January 18, 2024

*via Electronic mail*

The Honorable Bernie Sanders

Chairman, Committee on Health, Education, Labor and Pensions

428 Senate Dirksen Office Building

Washington, D.C. 20510

The Honorable Bill Cassidy

Ranking Member, Committee on Health, Education, Labor and Pensions

428 Senate Dirksen Office Building

Washington, D.C. 20510

**RE: Hearing on “Addressing Long COVID: Advancing Research and Improving Patient Care”**

Dear Chair Sanders and Ranking Member Cassidy:

The Disability Rights Education & Defense Fund (DREDF) thanks you for holding today’s hearing on *Addressing Long COVID: Advancing Research and Improving Patient Care*. We deeply appreciate the opportunity to provide comments on the importance of maintaining federal efforts to advance research and improve patient care on Long COVID. Disability Rights Education and Defense Fund (DREDF) is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. In the more than 40 years that have passed since our founding, we have persistently fought for the right of people with disabilities to be fully integrated within all aspects of community life. DREDF's work is based on the knowledge that people with disabilities of varying ages, racial and ethnic backgrounds, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports, protection from discrimination, and the reasonable accommodations and modifications enshrined in U.S. law.

Today we are four years out from the beginning of the COVID-19 pandemic. In that time, the term “Long COVID” has clearly entered our vocabulary. [Mainstream media](https://www.cbsnews.com/news/long-covid-americans-new-cdc-survey-data/) reports that almost 7% of adults in the U.S. reported having had Long COVID and half of those said they currently had the condition while being surveyed in 2022, while also stating that “exact definitions vary, but long COVID can be described as a post-infection set of symptoms lasting 3 months or longer after a person caught COVID-19.”[[1]](#footnote-1) In other words, the reports mirror where the country is when it comes to Long COVI. We have a name. We have a wide array of possible symptoms. We have millions of people who experience impairment of their health and profound disruptions to their functional, economic, and social capacity and their well-being for months at a time. And we all still have many questions about how Long-COVID works, why its impact varies so much, how to best treat it, and how to equitably help those who live with it.

In some ways, the more researchers discover, the more work remains. Attempts made in a large 2023 study to quantify the “disease burden” of Long COVID in the U.S. led to the finding that the condition generated a higher burden by far than either heart disease or cancer.[[2]](#footnote-2) The study stands out for having a large number of participants (almost 140,000 from the U.S. Department of Veteran Affairs) who were followed over a two year period, during which they were assessed for the risk of death as well as 80 pre-identified potential Long COVID symptoms. Unfortunately, the study also used disability adjusted life-years (DALY) as its measure of disease burden. Each DALY represents one year of “healthy life” that is lost to illness, and is a measure that can inherently devalue the worth of, and underestimate the impact of a condition on, people with disabilities who are assumed to not have “healthy lives” to begin with. Nonetheless, the veterans study is valuable for highlighting the burden that Long COVID places on those who are living with it and on the country’s health care system. The study also highlights the value of complementary research that focuses on [how race and ethnicity affect the impact of post-COVID conditions](https://www.ajpmfocus.org/article/S2773-0654%2823%2900118-9/fulltext) for example, or looks at [long-term health impacts and how to enhance recovery among pregnant adults and children who were exposed to COVID in utero](https://pubmed.ncbi.nlm.nih.gov/38128008/). We are at a stage in this condition where we still need reliable, basic information about how the condition works over time, but we also live in a diverse society where we don’t fully understand how various personal characteristics and contexts affect the severity, length, and breadth of the condition’s impact on individuals and families.

Another recent piece of journalism investigated why the number of working-age adults self-reporting “serious difficulty” in thinking (remembering, concentrating, or making decisions) has climbed by an estimated one million people to its highest point in 15 years.[[3]](#footnote-3) The report found that the “sharp increase captures the effects of long Covid for a small but significant portion of younger adults, researchers say, most likely in addition to other effects of the pandemic, including psychological distress.” The findings and the first-hand accounts of young adults in their 30s helps to combat the misperception that Long-COVID is always at its worst for older persons who were already at serious risk from COVID-19, or the false assumption that Long-COVID doesn’t affect young, healthy, productive people. Whether an initial encounter with COVID is mild or serious, studies have shown that 20-30 percent experience some degree of cognitive impairment months later. And as the chair of rehabilitation medicine at the University of Texas Health Science Center explains, “It’s not just fog, it’s a brain injury, . . . There are neurovascular changes. There’s inflammation. There are changes on M.R.I.s.”[[4]](#footnote-4)

Ultimately, what we know now about Long COVID is what we have learned from two equally important sources: scientific/medical researchers and the experiences of those who are living with Long COVID, people with disabilities. DREDF deeply appreciates the Senate HELP Committee for continuing to elevate this condition and the many questions that it still raises. We support the work of the Office of Long COVID Research and Practice at the Office of the Assistant Secretary for Health as it works to elevate key research findings and emphasizes outreach. Accurate information is needed now more than ever. We have studies that show how [vaccination can reduce the impact of Long COVID](https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwj-kvnAvOWDAxUvHDQIHZh_BMkQFnoECCUQAQ&url=https%3A%2F%2Fwww.ncbi.nlm.nih.gov%2Fpmc%2Farticles%2FPMC9978692%2F&usg=AOvVaw0FUZSK_O4U3tTVry8MZqhI&opi=89978449) and yet we continue to see illogically low vaccination rates, even among older persons who remain more vulnerable to COVID infection. The National Institutes of Health, the Federal Drug Administration, and other partners, including state departments of health and Medicaid agencies, must cooperate to combat the spread of disinformation as well as an ongoing tendency to make light of those who are living with Long COVID which is rooted in ableism, sexism (more women experience Long COVID than men), and racism (people of color are less likely to have an “official” COVID diagnosis from those early days of the pandemic before tests were developed and broadly disseminated).

Thank you for your consideration and for all you do on behalf of people with disabilities. Please

Contact Silvia Yee at syee@dredf.org with questions. We are eager to support your efforts to ensure adequate funding for research and improved patient care, services and supports for all those impacted by Long COVID.

Sincerely,

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Silvia Yee

Senior Staff Attorney

1. Sara Moniuszko, “Long COVID Has Affected Nearly 7% of American Adults, CDC Survey Data Finds,” (September 26, 2023), CBS News Healthwatch, <https://www.cbsnews.com/news/long-covid-americans-new-cdc-survey-data/>. [↑](#footnote-ref-1)
2. Bowe, B., Xie, Y. & Al-Aly, Z. Postacute Sequelae of COVID-19 at 2 years. *Nat Med* **29**, 2347–2357 (2023). <https://doi.org/10.1038/s41591-023-02521-2>. [↑](#footnote-ref-2)
3. Francesca Paris, “Can’t Think, Can’t Remember: More Americans Say They’re in a Cognitive Fog,” (November 13/23), New York Times, <https://www.nytimes.com/2023/11/13/upshot/long-covid-disability.html>. [↑](#footnote-ref-3)
4. Paris, “Can’t Think, Can’t Remember.” [↑](#footnote-ref-4)