

108TH CONGRESS
1ST SESSION

S. 1496

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.

IN THE SENATE OF THE UNITED STATES

JULY 30 (legislative day, JULY 21), 2003

Mrs. HUTCHISON (for herself, Mr. KENNEDY, Mrs. FEINSTEIN, and Mr. HARKIN) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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 2003”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

1 (1) There are more than 9,600,000 individuals
2 in the United States today who are cancer survivors
3 (living with, through, and beyond cancer).

4 (2) 61 percent of cancer survivors are 65 years
5 of age and older.

6 (3) 62 percent of adults diagnosed with cancer
7 today will be alive 5 years from now.

8 (4) In 1960, 4 percent of children with cancer
9 survived more than 5 years.

10 (5) 77 percent of children (age 0 through 14)
11 diagnosed with cancer today will be living five years
12 from now.

13 (6) Three out of every four American families
14 will have at least one family member diagnosed with
15 cancer.

16 (7) 24 percent of adults with cancer are parents
17 who have a child 18 years or younger living in the
18 home.

19 (8) One of every four deaths in the United
20 States is from cancer. In 2002, 556,500 Americans
21 will die of cancer—more than 1,500 people a day.

22 (9) The annual cost of cancer in the United
23 States is \$180,000,000,000 in direct and indirect
24 costs.

1 (10) In fiscal year 2001 the National Institutes
2 of Health invested \$38,000,000 in survivorship—less
3 than \$4.25 per survivor.

4 **SEC. 3. CANCER CONTROL PROGRAMS.**

5 Section 412 of the Public Health Service Act (42
6 U.S.C. 285a–1) is amended—

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

9 (2) in paragraph (1)(B), by striking “cancer
10 patients” and all that follows and inserting the fol-
11 lowing: “cancer patients, families of cancer patients,
12 and cancer survivors, and”; and

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

16 **SEC. 4. EXPANSION AND COORDINATION OF ACTIVITIES OF**
17 **NATIONAL INSTITUTES OF HEALTH WITH RE-**
18 **SPECT TO CANCER SURVIVORSHIP RE-**
19 **SEARCH.**

20 (a) IN GENERAL.—

21 (1) TECHNICAL AMENDMENT.—Section 3 of
22 Public Law 107–172 (116 Stat. 541) is amended by
23 striking “section 419C” and inserting “section
24 417C”.

1 (2) NEW SECTION.—Subpart 1 of part C of
 2 title IV of the Public Health Service Act (42 U.S.C.
 3 285 et seq.), as amended pursuant to paragraph (1)
 4 of this subsection, is amended by adding at the end
 5 the following:

6 **“SEC. 417E. EXPANSION AND COORDINATION OF ACTIVI-**
 7 **TIES WITH RESPECT TO CANCER SURVIVOR-**
 8 **SHIP RESEARCH.**

9 “(a) IN GENERAL.—

10 “(1) EXPANSION OF ACTIVITIES.—The Director
 11 of NIH shall expand and coordinate the activities of
 12 the National Institutes of Health with respect to
 13 cancer survivorship research.

14 “(2) ADMINISTRATION OF PROGRAM; COLLABO-
 15 RATION AMONG AGENCIES.—The Director of NIH
 16 shall carry out this section acting through the Direc-
 17 tor of the National Cancer Institute and in collabo-
 18 ration with any other agencies that the Director de-
 19 termines appropriate.

20 “(b) OFFICE ON SURVIVORSHIP.—

21 “(1) IN GENERAL.—The Director of NIH shall
 22 establish an Office on Cancer Survivorship within
 23 the National Cancer Institute through which the ac-
 24 tivities under subsection (a)(1) shall be implemented
 25 and directed.

1 “(2) ASSOCIATE DIRECTOR FOR CANCER SURVI-
 2 VORSHIP; APPOINTMENT; FUNCTION.—There shall be
 3 in the National Cancer Institute an Associate Direc-
 4 tor for Cancer Survivorship to coordinate and pro-
 5 mote the programs in the Institute concerning can-
 6 cer survivorship research. The Associate Director
 7 shall be appointed by the Director of the Institute
 8 from among individuals who, because of their profes-
 9 sional training or experience, are equipped to ad-
 10 dress the breadth of needs associated with cancer
 11 survivorship.”.

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

15 “(e) OFFICE ON CANCER SURVIVORSHIP.—Of the
 16 amounts appropriated for the National Cancer Institute
 17 for a fiscal year, the Director of the Institute shall reserve
 18 an amount for the Office of Cancer Survivorship under
 19 section 417E(b)(1).”.

20 **SEC. 5. EXPANSION OF CDC COMPREHENSIVE CANCER**
 21 **PROGRAMS; PROGRAMS TO IMPROVE CAN-**
 22 **CER SURVIVORSHIP.**

23 (a) IN GENERAL.—The Secretary of Health and
 24 Human Services (referred to in this section as the “Sec-

1 retary”), acting through the Director of the Centers for
 2 Disease Control and Prevention, shall—

3 (1) expand and update the National Com-
 4 prehensive Cancer Control Program;

5 (2) assist States, territories, tribal organiza-
 6 tions, and the District of Columbia in developing
 7 and implementing a cancer prevention and control
 8 program so that each entity will have an active plan
 9 in place and so that States, territories, tribal organi-
 10 zations, and the District of Columbia will conduct
 11 activities to prevent and control cancer and so that
 12 disparities in specific populations will be addressed;

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

19 (4) promote cancer education, prevention, and
 20 early detection of cancer; and

21 (5) award grants to public and nonprofit orga-
 22 nizations for cancer control and prevention.

23 (b) CERTAIN STUDIES AND PROGRAMS.—

24 (1) IN GENERAL.—The Secretary, acting
 25 through the Director of the Centers for Disease

1 Control and Prevention and in collaboration with the
2 Director of the Office of Cancer Survivorship within
3 the National Cancer Institute, shall study the unique
4 health challenges associated with cancer survivorship
5 and carry out projects and interventions to improve
6 the long-term health status of cancer survivors. Such
7 projects shall be carried out directly and through the
8 awards of grants or contracts.

9 (2) CERTAIN ACTIVITIES.—Activities under
10 paragraph (1) include—

11 (A) the expansion, in collaboration with
12 the Surveillance, Epidemiology, and End Re-
13 sults Program (SEER) at the National Cancer
14 Institute and with the Agency for Healthcare
15 Research and Quality, of current cancer surveil-
16 lance systems to track the health status of can-
17 cer survivors and determine whether cancer sur-
18 vivors are at-risk for other chronic and dis-
19 abling conditions;

20 (B) assess the unique public health chal-
21 lenges associated with cancer survivorship; and

22 (C) the development and implementation of
23 a national public health cancer survivorship ac-
24 tion plan, in partnership with health organiza-
25 tions focused on cancer survivorship, to be car-

ried out in coordination with the State-based comprehensive cancer control program of the Centers for Disease Control and Prevention, in collaboration with the Office of Cancer Survivorship at the National Cancer Institute, and in consultation with other appropriate entities, to support and advance cancer survivorship through—

(i) surveillance and research;

(ii) communication, education, and training;

(iii) program, policies, and infrastructure; and

(iv) access to quality care and services.

(c) COORDINATION OF ACTIVITIES.—The Secretary shall assure that activities under this section are coordinated as appropriate with other agencies of the Public Health Service.

(d) REPORT TO CONGRESS.—Not later than October 1, 2004, the Secretary shall submit to the Congress a report describing the results of the evaluation under subsection (a), and as applicable, the strategies developed under such subsection.

1 (e) AUTHORIZATION OF APPROPRIATIONS.—For the
2 purpose of carrying out this section, there are authorized
3 to be appropriated such sums as may be necessary for
4 each of the fiscal years 2004 through 2008.

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

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

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

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

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

23 “(1) operates a statewide cancer registry with
24 funds from a grant made under section 399B for
25 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 such sums as may be necessary for
2 each of the fiscal years 2004 through 2008.”.

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),”.

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