

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 2365
OFFERED BY MR. BILIRAKIS OF FLORIDA**

Strike all after the enacting clause and insert the following:

1 SECTION 1. SHORT TITLE.

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

4 SEC. 2. NATIONAL PARKINSON’S PROJECT.

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

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

9 “SEC. 3990O. NATIONAL PARKINSON’S PROJECT.

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

12 “(1) Parkinson’s disease; and

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

17 “(b) ESTABLISHMENT.—The Secretary shall carry
18 out a national project, to be known as the National Par-

1 kinson's Project (referred to in this section as the
2 'Project'), to prevent, diagnose, treat, and cure Parkin-
3 son's.

4 “(c) ACTIVITIES CARRIED OUT THROUGH
5 PROJECT.—In carrying out the Project, the Secretary
6 shall—

7 “(1) create, maintain, and periodically update
8 an integrated national plan to prevent, diagnose,
9 treat, and cure Parkinson's, ameliorate symptoms,
10 and slow or stop progression;

11 “(2) carry out the annual assessment under
12 subsection (d);

13 “(3) provide information, including—

14 “(A) an estimate of the level of current
15 Federal investment in preventing, diagnosing,
16 treating, and curing Parkinson's, ameliorating
17 symptoms, and slowing or stopping progression;
18 and

19 “(B) if applicable, an estimate of the in-
20 vestment necessary to prevent, diagnose, treat,
21 and cure Parkinson's, ameliorate symptoms,
22 and slow or stop progression;

23 “(4) coordinate research and services across all
24 Federal agencies related to Parkinson's;

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

5 “(6) improve the—

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

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

9 “(7) review the impact of Parkinson’s on the
10 physical, mental, and social health of individuals liv-
11 ing with Parkinson’s and their caregivers and fami-
12 lies;

13 “(8) coordinate with international bodies, to the
14 extent possible, to integrate and inform the mission
15 to prevent, diagnose, treat, and cure Parkinson’s,
16 ameliorate symptoms, and slow or stop progression
17 globally; and

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

21 “(d) ANNUAL ASSESSMENT.—Not later than 24
22 months after the date of enactment of this section, and
23 annually thereafter, the Secretary shall carry out an as-
24 sessment of the Nation’s progress in preparing for, and

1 responding to, the escalating burden of Parkinson's, in-
2 cluding—

3 “(1) recommendations for priority actions based
4 on the assessment;

5 “(2) a description of any steps that are planned
6 or have already been taken to implement such rec-
7 ommendations, including whether such recommenda-
8 tions can be implemented under existing law; and

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

11 “(e) ADVISORY COUNCIL.—

12 “(1) IN GENERAL.—The Secretary shall estab-
13 lish and maintain an Advisory Council on Parkin-
14 son's Research, Care, and Services (referred to in
15 this section as the 'Advisory Council') to advise the
16 Secretary on Parkinson's-related issues.

17 “(2) MEMBERSHIP.—

18 “(A) FEDERAL MEMBERS.—The Advisory
19 Council shall be comprised of experts, to be ap-
20 pointed by the Secretary, who collectively are
21 from various backgrounds and perspectives, in-
22 cluding at least one member from each of—

23 “(i) the Centers for Disease Control
24 and Prevention;

1 “(ii) the Administration on Commu-
2 nity Living;

3 “(iii) the Centers for Medicare & Med-
4 icaid Services;

5 “(iv) the National Institutes of
6 Health;

7 “(v) the Agency for Healthcare Re-
8 search and Quality;

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

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

13 “(viii) the National Science Founda-
14 tion;

15 “(ix) the Department of Defense;

16 “(x) the Environmental Protection
17 Agency;

18 “(xi) the Office of Minority Health;

19 “(xii) the Indian Health Service;

20 “(xiii) the Surgeon General of the
21 Public Health Service; and

22 “(xiv) other relevant Federal depart-
23 ments and agencies as determined by the
24 Secretary.

1 “(B) NON-FEDERAL MEMBERS.—In addi-
2 tion to the members listed in subparagraph (A),
3 the Advisory Council shall include 10 expert
4 members, to be appointed by the Secretary, who
5 shall include representatives of minority com-
6 munities, communities disproportionately af-
7 fected by Parkinson’s, and communities under-
8 represented in Parkinson’s research, who shall
9 each be from outside the Federal Government,
10 and who shall include—

11 “(i) 2 Parkinson’s patient advocates,
12 at least 1 of whom is living with young-
13 onset Parkinson’s;

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

15 “(iii) 1 health care provider;

16 “(iv) 2 biomedical researchers with
17 Parkinson’s-related expertise in basic,
18 translational, clinical, or drug development
19 science;

20 “(v) 1 movement disorder specialist
21 who treats Parkinson’s patients;

22 “(vi) 1 dementia specialist who treats
23 Parkinson’s patients; and

24 “(vii) 2 representatives from nonprofit
25 organizations that have demonstrated ex-

1 perience in Parkinson’s-related research or
2 Parkinson’s-related patient care and other
3 services.

4 “(C) REPRESENTATION.—The Secretary
5 shall ensure that the members of the Advisory
6 Council are collectively representative of agen-
7 cies, professions, individuals, and entities con-
8 cerned with, or affected by, activities under this
9 section.

10 “(3) MEETINGS.—

11 “(A) FREQUENCY.—The Advisory Council
12 shall meet—

13 “(i) at least once each quarter during
14 the 2-year period beginning on the date on
15 which the Advisory Council is established;
16 and

17 “(ii) at the Secretary’s discretion
18 after such period.

19 “(B) ANNUAL RESEARCH MEETING.—Not
20 later than 24 months after the date of enact-
21 ment of this section, and every year 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
2 under subparagraphs (A) and (B) shall be open
3 to the public.

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

9 “(A) a list of all federally-funded efforts in
10 Parkinson’s research, prevention, diagnosis,
11 treatment, clinical care, and institutional-,
12 home-, and community-based programs and the
13 outcomes of such efforts;

14 “(B) recommendations for priority actions
15 to expand, eliminate, coordinate, refocus,
16 streamline, or condense Federal programs based
17 on each program’s performance, mission, scope,
18 and purpose;

19 “(C) recommendations to—

20 “(i) reduce the financial impact of
21 Parkinson’s on families living with Parkin-
22 son’s;

23 “(ii) improve health outcomes for, and
24 the quality of life of, individuals living with
25 Parkinson’s;

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

3 “(iv) improve the quality of care pro-
4 vided to beneficiaries with Parkinson’s who
5 receive coverage through a federally-funded
6 health care program, such as the Medicare
7 program under title XVIII of the Social
8 Security Act or the Medicaid program
9 under title XIX of such Act;

10 “(v) research the association between
11 environmental triggers and Parkinson’s to
12 help reduce exposure to potential triggers;
13 and

14 “(vi) research and better understand
15 the underlying factors contributing to Par-
16 kinson’s;

17 “(D) priority actions to improve all feder-
18 ally-funded efforts in Parkinson’s research, pre-
19 vention, diagnosis, treatment, clinical care, and
20 institutional-, home-, and community-based pro-
21 grams;

22 “(E) an evaluation of the implementation,
23 including outcomes, of the national plan under
24 subsection (c)(1); and

1 “(F) implementation steps to address the
2 recommendations and priority actions under
3 subparagraphs (B), (C), and (D), based in part
4 on the evaluation under subparagraph (E).

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

7 “(f) INFORMATION SHARING.—Each Federal depart-
8 ment and agency that has information relating to Parkin-
9 son’s shall share such information with the Secretary con-
10 sistent with the statutory obligations of such department
11 or agency regarding disclosure of information, as nec-
12 essary to enable the Secretary to complete a report under
13 subsection (e)(4).

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

Amend the title so as to read: “A bill 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.”.

