

ALZHEIMER’S ACCOUNTABILITY AND INVESTMENT ACT

MAY 31, 2024.—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. 620]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 620) to require an annual budget estimate for the initiatives of the National Institutes of Health pursuant to reports and recommendations made under the National Alzheimer’s Project Act, having considered the same, reports favorably thereon without amendment and recommends that the bill do pass.

CONTENTS

|                                                                         |           |
|-------------------------------------------------------------------------|-----------|
| Purpose and Summary .....                                               | Page<br>1 |
| Background and Need for Legislation .....                               | 2         |
| Committee Action .....                                                  | 2         |
| Committee Votes .....                                                   | 2         |
| Oversight Findings and Recommendations .....                            | 4         |
| New Budget Authority, Entitlement Authority, and Tax Expenditures ..... | 4         |
| Congressional Budget Office Estimate .....                              | 4         |
| Federal Mandates Statement .....                                        | 4         |
| Statement of General Performance Goals and Objectives .....             | 4         |
| Duplication of Federal Programs .....                                   | 4         |
| Related Committee and Subcommittee Hearings .....                       | 4         |
| Committee Cost Estimate .....                                           | 5         |
| Earmark, Limited Tax Benefits, and Limited Tariff Benefits .....        | 5         |
| Advisory Committee Statement .....                                      | 5         |
| Applicability to Legislative Branch .....                               | 5         |
| Section-by-Section Analysis of the Legislation .....                    | 5         |
| Changes in Existing Law Made by the Bill, as Reported .....             | 5         |

PURPOSE AND SUMMARY

H.R. 620 requires the National Institutes of Health (NIH) to continue to submit an annual professional judgement budget estimate to Congress to achieve the initiatives and goals included in the National Plan to Address Alzheimer’s Disease.

## BACKGROUND AND NEED FOR LEGISLATION

In 2023, providing care for people with Alzheimer’s disease cost Medicare and Medicaid an estimated \$222 billion.<sup>1</sup> Currently, Medicare is spending 1 in every 7 dollars on services for beneficiaries with Alzheimer’s disease. This spending is projected to increase to \$644 billion in 2050.<sup>2</sup> Continued investment in researching prevention and treatment of Alzheimer’s disease and dementia will improve the quality of life for millions of Americans and could lead to significant long-term financial savings. This bill helps ensure that Congress can effectively assess funding of Alzheimer’s research in relation to the goals of the National Alzheimer’s Project Act.

## COMMITTEE ACTION

On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 620. The title of the hearing was “Legislative Proposals to Support Patients and Caregivers.” The Subcommittee received testimony from:

- Andy Shih, PhD, Chief Science Officer, Autism Speaks;
- Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes’ Foundation;
- Joanne Pike, DrPH, President and CEO, Alzheimer’s Association;
- Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;
- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

On March 12, 2024, the Subcommittee on Health met in open markup session and forwarded H.R. 620, without amendment, to the full Committee by a record vote of 26 yeas and 0 nays.

On March 20, 2024, the full Committee on Energy and Commerce met in open markup session and ordered H.R. 620, without amendment, favorably reported to the House by a record vote of 43 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:

<sup>1</sup>Alzheimer’s Association, “Fact Sheet: NAPA Reauthorization Act & Alzheimer’s Accountability and Investment Act”, 2023. <https://alzimpact.org/sites/default/files/2023-03/NAPA%20Reauthorization%20Act%20and%20the%20Alzheimer%27s%20Accountability%20and%20Investment%20Act%20282%29.pdf>.

<sup>2</sup>*Id.*

**COMMITTEE ON ENERGY AND COMMERCE  
118TH CONGRESS  
ROLL CALL VOTE # 6**

**BILL:** H.R. 620, Alzheimer's Accountability and Investment Act

**AMENDMENT:** A motion by Chair Rodgers to order H.R. 620 favorably reported to the House, without amendment (Final Passage)

**DISPOSITION:** AGREED TO, by a roll call vote of 43 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          | X    |      |         |
| Rep. Bilirakis    | X    |      |         | Rep. Castor          | X    |      |         |
| Rep. Bucshon      | X    |      |         | Rep. Sarbanes        | X    |      |         |
| Rep. Hudson       |      |      |         | Rep. Tonko           | X    |      |         |
| Rep. Walberg      | X    |      |         | Rep. Clarke          | X    |      |         |
| Rep. Carter       | X    |      |         | Rep. Cárdenas        | X    |      |         |
| Rep. Duncan       | X    |      |         | Rep. Ruiz            | X    |      |         |
| Rep. Palmer       | X    |      |         | Rep. Peters          | X    |      |         |
| Rep. Dunn         | X    |      |         | Rep. Dingell         | X    |      |         |
| Rep. Curtis       |      |      |         | Rep. Veasey          | X    |      |         |
| Rep. Lesko        | X    |      |         | Rep. Kuster          |      |      |         |
| Rep. Pence        | X    |      |         | Rep. Kelly           |      |      |         |
| Rep. Crenshaw     |      |      |         | Rep. Barragán        | X    |      |         |
| Rep. Joyce        | X    |      |         | Rep. Blunt Rochester |      |      |         |
| Rep. Armstrong    | X    |      |         | Rep. Soto            | X    |      |         |
| Rep. Weber        |      |      |         | Rep. Craig           | X    |      |         |
| Rep. Allen        | X    |      |         | Rep. Schrier         | X    |      |         |
| Rep. Balderson    | X    |      |         | Rep. Trahan          | X    |      |         |
| Rep. Fulcher      | X    |      |         | Rep. Fletcher        | X    |      |         |
| Rep. Pfluger      | X    |      |         |                      |      |      |         |
| Rep. Harshbarger  | X    |      |         |                      |      |      |         |
| Rep. Miller-Meeks |      |      |         |                      |      |      |         |
| Rep. Cammack      | X    |      |         |                      |      |      |         |
| Rep. Obermole     | X    |      |         |                      |      |      |         |
|                   |      |      |         |                      |      |      |         |

03/20/2024

#### 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. 620 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 promote effective coordination and planning for the continued investment in Alzheimer's disease and dementia research.

#### DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 620 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. 620:

- On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 620. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:
  - Andy Shih, PhD, Chief Science Officer, Autism Speaks;
  - Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
  - Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
  - Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein Col-

lege of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;

- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

#### 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. 620 contains no earmarks, limited tax benefits, or limited tariff benefits.

#### ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

#### 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 “Alzheimer’s Accountability and Investment Act”.

##### *Section 2. Extension of project*

Section 2 requires the Director of the National Institutes of Health to prepare and submit an annual professional judgement budget estimate for the reports and recommendations made under the National Alzheimer’s Project Act.

#### 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 (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics, and existing law in which no change is proposed is shown in roman):

## NATIONAL ALZHEIMER'S PROJECT ACT

\* \* \* \* \*

### SEC. 2. THE NATIONAL ALZHEIMER'S PROJECT.

(a) **DEFINITION OF ALZHEIMER'S.**—In this Act, the term “Alzheimer's” means Alzheimer's disease and related dementias.

(b) **ESTABLISHMENT.**—There is established in the Office of the Secretary of Health and Human Services the National Alzheimer's Project (referred to in this Act as the “Project”).

(c) **PURPOSE OF THE PROJECT.**—The Secretary of Health and Human Services, or the Secretary's designee, shall—

(1) be responsible for the creation and maintenance of an integrated national plan to overcome Alzheimer's;

(2) provide information and coordination of Alzheimer's research and services across all Federal agencies;

(3) accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's;

(4) improve the—

(A) early diagnosis of Alzheimer's disease; and

(B) coordination of the care and treatment of citizens with Alzheimer's;

(5) ensure the inclusion of ethnic and racial populations at higher risk for Alzheimer's or least likely to receive care, in clinical, research, and service efforts with the purpose of decreasing health disparities in Alzheimer's; and

(6) coordinate with international bodies to integrate and inform the fight against Alzheimer's globally.

(d) **DUTIES OF THE SECRETARY.**—

(1) **IN GENERAL.**—The Secretary of Health and Human Services, or the Secretary's designee, shall—

(A) oversee the creation and updating of the national plan described in paragraph (2); and

(B) use discretionary authority to evaluate all Federal programs around Alzheimer's, including budget requests and approvals.

(2) **NATIONAL PLAN.**—The Secretary of Health and Human Services, or the Secretary's designee, shall carry out an annual assessment of the Nation's progress in preparing for the escalating burden of Alzheimer's, including both implementation steps and recommendations for priority actions based on the assessment.

(e) **ADVISORY COUNCIL.**—

(1) **IN GENERAL.**—There is established an Advisory Council on Alzheimer's Research, Care, and Services (referred to in this Act as the “Advisory Council”).

(2) **MEMBERSHIP.**—

(A) **FEDERAL MEMBERS.**—The Advisory Council shall be comprised of the following experts:

(i) A designee of the Centers for Disease Control and Prevention.

(ii) A designee of the Administration on Aging.

(iii) A designee of the Centers for Medicare & Medicaid Services.

(iv) A designee of the Indian Health Service.

(v) A designee of the Office of the Director of the National Institutes of Health.

(vi) The Surgeon General.

(vii) A designee of the National Science Foundation.

(viii) A designee of the Department of Veterans Affairs.

(ix) A designee of the Food and Drug Administration.

(x) A designee of the Agency for Healthcare Research and Quality.

(B) NON-FEDERAL MEMBERS.—In addition to the members outlined in subparagraph (A), the Advisory Council shall include 12 expert members from outside the Federal Government, which shall include—

(i) 2 Alzheimer’s patient advocates;

(ii) 2 Alzheimer’s caregivers;

(iii) 2 health care providers;

(iv) 2 representatives of State health departments;

(v) 2 researchers with Alzheimer’s-related expertise in basic, translational, clinical, or drug development science; and

(vi) 2 voluntary health association representatives, including a national Alzheimer’s disease organization that has demonstrated experience in research, care, and patient services, and a State-based advocacy organization that provides services to families and professionals, including information and referral, support groups, care consultation, education, and safety services.

(3) MEETINGS.—The Advisory Council shall meet quarterly and such meetings shall be open to the public.

(4) ADVICE.—The Advisory Council shall advise the Secretary of Health and Human Services, or the Secretary’s designee.

(5) ANNUAL REPORT.—The Advisory Council shall provide to the Secretary of Health and Human Services, or the Secretary’s designee and Congress—

(A) an initial evaluation of all federally funded efforts in Alzheimer’s research, clinical care, and institutional-, home-, and community-based programs and their outcomes;

(B) initial recommendations for priority actions to expand, eliminate, coordinate, or condense programs based on the program’s performance, mission, and purpose;

(C) initial recommendations to—

(i) reduce the financial impact of Alzheimer’s on—

(I) Medicare and other federally funded programs; and

(II) families living with Alzheimer’s disease; and

(ii) improve health outcomes; and

(D) annually thereafter, an evaluation of the implementation, including outcomes, of the recommendations, including priorities if necessary, through an updated national plan under subsection (d)(2).

(6) TERMINATION.—The Advisory Council shall terminate on December 31, 2025.

(f) DATA SHARING.—Agencies both within the Department of Health and Human Services and outside of the Department that have data relating to Alzheimer’s shall share such data with the Secretary of Health and Human Services, or the Secretary’s designee, to enable the Secretary, or the Secretary’s designee, to complete the report described in subsection (g).

(g) ANNUAL REPORT.—The Secretary of Health and Human Services, or the Secretary’s designee, shall submit to Congress—

(1) an annual report that includes an evaluation of all federally funded efforts in Alzheimer’s research, clinical care, and institutional-, home-, and community-based programs and their outcomes;

(2) an evaluation of all federally funded programs based on program performance, mission, and purpose related to Alzheimer’s disease;

(3) recommendations for—

(A) priority actions based on the evaluation conducted by the Secretary and the Advisory Council to—

(i) reduce the financial impact of Alzheimer’s on—

(I) Medicare and other federally funded programs; and

(II) families living with Alzheimer’s disease; and

(ii) improve health outcomes;

(B) implementation steps; and

(C) priority actions to improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based programs of Alzheimer’s disease for individuals with Alzheimer’s disease and their caregivers; and

(4) an annually updated national plan.

(h) PROFESSIONAL JUDGMENT BUDGET.—*For fiscal year 2024 and each subsequent fiscal year, the Director of the National Institutes of Health shall prepare and submit, directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary of Health and Human Services and the Advisory Council, an annual budget estimate for the initiatives of the National Institutes of Health pursuant to the reports and recommendations made under this Act, including an estimate of the number and type of personnel needs for the National Institutes of Health.*

[(h)] (i) SUNSET.—The Project shall expire on December 31, 2025.