

109<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 5390

To provide for the expansion and coordination of activities of the National Institutes of Health and the Centers for Disease Control and Prevention with respect to research and programs on cancer survivorship, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MAY 16, 2006

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

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## A BILL

To provide for the expansion and coordination of activities of the National Institutes of Health and the Centers for Disease Control and Prevention with respect to research and programs on cancer survivorship, 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 “Cancer Survivorship  
5 Research and Quality of Life Act of 2006”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

1           (1) There are more than 10 million cancer sur-  
2           vivors (those living with, through, and beyond can-  
3           cer) in the United States.

4           (2) One out of two men and one out of three  
5           women will receive a cancer diagnosis during their  
6           lifetime.

7           (3) One of every four deaths in the United  
8           States is from cancer. In 2005, 570,000 Americans,  
9           or more than 1,500 a day, will die from cancer.

10          (4) Despite the significant annual burden of  
11          cancer deaths, improvements in detection and treat-  
12          ment have prolonged the lives of many cancer sur-  
13          vivors or resulted in cures for others. As a result of  
14          these developments, the number of survivors con-  
15          tinues to grow.

16          (5) More than three-fifths of adults diagnosed  
17          with cancer today will be alive five years from now.

18          (6) In 1960, only four percent of children with  
19          cancer survived more than five years, but treatment  
20          advances have changed the outlook for many chil-  
21          dren diagnosed with cancer.

22          (7) The five-year survival rate for children with  
23          cancer improved from 56 percent for those diag-  
24          nosed between 1974 and 1976 to 79 percent for  
25          those diagnosed between 1995 and 2000.

1           (8) The size of the population of survivors of  
2 childhood cancers has grown dramatically, to  
3 270,000 individuals of all ages as of 1997, which  
4 means that 1 in 640 adults from age 20 to 39 has  
5 a history of cancer.

6           (9) Adults who are treated for cancer may have  
7 complex and long-term effects from their treatment,  
8 resulting in unique health care needs.

9           (10) Some effects of treatment may be experi-  
10 enced at the time of treatment or soon after, while  
11 others may not be noticed until the patient ages or  
12 develops other health conditions.

13           (11) As many as two-thirds of childhood cancer  
14 survivors are likely to experience at least one late ef-  
15 fect of treatment, with as many as one-fourth experi-  
16 encing a late effect that is serious or life-threat-  
17 ening.

18           (12) Some late effects are identified early in  
19 follow-up and are easily resolved, while others may  
20 become chronic problems in adulthood and may have  
21 serious consequences.

22           (13) The late effects of treatment may change  
23 as treatments evolve, which means that the moni-  
24 toring and treatment of late effects may need to be  
25 modified on a routine basis.

1           (14) The Institute of Medicine, in its reports on  
2 cancer survivorship entitled “Childhood Cancer Sur-  
3 vivorship: Improving Care and Quality of Life” and  
4 “From Cancer Patient to Cancer Survivor: Lost in  
5 Transition,” has offered a number of recommenda-  
6 tions for improving the monitoring and follow-up  
7 care for cancer survivors and enhancing the cancer  
8 survivorship research agenda.

9           (15) The Institute of Medicine has also noted  
10 the significant health insurance problems that may  
11 be experienced by survivors of childhood cancer as  
12 well as adult cancer survivors and has recommended  
13 that policy makers take action to ensure access to  
14 care, including appropriate follow-up care, by all  
15 cancer survivors.

16           (16) The annual cost of cancer in the United  
17 States is almost \$190 billion in direct and indirect  
18 costs.

19 **SEC. 3. CANCER CONTROL PROGRAMS.**

20           Section 412 of the Public Health Service Act (42  
21 U.S.C. 285a-1) is amended—

22           (1) in the first sentence, by inserting “, for sur-  
23 vivorship,” after “treatment of cancer”;

24           (2) in paragraph (1)(B), by striking “cancer  
25 patients” and all that follows and inserting “cancer

1 patients, families of cancer patients, and cancer sur-  
2 vivors; and”; and

3 (3) in paragraph (3), by inserting “and con-  
4 cerning cancer survivorship programs,” after “con-  
5 trol of cancer”.

6 **SEC. 4. EXPANSION AND COORDINATION OF ACTIVITIES OF**  
7 **NATIONAL INSTITUTES OF HEALTH WITH RE-**  
8 **SPECT TO CANCER SURVIVORSHIP RE-**  
9 **SEARCH.**

10 (a) IN GENERAL.—

11 (1) TECHNICAL AMENDMENT.—Section 3 of  
12 Public Law 107–172 (116 Stat. 541) is amended by  
13 striking “section 419C” and inserting “section  
14 417C”.

15 (2) NEW SECTION.—Subpart 1 of part C of  
16 title IV of the Public Health Service Act (42 U.S.C.  
17 285 et seq.), as amended pursuant to paragraph (1)  
18 of this subsection, is amended by adding at the end  
19 the following section:

20 **“SEC. 417E. CANCER SURVIVORSHIP.**

21 **“(a) EXPANSION AND COORDINATION OF RE-**  
22 **SEARCH.—**

23 **“(1) IN GENERAL.—**The Director of NIH shall  
24 expand and coordinate the activities of the National

1 Institutes of Health with respect to cancer survivor-  
2 ship research.

3 “(2) PRIORITIES.—In carrying out this sub-  
4 section, the Director of NIH, in coordination with  
5 the Director of the Centers for Disease Control and  
6 Prevention and nonprofit organizations that focus on  
7 cancer survivorship, shall establish cancer survivor-  
8 ship research priorities.

9 “(3) COLLABORATION.—In carrying out this  
10 subsection, the Director of NIH may collaborate  
11 with such other agencies as the Director determines  
12 appropriate.

13 “(b) DIVISION OF CANCER SURVIVORSHIP.—

14 “(1) ESTABLISHMENT.—In carrying out sub-  
15 section (a), the Director of NIH shall establish a Di-  
16 vision of Cancer Survivorship within the National  
17 Cancer Institute through which the research activi-  
18 ties under subsection (a) shall be implemented and  
19 directed.

20 “(2) DIRECTOR; APPOINTMENT.—The Director  
21 of NIH shall appoint a Director to head the Divi-  
22 sion. The Director of the Division shall be selected  
23 from among individuals who, because of their profes-  
24 sional training or experience, are equipped to ad-

1 dress the breadth of needs associated with cancer  
2 survivorship.

3 “(3) COORDINATION.—The Director of NIH,  
4 acting through the Director of the Division, shall co-  
5 ordinate and promote the programs of the National  
6 Institutes of Health concerning cancer survivorship  
7 research.

8 “(4) DEFINITIONS.—In this subsection:

9 “(A) The term ‘Director of NIH’ means  
10 the Director of NIH, acting through the Direc-  
11 tor of the National Cancer Institute.

12 “(B) The term ‘Division’ means the Divi-  
13 sion of Cancer Survivorship established under  
14 paragraph (1).

15 “(c) NCI-DESIGNATED CANCER CENTERS.—

16 “(1) IN GENERAL.—In carrying out subsection  
17 (a), the Director of NIH shall provide for the expan-  
18 sion and coordination of cancer survivorship re-  
19 search activities at National Cancer Institute-des-  
20 ignated cancer centers.

21 “(2) COMPREHENSIVE CANCER SURVIVORSHIP  
22 CENTERS.—

23 “(A) IN GENERAL.—The Director of NIH  
24 shall provide assistance to National Cancer In-  
25 stitute-designated cancer centers for the pur-

1           pose of establishing or improving comprehensive  
2           cancer survivorship centers described in sub-  
3           paragraph (B).

4           “(B) CENTER DESCRIPTION.—A com-  
5           prehensive cancer survivorship center described  
6           in this subparagraph is a center within a Na-  
7           tional Cancer Institute-designated cancer center  
8           designed to serve as a comprehensive, one-stop  
9           source of information, care, and services for  
10          cancer survivors, family members, and service  
11          providers.

12          “(3) EVALUATION OF MODELS OF SURVIVOR-  
13          SHIP CARE.—The Director of NIH shall provide as-  
14          sistance to one or more National Cancer Institute-  
15          designated cancer centers for research to evaluate  
16          models of survivorship care.

17          “(4) DEFINITION.—In this subsection, the term  
18          ‘Director of NIH’ means the Director of NIH, act-  
19          ing through the Director of the National Cancer In-  
20          stitute.”.

21          (b) FUNDING.—Section 417B of the Public Health  
22          Service Act (42 U.S.C. 285a–8) is amended by adding at  
23          the end the following subsection:

24          “(e) CANCER SURVIVORSHIP RESEARCH.—Of the  
25          amounts appropriated for the National Cancer Institute

1 for a fiscal year, the Director of the Institute shall reserve  
2 not less than \$50,000,000 to the Division of Cancer Survi-  
3 vorship to carry out section 417E (other than section  
4 417E(c)).

5 “(f) NCI-DESIGNATED CANCER CENTERS.—For the  
6 purpose of carrying out section 417E(c), there are author-  
7 ized to be appropriated \$61,000,000 for each of fiscal  
8 years 2007 through 2011.”.

9 **SEC. 5. NATIONAL COMPREHENSIVE CANCER CONTROL**  
10 **PROGRAM.**

11 Part B of title III of the Public Health Service Act  
12 (42 U.S.C. 243 et seq.) is amended by inserting after sec-  
13 tion 317S the following:

14 **“SEC. 317T. NATIONAL COMPREHENSIVE CANCER CONTROL**  
15 **PROGRAM.**

16 “(a) EXPANSION OF PROGRAM.—The Secretary, act-  
17 ing through the Director of the Centers for Disease Con-  
18 trol and Prevention, shall expand and update the National  
19 Comprehensive Cancer Control Program.

20 “(b) IMPLEMENTATION GRANTS.—

21 “(1) AUTHORIZATION.—In carrying out the Na-  
22 tional Comprehensive Cancer Control Program, the  
23 Secretary may make grants to eligible entities to es-  
24 tablish and implement plans for an integrated and  
25 coordinated approach to reducing cancer incidence,

1 morbidity, and mortality through prevention, early  
2 detection, treatment, rehabilitation, palliation, and  
3 quality-of-life interventions.

4 “(2) SUBMISSION OF PLANS.—To seek a grant  
5 under this subsection, an eligible entity shall submit  
6 a plan for an integrated and coordinated approach  
7 to reducing cancer incidence, morbidity, and mor-  
8 tality. Such plan shall—

9 “(A) identify priorities, strategies, and pro-  
10 grams through which communities and their  
11 partners may pool resources to reduce cancer  
12 risk, promote cancer prevention, improve cancer  
13 detection, increase access to health and social  
14 services, address disparities in specific popu-  
15 lations, improve cancer treatment, reduce the  
16 burden of cancer, enhance quality of life for  
17 cancer patients, and address survivorship needs;  
18 and

19 “(B) provide for collection, evaluation, and  
20 submission to the Secretary of data on the de-  
21 livery and quality of cancer care, screening and  
22 early detection rates, and the quality of life for  
23 survivors and their families.

24 “(3) DATA ANALYSIS.—The Secretary shall  
25 analyze the data submitted under this section to en-

1       sure that plans funded under this subsection have a  
2       systematic, nationwide, positive impact on the deliv-  
3       ery and quality of cancer care, including by—

4               “(A) increasing screening and early detec-  
5               tion rates; and

6               “(B) improving the quality of life for can-  
7               cer survivors and their families.

8               “(4) DEFINITION.—In this section, the term  
9       ‘eligible entity’ includes a State, a territory, a tribal  
10       organization, and the District of Columbia.

11       “(c) ADDITIONAL ACTIVITIES.—In carrying out the  
12       National Comprehensive Cancer Control Program, in ad-  
13       dition to making grants under subsection (b), the Sec-  
14       retary shall—

15               “(1) establish programs that demonstrate how  
16               to prevent and control cancer and improve access to  
17               and the quality of cancer care among racial and eth-  
18               nic minority and medically underserved populations  
19               with disproportionate incidence of or death from  
20               cancer;

21               “(2) promote cancer education, prevention, and  
22               early detection of cancer; and

23               “(3) award grants to public and nonprofit orga-  
24               nizations for cancer control and prevention.

1       “(d) CANCER SURVIVORSHIP GRANTS.—In carrying  
2 out the National Comprehensive Cancer Control Program,  
3 in addition to the activities described in subsections (b)  
4 and (c) the Secretary may award grants to community-  
5 based programs, nonprofit organizations, and other enti-  
6 ties for the purpose of providing programs and direct serv-  
7 ices to improve cancer survivorship and the quality of life  
8 of cancer survivors.

9       “(e) CERTAIN STUDIES AND PROGRAMS.—

10           “(1) IN GENERAL.—The Secretary, acting  
11 through the Director of the Centers for Disease  
12 Control and Prevention and in collaboration with the  
13 Director of the Division of Cancer Survivorship in  
14 the National Cancer Institute, shall—

15                   “(A) study the unique health challenges  
16 associated with cancer survivorship; and

17                   “(B) carry out (directly or through the  
18 award of grants or contracts) projects and  
19 interventions to improve the long-term health  
20 status of cancer survivors.

21           “(2) CERTAIN ACTIVITIES.—Activities under  
22 paragraph (1) may include—

23                   “(A) the expansion, in collaboration with  
24 the Surveillance, Epidemiology, and End Re-  
25 sults (SEER) Program at the National Cancer

1 Institute, the National Program of Cancer Reg-  
2 istries at the Centers for Disease Control and  
3 Prevention, and the Agency for Healthcare Re-  
4 search and Quality, of current cancer surveil-  
5 lance systems to track the health status of can-  
6 cer survivors and determine whether cancer sur-  
7 vivors are at-risk for other chronic and dis-  
8 abling conditions;

9 “(B) the assessment of the unique public  
10 health challenges associated with cancer survi-  
11 vorship; and

12 “(C) the implementation and evaluation of  
13 the national public health cancer survivorship  
14 action plan, in partnership with health organi-  
15 zations focused on cancer survivorship, to be  
16 carried out in coordination with the State pro-  
17 grams funded under subsection (b), in collabo-  
18 ration with the Associate Director for Cancer  
19 Survivorship, and in consultation with other ap-  
20 propriate entities, to support and advance can-  
21 cer survivorship through—

22 “(i) surveillance and research;

23 “(ii) communication, education, and  
24 training;

1                   “(iii) program, policies, and infra-  
2                   structure; and

3                   “(iv) access to quality care and serv-  
4                   ices.

5           “(f) COORDINATION OF ACTIVITIES.—The Secretary  
6 shall assure that activities of the Centers for Disease Con-  
7 trol and Prevention under this section are coordinated as  
8 appropriate with other agencies of the Public Health Serv-  
9 ice.

10          “(g) REPORT TO CONGRESS.—Not later than October  
11 1, 2007, the Secretary shall submit to the Congress a re-  
12 port describing the results of activities carried out under  
13 this section.

14          “(h) AUTHORIZATION OF APPROPRIATIONS.—There  
15 are authorized to be appropriated—

16               “(1) for purposes of this section (other than  
17 subsections (b) and (d)), such sums as may be nec-  
18 essary for each of the fiscal years 2007 through  
19 2011;

20               “(2) for purposes of subsection (b),  
21 \$50,000,000 for fiscal year 2007 and a total of  
22 \$200,000,000 for the period of fiscal years 2008  
23 through 2011; and

24               “(3) for purposes of subsection (d), \$6,000,000  
25 for fiscal year 2007, \$7,000,000 for fiscal year

1 2008, \$8,000,000 for fiscal year 2009, \$9,000,000  
2 for fiscal year 2010, and \$10,000,000 for fiscal year  
3 2011.”.

4 **SEC. 6. MONITORING AND EVALUATING QUALITY CANCER**  
5 **CARE AND CANCER SURVIVORSHIP.**

6 (a) IN GENERAL.—Part M of title III of the Public  
7 Health Service Act (42 U.S.C. 280e et seq.) is amended  
8 by inserting after section 399E the following section:

9 **“SEC. 399E-1. MONITORING AND EVALUATING QUALITY**  
10 **CANCER CARE AND CANCER SURVIVORSHIP.**

11 “(a) IN GENERAL.—The Secretary shall make grants  
12 to eligible entities for the purpose of enabling such entities  
13 to monitor and evaluate the quality of cancer care, develop  
14 information concerning the quality of cancer care, and  
15 monitor cancer survivorship. The Secretary shall carry out  
16 this section jointly through the Director of the Centers  
17 for Disease Control and Prevention and the Director of  
18 the National Cancer Institute.

19 “(b) ELIGIBLE ENTITIES.—For purposes of this sec-  
20 tion, an entity is an eligible entity for a fiscal year if the  
21 entity—

22 “(1) operates a statewide cancer registry with  
23 funds from a grant made under section 399B for  
24 such fiscal year;

1           “(2) is certified by the North American Asso-  
2           ciation of Central Cancer Registries;

3           “(3) has personnel scientifically qualified to  
4           conduct population-based epidemiology or analyze  
5           health services or outcomes research; and

6           “(4) has access to a broad-based clinical re-  
7           search cohort or an established clinical case base.

8           “(c) CONTRACTING AUTHORITY.—In carrying out the  
9           purpose described in subsection (a), an eligible entity may  
10          expend a grant under such subsection to enter into con-  
11          tracts with academic institutions, cancer centers, and  
12          other entities, when determined appropriate by the Sec-  
13          retary.

14          “(d) APPLICATION FOR GRANT.—A grant may be  
15          made under subsection (a) only if an application for the  
16          grant is submitted to the Secretary and the application  
17          is in such form, is made in such manner, and contains  
18          such agreements, assurances, and information as the Sec-  
19          retary determines to be necessary to carry out this section.

20          “(e) AUTHORITY OF SECRETARY REGARDING USE OF  
21          GRANT.—The Secretary shall determine the appropriate  
22          uses of grants under subsection (a) to achieve the purpose  
23          described in such subsection.

24          “(f) AUTHORIZATION OF APPROPRIATIONS.—For the  
25          purpose of carrying out this section, there are authorized

1 to be appropriated \$5,000,000 for each of the fiscal years  
2 2007 through 2011.”.

3 (b) CONFORMING AMENDMENT REGARDING AU-  
4 THORIZATION OF APPROPRIATIONS.—Section 399F(a) of  
5 the Public Health Service Act (42 U.S.C. 280e–4(a)) is  
6 amended in the first sentence by striking “this part,” and  
7 inserting “this part (other than section 399E–1),”.

8 **SEC. 7. NATIONAL COMMISSION ON CANCER SURVIVOR-**  
9 **SHIP.**

10 (a) IN GENERAL.—The Secretary of Health and  
11 Human Services shall establish a National Commission on  
12 Cancer Survivorship (referred to in this section as the  
13 “Commission”) to coordinate the activities of the Depart-  
14 ment of Health and Human Services related to cancer sur-  
15 vivorship with such activities of other governmental agen-  
16 cies and private entities.

17 (b) COMPOSITION.—The Commission shall consist of  
18 not more than 15 members to be appointed by the Sec-  
19 retary, of which—

20 (1)  $\frac{2}{3}$  of such members shall be representatives  
21 of governmental agencies conducting activities with  
22 respect to cancer survivorship, including the Na-  
23 tional Institutes of Health, the National Cancer In-  
24 stitute, the Centers for Disease Control and Preven-  
25 tion, the Centers for Medicare & Medicaid Services,

1 the Health Resources and Services Administration,  
2 the Agency for the Healthcare Research and Qual-  
3 ity, the Department of Defense, and the Department  
4 of Veterans Affairs; and

5 (2)  $\frac{1}{3}$  of such members shall be representatives  
6 of private organizations and patient representatives.

7 (c) TERMS.—

8 (1) IN GENERAL.—Except as provided in para-  
9 graphs (2) and (3), members of the Commission  
10 shall be appointed for a term of 3 years, and may  
11 serve an unlimited number of terms if reappointed.

12 (2) TERMS OF INITIAL APPOINTEES.—As des-  
13 igned by the Secretary at the time of appointment,  
14 of the 15 members first appointed—

15 (A) 5 shall be appointed for a term of 3  
16 years;

17 (B) 5 shall be appointed for a term of 4  
18 years; and

19 (C) 5 shall be appointed for a term of 5  
20 years.

21 (3) VACANCIES.—Any member of the Commis-  
22 sion appointed to fill a vacancy occurring before the  
23 expiration of the term for which the member's pred-  
24 ecessor was appointed shall be appointed only for  
25 the remainder of that term. A member may serve

1 after the expiration of that member's term until a  
2 successor has taken office.

3 (d) CHAIR.—The Chair of the Commission shall be  
4 appointed by the Secretary of Health and Human Services  
5 from among the 15 members of the Commission. The  
6 Chair of the Commission shall be directly responsible to  
7 the Secretary. The Chair of the Commission shall be ap-  
8 pointed for a term of 2 years and may be reappointed.

9 (e) ANNUAL REPORT.—The Commission shall pre-  
10 pare an annual report to Congress on cancer survivor-  
11 ship—

12 (1) identifying cross-agency activities and pub-  
13 lic-private partnerships that support or improve can-  
14 cer survivorship; and

15 (2) listing existing and ongoing gaps in care for  
16 cancer survivors.

17 (f) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;  
18 OTHER PROVISIONS.—The following shall apply with re-  
19 spect to the Commission:

20 (1) The Commission shall receive necessary and  
21 appropriate administrative support from the Depart-  
22 ment of Health and Human Services.

23 (2) The Commission shall meet as determined  
24 appropriate by the Secretary, in consultation with

- 1 the Chair of the Commission, but not less than 3
- 2 times each year.

○