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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

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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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Alzheimer's Breakthrough Act of 2009''.

SEC. 2. FINDINGS.

Congress makes the following findings:

(1) Alzheimer's disease is a disorder that destroys cells in the brain. The disease is the leading cause of dementia, a condition that involves gradual memory loss, decline in the ability to perform routine tasks, disorientation, difficulty in learning, loss of language skills, impairment of judgment, and personality changes. As the disease progresses, people with Alzheimer's disease become unable to care for themselves. The loss of brain cells eventually leads to the failure of other systems in the body.

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

(3) One in 8 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 disease.

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

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

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

(6) Ninety-five percent of Medicare beneficiaries with Alzheimer's disease have one or more other chronic conditions that are common in the elderly, such as coronary heart disease (26 percent), congestive heart failure (16 percent), diabetes (23 percent), and chronic obstructive pulmonary disease (15 percent).

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

(8) Half of all nursing home residents have Alzheimer's disease or a related disorder. The average annual cost of Alzheimer's disease nursing home care is more than $77,000. Medicaid pays half of the total nursing home bill and helps 2 out of 3 residents pay for their care. Medicaid expenditures for nursing home care for people with Alzheimer's dis-

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

(9) In fiscal year 2007, the Federal Government spent an estimated $411,000,000 on Alzheimer's disease research. Over the next 40 years, Alzheimer's disease-related costs to Medicare and Medicaid alone are projected to total $20,000,000,000,000 in constant dollars, rising to over $1,000,000,000,000 per year by 2050. This amounts to less than a penny spent on Alzheimer's disease research for each dollar that the Federal Government spends on Alzheimer's disease-related costs each year.

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

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

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

TITLE I—INCREASING THE FEDERAL COMMITMENT TO ALZHEIMER'S RESEARCH

SEC. 101. DOUBLING NIH FUNDING FOR ALZHEIMER'S DISEASE RESEARCH.

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

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

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

(1) by striking ''The general'' and inserting the following:

''(a) IN GENERAL.—The general;'' and

(2) by adding at the end the following:

''(b) PRIORITIES.—The Director of the Institute shall, in expending amounts appropriated to carry out this subpart, give priority to conducting and supporting Alzheimer's disease research.''.

SEC. 103. ALZHEIMER'S DISEASE PREVENTION INITIATIVE.

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

''(c) PREVENTION TRIALS.—The Director of the Institute shall increase the emphasis on the need to conduct Alzheimer's disease prevention trials within the National Institutes of Health.

''(d) NEUROSCIENCE INITIATIVE.—The Director of the Institute shall ensure that Alzheimer's disease is maintained as a high priority for the neuroscience initiative of the National Institutes of Health.''.

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:

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

''(a) IN GENERAL.—The Director of the Institute, pursuant to section 444(d), shall conduct and support cooperative clinical research regarding Alzheimer's disease. Such research shall include—

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

''(2) enhancing the national infrastructure for the conduct of clinical trials on Alzheimer's disease;

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

''(4) facilitating the enrollment of patients for such trials, including patients from diverse populations;

''(5) developing improved diagnostics and means of patient assessment for Alzheimer's disease;

''(6) the conduct of clinical trials on potential therapies, including readily available compounds such as herbal remedies and other alternative treatments;

''(7) research to develop better methods of early diagnosis, including the use of current imaging techniques; and

''(8) other research, as determined appropriate by the Director of the Institute after consultation

with the Alzheimer's disease centers and Alzheimer's disease research centers established under section 445.

''(b) EARLY DIAGNOSIS AND DETECTION RESEARCH.—

''(1) IN GENERAL.—The Director of the Institute, in consultation with the directors of other relevant institutes and centers of the National Institutes of Health, shall conduct, or make grants for the conduct of, research related to the early detection, diagnosis, and prevention of Alzheimer's disease and of mild cognitive impairment or other potential precursors to Alzheimer's disease.

''(2) EVALUATION.—The research described in paragraph (1) may include the evaluation of diagnostic tests and imaging techniques.

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

such individuals, including problems accessing government services.

''(c) VASCULAR DISEASE.—The Director of the Institute, in consultation with the directors of other relevant institutes and centers of the National Institutes of Health, shall conduct, or make grants for the conduct of, research related to the relationship of vascular disease and Alzheimer's disease, including clinical trials to determine whether drugs developed to prevent cerebrovascular disease can prevent the onset or progression of Alzheimer's disease.

''(d) TREATMENTS AND PREVENTION.—The Director of the Institute shall place special emphasis on expediting the translation of research findings under this section into effective treatments and prevention strategies for individuals at risk of Alzheimer's disease and other dementias.

''(e) NATIONAL ALZHEIMER'S COORDINATING CENTER.—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 445(a)(1) of the Public Health Service Act (42 U.S.C. 285e–2(a)(1)) is amended by inserting '', outcome meas-

ures, and disease management,'' after ''treatment methods''.

SEC. 105. RESEARCH ON ALZHEIMER'S DISEASE CAREGIVING.

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

(1) by striking ''SEC. 445C. RESEARCH PROGRAM AND PLAN (a)'' and inserting the following:

''SEC. 445C. RESEARCH ON ALZHEIMER'S DISEASE SERVICES AND CAREGIVING.

''(a) SERVICES RESEARCH.—'';

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

(3) by inserting after subsection (a) the following:

''(b) INTERVENTIONS RESEARCH.—The Director of the Institute shall, in collaboration with the directors of the other relevant institutes and centers of the National Institutes of Health, conduct, or make grants for the conduct of, clinical, social, and behavioral research related to interventions designed to help caregivers of patients with Alzheimer's disease and other dementias and improve patient outcomes.'';

(4) by redesignating subsection (d) as subsection (c); and

(5) in subsection (c) (as redesignated by paragraph (4)), by striking ''the Director'' and inserting ''MODEL CURRICULA AND TECHNIQUES.—The Director''.

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

(a) IN GENERAL.—Not later than 3 years after the date of enactment of this Act, and every 3 years thereafter, the Secretary of Health and Human Services (referred to in this section as the ''Secretary'') shall convene a National Summit on Alzheimer's Disease to—

(1) provide a detailed overview of current research activities relating to Alzheimer's disease at the National Institutes of Health; and

(2) discuss and solicit input related to potential areas of collaboration between the National Institutes of Health and other Federal health agencies, including the Centers for Disease Control and Prevention, the Administration on Aging, the Agency for Healthcare Research and Quality, and the Health Resources and Services Administration, related to research, prevention, and treatment of Alzheimer's disease.

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

public health professionals, and representatives of voluntary health agencies as participants.

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

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

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

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

(4) information and education programs for health care professionals and the public relating to Alzheimer's disease;

(5) priorities among the programs and activities of the various Federal agencies regarding Alzheimer's disease and other dementias; and

(6) challenges and opportunities for scientists, clinicians, patients, and voluntary organizations relating to Alzheimer's disease.

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

pare and submit to the appropriate committees of Congress a report that includes a summary of the proceedings of the summit and a description of Alzheimer's disease research, education, and other activities that are conducted or supported through the National Institutes of Health.

(e) PUBLIC INFORMATION.—The Secretary shall make readily available to the public information about the research, education, and other activities relating to Alzheimer's disease and other related dementias, that are conducted or supported by the National Institutes of Health.

TITLE II—PUBLIC HEALTH PROMOTION AND PREVENTION OF ALZHEIMER'S DISEASE

SEC. 201. ENHANCING PUBLIC HEALTH ACTIVITIES RELATED TO COGNITIVE HEALTH, ALZHEIMER'S DISEASE, AND OTHER DEMENTIAS.

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

(1) by redesignating the second and third sections 399R as sections 399S and 399T, respectively; and

(2) by adding at the end the following:

"SEC. 399U. ALZHEIMER'S DISEASE PUBLIC EDUCATION CAMPAIGN.

"(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall directly or through grants, cooperative agreements, or contracts to eligible entities—

"(1) conduct, support, and promote 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 other dementias; and

"(2) seek early recognition of, and early intervention in the course of, Alzheimer's disease and other dementias.

"(b) CERTAIN ACTIVITIES.—Activities under subsection (a) shall include—

"(1) providing support for the dissemination and implementation of the Roadmap to Maintaining Cognitive Health of the Centers for Disease Control and Prevention to effectively mobilize the public 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;

''(3) the development of targeted communication strategies and tools to educate health professionals and service providers about the early recognition, diagnosis, care, and management of Alzheimer's disease and other dementias, and to provide consumers with information about interventions, products, and services that promote cognitive health and assist consumers in maintaining current understanding about cognitive health based on the best science available; and

''(4) providing support for the collection, publication, and analysis of data and the prevalence and incidence of cognitive health, Alzheimer's disease, and other dementias, and the evaluation of existing population-based surveillance systems (such as the Behavioral Risk Factors Surveillance Survey (BRFSS) and the National Health Interview Survey (NHIS)) to identify limitations that exist in the area of cognitive health, and if necessary, the development of a surveillance system for cognitive decline, including Alzheimer's disease and other dementias.

''(c) GRANTS.—The Secretary may award grants under this section—

''(1) to State and local health agencies for the purpose of—

"(A) coordinating activities related to cognitive health, Alzheimer's disease, and other dementias with existing State-based health programs and community-based organizations;

"(B) providing Alzheimer's disease education and training opportunities and programs for health professionals; and

"(C) developing, testing, evaluating, and replicating effective Alzheimer's disease intervention programs to maintain or improve cognitive health; and

"(2) to nonprofit private health organizations with expertise in providing care and services to individuals with Alzheimer's disease for the purpose of—

"(A) disseminating information to the public;

"(B) testing model intervention programs to improve cognitive health; and

"(C) coordinating existing services related to cognitive health, Alzheimer's disease, and other dementias with State-based health programs.

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

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

TITLE III—ASSISTANCE FOR CAREGIVERS

SEC. 301. ALZHEIMER'S CALL CENTER.

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

''SEC. 399V. ALZHEIMER'S CALL CENTER.

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

''(b) ACTIVITIES.—The Alzheimer's Call Center established under subsection (a) shall—

''(1) collaborate with the Administration on Aging in the development, modification, and execution of the Call Center's work plan;

''(2) assist the Administration on Aging in developing and sustaining collaborations between the

Call Center, the Eldercare Locator of the Administration of Aging, and the grantees under the Alzheimer's disease demonstration program under subpart II of part K;

''(3) provide a 24 hours a day, 7 days a week toll-free call center with trained professional staff who are available to provide care consultation and crisis intervention to individuals with Alzheimer's disease and other dementias, their family and informal caregivers, and others as appropriate;

''(4) be accessible by telephone through a single toll-free telephone number, website, and e-mail address; and

''(5) evaluate the impact of the Call Center's activities and services.

''(c) MULTILINGUAL CAPACITY.—The Call Center established under this section shall have a multilingual capacity and shall respond to inquiries in at least 140 languages through its own bilingual staff and with the use of a language translation service.

''(d) RESPONSE TO EMERGENCY AND ONGOING NEEDS.—The Call Center established under this section shall collaborate with community-based organizations, including non-profit agencies and organizations, to ensure local, on-the-ground capacity to respond to emergency and

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

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

SEC. 302. INNOVATIVE ALZHEIMER'S CARE STATE MATCHING GRANT PROGRAM.

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

(1) by striking ''and such'' and inserting ''such''; and

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

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

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

ning and problem solving, and providing supportive listening,'';

(2) in paragraph (3), by striking ''; and'' and inserting the following: '', and individuals in frontier areas (in this subsection, defined as areas with 6 or fewer people per square mile or areas in which residents must travel at least 60 minutes or 60 miles to receive health care services);'';

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

(4) by adding at the end the following:

''(5) to encourage grantees under this section to coordinate activities with other State officials administering efforts to promote long-term care options 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;

''(6) to encourage grantees under this section to—

''(A) engage in activities that support early detection and diagnosis of Alzheimer's disease and other dementias;

''(B) provide training about how Alzheimer's disease can affect behavior and impede

communication in medical and community settings to—

"(i) medical personnel, including hospital staff, emergency room personnel, home health care workers and physician office staff;

"(ii) rehabilitation services providers; and

"(iii) caregivers of individuals with Alzheimer's disease;

"(C) develop guidelines to provide the medical community with up-to-date information about the best methods of care for individuals with Alzheimer's disease;

"(D) inform community physicians about available resources to assist the physician in detecting and managing Alzheimer's disease; and

"(E) raise awareness among community physicians about the availability of community-based organizations which can assist individuals with Alzheimer's disease and their caregivers;

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

support individuals with Alzheimer's disease and their caregivers; and

''(8) to encourage grantees under this section to incorporate best practices for effectively serving individuals with Alzheimer's disease in community-based settings into systems initiatives and long-term care activities.''.

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