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(Original Signature of Member)

113TH CONGRESS
1ST SESSION

H. R.

To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Mr. BLUMENAUER introduced the following bill; which was referred to the Committee on _____

A BILL

To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, 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; FINDINGS; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Personalize Your Care Act of 2013”.

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

7 (1) All individuals should be afforded the oppor-
8 tunity to fully participate in decisions related to

1 their health care or the care of a person for whom
2 they are the proxy or surrogate.

3 (2) Every individual's values and goals should
4 be identified, understood, and respected. Particular
5 attention should be paid to populations which have
6 not regularly had the opportunity to express their
7 choices or preferences.

8 (3) Advance care planning plays a valuable role
9 in achieving quality care by informing physicians
10 and family members of an individual's treatment
11 preferences should he or she become unable to direct
12 care.

13 (4) Early advance care planning is ideal be-
14 cause a person's ability to make decisions may di-
15 minish over time and the person may suddenly lose
16 the capability to participate in their health care deci-
17 sions.

18 (5) Advance directives (such as living wills and
19 durable powers of attorney for health care) must be
20 prepared while individuals have the capacity to com-
21 plete them and only apply to future medical cir-
22 cumstances when decisionmaking capacity is lost. An
23 individual can change or revoke an advance directive
24 at any time.

1 (6) Physician orders for life-sustaining treat-
2 ment complement advance directives by providing a
3 process to focus patients' values, goals, and pref-
4 erences on current medical circumstances and to
5 translate them into visible and portable medical or-
6 ders applicable across care settings. A patient (or
7 proxy or surrogate) can change or revoke a physi-
8 cian order for life-sustaining treatment at any time.

9 (7) Advance care planning should be routinely
10 conducted in community and clinical practices. Care
11 plans should be periodically revisited to reflect a per-
12 son's changes in values and perceptions at different
13 stages and circumstances of life. This shared deci-
14 sionmaking and collaborative planning between the
15 patient (or proxy or surrogate) and the clinician of
16 their choice will lead to more person-centered, cul-
17 turally appropriate care.

18 (8) Effective, respectful, and culturally com-
19 petent advance care planning requires recognition
20 that both overtreatment and undertreatment may be
21 concerns of individuals contemplating future care.

22 (9) More should be done within local health sys-
23 tems to establish specific policies and programs to
24 assist people with sensory, mental, and other disabil-
25 ities in order to maximize the degree to which they

1 are active participants in the decisions related to
2 their health care, including training health care pro-
3 viders to be aware of augmentative communication
4 devices and how to communicate with people with
5 developmental, psychiatric, speech, and sensory dis-
6 abilities.

7 (10) Studies funded by the Agency for
8 Healthcare Research and Quality have shown that
9 individuals who talked with their families or physi-
10 cians about their preferences for care had less fear
11 and anxiety, felt they had more ability to influence
12 and direct their medical care, believed that their
13 physicians had a better understanding of their wish-
14 es, and indicated a greater understanding and com-
15 fort level than they had before the discussion. Pa-
16 tients who had advance planning discussions with
17 their physicians continued to discuss and talk about
18 these concerns with their families. Such discussions
19 enabled patients and families to reconcile any dif-
20 ferences about care and could help the family and
21 physician come to agreement if they should need to
22 make decisions for the patient.

23 (11) A decade of research has demonstrated
24 that physician orders for life-sustaining treatment
25 effectively convey patient preferences and guide med-

1 ical personnel toward medical treatment aligned with
2 patient wishes. Programs for these orders have de-
3 veloped locally on a statewide or communitywide
4 basis and have different program names, forms, and
5 policies, but all follow the principle of patient-cen-
6 tered care.

7 (12) According to research published in the Ar-
8 chives of Internal Medicine, between 65 and 76 per-
9 cent of physicians whose patients had an advance di-
10 rective were not aware that it existed.

11 (13) Including completed advance care planning
12 documents within a patient's electronic health record
13 can increase the likelihood these documents are kept
14 up-to-date and available at the right place at the
15 right time.

16 (c) TABLE OF CONTENTS.—The table of contents of
17 this Act is as follows:

Sec. 1. Short title; findings; table of contents.

Sec. 2. Voluntary advance care planning consultation coverage under Medicare and Medicaid.

Sec. 3. Grants for programs for physician orders for life-sustaining treatment.

Sec. 4. Advance care planning standards for electronic health records.

Sec. 5. Portability of advance directives.

18 **SEC. 2. VOLUNTARY ADVANCE CARE PLANNING CONSULTA-**
19 **TION COVERAGE UNDER MEDICARE AND**
20 **MEDICAID.**

21 (a) MEDICARE.—

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

3 (A) in subsection (s)(2)—

4 (i) by striking “and” at the end of
5 subparagraph (EE);

6 (ii) by adding “and” at the end of
7 subparagraph (FF); and

8 (iii) by adding at the end the fol-
9 lowing new subparagraph:

10 “(GG) voluntary advance care planning
11 consultation (as defined in subsection (iii)(1));”;

12 and

13 (B) by adding at the end the following new
14 subsection:

15 “Voluntary Advance Care Planning Consultation

16 “(iii)(1) Subject to paragraphs (3) and (4), the term
17 ‘voluntary advance care planning consultation’ means an
18 optional consultation between the individual and a practi-
19 tioner described in paragraph (2) regarding advance care
20 planning. Such consultation may include the following, as
21 specified by the Secretary:

22 “(A) An explanation by the practitioner of ad-
23 vance care planning and the uses of advance direc-
24 tives.

1 “(B) An explanation by the practitioner of the
2 role and responsibilities of a proxy or surrogate.

3 “(C) An explanation by the practitioner of the
4 services and supports available under this title dur-
5 ing chronic and serious illness, including palliative
6 care, home care, long-term care, and hospice care.

7 “(D) An explanation by the practitioner of phy-
8 sician orders for life-sustaining treatment or similar
9 orders in States where such orders or similar orders
10 exist.

11 “(E) Facilitation by the practitioner of shared
12 decisionmaking with the patient (or proxy or surro-
13 gate) which may include—

14 “(i) use of decision aids and patient sup-
15 port tools;

16 “(ii) the provision of patient-centered,
17 easy-to-understand information about advance
18 care planning or disease-specific care planning;
19 and

20 “(iii) the incorporation of patient pref-
21 erences and values into the medical plan, an ad-
22 vance directive, and a physician order for life-
23 sustaining treatment as appropriate.

1 “(2) A practitioner described in this paragraph is a
2 physician (as defined in subsection (r)(1)), nurse practi-
3 tioner, or physician assistant.

4 “(3) Payment may not be made under this title for
5 a voluntary advance care planning consultation furnished
6 more often than once every 5 years unless there is a sig-
7 nificant change in the health, health-related condition, or
8 care setting of the individual.

9 “(4) For purposes of this section, the term ‘physician
10 order for life-sustaining treatment’ means, with respect to
11 an individual, an actionable medical order relating to the
12 treatment of that individual that effectively communicates
13 the individual’s preferences regarding life-sustaining treat-
14 ment, is in a form that is sanctioned or approved under
15 State law or regulation or is widely recognized by health
16 care providers in the State, and permits it to be followed
17 by health care professionals across the continuum of care.
18 Such an order may be changed or revoked by the indi-
19 vidual (or proxy or surrogate) at any time.”.

20 (2) CONSTRUCTION.—The voluntary advance
21 care planning consultation described in section
22 1861(iii) of the Social Security Act, as added by
23 paragraph (1), shall be completely optional. Nothing
24 in this section shall—

1 (A) require an individual to complete an
2 advance directive or a physician order for life-
3 sustaining treatment;

4 (B) require an individual to consent to re-
5 strictions on the amount, duration, or scope of
6 medical benefits an individual is entitled to re-
7 ceive under this title; or

8 (C) violate the Assisted Suicide Funding
9 Restriction Act of 1997 (Public Law 105–12)
10 by encouraging the promotion of suicide or as-
11 sisted suicide.

12 (3) PAYMENT.—Section 1848(j)(3) of such Act
13 (42 U.S.C. 1395w–4(j)(3)) is amended by inserting
14 “(2)(GG),” before “(3),”.

15 (4) FREQUENCY LIMITATION.—Section 1862(a)
16 of such Act (42 U.S.C. 1395y(a)) is amended—

17 (A) in paragraph (1)—

18 (i) in subparagraph (O), by striking
19 “and” at the end;

20 (ii) in subparagraph (P) by striking
21 the semicolon at the end and inserting “,
22 and”; and

23 (iii) by adding at the end the fol-
24 lowing new subparagraph:

1 “(Q) in the case of voluntary advance care
2 planning consultations (as defined in paragraph
3 (1) of section 1861(iii)), which are performed
4 more frequently than is covered under such sec-
5 tion;” and

6 (B) in paragraph (7), by striking “or (P)”
7 and inserting “(P), or (Q)”.

8 (5) EFFECTIVE DATE.—The amendments made
9 by this subsection shall apply to consultations fur-
10 nished on or after January 1, 2014.

11 (b) MEDICAID.—

12 (1) MANDATORY BENEFIT.—Section
13 1902(a)(10)(A) of the Social Security Act (42
14 U.S.C. 1396a(a)(10)(A)) is amended, in the matter
15 preceding clause (i), by striking “and (28)” and in-
16 serting “, (28), and (29)”.

17 (2) MEDICAL ASSISTANCE.—Section 1905(a) of
18 such Act (42 U.S.C. 1396d(a)) is amended—

19 (A) by striking “and” at the end of para-
20 graph (28);

21 (B) by redesignating paragraph (29) as
22 paragraph (30); and

23 (C) by inserting after paragraph (28) the
24 following new paragraph:

1 “(29) voluntary advance care planning con-
2 sultation (as defined in section 1861(iii)(1)); and”.

3 (c) DEFINITION OF ADVANCE DIRECTIVE UNDER
4 MEDICARE AND MEDICAID.—

5 (1) MEDICARE.—Section 1866(f)(3) of the So-
6 cial Security Act (42 U.S.C. 1395cc(f)(3)) is amend-
7 ed by striking “means” and all that follows and in-
8 serting the following: “means a living will, medical
9 directive, health care power of attorney, durable
10 power of attorney for health care, advance health
11 care directive, health care directive, or other state-
12 ment that is recorded and completed in a manner
13 recognized under State law by an individual with ca-
14 pacity to make health care decisions and that indi-
15 cates the individual’s wishes regarding medical treat-
16 ment in the event of future incapacity of the indi-
17 vidual to make health care decisions.”.

18 (2) MEDICAID.—Section 1902(w)(4) of such
19 Act (42 U.S.C. 1396a(w)(4)) is amended by striking
20 “means” and all that follows and inserting the fol-
21 lowing: “means a living will, medical directive,
22 health care power of attorney, durable power of at-
23 torney for health care, advance health care directive,
24 health care directive, or other statement that is re-
25 corded and completed in a manner recognized under

1 State law by an individual with capacity to make
2 health care decisions and that indicates the individ-
3 ual's wishes regarding medical treatment in the
4 event of future incapacity of the individual to make
5 health care decisions.”.

6 (d) EFFECTIVE DATE.—The amendments made by
7 this section take effect on January 1, 2014.

8 **SEC. 3. GRANTS FOR PROGRAMS FOR PHYSICIAN ORDERS**
9 **FOR LIFE-SUSTAINING TREATMENT.**

10 (a) IN GENERAL.—The Secretary of Health and
11 Human Services shall make grants to eligible entities for
12 the purpose of—

13 (1) establishing statewide programs for physi-
14 cian orders for life-sustaining treatment; or

15 (2) expanding or enhancing existing programs
16 for physician orders for life-sustaining treatment.

17 (b) AUTHORIZED ACTIVITIES.—Activities funded
18 through a grant under this section for an area may in-
19 clude—

20 (1) developing such a program for the area that
21 includes hospitals, home care, hospice, long-term
22 care, community and assisted living residences,
23 skilled nursing facilities, and emergency medical
24 services within a State; and

1 (2) expanding an existing program for physi-
2 cian orders regarding life-sustaining treatment to
3 serve more patients or enhance the quality of serv-
4 ices, including educational services for patients and
5 patients' families, training of health care profes-
6 sionals, or establishing a physician orders for life-
7 sustaining treatment registry.

8 (c) DISTRIBUTION OF FUNDS.—In funding grants
9 under this section, the Secretary shall ensure that, of the
10 funds appropriated to carry out this section for each fiscal
11 year—

12 (1) at least one-half are used for establishing
13 new programs for physician orders regarding life-
14 sustaining treatment; and

15 (2) remaining funds are to be used for expand-
16 ing or enhancing existing programs for physician or-
17 ders regarding life-sustaining treatment.

18 (d) DEFINITIONS.—In this section:

19 (1) The term “eligible entity” includes—

20 (A) an academic medical center, a medical
21 school, a State health department, a State med-
22 ical association, a multistate task force, a hos-
23 pital, or a health system capable of admin-
24 istering a program for physician orders regard-
25 ing life-sustaining treatment for a State; or

1 (B) any other health care agency or entity
2 as the Secretary determines appropriate.

3 (2) The term “physician order for life-sus-
4 taining treatment” has the meaning given such term
5 in section 1861(iii)(4) of the Social Security Act, as
6 added by section 2.

7 (3) The term “program for physician orders for
8 life-sustaining treatment” means a program that—

9 (A) supports the active use of physician or-
10 ders for life-sustaining treatment in the State;
11 and

12 (B) is guided by a coalition of stakeholders
13 that includes patient advocacy groups and rep-
14 resentatives from across the continuum of
15 health care services, such as disability rights
16 advocates, senior advocates, emergency medical
17 services, long-term care, medical associations,
18 hospitals, home health, hospice, the State agen-
19 cy responsible for senior and disability services,
20 and the State department of health.

21 (4) The term “Secretary” means the Secretary
22 of Health and Human Services.

23 (e) AUTHORIZATION OF APPROPRIATIONS.—To carry
24 out this section, there are authorized to be appropriated

1 such sums as may be necessary for each of the fiscal years
2 2014 through 2019.

3 **SEC. 4. ADVANCE CARE PLANNING STANDARDS FOR ELEC-**
4 **TRONIC HEALTH RECORDS.**

5 Notwithstanding section 3004(b)(3) of the Public
6 Health Service Act (42 U.S.C. 300jj-14(b)(3)), not later
7 than January 1, 2015, the Secretary of Health and
8 Human Services shall adopt, by rule, standards for a
9 qualified electronic health record (as defined in section
10 3000(13) of such Act (42 U.S.C. 300jj(13)), with respect
11 to patient communications with a health care provider
12 about values and goals of care, to adequately display the
13 following:

14 (1) The patient's current advance directive (as
15 defined in section 1866(f)(3) of the Social Security
16 Act (42 U.S.C. 1395cc(f)(3)), as applicable.

17 (2) The patient's current physician order for
18 life-sustaining treatment (as defined in section
19 1861(iii)(4) of the Social Security Act (42 U.S.C.
20 1395x(iii)(4)), as applicable.

21 A standard adopted under this section shall be treated as
22 a standard adopted under section 3004 of the Public
23 Health Service Act (42 U.S.C. 300jj-14) for purposes of
24 certifying qualified electronic health records pursuant to

1 section 3001(c)(5) of such Act (42 U.S.C. 300jj–
2 11(c)(5)).

3 **SEC. 5. PORTABILITY OF ADVANCE DIRECTIVES.**

4 (a) IN GENERAL.—Section 1866(f) of the Social Se-
5 curity Act (42 U.S.C. 1395cc(f)) is amended by adding
6 at the end the following new paragraph:

7 “(5)(A) An advance directive validly executed outside
8 the State in which such directive is presented must be
9 given effect by a provider of services or organization to
10 the same extent as an advance directive validly executed
11 under the law of the State in which it is presented.

12 “(B) In the absence of knowledge to the contrary,
13 a physician or other health care provider or organization
14 may presume that a written advance health care directive
15 or similar instrument, regardless of where executed, is
16 valid.

17 “(C) In the absence of a validly executed advance di-
18 rective, any authentic expression of a person’s wishes with
19 respect to health care shall be honored.

20 “(D) The provisions of this paragraph shall preempt
21 any State law on advance directive portability to the extent
22 such law is inconsistent with such provisions. Nothing in
23 the paragraph shall be construed to authorize the adminis-
24 tration of health care treatment otherwise prohibited by
25 the laws of the State in which the directive is presented.”.

1 (b) MEDICAID.—Section 1902(w) of the Social Secu-
2 rity Act (42 U.S.C. 1396a(w)) is amended by adding at
3 the end the following new paragraph:

4 “(6)(A) An advance directive validly executed outside
5 the State in which such directive is presented must be
6 given effect by a provider or organization to the same ex-
7 tent as an advance directive validly executed under the law
8 of the State in which it is presented.

9 “(B) In the absence of knowledge to the contrary,
10 a physician, other health care provider, or organization
11 may presume that a written advance health care directive
12 or similar instrument, regardless of where executed, is
13 valid.

14 “(C) In the absence of a validly executed advance di-
15 rective, any authentic expression of a person’s wishes with
16 respect to health care shall be honored.

17 “(D) The provisions of this paragraph shall preempt
18 any State law on advance directive portability to the extent
19 such law is inconsistent with such provisions. Nothing in
20 the paragraph shall be construed to authorize the adminis-
21 tration of health care treatment otherwise prohibited by
22 the laws of the State in which the directive is presented.”.