

119TH CONGRESS
2D SESSION

H. R. 7336

To amend title XVIII of the Social Security Act to provide coverage of ALS-related services under the Medicare program for individuals diagnosed with amyotrophic lateral sclerosis, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 3, 2026

Ms. SCHAKOWSKY (for herself, Mr. FITZPATRICK, Mr. CROW, and Mr. QUIGLEY) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, 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

A BILL

To amend title XVIII of the Social Security Act to provide coverage of ALS-related services under the Medicare program for individuals diagnosed with amyotrophic lateral sclerosis, and for other purposes.

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 “ALS Better Care Act”.

5 **SEC. 2. FINDINGS.**

6 Congress makes the following findings:

1 (1) Amyotrophic lateral sclerosis (in this sec-
2 tion, referred to as “ALS”) is a progressive and de-
3 bilitating neurodegenerative disease.

4 (2) Key services that include (but are not lim-
5 ited to) providing specialized physician or nurse
6 practitioner support, occupational therapy support,
7 speech pathology support, physical therapy, dietary
8 support, respiratory support, registered nurse sup-
9 port, and coordination of the furnishing of durable
10 medical equipment are crucial for managing the
11 complex medical needs of ALS patients.

12 (3) Studies have shown ALS clinics that pro-
13 vide these key services to ALS patients extend these
14 patients’ lifespans and improve the quality of their
15 lives.

16 (4) These key services are furnished by a range
17 of healthcare professionals.

18 (5) Facilities providing care to ALS patients
19 currently face inadequate Medicare reimbursement
20 for the key services they offer to these patients.

21 (6) Insufficient reimbursement creates signifi-
22 cant challenges for facilities specializing in ALS
23 care, resulting in extended wait times for patients in
24 need of crucial services and hampering the ability of

1 these facilities to innovate and improve the quality
2 of care provided to ALS patients.

3 (7) Improved reimbursement rates would en-
4 courage facilities to invest in research, innovation,
5 and technology, leading to enhanced treatment op-
6 tions for ALS and improved patient outcomes.

7 (8) Remote medical management options for in-
8 dividuals suffering from ALS must be a crucial part
9 of access to care for such individuals, especially
10 those living in rural areas or care deserts.

11 (9) Telehealth is an essential management op-
12 tion referred to in paragraph (8) and can assist in
13 delivering timely and comprehensive care, as ALS
14 patients living in rural areas or care deserts often
15 face challenges in accessing specialized ALS care
16 and could otherwise be required to travel long dis-
17 tances—often with caregivers or family members.

18 (10) Telehealth is especially important in main-
19 taining access to care for ALS patients as the dis-
20 ease progresses and ALS patients have more limited
21 mobility, which may make it challenging to attend
22 in-person appointments regularly.

23 (11) Low funding and difficulty in staffing for
24 ALS clinical trials delay the development and avail-

ability of potential treatments and therapies for individuals living with the disease.

(12) Inadequate funding for ALS clinical trials also impedes the ability to attract and retain qualified researchers, clinicians, and support staff, limiting the overall progress and success of these trials.

SEC. 3. PROVIDING FOR COVERAGE OF ALS-RELATED SERVICES UNDER THE MEDICARE PROGRAM FOR INDIVIDUALS DIAGNOSED WITH AMYOTROPHIC LATERAL SCLEROSIS.

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

(1) in subsection (s)(2)—

(A) by adding “and” at the end of subparagraph (JJ); and

(B) by adding at the end the following new subparagraph:

“(KK) ALS-related services (as defined in subsection (nnn)) furnished on or after January 1, 2027;” and

(2) by adding at the end the following new subsection:

“(nnn) ALS-Related Services.—

“(1) ALS-RELATED SERVICES.—The term ‘ALS-related services’ means the following items and

1 services that are furnished to a covered ALS indi-
2 vidual in an outpatient setting by a qualified pro-
3 vider (as defined in section 1834(aa)(6)) (or by an-
4 other provider of services under an arrangement
5 made by a qualified provider) for the care and treat-
6 ment of such an individual with respect to the pro-
7 gression of amyotrophic lateral sclerosis:

8 “(A) Specialized physician or nurse practi-
9 tioner support.

10 “(B) Occupational therapy support.

11 “(C) Speech pathology support.

12 “(D) Physical therapy.

13 “(E) Dietary support.

14 “(F) Respiratory support.

15 “(G) Registered nurse support.

16 “(H) Coordination of the furnishing of du-
17 rable medical equipment necessary for the man-
18 agement of the complex medical needs of a cov-
19 ered ALS individual.

20 “(2) COVERED ALS INDIVIDUAL.—The term
21 ‘covered ALS individual’ means an individual who is
22 medically determined to have amyotrophic lateral
23 sclerosis (as described in section 226(h)).”.

24 (b) PAYMENT FOR ALS-RELATED SERVICES.—Sec-
25 tion 1834 of the Social Security Act (42 U.S.C. 1395m)

1 is amended by adding at the end the following new sub-
2 sections:

3 “(aa) Payment for ALS-Related Services.—

4 “(1) IN GENERAL.—The Secretary shall imple-
5 ment a payment system under which a single pay-
6 ment determined in accordance with the succeeding
7 paragraphs is made to a qualified provider (as de-
8 fined in paragraph (6)) for ALS-related services (as
9 defined in paragraph (1) of section 1861(nnn)) fur-
10 nished to a covered ALS individual (as defined in
11 paragraph (2) of such section) during a visit, in ad-
12 dition to any other payment that may be made for
13 such services under this title.

14 “(2) BASE PAYMENT AMOUNT.—

15 “(A) IN GENERAL.—The amount of the
16 single payment described in paragraph (1) for
17 ALS-related services furnished during a year is
18 equal to—

19 “(i) for 2027, \$800;

20 “(ii) for 2028, \$800 (or, if greater,
21 the payment amount recommended by the
22 Comptroller General of the United States
23 in the report described in subparagraph
24 (C)); and

1 “(iii) for 2029 and each subsequent
2 year—

3 “(I) the amount for the pre-
4 ceding year, increased by the ALS
5 services market basket percentage in-
6 crease (as defined in clause (i) of sub-
7 paragraph (B)) for such year; or

8 “(II) in the case such year is an
9 applicable year (as defined in clause
10 (ii) of such subparagraph), the pay-
11 ment amount recommended by the
12 Comptroller General in the most re-
13 cent report submitted under subpara-
14 graph (C), if greater than the amount
15 that would be determined for such
16 year under subclause (I).

17 “(B) DEFINITIONS.—In this paragraph:

18 “(i) ALS SERVICES MARKET BASKET
19 PERCENTAGE INCREASE.—The term ‘ALS
20 services market basket percentage increase’
21 means, for a year, the Secretary’s estimate
22 of the percentage increase in costs of an
23 appropriate mix, as determined by the Sec-
24 retary, of items and services that are ALS-
25 related services over the preceding year.

1 “(ii) APPLICABLE YEAR.—The term
2 ‘applicable year’ means 2030 and every
3 third year thereafter.

4 “(C) REPORT BY THE COMPTROLLER GEN-
5 ERAL.—

6 “(i) IN GENERAL.—Not later than
7 January 1, 2027, and not later than Janu-
8 ary 1 of every third year thereafter, the
9 Comptroller General of the United States
10 shall, in consultation with qualified pro-
11 viders eligible for payment under this sub-
12 section, submit to the Secretary a report
13 that recommends a single payment amount
14 for ALS-related services that takes into ac-
15 count the average amount of payment for
16 each item or service included in ALS-re-
17 lated services that the Comptroller General
18 estimates would have been payable—

19 “(I) under this title for such a
20 service based on per patient utilization
21 data from whichever single year dur-
22 ing the covered period (as defined in
23 clause (ii)) with respect to such report
24 has the highest per patient utilization
25 of ALS-related services, even if such

1 service is not payable for a particular
2 covered ALS individual because of the
3 application of section 1862(a)(1)(A)
4 with respect to an item or service pro-
5 vided to such individual;

6 “(II) in the case an estimate is
7 unable to be determined pursuant to
8 subclause (I), by health insurance
9 issuers and group health plans (as
10 such terms are defined in section
11 2791 of the Public Health Service
12 Act) and MA plans under part C for
13 such a service, based on such data
14 from whichever single year during the
15 covered period with respect to such re-
16 port has the highest per patient utili-
17 zation of ALS-related services; and

18 “(III) in the case an estimate is
19 unable to be determined pursuant to
20 subclause (II), based on the rec-
21 ommendation of the Specialty Society
22 Relative Value Scale Update Com-
23 mittee of the American Medical Asso-
24 ciation or the estimate of the Comp-
25 troller General for such a service.

1 “(ii) DEFINITION OF COVERED PE-
2 RIOD.—In this subparagraph, the term
3 ‘covered period’ means—

4 “(I) with respect to the first re-
5 port submitted under this subpara-
6 graph, 2022 through 2024;

7 “(II) with respect to the second
8 such report, 2026 through 2028; and

9 “(III) with respect to the third
10 report and each subsequent report,
11 the period that begins 3 years after
12 the covered period for the preceding
13 report.

14 “(3) PAYMENT ADJUSTMENTS.—The payment
15 system under this subsection shall include a payment
16 adjustment—

17 “(A) for each qualified provider that is
18 participating in at least one clinical trial identi-
19 fied on the clinicaltrials.gov database (or any
20 successor database) of the National Institutes
21 of Health to account for the increased cost
22 borne by such a qualified provider during such
23 a clinical trial; and

24 “(B) for a medical service or technology
25 which is furnished as a part of ALS-related

1 services for which, as determined by the Sec-
2 retary—

3 “(i) payment under this subsection for
4 such service or technology was not being
5 made in the preceding year; and

6 “(ii) the cost of such service or tech-
7 nology is not insignificant in relation to the
8 payment amount (as determined under this
9 subsection) payable for ALS-related serv-
10 ices.

11 “(4) MECHANISM FOR PAYMENTS.—For pur-
12 poses of making payments for ALS-related services,
13 the Secretary shall establish a mechanism under the
14 payment system under this subsection which makes
15 payment when a qualified provider submits a claim
16 for payment which includes, with respect to a cov-
17 ered ALS individual, an alphanumeric code issued
18 under the International Classification of Diseases,
19 10th Revision, Clinical Modification (‘ICD–10–CM’)
20 and its subsequent revisions that is for the treat-
21 ment of a diagnosis of amyotrophic lateral sclerosis.

22 “(5) NO COST SHARING.—Payment under this
23 subsection shall be made only on an assignment-re-
24 lated basis without any cost sharing.

1 “(6) QUALIFIED PROVIDER.—In this section,
2 the term ‘qualified provider’ means a provider of
3 services that—

4 “(A) is capable of furnishing ALS-related
5 services; and

6 “(B) meets requirements as the Secretary
7 prescribes by regulation to implement subpara-
8 graph (A), in consultation with—

9 “(i) covered ALS individuals and their
10 representatives;

11 “(ii) physicians who provide ALS-re-
12 lated services and their representatives;
13 and

14 “(iii) professional and non-profit orga-
15 nizations with expertise in amyotrophic lat-
16 eral sclerosis.

17 “(7) IMPLEMENTATION.—

18 “(A) IN GENERAL.—Except as provided
19 under subparagraph (B), the Secretary may im-
20 plement the provisions of this subsection by
21 program instruction or otherwise.

22 “(B) RULEMAKING.—The Secretary shall
23 implement paragraph (6), through notice and
24 comment rulemaking.”.

25 (c) CONFORMING AMENDMENTS.—

1 (1) SECTION 1833(T).—Section 1833(t) of the
 2 Social Security Act (42 U.S.C. 1395(t)) is amended
 3 by adding at the end the following new paragraph:

4 “(23) ENSURING SUPPLEMENTAL PAYMENTS
 5 FOR ALS-RELATED SERVICES.—Any covered OPD
 6 service furnished to a covered ALS individual (as de-
 7 fined in section 1861(nnn)(2)) that is otherwise pay-
 8 able to a qualified provider (as defined in section
 9 1834(aa)(6)) pursuant to paragraph (4) shall be
 10 payable under such paragraph notwithstanding any
 11 payment made under section 1834(aa).”.

12 (2) DEFINITION OF ARRANGEMENTS.—Section
 13 1861(w)(1) of the Social Security Act (42 U.S.C.
 14 1395x(w)(1)) is amended by inserting “qualified
 15 provider (as defined in section 1834(aa)(6)) with re-
 16 spect to ALS-related services (as defined in sub-
 17 section (nnn)),” before “or hospice program”.

18 **SEC. 4. REPORT ON CHALLENGES WITH RESPECT TO THE**
 19 **ADMINISTRATION AND STAFFING OF**
 20 **AMYOTROPHIC LATERAL SCLEROSIS CLIN-**
 21 **ICAL TRIALS.**

22 Not later than 90 days after the date of the enact-
 23 ment of this Act, the Secretary of Health and Human
 24 Services, acting through the Director of the National In-
 25 stitute of Neurological Disorders and Stroke of the Na-

1 tional Institutes of Health, shall submit to Congress and
2 publish on the internet website of the agency a report that
3 identifies—

4 (1) any challenges with respect to the adminis-
5 tration and staffing of clinical trials for the preven-
6 tion, diagnosis, mitigation, treatment, or cure of
7 amyotrophic lateral sclerosis;

8 (2) actions that the Director of the National In-
9 stitute of Neurological Disorders and Stroke can
10 take to address such challenges; and

11 (3) any legislative recommendations (including
12 requests for appropriations) to further improve the
13 administration of such clinical trials.

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