

7/14/2022

The Honorable Patty Murray
Chair
Senate Committee on Health, Education,
Labor and Pensions
Washington, DC 20510

The Honorable Richard Burr
Ranking Member
Senate Committee on Health, Education
Labor and Pensions
Washington, DC 20510

The Honorable Frank Pallone
Chair
House Committee on Energy and Commerce
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
House Committee on Energy and Commerce
Washington, DC 20515

Re: Understanding the implications of Long COVID

Dear Chairs Murray and Pallone, and Ranking Members Burr and McMorris Rodgers:

The undersigned organizations, representing millions of patients that have been or will be affected by “Long COVID”, i.e. post-acute sequelae of SARS-CoV-2 infection (PASC), and the physicians who care for them, urge Congress to explore this growing issue. The undersigned organizations remain dedicated to enhancing our understanding and ensuring adequate resources are being invested into the impact of PASC on patients and hope your committees will consider this a priority issue.

Since 2020, our knowledge of COVID-19 has significantly grown. With science at the forefront of policymaking, synthesizing research to formulate the best path forward is imperative. Ultimately, there are over 87 million survivors of COVID in the US, and it is estimated that 33 percent have PASC. According to one study, one-third of patients diagnosed with COVID-19 developed psychiatric or neurologic disorders within six months, including depression, anxiety, stroke, and dementia. In that same study, researchers who evaluated more than 230,000 electronic health records, which includes anonymous data from 81 million patients, primarily in the US, found that among COVID-19 patients admitted to an intensive care unit (ICU), the incidence of developing a psychiatric or neurologic disorder rose to an unprecedented 46 percent.¹

In another study, researchers identified post-COVID health problems in many different organ systems, including the heart, lungs and kidneys.² Other issues identified in the study involved blood circulation, the musculoskeletal system and the endocrine system; gastrointestinal conditions, neurological problems and psychiatric symptoms. The study examined over 353,000 patients that were diagnosed with COVID-19 at the start of the pandemic, and it found that COVID-19 patients had twice the risk of uninfected people of developing respiratory symptoms and lung problems, including pulmonary embolism. Post-COVID patients aged 65 and older were at greater risk than the younger group of developing kidney failure, neurological conditions and most mental health conditions. These findings

¹ https://journals.lww.com/neurotodayonline/Fulltext/2021/06030/6_Months_After_COVID_19_Infection,_1_in_3_Develop.4.aspx

² <https://www.nytimes.com/2022/05/24/health/long-covid-infections.html>

have been reinforced by another study that found that after the first 30 days of infection, individuals with COVID-19 are at increased risk of incident cardiovascular disease spanning several categories, including cerebrovascular disorders, dysrhythmias, ischemic and non-ischemic heart disease, pericarditis, myocarditis, heart failure and thromboembolic disease.³ If left unchecked, PASC could leave many unable to perform their jobs, severely impacting the workforce, and increasing costs of health care in the long term.

Given the number of COVID-19 cases across the US, the impact of post-COVID symptoms is likely enormous, and without proper information sharing, patients could suffer devastating consequences and misdiagnoses. Additionally, understanding the core causes of PASC will make it easier for providers to identify patients who are more at risk of developing its chronic symptoms, and potentially providing early interventions.

We ask you to explore this issue further by convening hearings to explore potential solutions, encompassing broad themes such as: unifying definitions and language around PASC; enhancing research, data collection, and surveillance and identifying additional opportunities; focusing on patient diversity in research and mitigating disparities in care; defining outcomes; educating medical professionals and patients about PASC; and the development of guidance for clinical treatment and care coordination across primary care and several specialty providers.

Several bills have been introduced to Congress that focus on these broad themes that could serve as a potential starting point for assessing this rapidly developing issue. These include: the Cures 2.0 Act (H.R. 6000); the COVID-19 Long Haulers Act (H.R. 2754); the CARE for Long COVID Act (S. 3726); the TREAT Long COVID Act (H.R. 7482/S. 4015); and the Brycen Gray and Ben Price COVID-19 Cognitive Research Act (H.R. 7180/S. 4014), which was recently reported favorably by the House Committee on Science, Space and Technology.

Additionally, such hearings would be timely due to the Biden Administration's recent directive to coordinate efforts across the federal government to develop and issue the first-ever interagency national research action plan on PASC. We agree that focused attention on this issue will help advance progress in prevention, diagnosis, treatment, and provision of services, supports, and interventions for individuals experiencing PASC. Ultimately, we believe that we must follow the science as it relates to researching and caring for people affected by PASC. To do this, we must enhance our understanding of this condition and how to treat it. Providing a national spotlight on this issue will help continue the national dialogue with leading experts, ensure that progress is being made on key priorities, and identify areas for continued federal investment.

In conclusion, we hope the committee will consider PASC a priority and look forward to working with Congress to ensure patients suffering from PASC can receive the timely care coordination they need. If you have any questions or require additional information, please do not hesitate to contact Derek Brandt, Director of Congressional Affairs at the American Academy of Neurology at dbrandt@aan.com. We look forward to working with you as we all strive to improve care for Americans who are struggling with the lingering effects of COVID-19.

³ <https://www.nature.com/articles/s41591-022-01689-3>

Sincerely,

Alliance for Patient Access
ALS Association
Alzheimer's Association
Alzheimer's Impact Movement
American Academy of Allergy, Asthma & Immunology
American Academy of Family Physicians
American Academy of Hospice and Palliative Medicine
American Academy of Neurology
American Academy of Physical Medicine & Rehabilitation
American Association of Child and Adolescent Psychiatry
American Association of Clinical Urologists
American Association of Neurological Surgeons
American Association of Orthopaedic Surgeons
American Brain Coalition
American College of Cardiology
American College of Emergency Physicians
American College of Rheumatology
American Epilepsy Society
American Gastroenterological Association
American Geriatrics Society
American Headache Society
American Heart Association
American Psychiatric Association
American Society of Anesthesiologists
American Society of Hematology
American Society of Neuroimaging
American Society of Neuroradiology
American Society of Pediatric Nephrology
Anxiety and Depression Association of America
Association of Academic Physiatrists
Association of University Professors of Neurology
Bobby Jones Chiari & Syringomyelia Foundation
Brain Injury Association of America
California Neurology Society
Center for Law, Brain & Behavior, Massachusetts General Hospital
CHAMP - Coalition for Headache and Migraine Patients
Child Neurology Society
Chronic Migraine Awareness, Inc
Cohen Veterans Bioscience
College of American Pathologists
Commonwealth Neurological Society
Congress of Neurological Surgeons
Epilepsy Foundation

Federation of American Hospitals
Florida Society of Neurology
Georgia Neurological Society
Heart Failure Society of America
Hope for HIE
Hydrocephalus Association
Infectious Diseases Society of America
Alliance for Headache Disorders Advocacy
Massachusetts Neurologic Association
Miles for Migraine
MLD Foundation
Multiple Sclerosis Association of America
National Association of State Head Injury Administrators
National MS Society
National Organization for Tardive Dyskinesia
North Carolina Neurological Society
Parkinson's Foundation
Peripheral Nerve Society
Renal Physicians Association
Society for Cardiovascular Angiography and Interventions
Society for Neuroscience
Society for Vascular Surgery
Society of General Internal Medicine
Society of Interventional Radiology
Solve M.E.
SynGAP Research Fund, 501c3
Texas Neurological Society
Texas Tech University Health Sciences Center El Paso
The Headache and Migraine Policy Forum
The Michael J. Fox Foundation for Parkinson's Research
The Society of Thoracic Surgeons
United Council for Neurologic Subspecialties
Wisconsin Neurological Society (WNS)