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Contact: Rich Davidson
(202) 228-6291 (press office)

Whitehouse, Markey Push NIH on Slow Pace of Research into Long COVID

*Long COVID afflicts between 7.7 and 23 million Americans, yet reliable information
on the condition is hard to come by*

Whitehouse writes separately to SSA on long COVID and SSDI benefits

Washington, DC – Senators Sheldon Whitehouse (D-RI) and Edward J. Markey (D-MA) are pressing the National Institutes of Health (NIH) about the slow pace of research into “Post-Acute Sequelae of SARS-CoV-2 infection” or “long COVID.” In a [letter](#), the senators asked the NIH about the status of research into the long-term health effects of COVID-19, as requested by Congress over two years ago.

“Given that COVID-19 is a novel virus, research on long COVID is still in its infancy. There are currently no evidence-based treatments for long COVID,” wrote the senators to the NIH. **“In the absence of effective therapies, we are concerned by reports of individuals pedaling unapproved treatment regimens to vulnerable patients.”**

Congress asked the NIH to research the condition in December 2020 and allocated \$1.15 billion to carry it out. So far, however, the agency has been slow to launch observational studies and evaluate possible treatments and therapeutics. Whitehouse and Markey wrote that the absence of clear information on long COVID and potential treatments leaves patients vulnerable to unapproved and possibly dangerous alternative treatment regimens.

In a separate [letter](#) to the Social Security Administration (SSA), Whitehouse is seeking information about the SSA’s evaluation of Social Security Disability Insurance (SSDI) claims and benefits awarded to Americans with long COVID. Whitehouse highlights the need to understand the burden of long COVID on the SSDI program, and to improve the SSDI application and approval process for Americans suffering from the condition. Many of the symptoms of long COVID – such as chronic pain, brain fog, and fatigue – make it difficult to work, driving many individuals toward the SSDI programs. But the dearth of reliable information on the condition makes it difficult to document a potential recipient’s inability to work, contributing to delays and the denial of benefits.

“Long COVID patients, including my constituents, report being denied disability benefits and being forced to go through burdensome appeals processes to demonstrate that they are in fact suffering from debilitating long COVID,” wrote Whitehouse to the Social Security Administration. **“While long COVID symptoms can be difficult to detect and measure, the lack of verifiable symptoms does not mean a patient is not suffering from debilitating long COVID and eligible for disability benefits.”**

While most people with COVID-19 make a full recovery within a matter of weeks, a subset of patients suffer symptoms lasting a month or longer. Health care providers have observed an

array of symptoms among these long COVID patients, from shortness of breath to skin conditions. According to the Government Accountability Office, long COVID afflicts between 7.7 and 23 million Americans.

Despite the slow pace of research from some areas of the federal government, respected research institutions have launched promising efforts to study the effects of long COVID. For instance, Brown University's School of Public Health [launched](#) an initiative to study long COVID's effect on individuals, workplaces, health care settings, and society as a whole.

PDF copies of the letters are available [here](#) and [here](#).

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