



MEMORANDUM

April 24, 2021

**To: Subcommittee on Health Members and Staff**

**Fr: Committee on Energy and Commerce Staff**

**Re: Legislative Hearing on “The Long Haul: Forging a Path through the Lingering Effects of COVID-19”**

On Wednesday, April 28, 2021 at 11 am (EDT) via Cisco Webex online video conferencing, the Subcommittee on Health will hold a hearing entitled, “The Long Haul: Forging a Path through the Lingering Effects of COVID-19.”

**I. BACKGROUND**

The coronavirus disease of 2019 (COVID-19) has had a significant impact for many Americans. In the last year, over 30 million Americans have tested positive for COVID-19 and over 550,000 have passed away from the disease.<sup>1</sup> While the majority of patients experience no or mild symptoms and recover, there is an emerging number of patients who report lingering effects of COVID-19, weeks and months after infection.<sup>2</sup> The scientific community has referred to this phenomenon by multiple names, such as post-acute sequelae of COVID-19 (PASC), post-acute COVID-19, long-haul COVID, or long COVID.<sup>3</sup> In this memorandum, the condition is referred to as long COVID.

Generally, long COVID is a range of symptoms that continue or appear weeks and months after an initial COVID-19 infection.<sup>4</sup> According to the Centers for Disease Control and Prevention (CDC), long COVID can present itself in anyone who has had COVID-19, including

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<sup>1</sup> John Hopkins University Coronavirus Resource Center, *COVID-19 Dashboard by the Center for Systems Science and Engineering at Johns Hopkins University*, ([coronavirus.jhu.edu/map.html](https://coronavirus.jhu.edu/map.html)) (accessed April 15, 2021).

<sup>2</sup> National Institutes of Health, *NIH experts discuss post-acute COVID-19*, ([www.nih.gov/news-events/news-releases/nih-experts-discuss-post-acute-covid-19](https://www.nih.gov/news-events/news-releases/nih-experts-discuss-post-acute-covid-19)) (April 13, 2021).

<sup>3</sup> *Id.*

<sup>4</sup> *Id.*

asymptomatic patients.<sup>5</sup> Symptoms may include fatigue, brain fog, headache, loss of smell or taste, dizziness, heart palpitations, chest pain, shortness of breath, cough, joint or muscle pain, fever, depression, or anxiety.<sup>6</sup> In severe cases, critical organ functions of the heart, lungs, kidneys, and brain can be affected.<sup>7</sup>

Although there is not yet consensus as to the full impact of long COVID, there is reason for concern. One study of more than 3,700 self-identified long COVID patients found that nearly half could not work full-time six months after developing COVID-19 symptoms.<sup>8</sup> Long COVID also impacts young adults, causing disability that may preclude them from maintaining employment and negatively impact the quality of their lives.<sup>9,10</sup> In addition, it is not yet understood how best to prevent or treat long COVID; the complex care needs for these patients has the potential to overwhelm our healthcare system in the long-term.<sup>11</sup> These issues require further research to better understand the impact of long COVID on individuals as well as population health and identify how to prevent or treat this rapidly emerging consequence of the pandemic.

## II. LONG COVID RESEARCH

Existing studies of long COVID are small in scale but underscore the urgency of long COVID. In one study of 4,182 self-reporting participants who tested positive for COVID-19, 13.3 percent of patients experienced symptoms lasting longer than four weeks, 4.5 percent experienced symptoms longer than eight weeks, and 2.5 percent reported symptoms longer than 12 weeks.<sup>12</sup> The same study suggested that people with multiple symptoms during initial

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<sup>5</sup> Centers for Disease Control and Prevention, *COVID-19 Long-Term Effects* (April 8, 2021) ([www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html](http://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html)).

<sup>6</sup> *Id.*

<sup>7</sup> *Id.*

<sup>8</sup> *Trying to Make Sense of Long COVID Syndrome*, NIH Director's Blog (January 19, 2021) ([directorsblog.nih.gov/2021/01/19/trying-to-make-sense-of-long-covid-syndrome/](http://directorsblog.nih.gov/2021/01/19/trying-to-make-sense-of-long-covid-syndrome/)).

<sup>9</sup> *Long-lasting COVID symptoms from lungs to limbs linger in coronavirus 'long haulers'*, USA Today News (July 25, 2020) ([www.usatoday.com/in-depth/news/health/2020/07/25/covid-19-long-haulers-fight-months-lingering-symptoms/5420534002/](http://www.usatoday.com/in-depth/news/health/2020/07/25/covid-19-long-haulers-fight-months-lingering-symptoms/5420534002/)).

<sup>10</sup> *A college Runner is Still Struggling with Symptoms Months After COVID-19 Diagnosis*, Runner's World (Sept. 15, 2020) ([www.runnersworld.com/runners-stories/a33984743/covid-19-diagnosis-natalie-hakala/](http://www.runnersworld.com/runners-stories/a33984743/covid-19-diagnosis-natalie-hakala/)).

<sup>11</sup> Sudre, C.H., Murray, B., Varsavsky, T. *et al. Attributes and predictors of long COVID*, Nature Medicine (March 10, 2021) ([www.nature.com/articles/s41591-021-01292-y#citeas](http://www.nature.com/articles/s41591-021-01292-y#citeas)).

<sup>12</sup> *Id.*

infection, older individuals, and women were more likely to develop long COVID.<sup>13</sup> There is also some evidence that long COVID can present even in healthy individuals. A recent study also found that long COVID is prevalent among healthcare workers with one in 10 young, healthy adult healthcare workers in Sweden who initially had mild COVID symptoms continuing to struggle with moderate to severe symptoms months later.<sup>14</sup>

Professional football, baseball, and basketball stars have also suffered from long COVID, experiencing season-ending symptoms and a long road back to pre-COVID performance.<sup>15</sup> While anecdotal evidence from some patients suggests vaccines may ease long COVID symptoms, there is no scientific consensus.<sup>16</sup>

The National Institutes of Health (NIH) is leading research efforts on long COVID in the United States. On December 3, 2020, NIH's National Institute of Allergy and Infectious Diseases held a two-day workshop on long COVID with discussions around its challenges, clinical observations, and the potential intersection of social determinants of health and race/ethnicity, among other topics.<sup>17</sup> Shortly after this workshop, on February 23, 2021, NIH Director Francis Collins announced the NIH PASC Initiative to identify the causes of long COVID and the means to prevent and treat the condition in patients who test positive for COVID-19.<sup>18</sup> The project seeks to answer the following initial underlying questions: (1) What does the spectrum of recovery from COVID-19 look like across the population?; (2) How many people continue to have symptoms of COVID-19, or develop new symptoms, after acute infection?; (3) What is the biological cause of prolonged symptoms?; (4) What makes some individuals vulnerable to long COVID but not others?; and (5) Does COVID-19 trigger a biological reaction that increases the risk of other conditions, like chronic heart or brain

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<sup>13</sup> *Id.*

<sup>14</sup> Carfi A, Bernabei R, Landi F; Gemelli, *Against COVID-19 Post-Acute Care Study Group*. *Persistent symptoms in patients after acute COVID-19*, JAMA (April 7, 2020).

<sup>15</sup> Sydney Umeri, *How elite athletes have struggled with the long-term effects of Covid*, SB Nation (March 3, 2021) ([www.sbnation.com/nba/2021/3/3/22292213/athletes-covid-recovery-stories-jayson-tatum-mo-bamba-asia-durr](http://www.sbnation.com/nba/2021/3/3/22292213/athletes-covid-recovery-stories-jayson-tatum-mo-bamba-asia-durr)).

<sup>16</sup> *Mysterious Ailment, Mysterious Relief: Vaccines Help Some COVID Long-Haulers*, NPR (March 31, 2021) ([www.npr.org/sections/health-shots/2021/03/31/982799452/mysterious-ailment-mysterious-relief-vaccines-help-some-covid-long-haulers](http://www.npr.org/sections/health-shots/2021/03/31/982799452/mysterious-ailment-mysterious-relief-vaccines-help-some-covid-long-haulers)).

<sup>17</sup> National Institutes of Health, *Workshop on Post-Acute Sequelae of COVID-19*, ([www.niaid.nih.gov/news-events/workshop-post-acute-sequelae-covid-19](http://www.niaid.nih.gov/news-events/workshop-post-acute-sequelae-covid-19)) (accessed April 19, 2021).

<sup>18</sup> National Institutes of Health, *NIH launches new initiative to study Long COVID*, (February 23, 2021) ([www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid](http://www.nih.gov/about-nih/who-we-are/nih-director/statements/nih-launches-new-initiative-study-long-covid)).

disorders?<sup>19</sup> After addressing these underlying questions, NIH anticipates opportunities to start clinical trials and test strategies for treating long COVID.<sup>20</sup>

CDC is also monitoring and responding to long COVID. Their goal throughout the pandemic has been to develop a complete picture of the natural history of the virus that causes COVID-19, to inform care, enhance clinical decision making, and implement the right public health responses.<sup>21</sup> Early last year, CDC established a COVID-19 Response Clinical Team to provide clinicians with effective evaluation information.<sup>22</sup> Subsequently, the CDC COVID-19 Response Clinical Team established a Late Sequelae Unit.<sup>23</sup> The objectives of the unit are to identify the signs and symptoms of long COVID, potential multidisciplinary teams for patients, challenges to long COVID care, and examples of patient-centered, interdisciplinary care.<sup>24</sup> In addition to their own research and cohort studies, CDC will partner with other agencies and organizations to understand and characterize long COVID.<sup>25</sup>

### III. CONGRESSIONAL ACTION

Since March 2020, multiple legislative packages responding to the COVID-19 pandemic have been signed into law, including: the Coronavirus Preparedness and Response Supplemental Appropriations Act, 2020<sup>26</sup>, Families First Coronavirus Response Act<sup>27</sup>, the Coronavirus Aid, Relief, and Economic Security (CARES) Act<sup>28</sup>, the Paycheck Protection Program and Health Care Enhancement Act<sup>29</sup>, Coronavirus Response and Relief Supplemental Appropriations Act,

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<sup>19</sup> *Id.*

<sup>20</sup> *Id.*

<sup>21</sup> Centers for Disease Control and Prevention, *Post-COVID Conditions*, ([www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fhcp%2Fclinical-care%2Flate-sequelae.html](http://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fhcp%2Fclinical-care%2Flate-sequelae.html)) (accessed April 16, 2021).

<sup>22</sup> Centers for Disease Control and Prevention, *CDC Response to COVID-19*, ([www.cdc.gov/about/24-7/response-to-covid-19.html](http://www.cdc.gov/about/24-7/response-to-covid-19.html)) (accessed April 16, 2021).

<sup>23</sup> Centers for Disease Control and Prevention, *Treating Long COVID: Clinician Experience with Post-Acute COVID-19 Care* (January 28, 2021) ([emergency.cdc.gov/coca/ppt/2021/012821\\_slide.pdf](http://emergency.cdc.gov/coca/ppt/2021/012821_slide.pdf)).

<sup>24</sup> *Id.*

<sup>25</sup> *Id.*

<sup>26</sup> Pub. L. No. 116-123 (2020).

<sup>27</sup> Pub. L. No. 116-127 (2020).

<sup>28</sup> Pub. L. No. 116-136 (2020).

<sup>29</sup> Pub. L. No. 116-136 (2020).

2021<sup>30</sup>, and the American Rescue Plan Act of 2021.<sup>31</sup> Within these packages, Congress has specifically targeted funding to research the evolving nature of COVID-19 and its effects. Notably, the Coronavirus Response and Relief Supplemental Appropriations Act, 2021, allocated \$1.15 billion to NIH to research and initiate clinical trials related to long COVID.<sup>32</sup> Most recently, the American Rescue Plan Act allocated \$7.5 billion to CDC for vaccine activities, \$1.75 billion to monitor and sequence coronavirus variants, and \$750 million to support the global health response.<sup>33</sup>

#### IV. WITNESSES

##### **Panel 1:**

**Francis S. Collins, M.D., Ph.D.**

Director

National Institutes of Health

**John T. Brooks, M.D.**

Chief Medical Officer, CDC COVID-19 Response

Centers for Disease Control and Prevention

##### **Panel 2:**

**Steven Deeks, M.D.**

Professor of Medicine

University of California, San Francisco

**Jennifer Possick, M.D.**

Associate Professor, Section of Pulmonary, Critical Care and Sleep Medicine, Yale School of Medicine

Director, Post-COVID Recovery Program

Winchester Center for Lung Disease, Yale-New Haven Hospital

**Natalie Hakala**

Patient

Eugene, OR

**Lisa McCorkell**

Patient

Oakland, CA

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<sup>30</sup> Pub. L. No. 116-260 (2020).

<sup>31</sup> Pub. L. No. 117-2 (2021).

<sup>32</sup> See note 18.

<sup>33</sup> See note 24.

**Chimere Smith**  
Patient  
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