# Testimony of Monica Verduzco-Gutierrez, MD Professor and Distinguished Chair, Department of Rehabilitation Medicine University of Texas Health Science Center at San Antonio

## Before the Select Subcommittee on the Coronavirus Crisis United States House of Representatives

# "Understanding and Addressing Long COVID and its Consequences"

## July 19, 2022

Chairman Clyburn, Ranking Member Scalise, and Members of the Select Subcommittee on the Coronavirus Crisis:

Thank you for the opportunity to testify today regarding impacts of a new disabling condition created by Post-Acute Sequelae of SARS-CoV-2 infection, also known as "PASC" or "Long COVID." I would also like to take this opportunity to thank you all for the work Congress and the federal government has undertaken over the past two and a half years to respond to the COVID-19 pandemic. I look forward to discussing issues related to the consequences of Long COVID with this committee in hopes that additional steps can be taken to address this alarming condition.

My name is Monica Verduzco-Gutierrez. I am a physiatrist working at the Joe. R and Teresa Lozano Long School of Medicine at the University of Texas Health Science Center at San Antonio, a member of the American Academy of Physical Medicine & Rehabilitation (AAPM&R), and a trustee for the Association of Academic Physiatrists. Physiatrists are physicians who are specialists in Physical Medicine and Rehabilitation (PM&R), treating a wide variety of conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. We evaluate and treat injuries, illnesses, and disabilities, and we are experts in designing comprehensive, patient-centered treatment plans. We utilize cutting-edge as well as time-tested treatments to maximize function and quality of life.

My own subspecialities in PM&R are Neuro Rehabilitation and Brain Injury Medicine. Prior to the pandemic, I saw patients in various settings, from the intensive care unit to the outpatient clinic. I even previously trained and worked at the rehabilitation hospital that cared for Congresswoman Giffords. During my career, I have been blessed to see the miraculous recoveries of those waking up out of a coma or the paralyzed walking again, along with all sorts of physical and mental healing through multidisciplinary teamwork.

## Impacts of the COVID-19 Pandemic on Persons with Disabilities

The Centers for Disease Control and Prevention (CDC) estimates that 1 in 4 Americans are living with some type of disability.<sup>1</sup> Historically, people with disabilities, especially those needing assistance and living in care facilities, are at increased risks during pandemics because of disruption of routine and long-term care. Physiatrists work with patients who experience health and healthcare disparities due to an intersection of race/ethnicity, gender, socioeconomic class, and physical and cognitive disabilities. Central to the current human suffering with the pandemic is the disproportionate impact it is having on the disability community and others from marginalized communities. The pandemic has offered us a closer look into health and healthcare disparities that reinforce this trend.

Aside from the direct illness caused by COVID-19 on the disability community - and the disparate effect that the virus has had on marginalized communities - the global pandemic has overstretched health care resources in many regions of the country. As health care systems focus on treating those with COVID-19 infection, there are fewer assets to provide care for other chronic and acute conditions.

### A New Population of Disabled Americans with COVID-19 Related Disabilities

Significant long-term disability with multisystem involvement has now been seen in a growing population of patients who have survived COVID-19. There is a myriad of clinical syndromes involved in PASC and the phenotypes are yet to be elucidated. In some studies, there have been over 50 to 100 symptoms described.<sup>2</sup> The World Health Organization defines post-COVID conditions as occurring in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually within 3 months from the onset of COVID-19, with symptoms that last for at least two months and cannot be explained by an alternative diagnosis.<sup>3</sup> Each of these persons with Long COVID are suffering and has a story that needs to be heard. Each of them has a different course – some even starting as asymptomatic or mild COVID-19 – with

<sup>&</sup>lt;sup>1</sup> Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults – United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882-887

<sup>&</sup>lt;sup>2</sup> Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. EClinicalMedicine. 2021 Aug;38:101019.

<sup>&</sup>lt;sup>3</sup> https://www.who.int/publications/i/item/WHO-2019-nCoV-Post\_COVID-19\_condition-Clinical\_case\_definition-2021.1 Last updated October 6, 2021.

lingering and debilitating symptoms. I have had cancer survivors get Long COVID. They tell me that their post-COVID fatigue is 100-times worse than their cancer fatigue ever was. I have treated many nurses and physicians. Some have not been able to return to the operating room or to the frontline or the patient bedside. Marathon runners who cannot even walk a mile. A young mother who can't run after her children without her heart rate going to 180 and getting short of breath.

Due to the nature of our specialty and our experience working with and coordinating care for people with complex disabilities and chronic conditions, physical medicine and rehabilitation physicians have been recognized as the leading specialty for assessing and treating patients experiencing the condition known as Long COVID. Common symptoms include fatigue, post-exertional malaise, cognitive dysfunction (colloquially referred to as brain fog), shortness of breath, headaches, along with others that generally have an impact on everyday functioning. It is currently estimated that 10-30%<sup>4</sup> of people who had COVID-19 will experience Long COVID symptoms and new data from the Household Pulse Survey show that more than 40% of adults in the United States reported having COVID-19 in the past, and 19% are currently still having symptoms of Long COVID. <sup>5</sup> Additionally, these symptoms often appear in patients who were asymptomaticand may not have known they were infected with COVID-19 in the first place.

Throughout the pandemic, starting as early as April 2020, many physical medicine and rehabilitation physicians and other clinicians came together to understand and address Long COVID by opening multidisciplinary Long COVID clinics, in addition to our existing physician duties. These multi-disciplinary clinics often serve as a "one-stop shop" to help this population address their new, varied, and often debilitating symptoms, including neurological challenges, gastrointestinal symptoms, anxiety, depression, 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.<sup>6</sup> Furthermore, telemedicine has been vital in allowing me to provide care to my patients with disabilities during the pandemic. Patients have felt safe by having less exposure to infectious diseases, saving money and time, and I have been able to see more of their home surroundings and social determinants of health.

<sup>&</sup>lt;sup>4</sup> Rubin R. As Their Numbers Grow, COVID-19 "Long Haulers" Stump Experts. JAMA. 2020;324(14):1381–1383. doi:10.1001/jama.2020.17709.

<sup>&</sup>lt;sup>5</sup> National Center for Health Statistics. Nearly One in Five American Adults Who Have Had COVID-19 Still Have "Long COVID." Centers for Disease Control and Prevention. Last updated June 22, 2022.

 $https://www.cdc.gov/nchs/pressroom/nchs\_press\_releases/2022/20220622.htm$ 

<sup>&</sup>lt;sup>6</sup> Verduzco-Gutierrez M, Estores IM, Graf MJP, et al. Models of Care for Postacute COVID-19 Clinics: Experiences and a Practical Framework for Outpatient Physiatry Settings. *Am J Phys Med Rehabil*. 2021;100(12):1133-1139.

Given the tendency for SARS-CoV-2 to cause immune mediated injury to the endothelium causing neurovascular injury and therefore neurologic complications, I have collaborated with local brain and Alzheimer's disease experts. UT Health San Antonio is actively illustrating how The Biggs Institute for Alzheimer's and Neurodegenerative Diseases at UTHSA is transforming dementia care as a National Institute on Aging (NIA)-designated Alzheimer's Disease Research Center. We are now 1 of 33 nationally designated centers and the only one in Texas.

At the start of the pandemic, I returned to my roots to work and live in South Texas. I currently lead two such clinics, the Post-COVID Recovery Clinic at UT Health San Antonio and the Post-COVID Recovery Clinic at University Health. The AAPM&R has gathered 40 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 address health equity. These collaborative discussions have illuminated the consistent infrastructure and access barriers we are seeing. I have witnessed this in my own clinics. The clinic at UT Health is set up like an academic-private practice hybrid; the other clinic at University Health, is at the county safety-net hospital and level-1 trauma center. It is a tale of the "haves" and the "have-nots" in one city. At UT Health, most of my patients are in the 30 to 50-year-old range and are employed, have commercial insurance, FMLA and/or short-term disability benefits. They have access to specialists, specialized therapy services, and jobs that allow for accommodations such as work from home part-time. These patients can easily sign on to the electronic patient portal with their broadband internet service and do a telemedicine visit. The underinsured patients at the county hospital system have much more difficulty accessing telehealth (barriers are sometimes related to broadband or literacy to understand the technology needed). The wait time to get into clinic is up to 5-6 months. Unfortunately, the no show rate to clinic is upwards of 40%. If a patient gets in and they get orders for basic therapy services, there is another month wait, and longer for some specialists.

The needs of persons with Long COVID 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 insurance, and other benefits. Even in my own clinic there is not direct access to social work support.

Early in the pandemic, AAPM&R has called on the Administration and Congress to develop a comprehensive federal plan to defeat the national Long COVID crisis. In April of this year,

President Biden issued a Presidential Memorandum outlining a "whole-of-government" response to the long-term impacts of COVID, a critical step in coordinating federal activities to support individuals with Long COVID and the providers who treat them. The Administration will be undertaking numerous important efforts to implement this Memorandum, including the release of two reports on long-term services and supports and a National Research Action Plan on Long COVID, expected in early August. However, Congressional action is needed to ensure that individuals with Long COVID are able to access the care they need. AAPM&R has worked with several of your colleagues to develop and improve pending legislation to address the myriad needs related to the Long COVID crisis, and I would like to briefly mention a few of these:

- The Targeting Resources for Equitable Access to Treatment (TREAT) for Long COVID Act (H.R. 7482/S. 4015): This legislation is critical to supporting and expanding multidisciplinary Long COVID clinics, which are treating the diverse symptoms of individuals with Long COVID and are currently stretched to maximum capacity, resulting in long wait times and diminished access to care. The TREAT Long COVID Act would authorize a grant program to fund new and existing multidisciplinary clinics, prioritizing funding for health providers that plan to engage medically underserved populations and those disproportionately impacted by COVID-19; ensure Long COVID treatment is not denied based on insurance coverage, date or method of diagnosis, or previous hospitalization; and encourage ongoing medical training for physicians in Long COVID clinics and other health care providers.
- 2. The Comprehensive Access to Resources and Education (CARE) for Long COVID Act (S. 3726)/COVID-19 Long-Haulers Act (H.R. 2754): These bills would help advance critical research into Long COVID, including authorizing a patient registry developed by the Patient-Centered Outcomes Research Trust Fund, conducting research into the health system's response to Long COVID, and collecting data through Medicaid on items and services furnished to beneficiaries with Long COVID. The CARE for Long COVID Act would also authorize a grant program to support legal and social service assistance for individuals with Long COVID.
- 3. Cures 2.0 Act (H.R. 6000): This broad-based legislation on the discovery, development, and delivery of 21<sup>st</sup> century cures includes important provisions to better understand Long COVID, including conducting a large national survey of patients with Long COVID, developing a Long COVID "learning collaborative," conducting a study on Long COVID disparities, and educating the public and health care providers on Long COVID.

These bills would address numerous hurdles facing individuals with Long COVID, detailed further below. These policies and additional legislation will support those with Long COVID, in conjunction with the Administration's efforts. These policies would support new and existing clinics to bolster this successful and sorely needed model for addressing the clinical needs of patients with Long COVID and to help patients optimize their health and function in the near term. In particular, clinics have expressed a need for: funds to support workforce capacity, including hiring patient coordinators, staff therapists, and non-physician practitioners specializing in disability documentation; "start-up" support to help new clinics open, especially in rural and underserved areas; and greater coordination and collection of data on diagnoses, treatment, and outcomes across specialty clinics addressing Long COVID.

#### I. Access Barriers

The World Health Organization has recommended the use of rehabilitation as a key to improving health outcomes of patients with COVID-19.<sup>7</sup> Not all insurers and health plans cover rehabilitation services, specialty home-based services, or post-acute care for these newly acquired COVID-19 brain injuries and neurorehabilitation. These services are vitally important for a population that is experiencing a breadth of symptoms who often have difficulty coordinating care and traveling to many different doctors' offices. Moreover, some social determinants of health (e.g., lack of health insurance) will preclude access to rehabilitation services and physicians, negatively impacting outcomes. Right now, access to vaccines is free to patients. Monoclonal antibodies are free to patients. Patients with severe COVID-19 are treated in the hospital if they require it. This contrasts with persons with Long COVID who do not have covered visits at specialty clinics nor accessible rehabilitation services. We all recognize that the COVID-19 pandemic is stressing the healthcare system. Furthermore, Physiatry is currently undersized to deliver services to everyone in the United States who needs this care.

Unfortunately, we also see increasing reports of insurers denying coverage of these services for individuals with PASC, citing a lack of evidence-based practice guidelines, which often take years to develop and are regularly changing even for well-understood conditions. I have been told a patient with Long COVID cannot do a Neuro Rehabilitation program because they do not have a "traditional" brain injury or stroke, though a recent comprehensive review described the psychiatric and neuropsychiatric sequelae of COVID-19,<sup>8</sup> many of which overlap with symptoms seen after brain injury. The

<sup>&</sup>lt;sup>7</sup> *Rehabilitation Considerations During The COVID-19 Outbreak.* Pan American Health Organization; 2020. https://iris.paho.org/bitstream/handle/10665.2/52035/NMHMHCOVID19200010\_eng.pdf?sequence=6&isAllowed= v.

<sup>&</sup>lt;sup>8</sup> Schou TM, Joca S, Wegener G, Bay-Richter C. Psychiatric and neuropsychiatric sequelae of COVID-19 - A

neuropsychiatric symptoms of PASC include depression, anxiety, post-traumatic stress disorder, obsessive-compulsive disorder and psychotic disorders, cognitive deficits, fatigue, sleep disturbances, along with high rate of suicidal ideation, attempts and completion. Because there is not adequate coverage, many patients cannot access these services as chronic symptoms are typically not considered as "acute" or "emergent." 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 appropriate treatment and the long-lasting, potentially permanent, effects of this condition.

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 signs through imaging of their lungs. A patient with brain fog who cannot find their words or have head vibrations or dizziness, may have a normal MRI of their brain. The patient with fatigue 100-times worse than cancer fatigue will have all labs return normal. This has been a longstanding problem for patients with other long-term, chronic, and poorly delineated conditions, such as chronic fatigue syndrome and other complex disease states, and often contributes to patients' issues with insurer coverage and access to condition-specific care and disability benefits. Perhaps one silver lining of Long COVID will be an enhanced capacity for our health system to address the needs of individuals with complex and chronic conditions overall. This underscores the need for research on PASC to be conducted rapidly and translated to providers so the symptoms this new population is suffering can be more easily recognized and addressed, instead of being dismissed for not fitting within existing medical paradigms.

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, brain fog, and other debilitating PASC symptoms. The multi-disciplinary clinic approach, to the contrary, creates a central hub where a patient can consult with all the specialists needed, complete their testing, and meet with any needed therapists through a comprehensive, coordinated approach. It is one of the reasons these clinics have

systematic review. Brain Behav Immun. 2021 Oct;97:328-348. doi: 10.1016/j.bbi.2021.07.018. Epub 2021 Jul 30.

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 may have significant financial reserves, physical space, and existing networks of specialists to pull from when coordinating a clinic. Yet many other centers - like my own - do not have those resources. 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.

#### **II. 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 per patient. 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 who may have 15 symptoms to discuss. 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 majority of 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. I have often described it as, "robbing Peter to pay Paul." I have finite clinical time. If I see more patients with Long COVID, I see less patients with an acquired brain injury and vice versa. A relative dearth of physicians has resulted in wait times of four to six months for patients before they can be seen by many of the specialists necessary to treat their Long COVID symptoms. Unfortunately, we expect these backlogs to worsen as more and more individuals develop Long COVID symptoms, unless action is taken to support the Long COVID provider workforce. Along these lines, I appreciate your support in continuing to expand graduate medical education, so we can continue to train enough physicians to care for the growing number of individuals with disabilities.

I urge you to consider policies to support new and existing clinics to bolster this successful and sorely needed model for addressing the clinical needs of patients with Long COVID and to help patients optimize their health and function in the near term. In particular, clinics have expressed a need for: funds to support workforce capacity, including hiring patient coordinators, staff therapists, and non-physician practitioners specializing in disability documentation; "start-up" support to help new clinics open, especially in rural and underserved areas; and greater coordination and collection of data on diagnoses, treatment, and outcomes across specially clinics addressing Long COVID.

#### III. Additional Needs of Long COVID Patients and Persons with Disabilities

The significant and time sensitive clinical needs of Long COVID patients only reflect one aspect of the impacts of Long COVID on the country. Individuals with Long COVID are often of working age, with the average age of patients in my clinic being early 40s. Many patients are likely to experience long-term or even permanent functional impairment and disability because of Long COVID. Like my patients from before the pandemic with acquired disabilities, these individuals will face significant additional obstacles in their daily life 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. These are just some of the additional needs identified with Long COVID patients.

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I thank the subcommittee for its leadership in recognizing this critical issue for COVID-19 survivors 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, I offer my support as an expert and on behalf of the medical specialty of physiatry, and urge the subcommittee to consider AAPM&R and the Multi-Disciplinary PASC Collaborative as a resource.

Sincerely,

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Monica Verduzco-Gutierrez, MD Professor & Distinguished Chair, Rehabilitation Medicine University of Texas Health Science Center at San Antonio

Additional Resources for the Subcommittee

The Academy of Physical Medicine & Rehabilitation has produced resources on Long COVID, including clinical consensus guidance and a Long COVID dashboard to estimate the burden of Long COVID. These resources were and are being developed by the AAPM&R Multi-Disciplinary PASC Collaborative.

- Multi-Disciplinary Clinical Guidance Statements
  - <u>Multi-Disciplinary Collaborative Consensus Guidance Statement on the Assessment and</u> <u>Treatment of Cardiovascular Complications in Patients with Post-Acute Sequelae of</u> <u>SARS-CoV-2 Infection (PASC)</u>
  - <u>Multi-Disciplinary Collaborative Consensus Guidance Statement on the Assessment and</u> <u>Treatment of Breathing Discomfort and Respiratory Sequelae in Patients with Post-</u> <u>Acute Sequelae of SARS-CoV-2 Infection (PASC)</u>
  - Multi-Disciplinary Collaborative Consensus Guidance Statement on the Assessment and <u>Treatment of Cognitive Symptoms in Patients with Post-Acute Sequelae of SARS-CoV-</u> 2 infection (PASC)
  - <u>Multidisciplinary collaborative consensus guidance statement on the assessment and</u> treatment of fatigue in postacute sequelae of SARS-CoV-2 infection (PASC) patients
- Long COVID Dashboard: <u>https://pascdashboard.aapmr.org/</u>
- All of AAPM&R's work in Long COVID can be found at: www.aapmr.org/longcovid