

102D CONGRESS
2D SESSION

H. R. 4206

To amend the Public Health Service Act to provide for the establishment or support by States of registries regarding cancer, to provide for a study regarding the elevated rate of mortality for breast cancer in certain States, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 7, 1992

Mr. SANDERS (for himself, Mr. McDERMOTT, Mrs. MORELLA, Mr. DeFAZIO, Mr. LaFALCE, Mr. McGRATH, Mrs. JOHNSON of Connecticut, Mr. STAGGERS, Mr. OWENS of New York, Mr. JONES of North Carolina, Mr. PAYNE of New Jersey, Mr. TRAFICANT, Mr. LEHMAN of Florida, Ms. PELOSI, Mr. MFUME, Mr. MURPHY, Mr. MARTINEZ, Mr. FASCELL, Mr. OBERSTAR, Mr. HORTON, Mr. SMITH of New Jersey, Mr. KOLTER, Ms. KAPTUR, Mr. SAVAGE, Mr. EVANS, Mr. ROGERS, Mr. MILLER of California, Mr. ANDREWS of Maine, Mr. DONNELLY, Mr. ANDREWS of New Jersey, Mr. MRAZEK, Mr. TORRES, Ms. OAKAR, Mr. SANGMEISTER, Mr. SCHEUER, Mr. BERMAN, Mr. CONYERS, Mr. LEVINE of California, Ms. WATERS, Mr. PETERSON of Minnesota, Mr. FRANK of Massachusetts, Mr. LEWIS of Georgia, Mr. KANJORSKI, Mr. HAYES of Illinois, Mr. ABERCROMBIE, Mr. KENNEDY, Mr. WISE, Mr. FLAKE, Mr. DELLUMS, Mr. MAZZOLI, Mr. WYDEN, Mr. MATSUI, Mr. SCHUMER, Mr. JEFFERSON, Mr. ROYBAL, Mr. RANGEL, and Mr. FROST) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for the establishment or support by States of registries regarding cancer, to provide for a study regarding the elevated rate of mortality for breast cancer in certain States, 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 Registries
5 Amendment Act".

6 **SEC. 2. FINDINGS AND PURPOSE.**

7 (a) FINDINGS.—Congress finds that—

8 (1) cancer control efforts, including prevention
9 and early detection, are best addressed locally by
10 State health departments that can identify unique
11 needs;

12 (2) cancer control programs and existing state-
13 wide population-based cancer registries have identi-
14 fied cancer incidence and cancer mortality rates that
15 indicate the burden of cancer for Americans is sub-
16 stantial and varies widely by geographic location and
17 by ethnicity;

18 (3) statewide cancer incidence and cancer mor-
19 tality data, can be used to identify cancer trends,
20 patterns, and variation for directing cancer control
21 intervention;

22 (4) the American Association of Central Cancer
23 Registries (AACCR) cites that of the 50 States, ap-
24 proximately 38 have established cancer registries,

1 many are not statewide and 10 have no cancer reg-
2 istry; and

3 (5) AACCR also cites that of the 50 States, 39
4 collect data on less than 100 percent of their popu-
5 lation, and less than half have adequate resources
6 for insuring minimum standards for quality and for
7 completeness of case information.

8 (b) PURPOSE.—It is the purpose of this Act to estab-
9 lish a national program of cancer registries.

10 **SEC. 2. ESTABLISHMENT OF A NATIONAL PROGRAM OF**
11 **CANCER REGISTRIES.**

12 Title III of the Public Health Service Act (42 U.S.C.
13 241 et seq.), as amended by section 101 of Public Law
14 101-616, is amended by adding at the end the following
15 new part:

16 **“PART M—NATIONAL PROGRAM OF CANCER**
17 **REGISTRIES**

18 **“SEC. 399B. NATIONAL PROGRAM OF CANCER REGISTRIES.**

19 “(a) IN GENERAL.—The Secretary may make grants
20 to States, or may make grants or enter into contracts with
21 academic or non-profit organizations designated by the
22 State to operate the State’s cancer registry in lieu of mak-
23 ing a grant directly to the State, to support the operation
24 of population-based, statewide cancer registries in order
25 to collect, for each form of in-situ and invasive cancer with

1 the exception of basal cell and squamous cell carcinoma
2 of the skin, data concerning—

3 “(1) demographic information about each case
4 of cancer;

5 “(2) administrative information, including date
6 of diagnosis and source of information;

7 “(3) pathological data characterizing the can-
8 cer, including the cancer site, stage of disease (Stag-
9 ing Guide), incidence, and type of treatment; and

10 “(4) other elements determined appropriate by
11 the Secretary.

12 “(b) MATCHING FUNDS.—

13 “(1) IN GENERAL.—The Secretary may make a
14 grant under subsection (a) only if the State involved
15 agrees, with respect to the costs of the program to
16 be carried out by the State pursuant to such sub-
17 section, to make available (directly or through dona-
18 tions from public or private entities) non-Federal
19 contributions toward such costs in an amount that
20 is not less than 25 percent of such costs or \$1 for
21 every \$3 of Federal funds provided in the grant.

22 “(2) DETERMINATION OF AMOUNT OF NON-
23 FEDERAL CONTRIBUTION; MAINTENANCE OF EF-
24 FORT.—

1 “(A) Non-Federal contributions required in
2 paragraph (1) may be in cash or in kind, fairly
3 evaluated, including plant, equipment, or serv-
4 ices. Amounts provided by the Federal Govern-
5 ment, or services assisted or subsidized to any
6 significant extent by the Federal Government,
7 may not be included in determining the amount
8 of such non-Federal contributions.

9 “(B) With respect to a State in which the
10 purpose described in subsection (a) is to be car-
11 ried out, the Secretary, in making a determina-
12 tion of the amount of non-Federal contributions
13 provided under paragraph (1), may include only
14 such contributions as are in excess of the aver-
15 age amount of such contributions made by the
16 State toward the collection of data on cancer
17 for the 2-year period preceding the first fiscal
18 year for which a grant under subsection (a) is
19 made with respect to the State. State con-
20 tributions towards cancer control prevention
21 services made during fiscal year 1992 shall be
22 included in satisfying the State matching re-
23 quirement for the initial fiscal year during
24 which this section is in effect.

25 “(c) ELIGIBILITY FOR GRANTS.—

1 “(1) IN GENERAL.—No grant shall be made by
2 the Secretary under subsection (a) unless an appli-
3 cation therefore has been submitted to, and ap-
4 proved by, the Secretary. Such application shall be
5 in such form, submitted in such a manner, and be
6 accompanied by such information, as the Secretary
7 may specify. No such application may be approved
8 unless it contains assurances that the applicant will
9 use the funds provided only for the purpose specified
10 in the approved application and in accordance with
11 the requirements of this section, and that the appli-
12 cation will establish such fiscal control and fund ac-
13 counting procedures as may be necessary to assure
14 proper disbursement and accounting of Federal
15 funds paid to the applicant under subsection (a) of
16 this section.

17 “(2) ASSURANCES.—Each applicant, prior to
18 receiving Federal funds under subsection (a), shall
19 provide assurances satisfactory to the Secretary that
20 the applicant will—

21 “(A) provide for the establishment of a
22 statewide population-based cancer registry by
23 the State health department, or by one or more
24 academic health centers, nonprofit cancer re-
25 search and prevention organizations, or medical

1 societies acting in collaboration with the State
2 health department;

3 “(B) comply with appropriate standards of
4 completeness, timeliness, and quality or popu-
5 lation-based cancer registry data;

6 “(C) provide for the annual publication of
7 reports of cancer data under subsection (a);
8 and

9 “(D) provide for the authorization under
10 State law of the statewide cancer registry,
11 including—

12 “(i) a means to assure complete re-
13 porting of cancer cases (as described in
14 subsection (a)) to the statewide cancer reg-
15 istry by hospitals or other facilities provid-
16 ing screening, diagnostic or therapeutic
17 services to patients;

18 “(ii) a means to assure the complete
19 reporting of cancer cases (as defined in
20 subsection (a)) to the statewide cancer reg-
21 istry by physicians, surgeons, and all other
22 health care practitioners diagnosing or pro-
23 viding treatment for cancer patients, ex-
24 cept for cases directly referred to or pre-
25 viously admitted to a hospital or other fa-

1 facility providing screening, diagnostic or
2 therapeutic services to patients in that
3 State and reported by those facilities;

4 “(iii) a means for the statewide cancer
5 registry to access all records of physicians
6 and surgeons, hospitals, outpatients clinics,
7 nursing homes, and all other facilities, in-
8 dividuals, or agencies providing screening,
9 diagnostic or therapeutic services to pa-
10 tients which would identify cases of cancer
11 or would establish characteristics of the
12 cancer, treatment of the cancer, or medical
13 status of any identified patient;

14 “(iv) the reporting of cancer case data
15 to the statewide cancer registry in such a
16 format, with such data elements, and in
17 accordance with such standards of quality
18 timeliness and completeness, as may be es-
19 tablished by the Secretary;

20 “(v) the protection of the con-
21 fidentiality of all cancer case data reported
22 to the statewide cancer registry, including
23 a prohibition on disclosure to any person of
24 information report to the statewide cancer
25 registry that identifies, or could lead to the

1 identification of, an individual cancer pa-
2 tient, except for disclosure to other States
3 cancer registries and local and State health
4 officers;

5 “(vi) the promulgation of regulations
6 under which confidential case data may be
7 disclosed to cancer researchers for the pur-
8 poses of cancer prevention, control and re-
9 search;

10 “(vii) the authorization or the con-
11 duct, by the statewide cancer registry or
12 other persons and organizations, of studies
13 utilizing statewide cancer registry data, in-
14 cluding studies of the sources and causes
15 of cancer, evaluations of the cost, quality,
16 efficacy, and appropriateness of diagnostic,
17 therapeutic, rehabilitative, and preventive
18 services and programs relating to cancer,
19 and any other clinical, epidemiological, or
20 other cancer research; and

21 “(viii) protection for individuals com-
22 plying with the law, specifically that no
23 person shall be held liable in any civil ac-
24 tion with respect to a cancer case report
25 provided to the statewide cancer registry,

1 or with respect to access to cancer case in-
2 formation provided to the statewide cancer
3 registry.

4 “(d) RELATIONSHIP TO CERTAIN PROGRAMS.—This
5 section may not be construed as requiring the Secretary
6 to modify or terminate the program carried out by the
7 Director of the National Cancer Institute and designated
8 by such Director as the Surveillance, Epidemiology, and
9 End Results Program (SEER). Where both programs
10 exist, the Secretary shall ensure the SEER support is not
11 supplanted and that any additional activities are consist-
12 ent with the guidelines provided for in subsection (c)(2)
13 (C) and (D). The Secretary may not transfer administra-
14 tion responsibility for such SEER program from such Di-
15 rector.

16 “(e) REQUIREMENT REGARDING CERTAIN STUDY ON
17 BREAST CANCER.—In the case of a grant under sub-
18 section (a) to any State specified in section 399D(a)(2),
19 the Secretary may establish such conditions regarding the
20 receipt of the grant as the Secretary determines are nec-
21 essary to facilitate the collection of data for the study car-
22 ried out under section 399C.

23 “SEC. 399C. PLANNING GRANTS REGARDING REGISTRIES.

24 “(a) IN GENERAL.—

1 “(1) STATES.—The Secretary may make grants
2 to States for the purpose of developing plans that
3 meet the assurances required by the Secretary under
4 section 399B(c)(2).

5 “(2) OTHER ENTITIES.—For the purpose de-
6 scribed in paragraph (1), the Secretary may make
7 grants to public entities other than States and to
8 nonprofit private entities. Such a grant may be
9 made to an entity only if the State in which the pur-
10 pose is to be carried out has certified that the State
11 approves the entity as qualified to carry out the pur-
12 pose.

13 “(b) APPLICATION.—The Secretary may make a
14 grant under subsection (a) only if an application for the
15 grant is submitted to the Secretary, the application con-
16 tains the certification required in subsection (a)(2) (if the
17 application is for a grant under such subsection), and the
18 application is in such form, is made in such manner, and
19 contains such agreements, assurances, and information as
20 the Secretary determines to be necessary to carry out this
21 section.

22 “(c) FUNDING.—Of the amounts appropriated under
23 section 399F for a fiscal year, the Secretary may obligate
24 not more than 25 percent for carrying out this section.

1 "SEC. 399D. STUDY IN CERTAIN STATES TO DETERMINE
2 THE FACTORS CONTRIBUTING TO THE ELE-
3 VATED BREAST CANCER MORTALITY RATES.

4 "(a) FINDING.—

5 "(1) IN GENERAL.—Congress finds that the Di-
6 rector of the National Cancer Institute has deter-
7 mined that the rates of mortality for breast cancer
8 in the States specified in paragraph (2) are elevated
9 compared to rates in other States.

10 "(2) RELEVANT STATES.—The States referred
11 to in paragraph (1) are Connecticut, Delaware,
12 Maryland, Massachusetts, New Hampshire, New
13 Jersey, New York, Rhode Island, Vermont, and the
14 District of Columbia.

15 "(b) STUDY TO DETERMINE THE FACTORS CONTRIB-
16 UTING TO ELEVATED MORTALITY RATES.—

17 "(1) IN GENERAL.—Subject to paragraphs (2)
18 and (3), the Secretary shall conduct a study for the
19 purpose of determining factors contributing to the
20 determination described in subsection (a) with re-
21 spect to the States.

22 "(2) COOPERATION OF STATE.—The Secretary
23 may conduct a study required in paragraph (1) in a
24 State only if the State agrees to cooperate with the
25 Secretary in the conduct of the study, including pro-

1 viding information from any registry operated by the
2 State pursuant to section 399B(a).

3 “(3) PLANNING, COMMENCEMENT, AND DURA-
4 TION.—The Secretary shall, during each of the fiscal
5 years 1993 and 1994, develop a plan for conducting
6 the study required in paragraph (1). The study shall
7 be initiated by the Secretary not later than fiscal
8 year 1994, and the collection of data under the
9 study may continue through fiscal year 1998.

10 “(4) REPORT.—Not later than September 30,
11 1999, the Secretary shall complete the study re-
12 quired in paragraph (1) and submit to the appro-
13 priate committees of Congress the findings and rec-
14 ommendations made as a result of the study.

15 “(5) DEFINITION.—As used in this subsection,
16 the term ‘relevant State’ means a State specified in
17 subsection (a)(2).

18 **“SEC. 399E. TECHNICAL ASSISTANCE IN OPERATIONS OF**
19 **STATEWIDE CANCER REGISTRIES.**

20 “The Secretary may, directly or through grants and
21 contracts, or both, provide technical assistance to the
22 States in the establishment and operation of statewide
23 registries, including assistance in the development of
24 model legislation for statewide cancer registries and assist-

1 ance in establishing a computerized reporting and data
2 processing system.

3 **"SEC. 399F. AUTHORIZATION OF APPROPRIATIONS.**

4 “(A) REGISTRIES.—For the purpose of carrying out
5 this part, there are authorized to be appropriated
6 \$30,000,000 for each of fiscal years 1993 through 1999,
7 not more than 10 percent of which may be expended for
8 assessing the accuracy, completeness and quality of data
9 collected, and not more than 10 percent of which is to
10 be expended under subsection 399E.

11 “(b) BREAST CANCER STUDY.—For the purpose of
12 carrying out section 399D, the Secretary shall submit to
13 the appropriate committees of Congress, a 5-year study
14 plan and budget for each of fiscal years 1994 through
15 1999.”.

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