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(Original Signature of Member)

110TH CONGRESS
1ST SESSION

H. R.

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 HOUSE OF REPRESENTATIVES

Mr. MARKEY introduced the following bill; which was referred to the Committee on _____

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,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Alzheimer’s Break-
5 through Act of 2007”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

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

11 (2) An estimated 4,500,000 Americans have
12 Alzheimer's disease and 1 in 10 individuals have a
13 family member with the disease. By 2050, the num-
14 ber of individuals with the disease could range from
15 13,000,000 to 16,000,000 unless science finds a way
16 to prevent or cure the disease.

17 (3) One in 10 people over the age of 65, and
18 nearly half of those over the age of 85 have Alz-
19 heimer's disease. Younger people also get the dis-
20 ease.

21 (4) The Alzheimer's disease process may begin
22 in the brain as many as 20 years before the symp-
23 toms of Alzheimer's disease appear. An individual
24 will live an average of 8 years and as many as 20
25 once the symptoms of Alzheimer's disease appear.

1 (5) The average lifetime cost of care for an in-
2 dividual with Alzheimer's disease is \$170,000.

3 (6) In 2005, Medicare alone spent
4 \$91,000,000,000 for the care of individuals with
5 Alzheimer's disease and this amount is projected to
6 increase to \$160,000,000,000 in 2010.

7 (7) Ninety-five percent of Medicare beneficiaries
8 with Alzheimer's disease have one or more other
9 chronic conditions that are common in the elderly,
10 coronary heart disease (30 percent), congestive heart
11 failure (28 percent), diabetes (21 percent), and
12 chronic obstructive pulmonary disease (17 percent).

13 (8) Seven in 10 individuals with Alzheimer's
14 disease live at home. While almost 75 percent of
15 home care is provided by family and friends, the av-
16 erage annual cost of paid care for people with Alz-
17 heimer's disease at home is \$19,000 per year. Al-
18 most all families pay this cost out of pocket.

19 (9) Half of all nursing home residents have Alz-
20 heimer's disease or a related disorder. The average
21 annual cost of Alzheimer's disease nursing home
22 care is more than \$70,000. Medicaid pays half of
23 the total nursing home bill and helps 2 out of 3 resi-
24 dents pay for their care. Medicaid expenditures for
25 nursing home care for people with Alzheimer's dis-

1 ease are estimated to increase from \$21,000,000,000
2 in 2005 to \$24,000,000,000 in 2010.

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

16 (11) An analysis by the Montefiore Medical
17 Center and the Albert Einstein College of Medicine
18 estimated that the annual value of the informal care
19 system is \$306,000,000,000. Family caregiving
20 comes at enormous physical, emotional, and financial
21 sacrifice, putting the whole system at risk.

22 (12) One in 8 Alzheimer's disease caregivers be-
23 comes ill or injured as a direct result of caregiving.
24 One in 3 uses medication for problems related to
25 caregiving. Older caregivers are 3 times more likely

1 to become clinically depressed than others in their
2 age group.

3 (13) Elderly spouses strained by caregiving are
4 63 percent more likely to die during a given 4-year
5 period than other spouses their age.

6 (14) Almost 3 of 4 caregivers are women. One
7 in 3 has children or grandchildren under the age of
8 18 living at home. Caregiving leaves them less time
9 for other family members and they are much more
10 likely to report family conflicts because of their
11 caregiving role.

12 (15) Most Alzheimer's disease caregivers work
13 outside the home before beginning their caregiving
14 careers, but caregiving forces them to miss work, cut
15 back to part-time, take less demanding jobs, choose
16 early retirement, or give up work altogether. As a
17 result, in 2002, Alzheimer's disease cost American
18 business an estimated \$36,500,000,000 in lost pro-
19 ductivity, as well as an additional \$24,600,000,000
20 in business contributions to the total cost of care.

1 **TITLE I—INCREASING THE FED-**
2 **ERAL COMMITMENT TO ALZ-**
3 **HEIMER’S RESEARCH**

4 **SEC. 101. DOUBLING NIH FUNDING FOR ALZHEIMER’S DIS-**
5 **EASE RESEARCH.**

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

13 **SEC. 102. PRIORITY TO ALZHEIMER’S DISEASE RESEARCH.**

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

16 (1) by striking “The general” and inserting
17 “(a) IN GENERAL.—The general”; and

18 (2) by adding at the end the following:

19 “(b) PRIORITIES.—The Director of the Institute
20 shall, in expending amounts appropriated to carry out this
21 subpart, give priority to conducting and supporting Alz-
22 heimer’s disease research.”.

1 **SEC. 103. ALZHEIMER'S DISEASE PREVENTION INITIATIVE.**

2 Section 443 of the Public Health Service Act (42
3 U.S.C. 285e), as amended by section 102, is further
4 amended by adding at the end the following:

5 “(c) PREVENTION TRIALS.—The Director of the In-
6 stitute shall increase the emphasis on the need to conduct
7 Alzheimer's disease prevention trials within the National
8 Institutes of Health.

9 “(d) NEUROSCIENCE INITIATIVE.—The Director of
10 the Institute shall ensure that Alzheimer's disease is main-
11 tained as a high priority for the existing neuroscience ini-
12 tiative.”.

13 **SEC. 104. ALZHEIMER'S DISEASE CLINICAL RESEARCH.**

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

17 **“SEC. 445J. ALZHEIMER'S DISEASE CLINICAL RESEARCH.**

18 “(a) IN GENERAL.—The Director of the Institute,
19 pursuant to section 444(d), shall conduct and support co-
20 operative clinical research regarding Alzheimer's disease.
21 Such research shall include—

22 “(1) investigating therapies, interventions, and
23 agents to detect, treat, slow the progression of, or
24 prevent Alzheimer's disease;

25 “(2) enhancing the national infrastructure for
26 the conduct of clinical trials;

1 “(3) developing and testing novel approaches to
2 the design and analysis of such trials;

3 “(4) facilitating the enrollment of patients for
4 such trials, including patients from diverse popu-
5 lations;

6 “(5) developing improved diagnostics and
7 means of patient assessment for Alzheimer’s disease;

8 “(6) the conduct of clinical trials on potential
9 therapies, including readily available compounds
10 such as herbal remedies and other alternative treat-
11 ments;

12 “(7) research to develop better methods of early
13 diagnosis, including the use of current imaging tech-
14 niques; and

15 “(8) other research as determined appropriate
16 by the Director of the Institute, the Alzheimer’s Dis-
17 ease Centers and Alzheimer’s Disease Research Cen-
18 ters established under section 445.

19 “(b) EARLY DIAGNOSIS AND DETECTION RE-
20 SEARCH.—

21 “(1) IN GENERAL.—The Director of the Insti-
22 tute, in consultation with the directors of other rel-
23 evant institutes and centers of the National Insti-
24 tutes of Health, shall conduct, or make grants for
25 the conduct of, research related to the early detec-

1 tion, diagnosis, and prevention of Alzheimer’s dis-
2 ease and of mild cognitive impairment or other po-
3 tential precursors to Alzheimer’s disease.

4 “(2) EVALUATION.—The research described in
5 paragraph (1) may include the evaluation of diag-
6 nostic tests and imaging techniques.

7 “(3) STUDY.—Not later than 1 year after the
8 date of enactment of this section, the Director of the
9 Institute, in cooperation with the heads of other rel-
10 evant Federal agencies, shall conduct a study, and
11 submit to Congress a report, to estimate the number
12 of individuals with early-onset Alzheimer’s disease
13 (those diagnosed before the age of 65) and related
14 dementias in the United States, the causes of early-
15 onset dementia, and the unique problems faced by
16 such individuals, including problems accessing gov-
17 ernment services.

18 “(c) VASCULAR DISEASE.—The Director of the Insti-
19 tute, in consultation with the directors of other relevant
20 institutes and centers of the National Institutes of Health,
21 shall conduct, or make grants for the conduct of, research
22 related to the relationship of vascular disease and Alz-
23 heimer’s disease, including clinical trials to determine
24 whether drugs developed to prevent cerebrovascular dis-

1 ease can prevent the onset or progression of Alzheimer’s
2 disease.

3 “(d) TREATMENTS AND PREVENTION.—The Director
4 of the Institute shall place special emphasis on expediting
5 the translation of research findings under this section into
6 effective treatments and prevention strategies for at-risk
7 individuals.

8 “(e) NATIONAL ALZHEIMER’S COORDINATING CEN-
9 TER.—The Director of the Institute may establish a Na-
10 tional Alzheimer’s Coordinating Center to facilitate col-
11 laborative research among the Alzheimer’s Disease Cen-
12 ters and Alzheimer’s Disease Research Centers established
13 under section 445.”.

14 (b) ALZHEIMER’S DISEASE CENTERS.—Section
15 445(a)(1) of the Public Health Service Act (42 U.S.C.
16 285e–2(a)(1)) is amended by inserting “, and outcome
17 measures and disease management,” after “treatment
18 methods”.

19 **SEC. 105. RESEARCH ON ALZHEIMER’S DISEASE**
20 **CAREGIVING.**

21 Section 445C of the Public Health Service Act (42
22 U.S.C. 285e–5) is amended—

23 (1) by striking “SEC. 445C. (a)” and inserting
24 the following:

1 **“SEC. 445C. RESEARCH ON ALZHEIMER’S DISEASE SERV-**
2 **ICES AND CAREGIVING.**

3 “(a) SERVICES RESEARCH.—”;

4 (2) by striking subsections (b), (c), and (e);

5 (3) by inserting after subsection (a) the fol-
6 lowing:

7 “(b) INTERVENTIONS RESEARCH.—The Director
8 shall, in collaboration with the directors of the other rel-
9 evant institutes and centers of the National Institutes of
10 Health, conduct, or make grants for the conduct of, clin-
11 ical, social, and behavioral research related to interven-
12 tions designed to help caregivers of patients with Alz-
13 heimer’s disease and related disorders and improve patient
14 outcomes.”; and

15 (4) in subsection (d) by striking “(d) the Direc-
16 tor” and inserting “(c) MODEL CURRICULA AND
17 TECHNIQUES.—The Director”.

18 **SEC. 106. NATIONAL SUMMIT ON ALZHEIMER’S DISEASE.**

19 (a) IN GENERAL.—Not later than 3 years after the
20 date of enactment of this Act, and every 3 years there-
21 after, the Secretary of Health and Human Services (re-
22 ferred to in this section as the “Secretary”) shall convene
23 a summit of researchers, representatives of academic insti-
24 tutions, Federal and State policymakers, public health
25 professionals, and representatives of voluntary health
26 agencies to provide a detailed overview of current research

1 activities at the National Institutes of Health, as well as
2 to discuss and solicit input related to potential areas of
3 collaboration between the National Institutes of Health
4 and other Federal health agencies, including the Centers
5 for Disease Control and Prevention, the Administration on
6 Aging, the Agency for Healthcare Research and Quality,
7 and the Health Resources and Services Administration,
8 related to research, prevention, and treatment of Alz-
9 heimer's disease.

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

12 (1) a broad range of Alzheimer's disease re-
13 search activities relating to biomedical research, pre-
14 vention research, and caregiving issues;

15 (2) clinical research for the development and
16 evaluation of new treatments for the disease;

17 (3) translational research on evidence-based and
18 cost-effective best practices in the treatment and
19 prevention of the disease;

20 (4) information and education programs for
21 health care professionals and the public relating to
22 the disease;

23 (5) priorities among the programs and activities
24 of the various Federal agencies regarding such dis-
25 eases; and

1 (6) challenges and opportunities for scientists,
2 clinicians, patients, and voluntary organizations re-
3 lating to the disease.

4 (c) REPORT.—Not later than 180 days after the date
5 on which the National Summit on Alzheimer’s Disease is
6 convened under subsection (a), the Director of National
7 Institutes of Health shall prepare and submit to the ap-
8 propriate committees of Congress a report that includes
9 a summary of the proceedings of the summit and a de-
10 scription of Alzheimer’s research, education, and other ac-
11 tivities that are conducted or supported through the na-
12 tional research institutes.

13 (d) PUBLIC INFORMATION.—The Secretary shall
14 make readily available to the public information about the
15 research, education, and other activities relating to Alz-
16 heimer’s disease and other related dementias, conducted
17 or supported by the National Institutes of Health.

1 **TITLE II—PUBLIC HEALTH PRO-**
2 **MOTION AND PREVENTION**
3 **OF ALZHEIMER’S DISEASE**

4 **SEC. 201. ENHANCING PUBLIC HEALTH ACTIVITIES RE-**
5 **LATED TO COGNITIVE HEALTH, ALZHEIMER’S**
6 **DISEASE, AND OTHER DEMENTIA’S.**

7 Part P of title III of the Public Health Service Act
8 (42 U.S.C. 280g et seq.) is amended by adding at the end
9 the following:

10 **“SEC. 399R. ALZHEIMER’S DISEASE PUBLIC EDUCATION**
11 **CAMPAIGN.**

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

23 “(b) CERTAIN ACTIVITIES.—Activities under sub-
24 section (a) shall include—

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

5 “(2) the development of coordinated public edu-
6 cation programs, services, and demonstrations which
7 are designed to increase general awareness of cog-
8 nitive function and promote a brain healthy lifestyle;

9 “(3) the development of targeted communica-
10 tion strategies and tools to educate health profes-
11 sionals and service providers about the early recogni-
12 tion, diagnosis, care, and management of Alz-
13 heimer’s disease and dementia, and to provide con-
14 sumers with information about interventions, prod-
15 ucts, and services that promote cognitive health and
16 assist consumers in maintaining current under-
17 standing about cognitive health based on the best
18 science available; and

19 “(4) provide support for the collection, publica-
20 tion, and analysis of data on the prevalence and inci-
21 dence of cognitive health, Alzheimer’s disease, and
22 other dementias, and the evaluation of existing pop-
23 ulation-based surveillance systems (such as the Be-
24 havioral Risk Factors Surveillance Survey (BRFFS)
25 and the National Health Interview Survey (NHIS))

1 to identify limitations that exist in the area of cog-
2 nitive health, and if necessary, the development of a
3 surveillance system for cognitive decline, including
4 Alzheimer's disease and dementia.

5 “(c) GRANTS.—The Secretary may award grants
6 under this section—

7 “(1) to State and local health agencies for the
8 purpose of—

9 “(A) coordinating activities related to cog-
10 nitive health, Alzheimer's disease, and other de-
11 mentias with existing State-based health pro-
12 grams and community-based organizations;

13 “(B) providing Alzheimer's disease edu-
14 cation and training opportunities and programs
15 for health professionals; and

16 “(C) developing, testing, evaluating, and
17 replicating effective Alzheimer's disease inter-
18 vention programs to maintain or improve cog-
19 nitive health; and

20 “(2) to nonprofit private health organizations
21 with expertise in providing care and services to indi-
22 viduals with Alzheimer's disease for the purpose
23 of—

24 “(A) disseminating information to the pub-
25 lic;

1 “(B) testing model intervention programs
2 to improve cognitive health; and

3 “(C) coordinating existing services with
4 State-based health programs.

5 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
6 purpose of carrying out this section, there are authorized
7 to be appropriated \$15,000,000 for fiscal year 2008, and
8 such sums as may be necessary for each of fiscal years
9 2009 through 2012.”.

10 **TITLE III—ASSISTANCE FOR** 11 **CAREGIVERS**

12 **SEC. 301. ALZHEIMER’S DISEASE CALL CENTER.**

13 Part P of title III of the Public Health Service Act
14 (42 U.S.C. 280g et seq.), as amended by section 201, is
15 further amended by adding at the end the following:

16 **“SEC. 399S. ALZHEIMER’S DISEASE CALL CENTER.**

17 “(a) IN GENERAL.—The Secretary, acting through
18 the Administration on Aging, shall award a cooperative
19 grant to a non-profit or community-based organization to
20 support the establishment and operation of an Alzheimer’s
21 Call Center that is accessible 24 hours a day, 7 days a
22 week, to provide expert advice, care consultation, informa-
23 tion, and referrals nationwide at the national and local
24 level regarding Alzheimer’s disease.

1 “(b) ACTIVITIES.—The Alzheimer’s Call Center es-
2 tablished under subsection (a) shall—

3 “(1) collaborate with the Administration on
4 Aging in the development, modification, and execu-
5 tion of the Call Center’s work plan;

6 “(2) assist the Administration on Aging in de-
7 veloping and sustaining collaborations between the
8 Alzheimer’s Call Center, the Eldercare Locator, the
9 grantees under the Alzheimer’s Demonstration Pro-
10 gram, and the Aging Network;

11 “(3) provide a 24-hour a day, 7-days a week
12 toll-free Call Center with trained professional staff
13 who are available to provide care consultation and
14 crisis intervention to individuals with Alzheimer’s
15 disease and other dementias, their family and infor-
16 mal caregivers, and others as appropriate;

17 “(4) be accessible by telephone through a single
18 1–800 telephone number, website, and e-mail ad-
19 dress; and

20 “(5) evaluate the impact of the Call Center’s
21 activities and services.

22 “(c) MULTILINGUAL CAPACITY.—The Call Center es-
23 tablished under this section shall have a multilingual ca-
24 pacity and shall respond to inquiries in at least 140 lan-

1 guages through its own bilingual staff and with the use
2 of a language translation service.

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

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

15 **SEC. 302. INNOVATIVE ALZHEIMER’S CARE STATE MATCH-**
16 **ING GRANT PROGRAM.**

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

20 (1) by striking “and such” and inserting
21 “such”; and

22 (2) by inserting before the period the following
23 : “, \$25,000,000 for fiscal year 2008, and such
24 sums as may be necessary for each of fiscal years
25 2009 through 2012”.

1 (b) PROGRAM EXPANSION.—Section 398(a) of the
2 Public Health Service Act (42 U.S.C. 280c-3(a))

3 (1) in paragraph (2), by inserting after “other
4 respite care” the following: “and care consultation
5 including assessment of needs, assistance with plan-
6 ning and problem solving and providing supportive
7 listening”;

8 (2) in paragraph (3), by striking “; and” and
9 inserting the following: “, and individuals in frontier
10 areas (as defined as areas with 6 or fewer people per
11 square mile or areas in which it takes people at least
12 60 minutes or 60 miles to reach a market or service
13 area);”;

14 (3) in paragraph (4), by striking the period at
15 the end and inserting a semicolon; and

16 (4) by adding at the end the following:

17 “(5) to encourage grantees under this section to
18 coordinate activities with other State officials admin-
19 istering efforts to promote long-term care options
20 that enable older individuals to receive long-term
21 care in home- and community-based settings, in a
22 manner responsive to the needs and preferences of
23 older individuals and their family caregivers;

24 “(6) to encourage grantees under this section
25 to—

1 “(A) engage in activities that support early
2 detection and diagnosis of Alzheimer’s disease
3 and related dementia;

4 “(B) provide training to medical personnel
5 including hospital staff, emergency room per-
6 sonnel, home health care workers and physician
7 office staff, rehabilitation services providers,
8 and caregivers about how Alzheimer’s can affect
9 behavior and impede communication in medical
10 and community settings;

11 “(C) develop guidelines to provide the med-
12 ical community with up-to-date information
13 about the best methods of care for individuals
14 with Alzheimer’s disease;

15 “(D) inform community physicians about
16 available resources to assist them in detecting
17 and managing Alzheimer’s; and

18 “(E) raise awareness among community
19 physicians about the availability of community-
20 based organizations which can assist individuals
21 with Alzheimer’s and their caregivers;

22 “(7) to encourage grantees under this section to
23 engage in activities that use findings from evidence-
24 based research on service models and techniques to

1 support individuals with Alzheimer’s disease and
2 their caregivers; and

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