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

IN THE SENATE OF THE UNITED STATES
MARCH 2, 2022
Mr. Kaine (for himself, Mr. Markey, and Ms. Duckworth) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Comprehensive Access to Resources and Education for Long COVID Act” or the “CARE for Long COVID Act”.

SEC. 2. AUTHORIZATION TO FUND RESEARCH OF THE
LONG-TERM SYMPTOMS OF COVID–19 BY THE
PATIENT-CENTERED OUTCOMES RESEARCH
TRUST FUND.

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

(b) Activities Described.—For purposes of sub-
section (a), activities described in this subsection shall in-
clude—

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

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

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

(2) creating a patient registry, informed by the
survey described in paragraph (1), for individuals
with suspected or confirmed PASC and related post-
viral illnesses or conditions—
(A) with information that is culturally and linguistically appropriate and easily accessible to people with disabilities, and which may include—

(i) symptoms that arise while an individual is initially infected with COVID–19 and that may resolve over time or extend beyond the resolution of the initial symptoms;

(ii) persistent symptoms that arise after an individual is initially infected with COVID–19 and that the clinician of such individual has reason to suspect were related to the COVID–19 diagnosis;

(iii) symptoms that arise in an individual that may be related to COVID–19 but a diagnosis of COVID–19 was not obtained and cannot be identified due to a lack of antibodies, false negative test results, or lack of access to timely testing;

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

(v) any other relevant questions or issues related to individuals who experience
a diagnosis of, treatment for, and manage-
ment of care with COVID–19, PASC, or
related post-viral illnesses;

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

(C) that synthesizes information relating


to individuals experiencing PASC or related
post-viral illnesses or conditions from the survey
described in paragraph (1) and other informa-
tion available through the patient registry; and

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

(3) outreach to, and inclusion (as appropriate)
of, individuals, including children and older adults,
from communities impacted by high COVID–19
rates, communities affected by health disparities and
inequities, including Indian Tribes and Tribal orga-
nizations, urban Indian organizations, people with
disabilities, individuals with related post-viral illnesses or conditions, health care providers, first responders, and frontline workers who may be impacted by high COVID–19 rates, and health care providers from diverse disciplines that may treat individuals with COVID–19, PASC, or related post-viral illnesses and conditions.

(c) Privacy Protections.—Participation in the registry described in subsection (b)(2) shall be voluntary and personal and health information of participants, including information voluntarily submitted through the registry, shall be subject to all applicable privacy protections under Federal or State law.

(d) Report.—Not later than 1 year after the establishment of the synthesized patient registry under subsection (b)(2), and annually thereafter, the Patient-Centered Outcomes Research Institute shall submit data, findings, and information with respect to the status of the patient registry (including progress, barriers, and issues) to Congress and the President.

(e) Authorization of Appropriations.—To carry out this section, there is authorized to be appropriated $30,000,000 for fiscal year 2023, which shall remain available until expended.
SEC. 3. RESEARCH ON UNITED STATES HEALTH CARE SYSTEM'S RESPONSE TO PASC.

(a) IN GENERAL.—The Secretary of Health and Human Services (referred to in this Act as the “Secretary”), in coordination with the Director of the Agency for Healthcare Research and Quality, the Director of the National Institutes of Health, and the Director of the Centers for Disease Control and Prevention, shall conduct or support research related to the United States health care system’s response to PASC, including with respect to—

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

(A) identifying obstacles to access for treatment of COVID–19, PASC, or related post-viral illnesses and conditions for veterans, older adults, people with disabilities, children and young adults, communities of color, underserved and rural communities, and other groups impacted by high rates of COVID–19, as determined by the Secretary;

(B) evaluating and identifying potential gaps or other weaknesses that contribute to age, gender, geographic location, disability, occupation, and racial and ethnic disparities with respect to COVID–19 infection rates, severity and length of symptoms, and outcomes; and
(C) identifying trends associated with differences in diagnosis and treatment of PASC and related post-viral illnesses and conditions by demographic factors such as age, gender, geographic location, disability, occupation, race, ethnicity, or other factors identified by the Secretary to promote health equity; and

(2) conducting and supporting research to—

(A) identify health care strategies that help mitigate age, gender, geographic location, disability, occupation, and racial and ethnic disparities in COVID–19 infection rates, hospitalizations, severity and length of symptoms, secondary illnesses, and outcomes;

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

(C) provide recommendations on ensuring equity in diagnosis and access to quality post-infectious treatments that may be advanced to mitigate such disparities, going forward.

(b) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there is authorized to be appropriated
$15,000,000 for fiscal year 2023, which shall remain available until expended.

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

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

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

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

(A) myalgic encephalomyelitis/chronic fatigue syndrome and fibromyalgia;

(B) postural orthostatic tachycardia syndrome and other forms of dysautonomia;

(C) autoimmune diseases associated with viral triggers;
(D) connective tissue diseases exacerbated
or triggered by infections;

(E) mast cell activation syndrome;

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

and

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

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

(b) POST-ACUTE SEQUELAE OF COVID–19 (PASC)

PROVIDER EDUCATION PROGRAM.—The Secretary, acting
through the Director of the Centers for Disease Control
and Prevention, shall, in consultation with representatives
from impacted communities and health care providers who
treat these communities or individuals, develop and dis-
seminate to health care providers information on PASC,
recommended assessment tools, and management of PASC
and related conditions for the purpose of ensuring that
health care providers remain informed about current infor-
mation on such emerging illness and related post-infec-
tious illnesses, which have been shown to be closely related
to PASC, including information on—
(1) PASC symptoms such as cognitive, neurological, psychiatric, gastrointestinal, respiratory, and cardiovascular symptoms;

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

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

(4) autoimmune diseases associated with viral triggers;

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

(6) mast cell activation syndrome;

(7) related conditions and illnesses that may affect adults, young adults, or children; and

(8) other conditions as the Secretary determines appropriate.

(c) CONSIDERATIONS.—In developing and disseminating information in subsections (a) and (b), the Secretary shall ensure that—

(1) guidance on PASC diagnostics, treatments, and care include demographic factors such as age, gender, geographic location, disability, occupation, race and ethnicity, and other factors identified by the Secretary to promote health equity; and
(2) individuals with PASC or related post-viral illnesses and conditions, and entities representing such individuals, are empowered to participate in protocol development and outreach and education strategies.

(d) Dissemination of Information.—The Secretary shall disseminate, in plain language and in a manner that is culturally and linguistically appropriate and easily accessible to people with disabilities and individuals with limited English proficiency, information under subsections (a) and (b), directly or through arrangements with intra-agency initiatives, nonprofit organizations, consumer groups, institutions of higher learning (as defined in section 101 of the Higher Education Act of 1965 (20 U.S.C. 1001)), local educational agencies or State educational agencies (as defined in section 8101 of the Elementary and Secondary Education Act of 1965 (20 U.S.C. 7801)), or Federal, State, Tribal, or local public private partnerships.

(e) Authorization of Appropriations.—To carry out this section, there is authorized to be appropriated $30,000,000 for each of fiscal years 2023 through 2025, which shall remain available until expended.
SEC. 5. INTERAGENCY COORDINATION ON PUBLIC ENGAGEMENT AND INFORMATION DISSEMINATION ON PASC.

(a) In General.—The Secretary of Health and Human Services shall convene relevant agencies to develop information and resources to make available to the public and for dissemination to individuals and communities impacted by PASC and related post-viral illness and conditions to raise awareness and provide education on the impact PASC or related post-viral illness and conditions may have on rights associated with employment, disability status, and education afforded under Federal and State law.

(b) Collaboration and Consultation.—In developing the information and resources under subsection (a), the Secretary of Health and Human Services—

(1) shall collaborate with—

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

(B) the Department of Education;

(C) the Social Security Administration;

(D) relevant agencies within the Department of Health and Human Services, including—

(i) the Centers for Disease Control and Prevention;
(ii) the National Institutes of Health;

(iii) the Centers for Medicare & Medicaid Services;

(iv) the Administration for Children and Families; and

(v) the Administration on Community Living; and

(E) other Federal departments, agencies, or offices, as the Secretary determines appropriate to carry out the activities described in this section; and

(2) may consult with—

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

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

(C) organizations and experts that represent the rights and interests of the groups described in subparagraphs (A) and (B).

(c) INFORMATION AND RESOURCES DEVELOPED.—Not later than 1 year after the date of enactment of this Act, the entities described in subsection (b) shall develop information and resources to include—

(1) educational materials to school administrators, counselors, educators, parents, coaches, school
nurses, and other school staff about PASC and related post-viral illnesses and conditions with clear guidance on appropriate academic, social, and emotional supports and services, and the rights of students with disabilities, available to students and families;

(2) guidance for employers on the rights of people with disabilities related to PASC and related post-viral illnesses and conditions; and

(3) guidance on PASC and related post-viral illnesses and conditions as a disability, including recommendations to streamline the process of applying for benefits through the Social Security Administration, including guidance on evaluating PASC and related post-viral illnesses and conditions for individuals under the age of 18, continuing disability reviews, and the payment of benefits under part L of title I of the Omnibus Crime Control and Safe Streets Act of 1968 (34 U.S.C. 10281 et seq.).

(d) Appropriations.—To carry out this section, there is authorized to be appropriated $30,000,000 for each of fiscal years 2023 through 2025, which shall remain available until expended.
SEC. 6. RESEARCH WITH RESPECT TO MEDICAID COVERAGE OF LONG-TERM SYMPTOMS OF COVID–19.

(a) Research.—The Secretary of Health and Human Services shall expand the Chronic Conditions Data Warehouse research database of the Centers for Medicare & Medicaid Services to collect data on items and services furnished to individuals under a State plan (or a waiver of such a plan) under the Medicaid program under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) or under a State child health plan (or a waiver of such a plan) under the Children’s Health Insurance Program under title XXI of such Act (42 U.S.C. 1397aa et seq.) for the treatment of PASC, for purposes of assessing the frequency at which COVID–19 survivors are furnished such items and services.

(b) Authorization of Appropriations.—To carry out this section, there is authorized to be appropriated $3,000,000 for fiscal year 2022, which shall remain available until expended.

SEC. 7. PROGRAM TO SUPPORT LEGAL AND SOCIAL SERVICE ASSISTANCE FOR INDIVIDUALS WITH PASC.

(a) In General.—The Secretary of Health and Human Services, acting through the Administrator of the Administration for Community Living, shall award grants
or contracts to eligible entities for purposes of establishing
or expanding medical-legal partnerships, or increasing the
availability of legal assistance or social supports necessary,
to provide effective aid or support to individuals with
PASC or related post-viral illnesses and conditions who
are seeking assistance in obtaining or maintaining access
to, or in legal matters relating to, any of the following
services, at minimal or no cost to the individuals:

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

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

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

(4) Housing matters.

(5) Access to medical care.

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

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

(9) The low-income home energy assistance program established under the Low-Income Home Energy Assistance Act of 1981 (42 U.S.C. 8621 et seq.).

(10) Employment supports.

(11) Nutrition assistance.

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

(b) ELIGIBILITY FOR AWARDS.—

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

(A) be—

(i) a State, or an agency implementing the State protection and advocacy system (as defined in section 102 of the Developmental Disabilities Assistance and
Bill of Rights Act of 2000 (42 U.S.C. 15002));

(ii) a nonprofit entity or a publicly funded organization not acting in a governmental capacity, such as a law school;

(iii) an Indian Tribe or Tribal organization;

(iv) an urban Indian organization;

(v) a territory;

(vi) a health care provider with an existing multi-disciplinary clinic or other specialized program focused on serving individuals with PASC, underserved communities, or low-income patients, or with a demonstrated intent to create such a program;

(vii) an entity providing legal services;

or

(viii) a consortium of entities described in clauses (i) through (vii);

(B) agree to use the award for the purposes described in subsection (c); and

(C) partner with at least one community-based organization with a demonstrated history of serving people with disabilities, including
helping people with disabilities access supportive services, or a demonstrated history of serving impacted communities, including limited-English proficient communities.

(2) PRIORITY.—In making awards under subsection (a), the Secretary shall give priority to entities described in paragraph that certify in writing that any person providing legal assistance through a program supported by the award—

(A)(i) has demonstrated expertise in providing legal assistance to people with disabilities; or

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

(B) has completed, or will complete, training in connection with disability-related legal issues.

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

(1) establish or expand medical-legal partnerships or other cooperative efforts between community-based organizations, medical and social service providers, and legal assistance providers to provide
legal assistance and help accessing or maintaining
social services for individuals with PASC;

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

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

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

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

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

(f) Authorization of Appropriations.—

(1) In general.—There is authorized to be
appropriated to carry out this section $50,000,000
for each of fiscal years 2023 through 2027.

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

SEC. 8. DEFINITIONS.

In this Act:

(1) Indian tribe; tribal organization.—
The terms “Indian Tribe” and “Tribal organiza-
tion” have the meanings given the terms “Indian
tribe” and “tribal organization” in section 4 of the
Indian Self-Determination and Education Assistance
(2) PASC.—The term “PASC” means post-acute sequelae of COVID–19, commonly referred to as “long COVID”.

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