

105TH CONGRESS  
1ST SESSION

# H. R. 2009

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.

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## IN THE HOUSE OF REPRESENTATIVES

JUNE 23, 1997

Mr. CAPPS (for himself and Mr. GILMAN) introduced the following bill; which was referred to the Committee on Ways and Means, and in addition to the Committee on Commerce, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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## 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,*

1 **SECTION 1. SHORT TITLE; FINDINGS.**

2 (a) SHORT TITLE.—This Act may be cited as the  
3 “Amyotrophic Lateral Sclerosis (ALS) Research, Treat-  
4 ment, and Assistance Act of 1997”.

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

6 (1) Amyotrophic Lateral Sclerosis (ALS), com-  
7 monly known as Lou Gehrig’s Disease, is a progres-  
8 sive neuromuscular disease characterized by a degen-  
9 eration of the nerve cells of the brain and spinal  
10 cord leading to the wasting of muscles, paralysis,  
11 and eventual death.

12 (2) Approximately 30,000 individuals in the  
13 United States are afflicted with ALS at any time,  
14 with approximately 5,000 new cases appearing each  
15 year.

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

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

20 (5) There is no know cure or cause for ALS.

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

1 (c) PURPOSES.—It is the purposes of this Act—

2 (1) to assist individuals suffering from ALS by  
 3 waiving the 24-month waiting period for medicare  
 4 eligibility on the basis of disability for ALS patients  
 5 and to provide medicare coverage for outpatient  
 6 drugs and therapies for ALS; and

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

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

13 (a) IN GENERAL.—Section 226(b) of the Social Secu-  
 14 rity Act (42 U.S.C. 426(b)) is amended—

15 (1) by redesignating subsection (h) as sub-  
 16 section (j) and by moving such subsection to the end  
 17 of the section, and

18 (2) by inserting after subsection (g) the follow-  
 19 ing new subsection:

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

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

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

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

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

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

12           “(1) The initial enrollment period under sub-  
13          section (d) shall begin on the first day of the first  
14          month in which the individual satisfies the require-  
15          ment of section 1836(1).

16           “(2) In applying subsection (g)(1), the initial  
17          enrollment period shall begin on the first day of the  
18          first month of entitlement to disability insurance  
19          benefits referred to in such subsection.”.

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

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

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

5 (1) by striking “and” at the end of subpara-  
6 graphs (N) and (O),

7 (2) by adding “and” at the end of subpara-  
8 graph (Q), and

9 (3) by adding at the end the following new sub-  
10 paragraph:

11 “(R) any drug (which is approved by the Fed-  
12 eral Food and Drug Administration) prescribed for  
13 use in the treatment or alleviation of symptoms re-  
14 lating to amyotrophic lateral sclerosis (ALS);”.

15 (b) EFFECTIVE DATE.—The amendments made by  
16 subsection (a) shall apply to drugs furnished on or after  
17 the first day of the first month beginning after the date  
18 of the enactment of this Act.

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

21 For the purpose of conducting or supporting research  
22 on amyotrophic lateral sclerosis through the National In-  
23 stitutes of Health, there are authorized to be appropriated  
24 \$25,000,000 for fiscal year 1998, and such sums as may  
25 be necessary for each of the fiscal years 1999 through  
26 2002. Such authorization is in addition to any other au-

- 1 thORIZATION OF APPROPRIATIONS THAT MAY BE AVAILABLE FOR
- 2 SUCH PURPOSE.

