

Union Calendar No. 253

118TH CONGRESS
1ST SESSION

H. R. 2365

[Report No. 118–313]

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 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

DECEMBER 12, 2023

Additional sponsors: Ms. BONAMICI, Mrs. TRAHAN, Mr. QUIGLEY, Mr. CARBAJAL, Mrs. BICE, Ms. MATSUI, Mr. NORCROSS, Ms. LOIS FRANKEL of Florida, Ms. CHU, Mr. GRIJALVA, Ms. DEAN of Pennsylvania, Mr. SCOTT FRANKLIN of Florida, Mr. SMITH of Washington, Mr. GOMEZ, Mr. SWALWELL, Mr. PAPPAS, Ms. WEXTON, Mr. BACON, Mr. NADLER, Mrs. NAPOLITANO, Mr. KIM of New Jersey, Ms. SEWELL, Mrs. DINGELL, Mr. EVANS, Mr. GARCÍA of Illinois, Mr. CONNOLLY, Ms. NORTON, Mr. MORELLE, Mrs. CHERFILUS-McCORMICK, Mr. CORREA, Mr. KILMER, Ms. DELBENE, Mr. SCHNEIDER, Ms. PORTER, Mr. SMUCKER, Mr. MCGOVERN, Ms. MACE, Mr. MOONEY, Mr. DAVIS of North Carolina, Mr. RUTHERFORD, Mr. CÁRDENAS, Ms. TITUS, Mr. MULLIN, Mr. CAREY, Mr. JOHNSON of Georgia, Ms. BLUNT ROCHESTER, Mr. VAN DREW, Mr. FLEISCHMANN, Ms. MALLIOTAKIS, Mrs. PELTOLA, Ms. WILD, Mr. BURCHETT, Mr. GRAVES of Louisiana, Mr. LUETKEMEYER, Mr. LAHOOD, Mr. RASKIN, Mr. PANETTA, Mr. LYNCH, Mr. EDWARDS, Mr. HIMES, Ms. CLARKE of New York, Mr. WILSON of South Carolina, Mr. DUNN of Florida, Mrs. HOUCHIN, Ms. CRAIG, Mr. LIEU, Mr. PETERS, Mrs. MILLER of West Virginia, Mr. TIMMONS, Mr. NEGUSE, Mr. CRENSHAW, Mrs. FLETCHER, Mr. ALLRED, Mr. FROST, Mr. PASCRELL, Ms. SHERRILL, Ms. MENG, Ms. LEE of Nevada, Mrs. SYKES, Mr. COSTA, Mr.

TURNER, Mr. MCGARVEY, Mr. AUSTIN SCOTT of Georgia, Ms. HOYLE of Oregon, Mr. LANDSMAN, Ms. TLAIB, Mr. STANTON, Mr. GOTTHEIMER, Mr. SHERMAN, Mr. WALBERG, Mr. EZELL, Mr. BLUMENAUER, Ms. LEE of California, Mr. KILDEE, Ms. SCANLON, Mr. LEVIN, Mr. BALDERSON, Ms. CARAVEO, Ms. SALINAS, Mr. LARSEN of Washington, Mr. MAGAZINER, Mr. TRONE, Mr. CLEAVER, Ms. BROWNLEY, Ms. LEGER FERNANDEZ, Mr. VEASEY, Mr. GARAMENDI, Mr. THOMPSON of Pennsylvania, Mr. JACKSON of North Carolina, Mr. LATURNER, Ms. HOULAHAN, Mr. HUIZENGA, Mr. CARL, Mr. MENENDEZ, Mr. MANN, Mr. MOOLENAAR, Ms. PETERSEN, Ms. MCCLELLAN, Ms. PEREZ, Mr. CROW, Ms. DAVIDS of Kansas, Ms. STRICKLAND, Ms. STEVENS, Ms. ADAMS, Mr. TAKANO, Ms. LOFGREN, Ms. SLOTKIN, Mr. BEAN of Florida, Mr. CISCOMANI, Mr. CASTRO of Texas, Ms. MANNING, Mr. FINSTAD, Mrs. SPARTZ, Ms. HAGEMAN, Mr. KELLY of Pennsylvania, Mr. LAWLER, Mr. GARBARINO, Mr. PENCE, Mr. LAMALFA, Mr. KUSTOFF, Mr. MEEKS, Ms. MOORE of Wisconsin, Mr. SCOTT of Virginia, Mr. KRISHNAMOORTHY, Mr. BOWMAN, Ms. OMAR, Ms. DE LA CRUZ, Ms. STANSBURY, Ms. ESCOBAR, Ms. CROCKETT, Ms. TOKUDA, Mr. JOHNSON of Ohio, Mr. CASTEN, Ms. SALAZAR, Mrs. STEEL, Mr. MRVAN, Mr. LANGWORTHY, Mr. KEAN of New Jersey, Mr. ROUZER, Mr. POCAN, Mr. MCCAUL, Mrs. CAMMACK, and Mr. RYAN

DECEMBER 12, 2023

Reported with amendments, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italic*]

[For text of introduced bill, see copy of bill as introduced on March 29, 2023]

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 “(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 sub-
6 section (d);

7 “(3) provide information, including—

8 “(A) an estimate of the level of current Fed-
9 eral investment in preventing, diagnosing, treat-
10 ing, and curing Parkinson’s, ameliorating symp-
11 toms, and slowing or stopping progression; and

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

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

18 “(5) encourage the development of safe and effec-
19 tive treatments, strategies, and other approaches to
20 prevent, diagnose, treat, and cure Parkinson’s, ame-
21 liorate symptoms, and slow or stop progression;

22 “(6) improve the—

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

24 “(B) coordination of the care and treatment
25 of individuals with Parkinson’s;

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

5 “(8) coordinate with international bodies, to the
6 extent possible, to integrate and inform the mission to
7 prevent, diagnose, treat, and cure Parkinson’s, ame-
8 liorate symptoms, and slow or stop progression glob-
9 ally; and

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

13 “(d) ANNUAL ASSESSMENT.—Not later than 24
14 months after the date of enactment of this section, and an-
15 nually thereafter, the Secretary shall carry out an assess-
16 ment of the Nation’s progress in preparing for, and re-
17 sponding to, the escalating burden of Parkinson’s, includ-
18 ing—

19 “(1) recommendations for priority actions based
20 on the assessment;

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

1 “(3) *such other items as the Secretary determines*
2 *appropriate.*

3 “(e) *ADVISORY COUNCIL.—*

4 “(1) *IN GENERAL.—The Secretary shall establish*
5 *and maintain an Advisory Council on Parkinson’s*
6 *Research, Care, and Services (referred to in this sec-*
7 *tion as the ‘Advisory Council’) to advise the Secretary*
8 *on Parkinson’s-related issues.*

9 “(2) *MEMBERSHIP.—*

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

15 “(i) *the Centers for Disease Control*
16 *and Prevention;*

17 “(ii) *the Administration on Commu-*
18 *nity Living;*

19 “(iii) *the Centers for Medicare & Med-*
20 *icaid Services;*

21 “(iv) *the National Institutes of Health;*

22 “(v) *the Agency for Healthcare Re-*
23 *search and Quality;*

24 “(vi) *the Department of Veterans Af-*
25 *airs;*

1 “(vii) the Food and Drug Administra-
2 tion;

3 “(viii) the National Science Founda-
4 tion;

5 “(ix) the Department of Defense;

6 “(x) the Environmental Protection
7 Agency;

8 “(xi) the Office of Minority Health;

9 “(xii) the Indian Health Service;

10 “(xiii) the Surgeon General of the Pub-
11 lic Health Service; and

12 “(xiv) other relevant Federal depart-
13 ments and agencies as determined by the
14 Secretary.

15 “(B) NON-FEDERAL MEMBERS.—In addi-
16 tion to the members listed in subparagraph (A),
17 the Advisory Council shall include 10 expert
18 members, to be appointed by the Secretary, who
19 shall include representatives of minority commu-
20 nities, communities disproportionately affected
21 by Parkinson’s, and communities underrep-
22 resented in Parkinson’s research, who shall each
23 be from outside the Federal Government, and
24 who shall include—

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

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

5 “(iii) 1 health care provider;

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

10 “(v) 1 movement disorder specialist
11 who treats Parkinson’s patients;

12 “(vi) 1 dementia specialist who treats
13 Parkinson’s patients; and

14 “(vii) 2 representatives from nonprofit
15 organizations that have demonstrated expe-
16 rience in Parkinson’s-related research or
17 Parkinson’s-related patient care and other
18 services.

19 “(C) REPRESENTATION.—The Secretary
20 shall ensure that the members of the Advisory
21 Council are collectively representative of agen-
22 cies, professions, individuals, and entities con-
23 cerned with, or affected by, activities under this
24 section.

25 “(3) MEETINGS.—

1 “(A) *FREQUENCY.*—*The Advisory Council*
2 *shall meet—*

3 “(i) *at least once each quarter during*
4 *the 2-year period beginning on the date on*
5 *which the Advisory Council is established;*
6 *and*

7 “(ii) *at the Secretary’s discretion after*
8 *such period.*

9 “(B) *ANNUAL RESEARCH MEETING.*—*Not*
10 *later than 24 months after the date of enactment*
11 *of this section, and every year thereafter, the Ad-*
12 *visory Council shall convene a meeting of Fed-*
13 *eral and non-Federal organizations to discuss*
14 *Parkinson’s research.*

15 “(C) *OPEN MEETINGS.*—*The meetings under*
16 *subparagraphs (A) and (B) shall be open to the*
17 *public.*

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

23 “(A) *a list of all federally-funded efforts in*
24 *Parkinson’s research, prevention, diagnosis,*
25 *treatment, clinical care, and institutional-,*

1 *home-, and community-based programs and the*
2 *outcomes of such efforts;*

3 “(B) *recommendations for priority actions*
4 *to expand, eliminate, coordinate, refocus, stream-*
5 *line, or condense Federal programs based on each*
6 *program’s performance, mission, scope, and pur-*
7 *pose;*

8 “(C) *recommendations to—*

9 “(i) *reduce the financial impact of*
10 *Parkinson’s on families living with Parkin-*
11 *son’s;*

12 “(ii) *improve health outcomes for, and*
13 *the quality of life of, individuals living with*
14 *Parkinson’s;*

15 “(iii) *prevent Parkinson’s, ameliorate*
16 *symptoms, and slow or stop progression;*

17 “(iv) *improve the quality of care pro-*
18 *vided to beneficiaries with Parkinson’s who*
19 *receive coverage through a federally-funded*
20 *health care program, such as the Medicare*
21 *program under title XVIII of the Social Se-*
22 *curity Act or the Medicaid program under*
23 *title XIX of such Act;*

24 “(v) *research the association between*
25 *environmental triggers and Parkinson’s to*

1 *help reduce exposure to potential triggers;*
2 *and*

3 “(vi) *research and better understand*
4 *the underlying factors contributing to Par-*
5 *kinson’s;*

6 “(D) *priority actions to improve all feder-*
7 *ally-funded efforts in Parkinson’s research, pre-*
8 *vention, diagnosis, treatment, clinical care, and*
9 *institutional-, home-, and community-based pro-*
10 *grams;*

11 “(E) *an evaluation of the implementation,*
12 *including outcomes, of the national plan under*
13 *subsection (c)(1); and*

14 “(F) *implementation steps to address the*
15 *recommendations and priority actions under*
16 *subparagraphs (B), (C), and (D), based in part*
17 *on the evaluation under subparagraph (E).*

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

20 “(f) *INFORMATION SHARING.—Each Federal depart-*
21 *ment and agency that has information relating to Parkin-*
22 *son’s shall share such information with the Secretary con-*
23 *sistent with the statutory obligations of such department*
24 *or agency regarding disclosure of information, as necessary*

1 *to enable the Secretary to complete a report under sub-*
2 *section (e)(4).*

3 “(g) *SUNSET.—The section shall cease to be effective*
4 *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.”.

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