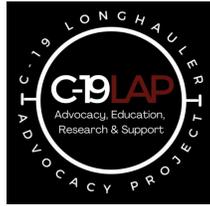


The Long COVID community calls for the immediate creation of Long COVID Assistance Programs (LCAP) and a Long COVID Task Force (LCTF).

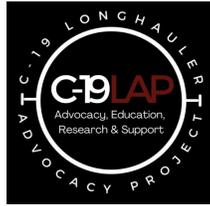
Establish Long COVID Assistance Programs to meet the immediate needs of COVID Longhaulers and their families

- 1. Implement a financial assistance program for COVID Longhaulers, their caretakers and their minor children. Build a federal plan that States cannot decline to participate in (as happened with the federal unemployment programs) and mobilize FEMA and redirect other funds if needed to make this happen.**
 - a. Establish this as either a new program for Longhaulers or a mandatory extension of existing unemployment programs.
 - b. Provide a livable income, at least until the Social Security Disability system recognizes Long COVID and its associated conditions like Dysautonomia and ME/CFS.

- 2. Create an assistance program for Healthcare Workers, First Responders, Military Personnel and Educators:**
 - a. Create and pass legislation making COVID-19 a presumed “on the job infection,” similar to the [“Heart and Lung Bill.”](#) and create a Long Covid Fund similar to [9-11 Victims Compensation Fund](#) that can also be run through the Department of Justice.
 - b. All Line of Duty (LOD) Disability and Death benefits should apply to the population of COVID Longhaulers, including their family members as beneficiaries in the case of death.
 - c. Provide mandatory, quality workers’ compensation and short and long term disability coverage.
 - d. Eliminate penalties on early retirement and Deferred Retirement Option Plan (DROP) withdrawals. Mandate continued health care coverage through Long Covid patients’ employers, even after disability and termination of employment. (Potential reimbursement to employers TBD.)
 - e. Provide college funds for the children of COVID Longhaulers disabled or deceased from COVID-19 or Long Covid-related conditions.



3. **Erase medical debt and waive co-pays and deductibles for medical appointments, testing and medications for the treatment of Long Covid and its associated conditions.**
4. **Include Long Covid as an eligible condition under Social Security Disability (SSD), or, alternately, as a “compassionate care condition” while a permanent program, research, and clinical trials and treatments are pending. Provide free legal assistance to COVID Longhaulers completing SSD applications.**
5. **Remove work requirements and eliminate or raise household income caps in addition to expanding the definition of disability under programs such as medicaid, food stamps, housing assistance, temporary cash assistance, and other assistance programs in order to enable COVID Longhaulers and their families to qualify.**
6. **Implement a program similar to the Emergency Broadband Program for Long Covid families, and expand it to include utilities, water/sewage, phone/internet, and other essential household bills.**
7. **Implement additional rental assistance and offer homeowner assistance, including HOA payments, special assessments, property taxes, property insurance, utilities, maintenance and repairs, and other costs. All federal programs to date have been for renters.**
8. **Implement programs to erase credit card and loan debt, including interest and late fees, accumulated by COVID Longhaulers from date of infection to date.**
9. **Mandate CEU's/CME's on Long COVID topics and make Long COVID a mandatory reporting condition for all practicing Physicians, Physicians Assistants, and Nurse Practitioners on Long Covid.** Every primary care provider in the country must have the ability to identify and treat Long Covid. General practitioners often advise patients to see a “Long Covid expert,” yet these do not exist and existing post-COVID Care Centers have largely failed patients. Some doctors do not acknowledge Long COVID's existence. This results in improper use of medical coding critical for identifying COVID Longhaulers.

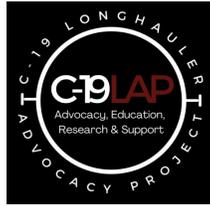


Establish a White-House Level Long Covid Task Force to Investigate Long COVID in Real Time to Develop & Implement Long-Term Plans & Programs to Assist the Long COVID Community While Awaiting Answers & Solutions from Research.

This task force should be composed of patient experts, leading COVID-19 and Long Covid researchers, as well as the leading post-viral disease experts, congressional and health agency representatives, public health advisors, and economic advisors.

1. Help mobilize and oversee programs that will:

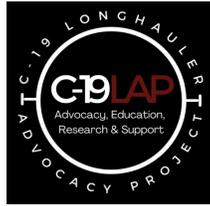
- a. Quantify, analyze, and address the number of Longhaulers.
 - i. Reverse Contact Tracing: Contact by phone or text each person who has tested positive for COVID-19 since the start of the pandemic and inquire about continued symptoms and new diagnoses. Document those who have long-term symptoms and provide necessary resources. (Note that this process will not result in a full count of people with Long Covid, as only those who had access to testing and had a positive test result would be contacted.)
 - ii. Send automated text or email surveys to people two months post-infection to assess if they have developed Long Covid. Those who do not respond should be followed up with a phone call.
- b. Analyze and address the economic impact of Long Covid by adding questions about Long COVID to the monthly Bureau of Labor Statistics Current Population Survey that ask about new or prolonged symptoms for all members of a family, and employment status. Questions could include:
 - i. Have you been experiencing new and prolonged symptoms and health issues after a COVID-19 infection or suspected COVID-19 infection?
 - ii. Are you out of work due to health issues that began after a COVID-19 or suspected COVID-19 infection and for how long? If not out of work, have you been reduced to part-time work due to health issues after a COVID-19 or suspected COVID-19 infection and for how long?
 - iii. How many people in your household have health issues after a COVID-19 infection or suspected COVID-19 infection?
 - iv. Has your employment been impacted because you are caring for a member of your household with prolonged or new health issues after a suspected or confirmed COVID-19 infection and if yes for how long?
- c. Analyze and address the health impacts of Long Covid.
 - i. Create a Long COVID insurance program, which can serve as an example of a national healthcare system and future pandemic financial preparedness. This will enable the U.S. to track Long Covid and its associated conditions, to gauge the associated costs, and to budget for future costs.
 - ii. Help prioritize research by convening with post viral experts and Long Covid patients.



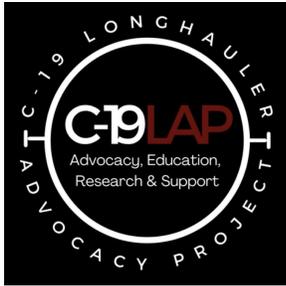
- d. Begin to prepare long-term programs using the information from the above points to provide assistance to Longhaulers and allow these programs to serve as an example for future Pandemic Preparedness Programs for those whose health is impacted by the pandemic.
 - i. Develop an outline that presents the funding needed for direct assistance to COVID Longhaulers, their medical care, research into Long Covid and its associated conditions, along with continued observation of the community and at minimum, the economic impact over the next 2 decades.
 - ii. Help oversee Long Covid / Post COVID Care Centers, with the hopes of making them Comprehensive Centers with involvement from Long Covid patient leaders.
 - iii. Advise our health agencies and government on the pandemic from the Long Covid perspective, and create COVID-19 policies from the data gathered collectively from these programs. This would include disability programs, state benefits programs, mitigation efforts, etc.

2. Create a Nationwide Public Awareness Campaign

- a. President Biden, Government Officials and Healthcare Leaders must publicly speak about Long COVID to warn and educate the American people about the potential long-term effects of contracting COVID-19 and the difficulties people with Long COVID Face. More awareness and education will hopefully result in better and more informed decisions by the American public.
- b. Create informative billboards, commercials, and signage for public spaces and healthcare facilities about Long Covid. The Department of Health and Human Services and Centers for Disease Control and Prevention should be involved with this and coordinate with local Long Covid advocates in these efforts.
- c. Share phone numbers, email addresses, and websites for self-reporting of Long Covid symptoms and for information and resources about Long Covid.
- d. Educate parents, educators, and coaches about Long Covid in children, including what to look for and how to offer help and accommodations.
- e. Educate employers about Long Covid, and how to offer help and accommodations.
- f. Educate the public that Long Covid can, and commonly does, occur in young, previously healthy individuals and even those with asymptomatic or mild cases of COVID-19.
- g. Educate the public that Long Covid can occur in children, who can develop the same conditions as adults and can become just as disabled.
- h. Educate the public that Long Covid can occur even in vaccinated individuals, which makes continued mask wearing and social distancing, in addition to vaccination, essential.



We respectfully ask that agencies and organizations review these actions, our [letter](#) and [estimates](#), and consider the urgent needs of the Long Covid patient population. We, as patient representatives, are happy to coordinate in the implementation of these action items.



Karyn Bishof, Founder & President
March 2020 Longhailer

Lisa O'Brien, Secretary
March 2020 Longhailer

www.Longhailer-Advocacy.Org
Contact@Longhailer-Advocacy.org

Ann E. Wallace, PhD, Vice President
March 2020 Longhailer

Stephanie Gedgudas, Treasurer
March 2020 Longhailer

Twitter: [@C19LH_Advocacy](https://twitter.com/C19LH_Advocacy)
www.Facebook.com/Groups/C19LAP