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July 19, 2021

The Honorable Diana DeGette  
U.S. House of Representatives  
2111 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Fred Upton  
U.S. House of Representatives  
2183 Rayburn House Office Building  
Washington, D.C. 20515

Dear Representatives DeGette and Upton,

The COVID Patient Recovery Alliance, a multi-sector collaboration committed to identifying federal policy solutions to help the health care sector respond to long-COVID, thanks you for the inclusion of two policies on long-COVID in your CURES 2.0 Act draft, which was released on June 22.<sup>i</sup> The inclusion of long-COVID policies in your legislation demonstrates that you understand the needs of the health care sector and policymakers to monitor, understand, and respond to this evolving challenge.

We support the policies in Cures 2.0 that would help address long-COVID. The first policy would require HHS to “conduct a large national survey of patients who self-identify as having long-COVID to assess sources of health coverage, long-term care coverage, and disability coverage.” The second policy would direct HHS to convene a series of national meetings “to serve as the basis of an ongoing long-COVID learning collaborative. . . .” Both policies are responsible steps forward for helping to improve understanding of long-COVID in the health sector and policymaking community.

We share your interest and concern regarding long-COVID. As part of the national response to the COVID-19 pandemic, the COVID Patient Recovery Alliance sees the importance of working together to better understand long-COVID and how its effects may impact our health care system, our communities, and our path on the road to recovery. We have been at work since last year with the mission of supporting the energy and innovation of public-sector and private-sector leaders as they ensure care for individuals experiencing long-COVID. Our Alliance is composed of leaders in business, health care, patient and consumer advocacy, research, academia, and data science who are dedicated to helping understand and meet the needs of individuals with long-COVID.<sup>ii</sup>

While much is not yet fully understood about long-COVID, individuals with long-COVID are facing real and extensive needs. Published estimates suggest that somewhere between 10 to 30 percent of individuals who recovered from COVID-19 may have long-COVID to some degree for some period of time.<sup>iii</sup> The Centers for Disease Control and Prevention estimates that more than 114 million Americans have been infected with COVID-19 during the public health emergency; thus, the number of Americans with long-COVID who are grappling with ongoing sequelae from COVID-19 is likely quite larger than is widely understood. With millions of Americans experiencing some degree of long-COVID disruption in their lives, the ramifications for their full recovery, ability to return to work, and resume their roles in their families and communities are significant.<sup>iv</sup>

As the Cures 2.0 legislation moves through the legislative process, the COVID Patient Recovery Alliance welcomes the chance to work with you and your offices to build on the two policies you included in the draft. Over the last few months, the Alliance has been building out a suite of targeted, actionable policies that federal policymakers in Congress and the Administration can execute to help better respond to the needs of individuals with long-COVID.

Through our collaborative, consensus-based process, we have been focusing our policy efforts on:

- **Models of Care** – Targeted federal policies that support the adoption models of care to ensure individuals with long-COVID – especially those who are underserved or are already facing disparities and inequities – have quality care.
- **Payment Models** – Targeted federal policies based on identified opportunities or gaps in current payment approaches to ensure patients with long-COVID receive adequate care.

In both domains, our suite of federal policy solutions is designed to ensure that individuals with long-COVID get the care and support they need, based on evidence, best practices, and patients’ needs and characteristics. We anticipate interim recommendations next month and welcome the chance to share them with you to inform potential new policies that could be considered as Cures 2.0 advances through the legislative process.

Thank you again for your inclusion of long-COVID policies in Cures 2.0. As you and your colleagues in Congress seek to more fully understand and respond to long-COVID, the COVID Patient Recovery Alliance welcomes the opportunity to serve as a resource to you on these important issues on an ongoing basis.

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Sincerely,

### Members of the COVID-19 Patient Recovery Alliance

Governor Michael Leavitt, Co-Convener  
Nancy-Ann DeParle, Co-Convener  
Ambitna  
American Heart Association  
Arcadia  
Atrium Health  
Cync Health  
Duke Clinical Research Institute

Health Catalyst  
Health Rosetta  
Intermountain Healthcare  
MedStar Health  
Mount Sinai Health System  
One Call  
Survivor Corps  
University Hospitals

### Policy Experts

Donald Berwick, MD  
*President Emeritus and Senior Fellow, Institute for Healthcare Improvement and Former Administrator, Centers for Medicare & Medicaid Services*

Charlene Frizzera  
*President and CEO of CF Health Advisors and Former Acting Administrator, Centers for Medicare & Medicaid Services*

Brett Giroir, MD  
*Leavitt Partners Distinguished Visiting Executive and Former Assistant Secretary for Health, U.S. Department of Health and Human Services*

William Winkenwerder, MD  
*Chairman, CitiusTech and Former Assistant Secretary of Defense and Health Affairs and Former CEO, Highmark Health*

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<sup>i</sup> <https://degette.house.gov/media-center/press-releases/CURES2>

<sup>ii</sup> <https://covid19patientrecovery.org/about-us/#contributors>

<sup>iii</sup> [https://covid19patientrecovery.org/wp-content/uploads/2021/04/Long-COVID-Backgrounder\\_Final-V2.pdf](https://covid19patientrecovery.org/wp-content/uploads/2021/04/Long-COVID-Backgrounder_Final-V2.pdf)

<sup>iv</sup> Estimate based on symptomatic confirmed cases and estimated asymptomatic cases. Centers for Disease Control and Prevention. Estimated disease burden of COVID-19 (updated April 14, 2021) of 114.6 million total infections from February 2020 – March 2021. <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html>. website accessed July 8, 2021.