

107TH CONGRESS
2D SESSION

H. R. 4606

To amend the Public Health Service Act to provide for Alzheimer's disease research and demonstration grants.

IN THE HOUSE OF REPRESENTATIVES

APRIL 25, 2002

Mr. MARKEY (for himself, Mr. DINGELL, and Mr. SMITH of New Jersey) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for Alzheimer's disease research and demonstration grants.

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 "Alzheimer's Disease
5 Research, Prevention, and Care Act of 2002".

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Alzheimer's disease is a disorder that de-
9 stroys cells in the brain. The disease is the leading
10 cause of dementia, a condition that involves gradual

1 memory loss, decline in the ability to perform rou-
2 tine tasks, disorientation, difficulty in learning, loss
3 of language skills, impairment of judgment, and per-
4 sonality changes. As the disease progresses, people
5 with Alzheimer's disease become unable to care for
6 themselves. The loss of brain cells eventually leads
7 to the failure of other systems in the body.

8 (2) In the United States, 4,000,000 people have
9 Alzheimer's disease and 19,000,000 people say that
10 they have a family member with the disease. By
11 2050, 14,000,000 people in the United States will
12 have Alzheimer's disease unless science finds a way
13 to prevent or cure the disease.

14 (3) One in 10 people over the age of 65, and
15 nearly half of those over the age of 85 have Alz-
16 heimer's disease. Younger people also get the dis-
17 ease.

18 (4) The Alzheimer's disease process may begin
19 in the brain as many as 20 years before the symp-
20 toms of Alzheimer's disease appear. A person will
21 live an average of 8 years and as many as 20 once
22 the symptoms of Alzheimer's disease appear.

23 (5) The average lifetime cost of Alzheimer's dis-
24 ease, per person, is \$174,000. The total annual cost

1 of Alzheimer's disease care in the United States
2 today is not less than \$100,000,000,000.

3 (6) In 2000, medicare alone spent
4 \$31,900,000,000 for the care of individuals with
5 Alzheimer's disease and this amount is projected to
6 increase to \$49,300,000,000 in 2010.

7 (7) Forty-nine percent of medicare beneficiaries
8 who have Alzheimer's disease also receive medicaid.
9 Of the total population dually eligible for medicare
10 and medicaid, 22 percent have Alzheimer's disease.

11 (8) Seven in 10 people with Alzheimer's disease
12 live at home. While almost 75 percent of home care
13 is provided by family and friends, the average an-
14 nual cost of paid care for people with Alzheimer's
15 disease at home is \$12,500.

16 (9) At least half of all nursing home residents
17 have Alzheimer's disease or another dementia. The
18 average annual cost of Alzheimer's disease nursing
19 home care is \$42,000 but exceeds \$70,000 in some
20 areas. Medicaid pays nearly half of the total nursing
21 home bill and helps 2 out of 3 residents pay for
22 their care. Medicaid expenditures for nursing home
23 care for people with Alzheimer's disease are esti-
24 mated to increase from \$18,200,000,000 in 2000 to
25 \$33,000,000,000 in 2010.

1 (10) In fiscal year 2002, the Federal Govern-
2 ment will spend an estimated \$585,000,000 on Alz-
3 heimer's disease research, a modest investment when
4 compared with the annual \$100,000,000,000 cost of
5 the disease. If science can find a way to delay the
6 onset of Alzheimer's disease symptoms for even 5
7 years, our Nation will save at least \$50,000,000,000
8 in annual health and long term care costs.

9 (11) Seventy percent of people with Alzheimer's
10 disease live at home where families provide at least
11 75 percent of their care.

12 (12) A study commissioned by the United Hos-
13 pital Fund estimated that the annual value of this
14 informal care system is \$196,000,000,000. Family
15 caregiving comes at enormous physical, emotional,
16 and financial sacrifice, putting the whole system at
17 risk.

18 (13) One in 8 Alzheimer's disease caregivers be-
19 comes ill or injured as a direct result of caregiving.
20 One in 3 uses medication for problems related to
21 caregiving. Older caregivers are 3 times more likely
22 to become clinically depressed than others in their
23 age group.

1 (14) Elderly spouses strained by caregiving are
2 63 percent more likely to die during a given 4-year
3 period than other spouses their age.

4 (15) Three of 4 caregivers are women. One in
5 3 has children or grandchildren under the age of 18
6 living at home. Caregiving leaves them less time for
7 other family members and they are much more likely
8 to report family conflicts because of their caregiving
9 role.

10 (16) Most Alzheimer’s disease caregivers work
11 outside the home before beginning their caregiving
12 careers, but caregiving forces them to miss work, cut
13 back to part-time, take less demanding jobs, choose
14 early retirement, or give up work altogether. As a
15 result, in 2002, Alzheimer’s disease will cost Amer-
16 ican business an estimated \$36,500,000,000 in lost
17 productivity, as well as an additional
18 \$24,600,000,000 in business contributions to the
19 total cost of care.

20 **SEC. 3. PURPOSE OF THE NATIONAL INSTITUTE ON AGING.**

21 Section 443 of the Public Health Service Act (42
22 U.S.C. 285e) is amended by inserting “, Alzheimer’s dis-
23 ease and related disorders,” after “aging process”.

1 **SEC. 4. ALZHEIMER'S DISEASE PREVENTION INITIATIVE.**

2 Section 444 of the Public Health Service Act (42
3 U.S.C. 285e-1) is amended—

4 (1) in subsection (d), by inserting “and train-
5 ing” after “conduct research”; and

6 (2) by adding at the end the following:

7 “(e) The Director of the Institute shall, in collabora-
8 tion with the directors of the other relevant institutes and
9 centers of the National Institutes of Health, and with vol-
10 unteer organizations and other stakeholders, undertake an
11 Alzheimer’s Disease Prevention Initiative to—

12 “(1) accelerate the discovery of new risk and
13 protective factors for Alzheimer’s disease;

14 “(2) rapidly identify candidate diagnostics,
15 therapies, or preventive interventions or agents for
16 clinical investigation and trials relating to Alz-
17 heimer’s disease;

18 “(3) support or undertake such investigations
19 and trials; and

20 “(4) implement effective prevention and treat-
21 ment strategies, including strategies to improve pa-
22 tient care and alleviate caregiver burdens relating to
23 Alzheimer’s disease.”.

1 **SEC. 5. ALZHEIMER'S DISEASE CLINICAL RESEARCH.**

2 (a) CLINICAL RESEARCH.—Section 445F of the Pub-
3 lic Health Service Act (42 U.S.C. 285e–8) is amended to
4 read as follows:

5 **“SEC. 445F. ALZHEIMER'S DISEASE COOPERATIVE STUDY**
6 **GROUP.**

7 “(a) IN GENERAL.—The Director of the Institute,
8 pursuant to subsections (d) and (e) of section 444, shall
9 establish and support a national consortium for coopera-
10 tive clinical research regarding Alzheimer's disease. Such
11 a consortium shall—

12 “(1) investigate therapies, interventions, and
13 agents to detect, treat, slow the progression of, or
14 prevent Alzheimer's disease;

15 “(2) enhance the national infrastructure for the
16 conduct of clinical trials;

17 “(3) develop and test novel approaches to the
18 design and analysis of such trials;

19 “(4) facilitate the enrollment of, and expand
20 the range of, patients for such trials, including pa-
21 tients from diverse populations;

22 “(5) develop improved diagnostics and means of
23 patient assessment for Alzheimer's disease; and

24 “(6) include, as determined appropriate by the
25 Director of the Institute, the Alzheimer's Disease

1 Centers and Alzheimer’s Disease Research Centers
2 established under section 445.

3 “(b) EARLY DIAGNOSIS AND DETECTION RE-
4 SEARCH.—

5 “(1) IN GENERAL.—The Director of the Insti-
6 tute, in consultation with the directors of other rel-
7 evant institutes and centers of the National Insti-
8 tutes of Health, shall conduct, or make grants for
9 the conduct of, research related to the early detec-
10 tion and diagnosis of Alzheimer’s disease and of
11 mild cognitive impairment or other potential precu-
12 sors to Alzheimer’s disease.

13 “(2) EVALUATION.—The research described in
14 paragraph (1) may include the evaluation of diag-
15 nostic tests and imaging techniques.

16 “(c) VASCULAR DISEASE.—The Director of the Insti-
17 tute, in consultation with the directors of other relevant
18 institutes and centers of the National Institutes of Health,
19 shall, conduct or make grants for the conduct of, research
20 related to the relationship of vascular disease and Alz-
21 heimer’s disease, including clinical trials to determine
22 whether drugs developed to prevent cerebrovascular dis-
23 ease can prevent the onset or progression of Alzheimer’s
24 disease.

1 Health, conduct, or make grants for the conduct of, clin-
2 ical, social, and behavioral research related to interven-
3 tions designed to help caregivers of patients with Alz-
4 heimer’s disease and related disorders.”; and

5 (4) in subsection (d) by striking “(d) the Direc-
6 tor” and inserting “(c) MODEL CURRICULA AND
7 TECHNIQUES.—The Director”.

8 **SEC. 7. AUTHORIZATION OF APPROPRIATIONS.**

9 (a) IN GENERAL.—Section 445J of the Public Health
10 Service Act (42 U.S.C. 285e–11) is amended by striking
11 “\$500,000,000 for fiscal year 1994, and such sums as
12 may be necessary for each of the fiscal years 1995 and
13 1996.” and inserting “\$1,500,000,000 for fiscal year
14 2003, and such sums as may be necessary for each of the
15 fiscal years 2004 through 2007.”.

16 (b) AGING PROCESS REGARDING WOMEN.—Section
17 445H(b) of the Public Health Service Act (42 U.S.C.
18 285e–10(b)) is amended by striking “2003” and inserting
19 “2007”.

20 (c) CLINICAL RESEARCH AND TRAINING AWARDS.—
21 Section 445I(d) of the Public Health Service Act (42
22 U.S.C. 285e–10a(d)) is amended by striking “2005” and
23 inserting “2007”.

1 **SEC. 8. ALZHEIMER'S DISEASE DEMONSTRATION GRANTS.**

2 Section 398B(e) of the Public Health Service Act (42
3 U.S.C. 280e-5(e)) is amended—

4 (1) by striking “and such” and inserting
5 “such”; and

6 (2) by inserting before the period “,
7 \$25,000,000 for fiscal year 2003, and such sums as
8 may be necessary for each of the fiscal years 2004
9 through 2007”.

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