



## **The Comprehensive Access to Resources and Education (CARE) for Long COVID Act**

**Led by Senators Kaine, Markey, and Duckworth**

### **Why do we need the CARE for Long COVID Act?**

According to a February 2023 survey by the [National Center for Health Statistics](#), nearly 28 percent of adults who have experienced a COVID-19 infection have, at some point, experienced serious lingering symptoms, including neurological, cardiovascular, respiratory, and mental health symptoms, sometimes months after their infection. With [over 100 million cases of COVID-19](#) recorded in the United States, Long COVID is a wide range of new, returning, or ongoing health problems that people experience after being infected with COVID-19 and has emerged as a complex and urgent public health concern.

While some initiatives exist to understand the long-term effects of COVID-19 and to improve patient-centered care, such as at the [National Institutes of Health](#) (NIH) and the Agency for Healthcare Research and Quality (AHRQ), additional resources are needed to aid our understanding of the symptoms of Long COVID, as well as to reduce barriers to care and disparities in diagnosis and treatment. [Over 25 percent of adults](#) with Long COVID state that their symptoms significantly limit their daily activity, and the economic impact of lost wages due to Long COVID is estimated to be upwards of [\\$200 billion per year](#).

Adults and children with Long COVID require resources to navigate workplaces and schools, including support in accessing disability benefits if needed. The Biden Administration has taken the important first step of [recognizing Long COVID as a disability](#), but we must do more to ensure that people have access to adequate social supports and accommodations or other resources as required by law.

### **What will the CARE for Long COVID Act do?**

The CARE for Long COVID Act will:

- [Accelerate Long COVID research](#) by authorizing the Secretary of the Department of Health and Human Services (HHS), in coordination with the Patient-Centered Outcomes Research Institute (PCORI), to centralize and synthesize robust data-sets regarding patient experiences with Long COVID and related conditions for future research;
- [Improve understanding of Long COVID treatment efficacy and disparities](#) by authorizing the Secretary of HHS to study and provide recommendations on improving the health care system's response to Long COVID;
- [Educate Long COVID patients and medical providers](#) through efforts at the Centers for Disease Control and Prevention (CDC) to develop and disseminate information on common symptoms and treatment for Long COVID and related conditions;
- [Facilitate interagency coordination to educate the public](#), including employers and schools, on the impact of Long COVID and the rights associated with employment, disability status, and education for individuals with Long COVID; and
- [Develop partnerships between community-based organizations, social service providers, and legal assistance providers](#) to help individuals with Long COVID access needed services.

**Cosponsors:** Senators Blumenthal, Smith, Padilla, Whitehouse, Stabenow, Reed, Klobuchar, King

**Supporting Organizations:**

1. Allergy and Asthma Network
2. Alliance for Headache Disorders Advocacy
3. Alliance for Patient Access
4. Alzheimer's Association
5. Alzheimer's Impact Movement
6. American Academy of Allergy, Asthma & Immunology
7. American Academy of Neurology
8. American Academy of Physical Medicine and Rehabilitation
9. American Association of Neurological Surgeons
10. American Brain Coalition
11. American Epilepsy Society
12. American Federation of State, County, and Municipal Employees (AFSCME)
13. American Gastroenterological Association
14. American Geriatrics Society
15. American Heart Association
16. American Physical Therapy Association
17. American Society of Anesthesiologists
18. American Society of Neuroradiology
19. American Society of Pediatric Nephrology
20. Anxiety and Depression Association of America
21. Association of Academic Physiatrists
22. Association for University Centers on Disabilities
23. Ballard Health
24. Brain Injury Association of America
25. Cohen Veterans Bioscience
26. Community Legal Services of Philadelphia
27. Congress of Neurological Surgeons
28. COVID Survivors for Change
29. COVID-19 Health and Safety Taskforce
30. COVID-19 Longhailer Advocacy Project
31. Derma Care Access Network
32. Dysautonomia International
33. Federation of American Hospitals
34. Heart Failure Society of America
35. Hope for HIE
36. International Association of Fire Fighters
37. Kennedy Krieger Institute
38. Long COVID Families
39. National Association of State Head Injury Administrators
40. National Center for Health Research
41. National Organization of Social Security Claimants' Representatives (NOSSCR)
42. National Council of Urban Indian Health
43. National Hispanic Medical Association
44. Pandemic Patients
45. Partnership to Advance Cardiovascular Health
46. Patient-Led Research Collaborative
47. Social Security Action
48. Society for Cardiovascular Angiography and Interventions
49. Society of Interventional Radiology

50. Society of Thoracic Surgeons
51. Solve M.E.
52. The Arc
53. The Headache and Migraine Policy Forum
54. The Michael J. Fox Foundation for Parkinson's Research

# **The Comprehensive Access to Resources and Education (CARE) for Long COVID Act**

## **Section by Section**

### **SECTION 1. SHORT TITLE**

This Act may be cited as the "Comprehensive Access to Resources and Education for Long COVID Act" or the "CARE for Long COVID Act".

### **SECTION 2. AUTHORIZATION TO FUND A PATIENT REGISTRY FOR RESEARCH ON LONG COVID AND RELATED CONDITIONS**

- a) Directs the Secretary of HHS, in coordination with the Patient-Centered Outcomes Research Institute, to fund activities related to the improvement of treatment and outcomes for individuals with Long COVID and related conditions
- b) These activities include creating or maintaining a regularly updated patient registry of Long COVID and related conditions, including information on symptoms, treatments, and comorbidities. Such a registry should utilize common data elements and definitions to promote data sharing for ongoing and future research
- c) Requires that participation in the registry be voluntary and clarifies that all personal and health information in the registry is subject to applicable privacy protections
- d) Directs the Secretary to submit an annual report to Congress and the President on the data, findings, and status of the registry
- e) Authorizes \$30 million for FY24 to carry out this section

### **SECTION 3. RESEARCH ON UNITED STATES HEALTH CARE SYSTEM'S RESPONSE TO LONG COVID**

- a) Instructs the Secretary of HHS, in coordination with the AHRQ, the NIH, and the CDC, to conduct and support research related to the health care system's response to Long COVID, including:
  - 1) Expansion and effectiveness of post-infectious disease treatment, with a focus on:
    - A) Identifying barriers to access to treatment for groups impacted by high rates of COVID-19 and Long COVID;
    - B) Evaluating and identifying potential gaps that contribute to disparities in COVID-19 infection rates, severity and length of symptoms, and outcomes; and
    - C) Identifying trends associated with differences in diagnosis and treatment of Long COVID and related conditions by demographic factors
  - 2) Conducting and supporting research to:
    - A) Identify health care strategies that help mitigate disparities in COVID-19 infection rates, hospitalizations, severity and length of symptoms, secondary illnesses, and outcomes;
    - B) Identify health care-related factors contributing to such disparities; and
    - C) Provide recommendations on ensuring equity in diagnosis and access to quality post-infectious treatments
- b) Authorizes \$15 million for FY24 to carry out this section

#### **SECTION 4. EDUCATION AND DISSEMINATION OF INFORMATION ON LONG COVID**

- a) Directs the Secretary to develop and regularly disseminate information on Long COVID to the public, in plain language and in a manner that is accessible. This information shall include:
  - 1) Awareness, incidence, and short- and long-term health effects associated with COVID-19 infection, including Long COVID associated disability;
  - 2) Illnesses related and often comorbid with Long COVID;
  - 3) Availability of treatment options for Long COVID and related conditions; and
  - 4) Strategies for reducing the likelihood of developing Long COVID
- b) Instructs the Secretary, working in consultation with representatives from communities impacted by Long COVID and health care providers who treat these communities to develop and disseminate to health care providers information on Long COVID, recommended assessment tools, and illnesses related and often comorbid with Long COVID
- c) Ensures that guidance on Long COVID diagnostics, treatments, and care includes demographic factors and individuals with Long COVID or related conditions are empowered to participate in protocol development and outreach and education strategies
- d) Allows for the dissemination of this information
- e) Authorizes \$30 million for each year, FY24-FY26 to carry out this section

#### **SECTION 5. INTERAGENCY COORDINATION AND INFORMATION DISSEMINATION ON RIGHTS ASSOCIATED WITH LONG COVID**

- a) Directs the Secretary of HHS to convene relevant agencies to develop information and resources on the impact of Long COVID and related conditions regarding rights associated with employment, disability status, and education
- b) Instructs the Secretary to collaborate and consult with relevant agencies, communities and professions impacted by high COVID-19 rates
- c) Directs these entities to develop and annually update:
  - 1) Educational materials for school staff about Long COVID and related conditions with clear guidance on appropriate academic, social, and emotional supports and services, and the rights of students with disabilities;
  - 2) Guidance for employers on the rights of people with disabilities related to Long COVID and related conditions, including how employers can support such individuals in the workplace; and
  - 3) Guidance on Long COVID and related conditions as a disability, including recommendations to streamline the process of applying for benefits through the Social Security Administration and the Public Safety Officers' Benefits Program
- d) Requires that the Secretary disseminate information to various entities
- e) Authorizes \$30 million for each year, FY24-FY26 to carry out this section

#### **SECTION 6. PROGRAM TO SUPPORT LEGAL AND SOCIAL SERVICE ASSISTANCE FOR INDIVIDUALS WITH LONG COVID**

- a) Directs the Administration for Community Living to award grants for establishing or expanding medical-legal partnerships and increasing the availability of social supports to

provide effective aid to individuals with Long COVID or related conditions in matters relating Social Security programs, housing, access to medical care, early intervention, specialized instruction and related services, low-income home energy assistance, employment supports, nutrition assistance, traumatic brain injury supports, and other support services

b) Eligibility for Awards -

- 1) To be eligible, organizations must be a State, a State protection and advocacy system, a state area agency on aging, a nonprofit entity, a publicly funded organization not acting in a governmental capacity (such as a law school), an Indian Tribe or Tribal organization, an urban Indian organization, a territory, a health care provider serving populations impacted by COVID-19 or Long COVID, underserved communities, or low-income patients, or an entity providing legal services;
- 2) Priority is given to entities that certify in writing that any person providing legal assistance has demonstrated expertise in providing such assistance to people with disabilities

c) These funds may be used to:

- 1) Establish or expand medical-legal partnerships between community-based organizations, medical and social service providers, and legal assistance providers to help individuals with Long COVID access or maintain social services;
- 2) Establish or expand efforts to provide legal assistance for individuals with Long COVID by organizations with a demonstrated history of providing direct legal or advocacy services on behalf of people with disabilities;
- 3) Provide technical assistance around educating individuals with Long COVID or parents caring for children with Long COVID about rights related to accommodations in employment, education, or other matters as determined by the Secretary; and
- 4) Employ staff or educate current staff on assisting individuals with Long COVID in obtaining health care, social services, or legal services

d) Directs grant awardees to collect and report data to the HHS Secretary

e) Instructs the Secretary to submit an annual report to Congress detailing the number of individuals who sought services offered by grant recipients, the services provided, and a summary of activities conducted under the grant program

f) Authorizes \$50 million for each year, FY24-FY28 to carry out this section and specifies that this funding will supplement and not supplant other Federal, state, and local funds

## **SECTION 7. DEFINITIONS**

(1-4) Defines the terms Indian Tribe, Long COVID, urban Indian organization, and Tribal Organization