

114TH CONGRESS
1ST SESSION

H. R. 3119

To amend the Public Health Service Act to increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs, to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine.

IN THE HOUSE OF REPRESENTATIVES

JULY 21, 2015

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

A BILL

To amend the Public Health Service Act to increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs, to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine.

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.**

2 This Act may be cited as the “Palliative Care and
3 Hospice Education and Training Act”.

4 **SEC. 2. FINDINGS.**

5 Congress makes the following findings:

6 (1) Health care providers need better education
7 about pain management and palliative care. Stu-
8 dents graduating from medical school have very lit-
9 tle, if any, training in the core precepts of pain and
10 symptom management, advance care planning, com-
11 munication skills, and care coordination for patients
12 with serious, life-threatening, or terminal illness.

13 (2) Palliative care is interdisciplinary, patient-
14 and family-centered health care for people with seri-
15 ous illnesses. This type of care is focused on pro-
16 viding patients with relief from the symptoms, pain,
17 and stress of a serious illness, whatever the diag-
18 nosis. The goal of palliative care is to relieve suf-
19 fering and improve quality of life for both patients
20 and their families. Palliative care is provided by a
21 team of doctors, nurses, social workers, physician as-
22 sistants, chaplains, and other specialists who work
23 with a patient’s other health care providers to pro-
24 vide an extra layer of support, including assistance
25 with difficult medical decisionmaking and coordina-
26 tion of care among specialists. Palliative care is ap-

1 appropriate at any age and at any stage in a serious
2 illness, and can be provided together with curative
3 treatment. Palliative care is not dependent on a life-
4 limiting prognosis and may actually help an indi-
5 vidual recover from illness by relieving symptoms,
6 such as pain, anxiety, or loss of appetite, while un-
7 dergoing sometimes difficult medical treatments or
8 procedures, such as surgery or chemotherapy. In
9 2013, 1,744 United States hospitals with 50 or more
10 beds had a palliative care program.

11 (3) Hospice is palliative care for patients in
12 their last year of life. Considered the model for qual-
13 ity compassionate care for individuals facing a life-
14 limiting illness, hospice provides expert medical care,
15 pain management, and emotional and spiritual sup-
16 port expressly tailored to the patient's needs and
17 wishes. In most cases, care is provided in the pa-
18 tient's home but may also be provided in free-
19 standing hospice centers, hospitals, nursing homes,
20 and other long-term care facilities. In 2012, an esti-
21 mated 1.5 million to 1.6 million patients received
22 services from hospice, including non-Medicare bene-
23 ficiaries. Nearly 45 percent of all deaths in the
24 United States in 2011 occurred under the care of a
25 hospice program. Hospice is a covered benefit under

1 the Medicare program. There were 3,782 Medicare-
2 certified hospices serving more than 1,200,000 Medi-
3 care beneficiaries in 2012.

4 (4) Despite a high intensity of medical treat-
5 ment, many seriously ill patients experience trou-
6 bling symptoms, unmet psychological and personal
7 care needs, and high caregiver burden. Numerous
8 studies have shown that adding palliative care can
9 improve pain and symptom control, quality of life,
10 and family satisfaction with care.

11 (5) A 2005 study at Michigan State University
12 found that the formal training of United States doc-
13 tors in palliative care is “grossly inadequate”. When
14 the American Society of Clinical Oncology surveyed
15 their members, 65 percent said they had received in-
16 adequate education in controlling symptoms associ-
17 ated with cancer, and 81 percent felt they had inad-
18 equate mentoring in discussing a poor prognosis
19 with their patients and families. Training in pedi-
20 atric palliative care is also seriously lacking accord-
21 ing to physicians, residents, and medical students re-
22 sponding to a survey presented at a meeting of
23 American Federation for Medical Research.

24 (6) The American Board of Medical Specialties
25 (ABMS) and the Accreditation Council for Graduate

1 Medical Education (ACGME) provided formal sub-
2 specialty status for hospice and palliative medicine
3 (HPM) in 2006, and the Centers for Medicare &
4 Medicaid Services recognized hospice and palliative
5 medicine as a medical subspecialty in October of
6 2008.

7 (7) As of April 2015, there were a total of 106
8 hospice and palliative medicine training programs
9 accredited by the Accreditation Council for Graduate
10 Medical Education. For the 2014–2015 academic
11 year, these programs were training 265 physicians in
12 hospice and palliative medicine. Some programs in-
13 clude an additional track in research, geriatrics, pe-
14 diatrics, or public health.

15 (8) There is a large gap between those prac-
16 ticing in the palliative medicine field and the number
17 of physicians needed. A mid-range estimate by the
18 American Academy of Hospice and Palliative Medi-
19 cine’s Workforce Task Force calls for 6,000 or more
20 full-time equivalents to serve current needs in hos-
21 pice and palliative care programs. At maximum ca-
22 pacity, the current system would produce roughly
23 5,300 new hospice and palliative medicine certified
24 physicians over the next 20 years, during which time
25 some 70,000,000 new Medicare beneficiaries will

1 enter the Medicare program. At the same time, there
2 is expected to be increasing acceptance of the hos-
3 pice and palliative approach to care among the gen-
4 eral population and health care providers.

5 (9) According to the Institute of Medicine,
6 there is a “need for better understanding of the role
7 of palliative care among both the public and profes-
8 sionals across the continuum of care so that hospice
9 and palliative care can achieve their full potential for
10 patients and their families”.

11 **SEC. 3. PALLIATIVE CARE AND HOSPICE EDUCATION AND**
12 **TRAINING.**

13 (a) IN GENERAL.—Part D of title VII of the Public
14 Health Service Act (42 U.S.C. 294 et seq.) is amended
15 by adding at the end the following:

16 **“SEC. 759A. PALLIATIVE CARE AND HOSPICE EDUCATION**
17 **AND TRAINING.**

18 “(a) PALLIATIVE CARE AND HOSPICE EDUCATION
19 CENTERS.—

20 “(1) IN GENERAL.—The Secretary shall award
21 grants or contracts under this section to entities de-
22 scribed in paragraph (1), (3), or (4) of section
23 799B, and section 801(2), for the establishment or
24 operation of Palliative Care and Hospice Education

1 Centers that meet the requirements of paragraph
2 (2).

3 “(2) REQUIREMENTS.—A Palliative Care and
4 Hospice Education Center meets the requirements of
5 this paragraph if such Center—

6 “(A) improves the training of health pro-
7 fessionals in palliative care, including residen-
8 cies, traineeships, or fellowships;

9 “(B) develops and disseminates curricula
10 relating to the palliative treatment of the com-
11 plex health problems of individuals with serious
12 or life threatening illnesses;

13 “(C) supports the training and retraining
14 of faculty to provide instruction in palliative
15 care;

16 “(D) supports continuing education of
17 health professionals who provide palliative care
18 to patients with serious or life threatening ill-
19 ness;

20 “(E) provides students (including resi-
21 dents, trainees, and fellows) with clinical train-
22 ing in palliative care in long-term care facilities,
23 home care, hospices, chronic and acute disease
24 hospitals, and ambulatory care centers;

1 “(F) establishes traineeships for individ-
 2 uals who are preparing for advanced education
 3 nursing degrees, social work degrees, or ad-
 4 vanced degrees in physician assistant studies,
 5 with a focus in palliative care in long-term care
 6 facilities, home care, hospices, chronic and
 7 acute disease hospitals, and ambulatory care
 8 centers; and

9 “(G) does not duplicate the activities of ex-
 10 isting education centers funded under this sec-
 11 tion or under section 753 or 865.

12 “(3) EXPANSION OF EXISTING CENTERS.—
 13 Nothing in this section shall be construed to—

14 “(A) prevent the Secretary from providing
 15 grants to expand existing education centers, in-
 16 cluding geriatric education centers established
 17 under section 753 or 865, to provide for edu-
 18 cation and training focused specifically on pal-
 19 liative care, including for non-geriatric popu-
 20 lations; or

21 “(B) limit the number of education centers
 22 that may be funded in a community.

23 “(b) PALLIATIVE MEDICINE PHYSICIAN TRAINING.—

24 “(1) IN GENERAL.—The Secretary may make
 25 grants to, and enter into contracts with, schools of

1 medicine, schools of osteopathic medicine, teaching
2 hospitals, and graduate medical education programs,
3 for the purpose of providing support for projects
4 that fund the training of physicians (including resi-
5 dents, trainees, and fellows) who plan to teach pal-
6 liative medicine.

7 “(2) REQUIREMENTS.—Each project for which
8 a grant or contract is made under this subsection
9 shall—

10 “(A) be staffed by full-time teaching physi-
11 cians who have experience or training in pallia-
12 tive medicine;

13 “(B) be based in a hospice and palliative
14 medicine fellowship program accredited by the
15 Accreditation Council for Graduate Medical
16 Education;

17 “(C) provide training in palliative medicine
18 through a variety of service rotations, such as
19 consultation services, acute care services, ex-
20 tended care facilities, ambulatory care and com-
21 prehensive evaluation units, hospice, home
22 health, and community care programs;

23 “(D) develop specific performance-based
24 measures to evaluate the competency of train-
25 ees; and

1 “(E) provide training in palliative medicine
2 through one or both of the training options de-
3 scribed in subparagraphs (A) and (B) of para-
4 graph (3).

5 “(3) TRAINING OPTIONS.—The training options
6 referred to in subparagraph (E) of paragraph (2)
7 shall be as follows:

8 “(A) 1-year retraining programs in hospice
9 and palliative medicine for physicians who are
10 faculty at schools of medicine and osteopathic
11 medicine, or others determined appropriate by
12 the Secretary.

13 “(B) 1- or 2-year training programs that
14 shall be designed to provide training in hospice
15 and palliative medicine for physicians who have
16 completed graduate medical education programs
17 in any medical specialty leading to board eligi-
18 bility in hospice and palliative medicine pursu-
19 ant to the American Board of Medical Special-
20 ties.

21 “(4) DEFINITIONS.—For purposes of this sub-
22 section the term ‘graduate medical education’ means
23 a program sponsored by a school of medicine, a
24 school of osteopathic medicine, a hospital, or a pub-
25 lic or private institution that—

1 “(A) offers postgraduate medical training
2 in the specialties and subspecialties of medicine;
3 and

4 “(B) has been accredited by the Accredita-
5 tion Council for Graduate Medical Education or
6 the American Osteopathic Association through
7 its Committee on Postdoctoral Training.

8 “(c) PALLIATIVE MEDICINE AND HOSPICE AKA-
9 DEMIC CAREER AWARDS.—

10 “(1) ESTABLISHMENT OF PROGRAM.—The Sec-
11 retary shall establish a program to provide awards,
12 to be known as the ‘Palliative Medicine and Hospice
13 Academic Career Awards’, to eligible individuals to
14 promote the career development of such individuals
15 as academic hospice and palliative care physicians.

16 “(2) ELIGIBLE INDIVIDUALS.—To be eligible to
17 receive an award under paragraph (1), an individual
18 shall—

19 “(A) be board certified or board eligible in
20 hospice and palliative medicine; and

21 “(B) have a junior (non-tenured) faculty
22 appointment at an accredited (as determined by
23 the Secretary) school of medicine or osteopathic
24 medicine.

1 “(3) LIMITATIONS.—No award under para-
2 graph (1) may be made to an eligible individual un-
3 less the individual—

4 “(A) has submitted to the Secretary an ap-
5 plication, at such time, in such manner, and
6 containing such information as the Secretary
7 may require, and the Secretary has approved
8 such application;

9 “(B) provides, in such form and manner as
10 the Secretary may require, assurances that the
11 individual will meet the service requirement de-
12 scribed in paragraph (6); and

13 “(C) provides, in such form and manner as
14 the Secretary may require, assurances that the
15 individual has a full-time faculty appointment
16 in a health professions institution and docu-
17 mented commitment from such institution to
18 spend a majority of the total funded time of
19 such individual on teaching and developing
20 skills in interdisciplinary education in palliative
21 care.

22 “(4) MAINTENANCE OF EFFORT.—An eligible
23 individual who receives an award under paragraph
24 (1) shall provide assurances to the Secretary that
25 funds provided to the eligible individual under this

1 subsection will be used only to supplement, not to
2 supplant, the amount of Federal, State, and local
3 funds otherwise expended by the eligible individual.

4 “(5) AMOUNT AND TERM.—

5 “(A) AMOUNT.—The amount of an award
6 under this subsection shall be equal to the
7 award amount provided for under section
8 753(c)(5)(A) for the fiscal year involved.

9 “(B) TERM.—The term of an award made
10 under this subsection shall not exceed 5 years.

11 “(C) PAYMENT TO INSTITUTION.—The
12 Secretary shall make payments for awards
13 under this subsection to institutions which in-
14 clude schools of medicine and osteopathic medi-
15 cine.

16 “(6) SERVICE REQUIREMENT.—An individual
17 who receives an award under this subsection shall
18 provide training in palliative care and hospice, in-
19 cluding the training of interdisciplinary teams of
20 health care professionals. The provision of such
21 training shall constitute a majority of the total fund-
22 ed obligations of such individual under the award.

23 “(d) PALLIATIVE CARE WORKFORCE DEVELOP-
24 MENT.—

1 “(1) IN GENERAL.—The Secretary shall award
2 grants or contracts under this subsection to entities
3 that operate a Palliative Care and Hospice Edu-
4 cation Center pursuant to subsection (a)(1).

5 “(2) APPLICATION.—To be eligible for an
6 award under paragraph (1), an entity described in
7 such paragraph shall submit to the Secretary an ap-
8 plication at such time, in such manner, and con-
9 taining such information as the Secretary may re-
10 quire.

11 “(3) USE OF FUNDS.—Amounts awarded under
12 a grant or contract under paragraph (1) shall be
13 used to carry out the fellowship program described
14 in paragraph (4).

15 “(4) FELLOWSHIP PROGRAM.—

16 “(A) IN GENERAL.—Pursuant to para-
17 graph (3), a Palliative Care and Hospice Edu-
18 cation Center that receives an award under this
19 subsection shall use such funds to offer short-
20 term intensive courses (referred to in this sub-
21 section as a ‘fellowship’) that focus on palliative
22 care that provide supplemental training for fac-
23 ulty members in medical schools and other
24 health professions schools with programs in
25 psychology, pharmacy, nursing, social work,

1 physician assistant education, chaplaincy, or
2 other health disciplines, as approved by the Sec-
3 retary. Such a fellowship shall be open to cur-
4 rent faculty, and appropriately credentialed vol-
5 unteer faculty and practitioners, who do not
6 have formal training in palliative care, to up-
7 grade their knowledge and clinical skills for the
8 care of individuals with serious or life-threat-
9 ening illness and to enhance their interdiscipli-
10 nary and interprofessional teaching skills.

11 “(B) LOCATION.—A fellowship under this
12 paragraph shall be offered either at the Pallia-
13 tive Care and Hospice Education Center that is
14 sponsoring the course, in collaboration with
15 other Palliative Care and Hospice Education
16 Centers, or at medical schools, schools of nurs-
17 ing, schools of pharmacy, schools of social work,
18 schools of chaplaincy or pastoral care education,
19 graduate programs in psychology, physician as-
20 sistant education programs, or other health pro-
21 fessions schools approved by the Secretary with
22 which the Centers are affiliated.

23 “(C) CONTINUING EDUCATION CREDIT.—
24 Participation in a fellowship under this para-
25 graph shall be accepted with respect to com-

plying with continuing health profession education requirements. As a condition of such acceptance, the recipient shall subsequently provide a minimum of 18 hours of voluntary instruction in palliative care content (that has been approved by a palliative care and hospice education center) to students or trainees in health-related educational, home, hospice, or long-term care settings.

“(5) TARGETS.—A Palliative Care and Hospice Education Center that receives an award under this subsection shall meet targets approved by the Secretary for providing palliative care training to a certain number of faculty or practitioners during the term of the award, as well as other parameters established by the Secretary.

“(6) AMOUNT OF AWARD.—An award under this subsection shall be in an amount of \$150,000. Not more than 24 Palliative Care and Hospice Education Centers may receive an award under this subsection.

“(7) MAINTENANCE OF EFFORT.—A Palliative Care and Hospice Education Center that receives an award under this subsection shall provide assurances to the Secretary that funds provided to the Center

1 under the award will be used only to supplement,
2 not to supplant, the amount of Federal, State, and
3 local funds otherwise expended by such Center.

4 “(e) PALLIATIVE CARE AND HOSPICE CAREER IN-
5 CENTIVE AWARDS.—

6 “(1) IN GENERAL.—The Secretary shall award
7 grants or contracts under this subsection to individ-
8 uals described in paragraph (2) to foster greater in-
9 terest among a variety of health professionals in en-
10 tering the field of palliative care.

11 “(2) ELIGIBLE INDIVIDUALS.—To be eligible to
12 receive an award under paragraph (1), an individual
13 shall—

14 “(A) be an advanced practice nurse, a so-
15 cial worker, physician assistant, pharmacist,
16 chaplain, or student of psychology who is pur-
17 suing a doctorate, masters, or other advanced
18 degree with a focus in palliative care or related
19 fields in an accredited health professions school;
20 and

21 “(B) submit to the Secretary an applica-
22 tion at such time, in such manner, and con-
23 taining such information as the Secretary may
24 require.

1 “(3) CONDITIONS OF AWARD.—As a condition
2 of receiving an award under this subsection, an indi-
3 vidual shall agree that, following completion of the
4 award period, the individual will teach or practice
5 palliative care in health-related educational, home,
6 hospice or long-term care settings for a minimum of
7 5 years under guidelines established by the Sec-
8 retary.

9 “(4) PAYMENT TO INSTITUTION.—The Sec-
10 retary shall make payments for awards under this
11 subsection to institutions which include schools of
12 medicine, osteopathic medicine, nursing, social work,
13 psychology, chaplaincy or pastoral care education,
14 dentistry, and pharmacy, or other allied health dis-
15 cipline in an accredited health professions school or
16 program (such as a physician assistant education
17 program) that is approved by the Secretary.

18 “(f) AUTHORIZATION OF APPROPRIATIONS.—There
19 are authorized to be appropriated to carry out this section,
20 \$44,100,000 for each of the fiscal years 2016 through
21 2020.”.

22 (b) EFFECTIVE DATE.—The amendment made by
23 this section shall be effective beginning on the date that
24 is 90 days after the date of enactment of this Act.

1 **SEC. 4. HOSPICE AND PALLIATIVE NURSING.**

2 (a) PREFERENCE FOR GRANTS OR AWARDS FOR
3 NURSING WORKFORCE DEVELOPMENT PROJECTS.—Sec-
4 tion 805 of the Public Health Service Act (42 U.S.C.
5 296d) is amended—

6 (1) by striking “or help” and inserting “help”;

7 and

8 (2) by inserting the following before the period
9 at the end: “, or for education and training in hos-
10 pice and palliative nursing”.

11 (b) ADVANCED EDUCATION NURSING GRANTS.—Sec-
12 tion 811 of the Public Health Service Act (42 U.S.C.
13 296j) is amended—

14 (1) in subsection (a)—

15 (A) in paragraph (1), by striking “and” at
16 the end;

17 (B) by redesignating paragraph (2) as
18 paragraph (3);

19 (C) by inserting after paragraph (1), the
20 following new paragraph:

21 “(2) palliative care and hospice career incentive
22 awards authorized under section 759A(e); and”; and

23 (D) in subsection (g)(2), by inserting “or
24 for education and training in hospice and pal-
25 liative nursing” after “section 332”.

1 (c) NURSE EDUCATION, PRACTICE, AND QUALITY
2 GRANTS.—Section 831 of the Public Health Service Act
3 (42 U.S.C. 296p) is amended—

4 (1) in subsection (a)—

5 (A) by striking “or” at the end of para-
6 graph (1);

7 (B) by striking the period at the end of
8 paragraph (2) and inserting “; or”; and

9 (C) by adding at the end the following new
10 paragraph:

11 “(3) education and training in hospice and pal-
12 liative nursing.”; and

13 (2) in subsection (b)(3), by inserting “hospice
14 and palliative nursing,” after “coordinated care,”.

15 (d) NURSE RETENTION GRANTS.—Section 831A of
16 the Public Health Service Act (42 U.S.C. 296p–1) is
17 amended—

18 (1) in subsection (c)(2), by adding at the end
19 the following: “The Secretary shall also give pref-
20 erence to applicants with programs that include ini-
21 tiatives to train nurses in hospice and palliative
22 nursing.”; and

23 (2) in subsection (d), by adding at the end the
24 following: “The Secretary may also award grants to,

1 or enter into contracts with, eligible entities to train
2 nurses in hospice and palliative nursing.”.

3 (e) ADDITIONAL PALLIATIVE CARE AND HOSPICE
4 EDUCATION AND TRAINING PROGRAMS.—Part D of title
5 VIII of the Public Health Service Act (42 U.S.C. 296p
6 et seq.) is amended by adding at the end the following:

7 **“SEC. 832. PALLIATIVE CARE AND HOSPICE EDUCATION**
8 **AND TRAINING.**

9 “(a) PROGRAM AUTHORIZED.—The Secretary shall
10 award grants to eligible entities to develop and implement,
11 in coordination with programs under section 759A, pro-
12 grams and initiatives to train and educate individuals in
13 providing palliative care in health-related educational, hos-
14 pice, home, or long-term care settings.

15 “(b) USE OF FUNDS.—An eligible entity that receives
16 a grant under subsection (a) shall use funds under such
17 grant to—

18 “(1) provide training to individuals who will
19 provide palliative care in health-related educational,
20 home, hospice, or long-term care settings;

21 “(2) develop and disseminate curricula relating
22 to palliative care in health-related educational, home,
23 hospice, or long-term care settings;

1 “(3) train faculty members in palliative care in
2 health-related educational, home, hospice, or long-
3 term care settings; or

4 “(4) provide continuing education to individuals
5 who provide palliative care in health-related edu-
6 cational, home, hospice, or long-term care settings.

7 “(c) APPLICATION.—An eligible entity desiring a
8 grant under subsection (a) shall submit an application to
9 the Secretary at such time, in such manner, and con-
10 taining such information as the Secretary may reasonably
11 require.

12 “(d) ELIGIBLE ENTITY.—For purposes of this sec-
13 tion, the term ‘eligible entity’ shall include a school of
14 nursing, a health care facility, a program leading to cer-
15 tification as a certified nurse assistant, a partnership of
16 such a school and facility, or a partnership of such a pro-
17 gram and facility.

18 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
19 are authorized to be appropriated to carry out this section
20 \$5,000,000 for each of fiscal years 2016 through 2020.”.

21 **SEC. 5. NATIONAL PALLIATIVE CARE EDUCATION AND**
22 **AWARENESS CAMPAIGN.**

23 Part A of title IX of the Public Health Service Act
24 (42 U.S.C. 299 et seq.) is amended by adding at the end
25 the following new section:

1 **“SEC. 904. NATIONAL PALLIATIVE CARE EDUCATION AND**
2 **AWARENESS CAMPAIGN.**

3 “(a) IN GENERAL.—Under the authority under sec-
4 tion 902(a) to disseminate information on health care and
5 on systems for the delivery of such care, the Director shall
6 provide for the planning and implementation of a national
7 education and awareness campaign to inform patients,
8 families, and health professionals about the benefits of
9 palliative care throughout the continuum of care for pa-
10 tients with serious or life-threatening illness.

11 “(b) INFORMATION DISSEMINATED.—

12 “(1) MANDATORY INFORMATION.—The cam-
13 paign under subsection (a) shall include dissemina-
14 tion of the following:

15 “(A) PALLIATIVE CARE.—Information, re-
16 sources, and communication materials about
17 palliative care as an essential part of the con-
18 tinuum of quality care for patients and families
19 facing serious or life-threatening illness (includ-
20 ing cancer; heart, kidney, liver, lung, and infec-
21 tious diseases; as well as neurodegenerative dis-
22 ease such as dementia, Parkinson’s disease, or
23 amyotrophic lateral sclerosis (ALS)).

24 “(B) PALLIATIVE CARE SERVICES.—Spe-
25 cific information regarding the services provided
26 to patients by professionals trained in hospice

1 and palliative care, including pain and symptom
2 management, support for shared decisionmak-
3 ing, care coordination, psychosocial care, and
4 spiritual care, explaining that such services may
5 be provided starting at the point of diagnosis
6 and alongside curative treatment and are in-
7 tended to—

8 “(i) provide patient-centered and fam-
9 ily-centered support throughout the con-
10 tinuum of care for serious and life-threat-
11 ening illness;

12 “(ii) anticipate, prevent, and treat
13 physical, emotional, social, and spiritual
14 suffering;

15 “(iii) optimize quality of life; and

16 “(iv) facilitate and support goals and
17 values of patients and the families of pa-
18 tients.

19 “(C) PALLIATIVE CARE PROFESSIONALS.—

20 Specific materials that explain the role of pro-
21 fessionals trained in hospice and palliative care
22 in providing team-based care (including pain
23 and symptom management, support for shared
24 decisionmaking, care coordination, psychosocial
25 care, and spiritual care) for patients and fami-

1 lies throughout the continuum of care for seri-
2 ous or life-threatening illness.

3 “(D) RESEARCH.—Evidence-based re-
4 search demonstrating the benefits of patient ac-
5 cess to palliative care throughout the continuum
6 of care for serious or life-threatening illness.

7 “(E) POPULATION-SPECIFIC MATERIALS.—
8 Materials shall be developed that target specific
9 populations, including patients with serious or
10 life-threatening illness who are among medically
11 underserved populations (as defined in section
12 330(b)(3)) and families of such patients or
13 health professionals serving medically under-
14 served populations. Such populations shall in-
15 clude pediatric patients, young adult and ado-
16 lescent patients, racial and ethnic minority pop-
17 ulations, and other priority populations speci-
18 fied by the Director.

19 “(2) OTHER INFORMATION.—In addition to the
20 information described in paragraph (1), such cam-
21 paign may include dissemination of such other infor-
22 mation as the Director determines to be relevant.

23 “(3) INFORMATION FORMAT.—The information
24 and materials required to be disseminated under
25 paragraph (1) and any information disseminated

1 under paragraph (2) shall be presented in a variety
2 of formats (such as posted online, in print, and
3 through public service announcements).

4 “(4) REQUIRED PUBLICATION.—The informa-
5 tion and materials required to be disseminated under
6 paragraph (1) and any information disseminated
7 under paragraph (2) shall be posted on the Internet
8 web sites of relevant Federal agencies and Depart-
9 ments, including the Agency for Healthcare Re-
10 search and Quality, the Centers for Medicare &
11 Medicaid Services, the Administration on Aging, the
12 Centers for Disease Control and Prevention, and the
13 Department of Veterans Affairs.

14 “(c) CONSULTATION.—The Director shall consult
15 with appropriate professional societies, hospice and pallia-
16 tive care stakeholders, and relevant patient advocate orga-
17 nizations with respect to palliative care, psychosocial care,
18 and complex chronic illness with respect to the following:

19 “(1) The planning and implementation of the
20 national palliative care education and awareness
21 campaign under this section.

22 “(2) The development of information to be dis-
23 seminated under this section.

24 “(3) A definition of the term ‘serious or life-
25 threatening illness’ for purposes of this section.”.

1 **SEC. 6. ENHANCING NIH RESEARCH IN PALLIATIVE CARE.**

2 (a) IN GENERAL.—Part B of title IV of the Public
3 Health Service Act (42 U.S.C. 284 et seq.) is amended
4 by adding at the end the following new section:

5 **“SEC. 409K. ENHANCING RESEARCH IN PALLIATIVE CARE.**

6 “(a) IN GENERAL.—The Secretary, acting through
7 the Director of the National Institutes of Health, shall de-
8 velop and implement a strategy to be applied across the
9 institutes and centers of the National Institutes of Health
10 to expand national research programs in palliative care.

11 “(b) RESEARCH PROGRAMS.—The Director of the
12 National Institutes of Health shall expand and intensify
13 research programs in palliative care to address the quality
14 of care and quality of life for the rapidly growing popu-
15 lation of patients in the United States with serious or life-
16 threatening illnesses, including cancer; heart, kidney, liver,
17 lung, and infectious diseases; as well as neurodegenerative
18 disease such as dementia, Parkinson’s disease, or
19 amyotrophic lateral sclerosis (ALS).”.

20 (b) EXPANDING TRANS-NIH RESEARCH REPORTING
21 TO INCLUDE PALLIATIVE CARE RESEARCH.—Section
22 402A(c)(2)(B)(i) of the Public Health Service Act (42
23 U.S.C. 282a(c)(2)(B)(i)) is amended by inserting “and,
24 beginning January 1, 2017, for conducting or supporting

- 1 research with respect to palliative care” after “or national
- 2 centers”.

