American Academy of
Physical Medicine and Rehabilitation

TESTIMONY FOR THE WRITTEN RECORD
FROM THE

AMERICAN ACADEMY OF PHYSICAL MEDICINE & REHABILITATION (AAPM&R)

SUBCOMMITTEE ON HEALTH
COMMITTEE ON ENERGY AND COMMERCE
UNITED STATES HOUSE OF REPRESENTATIVES

A COMPREHENSIVE FEDERAL RESPONSE TO ADDRESS POST-ACUTE SEQUELAE OF SARS-COV-2 INFECTION (PASC), OR "LONG COVID"

HEARING ON

"THE LONG HAUL: FORGING A PATH THROUGH THE LINGERING EFFECTS OF COVID-19"

APRIL 28, 2021

AMERICAN ACADEMY OF PHYSICAL MEDICINE & REHABILITATION
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Chairwoman Eshoo, Ranking Member Guthrie, and Members of the Energy and Commerce Health Subcommittee:

Thank you for the opportunity to submit testimony today regarding Post-Acute Sequelae of SARS-CoV-2 infection, also known as "PASC" or "Long COVID." On behalf of the American Academy of Physical Medicine and Rehabilitation ("AAPM&R" or the "Academy"), I am grateful for the Committee's attention to this dire and complex issue. I would also like to take this opportunity to thank Congress for the $1.15 billion in funds allocated to the National Institutes of Health (NIH) in the recently passed Consolidated Appropriations Act of 2021, Public Law 116-260, as well as the work Congress and the federal government has undertaken over the past year to respond to the COVID-19 pandemic.

I am a physiatrist, working at University of Texas Health San Antonio Long School of Medicine and a member of the AAPM&R. The Academy is the national medical specialty organization representing more than 9,000 physicians who are specialists in physical medicine and rehabilitation (PM&R). PM&R physicians, also known as physiatrists, are medical experts in treating a wide variety of conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. PM&R physicians evaluate and treat injuries, illnesses, and disabilities, and are experts in designing comprehensive, patient-centered treatment plans. Physiatrists utilize cutting-edge as well as time-tested treatments to maximize function and quality of life.

Due to the nature of our specialty and our experience working with and coordinating care for people with complex disabilities and chronic conditions, physiatrists have been recognized as the leading specialty for assessing and treating patients experiencing the condition known as Long COVID. It is currently

estimated that 10-30%[1] of people who had COVID-19 will experience long COVID symptoms. Even considering the conservative estimate of 10%, this represents well over 8 million people[2] given the infection rate of this virus. Additionally, these symptoms often appear in patients who were asymptomatic and may have never even known they were infected with COVID in the first place.

Over the past six months, physiatrists and other clinicians have come together to address Long COVID by opening multi-disciplinary Long COVID clinics, in addition to our existing physician duties. These multi-disciplinary clinics serve as a "one-stop shop" to help this population address their new, varied, and debilitating symptoms, including neurological challenges, cognitive problems such as brain fog, shortness of breath, fatigue, musculoskeletal pain, and mobility impairments. These clinics convene different physician specialists, therapists, social workers, and sometimes researchers who are gathering vital data from patients with PASC. I currently lead two such clinics, Post-COVID Recovery Clinic at UT Health San Antonio and the Post-COVID Recovery Clinic at University Health. AAPM&R has gathered 26 of these institutions to create a Multi-Disciplinary PASC Collaborative of experts to develop clinical guidance to improve quality of care, formal education, and resources to improve the experience of care and health equity. These collaborative discussions have illuminated the consistent infrastructure and access barriers we are seeing across the various multi-disciplinary clinics that have organically "popped up" across the country. Additionally, the needs of Long COVID patients are already spreading far beyond the clinical sphere, as patients face difficulties in returning to work, receiving necessary workplace accommodations, and accessing Social Security, disability, and other benefits. **AAPM&R has called on the Administration and Congress to develop a comprehensive federal plan to defeat the national**

[1] Rubin R. As Their Numbers Grow, COVID-19 "Long Haulers" Stump Experts. JAMA. 2020;324(14):1381–1383. doi:10.1001/jama.2020.17709.
[2] Estimated Disease Burden of COVID-19. Centers for Disease Control and Prevention. January 19, 2021. https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html

Long COVID crisis. To develop such a plan, to assess the varied policy considerations and far-reaching impacts of Long COVID, and to obtain meaningful input from a wide range of stakeholders, AAPM&R recommends the immediate formation of a federal commission with a diversity of expertise to develop priority recommendations for addressing infrastructure needs and other gaps in access to timely and appropriate clinical care for all individuals with PASC.

Access Barriers

Not all insurers and health plans cover rehabilitation services, specialty home services, or post-acute care for brain injury and neurorehabilitation. These services are vitally important for this population that is experiencing a breadth of symptoms and who often have difficulty organizing and traveling to many different doctors' offices. Because there is not adequate coverage, many patients cannot access these services as chronic symptoms are typically not considered as acute or emergencies. Many patients are simply unable to afford the costs of Long COVID treatment out of pocket, especially given the wide range of services required for adequate treatment and the long-lasting, potentially even permanent, effects of this condition.

In addition to financial barriers, individuals experiencing PASC are subject to the same systemic barriers to care that individuals with other complex, chronic conditions experience. For instance, when a patient visits their primary care provider to discuss their PASC symptoms, they are often provided with several referrals to specialists to address the confluence of their symptoms. Such patients may receive a referral to a cardiologist, pulmonologist, neurologist, psychiatrist, and orders for various labs and other tests. This puts the patient in the position of coordinating their own complex care and having to attend many different appointments, if they are even able to secure appointments in a timely manner. This is particularly difficult for a population encountering significant fatigue and other debilitating PASC

symptoms. The multi-disciplinary clinic approach, to the contrary, creates a hub where a patient can see a physiatrist and consult with all these specialists, complete their testing, and meet with any needed therapists through a comprehensive, coordinated approach. It is one of the reasons these clinics have months-long waiting lists just to be evaluated for the first time.

The PASC clinics that are growing across the country are typically part of an academic medical center or other health system that has the resources and capacity to develop these clinics quickly. These systems have significant financial reserves, physical space, and existing networks of specialists to erect these multi-disciplinary clinics quickly. In addition, practitioners leading these clinics can be given the leeway to devote their time and energy to developing a new model of care for their patients with PASC. For the vast majority of health care providers across the nation, these capabilities will not be available to adequately support such multi-disciplinary clinics without some form of financial assistance to jumpstart their development, even as they are proving highly effective in meeting the needs of patients with Long COVID. To put it plainly, the need for these clinics far outstrips the resources available in many areas of the country.

Payment Issues for Patients and Providers

Typically, clinical visits to evaluate, diagnose, and coordinate treatment for patients with Long COVID symptoms take an hour or more. Such complex and lengthy visits are simply not in sync with the typical reimbursement models for medical practice and the existing Evaluation and Management (E&M) codes are not equitable for the work required to treat these patients. Existing E&M codes are based upon a standard 15-minute patient visit, which is not a reasonable amount of time to evaluate complex PASC patients. This discrepancy in reimbursement and the time expended may be why more doctors are not able to adequately care for these patients. Improved reimbursement policies, such as a Long COVID add-on

code, are desperately needed to ensure that physicians can dedicate the time and resources necessary to provide appropriate care to Long COVID patients. Such reforms will make it feasible for physicians to provide this care, increasing the supply of providers offering Long COVID treatment and reducing wait times and other barriers to accessing care for patients. Currently, the physicians working in these clinics are doing so as an adjunct to their existing clinical responsibilities, making it difficult for many physicians to participate in this new model of care. A relative dearth of physicians has resulted in wait times of four to six months for patients before they can even be seen by many of the specialists necessary to treat their Long COVID symptoms.

Multi-disciplinary clinics are proving to be successful and a sorely needed model for addressing the multi-disciplinary clinical needs associated with Long COVID, but as described, there are several barriers to patients accessing such care. Funding or grants to establish these clinics would help create more of these clinics, streamline care, and help patients optimize their health and function faster.

Other Access Issues

Telemedicine has rapidly evolved over the past year and has been widely adopted throughout the pandemic. For safety reasons and the nature of Long COVID, telemedicine has been vital in treating patients with PASC. It allows patients access to a multi-disciplinary clinic that may not exist in their geographic area, a common concern for many patients nationwide, especially those residing in rural areas. However, many individuals in rural and low-income neighborhoods and across the country still do not have access to critical broadband internet and other technological requirements to appropriately access virtual care. This needs to be rectified for patients enduring the effects of Long COVID and all patients seeking virtual health care during the pandemic and beyond.

Many patients experiencing PASC may not have been specifically tested for COVID-19 nor exhibit antibodies, which results in some providers not knowing to refer them to a PASC clinic. Since PASC symptoms can appear in people who had asymptomatic cases of COVID, many may not even identify their symptoms as COVID-related. Additionally, there have been barriers to accurate testing throughout the pandemic for different populations, especially communities of color and people with disabilities. As treatments and reimbursement for Long COVID patients evolve, it is crucial that we not create additional barriers to access, such as a requirement for a positive COVID-19 test to gain access to a multi-disciplinary clinic.

The nature of Long COVID also means that many patients present with symptoms that do not appear in a normally recognized test. For example, patients may complain of shortness of breath, but show no discernible physical issues in imaging of their lungs. This has been a longstanding problem for patients with other long-term, chronic, and not clearly delineated conditions, such as chronic fatigue syndrome and other complex disease states. We hope that the efforts to improve multi-disciplinary care for patients with Long COVID can also benefit individuals with other complicated medical conditions. This underscores the need for research on PASC to be conducted rapidly and translated to providers so that this new population can be recognized for the symptoms they are suffering, instead of being dismissed for not fitting existing medical paradigms.

The infrastructure and access issues encountered by these multi-disciplinary PASC clinics are not new issues. Patients with disabilities and complex conditions have experienced these same barriers in our health system for years. The influx of people into the disability and chronic illness community from the rapidly growing population of people with Long COVID has shone a light on these barriers and gaps in

care for so many American patients. Long-term, ongoing support for multidisciplinary care is desperately needed.

Additional Needs of Long COVID Patients

The significant and time sensitive clinical needs of Long COVID patients only reflect one aspect of the impacts of Long COVID on the country. As we continue to develop a deeper understanding of Long COVID, some patients are likely to experience long-term or even permanent Long COVID symptoms, potentially impacting their ability to function independently for years to come. As a result, we expect that many Long COVID patients will become members of the disability community in the coming months and even years. These individuals will face significant additional barriers because of their symptoms. It is critical to consider how individuals with Long COVID will be able to access disability benefits, including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI); the accommodations these individuals may need to return to work, if they are able; the availability of Long-Term Services and Supports (LTSS) that may be necessary; the education these individuals may need to understand the services available to them and their rights under the Americans with Disabilities Act and other federal statutes; and much more. There are many facets to the Long COVID crisis, and the need for policy solutions is likely to only grow over the coming months. In order to coordinate the federal response to Long COVID, and to ensure that recommendations for statutory and regulatory changes can be made through a unified, recognized body with the imprimatur of the federal government, AAPM&R strongly recommends the formation of a commission, task force, or other federal interagency entity, led by the White House or at senior levels within the Department of Health and Human Services, and tasked with development of a crisis plan to address the immediate and long-term impacts of Long COVID-19. We encourage the subcommittee to consider this need and offer our assistance in any way we can to advance policy for those living with Long COVID.

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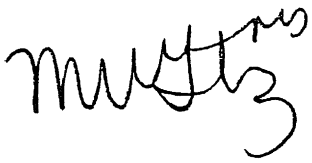
We thank the subcommittee for its leadership in recognizing this critical issue for individuals across the country and appreciate the opportunity to submit this written testimony. As the subcommittee, Congress, and the federal government continue to consider policies to address the Long COVID crisis, we offer our support as an organization and on behalf of the physiatry profession and urge the subcommittee to consider AAPM&R and the Multi-Disciplinary PASC Collaborative as a resource. We look forward to working with you to serve the needs of the millions of patients nationwide experiencing the debilitating effects of Long COVID.

Sincerely,



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Member of AAPM&R's Multi-Disciplinary PASC Collaborative
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Post-COVID Recovery Clinic at University Health

Appendix I: Current List of Institution Members Participating in the Multi-Disciplinary PASC Collaborative

- University of Washington
- Icahn School of Medicine at Mount Sinai
- UT Health San Antonio
- Rusk Rehabilitation, NYU Langone Health
- UT Southwestern Medical Center
- Shirley Ryan AbilityLab
- Penn Medicine
- Beth Israel Deaconess Medical Center
- OHSU - Oregon Health & Science University
- Johns Hopkins Medicine
- University of Kansas Health System
- Ascension Medical Group
- Mayo Clinic
- Cedars Sinai – LA
- GW Medical Faculty Associates
- JFK Johnson Rehabilitation Institute at Hackensack Meridian Health
- UNC-Chapel Hill
- University of Colorado
- UC Davis Health
- Vanderbilt University Medical Center
- Kennedy Krieger Institute - Pediatric Post COVID-19 Rehabilitation Clinic
- Montefiore-Einstein COVID-19 Recovery (CORE) Clinic
- Hartford HealthCare's COVID Recovery Center
- Tulane Neurology Post COVID Care Clinic
- Northwestern Medicine Comprehensive COVID-19 Center
- MetroHealth Post-COVID Clinic