1998

Mr. TORRICELLI (for himself and Mr. WELLSTONE) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL

To amend the Social Security Act to waive the 24-month waiting period for Medicare coverage of individuals disabled with amyotrophic lateral sclerosis (ALS), to provide Medicare coverage of drugs used for treatment of ALS, and to amend the Public Health Service Act to increase Federal funding for research on ALS.

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; FINDINGS; PURPOSES.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Amyotrophic Lateral Sclerosis (ALS) Research, Treat-
6 ment, and Assistance Act of 1998”.

1 (b) FINDINGS.—Congress finds the following:

2 (1) Amyotrophic lateral sclerosis (ALS), com-
3 monly known as Lou Gehrig’s Disease, is a progres-
4 sive neuromuscular disease characterized by a degen-
5 eration of the nerve cells of the brain and spinal
6 cord leading to the wasting of muscles, paralysis,
7 and eventual death.

8 (2) Approximately 30,000 individuals in the
9 United States are afflicted with ALS at any time,
10 with approximately 5,000 new cases appearing each
11 year.

12 (3) ALS usually strikes individuals who are 50
13 years of age or older.

14 (4) The life expectancy of an individual with
15 ALS is 3 to 5 years from the time of diagnosis.

16 (5) There is no known cure or cause for ALS.

17 (6) Aggressive treatment of the symptoms of
18 ALS can extend the lives of those with the disease.
19 Recent advances in ALS research have produced
20 promising leads, many related to shared disease
21 processes that appear to operate in many
22 neurodegenerative diseases.

23 (c) PURPOSES.—The purposes of this Act are—

24 (1) to assist individuals suffering from ALS by
25 waiving the 24-month waiting period for medicare

1 eligibility on the basis of disability for ALS patients
 2 and to provide medicare coverage for outpatient
 3 drugs and therapies for ALS; and

4 (2) to increase Federal funding of research into
 5 the cause, treatment, and cure of ALS.

6 **SEC. 2. WAIVER OF 24-MONTH WAITING PERIOD FOR MEDI-**
 7 **CARE COVERAGE OF INDIVIDUALS DISABLED**
 8 **WITH AMYOTROPHIC LATERAL SCLEROSIS**
 9 **(ALS).**

10 (a) IN GENERAL.—Section 226 of the Social Security
 11 Act (42 U.S.C. 426) is amended—

12 (1) by redesignating subsection (h) as sub-
 13 section (j); and

14 (2) by inserting after subsection (g) the follow-
 15 ing new subsection:

16 “(h) For purposes of applying this section in the case
 17 of an individual medically determined to have amyotrophic
 18 lateral sclerosis (ALS), the following special rules apply:

19 “(1) Subsection (b) shall be applied as if there
 20 were no requirement for any entitlement to benefits,
 21 or status, for a period longer than 1 month.

22 “(2) The entitlement under such subsection
 23 shall begin with the first month (rather than twenty-
 24 fifth month) of entitlement or status.

25 “(3) Subsection (f) shall not be applied.”.

1 (b) CONFORMING AMENDMENT.—Section 1837 of
 2 such Act (42 U.S.C. 1395p) is amended by adding at the
 3 end the following new subsection:

4 “(j) In applying this section in the case of an individ-
 5 ual who is entitled to benefits under part A pursuant to
 6 the operation of section 226(h), the following special rules
 7 apply:

8 “(1) The initial enrollment period under sub-
 9 section (d) shall begin on the first day of the first
 10 month in which the individual satisfies the require-
 11 ment of section 1836(1).

12 “(2) In applying subsection (g)(1), the initial
 13 enrollment period shall begin on the first day of the
 14 first month of entitlement to disability insurance
 15 benefits referred to in such subsection.”.

16 (c) EFFECTIVE DATE.—The amendments made by
 17 this section shall apply to benefits for months beginning
 18 after the date of enactment of this Act.

19 **SEC. 3. MEDICARE COVERAGE OF DRUGS TO TREAT**
 20 **AMYOTROPHIC LATERAL SCLEROSIS (ALS).**

21 (a) IN GENERAL.—Section 1861(s)(2) of the Social
 22 Security Act (42 U.S.C. 1395x(s)(2)) is amended—

23 (1) by striking “and” at the end of subpara-
 24 graph (S);

1 (2) by striking the period at the end of sub-
2 paragraph (T) and inserting “; and”; and

3 (3) by adding at the end the following:

4 “(U) any drug (which is approved by the Fed-
5 eral Food and Drug Administration) prescribed for
6 use in the treatment or alleviation of symptoms re-
7 lating to amyotrophic lateral sclerosis (ALS);”.

8 (b) **EFFECTIVE DATE.**—The amendments made by
9 subsection (a) shall apply to drugs furnished on or after
10 the first day of the first month beginning after the date
11 of enactment of this Act.

12 **SEC. 4. INCREASED FEDERAL FUNDS FOR RESEARCH INTO**
13 **AMYOTROPHIC LATERAL SCLEROSIS (ALS).**

14 For the purpose of conducting or supporting research
15 on amyotrophic lateral sclerosis through the National In-
16 stitutes of Health, there are authorized to be appropriated
17 \$25,000,000 for fiscal year 1999, and such sums as may
18 be necessary for each of the fiscal years 2000 through
19 2003. Such authorization is in addition to any other au-
20 thorization of appropriations that may be available for
21 such purpose.

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