Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act

[Public Law 118–66]

[This law has not been amended]

[Currency: This publication is a compilation of the text of Public Law 118–66. It was last amended by the public law listed in the As Amended Through note above and below at the bottom of each page of the pdf version and reflects current law through the date of the enactment of the public law listed at https://www.govinfo.gov/app/collection/comps/]

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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. [42 U.S.C. 201 note] SHORT TITLE.

This Act may be cited as the "Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton 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. 399OO. [42 U.S.C. 280n] 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 Office of 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.”.