

118TH CONGRESS
1ST SESSION

H. R. 2365

IN THE SENATE OF THE UNITED STATES

DECEMBER 14, 2023

Received; read twice and referred to the Committee on Health, Education,
Labor, and Pensions

AN ACT

To direct the Secretary of Health and Human Services to carry out a national project to prevent, diagnose, treat, 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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Dr. Emmanuel Bili-
3 rakis and Honorable Jennifer Wexton National Plan to
4 End Parkinson’s Act”.

5 **SEC. 2. NATIONAL PARKINSON’S PROJECT.**

6 Title III of the Public Health Service Act (42 U.S.C.
7 241 et seq.) is amended by adding at the end:

8 **“PART W—PARKINSON’S AND RELATED**
9 **DISORDERS**

10 **“SEC. 39900. NATIONAL PARKINSON’S PROJECT.**

11 “(a) DEFINITION OF PARKINSON’S.—In this section,
12 the term ‘Parkinson’s’ means—

13 “(1) Parkinson’s disease; and

14 “(2) all other neurodegenerative Parkinsonisms,
15 including multiple system atrophy, corticobasal de-
16 generation, progressive supranuclear palsy, and Par-
17 kinson’s-related dementia.

18 “(b) ESTABLISHMENT.—The Secretary shall carry
19 out a national project, to be known as the National Par-
20 kinson’s Project (referred to in this section as the
21 ‘Project’), to prevent, diagnose, treat, and cure Parkin-
22 son’s.

23 “(c) ACTIVITIES CARRIED OUT THROUGH
24 PROJECT.—In carrying out the Project, the Secretary
25 shall—

1 “(1) create, maintain, and periodically update
2 an integrated national plan to prevent, diagnose,
3 treat, and cure Parkinson’s, ameliorate symptoms,
4 and slow or stop progression;

5 “(2) carry out the annual assessment under
6 subsection (d);

7 “(3) provide information, including—

8 “(A) an estimate of the level of current
9 Federal investment in preventing, diagnosing,
10 treating, and curing Parkinson’s, ameliorating
11 symptoms, and slowing or stopping progression;
12 and

13 “(B) if applicable, an estimate of the in-
14 vestment necessary to prevent, diagnose, treat,
15 and cure Parkinson’s, ameliorate symptoms,
16 and slow or stop progression;

17 “(4) coordinate research and services across all
18 Federal agencies related to Parkinson’s;

19 “(5) encourage the development of safe and ef-
20 fective treatments, strategies, and other approaches
21 to prevent, diagnose, treat, and cure Parkinson’s,
22 ameliorate symptoms, and slow or stop progression;

23 “(6) improve the—

24 “(A) early diagnosis of Parkinson’s; and

1 “(B) coordination of the care and treat-
2 ment of individuals with Parkinson’s;

3 “(7) review the impact of Parkinson’s on the
4 physical, mental, and social health of individuals liv-
5 ing with Parkinson’s and their caregivers and fami-
6 lies;

7 “(8) coordinate with international bodies, to the
8 extent possible, to integrate and inform the mission
9 to prevent, diagnose, treat, and cure Parkinson’s,
10 ameliorate symptoms, and slow or stop progression
11 globally; and

12 “(9) to the extent practicable, collaborate with
13 other entities to prevent duplication of existing re-
14 search activities for related disorders.

15 “(d) ANNUAL ASSESSMENT.—Not later than 24
16 months after the date of enactment of this section, and
17 annually thereafter, the Secretary shall carry out an as-
18 sessment of the Nation’s progress in preparing for, and
19 responding to, the escalating burden of Parkinson’s, in-
20 cluding—

21 “(1) recommendations for priority actions based
22 on the assessment;

23 “(2) a description of any steps that are planned
24 or have already been taken to implement such rec-

1 ommendations, including whether such recommenda-
2 tions can be implemented under existing law; and

3 “(3) such other items as the Secretary deter-
4 mines appropriate.

5 “(e) ADVISORY COUNCIL.—

6 “(1) IN GENERAL.—The Secretary shall estab-
7 lish and maintain an Advisory Council on Parkin-
8 son’s Research, Care, and Services (referred to in
9 this section as the ‘Advisory Council’) to advise the
10 Secretary on Parkinson’s-related issues.

11 “(2) MEMBERSHIP.—

12 “(A) FEDERAL MEMBERS.—The Advisory
13 Council shall be comprised of experts, to be ap-
14 pointed by the Secretary, who collectively are
15 from various backgrounds and perspectives, in-
16 cluding at least one member from each of—

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

19 “(ii) the Administration on Commu-
20 nity Living;

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

23 “(iv) the National Institutes of
24 Health;

1 “(v) the Agency for Healthcare Re-
2 search and Quality;

3 “(vi) the Department of Veterans Af-
4 fairs;

5 “(vii) the Food and Drug Administra-
6 tion;

7 “(viii) the National Science Founda-
8 tion;

9 “(ix) the Department of Defense;

10 “(x) the Environmental Protection
11 Agency;

12 “(xi) the Office of Minority Health;

13 “(xii) the Indian Health Service;

14 “(xiii) the Office of the Surgeon Gen-
15 eral of the Public Health Service; and

16 “(xiv) other relevant Federal depart-
17 ments and agencies as determined by the
18 Secretary.

19 “(B) NON-FEDERAL MEMBERS.—In addi-
20 tion to the members listed in subparagraph (A),
21 the Advisory Council shall include 10 expert
22 members, to be appointed by the Secretary, who
23 shall include representatives of minority com-
24 munities, communities disproportionately af-
25 fected by Parkinson’s, and communities under-

1 represented in Parkinson’s research, who shall
2 each be from outside the Federal Government,
3 and who shall include—

4 “(i) 2 Parkinson’s patient advocates,
5 at least 1 of whom is living with young-
6 onset Parkinson’s;

7 “(ii) 1 Parkinson’s family caregiver;

8 “(iii) 1 health care provider;

9 “(iv) 2 biomedical researchers with
10 Parkinson’s-related expertise in basic,
11 translational, clinical, or drug development
12 science;

13 “(v) 1 movement disorder specialist
14 who treats Parkinson’s patients;

15 “(vi) 1 dementia specialist who treats
16 Parkinson’s patients; and

17 “(vii) 2 representatives from nonprofit
18 organizations that have demonstrated ex-
19 perience in Parkinson’s-related research or
20 Parkinson’s-related patient care and other
21 services.

22 “(C) REPRESENTATION.—The Secretary
23 shall ensure that the members of the Advisory
24 Council are collectively representative of agen-
25 cies, professions, individuals, and entities con-

1 cerned with, or affected by, activities under this
2 section.

3 “(3) MEETINGS.—

4 “(A) FREQUENCY.—The Advisory Council
5 shall meet—

6 “(i) at least once each quarter during
7 the 2-year period beginning on the date on
8 which the Advisory Council is established;
9 and

10 “(ii) at the Secretary’s discretion
11 after such period.

12 “(B) ANNUAL RESEARCH MEETING.—Not
13 later than 24 months after the date of enact-
14 ment of this section, and every year thereafter,
15 the Advisory Council shall convene a meeting of
16 Federal and non-Federal organizations to dis-
17 cuss Parkinson’s research.

18 “(C) OPEN MEETINGS.—The meetings
19 under subparagraphs (A) and (B) shall be open
20 to the public.

21 “(4) ANNUAL REPORT.—Not later than 18
22 months after the date of enactment of this section,
23 and every year thereafter, the Advisory Council shall
24 provide to the Secretary and Congress a report con-
25 taining—

1 “(A) a list of all federally-funded efforts in
2 Parkinson’s research, prevention, diagnosis,
3 treatment, clinical care, and institutional-,
4 home-, and community-based programs and the
5 outcomes of such efforts;

6 “(B) recommendations for priority actions
7 to expand, eliminate, coordinate, refocus,
8 streamline, or condense Federal programs based
9 on each program’s performance, mission, scope,
10 and purpose;

11 “(C) recommendations to—

12 “(i) reduce the financial impact of
13 Parkinson’s on families living with Parkin-
14 son’s;

15 “(ii) improve health outcomes for, and
16 the quality of life of, individuals living with
17 Parkinson’s;

18 “(iii) prevent Parkinson’s, ameliorate
19 symptoms, and slow or stop progression;

20 “(iv) improve the quality of care pro-
21 vided to beneficiaries with Parkinson’s who
22 receive coverage through a federally-funded
23 health care program, such as the Medicare
24 program under title XVIII of the Social

1 Security Act or the Medicaid program
2 under title XIX of such Act;

3 “(v) research the association between
4 environmental triggers and Parkinson’s to
5 help reduce exposure to potential triggers;
6 and

7 “(vi) research and better understand
8 the underlying factors contributing to Par-
9 kinson’s;

10 “(D) priority actions to improve all feder-
11 ally-funded efforts in Parkinson’s research, pre-
12 vention, diagnosis, treatment, clinical care, and
13 institutional-, home-, and community-based pro-
14 grams;

15 “(E) an evaluation of the implementation,
16 including outcomes, of the national plan under
17 subsection (c)(1); and

18 “(F) implementation steps to address the
19 recommendations and priority actions under
20 subparagraphs (B), (C), and (D), based in part
21 on the evaluation under subparagraph (E).

22 “(5) TERMINATION.—The Advisory Council
23 shall terminate at the end of calendar year 2035.

24 “(f) INFORMATION SHARING.—Each Federal depart-
25 ment and agency that has information relating to Parkin-

1 son’s shall share such information with the Secretary con-
2 sistent with the statutory obligations of such department
3 or agency regarding disclosure of information, as nec-
4 essary to enable the Secretary to complete a report under
5 subsection (e)(4).

6 “(g) SUNSET.—The section shall cease to be effective
7 at the end of calendar year 2035.”.

Passed the House of Representatives December 14,
2023.

Attest: KEVIN F. MCCUMBER,
Clerk.