

117TH CONGRESS
2^D SESSION

S. _____

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

IN THE SENATE OF THE UNITED STATES

Mr. KAINE (for himself, Mr. MARKEY, and Ms. DUCKWORTH) introduced the following bill; which was read twice and referred to the Committee on

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 RESEARCH OF THE**
2 **LONG-TERM SYMPTOMS OF COVID-19 BY THE**
3 **PATIENT-CENTERED OUTCOMES RESEARCH**
4 **TRUST FUND.**

5 (a) IN GENERAL.—The Patient-Centered Outcomes
6 Research Trust Fund under section 1181 of the Social Se-
7 curity Act (42 U.S.C. 1320e(b)) shall fund activities de-
8 scribed in subsection (b) to improve treatment and out-
9 comes for individuals with PASC.

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

13 (1) prior to creating a patient registry described
14 in paragraph (2)—

15 (A) surveying existing patient registries
16 that include individuals experiencing PASC and
17 other relevant chronic disease or health reg-
18 istries; and

19 (B) identifying common data elements and
20 definitions for use, in order to promote appro-
21 priate data sharing for ongoing and future re-
22 search;

23 (2) creating a patient registry, informed by the
24 survey described in paragraph (1), for individuals
25 with suspected or confirmed PASC and related post-
26 viral illnesses or conditions—

1 (A) with information that is culturally- and
2 linguistically-appropriate and easily accessible
3 to people with disabilities, and which may in-
4 clude—

5 (i) symptoms that arise while an indi-
6 vidual is initially infected with COVID–19
7 and that may resolve over time or extend
8 beyond the resolution of the initial symp-
9 toms;

10 (ii) persistent symptoms that arise
11 after an individual is initially infected with
12 COVID–19 and that the clinician of such
13 individual has reason to suspect were re-
14 lated to the COVID–19 diagnosis;

15 (iii) symptoms that arise in an indi-
16 vidual that may be related to COVID–19
17 but a diagnosis of COVID–19 was not ob-
18 tained and cannot be identified due to a
19 lack of antibodies, false negative test re-
20 sults, or lack of access to timely testing;

21 (iv) treatments of individuals after
22 primary diagnosis of COVID–19 and the
23 effectiveness of such treatments; and

24 (v) any other relevant questions or
25 issues related to individuals who experience

1 a diagnosis of, treatment for, and manage-
2 ment of care with COVID–19, PASC, or
3 related post-viral illnesses;

4 (B) that collects information regarding co-
5 morbidities, vaccination status, and demo-
6 graphics, including age, gender, race and eth-
7 nicity, geographic location, disability, and occu-
8 pation of registry participants;

9 (C) that synthesizes information relating
10 to individuals experiencing PASC or related
11 post-viral illnesses or conditions from the survey
12 described in paragraph (1) and other informa-
13 tion available through the patient registry; and

14 (D) that disseminates information to rel-
15 evant Federal departments and agencies and
16 patients participating in the registry to inform
17 treatment and policy related to COVID–19,
18 PASC, or related post-viral illnesses and condi-
19 tions; and

20 (3) outreach to, and inclusion (as appropriate)
21 of, individuals, including children and older adults,
22 from communities impacted by high COVID–19
23 rates, communities affected by health disparities and
24 inequities, including Indian Tribes and Tribal orga-
25 nizations, urban Indian organizations, people with

1 disabilities, individuals with related post-viral ill-
2 nesses or conditions, health care providers, first re-
3 sponders, and frontline workers who may be im-
4 pacted by high COVID–19 rates, and health care
5 providers from diverse disciplines that may treat in-
6 dividuals with COVID–19, PASC, or related post-
7 viral illnesses and conditions.

8 (c) PRIVACY PROTECTIONS.—Participation in the
9 registry described in subsection (b)(2) shall be voluntary
10 and personal and health information of participants, in-
11 cluding information voluntarily submitted through the reg-
12 istry, shall be subject to all applicable privacy protections
13 under Federal or 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 Patient-Cen-
17 tered Outcomes Research Institute shall submit data, find-
18 ings, and information with respect to the status of the pa-
19 tient registry (including progress, barriers, and issues) to
20 Congress and the 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 2023, which shall remain
24 available until expended.

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

3 (a) IN GENERAL.—The Secretary of Health and
4 Human Services (referred to in this Act as the “Sec-
5 retary”), in coordination with the Director of the Agency
6 for Healthcare Research and Quality, the Director of the
7 National Institutes of Health, and the Director of the Cen-
8 ters for Disease Control and Prevention, shall conduct or
9 support research related to the United States health care
10 system’s response to PASC, including with respect to—

11 (1) the expansion and efficacy of post-infectious
12 disease treatment, including—

13 (A) identifying obstacles to access for
14 treatment of COVID–19, PASC, or related
15 post-viral illnesses and conditions for veterans,
16 older adults, people with disabilities, children
17 and young adults, communities of color, under-
18 served and rural communities, and other groups
19 impacted by high rates of COVID–19, as deter-
20 mined by the Secretary;

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

1 (C) identifying trends associated with dif-
2 ferences in diagnosis and treatment of PASC
3 and related post-viral illnesses and conditions
4 by demographic factors such as age, gender, ge-
5 ographic location, disability, occupation, race,
6 ethnicity, or other factors identified by the Sec-
7 retary to promote 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, going forward.

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

1 \$15,000,000 for fiscal year 2023, which shall remain
2 available until expended.

3 **SEC. 4. EDUCATION AND DISSEMINATION OF INFORMATION**
4 **ON PASC.**

5 (a) POST-ACUTE SEQUELAE OF COVID-19 (PASC)
6 PUBLIC EDUCATION PROGRAM.—The Secretary, acting
7 through the Director of the Centers for Disease Control
8 and Prevention, shall develop and disseminate to the pub-
9 lic information regarding PASC, in plain language and in
10 a manner that is culturally- and linguistically-appropriate
11 and easily accessible to people with disabilities and people
12 with limited English proficiency, including information
13 on—

14 (1) the awareness, incidence, and short- and
15 long-term health effects associated with COVID-19
16 infection;

17 (2) illnesses related and often comorbid with
18 PASC, which may include—

19 (A) myalgic encephalomyelitis/chronic fa-
20 tigue syndrome and fibromyalgia;

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

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

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

3 (E) mast cell activation syndrome;

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

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

9 (3) the availability, as medically appropriate, of
10 treatment options for PASC and related post-viral
11 illnesses and conditions overlapping with PASC iden-
12 tified under paragraph (2).

13 (b) POST-ACUTE SEQUELAE OF COVID-19 (PASC)
14 PROVIDER EDUCATION PROGRAM.—The Secretary, acting
15 through the Director of the Centers for Disease Control
16 and Prevention, shall, in consultation with representatives
17 from impacted communities and health care providers who
18 treat these communities or individuals, develop and dis-
19 seminate to health care providers information on PASC,
20 recommended assessment tools, and management of PASC
21 and related conditions for the purpose of ensuring that
22 health care providers remain informed about current infor-
23 mation on such emerging illness and related post-infec-
24 tious illnesses, which have been shown to be closely related
25 to PASC, including information on—

1 (1) PASC symptoms such as cognitive, neuro-
2 logical, psychiatric, gastrointestinal, respiratory, and
3 cardiovascular symptoms;

4 (2) myalgic encephalomyelitis/chronic fatigue
5 syndrome and fibromyalgia;

6 (3) postural orthostatic tachycardia syndrome
7 and other forms of dysautonomia;

8 (4) autoimmune diseases associated with viral
9 triggers;

10 (5) connective tissue diseases exacerbated or
11 triggered by infections;

12 (6) mast cell activation syndrome;

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

15 (8) other conditions as the Secretary deter-
16 mines appropriate.

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

20 (1) guidance on PASC diagnostics, treatments,
21 and care include demographic factors such as age,
22 gender, geographic location, disability, occupation,
23 race and ethnicity, and other factors identified by
24 the Secretary to promote health equity; and

1 (2) individuals with PASC or related post-viral
2 illnesses and conditions, and entities representing
3 such individuals, are empowered to participate in
4 protocol development and outreach and education
5 strategies.

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

20 (e) AUTHORIZATION OF APPROPRIATIONS.—To carry
21 out this section, there is authorized to be appropriated
22 \$30,000,000 for each of fiscal years 2023 through 2025,
23 which shall remain available until expended.

1 **SEC. 5. INTERAGENCY COORDINATION ON PUBLIC EN-**
2 **GAGEMENT AND INFORMATION DISSEMINA-**
3 **TION ON PASC.**

4 (a) IN GENERAL.—The Secretary of Health and
5 Human Services shall convene relevant agencies to develop
6 information and resources to make available to the public
7 and for dissemination to individuals and communities im-
8 pacted by PASC and related post-viral illness and condi-
9 tions to raise awareness and provide education on the im-
10 pact PASC or related post-viral illness and conditions may
11 have on rights associated with employment, disability sta-
12 tus, and education afforded under Federal and State law.

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

16 (1) shall collaborate with—

17 (A) the Department of Labor, including
18 the Office of Disability Employment Policy of
19 the Department of Labor;

20 (B) the Department of Education;

21 (C) the Social Security Administration;

22 (D) relevant agencies within the Depart-
23 ment of Health and Human Services, includ-
24 ing—

25 (i) the Centers for Disease Control
26 and Prevention;

1 (ii) the National Institutes of Health;

2 (iii) the Centers for Medicare & Med-

3 icaid Services;

4 (iv) the Administration for Children
5 and Families; and

6 (v) the Administration on Community
7 Living; and

8 (E) other Federal departments, agencies,
9 or offices, as the Secretary determines appro-
10 priate to carry out the activities described in
11 this section; and

12 (2) may consult with—

13 (A) communities and professions impacted
14 by high COVID–19 rates;

15 (B) individuals with PASC or related post-
16 viral illnesses and conditions; and

17 (C) organizations and experts that rep-
18 resent the rights and interests of the groups de-
19 scribed in subparagraphs (A) and (B).

20 (c) INFORMATION AND RESOURCES DEVELOPED.—

21 Not later than 1 year after the date of enactment of this
22 Act, the entities described in subsection (b) shall develop
23 information and resources to include—

24 (1) educational materials to school administra-
25 tors, counselors, educators, parents, coaches, school

1 nurses, and other school staff about PASC and re-
2 lated post-viral illnesses and conditions with clear
3 guidance on appropriate academic, social, and emo-
4 tional supports and services, and the rights of stu-
5 dents with disabilities, available to students and
6 families;

7 (2) guidance for employers on the rights of peo-
8 ple with disabilities related to PASC and related
9 post-viral illnesses and conditions; and

10 (3) guidance on PASC and related post-viral ill-
11 nesses and conditions as a disability, including rec-
12 ommendations to streamline the process of applying
13 for benefits through the Social Security Administra-
14 tion, including guidance on evaluating PASC and re-
15 lated post-viral illnesses and conditions for individ-
16 uals under the age of 18, continuing disability re-
17 views, and the payment of benefits under part L of
18 title I of the Omnibus Crime Control and Safe
19 Streets Act of 1968 (34 U.S.C. 10281 et seq.).

20 (d) APPROPRIATIONS.—To carry out this section,
21 there is authorized to be appropriated \$30,000,000 for
22 each of fiscal years 2023 through 2025, which shall re-
23 main available until expended.

1 **SEC. 6. RESEARCH WITH RESPECT TO MEDICAID COV-**
2 **ERAGE OF LONG-TERM SYMPTOMS OF COVID-**
3 **19.**

4 (a) RESEARCH.—The Secretary of Health and
5 Human Services shall expand the Chronic Conditions
6 Data Warehouse research database of the Centers for
7 Medicare & Medicaid Services to collect data on items and
8 services furnished to individuals under a State plan (or
9 a waiver of such a plan) under the Medicaid program
10 under title XIX of the Social Security Act (42 U.S.C.
11 1396 et seq.) or under a State child health plan (or a waiv-
12 er of such a plan) under the Children’s Health Insurance
13 Program under title XXI of such Act (42 U.S.C. 1397aa
14 et seq.) for the treatment of PASC, for purposes of assess-
15 ing the frequency at which COVID–19 survivors are fur-
16 nished such items and services.

17 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry
18 out this section, there is authorized to be appropriated
19 \$3,000,000 for fiscal year 2022, which shall remain avail-
20 able until expended.

21 **SEC. 7. PROGRAM TO SUPPORT LEGAL AND SOCIAL SERV-**
22 **ICE ASSISTANCE FOR INDIVIDUALS WITH**
23 **PASC.**

24 (a) IN GENERAL.—The Secretary of Health and
25 Human Services, acting through the Administrator of the
26 Administration for Community Living, shall award grants

1 or contracts to eligible entities for purposes of establishing
2 or expanding medical-legal partnerships, or increasing the
3 availability of legal assistance or social supports necessary,
4 to provide effective aid or support to individuals with
5 PASC or related post-viral illnesses and conditions who
6 are seeking assistance in obtaining or maintaining access
7 to, or in legal matters relating to, any of the following
8 services, at minimal or no cost to the individuals:

9 (1) The Social Security Disability Insurance
10 program under section 223 of the Social Security
11 Act (42 U.S.C. 423).

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

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

17 (4) Housing matters.

18 (5) Access to medical care.

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

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

1 (8) Early intervention, specialized instruction,
2 and related services and accommodations for chil-
3 dren provided under parts B and C of the Individ-
4 uals with Disabilities Education Act (20 U.S.C.
5 1411 et seq.; 20 U.S.C. 1431 et seq.) and section
6 504 of the Rehabilitation Act of 1973 (29 U.S.C.
7 794).

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

12 (10) Employment supports.

13 (11) Nutrition assistance.

14 (12) Other support services for low-income indi-
15 viduals and people with disabilities (as defined in
16 section 3 of the Americans with Disabilities Act of
17 1990 (42 U.S.C. 12102).

18 (b) ELIGIBILITY FOR AWARDS.—

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

21 (A) be —

22 (i) a State, or an agency imple-
23 menting the State protection and advocacy
24 system (as defined in section 102 of the
25 Developmental Disabilities Assistance and

1 Bill of Rights Act of 2000 (42 U.S.C.
2 15002));

3 (ii) a nonprofit entity or a publicly
4 funded organization not acting in a govern-
5 mental capacity, such as a law school;

6 (iii) an Indian Tribe or Tribal organi-
7 zation;

8 (iv) an urban Indian organization;

9 (v) a territory;

10 (vi) a health care provider with an ex-
11 isting multi-disciplinary clinic or other spe-
12 cialized program focused on serving indi-
13 viduals with PASC, underserved commu-
14 nities, or low-income patients, or with a
15 demonstrated intent to create such a pro-
16 gram;

17 (vii) an entity providing legal services;

18 or

19 (viii) a consortium of entities de-
20 scribed in clauses (i) through (vii);

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

23 (C) partner with at least one community-
24 based organization with a demonstrated history
25 of serving people with disabilities, including

1 helping people with disabilities access sup-
2 portive services, or a demonstrated history of
3 serving impacted communities, including lim-
4 ited-English proficient communities.

5 (2) PRIORITY.—In making awards under sub-
6 section (a), the Secretary shall give priority to enti-
7 ties described in paragraph that certify in writing
8 that any person providing legal assistance through a
9 program supported by the award—

10 (A)(i) has demonstrated expertise in pro-
11 viding legal assistance to people with disabil-
12 ities; or

13 (ii) is partnered with a person that has
14 demonstrated expertise described in clause (i);
15 and

16 (B) has completed, or will complete, train-
17 ing in connection with disability-related legal
18 issues.

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

21 (1) establish or expand medical-legal partner-
22 ships or other cooperative efforts between commu-
23 nity-based organizations, medical and social service
24 providers, and legal assistance providers to provide

1 legal assistance and help accessing or maintaining
2 social services for individuals with PASC;

3 (2) establish or expand efforts and projects to
4 provide legal assistance for individuals with PASC
5 by organizations with a demonstrated history of pro-
6 viding direct legal or advocacy services on behalf of
7 people with disabilities;

8 (3) provide technical assistance to organizations
9 or agencies for educating individuals with PASC or
10 parents, including foster parents, caring for children
11 with PASC about rights related to accommodations
12 in employment, education, or other matters as deter-
13 mined by the Secretary; and

14 (4) employ staff or educate current staff on as-
15 sisting individuals with PASC in obtaining health
16 care, social services, or legal services.

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

21 (e) EVALUATION.—Not later than 1 year after the
22 date of enactment of this Act, and annually thereafter,
23 the Secretary of Health and Human Services shall submit
24 a report to the Committee on Health, Education, Labor,
25 and Pensions of the Senate and the Committee on Energy

1 and Commerce of the House of Representatives, which
2 shall also be made publicly available, outlining the number
3 of individuals who sought services offered by recipients of
4 awards under this section and the services provided. Such
5 report shall include a summary of activities conducted
6 under the program under this section, and information
7 broken down by award recipient.

8 (f) AUTHORIZATION OF APPROPRIATIONS.—

9 (1) IN GENERAL.—There is authorized to be
10 appropriated to carry out this section \$50,000,000
11 for each of fiscal years 2023 through 2027.

12 (2) NONSUPPLANTATION.—Amounts made
13 available under this section shall be used to supple-
14 ment and not supplant other Federal, State, and
15 local funds expended to further the purpose of this
16 section.

17 **SEC. 8. DEFINITIONS.**

18 In this Act:

19 (1) INDIAN TRIBE; TRIBAL ORGANIZATION.—
20 The terms “Indian Tribe” and “Tribal organiza-
21 tion” have the meanings given the terms “Indian
22 tribe” and “tribal organization” in section 4 of the
23 Indian Self-Determination and Education Assistance
24 Act (25 U.S.C. 5304).

1 (2) PASC.—The term “PASC” means post-
2 acute sequelae of COVID–19, commonly referred to
3 as “long COVID”.

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