

Legislative Bill Drafting Commission  
09897-01-1

S. -----  
Senate  
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IN SENATE--Introduced by Sen

--read twice and ordered printed,  
and when printed to be committed  
to the Committee on

----- A.  
Assembly  
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IN ASSEMBLY--Introduced by M. of A.

with M. of A. as co-sponsors

--read once and referred to the  
Committee on

**\*PUBHEALA\***

(Enacts the New York State COVID-19  
Health Registry Act)

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Pub Heal. NYS COVID-19 registry

AN ACT

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

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

IN SENATE

Senate introducer's signature

The senators whose names are circled below wish to join me in the sponsorship  
of this proposal:

s15 Addabbo	s17 Felder	s07 Kaplan	s58 O'Mara	s10 Sanders
s52 Akshar	s59 Gallivan	s26 Kavanagh	s62 Ortt	s23 Savino
s36 Bailey	s05 Gaughran	s63 Kennedy	s01 Palumbo	s32 Sepulveda
s30 Benjamin	s12 Gianaris	s28 Krueger	s21 Parker	s41 Serino
s34 Biaggi	s22 Gounardes	s24 Lanza	s19 Persaud	s29 Serrano
s57 Borrello	s47 Griffo	s11 Liu	s13 Ramos	s39 Skoufis
s04 Boyle	s40 Harckham	s50 Mannion	s61 Rath	s16 Stavisky
s44 Breslin	s54 Helming	s42 Martucci	s38 Reichlin-	s45 Stec
s25 Brisport	s46 Hinchey	s02 Mattera	Melnick	s35 Stewart-
s08 Brooks	s27 Hoylman	s53 May	s48 Ritchie	Cousins
s55 Brouk	s31 Jackson	s37 Mayer	s33 Rivera	s49 Tedisco
s14 Comrie	s43 Jordan	s20 Myrie	s60 Ryan	s06 Thomas
s56 Cooney	s09 Kaminsky	s51 Oberacker	s18 Salazar	s03 Weik

IN ASSEMBLY

Assembly introducer's signature

The Members of the Assembly whose names are circled below wish to join me in the  
multi-sponsorship of this proposal:

a049 Abbate	a063 Cusick	a075 Gottfried	a020 Miller, M.	a121 Salka
a092 Abinanti	a045 Cymbrowitz	a021 Griffin	a051 Mitaynes	a111 Santabarbara
a031 Anderson	a018 Darling	a100 Gunther	a015 Montesano	a090 Sayegh
a122 Angelino	a053 Davila	a139 Hawley	a145 Morinello	a099 Schmitt
a107 Ashby	a072 De La Rosa	a083 Heastie	a065 Niou	a076 Seawright
a035 Aubry	a003 DeStefano	a028 Hevesi	a037 Nolan	a084 Septimo
a120 Barclay	a070 Dickens	a128 Hunter	a144 Norris	a016 Sillitti
a030 Barnwell	a054 Dilan	a029 Hyndman	a069 O'Donnell	a052 Simon
a106 Barrett	a081 Dinowitz	a079 Jackson	a091 Otis	a114 Simpson
a060 Barron	a147 DiPietro	a104 Jacobson	a132 Palmesano	a005 Smith
a082 Benedetto	a009 Durso	a011 Jean-Pierre	a088 Paulin	a118 Smullen
a042 Bichotte	a048 Eichenstein	a134 Jensen	a141 Peoples-	a022 Solages
Hermelyn	a004 Englebright	a115 Jones	Stokes	a110 Steck
a117 Blankenbush	a074 Epstein	a077 Joyner	a058 Perry	a010 Stern
a098 Brabenec	a109 Fahy	a125 Kelles	a023 Pheffer	a127 Stirpe
a026 Braunstein	a061 Fall	a040 Kim	Amato	a102 Tague
a138 Bronson	a080 Fernandez	a105 Lalor	a086 Pichardo	a064 Tannousis
a012 Brown	a008 Fitzpatrick	a013 Lavine	a089 Pretlow	a071 Taylor
a093 Burdick	a057 Forrest	a097 Lawler	a073 Quart	a001 Thiele
a085 Burgos	a124 Friend	a126 Lemondes	a019 Ra	a033 Vanel
a142 Burke	a046 Frontus	a135 Lunsford	a038 Rajkumar	a116 Walczyk
a119 Buttenschon	a095 Galef	a123 Lupardo	a006 Ramos	a055 Walker
a094 Byrne	a050 Gallagher	a129 Magnarelli	a062 Reilly	a143 Wallace
a133 Byrnes	a131 Gallahan	a036 Mamdani	a087 Reyes	a112 Walsh
a103 Cahill	a007 Gandolfo	a130 Manktelow	a043 Richardson	a041 Weinstein
a044 Carroll	a002 Giglio, J.A.	a108 McDonald	a078 Rivera, J.	a024 Weprin
a136 Clark	a148 Giglio, J.M.	a014 McDonough	a149 Rivera, J.D.	a059 Williams
a047 Colton	a066 Glick	a146 McMahon	a068 Rodriguez	a113 Woerner
a140 Conrad	a034 Gonzalez-	a137 Meeks	a027 Rosenthal, D.	a096 Zebrowski
a032 Cook	Rojas	a017 Mikulin	a067 Rosenthal, L.	a056 Zinerman
a039 Cruz	a150 Goodell	a101 Miller, B.	a025 Rozic	

1) Single House Bill (introduced and printed separately in either or  
both houses). Uni-Bill (introduced simultaneously in both houses and printed  
as one bill. Senate and Assembly introducer sign the same copy of the bill).

2) Circle names of co-sponsors and return to introduction clerk with 2  
signed copies of bill and: in Assembly 2 copies of memorandum in support, in  
Senate 4 copies of memorandum in support (single house); or 4 signed copies  
of bill and 6 copies of memorandum in support (uni-bill).

1 Section 1. Article 21 of the public health law is amended by adding a  
2 new title 9 to read as follows:

3 TITLE 9

4 New York State COVID-19 Health Registry

5 Section 2185. Legislative findings and purpose.

6 2185-a. Definitions.

7 2185-b. New York state COVID-19 health registry.

8 2185-c. Enrollment and eligibility.

9 2185-d. Confidentiality.

10 2185-e. Annual report.

11 § 2185. Legislative findings and purpose. 1. The legislature hereby  
12 finds, determines and declares that COVID-19 has had a devastating  
13 impact on the state of New York. Since the first recorded death of a  
14 New York resident from the virus on March fourteenth, two thousand twen-  
15 ty, tens of thousands of New Yorkers have lost their lives to COVID-19,  
16 and over one and a half million confirmed cases have been diagnosed as  
17 of the effective date of this article. The sudden emergence and rapid  
18 spread of COVID-19 around the world has led to an evolving understanding  
19 of the transmissibility, virulence, and symptoms of the virus by scien-  
20 tists and public health experts that continues to this day. Questions  
21 remain as to why approximately eighty percent of those infected with  
22 COVID-19 experience mild to no symptoms, while the remainder experience  
23 a more severe response that can result in hospitalization or death, and  
24 weeks-long recoveries for those who survive. There is also growing  
25 awareness and concern about post-acute COVID-19 syndrome, sometimes  
26 referred to as "long COVID," in which a small but significant percentage  
27 of patients experience persistent symptoms weeks or months after recov-  
28 ering from their initial infection.

1 It is vital that the state of New York commit to monitoring and track-  
2 ing the long-term health impacts of COVID-19, even as effective vaccines  
3 become more widely available. The establishment of a voluntary registry  
4 of New Yorkers who survived COVID-19 infection holds the promise of  
5 providing public health experts with a database of information that may  
6 lead to a better understanding of trends in long-term illness and recov-  
7 ery, and the needs of survivors, particularly those suffering from post-  
8 acute COVID-19 syndrome.

9 § 2185-a. Definitions. As used in this title:

10 1. "COVID-19" means infection with or the disease caused by the severe  
11 acute respiratory syndrome coronavirus 2 (SARS-CoV-2);

12 2. "Registry" means the COVID-19 health registry established by this  
13 title.

14 § 2185-b. New York state COVID-19 health registry. The department is  
15 hereby authorized and directed to establish a voluntary statewide  
16 COVID-19 health registry for the purpose of monitoring the long-term  
17 health impacts of the virus. The registry shall serve, and shall be  
18 administered consistent with, the following public health purposes:

19 1. Monitoring the long-term physical and mental health impacts of  
20 COVID-19 infections, including, but not limited to, post-acute COVID-19  
21 syndrome;

22 2. Periodically surveying registry enrollees to gather relevant infor-  
23 mation for the purposes of monitoring the long-term physical and mental  
24 health impacts of COVID-19 infections;

25 3. Sharing, subject to the confidentiality requirements of section  
26 twenty-one hundred eighty-five-d of this title and any other applicable  
27 state or federal laws or regulations, de-identified survey data or other  
28 registry information with researchers for the purpose of medical, public

health or other scientific research. As a condition of sharing such data or information, any subsequently published studies, reports or findings that used such data or information shall be made available at no charge to the public on the department's website; and

4. Providing enrollees with information about COVID-19-related health studies, programs, benefits, and other relevant information.

§ 2185-c. Enrollment and eligibility. 1. The initial enrollment period for the registry shall begin ninety days after the effective date of this section. The commissioner may set a date upon which the initial enrollment period ends, but such date shall not be prior to one year after the initial enrollment period begins.

2. The commissioner may, at his or her discretion, order additional enrollment periods subsequent to the initial enrollment period, of such lengths as he or she determines.

3. The commissioner shall promulgate regulations to establish eligibility for enrollment in the registry. Eligible participants shall, at a minimum, include New York residents who receive a diagnosis of post-acute COVID-19 syndrome made by an individual licensed to provide health care services within the state of New York.

§ 2185-d. Confidentiality. 1. All registry information shall be kept confidential by the department and may not be disclosed except for a permitted purpose.

2. The commissioner shall promulgate regulations establishing permitted purposes and uses of registry information.

(a) All such regulations shall maintain the anonymity of individuals enrolled in the registry and govern access to information maintained by the registry.

1     **(b) It shall not be a permitted purpose for the department or any**  
2     **authorized user of the registry to provide information contained in the**  
3     **registry with immigration authorities.**

4     **3. The registry shall comply with all state and federal laws and regu-**  
5     **lations related to maintaining the privacy and confidentiality of**  
6     **records contained with the registry.**

7     **§ 2185-e. Annual report. The commissioner shall submit on or before**  
8     **December first, an annual report to the governor and the legislature**  
9     **concerning the operation of the registry. The first such report required**  
10    **under this section shall be published on December first of the calendar**  
11    **year following the commencement of the initial enrollment period for the**  
12    **registry, and shall include strategies for implementation of the regis-**  
13    **try and for promoting the registry to the general public, with a partic-**  
14    **ular focus on eligible enrollees belonging to racial or ethnic groups**  
15    **that have been disproportionately impacted by the COVID-19 pandemic.**  
16    **Subsequent annual reports shall include the findings of any surveys**  
17    **conducted by the department of registry enrollees, the findings of any**  
18    **scientific studies, papers, or reports produced using data or informa-**  
19    **tion collected in the registry, and recommendations for state action to**  
20    **address health issues or trends identified by the department.**

21    **§ 2. This act shall take effect on the ninetieth day after it shall**  
22    **have become a law.**