

DR. EMMANUEL BILIRAKIS NATIONAL PLAN TO END  
PARKINSON'S ACT

DECEMBER 12, 2023.—Committed to the Committee of the Whole House on the State  
of the Union and ordered to be printed

Mrs. RODGERS of Washington, from the Committee on Energy and  
Commerce, submitted the following

R E P O R T

[To accompany H.R. 2365]

The Committee on Energy and Commerce, to whom was referred the bill (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, having considered the same, reports favorably thereon with amendments and recommends that the bill as amended do pass.

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The amendments are as follows:

Strike all after the enacting clause and insert the following:

**SECTION 1. SHORT TITLE.**

This Act may be cited as the “Dr. Emmanuel Bilirakis National Plan to End Parkinson’s Act”.

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

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

**“PART W—PARKINSON’S AND RELATED DISORDERS****“SEC. 39900. NATIONAL PARKINSON’S PROJECT.**

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

“(1) Parkinson’s disease; and

“(2) all other neurodegenerative Parkinsonisms, including multiple system atrophy, corticobasal degeneration, progressive supranuclear palsy, and Parkinson’s-related dementia.

“(b) ESTABLISHMENT.—The Secretary shall carry out a national project, to be known as the National Parkinson’s Project (referred to in this section as the ‘Project’), to prevent, diagnose, treat, and cure Parkinson’s.

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

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

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

“(3) provide information, including—

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

“(B) if applicable, an estimate of the investment necessary to prevent, diagnose, treat, and cure Parkinson’s, ameliorate symptoms, and slow or stop progression;

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

“(5) encourage the development of safe and effective treatments, strategies, and other approaches to prevent, diagnose, treat, and cure Parkinson’s, ameliorate symptoms, and slow or stop progression;

“(6) improve the—

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

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

“(7) review the impact of Parkinson’s on the physical, mental, and social health of individuals living with Parkinson’s and their caregivers and families;

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

“(9) to the extent practicable, collaborate with other entities to prevent duplication of existing research activities for related disorders.

“(d) ANNUAL ASSESSMENT.—Not later than 24 months after the date of enactment of this section, and annually thereafter, the Secretary shall carry out an assessment of the Nation’s progress in preparing for, and responding to, the escalating burden of Parkinson’s, including—

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

“(2) a description of any steps that are planned or have already been taken to implement such recommendations, including whether such recommendations can be implemented under existing law; and

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

“(e) ADVISORY COUNCIL.—

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

“(2) MEMBERSHIP.—

“(A) FEDERAL MEMBERS.—The Advisory Council shall be comprised of experts, to be appointed by the Secretary, who collectively are from various backgrounds and perspectives, including at least one member from each of—

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

“(ii) the Administration on Community Living;

- “(iii) the Centers for Medicare & Medicaid Services;
- “(iv) the National Institutes of Health;
- “(v) the Agency for Healthcare Research and Quality;
- “(vi) the Department of Veterans Affairs;
- “(vii) the Food and Drug Administration;
- “(viii) the National Science Foundation;
- “(ix) the Department of Defense;
- “(x) the Environmental Protection Agency;
- “(xi) the Office of Minority Health;
- “(xii) the Indian Health Service;
- “(xiii) the Surgeon General of the Public Health Service; and
- “(xiv) other relevant Federal departments and agencies as determined by the Secretary.

“(B) NON-FEDERAL MEMBERS.—In addition to the members listed in subparagraph (A), the Advisory Council shall include 10 expert members, to be appointed by the Secretary, who shall include representatives of minority communities, communities disproportionately affected by Parkinson’s, and communities underrepresented in Parkinson’s research, who shall each be from outside the Federal Government, and who shall include—

- “(i) 2 Parkinson’s patient advocates, at least 1 of whom is living with young-onset Parkinson’s;
- “(ii) 1 Parkinson’s family caregiver;
- “(iii) 1 health care provider;
- “(iv) 2 biomedical researchers with Parkinson’s-related expertise in basic, translational, clinical, or drug development science;
- “(v) 1 movement disorder specialist who treats Parkinson’s patients;
- “(vi) 1 dementia specialist who treats Parkinson’s patients; and
- “(vii) 2 representatives from nonprofit organizations that have demonstrated experience in Parkinson’s-related research or Parkinson’s-related patient care and other services.

“(C) REPRESENTATION.—The Secretary shall ensure that the members of the Advisory Council are collectively representative of agencies, professions, individuals, and entities concerned with, or affected by, activities under this section.

“(3) MEETINGS.—

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

- “(i) at least once each quarter during the 2-year period beginning on the date on which the Advisory Council is established; and
- “(ii) at the Secretary’s discretion after such period.

“(B) ANNUAL RESEARCH MEETING.—Not later than 24 months after the date of enactment of this section, and every year thereafter, the Advisory Council shall convene a meeting of Federal and non-Federal organizations to discuss Parkinson’s research.

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

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

- “(A) a list of all federally-funded efforts in Parkinson’s research, prevention, diagnosis, treatment, clinical care, and institutional-, home-, and community-based programs and the outcomes of such efforts;
- “(B) recommendations for priority actions to expand, eliminate, coordinate, refocus, streamline, or condense Federal programs based on each program’s performance, mission, scope, and purpose;
- “(C) recommendations to—

- “(i) reduce the financial impact of Parkinson’s on families living with Parkinson’s;
- “(ii) improve health outcomes for, and the quality of life of, individuals living with Parkinson’s;
- “(iii) prevent Parkinson’s, ameliorate symptoms, and slow or stop progression;
- “(iv) improve the quality of care provided to beneficiaries with Parkinson’s who receive coverage through a federally-funded health care program, such as the Medicare program under title XVIII of the Social Security Act or the Medicaid program under title XIX of such Act;
- “(v) research the association between environmental triggers and Parkinson’s to help reduce exposure to potential triggers; and
- “(vi) research and better understand the underlying factors contributing to Parkinson’s;

“(D) priority actions to improve all federally-funded efforts in Parkinson’s research, prevention, diagnosis, treatment, clinical care, and institutional-, home-, and community-based programs;

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

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

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

“(f) INFORMATION SHARING.—Each Federal department and agency that has information relating to Parkinson’s shall share such information with the Secretary consistent with the statutory obligations of such department or agency regarding disclosure of information, as necessary to enable the Secretary to complete a report under subsection (e)(4).

“(g) SUNSET.—The section shall cease to be effective 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.

#### PURPOSE AND SUMMARY

H.R. 2365 requires the Department of Health and Human Services (HHS) to carry out a national project to prevent, diagnose, treat, and cure Parkinson’s disease and other neurodegenerative Parkinsonisms and related diseases, to be known as the National Parkinson’s Project. In carrying out the project, the Secretary must provide an annual assessment of the nation’s progress in preparing for and responding to the increased burden of Parkinson’s; provide information, facilitate collaboration, and encourage development of innovative approaches to prevent, diagnose, treat, and cure Parkinson’s and related diseases; and coordinate and avoid duplication of related research activities across involved entities; among other things. The bill also establishes an Advisory Council, comprised of federal and nonfederal stakeholders, to advise HHS on Parkinson’s-related issues, including providing an annual report outlining current activities, recommendations, and priority actions to improve efforts related to the prevention, diagnosis, treatment, and curing of Parkinson’s and related diseases. The provisions of the bill terminate at the end of calendar year 2035.

#### BACKGROUND AND NEED FOR LEGISLATION

It is estimated that Parkinson’s disease affects nearly 1 million people in the United States and more than 6 million people worldwide. It is the second most common neurological disease globally with nearly 90,000 new cases diagnosed every year. The cause of Parkinson’s remains largely unknown. While there is no cure, treatment options vary and include medications, lifestyle adjustments, and surgery.

The estimated total cost of Parkinson’s disease to individuals, families, and the United States government is estimated to be about \$51.9 billion every year, with \$25.4 billion attributable to direct medical costs (e.g., hospitalizations, medication) and \$26.5 billion in non-medical costs like missed work, lost wages, early forced retirement, and family caregiver time. According to a recent study,

the federal government spends nearly \$25 billion annually in caring for people with Parkinson's. About \$2 billion of that is shouldered by Social Security, and the remaining \$23 billion is in Medicare costs.

H.R. 2365 would establish a National Plan to streamline and coordinate efforts to prevent, diagnose, treat, and cure Parkinson's and encourage development of innovative approaches for treatments and cures.

#### COMMITTEE ACTION

On June 14, 2023, the Subcommittee on Health held a hearing on H.R. 2365. The title of the hearing was "Examining Proposals that Provide Access to Care for Patients and Support Research for Rare Diseases." The Subcommittee received testimony from:

- Dr. Elizabeth Cherot, MD, MBA, Senior Vice President and Chief Medical Health Officer, March of Dimes;
  - Dr. Alexis A. Thompson, MD, MPH, Chief of Division of Hematology, Elias Schwartz MD Endowed Chair in Hematology, Children's Hospital of Philadelphia, Professor of Pediatrics, University of Pennsylvania Perelman School of Medicine;
  - Dr. Meredith McNamara, MD, MS, FAAP, Assistant Professor, Yale School of Medicine;
  - Dr. Miriam Grossman, MD, Child, Adolescent, and Adult Psychiatrist;
  - Mr. George Manahan, Parkinson's Advocate and Patient;
- and,
- Mr. Kevin O'Connor, Assistant to the General President for Government Affairs and Political Action, International Association of Fire Fighters.

On July 13, 2023, the Subcommittee on Health met in open markup session and forwarded H.R. 2365, without amendment, to the full Committee by a voice vote. On December 5 and 6, 2023, the full Committee on Energy and Commerce met in open markup session and ordered H.R. 2365, as amended, favorably reported to the House by a record vote of 47 yeas and 0 nays.

#### COMMITTEE VOTES

Clause 3(b) of rule XIII requires the Committee to list the record votes on the motion to report legislation and amendments thereto. The following reflects the record votes taken during the Committee consideration:

**COMMITTEE ON ENERGY AND COMMERCE  
118TH CONGRESS  
ROLL CALL VOTE #41**

**BILL:** H.R. 2365, National Plan to End Parkinson's Act

**AMENDMENT:** A motion by Chair Rodgers to order H.R. 2365 favorably reported to the House, as amended (Final Passage).

**DISPOSITION: AGREED TO**, by a roll call vote of 47 yeas to 0 nays.

REPRESENTATIVE	YEAS	NAYS	PRESENT	REPRESENTATIVE	YEAS	NAYS	PRESENT
Rep. Rodgers	X			Rep. Pallone	X		
Rep. Burgess	X			Rep. Eshoo	X		
Rep. Latta	X			Rep. DeGette	X		
Rep. Guthrie	X			Rep. Schakowsky	X		
Rep. Griffith	X			Rep. Matsui			
Rep. Bilirakis	X			Rep. Castor	X		
Rep. Johnson	X			Rep. Sarbanes	X		
Rep. Bucshon	X			Rep. Tonko	X		
Rep. Hudson	X			Rep. Clarke	X		
Rep. Walberg	X			Rep. Cárdenas	X		
Rep. Carter	X			Rep. Ruiz	X		
Rep. Duncan	X			Rep. Peters	X		
Rep. Palmer	X			Rep. Dingell			
Rep. Dunn				Rep. Veasey	X		
Rep. Curtis	X			Rep. Kuster	X		
Rep. Lesko	X			Rep. Kelly	X		
Rep. Pence	X			Rep. Barragán	X		
Rep. Crenshaw	X			Rep. Blunt Rochester	X		
Rep. Joyce	X			Rep. Soto	X		
Rep. Armstrong	X			Rep. Craig			
Rep. Weber	X			Rep. Schrier	X		
Rep. Allen	X			Rep. Trahan	X		
Rep. Balderson	X			Rep. Fletcher			
Rep. Fulcher	X						
Rep. Pfluger	X						
Rep. Harshbarger	X						
Rep. Miller-Meeks	X						
Rep. Cammack	X						
Rep. Obernolte	X						

#### OVERSIGHT FINDINGS AND RECOMMENDATIONS

Pursuant to clause 2(b)(1) of rule X and clause 3(c)(1) of rule XIII, the Committee held a hearing and made findings that are reflected in this report.

#### NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Pursuant to clause 3(c)(2) of rule XIII, the Committee finds that H.R. 2365 would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

#### CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII, at the time this report was filed, the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974 was not available.

#### FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

#### STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to prevent, diagnose, treat, and cure Parkinson's disease and other neurodegenerative Parkinsonisms and related diseases.

#### DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 2365 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111-139 or the most recent Catalog of Federal Domestic Assistance.

#### RELATED COMMITTEE AND SUBCOMMITTEE HEARINGS

Pursuant to clause 3(c)(6) of rule XIII, the following related hearing was used to develop or consider H.R. 2365:

- On June 14, 2023, the Subcommittee on Health held a hearing on H.R. 2365. The title of the hearing was "Examining Proposals that Provide Access to Care for Patients and Support Research for Rare Diseases." The Subcommittee received testimony from:
  - Dr. Elizabeth Cherot, MD, MBA, Senior Vice President and Chief Medical Health Officer, March of Dimes;
  - Dr. Alexis A. Thompson, MD, MPH, Chief of Division of Hematology, Elias Schwartz MD Endowed Chair in Hematology, Children's Hospital of Philadelphia, Professor of Pediatrics, University of Pennsylvania Perelman School of Medicine;
  - Dr. Meredith McNamara, MD, MS, FAAP, Assistant Professor, Yale School of Medicine;

- Dr. Miriam Grossman, MD, Child, Adolescent, and Adult Psychiatrist;
- Mr. George Manahan, Parkinson’s Advocate and Patient; and,
- Mr. Kevin O’Connor, Assistant to the General President for Government Affairs and Political Action, International Association of Fire Fighters.

#### COMMITTEE COST ESTIMATE

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974. At the time this report was filed, the estimate was not available.

#### EARMARK, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 2365 contains no earmarks, limited tax benefits, or limited tariff benefits.

#### ADVISORY COMMITTEE STATEMENT

Pursuant to section 5(b) of the Federal Advisory Committee Act (FACA), the Committee finds that new subsection 39900(e) of the Public Health Service Act, as provided in section 2 of H.R. 2365, does establish or authorize the establishment of an advisory committee as defined in section 3(2) of FACA. The Committee does not find that the functions of the proposed advisory committee are being or could be performed by one or more agencies or by an advisory committee already in existence, or by enlarging the mandate of an existing advisory committee.

#### APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

#### SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

##### *Section 1. Short title*

Section 1 provides that the Act may be cited as the “Dr. Emmanuel Bilirakis National Plan to End Parkinson’s Act”.

##### *Section 2. National Parkinson’s Project*

Section 2 would add a new section (“sec. 39900. National Parkinson’s Project”) to the Public Health Service Act directing the Secretary of the Department of Health and Human Services (HHS) to carry out the National Parkinson’s Project.

Section 2 would define the term “Parkinson’s” to mean (1) Parkinson’s disease; and (2) all other neurodegenerative Parkinsonisms, including multiple system atrophy, corticobasal degeneration, progressive supranuclear palsy, and Parkinson’s-related dementia.”



New subsection (c) would direct the Secretary to (1) create, maintain, and update an integrated national plan to prevent, diagnose, treat, and cure Parkinson's, ameliorate symptoms, and slow or stop progression; (2) carry out an annual assessment; (3) provide specified information; (4) coordinate Parkinson's related research and services across all Federal agencies; (5) encourage the development of safe and effective treatments, strategies, and other approaches to prevent, diagnose, treat, and cure Parkinson's, ameliorate symptoms, and slow or stop progression; (6) improve both the early diagnosis of Parkinson's and coordination of the care and treatment of individuals with Parkinson's; (7) review the impact of Parkinson's on the physical, mental, and social health of individuals living with Parkinson's and their caregivers and families; (8) to the extent possible—coordinate with international bodies to integrate and inform the mission to prevent, diagnose, treat, and cure Parkinson's, ameliorate symptoms, and slow or stop progression globally; and (9) to the extent practicable—collaborate with other entities to prevent duplication of existing research activities for related disorders.

New subsection (d) describes the annual assessment that the Secretary must carry out within 24 months of the date of enactment and annually thereafter. This shall include an assessment of the Nation's progress in preparing for and responding to the escalating burden of Parkinson's, including (1) recommendations for priority actions, and (2) a description of steps planned or already taken to implement such recommendations—including whether such recommendation can be implemented under existing law.

The Committee anticipates that the Secretary will provide to the Committee on Energy and Commerce a copy of the assessment—both electronically and in paper format—promptly upon completion of the assessment and subsequent assessments.

New subsection (e) would direct the Secretary to establish and maintain an Advisory Council on Parkinson's Research, Care, and Services to advise the Secretary on Parkinson's-related issues. The Advisory Council shall be comprised of federal and non-federal stakeholders, and shall convene meetings as specified. The Advisory Council shall provide regular reports, as specified, including current activities, recommendations, priority actions, and implementation steps to improve efforts related to the prevention, diagnosis, treatment, and curing of Parkinson's and related diseases. The Advisory Council shall terminate at the end of calendar year 2035.

New subsection (f) would direct each Federal department and agency that has information relating to Parkinson's to share such information with the Secretary consistent with the statutory obligations of such department or agency regarding disclosure of information, as necessary to enable the Secretary to complete the required annual report to Congress.

New subsection (g) provides that this new section of the Public Health Service Act, regarding the "National Parkinson's Project" shall cease to be effective at the end of calendar year 2035.

#### CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (new matter is printed in italics)

and existing law in which no change is proposed is shown in roman):

**PUBLIC HEALTH SERVICE ACT**

\* \* \* \* \*

**TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE**

\* \* \* \* \*

**PART W—PARKINSON’S AND RELATED DISORDERS**

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

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

- (1) *Parkinson’s disease; and*
- (2) *all other neurodegenerative Parkinsonisms, including multiple system atrophy, corticobasal degeneration, progressive supranuclear palsy, and Parkinson’s-related dementia.*

(b) *ESTABLISHMENT.*—*The Secretary shall carry out a national project, to be known as the National Parkinson’s Project (referred to in this section as the “Project”), to prevent, diagnose, treat, and cure Parkinson’s.*

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

- (1) *create, maintain, and periodically update an integrated national plan to prevent, diagnose, treat, and cure Parkinson’s, ameliorate symptoms, and slow or stop progression;*
- (2) *carry out the annual assessment under subsection (d);*
- (3) *provide information, including—*
  - (A) *an estimate of the level of current Federal investment in preventing, diagnosing, treating, and curing Parkinson’s, ameliorating symptoms, and slowing or stopping progression; and*
  - (B) *if applicable, an estimate of the investment necessary to prevent, diagnose, treat, and cure Parkinson’s, ameliorate symptoms, and slow or stop progression;*
- (4) *coordinate research and services across all Federal agencies related to Parkinson’s;*
- (5) *encourage the development of safe and effective treatments, strategies, and other approaches to prevent, diagnose, treat, and cure Parkinson’s, ameliorate symptoms, and slow or stop progression;*
- (6) *improve the—*
  - (A) *early diagnosis of Parkinson’s; and*
  - (B) *coordination of the care and treatment of individuals with Parkinson’s;*
- (7) *review the impact of Parkinson’s on the physical, mental, and social health of individuals living with Parkinson’s and their caregivers and families;*
- (8) *coordinate with international bodies, to the extent possible, to integrate and inform the mission to prevent, diagnose,*

*treat, and cure Parkinson's, ameliorate symptoms, and slow or stop progression globally; and*

*(9) to the extent practicable, collaborate with other entities to prevent duplication of existing research activities for related disorders.*

*(d) ANNUAL ASSESSMENT.—Not later than 24 months after the date of enactment of this section, and annually thereafter, the Secretary shall carry out an assessment of the Nation's progress in preparing for, and responding to, the escalating burden of Parkinson's, including—*

*(1) recommendations for priority actions based on the assessment;*

*(2) a description of any steps that are planned or have already been taken to implement such recommendations, including whether such recommendations can be implemented under existing law; and*

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

*(e) ADVISORY COUNCIL.—*

*(1) IN GENERAL.—The Secretary shall establish and maintain an Advisory Council on Parkinson's Research, Care, and Services (referred to in this section as the "Advisory Council") to advise the Secretary on Parkinson's-related issues.*

*(2) MEMBERSHIP.—*

*(A) FEDERAL MEMBERS.—The Advisory Council shall be comprised of experts, to be appointed by the Secretary, who collectively are from various backgrounds and perspectives, including at least one member from each of—*

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

*(ii) the Administration on Community Living;*

*(iii) the Centers for Medicare & Medicaid Services;*

*(iv) the National Institutes of Health;*

*(v) the Agency for Healthcare Research and Quality;*

*(vi) the Department of Veterans Affairs;*

*(vii) the Food and Drug Administration;*

*(viii) the National Science Foundation;*

*(ix) the Department of Defense;*

*(x) the Environmental Protection Agency;*

*(xi) the Office of Minority Health;*

*(xii) the Indian Health Service;*

*(xiii) the Surgeon General of the Public Health Service; and*

*(xiv) other relevant Federal departments and agencies as determined by the Secretary.*

*(B) NON-FEDERAL MEMBERS.—In addition to the members listed in subparagraph (A), the Advisory Council shall include 10 expert members, to be appointed by the Secretary, who shall include representatives of minority communities, communities disproportionately affected by Parkinson's, and communities underrepresented in Parkinson's research, who shall each be from outside the Federal Government, and who shall include—*

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

*(ii) 1 Parkinson's family caregiver;*

*(iii) 1 health care provider;*

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

(v) 1 movement disorder specialist who treats Parkinson's patients;

(vi) 1 dementia specialist who treats Parkinson's patients; and

(vii) 2 representatives from nonprofit organizations that have demonstrated experience in Parkinson's-related research or Parkinson's-related patient care and other services.

(C) REPRESENTATION.—The Secretary shall ensure that the members of the Advisory Council are collectively representative of agencies, professions, individuals, and entities concerned with, or affected by, activities under this section.

(3) MEETINGS.—

(A) FREQUENCY.—The Advisory Council shall meet—

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

(ii) at the Secretary's discretion after such period.

(B) ANNUAL RESEARCH MEETING.—Not later than 24 months after the date of enactment of this section, and every year thereafter, the Advisory Council shall convene a meeting of Federal and non-Federal organizations to discuss Parkinson's research.

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

(4) ANNUAL REPORT.—Not later than 18 months after the date of enactment of this section, and every year thereafter, the Advisory Council shall provide to the Secretary and Congress a report containing—

(A) a list of all federally-funded efforts in Parkinson's research, prevention, diagnosis, treatment, clinical care, and institutional-, home-, and community-based programs and the outcomes of such efforts;

(B) recommendations for priority actions to expand, eliminate, coordinate, refocus, streamline, or condense Federal programs based on each program's performance, mission, scope, and purpose;

(C) recommendations to—

(i) reduce the financial impact of Parkinson's on families living with Parkinson's;

(ii) improve health outcomes for, and the quality of life of, individuals living with Parkinson's;

(iii) prevent Parkinson's, ameliorate symptoms, and slow or stop progression;

(iv) improve the quality of care provided to beneficiaries with Parkinson's who receive coverage through a federally-funded health care program, such as the Medicare program under title XVIII of the Social Security Act or the Medicaid program under title XIX of such Act;

(v) research the association between environmental triggers and Parkinson's to help reduce exposure to potential triggers; and

(vi) research and better understand the underlying factors contributing to Parkinson's;

(D) priority actions to improve all federally-funded efforts in Parkinson's research, prevention, diagnosis, treatment, clinical care, and institutional-, home-, and community-based programs;

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

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

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

(f) INFORMATION SHARING.—Each Federal department and agency that has information relating to Parkinson's shall share such information with the Secretary consistent with the statutory obligations of such department or agency regarding disclosure of information, as necessary to enable the Secretary to complete a report under subsection (e)(4).

(g) SUNSET.—The section shall cease to be effective at the end of calendar year 2035.S6602

\* \* \* \* \*

