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Dr. Marcella Nunez-Smith
COVID-19 Health Equity Task Force
Office of Minority Health
Department of Health and Human Services

July 1, 2021

RE: 5th COVID-19 Health Equity Task Force Meeting

Dear Dr. Nunez-Smith:

Thank you for the opportunity to submit comments 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 Task Force's attention to this dire and complex issue. I would also like to take this opportunity to thank the Administration and 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 the Task Force and the broader federal government has undertaken over the past year to respond to the COVID-19 pandemic. We recognize the significant progress the country has made in increasing widespread vaccinations, stabilizing the health care infrastructure for acute COVID treatment, and expanding the availability of testing and treatment – but this work is not yet finished. As the Task Force is aware, the effects of

Long COVID are already impacting significant portions of the population, and the numbers affected by these symptoms are only expected to grow. I urge the COVID-19 Health Equity Task Force and the Biden Administration to make an immediate public commitment addressing individuals with Long COVID assuring them that a comprehensive federal government response is a top priority. Due to the varying symptoms and severity of Long COVID, and the fact that this is a novel, perplexing, and widely misunderstood post-viral illness, many patients are being dismissed or ignored throughout the nation. This large and growing population needs acknowledgement and to hear that help is on the way at the highest levels and across the government.

On the Friday, June 25 meeting of the COVID-19 Health Equity Task Force, the Communications and Collaborations Subcommittee presented a recommendation for a federal advisory committee comprised of Long COVID patients, disability advocates, experts in researching and treating Long COVID, and staff from across the federal government to address clinical issues of Long COVID. Elements, even as basic as a consistent case definition, are needed. The Subcommittee also presented a recommendation for an interagency federal committee focused on helping people with Long COVID access needed resources. We support both recommendations, as they are very much in line with AAPM&R's policy stance that a federal commission or otherwise coordinated body of

individuals with diverse expertise is needed to tackle Long COVID to ensure a comprehensive, effective, and efficient response. **In the creation of the federal advisory committee, we urge the Task Force to include AAPM&R given our experience and medical expertise in working with patients with Long COVID and other post-viral and complex illnesses.** Additionally, AAPM&R actively supports the creation of unified ICD-10 codes for Long COVID, the federal governments consulting with appropriate healthcare professionals including physiatrists, and many other recommendations made during the June 25th public meeting of the Task Force.

I am a physiatrist, working at Penn Medicine and an Assistant Professor at the University of Pennsylvania as well as 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.

Physiatrists, as trained physician experts in medical rehabilitation, have played and continue playing a unique role in helping American patients recover from the acute phase of COVID-19, working on the front lines of the pandemic since the beginning of the public health emergency. In the spring of 2020, we transformed inpatient rehabilitation facilities to take care of acutely ill patients in order to help decompress the massive surge of patients being admitted to acute care hospitals. This soon evolved to treating recovering COVID-19 patients who had been in the intensive care unit and suffered multi-system organ failure and complications (such as strokes and critical illness polyneuropathy). These patients required rehabilitation to regain their previous functional abilities and independence. While we continue to treat these patients, over the past ten months our outpatient practice also began treating patients suffering from the prolonged effects of COVID-19, often called PASC, "post-covid syndrome," or "Long COVID."

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 one of the leading specialties for assessing and treating patients experiencing Long COVID. It is currently estimated that 10-30%[1] of people who had COVID-19, including

[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.

asymptomatic cases, will experience prolonged effects related to their previous COVID-19 infection. Even considering the conservative estimate of 10%, this represents over 11 million people[2] given the infection rate of this virus.

Over the past year, physiatrists and other clinicians have come together to address Long COVID by opening multi-disciplinary Long COVID clinics. Typically, this is 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, such as cognitive impairment (often called "brain fog"), shortness of breath, fatigue, pain, and mobility difficulties. These clinics convene different physician specialists, therapists, social workers, and sometimes researchers who are gathering vital data from patients with PASC. I currently lead such a clinic, the Penn Medicine Post-COVID Assessment and Recovery Clinic. AAPM&R has gathered 28 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

[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

across the various multi-disciplinary clinics that have organically started 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 and school, 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 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 (or other similarly empowered coordinating body, such as that recommended by the Communications and Collaborations Subcommittee) 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 neurorehabilitation. Patients often end up needing to fight with their insurers to be seen and treated. These services are vitally important for this population experiencing the breadth of

Long COVID symptoms and who often have difficulty organizing their care 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 Long COVID 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 patients with Long COVID who are suffering new physical and cognitive impairments. The multi-disciplinary clinic approach, however, creates a hub where a patient can see a physiatrist,

consult with other specialists, complete their testing, and meet with needed therapists through a comprehensive, coordinated approach.

A recent survey of Long COVID clinics illustrated that 77% of clinics recognized barriers to patient care. The most commonly reported barrier for these clinics were lack of resources in treating these patients including lack of clinicians and financial coverage for patients to receive the care that they need. Given this lack of resources, patients often have to wait several months to access these clinics. Furthermore, even when seen in these clinics, patients may have difficulty receiving the assessments and treatments they need. Countless patients are denied testing (echocardiograms, pulmonary function tests) and treatments (neuropsychology, speech therapy, and medications).

The PASC clinics that are emerging across the country typically operate as part of an academic medical center or other health system that has the resources and capacity to develop these clinics quickly, and without the existence of a specific reimbursement structure for such coordinated care. These systems have significant financial reserves, physical space, and existing networks of specialists to rapidly develop these multi-disciplinary clinics and begin seeing patients. 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.

Additionally, and most importantly, most patients do not have the ability to access these clinics and therefore are unable to receive the most appropriate and effective care for this illness. Currently, the patients we are seeing in our clinic are simply not representative of the actual Long COVID population. Our patients are more likely to be middle/upper-middle class, middle-aged, and white than the typical COVID-19 patient. This clearly demonstrates the ongoing problem with equitable access to COVID-related care (and by extension, equitable access throughout our health care system). We do not believe that the population we are seeing is more severely affected by Long COVID, but rather this population has adequate access to this care, as compared to populations facing health inequities who may not even been aware of the existence of these clinics, much less have the resources and connections to secure a referral and treatment. The disparate care evidenced in acute COVID is being extended in cases of Long COVID

– we must address these issues as quickly as possible if we hope to manage the scourge of Long COVID fairly and effectively.

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 in our health care system, 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 patients, such as those with PASC. 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 an appropriate ICD-10 code or 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 more 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 in many cases has resulted in wait times beyond four months for patients to see 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. 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. There are numerous reasons a patient may not have COVID-19 on their health record, including the many cases at the onset of the pandemic in which patients with moderate COVID-19 were told explicitly not to bother with a test, or the patients who shared a household with someone who tested positive for COVID-19 were presumed to have it, testing was more accessible for some than others, and testing accuracy was heavily dependent on when and how the test was administered. For these and other reasons, patients may not have COVID-19 in their medical history and are now being turned away or face significant hurdles in accessing the care they need for lack of this documentation. The Centers for Disease Control and Prevention (CDC) interim guidance do not require a history of COVID-19 for Long COVID

diagnosis, and we assert that all federal accommodations and benefits should follow the CDC's example.

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 and consequently not receiving the accommodations or benefits they need. It is often devastating to patients to have to choose between their jobs and their health.

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 patients. Long-term, ongoing support for multidisciplinary care is desperately needed to begin to address these inequities individuals with complex needs.

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 and school, 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. These considerations will involve the jurisdictions of many federal agencies, underscoring the need for a clearly coordinated and managed response.

There are many facets to the Long COVID crisis, and the need for policy solutions is only going to 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 Task Force 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 Task Force for its leadership in recognizing this critical issue for individuals across the country and appreciate the opportunity to submit this written testimony. **As the federal government continues to consider policies to address the Long COVID crisis, we offer our support as an**

organization and on behalf of the physiatry profession. We urge the Task Force to consider AAPM&R and the Multi-Disciplinary PASC Collaborative as a resource and to be included as a member of any federal advisory committee. 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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Director of the Post-COVID Assessment and Recovery Clinic
Co-Chair of AAPM&R's Multi-Disciplinary PASC Collaborative

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
- Ballad Health
- Spaulding Rehabilitation Network & Department of Physical Medicine and Rehabilitation at Massachusetts General Hospital