

111TH CONGRESS  
1ST SESSION

# S. 1555

To establish the Office of the National Alzheimer's Project.

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## IN THE SENATE OF THE UNITED STATES

JULY 31, 2009

Mr. MARTINEZ (for himself, Mr. BAYH, Ms. COLLINS, Mr. BENNET, Mr. FEINGOLD, and Mr. TESTER) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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## A BILL

To establish the Office of the National Alzheimer's Project.

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; FINDINGS.**

4       (a) SHORT TITLE.—This Act may be cited as the  
5       “Office of the National Alzheimer's Project Act”.

6       (b) FINDINGS.—Congress finds that according to the  
7       2009 Alzheimer's Study Group National Strategic Plan  
8       and the 2009 Alzheimer's Disease Facts and Figures re-  
9       port of the Alzheimer's Association—

10               (1) Alzheimer's disease is a progressive, debili-  
11       tating, terminal disease with no known cure;

1           (2) Alzheimer's disease was the sixth leading  
2           cause of death in the United States for all ages in  
3           2006 and the fifth leading cause of death for people  
4           age 65 and older;

5           (3) currently, an estimated 5,300,000 Ameri-  
6           cans of all ages have Alzheimer's disease, and 13  
7           percent of people age 65 and older have Alzheimer's  
8           disease;

9           (4) of those with Alzheimer's disease some mi-  
10          nority populations are disproportionately suffering  
11          from the disease;

12          (5) there are 78,000,000 people in the baby  
13          boom generation, and in 2011, the first baby  
14          boomers will turn 65, and by 2029, all baby boomers  
15          will be at least 65 years old;

16          (6) the number of people aged 65 and older  
17          with Alzheimer's disease is estimated to reach  
18          7,700,000 in 2030, more than a 50 percent increase  
19          from the 5,100,000 aged 65 and older who are cur-  
20          rently affected;

21          (7) the 85 years and older population currently  
22          comprises nearly 50 percent of the individuals with  
23          Alzheimer's disease, or about 2,700,000 people, and  
24          by the time the first wave of baby boomers reaches  
25          age 85 years (2031), there will be an estimated

1 3,500,000 people aged 85 and older with Alz-  
2 heimer's;

3 (8) in 2008, 9,900,000 unpaid caregivers pro-  
4 vided care valued at \$94,000,000,000 for a person  
5 with Alzheimer's disease or other dementia;

6 (9) total per-person payments from all sources  
7 for health and long-term care were three times high-  
8 er for Medicare beneficiaries with Alzheimer's dis-  
9 ease: \$33,007 compared to \$10,603;

10 (10) in 2009 the Federal Government will  
11 spend more than \$100,000,000,000 through Medi-  
12 care and Medicaid to care for those with Alzheimer's  
13 disease;

14 (11) if the United States follows current trends  
15 the Federal Government will spend more than  
16 \$1,000,000,000,000 per year by 2050 on Alz-  
17 heimer's disease care; and

18 (12) between 2010 and 2050 Medicare and  
19 Medicaid programs are projected to spend  
20 \$20,000,000,000,000 for Alzheimer's disease care.

21 **SEC. 2. OFFICE OF THE NATIONAL ALZHEIMER'S PROJECT.**

22 (a) ESTABLISHMENT OF OFFICE.—There is estab-  
23 lished in the Office of the President the Office of the Na-  
24 tional Alzheimer's Project (referred to in this Act as the  
25 "Office").

1 (b) PURPOSE OF THE OFFICE.—The Office shall—

2 (1) accelerate the development of treatments  
3 that would prevent, halt, or reverse the course of  
4 Alzheimer’s;

5 (2) be responsible for the creation and mainte-  
6 nance of an integrated national plan to overcome  
7 Alzheimer’s;

8 (3) help to coordinate the health care and treat-  
9 ment of citizens with Alzheimer’s;

10 (4) ensure the inclusion of ethnic and racial  
11 populations at higher risk for Alzheimer’s or least  
12 likely to receive care, in clinical, research, and serv-  
13 ice efforts with the purpose of decreasing health dis-  
14 parities in Alzheimer’s; and

15 (5) coordinate with international bodies to inte-  
16 grate and inform the fight against Alzheimer’s glob-  
17 ally.

18 (c) DIRECTOR OF THE OFFICE.—

19 (1) APPOINTMENT.—The President by and with  
20 the advice and consent of the Senate shall appoint  
21 a Director of the Office.

22 (2) DUTIES OF THE DIRECTOR.—

23 (A) IN GENERAL.—The Director of the Of-  
24 fice shall—

1 (i) oversee the creation and updating  
2 of the national plan described in subpara-  
3 graph (B);

4 (ii) use discretionary authority to  
5 evaluate all Federal programs around Alz-  
6 heimer's, including budget requests and  
7 approvals; and

8 (iii) prepare and submit to the Presi-  
9 dent the annual budget estimate for the  
10 Office.

11 (B) NATIONAL PLAN.—The Director of the  
12 Office shall carry out an annual assessment of  
13 the Nation's progress in preparing for the esca-  
14 lating burden of Alzheimer's, including both im-  
15 plementation steps and recommendations for  
16 priority actions based on the assessment.

17 (3) SERVICE BY DIRECTOR.—The Director of  
18 the Office shall serve—

19 (A) on the advisory board of the Office of  
20 Science and Technology to promote research ef-  
21 forts into mechanisms to slow and stop the de-  
22 velopment of Alzheimer's for those at risk of  
23 developing the disease, or may appoint a des-  
24 ignee to sit on such board; and

1 (B) on the Domestic Policy Council to rep-  
2 resent those who have or will develop Alz-  
3 heimer's, including on matters of housing,  
4 transportation, and education.

5 (d) ADVISORY COUNCIL.—

6 (1) IN GENERAL.—There is established in the  
7 Office an Advisory Council on Alzheimer's Research  
8 and Treatment (referred to in this Act as the “Advi-  
9 sory Council”).

10 (2) MEMBERSHIP.—

11 (A) IN GENERAL.—The Advisory Council  
12 shall be comprised of the following:

13 (i) A designee of the Office of Science  
14 of the Department of Energy.

15 (ii) A designee of the Office of the  
16 Secretary of the Department of Health and  
17 Human Services.

18 (iii) A designee of the Administration  
19 on Aging.

20 (iv) A designee of the Centers for  
21 Medicare & Medicaid Services.

22 (v) A designee of the Indian Health  
23 Service.

1 (vi) A designee of the Office of the  
2 Director of the National Institutes of  
3 Health.

4 (vii) The Surgeon General.

5 (viii) A designee of the National  
6 Science Foundation.

7 (ix) A designee of the Department of  
8 Veterans Affairs.

9 (B) NON-FEDERAL MEMBERS.—

10 (i) IN GENERAL.—In addition to the  
11 members outlined in subparagraph (A), the  
12 Advisory Council shall include 12 members  
13 from outside the Federal Government, in-  
14 cluding 2 members who are patient advo-  
15 cate members and 2 members who rep-  
16 resent States, and members appointed pur-  
17 suant to clause (ii).

18 (ii) CONGRESSIONAL APPOINT-  
19 MENTS.—

20 (I) IN GENERAL.—In addition to  
21 the members outlined in subparagraph  
22 (A) and clause (i), the majority and  
23 minority leaders of the Senate and the  
24 Speaker and minority leader of the  
25 House of Representatives shall each

1           appoint 2 members from the pool de-  
2           scribed in clause (II) to the Advisory  
3           Council for a 2-year term, with each  
4           such member eligible to be re-  
5           appointed.

6                   (II) REMAINING NON-FEDERAL  
7           MEMBERS.—The remaining non-Fed-  
8           eral members shall be representatives  
9           of academia, research, health and  
10          elder care delivery (both community-  
11          based and institutional), technology,  
12          or other related sectors.

13                   (III) VACANCIES.—Any member  
14          appointed under this clause to fill a  
15          vacancy occurring prior to the expira-  
16          tion of the term for which the mem-  
17          ber's predecessor was appointed shall  
18          be appointed for the remainder of  
19          such term. A member appointed under  
20          this clause shall serve until the mem-  
21          ber's replacement has been appointed.

22                   (3) MEETINGS.—The Advisory Council shall  
23          meet quarterly and such meetings shall be open to  
24          the public.



1           (4) ADVICE.—The Advisory Council shall advise  
2 the Director of the Office.

3           (5) ANNUAL REPORT.—The Advisory Council  
4 shall provide to the Director of the Office—

5                   (A) recommendations for information to be  
6 included in the annual report to Congress by  
7 the Office; and

8                   (B) an annually updated national plan.

9           (e) ANNUAL REPORT.—The Director of the Office  
10 shall submit to Congress—

11                   (1) an annual report that includes an evalua-  
12 tion of all nationally and federally funded efforts in  
13 Alzheimer’s research, clinical care, institutional, and  
14 home- and community-based programs and their  
15 outcomes; and

16                   (2) an annually updated national plan.

17           (f) SUNSET.—The Office shall expire on December  
18 31, 2025.

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