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To create a patient-centered quality of care initiative for seriously ill patients through the establishment of a stakeholder strategic summit, quality of life education and awareness initiative, health care workforce training, an advisory committee, and palliative care focused research, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

APRIL 23, 2013

Mr. CLEAVER (for himself and Mr. BACHUS) introduced the following bill; which was referred to the Committee on Energy and Commerce

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A BILL

To create a patient-centered quality of care initiative for seriously ill patients through the establishment of a stakeholder strategic summit, quality of life education and awareness initiative, health care workforce training, an advisory committee, and palliative care focused research, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Patient Centered Quality Care for Life Act''.

SEC. 2. FINDINGS.

Congress finds the following:

(1) Studies demonstrate that, despite very high health expenditures, seriously ill patients are not satisfied with the quality of their medical care, characterized by untreated symptoms, unmet psychosocial and personal care needs, high caregiver burden, and low patient and family satisfaction.

(2) Health care delivery systems in the United States are not set up to address the complex chronic care needs that are increasingly becoming the norm for more patients and survivors (and family caregivers of such patients and survivors) facing serious illness like cancer; heart, renal and liver failure; lung disease; Alzheimer's disease and related dementias, which are care needs that can span over many years or even decades and impose significant burdens on family caregivers.

(3) Public outreach and education for seriously ill patients, survivors, and their families to improve awareness of and demand for the benefits of integrating symptom management alongside disease-directed treatment is essential to improving the quality of life of patients, survivors, and their families, which should be an integral element of quality health care.

(4) Palliative care is specialized medical care for seriously ill patients. This type of care is focused on providing patients with relief from the symptoms, pain, and stresses of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

(5) Medical teams that help patients manage pain and stress during, alongside, and after treatment provide patients with better quality of life. Evidence-based research shows that such care may also lead to increased survival. These teams also reduce preventable suffering and caregiver breakdown.

(6) Patients receiving palliative or coordinated care feel better and are more likely to keep their doctor's appointments, complete their treatment, and take their medications. If patient disease-related and treatment-related symptoms such as pain, nausea, depression, fatigue, and breathlessness are managed, patients are more likely to eat well, exercise, social-

ize, and take pleasure in things that can help them feel better emotionally and physically and help them fight chronic illness.

(7) A 2010 Harris Interactive poll commissioned by the American Cancer Society Cancer Action Network (ACSCAN) among cancer patients, survivors, and their family caregivers found that fewer than one-third of the patients and survivors were asked by their doctor about what is important to such patients and survivors in terms of quality of life. In that same poll, fewer than one-third of the patients and survivors were asked if they were having stress, depression, anxiety, or other emotional concerns related to the cancer or discussed ways to help with those emotional effects, though more than one-third of such patients and survivors said they had these emotional concerns.

(8) A report commissioned by the Health Resources Service Administration (HRSA) in 2002 projected significant shortfalls in the number of palliative medicine specialists in the United States and called for increased education and training in symptom assessment and management and other palliative care core competencies across all clinical specialties serving seriously ill patients. Several Institute of

Medicine cancer reports, including on palliative care in 2001, survivorship in 2006, psychosocial care in 2007, and pain in 2011 have also consistently signaled the need for skills training to improve health professional communication with patients and families regarding symptoms, establishing goals of care, tailoring treatments to those goals, and other quality of life concerns.

SEC. 3. NATIONAL PATIENT-CENTERED HEALTH CARE AND QUALITY OF LIFE STAKEHOLDER STRATEGIC SUMMIT.

(a) SUMMIT.—Not later than one year after the date of the enactment of this section, the Secretary of Health and Human Services shall convene a Patient-Centered Health Care and Quality of Life Stakeholder Strategic Summit (in this Act to be referred to as the ''Summit'') to be composed of individuals with appropriate expertise to—

(1) analyze key health system barriers to providing patient-centered health care that integrates symptom management and other aspects of coordinated or palliative care; and

(2) identify strategic solutions for collectively addressing quality of life concerns for the rapidly expanding population of patients and survivors facing

serious, complex, and chronic illness in the United States and for the families of such patients and survivors.

(b) PARTICIPANTS.—The Summit shall include representatives from at least the following:

(1) Federal agencies, including—

(A) the Department of Health and Human Services, including from the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the Agency for Healthcare Research and Quality, the Centers for Medicare & Medicaid Services, and the National Institutes of Health;

(B) the Department of Veterans Affairs; and

(C) the Department of Defense.

(2) Private organizations, including—

(A) health professional organizations that represent physicians, nurses, pharmacists, and social workers;

(B) patient non-profit organizations (as defined in section 4(g));

(C) private health insurance organizations;

(D) faith community representatives; and

(E) other professionals as deemed appropriate by the Secretary.

(c) STEERING COMMITTEE.—

(1) IN GENERAL.—The Secretary shall establish a Summit Steering Committee to plan the Summit, coordinate participants of the Summit, develop an agenda for the Summit that is in accordance with subsection (d), and draft a summary report detailing recommendations made by the participants of the Summit for a national strategic action agenda to improve patient-centered care and quality of life (in this Act to be referred to as the ''National Action Agenda'') in accordance with subsection (d)(4). The Secretary shall appoint the representatives described in paragraph (2)(A) and shall seek nominations from relevant stakeholders and, from such nominations, appoint representatives described in paragraph (2)(B).

(2) COMPOSITION.—The Summit Steering Committee shall consist of at least the following members:

(A) MEMBERS FROM FEDERAL AGENCIES.—

(i) The Secretary, who will serve as chair of the Committee.

(ii) Four representatives from Federal agencies described in subsection (b) (or any other Federal agency deemed appropriate by the Secretary), to be appointed by the Secretary.

(B) MEMBERS REPRESENTING STAKEHOLDER ENTITIES.—

(i) Six representatives of health professionals (with each of such 6 representatives having research, clinical, and teaching or mentoring expertise);

(ii) Three representatives of patient advocacy organizations.

(iii) One representative of a private health insurance organization.

(iv) One representative of faith communities.

(v) Two physicians.

(vi) Two nurses.

(vii) One social worker.

(d) AGENDA.—The agenda for the Summit shall focus on specific areas that include at least the following:

(1) Improving communication and coordination of health care among primary care providers, medical specialists, and other health professionals and

seriously ill patients and families of such patients to ensure that symptoms are managed and other quality of life needs are met to support the continued functioning and well-being of such patients.

(2) Examining the appropriate roles of both physician and non-physician professionals (such as nurse practitioners, clinical social workers, physician assistants, and other patient or survivor navigators or case coordinators) in strengthening access to integrated, coordinated, or palliative care across care settings for all seriously ill patients and families of such patients.

(3) Examining the role of health information technology in promoting delivery of integrated care to such patients.

(4) Developing recommendations for a National Action Agenda, which shall specify research, surveillance, health information technology, workforce training, delivery of care, and communication activities required to collectively address barriers to achieving integrated palliative care for seriously ill patients in all care settings. Such agenda shall include strategies for reducing disparities among medically underserved populations.

(e) REPORT.—Not later than one year after the last day of the Summit, the Secretary of Health and Human Services shall submit to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate a report on the recommendations made by the participants of the Summit and shall make such recommendations available to the public.

(f) SERIOUSLY ILL PATIENT DEFINED.—For purposes of this Act, the term ''seriously ill patient'' means an individual who has a serious health condition (as defined in section 101(11) of the Family and Medical Leave Act of 1993 (26 U.S.C. 2911(11)).

(g) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section such sums as are necessary for each of the fiscal years 2014 through 2018.

SEC. 4. QUALITY OF LIFE PATIENT AND PROFESSIONAL AWARENESS GRANTS PROGRAM INITIATIVE.

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following new part:

"PART W—PROGRAMS RELATING TO PALLIATIVE CARE

"SEC. 399OO. QUALITY OF LIFE PATIENT AND PROFESSIONAL AWARENESS GRANTS PROGRAM INITIATIVE.

''(a) IN GENERAL.—Not later than 6 months after the date of the submission of the report by the Patient-Centered Health Care and Quality of Life Stakeholder Strategic Summit under section 3(e) of the Patient Centered Quality Care for Life Act, the Secretary, through the Director of the Centers for Disease Control and Prevention, shall establish a national quality of life education and awareness grants program initiative for seriously ill patients, families of such patients, and health professionals who treat such patients for the purposes of encouraging an increased demand for and delivery of integrated and patient-centered care for managing pain and symptoms of such patients and improving the quality of life of such patients. Under the initiative, the Secretary shall, subject to subsection (h), award competitive grants to eligible entities described in subsection (b) to develop new and expand existing information, resources, and communication materials about symptom management and other aspects of patient-centered care as an integral part of quality care for serious illnesses such as cancer; heart, renal and liver failure; lung disease; and Alzheimer's dis-

ease and related dementias. Such materials shall be presented in a variety of formats (such as online, print, and public service announcement).

"(b) ELIGIBLE ENTITIES.—For purposes of this section, an eligible entity includes only a State health department, community health center, State or territory program supported by the National Comprehensive Cancer Control Program of the Centers for Disease Control and Prevention, health profession school, chronic disease or cancer center, academic medical center, physician practice, home health care agency, palliative care or psychosocial care team (as defined in subsection (g)), hospice program, patient non-profit organization (as defined in subsection (g)), clinical pastoral education program, long-term care facility, faith community organization, or other public or private entity or organization addressing patient-centered care and quality of life concerns of seriously ill patients.

"(c) APPLICATION.—To be eligible to receive a grant under this section, an entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Director may require, including assurances that the entity will—

"(1) evaluate programs carried out by the entity through a grant provided under this section;

1 "(2) submit to the Secretary a report on the
2 findings of such evaluations; and
3 "(3) coordinate the dissemination of such find-
4 ings with the Secretary.
5 "(d) USE OF FUNDS.—An entity awarded a grant
6 under this section shall use such grant to carry out pro-
7 grams described in subsection (e), for patients and fami-
8 lies of such patients that further the purposes described
9 in subsection (a).
10 "(e) PROGRAMS.—Programs described in this sub-
11 section, for which a grant awarded under this section may
12 be used, include programs to—
13 "(1) navigate the health system, including as-
14 sistance to patients with finding health professionals
15 to support quality of life needs, care decision-making
16 and coordination, and transitions across care set-
17 tings;
18 "(2) provide general advocacy on behalf of pa-
19 tients and survivors to provide patients information
20 to help them effectively communicate with health
21 care providers about pain, physical and psychosocial
22 symptoms, and barriers they are facing in adhering
23 to curative or disease-directed treatments;
24 "(3) encourage health professionals to request
25 coordinated patient-centered care consults for pa-

tients that are integrated alongside disease directed treatment in various care settings; and

"(4) collect and analyze data related to the effectiveness of the initiative under subsection (a).

"(f) PRIORITY.—In carrying out the grant program under this section, the Secretary shall give priority to applications that include an emphasis on addressing outreach efforts for seriously ill patients who are among medically underserved populations (as defined in section 1302(7)) and families of such patients or health professionals serving medically underserved populations. Such populations would include pediatric patients, young adult and adolescent patients, racial and ethnic minority populations, and other priority populations specified by the Secretary.

"(g) DEFINITIONS.—For purposes of this section:

"(1) PSYCHOSOCIAL CARE TEAM.—The term 'psychosocial care team' means health professionals focused on addressing social and emotional concerns of serious illness, and may include professionals such as social workers, psychiatrists, psychologists, nurses, child life specialists, teachers, chaplains, spiritual counselors, physical and occupational therapists, nutritionists, integrative medicine specialists,

patient service coordinators, patient navigators, and patient representatives.

"(2) PATIENT NON-PROFIT ORGANIZATION.—The term 'patient non-profit organization' means a nonprofit entity primarily engaged in raising funds for health-related research, such as disease prevention, health education, and patient services.

"(h) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section such sums as are necessary.".

SEC. 5. PROFESSIONAL WORKFORCE TRAINING GRANTS PROGRAM INITIATIVE.

Part W of title III of the Public Health Service Act, as added by section 4, is amended by adding at the end the following new section:

"SEC. 399OO–1. PROFESSIONAL WORKFORCE TRAINING GRANTS PROGRAM INITIATIVE.

"(a) INITIATIVE.—

"(1) IN GENERAL.—Not later than 6 months after the date of the submission of the report by the Patient-Centered Health Care and Quality of Life Stakeholder Strategic Summit under section 3(e) of the Patient Centered Quality Care for Life Act, the Secretary, through the Administrator of the Health Resources and Services Administration, shall estab-

lish a health care professional workforce training grants program initiative for the purposes of promoting and enhancing symptom assessment and management, communications skills, coordinated patient-centered care, and other quality of life focused clinical core competencies (as described in paragraph (2)) across all clinical specialties that serve seriously ill patients and patients with multiple or complex chronic diseases, such as patients with cancer; heart, renal, and liver failure; lung disease; and Alzheimer's disease and related dementias. Under such initiative, the Secretary shall, subject to subsection (i), award competitive grants to eligible entities to provide evidence-based training and develop new training for health professionals, including physicians, nurses, social workers, and professional chaplains for the purposes described in the previous sentence.

"(2) QUALITY OF LIFE FOCUSED CLINICAL CORE COMPETENCIES DESCRIBED.—For purposes of paragraph (1), quality of life focused clinical core competencies include, at a minimum, the assessment and management of physical, psychological, and spiritual symptoms; establishment of patient-centered goals of care; support to patient and family

1 caregivers; and management of transitions across
2 care sites.
3 "(b) ELIGIBLE ENTITIES.—For purposes of sub-
4 section (a), an eligible entity is an entity described in sec-
5 tion 399OO(b).
6 "(c) APPLICATION.—To be eligible to receive a grant
7 under this section, an entity shall submit to the Secretary
8 an application at such time, in such manner, and con-
9 taining such information as the Secretary may require, in-
10 cluding assurances that the entity will—
11 "(1) evaluate programs carried out by the enti-
12 ty through the grant provided under this section;
13 "(2) submit to the Secretary a report on the
14 findings of such evaluations; and
15 "(3) coordinate the dissemination of such find-
16 ings with the Secretary.
17 "(d) USE OF FUNDS.—An entity awarded a grant
18 under this section shall use such grant to carry out pro-
19 grams described in subsection (e) to train health care pro-
20 fessionals described in subsection (a)(1) for the purposes
21 described in such subsection.
22 "(e) PROGRAMS.—Programs described in this sub-
23 section, for which a grant awarded under this section may
24 be used, include programs to—

1 "(1) enhance health professional communication
2 skills in caring for seriously ill patients and sur-
3 vivors, establishing goals of care, and tailoring treat-
4 ments;
5 "(2) improve health profession identification of
6 patient populations that benefit from coordinated
7 palliative care and appropriate referral of patients
8 for consultations with specialized interdisciplinary
9 palliative care teams;
10 "(3) improve health professional skills in symp-
11 toms assessment and management, developing com-
12 prehensive care coordination and discharge plans to
13 support transitions across care settings, managing
14 patients with complex or multiple chronic conditions,
15 and preparing survivorship care plans;
16 "(4) promote quality of life focused clinical core
17 competencies (as described in subsection (a)(2))
18 across all clinical specialties serving seriously ill pa-
19 tients;
20 "(5) provide technical assistance to hospitals
21 and other care settings to establish coordinated pal-
22 liative care teams;
23 "(6) create and expand coordinated palliative
24 care leadership centers (as defined in subsection
25 (h));

1 "(7) provide mentoring and training to health
2 professionals;
3 "(8) improve cultural sensitivity communication
4 and patient care for minority and medically under-
5 served populations, including by addressing the par-
6 ticular needs of children, adolescents, and families of
7 such children and adolescents; racial and ethnic
8 groups; and other medically underserved patient and
9 survivor populations; and
10 "(9) collect and analyze data related to the ef-
11 fectiveness of health professional education and
12 training efforts carried out pursuant to this section.
13 "(f) PRIORITY.—In carrying out the grant program
14 under this section, the Secretary shall give priority to ap-
15 plications that include an emphasis on addressing out-
16 reach efforts for seriously ill patients who are among
17 medically underserved populations (as defined in section
18 1302(7)) and families of such patients or health profes-
19 sionals serving medically underserved populations. Such
20 populations would include pediatric patients, young adult
21 and adolescent patients, racial and ethnic minority popu-
22 lations, and other priority populations specified by the
23 Secretary.
24 "(g) STUDY.—Not later than one year after the date
25 of the enactment of the Patient Centered Quality Care for

1 Life Act, the Secretary shall update and expand the Sep-
2 tember 2002 report of the Health Resources and Services
3 Administration, titled 'The Supply, Demand and Use of
4 Palliative Care Physicians in the United States'. Such up-
5 date and expansion shall be based on an examination of
6 workforce trends, workforce capacity, and training needs
7 for palliative medicine physicians, physician assistants,
8 nurse practitioners, and other palliative care team mem-
9 bers in all care settings in the United States, as well as
10 training needs for other medical specialists and non-physi-
11 cian clinicians.

12 ''(h) PALLIATIVE CARE LEADERSHIP CENTER DE-
13 FINED.—For purposes of this section, the term 'palliative
14 care leadership center' means a center—

15 ''(1) that trains hospital palliative care pro-
16 grams;

17 ''(2) that provides intensive operational training
18 and mentoring for palliative care programs at every
19 stage of development and growth; and

20 ''(3) that provides training oriented to teams
21 rather than individuals, and involves participation by
22 teams of hospital and hospice health care profes-
23 sionals involved in starting or running a palliative
24 care program, including physicians, nurses, social
25 workers, administrators and financial managers.

"(i) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section such sums as are necessary for each of the fiscal years 2014 through 2019.".

SEC. 6. QUALITY OF LIFE CROSS-AGENCY ADVISORY COMMITTEE.

Part W of title III of the Public Health Service Act, as added by section 4 and amended by section 5, is further amended by adding at the end the following new section:

"SEC. 399OO–2. QUALITY OF LIFE CROSS-AGENCY ADVISORY COMMITTEE.

"(a) ESTABLISHMENT.—Not later than 90 days after the date of the enactment of this section and subject to subsection (e), the Secretary shall establish a Quality of Life Cross-Agency Advisory Committee (in this section to be referred to as the 'Advisory Committee') to advise, coordinate, and assist the Centers for Disease Control and Prevention and the Health Resources and Services Administration in creating and conducting the national quality of life education and awareness initiative under section 399OO and the health care professional workforce training initiative under section 399OO–1 and disseminate findings that have been identified from such initiatives for cross agency implementation of best practices.

1 "(b) MEMBERSHIP.—The Advisory Committee shall
2 be composed of members who shall be appointed by the
3 Secretary and shall include representatives of—
4 "(1) the Department of Health and Human
5 Services, including from the Centers for Disease
6 Control and Prevention, the Health Resources and
7 Services Administration, the Agency for Healthcare
8 Research and Quality, the Centers for Medicare &
9 Medicaid Services, and the National Institutes of
10 Health;
11 "(2) the Department of Veterans Affairs;
12 "(3) the Department of Defense;
13 "(4) public and private organizations with ex-
14 pertise in patient-centered care, palliative care, psy-
15 chosocial care, and symptom management and survi-
16 vorship; and
17 "(5) such other representatives as the Secretary
18 deems necessary.
19 "(c) DUTIES.—The Advisory Committee shall—
20 "(1) evaluate the results of the programs fund-
21 ed by the grants awarded under section 399OO(b)
22 and under section 399OO–1(b);
23 "(2) coordinate and implement a cross-agency
24 strategic plan, with respect to the agencies specified

in subsection (b), to disseminate findings from such programs;

"(3) advise the Secretary of Health and Human Services on strategies for disseminating across agencies specified in subsection (b) recommendations from the National Action Agenda described in section 3(c)(1) of the Patient Centered Quality Care for Life Act;

"(4) consider and summarize recent advances achieved in symptom management and survivorship research relevant to the goals of this part and make recommendations to the Director of the National Institutes of Health on gaps in basic, clinical, behavioral, or other research required to achieve further improvements in care to support quality of life and survivorship;

"(5) develop a strategy for developing new and enhancing health surveillance tools used to track symptoms, late effects, and quality care trends over time, including national surveys of the overall population of the United States, such as the National Health Interview Survey and the Behavioral Risk Factor Surveillance System conducted by the Centers for Disease Control and Prevention and the Health Information National Trends Survey con-

ducted by the National Institutes of Health, as well as administrative databases and disease registries such as databases of the Centers for Medicare & Medicaid Services, the Surveillance Epidemiology and End Results (SEER) cancer registries program of the National Cancer Institute, the SEER–Medicare Linked Database of the National Cancer Institute, and the National Program of Cancer Registries of the Centers for Disease Control and Prevention; and

"(6) make appropriate updates and addendums annually to the National Action Agenda.

"(d) MEETINGS.—The Advisory Committee shall meet at least once a year.

"(e) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section such sums as are necessary for each of the fiscal years 2014 through 2019.".

SEC. 7. ENHANCING RESEARCH IN SUPPORT OF PATIENT QUALITY OF LIFE.

(a) IN GENERAL.—Part W of title III of the Public Health Service Act, as added by section 4 and amended by sections 5 and 6, is further amended by adding at the end the following new section:

"SEC. 399OO–3. ENHANCING RESEARCH IN SUPPORT OF PATIENT QUALITY OF LIFE.

"(a) IN GENERAL.—The Secretary, acting through the Director of the National Institutes of Health, shall develop and implement a strategy to be applied across the institutes and centers of the National Institutes of Health that is in accordance with recommendations of the Advisory Committee established under section 399OO–2 to expand national research programs in symptom management, palliative, psychosocial, and survivorship care.

"(b) RESEARCH PROGRAMS.—The Director of the National Institutes of Health shall expand and intensify research programs in symptom management and palliative, psychosocial, and survivorship care and research programs that address the quality of life needs for the rapidly growing population in the United States of seriously ill patient (with illnesses such as cancer; heart, renal and live failure; lung disease; and Alzheimer's disease and related dementias).".

(b) EXPANDING TRANS-NIH RESEARCH REPORTING TO INCLUDE QUALITY OF LIFE AND SURVIVORSHIP RESEARCH.—

(1) IN GENERAL.—Section 402A(c)(2)(B)(i) of the Public Health Service Act (42 U.S.C. 282a(c)(2)(B)(i)) is amended by inserting "and for conducting or supporting research with respect to

1 quality of life and survivorship'' after ''or national
2 centers''.
3 (2) EFFECTIVE DATE.—The amendment made
4 by paragraph (1) shall apply with respect to reports
5 required on or after January 1, 2014.

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