

111TH CONGRESS
1ST SESSION

H. R. 745

To amend the Public Health Service Act to provide for a Pancreatic Cancer Initiative, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 28, 2009

Ms. ESHOO (for herself, Ms. GINNY BROWN-WAITE of Florida, Mrs. CAPPS, Mr. CUMMINGS, and Mr. PLATTS) 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 a Pancreatic Cancer Initiative, 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; FINDINGS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Pancreatic Cancer Research and Education Act”.

6 (b) FINDINGS.—The Congress finds the following:

7 (1) Nearly 38,000 Americans will be diagnosed
8 with pancreatic cancer this year, and over 34,000
9 will die from the disease. The incidence among Afri-

1 can-Americans is 40 to 50 percent higher than other
2 ethnic groups.

3 (2) Pancreatic cancer is one of the few cancers
4 for which survival has not improved substantially
5 over the past 30 years. As a result, in 2003, pan-
6 creatic cancer surpassed prostate cancer as the 4th
7 leading cause of cancer-related death in the United
8 States.

9 (3) Seventy-five percent of pancreatic cancer
10 patients die within the first 12 months of the diag-
11 nosis. The 5-year survival rate is 5 percent.

12 (4) Scientific understanding of pancreatic can-
13 cer—its etiology, pathogenesis, detection, and treat-
14 ment—lags far behind that of most other forms of
15 cancer. In fact, pancreatic cancer research is where
16 breast cancer research was in the 1930s—little un-
17 derstanding of the causes, no early detection, few ef-
18 fective treatments, and single-digit survival rates.

19 (5) In 2001, the National Cancer Institute de-
20 veloped “Pancreatic Cancer: An Agenda for Action”.
21 Seven years later, only five of the report’s 39 rec-
22 ommendations have been implemented because of a
23 lack of funding, focus, and commitment. In the
24 meantime, pancreatic cancer death rates have con-
25 tinued to increase.

1 (6) Pancreatic cancer research constitutes less
2 than 2 percent of the National Cancer Institute’s
3 Federal research funding, a figure far too low given
4 the severity of the disease, its mortality rate, and
5 how little is known about how to arrest the disease.

6 (7) Of the more than 5,000 research grants
7 awarded annually by the Nations Cancer Institute in
8 2006, only 134 (approximately 3 percent) were cat-
9 egorized by the Institute as at least 50 percent rel-
10 evant to pancreatic cancer research.

11 (8) The future supply of scientists entering this
12 field of study is in serious jeopardy. There are cur-
13 rently fewer than 58 principal investigators who
14 have multiple grants or a primary career focus on
15 pancreatic cancer. Further, in the last 3 years, the
16 National Cancer Institute has awarded only 5 grants
17 for training and supporting young principal inves-
18 tigators in pancreatic cancer.

19 (9) In 2007, the Scientific Advisory Board of
20 the Pancreatic Cancer Action Network reviewed the
21 current state of the science and the Federal Govern-
22 ment’s efforts on pancreatic cancer research and
23 prepared “The National Plan to Advance Pancreatic
24 Cancer Research” to identify the highest research
25 priorities, scientific infrastructure needs, and work-

1 force training requirements that are needed to pro-
2 vide the answers that pancreatic cancer patients and
3 their families and loved ones so desperately need.

4 **SEC. 2. PANCREATIC CANCER INITIATIVE.**

5 Part B of title III of the Public Health Service Act
6 (42 U.S.C. 243 et seq.) is amended by adding at the end
7 the following:

8 **“SEC. 320B. PANCREATIC CANCER INITIATIVE.**

9 **“(a) PANCREATIC CANCER INITIATIVE.—**

10 **“(1) ESTABLISHMENT.—**The Secretary shall es-
11 tablish and implement a Pancreatic Cancer Initiative
12 to assist in coordinating activities to address the
13 high mortality rate associated with pancreatic can-
14 cer. Such Initiative shall focus on—

15 **“(A)** advancing research on the causes, di-
16 agnosis, and treatment of pancreatic cancer
17 with the goal of increasing the 5-year survival
18 rate;

19 **“(B)** promoting a cadre of new investiga-
20 tors in the field of pancreatic cancer research;
21 and

22 **“(C)** increasing physician and public
23 awareness of pancreatic cancer.

24 **“(2) CONSULTATION.—**In carrying out this sub-
25 section, the Secretary shall consult with the Director

1 of the National Institutes of Health, the Director of
2 the National Cancer Institute, the Director of the
3 Centers of Disease Control and Prevention, and the
4 Interdisciplinary Pancreatic Cancer Coordinating
5 Committee established under subsection (b).

6 “(b) INTERDISCIPLINARY PANCREATIC CANCER CO-
7 ORDINATING COMMITTEE.—

8 “(1) ESTABLISHMENT.—Not later than 60 days
9 after the date of the enactment of this section, the
10 Secretary, in consultation with the Director of the
11 National Institutes of Health, shall establish a com-
12 mittee to be known as the Interdisciplinary Pan-
13 creatic Cancer Coordinating Committee (in this sub-
14 section referred to as the ‘Committee’).

15 “(2) MEMBERSHIP.—

16 “(A) IN GENERAL.—The members of the
17 Committee shall be appointed by the Secretary,
18 in consultation with the Director of the Na-
19 tional Institutes of Health, and shall consist of
20 13 individuals as follows:

21 “(i) Nine experts in pancreatic cancer
22 research, who are each a full professor at
23 a major academic research institution and
24 who have each received multiple grants
25 from the National Cancer Institute or

1 other entities of the National Institutes of
2 Health with a primary focus on pancreatic
3 cancer research.

4 “(ii) Two young principal investiga-
5 tors in pancreatic cancer, who are each an
6 assistant-level professor in a major aca-
7 demic research institution and who have
8 each received at least one grant from the
9 National Cancer Institute or another entity
10 of the National Institutes of Health with a
11 primary focus in pancreatic cancer re-
12 search.

13 “(iii) One pancreatic cancer advocate.

14 “(iv) The Director of the National
15 Cancer Institute (or the Director’s des-
16 ignee).

17 “(B) CHAIR.—The Secretary shall des-
18 ignate the Chair of the Committee from among
19 its members.

20 “(C) PUBLICATION OF NAMES.—Not later
21 than 30 days after the establishment of the
22 Committee, the Secretary shall publish the
23 names of the Chair and members of the Com-
24 mittee on the Website of the Department of
25 Health and Human Services.

1 “(D) TERMS.—The members of the Com-
2 mittee shall each be appointed for a 3-year term
3 and, at the end of each such term, may be re-
4 appointed.

5 “(E) VACANCIES.—A vacancy on the Com-
6 mittee shall be filled by the Secretary in the
7 same manner in which the original appointment
8 was made.

9 “(3) RESPONSIBILITIES.—The Committee
10 shall—

11 “(A) provide advice on overall research ob-
12 jectives and benchmarks for pancreatic cancer
13 research;

14 “(B) develop and annually update a stra-
15 tegic plan in accordance with paragraph (4) for
16 the conduct and support of pancreatic cancer
17 research awareness during the upcoming year;
18 and

19 “(C) conduct evaluations and make rec-
20 ommendations to the Secretary, the Director of
21 the National Institutes of Health, and the Di-
22 rector of the National Cancer Institute in ac-
23 cordance with paragraph (5) regarding the
24 prioritization and award of National Institutes

1 of Health research grants relating to pancreatic
2 cancer.

3 “(4) STRATEGIC PLAN.—

4 “(A) DEVELOPMENT.—The Committee
5 shall develop and annually update a strategic
6 plan for the conduct and support of pancreatic
7 cancer research and awareness during the up-
8 coming fiscal year.

9 “(B) SUBMISSION.—The Committee
10 shall—

11 “(i) submit to the Secretary each stra-
12 tegic plan developed under subparagraph
13 (A) for the upcoming fiscal year; and

14 “(ii) publish each such plan on the
15 Website of the Department of Health and
16 Human Services within 30 days after the
17 earlier of—

18 “(I) the date of submission of the
19 plan to the Secretary under clause (i);
20 or

21 “(II) June 1.

22 “(C) CONTENTS.—Each strategic plan de-
23 veloped under subparagraph (A) shall include—

24 “(i) recommended budgetary require-
25 ments for pancreatic cancer research, in-

cluding research grants awarded through the National Cancer Institute, funding for Specialized Programs of Research Excellence (SPORE) that are focused on pancreatic cancer, and funding for the portion of the cancer research incubator pilot project established by section 409J(a) that is focused on pancreatic cancer;

“(ii) recommendations on the coordination of extramural and intramural pancreatic cancer research initiatives and possibilities for partnerships among the national research institutes, including the National Cancer Institute, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute of Environmental Health Sciences, the National Center for Complementary and Alternative Medicine, and the National Center on Minority Health and Health Disparities;

“(iii) recommendations for improving physician and public education about pancreatic cancer;

“(iv) recommendations for increasing the number of scientists with doctorate de-

1 grees and clinician-scientists specializing in
2 pancreatic cancer research; and

3 “(v) guidelines for information gath-
4 ered by pancreatic cancer patient registries
5 and tissue banks to ensure uniformity and
6 accessibility to the research community.

7 “(5) PRIORITIZATION AND AWARD OF NIH RE-
8 SEARCH GRANTS.—

9 “(A) IN GENERAL.—The Committee shall
10 conduct evaluations and make recommendations
11 to the Secretary, the Director of the National
12 Institutes of Health, and the Director of the
13 National Cancer Institute regarding the
14 prioritization and award of National Institutes
15 of Health research grants relating to pancreatic
16 cancer.

17 “(B) PEER REVIEW COMMITTEE.—In car-
18 rying out subparagraph (A), the Committee
19 may appoint a peer review committee to assist
20 in the evaluation of pancreatic cancer grant ap-
21 plications to ensure that such applications are
22 reviewed by individuals with the appropriate ex-
23 pertise.

24 “(C) EVALUATION.—In evaluating pan-
25 creatic cancer grant applications under sub-

1 paragraph (A), the Committee shall emphasize
2 grants that achieve at least one of the following
3 goals:

4 “(i) The grant is determined to be at
5 least 75 percent relevant to pancreatic can-
6 cer research and has a primary focus on at
7 least one of the following areas:

8 “(I) Basic research to advance
9 the understanding of the biology of
10 pancreatic cancer, its natural history,
11 and the genetic and environmental
12 factors that contribute to its develop-
13 ment.

14 “(II) Research on more precise
15 diagnostic methods and screening to
16 detect pancreatic cancer in earlier
17 stages.

18 “(III) Advanced innovative clin-
19 ical trials testing targeted thera-
20 peutics and novel agents that will ex-
21 tend the survival of pancreatic cancer
22 patients and improve their quality of
23 life.

1 “(ii) The grant will increase the num-
2 ber of young pancreatic cancer investiga-
3 tors.

4 “(iii) The grant will meet identified
5 needs, criteria, or specific research goals
6 set forth in the strategic plan developed
7 under paragraph (3)(B).

8 “(D) RECOMMENDATIONS.—The Com-
9 mittee shall make recommendations for excep-
10 tion funding for grant applications that—

11 “(i) have 75 percent or greater rel-
12 evance to pancreatic cancer; and

13 “(ii) score within 10 points of the
14 payline.

15 “(c) PHYSICIAN AWARENESS.—

16 “(1) PROGRAM.—The Secretary, in consultation
17 with the Director of the National Institutes of
18 Health, the Director of the Centers for Disease Con-
19 trol and Prevention, and relevant patient advocate
20 and physician organizations, shall develop a primary
21 care provider education program on pancreatic can-
22 cer. The Secretary may include in such program ac-
23 credited continuing medical education and such
24 other activities as the Secretary determines appro-
25 priate.

1 “(2) DEFINITION.—The term ‘relevant patient
2 advocate and physician organization’ means a na-
3 tionwide organization that—

4 “(A) provides evidence-based disease infor-
5 mation to the public in a case management
6 style;

7 “(B) directly funds research in an unbi-
8 ased manner by working collaboratively with
9 health professionals at a variety of institutions
10 and using a peer-reviewed grant mechanism;

11 “(C) advocates public policy outcomes that
12 reflect the needs of patients; and

13 “(D) provides information to patients,
14 families, and health professionals at the com-
15 munity level.

16 “(d) COMMUNICATION TOOL KIT.—The Director of
17 the National Institutes of Health and the Director of the
18 Centers for Disease Control and Prevention, working col-
19 laboratively with patient advocate organizations, shall de-
20 velop a communication tool kit for patients and their fami-
21 lies that focuses on specific pancreatic cancer issues re-
22 lated to patient choices and patient care.

23 “(e) REPORT TO CONGRESS.—Not later than 1 year
24 after the date of the enactment of this section, and annu-
25 ally thereafter, the Secretary shall submit a report to the

1 Congress identifying the steps taken to implement the
2 Pancreatic Cancer Initiative under subsection (a). The re-
3 port shall include—

4 “(1) an assessment of the progress in improv-
5 ing outcomes and reducing mortality rates for those
6 diagnosed with pancreatic cancer;

7 “(2) an explanation of how recommendations of
8 the Interdisciplinary Pancreatic Cancer Coordinating
9 Committee in the strategic plan developed under
10 subsection (b)(3)(B) for the preceding year have
11 been implemented;

12 “(3) a summary of the recommendations that
13 were made by the Interdisciplinary Pancreatic Can-
14 cer Coordinating Committee for grant funding, in-
15 cluding exception funding, the number of such rec-
16 ommendations that were met, and the reasons why
17 any recommendations were not met;

18 “(4) a breakdown of research grant award
19 amounts by the National Institutes of Health during
20 the past year that are deemed relevant to pancreatic
21 cancer research along with a quantifiable measure as
22 to the relevancy of the grants to pancreatic cancer;

23 “(5) the number of such grants awarded to
24 young principal investigators in pancreatic cancer
25 described in subsection (b)(2)(A)(ii); and

1 “(6) a summary of progress and deficiencies
 2 that were made in pancreatic cancer research during
 3 the preceding year.

4 “(f) AUTHORIZATION OF APPROPRIATIONS.—There
 5 are authorized to be appropriated—

6 “(1) to carry out subsection (a), \$140,000,000
 7 for fiscal year 2010 and such sums as may be nec-
 8 essary for fiscal years 2011 through 2014;

9 “(2) to carry out subsection (c), \$2,000,000 for
 10 fiscal year 2010 and such sums as may be necessary
 11 for fiscal years 2011 through 2014; and

12 “(3) to carry out subsection (d), \$2,000,000 for
 13 fiscal year 2010 and such sums as may be necessary
 14 for fiscal years 2011 through 2014.”.

15 **SEC. 3. NATIONAL INSTITUTES OF HEALTH RESEARCH.**

16 Part B of title IV of the Public Health Service Act
 17 (42 U.S.C. 284 et seq.) is amended by adding at the end
 18 the following:

19 **“SEC. 409J. CANCER RESEARCH.**

20 “(a) CANCER RESEARCH INCUBATOR PILOT
 21 PROJECT.—

22 “(1) GRANTS.—

23 “(A) IN GENERAL.—The Secretary may
 24 award grants to research institutions for use in
 25 developing innovative compounds or tech-

1 nologies for the prevention, early detection, or
2 treatment of those cancers with 5-year survival
3 rates of less than 50 percent.

4 “(B) RELATION TO OTHER NIH GRANTS.—

5 Subject to subparagraph (A), the Secretary
6 shall encourage each recipient of a grant under
7 this section to use the grant for research activi-
8 ties that may serve as a springboard for the re-
9 ceipt of other grants, including Specialized Pro-
10 grams of Research Excellence (SPORE) grants,
11 from the National Institutes of Health and its
12 national research institutes.

13 “(2) GRANT PERIOD.—The period of a grant

14 under this section shall be 5 years.

15 “(3) FOCUS.—During the initial 5 fiscal years

16 of carrying out this section, the Secretary shall focus
17 on awarding grants for use in developing innovative
18 compounds or technologies for the prevention, early
19 detection, or treatment of pancreatic cancer.

20 “(4) REPORT.—Not later than 5 years after the

21 date of the enactment of this section, the Secretary
22 shall submit a report to the Congress evaluating the
23 program under this section and making rec-
24 ommendations for expansion of the program to other
25 cancers.

1 “(5) AUTHORIZATION OF APPROPRIATIONS.—

2 To carry out this subsection, there are authorized to
3 be appropriated \$5,000,000 for fiscal year 2010 and
4 such sums as may be necessary for fiscal years 2011
5 through 2014.

6 “(b) CENTERS OF EXCELLENCE.—

7 “(1) DESIGNATION.—The Secretary may des-
8 ignate two additional Specialized Programs of Re-
9 search Excellence (SPOREs) focusing solely on pan-
10 creatic cancer research. In carrying out this para-
11 graph, the Secretary may choose to designate one or
12 more satellite centers that augment the work of a
13 previously designated Specialized Program of Re-
14 search Excellence.

15 “(2) AUTHORIZATION OF APPROPRIATIONS.—

16 To carry out this subsection, there are authorized to
17 be appropriated \$20,000,000 for fiscal year 2010
18 and such sums as may be necessary for fiscal years
19 2011 through 2014.”.

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