

**NEW YORK STATE SENATE
INTRODUCER'S MEMORANDUM IN SUPPORT
submitted in accordance with Senate Rule VI. Sec 1**

BILL NUMBER:

SPONSOR: HOYLMAN

TITLE OF BILL:

An act to amend the public health law, in relation to enacting the New York State COVID-19 Health Registry Act

PURPOSE:

To establish a New York State COVID-19 Health Registry within the New York State Department of Health to track the long-term health impacts and outcomes of volunteer enrollees who have been infected with COVID-19

SUMMARY OF PROVISIONS:

Section 1 of the bill amends article 21 of the Public Health Law ("Control of Communicable Diseases") to add a new title 9 entitled "New York State COVID-19 Health Registry." The new title 9 consists of the following sections:

-Section 2185: Establishes the legislative findings and purpose of the COVID-19 Health Registry.

-Section 2185-a: Defines terms used in the new title 9.

-Section 2185-b: Authorizes and directs the New York State Department of Health (DOH) to establish a voluntary statewide COVID-19 Health Registry for the purpose of monitoring the long-term physical and mental health impacts of COVID-19 infections; periodically surveying Registry enrollees; sharing de-identified survey data or other Registry information with researchers for the purpose of medical, public health or other scientific research; and providing enrollees with information about COVID-19-related health studies, programs, benefits and other relevant information. Any enrollees data shared by the Registry with researchers must comply with confidentiality requirements and be conditioned on the free public accessibility of any resulting public studies, reports or findings.

-Section 2185-c: Sets an initial enrollment period for the Registry that begins 90 days after the effective date of the Act (for a total of 180 days after the Act is signed into law) and ends at a date to be determined by the DOH Commissioner at least a year after the enrollment period begins. The DOH Commissioner is directed to promulgate regulations to establish eligibility for enrollment in the Registry, but at a minimum it shall include New York residents who receive a diagnosis of post-acute COVID-19 syndrome made by a New York-licensed health professional.

-Section 2185-d: Governs the confidentiality of enrollee information and directs the DOH Commissioner to promulgate regulations establishing permitted purposes and uses of Registry information. DOH would be expressly prohibited from sharing any Registry information with immigration authorities.

-Section 2185-e: Directs DOH to issue annual reports on the Registry, with the first such report including strategies for implementation of the Registry and promotion of the Registry to the general public, with a particular focus on enrollees belonging to racial and ethnic groups that have been disproportionately impacted by the COVID-19 pandemic. Subsequent annual reports shall include findings of any surveys conducted by DOH of Registry enrollees, the findings of any scientific studies, papers or reports produced using data or information collected in the Registry, and recommendations for State action to address health issues or trends identified by DOH.

Section 2 of the bill is the effective date.

JUSTIFICATION:

COVID-19 has had a devastating impact on the State of New York. Since the first recorded death of a New York resident from the virus on March 14, 2020, tens of thousands of New Yorkers have lost their lives to COVID-19, and over one and a half million confirmed cases have been diagnosed.

The sudden emergence and rapid spread of COVID-19 around the world has led to an evolving understanding of the transmissibility, virulence, and symptoms of the virus by scientists and public health experts that continues to this day. Questions remain as to why approximately 80% of those infected with COVID-19 experience mild to no symptoms, while the remainder experience a more severe response that can result in hospitalization or death, and weeks-long recoveries for those who survive.

There is also growing awareness and concern about post-acute COVID-19 syndrome, sometimes referred to as "long COVID," in which a small but significant percentage of patients experience persistent symptoms weeks or months after recovering from their initial infection.

It is vital that the State of New York commit to monitoring and tracking the long-term health impacts of COVID-19, even as effective vaccines become more widely available. The establishment of a voluntary registry of New Yorkers who survived COVID-19 infection holds the promise of providing public health experts with a database of information that may lead to a better understanding of trends in long-term illness and recovery, and the needs of survivors, particularly those suffering from post-acute COVID-19 syndrome.

LEGISLATIVE HISTORY:

None, new bill.

FISCAL IMPLICATIONS:

To be determined.

EFFECTIVE DATE:

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