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(Original Signature of Member)

117TH CONGRESS
1ST SESSION

H. R.

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

Mr. BEYER introduced the following bill; which was referred to the Committee on _____

A BILL

To authorize the Patient-Centered Outcomes Research Trust Fund to fund research of the symptoms of COVID-19, 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.**

4 This Act may be cited as the “COVID-19 Long
5 Haulers 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 research de-
8 scribed in subsection (b).

9 (b) RESEARCH DESCRIBED.—For purposes of sub-
10 section (a), research described in this subsection shall in-
11 clude—

12 (1) prior to creating a patient registry described
13 in paragraph (2), survey existing patient registries
14 that include individuals experiencing post-acute
15 sequelae of COVID-19 (in this section, referred to
16 as “PASC”);

17 (2) creating a patient registry for those with
18 COVID-19 with information that—

19 (A) contains the—

20 (i) symptoms that arise while an indi-
21 vidual is initially infected with COVID-19
22 and that resolve over time;

23 (ii) symptoms that arise while an indi-
24 vidual is initially infected with COVID-19
25 and that extend beyond the resolution of
26 initial symptoms;

1 (iii) symptoms that arise after an in-
2 dividual is initially infected with COVID-
3 19 and that endure and that the clinician
4 of such individual has reason to suspect
5 were related to the COVID-19 diagnosis;

6 (iv) symptoms that arise in an indi-
7 vidual that may be related to COVID-19
8 but a diagnosis of COVID-19 was not ob-
9 tained and cannot be identified due to a
10 lack of antibodies, false negative test re-
11 sults, or lack of access to timely testing;

12 (v) treatments of individuals after pri-
13 mary diagnosis to COVID-19 and the ef-
14 fectiveness of such treatments
15 disaggregated by age, gender, race or eth-
16 nicity, and co-morbidities and related post-
17 viral illnesses overlapping with PASC; and

18 (vi) any other relevant questions or
19 issues related to individuals who experience
20 a diagnosis of, treatment for, and manage-
21 ment of care with COVID-19, PASC, or
22 related post-viral illnesses overlapping with
23 PASC;

24 (B) synthesizes information relating to in-
25 dividuals experiencing post-acute sequelae of

1 COVID–19 identified from the survey described
2 in paragraph (1) and information under the pa-
3 tient registry described in paragraph (2); and
4 (3) outreach and inclusion (as appropriate) in-
5 dividuals from communities with PASC, traditional
6 health 3 disparities and inequities and related post-
7 viral illnesses overlapping with PASC.

8 (c) REPORT.—Not later than 1 year after the estab-
9 lishment of the synthesized patient registry described in
10 subsection (a)(2), and annually thereafter, the Patient-
11 Centered Outcomes Research Institute shall submit data,
12 findings, and information with respect to the status of the
13 patient registry (including progress, barriers, and issues)
14 to Congress and the President.

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

19 **SEC. 3. RESEARCH ON UNITED STATES HEALTH CARE SYS-**
20 **TEM'S RESPONSE TO LONG-TERM SYMPTOMS**
21 **OF COVID-19.**

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

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

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

5 (A) identifying obstacles to access for vet-
6 erans, the elderly, disabled, and low-income
7 communities;

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

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

15 (D) evaluating whether diagnosis, access
16 to, or treatment associated with medical pro-
17 viders and care delivered in different settings
18 varied by gender, disability, geographic, racial
19 and ethnic group; and

20 (2) conducting and support rapid turnaround
21 research to—

22 (A) identify health care strategies that
23 help mitigate gender, geographic, disability, ra-
24 cial and ethnic disparities in COVID-19 infec-

1 tion rates, severity and length of symptoms,
2 secondary illnesses, and outcomes;

3 (B) identify health care-related factors
4 contributing to such disparities in COVID-19
5 infection rates, hospitalizations, severity and
6 length of disease, secondary illnesses, and out-
7 comes; and

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

12 (b) PROTOCOLS ON PASC PATIENTS.—The Secretary
13 of Health and Human Services, acting through the Direc-
14 tor of the Agency for Healthcare Research and Quality,
15 shall coordinate cross-agency engagement with leaders
16 from communities with PASC, traditional health dispari-
17 ties and inequities and related post-viral illnesses overlap-
18 ping with PASC—

19 (1) to develop protocols that ensure PASC pa-
20 tients have access to medical professionals educated
21 about post-infectious disease and treatments; and

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

1 (c) AUTHORIZATION OF APPROPRIATIONS.—There is
2 authorized to be appropriated to carry out this section
3 \$30,000,000 for fiscal year 2022 to carry out this section,
4 which shall remain available until expended.

5 **SEC. 4. EDUCATION AND DISSEMINATION OF INFORMATION**
6 **WITH RESPECT TO LONG-TERM SYMPTOMS**
7 **OF COVID-19.**

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

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

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

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

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

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

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

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

5 (3) the availability, as medically appropriate, of
6 treatment options for PASC and related post-viral
7 illnesses overlapping with PASC, as identified in sec-
8 tion (2) above.

9 (b) POST-ACUTE SEQUELAE OF COVID-19 (PASC)
10 PROVIDER EDUCATION PROGRAM.—The Secretary of
11 Health and Human Services, acting through the Director
12 of the Centers for Disease Control and Prevention, shall
13 in consultation with communities with PASC, traditional
14 health disparities and inequities and related post-viral ill-
15 nesses overlapping with PASC, develop and disseminate
16 to health care providers information on PASC for the pur-
17 pose of ensuring that health care providers remain in-
18 formed about current information on this emerging illness
19 and related post-infectious illnesses, which have been
20 shown to be closely related to PASC including information
21 on—

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

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

1 (3) autoimmune diseases associated with viral
2 triggers;

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

5 (5) mast cell activation syndrome (MCAS).

6 (c) DISSEMINATION OF INFORMATION.—The Sec-
7 retary may disseminate information under subsection (a)
8 and subsection (b) directly or through arrangements with
9 intra-agency initiatives, nonprofit organizations, consumer
10 groups, institutions of higher learning (as defined in sec-
11 tion 101 of the Higher Education Act of 1965 (20 U.S.C.
12 1001)), or Federal, State, or local public private partner-
13 ships.

14 (d) AUTHORIZATION OF APPROPRIATIONS.—There is
15 authorized to be appropriated to carry out this section
16 \$30,000,000 for fiscal year 2022 to carry out this section,
17 which shall remain available until expended.

18 **SEC. 5. RESEARCH WITH RESPECT TO MEDICAID COV-**
19 **ERAGE OF LONG-TERM SYMPTOMS OF COVID-**
20 **19.**

21 (a) RESEARCH.—The Administrator of the Centers
22 for Medicare & Medicaid Services (referred to in this sec-
23 tion as the “Administrator”) shall expand the Chronic
24 Conditions Data Warehouse research database of such
25 Centers for Medicare and Medicaid Services to collect data

1 on items and services furnished to individuals experiencing
2 post-acute sequelae of COVID–19 under a State plan (or
3 a waiver of such a plan) under the Medicaid program
4 under title XIX of the Social Security Act (42 U.S.C.
5 1396 et seq.) or under a State child Health plan (or a
6 waiver of such a plan) under the Children’s Health Insur-
7 ance Program under title XXI of such Act (42 U.S.C.
8 1397aa et seq.) for the treatment of post-acute sequelae
9 of COVID-19 for purposes of assessing the frequency at
10 which COVID-19 survivors are furnished such items and
11 services.

12 (b) AUTHORIZATION OF APPROPRIATIONS.—There is
13 authorized to be appropriated to carry out this section
14 \$3,000,000 for fiscal years 2022 to carry out this section,
15 which shall remain available until expended.