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LONG COVID
ALLIANCE

ADVOCACY WEEK

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#StopTheLonghaul The COVID-19 Longhaulers Act Data-Driven Solutions for Long COVID Care, Education, and Equity

Representatives Don Beyer (VA-08) and Jack Bergman (MI-01) will be re-introducing the COVID-19 Long Haulers Act, which would authorize and fund research and education initiatives to benefit so-called “long haulers,” an estimated 25–35% of COVID-19 patients who experience long term effects of COVID-19 infections.

Post-acute sequelae of COVID-19 (PASC), or the patient-preferred term “Long COVID,” describes a collection of post-viral symptoms which persist even after the patient no longer tests positive for the SARS-CoV-2 virus or antibodies and impacts an estimated 3.2 million Americans, regardless of their initial infection severity.

The COVID-19 Longhaulers Act will...

✓ Accelerate Long COVID Research through Data Harmonization

The COVID-19 Longhaulers Act will authorize \$30 million in FY22 for research and development of patient registries and biobanks through the Patient-Centered Outcomes Research Institute (PCORI) to centralize and synthesize robust data-sets regarding longitudinal outcomes of diverse symptoms and patient experiences.

✓ Research Long COVID Treatment Efficacy and Disparities

The COVID-19 Longhaulers Act will authorize \$33 million in FY22 for the Agency of Healthcare Quality and Research (AHRQ) and Centers for Medicare & Medicaid Services (CMS) to research and provide recommendations to improve the health care system’s response to long-term symptoms of COVID–19 including:

- access for veterans, the elderly, disabled, and low-income communities to treatment,
- expand the Chronic Conditions Data Warehouse research database to collect data on Long COVID treatment and service delivery,
- identify health care strategies that help mitigate disparities and ensure equity in diagnosis and access to post-infectious treatments, and
- develop protocols that ensure PASC patients have access to medical professionals educated about post-infectious disease and treatments.

✓ Educate Long COVID Patients and Medical Providers

The COVID-19 Longhaulers Act would authorize \$30 million in FY22 for the CDC to develop and disseminate information for medical providers and the general public about common symptoms, treatment, and other post-viral illnesses related to PASC.

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For more information, please contact Kate Schisler in the office of Representative Don Beyer.