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117TH CONGRESS
1ST SESSION

H. R. 2754

To authorize the Patient-Centered Outcomes Research Trust Fund to fund research of the symptoms of COVID–19, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

APRIL 22, 2021

Mr. BEYER (for himself and Mr. BERGMAN) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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A BILL

To authorize the Patient-Centered Outcomes Research Trust Fund to fund research of the symptoms of COVID–19, and for other purposes.

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 "COVID–19 Long Haulers 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 Security Act (42 U.S.C. 1320e(b)) shall fund research described in subsection (b).

(b) RESEARCH DESCRIBED.—For purposes of subsection (a), research described in this subsection shall include—

(1) prior to creating a patient registry described in paragraph (2), survey existing patient registries that include individuals experiencing post-acute sequelae of COVID–19 (in this section, referred to as ''PASC'');

(2) creating a patient registry for those with COVID–19 with information that—

(A) contains the—

(i) symptoms that arise while an individual is initially infected with COVID–19 and that resolve over time;

(ii) symptoms that arise while an individual is initially infected with COVID–19 and that extend beyond the resolution of initial symptoms;

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

(iv) 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;

(v) treatments of individuals after primary diagnosis to COVID–19 and the effectiveness of such treatments disaggregated by age, gender, race or ethnicity, and co-morbidities and related post-viral illnesses overlapping with PASC; and

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

(B) synthesizes information relating to individuals experiencing post-acute sequelae of

COVID–19 identified from the survey described in paragraph (1) and information under the patient registry described in paragraph (2); and

(3) outreach and inclusion (as appropriate) individuals from communities with PASC, traditional health 3 disparities and inequities and related post-viral illnesses overlapping with PASC.

(c) REPORT.—Not later than 1 year after the establishment of the synthesized patient registry described in subsection (a)(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.

(d) AUTHORIZATION OF APPROPRIATIONS.—There is hereby authorized $30,000,000 for fiscal year 2022 to carry out this section, which shall remain available until expended.

SEC. 3. RESEARCH ON UNITED STATES HEALTH CARE SYSTEM'S RESPONSE TO LONG-TERM SYMPTOMS OF COVID–19.

(a) IN GENERAL.—The Secretary of Health and Human Services, acting through the Director of the Agency for Healthcare Research and Quality, shall conduct or support research related to the United States health care

system's response to long-term symptoms of COVID–19, including with respect to—

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

(A) identifying obstacles to access for veterans, the elderly, disabled, and low-income communities;

(B) evaluating and identifying potential gaps or other weaknesses that bear on gender, geographic, racial and ethnic disparities on COVID–19 infection rates, severity and length of symptoms, and outcomes;

(C) identifying gaps in compliance with health care privacy and security rules; and

(D) evaluating whether diagnosis, access to, or treatment associated with medical providers and care delivered in different settings varied by gender, disability, geographic, racial and ethnic group; and

(2) conducting and support rapid turnaround research to—

(A) identify health care strategies that help mitigate gender, geographic, disability, racial and ethnic disparities in COVID–19 infec-

tion rates, 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 disease, 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) PROTOCOLS ON PASC PATIENTS.—The Secretary of Health and Human Services, acting through the Director of the Agency for Healthcare Research and Quality, shall coordinate cross-agency engagement with leaders from communities with PASC, traditional health disparities and inequities and related post-viral illnesses overlapping with PASC—

(1) to develop protocols that ensure PASC patients have access to medical professionals educated about post-infectious disease and treatments; and

(2) to provide guidance on PASC diagnostics, treatments, and care that takes into account gender, geographic, racial and ethnic disparities.

(c) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section $30,000,000 for fiscal year 2022 to carry out this section, which shall remain available until expended.

SEC. 4. EDUCATION AND DISSEMINATION OF INFORMATION WITH RESPECT TO LONG-TERM SYMPTOMS OF COVID–19.

(a) POST-ACUTE SEQUELAE OF COVID–19 (PASC) PUBLIC EDUCATION PROGRAM.—The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, shall develop and disseminate to the public information regarding PASC, including information on—

(1) the awareness, incidence, and common symptoms of PASC among COVID–19 patients;

(2) illnesses related and often comorbid with PASC, including but not limited to,

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

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

(C) autoimmune diseases associated with viral triggers;

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

(E) mast cell activation syndrome (MCAS); and

(3) the availability, as medically appropriate, of treatment options for PASC and related post-viral illnesses overlapping with PASC, as identified in section (2) above.

(b) POST-ACUTE SEQUELAE OF COVID–19 (PASC) PROVIDER EDUCATION PROGRAM.—The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, shall in consultation with communities with PASC, traditional health disparities and inequities and related post-viral illnesses overlapping with PASC, develop and disseminate to health care providers information on PASC for the purpose of ensuring that health care providers remain informed about current information on this emerging illness and related post-infectious illnesses, which have been shown to be closely related to PASC including information on—

(1) myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and fibromyalgia (FM);

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

(3) autoimmune diseases associated with viral triggers;

(4) connective tissue diseases exacerbated or triggered by infections; and

(5) mast cell activation syndrome (MCAS).

(c) DISSEMINATION OF INFORMATION.—The Secretary may disseminate information under subsection (a) and subsection (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)), or Federal, State, or local public private partnerships.

(d) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section $30,000,000 for fiscal year 2022 to carry out this section, which shall remain available until expended.

SEC. 5. RESEARCH WITH RESPECT TO MEDICAID COVERAGE OF LONG-TERM SYMPTOMS OF COVID–19.

(a) RESEARCH.—The Administrator of the Centers for Medicare & Medicaid Services (referred to in this section as the ''Administrator'') shall expand the Chronic Conditions Data Warehouse research database of such Centers for Medicare and Medicaid Services to collect data

on items and services furnished to individuals experiencing post-acute sequelae of COVID–19 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 post-acute sequelae of COVID–19 for purposes of assessing the frequency at which COVID–19 survivors are furnished such items and services.

(b) AUTHORIZATION OF APPROPRIATIONS.—There is authorized to be appropriated to carry out this section $3,000,000 for fiscal years 2022 to carry out this section, which shall remain available until expended.

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