

**Suspend the Rules And Pass the Bill, H.R. 2365, with Amendments**

**(The amendments strike all after the enacting clause and insert a new text and a new title)**

118<sup>TH</sup> CONGRESS  
1<sup>ST</sup> SESSION

# H. R. 2365

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.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 29, 2023

Mr. BILIRAKIS (for himself, Mr. TONKO, Mrs. HARSHBARGER, Ms. SCHAKOWSKY, Mr. FITZPATRICK, Ms. KUSTER, Mrs. KIM of California, Ms. BARRAGÁN, Mr. VALADAO, and Mr. HIGGINS of New York) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## 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,*

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. 3990O. 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.”.

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.”.