

117TH CONGRESS
2D SESSION

S. 4851

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

SEPTEMBER 14, 2022

Mrs. CAPITO (for herself, Mr. MURPHY, Ms. SMITH, and Mr. MARSHALL) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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) Parkinsonisms, including multiple system
3 atrophy, Lewy body disease, corticobasal degenera-
4 tion, progressive supranuclear palsy, and Parkin-
5 son’s-related dementia.

6 (b) ESTABLISHMENT.—The Secretary of Health and
7 Human Services (in this section referred to as the “Sec-
8 retary”) shall carry out a national project to prevent and
9 cure Parkinson’s, to be known as the National Parkinson’s
10 Project (referred to in this section as the “Project”).

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

13 (1) create, maintain, and periodically update an
14 integrated national plan to prevent and cure Parkin-
15 son’s;

16 (2) carry out the annual assessment under sub-
17 section (d);

18 (3) evaluate all Federal programs related to
19 Parkinson’s, including budget requests and approv-
20 als;

21 (4) provide information (including an estimate
22 of the level of Federal investment necessary to pre-
23 vent and cure Parkinson’s), and coordination of Par-
24 kinson’s research and services, across all Federal
25 agencies;

1 (5) accelerate the development of treatments
2 and other approaches to prevent, halt, or reverse the
3 course of, Parkinson's;

4 (6) improve the—

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

6 (B) coordination of the care and treatment
7 of individuals with Parkinson's;

8 (7) ensure the inclusion of populations at high-
9 er risk for Parkinson's—or least likely to receive a
10 diagnosis or care with respect to Parkinson's—in
11 clinical research, and implement service efforts to
12 decrease health disparities with respect to Parkin-
13 son's;

14 (8) review the impact of Parkinson's on the
15 physical, mental, and social health of those living
16 with Parkinson's and their care partners;

17 (9) review social determinants of health, diver-
18 sity, equity, and inclusion associated with Parkin-
19 son's; and

20 (10) coordinate with international bodies to in-
21 tegrate and inform the global mission to prevent and
22 cure Parkinson's.

23 (d) ANNUAL ASSESSMENT.—Not later than 24
24 months after the date of enactment of this Act, and annu-
25 ally thereafter, the Secretary shall carry out an assess-

1 ment of the Nation’s progress in preparing for and re-
 2 sponding to the escalating burden of Parkinson’s, includ-
 3 ing—

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

6 (2) a description of the steps that have been or
 7 should be taken to implement the recommendations;
 8 and

9 (3) such other items as the Secretary deems ap-
 10 propriate.

11 (e) ADVISORY COUNCIL.—

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

16 (2) MEMBERSHIP.—

17 (A) FEDERAL MEMBERS.—The Advisory
 18 Council shall be comprised of diverse and inclu-
 19 sive representatives from—

20 (i) the Centers for Disease Control
 21 and Prevention;

22 (ii) the Administration on Aging;

23 (iii) the Centers for Medicare & Med-
 24 icaid Services;

25 (iv) the Indian Health Service;

1 (v) the Office of the Director of the
2 National Institutes of Health;

3 (vi) the National Institute of Neuro-
4 logical Disorders and Stroke;

5 (vii) the National Institute of Envi-
6 ronmental Health Sciences;

7 (viii) the National Institute on Aging;

8 (ix) the National Science Foundation;

9 (x) the Department of Veterans Af-
10 fairs;

11 (xi) the Food and Drug Administra-
12 tion;

13 (xii) the Department of Defense;

14 (xiii) the Environmental Protection
15 Agency;

16 (xiv) the Office of Minority Health;
17 and

18 (xv) other relevant Federal depart-
19 ments and agencies as determined by the
20 Secretary.

21 (B) NON-FEDERAL MEMBERS.—In addi-
22 tion to the members listed in subparagraph (A),
23 the Advisory Council shall include 17 expert
24 members from outside the Federal Government,

to be appointed by the Secretary, which members shall include—

(i) 4 Parkinson’s patient advocates, one of whom is living with young-onset Parkinson’s;

(ii) 2 Parkinson’s family caregivers;

(iii) 2 health care providers;

(iv) 2 representatives of State health departments;

(v) 2 biomedical researchers with Parkinson’s-related expertise in basic, translational, clinical, or drug development science;

(vi) 1 movement disorder specialist who treats Parkinson’s patients;

(vii) 1 dementia specialist who treats Parkinson’s patients; and

(viii) 3 representatives, one from each of 3 nonprofit organizations that have demonstrated experience in Parkinson’s research or Parkinson’s patient care and other services.

(3) MEETINGS.—

1 (A) QUARTERLY MEETINGS.—The Advi-
2 sory Council shall meet at least once each quar-
3 ter.

4 (B) ANNUAL RESEARCH MEETING.—The
5 Advisory Council shall convene an annual meet-
6 ing of Federal and non-Federal organizations to
7 discuss Parkinson’s research.

8 (C) OPEN MEETINGS.—The meetings of
9 the Advisory Council shall be open to the pub-
10 lic.

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

13 (5) ANNUAL REPORT.—Not later than 18
14 months after the date of enactment of this Act and
15 annually thereafter, the Advisory Council shall pro-
16 vide to the Secretary and Congress a report con-
17 taining—

18 (A) an evaluation of all federally funded ef-
19 forts in Parkinson’s research, prevention, clin-
20 ical care, and institutional-, home-, and commu-
21 nity-based programs and the outcomes of such
22 efforts;

23 (B) recommendations for priority actions
24 to expand, eliminate, coordinate, refocus, or

1 condense Federal programs based on each pro-
 2 gram’s performance, mission, and purpose;

3 (C) recommendations to—

4 (i) reduce the financial impact of Par-
 5 kinson’s on—

6 (I) the Medicare program and
 7 other federally funded programs; and

8 (II) families living with Parkin-
 9 son’s;

10 (ii) improve health outcomes;

11 (iii) prevent Parkinson’s; and

12 (iv) eliminate exposure to environ-
 13 mental triggers of Parkinson’s; and

14 (D) an evaluation of the implementation,
 15 including outcomes, of the national plan under
 16 subsection (c)(1).

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

19 (f) DATA SHARING.—Agencies both within the De-
 20 partment of Health and Human Services and outside of
 21 the Department that have data relating to Parkinson’s
 22 shall share such data with the Secretary of Health and
 23 Human Services, or the Secretary’s designee, to enable the
 24 Secretary, or the Secretary’s designee, to complete the re-
 25 port described in subsection (g).

1 (g) ANNUAL REPORT.—The Secretary shall submit
2 to the Congress—

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

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

10 (3) recommendations for—

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

14 (i) reduce the financial impact of Par-
15 kinson’s on—

16 (I) the Medicare program and
17 other federally funded programs; and

18 (II) families living with Parkin-
19 son’s disease;

20 (ii) improve health outcomes;

21 (iii) prevent Parkinson’s; and

22 (iv) eliminate exposure to environ-
23 mental triggers of Parkinson’s;

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.

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