

118TH CONGRESS
1ST SESSION

S. _____

To direct the Secretary of Health and Human Services to carry out a national project to prevent and cure Parkinson's, to be known as the National Parkinson's Project, and for other purposes.

IN THE SENATE OF THE UNITED STATES

Mrs. CAPITO (for herself and Mr. MURPHY) introduced the following bill;
which was read twice and referred to the Committee on

A BILL

To direct the Secretary of Health and Human Services to carry out a national project to prevent and cure Parkinson's, to be known as the National Parkinson's Project, 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 “National Plan to End
5 Parkinson's Act”.

6 **SEC. 2. NATIONAL PARKINSON'S PROJECT.**

7 (a) DEFINITION OF PARKINSON'S.—In this section,
8 the term “Parkinson's” means—

1 (1) Parkinson’s disease; and

2 (2) other neurodegenerative Parkinsonisms, in-
3 cluding, but not limited to, multiple system atrophy,
4 Lewy body disease, corticobasal degeneration, pro-
5 gressive supranuclear palsy, and Parkinson’s-related
6 dementia.

7 (b) ESTABLISHMENT.—The Secretary of Health and
8 Human Services (in this section referred to as the “Sec-
9 retary”) shall carry out a national project to prevent and
10 cure Parkinson’s, ameliorate its symptoms, and slow or
11 stop its progression, to be known as the National Parkin-
12 son’s Project (referred to in this section as the “Project”).

13 (c) ACTIVITIES CARRIED OUT THROUGH PROJECT.—
14 In carrying out the Project, the Secretary shall—

15 (1) create, maintain, and periodically update an
16 integrated national plan to prevent and cure Parkin-
17 son’s, ameliorate its symptoms, and slow or stop its
18 progression;

19 (2) carry out the annual assessment under sub-
20 section (d);

21 (3) provide information (including an estimate
22 of the level of Federal investment necessary to pre-
23 vent and cure Parkinson’s, ameliorate its symptoms,
24 and slow or stop its progression), and coordination

1 of Parkinson's research and services, across all Fed-
2 eral agencies;

3 (4) encourage the development of safe and ef-
4 fective treatments, strategies, and other approaches
5 to prevent, halt, or slow the course of Parkinson's or
6 to enhance functioning and improve quality of life;

7 (5) promote the—

8 (A) early diagnosis of Parkinson's; and

9 (B) coordination of the care and treatment
10 of individuals with Parkinson's;

11 (6) review the impact of Parkinson's on the
12 physical, mental, and social health of those living
13 with Parkinson's and their care partners;

14 (7) coordinate with international bodies, to the
15 degree possible, to integrate and inform the global
16 mission to prevent and cure Parkinson's, ameliorate
17 its symptoms, and slow or stop its progression; and

18 (8) carry out other such activities as the Sec-
19 retary deems appropriate.

20 (d) ANNUAL ASSESSMENT.—Not later than 24
21 months after the date of enactment of this Act, and annu-
22 ally thereafter, the Secretary shall carry out an assess-
23 ment of the Nation's progress in preparing for and re-
24 sponding to the escalating burden of Parkinson's, includ-
25 ing—

1 (1) the formulation of recommendations for pri-
2 ority actions based on the assessment;

3 (2) a description of the steps that have been or
4 should be taken to implement the recommendations;
5 and

6 (3) such other items as the Secretary deems ap-
7 propriate.

8 (e) ADVISORY COUNCIL.—

9 (1) IN GENERAL.—The Secretary shall establish
10 and maintain an Advisory Council on Parkinson’s
11 Research, Care, and Services (referred to in this sec-
12 tion as the “Advisory Council”).

13 (2) MEMBERSHIP.—

14 (A) FEDERAL MEMBERS.—The Advisory
15 Council shall be comprised of diverse and inclu-
16 sive representatives from—

17 (i) the Centers for Disease Control
18 and Prevention;

19 (ii) the Administration on Community
20 Living;

21 (iii) the Centers for Medicare & Med-
22 icaid Services;

23 (iv) the Office of the Director of the
24 National Institutes of Health;

1 (v) the National Institute of Neuro-
2 logical Disorders and Stroke;

3 (vi) the National Institute of Environ-
4 mental Health Sciences;

5 (vii) the Department of Veterans Af-
6 fairs;

7 (viii) the Food and Drug Administra-
8 tion;

9 (ix) the Department of Defense;

10 (x) the Environmental Protection
11 Agency;

12 (xi) the Office of Minority Health;
13 and

14 (xii) other relevant Federal depart-
15 ments and agencies as determined by the
16 Secretary.

17 (B) NON-FEDERAL MEMBERS.—In addi-
18 tion to the members listed in subparagraph (A),
19 the Advisory Council shall include 10 expert
20 members from outside the Federal Government,
21 to be appointed by the Secretary, which mem-
22 bers shall include—

23 (i) 2 Parkinson's patient advocates, at
24 least 1 of whom is living with young-onset
25 Parkinson's;

- 1 (ii) 1 Parkinson's family caregiver;
2 (iii) 1 health care provider;
3 (iv) 2 biomedical researchers with
4 Parkinson's-related expertise in basic,
5 translational, clinical, or drug development
6 science;
7 (v) 1 movement disorder specialist
8 who treats Parkinson's patients;
9 (vi) 1 dementia specialist who treats
10 Parkinson's patients; and
11 (vii) 2 representatives from nonprofit
12 organizations that have demonstrated ex-
13 perience in Parkinson's research or Par-
14 kinson's patient care and other services.

15 (3) MEETINGS.—

16 (A) QUARTERLY MEETINGS.—The Advi-
17 sory Council shall meet at least once each quar-
18 ter.

19 (B) BIENNIAL RESEARCH MEETING.—Not
20 later than 24 months after the date of enact-
21 ment of this Act, and every 2 years thereafter,
22 the Advisory Council shall convene a meeting of
23 Federal and non-Federal organizations to dis-
24 cuss Parkinson's research.

1 (C) OPEN MEETINGS.—The meetings of
2 the Advisory Council shall be open to the pub-
3 lic.

4 (4) ADVICE.—The Advisory Council shall advise
5 the Secretary on Parkinson’s-related issues.

6 (5) BIENNIAL REPORT.—Not later than 18
7 months after the date of enactment of this Act, and
8 every 2 years thereafter, the Advisory Council shall
9 provide to the Secretary and Congress a report con-
10 taining—

11 (A) an evaluation of all federally funded ef-
12 forts in Parkinson’s research, prevention, clin-
13 ical care, and institutional-, home-, and commu-
14 nity-based programs and the outcomes of such
15 efforts;

16 (B) recommendations for priority actions
17 to expand, eliminate, coordinate, refocus, or
18 condense Federal programs based on each pro-
19 gram’s performance, mission, and purpose;

20 (C) recommendations to—

21 (i) reduce the financial impact of Par-
22 kinson’s on—

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

1 (II) families living with Parkin-
2 son's;

3 (ii) improve health outcomes and
4 quality of life;

5 (iii) prevent Parkinson's; and

6 (iv) research the association between
7 environmental triggers and Parkinson's to
8 help reduce exposure to potential triggers;
9 and

10 (D) an evaluation of the implementation,
11 including outcomes, of the national plan under
12 subsection (c)(1).

13 (6) TERMINATION.—The Advisory Council shall
14 terminate at the end of calendar year 2035.

15 (f) DATA SHARING.—Agencies both within the De-
16 partment of Health and Human Services and outside of
17 the Department that have data relating to Parkinson's
18 shall share such data with the Secretary of Health and
19 Human Services, or the Secretary's designee, consistent
20 with the statutory obligations regarding disclosure of in-
21 formation for that department or agency, to enable the
22 Secretary, or the Secretary's designee, to complete the re-
23 port described in subsection (g).

24 (g) BIENNIAL REPORT.—The Secretary shall submit
25 to the Congress—

1 (1) a Biannual report that includes an evalua-
2 tion of all federally funded efforts in Parkinson's re-
3 search, prevention, diagnosis, treatment, clinical
4 care, and institutional-, home-, and community-
5 based programs and the outcomes of such efforts;

6 (2) an evaluation of all such programs based on
7 performance, mission, and purpose;

8 (3) recommendations for—

9 (A) priority actions based on the evalua-
10 tion conducted by the Secretary and the Advi-
11 sory Council to—

12 (i) reduce the financial impact of Par-
13 kinson's on—

14 (I) the Medicare program and
15 other federally funded programs; and

16 (II) families living with Parkin-
17 son's disease;

18 (ii) improve health outcomes and
19 quality of life;

20 (iii) prevent Parkinson's; and

21 (iv) research the association between
22 environmental triggers and Parkinson's to
23 help reduce exposure to potential triggers;

24 (B) priority actions to improve all federally
25 funded efforts in Parkinson's research, preven-

1 tion, diagnosis, treatment, clinical care, and in-
2 stitutional-, home-, and community-based pro-
3 grams; and

4 (C) implementation steps to address pri-
5 ority actions described in subparagraphs (A)
6 and (B); and

7 (4) an up-to-date version of the national plan
8 under subsection (c)(1).

9 (h) SUNSET.—The section shall cease to be effective
10 at the end of calendar year 2035.