



Sen. Tim Kaine (D-VA)  
231 Russell Senate Office Building  
Washington, D.C. 20510

Sen. Tammy Duckworth (D-IL)  
524 Hart Senate Office Building  
Washington, DC 20510

Sen. Ed Markey (D-MA)  
255 Dirksen Senate Office Building  
Washington, DC 20510

CC:

Sen. Patty Murray (D-WA)  
Chair, Senate Committee on Health, Education, Labor & Pensions  
154 Russell Senate Office Building  
Washington, D.C. 20510

Sen. Richard Burr (R-NC)  
Ranking Member, Senate Committee on Health, Education, Labor & Pensions  
217 Russell Senate Office Building  
Washington, DC 20510

Re: S. 3726, the *Comprehensive Access to Resources and Education (CARE) for Long COVID Act*

Sens. Kaine, Duckworth, and Markey:

My name is Andrew Wylam, and I am writing to you on behalf of Pandemic Patients, which is a 501(c)(3) non-profit patient advocacy organization that works to relieve the harm caused by COVID-19 and post-COVID conditions. A recent study examining the prevalence of long COVID symptoms in the six months following diagnosis with COVID-19 found that over one in three patients experienced one or more symptoms of long COVID, including chest pain, fatigue, anxiety, depression, pain, headache, cognitive dysfunction, myalgia, and more.<sup>1</sup> Moreover, some public health experts predict that over 15 million Americans will develop long COVID as a result of the coronavirus pandemic.<sup>2</sup> Because of the unfathomable scope of this encroaching public health crisis, we believe that Congress has a responsibility to advance a national strategy for addressing the needs of patients with long COVID.

We are incredibly grateful for your recent introduction of S. 3726, the *Comprehensive Access to Resources and Education (CARE) for Long COVID Act*, on March 2, 2022. If enacted, this legislation will invigorate the federal government's response to the growing needs of patients living with long COVID. Specifically, the *CARE for Long COVID Act* will:

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<sup>1</sup> <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003773>.

<sup>2</sup> <https://www.nejm.org/doi/full/10.1056/NEJMp2109285>.

- Authorize \$30,000,000 of funding for FY'23 through the Patient-Centered Outcomes Research Trust Fund to improve treatment and outcomes for patients with long COVID, including the creation of a voluntary patient registry (Sec. 2);
- Authorize \$15,000,000 of funding for FY'23 through the U.S. Department of Health and Human Services to conduct or support research related to the US health care system's response to long COVID (Sec. 3);
- Authorize \$30,000,000 for each of FY'23, FY'24, and FY'25 through the U.S. Centers for Disease Control and Prevention to develop and disseminate information to the public regarding long COVID and associated conditions. This funding will also support a health care provider education program that will advance the proficiency of health care providers for treating patients with long COVID and associated conditions (Sec. 4);
- Authorize \$30,000,000 for each of FY'23, FY'24, and FY'25 through the U.S. Department of Health and Human Services to raise awareness about the impact long COVID and associated conditions may have on rights associated with employment, disability status, and education under state and federal law (Sec. 5);
- Authorize \$3,000,000 for FY'22 through the U.S. Department of Health and Human Services to collect data through the Medicaid program and the Children's Health Insurance Program on items and services that are furnished to individuals with long COVID (Sec. 6); and
- Authorize \$50,000,000 for each of FY'23, FY'24, FY'25, FY'26, and FY'27 through the U.S. Department of Health and Human Services to award grants and contracts to organizations that will increase the availability of critical social supports for patients with long COVID, including legal assistance (Sec. 7).

An important feature of this legislation is how it authorizes funding for non-profit organizations like Pandemic Patients to provide services and supports to patients with long COVID. Pandemic Patients stands ready to partner with the federal government to launch these critical programs once robust funding becomes available. However, we feel that Congress should not delay in authorizing the funding for many of these programs. We urge you to consider amending the *CARE for Long COVID Act* by authorizing funding for FY'22 for the activities described in Secs. 3, 4, and 7. Authorizing these funds for FY'22 would allow the federal government to begin addressing the needs of patients with long COVID immediately instead of requiring them to wait until FY'23 for these critical supports to become available.

Additionally, this legislation calls for a multi-agency effort to issue "guidance on PASC and related post-viral illnesses and conditions as a disability, including recommendations to streamline the process of applying for benefits through the Social Security Administration." This guidance is critical, as many patients with long COVID have experienced challenges applying for disability benefits through the Social Security Administration.<sup>3</sup> Streamlining the Social Security Administration's disability application process and providing more clarity about disability benefit eligibility criteria for long COVID patients will ensure that more patients will be able to successfully transition into the Social Security Disability Insurance program. Taking steps to provide these safety net resources to long COVID patients will bring much-needed financial stability to many Americans who are newly disabled and who are experiencing formidable challenges after leaving the workforce.

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<sup>3</sup> <https://www.washingtonpost.com/business/2022/03/08/long-covid-disability-benefits/>;  
<https://www.morningbrew.com/hr/stories/2021/10/20/prepare-for-a-tsunami-of-long-covid-disability-claims>.

Thank you again for lending your support to patients with long COVID by introducing this legislation. If you have any questions or comments about our position on the *CARE for Long COVID Act*, or if you need any additional information, please contact me at [j.a.wylam@pandemicpatients.org](mailto:j.a.wylam@pandemicpatients.org).

Respectfully,

A handwritten signature in black ink, consisting of the initials 'JW' in a cursive, flowing style.

J. Andrew Wylam, Esq.  
President  
Pandemic Patients