I

111TH CONGRESS
1ST SESSION

H. R. 2987

To amend the Public Health Service Act to ensure sufficient resources and increase efforts for research at the National Institutes of Health relating to Alzheimer's disease, to authorize an education and outreach program to promote public awareness and risk reduction with respect to Alzheimer's disease (with particular emphasis on education and outreach in Hispanic populations), and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JUNE 19, 2009

Ms. LINDA T. SÁNCHEZ of California (for herself, Ms. BERKLEY, Mr. BISHOP of Georgia, Ms. BORDALLO, Mr. BRADY of Pennsylvania, Mr. GRIJALVA, Mr. HOLT, Ms. KAPTUR, Ms. LEE of California, Mr. MCGOVERN, Mr. NADLER of New York, Mrs. NAPOLITANO, Mr. PAYNE, Mr. PIERLUISI, Mr. REYES, Ms. ROS-LEHTINEN, Mr. RYAN of Ohio, Mr. SERRANO, Mr. SIRES, Ms. WATERS, Mr. WEXLER, and Mr. WU) 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 ensure sufficient resources and increase efforts for research at the National Institutes of Health relating to Alzheimer's disease, to authorize an education and outreach program to promote public awareness and risk reduction with respect to Alzheimer's disease (with particular emphasis on education and outreach in Hispanic populations), and for other purposes.

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 ‘‘Cure and Understanding through Research for Alzheimer's Act of 2009'' or the ‘‘La Cura Act of 2009''.

SEC. 2. FINDINGS.

The Congress finds as follows:

(1) Alzheimer's disease is the seventh leading cause of death of all ages in the United States (and the fifth leading cause of death for people over 65 years of age), with 5.2 million individuals in the United States living with Alzheimer's disease. Currently, one of each eight individuals in the United States over age 65 has Alzheimer's disease. Every 71 seconds, an individual in the United States develops Alzheimer's disease, and by 2050, every 33 seconds an individual in the United States will develop this disease. By 2050, the number of individuals in the United States age 65 and over with Alzheimer's disease will range from 11 million to 16 million individuals.

(2) The prevalence of Alzheimer's disease and dementia seems to be higher among individuals with fewer years of education. Individuals with fewer than

12 years of education have a 15 percent greater risk of developing dementia than individuals with 12 to 15 years of education and a 35 percent greater risk of developing dementia than individuals with more than 15 years of education.

(3) Hispanics are the fastest growing population in the Nation and by 2050, will have a life expectancy of 87 years, longer than any other ethnic or racial group. The Hispanic community in the United States is projected to experience a six-fold increase in Alzheimer's disease (from fewer than 200,000 to as many as 1.3 million) by 2050.

(4) Hispanics may be at a greater risk of developing dementia than other ethnic or racial groups: Hispanics' 64-percent higher incidence of diabetes than non-Hispanic White Americans is of particular concern in light of new findings that diabetes is the one vascular risk factor that, in the absence of stroke, is related to an increased risk of Alzheimer's disease.

(5) Research on disparities in Alzheimer's risk factors between Hispanic and other ethnic and racial groups is only beginning to sort out complex differences: for example, even in the absence of the APOE-e4 allele, the one known genetic risk factor

for late onset Alzheimer's, Caribbean Hispanics have a cumulative risk for Alzheimer's twice that of non-Hispanic Whites.

(6) The shortage of bilingual health professionals, combined with the large population of monolingual Spanish-speaking seniors, makes adequate testing and diagnosis of Alzheimer's among elderly Hispanics difficult and may lead to cultural biases in cognitive testing. Moreover, inadequate translation of diagnostic tools can lead to improper diagnoses, and there may be poor understanding of recommended treatment and self-care even among those who are properly diagnosed.

(7) Hispanics are far more likely to be uninsured than any other ethnic group: the Bureau of the Census reports that 34.1 percent of the Hispanic population in the United States is uninsured, compared to 10.8 percent for non-Hispanic Whites and 15.3 percent for all United States residents.

(8) Lack of access to health care and a strong cultural commitment to caring for one's elders within the family are among the factors that make Hispanics with dementia less likely than non-Hispanics to see a physician and use related services provided by formal health professionals. Hispanic caregivers

surveyed were significantly more likely (33 percent) than caregivers of other races (23 percent) to believe that Alzheimer's disease is a normal part of the aging process and were also significantly more likely (67 percent) to dismiss the symptoms of Alzheimer's disease as old age than other respondents of other races (53 percent). Delays in diagnosis and lack of early and consistent treatment can lead to higher levels of impairment and increased stress on family caregivers.

(9) Hispanic elders are second most likely, after Asian-Americans, to live with their families rather than in long-term care facilities. More research is needed to better understand the effects of differing care settings on family caregivers and Alzheimer's patients.

(10) Alzheimer's disease costs the United States $148 billion each year in direct and indirect costs to business, the Medicare program, and the Medicaid program (not including private health insurance costs). If the prevalence of Alzheimer's disease continues to increase as expected, the $91 billion spent in 2005 on Medicare costs for care of individuals with Alzheimer's disease and dementia pa-

tients is projected to increase to $189 billion by 2015.

SEC. 3. NIH RESEARCH AND EDUCATION ON ALZHEIMER'S DISEASE.

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 new section:

"SEC. 445J. NIH RESEARCH AND EDUCATION ON ALZHEIMER'S DISEASE.

"(a) RESEARCH ACTIVITIES.—In conducting research relating to Alzheimer's disease, the Director of the National Institutes of Health shall ensure sufficient resources for activities relating to Alzheimer's disease and Hispanic communities, including by—

"(1) increasing efforts in epidemiological work in Hispanic subgroups;

"(2) allocating resources to the National Institute on Aging Alzheimer's disease research centers and other academic centers involved in Alzheimer's disease research to increase participation of Hispanics and other underrepresented ethnic groups in research and clinical trials in sufficient numbers to draw valid conclusions; and

"(3) conducting social, behavioral, and health services research—

“(A) to understand more fully the underlying reasons that Hispanic individuals delay diagnosis and underutilize services;

“(B) to identify culturally and linguistically appropriate approaches for addressing such delays and underutilization; and

“(C) to identify approaches for providing, and improving the quality of, culturally competent care.

“(b) EDUCATION ACTIVITIES.—The Director of the National Institutes of Health shall expand and intensify efforts of the National Institutes of Health—

“(1) to educate communities about the importance of research relating to Alzheimer’s disease; and

“(2) to respond effectively to cultural concerns about participation in such research, especially with respect to sensitive matters like the collection of brain tissue and genetic information.”.

SEC. 4. INCREASED FUNDING FOR ALZHEIMER’S DISEASE DEMONSTRATION GRANTS.

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 at the end ", $25,000,000 for fiscal year 2010, and such sums as may be necessary for each of the fiscal years 2011 through 2014".

SEC. 5. CDC OUTREACH AND EDUCATION.

Part B of title III of the Public Health Service Act (42 U.S.C. 243 et seq.) is amended by inserting after section 317T the following:

"SEC. 317U. EDUCATION AND OUTREACH ON ALZHEIMER'S DISEASE.

"(a) PURPOSES.—The purposes of this section are the following:

"(1) To reduce the risk of Alzheimer's disease through reduction of vascular risk factors.

"(2) To encourage early recognition and diagnosis of dementia.

"(3) To train public health personnel to recognize, assess, diagnose, and treat Alzheimer's disease in ways that are culturally appropriate and supportive of families.

"(b) EDUCATION AND OUTREACH.—To achieve the purposes of this section, the Secretary, acting through the Centers for Disease Control and Prevention, shall conduct an aggressive, evidence-based education and outreach program to promote public awareness and risk reduction with respect to Alzheimer's disease. In conducting the outreach program, the Secretary shall consult with State Health Departments and may consult with other appropriate entities, including the Alzheimer's Association and the Alzheimer's Foundation of America.

"(c) EMPHASIS.—In carrying out this section, the Secretary shall give particular emphasis to education and outreach in Hispanic populations.".

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