

111TH CONGRESS  
2D SESSION

# H. R. 5560

To amend the Public Health Service Act to improve quality of cancer care and quality of life for patients and survivors by coordinating development and distribution of information about relieving pain, symptoms, side effects, and stress; increasing awareness of treatment and post-treatment health risks for survivors; enhancing research into symptom management and survivorship; increasing health care professional education and training; reducing health disparities in cancer treatment, symptom management, and survivorship care; and expanding and enhancing cancer registries; and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JUNE 17, 2010

Mr. MOORE of Kansas (for himself, Ms. BERKLEY, Mr. BERMAN, Mr. CAO, Mr. CLAY, Mr. CLEAVER, Mr. CONYERS, Mr. LINCOLN DIAZ-BALART of Florida, Ms. EDWARDS of Maryland, Mr. ELLISON, Mr. FRANK of Massachusetts, Ms. KILROY, Mr. LOBIONDO, Mrs. MCCARTHY of New York, Mr. MARKEY of Massachusetts, Mr. MEEKS of New York, Ms. MOORE of Wisconsin, Ms. RICHARDSON, Ms. SCHAKOWSKY, Mr. SPRATT, and Ms. WATERS) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to improve quality of cancer care and quality of life for patients and survivors by coordinating development and distribution of information about relieving pain, symptoms, side effects, and stress; increasing awareness of treatment and post-treatment health risks for survivors; enhancing research into symptom management and survivorship; increasing

health care professional education and training; reducing health disparities in cancer treatment, symptom management, and survivorship care; and expanding and enhancing cancer registries; 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 “Quality Cancer Care  
 5 for Life Act of 2010”.

6 **SEC. 2. IMPROVING QUALITY OF CANCER CARE AND QUAL-**  
 7 **ITY OF LIFE FOR PATIENTS AND SURVIVORS.**

8 Title III of the Public Health Service Act (42 U.S.C.  
 9 243 et seq.) is amended by adding at the end the fol-  
 10 lowing:

11 **“SEC. 317U. INFORMATION, SUPPORT, AND OUTCOMES**  
 12 **MONITORING TO IMPROVE QUALITY CARE**  
 13 **AND QUALITY OF LIFE FOR CANCER PA-**  
 14 **TIENTS AND SURVIVORS.**

15 “(a) IN GENERAL.—The Secretary, acting through  
 16 the Director of the Centers for Disease Control and Pre-  
 17 vention (in this section referred to as the ‘Director’), shall  
 18 improve the quality of cancer care and quality of life for  
 19 cancer patients and survivors by expanding cancer control  
 20 programs of the Centers for Disease Control and Preven-  
 21 tion, including the National Comprehensive Cancer Con-

1 trol Program and the National Program of Cancer Reg-  
2 istries.

3 “(b) COORDINATION OF FEDERAL CANCER CARE  
4 AND SURVIVORSHIP.—

5 “(1) IN GENERAL.—The Secretary shall direct  
6 the coordination of appropriate agencies described in  
7 paragraph (2) for the following purposes:

8 “(A) To develop information and support  
9 to States to—

10 “(i) incorporate evidence-based, best  
11 practice strategies into Comprehensive  
12 Cancer Control Program activities and  
13 services of such States; and

14 “(ii) improve systems of care and care  
15 delivery by including promotion of care  
16 supporting quality of life for cancer pa-  
17 tients, survivors, and the family caregivers  
18 of such patients and survivors.

19 “(B) To develop service delivery efforts  
20 with special emphasis on addressing the par-  
21 ticular needs of childhood and adolescent cancer  
22 patients and survivors, as well as patients and  
23 survivors in low-income, racial, or ethnic minor-  
24 ity groups, and other medically underserved  
25 populations.

1           “(C) To improve the National Program of  
2           Cancer Registries and other existing surveil-  
3           lance systems for tracking cancer patients and  
4           survivors and assessing their health status and  
5           risk for other chronic and disabling conditions.

6           “(2) APPROPRIATE AGENCIES.—Appropriate  
7           agencies described in this paragraph include the Of-  
8           fice of Cancer Survivorship at the National Cancer  
9           Institute, the National Institute of Nursing Re-  
10          search, and such other appropriate agencies as de-  
11          termined by the Secretary.

12          “(c) IMPROVING STATE AND LOCAL PROGRAMS TO  
13          ADDRESS CANCER CARE AND SURVIVORSHIP.—In con-  
14          ducting or supporting State and local comprehensive can-  
15          cer control programs through the Centers for Disease  
16          Control and Prevention, the Secretary shall provide fund-  
17          ing and support to States, localities, and territories to ex-  
18          pand and enhance such programs for the following pur-  
19          poses:

20               “(1) To include emphasis on quality cancer care  
21               and survivorship, and provide information and sup-  
22               port for quality care initiatives for all cancer patient  
23               and survivor populations including women, children,  
24               adolescent, minority, and other medically under-  
25               served populations.

1           “(2) To develop and strengthen community out-  
2 reach and education programs, resources, interven-  
3 tions, and campaigns; strengthen community infor-  
4 mation delivery systems to inform patients, sur-  
5 vivors, and family members about quality of life sup-  
6 port and services available to relieve pain, symptoms  
7 and stress; increase awareness of treatment and  
8 post-treatment health risks and challenges; and pro-  
9 vide follow-up care important for survivors. Such  
10 programs may—

11               “(A) create and disseminate easily acces-  
12 sible, culturally appropriate communication ma-  
13 terials and resources tailored to specific audi-  
14 ences;

15               “(B) inform patients, survivors, and family  
16 caregivers about particular symptoms, side ef-  
17 fects, and late effects often associated with spe-  
18 cific types of cancer or treatments and the im-  
19 portance of addressing them as essential ele-  
20 ments of quality health care across the life  
21 course, including information on pain, nausea,  
22 fatigue, or other physical symptoms; worry,  
23 stress, or other psychological or emotional  
24 symptoms; lymphedema; cancer-related oral  
25 health issues and oral care; sexual dysfunction;

1 fertility concerns and fertility preservation op-  
2 tions; specific side effects or late effects that  
3 may affect overall health and well being; survi-  
4 vorship follow up care; and any other health-re-  
5 lated conditions that are known to be experi-  
6 enced as a result of cancer by patients, sur-  
7 vivors, and their family caregivers across the  
8 life course;

9 “(C) provide resource and referral infor-  
10 mation about other specific issues faced by can-  
11 cer patients, survivors, and their families, in-  
12 cluding financial concerns, employment rights,  
13 medical leave, insurance coverage, anticipating  
14 and managing late effects of treatment and re-  
15 current disease, advance care planning (includ-  
16 ing advance directives, living wills, and durable  
17 powers of attorney), and other care planning in-  
18 volved in health and medical decision-making;  
19 and

20 “(D) assist patients, survivors, and family  
21 caregivers with information about how to com-  
22 municate effectively with health professionals  
23 about physical and psychological symptoms, and  
24 limitations or barriers to normal daily function  
25 that may be caused by treatment of cancer.

1           “(3) To include special emphasis on addressing  
2           the particular needs of children and adolescent can-  
3           cer patients and survivors, as well as patients and  
4           survivors in low-income, racial, or ethnic minority  
5           groups, and other medically underserved popu-  
6           lations.

7           “(d) CANCER CARE AND SURVIVORSHIP DEM-  
8           ONSTRATION GRANTS.—

9           “(1) IN GENERAL.—The Director shall award  
10          competitive grants to States, localities, and not-for-  
11          profit organizations for the purposes of developing,  
12          implementing, and evaluating cancer case manage-  
13          ment and coordination programs to enhance the  
14          quality of cancer care and quality of life for patients  
15          and survivors and to improve cancer outcomes. Spe-  
16          cific emphasis shall be on addressing relief of symp-  
17          toms, pain, side effects, and stress; increasing pa-  
18          tient awareness of treatment and post-treatment  
19          health risks; and survivor care.

20          “(2) APPLICATION.—A State, locality, or not-  
21          for-profit organization seeking a grant under this  
22          subsection shall submit to the Director an applica-  
23          tion (at such time, in such manner, and containing  
24          such information as the Director may require), in-

1 including assurances that the State, locality, or entity  
2 will—

3 “(A) serve medically underserved popu-  
4 lations through specific outreach activities and  
5 coordinate culturally competent and appropriate  
6 care in accordance with existing, relevant de-  
7 partmental guidelines; and

8 “(B) evaluate and disseminate to the pub-  
9 lic annually detailed information about program  
10 activities.

11 “(3) USE OF FUNDS.—A State, locality, or not-  
12 for-profit entity shall use grant amounts awarded  
13 under this subsection to carry out programs that  
14 create partnerships with community organizations,  
15 including health care providers, cancer centers, hos-  
16 pitals, community health centers, palliative care pro-  
17 grams, psychosocial care programs, hospice pro-  
18 grams, home care, nonprofit organizations, health  
19 plans to facilitate access to integrated care services  
20 that support quality of life needs for patients, sur-  
21 vivors, and family caregivers. Such activities shall in-  
22 clude—

23 “(A) patient navigation and referrals, in-  
24 cluding assistance to patients and survivors in  
25 finding support groups;



1           “(B) interventions for patients, survivors,  
2           and caregivers; pain management; palliative  
3           care; psychosocial care; hospice; or other end of  
4           life care programs;

5           “(C) general advocacy on behalf of pa-  
6           tients, survivors, and families; and

7           “(D) an evaluation to identify best prac-  
8           tices to improve the coordination of cancer and  
9           survivorship care services and activities.

10          “(4) EVALUATION AND REPORTING.—The Di-  
11          rector shall evaluate activities funded under this  
12          subsection and shall submit to Congress (and dis-  
13          seminate to the public) reports related to such eval-  
14          uation, including findings, outcomes, and other pro-  
15          gram information. The first report shall be sub-  
16          mitted not later than January 1, 2013, with updates  
17          provided every three years thereafter.

18          “(e) HEALTH CARE PROFESSIONAL EDUCATION AND  
19          TRAINING DEMONSTRATION GRANTS.—

20          “(1) IN GENERAL.—The Director shall award  
21          competitive grants to not-for-profit entities or quali-  
22          fied individuals for the purpose of training individ-  
23          uals to undertake the quality of life needs of cancer  
24          patients, survivors, and family caregivers.

1           “(2) APPLICATION.—A not-for-profit entity or  
2           qualified individual seeking a grant under this sub-  
3           section shall submit an application to the Director at  
4           such time, and in such manner, and containing such  
5           information as the Director may require, including  
6           assurances that the entity or individual will—

7                   “(A) improve health professional commu-  
8                   nication skills in caring for patients and sur-  
9                   vivors to more effectively assess and address  
10                  their quality of life or survivorship concerns;

11                  “(B) assess and relieve pain, symptoms,  
12                  side effects, and stress associated with cancer  
13                  and its treatment;

14                  “(C) promote care planning to align treat-  
15                  ment with patient and family goals;

16                  “(D) anticipate and communicate about  
17                  cancer treatment and post-treatment health  
18                  risks and follow-up care;

19                  “(E) provide palliative, psychosocial, or  
20                  other care to support quality of life integrated  
21                  as part of disease-directed treatment to improve  
22                  quality of cancer care;

23                  “(F) promote use of survivorship care  
24                  planning;

1           “(G) improve cultural sensitivity, commu-  
2           nication, and patient care for minority and  
3           medically underserved populations, including  
4           addressing the particular needs of children,  
5           adolescents, and their families; racial and ethnic  
6           groups, and other medically underserved cancer  
7           patient and survivor populations; and

8           “(H) collect and analyze data related to  
9           the effectiveness of education and training ef-  
10          forts.

11          “(3) USE OF FUNDS.—An eligible entity shall  
12          use grant amounts awarded under this subsection to  
13          train and develop individuals with skills needed to  
14          assist the quality of life needs of cancer patients,  
15          survivors, and family caregivers by addressing symp-  
16          toms, pain, side effects, stress, treatment, and post-  
17          treatment health risks and train individuals to assist  
18          in arranging follow-up care across the life course.

19          “(4) EVALUATION.—The Secretary shall de-  
20          velop and implement a plan for evaluating the ef-  
21          fects of professional training programs funded  
22          through this subsection.

23          “(5) DEFINITION.—For purposes of this sub-  
24          section, the term ‘qualified individual’ means a phy-  
25          sician, nurse, social worker, chaplain, psychologist,

1 or other individual who is involved in providing pal-  
2 liative care and symptom management services to  
3 cancer patients.

4 “(f) QUALITY OF LIFE ADVISORY COMMITTEE.—

5 “(1) ESTABLISHMENT.—Not later than 90 days  
6 after the date of the enactment of this section, the  
7 Secretary shall establish a Quality of Life Advisory  
8 Committee (in this subsection referred to as the ‘ad-  
9 visory committee’) to advise, coordinate, and assist  
10 the Centers for Disease Control and Prevention in  
11 creating and conducting the cancer quality of life  
12 and survivorship activities, program enhancements,  
13 and training initiatives specified in subsections (a)  
14 through (e).

15 “(2) MEMBERSHIP.—The Secretary shall ap-  
16 point to the advisory committee such members as  
17 the Secretary considers necessary, and shall include  
18 individuals and representatives of public and private  
19 organizations with expertise in cancer treatment and  
20 care; pain, symptom, and stress management; and  
21 cancer survivorship.

22 “(3) DUTIES.—The advisory committee shall  
23 meet at least once a year and shall—

24 “(A) consider and summarize recent ad-  
25 vances achieved in cancer symptom manage-

ment and survivorship research relevant to the goals of this section and identify gaps in basic, clinical, behavioral, or other research required to achieve further improvements in care to support quality of life and survivorship; and

“(B) annually submit to the Secretary a report on the findings described in subparagraph (A) with recommendations about additional research needed to improve care for cancer patients, survivors, and families that will support quality of life and survivorship.

“(g) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there is authorized to be appropriated such sums as are necessary.”.

**SEC. 3. ENHANCING RESEARCH IN SUPPORT OF QUALITY OF LIFE, AND CANCER SURVIVORSHIP.**

Part B of title IV of the Public Health Service Act (42 U.S.C. 284 et seq.) is amended by adding at the end the following:

**“SEC. 409K. QUALITY CANCER CARE AND CANCER SURVIVORSHIP RESEARCH.**

“(a) IN GENERAL.—The Director of the National Institutes of Health shall, in coordination with recommendations of the Quality of Life Advisory Committee established under section 317U(f), undertake additional cancer

1 quality of life and survivorship research that addresses  
2 pain, symptom management, side effects and late effects,  
3 and psychosocial factors to improve cancer clinical com-  
4 munication and care planning, treatment and post-treat-  
5 ment, and follow-up care across the life course.

6 “(b) AUTHORIZED RESEARCH.—Research supported  
7 under this section may include at least the following:

8 “(1) Examination of evidence-based practices  
9 relating to cancer care, survivorship, and follow-up  
10 care including comparing community-based public  
11 health interventions.

12 “(2) Analysis of the translation of cancer inter-  
13 ventions from academic settings to real world set-  
14 tings.

15 “(3) Lifestyle, behavioral, and other research  
16 on the impact of cancer treatment and survivorship.

17 “(4) Formative research to assist with the de-  
18 velopment of educational messages and information,  
19 for dissemination to targeted populations such as  
20 children, adolescents, racial and ethnic minority  
21 groups, and other medically underserved groups, on  
22 the residual effects of cancer treatment.

23 “(5) Health disparities in cancer survivorship  
24 outcomes within minority or other medically under-  
25 served populations.

1           “(6) Intervention research to prevent or treat  
2           the post-treatment effects of cancer treatment.

3           “(7) Identification of the unique needs of pa-  
4           tients who are diagnosed with rare or deadly cancers  
5           or cancers that have not been well studied.

6           “(8) Development of a consistent, standardized  
7           model of service delivery for cancer-related follow-up  
8           care across cancer centers and community oncology  
9           practices.

10          “(9) Development, testing, and communication  
11          of messages for patients, survivors, and health pro-  
12          fessionals that will improve understanding, demand  
13          for, and delivery of care to relieve pain, symptoms,  
14          stress, and other quality of life factors associated  
15          with serious illnesses such as cancer.

16          “(c) FUNDING.—Such funds as necessary to accom-  
17          plish the requirements of subsection (a) shall be available  
18          from funds reserved under section 402A(c)(1) for the  
19          Common Fund or otherwise available for such initia-  
20          tives.”.

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