

111TH CONGRESS
1ST SESSION

H. R. 3286

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

JULY 22, 2009

Mr. MARKEY of Massachusetts (for himself, Mr. SMITH of New Jersey, Mr. CARNAHAN, Mr. GENE GREEN of Texas, Mr. KIND, Mr. LATOURETTE, Mr. LOBIONDO, Ms. ZOE LOFGREN of California, Mr. MURPHY of Connecticut, Mr. PLATTS, Mr. RAHALL, Mr. RUSH, Ms. SCHAKOWSKY, Ms. SUTTON, Mr. WEXLER, and Mr. YARMUTH) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 2009”.

1 **SEC. 2. FINDINGS.**

2 Congress makes the following findings:

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

13 (2) An estimated 5,300,000 Americans have
14 Alzheimer's disease and 1 in 10 individuals has a
15 family member with the disease. By 2050, the num-
16 ber of individuals with the disease could reach
17 16,000,000 unless science finds a way to prevent or
18 cure the disease.

19 (3) One in 8 people over the age of 65, and
20 nearly half of those over the age of 85 have Alz-
21 heimer's disease. Younger people also get the dis-
22 ease.

23 (4) The Alzheimer's disease process may begin
24 in the brain as many as 20 years before the symp-
25 toms of Alzheimer's disease appear. An individual
26 will live an average of 4 to 6 years, and as many as

1 20 years, once the symptoms of Alzheimer's disease
2 appear.

3 (5) 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 (6) 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 such as coronary heart disease (26 percent), conges-
11 tive heart failure (16 percent), diabetes (23 percent),
12 and chronic obstructive pulmonary disease (15 per-
13 cent).

14 (7) Seven in 10 individuals with Alzheimer's
15 disease live at home. Cost for care at home is higher
16 for people with Alzheimer's disease than other indi-
17 viduals. Almost all families pay some out-of-pocket
18 costs.

19 (8) 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 \$77,000. 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 (9) In fiscal year 2007, the Federal Govern-
4 ment spent an estimated \$411,000,000 on Alz-
5 heimer's disease research. Over the next 40 years,
6 Alzheimer's disease-related costs to Medicare and
7 Medicaid alone are projected to total
8 \$20,000,000,000,000 in constant dollars, rising to
9 over \$1,000,000,000,000 per year by 2050. This
10 amounts to less than a penny spent on Alzheimer's
11 disease research for each dollar that the Federal
12 Government spends on Alzheimer's disease-related
13 costs each year.

14 (10) It is estimated that the annual value of the
15 informal care system is \$94,000,000,000. Family
16 caregiving comes at enormous physical, emotional,
17 and financial sacrifice, putting the whole system at
18 risk.

19 (11) Almost 60 percent of caregivers of individ-
20 uals with Alzheimer's disease are women, and over
21 one-fourth have children or grandchildren under the
22 age of 18 living at home. Caregiving leaves them less
23 time for other family members and they are much
24 more likely to report family conflicts because of their
25 caregiving role.

1 (12) Most Alzheimer’s disease caregivers work
2 outside the home before beginning their caregiving
3 careers, but caregiving forces them to miss work, cut
4 back to part-time, take less demanding jobs, choose
5 early retirement, or give up work altogether. As a
6 result, in 2002, Alzheimer’s disease cost American
7 business an estimated \$36,500,000,000 in lost pro-
8 ductivity, as well as an additional \$24,600,000,000
9 in business contributions to the total cost of care.

10 **TITLE I—INCREASING THE FED-**
11 **ERAL COMMITMENT TO ALZ-**
12 **HEIMER’S RESEARCH**

13 **SEC. 101. DOUBLING NIH FUNDING FOR ALZHEIMER’S DIS-**
14 **EASE RESEARCH.**

15 For the purpose of conducting and supporting re-
16 search on Alzheimer’s disease (including related activities
17 under subpart 5 of part C of title IV of the Public Health
18 Service Act (42 U.S.C. 285e et seq.)), there are authorized
19 to be appropriated \$2,000,000,000 for fiscal year 2010,
20 and such sums as may be necessary for each of fiscal years
21 2011 through 2014.

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

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

1 (1) by striking “The general” and inserting the
2 following:

3 “(a) IN GENERAL.—The general;” and

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

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

9 **SEC. 103. ALZHEIMER’S DISEASE PREVENTION INITIATIVE.**

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

13 “(c) PREVENTION TRIALS.—The Director of the In-
14 stitute shall increase the emphasis on the need to conduct
15 Alzheimer’s disease prevention trials within the National
16 Institutes of Health.

17 “(d) NEUROSCIENCE INITIATIVE.—The Director of
18 the Institute shall ensure that Alzheimer’s disease is main-
19 tained as a high priority for the neuroscience initiative of
20 the National Institutes of Health.”.

21 **SEC. 104. ALZHEIMER’S DISEASE CLINICAL RESEARCH.**

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

1 **“SEC. 445J. ALZHEIMER’S DISEASE CLINICAL RESEARCH.**

2 “(a) IN GENERAL.—The Director of the Institute,
3 pursuant to section 444(d), shall conduct and support co-
4 operative clinical research regarding Alzheimer’s disease.

5 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 on Alzheimer’s disease;

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 after consultation

1 with the Alzheimer’s disease centers and Alzheimer’s
2 disease research centers established under section
3 445.

4 “(b) EARLY DIAGNOSIS AND DETECTION RE-
5 SEARCH.—

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

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

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

1 such individuals, including problems accessing gov-
2 ernment services.

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

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 individ-
16 uals at risk of Alzheimer’s disease and other dementias.

17 “(e) NATIONAL ALZHEIMER’S COORDINATING CEN-
18 TER.—The Director of the Institute may establish a Na-
19 tional Alzheimer’s Coordinating Center to facilitate col-
20 laborative research among the Alzheimer’s Disease Cen-
21 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 “, outcome meas-

1 ures, and disease management,” after “treatment meth-
2 ods”.

3 **SEC. 105. RESEARCH ON ALZHEIMER’S DISEASE**
4 **CAREGIVING.**

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

7 (1) by striking “SEC. 445C. RESEARCH PRO-
8 GRAM AND PLAN (a)” and inserting the following:

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

11 “(a) SERVICES RESEARCH.—”;

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

13 (3) by inserting after subsection (a) the fol-
14 lowing:

15 “(b) INTERVENTIONS RESEARCH.—The Director of
16 the Institute shall, in collaboration with the directors of
17 the other relevant institutes and centers of the National
18 Institutes of Health, conduct, or make grants for the con-
19 duct of, clinical, social, and behavioral research related to
20 interventions designed to help caregivers of patients with
21 Alzheimer’s disease and other dementias and improve pa-
22 tient outcomes.”;

23 (4) by redesignating subsection (d) as sub-
24 section (c); and

1 (5) in subsection (c) (as redesignated by para-
2 graph (4)), by striking “the Director” and inserting
3 “MODEL CURRICULA AND TECHNIQUES.—The Di-
4 rector”.

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

6 (a) IN GENERAL.—Not later than 3 years after the
7 date of enactment of this Act, and every 3 years there-
8 after, the Secretary of Health and Human Services (re-
9 ferred to in this section as the “Secretary”) shall convene
10 a National Summit on Alzheimer’s Disease to—

11 (1) provide a detailed overview of current re-
12 search activities relating to Alzheimer’s disease at
13 the National Institutes of Health; and

14 (2) discuss and solicit input related to potential
15 areas of collaboration between the National Insti-
16 tutes of Health and other Federal health agencies,
17 including the Centers for Disease Control and Pre-
18 vention, the Administration on Aging, the Agency
19 for Healthcare Research and Quality, and the
20 Health Resources and Services Administration, re-
21 lated to research, prevention, and treatment of Alz-
22 heimer’s disease.

23 (b) PARTICIPANTS.—The summit convened under
24 subsection (a) shall include researchers, representatives of
25 academic institutions, Federal and State policymakers,

1 public health professionals, and representatives of vol-
2 untary health agencies as participants.

3 (c) FOCUS AREAS.—The summit convened under
4 subsection (a) shall focus on—

5 (1) a broad range of Alzheimer’s disease re-
6 search activities relating to biomedical research, pre-
7 vention research, and caregiving issues;

8 (2) clinical research for the development and
9 evaluation of new treatments for Alzheimer’s dis-
10 ease;

11 (3) translational research on evidence-based and
12 cost-effective best practices in the treatment and
13 prevention of Alzheimer’s disease;

14 (4) information and education programs for
15 health care professionals and the public relating to
16 Alzheimer’s disease;

17 (5) priorities among the programs and activities
18 of the various Federal agencies regarding Alz-
19 heimer’s disease and other dementias; and

20 (6) challenges and opportunities for scientists,
21 clinicians, patients, and voluntary organizations re-
22 lating to Alzheimer’s disease.

23 (d) REPORT.—Not later than 180 days after the date
24 on which the summit is convened under subsection (a),
25 the Director of the National Institutes of Health shall pre-

1 pare and submit to the appropriate committees of Con-
2 gress a report that includes a summary of the proceedings
3 of the summit and a description of Alzheimer’s disease re-
4 search, education, and other activities that are conducted
5 or supported through the National Institutes of Health.

6 (e) PUBLIC INFORMATION.—The Secretary shall
7 make readily available to the public information about the
8 research, education, and other activities relating to Alz-
9 heimer’s disease and other related dementias, that are
10 conducted or supported by the National Institutes of
11 Health.

12 **TITLE II—PUBLIC HEALTH PRO-**
13 **MOTION AND PREVENTION**
14 **OF ALZHEIMER’S DISEASE**

15 **SEC. 201. ENHANCING PUBLIC HEALTH ACTIVITIES RE-**
16 **LATED TO COGNITIVE HEALTH, ALZHEIMER’S**
17 **DISEASE, AND OTHER DEMENTIAS.**

18 Part P of title III of the Public Health Service Act
19 (42 U.S.C. 280g et seq.) is amended—

20 (1) by redesignating the second and third sec-
21 tions 399R as sections 399S and 399T, respectively;
22 and

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

1 **“SEC. 399U. ALZHEIMER’S DISEASE PUBLIC EDUCATION**
2 **CAMPAIGN.**

3 “(a) IN GENERAL.—The Secretary, acting through
4 the Director of the Centers for Disease Control and Pre-
5 vention, shall directly or through grants, cooperative
6 agreements, or contracts to eligible entities—

7 “(1) conduct, support, and promote the coordi-
8 nation of research, investigations, demonstrations,
9 training, and studies relating to the control, preven-
10 tion, and surveillance of the risk factors associated
11 with cognitive health, Alzheimer’s disease, and other
12 dementias; and

13 “(2) seek early recognition of, and early inter-
14 vention in the course of, Alzheimer’s disease and
15 other dementias.

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

18 “(1) providing support for the dissemination
19 and implementation of the Roadmap to Maintaining
20 Cognitive Health of the Centers for Disease Control
21 and Prevention to effectively mobilize the public
22 health community into action;

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

1 “(3) the development of targeted communica-
2 tion strategies and tools to educate health profes-
3 sionals and service providers about the early recogni-
4 tion, diagnosis, care, and management of Alz-
5 heimer’s disease and other dementias, and to provide
6 consumers with information about interventions,
7 products, and services that promote cognitive health
8 and assist consumers in maintaining current under-
9 standing about cognitive health based on the best
10 science available; and

11 “(4) providing support for the collection, publi-
12 cation, and analysis of data and the prevalence and
13 incidence of cognitive health, Alzheimer’s disease,
14 and other dementias, and the evaluation of existing
15 population-based surveillance systems (such as the
16 Behavioral Risk Factors Surveillance Survey
17 (BRFSS) and the National Health Interview Survey
18 (NHIS)) to identify limitations that exist in the area
19 of cognitive health, and if necessary, the develop-
20 ment of a surveillance system for cognitive decline,
21 including Alzheimer’s disease and other dementias.

22 “(c) GRANTS.—The Secretary may award grants
23 under this section—

24 “(1) to State and local health agencies for the
25 purpose of—

1 “(A) coordinating activities related to cog-
2 nitive health, Alzheimer’s disease, and other de-
3 mentias with existing State-based health pro-
4 grams and community-based organizations;

5 “(B) providing Alzheimer’s disease edu-
6 cation and training opportunities and programs
7 for health professionals; and

8 “(C) developing, testing, evaluating, and
9 replicating effective Alzheimer’s disease inter-
10 vention programs to maintain or improve cog-
11 nitive health; and

12 “(2) to nonprofit private health organizations
13 with expertise in providing care and services to indi-
14 viduals with Alzheimer’s disease for the purpose
15 of—

16 “(A) disseminating information to the pub-
17 lic;

18 “(B) testing model intervention programs
19 to improve cognitive health; and

20 “(C) coordinating existing services related
21 to cognitive health, Alzheimer’s disease, and
22 other dementias with State-based health pro-
23 grams.

24 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
25 purpose of carrying out this section, there are authorized

1 to be appropriated \$15,000,000 for fiscal year 2010, and
2 such sums as may be necessary for each of fiscal years
3 2011 through 2014.”.

4 **TITLE III—ASSISTANCE FOR**
5 **CAREGIVERS**

6 **SEC. 301. ALZHEIMER’S CALL CENTER.**

7 Part P of title III of the Public Health Service Act
8 (42 U.S.C. 280g et seq.), as amended by section 201, is
9 further amended by adding at the end the following:

10 **“SEC. 399V. ALZHEIMER’S CALL CENTER.**

11 “(a) IN GENERAL.—The Secretary, acting through
12 the Administration on Aging, shall award a cooperative
13 grant to a non-profit or community-based organization to
14 support the establishment and operation of an Alzheimer’s
15 Call Center that is accessible 24 hours a day, 7 days a
16 week, at the national and local levels, to provide expert
17 advice, care consultation, information, and referrals re-
18 garding Alzheimer’s disease.

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

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

24 “(2) assist the Administration on Aging in de-
25 veloping and sustaining collaborations between the

1 Call Center, the Eldercare Locator of the Adminis-
2 tration of Aging, and the grantees under the Alz-
3 heimer’s disease demonstration program under sub-
4 part II of part K;

5 “(3) provide a 24 hours a day, 7 days a week
6 toll-free call center with trained professional staff
7 who are available to provide care consultation and
8 crisis intervention to individuals with Alzheimer’s
9 disease and other dementias, their family and infor-
10 mal caregivers, and others as appropriate;

11 “(4) be accessible by telephone through a single
12 toll-free telephone number, website, and e-mail ad-
13 dress; and

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

16 “(c) MULTILINGUAL CAPACITY.—The Call Center es-
17 tablished under this section shall have a multilingual ca-
18 pacity and shall respond to inquiries in at least 140 lan-
19 guages through its own bilingual staff and with the use
20 of a language translation service.

21 “(d) RESPONSE TO EMERGENCY AND ONGOING
22 NEEDS.—The Call Center established under this section
23 shall collaborate with community-based organizations, in-
24 cluding non-profit agencies and organizations, to ensure
25 local, on-the-ground capacity to respond to emergency and

1 on-going needs of individuals with Alzheimer’s disease and
2 other dementias, their families, and informal caregivers.

3 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the
4 purpose of carrying out this section, there are authorized
5 to be appropriated \$1,000,000 for fiscal year 2010, and
6 such sums as may be necessary for each of fiscal years
7 2011 through 2014.”.

8 **SEC. 302. INNOVATIVE ALZHEIMER’S CARE STATE MATCH-**
9 **ING GRANT PROGRAM.**

10 (a) AUTHORIZATION OF APPROPRIATIONS.—Section
11 398B(e) of the Public Health Service Act (42 U.S.C.
12 280c–5(e)) is amended—

13 (1) by striking “and such” and inserting
14 “such”; and

15 (2) by inserting before the period the following:
16 “, \$25,000,000 for fiscal year 2010, and such sums
17 as may be necessary for each of fiscal years 2011
18 through 2014”.

19 (b) PROGRAM EXPANSION.—Section 398(a) of the
20 Public Health Service Act (42 U.S.C. 280c–3(a)) is
21 amended—

22 (1) in paragraph (2), by inserting after “other
23 respite care” the following: “and care consultation,
24 including assessment of needs, assistance with plan-

1 ning and problem solving, and providing supportive
2 listening,”;

3 (2) in paragraph (3), by striking “; and” and
4 inserting the following: “, and individuals in frontier
5 areas (in this subsection, defined as areas with 6 or
6 fewer people per square mile or areas in which resi-
7 dents must travel at least 60 minutes or 60 miles to
8 receive health care services);”;

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

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

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

19 “(6) to encourage grantees under this section
20 to—

21 “(A) engage in activities that support early
22 detection and diagnosis of Alzheimer’s disease
23 and other dementias;

24 “(B) provide training about how Alz-
25 heimer’s disease can affect behavior and impede

1 communication in medical and community set-
2 tings to—

3 “(i) medical personnel, including hos-
4 pital staff, emergency room personnel,
5 home health care workers and physician of-
6 fice staff;

7 “(ii) rehabilitation services providers;
8 and

9 “(iii) caregivers of individuals with
10 Alzheimer’s disease;

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 the physician in de-
17 tecting and managing Alzheimer’s disease; 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 disease 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 systems initiatives and long-term care
7 activities.”.

○