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April 19, 2022

Mr. Lawrence A. Tabak, Acting Director
National Institutes of Health
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Acting Director Tabak:

We write to you regarding NIH's efforts to study the long-term health effects of COVID-19. Millions of Americans report suffering from lingering COVID-19 symptoms long after their initial infection, a condition termed "Post-Acute Sequelae of SARS-CoV-2 infection" (PASC) or long COVID. It is imperative that we commit the necessary federal resources to understand the causes of so-called "long COVID" and identify potential treatments as quickly as possible. While we are pleased that the Biden Administration released a government-wide strategy on long COVID that included prioritizing research into the condition, we are requesting additional information about the National Institutes of Health's (NIH) progress in studying PASC and identifying viable treatments and therapies.

As you know, COVID-19 has infected nearly 80 million Americans.[1] While many fully recovered from the virus, others report lingering side effects. PASC patients report a variety of symptoms, including difficulty breathing, chronic fatigue, loss of smell or taste, and cognitive challenges (or "brain fog").[2] Preliminary research finds troubling connections between COVID-19 infection and organ damage, including heart complications, chronic kidney impairment, and increased risk of stroke.[3] While some individuals' symptoms are mild, others are severe, affecting their ability to work and handle family responsibilities.

Long COVID will likely pose continued challenges in the years ahead. GAO estimates that between 7.7 and 23 million Americans suffer from long-COVID.[4] Should this projection prove accurate, our health care system will face increased strain in the years to come. In addition to these effects on health care, long COVID threatens our economic recovery, potentially exacerbating workforce shortages and straining social safety net programs.[5] Early research also indicates that long COVID disproportionately affects

[1] https://www.cdc.gov/coronavirus/2019-ncov/covid-data/covidview/index.html
[2] https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/coronavirus-long-term-effects/art-20490351
[3] https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/coronavirus-long-term-effects/art-20490351
[4] https://www.gao.gov/products/gao-22-105666
[5] https://www.brookings.edu/research/is-long-covid-worsening-the-labor-shortage/

low-income communities and communities of color, mirroring the racial and ethnic disparities of COVID infections.[6]

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.[7] In the absence of effective therapies, we are concerned by reports of individuals pedaling unapproved treatment regimens to vulnerable patients.[8] Still, there is reason to be hopeful, as researchers around the country begin efforts to study this illness.

As you know, in December 2020, Congress provided the NIH with $1.15 billion to research PASC.[9] We are concerned by reports that the agency has been slow to launch COVID research efforts and prioritized long COVID observational studies over investigations of possible treatments and therapeutics to help those suffering from its symptoms.[10] While research on the underlying science of long COVID is critical to enhancing our understanding of the condition, trials and research on treatments may help provide relief to individuals experiencing the effects of long COVID today. It is also critical that NIH and grantees involved in long COVID research engage with the patient community to ensure long COVID patients are a central partner in this research. Additionally, we are concerned by reports highlighting the NIH's failure to recruit long COVID participants for research trials.

In order to assess the status of the NIH PASC Initiative, we request written answers to the following questions by May 15, 2022:

1. What projects are currently funded as part of the NIH PASC Initiative? When does the agency plan to launch clinical trials to test potential therapeutics and treatments, in addition to ongoing observational studies?
2. Of the $1.15 billion Congress appropriated to support long COVID research, how much funding remains? What other funding streams, if any, exist to support research on PASC?
3. What barriers is the NIH facing in recruiting participants for the NIH's PASC initiative, particularly individuals from the communities hardest hit by the pandemic? How does the agency plan to address these challenges?
4. How can Congress support NIH research on the long-term health effects of COVID-19? Would additional funding or authorities support these efforts?

The NIH has proven it can rise to the challenge of developing safe and effective COVID-19 vaccines in record time. Now we must replicate this success in helping long COVID patients suffering from the virus's lingering effects. We are hopeful that your efforts will help millions of Americans and support our country's full recovery from the pandemic.

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[6] https://www.statnews.com/2021/05/10/with-long-covid-history-may-be-repeating-itself-among-people-of-color/

[7] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02798-7/fulltext

[8] https://www.motherjones.com/politics/2022/01/desperate-patients-are-shelling-out-thousands-for-a-long-covid-cure-is-it-for-real/

[9] https://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid

[10] https://www.statnews.com/2022/03/29/nih-long-covid-sluggish-study/?utm_source=STAT+Newsletters&utm_campaign=b7556b96de-MR_COPY_01&utm_medium=email&utm_term=0_8cab1d7961-b7556b96de-136710605

We appreciate your attention to this matter.

Sincerely,

Sheldon Whitehouse
United States Senator

Edward J. Markey
United States Senator