

110TH CONGRESS
2D SESSION

H. R. 6203

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 5, 2008

Ms. LINDA T. SÁNCHEZ of California (for herself, Ms. BERKLEY, Mr. BERMAN, Mr. BISHOP of Georgia, Mr. BISHOP of New York, Ms. BORDALLO, Mr. BRADY of Pennsylvania, Mr. CAPUANO, Mr. CLAY, Mr. COHEN, Mr. COURTNEY, Mrs. DAVIS of California, Mr. GRIJALVA, Mr. HARE, Mr. HIGGINS, Mr. HINOJOSA, Mr. HOLT, Mr. INSLEE, Mr. ISRAEL, Mr. LARSON of Connecticut, Ms. LEE, Mr. MARKEY, Mr. MCGOVERN, Mr. McNULTY, Mrs. NAPOLITANO, Mr. ORTIZ, Mr. REYES, Mr. RODRIGUEZ, Ms. ROS-LEHTINEN, Mr. RYAN of Ohio, Ms. LORETTA SANCHEZ of California, Mr. SIRES, Ms. SOLIS, Ms. WATERS, Mr. WATT, Mr. WEXLER, and Mr. WU) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 2008”
6 or the “La Cura Act of 2008”.

7 **SEC. 2. FINDINGS.**

8 The Congress finds as follows:

9 (1) The incidence and prevalence of Alzheimer’s
10 disease increase with age. Alzheimer’s disease is cur-
11 rently the seventh leading cause of death of all ages
12 in the United States (and the fifth leading cause of
13 death for people over 65 years of age), with 5.2 mil-
14 lion individuals in the United States living with Alz-
15 heimer’s disease. Currently, one of each eight indi-
16 viduals in the United States over age 65 has Alz-
17 heimer’s disease. Every 71 seconds, an individual in
18 the United States develops Alzheimer’s disease, and
19 by 2050, every 33 seconds an individual in the
20 United States will develop this disease. By 2050, the
21 number of individuals in the United States age 65
22 and over with Alzheimer’s disease will range from 11
23 million to 16 million individuals. It is projected that
24 by 2050, more than 60 percent of individuals in the

1 United States with Alzheimer's disease will be age
2 85 or older.

3 (2) The prevalence of Alzheimer's disease and
4 dementia seems to be higher among individuals with
5 fewer years of education. Individuals with fewer than
6 12 years of education have a 15 percent greater risk
7 of developing dementia than individuals with 12 to
8 15 years of education and a 35 percent greater risk
9 of developing dementia than individuals with more
10 than 15 years of education.

11 (3) Hispanics are the fastest growing popu-
12 lation in the Nation and by 2050, will have a life ex-
13 pectancy of 87 years, longer than any other ethnic
14 or racial group. The Hispanic community in the
15 United States is projected to experience a six-fold in-
16 crease in Alzheimer's disease (from fewer than
17 200,000 to as many as 1.3 million) by 2050.

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

1 (5) Research on disparities in Alzheimer’s risk
2 factors between Hispanic and other ethnic and racial
3 groups is only beginning to sort out complex dif-
4 ferences: for example, even in the absence of the
5 APOE-e4 allele, the one known genetic risk factor
6 for late onset Alzheimer’s, Caribbean Hispanics have
7 a cumulative risk for Alzheimer’s twice that of non-
8 Hispanic whites.

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

19 (7) Hispanics are far more likely to be unin-
20 sured than any other ethnic group: the Bureau of
21 the Census reports that 34.1 percent of the Hispanic
22 population in the United States is uninsured, com-
23 pared to 10.8 percent for non-Hispanic whites and
24 15.3 percent for all United States residents.

1 (8) Lack of access to health care and a strong
2 cultural commitment to caring for one’s elders with-
3 in the family are among the factors that make His-
4 panics with dementia less likely than non-Hispanics
5 to see a physician and use related services provided
6 by formal health professionals: delays in diagnosis
7 and lack of early and consistent treatment can lead
8 to higher levels of impairment and increased stress
9 on family caregivers.

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

16 (10) Alzheimer’s disease costs the United
17 States \$148 billion each year in direct and indirect
18 costs to business, the Medicare program, and the
19 Medicaid program (not including private health in-
20 surance costs).

21 **SEC. 3. NIH RESEARCH AND EDUCATION ON ALZHEIMER’S**
22 **DISEASE.**

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

1 **“SEC. 445J. NIH RESEARCH AND EDUCATION ON ALZ-**
2 **HEIMER’S DISEASE.**

3 “(a) RESEARCH ACTIVITIES.—In conducting re-
4 search relating to Alzheimer’s disease, the Director of the
5 National Institutes of Health shall ensure sufficient re-
6 sources for activities relating to Alzheimer’s disease and
7 Hispanic communities, including by—

8 “(1) increasing efforts in epidemiological work
9 in Hispanic subgroups;

10 “(2) allocating resources to the National Insti-
11 tute on Aging Alzheimer’s disease research centers
12 and other academic centers involved in Alzheimer’s
13 disease research to increase participation of His-
14 panics and other under represented ethnic groups in
15 research and clinical trials in sufficient numbers to
16 draw valid conclusions; and

17 “(3) conducting social, behavioral, and health
18 services research—

19 “(A) to understand more fully the under-
20 lying reasons that Hispanic individuals delay di-
21 agnosis and underutilize services;

22 “(B) to identify culturally and linguis-
23 tically appropriate approaches for addressing
24 such delays and underutilization; and

1 “(C) to identify approaches for providing,
2 and improving the quality of, culturally com-
3 petent care.

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

7 “(1) to educate communities about the impor-
8 tance of research relating to Alzheimer’s disease;
9 and

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

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

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

18 (1) by striking “and such” and inserting
19 “such”; and

20 (2) by inserting before the period at the end “,
21 \$25,000,000 for fiscal year 2009, and such sums as
22 may be necessary for each of the fiscal years 2010
23 through 2013”.

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

2 Part B of title III of the Public Health Service Act
3 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
4 tion 317S the following:

5 **“SEC. 317T. EDUCATION AND OUTREACH ON ALZHEIMER’S**
6 **DISEASE.**

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

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

11 “(2) To encourage early recognition and diag-
12 nosis of dementia.

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

17 “(b) **EDUCATION AND OUTREACH.**—To achieve the
18 purposes of this section, the Secretary, acting through the
19 Centers for Disease Control and Prevention, shall conduct
20 an aggressive, evidence-based education and outreach pro-
21 gram to promote public awareness and risk reduction with
22 respect to Alzheimer’s disease. In conducting the outreach
23 program, the Secretary shall consult with State Health
24 Departments and may consult with other appropriate enti-
25 ties, including the Alzheimer’s Association.

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

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