

## **CALL TO ACTION: AMERICA NEEDS A FEDERAL COMMISSION TO DEVELOP A COMPREHENSIVE NATIONAL PLAN TO DEFEAT THE LONG COVID “PASC” CRISIS**

An estimated 10-30% of individuals infected with COVID-19 develop Post-Acute Sequelae of SARS-CoV-2 infection (“PASC” or “Long COVID”), regardless of whether these individuals exhibited COVID-19 symptoms. Due to the high infection rate in the United States, 3-10 million Americans are likely to experience the varied and often debilitating PASC symptoms, preventing them from fully recovering and America from restoring economic stability. *A comprehensive federal plan is needed to defeat this national crisis.* The undersigned groups represent the providers, clinicians, patients, patient caregivers, and other stakeholders who are most familiar with these new conditions and witness the lack of coordinated, multidisciplinary resources needed to treat the influx of individuals impacted by PASC.

A comprehensive national plan must include a commitment to three major priorities:

- (1) Resources to build necessary clinical infrastructure to address the needs of individuals with PASC;
- (2) Equitable access to care for all individuals affected by PASC; and
- (3) Continued funding for research that advances a fundamental understanding of PASC and rapid dissemination of best practices to mitigate its effects.

**To develop this comprehensive plan, we recommend 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.**

Resources to Build Necessary Infrastructure and PASC Treatment Capacity: Currently, the rehabilitation system in the United States lacks the infrastructure and funding to meet this crisis. Over recent months, clinics to address PASC have opened throughout the country. However, the need for these clinics far outstrips the resources available. Local health systems need resources—perhaps as part of the recently enacted *American Rescue Plan Act* – for the necessary facilities, medical professionals, and supplies to support patients and provide expert care. Additionally, this care must be supported through appropriate reimbursement to ensure clinicians are able to provide care to PASC patients consistently. Appropriate ICD-10 codes must be developed for PASC in the immediate term and a formal provider designation for these PASC multidisciplinary clinics or another long-term payment strategy should be established under the Medicare program.

Equitable Access to Care for All Patients with PASC: All PASC patients need timely and local access to multidisciplinary care to ensure their broad and varied PASC symptoms are addressed. It is imperative that the commission’s plan address inequities in our health care system that result in diminished and limited access to sustainable quality PASC care due to race, ethnicity, neighborhood or geographic location, socioeconomic factors, and disability status. Additionally, patients who do not recover quickly need equitable access to strengthened safety-net care, including disability evaluation and benefits.

Continued Funding for Research that Advances Medical Understanding and Treatment of PASC: Results from ongoing and future PASC research are needed to support providers in real-time through rapid development and widespread dissemination of best practices for PASC care. Research must be inclusive of all populations, including people with disabilities and underlying health conditions.

**The undersigned urge the Biden Administration to launch a federal commission of diverse experts to develop a comprehensive federal crisis plan and prioritize actions to address the care needs of patients with PASC.**

American Academy of Physical Medicine and Rehabilitation

Patient Organizations

ACCSESS

American Association of Clinical Endocrinology  
American Association on Health and Disability  
American Network of Community Options and Resources  
American Spinal Injury Association  
Association of Assistive Technology Act Program  
Association of University Centers on Disabilities  
Autistic Self Advocacy Network  
Blooming Magnolia  
Body Politic  
Brain Injury Association of America  
Center for Medicare Advocacy  
Child Neurology Foundation  
Christopher & Dana Reeve Foundation  
Council of Medical Specialty Societies  
Disability Rights Education and Defense Fund  
Easterseals  
Epilepsy Foundation  
Falling Forward Foundation  
Heart Failure Society of America (HFSA)  
Long COVID Alliance  
Long COVID India  
Long Haul COVID Fighters  
Looms for Lupus  
Massachusetts ME/CFS and FM Association  
Michael J Fox Foundation for Parkinson's Research  
Minnesota ME/CFS Alliance  
National Alliance on Mental Illness  
National Association of Councils on Developmental Disabilities  
National Council on Independent Living  
National Health Council  
NoVA CFS/ME, FMS, OI, & Long COVID Support Group  
Patient-Led Research Collaborative  
Post-COVID Recovery Team  
Solve ME  
Spina Bifida Association  
The Cranky Queer Guide to Chronic Illness  
United Cerebral Palsy National

Provider Organizations

American Academy of Family Physicians  
American Academy of Hospice and Palliative Medicine  
American Academy of Neurology  
American Association of Neurological Surgeons  
American College of Emergency Physicians  
American College of Rheumatology  
American Congress of Rehabilitation Medicine  
American Gastroenterological Association  
American Geriatrics Society  
American Medical Rehabilitation Providers (AMRPA)  
American Music Therapy Association  
American Occupational Therapy Association  
American Physical Therapy Association  
American Society for Clinical Pathology

American Society of Anesthesiologists (ASA)  
American Society of Nephrology  
American Society of Plastic Surgeons  
American Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
Assistive Technology Industry Association (ATIA)  
Association of Academic Physiatrists  
Association of Rehabilitation Nurses  
Clinician Task Force  
Congress of Neurological Surgeons  
H&D Physical Therapy  
Hartford HealthCare  
International Association of Yoga Therapists  
Jesse Brown VA – Chicago  
JOGO Health Inc  
National Association for the Advancement of Orthotics and Prosthetics  
National Association of Social Workers (NASW)  
National Association of State Head Injury Administrators  
National Athletic Trainers' Association  
Physical Therapist/Occupational Therapist Resources for Treating ME/CFS  
Rehabilitation Engineering and Assistive Technology Society of North America  
Society of Hospital Medicine  
Spaulding Rehabilitation Network/Department of Physical Medicine and Rehabilitation, Harvard Medical School

Hospital Systems & Corporations

JFK Johnson Rehabilitation Institute at Hackensack Meridian Health  
Johns Hopkins Post-Acute COVID-19 Team (JH PACT) Program  
Kennedy Krieger Institute  
Lakeshore Foundation  
Mount Sinai Health System, Icahn SOM  
NYU Langone Health  
Shepherd Center  
Tobii Dynavox  
University of Kansas Health System  
University of Texas Health Science Center in San Antonio  
US Physiatry  
UW Medicine