

March 17, 2022

Kilolo Kijakazi  
Acting Commissioner  
Social Security Administration  
Woodlawn, MD 21207

Dear Commissioner Kijakazi,

We write to urge the Social Security Administration (SSA) to improve, formalize, and communicate guidance on the consideration of disability applications for individuals living with post-COVID conditions, also known as “long COVID.” As we continue to address the COVID-19 pandemic, we also must contend with the impacts of long COVID. Although SSA has taken steps to facilitate applications for those living with long COVID, existing SSA guidance requires applicants to provide a positive COVID-19 test or diagnosis with limited exceptions, which many living with long COVID cannot produce. We are concerned that, as currently drafted, this guidance may inappropriately limit access to disability benefits for those with long COVID. We urge you to revise this testing requirement to acknowledge that at many times throughout the pandemic, COVID testing has been inaccessible, especially for communities of color, and to do more to ensure individuals experiencing disability due to long COVID have the support they need when applying for disability benefits.

Although the exact number of patients with long COVID is unknown, research suggests that one-third to over one-half of surviving COVID patients will develop symptoms of long COVID.<sup>1</sup> Even using a relatively conservative estimate, the American Academy of Physical Medicine and Rehabilitation estimates more than 23.5 million COVID-19 survivors in America will develop long COVID.<sup>2</sup> Long COVID patients experience symptoms at least one month after infection with the virus that causes COVID-19, including symptoms such as fatigue, brain fog, shortness of breath, chest pain, heart palpitations, exercise intolerance, and chronic joint or muscle pain.<sup>3</sup> For those afflicted, fatigue associated with long COVID can be substantial and debilitating.<sup>4</sup> Long COVID patients also may experience post-viral conditions, such as Postural Orthostatic

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<sup>1</sup> Destin Groff et al., *Short-term and Long-term rates of Postacute Sequelae of SARS-COV-2 Infection: A Systematic Review*, JAMA Network Open, (Oct. 13, 2021),

[https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2784918?utm\\_source=For\\_The\\_Media&utm\\_medium=referral&utm\\_campaign=ftm\\_links&utm\\_term=101321](https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2784918?utm_source=For_The_Media&utm_medium=referral&utm_campaign=ftm_links&utm_term=101321); Maxime Tacquet, et al., *Incidence, co-occurrence, and evolution of long-COVID features: A 6-month retrospective cohort study of 273,618 survivors of COVID-19*, PLOS Medicine, (Sept. 28, 2021), <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003773>.

<sup>2</sup> American Academy of Physical Medicine and Rehabilitation, *PASC Dashboard*, <https://pascdashboard.aapmr.org/> (last access Mar. 10, 2022).

<sup>3</sup> Centers for Disease Control and Prevention, *Post-COVID Conditions*, (Sept. 16, 2021), <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>.

<sup>4</sup> *Post-Acute Sequelae of SARS-Cov-2, Hearing on Bridging Health Equity Gaps for People with Disabilities & Chronic Illnesses before the House Ways and Means Health Subcommittee*, 117<sup>th</sup> Cong. (2022) (Testimony of Monica Verduzco-Gutierrez, M.D., Professor and Chair, Department of Rehabilitative Medicine at the Joe R. and Teresa Lozano Long School of Medicine), available at <https://waysandmeans.house.gov/sites/democrats.waysandmeans.house.gov/files/documents/Verduzco-Gutierrez%20Testimony.pdf>.

Tachycardia Syndrome (POTS)<sup>5</sup> and Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS).<sup>6</sup> Diagnosis for these conditions can take months to years and require patients to see many specialists to treat the wide range of symptoms affecting multiple systems,<sup>7</sup> in part because there is no definitive test for CFS.<sup>8</sup>

Importantly, long COVID is not always associated with more severe cases of COVID-19. According to the Centers for Disease Control and Prevention (CDC), “symptoms [of post-COVID conditions] can happen to anyone who has had COVID-19, even if the illness was mild, or if they had no initial symptoms.”<sup>9</sup> In one study, as many as 40 percent of those afflicted by long COVID did not experience symptoms in the initial period following their infection but developed symptoms later.<sup>10</sup> Additionally, CDC data indicates that rates of patients reporting long COVID symptoms two months after their positive test were higher among Black patients, female patients, and patients with pre-existing conditions.<sup>11</sup>

Given the significant impact of long COVID, we appreciate that the SSA has taken steps to communicate guidance on long COVID to applicants and SSA staff. On April 16, 2021, SSA released an Emergency Message providing “policy guidance for evaluating adult disability cases that include an allegation or diagnosis of Coronavirus Disease 2019 (COVID-19).”<sup>12</sup> This emergency guidance describes the approach to establishing and coding a medically determinable impairment (MDI) for COVID-19, including long COVID, as well as sets standards for severity and duration of the MDI. However, the April 16, 2021 guidance requires “a report of a positive viral test for SARS-CoV-2, a diagnostic test with findings consistent with COVID-19 (e.g. chest x-ray with lung abnormalities, etc.), or a diagnosis of COVID-19 with signs consistent with COVID-19 (e.g., fever, cough, etc.)”<sup>13</sup>

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<sup>5</sup> Lisa Eddy, *On the Heels of COVID-19: Influx of Patients with POTS Symptoms*, Johns Hopkins Medicine News and Publications, (Apr. 30, 2021), <https://www.hopkinsmedicine.org/news/articles/on-the-heels-of-covid-19-influx-of-patients-with-pots-symptoms>.

<sup>6</sup> Mark Tenforde et al, *Symptom Duration and Risk Factors for Delayed Return to Usual Health Among Outpatients with COVID-19 in a Multistate Health Care Systems Network — United States, March–June 2020*, Morbidity and Mortality Weekly Report, (July 31, 2020), <https://www.cdc.gov/mmwr/volumes/69/wr/mm6930e1.htm>.

<sup>7</sup> Cindy Loose, *Little-Known Illnesses Turning Up in Covid Long-Haulers*, Kaiser Health News, (June 1, 2021), <https://khn.org/news/article/covid-long-haul-illness-pots-autonomic-disorder/>.

<sup>8</sup> Mayo Clinic, *Chronic Fatigue Syndrome, Patient Care and Health Information*, (Sept. 24, 2020), <https://www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/diagnosis-treatment/drc-20360510>.

<sup>9</sup> Centers for Disease Control and Prevention, *Post-COVID Conditions*, (Sept. 16, 2021), <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>.

<sup>10</sup> Maxime Tacquet, et al., *Incidence, co-occurrence, and evolution of long-COVID features: A 6-month retrospective cohort study of 273,618 survivors of COVID-19*, PLOS Medicine, (Sept. 28, 2021), <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003773>.

<sup>11</sup> Kyle Yomogida et al., *Post-Acute Sequelae of SARS-CoV-2 Infection Among Adults Aged ≥18 Years — Long Beach, California, April 1–December 10, 2020*, Morbidity and Mortality Weekly Report (Sept. 17, 2021), ([https://www.cdc.gov/mmwr/volumes/70/wr/mm7037a2.htm?s\\_cid=mm7037a2\\_x](https://www.cdc.gov/mmwr/volumes/70/wr/mm7037a2.htm?s_cid=mm7037a2_x)).

<sup>12</sup> Social Security Administration, *Emergency Message: Evaluating Cases with Coronavirus 2019 (COVID-19)*, (Apr. 16, 2021), <https://secure.ssa.gov/apps10/reference.nsf/links/04162021020344PM>.

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

We are concerned that the testing requirements in the current guidance do not reflect the barriers experienced by patients with long COVID. Access to testing, including both PCR and rapid antigen testing, has been limited at multiple points during the pandemic, particularly during the onset of the pandemic in March 2020<sup>14</sup> and recently during the peak of the Omicron variant in December 2021.<sup>15</sup> In March 2020, politicians and public health leaders dissuaded both people with or without COVID-19 symptoms from testing, and many were turned away from testing sites.<sup>16</sup> In August 2020, the CDC modified COVID testing guidance to exclude pre-symptomatic and asymptomatic people, including those who had been exposed to COVID-19.<sup>17</sup> During the recent Omicron variant wave, insufficient testing capacity forced patients experiencing COVID symptoms to wait hours for testing, and many patients could not access PCR testing appointments or rapid tests, or were turned away at emergency rooms.<sup>18</sup>

Long COVID patients also may not present with abnormal findings consistent with COVID-19 on diagnostic tests. Long COVID patients, including those with POTS and ME/CFS can present with normal test and scan results, including lung X-rays, CTs, ultrasounds, MRIs, and endoscopy and colonoscopies.<sup>19</sup> Using the current SSA criteria may prevent those with long COVID symptoms and conditions from receiving benefits because their multi-system disorders do not show up on these tests. We ask that SSA update its guidance to acknowledge the barriers to access to testing and the difficulties in diagnosing multi-system disorders so that the lack of a positive test result does not prevent long COVID patients from accessing disability benefits.

In addition to improving upon the guidance, we ask that the SSA formalize and elevate disability benefits guidance on long COVID from an Emergency Message to a Social Security Ruling (SSR). SSRs are precedential decisions that are “binding on all components of the Social Security Administration”.<sup>20</sup> Once formalized, we ask that SSA communicate these updated

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<sup>14</sup> Robert Kuznia, Curt Devine, and Drew Griffin, *Severe Shortages of swabs and other supplies hamper coronavirus testing*, CNN, (Mar. 18, 2020), <https://www.cnn.com/2020/03/18/us/coronavirus-testing-supply-shortages-invs/index.html>.

<sup>15</sup> Bryan Pietsch, *More coronavirus tests will be available next month, Fauci says, as U.S. struggles with shortage*, Washington Post, (Dec. 27, 2021), <https://www.washingtonpost.com/health/2021/12/27/omicron-covid-test-shortage-fauci/>.

<sup>16</sup> Shawn Boburg, Emma Brown, Derek Hawkins, and Amy Goldstein, *After Trump promised ‘anybody’ can get coronavirus testing, patients and doctors still complain of roadblocks*, (Mar. 12, 2020), [https://www.washingtonpost.com/investigations/coronavirus-testing-denials/2020/03/12/a70eca1e-63df-11ea-912d-d98032ec8e25\\_story.html](https://www.washingtonpost.com/investigations/coronavirus-testing-denials/2020/03/12/a70eca1e-63df-11ea-912d-d98032ec8e25_story.html).

<sup>17</sup> Katherine J. Wu, *C.D.C. Now Says People Without COVID-19 Symptoms Do Not Need Testing*, N.Y. Times, (Aug. 25, 2020), <https://www.nytimes.com/2020/08/25/health/covid-19-testing-cdc.html>.

<sup>18</sup> Hanna Krueger and Anissa Gardizy, *‘Oppressive’ and ‘unbelievable’: Long testing lines frustrate Mass. Residents and obscure COVID surge reality*, Boston Globe, (Dec. 29, 2021),

<https://www.bostonglobe.com/2021/12/29/nation/long-lines-reflect-states-continued-testing-woes/>; Jenna Portnoy and Rebecca Tan, Hospitals, already under strain from covid cases, discourage ER visits for coronavirus tests, Washington Post, (Dec. 30, 2021), <https://www.washingtonpost.com/dc-md-va/2021/12/30/tests-er-covid-shortage/>.

<sup>19</sup> Amanda Morris, *Another Struggle for Long Covid Patients: Disability Benefits*, N.Y. Times, (Oct. 27, 2021), <https://www.nytimes.com/2021/10/27/us/long-covid-disability-benefits.html>; Josh Keller, *How Long Covid Exhausts the Body*, N.Y. Times, (Feb.19, 2022), <https://www.nytimes.com/interactive/2022/02/19/science/long-covid-causes.html>.

<sup>20</sup> Social Security Administration, Social Security Ruling Definition, <https://www.ssa.gov/regulations/def-ssr.htm>.

testing, diagnostic, and symptom evaluation criteria to SSA staff, Administrative Law Judges (ALJ's), potential and current applicants, and disability representatives.

Based on these issues, we request that SSA respond in writing and with a staff-level briefing to the following questions by March 29<sup>th</sup>, 2022:

1. How many applications to date has SSA received for adult disability cases including an allegation or diagnosis of COVID-19?
  - a. How many of these applications were approved? How many were denied?
  - b. How do these approval rates compare to other similar disabilities such as POTS and ME/CFS?
  - c. Were the number of applications, approvals, and denials proportionate by race, sex, and age to the number of COVID cases and hospitalizations for these groups?
  - d. How many applications involving alleged COVID symptoms were approved on the basis of other conditions due to the absence of a positive COVID-19 test?
  - e. For how many cases was the lack of positive COVID-19 test, whether antigen or PCR, the primary reason for a denial?
2. Was the lack of a diagnostic test consistent with COVID-19 symptoms such as lung abnormalities the primary reason for any denials? If so, how many denials resulted from the lack of presentation on scans or tests?
3. Has SSA considered alternatives to the testing or diagnostic testing requirements for disability qualification?
  - a. If so, which long COVID patients, physicians who treat COVID and long COVID, and disability rights organizations has SSA consulted with on the guidance?
4. What steps has SSA taken, to date, to ensure long COVID guidance has been received and understood by SSA staff, Administrative Law Judges (ALJs), applicants, and representatives and legal service organizations assisting applicants?
5. What has SSA done to ensure materials are accessible to everyone, including those who may lack access to the internet and individuals with limited English proficiency?
6. What has SSA done to ensure patients with COVID and long COVID are aware of long COVID symptoms, diagnosis, and SSA disability guidance?
  - a. Has SSA considered creating a webpage specifically about long COVID symptoms, diagnosis, and SSA disability processes? If so, what steps have already been taken to launch this webpage?
7. What steps has SSA taken to ensure access for individuals who may be unable to come to SSA offices in person? Is assistance being provided to submit SSA disability for applicants?

Thank you in advance for your attention to this matter. If you have any questions, please contact Sedef Berk of Senator Markey's office at [Sedef\\_berk@markey.senate.gov](mailto:Sedef_berk@markey.senate.gov) and Veena Muraleetharan of Senator Kaine's office at [Veena\\_Muraleetharan@kaine.senate.gov](mailto:Veena_Muraleetharan@kaine.senate.gov).

Sincerely,



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Edward J. Markey  
United States Senator



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Tim Kaine  
United States Senator



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Tammy Duckworth  
United States Senator