108TH CONGRESS 1ST SESSION

H. R. 2986

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 HOUSE OF REPRESENTATIVES

July 25, 2003

Mr. Wicker (for himself, Mr. Hoyer, Mr. Blunt, Mrs. Capps, Mr. Taylor of Mississippi, Ms. Corrine Brown of Florida, Mr. Wamp, Ms. Delauro, Mr. Cunningham, Mr. Goode, Ms. Norton, Mr. Tiberi, Ms. Ros-Lehtinen, Mr. Waxman, Mr. Kennedy of Rhode Island, Mr. Rahall, and Mr. King of New York) introduced the following bill; which was referred to the Committee on Energy and Commerce

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".

1 SEC. 2. FINDINGS.

The Congress finds as follows:
(1) There are more than 9,600,000 individuals
in the United States today who are cancer survivors
(living with, through, and beyond cancer).
(2) 61 percent of cancer survivors are 65 years
of age and older.
(3) 62 percent of adults diagnosed with cancer
today will be alive 5 years from now.
(4) In 1960, 4 percent of children with cancer
survived more than 5 years.
(5) 77 percent of children (age 0 through 14)
diagnosed with cancer today will be living five years
from now.
(6) Three out of every four American families
will have at least one family member diagnosed with
cancer.
(7) 24 percent of adults with cancer are parents
who have a child 18 years or younger living in the
home.
(8) One of every four deaths in the United
States is from cancer. In 2003, 556,500 Americans
will die of cancer—more than 1,500 people a day.
(9) The annual cost of cancer in the United
States is \$180,000,000,000 in direct and indirect

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-091) 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 107–09172 (116 Stat. 541) is amended
23	by 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 section:
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 in the National Cancer Institute an Associate Direc-3 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-098) is amended by adding
- 14 at the end the following subsection:
- 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-

- 6 retary"), acting through the Director of the Centers for 2 Disease Control and Prevention, shall— 3 (1) expand and update the National Comprehensive Cancer Control Program; (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.
 - (b) CERTAIN STUDIES AND PROGRAMS.—
 - IN (1)GENERAL.—The Secretary, acting through the Director of the Centers for Disease

23

24

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

- (2) CERTAIN ACTIVITIES.—Activities under paragraph (1) include—
 - (A) the expansion, in collaboration with the Surveillance, Epidemiology, and End Results Program (SEER) at the National Cancer Institute and with the Agency for Healthcare Research and Quality, of current cancer surveillance systems to track the health status of cancer survivors and determine whether cancer survivors are at-risk for other chronic and disabling conditions;
 - (B) assess the unique public health challenges associated with cancer survivorship; and
 - (C) the development and implementation of a national public health cancer survivorship action plan, in partnership with health organizations focused on cancer survivorship, to be car-

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

1	ried out in coordination with the State-based
2	comprehensive cancer control program of the
3	Centers for Disease Control and Prevention, in
4	collaboration with the Office of Cancer Survi-
5	vorship at the National Cancer Institute, and in
6	consultation with other appropriate entities, to
7	support and advance cancer survivorship
8	through—
9	(i) surveillance and research;
10	(ii) communication, education, and
11	training;
12	(iii) program, policies, and infrastruc-
13	ture; and
14	(iv) access to quality care and serv-
15	ices.
16	(c) Coordination of Activities.—The Secretary
17	shall assure that activities under this section are coordi-
18	nated as appropriate with other agencies of the Public
19	Health Service.
20	(d) REPORT TO CONGRESS.—Not later than October
21	1, 2004, the Secretary shall submit to the Congress a re-
22	port describing the results of the evaluation under sub-
23	section (a), and as applicable, the strategies developed

24 under such subsection.

- 1 (e) AUTHORIZATION OF APPROPRIATIONS.—For the 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. 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 by inserting after section 399E the following section: "SEC. 399E-091. MONITORING AND EVALUATING QUALITY 11 CANCER CARE AND CANCER SURVIVORSHIP. "(a) IN GENERAL.—The Secretary shall make grants 12 to eligible entities for the purpose of enabling such entities to monitor and evaluate quality cancer care, develop infor-14 15 mation concerning quality cancer care, and monitor cancer survivorship. The Secretary shall carry out this section 16 jointly through the Director of the Centers for Disease 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
- funds from a grant made under section 399B for 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–094(a))
- 6 is amended in the first sentence by striking "this part,"
- 7 and inserting "this part (other than section 399E-091),".