Calendar No. 330

110TH CONGRESS 1ST SESSION

S. 898

To amend the Public Health Service Act to fund breakthroughs in Alzheimer's disease research while providing more help to caregivers and increasing public education about prevention.

IN THE SENATE OF THE UNITED STATES

March 15, 2007

Ms. MIKULSKI (for herself, Mr. BOND, Mrs. CLINTON, Ms. COLLINS, Mr. MENENDEZ, Mr. DODD, Mr. KOHL, Mr. ISAKSON, Mrs. BOXER, Mr. BAYH, Mr. BROWN, Mr. COLEMAN, Mr. DURBIN, Mr. REED, Mr. CAR-PER, Mr. LUGAR, Mr. SANDERS, Ms. KLOBUCHAR, Mr. BURR, Mrs. MUR-RAY, Mr. SALAZAR, Mr. LAUTENBERG, and Mrs. LINCOLN) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

August 3, 2007

Reported by Mr. KENNEDY, with an amendment and an amendment to the title

[Strike out all after the enacting clause and insert the part printed in italic]

A BILL

- To amend the Public Health Service Act to fund breakthroughs in Alzheimer's disease research while providing more help to caregivers and increasing public education about prevention.
 - 1 Be it enacted by the Senate and House of Representa-
 - 2 tives of the United States of America in Congress assembled,

1 SECTION 1. SHORT TITLE.

2 This Act may be cited as the "Alzheimer's Break3 through Act of 2007".

4 SEC. 2. FINDINGS.

5 Congress makes the following findings:

6 (1) Alzheimer's disease is a disorder that de-7 stroys cells in the brain. The disease is the leading 8 cause of dementia, a condition that involves gradual 9 memory loss, decline in the ability to perform rou-10 tine tasks, disorientation, difficulty in learning, loss 11 of language skills, impairment of judgment, and per-12 sonality changes. As the disease progresses, people 13 with Alzheimer's disease become unable to care for 14 themselves. The loss of brain cells eventually leads 15 to the failure of other systems in the body.

16 (2) An estimated 4,500,000 Americans have
17 Alzheimer's disease and 1 in 10 individuals have a
18 family member with the disease. By 2050, the num19 ber of individuals with the disease could range from
20 13,000,000 to 16,000,000 unless science finds a way
21 to prevent or cure the disease.

(3) One in 10 people over the age of 65, and
nearly half of those over the age of 85 have Alzheimer's disease. Younger people also get the discase.

 $\mathbf{2}$

1	(4) The Alzheimer's disease process may begin
2	in the brain as many as 20 years before the symp-
3	toms of Alzheimer's disease appear. An individual
4	will live an average of 8 years and as many as 20
5	once the symptoms of Alzheimer's disease appear.
6	(5) The average lifetime cost of care for an in-
7	dividual with Alzheimer's disease is \$170,000.
8	(6) In 2005, Medicare alone spent
9	\$91,000,000,000 for the care of individuals with
10	Alzheimer's disease and this amount is projected to
11	increase to \$160,000,000,000 in 2010.
12	(7) Ninety-five percent of Medicare beneficiaries
13	with Alzheimer's disease have one or more other
14	chronic conditions that are common in the elderly,
15	coronary heart disease (30 percent), congestive heart
16	failure (28 percent), diabetes (21 percent), and
17	chronic obstructive pulmonary disease (17 percent).
18	(8) Seven in 10 individuals with Alzheimer's
19	disease live at home. While almost 75 percent of
20	home care is provided by family and friends, the av-
21	erage annual cost of paid care for people with Alz-
22	heimer's disease at home is \$19,000 per year. Al-
23	most all families pay this cost out of pocket.
24	(9) Half of all nursing home residents have Alz-
25	heimer's disease or a related disorder. The average

1 annual cost of Alzheimer's disease nursing home 2 eare is more than \$70,000. Medicaid pays half of 3 the total nursing home bill and helps 2 out of 3 resi-4 dents pay for their eare. Medicaid expenditures for 5 nursing home eare for people with Alzheimer's dis-6 ease are estimated to increase from \$21,000,000,000 7 in 2005 to \$24,000,000,000 in 2010.

8 (10) In fiscal year 2007, the Federal Govern-9 ment will spend an estimated \$642,000,000 on Alz-10 heimer's disease research. If the United States 11 achieves its research goals (preventing the onset of 12 Alzheimer's disease in those at risk and treating and 13 delaying progression of the disease in those who 14 have symptoms), annual Medicare savings would be 15 \$51,000,000,000 by 2015 and \$88,000,000,000 by 16 2020. Annual Medicaid savings would be 17 \$10,000,000,000 in 2015 and \$17,000,000,000 by 18 2020 and the projected number of cases of Alz-19 heimer's disease can be reduced by 40 percent by 20 the middle of the century.

21 (11) An analysis by the Montefiore Medical
22 Center and the Albert Einstein College of Medicine
23 estimated that the annual value of the informal care
24 system is \$306,000,000,000. Family caregiving

1	comes at enormous physical, emotional, and financial
2	sacrifice, putting the whole system at risk.
3	(12) One in 8 Alzheimer's disease caregivers be-
4	comes ill or injured as a direct result of caregiving.
5	One in 3 uses medication for problems related to
6	caregiving. Older caregivers are 3 times more likely
7	to become clinically depressed than others in their
8	age group.
9	(13) Elderly spouses strained by caregiving are
10	63 percent more likely to die during a given 4-year
11	period than other spouses their age.
12	(14) Almost 3 of 4 caregivers are women. One
13	in 3 has children or grandchildren under the age of
14	18 living at home. Caregiving leaves them less time
15	for other family members and they are much more
16	likely to report family conflicts because of their
17	caregiving role.
18	(15) Most Alzheimer's disease caregivers work
19	outside the home before beginning their caregiving
20	careers, but caregiving forces them to miss work, cut
21	back to part-time, take less demanding jobs, choose
22	early retirement, or give up work altogether. As a
23	result, in 2002, Alzheimer's disease cost American
24	business an estimated \$36,500,000,000 in lost pro-

1ductivity, as well as an additional \$24,600,000,0002in business contributions to the total cost of care.

3 TITLE I—INCREASING THE FED 4 ERAL COMMITMENT TO ALZ 5 HEIMER'S RESEARCH

6 SEC. 101. DOUBLING NIH FUNDING FOR ALZHEIMER'S DIS-

7

EASE RESEARCH.

8 (a) IN GENERAL.—For the purpose of conducting 9 and supporting research on Alzheimer's disease (including 10 related activities under subpart 5 of part C of title IV of 11 the Public Health Service Act (42 U.S.C. 285e et seq.) 12 there is authorized to be appropriated \$1,300,000,000 for 13 fiscal year 2008, and such sums as may be necessary for 14 each of fiscal years 2009 through 2012.

(b) AGING PROCESS REGARDING WOMEN. Section
445H(b) of the Public Health Service Act (42 U.S.C.
285e-10(b)) is amended by striking "2003" and inserting
"2012".

(c) CLINICAL RESEARCH AND TRAINING AWARDS.
20 Section 445I(d) of the Public Health Service Act (42
21 U.S.C. 285e–10a(d)) is amended by striking "2005" and
22 inserting "2012".

23 sec. 102. priority to alzheimer's disease research.

24 Section 443 of the Public Health Service Act (42
25 U.S.C. 285e) is amended—

1	(1) by striking "The general" and inserting
2	"(a) IN GENERAL .—The general"; and
3	(2) by adding at the end the following:
4	"(b) PRIORITIES.—The Director of the Institute
5	shall, in expending amounts appropriated under this sub-
6	part, give priority to conducting and supporting Alz-
7	heimer's disease research.".
8	SEC. 103. ALZHEIMER'S DISEASE PREVENTION INITIATIVE.
9	Section 443 of the Public Health Service Act (42)
10	U.S.C. 285e), as amended by section 102, is further
11	amended by adding at the end the following:
12	"(c) PREVENTION TRIALS.—The Director of the In-
13	stitute shall increase the emphasis on the need to conduct
14	Alzheimer's disease prevention trials within the National
15	Institutes of Health.
16	"(d) NEUROSCIENCE INITIATIVE.—The Director of
17	

17 the Institute shall ensure that Alzheimer's disease is main18 tained as a high priority for the existing neuroscience ini19 tiative.".

20 SEC. 104. ALZHEIMER'S DISEASE CLINICAL RESEARCH.

21 (a) CLINICAL RESEARCH.—Subpart 5 of part C of
22 title IV of the Public Health Service Act (42 U.S.C. 285e
23 et seq.) is amended by adding at the end the following:

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1 "SEC. 445J. ALZHEIMER'S DISEASE CLINICAL RESEARCH.

2	"(a) IN GENERAL.—The Director of the Institute,
3	pursuant to subsections (d) and (e) of section 444, shall
4	conduct and support cooperative clinical research regard-
5	ing Alzheimer's disease. Such research shall include—
6	^{"(1)} investigating therapies, interventions, and
7	agents to detect, treat, slow the progression of, or
8	prevent Alzheimer's disease;
9	${}(2)$ enhancing the national infrastructure for
10	the conduct of clinical trials;
11	${}$ (3) developing and testing novel approaches to
12	the design and analysis of such trials;
13	${}$ (4) facilitating the enrollment of patients for
14	such trials, including patients from diverse popu-
15	lations;
16	"(5) developing improved diagnostics and
17	means of patient assessment for Alzheimer's disease;
18	${}$ (6) the conduct of clinical trials on potential
19	therapies, including readily available compounds
20	such as herbal remedies and other alternative treat-
21	ments;
22	${}$ (7) research to develop better methods of early
23	diagnosis, including the use of current imaging tech-
24	niques; and
25	${}$ (8) other research as determined appropriate
26	by the Director of the Institute, the Alzheimer's Dis-
	a

ease Centers and Alzheimer's Disease Research Cen ters established under section 445.

3 ^{((b)} EARLY DIAGNOSIS AND DETECTION RE-4 search.—

"(1) IN GENERAL.—The Director of the Insti-5 tute, in consultation with the directors of other rel-6 7 evant institutes and centers of the National Insti-8 tutes of Health, shall conduct, or make grants for 9 the conduct of, research related to the early detee-10 tion, diagnosis, and prevention of Alzheimer's dis-11 ease and of mild cognitive impairment or other po-12 tential precursors to Alzheimer's disease.

13 <u>"(2) EVALUATION.—The research described in</u>
 14 paragraph (1) may include the evaluation of diagnostic tests and imaging techniques.

"(3) STUDY.—Not later than 1 year after the 16 17 date of enactment of this section, the Director of the 18 Institute, in cooperation with the heads of other rel-19 evant Federal agencies, shall conduct a study, and 20 submit to Congress a report, to estimate the number 21 of individuals with early-onset Alzheimer's disease 22 (those diagnosed before the age of 65) and related 23 dementias in the United States, the causes of early-24 onset dementia, and the unique problems faced by such individuals, including problems accessing gov ernment services.

"(e) VASCULAR DISEASE.—The Director of the Insti-3 tute, in consultation with the directors of other relevant 4 5 institutes and centers of the National Institutes of Health, shall conduct, or make grants for the conduct of, research 6 7 related to the relationship of vascular disease and Alz-8 heimer's disease, including elinical trials to determine whether drugs developed to prevent cerebrovascular dis-9 10 ease can prevent the onset or progression of Alzheimer's disease. 11

12 "(d) TREATMENTS AND PREVENTION.—The Director 13 of the Institute shall place special emphasis on expediting 14 the translation of research findings under this section into 15 effective treatments and prevention strategies for at-risk 16 individuals.

17 "(e) NATIONAL ALZHEIMER'S COORDINATING CEN18 TER. The Director of the Institute may establish a Na19 tional Alzheimer's Coordinating Center to facilitate col20 laborative research among the Alzheimer's Disease Cen21 ters and Alzheimer's Disease Research Centers established
22 under section 445.".

23 (b) ALZHEIMER'S DISEASE CENTERS. Section
24 445(a)(1) of the Public Health Service Act (42 U.S.C.
25 285e-2(a)(1)) is amended by inserting ", and outcome

measures and disease management" after "treatment

methods". 2 3 SEC. 105. RESEARCH ON **ALZHEIMER'S** DISEASE 4 **CAREGIVING.** 5 Section 445C of the Public Health Service Act (42 U.S.C. 285e-5) is amended— 6 (1) by striking "SEC. 445C. (a)" and inserting 7

8 the following:

9 "SEC. 445C. RESEARCH ON ALZHEIMER'S DISEASE SERV-

10 **ICE**

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ICES AND CAREGIVING.

11 <u>"(a) SERVICES RESEARCH.</u>";

12 (2) by striking subsections (b), (c), and (c);

13 (3) by inserting after subsection (a) the fol14 lowing:

15 "(b) INTERVENTIONS RESEARCH.—The Director shall, in collaboration with the directors of the other rel-16 evant institutes and centers of the National Institutes of 17 Health, conduct, or make grants for the conduct of, clin-18 ical, social, and behavioral research related to interven-19 tions designed to help caregivers of patients with Alz-20 21 heimer's disease and related disorders and improve patient 22 outcomes."; and

23 (4) in subsection (d) by striking "(d) the Direc24 tor" and inserting "(c) MODEL CURRICULA AND
25 TECHNIQUES.—The Director".

12

1 SEC. 106. NATIONAL SUMMIT ON ALZHEIMER'S DISEASE.

(a) IN GENERAL.—Not later than 3 years after the 2 date of enactment of this Act, and every 3 years there-3 after, the Secretary of Health and Human Services (re-4 5 ferred to in this section as the "Secretary") shall convene a summit of researchers, representatives of academic insti-6 7 tutions, Federal and State policymakers, public health 8 professionals, and representatives of voluntary health agencies to provide a detailed overview of current research 9 activities at the National Institutes of Health, as well as 10 to discuss and solicit input related to potential areas of 11 collaboration between the National Institutes of Health 12 and other Federal health agencies, including the Centers 13 for Disease Control and Prevention, the Administration on 14 Aging, the Agency for Healthcare Research and Quality, 15 and the Health Resources and Services Administration, 16 related to research, prevention, and treatment of Alz-17 heimer's disease. 18

19 (b) FOCUS AREAS.—The summit convened under
20 subsection (a) shall focus on—

- 21 (1) a broad range of Alzheimer's disease re22 search activities relating to biomedical research, pre23 vention research, and caregiving issues;
- 24 (2) clinical research for the development and
 25 evaluation of new treatments for the disease;

1	(3) translational research on evidence-based and
2	cost-effective best practices in the treatment and
3	prevention of the disease;
4	(4) information and education programs for
5	health care professionals and the public relating to
6	the disease;
7	(5) priorities among the programs and activities
8	of the various Federal agencies regarding such dis-
9	eases; and
10	(6) challenges and opportunities for scientists,
11	elinicians, patients, and voluntary organizations re-
12	lating to the disease.
13	(c) REPORT.—Not later than 180 days after the date
14	on which the National Summit on Alzheimer's Disease is
15	convened under subsection (a), the Director of National
16	Institutes of Health shall prepare and submit to the ap-
17	propriate committees of Congress a report that includes
18	a summary of the proceedings of the summit and a de-
19	scription of Alzheimer's research, education, and other ac-
20	tivities that are conducted or supported through the na-
21	tional research institutes.

22 (d) PUBLIC INFORMATION.—The Secretary shall
23 make readily available to the public information about the
24 research, education, and other activities relating to Alz-

heimer's disease and other related dementias, conducted 1 or supported by the National Institutes of Health. 2 TITLE II—PUBLIC HEALTH PRO-3 PREVENTION MOTION AND 4 **OF ALZHEIMER'S DISEASE** 5 SEC. 201. ENHANCING PUBLIC HEALTH ACTIVITIES RE-6 7 LATED TO COGNITIVE HEALTH, ALZHEIMER'S 8 **DISEASE, AND OTHER DEMENTIA'S.** 9 Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.) is amended by adding at the end 10

11 the following:

12 "SEC. 399R. ALZHEIMER'S DISEASE PUBLIC EDUCATION 13 CAMPAIGN.

14 "(a) IN GENERAL.—The Secretary, acting through 15 the Director of the Centers for Disease Control and Prevention, shall directly or through grants, cooperative 16 agreements, or contracts to eligible entities, conduct, sup-17 port, and promote the coordination of research, investiga-18 tions, demonstrations, training, and studies relating to the 19 control, prevention, and surveillance of the risk factors as-20 21 sociated with cognitive health, Alzheimer's disease, and 22 other dementia's, and seek early recognition and interven-23 tion in the course of Alzheimer's disease and other demen-24 tias.

1 <u>"(b)</u> CERTAIN ACTIVITIES.—Activities under sub-2 section (a) shall include—

3 "(1) providing support for the dissemination
4 and implementation of the Roadmap to Maintaining
5 Cognitive Health to effectively mobilize the public
6 health community into action;

7 ⁽⁽²⁾ the development of coordinated public edu-8 cation programs, services, and demonstrations which 9 are designed to increase general awareness of cog-10 nitive function and promote a brain healthy lifestyle; 11 ⁽⁽³⁾ the development of targeted communica-12 tion strategies and tools to educate health profes-

13 sionals and service providers about the early recogni-14 tion, diagnosis, care, and management of Alz-15 heimer's disease and dementia, and to provide con-16 sumers with information about interventions, prod-17 ucts, and services that promote cognitive health and 18 assist consumers in maintaining current under-19 standing about cognitive health based on the best 20 science available; and

21 "(4) provide support for the collection, publica-22 tion, and analysis of data on the prevalence and inci-23 dence of cognitive health, Alzheimer's disease, and 24 other dementias, and the evaluation of existing pop-25 ulation-based surveillance systems (such as the Be-

1	havioral Risk Factors Surveillance Survey (BRFFS)
2	and the National Health Interview Survey (NHIS))
3	to identify limitations that exist in the area of cog-
4	nitive health, and if necessary, the development of a
5	surveillance system for cognitive decline, including
6	Alzheimer's disease and dementia.
7	"(c) GRANTS.—The Secretary may award grants
8	under this section—
9	${}(1)$ to State and local health agencies for the
10	purpose of—
11	${(A)}$ coordinating activities related to cog-
12	nitive health, Alzheimer's disease, and other de-
13	mentias with existing State-based health pro-
14	grams and community-based organizations;
15	"(B) providing Alzheimer's disease edu-
16	cation and training opportunities and programs
17	for health professionals; and
18	"(C) developing, testing, evaluating, and
19	replicating effective Alzheimer's disease inter-
20	vention programs to maintain or improve cog-
21	nitive health; and
22	$\frac{(2)}{(2)}$ to nonprofit private health organizations
23	with expertise in providing care and services to indi-
24	viduals with Alzheimer's disease for the purpose
25	of —

1	"(A) disseminating information to the pub-
2	lie;
3	"(B) testing model intervention programs
4	to improve cognitive health; and
5	"(C) coordinating existing services with
6	State-based health programs.
7	"(d) Authorization of Appropriations.—For the
8	purpose of carrying out this section, there are authorized
9	to be appropriated \$15,000,000 for fiscal year 2008, and
10	such sums as may be necessary for each of fiscal years
11	2009 through 2012.".
12	TITLE III—ASSISTANCE FOR
13	CAREGIVERS
14	SEC. 301. ALZHEIMER'S DISEASE CALL CENTER.
15	Part P of title III of the Public Health Service Act
16	(42 U.S.C. 280g et seq.), as amended by section 201, is
17	further amended by adding at the end the following:
18	"SEC. 399S. ALZHEIMER'S DISEASE CALL CENTER.

19 "(a) IN GENERAL.—The Secretary, acting through 20 the Administration on Aging, shall award a cooperative 21 grant to a non-profit or community-based organization to 22 support the establishment and operation of an Alzheimer's 23 Call Center that is accessible 24 hours a day, 7 days a 24 week, to provide expert advice, care consultation, informa-

tion, and referrals nationwide at the national and local 1 level regarding Alzheimer's disease. 2 3 "(b) ACTIVITIES.—The Alzheimer's Call Center es-4 tablished under subsection (a) shall— 5 "(1) collaborate with the Administration on Aging in the development, modification, and execu-6 7 tion of the Call Center's work plan; 8 "(2) assist the Administration on Aging in de-9 veloping and sustaining collaborations between the 10 Alzheimer's Call Center, the Eldereare Locator, the 11 grantees under the Alzheimer's Demonstration Pro-12 gram, and the Aging Network; 13 "(3) provide a 24-hour a day, 7-days a week 14 toll-free Call Center with trained professional staff who are available to provide eare consultation and 15 16 crisis intervention to individuals with Alzheimer's 17 disease and other dementias, their family and infor-18 mal caregivers, and others as appropriate; 19 $\frac{}{}$ (4) be accessible by telephone through a single 20 1-800 telephone number, website and e-mail ad-21 dress: and 22 "(5) evaluate the impact of the Call Center's 23 activities and services. 24 "(e) MULTILINGUAL CAPACITY.—The Call Center es-25 tablished under this section shall have a multilingual eapacity and shall respond to inquiries in at least 140 lan guages through its own bilingual staff and with the use
 of a language translation service.

4 "(d) RESPONSE TO EMERGENCY AND ONGOING 5 NEEDS.—The Call Center established under this section 6 shall collaborate with community-based organizations, in-7 eluding non-profit agencies and organizations, to ensure 8 local, on-the-ground capacity to respond to emergency and 9 on-going needs of Alzheimer's patients, their families, and 10 informal caregivers.

11 "(e) AUTHORIZATION OF APPROPRIATIONS.—For the 12 purpose of carrying out this section, there are authorized 13 to be appropriated \$1,000,000 for fiscal year 2008, and 14 such sums as may be necessary for each of fiscal years 15 2009 through 2012.".

16 SEC. 302. INNOVATIVE ALZHEIMER'S CARE STATE MATCH-17 ING GRANT PROGRAM.

18 (a) AUTHORIZATION OF APPROPRIATIONS. Section
19 398B(e) of the Public Health Service Act (42 U.S.C.
20 280c-5(e)) is amended—

21 (1) by striking "and such" and inserting
22 "such"; and

23 (2) by inserting before the period the following:
24 ", \$25,000,000 for fiscal year 2008, and such sums

1	as may be necessary for each of fiscal years 2009
2	through 2012".
3	(b) Program Expansion.—Section 398(a) of the
4	Public Health Service Act (42 U.S.C. 280c–3(a))
5	(1) in paragraph (2) , by inserting after "other
6	respite care" the following: "and care consultation
7	including assessment of needs, assistance with plan-
8	ning and problem solving and providing supportive
9	listening";
10	(2) in paragraph (3), by striking "; and" and
11	inserting the following: "and individuals in frontier
12	areas (as defined as areas with 6 or fewer people per
13	square mile or areas in which it takes people at least
14	60 minutes or 60 miles to reach a market or service
15	area);'';
16	(3) in paragraph (4) , by striking the period at
17	the end and inserting a semicolon; and
18	(4) by adding at the end the following:
19	${}$ (5) to encourage grantees under this section to
20	coordinate activities with other State officials admin-
21	istering efforts to promote long-term care options
22	that enable older individuals to receive long-term

care in home- and community-based settings, in a

manner responsive to the needs and preferences of

older individuals and their family caregivers;

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1	"(6) to encourage grantees under this section
2	to
3	"(A) engage in activities that support early
4	detection and diagnosis of Alzheimer's disease
5	and related dementia;
6	"(B) provide training to medical personnel
7	including hospital staff, emergency room per-
8	sonnel, home health care workers and physician
9	office staff, rehabilitation services providers,
10	and caregivers about how Alzheimer's can affect
11	behavior and impede communication in medical
12	and community settings;
13	"(C) develop guidelines to provide the med-
14	ical community with up-to-date information
15	about the best methods of care for individuals
16	with Alzheimer's disease;
17	"(D) inform community physicians about
18	available resources to assist them in detecting
19	and managing Alzheimer's; and
20	"(E) raise awareness among community
21	physicians about the availability of community-
22	based organizations which can assist individuals
23	with Alzheimer's and their caregivers;
24	${}$ (7) to encourage grantees under this section to
25	engage in activities that use findings from evidence-

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based research on service models and techniques to
 support individuals with Alzheimer's disease and
 their caregivers; and

4 "(8) to encourage grantees under this section to
5 incorporate best practices for effectively serving indi6 viduals with Alzheimer's disease in community-based
7 settings into ongoing State systems change and
8 long-term care activities.".

9 SECTION 1. SHORT TITLE.

10 This Act may be cited as the "Alzheimer's Break-11 through Act of 2007".

12 SEC. 2. FINDINGS.

13 Congress makes the following findings:

14 (1) Alzheimer's disease is a disorder that de-15 stroys cells in the brain. The disease is the leading 16 cause of dementia, a condition that involves gradual 17 memory loss, decline in the ability to perform routine 18 tasks, disorientation, difficulty in learning, loss of 19 language skills, impairment of judgment, and person-20 ality changes. As the disease progresses, people with 21 Alzheimer's disease become unable to care for them-22 selves. The loss of brain cells eventually leads to the 23 failure of other systems in the body.

24 (2) An estimated 4,500,000 Americans have Alz25 heimer's disease and 1 in 10 individuals have a fam-

1	ily member with the disease. By 2050, the number of
2	individuals with the disease could range from
3	13,000,000 to 16,000,000 unless science finds a way
4	to prevent or cure the disease.
5	(3) One in 10 people over the age of 65, and
6	nearly half of those over the age of 85 have Alz-
7	heimer's disease. Younger people also get the disease.
8	(4) The Alzheimer's disease process may begin in
9	the brain as many as 20 years before the symptoms
10	of Alzheimer's disease appear. An individual will live
11	an average of 8 years and as many as 20 once the
12	symptoms of Alzheimer's disease appear.
13	(5) The average lifetime cost of care for an indi-
14	vidual with Alzheimer's disease is \$170,000.
15	(6) In 2005, Medicare alone spent
16	\$91,000,000,000 for the care of individuals with Alz-
17	heimer's disease and this amount is projected to in-
18	crease to \$160,000,000,000 in 2010.
19	(7) Ninety-five percent of Medicare beneficiaries
20	with Alzheimer's disease have one or more other
21	chronic conditions that are common in the elderly,
22	coronary heart disease (30 percent), congestive heart
23	failure (28 percent), diabetes (21 percent), and chron-
24	ic obstructive pulmonary disease (17 percent).

1	(8) Seven in 10 individuals with Alzheimer's
2	disease live at home. While almost 75 percent of home
3	care is provided by family and friends, the average
4	annual cost of paid care for people with Alzheimer's
5	disease at home is \$19,000 per year. Almost all fami-
6	lies pay this cost out of pocket.
7	(9) Half of all nursing home residents have Alz-
8	heimer's disease or a related disorder. The average
9	annual cost of Alzheimer's disease nursing home care
10	is more than \$70,000. Medicaid pays half of the total
11	nursing home bill and helps 2 out of 3 residents pay
12	for their care. Medicaid expenditures for nursing
13	home care for people with Alzheimer's disease are esti-
14	mated to increase from \$21,000,000,000 in 2005 to
15	\$24,000,000,000 in 2010.
16	(10) In fiscal year 2007, the Federal Government
17	will spend an estimated \$642,000,000 on Alzheimer's
18	disease research. If the United States achieves its re-
19	search goals (preventing the onset of Alzheimer's dis-
20	ease in those at risk and treating and delaying pro-
21	gression of the disease in those who have symptoms),
22	annual Medicare savings would be \$51,000,000,000
23	by 2015 and \$88,000,000,000 by 2020. Annual Med-
24	icaid savings would be \$10,000,000,000 in 2015 and
25	\$17,000,000,000 by 2020 and the projected number of

1	cases of Alzheimer's disease would be reduced by 40
2	percent by the middle of the century.
3	(11) An analysis by the Montefiore Medical Cen-
4	ter and the Albert Einstein College of Medicine esti-
5	mated that the annual value of the informal care sys-
6	tem is \$306,000,000,000. Family caregiving comes at
7	enormous physical, emotional, and financial sacrifice,
8	putting the whole system at risk.
9	(12) One in 8 Alzheimer's disease caregivers be-
10	comes ill or injured as a direct result of caregiving.
11	One in 3 uses medication for problems related to
12	caregiving. Older caregivers are 3 times more likely
13	to become clinically depressed than others in their age
14	group.
15	(13) Elderly spouses strained by caregiving are
16	63 percent more likely to die during a given 4-year
17	period than other spouses their age.
18	(14) Almost 3 of 4 caregivers are women. One in
19	3 has children or grandchildren under the age of 18
20	living at home. Caregiving leaves them less time for
21	other family members and they are much more likely
22	to report family conflicts because of their caregiving
23	role.
24	(15) Most Alzheimer's disease caregivers work

25 outside the home before beginning their caregiving ca-

1 reers, but caregiving forces them to miss work, cut 2 back to part-time, take less demanding jobs, choose 3 early retirement, or give up work altogether. As a re-4 sult, in 2002, Alzheimer's disease cost American busi-5 ness an estimated \$36,500,000,000 in lost produc-6 tivity, as well as an additional \$24,600,000,000 in 7 business contributions to the total cost of care. TITLE I—INCREASING THE FED-8 ERAL COMMITMENT TO ALZ-9 HEIMER'S RESEARCH 10 11 SEC. 101. INCREASE IN NIH FUNDING FOR ALZHEIMER'S 12 DISEASE RESEARCH.

13 For the purpose of conducting and supporting research on Alzheimer's disease, cognitive health, and related dis-14 15 orders (including related activities under subpart 5 of part C of title IV of the Public Health Service Act (42 U.S.C. 16 285e et seq.) there is authorized to be appropriated 17 \$780,000,000 for fiscal year 2008, \$910,000,000 for fiscal 18 19 \$1,040,000,000 for fiscal year 2009. year 2010.\$1,170,000,000 for fiscal year 2011, and \$1,300,000,000 for 20 21 fiscal year 2012.

22 SEC. 102. PRIORITY TO ALZHEIMER'S DISEASE RESEARCH.

23 Section 444(d) of the Public Health Service Act (42
24 U.S.C. 285e-1(d)) is amended by adding at the end the fol25 lowing: "The Director of the Institute shall continue to

make research related to Alzheimer's Disease, cognitive
 health, and related disorders', a priority within the Insti tute's activities consistent with the peer-review process.".

4 SEC. 103. ALZHEIMER'S DISEASE PREVENTION INITIATIVE.

5 Section 444 of the Public Health Service Act (42
6 U.S.C. 285e-1), as amended by section 102, is further
7 amended by adding at the end the following:

8 "(e) PREVENTION TRIALS.—The Director of the Insti-9 tute, shall increase the emphasis on the need to conduct Alz-10 heimer's disease, cognitive health, and related disorders pre-11 vention trials within the National Institutes of Health.

12 "(f) NEUROSCIENCE INITIATIVE.—The Director of the
13 Institute, shall ensure that Alzheimer's disease, cognitive
14 health, and related disorders is maintained as a high pri15 ority for the existing neuroscience initiative.".

16 SEC. 104. ALZHEIMER'S DISEASE CLINICAL RESEARCH.

(a) CLINICAL RESEARCH.—Subpart 5 of part C of title
IV of the Public Health Service Act (42 U.S.C. 285e et seq.)
is amended by adding at the end the following:

20 "SEC. 445J. ALZHEIMER'S DISEASE CLINICAL RESEARCH.

21 "(a) IN GENERAL.—The Secretary, acting through the
22 Director of the Institute, pursuant to subsection (d) of sec23 tion 444, shall, consistent with the peer-review and priority
24 setting process of the Institute, conduct and support cooper25 ative clinical research regarding Alzheimer's disease, cog-

1 nitive health, and related disorders. Such research may in-

2	clude—
3	"(1) investigating therapies, interventions, and
4	agents to detect, treat, slow the progression of, or pre-
5	vent Alzheimer's disease;
6	"(2) enhancing the national infrastructure for
7	the conduct of clinical trials;
8	"(3) developing and testing novel approaches to
9	the design and analysis of such trials;
10	"(4) facilitating the enrollment of patients for
11	such trials, including patients from diverse popu-
12	lations;
13	"(5) developing improved diagnostics and means
14	of patient assessment for Alzheimer's disease;
15	"(6) the conduct of clinical trials on potential
16	therapies, including readily available compounds such
17	as herbal remedies and other alternative treatments;
18	"(7) research to develop better methods of early
19	diagnosis, including the use of current imaging tech-
20	niques;
21	"(8) enhance research currently being done on
22	minorities and health disparities; and
23	"(9) other research as determined appropriate by
24	the Director of the Institute, the Alzheimer's Disease

3 "(b) EARLY DIAGNOSIS AND DETECTION RE-4 SEARCH.—

"(1) GENERAL.—The 5 INSecretary, acting 6 through the Director of the Institute, in consultation 7 with the directors of other relevant institutes and cen-8 ters of the National Institutes of Health, shall con-9 duct, or make grants for the conduct of, research re-10 lated to the early detection, diagnosis, and prevention 11 of Alzheimer's disease and of mild cognitive impair-12 ment or other potential precursors to Alzheimer's dis-13 ease.

14 "(2) EVALUATION.—The research described in
15 paragraph (1) may include the evaluation of diag16 nostic tests and imaging techniques.

17 "(3) STUDY ON THE PREVALENCE AND CAUSES
18 OF EARLY ONSET DEMENTIA.—The Director of the In19 stitute is encouraged to explore the feasibility and sci20 entific opportunities in research regarding the preva21 lence and causes of early onset dementia (diagnosed
22 before the age of 65).

23 "(c) VASCULAR DISEASE.—The Secretary, acting
24 through the Director of the Institute, in consultation with
25 the directors of other relevant institutes and centers of the

National Institutes of Health, are strongly encouraged to
 conduct or make grants for the conduct of research related
 to the relationship of vascular disease and Alzheimer's dis ease and related disorders, including clinical trials to deter mine whether drugs developed to prevent cerebrovascular
 disease can prevent the onset or progression of Alzheimer's
 disease.

8 "(d) TREATMENTS AND PREVENTION.—The Secretary, 9 acting through the Director of the Institute, shall place spe-10 cial emphasis on expediting the translation of research find-11 ings under this section into effective treatments and preven-12 tion strategies for at-risk individuals.

"(e) NATIONAL ALZHEIMER'S COORDINATING CENTER.—The Secretary, acting through the Director of the Institute, may establish a National Alzheimer's Coordinating
Center to facilitate collaborative research among the Alzheimer's Disease Centers and Alzheimer's Disease Research
Centers established under section 445.".

(b) ALZHEIMER'S DISEASE CENTERS.—Section
20 445(a)(1) of the Public Health Service Act (42 U.S.C. 285e–
21 2(a)(1)) is amended by inserting ", and outcome measures
22 and disease management" after "treatment methods".

1	SEC.	105.	RESEARCH	ON	ALZHEIMER'S	DISEASE
2			CAREGIVING.			
3	Sec	ction	445C of the	Publi	c Health Servic	xe Act (42
4	U.S.C. 2	285e-:	5) is amended	<u> </u>		
5		(1)	by striking	"SEC.	445C. (a)" and	l inserting
6	the	folloi	wing:			
7	"SEC. 4	45C. 1	RESEARCH O	N ALZ	HEIMER'S DISEA	ASE SERV-
8			ICES AND CA	REGIV	ING.	
9	"(0	a) Sei	RVICES RESEA	ARCH	—";	
10		(2)	by striking s	ubsecti	ons (b), (c), and	(e);
11		(3)	by inserting	g afte	r subsection (a) the fol-
12	lou	ving:				
13	"(l) INT	ERVENTIONS	Resea	RCH.—The Secr	retary, act-
14	ing thre	ough	the Director,	shall,	in collaboration	ı with the
15	director	s of th	he other relev	oant in	estitutes and cen	ters of the
16	Nationa	ıl Inst	titutes of Hea	ulth, co	mduct, or make	grants for
17	the cond	duct o	f, clinical, so	cial, a	nd behavioral r	esearch re-
18	lated to	inter	ventions desig	med to	help caregivers	of patients
19	with Al	zheim	er's disease a	nd rela	nted disorders an	ed improve
20	patient	outco	mes."; and			
21		(4)	in subsection	n (d) l	y striking "(d)	the Direc-
22	tor	" an	d inserting	"(c)	Model Currie	CULA AND
22	$m_{\rm T}$	ann		Jinata	·····	

1SEC. 106. NATIONAL SUMMIT ON ALZHEIMER'S DISEASE2AND RELATED DISORDERS.

3 (a) IN GENERAL.—Not later than 3 years after the date of enactment of this Act, and every 3 years thereafter, 4 5 the Secretary of Health and Human Services (referred to in this section as the "Secretary") shall convene a summit 6 7 of researchers, representatives of academic institutions, Fed-8 eral and State policy makers, public health professionals, 9 community health organizations, and representatives of voluntary health organizations to provide a detailed overview 10 11 of current research activities at the National Institutes of Health, as well as to discuss and solicit input related to 12 13 potential areas of collaboration between the National Institutes of Health and other Federal health agencies, including 14 the Centers for Disease Control and Prevention, the Admin-15 16 istration on Aging, the Agency for Healthcare Research and Quality, and the Health Resources and Services Adminis-17 tration, related to research, prevention, and treatment of 18 19 Alzheimer's disease.

20 (b) FOCUS AREAS.—The summit convened under sub21 section (a) shall focus on—

(1) a broad range of Alzheimer's disease research
activities relating to breakthroughs in biomedical research, prevention research, and caregiving issues;

25 (2) clinical research for the development and
26 evaluation of new treatments for Alzheimer's disease;

1	(3) translational research on evidence-based and
2	cost-effective best practices in the treatment and pre-
3	vention of Alzheimer's disease;
4	(4) international research and activities relating
5	to breakthroughs in prevention, diagnosis, and treat-
6	ment of Alzheimer's disease;
7	(5) advances in complimentary and alternative
8	medicine related to Alzheimer's disease;
9	(6) information and education programs for
10	health care professionals and the public relating to
11	Alzheimer's disease;
12	(7) priorities among the programs and activities
13	of the various Federal agencies related to Alzheimer's
14	disease; and
15	(8) challenges and opportunities for scientists,
16	clinicians, patients, and voluntary organizations re-
17	lating to Alzheimer's disease.
18	(c) REPORT.—Not later than 180 days after the date
19	on which the National Summit on Alzheimer's Disease is
20	convened under subsection (a), the Secretary, acting
21	through the Director of National Institutes of Health, shall
22	prepare and submit to the appropriate committees of Con-
23	gress a report that includes a summary of the proceedings
24	of the summit and a description of Alzheimer's research,

education, and other activities that are conducted or sup ported through the national research institutes.

3 (d) PUBLIC INFORMATION.—The Secretary shall make
4 readily available to the public information about the re5 search, education, and other activities relating to Alz6 heimer's disease and other related dementias, conducted or
7 supported by the National Institutes of Health.

8 TITLE II—ENHANCED PUBLIC 9 HEALTH ACTIVITIES RELATED 10 TO COGNITIVE HEALTH, ALZ11 HEIMER'S DISEASE AND 12 OTHER DEMENTIAS

13 SEC. 201. ENHANCED PUBLIC HEALTH ACTIVITIES RELATED
14 TO COGNITIVE HEALTH, ALZHEIMER'S DIS15 EASE, AND OTHER DEMENTIAS.

16 Part P of title III of the Public Health Service Act
17 (42 U.S.C. 280g et seq.) is amended by adding at the end
18 the following:

19 "SEC. 399R. ALZHEIMER'S DISEASE PUBLIC EDUCATION20AWARENESS PROGRAM.

21 "(a) IN GENERAL.—The Secretary, acting through the
22 Director of the Centers for Disease Control and Prevention,
23 shall directly or through grants, cooperative agreements, or
24 contracts to eligible entities, conduct, support, and promote
25 the coordination of research, investigations, demonstrations,

training, and studies relating to the control, prevention,
 and surveillance of the risk factors associated with cognitive
 health, Alzheimer's disease, and related disorders, and seek
 early recognition and intervention in the course of Alz heimer's disease and related disorders.

6 "(b) CERTAIN ACTIVITIES.—Activities under sub7 section (a) may include—

8 "(1) providing support for the dissemination 9 and implementation of the Roadmap to Maintaining 10 Cognitive Health to effectively mobilize the public 11 health community into action;

"(2) the development of coordinated public education programs, services, and demonstrations which
are designed to increase general awareness of cognitive function and promote a brain healthy lifestyle;

16 "(3) the development of targeted communication 17 strategies and tools to educate health professionals 18 and service providers about the early recognition, di-19 agnosis, care, and management of Alzheimer's disease 20 and related disorders, and to provide consumers with information about interventions, products, and serv-21 22 ices that promote cognitive health and assist con-23 sumers in maintaining current understanding about 24 cognitive health based on the best science available: 25 and

1	"(4) provide support for the collection, publica-
2	tion, and analysis of data on the prevalence and inci-
3	dence of cognitive function, Alzheimer's disease and
4	related disorders, and the related public health bur-
5	den, and the evaluation of existing population-based
6	surveillance systems (such as the Behavioral Risk
7	Factors Surveillance Survey (BRFFS) and the Na-
8	tional Health Interview Survey (NHIS)) to identify
9	limitations that exist in the area of cognitive health,
10	and if necessary, the development of a surveillance
11	system for cognitive decline, including Alzheimer's
12	disease and related disorders.
14	
12	"(c) GRANTS.—The Secretary may award grants
13	"(c) GRANTS.—The Secretary may award grants
13 14	"(c) GRANTS.—The Secretary may award grants under this section—
13 14 15	"(c) GRANTS.—The Secretary may award grants under this section— "(1) to State and local health agencies and
 13 14 15 16 	"(c) GRANTS.—The Secretary may award grants under this section— "(1) to State and local health agencies and health organizations for the purpose of—
 13 14 15 16 17 	"(c) GRANTS.—The Secretary may award grants under this section— "(1) to State and local health agencies and health organizations for the purpose of— "(A) coordinating activities related to Alz-
 13 14 15 16 17 18 	"(c) GRANTS.—The Secretary may award grants under this section— "(1) to State and local health agencies and health organizations for the purpose of— "(A) coordinating activities related to Alz- heimer's disease, cognitive health, and related
 13 14 15 16 17 18 19 	"(c) GRANTS.—The Secretary may award grants under this section— "(1) to State and local health agencies and health organizations for the purpose of— "(A) coordinating activities related to Alz- heimer's disease, cognitive health, and related disorders with existing State-based health pro-
 13 14 15 16 17 18 19 20 	"(c) GRANTS.—The Secretary may award grants under this section— "(1) to State and local health agencies and health organizations for the purpose of— "(A) coordinating activities related to Alz- heimer's disease, cognitive health, and related disorders with existing State-based health pro- grams and community-based organizations;
 13 14 15 16 17 18 19 20 21 	"(c) GRANTS.—The Secretary may award grants under this section— "(1) to State and local health agencies and health organizations for the purpose of— "(A) coordinating activities related to Alz- heimer's disease, cognitive health, and related disorders with existing State-based health pro- grams and community-based organizations; "(B) providing Alzheimer's disease, cog-

1	``(C) developing, testing, evaluating, and
2	replicating effective Alzheimer's disease and re-
3	lated disorders intervention programs to main-
4	tain or improve cognitive health; and
5	"(2) to nonprofit private health organizations
6	with expertise in providing care and services to indi-
7	viduals with Alzheimer's disease and related disorders
8	for the purpose of—
9	"(A) disseminating information to the pub-
10	lic;
11	(B) testing model intervention programs to
12	improve cognitive health; and
13	(C) coordinating existing services with
14	State-based health programs.
15	"(d) AUTHORIZATION OF APPROPRIATIONS.—For the
16	purpose of carrying out this section, there are authorized
17	to be appropriated \$3,000,000 for each of fiscal years 2008
18	through 2012.".
19	TITLE III—ASSISTANCE FOR
20	CAREGIVERS
21	SEC. 301. ALZHEIMER'S DISEASE CALL CENTER.
22	Part P of title III of the Public Health Service Act
23	(42 U.S.C. 280g et seq.), as amended by section 201, is fur-
24	ther amended by adding at the end the following:

1 "SEC. 399S. ALZHEIMER'S DISEASE CALL CENTER.

2 "(a) IN GENERAL.—The Secretary, acting through the Administration on Aging, shall award a cooperative grant 3 to a non-profit or community-based organization to support 4 5 the establishment and operation of an Alzheimer's Call Center that is accessible 24 hours a day, 7 days a week, to 6 7 provide expert advice, care consultation, information, and 8 referrals nationwide at the national and local level regard-9 ing Alzheimer's disease and related disorders.

10 "(b) ACTIVITIES.—The Alzheimer's Call Center estab11 lished under subsection (a) shall—

12 "(1) collaborate with the Administration on
13 Aging in the development, modification, and execu14 tion of the Call Center's work plan;

"(2) assist the Administration on Aging in developing and sustaining collaborations between the
Alzheimer's Call Center, the Eldercare Locator, the
grantees under the Alzheimer's Demonstration Program, and the Aging Network;

20 "(3) provide a 24-hour a day, 7-days a week toll21 free Call Center with trained professional staff who
22 are available to provide care consultation and crisis
23 intervention to individuals with Alzheimer's disease
24 and other dementias, their family and informal care25 givers, and others as appropriate;

3 and

1

2

4 "(5) evaluate the impact of the Call Center's ac5 tivities and services.

6 "(c) MULTILINGUAL CAPACITY.—The Call Center es-7 tablished under this section shall have a multilingual ca-8 pacity and shall respond to inquiries in at least 140 lan-9 guages through its own bilingual staff and with the use of 10 a language translation service.

11 "(d) RESPONSE TO EMERGENCY AND ONGOING 12 NEEDS.—The Call Center established under this section 13 shall collaborate with community-based organizations, in-14 cluding non-profit agencies and organizations, to ensure 15 local, on-the-ground capacity to respond to emergency and 16 on-going needs of Alzheimer's patients, their families, and 17 informal caregivers.

18 "(e) AUTHORIZATION OF APPROPRIATIONS.—For the
19 purpose of carrying out this section, there are authorized
20 to be appropriated \$1,000,000 for fiscal year 2008, and
21 such sums as may be necessary for each of fiscal years 2009
22 through 2012.".

1	SEC. 302. INNOVATIVE ALZHEIMER'S CARE STATE MATCH-
2	ING GRANT PROGRAM.
3	(a) AUTHORIZATION OF APPROPRIATIONS.—Section
4	398B(e) of the Public Health Service Act (42 U.S.C. 280c-
5	5(e)) is amended—
6	(1) by striking "and such" and inserting "such";
7	and
8	(2) by inserting before the period the following:
9	", and \$20,000,000 for each of fiscal years 2008
10	through 2012".
11	(b) Program Expansion.—Section 398(a) of the Pub-
12	lic Health Service Act (42 U.S.C. 280c–3(a))
13	(1) in paragraph (2), by inserting after "other
14	respite care" the following: "and care consultation in-
15	cluding assessment of needs, assistance with planning
16	and problem solving and providing supportive listen-
17	ing";
18	(2) in paragraph (3), by striking "; and" and
19	inserting the following: "and individuals in frontier
20	areas (as defined as areas with 6 or fewer people per
21	square mile or areas in which it takes people at least
22	60 minutes or 60 miles to reach a market or service
23	area);";
24	(3) in paragraph (4), by striking the period at
25	the end and inserting a semicolon; and
26	(4) by adding at the end the following:

1	"(5) to encourage grantees under this section to
2	coordinate activities with other State officials admin-
3	istering efforts to promote long-term care options that
4	enable older individuals to receive long-term care in
5	home- and community-based settings, in a manner re-
6	sponsive to the needs and preferences of older individ-
7	uals and their family caregivers;
8	"(6) to encourage grantees under this section
9	to—
10	"(A) engage in activities that support early
11	detection and diagnosis of Alzheimer's disease
12	and related disorders;
13	"(B) provide training to medical personnel
14	including hospital staff, emergency room per-
15	sonnel, home health care workers and physician
16	office staff, rehabilitation services providers, and
17	caregivers about how Alzheimer's can affect be-
18	havior and impede communication in medical
19	and community settings;
20	(C) develop guidelines to provide the med-
21	ical community with up-to-date information
22	about the best methods of care for individuals
23	with Alzheimer's disease and related disorders;
24	"(D) inform community physicians about
25	available resources to assist them in detecting

Amend the title so as to read: "A bill to amend the Public Health Service Act to fund breakthroughs in Alzheimer's disease research while providing more help to caregivers and increasing public and provider awareness about steps that may be taken to respond rapidly to breakthroughs in prevention, early detection, and management, about cognitive health, Alzheimer's disease, and other dementias related to aging.".

Calendar No. 330

110TH CONGRESS S. 898

A BILL

To amend the Public Health Service Act to fund breakthroughs in Alzheimer's disease research while providing more help to caregivers and increasing public education about prevention.

August 3, 2007

Reported with an amendment and an amendment to the title