Senator Hoylman Announces Legislation to Establish COVID-19 Health Registry to Monitor "Long COVID"

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| ISSUE: **SENATOR BRAD HOYLMAN**, **SD 27**, **HEALTH REGISTRY**, **LONG COVID**

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NEW YORK -- Today, State Senator Brad Hoylman (Manhattan-D/WFP) introduced new legislation to establish a voluntary New York COVID-19 Health Registry to provide baseline health data to allow researchers and health professionals the ability to track and investigate the condition of "long-haul" COVID-19, as well as other physical and mental health impacts of the disease. The COVID-19 Health Registry is modeled after the World Trade Center Health Registry used to monitor over time the health of people directly exposed to the 9/11 World Trade Center disaster.

Senator Brad Hoylman said: "It's estimated that more than 10 percent of COVID-19 infections will develop into 'Long COVID,' the symptoms of which can include lingering respiratory problems, difficulty concentrating and potentially long-term disabilities. We owe it to New Yorkers afflicted with Long COVID to follow their long-term health outcomes to develop strategies to help them cope with this syndrome and understand the scope of this growing public health concern."

Lorna Thorpe, PhD, MPH, Director of the Division of Epidemiology in the Department of Population Health, NYU Langone said: "The long-term impacts of infection with SARS CoV-2 are not yet well understood. At this moment, we have a critical window of opportunity to learn about the health needs of people experiencing prolonged physical symptoms and mental health issues in order to develop strategies to prevent and address them. Registries have effectively been used after prior disasters to guide a coordinated and systematic scientific agenda to address such public health priorities. We applaud the efforts underway now to establish a COVID-19 Health Registry in the New York State Department of Health."

Mario Cilento, President of New York State AFL-CIO said: "We appreciate that Senator Hoylman is taking the lead to make sure that moving forward we minimize the long-term impact that this pandemic will have on individuals and our state.   This Registry will establish a voluntary system so we can monitor the health, mental health, and other effects that COVID-19 has on working people who have borne the brunt of this terrible disease, and any individual who has contracted COVID. It will allow us to better prepare for any future manifestations of this disease or health care problems. This is critical in determining how to treat these conditions and pay for medical care, lost wages and other costs associated with COVID-19, something we clearly were not prepared for at the onset of the pandemic."

Senator Hoylman's legislation, which currently has 17 co-sponsors in the New York Senate, would establish the COVID-19 Health Registry within the New York State Department of Health (DOH), a voluntary database tracking information about enrollees who have survived COVID-19 infections, with a particular focus on the so-called "long haulers" diagnosed with post-acute COVID-19 syndrome. The DOH Commissioner would be required to publish an annual report on the operation and implementation of the registry, including the findings of any surveys conducted by DOH, the findings of any scientific studies, papers, or reports produced using data or information collected by the registry, and recommendations for state action to address health issues or trends identified by DOH.

Given the inequity in how COVID-19 has impacted New York, the legislation takes special measures to ensure data is produced that will help the communities—primarily communities of color—that have been hit hardest by this disease. In its first year, the registry's report would have a special focus on enrollees belonging to racial or ethnic groups that have been disproportionately impacted by the COVID-19 pandemic. By enrolling a diverse cross-section of New Yorkers, the registry will be able to shed light on the racial and ethnic disparities in the pandemic's impact.

All registry information would be kept confidential by DOH and would not be disclosed except for a permitted purpose. Additionally it would comply with all state and federal laws and regulations maintaining the privacy and confidentiality of records contained with the registry.

This registry mirrors the work of the World Trade Center Health Registry which has tracked complications of people who lived, worked, or went to school in the area of the World Trade Center terrorist attack on September 11, 2001.

The bill draft and sponsor's memo are attached.

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