

Calendar No. 675

111TH CONGRESS
2^D SESSION

S. 3036

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

IN THE SENATE OF THE UNITED STATES

FEBRUARY 24, 2010

Mr. BAYH (for himself, Ms. COLLINS, Mr. LEMIEUX, Mr. TESTER, Mr. WHITEHOUSE, Ms. LANDRIEU, Mr. FEINGOLD, Ms. STABENOW, Mr. CONRAD, Mrs. MCCASKILL, Mr. CHAMBLISS, Mr. SCHUMER, Mrs. GILLIBRAND, Mr. LIEBERMAN, Mr. JOHNSON, Mr. MENENDEZ, Mr. GREGG, Mr. LAUTENBERG, Mr. WARNER, Mr. CARPER, Mr. BENNET, Mr. CASEY, Ms. CANTWELL, Mr. AKAKA, Mr. CARDIN, Mr. KOHL, Mrs. SHAHEEN, Mr. DODD, Mrs. LINCOLN, Mrs. BOXER, Ms. SNOWE, Mr. KAUFMAN, Mr. INOUYE, and Mr. BURR) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

DECEMBER 6, 2010

Reported by Mr. HARKIN, with an amendment and an amendment to the title
[Strike out all after the enacting clause and insert the part printed in italic]

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “National Alzheimer’s
3 Project Act”.

4 **SEC. 2. OFFICE OF THE NATIONAL ALZHEIMER’S PROJECT.**

5 (a) **ESTABLISHMENT OF OFFICE.**—There is estab-
6 lished in the Office of the Secretary of Health and Human
7 Services the Office of the National Alzheimer’s Project
8 (referred to in this Act as the “Office”).

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

10 (1) accelerate the development of treatments
11 that would prevent, halt, or reverse the course of
12 Alzheimer’s;

13 (2) be responsible for the creation and mainte-
14 nance of an integrated national plan to overcome
15 Alzheimer’s;

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

18 (4) ensure the inclusion of ethnic and racial
19 populations at higher risk for Alzheimer’s or least
20 likely to receive care, in clinical, research, and serv-
21 ice efforts with the purpose of decreasing health dis-
22 parities in Alzheimer’s;

23 (5) coordinate with international bodies to inte-
24 grate and inform the fight against Alzheimer’s glob-
25 ally; and

1 (6) provide information and coordination of Alz-
2 heimer's research and services across all Federal
3 agencies.

4 (c) DIRECTOR OF THE OFFICE.—

5 (1) APPOINTMENT.—The President shall ap-
6 point a Director of the Office.

7 (2) DUTIES OF THE DIRECTOR.—

8 (A) IN GENERAL.—The Director of the Of-
9 fice shall—

10 (i) oversee the creation and updating
11 of the national plan described in subpara-
12 graph (B);

13 (ii) use discretionary authority to
14 evaluate all Federal programs around Alz-
15 heimer's, including budget requests and
16 approvals; and

17 (iii) prepare and submit to the Presi-
18 dent the annual budget estimate for the
19 Office.

20 (B) NATIONAL PLAN.—The Director of the
21 Office shall carry out an annual assessment of
22 the Nation's progress in preparing for the esca-
23 lating burden of Alzheimer's, including both im-
24 plementation steps and recommendations for
25 priority actions based on the assessment.

1 (3) SERVICE BY DIRECTOR.—The Director of
2 the Office shall serve on the advisory board of the
3 Office of Science and Technology to promote re-
4 search efforts into mechanisms to slow and stop the
5 development of Alzheimer’s for those at risk of de-
6 veloping the disease.

7 (d) ADVISORY COUNCIL.—

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

12 (2) MEMBERSHIP.—

13 (A) FEDERAL MEMBERS.—The Advisory
14 Council shall be comprised of the following ex-
15 perts:

16 (i) A designee of the Centers for Dis-
17 ease Control and Prevention.

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

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

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

24 (v) A designee of the Office of the Di-
25 rector of the National Institutes of Health.

1 (vi) The Surgeon General.

2 (vii) A designee of the National
3 Science Foundation.

4 (viii) A designee of the Department of
5 Veterans Affairs.

6 (B) ~~NON-FEDERAL MEMBERS.~~—In addi-
7 tion to the members outlined in subparagraph
8 (A), the Advisory Council shall include 12 ex-
9 pert members from outside the Federal Govern-
10 ment, which shall include—

11 (i) 2 Alzheimer patient advocates;

12 (ii) 2 Alzheimer caregivers;

13 (iii) 2 health care providers;

14 (iv) 2 representatives of State health
15 departments;

16 (v) 2 researchers with Alzheimer-re-
17 lated expertise in basic, translational, clin-
18 ical, or drug development science; and

19 (vi) 2 voluntary health association
20 representatives, including a national Alz-
21 heimer's disease organization that funds
22 research and has demonstrated experience
23 in care and patient services, and a State-
24 based advocacy organization that provides
25 services to families and professionals, in-

1 cluding information and referral, support
2 groups, care consultation, education, and
3 safety services.

4 ~~(3)~~ MEETINGS.—The Advisory Council shall
5 meet quarterly and such meetings shall be open to
6 the public.

7 ~~(4)~~ ADVICE.—The Advisory Council shall advise
8 the Director of the Office.

9 ~~(5)~~ ANNUAL REPORT.—The Advisory Council
10 shall provide to the Director of the Office—

11 (A) recommendations for information to be
12 included in the annual report to Congress by
13 the Office; and

14 (B) an annually updated national plan.

15 ~~(e)~~ ANNUAL REPORT.—The Director of the Office
16 shall submit to Congress—

17 (1) an annual report that includes an evalua-
18 tion of all nationally and federally funded efforts in
19 Alzheimer’s research, clinical care, institutional, and
20 home- and community-based programs and their
21 outcomes; and

22 (2) an annually updated national plan.

23 ~~(f)~~ SUNSET.—The Office shall expire on December
24 31, 2025.

1 **SECTION 1. SHORT TITLE.**

2 *This Act may be cited as the “National Alzheimer’s*
3 *Project Act”.*

4 **SEC. 2. THE NATIONAL ALZHEIMER’S PROJECT.**

5 (a) *DEFINITION OF ALZHEIMER’S.—In this Act, the*
6 *term “Alzheimer’s” means Alzheimer’s disease and related*
7 *dementias.*

8 (b) *ESTABLISHMENT.—There is established in the Of-*
9 *fice of the Secretary of Health and Human Services the Na-*
10 *tional Alzheimer’s Project (referred to in this Act as the*
11 *“Project”).*

12 (c) *PURPOSE OF THE PROJECT.—The Secretary of*
13 *Health and Human Services, or the Secretary’s designee,*
14 *shall—*

15 (1) *be responsible for the creation and mainte-*
16 *nance of an integrated national plan to overcome Alz-*
17 *heimer’s;*

18 (2) *provide information and coordination of Alz-*
19 *heimer’s research and services across all Federal agen-*
20 *cies;*

21 (3) *accelerate the development of treatments that*
22 *would prevent, halt, or reverse the course of Alz-*
23 *heimer’s;*

24 (4) *improve the—*

25 (A) *early diagnosis of Alzheimer’s disease;*

26 *and*

1 (B) coordination of the care and treatment
2 of citizens with Alzheimer's;

3 (5) ensure the inclusion of ethnic and racial pop-
4 ulations at higher risk for Alzheimer's or least likely
5 to receive care, in clinical, research, and service ef-
6 forts with the purpose of decreasing health disparities
7 in Alzheimer's; and

8 (6) coordinate with international bodies to inte-
9 grate and inform the fight against Alzheimer's glob-
10 ally.

11 (d) DUTIES OF THE SECRETARY.—

12 (1) IN GENERAL.—The Secretary of Health and
13 Human Services, or the Secretary's designee, shall—

14 (A) oversee the creation and updating of the
15 national plan described in paragraph (2); and

16 (B) use discretionary authority to evaluate
17 all Federal programs around Alzheimer's, in-
18 cluding budget requests and approvals.

19 (2) NATIONAL PLAN.—The Secretary of Health
20 and Human Services, or the Secretary's designee,
21 shall carry out an annual assessment of the Nation's
22 progress in preparing for the escalating burden of
23 Alzheimer's, including both implementation steps and
24 recommendations for priority actions based on the as-
25 sessment.

1 (e) *ADVISORY COUNCIL.*—

2 (1) *IN GENERAL.*—*There is established an Advisory*
3 *Council on Alzheimer’s Research, Care, and*
4 *Services (referred to in this Act as the “Advisory*
5 *Council”).*

6 (2) *MEMBERSHIP.*—

7 (A) *FEDERAL MEMBERS.*—*The Advisory*
8 *Council shall be comprised of the following ex-*
9 *perts:*

10 (i) *A designee of the Centers for Dis-*
11 *ease Control and Prevention.*

12 (ii) *A designee of the Administration*
13 *on Aging.*

14 (iii) *A designee of the Centers for*
15 *Medicare & Medicaid Services.*

16 (iv) *A designee of the Indian Health*
17 *Service.*

18 (v) *A designee of the Office of the Di-*
19 *rector of the National Institutes of Health.*

20 (vi) *The Surgeon General.*

21 (vii) *A designee of the National Science*
22 *Foundation.*

23 (viii) *A designee of the Department of*
24 *Veterans Affairs.*

1 *(ix) A designee of the Food and Drug*
2 *Administration.*

3 *(x) A designee of the Agency for*
4 *Healthcare Research and Quality.*

5 *(B) NON-FEDERAL MEMBERS.—In addition*
6 *to the members outlined in subparagraph (A),*
7 *the Advisory Council shall include 12 expert*
8 *members from outside the Federal Government,*
9 *which shall include—*

10 *(i) 2 Alzheimer’s patient advocates;*

11 *(ii) 2 Alzheimer’s caregivers;*

12 *(iii) 2 health care providers;*

13 *(iv) 2 representatives of State health*
14 *departments;*

15 *(v) 2 researchers with Alzheimer’s-re-*
16 *lated expertise in basic, translational, clin-*
17 *ical, or drug development science; and*

18 *(vi) 2 voluntary health association rep-*
19 *resentatives, including a national Alz-*
20 *heimer’s disease organization that has dem-*
21 *onstrated experience in research, care, and*
22 *patient services, and a State-based advocacy*
23 *organization that provides services to fami-*
24 *lies and professionals, including informa-*

1 *tion and referral, support groups, care con-*
2 *sultation, education, and safety services.*

3 (3) *MEETINGS.*—*The Advisory Council shall*
4 *meet quarterly and such meetings shall be open to the*
5 *public.*

6 (4) *ADVICE.*—*The Advisory Council shall advise*
7 *the Secretary of Health and Human Services, or the*
8 *Secretary's designee.*

9 (5) *ANNUAL REPORT.*—*The Advisory Council*
10 *shall provide to the Secretary of Health and Human*
11 *Services, or the Secretary's designee and Congress—*

12 (A) *an initial evaluation of all federally*
13 *funded efforts in Alzheimer's research, clinical*
14 *care, and institutional-, home-, and community-*
15 *based programs and their outcomes;*

16 (B) *initial recommendations for priority*
17 *actions to expand, eliminate, coordinate, or con-*
18 *dense programs based on the program's perform-*
19 *ance, mission, and purpose;*

20 (C) *initial recommendations to—*

21 (i) *reduce the financial impact of Alz-*
22 *heimer's on—*

23 (I) *Medicare and other federally*
24 *funded programs; and*

1 (ii) families living with Alz-
2 heimer's disease; and

3 (iii) improve health outcomes; and

4 (D) annually thereafter, an evaluation of
5 the implementation, including outcomes, of the
6 recommendations, including priorities if nec-
7 essary, through an updated national plan under
8 subsection (d)(2).

9 (6) *TERMINATION.*—The Advisory Council shall
10 terminate on December 31, 2025.

11 (f) *DATA SHARING.*—Agencies both within the Depart-
12 ment of Health and Human Services and outside of the De-
13 partment that have data relating to Alzheimer's shall share
14 such data with the Secretary of Health and Human Serv-
15 ices, or the Secretary's designee, to enable the Secretary, or
16 the Secretary's designee, to complete the report described in
17 subsection (g).

18 (g) *ANNUAL REPORT.*—The Secretary of Health and
19 Human Services, or the Secretary's designee, shall submit
20 to Congress—

21 (1) an annual report that includes an evaluation
22 of all federally funded efforts in Alzheimer's research,
23 clinical care, and institutional-, home-, and commu-
24 nity-based programs and their outcomes;

1 (2) *an evaluation of all federally funded pro-*
2 *grams based on program performance, mission, and*
3 *purpose related to Alzheimer’s disease;*

4 (3) *recommendations for—*

5 (A) *priority actions based on the evaluation*
6 *conducted by the Secretary and the Advisory*
7 *Council to—*

8 (i) *reduce the financial impact of Alz-*
9 *heimer’s on—*

10 (I) *Medicare and other federally*
11 *funded programs; and*

12 (II) *families living with Alz-*
13 *heimer’s disease; and*

14 (ii) *improve health outcomes;*

15 (B) *implementation steps; and*

16 (C) *priority actions to improve the preven-*
17 *tion, diagnosis, treatment, care, institutional-,*
18 *home-, and community-based programs of Alz-*
19 *heimer’s disease for individuals with Alzheimer’s*
20 *disease and their caregivers; and*

21 (4) *an annually updated national plan.*

22 (h) *SUNSET.—The Project shall expire on December*
23 *31, 2025.*

Amend the title so as to read: “A bill to establish the National Alzheimer’s Project.”.

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11TH CONGRESS
2^D Session

S. 3036

A BILL

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

DECEMBER 6, 2010

Reported with an amendment and an amendment to the
title