

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.

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## 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.

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 “Cure and Under-  
5 standing through Research for Alzheimer’s Act of 2009”  
6 or the “La Cura Act of 2009”.

7 **SEC. 2. FINDINGS.**

8        The Congress finds as follows:

9            (1) Alzheimer’s disease is the seventh leading  
10        cause of death of all ages in the United States (and  
11        the fifth leading cause of death for people over 65  
12        years of age), with 5.2 million individuals in the  
13        United States living with Alzheimer’s disease. Cur-  
14        rently, one of each eight individuals in the United  
15        States over age 65 has Alzheimer’s disease. Every  
16        71 seconds, an individual in the United States devel-  
17        ops Alzheimer’s disease, and by 2050, every 33 sec-  
18        onds an individual in the United States will develop  
19        this disease. By 2050, the number of individuals in  
20        the United States age 65 and over with Alzheimer’s  
21        disease will range from 11 million to 16 million indi-  
22        viduals.

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

1 12 years of education have a 15 percent greater risk  
2 of developing dementia than individuals with 12 to  
3 15 years of education and a 35 percent greater risk  
4 of developing dementia than individuals with more  
5 than 15 years of education.

6 (3) Hispanics are the fastest growing popu-  
7 lation in the Nation and by 2050, will have a life ex-  
8 pectancy of 87 years, longer than any other ethnic  
9 or racial group. The Hispanic community in the  
10 United States is projected to experience a six-fold in-  
11 crease in Alzheimer's disease (from fewer than  
12 200,000 to as many as 1.3 million) by 2050.

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

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

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

4 (6) The shortage of bilingual health profes-  
5 sionals, combined with the large population of  
6 monolingual Spanish-speaking seniors, makes ade-  
7 quate testing and diagnosis of Alzheimer's among el-  
8 derly Hispanics difficult and may lead to cultural bi-  
9 ases in cognitive testing. Moreover, inadequate  
10 translation of diagnostic tools can lead to improper  
11 diagnoses, and there may be poor understanding of  
12 recommended treatment and self-care even among  
13 those who are properly diagnosed.

14 (7) Hispanics are far more likely to be unin-  
15 sured than any other ethnic group: the Bureau of  
16 the Census reports that 34.1 percent of the Hispanic  
17 population in the United States is uninsured, com-  
18 pared to 10.8 percent for non-Hispanic Whites and  
19 15.3 percent for all United States residents.

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

1 surveyed were significantly more likely (33 percent)  
2 than caregivers of other races (23 percent) to believe  
3 that Alzheimer's disease is a normal part of the  
4 aging process and were also significantly more likely  
5 (67 percent) to dismiss the symptoms of Alzheimer's  
6 disease as old age than other respondents of other  
7 races (53 percent). Delays in diagnosis and lack of  
8 early and consistent treatment can lead to higher  
9 levels of impairment and increased stress on family  
10 caregivers.

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

17 (10) Alzheimer's disease costs the United  
18 States \$148 billion each year in direct and indirect  
19 costs to business, the Medicare program, and the  
20 Medicaid program (not including private health in-  
21 surance costs). If the prevalence of Alzheimer's dis-  
22 ease continues to increase as expected, the \$91 bil-  
23 lion spent in 2005 on Medicare costs for care of in-  
24 dividuals with Alzheimer's disease and dementia pa-



1           “(A) to understand more fully the under-  
2           lying reasons that Hispanic individuals delay di-  
3           agnosis and underutilize services;

4           “(B) to identify culturally and linguis-  
5           tically appropriate approaches for addressing  
6           such delays and underutilization; and

7           “(C) to identify approaches for providing,  
8           and improving the quality of, culturally com-  
9           petent care.

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

13           “(1) to educate communities about the impor-  
14           tance of research relating to Alzheimer’s disease;  
15           and

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

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

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

24           (1) by striking “and such” and inserting  
25           “such”; and

1           (2) by inserting before the period at the end “,  
2           \$25,000,000 for fiscal year 2010, and such sums as  
3           may be necessary for each of the fiscal years 2011  
4           through 2014”.

5 **SEC. 5. CDC OUTREACH AND EDUCATION.**

6           Part B of title III of the Public Health Service Act  
7 (42 U.S.C. 243 et seq.) is amended by inserting after sec-  
8 tion 317T the following:

9 **“SEC. 317U. EDUCATION AND OUTREACH ON ALZHEIMER’S**  
10 **DISEASE.**

11           “(a) **PURPOSES.**—The purposes of this section are  
12 the following:

13           “(1) To reduce the risk of Alzheimer’s disease  
14 through reduction of vascular risk factors.

15           “(2) To encourage early recognition and diag-  
16 nosis of dementia.

17           “(3) To train public health personnel to recog-  
18 nize, assess, diagnose, and treat Alzheimer’s disease  
19 in ways that are culturally appropriate and sup-  
20 portive of families.

21           “(b) **EDUCATION AND OUTREACH.**—To achieve the  
22 purposes of this section, the Secretary, acting through the  
23 Centers for Disease Control and Prevention, shall conduct  
24 an aggressive, evidence-based education and outreach pro-  
25 gram to promote public awareness and risk reduction with

1 respect to Alzheimer’s disease. In conducting the outreach  
2 program, the Secretary shall consult with State Health  
3 Departments and may consult with other appropriate enti-  
4 ties, including the Alzheimer’s Association and the Al-  
5zheimer’s Foundation of America.

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

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