

116TH CONGRESS  
2D SESSION

# H. R. 9027

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

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## IN THE HOUSE OF REPRESENTATIVES

DECEMBER 18, 2020

Mr. BEYER 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 Institute 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 **INSTITUTE.**

5 (a) IN GENERAL.—The Patient-Centered Outcomes  
6 Research Institute under section 1181(b) 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;

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

18 (A) contains the—

19 (i) symptoms that arise while an indi-  
20 vidual is actively infected with COVID-19  
21 and that resolve while such individual is  
22 actively infected;

23 (ii) symptoms that arise while an indi-  
24 vidual is actively infected with COVID-19  
25 and that extend after the infection has re-  
26 solved;

1 (iii) symptoms that arise after an in-  
2 dividual is actively 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;

11 (v) treatments of individuals after pri-  
12 mary diagnosis to COVID-19 and the ef-  
13 fectiveness of such treatments disaggre-  
14 gated by age, gender, and race or eth-  
15 nicity; and

16 (vi) any other relevant questions or  
17 issues related to individuals who experience  
18 a diagnosis of, treatment for, and manage-  
19 ment of care with COVID-19;

20 (B) synthesizes information relating to in-  
21 dividuals experiencing post-acute sequelae of  
22 COVID-19 identified from the survey described  
23 in paragraph (1) and information under the pa-  
24 tient registry described in paragraph (2); and

1           (3) outreach and inclusion (as appropriate) in-  
2           dividuals from communities with traditional health  
3           disparities and inequities.

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

11          (d) AUTHORIZATION OF APPROPRIATIONS.—There is  
12          hereby authorized \$30,000,000 for fiscal year 2021 to  
13          carry out this section, which shall remain available until  
14          expended.

15 **SEC. 3. AUTHORIZATION OF APPROPRIATIONS FOR RE-**  
16 **SEARCH WITH RESPECT TO INDIVIDUALS EX-**  
17 **PERIENCING POST-ACUTE SEQUELAE OF**  
18 **COVID-19 BY THE NIH.**

19          (a) IN GENERAL.—The Director of the National In-  
20          stitutes of Health conduct research with respect to individ-  
21          uals experiencing post-acute sequelae of COVID-19.

22          (b) AUTHORIZATION OF APPROPRIATIONS.—There is  
23          hereby authorized \$100,000,000 for fiscal year 2021 to

- 1 carry out this section, which shall remain available until
- 2 expended.

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