

118TH CONGRESS
1ST SESSION

H. R. 1616

To address research on, and improve access to, supportive services for individuals with Long COVID.

IN THE HOUSE OF REPRESENTATIVES

MARCH 17, 2023

Mr. BEYER (for himself and Mr. BERGMAN) introduced the following bill;
which was referred to the Committee on Energy and Commerce

A BILL

To address research on, and improve access to, supportive services for individuals with Long COVID.

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 “Comprehensive Access
5 to Resources and Education for Long COVID Act” or the
6 “CARE for Long COVID Act”.

1 **SEC. 2. AUTHORIZATION TO FUND A PATIENT REGISTRY**
2 **FOR RESEARCH ON LONG COVID AND RE-**
3 **LATED CONDITIONS.**

4 (a) IN GENERAL.—The Secretary of Health and
5 Human Services (referred to in this Act as the “Sec-
6 retary”), acting in coordination with the Patient-Centered
7 Outcomes Research Institute established under section
8 1181 of the Social Security Act (42 U.S.C. 1320e(b)),
9 shall fund activities described in subsection (b) to improve
10 treatment and outcomes for individuals with Long COVID
11 and related conditions.

12 (b) ACTIVITIES DESCRIBED.—For purposes of sub-
13 section (a), activities described in this subsection shall in-
14 clude—

15 (1) creating or maintaining a regularly updated
16 patient registry of individuals with suspected or con-
17 firmed Long COVID and related conditions, includ-
18 ing information on—

19 (A) symptoms that arise while an indi-
20 vidual is initially infected with COVID–19 and
21 that may resolve over time or extend beyond the
22 resolution of the initial symptoms;

23 (B) persistent symptoms that arise after
24 an individual is initially infected with COVID–
25 19 and that the clinician of such individual has

1 reason to suspect were related to the COVID-
2 19 diagnosis;

3 (C) symptoms that arise in an individual
4 that may be related to COVID-19, but a diag-
5 nosis of COVID-19 was not obtained and can-
6 not be identified due to a lack of antibodies,
7 false negative test results, or lack of access to
8 timely testing;

9 (D) treatments of individuals after primary
10 diagnosis of COVID-19 and the effectiveness of
11 such treatments;

12 (E) any other relevant questions or issues
13 related to individuals who experience a diag-
14 nosis of, treatment for, and management of
15 care with COVID-19, Long COVID, and re-
16 lated conditions; and

17 (F) comorbidities, vaccination status, and
18 demographics, including age, gender, race and
19 ethnicity, geographic location, disability, and oc-
20 cupation of registry participants;

21 (2) synthesis of information relating to individ-
22 uals experiencing Long COVID and related condi-
23 tions and other information available through the
24 patient registry;

1 (3) dissemination of information to relevant
2 Federal departments and agencies and patients par-
3 ticipating in the registry to inform treatment and
4 policy related to COVID–19, Long COVID, and re-
5 lated conditions;

6 (4) an assurance that the registry utilizes com-
7 mon data elements and definitions for use in order
8 to promote appropriate data sharing for ongoing and
9 future research; and

10 (5) outreach to, and inclusion in the patient
11 registry, as appropriate, of individuals, including
12 children and older adults, from communities im-
13 pacted by high COVID–19 and Long COVID rates,
14 communities affected by health disparities and in-
15 equities (including Indian Tribes and Tribal organi-
16 zations, urban Indian organizations, and people with
17 disabilities), individuals with related conditions,
18 health care providers, first responders, military serv-
19 ice members, veterans, pregnant and lactating
20 women, frontline workers who may be impacted by
21 high COVID–19 and Long COVID rates, and health
22 care providers from diverse disciplines that may
23 treat individuals with COVID–19, Long COVID,
24 and related conditions.

1 (c) VOLUNTARY PARTICIPATION; PRIVACY PROTEC-
2 TIONS.—

3 (1) VOLUNTARY PARTICIPATION.—Participation
4 in the registry described in subsection (b)(1) shall be
5 voluntary, and a person creating, assisting in the
6 creation of, or maintaining the registry shall not in-
7 clude in the registry information about an individual
8 unless the individual consents to the inclusion of
9 such information.

10 (2) PRIVACY PROTECTIONS.—Information about
11 an individual that is included in the registry shall be
12 subject to all applicable privacy protections under
13 Federal and State law.

14 (d) REPORT.—Not later than 1 year after the estab-
15 lishment of the synthesized patient registry under sub-
16 section (b)(2), and annually thereafter, the Secretary shall
17 submit a report that includes data, findings, and informa-
18 tion with respect to the status of the patient registry (in-
19 cluding progress, barriers, and issues) to Congress and the
20 President.

21 (e) AUTHORIZATION OF APPROPRIATIONS.—To carry
22 out this section, there is authorized to be appropriated
23 \$30,000,000 for fiscal year 2024, which shall remain
24 available until expended.

1 **SEC. 3. RESEARCH ON UNITED STATES HEALTH CARE SYS-**
2 **TEM'S RESPONSE TO LONG COVID.**

3 (a) IN GENERAL.—The Secretary, in coordination
4 with the Director of the Agency for Healthcare Research
5 and Quality, the Director of the National Institutes of
6 Health, and the Director of the Centers for Disease Con-
7 trol and Prevention, shall conduct or support research re-
8 lated to the United States health care system's response
9 to Long COVID, including with respect to—

10 (1) the expansion and effectiveness of post-in-
11 fectious disease treatment, including—

12 (A) identifying barriers to access for treat-
13 ment of COVID–19, Long COVID, and related
14 conditions for veterans, older adults, people
15 with disabilities, children and young adults,
16 communities of color, underserved and rural
17 communities, and other groups impacted by
18 high rates of COVID–19, as determined by the
19 Secretary;

20 (B) evaluating and identifying potential
21 gaps or other weaknesses that contribute to
22 age, gender, geographic location, disability, oc-
23 cupation, and racial and ethnic disparities with
24 respect to COVID–19 infection rates, severity
25 and length of symptoms, associated diagnoses,
26 and outcomes; and

1 (C) identifying trends associated with dif-
2 ferences in diagnosis and treatment of Long
3 COVID and related conditions by demographic
4 factors such as age, gender, geographic loca-
5 tion, disability, occupation, race, ethnicity, or
6 other factors identified by the Secretary to pro-
7 mote health equity; and

8 (2) conducting and supporting research to—

9 (A) identify health care strategies that
10 help mitigate age, gender, geographic location,
11 disability, occupation, and racial and ethnic dis-
12 parities in COVID–19 infection rates, hos-
13 pitalizations, severity and length of symptoms,
14 secondary illnesses, and outcomes;

15 (B) identify health care-related factors
16 contributing to such disparities in COVID–19
17 infection rates, hospitalizations, severity and
18 length of symptoms, secondary illnesses, and
19 outcomes; and

20 (C) provide recommendations on ensuring
21 equity in diagnosis and access to quality post-
22 infectious treatments that may be advanced to
23 mitigate such disparities.

24 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry
25 out this section, there is authorized to be appropriated

1 \$15,000,000 for fiscal year 2024, which shall remain
2 available until expended.

3 **SEC. 4. EDUCATION AND DISSEMINATION OF INFORMATION**
4 **ON LONG COVID.**

5 (a) LONG COVID PUBLIC EDUCATION PROGRAM.—

6 The Secretary shall develop and disseminate to the public
7 regularly updated information regarding Long COVID, in
8 plain language and in a manner that is culturally and lin-
9 guistically appropriate and easily accessible to people with
10 disabilities and people with limited English proficiency, in-
11 cluding information on—

12 (1) the awareness, incidence, and short- and
13 long-term health effects associated with COVID–19
14 infection, including Long COVID associated dis-
15 ability;

16 (2) illnesses related and often comorbid with
17 Long COVID, which may include—

18 (A) myalgic encephalomyelitis/chronic fa-
19 tigue syndrome;

20 (B) fibromyalgia;

21 (C) postural orthostatic tachycardia syn-
22 drome and other forms of dysautonomia;

23 (D) autoimmune diseases associated with
24 viral triggers;

1 (E) connective tissue diseases exacerbated
2 or triggered by infections;

3 (F) mast cell activation syndrome;

4 (G) related conditions and illnesses that
5 may affect adults, young adults, or children;
6 and

7 (H) other conditions, as the Secretary de-
8 termines appropriate;

9 (3) the availability, as medically appropriate, of
10 treatment options for Long COVID and related con-
11 ditions overlapping with Long COVID identified
12 under paragraph (2); and

13 (4) strategies for reducing the likelihood of de-
14 veloping Long COVID.

15 (b) LONG COVID PROVIDER EDUCATION PRO-
16 GRAM.—The Secretary, in consultation with representa-
17 tives from impacted communities and health care pro-
18 viders who treat such communities or individuals, shall de-
19 velop and disseminate to health care providers, including
20 by developing or improving continuing medical education
21 programs that advance the education of such providers,
22 information on Long COVID, recommended assessment
23 tools, including how to assess patients' functional capacity
24 to support applications for disability benefits, and man-
25 agement of Long COVID and related conditions for the

1 purpose of ensuring that health care providers remain in-
2 formed about current information on Long COVID and
3 related conditions, including information on—

4 (1) Long COVID symptoms such as cognitive,
5 neurological, psychiatric, gastrointestinal, res-
6 piratory, and cardiovascular symptoms;

7 (2) myalgic encephalomyelitis/chronic fatigue
8 syndrome and fibromyalgia;

9 (3) postural orthostatic tachycardia syndrome
10 and other forms of dysautonomia;

11 (4) autoimmune diseases associated with viral
12 triggers;

13 (5) connective tissue diseases exacerbated or
14 triggered by infections;

15 (6) mast cell activation syndrome;

16 (7) related conditions and illnesses that may af-
17 fect adults, young adults, or children; and

18 (8) other conditions as the Secretary deter-
19 mines appropriate.

20 (c) CONSIDERATIONS.—In developing and dissemi-
21 nating information in subsections (a) and (b), the Sec-
22 retary shall ensure that—

23 (1) guidance on Long COVID diagnostics,
24 treatments, and care include demographic factors
25 such as age, gender, geographic location, disability,

1 occupation, race and ethnicity, and other factors
2 identified by the Secretary to promote health equity;
3 and

4 (2) individuals with Long COVID and related
5 conditions, and entities representing such individ-
6 uals, are empowered to participate in protocol devel-
7 opment and outreach and education strategies.

8 (d) DISSEMINATION OF INFORMATION.—The Sec-
9 retary shall disseminate, in plain language and in a man-
10 ner that is culturally and linguistically appropriate and
11 easily accessible to people with disabilities and individuals
12 with limited English proficiency, information under sub-
13 sections (a) and (b), directly or through arrangements
14 with intra-agency initiatives, nonprofit organizations, con-
15 sumer groups, Federally qualified health centers, institu-
16 tions of higher learning (as defined in section 101 of the
17 Higher Education Act of 1965 (20 U.S.C. 1001)), local
18 educational agencies or State educational agencies (as de-
19 fined in section 8101 of the Elementary and Secondary
20 Education Act of 1965 (20 U.S.C. 7801)), or Federal,
21 State, Tribal, or local public private partnerships.

22 (e) AUTHORIZATION OF APPROPRIATIONS.—To carry
23 out this section, there is authorized to be appropriated
24 \$30,000,000 for each of fiscal years 2024 through 2026,
25 which shall remain available until expended.

1 **SEC. 5. INTERAGENCY COORDINATION AND INFORMATION**
2 **DISSEMINATION ON RIGHTS ASSOCIATED**
3 **WITH LONG COVID.**

4 (a) IN GENERAL.—The Secretary shall convene rel-
5 evant agencies to develop information and resources to
6 make available to the public and for dissemination to indi-
7 viduals and communities impacted by Long COVID and
8 related conditions to raise awareness and provide edu-
9 cation on the impact Long COVID and related conditions
10 may have on rights associated with employment, disability
11 status, and education afforded under Federal and State
12 law.

13 (b) COLLABORATION AND CONSULTATION.—In devel-
14 oping the information and resources under subsection (a),
15 the Secretary—

16 (1) shall collaborate with—

17 (A) the Secretary of Labor and the Assist-
18 ant Secretary of Labor for Disability Employ-
19 ment Policy;

20 (B) the Secretary of Education;

21 (C) the Commissioner of the Social Secu-
22 rity Administration;

23 (D) the Secretary of Veterans Affairs;

24 (E) the heads of relevant agencies within
25 the Department of Health and Human Services,
26 including—

- 1 (i) the Director of the Centers for
2 Disease Control and Prevention;
- 3 (ii) the Director of the National Insti-
4 tutes of Health;
- 5 (iii) the Administrator of the Centers
6 for Medicare & Medicaid Services;
- 7 (iv) the Administrator of the Adminis-
8 tration for Children and Families; and
- 9 (v) the Administrator of the Adminis-
10 tration for Community Living; and
- 11 (F) the heads of other Federal depart-
12 ments, agencies, or offices, as the Secretary de-
13 termines appropriate to carry out the activities
14 described in this section; and
- 15 (2) may consult with—
- 16 (A) communities and professionals im-
17 pacted by high COVID–19 rates;
- 18 (B) individuals with Long COVID and re-
19 lated conditions;
- 20 (C) caregivers of individuals with Long
21 COVID and related conditions; and
- 22 (D) organizations and experts that rep-
23 resent the rights and interests of the groups de-
24 scribed in subparagraphs (A), (B), and (C).

1 (c) INFORMATION AND RESOURCES DEVELOPED.—

2 Not later than 1 year after the date of enactment of this
3 Act, and annually thereafter, the entities described in sub-
4 section (b) shall develop information and resources to in-
5 clude—

6 (1) educational materials to school administra-
7 tors, counselors, educators, parents, coaches, school
8 nurses, and other school staff about Long COVID
9 and related conditions with clear guidance on appro-
10 priate academic, social, and emotional supports and
11 services, and the rights of students with disabilities,
12 available to students and families;

13 (2) guidance for employers on the rights of peo-
14 ple with disabilities related to Long COVID and re-
15 lated conditions, including strategies for how em-
16 ployers can support such individuals in the work-
17 place; and

18 (3) guidance on Long COVID and related con-
19 ditions as a disability, including recommendations to
20 streamline the process of applying for benefits
21 through the Social Security Administration, includ-
22 ing guidance on evaluating Long COVID and related
23 conditions for individuals under the age of 18, con-
24 tinuing disability reviews, and the payment of bene-
25 fits under part L of title I of the Omnibus Crime

1 Control and Safe Streets Act of 1968 (34 U.S.C.
2 10281 et seq.).

3 (d) DISSEMINATION OF INFORMATION.—The Sec-
4 retary shall disseminate the information and resources de-
5 veloped under subsection (c) to—

6 (1) States or State agencies implementing the
7 State protection and advocacy system (as defined in
8 section 102 of the Developmental Disabilities Assist-
9 ance and Bill of Rights Act of 2000 (42 U.S.C.
10 15002));

11 (2) State agencies on aging or area agencies on
12 aging (as such terms are defined in section 102 of
13 the Older Americans Act of 1965 (42 U.S.C. 3002));

14 (3) organizations and experts that represent
15 workers' rights and education; and

16 (4) other organizations and experts that rep-
17 resent the rights and interests of individuals with
18 Long COVID and related conditions.

19 (e) APPROPRIATIONS.—To carry out this section,
20 there is authorized to be appropriated \$30,000,000 for
21 each of fiscal years 2024 through 2026, which shall re-
22 main available until expended.

1 **SEC. 6. PROGRAM TO SUPPORT LEGAL AND SOCIAL SERV-**
2 **ICE ASSISTANCE FOR INDIVIDUALS WITH**
3 **LONG COVID.**

4 (a) IN GENERAL.—The Secretary, acting through the
5 Administrator of the Administration for Community Liv-
6 ing, shall award grants or contracts to eligible entities for
7 purposes of establishing or expanding medical-legal part-
8 nerships, or increasing the availability of legal assistance
9 or social supports necessary, to provide effective aid or
10 support to individuals with Long COVID and related con-
11 ditions, and their caregivers, who are seeking assistance
12 in obtaining or maintaining access to, or in legal matters
13 relating to, any of the following services, at minimal or
14 no cost to the individuals:

15 (1) The Social Security Disability Insurance
16 program under section 223 of the Social Security
17 Act (42 U.S.C. 423).

18 (2) The supplemental security income program
19 under title XVI of the Social Security Act (42
20 U.S.C. 1381 et seq.).

21 (3) Survivors benefits under title II of the So-
22 cial Security Act (42 U.S.C. 401 et seq.).

23 (4) Housing matters.

24 (5) Access to medical care.

1 (6) Access to vocational rehabilitation services
2 under title I of the Rehabilitation Act of 1973 (29
3 U.S.C. 720 et seq.).

4 (7) Access to assistive technology under the As-
5 sistive Technology Act of 1998 (29 U.S.C. 3001 et
6 seq.).

7 (8) Early intervention, specialized instruction,
8 and related services and accommodations for chil-
9 dren provided under parts B and C of the Individ-
10 uals with Disabilities Education Act (20 U.S.C.
11 1411 et seq.; 20 U.S.C. 1431 et seq.) and section
12 504 of the Rehabilitation Act of 1973 (29 U.S.C.
13 794).

14 (9) The low-income home energy assistance pro-
15 gram established under the Low-Income Home En-
16 ergy Assistance Act of 1981 (42 U.S.C. 8621 et
17 seq.).

18 (10) Employment supports.

19 (11) Nutrition assistance.

20 (12) Traumatic brain injury supports.

21 (13) Other support services for low-income indi-
22 viduals and people with disabilities (as defined in
23 section 3 of the Americans with Disabilities Act of
24 1990 (42 U.S.C. 12102)).

25 (b) ELIGIBILITY FOR AWARDS.—

1 (1) IN GENERAL.—To be eligible to receive an
2 award under this section, an entity shall—

3 (A) be—

4 (i) a State, or an agency imple-
5 menting the State protection and advocacy
6 system (as defined in section 102 of the
7 Developmental Disabilities Assistance and
8 Bill of Rights Act of 2000 (42 U.S.C.
9 15002));

10 (ii) a State agency or area agency on
11 aging (as such terms are defined in section
12 102 of the Older Americans Act of 1965
13 (42 U.S.C. 3002));

14 (iii) a nonprofit entity or a publicly
15 funded organization not acting in a govern-
16 mental capacity, such as a law school;

17 (iv) an Indian Tribe or Tribal organi-
18 zation;

19 (v) an urban Indian organization;

20 (vi) a territory;

21 (vii) a health care provider with an
22 existing multi-disciplinary clinic or other
23 specialized program focused on serving in-
24 dividuals with Long COVID, underserved
25 communities, or low-income patients, or

1 with a demonstrated intent to create such
2 a program;

3 (viii) an entity providing legal serv-
4 ices; or

5 (ix) a consortium of entities described
6 in clauses (i) through (viii);

7 (B) agree to use the award for the pur-
8 poses described in subsection (c); and

9 (C) partner with at least one community-
10 based organization with a demonstrated history
11 of serving people with disabilities, including
12 helping people with disabilities access sup-
13 portive services, or a demonstrated history of
14 serving impacted communities, including lim-
15 ited-English proficient communities.

16 (2) PRIORITY.—In making awards under sub-
17 section (a), the Secretary shall give priority to enti-
18 ties described in paragraph (1) that certify in writ-
19 ing that any person providing legal assistance
20 through a program supported by the award—

21 (A)(i) has demonstrated expertise in pro-
22 viding legal assistance to people with disabil-
23 ities; or

1 (ii) is partnered with a person or organiza-
2 tion that has demonstrated expertise described
3 in clause (i); and

4 (B) has completed, or will complete, train-
5 ing in connection with disability-related legal
6 issues.

7 (c) USE OF FUNDS.—An eligible entity receiving an
8 award under this section may use such award to—

9 (1) establish or expand medical-legal partner-
10 ships or other cooperative efforts between commu-
11 nity-based organizations, medical and social service
12 providers, and legal assistance providers to provide
13 legal assistance and help accessing or maintaining
14 social services for individuals with Long COVID;

15 (2) establish or expand efforts and projects to
16 provide legal assistance for individuals with Long
17 COVID by organizations with a demonstrated his-
18 tory of providing direct legal or advocacy services on
19 behalf of people with disabilities;

20 (3) provide technical assistance to organizations
21 or agencies for educating individuals with Long
22 COVID, caregivers, and parents, including foster
23 parents, caring for children with Long COVID about
24 rights related to accommodations in employment,

1 education, or other matters as determined by the
2 Secretary; and

3 (4) employ staff or educate current staff on as-
4 sisting individuals with Long COVID in obtaining
5 health care, social services, or legal services.

6 (d) REPORTING.—Eligible entities receiving an award
7 under this section shall collect data and report information
8 to the Secretary of Health and Human Services in a man-
9 ner prescribed by such Secretary.

10 (e) EVALUATION.—Not later than 1 year after the
11 date of enactment of this Act, and annually thereafter,
12 the Secretary of Health and Human Services shall submit
13 a report to the Committee on Health, Education, Labor,
14 and Pensions of the Senate and the Committee on Energy
15 and Commerce of the House of Representatives, which
16 shall also be made publicly available, outlining the number
17 of individuals who sought services offered by recipients of
18 awards under this section and the services provided. Such
19 report shall include a summary of activities conducted
20 under the program under this section, and information
21 broken down by award recipient.

22 (f) AUTHORIZATION OF APPROPRIATIONS.—

23 (1) IN GENERAL.—There is authorized to be
24 appropriated to carry out this section \$50,000,000
25 for each of fiscal years 2024 through 2028.

1 (2) NONSUPPLANTATION.—Amounts made
2 available under this section shall be used to supple-
3 ment and not supplant other Federal, State, and
4 local funds expended to further the purpose of this
5 section.

6 **SEC. 7. DEFINITIONS.**

7 In this Act:

8 (1) INDIAN TRIBE.—The terms “Indian Tribe”
9 has the meaning given the term “Indian tribe” in
10 section 102 of the Federally Recognized Indian
11 Tribe List Act of 1994 (25 U.S.C. 5130).

12 (2) LONG COVID.—The term “Long COVID”
13 means health conditions that may result, directly or
14 indirectly, from COVID–19.

15 (3) URBAN INDIAN ORGANIZATION.—The term
16 “urban Indian organization” has the meaning given
17 such term in section 4 of the Indian Health Care
18 Improvement Act (25 U.S.C. 1603).

19 (4) TRIBAL ORGANIZATION.—The term “Tribal
20 organization” means the recognized governing body
21 of any Indian Tribe; any legally established organi-
22 zation of Indians which is controlled, sanctioned, or
23 chartered by such governing body or which is demo-
24 cratically elected by the adult members of the Indian
25 community to be served by such organization and

1 which includes the maximum participation of Indi-
2 ans in all phases of its activities: *Provided*, That in
3 any case where a contract is let or grant made to
4 an organization to perform services benefitting more
5 than one Indian Tribe, the approval of each such In-
6 dian Tribe shall be a prerequisite to the letting or
7 making of such contract or grant.

○