

STATE OF NEW YORK

8849

IN SENATE

April 25, 2022

Introduced by Sen. HOYLMAN -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to establishing a long COVID-19 review board

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

1 Section 1. Legislative intent. The legislature finds, determines and
2 declares that COVID-19 has had a devastating impact on the state of New
3 York. Since the first recorded death of a New York resident from the
4 virus on March fourteenth, two thousand twenty, tens of thousands of New
5 Yorkers have lost their lives to COVID-19. The sudden emergence and
6 rapid spread of COVID-19 around the world has led to an evolving under-
7 standing of the transmissibility, virulence, and symptoms of the virus
8 by scientists and public health experts that continues to this day.
9 There is growing awareness and concern about post-COVID conditions,
10 sometimes referred to as "long COVID," in which a small but significant
11 percentage of patients experience persistent symptoms weeks or months
12 after recovering from their initial infection. It is vital that the
13 state of New York commit to monitoring and tracking the long-term health
14 impacts of COVID-19, even as effective vaccines are widely available.
15 Studying New Yorkers who survived COVID-19 infection holds the promise
16 of providing public health experts with information that may lead to a
17 better understanding of trends in long-term illness and recovery, and
18 the needs of survivors, particularly those suffering from post-COVID
19 conditions.

20 § 2. Section 2180 of the public health law is amended by adding a new
21 subdivision 12 to read as follows:

22 12. "Long COVID" means symptoms that persist after the acute COVID-19
23 infection has resolved.

24 § 3. The public health law is amended by adding a new section 2183 to
25 read as follows:

26 § 2183. Long COVID-19 study. 1. There is hereby established in the
27 department the long COVID-19 review board for the purpose of reviewing
28 the research and data in the state on long COVID and developing and

EXPLANATION--Matter in italics (underscored) is new; matter in brackets
[-] is old law to be omitted.

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1 disseminating findings, recommendations, and best practices to contrib-
2 ute to the prevention of long COVID.

3 2. (a) The board shall be composed of at least fifteen members, all of
4 whom shall be appointed by the commissioner. The board shall be
5 comprised of multidisciplinary experts in the field of virology, immu-
6 nology, COVID-19 and public health, and shall include health care
7 professionals or other experts who serve and are representative of the
8 diversity of New Yorkers in medically underserved areas of the state or
9 areas of the state with disproportionately high occurrences of COVID-19.

10 (b) Board members shall serve for terms of three years. The commis-
11 sioner may choose to reappoint board members to additional three-year
12 terms.

13 (c) A majority of the appointed membership of the board shall consti-
14 tute a quorum.

15 (d) If any member of the state board fails to attend three consecutive
16 regular meetings, unless such absence is for good cause, that membership
17 may be deemed vacant for purposes of the appointment of a successor.

18 (e) Meetings of the state board shall be held at least twice a year
19 but may be held more frequently as deemed necessary, subject to request
20 of the department.

21 (f) Members of boards shall be indemnified under section seventeen of
22 the public officers law or section fifty-k of the general municipal law,
23 as applicable.

24 (g) Members of the board shall not be compensated for their partic-
25 ipation on the board but shall receive reimbursement for their ordinary
26 and necessary expenses of participation in activities of the board.

27 (h) Membership on the board shall not disqualify any person from hold-
28 ing any public office or employment.

29 3. The board, in conjunction with other departments or experts within
30 the field, shall conduct a comprehensive study for the purpose of moni-
31 toring the long-term health impacts of the COVID-19 virus. The data
32 collected shall only be utilized as authorized under state and federal
33 law to inform the state's efforts to advance the care of people recover-
34 ing from COVID-19. The purpose of the study shall be to:

35 (a) monitor the long-term physical and mental health impacts of
36 COVID-19 infections, including, but not limited to, post-COVID condi-
37 tions;

38 (b) identify racial, gender and sexual orientation disparities in long
39 COVID;

40 (c) review current protocols for treatment of long COVID;

41 (d) develop and disseminate strategies for reducing the risk of long
42 COVID, including risk resulting from racial, economic, or other dispari-
43 ties; and

44 (e) advance prevention, diagnosis, treatment and interventions for
45 individuals experiencing long COVID.

46 4. The commissioner may request and shall receive upon request from
47 any department, division, board, bureau, commission, local health
48 departments or other agency of the state or political subdivision there-
49 of or any public authority, as well as hospitals established pursuant to
50 article twenty-eight of this chapter, birthing facilities, medical exam-
51 iners, coroners and coroner physicians and any other facility providing
52 services associated with COVID-19, such information, including, but not
53 limited to, death records, medical records, autopsy reports, toxicology
54 reports, hospital discharge records, birth records and any other infor-
55 mation that will help the department to properly carry out the func-
56 tions, powers and duties of the board as described in this section.

1 5. (a) The commissioner may solicit voluntary information, including
2 oral or written statements, relating to long COVID cases, from any fami-
3 ly member or other interested party including the patient, oral state-
4 ments received under this paragraph shall be transcribed or summarized
5 in writing. The commissioner shall transmit information obtained pursu-
6 ant to this subdivision to the board.

7 (b) Before transmitting any information to the board, the commissioner
8 shall remove all personal identifying information of the patient, health
9 care practitioner or practitioners or anyone else individually named in
10 such information, as well as the hospital or facility that treated the
11 patient, and any other information such as geographic location that may
12 inadvertently identify the patient, practitioner or facility. This para-
13 graph shall not preclude the transmitting of information to the board
14 that is reasonably necessary to enable the board to perform an appropri-
15 ate review under this section.

16 (c) The commissioner may share non-patient specific information
17 obtained pursuant to this subdivision with researchers for the purpose
18 of medical, public health or other scientific research. As a condition
19 of sharing such data or information, any subsequently published studies,
20 reports or findings that used such data or information shall be made
21 available at no charge to the public on the department's website.

22 (d) All personal information about people recovering from COVID-19
23 shall be kept confidential by the department and may not be disclosed
24 except for the purposes described in this subdivision.

25 (e) The commissioner shall promulgate regulations establishing permit-
26 ted purposes and uses of study information. All such regulations shall
27 maintain the anonymity of individuals and govern access to information
28 maintained by the department. It shall not be a permitted purpose for
29 the department or any authorized user of the study to provide informa-
30 tion contained in the study with immigration authorities. The study
31 shall comply with all state and federal laws and regulations related to
32 maintaining the privacy and confidentiality of records contained with
33 the study.

34 6. (a) The commissioner shall submit on or before December first, an
35 annual report to the governor and the legislature concerning the opera-
36 tion and findings of the study. The first such report required under
37 this section shall be published on December first of the calendar year
38 following the commencement of the study, and shall include the findings
39 of any surveys conducted by the department on long COVID-19, the find-
40 ings of any scientific studies, papers, or reports produced using data
41 or information collected in the study, and recommendations for state
42 action to address health issues or trends identified by the department.

43 (b) The commissioner, within their legal authority, may use the recom-
44 mendations and findings of the board to develop guidance and other
45 actions relating to best practices, and shall disseminate information
46 relating to that guidance and other actions to appropriate health care
47 providers.

48 § 4. This act shall take effect on the ninetieth day after it shall
49 have become a law.