



# COVID-19 Longhauler Advocacy Project

The Honorable Jim Clyburn, Chairman  
Select Subcommittee on the Coronavirus Crisis  
Washington, DC 20515

The Honorable Steve Scalise Ranking Member  
Select Subcommittee on the Coronavirus Crisis  
Washington, DC 20515

**July 19, 2022**

Please accept this letter for the record for the Select Subcommittee's Hearing on Understanding and Addressing Long COVID and Its Consequences.

Since June 2020, we have been on the front lines, advocating for the Long COVID community. We are "Longhaulers," also known as the patients, or carnage, left behind after being infected with COVID-19. Sadly, we are not rare. We are not unique.

According to the CDC, [at least 1 in 5 Americans](#) has or will develop Long COVID after a COVID infection, regardless if they presented with a [mild or even asymptomatic infection](#).

Given the speed at which we delivered a vaccine to protect and save tens of millions in the United States from this invisible enemy, so too should we be able to offer basic national education about Long COVID and offer the tens of millions suffering from Long COVID, groundbreaking treatments and financial assistance that covers health care, housing, food and other basics to relieve or resolve their suffering after a COVID-19 infection.

We are not a "never before seen phenomenon." Millions of Americans suffer silently with complex chronic illnesses in the U.S., especially women and people of color. Moreover, most with "invisible" chronic illnesses or disabilities, meaning those which someone cannot physically see, tend to face years of diagnostic delays and medical gaslighting, also delaying access to assistance programs that require provider documentation and sometimes, work search or requirement waivers. Women and people of color who face medical gaslighting also lack accessible workplace accommodations, and with ~85% of Longhaulers being women, we face a very large problem.

We are in our current position due to the failure to acknowledge, teach, and treat many of the conditions being diagnosed in those presenting with Long COVID, including but not limited to: Dysautonomia, Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Mast Cell Activation

Syndrome, Fibromyalgia, Ehlers-Danlos and more. The United States is not only home to the largest number of COVID infections, but also the largest population of Longhaulers in the world (approximately 18-72M Longhaulers). [Please note: 18M reflects the ~90M \*documented COVID-19 cases with 1 in 5 becoming a Longhauler. 72M reflects the CDC'S estimate that only 1 in 4 cases are actually documented. \*at-home testing needs a centralized tracking system that allows for +/- tests to be added to public data results\*]

In January 2022, we released a [report and an open letter](#) to national leadership - including all Members of Congress and Committees, as well as Health and other government agencies - requesting the formation of [Long COVID Assistance Programs and a Long COVID Task Force](#).

To emphasize the urgency to act on Long COVID and its associated conditions, after trending the communities experiences for nearly a year, we conducted a deep dive on the long-term economic burden already being felt by those who became Longhaulers during the first major wave of COVID infections in the U.S.; we refer to those who were first infected during Fall 2019/ Spring 2020 as “first-wavers.” First-wavers have been instrumental in this fight to raise awareness because they were the first to sound the alarms. They have been sick the longest, fighting to be heard, to be believed, to be helped and most importantly, to educate others, especially lawmakers, about the long-term implications of COVID-19 infections, including Long COVID, its associated conditions, and other post-viral conditions.

Longhaulers, and their families, have not only been facing a health crisis, but also the mental health toll upon the family due to chronic illness and the ripple effect on one's life, such as socio-economic impacts that may affect generations. Some families, for over two and a half years, have had to figure out, after barely getting by on two incomes, how to get by on one, and pick up an extra \$1,000 in medical bills a month, on top of current costs of living.

In a nation, where the majority of Americans are living paycheck to paycheck and in a healthcare desert, how would one of your constituents manage Long COVID?

What would one of your congressional aides do if they got sick tomorrow from COVID-19 and became a member of the 20% that never recovered?

What would they do without physical, financial, or medical support?

What would they tell you, their employer, regarding when they can return to work?

You would need to be prepared to explain that, not only are there no immediate government resources available to them, but that their journey may also include multiple years of trying to survive as they face: income loss due to disability, housing insecurity due to eviction, losing their partner following divorce or separation, an ensuing custody battle for their child(ren), trauma faced by children witnessing their parents daily functioning deteriorate and parents in agony watching their child diagnosed with multiple disabilities and a need for medical care they cannot access due to loss of employer-provided insurance while rationing medication and being told you no longer qualify for life insurance due to your Long COVID diagnosis?

At the time of our [report](#) , the United States had documented 52 million COVID-19 cases over 21 months into the pandemic. However, the CDC estimates [only 1 in 4](#) COVID-19 cases were actually documented at that time, which pushes the estimated number of COVID-19 cases closer to 200 million.

In about a week, we will hit 90 million \*documented\* cases of COVID-19 in the U.S. In the last seven months, due to continued failed public health policy and messaging, and continued short-term thinking, we have allowed 38 million more cases to occur, which is a staggering 73% of previous cases over 21-months, in a third of the time. That is at least 7.6 million more Longhaulers and \$113,433,400,000 ([~41% needing SSD](#)). It is essential to note that [69%](#) of Americans have fewer than \$1,000 in savings and that [50%](#) of American women, especially in BIPOC communities (the population with the greatest incidence of Long COVID) have no savings at all.

Why is the amount of savings such a crucial statistic? Because Longhaulers are denied unemployment benefits as they are not “able and available to work,” and yet at the same time they are being denied Social Security Disability benefits because they do not meet the criteria. Furthermore, other financial-based entitlements, such as TANF (Temporary Assistance for Needy Families), do not even approach the amount necessary to close this gap. For example, in Florida, the state that serves as home base for our organization, temporary cash assistance for a family of two is \$158 per month; this doesn’t even pay the power bill.

Unfortunately, this is not a new phenomenon. While the families of those with chronic illness and/or disability have been living like this for years, few are willing to serve as a champion for financial assistance for those whose challenges pre-date that of Long COVID, for Longhaulers themselves, nor for those who will inevitably come after us with complex chronic medical conditions. Many of these issues and those below were discussed in [our meetings](#) with the [DOL](#).

### **Data Collected From The COVID-19 Longhailer Advocacy Project October Through December 2021**

- Medical Care
  - 85% never hospitalized.
  - 67% diagnosed with dysautonomia, 46% diagnosed with me/cfs.
  - Pre-COVID there was ~ 3.1M in the U.S. with Dysautonomia, and ~1.7M with me/cfs.
  - By Dec. 2021, COVID-19 had added another ~3.5M with Dysautonomia and ~2.4M with me/cfs.
- Employment/ Economics
  - 44% out of work completely with 67% out for over a year.
  - 51% reduced to part time work with 63% reduced for over a year.
  - Only 5% able to work at 100% capacity/ did not have employment impacted.
  - Average national income loss per Longhailer per year \$17,800
  - Average national healthcare cost per Longhailer per year \$18,600
  - Total national cost per Longhailer per year \$36,400/ \$189B Collectively
  - 48% said they are experiencing financial ruin that without assistance, they will never recover from.
  - 42% said they have medical bills over \$5,000.
  - 41% said they have filed for or are preparing to file for social security disability.

- Demographics
  - 85% were women.
  - 28% are healthcare workers, first responders/ military or educators.
  - 9% are single parents or single caretakers.

*At present, there are [90 million U.S. COVID-19 cases](#) which encompass at least 18-72 million Longhaulers, meaning that \$189 billion yearly cost rises to \$255 billion annually. The White House Office of Public Engagement Briefing on the Presidential Memorandum Reports on the Long-Term Impacts of COVID-19 on July 15, 2022 stated that the best prevention of Long COVID was to prevent COVID. A lack of consistent policies have led us to not prevent COVID while those who are immunocompromised have been further isolated and marginalized from society. Our leaders have been disproportionately concerned about the economic impact of mere weeks-long mitigation efforts, while failing to take into account the long-term burden of Long COVID. When our leaders allow case numbers to rise, they are setting the stage to create more and more Longhaulers. So many Longhaulers are just starting their lives and careers. Approximately 1 in 5 Longhaulers are children. Most Longhaulers will face a lifetime of instability regarding their housing, medical care, food, and their children.*

*These folks who are just starting their lives are now left disabled and without resources trying to navigate a broken healthcare and social services system. Further, because of their age, this may be what they can expect for the next 60+ years or more, especially if they are a pediatric Longhauler, which will invariably assure that this burden will be carried on by the next generation and continue a cycle of poverty that did not have to begin.*

*We need a champion for financial aid and support for the Long COVID community; genuine, sustainable support. Many of us have been out of work since the Spring of 2020. We have accumulated credit card debt from which we might never recover, thus devastating our credit history and preventing us from accessing new housing opportunities (also compounded by inflation and a lack of work history since we became sick). . There have been ongoing discussions about the mental health needs in our community, yet everyone continues to look past how many of these mental health concerns could be mitigated if we simply had access to the resources we need to survive. Every day, Longhaulers crisis after crisis that continue to go unanswered*

*None of the introduced Long COVID legislation addresses direct financial assistance to Longhaulers and their families. While we have started a chapter of our organization that allows people to post crowdfunding for various needs related to their Long COVID struggles, one of our top goals is to identify funding to provide this much-needed resource to the community. . However, there is no way that we will be able to financially sustain Longhaulers across the country by fundraising efforts within our community. There must be federal and state efforts to ensure that tens of millions of Longhaulers, missing from our work force as they were simultaneously disabled by one of the worst viruses seen, are provided the tools and resources needed to sustain long-term, safe, dignified daily living.*

*Prior to the pandemic, patients with these conditions waited months, sometimes years, sometimes having to fly across the country, to see specialists in these fields. Above, our report and open-letter data showed you that from the start of the pandemic through December 2021, the number of Dysautonomia patients and ME/CFS patients basically doubled, due to COVID infections. Sadly, when we did these calculations, we only used an estimate of 10% becoming Longhaulers. With the CDC'S new estimate of 1 in 5 (20%) becoming Longhaulers and now 90 million cases (previously 52 million), post- COVID Dysautonomia cases are ~12 million and ME/CFS cases are ~8.3 million. Not only can people not afford to survive, but they cannot find medical care from a provider who is adequately informed about their condition. Immediate implementation of mandatory education programs on Long COVID and its associated conditions must begin and must include patient, post-viral, autonomic, and other experts (for which we are happy to provide a list of recommendations).*

Estimates based on report and open-letter data, extrapolated out to the community. (Data for other conditions not available and needed.)

	Pre-Pandemic	December 2021	July 2022		Pre-Pandemic	December 2021	July 2022
<u>Dysautonomia</u>	~3.1M →	~6.6M →	~12M	<u>Myalgic Encephalomyelitis</u>	~1.7M →	~4.1M →	~8.3M

The majority of Longhaulers have developed numerous conditions resulting in the need for comprehensive care, which as of yet has been nearly impossible to locate and obtain. Many Longhaulers have been waiting anywhere from 6 to 18 months for appointments, during which physicians give their patient as little as 15 minutes to discuss up to two and a half years of medical records. Longhaulers are still constantly encountering medical providers and healthcare professionals who are completely unfamiliar with Long Covid and its Associated Conditions. As a result, we find ourselves relying on medical providers unwilling to handle our complex medical conditions or assist with any benefits-related paperwork if the reason for seeking those benefits is due to Long COVID.

Through our open-letter, our comprehensive approach to successful outcomes for Longhaulers, and meetings with the White House COVID Response Team, various divisions within HHS, NIH, lawmakers and more, we have identified the experiences, issues and barriers faced within the Long COVID community, and have outlined them along with targeted, strategic solutions developed by patients, for patients. Still, these issues remain unaddressed and social and medical systems unaltered, leaving Longhaulers caught in a dangerous cycle.

## **Barriers**

### Employment

1. Barriers to medical care
2. Vast number of symptoms, many of which can be disabling
3. Waxing and waning nature of symptoms, in both frequency & severity
4. Unpredictability of symptoms, leaving patients unable to plan ahead
5. Frequency and volume of medical appointments
6. Lack of leave/PTO (this applies to caregivers as well)
7. Prevalence of uncooperative employers and lack of work-place accommodations
8. Inadequate or ineffective accommodations for those who have received them
9. Challenges of adjusting to a new career for those no longer able to continue in former positions

10. Inability to undergo career training due to health and finances
11. Barriers to insurance that is portable; that covers specialists out of state in rural areas
12. Employers do not have clear framework for complying with the American with Disabilities Act
13. Public space is now inaccessible for a more significant number of Americans and actions must be taken like increased air filtration, masking, etc. in public spaces so immunocompromised can travel, go inside public buildings etc.

### Medical Care

1. Lack of public education and awareness campaigns
2. Lack of provider and researcher knowledge, understanding, and expertise
3. Lack of mandated provider education about Long Covid and its associated conditions
4. Lack of research and treatment in the associated conditions of Long Covid
5. Lack of ICD-10 codes for the conditions associated with Long Covid
6. Economic devastation, inability to afford medical appointments, testing, and medications
7. Loss of health insurance
8. Lack of objective, visible evidence (*this is an important separate conversation*) and efficacious tests
9. Lack of willingness by providers to work with complex chronic illness patients
10. Lack of ability to cross state lines to seek specialty care from long covid clinics, autonomic clinics, post-viral clinics, no coverage from many carriers at sites like Mayo Clinic- need more comprehensive, accessible, national care and coverage.

### Resources and Assistance

1. Inaccessible medical care
2. Patients ineligible for Post-COVID Clinics
3. Social Security Disability not accepting COVID-19 Longhaulers or recognizing the conditions associated with Long Covid
4. Employers not covering workers under workers' compensation or short or long term disability programs (*please issue guidance: we recently provided recommendations to Amy Chang*)
5. Discrimination against and job loss of parents or caretakers of Longhaulers
6. Need for resources for caretakers as nondisabled persons caring for disabled persons not yet able to access needed programs
7. Lack of interim programs for those with Long Covid, especially for financial assistance/ supplemental income

## **Addressing Our Barriers**

### National Awareness and Education Campaigns

Much of the American public is not aware of Long Covid. Because of this, many are not able to identify their newly developed health issues as related to COVID-19 infection. This, therefore, results in cases of Long Covid not being documented, which results in both a lack of governmental action and a lack of education within medical fields.

1. Long Covid commercials, billboards, social media and print campaigns, posters within public transportation facilities and in medical offices, workplaces, and schools. (HHS, CDC, Local Health Depts). These should include phone numbers and websites people can call to self report as a Longhailer and receive resources and be added to the National Long Covid Database.
2. Quality Long Covid messaging from national leadership and trusted community partners.
3. Mandatory education (CEU's/CME's) for medical providers (Physicians, P.A.s, N.P's, R.N's and those working at Post Covid Centers/ COE's and study sites, including RECOVER and other federally and state funded facilities), as many have never heard of the conditions associated with Long Covid and are not providing quality patient care, in addition to there not being enough specialists in these fields to treat the number of Longhailers. Educational efforts will result in

- more accurate documentation crucial for long-term planning.
4. Consistent efforts within the medical community to identify Long Covid in both unaware patients and those self reporting to providers as Longhaulers.
  5. The proper and consistent use of Long Covid diagnostic codes within medical facilities, allowing researchers to better identify the population affected.
  6. The creation of a National Long Covid Database for reporting Long Covid cases (including basic information, such as DOI, Zip Code, Sex, Age, Ethnicity, ICD-10 codes)
  7. The dissemination of resources to patients, such as patient-led organizations and groups, currently enrolling research studies, local post-covid centers or specialists, if available/applicable.
  8. Mandatory Employer and School District Education on Long Covid.

### Counting, Documenting, and Planning for Long COVID

To date, there is no system in place to document or report cases of Long Covid in order to follow this population. This is essential in order determine Long Covid's prevalence and risk factors, accurately gauge the economic impact on individuals and the national economy, equip the national healthcare system to respond to the Long Covid Pandemic, and to plan for and create assistance programs desperately needed by millions of COVID Longhaulers. To oversee and develop this process, we need:

1. A Long Covid Task Force (LCTF) comprised of post-viral disease experts; experts from the Long Covid community including trusted patient-led Long Covid organizations; experts and patient leaders from other chronic illnesses now seen in Long Covid; and representatives from each of the following agencies: NIH, CDC, WHO, FDA, and HHS. The task force would oversee and work closely with Post Covid Centers/ COE.
2. Live tracking of Long Covid:
  - a. Reverse contact tracing: Reviewing old case records to call, email, text people who tested positive for COVID-19 and asking if, since the time of infection, they have experienced continued symptoms, new symptoms, or new health issues. When Long Covid is suspected, the patient's information is added to a national database and they are provided with referrals to local post covid centers, currently enrolling studies, and patient organizations.
  - b. Current contact tracing: New COVID-19 cases are to be documented in a separate database. Patients are contacted 5 weeks post-infection to assess for potential Long Covid. If identified, patients are added to the Long Covid database and provided the same resources as above. This process is repeated at 3 months as there can be delayed onset or delayed recovery.
  - c. Mandated provider reporting (reliant on essential mandated provider education): All medical providers with patient contact will have access to the database and be mandated to report all patients identified as having Long Covid. Providers will have the ability to look up patients to check if they are already in the database from either program above or another provider.
  - d. Self reporting database: People who believe they have Long Covid and are not already in the database can self report their Long Covid in a separate database. Tracers will contact those patients to conduct interviews and offer referrals as above, and enter their information into the main Long Covid database.
  - e. Questions added to the monthly Bureau of Labor Statistics Current Population Survey asking about new or prolonged health issues since a confirmed or suspected COVID-19 infection, their work status, and the status of others in the household.
  - f. To plan for and implement Long Covid Assistance Programs (LCAP's) based on accurate case counts, in order to allocate the needed funding for appropriate programs; promote Long Covid awareness and education; affirm the role of mitigation strategies in reducing Long Covid; and predict and plan for the demand on the medical system in providing quality care to Long Covid patients.
    - a. Utilize the data from the tracking of Long Covid methods and Long Covid Task Force above to inform the planning, decision making and implementation of

Long Covid Assistance Programs as well as create outlines of the funding needed for said programs and related initiatives.

- b. To better meet the long-term demands of Long Covid on the medical system, grants and fellowships must be funded to enable medical students and current practitioners to study in the fields most needed in Long Covid and other post-viral care.

### Long COVID Assistance Programs

The following actions can prevent life-long debt, generational poverty, and loss of homes, savings, and other assets:

1. Implement immediate supplemental income programs for COVID Longhaulers & their children through age 26 if enrolled in school or vocational training.
2. Create a long-term Long Covid program that can provide financial security and other forms of assistance.
3. Expand programs such as Medicaid, food assistance, temporary cash assistance, and housing assistance for Long Covid families and waive household income caps and work requirements.
4. Add Long Covid as a covered condition under Social Security Disability.
5. Provide mandatory workers compensation coverage for all healthcare workers, first responders, educators, and military personnel.
6. Provide mortgage, rent and utility assistance, potentially something that mimics a program like the Emergency Broadband Program. Most programs to date have been for rental assistance, but there has been nothing to help homeowners or those struggling to keep the power and water on or make HOA related payments..
7. Create a pharmacy program, with full coverage of medications for COVID Longhaulers and their families, and allowing for off-label prescription use for Long Covid until Long Covid medications are identified.
8. Erase medical debt, waive co-pays and deductibles for those with Long Covid and its associated conditions.
9. Erase credit card and loan debt, including interest and late fees, accumulated by Longhaulers since the date of infection.
10. Provide case or care coordinators to help COVID Longhaulers navigate medical appointments, specialists, prescriptions, and referrals,
11. Provide disability advocates or case workers to help COVID Longhaulers navigate benefits and disability programs, including social security.

### Long COVID Care Programs

Long Covid Care Programs include Comprehensive Post-Covid Care Centers (CPCCC) and Centers of Excellence (COE). Unfortunately, existing centers have failed patients, and patients are asking for more comprehensive and knowledgeable centers. This emphasizes why mandatory provider education, as outlined earlier, is critical. Many HCP's refuse to treat Long Covid patients and instead refer them to a Post-Covid Center or urge them to enroll in a research study. That does no good for patients when the Post-Covid Care Centers are not equipped to treat them either. Each Post-Covid Care Center will serve 3 purposes:

#### Patient Care:

1. A team of providers will work collaboratively with each patient. Providers will cover an array of specialties, which must include autonomic specialists and post-viral experts.
2. Patients and providers will have the opportunity to sit down with the entire care team every 6 months to talk through the patient's case and create an updated plan of care for the next 6 months.
3. Providers from the center will work with patients' external providers to ensure continuity of care.

#### Data Collection & Research:

1. The Long Covid Database will feed Longhaulers into their Local CPCCC's and vice versa.
2. CPCCC's will add to the national Long Covid database by documenting Longhaulers' diagnoses



received both prior to enrollment and while enrolled at the center. This will help better direct research funding and focus.

3. CPCCC's will be encouraged to partner with independent or private researchers to expedite potential solutions, including clinical trials, for patients.
4. CPCCC's, the RECOVER initiative, and other large-scale studies or centers should have data-sharing capabilities and collectively summarize and review findings every 6 months.

#### Community Education & Resources:

1. Through patient-provider semi-annual meetings, providers will educate patients on their conditions, findings, and continued plan of care, and provide resources such as enrolling studies, educational materials on Long Covid and its associated conditions, including websites, support groups, and local specialists.
2. Centers should offer educational materials for caretakers, employers, schools and local providers.
3. Centers should offer presentations to smaller local hospitals, employers, schools, etc.
4. Centers must work with credible patient-led organizations to assess the needs of the Long Covid community, create valuable and accurate educational materials, and ensure the patient experience at the center is satisfactory, productive, and helpful.

#### Long COVID Research Programs

Long Covid Research Programs will include programs like the RECOVER Initiative and other national, state, university or private studies on Long Covid and its associated conditions. Private or independent research studies are also crucial at this time, as government-funded studies entail a lengthy startup process; may not assess all of conditions associated with Long Covid; may not include the first-wave (and most impacted) population of COVID Longhaulers from 2019-20; and/or may be too small in scope.

1. LCRP's should include millions of COVID Longhaulers throughout the U.S. in order to thoroughly assess the decades' long pandemic that is Long Covid. Studies must include pediatrics, first-wave Longhaulers (from 10/19-4/20) as the longest and most severely impacted Long Covid cohort, those without "proof of positivity," and those with post-viral illness prior to infection then exacerbated by COVID-19.
2. LCRP's should always disclose personal data and findings to the patient, and, if the patient is dual-enrolled, data should be shared with that site as well, including RECOVER.
3. LCRP's should coordinate with local providers caring for Long Covid patients who may undergo procedures in which biopsies are taken, in order to facilitate tissue sample collection and distribution to study sites.
4. LCRP's conducting multi-year studies should issue generalized findings/updates every 6 months.
5. LCRP's must also study the socio-economic and disability impacts of Long Covid in order that social support service agencies and Long Covid Assistance Programs will be better prepared to meet patient needs.

#### Expansion of Social Security Disability to include Long COVID & Associated Conditions.

1. Requires immediate mass hiring of qualified training staffing to handle the 1 million+ application backlog in general let alone handle the influx of Long COVID applications coming in.
2. Requires specialized training for case reviewers and screeners. Utilize disease experts, especially those recommended and used by the patient and advocacy organizations.
3. May need a specialized unit due to the sheer number of applications, see below for concept of "pandemic patients."

#### Other Long-Term Assistance Programs for Longhaulers & Future Pandemic Patients

A long-term assistance program for Longhaulers, future pandemic patients, and patients of other mass disabling events would enable an efficient way to follow these populations over time. The program should mimic efforts outlined in Stages One and Two, becoming a long-term comprehensive program, monitoring not only health, but socio-economic impacts, level of disability within the community, and necessary steps and actions to reach desired outcomes for that community.

1. The program would better inform prevention, planning, and response efforts, and inform policy and research decision makers.
2. The program would work collaboratively with SSD, HHS, and other healthcare and government agencies.
3. Public education efforts, as well as the hiring and training of personnel, should be implemented immediately during future mass disabling events, in order to reach patients in a timely manner.
4. Mandatory Assistance program for healthcare workers, first responders, military personnel and educators:
  - a. Workers compensation coverage and Line of Duty Death & Disability Benefits
  - a. legislation similar to the heart and lung bill
  - b. Long Covid Fund similar to the 9-11 Victims Compensation Fund.
  - c. Eliminate penalties on DROP (Deferred Retirement Option Plan) withdrawals and other retirement programs, even after disability or termination of employment.
  - d. College funds for the children of Longhaulers disabled or deceased from COVID-19 or Long Covid related conditions.

#### The Comprehensive Approaches Above, Collectively Support A Return to Health Agenda

1. It is first important to note that some of these conditions can go into remission for years, leading the patient to believe they have recovered. Sadly, many will experience relapses later. We must remain cognizant of this and reserve the patient's right to disability benefits, including a clause that allows them to regain benefits without starting the disability application process all over again.
2. We must implement long-term programs and studies to follow the Long Covid population over time. We must assess why some patient populations improve or recover while others do not, and track long-term health impacts along with the incidence and prevalence of relapses.
3. It is first important to note that some of these conditions can go into remission for years, leading the patient to believe they have recovered. Sadly, many will experience relapses later. We must remain cognizant of this and reserve the patient's right to disability benefits, including a clause that allows them to regain benefits without starting the disability application process all over again.
4. We must implement long-term programs and studies to follow the Long Covid population over time. We must assess why some patient populations improve or recover while others do not, and track long-term health impacts along with the incidence and prevalence of relapses.

In 2022, Longhaulers cannot wrap their heads around 18-72 million people becoming disabled in a two and a half year time period and the majority of our population continuing to operate as if this threat will never reach them or their families. The COVID-19 pandemic is not over and neither are the lives of Longhaulers. Our government has a duty to act to protect the people of the United States, even if it is from an enemy that they cannot see, and even if that enemy is

sometimes the person staring back in the mirror at us, sitting across the aisle or even sitting right next to us.

The United States is supposed to be a leader on the world stage, but leading the world in the most COVID-19 and Long COVID cases, is not the type of leader we should aspire to be. Having the world's largest chronically ill and disabled population after a pandemic, in a country that is supposed to have the best healthcare and resources in the world, does not reflect leadership. Leadership takes the courage to admit when you may have gotten it wrong, and identify the gaps and shortcomings, and work collaboratively with the communities impacted to strategically address their needs in a swift and comprehensive way to ensure successful outcomes for not only them, but their families, their communities and their overall futures.

We are eager to work with the Select Subcommittee and others to help ensure the needs and experiences of the patient community continue to be represented and heard, as well as to educate those who have the power to drive and create the much needed change for not only tens of millions of Longhaulers, but tens, if not millions, living with complex, chronic illnesses. We appreciate the work you're doing and look forward to working with you in the near future.

### ***The COVID-19 Longhailer Advocacy Project***

Karyn Bishof- Director of Advocacy, Founder, President

Netia McCray-Director of Education

Marie Follayttar- Director of Development, Secretary

Rebecca Jacobs- Director of Community Support

Michael Clark- Director of Finance, Treasurer

[The COVID-19 Longhailer Advocacy Project](#) is a grassroots organization formed in June 2020 by an indigenous, single-parent, south Florida Firefighter, now disabled due to Long COVID and its associated conditions. It has since become a nonprofit whose mission is to advance the understanding of Long COVID and expedite solutions and assistance for Longhailers and their families through advocacy, education, research, and support. The organization has [50 state groups](#) plus D.C and [9 special populations groups](#) including pediatrics, teens, pregnancies and family planning, single parents and caretakers, educators, BIPOC, first responders and military personnel, healthcare workers and researchers, and fundraising and financial assistance.

We began our work with one of the first Long COVID studies to be done in June 2020 which compared confirmed and unconfirmed cases. We then completed the [first experiences and needs survey for the Long COVID community](#) in October 2020. We created various resources such as our [comprehensive guide for Longhailers and providers](#), a [COVID competent providers list](#) and several public service announcements, all of which you can find on [our website](#), where we also just launched a Long COVID Dashboard and will shortly be launching a Long COVID Resource Map. We co-drafted the [Treat Long COVID Act](#) and a [\\$60M/yr appropriations request](#) which includes Long COVID associated conditions (LCAC). We have provided language to 5 other bills and 2 other budget items to support the Long COVID community and a [\\$125M/yr appropriations request](#) in the senate, echoing the house version. We published a groundbreaking [report and open letter](#) to national leadership calling for the immediate formation of Long COVID Assistance Programs and a Long COVID Task Force and created a [Roadmap to Successful Outcomes for Longhailers](#). We also co-founded the [Long COVID Alliance](#), and we became members of the [Disability Economic Justice Collaborative](#) and [National Network for Long COVID Justice](#). We have met, and continue to meet, with various government and health agencies to try to educate them about the needs of the Long COVID community, reinforcing the necessity for meaningful, weighted patient engagement at every stage, of every action, for Long COVID and its associated conditions. Our president and founder also serves on the NIH'S [RECOVER Initiative](#)'s Ancillary Studies Oversight Committee and on the [Long COVID Research Fund's](#) Advisory Board and was also just a recipient of the Amelia Moore Sparkle Award for Compassionate Advocacy from Dysautonomia International.