| 118TH CONGRESS 2D SESSION | S. _ | | | |
|------------------------------|----------------------------------|----------|----------------|--|
| | on, and suppor s of Health to | t for af | fected individ | COVID, including luals, to direct the OVID research pro- |
| IN THE SE | NATE OF | THE | UNITED | STATES |
| and referred | introduced to the Commit | | wing bill; whi | ch was read twice |

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— |
| | |

| "(i) experience managing clinical or |
|---|
| research programs focused on pathogenic |
| mechanisms and biological pathways re- |
| lated to Long COVID; and |
| "(ii) demonstrated commitment to ad- |
| dressing Long COVID and other infection- |
| associated chronic conditions, such as |
| myalgic encephalomyelitis/chronic fatigue |
| syndrome, postural orthostatic tachycardia |
| syndrome, and post-treatment Lyme dis- |
| ease syndrome/persistent Lyme disease. |
| "(B) Consultation.—In appointing the |
| Director under subparagraph (A), the Secretary |
| shall consult with independent, patient-led orga- |
| nizations or advocacy groups representing Long |
| COVID patients and their families. |
| "(2) RESPONSIBILITIES.—The Director of the |
| Program shall— |
| "(A) act as the primary Federal official |
| with responsibility for coordinating all Long |
| COVID research conducted or supported by the |
| National Institutes of Health; |
| "(B) represent the National Institutes of |
| 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; |
| | |

"(5) conduct comparative research to understand the similarities and differences between Long COVID and other infection-associated chronic conditions with similar phenotypes, such as myalgic encephalomyelitis/chronic fatigue syndrome, postural orthostatic tachycardia syndrome, and post-treatment Lyme disease syndrome/persistent Lyme disease, and how activities funded by the Program could improve understanding of such other conditions; and

"(6) conduct comparative research to understand the similarities and differences between Long COVID and severe, long-term effects from COVID—19 vaccinations.

"(d) Duties.—

"(1) Interagency coordination of Long Covid activities.—The Director of the Program shall coordinate with the national research institutes and national centers, as appropriate, on Long COVID research. In carrying out this paragraph, the Director of the Program shall evaluate the Long COVID activities of each such institute or center and shall provide for the periodic reevaluation of 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 myalgio |
| 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
- 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
- meet at the call of the chairman or upon request of
- the Director of the Program established under sec-
- tion 499B, but not less often than monthly in the
- 16 first year after establishment, then not less often
- than 6 times a year for each subsequent year. The
- meetings of the Advisory Board may be held vir-
- tually.
- 20 "(2) Purpose.—Of the meetings held, one or
- 21 more shall be held to address research priorities of
- 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- |

| I | 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 overal |
| 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.". |
| 12 | "SEC 400D E DATA SYSTEM AND STEADINGHOUSE ON DE |
| 13 | "SEC. 499B-5. DATA SYSTEM AND CLEARINGHOUSE ON RE |
| 13 14 | SEARCH INFORMATION. |
| | |
| 14 | SEARCH INFORMATION. |
| 14 15 | SEARCH INFORMATION. "(a) Data System.— |
| 141516 | SEARCH INFORMATION. "(a) Data System.— "(1) In general.—The Director of the Na- |
| 14151617 | SEARCH INFORMATION. "(a) Data System.— "(1) In general.—The Director of the National Institutes of Health, in consultation with the |
| 14 15 16 17 18 | SEARCH INFORMATION. "(a) Data System.— "(1) In general.—The Director of the National Institutes of Health, in consultation with the Director of the Program established under section |
| 14 15 16 17 18 19 | **SEARCH INFORMATION. "(a) Data System.— "(1) In general.—The Director of the National Institutes of Health, in consultation with the Director of the Program established under section 499B and the Director of the National Library of |
| 14 15 16 17 18 19 20 | **SEARCH INFORMATION. "(a) Data System.— "(1) In general.—The Director of the National Institutes of Health, in consultation with the Director of the Program established under section 499B and the Director of the National Library of Medicine shall establish, maintain, and operate a |
| 14 15 16 17 18 19 20 21 | **SEARCH INFORMATION. "(a) Data System.— "(1) In General.—The Director of the National Institutes of Health, in consultation with the Director of the Program established under section 499B and the Director of the National Library of Medicine shall establish, maintain, and operate a data system for the collection, storage, analysis, re- |
| 14 15 16 17 18 19 20 21 22 | SEARCH INFORMATION. "(a) Data System.— "(1) In general.—The Director of the National Institutes of Health, in consultation with the Director of the Program established under section 499B and the Director of the National Library of Medicine shall establish, maintain, and operate a data system for the collection, storage, analysis, retrieval, and timely dissemination of primary data retrieval. |

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

"(2) Registry.—

"(A) IN GENERAL.—The data system established under paragraph (1) shall include a registry of clinical trials of experimental treatments that have been developed for research on Long COVID. Such registry shall include information on patient eligibility criteria, including the definition of Long COVID, and, as applicable, demographic information, including sex, age, disability status, ethnicity, and race, and the location of the trial site or sites.

"(B) Submission of information.—
Principal investigators of trials described in subparagraph (A) shall provide such information to the registry not later than 30 days after public announcement of the clinical trial. Once a trial has been completed, the principal investigator shall provide the registry with information pertaining to the results, including potential toxicities or adverse effects associated with the experimental treatment or treatments evaluated.

| 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- |
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| 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 | "(3) support the development and dissemination |
|--|--|
| 2 | of public information and educational materials on |
| 3 | Long COVID, including materials to address misin- |
| 4 | formation and disinformation; |
| 5 | "(4) support laboratory capacity for screening |
| 6 | and diagnosis of Long COVID and associated symp- |
| 7 | toms; and |
| 8 | "(5) build, maintain, and sustain jurisdiction- |
| 9 | level infrastructure related to preparedness for post- |
| 10 | infectious syndromes. |
| 11 | "(c) Authorization of Appropriations.—For |
| 12 | purposes of carrying out this section, there are authorized |
| 13 | to be appropriated \$45,000,000 for each of fiscal years |
| | |
| 14 | 2025 through 2034. |
| 14 15 | 2025 through 2034. "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN |
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| 15 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN |
| 15 16 17 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN ON LONG COVID. |
| 15 16 17 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN ON LONG COVID. "(a) IN GENERAL.—The Secretary, acting through |
| 15 16 17 18 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN ON LONG COVID. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Pre- |
| 15 16 17 18 19 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN ON LONG COVID. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in collaboration with national, State, local, |
| 15 16 17 18 19 20 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN ON LONG COVID. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in collaboration with national, State, local, and Tribal public health partners, shall develop a public |
| 15 16 17 18 19 20 21 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN ON LONG COVID. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in collaboration with national, State, local, and Tribal public health partners, shall develop a public education campaign for patients, families, and caregivers |
| 15 16 17 18 19 20 21 22 | "SEC. 399PP-2. NATIONAL PUBLIC EDUCATION CAMPAIGN ON LONG COVID. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, and in collaboration with national, State, local, and Tribal public health partners, shall develop a public education campaign for patients, families, and caregivers to educate and increase awareness about Long COVID in |

| 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. |
| 1314 | DISABILITIES. (a) IN GENERAL.—Section 240(b)(2)(C) of the Reha- |
| | |
| 14 15 | (a) In General.—Section 240(b)(2)(C) of the Reha- |
| 14 15 | (a) In General.—Section 240(b)(2)(C) of the Rehabilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amend- |
| 141516 | (a) IN GENERAL.—Section 240(b)(2)(C) of the Rehabilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amended— |
| 14151617 | (a) In General.—Section 240(b)(2)(C) of the Rehabilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amended— (1) in clause (v), by striking "; and" and insert- |
| 14 15 16 17 18 | (a) IN GENERAL.—Section 240(b)(2)(C) of the Rehabilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amended— (1) in clause (v), by striking "; and" and inserting a semicolon; |
| 14 15 16 17 18 19 | (a) IN GENERAL.—Section 240(b)(2)(C) of the Rehabilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amended— (1) in clause (v), by striking "; and" and inserting a semicolon; (2) in clause (vi), by striking the period and inserting and insert |
| 14151617181920 | (a) IN GENERAL.—Section 240(b)(2)(C) of the Rehabilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amended— (1) in clause (v), by striking "; and" and inserting a semicolon; (2) in clause (vi), by striking the period and inserting "; and"; and |
| 14 15 16 17 18 19 20 21 | (a) In General.—Section 240(b)(2)(C) of the Rehabilitation Act of 1973 (29 U.S.C. 764(b)(2)(C)) is amended— (1) in clause (v), by striking "; and" and inserting a semicolon; (2) in clause (vi), by striking the period and inserting "; and"; and (3) by adding at the end the following: |

- 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.