### 110TH CONGRESS 2D SESSION

# S. 3092

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 SENATE OF THE UNITED STATES

June 5, 2008

Mr. Menendez (for himself and Ms. Mikulski) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

# 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,

### 1 SECTION 1. SHORT TITLE.

- This Act may be cited as the "Cure and Under-
- 3 standing through Research for Alzheimer's Act of 2008",
- 4 or the "CURA Act of 2008".

### 5 SEC. 2. FINDINGS.

- 6 Congress makes the following findings:
- 7 (1) The incidence and prevalence of Alzheimer's 8 disease increase with age. Alzheimer's disease is cur-9 rently the 7th leading cause of death of all ages in 10 the United States (number 5 for people over 65 11 years of age), with 5,200,000 Americans living with 12 Alzheimer's. Currently, 1 in 8 Americans over age 13 65 has Alzheimer's. Every 71 seconds, someone de-14 velops Alzheimer's disease, and by 2050, someone 15 will develop this disease every 33 seconds. By 2050, 16 the number of individuals age 65 and over with Alz-17 heimer's will range from 11,000,000 to 16,000,000 18 people. It is projected that by 2050, more than 60 19 percent of people with Alzheimer's disease will be 20 age 85 or older.
  - (2) The prevalence of Alzheimer's disease and dementia seem to be higher among people with fewer years of education. People with less than 12 years of education have a 15 percent greater risk of developing dementia than people with 12 to 15 years of education and a 35 percent greater risk of developments.

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- oping dementia than people with more than 15 years of education.
- 3 (3) Hispanics are the fastest growing population in the United States 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 sixfold increase in Alzheimer's disease (from fewer than 200,000 to as many as 1,300,000) by 2050.
  - (4) Hispanics may be at a greater risk of developing dementia than other ethnic or racial groups. Hispanics have a 64 percent higher incidence of diabetes than non-Hispanic white Americans, and this 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 profes-sionals, combined with the large population of monolingual Spanish-speaking seniors, makes adequate testing and diagnosis of Alzheimer's among el-derly Hispanics difficult and may lead to cultural bi-ases 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 Census Bureau reports that 34.1 percent of Hispanics in the United States are uninsured, compared to 10.8 percent for non-Hispanic whites and 15.3 percent for all United States residents.
  - (8) Lack of access to healthcare 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. Delays in diagnosis and lack of early and consistent treatment can lead to higher levels of impairment and increased stress on family caregivers.

1	(9) Hispanic elders are second most likely, after
2	Asian-Americans, to live with their families rather
3	than in long term care facilities. More research is
4	needed to better understand the effects of differing
5	care settings on family caregivers and Alzheimer's
6	patients.
7	(10) Alzheimer's disease costs the United
8	States \$148,000,000,000 a year in direct and indi-
9	rect costs to business, Medicare, and Medicaid (not
10	including private insurance).
11	SEC. 3. NIH RESEARCH AND EDUCATION ON ALZHEIMER'S
12	DISEASE.
12 13	DISEASE.  (a) RESEARCH ACTIVITIES.—In conducting research
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113 114 115 116 117	(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
13 14 15 16 17 18	(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;
13 14 15 16 17 18 19 20	(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 Insti-

panics and other underrepresented ethnic groups in

1	research and clinical trials in sufficient numbers to
2	draw valid conclusions; and
3	(3) conducting social, behavioral, and health
4	services research—
5	(A) to understand more fully the under-
6	lying reasons that Hispanic individuals delay di-
7	agnosis and underutilize services;
8	(B) to identify culturally and linguistically
9	appropriate approaches for addressing such
10	delays and underutilization; and
11	(C) to identify what is culturally competent
12	care.
13	(b) EDUCATION ACTIVITIES.—The Director of the
14	National Institutes of Health shall expand and intensify
15	the efforts of the Institutes—
16	(1) to educate communities about the impor-
17	tance of research relating to Alzheimer's disease;
18	and
19	(2) to respond effectively to cultural concerns
20	about participation in such research, especially with
21	respect to sensitive matters like the collection of
22.	brain tissue and genetic information

1	SEC. 4. INCREASED FUNDING FOR ALZHEIMER'S DISEASE
2	DEMONSTRATION GRANTS.
3	Section 398B(e) of the Public Health Service Act (42
4	U.S.C. 280c-5(e)) is amended—
5	(1) by striking "and such" and inserting
6	"such"; and
7	(2) by inserting before the period the following:
8	", \$25,000,000 for fiscal year 2009, and such sums
9	as may be necessary for each of fiscal years 2010
10	through 2013".
11	SEC. 5. CDC OUTREACH AND EDUCATION.
12	Part B of title III of the Public Health Service Act
13	(42 U.S.C. 243 et seq.) is amended by inserting after sec-
14	tion 317S the following:
15	"SEC. 317T. EDUCATION AND OUTREACH ON ALZHEIMER'S
16	DISEASE.
17	"(a) Purposes.—The purposes of this section are
18	the following:
19	"(1) To reduce the risk of Alzheimer's disease
20	through the reduction of vascular risk factors.
21	"(2) To encourage the early recognition and di-
22	agnosis of dementia.
23	"(3) To train public health personnel to recog-
24	nize, assess, diagnose, and treat Alzheimer's disease
25	in ways that are culturally appropriate and sup-
26	portive of families.

- 1 "(b) EDUCATION AND OUTREACH.—To achieve the
- 2 purposes of this section, the Secretary, acting through the
- 3 Centers for Disease Control and Prevention, shall conduct
- 4 an aggressive, evidence-based education and outreach pro-
- 5 gram to promote public awareness and risk reduction with
- 6 respect to Alzheimer's disease. In conducting the outreach
- 7 program, the Secretary shall consult with State health de-
- 8 partments and other appropriate entities, including the
- 9 Alzheimer's Association.
- 10 "(c) Emphasis.—In carrying out this section, the
- 11 Secretary shall give particular emphasis to education and
- 12 outreach in Hispanic populations.".

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