

118TH CONGRESS  
1ST SESSION

# S. 2560

To address and support research on Long COVID.

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IN THE SENATE OF THE UNITED STATES

JULY 27, 2023

Mr. KAINE (for himself and Mr. YOUNG) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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## A BILL

To address and support research on 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 “Long COVID Support  
5 Act”.

6 **SEC. 2. VOLUNTARY PATIENT REGISTRY FOR RESEARCH**  
7 **ON LONG COVID AND RELATED CONDITIONS.**

8 (a) IN GENERAL.—The Secretary of Health and  
9 Human Services (referred to in this Act as the “Sec-  
10 retary”) shall carry out activities described in subsection

1 (b) for treatment related to Long COVID and related con-  
2 ditions.

3 (b) ACTIVITIES DESCRIBED.—For purposes of sub-  
4 section (a), activities described in this subsection shall in-  
5 clude—

6 (1) creating or maintaining a regularly updated  
7 voluntary patient registry of individuals with sus-  
8 pected or confirmed Long COVID and related condi-  
9 tions, including information on—

10 (A) symptoms that arise while an indi-  
11 vidual is initially infected with COVID–19 and  
12 that may resolve over time or extend beyond the  
13 resolution of the initial symptoms;

14 (B) persistent symptoms that arise after  
15 an individual is initially infected with COVID–  
16 19 and that the clinician of such individual has  
17 reason to suspect were related to the COVID–  
18 19 diagnosis;

19 (C) symptoms that arise in an individual  
20 that may be related to COVID–19, but a diag-  
21 nosis of COVID–19 was not obtained and can-  
22 not be identified due to a lack of antibodies,  
23 false negative test results, or lack of access to  
24 timely testing;

1 (D) treatments of individuals after primary  
2 diagnosis of COVID–19 and the effectiveness of  
3 such treatments;

4 (E) any other relevant questions or issues  
5 related to individuals who experience a diag-  
6 nosis of, treatment for, and management of  
7 care with COVID–19, Long COVID, and re-  
8 lated conditions; and

9 (F) comorbidities, vaccination status, and  
10 demographics, including age, gender, race and  
11 ethnicity, geographic location, and occupation of  
12 registry participants;

13 (2) information relating to individuals experi-  
14 encing Long COVID and related conditions and  
15 other information available through the voluntary  
16 patient registry;

17 (3) dissemination of information to relevant  
18 Federal departments and agencies and patients par-  
19 ticipating in the voluntary patient registry related to  
20 COVID–19, Long COVID, and related conditions;

21 (4) an assurance that the voluntary patient reg-  
22 istry utilizes common data elements and definitions  
23 for use in order to promote appropriate data sharing  
24 for ongoing and future research; and

1           (5) outreach to, and inclusion in the voluntary  
2 patient registry, as appropriate, of individuals from  
3 communities impacted by high COVID–19 and Long  
4 COVID rates and health care providers from diverse  
5 disciplines that may treat individuals with COVID–  
6 19, Long COVID, and related conditions.

7           (c) VOLUNTARY PARTICIPATION; PRIVACY PROTEC-  
8 TIONS.—

9           (1) VOLUNTARY PARTICIPATION.—Participation  
10 in the patient registry described in subsection (b)(1)  
11 shall be voluntary, and a person creating, assisting  
12 in the creation of, or maintaining the registry shall  
13 not include in the registry information about an in-  
14 dividual unless the individual consents to the inclu-  
15 sion of such information.

16           (2) PRIVACY PROTECTIONS.—Information about  
17 an individual that is included in the registry shall be  
18 subject to all applicable privacy protections under  
19 Federal and State law.

20           (d) REPORT.—Not later than 1 year after the estab-  
21 lishment of the patient registry under subsection (b)(2),  
22 and annually thereafter, the Secretary shall submit a re-  
23 port that includes data, findings, and information with re-  
24 spect to the status of the patient registry (including

1 progress, barriers, and issues) to Congress and the Presi-  
2 dent.

3 **SEC. 3. RESEARCH AND COORDINATION OF ACTIVITIES**  
4 **CONCERNING THE LONG-TERM HEALTH EF-**  
5 **FECTS OF LONG COVID AND RELATED CONDI-**  
6 **TIONS.**

7 (a) IN GENERAL.—The Secretary of Health and  
8 Human Services (referred to in this section as the “Sec-  
9 retary”) shall, as appropriate—

10 (1) coordinate activities among relevant Federal  
11 departments and agencies with respect to addressing  
12 the long-term health effects of Long COVID and re-  
13 lated conditions, which may include conditions that  
14 arise as a result of such infection;

15 (2) continue to conduct or support basic, clin-  
16 ical, epidemiological, behavioral, and translational  
17 research and public health surveillance related to the  
18 pathogenesis, prevention, diagnosis, and treatment  
19 of the long-term health effects of Long COVID and  
20 related conditions, which may include conditions and  
21 any effects on development, cognition, and neural  
22 structure and function that arise as a result of such  
23 infection; and

24 (3) consistent with the findings of studies and  
25 research under paragraph (1), in consultation with

1 health and public health professional associations,  
2 scientific and medical researchers, and other rel-  
3 evant experts, develop and inform recommendations,  
4 guidance, and educational materials on the long-  
5 term effects of Long COVID and related conditions,  
6 which may include conditions that arise as a result  
7 of such infection, and provide such recommenda-  
8 tions, guidance, and educational materials to health  
9 care providers and the general public.

10 (b) CONSIDERATIONS.—In conducting or supporting  
11 research under this section, the Secretary shall consider  
12 the diversity of research participants or cohorts to ensure  
13 inclusion of a broad range of participants, as applicable  
14 and appropriate.

15 (c) ADDITIONAL ACTIVITIES.—The Secretary may—

16 (1) acting through the Director of the Agency  
17 for Healthcare Research and Quality, conduct or  
18 support research related to—

19 (A) the improvement of health care deliv-  
20 ery for individuals experiencing long-term  
21 health effects of Long COVID and related con-  
22 ditions, which may include conditions that arise  
23 as a result of such infection;

24 (B) the identification of any trends associ-  
25 ated with differences in diagnosis and treat-

1           ment of the long-term health effects of Long  
2           COVID and related conditions; and

3           (C) the development or identification of  
4           tools and strategies to help health care entities  
5           and providers care for such populations, which  
6           may include addressing any differences identi-  
7           fied pursuant to subparagraph (B);

8           (2) publicly disseminate the results of such re-  
9           search; and

10          (3) establish a primary care technical assistance  
11          initiative to convene primary care providers and or-  
12          ganizations, which may include support for con-  
13          tinuing training and education for such providers, as  
14          applicable and appropriate, in order to collect and  
15          disseminate best practices related to the care of indi-  
16          viduals with long-term health effects of Long  
17          COVID and related conditions.

18          (d) ANNUAL REPORTS.—Not later than 1 year after  
19          the date of enactment of this Act, and annually thereafter  
20          for the next 4 years, the Secretary shall prepare and sub-  
21          mit a report to the Committee on Health, Education,  
22          Labor, and Pensions of the Senate and the Committee on  
23          Energy and Commerce of the House of Representatives  
24          regarding an overview of the research conducted or sup-  
25          ported under this section and any relevant findings. Such

1 reports may include information about how the research  
2 and relevant findings under this section relate to other re-  
3 search efforts supported by other public or private entities.

4 (e) PUBLIC AVAILABILITY OF INFORMATION.—In  
5 making information or reports publicly available under  
6 this section, the Secretary shall take into consideration the  
7 delivery of such information in a manner that takes into  
8 account the range of communication needs of the intended  
9 recipients, including at-risk individuals.

10 (f) AUTHORIZATION OF APPROPRIATIONS.—To carry  
11 out subsection (e), there are authorized to be appropriated  
12 \$10,000,000 for each of fiscal years 2024 through 2028.

13 **SEC. 4. EDUCATION AND DISSEMINATION OF INFORMATION**  
14 **ON LONG COVID.**

15 (a) LONG COVID PUBLIC EDUCATION PROGRAM.—  
16 The Secretary shall develop and disseminate to the public  
17 regularly updated information regarding Long COVID, in  
18 plain language, including information on—

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

22 (2) conditions related and often comorbid with  
23 Long COVID;

24 (3) the availability, as medically appropriate, of  
25 treatment options for Long COVID and related con-



1        ditions overlapping with Long COVID described in  
2        paragraph (2); and

3               (4) strategies for reducing the likelihood of de-  
4        veloping Long COVID.

5        (b) LONG COVID PROVIDER EDUCATION PRO-  
6        GRAM.—The Secretary, in consultation with representa-  
7        tives from impacted communities and health care pro-  
8        viders who treat such communities or individuals, shall de-  
9        velop and disseminate to health care providers, including  
10       by developing or improving continuing medical education  
11       programs that advance the education of such providers,  
12       information on Long COVID, recommended assessment  
13       tools, and management of Long COVID and related condi-  
14       tions for the purpose of ensuring that health care pro-  
15       viders remain informed about current information on  
16       Long COVID and related conditions.

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 Long COVID diagnostics,  
21        treatments, and care include demographic factors to  
22        address health disparities; and

23               (2) individuals with Long COVID and related  
24        conditions, and entities representing such individ-

1 uals, are empowered to participate in protocol devel-  
2 opment and outreach and education strategies.

3 (d) DISSEMINATION OF INFORMATION.—The Sec-  
4 retary shall disseminate, in plain language, information  
5 under subsections (a) and (b), directly or through arrange-  
6 ments with intra-agency initiatives, nonprofit organiza-  
7 tions, consumer groups, Federally qualified health centers,  
8 institutions of higher learning (as defined in section 101  
9 of the Higher Education Act of 1965 (20 U.S.C. 1001)),  
10 local educational agencies or State educational agencies  
11 (as defined in section 8101 of the Elementary and Sec-  
12 ondary Education Act of 1965 (20 U.S.C. 7801)), or Fed-  
13 eral, State, Tribal, or local public private partnerships.

14 **SEC. 5. DEFINITION.**

15 In this Act, the term “Long COVID” means health  
16 conditions that may result, directly or indirectly, from  
17 COVID–19.

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