

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
Brain Injury Association of America
Falling Forward Foundation
Spina Bifida Association
American Congress of Rehabilitation Medicine
American Physical Therapy Association
American Association on Health and Disability
Lakeshore Foundation
American Therapeutic Recreation Association
ACCSESS
Easterseals
Clinician Task Force
American Network of Community Options and Resources
United Cerebral Palsy National
Rehabilitation Engineering and Assistive Technology Society of North America
American College of Emergency Physicians
American Society for Clinical Pathology
Association of Academic Physiatrists
American Speech-Language-Hearing Association
American Occupational Therapy Association
University of Kansas Health System
American Academy of Neurology
National Association of Councils on Developmental Disabilities
Epilepsy Foundation
Child Neurology Foundation
JFK Johnson Rehabilitation Institute at Hackensack Meridian Health
National Association for the Advancement of Orthotics and Prosthetics
American Spinal Injury Association
National Health Council
Center for Medicare Advocacy
American Society of Nephrology
American Music Therapy Association
Michael J Fox Foundation for Parkinson's Research
Association of University Centers on Disabilities
American Academy of Family Physicians
Body Politic
Patient-Led Research Collaborative
Johns Hopkins Post-Acute COVID-19 Team (JH PACT) Program
Kennedy Krieger Institute
National Council on Independent Living
NYU Langone Health
Mount Sinai Health System, Icahn SOM
UW Medicine
American Association of Clinical Endocrinology
Council of Medical Specialty Societies
University of Texas Health Science Center in San Antonio
Solve ME
Christopher & Dana Reeve Foundation
Autistic Self Advocacy Network
Association of Assistive Technology Act Program
Association of Rehabilitation Nurses
Society of Hospital Medicine
Disability Rights Education and Defense Fund
American Geriatrics Society
National Association of Social Workers (NASW)
American College of Rheumatology
American Medical Rehabilitation Providers (AMRPA)

Tobii Dynavox
American Society of Plastic Surgeons
American Gastroenterological Association
Heart Failure Society of America (HFSA)
The Cranky Queer Guide to Chronic Illness
Assistive Technology Industry Association (ATIA)
American Academy of Hospice and Palliative Medicine
Looms for Lupus
Blooming Magnolia
American Society of Anesthesiologists (ASA)
Physical Therapist/Occupational Therapist Resources for Treating ME/CFS
International Association of Yoga Therapists
H&D Physical Therapy
NoVA CFS/ME, FMS, OI, & Long COVID Support Group
National Association of State Head Injury Administrators
Long COVID Alliance
National Athletic Trainers' Association
JOGO Health Inc
Long Haul COVID Fighters
Long COVID India
Massachusetts ME/CFS and FM Association
National Alliance on Mental Illness
Minnesota ME/CFS Alliance
Hartford HealthCare
Spaulding Rehabilitation Network/Department of Physical Medicine and
Rehabilitation, Harvard Medical School
Jesse Brown VA - Chicago
American Association of Neurological Surgeons
Congress of Neurological Surgeons