

117TH CONGRESS
2D SESSION

H. R. 9638

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

DECEMBER 20, 2022

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

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 “Medicare Payment Re-
5 form for People with ALS Act of 2022”.

1 **SEC. 2. PROVIDING FOR COVERAGE OF ALS-RELATED SERV-**
2 **ICES UNDER THE MEDICARE PROGRAM FOR**
3 **INDIVIDUALS DIAGNOSED WITH**
4 **AMYOTROPHIC LATERAL SCLEROSIS.**

5 (a) IN GENERAL.—Subtitle E of title XVIII of the
6 Social Security Act (42 U.S.C. 1395 et. seq.) is amended
7 by inserting after section 1881A the following new section:

8 **“SEC. 1881B. MEDICARE COVERAGE OF ALS-RELATED SERV-**
9 **ICES FOR INDIVIDUALS DIAGNOSED WITH**
10 **AMYOTROPHIC LATERAL SCLEROSIS.**

11 “(a) IN GENERAL.—In the case of a covered ALS
12 individual, the Secretary shall establish a supplemental fa-
13 cility-based payment system described in subsection (d)
14 for ALS-related services provided to such an individual.

15 “(b) COVERED ALS INDIVIDUAL.—For purposes of
16 this section, the term ‘covered ALS individual’ means an
17 individual who is medically determined to have
18 amyotrophic lateral sclerosis (as described in section
19 226(h)).

20 “(c) ALS-RELATED SERVICES.—For purposes of this
21 section, the term ‘ALS-related services’ means items and
22 services that are ordinarily furnished to a covered ALS
23 individual in an outpatient setting by a qualified provider
24 (or by others under arrangements with them made by the
25 qualified provider) consistent with a multidisciplinary ap-
26 proach (as determined by the Secretary) for the care and

1 treatment of such an individual with respect to the pro-
2 gression of amyotrophic lateral sclerosis.

3 “(d) PAYMENT SYSTEM.—

4 “(1) AUTHORITY.—The Secretary shall estab-
5 lish a facility-based payment system under which a
6 single payment determined in accordance with the
7 succeeding paragraphs is made to a qualified pro-
8 vider for ALS-related services furnished to a covered
9 ALS individual during a visit beginning on and after
10 January 1, 2024.

11 “(2) BASE PAYMENT AMOUNT.—

12 “(A) 2024.—For coverage year 2024, the
13 Secretary shall establish a single payment
14 amount for ALS-related services equal to \$800
15 for such services furnished for each visit during
16 such year.

17 “(B) 2025.—

18 “(i) IN GENERAL.—For coverage year
19 2025, the Secretary shall establish a single
20 payment amount for ALS-related services
21 furnished for each visit during such year
22 that is the greater of—

23 “(I) taking into account the pay-
24 ment amount recommended by the
25 Comptroller General in the report de-

scribed in clause (ii), the amount
specified by the Secretary; or

“(II) the amount specified in
subparagraph (A).

“(ii) REPORT BY THE COMPTROLLER
GENERAL.—Not later than January 1,
2024, the Comptroller General shall, in
consultation with qualified providers sub-
mit to the Secretary of Health and Human
Services a report that recommends a single
payment amount for ALS-related services
that takes into account the average
amount of payment for each item or serv-
ice included in ALS-related services that
the Comptroller General estimates would
have been payable—

“(I) under this title for such a
service based on per patient utilization
data from whichever single coverage
year from 2020 through 2022 has the
highest per patient utilization of ALS-
related services, even if such service is
not payable for a particular ALS indi-
vidual because of the application of
section 1862(a)(1)(A) with respect to

1 an item or service provided to such in-
2 dividual;

3 “(II) in the case an estimate is
4 unable to be determined pursuant to
5 subclause (I), by health insurance
6 issuers and group health plans (as
7 such terms are defined in section
8 2791 of the Public Health Service
9 Act) and MA plans under part C for
10 such a service, based on such data
11 from whichever single coverage year
12 from 2020 through 2022 has the
13 highest per patient utilization of ALS-
14 related services; and

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

23 “(C) 2026 AND SUBSEQUENT YEARS.—For
24 each coverage year beginning with coverage
25 year 2026, the Secretary shall annually increase

1 the payment amount for each visit determined
2 under this paragraph by an ALS services mar-
3 ket basket percentage increase (as determined
4 by the Secretary) that reflects changes over
5 time in the prices of an appropriate mix of
6 goods and services that are ALS-related serv-
7 ices.

8 “(3) PAYMENT ADJUSTMENTS.—The payment
9 system under this subsection—

10 “(A) shall include a payment adjustment
11 based on case mix that may take into account
12 comorbidities, length of time from diagnosis,
13 age, race, ethnicity, and other appropriate fac-
14 tors;

15 “(B) shall include a payment adjustment
16 for high-cost outliers due to unusual variations
17 in the type or amount of medically necessary
18 care;

19 “(C) shall include a payment adjustment
20 that reflects the extent to which costs incurred
21 by low-volume facilities (as defined by the Sec-
22 retary) in furnishing ALS-related services ex-
23 ceed the costs incurred by other facilities in fur-
24 nishing such services, and such payment adjust-
25 ment may not be less than 10 percent;

1 “(D) shall include a payment adjustment
2 for a medical service or technology which is fur-
3 nished as a part of ALS-related services for
4 which, as determined by the Secretary—

5 “(i) payment for the service or tech-
6 nology as part of ALS-related services
7 under this section was not being made in
8 the preceding coverage year; and

9 “(ii) the cost of the service or tech-
10 nology is not insignificant in relation the
11 payment amount (as determined under this
12 subsection) payable for ALS-related serv-
13 ices; and

14 “(E) may include such other payment ad-
15 justments as the Secretary deems appropriate,
16 including a payment adjustment for—

17 “(i) a geographic index, such as the
18 index referred to in section 1886(d)(3)(E);

19 “(ii) the status of the facility as pro-
20 vider-based or free-standing (as such terms
21 are defined in section 413.65(a)(2), title
22 42, Code of Federal Regulations); and

23 “(iii) qualified providers located in
24 rural areas (as defined in section
25 1886(d)(2)(D)).

1 “(4) MECHANISM FOR PAYMENTS.—For pur-
2 poses of making payments for ALS-related services,
3 the Secretary shall establish a mechanism under the
4 payment system under this subsection which makes
5 payment when a qualified provider submits a claim
6 for reimbursement which includes, with respect to a
7 covered ALS individual, an alphanumeric code
8 issued under the International Classification of Dis-
9 eases, 10th Revision, Clinical Modification (‘ICD-
10 10-CM’) and its subsequent revisions that is for the
11 treatment of a diagnosis of amyotrophic lateral sle-
12 rosis.

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

16 “(6) QUALIFIED PROVIDER DEFINED.—In this
17 section, the term ‘qualified provider’ means a pro-
18 vider of services which meets requirements as the
19 Secretary prescribes by regulation.

20 “(e) CLARIFICATION.—Payment under subsection (d)
21 shall be in addition to, and shall not supplant, any pay-
22 ment that would be otherwise made to a provider of serv-
23 ices, physician, practitioner, supplier, or laboratory under
24 any other provision of this title for an item or service fur-
25 nished to a covered ALS individual.

1 “(f) IMPLEMENTATION.—

2 “(1) IN GENERAL.—Except as provided under
3 paragraph (2), the Secretary may implement the
4 provisions of this section by program instruction or
5 otherwise.

6 “(2) RULEMAKING.—The Secretary shall imple-
7 ment subsections (c) and (d)(6) through notice and
8 comment rulemaking.

9 “(g) FUNDING.—For purposes of carrying out this
10 section, subject to subsection (e), payment under this sec-
11 tion shall be made from the Federal Supplementary Med-
12 ical Insurance Trust Fund under section 1841 or from
13 the Federal Hospital Insurance Trust Fund under section
14 1817.”.

15 (b) CONFORMING AMENDMENTS.—

16 (1) Section 1833(t) of the Social Security Act
17 (42 U.S.C. 1395(t) is amended by adding at the end
18 the following new paragraph:

19 “(23) ENSURING SUPPLEMENTAL PAYMENTS
20 FOR ALS-RELATED SERVICES.—Any covered OPD
21 service furnished to a covered ALS individual (as de-
22 fined in section 1881B(b)) that is otherwise payable
23 to a qualified provider (as defined in section
24 1881B(d)(6)) pursuant to paragraph (4) shall be

1 payable under such paragraph notwithstanding any
2 payment made under section 1881B(d).”.

3 (2) Section 1861(w)(1) of the Social Security
4 Act (42 U.S.C. 1395x(w)(1)) is amended by insert-
5 ing “qualified provider (as defined in section
6 1881B(d)(6)(A)) with respect to ALS-related serv-
7 ices (as defined in section 1881B(c)),” before “or
8 hospice program”.

9 **SEC. 3. EFFECTIVE DATE.**

10 The amendments made by this Act shall take effect
11 on the date of the enactment of this Act.

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