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(Original Signature of Member)

118TH CONGRESS
1ST SESSION

H. R. _____

To provide for optimized care, a coordinated Federal Government response, public education, and insurance reimbursement guidance for Long COVID, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Ms. BLUNT ROCHESTER introduced the following bill; which was referred to the Committee on _____

A BILL

To provide for optimized care, a coordinated Federal Government response, public education, and insurance reimbursement guidance for Long COVID, 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; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as
5 the“Long COVID Response is Care Optimized and Vitally
6 Essential Resources that Yield New Opportunities for

1 Wellness Act” or the “Long COVID RECOVERY NOW
2 Act”.

3 (b) TABLE OF CONTENTS.—The table of contents for
4 this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Targeting resources for equitable access to treatment of Long COVID.
- Sec. 3. National Long COVID technical assistance dissemination program.
- Sec. 4. Mental health and suicide prevention and treatment.
- Sec. 5. ONC best practices for Long COVID data.
- Sec. 6. Long COVID Education Website.
- Sec. 7. Providing Support for Long COVID Registries.
- Sec. 8. Medicaid Health Homes for Individuals with Long COVID.
- Sec. 9. State health officials guidance.
- Sec. 10. Support under Medicaid for State Collection of Long COVID Data.
- Sec. 11. Grants for Pediatric Research on Long COVID.

5 **SEC. 2. TARGETING RESOURCES FOR EQUITABLE ACCESS**
6 **TO TREATMENT OF LONG COVID.**

7 (a) ESTABLISHMENT.—

8 (1) IN GENERAL.—Not later than 1 year after
9 the date of the enactment of this Act, the Secretary
10 of Health and Human Services shall award, subject
11 to subsection (f) and in accordance with the provi-
12 sions of this section, grants described in the fol-
13 lowing subsections to carry out the purposes de-
14 scribed in such subsections.

15 (2) ELIGIBILITY.—The Secretary may establish
16 a process for evaluating and determining the eligi-
17 bility of Federally qualified health centers and rural
18 health clinics for receiving a grant under this sec-
19 tion.

1 (b) GRANTS TO FQHCS AND RHCs.—For purposes
2 of subsection (a), the grants described in this subsection
3 are grants to Federally qualified health centers (as defined
4 in section 1861(aa)(4) of the Social Security Act (42
5 U.S.C. 1395x(aa)(4)) and rural health clinics (as defined
6 in section 1861(aa)(2) of such Act (42 U.S.C.
7 1395x(aa)(2)) to—

8 (1) adopt evidence-based Long COVID clinical
9 practices that have been demonstrated to improve
10 the wellness of individuals with Long COVID, in-
11 cluding clinical validation of patient reported symp-
12 toms using established measures that yield struc-
13 tured, comparable data;

14 (2) establish or expand screening, referral, and
15 navigation processes for health-related social needs
16 that could interfere with Long COVID treatment,
17 including food insecurity, housing instability, trans-
18 portation needs, utility difficulties, and interpersonal
19 safety; and

20 (3) submit to the Secretary of Health and
21 Human Services (in a format consistent with the
22 standards and activities under the Data Moderniza-
23 tion Initiative of the Centers for Disease Control
24 and Prevention) standardized, disaggregated,
25 deidentified data (as specified by the Secretary) on

1 the characteristics, diagnoses, and health care serv-
2 ice utilization of Long COVID patients served under
3 such grant, including disaggregated data on Long
4 COVID patient characteristics, including patient
5 age, gender, race, ethnicity, language spoken, dis-
6 ability status, nature and duration of validated
7 symptoms, and other characteristics necessary to in-
8 form considerations for effective and equitable treat-
9 ment for patients with Long COVID.

10 (c) GRANTS TO PRIMARY CARE PRACTICES.—For
11 purposes of subsection (a), the grants described in this
12 subsection are grants to primary care practices (other
13 than Federally qualified health centers and rural health
14 clinics) that satisfy such criteria as may be established by
15 the Secretary to carry out the purposes described in para-
16 graphs (1) and (3) of subsection (b).

17 (d) GRANTS FOR MULTIDISCIPLINARY TREATMENT
18 AND COORDINATION.—

19 (1) IN GENERAL.—The Secretary of Health and
20 Human Services (in this section referred to as the
21 “Secretary”) shall award grants on a competitive
22 basis to eligible entities for the purpose of creating
23 or enhancing capacity to treat patients with Long
24 COVID through a multidisciplinary approach. The
25 term “multidisciplinary” in this section refers to the

1 coordinated work to provide care or treatment to a
2 patient by physicians and other professionals, such
3 as specialty or subspecialty providers, nurses and
4 nurse care coordinators, dietitians, nutritionists, so-
5 cial workers, behavioral health professionals, phys-
6 ical and occupational therapists, speech pathologists,
7 or any professionals determined to be appropriate by
8 the State and approved by the Administrator of the
9 Centers for Medicare & Medicaid Services.

10 (2) USE OF FUNDS.—An eligible entity receiv-
11 ing a grant under this section shall use the grant,
12 for the purpose described in subsection (a), to—

13 (A) enhance the capacity of one or more
14 existing multidisciplinary Long COVID clinics
15 to serve the Long COVID population; or

16 (B) create one or more multidisciplinary
17 clinics to address the physical and mental
18 health needs of Long COVID patients.

19 (3) ELIGIBLE ENTITIES.—To be eligible to re-
20 ceive a grant under this section, an entity shall be
21 a health care provider, Federally qualified health
22 center (as defined in section 1861(aa) of the Social
23 Security Act (42 U.S.C. 1395x(aa))), rural health
24 clinic, urban Indian health center, or State or local
25 public health department, that—

1 (A)(i) operates an existing multidisci-
2 plinary Long COVID clinic or other specialized
3 Long COVID program; or

4 (ii) is an existing health care provider with
5 experience providing care for individuals with
6 Long COVID and who demonstrates an intent
7 to create a multidisciplinary Long COVID clinic
8 or other specialized Long COVID program;

9 (B) submits to the Secretary an applica-
10 tion at such time, in such manner, and con-
11 taining such information and assurances as the
12 Secretary may require; and

13 (C) employs a framework that incentivizes
14 participants to attain the program's goals to es-
15 tablish and disseminate best practices, and allo-
16 cates funds based on such attainment.

17 (4) SPECIAL RULE.—A physical clinical facility
18 is not a requirement for eligibility.

19 (5) PRIORITY.—In awarding grants under this
20 subsection, the Secretary shall give priority to eligi-
21 ble entities that—

22 (A) submit a plan to engage with medically
23 underserved communities, and with populations
24 disproportionately impacted by COVID–19;

1 (B) demonstrate capacity (or an intent to
2 build capacity) to provide personalized treat-
3 ment and facilitate patient access to multidisci-
4 plinary health care providers with expertise in
5 treating Long COVID symptoms, including
6 such providers who are primary and specialty
7 care physicians (such as physiatrists, neurolo-
8 gists, cardiologists, immunologists, and
9 pulmonologists), therapists, nurses, care coordi-
10 nators, social workers, nutritionists, and behav-
11 ioral health specialists; and

12 (C) submit a plan to ensure ongoing multi-
13 disciplinary continuing education on infection-
14 triggered conditions for—

15 (i) physicians treating Long COVID;

16 and

17 (ii) other physicians and health care
18 workers who are not treating Long
19 COVID, but are otherwise serving patients
20 in the community.

21 (e) **EQUITABLE ACCESS.**—In order to ensure equi-
22 table access treatment—

23 (1) no grantee under this section shall deny ac-
24 cess to treatment with respect to Long COVID

1 based on insurance coverage, date of diagnosis, or
2 previous hospitalization;

3 (2) a grantee under this section shall with re-
4 spect to Long COVID—

5 (A) offer equity-centered resources (such
6 as the ability to offer resources in various lan-
7 guages), information, and training to safety net
8 health systems; and

9 (B) disseminate to individuals and organi-
10 zations that provide care best practices and
11 treatment approaches that enhance access to
12 high-quality care to everyone where they live;
13 and

14 (3) treatment for Long COVID shall be in-
15 cluded as a COVID–19 treatment, consistent with
16 the American Rescue Plan Act of 2021 (Public Law
17 117–2).

18 (f) DEVELOPMENT OF EVIDENCE-BASED STRATE-
19 GIES FOR HIGH-VALUE CARE FOR INDIVIDUALS WITH
20 LONG COVID.—

21 (1) IN GENERAL.—Not later than 1 year after
22 the date of the enactment of this Act, the Agency
23 for Healthcare Research and Quality shall, subject
24 to appropriations pursuant to subsection (i), award
25 multi-year grants to eligible entities meeting such

1 criteria as specified by the Secretary through rule-
2 making for the purposes of—

3 (A) supporting the generation of evidence
4 about how to deliver high quality, high-value
5 health care for individuals with Long COVID
6 for the treatment of the condition;

7 (B) creating tools and strategies to help
8 health systems and hospitals, primary and spe-
9 cialty physicians, nurses, allied health care pro-
10 fessionals, and caregivers provide high-quality,
11 high-value care for individuals with Long
12 COVID; and

13 (C) providing educational materials for
14 health care providers, payers, and consumers on
15 high-value care for individuals with Long
16 COVID.

17 (2) ELIGIBILITY.—The Secretary shall, through
18 rulemaking, specify a process for evaluating and de-
19 termining the eligibility of primary care providers in-
20 cluding federally qualified health centers and rural
21 health clinics; specialty care providers, hospitals,
22 health systems, academic medical centers; and other
23 entities for receiving a grant under this subsection.
24 Such rules shall prohibit grant funds from being
25 used to compensate or reimburse individuals or orga-

1 nizations excluded pursuant to section 1128 of the
2 Social Security Act (42 U.S.C. 1320a-7) from par-
3 ticipation under the Medicare program under title
4 XVIII of such Act.

5 (g) LONG COVID DEFINED.—For purposes of this
6 Act, the term “Long COVID” (also referred to as “post-
7 acute sequelae of COVID–19”, “post-COVID conditions”,
8 or “persistent symptoms post-COVID”) means the ongo-
9 ing sequelae of COVID–19 that some individuals experi-
10 ence after infection with the SARS–CoV–2 virus, as diag-
11 nosed by a qualified health care provider. Such sequelae
12 are defined as the “Post-COVID Conditions” identified
13 and defined by the Centers for Disease Control and Pre-
14 vention in 2021, or in subsequent revisions by the Centers
15 for Disease Control and Prevention.

16 (h) REPORTS.—

17 (1) ANNUAL REPORTS BY GRANTEES TO SEC-
18 RETARY.—On an annual basis, a recipient of a grant
19 under this section shall—

20 (A) submit to the Secretary, and make
21 publicly available, a report on the activities car-
22 ried out through the grant; and

23 (B) include evaluations of such activities,
24 including the experience of individuals who re-
25 ceived health care through such grant.

1 (2) ANNUAL REPORTS BY SECRETARY TO CON-
2 GRESS.—Not later than the end of each of fiscal
3 years 2024 through 2026, the Secretary shall submit
4 to the Congress, and make publicly available, a re-
5 port that—

6 (A) summarizes the reports received under
7 paragraph (1);

8 (B) evaluates the effectiveness of grants
9 under this section; and

10 (C) makes recommendations with respect
11 to expanding coverage for clinical care for Long
12 COVID.

13 (i) AUTHORIZATION OF APPROPRIATIONS.—

14 (1) IN GENERAL.—To carry out this section,
15 there are authorized to be appropriated such sums
16 as may be necessary for each of fiscal years 2024
17 through 2026.

18 (2) ADMINISTRATIVE EXPENSES.—Not more
19 than 15 percent of the amounts made available to
20 carry out this section for any fiscal year may be
21 used for administrative expenses to operate the
22 grants under this section.

1 **SEC. 3. NATIONAL LONG COVID TECHNICAL ASSISTANCE**
2 **DISSEMINATION PROGRAM.**

3 (a) IN GENERAL.—The Secretary of Health and
4 Human Services shall—

5 (1) establish a structured process to seek ongoing
6 input from medical societies representing primary
7 care, specialty care, and subspecialty care regarding
8 the proven and promising practices for
9 treating individuals who are diagnosed with Long
10 COVID to support their wellness and recovery; and

11 (2) enter into a memorandum of understanding
12 with one or more organizations with specific medical
13 knowledge on Long COVID or experience providing
14 care and medical treatment to individuals with Long
15 COVID to support the ongoing dissemination to the
16 broader medical community of existing open source
17 evidence, tools and strategies.

18 (b) ORGANIZATION DESCRIBED.—For purposes of
19 subsection (a), and organization described in this paragraph
20 is an organization that satisfies at least the following:
21

22 (1) The organization has clinical expertise related
23 to the treatment of Long COVID.

24 (2) The organization has a robust understanding
25 of clinical and business practices.

1 (3) The organization has the ability to convene
2 groups and disseminate information nationally.

3 (4) The organization consults with medical spe-
4 cialty associations for purposes of developing and
5 distributing clinical best practices for Long COVID
6 diagnosis and treatment.

7 **SEC. 4. MENTAL HEALTH AND SUICIDE PREVENTION AND**
8 **TREATMENT.**

9 Section 1911(b)(1) of the Public Health Service Act
10 (42 U.S.C. 300x(b)(1)) is amended by inserting “and, for
11 each of fiscal years 2024 through 2026, individuals with
12 Long COVID (as defined in section 2 of the Long COVID
13 RECOVERY NOW Act) who have also been diagnosed
14 with a mental health condition (such as a serious mental
15 illness or a serious emotional disturbance)” after
16 “1912(c)”.

17 **SEC. 5. ONC BEST PRACTICES FOR LONG COVID DATA.**

18 (a) IN GENERAL.—Not later than 6 months after the
19 date of the enactment of this Act, the Secretary of Health
20 and Human Services, acting through the National Coordi-
21 nator for Health Information Technology, shall convene
22 health care stakeholders to identify potential best prac-
23 tices for collecting, aggregating, and disseminating to
24 health care researchers deidentified data that promotes
25 learning about Long COVID and supports the further re-

1 search of the characteristics of individuals diagnosed with
2 Long COVID.

3 (b) REPORT.—Not later than 160 days after the first
4 meeting of such stakeholders pursuant to subsection (a),
5 the Secretary shall submit to Congress (and make publicly
6 available on the website of the Office of the National Coor-
7 dinator of Health Information Technology) a report sum-
8 marizing the meetings and findings of the stakeholders as
9 well as any recommendations, including recommendations
10 on ways that federal health care policy can better support
11 an understanding of the etiology, characteristics, care and
12 potential treatments for individuals Long COVID to sup-
13 port individuals' recovery and wellness. Such recommenda-
14 tions shall—

15 (1) take into account the perspectives of health
16 data scientists, health services researchers, medical
17 providers, health plans, hospitals and health sys-
18 tems, epidemiologists, public health experts, patient
19 representatives and groups, health information tech-
20 nology companies, and other stakeholders; and

21 (2) be informed by public and private sector ef-
22 forts to characterize Long COVID, aggregate and
23 disaggregate data, and promote data standardiza-
24 tion, data standards, or open data access for fur-
25 thering a greater understanding of Long COVID.

1 **SEC. 6. LONG COVID EDUCATION WEBSITE.**

2 Not later than 6 months after the date of the enact-
3 ment of this Act, the Secretary of Health and Human
4 Services shall, in consultation with medical societies rep-
5 resenting the perspectives of primary care, specialty care,
6 mental health professionals, medical researchers (includ-
7 ing through the National Institutes of Health), public
8 health experts (including the Centers for Disease Control
9 and Prevention), and patient advocates, implement a Fed-
10 eral website (which may be implemented through an exist-
11 ing public website of the Department of Health and
12 Human Services) that—

13 (1) collects, and curates educational materials
14 for health care providers and consumers about Long
15 COVID (as defined in section 2(e)) symptoms, diag-
16 nosis, characteristics, treatment, and access to care;
17 and

18 (2) includes, or provides a link to, comprehen-
19 sive educational resources for health care providers,
20 such as the interim guidance (and subsequent up-
21 dates) for health care providers published by the
22 Centers for Disease Control and Prevention on how
23 to treat individuals with Long COVID.

1 **SEC. 7. PROVIDING SUPPORT FOR LONG COVID REG-**
2 **ISTRIES.**

3 (a) IN GENERAL.—Not later than one year after the
4 date of the enactment of this Act, the Secretary of Health
5 and Human Services, acting through the Director of the
6 Agency for Healthcare Research and Quality shall, subject
7 to appropriations pursuant to subsection (d), award multi-
8 year grants to eligible entities described in subsection (b)
9 for the purposes of—

10 (1) supporting existing or creating new Longi-
11 tudinal registries of patients with Long COVID (as
12 defined in section 2(g));

13 (2) establishing voluntary standards for such
14 registries that include common data elements and
15 clear data definitions to enable the comparability
16 and synchronization of data by researchers;

17 (3) utilize data from such registries to help in-
18 form understanding regarding the efficacy of care,
19 diagnostics, therapeutics, care pathways, behavioral
20 health interventions, and other dynamics regarding
21 individuals with Long COVID; and

22 (4) informing health care providers' efforts re-
23 lated to improving equitable access to health care by
24 collecting data through such registries from individ-
25 uals with Long COVID, including social needs, med-
26 ical history, race and ethnicity, language, gender,

1 and disability status, as specified by the Secretary of
2 Health and Human Services.

3 (b) ELIGIBLE ENTITIES.—

4 (1) IN GENERAL.—To be eligible for a grant
5 under subsection (a) an entity shall—

6 (A) submit an application to the Secretary
7 in such form and manner as the Secretary may
8 require;

9 (B) agree to adhere to such data defini-
10 tions and standards as the Secretary may re-
11 quire, including privacy and security require-
12 ments, requirements to make findings of the or-
13 ganization, and the use of open-source tech-
14 nology to promote the dissemination of informa-
15 tion related to Long COVID;

16 (C) agree to make any information col-
17 lected or produced by the entity pursuant to the
18 grant available to the public through secure,
19 non-proprietary means without a paywall or fee;

20 (D) demonstrate to the Secretary, in a
21 form and manner specified by the Secretary,
22 that the entity has in place appropriate stand-
23 ards for handling proprietary, confidential, and
24 medical information securely and in a manner
25 that is compliant with applicable law;

1 (E) have in place and demonstrate to the
2 Secretary the adequacy of a plan for the
3 Longer-term financial sustainability of such
4 registry; and

5 (F) be an organization described in para-
6 graph (2).

7 (2) ORGANIZATIONS.—For purposes of para-
8 graph (1), an organization described in this para-
9 graph is any of the following:

10 (A) A non-profit organization representa-
11 tive of individuals with Long COVID.

12 (B) An organization of health care pro-
13 viders, such as health systems and hospitals.

14 (C) An organization of data scientists.

15 (D) Multi-sector groups that consist of or-
16 ganizations described in 2 or more of the pre-
17 ceding subparagraphs that meet such standards
18 as the Secretary may require.

19 (c) CONSIDERATION.—In carrying out the purposes
20 described in subsection (a), an eligible entity shall take
21 into consideration the report made available under section
22 4(b).

23 (d) AUTHORIZATION OF APPROPRIATIONS.—There is
24 authorized to be appropriated to carry out this section
25 \$10,000,000 for each of fiscal years 2024 through 2028.

1 **SEC. 8. MEDICAID HEALTH HOMES FOR INDIVIDUALS WITH**
2 **LONG COVID.**

3 (a) HEALTH HOMES FOR INDIVIDUALS WITH
4 CHRONIC CONDITIONS.—Section 1945(h)(1)(A)(ii) of the
5 Social Security Act (42 U.S.C. 1396w–4(h)(1)(A)(ii)) is
6 amended—

7 (1) in subclause (II), by striking at the end
8 “or”;

9 (2) in subclause (III), by striking at the end the
10 period and inserting “; or”; and

11 (3) by adding at the end the following new sub-
12 clause:

13 “(IV) Long COVID (as defined
14 in section 2(g) of the Long COVID
15 RECOVERY NOW Act).”.

16 (b) HEALTH HOMES FOR CHILDREN WITH MEDI-
17 CALLY COMPLEX CONDITIONS.—Section
18 1945A(i)(1)(A)(ii) of the Social Security Act (42 U.S.C.
19 1396w–4a(i)(1)(A)(ii)) is amended—

20 (1) in subclause (I), by striking at the end
21 “or”;

22 (2) in subclause (II), by striking at the end the
23 period and inserting “; or”; and

24 (3) by adding at the end the following new sub-
25 clause:

1 “(III) Long COVID (as defined
2 in section 2(g) of the Long COVID
3 RECOVERY NOW Act).”.

4 **SEC. 9. STATE HEALTH OFFICIALS GUIDANCE.**

5 Not later than 18 months after the date of the enact-
6 ment of this Act, the Secretary of Health and Human
7 Services shall issue guidance to State health officials speci-
8 fying tools and strategies that may help States improve
9 the health and wellness of individuals enrolled under the
10 Medicaid program under title XIX of the Social Security
11 Act or the Children’s Health Insurance Program under
12 title XXI of such Act who have been diagnosed with Long
13 COVID by facilitating strong primary care and supporting
14 linkages to specialists, relevant social supports, or commu-
15 nity-based organizations at the local level, that can help
16 support the recovery and wellness of such individuals.

17 **SEC. 10. SUPPORT UNDER MEDICAID FOR STATE COLLEC-**
18 **TION OF LONG COVID DATA.**

19 Section 1903(a)(3) of the Social Security Act (42
20 U.S.C. 1396b(a)(3)) is amended by adding at the end the
21 following new subparagraph:

22 “(I) 75 percent of the sums expended during a
23 fiscal year quarter in 2024, 2025, or 2026 as are at-
24 tributable to the collection and reporting of claims
25 and encounter data on Long COVID (including

1 identification of race, language, ethnicity, and dura-
2 tion of treatment) using the ICD–10 code U09.9
3 post COVID–19 condition, unspecified (or any suc-
4 cessor to such code);”.

5 **SEC. 11. GRANTS FOR PEDIATRIC RESEARCH ON LONG**
6 **COVID.**

7 (a) IN GENERAL.—The Secretary of Health and
8 Human Services, acting through the Director of the Na-
9 tional Institutes of Health (in this section, referred to as
10 the “Secretary”), shall award grants to eligible entities to
11 conduct research on Long COVID in pediatric popu-
12 lations.

13 (b) USE OF FUNDS.—An eligible entity selected to
14 receive a grant under this subsection may use funds re-
15 ceived through the grant to conduct research described in
16 subsection (a), with a focus on pediatric immune system
17 responses and neurodevelopment.

18 (c) ELIGIBLE ENTITY DEFINED.—In this section, the
19 term “eligible entity” means a children’s hospital, pedi-
20 atric researcher, pediatrician, academic medical center, or
21 other organization determined appropriate by the Sec-
22 retary.

23 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
24 out this section, there are authorized to be appropriated

- 1 such sums as may be necessary for each of fiscal years
- 2 2024 through 2026.