

118TH CONGRESS
2D SESSION

S. 4964

To provide for a comprehensive Federal response to Long COVID, including research, education, and support for affected individuals, to direct the National Institutes of Health to establish a Long COVID research program, and for other purposes.

IN THE SENATE OF THE UNITED STATES

AUGUST 1, 2024

Mr. SANDERS (for himself, Ms. DUCKWORTH, Mr. KAINÉ, Mr. MARKEY, Ms. SMITH, and Mr. WELCH) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To provide for a comprehensive Federal response to Long COVID, including research, education, and support for affected individuals, to direct the National Institutes of Health to establish a Long COVID research program, 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,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Long COVID Research
5 Moonshot Act”.

1 **TITLE I—LONG COVID**
2 **BIOMEDICAL RESEARCH**

3 **SEC. 101. ESTABLISHMENT OF LONG COVID RESEARCH**
4 **PROGRAM.**

5 Title IV of the Public Health Service Act (42 U.S.C.
6 281 et seq.) is amended by adding at the end the fol-
7 lowing:

8 **PART K—LONG COVID PROGRAMS**

9
10 **“SEC. 499B. ESTABLISHMENT OF LONG COVID RESEARCH**
11 **PROGRAM.**

12 “(a) IN GENERAL.—There is established within the
13 Office of the Director of the National Institutes of Health
14 a research program, to be known as the Long COVID Re-
15 search Program (referred to in this part as the ‘Pro-
16 gram’), for purposes of expediting research to identify new
17 ways to prevent, detect, manage, and treat symptoms as-
18 sociated with Long COVID.

19 “(b) DIRECTOR.—

20 “(1) APPOINTMENT.—

21 “(A) IN GENERAL.—The Program shall be
22 headed by a Director, appointed by the Sec-
23 retary, in consultation with the Director of
24 NIH, who has—

1 “(i) experience managing clinical or
2 research programs focused on pathogenic
3 mechanisms and biological pathways re-
4 lated to Long COVID; and

5 “(ii) demonstrated commitment to ad-
6 dressing Long COVID and other infection-
7 associated chronic conditions, such as
8 myalgic encephalomyelitis/chronic fatigue
9 syndrome, postural orthostatic tachycardia
10 syndrome, and post-treatment Lyme dis-
11 ease syndrome/persistent Lyme disease.

12 “(B) CONSULTATION.—In appointing the
13 Director under subparagraph (A), the Secretary
14 shall consult with independent, patient-led orga-
15 nizations or advocacy groups representing Long
16 COVID patients and their families.

17 “(2) RESPONSIBILITIES.—The Director of the
18 Program shall—

19 “(A) act as the primary Federal official
20 with responsibility for coordinating all Long
21 COVID research conducted or supported by the
22 National Institutes of Health;

23 “(B) represent the National Institutes of
24 Health Long COVID Research Program at all

1 relevant Executive branch task force meetings
2 and committees; and

3 “(C) maintain communication with all rel-
4 evant Federal departments and agencies to en-
5 sure the timely transmission of information con-
6 cerning advances in Long COVID research and
7 the clinical treatment of Long COVID and
8 other infection-associated chronic conditions be-
9 tween such departments and agencies, and for
10 dissemination to affected communities and
11 health care providers.

12 “(c) ACTIVITIES.—The Program shall—

13 “(1) investigate the etiology, pathophysiology,
14 risk factors, and pathology of Long COVID in
15 adults and children;

16 “(2) explore the best ways to prevent, detect,
17 monitor, manage, and treat Long COVID in adults
18 and children;

19 “(3) contribute knowledge to the under-
20 standing, prevention, mitigation, management, and
21 treatment of Long COVID;

22 “(4) develop and facilitate programs on Long
23 COVID, within the National Institutes of Health
24 and in other settings;

1 “(5) conduct comparative research to under-
2 stand the similarities and differences between Long
3 COVID and other infection-associated chronic condi-
4 tions with similar phenotypes, such as myalgic
5 encephalomyelitis/chronic fatigue syndrome, postural
6 orthostatic tachycardia syndrome, and post-treat-
7 ment Lyme disease syndrome/persistent Lyme dis-
8 ease, and how activities funded by the Program
9 could improve understanding of such other condi-
10 tions; and

11 “(6) conduct comparative research to under-
12 stand the similarities and differences between Long
13 COVID and severe, long-term effects from COVID-
14 19 vaccinations.

15 “(d) DUTIES.—

16 “(1) INTERAGENCY COORDINATION OF LONG
17 COVID ACTIVITIES.—The Director of the Program
18 shall coordinate with the national research institutes
19 and national centers, as appropriate, on Long
20 COVID research. In carrying out this paragraph,
21 the Director of the Program shall evaluate the Long
22 COVID activities of each such institute or center
23 and shall provide for the periodic reevaluation of
24 such activities.

1 “(2) CONSULTATION.—The Director of the Pro-
2 gram shall carry out all duties, including the devel-
3 opment of the research plan under section 499B–1
4 in consultation with the heads of the national re-
5 search institutes and national centers, with the advi-
6 sory councils of such institutes and centers, and with
7 the Long COVID Research Program Advisory Board
8 established under section 499B–4.

9 “(e) NON-DUPLICATION OF EFFORT.—The Director
10 shall ensure that activities carried out under this section
11 do not unnecessarily duplicate the efforts of other Federal
12 departments or agencies.

13 **“SEC. 499B–1. LONG COVID RESEARCH PLAN.**

14 “(a) IN GENERAL.—Not later than 1 year after the
15 date of enactment of the Long COVID Research Moonshot
16 Act, the Director of the Program established under section
17 499B shall develop and make public a comprehensive re-
18 search plan for the conduct and support of all Long
19 COVID research activities of the national research insti-
20 tutes and national centers. The Director of the Program
21 shall update such plan annually.

22 “(b) CONTENTS.—The research plan developed under
23 subsection (a) shall—

24 “(1) identify current Long COVID research
25 conducted or supported by the national research in-

1 stitutes and national centers, opportunities and
2 needs for additional research, including among pa-
3 tients who face the highest disease burden and pedi-
4 atric patients, and priorities for such research;

5 “(2) evaluate the progress of Long COVID re-
6 search against strategic priorities, goals, and objec-
7 tives, identified in previous versions of the research
8 plan;

9 “(3) make recommendations for the coordina-
10 tion of such research conducted or supported by the
11 National Institutes of Health and other agencies of
12 the Federal Government; and

13 “(4) include goals and objectives of the Pro-
14 gram for conducting, supporting, and coordinating
15 Long COVID research.

16 “(c) REQUIREMENTS.—In developing the research
17 plan under subsection (a), the Director of the Program
18 shall—

19 “(1) ensure that the plan establishes priorities
20 among Long COVID research that the Program is
21 authorized to carry out;

22 “(2) ensure that the plan establishes objectives
23 regarding such research and describes the means for
24 achieving the objectives;

1 “(3) ensure that all amounts appropriated for
2 such research under section 499B–6 are expended in
3 accordance with the plan;

4 “(4) review the plan not less frequently than
5 annually, and revise the plan as appropriate to
6 prioritize funding and research relative to scientific
7 urgency;

8 “(5) ensure that the plan serves as a broad,
9 binding statement of policies regarding Long
10 COVID research of the National Institutes of
11 Health, but does not affect the responsibility of any
12 of the national research institutes or centers with re-
13 spect to the programs or projects of such institutes
14 and centers; and

15 “(6) annually prepare and submit to the Direc-
16 tor of NIH for review and transmittal by the Direc-
17 tor of NIH to the President and to Congress a
18 budget estimate for carrying out the plan for the up-
19 coming fiscal year.

20 “(d) CONSULTATION.—In developing, implementing,
21 reviewing, and prioritizing elements of the research plan
22 under this section, the Director of the Program shall con-
23 sult, as appropriate with—

24 “(1) representatives of other Federal agencies
25 involved in Long COVID research, including the

1 Centers for Disease Control and Prevention, the
2 Agency for Healthcare Research and Quality, and
3 the Administration for Community Living;

4 “(2) the Long COVID Research Advisory
5 Board established under section 499B–4;

6 “(3) the Office of Long COVID Research and
7 Practice of the Department of Health and Human
8 Services;

9 “(4) leading scientific experts on Long COVID;
10 and

11 “(5) independent, patient-led organizations or
12 advocacy groups representing patients with Long
13 COVID and other infection-associated chronic condi-
14 tions with similar phenotypes, and the families of
15 such patients.

16 “(e) REPORT.—The Director of the Program shall
17 submit the research plan developed under subsection (a),
18 and updates to such plan, to—

19 “(1) the Committee on Health, Education,
20 Labor, and Pensions of the Senate;

21 “(2) the Committee on Energy and Commerce
22 of the House of Representatives;

23 “(3) the Secretary;

1 “(4) the Office of Long COVID Research and
2 Practice of the Department of Health and Human
3 Services; and

4 “(5) the Director of NIH, who shall post the
5 plan, and updates to the plan, on the website of the
6 National Institutes of Health.

7 **“SEC. 499B-2. EXPEDITED LONG COVID RESEARCH.**

8 “(a) IN GENERAL.—The Director of NIH shall estab-
9 lish a process to expedite the award of grants, contracts,
10 and cooperative agreements for research projects con-
11 ducted or supported by the National Institutes of Health
12 and relating to Long COVID.

13 “(b) REQUIREMENTS FOR MAKING EXTERNAL
14 FUNDING AVAILABLE.—With respect to programs of
15 grants, contracts, and cooperative agreements described in
16 subsection (a), the Director of NIH shall—

17 “(1) make publicly available the deadlines for
18 submitting applications for such programs, and en-
19 sure that such deadlines provide applicants with suf-
20 ficient time from the date of the announcement for
21 such grant, contract, and cooperative agreement to
22 submit an application;

23 “(2) ensure that applicants receive a final deci-
24 sion on their applications within 120 days of submis-
25 sion; and

1 “(3) with respect to applications that are de-
2 nied, provide a written explanation to the applicant
3 on the reasons for the denial.

4 “(c) EVALUATION OF GRANT APPLICATIONS.—In
5 making a determination to award a grant, contract, and
6 cooperative agreement for research projects described in
7 subsection (a), the Director of NIH shall—

8 “(1) give priority to research that—

9 “(A) tests the outcomes of existing drug
10 and device interventions in patients with Long
11 COVID;

12 “(B) focuses on identifying interventions
13 for pediatric patients with Long COVID;

14 “(C) aids in the development of new inter-
15 ventions that have evidence to suggest effective-
16 ness in treating or curing Long COVID; or

17 “(D) includes institutions that represent,
18 or have a successful track record of providing
19 equitable care or services to, historically under-
20 served communities;

21 “(2) consider research that has the ability to
22 begin interventions in a timely manner;

23 “(3) consider research that uses decentralized
24 trials or remote monitoring techniques for data col-
25 lection; and

1 “(4) consider research that includes patients
2 with other infection-associated chronic conditions
3 with similar phenotypes, such as myalgic
4 encephalomyelitis/chronic fatigue syndrome, postural
5 orthostatic tachycardia syndrome, and post-treat-
6 ment Lyme disease syndrome/persistent Lyme dis-
7 ease.

8 “(d) REASONABLE PRICING.—In awarding contracts,
9 grants, and cooperative agreements for research projects
10 described in subsection (a) that relates to the development
11 of a drug or device for the potential treatment or manage-
12 ment of Long COVID, or identifying a new indication or
13 use specific to the treatment or management of Long
14 COVID in a drug or device that is already approved or
15 cleared by the Food and Drug Administration, the Direc-
16 tor of NIH shall include terms and conditions requiring
17 that the price of such a drug or device for purposes of
18 procurement by the Federal Government or if sold on the
19 commercial market, whether procured from, or sold by, the
20 recipient of such Federal award or another person—

21 “(1) is fair and reasonable, taking into ac-
22 count—

23 “(A) the value of the drug and device to
24 the public health, including the impact of the
25 price on access to the drug or device;

1 “(B) the costs incurred by the Federal
2 Government in research and development of the
3 drug or device;

4 “(C) the costs incurred by the recipient of
5 the award in research and development of the
6 drug or device, and the costs of manufacturing
7 such drug or device;

8 “(D) whether the drug or device provided
9 a significant improvement in health outcomes,
10 compared to other therapies available at the
11 time of its approval or authorization;

12 “(E) the cumulative expected global reve-
13 nues generated by the drug or device; and

14 “(F) other factors, as the Secretary deter-
15 mines appropriate; and

16 “(2) does not exceed the lowest price charged
17 for such drug or device, among Canada, France,
18 Germany, Italy, Japan, and the United Kingdom.

19 “(e) CONSULTATION.—In making a determination to
20 award a grant, contract, or cooperative agreement for re-
21 search projects relating to Long COVID, the Director of
22 NIH shall consult with the Long COVID Research Advi-
23 sory Board. Members of the Long COVID Research Advi-
24 sory Board shall provide a recommendation on any final
25 funding decisions. If the Director of NIH makes a decision

1 that is different than the recommendation, the Director
2 of NIH shall provide a written justification for the deci-
3 sion within 5 days.

4 **“SEC. 499B-3. SCIENTIFIC REVIEW GROUP.**

5 “(a) IN GENERAL.—In order to ensure high quality,
6 rigorous scientific review of applications for grants, con-
7 tracts, and cooperative agreements described in section
8 499B-2(a), consistent with section 492, the Director of
9 NIH shall establish a scientific review group on Long
10 COVID and other infection-associated chronic conditions,
11 and shall convene a group of leading scientific experts to
12 serve on such group, for terms of up to 5 years.

13 “(b) DUTIES.—The scientific research group shall
14 conduct an initial review of applications for grants, con-
15 tracts, and other cooperative agreements described in sec-
16 tion 499B-2(a), and submit a funding recommendation to
17 the Director of NIH for final determination.

18 **“SEC. 499B-4. LONG COVID RESEARCH PROGRAM ADVISORY**
19 **BOARD.**

20 “(a) IN GENERAL.—The Director of NIH shall estab-
21 lish the Long COVID Research Program Advisory Board
22 (referred to in this section as the ‘Advisory Board’).

23 “(b) MEMBERSHIP.—

24 “(1) IN GENERAL.—The Advisory Board shall
25 be comprised of 18 members, including appointed

1 members and nonvoting ex officio members, as fol-
2 lows:

3 “(A) The Secretary shall conduct a nomi-
4 nation process that allows for public input on
5 nominees. The Secretary shall appoint nomi-
6 nated individuals, giving particular consider-
7 ation to individuals from backgrounds that rep-
8 resent the diversity of the Long COVID popu-
9 lation, with an emphasis on patients who face
10 the highest disease burden. Individuals so ap-
11 pointed shall include the following:

12 “(i) 10 members who are scientists,
13 physicians, and other health care profes-
14 sionals, who are not officers or employees
15 of the Federal Government, and who have
16 primary expertise in Long COVID and
17 other infection-associated chronic condi-
18 tions, with consideration given to such in-
19 dividuals with expertise in pediatric popu-
20 lations.

21 “(ii) 5 members who live with Long
22 COVID.

23 “(iii) 1 member who is a caregiver to
24 an individual with Long COVID.

1 “(iv) 2 members who are employed by
2 the National Institutes of Health and have
3 expertise in Long COVID research.

4 “(B) The following shall be ex officio mem-
5 bers of the Advisory Board:

6 “(i) A representative of the Long
7 COVID Research Program established
8 under section 499.

9 “(ii) A representative of the National
10 Institutes of Health.

11 “(iii) A representative of the National
12 Institutes of Neurological Disorders and
13 Stroke.

14 “(iv) A representative of the National
15 Heart, Lung, and Blood Institute.

16 “(v) A representative of the National
17 Institute of Allergy and Infectious Dis-
18 eases.

19 “(vi) A representative of the Office of
20 the Assistant Secretary for Health.

21 “(vii) A representative of the Centers
22 for Disease Control and Prevention.

23 “(viii) A representative of the Admin-
24 istration for Community Living.

1 “(ix) A representative of the Agency
2 for Healthcare Research and Quality.

3 “(x) Representatives of any other
4 agency or office of the Department of
5 Health and Human Services that the Sec-
6 retary determines appropriate for the Advi-
7 sory Board to carry out its function.

8 “(2) ENGAGEMENT WITH ORGANIZATIONS.—In
9 appointing individuals to the Advisory Board, the
10 Secretary shall engage with leading scientific experts
11 on Long COVID and independent, patient-led orga-
12 nizations of advocacy groups representing Long
13 COVID patients.

14 “(c) COMPENSATION.—Ex officio members of the Ad-
15 visory Board who are officers or employees of the Federal
16 Government shall not receive any compensation for service
17 on the Advisory Board. Non-Federal members of the Advi-
18 sory Board may receive, for each day (including travel
19 time) they are engaged in the performance of the functions
20 of the advisory committee, compensation at rates not to
21 exceed the daily equivalent to the annual rate of basic pay
22 for level III of the Executive Schedule under section 5314
23 of title 5, United States Code.

24 “(d) TERMS.—The term of office of an appointed
25 member of the Advisory Board is 5 years. Any member

1 appointed to fill a vacancy for an unexpired term shall
2 be appointed for the remainder of such term. A member
3 may serve after the expiration of the member's term until
4 a successor has taken office. If a vacancy occurs in the
5 Advisory Board, the Secretary shall make an appointment
6 to fill the vacancy not later than 60 days from the date
7 the vacancy occurred.

8 “(e) CHAIR.—The members of the Advisory Board
9 shall select a chair from among the appointed members.
10 The term of the Office of Chair shall be 2 years.

11 “(f) MEETINGS.—

12 “(1) IN GENERAL.—The Advisory Board shall
13 meet at the call of the chairman or upon request of
14 the Director of the Program established under sec-
15 tion 499B, but not less often than monthly in the
16 first year after establishment, then not less often
17 than 6 times a year for each subsequent year. The
18 meetings of the Advisory Board may be held vir-
19 tually.

20 “(2) PURPOSE.—Of the meetings held, one or
21 more shall be held to address research priorities of
22 the National Institutes of Health relating to Long
23 COVID.

24 “(3) PUBLICATION OF SUMMARY.—For each
25 meeting held, the Director of NIH shall post on the

1 website of the National Institutes of Health a sum-
2 mary of the proceedings.

3 “(g) DUTIES.—The Advisory Board shall, subject to
4 the direction and supervision of the Director of NIH—

5 “(1) review, approve, and evaluate the imple-
6 mentation of the research plan issued under section
7 499B–1, and advise in updating the plan;

8 “(2) provide guidance to the Director of the
9 Program established under section 499B with re-
10 spect to appropriate research activities to be under-
11 taken regarding the clinical treatment of Long
12 COVID, which may include—

13 “(A) research on interventions for pre-
14 venting, treating, and understanding the mech-
15 anisms of Long COVID;

16 “(B) research on the effectiveness of treat-
17 ing Long COVID with drugs that are not yet
18 approved by the Food and Drug Administration
19 for the treatment of Long COVID;

20 “(C) reviewing ongoing publicly- and pri-
21 vately-supported research on treatments for
22 Long COVID;

23 “(D) issue and make available to health
24 care professionals and the public reports de-

1 scribing and evaluating research described in
2 subparagraphs (A), (B), and (C); and

3 “(E) convene accessible meetings for the
4 purpose of determining the recommendations
5 which may inform development of clinical guide-
6 lines by health care provider organizations; and

7 “(3) engage in other necessary activities to con-
8 tribute to the National Institutes of Health’s overall
9 research priorities related to Long COVID, and en-
10 sure accountability, transparency, and communica-
11 tion of results of the Program established under sec-
12 tion 499B.”.

13 **“SEC. 499B-5. DATA SYSTEM AND CLEARINGHOUSE ON RE-**
14 **SEARCH INFORMATION.**

15 “(a) DATA SYSTEM.—

16 “(1) IN GENERAL.—The Director of the Na-
17 tional Institutes of Health, in consultation with the
18 Director of the Program established under section
19 499B and the Director of the National Library of
20 Medicine shall establish, maintain, and operate a
21 data system for the collection, storage, analysis, re-
22 trieval, and timely dissemination of primary data re-
23 garding research on Long COVID that is conducted
24 or supported by the Program. Information from the
25 data system shall be available through information

1 systems available to health care professionals and
2 providers, researchers, and members of the public.

3 “(2) REGISTRY.—

4 “(A) IN GENERAL.—The data system es-
5 tablished under paragraph (1) shall include a
6 registry of clinical trials of experimental treat-
7 ments that have been developed for research on
8 Long COVID. Such registry shall include infor-
9 mation on patient eligibility criteria, including
10 the definition of Long COVID, and, as applica-
11 ble, demographic information, including sex,
12 age, disability status, ethnicity, and race, and
13 the location of the trial site or sites.

14 “(B) SUBMISSION OF INFORMATION.—

15 Principal investigators of trials described in
16 subparagraph (A) shall provide such informa-
17 tion to the registry not later than 30 days after
18 public announcement of the clinical trial. Once
19 a trial has been completed, the principal investi-
20 gator shall provide the registry with information
21 pertaining to the results, including potential
22 toxicities or adverse effects associated with the
23 experimental treatment or treatments evalu-
24 ated.

1 “(C) PUBLIC AVAILABILITY.—The registry
2 described in this paragraph shall be made avail-
3 able to researchers and the general public, in a
4 machine-readable format.

5 “(b) CLEARINGHOUSE.—The Director of NIH, in
6 consultation with the Director of the Program and with
7 the National Library of Medicine, shall establish, main-
8 tain, and operate a program to provide information on re-
9 search and prevention activities of the national research
10 institutes that relate to research on Long COVID.

11 **“SEC. 499B-6. APPROPRIATIONS.**

12 “For purposes of carrying out this part, there are ap-
13 propriated, out of amounts in the Treasury not otherwise
14 appropriated, \$1,000,000,000 for each of fiscal years
15 2025 through 2034, to remain available until expended.”.

16 **TITLE II—PUBLIC HEALTH RE-**
17 **SEARCH, SURVEILLANCE AND**
18 **RELATED ACTIVITIES**

19 **SEC. 201. LONG COVID PROGRAMS.**

20 Title III of the Public Health Service Act (42 U.S.C.
21 241 et seq.) is amended by adding at the end the fol-
22 lowing:

1 **“PART X—LONG COVID ACTIVITIES**
2 **“SEC. 399PP. PUBLIC HEALTH SURVEILLANCE OF LONG**
3 **COVID AND INFECTION-ASSOCIATED CHRON-**
4 **IC CONDITIONS.**

5 “(a) IN GENERAL.—The Secretary, acting through
6 the Director of the Centers for Disease Control and Pre-
7 vention, shall establish or continue, as applicable, surveil-
8 lance activities to better understand the burden and sever-
9 ity of Long COVID and related infection-associated chron-
10 ic conditions, with specific consideration given to vulner-
11 able populations, such as children. In carrying out this
12 section, the Secretary shall—

13 “(1) collect data on the incidence, prevalence,
14 and severity of Long COVID and related infection-
15 associated chronic conditions;

16 “(2) monitor for Long COVID and Long
17 COVID-like conditions, as appropriate, to enable
18 early intervention and identification of factors asso-
19 ciated with severity of symptoms;

20 “(3) compile, and make publicly available, in
21 accessible formats, Long COVID data collected
22 under paragraph (1);

23 “(4) develop and disseminate best practices for
24 conducting surveillance for State, local, and Tribal
25 public health officials, and other relevant public
26 health stakeholders;

1 “(5) provide technical assistance to inter-
2 national organizations, as applicable, regarding the
3 monitoring of Long COVID; and

4 “(6) conduct additional surveillance activities,
5 as the Secretary determines appropriate, to better
6 understand the burden and severity of Long COVID.

7 “(b) AUTHORIZATION OF APPROPRIATIONS.—For
8 purposes of carrying out this section, there are authorized
9 to be appropriated \$32,000,000 for each of fiscal years
10 2025 through 2034.

11 **“SEC. 399PP-1. PUBLIC HEALTH PROGRAMMING.**

12 “(a) IN GENERAL.—The Secretary, acting through
13 the Director of the Centers for Disease Control and Pre-
14 vention, shall make grants to State, local, and Tribal
15 health departments for the purpose of carrying out activi-
16 ties related to Long COVID.

17 “(b) USE OF FUNDS.—A State, local, or Tribal
18 health department that receives a grant under subsection
19 (a) may use funds received through such grant to—

20 “(1) provide training on the identification of
21 Long COVID to clinicians, public health experts,
22 and other relevant health care professionals;

23 “(2) link individuals with Long COVID to care,
24 as appropriate and applicable;

1 “(2) how to prevent and seek treatment for
2 Long COVID;

3 “(3) self-management tools and support serv-
4 ices; and

5 “(4) other topics, as the Secretary determines
6 appropriate.

7 “(b) CONSULTATION.—In developing materials for
8 the campaign, the Secretary shall consult with inde-
9 pendent, patient-led organizations or advocacy groups rep-
10 resenting Long COVID patients and their families and
11 other relevant stakeholders.

12 “(c) ACCESSIBILITY.—The public education cam-
13 paign under this section shall be made available in mul-
14 tiple languages, including American Sign Language.

15 “(d) AUTHORIZATION OF APPROPRIATIONS.—For
16 purposes of carrying out this section, there are authorized
17 to be appropriated \$21,500,000 for each of fiscal years
18 2025 through 2029.

19 **“SEC. 399PP-3. PROVIDER EDUCATION.**

20 “(a) IN GENERAL.—The Secretary shall—

21 “(1) develop and make publicly available best
22 practices for coordinated, multidisciplinary care for
23 individuals with Long COVID;

24 “(2) develop, update, as appropriate, and make
25 publicly available clinical guidance and provider edu-

1 cation materials, including for providers working
2 with pediatric populations; and

3 “(3) facilitate provider education on Long
4 COVID signs, symptoms, maintenance, and treat-
5 ment, including through technology-enabled collabo-
6 rative learning.

7 “(b) AUTHORIZATION OF APPROPRIATIONS.—For the
8 purpose of carrying out this section, there are authorized
9 to be appropriated \$3,000,000 for each of fiscal years
10 2025 through 2034.”.

11 **SEC. 202. REHABILITATION RESEARCH AND TRAINING CEN-**
12 **TER ON LONG COVID AMONG PEOPLE WITH**
13 **DISABILITIES.**

14 (a) IN GENERAL.—Section 240(b)(2)(C) of the Reha-
15 bilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amend-
16 ed—

17 (1) in clause (v), by striking “; and” and insert-
18 ing a semicolon;

19 (2) in clause (vi), by striking the period and in-
20 serting “; and”; and

21 (3) by adding at the end the following:

22 “(vii) applied research regarding evi-
23 dence-based treatments, services, and sup-
24 ports for individuals with disabilities with

1 Long COVID or other infection-associated
2 chronic conditions.”.

3 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry
4 out the amendment made by subsection (b), there are au-
5 thorized to be appropriated to the Director of the National
6 Institute on Disability, Independent Living, and Rehabili-
7 tation Research, \$10,000,000 for the period of fiscal years
8 2025 through 2029.

9 **SEC. 203. CLINICAL OUTCOMES ASSESSMENTS.**

10 (a) IN GENERAL.—The Secretary of Health and
11 Human Services, acting through the Commissioner of
12 Food and Drugs, shall establish or continue the develop-
13 ment and validation of clinical outcomes assessments to
14 support regulatory decision making for drugs, including
15 biological products, and devices used to treat Long
16 COVID.

17 (b) AUTHORIZATION OF APPROPRIATIONS.—For pur-
18 poses of carrying out this section, there are authorized to
19 be appropriated \$9,000,000 for each of fiscal years 2025
20 through 2034.

21 **SEC. 204. ELECTRONIC REPORTING FORM.**

22 (a) IN GENERAL.—The Secretary of Health and
23 Human Services, acting through the Commissioner of
24 Food and Drugs, shall establish or continue the develop-
25 ment, refinement, and maintenance of a Long COVID

1 electronic reporting form for patients to identify current
2 treatments and treatments under development for Long
3 COVID.

4 (b) AUTHORIZATION OF APPROPRIATIONS.—For pur-
5 poses of carrying out this section, there are authorized to
6 be appropriated \$16,600,000 for each of fiscal years 2025
7 through 2034.

8 **SEC. 205. LONG COVID CARE NETWORK.**

9 (a) IN GENERAL.—The Secretary of Health and
10 Human Services, acting through the Director of the Agen-
11 cy for Healthcare Research and Quality, shall develop, or
12 continue to support, multidisciplinary Long COVID clinics
13 to provide access to comprehensive, coordinated care for
14 individuals with Long COVID, particularly underserved
15 populations that are disproportionately impacted by the
16 effects of Long COVID.

17 (b) AUTHORIZATIONS OF APPROPRIATIONS.—For
18 purposes of carrying out this section, there are authorized
19 to be appropriated \$10,000,000 for each of fiscal years
20 2025 through 2034.

21 **SEC. 206. RESEARCH ON LONG COVID BEST PRACTICES.**

22 (a) IN GENERAL.—The Secretary of Health and
23 Human Services, in coordination with the Director of the
24 Agency for Healthcare Research and Quality, shall de-
25 velop, test, synthesize, and disseminate best practices and

1 decision support tools related to the clinical care organiza-
2 tion, delivery, and integration of clinical and social services
3 for Long COVID and other infection-associated chronic
4 conditions.

5 (b) AUTHORIZATION OF APPROPRIATIONS.—For the
6 purposes of carrying out this section, there are authorized
7 to be appropriated \$10,000,000 for each of fiscal years
8 2025 through 2034.

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