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.
 - (2) Pancreatic cancer is one of the few cancers for which survival has not improved substantially over the past 30 years. As a result, in 2003, pancreatic cancer surpassed prostate cancer as the 4th leading cause of cancer-related death in the United States.
 - (3) Seventy-five percent of pancreatic cancer patients die within the first 12 months of the diagnosis. The 5-year survival rate is 5 percent.
 - (4) Scientific understanding of pancreatic cancer—its etiology, pathogenesis, detection, and treatment—lags far behind that of most other forms of cancer. In fact, pancreatic cancer research is where breast cancer research was in the 1930s—little understanding of the causes, no early detection, few effective treatments, and single-digit survival rates.
 - (5) In 2001, the National Cancer Institute developed "Pancreatic Cancer: An Agenda for Action". Seven years later, only five of the report's 39 recommendations have been implemented because of a lack of funding, focus, and commitment. In the meantime, pancreatic cancer death rates have continued to increase.

- (6) Pancreatic cancer research constitutes less than 2 percent of the National Cancer Institute's Federal research funding, a figure far too low given the severity of the disease, its mortality rate, and how little is known about how to arrest the disease.
 - (7) Of the more than 5,000 research grants awarded annually by the Nations Cancer Institute in 2006, only 134 (approximately 3 percent) were categorized by the Institute as at least 50 percent relevant to pancreatic cancer research.
 - (8) The future supply of scientists entering this field of study is in serious jeopardy. There are currently fewer than 58 principal investigators who have multiple grants or a primary career focus on pancreatic cancer. Further, in the last 3 years, the National Cancer Institute has awarded only 5 grants for training and supporting young principal investigators in pancreatic cancer.
 - (9) In 2007, the Scientific Advisory Board of the Pancreatic Cancer Action Network reviewed the current state of the science and the Federal Government's efforts on pancreatic cancer research and prepared "The National Plan to Advance Pancreatic Cancer Research" to identify the highest research 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 pancreation
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-

1	cluding research grants awarded through
2	the National Cancer Institute, funding for
3	Specialized Programs of Research Excel-
4	lence (SPORE) that are focused on pan-
5	creatic cancer, and funding for the portion
6	of the cancer research incubator pilot
7	project established by section 409J(a) that
8	is focused on pancreatic cancer;
9	"(ii) recommendations on the coordi-
10	nation of extramural and intramural pan-
11	creatic cancer research initiatives and pos-
12	sibilities for partnerships among the na-
13	tional research institutes, including the
14	National Cancer Institute, the National In-
15	stitute of Diabetes and Digestive and Kid-
16	ney Diseases, the National Institute of En-
17	vironmental Health Sciences, the National
18	Center for Complementary and Alternative
19	Medicine, and the National Center on Mi-
20	nority Health and Health Disparities;
21	"(iii) recommendations for improving
22	physician and public education about pan-
23	creatic cancer;
24	"(iv) recommendations for increasing
25	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—

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- "(1) an assessment of the progress in improving outcomes and reducing mortality rates for those
 diagnosed with pancreatic cancer;
 - "(2) an explanation of how recommendations of the Interdisciplinary Pancreatic Cancer Coordinating Committee in the strategic plan developed under subsection (b)(3)(B) for the preceding year have been implemented;
 - "(3) a summary of the recommendations that were made by the Interdisciplinary Pancreatic Cancer Coordinating Committee for grant funding, including exception funding, the number of such recommendations that were met, and the reasons why any recommendations were not met;
 - "(4) a breakdown of research grant award amounts by the National Institutes of Health during the past year that are deemed relevant to pancreatic cancer research along with a quantifiable measure as to the relevancy of the grants to pancreatic cancer;
 - "(5) the number of such grants awarded to young principal investigators in pancreatic cancer 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 (e), \$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-

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

- "(B) RELATION TO OTHER NIH GRANTS.—
 Subject to subparagraph (A), the Secretary shall encourage each recipient of a grant under this section to use the grant for research activities that may serve as a springboard for the receipt of other grants, including Specialized Programs of Research Excellence (SPORE) grants, from the National Institutes of Health and its national research institutes.
- "(2) Grant Period.—The period of a grant under this section shall be 5 years.
- "(3) Focus.—During the initial 5 fiscal years of carrying out this section, the Secretary shall focus on awarding grants for use in developing innovative compounds or technologies for the prevention, early detection, or treatment of pancreatic cancer.
- "(4) Report.—Not later than 5 years after the date of the enactment of this section, the Secretary shall submit a report to the Congress evaluating the program under this section and making recommendations for expansion of the program to other 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.

"(b) Centers of Excellence.—

"(1) Designation.—The Secretary may designate two additional Specialized Programs of Research Excellence (SPOREs) focusing solely on pancreatic cancer research. In carrying out this paragraph, the Secretary may choose to designate one or more satellite centers that augment the work of a previously designated Specialized Program of Research Excellence.

"(2) AUTHORIZATION OF APPROPRIATIONS.—
To carry out this subsection, there are authorized to be appropriated \$20,000,000 for fiscal year 2010 and such sums as may be necessary for fiscal years 2011 through 2014.".

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