

118TH CONGRESS
1ST SESSION

S. _____

To address and support research on Long COVID.

IN THE SENATE OF THE UNITED STATES

Mr. KAINE (for himself and Mr. YOUNG) introduced the following bill; which
was read twice and referred to the Committee on _____

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
11 (b) for treatment related to Long COVID and related con-
12 ditions.

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

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

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

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

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

23 (D) treatments of individuals after primary
24 diagnosis of COVID–19 and the effectiveness of
25 such treatments;

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

6 (F) comorbidities, vaccination status, and
7 demographics, including age, gender, race and
8 ethnicity, geographic location, and occupation of
9 registry participants;

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

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

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

22 (5) outreach to, and inclusion in the voluntary
23 patient registry, as appropriate, of individuals from
24 communities impacted by high COVID–19 and Long
25 COVID rates and health care providers from diverse

1 disciplines that may treat individuals with COVID–
2 19, Long COVID, and related conditions.

3 (c) VOLUNTARY PARTICIPATION; PRIVACY PROTEC-
4 TIONS.—

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

12 (2) PRIVACY PROTECTIONS.—Information about
13 an individual that is included in the registry shall be
14 subject to all applicable privacy protections under
15 Federal and State law.

16 (d) REPORT.—Not later than 1 year after the estab-
17 lishment of the patient registry under subsection (b)(2),
18 and annually thereafter, the Secretary shall submit a re-
19 port that includes data, findings, and information with re-
20 spect to the status of the patient registry (including
21 progress, barriers, and issues) to Congress and the Presi-
22 dent.

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

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

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

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

22 (3) consistent with the findings of studies and
23 research under paragraph (1), in consultation with
24 health and public health professional associations,
25 scientific and medical researchers, and other rel-
26 evant experts, develop and inform recommendations,

1 guidance, and educational materials on the long-
2 term effects of Long COVID and related conditions,
3 which may include conditions that arise as a result
4 of such infection, and provide such recommenda-
5 tions, guidance, and educational materials to health
6 care providers and the general public.

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

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

13 (1) acting through the Director of the Agency
14 for Healthcare Research and Quality, conduct or
15 support research related to—

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

21 (B) the identification of any trends associ-
22 ated with differences in diagnosis and treat-
23 ment of the long-term health effects of Long
24 COVID and related conditions; and

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

6 (2) publicly disseminate the results of such re-
7 search; and

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

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

1 and relevant findings under this section relate to other re-
2 search efforts supported by other public or private entities.

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

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

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

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

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

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

23 (3) the availability, as medically appropriate, of
24 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.